# Looking after them?
# The provision of care for people affected by hepatitis C - in private general practice in South Australia

by

**Jane Scarborough, BSocSc (HumServ), MPH**

*Thesis*
*Submitted to Flinders University*
*for the degree of*

**Doctor of Philosophy**

College of Medicine and Public Health
March 2021

# CONTENTS

# *LIST OF TABLES*

# *LIST OF FIGURES*

# *LIST OF ABBREVIATIONS*

| Abbreviation | Term |
|---|---|
| ACCHO | Aboriginal Community Controlled Health Organisation |
| ACRRM | Australian College of Rural and Remote Medicine |
| AHPRA | Australian Health Profession Regulation Authority |
| AIDS | Acquired Immunodeficiency Syndrome |
| APRI | Aspartate Aminotransferase to Platelet Ratio Index |
| ASHM | Australasian Society for HIV, Viral Hepatitis and Sexual Health Medicine |
| BEACH | Bettering the Evaluation and Care of Health |
| CME | Continuing Medical Education |
| CPD | Continuing Professional Development |
| DAA | DAA Treatment for HCV |
| DASSA | Drug and Alcohol Services South Australia |
| DWS | District of workforce shortage |
| GP | General Practitioner |
| GPN | General Practice Nurse |
| HCC | Hepatocellular Carcinoma |
| HCV | Chronic Hepatitis C |
| HIV | Human Immunodeficiency Virus |
| HWA | Health Workforce Australia |
| IDU | Injecting Drug Use |
| IFN-a | Interferon-alpha |
| IMG | International Medical Graduate |
| MATOD | Medication Assisted Treatment for Opioid Dependence |
| MBA | Medical Board of Australia |
| MBS | Medicare Benefits Schedule |
| MBSRT | Medicare Benefits Schedule Review Taskforce |
| NNDSS | National Notifiable Disease Surveillance System |
| NSW | New South Wales |
| OST | Opioid Substitution Prescriber |

| Abbreviation | Term |
|---|---|
| PBS | Pharmaceutical Benefits Scheme |
| PCR | Polymerase Chain Reaction |
| PDP | Professional Development Program |
| PHC | Primary Healthcare |
| PHN | Primary Health Network |
| PIP | Practice Incentives Program |
| PWHCV | People with Hepatitis C |
| PWID | People who Inject Drugs |
| RACGP | Australian Royal College of General Practitioners |
| RNA | Ribonucleic Acid |
| SA | South Australia |
| SVR | Sustained Virological Response |
| SVR12 | Sustained Virological Response measured after 12 weeks |
| VHN | Viral Hepatitis Nurse |
| VRGP | Vocationally Registered General Practitioners |
| WHO | World Health Organisation |

# *CANDIDATE'S DECLARATION*

I certify that this thesis does not incorporate without acknowledgment any material previously submitted for a degree or diploma in any university; and that to the best of my knowledge and belief it does not contain any material previously published or written by another person except where due reference is made in the text.

Signed

Date 28/10/2020

# *ACKNOWLEDGEMENTS*

I wish to thank the multitude of people who have helped me along the long and winding journey of my PhD candidature.

I have been extremely lucky to have highly supportive and knowledgeable supervisors. Dr Emma Miller and Dr Paul Aylward have been with me from the start to finish and I am sure have wondered if the journey would ever end. Dr Miller's expertise regarding hepatitis C, populations affected by substance use issues and epidemiology, have been particularly appreciated. Dr Aylward's has shared his in-depth knowledge of qualitative methods and his vast experience of working with vulnerable populations. Dr Jaklin Eliott was my principal supervisor when I was based at Adelaide University. The hardest part of my decision to leave Adelaide University was that this decision led to me no longer being supervised by Dr Elliott. Dr Eliott's qualitative research expertise is phenomenal, as is her ability to trim any sentence to fit the word count. I have been lucky to have felt valued by my supervisors as both a student and as an individual.

My family and friends have also been along for the ride. Thanks to my husband Paul and children Haley, Philip and Caitlin, for being the sounding board for the enthusiasm and frustrations I have felt during my candidature. At one point in time, all have asked, "Are we there yet?". Throughout their life with me, I have always been studying something, and I promise that this is the last assignment that ever needs to be completed. My mother, siblings, in-laws and various extended family, have also played a part. My mother: Mary Wilson, was a primary school teacher who taught me to value learning. She died last year, and I miss her. I know that I could have relied on Mum to read the final draft, and with a red pen, mark the numerous errors only she could detect. Old friends have stuck by me, providing me with perspective and keeping me sane. New friends were made who I greatly admire and value, especially through the PhD writing group at Adelaide University. Time now to catch up for a coffee.

The support I received from staff at Hepatitis SA, Drug and Alcohol Services South Australia (DASSA), Adelaide University and Flinders University allowed me to complete the research. My manager at DASSA, Dr Chris Holmwood, encouraged me to start the PhD. With his support I was granted time-off by DASSA to concentrate on my candidature. Hepatitis SA is

an amazing organisation with hard working and talented staff. Hepatitis SA and DASSA both facilitated recruitment of study participants. During my candidature, Adelaide University and Flinders University staff have had to cope with stressful changes to their work environment. At all times I have felt shielded from this stress and have been given great service.

Finally, I would like to thank the participants in my study. These participants generously provided me with their time and expertise. I hope I have done your words justice.

This thesis is supported by an Australian Government Research Training Program Scholarship.

# *ABSTRACT*

With more than 1% of the Australian population chronically infected, hepatitis C virus (HCV) is a significant contributor to morbidity and mortality in Australia. Whilst direct acting antiviral treatment for HCV (DAA) with high cure rates is now available for Australian people with HCV (PWHCV), there remains a substantial proportion of the affected population who remain undiagnosed and untreated. Australian private General Practitioners (GPs) are professionally and geographically well placed to diagnose HCV and prescribe DAA, yet there are gaps in the care provided by these GPs.

The original contribution to knowledge in this thesis is the presentation of additional recommendations to increase the provision of DAA in this setting, that originate from a re-examination of the assumptions about the provision of care within the GP-patient relationship in the Australian context. A strength of this thesis is the in-depth understanding of this context provided by studies focused on the 'healthcare system' (*Study 1*), 'patient' (*Study 2*) and 'GP' (*Study 3*) system components individually, and the interactions between these.

A document analysis of HCV specific and two broad primary healthcare policies, *Study 1,* demonstrated a lack of coherence between the documents that prevented equity of healthcare access for PWHCVs. Recommendations to facilitate cross-referencing between the disease specific and broad policies are provided. Semi-structured interviews were thematically analysed in *Study 2* and *Study 3*, respectively examining the experiences and perspectives of people affected by HCV, regarding engagement for HCV care (N=22), and the experiences and perspectives of GPs with the provision of this care (N-=9). Decisions about engagement and disclosure to GPs were made by PWHCV by weighing up their perceptions of the potential risks and potential benefits. Potential risks included risk to the confidentiality of sensitive information, risk to usual care and risk of exposure to discrimination. For PWHCV the perception of benefit would only occur if the GP was capable of providing an appropriate level of care and this was not assumed for all GPs. GPs described limits to their scope of practice and that inclusion of prescribing DAA was not automatic. The perceived prevalence of conditions within their patient population influenced GPs' scope of practice. GPs considered the provision of DAA as a ‘special interest’. GPs that provided DAA felt confident and supported to provide this care.

The overall conclusion is that GPs will not automatically provide care for HCV to ‘their’ patients and PWHCV will not always engage with ‘their’ GP for this care. While the profession of general practitioners is appropriate to provide DAA, not all GPs will choose to include this care in their scope of practice. Australian PWHCV also have choice about their engagement with individual GPs and about disclosure of HCV. Suggested recommendations centred around supporting GPs who choose to provide HCV care to provide best-practice care and providing pathways for PWHCV to receive care from these GPs. GP-to-GP referral, expansion of the role of Viral Hepatis Nurses, and a register of GP DAA providers, are amongst recommendations provided to achieve this outcome.

# CHAPTER 1.

# *INTRODUCTION TO THE THESIS*

## 1.1 Introduction to the thesis topic

Chronic hepatitis C (HCV) is a significant public health problem in Australia with more than 1% of the Australian population chronically affected, including people whose HCV remains undiagnosed (The Kirby Institute, 2018a). Chronic HCV infection is associated with the development of serious liver disease, including cirrhosis, liver failure and hepatocellular carcinoma (Dore, Temple-Smith et al. 2009). HCV is a blood borne virus that has predominantly been transmitted through sharing injecting drug equipment in Australia. Its association with injecting drug use (IDU) has been found to result in stigma being attached to the diagnosis with HCV (Butt, 2008; Richmond, Dunning, & Desmond, 2007). This diagnosis has therefore been described as both a medical and a social diagnosis (Richmond, Dunning, & Desmond, 2004). Direct Acting Antiviral treatment for HCV (DAA) can be prescribed by general practitioners (GPs) in private practice (Hepatitis C Virus Infection Consensus Statement Working Group, 2018), with cure rates for patients of greater than 95% (The Kirby Institute, 2018b). The proportion of Australian patients who have received this treatment from a GP is 32%, and in 2017, 43% of all DAA was prescribed by GPs (MacLachlan, Smith, Towell, & Cowie, 2020). In 2016 Australia adopted the World Health Organisation's (WHO) target of elimination of HCV (Australian Government - Department of Health, 2018b; World Health Organization, 2016b) however, to reach this target, rates of both HCV diagnoses and provision of DAA by GPs must improve (Burnet Institute and Kirby Institute, 2019).

GPs working in private general practice in Australia are professionally and geographically well placed to be involved with the provision of care for PWHCV (PWHCV), including the provision of DAA (Hepatitis C Virus Infection Consensus Statement Working Group, 2018). The profession of General Practitioner is a recognised and regulated specialty with registration regulated by the Australian Health Profession Regulation Authority (AHPRA) (Australian Government - Department of Health, 2018e). A requirement of registration is that GPs maintain membership with either the Australian Royal College of General

Practitioners (RACGP) or the Australian College of Rural and Remote Medicine (ACRRM) (Australian Government - Department of Health, 2018e). The provision of primary healthcare by GPs in private general practice in Australia underpins what has been described as a ‘universal’ health system (Mossialos, Djordjevic, Osborn, & Sarnak, 2017). Most Australians and permanent Australian residents can access subsidised GP appointments through the federally funded Medicare system, and prescribed pharmaceuticals that are subsidised through the Pharmaceutical Benefits Scheme (PBS) (Australian Government - Department of Health, 2020a). After successful trials, DAA was added to the PBS in 2016 when Australian GPs were granted the right to prescribe the treatment (Khoo & Tse, 2016). Over time, exclusions or restrictions to access to DAA have been removed, with very few counter-indications for treatment remaining (Hepatitis C Virus Infection Consensus Statement Working Group, 2018). These measures have reduced or overcome many of the system-based barriers to the provision of DAA by GPs that have been reported in other countries (World Health Organization, 2016b). However, not all eligible in Australia who could receive this treatment from a GP and be cured are receiving treatment.

The aim of this thesis was to understand the provision of DAA by GPs in private general practice, to allow the development of recommendations that improve the rate of the provision of this treatment in this setting. Provision of DAA by GPs is a new development, which has not been previously comprehensively investigated. Thus, further research in this area was warranted to inform recommendations. In Australia, provision of DAA by GPs, occurs during consultations between patients and GPs, within the context of the general practice, local community and wider health system (Crabtree, Miller, & Stange, 2001). When developing recommendations in the context of general practice settings, it is important to understand the individual components and manner of interaction, in what has been described as a complex adaptive system (Crabtree et al., 2001). This thesis examined the context in which the GP-patient consult takes place in Australian private general practice and focused on eliciting the experiences and perspectives of GPs and PWHCV (or at risk for HCV), when engaging in DAA in this setting. Based on the understanding gained, recommendations to increase the provision of DAA are proposed.

## 1.2 PhD candidates' background

I developed my knowledge about this issue when working collaboratively with HCV organisations to increase the understanding and skills of GPs regarding care for HCV. My paid work involves recruiting and supporting private GPs who provide opioid substitution treatment (OST) using methadone and buprenorphine. I started my PhD candidature in 2012, when most people who received opioid dependence treatment had a history of IDU and were exposed to HCV through sharing needles (Australian Institute of Health and Welfare, 2013).

At the time of commencing my candidature, there was an estimated 20% of PWHCV who remained undiagnosed, with less than 2% entering treatment (The Kirby Institute, 2017a; Thein & Dore, 2009), representing a gap between the ideal and actual involvement of GPs in providing HCV care. I believed that if these gaps existed in relation to other health issues, questions would be asked and there would be calls for action. It was my opinion that the association of HCV with illicit injecting drug use limited this public reaction. Through my work, I am continually confronted by GPs' reluctance to be involved in the provision of care for people with a history of IDU and have been asked "Why would I look after them?". I therefore had an understanding that the identified problem may be associated with this reluctance and research into this area might provide some useful solutions to the low levels of HCV treatment provision.

## 1.3 Approach taken to this thesis

This inquiry draws on pragmatist philosophy as described by Morgan (Morgan, 2007, 2014) and others (Badley, 2015; Hildreth, 2009) who described pragmatist philosophy as particularly suited to provide solutions to an identified problem (Badley, 2015, p 2). As such, pragmatist philosophy suited my research, which aimed to answer the problem I identified as: '*A substantial proportion of PWHCV in Australia are not receiving treatment that is likely to cure their HCV*'.

Qualitative methods were chosen to understand various components of the primary healthcare system in Australia, which was considered as a dynamic complex adaptive system (Crabtree et al., 2001). In *Study 1*, a document analysis was conducted to investigate the way the provision of care for HCV was framed at the healthcare system level (Bacchi, 2009, 2016). Thematic analysis (Braun, Clarke, Hayfield, & Terry, 2019) of semi-structured interviews (DeJonckheere & Vaughn, 2019) was used in *Study 2* and *Study 3*. In *Study 2* the perceptions and experiences of PWHCV of engagement with GPs in private general practice for care for HCV were investigated. In *Study 3* the perceptions and experiences of GPs in the provision of care for PWHCV were investigated.

## 1.4 Relevance and significance of the thesis study

I argue in this thesis that the re-examination of the assumptions about the GP-patient relationship in Australia, expands the way recommendations that aim to enable increased provision of best practice care for PWHCV by GPs in private general practice, can be imagined. The findings of my thesis are that there is a need to go beyond presuming that GPs will automatically provide this care to 'their' patients and that PWHCV will engage with 'their' GP for this care.

## 1.5 Context of the research

This research took place at a time during which the clinical options available for PWHCV in Australia underwent dynamic and positive advances (Hepatitis C Virus Infection Consensus Statement Working Group, 2018). The Australian Federal Government have committed to making this DAA available for all Australian citizens with HCV as part of their overall commitment to the elimination of HCV (Ley, 2015). In parallel, the role of GPs in the delivery of this treatment has expanded, and GPs have the right to prescribe DAA for the majority of PWHCV (Hepatitis C Virus Infection Consensus Statement Working Group, 2018). The perceptions of GPs and PWHCV about engagement in care for HCV have developed over time and may not always reflect the current context. Experiences and perceptions formed in the era of interferon-based HCV treatment need to be considered when understanding current engagement in care for HCV.

When interferon-based HCV treatments were the mainstay, GPs were minimally involved in treatment prescription with their main role focused on diagnosis, initial assessment, referral to specialists and ongoing monitoring of patients with chronic HCV (Dore, Temple-Smith, & Lloyd, 2009). Clinical decisions regarding treatment at the time were complex (Backx et al., 2014), with disease progression variable and unpredictable, available treatments providing low and variable cure rates, and often involving severe negative side-effects (Carvalho-Filho

& Dalgard, 2010; Feld & Hoofnagle, 2005; Sublette, Smith, George, McCaffery, & Douglas, 2015). In this era, there were reports of some patients with HCV being provided less than optimal care, as well as numerous reports regarding a range of barriers to the provision of care (Blixen et al., 2008; Treloar, Newland, Harris, Deacon, & Maher, 2010). Unsurprisingly, there was a low number of people entering antiviral treatment for HCV, with an annual uptake rate of 2% (Australian Government - Department of Health and Ageing, 2010b). While the current DAA represents a vast improvement, this has not yet overcome negative perceptions and experiences (Bryant, Rance, Hull, Mao, & Treloar, 2019; Richmond & Wallace, 2018).

For the benefits of DAA to be realised, GPs and PWHCV may need to update their knowledge and change their perception regarding the benefit of treatment available for HCV (McNally, Temple-Smith, Sievert, & Pitts, 2006; Wade et al., 2017). However, clinical advances in the treatment of HCV may not be enough to overcome barriers whilst the negative social aspects of the diagnosis are unchanged. Previously reported stigma and discrimination associated with HCV (Fry & Bates, 2011; Miller, McNally, Wallace, & Schlichthorst, 2012; Treloar & Rhodes, 2009), may remain as a major barrier to treatment. Understanding the intersection of the historical, social and current context is therefore critical in order to develop effective recommendations to improve the uptake of DAA.

## 1.6 Research questions

The following research questions were developed to answer the identified problem of '*A substantial proportion of PWHCV in Australia are not receiving treatment that is likely to cure their HCV*':

1. Do Australian healthcare policies address equity in primary healthcare delivery for the provision of care for HCV by GPs in private general practice?
2. What are the experiences of people with or at risk of HCV of engagement with GPs in private general practice and how does this affect their perceptions of the engagement for the provision of care for HCV?

3. What are the experiences of GPs in private general practice about the provision of care for people with or at risk of HCV and how does this affect their perceptions of engagement in this care?
4. What recommendations will enable the provision of best practice care for PWHCV by GPs in private general practice?

## 1.7 Overview of the thesis chapters

Following is an outline of the contents of the chapters contained within this thesis.

### 1.7.1 Chapter 2 – Literature review

This chapter provides a summary and synthesis of the extant literature that informed this thesis. The literature review was tightly focused on the context of HCV care delivery by GPs in Australia. An outline of the HCV epidemic and treatment of HCV in Australia is provided. The Australian primary health system and the role of private GPs within this system is described. Concepts of 'disease prestige' and 'sustainment' are presented as a framework to understand the barriers and facilitators of GPs providing HCV care, including DAA. The current literature concerning the barriers and facilitators of PWHCV in engaging with GPs for care, is summarised. The 'problem' that the thesis is addressing is then stated and the research questions framed to provide answers to this problem are listed.

### 1.7.2 Chapter 3 – Methodology and methods

This chapter presents the philosophy of pragmatism (Morgan, 2007, 2014) underpinning the inquiry of the thesis and, in line with this philosophy, the choices made in undertaking my research are discussed. Details of the method of document analysis conducted for *Study 1* and thematic analysis of semi-structured interviews conducted for *Study 2* and *Study 3* are provided. This includes detailed descriptions of the sampling, recruitment, and data collection conducted for these studies. Ethical considerations and processes involved in the studies and the values and beliefs that I, as the researcher, brought to the study are described.

### 1.7.3 Chapter 4 - *Study 1* - Document Analysis

This chapter outlines the document analysis of three relevant documents published by the Federal Government of Australia. These included, two broad policies that related to the

Australian primary healthcare system (Australian Government - Department of Health and Ageing, 2010a) and Australian health workforce (Health Workforce Australia, 2011), and a third document specifically describing the Australian HCV policy (Australian Government - Department of Health and Ageing, 2010b). The content of each document and the coherence between them was investigated. The analysis of the strategies involved deconstruction of the framing of the 'problem' addressed within each document, examining the underlying assumptions and questioning the articulated solutions (Bacchi, 2009, 2016). This study formed the basis of my understanding of the health system context that GPs in private general practice operate within.

### 1.7.4 Chapter 5 – *Study 2* – Experiences and perspectives of people with or at risk of HCV

Within this chapter the results and discussion relating to *Study 2* regarding the experiences and perspectives of people with or at risk of HCV with care provided by GPs in private general practice are presented. This study involved thematic analysis of semi-structured interviews with twenty-two participants that took place in 2013-2014. The study aimed to identify experiences and perspectives of HCV care provided by GPs in people affected by HCV, or whose clients were affected by HCV. The analysis provided an understanding of the patient component involved in the provision of care for HCV.

### 1.7.5 Chapter 6 – *Study 3* – GPs engagement in the provision of care for HCV in private general practice

This chapter provides the results and discussion relating to *Study 3,* which investigated GPs' experiences and perceptions of engagement in the provision of care for HCV in private general practice. This study took place in 2018 and involved thematic analysis of semi-structured interviews with seven GPs and two practice nurses. The analysis provided an understanding of the GP (and practice nurse) component involved in the provision of DAA.

### 1.7.6 Chapter 7 – Recommendations generated from the synthesis of study findings

Based on the understandings gained throughout the PhD candidature, this chapter provides my recommendations to address the problem this thesis addresses. These interventions aim to enable increased provision by GPs in private general practice of best practice care, for PWHCV, including DAA which is likely to cure their HCV.

## 1.8 Chapter Summary

This chapter has introduced the identified problem, the context (historical, social and current) of the investigation and me, as the researcher. The next chapter critically reviews the relevant key literature, to further outline the context of the research and to identify gaps in current knowledge.

# CHAPTER 2.

# *LITERATURE REVIEW*

## 2.1 Introduction

This chapter provides a summary and synthesis of the extant literature that informed this thesis. When commencing my PhD in 2012, my impetus was to improve the understanding of factors that determined the care provided to people with hepatitis C (HCV) by private General Practitioners (GPs) in South Australia and subsequently identify GP-related recommendations that might optimise this care. I had observed that the scope of practice of some GPs, included the provision of care for PWHCV and they were successful in engaging patients with HCV in this care. I was interested in understanding what facilitated this, what prevented others from doing the same and what supported willing GPs to provide best practice care.

The literature review focused on the engagement between private GPs and PWHCV, and the provision of care for HCV by GPs in Australia. To understand the context in which these actions occur, literature on the Australian private general practice system was examined. To ascertain what was considered best practice care at the time, guidelines and other resources regarding the screening, diagnosis, assessment, referral and provision of antiviral treatment for HCV, were examined. Literature was surveyed to determine the nature of the care provided to PWHCV and establish any gaps in its provision. In regard to GPs and people living with HCV, I was interested in determining the knowledge these groups had about potential HCV sequelae, the ability of medical care to ameliorate these health effects, and regulations guiding access to treatment. Literature regarding the experiences and perceptions of these groups was searched to identify what other factors may affect their decisions. The literature regarding the effect stigma associated with IDU may have on engagement and care provision was a focus of the investigation. The literature review was continually updated throughout my PhD candidature to incorporate changes that affected the provision of care for HCV - in particular, the introduction of DAA and GPs involvement in the prescribing of this treatment.

The literature review was tightly focused on the context of HCV care delivery by GPs. Excluded was literature on the provision of care for PWHCV in primary healthcare sites other than private general practice, such as outreach services, drug treatment facilities, prisons, community health clinics or outpatient clinics where private GPs were not involved. The search of the pharmacotherapy literature for new HCV antiviral treatments was restricted to literature reporting characteristics of the treatment regimes, outcomes, and side effects that might influence the complexity of providing the treatment and the attractiveness of these treatments to patients. Studies focusing on the epidemiology of HCV were also excluded, other than those that explored the epidemiological knowledge of GPs and PWHCV in so much that this might affect engagement in and provision of care.

## 2.2 Search strategy

The literature was searched using search terms for General Practice, General Practitioners, primary health care and HCV, which are sensitive terms appropriate in Australia and internationally with the specific terms outlined in Table 1. The electronic database PubMed was the primary electronic citation database used to initially identify relevant literature.

**Table 1: Search term used for literature review.**

| Specific search terms |
|---|
| (general practice[mh] OR general practice*[tw] OR family care[tw] OR family medicine[tw] OR family practice*[tw] OR family health care[tw] OR family healthcare[tw] OR family physician*[tw] OR physicians, family[mh] OR family doctor*[tw] OR general practitioner*[tw] OR family practitioner*[tw] OR gp[tw] OR gps[tw] OR general doctor*[tw] OR general physician*[tw] OR primary health care[mh] OR primary healthcare[tw] OR primary care[tw] OR primary practitioner*[tw] OR primary physician*[tw] OR physicians, primary care[mh] OR primary practitioner*[tw] OR primary health care practitioner*[tw] OR primary healthcare practitioner*[tw] OR primary health care physician*[tw] OR primary healthcare physician*[tw]) AND (Hepatitis C[MH] OR hepatitis C[tw]). |

The titles and then abstracts of identified publications were scanned and the reference lists of retrieved publications were examined for any further relevant literature that had not yet been identified. Literature identified through web-based searches included both peer reviewed published literature as well as grey literature, for example: media reports, government reports, policy documents, national strategies. In addition, electronic searches based on the authors of identified publications were conducted using authors' webpages, PubMed and Google Scholar and relevant references were included in the review. Searches of reference lists and author searches were repeated until no further references were identified. National Center for Biotechnology Information email alerts were put in place for the search term and key references, to allow for literature published during the thesis to be identified.

The citations and references of retrieved publications were downloaded and stored using the EndNote reference management software package (Clarivate Analytics, 2018). The content of each reference was determined by reading the abstract, scanning the reference or reading the whole paper, and then assigning it to one or more groups created in the Endnote software. The process of creating groups and assigning references to these groups was an iterative process, with groups being added and names being refined to reflect themes and categories identified in the literature. Using this process allowed me to determine the body of relevant literature, identify gaps in the existing research and provided a framework to address these gaps.

## 2.3 Australian GPs

Understanding the profession of General Practitioner in Australia and the system in which it operates, is a first step in identifying how to influence the behaviour of this group. I will outline the approach I adopted to examine the GP-patient relationship, the Australian healthcare system that GPs work within, and describe some relevant aspects of the GP workforce. Finally, I will consider the discretion GPs have in deciding the patients they provide care to and the care they provide.

### 2.3.1 The GP-patient relationship as part of a dynamic complex adaptive system.

To improve access to high quality care, the literature highlighted the need to understand the doctor-patient relationship as part of a "dynamic complex adaptive system" (Crabtree et al., 2011, p 1) in which clinical encounters take place (Comino et al., 2012; Crabtree et al., 2011;

Thompson, Fazio, Kustra, Patrick, & Stanley, 2016). Crabtree et al. (2011) researched transformation in primary care practices in America for over 15 years (Crabtree et al., 2011) and developed a system model of primary care practice as shown in **Error! Reference source not found.** (Crabtree et al., 2001). Clinical encounters were influenced by the context of the practice, local community and health system that they operated within (Crabtree et al., 2011). This groups' study interest was broader than primary care provided by doctors, however the model they developed can be applied to understanding the different influences on the provision of health care by GPs in private general practice.

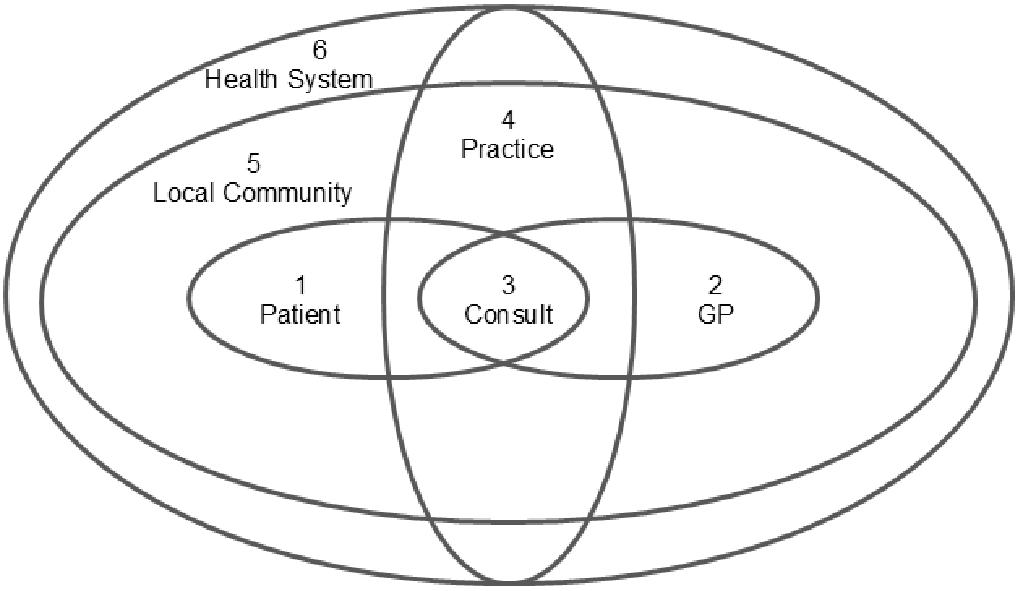


**Figure 1: Systematic Model of Primary Care (Adapted from: Crabtree et al., 2001, p 883)**

**(Reporoduced with permission from The Journal of Family Practice®. 2001 October 50(10):881-887. ©2001, Frontline Medical Communications Inc.)**

As there was a high degree of variability found in the international models of general practice (Mossialos et al., 2017), it is necessary to consider the specific context of the Australian model of general practice to understand the barriers and facilitators for care for HCV in this setting. This approach was applied when examining the literature regarding the provision of care in private general practice in Australia. This assisted the review of what was known about factors shaping the work of GP in the context of the Australian health system, how GPs regarded provision of care for HCV, and how PWHCV shaped the provision of that care.

### 2.3.2 The Australian primary health care system

Australia's health care system has been described as providing 'universal' health care for its citizens, with government subsidised medical practitioner visits, subsidised pharmaceuticals and free hospital care available (Mossialos et al., 2017). The Australian Federal government manages and funds the Medicare and Pharmaceuticals Benefit Scheme (PBS) schemes, through which subsidies are provided respectively for medical practitioner services and a specified range of prescribed pharmaceuticals (Mossialos et al., 2017). The Medicare program funds primary health care (PHC), but the Australian health system relies on the delivery of PHC by GPs through private general practices (Australian Government - Australian Institute of Health and Welfare, 2016; Mossialos et al., 2017). The overwhelming majority of the primary health budget in Australia is spent via payments to these private businesses (Australian Government - Productivity Commission, 2017; Mossialos et al., 2017; Willcox, Lewis, & Burgers, 2011). The provision of PHC by medical practitioners is excluded from private health insurance policies (Buchmueller, Fiebig, Jones, & Savage, 2013) and the majority of the cost for this care is paid for by the Australian Federal government.

The Medicare scheme has been in operation in Australia since 1984 and was preceded by a similar Commonwealth-funded health insurance scheme called Medibank that was introduced in 1975 (Biggs, 2004). The operation of the schemes has attracted debate between the major Australian political parties (Australian Labor Party, 2016; Senate Select Committee on Health, 2014) and undergone a series of changes that have added to the complexity of subsidies offered and revenue raising for the scheme (Biggs, 2004). The Medicare scheme is partly funded by a 2% income levy on incomes above a certain threshold, and collection of the Medicare levy surcharge, charged based on individual's taxable income and their level of private patient hospital cover. The remainder of the funding comes from general revenue (Australian Government - Australian Taxation Office, 2018). In 2017-18, $23.5 billion dollars was paid in benefits and 25.3 million individuals were enrolled in the Medicare scheme (Australian Government - Department of Human Services, 2018a).

For services provided by medical practitioners, the Medicare scheme provides payment of 85% of the scheduled fee listed in the Medicare Benefits Schedule (MBS) (Australian Government - Department of Human Services, 2018e). Medical practitioners can choose to offer a bulk-billed service, whereby the medical practitioner accepts the 85% of the MBS listed fee as full payment and no additional payment is required by the patient (Australian Government - Department of Human Services, 2018c). Alternatively, the medical practitioner can choose to set their own fees, that are paid by the patient, who is then reimbursed 85% of the MBS listed fee. The fee paid by the patient in these circumstances is called a 'gap fee' and is the difference between the fee charged and the reimbursement. 'Safety net' schemes exist that allow individuals and families to claim back all or up to 80% of the gap fees they have paid (Australian Government - Department of Health, 2018g) after a threshold has been reached in a calendar year. For the majority of items listed on the MBS there is no capping of the number of times a patient can access these items (Australian Government - Department of Health, 2020e).

An Australian PBS was started in 1948 and the current scheme subsidises the cost of medicine for most medical conditions, with patients making a co-payment of up to $41.00, or $6.60 for concession cardholders, per medicine and the Federal government paying the remaining cost (Australian Government - Department of Health, 2020a). In 2020, the concession rate applied to approximately one-fifth of the Australian population who are eligible for concession cards (Australian Government - data.gov.au, 2020). There is also a safety net scheme for pharmaceuticals. Once the government co-payments for a family unit reach the threshold ($384 for concession card holders and $1521.80 for others), all further PBS prescriptions are dispensed without cost for the remainder of the calendar year (Australian Government - Department of Health, 2020a). There was $ 11.8 billion of Federal Government expenditure on PBS in 2017-2018. The inclusion of DAA onto the PBS subsidised list, including the process for inclusion (Australian Government - Department of Health, 2016a), will be discussed in Section 2.4.4.. High level private health insurance may also include additional rebates for pharmaceuticals that are not included on the PBS (Buchmueller et al., 2013).

The responsibility of the Federal government for general practice and PHC is set out in the Commonwealth Heads of Government Meeting (CHOGM) agreement between the Australian Commonwealth and States and Territories (Council of Australian Governments, 2018). Under this agreement State and Territory governments, are responsible for state-run hospitals and other state health services (Mossialos et al., 2017) and receive Federal

Government funding to support these services. There are some state-run health services that incorporate PHC by medical practitioners, including community health services, prison health services, drug and alcohol services, mental health services, and sexual health clinics (Central Adelaide Local Health Network, 2016; Nunkuwarrin Yunti of South Australia Inc., 2017). Australian's access to state-run GP care is limited, with only 2.2% of all employed GPs working in these scarce health services (Australian Government - Australian Institute of Health and Welfare, 2016). In addition, State-run services usually offer only a limited scope of services, serve only specific populations and/or offer services in limited geographical locations (Australian Government - Productivity Commission, 2017). Whilst the Federal government, is generally not directly involved with service delivery of PHC by medical practitioners, (Australian Government - Department of Health, 2018c) a notable exception is the direct funding of Aboriginal Community Controlled Health Organisations (ACCHOs). Whilst these services are important sources of primary health care for the Australian Aboriginal population, they represent only a small proportion of PHC compared to care provided by GPs in private general practice.

Since the Federal Labour Government clarified federal responsibility for funding and policy formation for all GP and primary healthcare services in 2010 (Rudd, Swan, Roxon, & Australian Government - Department of Health and Ageing, 2010), successive Australian governments have emphasised their commitment to providing universal access to coordinated primary care in private practice (Abbott, 2010; Australian Government - Department of Health, 2019a; Australian Labor Party, 2016; Rudd, 2013; Turnbull, 2016a). Concurrent with this commitment was reform introduced to manage expenditure in the context of an aging population with an increased burden of chronic disease (Liberal Party of Australia, 2013; Rudd et al., 2010). There have been critiques of the success of this reform, with primary healthcare policy being described as "under done" (Swerissen & Duckett, 2018, p 3). The Liberal/National Coalition came to power in 2013 and have introduced a series of reforms and policies including the introduction of the Health Care Homes trial, creation of the Medicare Benefits Schedule Review Taskforce (MBSRT), reviews of the Practice Incentives Program (PIP) and replacing Medicare Locals regional primary health organisations with Primary Health Networks (PHN). These reforms and the PIP are detailed in Table 2, Table 3 and Table 4. The Health Care Homes trial, MBSRT review and PIP reforms include modifications to the GP-patient registration requirements and/or modifications to the financial incentives provided via Medicare.

**Table 2: Healthcare Homes trials - Summary**

- Introduced 2017.
- Aims to improve the care of patients with chronic and complex conditions by centring their care within one general practice and allowing flexibility in the delivery of this care (Australian Government - Department of Health, 2018f).
- Involves private general practices signing up for the scheme and receiving bundled payments to manage the chronic disease of patients, who voluntarily register with the practice (Australian Government - Department of Health, 2018f, 2019c).
- Issues encountered with attracting and retaining private general practices to take part, due to the uncertainty of these private businesses maintaining profitability under the funding model and lower than expected patient enrolment (Australian Medical Association, 2018; Lyons, 2017).

**Table 3: Medicare Benefits Schedule Review Taskforce - Summary**

- Established in 2015.
- Aimed to review the 5 700 items on the MBS to ensure they are based on clinical evidence and identify items that were "unnecessary, outdated or potentially unsafe." (Medicare Benefits Schedule Review Taskforce, 2018, p 7).
- 70 clinical committees were established to review items.
- The 'General Practice and Primary Care Clinical Committee' established in 2016.
- Made recommendations for MBS items to be deleted in 2016 (Medicare Benefits Schedule Review Taskforce, 2017).
- In 2018 Phase 2 recommendations included recommendations for a new model for primary care funding (Medicare Benefits Schedule Review Taskforce, 2018).
- Proposed reforms to the model would include options for items which required the voluntary enrolment of patients to general practices (Medicare Benefits Schedule Review Taskforce, 2018).
- The rationale for this registering of the patient-GP relationship was to improve the continuity and coordination of care for patients, allow for reimbursement of diverse forms of care delivery and to facilitate data driven system improvements (Medicare Benefits Schedule Review Taskforce, 2018).
- Federal government decisions on which clinical committees' recommendations were adopted, were criticised as predominantly based on reducing budget costs (Rollins, 2016) and the effect of the recent recommendations on future models is uncertain.

**Table 4: Practice Incentive Programs (PIP) - Summary**

- Introduced 1998 (Cashin & Chi, 2011).
- Provides financial incentives to voluntarily enrolled private general practices when defined targets are met e.g. target for rates of cervical screening (Australian Government - Department of Human Services, 2018b).
- Ongoing review has occurred to payments with further changes expected to come into effect in April 2019 (Australian Government - Department of Human Services, 2018d).
- Payments of $342.9 million in 2017-18, represent a small proportion of Medicare payments made to GPs (Australian Government - Department of Human Services, 2018a) and over 90% of GPs reported that income in 2008-2011 from PIP formed 10% or less of their income (Kecmanovic & Hall, 2015).

There is no formal registration of patients with a particular GP or general practice and registration is not required for Medicare fee-for-service payments. Patients are free to seek care from any private general practitioner. Thus, the lack of a formal relationship means that the GP’s responsibility for providing care for an individual patient’s range of health care needs tends to be fluid and ill-defined. The general practices registered in the Health Care Homes trial are responsible for the provision of care for the chronic condition of the registered patients in the scheme at their practice, but the responsibility for other health needs of these patients remain unchanged. The MBS Review Taskforce has also suggested reforms regarding patient registration, including additional items that would require the voluntary enrolment of patients to general practices. The MBS Review Taskforce outlined the benefits that this would bring about due to increased continuity to the GP–patient relationship (Medicare Benefits Schedule Review Taskforce, 2018). As patients with chronic conditions were generally older and commonly attended only one general practice, there was minimum change in patient’ behaviour required for this reform. Importantly, however, this recommendation introduced the concept of “mutual obligations on the GP” (Medicare Benefits Schedule Review Taskforce, 2018, p 30). These obligations would include a minimum level of care provided by GPs receiving a payment for enrolling a patient in their practice – for example, access to out of hours care for the enrolled patient. The Health Care

Homes trial and MBS Review Taskforce recommendations involve voluntary enrolment, rather than a system wide change to the current arrangement.

It is not a straightforward process to determine the influence of the financial incentives within the reforms on individual GPs' scope of work and they may have limited effect on GPs engagement in particular areas of work (Broadway, Kalb, Li, & Scott, 2017). Private general practices are private businesses and need to be financially viable. Individual GPs within these practices, however, may prioritise other considerations over financial gain, for example; outcomes for patients (Scarborough, Eliott, & Braunack-Mayer, 2011) or work-life balance (Broadway et al., 2017). Private practices have varying ownership models and the benefit of these incentives for GPs may differ depending on whether they are salaried, owners or associates, and the details of these arrangements (Joyce, McDonald, & Lawlor-Smith, 2016). Phase 1 of the MBSRT was largely about the removal of items identified as "…unnecessary, outdated or potentially unsafe." (Medicare Benefits Schedule Review Taskforce, 2018, p 7) rather than directing GPs to include particular activities or services in their scope of practice. In the Health Care Home trial, uncertainty about the financial viability of private practices was considered a barrier to involvement (Lyons, 2017) and the interim evaluation of the program has shown that the economic viability of the model remains uncertain (Health Policy Analysis, 2019). Administrative costs involved in participation in the PIP program (Kecmanovic & Hall, 2015) and the low percentage of income earned through PIP (Australian Government - Department of Human Services, 2018a) limits the ability of the scheme to influence care provided.

The Federal government funds PHNs, which are regional primary healthcare organisations that aim to support and coordinate GPs and other providers of primary care, to provide 'the right care, in the right place, at the right time' (Australian Government - Department of Health, 2018a). PHNs are not direct providers of care, but may commission the provision of healthcare to address identified gaps in healthcare of their region (Australian Government - Department of Health, 2018a). PHNs have no regulatory authority to compel the activities of private general practice (Duckett et al., 2015). Conversely, the requirement for PHNs to have GP led Clinical Councils and 'skills-based' boards (Australian Government - Department of Health, 2016c) embed GPs' influence on PHNs. The mechanism that PHNs primarily seek to influence provision of healthcare by GPs in private general practice, therefore, is by providing support and information to the sector (Australian Government - Department of Health, 2018a).

The funding of primary health care by private GPs is provided by the Federal Australian Government through fee-for-service Medicare payments. The Federal Government defines the services that will be funded in the MBS, but private GPs are free to use their professional discretion to decide which of these services they provide and to whom. An understanding of the GP profession and general practice in Australia will also help to understand the provision of care for HCV within this context.

### 2.3.3 The GP workforce in Australia

In Australia, there were 37 642 GPs who provided at least one Medicare service in 2018-19, which equates to a full-time equivalent (7.5 hours, 5 days a week) of 29 510 GPs (Australian Government - Department of Health, 2020d). GPs provide the first point of contact for medical primary healthcare across the Australian population and, where necessary, act as gatekeepers to other specialists with a referral generally being required to access these practitioners (Royal Australian College of General Practitioners, 2018c). While the overall number of GPs is estimated to be adequate to serve the Australian population (Laurence & Karnon, 2017), the distribution of GPs across Australia is not even, with maldistribution negatively affecting rural and remote areas as well as some urban settings (Australian Government - Department of Health, 2018d). There are several policies directed at addressing districts of workforce shortage and areas of need. A significant measure involves accepting international medical graduates (IMGs) into Australia based on a commitment from them to work only in these areas. The moratorium period served by IMGs is usually for ten years, however there may be reductions to this requirement based on remoteness and there have been variations in the designation of area of workplace shortage over time (Australian Government - Department of Health, 2012, 2015a). Another scheme is the Bonded Medical Places Scheme in which participants agree to work in an area of workforce shortage for one to six years in exchange for a training place at an Australian medical school (Australian Government - Department of Health, 2020b). Excluding participants of this scheme and IMGs serving their moratorium period, GPs have no regulatory restriction on where they can practice in Australia.

In Australia the profession of General Practitioner is a recognised specialty of medicine (Australian Government - Department of Health, 2018e) that is regulated by the national AHPRA (Australian Government - Department of Health, 2018e). General practice was recognised as a medical speciality in 2002 after a stepwise process (Harris & Zwar, 2014). From 1989 until 1995, medical practitioners who had five-years' experience working in general practice could be eligible to receive vocational recognition (Australian Government - Department of Health, 2018e) with these GPs termed 'vocationally registered general practitioners' (VRGP). GPs with this status were able to attract higher Medicare rebates (Harris & Zwar, 2014). Quasi-recognition of general practice as a specialty occurred in 1996 when legislation was introduced that limited the access to the recognition as a VRGP to doctors who had completed additional recognised training with formal recognition following in 2002 (Harris & Zwar, 2014). The Medical Board of Australia (MBA) accepts fellowship of the RACGP (Royal Australian College of General Practitioners, 2018a) or the ACRRM (Australian College of Rural and Remote Medicine, 2018) as the standard required for medical practitioners to be awarded specialist status. There are a variety of pathways and training programs that can lead to medical practitioners achieving fellowship status with the RACGP and ACRRM (Australian Government - Department of Health, 2020c), which vary in the supervision, education and recognition of prior learning. There are specific pathways for general practice in rural/remote locations and specific pathways for IMGs (Australian Government - Department of Health, 2020c). To maintain fellowship of the colleges, GPs must complete requirements within the triennium of either the RACGP, Continuing Medical Education (CME) (Royal Australian College of General Practitioners, 2020a; The Royal Australian College of General Practitioners, 2016) program or the ACRRM Professional Development Program (PDP) (Australian College of Rural and Remote Medicine, 2020)

The professional standards of GPs are the responsibility of the MBA and AHPRA and are managed via a set of required mandatory professional standards for yearly registration and a notification process (Medical Board of Australia, 2016a). One of the mandatory standards for registration is fulfilling a CME registration standard and the MBA recognises the fulfilment of GP college ongoing CME/PDP requirements as meeting this standard for GP registration (Medical Board of Australia, 2016a). Other standards include recency of practice, professional indemnity insurance cover, criminal history checks, proof of identity and English language skills (Medical Board of Australia, 2016a). The MBA investigates notifications that relate to unprofessional conduct, professional misconduct and unsatisfactory professional performance of GPs, where their health may impact on their practice and constitute a risk to the public (Australian Health Practitioner Regulation Agency, 2017). When making a negative finding, the MBA may withdraw registration for medical practitioners or place conditions on their registration (Australian Health Practitioner Regulation Agency, 2018).

The number, location and ownership of private general practices is not regulated in Australia and there is a lack of up-to-date data regarding these aspects of Australian private general practice (Britt, Miller, Valenti, et al., 2016; Erny-Albrecht & Bywood, 2016; Royal Australian College of General Practitioners, 2019; Swerissen & Duckett, 2018). The number of GP clinics in Australia in 2019 was reported to be 8147 (Australian Government - Productivity Commission, 2020). Historically, Australian general practices have been privately-owned, small businesses and commonly operated as solo practices, partnerships or associateships. In the 1990s, however, corporate general practice emerged as an additional ownership model (Erny-Albrecht & Bywood, 2016). There is debate about the impact on care of this corporatisation (Erny-Albrecht & Bywood, 2016) but there is a lack of data to evaluate this effect. Joyce et al. (2016) stated that in 2015: “no published data on GPs’ business relationship with their practices exists.” (Joyce et al., 2016, p 1). These authors determined from unpublished data from the *Medicine in Australia – Balancing Employment and Life* study that 75% of GPs were working in practices as associates, employees or contractors with 25% as principals or partners in their practice. The size of general practices has increased over time, which is likely to be associated with the change in ownership (Royal Australian College of General Practitioners, 2019). Comparisons between 1990-91 and 2013-15 showed that there was trend away from solo practice, with only 9% of GPs working in a solo practice, 33% in practices with four or more GPs and increasing proportions of GPs (27%) working in practices with more than 10 GPs (Britt, Miller, Valenti, et al., 2016). In 2019 RACGP surveyed 1174 of their members, 90% of the GPs surveyed worked in private general practice, 4% in solo practice and 86% in group practices with 16% identifying their main practice as a corporate practice (Royal Australian College of General Practitioners, 2019).

Australian general practices are accredited under the *National General Practice Accreditation Scheme* (The Australian Commission on Safety and Quality in Health Care, 2019) against the RACGP *Standards for general practice* (The Royal Australian College of General Practitioners, 2020). This accreditation is not mandatory but is a requirement for eligibility in the PIP (Australian Government - Department of Human Services, 2018b). In 2018-19 there were 6133 general practices participating in the program and $339.8 million were paid through this scheme (Australian Government - Department of Human Services, 2019) a slight decrease from the 2017-2018 period (Australian Government - Department of Human Services, 2018a).

### 2.3.4 GP's discretion in their scope of practice and the patients whom they provide care to.

In considering provision of care in private general practice, a critical aspect was found to be that GPs had a great deal of discretion, to provide or withhold treatment for PWHCV. Australian GPs could, to a large extent, adopt measures that influenced who attended their practice, determine their scope of practice, and choose the area of CME. There are no overarching regulations that control where GPs practice, and except for IMG in their moratorium period or doctors with return of service obligations under the Bonded Medical Places Scheme, GPs are at liberty to choose their practice location.

Access to care in private general practice is not guaranteed for all Australian citizens and general practices have discretion regarding who they accept as patients in their practice and whether appointment requests are granted. As stated in *Building a 21st Century Primary Health Care System: Australia's First National Health Care Strategy*:

> For many individuals, the primary health care services they access and the quality of care that results, has depended on where they live, their specific condition, and the service providers involved, as much as their clinical needs and circumstances. (Australian Government - Department of Health and Ageing, 2010a, p 9).

The Australian Medicare system has been described as a universal health care system (Mossialos et al., 2017), but no mechanism or regulations guarantee individuals universal access to private general practice care. Unlike health systems in other countries, no requirement exists in Australia for patients to be registered with one practice for rebates to be paid (Mossialos et al., 2017). Studies examining the response to requested appointments found there have been difficulties for Australians accessing care when required (Schoen, Osborn, How, Doty, & Peugh, 2009). It has been reported that in any year, 83% of the population visit a GP but 23% of the people who needed to see a GP at least once in the year, delayed seeing or did not see a GP (Australian Bureau of Statistics, 2019). Where people accessed GPs, there is no evidence as to whether their range of health care needs were met.

One way that Australian GPs and practices could influence which patients access their services, and what services are requested, is by their decisions regarding the charging of co-payments to patients (Magin et al., 2006). The majority of GP income is earned via Medicare fee-for-service payments (Healym, Sharman, & Lokuge, 2006) but additional co-payments are frequently charged. There are incentives to bulk bill patients, and 86% of GP services were bulk billed in 2018 (Hunt, 2018). However, there is no universal or guaranteed access to bulk billing and medical practitioners have discretion as to who is bulk billed and for which services. As Malcolm Turnbull, then Prime Minister of Australia, said in 2016, "Doctors are free to charge whatever they like, obviously, but they operate in a competitive environment. And plainly, that is why bulk billing is at all-time highs." (Turnbull, 2016b, p 2). This statement highlights GPs' discretion to bulk bill and highlights the influence of competition on bulk billing rates. As previously discussed (section 1.5), there are areas of Australia that are underserved by GPs (Australian Government - Department of Health, 2018d) and this competitive influence may be weaker in these areas. The Medicare 'safety net' programs require enrolment and the ability of patients to pay up to the threshold ($461.30 in 2018) (Australian Government - Department of Health, 2018g) which can limit the ability of the schemes to ameliorate the effect of fees charged by GPs.

Even when people are able to access GP care, they may not have been provided with best practice care for all of their health needs (Elkin, Spittal, Elkin, & Studdert, 2012; Runciman et al., 2012). During the GP-patient consultation, a range of both GP and patient factors will determine what is addressed during the consult and what is addressed over time (Agledahl, Gulbrandsen, Førde, & Wifstad, 2011; Stuart et al., 2019; Taylor, Horey, Livingstone, Chan, & Swerissen, 2013). There were difficulties identified in measuring quality of care in the provision of care by general practice (Elshaug, Watt, Mundy, & Willis, 2012; Runciman et al., 2012). The Australian Health Practitioner Regulation authority requires GPs to be ‘competent’ to be registered but competency is not externally monitored, and registration relies on GP declarations that they had met this requirement. GPs may not always be reliable judges of their own competency (Davis et al., 2006) and so may make honest but inaccurate declarations. To comply with MBA requirements, GPs may limit their scope of practice to areas of existing competency, rather than broadening their knowledge and skills. The MBA registration standard states: ‘

> Medical practitioners who are engaged in any form of practice are required to participate regularly in CPD [continuing professional development] that is relevant to their scope of practice in order to maintain, develop, update and enhance their knowledge, skills and performance to ensure that they deliver appropriate and safe care. (Medical Board of Australia, 2016b, p 2).

Lack of knowledge has been found to be a barrier to involvement in the provision of DAA (Sud et al., 2018; Wade et al., 2017; Wade et al., 2018), which may be evidence of GPs limiting their scope of practice to comply with MBA standards. As discussed, GPs are required to undertake accredited CME to maintain their registration with professional colleges (Australian College of Rural and Remote Medicine, 2020; Royal Australian College of General Practitioners, 2020a), but are free to choose which CME activities they attend. The literature on activities undertaken by Australian GPs tended to be about specific topics (Holliday et al., 2017; Schütze, Shell, & Brodaty, 2018) and there does not appear to be a large body of literature regarding how Australian GPs choose or prioritise the CME they attend (Cooke, Valenti, Glasziou, & Britt, 2013). The two Australian GP colleges; RACGP and ACRRM, have not published data in the last three trienniums; 2017-2019, 2014 -2016, or 2011-2013, regarding the education that their members undertook [private communication]. The data held by these colleges could provide information about CME topics selected and their preferred format, but not the basis on which the CME was chosen by these GPs.

It has been suggested that GPs need to prioritise the focus of their participation in CME (Cooke et al., 2013) due to the breadth of conditions they encounter (Britt, Miller, Bayram, et al., 2016) and that it is logical to do so based on the frequency of conditions that they see. The rationale provided for this approach was: “GPs need to know a lot about the conditions they see daily or weekly, less about those they see monthly or yearly, and little or nothing about rarities until they are encountered.” (Cooke et al., 2013, p 65). There is evidence that American GPs do prioritise CME in this way with the ‘relevance of the topic’, ranked highest in prioritising participation in CME (Cook, Price, Wittich, West, & Blachman, 2017; Price et al., 2002). Further, 85% of family physicians in the United States of America chose CME areas of interest that matched the perceived frequency of the conditions they encountered in their practices (Price et al., 2002). Under this scenario, to ensure best practice care was provided for low prevalence conditions, GPs would be required to have basic competencies to diagnose these conditions and, once encountered, undertake CME to bridge any gap in knowledge regarding the condition. Given it has been estimated that 20% of PWHCV remain undiagnosed in Australia (The Kirby Institute, 2016), and in the context of 87% of Australians attending general practices per year, there seems to have been relatively low GP ascertainment of HCV in their patients. The lack of recognition of competency, the selection of a narrow scope of practice and the prioritising of CME based on perceived frequency, may mean that GPs do not attend CME events around particular topics and, therefore, do not achieve or maintain their competency in the provision of care for HCV.

The Australian primary health system provides GPs with substantial discretion regarding the provision of care and how GPs exercise this discretion could be a determining factor in the provision of care for PWHCV. The basis of the decisions by GPs and general practices about the services they provide, and to whom, has not been transparent or well researched to date.

## 2.4 HCV in Australia

Worldwide, HCV causes significant mortality and morbidity (World Health Organization, 2017) however considerable variation exists in the epidemiology and response to the disease between countries (World Health Organization, 2017). The following sections relate to the literature regarding the HCV epidemic in Australia and provision of care for HCV in the Australian context.

### 2.4.1 The HCV epidemic in Australia.

Chronic HCV is a significant public health problem in Australia, with the number of Australians chronically affected at the end of 2018 estimated to be over 130 000 (The Kirby Institute, 2018a). There were 10 537 new HCV diagnoses reported in Australia in 2017 (The Kirby Institute, 2018a) with the notification rate remaining stable overtime (Kirby Institute, 2019). The acute phase of HCV infection is usually asymptomatic, with the virus clearing spontaneously within six months of infection in up to 25% of cases (Micallef, Kaldor, & Dore, 2006). Chronic HCV infection, however, has had a significant contribution to morbidity, subsequent healthcare costs and mortality in Australia (Grebely & Dore, 2011; The Kirby Institute, 2018a). Symptoms of chronic HCV vary, but left untreated may progress to hepatitis fibrosis, cirrhosis and hepatocellular carcinoma (HCC) (Hajarizadeh, Grebely, & Dore, 2013). These conditions may persist and progress, even when individuals have been in treatment and achieved clearance of the HCV virus (The Kirby Institute, 2018a). In Australia in 2017, it was estimated that individuals who had HCV related morbidity included: 145 294 with early to moderate fibrosis; 25 261 with severe fibrosis; 9 833 individuals with cirrhosis; and 1 600 who had decompensated cirrhosis or HCC (The Kirby Institute, 2018a). HCV-related advanced liver disease is the most common indication for adult liver transplants in Australia (Australia and New Zealand Liver Transplant Registry, 2019). In 2017, it was estimated that 583 HCV related deaths occurred (The Kirby Institute, 2018a).

Recognition of HCV as a distinct form of hepatitis is relatively recent, for while cases of hepatitis were recognised as distinct from hepatitis A and B in the early 1970s, the subsequent identification of HCV as the causal agent did not occur till 1989 (Di Bisceglie, 1998). In the early 1970s, post-transfusion hepatitis cases were investigated after hepatitis A and B were excluded, and these cases became referred to as non-A, non-B hepatitis (Seeff, 2009). In 1989 the ribonucleic acid (RNA) of HCV was isolated (Choo et al., 1989) and a specific assay developed to detect the newly named HCV virus (Kuo et al., 1989). The HCV genome has since been described and found to have a high level of heterogeneity, with HCV classified into seven major genotypes and further diverse subtypes (Bukh, 2016). The distribution of HCV genotypes varies between countries (Gower, Estes, Blach, Razavi-Shearer, & Razavi, 2014), with genotype 1 and genotype 3 being the most common in Australia (The Kirby Institute, 2016). The current diagnosis of HCV uses a two-stage diagnostic test with the initial use of HCV serology to test for markers of HCV infection. Current infection is confirmed by detecting HCV RNA using a sensitive Polymerase Chain Reaction (PCR) assay performed twice within a six-month period (to exclude the natural clearance of the infection) (Hepatitis C Virus Infection Consensus Statement Working Group, 2018). Point-of-care testing for HCV and dried blood spot sampling are being investigated as ways of increasing the diagnosis and engagement in care for HCV, especially for patients with IDU (Chevaliez et al., 2020). Dry spot methods can be used without the need for venous access, which may be difficult if IDU has caused venous damage (Chevaliez et al., 2020). Rapid point of care diagnosis shortens the time to results and has the potential for patients to be tested and receive their results in one visit (Chevaliez et al., 2020).

Individual Australian jurisdictions maintain disease surveillance systems and have legislation, designating HCV as a notifiable disease (Gibney, Cheng, Hall, & Leder, 2017). Cases are notified by the doctor, diagnosing laboratory, hospital or a mixture of these (The Kirby Institute, 2017a). In Australia, HCV became the most commonly notified communicable blood-borne disease (Commonwealth of Australia, 2003). The National Notifiable Disease Surveillance System (NNDSS) receives de-identified unit records of these notifications from each State and Territory body, with HCV included in the list of diseases reported in the NNDSS in 1996 (Gibney et al., 2017). Over time, estimates of the number of individuals with HCV may be modified, for example data linkage projects revealed that there was a significant number of duplicates for the same individual submitted by different Australian states (MacLachlan et al., 2020). Current notifications are classified as either 'Hepatitis C newly acquired' or 'Hepatitis C unspecified' (Australian Government - Department of Health, 2015b). The HCV data from the NNDSS are reported on an ongoing basis in annual surveillance reports produced by the Kirby Institute (The Kirby Institute, 2018a).

While HCV testing became available in Australia in early 1990 (Commonwealth of Australia, 2003), cases of HCV were retrospectively identified in patients' stored blood samples collected in 1971 (Rodger et al., 1999). These early cases of HCV were identified in Australia from patients admitted to a Melbourne hospital with hepatitis, and identified as having injected drugs (Rodger et al., 1999). It has been postulated that HCV may have affected a significant number of people even earlier, in the late 1960s (Commonwealth of Australia, 2003). Between 1991 and 1997, more than 110 000 diagnoses of HCV were notified to the State and Territory surveillance systems (Law, 1999). Early modelling of the epidemiology of HCV in Australia, using NNDSS data, estimated that there were over 110 000 people diagnosed with HCV antibodies by the end of 1997. The modelling estimated approximately 80% of these people had been infected through IDU, 5-10% through administration of blood or blood products and 5-10% via other routes, such as occupational needle stick injuries or tattoos (Law, 1999). With the virtual elimination of transmission via blood products by 2000 (The Senate Community Affairs References Committee, 2004), the relative proportion of incident cases attributable to IDU in Australia increased to more than 90%. Migration from countries with a higher HCV prevalence is another significant contributor to overall cases notified in Australia (11%) (Sievert et al., 2011). In Australia, HCV is notified for males at a higher rate than females, with a notification rate in 2015 of 69 per 100 000 for males and 31 per 100 000 for females (The Kirby Institute, 2018a). Australian Aboriginal and Torres Strait Islander populations, comprising 3% of the Australian population, have disproportionately higher rates of HCV notification compared to the non-Indigenous population, with 11% of notifications occurring among Australian Aboriginal and Torres Strait Islander in 2017 (The Kirby Institute, 2018a). The reporting fraction (those diagnosed among those infected) in Australia of approximately 81% is high relative to those reported internationally (Hajarizadeh et al., 2013; The Kirby Institute, 2017a) but there remains a large number of people infected with HCV who remain unaware of their status (The Kirby Institute, 2017a).

The progression of HCV is highly variable, and development of cirrhosis, liver failure and hepatocellular carcinoma are not inevitable or predictable (Dore et al., 2009). Liver function tests do not consistently indicate severity or stage of disease (Dore et al., 2009). The progression of the disease may be further influenced in a variety of ways by co-morbid conditions (Dore et al., 2009). Symptoms often take 20 years to develop, and consideration of this delay is important when modelling the expected burden of disease attributable to HCV (Grebely & Dore, 2011). In Australia, the burden of disease from HCV was steadily increasing as those who were infected during the peak incidence of HCV in the 1980 - 1990s began to age and were increasingly affected by HCV-related liver disease (Grebely & Dore, 2011). The estimated number of PWHCV-related cirrhosis peaked in 2015 before declining between 2015 and 2017. New cases of HCV decompensated cirrhosis and HCC also peaked in 2015, but then stabilised between 2015 and 2017 (The Kirby Institute, 2018a). In 2015-2016, the first decrease in HCV-related mortality in a decade was reported (The Kirby Institute, 2017a) and mortality rates continued to fall between 2016 and 2017 (The Kirby Institute, 2018a), with this decrease likely due to the uptake of new DAA treatment (The

Kirby Institute, 2017a). Continued decreases will rely on continued increases in treatment uptake (The Kirby Institute, 2017a).

### 2.4.2 Provision of care for HCV – The cascade of care

The ‘cascade of care’ is a concept that was developed in relation to HIV (human immunodeficiency virus) used to define the stages required to achieve care, and subsequently to examine the barriers and facilitators that exist at each stage of the cascade (Kilmarx & Mutasa-Apollo, 2013). The most basic description of the ‘stages’ or ‘phases’ within a cascade of care are diagnosis, treatment and cure (Safreed-Harmon et al., 2019). However, the delineation of phases is subjective and there have been various stages applied to the cascade of care for HCV (Safreed-Harmon et al., 2019). The phases of screening, diagnosis, assessment, provision of treatment or referral to a specialist for treatment and are relevant phases of the cascade of care for HCV, for GPs (Hajarizadeh et al., 2017; Simmons et al., 2018). Modelled projections have concluded that improvements in all these phases of the cascade of care for HCV are necessary to reach the target of eliminating HCV (Scott, Doyle, et al., 2017). Prior to the introduction of DAA in Australia, the GPs were not generally involved in the provision of anti-viral treatment (Sievert, 2003) but are now involved in this phase of the cascade of care (Wade et al., 2018). The specialist’s role in the provision of DAA HCV treatment was largely redefined as a consultation service for GPs who provided this treatment, with referral to specialists only being required in specific, limited circumstances such as the presentation of cirrhosis or specific comorbidities, or prior unsuccessful treatment (Sud et al., 2018; Wade et al., 2018).

### 2.4.3 HCV treatment prior to DAA Treatment.

It is important to understand the context of HCV treatment choices in the interferon-era, in which the perceptions and experiences of PWHCV and GPs may have been formed. Preceding the identification of HCV, the first treatments for non-A, non-B hepatitis were trialled with Interferon-alpha (IFN-$\alpha$) at various dose strengths and duration of treatment (Feld & Hoofnagle, 2005). In 1986, American trials (Feld & Hoofnagle, 2005) showed improvement to aminotransferase levels and hepatic histology with 12 months of treatment for eight out of ten patients. Similar trials were initiated in Australia at Westmead Hospital in New South Wales (NSW) in 1988 (Harvey & Loveday, 1999). The isolation of the HCV virus in 1989 allowed the measurement of sustained virological response (SVR), defined as "the loss of detectable HCV RNA during treatment and its continued absence for at least 6 months" (Feld & Hoofnagle, 2005, p 967). From a base of 6-12% SVR, the cure rate improved with additions and changes to the treatment regimens i.e. IFN-$\alpha$ +ribavirin / 35-44%, pegylated IFN-$\alpha$ / 54-56% (Feld & Hoofnagle, 2005). Across population groups, the cure rates were found to vary according to various host and viral characteristics. SVR was more likely when the patient was female, younger in age, had less fibrosis, lower body weight and body mass index, and had no significant co-morbidities. Viral clearance was also dependent on race , i.e., higher clearance rates for non-African American. SVR was also more likely where there was a lower baseline viral level, greater quasi species diversity, and where the disease was in the acute phase (Feld & Hoofnagle, 2005). Cure rates varied dependent on the genotype, with the most common genotype in Australia, genotype 1, being associated with lower cure rates (40–50%) than the next most common, genotype 3 (80%) (Carvalho-Filho & Dalgard, 2010). In the context of low overall cure rates using interferon-based HCV treatment, determining the likely outcome for an individual with HCV therefore involved assessing and considering a complex range of viral, clinical and patient-related factors (Carvalho-Filho & Dalgard, 2010).

Prior to DAAs, the provision of treatment in Australia was led by specialists and was largely hospital-based (Australian Government - Department of Health and Aged Care, 2000; Gidding et al., 2009). HCV antiviral therapy with interferon was provided under the Highly Specialised Drugs Program Section 100 of the National Health Act with States responsible for regulating the prescribing of these drugs (Lambert et al., 2011). Prescribing was initially limited to specialists and only permitted within established outpatient liver or infectious disease clinics that could meet additional criteria, such as 24-hour access to medical advice. In this situation, PWHCV had to negotiate clinic access and deal with unknown clinical staff, which could expose the patient to discrimination (Dutertre & McNally, 2008) - all of which represented a barrier to treatment. Creating a further barrier, given the many exclusions that applied at that time, patients seeking treatment may not have been eligible or deemed appropriate for treatment (Gidding et al., 2011; Stewart, Mikocka-Walus, Harley, & Andrews, 2012). Recommendations could improve the pathway to specialist care (Howes, Lattimore, Irving, & Thomson, 2016) but any barriers associated with access to specialists could be not be completely overcome if treatment remained only available in this setting.

Prior to the introduction of DAA, there was low treatment uptake in Australia (<2%) and internationally (1 – 5%) (Dore, Ward, & Thursz, 2014), and people with chronic HCV usually experienced this condition as a long-term chronic condition. This is despite benefits being maximised the earlier treatment is provided to people with a diagnosis of chronic HCV (Attar & Van Thiel, 2016; Martin et al., 2016; Pinsky, Mitchell, Sanchez, Johnson, & Sammy, 2018). Reported benefits of early uptake of antiviral treatment includes improved quality of life for affected individuals, reduction of progression of liver disease with subsequent reduction of cost to health care systems (Pinsky et al., 2018), and maximising the effect of treatment as prevention (Hajarizadeh et al., 2016). However, PWHCV may have delayed the decision to enter treatment, particularly whilst they were asymptomatic (Butt, McGuinness, Buller-Taylor, & Mitchell, 2013; Khokhar & Lewis, 2007). Once PWHCV actively deliberated on entering treatment, the decision would involve consideration of factors relating to treatment efficacy and treatment side effects (McNally et al., 2006). It is difficult to know the basis on which decisions were made, as the extent to which individual patients and their GPs were aware of the treatment options, is not clear (Dore et al., 2009; Treloar et al., 2010). Low cure rates were associated with the formerly available, interferon-based, HCV antiviral treatments (Feld & Hoofnagle, 2005), as well as negative side effects (Dieperink, Ho, Thuras, & Willenbring, 2003; Fraenkel, McGraw, Wongcharatrawee, & Garcia-Tsao, 2006; Sublette et al., 2015) and long, complicated treatment regimens (Carvalho-Filho & Dalgard, 2010; McCaughan et al., 2007). Table 5 summarises interferon side-effects as listed in the National Hepatitis C Resource Manual, 2001 (McNally, Temple-Smith, & Pitts, 2004). People undertaking interferon-based treatments reported the severe negative impact of associated side-effects on their ability to function normally in all spheres of their lives (Fraenkel et al., 2006; Treloar & Hopwood, 2008). These treatments were understandably perceived by PWHCV as "gruesome" (Treloar et al., 2015, p 8) and were a factor that deterred PWHCV from entering and completing treatment (McNally et al., 2006).

**Table 5: Side-effects of interferon and ribavirin antiviral therapy for HCV (Adapted from:McNally et al., 2004, p 14)**

| | |
|---|---|
| Interferon side-effect categories | Systemic: Flu-like symptoms including fever, headache, rigours and coughing, nausea, weight loss, diarrhoea, temporary hair loss, exacerbation of current conditions such as diabetes |
| | Neurological: Loss of concentration, loss of sensation, insomnia, visual and auditory loss (rare), exacerbation of epilepsy |
| | Psychological: Anxiety, depression, irritability, psychosis |
| | Myelosuppression: Low white blood cell count, thrombocytopaenia |
| | Induction of autoimmunity: Overactive thyroid, psoriasis or worsening of these |
| | Cardiac: Arrhythmia, congestive failure |
| | Susceptibility to infection |
| Ribavirin side-effect categories | Haematological: Haemolytic anaemia |
| | Respiratory: Cough, breathlessness, pharyngitis, sinusitis |
| | Dermatological: Rash |
| | Embryonic development: Possible birth defects |

**(Used with permission from La Trobe University, adapted from McNally S, Temple-Smith Meredith et al. 2004, p 14, ‘Making decisions about hepatitis C treatment’ Australian Research Centre in Sex, Health and Society used with permission from La Trobe University.)**

The conundrum regarding the timing of uptake of treatment for patients and their treating doctor (Wagner et al., 2009) was made more complex (Backx et al., 2014) by the prospect of the upcoming availability of the new DAA (Casey & Lee, 2013; Dore & Feld, 2015). While there had been stepwise progress involving refinements to interferon-based treatments (Casey & Lee, 2013; Dore & Feld, 2015), reports were emerging of the development of radically improved DAA. There was excitement about what was perceived as a realistic hope that these new, well-tolerated therapies involving a short duration, all oral therapies, would soon be widely available (Casey & Lee, 2013; Dore & Feld, 2015). The optimism regarding this treatment was reflected in the term ‘perfectovir’ coined for this expected revolutionary treatment (Dore & Feld, 2015). The results of international trials were reported in 2014 at the International Liver Congress (Dore & Feld, 2015). Optimism for the new treatment was tempered with acknowledgement that the potential of these treatments could be limited by the cost of the drug, prioritisation of making this treatment available within healthcare budgets and issues related to lack of screening and incomplete disease assessment (Dore & Feld, 2015).

While the promise of DAA made attractive the option to delay treatment, delaying treatment can also have significant, negative outcomes regarding the progression of patients’ HCV (Attar & Van Thiel, 2016; Martin et al., 2016; Pinsky et al., 2018). Many ‘unknowns’ factored into this decision, including the likely progression of an individual patient’s HCV, the likelihood of interferon-based treatment achieving cure compared to DAA, the length of delay until DAA became available, potential access restrictions to DAA, the potential cost for the patient of DAA compared to the subsidised interferon-based treatment, and the patient’s tolerance to the side-effects of either treatment. With the introduction of DAA, getting people into treatment in as short time frame as possible, became the clear-cut target.

### 2.4.4 DAA treatment for HCV

In contrast to former treatments, the new DAAs offers high cure rates, a short treatment duration of 8-12 weeks, simple oral pill regimens and nil to negligible side effects (Haridy et al., 2018; Hepatitis C Virus Infection Consensus Statement Working Group, 2018; Pawlotsky, 2014). The introduction of pangenotypic DAA has further simplified the treatment planning for patients with HCV (World Health Organization, 2018; Zoratti et al., 2020). Real-world outcomes of treatment with DAA have now been reported in Australia (Haridy et al., 2018; The Kirby Institute, 2018b). This included outcomes for cases where treatment was completed, as well as cases of ‘intended for treatment’ where patients had not started, or completed, their treatment for any reason (Haridy et al., 2018; The Kirby Institute, 2018b). Treatment outcomes varied for different subgroups, but cure rates for all groups were above previous cure rates. Outcomes from the REACH-C network, a national network of diverse clinical services across Australia, were reported for 4 223 individuals initiated on DAA (The Kirby Institute, 2018b). For individuals with known treatment outcomes (N=3805), 96% achieved SVR12. For all patients with an intention to treat (N=4223), 80.1% achieved SVR12. This study showed lower rates of cure for patients with cirrhosis (92%), and where patients were treatment experienced (92%). Overall cure rates measured by SVR12, of 96% were found for patients completing treatment, between March 2016 and February 2017 (n=1534) in South Australia (Haridy et al., 2018). The cure rate for all subjects intended for treatment (n=1909) in this study, was 80.4%, with 0.5% of all reported discontinuation due to adverse effects of treatment. Cure rates were lower for genotype 2 (92.3%) and genotype 3 (92.3%), and these rates were further affected where patients were cirrhotic or who were treatment experienced (Haridy et al., 2018).

With the release of DAA onto the market, there was a fundamental change in the outcome ambitions of the provision of medical care for HCV in Australia and internationally, and the 'elimination of HCV' became a stated aim of provision of care (Burki, 2014; Grebely, Dore, Morin, Rockstroh, & Klein, 2017; Hellard, Sacks-Davis, & Doyle, 2016; Scott, Doyle, et al., 2017; Ward, 2016; World Health Organization, 2016a). Modelled projections showed the possibility of reducing overall HCV incidence by achieving significant HCV cure rates with DAAs (Martin, Hickman, Hutchinson, Goldberg, & Vickerman, 2013; Martin, Vickerman, & Hickman, 2017; Scott, McBryde, Thompson, Doyle, & Hellard, 2017). The goal to eliminate HCV was proposed by the WHO with targets to achieve a 90% reduction in new infections and a 65% reduction in mortality by 2030 (World Health Organization, 2016b). This replaced the less ambitious aims to decrease transmission and increase treatment uptake, as expressed in the Fourth National Hepatitis C strategy 2014-2017 (Australian Government - Department of Health and Ageing, 2014). This latter strategy included the goal to "increase the number of people receiving antiviral treatment by 50 per cent each year" (Australian Government - Department of Health and Ageing, 2014, p 6). Due to the extremely low base rate of approximately 1% uptake of treatment in 2014 (McGregor, McManus, Gray, & Costello, 2015), even if the goal of increasing uptake each year by 50% was achieved, by 2017 the uptake rate would still have been as low as 16%. Even this modest goal was couched in the term "aspirational" (Australian Government - Department of Health and Ageing, 2014, p 6), which highlighted the previous low benchmark of treatment goals when contrasted with the elimination discourse, in use by 2017. Modelled projections in Australia showed that to reach the target of elimination by 2030 a sustained uptake of DAA, with approximately twenty thousand people entering this treatment each year, would be required (Kwon et al., 2018).

To facilitate the timely uptake of DAA, the Australian Federal Government introduced regulations in relation to the provision of DAA to allow all Australian citizens with HCV to be treated (Dore & Hajarizadeh, 2018; Ley, 2016) and announced a significant $1 billion investment "to cure Hep C" (Ley, 2015, p 1). An expenditure of this magnitude was required for the anticipated increased uptake of new DAA medication, with an estimated cost between $66,000 to $98,000 AUD per patient compared to the previous cost of interferon-based treatment ($12,000 to $45,000 AUD per patient) (Lee, van Driel, & Crawford, 2017). The cost of treatment was reported as a major barrier to access to DDA treatment internationally with this cost variously borne by governments, individuals or a combination of these (Millman et al., 2017; Monforte et al., 2017; Ward & Mermin, 2015; World Health Organization, 2016b). As discussed, medications included in the Australian PBS are bulk purchased by the government and then made available to Australian citizens at a reduced or subsidised rate (Vitry & Shute, 2018). The highly subsidised cost for Australia citizens was highlighted by the then Federal Health Minister, Sussan Ley, in her press release regarding the inclusion of the HCV DAAs on the PBS,

> Australians with Hep C would now pay just $6.20 a prescription if they were a concession card holder or $38.30 a prescription as a general patient for four different cures listed on the Pharmaceutical Benefits Scheme today – saving patients as much as $100,000 for treatment. (Ley, 2016, p 1).

Consideration of drugs for inclusion onto the PBS requires a cost-effectiveness analysis (Australian Government - Department of Health, 2016a). In the modelling, the cost of treatment was offset by the reduced ongoing costs to the Australian Government achieved by reducing the burden of HCV infection, including medical costs such as for liver transplantation (Australian Government - Department of Health The Pharmaceutical Benefits Scheme, 2015). The inclusion of this treatment onto the PBS made these treatment affordable for all affected Australians (Ley, 2016; Vitry & Shute, 2018).

In 2016 the Australian Government negotiated a five-year purchasing agreement with the pharmaceutical suppliers of the DAA, which provided an imperative to treat as many

PWHCV as possible, within the term of the agreement (Dore & Grebely, 2017; Dore & Hajarizadeh, 2018). The details of the negotiations were treated as commercial in confidence, however it was reported the agreement included a ‘Risk Sharing Arrangement’ clause whereby treatments were to be provided free after a set number of treatments were purchased (Australian Government - Department of Health The Pharmaceutical Benefits Scheme, 2015). When additional DAA drugs for HCV were added to the PBS they did so based on the drugs being added to the existing financial risk sharing arrangements (Pharmaceutical Benefit Scheme, 2016). In other countries, caps were placed on treatment places as a way of limiting costs to governments (Marshall, Cunningham, et al., 2018). The Australian funding arrangement, however, provided the government with a cost savings incentive if the number of treatments purchased during the agreement exceeded the capped treatment purchase number (Martinello, Hajarizadeh, & Dore, 2018). With free treatments only being provided after the cap was exceeded and before the end of the negotiated agreement, this clause acted as an additional structural driver to the imperative to get PWHCV treated as quickly as possible. While reports exist that show GPs have a sense of responsibility to the maintain the sustainability of the health care system (Manning, 2011; Robertson, Walkom, & Henry, 2011), GPs must understand the arrangement and the imperative it creates, before this healthcare system arrangement can influence the provision of DAA by GPs. No literature however was found regarding GPs’ understanding of this arrangement.

By 2017, Australia had wide eligibility criteria for patients to access DAA which were independent of the severity of their liver disease, alcohol use or illicit drug use status (Hepatitis C Virus Infection Consensus Statement Working Group, 2017), whilst internationally a variety of limitations remained (Marshall, Pawlotsky, et al., 2018). Before the introduction of DAA in Australia, there had been limitations placed on eligibility to treatment such as exclusion of current PWID (Lowe & Cotton, 1999), although this exclusion had been gradually relaxed. The rationale behind these previous criteria were not always made explicit (Craxi et al., 2016), however studies had demonstrated comparable cure rates of DAA amongst PWID (Seal et al., 2007) and this negated the medical rationale for PWID to be excluded. Cost and eligibility factors were therefore largely overcome for Australian citizens accessing DAA.

The reduction of these barriers and the changed targets for the provision of care for HCV, led to questions about the capacity of the health system to provide this care, and a re-examination of the role of GPs in this provision of care (Kaan, Jones, & McCaughan, 2017). After the approval of HCV DAA onto the PBS in Australia in 2016, there was a focus on increasing the capacity of GPs to provide this treatment and the regulations and guidelines were incrementally and rapidly changed to give increasing prescribing rights to GPs (Hepatitis C Virus Infection Consensus Statement Working Group, 2018). Similar to the experience of treatments for other conditions (such as diabetes and HIV) that were previously provided by specialists and then shifted to provision by GPs (Basudev et al., 2016; Newman et al., 2011), the potential role of GPs in the prescribing of treatment to PWHCV has increased dramatically overtime.

More than 70 000 people have received DAA therapy for HCV in Australia since unrestricted access to this treatment became available in March 2016 (Kirby Institute, 2019). Between 2014 and 2015, it is estimated that an additional 4 340 people received treatment, via early access pathways including clinical trials, generic importation and pharmaceutical industry compassionate access programs (Hajarizadeh, Grebely, Matthews, Martinello, & Dore, 2018; Kirby Institute, 2019). The uptake of treatment has not been consistent, with an initial surge of 32 610 individuals entering treatment in 2016, then 21 540 in 2017, and 16 110 in 2018 (Kirby Institute, 2019). The initial surge can be explained by a ‘warehousing effect’ HCV treatment was delayed in a group of patients until DAA became proven and generally available (Aronsohn & Jensen, 2012; Palak, Livoti, & Audibert, 2017). While the overall number of individuals treated in Australia is impressive, modelling suggests the current rate of treatment is not high enough to reach the level required to reach elimination (Burnet Institute and Kirby Institute, 2019). The potential role of private GPs in Australia in the provision of care for HCV, increased in scope and significance after DAA became available in 2016 (Hepatitis C Virus Infection Consensus Statement Working Group, 2018). While the proportion of patients being prescribed DAA by GPs has been increasing and cure rates are comparable to other settings (MacLachlan et al., 2020; MacLachlan, Thomas, Cowie, & Allard, 2018), this involvement must increase to the level of treatment required to reach elimination targets (Burnet Institute and Kirby Institute, 2019).

## 2.5 The care provided for HCV by GPs in private general practice in Australia

The literature encompasses GP involvement in all aspects of the cascade of care for PWHCV. There was a body of literature that was directed at GPs to provide instruction on the provision of best practice care for the provision of care for HCV in their practice (outlined in section 2.5.1). Other literature was in the form of regular reports that provided detailed quantitative information about HCV diagnoses, monitoring, treatment and referral to specialists in Australia, as well as categories of professions providing this care. These include the *Viral Hepatitis Mapping Project National Reports* (MacLachlan et al., 2020; MacLachlan, Thomas, & Cowie, 2019) and *Monitoring hepatitis C treatment uptake in Australia* reports (Kirby Institute, 2017, 2018, 2019; The Kirby Institute, 2017b). Additional qualitative and quantitative information regarding the provision of care for HCV provide is published in the literature, from both the current and pre-DAA eras. I will discuss the involvement of GPs in the provision of care for HCV and the gaps in the literature in this regard.

While examining the literature regarding the provision of care for HCV by GPs for this thesis I took specific note of the setting in which this care took place, and the timing of this care. My research was specifically interested in the provision of care in private general practice, however the setting where GP provided HCV care was not always specified in the literature. Thus, care could have been provided in private general practice or other sites where GPs were employed, such as specialist drug clinics, ACCHO, other community health clinics and prison health services (Bartlett et al., 2018; Lee et al., 2018; Read et al., 2017). While the proportion of GPs employed in these settings is low (Health, 2016; Royal Australian College of General Practitioners, 2019), PWHCV may disproportionately engage with GPs working in these alternative settings. I will highlight when the setting is not stated or ambiguous. Another important aspect when reviewing the literature on the involvement of GPs in the provision of care for HCV, it is to consider the timing of when the care under investigation was provided (Iversen et al., 2017; Martin et al., 2017; Scott, Doyle, et al., 2017). For example, prior to the introduction of DAA, GPs were following best practice care, by referring HCV patients to specialists when treatment was indicated (Batey, 2003). Also, as eligibility criteria were progressively reviewed (Lowe & Cotton, 1999), when examining GPs' advice to patients the specific regulatory context in which this advice was given must be considered. Although there has been continuous change, it is important to consider how the specific conditions in place at any one time, may have shaped involvement of GPs in care at that time. Part of this consideration is any lags in understanding about these changes that may have occurred in GPs and PWHCV (Hellard & Wang, 2009). The involvement of GPs in the different stages of the cascade of care will be presented, noting the historical context and how this may have influenced involvement.

### 2.5.1 Clinical information available for GPs to support the provision of care for HCV

The literature includes information for GPs to provide care for patients with HCV in the form of guidelines and instructive articles (Baker, Balcomb, O'Loan, & Howell, 2019; Chan et al., 2019; Draper, Layton, & Doyle, 2019; Hepatitis C Virus Infection Consensus Statement Working Group, 2018; Khoo & Tse, 2016; Layton, Richmond, & Baker, 2019; Purcell, Wade, & Accadia, 2019; Strasser, 2017; World Health Organization, 2018). These include a five-part *Eliminating Hepatitis C* series of articles written by Australian clinicians for the Australian context. The topics covered in this series are: finding patients with HCV (Draper et al., 2019), assessing patients for DAA (Layton et al., 2019), curing HCV in general practice (Purcell et al., 2019), ongoing care after DAA (Chan et al., 2019) and practical steps for micro-elimination in GPs' practices (Baker et al., 2019). Topics covered represent the stages involved in the cascade of care that are critical for DAA to be provided in general practice. Education and resources are also available in different formats, for upskilling GPs to provide this care (ASHM, 2018; Gastroenterological Society of Australia et al., 2020). Some aspects of this care involve core skills that are common to providing care to all patients, for example history taking, developing rapport with patients, confidentiality, pre- and post-test counselling (Royal Australian College of General Practitioners, 2016). While these are core skills, a high level of competency and specific approaches to these tasks may be ideal when providing care to PWHCV (Baker et al., 2019; Draper et al., 2019), for example the specific language used (Wilson, 2020). In addition, there are skills and knowledge that are specific to providing care to patients with HCV, for example diagnostic testing, DAA planning, DAA provision and post DAA care (Chan et al., 2019; Hepatitis C Virus Infection Consensus Statement Working Group, 2020; Layton et al., 2019; Purcell et al., 2019).

The proportion of HCV that is likely to be undiagnosed is estimated to be 20% (The Kirby Institute, 2017a) and this high proportion underscores the importance of the detection of risk factors and subsequent screening for HCV by GPs, as part of addressing HCV in the population (Draper et al., 2019). While this is an important step it is not necessarily covered in the HCV-specific literature and guidelines are often written assuming that the patient has an existing diagnosis of HCV, and that this diagnosis is known to the treating doctor (Hepatitis C Virus Infection Consensus Statement Working Group, 2018; Khoo & Tse, 2016; Strasser, 2017). The articles by Draper et al. (2019) and Baker et al. (2019) that cover the topic of finding patients with HCV, are written without the assumption that GPs are aware of the patient's HCV status. The article outlines processes by which existing and new patient histories can be taken to maximise disclosure of HCV risk factors. Advice about the points to cover pre and post HCV testing are outlined and include providing the patient with information, gathering informed consent and informing patients of the options available if a result is positive. Information is provided about the two-stage testing process involving the HCV antibody test, followed by the HCV RNA PCR test and interpreting the results. This article provides general information about HCV, emphasises the part GPs can play in providing DAA and the possibility of elimination of HCV through widespread uptake of this treatment in Australia.

Once patients are diagnosed with HCV, the next step is to assess a patient's eligibility for DAA, with the majority of patients being able to be treated by GP, and a small number of cases requiring referral to specialists (Layton et al., 2019). The article by Layton et al. (2019) on the topic of assessing patients for DAA, guides GPs through this process. The guide details the required pre-treatment assessment including taking a patient history, establishing concomitant medications, physical examination, virology and other investigations. As part of determining whether the patient can be safely treated by GPs, it is a requirement for cirrhosis to be excluded. Aspartate aminotransferase to Platelet Ratio Index (APRI) and/or transient elastography, such as Fibrocan®, can be used to carry out a liver fibrosis assessment and where cirrhosis is present referral to a specialist is recommended. Likewise, where patients have previously failed DAA or have complex co-morbidities, referral to a specialist is recommended. The article flags that the requirement to determine the HCV genotype may become redundant with the approval of pangenotypic DAAs by the PBS. Since the publication of the article, pangenotypic regimens have been approved (Hepatitis C Virus Infection Consensus Statement Working Group, 2020) providing an example of the difficulty of maintaining the currency of information provided for GPs. In addition the *Remote consultation request for intiation of hepatitis C treatment* form (Appendix 1) lists all the steps required to establish a treatment plan for DAA for patients with HCV (Gastroenterological Society of Australia, 2019).

Detailed guidance for the provision of DAA in general practice and follow up care is provided in the articles by Purcell et al. (2019) and Chan et al. (2019). These guides include information about assessing possible adherence barriers for patients, advice to patients, managing drug-to-drug interactions, writing scripts, post treatment testing and other ongoing care after DAA. HCV cure is assessed 12 weeks (or later) from the completion of DAA, by HCV RNA PCR testing tests. A negative test indicates a sustained virologic response at 12 weeks, with the abbreviation of SVR12 used to describe that the patient is considered cured. When a cure has not been achieved, then referral to a specialist is recommended. Patients with persistent abnormal liver function tests after DAA and with cirrhosis also require referral to specialists for investigation and monitoring. Patients who have been cured are likely to remain positive for HCV antibodies indefinitely, however past infection does not provide immunity. People at risk of reinfection should be offered annual testing for HCV and provided with access to harm reduction programs, for example OST, and needle and syringe programs.

The Hepatitis C Virus Infection Consensus Statement is a fifty-nine page document which provides detailed information about HCV in Australia and clinical advice about providing care for HCV, which has been updated since the introduction of DAA (Hepatitis C Virus Infection Consensus Statement Working Group, 2020). Although comprehensive, the volume of information in this document may not encourage GPs to view the process of prescribing DAA as stratightforward. The *Clinical guidance for treating hepatitis C virus infection: a summary* (Gastroenterological Society of Australia et al., 2020) represents a concise, two-page resource that provides the information required to guide a GP through the assessment and provision of DAA for patients with HCV.

Having guidelines and resources available does not necessarily translate into these being used by GPs and as noted in the case of the article by Layton et al. (2019) maintaining currency of information is difficult (Basedow, Runciman, Lipworth, & Esterman, 2016; De

Angelis et al., 2016). The level of GP access to these articles, and the effect on the provision of DAA is difficult to establish from the published literature.

### 2.5.2 Provision of screening, diagnosis, testing and other management of HCV by GPs

The first step in the cascade of care for HCV is screening for HCV risk factors, including IDU, to determine which patients should be offered diagnostic testing. GPs are reluctant, however, to investigate these risk factors with patients (Dore et al., 2009; McLeod et al., 2017). The lack of screening for risk factors is not restricted to IDU however, with Australian GPs found to incompletely screen for the modifiable lifestyle risk factors of smoking (74%), nutrition (22%), alcohol (63%) and physical activity (28%) (Denney-Wilson et al., 2010). Only 13% of GPs surveyed correctly identified all HCV risk factors when surveyed (Gooey et al., 2020). A Scottish study that included an intervention to increase HCV testing (McLeod et al., 2017), found that GPs were reluctant to investigate patient's risk factors but did usually offer testing when aware of patient's IDU (88%). The lack of patient registration with general practices in Australia may reduce the opportunity for follow-up by GPs. It is therefore not clear whether a similar testing rate occurs in Australia after identification of risk factors (even if a similar intervention to the Scottish study was implemented). When HCV diagnostic testing is conducted, it is recommended that pre- and post-testing counselling occurs. Aspects of this counselling have been described in published evaluations (Gifford, O'Brien, Bammer, Banwell, & Stoove, 2003; Gifford et al., 2005) none of which are recent publications. In addition, these publications do not provide details regarding the practitioner who conducted the testing and it is therefore not clear whether private GPs were involved. There are suggestions that some HCV diagnostic testing may have occurred without the permission of the patient (Gifford et al., 2005) and the general standard of pre- and post-testing counselling has been questioned (Treloar et al., 2010), with patients reporting its limited occurrence and low quality (Gifford et al., 2003; Gifford et al., 2005; Richmond, 2008). Again, these publications are not recent and may not reflect the current situation. While gaps in risk factor screening may provide a significant barrier to the diagnosis of HCV, Australian studies regarding screening for HCV are not recent and further research is warranted to address this gap.

Testing for HCV is the next step in the cascade of care for HCV and GPs have been involved in testing for HCV since this testing was introduced in Australia in 1990 (Commonwealth of Australia, 2003). Before the introduction of DAA, it was reported that the majority of HCV diagnoses were undertaken by GPs (Dore et al., 2009). These GPs may have been located outside of private general practice however studies supported that GPs in private practice were involved in the diagnosis of HCV (Day et al., 2008; Gifford et al., 2003; Gifford et al., 2005). In studies that investigated HCV diagnostic experiences (Gifford et al., 2003; Gifford et al., 2005), 50% of both male and female participants had been diagnosed by their 'regular' GP. Day et al. (2008) surveyed PWID in Sydney, Australia, in 2005 and found that 53% had been tested for HCV in private general practices. Notification data shows that 56% of new HCV notifications in South Australia from 2010 till 2016 were made by private GPs (Edmunds, Miller, & Tsourtos, 2019; The Kirby Institute, 2017a). While aspects of HCV notifications are regularly reported (Burnet Institute and Kirby Institute, 2019; MacLachlan et al., 2020; MacLachlan et al., 2018) details about the notifying doctors are not included in these reports. To assist the planning of interventions to increase the participation of private GPs in diagnostic testing, it would be advantageous if these details were also regularly reported in these reports.

Confusion among patients and GPs around the diagnostic testing process was reported, with limited use of confirmatory PCR testing occurring after antibody testing for HCV exposure (Butler et al., 2017; Carruthers & Ryan, 2012; Gupta, Shah, & Ward, 2006). Patients may be confused about the meaning of test results with a study finding that only 19% of people who believed they had a diagnosis of HCV, were able to describe the function of the confirmatory PCR test (Carruthers & Ryan, 2012). In 2015, Butler et al. (2017) surveyed people who injected drugs (PWID), demonstrating that this group received antibody testing most frequently from their regular GP. However, only 48% of those tested had subsequently received confirmatory PCR testing after returning a positive antibody test (Butler et al., 2017). It was previously found that 25% of medical practitioners believed that a positive HCV antibody result indicated current infection (Richmond et al., 2007) and GPs reported that they needed further skill development around therapeutic and diagnostic testing (Gupta et al., 2006). Another more recent study using data from the MedicineInsight program (Busingye et al., 2019) examined the management of HCV in primary care

(Chidwick et al., 2018) and also found deficiencies in diagnostic testing. The participants for the study were included if they were 18 years or older, had visited the practice on three occasions between from January 1 2013 and August 31 2017, and had a new HCV-related entry recorded in this time period. The study aimed to determine what testing had been conducted for the patients included in the MedicineInsight program study (Chidwick et al., 2018). From a total of 2.63 million patients in the practices involved in the data collection, 4 025 patients were classified as having confirmed HCV and 3137 were classified as having indeterminate HCV infection. The results indicated that it is likely that incomplete testing and assessment of HCV, for example no confirmatory PCR test, applied to 50% of patients who received a positive antibody test. Among GPs surveyed in 2017, 88% identified the need for the two-stage test to confirm a diagnosis of HCV, up from 74% when surveyed in the year before (Gooey et al., 2020). While the improvements described may be significant, the study acknowledged that GPs interested in HCV may have been more likely to respond to the survey and the improved knowledge even within this select group still would lead to 12% of GPs not being aware that a diagnosis of HCV required the confirmatory PCR test.

Deficiencies in HCV testing after HCV diagnosis have been noted (Busingye et al., 2019; MacLachlan et al., 2018). The *Hepatitis Mapping Project* reported on HCV testing including HCV RNA viral load and genotype tests, ordered by non-specialists as a proportion of test conducted (MacLachlan et al., 2018). It was noted that these tests were commonly ordered by GPs in the pre-DAA era and the proportion of such tests ordered by non-specialists had increased since the introduction of DAA. In the period September 2016 through February 2017, the proportion of viral load tests ordered by non-specialists increased from 54 to 60% and genotype testing from 51 to 72%. Data on the absolute number of tests ordered, and category of professional ordering them, were not supplied. Again, the nature of the site where the non-specialist worked was not detailed. Data examined from the MedicineInsight program (Busingye et al., 2019) reported that at primary care sites, less than ideal testing had also occurred in respect to quantitative RNA testing (65.8%); LFT (Liver Function Test), FBC (Full Blood Count) and/or UEC (Urea Electrolytes and Creatinine) tests (50%); and screening for HIV (13%) or Hepatitis A (0.5%) or B (12.7%) coinfection or HCV serology (12.2%). It was noted that these figures and those relating to confirmatory PCR testing may have been an underestimate of the tests conducted, due to the methods used to extract the data, and that these tests may have been conducted in alternative settings. This study acknowledged that the data “does not capture whether patients have declined offered treatment or reasons why a patient may decline testing or treatment when it has been offered” (Chidwick et al., 2018, p 643). In addition to the findings reported in the study, the extraction process of data, highlighted the complexity of using electronic health records for research purposes. The problems of such a process would be amplified for general practices, where the same level of resources and skills provided as part of involvement in the MedicineInsight program, would not be expected. The low level of cases who matched the criteria of inclusion in the study, (N= 7 162 from a total of 2.63 million patients), indicates that GPs may not have patients in their practice who have a recognised diagnosis of HCV.

Prior to the general availability of DAA, studies reported the management of HCV by GPs and rates of referral to specialists. While the treatment and pathway to treatments described are largely redundant, these studies demonstrate the complexity of the treatment decisions in this era and provide the background context to GPs’ current involvement. In the pre-DAA period, GPs had a limited role in prescribing treatment but were responsible for conducting correct assessments and appropriately referring patients to specialists. McNally and Temple-Smith (2006) reported that 47% of HCV-infected people were seeing a GP for their HCV. The study reported rates of referral to specialist and other services but did not report if a private GP was responsible for these referrals. From a sample of 458 Australian GPs surveyed in 2005 (Gupta et al., 2006), 76% indicated they had managed a patient with HCV in the previous 12-month period. Considering the last patient these GPs had managed, 55% of GPs reported that they had made referrals to a specialist consultant, 46% to specialist hospital units, 25% had managed the patient alone and 10% with another GP, and 4% had referred patients to community support. The study relied on self-reported data and the authors indicated that there may have been a ‘degree of social response bias’ (Gupta et al., 2006, p 5) in the responses given. Gifford et al. (2003) described how 52% (N=462) of women with HCV in the Australian state of Victoria and the Australian Capital Territory, reported being referred to a specialist. There were differential rates of referral reported according to IDU status, with 73% of non-PWID patients, 66% of former PWID and 32% current PWID referred to a liver clinic. Referral to a specialist did not always translate into these patients having received treatment, with only 17% of the total sample in this study having received treatment for HCV. Diagnoses with HCV also did not always translate into patients receiving ongoing HCV care, with only 56% of participants at the time of the study remaining in the care of a doctor for their HCV. As this study was conducted when PWID were excluded from receiving antiviral treatment, this would have limited the imperative for a referral to specialists for these patients. A similar study was earlier conducted (2002-2003) by Gifford et al. (2005) with 312 men who had been diagnosed with HCV. The authors found that 43% saw a doctor for their HCV, with 30% ever having been referred to a specialist. Again, these proportions may have reflected the conditions in place at the time regarding criteria for antiviral treatment as well as the GPs' knowledge of these. A lag in GP awareness of changing treatment eligibility requirements, treatment options and guidelines was observed (Hellard & Wang, 2009). In a 2006 report, GPs reported that they had an improved knowledge of HCV and increased comfort in prescribing relative to the preceding five-year period (Gupta et al., 2006), but there was no evidence as to whether this improvement translated into improved care or whether any improvement was ongoing.

Prior to the introduction of DAA, studies also reported the perspectives of PWHCV on the provision of care by GPs after diagnosis of HCV. Patients' experiences of care in the past, can shape patient' perceptions and expectations of current engagement with GPs for HCV care. In one study, participants expressed a lack of support at the time of HCV diagnosis, particularly in relation to psychological support (Stewart et al., 2012). The participants described GPs who were knowledgeable regarding medical information but lacking in understanding of what it was like to live with chronic HCV. This result supported those of an earlier study (Gupta et al., 2006), which found that whilst 39% of GPs self-reported that they were highly likely to discuss psychological issues after diagnosis, 37% reported that they would find it difficult to be the main provider in the medical and psychological care of PWHCV. There were also positive reports about HCV care provided by GPs. McNally et al. (2006) reported that the majority of patients seeing a GP for their HCV care were confident of their doctor's HCV knowledge. Of these patients, 65% were satisfied or very satisfied with the care provided by their GP and 46% rated their regular GP as playing an important role in the management of their HCV. These studies relied on self-report and the clinical outcomes for these patients were not included in the outcomes reported.

Before GPs can provide appropriate care for people with a diagnosis of HCV, they must be aware of their patients' HCV status. Reports from the 'Bettering the Evaluation and Care of Health (BEACH)' program, which surveyed 1000 GPs annually, between 2001 and 2016, showed that GPs were able to identify within their patient population, patients with a known diagnosis of HCV. The BEACH study has been criticised as providing useful but limited data (Swerissen & Duckett, 2018) and these criticisms apply to the data provided regarding HCV. As part of the BEACH study, a Supplementary Analysis of Nominated Data (SAND) (Britt, Miller, Bayram, et al., 2016) regarding the prevalence and management of HCV was conducted in 2014 (Family Medicine Research Centre, 2015). This analysis identified that 61 of 5 855 patients, seen by 198 GPs, had a known diagnosis of HCV and these 61 patients' demographic information and information regarding their HCV status, origin, treatment and referral was reported. While the rate of HCV of around 1% matches the estimated Australian population rate of HCV (The Kirby Institute, 2018a), the study did not comment on whether this rate reflects the expected rate of HCV within the surveyed GPs' patient population. In addition, this snapshot of patients provided little indication of the actual GP care provided to these patients, whether the care provided was appropriate or about outcomes of the treatment provided. Due to limitations of the study to collect information on low prevalence conditions, such as HCV, limited information about HCV-specific care was provided in the yearly BEACH program reports (The University of Sydney, 2017). For example, in the final BEACH report (Britt, Miller, Bayram, et al., 2016), HCV was not included in the list of the top 30 of conditions managed by GPs in the previous decade. While the report provided the information that hepatitis serology accounted for 1% of the total pathology ordered in 2015-16 and 7% of the GP participants ordered these tests, the report did not distinguish between hepatitis serology for HCV, hepatitis B or hepatitis A (Britt, Miller, Bayram, et al., 2016). Further, HCV services provided by GPs may not have been captured due to the method used to classify problems managed. For instance, treatment for depression may have been listed as the reason for a consult, but this depression may have had its aetiology in the person's HCV treatment. Overall, the findings of this study do not test the reliability of GPs ability to identify patients within their practice with HCV, and reinforces the perception of a relatively low prevalence of this condition compared to others that GPs encounter in their practice population.

### 2.5.3 Interferon-based treatment - GP involvement in treatment

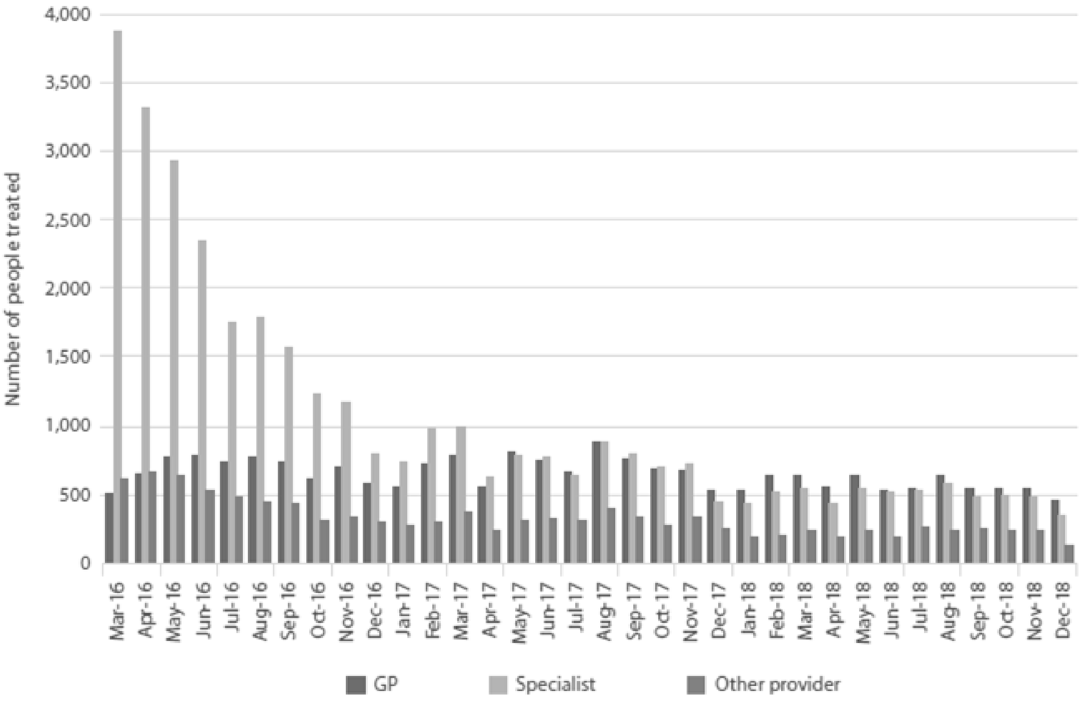
Prior to the availability of DAA, when treatment was led by hospital- based specialists, various jurisdictions (including Western Australia, Queensland, New South Wales and Victoria) set up programs to encourage wider GP involvement in the provision of treatment. (Baker et al., 2014; Hopwood & Treloar, 2013; Lambert et al., 2011). Concerns were expressed that patient care and safety could be negatively affected by changes to prescribing conditions, and so a cautious approach to the establishment of these programs was adopted (Australian Government - Department of Health and Aged Care, 2000).

A pilot project in 2010-13 in New South Wales (NSW) was evaluated in terms of medical outcomes (Baker et al., 2014) as well as by investigating the perspectives of a small number of GP prescribers and patients (Hopwood & Treloar, 2013), and supported the feasibility of GP prescribing for HCV. The pilot involved NSW medical practitioners working at public and private community-based medical clinics providing interferon-based HCV treatment in a shared-care model with clinicians from authorised tertiary liver clinics. The GPs received two days of training, which authorised them to be accredited to prescribe interferon for patients with genotype 2 or 3 and, after initial specialist assessment, for patients with genotype 1 (Baker et al., 2014; Hopwood & Treloar, 2013). During the pilot, 41 patients were initiated onto treatment (23 private patients and 18 public patients) with some additional patients initiated at these sites outside of the study (Baker et al., 2014). The relatively low numbers made it difficult to compare the medical outcomes of the pilot and standard treatment, however the overall SVR was considered favourable considering the characteristics of patients initiated onto treatment (Baker et al., 2014). Eight patients and seven (of eleven) GPs involved in the pilot were interviewed (Hopwood & Treloar, 2013). The GPs stated that it was necessary to have a ‘reasonable’ caseload of HCV patients for training to be effective, lags between training and providing treatment may be problematic, that providing treatment remained challenging and that a good relationship with the specialist clinicians was necessary. The patients in the study reported positive perceptions and experiences of having HCV treatment provided by their GP. Patients particularly appreciated receiving continuity of care under this arrangement, valuing the ongoing, trusting and supportive relationships with their GP and practice staff. Attending the general practice was perceived by patients as convenient as it mitigated the need the need to negotiate an additional tertiary site for this care, which was perceived as having the potential to expose them to stigma and discrimination (Hopwood & Treloar, 2013).

The findings may however have limited generalisability. The patient participants in the study were all receiving OST from GP participants in the study. To receive OST requires an established therapeutic GP-patient relationship where the GP is aware of the patient's HCV risk factor of IDU, is willing to provide this treatment and the patient consents to this treatment (Gowing, Ali, Dunlop, Farrell, & Lintzeris, 2014). However, not all HCV transmission involves IDU (Sievert et al., 2011) and not all PWHCV with the risk factor of IDU (either current or historical) seek OST (Teesson et al., 2015). All GPs involved in this evaluation were OST prescribers with a high caseload of patients receiving OST whereas only a small proportion of GPs working in private practice prescribe OST for any patients (Australian Government - Australian Institute of Health and Welfare, 2019). These GP participants would be more likely to have developed skills and confidence in working with patients with a history of IDU (Scarborough et al., 2011) and by participating in the study additionally demonstrated an interest in providing treatment for HCV for their patients. Therefore, the findings may not be applicable to the majority of the private GP workforce or for PWHCV not receiving OST.

### 2.5.4 GP involvement in providing DAA treatment

GPs were included in the range of provider types who between March 2016 and June 2019, provided 74 704 Australians DAA. The number of people treated per month started at a high rate but has decreased dramatically overtime. Between March-June 2016, 17 648 patients, initiated treatment, with this falling to 3 988 patients in the March-June period in 2019. The number of patients treated over time by GPs, however, has remained relatively steady at around 1 900 patients per quarter (See Figure 2) (Doyle et al., 2019; MacLachlan et al., 2020). The drop in the number of patients treated has largely occurred in patients treated by specialists, leading to a steady increase in the proportion of treatment provided by GPs compared to all other provider types. The provider types reported were GPs, specialists (the traditional providers of antiviral treatment for HCV) and 'other providers', which includes nurse practitioners, temporary resident doctors, locum relief doctors, and others not able to be classified as either GP or specialist. GPs prescribed 32% of all DAA between March 2016 and December 2018 and prescribing of this treatment by GPs is now more common than prescribing by specialists (MacLachlan et al., 2020).



Data source: Treatment data sourced from Department of Human Services Medicare statistics.

*Provider type is derived by Medicare using the clinician's service history.

**Figure 2: HCV treatment in Australia by provider type and month. March 2016 – December 2018 (MacLachlan et al., 2020, p 80)**

**(Reproduced with permission from ASHM from: MacLachlan JH, Smith C, Towell V, Cowie BC. Viral Hepatitis Mapping Project: National Report 2018–19. Darlinghurst, NSW, Australia: Australasian Society for HIV, Viral Hepatitis and Sexual Health Medicine (ASHM), 2020; https://ashm.org.au/programs/ Viral-Hepatitis-Mapping-Project/)**

Prescribing of DAA by GPs has been proportionally even higher to other provider types in PHNs in rural and remote areas (The Pharmaceutical Benefits Scheme - Drug Utilisation Sub-committee, 2018), with GPs initiating treatment for 50% of regional and 86% of remote prescriptions in 2017 (Doyle et al., 2019). This is likely due to the lack of access to specialists in these regions (Doyle et al., 2019; The Pharmaceutical Benefits Scheme - Drug Utilisation Sub-committee, 2018).

The outcomes for prescribing DAA in a primary healthcare setting, were found to be comparable to those for treatment provided in tertiary settings (Bloom et al., 2017; Haridy et al., 2020; Pourmarzi et al., 2019). In PWID with HCV, offering DAA in primary care settings resulted in increased treatment uptake and cure rates relative to hospital-based prescribing (Wade, Doyle et al. 2020) at reduced cost (Palmer et al., 2019; Ramachandran et al., 2019). Where GPs had engaged in remote consultation with tertiary liver clinics, and patients had completed treatment, there was a cure rate of 98% SVR12 and 65% for all patients intended for treatment (Haridy et al., 2020). It was noted in this study that while most (91%) remote consultation forms were returned without amendment, there were forms in which the treatment field was left blank by the GP and the treatment duration incorrect (Haridy et al., 2020). From the details provided in the studies, it was difficult to establish the nature of the primary healthcare setting and/or whether the healthcare professionals involved in prescribing the DAA were GPs. Of note there was a lack of SVR12 results recorded for patients receiving DAA in primary care (Haridy et al., 2020; Read et al., 2017), with this result missing in 47% of patient records examined in 2017 (Read et al., 2017). While overall cure rates are high for GP prescribers, one study (Wade et al., 2018) found that two of the 95 prescriptions written by the GP prescribers, were inconsistent with the specialist advice and would not have resulted in a cure.

Only a small percentage of GPs have been involved in prescribing DAA and individual GP’s involvement in the provision of DAA is generally at a low level. From March 2016, to May 2017, a substantial proportion of GPs involved in providing DAA provided this treatment to only one patient, with the maximum per GP of 657 patients, and the mean number treated of 5.7 patients (The Pharmaceutical Benefits Scheme - Drug Utilisation Sub-committee, 2018). There were 2 488 GPs involved in prescribing DAA between March 1 2016 to February 28 2017 (54 841 number of prescriptions), and 3 493 GPs from March 1 2017 – February 28 2018, (44 727 Number of prescriptions) (The Pharmaceutical Benefits Scheme - Drug Utilisation Sub-committee, 2018). In a South Australian study, GPs were involved in remote consultations with specialists regarding 447 patients between March 1 2016 and February 28 2017(Haridy et al., 2020). Among these GPs, there were 109 referrers and the median number of referral(s) per GP was one (range one-49). ASHM has hosted a campaign, *AUS GPs end Hep C*, that has a stated aim to increase the number of GPs prescribing DAA, from 10% to 20% by 2020 and 75% by 2025 (O'Loan et al., 2020). Even where GPs are involved in the management of HCV, they may not be prescribing HCV treatment (i.e., DAAs) for these patients. According to the *Hepatitis C Mapping Project* report (MacLachlan et al., 2018), there is a gap in the care cascade in primary health, with 75% of HCV RNA or genotype tests ordered by non-specialist in 2015-16 but only around 50% of patients received treatment from these clinicians. While this gap was identified by the authors, the reasons behind this discrepancy cannot be discerned from the population-level data analysed in the report. A gap of care was also noted in a study of the development of a consultation pathway (Wade et al., 2018), where 114 referrals were considered appropriate for treatment by the referring GP, however only 95 patients were prescribed DAA by the GP and no data were collected on why the remaining 19 patients were not provided with treatment.

Studies have been published which investigate primary healthcare professionals perceptions and experiences of their role in prescribing of DAA in Australia (Gooey et al., 2020; Heard, Massi, Smirnov, & Selvey, 2019; Marshall, Grebely, Dore, & Treloar, 2019; Pourmarzi, Smirnov, Hall, Thompson, et al., 2020; Richmond & Wallace, 2018; Sud et al., 2018; Wade et al., 2017). The methods used in these studies have used have included surveys (Gooey et al., 2020; Sud et al., 2018; Wade et al., 2017) and thematic analysis of focus groups (Heard et al., 2019) and interviews (face-to-face or telephone) (Heard et al., 2019; Marshall et al., 2019; Pourmarzi, Smirnov, Hall, Thompson, et al., 2020; Richmond & Wallace, 2018). Studies using survey methods sampled GPs from regions within the Australian states of New South Wales (Sud et al., 2018) and two from Victoria (Gooey et al., 2020; Wade et al., 2017), with sample sizes of N=131, N=191 and N=164, respectively. Participants targeted for interviews included patient and health care professionals, with GPs included within the healthcare professional group (Heard et al., 2019; Marshall et al., 2019; Pourmarzi, Smirnov, Hall, Thompson, et al., 2020; Richmond & Wallace, 2018). The settings that GPs participants were drawn from included private general practice (Heard et al., 2019; Marshall et al., 2019; Pourmarzi, Smirnov, Hall, Thompson, et al., 2020; Richmond & Wallace, 2018). Where the participants were drawn from different professions and settings, the results and discussion did not always discern between the healthcare professionals or settings of participants. Selective recruitment criteria of GP participants occurred in several studies, based on involvement in OST (Marshall et al., 2019), having a known interest in HCV (Heard et al., 2019) and being identified as a key stakeholder by the researchers (Richmond & Wallace, 2018). Interviews varied in length between studies ranging from 18 to 48 minutes

(Pourmarzi, Smirnov, Hall, Thompson, et al., 2020), 10 – 60 minutes (Heard et al., 2019) and approximately 45 minutes long (Richmond & Wallace, 2018), with one study not stating the interview length (Marshall et al., 2019). While the participants were not necessarily GPs working in private general practice, the studies provide useful information for understanding the provision of care for HCV in this setting. I will outline the findings under the themes of knowledge, training, access to clinical resources, and patient factors.

Knowledge of DAA was viewed as an enabler and lack of knowledge as a barrier (Heard et al., 2019; Pourmarzi, Smirnov, Hall, Thompson, et al., 2020; Richmond & Wallace, 2018; Sud et al., 2018) to the provision of DAA by GPs. Having an understanding of the possible long-term effects of HCV was viewed as important to give GPs an imperative to treat HCV (Marshall et al., 2019; Richmond & Wallace, 2018). Clinicians' knowledge about the effectiveness of DAA, involving uncomplicated oral regimens, with minimal side-effects was found to be important in their decision to be involved in providing this treatment (Heard et al., 2019; Marshall et al., 2019; Pourmarzi, Smirnov, Hall, Thompson, et al., 2020). However, one survey showed that only 51% of participants were aware that the cure rate for DAA was greater than 90% and that 21% did not know that DAA involved oral regimens (Sud et al., 2018). The studies reported that there was uncertainty about whether patients would benefit from treatment (Heard et al., 2019; Sud et al., 2018) and about eligibility for treatment. In particular, 45% of GPs surveyed, believed IDU would be an exclusion criteria for treatment (Sud et al., 2018). Participants were unclear about the possible complications due to patient's co-morbid conditions (Heard et al., 2019), such as drug-to-drug interactions (Heard et al., 2019) and general uncertainty regarding the drugs used for DAA (Sud et al., 2018).

The availability of training to overcome the lack of knowledge was seen as important (Heard et al., 2019; Richmond & Wallace, 2018) with consideration given to GPs need for "just in time learning" (Richmond & Wallace, 2018, p 116). These studies did not report on training individuals had undertaken (if any) regarding HCV, although it was possible that GP participants with an increased interest in DAA prescribing were over represented in the studies (Wade et al., 2018). Thus, GPs without a special interest in DAA prescribing, or HCV in general, were likely to have an even lower level of the knowledge and skills to provide care for this condition. The use of local champions was suggested as a strategy to increase the knowledge and support GPs to prescribe DAA (Heard et al., 2019; Richmond & Wallace, 2018).

For GPs to consider the provision of DAA there was a need to have available appropriate phlebologist services (Heard et al., 2019; Marshall et al., 2019), access to tools to measure liver fibrosis (Heard et al., 2019; Marshall et al., 2019), a dispensing pharmacy (Sud et al., 2018) and clear pathways for the required specialist consultations (Pourmarzi, Smirnov, Hall, Thompson, et al., 2020; Wade et al., 2018). There has been development of methods that minimise the need for the taking of blood which may be particularly problematic when there has been vein damage during IDU (Madden, Hopwood, Neale, & Treloar, 2018). Similarly, access to tools for determining the level of liver fibrosis were reported as having improved over time (Strasser, 2017) and alternative methodologies such as transient elastography have been validated (Doyle et al., 2018; Huang, Adams, Joseph, Bulsara, & Jeffrey, 2017; Kelly, Riordan, Bopage, Lloyd, & Post, 2018). Programs have been designed to link tertiary based liver clinics with GPs. These have included outreach by Viral Hepatitis Nurses (Government of South Australia - SA Health, 2019) and the establishment of successful remote consultation pathways (Wade et al., 2018). GPs may have uncertainty regarding the availability of pharmacies that dispense the medication (Sud et al., 2018) which may be limited, particularly in remote geographical areas (Doyle et al., 2019).

GPs' recognition of their patients affected by HCV and GPs' perceptions of PWHCV may have an important effect on the provision of DAA (Marshall et al., 2019; Pourmarzi, Smirnov, Hall, Thompson, et al., 2020; Richmond & Wallace, 2018; Sud et al., 2018). GPs may have minimal awareness of their patients being affected by HCV, which may be due to a lack of diagnosis, there being no record of the patient's diagnosis and/or a lack of willingness of patients to disclose (Richmond & Wallace, 2018). There may be perceptions of patients with IDU as difficult to manage (Pourmarzi, Smirnov, Hall, Thompson, et al., 2020) and that there would be difficulties with patients adhering to treatment (Sud et al., 2018). Where GPs had relationships with patients, and were aware of their HCV diagnosis, it was seen as part of being a "good doctor" (Marshall et al., 2019, p 3) to provide DAA. Patients who are motivated to enter treatment may motivate GPs to provide this care (Pourmarzi, Smirnov, Hall, Thompson, et al., 2020). In turn, providing valuable treatment to patients, facilitated GPs with a sense of professional fulfilment in GPs (Marshall et al., 2019). The success of treatment was enhanced when GPs understood the patients' situation, including the need for flexibility and support, and the financial constraints faced by patients (Marshall et al., 2019). Having practice software setup to provide follow-up reminders regarding DAA was seen to support GPs to provide this treatment for their patients (Heard et al., 2019). Lack of practice support and prioritisation of the provision of DAA was seen as a barrier for GPs to provide this treatment (Marshall et al., 2019; Pourmarzi, Smirnov, Hall, Thompson, et al., 2020). Despite most patients being able to be treated in general practice by GPs some GPs may still view provision of DAA as a specialist medical area and would refer patients to specialists for treatment (Pourmarzi, Smirnov, Hall, Thompson, et al., 2020).

### 2.5.5 Patients' perspectives of the provision of care for HCV by GPs.

There have been recent Australian studies that have reported the perspectives of people with a diagnosis of, or with risk factors for HCV, regarding the provision of HCV care, including care provided by GPs (Bryant et al., 2019; Heard et al., 2019; Pourmarzi, Smirnov, Hall, FitzGerald, & Rahman, 2020; Pourmarzi, Smirnov, Hall, Thompson, et al., 2020; Richmond & Wallace, 2018). These studies have used surveys (Bryant et al., 2019) and/or interviews, either face-to-face or by telephone, to collect data (Bryant et al., 2019; Heard et al., 2019; Pourmarzi, Smirnov, Hall, FitzGerald, et al., 2020; Pourmarzi, Smirnov, Hall, Thompson, et al., 2020; Richmond & Wallace, 2018). The majority of the studies have participants who report current or past IDU, often classified as PWID. Participants' experience with engagement for care, including for HCV, occurred in a mixture of settings that included general practice, drug and alcohol services and hospitals. GPs referred to in these studies, may have worked in private general practice or other settings, such as a drug and alcohol service. Other studies conducted prior to the availability of DAA are also relevant as people's perspectives may have been formed based on this era and I will include them when relevant below.

Before PWHCV seek care, they need an awareness that they potentially have HCV or that the symptoms that they experience are HCV-related. It has been reported that people with ongoing IDU expect to have contracted HCV (Carruthers & Ryan, 2012). People who engaged in brief periods of IDU in an earlier period of their life, however, may not suspect that this was the case (Gifford et al., 2003). As PWHCV can display a range of symptoms and have other co-morbidities, it can be difficult for the person and GPs to know what symptoms are attributable to HCV infection (Denney-Wilson et al., 2010; Dore et al., 2009; Pourmarzi, Smirnov, Hall, Thompson, et al., 2020). McNally et al. (2006) found that participants reported their health status as poor or fair (46%) but reported no HCV-related symptoms, and 18% were unclear as to whether their current symptoms were related to their HCV. Patients who are asymptomatic may not be convinced that they require treatment (Pourmarzi, Smirnov, Hall, Thompson, et al., 2020). Patients may lack awareness of a previous diagnosis of HCV or not have concern about the diagnosis, due to the limited importance that their GP was perceived to ascribe to the diagnosis (Richmond & Wallace, 2018). While positive about the treatment and indicating that they may at some time enter treatment (Bryant et al., 2019), PWHCV may not ascribe urgency to entering treatment, for example delaying treatment until they stopped IDU (Richmond & Wallace, 2018).

Among those engaging with GPs for care, an HCV diagnosis may not be made due to peoples' reluctance to disclose their IDU status (past or current) due to the stigma associated with this practice and past negative experiences with disclosure (Anti-Discrimination Board of New South Wales, 2001; Day, Jayasuriya, & Stone, 2004; Day, Ross, & Dolan, 2003; Fry & Bates, 2011; Gifford et al., 2003; Gifford et al., 2005; Hopwood & Treloar, 2004; Hopwood, Treloar, & Bryant, 2006; Islam et al., 2013; Pourmarzi, Smirnov, Hall, FitzGerald, et al., 2020; Treloar, Hopwood, & Loveday, 2002). Staff and GPs in private practice may be perceived as judgmental by patients (Pourmarzi, Smirnov, Hall, Thompson, et al., 2020). People who previously engaged with healthcare professionals, including in private general practice, and had negative perceptions of their experience may not engage with private GPs for future care for their HCV (Brener, Horwitz, von Hippel, Bryant, & Treloar, 2015; Treloar et al., 2010). Without centralised medical records when engaging with a GP, patients are able to choose what information they share with them (Nøhr et al., 2017).

Patients may have perceptions about seeking care for their HCV based on redundant information regarding the interferon-based treatment era, for example cure rates, side effects, regimens, liver biopsy requirements, exclusion criteria etc. (Dore et al., 2009; Pourmarzi, Smirnov, Hall, Thompson, et al., 2020; Richmond et al., 2018; Treloar et al., 2010). Lags in patient awareness of treatments were found in the pre-DAA treatment era, with participants in one study who were diagnosed in the preceding five years being more likely to have engaged with care delivered by specialists (69 %), who were the providers of antiviral treatment at the time, relative to those diagnosed more than five years before the study (35 %) (McNally et al., 2006). There is a range of views about treatment reported in the recent literature. PWHCV may be sceptical about the claims of minimal side-effects of the new treatment (Bryant et al., 2019; Richmond & Wallace, 2018) and concern over possible side-effects may still deter them from seeking treatment (Bryant et al., 2019). Positive views of treatment have also been expressed, with contact with peers with positive experiences of treatment reported to have contributed to this view (Bryant et al., 2019). There has been advocacy for the use of peer education to promote a positive view of DAA (Pourmarzi, Smirnov, Hall, FitzGerald, et al., 2020; Richmond & Wallace, 2018). Participants in one study, were confident in their knowledge regarding HCV treatment and expressed the view that information was so prevalent that it was difficult to avoid being exposed to information in this regard (Bryant et al., 2019). Confusion continues to exists for some people affected by HCV, however, with 25% of survey respondents incorrectly indicating that their IDU would make them ineligible for treatment (Bryant et al., 2019). People may also not be aware that treatment was available from GPs (Pourmarzi, Smirnov, Hall, Thompson, et al., 2020).

There are limited published studies that describe patients’ engagement with GPs for DAA and this engagement is not the focus of the studies (Pourmarzi, Smirnov, Hall, FitzGerald, et al., 2020; Richmond et al., 2018). These published studies have reported both positive and negative experiences. For example, while one patient was willing to enter treatment, the GP they approached was unwilling to prescribe DAA due to their lack of knowledge (Richmond et al., 2018). Despite the improvements to treatment, patients encountered the need to manage interaction with medications, co-morbid conditions and side-effects (Richmond et al., 2018). Patients did describe feeling supported by GPs, for example responding to and reassuring a patient when a dose was missed (Richmond et al., 2018), and access to DAA from their general practice was described by patients as relatively easy compared to a hospital settings (Pourmarzi, Smirnov, Hall, FitzGerald, et al., 2020). Due to patients being recruited who had either completed treatment (Richmond et al., 2018) or where treatment was underway (Pourmarzi, Smirnov, Hall, FitzGerald, et al., 2020) these studies may not capture the experiences and perceptions of patients who had started treatment but had withdrawn for any reason.

When DAA outcomes are reported the number of people with a diagnosis of HCV that were in the group, ‘intention to enter treatment’ (Haridy et al., 2020) or ‘intention to treat’ (The Kirby Institute, 2018b) are high. These people represent people who complete the majority of phases in the cascade of care to receive DAA but have not yet received this treatment. The patient journey for this group has not specifically been described in the literature.

## 2.6 Concepts for understanding GPs’ scope of practice

While there was copious literature that investigated how to increase Australian GPs’ involvement in particular areas of work (Gillespie, Mullan, & Harrison, 2019; Gonzalez-Chica et al., 2019; Harding, Seal, Duncan, & Gilmour, 2019; Rhee et al., 2020), there was sparse literature identified that examined the process by which GPs determined their overall scope of practice. Whilst not directly involving GPs’ scope of work, the concepts explored in the literature of ‘disease prestige’ and ‘sustainment’, did involve examination of the choices GPs make in regard to their work. Disease prestige is a concept that has been used to examine how medical practitioners ranked disease. The concept of sustainment was developed to understand the career choices of GPs. I will discuss these concepts in relation to the inclusion of provision of care for HCV in GPs’ scope of practice.

### 2.6.1 Using the concept of ‘Disease prestige’ to examine the provision of care for HCV by GPs

The concept of disease prestige has been coined to describe the ranking of diseases by medical practitioners (Album, Johannessen, & Rasmussen, 2017; Album & Westin, 2008), and authors proposed that this concept of hierarchy affects the provision of care in the Australian context (Stone, 2015, 2018). The research literature examined in section 2.4, indicates that HCV is awarded a low disease prestige and that medical practitioners are reluctant to provide care to PWHCV, which matches the perceptions reported by PWHCV regarding the care provided to them.

Album et al. (2017; 2008) investigated the concept of disease prestige. They found that groups of doctors and medical students from Norway could assign a rank to diseases and did so in a consistent way between groups and over time. They suggested three sets of prestige criteria that contributed to the ranking of the diseases with one set related to the disease and its typical trajectory, another set related to the treatment of the disease, and a third set related to the typical patient with the disease (Table 6). HCV was not one of the 38 diseases presented for ranking by participants, but hepatocirrhosis, a possible outcome of HCV, was assigned in the lowest fourth position in each phase of the study, by each type of participant. Outlined below are the expanded sets of criteria suggested by Album et al. (2017; 2008) to which I have added a description of how these may be related to known perceptions regarding HCV. I have further outlined below some of the aspects of the HCV disease and its typical trajectory, treatment of HCV and the perception of the typical patient with HCV that may affect the prestige ranking and therefore the provision of care.

**Table 6: Disease prestige criteria (Album et al., 2017; Album & Westin, 2008) as related to HCV.**

| Criteria related to: | Criteria | As related to HCV |
|---|---|---|
| The disease and its typical trajectory | Non-self-inflicted, acute and lethal diseases with clear diagnostic signs, located in the upper part of the body, preferably the brain or the heart, are typically awarded high prestige. | • May be perceived as self-inflicted through IDU.<br>• Prior to the availability of DAA, 98% of people with chronic HCV would experience this condition as a long-term condition.<br>• HCV with has non-specific signs and symptoms and left untreated HCV has uncertain progression.<br>• Perceived as a disease of the liver, although has effects outside of the liver. |
| The typical treatment of the disease | Disease categories associated with active, risky and high technology treatment leading to a speedy and effective recovery are awarded high prestige. | • Previous treatment involved long-term provision of treatment with low cure rates.<br>• Treatment not associated with active, risky or high technology.<br>• DAA does involve speedy and effective outcomes.<br>However, the total cascade of care for HCV may involve a long process and may not always lead to patients receiving DAA and therefore achieving cure. |

| Criteria related to: | Criteria | As related to HCV |
|---|---|---|
| The typical patient with the disease | Disease categories associated with young patients, patients who accept the physician's understanding of the disease, and whose treatment results do not involve disfigurement, helplessness or other heavy burdens, are awarded high prestige | • The typical patient with HCV is associated with the stereotype of PWID.<br>• Due to the length of time a patient may have lived with an HCV diagnosis, the patient may have an in-depth understanding of the disease that exceeds the knowledge of the doctor.<br>• Doctors who promoted treatment prior to DAA, where patients chose not to enter treatment, doctors may not have understood or respected the patient’s choice.<br>• As HCV has non-specific signs and symptoms patients and doctors may attribute these to HCV differentially.<br>• Previous treatment could involve serious negative long-lasting side-effects e.g., depression. |

#### 2.6.1.1 HCV and its typical trajectory

The characteristics of HCV and its trajectory do not align with, and are often diametrically opposed to, the disease criteria associated with high prestige diseases. Firstly, a large majority of PWHCV contracted the disease via illicit IDU (Sievert et al., 2011) leading to a perception that HCV is self-inflicted, whereas diseases considered non-self-inflicted are awarded high prestige. One study (Richmond et al., 2007) which included GPs in the sample of health providers, found that compassion towards PWHCV by health providers depended on how people contracted the disease, with 95% indicating compassion if HCV was contracted through blood transfusion (not self-inflicted) and 63% when contracted via IDU (self-inflicted). Even where HCV was contracted in other ways, there was a perception by PWHCV that they were presumed to have contracted HCV via drug use (Fry & Bates, 2011). Stigma associated with perceptions of the typical HCV patient as a drug user will be discussed in more detail in section 2.6.1.3.

Whilst the characteristics of a disease having 'clear diagnostic signs' or potentially 'lethal' awarded diseases high prestige, as discussed in section 2.5.1, diagnosis of chronic HCV is not straightforward (Hepatitis C Virus Infection Consensus Statement Working Group, 2018) and progression of HCV is highly variable, not inevitable or predictable (Dore et al., 2009). PWHCV may be asymptomatic or have a range of non-specific symptoms (Draper et al., 2019). Diagnosis of HCV involves two steps of testing, followed six months later by a confirmatory test (Hepatitis C Virus Infection Consensus Statement Working Group, 2018). The use of liver function tests does not give a clear-cut indication of the severity or stage of disease (Dore et al., 2009). Without treatment, HCV was considered a chronic disease rather than as an acute disease that would attract high prestige.

Whilst the infectiousness of a disease was not discussed in relation to disease prestige, fear of contracting HCV from patients was an issue historically expressed by medical practitioners (Richmond et al., 2007) and this aspect may add to the low prestige of infectious diseases. Further evidence of this fear was that PWHCV reported being treated with more caution by GPs in relation to their infectious status (Fry & Bates, 2011). Standard precautions, with all blood being treated as potentially infectious, have been recommended to prevent occupational transmission for all patient encounters (Deuffic-Burban, Delarocque-Astagneau, Abiteboul, Bouvet, & Yazdanpanah, 2011). GPs and other health care workers have been trained in this approach for over ten years. Standard precautions should mean that all people are treated as if they had an infectious disease, and therefore infectiousness should not affect disease prestige.

#### 2.6.1.2 HCV - typical treatment of the disease

DAA has provided speedy and effective recovery (Pawlotsky, 2014), which is associated with disease treatments with high prestige. However, providing DAA which involves assessment and writing of a prescription DAA, is not considered risky, no technology is involved, and the GP is not providing 'active treatment' such as surgery. Treatment available for HCV prior to the introduction of DAAs was neither speedy nor effective, and involved serious negative side-effects (Carvalho-Filho & Dalgard, 2010; Feld & Hoofnagle, 2005; Sublette et al., 2015). If GPs lack knowledge of the new treatment, their perception of the ranking of disease prestige may be formed based on the characteristics of the former treatment.

When forming their perceptions of the effectiveness of providing HCV treatment, GPs may consider their involvement in the total cascade of care for HCV rather than just the final DAA treatment. GPs may perceive that IDU by PWHCV, limits the capacity of PWHCV's involvement in the cascade of care necessary to achieve cure with DAA. This may be justified by the number of patient participants in the literature described as "lost to follow-up", for example, Wade et al (2020) reported positive outcomes for PWID treated with DAA in primary care settings but also reported a high proportion of patients in the study as lost-to-follow up. Reinfection is an issue of concern raised in regard to provision of DAA (Cunningham et al., 2020; Hosseini-Hooshyar et al., 2020) and where reinfection occurs GPs may not perceive that their involvement in the provision of care for HCV was effective. There have been reports of GPs having a sense of responsibility for maintaining the financial sustainability of the healthcare system (Manning, 2011; Robertson et al., 2011). The high cost of DAA has been widely publicised (Brennan, 2016; Ley, 2016; Martinello et al., 2018) and GPs may consider this cost when evaluating the effectiveness of treatment. The literature did not report on what contributes to GPs' perception of the effectiveness of DAA.

#### 2.6.1.3 HCV – Perceptions of the 'typical' patient.

A study on GP attitudes demonstrated that some GPs held negative views of PWHCV based on the association of HCV with IDU (Richmond et al., 2007), thus the 'typical patient' with HCV does not fit with the criteria that would award the disease high prestige. These findings align with reports from PWHCV of negative experiences when seeking care in health settings that were perceived to result from stigma related to HCV and its connection with IDU (Anti-Discrimination Board of New South Wales, 2001; Day et al., 2004; Day et al., 2003; Fry & Bates, 2011; Gifford et al., 2003; Gifford et al., 2005; Hopwood & Treloar, 2004; Hopwood et al.; Treloar et al., 2002). Whilst there was substantial literature available on this topic, the data were generally not recently collected and there was a gap in recent information on this topic in Australia.

There have been few studies that examined the way doctors' attitudes to PWHCV and PWID translated into the exercising of discretion in the provision of care for PWHCV (Butt, 2008). The majority of studies relating to HCV-related stigma focused on the impact of stigma on PWHCV seeking care (Butt, 2008). There was a lack of literature providing an in depth understanding of the way GPs made decisions in this regard, which could be used to determine strategies to influence the professional attitudes of GPs around confidence to treat, legitimacy of responding and personal attitudes around GPs' sense of social responsibility (Dharamsi, Ho, Spadafora, & Woollard, 2011; Skinner, Roche, Freeman, & Mckinnon, 2009).

Richmond (Richmond, 2009) described the ideal provision of GP care for PWHCV, highlighting the importance of PWHCV being able to access high quality health care without fear of discrimination or judgemental attitudes. In 2003, Richmond et al. (2007) surveyed health professionals, including 291 medical practitioners, in the Australian state of Victoria. The authors found that health professionals' knowledge about HCV was adequate but that their attitudes towards PWHCV were, in some cases, intolerant. Much of this intolerance was based on negative perceptions and attitudes held by medical practitioners towards people who are PWID, with 13% of the GPs surveyed indicating that they would not treat PWID if given a choice. A considerable length of time has elapsed has since this study was conducted in 2003, but the findings have been supported by more recent studies which also found negative attitudes to the provision of treatment for people with drug abuse issues (Ahmed. A, Metheson. C, & Bond. C, 2009; Longman, Temple-Smith, Gilchrist, & Lintzeris, 2012). PWHCV reported that they were still identified with the 'drug user' stereotype and treated accordingly, despite their drug use being historical (Fry & Bates, 2011). Whether medical practitioners were discerning between people with current or past IDU, did not appear to have been investigated. Such discernment may have been important to the attitudes of medical practitioners and the services they provide (Butler & Sheridan, 2010).

One criterion for high prestige diseases is that patients accept the doctor's understanding of the disease and this may not be the case for patients with HCV. In studies conducted before DAA, patients reported that their GPs took a purely biomedical approach and they had benefited from 'utilising a range of resources such as self-monitoring, complementary therapies, research and medical advice.' (Fry & Bates, 2011, p 465). HCV patients may have accumulated a high-level of knowledge about their condition (Mah et al., 2017), which may not be recognised or appreciated by the GP (Snow, Humphrey, & Sandall, 2013).

#### 2.6.1.4 Effect of disease prestige and stigma on care provided for HCV

The published research did not investigate how the ranking of a disease affected the provision of care for specific conditions, however studies focussing on medically unexplained conditions identified the application of the hierarchy of disease prestige concept in the Australian setting (Stone, 2015, 2018). The literature described the ranking of disease prestige over time as consistent (Album et al., 2017; Album & Westin, 2008), but these results may not have included situations where dramatic changes have occurred to treatment and other management. The perceptions of GPs and PWHCV about the prestige of the disease would have been formed based on experiences both before and after the change in HCV treatment options, and awareness of the changes may not have been pervasive. Therefore, understanding both the current and past context of the provision of this care is important. The relative importance of each criterion to the overall ranking may mean that even where dramatic change occurs to one set of criteria, for example improved treatment, the overall ranking of the condition may not be changed.

GPs' decisions are made within their general practice setting and these organisations may influence the decisions of the GPs and the care they provide (Matheson, Porteous, van Teijlingen, & Bond, 2010) by either ameliorating or supporting the perceptions and practices of GPs towards PWHCV. Receptionists in private general practices have been found to play a key part in triaging appointments (Hall, Phillips, Gray, Barnard, & Batt, 2011) and this may give them discretion in regard to the provision of services. If and how this power is exercised in respect to PWHCV has not been studied, however understanding the way discrimination and stigma operated within the organisation of general practice may help in shaping implementation strategies for the improvement of the provision of care for PWHCV.

#### 2.6.1.5 Effects of HCV disease hierarchy at the health system level

Disease hierarchy has been described at the level of the GP-patient relationship but also can be seen to operate at the health system level. Here, disease hierarchy affects the politics involved with different diseases and the subsequent policy making that can affect the provision of care. Ballard (Australasian Society for HIV Medicine, 2005) compared and contrasted the different history of policy making between HIV and HCV in Australia. He pointed out that, whilst the diseases share some common features, the social meaning of the two diseases, and the political advocacy of the affected populations, are different and, these differences affected the policies and outcomes of these policy interventions. Ballard's (Australasian Society for HIV Medicine, 2005) analysis of the formation of these policies also outlined the effect that individual agents involved had on countering the disease hierarchy and subsequent provision of care. At the time of writing there does not appear to have been an examination of the federal policies that may have affected the provision of care for HCV in private general practice.

### 2.6.2 Use of the concept of 'sustainment' to examine the provision of care for HCV by GPs

The concept of sustainment provides another theoretical framework that may be useful to understanding the basis on which GPs choose to include the provision of care for HCV in their scope of work. An examination by Piko (2014) of career choices by GPs led to the *Theory of Optimising Professional Life* which included the concept of sustainment.

> …the concept of sustainment is offered as an overarching career value for doctors that encompasses the need for self-care to sustain well-being, staying interested in the work to sustain work interest and the need for financial reward to sustain lifestyle. (Piko, 2014, p 18, underlining added for emphasis)

In making career choices, individual GPs are aiming to maximise sustainment within a set of constraints. When GPs are experiencing dissatisfaction with their work or 'stage of discomfort', they will identify potential changes and assess whether these changes will maximise sustainment.

Solutions are found in four dimensions – treating patients (control over work content and how the work is done), structuring the work day (administrative structure of the day), integrating work and personal life (balance between personal and professional life) and adapting oneself (building resilience and skills, changing perceptions and attitudes) (Piko, 2014). While the theory was developed in relation to career choices, the framework is applicable to GPs' decisions about scope of work and scope of work was a component of career choice that Piko (2014) investigated. The perceptions and experiences of GPs may influence how they consider the provision of care for HCV may impact on their financial reward for the work, self-care, and whether the work would sustain their interest.

#### 2.6.2.1 Provision of care for HCV – financial reward for the work

Private general practices are businesses and individual GPs within these businesses are likely to be influenced by the financial aspects required of being part of a business (Erny-Albrecht & Bywood, 2016; Piko, 2014), but there is sparse literature on the effect of these financial aspects on GPs' scope of work. The employment relationship that GPs have within their practice place constraints on their decision making relating to maximising financial reward. For example, the income for salaried staff may not be directly affected by the type of work carried out, but these GPs may have limited control over aspects of consult billing, patients seen or other aspects of their work practice, and may feel pressured to meet benchmarks for income generation (Erny-Albrecht & Bywood, 2016).

The GPs' perception of the 'typical' patient and work involved with the provision of HCV care will affect their perception of the financial reward for this work. A GP may avoid this work if they feel that the typical patient with HCV is unlikely to attend booked appointments. As no MBS fees are generated for non-attendance, any level of non-attendance leads to a negative financial impact for GPs (Dantas, Fleck, Oliveira, & Hamacher, 2018). GPs may avoid work that requires longer consults as these are remunerated by the MBS at a lower rate per minute than shorter consults (Dow, 2018; Piko, 2014; Pond & Regan, 2019), but further research is needed to test this conjecture. If HCV patients, or the provision of HCV care, are perceived as complex and requiring long appointments, GPs may avoid this work to maximise their income. The MBS scheme provides payments for face-to-face patient care but does provide payments for other related patient care, for example arranging tests or referrals (Henderson et al., 2016). Again, if GPs perceive that providing care for HCV involves this type of additional unpaid work then they may avoid this work for financial reasons. Where charged, gap payments are not consistently applied by GPs across their patient population; often charged at the discretion of the GP (De Abreu Lourenco, Kenny, Haas, & Hall, 2015). GPs may discourage or limit the number of patients who they feel cannot afford a gap fee. Thus, if typical HCV patients are perceived to have less capacity to pay gap fees, GPs may avoid providing this care.

Individual GPs and general practices can use different approaches to how they claim MBS items that may mitigate the effect on financial reward associated with the choice of scope of work. Published guides outline how to optimise the use of MBS items with particular issues treated, for example patients with drug and alcohol problems (PHN South Western Sydney, 2018). Again, how these items affect the scope of practice of GPs has not been investigated in depth. For example, there are MBS items such as the GP Management Plans and Team Care Arrangements (Erny-Albrecht & Bywood, 2016) that provide incentives to GPs to be involved in chronic disease management. There have been reports of over servicing using these MBS items and the effectiveness of these items in optimising patient care has been questioned (Dow, 2018; Erny-Albrecht & Bywood, 2016).

#### 2.6.2.2 Provision of care for HCV – impact on self-care aspect

Piko (Piko, 2014) primarily discussed self-care in respect to achieving work life balance, but the selection of scope of work was also included in relation to choices made to maximise self-care. For example, one participant "advertises his special interests thereby reducing the types of conditions he treats" (Piko, 2014, p 102). The perception of impact on self-care associated with a particular scope of work may also be influenced by the perception of the typical patient associated with the condition. 'Doctor shoppers' (Biernikiewicz, Taieb, & Toumi, 2019) and violent patients (Raveel & Schoenmakers, 2019) are categories of patients described that may impact on the self-care aspect of being a GP. These categories of patients are particularly associated with patients with IDU (Biernikiewicz et al., 2019; Raveel & Schoenmakers, 2019). If GPs perceive that patients affected by HCV are more likely to fit within these categories, they may discourage patients with HCV from their practice and avoid providing care for HCV.

#### 2.6.2.3 Provision of care for HCV – interesting work

Piko (Piko, 2014) found that there was a balance to be sought between work that was intellectually satisfying in its variety and breadth, but which may be tiring in relation to retaining the degree of knowledge required. To manage this, GPs may reduce the breadth of their scope of work and concentrate their education and skill development in a limited scope of work (Piko, 2014). The way that GPs choose particular areas of work to focus on, and what factors facilitate or act as barriers to select the provision of HCV as one of these areas, has not been investigated in depth.

## 2.7 The framing of the problem and research questions

The impetus for undertaking this thesis was to understand the gaps in the provision of care for PWHCV that I became aware of through my paid employment. Through the literature review process, I confirmed that a gap existed and defined the nature of the gap. This gap represented a problem to be addressed and I framed this problem as: *'A substantial proportion of PWHCV in Australia are not receiving treatment that is likely to cure their HCV'*. The literature review included literature on designing healthcare interventions. I was particularly influenced by the work of Crabtree et al. (2001), who proposed that it is necessary to understand the different components that affect the provision of primary healthcare when designing primary healthcare interventions (outlined in section 2.8). I aimed when defining my research questions and choosing my research design, to understand the various components of the Australian primary healthcare system that formed the context of the provision of HCV care.

As part of the literature review, I sought to understand how the Australian health system influences care of PWHCV within private general practice. I identified policies current in 2014 that related to private general practice, GPs and HCV. Three Federal Government policies relevant to these topics were: *Building a 21st Century Primary Health Care System* (Australian Government - Department of Health and Ageing, 2010a), *National Health Workforce Innovation and Reform Strategic Framework for Action 2011–2015* (Health Workforce Australia, 2011) and the *Third National Hepatitis C Strategy 2010–2013* (Australian Government - Department of Health and Ageing, 2010b). There were equity statements contained in these policies, but there appeared to be gaps in the way these policies addressed provision of care for HCV. The identification of this gap directed the first research question:

1. Do Australian healthcare policies address equity in primary healthcare delivery for the provision of care for HCV by GPs in private general practice?

Additional suggested solutions aimed at the health system level specifically for HCV, have involved providing affordable DAA (Ley, 2016; Vitry & Shute, 2018) and authorising the prescribing of DAA for most patients with HCV by private Australian GPs (Hepatitis C Virus Infection Consensus Statement Working Group, 2018).

I further examined the literature to establish the existing understanding of how the ‘Patient’ and ‘GP’ component of the primary care system (Crabtree et al., 2001) influences the provision of care for HCV. I identified that solving the problem would require actions to overcome barriers to the engagement of PWHCV and/or barriers to engagement in the provision of HCV care by private GPs. To determine the appropriate actions, there was a need to reflect on the social and historical context influencing this engagement. The association of HCV with the stigmatised practice of illicit IDU is potentially an important social factor to be considered in developing a solution compared to engagement in other areas of health care. PWHCV and private GPs have had experiences and developed their perceptions over a period of time, during which treatment options and regulations have changed. Therefore, to understand the perceptions and experiences of both patients and GPs, the historic context must be considered. From the literature, it is unclear how PWHCV or GPs make decisions about engagement in care for HCV in private general practice. The following two questions were formulated to understand the experiences and perceptions of people regarding engagement in care for HCV.

2. What are the experiences of people with, or at risk of HCV of engagement with GPs in private general practice and how does

this affect their perceptions of the engagement for the provision of care for HCV?

3. What are the experiences of GPs in private general practice about the provision of care for people with or at risk of HCV and how does this affect their perceptions of engagement in this care?

The final research question was formulated to provide suggested recommendations to maximise the provision of care to PWHCV by GPs working in private practice in South Australia.

4. What recommendations will enable the provision of best practice care for PWHCV by GPs in private general practice?

## 2.8 Chapter Summary

This review examined the literature to gain an understanding of the factors that determined the care provided to PWHCV by private GPs in South Australia. Further I have summarised and critiqued this literature to identify gaps in the existing knowledge.

Chronic HCV infection contributes significantly to morbidity, subsequent healthcare costs and mortality in Australia. For most people affected by HCV, DAA offers a potential cure and in Australia, for the vast majority of PWHCV, this treatment can be provided by GPs working in private general practice.

The Australian government has undertaken measures to make DAA widely available for its citizens. Criteria that limit the eligibility for patients to receive antiviral treatment for HCV, have been progressively removed. The treatment is included on the Australian PBS and therefore this medication is available at a subsidised, affordable rate for patients. With the introduction of DAA in Australia the right to prescribe HCV antiviral medication, was extended to GPs. In consultation with a specialist, all GPs can prescribe DAA and a process has been developed for this consultation to occur remotely. With GPs visits subsidised through MBS rebates; Australian citizens have had what has been described as ‘universal access’ to GPs.

Over time, GPs have been involved in the provision of treatment for HCV and DAA. Comparable outcomes have been achieved between DAA delivered by GPs in the private practice setting and treatment delivered in tertiary liver clinics. As part of reaching elimination targets, the involvement in the identification and treatment of PWHCV by GPs in private general practice must be increased.

To understand the factors that affect the provision of DAA in this setting, it is necessary to examine the dynamic, complex and adaptive context in which the GP-patient consultations occur. An important conclusion from examining the literature, is that a great deal of choice and flexibility is afforded to GPs working in private practice in Australia. At a healthcare system level, there is no mechanism or requirement for patients to be registered with a GP for 'fee for service' Medicare rebates to be paid. Within market limitations, patients have choice about which GP(s) they access, whether to access more than one general practice, and what issues they seek care for. There is also discretion for patients about what information they share with any individual GP they engage with. Private general practices operate as independent businesses and there is no requirement to provide a specific suite of services, or to provide services to a defined patient population. At an individual level, GPs have discretion about who they provide services to and have a number of mechanisms available to influence the patients who access their practice. The scope of work that falls under the profession of general practitioner is vast and GPs may place limits on their individual scope of practice. During the GP-patient consultation, a range of both GP and patient factors will determine what is addressed during the consult, what is addressed overtime and the quality of the care provided. These factors can influence the identification of risk factors for HCV and patient engagement throughout the phases of the cascade of care required for DAA to be delivered.

From the literature, I have identified levels of knowledge, access to training, access to clinical resources and patient factors that have all been found to affect GPs' provision of care for patients with HCV. The patient factors that affected the engagement of people with, or at risk for, HCV engaging with GPs included the level of awareness of their HCV diagnosis, effect of stigma on disclosure and understanding of the available treatment options.

There is limited literature regarding how GPs in Australia make choices about their scope of practice and, in particular, GPs' choices regarding involvement in providing the breadth of care for patients with HCV. I have applied frameworks associated with the concepts of ‘disease prestige’ and ‘sustainment’ to examine the literature regarding choices of GPs in this regard.

The problem this thesis aimed to solve was defined as: ‘*A substantial proportion of PWHCV in Australia are not receiving treatment that is likely to cure their HCV*’. The research questions formed to frame the investigation of this problem were:

1. Do Australian healthcare policies address equity in primary healthcare delivery for the provision of care for HCV by GPs in private general practice?
2. What are the experiences of people with or at risk of HCV of engagement with GPs in private general practice and how does this affect their perceptions of the engagement for the provision of care for HCV?
3. What are the experiences of GPs in private general practice about the provision of care for people with or at risk of HCV and how does this affect their perceptions of engagement in this care?
4. What recommendations will enable the provision of best practice care for PWHCV by GPs in private general practice?

When I had defined the problem to be addressed and formed the research questions to answer this problem, it became apparent that the inquiry that I wished to conduct fitted with the philosophy of pragmatism. This philosophy is particularly suited to producing solutions for identified problems. In the next chapter, I will outline the philosophy of pragmatism used in this thesis and the methods chosen to answer the specific research questions.

# CHAPTER 3.

# *METHODOLOGY AND METHODS*

## 3.1 Introduction

In this chapter I will outline the philosophy of pragmatism (Morgan, 2007, 2014) applied during the inquiry of the thesis. In line with this philosophy, I will discuss the choices made in undertaking my research. This includes the choice to undertake a document analysis to answer *Research Question 1,* and semi-structured interviews to collect qualitative data and the analysis of this data using thematic analysis (Braun & Clarke, 2008) to answer *Research Questions 2 and 3*. A discussion of the ethical issues involved will be provided, as well as a description of the ethical approval processes undertaken. Detailed descriptions of the sampling, recruitment, and data collection conducted for the thesis will be provided.

## 3.2 Philosophy of Pragmatism applied during the thesis inquiry

The philosophy of pragmatism was suited to my research as this approach supports the production of practical solutions or 'actions' for identified problems (Morgan, 2014). This inquiry draws on pragmatist philosophy as described by Morgan (Morgan, 2007, 2014) and others (Badley, 2015; Hildreth, 2009). In their description of pragmatism and its application to social research, these academics focus on the work of John Dewey (Dewey, 1910, 1940, 1941). An illustration of Dewey's model of inquiry is given below in Figure 3. In response to a recognised problem, Dewey advocated that people should conduct deliberate, reflexive inquiry to provide suggested solutions to the problem, in the form of actions to be taken. This is summed up by Badley (2015) as: "…adopting a pragmatic stance is concerned with seeing our thinking as producing useful suggestions for action" (Badley, 2015, p 2). The research process and production of this thesis, is a particular form of inquiry, that aimed to provide solutions to defined research questions, and meaning was formed through this inquiry process (Morgan, 2014). Dewey used the term 'warranted assertion' (Dewey, 1941) to emphasise that meaning and proposed solutions, are achieved through the inquiry process, rather than objective knowledge (Dewey, 1941; Morgan, 2014). To understand the formation of meaning, requires examination of the inquiry process undertaken, including examining the choices made by individuals conducting the inquiry (Dewey, 1941; Morgan, 2014).

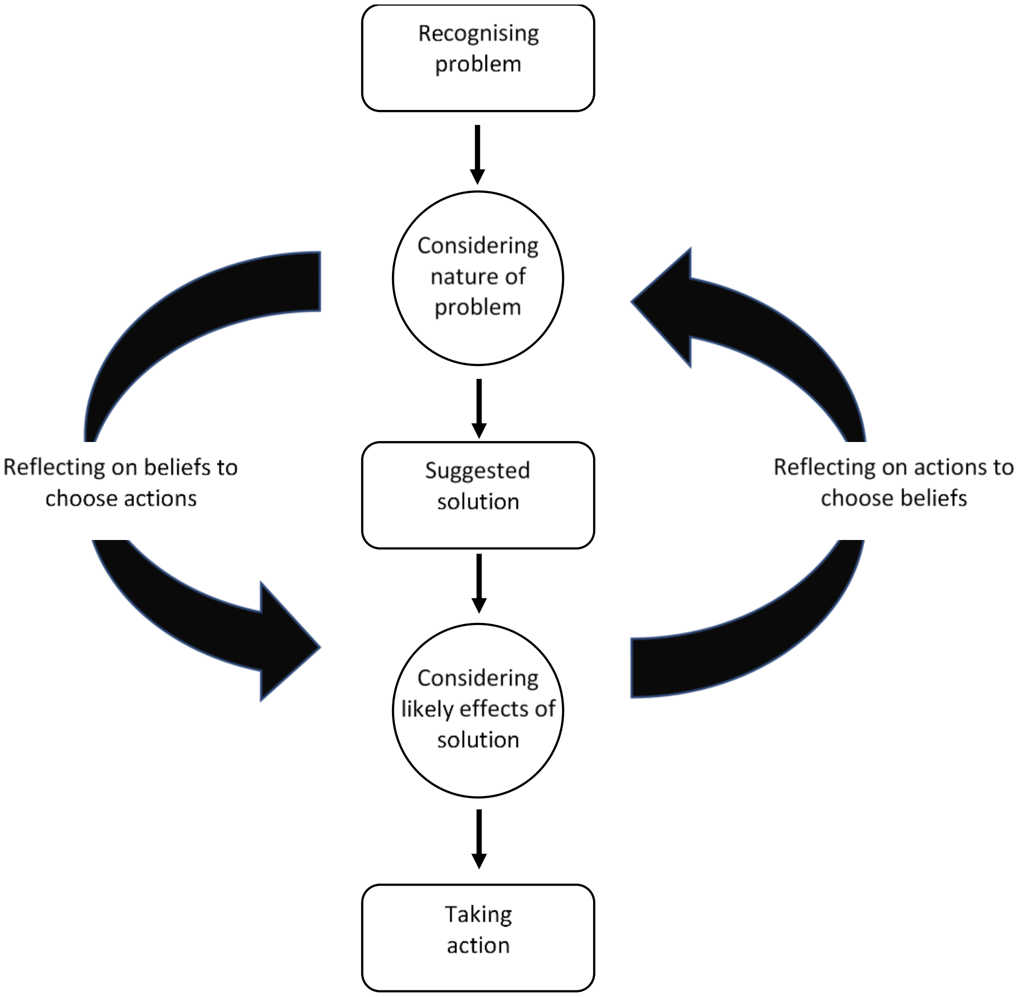


**Figure 3: Dewey's Model of Inquiry (Adapted from: Morgan, 2014, p 1047)**

**(Reproduced with permission from SAGE Publications from: Morgan, D. L. (2014). Pragmatism as a paradigm for social research. *Qualitative Inquiry, 20*(8), 1045-1053. doi:10.1177/1077800413513733)**

Dewey emphasised the interpretation individuals derive from their experiences, are influenced by contextual, social and emotional factors which also need to be considered when understanding the formation of meaning (Morgan, 2014). Therefore, I will provide information regarding the historical and social context in which the individual studies took place in the introduction to chapters four, five and six.

## 3.3 Centralising the Researcher

As the researcher, I recognise that there were choices involved at different stages of the inquiry. I adopted reflective practices, to elucidate the basis of choices that I made, including reflecting on my beliefs and values of that influenced these choices (Badley, 2015; Morgan, 2014). In the philosophy of pragmatism, the researcher is not just viewed as 'carrying out research' but, due to the choices they make during research, the researcher is viewed as central to the process (Morgan, 2014). In sections 3.3.1 to 3.3.4, I will make explicit these choices and reflect on the basis of the choices made.

### 3.3.1 Undertaking PhD research

My choice to undertake research as a PhD project shaped the inquiry process as it involves a formal, regulated approach to inquiry that has developed overtime. I value the supervision, support, structure and authority associated with conducting research as part of a PhD. I decided to apply for admission to a PhD on this topic at the University of Adelaide where I had previously completed a Master of Public Health. An attraction to applying for PhD candidature at the University of Adelaide was the availability of supervisors who had an interest in the topic, appropriate research skills, and shared values.

The selection of PhD supervisors is affected by the approach chosen to conduct the research and has an ongoing effect on the approach taken. The application for admission involved an initial research proposal, which was formulated with the assistance of Dr Emma Miller who had a background in HCV research and who became one of my supervisors. Through my Master of Public Health, I developed skills in conducting semi-structured qualitative interviews and my initial proposal included the use of qualitative interviews. Dr Jaklin Eliott, who has expertise in qualitative research and supervised my masters project, supported the use of qualitative methods and agreed to be my primary supervisor. Once my application was approved, Dr Paul Aylward joined the supervision team, bringing his qualitative research experience with healthcare providers and vulnerable groups, including PWID.

The option of 'PhD by publication' offered at the university was also attractive to me, as I felt that this would allow results to reach the intended audience sooner and more effectively than by traditional thesis submission. This was particularly relevant for me as I was primarily a part-time student and the publication of my thesis would thus involve a significant time lag. In September 2017, I decided to move my PhD candidature to Flinders University to join both Dr Miller (now my primary supervisor) and Dr Aylward who had moved to Flinders University in 2014. This move required the submission of a traditional thesis and therefore removed the emphasis on publication of results in peer review journals. The advantage of earlier publication under the former option was mitigated however as one set of results had been published (Scarborough, Miller, Aylward, & Eliott, 2017) and the time to completion was shortened. As the research questions and methodology were already well established, transition to Flinders University did not involve any change to these aspects of the research.

### 3.3.2 My values and beliefs that influenced the research

The problem I identified, and the research questions I generated, were aimed at examining and addressing healthcare equity for PWHCV. Equitable access to quality healthcare is an important social justice issue for me and the pragmatic approach fits well with developing action to address such issues. Pragmatism has ongoing links with research that has as a social justice agenda requiring political action with the recognition that there is: ′a natural fit between pragmatism and many versions of transformative or emancipatory research through a shared emphasis on openness, fairness, and freedom from oppression.′ (Morgan, 2014, p 1050). In recent times there has been growing recognition that entrenched power hierarchies exist within societies, which limit the ability of oppressed individuals and groups to participate in the inquiry process and take action to achieve social justice aims (Hildreth, 2009; Morgan, 2014). There is a therefore a need to incorporate advocacy into the pragmatic approach to address such imbalances (Hildreth, 2009; Morgan, 2014). I recognised that I was in the privileged position of having the capacity to carry out research. I had completed an undergraduate and master's degree and had financial freedom and time to dedicate to research. I have relevant networks, knowledge and skills gained through my work and previous research experience (Scarborough et al., 2011) to undertake research on this particular topic. As part of commitment to social justice, I felt that this capacity would be well served researching this topic.

### 3.3.3 Reflexivity

I incorporated reflexive practices at all stages of my research throughout fieldwork, analysis and writing as advocated within the philosophy of pragmatism (Morgan, 2007, 2014) and reflected in the method of thematic analysis (Braun & Clarke, 2019; Braun et al., 2019). I reflected on what I as the researcher, brought to the inquiry, and how this influenced how I conducted the research. I considered the perceptions formed about me as the interviewer/researcher by the participants, and the perceptions I had about the various groups of participants, and how these would influence the inquiry. I will detail my reflective practice and how this affected the inquiry.

People with a history of IDU or HCV, may interact differently with a researcher based on their perception or knowledge of the HCV or IDU status of the researcher (Harris, 2009). To address power imbalances between interviewer and interviewee, it has been posited that it is important that participants and the researchers are members of the same stigmatised group, for instance HCV positive or a PWID (Harris, 2009). As I, the interviewer, had no history of illicit drug use or HCV, I was careful to present as having no such history. Being honest and upfront about this allowed participants' decisions to be involved in the research and share information to be based on informed consent. To reduce any perceived power imbalances, I emphasised that I regarded participants as experts, with unique knowledge to share about their perceptions and experiences. In addition, I expressed my sincere gratitude to all participants for their involvement in the research.

At the initiation of my PhD candidature, my perceptions of people with a history of IDU had largely been formed through my work, since 2005, at Drug and Alcohol Services South Australia (DASSA). DASSA is a South Australian Government organisation which provides clinical services and policy input regarding drug and alcohol issues (Government of South Australia  - SA Health, 2020). My work in a non-clinical, project officer role, supporting GPs with involvement in prescribing OST. In this role I have ongoing interaction with workers from Hepatitis SA, which is a non-profit, community-based organisation that provides information, education and support services to South Australians affected by HCV or hepatitis B (Hepatitis SA, 2020a). My role brings me into contact with DASSA Community Participants and Peer Workers at Hepatitis SA, who have lived experience of IDU and/or a diagnosis of HCV. These people would generally describe themselves as former PWIDs and their roles involve disclosure of this history. I have been co-located with a DASSA clinical service and came into casual contact with clients of the service, the majority of whom have a history of IDU and were receiving OST. These clients represented a segment of the PWID population who were engaging with a service. Most of the behaviour of patients and clients reported to me by GPs I support, and colleagues in clinical roles, has been unremarkable, but I have had infrequent reports of behaviour that has been aggressive, manipulative and criminal.

Through this exposure I believed that I had a nuanced view of people with a history of IDU, counter to many family and friends, who generally associate PWID with ongoing addiction and use stereotypes to describe PWID. My view included consideration that IDU could encompass a range of behaviours and an individual's relationship to IDU could change over time. I had exposure to people who had once been addicted to drugs, who were no longer involved with IDU and were leading lives that were not defined by their IDU history. As well, I interacted with people who were receiving treatment and had not yet reached this point, and some who may never do so. Therefore, when developing the interview guide at the initiation of *Study 2,* I included questions to explore participants individual relationship to IDU. The input of participants during *Study 2,* further uncovered and challenged assumptions and positions that I had about people with or at risk of HCV. Through interaction with the 12 participants with a history of IDU from *Study 2*, I was further exposed to people with such a history and it highlighted to me the heterogeneity that can occur regarding the significance of drug use to individuals' lives. Having this understanding allowed me to envisage the range of ways that IDU may be perceived by individuals affected by HCV, outside of the previously narrow view of a person with IDU who developed addiction and sought treatment, represented by DASSA clients. I incorporated this knowledge into the analysis of data*,* the development of the interview guide for *Study 3*, and the recommendations suggested.

I have ongoing relationships with participants who were involved with OST programs who were recruited as Key Workers for *Study 2* and GPs recruited for *Study 3,* which could have affected the interactions with these participants and shaped my interpretation of the interview data. I perceived that there were shared understandings between participants and me based on prior interactions regarding patients receiving OST. Coming into the interviews I was aware that participants working with patients receiving OST, regularly made the distinction between people who use illicit drugs, people seeking treatment, people at early stages on the program and people who are stable on the program. These participants had relayed their experiences of client'/patient' behaviour ranging from ordinary to problematic behaviour which could match the stereotypical representation of an injecting drug user. OST prescribers often presented patient's behaviour as not static, with improvements occurring when patients become stable on opioid substitution and reverting if the patient relapses. Opioid prescribers have talked about the satisfaction of being involved in the work and the long-term positive relationships they have formed with some patients on the program. Another common understanding is that at the health system level, patients on the program are often stereotyped and unfairly treated due to their association with IDU. In this regard we have discussed the highly regulated nature of the program (Wood, Opie, Tucci, Franklin, & Anderson, 2019) and the lack of means testing applied to the cost of prescribing fees for patients on the program (Shepherd, Perrella, & Hattingh, 2014). During annual education events and mailouts I was involved in distributing information, resources and promoting training for DAA. Participants who were OST prescribers or Key Workers from DASSA or Hepatitis SA, would be aware that this was an area that I was interested in promoting. I recognised that during interviews, participants may leave unspoken their perceptions and experiences where my knowledge of these was assumed. When interviewing people who I had an existing relationship with, I emphasised that the interview transcript was the exclusive source of data used for analysis. During interviews I monitored for situations where shared information was being assumed and asked for elaboration, emphasising again to participants, the importance of having the information included in the transcript.

I recognised that for all participants it may be difficult to separate my role as a DASSA worker and as a PhD candidate conducting research. I considered how this may have affected their perception of informed choice to participate, rapport developed with the participants and the information provided during the interviews (McDermid, Peters, Jackson, & Daly, 2014). Specific procedures to ensure informed choice are included in the for Ethical consideration section, 3.7.2. During interviews I attended to responses where participants appeared reluctant to provide information due to their concern about offending me in some way, for example, when participants spoke of negative experiences in relation to DASSA, the OST program, PWID or involvement with providing care to PWHCV. At all times I emphasised to participants that there were no right or wrong answers, and that I was interested in their perceptions and experiences, even when these were critical.

The members of my supervision team encouraged and aided my reflexivity and, as they came from a variety of professional backgrounds, provided an 'outsider' view to the research. Collective discussions influenced the development of themes during analysis of the data. During these discussions, the assumptions that underpinned my analyses were often questioned, leading to additional or alternative ways of viewing the data being explored. This reflection directed my exploration of emerging themes in subsequent interviews. Similarly, exposure to questioning occurred in different fora where I presented my work, which included a PhD student writing group, conference presentations and talks given to local groups. The audience of these presentations represented a varied range of expertise in HCV (from specialist, lived experience to no expertise at all) and a large variety of backgrounds (professional, cultural, educational, etc.). These audiences provided input that further assisted me in identifying my previous assumptions. Throughout my PhD candidature, I have continued to review the literature, attend presentations and reflect on my work in relation to the work of others in the field. I was then able to re-examine the data and reflect on the validity and effect of these assumptions on my findings and modify them through this reflexive practice. I have endeavoured to be explicit in this thesis about the choices I have made in my project, to allow transparency in relation to my underpinning assumptions and positions.

### 3.3.4 Ethical considerations of research

The consideration of ethical issues drove choices I made about the nature of the research, the research process and the publishing of the research. The *Australian Code for the Responsible Conduct of Research* (National Health and Medical Research Council, 2018) and the *National Statement on Ethical Conduct in Human Research 2007 (updated 2018)* (The National Health and Medical Research Council - The Australian Research Council and Universities Australia, 2018) provide a framework for carrying out ethical research. In the code there are eight principles of responsible research conduct provided: 'Honesty, Rigour, Transparency, Fairness, Respect, Recognition, Accountability and Promotion' (National Health and Medical Research Council, 2018, p 2).

Throughout the PhD process, I reflected on the ethics of the research and actively sought to ensure that my approach met the standards of the code of practice. I will discuss the ethical considerations for each study and provide details of the formal ethic approvals granted in the sections 3.7.1, 3.7.2, 3.8.1 and 3.8.2 below.

## 3.4 Methods

Morgan points out that the adoption of pragmatism does not define the use of any method or approach, but frees the researcher to select method(s) based on whether they believe that the inquiry undertaken can contribute to solutions that address the problem recognised by them (Morgan, 2014). However, ‘freedom to choose methods’ does not equate to ‘methods not mattering’ (Morgan, 2014). I will therefore justify my selection of the methods I used and seek to demonstrate that these methods were used appropriately.

### 3.4.1 Choice of study design

To answer the research questions that I had developed, I chose a study design involving three separate studies, followed by an examination of the combined study results. *Study 1* did not require ethics approval, as it involved document analysis of public policies. This study was undertaken whilst completing the complex and time-consuming ethics approval process for *Study 2*. I decided to conduct separate studies to address research questions two and three, starting with the investigation of the people at risk or with HCV (*Study 2*), followed by the investigation of GP perspectives and experiences (*Study 3*). The separation of these studies allowed me to concentrate on maximising the recruitment of participants for each study (see section 3.7.3 and 3.8.3) and for the findings of *Study 2* to be further explored with GP participants. *Study 2* was conducted during my candidature at the University of Adelaide and *Study 3* was conducted after my move to Flinders University. The fourth research question involved a synthesis of the results from *Studies 1*, *2* and *3*, and consideration of what implementation strategies could work in the context of the Australian context at the time of the completion of the thesis.

## 3.5 *Study 1* - An examination of the cohesiveness of strategies relating to the primary healthcare system, the health workforce and HCV

### 3.5.1 Document selection

During the initial review of literature in 2014, three Australian strategy documents were identified for analysis as appropriate documents for *Study 1* (Bowen, 2009). These documents were:

A. Third National Hepatitis C Strategy 2010–2013 (Australian Government - Department of Health and Ageing, 2010b), (the HCV Strategy ),

B. Building a 21st Century Primary Health Care System (Australian Government - Department of Health and Ageing, 2010a), (the Primary Healthcare System Strategy), and

C. The National Health Workforce Innovation and Reform Strategic Framework for Action 2011–2015(Health Workforce Australia, 2011), (the Health Workforce Strategy).

In 2014 these documents represented the most recently published Federal Government of Australia strategy or policy relating to these topics. The *HCV strategy* identified the priority actions to addressing the HCV epidemic in Australia, funded under the National Healthcare Agreement (Australian Government - Department of Health and Ageing, 2010b). The *Primary Healthcare System Strategy* was the first of its kind in Australia and developed from an extensive consultation process (Australian Government - Department of Health and Ageing, 2010a; Commonwealth of Australia, 2008). The strategy release was concurrent with the Federal Government taking full funding and policy responsibility for primary healthcare. The document was described as '…a national road map to guide future primary health care policy and planning…' (Australian Government - Department of Health and Ageing, 2010a, p 3). *The **Health Workforce Strategy*** was developed by federally funded, Health Workforce Australia (HWA) organisation. The document was '…designed to provide an overarching, national platform that will guide future health workforce policy and planning in Australia.′ (Health Workforce Australia, 2011, p 1). These documents were published and made publicly available by the Federal Government to present their approach to policy issues, and therefore analysis of these documents did not require ethics approval.

### 3.5.2 Document analysis

To analyse the selected policies I adopted the What's the problem represented to be? approach of Bacchi (2009, 2016). Rather than accepting that policies are written to solve a predetermined problem, Bacchi proposes that questioning how problems are represented in health policies is integral to the analysis of these documents. This approach provides a set of questions, described below in Table 7, which form a tool for deconstructing the way the problem is represented, the associated assumptions and to indicate possible alternatives.

**Table 7: Questions posed in the *What's the problem represented to be?* approach to policy analysis. (Adapted from: Bacchi, 2009, p 2)**

1. What's the 'problem' (e.g., workforce capacity, health inequality, health literacy, knowledge translation, inadequate resource etc.) represented to be in a specific policy?
2. What presuppositions or assumptions underlie this representation for the 'problem'?
3. How has the representation of the 'problem' come about?
4. What is left unproblematic in this problem representation? Where are the silences? Can the 'problem' be thought about differently?
5. What effects are produced by this representation of the 'problem'?
6. How / where has this representation of the 'problem' been produced, disseminated and defended? How could it be questioned, disrupted and replaced?

Using Bacchi's approach (2009, 2016), I analysed the strategies by deconstructing the framing of this problem, examining the underlying assumptions and questioning the articulated solutions. The documents were scanned to identify content concerning the provision of healthcare in private general practice and specifically issues around equity and access. Investigating the allocation of funding within proposals is one way that assists in identifying problem representations and how they are prioritised, therefore, the funding within each strategy was investigated. This was determined by identifying the nominated 'priority groups' and process of determining the future need. Further, the linkages between the documents were analysed, to inform improvements to the cohesiveness of future strategies.

## 3.6 *Study 2* and *Study 3* - Qualitative methods used

For both *Study 2* and *Study 3*, I used semi-structured interviews to collect data, transcribed these interviews verbatim and analysed this data using thematic analysis. A detailed outline of the use of these methods is provided below. I will then outline the ethics application process, ethical considerations, recruitment, participation and data collection aspects of both *Study 2* and *Study 3*.

### 3.6.1 Semi-structured interviews to gather data

I chose face-to-face, audio-recorded, semi-structured interviews as a way of eliciting the experiences and perceptions of PWHCV, key workers and GPs about engagement in the provision of care for HCV within private general practice. I was guided throughout the selection and conduct of the semi- structured interviews by the work of DeJonckheere and Vaughn (DeJonckheere & Vaughn, 2019) in their discussion about qualitative research in primary care research. Semi-structured interviews are often used in primary care research where it is important to understand the experiences, beliefs, attitudes and perceptions of people on the topic of interest. The topic of HCV and its association with illicit IDU can be viewed as a sensitive issue, which are particularly suited to being investigated using face-to-face interview. The ability to maintain confidentiality is also important where sensitive issues are involved. Participants were offered a level of assurance in this regard as interviews were audio-recorded (as opposed to video recorded) and informed of other processes to maintain confidentiality outlined in section 3.7.2.

My overall aims when using semi-structured interviews to gather data, aligned with the aims of DeJonckheere and Vaughn's (DeJonckheere & Vaughn, 2019) in their discussion about qualitative research. When interacting with participants my aim was to make the participants feel that their contribution was respected and that they felt comfortable to share their perspectives and experiences, which were potentially of a sensitive nature. Throughout the recruitment and interview process I paid attention to establishing trust and rapport with participants to promote frank discussion. At all times, I aimed to be friendly and non-judgemental. The location and timing of the interviews was chosen to be convenient for the participant, provide a level of comfort and allow the conversation to be private and uninterrupted. During the face-to-face interviews, I positioned the participants as the 'expert'. I understood that it was important that participants felt listened to, therefore during the interviews I provided verbal and nonverbal feedback and demonstrated additional active listening techniques. The rapport established allowed me to elicit the experiences and perceptions of the participants, which provided the data for analysis.

For the semi-structured interviews conducted, I prepared an interview guide that included open ended questions, specifically formulated to address the research questions. These research questions were defined by me and were based on previous literature on the topic. The interview guides were reviewed by my supervisors, who were able to provide suggested modifications based on their qualitative interview experiences with similar participant groups. I enlisted family, friends and work colleagues to test each guide and assess whether the language, phrasing and order of questions elicited discussion and if the questions could be covered within the allocated interview time. I ordered questions in the interview guide so that I started with general introductory questions, before asking core questions that were about more sensitive and specific questions. This ordering of questions helped to put the participants at ease and to encourage them to talk openly. I prepared follow-up questions and also allowed time for unplanned follow-up questions to be asked. I reflected on each interview and modified the articulation of questions or added additional questions where necessary. In this way, the core questions were retained across the interviews, but there was flexibility to include additional topics introduced by the participant and to explore participant's responses in more depth (Adams, 2015).

The use of semi-structured interviews was my choice of method to enhance the flexibility and capacity of this approach to elicit in-depth knowledge about experiences and perceptions to answer my defined set of research questions, and this would not have been possible using other research methods such as surveys (DeJonckheere & Vaughn, 2019; DiCicco-Bloom & Crabtree, 2006). Using an interview guide for semi-structured interviews maximises the ability to collect data when participants are limited to being available on one occasion, for a limited amount of time (DiCicco-Bloom & Crabtree, 2006). The incorporation of core questions in the guide, allowed me to make comparisons between interviews, and for specific details relevant to the research questions to be collected about each participant, for example, experience with HCV treatment. Whilst participants are asked the same core questions, this method allows the flexibility for further exploration of the complexities of meanings, contexts and experiences each participant brings to the interview.

### 3.6.1.1 Interview guide *Study 2*

The initial interview guides for *Study 2* (Appendix 2 and Appendix 3) were developed to facilitate participants' discussion on a range of topics about their perceptions and experiences of peoples' engagement with private GPs regarding care for HCV. The topics explored, and subsequent questions developed, were informed by the existing literature (Evon et al., 2010; Miller et al., 2012; Sublette et al., 2015; Swan et al., 2010; Yap et al., 2014). The interview questions included questions about perceptions of private GPs ('What for you makes a good private general practitioner?), experience of HCV ('Can you tell me the effect of HCV on your life?'), HCV knowledge ('Tell me how you gained your knowledge about HCV?'), and experience of care provided by GPs ('Can you describe any situations where you have received medical care from private GPs that relates to HCV?').

The interview guide was modified over the course of the interviews for several reasons. The original wording of the questions was tailored to suit the group that the participant was drawn from with questions that varied depending on whether the experience was personal (Group A) or that of a client (Group B). The first participant; recruited as a key worker, disclosed that they had personal experience with a diagnosis of HCV and therefore the questions were adapted to include both personal and client perspectives and experiences. The semi-structured nature of the interviews allowed flexibility to re-order the questions as required, and the open-ended nature of the questions often led to participants discussing topics that made later questions in the interview guide redundant. Interviews were transcribed as soon as possible after the interview took place and initial aspects of the interview flow and the data gathered, were reflected upon and the interview guide was modified where required (DiCicco-Bloom & Crabtree, 2006).

### 3.6.1.2 Interview guide *Study 3*

The interview guide for *Study 3* (Appendix 4) was developed to facilitate participant discussion across a range of topics regarding their perceptions and experiences of the provision of care for HCV in private general practice. The topics explored, and subsequent questions developed, were informed by the existing literature (Hopwood & Treloar, 2013; McNally et al., 2006; Sievert et al., 2014; Wade et al., 2017). The phasing of the research allowed the findings of the thematic analysis of *Study 2* to be incorporated into the semi-structured interview schedule of *Study 3*. Perceptions and experiences of people at risk of

HCV and key workers with this group could therefore be explored and compared with the experiences of GPs.

The interview questions included questions about the professional background of the participants (‘What brought you to work in general practice?’), the participants choices regarding professional development (‘How do you choose the education you are involved in?’), specifically about HCV education (‘Can you tell me about any HCV education that has been offered?’, ‘Describe any further education you would like in this area?’), about the general practice they work in (‘Tell me a bit about your practice’), their patients and HCV (‘Do you think patients know their HCV status?’), and care provided for HCV (‘Can you tell me about the care that has been provided here for PWHCV?’) and similarly IDU. Further points were added to provide further clarification of the question or to suggest subtopics for discussion. I reviewed the interview guide after each interview and made slight modifications to the guide. I found that the GP participants needed to be encouraged away from providing brief factual responses, so I modified the questions to maximise their open-ended nature, to elicit more in-depth responses regarding their experiences and perceptions. For example, one question I altered was ‘Tell me about your background’. My intent of this question was to elicit the GPs’ professional background, but one GP took offence believing that I meant his cultural background. I subsequently included reference to ‘professional background’ in this question.

### 3.6.2 Thematic analysis

Thematic analysis, as outlined by Braun et al. (2019), was the method I chose to analyse the participant interviews. Thematic analysis is “a method for systematically identifying, organizing, and offering insights into patterns of meaning (themes) across a data set.” (Braun et al., 2019, p 57). Thematic analysis is not tied to one specific qualitative methodology, but it is critical to be explicit about the choice of methodological approach used (Braun et al., 2019). This aligns with the philosophy of pragmatism, which also emphasises the need to explicitly state the choices made in the inquiry process.

I used the steps outlined by Braun and Clarke (Braun & Clarke, 2008) to carry out the thematic analysis of the data I generated (see Table 8). Rather than strictly moving from one phase to another in a linear fashion, the process involved going back and forth through the different phases. Each phase of the process involves a degree of choice, and therefore flexibility, and as advocated by Braun and Clarke (2008) I will make explicit the choices that were made.

**Table 8: Phases of thematic analysis (Adapted from: Braun and Clarke 2008, p 87).**

Image removed due to copyright restriction. Original can be viewed online at: http://www.tandfonline.com/doi/abs/10.1191/1478088706qp063oa

### 3.6.3 Use of NVivo for Thematic Analysis

I analysed the transcripts with the aid of NVivo computer assisted qualitative data analysis software (QSR International Pty Ltd., 2019; Welsh, 2002). The advantage of using this software was the ability to digitally store the data and record steps of the analysis. I used NVivo for the thematic analysis phases 2- 6, as outlined in Table 8. After loading the deidentified transcripts, I worked through each transcript by coding the text with initial codes. These initial codes tended to be based on topics identified in the literature review, as was reflected in the interview schedule, and were largely descriptive. As allowed by the software, where I identified potential themes, I coded for these as well. Rereading the text, I further named, refined and reviewed the themes to provide more interpretive themes (Braun & Clarke, 2008) that would be applicable to answering the research questions. Throughout the process I used the 'Annotations' function of the NVivo software to record notes about my reflections on the text. The details of the coding conducted for each study will be described in the results section for each study.

### 3.6.4 Transcription

Appropriate for my analyses, I undertook verbatim transcription of interviews that recorded all spoken words and only included additional text to explain the context of these words or body language. Interviews were transcribed and de-identified as soon as practicable after the interview. The process of transcribing interviews involved repeatedly listening to the recording and therefore combines the production of text with the first phase of thematic analysis 'Familiarizing yourself with your data' (Braun & Clarke, 2008). For *Study 2* I transcribed each interview (n=22). For *Study 3*, I transcribed the initial four interviews and then, due to time limitations, engaged a professional transcription service for the four remaining interviews. When producing and reviewing the transcripts, I used repeated listening of the interview and checking of the text and paid attention to the punctuation used, to ensure that the text captured the spoken word accurately (Poland, 1995). All transcribing and reviews of interviews occurred shortly after the interviews took place, which allowed the memory of the interview content to be fresh and for initial analysis and reflection to take place. This timing also allowed for interview guides to be shaped iteratively in response to the interviews undertaken (DeJonckheere & Vaughn, 2019).

To protect the confidentiality of participants I have used 'they' or 'them' rather than using the gender specific pronouns of 'she' and 'he' and removed any personal identifiers from the participant quotes.

### 3.6.5 Selection of sample composition and determination of sample size

For my research I used purposive sampling and, specifically, the method of maximum variation sampling. Purposive sampling is defined as: "…the deliberate choice of a participant due to the qualities the participant possesses." (Etikan, Musa, & Alkassim, 2016, p 2). I used this non-probability sampling technique with the aims of including participants who I believed would provide data, that I could use to provide answers to my research questions. From the variety of purposive sampling methods which can be used, I chose maximum variation sampling, with the aim of including participants with a broad range of characteristics relevant to my selected topics (Etikan et al., 2016). The characteristics I selected as important to sample for, were shaped by the literature review and the understanding I developed from this stage of inquiry (Etikan et al., 2016). I considered that themes identified from a heterogenous sample were more likely to be generalisable to a broader defined population targeted for interventions, than findings from a homogenous sample where findings may only apply to individuals who have the same sampled characteristics (Robinson, 2014). I will discuss the details of the characteristics chosen for maximum variation in the recruitment section for *Study 2* (section 3.7.3) and *Study 3* (section 3.8.3).

Although larger samples are generally considered better for quantitative analyses, Braun and Clark (2016) point out that for thematic analysis: 'The bigger the sample, the greater the risk of failing to do justice to the complexity and nuance contained within the data.' (Braun & Clarke, 2016, p 742). Therefore, for *Study 2* and *Study 3*, a minimum sample size was not defined. The most important consideration for me in deciding the sample size, was whether it was possible to derive themes from the data gathered from the sample, that would be useful to answering my research questions. This did not equate to the sample size being determined by setting a specific number of themes being generated from the data as a cut-off point or on reaching a 'saturation' of themes. Braun and Clarke (Braun & Clarke, 2016) argue that strict formulaic approaches are problematic as they involve counts of 'discovered' themes that therefore posit objectivity (Fugard & Potts, 2015). In arguing for using 'saturation' of themes as an endpoint to recruitment of participants (Mason, 2010) concedes that:

> The point of saturation is…. a rather difficult point to identify and of course a rather elastic notion. New data (especially if theoretically sampled) will always add something new, but there are diminishing returns, and the cut off between adding

> to emerging findings and not adding, might be considered inevitably arbitrary.
> (Mason, 2010, p 16)

The final sample size for *Study 2* (N=22) and *Study 3* (N=9), was determined in conjunction with decisions about the recruitment process, and initial analysis of data gathered in these studies. I determined from an initial analysis of interview data from the *Study 2*, that the data would provide information useful to answers to the associated research question. The possibility of gaining additional data by recruiting and interviewing additional participants was balanced by the desire to do justice to the data already collected. More detail of the recruitment process that provided the sample size N= 22 participants, is described in section (section 3.7.3). The initial analysis of data from the sample recruited for *Study 3* (N=9), also indicated that the data collected would be useful to answer the associated research question. For this study, the recruitment process was proving difficult and time consuming and there was no guarantee that further resources would guarantee additional participants. Further detail of the recruitment process for *Study 3* that provided the sample of nine participants, is available in section (section 3.8.3).

## 3.7 *Study 2* – Engagement of people with or at risk of HCV with care for HCV in private general practice.

### 3.7.1 Ethics approval process

Ethics approval for *Study 2* was obtained from the:

- South Australian Health Human Research Ethics Committee (Reference No.: HREC/13/SAH/38),
- Aboriginal Health Research Ethics Committee (a sub-committee of the Aboriginal Health Council of South Australia Inc.) (Reference No: 04-13-514),

and notification of this approval was provided to:

- Human Research Ethics Committee of the University of Adelaide (Notification ID.: 000016938).

Recruitment at South Australian government health sites required ethics approval from the South Australian Health Human Research Ethics Committee. This approval was accepted by the Human Research Ethics Committee of the University of Adelaide to meet the ethics approval requirement for research involving humans conducted by researchers at the

University of Adelaide. As an overrepresentation of people at the DASSA and Clean Needle recruitment sites who identified as Aboriginal or Torres Strait Islander was subsequently identified, ethics approval for *Study 2* was also required from the Aboriginal Health Research Ethics Committee. The proportion of clients of who identified as Aboriginal and/or Torres Strait Islander peoples in 2011 was estimated to be 15.5% (personal communication from DASSA) and the Australian Bureau of Statistics estimating that in 2011, 1.9% of the total population of South Australia was Indigenous (Australian Bureau of Statistics, 2012). Overrepresentation of Indigenous people was also likely at the clean needle sites with the Australian Needle and Syringe Program Survey in 2010 (Iversen & Maher, 2013), in which it was reported that 14% of their South Australian sample identified as Indigenous. Ethics approval documentation is provided in Appendix 5.

### 3.7.2 Ethical considerations

Various ethical considerations are associated with recruitment and participation of members from the groups targeted for recruitment. These groups included people with a history of IDU, PWHCV and/or key workers from organisations that provide services to these people. Additional complexity occurred due to overlap between groups. Participation in the research may expose participants to the harm of stigma and discrimination that is frequently associated with IDU and HCV. The risk of harm and the burden of participation must be balanced with the benefits of involvement by participants. The potential benefits for participants in my research was their opportunity to share their experiences and contribute to potential improvements in the provision of care for PWHCV in private general practice. During semi-structured interviews, the aim is to position the participant as the expert, privileging their knowledge about their experiences and perceptions by taking this respectful stance (DeJonckheere & Vaughn, 2019). For participants in my project, the reduction of potential harms was achieved through ensuring the participants' informed consent and strictly adhering to confidentiality around their involvement and the information they provided.

Informed consent of participants relies on the ability of the participant to understand what participation involves and any associated risks, for which the level of capacity was screened in a variety of ways. To respond to the recruitment advertisement and make interview arrangements, the potential participants required a level of intellectual ability and stability of any mental health issues. The potential participants were asked prior to the interview if they were able to be interviewed in English and if they were 18 years of age or older. The participants were only included where they could participate in the interviews in English and when their level of English gave them the capacity to provide informed consent.

I felt that I had an ethical responsibility to ensure that all people had the opportunity to make informed choices about participation in the research, including Indigenous people who were overrepresented at recruitment sites. The burden of participation and risks of harm needs to be balanced with the benefits to any minority involvement in research (Braunack-Mayer & Gibson, 2017; Sherwood, 2010). As a non-Indigenous woman, with no strong networks within the Indigenous community, I understood that my capacity to attract Aboriginal and Torres Strait Islander peoples as participants was limited. In developing my ethics application to the Aboriginal Health Research Ethics Committee, the committee's, then Senior Research and Ethics Officer, Dr Rosie King, was consulted. In response to Dr King's advice, I modified recruitment documents and the importance of face-to-face recruitment strategy was reinforced to give Indigenous people the choice to participate.

Information about what the research involved and who to contact if their participation raised any negative issues was provided in the *Participant Information Sheet.* This information was reviewed prior to the interview, and participants were given the opportunity to ask questions and have information clarified. Participants indicated their informed consent by signing a *Consent Form* prior to the interview taking place.

There are additional ethical issues raised when the researcher has an existing working relationship with participants, in relation to informed consent and conflict of interest (McDermid et al., 2014). In my non-clinical role at DASSA, I interacted with key workers from both DASSA and Hepatitis SA. To avoid any potential ambiguity, I explained my role as a researcher and how this was separate to my role at DASSA, and emphasised the processes used to protect confidentiality. Participant responses indicated that they understood choice regarding participation and that participation would not affect their ongoing relationships with me or DASSA. Where participants were recruited through my workplace, there was the potential for participants to confuse my roles as researcher and DASSA staff member. In the participant information sheet, during the introduction to the interview and during the interview, the participants were informed that my role was as a researcher and that I was unable to act on their individual behalf. Included in the *Participant Information Sheet* was information about the services that were available to them.

There were measures put in place to maximise the confidentiality of participants' involvement and information provided in the research process. The recruitment materials and processes were designed to avoid participants being identified as being from the targeted populations or as participants in the study. All participant contact details were stored securely and erased at the completion of the data collection phase of *Study 2*. The interviews were conducted at sites where the interview could not be overheard or observed, for example in the participant's home, participant's private office, in a private space within a library. After interviews took place the audio-recording devices used were kept secure and shortly afterwards the interviews were transcribed and deidentified. The original audio-recordings were then erased. The de-identified transcripts were stored as password protected computer files and only viewed by myself and my supervisors. During publication of this research, care was taken to not include any participant information, including quotes which may allow the identity of the participant to be revealed. All documents pertaining to consent and other ethical requirements are provided in Appendix 6.

### 3.7.3 Recruitment

There were three groups recruited based on their ability to provide insights useful to answering the research question:

A. People self-reporting a diagnosis of HCV or at risk of HCV.

B. Key workers providing care to clients with HCV.

C. Key workers who also reported a personal experience of a diagnosis of HCV and illicit drug use history.

The initial strategy aimed to recruit Groups A and B, but it was found that these two groups were not discrete, with key workers sometimes self-reporting a diagnosis of HCV.

Group A included people either at risk for, or self-reporting a diagnosis of HCV. Participants who did not report a diagnosis of HCV, were at risk of having been infected with HCV due to their self-reported history of illicit IDU. These individuals may not have had a current HCV infection, or may have been amongst the 20% of Australians with chronic infection who remained undiagnosed (Hajarizadeh et al., 2017). People affected by HCV in this way were included to provide insights into their perspectives and direct experiences about the provision of care by private GPs. A purposive sampling strategy was chosen to gain a range of perspectives and experiences of individuals with or at risk of HCV in engagement of healthcare related to HCV by GPs in private general practice. Some of the purposively sampled characteristics of participants were drug use status, awareness of HCV, duration of infection, and treatment status.

Key workers who were involved with providing care to clients affected by HCV, including clinicians and peer workers, were targeted for recruitment as these individuals were able to provide valuable insights about care sought and provided, based on their long engagement with, and advocacy for, clients affected by HCV. The key workers who reported personal experience of a diagnosis of HCV and history of IDU were able to give perspectives based upon their own, and their client's experiences.

Recruitment occurred primarily through two organisations, Hepatitis SA and DASSA. Hepatitis SA is a community organisation that provides information and advocacy services, including peer education, for people affected by viral hepatitis. DASSA is an agency of the South Australian Health Department with clinics offering a variety of services including clean needle provision, opioid substitution therapy (OST) and drug counselling. In the first phase of recruitment, key workers were recruited from DASSA and Hepatitis SA through targeted emails, as well as attendance at staff meetings. The key workers targeted for recruitment included medical practitioners, nurses, social workers, psychologists, and peer educators. To recruit people affected by HCV, an advertisement was placed in the quarterly Hepatitis SA newsletter, distributed throughout South Australia in both digital form and hardcopy. Recruitment targeting people who had a history of IDU occurred through DASSA clinics, via the placement of posters and information packs and subsequent personal approaches at the clinics. At the initiation of *Study 1*, I was employed at DASSA and this facilitated access to recruitment sites and potential participants who could provide the perspectives and experiences of people at risk of HCV. My presence at recruitment sites allowed some familiarity between myself and potential participants, which I felt would also improve recruitment rates.

Recruitment continued while interviews were conducted, and decisions about further recruitment were made based the initial analysis of the data. The first interviews I coded and initially analysed, were the key worker interviews. I found that during the coding process for the interviews from Group B, key workers with no personal experience of HCV, that a low number of new codes was generated for each interview and I was generally using the same codes for each interview. This contrasted with the coding of the Group C, key workers with personal experience of HCV, where I was generating several new codes for each interview, with these codes mainly relating to their personal experiences of HCV. The Key Workers (n=12) recruited during the initial round of invites, represented a range of professions, gender (4♀, 8 ♂), and other demographic characteristics. I decided to concentrate on the recruitment of people with or at risk of HCV. I felt that further purposive sampling of Key Workers would not necessarily generate more themes useful to answering my research questions that would not be generated from people recruited with or at risk of HCV.

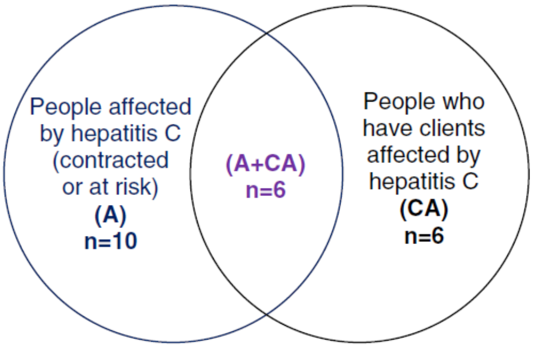
Interviews (n=10) were then conducted with participants from Group A, people with or at risk of HCV, recruited through the Hepatitis SA newsletter, through advertising at DASSA and Clean Needle sites, and through face-to-face recruitment at DASSA clinical sites. The demographics of these participants were diverse, as were some of the experiences and perceptions that they reported. Participants of both genders were recruited (6♀, 4 ♂). I was still generating some new codes for each additional interview analysed, but I felt at this time that I should prioritise analysing the data that I had collected. From further analysis I felt that that I could identify themes across the total set of twenty-two interviews, that could be useful to answering my research questions. In consultation with my supervisors, I made the decision to end recruitment for *Study 1* at this stage.

### 3.7.4 Participants

All potential participants were included as they were 18 years of age or older, they could participate in the interviews in English and their level of English was determined to have given them the capacity to provide informed consent (see also section 3.7.2).

There were 22 participants recruited to *Study 1*. The sample consisted of ten people affected by HCV (6♀, 4 ♂), six people who had clients affected by HCV (2♀, 4 ♂), and six people who were both affected by HCV and had clients affected by HCV (2♀, 4 ♂) (see Figure 4.).

**Figure 4: Final Sample *Study 1*. (Adapted from,Scarborough et al., 2017, p 2)**



Participants were asked to indicate that they met the inclusion criteria of being over 18 years of age. Additional demographic details were not formally collected, however the demographic information described below was provided during the interviews. Most participants resided in the metropolitan suburbs of Adelaide, the capital city of South Australia (SA), with one participant from the affected group previously residing in a regional area and only one participant residing in a regional area who was from the key worker group. Participants with clients affected by HCV provided services to HCV-affected clients across SA. The age range of participants was from early 20s to over 60. One participant reported they were from a non-English speaking, first-generation migrant background. No participants indicated during the interviews that they identified as Indigenous Australian.

Except for one participant who reported that transmission was via non-sterile tattooing, all participants reporting a diagnosis of HCV also reported a history of illicit IDU and assumed that HCV transmission occurred via this practice. The pattern of self-reported illicit drug use across participants varied in severity (chronic and relapsing, to occasional and controlled) and currency (from recent to historical). At the time of the interview, some participants reported being highly engaged with private GPs. All participants indicated that they had the choice to access private GPs. Participants self-reported a range of HCV diagnosis including previous HCV infection (naturally cleared), cured of chronic HCV infection, current chronic HCV infection, and intention to be tested (see Table 9). Participants from the groups affected by HCV also self-reported a range of involvement in HCV treatment: had decided against interferon-based treatment available at the time of the study, successful and unsuccessful completion of treatment, current involvement in treatment and seeking treatment (see Table 10).

**Table 9: Self-reported HCV status of all participants affected by HCV (n=16).**

| |
|---|
| Unknown but intention to be tested as part of initiation into OST treatment (n=1) |
| Contracted HCV recently and waiting for confirmation that had naturally cleared the virus (n=1) |
| HCV cleared naturally (n=1) |
| HCV cured (n=1) |
| Diagnosis of chronic HCV (n=12) - ranging from recent diagnosis to late 1980s |

**Table 10: Self-reported HCV treatment status of all participants affected by HCV (n=16).**

| HCV Treatment Status |
|---|
| Seeking antiviral treatment for chronic HCV (n=3) |
| Undergoing treatment (n=1) |
| Successful clearance of the virus with treatment (n=1) |
| Unsuccessfully treated (n=1) |
| Chronically infected with HCV but at the time of the study not intending to undertake Interferon-based treatment (n=10) |

### 3.7.5 Data collection

Interviews commenced in November 2013, and the last of the twenty-two interviews was conducted in August 2014. DAAs for HCV were being clinically trialled in Australia at this time but had not been approved for broader use or included on the PBS. The location of interviews was guided by the participants and conducted in a range of settings, including in the home of a participant, DASSA sites and public libraries.

The median length of interviews was 58 minutes, ranging in duration from 19 minutes to 87 minutes. The interview outline was covered during all interviews, although one participant requested that the interview be kept brief. A $20 supermarket gift voucher was provided to participants as compensation for their time.

## 3.8 *Study 3* – GPs engagement in the provision of care for HCV in private general practice.

### 3.8.1 Ethics approval process

Ethics approval was granted by the Flinders University Social and Behavioural Research Ethics Committee (Project number: 7823) (Appendix 7).

### 3.8.2 Ethical considerations

I considered that GPs and practice staff had the capacity to give informed consent once provided with information about what participation involved and the associated risks. The benefit to participants was the ability to reflect on their practice and contribute to the improvement of care for HCV for patients in general practice. It was identified that there were minimal risks associated with participation and that the main burden for participants was the time involved. The *Participant Information Sheet* provided participants with information about what the research involved and contact information if their participation raised any negative issues. I perceived that there was the potential for coercion of the nurses by the GP to take part in the group interview, as the GP was the employer of the nurses. During contact with the nurses prior to the interviews, they demonstrated keenness to be involved in the interview, and that their preference was for a group interview. Participants indicated their informed consent by signing a *Consent Form* prior to the interview taking place.

As discussed in section 3.7.2, there are additional ethical issues raised when conducting research where the researcher has an existing working relationships with participants in particular conflict of interest (McDermid et al., 2014). In my work role at DASSA I am involved in recruiting GPs to do training to provide opioid substitution treatment with methadone and buprenorphine, and then providing ongoing resources and support to these GPs. I felt that GPs may be more willing to be involved with someone that they have had previous positive contact with, but felt that as time poor professionals, GPs would be experienced in declining invitations and feel free to decline my approach. Information that clarified that I was conducting the research as part of a PhD and that the research was in no way related to my work role, was included in the *Participation Information Sheet* and in the introduction to the interview. Further, participants were informed their decisions regarding participation would not be shared or affect their interaction with DASSA, participation was entirely voluntary, they were free to withdraw from the interviews and were free to not provide answers to any questions. In response to the initial ethics application the committee required the further measure of my supervisor making the initial approach to potential participants in the form of a *Letter of introduction*, that provided information about me and my project. All documents pertaining to consent and other ethical requirements are provided in Appendix 8.

### 3.8.3 Recruitment

A purposive sampling strategy was chosen to gain a range of perspectives and experiences of individual GPs and practice staff regarding the provision of care for HCV in private general practice. Some of the purposively sampled GP practice characteristics included whether the practice catchment was identified as:

- having a high / medium / low socio-economic status, and
- rural / metropolitan.

I aimed to purposively sample GPs for the following characteristics:

- have / have not prescribed DAA,
- have / have not attended education for prescribing of DAA,
- are / are not prescribers of OST,
- have recently qualified / have practiced for a considerable time,
- are a graduate from an Australian Medicine School / IMG, and
- are male / female gender.

I considered that it would be ideal if I could sample for this variety but was aware that this would be difficult due to potential limits to the willingness of GPs to be involved in research. Therefore, while I used a purposive sampling strategy, there were no inclusion or exclusion criteria and if any South Australian GP wished to be involved in the study they would have been included.

GPs are often targeted for primary healthcare research participation in a range of activities including surveys, interviews, and for access to patients or patient' information (Jones, Dixon, & Dixon, 2012). This research demand has been associated with difficulties in recruitment in GP populations (Jones et al., 2012; McKenzie, Larkins, & Spillman, 2015; Parkinson et al., 2015; Sahin, Yaffe, Sussman, & McCusker, 2014). Reasons for reluctance to participate in research involving interviews include perceived lack of time, lack of interest in research and specific research topics, disruption to clinical care, competing research recruitment, and lack of confidence in the benefit of research to practice (Sahin et al., 2014). By conducting *Study 2*, prior to conducting this study, I felt that if I could then demonstrate prior involvement in HCV research, my authority to carry out this research would be enhanced and therefore recruitment rates could be maximised.

Recruitment occurred in several ways. Study recruitment flyers were added in the newsletter of the DASSA GP Program, which is sent to GPs in the community who have been involved in the Medication Assisted Treatment programs in South Australia (approximately 360 GPs). This included accredited prescribers and non-accredited prescribers, as well as some GPs who have not prescribed opioid substitution therapy but have indicated an interest in receiving the newsletter. Hepatitis SA maintain a mailing list that includes South Australian GPs with a range of involvement in providing care for HCV. This includes GPs who have prescribed DAA for their HCV patients, but may involve GPs who had contact with Hepatitis SA at some time but subsequently have had minimal involvement in the provision of care for patients with HCV. To maintain confidentiality of the mailing list, Hepatitis SA mailed a recruitment package containing an introduction letter, flyer, participant information sheet and consent form (see Appendix 8) to the GPs on their list on my behalf (approximately 330 GPs). After these two strategies were underway, I developed a database to be used for further recruitment from publicly available information, of general practices (N=242) in South Australia and GPs within these practices. This recruitment targeted individual general practices (N=10) and/or individual GPs within them (N=40). The GPs targeted for recruitment by this direct method were chosen based on their individual characteristics and those of their practice as part of the maximum variation sampling strategy (see section: 3.6.5), and were sent recruitment information via mail and facsimile (see Appendix 8) in batches of ten. As GPs and practices may have received recruitment material from more than one source, and recruitment text encouraged recipients to "*pass on this information to others in your practice who may be interested*" (see Appendix 8) the specific path of recruitment of participants was not able to be identified. Recruitment continued during throughout the interview period.

After each participant was recruited and interviewed, their characteristics were compared to the set of characteristics I had selected as important for sampling, to determine if the sought-after variety was achieved. With the exception of recruiting an international medical graduate, after the seventh interview the sample I recruited included all of the characteristics for which I had purposively sampled. Interviews were transcribed, and analysis started as soon as practicable after the interviews took place. One of the features that I noted from the initial analysis of the interviews was that GPs reported many characteristics that affected the scope of practice of individual GPs, that I had not included in my original list. For example, the business model of the general practices and GPs involvement in procedural work. Ideally, I would have recruited additional participants to include variety in relation to these characteristics. At this time direct recruitment to targeted GPs and general practices, was the strategy being used and this strategy was not attracting additional participants. It may have been possible to modify the strategies, gaining additional ethics approval and continue further recruitment, however it was not clear that this would result in increased recruitment or increase the usefulness of findings in regard to my research questions. In consultation with my supervisors, I decided to cease recruitment and concentrate on the analysis and publication of the results based on the interview data collected.

### 3.8.4 Participants

There was a total of nine participants comprising three female medical practitioners, four male medical practitioners and two female nurses. The general practices were in a variety of locations including rural, semi-rural, metropolitan and city locations. These general practices were in locations that generally served low socio-economic areas to high socio-economic areas. Demographic details were not formally collected; however, the following demographic information was provided during the interviews. Participants' age ranged from early 30s to over 60 years. All medical practitioners held fellowship with an Australian college of general practitioners. All medical practitioner participants were graduates from South Australian universities. One GP entered undergraduate medicine as a mature age student. The year of graduation varied from the early 1970s until the early 2010s. One GP worked part-time, with the remainder of participants working full-time. Of the GP participants, three were current, active, accredited prescribers of OST, one had formerly been an accredited prescriber of OST and three had not been involved in OST prescribing.

### 3.8.5 Data collection

Interviews commenced in May 2018 and the last of the seven interviews was conducted in November 2018. Six of the interviews were with individual GPs. The remaining participants were from the same practice and requested a group interview, involving a GP and two practice nurses. The location of interviews was guided by the participants, with five interviews conducted in the GP participants' offices at their general practices, one interview in a private meeting room of a library and one at a café. Interviews varied in length from 48 minutes to 79 minutes, with most interviews being conducted in just under one hour. Participants were not offered recompense for their involvement in the study.

## 3.9 Chapter summary

I have outlined the philosophy of pragmatism applied during this thesis inquiry. In line with this philosophy, I have made explicit the choices made by me throughout my PhD research. I have provided an explanation of the reflective practices I undertook, including the values and beliefs that I brought to the study.

The research design adopted to answer these questions involved three studies. In recognition that the consultations between GPs and patients occurred in a dynamic complex adaptive system of private general practice in Australia, each study concentrated on an individual component of this system. *Study 1* was concentrated on the healthcare system level component, while *Study 2* investigated the patient component and *Study 3* the GP component.

The method chosen for *Study 1* was document analysis. Of the three documents chosen, two were broad policies relating to the primary healthcare system and the health workforce and one was the HCV strategy: a disease specific policy. To analyse the selected policies, I adopted the *What's the problem represented to be?* approach of Bacchi.

For *Study 2* and *Study 3* I conducted a series of semi-structured interviews. The transcripts produced in these studies formed the data that were then thematically analysed as described by Braun and Clarke. Participants recruited for *Study 2* were people with, or at risk for, HCV and/or people with clients with, or at risk for, HCV. This study sought to understand the experiences and perspectives of people affected by HCV in regard to engagement with GPs for HCV care. *Study 2* was completed before *Study 3* commenced and the results informed the conduct of *Study 3*. GPs in private general practice and their staff, were recruited as participants for *Study 3*. The study was aimed at forming an understanding of the experiences and perspectives of the provision of care for HCV, and the provision of DAA in particular.

In the following three chapters I present the results and discussion regarding these studies with Chapter 4 relating to *Study 1*, Chapter 5 relating to *Study 2* and Chapter 6 relating to *Study 3.* In the final chapter I will reflect on the overall findings and provide my suggested recommendations to answer the identified problem.

# CHAPTER 4.

# *STUDY 1 - DOCUMENT ANALYSIS*

## 4.1 Introduction

In this chapter I will provide the results from a key document content analysis conducted in 2014. I analysed three Australian Federal Government strategy documents, relating to the 'health system' level of the model of primary care, as described by Crabtree et al. (2001). I was interested in content within each of these policies, as well as the coherence between the documents. I concentrated on content that related to the achievement of equity of access to primary healthcare and equity of this access for PWHCV. The analysis of the strategies involved deconstruction of the how the problem of equity was framed, examining the underlying assumptions and questioning the articulated solutions (Bacchi, 2009, 2016). This analysis formed the basis of my understanding of the health system context in which the experiences and perspectives of PWHCV and GPs were formed, which were examined in *Study 2* and *Study 3,* respectively. Drawing on my analysis, I developed recommendations to enhance coherence when preparing subsequent documents to increase equity of access for PWHCV, which will be provided in the Chapter 7.

## 4.2 Research question

*Study 1* was conducted to answer the following research question:

1. Do Australian healthcare policies address equity in primary healthcare delivery for the provision of care for HCV by GPs in private general practice?

## 4.3 Publication history

A summary of this document analysis was published in 2015 as:

> Scarborough, J., Eliott, J., Miller, E. R., & Aylward, P. (2015). Equity in primary health care delivery: an examination of the cohesiveness of strategies relating to the primary healthcare system, the health workforce and hepatitis C. *Australian Health Review*, 39(2), 175-182. doi:10.1071/ah14073

As the first author I conceived the idea to undertake the document analysis. With guidance from my supervisors, who were co-authors, I analysed the documents and prepared the submitted manuscript. The results section of this thesis chapter largely replicates the results section of the published article. The discussion section in this chapter has been refined to include contemporary literature and to reflect on the contemporary context.

## 4.4 Background

The philosophical stance of pragmatism requires consideration of the specific historical and social context of the formation of understanding (Morgan, 2014). Below I outline the context in which this study took place and I provide reflection on what I, as the researcher, have brought to the interpretation of the data.

### 4.4.1 Political context of the document formation

Prior to 2014, successive Australian Federal Governments from both major parties emphasised that they were committed to the provision of universal access to private general practice (Abbott & Liberal Party of Australia, 2010; Rudd, 2013), with this topic remaining at the forefront of political campaigning in subsequent elections (Gillespie, 2016). The direct federal spending on healthcare through the MBS and the PBS in 2013-2014 was over $37.7 billion dollars, representing a ratio of health expenditure to taxation revenue of 24.7% (Australian Institute of Health and Welfare, 2015). The rationale for reforms was framed as being required to achieve financial sustainability to the Australian healthcare system, in the face of an ageing Australian population and increased prevalence of chronic disease in the population (Liberal Party of Australia, 2013; Rudd et al., 2010).

### 4.4.2 Context of provision of care for HCV by private GPs during the document formation

Before the publication of the documents in 2010-2011, the main role for private GPs in relation to HCV was diagnosis, monitoring of chronic HCV and/or referral to specialists for HCV treatment (Dore et al., 2009). As it had only been since 1989 that HCV RNA was first isolated and a specific assay for HCV antibodies developed (Choo et al., 1989; Kuo et al., 1989), any involvement for GPs in providing care for HCV was relatively recent. As previously discussed, available HCV treatment in 2010 involved serious side-effects, lengthy and complicated treatment regimens, and treatment success that varied widely dependent on genotype and other factors (Manos, Ho, Murphy, & Shvachko, 2013). The right to prescribe these treatments was not generally available to GPs (Lambert et al., 2011). At that time, DAA was being clinically trialled and showed promise in improving cure rates, shorter and simpler treatment regimens, and less severe side-effects (Dore & Feld, 2015). The variable progression of HCV, combined with the possibility of improved treatment becoming available in the future, complicated decisions regarding undergoing available treatment (McNally et al., 2006). Until the trials of DAA were completed, approved and became widely available, treatment was delayed for a large group of patients who were essentially "warehoused" (Aronsohn & Jensen, 2012, p 1591).

As outlined in Chapter 2.7, while GPs were involved in providing a range of care for HCV (Gifford et al., 2003; Gifford et al., 2005), reports regarding the quality of care were varied (Butler et al., 2017; Carruthers & Ryan, 2012; Gupta et al., 2006; Richmond et al., 2007) and discrimination was reported by patients in healthcare settings due to the connection of HCV with IDU (Australasian Society for HIV Medicine, 2005). The estimated prevalence of HCV of approximately 1% (Thein & Dore, 2009) is low relative to more commonly presenting conditions encountered by Australian GPs, for example asthma (10% of the population) or arthritis (15% of the population) (Australian Bureau of Statistics, 2018). Additionally patients with an existing known diagnosis of HCV, or the HCV risk factors of IDU, may be reluctant to disclose this information to GPs (Day et al., 2004; Fry & Bates, 2011; Gifford et al., 2005; Hopwood & Treloar, 2004; Hopwood et al., 2006; MacNeil, 2012) meaning that in 2011-12 few patients were likely to engage with GPs regarding HCV, compared to other conditions.

## 4.5 Results[1]

Despite the three contemporaneous documents examined, all being sponsored by the Australian Federal Government, all relating to healthcare and each including aims of

---

[1] An earlier version of the text in this section appeared in:
Scarborough, J., Eliott, J., Miller, E. R., & Aylward, P. (2015). Equity in primary health care delivery: an examination of the cohesiveness of strategies relating to the primary healthcare system, the health workforce and hepatitis C. Australian Health Review, 39(2), 175-182. doi:10.1071/ah14073
Available at: https://www.publish.csiro.au/ah/ah14073

increasing the equity of access to primary healthcare, there appeared no mechanism to link together the broad documents and the disease specific document.

### 4.5.1 Document formation[2]

The three policy documents reviewed were:

A. ***Third National Hepatitis C Strategy 2010–2013*** **(Australian Government - Department of Health and Ageing, 2010b) (the *HCV Strategy* ),**
B. ***Building a 21st Century Primary Health Care System*** **(Australian Government - Department of Health and Ageing, 2010a) (the *Primary Healthcare System Strategy*) and the**
C. **National health workforce innovation and reform strategic framework for action 2011-2015 (Health Workforce Australia, 2011), (the Health Workforce Strategy).**

The *HCV Strategy* built upon the previous two strategies, with the first national HCV policy released in 2000. The *Primary Healthcare System Strategy* was described as "a national road map to guide future primary health care policy and planning" (Australian Government - Department of Health and Ageing, 2010a, p 3) and the *Health Workforce Strategy* as "a national call to action for workforce reform" (Health Workforce Australia, 2011, p 1), and these descriptions introduced the two broad strategies as new initiatives.

Separate organisations were responsible for developing each of the strategies, with a variety of processes used to develop them and with contributions from various sources (See Table 11). Despite the pivotal role of primary healthcare, and particularly private GPs in the prevention, treatment and management of HCV, there appeared to be no attempts to provide cohesion between these documents and no mechanism for this to occur.

---

[2] An earlier version of the text in this section appeared in:

Scarborough, J., Eliott, J., Miller, E. R., & Aylward, P. (2015). Equity in primary health care delivery: an examination of the cohesiveness of strategies relating to the primary healthcare system, the health workforce and hepatitis C. Australian Health Review, 39(2), 175-182. doi:10.1071/ah14073

Available at: https://www.publish.csiro.au/ah/ah14073

**Table 11: Organisation responsible for developing the documents and contributors (Adapted from: Scarborough, Eliott et al. 2015, p 176)**

| |
|---|
| *HCV Strategy*<br>Blood Borne Virus and Sexually Transmissible Infections Subcommittee of the Australian Population Health Development Committee.<br>“While governments are the formal parties to this document, a partnership approach has been central to the development of this strategy. This has included significant consultation with, and input from community organisations, researchers, clinicians and health sector workforce organisations. These organisations are represented on advisory committees detailed below that have provided valuable advice during the development process.” (Australian Government - Department of Health and Ageing, 2010b, p 1) |
| *Primary Healthcare System Strategy*<br>Australian Government, Department of Health and Ageing<br>“The development of the Strategy has been informed by the extensive health reform consultations undertaken by the Australian Government. It has taken into account the advice and expertise provided by the External Reference Group chaired by Dr Tony Hobbs, and has drawn upon the detailed information provided in 265 written submissions that were received in response to the *Discussion Paper: Towards a National Primary Health Care Strategy”*<br>(Australian Government - Department of Health and Ageing, 2010a, p 7) |
| *Health Workforce Strategy*<br>Health Workforce Australia<br>“The National Health Workforce Innovation and Reform Strategic Framework for Action 2011–2015 was developed by HWA with guidance and support from Siggins Miller Consultants and with the input of key national and international experts. HWA wishes to thank all those who provided input via the national consultation phase, through workshop attendance and written submissions.”<br>(Health Workforce Australia, 2011, inside front cover) |

### 4.5.2 Content relating to GPs[3]

While recognising that there were other providers of primary healthcare than GPs, the role of GPs predominated in both the *Primary Healthcare System* and *Health Workforce* strategies. The role of GPs was addressed within the five key building blocks described as necessary for 'a modern primary healthcare system' (Australian Government - Department of Health and Ageing, 2010a, p 10) and the four 'key priority areas of change' listed in the *Primary Healthcare System Strategy*. The *Health Workforce Strategy,* similarly, contained five domains for action, which included strategies targeted particularly at the GP workforce. There were six priority areas in the *HCV Strategy* that each included interventions aimed at GPs, although peer workers and other groups were also acknowledged as important contributors to the health and wellbeing of PWHCV.

### 4.5.3 Resource allocation – Equity statements[4]

The strategies all included aims of improving access to primary healthcare and reducing inequity (see Table 12 below).

---

[3] An earlier version of the text in this section appeared in:

Scarborough, J., Eliott, J., Miller, E. R., & Aylward, P. (2015). Equity in primary health care delivery: an examination of the cohesiveness of strategies relating to the primary healthcare system, the health workforce and hepatitis C. Australian Health Review, 39(2), 175-182. doi:10.1071/ah14073

Available at: https://www.publish.csiro.au/ah/ah14073

[4] As above.

**Table 12: Equity statements (Adapted from: Scarborough, Eliott et al. 2015, p 177)**

| |
|---|
| *HCV Strategy*<br>“People with HIV [Human Immunodeficiency Virus], STIs [sexually transmissible infections] and viral hepatitis have a right to participate in the community without experience of stigma or discrimination, and have the same rights to comprehensive and appropriate health care as other members of the community.” (Australian Government - Department of Health and Ageing, 2010b, p 12) |
| *Primary Healthcare System Strategy*<br>Acknowledging that inequity exists:<br>“...range of areas and populations facing significant service gaps.”<br>(Australian Government - Department of Health and Ageing, 2010a, p 3)<br>First of four key priority areas listed for change:<br>“Improving access and reducing inequity.”<br>(Australian Government - Department of Health and Ageing, 2010a, p 11) |
| *Health Workforce Strategy*<br>“Address workforce issues in ways that recognise Australia’s social and cultural diversity and promote equity of access and outcomes across communities, geographic areas and age groups.”<br>(Health Workforce Australia, 2011, p 7) |

Within the *HCV Strategy,* access to equitable access to care was identified as a human right and discrimination was identified as a barrier to the provision of equitable care. The *Primary Healthcare System* and *Health Workforce* documents included non-specific and general equity statements. The actions they suggested to increase equity and to overcome barriers to access were limited to identified service gaps and to identified priority groups (Section 4.7 and 4.8).

### 4.5.4 Initial resource allocation – ‘Priority’ or ‘targeted’ groups[5]

To determine the initial resource allocation and the way these resources were allocated, the targeted or priority populations in the strategies were ascertained.

**Table 13: Priority groups (Adapted from: Scarborough, Eliott et al. 2015, p 178)**

| *HCV Strategy* | *Primary Healthcare System Strategy* | *Health Workforce Strategy* |
|---|---|---|
| PWHCV | | |
| Aboriginal and Torres Strait Islander people | Aboriginal and Torres Strait Islander people | Aboriginal and Torres Strait Islander people |
| Culturally and linguistically diverse populations | Australians living outside of the capital cities | Australians living outside of the capital cities |
| | | In addition: |
| PWID.<br>People in custodial settings | People with mental illness | People with mental health problems |
| | Older people | Older people |
| | | People with chronic diseases |
| Multiple and cumulative basis of inequity prioritised (e.g., Aboriginal and Torres Strait Islander people who inject drugs) | | |

The priority groups listed in the *HCV Strategy* were the groups most affected, or at risk for, HCV and the rationale for including these groups was explicit. In the *Primary Healthcare*

---

[5] An earlier version of the text in this section appeared in:
Scarborough, J., Eliott, J., Miller, E. R., & Aylward, P. (2015). Equity in primary health care delivery: an examination of the cohesiveness of strategies relating to the primary healthcare system, the health workforce and hepatitis C. Australian Health Review, 39(2), 175-182. doi:10.1071/ah14073
Available at: https://www.publish.csiro.au/ah/ah14073

*System* and *Health Workforce* strategies, the groups were categorised in several ways, for example by disease type or nature, patient age, race and geographical location. A detailed rationale for inclusion of these groups was not provided, but the basis of inclusion was described in terms of the cost savings that were achievable by the provision of appropriate care, addressing access inequity and service gaps.

Except for one additional group: ‘People with chronic diseases’ in the *Health Workforce Strategy*, the groups included were mirrored in the broad strategies. As a priority group ‘Aboriginal and Torres Strait Islander people’ were listed in all three documents. Other than this group, there appears to be disparity between the *HCV Strategy* and the broader strategies’ priority groups, however further linkages can be made. The population of PWID may include people with the mental health condition of addiction, so this *HCV Strategy* priority group has coverage in the broad documents. At the time the document was published, the low treatment coverage of approximately 2% meant that most PWHCV were living with this condition as a chronic disease, therefore these people could have been considered as included in the priority group of people with chronic disease in the *Health Workforce Strategy.*

The *HCV Strategy* highlights that there may be a cumulative effect of being an individual with membership of more than one priority group, and that additional consideration should be made to meet the needs of these people. By leaving out the possibility of overlap, the broad strategies present the priority groups as discrete.

### 4.5.5 The framing of requirements to ensure access and equity[6]

The three documents demonstrate the assumption that best practice care will be achieved by the provision of evidence-based resources, for example clinical guidelines, and the provision of relevant continuing education. In the *Primary Healthcare System* and *Health Workforce* strategies, the solution to providing access to care and equity is framed around ensuring the provision of services by GPs in locations accessible to the population (see Table

---

[6] An earlier version of the text in this section appeared in:

Scarborough, J., Eliott, J., Miller, E. R., & Aylward, P. (2015). Equity in primary health care delivery: an examination of the cohesiveness of strategies relating to the primary healthcare system, the health workforce and hepatitis C. Australian Health Review, 39(2), 175-182. doi:10.1071/ah14073

Available at: https://www.publish.csiro.au/ah/ah14073

14). There is an underlying assumption present in these broad documents that there will be willingness on the part of qualified, registered medical practitioners to provide primary healthcare for all Australians, for all health conditions. An internal contradiction to this assumption is the inclusion in these strategies of incentives for GPs to carry out specific work, in specific locations (see Table 15). This inclusion acknowledges that GPs have discretion regarding the population they serve, areas of work they choose to provide and how these services are provided, and that these choices may be influenced by government provided financial incentives.

The *HCV Strategy* highlights that PWHCV are not necessarily provided with best practice care from GPs and can experience discrimination in healthcare settings. The solution to this problem is framed as a lack of education, and the development of a public education plan was proposed to affect change to the discriminatory attitudes and behaviour across settings. Whilst stigma and discrimination had been found to affect those with mental health issues (Clement et al., 2014) and Aboriginal and Torres Strait Islanders (Larson, Gillies, Howard, & Coffin, 2007), both named as priority groups, there is no mention of this issue in the broader documents.

**Table 14: Framing of requirements to ensure access and equity (Adapted from: Scarborough, Eliott et al. 2015, p 179).**

| |
|---|
| *HCV Strategy*<br>"States the need for a: skilled, well trained, competent and professional primary health care workforce." (Australian Government - Department of Health and Ageing, 2010b, p 18) |
| *Primary Healthcare System Strategy*<br>Medicare Local conducting regional needs assessment<br>"...identify groups of people missing out on [general practitioner] and primary health care, or services that a local area needs, and better target services to respond to these gaps." (Australian Government - Department of Health and Ageing, 2010a, p 13) |
| *Health Workforce Strategy*<br>"Strengthen Aboriginal and Torres Strait Islander health service delivery and accessibility by ensuring education and training programs prepare the workforce to deliver culturally appropriate and safe health care in all settings." (Health Workforce Australia, 2011, p 20) |

**Table 15: Incentives (Adapted from: Scarborough, Eliott et al. 2015, p 179).**

| |
|---|
| *Primary Healthcare System Strategy*<br>An example of the use of incentives to direct GPs to choose diabetes management in their scope of work.<br>"Patients diagnosed with diabetes will have the option of enrolling with a GP practice of their choice to receive high quality coordinated care and help them access a range of additional services...with GP practices being rewarded for meeting performance benchmarks." (Australian Government - Department of Health and Ageing, 2010a, p 31, emphasis added) |
| *Health Workforce Strategy*<br>Acknowledgement of GPs' financial considerations<br>"Address remuneration, payment arrangements and terms and conditions to support workforce models that increase accessibility, improve workforce retention and productivity and encourage interprofessional practice." (Health Workforce Australia, 2011, p 29) |

### 4.5.6 Future resource allocation – Approaches to determining need and identifying gaps[7]

By examining methods to determine need and to identify gaps, the future resource allocation of resources included in the documents was determined.

---

[7] An earlier version of the text in this section appeared in:
Scarborough, J., Eliott, J., Miller, E. R., & Aylward, P. (2015). Equity in primary health care delivery: an examination of the cohesiveness of strategies relating to the primary healthcare system, the health workforce and hepatitis C. Australian Health Review, 39(2), 175-182. doi:10.1071/ah14073
Available at: https://www.publish.csiro.au/ah/ah14073

**Table 16: Establishing future priorities (Adapted from: Scarborough, Eliott et al. 2015, p 178)**

| |
|---|
| *HCV Strategy*<br>Identifies gaps in doctors’ scope of practice around HCV.<br>“It is estimated that there is a pool of between 40 000 and 50 000 undiagnosed people in the community.” (Australian Government - Department of Health and Ageing, 2010b, p 25)<br>‘The participation and support of primary healthcare providers in managing hepatitis C remains low and needs to be encouraged to increase the availability of treatment and care.” (Australian Government - Department of Health and Ageing, 2010b, p 29)<br>“Greater capacity in the primary healthcare sector to contribute to service delivery in hepatitis C treatment and care is required and should be explored.” (Australian Government - Department of Health and Ageing, 2010b, p 26) |
| *Primary Healthcare System Strategy*<br>Medicare Local conducting regional needs assessment<br>“...identify groups of people missing out on [general practitioner] and primary health care, or services that a local area needs, and better target services to respond to these gaps.” (Australian Government - Department of Health and Ageing, 2010a, p 13) |
| *Health Workforce Strategy*<br>Future needs assessed on a regional basis in consultation with consumers.<br>“...starts with community needs-analysis at the local level.” (Health Workforce Australia, 2011, p 24) |

The *HCV Strategy* proposed using enhanced surveillance to inform the provision of care for HCV and prevention interventions. The inclusion of people affected by HCV was prioritised in the development of future interventions. The *Primary Healthcare System Strategy* relied heavily on the involvement of Medicare Locals, newly developed at the time, to identify gaps in service and identify future needs. As the name suggested, the Medicare Locals were set up in 2011 with a focus on decentralisation of the coordination of primary healthcare to 61 regions of Australia (Australian Government - Medicare Local, 2012). The local level of the proposed community needs analysis of the *Health Workforce Strategy* was not defined within the document.

## 4.6 Discussion[8]

The documents chosen for the 2014 document analysis, represented the most recently published Federal Government of Australia strategy or policy, relating to these topics. Since then the Fourth and Fifth National HCV strategies (Australian Government - Department of Health, 2018b; Australian Government - Department of Health and Ageing, 2014) have been published, the HWA organisation that produced the Health Workforce strategy, was abolished by the Liberal federal government (Commonwealth of Australia - Australian National Audit Office, 2018), and the Federal Labour party who developed the Primary Healthcare System Strategy, have been defeated at the three subsequent elections. Whilst the documents and institutions involved in producing them have changed, *Study 1* has continuing relevance.

Through examining health policies and strategies, *Study 1* contributes to understanding the health-system context, operating at a critical timepoint in Australia, in relation to the provision of DAA by GPs in private general practice. The ongoing development of health policies and strategies from this time, can be tracked to critique their ability to address the provision of this and other care for HCV in this setting. The way that problems are framed in the documents can be compared to and contrasted with contemporary documents. In particular, the framework developed in this study can be utilised to critique how current HCV policies and broader health policies interrelate.

### 4.6.1 Equitable access[9]

The *Primary Healthcare System* and *Health Workforce* strategies had a stated aim to increase access and address inequity in primary healthcare, however, the proposed allocation of resources appeared insufficient to address these issues for PWHCV. This examination showed a contrast in the way that the problem of ‘equitable access to healthcare’ was framed between the disease specific *HCV Strategy* and the broader *Primary Healthcare System* and *Health Workforce* strategies. The broad strategies emphasised

---

[8] An earlier version of the text in this section appeared in:

Scarborough, J., Eliott, J., Miller, E. R., & Aylward, P. (2015). Equity in primary health care delivery: an examination of the cohesiveness of strategies relating to the primary healthcare system, the health workforce and hepatitis C. Australian Health Review, 39(2), 175-182. doi:10.1071/ah14073

Available at: https://www.publish.csiro.au/ah/ah14073

[9] As above.

consideration of ‘priority’ groups in respect to current actions, processes for identifying future need and the subsequent allocation of future resources. With the problem of equitable access targeted at the identified priority groups, interventions aimed at addressing barriers and facilitators to access for people not identified as belonging to these groups, were excluded or limited.

Political drivers can influence the content of broad strategies (Flitcroft, Gillespie, Salkeld, Carter, & Trevena, 2011) as well as the allocation of resources to address the issues of inequality and access for PWHCV (Australasian Society for HIV Medicine, 2005). Illicit IDU, whether current or past, is highly stigmatised (Australian Government - Department of Health and Ageing, 2010b) and PWHCV who have, or are assumed to have, acquired the disease through illicit IDU have suffered discrimination (Australasian Society for HIV Medicine, 2005; Broady, Brener, Cama, Hopwood, & Treloar, 2020; van Boekel, Brouwers, van Weeghel, & Garretsen, 2013). The capacity for people who have an HCV diagnosis to exercise political influence may be limited (Australian Injecting and Illicit Drug Users League, 2010). Groups are actively advocating to overcome discrimination and for equitable access to healthcare for PWHCV (Hepatitis Australia, 2020) and PWID (Australian Injecting and Illicit Drug Users League, 2020). Hepatitis Australia campaigned in 2015 for equitable, affordable access to DAA for all Australians eligible for Medicare registration (Tyrrell, 2016), which was achieved in 2016. It is difficult to measure the effect of this advocacy however, this achievement went beyond the restricted access promoted by Australian clinicians at the time (Tyrrell, 2016). It seems unlikely that within the broad strategies there would be any political benefit involved with granting priority group status for PWHCV, above more prevalent and politically ‘acceptable’ populations.

### 4.6.2 Need assessment[10]

The broad strategy documents outlined methods to identify future needs and future priorities of resource allocation, but these methods may have been insufficient to accurately capture the inequalities experienced by PWHCV. This may be attributable to the under-

---

[10] An earlier version of the text in this section appeared in:
Scarborough, J., Eliott, J., Miller, E. R., & Aylward, P. (2015). Equity in primary health care delivery: an examination of the cohesiveness of strategies relating to the primary healthcare system, the health workforce and hepatitis C. Australian Health Review, 39(2), 175-182. doi:10.1071/ah14073
Available at: https://www.publish.csiro.au/ah/ah14073

diagnosis of HCV (The Kirby Institute, 2018a), and the stigma attached to the condition, exacerbated by the regional basis of the approach (Australian Injecting and Illicit Drug Users League, 2010). The methods described depended on advocacy from patients or carers, or feedback from professional groups. Approaches that rely on input from patients and local medical professionals will not be capable of bringing attention to the unmet need associated with under-diagnosis. Although the prevalence of HCV is significant on a population basis, cases are dispersed (MacLachlan et al., 2019) and pinpointing geographical areas of need is not always accurate. Furthermore, the effect of stigma can be amplified when a regional basis of need assessment is used. Medical professionals with an established interest in and knowledge of HCV who could contribute to advocacy were at the time more likely to be associated with metropolitan hospital HCV treatment centres (Australasian Society for HIV Medicine, 2014). Negative perceptions about the risk of disclosure exist for PWHCV, (Miller, Sheppard, Colenda, & Magen, 2001), which may be particularly salient for people in regional settings, and make them less likely to participate in self-advocacy in their local region (Australian Injecting and Illicit Drug Users League, 2010; Aylward, 2003, 2012).

### 4.6.3 GP workforce[11]

The provision of a sufficiently large and adequately resourced GP workforce, with access to continuing medical education, is fundamental to the delivery of best practice primary healthcare. However, there is no mechanism to ensure the GP workforce has the capacity and willingness to provide the required care to all patients, for all conditions, including for PWHCV. Admission to general practitioner colleges require a set of competencies to be achieved (Australian Government - Department of Health, 2020c). Competencies relevant to providing care to PWHCV that are generic to a range of GPs' scope of practice can and should be included in the set of required competencies. These competencies include taking medical histories in a non-judgemental way, delivering pre- and post-test counselling appropriately, knowledge and communication of diagnostic testing, and obtaining informed consent (Hepatitis C Virus Infection Consensus Statement Working Group, 2018). It is not

---

[11] An earlier version of the text in this section appeared in:

Scarborough, J., Eliott, J., Miller, E. R., & Aylward, P. (2015). Equity in primary health care delivery: an examination of the cohesiveness of strategies relating to the primary healthcare system, the health workforce and hepatitis C. Australian Health Review, 39(2), 175-182. doi:10.1071/ah14073

Available at: https://www.publish.csiro.au/ah/ah14073

feasible however for GP colleges to require members to have in-depth knowledge of all conditions that can be included in the scope of practice of GPs. Requirements for ongoing medical education (Australian College of Rural and Remote Medicine, 2020; Royal Australian College of General Practitioners, 2020a) can extend the knowledge and skills of GPs and CME regarding HCV is promoted to GPs (ASHM, 2017, 2018, 2019a). GPs can be encouraged to choose to participate in this training but there is no mechanism to link the training GPs participate in with the complex and wide-ranging needs of all patients who may access general practice for care. The Medical Board of Australia has the function of addressing inadequacies in GPs' competency but investigations are largely triggered when complaints are raised about care provided (Australian Health Practitioner Regulation Agency, 2018). Where GPs omit provision of care for HCV, including DAA treatment, from their scope of practice, it is unlikely that this will trigger a complaint. In addition to limits to competency, there will also be limits to the number of consultations GPs can conduct and, therefore, limits to the patient base that each can serve. Individual GPs, therefore, necessarily make choices about the patients they see, the prioritisation of patient issues, the professional resources accessed and continuing medical education attendance (Scarborough, Eliott, Miller, & Aylward, 2015). Incentives offered to influence these choices have limited effect (Kecmanovic & Hall, 2015) and the application of incentives to particular conditions will be subject to political influences and the comprehensiveness of needs assessment processes, as previously described. The limitations and lack of mechanisms to ensure the required care is provided by GPs for all patients for all conditions is not explicitly acknowledged in the various polices. This issue must be addressed before policies and strategies can be developed to address this issue.

Meanwhile actions proposed in broad strategies regarding priority groups, should be investigated and critiqued to determine whether a similar benefit would apply to the provision of care for PWHCV. Exposing GPs to PWHCV during training could enhance skills and give GPs confidence to include this work in their scope of practice (Davis, Tapley, Morgan, van Driel, & Magin, 2017). Support could be provided to GPs via technology to link them with other health professionals with specialised knowledge of HCV (Keogh et al., 2016; Lee et al., 2018; Schulz, Kanhutu, Sasadeusz, Watkinson, & Biggs, 2020). Providing Medicare Benefits Schedule (MBS) and PBS benefits for HCV nurses could facilitate the expansion of care options available to PWHCV and the pool of professionals with specialised skills in this area (Halcomb & Ashley, 2019; Lobo, Mascarenhas, Worthington, Bevan, & Mak, 2015; Starbird et al., 2018). The role of HCV nurses will be further discussed in subsequent chapters.

### 4.6.4 Document coherence[12]

Coherence should be able to be achieved between broad documents and disease specific documents, even when the disease or population is not listed as a priority in the broad documents. To allow for critique of the method for inclusion, the basis for determining priority groups should be made explicit. However, only a limited number of conditions and populations will be named as priorities in any broad documents. This may be due low prevalence of the disease, for example cystic fibrosis, or low severity of diseases. Aims of the broad policies such as increasing access and equity for Australians to healthcare, improving health outcomes and managing budget demands, apply to all healthcare funded by the Australian government and are not exclusive to priority conditions.

Actions outlined in broad documents to reach these aims in regard to priority groups may also be appropriate for conditions that are not defined as priorities. Statements could be added in the broad documents to indicate that the action will be applied where it will achieve these aims for all conditions. The disease specific documents, such as the HCV strategy, could then cross reference these statements, outlining how particular actions could achieve these aims in regard to HCV. An example of how this process could have been applied to the documents analysed in this study is presented below (see Table 17). The recommended changes to the broad strategy documents would minimally change the content of the strategies and would therefore be politically neutral.

---

[12] An earlier version of the text in this section appeared in:

Scarborough, J., Eliott, J., Miller, E. R., & Aylward, P. (2015). Equity in primary health care delivery: an examination of the cohesiveness of strategies relating to the primary healthcare system, the health workforce and hepatitis C. Australian Health Review, 39(2), 175-182. doi:10.1071/ah14073
Available at: https://www.publish.csiro.au/ah/ah14073

**Table 17: Aims and actions in the Primary Healthcare System Strategy and the Health Workforce Strategy, and recommendations to apply, extend, or link these in the HCV Strategy**

| Primary Healthcare System Strategy and Health Workforce Strategy | Application to the HCV strategy |
|---|---|
| “The Australian government will transform the way patients with chronic disease are treated.” (Australian Government - Department of Health and Ageing, 2010a, p 31) | Extend this to patients with HCV and give patients the option of enrolling with one GP and providing financial reward for the GP to gain the required skills and provide best practice care. |
| “…patients diagnosed with diabetes will have the option of enrolling with a GP practice of their choice to receive high quality coordinated care and help them access a range of additional services” (Australian Government - Department of Health and Ageing, 2010a, p 31) | |
| “GP Super Clinics will provide a wide range of services that target the health needs of local communities. They will also support clinical training placements to train the next generation of primary healthcare professionals – GPs, nurses and allied health professionals – to ensure a robust future health workforce.” (Australian Government - Department of Health and Ageing, 2010a, p 21) | GP super clinics[13] used to deliver services to underserved PWHCV and provide opioid substitution treatment.<br>Use these centres for training to ensure medical practitioners’ exposure to this type of work and people with an injecting drug history. |
| “Providing access to MBS and PBS benefits for nurse practitioners” (Australian Government - Department of Health and Ageing, 2010a, p 19) | Present evidence and advocate for the expansion of training of HCV nurses to be involved and funded to provide care to PWHCV. |

---

[13] GP super clinics were 2010 initiative of the Labor Federal Government (Hansard, 2010). After difficulties in attracting GP involvement, funding for expansion of this initiative ceased in 2014 (Australian Medical Association, 2014).

| Primary Healthcare System Strategy and Health Workforce Strategy | Application to the HCV strategy |
|---|---|
| "Expand clinical training places in undeserved and non-traditional settings to maximise learning opportunities and future career choices in these settings." (Health Workforce Australia, 2011, p 20) | Provide training opportunities for GPs in centres where there is a high prevalence of clients with HCV, a history of IDU or both. |
| "Facilitate the uptake of technologies that enhance workforce practice and productivity, with an emphasis on underserved communities and populations." (Health Workforce Australia, 2011, p 20) | Provide resources regarding best practice care that are designed to be integrated into practices' electronic patient management systems.<br>Linking GPs who have specialise in providing care for HCV using technology. |

### 4.6.5 Subsequent primary healthcare policy documents

There was a dearth of primary healthcare policy published by the Federal Government since the document analysis took place in 2012. The *Australia's long term national health plan: to build the world's best health system* (Health, 2019a) is one of the few broad policy documents released with content relating to primary healthcare. The document is brief, consisting of twenty -four pages, with only four pages relating to primary health care. The brevity of the document is particularly notable considering the proportion of the Federal budget spent on primary healthcare (Australian Government - Department of Human Services, 2018a) and the importance of primary healthcare to Australian citizens (Cameron & McAllister, 2019). The document includes "Pillar one: Guaranteeing Medicare, stronger primary care and improving access to medicines through the PBS" (Health, 2019a, p 5) however, there is sparse detail in the policy regarding how this aim will be achieved. The document refers to the "*10-year plan for primary care*" (Health, 2019a, p 7) but the *Primary Health Reform Steering Group* was only established in October 2019 (Health, 2019b) and the plan remains unpublished. Also referenced in the national health plan (Health, 2019a) is the review undertaken of the Medical Benefits Schedule (Health, 2019a, p 6). The *Medicare Benefits Schedule Review Taskforce Report* (Medicare Benefits Schedule Review Taskforce,

2020) was released in 2020 and contained recommendations regarding the inclusion of items on the MBS and also suggested further reform to the primary health care system. Rather than being a government policy this document was produced by an independent taskforce and it has been noted that under this arrangement the government has the choice to accept or reject the recommendations and there is no timeline set for these decisions to be made (Russell, 2020). As the health minister Greg Hunt stated, "This is a report to government and not of government, and we will now consider, consult and respond as we have done throughout the course of the review in relation to all previous proposals" (Russell, 2020, p 1). While there has been a considerable effort expended in creating these reports to government (Medicare Benefits Schedule Review Taskforce, 2020), the government's response to specific recommendations in these reports is difficult to ascertain and therefore critique.

Political considerations influence whether policy documents are produced and affect their content. These political considerations are discussed in the *Review of Labor's 2019 Federal Election Campaign* (Emerson & Weatherill, 2019) which listed one of the major reasons that Labor lost the 2019 election as: "a cluttered policy agenda that looked risky" (Emerson & Weatherill, 2019, p 7) and suggested "policies can be bold but should form part of a coherent Labor story, be limited in number and be easily explainable, making them less capable of misrepresentation." (Emerson & Weatherill, 2019, p 8). Omitting producing a policy document on a particular topic would be politically wise where political parties support similar policies or if the policy document actions could be perceived or represented by the opposing party as 'risky'. Brief and uncontroversial statements may provide a less risky alternative to provide the perception of positive policy. For example, it is difficult to be negative or critical of statements in the *Our plan – Better health care* section of the Liberal Party website such as, "Our Government has expanded free access to glucose monitoring devices for pregnant women, children and more adults with type 1 diabetes, saving Australians up to $7,000 a year." (Liberal Party of Australia, 2020, p 3). In addition, this approach to policy announcements can be tailored and tested to appeal to the targeted electorate (Emerson & Weatherill, 2019).

The Fourth and Fifth National HCV strategies (Australian Government - Department of Health, 2018b; Australian Government - Department of Health and Ageing, 2014) have been published since the initial analysis in 2012. Compared to policy documents that cover broader topics and affect the wider population, political considerations are less likely to affect the formulation of HCV strategies which have a limited and specific audience. In addition, the HCV strategy cover a specific period of time, for instance 2018-2022 for the fifth HCV strategy, and when they are due, stakeholders play a pivotal role in driving the formation of the HCV strategies. An underlying assumption I made when discussing the coherence of the analysed policies was that similar policy documents would be produced into the future. However, while the HCV strategies are likely to be regularly published, it is unclear when (or if) broader policy documents relating to primary healthcare or primary healthcare workforce will be published.

## 4.7 Chapter Summary

The healthcare system context of the provision of care for HCV was the focus of *Study 1*. The lack of coherence between the three policies examined, is the main finding of this study. This finding is important as the lack of coherence may have diminished the influence of each policy to address equitable access to healthcare for PWHCV. The three policies that were included in the document analysis were: *Third National Hepatitis C Strategy 2010–2013* (Australian Government - Department of Health and Ageing, 2010b) (the *HCV Strategy*), *Building a 21st Century Primary Health Care System* (Australian Government - Department of Health and Ageing, 2010a) (the *Primary Healthcare System Strategy*) and the *National health workforce innovation and reform strategic framework for action 2011-2015* (Health Workforce Australia, 2011), (the *Health Workforce Strategy*). These policies each placed GPs at the forefront of the provision of primary healthcare and included aims of achieving equitable access to this healthcare for Australian citizens. The way to provide access to the required primary healthcare was framed around ensuring that there was an adequate number of skilled and trained GPs available to provide care. While all policies were produced by the Australian Federal Government at a similar time point, there were no mechanisms to provide connections between the documents.

Unsurprisingly, the *HCV strategy* as a disease specific policy addressed GP involvement in care for HCV. Listed priority groups in the *HCV Strategy* showed a significant overlap with the other policies examined. However, there was no reference to broader health policies that could link the provision of healthcare for HCV to the overall provision of primary healthcare in Australia. The broader polices; *Primary Healthcare System Strategy* and *Health Workforce Strategy*, listed actions that could improve the provision of care for HCV. Within the broad strategies, the application of measures was specifically associated with identified priority groups, for example, the provision of incentives to direct GPs to include diabetes management in their scope of practice. In this way the application of these measures to other groups was excluded or omitted and subsequently denying the associated benefit beyond the listed priority groups. If these measures were more broadly applied, they would not necessarily increase overall expenditure, for example the cost neutral measures of expansion of the role of nurse practitioners in provision of primary healthcare. In addition, needs assessment approaches outlined in the broad policies are not adequate to detect the health needs of PWHCV and other health conditions. As needs assessments form the basis of resource allocation, to ensure equitable distribution of these resources, it is important to allow for alternative approaches to be used to identify the wider primary healthcare needs of Australian citizens. The recognition that the *HCV strategy* and broader primary healthcare strategies are siloed and that this produces negative outcomes for the equity of access to healthcare for PWHCV forms the basis of 0.

In addition to the lack of cohesion between documents, another important finding related to the scope of practice of GPs. An internal contradiction to the framing of the 'problem' (Bacchi, 2009, 2016) of the provision of primary healthcare was found across the three policies. The policies framed the 'problem' in terms of a lack of an adequate number of skilled and trained GPs available to provide care. This demonstrated an underlying assumption that all GPs will provide all types of care in their scope of practice. However, the inclusion of incentives for GPs to include particular work in their scope of practice, recognises that GPs have discretion in their scope of practice and remuneration may be a motivating consideration for deciding individual GP's scope of practice. The discretion regarding GPs scope of practice and the effect on this on the provision of DAA by GPs was further examined in *Study 2* and *Study 3*.

Opportunities exist to improve cohesion between future national primary healthcare strategies and HCV strategies and, ultimately, to improve equity and access to primary healthcare for PWHCV. To increase the inequity and access to primary healthcare for this group, needs assessment methodology should be broadened, acknowledging that the current regional approach may not identify the needs of PWHCV. Actions in the *Primary Healthcare System Strategy* and *Health Workforce Strategy* should be extended to additional groups beyond those listed as priority groups within the strategies. Future HCV strategies should outline appropriate, detailed needs assessment methodology and specify how actions in the broad strategies can be applied to benefit the primary healthcare needs of PWHCV. Only through such action can we ensure equity in primary care delivery. The findings of this study informed the overall recommendations outlined in Chapter 7 and specifically the recommendation outlined in section 7.5 *Generate cohesion between the HCV strategy and other policy documents.*

# CHAPTER 5.

# *STUDY 2 - EXPERIENCES AND PERSPECTIVES OF PEOPLE WITH OR AT RISK OF HCV WITH CARE PROVIDED BY GPS IN PRIVATE GENERAL PRACTICE*

## 5.1 Introduction

In this chapter I will outline the results of *Study 2* regarding the experiences and perspectives of people with or at risk of HCV with care provided by GPs in private general practice. This study involved thematic analysis of semi-structured interviews with twenty-two participants and took place in 2013-2014. The study recruited people affected by HCV (PWHCV or people at risk of HCV) as well as key workers whose clients were affected by HCV. The key workers were targeted for recruitment as they had long-term engagement with PWID. These keyworkers shared insights across their experiences with clients, that included advocating and advising clients regarding primary healthcare engagement. There was overlap between these groups and the final sample consisted of ten participants affected by HCV (A), six participants who had clients affected by HCV (CA) and six people who were both affected by HCV and who had clients affected by HCV (A + CA). Further detail about recruitment and participants is provided in section 3.7.3 and 3.7.4.

HCV-affected participants reported a range of diagnostics experiences, varied in terms of their involvement in interferon-based treatments (available at the time) and differed in terms of their ability to access private GPs. All participants reporting a diagnosis of HCV also reported a history of illicit IDU. The analysis provided an understanding of the patient component involved in the provision of care for HCV. Together with the findings of *Study 1*, which examined the healthcare system component and *Study 3,* which examined the GP component, I sought to understand the complex adaptive system which formed the context in which DAA was provided. This understanding will inform proposed recommendations to increase the provision of this treatment discussed in Chapter 7.

## 5.2 Research question

*Study 2* was conducted to answer the following research question:

2. What are the experiences of people with or at risk of HCV of engagement with GPs in private general practice and how does this affect their perceptions of the engagement for the provision of care for HCV?

## 5.3 Publication history

The following article (Appendix 10) based on this study was published in 2017:

> Scarborough, J., Miller, E. R., Aylward, P., & Eliott, J. (2017). 'Sussing that doctor out.' Experiences and perspectives of people affected by hepatitis C regarding engagement with private general practitioners in South Australia: a qualitative study. BMC Family Practice, 18(1), 97. doi:10.1186/s12875-017-0669-2

As the first author I conceived the idea to conduct the study and with my supervisors, who were co-authors, developed the study design. I recruited participants, conducted the interviews, and produced the transcripts. After conducting a preliminary analysis of the data, I was given feedback and guidance by my supervisors to complete the data analysis. I prepared the initial manuscript and was given guidance and feedback from my supervisors to produce the final submitted manuscript.

A poster (Appendix 11) reporting aspects of this study, was presented at the 4th International Symposium on Hepatitis Care in Substance Users in 2015 titled:

> Scarborough, J., Eliott, J., Miller, E. R., & Aylward, P. (2015). Care Provided for hepatitis C: congruence between patient self-identity and stereotypes applied by general practitioners (GPs). Paper presented at the International Symposium on Hepatitis Care in Substance Users, Sydney, Australia. https://na.eventscloud.com/file_uploads/fb78da73072daf0596a54cc4434ea534_JaneScarborough.pdf

As the first author I designed and produced the poster. My supervisors, who were co-authors assisted with developing the text. Relevant content from the published article has been included in the *Introduction*, *Literature Review* and *Methodology and Methods* chapters of this thesis. With only minor changes, the results section of this thesis chapter, reflects the results section of the published article. The discussion section of this chapter incorporates the discussion presented in the published article and additional aspects regarding self-identity and stereotypes presented in the poster. The discussion section in this chapter has been refined to include contemporary literature and to reflect on the contemporary context.

## 5.4 Background

In adopting the philosophy of pragmatism, I will begin by considering the context in which *Study 2* took place (see Section 3.2) in 2013-2014. I will outline the context of the interferon-based treatment for HCV available, and the involvement of GPs in the cascade of care for HCV, at this time.

### 5.4.1 Availability of treatment for HCV at the time of the study

This study took place between November 2013 and August 2014 when the available treatment for HCV was interferon-based treatment and primarily prescribed at tertiary liver clinics. Although these antiviral treatments were available in Australia, as few as 2% of those infected entered this treatment annually (Hajarizadeh et al., 2017). This was explained in part because previous treatments involved complicated medication regimes, severe side effects, long treatment periods and variable rates of cure (Sublette et al., 2015).

While stepwise progress had been made involving refinements to interferon-based treatments (Casey & Lee, 2013; Dore & Feld, 2015), reports were beginning to emerge on the development of DAA. There was excitement about what was perceived as a realistic hope that these new well-tolerated therapies involving a short duration, all-oral regimens, would soon be widely available (Casey & Lee, 2013; Dore & Feld, 2015). The optimism regarding this treatment was reflected in the term ‘perfectovir’ coined for this expected revolutionary treatment (Dore & Feld, 2015). The results of international trials were reported in 2014 at the International Liver Congress. Optimism for the new treatment was tempered with acknowledgement that the potential of these treatments could be limited by the cost of the drug, prioritisation of making this treatment available within healthcare budgets and issues of screening and disease assessment (Dore & Feld, 2015).

There was a conundrum regarding the timing of uptake of treatment for patients and their treating doctor (Wagner et al., 2009). The extent to which individual patients and their GPs were aware of the treatment options was not clear (Dore et al., 2009; Treloar et al., 2010) and therefore it was difficult to know if informed decisions making was involved when PWHCV were deciding to enter treatment or not.

### 5.4.2 Involvement in the provision of care for HCV by Australian GPs working in private general practice

At the time of this study, most people diagnosed with HCV in Australia were diagnosed by GPs (McNally et al., 2004). GPs also played a gate-keeping role to medical specialists involved in the management of HCV and related complications (Mossialos, Wenzl, Osborn, & Anderson, 2016). There was uncertainty about the capacity for existing specialist services to manage any increase in treatment demand If demand for new DAAs intensified and it was expected that GP delivered HCV care would be even more important (Afdhal et al., 2013; Hellard & Wang, 2009; Lambert et al., 2011). Barriers to GPs being involved in this work were reported, with findings indicating that, in addition to addressing system barriers, there was a need for additional capacity building for GPs involved in this work. HCV education to optimally equip GPs for this role was proposed (Davis et al., 2017; Sud, Zekry, & Freiman, 2016; Wade et al., 2017) and there were suggestions that this education could benefit by the inclusion of perspectives of people affected by HCV (Byrne, Happell, Welch, & Moxham, 2013).

A number of studies had examined the barriers and facilitators to seeking HCV-related care amongst a range of populations, various settings, and at different stages of the cascade of care (Evon et al., 2010; Miller et al., 2012; Sublette et al., 2015; Swan et al., 2010; Yap et al., 2014). Reported barriers to treatment access included negative patient perceptions of biomedical factors such as counter indications, side effects, and poor efficacy (Miller et al., 2012). Avoidance of the negative side-effect of stigma attached to the diagnosis of HCV due to its association with IDU (Butt, 2008; Richmond et al., 2007) may also have acted as a barrier to care (Islam et al., 2013; van Boekel et al., 2013).

## 5.5 Results[14]

The participants described approaches of PWHCV's to engagement with GPs for care for HCV and how they weighed up the potential risks and benefits in making a choice whether to engage. The major themes identified in *Study 2* related to participant's perception of engagement of PWHCV with GPs about care for HCV. The five themes identified are outlined in Table 18 below

**Table 18 *Study 2* - Themes identified**

| |
|---|
| Disclosure choices and strategies |
| Risk to confidentiality of sensitive information |
| Risk of discrimination and negative judgement from GPs, and change to care provided |
| Uncertainty about the benefit of engaging about HCV |
| Perception of antiviral treatment affecting engagement |

Provided with the quotes are the participant group labels of: (A) for participants affected by HCV, (CA) for key worker participants with clients affected by HCV or (A + CA) for key worker participants who had clients affected by HCV and who were affected by HCV. All groups reported similar experiences and described similar perceptions regarding interview topics, with some exceptions as noted.

### 5.5.1 Engagement about HCV – disclosure choices and strategies[15]

Participants viewed GPs as a source of general healthcare that potentially includes care for issues related to HCV. Several participants stated that when they were 'lucky' to find a good doctor, they would attempt to continue to engage with them.

---

[14] An earlier version of the text in this section appeared in:
Scarborough, J., Miller, E. R., Aylward, P., & Eliott, J. (2017). 'Sussing that doctor out.' Experiences and perspectives of people affected by hepatitis C regarding engagement with private general practitioners in South Australia: a qualitative study. BMC family practice, 18(1), 97. doi:10.1186/s12875-017-0669-2
Available at: https://bmcfampract.biomedcentral.com/articles/10.1186/s12875-017-0669-2

[15] An earlier version of the text in this section appeared in:
Scarborough, J., Miller, E. R., Aylward, P., & Eliott, J. (2017). 'Sussing that doctor out.' Experiences and perspectives of people affected by hepatitis C regarding engagement with private general practitioners in South Australia: a qualitative study. BMC family practice, 18(1), 97. doi:10.1186/s12875-017-0669-2
Available at: https://bmcfampract.biomedcentral.com/articles/10.1186/s12875-017-0669-2

> *My doctor's interested in what's happening, asks me the right questions. Asks me what testing I'd liked to be done. Won't write "hep C" on a referral to anyone else, without my express consent. (A)*

Some participants held that the benefit of engaging with GPs could only be fully realised if they disclosed their HCV positive status and/or drug use history, placed their trust in the GPs professionalism, and were accepting of the care they received.

> *You know if I'm sick I'm going to have to say, "Might be because…". I want to go to find out; go to every aspect of why I might be sick.* (A)

Where they perceived a lack of benefit associated with disclosure and a risk of consequences in disclosure (either within the patient–doctor relationship, or in their wider lives), PWHCV were cautious about disclosing HCV. A process of judging or 'sussing' out the GP before disclosing was repeatedly described.

> *So, I think it would an issue of the client sussing that doctor out and thinking "No I don't think that they could deal with that," and I think they're pretty good at that.* (CA)

> *I can tell what kind of character he is you know. He would be one of those that just, you could just see that. He would go out of his way, but as for other doctors I'm not real sure about that you know.* (A)

> *...clients will just go to drop in, bulk billing places at times when they need something, and then they [the client] may link with a GP if they [the client] find they got on well with the person... (CA)*

Often participants outlined they or their clients adopting a strategy of having one GP that they engage with for HCV-related issues, but maintaining non-disclosure with other GPs. Engagement with a nurse trained to support PWHCV to gain appropriate care in a shared care arrangement was also regarded as an effective strategy to maximise care for HCV.

> *I go between a couple of GPs. I also go out and see [name of doctor] out at [surgery that has blood borne virus treatment specialty] and so yeah. He's a lot more reasonable.* (A)

> *There's a hep C place over at the [name of practice] over there and that's where my nurse is. You know they're pretty supportive there.* (A)

### 5.5.2 Risk to confidentiality of sensitive information[16]

Participants perceived a risk that disclosure of an HCV positive status in the context of the GP-Patient relationship may lead to disclosure of this closely guarded information to their wider contacts, with serious consequences. Some participants had not disclosed their HCV status to their work, families, or their intimate partners. They reflected that their illicit drug use was part of their past and that they should be in control of the decision to disclose any of this information. These participants said that they were not suspected of a past drug history and that this history would remain secure if they managed disclosure about HCV.

> *Well, I still haven't told my parents.* (A+CA)
>
> *... my partner doesn't know and I'll never tell him. I don't think it's relevant.* (A+CA)

Possible breaches of confidentiality by medical practitioners providing HCV related care, were seen to diminish the non-disclosure choice of people affected by HCV. Participants described people affected by HCV as being '*on constant guard'* to protect this information. The need for a person's HCV status to be shared between health care workers was questioned, as the participants expected that all health practitioners should use universal precautions to avoid transmission and considered that this would negate the need to share this information in most circumstances. Where breaches of confidentiality had occurred, this led affected participants to question whether the health practitioners involved in their care understood the significance of their choice to limit the disclosure of their HCV positive status.

> *... my kids got asked "Could you get your mum to ring the hospital urgently?" and I'd made it really clear I have not told anybody in my family about this, do not leave messages.* (A+CA)
>
> *I used to tell them [health care workers] because, "It's my responsibility of blood you know, infectious blood", and all that sort of thing. And then in at the [name of hepatitis C support organisation] they said "Well actually it is their responsibility. You don't have to tell anybody."* (A)

---

[16] An earlier version of the text in this section appeared in:
Scarborough, J., Miller, E. R., Aylward, P., & Eliott, J. (2017). 'Sussing that doctor out.' Experiences and perspectives of people affected by hepatitis C regarding engagement with private general practitioners in South Australia: a qualitative study. BMC family practice, 18(1), 97. doi:10.1186/s12875-017-0669-2
Available at: https://bmcfampract.biomedcentral.com/articles/10.1186/s12875-017-0669-2

HCV-affected participants reported feeling discomfort when their HCV status was recorded on patient records. They felt that the standard practices associated with data collection and patient records presented a risk to confidentiality and control of information. Participants proposed that engagement with GPs was affected by these concerns and that they, or their clients, had not disclosed information, and indeed, avoided returning to practices where they had reluctantly disclosed.

> *Every worker can look up my records. Do I like that? No, I hate that with a passion.* (A+CA)

> *... this form, this is really bad; this form goes to the receptionist and the receptionist keeps it there, puts whatever she wants, [it] sits on the receptionist's desk and then it gets given back to and given back to the doctor. So, this form is floating all around the place…* (A)

The understanding of the sharing of information was informed by participants' involvement in highly regulated opioid substitution programs. One participant perceived that this healthcare was only available on the condition that they subjected themselves to the rules of the program, including being tested for HCV, stating '*I've got to do a blood test soon*.' (A), and that information would be electronically shared between the program and GPs, as '*It's all linked'* (A).

### 5.5.3 Risk of discrimination and negative judgement from GPs and change to care provided .[17]

When engaging for care for HCV participants perceived that GPs may react negatively. Based on their expectations and experiences, participants did not assume that GPs would be willing to provide care for HCV-related issues in a non-discriminatory, non-judgemental way. Participants stated they understood that GPs could develop negative attitudes to people with a drug history due to being exposed to 'drug seeking' or 'doctor shopping' behaviour, and categorised this reaction by GPs as somewhat reasonable. The majority of participants

---

[17] An earlier version of the text in this section appeared in:
Scarborough, J., Miller, E. R., Aylward, P., & Eliott, J. (2017). 'Sussing that doctor out.' Experiences and perspectives of people affected by hepatitis C regarding engagement with private general practitioners in South Australia: a qualitative study. BMC family practice, 18(1), 97. doi:10.1186/s12875-017-0669-2
Available at: https://bmcfampract.biomedcentral.com/articles/10.1186/s12875-017-0669-2

detailed how they or their clients had participated in these behaviours to obtain drugs to be used for non-medical purposes.

> *But you can't blame the GPs being like they are because you've got no idea what some people do to get drugs out of them.* (A)

> *Depending on the doctor you could pretty much talk your way into getting anything you want, but if you do want something in the future and you do actually need it, they're not going to give it to you if they've found out you've lied....* (A)

Two participants described GP practices as 'banning' a patient in response to patient bad behaviour and an expectation that if a patient was suspected of 'doctor shopping' or 'drug seeking,' they may be banned. For one patient, such a ban meant that there was no primary health care available in the local area.

> *...of course, when they [patients] act up then they've got bans [from attending GP practices] and things like that, so yes there are issues.... I've got one client in [neighbouring rural town] that has been banned from every clinic in [major rural centre] plus [neighbouring rural town within travelling distance for client].* (CA)

One participant reported their perception there was a hurdle of stigmatisation to overcome when telling a GP about drug use, which as a necessary step to getting help meant that help was therefore not assured. This participant was affected by HCV and described approaching GPs for help for drug issues as part of the process of engaging with them regarding HCV.

> *You don't tell a doctor "I'm using drugs. Don't help me please." It's a cry out for help isn't it? You know. Like it means if you get ignored you're like "What did I bother telling them for?" Especially when it's such a frowned upon thing.* (A)

Whilst overt discrimination by GPs based on HCV status was not reported, a perception of subtle changes to GP behaviour upon disclosure of HCV status was.

> *Yeah, just her [the GP's] whole attitude like really changed towards, you know there wasn't that kind conversation anymore, yeah you know.* (A)

Participants reported exposure to discrimination in other health care settings and this exposure appeared to be incorporated into their calculation of expected risk, and increased their expectation, of discrimination from GPs.

> *…and he [surgeon] said "I see you've had treatment." And I said, "Yeah but it didn't work." And it was like he was on a rubber band; he flew back to the back of his chair. …and then he came up with all these excuses why I couldn't have this operation.* (A)

Participants also described experiencing a shift of attributed identity upon disclosure—from 'patient' to 'drug-addicted patient', with an associated change to the care received. For instance, participants related that they were prescribed drugs of dependence when their HCV status was unknown, but that GPs would become extremely reluctant to prescribe these drugs once aware of their HCV status. Some participants framed their past illicit drug use as something that they had left behind and as not requiring treatment. Offers by GPs for drug treatment were considered by these participants as well-intentioned, but misplaced and irrelevant.

> *If I said you know, had injected drugs in the past they would always enquire whether I needed 'rehabilitation' and it was if ever I needed any pain relief, I broke a rib once and the doctor said, "I can't give you anything stronger than Panadol unless I send you off for an X-ray."* (A+CA)

Some HCV-positive participants expressed fear of having important aspects of their lives judged by GPs and other healthcare workers. In particular, participants expressed concern that their decision to have children would be negatively judged due to the children being 'exposed' to the risk of transmission through household or in utero transmission.

> *… I've heard some horror stories of what people have you know experienced with GPs and hospitals,…there's even this feeling that you know you don't deserve to have children because you know the risk that you're putting them through...* (A)

### 5.5.4 Uncertainty about the benefit of engaging with GPs about HCV[18]

Based on perceived misinformation provided and information gaps from GPs there was uncertainty about the benefit of engaging with GPs about HCV. Participants described that they and other PWHCV had developed knowledge about HCV, sometimes over the long duration since diagnosis. They proposed that their HCV knowledge could sometimes exceed

---

[18] An earlier version of this text appeared in
Scarborough, J., Miller, E. R., Aylward, P., & Eliott, J. (2017). 'Sussing that doctor out.' Experiences and perspectives of people affected by hepatitis C regarding engagement with private general practitioners in South Australia: a qualitative study. BMC family practice, 18(1), 97. doi:10.1186/s12875-017-0669-2
Available at: https://bmcfampract.biomedcentral.com/articles/10.1186/s12875-017-0669-2

that expected of their GPs: '*I...found out what I could and what I needed to know.*' (A). The difficulty of GPs keeping abreast of all of the detail of the conditions that they encounter was often acknowledged by participants.

> *...hep C [is] not fully understood by GPs and I'm not blaming them for that, just 'cause they're trying to grapple with so many attends [sic], that's impossible.* (A)

Some participants also acknowledged that they had misunderstood what they had been told: '***I didn't understand I had hep C***' (A+CA).

Most participants reported that HCV-affected people had accumulated experiences of being provided what they perceived to be inadequate or inaccurate information by GPs in regard to HCV. This perception contributed to a lack of certainty by participants that GPs would provide accurate, up-to-date information regarding HCV. Some participants spoke of errors by some GPs, which they attributed to GPs limited knowledge about HCV testing, sometimes leading to serious repercussions for patients. A participant stated one of their clients was given a diagnosis of HCV, which subsequently found to be incorrect. Another stated that they had been told that they had cleared the virus when they had not.

> *...she believed she had hep C for over 12 years and was in [rural town] and the GP had never done a PCR test [PCR test that is required to confirm active HCV infection].* (A+CA)

> *... I was told that my bloods functions were back to normal and that I had cleared the virus. Not knowing any different I believed it....* (A)

Some participants affected by HCV articulated previous gaps in their knowledge about transmission and suggested that GPs had missed opportunities during consultations to provide such important information. For example, it was reported that GPs did not provide safe-injecting information to those patients they knew injected illicit drugs, or did not provide information about household transmission to people with a diagnosis of HCV.

> *Just didn't tell me how it was passed on or anything like that. I'd been seeing this guy [GP] on and off for 20 years so he know [sic] all my background and everything anyway so I suppose he didn't even think to mention anything to me...* (A)

Some HCV–affected participants stated that they had an incorrectly reduced perception of harms associated with HCV based on what a GP had told them, or from the GP's lack of follow-up or encouragement to enter treatment. Some participants expressed unease that clients were not appropriately monitored by GPs, with blood tests or liver scans, for example.

> *I took the doctors on their word and pretty much didn't worry about it.* (A+CA)

> *…doctors are telling people that you know that they [alanine aminotransferase levels which indicates liver damage or disease] might be slightly elevated but, "that's OK so don't worry about it," so they're not actually giving them information. So as long as you're not experiencing symptoms then it's OK.* (A+CA)

> *I am aware that some GPs never do bloods and they don't seem to monitor people that even if they know that clients got hep C...* (CA)

Several participants who had delayed antiviral treatment as a consequence of a perceived lack of GP concern stated their specialists had indicated that the delay had caused negative effects on their health by the time they commenced treatment.

> *I did ask doctors that question, "Is that OK?" and they would say, "Yes" now the specialists say, "No mate you should have had this years ago"* (A+CA)

### 5.5.5 Perception of treatment affecting engagement.[19]

PWHCV may decide to not engage with GPs regarding HCV if they had decided not to have the interferon-based treatment available at the time or thought engagement would not lead to the provision of antiviral treatment. This study was conducted whilst the new DAAs were in the trial phase and several participants who were affected by HCV spoke of the potential of new treatments to have fewer side effects, contributing to their decision to delay consideration of treatment. Participants indicated that they would revisit their decisions regarding antiviral treatment when the new treatment was available.

> *They [specialist at tertiary hospital] said that in the future there'd be medication coming out but at the moment I can't get this [interferon-based] medication because it's [HCV] not really bad yeah.* (A)

---

[19] An earlier version of the text in this section appeared in:
Scarborough, J., Miller, E. R., Aylward, P., & Eliott, J. (2017). 'Sussing that doctor out.' Experiences and perspectives of people affected by hepatitis C regarding engagement with private general practitioners in South Australia: a qualitative study. BMC family practice, 18(1), 97. doi:10.1186/s12875-017-0669-2
Available at: https://bmcfampract.biomedcentral.com/articles/10.1186/s12875-017-0669-2

Obtaining a referral for treatment by a specialist (required for previous interferon-based treatment) was the only rationale provided by many participants for engagement with a GP about HCV-related issues. Accordingly, patients deciding against this treatment at the time did not consider any benefit from engagement with GPs about HCV.

> *I mean the only basic help like that that they [GPs] could do for you is, you know, is write you out a referral to somewhere else but I've never seeked [sic] help before for my liver problem because of that reason.* (A)

Negative perceptions and experiences about the physical side-effects of treatment were relayed by participants and some had decided that treatment was not currently an option for them.

> *One of my friends went on that thing [antiviral treatment for HCV] to get rid of it but she got really sick from it …. Yeah, it dehydrated her brain; she nearly died...* (A)

> *One participant reported that their GP held negative views of the available antiviral treatment and this had led to him refusing to make a referral for a HCV-related investigation or for antiviral treatment: "He was quite clear that I shouldn't have that …".* (A)

Finally, some participants who had sought HCV antiviral treatment at tertiary centres cited situations in which the treatment had not been provided, despite their GP providing them with the required referral and even where the GP had actively followed up the progress of the referral. This led to a perception by participants that engagement with GPs was an ineffectual pathway to antiviral treatment for HCV.

> *But he's [the participant's GP] put referrals in through the [tertiary hospital #1] but I don't hear anything about the referrals ay.* (A)

> *…you get an appointment and then they [tertiary liver clinic] pretty much give you a blood test and then they say, "Come back in six months."* (A)

Patients' experience with tertiary liver clinics when seeking interferon-based HCV treatment may affect their ongoing engagement for DAA treatment. Patients may perceive that there is no urgency to enter DAA treatment after engaging with an HCV specialist and receiving no treatment. While most patients are able to be provided DAA treatment by GPs, patients previously referred to tertiary centres may not be aware of this development and not return to a GP to engage for this care.

## 5.6 Discussion [20]

This study took place in the era of interferon-based treatment before the availability of the radically improved DAA, and before the extension of prescribing rights to GPs. However, as the main findings related to the nature of disclosure and decision making around engagement with GPs and these findings are relevant to the current context. Most Australians (including all participants) access private, federally-subsidised GPs for their healthcare (Australian Bureau of Statistics, 2019) and for the majority of PWHCV in Australia, DAA can be delivered via private GPs (Hepatitis C Virus Infection Consensus Statement Working Group, 2018). While the treatment for HCV has undergone a remarkable transformation, these advances do not guarantee that PWHCV will engage with GPs in private general practice for this care.

To engage with GPs to access DAA in this setting, involves PWHCV negotiating disclosure, due to the invisible nature of HCV (Harris, 2009). For people with a diagnosis of HCV to access this treatment, they need to disclose their HCV status and be willing to engage with GPs about this issue. For people with un-diagnosed HCV, a trigger is needed for HCV testing to occur. This trigger may involve patient disclosure of HCV risk factors to the GP, or during other clinical investigations, for example, an unexplained abnormal liver test result (Iser & Ryan, 2013) or pregnancy (Homer, Oats, Middleton, Ramson, & Diplock, 2018). The diagnosis of HCV is then disclosed to the GP requesting the test. During ongoing care with GPs, further negotiation of disclosure may be involved, for example during patient history taking. The introduction of new treatment does not alter the requirement for disclosure or fundamentally change patients’ perceptions about disclosure (Fry & Bates, 2011).

The aim of this study was to better understand the experiences and perceptions of people affected by HCV regarding engagement between GPs and patients about issues relevant to HCV. Based on this understanding the way that the problem of increasing the provision of DAA by GPs in private general practice is framed can be deconstructed (Bacchi, 2009, 2016). Through this process underlying assumptions can be identified, and current interventions

---

[20] An earlier version of the text in this section appeared in:
Scarborough, J., Miller, E. R., Aylward, P., & Eliott, J. (2017). ‘Sussing that doctor out.' Experiences and perspectives of people affected by hepatitis C regarding engagement with private general practitioners in South Australia: a qualitative study. BMC family practice, 18(1), 97. doi:10.1186/s12875-017-0669-2
Available at: https://bmcfampract.biomedcentral.com/articles/10.1186/s12875-017-0669-2

based on these assumptions can be critiqued. This process can be used to guide the development of new interventions aimed at private GPs to reduce barriers to and improve the provision of best practice care, including DAA, for PWHCV in this setting.

### 5.6.1 Patient' decisions about engagement[21]

Like the general Australian community, people affected by HCV viewed GPs as a source of general healthcare (Australian Government - Department of Health, 2016b), potentially including issues related to HCV. Several participants reported being highly satisfied with the care provided by individual GPs including specific care for their HCV. This notwithstanding, they and other participants also relayed negative experiences and perceptions about engagement with GPs for HCV-related care. Consequently, participants often described people affected by HCV developing a strategy of 'sussing' out doctors before engaging and disclosing either an HCV diagnosis or risk factors, to individual GPs. The process involved weighing up the perceived risks and the perceived benefits and then deciding whether engagement and disclosure were worthwhile.

The disclosure strategies of participants mirrored 'strategic outness' coined by Orne (2011), whereby gay men manage, on an ongoing basis, who, how and why other people learn about their homosexuality. However, it is important to note how the disclosure of homosexuality and the disclosure of HCV, which is associated with IDU, differ. Participants in Orne's study were described as 'gay men', indicating that this aspect of their identity was fixed (Orne, 2011). However, PWHCV may never have been involved with IDU, and where they have been involved, this involvement may not be a fixed aspect of their identity. In addition, Orne's study (2011) was conducted in a context where homosexuality was decriminalised, and homosexuality was finding greater community acceptance. In contrast, while Australia has a policy of harm minimisation, most commonly injected drugs remain illegal (Australian Government - Department of Health, 2017) and IDU is stigmatised in

---

[21] An earlier version of the text in this section appeared in:
Scarborough, J., Miller, E. R., Aylward, P., & Eliott, J. (2017). 'Sussing that doctor out.' Experiences and perspectives of people affected by hepatitis C regarding engagement with private general practitioners in South Australia: a qualitative study. BMC family practice, 18(1), 97. doi:10.1186/s12875-017-0669-2
Available at: https://bmcfampract.biomedcentral.com/articles/10.1186/s12875-017-0669-2

Australia (Broady et al., 2020). Additional considerations are involved when disclosure is contemplated within a patient-GP relationship.

Participants acknowledged the difficulties for GPs dealing with ‘doctor shopping’ and other ‘drug seeking’ behaviour (Claire Van Hout, 2014; Martyres, Clode, & Burns, 2004) and, particularly where they had previously participated in it, expressed sympathy for doctors required to deal with such behaviours. The honest disclosure of current illicit drug use to a GP, however, would be illogical if the person was attempting to obtain drugs of dependence without genuine need. This is more likely to represent an attempt to elicit care for HCV, or a health issue related to drug use. Faced with this situation, GPs might offer people a range of information to prevent harm, for example, brochures regarding prevention of transmission of blood-borne viruses. In addition to the benefits for patients receiving opioid substitution treatment (Teesson M et al., 2006; White, Dore, Lloyd, Rawlinson, & Maher, 2014), GPs may find that drug-seeking behaviour is reduced when they offer such treatment (Scarborough et al., 2011).

As reported in previous studies (Day et al., 2004; Fry & Bates, 2011; Gifford et al., 2005; Hopwood & Treloar, 2004; Hopwood et al., 2006; MacNeil, 2012), many of these risks considered by participants when disclosing, were related to stigma, but several other factors also contributed to the decision-making process. If GPs are aware of the decision-making process that people affected by HCV undertake, the GPs can utilise strategies aimed at reducing their doubts and increasing their perceptions of benefit about the care they will receive, and tip patients’ decisions towards disclosure and engagement.

### 5.6.2 Expectations[22]

Based on their expectations and experiences participants did not assume that all GPs would be willing to provide care for HCV-related issues in a non-discriminatory, non-judgemental way. Expectations are formed overtime and can be influenced by personal experience and witnessed experiences (Orne, 2011). Importantly, no participant described overt

---

[22] An earlier version of the text in this section appeared in:
Scarborough, J., Miller, E. R., Aylward, P., & Eliott, J. (2017). ‘Sussing that doctor out.' Experiences and perspectives of people affected by hepatitis C regarding engagement with private general practitioners in South Australia: a qualitative study. BMC family practice, 18(1), 97. doi:10.1186/s12875-017-0669-2
Available at: https://bmcfampract.biomedcentral.com/articles/10.1186/s12875-017-0669-2

discrimination associated with HCV by GPs. Discrimination in other settings, including health settings, was described, and these experiences appeared incorporated into participants' expectation of encountering discrimination from GPs. Displaying posters and other information in the waiting room about HCV or drug use can signal to patients that the practice is willing to provide care for these conditions. This material would be timely as our participants' responses indicate that when the new DAA therapies were available, people affected by HCV would reassess their previous decision to not enter treatment. Additionally, publicity surrounding these new treatments may prompt people who are undiagnosed to consider their risk of exposure, and the presence of this material in the waiting room may prompt them to seek testing at the practice.

### 5.6.3 Changes to usual care based on limited perceptions of drug use[23]

Upon disclosure of an HCV diagnosis to GPs, some participants recounted experiences of unwelcome changes to their usual care, which precipitated reluctance to disclose to other practitioners in the future. Unwillingness to prescribe drugs of dependence and focussing on the patient's 'drug-use problem' were reported by participants as examples of GPs' reactions following disclosure of their HCV-status. Participants expressed a frustration that, whilst well intentioned, this change appeared to reflect GPs' incorrect assumptions concerning 'inherent' relationships between HCV and 'current' drug addiction, when in fact there is a great deal of heterogeneity of the population affected by HCV regarding such behaviours or identities (Hajarizadeh et al., 2017; Swan et al., 2010; White et al., 2014).

Whilst drug addiction is often described as a 'chronic relapsing disorder' (Badiani, 2014), not all PWHCV are, or have ever been, addicted to drugs (Hajarizadeh et al., 2017; Larney et al., 2015; Swan et al., 2010; White et al., 2014). Studies of the natural history of injecting drug use have been criticised as biased and therefore the conclusions reached are unreliable (Larney et al., 2015). For instance, where people were recruited from populations with engrained patterns of IDU, the persistence of IDU may be overestimated (Larney et al., 2015). Confusion about the persistence of IDU is also reflected in the commonly used term 'people who inject drugs' (PWID). The word 'who' implies currency, but the term is applied

---

[23] As above.

to cover a range of groups, including people defined as ‘former’ PWID (Larney et al., 2015). Patterns or significance of drug use by PWHCV, should not be assumed by GPs.

The significance of illicit drug use to a person’s self-identity may vary over time and between individuals, as demonstrated by participants in this study. A concept developed by Spencer-Oatley (2007) can be applied to understand the heterogeneity of the significance of drug use to an individual. This author proposed that individuals perceive and evaluate a self-aspect of themselves using a set of criteria including currency, centrality, valence (degree of attraction or aversion) and actuality (ideal versus actual). The application of these criteria to the illicit drug use described by participants, captures differences in the way that drug use is viewed by individuals and can be contrasted to the perception that participants felt that GPs had to drug use. Participants reported that PWHCV were treated at all times by GPs as though illicit drug use was the central and active, ongoing issue for their patient with HCV. Part of GPs treatment of this ‘problem’ of illicit drug use was aimed at transforming patients to a state of having aversion to this behaviour (expressed as shame) and changing the patient’s actual state of drug use to what the GP perceived as an ideal state - that is being abstinent from drugs. Many participants described their drug use in a way that contrasted to the perspectives of GPs. Some participants described drug use as an aspect of their identity that was historical and that was never central to their self-identity. In effect they had acquired HCV through IDU, but they had no ongoing problem with drug use. Another participant also did not perceive their current IDU as a ‘problem’, as they felt that they were someone who could ‘chose to use’ drugs. This aspect of their lives was not perceived as central and they had no aversion to their current drug use. When GPs are assessing whether a patient has any drug issues, eliciting the significance of drug use to the patient would allow GPs to provide targeted care.

Where patients are willing GPs can play an important part in addressing patients’ drug-use issues (British Medical Association, 2013) but should not assume that all patients presenting for HCV management require treatment for drug use. It is good practice for GPs to consistently exercise caution prescribing drugs of dependence (Badiani, 2014), but the use of these drugs are warranted to treat many conditions. In these circumstances, GPs should not deny drugs of dependence to patients based on the patient’s HCV status or even reported drug issues, but should exercise clinical judgement using appropriate safeguards when prescribing (Badiani, 2014).

### 5.6.4 Risk to confidentiality of sensitive information[24]

A source of concern for some participants was the loss of control of their information, with the subsequent risk to the confidentiality of sensitive information and potential associated serious consequences. Open disclosure within the patient-doctor relationship did not equate with disclosure to family, intimate partners, friends, or during employment. These participants wanted to avoid exposure to stigma due to their HCV status and their past injecting drug behaviour if this became known (Fry & Bates, 2011; Miller et al., 2012; Treloar & Rhodes, 2009). Australian general practice standards (The Royal Australian College of General Practitioners, 2015) require practices to adhere to policies regarding the protection of patient information. Routinely informing all patients that these systems are in place, would reduce fear, and encourage open and honest disclosure, about sensitive information, in particular drug-related or HCV-related conditions. Participants wanted to be reassured by their GP that their information would only be shared with their explicit permission, and only when relevant. Even when confidentiality policies are strictly adhered to, concerns about privacy may still be held by the patient. Being provided reassurance about this aspect of care is an important way to address concerns and improve engagement.

### 5.6.5 GP knowledge of HCV and treatment[25]

Participants recognised the difficulty of GPs maintaining in-depth knowledge over the wide scope of their work, yet, as reported elsewhere (Stevenson, Kerr, Murray, & Nazareth, 2007), it was common for participants to be critical of the information provided by some GPs regarding HCV. It is unsurprising that participants had a high level of knowledge underpinning this judgement as many had actively accumulated knowledge since receiving

---

[24] An earlier version of the text in this section appeared in:
Scarborough, J., Miller, E. R., Aylward, P., & Eliott, J. (2017). ‘Sussing that doctor out.' Experiences and perspectives of people affected by hepatitis C regarding engagement with private general practitioners in South Australia: a qualitative study. BMC family practice, 18(1), 97. doi:10.1186/s12875-017-0669-2
Available at: https://bmcfampract.biomedcentral.com/articles/10.1186/s12875-017-0669-2

[25] An earlier version of the text in this section appeared in:
Scarborough, J., Miller, E. R., Aylward, P., & Eliott, J. (2017). ‘Sussing that doctor out.' Experiences and perspectives of people affected by hepatitis C regarding engagement with private general practitioners in South Australia: a qualitative study. BMC family practice, 18(1), 97. doi:10.1186/s12875-017-0669-2
Available at: https://bmcfampract.biomedcentral.com/articles/10.1186/s12875-017-0669-2

their HCV diagnosis, had health related qualifications, and/or worked with clients affected by HCV. For PWHCV to be convinced that it is worthwhile to engage with a GP for DAA, it is important for GPs to be able to demonstrate up-to-date knowledge about HCV diagnosis and treatment. PWHCV seeking care may be made aware of training by GPs at the general practice level, for example on general practice websites, or via registers of GPs who have undergone training, on state HCV organisations' websites.

### 5.6.6 Continuity of care

In general, patients value continuity of care with a GP (Jackson & Ball, 2018; Wright & Mainous III, 2018), which can be defined as "when a patient has an ongoing sense of affiliation, collaboration and trust with a single provider." (Jackson & Ball, 2018, p 662). Continuity of care is reported to maximise patient health and as being at the core of the ideal GP-patient relationship (Gray, Sidaway-Lee, White, Thorne, & Evans, 2018; Hofer & McDonald, 2019; Jackson & Ball, 2018; Wright, 2019). A study into the provision of interferon-based treatment for HCV by GPs (Hopwood & Treloar, 2013) found that patients appreciated the continuity of care afforded by this arrangement. However, as patients in the study had entered treatment, disclosure of the diagnosis of HCV was no longer in play. In addition, these patients were receiving OST from their GPs so previous IDU disclosure was highly likely and the GP-patient relationship had continued upon disclosure. For many patients, the HCV disclosure may not have occurred with their usual GP. Participants in *Study 2* described varying levels of HCV and risk factor disclosure during GP engagement, and perceived that without disclosure, GPs would remain unaware of a diagnosis of HCV or HCV risk factors.

PWHCV may face dilemmas that have not previously been described when they value continuity of care and are in pursuit of the best care for their HCV. For PWHCV, the continuity of care with their GP may be perceived as at risk if the GP reacts negatively to their disclosure. Such a perception of risk was described by participants in respect to their usual care (as previously discussed in section 5.6.3.). This effect would be amplified if patients are not confident in their GP's ability to provide best practice care for HCV, and do not perceive that benefit is guaranteed by raising this issue with their regular GP (as previously discussed in section 5.6.5.). PWHCV may benefit from breaking their affiliation with a single provider and seeking care from an alternative provider. These people may visit another GP for care not associated with HCV to 'suss' them out, before risking disclosure. Findings in this study were that PWHCV may adopt a strategy of disclosing to one GP and non-disclosure with another. Lack of continuity of care may not have any particular association with patients' management of HCV disclosure.

In line with a significant proportion of the Australian population, continuity of care with one GP may not be experienced by PWHCV (Hofer & McDonald, 2019; Jackson & Ball, 2018). There are many other reasons that people may attend more than one GP (Hofer & McDonald, 2019) and, outside of market forces, there are no restrictions on doing so. There have been issues identified with continuity of care, including limited timely access to the GP, complacency of the treating GP leading to errors or omissions in care, and the chance that GP-patient relationship involves a poor-quality partnership (Hofer & McDonald, 2019). Participants in this study reported that they did not return to a GP practice where they had reluctantly disclosed their HCV status. When considering interventions to improve the provision of DAA by GPs, it cannot be assumed that continuity of care exists for PWHCV, nor that promoting continuity of care is unproblematic for patients with HCV.

### 5.6.7 Limitations[26]

The experience and perspectives of the participants in this study may not match those of all PWHCV. Additional research that involves recruitment of participants from more diverse populations, for example specific migrant groups, is warranted to determine whether the findings apply to these populations. In particular the lack of participants who identify as Indigenous Australians is a limitation to this study. As outlined in sections 3.7.1 Ethics approval process and 3.7.2 Ethical considerations, the sites selected for recruitment of people affected by HCV included, and were overrepresented, by Indigenous people. However, I understood that my capacity to attract Aboriginal and Torres Strait Islander peoples as participants, particularly male participants, was limited due to being a non-Indigenous woman, with no strong networks within the Indigenous community. As part of the ethics application to the Aboriginal Health Research Ethics Committee, modifications

---

[26] An earlier version of the text in this section appeared in:
Scarborough, J., Miller, E. R., Aylward, P., & Eliott, J. (2017). 'Sussing that doctor out.' Experiences and perspectives of people affected by hepatitis C regarding engagement with private general practitioners in South Australia: a qualitative study. BMC family practice, 18(1), 97. doi:10.1186/s12875-017-0669-2
Available at: https://bmcfampract.biomedcentral.com/articles/10.1186/s12875-017-0669-2

were suggested and subsequently adopted to the recruitment material and process, with the aim of maximising participation by Indigenous participants. However, no Indigenous people chose to participate in the research. Further research with Indigenous Australian participants is necessary to determine if the findings are applicable to this population, to identify any additional beliefs or practices that may contribute to their perspectives and experiences, and to outline the implications of same for best practice care (Braunack-Mayer & Gibson, 2017).

A further potential limitation of this study is that the findings in one Australian state (SA) may not be generalisable to jurisdictions where different systems of primary medical care exist, and other dynamics are present. Experiences of stigma have, however, been reported internationally (Miller et al., 2012) and our findings will be relevant wherever HCV-affected people face decisions about managing disclosure and engagement when seeking primary healthcare.

This study was conducted before DAAs for HCV options became widely available in Australia and this forms another potential limitation. Although participants indicated that they would reassess entering treatment when new DAAs became available, people would need to be assured that they could access this treatment via GPs; some may not engage and disclose if they perceive the associated risks to be too high. Understanding the patient decision-making process regarding engagement with GPs will therefore still be relevant in the era of DAA HCV treatment availability.

## 5.7 Chapter summary

The aim of *Study 2* was to gain further understanding of the patient component of the dynamic adaptive complex system in which engagement for care for HCV takes place. The main finding of this study is the identification of the varied considerations made by PWHCV regarding engagement for care and how these considerations contribute to the decision regarding engagement for HCV treatment. These findings inform interventions aimed at reducing the perception of potential negative outcomes and increasing the perception of potential benefits and sway PWHCV to engage with GPs for HCV care. PWHCV had mixed experiences and perceptions regarding the provision of care for HCV by private GPs. The experiences of some participants demonstrated that patients could be highly satisfied by care provided by GPs, but also revealed gaps in care and negative expectations of care from GPs. These experiences and perceptions could affect patient engagement for care in this setting.

An important aspect of patients’ decisions to engage for treatment for their HCV, was their perception of the effect of disclosure. Patients may have been aware of their HCV status and felt that disclosure of this to their GPs providing them with care, was necessary to maximise their care. However, a perception that potential risks of disclosure existed. These risks included exposure to discrimination, risks to confidentiality of sensitive information and withdrawal of usual care. In coming to a decision about whether to disclose or not, patients weighed up these potential risks against potential benefits or engagement. Potential benefits were perceived as relying on the likelihood of the GP being willing and competent to respond appropriately regarding the provision of care for HCV. Based on previous experience this was not perceived as guaranteed.

Continuity of care between a patient and a GP, has been promoted as positive for patient outcomes. However, people with HCV may perceive that the continuity of care with their GP may be at risk if the GP reacts negatively to their disclosure of HCV or associated risk factors. Patients may also be reticent to disclose if they are uncertain about the ability of GPs to provide appropriate care for their HCV. In these cases, patients may benefit from adopting a strategy of engaging with more than one GP. As with the general population, PWHCV may not experience continuity of GP care. The risk, or perception of risk, to patients’ existing access to continuity of care should be considered when planning interventions. The occurrence of continuity of care for patients with HCV should not be assumed.

# CHAPTER 6.

# *STUDY 3 – GPS' ENGAGEMENT IN THE PROVISION OF CARE FOR HCV IN PRIVATE GENERAL PRACTICE.*

## 6.1 Introduction

In this chapter I will present the results of *Study 3* regarding GPs' experiences and perceptions of engagement in the provision of care for HCV in private general practice. This study took place in 2018 and involved undertaking semi-structured interviews with nine participants. Invitations to participate (Appendix 8: Recruitment material *Study 3*) were included in the DASSA newsletter for clinicians involved in the South Australian OST program, distributed to the Hepatitis SA GP mailing list, and sent directly to general practices and/or GPs targeted as part of the purposive sampling strategy (see section 3.7.3. Recruitment). Invites were targeted to achieve a purposive sample, however there were no inclusion or exclusion criteria and if any South Australian GP wished to be involved in the study they would have been included. While the primary target of recruitment were GPs, mention of practice staff was included in the recruitment material. One GP participant indicated that they undertook a team approach to the provision of DAA in their practice and that two practice nurses were keen to share their experiences of provision of this care. The final sample included these two practice nurses and seven GPs. The sample included participants who had a range of involvement in DAA, including current, past and no involvement in the provision of this treatment. Transcripts of the interviews formed the data that was then thematically analysed. The analysis provided an understanding of the GP (and practice nurse) component involved in the provision of DAA. Together with the findings of *Study 1*, which examined the healthcare system component and *Study 2,* which examined the patient component, I sought to understand the complex adaptive system which formed the context in which DAA was provided. This understanding will inform recommendations to increase the provision of this treatment discussed in Chapter 7.

## 6.2 Research question

*Study 3* was conducted to answer the following research question:

3. What are the experiences of GPs in private general practice about the provision of care for people with or at risk for HCV and how does this affect their perceptions of engagement in this care?

## 6.3 Background

Adhering to the philosophy of pragmatism, I will begin by describing the context in which *Study 3* took place (see Section 3.2). As the context of the research includes the setting of private general practice, I will outline the concerns within this sector at the time. Aspects of the topic of prescribing of DAA including the right to prescribe, training, resources, and advice to patients will be described. GPs with experience as OST prescribers in South Australia were involved as participants in the research (n=4) (see Section 3.8.4) and some background data is provided about OST provision in private general practice in South Australia when the study was conducted.

### 6.3.1 Private general practice issues

At the time of *Study 3*, there was widespread concern among GPs about aspects of the business model of general practice and renumeration for their work, with GPs ranking Medicare rebates as a priority health policy issue (Royal Australian College of General Practitioners, 2018b). This finding was in the context of the Medicare rebates ‘freeze’ being in effect since November 2013 (Hendrie, 2019; Scott, 2017) and during the lead up to the 2019 Federal election, where the operation of Medicare was a political issue (Australian Medical Association, 2019). There was also continued debate around the effect on renumeration for the practice of bulk-billing (Bartone, 2017), particularly in relation to a move towards corporate ownership where the business model is more likely to involve all patients being bulk-billed (Scott, 2017). In 2017, most GPs worked in group practices with only 5% of GPs reporting working in a solo practice. The proportion of GPs who owned practices had decreased to 22% in that year. Corporate ownership of practices was subsequently increasing, however 66% of GP still worked in non-corporate practices (Royal Australian College of General Practitioners, 2018b).

### 6.3.2 GPs’ right to prescribe DAA

The study interviews took place between May and November 2018, more than two years since GPs were authorised to prescribe DAA in consultation with specialists in March 2016 (Haridy et al., 2018; Wade et al., 2018). The extension of prescribing rights to all GPs was a strategy implemented to expand workforce capacity so that rates of providing DAA were increased to a level whereby ‘elimination’ of HCV could be achieved (Hepatitis C Virus Infection Consensus Statement Working Group, 2016). When DAA became available, there was a small number of GPs categorised as ‘experienced’ across Australia, who could independently prescribe DAA (Haridy et al., 2018; Wade et al., 2018), but there were insufficient numbers to provide significant capacity (Sud et al., 2018).

### 6.3.3 Organisational support for GPs to prescribe DAA

There was a variety of training, tools and resources available to encourage and equip additional GPs to prescribe DAA from a range of organisations at the time of *Study 3*. The Gastroenterological Society of Australia developed consensus recommendations for the management of HCV in 2016 (Hepatitis C Virus Infection Consensus Statement Working Group, 2016), which presented advice from experts in the field. These recommendations were updated in 2017 and again in 2018 (Hepatitis C Virus Infection Consensus Statement Working Group, 2017, 2018). Training regarding care for PWHCV, including prescribing of DAA, was made available across Australia and included face-to-face and online training by the Australasian Society for HIV, Viral Hepatitis and Sexual Health Medicine (ASHM) (ASHM, 2017, 2018). HCV education provided by ASHM was attended by 1326 health care professionals in 2016-2017, 845 health care professionals in 2017-2018 (ASHM, 2019a) and 304 doctors in 2019 (ASHM, 2019a). Resources for GPs have been developed and updated overtime, for example ‘HCV New Treatments Quick Reference Tool’ and ‘Decision-making in HCV’ (ASHM, 2017). Viral Hepatitis Nurses (VHNs) based in metropolitan Adelaide, were employed by the State Government to work in shared arrangements with GPs for patients with HCV and to provide links to public hospital specialists (Government of South Australia - SA Health, 2017). The VHNs also provide support directly to PWHCV and are based either in tertiary liver clinics or in the community (Government of South Australia - SA Health 2019). Specialists including gastroenterologists, hepatologists and infectious diseases physicians are based at tertiary outpatient clinics and are available for consultation with GPs regarding DAA (Haridy et al., 2018).

### 6.3.4 Use of the remote consultation form

To facilitate consultation with specialists, remote consultation forms (Appendix 1) were developed to collect standard information (Gastroenterological Society of Australia, 2019) and have been used by GPs to fulfil this requirement (Haridy et al., 2018). The four public tertiary referral centres in South Australia (all based in metropolitan Adelaide) were involved in providing over 85% of consultations to South Australian GPs, from March 2016 to February 2017 (Haridy et al., 2018). The completion of the form was designed to guide the medical practitioner through the pre-treatment assessment and selection of regimen process, and to form the basis for specialist to provide feedback. The information collected in the form includes HCV history, intercurrent conditions, prior antiviral treatment, current medications, laboratory results (including HCV genotype and HCV RNA level), liver fibrosis assessment by elastography or serum biomarker, and the GPs' treatment regimen choice. Links to relevant resources are provided on the form, for example HCV treatment drug interactions as well as guides for clinical decision-making (ASHM, 2019b). The process involves the GP submitting the completed form, which is then reviewed within the specialist unit. If no further information is required, the form is returned to the GP with confirmation of the regimen selected by the GP or with an alternative recommendation from the specialist unit (ASHM, 2020b). Since the study took place, a central web-based hub has been developed where the forms can be submitted online, reviewed by a specialist who is highly experienced with HCV treatment and returned within 24 hours (ASHM, 2020b).

### 6.3.5 Advice for PWHCV about accessing DAA

At the time of this study PWHCV were advised to see 'their' doctor or their 'usual' doctor to get DAA, with the announcement of the Federal Government subsidisation of DAA, by the Health Minister, Ms Sussan Ley including the advice that: "…people with Hep C to consult their doctor about the best course of treatment for them." (Ley, 2016, p 2). Hepatitis Australia launched a national campaign in 2018 called *Test, Cure, Live* to encourage PWHCV to: "…speak to their doctor and find out about being free from hepatitis C." (Cameron, 2019, p 6). Over time a shift to this messaging occurred, with a move away from patients being directed to their GP, to patients being directed to a national information service. For example, on the Australian government funded *Healthdirect* website that aims to provide "quality, approved health information and advice" (Healthdirect, 2018b, p 2), under the topic of HCV, the advice provided to patients is: "For more information on how to get treatment, contact the National Hepatitis Info Line on 1800 437 222." (Healthdirect, 2018a, p 2). On the Hepatitis Australia website more detailed advice is included: "Your usual GP can now prescribe the new DAA medicines to cure hepatitis C, but they may seek advice from a specialist if they do not have a lot of experience with treating hepatitis C." (Hepatitis Australia, 2019a, p 2). Any evaluation of the extent to which these messages reached PWHCV has not been reported to date.

### 6.3.6 Provision of opioid substitution in private general practice in South Australia.

At the time of the study approximately 50 active accredited GP prescribers and approximately 170 non-accredited prescribers were working in private general practice, and held authorities to prescribe OST for approximately 1500 and 270 patients respectively (Australian Government - Australian Institute of Health and Welfare, 2020b). The number of OST prescribers working in private general practice and the number of patients on the program attending at these sites, has remained stable over time. There was a range of authorities for OST held by the individual OST prescribers, ranging from approximately 160 authorities held by one GP, down to one authority. Even for the few accredited prescribers who held a relatively high caseload of authorities, this represents a low proportion of their overall patient population to which they provide services. As there are several practices where there is more than one OST prescriber located, the number of general practices where OST is prescribed is less than the number of OST prescribers in South Australia. There has been an uneven spread of OST prescribers across the state with some rural regions having no accredited OST prescribers, requiring patients to travel significant distances to access OST (Le, 2019).

## 6.4 Results

All interviewed GPs (n=7) indicated experience in providing antiviral treatment to patients with HCV, six GPs had prescribed DAA, and four were currently providing this treatment to patients in their private general practice. Three GP participants were current, active, accredited prescribers of OST, one had formerly been an accredited prescriber of OST and three had not been involved in OST prescribing. Two practice nurses were also interviewed, as they worked as a team with the GP at their practice to provide care for their patients receiving DAA.

Quotes from all participants were selected as part of the analysis. Quotes that are unlabelled were provided by GP participants and where the nurse participants quotes were used these were labelled "(Nurse)". To protect the confidentiality of participants the quotes were de-identified. Where more than one quote within a paragraph is from the same participant, this is indicated with the use of "**and**", otherwise the quotes are provided from a number of participants.

During the semi-structured interviews, participants related their experiences and perceptions about the provision of DAA in private general practice. The three major themes identified during the analysis of the interviews conducted for *Study 3* were 'Fitting DAA into GPs' scope of practice', 'PWHCV as patients' and 'Doing the work'. Within each of these three major themes, three subthemes were further identified as outlined in Table 19. These themes will be discussed below.

**Table 19: Major themes and subthemes identified in *Study 3***

| Major Themes | Subthemes |
|---|---|
| Fitting DAA treatment into GPs' scope of practice | Constraints on GPs' scope of practice<br>Meeting patients' perceived needs<br>GPs' interests influencing their scope of practice |
| PWHCV as patients | Patient disclosure and stigma<br>Patients' awareness and agency in regard to HCV and DAA<br>Patients' capacity to be involved in DAA |

| Major Themes | Subthemes |
|---|---|
| Doing the work | HCV Training and information<br>Identifying patients with HCV<br>Prescribing DAA with support |

## 6.4.1 Theme 1 - Fitting DAA treatment into GPs' scope of practice

The theme of 'Fitting DAA into GPs' scope of practice' encompasses how GP participants perceived the provision of DAA fitting within the bounds of their profession of general practitioner. I further identified subthemes influencing the bounds of GPs' scope of practice of: 'Constraints', 'Meeting patient' needs' and 'GPs' interests'. Reflecting the complex adaptive system involved in the provision of care within private general practice (Crabtree et al., 2011) the factors influencing the constraints, meeting patient' needs and GPs' interests are interconnected and can change over time. These factors may involve interactions and influences between the different components of the system including patient, GP, general practice, local community and the healthcare system. Participants described the factors involved in determining their scope of practice generally. Part of this process involved deciding whether to include the provision of care for HCV and specifically DAA, in their scope of practice and the timing of this involvement.

### 6.4.1.1 Constraints on GPs' scope of practice

GP participants talked about the scope of general practice as being broad and increasing.

> *The trouble with general practice is that every politician, every group or every organisation, says 'This can be done by a GP' and the GPs don't necessarily feel confident about dealing with it because they just don't do enough at it.*

The diversity in general practice was considered both challenging and a positive aspect of being a GP. While expressing appreciation for the breadth available to GPs, participants described how their individual, narrower scope of practice was determined, including the choice to prescribe DAA. The breadth of their scope of practice was constrained by time, both in terms of the time available for GPs overall and time available during appointments, and the need to fit the work in with the business model of their general practice.

GP participants described time limitations on the total time available to them, when discussing their and other GPs' scope of practice in general practice. This time limitation impacted on the time available to include additional areas of work, to participate in further education, to provide service to particular subpopulations or to take on additional patients.

> *Yeah, generally I'm not taking new patients ……Grey hair, waiting lists, the whole lot yeah. I take on obviously family members because that's the ethics of this practice, but basically just loaded up.*
>
> *… as opposed to a partner, it's probably a bit easier [for a GP employee] to sort of pre-arrange leave for those sorts of [educational] things, because you don't have other managerial type responsibilities.*
>
> ***and***
>
> *It [area of advanced skills] provides a really good balance for me, for procedural versus non-procedural work.*
>
> *…when I'm teaching with medical students and the registrars that come through.*
>
> ***and***
>
> *…it [prescribing of DAA for HCV] isn't my focus because I'm mainly dealing with either pain dependence or mental health issues and I just – I don't want to stretch myself that little bit extra.*

The myriad of roles assigned to GPs was demonstrated by descriptions of GPs' different roles within general practice including managerial, teaching and clinical roles. Clinical roles were further described as procedural and non-procedural, and descriptions of areas of special interest that GPs could be involved in. In describing their personal choices, GP participants discussed how they aimed to achieve a balanced, enjoyable work life and how this was a factor in what they did, and did not, include in their scope of practice. DAA prescribing was work that GPs viewed as optional to include in their scope of practice.

Participants perceived that unless you were involved in a particular area of practice, that skills in this area would not be honed or developed. Conversely, where people were involved in one area of practice skills development would occur.

> *If you're involved in treating people with drug and alcohol problems or Hepatitis C you're going to take an appropriate history for that. If you don't deal with it, you're not going to.*
>
> *and*
>
> *The bulk of the work's just done by a small number, so they get comfortable.*
>
> *I don't even do Implanons [contraceptive implant] because when they first came out you had to do special training and I think you – and I was working with mainly men…*
>
> *I usually base it [topic of education attended] around things that I would see most commonly…*
>
> *Basically, you just sort of identify the gaps in your knowledge, depending on the patients you're seeing.*

Participants reported that when GPs narrowed their scope of practice, these decisions were subsequently reinforced.

Participants described constraints on time during each scheduled appointment and the process by which decisions are made about what gets covered in the time allotted for the appointment.

> *….the fine art of general practice is 'How quickly can you figure out exactly what the patient has come here for today?' and 'What else do you need to know today to manage it?', 'What else do you need to know to manage it later?', and 'How likely am I to get this patient back?'. So, whether you take the extra time to ask those questions, is based on a series of probabilities that you weigh up every minute.*
>
> and
>
> *…they are more senior, at least been a fellow GP for a few years that tends to make you a bit faster and you have an established patient body that isn't somebody new all the time.*
>
> *…lots of things don't get picked up because they [GP colleagues] focus on the one thing. It's a ten-minute appointment 'I'm only going to do this' and they don't look at the patient holistically. That was my experience in a bulk-bill clinic.*

There was tension between using appointment time to treat the acute problem the patient was presenting with and addressing patients' overall health issues. There was a perception that there were different levels of GPs' skills in, and focus on, providing holistic patient care. More experienced GPs were viewed as more efficient than less experienced GPs at addressing patients' wider health issues and this efficiency was aided when experienced GPs had a more stable patient base. Part of this decision-making process involved judging whether continuity of care was likely with the individual patient. The experience of working within a bulk-billing clinic, relayed by one participant, was that a 'ten-minute appointment' was the usual appointment time used and that this was an ever-present time constraint, limiting the capacity for GPs in this setting to have a role beyond the acute issue the patient presented with.

In addition to other constraints on GPs' scope of practice, participants expressed the requirement for this work to fit with the business model of general practice in terms of attracting a patient base and generating income.

> *…there's quite a few different practices around. I mean there's obviously bigger clinics too, that – I think that's why we try and provide a holistic type, continuing type care and hopefully that's why they would choose us.*
>
> *I think it's community health and I like to say financially we do quite well.*
>
> *…anybody who says, 'Will you bulk-bill me?' I don't think I – I say no to very few, no matter what their income is. Different doctors will do different things, you know.*
>
> *…it was a bulk-billing practice. They [patients] didn't care who they saw as long as they saw a doctor and they were not charged. No involvement in their care, so it doesn't matter whether they were thrown from one doctor to the other to the other, they really didn't care.*

> *I don't bulk-bill and there's a significant gap for ongoing treatment so people who are looking for a convenient and cost-free way of getting treatment [for specific conditions], or whatever, don't turn up and see me. Once I've actually seen people, I actually quite often find it difficult to get them to go and see anybody else.*

and

> *… if you're going to get your Hepatitis C treated by regular consultations and reviews to get the treatment instead of spending a lot of time to start with and perhaps paying for it, you know, ultimately the doctor will make the same or more money so it's just a matter of people thinking about whether they want to set the processes up or not.*

DAA prescribing participants described the importance of providing long-term, holistic care to attract and retain their patient base. They expressed their perception of this as a benefit to supporting the business aspect of their general practice, as well as patient care. The participants indicated that there was a large range of practices regarding gap payments, from bulk-billing nearly all patients (and, therefore, patients not being charged any gap payment) or selective bulk-billing, to having a policy of a significant gap payments from most patients. These participants indicated that they provided DAA in their general practice across the payment spectrum. There was a distinction made between the bulk-billing practice of individual GPs and the general practice itself being labelled a 'bulk-billing practice'. The business model of 'bulk-billing practices' was perceived as maximising income by focussing on short appointments and attracting a patient base from patients who prioritised cost over continuity or quality of care. One participant described how GPs working for bulk-billing clinics, could choose to structure the necessary appointments within short appointment times, thus allowing the provision of DAA within this business model.

One participant expressed the view that their practice would not choose to provide DAA, or other treatments relating specifically to people presenting for issues regarding IDU, as inclusion of this would not be financially viable.

> *I mean they might screen them but that would obviously; depends on the presentation and where you do – you screen pregnant women and all that, but I don't think, and they'd like say; we'll have anybody who'll prescribe MATOD [Medication Assisted Treatment for Opioid Dependence] or anything like that. I don't think so because we'll probably be out of business because they'll just – they'll probably be out of business because there's just not enough.*

**and**

> *…a lot of doctors are not very thorough when they see new patients in taking history, so I have no doubt we might be missing people, yeah.*

The participant's concept of financial viability was based on their perception of the prevalence of these issues not being high enough to warrant the resources involved in providing these services. This participant also acknowledged that there may be patients whose issues of HCV issues, or the risk factor of IDU may be 'missed'. The perception of financial viability was therefore based on a potentially false calculation of the prevalence of these conditions within their general practice.

#### 6.4.1.2 Meeting patients' perceived needs

Several GPs indicated that the scope of their practice, and education they undertook, was influenced by the population they or their practice serviced, and the prevalence of conditions within this population.

> *I found most of my patients who had Hep C and referred them off to private specialists or private people [before GP' prescribing rights to DAA available],… most of my work is actually being tied up enough in dealing with management problems without having to actually run a separate hepatitis C treatment.*

> *So, we've got a lot of retirees and that's where the chronic disease is of course, so we do a lot of chronic disease stuff.*

**and**

> *I'm not really interested in hepatitis C. You know for the twenty patients out of five thousand [general practice patient population], give me a break.*

> *I see also hep C being a significant problem to attack in the practice, so I've kept abreast with journals and with peers.*

> *...it's very urban, very upmarket, very – you do get the very occasional people who might be using drugs but, yeah, very, very little...*

The consideration of the population served, led different GPs to consider the provision of HCV in their practice as either relevant or of low priority, depending on their perception of the prevalence of HCV within their patients and/or within the population served by their general practice. One GP considered that they had reduced prevalence of HCV through referral to treatment and that there was no longer need within their practice for DAA. In turn this allowed them to prioritise their involvement in other areas of special interest which would address current and ongoing need of patients.

The type of relationship between the GP and the patient was a factor when participants considered patient' needs and the provision of DAA. Participants described one-to-one relationships with their patients and how this type of relationship was beneficial for the provision of care for HCV.

> *Quite a few [patients] have been coming for a long time.*
>
> *...we've been here for a long time and been the only practice in the area,...we were a little community practice that just absorbed the patients in the area and hence we've now got a long lineage of patients. I think patients do try and find us as well. But that's just because we've been here, and we've looked after, well I think we've looked after the patients and their families in all manners of medicine. Yeah.*
>
> and
>
> *I think a smaller practice is better than big practices, both for individual health of the patient but also I think community health of our cohorts is better because we are able to sort of take into account not just the person but the community that's affecting them.*
>
> *...patients who attend multiple clinics [are discouraged], it poses too much of a medico-legal risk. That's definitely discouraged. And being clear on the client information about 'We want you to attend one practice'.*

Five of the GPs, of whom four were currently prescribing DAA, as well as the practice nurses described having long-term relationship with 'their' patients. Participants emphasised the importance of having long-term, patient-GP relationships and/or consistency with the same general practice as a benefit to the patients' healthcare. Specifically mentioned was the importance of such relationships to the prescribing of DAA. Being a smaller clinic that aimed to take care of all their patients' health needs, was also reported as an advantage to involvement in this prescribing.

Some comments by GPs indicated that their scope of practice was determined by a combination of the total population that the practice served and patient preference.

> *...if they like you, if they like what you're presenting to them, if they are happy with your services then they'll say, 'Can we change to you?'.*

> *…[patients are allocated appointments with] whoever they like. There's a girl doctor, she gets the 'tears and smears'.*

> *They [patients] may ask for a particular doctor or they – on our web page it will describe what the doctor's interests are so that may prompt them to choose a particular doctor.*

The complexity of patient' choices about the GP they chose to engage with was highlighted, and these choices were understood to be based on a combination of factors such as reputation, gender, type of presentation, advertising of special interests and the patient's experience with the GP.

GPs considered being involved in providing DAA when they were aware of the benefits of this treatment for their patients, and perceived that there was limited capacity of the tertiary sector to provide this treatment to them.

> *because speciality clinics have their own doors closed, can only take so many and all that sort of thing, so I think it's important that GPs got involved [in prescribing DAA].*

> *they're not seeing enough in the [specialist] units, cause most of them aren't there, because most people with hepatitis C aren't sick. So, they know about all the druggies cause they are all in the drug; methadone program or somewhere, eventually on the methadone program and they know the AIDS people because some of the hepatitis C is in there too, but that's it. Everyone else is out in the hinterland somewhere so that's why they wanted general practice involved.*

> *…they [Fibroscan® machines] can be moved around rather than [patients] having to wait months, travel just to have a scan done.* (Nurse)

> *They were comfortable coming here. …a lot of patients actually, with the hep C, I think really don't like going to the hospital much. I think they're a bit*

> *intimidated. Maybe they're a bit worried because they're going to be labelled as drug addicts or something.*

There was a perception that specialty clinics had limited appointments available for patients and that GPs were well placed to reach and engage PWHCV for DAA. Participants considered that general practice sites were easier to access for patients with HCV than hospital sites. Participants noted that patients were familiar and comfortable attending their general practice, and there was reduced wait time for appointments in this setting. Also, patients were not exposed to potential stigma involved with attending a specific disease clinic at a hospital.

During the interviews, there were also reports of consultations, where no ongoing relationships between individual GPs and patients existed and a similar sense of responsibility or opportunity to provide care was not present. Participants described many consultations in which the GP could not be described at the patient's regular GP and where there was unlikely to be an ongoing relationship with the GP.

> *a lot of people do have their GP that they see for complicated things and the GP that they see for less complicated.*

> *I was a registrar [during GP training] at that time …and then the only tragedy was we had to move on eventually.*

> *I don't actually know how many patients with hepatitis C, where it's known hepatitis C or it's a new diagnosis, how many of them would be you know they're seen the same day clinic doctor or whether they would have a usual GP.*

and

> *And the third barrier is us having doctors who have enough regular appointments, instead of same day appointments so they can actually plan a treatment schedule, because it would probably be you know a good six to eight months of regular appointments from start to finish because of all the blood test, discussion, results, imaging, discussion, results, initial treatment plan and making sure they stick to the treatment and are coming in for reviews and I could imaging that could take a good eight months. So, trust is big. If they don't trust the doctor they're seeing, then they're not probably going to come back.*

There were limitations noted to patient's access to continuity of care imposed by factors at the general practice level and within these limits patients were seen to balance timely engagement for acute issues and benefits of continuity of care. The lack of availability of GPs rostered for regular appointments compared to same day appointments, was viewed as one such structural barrier at the general practice level. Patients may accept engaging with different doctor when their usual doctor had no timely appointments, or they may choose to see different doctors based on the complexity of the issue for which they are seeking consultations. A long-term relationship is not possible when GP trainee registrars are posted for limited time rotations (generally six-month periods) (Bentley et al., 2019) during their GP training. As previously noted, it was felt that bulk-billing clinics did not operate based on providing continuity of care with one doctor, with affordability being the main basis for patients choosing these types of clinics. Where continuity of care was not present it was perceived that not all the healthcare needs of patients would be addressed by the GP involved in these consults. One participant indicated their perception that PWHCV were more likely to attend the 'same day clinic' rather than have an ongoing relationship with one GP. The participant perceived that appointments with one GP, would be necessary over a considerable length of time, for patients to engage and allow the GP to provide DAA.

A consideration for providing care was whether this care could be provided in an alternative way. One way that GPs dealt with providing patients with care outside of their expertise was to refer patients to other GPs who had the required interest, experience and proficiency.

> *… there were other people [medical practitioners] who had particular interests in other areas. It might be sports medicine; it might be musculoskeletal. [I'm] Always happy to send [a patient] to a colleague who's actually got an expertise in that area.*
>
> *They [GP colleagues] send them [patients with HCV] to me. It's like their Suboxone where people can do their five. You know, I said, 'Look, I'll get them started, stable, then you can do it' but I end up seeing them for it….I send chronic fatigue to [Name of doctor #3] and, hormones, all those; she does hormones in conjunction with the specialist…*
>
> *I haven't actually gone out and said 'I'm treating hep C' but I think they [GP practice colleagues] know that I'm indirectly probably dealing with it because of the methadone program.*
>
> *because I was working in the [Government work site] at the time that they would send all these type of people to me saying that, 'that you manage drug, alcohol, that sort of stuff'.*

GPs reported receiving referrals based on their known area of interest. For some GPs, there appeared to be an expectation that this was a reciprocal arrangement. Where most participants described this referral arrangement as being in the patients' interest, one GP implied their GP colleagues were avoiding providing care to some patients by transferring patients to them. The participant felt that their GP colleagues justified this transfer based on the patient having particular issues that matched the skill sets of the GP participant.

It was perceived by one participant that some GPs may still refer PWHCV to a specialist when they were not comfortable in prescribing DAA.

> *…some of the GPs more than others, would be more comfortable with going through the full assessment and initiating the therapy with that sort of like fax-back approval system. And so for others it would be like be just like 'Nah, I'm not really sure I'll be really comfortable managing this so I'm just going to refer to a visiting liver clinic.*

Referral was described as a way that GPs could achieve DAA for their patients when they were not willing to prescribe this treatment themselves.

The ability of GPs to meet patient' needs can change over time. GPs may examine the inclusion of care for HCV in their scope of practice based on the success of the new DAA and their ability to prescribe this treatment to their patients.

> *I started working with this [patients with HCV] group …since [Year – early 2000s] and I don't know when the Ribavirin came out. I think that's when we first started -no, we had some who were just on the interferon many years ago.*
>
> *I had one patient that I treated for hepatitis C before the new medications came in and then about a month after they finished treatment the medications came in. So, I've had the experience of having one person on the old, nasty stuff.*

and

> *…so that's why I got involved, because now it's a potential real cure.*
>
> *Of course they did [failed to achieve cure of HCV]. We didn't have any success here with the old treatment. We only had two but they both failed.*

> *…it wasn't really impressive.*

and

> *…one of the local specialists who had said 'No, just wait for the next generation to come through'.*

Whilst some GPs had provided care for PWHCV in the interferon-based treatment era, including directly providing or referral to treatment, negatives about the treatment were noted in terms of success rate and side effects. Some participants were reluctant to promote this treatment due to these negative aspects. One participant reported receiving advice from a specialist to delay interferon-based antiviral treatment for HCV until the new DAA became available, which further reinforced their negative view of prescribing treatment at the time. Several GP participants spoke about their interest and knowledge regarding treating HCV prior to the introduction of DAA with participants indicating that they became involved in prescribing this treatment when the ease, lack of side-effects and high rates of cure were demonstrated with the new DAAs.

Participants spoke about the decision of the Federal Government to allocate a high level of resources to the elimination of HCV, including the subsidisation of DAA, and how this healthcare system level decision impacted on their provision of DAA. There was a sense that this allocation of resources may be reconsidered at some time, and this provided an imperative for participants to be involved in prescribing DAA in their practice and to have as many patients with HCV, treated as soon as possible.

> *when I've been talking to people that have - coming through with their Hep C I basically said 'Look, the government has put aside a large amount of money to eradicate this disease and we want everybody in Australia to get treatment. It doesn't matter if you have got cirrhosis and your liver's cactus, we still want to get you treated'*

> *…the reason the governments doing it is to stop people getting liver cancer and they've done the number crunching and that's why they're doing it, not for the benefit of drug users. … I suppose that's why I am a little bit more proactive about it cause I've got this feeling the government will pull the plug one day.*

> *I mean with the incredible cost of it - and that's what I put on patients and they're kind of quite responsible with that, about how much. I say, 'You know, the government does actually like you sometimes'.*

> *.. the government's financing this, they'd want to know it's working or not so I'm sure they have to provide some data back to the government, to the feds. Cause the Feds are spending a lot of money. It's a shitload.*

Participants remarked on the large budget allocated to the provision of care for HCV as positive but surprising. Participants perceived that governments make decisions based on short-term goals that could be shown to have a positive affect within an election cycle, whilst the financial payback involved in DAA provision was likely to be long term and therefore not guaranteed to directly benefit the budget bottom line of the incumbent government. In addition, the targeted disease was associated with stigmatised IDU and participants suggested that funding was not usually spent on this population. Participants understood that governments would require evidence of positive outcomes to support their funding decision and that they could contribute by providing data regarding their patients' positive treatment outcomes.

#### 6.4.1.3 GPs' interests influencing their scope of practice

Participants described GPs' scope of practice, as reflecting the particular interests of the GPs. These special interests may involve providing care for specific conditions or particular subpopulations. Some participants described how particular interests developed.

> *I generally see – well I certainly see some methadone patients, chronic pain patients, mental health and older geriatric and the girls see a bit of that, but a lot of children as well, so we've got a bit of diversity, and [Name of GP #1] he's our older GP, he sees a lot of mental health as well. Then [Name of GP #2] the new doctor is seeing everything so it's quite a mixed practice, which is good, I think.*

> *I see a lot of 'geris' and I love geriatrics, but I've done an online course on dementia…*

> *… [GPs scope of practice] comes down to, to what you're seeing come through the door. Patients that see you; sometimes it's the patient body will self-select you, as opposed to the other way around, which is sometimes a good thing. Especially if it's around an area that you have a particular interest in. Word gets out that "Oh this doctor was really good at that sort of thing" and then, you start getting a pattern of people coming to you for similar issues.*

> *[the relative] died of hepatitis, many years ago [late 1970s] and [relative's gender pronoun] had non-A non-B back then.*

When there were multiple GPs working at a general practice, participants spoke of the area in which each GP's special interest(s), and how patients needing these services were matched to these GPs. This diversity of interest was viewed as a positive for the practice and for patients. One participant described the development of special interest on the basis that they were fond of a particular patient group and their enjoyment of providing care to this group. Working with these subpopulations was described as involving specific skill and knowledge sets. The interplay between interests and patient preference was discussed. Where participants had developed skills and had an interest, this interest could be reinforced when they developed a reputation at being good at providing this care. Interest in a particular area of special interest, may develop through their personal experience, with one participant describing their early interest in HCV developing in the context of a relative who had been affected (prior to HCV virus specifically being identified) and their relative's unsuccessful experience of early treatment at that time.

Participants described their decision to become involved in the special interest of providing care for HCV and being involved in prescribing OST, which involved addressing a need, beyond the usual general practice catchment area.

> *I'm thinking particularly in the boarding house where I do – two lots of boarding houses, I just sort of feel – well, I know there's some drug use there and I'm not sure how clean it is. I just feel there's probably things there that are hidden, for sure, but screening would be a; required...*
>
> *I used to do rounds for the homeless some years ago and that was just when the hep C treatment was sort of being talked about; it wasn't available, but I started screening then, …*

GP participants described homeless people in their community and residents of a local boarding house as populations who they felt were at elevated risk of HCV who would benefit from DAA. They expressed a desire to reach and help these populations by providing screening and treatment for HCV.

> *I was just looking for something a little bit different. I know it [OST prescribing] was an area of need and I knew – well, basically I knew that it wasn't overly popular.*

and

> *…there are some that do come a reasonable distance because it's difficult to get those doctors I think, that prescribe Methadone.*

Provision of OST treatment, in turn, led the participant to consider the provision of HCV treatment to be a high priority and to develop the associated special interest in the provision of DAA.

Participants described varying levels of agency in choosing their work situation and in matching their work to their interests or preferences.

> *…change that [working in current practice] to being under somebody else? I'd rather be my own boss than anybody else.*

> *I'm very fortunate that they've [general practice management] allowed me to say, 'This is what I feel I'm capable of working at, at the moment.' And they're letting me do it. I don't think you'd get that anywhere else.*

> *…most of them were foreign, international graduates and they were doing it because they had no other option. They couldn't move out from there, so they had to do their ten years moratorium which is a DWS [District of Workforce Shortage] clinic ….*

Most of the participants were experienced and established GPs, who indicated that they had a large degree of choice about the general practice they worked in and autonomy over their working life. Two participants who were early in their careers indicated that they had less autonomy, with one participant describing their general practice management as 'allowing' them to work part-time. One participant described other GPs who they felt had little choice as they were bonded to a bulk-billing clinic that restricted their practice to a district of workforce shortage (Australian Government - Department of Health, 2015a). In the participants' view, the bulk-billing clinic's business model was associated with walk-in appointments, where patients were allotted to the next available GP and the time limitations associated with short appointments. GPs in this situation were perceived to have little agency to influence which patients they treated and were restricted in the ability to provide holistic care or to develop their own areas of special interest.

### 6.4.2 Theme 2 - PWHCV as patients

The participants described patient' factors as part of their perceptions and experience regarding the provision of DAA. Generally, when talking about PWHCV, participants did not distinguish this group of patients from other patients, except in relation to the subthemes I identified of: 'Disclosure and stigma' 'Awareness and agency' and 'Capacity'. There was consensus that patient behaviour was affected by the potential for stigma associated with HCV. Factors described included patients' disclosure of status or risk factors, HCV status knowledge, and willingness and capacity to engage in treatment. There was a range of perceptions expressed by participants about these factors. Some participants expressed uncertainty about the thought processes and knowledge of their patients, regarding engagement in care for HCV.

#### 6.4.2.1 Patient disclosure and stigma

Reluctance to disclose HCV status and patients' concerns regarding stigma were described by participants.

> *People who live with hepatitis C, I mean their close; their relatives or friends would know, but outside that it's not something you'd talk about. … People talk about their breast cancer and their broken leg and everything known to mankind, and their heart attack and they show you their scars from their heart operation, they don't talk about hepatitis C.*

> *It all adds up to a stigma for these people, that makes it hard to find a GP so you don't tell the GP about your drug involvement or your hep C status or the fact that you're feeling crappy because you want to go along and get somebody to treat you for your cold, sore throat, or whatever, and if GPs don't ask then they're not going to be told.*

While participants perceived that PWHCV may disclose to people close to them, the limited disclosure of HCV was contrasted with the enthusiastic disclosure of other health issues. Participants described withholding disclosure of information regarding IDU or HCV status by patients, as a deliberate strategy to maintain access to healthcare for other issues, that PWHCV felt was at risk if they disclosed. Reluctance to disclose was believed to make the identification of risk factors more difficult as well as preventing patients from presenting for care for HCV, including for treatment.

One participant indicated that it was not always clear whether patients lacked knowledge regarding their HCV status or were reluctant to disclose their HCV status due to the risk of stigma.

> *...sometimes they'll [PWHCV] be a bit surprised or they might not show so much knowledge about it, or there might be a little bit of stigma, ….but I find that's been a bit less lately. They realise that there is quite a bit of it around, it's sort of an epidemic, and there's a very good treatment for it so I think that the – because there's a good treatment for it, the stigma has lessened because they know they can get rid of it…*

This participant felt that the reluctance to disclose had decreased among patients due to the promotion of DAA and PWHCV being aware of the prevalence of HCV in the population.

One participant described their perceptions of patients' behaviour being due to the patients' shame regarding their IDU.

> *Them [patients with HCV] having that, I guess sense of self shame over actually having used, IV [Intravenous] drug use if that's the source or, and then understanding that it is treatable and there are better treatment options available.*

Again, this participant perceived that this sense of shame may be addressed by the promotion of the availability of the new DAA.

The choice to disclose or not to disclose, is not pertinent where patients have no knowledge of a positive diagnosis of HCV, or recognition of having IDU as a risk factor for HCV. Participants described situations where the patient was unaware of their HCV positive status and the route of transmission of HCV was not attributed to IDU.

> *…he didn't know how he got it [HCV], cause he was never into drugs but he was a [occupation]…. He used to remember getting cut lots and even though they wore gloves,…*

The participant indicated that the patient had likely contracted HCV through occupational exposure.

#### 6.4.2.2 Patients' awareness and agency in regard to HCV and DAA

Participants expressed polarised views regarding the awareness and agency of patients with HCV.

> *…the newer treatments have become widespread knowledge about that and they [patients receiving OST treatment with HCV] were quite keen and then realised that the side effects were a lot less and the success rate a lot higher, so in that case they were keen to go ahead. ……Sometimes I said 'You've got it; we should treat it' but other times they were actually - more or less asked themselves [for DAA].*

> *I will ask and say, 'What's your Hep C status?' and generally they will say 'It's negative' or they'll say, 'Yeah, it's positive and I've had treatment and it's been cured' so they're pretty aware of what's going on.*

> *I would think that most GPs will actually do that [monitor patient's HCV], and the patients will prompt them, to an extent…*

> *So, people really don't know their [HCV] status, it's usually because they're very marginalised and vulnerable populations.*

Patients receiving OST were generally regarded as more likely to be informed and willing to enter treatment. Participants proposed that patients were usually aware of their status and would actively press for the provision of HCV care. One participant proposed that patients were unaware of their HCV status and that this was due to their perception that the HCV-affected people were limited to membership of marginalised and vulnerable populations.

As perceived by participants, patients were generally interested in receiving DAA but may delay the initiation and require follow-up by the GP to enter treatment.

> *…well, one of them who came in again yesterday I'd seen six months before and he said, 'Oh yeah, look, I want to do something about it now'.*

As previously noted, an ongoing relationship with a GP who promoted this care is beneficial to the facilitation of the provision of DAA for patients in this situation.

Some participants expressed their perception that some of their patient's knowledge regarding their HCV status and DAA was out of date, and that patients based their treatment decisions on the side-effects of former treatment regimes.

> *…they will say 'I'm a carrier and I don't need treatment'. They will say 'It's not active. I don't need to do anything' and that goes back to when it was like, 'Until your liver functions were three times normal we don't put you on treatment.*

> *I mean I'm actively, going along saying 'Well, basically this works. Your chances are it will work. No, it is not going to make you incredibly*

> *depressed. No, you're not going to have to do a whole lot of injecting and other stuff and you're not going to feel sick as if you've got the flu for 18 months. This actually works' and they still don't want to. The negative publicity from, 'It didn't work. I felt lousy. I felt suicidal'.*

These participants actively worked with patients to educate them and encouraged them to enter DAA as soon as possible.

Participant perceptions of the patient's level of literacy about HCV were variable, however there was was widespread knowledge amongst patients that HCV could cause death, and that DAA could provide a cure and therefore extend their lives.

> *There are a few of the hep C people who take an interest in it but basically most of them just accept that there's treatment and they want a cure.*

> *All the ones; the ones who've got hepatitis C, even the druggies, know that it can kill you. They don't actually know that half the hepatitis C will cure itself, just like any other viral disease. They do know if it goes on and on and on, they could die from it. That's why they want the treatment.*

It was agreed that high levels of literacy were not necessary for patients to engage in DAA and that this basic knowledge was perceived as key to motivating PWHCV to engage for DAA treatment.

#### 6.4.2.3 Patients' capacity to be involved in DAA

Whilst GP participants were confident about prescribing DAA, they identified individual patients with characteristics that made it difficult to involve the patient in this treatment.

> *So, I had a guy in [Northern Adelaide Suburb with low socio-economic status] who was ex-prisoner, so he was – but oh my God, like they are like so difficult to pin down. He'd bring his mum. His mum used to drive him to the clinic appointments and had spoken to the [Tertiary hospital #3] Hep C nurses so many times. He never followed through. I got him back again and then he'd be involved somewhere, back into drugs and that sort of stuff, so it became really – it was just to nail him. He was supposed to be home, but he was never at home and, so wasn't able to prescribe to him, no.*

> *I mean there's one guy there who is going to be difficult, you know, getting him to pick up anything from the pharmacy every day, but he's got a NGO [Non-Government Organisation] kind of worker who will see him at least twice a week. Then we get the pharmacy to do it as well, but he would be the only problem one there and that's his – I've seen him for 10, 15 years and it's just been the same the whole way.*

Even where patients were supported by the GP and other workers, the GPs described difficulty in ensuring that some patients attended appointments with the GP, or at pharmacies, to a level that was required to be 'worked up' and receive DAA.

### 6.4.3 Theme 3 - Doing the work

The theme of 'Doing the work' encompasses various aspects of providing care for patients with HCV. The subthemes I identified were 'HCV Training and information', 'Identifying patients with HCV' and 'Ongoing support to prescribe DAA'.

#### 6.4.3.1 HCV Training and information

Participants generally perceived doing the work of prescribing DAA as straightforward and demonstrated confidence in their involvement in this work.

> *No, it's just a script and blood tests and you can get them done anywhere.*

Participants described a variety of training, over time, and access to ongoing information, that provided them with the confidence to prescribe DAA.

> *I did an all-day Hep C, becoming a prescriber, and just what's come up on the all-day DASSA meetings. I went to one ….. It was for specialists and special nurses and I kind of invited myself along.*

> *Oh well I was interested, because I follow this, because I don't know I seemed to have about half a dozen of these people [GP colleagues] every now and again they just ask, "Anything new on the horizon." "No, not that I've heard of." And then I heard about this stuff [be]cause there was an advertising blurb, but I don't know how they got my email, I got the emails and they were coming to Adelaide with their road show, so I went to the Adelaide meeting.*

> *I did attend a session, a forum…What I really liked is they gave a really good booklet, reference book, …I think before I went there you were wondering how it's all going to work and your knowledge, would that be good enough? and that sort of thing, but I think they certainly furnish you with enough information to get going.*

GPs who had been involved in prescribing OST had attended training regarding HCV treatment, prior to the introduction of DAA. One of these GPs described a long involvement with prescribing treatment for HCV, including prior to the introduction to the DAA, and actively pursuing high level training regarding prescribing of DAA. Many GPs described a background of monitoring the effectiveness of treatment for HCV over time, and then consolidating their knowledge when the DAA became available through workshops targeted at GPs, which provided them with the required information to prescribe DAA. One GP described their initial doubts about prescribing and how attending the training and resources provided gave them the confidence to proceed. During two interviews participants expressed appreciation of the hard copy resource provided at the training session and referred to these resources that they kept in their consultation rooms.

While most participants had completed their GP training before HCV was included in the curriculum, one GP described how this was included in their training.

> *…we got it [DAA for HCV] covered during general practice training as a registrar, we had some sessions on that. Otherwise um, I haven't done any specific additional training in it. In part because I did a [name of rotation type] rotation when I was a student and so I already had a decent familiarity with hepatitis C and actually saw some of the non-liver-based complications and other features…*

This participant recounted various points during training where the topic of HCV was covered, that provided them with confidence regarding their ability to diagnose HCV and provide DAA.

In addition to this initial training, participants spoke about a variety of options of sources of knowledge about treatment for HCV with DAA that they had accessed or could be consulted if required.

> *Saw an article on this someone on this very subject about a week or two ago from somewhere in Australia…. online I just. It was on hepatitis C, treatment of hepatitis.*

> *…the Australasian Sexual Health Medicine workshops at the college. They offer; I think there's an online module as well.*

> *… the evidence he [Pharmaceutical industry representative] showed, so I have definitely used it actually because it – that was Epclusa® [HCV DAA medication] actually but it was – coming across as quite convincing and working, high results and all genotypes so, yeah, I suppose it did have an effect on my prescribing…*

Participants expressed awareness of recent published articles and specific online resources that could be accessed. They also cited pharmaceutical industry representatives as sources of information regarding HCV.

#### 6.4.3.2 Identifying patients with HCV

Participants described a range of approaches taken to identify patients with HCV who would then be assessed for DAA initiation. They described situations where patients had existing HCV diagnoses, as well as the specific screening strategies used to identify patients with undiagnosed HCV and regular investigations that had led to patients being diagnosed with HCV. Participants reported approaches that aimed to encourage the patient to disclose risk factors, such as IDU or to self-identify for HCV testing.

When the DAA became available, this prompted several participants to audit patient records to identify people within their practice with HCV, who were then offered this treatment.

> *Yeah, we just did a data search and identified everybody, checked whether they were clean or not. Those that weren't we sent them out information.*

The above-quoted participant indicated that this approach was successful in having patients enter treatment, but they did not provide any comment on patients' reactions to being identified in this way.

When making suggestions about reducing barriers to treatment, one GP criticised the capacity of the patient records management system they used for auditing their patients' HCV status.

> *...get Medical Director® [an electronic patient management system] to accept that when you put in 'Hep C PCR negative' it doesn't come up every time you do an audit to find out who's got Hep C because then you come up with a hundred patients….. I think they've even got 'Hep C carrier' on there as a diagnosis.*

The participant described options available that represented outdated concepts of people being 'carriers' of HCV and also criticised the lack of an option to indicate that patients had successfully cleared HCV. The term 'carrier' was used in describing a now discredited understanding that people could be infected and transmit HCV without having symptoms of the disease (Prieto et al., 1995). The inclusion of this term was viewed as having the potential to reinforce patients', and less informed doctors', incorrect understanding of HCV. Consequently, this misunderstanding may lead to PWHCV believing that their HCV was not likely to damage their health and decrease the imperative to enter treatment. The lack of the option to record the status of 'HCV cured' added to the complexity and time involved in auditing patient records for cases, and the participant emphasised that audits needed to be straightforward for GPs to view these audits as worthwhile to invest their time in.

Some participants described targeting particular populations within their practice for screening and investigation. All participants involved in OST prescribing indicated that they routinely investigated the HCV status of their OST patients, tested for HCV if the patient was undiagnosed and assessed the progression of the disease in those known to have chronic HCV.

> *…with the Methadone it's part of the …… seeing what the liver's like and everything else and looking for it.*

> *…there aren't that many I've had that are just really recently diagnosed. A lot of them have been diagnosed some time before.*

For patients being prescribed OST, the participants indicated that many had been receiving this OST treatment for a substantial length of time and that their HCV positive status had been established at the initial stages of this treatment, rather than being a recent diagnosis.

Where patients with a history of IDU were willing to be tested for HCV, the difficulty of collection of blood samples from some patients who had damaged veins from IDU was described by several participants.

> *They're [veins for taking blood] not there. People say 'Oh look, get it from my neck. I'll do it for you'.*

> *…sometimes almost no venous access at all, so just getting the blood is a challenge, probably the biggest challenge. Sometimes we had to just get an update on their genotype and their liver functions and obviously see if they had cirrhosis or not...*

and

> *…and even though they're really good - at collection centres they're very good but they [patients with vein damage] still don't want to go along because they've had bad experiences so they either want me to have a go or they'll do it themselves. And they're amazing, how they can do it themselves, …*

In addition to finding it difficult to obtain their patients' blood, one GP described how patients had bad experiences at blood collection centres. They suggested that one alternative was for patients to take their own blood.

Some participants described a stepped approach to identifying their patients with HCV. Promoting DAA first to people with clear risk factors, then to people with potential risk factors, before moving onto patients in whom risk factors may not be obvious.

> *like what the rep [pharmaceutical drug representative] was saying when the rep came in we've done the ones that are like 'in your face'. Then he said, "Now you take it to the next step and you try and get the ones that are a bit harder"* (Nurse)

> *We were fairly aggressive initially, basically IV [Intravenous] drug user bang "You'll have a test" I didn't put it that passionately but most of them; I don't think anybody, I can not think of one person who objected. So that was good. We're now; I'm now, sort of basically anybody with a tattoo no matter when it was done, gets done [screened for HCV]. It's a nice simple way of doing it.*

> *I just think it's the easy ones to treat are the ones are regular attenders here and it would be the Methadone patients.*

and

> *…well, certainly anyone that comes in for – I'm not saying every single person that comes in for a routine blood test but certainly if there's any – not suspicion but any feeling that there may be a possibility of hep C hidden, then I mean hopefully with the patient's consent you'll screen for it.*

One participant spoke of a pharmaceutical industry representative, that proposed strategies for identifying patients with HCV suitable for treatment. The participants demonstrated enthusiasm for screening their patient population for HCV, but also consideration of patient consent to the process.

Participants discussed approaches that would be successful in encouraging patients to disclose IDU and HCV status, as well as the importance of taking a comprehensive patient history and the use of patient data once collected.

> *My experience is it's [HCV diagnosis] never been something completely hidden because it's either been like flagged on their health record or something, but there's a sense with the interaction that this is not something that they really want to talk about, or there might be a sense of shame about having had it, and it's important to recognise that because it completely changes the interaction with the patient.*

As described by this participant, patients can demonstrate reluctance to engaging with them for care around their HCV despite being recorded as having a diagnosis of HCV on their general practice patient database, suggesting that this may be due to the patient's sense of shame. This quote also indicates that patients who have been diagnosed with HCV and have ongoing engagement with a general practice, but not receive DAA.

Participants discussed how they take patient histories in order to maximise the disclosure of the patient's drug use.

> *Always ask about smoking and alcohol consumption, and when you are asking about that, ……… always ask the age that they first started smoking or drinking because if they started smoking or drinking before they were 14 they probably grew up too fast ….That makes an easy slide over to 'Have you ever used any recreational drugs, injected, etcetera?' It's just part of absolutely routine questions if they haven't already told you and if they do say, 'Yes, I have used drugs' 'What age did it start? What have you done?' Very simple.*

> *I guess I ask mine [about HCV risk factors]. I don't have to – it's not a beating around the bush so it's just part of; sometimes you might not ask them literally but, when you do their smoking, their alcohol, other illicits, 'Are you at risk of? Do you inject? Do you have sex?'.*

One GP participant described teaching GP registrars to take a history, instructing them to start out with general routine questions and then, depending on the patient's response, asking follow-up questions to elicit further information. Another GP emphasised that they incorporated questions about IDU with other standard questions regarding smoking and alcohol. These GPs had extensive experience treating people with histories of IDU and perceived they had developed skills in sensitively exploring these topics with patients.

One GP described taking different approaches in patients who had previously consulted other doctors in the practice relative to patients who were new to the practice.

> *Now, I don't sort of delve into the past of the patients who've already been coming to the practice for a long time….. when they're new patients I do ask if they use drugs, any illicit drug use, and most of the time not really,…*

This GP indicated that the responsibility for taking this history rested with the patients' regular GP.

Participants described promotional material for HCV screening and/or the availability of DAA to patients.

> *In my room I've got the patient chair here so that's [HCV treatment poster] what they have to look at when they're sitting there. So, if there are any questions that they're; "Every have a tattoo?", "Did I travel?" this that and like there's all different questions and so they go through. And I've had a couple go, "Oh! Should I have a blood test? I've had a tattoo."* (Nurse)
>
> *I probably should add it [willingness to prescribe DAA for HCV] to my profile now that we have on the web page, …They'd be more comfortable, you know, coming along.*

Promotional material for HCV treatment, including posters and business cards, were prominently displayed at one general practice to encourage patients to self-identify as having risk factors and to ask to be tested for HCV. The participants indicated that patients had requested testing in response to the promotional material. One GP participant indicated that one way to elicit patient requests for treatment was to add this aspect of their scope of practice to their profile on the general practice's website. This participant indicated that patients new to their general practice had requested appointments with particular doctors at their practice based on the information on the website, and that this was an effective way to communicate a special interest to patients.

GP participants described two clinical situations where tests for HCV would routinely be considered by themselves or other doctors in their practice, without the doctors having any knowledge of the patients' known risk factors, such as IDU.

> *…women who get pregnant, they all get tested for it, so we find out then. And we've had the odd one that's come back positive ….. "Your positive for C. How did this happen?" because they don't tell you about it. "Ah I played around with my ex." Or something, or some bullshit in the past,…*

and

> *…there was a guy here that I thought was just drinking too much, and then he had a raised liver enzyme or two, and so did a hep screen and found out eventually, you now eventually do the: dot the I's and cross the T's and found he had hep C positive. Then he told me, he didn't tell anybody he used to play with injecting himself with heroin when he was in Adelaide, when he was twenty. That's how it is. They don't tell you.*

> *…you just often routinely ask [the patient] about hepatitis, when you get an abnormal liver function test result for an unknown reason. That's just automatic, like it's part of the liver disfunction work-up.*

> *…if somebody comes in with a vague feeling of tiredness you're going to do basic liver and electrolyte functions or your liver functions off 'Is there any reason why this should be so?' and that might be the first hint that somebody's actually got anything going.*

Participants reported that pregnant patients were tested routinely for HCV, and that HCV testing would be considered where unusual liver test results were returned and there was no known explanation for the results. The participants described the screening as routine and part of being a 'thorough' clinician. Participants described questioning their patients about the results leading to the patients, for the first time, disclosing past IDU, to them.

Several participants acknowledged that there was a cohort of PWHCV who would be difficult to identify as having risk factors and, therefore be difficult to either diagnose or recruit to DAA for their HCV.

> *Most of the ones [patients with HCV] we have they're middle-class, just ordinary people.*

> *…there's still a large cohort of undiagnosed out there so we need some way of being able to pick them up and then just letting people be aware that we are interested in and aware and able to treat Hepatitis C.*

The importance of patients being aware of the availability of an effective treatment available, and the existence of GPs willing to treat them, was emphasised by participants.

### 6.4.3.3 Prescribing DAA with support

Participants described the work of prescribing DAA and a range of factors that supported them in this work. After receiving initial training and identifying their patients with HCV, participants perceived that for the majority of patients, prescribing DAA was straightforward. Participants reported that assessing patients for cirrhosis, to determine whether the patient should be referred to a specialist service for treatment was the first step. Once this was established the work required determining and completing the fields of the remote consultation form, which summarised relevant patient clinical information and the GPs' treatment plan proposal. They described a range of resources that supported them in this work, which included the design and utility of the consultation form, viral hepatitis nursing support and GP-General Practice Nurse teamwork.

GPs spoke of the requirement to assess cirrhosis before deciding whether to prescribe treatment or refer the patient to a specialist, and about alternative ways of measuring this. Several participants talked about viral hepatitis nurses attending with portable Fibroscan® machines to access cirrhosis.

> *…the drug rep, has actually suggested that we can do scanning clinics, if we need to so obviously if we've got a group of people need to be; they [the Fibroscan] can be moved around rather than [patients] having to wait months; travel just to have a scan done.* (Nurse)

> *She [a viral hepatitis nurse] actually came out and did mobile ones, which was very handy for some of the – because I had trouble getting the patients to the hospital, to get that organised. Some of them are a little bit unreliable so it was pretty good to actually have that service.*

> *… they said [Viral Hepatitis Nurse], 'Well, if you can get ten people to come along, we'll come out and do it [Fibroscan®] at your rooms'.*

Several participants mentioned that they became aware of the viral hepatitis nurse services through pharmaceutical industry representatives. The provision of services within private general practice was seen to overcome patients' issues of access to hospital provided services. There were several mentions of VHNs providing Fibroscans® when there were several patients that could be scheduled at the same time at the GPs' practice. This requirement to schedule a number of patients was not perceived as a barrier by the participant.

When talking about the provision of Fibroscans® by the VHNs, one medical practitioner expressed appreciation of the nurses' extensive experience and expertise with patients with HCV.

> *I preferred that [HCV nurse reviewing treatment] to having them [the patient] going – having the Elastoscan and not having that person – another second person to kind of look, who sees lots and lots of people, to say 'Yeah, that's fine'.*

and

> *One of them [a patient undergoing DAA] I didn't even know was; halfway through the treatment, was ringing them [Viral Hepatitis Nurses] and asking questions.*

The nurses' involvement provided assurance about the care they provided to patients with HCV. The above-quoted participant also reported patients being helped through treatment with direct support from VHNs.

Participants described access to cirrhosis using transient elastography, as varying between suburban and country locations.

> *It's changed and that's made life a bit easier now……Basically with the clinic at [Name of Tertiary hospital] making it [portable Fibroscan] much more available down here, at both [Name of location of nearby regional health service #1] and [Name of location of nearby regional health service #2] ……. also recently, the private radiology firms have started doing fibro-scans and will bulk-bill.*

> *We don't do the elasticity thing or whatever you like to call it, the ultra-scan thing, because it's too hard for us to do it [at the rural location], so we do it on, fiddling around with the blood numbers, working out a number [APRI score] and so far the numbers have always been under the number that's required [to indicate cirrhosis], but if we got a higher number then we would; well I would refer them...*

One metropolitan-based participant described that access to the measurement of cirrhosis had become easier, with more locations of public services available in Adelaide metropolitan areas and private radiology services also providing this service - potentially at no cost to the patient via bulk-billing arrangements. A participant from a rural general practice described how they did not use transient elastography but relied on initial assessment with APRI scores on blood samples. If the value was indicative of cirrhosis, the patient was then referred to specialists in Adelaide. As mentioned in section 6.4.3.2, difficulties with vein access may be encountered during collection of blood samples required for HCV assessment and treatment.

The process and design of the remote consultation form supported participants to confidently prescribe DAA. The form included links to clinical tools, could be used a checklist for the required steps and was viewed as an efficient way to receive specialist feedback on treatment plans. Participants expressed awareness of the consultation form process and talked of the ability to have the specialist recommend a treatment regimen, even where they were not providing DAA.

> *So, I'm familiar with the resources for like, the forms that you can access to be like "I need to make sure that I've done all these things" and you fax it off and get a "Yep, this patient's clear to start. We recommend this treatment". [not active prescriber]*
>
> *The drug reps are coming around and sort of saying 'Ah, well, you can assess whether they've got problems or not by using this little check list and, yep, if you hit this button you can go ahead and do that that way'.*
>
> *…what I do and what I tell the guys here to do, we don't have a lot of hepatitis C …. you fill out the form, you know do all the blood tests, the categories whether it's one to six or whatever it is, do the quantitative RNA thing, you know blah, blah blah all that stuff and then send it off…*

One GP participant recounted how the remote consultation form was promoted by a pharmaceutical drug company representative as a checklist, as part of their promotion of the treatment. Another GP described the detailed learning from a course they attended but indicated that the process for prescribing the DAA was outlined and guided by the remote consultation form. They championed this approach to their colleagues.

The consultation form was a way to have the specialist unit confirm the participant's choice of the appropriate medication regimen or have alternative regimens suggested.

> *I think, [the specialists] may have suggested a – one of the newer ones [DAA for HCV] - a couple of times, yeah.*
>
> *If there's a new; there's new drugs seem to be coming out every year for this stuff, new combinations…..So why bother? [reviewing the guidelines]? These are the guys [the specialist unit staff] that know about it. Why would I*

> *want to know about it? If the treatment fails I'll go back to him, he can sort it out or that unit can sort it out.*

The ability to have the medication regimens checked was perceived as particularly important in an environment where the drug regimens were rapidly changing, in terms of formulation and duration of treatment. The specialist was viewed as having the ability, and responsibility, to be up to date with all aspects of HCV treatment, and the form allowed this information to be efficiently communicated to the prescribing doctor.

The work of providing DAA was described by most GP participants as something they did without any additional input from their general practice colleagues. However, one GP participant described that treatment of HCV in their general practice utilised a team approach that included the general practice nurses. The GP and nurses expressed the view that it was apt that their participation in the current research should involve an interview with all three team members.

> *…we look at the blood test, we converse a lot and we learn a lot from [Doctor's first name]. For what these; so we're learning a lot, a lot of our basic learning; well for me especially through [Doctor's first name] and that's what they said they couldn't believe that "What you do the bloods?" "You look at this. You do that?". "Well yes!"* (Nurse)

> *We are a small team, so we can do everything as a team. We don't have to pigeonhole each other and obviously we can easily communicate cause it's wandering between rooms and just; yeah, I think that makes a difference.*

The nurses had become aware that their level of involvement in the provision of DAA, was not common when they attended an educational event directed at maximising nurses' involvement in the provision of care for HCV. The team was proud of the work they did together, and the nurses found the work interesting and worthwhile, and expressed gratitude for the opportunity to learn from the GP.

## 6.5 Discussion

The aim of this study was to gain an understanding of the experiences and perceptions about the provision of DAA and from this understanding, make recommendations to increase the provision of best practice care for HCV, including DAA in private general practice in South Australia. Results were organised into major themes identified as '*Fitting*

*DAA into GPs' scope of practice*', '*Doing the work*' and '*PWHCV as patients/potential patients*' but there were links and crossovers between these themes, reflecting the complex adaptive nature of primary healthcare (Crabtree et al., 2011). The findings relating to experiences about the prescribing of DAA and perceptions of patients with HCV, extend knowledge gained in other similar Australian studies (Heard et al., 2019; Marshall et al., 2019; Pourmarzi, Smirnov, Hall, Thompson, et al., 2020; Richmond & Wallace, 2018). How the provision of DAA is considered within the wider context of GPs' work has not previously been reported. This finding leads to alternative ways of representing the problem of access to DAA and, thus, make alternative recommendations to address this problem.

### 6.5.1 Framing of the problem and underlying assumptions

To allow current interventions to be critiqued and further interventions to address the problem to be envisioned the 'What's the problem represented to be approach' of Bacchi (2016) suggests deconstructing the way that problems are represented, including determining the underlying assumptions involved.

When considering how to increase GPs' involvement in DAA prescribing, the 'problem' has been represented as "So why not do it" (Heard et al., 2019, p 1053). This implies an expectation that all GPs will do this work and that GPs need to justify opting out of provision of this treatment. All participants supported the promotion of DAA, the inclusion of DAA into the scope of practice of the profession of general practitioner and general practice as a site that could benefit patient access to this treatment. Nonetheless, participants also described not being involved in the prescribing of this treatment. Participants viewed the provision of DAA as an area of work that not all GPs would be involved in and described factors that would lead them to opt in to providing this treatment. GPs explained the inclusion of particular areas of work in their scope of practice, based on their perception of the prevalence of conditions in their patient population and using the concept of 'special interests'.

As part of analysing current interventions, it is important to examine and critique the underlying assumptions involved (Bacchi, 2016). Advice to people to see 'their' doctor or their 'usual' doctor to get DAA, is premised on the assumption that all patients have this type of relationship with a GP, from whom they can access this healthcare. Participants described such relationships with patients, where continuity of care was an outcome of this relationship and where DAA was provided. However, participants also described many consults between GP and patients where no such relationship existed. Additionally, where continuity of care existed this did not guarantee that DAA would be provided to all patients.

### 6.5.2 Providing care based on their patients' needs and the prevalence of conditions in this population

Participants indicated that their perception of the needs of their patients was a major consideration in prioritising the work they included in their scope of practice. Rather than the needs of the wider population, Foster et al. (2016) found that doctors felt "accountable to the patient within the consultation" (Foster et al., 2016, p 526). However, GP participants indicated that there were limits to their ability to address all health needs of every patient they interacted with. The ideal provision of care, envisaged as occurring in an isolated doctor-patient relationship where doctors "pursue the very best for each patient who needs it…" (Tudor Hart, 1971, p 410) was critiqued by Hart (1971) as ignoring the needs of other people and their claim on the doctor's time. The results align with this critique and show that GPs prioritise and balance the need of individual patients with the need of the whole of their patient population, in the context of ongoing relationships with these patients.

The determination of patient' needs was influenced by the perceived prevalence of conditions within their patient population, including HCV, with GPs more likely to include in their scope of practice the provision of care for conditions perceived as more prevalent. Previous studies investigating the provision of care for HIV have reported that provision of care was also less likely where there is a 'low caseload' of patients with HIV (Newman et al., 2015). While finding that GPs consider disease prevalence when deciding their scope of practice, this study did not seek to quantify the magnitude of prevalence that influenced GPs to provide care. Each GP may have their own threshold as to how many patients with HCV warranted them to consider that they would provide DAA. In previous studies, an introduction to providing OST treatment was due to exposure to one patient (Scarborough et al., 2011). The determination of HCV prevalence based on which the perceptions of Australian GPs in private general practice are formed may not be straightforward.

The findings suggest that GPs may underestimate the prevalence of the disease in their practice due to their limited awareness of the diversity of the population who may be affected by HCV. Whilst the transmission of HCV in Australia is predominately through IDU not all patients with HCV will have any history or IDU. Patients' IDU may have occurred decades earlier, may have been fleeting and patients would not necessarily identify as having an IDU history of any significance to disclose to a GP. The patient's IDU status is likely to remain undisclosed during consults with GPs, unless the patient was seeking treatment such as OST (Fry & Bates, 2011; Scarborough et al., 2017). Participants were unaware of the HCV status of their patients and their history of IDU until this had been revealed, for example by routine screening during pregnancy. There were individual participants who demonstrated a narrow view of who is affected by HCV such as "*marginalised and vulnerable populations"*. This view matches a stereotype of a person who injects drugs and excludes people whose drug use has not been a significant factor in shaping their lives (Spencer-Oatey, 2007). GPs with similar views may underestimate the prevalence of the condition amongst their patients. Even with exposure to people with a variety of lived experience in training (Rowland et al., 2018) and through promotion of HCV treatment (Cresswell, 2006; Willis, 2018), GPs may still not associate that significant numbers of their patients may be affected by HCV.

In conjunction with a software tool, audits of patients' health records (including HCV status and IDU risk factors) have been trialled to estimate the prevalence of HCV within a private general practice population with the aim of influencing the provision of DAA (Chidwick et al., 2018; Horwood et al., 2020). Participants varied in their perceptions of the usefulness of audits, with one participant confident that they had 'found' all cases of HCV in their practice but another participant expressing frustration with the use of audits due to limitations of practice software. While most practices use electronic health records software, the usefulness of audits is limited due to non-standardised terminology, data stored as 'free text' and gaps in record keeping (Chidwick et al., 2018; Kitsos et al., 2019; Youens et al., 2020). The reluctance of patients to disclose IDU risk factors and HCV status and to have these details recorded in their patient records (Fry & Bates, 2011; Scarborough et al., 2017) may exacerbate the issue of incomplete patient records compared to the situation for other conditions. Even where participants were OST prescribers and patients engaging with GPs for this treatment reveal IDU risk factors, this does not mean that these details would be recorded in their patient record. In Australia, HCV prevalence has been estimated at the PHN level (MacLachlan et al., 2019) but GPs may not feel that these estimates apply to their practice where estimates based on the patient or practice population would be most relevant to GPs' decision making. In part, this may explain why there has been limited impact on the provision of care from interventions aiming to raise the awareness of the prevalence of HCV (McLeod et al., 2017). Even when the process is supported by external agencies, conducting audits consume resources (Chidwick et al., 2018; Horwood et al., 2020) and general practices would need to be convinced of the benefits to prioritise these resources. Audits may detect patients with documented HCV status, but are unlikely to be routinely effective at providing data that would change GPs' perception of the prevalence of HCV in their practice population.

Rather than GPs' scope of practice being determined by 'their' patients, 'their' patients may be influenced by the scope of services on offer and the capacity of GPs to deliver specific services (Scarborough et al., 2017).GPs may have a perception of 'their' patients and patients may nominate a 'usual GP' and a 'usual general practice', however these relationships are not fixed and are loosely defined (Wright, 2019). The difficulty arises in part due to the 'dynamic complex adaptive system' (Crabtree et al., 2011, p 1) that forms the context for the provision of care by GPs in private practice in Australia. The lack of the requirement to be registered with a GP or general practice for Medicare rebates to be paid (Mossialos et al., 2017), contributes to the adaptive nature of the system. Within market limitations (Mu, De Abreu Lourenco, van Gool, & Hall, 2018), patients may engage with a particular general practice and/or a particular GP, depending on a complex range of factors including GP preference, affordability, distance and availability of appointments (Goodall et al., 2016; McGrail, Humphreys, & Ward, 2015; Ward, Humphreys, McGrail, Wakerman, & Chisholm, 2015). Patients may also visit more than one general practice to meet their healthcare needs, with one study finding that 25% of patients attend more than one general practice in a 12-month period (Wright, 2019). Patients with HCV may change their 'usual GP', with study participants describing patients who presented to them with an existing diagnosis of HCV. While it is not clear where or when these patients received their initial diagnosis, these patients may represent the significant number of who no longer receive care from the diagnosing GP, with these patients reported as 'lost to follow-up' (Aleman, Soderholm, Busch, Kovamees, & Duberg, 2020). Particular patients may be attracted to or discouraged by the way GPs tailor the services they offer, including tailoring the scope of practice they provide and by charging gap fees (De Abreu Lourenco et al., 2015; Magin et al., 2006).

GPs rely on their perceptions that the breadth of their scope of their practice is meeting their patients' healthcare needs. Participants in part based their perception in this regard on their ability to retain patients, evidenced by the success of their general practice business. For a general practice business to be successful in the market, general practices must attract and retain patients from the community they serve, and to some extent this requires patients to feel that their needs are fulfilled (Foster et al., 2016). In line with previous research (Gray et al., 2018; Hofer & McDonald, 2019; Jackson & Ball, 2018), participants emphasised the importance of continuity of care for the health of their patients, and GPs may actively discourage patients from attending more than one practice. Where patients access another GP practice for their health needs (Wright, 2019), their usual GP is not automatically notified, and patients may withhold this information to protect their relationship with their usual GP. Patients cannot be aware of all of their health needs and may continue to access a general practice where some, but not all of their healthcare needs are addressed. General practices may therefore retain patients and be profitable, without providing the breadth of scope of practice that meets their patients' needs. Financial profits of general practices may influence the scope of practice provided, by omitting the provision of services renumerated at a lower rate (Medicare Benefits Schedule Review Taskforce, 2018). There is evidence that the provision of DAA was generally considered to require long consults and unpaid time on paperwork, negatively impacting the potential income of individual GPs and the general practice they work in (McIsaac, Scott, & Kalb, 2019).

Providing care for their patients may include GPs referring patients to other medical practitioners. Participants described the use of referral as a strategy to have their patients' needs for DAA met, when they themselves do not provide the required care. Referral types may include referral to specialists, GP-to-GP referral within practices, or GP-to-GP referral to external practices. The traditional pathway for GPs to access antiviral treatment for their patients was to refer them to tertiary liver clinics (Australian Government - Department of

Health and Aged Care, 2000; Gidding et al., 2009) and participants indicated that colleagues would choose to refer patients to specialist clinics, rather than provide DAA themselves. Tertiary liver clinics in Australia do not necessarily have a standardised process for processing referrals (Wade et al., 2018). Where there is no clinical reason for the patient to be under the care of a specialist for DAA, rather than accepting the patient referral, the referring GP may be provided with information and supported to prescribe the treatment (Lee et al., 2018). There are reports of GPs prescribing after receiving this advice (Lee et al., 2018), but it is unclear whether these GPs worked in private practice or settings where the provision of DAA was incorporated into the services provided by the employing organisation. There is no guarantee that the referring GP would provide DAA for the patient when the specialist clinic did not accept a referral to provide this treatment. Thus, strategies to ensure that the patient is not left without an option to receive DAA are needed.

### 6.5.3 Special interests within the profession of General practice scope of practice

Participants described GPs providing DAA, not as something that every GP would do, but as care that a limited number of GPs would include in their scope of practice - an area of special interest. The term 'special interest' has a broad meaning in Australia (Wilkinson, Dick, & Askew, 2005) and is used to encompass: "…finding one area of practice particularly interesting, through to having postgraduate qualifications and expertise in a defined component of practice, and plenty in between." (Wilkinson et al., 2005, p 84). There has been an increase in the identification of GPs' involvement in areas of special interest within the profession of general practitioner in Australia (Jiwa, Ee, & Beilby, 2007; Spurling & Jackson, 2009; Wilkinson et al., 2005) and overseas (Marbeen, 2019; Yellamaty, Ball, Crossland, & Jackson, 2019). The term 'area of special interest' is applied to a broad range of topics, based on subpopulations, conditions, treatment approaches or procedures (Royal Australian College of General Practitioners, 2020b; Wilkinson et al., 2005). Some GPs work at sites offering a limited range of services, for example travel clinics, but the participants described special interests as part of their work in general practices where a broad range of services were offered. The term 'focused practice' is used in Canada (Marbeen, 2019) to discuss GPs' special interests and reflects this inclusivity of special interests within a GPs' broader scope of practice. Understanding GPs' concept of special interest is important because GPs use this concept to explain how their work is prioritised.

Participants indicated that they prioritised their area(s) of special interest within their scope of practice, as well as the professional development they participate in. Previous studies have found that GPs appreciate the variety involved in their work (Cubaka et al., 2019; Le Floch et al., 2016), but report difficulty in maintaining in-depth knowledge, appropriate skills and time to fully address all conditions that they may encounter (Piko, 2014). The ability of individual GPs to provide high quality care across the breadth of conditions they encounter in the various sub-populations in their practice, will be limited by time for education, exposure to patients requiring care and experience of providing this care to patients (Johnson et al., 2014; Newman et al., 2015). GP participants described how the development of skills and accumulated experience facilitated improvements in the effectiveness and efficiency of the provision of care within their special interests. Supporting previous findings (Spurling & Jackson, 2009), this subsequently increased the satisfaction of doing this work and provided reinforcement of involvement. Participants described special interests developing over time as part of their, and other GPs', scope of practice, and considered the provision of DAA as one such interest.

The decision to provide DAA as an area of special interest is largely based on GP perception. Participants described the process of prescribing DAA as straightforward, but still applied the concept of special interest to this work, based on the specific knowledge and skills required. This included having specific knowledge regarding the remote consult form process and understanding how to determine each of the fields in the form. While GPs can be awarded 'experienced prescriber' status (Haridy et al., 2018), recognition is not required to prescribe DAA if doing so 'in consultation' via the remote consultation form. Medicare rebates for consultations regarding HCV are available to all GPs, unlike other special interests may involve formal recognition (Australian Government - Department of Health, 2020g). The lack of knowledge and perception of HCV as a specialist area, have been reported as barriers to participation (Pourmarzi, Smirnov, Hall, Thompson, et al., 2020). However, participants described having ready access to a variety of information sources and specialist support, which gave them knowledge and a skill set to confidently initiate prescribing DAA. If GPs are willing to invest time and prioritise this area of work, GPs' perception of the provision of DAA as a specialist area (Pourmarzi, Smirnov, Hall, Thompson, et al., 2020) does not in itself prevent GPs from being involved.

In addition to specific skills and knowledge associated with the provision of DAA, participants also spoke of standard tasks in general practice that were carried out in a specific way, that complimented involvement in areas of special interest, for example the way that patient histories were taken. History taking is a core GP competency (Royal Australian College of General Practitioners, 2016) and addiction focused may be taught as part of undergraduate medical training (Silins, Conigrave, Rakvin, Dobbins, & Curry, 2007). However, the incomplete screening of a range of modifiable risk factors by Australian GPs, for example 78% of patients screened for smoking and 22% for alcohol (Denney-Wilson et al., 2010), indicates that this training may not translate to ongoing practice. One of the major limitations to the eradication of HCV in Australia is under-diagnosis (Scott et al., 2020), which is partly due to the reluctance of patients to disclose the risk factor of IDU to GPs (Fry & Bates, 2011; Scarborough et al., 2017). GPs lack of screening of risk factors (Denney-Wilson et al., 2010) is also likely to contribute to this under-diagnosis. The participants reported that they were conscientious in taking patient histories and described their perception of having a high level of skill in taking these histories that encouraged patients to disclose their drug and alcohol history, including IDU. These skills and the comprehensiveness of patient histories were not tested in this study, but further research is warranted into successful ways for GPs to encourage patients to disclose various risk factors and behaviours. If the detection of risk factors is effective, GP involvement in HCV care may be reinforced (McLeod et al., 2017). Involvement in one area of special interest may be associated with involvement in another related area of special interest where skills, knowledge or patient groups overlap. However, this association should not be assumed.

Special interests are associated with GPs working with particular subpopulations ranging from categories such as ‘women’ to ‘Indigenous Australians’ (Spurling & Jackson, 2009), but it is important to disrupt the association of the provision of DAA with the subpopulation of PWID. As discussed, most PWHCV in Australia have acquired the infection via IDU, however not all PWHCV have a history of IDU (The Kirby Institute, 2018a). Where individuals with HCV have a history of IDU, their perceptions of this can vary greatly (Hajarizadeh et al., 2017; Swan et al., 2010; White et al., 2014). Individuals’ IDU may be current or historic, may or may not involve addiction, may be central to their lives or not (Spencer-Oatey, 2007). The common perception of PWHCV, relayed by participants, was that their behaviour was influenced by HCV being a stigmatised condition and being associated with stereotypes of drug addicts, rather than all PWHCV conforming with this stereotype. While one participant equated PWHCV with current IDU, collectively the participants described heterogeneity amongst individuals affected by HCV in regard to IDU. Only associating HCV with current IDU involving addiction, may lead to GPs underdiagnosing this condition in their patients if individual patients do not conform with the stereotype of this type of IDU. If GPs are uncomfortable with IDU then they may avoid involvement with any aspect of HCV care.

GPs may experience difficulty managing GP colleagues' expectations of expertise based on their special interest (Scarborough et al., 2011). One participant indicated that, rather than using referral as a strategy to benefit the patient, GP colleagues had used referral as a way of avoiding providing care to particular patients. It was not clear whether the avoidance of some 'types' of patients was a form of discrimination, based on a misunderstanding of the expertise or interest of the participant, a way of maximising income or a general shirking of work by the colleagues. Whatever the intentions of the referring GP, or how the GP receiving the referral views this referral, patient factors can affect referral outcomes. The perceptions formed by the patient may depend on their relationship with the referring GP, the relationship they form with the alternative GP or specialist, and the level of involvement they have been afforded in their own care under this arrangement (Perry, 2005). GPs may be willing to be involved in one area of special interest but want to avoid additional unwanted referrals and expectations.

For patients receiving OST who have HCV, there is a need to question the assumption that treatment will and should be provided by the GP who is providing their OST, noting that these patients may also have a 'usual' GP that they engage with. OST prescribers have been targeted for involvement in HCV education and care provision, including DAA (Litwin et al., 2019; Marshall et al., 2019) and provide this treatment at a higher rate than non-OST prescribers (Wade et al., 2018). Supporting previous findings (Marshall et al., 2019), participants who prescribed OST described how the provision of a range of care for HCV was incorporated into their provision of OST. In both studies, this finding could be due to participant selection bias towards participants who were OST prescribers with a special interest in provision of care for HCV, and also OST prescribers with a high caseload of patients requiring OST and DAA (Marshall et al., 2019). GPs providing OST have reported unwanted pressure to be experts in a wide range of conditions that other GPs associate with their special interest in OST (Scarborough et al., 2011). Most OST prescribers in South Australia hold fewer than five OST authorities (Australian Government - Australian Institute of Health and Welfare, 2018). As for most areas of work, GPs would become more efficient at prescribing DAA the higher their caseloads (Lambert et al., 2011). Training to become proficient at prescribing would be the same for one patient as for many, and prescribing experience would consolidate this knowledge. Even if the prevalence of HCV is high in their patients, the overall number of patients with HCV may be below the prevalence that would trigger a GP to prioritise this work. Recognising that OST prescribers may not have the capacity or interest to include DAA in their scope of work, alternative ways for these patients to receive DAA need to be provided.

Understanding the pathways by which GPs develop special interests may signpost points where interventions could be directed to promote involvement in DAA, and interventions may not be effective. Exposure during GP registrar training has been recommended to support involvement in particular areas of special interest including drug and alcohol (Bentley et al., 2019; Jansen C, Grinzi P, Monheit B, & Parker R, 2005; Martin, Laurence, Black, & Mugford, 2007). Analysis of the experience of Australian GP trainees found that clinical exposure to HCV care was limited, screening for HCV was misdirected and that further training was needed for GP trainees to develop the appropriate knowledge and skills (Davis et al., 2017). One participant described learning about HCV during a rotation as part of their GP training, as well as exposure during undergraduate training, and expressed confidence in prescribing DAA. This participant however was not currently involved in providing this care. While early exposure to areas of special interest may have an impact on participation in the provision of care in these topics, this impact may not be expressed until GPs progress in their career or other facilitators of involvement are in place.

The involvement in areas of special interest may be linked to the career trajectories of GPs (Piko, 2014; Piko & Phillips, 2010) with involvement associated with GPs ownership in their general practice, and the GPs’ age, which generally correlates with GP’ experience (Johnson et al., 2014). Experienced GPs and/or those having a form of ownership in their general practice business, may provide GPs with more agency to decide their scope of practice. In addition to the control that ownership conveys, the financial imperative may be reduced for experienced GPs and those with ownership in their practice, as both these factors are associated with higher earnings (Cheng et al., 2010). Changes to Medicare rebates have been proposed to remove the disincentives for longer consults (Cheng et al., 2010) and compensate GPs' time for work that does not involve face-to-face patient consults. Participants indicated that more experienced GPs had generally developed skills and knowledge that allowed them to be more efficient during consults. Experienced GPs were considered to be more likely to have a stable patient base, where a therapeutic relationship had been developed and tasks such as taking their patient's histories had been undertaken, freeing up time to extend their scope of practice. They are likely to have honed their skills in particular areas of work, find involvement in special interests intellectually challenging and have exposure to patients who they identify as having a need for the care involved in their special interest (Piko, 2014; Piko & Phillips, 2010). It is therefore more likely that more experienced GPs, with a form of ownership in their general practice, may be more successfully targeted to become involve in DAA.

Once developed, GPs can promote their special interest to facilitate engagement of people in need of specific areas of care (Wilkinson et al., 2005), but promoting the provision of DAA involves additional considerations. Patients have indicated they would be deterred from continuing to attend their general practice if they were aware of the provision of particular areas of care at their general practice, for example mental health (Magin et al., 2012) or OST (Holliday et al., 2012). As patients were unaware that they were already attending a practice that provided this care, indicates patients' responses were due to their own stigmatising attitude towards these groups rather than direct experience with them (Holliday et al., 2012). Whatever the basis of the patients' response, openly promoting DAA may negatively impact GPs engagement with existing patients if a substantial number of the existing patients associated DAA with IDU and disengaged with the GP or practice. GPs may consider their existing patient base, who they feel a responsibility to provide with continuity of care, and the impact on these patients when deciding whether or how to promote the provision of DAA treatment.

### 6.5.4 Supporting GPs to prescribe DAA

Participants reported that the work of prescribing DAA was relatively straight forward and that they felt well supported in this work. Rather than indicating major new interventions, the findings underscore the importance of continuation of current training and resources.

GPs lack of skills and knowledge is often proposed as a factor for lack of involvement in particular areas of work (Deed et al., 2016; Le et al., 2017; Mason et al., 2020) and this barrier has specifically been proposed in regard to the provision of DAA (Heard et al., 2019; Richmond & Wallace, 2018). Participants reported having access to a large variety of what they perceived as quality education regarding the prescribing of DAA, in a range of formats. The participants did not report any barriers to accessing this education and reported confidence in prescribing DAA after participation in training. ASHM is a major provider of HCV education and GPs have accessed this education since GPs were granted prescribing rights for DAA in 2016 (ASHM, 2017, 2018, 2019a). There was a range of views expressed by participants as to the preferred format for CME in general. The HCV education offered by ASHM is provided in a number of formats, including face-to-face workshops (subject to COVID-19 restrictions) in each state and via online courses (ASHM, 2020a), which would match the range of GP preferences. As education appears to be readily available, the problem can be reframed from ‘a lack of knowledge and skills’ to ‘a lack of prioritisation of involvement in CME on this topic’. It is difficult to get an understanding of how participation in regard to HCV, fits with the overall involvement of GPs in CME, as Australian GP colleges responsible for certifying GPs’ participation in CME, do not publish the data they hold in this regard (personal communication). Provision of more education will not be effective in increasing the provision of DAA unless GPs are convinced to prioritise this education above other CME.

GPs may find it overwhelming to maintain knowledge on topics undergoing continual change (Davis, Perrier, Ciurea, & Flanagan, 2004). Given that DAA is continually evolving, this could act as a disincentive to GPs attending CME and to including DAA in their scope of practice. Participants emphasised that the consultation form process allowed for review of their assessments and treatment plans by staff at specialist liver clinics. These specialists were perceived as having the opportunity and responsibility to have the most recent, in-depth knowledge and that the consultation form was an efficient way for this knowledge to be inputted into the GPs’ DAA planning. This process was perceived as straightforward and could be used as a model for consultation processes between specialists and GPs for other healthcare needs.

It has been suggested that inclusion of GPNs in a wide range of areas of care should be considered more widely (Halcomb & Ashley, 2019). This study provided an example of the inclusion of general practice nurses (GPN) in the diagnosis and provision of care for HCV. Both GPs and nurses perceived their involvement as having positive outcomes. The current study did not evaluate outcomes of GPN involvement, but a variety of benefits of their inclusion in patient care have been found elsewhere in Australia (Hills, Hills, Robinson, Northam, & Hungerford, 2019; Norful, Martsolf, de Jacq, & Poghosyan, 2017). Patient care provided by GPNs’ include clinical and administrative tasks, such as patient education, health assessments, point of care testing and coordination of care (McInnes, 2017; Norful et al., 2017). This work can supplement or replace care provided by GPs’ providing benefits for the patient, GP and general practice. The therapeutic relationship formed between patients and GPNs is valued by patients, who perceive that GPNs are less time restricted than GPs and appreciate the education that GPNs can provide (Young, Eley, Patterson, & Turner, 2016).

The job satisfaction of practice nurse is maximised when they feel that their full scope of practice is utilised, they spend time interacting with patients, their role is appreciated and they feel part a team (Halcomb & Ashley, 2017, 2019; Phillips et al., 2009). Practice nurse participants perceived their role was enhanced in this way during their involvement in care for PWHCV. The Australian Federal Government’s Practice Nurse Incentive Program (Australian Government - Department of Health, 2019d) incentivises increased utilisation of GPNs and further reforms to achieve this aim have also been recommended (Medicare Benefits Schedule Review Taskforce, 2018). However, this may not lead to increased involvement of GPNs in the provision of care for HCV. The nurse participants expressed the view that their level of involvement in providing HCV care was unusual and was facilitated by the individual GP they worked with, who also provided clinical education and guidance for this work. GPNs’ do not generally have the agency to independently define their role and tasks in general practices (Fuller et al., 2015). To increase the utilisation of GPNs for care of patients with HCV would require GPs and practice management staff to be convinced of the benefits of this involvement.

Viral Hepatitis Nurses (VHNs) are a resource for GPs and patients (Government of South Australia - SA Health, 2017, 2019; Lee et al., 2018; White et al., 2019) and VHNs' input was appreciated widely by the participants. VHNs provided the participants with confidence in the provision of care by providing information and a second opinion, even when the GP was an experienced DAA prescriber. Fibroscans® were provided for free by the VHNs at the GPs' practices and were perceived as of great benefit. The service was regarded as convenient to the patient and nullified the need for blood samples to be taken, which can be problematic if patients have damaged veins (Madden et al., 2018). Participants indicated that there was an expectation that patients would be scheduled in a block to receive the Fibroscan® to increase the efficiency of the VHNs visit, but this was not perceived as a problem by the participants. There is also an opportunity for the VHN and patients to form therapeutic relationships, which can provide further benefit to the patient by providing an additional source of information and support nurses with specialist knowledge and skills (Lobo et al., 2015). VHN involvement also provides patients with a sense of being looked after by a team rather than an individual GP.

### 6.5.5 Limitations

As with other similar studies the number of participants in this study was small (Heard et al., 2019; Pourmarzi, Smirnov, Hall, Thompson, et al., 2020). In common with other researchers (Jones et al., 2012; McKenzie et al., 2015; Parkinson et al., 2015; Sahin et al., 2014) and despite a variety of recruitment strategies, I encountered difficulties in recruiting time-poor GPs to be involved the study which required participation in interviews. With the sample size obtained, it was nonetheless possible to derive themes from the interview transcript data, that added to the body of knowledge and that were valuable to answering my research questions. Semi-structured interviews were particularly suited to the exploratory nature of the research into the new role of GPs prescribing treatment for HCV, triggered by with the availability of new DAA. The flexibility of this method allowed in-depth and iterative exploration of topics, within and between interviews. The interviews provided rich data and the sample size allowed thematic analysis to explore the "complexity and nuance" (Braun & Clarke, 2016, p 742) of this data.

To a large extent I was able to fulfill my initial purposive sampling strategy (See section 3.6.5). During the analysis of the data, I became aware of additional factors that added to the diversity of the profession of general practitioner, which highlighted other factors that should be explored in future studies. A notable finding of this study was the varying agency of GPs to decide their work. Future studies are warranted into the effect on GPs' agency of the various ownership structures of the general practices in Australia (Erny-Albrecht & Bywood, 2016). GPs who are International Medical Graduates are a group of GPs whose perceptions and experiences may also provide valuable insight into the provision of care for HCV. It would be of interest to contrast their experience and perceptions with Australian GP graduates, especially during their mandatory moratorium period, and when working in areas of workforce shortage. Additionally, the findings of this study may be further tested using methods, for example surveys, which are less time consuming for participants, and therefore more likely to attract participation by time-poor GPs.

Prior to participation in this study, some of the participants and I had existing work relationships, and this aspect was included in the study ethics application. While this form of 'insider research' is not necessarily problematic (Heslop, Burns, & Lobo, 2018) caution was exercised to minimise any possible issues. I feel the relationships developed prior to the interviews aided recruitment and facilitated the rapport required for the interview process. The participants were made aware that my role as researcher was separate to my work role. Participants were reminded that their participation was completely voluntary and their choice to participate (or not), did not affect interactions with me or the organisation who employs me (Heslop et al., 2018; McDermid et al., 2014). I took additional measures to ensure that common understandings were articulated during the interview, to allow these explanations to form part of the data analysed, for example clarifying the meaning of commonly used terms around IDU. I used reflective practice throughout the research process to check on my behaviour and consider the impact of the research on participants.

## 6.6 Chapter summary

The main finding of this study is that GPs do not consider the provision of DAA treatment in isolation but rather as part of the consideration of their overall scope of practice. These findings are important as GPs may not include the provision of DAA in their scope of practice despite being impressed by the ability of DAA to cure HCV and wanting patients with HCV to receive this cure. GPs can agree that DAA fits within the scope of practice of the profession of general practice, understand patient' benefits of receiving this treatment in the general practice setting and still not be involved in prescribing this treatment. Heard et. al ask: 'So why not do it'. The answer lies in not examining the provision of care for DAA in isolation; but examining how the provision of this care fits within the determination of the scope of practice of individual GPs. The boundaries of the scope of practice for the profession of general practitioner are broad and there is a depth of knowledge that GPs can utilise in their work. There are limits to the ability of individual GPs to cover the full scope of practice available to their profession. GPs shape their individual scope of practice within the vast scope available.

GP participants described their scope of practice in terms of prioritising inclusion of work based on the prevalence of conditions in their patient population. The prevalence of a condition within a GPs' population that would trigger involvement appears arbitrary. Rather than prevalence, GPs' perception of the prevalence of conditions is what influences the inclusion of particular areas of work in their scope of practice. GPs' patient populations are fluid and the prevalence of specific conditions is difficult for GPs to correctly determine. There are barriers to changing GPs perception of prevalence and other factors influence GPs' decisions.

GP participants considered that the provision of DAA as a 'special interest' and used the concept of special interests to explain how particular areas of work are included or excluded from their scope of practice. The classification of DAA provision as a special interest by GPs is based on the specific knowledge and skills involved. These include both standard tasks done in a specific way, and knowledge and skills specific to DAA. GPs' efficiency in providing an area of special interest, increases with experience. Special interests develop, and are reinforced, overtime and can be linked to their career trajectory. GPs choose involvement in particular special interests based on a set of complex factors including the prevalence of conditions in their patient population, their interests and the fit with the business model of their general practice. One area of special interest may be linked to another area of special interest, but this should not be assumed. Expectations formed by GPs' colleagues, based on GPs' involvement in particular special interests, may need to be managed.

GPs described challenges to identifying some patients with HCV risk factors and/or an existing diagnosis of HCV due to the patient's reluctance to disclose. Successful practices and techniques to elicit patient disclosure and patient histories, relevant to HCV, were described. Practice management software may not always be effective for identifying patients who would benefit from engagement with care for their HCV. Once patients are identified as having HCV, barriers can exist to patients engaging in this care. GPs perceived one barrier is that patients can lack understanding of HCV sequelae and DAA options. GPs described difficulty in establishing whether patients were displaying agency in their decision to not enter treatment, or if other factors were preventing the patient from doing so. Individual patient' characteristics that limited their engagement with care in general, were cited as barriers to patients successfully engaging in DAA.

When GPs decided to include the provision of DAA in their scope of work, they describe this work as relatively straightforward and rewarding. High quality education and clinical guides were available for GPs that provided GPs with confidence to initiate prescribing this treatment. Practice nurses involved in screening and other areas of care for HCV, found this professionally fulfilling and taking a 'practice team approach' to the provision of DAA was viewed as a worthwhile strategy. GPs valued the range of support available from Viral Hepatitis Nurses and in particular the provision of Fibroscan® services to assess fibrosis. The use of APRI scores was described to assess fibrosis where access to Fibroscan® services was limited. The remote consultation form was viewed as a valuable tool that facilitated review and input from specialist staff at tertiary liver clinics in an efficient manner.

# CHAPTER 7.
# *RECOMMENDATIONS GENERATED FROM THE SYNTHESIS OF STUDY FINDINGS*

## 7.1 Introduction

In this chapter I will present recommendations that aim to enable increased provision of best practice care for PWHCV by GPs in private general practice. These recommendations are derived from a synthesis of the findings of the three studies conducted.

Radical positive changes have occurred to the antiviral treatments available for HCV, since the first two studies were conducted (The Kirby Institute, 2018b). There has been a remarkable improvement to the prospects of people with HCV being cured, without having to endure significant side effects associated with previous interferon-based treatments (Treloar et al., 2015). Elimination of HCV in the population is now a possibility (Kwon et al., 2018). While this change has occurred, other aspects of the context of the provision of care for HCV have remained stable. The Australian healthcare system component (the focus of *Study 1*) has remained largely unchanged. While some reform has been mooted, there have been no fundamental changes that affect GPs working in private general practice (the focus of *Study 3*) (Swerissen & Duckett, 2018). While the clinical prognosis of HCV has improved, the social diagnosis (Richmond et al., 2004) remains unchanged. Use of a range of recreational drugs remains illegal in Australia (Australian Government - Department of Health, 2019b) and negative stereotypes are associated with people with history of IDU (Broady et al., 2020). People diagnosed with HCV (the focus of *Study 2*), may face stigma due to the association of HCV with IDU (Broady et al., 2020). The findings of my studies and the interventions determined from these findings are therefore relevant to the current context.

## 7.2 Research question

This chapter will consider the findings of the each of the individual studies conducted as part of this PhD to answer the following research question:

4. What interventions will enable the provision of best practice care for PWHCV by GPs in private general practice?

## 7.3 Publication history

This chapter includes materials from the following publications:

> Scarborough, J., Eliott, J., Miller, E. R., & Aylward, P. (2015). Equity in primary health care delivery: an examination of the cohesiveness of strategies relating to the primary healthcare system, the health workforce and hepatitis C. Australian Health Review, 39(2), 175-182. doi:10.1071/ah14073
>
> Scarborough, J., Miller, E. R., Aylward, P., & Eliott, J. (2017). 'Sussing that doctor out.' Experiences and perspectives of people affected by hepatitis C regarding engagement with private general practitioners in South Australia: a qualitative study. BMC family practice, 18(1), 97. doi:10.1186/s12875-017-0669-2
>
> Scarborough, J., Eliott, J., Miller, E. R., & Aylward, P. (2015). Care Provided for hepatitis C: congruence between patient self-identity and stereotypes applied by general practitioners (GPs). Paper presented at the International Symposium on Hepatitis Care in Substance Users, Sydney, Australia. https://na.eventscloud.com/file_uploads/fb78da73072daf0596a54cc4434ea534_JaneScarborough.pdf

The suggested interventions from these publications have been refined to match the current context. Refinement to the suggestions were also made based on the synthesis and analysis of the combined findings.

## 7.4 Summary of findings

This thesis provides an in-depth understanding of GP-patient relationship in the Australian context from studies that focused on the 'healthcare system' (*Study 1*), 'patient' (*Study 2*) and 'GP' (*Study 3*) system components individually, and the interactions between these.

Setting the background to these studies, the review of the literature highlighted that a great deal of choice and flexibility is afforded to GPs working in private practice in Australia and their patients. At a healthcare system level, there is no mechanism or requirement for patients to be registered with a GP (Mossialos et al., 2017). Patients have choice about which GP(s) they access, whether to access more than one general practice, what issues they seek care for and discretion about what information they share with GPs. There is no requirement for private general practices to provide a specific suite of services, or to provide services to a defined patient population. GPs have discretion about who they provide services to and have a number of mechanisms available to influence the patients who access their practice (Magin et al., 2006). The scope of work that falls under the profession of general practitioner is vast (Britt, Miller, Bayram, et al., 2016) and GPs may place limits on their individual scope of practice (Britt, Miller, Bayram, et al., 2016). During the GP-patient consultation, a range of both GP and patient factors will determine what is addressed during the consult, what is addressed overtime and the quality of the care provided (Agledahl et al., 2011; Elshaug et al., 2012; Runciman et al., 2012; Stuart et al., 2019; Taylor et al., 2013). These factors can influence the identification of risk factors for HCV and patient engagement throughout the phases of the cascade of care required for DAA to be delivered.

The healthcare system context of the provision of care for HCV was the focus of *Study 1*. The three policies that were included in the document analysis were: *Third National Hepatitis C Strategy 2010–2013* (Australian Government - Department of Health and Ageing, 2010b), (the *HCV Strategy*), *Building a 21st Century Primary Health Care System* (Australian Government - Department of Health and Ageing, 2010a), (the *Primary Healthcare System Strategy*) and the *National health workforce innovation and reform strategic framework for action 2011-2015* (Health Workforce Australia, 2011), (the *Health Workforce Strategy*). These policies each placed GPs at the forefront of the provision of primary healthcare and included aims of achieving equitable access to this healthcare for Australian citizens. The way to provide access to the required primary healthcare was framed around ensuring that there was an adequate number of skilled and trained GPs available to provide care, which I critiqued. While the broad documents provided suggestions that could aid the provision of DAA, the lack of coherence diminished the influence of each policy to address equitable access to healthcare for PWHCV.

Semi-structured interviews were thematically analysed in *Study 2* and *Study 3*, respectively examining the experiences and perspectives of people affected by HCV, regarding engagement for HCV care (N=22), and the experiences and perspectives of GPs with the provision of this care (N-=9). Decisions about engagement and disclosure to GPs were made by PWHCV by weighing up their perceptions of the potential risks and potential benefits. Potential risks included risk to the confidentiality of sensitive information, risk to usual care and risk of exposure to discrimination. For PWHCV the perception of benefit would only occur if the GP was capable of providing an appropriate level of care and this was not assumed for all GPs. GPs described limits to their scope of practice and that inclusion of prescribing DAA was not automatic. The perceived prevalence of conditions within their patient population influenced GPs' scope of practice. GPs considered the provision of DAA as a 'special interest'. GPs that provided DAA felt confident and supported to provide this care.

The overall conclusion is that GPs will not automatically provide care for HCV to 'their' patients and PWHCV will not always engage with 'their' GP for this care. While the profession of general practitioners is appropriate to provide DAA, not all GPs will choose to include this care in their scope of practice. Australian PWHCV also have choice about their engagement with individual GPs and about disclosure of HCV. Suggested recommendations drawn from these studies are provided below.

## 7.5 Generate cohesion between the HCV strategy and other policy documents

Findings from *Study 1* show that opportunities exist to improve cohesion between HCV strategies and other policies to enhance equity and access to primary healthcare for people with HCV. The HCV strategy should have interconnection with future national primary healthcare strategies policies.

**Recommendation 1.** **Identify broad policy documents which may affect equity and access to primary healthcare for people with HCV and advocate to align policy aims, reference appropriate need assessment approaches and clarify actions that achieve equity and access to healthcare for people with HCV.**

Peak HCV organisations, such as Hepatitis Australia, who are frequently involved in the formation of the HCV strategy (Australian Government - Department of Health, 2018b; Australian Government - Department of Health and Ageing, 2010b, 2014), are well placed to identify other policies that should be explicitly linked. Peak HCV organisations should advocate for input into the development of broad healthcare documents, to enable features within these broad documents to be cross-referenced within the HCV strategy. The HCV strategy would then provide detail of how the aims, need assessment approaches and actions in the broad healthcare documents can be applied to the provision of healthcare for PWHCV. Where priority groups have been identified in the broader healthcare policies, these broad documents can be constructed to allow for cross-referencing of actions that would benefit the provision of healthcare for a wider range of diseases and specific populations. Other disease specific organisations may also advocate for this type of change to achieve improved healthcare for their constituents, for example, Asthma Australia (Asthma Australia, 2020) and Asbestos Disease Support Society (Silicosis Support Network, 2020).

## 7.6 Promote GP-to-GP referral

A finding of *Study 3* was that GP-to-GP referral is commonly considered as a way for their patients to access care when the required care is outside of GPs' scope of practice.

**Recommendation 2. Promote and facilitate GP-GP referral to enable the provision of HCV care including DAA treatment.**

GPs should consider GP-to-GP referrals for the provision of DAA for their patients where they are not willing to provide this care. The GP-to-GP referrals reported in *Study 3* were generally between GPs within the same general practice. However, GP-to-GP referral, external to the GPs general practice, has been promoted, for example to increase access to intrauterine contraception (Bell, Harvey, Mack, Lambert, & Dean, 2019). GPs' may be reluctant to refer in this way due to GPs' ethos of maintaining continuity of care for their patients, which also supports the business model of general practice. However, DAA treatment can be completed within a short time frame (Baker et al., 2019; Hepatitis C Virus Infection Consensus Statement Working Group, 2020) and does not require patients to transfer permanently to another GP. Further studies should be conducted that investigate whether GPs may be more willing to investigate HCV if they can subsequently provide a pathway of care for their patients to DAA under this arrangement.

## 7.7 Develop a register of GPs with a special interest in HCV

GPs are well positioned to provide DAA to patients and *Studies 2* and *3* both included positive reports of GPs who were willing and capable to provide a high level of care for PWHCV including DAA. *Study 3* found that these GPs may be regarded as having a 'special interest' in HCV care including DAA. These GPs provided care, acknowledging the effect on patients of both the medical and the social diagnosis of HCV (Richmond et al., 2004). *Study 2* and *Study 3* also revealed a range of scenarios where alternative options for GP provision of DAA would benefit PWHCV to access this treatment. PWHCV may have what they regard as 'their' GP, but this GP may not include provision of DAA in their scope of practice. Independent of 'their' GPs' scope of practice, a patient may choose not to engage with that GP for this treatment. PWHCV may not have a regular GP who they can engage with for this treatment. There is a need to provide pathways for patients to engage with willing GPs for the provision of HCV care, including DAA treatment, to cater for these scenarios.

**Recommendation 3.** **Develop a register of GPs capable and willing to provide best practice care for HCV including DAA.**

A register should be developed to provide a list of GPs willing and capable to provide best practice care for HCV, including DAA, to PWHCV who are not currently their patients. This register can be used both GPs and PWHCV. The PHNs are ideally suited to create and manage such a list as this work fits with the key objectives of PHNs to improve "the efficiency and effectiveness of medical services for patients, particularly those at risk of poor health outcomes." and "…the coordination of care to ensure patients receive the right care, in the right place, at the right time." (Australian Government - Department of Health, 2018a, p 1). GPs are accustomed to seeking information from the PHNs websites, that provide 'pathways to care' for a range of conditions (Harris, 2016; PHN Adelaide, 2018). The list could also be available to GPs and people with HCV through a range of hepatitis organisations. In South Australia, for example, Hepatitis SA already offers a helpline for support of hepatitis related issues (Hepatitis SA, 2020b). VHNs can also be a point of contact for this information as part of their current role (Government of South Australia - SA Health, 2017; Haridy et al., 2020) and this would be in line with my suggested extension of their role (see section 7.8.). Contact numbers for this information could be included within all distributed DAA promotion material, for example material distributed through the *Test Cure Live* campaign (Hepatitis Australia, 2019b).

The PHNs have a commissioning function to meet the identified needs of people in their regions (Australian Government - Department of Health, 2018a). There is an identified need to increase the uptake of DAA treatment (Burnet Institute and Kirby Institute, 2019) and this treatment can be provided by the profession of general practitioner (Hepatitis C Virus Infection Consensus Statement Working Group, 2020). Where there are insufficient GPs identified for the register, the PHN should commission GPs to provide these services. There is the capacity for the PHNs to collaborate across PHN regions to provide these services and the use of remote consults would aid this collaborative model. There have been recent major advances in the use of telehealth in Australia due to the COVID-19 pandemic (O'Kane, 2020; Snoswell, Caffery, Haydon, Thomas, & Smith, 2020) which could apply to the provision of DAA treatment. Experienced GPs may be able to provide many aspects of DAA via remote consult, especially in a shared care model with local clinicians, and this would reduce the need for PWHCV to travel for appointments to receive this treatment. This would require the availability of MBS items for teleconference be continued beyond COVID-19 (Mazza, Deb, & Subasinghe, 2020) and for the current requirements for the consult to be with a patient's regular GP or medical practice to be lifted (Australian Government - Department of Health, 2020f).

## 7.8 Expanding the role of VHNs to improve the continuity of care for PWHCV

The phases of the cascade of care to the provision of DAA treatment are often interrupted, especially for PWID (Bajis et al., 2019), and in these circumstances, patients may be classified as 'lost to follow up' (Haridy et al., 2018; Wade et al., 2020). *Studies 2* and *3* provided examples of PWHCV who were provided with a diagnosis of HCV that for a range of reasons were not provided DAA. Using surveillance data to trace individuals with an HCV diagnosis raises privacy and confidentiality concerns (Stoové et al., 2019). The Australian centralised electronic health records system, My Health Record, has struggled to overcome citizen's concerns regarding the confidentiality of medical information (Pang et al., 2020). In line with the findings of *Study* 2, this concern may be heightened for PWHCV. If PWHCV are contemplating re-engaging in care for HCV, they may not wish to contact previous GPs, have no easy access to their medical records and have limited information available to assess the willingness and capacity of GPs to provide DAA. PWHCV would benefit from contact with a clinician with HCV expertise who could guide future engagement for HCV, and who could be trusted to hold health records regarding HCV.

**Recommendation 4.** **Expand the role of Viral Hepatitis Nurses (VHNs) to provide continuity of care for PWHCV.**

VHNs can provide a trusted contact point for PWHCV to re-engage for care for HCV and provide a level of continuity of care for these people. From *Study 2* and *Study* 3 there were positive reports regarding the support provided to people with HCV and GPs by VHNs. In South Australia VHNs have an established role in providing support to GPs in the community to provide DAA and to provide direct support to PWHCV (Government of South Australia - SA Health, 2017). Viral hepatitis nurse consultants working across Australia have been involved in providing DAA and other care for HCV (Haridy et al., 2020). This expanded role is in line with trials of nurse case management in America, where increased continuity of care for patients co-infected with HCV and HIV were found (Starbird et al., 2020).

The first step would be to create a National VHN service that would be a single point of contact for VHNs working across organisations. The service would primarily provide administrative support to VHNs and it is envisaged this can be achieved with minimal additional resources. PWHCV would be allocated a VHN based on current processes (Government of South Australia - SA Health, 2017). The involvement of the VHN would be patient led and patient centred. The permission of patients for their clinical information regarding HCV to be provided to VHN, would be routinely sought at the time of the ordering of investigations. The VHN's role in holding this health information would be explained to patients at the time, as part of the consent process. The organisations where VHNs work have existing capacity for storage and maintenance of confidentiality of patient information. The option for the results to be sent to the VHN would be included on any test request or consultation form. When a PWHCV was interested in re-engaging in DAA, they could then contact the VHN Service to connect with their allocated VHN. The VHN Service can link the person with capable and willing GPs that provide DAA. If the PWHCV was already engaged with a GP for this care, with patient consent, the GP can be provided with the patient's relevant clinical information and offered support from the VHNs. This intervention would provide continuity of care for PWHCV by expanding the role of the existing, highly skilled workforce.

## 7.9 Counteracting patients' previous experiences and perceptions of engagement for HCV care

People affected by HCV come to any GP-patient interaction with a background of experiences and perceptions, all of which shape their expectations of the benefits and risks of engagement. Being capable and willing to provide DAA may not be enough for PWHCV to engage with GPs to receive this care. GPs and general practices need to counteract the perceived risks and persuade those people "sussing them out" of the benefits of seeking HCV-related care from them. GPs must exhibit these features at all times, as their opportunity to influence perceptions of PWHCV frequently occurs before disclosure - often when they are engaging with a GP about another health concern.

### **Recommendation 5.** Provide GPs with strategies for counteracting negative previous experiences and promotion of DAA, to change the perception of PWHCV about the benefits of engaging for care for HCV.

GPs and their general practices need to become "hepatitis friendly" (Baker et al., 2019, p 27). The *Eliminating Hepatitis C* series of articles (Baker et al., 2019; Chan et al., 2019; Draper et al., 2019; Layton et al., 2019; Purcell et al., 2019) provide guidance on a range of measures that would counteract patients' reluctance to engage for HCV care. General practices should actively promote the benefits of DAA treatment to their patients for example, via screens and pamphlets in waiting rooms, and via general practice webpages. Results from *Study 3* included reports from practice nurses about the benefit of placing HCV information in their consultation area, to complement their efforts in encouraging screening for HCV. The results of *Study 2* and *Study 3* indicated that there was particular information that was important to emphasise in promoting DAA for PWHCV. This includes an emphasis on the substantial improvements the new DAA treatment offers relative to the old treatments, such as: cure rates of greater than 90 %; short treatment duration; minimal side effect; once a day tablet (no injections); low cost to patients (the cost of a regular PBS prescriptions); absence of exclusions; and easy availability via a GP.

Findings from *Study 2* indicated that patients may be sensitive to questions about the route of transmission and GPs need to make clear to patients the relevance of any question asked, for example to determine whether harm reduction advice is relevant. When patients disclose their HCV status, the foremost aim of the GP should be to reassure the patient that their intention is to achieve a cure of the patient's HCV. Results from *Studies 2* and *3* indicated that patients' understandings of treatment for HCV may be out of date and incorrect. The patient's knowledge of aspects of the DAA needs to be established and further explanations should be provided if knowledge gaps exist prior to seeking patient consent. Patients should be provided the details of VHN nurses and hepatitis support organisations and encouraged to make contact for additional support and information. In this way the GP advances PWHCV towards DAA even when patients do not continue to engage with this GP.

Results from *Study 2* highlighted the importance of providing reassurance to PWHCV regarding the maintenance of confidentiality of what they may perceive as highly sensitive information. Patients need to be assured by their GP that their information is only be shared with their explicit permission and only when relevant. Australian general practice standards (The Royal Australian College of General Practitioners, 2015) require practices to adhere to policies regarding the protection of patient information. Routinely informing all patients that these systems are in place would reduce fear and encourage open and honest disclosure about sensitive information, including information about drug-related or HCV-related conditions.

Results from *Study 3* included participants' descriptions of specific techniques when taking patient' histories to successfully elicit information regarding patient's drug use. These participants emphasised the importance of the GP presenting as non-judgmental, that these questions should routinely be included whenever taking a patient history and the importance of taking in-depth patient histories as part of providing care to patients. Results from *Study* 2 included examples where participants had both positive and negative experiences with GPs regarding the investigation of an HCV diagnosis and HCV risk factors and support that skilled history taking is pivotal to PWHCV disclosure and satisfaction with GPs care. Specific techniques for eliciting information in this regard should be included in all clinician's training. Practice nurse involvement in taking patient histories and involvement in HCV care should be considered. When GPs are assessing whether a patient has any drug issues, eliciting the significance of drug use to the patient would allow GPs to provide targeted care. GPs can play an important part in addressing drug-use issues (Australian Government - Australian Institute of Health and Welfare, 2020a) but should not assume that all patients presenting for HCV management require treatment for drug use. Whilst drug addiction is often described as a 'chronic relapsing disorder' (Badiani, 2014), not all people with HCV are, or have ever been, addicted to drugs (Hajarizadeh et al., 2017; Swan et al., 2010; White et al., 2014). It is good practice for GPs to consistently exercise caution prescribing drugs of dependence (Badiani, 2014), but the use of these drugs is warranted to treat many conditions. In these circumstances, GPs should not deny drugs of dependence to patients solely based on the patient's HCV status or even patient reported drug issues but should exercise clinical judgement using appropriate safeguards when prescribing (Badiani, 2014). GPs may feel challenged by patients who are ‘drug seeking’ and ‘doctor shopping’ (Claire Van Hout, 2014; Martyres et al., 2004) if this was the intention of patients, however, it is highly unlikely that they would disclose a diagnosis of HCV or IDU during their consultation.

## 7.10 Monitor success of existing support

Findings from *Study 3* showed that GPs who were involved in providing DAA treatment were confident in doing so. This confidence stemmed from the education that they had received, the remote consultation form process and the support received from VHNs. GPs reported that they had ready access to quality education regarding DAA treatment. The remote consultation process was described as straightforward and appreciated. The form acted as a checklist and link to resources for GPs to assess patients with HCV and create a treatment plan for the provision of DAA treatment. Review of the forms by staff at tertiary liver clinics, was seen as an efficient way to ensure that these treatment plans were appropriate for the patient. GPs felt that the tertiary liver clinic staff could remain abreast of any nuanced change to best practice regarding treatment of HCV and that the remote consultation process released them from the burden of having to do so. VHNs were often mentioned by GP participants as a great resource for themselves and for patients. Even where GPs were experienced prescribers of DAA treatment their support was appreciated.

**Recommendation 6.** **Monitor the success of existing support for prescribing DAA treatment including education, VHN support and the remote consultation process, to evidence the need for ongoing funding of the services involved.**

Rather than providing new recommendations in this regard, I suggest it is important to document the success of the existing support, so that this can be used as evidence to support ongoing funding of training organisations, VHNs and tertiary liver services. The experiences of existing DAA treatment prescribers, highlighting the ongoing support available, should be used to promote involvement in training and prescribing of DAA treatment to GPs.

## 7.11 Further research suggested

Further research involving people who have had a diagnosis of HCV is suggested from my research. During my PhD candidature, and especially from interviewing participants for *Study 2*, I gained an increased appreciation of the range of people who have contracted HCV. This diversity did not appear to have been captured in the literature. People who have ever been diagnosed with HCV, are a population who may provide additional perspectives on the life history of drug use, involving IDU, to populations studied previously (Larney et al., 2015). These life histories can be used to broaden the understanding of substance abuse, dependence and addiction (Badiani, 2014). The concept of 'recovery' has become widespread in relation to substance abuse (Bathish et al., 2017; Brekke, Lien, Davidson, & Biong, 2017; McKim et al., 2014). Many of the participants in *Study 2* represented people who had 'recovered' from IDU. My study was focused on the engagement with GPs for care, however further Investigation of additional aspects of the lived experience of people with HCV, would be useful to understanding and shaping the provision of services for IDU to achieve recovery.

Further research is needed to translate advances to healthcare, such as DAA, into the provision of this treatment in the private general practice setting. The findings of *Study 3* indicated that this translation principally relies on GPs choosing to include these new advances into their scope of practice and seeking out the required education to deliver this care. Further research into the way GPs' scope of practice is shaped is warranted as there appeared to be sparse literature in this respect. Further research into the utilisation of technology to facilitate GPs' knowledge regarding advances to healthcare (Liaw et al., 2017), should be conducted. Ideally practice management tools can be developed that 'push' relevant information to GPs when they are consulting with patients with particular issues, thus saving the GP time and aiding them to deliver best practice care.

## 7.12 Chapter summary

For Australian citizens many of the system-based barriers to the provision of DAA by GPs reported in other countries have been removed, however a substantial proportion of PWHCV who are eligible to receive this treatment from a GP and be cured, are not receiving this treatment.

In this thesis I have strived to understand the historical, social and current context to develop my recommendations. Additional research is suggested from my findings that would further aid the understanding of engagement by PWHCV in DAA and the provision of care by GPs of this treatment.

Recommendations generated from my research findings are:

1. Identify broad policy documents which may affect equity and access to primary healthcare for people with HCV and advocate to align policy aims, reference appropriate need assessment approaches and clarify actions that achieve equity and access to healthcare for people with HCV.

2. Promote and facilitate GP-GP referral to enable the provision of HCV care including DAA.

3. Develop a register of GPs capable and willing to provide best practice care for HCV, including DAA.

4. Expand the role of Viral Hepatitis Nurses (VHNs) to provide continuity of care for PWHCV.

5. Provide GPs with strategies for counteracting negative previous experiences and promotion of DAA, to change the perception of PWHCV about the benefits of engaging for care for HCV.

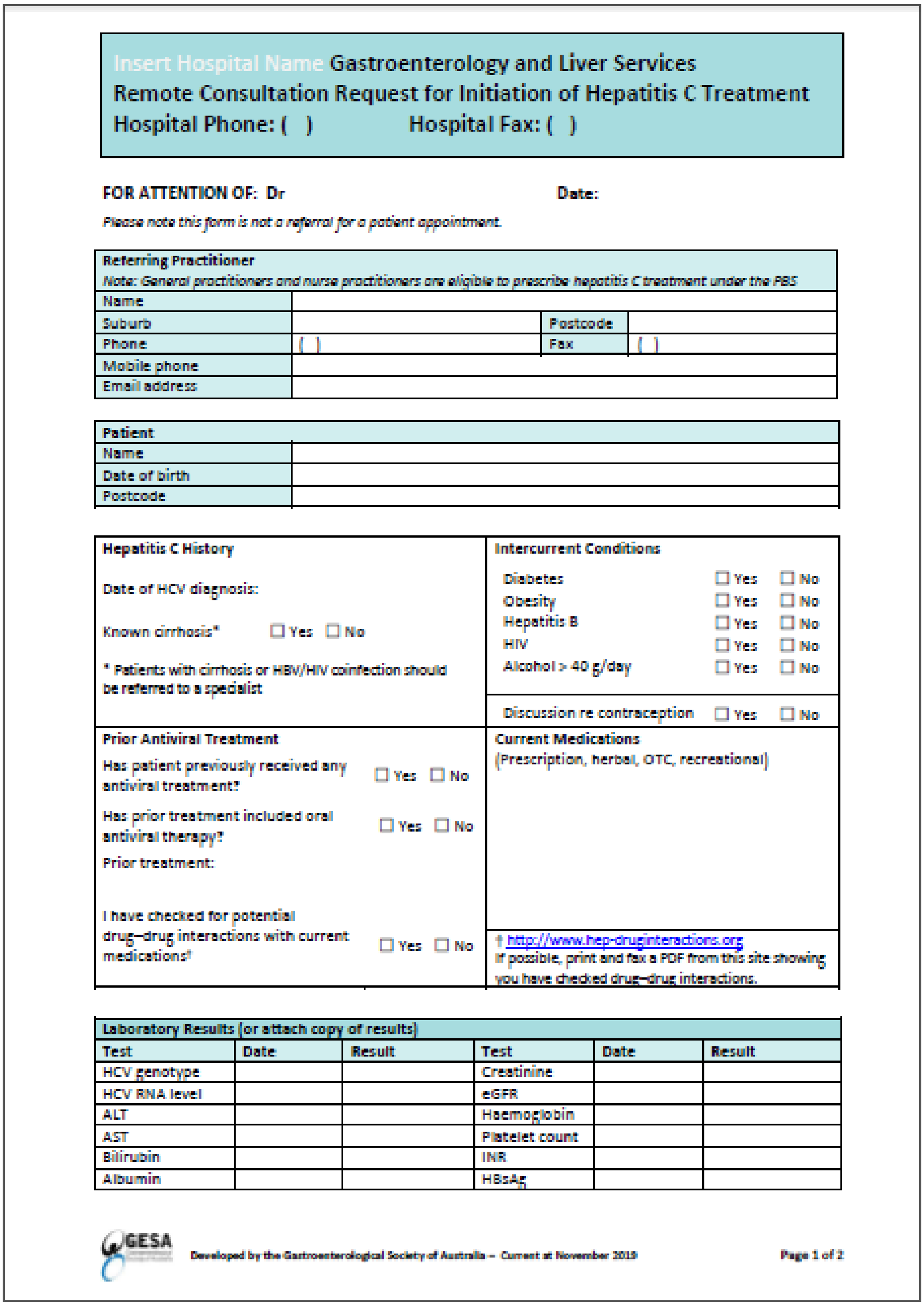
6. Monitor the success of existing support for prescribing DAA treatment including education, VHN support and the remote consultation process, to evidence the need for ongoing funding of the services involved.

My recommendations were made after examining assumptions about the GP-patient relationship in Australia. I argue that there is a need to go beyond presuming that GPs in private general practice will automatically provide this care to ‘their’ patients and that people with HCV will engage with ‘their’ GP for this care.

DAA represents a major advance to treatment for HCV and there has been considerable work undertaken to overcome system-based barriers to the provision of DAA by GPs in Australia. Adoption of these recommendations will allow these advances to be translated, enabling more PWHCV to achieve a cure for their HCV and thus furthering the aim of elimination of HCV in Australia.

# *APPENDIX*

## Appendix 1: *Gastroenterology and Liver Services Remote Consultation Request for Initiation of Hepatitis C Treatment* Form (Gastroenterological Society of Australia, 2019)



Insert Hospital Name Gastroenterology and Liver Services
Remote Consultation Request for Initiation of Hepatitis C Treatment
Hospital Phone: ( ) Hospital Fax: ( )

**FOR ATTENTION OF: Dr** **Date:**

*Please note this form is not a referral for a patient appointment.*

**Referring Practitioner**
*Note: General practitioners and nurse practitioners are eligible to prescribe hepatitis C treatment under the PBS*

| | | | |
|---|---|---|---|
| Name | | | |
| Suburb | | Postcode | |
| Phone | ( ) | Fax | ( ) |
| Mobile phone | | | |
| Email address | | | |

**Patient**

| | |
|---|---|
| Name | |
| Date of birth | |
| Postcode | |

**Hepatitis C History**

Date of HCV diagnosis:

Known cirrhosis* ☐ Yes ☐ No

* Patients with cirrhosis or HBV/HIV coinfection should be referred to a specialist

**Intercurrent Conditions**

| | | |
|---|---|---|
| Diabetes | ☐ Yes | ☐ No |
| Obesity | ☐ Yes | ☐ No |
| Hepatitis B | ☐ Yes | ☐ No |
| HIV | ☐ Yes | ☐ No |
| Alcohol > 40 g/day | ☐ Yes | ☐ No |
| Discussion re contraception | ☐ Yes | ☐ No |

**Prior Antiviral Treatment**

Has patient previously received any antiviral treatment? ☐ Yes ☐ No

Has prior treatment included oral antiviral therapy? ☐ Yes ☐ No

Prior treatment:

I have checked for potential drug–drug interactions with current medications† ☐ Yes ☐ No

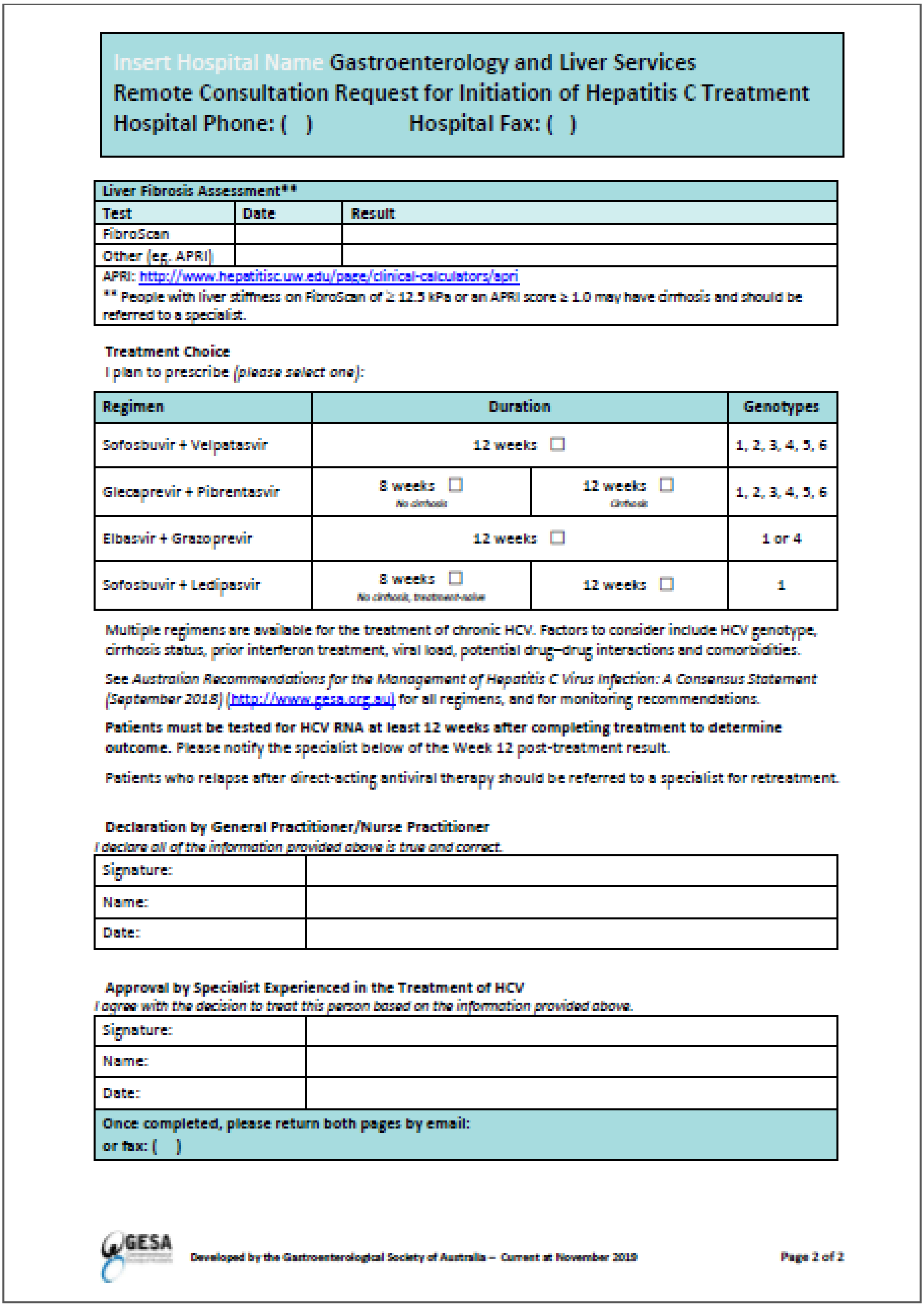
**Current Medications**
(Prescription, herbal, OTC, recreational)

† http://www.hep-druginteractions.org
If possible, print and fax a PDF from this site showing you have checked drug–drug interactions.

**Laboratory Results (or attach copy of results)**

| Test | Date | Result | Test | Date | Result |
|---|---|---|---|---|---|
| HCV genotype | | | Creatinine | | |
| HCV RNA level | | | eGFR | | |
| ALT | | | Haemoglobin | | |
| AST | | | Platelet count | | |
| Bilirubin | | | INR | | |
| Albumin | | | HBsAg | | |

GESA Developed by the Gastroenterological Society of Australia – Current at November 2019 Page 1 of 2



**Insert Hospital Name Gastroenterology and Liver Services**
**Remote Consultation Request for Initiation of Hepatitis C Treatment**
**Hospital Phone: ( ) Hospital Fax: ( )**

| **Liver Fibrosis Assessment**** | | |
|---|---|---|
| **Test** | **Date** | **Result** |
| FibroScan | | |
| Other (eg. APRI) | | |
| APRI: http://www.hepatitisc.uw.edu/page/clinical-calculators/apri<br>** People with liver stiffness on FibroScan of ≥ 12.5 kPa or an APRI score ≥ 1.0 may have cirrhosis and should be referred to a specialist. | | |

**Treatment Choice**

I plan to prescribe *(please select one)*:

| **Regimen** | **Duration** | | **Genotypes** |
|---|---|---|---|
| Sofosbuvir + Velpatasvir | 12 weeks ☐ | | 1, 2, 3, 4, 5, 6 |
| Glecaprevir + Pibrentasvir | 8 weeks ☐<br>*No cirrhosis* | 12 weeks ☐<br>*Cirrhosis* | 1, 2, 3, 4, 5, 6 |
| Elbasvir + Grazoprevir | 12 weeks ☐ | | 1 or 4 |
| Sofosbuvir + Ledipasvir | 8 weeks ☐<br>*No cirrhosis, treatment-naïve* | 12 weeks ☐ | 1 |

Multiple regimens are available for the treatment of chronic HCV. Factors to consider include HCV genotype, cirrhosis status, prior interferon treatment, viral load, potential drug–drug interactions and comorbidities.

See *Australian Recommendations for the Management of Hepatitis C Virus Infection: A Consensus Statement (September 2018)* (http://www.gesa.org.au) for all regimens, and for monitoring recommendations.

**Patients must be tested for HCV RNA at least 12 weeks after completing treatment to determine outcome.** Please notify the specialist below of the Week 12 post-treatment result.

Patients who relapse after direct-acting antiviral therapy should be referred to a specialist for retreatment.

**Declaration by General Practitioner/Nurse Practitioner**

*I declare all of the information provided above is true and correct.*

| | |
|---|---|
| Signature: | |
| Name: | |
| Date: | |

**Approval by Specialist Experienced in the Treatment of HCV**

*I agree with the decision to treat this person based on the information provided above.*

| | |
|---|---|
| Signature: | |
| Name: | |
| Date: | |
| **Once completed, please return both pages by email:**<br>**or fax: ( )** | |

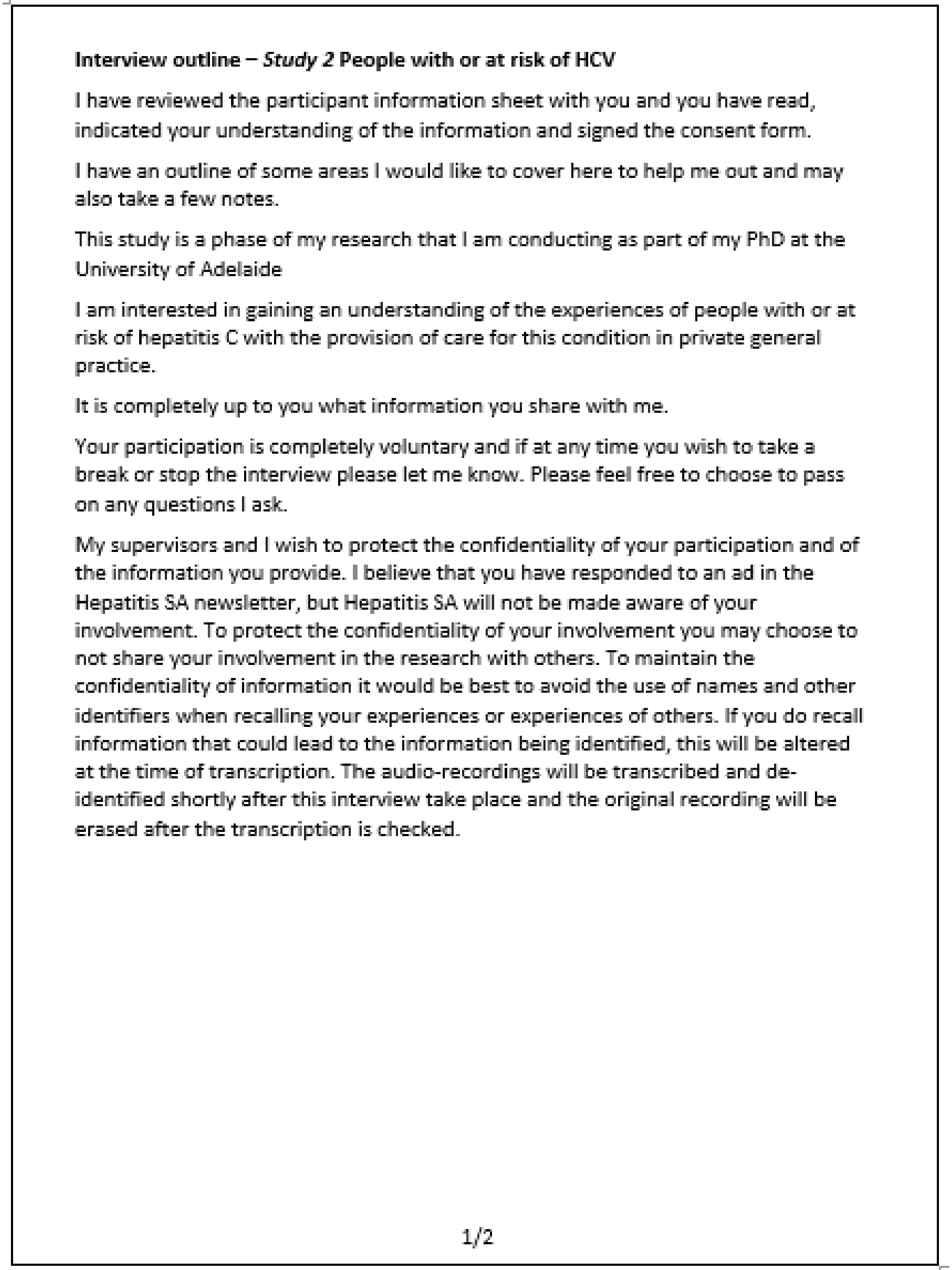
GESA

Developed by the Gastroenterological Society of Australia – Current at November 2019

Page 2 of 2

**(Reproduced with permission from Gastroenterological Society of Australia.)**

## Appendix 2 Interview guide *Study 2* – People with or at risk of HCV



**Interview outline – *Study 2* People with or at risk of HCV**

I have reviewed the participant information sheet with you and you have read, indicated your understanding of the information and signed the consent form.

I have an outline of some areas I would like to cover here to help me out and may also take a few notes.

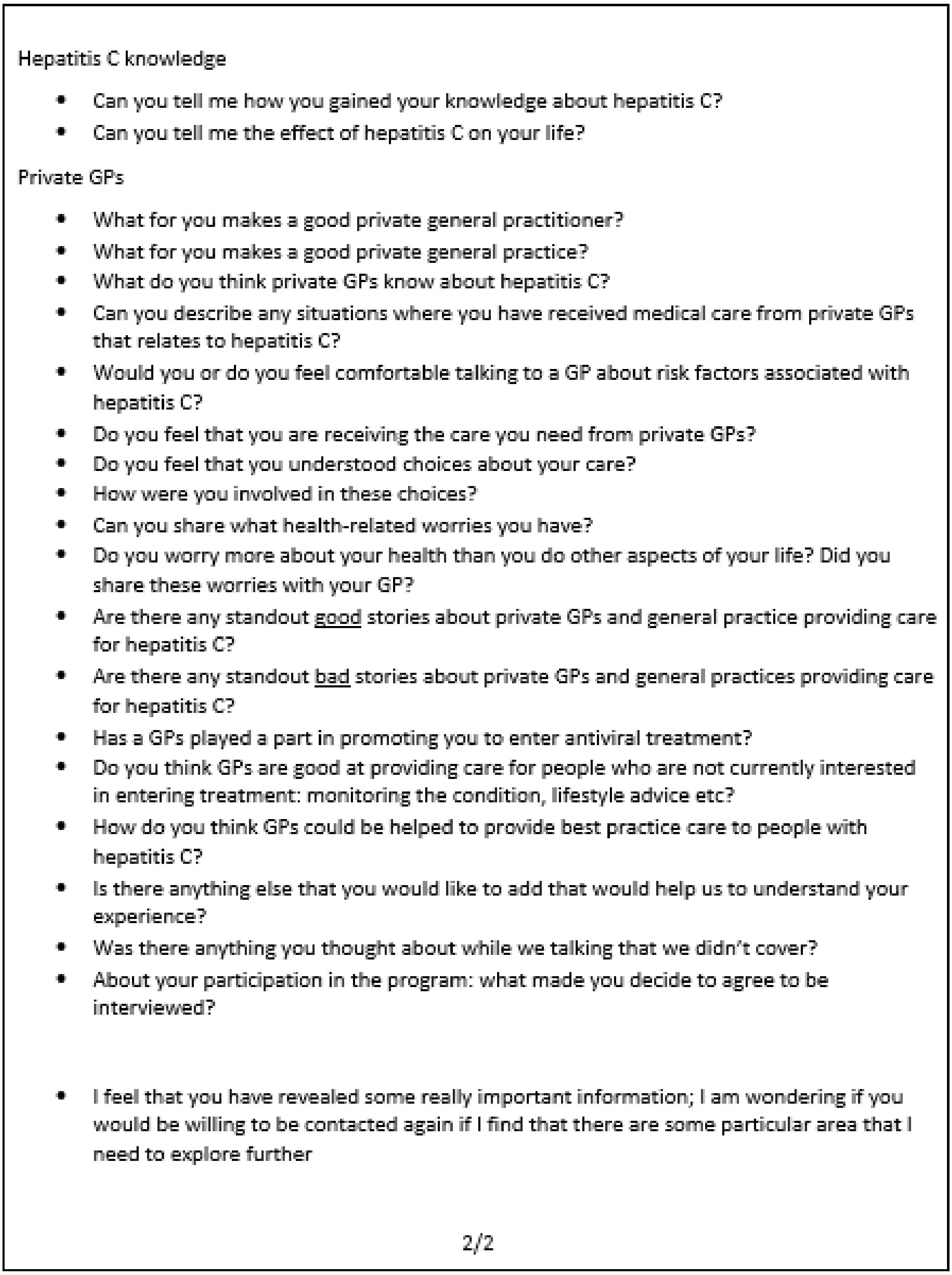
This study is a phase of my research that I am conducting as part of my PhD at the University of Adelaide

I am interested in gaining an understanding of the experiences of people with or at risk of hepatitis C with the provision of care for this condition in private general practice.

It is completely up to you what information you share with me.

Your participation is completely voluntary and if at any time you wish to take a break or stop the interview please let me know. Please feel free to choose to pass on any questions I ask.

My supervisors and I wish to protect the confidentiality of your participation and of the information you provide. I believe that you have responded to an ad in the Hepatitis SA newsletter, but Hepatitis SA will not be made aware of your involvement. To protect the confidentiality of your involvement you may choose to not share your involvement in the research with others. To maintain the confidentiality of information it would be best to avoid the use of names and other identifiers when recalling your experiences or experiences of others. If you do recall information that could lead to the information being identified, this will be altered at the time of transcription. The audio-recordings will be transcribed and de-identified shortly after this interview take place and the original recording will be erased after the transcription is checked.



Hepatitis C knowledge

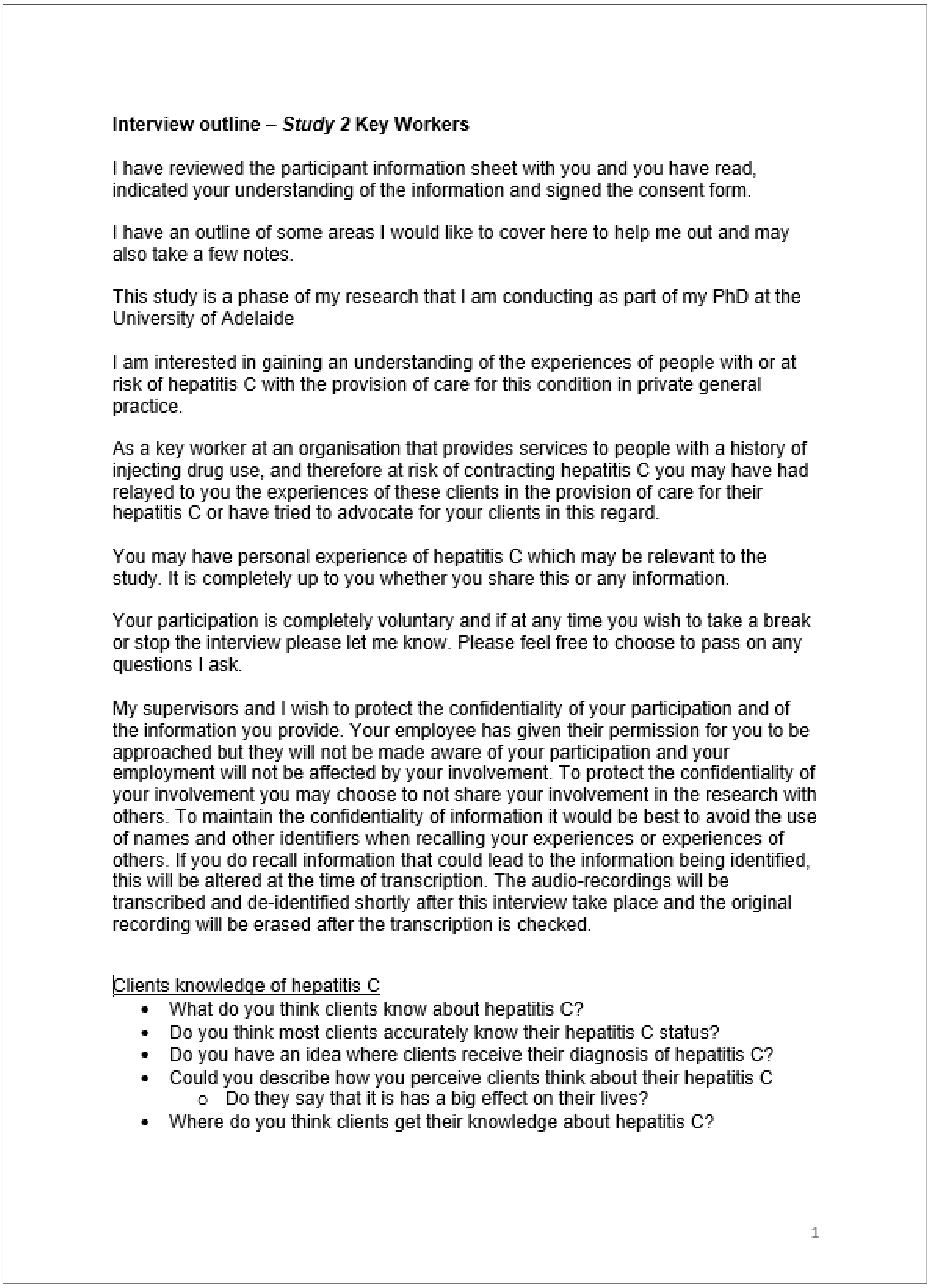
- Can you tell me how you gained your knowledge about hepatitis C?
- Can you tell me the effect of hepatitis C on your life?

Private GPs

- What for you makes a good private general practitioner?
- What for you makes a good private general practice?
- What do you think private GPs know about hepatitis C?
- Can you describe any situations where you have received medical care from private GPs that relates to hepatitis C?
- Would you or do you feel comfortable talking to a GP about risk factors associated with hepatitis C?
- Do you feel that you are receiving the care you need from private GPs?
- Do you feel that you understood choices about your care?
- How were you involved in these choices?
- Can you share what health-related worries you have?
- Do you worry more about your health than you do other aspects of your life? Did you share these worries with your GP?
- Are there any standout good stories about private GPs and general practice providing care for hepatitis C?
- Are there any standout bad stories about private GPs and general practices providing care for hepatitis C?
- Has a GPs played a part in promoting you to enter antiviral treatment?
- Do you think GPs are good at providing care for people who are not currently interested in entering treatment: monitoring the condition, lifestyle advice etc?
- How do you think GPs could be helped to provide best practice care to people with hepatitis C?
- Is there anything else that you would like to add that would help us to understand your experience?
- Was there anything you thought about while we talking that we didn't cover?
- About your participation in the program: what made you decide to agree to be interviewed?

- I feel that you have revealed some really important information; I am wondering if you would be willing to be contacted again if I find that there are some particular area that I need to explore further

## Appendix 3: Interview guide *Study 2* - Key Workers



**Interview outline – *Study 2* Key Workers**

I have reviewed the participant information sheet with you and you have read, indicated your understanding of the information and signed the consent form.

I have an outline of some areas I would like to cover here to help me out and may also take a few notes.

This study is a phase of my research that I am conducting as part of my PhD at the University of Adelaide

I am interested in gaining an understanding of the experiences of people with or at risk of hepatitis C with the provision of care for this condition in private general practice.

As a key worker at an organisation that provides services to people with a history of injecting drug use, and therefore at risk of contracting hepatitis C you may have had relayed to you the experiences of these clients in the provision of care for their hepatitis C or have tried to advocate for your clients in this regard.

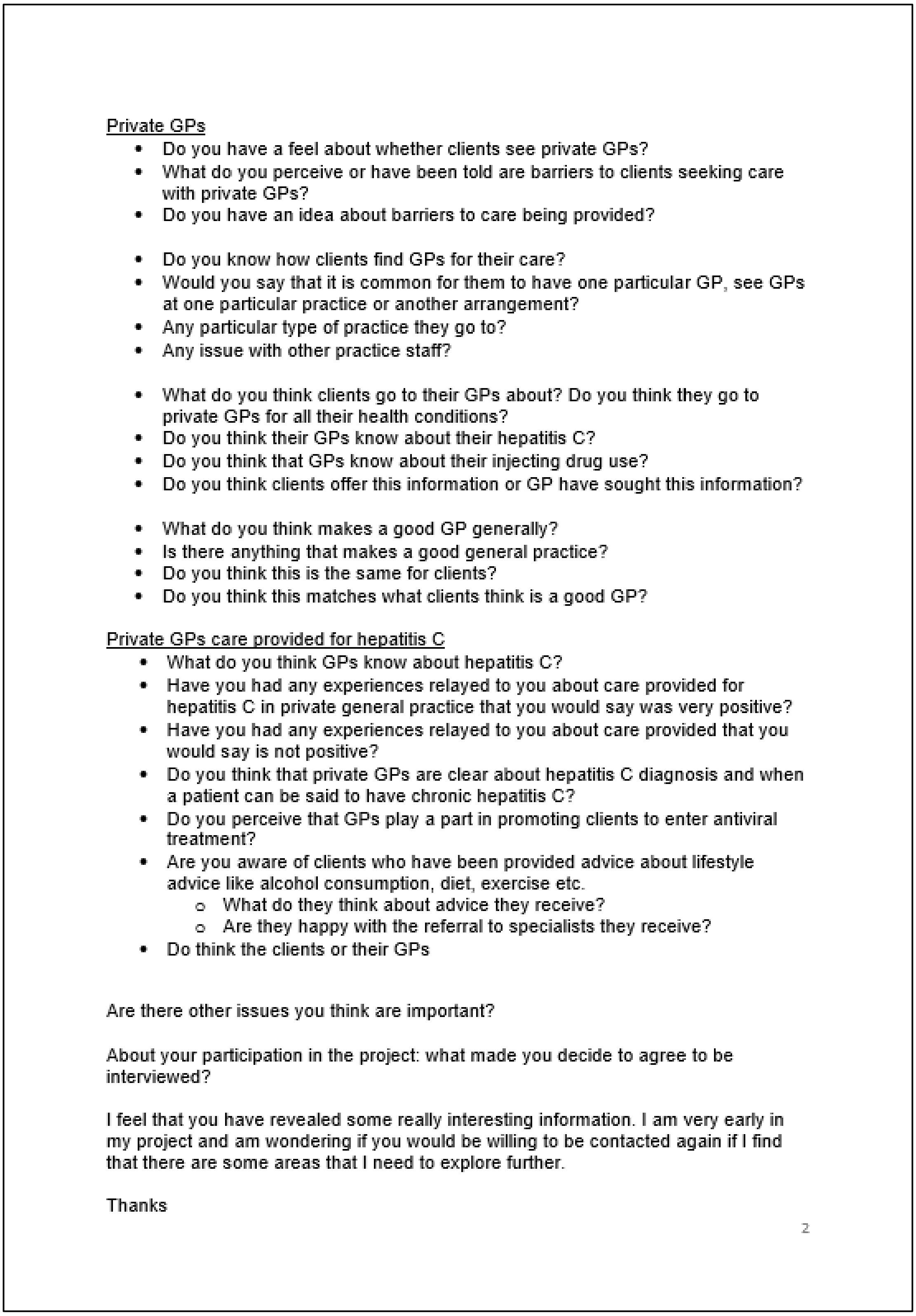
You may have personal experience of hepatitis C which may be relevant to the study. It is completely up to you whether you share this or any information.

Your participation is completely voluntary and if at any time you wish to take a break or stop the interview please let me know. Please feel free to choose to pass on any questions I ask.

My supervisors and I wish to protect the confidentiality of your participation and of the information you provide. Your employee has given their permission for you to be approached but they will not be made aware of your participation and your employment will not be affected by your involvement. To protect the confidentiality of your involvement you may choose to not share your involvement in the research with others. To maintain the confidentiality of information it would be best to avoid the use of names and other identifiers when recalling your experiences or experiences of others. If you do recall information that could lead to the information being identified, this will be altered at the time of transcription. The audio-recordings will be transcribed and de-identified shortly after this interview take place and the original recording will be erased after the transcription is checked.

Clients knowledge of hepatitis C

- What do you think clients know about hepatitis C?
- Do you think most clients accurately know their hepatitis C status?
- Do you have an idea where clients receive their diagnosis of hepatitis C?
- Could you describe how you perceive clients think about their hepatitis C
    - Do they say that it is has a big effect on their lives?
- Where do you think clients get their knowledge about hepatitis C?



## Private GPs

- Do you have a feel about whether clients see private GPs?
- What do you perceive or have been told are barriers to clients seeking care with private GPs?
- Do you have an idea about barriers to care being provided?

- Do you know how clients find GPs for their care?
- Would you say that it is common for them to have one particular GP, see GPs at one particular practice or another arrangement?
- Any particular type of practice they go to?
- Any issue with other practice staff?

- What do you think clients go to their GPs about? Do you think they go to private GPs for all their health conditions?
- Do you think their GPs know about their hepatitis C?
- Do you think that GPs know about their injecting drug use?
- Do you think clients offer this information or GP have sought this information?

- What do you think makes a good GP generally?
- Is there anything that makes a good general practice?
- Do you think this is the same for clients?
- Do you think this matches what clients think is a good GP?

## Private GPs care provided for hepatitis C

- What do you think GPs know about hepatitis C?
- Have you had any experiences relayed to you about care provided for hepatitis C in private general practice that you would say was very positive?
- Have you had any experiences relayed to you about care provided that you would say is not positive?
- Do you think that private GPs are clear about hepatitis C diagnosis and when a patient can be said to have chronic hepatitis C?
- Do you perceive that GPs play a part in promoting clients to enter antiviral treatment?
- Are you aware of clients who have been provided advice about lifestyle advice like alcohol consumption, diet, exercise etc.
    - What do they think about advice they receive?
    - Are they happy with the referral to specialists they receive?
- Do think the clients or their GPs

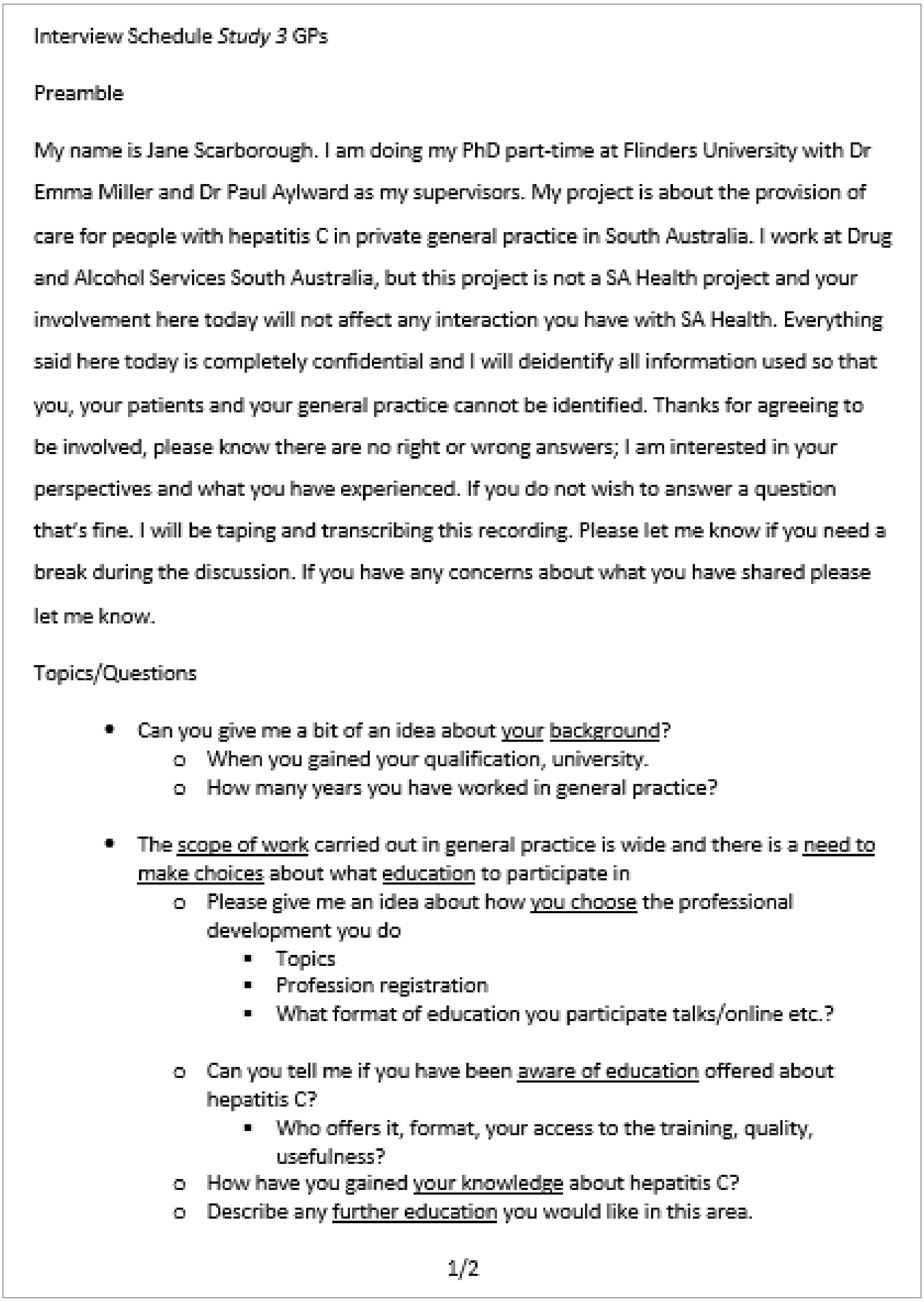
Are there other issues you think are important?

About your participation in the project: what made you decide to agree to be interviewed?

I feel that you have revealed some really interesting information. I am very early in my project and am wondering if you would be willing to be contacted again if I find that there are some areas that I need to explore further.

Thanks

## Appendix 4: Interview guide *Study 3*



Interview Schedule *Study 3* GPs

Preamble

My name is Jane Scarborough. I am doing my PhD part-time at Flinders University with Dr Emma Miller and Dr Paul Aylward as my supervisors. My project is about the provision of care for people with hepatitis C in private general practice in South Australia. I work at Drug and Alcohol Services South Australia, but this project is not a SA Health project and your involvement here today will not affect any interaction you have with SA Health. Everything said here today is completely confidential and I will deidentify all information used so that you, your patients and your general practice cannot be identified. Thanks for agreeing to be involved, please know there are no right or wrong answers; I am interested in your perspectives and what you have experienced. If you do not wish to answer a question that's fine. I will be taping and transcribing this recording. Please let me know if you need a break during the discussion. If you have any concerns about what you have shared please let me know.

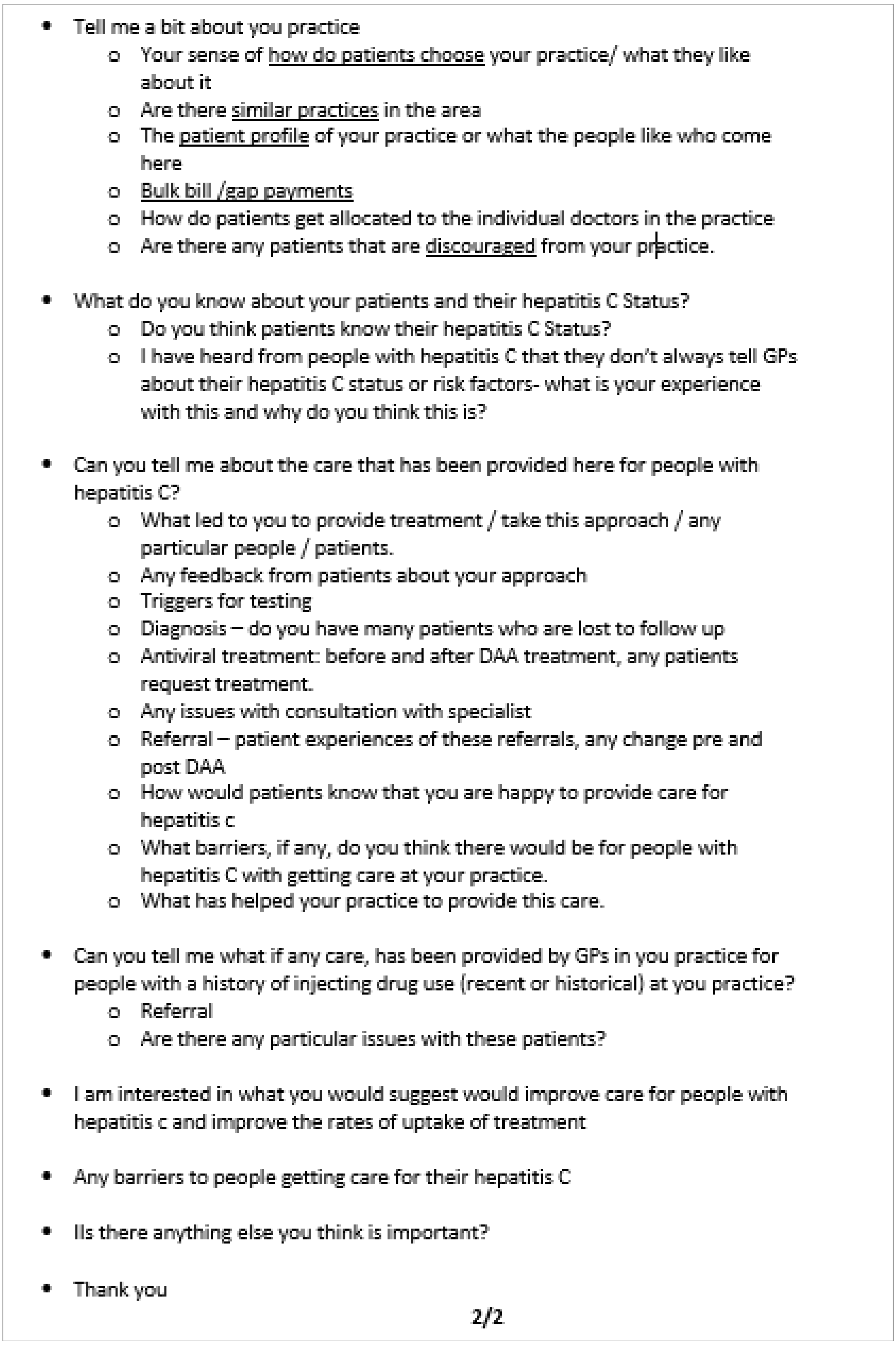
Topics/Questions

- Can you give me a bit of an idea about your background?
  - When you gained your qualification, university.
  - How many years you have worked in general practice?

- The scope of work carried out in general practice is wide and there is a need to make choices about what education to participate in
  - Please give me an idea about how you choose the professional development you do
    - Topics
    - Profession registration
    - What format of education you participate talks/online etc.?

  - Can you tell me if you have been aware of education offered about hepatitis C?
    - Who offers it, format, your access to the training, quality, usefulness?
  - How have you gained your knowledge about hepatitis C?
  - Describe any further education you would like in this area.

1/2



- Tell me a bit about you practice
    - Your sense of how do patients choose your practice/ what they like about it
    - Are there similar practices in the area
    - The patient profile of your practice or what the people like who come here
    - Bulk bill /gap payments
    - How do patients get allocated to the individual doctors in the practice
    - Are there any patients that are discouraged from your practice.

- What do you know about your patients and their hepatitis C Status?
    - Do you think patients know their hepatitis C Status?
    - I have heard from people with hepatitis C that they don't always tell GPs about their hepatitis C status or risk factors- what is your experience with this and why do you think this is?

- Can you tell me about the care that has been provided here for people with hepatitis C?
    - What led to you to provide treatment / take this approach / any particular people / patients.
    - Any feedback from patients about your approach
    - Triggers for testing
    - Diagnosis – do you have many patients who are lost to follow up
    - Antiviral treatment: before and after DAA treatment, any patients request treatment.
    - Any issues with consultation with specialist
    - Referral – patient experiences of these referrals, any change pre and post DAA
    - How would patients know that you are happy to provide care for hepatitis c
    - What barriers, if any, do you think there would be for people with hepatitis C with getting care at your practice.
    - What has helped your practice to provide this care.

- Can you tell me what if any care, has been provided by GPs in you practice for people with a history of injecting drug use (recent or historical) at you practice?
    - Referral
    - Are there any particular issues with these patients?

- I am interested in what you would suggest would improve care for people with hepatitis c and improve the rates of uptake of treatment

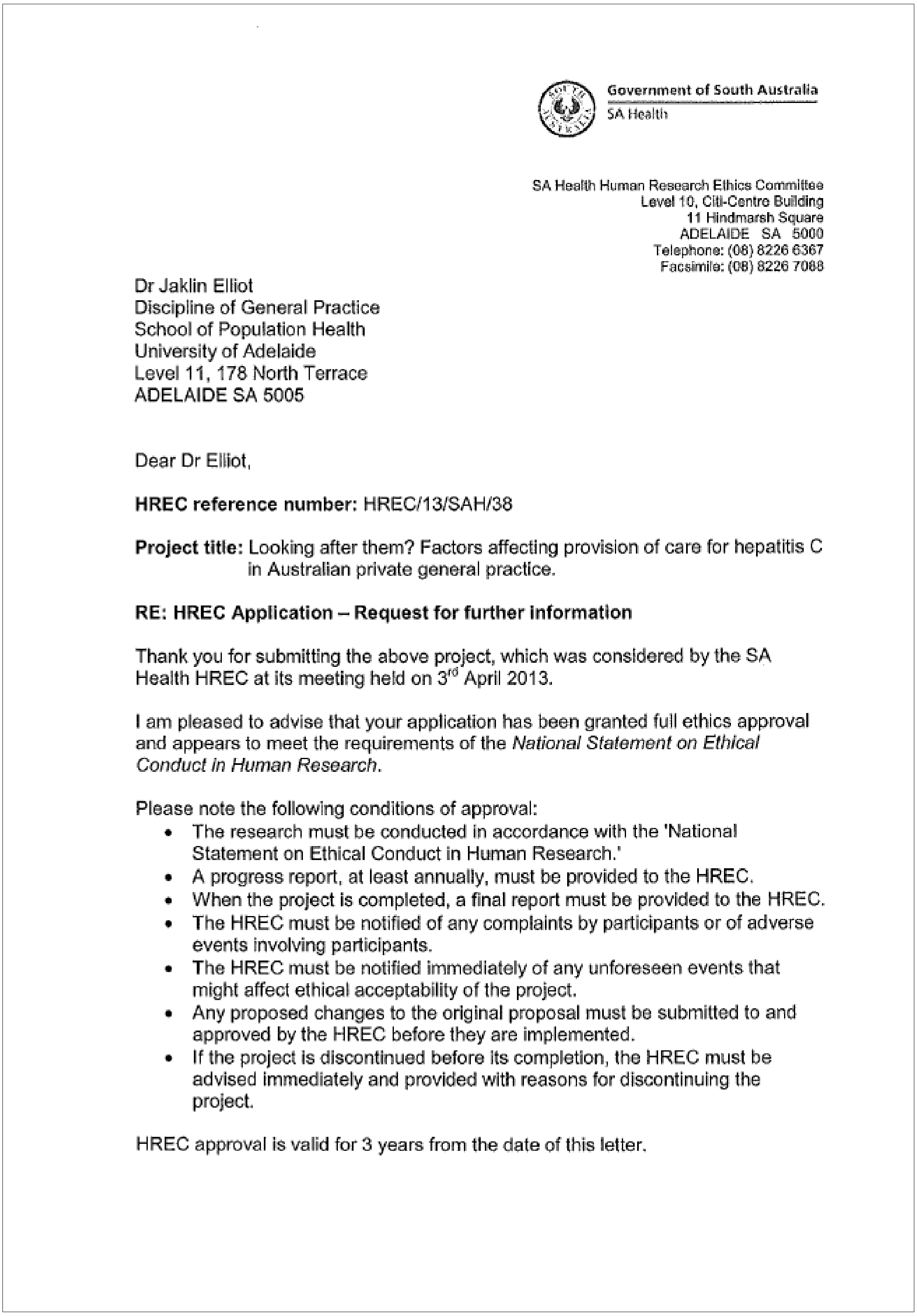
- Any barriers to people getting care for their hepatitis C

- IIs there anything else you think is important?

- Thank you

**2/2**

## Appendix 5: Ethics approvals *Study 2*



Government of South Australia
SA Health

SA Health Human Research Ethics Committee
Level 10, Citi-Centre Building
11 Hindmarsh Square
ADELAIDE SA 5000
Telephone: (08) 8226 6367
Facsimile: (08) 8226 7088

Dr Jaklin Elliot
Discipline of General Practice
School of Population Health
University of Adelaide
Level 11, 178 North Terrace
ADELAIDE SA 5005

Dear Dr Elliot,

**HREC reference number:** HREC/13/SAH/38

**Project title:** Looking after them? Factors affecting provision of care for hepatitis C in Australian private general practice.

**RE: HREC Application – Request for further information**

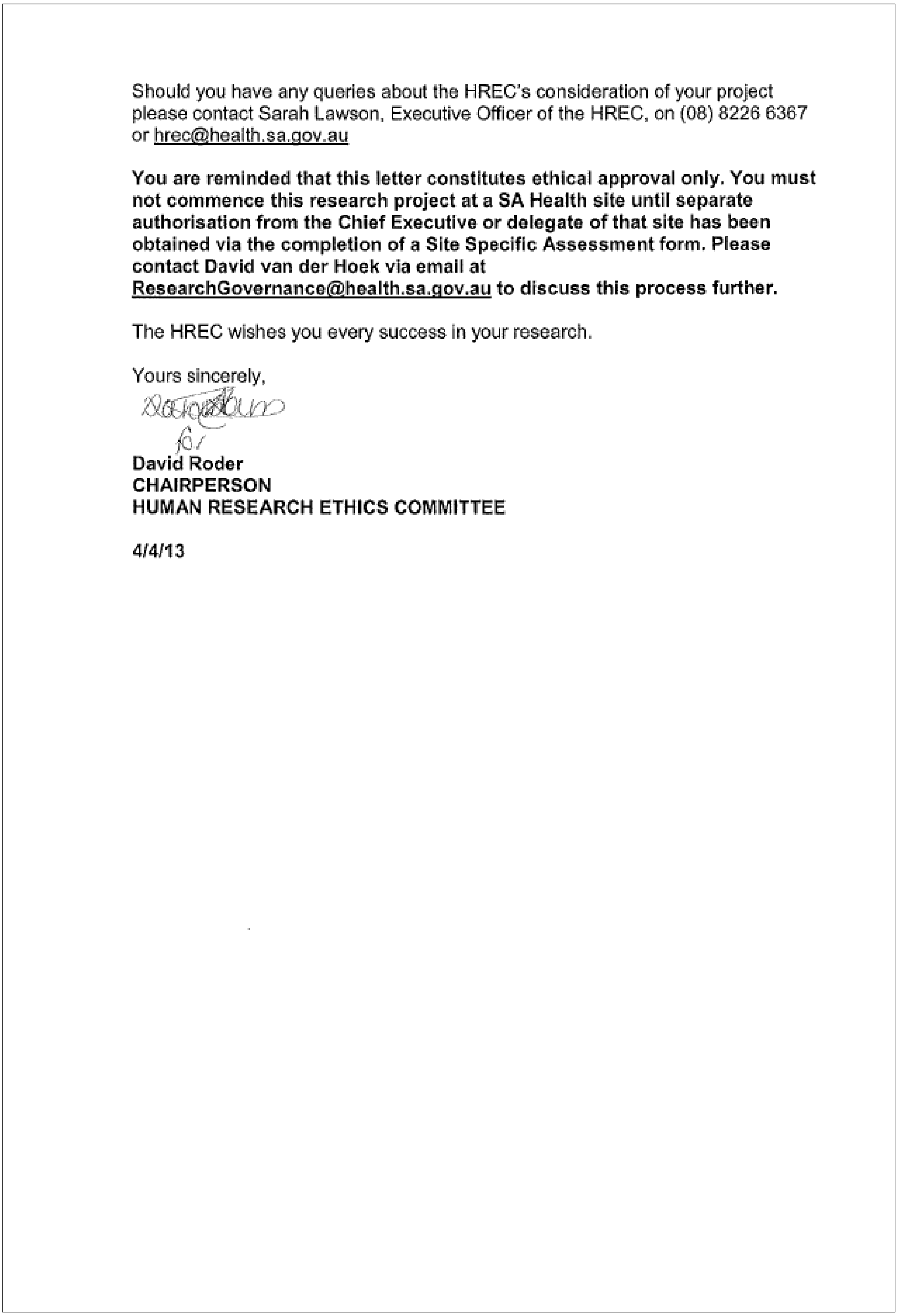
Thank you for submitting the above project, which was considered by the SA Health HREC at its meeting held on 3rd April 2013.

I am pleased to advise that your application has been granted full ethics approval and appears to meet the requirements of the *National Statement on Ethical Conduct in Human Research*.

Please note the following conditions of approval:

- The research must be conducted in accordance with the 'National Statement on Ethical Conduct in Human Research.'
- A progress report, at least annually, must be provided to the HREC.
- When the project is completed, a final report must be provided to the HREC.
- The HREC must be notified of any complaints by participants or of adverse events involving participants.
- The HREC must be notified immediately of any unforeseen events that might affect ethical acceptability of the project.
- Any proposed changes to the original proposal must be submitted to and approved by the HREC before they are implemented.
- If the project is discontinued before its completion, the HREC must be advised immediately and provided with reasons for discontinuing the project.

HREC approval is valid for 3 years from the date of this letter.



Should you have any queries about the HREC's consideration of your project please contact Sarah Lawson, Executive Officer of the HREC, on (08) 8226 6367 or hrec@health.sa.gov.au

**You are reminded that this letter constitutes ethical approval only. You must not commence this research project at a SA Health site until separate authorisation from the Chief Executive or delegate of that site has been obtained via the completion of a Site Specific Assessment form. Please contact David van der Hoek via email at ResearchGovernance@health.sa.gov.au to discuss this process further.**

The HREC wishes you every success in your research.

Yours sincerely,

for

**David Roder**
**CHAIRPERSON**
**HUMAN RESEARCH ETHICS COMMITTEE**

**4/4/13**

Aboriginal Health
Research Ethics Committee

9 July 2013

Jane Scarborough
Discipline of General Practice
School of Population Health
Level 11, 178 North Terrace
Mail Drop DX 650 207
University of Adelaide
Adelaide SA 5005

**RE: Looking after them? Factors affecting provision of care for hepatitis C in Australian private general practice. Phase 1: Perspective of people with hepatitis C or who have risk factors for having contracted hepatitis C and key workers from organisations that provide service to people with hepatitis C**
**REFERENCE NO: 04-13-514**

Dear Jane

Thank you for submitting your research project Looking after them? Factors affecting provision of care for hepatitis C in Australian private general practice. Phase 1: Perspective of people with hepatitis C or who have risk factors for having contracted hepatitis C and key workers from organisations that provide service to people with hepatitis C on the 4 July 2013 for ethical consideration.

I am pleased to inform you that this proposal has met with support and that the committee has decided that your application be recommended for approval. The duration of approval is from 1 June 2013 until the expected completion date of your project indicated as 1 June 2014.

In accordance with the NHMRC guidelines, *National Statement on Ethical Conduct in Human Research* (2007), we require at regular periods, at least annually, reports from principal researcher(s). An 'Annual Progress or Final Report' template is available at: http://www.ahcsa.org.au/research-ethics/

If you require any further information please do not hesitate to contact the Executive Officer or myself. We wish you well with the project and look forward to receiving a copy of your report.

Sincerely yours

Evans

**MS LUCY EVANS**
**CHAIRPERSON**
Ref: Proposal/Approval/ 4July2013

Aboriginal Health Council
of South Australia Inc.

AHREC is a sub-committee of AHCSA

9 King William Road Unley SA 5061 PO Box 98 Unley SA 5061
Tel: (08) 8273 7200 Fax: (08) 8273 7299 Email: ahcsa@ahcsa.org.au Website: www.ahcsa.org.au

DRUG & ALCOHOL SERVICES
SOUTH AUSTRALIA

161 Greenhill Road
Parkside SA 5063
Tel (08) 8274 3333
Fax (08) 8274 3399
ABN 30 206 083 199
www.dassa.sa.gov.au

2013-06667

Jane Scarborough
DASSA
161 Greenhill Road
Parkside SA 5061

31 July 2013

Dear ~~Ms Scarborough~~ Jane

**Re Research application: Looking after them? Factors affecting provision of care for hepatitis C in Australian private general practice**

Thank you for your application to undertake research at DASSA exploring the factors that affect provision of care in Australian private general practice for people with hepatitis C.

I am pleased to grant you approval to the conduct the research in DASSA's pharmacotherapy services. I trust you will continue to liaise closely with the DASSA managers at the Southern, Eastern, Western and Northern services in relation to recruitment of clients into the study.

This approval is subject to the completion of a signed Site Specific Assessment form.

Yours sincerely

Simone Cormack
**State Director**

Government
of South Australia
SA Health

## Appendix 6: Recruitment material *Study 2*

THE UNIVERSITY
*of* ADELAIDE

## Research Study

Looking after them? Factors affecting provision of care for hepatitis C in Australian private general practice

# Affected by hepatitis C?

We would like to talk to you about
care provided by private GPs.

To be part of the study you must be **over 18** and be able to **speak English**.

The interview should take about **one hour**.

Interviews can take place at Western DASSA
or other arrangements may be possible.

A $20 Woolworths essential voucher will be provided
as a token of appreciation for your time.

Further information is provided in the envelope below.
Please take an envelope if you're interested in participating.

## To get involved

**Call Jane or**
**Send your number by text to**

**0404 676 304**

If you wish to talk to Jane and she does not answer the phone,
please **ring back later**
or **leave a message** with your number, the best time to call back and first name (optional)
or **text this information.**

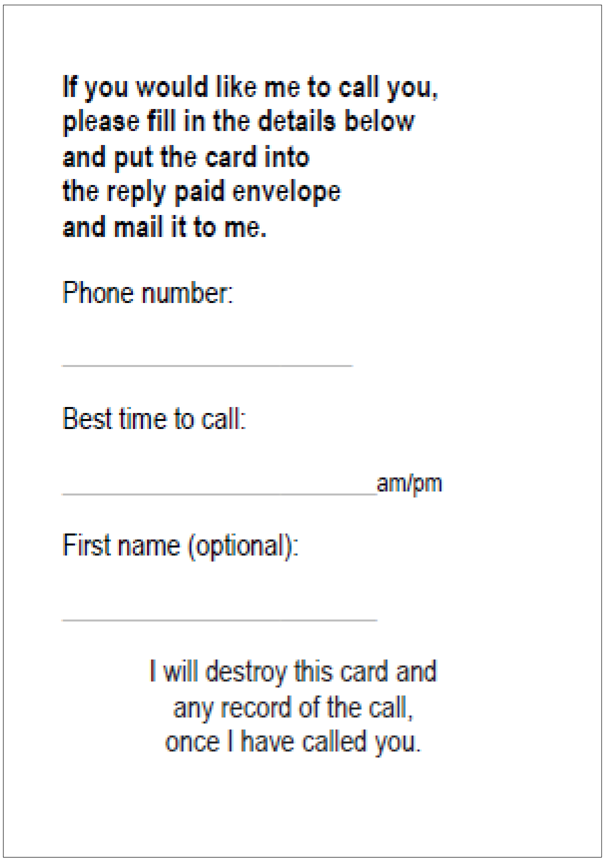
**Further information**

Jane Scarborough: jane.scarborough@adelaide.edu.au, Telephone: 8313 7583
Dr Jaklin Eliott: jaklin.eliott@adelaide.edu.au, Telephone: 8313 3855

This study has been approved by the University of Adelaide Human Research Ethics committee

Jane – Researcher
“Looking after them” study

**0404 676 304**



**If you would like me to call you, please fill in the details below and put the card into the reply paid envelope and mail it to me.**

Phone number:

______________________

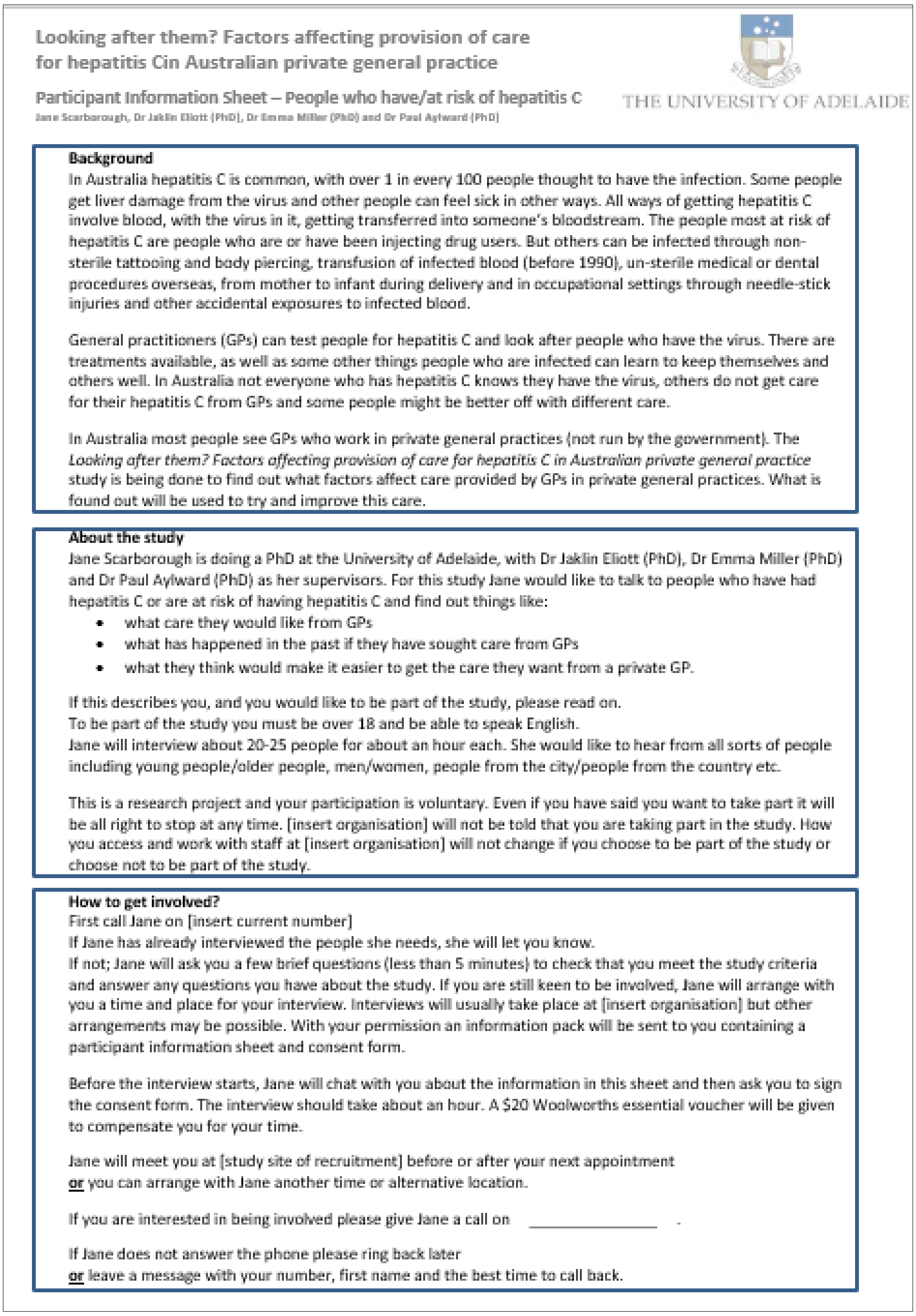
Best time to call:

________________________am/pm

First name (optional):

________________________

I will destroy this card and
any record of the call,
once I have called you.



## Looking after them? Factors affecting provision of care for hepatitis Cin Australian private general practice

### Participant Information Sheet – People who have/at risk of hepatitis C

Jane Scarborough, Dr Jaklin Eliott (PhD), Dr Emma Miller (PhD) and Dr Paul Aylward (PhD)

THE UNIVERSITY OF ADELAIDE

**Background**

In Australia hepatitis C is common, with over 1 in every 100 people thought to have the infection. Some people get liver damage from the virus and other people can feel sick in other ways. All ways of getting hepatitis C involve blood, with the virus in it, getting transferred into someone's bloodstream. The people most at risk of hepatitis C are people who are or have been injecting drug users. But others can be infected through non-sterile tattooing and body piercing, transfusion of infected blood (before 1990), un-sterile medical or dental procedures overseas, from mother to infant during delivery and in occupational settings through needle-stick injuries and other accidental exposures to infected blood.

General practitioners (GPs) can test people for hepatitis C and look after people who have the virus. There are treatments available, as well as some other things people who are infected can learn to keep themselves and others well. In Australia not everyone who has hepatitis C knows they have the virus, others do not get care for their hepatitis C from GPs and some people might be better off with different care.

In Australia most people see GPs who work in private general practices (not run by the government). The *Looking after them? Factors affecting provision of care for hepatitis C in Australian private general practice* study is being done to find out what factors affect care provided by GPs in private general practices. What is found out will be used to try and improve this care.

**About the study**

Jane Scarborough is doing a PhD at the University of Adelaide, with Dr Jaklin Eliott (PhD), Dr Emma Miller (PhD) and Dr Paul Aylward (PhD) as her supervisors. For this study Jane would like to talk to people who have had hepatitis C or are at risk of having hepatitis C and find out things like:

- what care they would like from GPs
- what has happened in the past if they have sought care from GPs
- what they think would make it easier to get the care they want from a private GP.

If this describes you, and you would like to be part of the study, please read on.
To be part of the study you must be over 18 and be able to speak English.
Jane will interview about 20-25 people for about an hour each. She would like to hear from all sorts of people including young people/older people, men/women, people from the city/people from the country etc.

This is a research project and your participation is voluntary. Even if you have said you want to take part it will be all right to stop at any time. [insert organisation] will not be told that you are taking part in the study. How you access and work with staff at [insert organisation] will not change if you choose to be part of the study or choose not to be part of the study.

**How to get involved?**

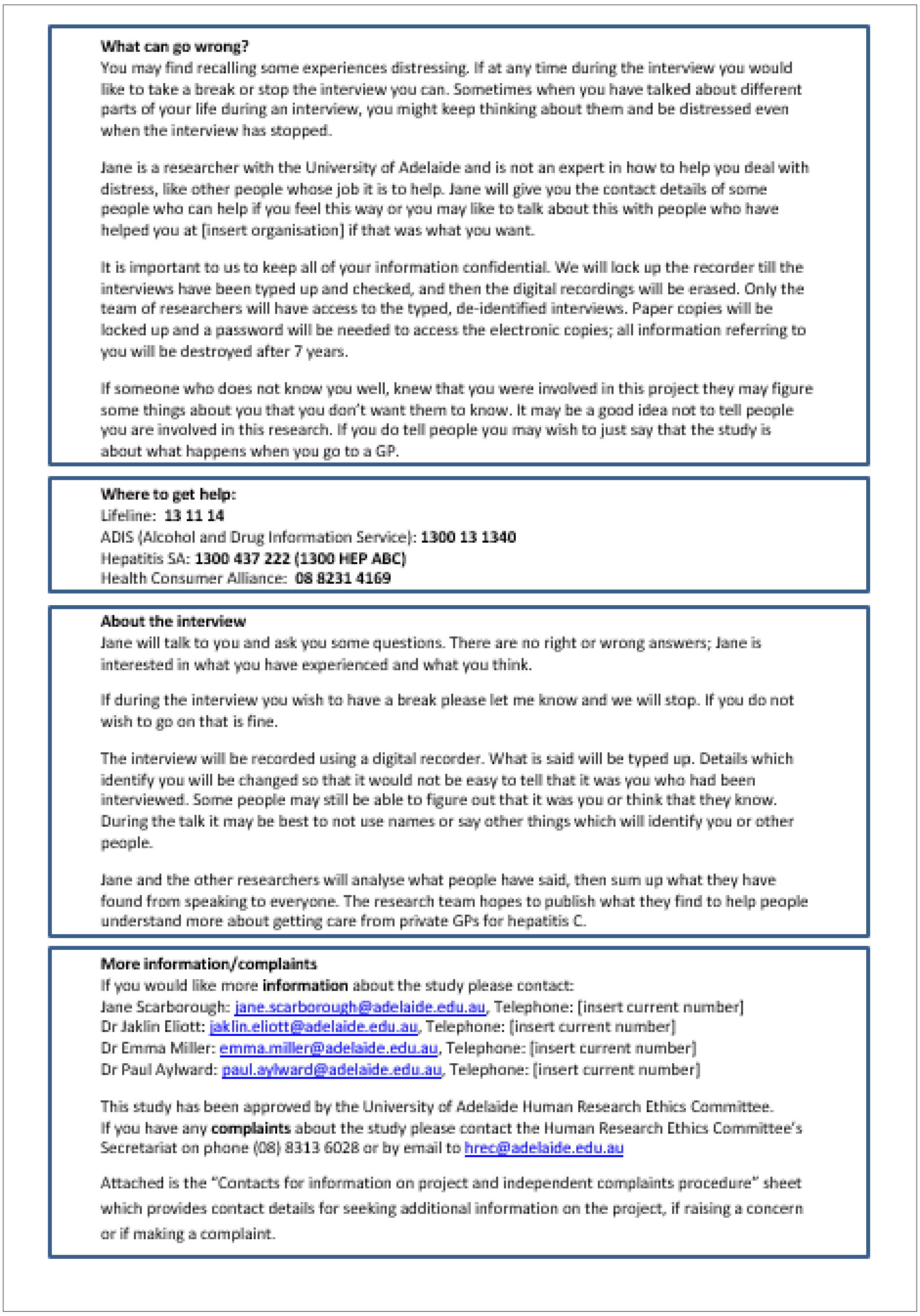
First call Jane on [insert current number]
If Jane has already interviewed the people she needs, she will let you know.
If not; Jane will ask you a few brief questions (less than 5 minutes) to check that you meet the study criteria and answer any questions you have about the study. If you are still keen to be involved, Jane will arrange with you a time and place for your interview. Interviews will usually take place at [insert organisation] but other arrangements may be possible. With your permission an information pack will be sent to you containing a participant information sheet and consent form.

Before the interview starts, Jane will chat with you about the information in this sheet and then ask you to sign the consent form. The interview should take about an hour. A $20 Woolworths essential voucher will be given to compensate you for your time.

Jane will meet you at [study site of recruitment] before or after your next appointment
**or** you can arrange with Jane another time or alternative location.

If you are interested in being involved please give Jane a call on ________________ .

If Jane does not answer the phone please ring back later
**or** leave a message with your number, first name and the best time to call back.



**What can go wrong?**
You may find recalling some experiences distressing. If at any time during the interview you would like to take a break or stop the interview you can. Sometimes when you have talked about different parts of your life during an interview, you might keep thinking about them and be distressed even when the interview has stopped.

Jane is a researcher with the University of Adelaide and is not an expert in how to help you deal with distress, like other people whose job it is to help. Jane will give you the contact details of some people who can help if you feel this way or you may like to talk about this with people who have helped you at [insert organisation] if that was what you want.

It is important to us to keep all of your information confidential. We will lock up the recorder till the interviews have been typed up and checked, and then the digital recordings will be erased. Only the team of researchers will have access to the typed, de-identified interviews. Paper copies will be locked up and a password will be needed to access the electronic copies; all information referring to you will be destroyed after 7 years.

If someone who does not know you well, knew that you were involved in this project they may figure some things about you that you don't want them to know. It may be a good idea not to tell people you are involved in this research. If you do tell people you may wish to just say that the study is about what happens when you go to a GP.

**Where to get help:**
Lifeline: **13 11 14**
ADIS (Alcohol and Drug Information Service): **1300 13 1340**
Hepatitis SA: **1300 437 222 (1300 HEP ABC)**
Health Consumer Alliance: **08 8231 4169**

**About the interview**
Jane will talk to you and ask you some questions. There are no right or wrong answers; Jane is interested in what you have experienced and what you think.

If during the interview you wish to have a break please let me know and we will stop. If you do not wish to go on that is fine.

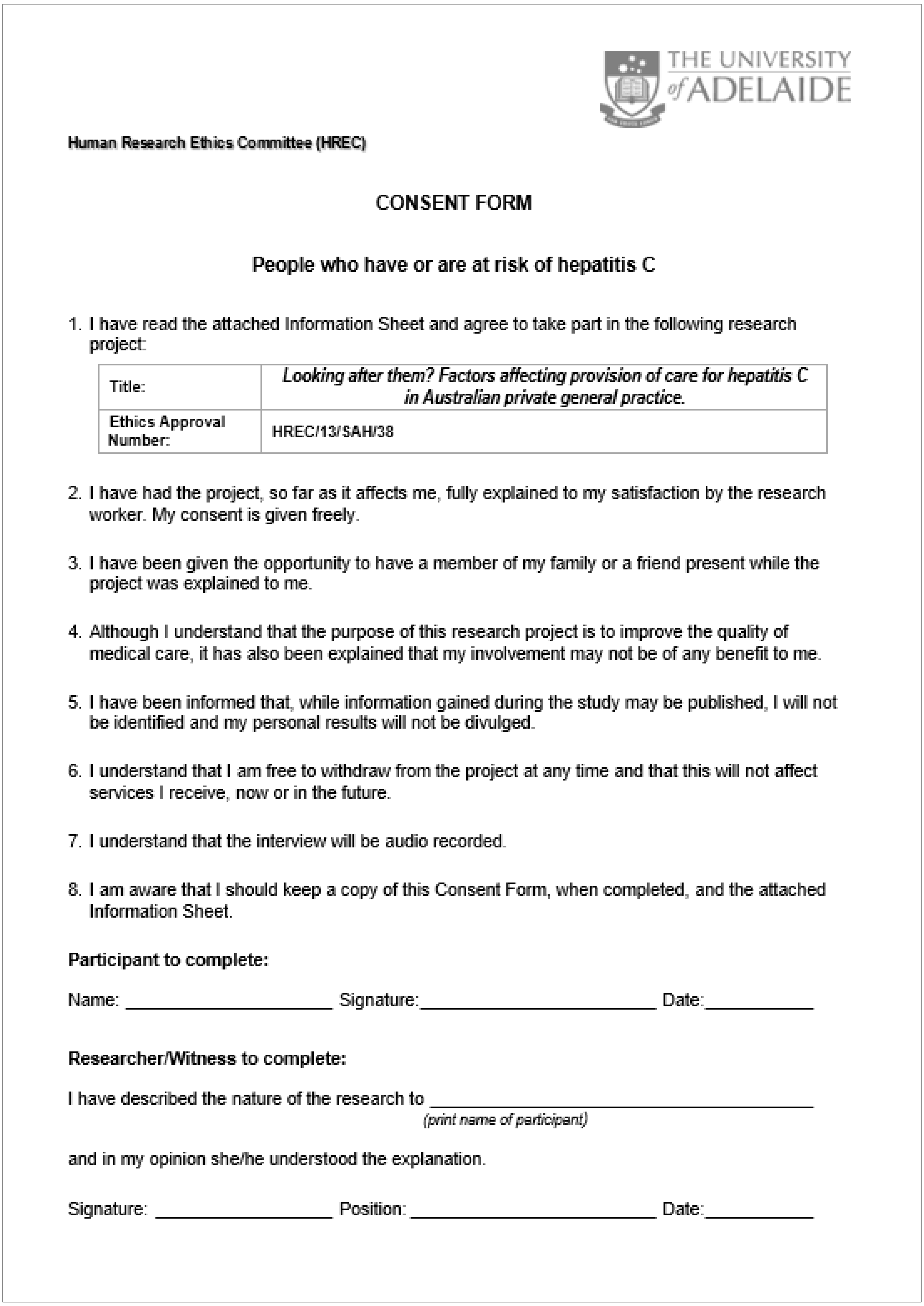
The interview will be recorded using a digital recorder. What is said will be typed up. Details which identify you will be changed so that it would not be easy to tell that it was you who had been interviewed. Some people may still be able to figure out that it was you or think that they know. During the talk it may be best to not use names or say other things which will identify you or other people.

Jane and the other researchers will analyse what people have said, then sum up what they have found from speaking to everyone. The research team hopes to publish what they find to help people understand more about getting care from private GPs for hepatitis C.

**More information/complaints**
If you would like more **information** about the study please contact:
Jane Scarborough: jane.scarborough@adelaide.edu.au, Telephone: [insert current number]
Dr Jaklin Eliott: jaklin.eliott@adelaide.edu.au, Telephone: [insert current number]
Dr Emma Miller: emma.miller@adelaide.edu.au, Telephone: [insert current number]
Dr Paul Aylward: paul.aylward@adelaide.edu.au, Telephone: [insert current number]

This study has been approved by the University of Adelaide Human Research Ethics Committee.
If you have any **complaints** about the study please contact the Human Research Ethics Committee's Secretariat on phone (08) 8313 6028 or by email to hrec@adelaide.edu.au

Attached is the "Contacts for information on project and independent complaints procedure" sheet which provides contact details for seeking additional information on the project, if raising a concern or if making a complaint.



THE UNIVERSITY of ADELAIDE

**Human Research Ethics Committee (HREC)**

## CONSENT FORM

### People who have or are at risk of hepatitis C

1. I have read the attached Information Sheet and agree to take part in the following research project:

| | |
|---|---|
| Title: | *Looking after them? Factors affecting provision of care for hepatitis C in Australian private general practice.* |
| Ethics Approval Number: | HREC/13/SAH/38 |

2. I have had the project, so far as it affects me, fully explained to my satisfaction by the research worker. My consent is given freely.
3. I have been given the opportunity to have a member of my family or a friend present while the project was explained to me.
4. Although I understand that the purpose of this research project is to improve the quality of medical care, it has also been explained that my involvement may not be of any benefit to me.
5. I have been informed that, while information gained during the study may be published, I will not be identified and my personal results will not be divulged.
6. I understand that I am free to withdraw from the project at any time and that this will not affect services I receive, now or in the future.
7. I understand that the interview will be audio recorded.
8. I am aware that I should keep a copy of this Consent Form, when completed, and the attached Information Sheet.

**Participant to complete:**

Name: ____________________ Signature:______________________ Date:__________

**Researcher/Witness to complete:**

I have described the nature of the research to ______________________________
*(print name of participant)*

and in my opinion she/he understood the explanation.

Signature: _________________ Position: ______________________ Date:__________

THE UNIVERSITY
OF ADELAIDE
AUSTRALIA

**Department of Population Health**
Division of General Practice

**Jane Scarborough**
PhD Candidate

Level 11, 178 North Tce,
THE UNIVERSITY OF ADELAIDE
SA 5005
AUSTRALIA

TELEPHONE +61 8 8313 7583
FACSIMILE +61 8 8313 3339
jane.scarborough@adelaide.edu.au
CRICOS Provider Number 00123M

22 January 2013

[Invitee's Name]
[Invitee's organisation]
[Street Address 1]
[Street Address 2]
[Suburb] SA [Postcode]

Dear [Invitee's name]

**Re: Getting care for hepatitis C from private GPs study - Invitation to participate**

Jane Scarborough is a PhD candidate, supervised by Dr Jaklin Eliott (PhD), Dr Emma Miller (PhD) and Dr Paul Aylward (PhD). Her project involves investigating the factors that determine the provision of care by private general practitioners (GPs) in Australia to people with hepatitis C. In the first stage of this project the aim is to gain an understanding of the experiences and perspectives of people with or likely to have hepatitis C regarding their engagement with private GPs for hepatitis C care.

We believe that as a [invitee's position] at [Invitee's organisation] you may have had clients relay their experiences in this regard and/or have advocated for clients seeking care from private GPs. You may also have personal experience with hepatitis C exposure or diagnosis.

Your contact details have been provided to us by [Invitee's organisation], but this is a research project and any involvement by you is entirely voluntary. [Invitee's organisation] will not be informed if you do or don't participate and your employment will not be affected by the decision you make in regard to participation. All your information will be treated confidentially throughout the project.

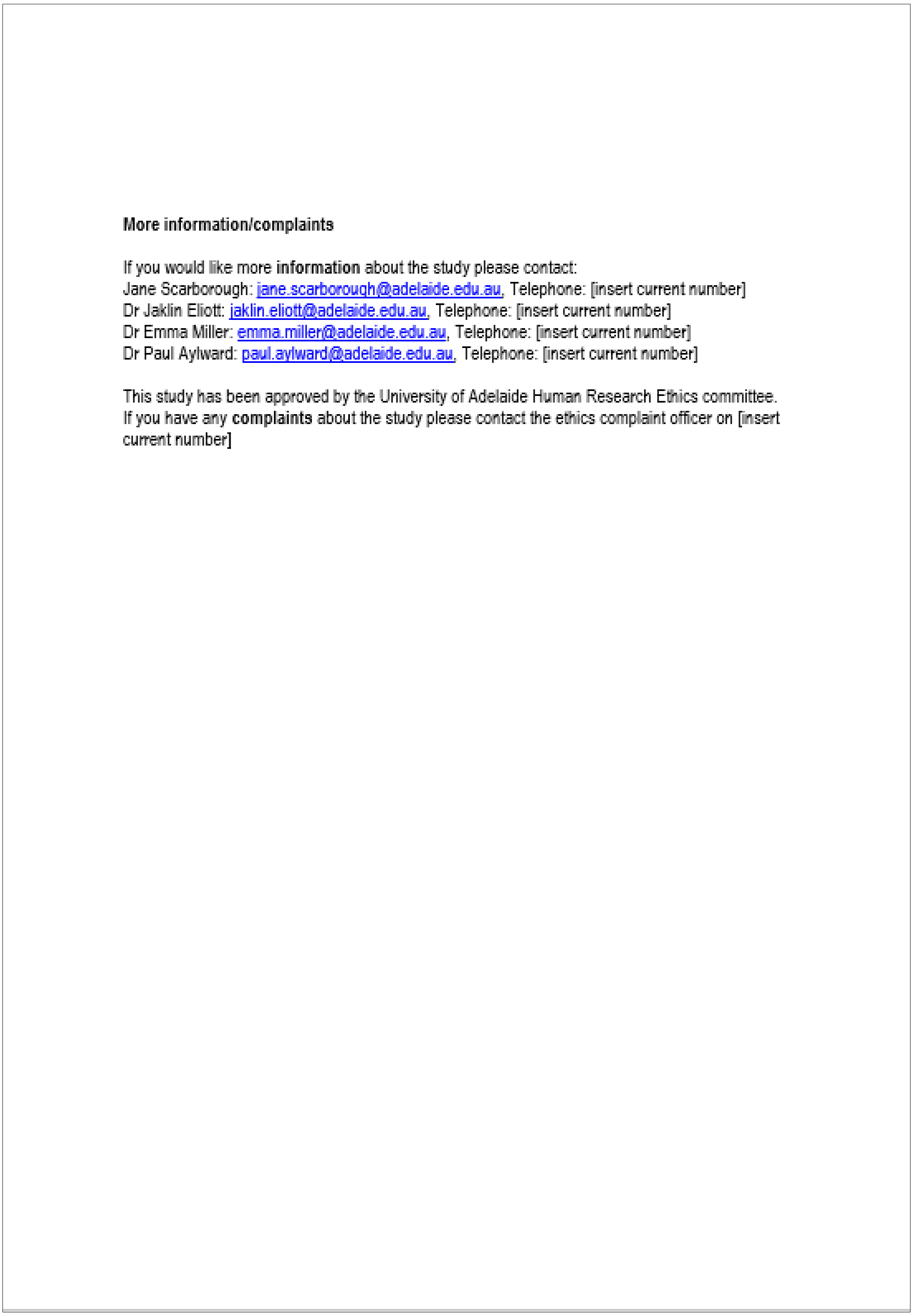
Enclosed is a *Participant Information Sheet* which provides further information about the project and what is involved. The interviews are anticipated to take around 1 hour. Please read through the information and if you choose to participate contact Jane Scarborough on [insert current number] to arrange an interview time.

Please see on the back of this page contact information for each of the research team if you have further questions or concerns regarding the project.

Thank you for your time in considering this invitation.

Yours sincerely

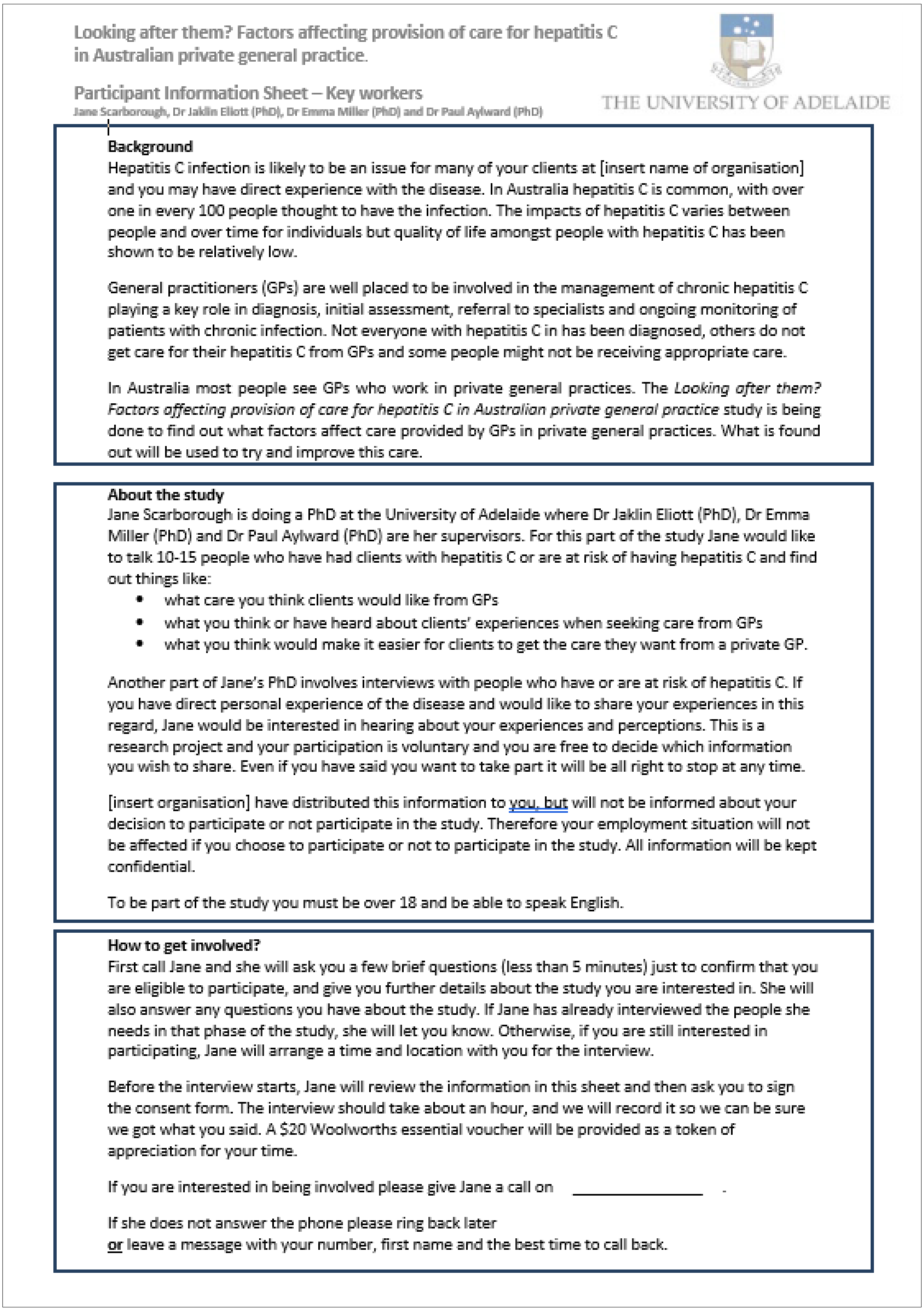
| | |
|---|---|
| JANE SCARBOROUGH | DR JAKLIN ELIOTT |
| PhD CANDIDATE | SENIOR LECTURER, PRINCIPAL SUPERVISOR |



**More information/complaints**

If you would like more **information** about the study please contact:
Jane Scarborough: jane.scarborough@adelaide.edu.au, Telephone: [insert current number]
Dr Jaklin Eliott: jaklin.eliott@adelaide.edu.au, Telephone: [insert current number]
Dr Emma Miller: emma.miller@adelaide.edu.au, Telephone: [insert current number]
Dr Paul Aylward: paul.aylward@adelaide.edu.au, Telephone: [insert current number]

This study has been approved by the University of Adelaide Human Research Ethics committee. If you have any **complaints** about the study please contact the ethics complaint officer on [insert current number]



## Looking after them? Factors affecting provision of care for hepatitis C in Australian private general practice.

THE UNIVERSITY OF ADELAIDE

### Participant Information Sheet – Key workers

Jane Scarborough, Dr Jaklin Eliott (PhD), Dr Emma Miller (PhD) and Dr Paul Aylward (PhD)

**Background**

Hepatitis C infection is likely to be an issue for many of your clients at [insert name of organisation] and you may have direct experience with the disease. In Australia hepatitis C is common, with over one in every 100 people thought to have the infection. The impacts of hepatitis C varies between people and over time for individuals but quality of life amongst people with hepatitis C has been shown to be relatively low.

General practitioners (GPs) are well placed to be involved in the management of chronic hepatitis C playing a key role in diagnosis, initial assessment, referral to specialists and ongoing monitoring of patients with chronic infection. Not everyone with hepatitis C in has been diagnosed, others do not get care for their hepatitis C from GPs and some people might not be receiving appropriate care.

In Australia most people see GPs who work in private general practices. The *Looking after them? Factors affecting provision of care for hepatitis C in Australian private general practice* study is being done to find out what factors affect care provided by GPs in private general practices. What is found out will be used to try and improve this care.

**About the study**

Jane Scarborough is doing a PhD at the University of Adelaide where Dr Jaklin Eliott (PhD), Dr Emma Miller (PhD) and Dr Paul Aylward (PhD) are her supervisors. For this part of the study Jane would like to talk 10-15 people who have had clients with hepatitis C or are at risk of having hepatitis C and find out things like:

- what care you think clients would like from GPs
- what you think or have heard about clients' experiences when seeking care from GPs
- what you think would make it easier for clients to get the care they want from a private GP.

Another part of Jane's PhD involves interviews with people who have or are at risk of hepatitis C. If you have direct personal experience of the disease and would like to share your experiences in this regard, Jane would be interested in hearing about your experiences and perceptions. This is a research project and your participation is voluntary and you are free to decide which information you wish to share. Even if you have said you want to take part it will be all right to stop at any time.

[insert organisation] have distributed this information to you, but will not be informed about your decision to participate or not participate in the study. Therefore your employment situation will not be affected if you choose to participate or not to participate in the study. All information will be kept confidential.

To be part of the study you must be over 18 and be able to speak English.

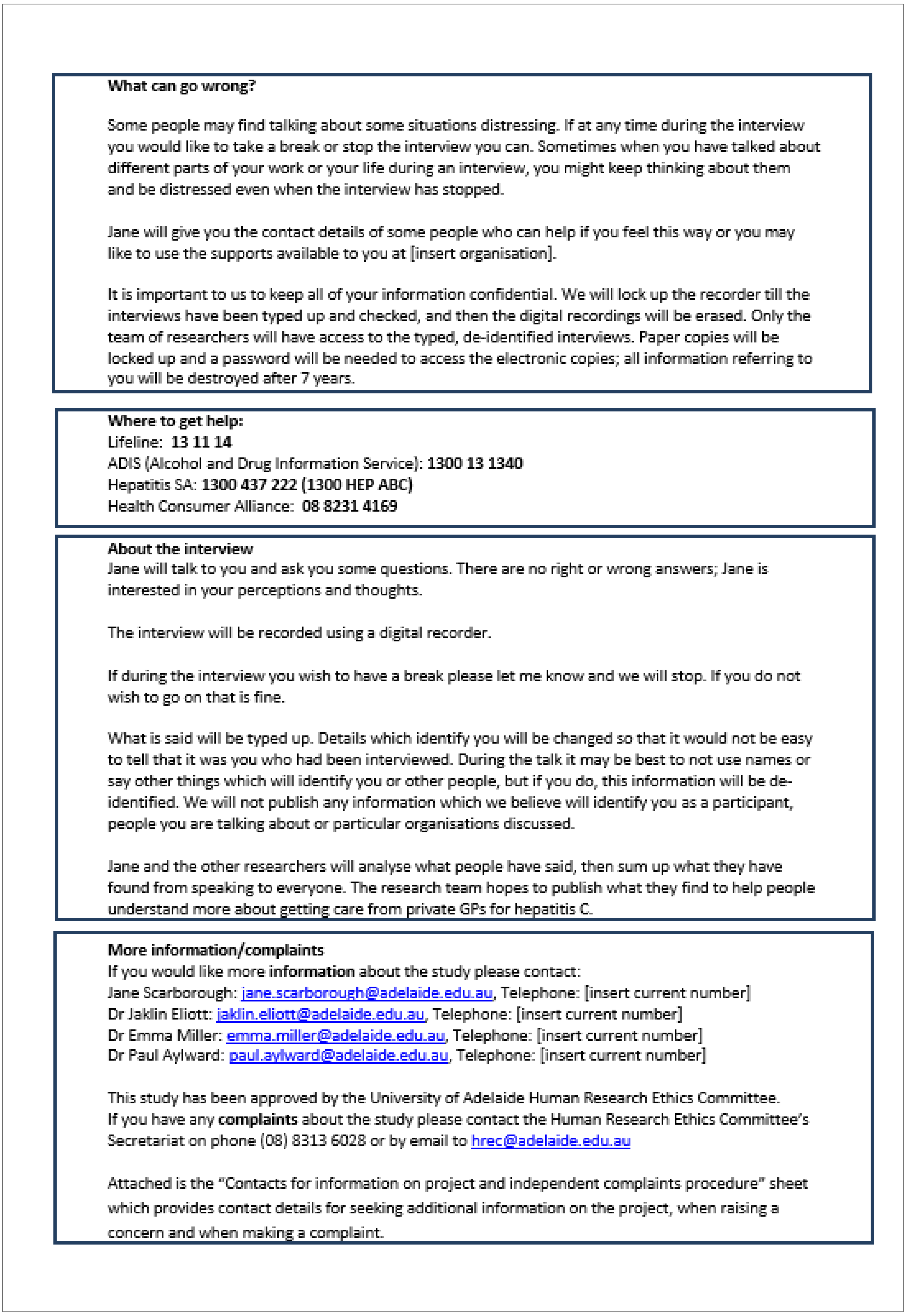
**How to get involved?**

First call Jane and she will ask you a few brief questions (less than 5 minutes) just to confirm that you are eligible to participate, and give you further details about the study you are interested in. She will also answer any questions you have about the study. If Jane has already interviewed the people she needs in that phase of the study, she will let you know. Otherwise, if you are still interested in participating, Jane will arrange a time and location with you for the interview.

Before the interview starts, Jane will review the information in this sheet and then ask you to sign the consent form. The interview should take about an hour, and we will record it so we can be sure we got what you said. A $20 Woolworths essential voucher will be provided as a token of appreciation for your time.

If you are interested in being involved please give Jane a call on ________________ .

If she does not answer the phone please ring back later
or leave a message with your number, first name and the best time to call back.



**What can go wrong?**

Some people may find talking about some situations distressing. If at any time during the interview you would like to take a break or stop the interview you can. Sometimes when you have talked about different parts of your work or your life during an interview, you might keep thinking about them and be distressed even when the interview has stopped.

Jane will give you the contact details of some people who can help if you feel this way or you may like to use the supports available to you at [insert organisation].

It is important to us to keep all of your information confidential. We will lock up the recorder till the interviews have been typed up and checked, and then the digital recordings will be erased. Only the team of researchers will have access to the typed, de-identified interviews. Paper copies will be locked up and a password will be needed to access the electronic copies; all information referring to you will be destroyed after 7 years.

**Where to get help:**
Lifeline: **13 11 14**
ADIS (Alcohol and Drug Information Service): **1300 13 1340**
Hepatitis SA: **1300 437 222 (1300 HEP ABC)**
Health Consumer Alliance: **08 8231 4169**

**About the interview**
Jane will talk to you and ask you some questions. There are no right or wrong answers; Jane is interested in your perceptions and thoughts.

The interview will be recorded using a digital recorder.

If during the interview you wish to have a break please let me know and we will stop. If you do not wish to go on that is fine.

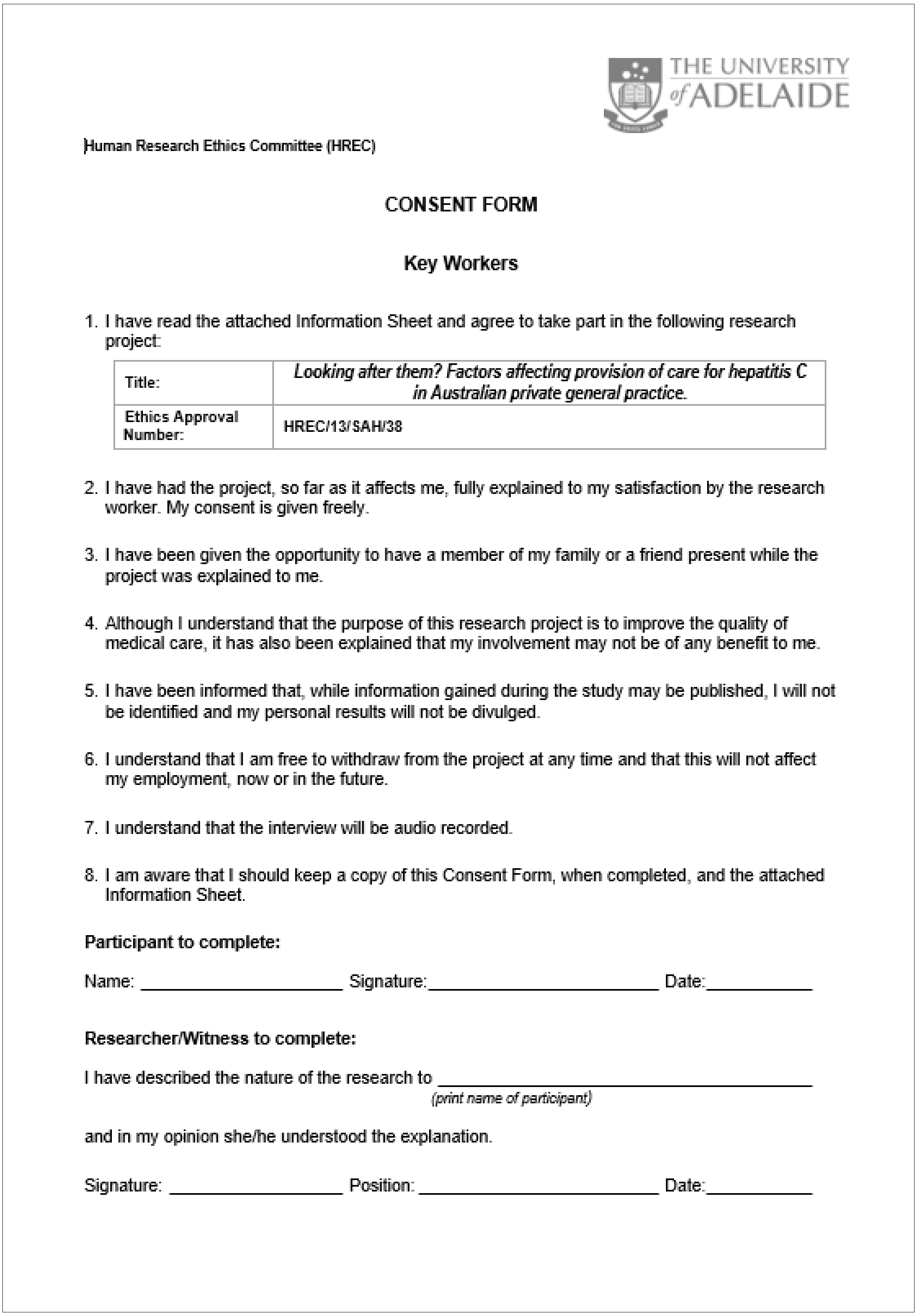
What is said will be typed up. Details which identify you will be changed so that it would not be easy to tell that it was you who had been interviewed. During the talk it may be best to not use names or say other things which will identify you or other people, but if you do, this information will be de-identified. We will not publish any information which we believe will identify you as a participant, people you are talking about or particular organisations discussed.

Jane and the other researchers will analyse what people have said, then sum up what they have found from speaking to everyone. The research team hopes to publish what they find to help people understand more about getting care from private GPs for hepatitis C.

**More information/complaints**
If you would like more **information** about the study please contact:
Jane Scarborough: jane.scarborough@adelaide.edu.au, Telephone: [insert current number]
Dr Jaklin Eliott: jaklin.eliott@adelaide.edu.au, Telephone: [insert current number]
Dr Emma Miller: emma.miller@adelaide.edu.au, Telephone: [insert current number]
Dr Paul Aylward: paul.aylward@adelaide.edu.au, Telephone: [insert current number]

This study has been approved by the University of Adelaide Human Research Ethics Committee.
If you have any **complaints** about the study please contact the Human Research Ethics Committee's Secretariat on phone (08) 8313 6028 or by email to hrec@adelaide.edu.au

Attached is the "Contacts for information on project and independent complaints procedure" sheet which provides contact details for seeking additional information on the project, when raising a concern and when making a complaint.



THE UNIVERSITY of ADELAIDE

Human Research Ethics Committee (HREC)

## CONSENT FORM

### Key Workers

1. I have read the attached Information Sheet and agree to take part in the following research project:

| | |
|---|---|
| Title: | *Looking after them? Factors affecting provision of care for hepatitis C in Australian private general practice.* |
| Ethics Approval Number: | HREC/13/SAH/38 |

2. I have had the project, so far as it affects me, fully explained to my satisfaction by the research worker. My consent is given freely.
3. I have been given the opportunity to have a member of my family or a friend present while the project was explained to me.
4. Although I understand that the purpose of this research project is to improve the quality of medical care, it has also been explained that my involvement may not be of any benefit to me.
5. I have been informed that, while information gained during the study may be published, I will not be identified and my personal results will not be divulged.
6. I understand that I am free to withdraw from the project at any time and that this will not affect my employment, now or in the future.
7. I understand that the interview will be audio recorded.
8. I am aware that I should keep a copy of this Consent Form, when completed, and the attached Information Sheet.

**Participant to complete:**

Name: ____________________ Signature:______________________ Date:__________

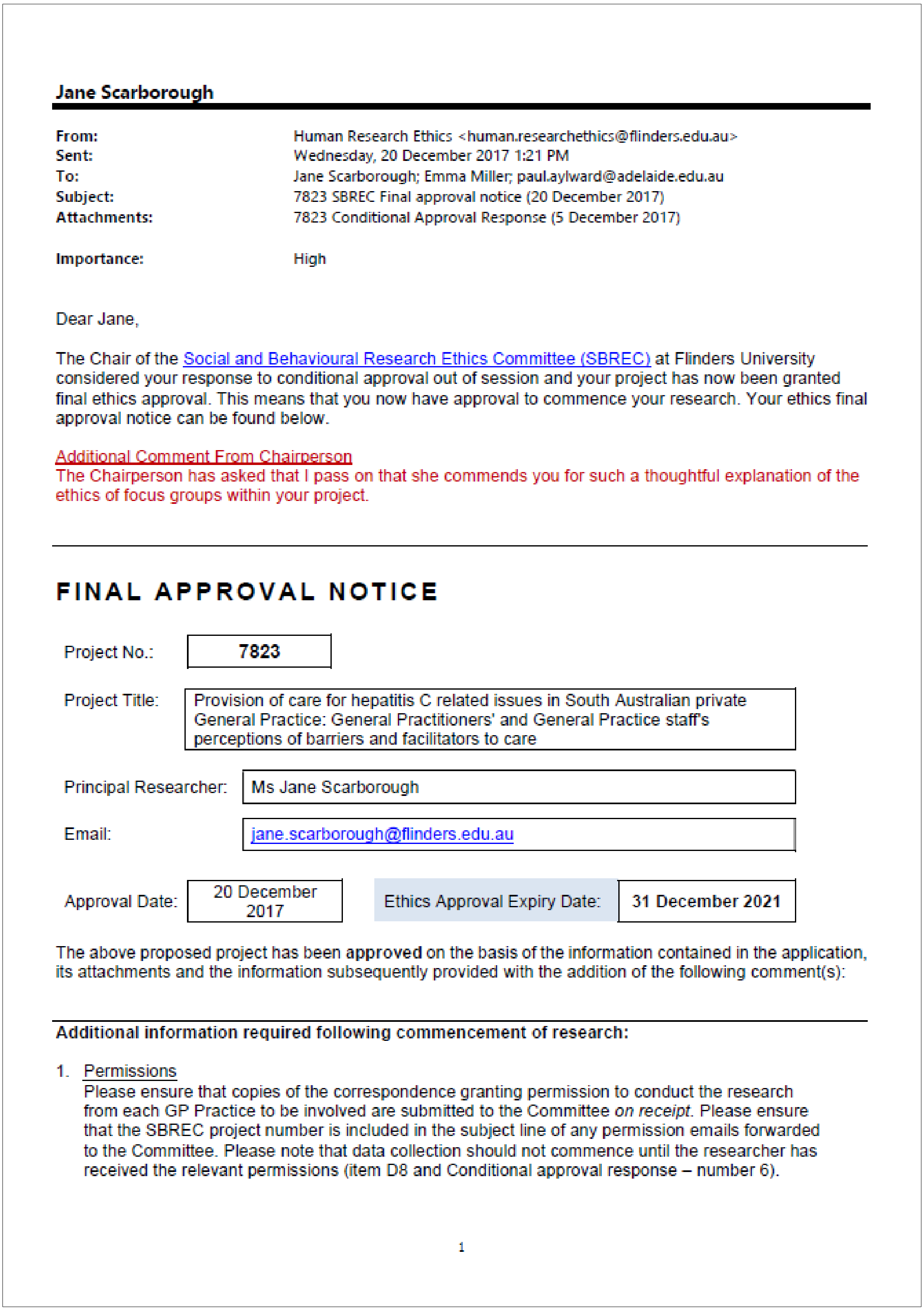
**Researcher/Witness to complete:**

I have described the nature of the research to ____________________________________
*(print name of participant)*

and in my opinion she/he understood the explanation.

Signature: ________________ Position: ______________________ Date:__________

## Appendix 7: Ethics approval *Study 3*



**Jane Scarborough**

**From:** Human Research Ethics <human.researchethics@flinders.edu.au>
**Sent:** Wednesday, 20 December 2017 1:21 PM
**To:** Jane Scarborough; Emma Miller; paul.aylward@adelaide.edu.au
**Subject:** 7823 SBREC Final approval notice (20 December 2017)
**Attachments:** 7823 Conditional Approval Response (5 December 2017)

**Importance:** High

Dear Jane,

The Chair of the Social and Behavioural Research Ethics Committee (SBREC) at Flinders University considered your response to conditional approval out of session and your project has now been granted final ethics approval. This means that you now have approval to commence your research. Your ethics final approval notice can be found below.

Additional Comment From Chairperson
The Chairperson has asked that I pass on that she commends you for such a thoughtful explanation of the ethics of focus groups within your project.

---

### FINAL APPROVAL NOTICE

Project No.: **7823**

Project Title: Provision of care for hepatitis C related issues in South Australian private General Practice: General Practitioners' and General Practice staff's perceptions of barriers and facilitators to care

Principal Researcher: Ms Jane Scarborough

Email: jane.scarborough@flinders.edu.au

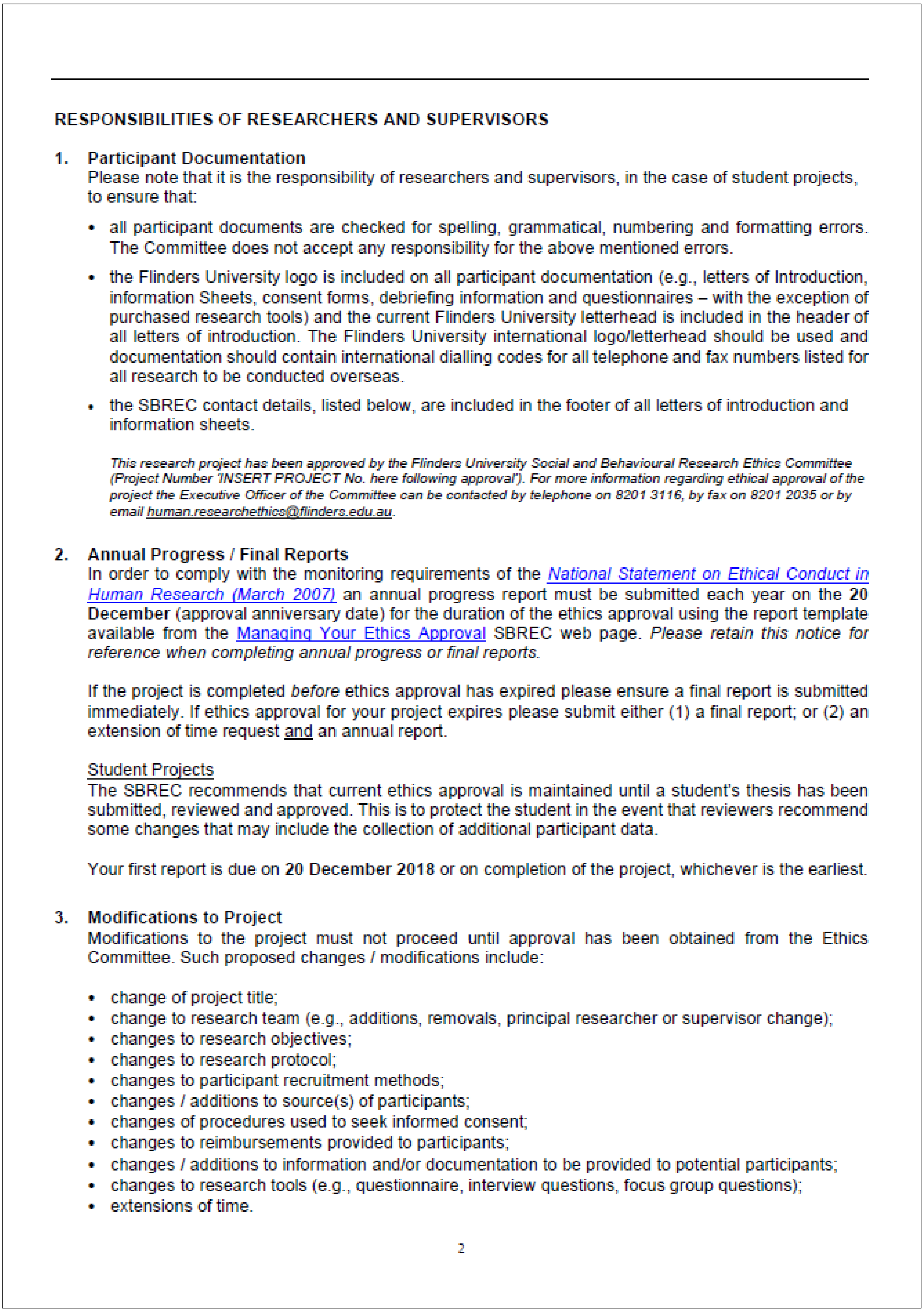
Approval Date: 20 December 2017

Ethics Approval Expiry Date: **31 December 2021**

The above proposed project has been **approved** on the basis of the information contained in the application, its attachments and the information subsequently provided with the addition of the following comment(s):

**Additional information required following commencement of research:**

1. Permissions
   Please ensure that copies of the correspondence granting permission to conduct the research from each GP Practice to be involved are submitted to the Committee *on receipt*. Please ensure that the SBREC project number is included in the subject line of any permission emails forwarded to the Committee. Please note that data collection should not commence until the researcher has received the relevant permissions (item D8 and Conditional approval response – number 6).



---

## RESPONSIBILITIES OF RESEARCHERS AND SUPERVISORS

### 1. Participant Documentation

Please note that it is the responsibility of researchers and supervisors, in the case of student projects, to ensure that:

- all participant documents are checked for spelling, grammatical, numbering and formatting errors. The Committee does not accept any responsibility for the above mentioned errors.
- the Flinders University logo is included on all participant documentation (e.g., letters of Introduction, information Sheets, consent forms, debriefing information and questionnaires – with the exception of purchased research tools) and the current Flinders University letterhead is included in the header of all letters of introduction. The Flinders University international logo/letterhead should be used and documentation should contain international dialling codes for all telephone and fax numbers listed for all research to be conducted overseas.
- the SBREC contact details, listed below, are included in the footer of all letters of introduction and information sheets.

> *This research project has been approved by the Flinders University Social and Behavioural Research Ethics Committee (Project Number 'INSERT PROJECT No. here following approval'). For more information regarding ethical approval of the project the Executive Officer of the Committee can be contacted by telephone on 8201 3116, by fax on 8201 2035 or by email human.researchethics@flinders.edu.au.*

### 2. Annual Progress / Final Reports

In order to comply with the monitoring requirements of the *National Statement on Ethical Conduct in Human Research (March 2007)* an annual progress report must be submitted each year on the **20 December** (approval anniversary date) for the duration of the ethics approval using the report template available from the Managing Your Ethics Approval SBREC web page. *Please retain this notice for reference when completing annual progress or final reports.*

If the project is completed *before* ethics approval has expired please ensure a final report is submitted immediately. If ethics approval for your project expires please submit either (1) a final report; or (2) an extension of time request and an annual report.

Student Projects

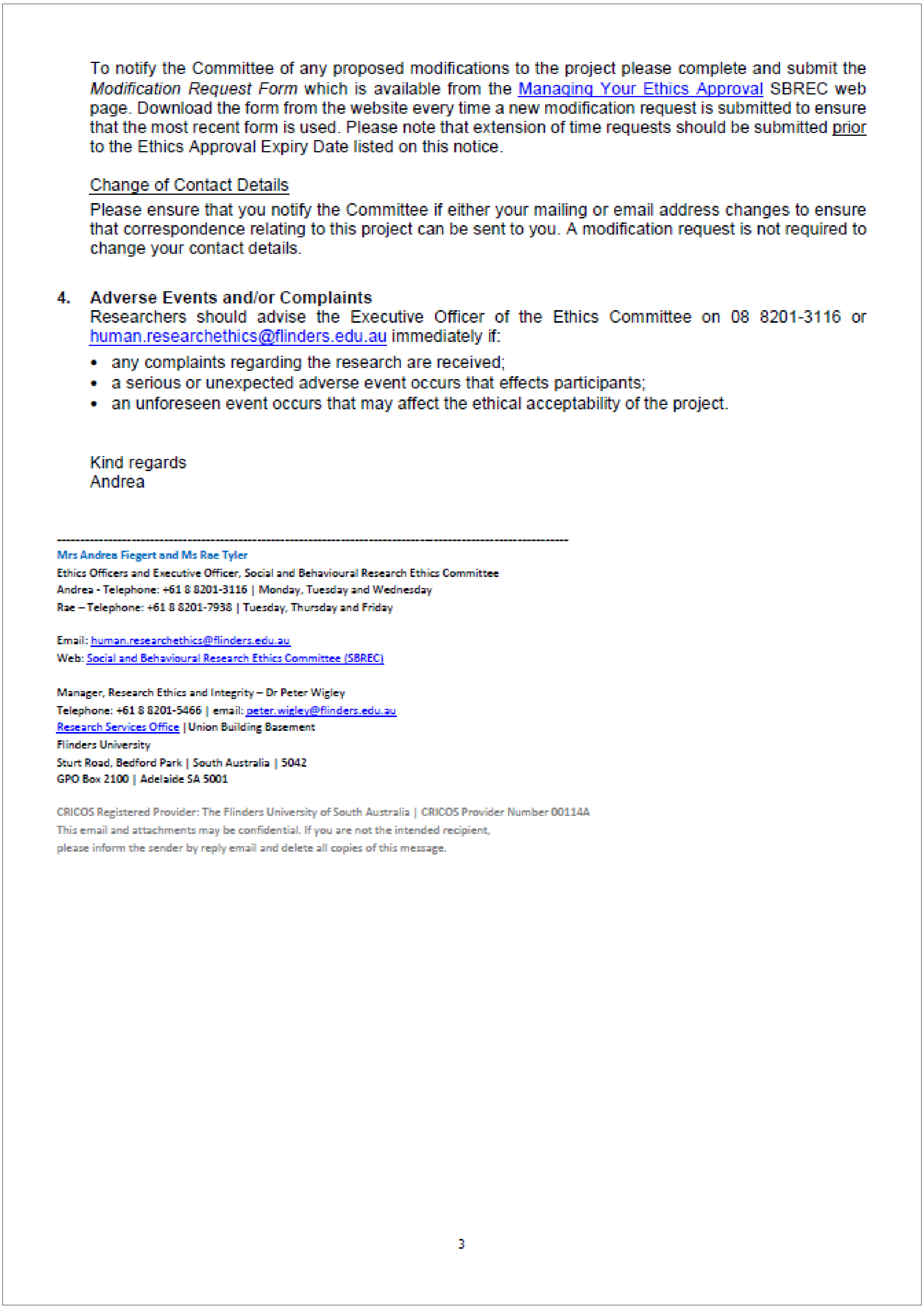
The SBREC recommends that current ethics approval is maintained until a student's thesis has been submitted, reviewed and approved. This is to protect the student in the event that reviewers recommend some changes that may include the collection of additional participant data.

Your first report is due on **20 December 2018** or on completion of the project, whichever is the earliest.

### 3. Modifications to Project

Modifications to the project must not proceed until approval has been obtained from the Ethics Committee. Such proposed changes / modifications include:

- change of project title;
- change to research team (e.g., additions, removals, principal researcher or supervisor change);
- changes to research objectives;
- changes to research protocol;
- changes to participant recruitment methods;
- changes / additions to source(s) of participants;
- changes of procedures used to seek informed consent;
- changes to reimbursements provided to participants;
- changes / additions to information and/or documentation to be provided to potential participants;
- changes to research tools (e.g., questionnaire, interview questions, focus group questions);
- extensions of time.



To notify the Committee of any proposed modifications to the project please complete and submit the *Modification Request Form* which is available from the Managing Your Ethics Approval SBREC web page. Download the form from the website every time a new modification request is submitted to ensure that the most recent form is used. Please note that extension of time requests should be submitted prior to the Ethics Approval Expiry Date listed on this notice.

Change of Contact Details

Please ensure that you notify the Committee if either your mailing or email address changes to ensure that correspondence relating to this project can be sent to you. A modification request is not required to change your contact details.

**4. Adverse Events and/or Complaints**

Researchers should advise the Executive Officer of the Ethics Committee on 08 8201-3116 or human.researchethics@flinders.edu.au immediately if:

- any complaints regarding the research are received;
- a serious or unexpected adverse event occurs that effects participants;
- an unforeseen event occurs that may affect the ethical acceptability of the project.

Kind regards
Andrea

---

**Mrs Andrea Fiegert and Ms Rae Tyler**
Ethics Officers and Executive Officer, Social and Behavioural Research Ethics Committee
Andrea - Telephone: +61 8 8201-3116 | Monday, Tuesday and Wednesday
Rae – Telephone: +61 8 8201-7938 | Tuesday, Thursday and Friday

Email: human.researchethics@flinders.edu.au
Web: Social and Behavioural Research Ethics Committee (SBREC)

Manager, Research Ethics and Integrity – Dr Peter Wigley
Telephone: +61 8 8201-5466 | email: peter.wigley@flinders.edu.au
Research Services Office |Union Building Basement
Flinders University
Sturt Road, Bedford Park | South Australia | 5042
GPO Box 2100 | Adelaide SA 5001

## Appendix 8: Recruitment material *Study 3*

HepatitisSA
Information • support • education
*Leading the South Australian community response to viral hepatitis*

26 July 2018

Dear Doctor

**Re: Invitation to participate in research study:** ***Looking after them? The provision of care of people affected by hepatitis C in private general practice in South Australia***

Due to your interest in viral hepatitis, Hepatitis SA is sending you this invitation to participate in the above research study, being undertaken by Flinders University Phd candidate, Jane Scarborough.

Please be assured that during the distribution of this invitation your information has not been released to a third party.

Please note that whilst Hepatitis SA has distributed the information, this project is not being conducted by Hepatitis SA. If you consider the information provided and want to be involved, please contact Jane Scarborough directly via the contact details provided.

Your involvement in the project is completely voluntary. Hepatitis SA will not be informed whether you participate in the research and any ongoing interaction with Hepatitis SA will not be affected by your decision in this regard.

The research has been granted ethics approval (Ref: 7283) by the Social and Behavioural Research Ethics Committee (SBREC) at Flinders University. Further details about the project are enclosed.

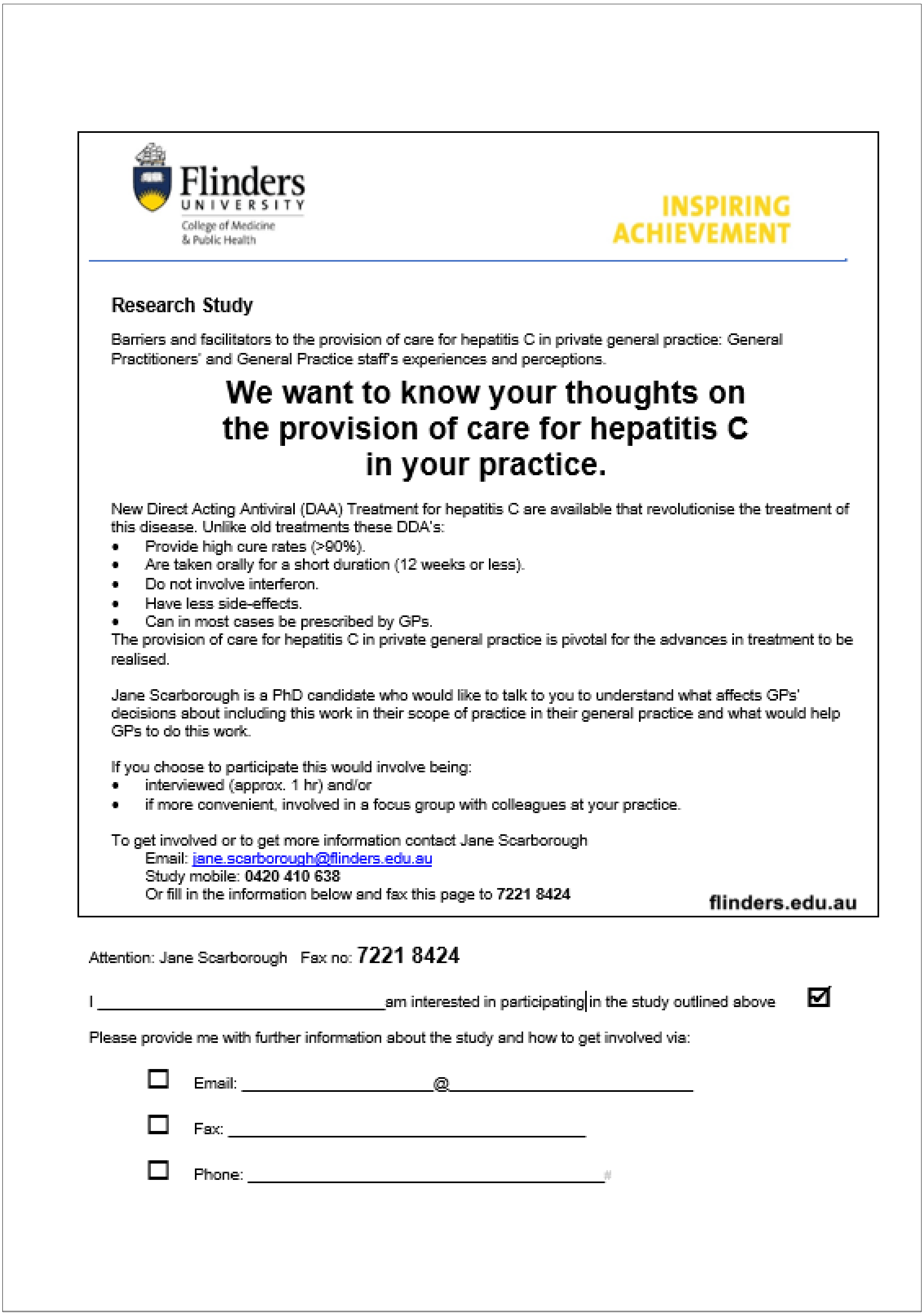
Hepatitis SA is very pleased to support South Australian research in viral hepatitis, and hope that you will be able to find the time to participate.

Thank you for considering this invitation.

Regards

K Paterson
Kerry Paterson
Executive Officer

Tel: 8362 8443 – Tel Regional: 1800 437 222 – Fax: 8362 8559
Email: admin@hepsa.asn.au – PO Box 782, Kent Town SA 5071 – 3 Hackney Road, Hackney SA 5069
www.hepsa.asn.au



Flinders UNIVERSITY
College of Medicine & Public Health

INSPIRING ACHIEVEMENT

**Research Study**

Barriers and facilitators to the provision of care for hepatitis C in private general practice: General Practitioners' and General Practice staff's experiences and perceptions.

**We want to know your thoughts on the provision of care for hepatitis C in your practice.**

New Direct Acting Antiviral (DAA) Treatment for hepatitis C are available that revolutionise the treatment of this disease. Unlike old treatments these DDA's:

- Provide high cure rates (>90%).
- Are taken orally for a short duration (12 weeks or less).
- Do not involve interferon.
- Have less side-effects.
- Can in most cases be prescribed by GPs.

The provision of care for hepatitis C in private general practice is pivotal for the advances in treatment to be realised.

Jane Scarborough is a PhD candidate who would like to talk to you to understand what affects GPs' decisions about including this work in their scope of practice in their general practice and what would help GPs to do this work.

If you choose to participate this would involve being:

- interviewed (approx. 1 hr) and/or
- if more convenient, involved in a focus group with colleagues at your practice.

To get involved or to get more information contact Jane Scarborough
Email: jane.scarborough@flinders.edu.au
Study mobile: **0420 410 638**
Or fill in the information below and fax this page to **7221 8424**

**flinders.edu.au**

Attention: Jane Scarborough Fax no: **7221 8424**

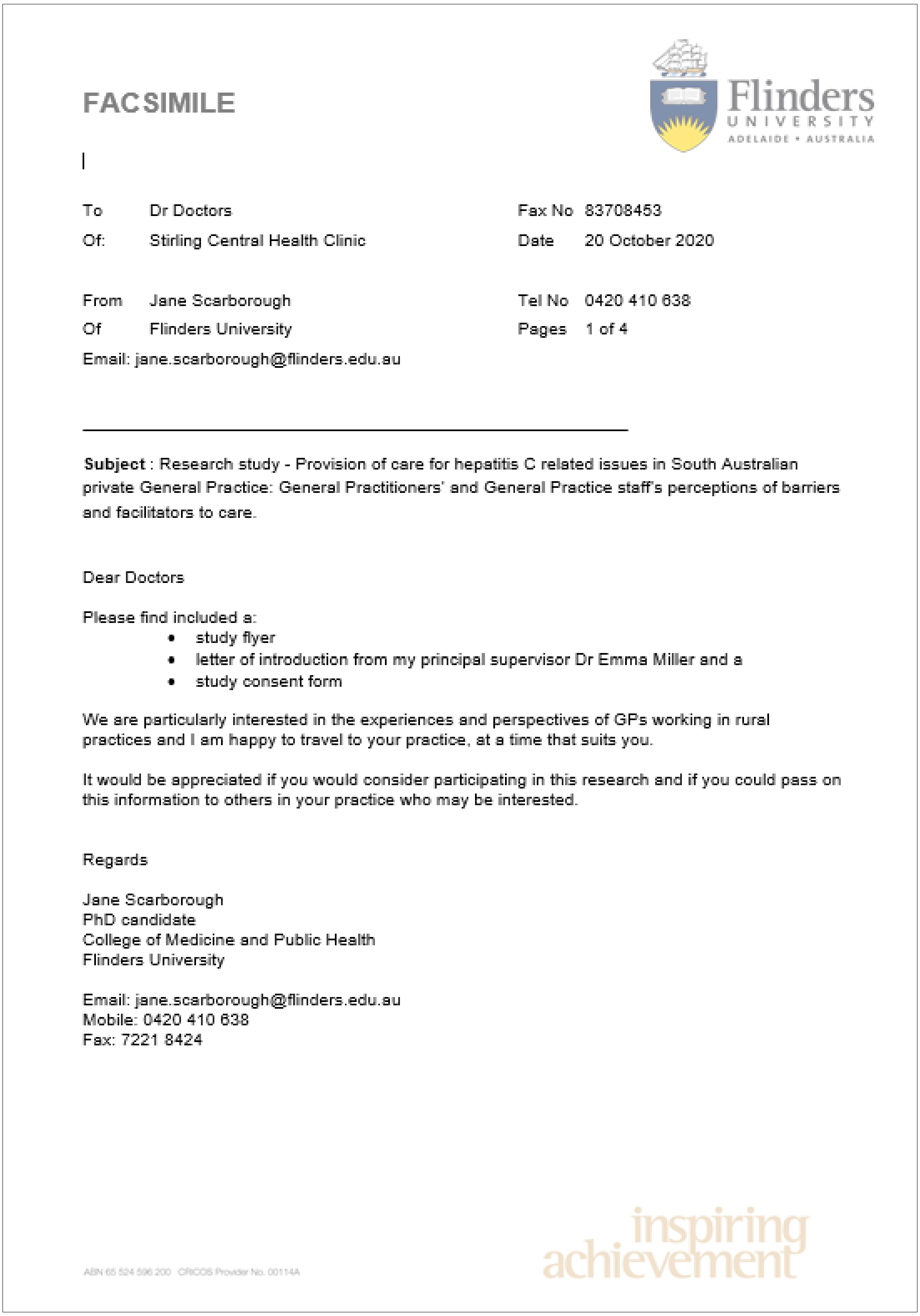
I ______________________________ am interested in participating in the study outlined above ☑

Please provide me with further information about the study and how to get involved via:

☐ Email: ____________________@__________________________

☐ Fax: ______________________________________

☐ Phone: ______________________________________



Flinders
UNIVERSITY
ADELAIDE • AUSTRALIA

## FACSIMILE

| | | | |
|---|---|---|---|
| To | Dr Doctors | Fax No | 83708453 |
| Of: | Stirling Central Health Clinic | Date | 20 October 2020 |
| From | Jane Scarborough | Tel No | 0420 410 638 |
| Of | Flinders University | Pages | 1 of 4 |

Email: jane.scarborough@flinders.edu.au

---

**Subject** : Research study - Provision of care for hepatitis C related issues in South Australian private General Practice: General Practitioners' and General Practice staff's perceptions of barriers and facilitators to care.

Dear Doctors

Please find included a:

- study flyer
- letter of introduction from my principal supervisor Dr Emma Miller and a
- study consent form

We are particularly interested in the experiences and perspectives of GPs working in rural practices and I am happy to travel to your practice, at a time that suits you.

It would be appreciated if you would consider participating in this research and if you could pass on this information to others in your practice who may be interested.

Regards

Jane Scarborough
PhD candidate
College of Medicine and Public Health
Flinders University

Email: jane.scarborough@flinders.edu.au
Mobile: 0420 410 638
Fax: 7221 8424

Flinders University

Dr Emma Miller
College of Medicine and Public Health
Health Sciences Building (2.17)

GPO Box 2100
Adelaide SA 5001
Tel: 08 72218445
Fax: 08 72218424
emma.miller@flinders.edu.au
https://www.flinders.edu.au/
CRICOS Provider No. 00114A

July 27, 2018

**LETTER OF INTRODUCTION**
(General Practitioners)

Dear Doctor

This letter is to introduce Mrs Jane Scarborough who is a PhD candidate in the College of Medicine and Public Health at Flinders University, under my supervision and under that of Dr Paul Aylward.

She is undertaking research leading to the production of a thesis and other publications on the subject of: "General Practitioners' and General Practice staff's perceptions of barriers and facilitators to the provision of care for hepatitis C in general practice".

Ms Scarborough would like to invite you to assist with this project by participating in a semi-structured interview, which would take about an hour. She is interested in your experiences and perceptions regarding the provision of care for people affected by hepatitis C by GPs in private general practice. Please note that your involvement would be completely voluntary, you can decline to answer questions during the interview and will be entirely free to discontinue your participation in the interview at any time.

Please be assured that any information provided will be treated by her and her supervisors, in the strictest confidence and no individuals or general practices will be identifiable in the resulting publications. However, if you choose to be interviewed at your practice, your colleagues may correctly identify you as a participant of this study, and therefore your involvement cannot be guaranteed to be anonymous.

Before participating, you will be required to complete the "Consent to participate" form (attached) which Ms Scarborough will collect prior to the interview. Your consent will be sought for a digital recording of the interview to be made, to use a transcription of the recording in publications, and on condition that your identity or general practice is not revealed. A transcription service may be used to transcribe the interview recording, in which case people providing this service will be required to sign an agreement to protect the confidentiality of the information provided.

Any enquiries you may have concerning this project should be directed to me at the address given above or by telephone on 08 72218445, fax 08 72218424 or e-mail emma.miller@flinders.edu.au.

To get information about involvement contact Jane Scarborough

- Email: jane.scarborough@flinders.edu.au
- Study mobile: 0420 410 638
- Or use the fax back sheet provided. Fax: 7221 8424

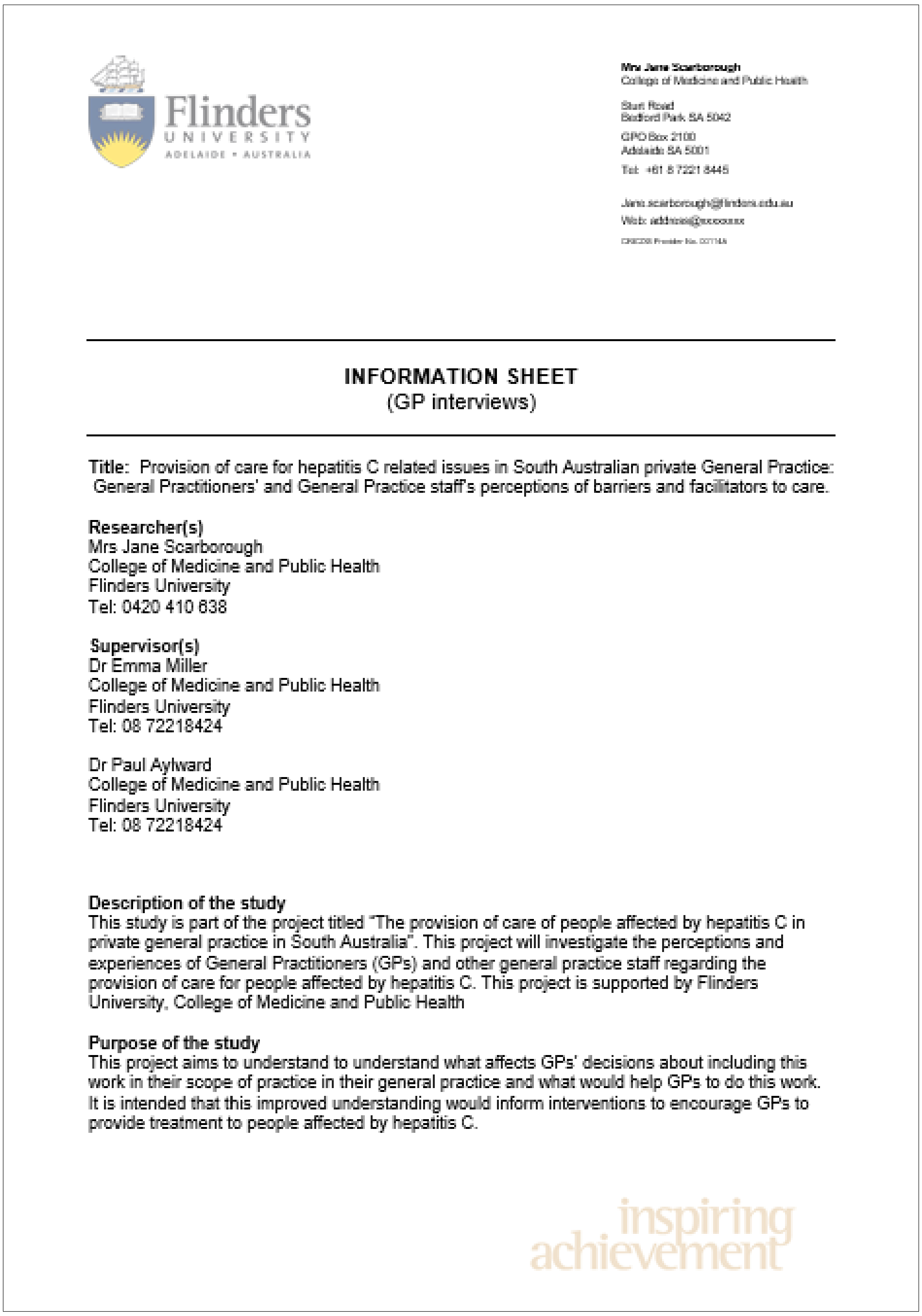
Thank you for your attention and assistance.

Yours sincerely

Dr Emma Miller
Teaching Program Director (Developing Researchers)
College of Medicine and Public Health

ABN 65 524 596 200 CRICOS Provider No. 00114A

inspiring achievement



**Mrs Jane Scarborough**
College of Medicine and Public Health

Sturt Road
Bedford Park SA 5042

GPO Box 2100
Adelaide SA 5001

Tel: +61 8 7221 8445

Jane.scarborough@flinders.edu.au
Web: address@xxxxxxx

CRICOS Provider No. 00114A

---

## INFORMATION SHEET
(GP interviews)

---

**Title:** Provision of care for hepatitis C related issues in South Australian private General Practice: General Practitioners' and General Practice staff's perceptions of barriers and facilitators to care.

**Researcher(s)**
Mrs Jane Scarborough
College of Medicine and Public Health
Flinders University
Tel: 0420 410 638

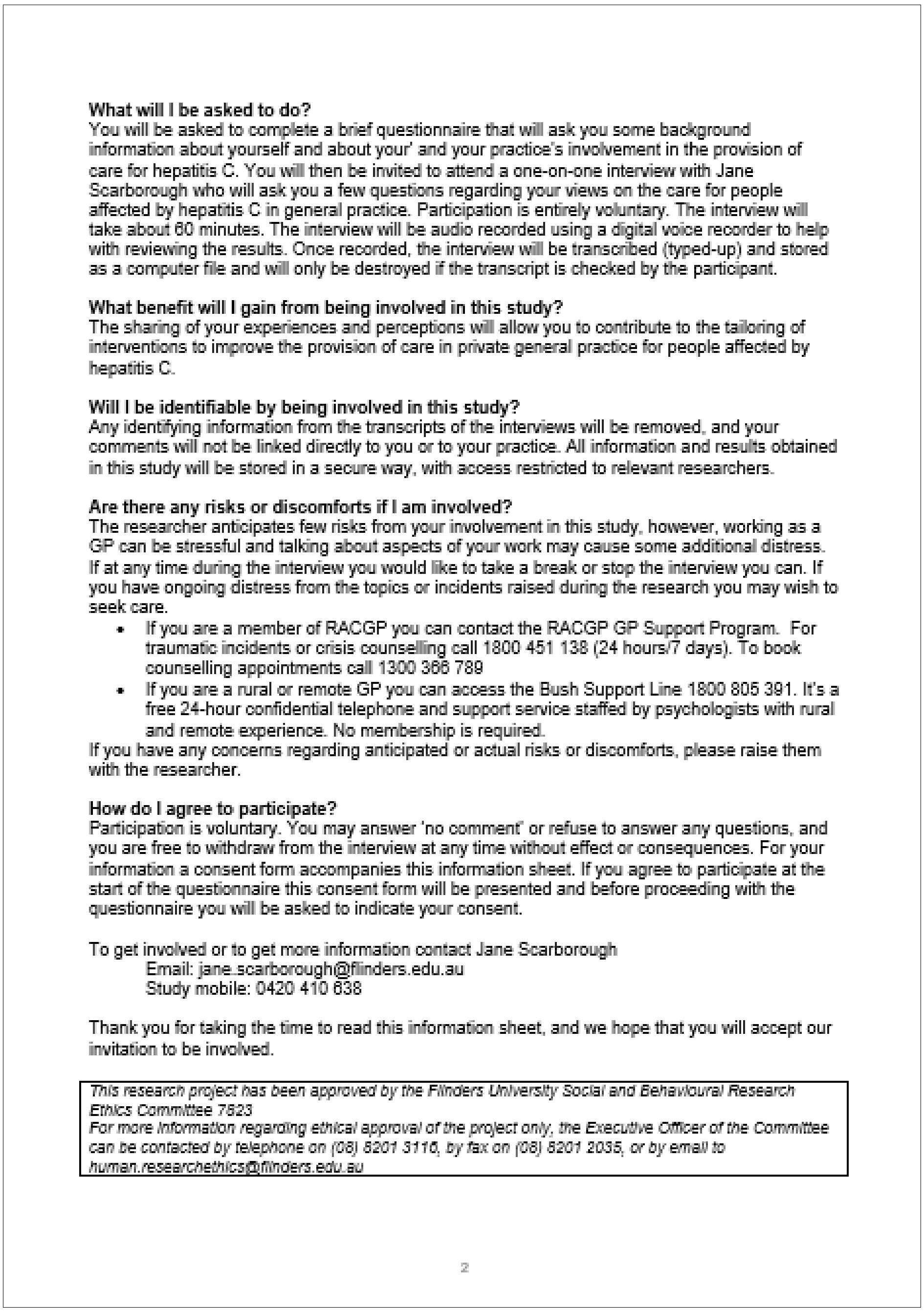
**Supervisor(s)**
Dr Emma Miller
College of Medicine and Public Health
Flinders University
Tel: 08 72218424

Dr Paul Aylward
College of Medicine and Public Health
Flinders University
Tel: 08 72218424

**Description of the study**
This study is part of the project titled "The provision of care of people affected by hepatitis C in private general practice in South Australia". This project will investigate the perceptions and experiences of General Practitioners (GPs) and other general practice staff regarding the provision of care for people affected by hepatitis C. This project is supported by Flinders University, College of Medicine and Public Health

**Purpose of the study**
This project aims to understand to understand what affects GPs' decisions about including this work in their scope of practice in their general practice and what would help GPs to do this work. It is intended that this improved understanding would inform interventions to encourage GPs to provide treatment to people affected by hepatitis C.

inspiring achievement



### What will I be asked to do?

You will be asked to complete a brief questionnaire that will ask you some background information about yourself and about your' and your practice's involvement in the provision of care for hepatitis C. You will then be invited to attend a one-on-one interview with Jane Scarborough who will ask you a few questions regarding your views on the care for people affected by hepatitis C in general practice. Participation is entirely voluntary. The interview will take about 60 minutes. The interview will be audio recorded using a digital voice recorder to help with reviewing the results. Once recorded, the interview will be transcribed (typed-up) and stored as a computer file and will only be destroyed if the transcript is checked by the participant.

### What benefit will I gain from being involved in this study?

The sharing of your experiences and perceptions will allow you to contribute to the tailoring of interventions to improve the provision of care in private general practice for people affected by hepatitis C.

### Will I be identifiable by being involved in this study?

Any identifying information from the transcripts of the interviews will be removed, and your comments will not be linked directly to you or to your practice. All information and results obtained in this study will be stored in a secure way, with access restricted to relevant researchers.

### Are there any risks or discomforts if I am involved?

The researcher anticipates few risks from your involvement in this study, however, working as a GP can be stressful and talking about aspects of your work may cause some additional distress. If at any time during the interview you would like to take a break or stop the interview you can. If you have ongoing distress from the topics or incidents raised during the research you may wish to seek care.

- If you are a member of RACGP you can contact the RACGP GP Support Program. For traumatic incidents or crisis counselling call 1800 451 138 (24 hours/7 days). To book counselling appointments call 1300 366 789
- If you are a rural or remote GP you can access the Bush Support Line 1800 805 391. It's a free 24-hour confidential telephone and support service staffed by psychologists with rural and remote experience. No membership is required.

If you have any concerns regarding anticipated or actual risks or discomforts, please raise them with the researcher.

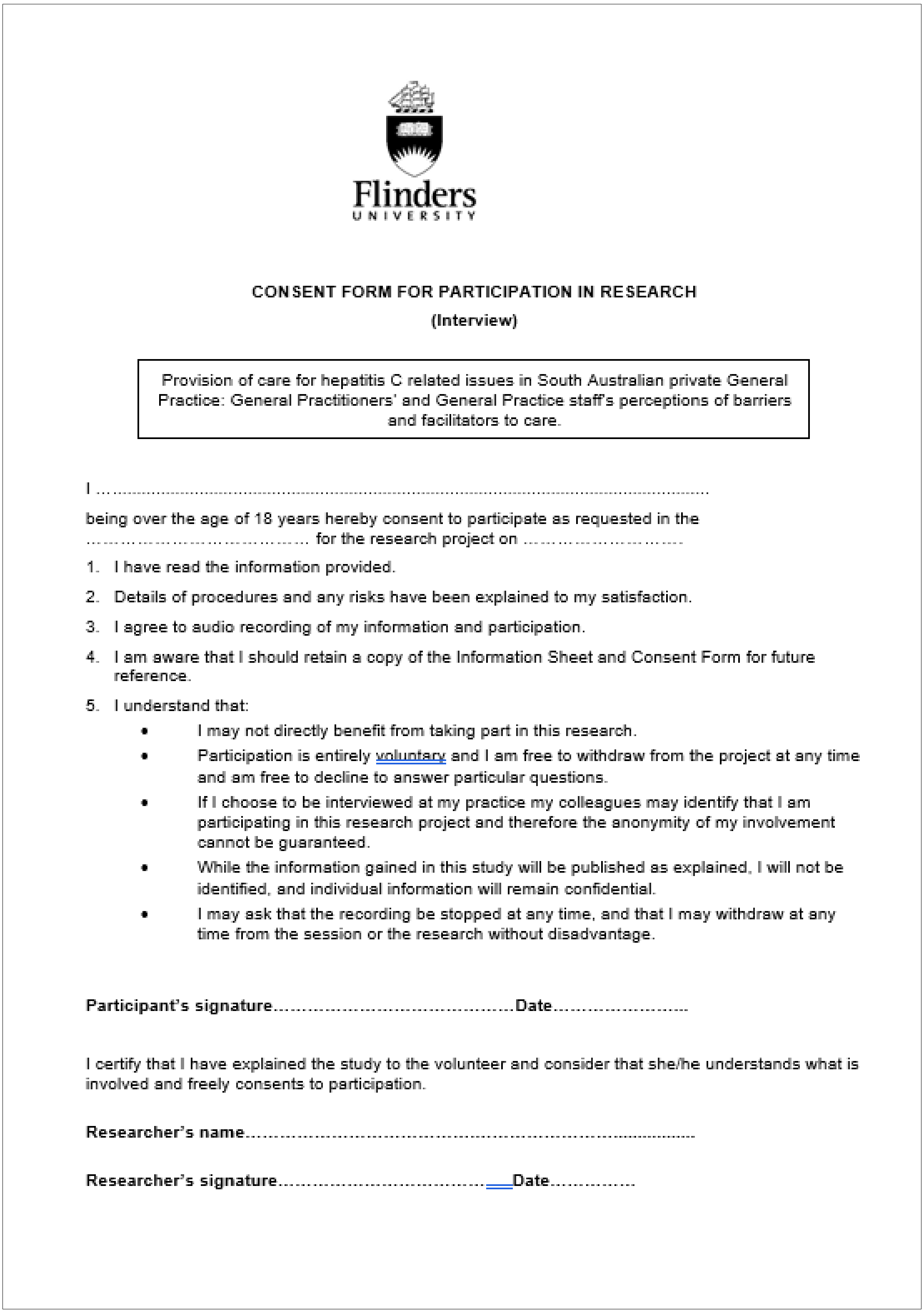
### How do I agree to participate?

Participation is voluntary. You may answer 'no comment' or refuse to answer any questions, and you are free to withdraw from the interview at any time without effect or consequences. For your information a consent form accompanies this information sheet. If you agree to participate at the start of the questionnaire this consent form will be presented and before proceeding with the questionnaire you will be asked to indicate your consent.

To get involved or to get more information contact Jane Scarborough
Email: jane.scarborough@flinders.edu.au
Study mobile: 0420 410 638

Thank you for taking the time to read this information sheet, and we hope that you will accept our invitation to be involved.

*This research project has been approved by the Flinders University Social and Behavioural Research Ethics Committee 7823*
*For more information regarding ethical approval of the project only, the Executive Officer of the Committee can be contacted by telephone on (08) 8201 3116, by fax on (08) 8201 2035, or by email to human.researchethics@flinders.edu.au*



Flinders
UNIVERSITY

### CONSENT FORM FOR PARTICIPATION IN RESEARCH

(Interview)

| |
|---|
| Provision of care for hepatitis C related issues in South Australian private General Practice: General Practitioners' and General Practice staff's perceptions of barriers and facilitators to care. |

I ……………………………………………………………………………………

being over the age of 18 years hereby consent to participate as requested in the …………………………………… for the research project on ……………………………

1. I have read the information provided.
2. Details of procedures and any risks have been explained to my satisfaction.
3. I agree to audio recording of my information and participation.
4. I am aware that I should retain a copy of the Information Sheet and Consent Form for future reference.
5. I understand that:
    - I may not directly benefit from taking part in this research.
    - Participation is entirely voluntary and I am free to withdraw from the project at any time and am free to decline to answer particular questions.
    - If I choose to be interviewed at my practice my colleagues may identify that I am participating in this research project and therefore the anonymity of my involvement cannot be guaranteed.
    - While the information gained in this study will be published as explained, I will not be identified, and individual information will remain confidential.
    - I may ask that the recording be stopped at any time, and that I may withdraw at any time from the session or the research without disadvantage.

**Participant's signature**……………………………………**Date**……………………..

I certify that I have explained the study to the volunteer and consider that she/he understands what is involved and freely consents to participation.

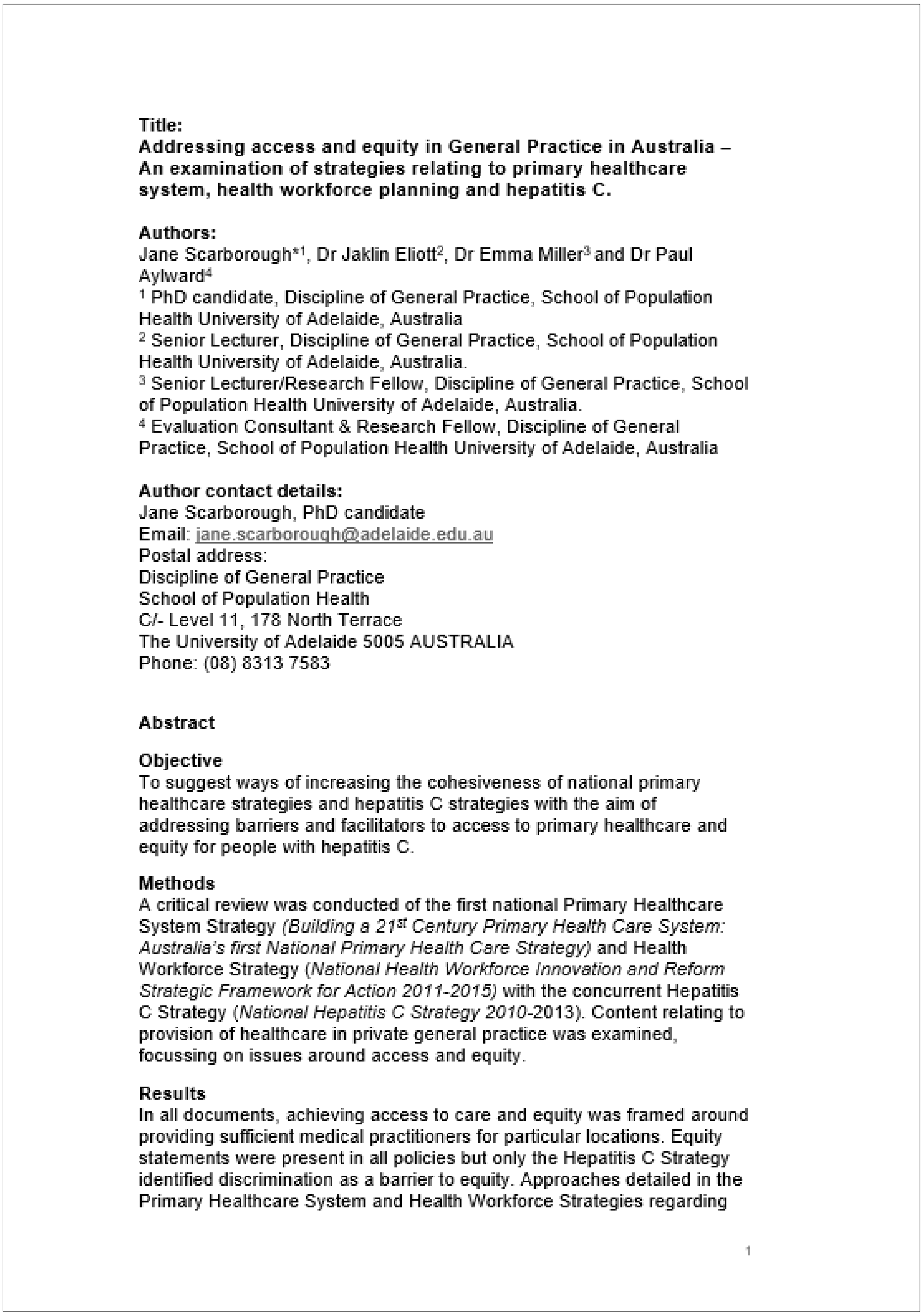
**Researcher's name**………………………………………………………………………

**Researcher's signature**………………………………___**Date**……………

## Appendix 9: Manuscript of “Equity in primary health care delivery: an examination of the cohesiveness of strategies relating to the primary healthcare system, the health workforce and hepatitis C.”

## The final published version is available from: https://doi.org/10.1071/AH14073

**Scarborough, J., Eliott, J., Miller, E. R., & Aylward, P. (2015). Equity in primary health care delivery: an examination of the cohesiveness of strategies relating to the primary healthcare system, the health workforce and hepatitis C. *Australian Health Review, 39*(2), 175-182. doi:10.1071/ah14073**



**Title:**

**Addressing access and equity in General Practice in Australia – An examination of strategies relating to primary healthcare system, health workforce planning and hepatitis C.**

**Authors:**
Jane Scarborough*[1], Dr Jaklin Eliott[2], Dr Emma Miller[3] and Dr Paul Aylward[4]
[1] PhD candidate, Discipline of General Practice, School of Population Health University of Adelaide, Australia
[2] Senior Lecturer, Discipline of General Practice, School of Population Health University of Adelaide, Australia.
[3] Senior Lecturer/Research Fellow, Discipline of General Practice, School of Population Health University of Adelaide, Australia.
[4] Evaluation Consultant & Research Fellow, Discipline of General Practice, School of Population Health University of Adelaide, Australia

**Author contact details:**
Jane Scarborough, PhD candidate
Email: jane.scarborough@adelaide.edu.au
Postal address:
Discipline of General Practice
School of Population Health
C/- Level 11, 178 North Terrace
The University of Adelaide 5005 AUSTRALIA
Phone: (08) 8313 7583

### Abstract

**Objective**

To suggest ways of increasing the cohesiveness of national primary healthcare strategies and hepatitis C strategies with the aim of addressing barriers and facilitators to access to primary healthcare and equity for people with hepatitis C.

**Methods**

A critical review was conducted of the first national Primary Healthcare System Strategy *(Building a 21st Century Primary Health Care System: Australia's first National Primary Health Care Strategy)* and Health Workforce Strategy (*National Health Workforce Innovation and Reform Strategic Framework for Action 2011-2015)* with the concurrent Hepatitis C Strategy (*National Hepatitis C Strategy 2010*-2013). Content relating to provision of healthcare in private general practice was examined, focussing on issues around access and equity.

**Results**

In all documents, achieving access to care and equity was framed around providing sufficient medical practitioners for particular locations. Equity statements were present in all policies but only the Hepatitis C Strategy identified discrimination as a barrier to equity. Approaches detailed in the Primary Healthcare System and Health Workforce Strategies regarding

current resource allocation, needs assessment and GP incentives were limited to groups defined within these documents and may not identify or meet the needs of people with hepatitis C.

## Conclusion

Opportunities exist for improved cohesion between future national primary healthcare strategies and hepatitis C strategies to improve equity and access to primary healthcare for people with hepatitis C.

### Introduction

General practitioners (GPs) are important contributors to the provision of primary healthcare to the Australian population (1, 2) and most GPs work in private general practice (3). Successive Australian federal governments have emphasised their commitment to providing universal access to co-ordinated primary care in private practice (4, 5) but reforms are cited as necessary to manage expenditure in the context of an ageing population with an increased burden of chronic disease (6, 7). In 2010 the Federal Labor Government clarified federal responsibility for funding and policy formation of all GP and primary health care services (6) and, as the principal funder of primary healthcare delivered by GPs via Medicare (1, 2, 8, 9), the Federal Government is well placed to achieve reform.

In 2010-2011 the Australian Federal Labor Government launched three apposite policy strategies: *Building a 21st Century Primary Health Care System* (Primary Healthcare System Strategy), described as "a national road map to guide future primary health care policy and planning" (10 p3); *National Health Workforce Innovation and Reform Strategic Framework for Action 2011-2015* (Health Workforce Strategy) "a national call to action for workforce reform" (11 p1); and the *Third National Hepatitis C Strategy 2010-2013* (Hepatitis C Strategy) (12). While the first two broad strategies were announced as new initiatives, the Hepatitis C Strategy represented a continuation of policy formation with the first Australian hepatitis C specific national policy released in 2000 (13). The strategies were developed by separate organisations, using a variety of processes with contributions from various sources (Box 1). Each strategy included a component that addressed the delivery of primary healthcare in private general practice with an objective of improving equity and access to this care.

Hepatitis C is predominantly transmitted through sharing injecting equipment (12) and is estimated to affect over 1% of the Australian population (12). Up to 25% of people exposed to the virus clear the virus naturally but the majority experience hepatitis C as a chronic condition (14). Treatments are available with the potential to cure hepatitis C(15). Emerging antiviral treatments offer improved cure rates and possible reduction of unwanted side effects (16) however treatment success varies depending on the genotype, and current treatment can be lengthy, with serious side effects (15). Currently, only around 2% of people with hepatitis C enter this treatment (17). Left untreated, the virus can cause serious liver disease including hepatocellular carcinoma (18). Hepatitis C is the primary disease indication recorded for 22.4% of liver transplants in Australia,1985 – 2012 (19). Cases of hepatitis C are dispersed and, due to the variable and often extended length of the exposure-diagnosis interval, it is difficult to accurately identify geographical areas where services for people with hepatitis C can be targeted (20).

It is critical that people with hepatitis C receive appropriate advice on their diagnosis, management and treatment for their disease, and GPs in private practice are uniquely positioned (both professionally and geographically) to provide this care (17, 21-23). Hepatitis C Guidelines for GPs (23) outline the role of GPs in assessing patient suitability and desire for treatment. When people diagnosed with hepatitis C have not been referred for treatment, private GPs are likely to be the main provider of primary healthcare for the person's chronic hepatitis C. Although most patients with hepatitis C are diagnosed by GPs (21), barriers to care provision have been reported (24, 25) and stigma attached to a diagnosis of the disease (26, 27) may contribute to barriers to care sought and provided (28). Hepatitis C is likely to be under-diagnosed (18) and appropriate pre- and post-test counselling may not always be delivered (29). A 2008 Australian study reported that people with hepatitis C were likely to seek information from a GP about hepatitis C but perceptions about the quality of this information ranged from very good to poor (30).

Despite the importance of primary healthcare to the prevention, treatment and management of hepatitis C, there is no recognition of the value of cohesion across the broad strategies and the Hepatitis C Strategy, and no framework for this to occur. If cohesion does not exist between the broad strategies and the Hepatitis C Strategy, barriers and facilitators to access and equity may not be addressed. Here, recommendations will be suggested to increase the cohesion between these documents in regard to equity and access issues, and thus to improve the healthcare provided in private general practice for people with hepatitis C.

## Methods

A critical review was carried out to examine the coherence between the broad strategies: the Primary Healthcare System (10) and Health Workforce (11) Strategies, and the concurrent disease-specific Hepatitis C Strategy (12). These were scanned for content relating to the provision of healthcare in private general practice and in particular issues around access and equity. Two questions drove the analysis: "*Who* gets resources'?" answered by an identification of priority groups and future needs within each strategy, and "*What* is needed to address access and equity?" answered by deconstructing the framing of the problem, its underlying assumptions and articulated solutions.

## Results

### Content relating to GPs

The Primary Healthcare System and Health Workforce Strategies recognise that there are providers of primary healthcare other than GPs but the role of GPs is predominant. In the Primary Healthcare System Strategy the role of GPs are addressed in each of the five key building blocks (10 p10) described as necessary for building a modern primary healthcare system and the four key priority areas of change listed (10 p11). Similarly in the Health Workforce Strategy the five domains for action listed (11 p15) include specific strategies aimed at the GP workforce. Whilst each of the six priority action areas in the Hepatitis C Strategy (12 p21-31) included actions targeted at GPs, the contribution of others ( e.g. peer educators) to the health and wellbeing of people with hepatitis C is highlighted.

### Resource allocation

### Equity Statements

All three strategies had aims for improving access to primary healthcare and reducing inequity (Box 2). In the broad strategies, the equity statements were general and non-specific, but actions listed to increase equity and overcome access barriers were limited to priority groups (see below) and identified service gaps. In the Hepatitis C Strategy, however, discrimination was specifically identified as a barrier to equitable care and equity was expressed in terms of human rights.

### Current priority groups

The stated priority (or targeted) population groups in the strategies were identified (Table 1) to determine who was to be allocated resources, and on what basis. Groups described in the broad strategies appear to be categorised according to a number of different factors: namely, geographical location, age, race, disease and disease nature. The basis of nomination of groups was not made explicit, but described in relation to inequity of access to services, improving gaps in health outcomes, and cost savings achieved from providing appropriate primary healthcare. By contrast, the priority groups in the Hepatitis C Strategy are based on groups most affected by, or most at risk for, hepatitis C and the rationale for the inclusion of each priority group is made explicit.

Aboriginal and Torres Strait Islander people are listed as a priority group across all three documents. The priority groups in the broad strategies also include Australians living outside capital cities, older people and people with mental illness; "people with chronic diseases" are defined as a priority group only in the Health Workforce document. However, there may be more overlap of the Hepatitis C Strategy priority groups and those listed in the other two documents than initial comparison suggests. Injecting drug users, a priority group in the Hepatitis C Strategy, may suffer addiction. This is classified as a "mental illness", noted as a priority group in the broad strategies. Furthermore, given that treatment uptake is less than 2% of the eligible population, most people with hepatitis C experience hepatitis C as a chronic disease and are therefore included within "people with chronic diseases", prioritised in the Health Workforce document.

It appears, therefore, that the broad strategy documents present discrete priority groups, overlooking the possibility of overlap. The hepatitis C strategy, however, emphasises the possibility that people may experience more than one type of access or equity barrier and consequently experience cumulative negative effects on their health outcomes.

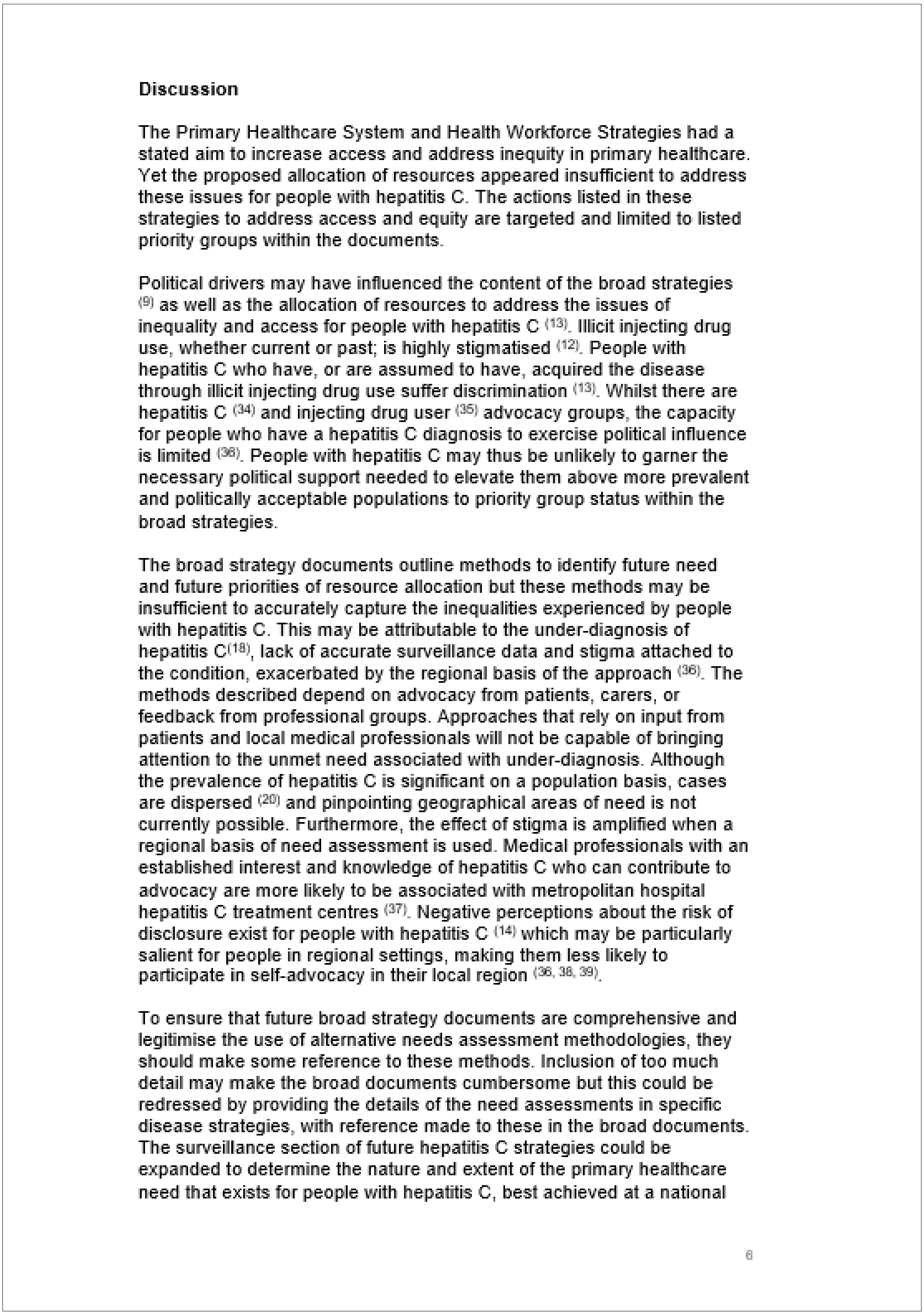
### Future priorities: Approaches for identifying gaps and determining need.

Approaches for identifying gaps and determining need in each document were examined to determine the future allocation of resources (Box 3). Methods proposed in the broad strategies included advocacy from patients, carers and feedback from professional groups on a regional basis. The Primary Healthcare System document denotes the 61 designated Medicare Local regions (created in 2011 to coordinate primary healthcare (31)) as the appropriate regional boundaries for these needs assessments. Specific regions are not stated in the Health Workforce document. The Hepatitis C Strategy asserts the need to enhance existing surveillance to inform the planning and delivery of disease management and prevention. This strategy emphasises the inclusion of people most affected by hepatitis C in developing responses to the impact of the disease. The Hepatitis C Strategy also identifies gaps in the delivery of care to people with hepatitis C.

### Requirements for ensuring access and equity

In the broad strategy documents, issues of access to care and equity centre on providing sufficient medical practitioners for particular locations (Box 4). Willingness to provide the primary care required by all Australians is an assumed part of GP qualification and registration. All three documents assume that the provision of appropriate continuing medical education and appropriate resources (such as clinical guidelines) are key to the delivery of best practice care for all medical conditions. The broad strategy documents further describe the use of incentives for GPs to undertake particular work in particular locations (Box 4). Offering such incentives contradicts the idea that increased numbers of GPs and provision of resources or education alone will ensure that all Australians receive equitable access to care.

The Hepatitis C Strategy reports that people with hepatitis C do not receive best practice care in general practice, identifying healthcare settings as a site of discrimination (involving a variety of health professional disciplines). Development of a national hepatitis C public education plan is proposed to reduce discriminatory attitudes and behaviour across settings. The broad strategy documents do not specifically address a need to overcome stigma or discrimination despite the recognised history of stigma and discrimination for the identified priority groups of people with mental health issues (32) and for the Indigenous population (33).



## Discussion

The Primary Healthcare System and Health Workforce Strategies had a stated aim to increase access and address inequity in primary healthcare. Yet the proposed allocation of resources appeared insufficient to address these issues for people with hepatitis C. The actions listed in these strategies to address access and equity are targeted and limited to listed priority groups within the documents.

Political drivers may have influenced the content of the broad strategies (9) as well as the allocation of resources to address the issues of inequality and access for people with hepatitis C (13). Illicit injecting drug use, whether current or past; is highly stigmatised (12). People with hepatitis C who have, or are assumed to have, acquired the disease through illicit injecting drug use suffer discrimination (13). Whilst there are hepatitis C (34) and injecting drug user (35) advocacy groups, the capacity for people who have a hepatitis C diagnosis to exercise political influence is limited (36). People with hepatitis C may thus be unlikely to garner the necessary political support needed to elevate them above more prevalent and politically acceptable populations to priority group status within the broad strategies.

The broad strategy documents outline methods to identify future need and future priorities of resource allocation but these methods may be insufficient to accurately capture the inequalities experienced by people with hepatitis C. This may be attributable to the under-diagnosis of hepatitis C(18), lack of accurate surveillance data and stigma attached to the condition, exacerbated by the regional basis of the approach (36). The methods described depend on advocacy from patients, carers, or feedback from professional groups. Approaches that rely on input from patients and local medical professionals will not be capable of bringing attention to the unmet need associated with under-diagnosis. Although the prevalence of hepatitis C is significant on a population basis, cases are dispersed (20) and pinpointing geographical areas of need is not currently possible. Furthermore, the effect of stigma is amplified when a regional basis of need assessment is used. Medical professionals with an established interest and knowledge of hepatitis C who can contribute to advocacy are more likely to be associated with metropolitan hospital hepatitis C treatment centres (37). Negative perceptions about the risk of disclosure exist for people with hepatitis C (14) which may be particularly salient for people in regional settings, making them less likely to participate in self-advocacy in their local region (36, 38, 39).

To ensure that future broad strategy documents are comprehensive and legitimise the use of alternative needs assessment methodologies, they should make some reference to these methods. Inclusion of too much detail may make the broad documents cumbersome but this could be redressed by providing the details of the need assessments in specific disease strategies, with reference made to these in the broad documents. The surveillance section of future hepatitis C strategies could be expanded to determine the nature and extent of the primary healthcare need that exists for people with hepatitis C, best achieved at a national and state level (36). Processes aimed at assisting individual private general practices to identify whether they are providing appropriate care for people with hepatitis C could be developed (40). This information could be collected and collated at a regional level to assist in identifying unmet need. (41)

The provision of a sufficiently large and adequately resourced GP workforce with access to continuing medical education is fundamental to the delivery of best practice primary healthcare. However, even where incentives are provided for GPs to practise in areas of identified need, this will not necessarily ensure equitable access for people with hepatitis C. Some general skills reasonably expected of every GP can be addressed through registration and requirements for ongoing medical education. These include taking medical histories in a non-judgemental way, delivering pre and post-test counselling appropriately, knowledge and communication of diagnostic testing, and obtaining informed consent. It cannot be expected and is impossible, however, to ensure that all GPs maintain a detailed level of knowledge relevant to all possible encounters. For example, it is unrealistic to expect every GP to prioritise their medical education to keep up with rapidly evolving hepatitis C treatment options. There will also be limits to the number of consultations GPs can conduct and, therefore, limits to the patient base that each can serve. Individual GPs necessarily make choices about the patients they see, the prioritisation of patient issues, professional resources accessed and continuing medical education attendance (42).

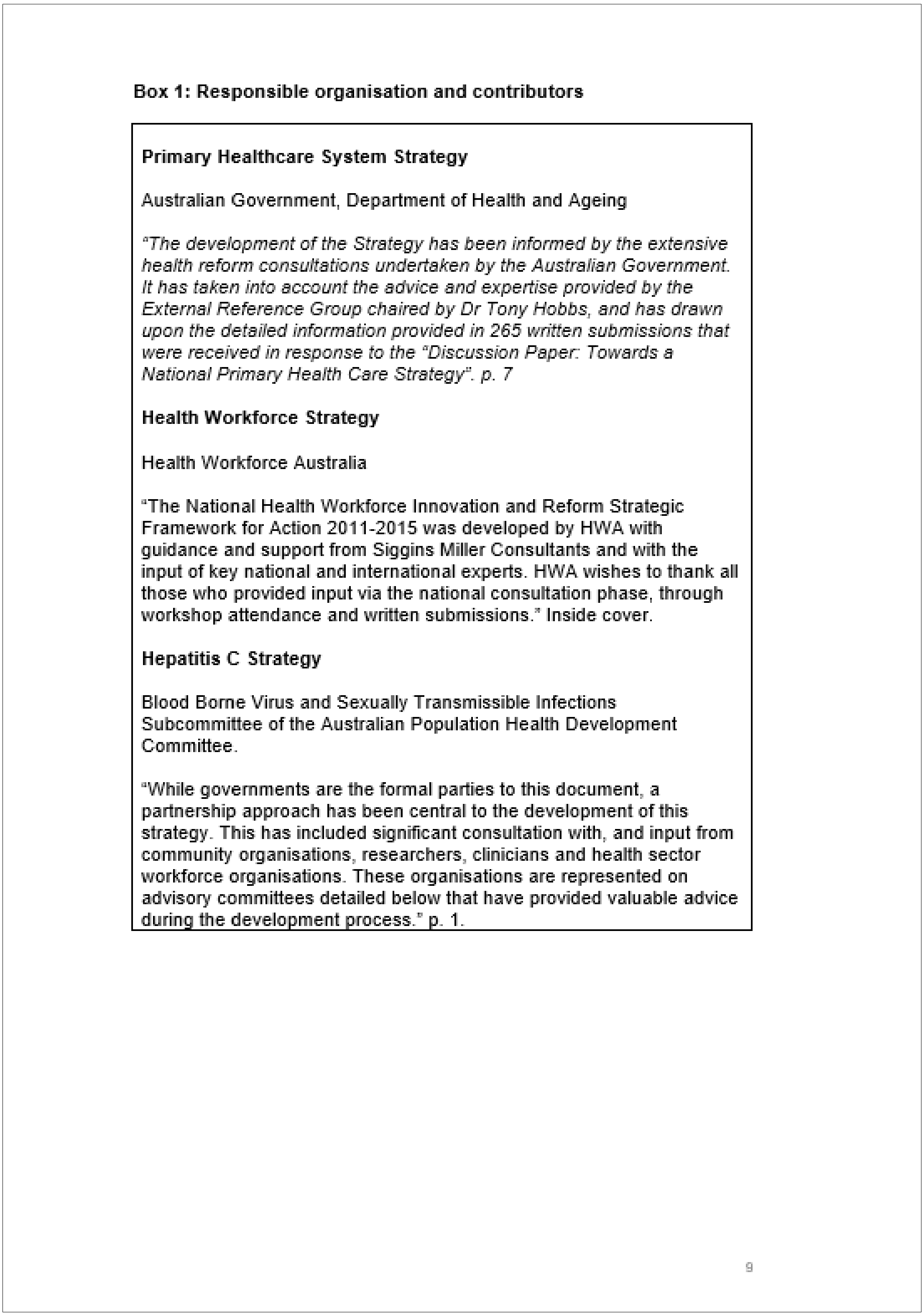
Primary healthcare system planning, including workforce planning, must consider appropriate care to be delivered by GPs and then provide incentives and support to ensure sufficient GPs with the will and capabilities to offer best practice care to people with hepatitis C. Actions around incentives, training, alternative workforce and use of technology proposed in the broad documents to address the access and equity issues for priority groups may be equally applicable to less politically acceptable groups (Table 2). General statements could be added to the effect that the action will be applied where it will increase access and equity, reduce costs and/or improve outcomes as outlined in specific disease strategies. The hepatitis C strategy could then cross-reference these statements, outlining how particular actions could achieve these aims in regard to hepatitis C.

The recommended changes to the broad documents would minimally change the content of the documents and would therefore be politically neutral. The actions from the broad documents cross-referenced in the hepatitis C document promote cost-savings as well as improved access, equity and health outcomes.

The 2014 elected government has retained federal responsibility for primary healthcare, promising a co-ordinated, financially sustainable primary health system which is accessible to all Australians, and reiterating the primary role of private general practice (7). This critical review can be used as a basis to analyse and direct this government's primary healthcare policies and how they inter-relate to the 4th National Hepatitis C policy.

## Conclusion

Opportunities exist to improve cohesion between future national primary healthcare strategies and hepatitis C strategies, and ultimately, to improve equity and access to primary healthcare for people with hepatitis C. To increase the inequity and access to primary healthcare for this group, needs assessment methodology should be broadened, acknowledging that the current regional approach may not identify the needs of people with hepatitis C. Actions in primary healthcare system and health workforce strategies can be extended to additional groups beyond those listed as priority groups within the documents. Future hepatitis C strategies could outline appropriate, detailed needs assessment methodology and specify how actions in the broad strategies can be applied to benefit the primary healthcare needs of people with hepatitis C.



**Box 1: Responsible organisation and contributors**

**Primary Healthcare System Strategy**

Australian Government, Department of Health and Ageing

*"The development of the Strategy has been informed by the extensive health reform consultations undertaken by the Australian Government. It has taken into account the advice and expertise provided by the External Reference Group chaired by Dr Tony Hobbs, and has drawn upon the detailed information provided in 265 written submissions that were received in response to the "Discussion Paper: Towards a National Primary Health Care Strategy". p. 7*

**Health Workforce Strategy**

Health Workforce Australia

"The National Health Workforce Innovation and Reform Strategic Framework for Action 2011-2015 was developed by HWA with guidance and support from Siggins Miller Consultants and with the input of key national and international experts. HWA wishes to thank all those who provided input via the national consultation phase, through workshop attendance and written submissions." Inside cover.

**Hepatitis C Strategy**

Blood Borne Virus and Sexually Transmissible Infections Subcommittee of the Australian Population Health Development Committee.

"While governments are the formal parties to this document, a partnership approach has been central to the development of this strategy. This has included significant consultation with, and input from community organisations, researchers, clinicians and health sector workforce organisations. These organisations are represented on advisory committees detailed below that have provided valuable advice during the development process." p. 1.

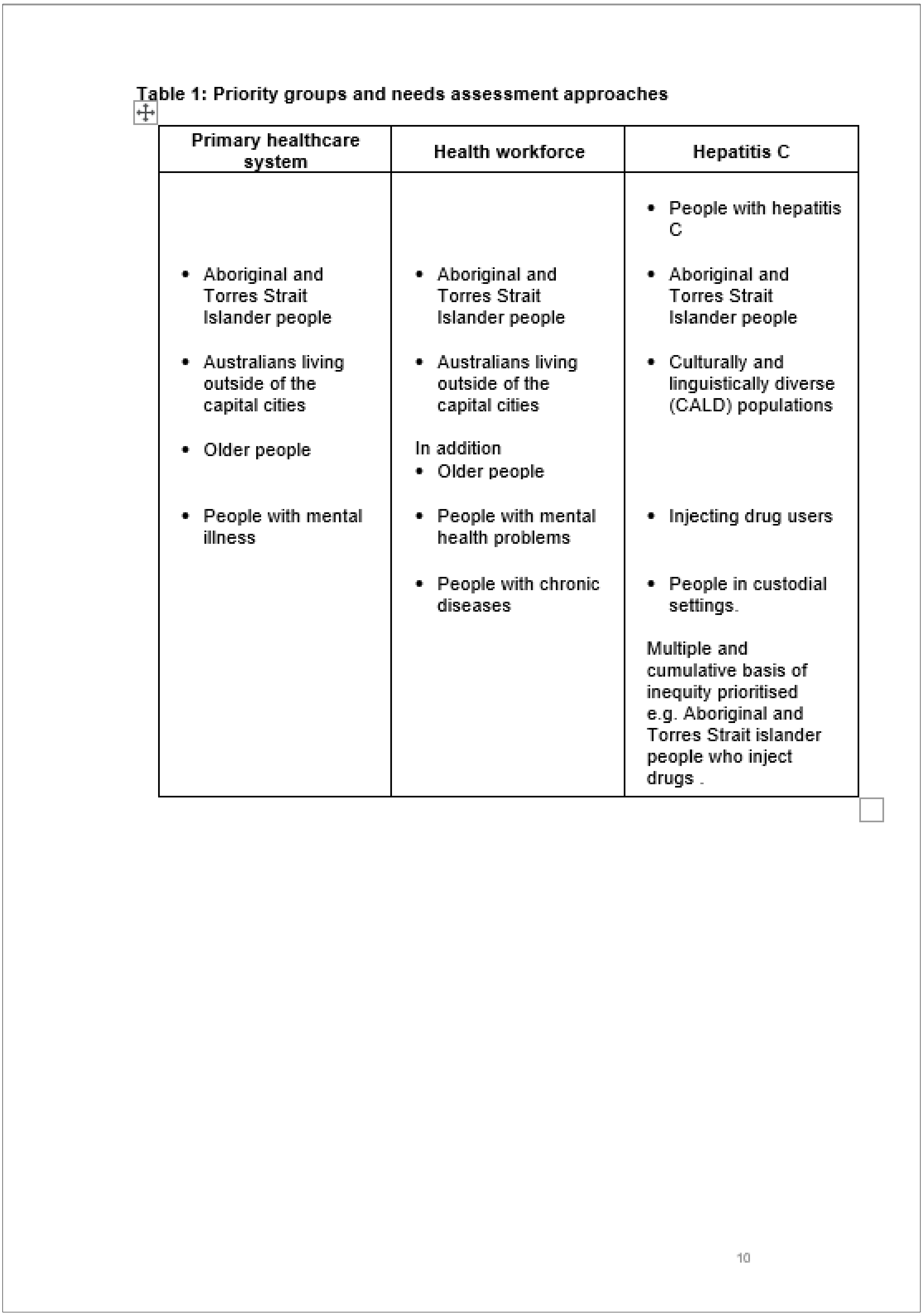
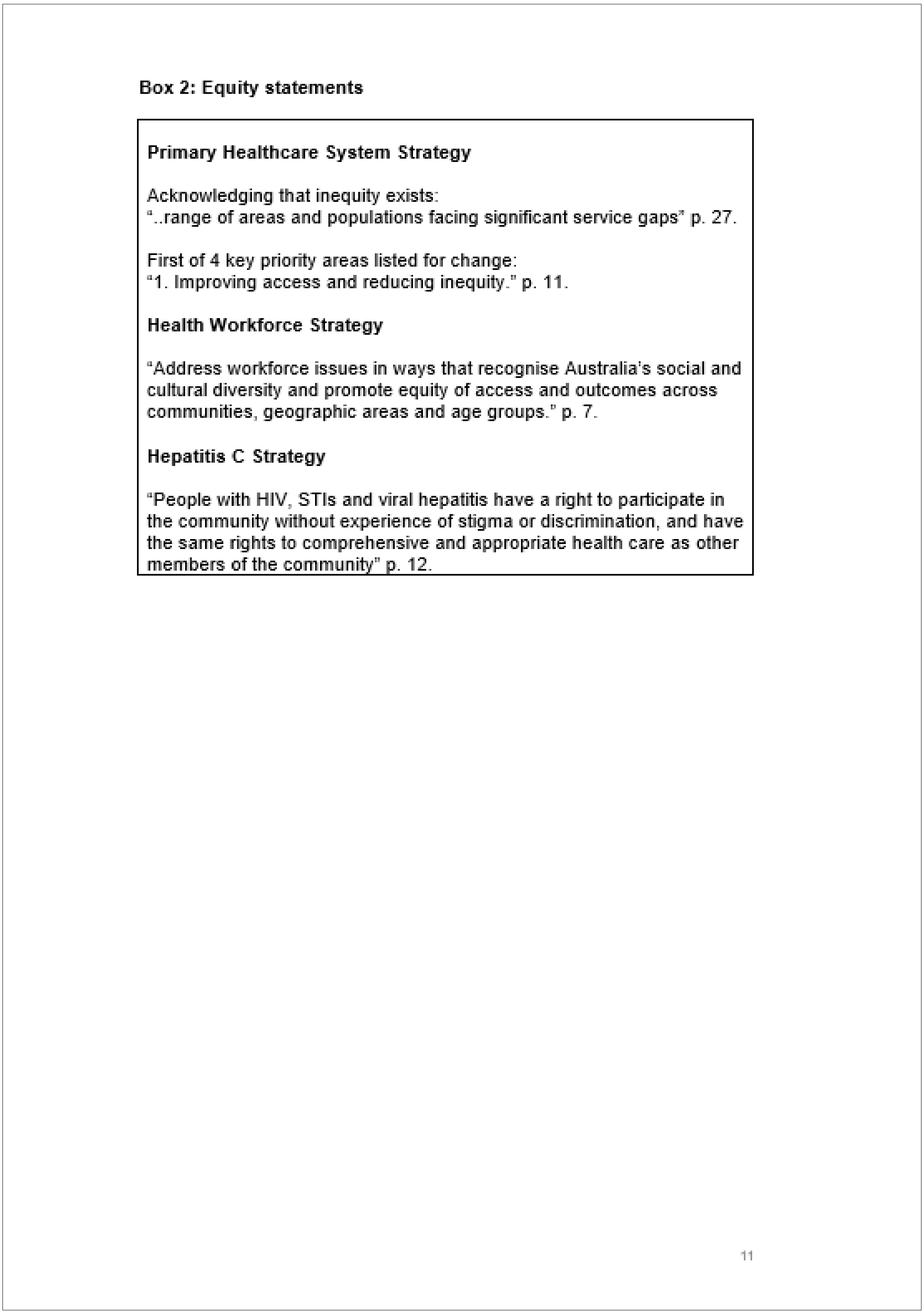


**Table 1: Priority groups and needs assessment approaches**

| Primary healthcare system | Health workforce | Hepatitis C |
|---|---|---|
| | | • People with hepatitis C |
| • Aboriginal and Torres Strait Islander people | • Aboriginal and Torres Strait Islander people | • Aboriginal and Torres Strait Islander people |
| • Australians living outside of the capital cities | • Australians living outside of the capital cities | • Culturally and linguistically diverse (CALD) populations |
| • Older people | In addition<br>• Older people | |
| • People with mental illness | • People with mental health problems | • Injecting drug users |
| | • People with chronic diseases | • People in custodial settings. |
| | | Multiple and cumulative basis of inequity prioritised e.g. Aboriginal and Torres Strait islander people who inject drugs . |



**Box 2: Equity statements**

**Primary Healthcare System Strategy**

Acknowledging that inequity exists:
"..range of areas and populations facing significant service gaps" p. 27.

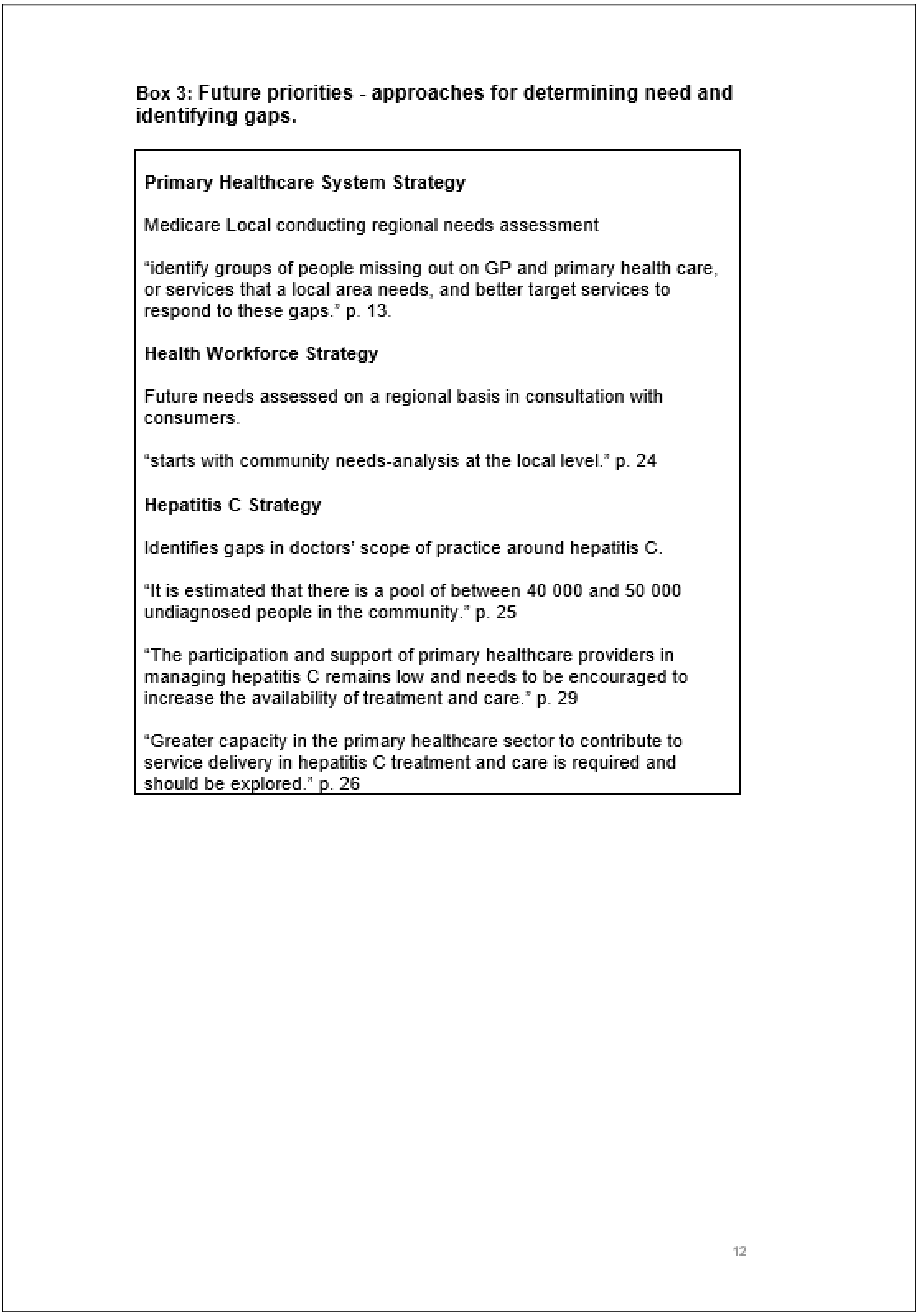
First of 4 key priority areas listed for change:
"1. Improving access and reducing inequity." p. 11.

**Health Workforce Strategy**

"Address workforce issues in ways that recognise Australia's social and cultural diversity and promote equity of access and outcomes across communities, geographic areas and age groups." p. 7.

**Hepatitis C Strategy**

"People with HIV, STIs and viral hepatitis have a right to participate in the community without experience of stigma or discrimination, and have the same rights to comprehensive and appropriate health care as other members of the community" p. 12.



### Box 3: Future priorities - approaches for determining need and identifying gaps.

**Primary Healthcare System Strategy**

Medicare Local conducting regional needs assessment

"identify groups of people missing out on GP and primary health care, or services that a local area needs, and better target services to respond to these gaps." p. 13.

**Health Workforce Strategy**

Future needs assessed on a regional basis in consultation with consumers.

"starts with community needs-analysis at the local level." p. 24

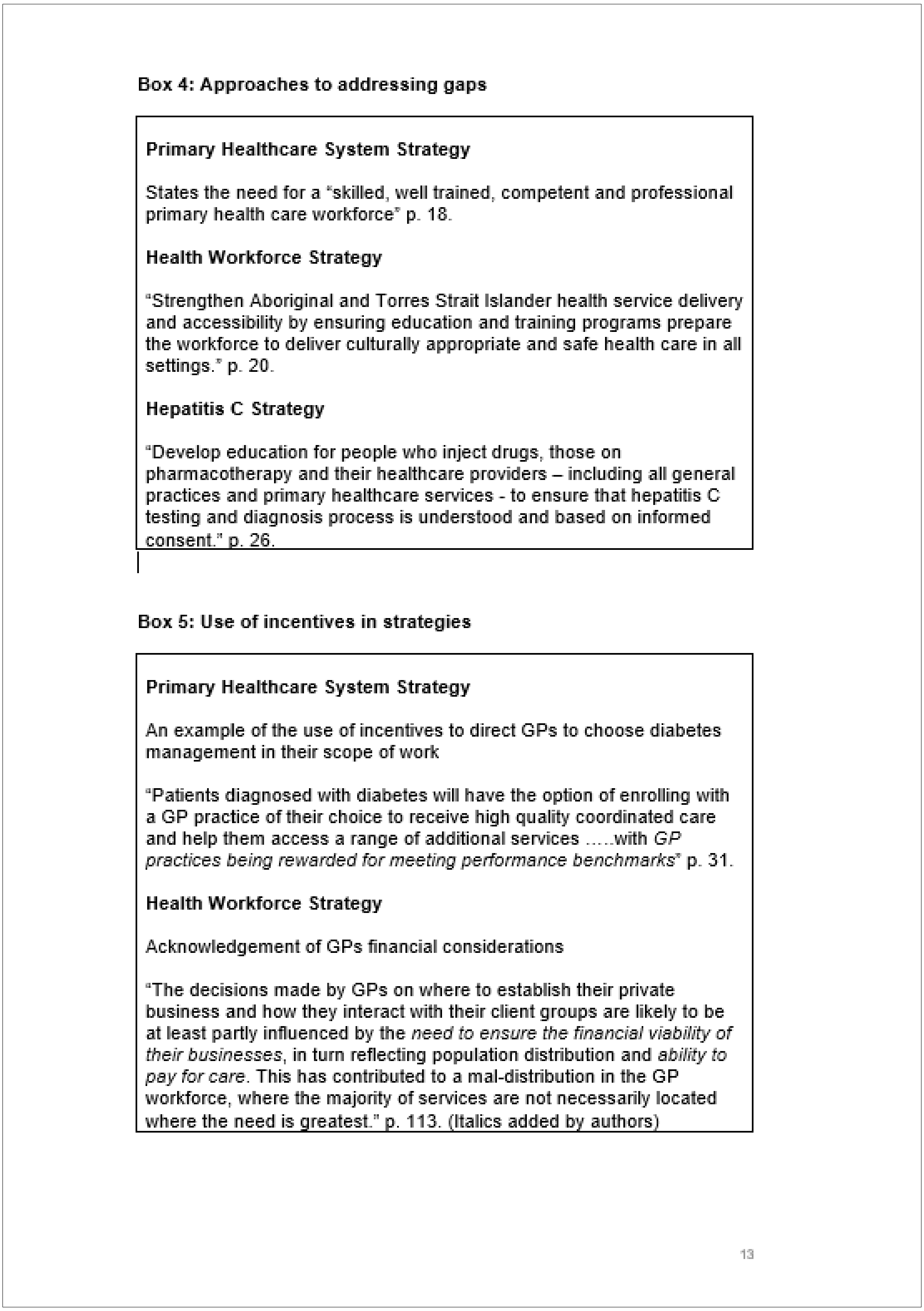
**Hepatitis C Strategy**

Identifies gaps in doctors' scope of practice around hepatitis C.

"It is estimated that there is a pool of between 40 000 and 50 000 undiagnosed people in the community." p. 25

"The participation and support of primary healthcare providers in managing hepatitis C remains low and needs to be encouraged to increase the availability of treatment and care." p. 29

"Greater capacity in the primary healthcare sector to contribute to service delivery in hepatitis C treatment and care is required and should be explored." p. 26



**Box 4: Approaches to addressing gaps**

**Primary Healthcare System Strategy**

States the need for a "skilled, well trained, competent and professional primary health care workforce" p. 18.

**Health Workforce Strategy**

"Strengthen Aboriginal and Torres Strait Islander health service delivery and accessibility by ensuring education and training programs prepare the workforce to deliver culturally appropriate and safe health care in all settings." p. 20.

**Hepatitis C Strategy**

"Develop education for people who inject drugs, those on pharmacotherapy and their healthcare providers – including all general practices and primary healthcare services - to ensure that hepatitis C testing and diagnosis process is understood and based on informed consent." p. 26.

**Box 5: Use of incentives in strategies**

**Primary Healthcare System Strategy**

An example of the use of incentives to direct GPs to choose diabetes management in their scope of work

"Patients diagnosed with diabetes will have the option of enrolling with a GP practice of their choice to receive high quality coordinated care and help them access a range of additional services …..with *GP practices being rewarded for meeting performance benchmarks*" p. 31.

**Health Workforce Strategy**

Acknowledgement of GPs financial considerations

"The decisions made by GPs on where to establish their private business and how they interact with their client groups are likely to be at least partly influenced by the *need to ensure the financial viability of their businesses*, in turn reflecting population distribution and *ability to pay for care*. This has contributed to a mal-distribution in the GP workforce, where the majority of services are not necessarily located where the need is greatest." p. 113. (Italics added by authors)

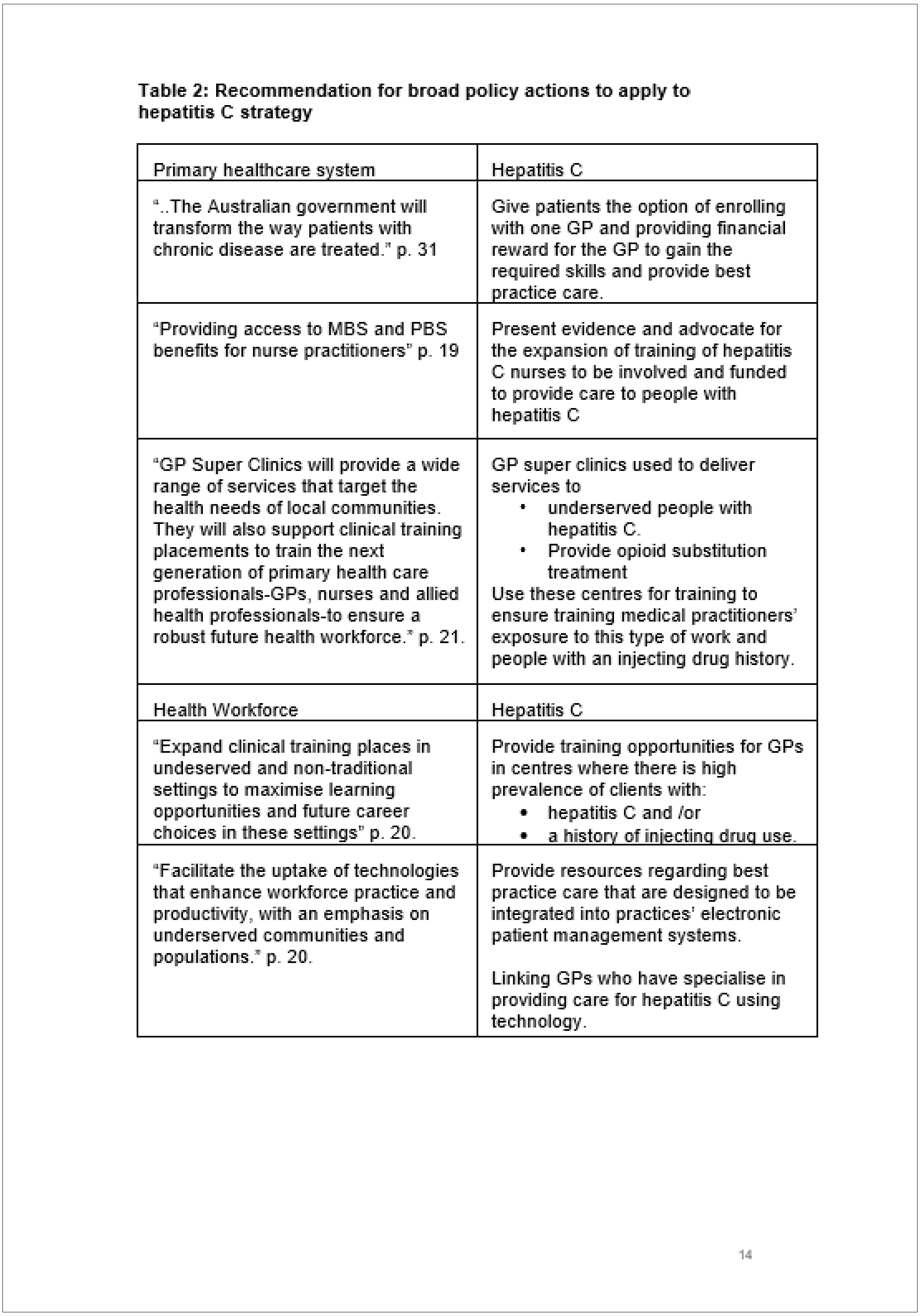
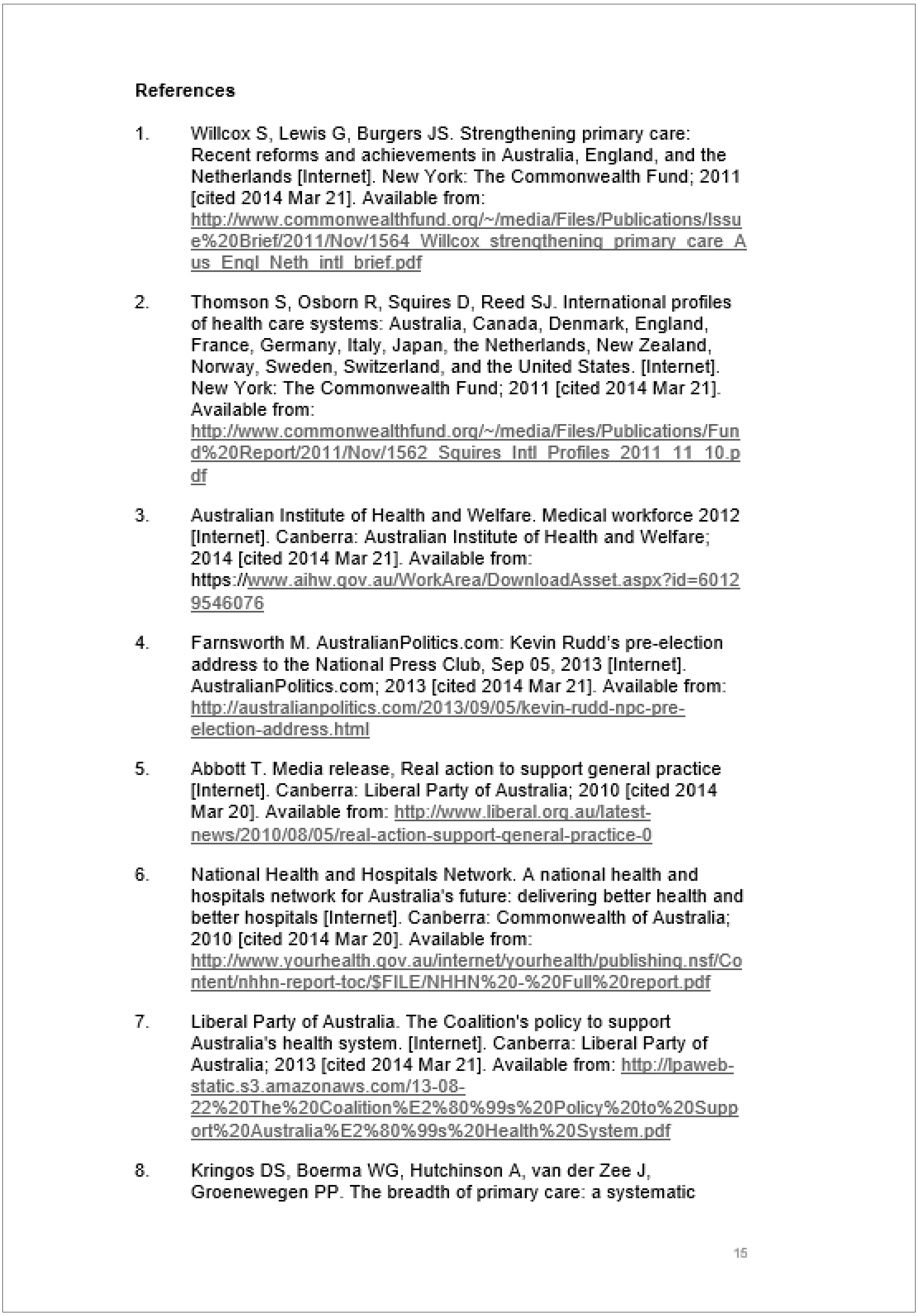


**Table 2: Recommendation for broad policy actions to apply to hepatitis C strategy**

| Primary healthcare system | Hepatitis C |
|---|---|
| "..The Australian government will transform the way patients with chronic disease are treated." p. 31 | Give patients the option of enrolling with one GP and providing financial reward for the GP to gain the required skills and provide best practice care. |
| "Providing access to MBS and PBS benefits for nurse practitioners" p. 19 | Present evidence and advocate for the expansion of training of hepatitis C nurses to be involved and funded to provide care to people with hepatitis C |
| "GP Super Clinics will provide a wide range of services that target the health needs of local communities. They will also support clinical training placements to train the next generation of primary health care professionals-GPs, nurses and allied health professionals-to ensure a robust future health workforce." p. 21. | GP super clinics used to deliver services to<br>• underserved people with hepatitis C.<br>• Provide opioid substitution treatment<br>Use these centres for training to ensure training medical practitioners' exposure to this type of work and people with an injecting drug history. |
| Health Workforce | Hepatitis C |
| "Expand clinical training places in undeserved and non-traditional settings to maximise learning opportunities and future career choices in these settings" p. 20. | Provide training opportunities for GPs in centres where there is high prevalence of clients with:<br>• hepatitis C and /or<br>• a history of injecting drug use. |
| "Facilitate the uptake of technologies that enhance workforce practice and productivity, with an emphasis on underserved communities and populations." p. 20. | Provide resources regarding best practice care that are designed to be integrated into practices' electronic patient management systems.<br>Linking GPs who have specialise in providing care for hepatitis C using technology. |



## References

1. Willcox S, Lewis G, Burgers JS. Strengthening primary care: Recent reforms and achievements in Australia, England, and the Netherlands [Internet]. New York: The Commonwealth Fund; 2011 [cited 2014 Mar 21]. Available from: http://www.commonwealthfund.org/~/media/Files/Publications/Issue%20Brief/2011/Nov/1564_Willcox_strengthening_primary_care_Aus_Engl_Neth_intl_brief.pdf

2. Thomson S, Osborn R, Squires D, Reed SJ. International profiles of health care systems: Australia, Canada, Denmark, England, France, Germany, Italy, Japan, the Netherlands, New Zealand, Norway, Sweden, Switzerland, and the United States. [Internet]. New York: The Commonwealth Fund; 2011 [cited 2014 Mar 21]. Available from: http://www.commonwealthfund.org/~/media/Files/Publications/Fund%20Report/2011/Nov/1562_Squires_Intl_Profiles_2011_11_10.pdf

3. Australian Institute of Health and Welfare. Medical workforce 2012 [Internet]. Canberra: Australian Institute of Health and Welfare; 2014 [cited 2014 Mar 21]. Available from: https://www.aihw.gov.au/WorkArea/DownloadAsset.aspx?id=60129546076

4. Farnsworth M. AustralianPolitics.com: Kevin Rudd's pre-election address to the National Press Club, Sep 05, 2013 [Internet]. AustralianPolitics.com; 2013 [cited 2014 Mar 21]. Available from: http://australianpolitics.com/2013/09/05/kevin-rudd-npc-pre-election-address.html

5. Abbott T. Media release, Real action to support general practice [Internet]. Canberra: Liberal Party of Australia; 2010 [cited 2014 Mar 20]. Available from: http://www.liberal.org.au/latest-news/2010/08/05/real-action-support-general-practice-0

6. National Health and Hospitals Network. A national health and hospitals network for Australia's future: delivering better health and better hospitals [Internet]. Canberra: Commonwealth of Australia; 2010 [cited 2014 Mar 20]. Available from: http://www.yourhealth.gov.au/internet/yourhealth/publishing.nsf/Content/nhhn-report-toc/$FILE/NHHN%20-%20Full%20report.pdf

7. Liberal Party of Australia. The Coalition's policy to support Australia's health system. [Internet]. Canberra: Liberal Party of Australia; 2013 [cited 2014 Mar 21]. Available from: http://lpaweb-static.s3.amazonaws.com/13-08-22%20The%20Coalition%E2%80%99s%20Policy%20to%20Support%20Australia%E2%80%99s%20Health%20System.pdf

8. Kringos DS, Boerma WG, Hutchinson A, van der Zee J, Groenewegen PP. The breadth of primary care: a systematic

literature review of its core dimensions. BMC Health Serv Res. 2010;10(65):1-13. DOI: 10.1186/1472-6963-10-65.

9. Flitcroft K, Gillespie J, Salkeld G, Carter S, Trevena L. Getting evidence into policy: The need for deliberative strategies? Social Science & Medicine. 2011;72(7):1039-46. DOI: 10.1016/j.socscimed.2011.01.034.

10. Commonwealth of Australia - Department of Health and Ageing. Building a 21st century primary health care system: Australia's first national health care strategy [Internet]. Canberra: Department of Health and Ageing; 2010 [cited 2014 Mar 21]. Available from: http://www.yourhealth.gov.au/internet/yourhealth/publishing.nsf/Content/nphc-draft-report-toc/$FILE/NPHC-Draft.pdf

11. Health Workforce Australia. National health workforce innovation and reform strategic framework for action 2011-2015 [Internet]. Adelaide: Health Workforce Australia; 2011 [cited 2014 Mar 21]. Available from: https://www.hwa.gov.au/sites/uploads/hwa-wir-strategic-framework-for-action-201110.pdf

12. Australian Department of Health and Ageing. Third national hepatitis C strategy 2010 - 2013 [Internet]. Canberra: Australian Department of Health and Ageing; 2010 [cited 2014 Mar 21]. Available from: http://www.health.gov.au/internet/main/publishing.nsf/Content/ohp-national-strategies-2010-hcv/$File/hcv.pdf

13. Australasian Society for HIV Medicine. HIV and hepatitis C: policy, discrimination, legal and ethical issues [Internet]. Darlinghurst, N.S.W: ASHM; 2005 [cited 2014 Mar 21]. Available from: http://www.ashm.org.au/images/Publications/Monographs/HIV_hepCpolicyissues/hiv-hepc-policy.pdf

14. Miller ER, McNally S, Wallace J, Schlichthorst M. The ongoing impacts of hepatitis C-a systematic narrative review of the literature. BMC Public Health. 2012;12(1):672. DOI: 10.1186/1471-2458-12-672.

15. Manos MM, Ho CK, Murphy RC, Shvachko VA. Physical, social, and psychological consequences of treatment for hepatitis C. The Patient-Patient-Centered Outcomes Research. 2013;6(1):23-34. DOI: 10.1007/s40271-013-0005-4.

16. Seden K, Back D, Khoo S. New directly acting antivirals for hepatitis C: potential for interaction with antiretrovirals. J Antimicrob Chemother. 2010;65(6):1079-85. DOI: 10.1093/jac/dkq086.

17. McNally S, Temple-Smith M, Sievert W, Pitts M. Now, later or never? Challenges associated with hepatitis C treatment. Aust N Z J Public Health. 2006;30(5):422-7.

18. Thein H-H, Dore G. Trends in chronic viral hepatitis: Notifications, treatment uptake and advanced disease burden. Cancer Forum [Internet]. 2009 [cited 2014 Mar 24];33(2). Available from: http://search.informit.com.au.proxy.library.adelaide.edu.au/fullText;dn=991472754177450;res=IELHEA

19. Australia and New Zealand Liver Transplant Registry. ANZLT Registry Report 2012. [Internet]. Brisbane: Australia and New Zealand Liver Transplant Registry; 2012 [cited 2014 Mar 21]. Available from: http://www.anzltr.org/Reports/24thReport.pdf

20. Seeff LB. Natural history of chronic hepatitis C. Hepatology. 2002;36(S1):S35-S46. DOI: IO. 1053/jhep.2002.36806.

21. Dore G, Temple-Smith M, Lloyd A, editors. Hepatitis C: An expanding perspective. East Hawthorn, Vic.: IP Communications; 2009.

22. Holmes J, Thompson A, Bell S. Hepatitis C-An update. Aust Fam Physician [Internet]. 2013 [cited 2014 Mar 24];42. Available from: http://www.racgp.org.au/afp/2013/july/hepatitis-c/

23. Australasian Society for HIV Medicine. General practitioners and hepatitis C. [Internet]. Darlinghurst, N.S.W.: Australasian Society for HIV Medicine; 2012 [cited 2014 Mar 21]. Available from: http://www.ashm.org.au/images/Publications/Booklets/PBB_GPsandHCV_V4.0_Aug2012_WEB.pdf

24. Treloar C, Newland J, Harris M, Deacon R, Maher L. A diagnosis of hepatitis C - insights from a study on patients' experiences. Aust Fam Physician [Internet]. 2010 [cited 2014 Mar 24];39(8). Available from: http://search.informit.com.au.proxy.library.adelaide.edu.au/fullText;dn=267570448881772;res=IELHEA

25. Blixen CE, Webster NJ, Hund AJ, Perzynski AT, Kanuch SW, Stoller EP, et al. Communicating about alcohol consumption to nonharmful drinkers with hepatitis C: patient and provider perspectives. J Gen Intern Med. 2008;23(3):242-7. DOI: 10.1007/s11606-007-0483-y.

26. Butt G. Stigma in the context of hepatitis C: Concept analysis. J Adv Nurs. 2008;62(6):712-24. DOI: 10.1111/j.1365-2648.2008.04641.x.

27. Richmond J, Dunning T, Desmond P. Health professionals' attitudes toward caring for people with hepatitis C. Journal of Viral Hepatitis. 2007;14(9):624-32. DOI: 10.1111/j.1365-2893.2007.00849.x.

28. van Boekel LC, Brouwers EP, van Weeghel J, Garretsen HF. Stigma among health professionals towards patients with substance use disorders and its consequences for healthcare

delivery: Systematic review. Drug Alcohol Depend. 2013;131(1):23-35. DOI: 10.1016/j.drugalcdep.2013.02.018.

29. O'Brien S, Day C, Black E, Dolan K. Injecting drug users' understanding of hepatitis C. Addict Behav. 2008;33(12):1602-5. DOI: 10.1016/j.addbeh.2008.07.005.

30. Richmond J. National hepatitis C needs assessment 2008 [Internet]. Canberra: Hepatitis Australia; 2008 [cited 2014 Mar 21]. Available from: https://static.squarespace.com/static/50ff0804e4b007d5a9abe0a5/t/51bed31ae4b06d4459ec5077/1371460378486/Do%20you%20C%20what%20I%20C%20-%20Needs%20Assessment%202008.pdf

31. Australian Government. What is a Medicare Local? [Internet]. Canberra: Australian Government; 2012 [cited 2014 Mar 4]. Available from: http://www.medicarelocals.gov.au/internet/medicarelocals/publishing.nsf/Content/home#.Ut3uVBBe7IU

32. Clement S, Schauman O, Graham T, Maggioni F, Evans-Lacko S, Bezborodovs N, et al. What is the impact of mental health-related stigma on help-seeking? A systematic review of quantitative and qualitative studies. Psychol Med. 2014:1-17. DOI: 10.1017/S0033291714000129.

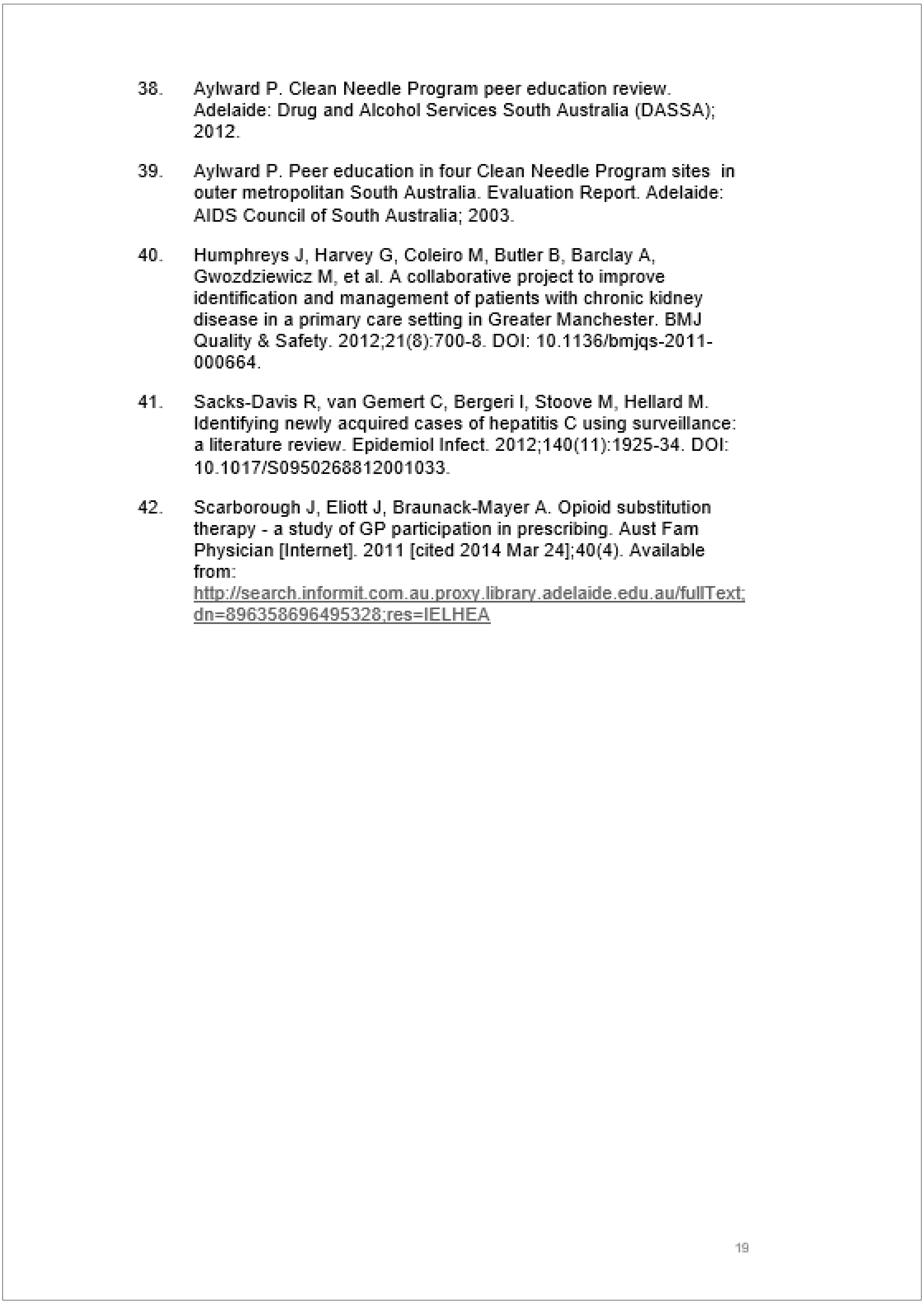
33. Larson A, Gillies M, Howard PJ, Coffin J. It's enough to make you sick: the impact of racism on the health of Aboriginal Australians. Aust N Z J Public Health. 2007;31(4):322-9. DOI: 10.1111/j.1753-6405.2007.00079.x.

34. Hepatitis Australia. Finding Services [Internet]. Canberra: Hepatitis Australia; 2014 [cited 2014 Mar 14]. Available from: http://www.hepatitisaustralia.com/services

35. Australian Injecting and Illicit Drug Users League. Member organisations [Internet]. Canberra: Australian Injecting and Illicit Drug Users League; 2010 [cited 2014 Mar 14]. Available from: http://www.aivl.org.au/#p=58

36. Australian Injecting and Illicit Drug Users League. AIVL Response to the Medicare Locals discussion paper on governance and functions. [Internet]. Canberra: Australian Injecting and Illicit Drug Users League; 2010 [cited 2014 Mar 20]. 1-12. Available from: http://www.aivl.org.au/database/sites/default/files/resources/RESPONSE%20TO%20THE%20MEDICARE%20LOCALS%20DISCUSSION%20PAPER.pdf

37. Australasian Society for HIV Medicine. HIV, Viral Hepatitis and related services directory [Internet]. Surry Hills, NSW: Australasian Society for HIV Medicine; 2014 [cited 2014 Mar 21]. Available from: http://www.ashm.org.au/default2.asp?active_page_id=191



38. Aylward P. Clean Needle Program peer education review. Adelaide: Drug and Alcohol Services South Australia (DASSA); 2012.

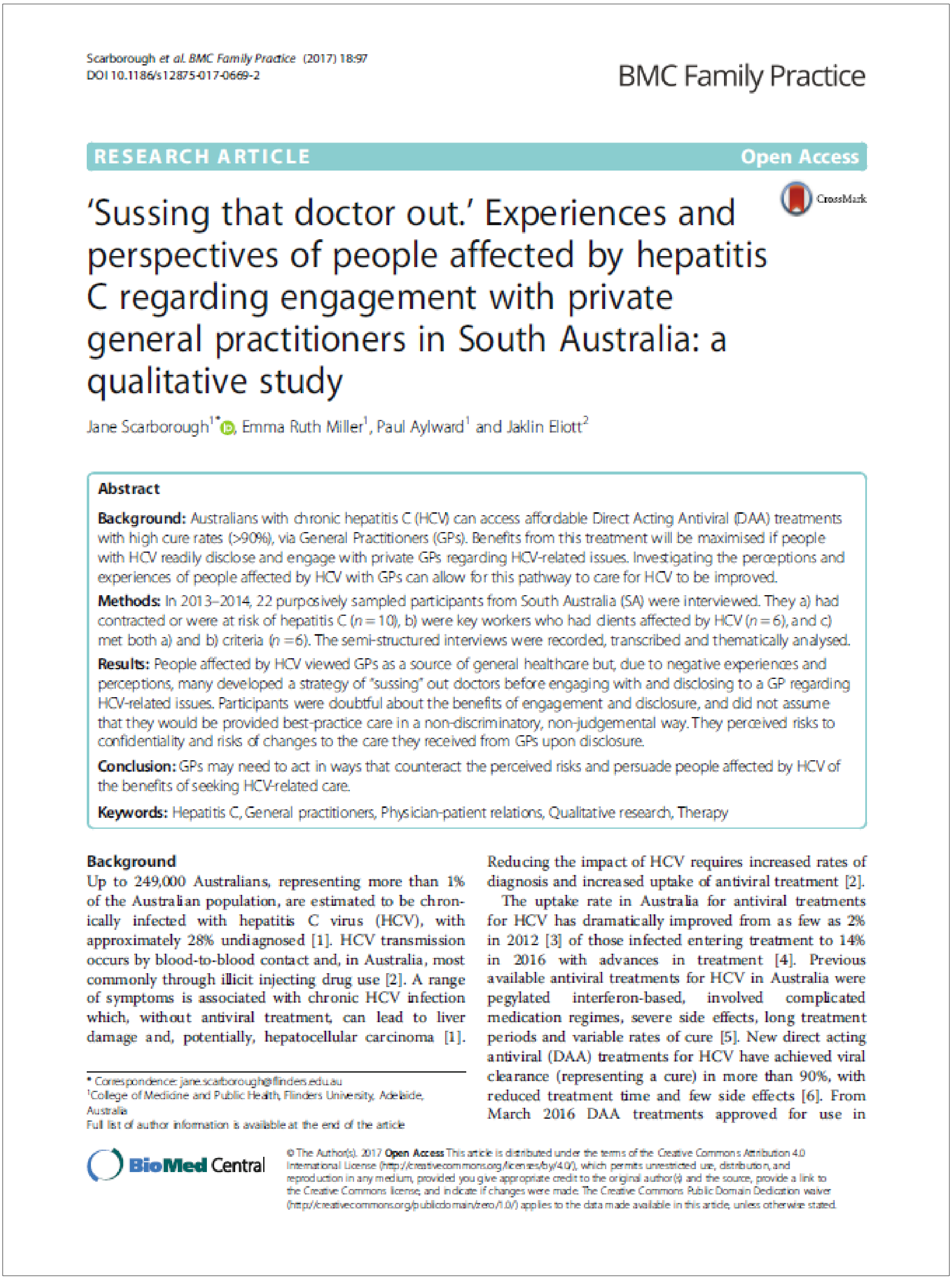
39. Aylward P. Peer education in four Clean Needle Program sites in outer metropolitan South Australia. Evaluation Report. Adelaide: AIDS Council of South Australia; 2003.

40. Humphreys J, Harvey G, Coleiro M, Butler B, Barclay A, Gwozdziewicz M, et al. A collaborative project to improve identification and management of patients with chronic kidney disease in a primary care setting in Greater Manchester. BMJ Quality & Safety. 2012;21(8):700-8. DOI: 10.1136/bmjqs-2011-000664.

41. Sacks-Davis R, van Gemert C, Bergeri I, Stoove M, Hellard M. Identifying newly acquired cases of hepatitis C using surveillance: a literature review. Epidemiol Infect. 2012;140(11):1925-34. DOI: 10.1017/S0950268812001033.

42. Scarborough J, Eliott J, Braunack-Mayer A. Opioid substitution therapy - a study of GP participation in prescribing. Aust Fam Physician [Internet]. 2011 [cited 2014 Mar 24];40(4). Available from: http://search.informit.com.au.proxy.library.adelaide.edu.au/fullText;dn=896358696495328;res=IELHEA

## Appendix 10: Scarborough, J., Miller, E. R., Aylward, P., & Eliott, J. (2017). 'Sussing that doctor out.' Experiences and perspectives of people affected by hepatitis C regarding engagement with private general practitioners in South Australia: a qualitative study. BMC family practice, 18(1), 97. doi:10.1186/s12875-017-0669-2



Scarborough *et al. BMC Family Practice* (2017) 18:97
DOI 10.1186/s12875-017-0669-2

BMC Family Practice

RESEARCH ARTICLE Open Access

# 'Sussing that doctor out.' Experiences and perspectives of people affected by hepatitis C regarding engagement with private general practitioners in South Australia: a qualitative study

Jane Scarborough[1*], Emma Ruth Miller[1], Paul Aylward[1] and Jaklin Eliott[2]

**Abstract**

**Background:** Australians with chronic hepatitis C (HCV) can access affordable Direct Acting Antiviral (DAA) treatments with high cure rates (>90%), via General Practitioners (GPs). Benefits from this treatment will be maximised if people with HCV readily disclose and engage with private GPs regarding HCV-related issues. Investigating the perceptions and experiences of people affected by HCV with GPs can allow for this pathway to care for HCV to be improved.

**Methods:** In 2013–2014, 22 purposively sampled participants from South Australia (SA) were interviewed. They a) had contracted or were at risk of hepatitis C (*n* = 10), b) were key workers who had clients affected by HCV (*n* = 6), and c) met both a) and b) criteria (*n* =6). The semi-structured interviews were recorded, transcribed and thematically analysed.

**Results:** People affected by HCV viewed GPs as a source of general healthcare but, due to negative experiences and perceptions, many developed a strategy of "sussing" out doctors before engaging with and disclosing to a GP regarding HCV-related issues. Participants were doubtful about the benefits of engagement and disclosure, and did not assume that they would be provided best-practice care in a non-discriminatory, non-judgemental way. They perceived risks to confidentiality and risks of changes to the care they received from GPs upon disclosure.

**Conclusion:** GPs may need to act in ways that counteract the perceived risks and persuade people affected by HCV of the benefits of seeking HCV-related care.

**Keywords:** Hepatitis C, General practitioners, Physician-patient relations, Qualitative research, Therapy

## Background

Up to 249,000 Australians, representing more than 1% of the Australian population, are estimated to be chronically infected with hepatitis C virus (HCV), with approximately 28% undiagnosed [1]. HCV transmission occurs by blood-to-blood contact and, in Australia, most commonly through illicit injecting drug use [2]. A range of symptoms is associated with chronic HCV infection which, without antiviral treatment, can lead to liver damage and, potentially, hepatocellular carcinoma [1]. Reducing the impact of HCV requires increased rates of diagnosis and increased uptake of antiviral treatment [2].

The uptake rate in Australia for antiviral treatments for HCV has dramatically improved from as few as 2% in 2012 [3] of those infected entering treatment to 14% in 2016 with advances in treatment [4]. Previous available antiviral treatments for HCV in Australia were pegylated interferon-based, involved complicated medication regimes, severe side effects, long treatment periods and variable rates of cure [5]. New direct acting antiviral (DAA) treatments for HCV have achieved viral clearance (representing a cure) in more than 90%, with reduced treatment time and few side effects [6]. From March 2016 DAA treatments approved for use in

---

* Correspondence: jane.scarborough@flinders.edu.au
[1]College of Medicine and Public Health, Flinders University, Adelaide, Australia
Full list of author information is available at the end of the article

Australia were included on the pharmaceutical benefits scheme (PBS), which subsidises treatment, making these treatments affordable for Australian citizens [7].

Australian General Practitioners (GPs) are well placed, professionally and geographically [8], to be involved in HCV diagnosis, prescribing antiviral treatment and referral to specialists for HCV [9–13]. Australia provides universal access to general practice, with the Federal Government subsidising fee-for-service payments through the Medicare program [14] and approximately 80% of Australians access general practice annually [15]. Most people diagnosed with HCV in Australia are diagnosed by GPs [16] and since the introduction of the new DAA for HCV 19% [4] of those treated have had this prescribed by GPs. The majority of people with HCV are expected to be prescribed DAA for HCV by GPs [17–21] and GP involvement in prescribing is necessary due to the limited capacity of specialists to meet demand for treatment [22].

However, barriers to GPs being involved in this work have been reported [23–25] with findings indicating that, in addition to addressing system barriers, there was a need for additional capacity building for GPs. HCV education to optimally equip GPs for this role has been proposed [24–26] and this education could benefit by including a consideration of perspectives of people affected by HCV [27].

Several studies have examined the barriers and facilitators to seeking HCV-related care amongst a range of populations, various settings, and at different stages of the cascade of care [5, 28–31]. Reported barriers to treatment access include negative patient perceptions of biomedical factors such as counter indications, side effects, and poor efficacy [31] – many of which relate to older, Interferon based treatments. Although these factors may be alleviated with the new antiviral treatments for HCV, HCV-affected people need to be aware of these advances [32], and remaining barriers may deter HCV-infected people from seeking treatment.

The association with injecting drug use often results in stigma being attached to a HCV diagnosis [33, 34]. People with HCV and people who inject drugs have reported negative experiences when seeking healthcare, and their perceptions are that this is due to stigma [35–41]. Indeed, several studies have demonstrated that some GPs hold negative views of people with HCV based on the association of the virus with injecting drug use [33, 34, 42]. This can adversely affect the nature of care provided and, subsequently, the extent to which care is sought for HCV [8, 43].

People with HCV or HCV-related issues in Australia may access GPs for their healthcare [15] but for care specific to HCV-related issues to be provided, the GP needs to be aware of the patient's HCV status or risk factors for HCV. There is no requirement for individuals to be registered with a GP or general practice in Australia [44], so patients are free to move between GPs. As no comprehensive electronic patient record system exists in Australia [44], GPs must rely on information provided by the patient. Some patients may disclose current illicit drug use to GPs to seek help for this issue [45]. Other patients may intentionally hide their current drug use from GPs to avoid stigmatisation [8, 46] or to enable 'doctor shopping' or 'drug seeking' for drugs to be used for non-medical purposes [47]. For those whose only indicator of past drug use may be HCV, disclosure of their past history is a matter of choice [39]. Where a GP is aware of a patient's HCV status, other health issues may be prioritised by the GP or by the patient.

Although GPs have been included as participants in previous HCV studies, these studies have not focused on the perception of care provided to the diverse range of people who would present to GPs with HCV health-related issues. Our study used qualitative methodology to investigate the perspectives and experiences of people affected by HCV with private GPs in Australia and the effect that the interactions have on perceptions about engaging with GPs about HCV-related issues. The insights gained could improve people's engagement with GPs about issues related to HCV, encourage uptake and adherence to DAA treatments, and more efficiently reduce the prevalence of this blood-borne virus in Australia.

## Methods

### Sample and recruitment

We used a purposive sampling strategy to gain a range of perspectives regarding individuals who potentially access HCV care in private general practice in South Australia (SA). Three groups were recruited (see Fig. 1). The first included people either at risk for, or self-reporting, a diagnosis of HCV (identified as "A": affected by HCV). This included participants with a history of illicit injecting drug use but not currently diagnosed with HCV, who are at risk of becoming infected, or may be amongst the 20% of Australians with chronic infection

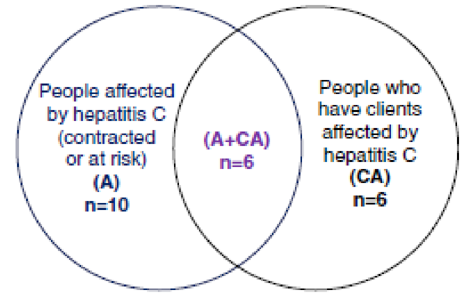


**Fig. 1** Final Sample

who remain undiagnosed [2]. People affected by HCV in this way can provide valuable insights into their perspectives and experiences about the provision of care by private GPs.

The second group comprised key workers providing care to clients affected by HCV (identified as "CA": clients affected) including clinicians and peer workers; these individuals can provide valuable insights about care sought and provided on the basis of their long engagement with, and advocacy for, clients affected by HCV. These two groups: "affected by HCV" and the "clients affected" were not discrete, however, as some key workers reported personal experience of a diagnosis of HCV and illicit injection drug use histories (identified as "A+CA": affected by HCV, with clients affected by HCV). These participants were able to give perspectives based upon their own, and their clients' experiences. Purposive sampling further aimed to include participants varying in drug use status, awareness of HCV, duration of infection, and treatment status.

Recruitment occurred in three phases and primarily through two organisations, Drug and Alcohol Services of South Australia (DASSA) and Hepatitis SA. DASSA is an agency of the SA Health Department with clinics offering a variety of services including clean needle provision, opioid substitution therapy (OST) and drug counselling. Hepatitis SA is a community organisation that provides information and advocacy services, including peer education, for people affected by viral hepatitis. Recruitment of key workers from DASSA and Hepatitis SA occurred through targeted emails, as well as researcher attendance at staff meetings. Key workers targeted for recruitment included medical practitioners, nurses, social workers, psychologists, and peer educators. To recruit people affected by HCV, an advertisement was placed in the quarterly Hepatitis SA newsletter, distributed throughout SA in both hardcopy and digital form. Recruitment targeting people who had a history of injecting drug use occurred through DASSA clinics via the placement of posters and information packs, and subsequent personal approaches at the clinics. Eligible participants were older than 18 years and able to participate in the interview in English. Signed informed consent was obtained before commencement of the interview.

### Participants

Twenty-two participants were recruited (11 female, 11 male), 10 people affected by HCV (A), 6 people who have clients affected by HCV (CA), and 6 who were both affected by HCV and had clients affected by HCV (A+CA). Other than indicating that they met the inclusion criteria of being over 18 years of age, participants were not asked to supply demographic details, but some demographic information was provided during the interviews. Participant responses indicated an age range from early 20s to over 60. Most participants were residents of Adelaide (the capitol of SA) metropolitan suburbs with only one participant (CA) residing in a regional area and one participant (A) previously residing in a regional area. Participants with clients affected by HCV provided services to HCV-affected clients across SA. One participant indicated a non-English speaking, 1st generation migrant background. No participants identified to the interviewer as an Indigenous Australian.

All participants reporting a diagnosis of HCV also reported a history of illicit injecting drug use, and that HCV transmission occurred via this practice, with the exception of one participant who reported that transmission was via non-sterile tattooing. The significance of this self-reported illicit drug use of participants varied in regard to currency (from recent to historical) and severity (chronic and relapsing, to occasional and controlled). All affected participants indicated that they had the choice to access private GPs, with some participants being currently highly engaged. Participants from the groups affected by HCV, self-reported a range of HCV diagnosis including current chronic HCV infection, intention to be tested, previous HCV infection (naturally cleared), and cured of chronic HCV infection. Participants from the groups affected by HCV also self-reported a range of involvement in HCV treatment: current, seeking treatment, successful and unsuccessful completion of treatment, decided against interferon-based treatment available at the time of the study.

### Data collection and analysis

Semi-structured qualitative interviews were conducted from November 2013 and August 2014, at a time when DAA treatment in Australia was being clinically trialled but yet to be approved for broader use or included on the PBS. Interviews were carried in a range of settings convenient to the participants, including DASSA sites, public library spaces and a participant's home. Interview outlines were informed by the existing literature [5, 28–31] and included questions about HCV knowledge ('Tell me how you gained your knowledge about hepatitis C'), experience of HCV ('Can you tell me the effect of hepatitis C on your life?'), perceptions of private GPs ('What for you makes a good private general practitioner?) and experience of care provided by GPs ('Can you describe any situations where you have received medical care from private GPs that relates to hepatitis C?'). Interviews ranged in length from 19 min to 87 min with the median length of 58 min. The interview outline was covered during all interviews, although one participant requested the interview was kept brief. Participants were given a $20 supermarket gift voucher as compensation for their time.

Interview audio recordings were transcribed verbatim as soon as possible after the interview took place. The transcripts were de-identified with participant names replaced with pseudonyms and the text entered into NVivo 10 software [48]. Transcriptions were thematically analysed in the process outlined by Braun and Clarke [49] to identify, analyse, and report on participants' perspectives of care provided by GPs for HCV. The interview text was then systematically coded, with some codes reflecting the literature-informed interview topics and others reflecting additional aspects of the experiences and perspectives of participants. The codes produced were then initially grouped to identify possible themes. The themes were reviewed and discussed amongst the authors to define and name the final themes reported. Pseudonyms used during the analysis were removed from the manuscript to protect participant confidentiality.

### Reflexivity

The first author works at clinical sites offering treatment for drug issues and in a role that involves interacting with a variety of private GPs. Other members of the research team were from a variety of professional backgrounds, and provided an 'outsider' perspective, which promoted a more reflexive analysis of the data Interpretation was enhanced through collective discussion and reflection upon emerging themes identified by the first author. This enabled different lenses to be applied and interpretive meaning across the data set to be agreed consensually. The possible effect of any one individual's bias was therefore ameliorated by having input from the four authors throughout the research process [49].

### Ethics approval and considerations

Ethics approval was obtained from the South Australian Health Human Research Ethics Committee, the Aboriginal Health Research Ethics Committee (a sub-committee of the Aboriginal Health Council of South Australia Inc.), and the Human Research Ethics Committee of the University of Adelaide.

The first author conducted the interviews and works at DASSA in a non-clinical role. To avoid any potential ambiguity, [50] the interviewer explained her role as researcher and her separate role at DASSA, and emphasized processes to be used to protect confidentiality. Participant responses indicated that they understood choice regarding participation and that participation would not affect their ongoing relationships. The drug use and HCV status of researchers has been presented as important aspect of prior research in this field [51]. The interviewer has no history of illicit drug use or HCV and was careful to present as having no such history, allowing the participants' decisions to be involved in the research and share information to be based on informed consent.

## Results

The experiences and perceptions of participants regarding engagement of people with HCV with GPs will be outlined. Similar experiences and perceptions were provided by participants independent of the basis of their recruitment as people directly affected by HCV (A), had clients affected by HCV (CA) or could provide both perspectives (C + CA).

### Engagement about HCV – Disclosure choices and strategies

Participants viewed GPs as a source of general health-care that potentially includes care for issues related to HCV. Several participants stated that when they were 'lucky' to find a good doctor, they would attempt to continue to engage with them.

> My doctor's interested in what's happening, asks me the right questions. Asks me what testing I'd liked to be done. Won't write "hep C" on a referral to anyone else, without my express consent. (A)

Some participants held that the benefit of engaging with GPs could only be fully realised if they disclosed their HCV positive status and/or drug use history, placed their trust in the GPs professionalism, and were accepting of the care they received.

> You know if I'm sick I'm going to have to say "Might be because ...". I want to go to find out; go to every aspect of why I might be sick. (A)

Where they perceived a lack of benefit associated with disclosure and a risk of consequences in disclosure (either within the patient–doctor relationship, or in their wider lives), people with HCV were cautious about disclosing HCV. A process of judging or 'sussing' out the GP before disclosing was repeatedly described.

> So I think it would an issue of the client sussing that doctor out and thinking "No I don't think that they could deal with that," and I think they're pretty good at that. (CA)

> I can tell what kind of character he is you know. He would be one of those that just, you could just see that. He would go out of his way, but as for other doctors I'm not real sure about that you know. (A)
>
> ... clients will just go to drop in, bulk-billing places at times when they need something, and then they [the client] may link with a GP if they [the client] find they got on well with the person ....(CA)

Often participants outlined that they or their clients adopting a strategy of having one GP that they engage with for HCV-related issues, but maintaining non-disclosure with other GPs. Engagement with a nurse trained to support people with HCV to gain appropriate care in a shared care arrangement was also regarded as an effective strategy to maximise care for HCV.

> I go between a couple of GPs. I also go out and see [name of doctor] out at [surgery that has blood borne virus treatment specialty] and so yeah. He's a lot more reasonable. (A)
>
> There's a hep C place over at the [name of practice] over there and that's where my nurse is. You know they're pretty supportive there. (A)

### Perception of engagement involving risk to confidentiality of sensitive information

Engagement with GPs that involved disclosure of HCV positive status was seen by some participants as a risk to the confidentiality of this sensitive information, with potential serious consequences. Some participants had not disclosed their HCV status to their work, families, or their intimate partners. They reflected that their illicit drug use was part of their past and that they should be in control of the decision to disclose any of this information. These participants said that they were not suspected of a past drug history and that this history would remain secure if they managed disclosure about HCV.

> Well I still haven't told my parents. (A+CA)

> ... my partner doesn't know and I'll never tell him. I don't think it's relevant. (A+CA)

Possible breaches of confidentiality by medical practitioners providing HCV-related care were seen to diminish the non-disclosure choice of people affected by HCV. Participants described people affected by HCV as being 'on constant guard' to protect this information. The need for a person's HCV status to be shared between healthcare workers was questioned, as the participants expected that all health practitioners should use universal precautions to avoid transmission, and considered that this would negate the need to share this information in most circumstances. Where breaches of confidentiality had occurred, this led affected participants to question whether the health practitioners involved in their care understood the significance of their choice to limit the disclosure of their HCV positive status.

> ... my kids got asked "Could you get your mum to ring the hospital urgently?" and I'd made it really clear I have not told anybody in my family about this, do not leave messages. (A+CA)

> I used to tell them [healthcare workers] because "it's my responsibility of blood you know, infectious blood" and all that sort of thing. And then in at the [name of hepatitis C support organisation] they said "Well actually it is their responsibility. You don't have to tell anybody." (A)

HCV-affected participants reported feeling discomfort when their HCV status was recorded on patient records. They felt that the standard practices associated with data collection and patient records presented a risk to confidentiality and control of information. Participants proposed that engagement with GPs was affected by these concerns and that they, or their clients, had not disclosed information, and indeed, avoided returning to practices where they had reluctantly disclosed.

> Every worker can look up my records. Do I like that? No I hate that with a passion. (A+CA)

> ... this form, this is really bad; this form goes to the receptionist and the receptionist keeps it there, puts whatever she wants, [it] sits on the receptionist's desk and then it gets given back to and given back to the doctor. So this form is floating all around the place ... (A)

The understanding of the sharing of information was informed by participants' involvement in highly regulated opioid substitution programs. One participant perceived that this healthcare was only available on the condition that they subjected themselves to the rules of the program, including being tested for HCV, stating "I've got to do a blood test soon" (A), and that information would be electronically shared between the program and GPs, as "It's all linked" (A).

### Perception of engagement involving risk of exposure to discrimination, negative judgement and change to care provided.

Based on their expectations and experiences, participants did not assume that all GPs would be willing to provide care for HCV-related issues in a non-discriminatory, non-judgemental way. Participants stated they understood that GPs could develop negative attitudes to people with a drug history due to being exposed to 'drug seeking' or 'doctor shopping' behaviour, and categorised this reaction by GPs as somewhat reasonable. The majority of participants detailed how they or their clients had participated in these behaviours to obtain drugs to be used for non-medical purposes.

> But you can't blame the GPs being like they are because you've got no idea what some people do to get drugs out of them. (A)

treatment and this had led to him refusing to make a referral for a HCV-related investigation or for antiviral treatment: "he was quite clear that I shouldn't have that …" (A).

Finally, some participants who had sought HCV antiviral treatment at tertiary centres cited situations in which the treatment had not been provided, despite their GP providing them with the required referral and even where the GP had actively followed up the progress of the referral. They recognised that the lack of treatment provision was the responsibility of the tertiary centre and not of the GP, but for these participants, engagement with GPs was perceived as an ineffectual pathway to their goal of antiviral treatment for HCV.

> But he's [the participant's GP] put referrals in through the [tertiary hospital #1] but I don't hear anything about the referrals, ay. (A)
> … you get an appointment and then they [tertiary liver clinic] pretty much give you a blood test and then they say "come back in six months." (A)

## Discussion

Since this study was conducted, affordable, direct acting, antiviral treatment for HCV has become available for Australian citizens [7] and this represents a spectacular advance in the potential to address the biomedical aspects of HCV infection [6]. Most Australians (including all participants) access private, federally-subsidised GPs for their healthcare [15] and,for the majority of people with HCV in Australia, this relatively new treatment can be delivered via private GPs [13]. For people to access this treatment, however, they need to disclose their HCV status or HCV risk factors and be willing to engage with GPs about this issue. The aim of this study was to better understand the experiences and perceptions of people affected by HCV regarding engagement between GPs and patients about issues relevant to HCV. This information could be used to guide the development of approaches for private GPs to reduce barriers to, and improve the delivery of, care for people with HCV.

Like the general Australian community, people affected by HCV viewed GPs as a source of general healthcare [13], potentially including issues related to HCV. Several participants reported being highly satisfied with the care provided by individual GPs including specific care for their HCV. This notwithstanding, they and other participants also relayed negative experiences and perceptions about engagement with GPs for HCV-related care. Consequently, participants often described people affected by HCV developing a strategy of "sussing" out doctors before engaging and disclosing to individual GPs. The process involved weighing up the perceived risks and the perceived benefits and then deciding whether engagement and disclosure were worthwhile. As reported in previous studies [35–40], many of these risks were related to stigma, but several other factors also contributed to the decision-making process. If GPs are aware of the decision-making process that people affected by HCV undertake, the GPs can utilise strategies aimed at reducing their doubts and increasing their perceptions of benefit about the care they will receive, and tip patients' decisions towards disclosure and engagement.

Participants acknowledged the difficulties for GPs dealing with 'doctor shopping' and other 'drug seeking' behaviour and, particularly where they had previously participated in it, expressed sympathy for doctors required to deal with such behaviours. The honest disclosure of current illicit drug use to a GP, however, would be illogical if the person was attempting to obtain drugs of dependence without genuine need. This is more likely to represent an attempt to elicit care for HCV, or a health issue related to drug use. Faced with this situation, GPs might offer people a range of information to prevent harm, for example, brochures regarding prevention of transmission of blood-borne viruses. In addition to the benefits for patients receiving opioid substitution treatment [52, 53], GPs may find that drug-seeking behaviour is reduced when they offer such treatment [45].

Based on their expectations and experiences participants did not assume that all GPs would be willing to provide care for HCV-related issues in a non-discriminatory, non-judgemental way. Importantly, no participant described overt discrimination associated with HCV by GPs. Discrimination in other settings, including health settings, was described, and these experiences appeared incorporated into participants' expectation of encountering discrimination from GPs. Displaying posters and other information in the waiting room about hepatitis C or drug use can signal to patients that the practice is willing to provide care for these conditions. This material would be timely as our participants' responses indicate that when the new DAA therapies were available, people affected by HCV would reassess their previous decision to not enter treatment. Additionally, publicity surrounding these new treatments may prompt people who are undiagnosed to consider their risk of exposure, and the presence of this material in the waiting room may prompt them to seek testing at the practice.

Upon disclosure of an HCV diagnosis to GPs, some participants recounted experiences of unwelcome changes to their usual care, which precipitated reluctance to disclose to other practitioners in the future. Unwillingness to prescribe drugs of dependence, and focussing on the patient's 'drug-use problem' were reported by participants as examples of GPs' reactions following disclosure of their HCV-status. Participants expressed a frustration that, whilst well intentioned, this change appeared to reflect GPs' incorrect assumptions concerning 'inherent' relationships between

HCV and 'current' drug addiction, when in fact there is a great deal of heterogeneity of the population affected by HCV regarding such behaviours or identities [2, 29, 52]. GPs can play an important part in addressing patients' drug-use issues [54] but should not assume that all patients presenting for HCV management require treatment for drug use. Whilst drug addiction is often described as a 'chronic relapsing disorder' [55], not all people with HCV are, or have ever been, addicted to drugs [2, 29, 52]. It is good practice for GPs to consistently exercise caution prescribing drugs of dependence [55], but the use of these drugs are warranted to treat many conditions. In these circumstances, GPs should not deny drugs of dependence to patients, based on the patient's HCV status or even reported drug issues, but should exercise clinical judgement using appropriate safeguards when prescribing [55].

A source of concern for some participants was the loss of control of their information, with the subsequent risk to the confidentiality of sensitive information and potential associated serious consequences. Open disclosure within the patient-doctor relationship did not equate with disclosure to family, intimate partners, friends, or during employment. These participants wanted to avoid exposure to stigma due to their HCV status and their past injecting drug behaviour if this became known [31, 39, 56]. Australian general practice standards [57] require practices to adhere to policies regarding the protection of patient information. Routinely informing all patients that these systems are in place, would reduce fear, and encourage open and honest disclosure, about sensitive information, in particular drug-related or HCV-related conditions. Participants wanted to be reassured by their GP that their information would only be shared with their explicit permission, and only when relevant. Even when confidentiality policies are strictly adhered to, concerns about privacy may still be held by the patient. Being provided reassurance about this aspect of care is an important way to address concerns and improve engagement.

Participants recognised the difficulty of GPs maintaining in-depth knowledge over the wide scope of their work, yet, as reported elsewhere [58], it was common for participants to be critical of the information provided by some GPs regarding HCV. It is unsurprising that participants had a high level of knowledge underpinning this judgement as many had actively accumulated knowledge since receiving their HCV diagnosis, had health related qualifications, and/or worked with clients affected by HCV. It is important for GPs to be able to demonstrate up-to-date knowledge about HCV diagnosis, management, and treatment to convince people affected by HCV to engage with them. The DAA treatment for HCV is relatively simple compared to former treatments and its availability provides a trigger for GPs to be recruited into education to bridge GPs' identified HCV knowledge gaps [24]. Education must take into account the time restraints of GPs and incorporate the patient perspective to barriers to treatment. Where GPs undertake education and training, it would be useful for people seeking care to be aware of this through a register and/or signage at GP practices.

All people affected by HCV should have access to GPs providing best practice care for HCV-related issues. This study has helped to illuminate how the perceptions of people affected by HCV influences and defines for them the nature of their engagement with GPs around HCV care. However, further research could usefully explore the nature of meanings and perceptions brought to the potential consultation by GPs, which may enhance or limit the extent to which they are able to appropriately and successfully engage with these patients and address the concerns raised in this paper. This may also allow the development of practices and policies that better address situations where HCV affected patients appear to have been effectively "banned" from certain South Australian practices.

The lack of participants who identify as Indigenous Australians is a limitation to this study. Further research with Indigenous Australian participants is necessary to determine if the findings are applicable to this population, to identify any additional beliefs or practices that may contribute to their perspectives and experiences, and to outline the implications of same for best practice care [59]. A further potential limitation of this study is that the findings in one Australian state (SA) may not be generalizable to jurisdictions where different systems of primary medical care exist and other dynamics are present. Experiences of stigma have, however, been reported internationally [31] and our findings will be relevant wherever HCV-affected people face decisions about managing disclosure and engagement when seeking primary healthcare. This study was conducted before DAA treatments for HCV options became widely available in Australia, and this forms another potential limitation. Although participants indicated that they would reassess entering treatment when new DAA treatments became available, people would need to be assured that they could access this treatment via GPs; some may not engage and disclose if they perceive the associated risks to be too high. Understanding the patient decision-making process regarding engagement with GPs will therefore still be relevant in the era of DAA HCV treatment availability.

## Conclusion

People affected by HCV come to any GP-patient interaction with a background of experiences and perceptions, all of which shape their expectations of the benefits and risks of engagement. Capable and willing GPs may need to act to counteract the perceived risks and persuade those people "sussing them out" of the benefits of seeking HCV-related care from them.

To do this, GPs can publicise that they are willing and able to provide care for HCV and related conditions, including making available information about the new DAA treatment for HCV and its benefits. Stating and demonstrating adherence to the confidentiality policy of their practice will reassure patients that they are in control of their information and that disclosing to the GP will not increase the risk of exposure to stigma. Each patient comes to the patient-doctor relationship with their own history, understandings, and set of needs. GPs can offer appropriate individualised care to patients affected by HCV by assessing each individual patient's situation and requirements.

### Abbreviations

DAA: Direct Acting Antivirals; DASSA: Drug and Alcohol Services South Australia; GPs: General Practitioners; HCV: Chronic hepatitis C; PBS: Pharmaceutical benefits scheme; SA: South Australia

### Acknowledgements

We would like to acknowledge the contribution of the participants in this study who shared their perspectives and experiences. We would also like to acknowledge Hepatitis SA and DASSA who assisted with the recruitment of participant into this study.

### Funding

JS was a recipient of an Australian Government Research Training Program Scholarship during the conduct of this study. No other funding was received for this study.

### Availability of data and materials

To protect the anonymity of participants, the qualitative data used in this research cannot be made publicly available.

### Authors' contributions

JS conceived the study, participated in design, recruited participants, conducted and transcribed interviews, undertook analysis and drafted the manuscript. EM, PA and JE participated in design and analysis, and contributed to drafting of the manuscript. All authors read and approved the final manuscript.

### Authors' information

Jane Scarborough is a PhD candidate (part-time) whose doctorate aims to understand GP, practice and patient factors that determine the provision of care provided in private general practice for people with hepatitis C. Jane also works supporting GPs prescribing opioid pharmacotherapy in the community.

### Ethics approval and consent to participate

Ethics approval was obtained from the South Australian Health Human Research Ethics Committee, the Aboriginal Health Research Ethics Committee (a sub-committee of the Aboriginal Health Council of South Australia Inc.), and the Human Research Ethics Committee of the University of Adelaide.

Participants gave informed written consent to participate in the study and for their data to be used in de-identified form for presentations and publications.

### Consent for publication

Not applicable.

### Competing interests

The authors declare that they have no competing interests.

## Publisher's Note

### Author details

[1] College of Medicine and Public Health, Flinders University, Adelaide, Australia. [2] School of Public Health, Faculty of Health and Medical Sciences, University of Adelaide, Adelaide, Australia.

**Received: 5 June 2017 Accepted: 20 November 2017**

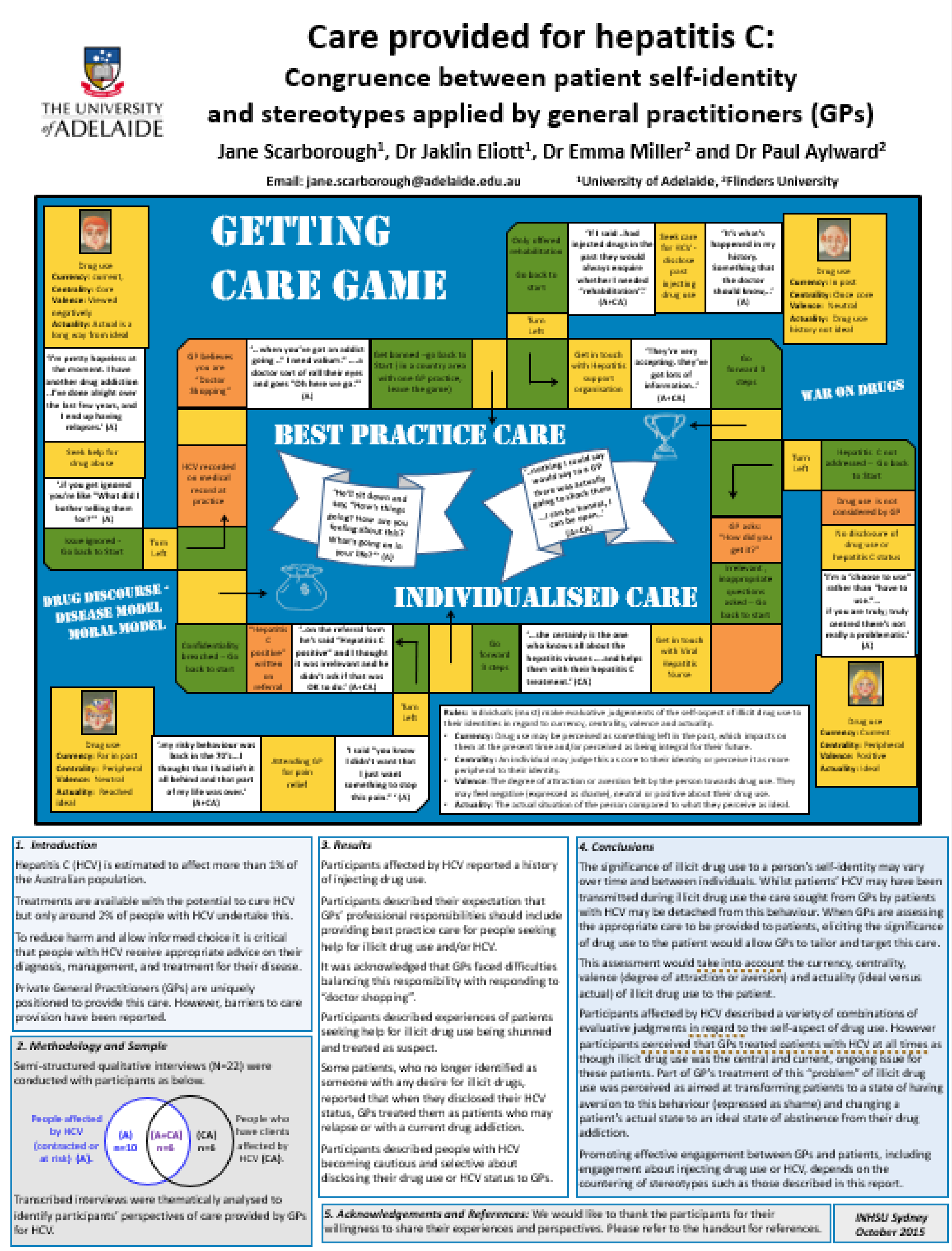
### References

1. The Kirby Institute. HIV, viral hepatitis and sexually transmissible infections in Australia annual surveillance report 2016. The Kirby Institute. 2016. https://kirby.unsw.edu.au/sites/default/files/kirby/report/SERP_Annual-Surveillance-Report-2016_UPD170627.pdf. Accessed 24 Nov 2017.
2. Hajarizadeh B, Grebely J, McManus H, Estes C, Razavi H, Gray RT, et al. Chronic hepatitis C burden and care cascade in Australia in the era of interferon-based treatment. J Gastroenterol Hepatol. 2017;32(1):229–36.
3. The Kirby Institute. HIV, viral hepatitis and sexually transmissible infections in Australia annual surveillance report 20123. The Kirby Institute. 2013. https://kirby.unsw.edu.au/sites/default/files/kirby/report/SERP_2013-Annual-Surveillance-Report.pdf. Accessed 20 Oct 2017.
4. Institute. TK. Monitoring hepatitis C treatment uptake in Australia Issue 7, July 2017. 2017. https://kirby.unsw.edu.au/sites/default/files/kirby/report/Monitoring-hep-C-treatment-uptake-in-Australia_Iss7-JUL17.pdf. Accessed 10 Oct 2017.
5. Sublette VA, Smith SK, George J, McCaffery K, Douglas MW. The hepatitis C treatment experience patients' perceptions of the facilitators of and barriers to uptake, adherence and completion. Psychol Health. 2015;30(8):987–1004.
6. Pawlotsky JM. New hepatitis C therapies: the toolbox, strategies, and challenges. Gastroenterology. 2014;146(5):1176–92.
7. Ley S. Hep C cures available today for as low as $6.20 a prescription - media release. Commonwealth Department of Health. 2016. http://www.health.gov.au/internet/ministers/publishing.nsf/Content/1EFB3D89E92B1627CA257F6800773A22/$File/SL014.pdf. Accessed 9 May 2017.
8. Islam MM, Topp L, Iversen J, Day C, Conigrave KM, Maher L. Healthcare utilisation and disclosure of injecting drug use among clients of Australia's needle and syringe programs. Aust N Z J Public Health. 2013;37(2):148–54.
9. Mossialos E, Wenzl M, Osborn R, Anderson C. 2015 International profiles of health care systems. The Commonwealth Fund. 2016. http://www.commonwealthfund.org/~/media/files/publications/fund-report/2016/jan/1857_mossialos_intl_profiles_2015_v7.pdf. Accessed 9 May 2017.
10. Holmes J, Thompson A, Bell S. Hepatitis C-an update. Aust Fam Physician. 2013;42:452–6.
11. Hepatitis C Virus Infection Consensus Statement Working Group. Australian recommendations for the management of hepatitis C virus infection: a consensus statement (January 2017). Gastroenterological Society of Australia. 2017. https://www.asid.net.au/documents/item/1208. Accessed 9 May 2017.
12. Baker D, Alavi M, Erratt A, Hill S, Balcomb A, Hallinan R, et al. Delivery of treatment for hepatitis C virus infection in the primary care setting. Eur J Gastroenterol Hepatol. 2014;26(9):1003–9.
13. Australian Government - Department of Health. Hepatitis C medicines fact sheet for community based prescribers. Australian Government - Department of Health. 2016. https://www.pbs.gov.au/info//publication/factsheets/hep-c/hepc-factsheet-community-based-prescribers. Accessed 9 May 2017.
14. Australian Government - Department of Human Services. Medicare services. Australian Government, Department of Human Services. 2017. https://www.humanservices.gov.au/customer/subjects/medicare-services. Accessed 9 May 2017.
15. Australian Bureau of Statistics. Patient experiences in Australia: summary of findings 2015–16, general practitioners. Australian Bureau of Statistics. 2016. http://www.abs.gov.au/ausstats/abs@.nsf/mf/4839.0. Accessed 24 Nov 2017.
16. McNally S, Temple-Smith Meredith, M P. Making decisions about hepatitis C treatment. The Australian Research Centre in Sex, Health and Society, La

Trobe University. 2004. https://www.latrobe.edu.au/arcshs/downloads/arcshs-research-publications/making_decisions_about_hepc_treatment.pdf. Accessed 9 May 2017.

17. Westergaard RP, Stockman LJ, Hyland HA, Guilfoyle SM, Fangman JJ, Vergeront JM. Provider workforce assessment in a rural hepatitis C epidemic implications for scale-up of antiviral therapy. J Prim Care Community Health. 2014;6(3):215–7.
18. Afdhal N, Zeuzem S, Schooley R, Thomas D, Ward J, Litwin A, et al. The new paradigm of hepatitis C therapy: integration of oral therapies into best practices. J Viral Hepat. 2013;20(11):745–60.
19. Hellard ME, Wang YH. The role of general practitioners in managing and treating hepatitis C. Med J Aust. 2009;191(10):523–4.
20. Lambert SM, Page AN, Wittmann J, Hayllar JS, Ferndale CW, Bain TM, et al. General practitioner attitudes to prescribing hepatitis C antiviral therapy in a community setting. Aust J Prim Health. 2011;17(3):282–7.
21. Ward JW. Global elimination of hepatitis C virus. Gastroenterol Hepatol (N Y). 2016;12(10):632.
22. Grebely J, Dore GJ, Morin S, Rockstroh JK, Klein MB. Elimination of HCV as a public health concern among people who inject drugs by 2030–what will it take to get there? J Int AIDS Soc. 2017;20(1):22146.
23. Scarborough J, Eliott J, Miller E, Aylward P. Equity in primary health care delivery: an examination of the cohesiveness of strategies relating to the primary healthcare system, the health workforce and hepatitis C. Aust Health Rev. 2014;39(2):175–82.
24. Sud R, Zekry A, Freiman J. General practitioners face significant barriers to prescribing direct-acting antiviral therapy for hepatitis C. J Gastroenterol Hepatol. 2016;31(Suppl 2):81.
25. Wade A, Draper B, Doyle J, Allard N, Grinzi P, Thompson A, et al. A survey of hepatitis C management by Victorian GPs after PBS-listing of direct-acting antiviral therapy. Aust Fam Physician. 2017;46(4):235.
26. Davis JS, Tapley A, Morgan S, van Driel ML, Magin PJ. Clinical experience of patients with hepatitis C virus infection among Australian GP trainees. Med J Aust. 2017;206(7):308.
27. Byrne L, Happell B, Welch T, Moxham LJ. 'Things you can't learn from books': teaching recovery from a lived experience perspective. Int J Ment Health Nurs. 2013;22(3):195–204.
28. Yap L, Carruthers S, Thompson S, Cheng W, Jones J, Simpson P, et al. A descriptive model of patient readiness, motivators, and hepatitis C treatment uptake among Australian prisoners. PLoS One. 2014;9(2):e87564.
29. Swan D, Long J, Carr O, Flanagan J, Irish H, Keating S, et al. Barriers to and facilitators of hepatitis C testing, management, and treatment among current and former injecting drug users: a qualitative exploration. AIDS Patient Care STDs. 2010;24(12):753–62.
30. Evon DM, Simpson KM, Esserman D, Verma A, Smith S, Fried MW. Barriers to accessing care in patients with chronic hepatitis C: the impact of depression. Aliment Pharmacol Ther. 2010;32(9):1163–73.
31. Miller ER, McNally S, Wallace J, Schlichthorst M. The ongoing impacts of hepatitis C-a systematic narrative review of the literature. BMC Public Health. 2012;12(1):672.
32. Carruthers SJ, Ryan C. Hepatitis C treatment and injecting drug users in Perth, Western Australia: knowledge of personal status and eligibility criteria for treatment. J Subst Use. 2012;17(1):32–4.
33. Butt G. Stigma in the context of hepatitis C: concept analysis. J Adv Nurs. 2008;62(6):712–24.
34. Richmond J, Dunning T, Desmond P. Health professionals' attitudes toward caring for people with hepatitis C. J Viral Hepat. 2007;14(9):624–32.
35. Day C, Jayasuriya R, Stone G. Hepatitis C-related discrimination in new South Wales. Aust Health Rev. 2004;27(2):57–60.
36. Hopwood M, Treloar C, Bryant J. Hepatitis C and injecting-related discrimination in new South Wales, Australia. Drugs (Abingdon Engl). 2006;13(1):61–75.
37. Hopwood M, Treloar C. Receiving a hepatitis C positive diagnosis. Intern Med J. 2004;34(9–10):526–31.
38. Gifford SM, O'Brien ML, Smith A, Temple-Smith M, Stoove M, Mitchell D, et al. Australian men's experiences of living with hepatitis C virus: results from a cross-sectional survey. J Gastroenterol Hepatol. 2005;20(1):79–86.
39. Fry M, Bates G. The tasks of self-managing hepatitis C: the significance of disclosure. Psychol Health. 2011;27(4):460–74.
40. MacNeil JM. The complexity of living with hepatitis C: a Newman perspective. Nurs Sci Q. 2012;25(3):261–6.
41. Harris M, Rhodes T. Hepatitis C treatment access and uptake for people who inject drugs: a review mapping the role of social factors. Harm Reduct J. 2013;10(1):7.
42. Sgorbini M, O'Brien L, Jackson D. Living with hepatitis C and treatment: the personal experiences of patients. J Clin Nurs. 2009;18(16):2282–91.
43. van Boekel LC, Brouwers EP, van Weeghel J, Garretsen HF. Stigma among health professionals towards patients with substance use disorders and its consequences for healthcare delivery: systematic review. Drug Alcohol Depend. 2013;131(1):23–35.
44. Thomson S, Osborn R, Squires D, Reed SJ. International profiles of health care systems, 2014: Australia, Canada, Denmark, England, France, Germany, Italy, Japan, the Netherlands, New Zealand, Norway, Sweden, Switzerland, and the United States. The Commonwealth Fund. 2015. http://www.commonwealthfund.org/~/media/files/publications/fund-report/2015/jan/1802_mossialos_intl_profiles_2014_v7.pdf. Accessed 9 May 2017.
45. Scarborough J, Eliott J, Braunack-Mayer A. Opioid substitution therapy - a study of GP participation in prescribing. Aust Fam Physician. 2011;40(4):241–5.
46. Hopwood M, Nakamura T, Treloar C. Disclosing hepatitis c infection within everyday contexts: implications for accessing support and healthcare. J Health Psychol. 2010;15(6):811–8.
47. Allan J, Herridge N, Griffiths P, Fisher A, Clarke I. Illicit fentanyl use in rural Australia–an exploratory study. J Alcohol Drug Depend. 2015;doi:10.4172/23296488.1000196.
48. QSR International Pty Ltd. NVivo 10 for windows: QSR International Pty Ltd.; 2014. http://www.qsrinternational.com/products_nvivo.aspx. Accessed 2 Dec 2014
49. Braun V, Clarke V. Using thematic analysis in psychology. Qual Res Psychol 2006;3(2):77-101.
50. McDermid F, Peters K, Jackson D, Daly J. Conducting qualitative research in the context of pre-existing peer and collegial relationships. Nurse Res. 2014;21(5):28–33.
51. Harris M. Injecting, infection, illness: abjection and hepatitis C stigma. Body Soc. 2009;15(4):33–51.
52. White B, Dore GJ, Lloyd AR, Rawlinson WD, Maher L. Opioid substitution therapy protects against hepatitis C virus acquisition in people who inject drugs: the HITS-c study. Med J Aust. 2014;201(6):326–9.
53. Teesson M, Ross J, Darke S, Lynskey M, Ali R, Ritter A, et al. One year outcomes for heroin dependence: findings from the Australian treatment outcome study (ATOS). Drug Alcohol Depend. 2006;83:174–80.
54. British Medical Association. Drugs of dependence: the role of medical professionals. British Medical Association. 2013. http://www.tdpf.org.uk/sites/default/files/BMA-drugs-of-dependence.pdf. Accessed 9 May 2017.
55. Badiani A. Is a 'general'theory of addiction possible? A commentary on: a multistep general theory of transition to addiction. Psychopharmacology. 2014;231(19):3923–7.
56. Treloar C, Rhodes T. The lived experience of hepatitis C and its treatment among injecting drug users: qualitative synthesis. Qual Health Res. 2009;19(9):1321–34.
57. The Royal Australian College of General Practitioners. The RACGP standards for general practices: 4th edition. The Royal Australian College of General Practitioners. 2015. https://www.racgp.org.au/your-practice/standards/standards4thedition/. Accessed 24 Nov 2017.
58. Stevenson FA, Kerr C, Murray E, Nazareth I. Information from the internet and the doctor-patient relationship: the patient perspective–a qualitative study. BMC Fam Pract. 2007; 10.1186/1471-2296-8-47.
59. Braunack-Mayer AJ, Gibson OR. Including minority populations in research: we must do better. Med J Aust. 2017;207(1):22–3.

**Appendix 11**: **Scarborough, J., Eliott, J., Miller, E. R., & Aylward, P. (2015). Care Provided for hepatitis C: congruence between patient self-identity and stereotypes applied by general practitioners (GPs). Paper presented at the International Symposium on Hepatitis Care in Substance Users, Sydney, Australia. https://na.eventscloud.com/file_uploads/fb78da73072daf0596a54cc4434ea534_JaneScarborough.pdf**



THE UNIVERSITY of ADELAIDE

# Care provided for hepatitis C:

## Congruence between patient self-identity and stereotypes applied by general practitioners (GPs)

Jane Scarborough[1], Dr Jaklin Eliott[1], Dr Emma Miller[2] and Dr Paul Aylward[2]

Email: jane.scarborough@adelaide.edu.au [1]University of Adelaide, [2]Flinders University

GETTING CARE GAME

Drug use
**Currency:** current,
**Centrality:** Core
**Valence:** Viewed negatively
**Actuality:** Actual is a long way from ideal

'I'm pretty hopeless at the moment. I have another drug addiction ..I've done alright over the last few years, and I end up having relapses.' (A)

Seek help for drug abuse

'If you get ignored you're like "What did I bother telling them for?"' (A)

Issue ignored - Go back to Start

Turn Left

HCV recorded on medical record at practice

GP believes you are "Doctor Shopping"

'…when you've got an addict going ..." I need valium." …a doctor sort of roll their eyes and goes "Oh here we go."' (A)

Get banned –go back to Start ( in a country area with one GP practice, leave the game)

Only offered rehabilitation

Go back to start

Turn Left

'If I said ..had injected drugs in the past they would always enquire whether I needed "rehabilitation".' (A+CA)

Seek care for HCV - disclose past injecting drug use

'It's what's happened in my history. Something that the doctor should know..' (A)

Drug use
**Currency:** In past
**Centrality:** Once core
**Valence:** Neutral
**Actuality:** Drug use history not ideal

Get in touch with Hepatitis support organisation

'They're very accepting, they've got lots of information.' (A+CA)

Go forward 3 steps

WAR ON DRUGS

BEST PRACTICE CARE

'He'll sit down and say, "How's things going? How are you feeling about this? What's going on in your life?"' (A)

'…nothing I could say would say to a GP there was actually going to shock them …I can be honest, I can be open..' (A+CA)

Turn Left

Hepatitis C not addressed – Go back to Start

Drug use is not considered by GP

No disclosure of drug use or hepatitis C status

'I'm a "choose to use" rather than "have to use."… If you are truly, truly centred there's not really a problematic.' (A)

GP asks: "How did you get it?"

Irrelevant, inappropriate questions asked – Go back to start

INDIVIDUALISED CARE

DRUG DISCOURSE - DISEASE MODEL MORAL MODEL

Confidentiality breached – Go back to start

"Hepatitis C positive" written on referral

'…on the referral form he's said "Hepatitis C positive" and I thought it was irrelevant and he didn't ask if that was OK to do.' (A+CA)

Go forward 3 steps

'…she certainly is the one who knows all about the hepatitis viruses ….and helps them with their hepatitis C treatment.' (CA)

Get in touch with Viral Hepatitis Nurse

Turn Left

Drug use
**Currency:** Current
**Centrality:** Peripheral
**Valence:** Positive
**Actuality:** Ideal

Drug use
**Currency:** For in past
**Centrality:** Peripheral
**Valence:** Neutral
**Actuality:** Reached ideal

'my risky behaviour was back in the 70's…I thought that I had left it all behind and that part of my life was over.' (A+CA)

Attending GP for pain relief

'I said "you know I didn't want that I just want something to stop this pain."' (A)

**Rules:** Individuals (must) make evaluative judgements of the self-aspect of illicit drug use to their identities in regard to currency, centrality, valence and actuality.

- **Currency:** Drug use may be perceived as something left in the past, which impacts on them at the present time and/or perceived as being integral for their future.
- **Centrality:** An individual may judge this as core to their identity or perceive it as more peripheral to their identity.
- **Valence:** The degree of attraction or aversion felt by the person towards drug use. They may feel negative (expressed as shame), neutral or positive about their drug use.
- **Actuality:** The actual situation of the person compared to what they perceive as ideal.

### *1. Introduction*

Hepatitis C (HCV) is estimated to affect more than 1% of the Australian population.

Treatments are available with the potential to cure HCV but only around 2% of people with HCV undertake this.

To reduce harm and allow informed choice it is critical that people with HCV receive appropriate advice on their diagnosis, management, and treatment for their disease.

Private General Practitioners (GPs) are uniquely positioned to provide this care. However, barriers to care provision have been reported.

### *2. Methodology and Sample*

Semi-structured qualitative interviews (N=22) were conducted with participants as below.

People affected by HCV (contracted or at risk) (A).

(A) n=10

(A+CA) n=6

(CA) n=6

People who have clients affected by HCV (CA).

Transcribed interviews were thematically analysed to identify participants' perspectives of care provided by GPs for HCV.

### *3. Results*

Participants affected by HCV reported a history of injecting drug use.

Participants described their expectation that GPs' professional responsibilities should include providing best practice care for people seeking help for illicit drug use and/or HCV.

It was acknowledged that GPs faced difficulties balancing this responsibility with responding to "doctor shopping".

Participants described experiences of patients seeking help for illicit drug use being shunned and treated as suspect.

Some patients, who no longer identified as someone with any desire for illicit drugs, reported that when they disclosed their HCV status, GPs treated them as patients who may relapse or with a current drug addiction.

Participants described people with HCV becoming cautious and selective about disclosing their drug use or HCV status to GPs.

### *4. Conclusions*

The significance of illicit drug use to a person's self-identity may vary over time and between individuals. Whilst patients' HCV may have been transmitted during illicit drug use the care sought from GPs by patients with HCV may be detached from this behaviour. When GPs are assessing the appropriate care to be provided to patients, eliciting the significance of drug use to the patient would allow GPs to tailor and target this care.

This assessment would take into account the currency, centrality, valence (degree of attraction or aversion) and actuality (ideal versus actual) of illicit drug use to the patient.

Participants affected by HCV described a variety of combinations of evaluative judgments in regard to the self-aspect of drug use. However participants perceived that GPs treated patients with HCV at all times as though illicit drug use was the central and current, ongoing issue for these patients. Part of GP's treatment of this "problem" of illicit drug use was perceived as aimed at transforming patients to a state of having aversion to this behaviour (expressed as shame) and changing a patient's actual state to an ideal state of abstinence from their drug addiction.

Promoting effective engagement between GPs and patients, including engagement about injecting drug use or HCV, depends on the countering of stereotypes such as those described in this report.

*5. Acknowledgements and References:* We would like to thank the participants for their willingness to share their experiences and perspectives. Please refer to the handout for references.

*INHSU Sydney October 2015*

# *BIBLIOGRAPHY*

Abbott, T. (2010). Media release, Real action to support general practice. Retrieved from https://parlinfo.aph.gov.au/parlInfo/search/display/display.w3p;query=Id:%22media/pressrel/CWJX6%22

Abbott, T., & Liberal Party of Australia. (2010). Real Action to Support General Practice Retrieved from https://parlinfo.aph.gov.au/parlInfo/download/media/pressrel/CWJX6/upload_binary/cwjx60.pdf;fileType=application%2Fpdf#search=%22media/pressrel/CWJX6%22

Adams, W. (2015). Conducting Semi-Structured Interviews. In K. E. Newcomer, H. P. Hatry, & J. S. Wholey (Eds.), *Handbook of Practical Program Evaluation* (4 ed.): Wiley Online Library.

Afdhal, N., Zeuzem, S., Schooley, R., Thomas, D., Ward, J., Litwin, A., . . . Muir, A. (2013). The new paradigm of hepatitis C therapy: integration of oral therapies into best practices. *Journal of Viral Hepatitis, 20*(11), 745-760. doi:10.1111/jvh.12173

Agledahl, K. M., Gulbrandsen, P., Førde, R., & Wifstad, Å. (2011). Courteous but not curious: how doctors' politeness masks their existential neglect. A qualitative study of video-recorded patient consultations. *Journal of Medical Ethics, 37*(11), 650-654. doi:10.1136/jme.2010.041988

Ahmed. A, Metheson. C, & Bond. C. (2009). General practitioners' management of psychostimulant drug misuse: Implications for eduction and training. *Drugs: Education, Prevention, and Policy, 16*(4), 343-354. doi:10.1080/09687630801889366

Album, D., Johannessen, L. E., & Rasmussen, E. B. (2017). Stability and change in disease prestige: A comparative analysis of three surveys spanning a quarter of a century. *Social Science and Medicine, 180*, 45-51. doi:10.1016/j.socscimed.2017.03.020

Album, D., & Westin, S. (2008). Do diseases have a prestige hierarchy? A survey among physicians and medical students. *Social Science and Medicine, 66*(1), 182-188. doi:10.1016/j.socscimed.2007.07.003

Aleman, S., Soderholm, J., Busch, K., Kovamees, J., & Duberg, A. S. (2020). Frequent loss to follow-up after diagnosis of hepatitis C virus infection: A barrier toward the elimination of hepatitis C virus. *Liver International*, 00:01–09. doi:10.1111/liv.14469

Anti-Discrimination Board of New South Wales. (2001). C Change: Report of the enquiry into hepatitis C related discrimination. Retrieved from https://www.antidiscrimination.justice.nsw.gov.au/Documents/hepc_report.pdf

Aronsohn, A., & Jensen, D. (2012). Informed deferral: a moral requirement for entry into the hepatitis C virus treatment warehouse. *Hepatology, 56*(5), 1591-1592. doi:10.1002/hep.25957

ASHM. (2017). ASHM Annual Report 2016-2017. Retrieved from http://bit.ly/ASHM_AR2018-PDF

ASHM. (2018). ASHM Annual Report 2017-2018. Retrieved from http://bit.ly/ASHM_AR2018-PDF

ASHM. (2019a). ASHM Annual Report 2018-2019. Retrieved from https://www.ashm.org.au/about/annual-reports/ASHM%20Annual%20Report%202018-2019.pdf

ASHM. (2019b). Reach-C Form. Retrieved from https://reach-c.ashm.org.au/

ASHM. (2020a). Hepatitis C Training. Retrieved from https://www.ashm.org.au/HCV/training/

ASHM. (2020b). Management and treatment of hepatitis C. Retrieved from https://www.ashm.org.au/HCV/management-hepc/

Asthma Australia. (2020). Asthma Australia - What we do. Retrieved from https://asthma.org.au/what-we-do/

Attar, B. M., & Van Thiel, D. H. (2016). Hepatitis C virus: A time for decisions. Who should be treated and when? *World Journal of Gastrointestinal Pharmacology and Therapeutics, 7*(1), 33. doi:10.4292/wjgpt.v7.i1.33

Australasian Society for HIV Medicine. (2005). HIV and hepatitis C: policy, discrimination, legal and ethical issues. Retrieved from http://bibliobase.sermais.pt:8008/BiblioNET/upload/PDF/0283_HIV%20and%20hepatitis%20Australia.pdf

Australasian Society for HIV Medicine. (2014). HIV, Viral Hepatitis and related services directory. Retrieved from http://www.ashm.org.au/default2.asp?active_page_id=191

Australia and New Zealand Liver Transplant Registry. (2019). 30th annual ANZLT report - Report data to December 2018. Retrieved from https://www3.anzltr.org/wp-content/uploads/Reports/30thReport.pdf

Australian Bureau of Statistics. (2012). 2011 Census counts — Aboriginal and Torres Strait Islander Peoples Retrieved from https://www.abs.gov.au/ausstats/abs@.nsf/Lookup/2075.0main+features32011#:~:text=In%202011%2C%20there%20were%20548%2C370,and%20Torres%20Strait%20Islander%20origin.

Australian Bureau of Statistics. (2018). 4364.0.55.001 - Australian Health Survey: First Results, 2011-12,. Retrieved from https://www.ausstats.abs.gov.au/ausstats/subscriber.nsf/0/1680ECA402368CCFCA257AC90015AA4E/$File/4364.0.55.001.pdf

Australian Bureau of Statistics. (2019). Patient experiences in Australia: summary of findings 2018-19, general practitioners. Retrieved from https://www.abs.gov.au/ausstats/abs@.nsf/Lookup/by%20Subject/4839.0~2018-19~Main%20Features~General%20practitioners~2

Australian College of Rural and Remote Medicine. (2018). Fellowship training with ACRRM. Retrieved from https://www.acrrm.org.au/training-towards-fellowship

Australian College of Rural and Remote Medicine. (2020). Personal Development Program 2020-2022 Handbook. Retrieved from https://www.acrrm.org.au/docs/default-source/all-files/pdp-2020-2022-handbook.pdf?sfvrsn=8f0c2a0c_2

Australian Government - Australian Institute of Health and Welfare. (2016). Medical practitioners workforce 2015. Retrieved from https://www.aihw.gov.au/reports/workforce/medical-practitioners-workforce-2015/contents/what-is-the-medical-practitioner-work-setting-like

Australian Government - Australian Institute of Health and Welfare. (2018, 31 March 2020). National Opioid Pharmacotherapy Statistics Annual Data collection (NOPSAD) 2018. Retrieved from https://www.aihw.gov.au/reports/alcohol-other-drug-treatment-services/national-opioid-pharmacotherapy-statistics-2019/contents/introduction

Australian Government - Australian Institute of Health and Welfare. (2019). National Opioid Pharmacotherapy Statistics Annual Data collection 2019. Retrieved from https://www.aihw.gov.au/reports/alcohol-other-drug-treatment-services/national-opioid-pharmacotherapy-statistics-2019/contents/introduction

Australian Government - Australian Institute of Health and Welfare. (2020a). Alcohol, tobacco & other drugs in Australia. *Cat. No. PHE 221.* Retrieved from https://www.aihw.gov.au/reports/alcohol/alcohol-tobacco-other-drugs-australia/contents/introduction

Australian Government - Australian Institute of Health and Welfare. (2020b). Data Tables: National Opioid Pharmacotherapy Statistics Annual Data collection 2019 Retrieved from https://www.aihw.gov.au/getmedia/d5199a4b-74d6-4e27-8776-74a73c278c41/Data-tables_-National-opioid-pharmacotherapy-statistics-annual-data-collection-2019.xls.aspx

Australian Government - Australian Taxation Office. (2018). Medicare levy. Retrieved from https://www.ato.gov.au/Individuals/Medicare-levy/

Australian Government - data.gov.au. (2020). DSS Demographics March 2020. Retrieved from https://data.gov.au/data/dataset/cff2ae8a-55e4-47db-a66de177fe0ac6a0/resource/f72fe318-bfec-46e0-9f54-3c4efacf93c0/download/dss-demographics-mar-2020-final.xlsx

Australian Government - Department of Health. (2012). Frequently asked questions about the International Recruitment Strategy. Retrieved from http://www.health.gov.au/internet/main/publishing.nsf/Content/work-pr-otd-faq

Australian Government - Department of Health. (2015a). District of workforce shortage factsheet. Retrieved from http://www.health.gov.au/internet/main/publishing.nsf/Content/work-pr-dws-fact

Australian Government - Department of Health. (2015b). Introduction to the National Notifiable Diseases Surveillance System. Retrieved from https://www1.health.gov.au/internet/main/publishing.nsf/Content/cda-surveil-nndss-nndssintro.htm

Australian Government - Department of Health. (2016a). Guidelines for preparing submissions to the Pharmaceutical Benefits Advisory Committee (PBAC). Retrieved from https://pbac.pbs.gov.au/

Australian Government - Department of Health. (2016b, 1 March 2016). Hepatitis C medicines fact sheet for community based prescribers. Retrieved from https://www.pbs.gov.au/info//publication/factsheets/hep-c/hepc-factsheet-community-based-prescribers

Australian Government - Department of Health. (2016c). Primary Health Networks Grant Programme Guidelines, V1.2. Retrieved from http://www.health.gov.au/internet/main/publishing.nsf/Content/F4F85B97E22A94CACA257F86007C7D1F/$File/Primary%20Health%20Network%20Grant%20Programme%20Guidelines%20-%20V1.2%20February%202016.pdf

Australian Government - Department of Health. (2017). National drug strategy 2017–2026. Retrieved from https://www.health.gov.au/sites/default/files/national-drug-strategy-2017-2026_1.pdf

Australian Government - Department of Health. (2018a). Fact Sheet: Primary Health Networks. *PHN - An Australian Government Initiative.* Retrieved from http://www.health.gov.au/internet/main/publishing.nsf/Content/Fact-Sheet-Primary-Health-Networks+

Australian Government - Department of Health. (2018b). Fifth National Hepatitis C Strategy 2018-2022. Retrieved from http://www.health.gov.au/internet/main/publishing.nsf/Content/ohp-bbvs-1//$File/Hep-C-Fifth-Nat-Strategy-2018-22.pdf

Australian Government - Department of Health. (2018c). For Consumers - Aboriginal and Torres Strait Islander Health - Funded Activities. Retrieved from http://www.health.gov.au/internet/main/publishing.nsf/Content/indigenous-funding-lp#primary

Australian Government - Department of Health. (2018d). GP Workforce Statistics - National, State & Remoteness Area 2000-01 onwards. *General Practice Statistics.* Retrieved from http://www.health.gov.au/internet/main/publishing.nsf/content/F210D973E08C0193CA257BF0001B5F1F/$File/GP-Workforce-Statistics-2017-18.xlsx

Australian Government - Department of Health. (2018e). GP Workforce Statistics Explanatory Notes 2016-17. Retrieved from http://www.health.gov.au/internet/main/publishing.nsf/Content/F210D973E08C0193CA257BF0001B5F1F/$File/GP%20Workforce%20Statistics%20Explanatory%20Notes%202016-17.pdf

Australian Government - Department of Health. (2018f). Health Care Homes -Health professionals. Retrieved from http://www.health.gov.au/internet/main/publishing.nsf/Content/health-care-homes-professional

Australian Government - Department of Health. (2018g). Medicare Safety Net Arrangements – 1 January 2018. Retrieved from http://www.mbsonline.gov.au/internet/mbsonline/publishing.nsf/Content/48EAB6E322A0412CCA258228000FE44A/$File/Medicare%20Safety%20Net%20Arrangements%20-%201%20Jan%202018.pdf

Australian Government - Department of Health. (2019a). Australia's long term national health plan. Retrieved from https://www.health.gov.au/sites/default/files/australia-s-long-term-national-health-plan_0.pdf

Australian Government - Department of Health. (2019b). Drug laws in Australia. Retrieved from https://www.health.gov.au/health-topics/drugs/about-drugs/drug-laws-in-australia

Australian Government - Department of Health. (2019c). Health Care Homes - Factsheet: Payment Information. Retrieved from https://www1.health.gov.au/internet/main/publishing.nsf/Content/health-care-homes-cp/$File/payment-information-factsheet-letterhead.pdf

Australian Government - Department of Health. (2019d). The practice nurse incentive program (PNIP). Retrieved from https://www1.health.gov.au/internet/main/publishing.nsf/Content/pnip

Australian Government - Department of Health. (2020a). About the PBS. Retrieved from https://www.pbs.gov.au/info/about-the-pbs#:~:text=The%20co%2Dpayment%20is%20the,Government%20pays%20the%20remaining%20cost.

Australian Government - Department of Health. (2020b). Bonded Medical Places (BMP) Scheme. Retrieved from https://www1.health.gov.au/internet/main/publishing.nsf/Content/work-st-bmp

Australian Government - Department of Health. (2020c). General Practice Training in Australia - the Guide. Retrieved from https://www.health.gov.au/sites/default/files/documents/2020/02/general-practice-training-in-australia-the-guide.pdf

Australian Government - Department of Health. (2020d). General Practice Workforce providing Primary Care services in Australia - Statistics by financial year. Retrieved from https://hwd.health.gov.au/ROGS/FinancialYear/Primary%20Care%20GP%20workforce%20statistics%20by%20financial%20year.xlsx

Australian Government - Department of Health. (2020e). The January 2020 Medicare Benefits Schedule. *MBS Online Medicare Benefits Schedule.* Retrieved from http://www.mbsonline.gov.au/internet/mbsonline/publishing.nsf/Content/Downloads-202001

Australian Government - Department of Health. (2020f). MBS Online Medicare Benefits Schedule - COVID-19 Temporary MBS Telehealth Services. Retrieved from http://www.mbsonline.gov.au/internet/mbsonline/publishing.nsf/Content/Factsheet-TempBB

Australian Government - Department of Health. (2020g). Medicare Benefits Schedule - Item 2715. *MBS Online Medicare Benefits Schedule.* Retrieved from http://www9.health.gov.au/mbs/fullDisplay.cfm?type=item&qt=ItemID&q=2715

Australian Government - Department of Health and Aged Care. (2000). National hepatitis C strategy : 1999-2000 to 2003-2004. Retrieved from https://www1.health.gov.au/internet/main/publishing.nsf/Content/46CB4B7FCAF6ECF9CA257BF0001FA220/$File/hepc_strat9900_0304.pdf

Australian Government - Department of Health and Ageing. (2010a). Building a 21st century primary health care system: Australia's first national health care strategy. Retrieved from http://pandora.nla.gov.au/pan/118026/20120131-0954/www.yourhealth.gov.au/internet/yourhealth/publishing.nsf/Content/3EDF5889BEC00D98CA2579540005F0A4/$File/6552%20NPHC%201205.pdf

Australian Government - Department of Health and Ageing. (2010b). Third national hepatitis C strategy 2010 - 2013. Retrieved from https://www.ach2.org.au/Websites/ach2/files/Content/3129792/Third_National_Hepatitis_C_Strategy_2010-2013.pdf

Australian Government - Department of Health and Ageing. (2014). Fourth national hepatitis C strategy 2014 - 2017. Retrieved from http://www.health.gov.au/internet/main/publishing.nsf/Content/A68444CDED77B3A9CA257BF0001CFD80/$File/Hep-C-Strategy2014-v3.pdf

Australian Government - Department of Health The Pharmaceutical Benefits Scheme. (2015). 5.06 DACLATASVIR *Public Summary Document – March 2015 PBAC Meeting.* Retrieved from http://www.pbs.gov.au/industry/listing/elements/pbac-meetings/psd/2015-03/Files/daclatasvir-psd-march-2015.docx

Australian Government - Department of Human Services. (2018a). Department of Human Services 2017-18 Annual report. Retrieved from https://www.humanservices.gov.au/sites/default/files/2018/10/8802-1810-annual-report-web-2017-2018.pdf

Australian Government - Department of Human Services. (2018b). Eligibility for the PIP. Retrieved from https://www.humanservices.gov.au/organisations/health-professionals/enablers/eligibility-pip

Australian Government - Department of Human Services. (2018c). Medicare Bulk Billing. Retrieved from https://www.humanservices.gov.au/individuals/services/medicare/medicare-bulk-billing

Australian Government - Department of Human Services. (2018d). Medicare Incentives News Update - November 2018. Retrieved from https://www.humanservices.gov.au/sites/default/files/2018/12/incentives-news-update-november-2018.pdf

Australian Government - Department of Human Services. (2018e). Medicare services. Retrieved from https://www.humanservices.gov.au/customer/subjects/medicare-services

Australian Government - Department of Human Services. (2019). Services Australia 2018-19 Annual report. Retrieved from https://www.servicesaustralia.gov.au/sites/default/files/annual-report-191019-v2.pdf

Australian Government - Medicare Local. (2012). What is a Medicare Local? *Medicare Locals.* Retrieved from https://webarchive.nla.gov.au/awa/20140125223220/http://www.medicarelocals.gov.au/internet/medicarelocals/publishing.nsf/Content/what-is

Australian Government - Productivity Commission. (2017). Report on Government Services 2017, Volume E, Chapter 10 Primary and community health and attachment tables. Retrieved from http://www.pc.gov.au/research/ongoing/report-on-government-services/2017/health/primary-and-community-health/rogs-2017-volumee-chapter10.pdf

Australian Government - Productivity Commission. (2020). Report on Government Services 2020 - Part E, Section 10, Primary and community health. Retrieved from https://www.pc.gov.au/research/ongoing/report-on-government-services/2020/archive/health/primary-and-community-health/rogs-2020-parte-section10.pdf

Australian Health Practitioner Regulation Agency. (2017). Notifications. Retrieved from https://www.medicalboard.gov.au/documents/default.aspx?record=WD12%2f7048&dbid=AP&chksum=IcKerLkKT1ByCBLd%2be3cHg%3d%3d

Australian Health Practitioner Regulation Agency. (2018). Annual Report 2017/18 - Notifications and monitoring. Retrieved from https://www.ahpra.gov.au/annualreport/2018/notifications.html#notifications

Australian Injecting and Illicit Drug Users League. (2010). AIVL Response to the Medicare Locals discussion paper on governance and functions. Retrieved from http://www.aivl.org.au/database/sites/default/files/resources/RESPONSE%20TO%20THE%20MEDICARE%20LOCALS%20DISCUSSION%20PAPER.pdf

Australian Injecting and Illicit Drug Users League. (2020). About us - Who is AIVL. Retrieved from http://aivl.org.au/about-us/

Australian Institute of Health and Welfare. (2013). Alcohol and other drug treatment services in Australia 2011-12 Retrieved from https://www.aihw.gov.au/getmedia/c604b04f-205d-4b79-a515-7d52aab1cd04/15344.pdf.aspx?inline=true

Australian Institute of Health and Welfare. (2015). Australian Institute of Health and Welfare Corporate Plan 2015–16 to 2018–19. Retrieved from https://www.aihw.gov.au/getmedia/b1e0ae66-e08e-4205-9495-08399314428c/19236.pdf.aspx?inline=true

Australian Labor Party. (2016). Bill's media releases - Labor's Medicare guarantee. *Bill's Media Releases.* Retrieved from http://www.billshorten.com.au/labor_s_medicare_guarantee

Australian Medical Association. (2014). GP Super Clinics 'not so super' - AMA. Retrieved from https://ama.com.au/media/gp-super-clinics-not-so-super-ama

Australian Medical Association. (2018). Health Care Homes trial in the spotlight. Retrieved from https://ama.com.au/gp-network-news/health-care-homes-trial-spotlight

Australian Medical Association. (2019). Key health issues for the 2019 federal election. Retrieved from https://ama.com.au/system/tdf/documents/Key%20Health%20Issues%20for%20the%202019%20Federal%20Election.pdf?file=1&type=node&id=50433

Aylward, P. (2003). *Peer education in four Clean Needle Program sites in outer metropolitan South Australia. Evaluation Report.* Retrieved from Adelaide:

Aylward, P. (2012). *Clean Needle Program peer education review.* Retrieved from Adelaide:

Bacchi, C. (2009). *Analysing Policy: what's the problem represented to be?* Retrieved from https://ebookcentral-proquest-com.ezproxy.flinders.edu.au/lib/flinders/reader.action?docID=5220591

Bacchi, C. (2016). Problematizations in health policy: questioning how “problems” are constituted in policies. *SAGE Open, 6*(2), 2158244016653986. doi:10.1177/2158244016653986

Backx, M., Lewszuk, A., White, J., Cole, J., Sreedharan, A., van Sanden, S., . . . Wiselka, M. (2014). The cost of treatment failure: resource use and costs incurred by hepatitis C virus genotype 1–infected patients who do or do not achieve sustained virological response to therapy. *Journal of Viral Hepatitis, 21*(3), 208-215. doi:10.1111/jvh.12132

Badiani, A. (2014). Is a ‘general’theory of addiction possible? A commentary on: a multistep general theory of transition to addiction. *Psychopharmacology, 231*(19), 3923-3927. doi:10.1007%2Fs00213-014-3627-x

Badley, G. F. (2015). Conversation piece? *Qualitative Inquiry, 21*(5), 418-425. doi:10.1177/1077800414566689

Bajis, S., Grebely, J., Hajarizadeh, B., Applegate, T., Marshall, A. D., Harrod, M. E., . . . Dore, G. J. (2019). Hepatitis C virus testing, liver disease assessment and treatment uptake among people who inject drugs pre- and post-universal access to direct-acting antiviral treatment in Australia: The LiveRLife study. *Journal of Viral Hepatitis*. doi:10.1111/jvh.13233

Baker, D., Alavi, M., Erratt, A., Hill, S., Balcomb, A., Hallinan, R., . . . Keats, J. (2014). Delivery of treatment for hepatitis C virus infection in the primary care setting. *European Journal of Gastroenterology and Hepatology, 26*(9), 1003-1009. doi:10.1097/meg.0000000000000150

Baker, D., Balcomb, A., O'Loan, J., & Howell, J. (2019). Eliminating hepatitis C: Part 5. Practical steps in your practice. *Medicine Today, 20*(10). Retrieved from https://medicinetoday.com.au/system/files/pdf/MT2019-11SUPPL-026-BAKER.pdf

Bartlett, S. R., Fox, P., Cabatingan, H., Jaros, A., Gorton, C., Lewis, R., . . . Russell, D. B. (2018). Demonstration of near-elimination of hepatitis C virus among a prison population:

The Lotus Glen Correctional Centre Hepatitis C Treatment Project. *Clinical Infectious Diseases, 67*(3), 460-463. doi:10.1093/cid/ciy210

Bartone, T. (2017). Let’s have a thorough conversation about bulk billing. Retrieved from https://ama.com.au/ausmed/let%E2%80%99s-have-thorough-conversation-about-bulk-billing

Basedow, M., Runciman, W. B., Lipworth, W., & Esterman, A. (2016). Australian general practitioner attitudes to clinical practice guidelines and some implications for translating osteoarthritis care into practice. *Australian Journal of Primary Health, 22*(5), 403-408. doi:10.1071/py15079

Basudev, N., Crosby-Nwaobi, R., Thomas, S., Chamley, M., Murrells, T., & Forbes, A. (2016). A prospective randomized controlled study of a virtual clinic integrating primary and specialist care for patients with type 2 diabetes mellitus. *Diabetic Medicine, 33*(6), 768-776. doi:10.1111/dme.12985

Batey, R. G. (2003). Chronic hepatitis C. *Australian Family Physician, 32*(10), 807. Retrieved from https://www.racgp.org.au/afpbackissues/2003/200310/20031001hepcchapter4.pdf

Bathish, R., Best, D., Savic, M., Beckwith, M., Mackenzie, J., & Lubman, D. I. (2017). “Is it me or should my friends take the credit?” The role of social networks and social identity in recovery from addiction. *Journal of Applied Social Psychology, 47*(1), 35-46. doi:10.1111/jasp.12420

Bell, S. F. E., Harvey, C., Mack, F., Lambert, S., & Dean, J. A. (2019). Rethinking referral pathways: increasing access to intrauterine contraception - GPIIN: general practice intrauterine inserter network project - a pilot project. Retrieved from https://espace.library.uq.edu.au/data/UQ_0f055ad/Bell_GPIIN_POSTER_158.pdf?dsi_version=0f84546e58a895d438db617b2d26f6d3&Expires=1603677903&Key-Pair-Id=APKAJKNBJ4MJBJNC6NLQ&Signature=PvpWJgEjgrLDLPfadKmw6DL6ff6ghlKwV~DLhIaErQwLEOGljByscxhtqLDwOtbuOTj-vOj2-V6--X2tilUGiZg4lQbf4Ivma50uw3uJaVkLCsaQGZE1wmHlnXXEvuay~y7ufU1N0ZnU0f8Rdrc

8AdgZv2NN6H1iE6m2eN~VoZlzHRO82Zmy8bs58ep8huBRdnEhlJmMmtv1bmrRbQ~QZcFRDtU9IfDNxoefRMh5I4tz51LVFmA0BuhxARu8YIesk5kUVzPw-htXo6eX-2JA4QKBgwo4Hl2HTdt-jELd9K8g6Sw-FIXFPzkdE-Eh0FA5j6jjqOpx~8zDNpTNY13HCg

Bentley, M., Kerr, R., Scott, F., Hansen, E., Magin, P., & Bonney, A. (2019). Exploring opportunities for general practice registrars to manage older patients with chronic disease: A qualitative study. *Australian Journal of General Practice, 48*(7), 451-456. doi:10.31128/ajgp-09-18-4694

Biernikiewicz, M., Taieb, V., & Toumi, M. (2019). Characteristics of doctor-shoppers: a systematic literature review. *Journal of Market Access and Health Policy, 7*(1), 1595953. doi:10.1016/j.jval.2018.09.898

Biggs, A. (2004). Medicare - Background Brief. *Current Issues.* Retrieved from https://www.aph.gov.au/About_Parliament/Parliamentary_Departments/Parliamentary_Library/Publications_Archive/archive/medicare

Blixen, C. E., Webster, N. J., Hund, A. J., Perzynski, A. T., Kanuch, S. W., Stoller, E. P., . . . Dawson, N. V. (2008). Communicating about alcohol consumption to nonharmful drinkers with hepatitis C: patient and provider perspectives. *Journal Of General Internal Medicine, 23*(3), 242-247. doi:10.1007/s11606-007-0483-y

Bloom, S., Lubel, J., Nicoll, A., Gow, P., Dev, A., Roberts, S., . . . Sood, S. (2017). Comparison of direct-acting antiviral therapy for hepatitis C between specialist centers and primary care: Efficacy and adherence to response assessment. *Journal of Gastroenterology and Hepatology, 32*, 65-66. doi:10.1111/dar.12903

Bowen, G. A. (2009). Document analysis as a qualitative research method. *Qualitative Research Journal, 9*(2), 27-40. doi:10.3316/QRJ0902027

Braun, V., & Clarke, V. (2008). Using thematic analysis in psychology. *Qualitative Research in Psychology, 3*(2), 77-101. doi:10.1191/1478088706qp063oa

Braun, V., & Clarke, V. (2016). (Mis) conceptualising themes, thematic analysis, and other problems with Fugard and Potts'(2015) sample-size tool for thematic analysis.

*International Journal of Social Research Methodology, 19*(6), 739-743. doi:10.1080/13645579.2016.1195588

Braun, V., & Clarke, V. (2019). Reflecting on reflexive thematic analysis. *Qualitative Research in Sport, Exercise and Health*, 1-9. doi:10.1080/2159676x.2019.1628806

Braun, V., Clarke, V., Hayfield, N., & Terry, G. (2019). Thematic analysis. *Handbook of Research Methods in Health Social Sciences*, 843-860. doi:10.1007/978-981-10-5251-4_103

Braunack-Mayer, A. J., & Gibson, O. R. (2017). Including minority populations in research: we must do better. *Medical Journal of Australia, 207*(1), 22-23. doi:10.5694/mja17.00305

Brekke, E., Lien, L., Davidson, L., & Biong, S. (2017). First-person experiences of recovery in co-occurring mental health and substance use conditions. *Advances in Dual Diagnosis*. doi:10.1108/ADD-07-2016-0015

Brener, L., Horwitz, R., von Hippel, C., Bryant, J., & Treloar, C. (2015). Discrimination by health care workers versus discrimination by others: Countervailing forces on HCV treatment intentions. *Psychology, Health and Medicine, 20*(2), 148-153. doi:10.1080/13548506.2014.923103

Brennan, I. (2016). Hepatitis C drugs Australia's most expensive, cost taxpayers $1 billion in four months. *The World Today.* Retrieved from https://www.abc.net.au/news/2016-12-05/hep-c-drugs-australias-most-expensive/8094188

British Medical Association. (2013). Drugs of dependence: the role of medical professionals. Retrieved from http://www.tdpf.org.uk/sites/default/files/BMA-drugs-of-dependence.pdf

Britt, H., Miller, G. C., Bayram, C., Henderson, J., Valenti, L., Harrison, C., . . . Wong, C. (2016). *A decade of Australian general practice activity 2006-07 to 2015-16* (9781743325155). Retrieved from Sydney:

https://ses.library.usyd.edu.au/bitstream/handle/2123/15482/9781743325162_ONLINE.pdf;jsessionid=11BB20AF02E7B109E834352B9E9FD57F?sequence=5

Britt, H., Miller, G. C., Valenti, L., Henderson, J., Bayram, C., & Gordon, J. (2016). The changing face of Australian general practice across the decades. *Australian Family Physician, 45*(9), 628. Retrieved from https://www.racgp.org.au/afp/2016/september/the-changing-face-of-australian-general-practice-across-the-decades/

Broadway, B., Kalb, G., Li, J., & Scott, A. (2017). Do financial incentives influence GPs' decisions to do after-hours work? A discrete choice labour supply model. *Health Economics, 26*(12), e52-e66. doi:10.1002/hec.3476

Broady, T., Brener, L., Cama, E., Hopwood, M., & Treloar, C. (2020). Stigmatising attitudes towards people who inject drugs, and people living with blood borne viruses or sexually transmissible infections in a representative sample of the Australian population. *PLoS ONE, 15*(4), e0232218. doi:10.1371/journal.pone.0232218

Bryant, J., Rance, J., Hull, P., Mao, L., & Treloar, C. (2019). Making sense of ‘side effects’: Counterpublic health in the era of direct-acting antivirals. *International Journal of Drug Policy, 72*, 77-83. doi:10.1016/j.drugpo.2019.06.002

Buchmueller, T. C., Fiebig, D. G., Jones, G., & Savage, E. (2013). Preference heterogeneity and selection in private health insurance: The case of Australia. *Journal of Health Economics, 32*(5), 757-767. doi:10.1016/j.jhealeco.2013.05.001

Bukh, J. (2016). The history of hepatitis C virus (HCV): Basic research reveals unique features in phylogeny, evolution and the viral life cycle with new perspectives for epidemic control. *Journal of Hepatology, 65*(1), S2-S21. doi:10.1016/j.jhep.2016.07.035

Burki, T. (2014). Elimination on the agenda for hepatitis C. *The Lancet Infectious Diseases, 14*(6), 452. doi:10.1016/s1473-3099(14)70704-2

Burnet Institute and Kirby Institute. (2019). Australia’s progress towards hepatitis C elimination annual report 2019. Retrieved from https://kirby.unsw.edu.au/sites/default/files/kirby/report/Australia%27s-progress-on-hepatitis-C-elimination-2019-report.pdf

Busingye, D., Gianacas, C., Pollack, A., Chidwick, K., Merrifield, A., Norman, S., . . . Havard, A. (2019). Data Resource Profile: MedicineInsight, an Australian national primary health care database. *International Journal of Epidemiology, 48*(6), 1741-1741h. doi:10.1093/ije/dyz147

Butler, K., Day, C., Sutherland, R., van Buskirk, J., Breen, C., Burns, L., & Larney, S. (2017). Hepatitis C testing in general practice settings: A cross-sectional study of people who inject drugs in Australia. *International Journal of Drug Policy*. doi:10.1016/j.drugpo.2017.07.008

Butler, R., & Sheridan, J. (2010). Innocent parties or devious drug users: the views of primary healthcare practitioners with respect to those who misuse prescription drugs. *Harm Reduction Journal, 7*(1), 1-21. doi:doi:10.1186/1477-7517-7-21

Butt, G. (2008). Stigma in the context of hepatitis C: concept analysis. *Journal of Advanced Nursing, 62*(6), 712-724. doi:10.1111/j.1365-2648.2008.04641.x

Butt, G., McGuinness, L., Buller-Taylor, T., & Mitchell, S. (2013). Reasons for nonattendance across the hepatitis C disease course. *ISRN Nursing, 2013*. doi:10.1155/2013/579529

Byrne, L., Happell, B., Welch, T., & Moxham, L. J. (2013). ‘Things you can't learn from books’: teaching recovery from a lived experience perspective. *International Journal of Mental Health Nursing, 22*(3), 195-204. doi:10.1111/j.1447-0349.2012.00875.x

Cameron, L. (2019). C is for Cure. Retrieved from https://www.adelaidenow.com.au/feature/special-features/c-is-for-cure/news-story/edfe6ace2dbc795087c44dcb96bd28ba

Cameron, S., & McAllister, I. (2019). 2019 Australian federal election: results from the Australian Election Study. Retrieved from https://australianelectionstudy.org/wp-content/uploads/The-2019-Australian-Federal-Election-Results-from-the-Australian-Election-Study.pdf

Carruthers, S. J., & Ryan, C. (2012). Hepatitis C treatment and injecting drug users in Perth, Western Australia: knowledge of personal status and eligibility criteria for treatment. *Journal of Substance Use, 17*(1), 32-34. doi:10.3109/14659891.2010.513757

Carvalho-Filho, R. J., & Dalgard, O. (2010). Individualized treatment of chronic hepatitis C with pegylated interferon and ribavirin. *Pharmacogenomics and Personalized Medicine, 3*, 1. doi:10.2147/pgpm.s4461

Casey, L. C., & Lee, W. M. (2013). Hepatitis C virus therapy update 2013. *Current Opinion in Gastroenterology, 29*(3), 243-249. doi:10.1097/MOG.0b013e32835ff972

Cashin, C., & Chi, Y.-L. (2011). Australia: the Practice Incentives Program (PIP). *Washington, DC: The World Bank*. Retrieved from https://www.rbfhealth.org/sites/rbf/files/Case%20study%20Australia%20Practice%20Incentive%20Program.pdf

Central Adelaide Local Health Network. (2016). Central Adelaide Local Health Network Annual Report 2015-16. Retrieved from https://www.sahealth.sa.gov.au/wps/wcm/connect/43fda2004f2a4eacb6e1f69ea2e2f365/CALHN+Annual+Report+2015-2016+CALHN+Media+Comms+20160928.pdf?MOD=AJPERES&CACHEID=ROOTWORKSPACE-43fda2004f2a4eacb6e1f69ea2e2f365-m08bCRg

Chan, K., Gooey, M., Hellard, M., Greenwood-Smith, B., Chaney, R., Baker, D., . . . Howell, J. (2019). Eliminating hepatitis C: Part 4. Ongoing care after hepatitis C treatment. *Medicine Today, 20*(9). Retrieved from https://medicinetoday.com.au/system/files/pdf/MT2019-11SUPPL-021-CHAN.pdf

Cheng, T. C., Scott, A., Jeon, S.-H., Kalb, G. R., Joyce, C., & Humphreys, J. (2010). What factors influence the earnings of GPs and medical specialists in Australia? Evidence from the MABEL Survey. *Melbourne Institute Working Paper, 12*. Retrieved from https://melbourneinstitute.unimelb.edu.au/downloads/working_paper_series/wp2010n12.pdf

Chevaliez, S., Wlassow, M., Volant, J., Roudot-Thoraval, F., Bachelard, A., Poiteau, L., . . . Dominguez, S. (2020). Assessing molecular point-of-care testing and dried blood spot for hepatitis C virus screening in people who inject drugs. *Open Forum Infectious Diseases*. doi:10.1093/ofid/ofaa196

Chidwick, K., Kiss, D., Gray, R., Yoo, J., Aufgang, M., & Zekry, A. (2018). Insights into the management of chronic hepatitis C in primary care using MedicineInsight. *Australian Journal of General Practice, 47*(9), 639. doi:10.31128/ajgp-02-18-4482

Choo, Q.-L., Kuo, G., Weiner, A. J., Overby, L. R., Bradley, D. W., & Houghton, M. (1989). Isolation of a cDNA clone derived from a blood-borne non-A, non-B viral hepatitis genome. *Science, 244*(4902), 359-362. doi:10.1126/science.2523562

Claire Van Hout, M. (2014). “Doctor shopping and pharmacy hopping”: practice innovations relating to codeine. *Drugs and Alcohol Today, 14*(4), 219-234. doi:10.1108/DAT-03-2014-0014

Clarivate Analytics. (2018). Endnote.   Retrieved from http://endnote.com/

Clement, S., Schauman, O., Graham, T., Maggioni, F., Evans-Lacko, S., Bezborodovs, N., . . . Thornicroft, G. (2014). What is the impact of mental health-related stigma on help-seeking? A systematic review of quantitative and qualitative studies. *Psychological Medicine*, 1-17. doi:10.1017/S0033291714000129

Comino, E. J., Davies, G. P., Krastev, Y., Haas, M., Christl, B., Furler, J., . . . Harris, M. F. (2012). A systematic review of interventions to enhance access to best practice primary health care for chronic disease management, prevention and episodic care. *BMC Health Services Research, 12*(1), 415. doi:10.1186/1472-6963-12-415

Commonwealth of Australia - Australian National Audit Office. (2018). The design, monitoring and implementation of health's savings measures : Department of Health.   Retrieved from https://apo.org.au/sites/default/files/resource-files/2018-06/apo-nid179921.pdf

Commonwealth of Australia. (2003). 2002 Reviews of the national HIV/Aids and hepatitis C strategies and strategic research. Retrieved from https://webarchive.nla.gov.au/awa/20060906070237/http://www.health.gov.au/internet/wcms/publishing.nsf/Content/health-pubhlth-publicat-document-metadata-hivhepc_review.htm/$FILE/hivhepc_review.pdf

Commonwealth of Australia. (2008). Towards a national primary health care strategy: A discussion paper from the Australian government. Retrieved from http://healthwest.org.au/wp-content/uploads/2014/11/Towards-a-National-Primary-Health-Care-Strategy.pdf

Cook, D. A., Price, D. W., Wittich, C. M., West, C. P., & Blachman, M. J. (2017). Factors influencing physicians' selection of continuous professional development activities: A cross-specialty national survey. *Journal of Continuing Education in the Health Professions, 37*(3), 154-160. doi:10.1097/ceh.0000000000000163

Cooke, G., Valenti, L., Glasziou, P., & Britt, H. (2013). Common general practice presentations and publication frequency. *Australian Family Physician, 42*, 65-68. Retrieved from https://www.racgp.org.au/afp/2013/januaryfebruary/common-general-practice-presentations/

Council of Australian Governments. (2018). Heads of Agreement between the Commonwealth and the States and Territories on public hospital funding and health reform. Retrieved from https://www.coag.gov.au/sites/default/files/agreements/heads-of-agreement-hospital-funding.pdf

Crabtree, B. F., Miller, W. L., & Stange, K. C. (2001). Understanding practice from the ground up. *Journal of Family Practice, 50*(10), 881-887. doi:10.1016/j.healthpol.2018.02.002

Crabtree, B. F., Nutting, P. A., Miller, W. L., McDaniel, R. R., Stange, K. C., Jaén, C. R., & Stewart, E. (2011). Primary care practice transformation is hard work: insights from a 15-year developmental program of research. *Medical Care, 49*(Suppl), S28. doi:10.1097/MLR.0b013e3181cad65c

Craxi, L., Sacchini, D., Refolo, P., Minacori, R., Daloiso, V., Ricci, G., . . . Spagnolo, A. G. (2016). Prioritization of high-cost new drugs for HCV: making sustainability ethical. *European Review for Medical and Pharmacological Sciences, 20*(6), 1044-1051. doi:10.1001/jama.2014.5899

Cresswell, A. (2006). The hidden epidemic. *Weekend Australian*. Retrieved from https://search-proquest-com.ezproxy.flinders.edu.au/anznews/docview/356166029/43AFF09784594B99PQ/6?accountid=10910

Cubaka, V. K., Dyck, C., Dawe, R., Alghalyini, B., Whalen-Browne, M., Cejas, G., & Gibson, C. (2019). A global picture of family medicine: the view from a WONCA Storybooth. *BMC Family Practice, 20*(1), 129. doi:10.1186/s12875-019-1017-5

Cunningham, E. B., Hajarizadeh, B., Amin, J., Hellard, M., Bruneau, J., Feld, J. J., . . . Marks, P. (2020). Reinfection following successful direct-acting antiviral therapy for hepatitis C infection among people who inject drugs. *Clinical Infectious Diseases*. doi:10.1093/cid/ciaa253

Dantas, L. F., Fleck, J. L., Oliveira, F. L. C., & Hamacher, S. (2018). No-shows in appointment scheduling – a systematic literature review. *Health Policy, 122*(4), 412-421. doi:10.1016/j.healthpol.2018.02.002

Davis, D. A., Mazmanian, P. E., Fordis, M., Van Harrison, R., Thorpe, K. E., & Perrier, L. (2006). Accuracy of physician self-assessment compared with observed measures of competence. *Journal of the American Medical Association, 296*(9), 1094-1102. doi:10.1001/jama.296.9.1094

Davis, D. A., Perrier, L., Ciurea, I., & Flanagan, T. M. (2004). Solving the information overload problem: a letter from Canada. *Medical Journal of Australia, 180*, S68-S71. doi:10.5694/j.1326-5377.2004.tb05952.x

Davis, J. S., Tapley, A., Morgan, S., van Driel, M. L., & Magin, P. J. (2017). Clinical experience of patients with hepatitis C virus infection among Australian GP trainees. *Medical Journal of Australia, 206*(7), 308. doi:10.5694/mja16.01106

Day, A., White, B., Thein, H., Doab, A., Dore, G., Bates, A., . . . Maher, L. (2008). Experience of hepatitis C testing among injecting drug users in Sydney, Australia. *AIDS Care, 20*(1), 116-123. doi:10.1080/09540120701426524

Day, C., Jayasuriya, R., & Stone, G. (2004). Hepatitis C-related discrimination in New South Wales. *Australian Health Review, 27*(2), 57-60. doi:10.1071/AH042720057

Day, C., Ross, J., & Dolan, K. (2003). Hepatitis C-related discrimination among heroin users in Sydney: drug user or hepatitis C discrimination? *Drug and Alcohol Review, 22*(3), 317-321. doi:10.1080/0959523031000154463

De Abreu Lourenco, R., Kenny, P., Haas, M. R., & Hall, J. P. (2015). Factors affecting general practitioner charges and Medicare bulk-billing: results of a survey of Australians. *Medical Journal of Australia, 202*(2), 87-90. doi:10.5694/mja16.01349

De Angelis, G., Davies, B., King, J., McEwan, J., Cavallo, S., Loew, L., . . . Brosseau, L. (2016). Information and communication technologies for the dissemination of clinical practice guidelines to health professionals: a systematic review. *JMIR Medical Education, 2*(2), e16. doi:10.2196/mededu.6288

Deed, G., Kilov, G., Phillips, P., Sharma, A., Leow, S., Arthur, I., . . . Kennedy, M. (2016). Peer-to-Peer, interactive GP education can reduce barriers to best practice in diabetes management. *Diabetes Therapy, 7*(1), 153-161. doi:10.1007/s13300-016-0156-0

DeJonckheere, M., & Vaughn, L. M. (2019). Semistructured interviewing in primary care research: a balance of relationship and rigour. *Family Medicine and Community Health, 7*(2), e000057. doi:10.1136/fmch-2018-000057

Denney-Wilson, E., Fanaian, M., Wan, Q., Vagholkar, S., Schutze, H., & Mark, M. (2010). Lifestyle risk factors in general practice - routine assessment and management. *Australian Family Physician, 39*(12), 950-953. Retrieved from https://www.racgp.org.au/download/documents/AFP/2010/December/201012denney-wilson.pdf

Deuffic-Burban, S., Delarocque-Astagneau, E., Abiteboul, D., Bouvet, E., & Yazdanpanah, Y. (2011). Blood-borne viruses in health care workers: Prevention and management. *Journal of Clinical Virology, 52*(1), 4-10. doi:10.1016/j.jcv.2011.05.016

Dewey, J. (1910). How we think.   Retrieved from http://www.gutenberg.org/files/37423/37423-h/37423-h.htm

Dewey, J. (1940). *Creative democracy: The task before us*: GP Putnam's Sons New York.

Dewey, J. (1941). Propositions, warranted assertibility, and truth. *The Journal of Philosophy, 38*(7), 169-186. doi:10.2307/2017978

Dharamsi, S., Ho, A., Spadafora, S. M., & Woollard, R. (2011). The physician as health advocate: translating the quest for social responsibility into medical education and practice. *Academic Medicine, 86*(9), 1108-1113. doi:10.1097/ACM.0b013e318226b43b

Di Bisceglie, A. M. (1998). Hepatitis C. *Lancet, 351*(9099), 351-355. doi:10.1016/s0140-6736(97)07361-3

DiCicco-Bloom, B., & Crabtree, B. F. (2006). The qualitative research interview. *Medical Education, 40*(4), 314-321. doi:10.1111/j.1365-2929.2006.02418.x

Dieperink, E., Ho, S. B., Thuras, P., & Willenbring, M. L. (2003). A prospective study of neuropsychiatric symptoms associated with interferon-α-2b and ribavirin therapy for patients with chronic hepatitis C. *Psychosomatics, 44*(2), 104-112. doi:10.1176/appi.psy.44.2.104

Dore, G. J., & Feld, J. J. (2015). Hepatitis C virus therapeutic development: in pursuit of "perfectovir". *Clinical Infectious Diseases, 60*(12), 1829-1836. doi:10.1093/cid/civ197

Dore, G. J., & Grebely, J. (2017). Negotiating better discounts for DAA therapy is critical to achieve HCV elimination by 2030. *Journal of Hepatology, 67*(2), 419-420. doi:10.1016/j.jhep.2017.03.035

Dore, G. J., & Hajarizadeh, B. (2018). Elimination of hepatitis C virus in Australia: laying the foundation. *Infectious Disease Clinics, 32*(2), 269-279. doi:10.1016/j.idc.2018.02.006

Dore, G. J., Temple-Smith, M., & Lloyd, A. (Eds.). (2009). *Hepatitis C: An expanding perspective*. East Hawthorn, Vic.: IP Communications.

Dore, G. J., Ward, J., & Thursz, M. (2014). Hepatitis C disease burden and strategies to manage the burden *Journal of Viral Hepatitis, 21*(s1), 1-4. doi:10.1111/jvh.12253

Dow, A. (2018). Bulk-billing clinics 'turning away' complex patients. Retrieved from https://www.smh.com.au/national/bulk-billing-clinics-turning-away-complex-patients-20180704-p4zpij.html

Doyle, J., Harney, B., Brainard, D., Osinusi, A., Stamm, L., Hellard, M. E., & Thompson, A. (2018). Evaluation of APRI index to identify cirrhosis prior to direct-acting antiviral HCV treatment. *Journal of Hepatology, 68*, S313-S314. doi:10.1016/s0168-8278(18)30845-6

Doyle, J. S., Scott, N., Sacks-Davis, R., Pedrana, A. E., Thompson, A. J., & Hellard, M. E. (2019). Treatment access is only the first step to hepatitis C elimination: experience of universal anti-viral treatment access in Australia. *Alimentary Pharmacology and Therapeutics*. doi:10.1111/apt.15210

Draper, B., Layton, C., & Doyle, J. (2019). Eliminating hepatitis C: Part 1. Finding your patients with hepatitis C. *Medicine Today, 20*(6), 34-40. Retrieved from https://medicinetoday.com.au/system/files/pdf/MT2019-11SUPPL-004-DRAPER.pdf

Duckett, S., Beaumont, M., Bell, G., Gunn, J., Murphy, A., Wilson, R., & Crowley, T. (2015). Leading change in primary care: Boards of Primary Health Networks can help improve the Australian health care system. Retrieved from https://ahha.asn.au/sites/default/files/docs/policy-issue/leading_change_in_primary_care.pdf

Dutertre, S., & McNally, S. (2008). *Improving and Increasing Access to Hepatitis C Treatment: A Research Project Exploring Barriers to Treatment for People of Vietnamese and*

*Cambodian Backgrounds*: Australian Research Centre in Sex, Health and Society, La Trobe University.

Edmunds, B. L., Miller, E. R., & Tsourtos, G. (2019). The distribution and socioeconomic burden of Hepatitis C virus in South Australia: a cross-sectional study 2010–2016. *BMC Public Health, 19*(1), 527. doi:10.1186/s12889-019-6847-5

Elkin, K., Spittal, M. J., Elkin, D., & Studdert, D. M. (2012). Removal of doctors from practice for professional misconduct in Australia and New Zealand. *BMJ Quality and Safety*. doi:10.1136/bmjqs-2012-000941

Elshaug, A. G., Watt, A. M., Mundy, L., & Willis, C. D. (2012). Over 150 potentially low-value health care practices: an Australian study. *Medical Journal of Australia, 197*(10), 556-560. doi:10.5694/mja12.11083

Emerson, C., & Weatherill, J. (2019). Review of Labor's 2019 federal election campaign. Retrieved from https://alp.org.au/media/2043/alp-campaign-review-2019.pdf

Erny-Albrecht, K., & Bywood, P. (2016). Corporatisation of general practice – impact and implications. *Primary Health Care Research and Information Service. , 10*. doi:10.5694/j.1326-5377.2002.tb04676.x

Etikan, I., Musa, S. A., & Alkassim, R. S. (2016). Comparison of convenience sampling and purposive sampling. *American Journal of Theoretical and Applied Statistics, 5*(1), 1-4. doi:10.11648/j.ajtas.20160501.11

Evon, D. M., Simpson, K. M., Esserman, D., Verma, A., Smith, S., & Fried, M. W. (2010). Barriers to accessing care in patients with chronic hepatitis C: the impact of depression. *Alimentary Pharmacology and Therapeutics, 32*(9), 1163-1173. doi:10.1111/j.1365-2036.2010.04460.x

Family Medicine Research Centre, U. o. S. (2015). SAND abstract No. 228 from the BEACH program: Prevalence and management of hepatitis C virus in general practice patients. *SAND Abstracts from the BEACH Program 2014-2015.* Retrieved from http://sydney.edu.au/medicine/fmrc/publications/sand-abstracts/228-Hepatitis_C.pdf

Feld, J. J., & Hoofnagle, J. H. (2005). Mechanism of action of interferon and ribavirin in treatment of hepatitis C. *Nature, 436*(7053), 967. doi:10.1038/nature04082

Flitcroft, K., Gillespie, J., Salkeld, G., Carter, S., & Trevena, L. (2011). Getting evidence into policy: The need for deliberative strategies? *Social Science and Medicine, 72*(7), 1039-1046. doi:10.1016/j.socscimed.2011.01.034

Foster, M., Henman, P., Gable, A., & Denton, M. (2016). Population health performance as primary healthcare governance in Australia: professionals and the politics of performance. *Policy Studies, 37*(6), 521-534. doi:10.4324/9781315102177-3

Fraenkel, L., McGraw, S., Wongcharatrawee, S., & Garcia-Tsao, G. (2006). Patients' experiences related to anti-viral treatment for hepatitis C. *Patient Education and Counseling, 62*(1), 148-155. doi:10.1016/j.pec.2005.06.019

Fry, M., & Bates, G. (2011). The tasks of self-managing hepatitis C: the significance of disclosure. *Psychology and Health, 27*(4), 460-474. doi:10.1080/08870446.2011.592982

Fugard, A. J., & Potts, H. W. (2015). Supporting thinking on sample sizes for thematic analyses: a quantitative tool. *International Journal of Social Research Methodology, 18*(6), 669-684. doi:10.1080/13645579.2015.1005455

Fuller, J., Koehne, K., Verrall, C. C., Szabo, N., Bollen, C., & Parker, S. (2015). Building chronic disease management capacity in general practice: The South Australian GP plus practice nurse initiative. *Collegian, 22*(2), 191-197. doi:10.1016/j.colegn.2014.02.002

Gastroenterological Society of Australia. (2019). Remote consultation request for initiation of hepatitis C treatment. Retrieved from https://www.gesa.org.au/public/13/files/Hepatitis%20C/Hep-C-remote-consultation-form-20191112.pdf

Gastroenterological Society of Australia, Australian Liver Association, Australasian Hepatology Association, ASID, ASHM, & Hepatitis Australia. (2020). Clinical guidance for treating hepatitis C virus infection: a summary. Retrieved from https://ashm.blob.core.windows.net/ashmpublic/GP-algorithm-v10-June-2020.pdf

Gibney, K., Cheng, A., Hall, R., & Leder, K. (2017). Australia's National Notifiable Diseases Surveillance System 1991–2011: expanding, adapting and improving. *Epidemiology and Infection, 145*(5), 1006-1017. doi:10.1017/s0950268816002752

Gidding, H., Topp, L., Middleton, M., Robinson, K., Hellard, M. E., McCaughan, G., . . . Law, M. G. (2009). The epidemiology of hepatitis C in Australia: Notifications, treatment uptake and liver transplantations, 1997–2006. *Journal of Gastroenterology and Hepatology, 24*(10), 1648-1654. doi:10.1111/j.1440-1746.2009.05910.x

Gidding, H. F., Law, M. G., Amin, J., Macdonald, G. A., Sasadeusz, J. J., Jones, T. L., . . . Dore, G. J. (2011). Predictors of deferral of treatment for hepatitis C infection in Australian clinics. *Medical Journal of Australia, 194*(8), 398-402. doi:10.5694/j.1326-5377.2011.tb03029.x

Gifford, S. M., O'Brien, M. L., Bammer, G., Banwell, C., & Stoove, M. (2003). Australian women's experiences of living with hepatitis C virus: Results from a cross-sectional survey. *Journal of Gastroenterology and Hepatology, 18*(7), 841-850. doi:10.1046/j.1440-1746.2003.03077.x

Gifford, S. M., O'Brien, M. L., Smith, A., Temple-Smith, M., Stoove, M., Mitchell, D., & Jolley, D. (2005). Australian men's experiences of living with hepatitis C virus: results from a cross-sectional survey. *Journal of Gastroenterology and Hepatology, 20*(1), 79-86. doi:10.1111/j.1440-1746.2004.03514.x

Gillespie, J. (2016). Labor’s ‘Mediscare’ campaign capitalised on Coalition history of hostility towards Medicare. Retrieved from https://theconversation.com/labors-mediscare-campaign-capitalised-on-coalition-history-of-hostility-towards-medicare-61976

Gillespie, R., Mullan, J., & Harrison, L. (2019). Deprescribing for older adults in Australia: factors influencing GPs. *Australian Journal of Primary Health, 24*(6), 463-469. doi:10.1071/py18056

Gonzalez-Chica, D. A., Bowden, J., Miller, C., Longo, M., Nelson, M., Reid, C., & Stocks, N. (2019). Patient-reported GP health assessments rather than individual cardiovascular risk burden are associated with the engagement in lifestyle changes: population-based survey in South Australia. *BMC Family Practice, 20*(1), 173. doi:10.1186/s12875-019-1066-9

Goodall, S., Kenny, P., Mu, C., Hall, J., Norman, R., Cumming, J., . . . Greene, J. (2016). Preferences and choice in primary care - Consumers and providers. Retrieved from https://rsph.anu.edu.au/files/Preferences%20and%20choice-Full%20Report%20FINAL.pdf

Gooey, M., Wong, E., Pedrana, A., Allard, N., Doyle, J., Hellard, M. E., & Wade, A. J. (2020). A survey of Australian general practitioners’ hepatitis C knowledge and management 2 years after subsidised direct-acting antiviral therapy became available. *Sexual Health*. doi:10.1071/sh19189

Government of South Australia - SA Health. (2017). Nursing model of care for viral hepatitis management in South Australia. Retrieved from https://www.sahealth.sa.gov.au/wps/wcm/connect/f5dc9e63-ad02-4d51-801c-164efc46143d/NursingMOCViralHepatitisManagementSA-CDCB-04122017.pdf?MOD=AJPERES&CACHEID=ROOTWORKSPACE-f5dc9e63-ad02-4d51-801c-164efc46143d-mMH6i7M

Government of South Australia - SA Health. (2019). Viral hepatitis nursing support. Retrieved from https://www.sahealth.sa.gov.au/wps/wcm/connect/public+content/sa+health+internet/clinical+resources/clinical+programs/viral+hepatitis+nursing+support

Government of South Australia - SA Health. (2020). Drug and Alcohol Services South Australia - About us Retrieved from https://www.sahealth.sa.gov.au/wps/wcm/connect/public+content/sa+health+internet/about+us/our+statewide+services/drug+and+alcohol+services+sa/drug+and+alcohol+services+south+australia

Gower, E., Estes, C., Blach, S., Razavi-Shearer, K., & Razavi, H. (2014). Global epidemiology and genotype distribution of the hepatitis C virus infection. *Journal of Hepatology*. doi:10.1016/j.jhep.2014.07.027

Gowing, L., Ali, R., Dunlop, A., Farrell, M., & Lintzeris, N. (2014). National guidelines for medication-assisted treatment of opioid dependence.   Retrieved from https://www.health.gov.au/sites/default/files/national-guidelines-for-medication-assisted-treatment-of-opioid-dependence.pdf

Gray, D. J. P., Sidaway-Lee, K., White, E., Thorne, A., & Evans, P. H. (2018). Continuity of care with doctors—a matter of life and death? A systematic review of continuity of care and mortality. *BMJ Open, 8*(6), e021161. doi:10.1136/bmjopen-2017-021161

Grebely, J., & Dore, G. J. (2011). What is killing people with hepatitis C virus infection? *Seminars in Liver Disease, 31*(04), 331-339. doi:10.1055/s-0031-1297922

Grebely, J., Dore, G. J., Morin, S., Rockstroh, J. K., & Klein, M. B. (2017). Elimination of HCV as a public health concern among people who inject drugs by 2030–What will it take to get there? *Journal of the International AIDS Society, 20*(1). doi:10.7448/ias.20.1.22146

Gupta, L., Shah, S., & Ward, J. E. (2006). Educational and health service needs of Australian general practitioners in managing hepatitis C. *Journal of Gastroenterology and Hepatology, 21*(4), 694-699. doi:10.1111/j.1440-1746.2006.04205.x

Hajarizadeh, B., Grebely, J., & Dore, G. J. (2013). Epidemiology and natural history of HCV infection. *Nature Reviews Gastroenterology and Hepatology, 10*(9), 553. doi:10.1038/nrgastro.2013.107

Hajarizadeh, B., Grebely, J., Martinello, M., Matthews, G. V., Lloyd, A. R., & Dore, G. J. (2016). Hepatitis C treatment as prevention: evidence, feasibility, and challenges.

*The Lancet Gastroenterology and Hepatology, 1*(4), 317-327. doi:10.1016/s2468-1253(16)30075-9

Hajarizadeh, B., Grebely, J., Matthews, G. V., Martinello, M., & Dore, G. J. (2018). Uptake of direct-acting antiviral treatment for chronic hepatitis C in Australia. *Journal of Viral Hepatitis, 25*(6), 640-648. doi:10.1111/jvh.12852

Hajarizadeh, B., Grebely, J., McManus, H., Estes, C., Razavi, H., Gray, R. T., . . . Sievert, W. (2017). Chronic hepatitis C burden and care cascade in Australia in the era of interferon-based treatment. *Journal of Gastroenterology and Hepatology, 32*(1), 229-236. doi:10.1111/jgh.13453

Halcomb, E., & Ashley, C. (2017). Australian primary health care nurses most and least satisfying aspects of work. *Journal of Clinical Nursing, 26*(3-4), 535-545. doi:10.1111/jocn.13479

Halcomb, E., & Ashley, C. (2019). Are Australian general practice nurses underutilised?: An examination of current roles and task satisfaction. *Collegian, 26*(5), 522-527. doi:10.1016/j.colegn.2019.02.005

Hall, S. J., Phillips, C. B., Gray, P., Barnard, A., & Batt, K. (2011). Where there is no gold standard: mixed method research in a cluster randomised trial of a tool for safe prioritising of patients by medical receptionists. *International Journal of Multiple Research Approaches, 5*(1), 25-39. doi:10.5172/mra.2011.5.1.25

Hansard, P. o. A.-. (2010). Health Insurance Amendment (Pathology Requests) Bill 2010. Retrieved from https://parlinfo.aph.gov.au/parlInfo/genpdf/chamber/hansardr/2010-05-12/0169/hansard_frag.pdf;fileType=application%2Fpdf

Harding, C., Seal, A., Duncan, G., & Gilmour, A. (2019). General practitioner and registrar involvement in refugee health: exploring needs and perceptions. *Australian Health Review, 43*(1), 92-97. doi:10.1071/ah17093

Haridy, J., Iyngkaran, G., Nicoll, A., Muller, K., Wilson, M., Wigg, A., . . . Sasadeusz, J. (2020). Outcomes of community-based hepatitis C treatment by general practitioners and nurses in Australia via remote specialist consultation. *Internal Medicine Journal*. doi:10.1111/imj.15037

Haridy, J., Wigg, A., Muller, K., Ramachandran, J., Tilley, E., Waddell, V., . . . Tse, E. (2018). Real-world outcomes of unrestricted direct-acting antiviral treatment for hepatitis C in Australia: The South Australian statewide experience. *Journal of Viral Hepatitis, 25*(11), 1287-1297. doi:10.1111/jvh.12943

Harris, M. (2009). Injecting, infection, illness: abjection and hepatitis C stigma. *Body and Society, 15*(4), 33-51. doi:10.1177/1357034X09347221

Harris, M. (2016). The interface between primary health care and population health: challenges and opportunities for prevention. *Public Health Research and Practice, 26*(1), e2611601. doi:10.17061/phrp2611601

Harris, M. F., & Zwar, N. A. (2014). Reflections on the history of general practice in Australia. *Medical Journal of Australia, 201*(S1), S37-S40. doi:10.5694/mja14.00141

Harvey, P., & Loveday, S. (1999). Hepatitis C timeline - a decade of development. Retrieved from http://www.hep.org.au/documents/1999Timeline-50KB.pdf

Health, A. G.-D. o. (2016). General practice 2016 Factsheet. Retrieved from https://hwd.health.gov.au/webapi/customer/documents/factsheets/2016/General%20practice.pdf

Health, A. G.-D. o. (2019a). Australia's long term national health plan: to build the world's best health system. Retrieved from https://www.health.gov.au/sites/default/files/australia-s-long-term-national-health-plan_0.pdf

Health, A. G.-M. D. o. (2019b). Primary Health Reform Steering Group Established - media release. Retrieved from https://www.health.gov.au/ministers/the-hon-greg-hunt-mp/media/primary-health-reform-steering-group-established

Health Policy Analysis. (2019). Evaluation of the Health Care Homes program – Interim evaluation report 2019, Volume 1: Summary report. .   Retrieved from https://www1.health.gov.au/internet/main/publishing.nsf/Content/AD51EBE397452EF5CA2580F700164BAD/$File/Evaluation%20of%20the%20HCH%20program%20-%20Interim%20evaluation%20report%202019.pdf

Health Workforce Australia. (2011). National health workforce innovation and reform strategic framework for action 2011-2015.   Retrieved from http://pandora.nla.gov.au/pan/133228/20120418-1228/www.hwa.gov.au/sites/uploads/hwa-wir-strategic-framework-for-action-201110.pdf

Healthdirect. (2018a). Hepatitis C.   Retrieved from https://www.healthdirect.gov.au/hepatitis-c

Healthdirect. (2018b). How healthdirect can help you.   Retrieved from https://www.healthdirect.gov.au/how-healthdirect-can-help-you

Healym, J., Sharman, E., & Lokuge, B. (2006). Australia health system review. *Health Systems in Transition, 8*(5), 1-158. Retrieved from https://apps.who.int/iris/bitstream/handle/10665/107803/HiT-8-5-2006-eng.pdf?sequence=4&isAllowed=y

Heard, E., Massi, L., Smirnov, A., & Selvey, L. (2019). Prescribing direct-acting antivirals to treat hepatitis C virus in a general practice setting in Australia:"So why not do it"? *Internal Medicine Journal*. doi:10.1111/imj.14648

Hellard, M. E., Sacks-Davis, R., & Doyle, J. (2016). Hepatitis C elimination by 2030 through treatment and prevention: think global, act in local networks. *Journal of Epidemiology and Community Health*, jech-2015-205454. doi:10.1136/jech-2015-205454

Hellard, M. E., & Wang, Y. H. (2009). The role of general practitioners in managing and treating hepatitis C. *Medical Journal of Australia, 191*(10), 523-524. doi:hel10410_fm [pii]

Henderson, J., Valenti, L. A., Britt, H. C., Bayram, C., Wong, C., Harrison, C., . . . Miller, G. C. (2016). Estimating non-billable time in Australian general practice. *Medical Journal of Australia, 205*(2), 79-83. doi:10.5694/mja16.00287

Hendrie, D. (2019). RACGP President calls on Labor to fix the freeze. *newsGP.* Retrieved from https://www1.racgp.org.au/newsgp/professional/%E2%80%98platitudes-don%E2%80%99t-pay-the-bills%E2%80%99-racgp-president-c

Hepatitis Australia. (2019a). A cure for hepatitis C. Retrieved from https://www.hepatitisaustralia.com/hepatitis-c-cures

Hepatitis Australia. (2019b). Our work - Hepatitis C Program -Test Cure Live. Retrieved from https://www.hepatitisaustralia.com/testcurelive

Hepatitis Australia. (2020). Our work - Policy and advocacy. Retrieved from https://www.hepatitisaustralia.com/Pages/Category/policy-advocacy

Hepatitis C Virus Infection Consensus Statement Working Group. (2016). Australian recommendations for the management of hepatitis C virus infection: a consensus statement 2016. Retrieved from http://www.gesa.org.au/files/editor_upload/File/PBS%20and%20MBS/Hepatitis%20C%20virus%20infection%20a%20consensus%20statement%202016.pdf

Hepatitis C Virus Infection Consensus Statement Working Group. (2017). Australian recommendations for the management of hepatitis C virus infection: a consensus statement (January 2017). Retrieved from https://www.asid.net.au/documents/item/1208

Hepatitis C Virus Infection Consensus Statement Working Group. (2018). Australian recommendations for the management of hepatitis C virus infection: a consensus statement (September 2018). Retrieved from https://ashm.blob.core.windows.net/ashmpublic/hepatitis%20C%20virus%20infection%20a%20consensus%20statement%20Sep%202018%20(1).pdf

Hepatitis C Virus Infection Consensus Statement Working Group. (2020). Australian recommendations for the management of hepatitis C virus infection: a consensus statement (June 2020). Retrieved from https://ashm.blob.core.windows.net/ashmpublic/hepatitis-C-virus-infection-a-consensus-statement-Jun-2020.pdf

Hepatitis SA. (2020a). About Hepatitis SA. Retrieved from https://hepatitissa.asn.au/about-us/about-hepatitis-sa

Hepatitis SA. (2020b). Support. Retrieved from https://hepatitissa.asn.au/services/support

Heslop, C., Burns, S., & Lobo, R. (2018). Managing qualitative research as insider-research in small rural communities. *Rural and Remote Health, 18*(3). doi:10.22605/RRH4576

Hildreth, R. W. (2009). Reconstructing Dewey on power. *Political Theory, 37*(6), 780-807. doi:10.1177/0090591709345454

Hills, D., Hills, S., Robinson, T., Northam, H., & Hungerford, C. (2019). General practice nurse–led screening for anxiety in later life in Australian primary care settings. *Australasian Journal on Ageing, 38*(4), e121-e126. doi:10.1111/ajag.12637

Hofer, A., & McDonald, M. (2019). Continuity of care: why it matters and what we can do. *Australian Journal of Primary Health, 25*(3), 214-218. doi:10.1071/py19041

Holliday, S. M., Hayes, C., Dunlop, A. J., Morgan, S., Tapley, A., Henderson, K. M., . . . Davey, A. (2017). Does brief chronic pain management education change opioid prescribing rates? A pragmatic trial in Australian early-career general practitioners. *Pain, 158*(2), 278-288. doi:10.1097/j.pain.0000000000000755

Holliday, S. M., Magin, P. J., Dunbabin, J. S., Ewald, B. D., Henry, J. M., Goode, S. M., . . . Dunlop, A. J. (2012). Waiting room ambience and provision of opioid substitution therapy in general practice. *Medical Journal of Australia, 196*(6), 391. doi:10.5694/mja11.11338

Homer, C. S., Oats, J., Middleton, P., Ramson, J., & Diplock, S. (2018). Updated clinical practice guidelines on pregnancy care. *Medical Journal of Australia, 209*(9), 409-412. doi:10.5694/mja18.00286

Hopwood, M., & Treloar, C. (2004). Receiving a hepatitis C positive diagnosis. *Internal Medicine Journal, 34*(9-10), 526-531. doi:10.1111/j.1445-5994.2004.00639.x

Hopwood, M., & Treloar, C. (2013). Under the watchful eye of 'a benevolent dictator': General practitioner and patient experiences of hepatitis C treatment initiation and shared-care in general practice. *Australian Family Physician, 42*(12), 900. Retrieved from https://www.racgp.org.au/download/Documents/AFP/2013/December/201312hopwood.pdf

Hopwood, M., Treloar, C., & Bryant, J. (2006). Hepatitis C and injecting-related discrimination in New South Wales, Australia. *Drugs: Education, Prevention, and Policy, 13*(1), 61-75. doi:10.1080/09687630500481150

Horwood, J., Clement, C., Roberts, K., Waldron, C. A., Irving, W. L., Macleod, J., & Hickman, M. (2020). Increasing uptake of hepatitis C virus infection case-finding, testing, and treatment in primary care: evaluation of the HepCATT (Hepatitis C Assessment Through to Treatment) trial. *The British Journal of General Practice*. doi:10.3399/bjgp20X708785

Hosseini-Hooshyar, S., Martinello, M., Yee, J., Read, P., Baker, D., Post, J. J., . . . Shaw, D. (2020). Low hepatitis C virus reinfection rate despite ongoing risk following universal access to direct-acting antiviral therapy among people living with HIV. *Aids, 34*(9), 1347-1358. doi:10.1097/qad.0000000000002562

Howes, N., Lattimore, S., Irving, W. L., & Thomson, B. J. (2016). Clinical care pathways for patients with hepatitis C: reducing critical barriers to effective treatment. *Open Forum Infectious Diseases*, ofv218. doi:10.1093/ofid/ofv218

Huang, Y., Adams, L. A., Joseph, J., Bulsara, M. K., & Jeffrey, G. P. (2017). The ability of Hepascore to predict liver fibrosis in chronic liver disease: a meta-analysis. *Liver International, 37*(1), 121-131. doi:10.1111/liv.13116

Hunt, G. (2018). Medicare bulk billing rate hits historic 86.1 per cent. Retrieved from http://www.health.gov.au/internet/ministers/publishing.nsf/Content/544046CB8449CF0BCA2582EA00782D91/$File/GH111.pdf

Iser, D., & Ryan, M. (2013). Fatty liver disease: a practical guide for GPs. *Australian Family Physician, 42*(7), 444. Retrieved from https://www.racgp.org.au/download/Documents/AFP/2013/July/201307iser.pdf

Islam, M. M., Topp, L., Iversen, J., Day, C., Conigrave, K. M., & Maher, L. (2013). Healthcare utilisation and disclosure of injecting drug use among clients of Australia's needle and syringe programs. *Australian and New Zealand Journal of Public Health, 37*(2), 148-154. doi:10.1111/1753-6405.12032

Iversen, J., Grebely, J., Catlett, B., Cunningham, P., Dore, G. J., & Maher, L. (2017). Estimating the cascade of hepatitis C testing, care and treatment among people who inject drugs in Australia. *International Journal of Drug Policy, 47*, 77-85. doi:10.1016/j.drugpo.2017.05.022

Iversen, J., & Maher, L. (2013). Australian Needle and Syringe Program national data report 2008-2013. Retrieved from https://kirby.unsw.edu.au/sites/default/files/kirby/report/ANSPS_2009-2013-Data-Report.pdf

Jackson, C., & Ball, L. (2018). Continuity of care - Vital, but how do we measure and promote it? *Australian Journal of General Practice, 47*(10), 662-664. doi:10.31128/AJGP-05-18-4568

Jansen C, Grinzi P, Monheit B, & Parker R. (2005). Addiction medicine - training for general practice registrars. *Australian Family Physician, 34*, 34-37. Retrieved from https://www.racgp.org.au/afpbackissues/2005/200512/200512jansen.pdf

Jiwa, M., Ee, H., & Beilby, J. (2007). Will promoting general practitioners with special interests threaten access to primary care? *Medical Journal of Australia, 187*(2). doi:10.5694/j.1326-5377.2007.tb01142.x

Johnson, C. E., Lizama, N., Garg, N., Ghosh, M., Emery, J., & Saunders, C. (2014). Australian general practitioners' preferences for managing the care of people diagnosed with cancer. *Asia-Pacific Journal of Clinical Oncology, 10*(2), e90-e98. doi:10.1111/ajco.12047

Jones, K. M., Dixon, M. E., & Dixon, J. B. (2012). General practice research - Does gender affect the decision to participate? *Australian Family Physician, 215*(35), 35-45. Retrieved from https://www.racgp.org.au/download/documents/AFP/2012/June/201206jones.pdf

Joyce, C., McDonald, H., & Lawlor-Smith, L. (2016). General practitioners' perceptions of different practice models: a qualitative study. *Australian Journal of Primary Health, 22*(5), 388-393. doi:10.1071/py15025

Kaan, I., Jones, T., & McCaughan, G. (2017). Have we significantly underestimated the capacity in the Australian health system to treat chronic hepatitis C infection in an interferon-free era? *Internal Medicine Journal, 47*(3), 269-274. doi:10.1111/imj.13262

Kecmanovic, M., & Hall, J. P. (2015). The use of financial incentives in Australian general practice. *Medical Journal of Australia, 202*(9), 488-491. doi:10.5694/mja14.00252

Kelly, M. L., Riordan, S. M., Bopage, R., Lloyd, A. R., & Post, J. J. (2018). Capacity of non-invasive hepatic fibrosis algorithms to replace transient elastography to exclude cirrhosis in people with hepatitis C virus infection: A multi-centre observational study. *PLoS ONE, 13*(2), e0192763. doi:10.1371/journal.pone.0192763

Keogh, K., Clark, P., Valery, P. C., McPhail, S. M., Bradshaw, C., Day, M., & Smith, A. C. (2016). Use of telehealth to treat and manage chronic viral hepatitis in regional Queensland. *Journal of Telemedicine and Telecare, 22*(8), 459-464. doi:10.1177/1357633x16673794

Khokhar, O. S., & Lewis, J. H. (2007). Reasons why patients infected with chronic hepatitis C virus choose to defer treatment: do they alter their decision with time? *Digestive Diseases and Sciences, 52*(5), 1168-1176. doi:10.1007/s10620-006-9579-1

Khoo, A., & Tse, E. (2016). A practical overview of the treatment of chronic hepatitis C virus infection. *Australian Family Physician, 45*(10), 718. Retrieved from https://www.racgp.org.au/download/Documents/AFP/2016/October/AFP-OCT-Clinical-Khoo.pdf

Kilmarx, P. H., & Mutasa-Apollo, T. (2013). Patching a leaky pipe: the cascade of HIV care. *Current Opinion in HIV and AIDS, 8*(1), 59-64. doi:10.1097/COH.0b013e32835b806e

Kirby Institute. (2017). Monitoring hepatitis C treatment uptake in Australia Issue 8, December 2017. Retrieved from https://kirby.unsw.edu.au/sites/default/files/kirby/report/Monitoring-hep-C-treatment-uptake-in-Australia_Iss8-DEC17.pdf

Kirby Institute. (2018). Monitoring hepatitis C treatment uptake in Australia Issue 9, July 2018. Retrieved from https://kirby.unsw.edu.au/sites/default/files/kirby/report/Monitoring-hep-C-treatment-uptake-in-Australia_Iss9-JUL18.pdf

Kirby Institute. (2019). Monitoring hepatitis C treatment uptake in Australia Issue 10, June 2019. Retrieved from https://kirby.unsw.edu.au/sites/default/files/kirby/report/Monitoring-hep-C-treatment-uptake-in-Australia_Iss10-JUN19.pdf

Kitsos, A., Peterson, G. M., Jose, M. D., Khanam, M. A., Castelino, R. L., & Radford, J. C. (2019). Variation in documenting diagnosable chronic kidney disease in general medical practice: Implications for quality improvement and research. *Journal of Primary Care and Community Health, 10*, 2150132719833298. doi:10.1177/2150132719833298

Kuo, G., Choo, Q.-L., Alter, H., Gitnick, G., Redeker, A., Purcell, R., . . . Stevens, C. (1989). An assay for circulating antibodies to a major etiologic virus of human non-A, non-B hepatitis. *Science, 244*(4902), 362-364. doi:10.1126/science.2496467

Kwon, J., Dore, G., Grebely, J., Hajarizadeh, B., Guy, R., Cunningham, E., . . . Gray, R. (2018). Australia on track to achieve WHO elimination targets following rapid initial DAA treatment uptake. *Journal of Hepatology, 68*, S153. doi:10.1111/jvh.13013

Lambert, S. M., Page, A. N., Wittmann, J., Hayllar, J. S., Ferndale, C. W., Bain, T. M., & Macdonald, G. A. (2011). General practitioner attitudes to prescribing hepatitis C antiviral therapy in a community setting. *Australian Journal of Primary Health, 17*(3), 282-287. doi:10.1071/PY10069 [doi]

Larney, S., Grebely, J., Hickman, M., De Angelis, D., Dore, G. J., & Degenhardt, L. (2015). Defining populations and injecting parameters among people who inject drugs: Implications for the assessment of hepatitis C treatment programs. *International Journal of Drug Policy, 26*(10), 950-957. doi:10.1016/j.drugpo.2015.07.010

Larson, A., Gillies, M., Howard, P. J., & Coffin, J. (2007). It's enough to make you sick: the impact of racism on the health of Aboriginal Australians. *Australian and New Zealand Journal of Public Health, 31*(4), 322-329. doi:10.1111/j.1753-6405.2007.00079.x

Laurence, C. O., & Karnon, J. (2017). What will make a difference? Assessing the impact of policy and non-policy scenarios on estimations of the future GP workforce. *Human Resources for Health, 15*(1), 43. doi:10.1186/s12960-017-0216-1

Law, M. G. (1999). Modelling the hepatitis C virus epidemic in Australia. *Journal of Gastroenterology and Hepatology, 14*(11), 1100-1107. doi:10.1016/j.drugalcdep.2007.05.026.

Layton, C., Richmond, J. A., & Baker, D. (2019). Eliminating hepatitis C: Part 2. Assessing your patient for antiviral treatment. *Medicine Today, 20*(7), 24-32. Retrieved from https://medicinetoday.com.au/system/files/pdf/MT2019-11SUPPL-010-LAYTON.pdf

Le, B., Eastman, P., Vij, S., McCormack, F., Duong, C., & Philip, J. (2017). Palliative care in general practice: GP integration in caring for patients with advanced cancer. *Australian Family Physician, 46*(1/2), 51. Retrieved from https://www.racgp.org.au/download/Documents/AFP/2017/Jan-Feb/AFP-Jan-Feb-2017-Research-Eastman.pdf

Le Floch, B., Bastiaens, H., Le Reste, J.-Y., Lingner, H., Hoffman, R., Czachowski, S., . . . Nabbe, P. (2016). Which positive factors determine the GP satisfaction in clinical practice? A systematic literature review. *BMC Family Practice, 17*(1), 133. doi:10.1186/s12875-016-0524-x

Le, P. P. (2019). Patient access to opioid substitution treatment pharmacy and medical service providers in South Australia: geospatial mapping. *Australian Journal of Primary Health, 25*(2), 125-130. doi:10.1071/py18099

Lee, A., Hanson, J., Fox, P., Spice, G., Russell, D., & Boyd, P. (2018). A decentralised, multidisciplinary model of care facilitates treatment of hepatitis C in regional Australia. *Journal of Virus Eradication, 4*(3), 160-164. doi:10.1016/s2055-6640(20)30270-3

Lee, A. S., van Driel, M. L., & Crawford, D. H. (2017). The cost of successful antiviral therapy in hepatitis C patients: a comparison of iFn-free versus iFn-based regimens at an individual patient level in Australia. *ClinicoEconomics and Outcomes Research, 9*, 595. doi:10.2147/ceor.s146280

Ley, S. (2015). Turnbull Govt invests over $1b to cure hep C [Press release]. Retrieved from http://www.health.gov.au/internet/ministers/publishing.nsf/Content/FAE2B65331456243CA257F20006D4C48/$File/SL-154.pdf

Ley, S. (2016). Hep C cures available today for as low as $6.20 a prescription - media release. Retrieved from https://parlinfo.aph.gov.au/parlInfo/download/media/pressrel/4401630/upload_binary/4401630.pdf;fileType=application%2Fpdf#search=%22media/pressrel/4401630%22

Liaw, S.-T., Kearns, R., Taggart, J., Frank, O., Lane, R., Tam, M., . . . Harris, M. (2017). The informatics capability maturity of integrated primary care centres in Australia. *International Journal of Medical Informatics, 105*, 89-97. doi:10.1016/j.ijmedinf.2017.06.002

Liberal Party of Australia. (2013). The Coalition's policy to support Australia's health system. Retrieved from http://lpaweb-static.s3.amazonaws.com/13-08-22%20The%20Coalition%E2%80%99s%20Policy%20to%20Support%20Australia%E2%80%99s%20Health%20System.pdf

Liberal Party of Australia. (2020). Our Plan - Better health care. Retrieved from https://www.liberal.org.au/our-plan/health

Litwin, A. H., Drolet, M., Nwankwo, C., Torrens, M., Kastelic, A., Walcher, S., . . . Grebely, J. (2019). Perceived barriers related to testing, management and treatment of HCV infection among physicians prescribing opioid agonist therapy: The C-SCOPE Study. *Journal of Viral Hepatitis, 26*(9), 1094-1104. doi:10.1111/jvh.13119

Lobo, R., Mascarenhas, L., Worthington, D., Bevan, J., & Mak, D. B. (2015). Evaluation of the regional nurse-supported hepatitis C shared care program in Western Australia: a mixed methods study. *BMC Health Services Research, 15*(1), 399. doi:10.1186/s12913-015-1055-1

Longman, C., Temple-Smith, M., Gilchrist, G., & Lintzeris, N. (2012). Reluctant to train, reluctant to prescribe: barriers to general practitioner prescribing of opioid substitution therapy. *Australian Journal of Primary Health, 18*(4), 346-351. doi:10.1071/PY11100

Lowe, D., & Cotton, R. (1999). Hepatitis C: a review of Australia's response. Retrieved from https://www1.health.gov.au/internet/main/publishing.nsf/Content/E70DC6DBA8370553CA257BF00018CD1C/$File/hepc_rev.pdf

Lyons, A. (2017). Doubts remain over funding for Health Care Homes trial. *newsGP.* Retrieved from https://www1.racgp.org.au/newsgp/racgp/doubts-remain-about-funding-for-health-care-homes

MacLachlan, J., Smith, C., Towell, V., & Cowie, B. C. (2020). Viral Hepatitis Mapping Project: National Report 2018–19. Retrieved from https://ashm.org.au/resources/hcv-resources-list/viral-hepatitis-mapping-project-national-report-2018-2019/ASHM_ViralHepReport18-19_WEB.pdf

MacLachlan, J., Thomas, L., & Cowie, B. (2019). Viral Hepatitis Mapping Project National Report 2017. Retrieved from https://ashm.org.au/products/product/Viral-Hepatitis-Mapping-Project-2017

MacLachlan, J., Thomas, L., Cowie, B., & Allard, N. (2018). Hepatitis C Mapping Project: Estimates of geographic diversity in chronic hepatitis C prevalence, diagnosis, monitoring and treatment - National Report 2016. Retrieved from https://ashm.blob.core.windows.net/ashmpublic/ASHM%20HCV%20Mapping%20National%20Report%202016%20ONLINE.pdf

MacNeil, J. M. (2012). The complexity of living with hepatitis C: a Newman perspective. *Nursing Science Quarterly, 25*(3), 261-266. doi:10.1177/0894318412447567

Madden, A., Hopwood, M., Neale, J., & Treloar, C. (2018). Beyond interferon side effects: What residual barriers exist to DAA hepatitis C treatment for people who inject drugs? *PLoS ONE, 13*(11), e0207226. doi:10.1371/journal.pone.0207226

Magin, P., Adams, J., Ireland, M., Joy, E., Heaney, S., & Darab, S. (2006). The response of general practitioners to the threat of violence in their practices: results from a qualitative study. *Family Practice, 23*(3), 273-278. doi:10.1093/fampra/cmi119

Magin, P., Holliday, S., Dunlop, A., Ewald, B., Dunbabin, J., Henry, J., . . . Baker, F. (2012). Discomfort sharing the general practice waiting room with mentally ill patients: a cross-sectional study. *Family Practice*. doi:10.1093/fampra/cms058

Mah, A., Hull, M. W., DeBeck, K., Milloy, M. J., Dobrer, S., Nosova, E., . . . Hayashi, K. (2017). Knowledge of hepatitis C and treatment willingness amongst people who inject drugs in an era of direct acting antivirals. *International Journal of Drug Policy, 47*, 137-143. doi:10.1016/j.drugpo.2017.02.006

Manning, J. (2011). Priority-setting processes for medicines: the United Kingdom, Australia and New Zealand. *Journal of law and medicine, 18*(3), 439-452.

Manos, M. M., Ho, C. K., Murphy, R. C., & Shvachko, V. A. (2013). Physical, social, and psychological consequences of treatment for hepatitis C. *The Patient-Patient-Centered Outcomes Research, 6*(1), 23-34. doi:10.1007/s40271-013-0005-4

Marbeen, M. I. (2019). *Focused Practice and Enhanced Skills PGY3 Training in Family Medicine: A Mixed Methods Study.* (Master of Clinical Science), The University of Western Ontaria. Retrieved from https://ir.lib.uwo.ca/etd/6686

Marshall, A. D., Cunningham, E. B., Nielsen, S., Aghemo, A., Alho, H., Backmund, M., . . . Flisiak, R. (2018). Restrictions for reimbursement of interferon-free direct-acting antiviral drugs for HCV infection in Europe. *The Lancet Gastroenterology and Hepatology, 3*(2), 125-133. doi:10.1016/S2468-1253(17)30284-4

Marshall, A. D., Grebely, J., Dore, G., & Treloar, C. (2019). Barriers and facilitators to engaging in hepatitis C management and DAA therapy among general practitioners and drug and alcohol specialists – The practitioner experience. *Drug and Alcohol Dependence*, 107705. doi:10.1016/j.drugalcdep.2019.107705

Marshall, A. D., Pawlotsky, J.-M., Lazarus, J. V., Aghemo, A., Dore, G. J., & Grebely, J. (2018). The removal of DAA restrictions in Europe–one step closer to eliminating HCV as a major public health threat. *Journal of Hepatology*. doi:10.1016/j.jhep.2018.06.016

Martin, A. A., Laurence, C. O., Black, L. E., & Mugford, B. V. (2007). General practice placements for pre-registration junior doctors: adding value to intern education and training. *Medical Journal of Australia, 186*(7), 346. doi:10.5694/j.1326-5377.2007.tb00934.x

Martin, N. K., Hickman, M., Hutchinson, S. J., Goldberg, D. J., & Vickerman, P. (2013). Combination interventions to prevent HCV transmission among people who inject drugs: modeling the impact of antiviral treatment, needle and syringe programs, and opiate substitution therapy. *Clinical Infectious Diseases, 57*(suppl 2), S39-S45. doi:10.1093/cid/cit296

Martin, N. K., Vickerman, P., Dore, G. J., Grebely, J., Miners, A., Cairns, J., . . . Martin, T. C. (2016). Prioritization of HCV treatment in the direct-acting antiviral era: an economic evaluation. *Journal of Hepatology, 65*(1), 17-25. doi:10.1016/j.jhep.2016.02.007

Martin, N. K., Vickerman, P., & Hickman, M. (2017). How to eliminate HCV infection by antiviral treatment. doi:10.1016/j.jhep.2017.03.008

Martinello, M., Hajarizadeh, B., & Dore, G. J. (2018). Observations on the launch of new drugs for hepatitis C. *Australian Prescriber, 41*(1), 4. doi:10.18773/austprescr.2018.005

Martyres, R. F., Clode, D., & Burns, J. M. (2004). Seeking drugs or seeking help? Escalating" doctor shopping" by young heroin users before fatal overdose. *Medical Journal of Australia, 180*(5), 211-215. doi:10.5694/j.1326-5377.2004.tb05887.x

Mason, M. (2010). Sample size and saturation in PhD studies using qualitative interviews. *Forum Qualitative Sozialforschung/Forum: Qualitative Social Research, 11*(3). doi:10.17169/fqs-11.3.1428

Mason, R., Doherty, K., Eccleston, C., Winbolt, M., Long, M., & Robinson, A. (2020). Effect of a dementia education intervention on the confidence and attitudes of general practitioners in Australia: a pretest post-test study. *BMJ Open, 10*(1). doi:10.1136/bmjopen-2019-033218

Matheson, C., Porteous, T., van Teijlingen, E., & Bond, C. (2010). Management of drug misuse: an 8-year follow-up survey of Scottish GPs. *The British Journal of General Practice, 60*(576), 517-520. doi:10.3399/bjgp10X514783

Mazza, D., Deb, S., & Subasinghe, A. (2020). Telehealth: an opportunity to increase access to early medical abortion for Australian women. *Medical Journal of Australia, 213*(7), 298-299. e291. doi:10.5694/mja2.50782

McCaughan, G. W., Omata, M., Amarapurkar, D., Bowden, S., Chow, W. C., Chutaputti, A., . . . Tateishi, R. (2007). Asian Pacific Association for the Study of the Liver consensus statements on the diagnosis, management and treatment of hepatitis C virus infection. *Journal of Gastroenterology and Hepatology, 22*(5), 615-633. doi:10.1111/j.1440-1746.2007.04883.x

McDermid, F., Peters, K., Jackson, D., & Daly, J. (2014). Conducting qualitative research in the context of pre-existing peer and collegial relationships. *Nurse Researcher, 21*(5), 28-33. doi:10.7748/nr.21.5.28.e1232

McGrail, M. R., Humphreys, J. S., & Ward, B. (2015). Accessing doctors at times of need–measuring the distance tolerance of rural residents for health-related travel. *BMC Health Services Research, 15*(1), 212. doi:10.1186/s12913-015-0880-6

McGregor, S., McManus, H., Gray, R., & Costello, J. (2015). *HIV, viral hepatitis and sexually transmissible infections in Australia Annual Surveillance Report 2015* (1838-5559). Retrieved from Syndney: https://kirby.unsw.edu.au/report/annual-surveillance-report-hiv-viral-hepatitis-stis-2015

McInnes, S. (2017). Exploring collaboration between registered nurses and general practitioners in Australian general practice. doi:10.1071/py00015

McIsaac, M., Scott, A., & Kalb, G. (2019). The role of financial factors in the mobility and location choices of General Practitioners in Australia. *Human Resources for Health, 17*(1), 34. doi:10.1186/s12960-019-0374-4

McKenzie, S., Larkins, S., & Spillman, M. (2015). Recruiting general practitioners for surveys and other research: additional lessons learned. *Australian Journal of Primary Health, 21*(2), 117-117. doi:10.1071/py14102

McKim, C., Warren, J., Asfaw, A. H., Balich, R., Nolte, M., Perkins, D., . . . Zakaria, N. S. (2014). An integrative model of recovery: A qualitative study of the perceptions of six counseling doctoral students. *Science and Education, 2*(1), 17-23. doi:10.12691/rpbs-2-1-4

McLeod, A., Cullen, B., Hutchinson, S., Roy, K., Dillon, J., Stewart, E., & Goldberg, D. (2017). Limited impact of awareness-raising campaigns on hepatitis C testing practices among general practitioners. *Journal of Viral Hepatitis*. doi:10.1111/jvh.12724

McNally, S., Temple-Smith, M., & Pitts, M. (2004). Making decisions about hepatitis C treatment. *ARCSHS Monograph Series: no. 49.* Retrieved from https://www.latrobe.edu.au/arcshs/downloads/arcshs-research-publications/making_decisions_about_hepc_treatment.pdf

McNally, S., Temple-Smith, M., Sievert, W., & Pitts, M. (2006). Now, later or never? Challenges associated with hepatitis C treatment. *Australian and New Zealand Journal of Public Health, 30*(5), 422-427. doi:10.1111/j.1467-842X.2006.tb00457.x

Medical Board of Australia. (2016a). Obligations on Medical Practitioners - continuing professional development (CPD) registration standard. Retrieved from https://www.medicalboard.gov.au/Registration/Obligations-on-Medical-Practitioners.aspx

Medical Board of Australia. (2016b). Registration standard: continuing professional development. Retrieved from http://www.medicalboard.gov.au/documents/default.aspx?record=WD16%2f19473&dbid=AP&chksum=r3KA%2fZ0ECm3jZ1M7CfEMSw%3d%3d

Medicare Benefits Schedule Review Taskforce. (2017). Interim report from the General Practice and Primary Care Clinical Committee. Retrieved from http://www.health.gov.au/internet/main/publishing.nsf/Content/mbs-review-2018-taskforce-reports-cp/$File/v2%20-%20General%20Practice%20and%20Primary%20Care%20Clinical%20Committee%20Phase%201%20Interim%20Rep.pdf

Medicare Benefits Schedule Review Taskforce. (2018). Report from the General Practice and Primary Care Clinical Committee: Phase 2. Retrieved from http://www.health.gov.au/internet/main/publishing.nsf/Content/mbs-review-2018-taskforce-reports-cp/$File/v2%20-%20General%20Practice%20and%20Primary%20Care%20Clinical%20Committee%20Phase%202%20Report.pdf

Medicare Benefits Schedule Review Taskforce. (2020). Medicare Benefits Schedule Review Taskforce Report on Primary Care. Retrieved from https://www.health.gov.au/sites/default/files/documents/2020/12/report-on-primary-care.pdf

Micallef, J., Kaldor, J., & Dore, G. (2006). Spontaneous viral clearance following acute hepatitis C infection: a systematic review of longitudinal studies. *Journal of Viral Hepatitis, 13*(1), 34-41. doi:10.1111/j.1365-2893.2005.00651.x

Miller, E. R., McNally, S., Wallace, J., & Schlichthorst, M. (2012). The ongoing impacts of hepatitis C - a systematic narrative review of the literature. *BMC Public Health, 12*(1), 672. doi:10.1186/1471-2458-12-672

Miller, S., Sheppard, L., Colenda, C., & Magen, J. (2001). Why physicians are unprepared to treat patients who have alcohol and drug-related disorders. *Academic Medicine, 76*(5), 410 - 418. doi:10.1097/00001888-200105000-00007

Millman, A. J., Ntiri-Reid, M. B., Irvin, R., Kaufmann, M. M. H., Aronsohn, A., Duchin, J. S., . . . Vellozzi, C. (2017). Barriers to treatment access for chronic hepatitis C virus infection: A case series. *Topics in Antiviral Medicine, 25*(3), 110. doi:10.15406/ghoa.2014.01.00005

Monforte, A. d. A., Cozzi-Lepri, A., Ceccherini-Silberstein, F., De Luca, A., Caputo, S. L., Castagna, A., . . . Shanyinde, M. (2017). Access and response to direct antiviral agents (DAA) in HIV-HCV co-infected patients in Italy: Data from the Icona cohort. *PLoS ONE, 12*(5), e0177402. doi:10.1371/journal.pone.0177402

Morgan, D. L. (2007). Paradigms lost and pragmatism regained: Methodological implications of combining qualitative and quantitative methods. *Journal of Mixed Methods Research, 1*(1), 48-76. doi:10.1177/2345678906292462

Morgan, D. L. (2014). Pragmatism as a paradigm for social research. *Qualitative Inquiry, 20*(8), 1045-1053. doi:10.1177/1077800413513733

Mossialos, E., Djordjevic, A., Osborn, R., & Sarnak, D. (2017). International Profiles of Health Care Systems 2017: Australia, Canada, Denmark, England, France, Germany, Italy, Japan, the Netherlands, New Zealand, Norway, Sweden, Switzerland, and the United States. Retrieved from http://www.commonwealthfund.org/~/media/files/publications/fund-report/2017/may/mossialos_intl_profiles_v5.pdf

Mossialos, E., Wenzl, M., Osborn, R., & Anderson, C. (2016). 2015 International profiles of health care systems. Retrieved from http://www.commonwealthfund.org/~/media/files/publications/fund-report/2016/jan/1857_mossialos_intl_profiles_2015_v7.pdf

Mu, C., De Abreu Lourenco, R., van Gool, K., & Hall, J. (2018). Is low-priced primary care bad for quality? Evidence from Australian general practice. *Applied Economics, 50*(5), 475-491. doi:10.1080/00036846.2017.1324610

National Health and Medical Research Council. (2018). Australian code for the responsible conduct of research 2018. Retrieved from https://www.nhmrc.gov.au/file/14384/download?token=gje4DNtT

Newman, C. E., De Wit, J. B., Crooks, L., Reynolds, R. H., Canavan, P. G., & Kidd, M. R. (2015). Challenges of providing HIV care in general practice. *Australian Journal of Primary Health, 21*(2), 164-168. doi:10.1071/PY13119

Newman, C. E., Kidd, M. R., de Wit, J. B. F., Reynolds, R. H., Canavan, P. G., & Kippax, S. C. (2011). What moves a family doctor to specialise in HIV? Interviews with Australian policy key informants. *Culture, Health and Sexuality, 13*(10), 1151-1164. doi:10.1080/13691058.2011.607904

Nøhr, C., Parv, L., Kink, P., Cummings, E., Almond, H., Nørgaard, J. R., & Turner, P. (2017). Nationwide citizen access to their health data: analysing and comparing experiences in Denmark, Estonia and Australia. *BMC Health Services Research, 17*(1), 1-11. doi:10.1186/s12913-017-2482-y

Norful, A., Martsolf, G., de Jacq, K., & Poghosyan, L. (2017). Utilization of registered nurses in primary care teams: A systematic review. *International Journal of Nursing Studies, 74*, 15-23. doi:10.1016/j.ijnurstu.2017.05.013

Nunkuwarrin Yunti of South Australia Inc. (2017). Nunkuwarrin Yunti of South Australia Inc. - Annual Report 2016-20117. Retrieved from http://nunku.org.au/wp-content/uploads/mp/files/resource_listings/files/nunku-annual-report-2017-proof-9.pdf

O'Loan, J., Balcomb, A., Elliott, S., Greenwood-Smith, B., Penn, M., & Dore, G. (2020). Aus GPs End Hep C. Retrieved from https://ashm.org.au/HCV/Aus-GPs-End-Hep-C/#:~:text=The%20absolute%20number%20of%20patients,treated%20by%20GPs%20in%202017.

O'Kane, G. (2020). Telehealth—Improving access for rural, regional and remote communities. *Australian Journal of Rural Health, 28*(4), 419. doi:10.1111/ajr.12663

Orne, J. (2011). 'You will always have to "out" yourself': Reconsidering coming out through strategic outness. *Sexualities, 14*(6), 681-703. doi:10.1177/1363460711420462

Palak, A., Livoti, C., & Audibert, C. (2017). Considerations on bringing warehoused HCV patients into active care following interferon-free, direct-acting antiviral drug approval. *Postgraduate Medicine, 129*(4), 471-475. doi:10.1080/00325481.2017.1304795

Palmer, A. Y., Wade, A. J., Draper, B., Howell, J., Doyle, J. S., Petrie, D., . . . Scott, N. (2019). A cost-effectiveness analysis of primary versus hospital-based specialist care for direct acting antiviral hepatitis C treatment. *International Journal of Drug Policy, 76*, 102633. doi:10.1016/j.drugpo.2019.102633

Pang, P. C.-I., McKay, D., Chang, S., Chen, Q., Zhang, X., & Cui, L. (2020). Privacy concerns of the Australian My Health Record: Implications for other large-scale opt-out personal health records. *Information Processing and Management*, 102364. doi:10.1016/j.ipm.2020.102364

Parkinson, A., Jorm, L., Douglas, K. A., Gee, A., Sargent, G. M., Lujic, S., & McRae, I. S. (2015). Recruiting general practitioners for surveys: reflections on the difficulties and some lessons learned. *Australian Journal of Primary Health, 21*(2), 254-258. doi:10.1071/py13129

Pawlotsky, J. M. (2014). New hepatitis C therapies: the toolbox, strategies, and challenges. *Gastroenterology, 146*(5), 1176-1192. doi:10.1053/j.gastro.2014.03.003

Perry, M. S. (2005). *Testing for Hepatitis C in General Practice Methadone Clinics: Does an Informed Consent Process Operate? A Case Study of General Practitioners' Ethical Perception.* (Degree of MD), The University of Manchester (United Kingdom), ProQuest. Retrieved from https://search.proquest.com/openview/2c7cf37de2a62213ced36a35b3e67a91/1?pq-origsite=gscholar&cbl=2026366&diss=y (13870688)

Pharmaceutical Benefit Scheme. (2016). Public Summary Document - July 2016 PBAC Meeting - 5.09 Grazoprevir 100 mg / Elbasvir 50 mg, fixed dose combination tablet, Zepatier®, Merck Sharp & Dohme Pty Ltd. Retrieved from http://www.pbs.gov.au/industry/listing/elements/pbac-meetings/psd/2016-07/files/grazoprevir-elbasvir-psd-july-2016.pdf

Phillips, C. B., Pearce, C., Hall, S., Kljakovic, M., Sibbald, B., Dwan, K., . . . Yates, R. (2009). Enhancing care, improving quality: the six roles of the general practice nurse. *Medical Journal of Australia, 191*(2), 92-97. doi:10.5694/j.1326-5377.2009.tb02701.x

PHN Adelaide. (2018). Healthpathways South Australia: an online resource for GPs and healthcare providers. Retrieved from https://adelaidephn.com.au/our-work/our-activities/directory-of-services-programs/healthpathways-south-australia-an-online-resource-for-gps-and-health-care-p

PHN South Western Sydney. (2018). Optimising MBS items for patients with drug and alcohol issues. Retrieved from https://sydneynorthhealthnetwork.org.au/wp-content/uploads/2018/03/Optimising-MBS-items-for-drug-and-alcohol-patients-FINAL.pdf

Piko, L. M. (2014). *Optimising professional life: a grounded theory of doctors' careers.* (Doctor of Philosophy), The Australian National University. Retrieved from https://openresearch-repository.anu.edu.au/handle/1885/13439

Piko, L. M., & Phillips, C. B. (2010). General practice as a career: insights for workforce policy. *Medical Journal of Australia, 193*(2), 99-100. doi:10.5694/j.1326-5377.2010.tb03813.x

Pinsky, B., Mitchell, D., Sanchez, Y., Johnson, S., & Sammy, S. (2018). Early versus delayed hepatitis C treatment provides increased health benefits at lower costs: A pan-genotypic cost effectiveness analysis set in Scotland. *Journal of Hepatology, 68*, S32. doi:10.1016/s0168-8278(18)30283-6

Poland, B. D. (1995). Transcription quality as an aspect of rigor in qualitative research. *Qualitative Inquiry, 1*(3), 290-310. doi:10.1177/107780049500100302

Pond, C. D., & Regan, C. (2019). Improving the delivery of primary care for older people. *Medical Journal of Australia, 211*(2), 60-62. doi:10.1007/978-3-030-10814-4_23

Pourmarzi, D., Smirnov, A., Hall, L., FitzGerald, G., & Rahman, T. (2020). 'I'm over the moon!': patient-perceived outcomes of hepatitis C treatment. *Australian Journal of Primary Health*. doi:10.1071/py20013

Pourmarzi, D., Smirnov, A., Hall, L., Thompson, H., FitzGerald, G., & Rahman, T. (2020). Enablers and barriers for the provision of community-based HCV treatment: A case study of a real-world practice. *Journal of Viral Hepatitis*. doi:10.1111/jvh.13259

Pourmarzi, D., Thompson, H., Thomas, J. A., Hall, L., Smirnov, A., FitzGerald, G., & Rahman, T. (2019). Outcomes of a tertiary-based innovative approach to engage primary care providers in provision of hepatitis C treatment in community settings. *BMC Public Health, 19*(1), 1335. doi:10.1186/s12889-019-7604-5

Price, D. W., Overton, C. C., Duncan, J. P., Wamsley, D. A., Havens, C., Steinbruegge, J., . . . Klein, F. (2002). Results of the first national Kaiser Permanente Continuing Medical

Education Needs Assessment Survey. *The Permanente Journal, 6*(1), 1-9. doi:10.7812/TPP/01-041

Prieto, M., Olaso, V., Verdú, C., Córdoba, J., Gisbert, C., Rayón, M., . . . Berenguer, J. (1995). Does the healthy hepatitis C virus carrier state really exist? An analysis using polymerase chain reaction. *Hepatology, 22*(2), 413-417. doi:10.1002/hep.1840220207

Purcell, T., Wade, A., & Accadia, L. (2019). Eliminating hepatitis C: Part 3. Curing hepatitis C in general practice. *Medicine Today, 20*(8), 20-26. Retrieved from https://medicinetoday.com.au/system/files/pdf/MT2019-11SUPPL-016-PURCELL.pdf

QSR International Pty Ltd. (2019). NVivo 10 for Windows.   Retrieved from http://www.qsrinternational.com/nvivo/support-overview/downloads/nvivo-10-for-windows

Ramachandran, J., Kaambwa, B., Muller, K., Haridy, J., Tse, E., Tilley, E., . . . Shaw, D. (2019). Cost effectiveness of treatment models of care for hepatitis C: the South Australian state-wide experience. *European Journal of Gastroenterology & Hepatology*. doi:10.1097/meg.0000000000001659

Raveel, A., & Schoenmakers, B. (2019). Interventions to prevent aggression against doctors: a systematic review. *BMJ Open, 9*(9), e028465. doi:10.1136/bmjopen-2018-028465

Read, P., Lothian, R., Chronister, K., Gilliver, R., Kearley, J., Dore, G. J., & van Beek, I. (2017). Delivering direct acting antiviral therapy for hepatitis C to highly marginalised and current drug injecting populations in a targeted primary health care setting. *International Journal of Drug Policy*. doi:10.1016/j.drugpo.2017.05.032

Rhee, J. J., Grant, M., Senior, H., Monterosso, L., McVey, P., Johnson, C., . . . Fallon-Ferguson, J. (2020). Facilitators and barriers to general practitioner and general practice nurse participation in end-of-life care: systematic review. *BMJ Supportive and Palliative Care*. doi:10.1136/bmjspcare-2019-002109

Richmond, J. A. (2008). National hepatitis C needs assessment 2008. Retrieved from https://static.squarespace.com/static/50ff0804e4b007d5a9abe0a5/t/51bed31ae4b06d4459ec5077/1371460378486/Do%20you%20C%20what%20I%20C%20-%20Needs%20Assessment%202008.pdf

Richmond, J. A. (2009). The role of the health care team. In G. Dore, M. Temple-Smith, & A. Lloyd (Eds.), *Hepatitis C : An Expanding Perspective*. East Hawthorn, Vic. : IP Communications.

Richmond, J. A., Dunning, P., & Desmond, P. (2004). Hepatitis C: A medical and social diagnosis. *Australian Nursing Journal, 12*(1), 23-25.

Richmond, J. A., Dunning, T., & Desmond, P. (2007). Health professionals' attitudes toward caring for people with hepatitis C. *Journal of Viral Hepatitis, 14*(9), 624-632. doi:10.1111/j.1365-2893.2007.00849.x

Richmond, J. A., Ellard, J., Wallace, J., Thorpe, R., Higgs, P., Hellard, M., & Thompson, A. (2018). Achieving a hepatitis C cure: a qualitative exploration of the experiences and meanings of achieving a hepatitis C cure using the direct acting antivirals in Australia. *Hepatology, Medicine and Policy, 3*(1), 1-9. doi:10.1186/s41124-018-0036-5

Richmond, J. A., & Wallace, J. (2018). Implementation of hepatitis C cure in Australia: one year on. *Journal of Virus Eradication, 4*(2), 115. doi:10.1016/s2055-6640(20)30254-5

Robertson, J., Walkom, E. J., & Henry, D. A. (2011). Health systems and sustainability: doctors and consumers differ on threats and solutions. *PLoS One, 6*(4), e19222. doi:10.1371/journal.pone.0019222

Robinson, O. C. (2014). Sampling in interview-based qualitative research: A theoretical and practical guide. *Qualitative Research in Psychology, 11*(1), 25-41. doi:10.1080/14780887.2013.801543

Rodger, A., Thomson, J., Thompson, S., Jolley, D., Mijch, A., Lanigan, A., & Crofts, N. (1999). Assessment of long-term outcomes of hepatitis C virus infection in a cohort of patients with acute hepatitis in 1971–1975: Results of a pilot study. *Journal of*

*Gastroenterology and Hepatology, 14*(3), 269-273. doi:10.1046/j.1440-1746.1999.01846.x

Rollins, A. (2016). Govt actions unhelpful, MBS review head admits. Retrieved from https://ama.com.au/ausmed/govt-actions-unhelpful-mbs-review-head-admits

Rowland, P., Anderson, M., Kumagai, A. K., McMillan, S., Sandhu, V. K., & Langlois, S. (2018). Patient involvement in health professionals' education: A meta-narrative review. *Advances in Health Sciences Education*, 1-23. doi:10.1007/s10459-018-9857-7

Royal Australian College of General Practitioners. (2016). Curriculum for Australian general practice 2016–CS16 core skills unit. Retrieved from https://www.racgp.org.au/education/education-providers/curriculum/2016-curriculum/core-skills-unit

Royal Australian College of General Practitioners. (2018a). Fellowship. Retrieved from https://www.racgp.org.au/education/registrars/fellowship-pathways

Royal Australian College of General Practitioners. (2018b). General Practice: Health of the Nation 2018. Retrieved from https://www.racgp.org.au/FSDEDEV/media/documents/Special%20events/Health-of-the-Nation-2018-Report.pdf

Royal Australian College of General Practitioners. (2018c). What is General Practice. Retrieved from https://www.racgp.org.au/education/students/a-career-in-general-practice/what-is-general-practice

Royal Australian College of General Practitioners. (2019). General Practice: Health of the Nation 2019. Retrieved from https://www.racgp.org.au/FSDEDEV/media/documents/Special%20events/Health-of-the-Nation-2019-Report.pdf

Royal Australian College of General Practitioners. (2020a). Handbook for general practitioners - CPD Program requirements for the 2020–22 triennium. Retrieved from https://www.racgp.org.au/getattachment/d0f40b8e-2f67-485a-a085-a06e0b2d6682/Handbook-for-general-practitioners.aspx

Royal Australian College of General Practitioners. (2020b). Specific Interests Networks. Retrieved from https://www.racgp.org.au/the-racgp/faculties/specific-interests/interest-groups

Rudd, K. (2013). Transcript Of Prime Minister Kevin Rudd's National Press Club Address Canberra September 05 2013. Retrieved from https://parlinfo.aph.gov.au/parlInfo/search/display/display.w3p;query=Id:%22media/pressrel/2729371%22

Rudd, K., Swan, W., Roxon, N., & Australian Government - Department of Health and Ageing. (2010). A national health and hospitals network for Australia's future: delivering better health and better hospitals. Retrieved from https://apo.org.au/sites/default/files/resource-files/2010-03/apo-nid20570.pdf

Runciman, W. B., Hunt, T. D., Hannaford, N. A., Hibbert, P. D., Westbrook, J. I., Coiera, E. W., . . . Braithwaite, J. (2012). CareTrack: assessing the appropriateness of health care delivery in Australia. *Medical Journal of Australia, 197*(2), 100-105. doi:10.5694/mja12.10510

Russell, L. (2020). What is the fate of the MBS Review Task Force and its work? Retrieved from https://www.croakey.org/what-is-the-fate-of-the-mbs-review-task-force-and-its-work/

Safreed-Harmon, K., Blach, S., Aleman, S., Bollerup, S., Cooke, G., Dalgard, O., . . . Grebely, J. (2019). The Consensus Hepatitis C Cascade of Care: standardized reporting to monitor progress toward elimination. *Clinical Infectious Diseases, 69*(12), 2218-2227. doi:10.1093/cid/ciz714

Sahin, D., Yaffe, M. J., Sussman, T., & McCusker, J. (2014). A mixed studies literature review of family physicians' participation in research. *Family Medicine, 46*(7), 503-514. doi:10.1016/j.jadohealth.2017.11.219

Scarborough, J., Eliott, J., & Braunack-Mayer, A. (2011). Opioid substitution therapy - a study of GP participation in prescribing. *Australian Family Physician, 40*(4), 241-245. Retrieved from Aust Fam Physician website: https://www.racgp.org.au/download/documents/AFP/2011/April/201104scarborough.pdf

Scarborough, J., Eliott, J., Miller, E. R., & Aylward, P. (2015). Equity in primary health care delivery: an examination of the cohesiveness of strategies relating to the primary healthcare system, the health workforce and hepatitis C. *Australian Health Review, 39*(2), 175-182. doi:10.1071/ah14073

Scarborough, J., Miller, E. R., Aylward, P., & Eliott, J. (2017). 'Sussing that doctor out.' Experiences and perspectives of people affected by hepatitis C regarding engagement with private general practitioners in South Australia: a qualitative study. *BMC Family Practice, 18*(1), 97. doi:10.1186/s12875-017-0669-2

Schoen, C., Osborn, R., How, S. K. H., Doty, M. M., & Peugh, J. (2009). In chronic condition: experiences of patients with complex health care needs, in eight countries, 2008. *Health Affairs, 28*(1), w1-w16. doi:10.1377/hlthaff.28.1.w1

Schulz, T. R., Kanhutu, K., Sasadeusz, J., Watkinson, S., & Biggs, B.-A. (2020). Using telehealth to improve access to hepatitis C treatment in the direct-acting antiviral therapy era. *Journal of Telemedicine and Telecare, 26*(3), 180-185. doi:10.1177/1357633x18806651

Schütze, H., Shell, A., & Brodaty, H. (2018). Development, implementation and evaluation of Australia's first national continuing medical education program for the timely diagnosis and management of dementia in general practice. *BMC Medical Education, 18*(1), 194. doi:10.1186/s12909-018-1295-y

Scott, A. (2017). ANZ-Melbourne Institute health sector report: General practice trends. Retrieved from https://www.anz.com.au/content/dam/anzcomau/pdf/ANZ%20Health%20Economics%20Report_ts%20(spread).final2%20no%20trims.pdf

Scott, N., Doyle, J. S., Wilson, D. P., Wade, A. J., Howell, J., Pedrana, A., . . . Hellard, M. E. (2017). Reaching hepatitis C virus elimination targets requires health system interventions to enhance the care cascade. *International Journal of Drug Policy*. doi:10.1016/s2055-6640(20)30800-1

Scott, N., McBryde, E. S., Thompson, A., Doyle, J. S., & Hellard, M. E. (2017). Treatment scale-up to achieve global HCV incidence and mortality elimination targets: a cost-effectiveness model. *Gut, 66*(8), 1507-1515. doi:10.1136/gutjnl-2016-311504

Scott, N., Sacks-Davis, R., Wade, A. J., Stoove, M., Pedrana, A., Doyle, J. S., . . . Hellard, M. E. (2020). Australia needs to increase testing to achieve hepatitis C elimination. *Medical Journal of Australia*. doi:10.5694/mja2.50544

Seal, K. H., Currie, S. L., Shen, H., Anand, B. S., Bini, E. J., Brau, N., . . . Group, V. H.-S. (2007). Hepatitis C treatment candidacy and outcomes among 4318 US veterans with chronic hepatitis C virus infection: does a history of injection drug use matter? *Journal of Clinical Gastroenterology, 41*(2), 199-205. doi:10.1097/01.mcg.0000212644.82853.51

Seeff, L. B. (2009). The history of the “natural history” of hepatitis C (1968–2009). *Liver International, 29*(s1), 89-99. doi:10.1111/j.1478-3231.2008.01927.x

Senate Select Committee on Health. (2014). Senate Select Committee on Health - First interim report. Retrieved from https://www.health.gov.au/sites/default/files/response-senate-select-committee-on-health-first-interim-report.pdf

Shepherd, A., Perrella, B., & Hattingh, H. L. (2014). The impact of dispensing fees on compliance with opioid substitution therapy: a mixed methods study. *Substance Abuse Treatment, Prevention, and Policy, 9*(1), 32. doi:10.1186/1747-597x-9-32

Sherwood, J. (2010). *Do no harm: decolonising Aboriginal health research.* (Doctor of Philosophy), University of New South Wales, Sydney. Retrieved from http://unsworks.unsw.edu.au/fapi/datastream/unsworks:8457/SOURCE02?view=true

Sievert, W. (2003). Antiviral therapy for chronic hepatitis C. *Australian Family Physician, 32*(10), 826-832. Retrieved from https://www.racgp.org.au/afpbackissues/2003/200310/20031001hepcchapter8.pdf

Sievert, W., Altraif, I., Razavi, H. A., Abdo, A., Ahmed, E. A., AlOmair, A., . . . El Khayat, H. (2011). A systematic review of hepatitis C virus epidemiology in Asia, Australia and Egypt. *Liver International, 31*(s2), 61-80. doi:10.1111/j.1478-3231.2011.02540.x

Sievert, W., Razavi, H., Estes, C., Thompson, A. J., Zekry, A., Roberts, S. K., & Dore, G. J. (2014). Enhanced antiviral treatment efficacy and uptake in preventing the rising burden of hepatitis C-related liver disease and costs in Australia. *Journal of Gastroenterology and Hepatology, 29*(S1), 1-9. doi:10.1111/jgh.12677

Silicosis Support Network. (2020). About Us: Introducing your support network. Retrieved from https://www.silicosissupport.org.au/about-us/

Silins, E., Conigrave, K. M., Rakvin, C., Dobbins, T., & Curry, K. (2007). The influence of structured education and clinical experience on the attitudes of medical students towards substance misusers. *Drug and alcohol review, 26*(2), 191-200. doi:10.1080/09595230601184661

Simmons, R., Ireland, G., Irving, W., Hickman, M., Sabin, C., Ijaz, S., . . . Mandal, S. (2018). Establishing the cascade of care for hepatitis C in England - benchmarking to monitor impact of direct acting antivirals. *Journal of Viral Hepatitis, 25*(5), 482-490. doi:10.1111/jvh.12844

Skinner, N., Roche, A. M., Freeman, T., & Mckinnon, A. (2009). Health professionals' attitudes towards AOD-related work: moving the traditional focus from education and training to organizational culture. *Drugs: Education, Prevention, and Policy, 16*(3), 232-249. doi:10.1080/09687630902876338

Snoswell, C. L., Caffery, L. J., Haydon, H. M., Thomas, E. E., & Smith, A. C. (2020). Telehealth uptake in general practice as a result of the coronavirus (COVID-19) pandemic. *Australian Health Review, 44*(5), 737-740. doi:10.1071/ah20183

Snow, R., Humphrey, C., & Sandall, J. (2013). What happens when patients know more than their doctors? Experiences of health interactions after diabetes patient education: a qualitative patient-led study. *BMJ Open, 3*(11), e003583. doi:10.1136/bmjopen-2013-003583

Spencer-Oatey, H. (2007). Theories of identity and the analysis of face. *Journal of Pragmatics, 39*(4), 639-656. doi:10.1016/j.pragma.2006.12.004

Spurling, G., & Jackson, C. (2009). GPs with special interests-benefits to patients, GPs and the community. *Australian Family Physician, 38*(5), 337. Retrieved from https://www.racgp.org.au/download/Documents/AFP/2009/May/200905spurling.pdf

Starbird, L. E., Budhathoki, C., Han, H. R., Sulkowski, M. S., Reynolds, N. R., & Farley, J. E. (2020). Nurse case management to improve the hepatitis C care continuum in HIV co-infection: Results of a randomized controlled trial. *Journal of Viral Hepatitis, 27*(4), 376-386. doi:10.1111/jvh.13241

Starbird, L. E., Han, H. R., Sulkowski, M. S., Budhathoki, C., Reynolds, N. R., & Farley, J. E. (2018). Care2Cure: A randomized controlled trial protocol for evaluating nurse case management to improve the hepatitis C care continuum within HIV primary care. *Research in Nursing and Health*. doi:10.1002/nur.21903

Stevenson, F. A., Kerr, C., Murray, E., & Nazareth, I. (2007). Information from the internet and the doctor-patient relationship: the patient perspective – a qualitative study. *BMC Family Practice, 8*(1), 47. Retrieved from BMC Fam Pract website: doi:10.1186/1471-2296-8-47

Stewart, B. J., Mikocka-Walus, A. A., Harley, H., & Andrews, J. M. (2012). Help-seeking and coping with the psychosocial burden of chronic hepatitis C: A qualitative study of patient, hepatologist, and counsellor perspectives. *International Journal of Nursing Studies, 49*, 560-569. doi:10.1016/j.ijnurstu.2011.11.004

Stone, L. (2015). Managing medically unexplained illness in general practice. *Australian Family Physician, 44*(9), 624. Retrieved from https://www.racgp.org.au/download/Documents/AFP/2015/September/September_Focus_Stone.pdf

Stone, L. (2018). Disease prestige and the hierarchy of suffering. *Medical Journal of Australia, 208* (2), 60-62. doi:10.5694/mja17.00503

Stoové, M., Wallace, J., Higgs, P., Pedrana, A., Goutzamanis, S., Latham, N., . . . Doyle, J. (2019). Treading lightly: Finding the best way to use public health surveillance of hepatitis C diagnoses to increase access to cure. *International Journal of Drug Policy, 75*, 102596. doi:10.1016/j.drugpo.2019.11.004

Strasser, S. I. (2017). Managing hepatitis C in general practice. *Australian Prescriber, 40*(2), 64. doi:10.18773/austprescr.2017.017

Stuart, B., Leydon, G., Woods, C., Gennery, E., Elsey, C., Summers, R., . . . Drew, P. (2019). The elicitation and management of multiple health concerns in GP consultations. *Patient Education and Counseling, 102*(4), 687-693. doi:10.1016/j.pec.2018.11.009

Sublette, V. A., Smith, S. K., George, J., McCaffery, K., & Douglas, M. W. (2015). The hepatitis C treatment experience: patients' perceptions of the facilitators of and barriers to uptake, adherence and completion. *Psychology and Health, 30*(8), 987-1004. doi:10.1080/08870446.2015.1012195

Sud, R., Tiwari, N., Forner, P., Dowdell, L., Freiman, J., & Zekry, A. (2018). General practitioners require more support to prescribe direct acting antiviral therapy for hepatitis C. *Internal Medicine Journal, 48*(1), 105-106. doi:10.1111/imj.13662

Sud, R., Zekry, A., & Freiman, J. (2016). General practitioners face significant barriers to prescribing direct-acting antiviral therapy for hepatitis C. *Journal of Gastroenterology and Hepatology, 31 Suppl 2*, 81. doi:10.1111/jgh.13519

Swan, D., Long, J., Carr, O., Flanagan, J., Irish, H., Keating, S., . . . Cullen, W. (2010). Barriers to and facilitators of hepatitis C testing, management, and treatment among current and former injecting drug users: a qualitative exploration. *AIDS Patient Care and STDs, 24*(12), 753-762. doi:10.1089/apc.2010.0142 [doi]

Swerissen, H., & Duckett, S. (2018). Mapping primary care in Australia. Retrieved from https://grattan.edu.au/wp-content/uploads/2018/07/906-Mapping-primary-care.pdf

Taylor, M. J., Horey, D., Livingstone, C., Chan, S.-P., & Swerissen, H. (2013). General practitioners and consultation drift: the effects of supply-side changes and reforms on service delivery patterns. *Australian Health Review*. doi:10.1071/ah12160

Teesson M, Ross J, Darke S, Lynskey M, Ali R, Ritter A, & Cooke R. (2006). One year outcomes for heroin dependence: Findings from the Australian Treatment Outcome Study (ATOS). *Drug and Alcohol Dependence, 83*, 174-180. doi:10.1016/j.drugalcdep.2005.11.009.

Teesson, M., Marel, C., Darke, S., Ross, J., Slade, T., Burns, L., . . . Mills, K. L. (2015). Long-term mortality, remission, criminality and psychiatric comorbidity of heroin dependence: 11-year findings from the Australian Treatment Outcome Study. *Addiction, 110*(6), 986-993. doi:10.1111/add.12860

The Australian Commission on Safety and Quality in Health Care. (2019). General Practice accreditation. Retrieved from https://www.safetyandquality.gov.au/our-work/primary-care/national-general-practice-accreditation-scheme#the-national-general-practice-accreditation-(ngpa)-scheme

The Kirby Institute. (2016). Hepatitis B and C in Australia Annual Surveillance Report Supplement 2016. Retrieved from https://kirby.unsw.edu.au/sites/default/files/kirby/report/SERP_HepBandC-Annual-Surveillance-Report-Supp-2016.pdf

The Kirby Institute. (2017a). HIV, viral hepatitis and sexually transmissible infections in Australia annual surveillance report 2017. Retrieved from https://kirby.unsw.edu.au/sites/default/files/kirby/report/SERP_Annual-Surveillance-Report-2017_compressed.pdf

The Kirby Institute. (2017b). Monitoring hepatitis C treatment uptake in Australia Issue 7, July 2017. Retrieved from https://kirby.unsw.edu.au/sites/default/files/kirby/report/Monitoring-hep-C-treatment-uptake-in-Australia_Iss7-JUL17.pdf

The Kirby Institute. (2018a). HIV, viral hepatitis and sexually transmissible infections in Australia annual surveillance report 2018. Retrieved from https://kirby.unsw.edu.au/report/hiv-viral-hepatitis-and-sexually-transmissible-infections-australia-annual-surveillance

The Kirby Institute. (2018b). Real world efficacy of antiviral therapy in chronic hepatitis C in Australia (Issue 2). Retrieved from https://kirby.unsw.edu.au/sites/default/files/kirby/report/REACH-C_Newsletter_Iss2-JUL18.pdf

The National Health and Medical Research Council - The Australian Research Council and Universities Australia. (2018). National statement on ethical conduct in human research 2007 (Updated 2018). Retrieved from https://www.nhmrc.gov.au/about-us/publications/national-statement-ethical-conduct-human-research#block-views-block-file-attachments-content-block-1

The Pharmaceutical Benefits Scheme - Drug Utilisation Sub-committee. (2018). Direct acting antiviral medicines for the treatment of chronic hepatitis C. Retrieved from https://www.pbs.gov.au/industry/listing/participants/public-release-docs/2018-09/hepatitis-c-review-prd-2018-19.pdf

The Royal Australian College of General Practitioners. (2015). The RACGP standards for general practices: 4th edition. Retrieved from http://www.racgp.org.au/download/documents/Standards/standards4thedition.pdf

The Royal Australian College of General Practitioners. (2016). RACGP QI& CPD Program 2017-2019 triennium handbook. Retrieved from https://www.racgp.org.au/FSDEDEV/media/documents/Education/Professional%20development/QI-CPD/QICPD-Handbook-2017-19-triennium.pdf

The Royal Australian College of General Practitioners. (2020). Standards for general practices: 5th edition. Retrieved from https://www.racgp.org.au/FSDEDEV/media/documents/Running%20a%20practice/Practice%20standards/5th%20edition/Standards-for-general-practice-5th-edition.pdf

The Senate Community Affairs References Committee. (2004). Hepatitis C and the blood supply in Australia. Retrieved from https://www.aph.gov.au/~/media/wopapub/senate/committee/clac_ctte/completed_inquiries/2002_04/hepc/report/report_pdf.ashx

The University of Sydney. (2017). The University of Sydney Family Medicine Research Centre Bettering the Evaluation and Care of Health (BEACH). Retrieved from http://sydney.edu.au/medicine/fmrc/beach/index.php

Thein, H.-H., & Dore, G. (2009). Trends in chronic viral hepatitis: Notifications, treatment uptake and advanced disease burden. *Cancer Forum.* Retrieved from http://search.informit.com.au.proxy.library.adelaide.edu.au/fullText;dn=991472754177450;res=IELHEA

Thompson, D. S., Fazio, X., Kustra, E., Patrick, L., & Stanley, D. (2016). Scoping review of complexity theory in health services research. *BMC Health Services Research, 16*(1), 87. doi:10.1186/s12913-016-1343-4

Treloar, C., & Hopwood, M. (2008). "Look, I'm fit, I'm positive and I'll be all right, thank you very much": Coping with hepatitis C treatment and unrealistic optimism. *Psychology, Health and Medicine, 13*(3), 360-366. doi:10.1080/13548500701477532

Treloar, C., Hopwood, M., & Loveday, S. (2002). Hepatitis C-related discrimination in healthcare. . *Medical Journal of Australia, 177*(5), 233-234. doi:10.5694/j.1326-5377.2002.tb04753.x

Treloar, C., Jackson, C., Gray, R., Newland, J., Wilson, H., Saunders, V., . . . Brener, L. (2015). Care and treatment of hepatitis C among Aboriginal people in New South Wales, Australia: implications for the implementation of new treatments. *Ethnicity and Health*(ahead-of-print), 1-19. doi:10.1080/13557858.2015.1004870

Treloar, C., Newland, J., Harris, M., Deacon, R., & Maher, L. (2010, 2014 Mar 24). A diagnosis of hepatitis C - insights from a study on patients' experiences. *Australian Family Physician.* Retrieved from http://search.informit.com.au.proxy.library.adelaide.edu.au/fullText;dn=267570448881772;res=IELHEA

Treloar, C., & Rhodes, T. (2009). The lived experience of hepatitis C and its treatment among injecting drug users: qualitative synthesis. *Qualitative Health Research, 19*(9), 1321-1334. doi:10.1177/1049732309341656

Tudor Hart, J. (1971). The inverse care law. *The Lancet, 297*(7696), 405-412. doi:10.1016/S0140-6736(71)92410-X

Turnbull, M. (2016a). Press Conference with Deputy Prime Minister - Sydney. Retrieved from https://www.malcolmturnbull.com.au/media/press-conference-with-deputy-prime-minister-sydney

Turnbull, M. (2016b). Transcript - Malcolm Turnbull Press Confernce, Sydney July 1 2016,. Retrieved from https://www.malcolmturnbull.com.au/media/press-conference-sydney

Tyrrell, H. (2016). *Advocacy for universal access to hep C medicines*. Paper presented at the Australasian Viral Hepatitis Conference 2016, Gold Coast. https://na.eventscloud.com/file_uploads/452e952b76a28462380be380f9f1476c_TYRRELL_AdvocacyforUniversalAccesstoMedicinesRead-Only.pdf

van Boekel, L. C., Brouwers, E. P., van Weeghel, J., & Garretsen, H. F. (2013). Stigma among health professionals towards patients with substance use disorders and its consequences for healthcare delivery: systematic review. *Drug and Alcohol Dependence, 131*(1), 23-35. doi:10.1016/j.drugalcdep.2013.02.018

Vitry, A. I., & Shute, R. (2018). Access to High-Cost Medicines in Australia *Equitable Access to High-Cost Pharmaceuticals* (pp. 165-181): Elsevier.

Wade, A. J., Doyle, J. S., Gane, E., Stedman, C., Draper, B., Iser, D., . . . Hellard, M. E. (2020). Outcomes of treatment for hepatitis C in primary care compared to hospital-based care: a randomised controlled trial in people who inject drugs. *Clinical Infectious Diseases, 70*(9), 1900-1906. doi:10.1093/cid/ciz546

Wade, A. J., Draper, B., Doyle, J., Allard, N., Grinzi, P., Thompson, A., & Hellard, M. (2017). A survey of hepatitis C management by Victorian GPs after PBS-listing of direct-acting antiviral therapy. *Australian Family Physician, 46*(4), 235. doi:10.1111/liv.13582

Wade, A. J., McCormack, A., Roder, C., McDonald, K., Davies, M., Scott, N., . . . Hellard, M. E. (2018). Aiming for elimination: outcomes of a consultation pathway supporting regional general practitioners to prescribe direct acting antiviral therapy for hepatitis C. *Journal of Viral Hepatitis*. doi:10.1111/jvh.12910

Wagner, G., Ryan, G., Osilla, K. C., Bhatti, L., Goetz, M., & Witt, M. (2009). Treat early or wait and monitor? A qualitative analysis of provider hepatitis C virus treatment decision-making in the context of HIV coinfection. *AIDS Patient Care and STDs, 23*(9), 715-725. doi:10.1089/apc.2009.0049

Ward, B., Humphreys, J., McGrail, M., Wakerman, J., & Chisholm, M. (2015). Which dimensions of access are most important when rural residents decide to visit a general practitioner for non-emergency care? *Australian Health Review, 39*(2), 121-126. doi:10.1071/ah14030

Ward, J. W. (2016). Global elimination of hepatitis C virus. *Gastroenterology and Hepatology, 12*(10), 632 -635. Retrieved from Gastroenterol Hepatol (N Y) website: https://www.ncbi.nlm.nih.gov/pmc/articles/PMC5114506/

Ward, J. W., & Mermin, J. H. (2015). Simple, effective, but out of reach? Public health implications of HCV drugs. *The New England Journal of Medicine.* doi:10.1056/nejme1513245

Welsh, E. (2002). Dealing with data: Using NVivo in the qualitative data analysis process. *Forum Qualitative Sozialforschung/Forum: Qualitative Social Research, 3*(2). doi:10.17169/fqs-3.2.865

White, B., Dore, G. J., Lloyd, A. R., Rawlinson, W. D., & Maher, L. (2014). Opioid substitution therapy protects against hepatitis C virus acquisition in people who inject drugs: the HITS-c study. *Medical Journal of Australia, 201*(6), 326-329. doi:10.5694/mja13.00153

White, L., Azzam, A., Burrage, L., Orme, C., Kay, B., Higgins, S., . . . Weston, N. (2019). Facilitating treatment of HCV in primary care in regional Australia: closing the access gap. *Frontline Gastroenterology, 10*(3), 210-216. doi:10.1136/flgastro-2018-101049

Wilkinson, D., Dick, M., & Askew, D. A. (2005). General practitioners with special interests: risk of a good thing becoming bad? *Medical Journal of Australia, 183*(2), 84. doi:10.5694/j.1326-5377.2005.tb06929.x

Willcox, S., Lewis, G., & Burgers, J. S. (2011). Strengthening primary care: Recent reforms and achievements in Australia, England, and the Netherlands. *Issues in International Health Policy.* Retrieved from http://www.commonwealthfund.org/~/media/Files/Publications/Issue%20Brief/2011/Nov/1564_Willcox_strengthening_primary_care_Aus_Engl_Neth_intl_brief.pdf

Willis, O. (2018). Fewer Australians are dying from hepatitis C, but thousands are still missing out on treatment. Retrieved from https://www.abc.net.au/news/health/2018-08-13/fewer-australians-dying-from-hepatitis-c/10107326

Wilson, H. (2020). How stigmatising language affects people in Australia who use tobacco, alcohol and other drugs. *Australian Journal of General Practice, 49*(3), 155. doi:10.31128/ajgp-07-19-4998

Wood, P., Opie, C., Tucci, J., Franklin, R., & Anderson, K. (2019). “A lot of people call it liquid handcuffs” – barriers and enablers to opioid replacement therapy in a rural area. *Journal of Substance Use, 24*(2), 150-155. doi:10.1080/14659891.2018.1523968

World Health Organization. (2016a). Combating hepatitis B and C to reach elimination by 2030: advocacy brief. Retrieved from http://apps.who.int/iris/bitstream/10665/206453/1/WHO_HIV_2016.04_eng.pdf

World Health Organization. (2016b). Global health sector strategy on viral hepatitis 2016–2021. . Retrieved from http://apps.who.int/iris/bitstream/handle/10665/246177/WHO-HIV-2016.06-eng.pdf;jsessionid=3BA9202D4B7DE9DD1BD85B1C02A23240?sequence=1

World Health Organization. (2017). Global hepatitis report 2017. Retrieved from http://apps.who.int/iris/bitstream/10665/255016/1/9789241565455-eng.pdf?ua=1

World Health Organization. (2018). Guidelines for the care and treatment of persons diagnosed with chronic hepatitis C virus infection. Retrieved from https://apps.who.int/iris/bitstream/handle/10665/273174/9789241550345-eng.pdf?ua=1

Wright, M., & Mainous III, A. G. (2018). Can continuity of care in primary care be sustained in the modern health system? *Australian Journal of General Practice, 47*(10), 667. doi:10.31128/ajgp-06-18-4618

Wright, M. C. (2019). *The value of continuity of care in Australian general practice.* (Doctor of Philosophy), Univeristy of Sydney. Retrieved from https://opus.lib.uts.edu.au/bitstream/10453/134137/1/01front.pdf

Yap, L., Carruthers, S., Thompson, S., Cheng, W., Jones, J., Simpson, P., . . . Lloyd, A. (2014). A descriptive model of patient readiness, motivators, and hepatitis C treatment uptake among Australian prisoners. *PLoS ONE, 9*(2), e87564. doi:10.1371/journal.pone.0087564

Yellamaty, V., Ball, L., Crossland, L., & Jackson, C. (2019). General practitioners with special interests: An integrative review of their role, impact and potential for the future. *Australian Journal of General Practice, 48*(9), 639. doi:10.31128/ajgp-02-19-4849

Youens, D., Moorin, R., Harrison, A., Varhol, R., Robinson, S., Brooks, C., & Boyd, J. (2020). Using general practice clinical information system data for research: the case in Australia. *International Journal of Population Data Science, 5*(1). doi:10.23889/ijpds.v5i1.1099

Young, J., Eley, D., Patterson, E., & Turner, C. (2016). A nurse-led model of chronic disease management in general practice: Patients' perspectives. *Australian Family Physician, 45*(12), 912. doi:10.14264/uql.2014.206

Zoratti, M. J., Siddiqua, A., Morassut, R. E., Zeraatkar, D., Chou, R., van Holten, J., . . . Druyts, E. (2020). Pangenotypic direct acting antivirals for the treatment of chronic hepatitis C virus infection: A systematic literature review and meta-analysis. *EClinicalMedicine, 18*, 100237. doi:10.1016/j.eclinm.2019.12.007