Improving the Medication Experience of Australians Living with Cancer

By

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THESIS SUMMARY

We use medicines to improve lives, but in reality they sometimes result in harm. The likelihood of experiencing medication-related harm is higher for people living with cancer. And yet, we know little about their experiences of using medicines in everyday life. Medication experience helps us recognise how medicines impact patients' lives. It also provides insight into how patient's actions impact medication-related outcomes. Thus, understanding medication experience is critical to design systems of care that minimise medication-related harm.

This thesis contributes knowledge that enriches our understanding of medication experience in cancer. This knowledge is made significant by applying a strategic management lens to identify feasible actions that can be taken within the system of care to improve the medication experience of Australians living with cancer.

Three research activities are presented: a patient interview study, a pharmacist interview study, and a scoping review. Reflexive thematic analysis and the Cynefin framework is used to make sense of the research findings, addressing the research objectives. First, the ways that cancer impacts the patient world is considered. This shows that people who are using medicines to manage chronic conditions throughout cancer diagnosis and treatment experience increased workload and dynamic fluctuations in capacity that can result in unpredictable imbalances in work and capacity. This is one of several types of medication-related issues patients can expect to encounter in their cancer journey. Whether such issues result in harm depends on the tactics employed. Increasing visibility of medication-related issues and effective self-management promotes timely and appropriate response to issues, optimising medication experience.

Second, the system of care that supports the medication management of Australian's living with cancer is analysed. This shows that while cancer-specific medication management services (MMS) may be scarce, generic MMS are underutilised by cancer populations. Generic MMS offer complementary value to those offered by specialist services and are accessible from the earliest stages of the cancer journey. The ways in which MMS providers create value is described using five archetypal roles. Prescription-focused roles of the Auditor, Expert and Teacher reduce risk within the system of care, while patient-centred roles of Intelligence Officer and Coach help to make the system more resilient by increasing visibility of medication-related issues and supporting patients to be effective in their self-management. On paper, there is a good fit between the MMS available and the needs of people with cancer, but this is not translating to uptake of MMS in real life. By working more

effectively within existing constraints, we can increase utilisation of available MMS and improve the medication experience of Australian's living without requiring extensive investment of time and resources.

These findings are made significant by informing actions that are feasible to implement. By using a strategic management lens these actions have been framed in terms that are relevant to those on whom we rely on to create this change: the independent businesses responsible for providing MMS. Policy makers can help to create favourable conditions, but it is the service providers that must heed the call to action.

DECLARATION

I certify that this thesis:

1. does not incorporate without acknowledgment any material previously submitted for a degree or diploma in any university, and
2. the research within will not be submitted for any other future degree or diploma without the permission of Flinders University; and
3. to the best of my knowledge and belief, does not contain any material previously published or written by another person except where due reference is made in the text.

No professional editing service or artificial intelligence has been used to produce this thesis.

Signed:…..... Date: April 26th, 2023

PUBLICATIONS DURING CANDIDATURE

Cortis, L. J., Ward, P. R., McKinnon, R. A., & Koczwara, B. (2017). Integrated care in cancer: What is it, how is it used and where are the gaps? A textual narrative literature synthesis. *Eur J Cancer Care* (Engl), 26(4), e12689. doi:10.1111/ecc.12689

Cortis, L.J., Ward, P.R., McKinnon, R.A., & Koczwara, B. (2016). Breaking the silos: Integrated care for cancer and chronic conditions. In Cancer and Chronic Conditions: Addressing the Problem of Multimorbidity in Cancer Patients and Survivors (pp. 287-313). Springer Singapore.

Cortis, L.J., McKinnon, R.A., Anderson, C. (2013). Palliative Care is Everyone's Business, Including Pharmacist's, *American Journal for Pharmaceutical Education*, 77(2), 21.

Cortis, L.J. (2017). A Qualitative Study to describe patient-specific factors that relate to clinical need for and potential to benefit from a medication management service in palliative care, *Journal of Pharmacy Practice and Research,* 47(1): 34-40

Cortis L.J., Koczwara B, McKinnon R.A., Ward P.R. (2019) Inattentional blindness and other lessons learned from exploring the experiences of pharmacists in cancer care. Poster 229. *Asia Pacific Journal of Clinical Oncology (Proceedings of COSA)* 15: Supplement 9 p 136, Adelaide, November

Cortis L.J., Koczwara B, McKinnon R.A., Ward P.R. (2019) Ninety-nine problems and the medicines are one: Experiences of people managing a pre-existing chronic condition through cancer diagnosis and treatment. *Asia Pacific Journal of Clinical Oncology (Proceedings of COSA)* 15: Supplement 9 p 137 Adelaide, November

Cortis, L.J., Ward, P.R.., McKinnon, R.A.., & Koczwara, B. (2015). *Integrated care in cancer: A literature review*. 91. Paper presented at 2015 Primary Health Care Research Conference, Adelaide, Australia.

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Thank you to the SA Health staff that helped me in the recruitment for the patient study. In particular, thank you to Kimberley-Ann Kerr. You came to my aid when I was beginning to lose all hope. Thank you to the participants who gave up their time to be interviewed.

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LIST OF ABBREVIATIONS

Abbreviation	Meaning	First appears
AML	Acute myeloid leukaemia	Chapter Six
B2B	Business to business	Chapter Ten
BMC	Business model canvas	Chapter Three
CAMs	Complementary and alternative medicines	Chapter Four
CAS	Complex adaptive system	Chapter Three
CHF	Consumer Health Forum	Chapter Two
COAD	Chronic obstructive airways disease	Chapter Six
CPA	Community pharmacy agreement	Chapter Two
CPAP	Continuous positive airway pressure	Chapter Three
D2C	Direct to consumer	Chapter Ten
DAA	Dose administration aid	Chapter Six
DTP	Drug therapy problem	Chapter One
DVT	Deep vein thrombosis	Chapter Five
FMC	Flinders Medical Centre	Chapter Three
GP	General practitioner	Chapter Two
HCP	Healthcare practitioner	Chapter One
HiMR	Hospital initiated medication review	Chapter Two
HIV	Human immunodeficiency virus	Chapter Six
HMR	Home medicines review	Chapter Two
HOMR	Hospital outreach medication review	Chapter Two
HONC	Haematology and oncology	Chapter Three
ICT	Information and communication technology	Chapter Eight
ICU	Intensive care unit	Chapter Five
JC virus	John Cunningham virus	Chapter Three
LMH	Lyell McEwin Hospital	Chapter Three
MAC	Mycobacterium avium complex	Chapter Six
MBS	Medicare benefits schedule	Chapter Two
MDT	Multidisciplinary team	Chapter Two
MMR	Medication management review	Chapter Two
MMS	Medication management service	Chapter One
MRH	Medication related harm	Chapter One
MS	Multiple sclerosis	Chapter Five

MUR	Medication use review	Chapter Two
NHPA	National Health Priority Area	Chapter Two
NSQHS	National safety and quality health service	Chapter Two
PBS	Pharmaceutical benefits scheme	Chapter Two
PC-MMS	Patient-centred medication management service	Chapter One
PEG	Percutaneous endoscopic gastrostomy	Chapter Four
PF-MMS	Prescription-focused medication management service	Chapter Two
PGA	Pharmacy Guild of Australia	Chapter Two
PhD	Doctor of Philosophy	Chapter One
PICC	Peripherally inserted central catheter	Chapter Four
PICF	Participant information and consent form	Chapter Three
PIMs	Potentially inappropriate medicines	Chapter Two
PPA	Pharmacy Practice Administrator	Chapter Two
PSA	Pharmaceutical Society of Australia	Chapter Two
SHPA	Society of Hospital Pharmacist Australia	Chapter Two
SME	Small or medium enterprise	Chapter One
TQEH	The Queen Elizabeth Hospital	Chapter Three
WHO	World Health Organization	Chapter One

SECTION ONE - THE RESEARCH FOUNDATIONS

Section One: The Foundation	• Chapter One - Introduction • Chapter Two – Literature review • Chapter Three - Methodology

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1 INTRODUCTION

1.1 Chapter introduction

This chapter is all about introductions. It begins by introducing myself, the researcher, and how I came to formulate the research question. The areas of inquiry are then described: the population of interest, the phenomenon of interest and key concepts. Finally, it sets out the research objectives and the structure of the overall thesis.

1.2 Reflexively arriving at the research question

If this PhD were a movie, it would be described as a coming-of-age drama. When I set out on my quest some ten years ago my motivations were quite flippant, as is so often the case in the classic films of this genre that, like me, were born in the 1980s[1]; a mixture of keeping pace with my peers, looking for something to do, and curiosity. I was not looking to build a career as an academic and I had very little idea of what a PhD entailed. I was working as the sole clinical pharmacist in a specialist palliative care unit that was based in a hospital but also provided outreach services to patients in the community. As a newly created position, I was tasked with designing and implementing a pharmaceutical care service. The unit was going through a major restructure at the time, merging two independent services together, resulting in numerous political and logistical challenges. My position did not place anyone else under threat, affording me a large amount of autonomy, which was a blessing and a curse when it came to the research component of the job. My undergraduate pharmacy training and experience in clinical trials had provided me with confidence and competence in quantitative methods, but most of the questions that were arising in my practice seemed better suited to qualitative methodology. After trying my hand with a small study[2] I quickly realised that I had much to learn about how to conduct robust qualitative research. I enrolled in a PhD with the hope of accessing supervision to support the fulfilment of my professional responsibilities and to push me further academically. But in early 2014, just six months full time equivalent into my PhD, I took maternity leave from that position. In order to make room for this new life role I had to decide whether I would return to my previous employment or continue with the PhD. This decision was far from flippant. With much deliberation I decided to resign from my secure, well-paid position in SA Health to become a part-time PhD student

[1] Favourites include: Ferris Bueller's Day Off, Stand by Me, The Goonies

[2] Cortis L, A qualitative study to describe patient-specific factors that relate to clinical need for and potential to benefit from a medication management service in palliative care, JPPR 2017Cortis, L. J. (2017). A qualitative study to describe patient-specific factors that relate to clinical need for and potential to benefit from a medication management service in palliative care. *Journal of Pharmacy Practice and Research*, *47*(1), 34-40. https://doi.org/10.1002/jppr.1147

living on a stipend. By doing so, I was no longer tethered to my research topic. I was now free to explore what I really cared about changing in practice.

My time working in the palliative care unit had a profound impact on my approach to pharmacy practice. In the first week of being in that role I had the privilege of attending a talk by Professor Eric Cassell[3], who spoke about how we need to change our definition of sickness from disease to something that impairs the patient from achieving their goals and purpose in life. This challenged me in the way that I thought about medicines and initiated my interest in medication experience[4] and patient-centred care. In my practice I became increasingly attentive to the ways that people interacted with their medicines, and the ways in which their experiences and beliefs influenced their medication taking behaviour and outcomes. One group of patients I found commonly experienced medication-related issues of this nature were people living with cancer. I will never forget meeting a man in his sixties who was suffering with crippling pain from bone metastases and pancreatic cancer but resisting the use of opioids. On speaking with him, I discovered that he had a past experience of constipation that was so severe he ended up having to go to hospital. He told me he would rather endure pain than risk becoming constipated again. While those concerns were valid, he was also regularly taking another drug that is known to commonly cause constipation and had a questionable indication for use. By considering this man's broader medication regimen and lived experience it was possible to alter his regimen to improve his pain management and manage his risk of constipation in ways that were acceptable to him. I had many examples of these types of encounters when caring for people with cancer, most of whom were also managing a chronic condition[5]. When I delved into the literature, I found that it reflected my clinical experience. There was very little consideration of the overall medication experience of people living with cancer, and what evidence was available suggested that medications used for chronic conditions significantly contributed to the high rates of medication related harm (MRH). I resolved that my research would help to improve

[3] Internationally renowned expert in palliative medicine and author of books including The Nature of Suffering and the Goals of Medicine Cassell, E. J. (2004). *The Nature of Suffering and the Goals of Medicine* (Second ed.). Oxford University Press.
[4] A subjective phenomenon resulting from cumulative encounters with medicines throughout life Hillman, L. A., Peden-McAlpine, C., Ramalho-de-Oliveira, D., & Schommer, J. C. (2020). The Medication Experience: A Concept Analysis. *Pharmacy (Basel)*, *9*(1). https://doi.org/10.3390/pharmacy9010007
[5] Managing a chronic condition and a chronic condition was identified as a patient factor associated with likelihood to benefit from patient-centred medication review Cortis, L. J. (2017). A qualitative study to describe patient-specific factors that relate to clinical need for and potential to benefit from a medication management service in palliative care. *Journal of Pharmacy Practice and Research*, *47*(1), 34-40. https://doi.org/10.1002/jppr.1147

the medication experience of people living with cancer, with a focus on those who were also managing chronic conditions.

Shifting my population of interest from palliative care to cancer and chronic conditions more generally afforded me the opportunity to enlist Professor Bogda Koczwara onto my supervisory team. An esteemed clinician and researcher with interest in cancer survivorship, she challenged me to consider my research through the lens of integrated care[6]. Unfamiliar with this concept, my first port of call was to explore the literature. First, I examined how the concept of integrated care had been applied within cancer research, resulting in my first published literature review (Cortis et al., 2017). Building on this, I explored the relevance of integrated care to cancer practice, resulting in the publication of a book chapter (Cortis et al., 2016). Throughout this exploration, it became obvious to me that the boundary-spanning nature of medication experience and medication management services (MMS)[7] provided a valuable platform for exploring the opportunities to achieve more integrated care in cancer. This thinking formed the foundation for two research activities: a patient interview study and a pharmacist interview study. Both studies were designed to better understand the medication experience of people undergoing cancer diagnosis and treatment and how they are supported by the system of care. At that point, my intention was to gain sufficient understanding to inform the development of a novel intervention specifically designed to meet the needs of people living with cancer.

Once the interview studies were complete and I started immersing myself in the analysis, I started having doubts about the intended outcome of the research. Integrated care is fundamentally about building more connected services, but from my perspective the divisions between hospital and community practice appeared to run too deep to bridge over at any scale broader than local implementation. I had always known these divisions existed; I had felt the frustration and inefficiencies that resulted from it in practice. But I had never before appreciated just how deeply those silos were entrenched. They seemed to be fractal in nature. Whether it be patient care process, remuneration models, technical infrastructure or professional associations, the same types of silos were evident. As I engaged with healthcare practitioner (HCP) colleagues about these issues, I started to realise that there was little appetite to break these silos down. I turned to the literature, undertaking a scoping

[6] Healthcare interventions designed to reduce fragmentations and provide a more seamless care experience Cortis, L. J., Ward, P. R., McKinnon, R. A., & Koczwara, B. (2017). Integrated care in cancer: What is it, how is it used and where are the gaps? A textual narrative literature synthesis. *Eur J Cancer Care (Engl)*, *26*(4), e12689. https://doi.org/10.1111/ecc.12689

[7] Healthcare interventions specifically designed to enhance medication-related outcomes Cipolle, R., Strand, L. M., & Morley, P. (2012). *Pharmaceutical Care Practice: The Patient-centred Approach to Medication Management Services*. McGraw-Hill Medical.

review of patient-centred MMS (PC-MMS) in cancer to see if there were any that breached this divide. Once again, the silos of care were strongly evident, with most interventions designed to fit within the silo of cancer care. What's more, many of these specialist interventions appeared to be less comprehensive than the generic PC-MMS available within the community. I started to wonder if this was one of the reasons that so many people with cancer seem to have medication-related needs that fall through the cracks; do we have an unrealistic expectation that specialist cancer services will meet the entirety of their medication-related needs? By now, the idea of developing a specialist intervention had lost its lustre and I was unsure that my research would be able to offer practical use after all. At this point, Professor Koczwara was amicably withdrawn from my supervisory panel as I decided to pursue an alternate direction.

Despite feeling disheartened, I was far from being without hope. My research findings were indicating that the generic PC-MMS initiatives that existed within the system of care had a lot of value to offer people living with cancer. But it was clear to me that there was a stark difference between having a service available that people could potentially benefit from and delivering services that people wish to actively engage with. This did not feel like a problem of intervention design to me, it felt like a marketing problem. Accepting this as a legitimate line of inquiry took me some time. I have long held prejudices against anything I perceived as fitting within the corporate world, and what could be considered as a certain degree of disdain toward HCPs who pursued profits assuming that this could only happen at the expense of patient care. I had a deep-seated belief that marketing was antithetical to healthcare services. And yet, I could not ignore what the data was telling me.

When I came across the work of Seth Godin[8] I started to feel more comfortable with the idea that marketing could be useful, or even good. Godin argues that you are doing a disservice to your customers (or patients) if you have a product or service that you know can make their lives better but fail to communicate with them to let them know that it is there. This empathetic approach to marketing revolves around serving the needs of a specific audience and is built upon an ethical foundation. Realising that some of my long-held assumptions had been poorly founded, I became more curious to explore other parts of the business literature that I had previously been closed off to. One facet that appeared to have direct

[8] I was first introduced to Seth Godin's work through a podcast episode Ferris, T. (2018). The Tim Ferris Show In *Seth Godin on How to Say "No," Market Like a Professional, and Win at Life (#343)*. https://tim.blog/2018/11/01/seth-godin-this-is-marketing/, which led me to his book *This Is Marketing: You can't be seen until you learn to see* Godin, S. (2018). *This is Marketing: You can't be seen unless you learn to see*. Portfolio. . In September 2020 I participated in a three month online interactive workshop based on the book, The Marketing Seminar created and delivered by Seth Godin Godin, S. (2020). *The Marketing Seminar* [Online participatory workshop]. Akimbo. https://akimbo.com/themarketingseminar.

relevance related to business models and strategy[9], in particular the work of Alexander Osterwalder whose business model canvas makes it easy to understand the practical ways in which businesses (or organisations) can create and deliver value to customers (or patients) (Osterwalder & Pigneur, 2010). This put words to what I had been trying to explain; that health services, just like other businesses, need to strive for product-market fit if they wish to make a positive contribution to patients' lives.

My newfound openness to the world of business and strategic management provided me with some assurance that my research findings could be used to contribute to practical improvements, but I still lacked the scholarly framework to make a clear connection between the data and the results. I explored systems thinking[10] and its foundational fields of cybernetics and system dynamics. This helped me to conceptualise the system of care, but it did not provide the framework for analysing the overall research findings that I needed. On discovering critical realism[11], I thought that I had found what I was looking for. Its realist ontology and relativist epistemology aligned with my philosophical position, and there was considerable overlap with the principles of systems thinking[12]. But as much as critical realism struck an intellectual chord with me, I had a lingering concern that developing a thesis based upon a critical realist approach would result in research findings that would be more theoretically interesting than practically relevant. I was also unsure about the way in which critical realism aligned, or rather conflicted, with my newly developing understanding of complex systems. Identifying underlying causal structures and mechanisms is central to critical realism (Danermark et al., 2019), but complexity science indicates that it is often not possible to attribute causality in a complex system (Cilliers, 1998).

[9] Throughout this reading I discovered the work of Michael Porter, whose writings on integration as a strategy to build competitive advantage are foundational to the concept of integrated care Porter, M. E. (1998). *Competitive Strategy: Techniques for Analyzing Industries and Competitors*. Free Press. , Porter, M. E. (1999). *Competitive Advantage: Creating and Sustaining Superior Performance*. Simon & Schuster. . Porter's later work moved into values-based healthcare Porter, M. E., & Guth, C. (2012). *Redefining German Health Care Moving to a Value-Based System* (1st 2012. ed.). Springer Berlin Heidelberg. https://doi.org/10.1007/978-3-642-10826-6

[10] My initial introduction to systems thinking was through the work of Peter Senge, a business consultant who popularised the application of systems-thinking in the business world through his 1990 book, *The Fifth Discipline: the art and practice of the learning organization* Senge, P. M. (2006). *The Fifth Discipline: The Art & Practice of the Learning Organization*. Doubleday & Co. .

[11] A meta-theory most commonly associated with the work of Roy Bhasker that is concerned with explaining social systems by identifying underlying structures and causal mechanisms Danermark, B., Ekstrom, M., & Karlsson, J. C. (2019). *Explaining Society: Critical Realism in the Social Sciences, 2nd edition*. Routledge. .

[12] John Mingers explores the relationship between systems thinking and critical realism in his book, *Systems Thinking, Critical Realism and Philosophy Mingers, J. (2015). Systems Thinking, Critical Realism and Philosophy: A Confluence of ideas. Taylor & Francis Ltd.*

Like systems thinking, complexity science helped me to conceptualise my interpretation of the system of care but once again my early exposure to complexity did not provide the type of framework I was looking for due to its emphasis on mathematics and computational modelling[13]. Eventually, I came across the work of Dave Snowden[14] and the Cynefin Framework, a tool designed to help decision-makers understand enough about their world in order to recognise how to take appropriate action (Snowden, 2021). Cynefin is built upon a theoretical foundation that Snowden refers to as anthro-complexity, the study of complexity in human systems (Snowden, 2021). This theory and pragmatic approach aligned closely with my needs, providing exactly what I had been looking for to bring everything together into a unified explanation and refinement of the research question.

1.3 The research question

The overarching research question addressed by this thesis is:

What feasible actions can be taken within the system of care to improve the medication experiences of people who are independently using medicines throughout cancer diagnosis and treatment?

1.4 Areas of inquiry

This thesis asserts that achieving a significant reduction in MRH requires a system of care that is intentionally designed to enhance medication experience. In the following section we will introduce the population of interest and key concepts that constitute the areas of enquiry for this research. This has been represented schematically in Figure 1.

[13] The Santa Fe Institute (SFI) is broadly regarded as the international hub of complexity science. They offer a range of no or low cost online courses in complexity through ComplexityExplorer.org, including the Introduction to Complexity which covers the foundations of complexity science, much of which relates to complex mathematics and computational modelling Ortolano Guisasola, S. (2021). *Introduction to complexity* Santa Fe Institute. https://www.complexityexplorer.org/

[14] Dave Snowden is a business consultant with a background in philosophy and knowledge management. I first encountered Dave Snowden's work through a podcast episode which led me to the suite of resources made available through Cognitive Edge Cognitive Edge. (2021a). *Cognitive Edge: The Cynefin Co*. Cognitive Edge. Retrieved October 21st from https://www.cognitive-edge.com/, including self-directed short online courses Cognitive Edge. (2021b). *Cynefin 101: Getting started* [Online course]. Cognitive Edge. , Cognitive Edge. (2021c). *Cynefin 102: Models & decision making* [Online course]. Cognitive Edge. , Cognitive Edge. (2021d). *Cynefin 110: Domain models (3x3)* [Online course]. Cognitive Edge. and an four day online workshop which I participated in during August 2021 Cognitive Edge. (2021e). *Cynefin Basecamp* [Participatory online workshop]. Cognitive Edge. .

1.4.1 The population of interest

This thesis explores the medication experience of a specific population: adults who independently use medicines to manage a chronic condition throughout cancer diagnosis and treatment. Around half a million Australians have experienced a cancer diagnosis within the past five years (AIHW, 2023), with an estimated 165,000 people being diagnosed within this calendar year (AIHW, 2023). Nearly two thirds of these people will also be managing one or more chronic conditions (Ng et al., 2023), a higher prevalence than the general population (Ng et al., 2018). The result is a growing population that is vulnerable to experiencing MRH. Indeed, people living with cancer experience higher rates of MRH than the general population, with three times higher incidence of medication-related hospital admission (Chan et al., 2014; Miranda et al., 2011; Roughead et al., 2016)(9-11). These statistics reflect my experience in practice which, as previously described, was the original reason for choosing this as the population of interest for this research (Cortis, 2017).

1.4.2 The patient world

Medication use occurs within what we will refer to as the *patient world*. Selection of medicines, decisions on how they are used, and the good and bad effects that result; none of these can exist without the patient.

1.4.2.1 Medication management

The terms *medicine* and *medication* are used interchangeably within this thesis, used to refer to any substance that is used with the intent of enhancing someone's physical or mental health or wellbeing, including prescription, non-prescription, investigational, clinical trial and complementary medicines (Commonwealth of Australia, 2022a). The term *medication management* is used as an overarching term, used to describe the variety of activities associated with the use of medicines, such as the way in which medicines are selected and prescribed, how they are accessed and used, and how they are stored and disposed of (Commonwealth of Australia, 2022a). These activities may be undertaken by the individual, their care provider, or the health system more broadly.

1.4.2.2 Medication related harm (MRH)

Any time a medicine is used it has the potential to result in harm. To some degree, the extent of MRH that is experienced by people living with cancer can be quantified through objective measures such as incidence of unplanned hospital admissions, adverse drug events and medication errors. Indeed, this is the way in which MRH is most commonly represented in the medication safety literature. This perspective on MRH, as something that can be objectively quantified, has influenced practice where this data has long been used to

argue for investment in medication safety initiatives (Runciman et al., 2003). Recognition of the need to reduce preventable MRH arose as part of the patient safety movement which began to gain traction during the 2000s following the landmark Institute of Medicine report *To Err is Human* which recognised the harms that resulted within the system of care through errors, accident and miscommunication *(2000)*. Underpinning this movement was Reason's Human Error theory, commonly referred to as the Swiss Cheese Model (Reason, 2000). The model introduced a systems-based approach to safety, identifying two sources of incidents: active failures and latent conditions. Based on an understanding that "we cannot change the human condition, but we can change the conditions under which humans work", the focus of the model is to change the design of the system to proactively alter latent conditions by introducing layers of defences, barriers and safeguards that target behaviours at individual, team, task, workplace, and the institutional levels (Reason, 2000). As a result, medication safety roles have become embedded into the system of care through pharmacy practice and other activities designed to reduce the risk associated with medication supply and transfers to and from institutional settings. This approach was strengthened in 2017 when the World Health Organization (WHO) made medication safety a priority patient safety area (WHO, 2019). In response, the Australian Commission for Safety and Quality in Healthcare (ACSQHC) set a goal *"to reduce medication errors, adverse drug events and medication-related hospital admissions by 50% by 2025"* (ACSQHC, 2020a). They put forward a collaborative approach focused on addressing inappropriate pharmacy, reducing harm from high-risk medicines, and improving medication safety at transitions of care.

There is no doubt that reducing the harms that are inflicted on patients by the system of care is a noble and worthwhile pursuit, but when it comes to MRH, the harms that occur within institutionalised settings represent just the tip of the iceberg. MRH includes more than that which can be objectively measured. It includes subjective elements that impact patients everyday experiences. These intangible aspects of MRH have been captured by the WHO definition of harm:In the system, harm is considered to be the impairment of structure or function of the body and/or any deleterious effect arising from, or associated with, plans or actions taken during the provision of primary health care. It includes disease, injury, suffering, disability, and death and may be physical, psychological, or social. (Cooper et al., 2018)

Cooper et al included these lesser recognised psychological and social aspects of harm in their definition to acknowledge the impact that incidents such as hospitalisations and medication-related issues have on the patient's lived experience (Cooper et al., 2018). Such effects of MRH can be long-lasting, and may extend beyond the individual patient

themselves, indirectly impacting family members or even HCPs through vicarious trauma. Recognising and addressing these subjective aspects of MRH is important because they shape the patient's medication experience and the ways in which patients engage with medication-related aspects of care (Cipolle et al., 2012).

1.4.2.3 Medication experience

Medication experience is the term used to describe the way that people make meaning of their experiences with medicines (Shoemaker & Ramalho de Oliveira, 2008). An internally constructed phenomenon, it is shaped by an external reality of medication-related events and experiences (Hillman et al., 2020). This reality is comprised of the innumerable medication-related encounters that accumulate throughout a lifetime (Cipolle et al., 2012). The way your mother gave you medicine at the slightest sign of a cold or fever as a child. Observing changes in a friend's behaviour after he was started on antidepressants. Reading an article in a glossy magazine about a celebrity who overdosed on opioids. Choking as you swallowed your morning dose of medication. We continually make meaning of medication-related encounters throughout our lives, and thus our medication experience is constantly evolving (Hillman et al., 2020). If quantitative data like medication-related hospital admissions and prevalence of adverse drug reactions represent the tip of the MRH iceberg, medication experience gives an idea of what lurks beneath, revealing insights into the MRH encountered as part of everyday life. Medication experience both influences and is influenced by medication-related outcomes. Because of this, it provides valuable insights into the presence of MRH that must be responded to and managed, as well as the potential for MRH that should be anticipated and monitored. One such area of insight relates to the patient's medication taking behaviour.

Medication taking behaviour

Patients who are prescribed medications regularly make decisions about how they choose to use them. We know that around half of people do not take their medications as prescribed, and around two thirds of this relates to intentional patient behaviour (WHO, 2003). A patient's medication taking behaviour directly impacts their health outcomes and resultant medication experience. If someone uses a dose of medication that is too low, they are less likely to achieve the intended benefit of the medicine. If someone uses a dose that is too high, they are more likely to experience side effects and toxicity. Both situations can negatively impact medication experience and future medication taking behaviour. One of the most obvious causes of inappropriate dosing is when a patient is non-adherent to an appropriately prescribed medication. However, prescribing of a medication regimen that is not appropriate for the patient's needs is also an important cause of inappropriate dosing

(Cipolle et al., 2012). In these circumstances, a patient's adherence to the prescribed medication regimen could be problematic, and intentional non-adherence could be considered consequence of poor medication experience and indication of an underlying *drug therapy problem* (DTP) (Cipolle et al., 2012).

Drug Therapy Problems

DTPs are the way in which HCPs who are providing MMS describe the underlying medication-related issues they identify that have either resulted in, or have the potential to result in, MRH. In their seminal 2012 text, Cipolle et al describe DTPs as the unmet medication-related needs of an individual that require professional judgement to resolve (Cipolle et al., 2012). They described seven categories of DTP as outlined in Table 1. Of these seven categories, non-adherence with an appropriately prescribed medication regimen is only category of DTP that results from the *actions of the patient* regarding their willingness or ability to use medication as prescribed (Cipolle et al., 2012). The remaining six categories of DTP all result from the *actions of the drug on the patient*, either relating to its indication (or lack thereof), insufficient efficacy, or safety (Cipolle et al., 2012). In their 2012 paper, Ramalho-de Oliveira and colleagues describe the utility of medication experience for pharmacists undertaking MMS, arguing that elucidating medication experience allows the pharmacist to identify and resolve underlying DTPs that would otherwise go unnoticed (Ramalho-de Oliveira et al., 2012). Examples of how the patient's narrative medication experience may relate to underlying DTPs are detailed in Table 1. This connection between medication experience and the HCPs identification and resultant management suggests that medication experience is a phenomena that can be recognised and influenced by HCPs within the system of care.

Table 1: Types of Drug-related problems (DTPs)

Drug-related need	Categories of DTP	Example of how the DTP may be expressed within a patient's narrative (the medication experience)
Indication	Unnecessary drug therapy Needs additional drug therapy	"I'm not sure why I still take that one, I haven't had any reflux for years"
Effectiveness	Ineffective drug Dosage too low	"I take it just like it says on the box, but it doesn't seem to do anything much"
Safety	Adverse drug reaction Dosage too high	"I feel a bit zonked out to be honest. Like I can't keep my eyes open even early in the day after I've had a good sleep"
Adherence	Unable or unwilling to use as intended	"I know I'm supposed to take it every day but when I do it makes me have to go to the toilet so urgently that I don't take it on days when I'm going out somewhere"

1.4.3 The system of care

The system of care interfaces with the patient world through the patient's interactions with HCPs and service providers. The extent and quality of these interactions is influenced not only by the patient's decisions, but also those of the HCPs. As we know from the social science concept of structure and agency, the actions of individuals are not solely determined by personal identity and acts of self-determination but are also shaped by systemic structures. Registered HCPs face a variety of structural clinical and corporate constraints imposed by regulatory bodies and employing organisations. Some of these are universal, defined at the macro- or policy-level such as legislation, ethical and professional standards of practice, and regulatory frameworks. Other structural constraints are defined at the meso- or service provider level, such as a local medicines formulary within an institution, policies and procedures, business strategy and operations.

Whether the HCP be employed as a sole trader, work for a small or medium enterprise (SME) or a large institution, three general levels of corporate decision-making remain evident: strategy, management, and operations. Each of these levels of corporate decision-making represent constraints that influence the behaviour of HCPs within the patient care setting. Strategic decision-making defines what an organisation intends to achieve and how it will go about achieving it. Mid-level decision-making is concerned with managing the implementation of the strategy by deciding upon the model of care or business model that will form the basis of the organisations operations. The lower-level or "on the ground" decision-making relates to operationalising the plan by executing the work. This operational level includes the clinical decisions made by HCPs as part of patient care, but also involves essential non-clinical aspects of care that are often the patients entry point into an interaction with the HCP, such as booking systems and referral pathways. Who is involved in these levels of decision-making will depend on the corporate structure of the organisation; a large institution will likely have an elaborate organisational structure with clear delegations, while an SME may require an individual to fulfil multiple decision-making roles within the organisation. The challenge this presents when it comes to identifying ways in which to improve the system of care is that a large proportion of healthcare organisations are privately owned not-for-profit or for-profit businesses that are each have their own set of corporate constraints. Understanding the ways in which the system of care constrain these independently owned and operated service providers is critical to identifying feasible opportunities for system intervention.

1.5 The research objectives

The overarching aim of this research was to identify feasible actions that can be taken within the system of care to improve the medication experiences of people who are independently using medicines throughout cancer diagnosis and treatment. This was examined through the conduct of three separate but inter-related research activities: a patient interview study, a pharmacist interview study, and a scoping literature review.

In combination, the research activities addressed the research question by meeting the specific objectives listed below.

1. Understand how cancer diagnosis and treatment alters the nature of reality in the patient world by interpreting the experiences of patients and pharmacists:
    1.1. Detail the ways in which cancer impacts patients workload associated with using medicines and their capacity to fulfil it.
    1.2. Recognise the types of medication-related issues encountered throughout cancer diagnosis and treatment.
    1.3. Examine the tactics employed by patients and their care providers in response to medication-related issues and how they impact on achieving timely and appropriate management.
2. Analyse the system of care that supports the medication management of Australians living with cancer:
    2.1. Critically compare the empirical evidence assessing PC-MMS in non-hospitalised adult cancer populations with generic community-based services.
    2.2. Characterise the roles of MMS providers within the system of care.
    2.3. Describe the constraints placed on pharmacists who provide MMS available to people living with cancer.

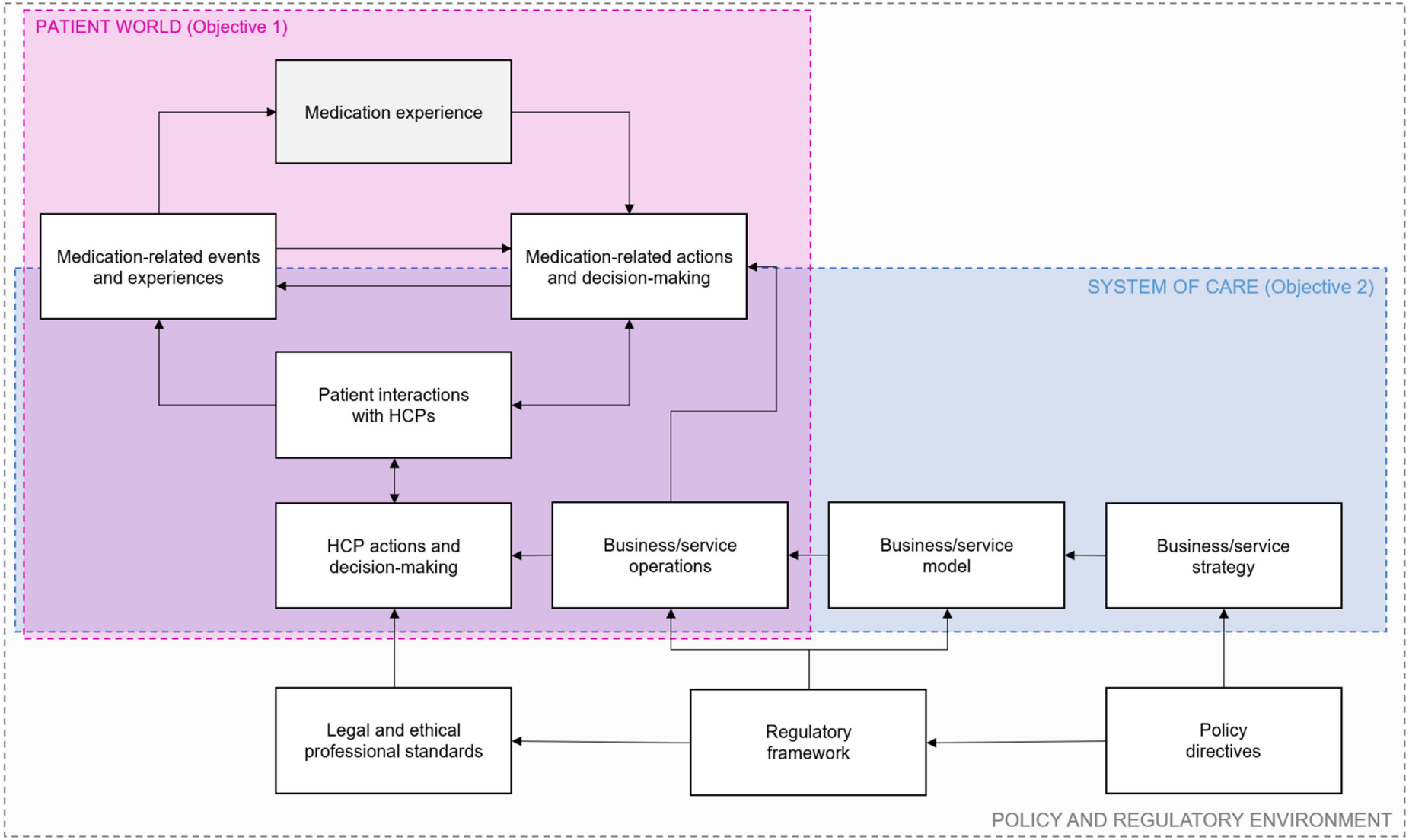

Figure 1: The areas of inquiry - the patient world and system of care

1.6 Structure of the thesis

The thesis is presented in three sections, as illustrated in Figure 2. **Section One: The Foundation** covers the foundations of the research. Chapter One has provided a contextualised introduction to the areas of inquiry, introducing the population of interest, central phenomenon of interest and detailing the research question and objectives. Chapter Two examines the literature relating to medication experience within the cancer population and identifies the gaps that exist. It also explores the reasons why the cancer population is at risk of MRH, and how MMS help to address this. Chapter Three provides a reflexive description of the research approach, articulating the philosophical assumptions that underpin the research and detailing the rationale behind the choice of methods. **Section Two: The Findings** presents and discusses the research findings in two parts. **Part A: The patient world** enriches our understanding of how cancer diagnosis and treatment changes the nature of reality in the patient world with a focus on medication experience. Chapter Four addresses objective 1.1, explaining how cancer impacts the work and capacity associated with medication use. Chapter Five addresses objective 1.2, detailing the types of medication-related issues encountered throughout the cancer journey. Chapter Six addresses objective 1.3, examining the tactics employed by patients and their care providers in response to medication-related issues. **Part B: The system of care** allows us to understand the system of care that supports the medication management of Australians living with cancer. Chapter Seven addresses objective 2.1, critically comparing the PC-MMS initiatives reported in the cancer literature to the generic programs that are readily available. Chapter Eight addresses objective 2.2, characterising the roles of MMS providers. Chapter Nine addresses objective 2.3, describing the constraints placed on pharmacists providing MMS within the system of care. Finally, **Section Three: The Insights** brings the research findings together to address the overall research question. Chapter Ten applies a strategic management lens to identify feasible actions that can be taken within the system of care to enhance the medication experience of Australians living with cancer. Chapter Eleven brings the thesis to its conclusion, offering a personal reflection on the original and significant contribution to research that it makes.

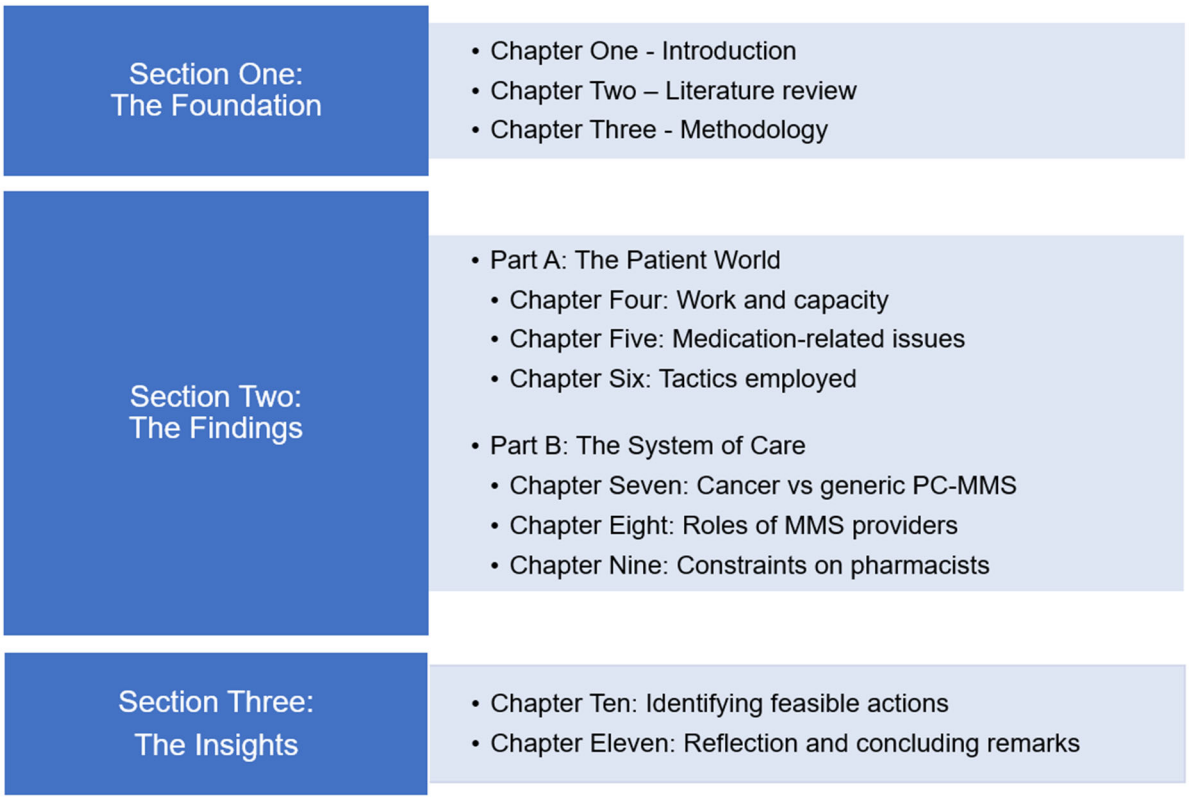

Figure 2: Thesis structure

1.7 Chapter summary

This chapter introduced the thesis and the context in which the work has taken place. It has introduced me, a researcher led by clinical curiosity with a hope to contribute knowledge that can be used in practice to achieve better patient outcomes, a purpose that underpins the philosophical foundations of the PhD. The chapter has also introduced the areas of inquiry of this thesis, describing how achieving a greater understanding about the medication experience of people who are independently using medicines to manage a chronic condition during cancer diagnosis and treatment can help to design a system of care that reduces MRH. Finally, it has explained how the thesis increases our knowledge of medication experience in cancer and identifies feasible opportunities to take action within the system of care by exploring multiple perspectives: the patient world, the system of care, and the interface between the two. The following chapter will focus further on the research problem and explore the literature related to medication experience of the cancer population and show some of the reasons why they are so likely to experience MRH.

2 LITERATURE REVIEW

2.1 Chapter Introduction

Chapter One explained how understanding more about the medication experience of people living with cancer and co-existing chronic conditions is integral to designing a system of care that results in minimal MRH. This chapter looks at what is already known within the literature. It begins by exploring how the concept of medication experience exists within the literature more broadly and then examine how the concept has been explored within the cancer literature, identifying the gap in the literature that this thesis helps to reduce. Following this, the reasons why MRH is experienced more commonly by people living with cancer that the general population are explored, considering the nature of medicines use, the nature of the population, and the nature of contemporary cancer care delivery. Next, it takes a closer look at MMS; the types of initiatives provided, the approach to implementing MMS initiatives in Australia, and some of the factors that are known to influence the actions of MMS providers and patients. To conclude the chapter, the focus is turned toward the ways in which we can take action within the system of care to produce different outcomes, introducing strategic management as a field that offers concepts that are equally applicable to healthcare systems as they are to corporate industry.

2.2 Medication experience

2.2.1 Medication experience as a concept in the literature

Medication experience is an emerging concept within the medical literature. While aspects of the lived experience of using medicines has been reported for many years, medication experience was first used as a conceptual term by Shoemaker and de Oliveira in their 2008 paper *Understanding the meaning of medications for patients: the medication experience* (Shoemaker & Ramalho de Oliveira, 2008). The paper introduced medication experience as a practice concept that pharmacists could utilise to provide more patient-centred care. Shoemaker and de Oliveira further this argument in their further work where they demonstrated the link between medication experience and underlying DTPs and the practical utility that it has in preventing MRH (Ramalho-de Oliveira et al., 2012; Shoemaker et al., 2011). Cipolle, Strand and Morley included reference to this work in the third edition of their aforementioned text detailing the patient centred approach to medication management which they refer to as the *pharmaceutical care philosophy of practice*[15] (Cipolle et al., 2012).

[15] This is unsurprising given that Strand and Morley co-advised both Shoemaker and de Oliveira in their PhDs at the University of Minnesota during the early 2000s.

As a result, the concept of medication experience can be considered to have permeated pharmacy practice research that has foundations in pharmaceutical care without necessarily being noted by the researchers as a foundational concept.

In 2021, Hillman and colleagues conducted a concept analysis to broaden understanding and develop an interdisciplinary definition of medication experience (Hillman et al., 2020). They conducted a literature review of studies reporting the perspectives of adult patients taking medicines in an ambulatory setting, excluding patients who were receiving palliative or end of life care. The review developed the following definition:

> *The medication experience is defined as an experience of ambivalence and vulnerability in which the patient is actively engaged in an ongoing process or negotiation, which is pragmatic to the ways in which patients live and experience life, contextualized and nuanced within the social construction of their individual realities*. (Hillman et al., 2020)

This definition and list of attributes helps in discerning the literature relating to medication experience. The review distinguishes between surrogate terms which can be used interchangeably with medication experience, and related concepts which have a relationship with medication experience but possess different attributes (Hillman et al., 2020). Surrogate terms listed in the review are “medication-taking experiences”, “medicines use”, “medication taking practices”, “medication practice” “meaning of medications”, and “medication-related experiences”, while the related concepts specifically noted in the review are “medication-related needs”, “medication taking behaviour” and “medication adherence” (Hillman et al., 2020).

2.2.2 Medication experience in cancer

There is a dearth of literature exploring the medication experience of people living with cancer. Of the 66 studies included in Hillman et al’s review, just one was conducted in a cancer population (Hillman et al., 2020). In addition to Gassmann et al’s study included in the review, further searching has identified three additional studies that explore medication experience in cancer: Stoner et al’s 2010 study (Stoner et al., 2010) which would not have met the inclusion criteria due to the palliative care population, Talens et al’s study (Talens et al., 2021) and Liu et al’s study (Liu et al., 2022), which were published after the literature review had been completed. Gassmann et al’s 2016 study interviewed six adult patients who were independently using oral chemotherapy to treat a diagnosed cancer (Gassmann et al., 2016). The interviews which specifically focused on the experience of using chemotherapy found that self-administering oral chemotherapy for cancer resulted in participants feeling as though they had conflicting priorities as they balanced the responsibility for implementing the medication regimen against the challenges of daily life. Talens et al’s 2021 study also

explored the medication experience of adults who were independently using oral chemotherapy to treat a diagnosed cancer, consisting of focus group discussions with 23 patients (Talens et al., 2021). As with Gassmann's study, focus group questions concentrated on the experience of using oral chemotherapy as well as practical aspects of overall medication use that affected adherence. They found that patients' emotional burden and motivation relating to their disease and medications impacted their adherence to oral chemotherapy, finding that patients were willing to put up with adverse effects if it was balanced by a perceived need for the treatment[16]. One of the factors that influenced these beliefs was access to information about the treatment. Stoner et al's 2010 study comprised of "brief interviews" of eleven adults with late-stage cancer who were independently using multiple medications in the home setting, ten of whom were receiving palliative chemotherapy (Stoner et al., 2010). The study appears to have explored the overall medication experience of participants, however the lack of detail within the published study limits it usefulness. Liu et al's most recent study looked at the experiences of people using oral-targeted therapy to treat lung cancer in China (Liu et al., 2022), based on semi-structured interviews conducted with 16 patients and 7 family caregivers. They found a diverse range of factors influenced non-adherence, including intentional and non-intentional behaviours. Three main themes were identified: cancer-related distress, inadequate social support, and forgetfulness. This study demonstrates the complex nature of non-adherence and its relationship to medication experience.

2.2.2.1 Literature exploring related concepts

When it comes to concepts that are related to medication experience, the body of literature is larger, mainly owing to the research focused on medication adherence. But even within this research, the use of qualitative methods to examine the patient lived experience remains scarce. This becomes starkly evident when looking at the systematic reviews that have examined factors influencing medication adherence in cancer populations (Lin et al., 2017; Mathes et al., 2014; Puts et al., 2014; Verbrugghe et al., 2013). Mathes et al's 2014 review examining adherence influencing factors in patients using oral chemotherapy excluded qualitative studies from the analysis (Mathes et al., 2014). A similar review conducted by Verbrugghe et al did include qualitative studies but identified just one study out of the twenty-five included, examining adherence to oral chemotherapy in patients with breast or colorectal cancer (Regnier Denois et al., 2011). The authors noted the lack of qualitative studies as

[16] This finding fits with Horne's necessity and concerns framework Horne, R., Chapman, S. C., Parham, R., Freemantle, N., Forbes, A., & Cooper, V. (2013). Understanding patients' adherence-related beliefs about medicines prescribed for long-term conditions: a meta-analytic review of the Necessity-Concerns Framework. *PLoS One*, *8*(12), e80633. https://doi.org/10.1371/journal.pone.0080633 .

being remarkable, acknowledging that qualitative designs are able to capture a more comprehensive understanding of the factors and processes associated with adherence (Verbrugghe et al., 2013). Puts et al's 2014 review of 22 studies examining factors influencing adherence in older adults with cancer found similar results. They also identified a single qualitative study[17], noting how it elicited factors that were otherwise unrecognised through quantitative studies, such as changes in regular routine and the convenience of dosing schedules (Puts et al., 2014). Quantitative methods and a positivist methodology dominate the literature on medication taking behaviour in cancer. An apparent exception to this within the cancer literature relates to studies conducted in the breast cancer and chronic myeloid leukaemia populations.

There is a growing body of qualitative evidence exploring patient experiences of using medicines in breast cancer, predominantly focused on the use of oral hormonal agents. Lin et al's 2017 review specifically examined psychosocial motivators and barriers to adherence in people with breast cancer. They identified three qualitative studies, which they note as having "provided rich insights about patient psychology and rationale beyond numbers", by examining how participants emotions and perceptions impacted not only directly impacted their medicines use, but also indirectly through their relationships with HCPs (Lin et al., 2017). In 2018 Lambert et al published an integrative review of patient-reported factors associated with adherence to hormonal therapy after breast cancer. They reviewed the findings of 43 manuscripts including 9 qualitative studies with a total of 379 participants. They noted the complementary value of qualitative and quantitative research in this field. Quantitative studies identify statistically significant factors, while qualitative studies provide critical context (Lambert et al., 2018). These ideas were further developed by Clancy et al, who in 2020 published a qualitative evidence synthesis of all available research on breast cancer patients' experiences relating to adherence to oral endocrine therapies. Twenty-four studies published between 2010 and 2018 were included in the synthesis, with a total of 577 participants. They found that fear was often the driving factor behind participants medication taking behaviour, something that can be exacerbated by missing information and inadequate knowledge (Clancy et al., 2020). Peddie et al published a similar review in 2021, exploring the impact of medication side effects on adherence to hormone therapy in breast cancer survivors. They identified four themes as having a significant influence on adherence to hormonal therapies: daily impact of side effects, role of HCPs, managing side effects and weighing up the pros and cons (Peddie et al., 2021).

[17] The same study identified by Verbrugghe et al

There is also a small body of qualitative evidence emerging within the literature exploring the experiences of people using tyrosine kinase inhibitors. Hewison et al's 2020 review examined the experiences of adults using tyrosine kinase inhibitors to manage chronic myeloid leukaemia. Nine qualitative studies were included, with three overarching themes identified: disease impacts whole life, disease management strategies, and valued aspects of care (Hewison et al., 2020). Importantly, they found that when patients experience side effects and related issues within the home setting, they often develop their own strategies to manage them which may not be disclosed to HCPs. Pin and colleagues recently published a similar review, looking at qualitative studies assessing chronic myeloid leukaemia patients experiences with tyrosine kinase inhibitors (Cachafeiro Pin et al., 2023). Despite not being published in English, it could be seen that no further qualitative studies have been reported in this patient population since Hewison et al's review.

2.2.3 The gap in the literature

The literature shows that medication experience and medication taking behaviour are inter-related concepts and social phenomena that benefit from qualitative and quantitative research methods. There is an obvious and critical gap in the literature pertaining to the lived experience of using medicines throughout cancer diagnosis and treatment, with a paucity of literature addressing the concept of medication experience in cancer. Of the three studies identified that explore medication experience in cancer, two concentrated on the use of oral chemotherapy agents and the third was conducted in a palliative population. Similar gaps are seen within the literature exploring the related concept of medication adherence. Of the few studies that do elicit the patient experience of using medicines, the vast majority are examining the experience of women with breast cancer who are taking oral hormonal therapies or patients with chronic myeloid leukaemia who are taking tyrosine kinase inhibitors. There is a near absence of literature exploring why or how cancer influences patients' overall medication taking behaviour. To understand the relevance of this gap and the need for research that considers the overall medication experience of people living with cancer rather than siloed components of it, we must look at the literature on MRH in cancer more generally.

2.3 Cancer: The perfect storm for medication-related harm

People who are living with cancer experience higher rates of MRH than the general population. Miranda at al's 2011 study in a Brazilian hospital found that MRH was associated with 8.5% of all hospital admissions and 13% of unplanned admissions within the oncology population (Miranda et al., 2011). Chan et al's 2014 study in Singapore found similar results, finding MRH to be the cause of 12.4% of all oncology admissions (Chan et al., 2014). By comparison, Australian data indicates that medicines result in 2 to 3% of unplanned hospital admissions each year across the general population, resulting in approximately 250,000 admissions with an associated cost of $1.375 billion (PSA, 2019). In many ways, it is not surprising that MRH is higher within the cancer population. The medicines used, the demographics of the population and the fragmented nature of contemporary cancer care create somewhat of a perfect storm for MRH.

2.3.1 The Nature of Medicines Use

2.3.1.1 Chemotherapy and narrow therapeutic range

Ask someone on the street what they know about cancer and they are likely to mention chemotherapy and its toxic effects. As such, some may consider MRH an inevitability in cancer treatment. And in many cases, they are right. Chemotherapy agents are commonly used as part of anti-cancer treatment. As drugs with a *narrow therapeutic index,* finding the dose that produces the desired effect for the patient while minimising toxicity is challenging. Because of this, they carry a high degree of drug-related risk. But while some degree of MRH associated with chemotherapy agents may be unavoidable, evidence examining medication-related hospital admissions in cancer populations shows that around half is potentially preventable (Chan et al., 2014; Miranda et al., 2011). One example of this is febrile neutropenia, the most common cause of medication-related hospital admissions in oncology populations (Chan et al., 2014; Miranda et al., 2011). Studies show that the incidence of febrile neutropenia can be reduced through early use of growth colony stimulating factors in high-risk patients who are receiving chemotherapy (Lyman & Poniewierski, 2017). Identifying these high-risk patients in practice though is not clear cut as there are no consensus guidelines. One factor that is recognised as contributing to the risk of febrile neutropenia are medications used of non-cancer conditions that also cause myelosuppression (Lyman et al., 2011). This is an example of a drug interaction which can be proactively identified and managed by the system of care in order to reduce the risk of MRH.

2.3.1.2 Drug interactions

Combined use of chemotherapy and other drugs resulting in myelosuppression is an illustration of an additive pharmacodynamic drug interaction[18].These types of interactions where adverse effects accumulate or are potentiated by drug combinations are particularly problematic within cancer where toxicity is not just unpleasant for the patient but in some cases, like peripheral neuropathy, can also limit cancer treatment options. Other times, medicines work at cross-purposes, reducing each other's efficacy. One example of this commonly encountered within the cancer setting is the concomitant use of antioxidants like vitamin C during chemotherapy, where there is concern that the agents may negate the effect of the chemotherapy.

Other drug interactions are *pharmacokinetic*[19] and *physiochemical*[20] which are particularly problematic for narrow therapeutic index drugs like chemotherapy agents[21]. There are many examples of chemotherapy agents that are susceptible to drug-drug interactions (Carcelero et al., 2013). It is therefore not surprising that the frequency of drug interactions within cancer populations is quite high, with studies estimating around one third of ambulatory cancer patients have a medication regimen containing at least one potential drug-drug interaction (Riechelmann & Del Giglio, 2009). Koubaity et al's recent study found that 45% of cancer patients who had an unplanned hospital readmission within 30 days after discharge or cancer treatment were prescribed medicines that included a D-type interaction that indicated the need to modify treatment, and 10% included an X-type drug interaction indicating a combination that should be avoided (Koubaity et al., 2021). While these interactions commonly involved chemotherapy agents, non-chemotherapy drugs are also implicated. Miranda et al's 2011 study found a low incidence (2%) of drug interactions causing unplanned hospital admission in people with cancer, but two thirds of these involved a high risk drugs that were not chemotherapy agents (Miranda et al., 2011).

[18] Pharmacodynamic drug interactions, also known as *drug-patient interactions,* occur when one drug or other substance changes the way that a patient is affected by another drugs or substances, either by increasing the effect or opposing it.
[19] Pharmacokinetic drug interactions occur when a drug or other substance (including food) impacts the amount of drug available to have its effect in the body, either by altering the way that the body handles the drug
[20] Physiochemical drug interactions, also called pharmaceutical occur when substances directly react with one another
[21] Drug-drug interactions that result in an increase in drug concentration have the potential to result in greater toxicity, while interactions that reduce drug concentration may mean that it is unable to achieve the desired therapeutic effect.

2.3.1.3 High risk drugs

The Australian Commission of Safety and Quality in Health Care (ACSQHC), classifies seven groups of medicines as high-risk due of causing harm, represented by the acronym "APINCH" (ACSQHC, 2019a) . Each of these groups of high-risk drugs are commonly used at various phases of the cancer care continuum. High risk antimicrobials ('A') vancomycin and gentamicin are commonly used in the treatment of febrile neutropenia, while amphotericin is used to treat opportunistic infections. Potassium and other electrolytes ('P') are used to manage the effects of chemotherapy. Insulin ('I') is used routinely in protocols for managing the effect of corticosteroids on patients with diabetes, Narcotics (opioids) and sedatives ('N') are used peri-operatively, as part of pain management, and to manage other symptoms such as breathlessness and agitation in palliative care. Chemotherapy agents ('C') are administered not only parenterally during the acute treatment phase but may also be administered orally over a long-term period in the home setting. Heparin and other parentally administered anticoagulants ('H') are used routinely in peri-operative settings to prevent venous thromboembolism associated with surgery. As such, people with cancer may be at risk of experiencing MRH related to high-risk drugs throughout the entirety of the cancer journey, especially when they are using medicines to treat coexisting chronic conditions.

2.3.1.4 High number of drugs

The nature of medicine use within the setting of cancer means that an increase in the number of prescribed drugs can be expected. Cancer and its treatment modalities often result in a range of symptoms and ailments which are commonly managed through the use of additional medicines. Sometimes these medicines produce side effects themselves. This process of new drugs being added to counteract the adverse effects of other drugs is referred to as a *prescribing cascade* (Kalisch et al., 2011). One of the unintended outcomes of this is *polypharmacy*.

Within the cancer literature, polypharmacy is typically defined as the regular use of five or more medicines (Mohamed et al., 2020; Turner, McKinnon, et al., 2016). Polypharmacy is considered problematic because it increases probability of drug-drug interactions and adverse drug reactions (Turner, McKinnon, et al., 2016). The prevalence of polypharmacy in cancer populations is unclear. Reported rates range from 2% to 80% depending on the population being studied and definition of polypharmacy being used (Mohamed et al., 2020). Two factors commonly associated with higher rates of polypharmacy are older age and presence of multiple chronic conditions, both of which are becoming increasingly common within cancer populations.

2.3.2 The Nature of the Population

2.3.2.1 Older people

Just like the general population, the demographics of Australia's cancer population are shifting to be older and with a greater prevalence of chronic disease, with more than half of newly diagnosed cancers occurring in people aged 65 years (AIHW, 2023). Two systematic reviews with meta-analysis have examined the association between polypharmacy and outcomes in older people with cancer (Chen et al., 2021; Mohamed et al., 2020). Both found an association between polypharmacy and postoperative complications, including readmission and occurrence of post-operative delirium. Chen et al conducted an additional meta-analysis which also showed statistically significant associations between polypharmacy and all-cause mortality, hospitalization and treatment-related toxicity (Chen et al., 2021).

2.3.2.2 Multimorbidity

Nearly two thirds of Australian cancer patients have *multimorbidity*, meaning that they are managing at least one chronic condition throughout their cancer diagnosis and treatment, with 21% of cancer patients managing three or more (Mohamed et al., 2020). Evidence shows that people with multimorbidity have higher rate of cancer-related deaths and all-cause mortality than those managing cancer as a single condition (Sarfati et al., 2016). At this stage we have limited understanding of how and why this occurs. Possible reasons for higher cancer-related deaths put forward in the literature relate to an individual's fitness for treatment. People with multimorbidity are less likely to receive adjuvant chemotherapy, more likely to receive less dose, more likely not complete chemotherapy treatment when initiated (Sogaard et al., 2013).

Patients with conditions that have modifiable risk factors have been found to have higher rates of all-cause mortality (Grunfeld & Earle, 2010). The precise reasons are unclear. Following a cancer diagnosis there appears to be a shift in focus on cancer needs compared with non-cancer needs that persists into survivorship, resulting in lesser quality care for comorbid conditions that the general population (Earle & Neville, 2004; Jabaaj et al., 2012). This is particularly significant in cancers with a good prognosis, such as post-menopausal breast cancer patients where the predicted ten-year risk of cardiovascular disease was equivalent to or higher than breast cancer recurrence risk (Bardia et al., 2012; Read et al., 2004).

Medicines are a primary treatment modality for chronic conditions; thus it is increasingly common for people to be using medicines for non-cancer indications at the time of being diagnosed with cancer. As has been described, these medicines have the potential to interact with medicines used in cancer care, potentially resulting in excessive toxicity or

reduced efficacy. Prescribers can manage these drug interactions by adjusting the medication regimen, but it is contingent on the prescriber being able to identify that an interaction exists.

2.3.2.3 Frailty

One patient group who are particularly vulnerable to iatrogenic harm are those that are considered *medically frail*. Most prevalent in people over the age of 65, frailty is a clinical syndrome that can be found in people of all ages who experience a decline in their reserve and function across multiple physiological systems (Ofori-Asenso et al., 2019). It is considered to be a dynamic process, comprised of three stages which patients can transition between: robust, pre-frail and frail (Ofori-Asenso et al., 2020). Frailty is characterised physically through signs such as unintentional weight loss, exhaustion, weakness, slowness, and low physical activity (Ofori-Asenso et al., 2019). Evidence shows that cancer and the presence of multimorbidity both increase the risk of a person becoming frail (Ofori-Asenso et al., 2019).

One way in which frailty influences a person's likelihood of experiencing MRH is by shifting the balance between the potential benefit and associated risk of their usual medication regimen. This shift may occur because of the effects of cancer and its treatment, such as a significant weight loss or dramatic change in eating habits. These shifts may be acute, such as fasting during the peri-operative period, or sustained, such as the development of cachexia as a result of disease progression. Medicines identified as having greater potential risk than benefit are collectively referred to by the term *potentially inappropriate medicines* (PIMs) (Turner, McKinnon, et al., 2016).

Identifying PIMs in people living with cancer involves clinical judgement based upon an understanding of the patient's clinical situation, including their medication experience (Turner, Jamsen, et al., 2016). As such, it can be difficult to interpret the literature and gain an understanding of the prevalence of PIMs in cancer populations. Todd et al's 2017 systematic review examined the rate of PIMs in people with advanced cancer and found lipid-lowering agents, antidiabetics, antihypertensives, antiplatelets and anti-ulcer medications to be the most common PIMs(Todd et al., 2017). Maggiore et al's study examining PIMs in 500 cancer patients aged 65 and over found between 11 and 29% of patients had at least one PIM, depending on the assessment tool used (Maggiore et al., 2014), with other studies showing similar results (Alkan et al., 2017; Park et al., 2016; Saarelainen et al., 2014). The clinical significance of PIMs in cancer remains unclear, with conflicting results regarding the association between PIMs and hospital presentations or chemotherapy related toxicity, usually due to the confounding effects of multimorbidity (Chen

et al., 2021; Feng et al., 2019; Maggiore et al., 2014; Mohamed et al., 2020). One association that is more consistently agreed upon is the relationship between PIMs and polypharmacy, and the increased potential for MRH relating to drug interactions.

Drug interactions are a particular concern in vulnerable sub-populations when they result in adverse effects that are associated with other issues of frailty such as falls, delirium, incontinence, and immobility. In their 2019 systematic review, Kotlinska-Lemieszek and colleagues examined the clinical significance of drug-drug interactions involving medicines used for symptom control in adults with advanced malignant disease (Kotlinska-Lemieszek et al., 2019). They found the drugs most often involved were antiepileptics, antidepressants, corticosteroids and nonopioid analgesics. Clinical manifestations of drug interactions included sedation, respiratory depression, serotonin syndrome, delirium, and seizures (Kotlinska-Lemieszek et al., 2019). Miranda et al's previously mentioned study found similar results. In addition to the drug interactions involving high risk drugs, pharmacodynamic interactions between antihypertensive agents, and between an antihypertensive and corticosteroid were other probable causes of hospital admission in patients who were noted to be frail due to their advanced cancer (Miranda et al., 2011). Chan et al's study also found pharmacodynamic interactions between antihypertensive agents resulting in weakness and dizziness that led to hospital admissions, indicating that the clinical impact of drug interactions is not merely theoretical (Chan et al., 2014).

2.3.3 The Nature of Care Delivery

So far, we have discussed how the nature of medicines used in cancer care along with the nature of the population create conditions that contribute to MRH. We now turn our attention to the ways in which the system of care also contributes. One way of describing how contemporary cancer care is organised is through the *cancer care continuum* illustrated in Figure 3 (Economou et al., 2012). This model is not intended to accurately depict the journey of the cancer patient, merely illustrate it as a simple abstraction by representing cancer care as being comprised of six phases: prevention and risk reduction, screening, diagnosis, treatment, survivorship, and end-of-life. As patients move throughout the continuum, patients receive care in different settings according to their needs and availability of services.

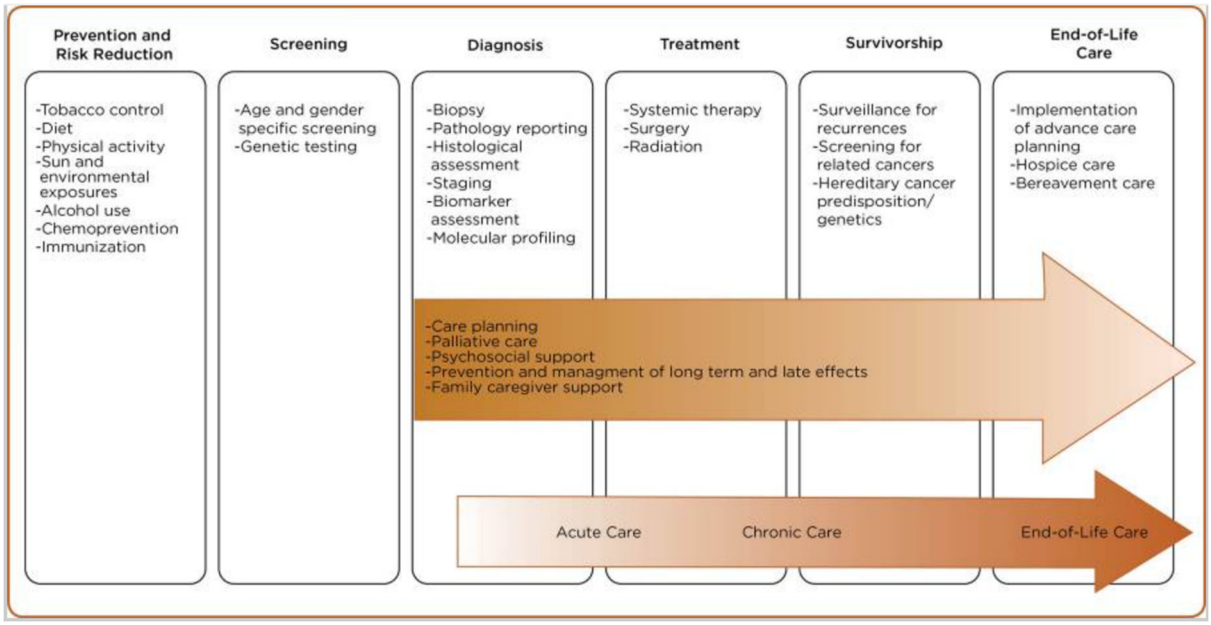

Figure 3: The cancer care continuum, reproduced from Economou, 2012 (Creative commons attribution license)

To understand how the cancer care continuum impacts the patient's experience of care and their potential for MRH, the structure of the Australian health system needs to be considered. Like other parts of the world, our healthcare system is usually described in relation to the focus of the care that is being delivered, such as primary care, specialist care, and hospital care. It is built upon a medical model of care, meaning that as a patient, your access to specialist healthcare practitioners depends upon your diagnoses. In some cases, such as acute haematological malignancies or cancers that result in significant symptoms, diagnosis may occur rapidly and take place within the hospital setting. However, for most people, cancer diagnosis is undertaken within the community setting overseen by the General Practitioner (GP). Cancer diagnosis is a care process that can take a number of weeks and is likely to involve multiple healthcare practitioners in varying settings of care.

Once a formal diagnosis has been achieved and the patient is formally under the care of a cancer clinician, they can continue to expect to encounter a variety of HCPs. The rapidly changing evidence base means it is not possible for medical practitioners to keep up to date across all cancer types, which has resulted in oncology branching into an array of sub-specialties. Coinciding with this has been increased recognition that people with cancer have needs that extend beyond the bio-medical domain. This has seen the cancer multidisciplinary team (MDT) expand beyond the medical and nursing professions to include a diverse range of disciplines. As a result, the cancer care system consists of a broad network of healthcare practitioners practicing in a variety of healthcare services and settings, all of which presents challenges when it comes to achieving continuity of care.

2.3.3.1 Ambulatory care

When patients transition between care settings, they are particularly vulnerable to disruptions in continuity that may contribute to MRH. Transitions between the hospital and community setting are typically presented as a linear process where a patient is admitted to hospital, changes are made within the hospital setting, and then the patient is discharged either to home or another care setting (ACSQHC, 2020a). However, in contemporary cancer care this process is not always so clearly cut. Much of cancer care occurs outside of the hospital setting. Chemotherapy and radiotherapy are increasingly being delivered through *ambulatory care* which do not require the patient to be admitted to hospital overnight. Some patients may even receive anti-cancer treatment in the home, usually with intermittent nursing support. In this type of care delivery, the work associated with the parts of the treatment protocol that are suitable for self-administration, as other aspects of care such as monitoring for adverse effects, shifts to the patient. associated with cancer care to the patient and their carer, such as the medicines used as part of the treatment protocol that are suitable for self-administration. As a result, medication-related outcomes in cancer care, as with chronic conditions, are greatly dependent on the patient's ability and willingness to use medicines effectively in the home setting.

2.3.3.2 Medication adherence in cancer

Rates of non-adherence appear to be lower in cancer than general chronic conditions, possibly related to a perception that the stakes are higher than in other chronic conditions. Non-adherence to cancer medications has been shown to be linked to decreased survival, higher rates of treatment failure and greater healthcare costs (51). However, the differences in reported outcomes and methods of measuring adherence make it difficult to be certain of rates of adherence. Systematic reviews report rates of adherence ranging from 46 to 100% depending on the population and medication studied (Greer et al., 2016; Puts et al., 2014). Evidence suggests adherence to oral anti-cancer medications such as oral endocrine therapies in breast cancer is highest in the early phases following diagnosis and decreases over time (Greer et al., 2016). Multiple systematic reviews have examined factors that influence medication adherence in cancer populations, each demonstrating that medication adherence should be considered a complex, multifaceted phenomenon. Many interrelated factors have been found to influence an individual's medication taking behaviour, including attitudes and beliefs toward medicines, depression and emotions, and the complexity of the medication regimen (Lin et al., 2017; Mathes et al., 2014; Verbrugghe et al., 2013). Although some may think of adherence as being more of an issue for older patients the evidence indicates both older and younger age have been associated with lower adherence (Calip et al., 2017; Mathes et al., 2014; Verbrugghe et al., 2013).

The literature exploring adherence to medications for chronic conditions throughout cancer diagnosis and treatment has predominantly been conducted in breast cancer patients. Overall, results suggest that cancer has a negative impact on adherence rates, however the impact on clinical management is uncertain. Calip et al's 2013 study of adherence to statins in a cohort of 4,221 women diagnosed with breast cancer found that level of adherence reduced during the treatment period, slowly returning to baseline as the patients entered the survivorship phase (Calip et al., 2013). Subsequent publications by the same research group examining adherence to diabetes medications in a cohort of 4,216 women diagnosed with breast cancer found similar results, that adherence declined following diagnosis and was maintained at a lower level throughout treatment and beyond (Calip et al., 2017; Calip et al., 2015). Santorelli et al's smaller study of 298 women with breast cancer who were also managing diabetes confirmed this finding, showing that adherence decreased following diagnosis and was lower than compared to women without a cancer diagnosis (Santorelli et al., 2016). However, they did not find the same results for women using antihypertensive medication, instead finding an improved adherence following diagnosis. Yang et al examined the adherence to oral medications for chronic conditions of 36,149 patients with early-stage breast cancer. They found a reduction in adherence during the first year after cancer diagnosis across a range of drug classes used to treat hypertension, thyroid disease, cholesterol, gastro-oesophageal reflux disease, diabetes and osteoporosis (Yang et al., 2016). Unlike Calip, they found those with older age were more likely to experience a reduction in their adherence. Chou et al also studied patients with breast cancer, assessing the disruptions in adherence to antidepressant medications in a cohort of 1,142 patients. They did not find any significant difference in adherence rates between those with cancer and the non-cancer controls (Chou et al., 2017).

A smaller number of studies have been conducted in general cancer populations, although those that have been published have been in large cohorts. Stuart et al's 2015 study of 4,348 patients with diabetes who had a subsequent cancer diagnosis similar results to those in breast cancer, finding a significant reduction in adherence to oral hypoglycaemic agents, renin angiotensin system inhibitors and statins (Stuart et al., 2015). Zanders et al's study of 3,281 patients with pre-existing diabetes found a clear and significant reduction in adherence to oral hypoglycaemic agents following cancer diagnosis (Zanders et al., 2015). More pronounced decreases were seen in patients with oesophageal, stomach, pancreas, liver, and pulmonary cancers, and in contradiction to other studies, no reduction was seen in patients with breast cancer (Zanders et al., 2015). This was not the case with Banegas et al's study of medication adherence to statins in a large cohort of 10,177 patients diagnosed with breast, prostate, or colorectal cancer. They found that adherence decreased in the two

years following cancer diagnosis, but overall returned to pre-diagnosis adherence rates after two years, most pronounced in those with breast or colorectal cancer (Banegas et al., 2018). Most recently, Lund et al published a study of 34,395 older adults diagnosed with breast, colorectal, lung or prostate cancer who were also managing diabetes, hyperlipidaemia, or hypertension. They found the largest declines in the proportion of patients adherent in the colorectal and lung cancer patients, while patients with prostate cancer either remained unchanged or slightly improved (Lund et al., 2021). These studies show that medication adherence can be expected to vary across cancer types and medication classes.

2.4 MMS and the system of care

So far in this chapter we have focused on medication experience in cancer and the reasons why people with cancer are at risk of experiencing MRH. We will now shift our focus to the healthcare services that are designed to reduce MRH and enhance medication experience: medication management services (MMS), and the approach for implementing those services within Australia.

MRH is a globally recognised issue, the focus of the WHO 2017 report, *Medication Without the Harm*, which set the goal of reducing preventable MRH[22] by half within five years (WHO, 2019). It is an issue that has long been recognised in Australia, where medicines are estimated to result in 250,000 hospital admissions each year, with an associated cost of $1.375 billion (PSA, 2019). Since the National Medicines Policy (Commonwealth of Australia, 1999) and the National Quality Use of Medicines (QUM) Strategy (Commonwealth of Australia, 2002) were introduced in the early 2000s, there has been consistent investment in a suite of systems level initiatives to tackle the issue of excessive MRH. Included within this has been the development of MMS, healthcare interventions designed to enhance medication experience and reduce MRH (Cipolle et al., 2012).

2.4.1 Medication management services (MMS)

This thesis describes MMS according to the two approaches identified by Cipolle, Strand and Morley: prescription-focused MMS (PF-MMS) and patient-centred MMS (PC-MMS) (Cipolle et al., 2012).

[22] Defined within the report as the type of MRH that directly results from shortcomings within the system of care, be it an error, accident, or miscommunication WHO. (2019). *Medication without the harm - Global patient safety challenge on medication safety*. WHO. https://www.who.int/publications/i/item/WHO-HIS-SDS-2017.6.

2.4.1.1 Prescription-focused MMS (PF-MMS)

PF-MMS are healthcare interventions that are typically initiated in relation to the prescribing of medicine and focus on reducing the incidence of MRH that results from error, accident, and miscommunication (Cipolle et al., 2012). One way of identifying these initiatives is through the medication management cycle, illustrated in Figure 4. This breaks the process of achieving safe and effective use of medicines into ten distinct activities which are undertaken by different healthcare practitioners, depending on their scope of practice (Stowasser et al., 2004). These activities are routinely undertaken by medical officers, nurses, and pharmacists as part of providing routine care to people living with cancer and are often embedded into care processes relating to medication supply and administration. While the patient is central to each of these activities, many occur "behind the scenes" and without their direct involvement.

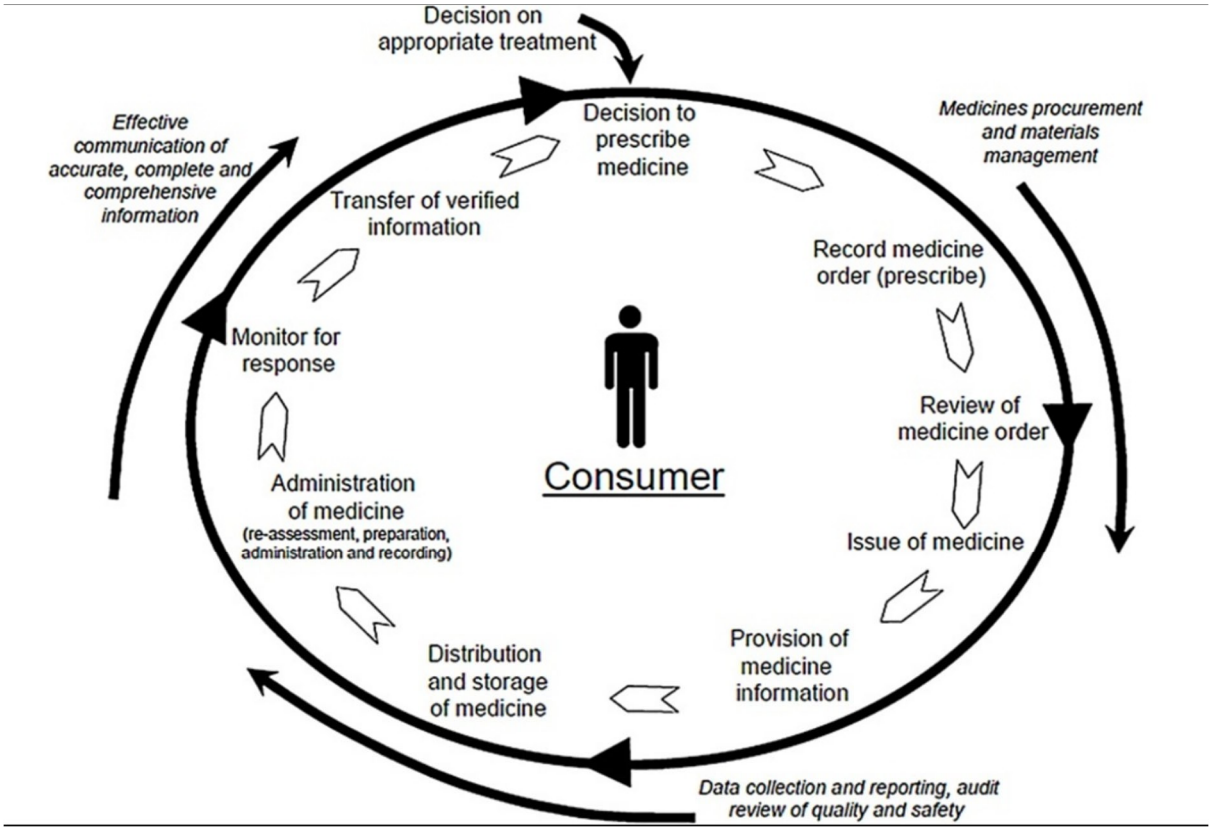

Figure 4: The medication management cycle (Stowasser et al., 2004) reprinted with permission from John Wiley and Sons.

2.4.1.2 Patient-centred MMS (PC-MMS)

PC-MMS initiatives occur separately to processes of supply and administration and focus on ensuring the patient's overall medication regimen is appropriately meeting their needs. PC-MMS involves a suitably skilled practitioner (usually a pharmacist) undertaking a systematic and comprehensive consultation with a patient to ensure that each of their medicines are

effective, safe, and that the patient is willing and able to take them as intended (Cipolle et al., 2012).

The patient care process for best practice PC-MMS involves three separate but overlapping types of patient encounters: the assessment (also called medication review), care plan (also called medication management plan) and ongoing evaluation (Cipolle et al., 2012). The purpose of the *assessment* is to identify the patient's unmet medication-related needs to ensure that their medication regimen is appropriate, effective and safe, and that they are willing and able to implement it as prescribed (Cipolle et al., 2012). Undertaking an assessment begins with the practitioner understanding the patient's medication experience. The output of the assessment is the identification of a patient's unmet medication-related needs, documented as DTPs. These should be contextualised by the practitioner undertaking the assessment, providing an indication of their clinical priority and recommendations for how they could be resolved. Following from the assessment, an individualised *care plan* is developed in collaboration with the patient and care team. Sometimes called a medication management plan, it should clearly document the goals of pharmacotherapy according to a patient's clinical conditions and symptoms, empowering the patient to take ownership of their medication management and effectively communicate information regarding their medicines to health professionals. Importantly, the development of the care plan should also involve follow up of any DTPs identified in the needs assessment and ensure that strategies to resolve them are in place. A care plan cannot be considered a static, once off document. Ongoing evaluation of the patient's medication-related needs and continued review of the appropriateness of their medication management plan is required to ensure that pharmacotherapy is continually optimised, and newly emerging risks acknowledged.

Internationally there are multiple examples of PC-MMS programs including Medication Therapy Management (USA), Home Medicine Review program (Australia), and Chronic Medication Service (Scotland). These PC-MMS programs can be further subdivided into two broad categories of PC-MMS: Medication Use Review (MUR) and Medication Management Review (MMR). PC-MMS initiatives that align with best practice fit within the MMR category, while those that do not address all elements of the patient care process are MURs.

2.4.2 Implementation of MMS in Australia

2.4.2.1 The political landscape

In October 2019 QUM and medication safety was recognised as the tenth National Health Priority Area (NHPA) by the Council of Australian Governments, formally acknowledging that the system of care needs to be improved (ACSQHC, 2020b). NHPAs were introduced in

1996 as a way of achieving a nationally coordinated strategy to improve the health and wellbeing of Australians by targeting areas of healthcare where it is deemed possible to achieve significant gains both in health outcomes and costs (APH website). In response to this, in December 2019 a consortium comprised of the Pharmaceutical Society of Australia[23] (PSA), the Consumer Health Forum of Australia (CHF), the Society of Hospital Pharmacists of Australia (SHPA) and NPS MedicineWise conducted a stakeholder forum with the objective of forming recommendations to governments on how they should "deliver success" on the tenth NHPA (PSA, 2020). Notably absent from the consortium making was the Pharmacy Guild of Australia[24] (PGA). Whether this exclusion was a result of lack of invitation or refusal to participate, it provides an indication of the political landscape that muddies the waters for policy makers and organisational decision makers responsible for overseeing the implementation of MMS.

The report resulting from the Medication Safety Forum called on governments to increase the accountability of the community and aged care sector, arguing that the "overwhelming majority" of MRH occurs from medicine use within these settings. A central recommendation of the forum was for governments to increase governance in primary care and aged care utilising a similar approach to that which has been implemented in hospitals, by introducing national performance indicators and incident monitoring systems (PSA, 2020). This emphasis on promoting medication safety, particularly for those who are considered vulnerable, has been embraced by the revised National Medicines Policy (NMP), released in December 2022 (Commonwealth of Australia, 2022b).

National Medicines Policy (NMP)

The revised NMP builds on the foundation of the original NMP, published in 2000 (1999) by aligning the policy with contemporary shifts that have taken place in healthcare and society more broadly, such as the increased focus on person-centred care, distributed health systems, and advances in digital technologies (Commonwealth of Australia, 2022b). The policy details four central pillars:

- equitable, timely, safe and reliable access to medicines and medicines-related services, at a cost that individuals and the community can afford
- medicines meet the required standards of quality, safety and efficacy
- quality use of medicines and medicines safety

[23] The PSA are national peak body representing pharmacists
[24] The Pharmacy Guild of Australia are an employer organisation who represent community pharmacy owners

- collaborative, innovative and sustainable medicines industry and research sectors with the capability, capacity and expertise to respond to current and future health needs.

Supporting these central pillars are the six fundamental principles: person-centred, equity and access, partnership-based and shared responsibility, accountability and transparency, innovation and continuous improvement, evidence-based, and sustainability. The revised NMP serves as a strong foundation to re-look at the way in which MMS are delivered in Australia, where the approach to implementation of MMS within Australia has been fragmented, traditionally divided between community and hospital-based service providers.

2.4.2.2 Hospital-based MMS

MMS implementation within hospitals has predominantly focused on reducing the risk of MRH by managing the points within the system that are vulnerable to error, such as the transition between care settings (ACSQHC, 2019b). Since 2013, all Australian hospitals have been required be accredited against the National Safety and Quality Health Service (NSQHS) Standards, which includes Standard 4: Medication Safety (ACSQHC, 2019b). The criteria of Standard 4 includes several MMS that can be considered the standard MMS initiatives undertaken within hospital settings: medication reconciliation, adverse drug reaction reporting, medication review, provision of medicines information for patients, and provision of a patient medicines list (ACSQHC, 2019b). The language used with the standards suggests that these activities are focused on risk reduction rather than centred on patient need, thus fitting within the definition of PF-MMS. Below are two examples from the Medication Standard, each with the primary subject underlined. In each example it is clear that the subject is the medicines, not the patient themselves.

Action 4.06 *medication reconciliation* states:

> *Clinicians review a patient's current medication orders against their best possible medication history and the documented treatment plan, and reconcile any discrepancies on presentation and at transitions of care* (ACSQHC, 2019b)

Action 4.10 *medication review* states:

> *For each medicine being reviewed, consider the clarity, validity, and appropriateness of the medicine order, as well as the expected treatment outcomes. A patient's experience of using medicines and their needs may change over time, especially during an admission to a health service organisation. This means that medicines may be reviewed more than once during an episode of care* (ACSQHC, 2019b)

Because they are embedded within routine processes of care that are evaluated against specific criteria, PF-MMS initiatives are consistently employed within hospital settings.

Hospital-based cancer services that administer chemotherapy can also be expected to employ additional PF-MMS initiatives in order to address action 4.15, *high risk medicines.* The result is an expectation of tight governance and rigid constraints for HCPs involved in the storage, prescribing, administration and distribution of chemotherapy agents (COSA, 2017).

Whether or not hospitals provide PC-MMS is determined at a local level. Public hospitals can access Activity Based Funding to provide hospital outreach medication reviews (HOMR) and other locally developed PC-MMS initiatives to non-admitted patients, but this is funding is not available to private hospitals.

2.4.2.3 Community-based MMS

Service providers responsible for delivering MMS initiatives in the community setting are predominantly privately owned and independently operated businesses including community pharmacy, medical practices (general practice and clinical specialists) and independent HCPs operating as sole traders. As businesses, they must remain financially viable in order to continue serving their communities. From the government's perspective, this means that they must be granted autonomy in their operations and afforded the opportunity to remain competitive. However, that is not to say they have the same degree of freedoms as other private industries. Most private MMS providers depend, at least in part, on remuneration through Commonwealth schemes. Doctors delivering MMS receive remuneration through the Medicare Benefits Schedule (MBS), while pharmacists are remunerated through the Pharmacy Programs Administrator (PPA), a government agency responsible for administering the programs funded through the Community Pharmacy Agreement (CPA).

The CPA are five yearly agreements which have historically been exclusively negotiated between the Commonwealth Government and the PGA (PGA, 2021). In addition to its primary role of determining the overarching architecture for the provision of subsidised medicines to the public through the Pharmaceutical Benefits Scheme (PBS), the CPA also determines the funding allocated to patient focused professional pharmacy programs such as PC-MMS initiatives. The seventh and current CPA (2020 to 2025) secured a funding package of approximately $18.3 billion with $1.2 billion allocated to professional pharmacy programs and was the first to include the PSA in the negotiations (PSA, 2021). This was seen as a progressive step within the industry where there has been longstanding tension extending to overt criticism over the political influence held by the PGA in shaping the implementation of community-based MMS (Hendrie, 2019; Knott, 2015; Russell, 2019).

To some extent, PF-MMS are consistently employed within community settings as they are within hospitals. Professional standards of practice articulate that PF-MMS are expected to

be undertaken as part of the prescribing (RACGP, 2020b) and dispensing processes (AHPRA, 2021). Thus, within the community setting PF-MMS are embedded within routine processes of care and remuneration models[25]. However, PF-MMS such as the provision of medicines information to the patient are not subject to any auditing activity. In practical terms, this means that the undertaking of PF-MMS depends on the practice of the individual HCP, resulting in variability of service provision.

Community-based PC-MMS programs are administered by the PPA who determine the business rules that specify approved service providers, eligibility criteria and the standardised process of care (PPA, 2021). This process of care involves multiple artefacts which can be audited, meaning that there is some level of consistency in the process of delivering PC-MMS. Two PC-MMS programs are available to people living independently in the community[26]: the Home Medicines Review (HMR) and MedsCheck programs, the differences between which are summarised in Table 2. MMS initiatives delivered through CPA programs remunerate HCPs on a fee for service basis and do not result in any expense to the patient, making them the most commonly available MMS initiatives within the community setting.

The HMR and MedsCheck programs

In Australia, the HMR program is the MMR initiative that is most accessible to those living independently in the community. Upon patient agreement, an HMR is initiated through an authorised medical practitioner, typically a GP, making a referral to an accredited pharmacist who they provide with relevant clinical information. HMRs can also be initiated by certain medical specialists, although they are not able to claim for their involvement in these services through the MBS. HMRs that are initiated by a medical specialist within a hospital are referred to as hospital-initiated medication reviews (HiMRs).

One a pharmacist receives an HMR referral they then contact the patient to arrange a visit in the home where they will conduct an assessment interview to explore how the patient relates to their medicines and undertake interventions to support them in their self-management as described above. Following the assessment, the pharmacist provides the referring medical officer with a written HMR report documenting the DTPs identified and making recommendations for how they are to be resolved. Traditionally, this is where the pharmacist responsibility ends, with development of the care plan and ongoing evaluation of therapy

[25] GPs are remunerated for services through patient billing of which a defined amount is rebated to the patient through the Medicare Benefits Schedule (MBS), Community Pharmacies with a section 90 license are remunerated for dispensing services through the PBS.
[26] The residential medication management review program is also available within the community setting for patients who are residents of Government-funded aged care facilities, but it is not relevant to the population of interest in this thesis.

undertaken by the medical practitioner in collaboration with the patient. This was amended in 2020, allowing pharmacists to undertake a further two follow up visits with the patient to aid the resolution of any DTPs identified in the original assessment. The HMR funding model does not require accredited pharmacists to be employed by a community pharmacy, enabling them to act as independent accredited pharmacists or be employed by a consulting group. HMR service providers are paid a flat fee per HMR service, with a claim limit of 30 HMR services per calendar month, plus follow up visits.

Unlike an HMR, the MedsCheck program does not require referral from a medical practitioner, meaning that the pharmacist undertaking the review has less access to relevant information. This focuses the MedsCheck on supporting self-management, assisting the patient in understanding their medication regimen and feeling confident in implementing it. MedsCheck services can therefore be considered a less comprehensive PC-MMS rather than best practice, fitting the category of MUR. Unlike the HMR program, MedsCheck must be conducted within a community pharmacy, with a limit of 20 service claims per calendar month. This means that pharmacists conducting MedsChecks are typically salaried employees of the community pharmacy.

2.4.2.4 Service providers

As described above, MMS initiatives are delivered by a variety of HCPs and are often embedded within usual processes of care that are undertaken within hospital and community settings. As a result, there are a myriad of institutions and organisations within the system of care who are responsible for delivering MMS. As introduced in Chapter One, each of these organisations contain structures that constrain the actions of HCPs delivering patient care.

Within the hospital setting constraints can be expected to vary according to whether they are public or private. While the NSQHS Standards provide some degree of standardisation regarding hospital-based PF-MMS the allocation of resources beyond the baseline requirement remains at the discretion of institutional management. This tends to be greater within public hospitals, many of which have been provided with specific resources[27] to

[27] In the first decade of this century, the Australian Commonwealth Government invited each of the States and Territories to participate in a process of pharmaceutical reform, allowing them to provide patients with medicines subsidised through the federally funded Pharmaceutical Benefits Scheme (PBS) Jackson, J. K. (2001). Analysis of the Impact of Public Hospital Pharmaceutical Reforms on Discharge Medication Supply. *The Australian Journal of Hospital Pharmacy*, *31*(4), 295-299. https://doi.org/10.1002/jppr2001314295 . As part of this agreement, participating hospitals were also required to improve the quality of their medication management by implementing the APAC Guiding Principles to Achieve Continuity in Medication Management. These guidelines published by the Australian Pharmaceutical Advisory Council (APAC) were written to provide guidance to health organisations in order to improve the interface between hospital and other settings which was recognised as being high risk and underpin NSQHS Standard 4 ACSQHC. (2019b). *Medication*

enable the delivery of services that will meet NSQHS Standard 4 (Jackson, 2001). In addition to this baseline resourcing, public hospitals are also able to receive funding for the provision of services to non-admitted patients who have complex needs through activity based funding, administered by the independent hospital pricing authority (SHPA, 2020).

The same is not the case for privately owned and operated hospitals. This is particularly relevant for people with cancer. 2019-20 data shows that private hospitals accounted for 62% of surgical hospitalisations and 55% of chemotherapy same-day admissions (AIHW, 2021). Private hospitals may provide pharmacy services internally or through external contracts with independent pharmacies[28]. This means that when it comes to providing PC-MMS to non-admitted patients, such as support for people throughout their cancer treatment, private hospitals are subject to similar constraints as the community sector.

The overwhelming majority of community-based service providers responsible for delivering publicly funded MMS programs are privately owned businesses such as general practices, community pharmacies and independently practicing accredited pharmacists. In Australia, General Practices can be owned by anybody. Most have ownership that includes one or more GP and are run as a SMEs, while around 10% owned by shareholders or corporate entities (RACGP, 2020a). GPs are commonly paid as a proportion of their patient billings rather than a fixed annual salary or wage (RACGP, 2020a). The situation for pharmacists is quite different.

Pharmacists who provide MedsChecks are paid by the community pharmacy, usually as salaried employees. Pharmacists accredited to undertake HMRs however, are typically remunerated by fee for service, or they may be a salaried employee of an organisation that is an approved service provider[29] (PPA, 2018). Unlike General Practices, ownership of community pharmacies is tightly regulated through legislation (Commonwealth of Australia, 1953). In practical terms, this means that all community pharmacies must operate as SMEs and cannot be corporately owned. However, while legislation restricts the capacity of pharmacies to merge into large corporate entities it does not restrict the formation of coalitions, known

Safety Standard. Australian Commission on Safety and Quality in Health Care. Retrieved July 28th from https://www.safetyandquality.gov.au/standards/nsqhs-standards/medication-safety-standard. New South Wales and the Australian Capital Territory were the only jurisdictions to refuse participation in the reforms, with the remaining states and territories signing agreements and implementing changes to service delivery between 2001 and 2010.

[28] Private hospital pharmacy contracts are often fulfilled through a combination of section 94 (hospital) pharmacies and section 90 (community) pharmacies

[29] Section 90 Community Pharmacies and business entities that have a relationship with an Accredited Pharmacist (including sole traders)

Table 2: PC-MMS initiatives available in Australia

	MedsCheck	HMR (includes HiMR)
Access		
Patient eligibility	Specific eligibility criteria based upon risk of medication misadventure or identified clinical need Medicare or DVA cardholder Living independently	Specific eligibility criteria based upon risk of medication misadventure or identified clinical need Medicare or DVA cardholder Living independently
Initiation	Self-initiated	Medical officer referral*
Location	Within community pharmacy	Home residence
Frequency	12 months	24 months or when the medical officer deems clinically necessary
Assessment		
Interview conducted by	Registered pharmacist	Accredited pharmacist
Considers all medicines?	Yes	Yes
Explores attitudes and beliefs about medicines?	Yes	Yes
Identifies DTPs	Yes	Yes
Communicate with other care providers to resolve DTPs	As required	Yes (HMR report)
Patient medication list	Yes	Yes
Educate patient about medicines	Yes	Yes
Address medication management skills	Yes	Yes
Care Plan		
Developed by	Registered pharmacist	Medical practitioner
Establish and document goals of therapy in care plan	Symptom/condition specific e.g. diabetes management plan Medication specific e.g. oral chemotherapy diary	Yes (medication management plan)
Evaluation		
Conducted by	-	Medical practitioner
Monitor and record actual patient outcomes	-	Yes
Evaluate progress in meeting goals of therapy	-	Yes
Reassess for new problems	-	Yes
Pharmacist follow up services to resolve DTPs identified in initial assessment	-	Two follow up visits able to occur between 1 and 9 months from initial visit
Remuneration model		
Approved service providers	S90 Community Pharmacies	S90 Community pharmacies and business entities that have a relationship with an accredited pharmacist (including sole traders) Approved referring medical practitioner: • General Practitioner (GP); • Specialist in Pain Medicine; • Specialist Physician; • Specialist Psychiatrist; or • Specialist in Palliative Medicine.
Pharmacist payment model	Limit of 20 MedsCheck and Diabetes MedsCheck services in total per service provider per calendar month $66.53 for initial MedsCheck service $99.79 for initial diabetes MedsCheck service	Limit of 30 HMR services per month $222.77 for initial HMR service $111.39 for first follow-up service $55.70 for second follow-up service
Medical officer payment	-	GP MBS item 900 $161.10

within the pharmacy industry as *banner groups*. These banner groups provide SMEs with opportunities to build economies of scale by offering centralised support in marketing, business consultancy, staff training, stock control and assistance in negotiations of trading terms with pharmacy wholesalers. 2019 data shows that 58%[30] of Australia's community pharmacies belong to a banner group (PGA, 2019). Most of the banner groups are owned by just four corporate entities: My Chemist Retail Group, Sigma Healthcare Limited, Australian Pharmaceutical Industries Limited, and EBOS Group Limited[31] (Richardson, 2021). Each of these corporate groups own multiple banner groups, branded to serve different parts of the market and align with different business strategies. So, while community pharmacy in Australia may appear to be independently owned and operated SMEs, it is not a sector that is without corporate strategic influence.

2.4.3 Evidence for MMS

MMS have been studied in a broad range of study populations, employing interventions which are often multifaceted and complex, utilising study methods that are commonly practice based and observational, and reporting a broad range of outcome measures. Such a heterogeneous body of literature makes interpreting the evidence relating to MMS challenging (Jokanovic, 2017; Melchiors et al., 2012; Saez-Benito et al., 2013; Silva et al., 2019). While MMS have not demonstrated a definitively positive effect on clinical outcomes such as mortality and hospital readmission, there is evidence that some types of MMS add value to patient care. Cooper et al's 2015 systematic review of interventions to improve the appropriate use of polypharmacy in older people found that PC-MMS interventions were effective in reducing the prevalence of inappropriate medications (Cooper et al., 2015). Similarly, in their 2014 Cochrane review of systematic reviews of interventions to improve safe and effective medicines use by consumers, Ryan and colleagues note that interventions that involve pharmacists in medicines management such as PC-MMS have demonstrated positive effects on adherence and use of medicines, reducing medicine-related problems and improving clinical outcomes (Ryan et al., 2014).

[30] 3344 of 5776 pharmacies belong to a banner group PGA. (2019). *Submission: Review of the retail grocery industry (unit pricing) code of conduct*. https://treasury.gov.au/sites/default/files/2021-05/c2018-174951_bogomolova.pdf

[31] Sigma Healthcare Limited, Australian Pharmaceutical Industries Limited, and EBOS Group also own the three largest upstream pharmaceutical wholesalers Sigma, API, and Symbion (owned by EBOS Group). Thus, while joining a banner group represents a horizontal integration strategy for community pharmacy owners, it represents a vertical integration strategy for the banner group owners who gain greater control over the distribution end of the supply chain. Sigma Healthcare Limited and EBOS Group have also expanded this reach into the hospital sector, with each maintaining a hospital services business as part of their portfolio.

There is very little known about overall medication management in the context of cancer, with most of the medicines-related cancer literature focusing specifically on issues associated with medicines used to treat cancer or cancer-related side-effects (Holle et al., 2016). Prior systematic reviews have examined two main segments of the evidence of MMS in cancer: pharmacist-led interventions and interventions to enhance adherence. Each have concluded that there is insufficient evidence available to guide practice and that higher quality studies are required.

Several systematic reviews on pharmacist-led interventions in non-hospitalised cancer populations demonstrate a small and varied evidence base (Colombo et al., 2017; Edwards et al., 2019; Maleki et al., 2019; Thoma et al., 2016). Colombo et al's 2017 and Maleki et al's 2019 reviews both suggest that pharmacist-led interventions may have a positive effect on adverse events, symptom management and quality of life (Colombo et al., 2017; Maleki et al., 2019). Importantly, they also note that the complexity of intervention types, limitations in methodological rigour and a dominance of US based research limits the ability to translate this evidence base into recommendations for practice change. This lack of methodological rigour can be further highlighted by Gatwood et al's review examining the US evidence of the impact of clinical pharmacists in outpatient oncology practices (Gatwood et al., 2017). While they claim that pharmacist-led interventions could help to overcome the oncology workforce shortage, it is based upon only eight studies, all of which were observational in nature.

Two systematic reviews assessing the efficacy of interventions designed to enhance adherence of oral cancer therapies have been reported in the cancer literature, each drawing the same conclusion that the low quality of evidence and inconsistency in outcome measures make it difficult to interpret the literature (Greer et al., 2016; Mathes et al., 2014) Indeed, this is an issue that has also been found in the broader literature. In their 2014 Cochrane review examining interventions for enhancing medication adherence Nieuwlaat et al found that nurses and pharmacists are frequently involved in delivering interventions designed to enhance adherence but because the interventions are usually complex, it is difficult to determine which components of the interventions are most important, presenting challenges in translating findings to other settings (Nieuwlaat et al., 2014). They argue that because adherence is something that needs to be supported throughout the entirety of the treatment regime, to achieve broadscale effects interventions targeting adherence need to be integrated into the existing healthcare system in a way that does not require intensive resources.

2.5 Taking action within the system of care

The purpose of this thesis is to produce knowledge that can inform feasible actions that can be taken within the system of care to improve medication experience. Identifying feasible actions requires an understanding of the decision-making that occurs within the system of care. To explore this decision-making further, let us borrow from the business field of *strategic management* which can offer some useful parallels.

2.5.1 Strategic management and levels of corporate decision-making

As a relatively young field, there remains debate regarding the definition of terminology used. This thesis will use a definition of strategic management that aligns well with its purpose, derived from the work of Nag, Hambrick and Chen (Nag et al., 2007):

> *The field of strategic management deals with the major intended and emergent initiatives taken by general managers on behalf of owners, involving utilization of resources, to enhance the performance of firms in their external environments – (Nag et al., 2007)*

Unlike the corporate industry where corporations and firms have clear organisational boundaries and rely solely on private sources of revenue, the healthcare system is a complicated mix of service providers, government and non-government organisations with diffuse organisational boundaries and mixed governance and funding structures. Yet even within this confusing mess, the same three levels of decision-making can be seen as within corporations: strategic, management and operational. Strategic level decision-making is concerned with defining intentions of what to achieve and how to go about doing it. Management level decision-making is concerned with implementing the strategic plan, and allocating the resources required to make it a reality. Operational level decision-making is concerned with executing the work involved with implementation. Another way this has been described is work as imagined, work as prescribed, and work as done (Shorrock, 2016). These levels of decision-making are fractal in nature, meaning that they are evident whether our perspective is zoomed in to view the system at an individual patient level, or out to the policy level view.

2.5.1.1 Strategic level decision making

As described earlier this chapter, organisations and businesses that provide MMS are constrained by Government policy whether that be the NSQHS Standards for hospital providers or the CPA for those delivering services in the community. These organisations and businesses will also develop their own strategic plan that is relevant to the needs of their local population or target market. This type of strategic-level decision making is usually made within the top tier of the organisation's governance structure.

Businesses typically design their strategy with the hope of attaining a competitive advantage that will increase, or at least protect, their profit share (Porter, 1998). According to Porter there are three generic strategies that businesses tend to pursue in attempt to gain competitive advantage: *cost leadership* by beating others on price, *differentiation* by offering customers something unique that is of value to them and *focus* by achieving cost-leadership or differentiation within a niche market (Porter, 1998). There are examples of each of these business strategies within the pharmacy sector. Discount pharmacy chains (e.g. Chemist Warehouse, Chemist King) have a clear cost leadership strategy, while other community pharmacy banner groups seek differentiation by being service-oriented (e.g. Terry White Chemmart, Amcal). There are also examples of community pharmacies that focus on niche markets, such as aged care or hospital services[32], including oncology.

While valuable for all organisations responsible for delivering MMS, defining an effective business strategy is of critical importance for those that are privately owned and operated who must remain financially viable in order to provide ongoing services to their community.

2.5.1.2 Management level decision-making

If we zoom into the organisations responsible for providing MMS, we arrive at the service providers who design and implement the localised models of care that enable PC-MMS.to be delivered to patients. Within strategic management this is known as the *business model.* Osterwalder describes the business model as "*like a blueprint for a strategy to be implemented through organizational structures, processes and systems*" (Osterwalder & Pigneur, 2010).

Businesses that participate in the Commonwealth funded PC-MMS programs (e.g. HMR and MedsCheck) must comply with the business rules, placing constraints on aspects of their business model by prescribing the key activities to be performed and defining the remuneration model. Whether or not this represents a significant constraint depends upon the businesses' reliance on these programs as a revenue stream. Traditionally, community pharmacy business models have been built around dispensing PBS medications, which contributes the majority of revenue for most pharmacies (Richardson, 2021). But in recent years this model has been challenged by PBS reforms and the growth of Chemist Warehouse, who attain approximately 60% of their revenue from retail sales (Richardson, 2021). As such, it is predicted that more pharmacies will be moving toward service-based business models and look to differentiate themselves through professional services

[32] Community pharmacies require a different license to supply medicines for use within hospitals, called a Section 94 license.

(Richardson, 2021). In doing so, they will need to decide how to balance the quality of the service provided with the need to remain financially viable.

2.5.1.3 Operational level decision making

Zooming in once more into the service providers that facilitate delivery of PC-MMS, we now find ourselves at the level of the patient and HCP interaction. The strategic management concepts of value proposition and fit are useful to understanding the way that patients and referring healthcare practitioners engage with the services that are being offered.

A value proposition can be thought of as the benefit that customers (or patients) can expect from a given product or service, as considered from the perspective of the customer and not the service provider (Osterwalder & Pigneur, 2010). This is not the perspective that is traditionally taken by healthcare service providers. Within a context of evidence-based medicine, healthcare services are interventions designed by experts to address objective problems, aligning with the way healthcare need is defined within the literature[33] (Stevens & Gillam, 1998). However, need for a service does not always mean that people will demand that service, or even accept it if it is offered to them (Wright et al., 1998).

Recognising that there can be disparity between how the experts and service providers view value and need compared with the consumer or referrer leads us to the concept of *fit*. Osterwalder describes three types of fit: problem-solution, product-market, and business model fit (Osterwalder et al., 2014). *Problem-solution fit* occurs when there is an 'on paper' fit between the value proposition of a product or service and the assumed needs of the customer. This type of fit provides confidence in testing the product or service in the market to see if it translates to product-market fit. In the context of healthcare, this could be considered comparable to gathering empiric evidence in a controlled setting to demonstrate the efficacy of an intervention (Greenhalgh & Papoutsi, 2019). Put crudely, *product-market fit* occurs when customers are buying what you are selling (Osterwalder et al., 2014). That is, they are demonstrating a level of felt and expressed need. This does not mean that they necessarily have a felt need for all aspects of your value proposition, just that it resonates with them enough to try it out. Achieving product-market fit is known to be difficult to achieve and takes considerable time. There are three general iterative approaches to try and achieve product-market fit. Either iterate on the design of the product or service, the choice of market, or the business model. In the context of healthcare, this could be considered comparable to small-scale iterative refinement of an evidence-based intervention in a real-

[33] Stevens and Gillam define healthcare need as the potential for a patient to benefit from a healthcare service Stevens, A., & Gillam, S. (1998). Health needs assessment: Needs assessment: from theory to practice. *BMJ*, *316*(7142), 1448-1452. https://doi.org/10.1136/bmj.316.7142.1448

world setting (Greenhalgh & Papoutsi, 2019). *Business model fit* occurs when a value proposition has been embedded within a sound business model that is able to be maintained at the desired scale. This means that the value proposition must be able to create sustained value for both the customer and the organisation. In the context of healthcare, this could be considered comparable to widescale implementation of an evidence-based intervention and acceptance into practice (Greenhalgh & Papoutsi, 2019).

2.5.1.4 Medication-related decision making at the individual patient level

If we look closer at the interactions at the individual patient and HCP level, we can see the same three levels of decision-making are evident in relation to medication management as based on a priori knowledge, At the strategic level are the overarching goals of care for the patient, such as a focus on longevity or quality of life. Management level decisions are made resulting in the formulation of a care plan, including such things as prescribed medications each with their specific performance measures. Operational decisions are required to implement the care plan on a day-to-day level, undertaking the work of administering medicines, scheduling and attending appointments and so on. Each level of decision making must involve the patient, but the extent of their involvement can be expected to vary according to the practitioner's philosophy of practice (e.g. patriarchal or collaborative, prescription-focused or patient-centred) and the level of patient activation[34].

It must also be recognised that there will be aspects of both the patient and HCP worlds that influence the nature of the interaction that sit outside the system of care. Constraints relating to professional practice such as laws, ethics and standards of practice are used to keep the influence of these factors on the actions of HCPs within acceptable professional limits. Factors that exist within the patient world, however, are beyond the control of the system of care. But while these factors may not be able to be managed, they can be better understood through conceptual models such as the cumulative complexity model.

The cumulative complexity model

One way of explaining the way in which patient factors influence their level of engagement with medication-related aspects of care is through Shippee et. al's cumulative complexity model, illustrated in Figure 5 (Shippee et al., 2012). It depicts a patient's ability to utilise healthcare services and enact self-management in terms of the relative balance between the intertwined factors of workload and capacity (Shippee et al., 2012). Patients may respond to these workload-capacity interactions through internal processes (path a), through actions

[34] *Patient activation* describes an individual's level of knowledge, skills, and confidence in managing aspects of their health. t is generally thought that more highly activated patients have more positive experiences of care Hibbard, J., & Gilburt, H. (2014). *Supporting people to manage their health: An introduction to patient activation*. .

and decision-making, such as prioritising their workload, mobilising resource to enhance capacity, or through improvisation, routinisation, and timing to match resources to demands. Workload and capacity interactions influence the way that patient's utilise healthcare services and enact behaviours of self-care (paths b and c) which can result in poor health outcomes as a result of unmet needs (paths d, e, f). Poor health outcomes may then inadvertently result in further intensification of therapy, resulting in a reinforcing feedback loop (paths g and h). This concept of balancing workload and capacity, and the impact of burden of treatment and burden of illness on balancing those demands, was used to help structure the exploration of patient experiences within this thesis.

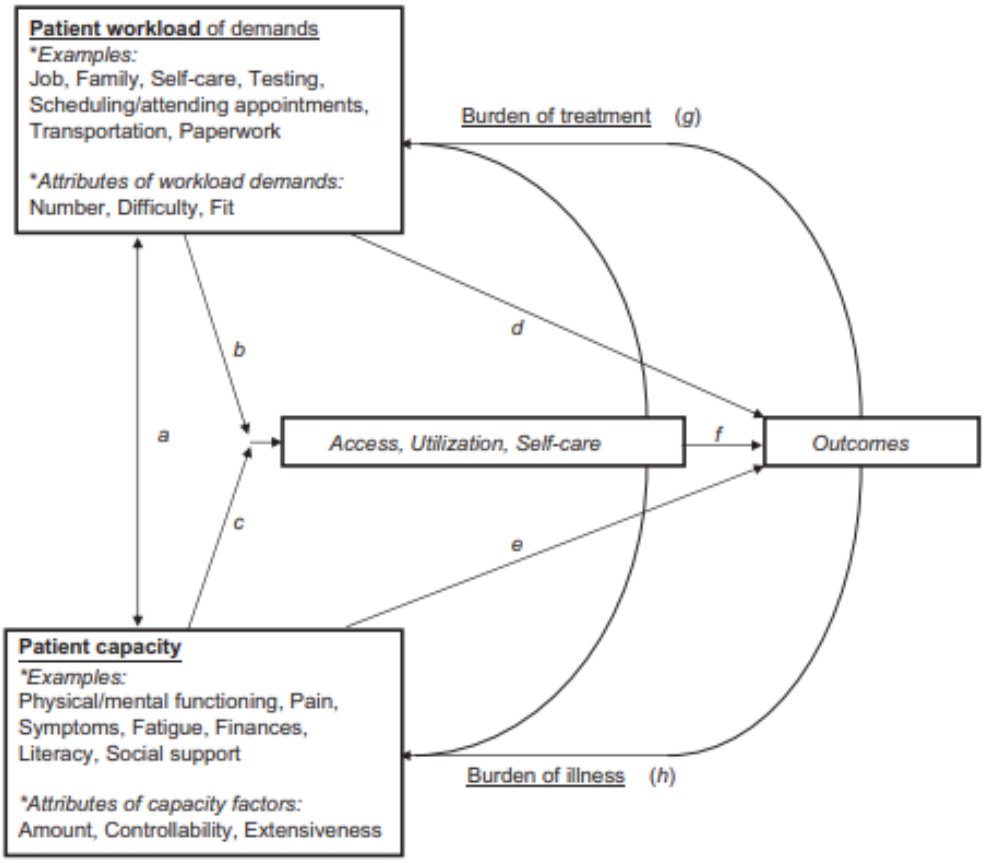

Figure 5: The cumulative complexity model (Shippee et al., 2012)
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2.6 Chapter Summary

This chapter has illuminated how little is known about the medication experience of people living with cancer and the MMS initiatives designed to support their overall medication management. The knowledge contributed by this research seeks to help reduce this large gap in the literature. This chapter has also shown why this lack of understanding has significance in the real world; because medication experience is inherently linked to MRH

which we know is more prevalent in cancer populations and is often associated with medicines used within the home. It has provided description of MMS, healthcare interventions designed to enhance medication experience, and explained the MMS initiatives that are readily available within the Australian's living with cancer within the current system of care. Finally, it has introduced some of the top-down constraints created at the policy and regulatory level that are known to influence service provision and patient engagement with MMS and shown that less is known about how policymakers can influence the locally developed corporate constraints that shape delivery of MMS in practice. In Chapter Three we turn our attention to the way in which this research addresses this large gap in the literature to improve the system of care and patient experience, providing a detailed account of the research approach.

3 METHODOLOGY

3.1 Chapter Introduction

Now that I have defined and contextualised the problem to be addressed by this research and shown how understanding medication experience in cancer can be used to improve the system of care and patient outcomes, we can now turn our attention toward *how* this research has been conducted. This chapter begins with the philosophy that underpins this research. Once those philosophical assumptions have been made clear, attention is turned toward the research approach and the rationale behind the choice of methods. The chapter concludes with a detailed account of the research methods employed.

3.2 The research philosophy

Research requires choices to be made. From the topic of study to the methods of investigation, all the way through to the way in which the results are interpreted and presented. Even the style in which this thesis is written is a conscious choice shaped by an underlying philosophy. To enable you, the reader, to assess the credibility of this research it is essential that these philosophical assumptions are clearly articulated.

The purpose of this research reflects my values and ethics which, as detailed in Chapter One, are shaped by my professional experiences as a pharmacist as well as my personal life experiences. I embarked on this research to produce knowledge that can be applied in practice to improve the lives of people living with cancer. As such, this research fits well with a pragmatic approach. Unlike other research paradigms, pragmatism is not prescriptive in its interpretive framework. Instead, it allows the researcher to make ontological, epistemological and methodological choices according to what is best suited to the research problem (McCaslin, 2008).

3.2.1 Ontological and epistemological assumptions

The concept of a research paradigm is most often associated with Thomas Kuhn who described paradigms as a set of shared assumptions held by the scientific community regarding the way in which science should be conducted (Kuhn, 2012). In the 1970s, Lincoln and Guba described two paradigms within the social sciences, each of which were based on what they considered opposing views of ontology and epistemology: the positivist and constructivist paradigms (2008)[35]. The positivist position takes a naïve realism ontological

[35] There have since been a proliferation of research paradigms which, if cited by a researcher, imply that a specific set of assumptions and methods underpin the research approach.

position. It considers reality as something that exists independently and can be discovered through empiric study (Lincoln & Guba, 2017). By contrast, the constructivist position is one of relativism which considers reality as something that is constructed within the minds of social actors (Lincoln & Guba, 2017). The position taken in this thesis is one of *ontological realism*, falling somewhere between these two extremes. It aligns closely with what Hammersley describes as a subtle approach to realism (Hammersley, 2002).

Hammersley's argument for subtle realism was based upon a desire to challenge the dichotomy of naïve realism and constructivism that he had observed within the field of ethnography (Hammersley, 2002). Hammersley's subtle realism agrees with the dominant view within ethnography that independent, knowable phenomena exist within the world, but asserts that it is not possible to have direct access to this reality for social phenomena (Hammersley, 2002). Rather, the social researcher accesses reality through socially constructed accounts of the world, both by eliciting and interpreting the accounts of others, and by constructing their own accounts through personal observations and interactions (Hammersley, 2002). The aim of research undertaken with a subtle realist approach is to offer a representation of reality, acknowledging that multiple valid descriptions and explanations of the same phenomenon can exist (Hammersley, 2002). If we revisit the central phenomenon of this research, the logic of why this position of subtle realism has been chosen is laid bare.

As introduced in Chapter One, medication experience is an internally constructed phenomenon that exists within the patient world and is shaped by the external reality of medication-related events and experiences (Hillman et al., 2020). As a socially constructed phenomenon, it is not appropriate for medication experience to be studied from a position of naïve realism because it cannot be directly accessed or observed, it can only be understood by eliciting and interpreting the lived experiences of people who are using medicines. The relativist position that is typically taken in the study of medication experience (Hillman et al., 2020) is useful for developing theoretical models, but is less aligned with the pragmatic approach on which this research is based. A subtle realist position represents a happy medium. It acknowledges that while medication experience is internally constructed within the patient world, it is shaped by medication-related events and experiences that can be observed within the system of care. By building a descriptive account of the current state we are able to identify actions that can be taken to move toward an improved future state.

The process of moving from a descriptive account of reality to identify actions to move to an improved future state is built on epistemological assumptions. A positivist paradigm is associated with an objectivist epistemology or search for an objective truth that is able to be

verified (Lincoln & Guba, 2017). By contrast, a constructivist paradigm takes a relativist position, assuming that all knowledge is dependent the knower (Danermark et al., 2019). This thesis takes a position of realist ontology and relativist epistemology, built on an assumption that while an independent reality exists outside of our consciousness, our ability to understand that reality is inherently subjective. It follows that the descriptive account of reality put forward in this thesis is but a conceptual abstraction of the system of care and how it influence medication experience, it does not purport to document a reproduction of reality. The findings of the research are entirely dependent on my actions as the researcher, informed by my experiences and the choices I have made.

3.2.2 Methodological assumptions

Methodology is concerned with the confidence that we can have in a researcher's interpretation by understanding the thought processes applied within the research (Creswell & Poth, 2017). It is important that any methodological assumptions are coherent with the overall interpretive framework or paradigm. In the case of this research, this means that the methodological assumptions should help to achieve a practical outcome and align with a realist ontology and relativist epistemology. This section explains why a qualitative approach was employed, the rationale behind the choice of research activities, and the modes of inference that were employed within this research.

3.2.2.1 A qualitative approach

Addressing the objectives detailed in Chapter One required research methods able to elicit participant's lived experience of using medicines and provide a rich description of the system of care in which that lived experience occurs. Describing a human system, whether it be through narrative description or sophisticated computational model, requires boundaries to be drawn to identify what is part of the system and what is external to it. Of course, in reality no such boundaries exist, meaning that the decision of where these boundaries are placed influences our understanding of the system of interest (Meadows, 2008). Make the boundary too finite and we will fail to consider important structural influences. Make it too diffuse and we will arrive at models with so much detail that they are essentially meaningless as they are beyond comprehension. The challenge with human systems is that it is not possible to know the significance of what is left out (Ackoff & Gharajedaghi, 1996). We know that within complex systems, small differences in conditions can result in vastly different outcomes; a phenomenon known colloquially as the butterfly effect (Waldrop, 1993). Because of this, complexity scholars such as Paul Cilliers argue that "the 'analysis' of complex systems will always impose serious distortions by 'cutting out' part of the system" (Cilliers, 1998). As

such, boundaries must be considered as a way of helping us describe and understand the world rather than being considered to be an accurate depiction of it (Cilliers, 1998).
If it never possible to fully know a human system, it is important for the researcher to endeavour to gain a rich picture of it that considers multiple perspectives, including their own (Mays & Pope, 2000). Scholars of health services research, systems and organizational complexity have described this in various ways. Health researchers Popay et al argue that research regarding appropriateness of care must "privilege subjective meaning or lay knowledge"(Popay et al., 1998), systems thinkers Ackoff refers to it as "formulation of the mess"(Ackoff et al., 1984), Checkland as "rich pictures"(Flood, 2000) Complexity scholar Cilliers argues for "different frames"(Cilliers, 2013), Tsoukas as a "system of picturing"(Tsoukas, 2017). Common to each way of describing this rich picture is an emphasis of the role of narrative accounts and the inherent subjectivity that exists. As such, this research sits firmly within a qualitative methodology.

3.2.2.2 Rationale for research methods

A variety of research methods could have been utilised to attain the type of rich narrative data required to understand a complex human system. Indeed, there may have been methods that in hindsight would have proven to be more appropriate that those which were utilised. But alas, I did not have the benefit of that hindsight at the time those decisions were made. This section describes how those decisions were made in context. It seeks to provide an honest and transparent account of what occurred and why.

Quantitative methods such as surveys and questionnaires were quickly dismissed due to their superficial nature. Ethnography was briefly entertained but also dismissed, primarily due to practical reasons. As detailed in Chapter One, at the time of designing the primary research activities my intention was to use them as preliminary data to inform an intervention study, likely utilising a quantitative or mixed methods approach to evaluation. It did not seem to be a good investment of my time and energy to pursue an ethnographic study. I considered focus groups but decided they were not the most appropriate choice because I felt the group dynamic could impede open and unhindered sharing of lived experiences amongst both patient and pharmacist groups. I was also concerned that focus groups would create a barrier to participation due to their requirement for attendees to be present at a time and place that is suitable for the group rather than the individual. One-on-one in-depth interviews was selected as the method to explore both patient and MMS provider perspectives primarily because they enabled elicitation of in-depth narrative experiences. The one-on-one nature of the interviews enabled greater flexibility in the time and place for interviews to occur and created an environment that allowed privacy and trust to develop so

that participants could share their experiences openly and honestly. In-depth interviews also fit well within my professional skill set. As a registered pharmacist who conducts medication reviews, I have training and experience in using semi-structured interview methods including active listening and questioning techniques that allow for probing and exploration of topics that emerge. Owing to my comfort with this type of interview technique and the practical assurance that having an interview guide provided me as a novice researcher, it was decided that the in-depth interviews would be semi-structured.

As I started to analyse and interpret the pharmacist interviews, I began to realise the potential diversity of PC-MMS initiatives in localised settings, particularly those that are offered by specialist cancer services and the prospect that I may be blind to the initiatives that are provided by non-pharmacist HCPs. To reduce this potential blind spot I decided to undertake a scoping review of the literature relating to patient-directed MMS initiatives evaluated in non-hospitalised cancer populations. The reason for undertaking a literature review rather than an alternative approach such as surveying specialist cancer centres was again a practical one. Preparing and conducting a survey takes time and resources, often resulting in response rates that are low. As such, the results gained from a survey cannot be relied upon to provide an accurate depiction of reality, but rather offer insight into the practice of those that respond. It was anticipated that a scoping literature review would achieve similar insights but would be faster to undertake and require less resources.

3.3 Research methods

Three research activities were undertaken: a patient interview study, a pharmacist interview study, and a scoping literature review. Each of the independent studies was designed to address the specific research objectives detailed in and illustrated in Figure 6.

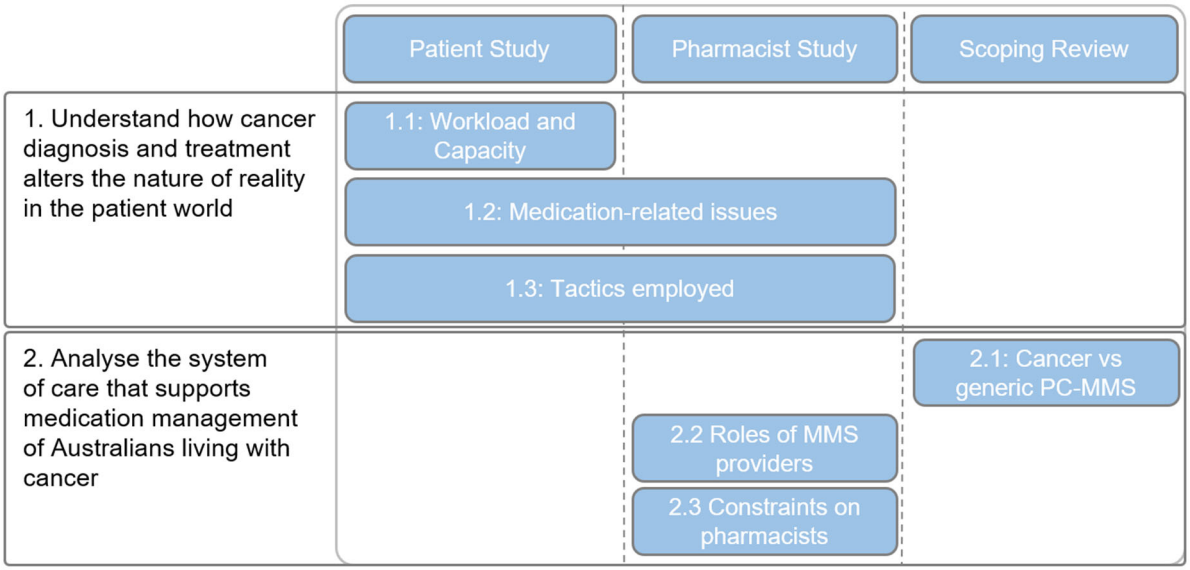


Figure 6: Research activities mapped to objectives

3.3.1 Interview Studies

Two interview studies designed to examine the overarching research question from the perspectives of the people who are living with cancer and coexisting chronic conditions, and the pharmacists who are providing MMS to this population. Both studies were conducted and analysed independently. This sections details the methods employed. It begins by detailing the methodological considerations that were specific to both the patient and participant study. Because both studies employed the same approach to data analysis and interpretation, the description of the methods employed has been combined in order to avoid repetition.

3.3.1.1 Specific considerations – Patient study

The patient interview study aims to explore, describe, and interpret the medication experiences of people using medicines to manage a pre-existing chronic condition throughout cancer diagnosis and treatment. The objectives addressed by the patient study have been detailed in Chapter One and illustrated in Figure 6, presented at the beginning of this chapter.

Setting and period of study

The patient interview study was conducted between January and September 2017, taking place locally within South Australia. People living in all regions of South Australia were eligible for inclusion in the study, with the option of phone interview to improve accessibility.

Eligibility criteria and sampling

Participants were eligible for inclusion in the study if they were adults, English speaking, within 2 to 18 months of cancer diagnosis and regularly using at least one prescribed medicine for a chronic condition. People living in a formal care facility such as residential aged care were excluded.

My initial approach to recruitment was to identify potential participants through the clinical staff at the Flinders Medical Centre (FMC), primarily the clinical pharmacist. I intended to undertake theoretical sampling, selectively seeking out diverse or extreme case sampling identified through the initial contact details. However, it quickly became obvious that this approach needed revising. Unfortunately, I did not build the engagement with the clinical pharmacist that I needed to facilitate recruitment at FMC. One of the factors that contributed to this was time taken to obtain governance approval to begin recruitment there, which I did not anticipate.

I approached the FMC pharmacy department in July 2016 while the ethics submission was still in development. At this time, I was well supported by the Director of Pharmacy who approved the ethics submission and introduced me to the clinical pharmacist to assist me with recruitment. Ethics approval was granted 28 July 2016 and I was able to meet with the clinical pharmacist at the end of August. She appeared supportive of being involved in recruitment, acknowledging that multimorbidity was a growing issue in oncology practice. Governance approval, however, was not received until 6 October 2016. Unfortunately, during this time the FMC pharmacist experienced what she described as "a busy patch" covering annual leave and sick leave reducing her patient contact. I kept in touch with her via email and received the first expression of interest November 8 and another November 11. Unfortunately, when I called them neither patient was interested in participating in the study. No further expressions of interest were received, and it became increasingly difficult to get in contact with the pharmacist. I recognised that I needed to amend my approach but approaching the Christmas break presented some challenges.

I could see that recruiting patients was going to be something more akin to a trickle than a flood. To make good use of my time, I decided to accelerate progress with the Pharmacist study and seek out additional recruitment sites for the patient study. I approached each of the metropolitan public hospitals with a pharmacy department servicing an oncology clinic and got positive responses from The Queen Elizabeth Hospital (TQEH) and Lyell McEwin Hospital (LMH). I amended my ethics submission and obtained governance approval to begin recruitment through TQEH (4 April 2017) and LMH (6 April 2017). I received the first expression of interest from the LMH May 8th and continued to receive a steady stream, with

15 EOIs in the first month. What became obvious at that point was the challenges in getting people to commit to an interview. Of that initial cohort, seven were not interested in participating, eight agreed to an interview, and six had interviews conducted (two no longer wanted to proceed). Of the six men, only one agreed to be interviewed. The time between initial EOI and the interview occurring in that initial cohort ranged from 22 days to 57 days. It quickly became apparent that while purposive sampling may be optimal, I needed to accept what I could get through a convenience sample. The pressures relating to recruitment were compounded by my own personal circumstances of pregnancy and planned maternity leave occurring in November 2017.

Unlike the LMH, recruitment never got off the ground at TQEH. As I found with the FMC pharmacist, TQEH pharmacists were much more difficult to contact via email and although expressed interest in participating in recruitment I could sense their reluctance. One of the key differences between that LMH pharmacist and pharmacists at other sites was that the LMH was a senior pharmacist with ongoing responsibility to the oncology unit. By comparison, pharmacists at other sites serviced oncology on a rotational basis and were uncertain of their ongoing work assignment. I think this had a strong impact on their willingness to take on responsibilities outside of usual patient care.

By November I had conducted nine interviews with what serendipitously turned out to be a somewhat diverse sample of participants. The sample included participants representing a variety of cancer types, chronic conditions, location (rural and metropolitan), ages, gender, and ethnic backgrounds.

Conduct of interviews

One on one interviews were conducted using a semi-structured approach, using a pre-defined interview schedule as a guide for questioning (Table 4). The interview schedule was based upon a published interview guide which had been used in multiple qualitative studies exploring the burden of treatment in patients with chronic conditions (Eton et al., 2012) with the addition of questions intended to explore the impact of cancer on capacity and managing workload capacity imbalances based upon the cumulative complexity model (Shippee et al., 2012) introduced in Chapter Two. Interviews were conducted in the participants' home or by telephone. All interviews were audio recorded and lasted 45 to 65 minutes in length.

Ethical considerations

This study was approved by the Southern Adelaide Clinical Human Research Ethics Committee on July 28, 2016 (239.16).

Potential participants were identified by haematology and oncology (HONC) clinic staff. They provided individuals meeting eligibility criteria with a brief verbal explanation of the study. Interested individuals were then provided with a copy of the participant information and consent form (PICF) and completed an expression of interest form which stated the contact details to be made available to the primary investigator. I then contacted potential participants through their preferred method to confirm eligibility, further explain the study and, if interested, arrange a time and place for an interview and to verbally explain the PICF. Participants were provided with opportunities to ask questions about the study both in the introductory phone call and prior to the interview taking place. If they agreed to participate, they completed a written consent form, or in the case of a phone interview provided verbal consent at the time of interview which formed part of the audio recording, in addition to providing a signed written consent sent through the post (replied paid envelope provided).

Written consent forms were kept in a secure location and audio files were stored electronically on the university network. An alias was assigned to each participant upon transcribing the interviews verbatim and used to identify all records used for analysis. Any information with potential to identify individuals, HCPs or sites of care was removed from the transcript to promote anonymity.

There was a risk that participants would experience some emotional distress as they recounted their experiences during the interview. Indeed, this was the reason cited for not participating in the study by several eligible participants. I had professional experience in working and talking with people with cancer and felt confident in my ability to identify if a participant was exhibiting a greater than normal level of distress and offer to discontinue the interview. I had plans in place to be able to debrief the specific scenario with my supervisor[36] to ensure appropriate follow up is in place for the participant. This was not required throughout the study.

Because the interview was to involve an exploration of the participant's medication management there was potential for information to arise that would suggest a participant's medication was not optimised. To manage this, at the conclusion of the interview all patients were be provided with written information from the National Prescribing Service, an independent, not for profit organisation providing evidence-based consumer medicines information. No potential safety issues arose that required the researcher to take action.

[36] Prof. Bogda Koczwara, a medical oncologist with significant clinical experience

Table 3: Interview schedule for patient study

Component	Areas of inquiry	Opening questions	Probing questions
Types of disruptions experienced – Biographical, relational, biological			
Patient workload All the demands in patients' lives **Burden of treatment** How activities associated with managing health contributes to patient workload	Job Family Caregiving Travel/transportation Paperwork Learn about conditions and care Medical appointments Monitoring health status Health behaviours/preventive care Medical equipment/devices Taking medication	Can you start by telling me a bit about yourself?	• Job - What do you do for work? • Family - do you live alone, with partner, children etc? • Caregiving responsibilities – children, disability, elders?
		What types of health problems are you dealing with right now?	• Where are you at with your cancer management at the moment?
		What kinds of things do you have to do to treat or care for your health conditions?	• Do you monitor your conditions on your own (e.g. check your blood pressure)? What type of monitoring do you do and how often? • Have you had to learn anything new in order to care for yourself? • Do you do anything to look after your health (exercise, diet)? • How many medical appointments did you have to coordinate? • How do you get to and from your medical appointments – drive, public transport, friend, taxi?
		How big a part of your life would you say is made up of activities you do to manage your health and illnesses?	• Has this changed at all since being diagnosed with cancer?
		Tell me about the medications you are taking at the moment (prescribed/OTC/CAMS). What are you taking, how long have you been taking them, what are you taking them for?	• Do you look after your medicines yourself or does someone help you? • Do you use anything to help organise your medicines (e.g. dosette, list) • Have there been any changes to your long term medicines since your cancer? – change in dose, interrupted, stopped, new?
Patient capacity The resources that affect a patients ability or readiness to do the work	Mental/physical functioning Socioeconomic and psychological resources Literacy Language Social support Attitudes and beliefs about health care	How would you describe your general approach or attitude toward taking medicines?	• Do you ever find it difficult to remember to take medicines? • Do you ever experience any practical difficulties taking particular medicines or using devices? • Do you ever feel worried or concerned about the medicines you take? If so, have you shared these worries or concerns with anyone? What happened?
		For some people, the personal work of caring for their health condition can be emotionally challenging. Is this true for you?	• Are there any things that you do to “stay positive” or “keep your spirits up”?
		Has your health care affected you at all financially?	• Have you ever had difficulty accessing medicines that you need because of cost or availability?
Burden of illness How illness impacts capacity to undertake work by influence on function and capacity		Since your cancer diagnosis, have you noticed any changes in the way you feel about managing your overall health?	• Has there been anything to do with your cancer and its treatment (e.g. symptoms, feelings, hospital admissions) that has impacted the way you use medicines to manage your other conditions? • Has there been anything to do with your other conditions (e.g. symptoms, feelings, hospital admissions) that has impacted the way you use medicines to manage your cancer?

Component	Areas of inquiry	Opening questions	Probing questions
Strategies implemented/ barriers encountered - Rationalized non-adherence, adaptive treatment work			
Workload-capacity interactions: How patients respond to imbalance in workload and capacity	Prioritization based on time or other constraints Synchronization of demands Mobilization and coordination of resources, limitations and their environments Improvisation of processes and routinize them into daily life The timing with which patients match resources to demands	Are there times when you find that it is difficult to do all the things that you have to do to maintain your health?	• Do you ever cut back on doing things for your health? • Have you ever needed to choose between managing your cancer and your other conditions? How did you decide? • Have you ever stopped taking or changed the dose of a medicine (with or without the Dr's knowledge) because you didn't like how it made you feel or didn't want to take it anymore?
		Are there things that you routinely do to make management of your health condition easier?	• Have you made any changes to do with the way that you use your medicines to make things easier for you?
Access, utilization, and self-care Satisfaction with, ease of access, continuity, transitions	Challenges/stressors that exacerbate felt burden Interpersonal challenges Financial challenges Medical challenges – self-care, providers, system	Tell me a little about the relationships that you have with your health care providers (doctors that prescribe your medications, pharmacies that supply it).	• Is communication between you and the providers particularly good or bad? Can you give an example to illustrate this? • Have relationships with any of your long term care providers changed since being diagnosed with cancer? How? • Have you ever been confused about information you've received, or where to go for help?
		In caring for your health, do you get support from other people?	• Who? • What kinds of things do they do to help you?
Outcomes Physical and mental health, disease control, role function		Thinking of all the things that you have to do to care for your health, how would you say they affect you or your life?	• Do your treatments or self-care affect your work, or your social and family life? • Has your healthcare ever created tension between you and other people? • Have there been any occasions in the past year where you've had to go to the ED or be admitted to hospital unexpectedly?
		Is there anything else that you would like to tell me about today regarding your health conditions and how they are cared for?	

3.3.1.2 Specific Considerations – Pharmacist Study

The pharmacist study aimed to explore and interpret the professional experiences of pharmacists who provide the MMS available to Australians living with cancer in community and hospital settings. The objectives addressed by the pharmacist study have been detailed in Chapter One and illustrated in Figure 17, presented at the beginning of the chapter.

Setting and period of study

The pharmacist interview study was conducted between February 2017 and December 2018. There were two major considerations to be made when considering the setting for studying the different sub-populations of Australian pharmacists (primary care and specialist HONC): population size and expected homogeneity.

Population size was important to consider for both recruitment and ensuring anonymity. As of June 2016, when the research was being designed, there were 1,973 pharmacists in South Australia holding General Registration with the Pharmacy Board of Australia, the majority of which practiced in primary care. Much fewer work in a hospital setting, of which only a small number work in the specialist field of HONC. It was expected that there would be a level of homogeneity regarding the professional experiences of the different sub-populations, but to a higher degree within primary care pharmacy because they are governed by national professional bodies and are expected to deliver Commonwealth funded MMS programs (HMR and MedsCheck) to agreed national standards. Hospital based MMS however are funded by State Governments and delivered under independent governance models, leading us to expect a greater amount of variation in service delivery. For these reasons, it was decided that recruitment of primary pharmacists would be maintained within the limits of South Australia, and hospital pharmacists nation-wide.

Eligibility criteria and sampling

To be eligible for recruitment, individuals were required to identify as a pharmacist registered to practice with the Australian Pharmacy Board and in employment where they may be required to provide direct patient care to people managing cancer and coexisting chronic conditions. A purposive sample of pharmacists was sought out to gain an understanding of the similarities and differences that are encountered within different practice settings. Because many pharmacists undertake roles that are multifaceted or have more than one employer, this was represented as practice profiles.

Recruitment of pharmacists occurred through existing professional networks utilising professional associations (e.g. Society of Hospital Pharmacists of Australia, Clinical Oncology Society of Australia) and publicly available contact details (e.g. list of accredited

pharmacists). Potential participants who expressed interest were provided with a participant information sheet and consent form and an opportunity to answer any questions prior to the interview taking place. If agreed, the interview was arranged at a time and place convenient for the participant, with an option of a telephone interview. Informed written consent was obtained by the researcher prior to the interview commencing, with telephone interviewees asked to provide verbal consent, documented in the interview recording.

Conduct of interviews

One on one interviews were conducted using a semi-structured approach using a pre-defined interview schedule as a guide for questioning designed to explore each of the study objectives (Table 5). Interviews were conducted at a mutually agreeable location, either the participants place of business, university office, public place, private residence or by telephone. All interviews were audio recorded and were 20 to 60 minutes in length.

Ethical considerations

This study was approved by the Southern Adelaide Clinical Human Research Ethics Committee on January 25, 2017 (462.16).

Informed consent was obtained by the researcher prior to the interview taking place. Potential participants were provided with a participant information and consent form, along with an opportunity to discuss the study and raise any concerns. If they agreed to participate, they provided their consent either in writing or verbally in the case of a phone interview, occurring at the beginning of the audio recording.

Written consent forms were kept in a secure location and audio files were stored electronically on the university network. An identifying number was assigned to each participant upon transcribing the interviews verbatim and used to identify all records used for analysis. I also needed to consider the privacy of individuals and organisations that were spoken about. Any information with potential to identify individuals or their workplaces was removed from the transcript to promote anonymity.

Table 4: Interview schedule for pharmacist study

Area of inquiry (objective addressed)	Opening question	Probing questions (Examples to be used as needed)
Context – role of the pharmacist in cancer care	Can you start by telling me a bit about how you are currently practicing as a pharmacist?	Do you have many patients who are… • going through acute cancer treatment? • being chronically managed on oral anti-cancer therapy? • have a history of cancer? What do you see is your role as a pharmacist providing care to people with cancer?
Concept of multimorbidity (Obj 2.1)	Thinking about multimorbidity. *Can you tell me a bit about what you understand by the term multimorbidity?*	• Do you think it's a big issue? • How does it affect you in your everyday practice? • What do you see is your role as a pharmacist providing care to people with multimorbidity?
	Thinking of the patients you've encountered with multimorbidity in general (i.e. not necessarily cancer). *Can you think of any examples where you've identified problems with their overall medication management that have been easy to resolve?*	• What was the problem/concern? • What happened? • Is there anything you think helped to resolve the problem? • Is there anything that could have helped you manage the problem better?
Concept of multimorbidity in the context of cancer (Obj 1.1, 1.2, 1.3)	Thinking of the patients you have encountered who are managing cancer and a chronic condition. *Can you think of any examples where you've identified that they were having problems with their overall medication management? (e.g. compliance etc.)*	• What was the problem/concern? • What was the outcome? • What did you have to do to resolve it? • Is there anything you think helped or hindered resolving the problem? • Is there anything that could have helped you manage the problem better?
	Thinking of the patients you've encountered who are managing a chronic condition while going through acute cancer treatment (chemotherapy, radiotherapy etc.). *Can you think of any examples where you've identified any drug related problems or concerns regarding their non-cancer conditions? (e.g. dosing, appropriateness of therapy etc.)*	• What was the problem/concern? • What was the outcome? • What did you have to do to resolve it? • Is there anything you think helped or hindered resolving the problem? • Is there anything that could have helped you manage the problem better?
Closing	*Is there anything else you'd like to tell me about providing medication management services to people who are managing cancer and chronic conditions?*	

3.3.1.3 Data analysis and interpretation

While the data analysis and interpretation of the pharmacist and patient interviews studies occurred independently, there was considerable overlap in the methods employed. The description of the data analysis and interpretation process for both interview studies has been presented together to avoid needless repetition.

Preparing the interviews for analysis

Each participant was assigned a pseudonym (patient study) or number (pharmacist study) following interview completion. This was used for all records used in data analysis. I

personally transcribed each of the Interviews in full. Any details that could be used as an identifier of an individual or institution were removed and replaced with a place holder, such as [spouse], [oncologist] or [public hospital]. Transcribing the interview allowed me to become familiar with the interview content, which I further developed through reading of the transcripts and checking for accuracy against the recording. No external validation of the transcripts was undertaken.

For the patient study I wrote a narrative for each participant outlining the story they shared with me in the interview to capture the overall context and feeling of the encounter as well as some personal reflection, and example of which is presented in Figure 7.

Across the small kitchen table sat Cass, a large woman who looked as though she had lived through more than her fair share of rough moments in her life. There was a smell of cigarettes, and the linoleum floor had a certain stickiness to it. Over the next 49 minutes, Cass shared some of her story with me in a gruff and unfiltered manner that never had me doubting her authenticity.

She was 45 years old when she found a lump in her breast just under a year ago. A difficult scenario for anyone to deal with, even more so when you have schizophrenia and bipolar disorder to manage as well.

Cass spoke about feeling suicidal and refusing treatment when she was first diagnosed. How she ended up in a psychiatric unit for ten days after having a double mastectomy. How she struggled to pay for unexpected medical bills. How she needed to take ongoing antibiotics and requiring further surgery to manage boils that were present under her arm since her operation.

She told me about her CPAP mask no longer fitting and working for her sleep apnoea since she lost 30kg. How she was admitted to hospital because her chemotherapy combined with her clozapine wiped out her white blood cells completely. The challenges of attending radiotherapy sessions each day for six weeks, while maintaining her psychiatrist appointments and not being able to drive or manage public transport.

When I tell Cass's story, I see a difficult and challenging journey. I see risks that could have been reduced, or even eliminated through early intervention. But Cass didn't tell it this way. It was just how it was to Cass. When talking about her oncology team, "I can't fault them Lauren, they've been brilliant. They have been absolutely brilliant. I even brought a thank you card".

Figure 7: Example of a case narrative

Approach to coding and analysis

Analysis and interpretation of the data obtained from interviews was based upon a *reflexive thematic analysis* approach. I chose to use reflexive thematic analysis as the approach for the analysis of the data obtained in the interview studies because it provided a good fit with the epistemological relativism that underpins this research. As with other forms of thematic analysis, the reflexive approach is concerned with identifying patterns of meaning in data to address a specific research question (Braun & Clarke, 2020). But unlike approaches to thematic analysis where themes are described as being uncovered through the process of coding of data, themes in reflexive thematic analysis are said to emerge as an outcome of coding through the active involvement of the researcher (Braun & Clarke, 2020). It is not a

method designed to enable findings to be reproduced by an alternative researcher undertaking the same methods, thus aligning with a relativist epistemology. In practical terms, this means that reflexive thematic analysis does not utilise methods such as coding frameworks, codebooks, inter-rater reliability, or thematic saturation. Instead, it utilises an iterative process of data familiarisation, coding, theme development and revision to make sense of data in order to address a specific research question (Braun & Clarke, 2020). Braun and Clarke developed reflexive thematic analysis to provide those who are new to qualitative research with a scaffold to learn the skills of thematic analysis. As a novice researcher, I found this scaffold to provide helpful guidance on how to structure the process of data analysis in a way that was neither too vague, nor too prescriptive.

NVivo software was used to assist in the coding of the interview transcripts to enable the conceptualisation of themes. The coding process detailed below was in line with the reflexive thematic analysis approach, also aligning with that described by Saldana, utilising multiple cycles and methods (Saldana, 2015), illustrated in Table 6.

All interviews were coded according to attributes using case classification. For the patient study, these were demographic attributes relating to their social and clinical situation. For the provider study, these were attributes relating to their practice profile.

Each interview transcript was pre-coded using participants actual words (or as close to them as possible) or a simple descriptor. The aim of the pre-coding was to capture the essence of what the participants were saying without making any attempt to interpret meaning. This process helped gain familiarity with the content and determine preliminary codes by grouping similar phrases together.

First-cycle coding was used to gain a deeper understanding of the data. I used an elemental descriptive approach to simplify the preliminary codes. The level of interpretation during first-cycle coding remained descriptive. Second wave coding interpreted the first-cycle codes with a focus on the research objectives. This process of interpretive focused coding helped to make sense of the data in relation to answering the research questions and understand relationships between the codes.

Codes were then grouped into categories to provide an overarching description. These descriptive categories informed the development of initial themes, allowing for broader conceptualisation. Through an iterative process of writing, revision and continued examination and coding of data, themes were conceptualised that would tell the story of the

data. Table 5 provides examples of how this process occurred, drawing from both the patient and provider interview studies.

3.3.2 Scoping review

When I initially embarked on the literature review, my intended research outcome was to produce some type of practice-based intervention that was informed by the findings of my research. Because of this, I approached it as a traditional systematic literature review, with the aim of examining the effectiveness of patient-directed interventions designed to improve safe and effective use of medicines by people with cancer. As I progressed, I realised that my conclusion was destined to be that of so many other systematic literature reviews: "not enough high-quality evidence is available to draw conclusions about efficacy, more rigorous studies are required". I was unsatisfied with this, and it made me revisit if I was asking the right question. When I took a step back and looked at the literature review, I could see there were two types of interventions being reported: interventions specifically addressing adherence to cancer-related medicines, and more general medication management interventions. It became clear to me that a traditional systematic review was not appropriate. Even within the subset of papers that were assessing adherence, there were no common outcome measures and the methods employed were so variable that it was like comparing apples and oranges. Because of this, it was not possible to aggregate findings or demonstrate an effect size mathematically in a meaningful way. In time, I came across an editorial by Greenhalgh, Thorne and Malterud challenging the "spurious hierarchy of systematic reviews" (Greenhalgh et al., 2018). This emboldened me in my position to revise my literature review and pursue it as a narrative review, this time addressing a different question.

Rather than focus on effectiveness of the PC-MMS initiatives, I decided to focus on the structure of the models of care investigated, and how they compare to the generic PC-MMS initiatives that are readily available within the community. The purpose of this review was to gain insights into the types of PC-MMS initiatives that specialist cancer services are providing, not to achieve a clear and definite picture. This was based on the assumption that if a hospital implemented a locally developed PC-MMS initiative, it would likely be developed through a practice-based research activity that attained specific funding, or it would be a matter of implementing a service that already had a body of evidence to support it[37]. With the

[37] It was already assumed that hospital-based services may provide PC-MMS initiatives based upon the pharmaceutical care evidence base, such as hospital outreach medication reviews SHPA. (2020). *Hospital-initiated medication reviews*. shpa.org.au

Table 5: Coding process examples

Verbatim from transcript	**Pre-coding** (Represent participants' words)	**First-cycle coding** (Organise pre-coding)	**Second-wave coding** (Focus on research objectives)	**Categories** (Describe code groups)	**Themes** (Conceptualisation of coding)
"they're also giving me that injection". *"Maxolon I've been on while I'm having chemotherapy"* *"I have to use special creams".* *"I go and get hooked up and I sit there for over six hours".* *"They gave me something for vomiting"* *"He gave me all these drops"* *"They give you that nausea tablet"* *"They sent me home with a pack"* *"that's the one they gave me when I left the hospital for pain relief".* *"The hospital give you them [loperamide]"*	New medicine Chemotherapy Anti-nausea Cream Fluids Eye drops Pain relief GI medicines Supply	Anti-cancer treatment Symptomatic treatment New medical problem	1.1 Impact of medicines on workload of demands	• Acute changes in medication management • Acute chemotherapy treatment • Learning about newly initiated medicines • Obtaining supply	Logistical work involved with implementing the care plan. • Work associated with in-home medicine use. Intellectual work of making sense of the current state • Learning about newly initiated medicines
"I didn't take my oral medication because I was vomiting". *"I stopped taking that back when I couldn't get anything down my throat".*	Vomiting oral meds Can't swallow oral meds.	Swallowing issues GI symptoms	1.2 Medication-related issues	Gastrointestinal effects of cancer and its treatment	Tangible experiences • Physical challenges of administering medicines
"For people with diabetes the steroids they take often mean their blood glucose levels go very high" *"Managing their blood sugar control does get troublesome"* *"they're already diabetic and their sugars go through the roof"*	Diabetes and steroids	Drug-patient interaction Clinical signs and symptoms	1.2 Types of medication-related issues	Clinical signs and symptoms relating to underlying condition.	Problems related to drug-related risk. • Exacerbation of underlying conditions
"There were arguments between" *"The doctor threw his hands up and said Well I don't know what she should be on"* *"I was the go between the GP and specialist".* *"The piggy in the middle"* *"I've been able to kind of work out a plan".* *"There was a little bit of working out with the cardiologist"*	Arguments Confusion Go between Piggy in the middle	The 'Go-Between'	2.1 The roles of MMS providers	Provider-facing roles Improve transfer of information	Patient-centred MMS roles • The intelligence officer

Verbatim from transcript	**Pre-coding** (Represent participants' words)	**First-cycle coding** (Organise pre-coding)	**Second-wave coding** (Focus on research objectives)	**Categories** (Describe code groups)	**Themes** (Conceptualisation of coding)
"I was going ah sugar rushes a lot and I was going down to two and so I had to build it up again. And then I put it down when I had to, I worked it out."	I had to/I put it/ I worked it out	Self-management Recognising medication-related issues	1.3 Tactics employed by patients and HCPs	Active actions taken by patients. Timely recognition of issue Self-management skills	Utilising resources already present within the patient world. • Independently managing day-to-day
Mandy's story describing her concern about using her MS medication throughout chemotherapy due to risk of excessive immunosuppression and JC virus and having to self-advocate to the care team	Drug interaction Medication concern Communication issues	Self-advocacy Recognising medication-related issues	1.3 Tactics employed by patients and HCPs	Timely recognition of drug interaction Self-management skills Management strategy agreeable to patient Active actions taken by patient.	Bringing in external resources from the system of care
"The infectious diseases team is very heavily involved" *"The protocol is to refer them into endocrinology"* *"Endocrine come and see them during their stay"* *"We get a psych review"*	Endocrinology Psych Infectious diseases Referral	Care team response Recognising medication-related issues	1.3 Tactics employed by patients and HCPs	Proactive response Active action taken by care team	Proactive tactics embedded into the system of care
"I don't tend to see them". *"they're not the referrals I would usually get".* *"I don't see many cancer patients".* *"I don't see that many people with cancer".* *"I don't get a lot of referrals for patients for that".* *"Not people actively receiving chemo"* *"I can't actually think of one where it's active treatment"*	Not seen No referrals	Not referred for HMRs	2.3 Constraints that effect achieving timely and appropriate management of medication-related issues	Generalist pharmacists perceptions relating to cancer care	Time and place

benefit of hindsight and further reading, I now understand that the methods employed in the literature review could best be described as a scoping review (Munn et al., 2018).

3.3.2.1 Aim

The aim of the literature review was to critically examine the overall body of empirical evidence assessing PC-MMS[38] in non-hospitalised adult cancer populations. Specifically, it aimed to compare the elements of the reported interventions to the common elements of the generic community-based PC-MMS initiatives[39].

3.3.2.2 Search strategy

A systematic search of the databases Medline, PsychINFO, CINAHL and EMBASE was conducted using the following search terms/medical subject headings (MeSHs): “Medical oncology” or “oncology nursing” or “oncology service, hospital” or “radiation oncology” or “neoplasms”, AND “Pharmacy” or “clinical pharmacy information systems” or “community pharmacy services” or “pharmacy service, hospital” or “pharmacy residencies” or "pharmaceutical services", “Medication adherence” or “medication errors” or “medication reconciliation” or “medication systems” or “medication systems, hospital” or “medication therapy management” or “patient medication knowledge” or "patient compliance" or “potentially inappropriate medication list” or “self-medication”. To ensure the results of the review reflected contemporary practice, publication dates were restricted to be between January 2000 and May 2019. Ongoing search through snowballing to identify articles of interest through reference lists and citation tracking through Google Scholar, monitoring of key publications until the end of August 2019.

3.3.2.3 Selection of studies

Abstracts of studies published in the English language were reviewed for inclusion according to the following eligibility criteria:

- *Participants*: adults with diagnosed malignancy (solid or haematological) in any care setting.
- *Intervention*: any intervention with a primary objective to optimise a medication-related outcome (e.g. adherence) which directly involved the patient.
- *Comparator*: only controlled experimental studies were included. Due to the likelihood of complex interventions, in addition to randomised controlled trials (RCTs) we also considered non-randomised controlled trials (NRCTs), controlled before and after

[38] Within the review, PC-MMS is used to describe any patient-directed intervention where the aim is to improve medication-related outcomes. Interventions targeting behaviours of healthcare providers (e.g. prescribing) or the system context (e.g. protocols) are not discussed. This literature review is concerned only with MMS activities that *directly* involve the patient. While it is likely that these
[39] Medication review (e.g. the Australian HMR program) and medication usage review (e.g. the Australian MedsCheck program)

studies (CBAs) and interrupted time series analyses (ITS) that met the EPOC criteria (EPOC, 2017).

- *Outcomes*: studies reporting on at least one objective outcome measure were included, such as a patient-reported outcome measure using a validated tool (e.g. medication adherence assessment), utilisation of health services (e.g. hospital admission). If uncertainty existed, the full text of the article was retrieved and reviewed.

3.3.2.4 Data extraction and quality appraisal

Full text articles were retrieved following abstract review to further determine eligibility. References were stored and managed in an Endnote database. A schema of papers inclusion in the study is included with the results, presented in Chapter Five. Two researchers[40] independently reviewed all papers considered eligible for the study using the Joanna Briggs Critical Appraisal Checklists for randomised controlled trials (JBI, 2017b) and quasi-experimental studies (JBI, 2017a). All papers were considered to meet the minimum quality standard for inclusion of the study, with no conflicts identified. For each paper, key data was extracted and documented on an Excel spreadsheet, including study details (design, aim, PICO, key findings), the nature of the intervention (why, what (materials and procedures), how, who, where, tailoring, results).

3.3.2.5 Analysis and interpretation

Borrowing from the hermeneutic approach (Boell & Cecez-Kecmanovic, 2014), mapping and classifying was undertaken to present the major concepts or outcomes of the literature in a concise way. Each study was mapped against the common elements of the Australian PC-MMS initiatives which were detailed in Chapter Two. A framework based upon seven of the elements of the business model canvas was developed to enable this cross-comparison.

Analytical framework

The analytical framework for this scoping review was based on the business model canvas (BMC), a sense-making tool designed to help organisations succinctly describe ways in which they go about creating, delivering and capturing value (Osterwalder & Pigneur, 2010). The BMC is comprised of nine constituent elements: value proposition, customer segments, customer relationships, channels, key partners, key activities, key resources, revenue and cost structures (Osterwalder & Pigneur, 2010). All elements excluding the financial elements of revenue and cost structures were adapted to form the

[40] Lauren Cortis and Prof. Paul Ward

analytical framework against which each of the interventions included in the review were analysed, detailed in Table 3.

Table 6: Analytical framework for the scoping review, informed by the BMC

Element	**PC-MMS-related description**[41]
Target population (or customer segments)	The groups of patients that the PC-MMS provider aims to reach and serve
Value proposition	The problem or need that the PC-MMS intends to solve for the patient.
Recruitment (or channels)	The way in which the PC-MMS provider communicates with and reaches their target populations to deliver their value proposition
Patient relationships (or customer relationships)	The types of relationships an PC-MMS provider establishes with their specific target populations
Key resources	The resources that are essential to making the overall business model (or service model) function
Patient care activities (or key activities)	Those activities that are essential to making the business model (or service model) function
Key partnerships	The network of partners that make the business model work

3.3.3 The Cynefin Framework[42]

The Cynefin Framework was used to make sense of the overall research findings and bring them together into a unified explanation. Cynefin was developed by Dave Snowden through his consultancy work in knowledge management. To understand the utility and theoretical basis of this framework we should start by briefly exploring the theory on which it is based.

3.3.3.1 Anthro-complexity: the theoretical foundation of Cynefin

The Cynefin framework is built upon a multidisciplinary theoretical framework which Snowden refers to as *anthro-complexity.* Similar to traditional complexity science approaches[43], anthro-complexity maintains the position that natural science and our knowledge of the three systems that exist in nature (ordered, complex and chaotic) can be applied to human systems. But unlike traditional complexity approaches, anthro-

[41] Adapted from the definitions in Osterwalder et al Osterwalder, A., & Pigneur, Y. (2010). *Business model generation*. John Wiley & Sons.
[42] This explanation represents an overall synthesis of my learnings about Cynefin, that have all been based upon the work of Dave Snowden and Cognitive Edge, including various workshops and readings that are detailed within the bibliography.
[43] Traditional complexity science approaches are sometimes referred to as the Santa Fe Institute approach owing to what is widely renowned as the home of complexity science Waldrop, M. M. (1993). *Complexity: The Emerging Science at the Edge of Order and Chaos*. Touchstone PR.

complexity argues that human systems have unique features that make them different to other complex adaptive systems (CAS) meaning their true complexity can never be fully described. As described by Archer's theory of analytical dualism, humans maintain multiple identities and can fluidly shift between them in unpredictable ways (Danermark et al., 2019). Humans are also able to demonstrate intentionality in decision-making and ascribe intentionality to behaviour of others even when there is none, meaning our actions are not always in accordance with predetermined rules (Kurtz & Snowden, 2003). Unlike other CAS where agents are restricted to locally available knowledge, humans are able to draw upon knowledge and understanding that extends through time and space (Snowden & Stanbridge, 2004). As a species, we are able to create order through imposing structures and normative conditions (Snowden, 2005). In some circumstances, this can result in stability and predictability, while in others it can lead to chaos. This idea is foundational to the Cynefin Framework. It is precisely *because* all human social systems are CAS, that we cannot singularly pursue methods that are based upon a complex context and abandon approaches that apply to the ordered and chaotic, because the existence of multiple ontologies is an inherent feature of a CAS. Snowden refers to this as the principle of *bounded applicability*, saying "there are few if any context-free solutions, but many valid context-specific ones" (Snowden, 2021).

This principle of bounded applicability and dynamic view of human systems is reflected by the name Cynefin, a Welsh word that roughly translates to "*place of your multiple belongings*" (Snowden, 2021). It is this that makes Cynefin a sense-making tool rather than a categorisation model or contingency framework. A *contingency framework* is designed to reduce uncertainty for decision-makers. With these types of frameworks, you consider your situation against the criteria of the categories, select the category that best fits your situation and proceed with the prescribed course of action. By contrast, *sense-making*[44] is concerned with our human acts of reasoning; how we can *"make sense of the*

[44] There are five theories of sense-making, the most well-known of which is associated with Karl Weick whose work has focused on the behaviour of organisations Moore, D. T., & Hoffman, R. R. (2011). Sensemaking: A transformative paradigm. *American Intelligence Journal*, *29*(1), 26-36. . Weick, an academic social psychologist, positions sensemaking as a collective social act Weick, K. E., Sutcliffe, K. M., & Obstfeld, D. (2005). Organizing and the process of sensemaking. *Organization science*, *16*(4), 409-421. , something that is *"social, retrospective, grounded on identity, narrative, and enactive"* Sandberg, J., & Tsoukas, H. (2015). Making sense of the sensemaking perspective: Its constituents, limitations, and opportunities for further development. *Journal of Organizational Behavior*, *36*(S1), S6-S32. https://doi.org/10.1002/job.1937 . This thesis is based upon Dave Snowden's approach of *naturalising sense-making*, developed from a practice-based perspective through his work in knowledge management Snowden, D. J. (2021). *Cynefin- Weaving Sense-Making into the Fabric of Our World*. Cognitive Edge Pty Ltd. .

world around us so that we can act in it" (Snowden, 2010). The Cynefin Framework views uncertainty as an inherent feature of a CAS. Rather than trying to reduce uncertainty, it aims to support decision-makers to take appropriate action in spite of it.

One of the reasons that uncertainty is an inherent feature of a CAS relates to boundaries. CAS are in a constant state of flux as they interact with their environment. Because of this they do not have hard and precise boundaries. Rather, boundaries within CAS are fuzzy and ambiguous. This applies not only to the broader CAS, but also to any sub-systems within it that remain open to their environment. Therefore, it follows that if the social world is considered a CAS, any boundaries that divide it into sub-systems, such as an organisation or departmental unit, maintain a degree of ambiguity. From this perspective, boundaries must be considered as a way of helping us describe and understand the world rather than being considered to be an accurate depiction of it (Cilliers, 1998). Understanding that boundaries are used to make sense of the world and are inherently uncertain is foundational to the Cynefin Framework.

3.3.3.2 A worked example

It is somewhat ironic that the Cynefin Framework is referred to as a sense-making tool because in my experience it makes little sense until you actually start working with it in practice. While it has strong theoretical foundations, Cynefin was designed to be a tool to facilitate shared understanding in participatory workshops where the framework (and more importantly, the insights) emerge from the data. To try and capture this, let us work through an example using the four-points method (Cognitive Edge, 2021e).This worked example will serve a dual purpose of introducing the framework and detailing the methods that have been used to undertake the interpretation of findings that have been presented in this thesis.

Cynefin should begin with a data set identified through a process of *discovery*, ideally sourced through the narrative experiences. Our exemplar data set is listed in Figure 8, based my a priori knowledge informed by my professional understanding and experiences with medication access and supply. The data set used within the thesis was sourced from the interview studies.

• Post-operative nausea and vomiting protocol • Pharmaceutical benefits scheme (general) • Pharmaceutical benefits scheme (authority) • Pharmaceutical benefits scheme (fraud) • Therapeutic guidelines • Off label use (evidence-based) • Off label use (no evidence)	• Self-initiated medication selection (pharmacy) • Self-initiated medication selection (supermarket) • Self-initiated medication selection (internet) • Chemotherapy prescribing • Hospital drug formulary • Hospital clinical guidelines • Black market medication supply

Figure 8: Exemplar data set

We start with what is essentially a blank piece of paper or whiteboard, with a note placed at each corner and a shaded area in the middle, as shown in Figure 9. These four notes form the anchor points for the framework. For the worked example, I have identified the anchors based on my understanding of Cynefin. The note in the bottom right corner reads “Follow pre-set rules, little room for clinical judgement”, the top right reads “Some degree of clinical judgement, within parameters”, the top left reads “Reliant on clinical judgement, professional standards and legislation”, and the bottom left reads “Unprofessional and/or illegal”. In a workshop setting the facilitator would help the group identify these anchor points, allowing them to reach a shared understanding of the Cynefin Framework without needing to understand the underlying theory.

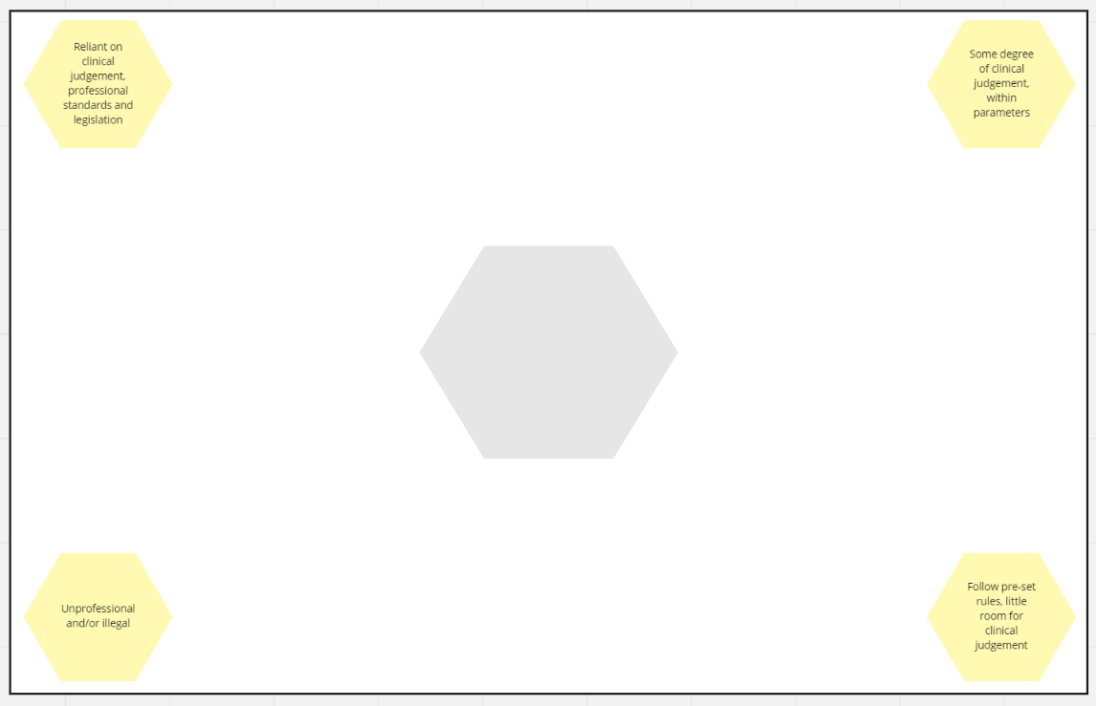


Figure 9: Four-points Cynefin – anchor points

In a group setting, they would be instructed to write each data point from Figure 8 onto an individual sticky note and to place each note on the board where they think it fits relative to the four anchor points. If there is uncertainty, the data point should be placed in the central grey area for further consideration, as illustrated by the “chemotherapy prescribing” data point in Figure 10.

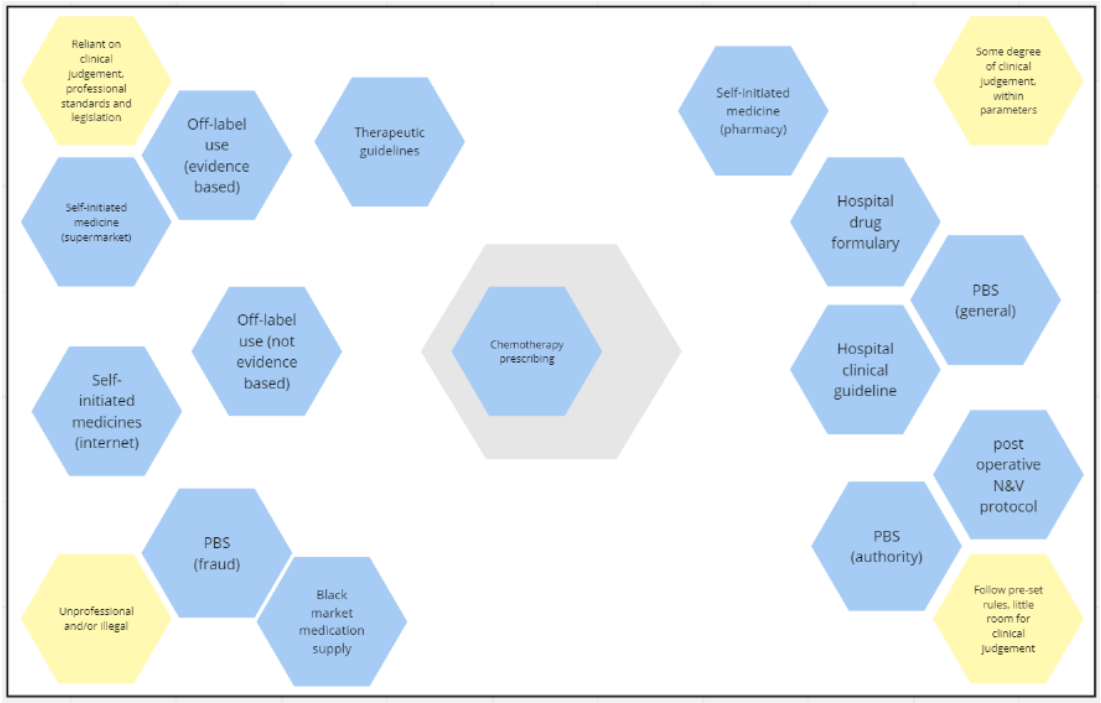


Figure 10: Four points Cynefin – phase one

When considering the data where there is uncertainty, it may be appropriate to increase the granularity of that data point by breaking it down further. In this worked example, chemotherapy prescribing could be broken into “chemotherapy on protocol” and “chemotherapy off protocol,” as illustrated in Figure 11. Prescribing undertaken for “chemotherapy on protocol” occurs within strict limits allowing little room for clinical judgement, while prescribing for “chemotherapy off protocol” allows clinicians to exercise a higher degree of clinical judgement.

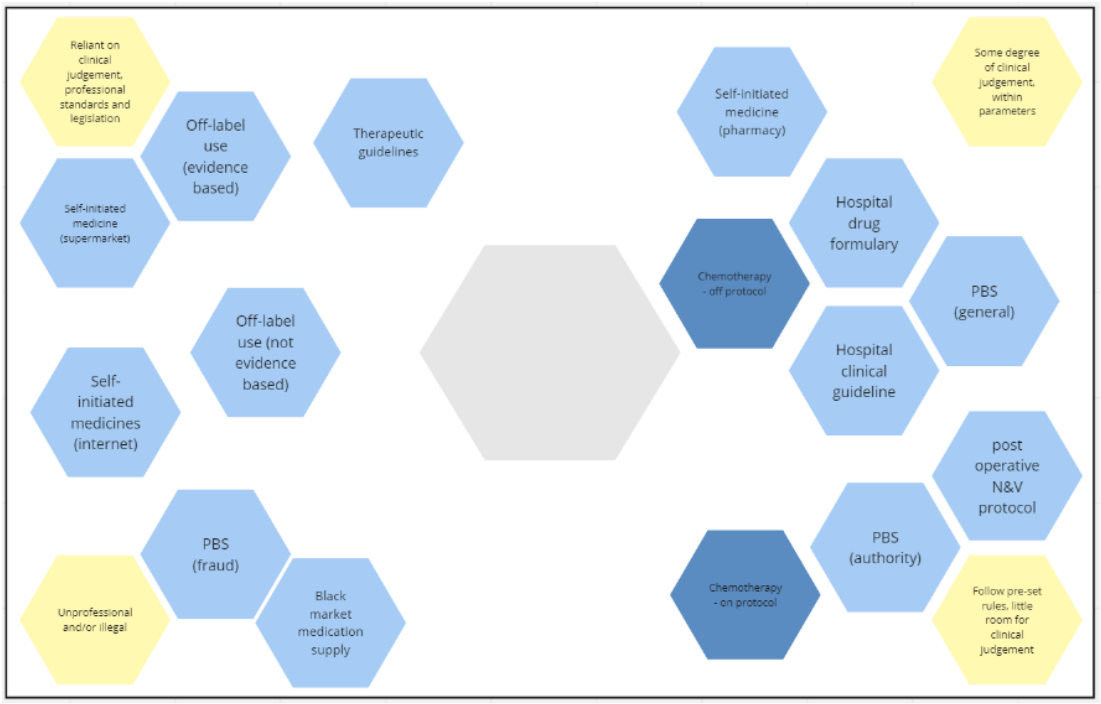


Figure 11: Four points Cynefin – phase two

Once the group are satisfied with how the data have been mapped in relation to the anchor points, four ribbons (or lines) are used to demarcate the data points that unambiguously fit within each domain, as illustrated in Figure 12. This may leave some data points where uncertainty remains. In this example, “self-initiated medicines (internet)”, “off label medicine use (not evidence based)”, and “hospital clinical guideline” all remain in the central zone.

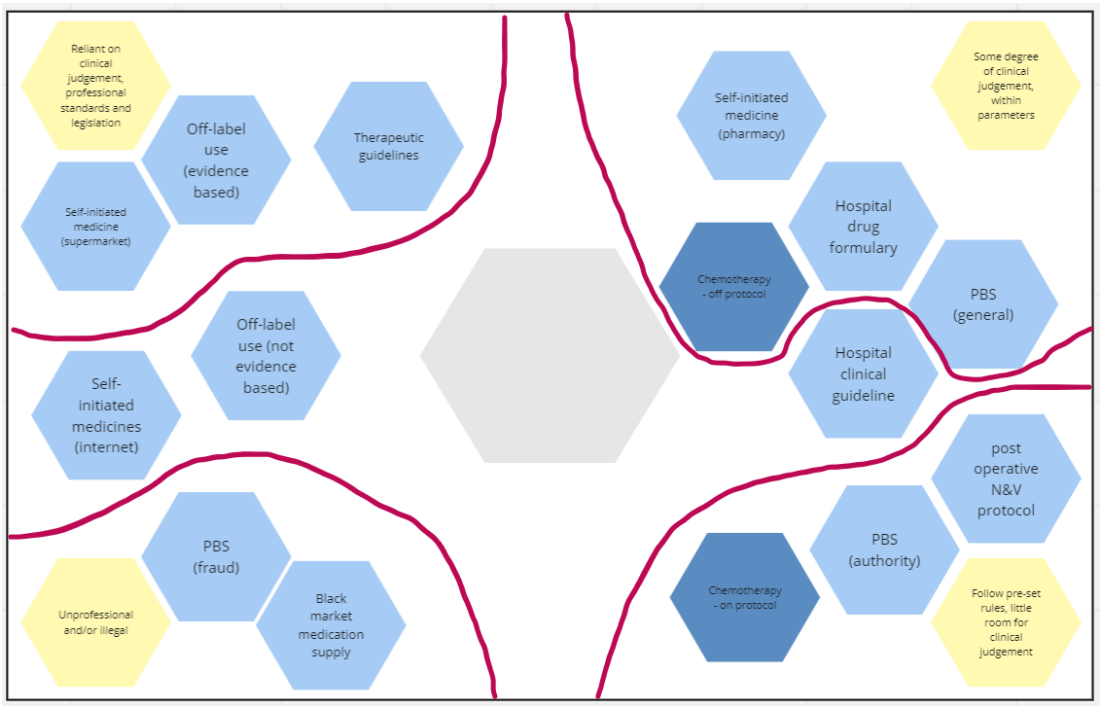


Figure 12: Four points Cynefin – phase three

Any data points that remain in the central zone require further consideration. As described above, this may require breaking data points down to provide increased granularity. In this example, “off-label use (non-evidence based)” is broken into that which is founded on reason, and that which is unfounded. In a group setting, achieving increased granularity will involve discussion and debate which continues as an iterative process until the group reaches a collective view where all data points fit comfortably within each of the four contextualised domains, as illustrated in Figure 13. The result is a contextualised model where all data points are mapped to the Cynefin Framework. By undergoing a *sense-making* process of working through each data point, the group achieves a shared understanding of the nature of the data and its context. This provides a solid foundation to identify develop contextually appropriate actions and *insights for action*.

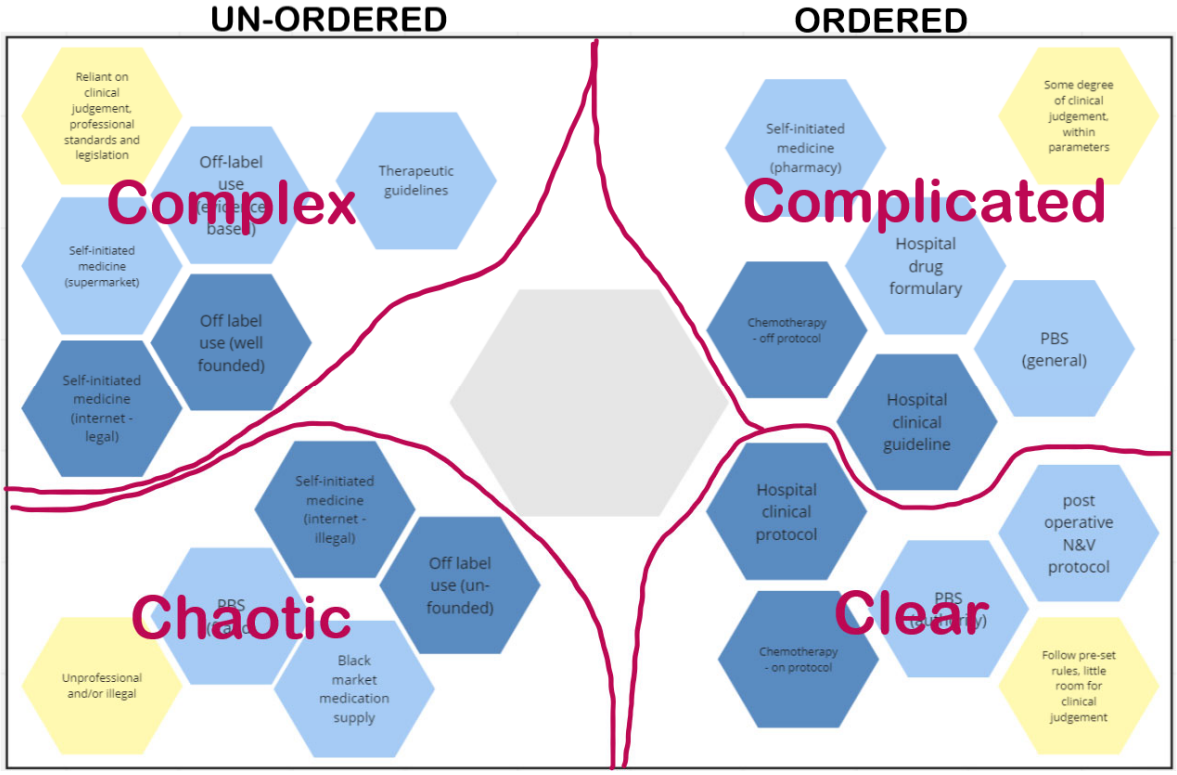


Figure 13: A contextualised Cynefin Framework

3.3.3.3 The Cynefin domains

By working through the above example, we have arrived at a contextualised understanding of the Cynefin Framework. The central grey area is known as the A/C (aporia/confused) domain. As illustrated by the worked example, this serves the purpose of an epistemological domain, used to recognise and reflect on data of which we are uncertain. It is epistemological in the sense that it is concerned with the process of understanding what we know rather than the nature of reality itself.

The four areas at each corner are ontological domains because they relate to how things are, or the nature of the context in which the data point is situated. On the right-hand side

are the ordered domains. There is limited variability in the behaviour of agents[45] within an ordered system due to the presence of active constraints. Within a *clear* context these constraints are rigid, designed to tightly control the action of agents. This results in highly predictable patterns of behaviour, allowing the relationship between cause and effect to be easily identified. Agents acting within a clear context are able to sense their surroundings, categorise the scenario and apply best practice. Constraints within a *complicated* context are more flexible, used to govern the action of agents without controlling it. Rather than working toward a single best way of doing things, agents acting within a complicated context must sense their environment, analyse it, and respond in order to achieve good practice. This results in a higher degree of variability in agent behaviour, but it remains relatively predictable to those with relevant expertise.

On the left-hand side are the un-ordered domains of complex and chaotic. There is a high degree of variability in the behaviour of agents within unordered systems. Constraints within a complex context are enabling in nature, designed to impact the disposition of the system rather than control the agents within it. The entanglement of inter-connections that exists within a complex system means that the discrete relationships between cause and effect do not exist. Because of this, future behaviour cannot be accurately predicted by past behaviour, limiting the role of analysis and categorisation. Instead, it is more appropriate for agents within a complex context to probe the system with an action that they think is a “good fit” with what change is trying to be achieved, seeing how it reacts and responding appropriately. If there is a favourable response it should be amplified, while if it undesirable responses must be dampened. The result is practice that is described as exaptive, meaning it repurposes existing capability by translating knowledge from one context and applying it to another. Constraints within a *chaotic* context are either absent or ineffective, meaning that actions of agents and resultant outcomes are inherently unpredictable. There is an urgent need to act in a chaotic context. Owing to this, the appropriate approach to decision making in chaotic contexts is to take action, sense the reaction, and respond, resulting in practice that is novel and innovative albeit stress induced.

3.3.3.4 Dynamics in Cynefin

The Cynefin Framework can also be used to capture the dynamic nature of human systems and their ability to shift between complexity and the ordered or chaotic domains. Snowden uses the analogy of water shifting in phase to describe this. Water shifts phase

[4545] An agent is considered anything that is able to act within a system or context, not limited to individual humans but could also be a collective group, a form of technology, or even a pervasive social narrative Snowden, D. J. (2021). *Cynefin- Weaving Sense-Making into the Fabric of Our World*. Cognitive Edge Pty Ltd.

through the breaking and formation of hydrogen bonds, influenced by environmental factors such as temperature and pressure. As with changing the state of water, transitions between domains require an input of energy that is focused on changing the interconnections between agents. Transitions between domains may occur intentionally or otherwise and are depicted in the framework by directional dotted lines. Intentional transitions are most likely to move from the un-ordered to the ordered. An example of an intentional transition from the complex to complicated domain would be the establishment of clinical guidelines arising from well-founded or evidence-based off-label use of medication, illustrated in Figure 14. Achieving this requires an input of resources, as guidelines are prepared and kept up to date over time. An example of an intentional transition from complicated to clear would be changing the PBS schedule of a medicine from general to authority; introducing more rigid constraints to tightly control prescribing habits. Maintaining the authority process requires an ongoing input of more resources than for the general PBS schedule. The transition from complicated to complex, or complex to chaotic may be intentional for the purposes of controlled experimentation to encourage innovation and novelty. Transitions from the clear to chaotic domain, however, occur across what Snowden describes as catastrophic fold. These transitions are most likely to occur unintentionally, resulting from over-constraining agents to the point where they develop workarounds or insubordinate behaviour. An example of this could be the tightly regulated prescribing of a medication making it difficult for patients to access, resulting in them seeking out supply from the black market. Oversight of this medication use becomes lost, as the patient acts independently from their doctor. Snowden uses the analogy of a cliff face to describe this boundary, explaining that it can be easy to fall off the cliff, but difficult to climb back up the cliff and restore order from chaos.

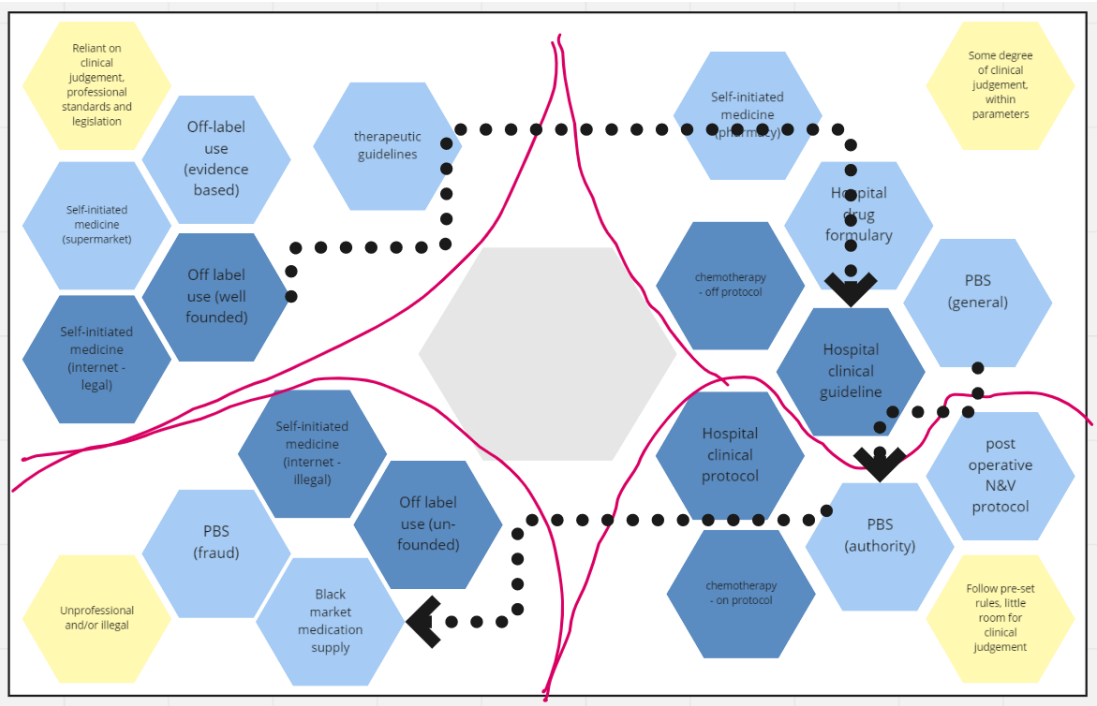


Figure 14: Dynamics in Cynefin

3.3.3.5 Cynefin diagrams

The Cynefin Framework was used to enable further interpretation of the research findings and move from a theory-based discussion about what interesting insights emerged from the lived experience to a practical discussion concerning how these insights can be used to identify actions that can be taken to incite change. As has been described, Cynefin is intended to be used as an epistemological device, seeking to better understand rather than describe an absolute truth. In a group workshop setting a contextualised Cynefin map would reflect the group's collective understanding. Within this thesis, Cynefin maps are used to communicate the understanding of myself, the researcher, to you, the reader. Some Cynefin diagrams have been used as tools to zoom out from the granular data to a more abstract perspective, while other times they have been used to dig deeper and provide a more enriched understanding of the data. This section will introduce the Cynefin diagrams that are used in the thesis, discussed in the order in which they appear and how they have been used to build layers of interpretation.

The first Cynefin diagram is found in Chapter Four, used to better understand the work activities and factors influencing capacity that result from cancer diagnosis and treatment, and how they shift throughout the cancer journey. This diagram is an abstraction of a Cynefin map that was developed using the previously described method. At the beginning of the mapping process, I was focused on the concrete, considering the discrete events within the patient's lived experience. As I continued in the exercise, I noticed that experiences relating to work of using medicines at the start of the patient's cancer journey were clustering in the clear domain, while experiences relating to the work of diagnosis

and treatment seemed to fit in the complicated domain. By contrast, the factors influencing capacity all appeared to fit within the complex domain due to the interrelationships that existed between them. Nothing was mapped to the chaotic domain for these mapping exercises because this represents my blind spots as a researcher, the unknown unknowns. The output of this mapping exercise is presented in Appendix I. The outcome of the exercise is that it helped me to conceptualise three distinct phases of the cancer journey: the starting conditions, diagnosis and treatment planning, and anti-cancer treatment. This outcome has been illustrated using the Cynefin diagram found in Chapter Four, Figure 22.

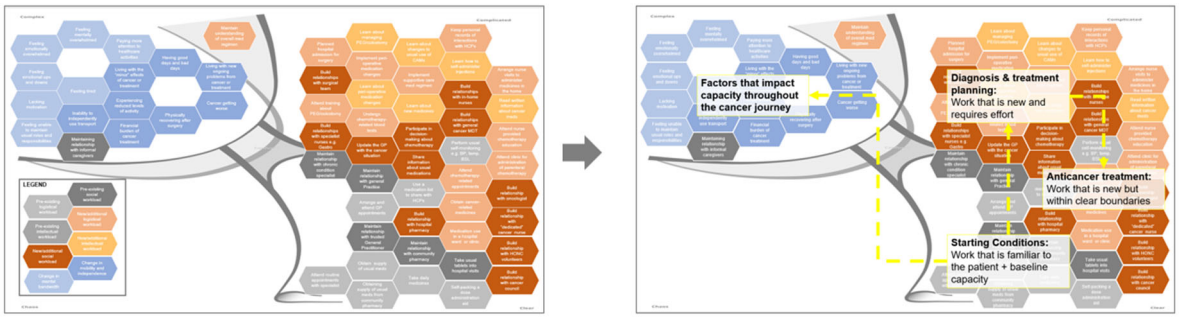


Figure 15: Development of the Cynefin diagram used in Chapter Four

The next Cynefin diagram found in Chapter Five is used to understand the types of medication-related issues that patients encounter throughout cancer diagnosis and treatment. Again, this exercise used the method described earlier in the chapter to develop an abstraction of a Cynefin map as illustrated in Figure 16. This started in the concrete, looking at the events that were described by patients and pharmacists and considering how easy it would be to identify the relationship between the lived experience and the underlying cause if it were experienced in real time. Those experiences I considered to have a clear relationship between medication and event were mapped to the clear domain, those that could be identified through analysis or expertise were mapped to the complicated, and those that required connections to be made between multiple information sources were mapped to the complex. Again, nothing was mapped to the chaotic domain because these experiences would not be recognised in real time, representing blind spots within the system of care. The output of this mapping exercise is presented in Appendix I. The outcome of the exercise is that it allowed me to better understand things from a systems perspective: medication-related issues are most visible if they exist within the clear or complicated domain. This has been presented diagrammatically using the Cynefin diagram in Chapter Five, Figure 24.

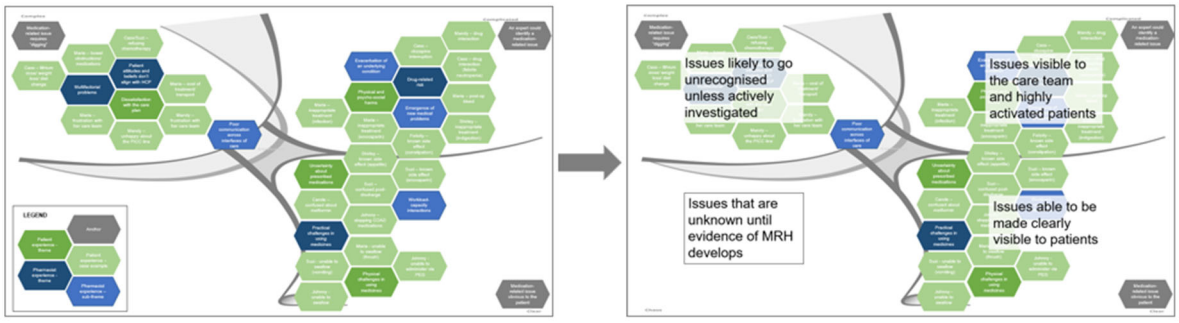


Figure 16: Development of the Cynefin diagram used in Chapter Five

Chapter Six presents a series of dynamic Cynefin maps. Again, these mapping exercises began in the concrete, this time relating to a specific patient experience. This experience was then broken down into constituent elements to provide a more enriched description what is occurring, comprising the small data set. Each of these data points was mapped to the Cynefin Framework, with directional lines indicating the sequence of events and resultant shifts in context that occurred. Like all of the mapping exercises, this required me to make choices that others may have approached differently. For example, I chose to map “prescribing of parenteral chemotherapy” to the clear domain because from my perspective, it is an activity where there are tight constraints that restrict the behaviour of the prescriber. A researcher with a different professional background may have considered it to fit better in the complicated domain, resulting in a different interpretation. Unlike the other maps described so far, these maps do utilise the chaotic domain. This is because we are able to use hindsight to illuminate blind spots that can only be identified in retrospect and would go unrecognised when experienced in real time. The outputs of these mapping exercises are presented in Chapter Six. The outcome of the exercise is that it helped me to undertake a series of case comparisons which allowed me to better understand the ways in which medication-related issues are responded to within the system of care, and how those tactics are impacted by the issue’s visibility, building on the knowledge contributed by Chapter Five as illustrated in Figure 17. This has been represented diagrammatically using the Cynefin diagram in Chapter Six, Figure 28.

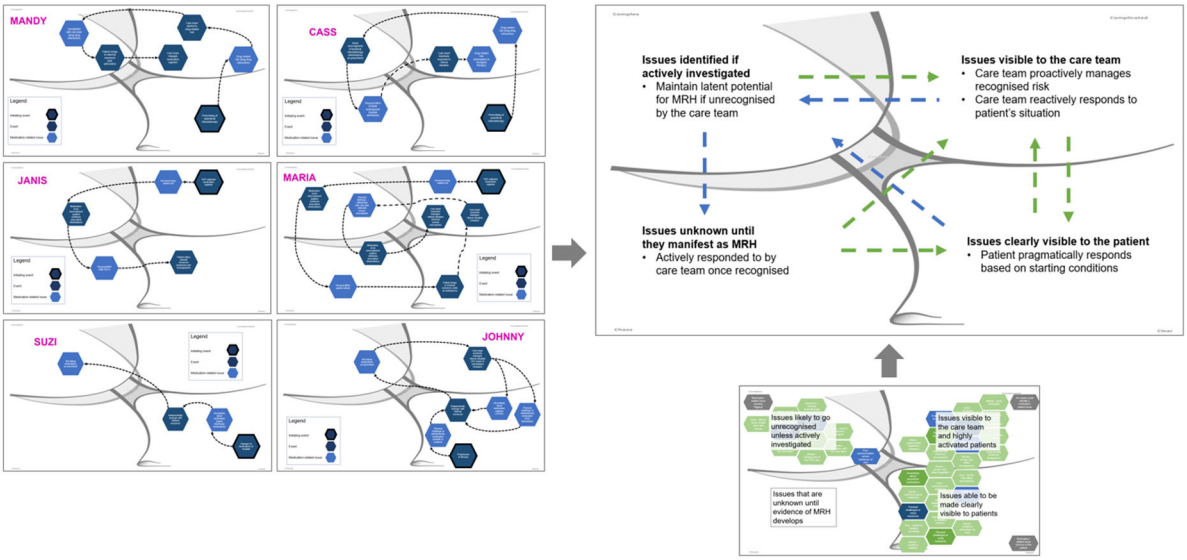


Figure 17: Development of the Cynefin diagram used in Chapter Six

At the conclusion of Section Two, Part A, a Cynefin diagram is used to provide a simplified illustration of health initiatives that could help people with cancer to achieve a timely and appropriate response to medication-related issues. This diagram is a further abstraction of those presented earlier in the thesis, as illustrated by Figure 18.

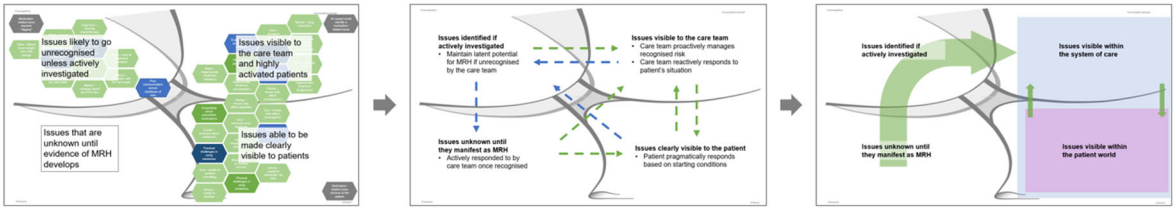


Figure 18: Development of the Cynefin diagram used in the summary of Part A

The Cynefin dynamics diagrams presented in Chapter Eight provide an abstraction of the research findings relating to objective 2.2, used to illustrate how the roles undertaken by MMS providers can shift the context in which decision-making occurs. This exercise allowed me to draw comparisons between the different roles and better describe their characteristics from a system point of view, showing how PF-MMS roles optimise functions that occur within the ordered domains, while PC-MMS roles bring medication-related issues into the ordered domains where they can be appropriately managed. This understanding was used to further develop the diagram presented at the end of Part A as illustrated by Figure 19.

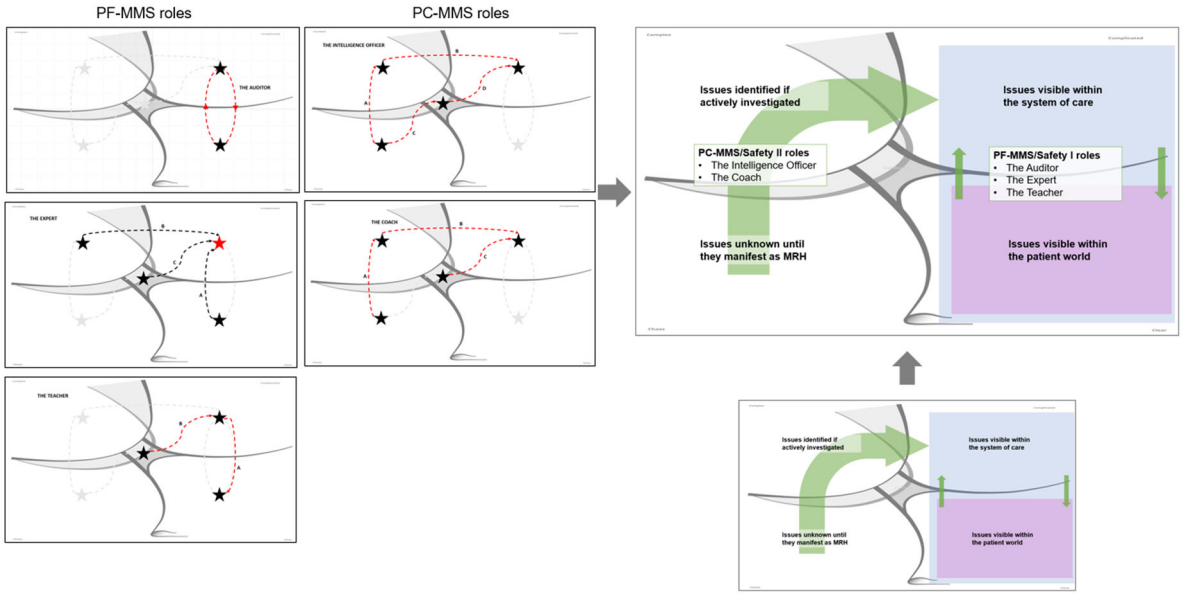


Figure 19: Development of the Cynefin diagram used in Chapter Eight

The final Cynefin diagram is presented in Chapter Nine. Again, this was developed as an abstraction of a Cynefin map as illustrated by Figure 20. This exercise started in the concrete, considering the pharmacists' lived experience. Constraints that were rigid in nature were mapped to the clear domain, those that were governing and allowed some degree of behavioural variation were mapped to the complicated domain, and those that were enabling and allowed for local variations in behaviour were mapped to the complex domain. No constraints were mapped to the chaotic domain because that domain represents an absence of effective constraint. The output of this mapping exercise is presented in Appendix I. The outcome of the exercise is that it helped to understand the feasibility of actions taken within the system of care: actions that influence constraints within the complex domain can be initiated from the bottom up to create local change within a short time-horizon, while actions taken from the top-down within the ordered domains enable broad scale change but require a longer time-horizon and investment of resources.

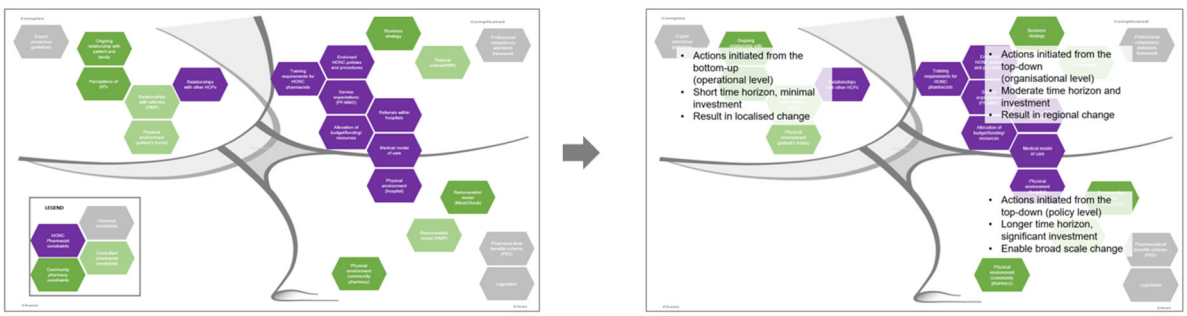


Figure 20: Development of the Cynefin diagram used in Chapter Nine

3.3.4 Modes of inference

This thesis moves from the concrete descriptions of participants to abstract conceptualisations of the system of care and finishes back in the concrete by identifying actions that can be taken to move from the current state to the desired future state. It does this by employing various modes of inference.

Modes of inference are the mental processes we use to derive conclusions and form arguments from sources of knowledge (Danermark, 2019). The two most commonly utilised modes of inference are deduction and induction. In addition to these processes of logical reasoning, this thesis also utilises abduction and retroduction (Danermark, 2019). This section provides an overview of each of these complementary modes, including examples of how they have been utilised within this research.

3.3.4.1 Deductive logic

Deductive arguments, or top-down logic, go from the general to the specific (Danermark, 2019). Deduction is a useful analytic tool, concerned with utilising theory to achieve certainty, reaching a specific conclusion which is described by its validity and soundness. A valid argument is one in which there is an indisputable link between the premises of the argument and the conclusion that follows. The truth of the conclusion is linked to the truth of the premises, and so it follows that a valid argument is not necessarily true. Soundness, on the other hand, refers to an argument that is both valid and one in which all the premises of the argument are known to be true (Danermark, 2019). As such, a sound argument helps us to determine what is true. Deduction is used an analytic tool and the only mode of inference that can determine certainty. However, it cannot be used to say anything about reality beyond that which is already known within the premises.

An example of deductive logic within this research is within the scoping literature review presented in Chapter Seven:

- Premise: best practice PC-MMS initiatives address the core service elements of patient-centred pharmaceutical care as defined by Cipolle et al (Cipolle, 2012)
- The null hypothesis: there is no difference between the cancer-specific MMS reported in the literature and the generic PC-MMS programs available in the community
- Results: the cancer-specific MMS did not address the defined core service elements of best-practice PC-MMS as consistently as the generic PC-MMS programs
- Deduced conclusion: Generic PC-MMS programs deliver care that is more comprehensive than the cancer-specific MMS reported in the literature

3.3.4.2 Inductive logic

Inductive arguments, or bottom-up logic, go from the specific to the general and use experience and observations of data to make generalisations to predict what might happen in the future (Danermark, 2019). Unlike deductive arguments, induction is not concerned with certainty and cannot be defined as valid or invalid (Danermark, 2019). Rather, induction seeks to bring us closer to the truth by describing what is probable in order to generate hypotheses or theory which can then be further tested. Induction is used to generate generalisations and hypotheses, moving beyond that which is known within the premises. However, its use is limited to the empirical domain and that which can be observed.

Examples of inductive logic within this research can be found in the analysis of the interview studies:

- Observed experience: Participants describe feeling the greatest amount of cognitive and emotional overwhelm during the weeks between cancer detection and diagnosis.
- Observed experience: Participants describe feeling at ease once they are connected to their cancer MDT.
- Pre-existing knowledge/experience: Patients come under the care of a cancer MDTs once they have a formal cancer diagnosis which can take weeks to months.
- Induced reasoning: Cancer MDTs help to reduce cognitive and emotional overwhelm.
- Alternate induced reasoning: Further support could benefit people during the diagnosis phase.

3.3.4.3 Abduction

Abduction uses all the information that is at hand to move toward a plausible explanation (Danermark, 2019). Unlike the modes of logical reasoning described thus far, abduction allows us to go beyond that which can be found in the empirical data and use all whatever information is available about known rules (premises) and observed effects to make an inference regarding a best possible explanation (Danermark, 2019). While it has a logical structure, abduction is not a form of pure logic. Rather, it has been described as a way of reasoning, thinking, and arguing in a wider sense (Mingers, 2015). Abduction is an interpretive act, involving the researcher to actively redescribe and recontextualize what has been observed within a different context of ideas (Reichertz, 2004). It allows the researcher to move from that which can be observed to the deeper layers of reality through forming associations and connections between data. Abduction is concerned with

what is plausible, intended to bring deeper understanding rather than identification of what is true.

Abduction is commonly employed as part of the process of clinical reasoning (Magnani, 2001). Not surprisingly, many of the examples of abduction within this research can be found in the interview studies where clinical reasoning was applied to make sense of described participant experiences:

- Observed experience: Cass described being admitted to hospital because "*my chemo bloods come back that a couple of my levels were really really dangerously low, so they had to stop my clozapine… I went into hospital and they put me on IV antibiotics*."
- Observed experience: At the time of hospital admission, Cass was taking clozapine and having parenteral chemotherapy. Hospital admission caused her chemotherapy and clozapine therapy to be put on hold.
- Pre-existing knowledge/experience: Concomitant use of clozapine with drugs that cause immunosuppression (e.g. chemotherapy) increases risk of febrile neutropenia (a condition involving low neutrophil count commonly encountered in people undergoing chemotherapy and treated with IV antibiotics)
- Plausible explanation: Cass experienced an episode of febrile neutropenia relating to her combined use of clozapine and chemotherapy

Care was taken to ensure that abduction was used to attain a deeper level of understanding of the events contained within a participant account, without superseding it. In all circumstances where a medication-related issue was identified through abductive reasoning, attempts were also made to convey the participants perception of the event and any emotional impact that it may or may not have had rather than merely reduce it to a technical explanation of events.

3.3.4.4 Retroduction

Retroduction does not involve a process of logical inference, rather it is a thought operation where we use the knowledge we have of one thing to create knowledge of something else (Danermark, 2019). Retroduction provides researchers with a mode of using rational thought processes to move between the concrete and the abstract, allowing research findings to be conceptualised more generally into an explanatory model (Mingers, 2015).

Five strategies for retroduction have been commonly used in research: counterfactual thinking, social experiments, studies of pathological cases, studies of extreme cases and comparative case studies (Danermark, 2019). In this section I will limit my discussion to

the retroduction strategies that were utilised in this research: studies of pathological cases, comparative case studies and counterfactual thinking.

Danermark et al describes the study of pathological cases as mode of retroduction "*where structural conditions are challenged and mechanisms are disturbed*" (Danermark et al., 2019). Within this research, the population of interest serves as an organically derived pathological circumstance in that people with cancer are at higher risk of experiencing MRH than the general population. By exploring how the system of care influences medication experience in high-risk contexts we can gain insights that directly apply to the population of interest and further develop our understanding of what occurs under 'normal' conditions experienced by the broader population. As Danermark et. al states "*we can learn about the conditions for the normal by studying the abnormal*" Danermark (Danermark et al., 2019).

Comparative case studies and counterfactual thinking were used in combination to compare a variety of patient experiences of medication-related issues. By mapping different experiences onto the Cynefin Framework, a process which is further discussed later in the chapter, I was able to compare the differences between what happened and what might have been.

Counterfactual thinking was used to explore the possible consequences or alternative outcomes of different scenarios. While we use abstraction to consider what might be, counterfactual thinking helps us to understand something by considering what it is not (Danermark, 2019). This type of counterfactual thinking was used in the interpretation of findings of the participant study. I employed counterfactual thinking to understand how the experience of people using medicines to manage a pre-existing condition at the time of cancer diagnosis may apply to those the who are in different circumstances by asking questions like "how would this have been if Mandy didn't self-advocate about her concern with the drug interaction?" and "what would the consequences have been if Suzi's vomiting had resulted in missing multiple days of her duloxetine?".

3.3.5 Promoting trustworthiness and rigour

There is longstanding debate regarding the quality of qualitative research and how it is best promoted in practice (Mays & Pope, 2000) (Popay et al., 1998). Several criteria for assessing quality exist, some of which are based upon a positivist paradigm, such as Lincoln & Guba's truth value, applicability, consistency, and neutrality, and Seale's Quality in qualitative research (Seale, 1999). Scholars including as Braun and Clarke contend that such criteria have limited applicability to research that employs qualitative methods within

a qualitative paradigm, which they refer to as “Big Q” qualitative methodology[46] (Braun & Clarke, 2020). They argue that while the quality of “Big Q” qualitative research remains important, it cannot be simply evaluated through criteria that is concerned with verifying the existence of a singular truth. Rather, trustworthiness and rigour must be established by being embedded in the researcher’s approach. This argument aligns with that of Mays and Pope, who suggest that “the basic strategy to ensure rigour, and thus quality, in qualitative research is systematic, self-conscious research design, data collection, interpretation and communication”(Mays & Pope, 2000). Reflexivity is critical to this approach, requiring the researcher to acknowledge how they have influence the research process, including their assumptions and biases, values and experiences (Mays & Pope, 2000). The following section seeks to provide this reflexive account and the steps that were taken with in the research to promote trustworthiness and rigour, using Popay et al’s markers of quality as a framework (Popay et al., 1998).

3.3.5.1 Evidence of responsiveness to social context and flexibility of design

“*Is there evidence of the adaption and responsiveness of the research design to the circumstances and issues of real-life social settings met during the course of the study*?” (Popay et al., 1998)

Qualitative research takes place within real life contexts, including all the mess that is involved in that. As such, it needs to be able to adapt to those circumstances as they exist, not just as they were planned to be (Popay et al., 1998) . As has been detailed in Chapter One and earlier sections of this chapter, I demonstrated flexibility and responsiveness throughout the entirety of the research process. From the formulation of the research question to the methods employed, to the analytical framework; executing this research involved a process of constant adaptation.

With regard to the conduct of interviews, I have provided the interview schedules that were used in each semi-structured interview study. This guide promoted a level of consistency whilst allowing me the flexibility to tailor my approach to the needs of the participant. Neither interview guide was changed throughout the duration of each study,

[46] “Big Q” qualitative methodology is described as “the use of qualitative techniques within a qualitative paradigm”, as compared with “small q” qualitative methodology, is described as “the use of qualitative techniques of data collection and analysis within a positivist paradigm” Braun, V., & Clarke, V. (2020). One size fits all? What counts as quality practice in (reflexive) thematic analysis? *Qualitative Research in Psychology*, 1-25. https://doi.org/10.1080/14780887.2020.1769238

however professional judgement was exercised in relation to the order of questions, use of probing questions and so forth.

3.3.5.2 Evidence of theoretical or purposeful sampling

"*Does the sample produce the type of knowledge necessary to understand the structures and processes within which the individuals or situations are located*?" (Popay et al., 1998)

The method of sampling employed in qualitative research must be fit for purpose (Popay et al., 1998). As explained earlier in the chapter, the purpose of the interview studies was to gain insight to the nature of the patient world and the system of care supporting medication management, there was no intent to describe a complete and accurate view of reality. In an ideal world purposeful sampling would have been employed in both interview studies. Unfortunately, my attempts for purposeful sampling in the patient study were thwarted by the practicalities of recruitment. As described earlier in the Chapter, I found myself in a position where I faced a choice between accepting a convenience sample or being significantly delayed. I was able to achieve purposeful sampling of key informants representing a variety of practice settings and levels of experience for the Pharmacist study however, this does not necessarily represent the full breadth of practice settings across Australia. While this approach to sampling introduces limitations to the research regarding its generalisability, it was deemed to fit within the philosophical position of the research which seeks to gain insight rather than establish a generalisable truth. As such, the sampling method for each study was deemed sufficient to address the research objectives of understanding how cancer diagnosis and treatment alters the nature of reality in the patient world, and analysing the system of care that supports the medication management of Australians living with cancer.

3.3.5.3 Evidence of adequate description

"*Is the description provided detailed enough to allow the researcher or reader to interpret the meaning and context of what is being researched*?" (Popay et al., 1998)

Popay et al argue that researchers must find ways of ensuring that the lay perspective is given equal worth to the professional one (Popay et al., 1998). Upholding this proved to be surprisingly challenging in practice. My professional experience and perspective was ever present, and I had to make conscious effort to ensure that my assessment of medication-related events that were described by participants did not supersede their lived experience. To achieve this, I located my interpretation within the data shared by participants in the interview studies, detailing participants accounts in their own words as much as possible as can be found in Section Two.

3.3.5.4 Evidence of data quality

"*How are different sources of knowledge about the same issue compared and contrasted?"* (Popay et al., 1998)

For interpretations to be robust and trustworthy, the researcher must have confidence that participant accounts are truthful and ensure that only valid information is included in the interpretation (Hammersley, 2002).Earlier in the chapter I provided a detailed account of how the data was collected and analysed. I accepted that each participant in the interview studies provided an account that was truthful to their experience. In terms of validity, I did not attempt to verify accuracy of accounts with any external source. I transcribed the interviews myself, but they were not checked for accuracy by the participant or a third party, introducing a potential source of error.

When abductive inferences were made as part of the analysis, they were limited to plausible explanations grounded in the observed experiences that could be found within the account. If this was unable to occur, no inference was made, and the participant's account was taken at face value. For example, Maria described an experience of a significant bleed that I suspect was related to concomitant use of enoxaparin and dipyridamole. However, because it was not clear if she was taking the dipyridamole at the time of her bleed within the transcript, I made the decision to exclude that from the interpretation, instead noting that it was not known whether she was taking her dipyridamole at the time.

3.3.5.5 Evidence of theoretical and conceptual adequacy

"*How does the research move from a description of the data, through quotation or examples, to an analysis and interpretation of the meaning and significance of it?"* (Popay et al., 1998)

The interpretations within this thesis are entirely subjective. If this research was undertaken by someone of a different professional background, or even someone of a shared professional background, the results would be vastly different. But while it is not possible to convey every detail of how this process was undertaken, attempt has been made to be transparent in describing the thought processes that were used, particularly the way in which the Cynefin framework was used to move between the concrete and the abstract.

3.3.5.6 Potential for assessing typicality

"What claims are being made for the generalizability of the findings to either other bodies of knowledge or other populations or groups?" (Popay et al., 1998)

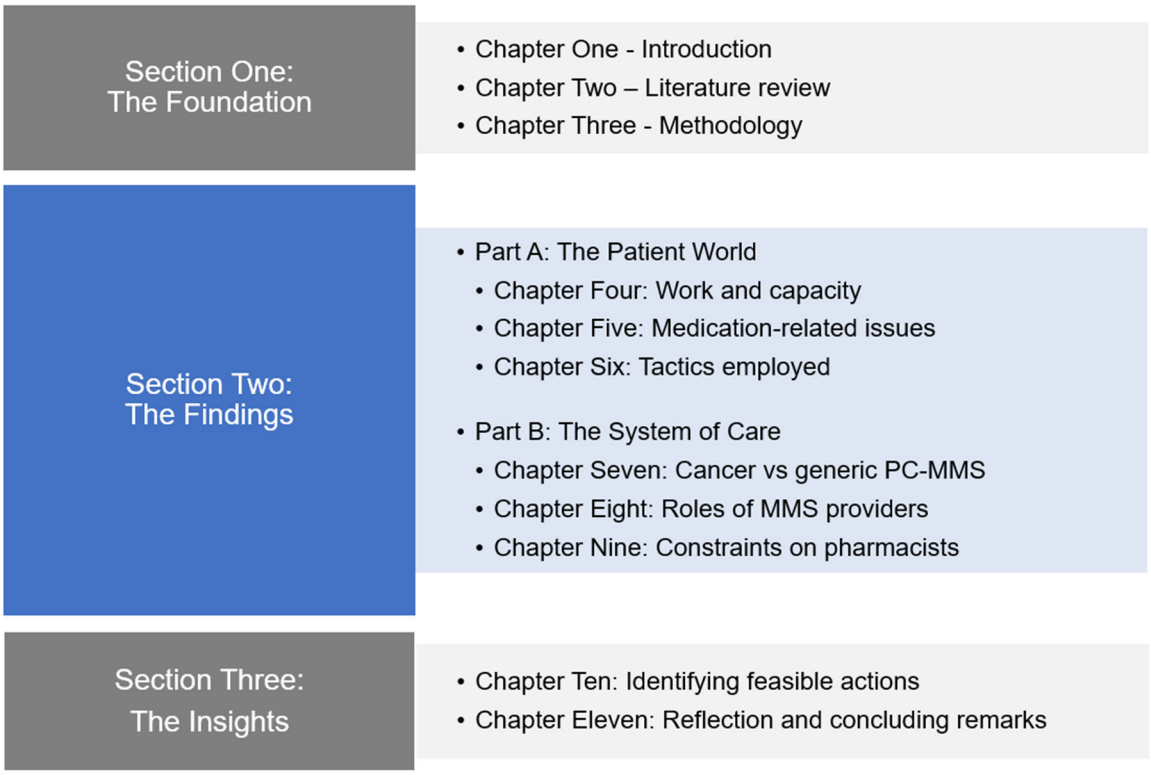
This research does not purport to make general claims regarding the structure of cancer care in Australia. The intent of this research was not to find “the right way”, but to identify feasible actions that could be taken that may (or may not) lead to a “better way”. As described earlier in the chapter, it is never possible to fully know a complex human system; we can but illuminate our understanding of it. This thesis seeks to try and learn about the broader cancer population by studying a small sample of people who are known to be at risk of experiencing MRH due to their comorbidity.

3.4 Chapter Summary

This chapter has described the approach taken to address the research question and the philosophy that has underpinned each of these choices. In its essence, this philosophy could be described as a form of pragmatism that uses a realist ontology and relativist epistemology to arrive at insights that can be used within practice to change the system of care to improve the medication experience of people living with cancer. Arriving at these insights requires methods of exploration and interpretation that are suited to deal with complexity. Because of this, the Cynefin Framework was chosen as the principle interpretive framework.

This chapter concludes Section One, establishing the research foundations. As we progress to Section Two, we turn our focus to the research finding, beginning with those that address Objective 1: Describe how cancer diagnosis and treatment alters the nature of reality in the patient world.

SECTION TWO – THE FINDINGS



Section One laid the foundations for the research, introducing the areas of inquiry, underpinning philosophy and methods employed. Section Two brings attention to the research findings, presented in two parts. Part A presents and interprets the research findings that improve our understanding of the ways in which cancer diagnosis and treatment alter the nature of reality in the patient world. Part B presents and interprets the research findings that address objective 2, analysing the system of care that supports medication management of Australians living with cancer.

Context of findings – interview studies

The two interview studies were conducted as independent research activities, each with their own interview schedule and process of analysis, as detailed in Chapter Three. Where both interview studies were used to address the same objective, the research findings have been presented side by side and brought together into a unified discussion using the Cynefin framework.

Patient study

Nine interviews were conducted between the period of January 2017 and June 2017. All but one of the cohort were female, with a variety of age groups, social situations, backgrounds, and cancer types represented. The specific demographic attributes of each participant can be found in Table 7. Interviews lasted between 31 and 64 minutes (average 51 minutes). Three interviews were conducted over the phone, and six in participant's homes.

Table 7: Characteristics of participants included in the patient study

Alias	Gender	Location	Cancer Type	Age	Living situation	Employment
Carole	Female	Metropolitan	Breast	45yo	Lives with partner and dependents	Currently employed
Cass	Female	Metropolitan	Breast	45yo	Lives alone	Long term unemployed
Felicity	Female	Metropolitan	Breast	68yo	Lives with family	Retired
Janis	Female	Metropolitan	Breast	62yo	Lives with partner	Retired
Johnny	Male	Rural	Oesophageal	67yo	Lives alone	Retired
Mandy	Female	Metropolitan	Breast	48yo	Lives with dependents	Recently unemployed
Maria	Female	Metropolitan	Colorectal	80yo	Lives alone	Retired
Shirley	Female	Metropolitan	Colorectal	72yo	Lives alone	Retired
Suzi	Female	Rural	Lung	55yo	Lives with partner	Currently employed

Pharmacist study

Nineteen interviews were conducted between the period of February 2017 and December 2018. The practice profiles of participating pharmacists can be found in Table 8. Interviews lasted between 20 and 60 minutes, with an average of 37 minutes. Five interviews were conducted via telephone, and the remainder were conducted face to face.

Table 8: Characteristics of participants included in the pharmacist study

Pharmacist ID	Inpatient HONC	Ambulatory HONC	Palliative Care	Community Pharmacy	Medication Reviews	Medical Practice	Hospital ID
1					*		-
2					*		-
3		*		*			Hospital 1
4					*		-
5					*	*	-
6				*			-
7		*		*			Hospital 2
8				*	*		-
9					*	*	-
10	*	*					Hospital 3
11		*					Hospital 4
12				*	*		-
13		*	*				Hospital 5
14			*		*		Hospital 6
15	*	*					Hospital 3
16	*	*					Hospital 7
17	*						Hospital 8
18	*						Hospital 8
19		*					Hospital 8

PART A: THE PATIENT WORLD

Part A is comprised of Chapters Four, Five and Six which address objectives 1.1, 1.2, and 1.3 respectively as illustrated in Figure 21. First, the ways in which cancer diagnosis and treatment impacts patients medication-related workload and their capacity to fulfil that work are detailed. Next, the types of medication-related issues encountered and consider how this is perceived differently from patient and HCP perspectives are recognised. Finally, the tactics employed by patients and their HCPs in response to the medication-related issues they encounter and how this influences the timely and appropriate management of medication-related issues and potential for MRH are examined. Part A concludes with a discussion that brings each of these objectives together into a unified explanation.

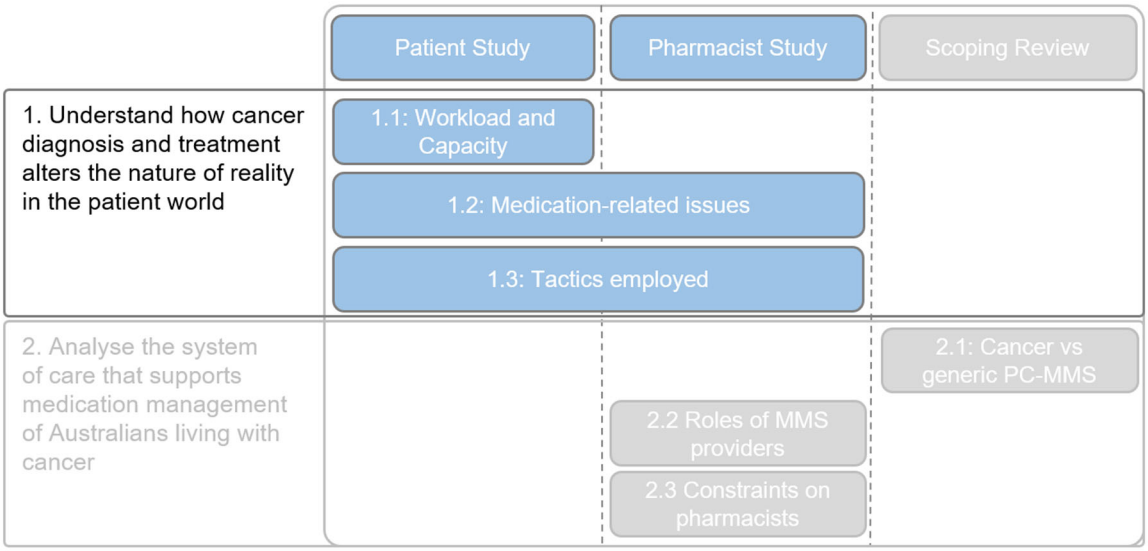


Figure 21: Research activities mapped to Objective 1

4 WORKLOAD AND CAPACITY

4.1 Chapter Introduction

This chapter presents and interprets the results from the patient interview study that address objective 1.1: detail the ways in which cancer impacts patients workload associated with using medicines and their capacity to fulfil it. This builds on Shippee et al's cumulative complexity model introduced in Chapter Two which informed the interview schedule for the patient study detailed in Chapter Three (Shippee et al., 2012). The chapter begins by describing the workload associated with medication using three themes: the logistical work of implementing the care plan, the social work of engaging with the care team, and the intellectual work of making sense of the current medication regimen. It then goes on to describe the impact of cancer on participants capacity to fulfil this work has been described using two themes: limited mental bandwidth and reduced mobility and independence. Following this, the Cynefin Framework is used to make sense of the findings, by moving beyond the granular detail to a more abstract explanation of the imbalances in work and capacity that can be anticipated as patients continue on their cancer journey.

Table 9: Themes identified that address objective 1.1

Objective	Major theme	Sub-themes
Workload associated with medication use	The logistical work of implementing the care plan	Work associated with hospital-based medication use
		Workload of in-home medication use
	Social work of engaging with the care team	New relationships with cancer care providers
		Sharing information with HCPs
	Intellectual work of making sense of the current state	Learning about newly initiated medicines
		Understanding changes made to usual medications
Impact of cancer on capacity to fulfil the workload	Limited mental bandwidth	Early cognitive and emotional overwhelm
		Ongoing ups and downs
		Increased attention to health
	Reduced mobility and independence	Physical effects of cancer treatment
		Social concerns

4.2 Workload associated with medication use

Cancer increases the logistical, social, and intellectual work associated with using medicines. For people who are already using medicines to manage a chronic condition,

this workload increases from the point of detecting a potential cancer and continues throughout their cancer journey.

4.2.1 The logistical work of implementing the care plan

Any use of medicines, be it in the home or otherwise, required participants to undertake logistical work. Even in circumstances where medicines use occurred within a formal care facility (e.g. hospital) participants were still required to undertake work in the form of booking and attending appointments and activities to prepare for their scheduled appointment, such as undergoing pathology tests or adjusting their usual medication regimen. In cases where medicines use occurred in the home, participants were responsible for administration of their medications, as well as monitoring and managing symptoms for which as needed medicines were prescribed.

4.2.1.1 Work associated with hospital-based medication use

Peri-operative considerations

The impact of cancer on workload was described by many participants early in the care trajectory due to peri-operative considerations. For many this occurred before a formal diagnosis of cancer was made. All nine participants undertook some form of surgical procedure. This took a variety of forms including the biopsy for diagnosis, surgery for removal of solid tumours (lumpectomy, mastectomy, lobectomy, bowel resection), and managing the effects of cancer or its treatment such as insertion of a percutaneous endoscopic gastrostomy (PEG) or stoma. One way peri-operative management resulted in work was requiring participants to implement acute changes to their medication regimen in the lead up to surgery; ceasing medications pre-operatively and re-initiating post-operatively:

> *When I had the operation, I had to stop one of my medicines. What one was it now? The big white one. So I was glad they stopped it because it was horrible.* - Shirley, 72yo female, colorectal cancer

> *Oh yeah* [I had to stop], *the thinners. And my sugar tablets.* – Janis, 62yo female, breast cancer

The other way in which peri-operative management contributed to the workload of using medicines concerned preparation for surgery, which Maria and Suzi each experienced. Maria was severely anaemic prior to her bowel surgery but her Jehovah's Witness faith meant that she would not consent to a red blood cell transfusion. She also had a history of thromboembolism, for which she was prescribed apixaban. Pre-surgery Maria had to cease her apixaban at the appropriate time and present earlier to hospital to receive an iron infusion. Suzi described how she was required to prepare for her lobectomy surgery

at home using topical medicinal products. This required her to follow the prescribed instructions both in terms of application and timing of the application beginning five days prior to her scheduled operation:

> *On the Friday I had to wash. So they send home these little tubes so I had to have a shower and wash in that, and you have to put this ointment up your nose twice because apparently that's where this infection can sit. And then on the Saturday you had to shower in it…And on the Sunday you again showered in it. Then the Monday you had to wash your hair and wash in it and do your nose all. And then… Tuesday…we had to be there by a quarter to seven [for surgery]*. - Suzi, 55yo female, lung cancer

Chemotherapy

Chemotherapy is itself a medication, meaning that each of the nine participants who underwent chemotherapy had some workload associated with it. Much of the workload described related to the processes surrounding chemotherapy administration such as the attendance at appointments, administration of pre-medications, and monitoring of central IV access as Johnny explains:

> *They give me a tablet to come home, two tablets, or four tablets to come home with for the nausea I assume, which I take on the, on the Wednesday I have the chemo. On the Friday after I go to [town] and have the bottle [of chemotherapy] taken off, because I have a bottle on for 45, 47 hours of chemo going into my system. Then the following Wednesday I go to [town] and have the PICC checked by a nurse in the hospital, and what they call redress it. And then the day before that I go see the specialist. So I'm going to the [closest metro hospital] every week either on a Wednesday or a Thursday.* – Johnny, 67yo male, oesophageal cancer

Several participants described how the timing of blood tests and return of results was critical to chemotherapy progressing as planned. Janis recognised this as an issue and developed a workaround in response to her blood test results not being available when she arrived at her appointment. This created extra logistical work for her but reduced her time at the outpatient chemotherapy centre:

> *I'm going for a blood test after. I'm going to do it today instead of tomorrow because they've never got it in when I'm there*. – Janis, 62yo female, breast cancer

The availability of home infusions reduced the time that Shirley and Johnny had to spend in hospital, enabling them to avoid hospital admission and return home with the support of in-home nurses:

> *I only stay in one day, that's about 6 hours, and then I go home with a bottle and a pump, what do you call it, a drip, into your vein…and then three days of that and then the district nurse comes and takes that out* - Shirley, 72yo female, colorectal cancer

4.2.1.2 Workload of in-home medication use

Using medicines at home contributed to the logistical workload of participants both in relation to ensuring an ongoing supply and implementing the medication regimen. As they did before cancer diagnosis and treatment, participants maintained their use of medicines to manage chronic conditions and acute symptomatic conditions such as coughs and colds, but for many participants the work associated with this became more demanding during cancer diagnosis and treatment. In-home medicine use was also an integral component of anti-cancer treatment in the form of post-operative management, supportive care associated with chemotherapy and radiotherapy, and the administration of the chemotherapy itself.

Maintaining usual medication regimen

Maintaining usual medication regimen throughout cancer diagnosis and treatment was not a simple case of participants continuing to take their medicines as they had previously been prescribed. Multiple participants described having to implement changes to their usual medication regimen. For Johnny, this was a direct result of his oesophageal cancer meaning he could no longer take solid oral dosage forms and had to have his medicines administered through a percutaneous endoscopic gastrostomy (PEG). In Maria's case, her poor prognosis resulted in the cessation of some of her long-term medications. Other participants, such as Janis, required alterations to their usual medications because of the effects of cancer treatment. She had her antihypertensive medication held during chemotherapy and had to adjust her diabetes medication due to the effect of the steroids on her blood sugar levels. None of the participants acknowledged this work as burdensome, but something that needed to be dealt with as part of their daily lives, as Janis puts it:

> *Take em, I just swallow them. I get em all ready and I count them, and I know what's what and I just swallow em all.* – Janis, 62yo female, breast cancer

Other participants also demonstrated what was a rather ambivalent attitude toward the logistical work associated with their usual medicines, which they had incorporated into their daily lives as a routine or normal behaviour, as Cass demonstrates:

> *I get up, I have a coffee, I have a cigarette, and then I take my tablets. I take my tablets at night between 8:30 and 9:00, sometimes maybe 8:00, it depends how tired I am*. – Cass, 45yo female, Breast cancer

In-home medication use associated with anti-cancer treatment

All forms of anti-cancer treatment, surgery, chemotherapy, and radiotherapy were associated with in-home medication use by participants which involved the addition of new medications to their usual medication regimen. In most cases this medicine use was transient, for short term symptomatic management. Surgical procedures gave rise to the prescription of medicines for post-operative concerns such as pain management, bowel management and prevention of venous thromboembolism. For Maria, this involved in-home nursing to administer enoxaparin injections. While this may appear to reduce the workload for Maria, she felt that it was burdensome and preferred to self-administer:

> *The nurse came every day because I still had the [enoxaparin] injections given but then when I came back, I said "I can give my own injections"* – Maria, 80yo female, colorectal cancer

Chemotherapy resulted in the prescription of additional medicines for all participants, used to manage common side effects such as nausea, diarrhoea, and oral mucosal effects:

> *I can't say I've ever felt bad with it. It can be tiny little things they warned me about, like diarrhoea mainly, but they give you tablets for that and give you tablets for sickness, but I've never been sick with it*. – Shirley, 72yo female, colorectal cancer

Cass required topical medication to manage side effects relating to her radiotherapy treatment:

> *I've got really nasty radiation burns at the moment…It's like really bad sunburn that I've got. So I have to use special creams three times a day* - Cass, 45yo female, Breast cancer

Participants with breast cancer described being prescribed new long-term medications to manage the effect of cancer and its treatment, which may or may not have involved self-administration, depending on patient preference. Mandy elected to have monthly injections, while Cass was initiated on daily oral tablets. Cass also experienced ongoing complications with recurrent boils following her mastectomy which required ongoing treatment with oral antibiotics and occasional hospital admissions for a course of IV antibiotics:

> *I've been on antibiotics since the operation. Four months. Nearly five months I've been on antibiotics* - Cass, 45yo female, Breast cancer

Obtaining ongoing supply of medications

All participants using medicines within the home setting were required to obtain supply for ongoing administration. The work associated with this differed depending on if it was a

cancer-related medicine or not. Many participants described obtaining their cancer-related medicines from the hospital:

> *I don't really have to worry too much about them [the nausea tablets] because it's all done through your chemo you know, your medication* – Shirley, 72yo female, colorectal cancer

However, this experience was not universal. Medicines obtained through the hospital appeared to be limited to those that were used to manage predictable side effects of chemotherapy, which would likely be included in the treatment protocol as part of supportive care. Medicines for managing cancer-related conditions, such as pain management, were obtained through the GP and community pharmacy. This created additional workload for participants, both relating to obtaining the prescription and the dispensing of medication. Maria was required to increase her frequency of GP visits to every two weeks to obtain ongoing supply of her pain medication:

> *I see him every fortnight…according to him he has to give the strength of the medication…for the pain* – Maria, 80yo female, colorectal cancer

Obtaining ongoing supply of medicines for non-cancer conditions also contributed to the workload of participants. Multiple participants described the need to obtain a prescription as the main trigger for them seeing the GP since their cancer diagnosis:

> *I've seen the GP once, just for like medicine really, script renewal* – Mandy, 48yo female, breast cancer

In terms of obtaining supply of medicines from a community pharmacy, most participants described maintaining their pre-established patterns of access either personally or by proxy:

> *There hasn't been any difference because I just go to whatever doctor I'm going to see and just give them [the pharmacy] my prescription* – Shirley, 72yo female, colorectal cancer

4.2.2 Social work of engaging with the care team

In order to access prescribed medicines, patients have to engage with HCPs to have the medication prescribed, dispensed, and be provided with information about how to use it. This required participants to engage with members of the care team, many of which were new relationships. Within the interactions with HCPs, participants were required to participate in building the therapeutic relationship and share medicines-related information.

4.2.2.1 New relationships with cancer care providers

Cancer diagnosis and treatment introduced many new HCPs into the patient world. The consistency and quality of these relationships was variable. Multiple participants spoke of challenges with building relationships with HCPs in the peri-operative period, as described by Suzi:

> *There were so many of them. Like six of them were coming around you know every day. So when we walked in one shook my hand and said "oh, do you remember me?" and I looked, and I went "no".* - Suzi, 55yo female, lung cancer

The work associated with managing these relationships resulted in logistical work for participants, as Suzi explains:

> *And I would write things down you know more so because I was seeing different people. Like one minute I saw, and to write the doctors names down so you know I had one for the chest clinic and I had questions for the surgeon*. - Suzi, 55yo female, lung cancer

Similar challenges were described in relation to building relationships with in-home nurses, which resulted in additional logistical work associated with arranging visits, as Cass described:

> *God they're hopeless. District nurses. One said only coming Monday, Wednesday, and Fridays and she thinks I have to see someone every day. She never got the message*. - Cass, 45yo female, Breast cancer

Once participants had received their formal cancer diagnosis, these relationships continued to grow as new members of the cancer MDT were introduced. Multiple participants described the relationship they had with the oncology team as a whole, like Mandy:

> *Whenever you had a problem, they had a solution. And even if, if I cried over anyone, which you do along the way, so like a social worker would be there within you know, the next time you come and say do you want to talk about this. And it's not that you felt they were palming you off, it was just, support was always offered*. - Mandy, 48yo female, breast cancer

Participants also specifically spoke of building trusted relationships with individual HCPs which for multiple participants, including Shirley, was with the oncologist:

> *I had my operation, and I was in the hospital, it must've been five or six days, when he [surgeon] came up to tell me. And when he told me he sort of shrugged his shoulders and I said "oh I'm going to die" …And then at home I started settling down a bit. Then I'd seen my own doctor, so I'd seen her, and I was just feeling a*

> *bit better as the time went, and then it was about five weeks before seeing [Oncologist] at the hospital, and everything changed since seeing him. He was just so brilliant* – Shirley, 72yo female, colorectal cancer

Of course, not all of the relationships between participants and members of the cancer MDT were positive, with some participants describing the challenges, such as Johnny who found that he did not receive enough information as a result of building relationships with multiple doctors rather than one key clinician:

> *I was left pretty well in the dark for quite a while with the radiation doctor because I seemed to be seeing the doctor's offsiders, not the doctor themselves if you understand what I mean…but since I've been with Dr [oncologist] I seem to be getting a lot more information coming back to me.* - Johnny

Suzi also described negative experiences with nursing staff. Her perception of this was that the work required to overcome such experiences and build positive relationships was too great, noting how it impacted her likelihood of seeking help in the future:

> *if I had, the second nurse I had, if I had her again, I was walking out. Oh my lordy lord. She forgot to give me my oral medication, she had to be told about that. She couldn't get like the needle in…with some, if I have a question like it's like yeah, it's the body language and stuff like that. Like so I've just given up.* – Suzi, 55yo female, lung cancer

4.2.2.2 Sharing information with HCPs

Individuals who use medicines play an integral role in ensuring that their medicines-related information is shared between care providers. This active role was clearly articulated by multiple participants. As previously described, peri-operative management often involved alterations of the usual medication regimen in preparation for surgery. In order to develop this plan, participants were required to provide care providers with complete and accurate information regarding their use of medicines. In many cases, this involved complying with the request to take in their usual medicines with them to their pre-admission visit, or upon admission for the procedure:

> *When I went in [for the lobectomy] …I had to take all these [usual medications] …I took all these tablets with me when I had to go in because they asked me to* - Suzi, 55yo female, lung cancer

Participants also described their role in keeping their usual care providers informed about their cancer care. Several participants described this, including Shirley who described making appointments with her GP to ensure they were kept informed:

At the moment I go around [to the GP] just to get medication and let her know how things are going – Shirley, 72yo female, colorectal cancer

4.2.3 Intellectual work of making sense of the current state

The changes made to participants medication regimes throughout cancer diagnosis and treatment involved more than logistical effort and social behaviours, they also required the participants to undertake intellectual work to make sense of their current state. The degree to which participants undertook this work varied according to personal characteristics and capability, but each account showed evidence that they had undertaken some amount of learning about their newly initiated medicines and understand changes to their usual medication regimen. Whether it be demonstrating their knowledge of a generic medication name, the nature of a drug formulation, a dose titration, or drug interaction, every participant experienced an increase in intellectual workload during their cancer diagnosis and treatment.

4.2.3.1 Learning about newly initiated medicines

Each of the participants who was started on new medicines throughout their cancer diagnosis and treatment demonstrated that they had engaged in learning about these medicines to some degree. Multiple participants noted how the workload associated with learning about anti-cancer medications was assisted by the specialist cancer services available to them through provision of written educational material:

I read all the pamphlets and things like that. And I know what's happening – Janis, 62yo female, breast cancer

Participants also demonstrated their understanding of newly initiated medicines through the way in which they recounted their medication regimen. One example of this was Mandy, who spoke of the experience of selecting her hormone treatment:

Because my cancer is hormone driven, so I had to choose the treatment, the hormone treatment. So I don't feed any cells or cancerous things in there. So I chose the monthly injection that will bring on menopause, so it's like menopause, boom! – Mandy, 48yo female, breast cancer

When Johnny described his use of morphine liquid, he indicated that he had developed an understanding of how to adjust his dose according to his pain needs, and the importance of monitoring his opioid intake:

I have got morphine liquid here…the doctor's allowed me to have 10mg of that, up to 10mg a day in four doses of 2.5mg. I've had to use it once or twice a day when the pain gets more severe. I've got a reasonably high tolerance for pain but some days it gets to me. But what have I used, about a five or six weeks ago I got the

> *first dose out of it. It's a 200mL bottle and I've used, I've still got 120mL in the bottle. I don't think I'm over-using it* – Johnny, 67yo male, oesophageal cancer

Learning about newly initiated medicines did not just involve understanding how the drugs work and how to use them, but in some circumstances also involved developing understanding of medical equipment and physiology. Johnny, who was required to change his method of drug administration from oral to PEG, was required to learn about things such as maintenance of the site and management of blockages in addition to processes of medication administration:

> *I was given about half an hour [earlier] this year, a quick learning curve of how to set myself up with a night feed, a day feed and put something through my PEG* - Johnny, 67yo male, oesophageal cancer

4.2.3.2 Understanding changes made to usual medication regimen

Multiple participants recounted changes that were made to their usual medication regimen. In some cases, this included an explanation of why these changes were made, indicating that they undertook work to achieve that knowledge. This was particularly evident in relation to changes to the use of complementary and alternative medicines (CAMs). Mandy, Carole, and Felicity each used CAMs as part of the management of their chronic conditions, but were instructed by their cancer care team that it could result in a drug interaction with the chemotherapy:

> *I used to take turmeric T100. And I used to get, and I used to drink mangosteen tablets because it also helps with circulation and cancer. But I was told before I was operated not to because it will go against anything* - Felicity, 68yo female, breast cancer

Through Johnny's recount, he demonstrated that he understood how his PEG insertion impacted his prostate therapy through his description of an experience with a formulation that was not suitable for PEG administration. This description indicated Johnny developed an understanding of the reason for the change in his medication regimen, and the need to re-titrate the dose of his newly prescribed therapy:

> *…what I was taking before was in a capsule form…the capsule couldn't be opened and put through the PEG. So we've had to change to a different tablet. Originally, I was only on half a milligram a day, half a milligram morning and night, and now I'm up to 2mg a day*. - Johnny, 67yo male, oesophageal cancer

4.3 Impact of cancer on capacity to fulfil the workload

Two themes were developed to describe how cancer impacted participants' capacity to independently manage their medications: limited mental bandwidth and reduced mobility and independence. Cancer impacted capacity from the point of detection of a potential cancer and throughout the entire cancer journey, changing capacity in dynamic and unpredictable ways.

4.3.1 Limited mental bandwidth

Fulfilling the work associated with medication management required cognitive capacity. Participants described various circumstances where their cancer diagnosis or treatment impacted this, notably early on during the detection and diagnosis phase, but also throughout treatment as they continued to manage the ongoing ups and downs. Alongside this, participants also described having an increased focus on their health during their cancer journey, suggesting that periods exist where cancer potentially increased the mental focus on medication management.

4.3.1.1 Early cognitive and emotional overload

Cancer had a cognitive and emotional impact on participants from the moment of detecting of a potential cancer, throughout diagnosis and treatment. This had a notable impact on individual participant's mental bandwidth for other responsibilities and aspects of life, including medication management. Multiple participants described how the emotional overload was heightened during the period of diagnosis:

> *When you first get it, you think of yourself dead and buried like. Oh, when I was in the hospital for those four, no seven days at the beginning I was like awful* – Shirley, 72yo female, colorectal cancer

For those participants with breast cancer the acute increase in overwhelm coincided with the discovery of a lump, abnormal mammogram finding or blood test result:

> *I knew straight away something was wrong for her to want to see me…when she told me I had breast cancer…my whole world fell apart* - Cass, 45yo female, Breast cancer

Each of the participants with other types of cancer (colorectal, lung, oesophagus) described a more insidious onset of concern and degradation of health recognised in hindsight, and a rapid increase in overwhelm once investigation of cancer became apparent. They described a period of months to years preceding diagnosis where they experienced generalised signs and symptoms gradually increasing in severity that eventually led them to present to their usual GP for help, triggering a more thorough

investigation and a diagnosis of cancer. Suzi's health had been declining for several years prior to her cancer diagnosis, negatively impacting her employment and quality of life. She had undertaken numerous investigations, with no cause identified. Yet, once a suspected cancer had been detected it all seemed to culminate and feel like things were happening very suddenly:

> *This happened so darn quickly. Um you know, like the 20th of February I went to work and later that night I was in hospital, and it all led to this, so I haven't had much time to really process everything*. – Suzi, 55yo female, lung cancer

4.3.1.2 Ongoing ups and downs

Participants described experiencing ongoing ups and downs throughout the process of cancer diagnosis and treatment, with the post-operative period also noted by participants to be a period of acute stress. For Cass who had a history of bipolar disorder and schizophrenia, this resulted in a hospital admission:

> *It took me about nine months to accept that I've got breast cancer. For six months, maybe six, seven months I was in denial. And then when I had my boobs removed it hit me big time, and I ended up in psychiatric hospital.* – Cass, 45yo female, Breast cancer

Several participants described the inner conflict of managing this limited mental bandwidth. As acknowledged by Suzi, despite having a desire to stay informed and understand the situation, there were still times where she would feel acutely overloaded and unable to process information:

> *I do ask questions because at the moment it's just so overwhelming. Like everybody was giving me information. There was just one day I threw it all away. I just couldn't cope with it anymore.* – Suzi, 55yo female, lung cancer

4.3.1.3 Increased attention to health

Despite the noticeable increase in cognitive and emotional load associated with cancer resulting in limitations in mental bandwidth and potentially reduced capacity to manage medicines, a number of participants described that they experienced an increase in focus on their health following their cancer diagnosis. In this sense, cancer diagnosis could paradoxically increase an individual's capacity to manage medications:

> *You know, everything you think about is for your health now*. – Shirley, 72yo female, colorectal cancer

Several participants who had pre-established self-management behaviours such as blood pressure or blood sugar monitoring, described how they had become more diligent in this activity since the cancer diagnosis, such as Johnny:

> *I'm doing it [blood sugar levels] a bit more regularly now. I do it four times a day, where I used to do it basically morning and night when I was doing it. And I do my temperature four times a day and I take my blood pressure four times a day.* – Johnny, 67yo male, oesophageal cancer

It should be noted though that this increased attention to healthcare was not always well accepted by participants. As noted by Cass, having health as a primary focus was also a source of frustration:

> *I get fed up taking all the medication that I have to take, going to the appointments that I have to go to, you know. It's just really draining. You know, it's a real effort for me* - Cass, 45yo female, Breast cancerReduced mobility and independence

Cancer diagnosis and treatment resulted in reduced mobility and independence for all participants. This was not isolated to the period of chemotherapy and radiotherapy, nor was it solely to do with the physical effects of cancer and its treatment, with psychosocial factors also evident.

4.3.1.4 Physical effects of cancer treatment

Overall physical effects of cancer and its treatment reduced participants functional independence and confidence in independently undertaking some activities of daily living. These physical effects had the potential to reduce as individual's capacity to independently manage both the logistical and the intellectual work associated with their medication use. For several participants, this was experienced in direct association with their chemotherapy:

> *I just get so dizzy…every time I have the chemo, whether it's the oral or the IV I am so so dizzy…Like I'm struggling to stand you know to peel vegetables or anything like that, I'm not walking my dogs at the moment, I'm struggling to get outside to feed my budgies...* – Suzi, 55yo female, lung cancer

Chemotherapy was not the only time that participants described marked reduction in functional independence relating to physical effects, also being described in relation to post-surgical recovery:

> *It's just when you get out of hospital, you can't walk, you can't do things* – Shirley, 72yo female, colorectal cancer

For Maria, who experienced post-surgical complications, this period of reduced functional independence was prolonged, lasting for a number of months after discharge from hospital:

> *I couldn't even go out. Because constantly was tied down in bed or in the house because as I said, nurse came twice a day and they had to redo the bandage each time* – Maria, 80yo female, colorectal cancer

Most participants described experiences of fatigue and loss of energy relating to the effects of cancer and its treatment, reducing their capacity to fulfil the intellectual work associated with medicine use such as maintaining and developing the working knowledge of their medicines. For some participants, this was transient, coming and going over time:

> *I just go through the treatment and up and down days. You know, you get your bad days. Which you do, you feel like you're drained. And your good days you can do what you want, so much exercise, you can do anything, you know.* – Janis, 62yo female, breast cancer

For other participants the loss of energy was more persistent. For Maria, who had ongoing issues with anaemia but would not accept red blood cell transfusions, and Mandy who was also managing MS, this persistent fatigue fits with their broader conditions:

> *The only thing I really notice now, I get tired. I get so tired. And you know, I do some dusting, I do this, I start off and then I'm oh, so I sit down, have a cup of tea or whatever…and then I get up and start again* - Maria, 80yo female, colorectal cancer

Suzi also described persistent fatigue, noting that she had been experiencing it for some years prior to her cancer diagnosis:

> *The only thing I can say is I have been so unmotivated and so tired…Most probably for five years, everything's an effort* – Suzi, 55yo female, lung cancer

Cass experienced persistent fatigue which she attributed to her chemotherapy and radiation:

> *the chemo and the radiation makes me really tired. Sometimes I'm in bed by 8:30 because I'm that tired – Cass, 45yo female, Breast cancer*

This fatigue had a pronounced impact on Cass's quality of life and functional independence, impacting her ability to do simple tasks such as go to the shops and cook for herself. It was also a source of frustration for Cass:

> *And I keep saying this to [my oncologist]. She's like, "How are you going?" "Tired", "How are you going?" "Tired". I say, I'm saying the same thing over and over and over again, I'm fed up saying it.* – Cass, 45yo female, Breast cancer

4.3.1.5 Social concerns

Participants required access to transport in order to fulfil much of the logistical work associated with medicines, such as attending appointments and collecting medicines. Concerns relating to transport were consistently raised by participants. The physical effects of cancer treatment, fatigue and reduced functional independence were noted to make driving and use of public transport more difficult. This, coupled with their increased need for transport during the diagnosis and treatment phase, presented challenges for multiple participants:

> *I'm allowed to drive but it's more the confidence. And with being tired. Sometimes I don't trust myself. So I'm happy to drive locally but I'm not like, I don't have the confidence…because I was just so tired. There was no way I was going to get behind a car* – Mandy, 48yo female, breast cancer

For Cass, who was usually reliant on public transport for her transport needs, this was particularly problematic. Her limited income meant that taxis were not very accessible, making her heavily reliant on help from family and friends:

> *I couldn't catch public transport while I'm having chemotherapy with the vomiting and the diarrhoea and that, you know.* – Cass, 45yo female, breast cancer

Johnny and Suzi, who both lived roughly 100km from the city, also found transport issues challenging. These areas are not served by public transport or taxi services, and the distance travelled was too far for them to go alone with their low functioning state:

> *When we were going to the [metro hospital] it was like, and you know, it's a three-hour trip basically* – Suzi, 55yo female, lung cancer

For Suzi, who lived 98km from the city, this was made even more challenging due to the inability to qualify for any financial assistance:

> *You've got to be over 100km radius to be determined as a country patient…what it means is that I can't get any benefits* - Suzi, 55yo female, lung cancer

These types of transport concerns contributed to the level of financial strain experienced by participants, which had the potential to impact their capacity to fulfil the work associated with using medicines directly (i.e. obtaining supply of medicines) and indirectly through accessing supports which are not publicly funded (e.g. medication delivery, dose administration aids). Carole and Suzi were the only participants who were employed prior to their cancer diagnosis, with Carole maintaining employment throughout her cancer diagnosis and treatment. While no participants explicitly described financial strain preventing them from obtaining supply of medicines, it was noted to be an area of concern

by multiple participants when asked if their healthcare had affected them at all financially as Suzi explains:

> *…I'll be honest. If mum hadn't died and left me an inheritance I don't know how I would have survived because that, living off us, because I've got no income at all coming in…So yeah, just to have some financial help would have been nice but yeah, I've just given up with that side now* – Suzi, 55yo female, lung cancer

4.4 Discussion: objective 1.1

4.4.1 The impact on work and capacity throughout the cancer journey

To further make sense of the findings presented in this chapter, the data obtained from the patient interviews was mapped onto the Cynefin Framework (Appendix I) through the process detailed in Chapter Two. Figure 27 represents an abstraction of these findings which revealed distinct differences between three phases of the early cancer journey: the starting conditions, diagnosis and treatment planning, and anti-cancer treatment. This section will discuss work and capacity that can be anticipated in each of these phases.

4.4.1.1 The starting conditions

People begin their cancer journey with a pre-existing workload, baseline capacity and established level of activation that we will collectively refer to as their *starting conditions*. If someone has been independently using medicines to manage a chronic condition prior to cancer diagnosis they have a pre-existing workload associated with it, with established routines and behaviours of medication management that are familiar to them. The individual's baseline capacity enables them to fulfil this work and can be thought of as all the resources within the patient world including their intellectual capability, physical condition, personal resilience, and social support networks. In addition to this baseline work and capacity patients can also be expected to start their cancer journey with an existing level of activation which can be thought of as the individual's level of knowledges, skills, and confidence in managing aspects of their health (Hibbard & Gilburt, 2014). Those with a lower level of activation are more passive in their health and lack knowledge or confidence, while those with a higher level of activation actively adopt the behaviours required of them to support their health (Hibbard & Gilburt, 2014). Unless the patient has fluctuating level of capacity to begin with such as a poorly managed chronic condition or emotional instability, their starting conditions can be expected to fit within the clear domain of the Cynefin Framework as illustrated in Figure 26, representing normalised or entrained behaviours that will persist throughout the cancer journey unless actively challenged.

4.4.1.2 Diagnosis and treatment planning

As the findings presented in this chapter show, when someone learns that they might be diagnosed with cancer, it can have an immediate impact on their capacity to fulfil the work of using medicines. Within the Cynefin Framework (Figure 22), all factors that influence capacity have been mapped to the complex domain because they involve an entanglement of non-linear relationships between the physical, cognitive, and emotional domains. Because of this, a patient's capacity can be expected to dynamically fluctuate throughout the entirety of the cancer journey.

Coinciding with these unpredictable fluctuations in capacity is a predictable increase in medication-related workload, starting from the time a potential cancer is detected, and persisting throughout the diagnosis and treatment planning phase, particularly if the patient requires a surgical procedure. In Figure 22, this workload fits within the complicated domain because it requires greater effort from patients than maintaining the status quo or merely following simple instructions. Logistically, patients are required to arrange and attend appointments across various settings of care. Socially, they are required to build relationships with multiple new care providers, often within a context that lacks any continuity of care. Intellectually, the workload will vary depending on the patient's level of activation. For those who are highly activated the treatment planning phase can be expected to demand a significant intellectual effort as they learn about their treatment options and discuss them with others in order to feel equipped to participate in this decision-making process. Those who have a lower level of activation may be less involved in treatment planning but will still have an intellectual workload associated with understanding any changes made to their medication regimen throughout this time.

4.4.1.3 Anti-cancer treatment

While the workload continues to increase for patients who undergo anti-cancer treatment, it may become less complicated for those who are under the care of the cancer MDT, represented in Figure 26 by a shift toward the clear domain. Improved continuity of care, clearer communication channels and defined treatment protocols help patients understand and maintain their new workload. As previously explained, capacity dynamically fluctuates following cancer diagnosis and these fluctuations may become more pronounced during anti-cancer treatment as the physical effects become more significant, which can adversely impact a patients emotional and cognitive state. Reduced mobility and independence is also expected to become more significant at this time which can further result in an imbalance between workload and capacity, negatively impacting a person's ability to fulfil the workload associated with their medicines. However, such imbalances may be corrected through utilisation of formal and informal supports which are more readily available at this time.

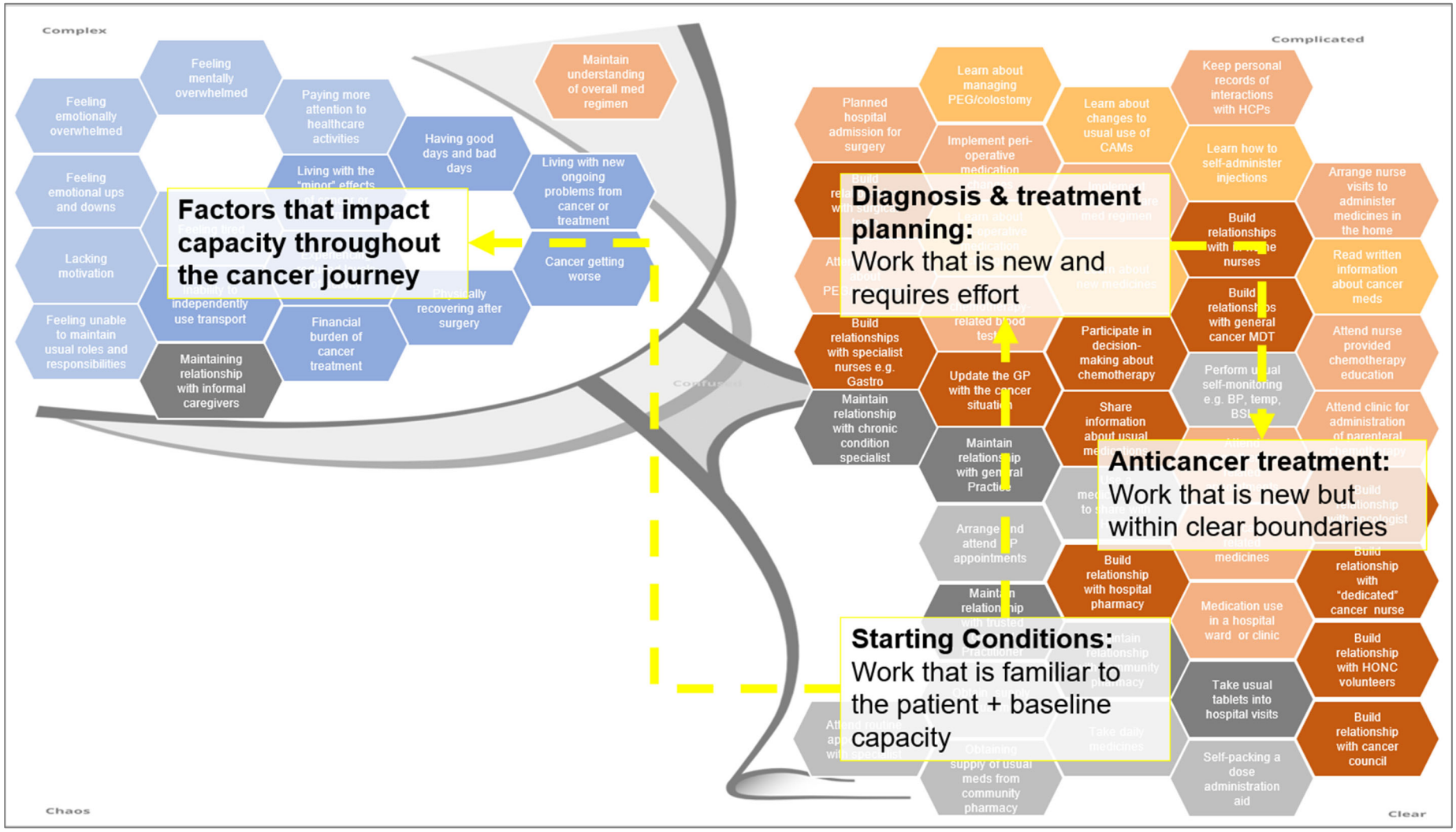


Figure 22: Cynefin diagram illustrating the impact of cancer on work and capacity

4.4.2 Imbalances in work and capacity are influenced by starting conditions

At this point it has been shown that a cancer diagnosis will result in imbalances in work and capacity that while unpredictable, can be anticipated. One of the factors that influences how such imbalances impact the patient's medication experience is their unique starting conditions. To explore this, let us consider what can be anticipated for different patient groups who have a comparable workload, but differ in their baseline capacity and level of activation. This thought exercise will be facilitated by using the two-by-two matrix in Figure 23, with baseline capacity represented by the y axis and level of patient activation represented by the x axis.

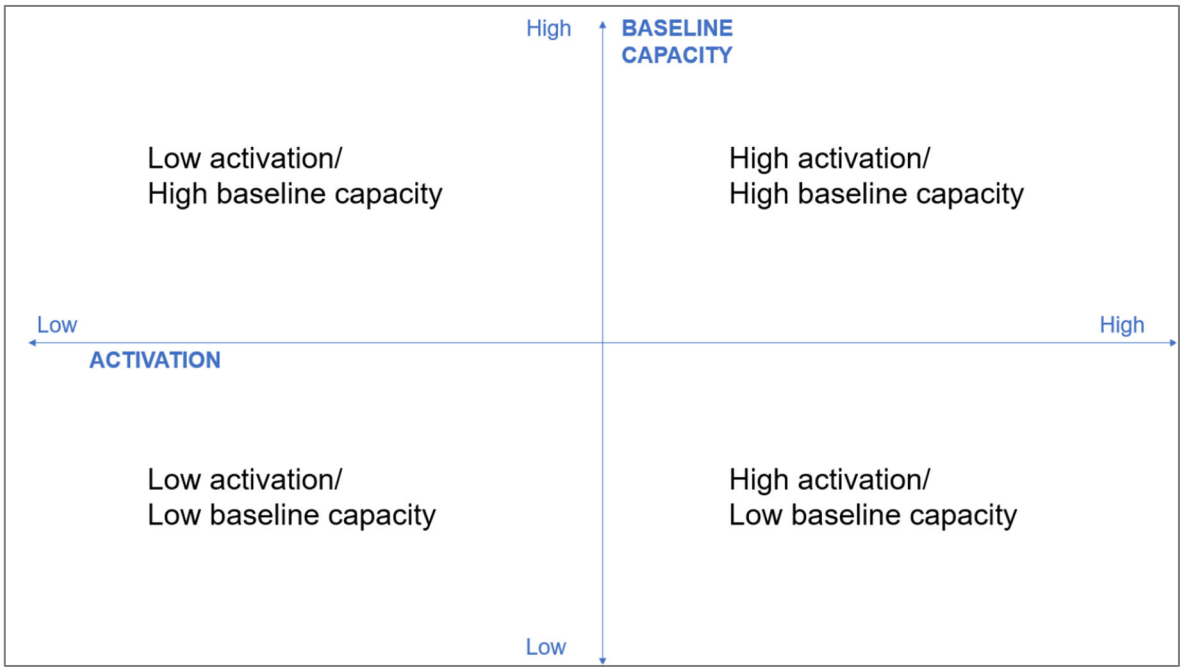


Figure 23: Starting conditions - baseline capacity and patient's level of activation

People with a high baseline capacity have resources available that enable them to fulfil the work associated with their usual medication regimen. However, their low activation means they may not have the skills or confidence to use these resources in circumstances when something like a cancer diagnosis challenges the status quo. As such, it can be expected that they will experience imbalances in workload and capacity during periods where their capacity is acutely diminished or where there is a steep increase in workload such as the peri-operative period or during anti-cancer treatment.

4.4.2.1 Low activation, low baseline capacity

People with a low level of activation and low baseline capacity not only have inadequate resources to fulfil the work of using medicines, but they also lack the skills and confidence to use what is available to them. As such, it can be expected that these patients may be experiencing imbalances in workload and capacity prior to their cancer diagnosis. Their

situation can be expected to worsen as these patients face the increase in workload and negative impacts on capacity that inevitably result from cancer diagnosis and treatment, which would compound any existing issues in addition to introducing new ones.

4.4.2.2 High activation, low baseline capacity

People with a high level of activation and low baseline capacity have skills and confidence in self-management but lack resources due to having a physical, mental, or cognitive health impairment, being socially isolated or experiencing financial issues. Similar to those with low activation and high baseline capacity, these patients are likely capable of fulfilling the work associated with their usual medication regimen, but they may experience imbalances as their cancer diagnosis and treatment interrupts their status quo. Owing to their high level of activation, this could be expected not only when they experience acute reductions in physical capacity, but also in circumstances of cognitive and emotional overload, such as the diagnosis and treatment planning phase where they may experience frustration associated with inability to fulfil the intellectual workload to the level that they desire.

4.4.2.3 High activation, high baseline capacity

People with a high level of activation and high baseline capacity have both the resources available and the skills and confidence to put them to use to execute the work of medication management. While these patients are less likely to experience imbalances in work and capacity, it may still occur as a result of acute changes in work and capacity.

4.5 Chapter Summary

This chapter has detailed how cancer diagnosis and treatment impact patient's work associated with using medicines and their capacity to fulfil that work. It has shown that people who are already independently using medicines at the time of cancer diagnosis will have pre-established starting conditions consisting of their normalised workload, baseline capacity and level of activation. A cancer diagnosis can be expected to challenge these starting conditions and create imbalances in workload and capacity through increased workload and dynamic fluctuations in capacity. Whether or not these imbalances will result in medication-related issues will depend on the individual's starting conditions. For some, these starting conditions will serve as an asset, helping them to cope with the workload imbalances they encounter, but for others these starting conditions create a potential liability. While it may not be possible to predict exactly when an individual will experience an acute imbalance, it can be anticipated during times where work associated with medicines is acutely increased, such as the peri-operative period, treatment planning and chemotherapy administration. Recognising a patient's level of activation and baseline

capacity at the beginning of their cancer journey can help to anticipate the imbalances they can be expected to encounter and provide an opportunity to positively challenge the starting conditions through interventions that reduce workload, bolster capacity, and actively engage them in their healthcare journey. In the next Chapter we look at the types of medication-related issues that people experience throughout cancer diagnosis and treatment.

5 MEDICATION-RELATED ISSUES

5.1 Chapter Introduction

This chapter continues to present and interpret the research findings that address Objective 1.2: Recognise the types of medication-related issues encountered throughout cancer diagnosis and treatment. As introduced in Chapter One, medication-related issues are those patient care experiences that have either resulted in, or have the potential to result in, medication-related harm. Medication-related issues exist within the patient world, but the technical nature of some of these issues means that some may occur outside of the patient's cognition. For this reason, this chapter draws from both the patient and pharmacist interview studies. Firstly, the findings from the patient study are presented, interpreted as two main themes: tangible experiences, and intangible experiences. Secondly, the findings from the pharmacist study are detailed, interpreted as three main themes: issues associated with drug-related risk, practical challenges of using medicines, and multifactorial problems. Following this, the results are brought together into a unified explanation using the Cynefin Framework.

Table 10: Themes associated with Objective 1.2

Section	Major theme	Sub-themes
Medication-related issues: the patient experience	Tangible experiences	Physical challenges of administering medicines
		Physical and psychosocial manifestations of MRH
	Intangible experiences	Feeling dissatisfied with the care plan
		Feeling uncertain about the prescribed medication regimen
Medication-related issues: the pharmacist experience	The patient's underlying degree of drug-related risk	Emergence of new medical problems
		Exacerbation of underlying conditions
		Adverse drug effects resulting from a shift in risk-benefit
	Practical challenges in using medicines	Workload and capacity challenges
		Confusion and miscommunication
	A complex interplay of patient factors	Managing multiple medical conditions
		Alignment of attitudes and beliefs

5.2 The patient experience

This section presents the findings of the patient study; the lived experience of medication-related issues. These experiences have been interpreted as tangible and intangible experiences. As explained in Chapter Three, abductive reasoning was used judiciously to interpret these lived experiences and connect them to underlying medication-related issues.

5.2.1 Tangible experiences

Tangible experiences of medication-related issues were recounted by participants as health events associated with physical challenges of administering medicines, or physical or psychosocial manifestations of MRH.

5.2.1.1 Physical challenges of administering medicines

Several participants described experiences where physical symptoms presented a challenge to them being able administer their medicines as prescribed. Often these challenges were temporary, such as the acute swallowing difficulties experienced by Shirley due to mucositis and Maria in relation to oral thrush:

> *I had a big problem with my mouth…Oh was it horrible. It was horrible. I couldn't swallow, it was right down my throat.* - Maria, 80yo female, colorectal cancer

Suzi experienced prolonged nausea and vomiting following her chemotherapy that resulted in her missing a dose of medication on at least one occasion:

> *last time I was so sick for eight days after my treatment, and it was horrible…I've just been so sick and last Wednesday, not last Wednesday, the Wednesday before I didn't take my oral medication because I was vomiting. Yeah, so I've actually missed one*. – Suzi, 55yo female, lung cancer

While missing a one-off dose is not a great concern, Suzi was at risk of experiencing further medication-related issues if this were to happen on multiple occasions, due to Suzi taking an antidepressant duloxetine which can cause withdrawal effects within two days of abrupt cessation.

For Johnny, who was living with oesophageal cancer, his swallowing difficulties were progressive and irreversible. This had an immediate impact on Johnny's ability to administer solid oral dosage forms which he was using to manage conditions such as diabetes, blood pressure and benign prostatic hypertrophy:

> *Well I stopped taking it [metformin] because I couldn't get it in me. I tried to, and every time I did, I'd sort of swell up and I'd bring it back up again. – Johnny, 67yo male, oesophageal cancer*

Thankfully, Johnny was not taking any medicines where abrupt cessation would be problematic, so this did not result in any physical manifestations of MRH. Once Johnny had a PEG tube inserted which presented new practical challenges of having to crush and/or disperse medicines in water:

> *I was on a granule for the replacement for Nexium, which is Somaz granules, but I found that mixing it with the water to get it in the PEG, half of it was staying on the cup, so I wasn't getting the 40mg of it down into me.* – Johnny, 67yo male, oesophageal cancer

Once again, thankfully Johnny was not taking any medicines where crushing or abrupt interruptions in therapy would result in clinical issues, but this was likely serendipity rather than design.

5.2.1.2 Physical and psychosocial manifestations of MRH

All participants described experiences of physical manifestations of MRH, which on occasion resulted in tangible harms within their psychosocial domain as well. For Shirley and Johnny, continued use of symptomatic drug therapy to treat persistent physical symptoms delayed their cancer diagnosis. Both had been using medications to manage what they thought was reflux and turned out to be gastrointestinal cancers, as Shirley described:

> *I went into the doctor thinking I had indigestion, and I was taking bottles and bottles I was buying each week of Mylanta. And the thing was, the Mylanta was making it better, so I think the Mylanta was curing it and the pain was going away you know? So I was just sent to the doctor for a prescription one day and I said to her "Could you give me something for indigestion?" and she says, "Oh I'll not give you anything until I see what you've actually got".* – Shirley, 72yo female, colorectal cancer

Participants who experienced a physical symptom that was a common or significant adverse effect of their anti-cancer treatment or supportive care medication tended to recognise that it was a medication-related issue, like Felicity and her constipation:

> *Oxycodone, which made me so bad that I cannot go to the toilet for five days, it was so hard.* – Felicity, 68yo female, breast cancer

In some cases, this type of physical symptom was accepted by the participant as an inevitable part of their cancer journey, such as Shirley's experience of persistent diarrhoea which persisted despite taking regular doses of anti-diarrhoeal medication. Increases in appetite relating to the use of steroids was another commonly encountered physical symptom that was accepted as part of the new normal. For Carole and Shirley who were both managing diabetes, this resulted in weight gain:

> *I've put five kilos on since I've been on chemo. I'm eating really well, cause they give you a couple of steroids with your treatment* – Shirley, 72yo female, colorectal cancer

Medications that resulted in localised skin reactions were also obvious to participants, as Suzi described regarding the administration of enoxaparin injections:

> *They were putting those injections in my stomach, and some of the staff they were as rough as guts doing that. My stomach, it was blue, yellow, purple, every colour*. – Suzi, 55yo female, lung cancer

In addition to common side effects, multiple participants described being instructed on the importance of actively monitoring for early signs of infection and more significant effects of their chemotherapy. Cass described how active monitoring of her blood tests resulted in identification of what sounded like an episode of febrile neutropenia:

> *my chemo bloods come back that a couple of my levels were really really dangerously low, so they had to stop my clozapine… I went into hospital, and they put me on IV antibiotics*. *– Cass, 45yo female, Breast cancer*

In addition to experiencing MRH in the form of febrile neutropenia, Cass unknowingly also faced another issue relating to the interruption of her clozapine. Prior to her hospital admission, Cass was taking clozapine, an antipsychotic medication that can cause neutropenia and agranulocytosis. The blood dyscrasias experienced with clozapine are known to be so significant that for it to be prescribed in Australia, the prescriber, dispensing pharmacist, and patient must each be registered with a monitoring program, which involves adhering to strict protocols regarding dose adjustments and blood tests. Clozapine is not recommended to be used in conjunction with other medicines that may impair bone marrow function (e.g. chemotherapy). The product information for clozapine states: "drugs known to have a substantial potential to depress bone marrow function should not be used concurrently with Clozaril" ("MIMS,"). While it is not explicitly clear from Cass's interview whether her clozapine therapy was considered by her prescribing oncologist or if consultation with her psychiatrist occurred prior to commencing chemotherapy, Cass did not appear to be aware of any discussion where the risk/benefit of continuing her clozapine throughout her chemotherapy and radiotherapy treatment was considered, nor did she appear to be prescribed any prophylactic therapy (e.g. G-CSF) until after the episode of febrile neutropenia:

> *After chemotherapy I get an injection, they call it Neulasta, something like that. It's to lift up the white blood counts because apparently my white blood count dropped very low*. - Carole, 45yo female, Breast cancer

Cass was in hospital for five days. As part of the management of her febrile neutropenia Cass's clozapine was held for 48 hours:

> *They stopped it [clozapine] on the Friday and the Saturday, and they put me back on it on the Sunday* - Cass, 45yo female, Breast cancer

This interruption in clozapine therapy placed Cass at further risk of experiencing MRH. The abrupt cessation of clozapine, although clinically indicated, placed Cass at risk of withdrawal effects (including cholinergic rebound syndrome) and relapse. Experiencing a relapse would have been a severe level of MRH for Cass who had been taking clozapine as part of her management for around twelve years, and described being reliant on them for her day-to-day functioning:

> *They [antipsychotics] keep me well. Without the medication I'm, I'm dangerous.* - Cass, 45yo female, Breast cancer

Thankfully, this did not occur. Cass experienced another near miss when her clozapine was restarted following a 48-hour break in dosing. It is recommended that patients who have an interval of 2 days or more since their last dose of clozapine should be restarted at a low dose, which should be gradually re-titrated to avoid toxicity.

Later in her cancer journey, Cass experienced ongoing issues with persistent fatigue and drowsiness which she attributed as an adverse effect of her chemotherapy and radiotherapy. Cass also experienced a 30kg weight loss (153 to 123kg) since starting chemotherapy along with changes in eating habits:

> *I did cook last night, and that was the first time in about a week that I'd actually cooked something. I live on quick and easy meals. Eggs on toast, you know your Heinz canned dinners, you know you get beef hotpot, beef, and vegetables, yeah. Or spaghetti on toast, or scrambled eggs or you know* - Cass, 45yo female, Breast cancer

Each of these changes had the potential to impact Cass's lithium therapy. Lithium is a narrow therapeutic index drug, the concentration of which can be affected by changes in salt and fluid intake, and significant changes in weight. Signs of chronic lithium toxicity are generalised symptoms such as drowsiness and gastrointestinal upset, both of which Cass described experiencing. In addition to this, Cass also suffered from obstructive sleep apnoea, for which she was using a CPAP machine. Cass's weight loss resulted in her CPAP mask no longer fit meaning that she had not been using it overnight for four months. This would likely also have been contributing to her ongoing fatigue.

Maria also experienced an unplanned hospital admission that was potentiated by medications, although she did not appear to recognise the involvement of her medications

in the adverse event. Maria's cancer journey began when a routine blood test and further investigation diagnosed a severe anaemia. At the time she was taking the anticoagulant apixaban due to her history of multiple pulmonary embolisms, as well as an aspirin/dipyridamole combination antiplatelet as part of her cardiovascular management; a drug combination placing her at risk of bleeding. The recommended initial management was a red blood cell transfusion, but due to her Jehovah's Witness faith she would not accept it:

> *So I told him [the GP] I said "no I can't have it" [the transfusion]. He said "OK", so he sent me for tests again. I had a bleeding inside. I was bleeding, that's why I have so low blood... About six weeks later I had my first operation. And I had the operation and they sent me home…I went back for my first operation in 50/50 chance. I thought "that's ok". I mean it is what it is…and they [the surgeons] still tried to talk me into it [the transfusion] but no, I said "no, it's no way".* - Maria, 80yo female, colorectal cancer

Maria's refusal to have a red blood cell transfusion was a point of conflict between her and the surgical team, who repeatedly tried to talk her into it in multiple consultations with varying degrees of respect, causing her psychological distress:

> *And the first thing when I come into his [the surgeon's] office, "have you changed religion yet?" I said "listen I don't change for you, for nobody else" … that's the only one I really went to town with.* - Maria, 80yo female, colorectal cancer

It is not clear what happened with her aspirin/dipyridamole medication during this time, but when specifically asked if she had to stop her apixaban prior to surgery, Maria responded:

> *Yeah, just two days before. And then soon after that I could start again.* - Maria, 80yo female, colorectal cancer

This suggests that Maria continued to use apixaban while she was anaemic, bleeding internally and preparing for surgery. According to the product information, apixaban is contraindicated in patients with clinically significant active bleeding (e.g. gastrointestinal bleed), and in patients "with a lesion or condition at significant risk of major bleeding such as…presence of malignant neoplasms at high risk of bleeding", suggesting that apixaban may not have been appropriate for Maria. Further to this risk of bleeding, Maria's account suggests that she was also started on daily enoxaparin injections following her surgery which were continued upon discharge from hospital:

> *I was in there [hospital] for ten days…They sent me home, that was Friday night, Sunday morning I was up in [metro hospital] again haemorrhaging* - Maria, 80yo female, colorectal cancer

This resulted in Maria being admitted to hospital and undergoing emergency surgery. She ended up having a prolonged stay in the intensive care unit (ICU) where she did not eat for five weeks and lost about 18kg. Maria also ended up with a colostomy bag, which she found distressing:

> *So, when she told me I screamed. Just one scream I made. And the nurse said to me, "that was horrible." It was frightening, you know, how can I cope? How can I cope?* – Maria, 80yo female, colorectal cancer

Eventually, Maria was discharged home, again with daily enoxaparin injections to be administered in the home by district nurses who also provided wound care. Over a period of weeks to months her wound did not heal. It was painful and offensive in odour:

> *All the pus came out of it and the stink, the smell, you have no idea…. It's about two or three months after and I still was oozing…Oh it was painful. And the smell it was absolutely, like rotten meat* – Maria, 80yo female, colorectal cancer

This untreated wound did not just result in physical manifestations of harm, but also had a psychosocial impact as Maria felt as though she was confined to her house to accommodate for the twice daily nursing visits to care for her wound and administer her enoxaparin injections:

> *I couldn't even go out. Because constantly was tied down in bed or in the house because as I said, nurse came twice a day and they had to redo the bandage each time* – Maria, 80yo female, colorectal cancer

The enoxaparin injections further exacerbated Maria's physical discomfort, injected each day into her abdomen area which was the site of her infected wound causing further swelling and discomfort. Maria was told that she had to have her enoxaparin injections administered by home nurses, which caused her further dissatisfaction. Eventually, she insisted on self-administering her injections, but the experience left her feeling resentful toward her care team:

> *They could have told me from the beginning "oh, we can show you how to do it"* – Maria, 80yo female, colorectal cancer

Sometime later, Maria began to have issues with intestinal obstruction which was managed with repeated hospital admissions. Maria had four hospital admissions to manage bowel obstructions within a year. She was started on chemotherapy[47] a few months after her initial bowel obstruction. After her third chemotherapy cycle, Maria experienced another blockage, which resulted in a weeklong hospital stay. All of this had a negative impact on Maria's psychosocial wellbeing:

[47] Anti-cancer treatments are commonly used to try and manage malignant bowel obstructions,

> *All that, all over the winter I was in and out. Sometimes three or four appointments I have to go to [the hospital], that cost you quite a bit. That's very expensive. Because although I have the taxi fare it still cost me fifty dollars a trip back and forth… But all in overall it cost a lot of money. It was really dear. And I'm on the pension…I can afford it, but then I have to cut out other things.* - Maria, 80yo female, colorectal cancer

Following that hospital admission, Maria's dietary restrictions became so strict that she was no longer able to eat anything with roughage, which she found very difficult not only because of the dietary impact, but also because of her love of cooking:

> *I tell you what, it's no fun. I can't eat any fruit… everything has to be sort of vitamised… Oh I loved cooking. And eating. Oh, it's the best, just the smell of it. And I can't eat much. I lost my appetite... Now I can eat only a tiny little bit of meat and pumpkin and broccoli. Sometimes I can't even eat that because my stomach is so sore… it's the hardest thing I have done. I think it's the hardest thing I ever have done.* - Maria, 80yo female, colorectal cancer

Throughout this time of experiencing significant bleeds and continued issues with her bowels, Maria was also taking verapamil to manage her ischaemic heart disease. Verapamil could have been problematic for Maria in two ways. Firstly, there is a pharmacokinetic drug interaction between verapamil and apixaban[48]. Normally this interaction is not considered clinically significant, however Maria had other factors (age > 75 years, concomitant use of aspirin/dipyridamole) that also placed her at risk of bleeding. Secondly, verapamil commonly causes constipation and has been reported to cause ileus[49], with the elderly known to be more sensitive to its adverse effects (Rossi, 2020). This could have potentially exacerbated her gastrointestinal issues and experiences of blockages. Maria was also using other medicines that could have been potentiating her gastrointestinal issues including calcium supplementation and opioids to manage her pain. Oral opioids are known to create a "vicious cycle" in patients with advanced cancer who suffer from bowel cancer due to a combination of reduced efficacy relating to poor absorption from the oral route, and adverse effects that can result in faecal impaction (Cherny et al., 2021). While it is not possible to be certain that Maria's medication regimen contributed to her repeated bowel obstructions and the cascade of physical and

[48] Verapamil is a moderate inhibitor of CYP3A4 and p-glycoprotein, of which apixaban is a substrate

[49] A non-mechanical obstruction of the bowel related to inhibition of peristalsis

psychosocial harms that followed, it is probable that her medications contributed by making a bad situation even worse.

5.2.2 Intangible experiences

Intangible experiences of medication-related issues were recounted by participants as negative emotional reactions to health events associated with feelings of dissatisfaction with the care plan and feeling uncertain about the medication regimen.

5.2.2.1 Feeling dissatisfied with the care plan

Maria's story detailed above is one example of a participant feeling dissatisfied with their care plan, resulting in physical and emotional distress. Mandy also described an experience of being dissatisfied with her care plan. Fortunately for Mandy, she was able to self-advocate to achieve a resolution prior to it manifesting as physical MRH.

Two years prior to finding her breast cancer, Mandy had been diagnosed with MS, which had been managed with a medication called Tecfidera[50] (dimethyl fumarate), prescribed by her Neurologist. When her oncologist recommended Mandy continue on her Tecfidera throughout chemotherapy, Mandy became concerned. She raised this concern with her oncologist during a treatment planning consultation:

> *I was like, "Does that do anything, do I have to go off my MS pills?", and [oncologist] was like "Oh I don't think so…we can have a look"* - Mandy, 48yo female, breast cancer

At the following consultation with her oncologist, Mandy was informed that there was no issue. But she remained concerned. Mandy asked if her neurologist could be included in the discussion, but this did not occur:

> *I came back the next time and I said so "what do you, what's happening?" And she said "yeah, we think you can stay on your Tecfidera." And I said "Really? Have you spoken to my neurosurgeon? Have you actually spoken to her? Because I'm just a little worried". And then I mentioned I've got the JC virus, because I thought once they hear I've got that and MS. And she said "ok". So she called up and so she said, "oh I'll talk to Dr [neurosurgeon]."* - Mandy, 48yo female, breast cancer

Mandy was asked by her oncologist to contact her neurosurgeon herself which presented further challenges as Mandy was required to act as the intermediary between the care providers, whilst also communicating with an intermediary gatekeeper in the form of the

[50] According to the AMH, "exact mode of action unknown; thought to involve antioxidative, immunomodulatory and anti-inflammatory effects", commonly causes leukopenia, lymphopenia, which increases the risk of progressive multifocal leukoencephalopathy (PML), an opportunistic viral infection caused by the JC virus

MS nurse:

> *They actually said at one stage, "Can you talk to Dr [neurologist]?" … so I phoned up Dr [neurologist]'s office and I just got the MS nurse…and I told her what my problems were, and she said, "I'll get onto Dr [neurologist]" … she said, "Oh Dr [neurologist] thinks you should come off." And I went in and told my oncologist "Dr [neurologist] thinks I should come off the medication before I start", and she was like "No, I really don't think so"* - Mandy, 48yo female, breast cancer

Eventually, the neurologist and oncologist communicated with one another directly and agreed that Mandy should cease her MS medication:

> *So then when she actually, the two got together, specifically got together and talked about me, she said "Yeah, we'll take you off"* - Mandy, 48yo female, breast cancer

This care experience resulted in a disrupted care experience for Mandy who was required to fulfil a greater workload acting as the intermediary between care providers, resulting in frustration and a heightened degree of caution as she continued throughout her cancer care:

> *And I thought, "Shouldn't she [neurologist] have been included?" I mean, that bothered me. If I hadn't had been, "No, no, no", I mean there's, that niggle was there for a reason.* – Mandy, 48yo female, breast cancer

Mandy also described an experienced of feeling dissatisfied with the proposed plan for administering her chemotherapy following an infection in her PICC line. The proposed nursing strategy was to simply administer the chemotherapy into a peripheral vein rather than replace the central line, but this was unacceptable to Mandy who understood the risks of extravasation and necrosis:

> *The PICC line got a little infected, so they took it out. And I went in for my next treatment and they wanted to put it into my arm, like straight into a vein…And I was going "No I don't want it", I just said, "Put another PICC line in me". So I had another PICC line put in. I just freaked out; I freaked out*. – Mandy, 48yo female, breast cancer

Multiple participants described feeling dissatisfied when it was initially suggested that they pursue chemotherapy, like Suzi:

> *Originally when they said about chemo and that like, and I was still in hospital after the lobectomy I wasn't going to have it. Like "Nup, I'm not doing it"*– Suzi, 55yo female, lung cancer

For Cass, the hesitation to accept her cancer diagnosis and emotional response to the proposal of chemotherapy was severe, also refusing treatment until confronted by her oncologist:

> *When she [GP] told me I had breast cancer…my whole world fell apart…I thought about suicide…I refused treatment at first…The vomiting, the diarrhoea, the pins and needles…I don't want to go through that, I'll be alright, I don't need it...* - Cass, 45yo female, Breast cancer

5.2.2.2 Feeling uncertain about the prescribed medication regimen

Multiple participants described feeling uncertain about their self-administered medication regimen. In circumstances where the patient was having medicines administered within hospital, this uncertainty did not result in an inability to use the medicines as directed but it did result in unnecessary confusion and frustration, as Suzi described in relation to her surgical admission for a lobectomy:

> *I took all these tablets with me when I had to go in because they asked me to, but I was on so much more medication… they were giving me pills left right and centre…I kept saying to like my husband, "bloody they've given me all these tablets, I don't know what they're for"* – Suzi, 55yo female, lung cancer

In cases where patients were self-administering medicines at home this uncertainty had the potential to adversely impact the effectiveness of their medication regimen and potentially result in physical MRH. Janis, Carole, and Maria each expressed uncertainty about changes made to their usual medications by their specialist clinicians while receiving chemotherapy which, as Carole describes, resulted in negative emotions:

> *I don't know why, they put me on two metformins now because the blood levels I'm getting was the same before the two. So I still have to go back and say "listen, this is the readings before the two tablets, this is the readings after the two tablets, compare them, I'm not happy I'm getting the same results". So I, you know, I think I should go back onto one tablet*. – Carole, 45yo female, Breast cancer

Not all participants uncertainty about the prescribed medications was expressed as confusion. For some, uncertainty was demonstrated through a lack of understanding regarding the therapeutic benefit, as shown by Johnny:

> *I have them [inhalers] here but I don't use them… the last month or so I haven't needed it. I'm not short of breath, so I'm not even worrying about the COAD at the moment*. – Johnny, 67yo male, oesophageal cancer

5.3 The pharmacist experience

This section presents the findings of the pharmacist study for the purpose of gaining further insight into the types of medication-related issues that are encountered by HCP that exist within the patient world. These issues have been interpreted as issues relating to drug-related risk, practical challenges in using medicines, and issues relating to a complex interplay of factors.

5.3.1 The patient's underlying degree of drug-related risk

Some of the medication-related issues encountered by pharmacists as they care for people living with cancer were clearly associated with the patient's underlying degree of drug-related risk. This includes both the degree of risk associated with the medication regimen itself, as well as the patient's vulnerability to MRH. Three main types of issues were described in relation to drug-related risk: emergence of new medical problems, exacerbation of an underlying condition, and shift in risk-benefit.

5.3.1.1 Emergence of new medical problems

There were multiple examples of new medical problems emerging as a result of cancer treatment, often associated with chemotherapy. Sometimes these symptoms were considered by patients and their HCPs as unremarkable, despite having a significant impact on the individual's quality of life:

> *…as part of his therapy he was routinely experiencing 96 hours of uncontrolled diarrhoea. He had mentioned he was having diarrhoea. He'd mentioned this to the [chemotherapy] infusion nurses, they said "take loperamide but don't take too much." So he was taking one tablet on a Friday night knowing diarrhoea would start on the Saturday and then he said, "oh I just stay at home". Now, massively dehydrated, all the problems that go along with that* – Pharmacist 7, Ambulatory HONC/Community pharmacist

Other times newly emergent problems negatively impacted the patients chemotherapy regimen in addition to causing physical symptoms that impacted their quality of life:

> *The other thing, of all the reasons that someone might have their chemo stopped…neuropathy. So they'll be responding quite well to their chemo but getting painful peripheral neuropathy or you know, inability to actually do up buttons* – Pharmacist 13, Ambulatory HONC/palliative care pharmacist

In some cases, emergent problems resulted in long term conditions requiring ongoing changes to their medication regimen, such as cardiotoxicity caused by anthracyclines:

> *We've had a couple of patients who've developed heart failure or had a reduced ejection fraction from kind of their exposure to those agents.* – Pharmacist 10, Inpatient/ambulatory HONC pharmacist

Steroids were also noted as being regularly problematic, resulting in issues for patients who did not necessarily have a pre-existing underlying condition:

> *Steroids as part of chemo are, particularly within haematology, problems*. *Patients can present problems with precipitating you know diabetes which may or may not get better once treatment has finished…sometimes in the younger patients they get psychosis or some side effects from the steroids* – Pharmacist 15, Inpatient/ambulatory HONC pharmacist

Most of the medication-related issues associated with chemotherapy were described by pharmacists working in the hospital setting. However, there were still experiences of pharmacists encountering such problems within community pharmacy practice and medication reviews as illustrated by Pharmacist 6's experience with a new customer who presented to the pharmacy for help with fluid replacement due to diarrhoea and was later discovered to also be experiencing issues with peripheral neuropathy:

> *…She was losing weight and losing fluid because she has developed diarrhoea from the current chemo that she's on and she wanted assistance in what could she do to replace the fluids…she stopped wanting to eat because she said she can't cook because the smell of cooking food makes her feel nauseated and she developed peripheral neuropathy as an effect of the chemo so she can't grab the fridge, the fridge door*. – Pharmacist 6, Community pharmacist

Community-based pharmacists also described issues patients experience with side effects to medicines used as part of supportive care, as Pharmacist 5 explains:

> *Sometimes you find people get a bit frustrated with the sedation, and sort of the cognitive side effects of opioids, especially if they're on say an antidepressant which has got anticholinergic effects or pregabalin or something*. *And you sometimes have carers complaining about that as well.* – Pharmacist 5, Accredited/GP practice pharmacist

5.3.1.2 Exacerbation of underlying conditions

Multiple pharmacists described encountering patients who had experienced medication-related issues that resulted in worsened management of their underlying conditions. Many of these experiences related to the impact of corticosteroids on blood sugar levels in people living with diabetes:

> *The things that always seem to become a problem revolve around the dexamethasone. Even if it's only a couple of days post chemo but they're already diabetic and their sugars go through the roof* – Pharmacist 13, Ambulatory HONC/palliative care pharmacist

Steroids were also noted to be problematic for people with underlying mental health conditions, particularly those with schizophrenia or psychosis:

> *Patients who have diabetes or mental health issues you know, pumping steroids into them makes things very hard. And you know we've had lots of those cases where they've caused psychosis in patients that have been a bit brittle* – Pharmacist 16, Inpatient/ambulatory HONC pharmacist

5.3.1.3 Adverse drug effects resulting from a shift in risk-benefit

Several pharmacists described situations where patients were continued on medications for their underlying chronic conditions despite a marked shift in the risk-benefit occurring. This was noted on a number of occasions in relation to anticoagulants and antiplatelets resulting in episodes of bleeding or blood dyscrasias. As Pharmacist 7 explains, balancing the benefit of continuing this type of therapy in the context of increased risk is a delicate balance:

> *We've had patients who have been on warfarin, ceased, gone into surgery, had bleeds on the table, had a couple of units pushed back into them and then they've been exiting [the hospital]…in one case just restarting warfarin saying "you'll be right" at the same time as the surgeon a had prescribed celecoxib…We had this situation where the patient actually exited [the hospital] had a gastric bleed, and you know it's the classic perfect storm. She was also in a rural location. But when we questioned it, we actually questioned it with the patient and she said, "oh no I was told by everyone it was ok".* – Pharmacist 7, Ambulatory HONC/Community pharmacist

5.3.2 Practical challenges in using medicines

Pharmacists described patients experiencing issues relating to practical challenges of using medicines. In some cases, this related to imbalance in work and capacity, while others were issues of confusion and miscommunication.

5.3.2.1 Workload and capacity challenges

Pharmacists in hospital and community settings all described situations where patients with cancer encounter practical challenges relating to the implementation of their medication regimen that appeared to be associated with an imbalance between workload and capacity. Several pharmacists noted that the issues experienced by patients who had

no prior experience with taking medicines, such as younger people, seemed to be different to those who were used to using medicines to manage pre-existing chronic conditions as Pharmacist 18 explains:

> *[in haematology] you probably get more people who are like "oh I don't take tablets normally" so it's quite a big move to kind of go from zero to three or four medications regularly a day, which is often the amount they'll end up on if they haven't had any complications. If they've had complications they'll end up on more, and if they're post-transplant there's even more than that, often there's usually at least six, five or six, sometimes 7, 8, 9, 10, depending on what they're on and what their complications have been. So yeah, it is, um, I think the big thing is people sort of jumping from not being on much to being on quite a bit, and sort of just having to come to terms with that a bit* - Pharmacist 18, Inpatient HONC pharmacist

In these types of situations, patients are required to learn not only about their new medications but the healthcare system itself. In the case of medicines use, this involves learning about how to access a concession card in order to make their medicines more affordable as newly prescribed medicines introduce a new expense into their monthly budget:

> *…. often they'll get diagnosed so quickly…and often what I end up doing is that when I give them the invoice to go home, that's the worst part of my job is giving the patient the invoice. Because I mean, if they're not on concession and our drugs are so expensive, you're looking at 30 odd bucks for each item for each month. And so you're looking at often $120 to $300 invoices that you're giving these patients that have just been diagnosed with leukaemia* – Pharmacist 18, Inpatient HONC pharmacist

Pharmacists also noted the impact of social supports on patients capacity to manage their medicines effectively within the home. In some cases, the lack of social supports was seen to contribute to people being unable to fulfil the work of using medicines, as described by Pharmacist 19:

> *With the patients which have more of a complicated history or ones which might be lacking that social support, you find that they might not be as compliant compared to those who do have a better support network at home, because at least they've got cues and reminders and surrounding support to help them out in that situation. And also people who are by themselves* – Pharmacist 19, Ambulatory HONC pharmacist

In other cases, pharmacists described the ways in which social supports bolstered a patient's capacity to fulfil the work of using medicines, as described by Pharmacist 10:

> *I remember there was one patient who came in and then was very vague, he was very vague about his medication so he needed his sister being there to help him take everything and kind of manage everything, and so that was just managed more through talking with his sister on admission and discharge and making sure that she was on the same page with what the plan was and she was able to help manage him, manage all his medications for him* – Pharmacist 10, Inpatient/ambulatory HONC pharmacist

As described in Chapter Four, obtaining ongoing supply of medications is part of the logistical work of using medicines. Several pharmacists described how this became more challenging during cancer treatment. Most hospitals restrict the supply of ongoing medicines to cancer-related medicines, requiring the patient to obtain other prescriptions from their community pharmacy. Pharmacist 3 described how a patient requiring insulin due to steroid therapy resulted in a fragmented care experience for a patient:

> *We don't even stock insulin so we then have to refer to a community [pharmacy] so I can only imagine how that's continued…The doctor wrote an initial prescription, but they obviously had to go to a community to get it* – Pharmacist 2, Ambulatory HONC/Community pharmacy

This reliance on community care providers to supply the patient with ongoing supply of their usual medications was a known source of frustration and disappointment for patients, as Pharmacist 11 describes:

> *I think patients just get so overwhelmed with having so many appointments that seeing a GP is at the bottom of their list. Sometimes when I have spoken to patients and they're getting treatment and they ask, you know, "Can I get a repeat script for this?" and I say, "You have to see your GP for that, have you got an appointment?" and they're like "Oh no"*– Pharmacist 11, Ambulatory HONC pharmacist

There was also a perception amongst HONC pharmacists that these mixed-supply arrangements contributed to sub-optimal care on occasion:

> *We occasionally get, I suppose negative reports that they've gone to their community pharmacy because they still felt sick after their chemo, and they've been offered something that's totally inappropriate. But then we have had positive reports that patients go to their community pharmacy and get referred you know told, refer themselves back to us*. – Pharmacist 15, Inpatient/ambulatory HONC pharmacist

The complicated dosing instructions of some cancer-related medicines were also noted to contribute to patient confusion with the medication regimen. Implementing these types of medication regimens involves an intellectual workload in addition to the logistical one which can be challenging for all types of patients:

> *It can be very confusing when you're starting all these new medications which have got a bit of a strange regimen. Like some of our regimens are like three weeks on, one week off, weekly dosing or twice weekly dosing, things like that. It just complicates things even more.* – Pharmacist 17, Inpatient HONC pharmacist

As described in Chapter Four, the patients pre-existing workload associated with their usual medications continues to contribute to the workload throughout cancer diagnosis and treatment. Pharmacist 14 describes how in some cases, this work could be actively reduced, especially for those who have had a shift in their goals of care from a curative to a more palliative intent:

> *When they are then diagnosed with a cancer…[with] a poor prognosis, there has not been a resetting of goals around some of those other conditions. So whether that be statins and cholesterol, being a very strong example of where that conversation hasn't been had where you know, well, your prognosis is probably months rather than years, and what is the benefit of continuing those?* - Pharmacist 14, Palliative care/accredited pharmacist

5.3.2.2 Confusion and miscommunication

Multiple pharmacists described patients experiencing practical difficulties in implementing their medication regimen that stemmed from issues of confusion and miscommunication. This was noted to be particularly problematic when patients moved between the hospital and home environments. As Pharmacist 13 explained, even patients who are considered to be highly capable in their medication management often experience confusion after being discharged from the hospice, often because there have been multiple changes made to their medication regimen during admission that have not been well understood:

> *…you [the patient] get told "Oh you've got two or three different things for nausea, for pain, a laxative", maybe they've been prescribed at different times by different people, maybe it's like we're saying, "Well if this doesn't work try that as well". And even if I've sat down with them, produced a list, gone through it and they've said "Yes, I understand" they will still often get home and go "now, which is the Paragen and which is the Endone?"*– Pharmacist 13, Ambulatory HONC/palliative care pharmacist

Pharmacists felt that these types of issues were particularly common in people who were managing chronic conditions as well as cancer, as described by Pharmacist 15, Inpatient/ambulatory HONC pharmacist:

> *We do often find …diabetic patients that are …a bit vague about what's happening… even asthma patients who have got inhalers who aren't really quite sure which ones to use. Or patients who may have had their medication changed by a GP or other specialist, but they have still got an old list from somewhere else and they're not actually sure what they're taking* – Pharmacist 15, Inpatient/ambulatory HONC pharmacist

Poor communication with the patient, whether it be an absence of information or inability of the patient to understand the information provided, was noted to regularly result in patient's not taking their medications as prescribed. As illustrated by the experience of Pharmacist 10, in the setting of cancer, this has the potential to be highly problematic:

> *Last week there was a gentleman who thought through miscommunication that he was supposed to stop all his myeloma treatment and then he wasn't taking anything and then on his next clinic visit all his myeloma markers were up and the consultant added on another medication assuming he'd been taking all the other things. And then when he came into the day oncology centre one of the nurses found out from him that he's actually not taking anything at all.* – Pharmacist 10, Inpatient/ambulatory HONC pharmacist

Poor communication between members of the health care team was also noted to result in medication-related issues. Several pharmacists described situations where a patient was taking an incorrect dose of medication due to the involvement of multiple prescribers across the interface of hospital and primary care. Pharmacist 3, who worked at both a hospital pharmacy and local community pharmacy was in a unique position to be able to identify these types of issues in practice:

> *They [patients] present with scripts from both the GP and scripts from here [hospital]. I've definitely seen a few errors even through that. Like dexamethasone, and I only know because I know their treatment. They're prescribed dexamethasone for five days at 100mg, but the GP had prescribed prednisolone at a different strength*– Pharmacist 2, Ambulatory HONC/Community pharmacy

5.3.3 A complex interplay of patient factors

Some of the medication-related issues encountered when caring for people living with cancer are complex, involving an interplay of patient factors. These types of multifaceted issues were commonly encountered when caring for someone with multimorbidity and patients with attitudes and beliefs that were not aligned with that of their HCPs.

5.3.3.1 Managing multiple medical conditions

Patients who are managing more than one medical condition are often taking multiple medications which, as explained in Chapter Two, increases the probability of adverse effects, some of which are similar to commonly experienced adverse effects of cancer and its treatment. Identifying causal relationships between medications and clinical effects within this context can therefore be challenging, as Pharmacist 10 describes in relation to a haematology patient who has abnormal liver function tests and is also taking a statin for their cardiovascular health:

> *It [the cause of the symptoms] could've been the statin, could've been the azole that they're on, could've been the chemotherapy that they've gotten* – Pharmacist 10, Inpatient/ambulatory HONC pharmacist

At times, this can result in what is referred to as a prescribing cascade, where additional medications are prescribed to manage the effects of other medications (Kalisch et al., 2011). Pharmacist 1 describes this in relation to the management of nerve pain in cancer:

> *You know, the nerve pain or the lymphoedema is affecting their pain in their hand or whatever and they get some Lyrica. It makes them confused, and they fall over, but did it really help the pain? And they say, "I don't really know what helps the pain dear, so that's why I continue to take my Targin and my Lyrica and my paracetamol and I use my Voltaren gel". And I go "Well which one is it that's actually helping? Are any of them helping?" So I try to get them to think a bit more, rather than continually adding in therapy is there anything that you can review, because they do start all adding to their side effects* – Pharmacist 1

Pharmacist 14, who worked in palliative care and aged care, shared an example that illustrates just how complex this can be in practice, particularly in patients with advanced disease who have a high symptom burden. This patient had a metastatic lung cancer which was causing him to be anaemic. He also had a history of COPD and ischaemic heart disease. At the time the Pharmacist reviewed him, the patient was using high doses of salbutamol to try and manage his ongoing shortness of breath:

> *…well, actually this is a multifactorial shortness of breath. It actually could be lots of these things, of which salbutamol is only actually going to manage a small amount, and it's in a situation where it's practically impossible to unpick to acknowledge that this is part of his cancer, but there are actually a number of other things that could be contributing to it as well* – Pharmacist 14, Palliative care/accredited pharmacist

Pharmacist 13, who also commonly worked with a geriatric population, noted the challenges of managing this biomedical complexity in frail elders:

> *We've got the population that's fairly frail and they might never come up with an official heart failure diagnosis, but it could still be that it tips them a little bit over the edge. So with steroids, weight gain, muscle weakness, fluid retention, hyperglycaemia, in a way I reckon I sometimes see those things more than the obvious predictable side effects of the chemo itself, which are problems but not necessarily in dealing with other illness* – Pharmacist 13, Ambulatory HONC/palliative care pharmacist

Poorly managed mental health conditions were also noted to introduce complexity into the management of someone undergoing cancer treatment. Pharmacist 18 described how a patient's schizophrenia catastrophically impacted his cancer treatment outcomes:

> *We had one guy come in with schizophrenia earlier this year, and just, his ability to you know, engage with the treatment and that sort of thing was not great. And we didn't even really get to start [treatment] on him, and he deteriorated quickly and we just, he couldn't convey his symptoms as well in the community. And like he deteriorated quickly and died in ICU about three weeks after admission.* – Pharmacist 18, Inpatient HONC pharmacist

The challenges of engaging patients with poorly managed mental health conditions in appropriate strategies of medication management was also described by Pharmacist 4. This example is a patient within the community setting who was a breast cancer survivor. She was referred to the pharmacist for an HMR by her GP, who was concerned that the patient continued to be prescribed hormonal therapy by her menopausal clinic despite having an oestrogen positive breast cancer, for which she was taking tamoxifen. The complexities of management were not just related to the patient's health, but also the care team, which was diverse and fragmented:

> *What I ended up doing was ringing up the menopause doctor in her natural health clinic and try just to find out, do they know that they're all doubling up, and also that this patient's also at risk of the cancer coming back? And everyone said "Yes, yes, we know what we're doing, we're aware of it, but this patient can't come off HRT because she also had mental health issues which was related to her menopause". So it was just going round. It was an impossible situation…I said, "What we need to do is get this woman back to seeing a psychiatrist" …It was my belief seeing the drugs the patient was on that the therapy was driven by the patient. I think he [the GP] threw his hands up and said, "I just don't know" and kept going. You know this person was on diazepam, temazepam, Ativan…she was on an SSRI, she was on mirtazapine, all of those.* – Pharmacist 4, Accredited pharmacist

While poorly managed mental health conditions were described by pharmacists as presenting challenges with achieving effective medication management, Pharmacist 14 also described a situation where the assumption of a mental health condition requiring pharmacotherapy was equally problematic. They received a referral to undertake a medication review for a woman with metastatic ovarian cancer, for the purpose of addressing the question *"does she need an antidepressant and was that going to be a problem with some of her other medications?".* By consulting with the patient and understanding their story, the pharmacist was able to identify a very different issue:

> *On the day that I saw her she [the patient] was sitting up in her front lounge room, but she described to me feeling that she'd lost her up and go…she wasn't engaging in her usual craft activities and things like that, and this for me was a little bit perplexing because where she was sitting, she was surrounded by craft activities. And so I was trying to work out, is she really? Does she truly have a depressed mood? Because it would seem unusual that she wasn't engaging in craft activities while she was sitting in that chair…I suppose in the course of an hour or so, what I realised was that she very rarely sat in that chair. She was actually spending her time, most of her time in bed. So I asked her why it was that she wasn't getting into that chair and stayed mostly in bed? …the toilet in the house was not set up in a way she could easily access, she needed grab rails. In her bedroom she had a commode and therefore that wasn't an issue. She didn't want to put the commode in the front living area… so she hadn't been sitting in the front room with her craft activities because she was worried about going to the toilet. And when I said to her, "if we could get the toilet fixed and you could sit in this front room, would you do your crafts?". "Probably, I'm sitting here". And it was*

> *a really nice example of saying "no, she doesn't need an antidepressant, someone just needs to fix her toilet"* – Pharmacist 14, Palliative care/accredited pharmacist

Another experience shared by Pharmacist 14 illustrates the challenges of identifying and resolving medication-related issues in patients with multiple conditions who are receiving care from multiple providers. This example was a patient who was undergoing chemotherapy for pancreatic cancer, had a history of type two diabetes managed on metformin, and developed a DVT which was being treated with enoxaparin injections. The patient was started on metoclopramide and dexamethasone as antiemetics as part of his chemotherapy regimen. He was told to take metoclopramide regularly four times a day, even when not on chemotherapy, and to take dexamethasone for three days out of seven, for three weeks out of four. This added complication to his usual medication regimen and increased the workload associated with his medication use. Soon he developed steroid induced hyperglycaemia which required insulin injections:

> *For him he was getting quite distressed from the number of injections because he was then on insulin daily for three weeks out of four, plus enoxaparin every day. His wife actually described him as getting quite distressed and crying from the pain and the bruising from those injections.* - Pharmacist 14, Palliative care/accredited pharmacist

By talking with the patient, the pharmacist achieved a greater understanding of his experiences and concerns.

> *He was telling me, "But I've never had nausea. I've had a little bit of nausea, but I don't think that I've ever vomited from my chemotherapy". And he was up to like cycle seven at this point in time. So we were able to track back a little bit, and he had kept excellent BSL records where you could see exactly when the hyperglycaemia, the steroid induced hyperglycaemia dropped off. It was normally about day 4. So we talked about what would happen even if we got rid of three days out of four of insulin, and he was like "yes, if I could get rid of any injections that would make all the difference in the world". - Pharmacist 14, Palliative care/accredited pharmacist*

Pharmacist 14 took the time to get to the bottom of this multifactorial issue, and in doing so was able to identify several changes to his medication regimen:

> *…I think for him there were potentially seven changes to his medications that we could make. And certainly his primary concern was about the injections, and we were able to follow that up* – Pharmacist 14, Palliative care/accredited pharmacist

5.3.3.2 Alignment of attitudes and beliefs

Several pharmacists described medication-related issues relating to patient's reluctance to accept treatment or follow a recommendation due to their attitudes and beliefs about medicines or broader worldview. In some cases, the patients dissatisfaction this arose from a position of uncertainty or misunderstanding about their medication regimen. For some patients this type of poor communication results in feelings of frustration and anger toward their care providers. As this story from Pharmacist 7 illustrates, describing the experience of a patient whose oncologist did not inform them that the dose of their usual chemotherapy had changed prior to collection of the prescription from the pharmacy:

> *The patient was literally in here screaming because well in their words we'd f'd up. You know "what are you, incompetent?" …they didn't understand why you'd want the dose to change,* – Pharmacist 7, Ambulatory HONC/Community pharmacist

In other cases, patient dissatisfaction with the care plan may indicate that conflicting goals of care exist within the broader care team, as explained by Pharmacist 17:

> *Sometimes the patient or the family haven't come to terms yet with the diagnosis and they might not actually want to stop these types of medicines*. – Pharmacist 17, Inpatient HONC pharmacist

The example shared by Pharmacist 18 illustrates how a patient's attitudes and beliefs about their medicines are not all superficial. This patient, who was undergoing treatment for acute myeloid leukaemia, was also managing Parkinson's Disease as a long-term condition:

> *That's been a bit of a struggle for him because his Parkinson's has sort of deteriorated a bit with having the* [AML] *treatment. And he, again, likes to be in control of his treatment, but yeah, it's sort of been mucked around with things. And he often sort of changes his doses at home. And he's coming in regularly and they're sort of getting neurology reviews every time he comes in, but then he sort of doesn't always do what they say, and he goes home.* – Pharmacist 18, Inpatient HONC pharmacist

Each of the cases above described a situation where the patient was active enough in their self-management that they could form their own ideas about whether or not the treatment plan was appropriate. Whatever the reasons, their attitudes and beliefs about medicines did not fully align with that of their care team at that point in time, resulting in a negative experience.

Another group of patients where a misalignment between attitudes and beliefs was often described were those who pursued the use of complementary and alternative medicines (CAMs). The use of CAMs throughout cancer treatment is not universally accepted by

HCPs. As a result, it can be a potential source of conflict. If an HCP recommends a patient ceases their CAMs use while undergoing treatment the patient may either accept that recommendation or pursue it against the wishes of their care team. Pharmacist 19 described how this involves a process of negotiation that requires the HCP to come from a position of empathy:

> *I guess one of the things that we need to be a bit more careful of, or just be aware, is that often it's like their last resort. They take off all their therapeutics and then just go the natural method, pay lots and lots of money for it too, get that information from a naturopath. And it's hard to let them know that you know, we're based on evidence-based practice… like what do you tell them? They've spent hundreds of dollars on this, and then they come in for chemo which has that evidence to back it up and they're asking "oh, can I take this with this? … All you can do is present the information, and most of the time you just advise them, "let's just stick with the chemo for now and hold it off."* – Pharmacist 19, Ambulatory HONC pharmacist

5.4 Discussion: Objective 1.2

5.4.1 Describing medication-related issues in relation to the patient experience

As introduced in Chapter One, within the medication safety literature, a patient's experience of medication-related issues is typically described as a DTP. DTPs describe issues in relation to the medication regimen using seven categories: unnecessary drug therapy, additional drug therapy needed, ineffective drug, dosage too low, adverse drug reaction, dosage too high, and patient unable or unwilling to use as intended (Cipolle et al., 2012). Rather than take this approach, this chapter has attempted to describe the medication-related issues in relation to the patient experience. How these issues are described depends on whether they are considered from the patient or HCP perspective.

When considered from the patient perspective, medication-related issues can be described as tangible or intangible experiences. Tangible medication-related issues include the physical challenges of administering medication, as well as the lived experience of the physical and psychosocial harms that manifest as a result of medication use. Intangible medication-related issues involve the negative feelings that arise in association with the medication regimen, such as feeling dissatisfied with the care plan, or feeling uncertain about the prescribed medications. These different types of issues can be interrelated; what may begin as an intangible experience of uncertainty may give rise to a tangible experience of MRH.

When considered from the perspective of the HCP, medication-related issues can be described as being associated with the patient's underlying degree of drug-related risk, the practical challenges of using medicines, and those that arise from a complex interplay of patient factors. Medication-related issues associated with drug-related risk are those that can be expected to directly result in tangible experiences for the patient if they are not appropriately managed, through the emergence of new medical problems or exacerbation of an existing underlying medical conditions. Issues associated with the practical challenges of using medicines may result from the patient's medication-related workload exceeding their capacity to fulfil it or could result from poor communication across an interface of care. Complex multifactorial issues arise when there are multiple inter-related factors at play. This may be associated with the management of multiple conditions and polypharmacy that often goes with it, or the misalignment between the patient's attitudes and beliefs about medicines and that of their care team.

5.4.2 Medication-related issues are common, but not always visible

Medication-related issues are commonly encountered as patients progress in their cancer journey, but patients are not always cognisant of them. The Cynefin Framework provides a useful tool for understanding how readily different types of medication-related issues are recognised by patients, as illustrated in Figure 24.

5.4.2.1 Medication-related issues that are clearly visible to the patient

A proportion of medication-related issues will be obvious to patients, with a clear relationship between medication use and their experience. These types of issues fit within the clear domain. Tangible experiences such as facing a practical challenge in administering a medicine, experiencing a common side effect, or encountering an imbalance in work and capacity are likely to be obvious to a patient, as are some intangible experiences relating to uncertainty about the medication regimen.

5.4.2.2 Medication-related issues that are visible to the care team

Other medication-related issues are visible to the patient only if they have a high level of knowledge or if the issues are made known to them through interactions with their care team. These types of issues fit within the complicated domain. Issues associated with drug-related risk tend to fit within this domain, particularly if that risk has manifested as an experience of MRH that required active management by the care team.

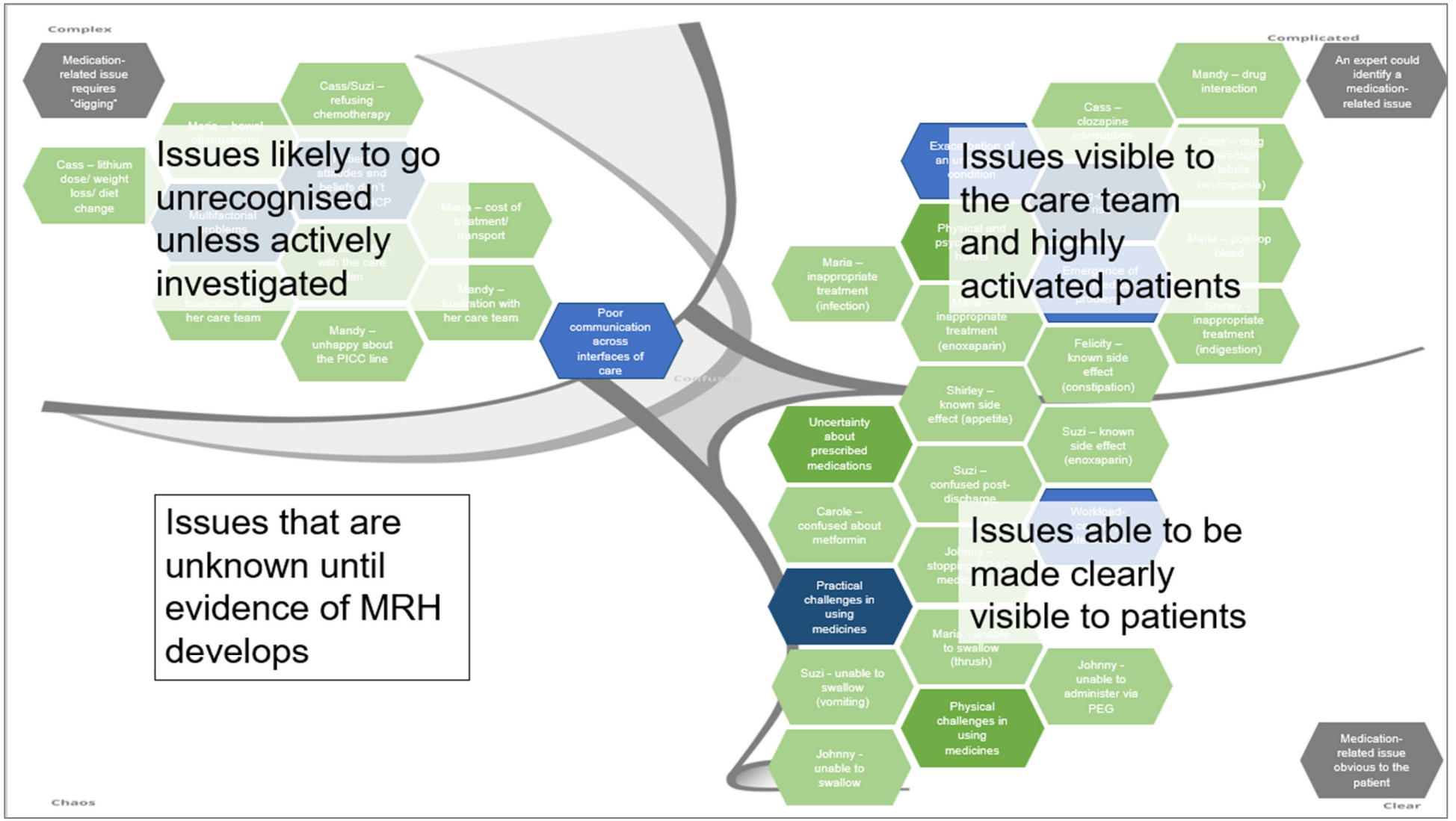


Figure 24: Visibility of medication-related issues

5.4.2.3 Medication-related issues identified through active investigation by an HCP

A proportion of medication-related issues will not be recognised as medication-related by patients or their care team unless they are actively uncovered by a suitably skilled HCP. These types of issues fit within the complex domain. Issues that have multiple contributing factors tend to fit within this domain as they require someone to identify relevant information and make connections between interrelated factors to make sense of the situation. These types of issues can be expected to persist until they eventually result in MRH.

5.4.2.4 Medication-related issues unknown until they manifest as MRH

Finally, some medication-related issues will remain unknown until evidence of MRH develops. These types of issues fit within the chaotic domain but will shift into the clear or complicated domain once they manifest as MRH and are recognised by the patient or their care team.

5.5 Chapter Summary

This findings presented in this chapter indicate that people who are independently using medicines throughout cancer diagnosis and treatment can be expected to encounter a medication-related issue at some point in their cancer journey. Such issues may be experienced by the patient as a tangible or emotional event. These issues may be associated with underlying drug-related risk, practical challenges of using medicines, or may be multifactorial problems associated with a complex interplay of factors. They can occur at any stage of the cancer journey, with each issue encountered carrying the potential to result in MRH. Importantly, not all medication-related issues are visible to the patient or their care team. A proportion of medication-related issues will remain unknown unless they are actively investigated or later manifest as MRH. In the next Chapter we look at the tactics employed by patients and their caregivers when they encounter a medication-related issue within the patient world.

6 TACTICS EMPLOYED

6.1 Chapter Introduction

In Chapters Four and Five considered the patient world in terms of the balance between workload and capacity associated with medicines, and the types of medication-related issues encountered throughout cancer diagnosis and treatment. This chapter presents the results that address Objective 1.3: Examine the tactics employed by patients and their care providers in response to medication-related issues and how they impact on achieving timely and appropriate management. As with Chapter Five, it is recognised that while medication-related issues exist within the patient world, patients may not always be actively involved in the tactics employed in response to them. Because of this, the chapter draws from both the patient and pharmacist studies. Firstly, the relevant findings of the patient study are presented, interpreted as four main themes: patients utilising resources already present within their patient world, patients bringing in external resources from the system of care, care team initiating an active response, and medication-related issue going unrecognised. Secondly, the findings of the pharmacist study are presented, interpreted as three main themes: patients acting pragmatically, systematic, and opportunistic proactive tactics of the care team, and care team reacting to an obvious issue. Following this, a series of case comparisons is used to examine how these tactics impact the timely and appropriate management of medication-related issues, brought together into a unified explanation using the Cynefin Framework.

Table 11: Themes identified associated with Objective 1.3

Objective	Major theme	Sub-themes
Tactics employed: patient experience	Utilising resources already present in the patient world	Mobilising informal support networks to fulfil the logistical work
		Independently managing day to day
	Bringing in external resources from the system of care	
	Care team initiates an active response	
	Medication-related issue goes unrecognised	
Tactics employed: pharmacist experience	Patients acting pragmatically	
	Systematic and opportunistic proactive tactics	Proactive tactics embedded into the system of care
		Proactive tactics employed at an HCP level
	Care teams reacting to an obvious issue	

6.2 The patient experience

This section presents findings of the patient study; an interpretation of their lived experience of how medication-related issues are responded to within the patient world. This interpretation has four tactics employed in response to medication-related issues: patients utilising resources already within the patient world, patients bringing in external resources for the system of care, the care team initiating an active response, and the medication-related issue going unrecognised.

6.2.1 Utilising resources already present within the patient world

As described in Chapter Four, all participants had pre-established logistical workload associated with their usual medication regimen, meaning that medication management was a normalised part of their daily life. Owing to this, when they encountered acute disturbances in the balance between workload and capacity, they employed tactics in the same way as they did other normalised activities, by utilising resources that were already present within their "patient world" though engaging informal support networks and independently managing day to day.

6.2.1.1 Mobilising informal support networks to fulfil the logistical workload

When faced with challenges relating to maintaining the logistical workload of using medicines amidst fluctuating capacity, all participants described their reliance on informal supports provided by family and friends. While they acknowledged that they needed to accept help from family and friends, they were not always entirely comfortable with it, recognising the impact that their cancer diagnosis and treatment had on their loved ones as Mandy described:

> *Sadly, like I've had to lean on my parents a lot. And it's been really hard for my family. But they're around, I've had a lot of family support.* - Mandy, 48yo female, breast cancer

Maria, who reluctantly accepted offers from friends to help her get to her appointments also acknowledged the imposition that her cancer diagnosis and treatment put on others, taking it upon herself to reimburse her friends for any costs incurred by providing her with transport:

> *Sometimes I had friends taking me [to appointments], but not because the money because you have to pay them too, I mean come on* – Maria, 80yo female, colorectal cancer

For Johnny and Suzi, who both lived around 100km from Adelaide, the reliance on family and friends for transport to and from appointments was even more pronounced due to the unavailability of public transport or taxi services. Johnny described how his friend provided

assistance not only with transport but also came to live with him for the first month and a half to ensure he had the support he needed. This support continued over a period of months as both Suzi and Johnny found that they were unable to drive long distances:

> *I've got a friend at the moment who will not let me drive any further south than [town] which is roughly 50km from here. He says that the trip down and trip back will tire you out too much so he's doing it* – Johnny, 67yo male, oesophageal cancer

6.2.1.2 Independently managing day to day

There was an overall sense amongst participants that they were managing day to day and doing what was needed to get through their cancer treatment, even if that meant putting things like social relationships and leisure activities on hold for the time being. Maintaining their ongoing routines and behaviours around medication use was considered a part of maintaining the status quo as best they could:

> *I just manage day to day. I take one day at a time. I don't plan ahead because you know, you just don't know what's going to happen.* – Cass, 45yo female, Breast cancer

It may be that this tactic of independently managing was a result of participants shared personal traits. Each of the participant shared stories that indicated they held an attitude of personal resilience and persistence, a lifetime of facing obstacles that needed to be figured out. Managing a cancer diagnosis and treatment was just one of these tough times. For several participants, this related to social experiences, such as the experience of immigration, war, marriage breakdowns, loss of loved ones and unemployment. As a result, there was a reluctant acceptance that life involves difficult situations and adversity that one must work to get through, as described by Shirley:

> *I don't know if it was 'cause I've come through the worst you could come through mentally. For some reason I took it quite well, it wasn't a problem... once I started seeing the doctor and he was so confident, and the chemo wasn't making me sick I relaxed*– Shirley, 72yo female, colorectal cancer

This depth and breadth of life experiences shaped individual participants' perspectives on health, their understanding of the health system, and the expectations they held of themselves and care providers. They considered themselves active in their healthcare and capable of managing without the need for formal support, regardless of how complex their healthcare needs may appear on paper. Maintaining this independence was considered an important part of maintaining their identify and sense of self.

For some participants this type of self-management was endorsed by the HCP who had provided parameters within which the participant was able to self-manage their condition

as they deemed appropriate. This was the case for Janis who had to adjust her usual insulin regimen in response to higher blood glucose levels that resulted from the use of her steroids:

> *I was getting sugar rushes a lot and I was going down to two and so I had to build it up again. And then I put it down when I had to, I worked it out*. – Janis, 62yo female, breast cancer

In the most part however, participants independent day-to-day management of their medication regimen was employed independently of their HCPs, as multiple participants demonstrated when they experienced uncertainty about their prescribed medications. Rather than seek assistance to clarify the confusion, they continued what they considered to be the most appropriate regimen. As described in Chapter Five, when Suzi was discharged from hospital, she was aware that she did not understand the changes that were made to her medications. But Suzi's expectations of the health system were tainted by her previous experiences of seeking help and being unable to get it:

> *There have been sometimes I think "oh bloody hell" you know, "how come we didn't get the support?" You know but like the [metro hospital] tried getting a district nurse. Well what do you do when they refuse?* - Suzi, 55yo female, lung cancer

So, when Suzi found herself uncertain about her medicines, she did not seek further help to clarify her concerns. Instead, she self-initiated an independent management tactic by returning to how she had always taken her medicines:

> *…basically I've just gone back to how I was.* - Suzi, 55yo female, lung cancer

Johnny's swallowing issues resulting in physical challenges of administering medicines were also described in Chapter Five. Like Suzi, Johnny independently managed the situation by ceasing the medicines he was unable to swallow, resulting in an additional medication-related issue of not taking his medicines as prescribed:

> *I stopped all of them, yep… A lot of it was self-done because it got to the point of putting it in and it'd come straight back out again* - Johnny, 67yo male, oesophageal cancer

In many cases, where participants independently managed their medication-related issues without communicating with HCPs, they inadvertently placed themselves at increased risk of experiencing MRH. For Shirley, her acceptance of ongoing diarrhoea as unavoidable and subsequent adjustment of her lifestyle as a management tactic resulted in her experiencing ongoing physical symptoms that placed her at risk of dehydration and electrolyte imbalance. For Suzi and Johnny, their independent self-management

introduced potential medication-related issues associated with the underlying drug-related risk.

6.2.2 Bringing in external resources from the system of care

When a patient was able to recognise they were experiencing a medication-related issue they had an opportunity to purposely engage with HCPs to resolve it by bringing in external resources from the system of care. Mandy provided the most prominent examples of this, describing two occasions where she self-advocated with HCPs to ensure a medication-related issue was appropriately managed.

As described in Chapter Five, Mandy felt dissatisfied when her oncologist proposed that she continue on her MS medication while being treated with chemotherapy. Her repeated attempts to self-advocate for a resolution of this issue resulted in frustration for Mandy but she persisted until she achieved an outcome she was satisfied with, avoiding any occurrence of MRH:

> *Because I knew about my JC virus you know I actually stepped up and said, "I'm concerned". And I think if I hadn't have pushed that, in fact I know, if I hadn't had pushed that I would have been on my Tecfidera and my chemo* – Mandy, 48yo female, breast cancer

Mandy's educational and professional background combined with her prior healthcare experiences provided her with a greater sense of confidence in navigating the healthcare system and upskilling herself in self-management:

> *I was already starting to step into the role [of self-manager] of reading a lot, being informed, and trying to advocate for myself when I can. Even if I don't do it at the time, because sometimes it's overwhelming when you're in there, but I'll go home and I'll think about it and then if there's something I feel like I need to do well I'll do it. I might not feel comfortable doing it, but I'll do what I need to do. So that hasn't changed [since being diagnosed with cancer] because I was already in that role. -* Mandy, 48yo female, breast cancer

Mandy also demonstrated effective self-management when her PICC line became infected, impacting her chemotherapy administration. Once again Mandy self-advocated to reach a management tactic that was mutually agreeable. These experiences reinforced to Mandy the need to remain self-informed and active in her care:

> *That whole train ride, yep, you just sort of sit in the carriage and trust in your driver, but you need to be watching. I found out you do need to be a little self-informed* – Mandy, 48yo female, breast cancer

Bringing in external resources was also evident in the experiences of participants who were initially hesitant about undergoing chemotherapy. As described in Chapter Five, multiple participants were dissatisfied when their doctor first informed them that chemotherapy would be required as part of their treatment plan. However, by engaging with their healthcare team, each was able to move past this dissatisfaction to a point of new understanding or acceptance. For Cass, this involved a confrontational consultation with her oncologist:

> *She [oncologist] said, "you don't do it, you'll be dead in six months". She said, "I'm sorry, I'm not lying to you, I'm not beating around the bush, but you'll be dead in six months". And then I thought "nup, I need to do my treatment"* - Cass, 45yo female, Breast cancer

6.2.3 Care team initiates an active response

In some circumstances, the participant's care team responded to a medication-related issue by initiating an active response, such as arranging formal social support services to help them meet the practical needs impacting their medication use such as transport and financial stress. Access to these supports was often linked to their phase of cancer treatment, either chemotherapy or radiotherapy:

> *When I started chemo, they worked it out I had a volunteer because it was too often. But then it fall to pieces because I stopped the chemo, so the volunteers were gone too.* - Maria, 80yo female, colorectal cancer

> *I was stressing thinking how am I going to get there [to radiotherapy] …And I was talking about my stressors, and they said oh look, we have drivers that we can send…so they set that up for me.* – Mandy, 48yo female, breast cancer

Cass spoke of accessing the support of a financial counsellor to ensure that she could afford her medication on an ongoing basis, arranged by her psychiatrist:

> *I went and saw a financial counsellor…and she really helped me…I was just worried about how I was going to manage from fortnight to fortnight, you know. And I didn't want to have to sacrifice my food, or my medication, or my bills you know* – Cass, 45yo female, Breast cancer

In the case of Maria and Cass's unplanned hospital admissions, there was an obvious response by care providers to manage their medication-related issues. When Cass experienced worsened anxiety following her mastectomy, it was able to be promptly recognised and responded to through the usual care provided by her mental health team, resulting in a hospital admission under the care of her usual psychiatrist. Similarly, when she experienced febrile neutropenia while on chemotherapy it was promptly recognised

and managed by her cancer care team. As detailed in Chapter Five, this resulted in an interruption in her clozapine therapy which could have had disastrous consequences but thankfully did not. In Maria's case her emergency admission for the acute management of her gastrointestinal bleed was the beginning of a cascade of adverse events, some of which were likely potentiated by medications. Maria suffered from a painful and uncomfortable infected wound and endured the discomfort of daily enoxaparin injections for several months, and it was not until Maria attended a routine appointment with her cardiologist that she found an HCP who recognised she had unmet needs:

> *She [cardiologist] said to me "How are you?" and I said, "The wound hasn't healed" … so she went on the phone, and she said "Why, what did you have?" and I said, "I don't know". It's about two or three months after and I still was oozing...She found out…She rang the lab, whatever you call it. And she said "I want all the detail for Maria. She has this open wound and blah blah blah". And then they told her. No doctor told me at [metro hospital]. She told me. She really went to town with them. See they should have told me because I didn't know anything about golden staph – Maria, 80yo female, colorectal cancer*

Maria's cardiologist also recognised that her enoxaparin injections were unnecessary and proceeded to put Maria back on her oral anticoagulant therapy, which she was taking prior to the operation, further reducing her abdominal discomfort.

Multiple participants also described the roles that GPs played in identifying and managing medication-related issues. Most often, the involvement of the GP in the participant's care was described as being for a "routine" visit rather than specifically seeking out their help on a specific medication-related issue. Both Johnny and Shirley had similar experiences of initiating a visit to the GP on the understanding that they were seeking help to manage their reflux, only to find that their GP was able to identify and manage an underlying medication-related issue. In both cases, the identification and management of the medication-related issue was a result of the GP demonstrating diligent practice looking for the cause of the symptoms rather than inappropriately treating with medication. Johnny described how this was only achieved through visiting his usual GP as compared with other doctors within the same practice:

> *During the December to February period where I had the weight loss, he [regular GP] was away on leave... I was suffering with what they called a problem with reflux, and I was seeing other members of the practice and they were going on my previous history with the reflux and putting it down to reflux without going any further. So when I was able to get back to him on the 10th of February, he noticed*

the change of weight and decided to start, to sort of get the ball rolling. - Johnny, 67yo male, oesophageal cancer

Routine interactions with GPs were also described by multiple participants as being critical to them feeling more comfortable with pursuing chemotherapy, as described by Carole:

So when I saw Dr [oncologist] and she said to me "No, they want to do the chemotherapy" I was like "Why?" …and then she started giving me information and I was enlightened I would say. So I went to my GP, and I said, "Listen, what do you think, you know?" And he said "If they offer it to you there's a reason that they want to do it. Because they did find some traces in the lymph system". And so then I said "Ok, I understand now". – Carole, 45yo female, Breast cancer

For Felicity, who experienced significant pain and problems with constipation following surgery. Her issues were not resolved until seeing her GP:

I have to be there for five days in pain. And we are talking about really hard pain. Like injections. Oxycodone which made me so bad that I cannot go to the toilet for five days. It was so hard. So they [surgeons] took pity on me and said we will take out the oxycodone and you can ask your GP. So she [GP] gave me another one [pain reliever] and after drinking that I can sleep. Targin. – Felicity, 68yo female, breast cancer

6.2.4 Medication-related issue goes unrecognised

In some cases, underlying medication-related issues went unrecognised by both the participant and the HCP, and no tactic was employed. Multiple participants described experiences that they and their HCPs attributed to the effects of cancer and its treatment but were potentially exacerbated by their medications. The two most significant examples of this described in Chapter Five were that of Maria with her repeated bowel obstructions while continuing on medications that may exacerbate constipation and ileus, and Cass's persistent fatigue which may have been exacerbated by her lithium.

Medication-related issues also went unrecognised by participants who were experiencing unmanaged symptoms but accepted them as a new part of their everyday lives, like Shirley. Despite regular use of anti-diarrhoeal medication Shirley experienced persistent diarrhoea that was interfering with her quality of life. In response to this, she adapted her lifestyle to accommodate what she considered an unavoidable consequence of living with cancer, avoiding exercise and walking her dog which she previously enjoyed for fear of needing to use the toilet:

My exercise I've left off the map a little bit. I'm always needing to go to the toilet if we go through parks, so I stay at home. - Shirley, 72yo female, colorectal cancer

In such circumstances where an underlying medication related issue is not identified and managed it persists as a latent problem with the potential to result in MRH at a later date.

6.3 The pharmacist experience

This section presents the findings of the pharmacist study, an interpretation of their professional experiences. The intention is to provide further insight into how medication-related issues are managed within the patient world. This identified three tactics employed in response to medication-related issues: patients acting pragmatically, care providers proactively employing tactics at system and HCP levels, and care teams reacting to obvious issues.

6.3.1 Patients acting pragmatically

In line with what was found in the patient interviews, pharmacists described tactics that involved patients acting pragmatically when faced with a medication-related issue; doing what they think needs to be done in a given situation based on their own world view. This type of behaviour was noted by several pharmacists as resulting in a patient self-initiating changes to their medication regimen, resulting in them not taking their medications as prescribed. One example of this was shared by Pharmacist 7, who described a patients response to encountering a practical challenge associated with an inability to afford their medication on their pension payments:

> *"He thought it didn't matter if the medication ran out. You know, if you went without it for a couple of weeks that was ok because you know a couple of weeks wasn't going to hurt you"* – Pharmacist 7, Ambulatory HONC/Community pharmacist

The outcome of not taking the medication as prescribed was not a simple reaction to not being able to pay for the medication, it reflected a pragmatic decision that reflected an underlying uncertainty about their medication regimen and the necessity of continuation. Pharmacist 9 described a similar scenario:

> *"I've had people who've had prescriptions given to them and they've not got them filled because they don't want to take the medication because they're frightened about what it could do to them"* – Pharmacist 9, Accredited/GP practice pharmacist

Pharmacists described patients taking actions that reflected their usual patterns of behaviour, making decisions based on what has worked for them in the past. One example of this was shared by Pharmacist 18 who described the impact of an acute myeloid leukaemia) AML diagnosis on the overall medication management of a patient with longstanding Parkinson's disease. This patient had self-managed the medications used for his Parkinson's disease for many years, adjusting the doses according to his

symptoms. Upon being diagnosed with AML, control of his condition became more difficult. When this occurred within the hospital environment the care team would respond by trying to acutely manage his situation, bringing in external expertise through a neurology review who would make changes to the prescribed medication regimen. But these changes were not always considered acceptable to the patient, who would make his own decisions based on what he thought was appropriate. As acknowledged by Pharmacist 18, this outcome appeared to reflect an underlying decision-making process rather than a mere misunderstanding of what he was being asked to do:

> *I think it was obviously previously a well-controlled condition for him and he was living independently and so it's just been a lot harder for him since the AML diagnosis in terms of that Parkinson's condition…I think with the Parkinson's he feels like he needs to be more in control, just because he feels the symptoms directly as a result of the medications as well…so he'll refuse to take these and stuff, so it's a bit of negotiating for that to happen* – Pharmacist 18, Inpatient HONC pharmacist

6.3.2 Systematic and opportunistic proactive tactics

Pharmacists have a different perspective on the system of care than patients, seeing what goes on behind the scenes within the patient world. This is reflected by the systematic and opportunistic proactive tactics described by pharmacists which are both embedded into the system and employed at an HCP level.

6.3.2.1 Proactive tactics embedded into the system of care

Within the hospital setting, tactics are sometimes put in place to manage medication-related issues that have occurred in the past, aiming to proactively preventing further recurrence. The most obvious example of this relates to the strict processes of care put in place to prevent errors in prescribing, supply, and administration of chemotherapy. This was described as a core part of specialist cancer care and was consistently reported across all hospital-based participants.

For frequently encountered or higher risk medication-related issues, these tactics may be embedded into routine processes of care in the form of a protocol or procedure. This was commonly described relating to the management of diabetes and heart disease:

> *The protocol is to refer them [patients with diabetes] into endocrinology so that they can start planning insulin and things like that before their steroids go in.* – Pharmacist 16, Inpatient/ambulatory HONC pharmacist

> *The tendency is they'll delay treatment, refer to the cardiologist, get a clearance and then continue… I know in the past week we've had three or four cases where*

we were concerned about cardiac toxicity, and they were sent off for review by cardiologists. – Pharmacist 7, Ambulatory HONC/Community pharmacist

6.3.2.2 Proactive tactics employed at an HCP level

Proactive tactics were also employed at the HCP level, often as patterns of practice that emerged through collective experience rather than being written into an official protocol or guideline:

If we have someone that's on a statin that's going to interact 3A4-wise we pretty much have to change them over because the antifungals we usually have people on for prophylaxis will interact and we're just trying to reduce the risk of those things going wrong – Pharmacist 18, Inpatient HONC pharmacist

For some medications, active surveillance was enabled through the measurement of specific laboratory tests, to identify the early signals of MRH and minimise the consequences. This was commonly employed for patients with underlying cardiovascular disease, as described by Pharmacist 16:

If we're worried about a blood pressure, we'll talk to the doctor and say, "look you know the blood pressure is dropping a little bit do we need to stop their treatment for the next couple of days?" …those sorts of things get done as routine practice – Pharmacist 16, Inpatient/ambulatory HONC pharmacist

Lab tests were also commonly utilised as part of the active surveillance of the impact of steroids on patients with diabetes:

For example, today was a patient with poorly controlled diabetes, they were on VCD, having like you know, high doses of dexamethasone and then they sort of realised "hey we probably shouldn't start this here as a day patient, he probably should be on like an insulin infusion upstairs [as an inpatient] when we start it". Because yeah, I think the random glucose was like 25 or something – Pharmacist 19, Ambulatory HONC pharmacist

Active surveillance through the use of laboratory tests and clinical indicators was noted to be particularly important in circumstances where proceeding with caution was considered the most appropriate tactic, as illustrated by this experience shared by Pharmacist 10:

Recently there's another MS patient on a drug I'd never heard of before that interacted with their high dose methotrexate [chemotherapy]. *So we had to find out how significant that interaction was…the management plan then had to be that they couldn't really come off it, or they could come off it, but it had such a long half-life that it didn't make any difference, so we just had to manage the methotrexate around it and watch for toxicity – Pharmacist 10, Inpatient/ambulatory HONC pharmacist*

In some cases, active surveillance involves coaching the patient on what to look out for so that any issues can be identified and managed as early as possible:

> *Especially those with history of things like ischaemic heart disease and when they're on various blood thinners, or history of like AF and you'll find that the risk/benefit of you know being on chemo versus the other conditions and how it's managed usually they just keep going, but just extra counselling about bleeding risk and things involved* – Pharmacist 19, Ambulatory HONC pharmacist

Active surveillance of early signals of medication-related issues was also implemented in relation to medication-taking behaviour. Multiple HONC pharmacists described situations in which something within a routine patient interaction (e.g. medication history) would flag a potential medication-related issue and result in them being opportunistic and reactively delving deeper:

> *As soon as you start picking up that someone is vague, or they tell you they're taking them [other medications] every day then we usually delve a bit deeper* – Pharmacist 15, Inpatient/ambulatory HONC pharmacist

Referral to a clinical pharmacist for expert medication review could also be considered a proactive tactic employed at the HCP level. This was frequently described in relation to the management of patients who were recognised as having a high level of drug-related risk, as seen in the example shared by Pharmacist 17:

> *We've got a patient at the moment who's got MAC, and so they're on like rifabutin, clarithromycin, all these you know* [CYP450] *inducing, inhibiting medication and of course, you know, the chemo that we're giving them are all like substrates* [of the CYP450]*, so just trying to work that out – Pharmacist 17, Inpatient HONC pharmacist*

HIV was specifically named as a condition that frequently prompted proactive medication review. In some cases, this required changes to be made to the management of the underlying condition:

> *I had an HIV patient who had actually come down from [another city] and they omitted medications at that point because of interactions with his antiretroviral. And he came down here and was reviewed by the team. They changed his antiretroviral to be able to get the chemo* – Pharmacist 17, Inpatient HONC pharmacist

Patients who were identified as taking CAMs were also noted as a common trigger for HCPs to proactively refer to a clinical pharmacist for a medication review within the hospital environment:

> *That actually came through I think one of the nurse practitioners. She said, "This lady's got a list of stuff that you need to look at before she starts treatment." I said "Ok" and then a few days later I'm still trying to figure it out – Pharmacist 16, Inpatient/ambulatory HONC pharmacist*

Pharmacists working in the community setting also described the use of proactive tactics at an HCP level, by opportunistically becoming involved in the care of people with cancer. These scenarios sometimes arose from a patient-initiated request for assistance with selecting over the counter products which served as an opening for the pharmacist to employ proactive tactics to manage and prevent further medication-related issues. One example of this was shared by Pharmacist 6:

> *She* [the customer] *wanted assistance in what she could do to replace the fluids, so that's how we started…she'd also had an ileostomy and colostomy bag, so because she's got the diarrhoea, she was having to change her bag two or three times every night while she was on the chemo. So yeah, all these issues that she was going through. And by the end of it she was…she was really grateful*– Pharmacist 6, Community pharmacist

Other times, it was the ongoing relationship with regular customers that allowed the community pharmacist to opportunistically provide them with proactive care:

> *I find myself being a little bit of a counsellor. Certainly assisting with day-to-day concerns that patients are left with while undergoing treatment for cancer. The dry mouth, the dry eyes, the burning sensation they often receive, the skin tears, so these adjunctive treatments, and also just the support* – Pharmacist 8, Accredited/Community pharmacist

6.3.3 Care teams reacting to an obvious issue

Many of the tactics employed by HCPs in response to medication-related issues that were described by pharmacists were reactive in nature, initiated only once an obvious and well-established medication-related issue or episode of MRH could be observed. This was particularly evident in relation to issues concerning a patient's medication taking behaviour. Most commonly, the tactics employed in response to an issue with medication-taking behaviour involved tools designed to address imbalances of workload and capacity, such as dose administration aids (DAAs). One example of this was shared by Pharmacist 10 who described the situation of a patient with hepatitis C who was also undergoing chemotherapy for a new cancer diagnosis:

> *… it was quite overwhelming for him. So we had to organise a dosette, a webster pack when he went home* – Pharmacist 10, Inpatient/ambulatory HONC pharmacist

Pharmacist 18 acknowledged that a DAA filled by a pharmacy was not always the most appropriate tactic for patients due to their inability to rapidly respond to changes in therapy:

> *I encourage patients if they really need a DAA to use a dosette box because their meds change so frequently, so webster packs are just a bit of a pain in the neck in that regard* – Pharmacist 18, Inpatient HONC pharmacist

The other obvious type of medication-related issue that resulted in reactive management tactics being employed by the care team related to issues associated with drug-related risk. This was frequently described in relation to managing the effects of chemotherapy. In some cases, such as peripheral neuropathy, this resulted in stopping the chemotherapy. In others, such as the development of cardiac effects, it also resulted in the introduction of new medications to their usual regimen:

> *"There's been at least three patients that …were requiring ACE inhibitors and beta blockers after that because of the anthracyclines"* – Pharmacist 10, Inpatient/ambulatory HONC pharmacist

Multiple pharmacists acknowledged that despite efforts to implement active surveillance or proactive tactics there are occasions where patients fall through the cracks. In these cases, the acute situation is managed reactively, as described by pharmacist 11:

> *The ones like rituximab which causes hypotension, we have to make sure that we know the patient is on an antihypertensive and that they know to stop it before they come in for treatment, which hasn't always been identified. I have had a case of sitting with a patient with rituximab running through their arm and saying, "did you take it this morning?" "Oh yes, I did", "OK, just keep sitting"* – Pharmacist 11, Ambulatory HONC pharmacist

Acute management of MRH was frequently described in relation to steroids, which were noted to cause disruptions in underlying conditions and acute behaviour changes:

> *As an inpatient if they're agitated or become anxious with the steroids it's often managed with things like short term…with benzodiazepines just to help manage them as an inpatient and make sure they're safe for themselves and the staff* - Pharmacist 10, Inpatient/ambulatory HONC pharmacist

6.4 Discussion: Objective 1.3

6.4.1 Comparing tactics employed in response to medication-related issues

To demonstrate how the tactics employed by patients or their HCPs impact the timely and effective management of a medication-related issue let us consider three sets of case comparisons. Each of these is illustrated by a Cynefin dynamics map to provide a visual aid in identifying how different tactics impacted the management of the medication-related issue, resulting in varying medication experiences.

6.4.1.1 Mandy and Cass – visibility of medication-related issues

Mandy (48yo female, breast cancer) and Cass (45yo female, breast cancer) both experienced issues relating to a drug interaction between their usual medication and chemotherapy that increased the risk of myelosuppression. In both cases, this risk was further compounded by potentially catastrophic outcomes. For Mandy, the risk of experiencing myelosuppression was associated with her dormant JC virus which could activate and result in progressive multifocal leukoencephalopathy, a severe type of brain infection. For Cass, the risk was that an episode of febrile neutropenia would result in an interruption in her clozapine therapy which Cass had been using long term to manage treatment resistant schizophrenia. Cass and Mandy's experiences have been represented using the Cynefin Framework in Figure 25. The starting point for each is the prescribing of chemotherapy according to protocol, located within the clear domain. When chemotherapy was prescribed in the presence of an interacting medication it introduced a medication-related issue associated with drug-related risk, bringing both Mandy and Cass's situation into the complicated domain, where it was possible to identify and manage the issue through further analysis or expertise. In Mandy's case, she had the expertise to identify the drug-interaction and recognise its clinical significance herself, alerting her care team to the drug-related risk. At first, Mandy's prescribing oncologist did not manage the issue in a way that she felt was acceptable, moving into the complex domain. Mandy's confidence in self-management enabled her to self-advocate, pushing her care team to utilise the expertise of her neurologist and reconsider their approach to management, moving the issue back into the complicated domain where it could be appropriately managed without any further issues.

While Cass's starting point was the same as Mandy's, her medication-related issue went unrecognised as neither Cass or her care team were able to identify the drug interaction and initiate a preventive course of action. Instead, chemotherapy was administered as initially prescribed without any proactive management of the drug-related risk (e.g. prophylactic G-CSF), moving the issue to the complex domain where it maintained its latent potential to result in MRH. Soon after, Cass experienced an episode of febrile

neutropenia, shifting her situation into the chaotic domain. When admitted to hospital, Cass's care team initiated an active response, bringing things back into the complicated domain through their clinical management approach. This acute management included an interruption in Cass's clozapine which introduced a new medication-related issue associated with drug-related risk. Thankfully, this did not result in an episode of MRH and shift back into the chaotic domain, despite having the potential to do so.

Both Mandy and Cass's cases were very similar in terms of drug-related risk, but each resulted in vastly different medication experiences. A key difference between the two was that Mandy's drug-related risk was made visible to her care team, enabling an appropriate response to be initiated prior to manifesting as MRH. Had Mandy not made the medication-related issue visible to the care team it is likely she would have endured a similar experience to Cass, who's drug-related risk went unrecognised, resulting in significant MRH that required reactive clinical management. This case comparison illustrates several learnings. Firstly, patients can only respond to medication-related issues that they are capable of identifying. Secondly, if a patient is unable to recognise they are experiencing a medication-related issue they are reliant on their care team doing so on their behalf. If an issue is not recognised by either the patient or their care team, it will delay the initiation of appropriate management and result in more significant MRH. It logically follows that increasing visibility of medication-related issues within the system of care could be a useful approach to reducing MRH.

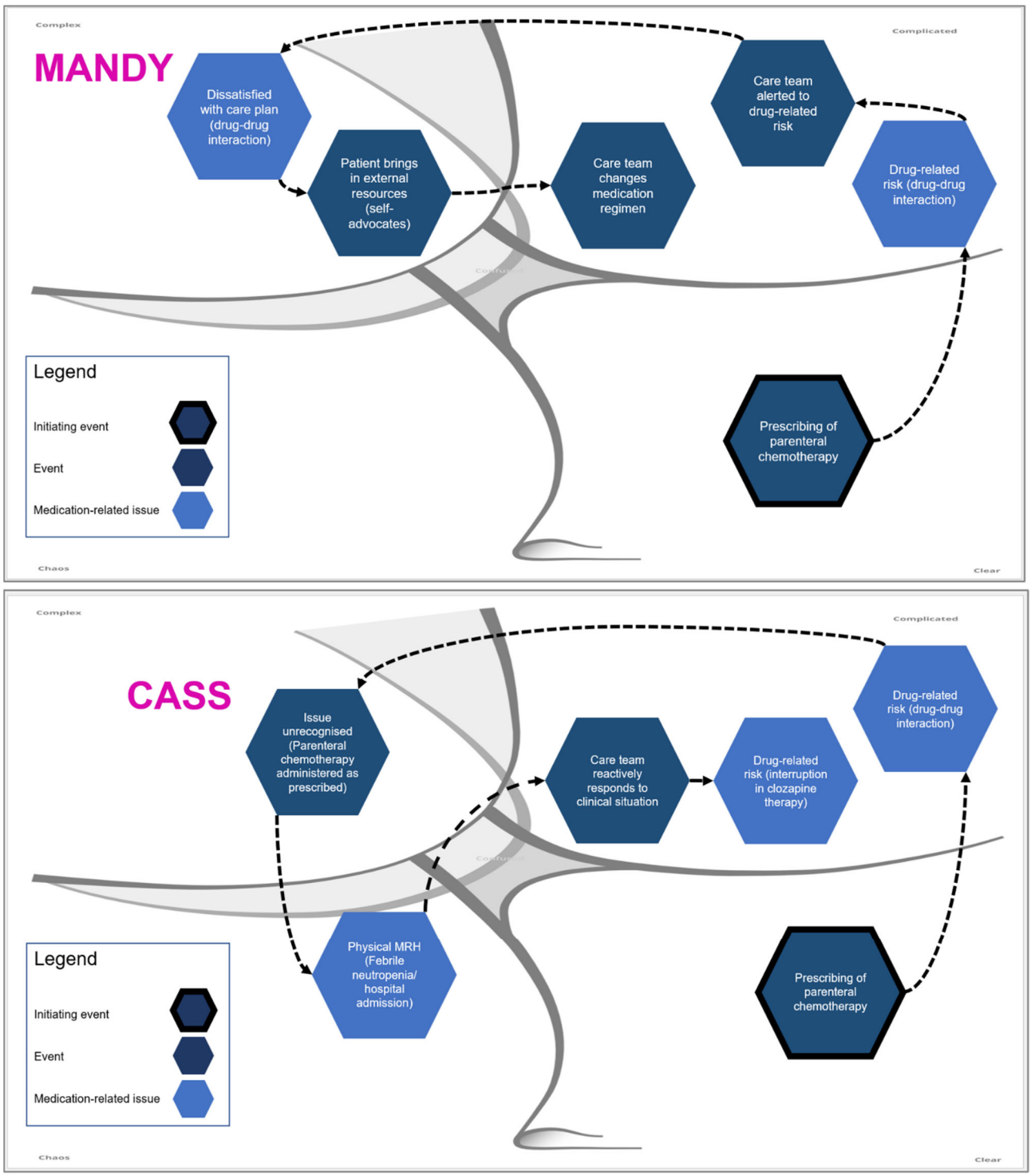


Figure 25: A case comparison of Mandy and Cass

6.4.1.3 Janis and Maria – knowing how to identify and escalate concerns

Janis (62yo female, breast cancer) and Maria (80yo female, colorectal cancer) each had experiences that were initiated by changes to their medication regimen made during their cancer journey which involved medications used within the home setting. When considered using the Cynefin Framework (Figure 26), both experiences began in the clear domain; a change to the medication regimen initiated in an ordered environment that was known to the patient. In each case, the medication changes resulted in a shift in the drug-related risk profile, creating a medication-related issue. This drug-related risk was not pro-actively managed for either Janis or Maria. Rather, they continued with the medication changes as prescribed as they moved to the home setting, shifting to the complex domain where the issue went unrecognised and maintained its latent potential to result in MRH. Eventually, this latent potential manifested as actual MRH, moving both cases into the chaotic domain. It is at this point that Maria and Janis' experiences diverted.

Janis's self-management skills and existing medication management behaviours enabled her to recognise that she was experiencing a medication-related issue before it manifest in any significant MRH. By actively monitoring her blood sugars, Janis was able to pick up early signals of harm, enabling her to respond rapidly by utilising resources already present within her patient world. As a result, there was negligible impact on Janis's medication experience. Maria was also able to recognise that she was experiencing a medication-related issue, but unlike Janis she was not able to detect early signals of MRH. By contrast, Maria only recognised the issue once it had manifest as severe MRH in the form of a medical emergency. Once this occurred, Maria responded appropriately by calling on external resources in the form of the ambulance service, bringing her situation back into the complicated domain of a hospital environment. Following this, her care team involved reactively managed her clinical condition, which included emergency surgery and a prolonged ICU admission. An unplanned result of this was new medication-related issues, in the form of physical manifestation of MRH (an untreated infected wound) and Maria's dissatisfaction with the care plan (ongoing enoxaparin injections). The ongoing nature of these issues saw Maria's situation shift into the chaotic domain, where she was experiencing tangible issues that were not being recognised and responded to by her care team. It was not until Maria attended a routine appointment with her Cardiologist that her situation was able to move from the chaotic to the complicated, as her medication-related issues were finally recognised and reactively managed in an appropriate way.

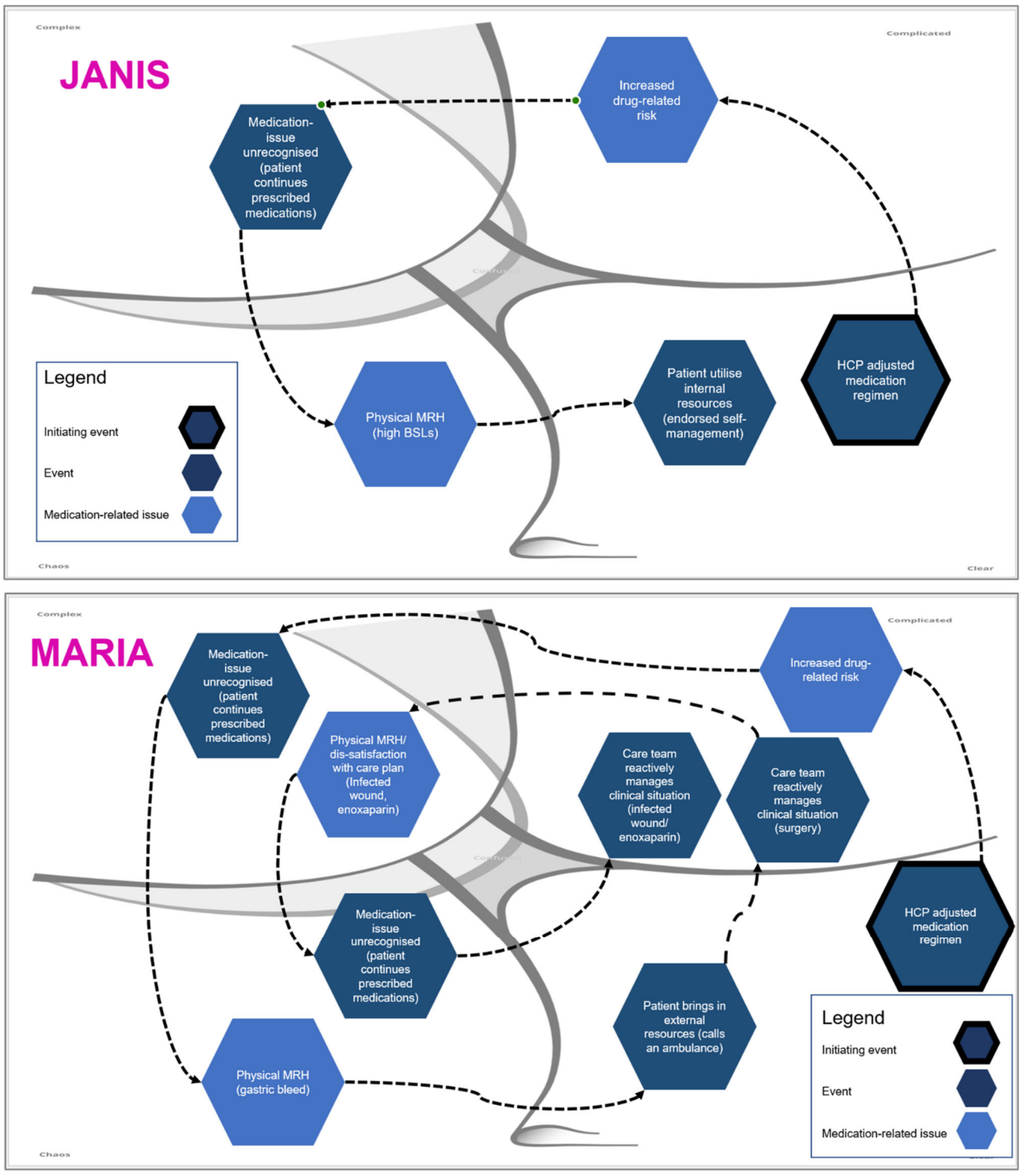


Figure 26: A case comparison of Janis and Maria

As with the prior case comparison of Cass and Mandy, Maria, and Janis both had experiences that began in the same way but resulted in vastly different outcomes. Janis's higher level of activation and capacity facilitated active surveillance of her drug-related risk even though she was not necessarily cognisant of it. Through routine monitoring of her blood glucose Janis was able to promptly identify her medication-related issue. By having a self-management plan in place, Janis was aware of how to escalate her issue, enacting behaviours that minimised any clinical consequences. Maria, however, was treated as a passive member of her care team. Despite being at high risk of experiencing a post-operative bleed, Maria was sent home without clear instruction on how to actively monitor for early signs of such an event, and what to do should they occur. Rather, it was not until after Maria experienced a medical emergency that her issues were eventually recognised and reactively managed by her care team. This then cascaded into further experience of MRH. In this case, Maria was able to recognise early signals of MRH, but her skills and confidence in self-advocacy were not sufficient to instigate an appropriate response from her care providers. Had Maria been encouraged to undertake active surveillance of her issues and informed of how to report and escalate these issues once identified, her experience may have been different.

6.4.1.4 Suzi and Johnny – willingness to bring in external resources from the system of care

Unlike the other case comparisons which shared similar starting points but resulted in vastly different experiences, Suzi (55yo female, lung cancer) and Johnny (67yo male, oesophageal cancer) both had different starting points that led to the same outcome: not taking their usual medications as prescribed. Suzi's case example began with changes being made to her usual medications during a hospital admission. When considered using the Cynefin Framework (Figure 27) this starting point is within the clear domain. Suzi was aware of changes being made to her medication regimen while in hospital and was cognisant of the fact that she was uncertain about her medication regimen once being discharged home. Her pragmatic approach to this, based on her prior experiences of asking for help and not receiving it, was to manage this uncertainty independently rather than seeking any external clarification. This resulted in Suzi self-initiating changes to her medication regimen, taking them differently to how they had been prescribed. While well intended, this action introduced a new medication-related issue that carried a latent potential to result in MRH, moving Suzi's situation into the complex domain. It is not known whether any actual episodes of MRH occurred as a result.

Johnny described three interrelated occasions that resulted in him not taking his medicines as prescribed. Like Suzi, Johnny's starting point in the Cynefin Framework (Figure 32) is within the clear domain, reflecting Johnny's awareness that he was

experiencing a medication-related issue. Johnny was living with oesophageal cancer which was making swallowing difficult. One day it got to the point where he was unable to swallow his tablets, resulting in a physical challenge in administering his medications. In response to this issue, Johnny utilised resources that were already present in his patient world, independently managing the situation in a way that he thought was appropriate, by stopping the regular medications that he could no longer swallow. In doing so, like Suzi, Johnny introduced a new medication-related issue of not taking his medications as prescribed, moving his situation into the complex domain. This self-initiated change to the medication regimen carried latent potential to result in MRH and persisted until Johnny's next routine medical appointment. By openly communicating with his doctor, Johnny made the medication-related issue visible to his care team, bringing his situation back into the ordered complicated domain.

Soon after Johnny lost his ability to swallow, he had a PEG tube inserted. This introduced new practical challenges when it came to administering some of his prescribed medicines as not all were formulated to be administered by this route. Once again, this issue was obvious to Johnny, fitting within the clear domain. As such, he responded by utilising resources that were already present within his patient world, managing independently in the way he thought was appropriate by making self-initiated changes to his medication regimen. Again, this inadvertently introduced a new medication-related issue with latent potential to result in MRH, moving Johnny's situation to the complex domain of the Cynefin Framework until his next routine medical appointment where his open communication with his care team brought him back into the ordered complicated domain.

The third situation that resulted in Johnny not taking his usual medications as prescribed happened in parallel to the other occasions described so far. As Johnny came to terms with his cancer diagnosis, he experienced uncertainty about the benefit of continuing with his COAD medications. This was an obvious issue to Johnny, fitting within the clear domain. Rather than seeking clarification or advice from an HCP, Johnny managed this issue independently by doing what he thought was appropriate. He decided it was unnecessary to use his COAD medications while he was not symptomatic and while the cancer was his main priority. As with the other scenarios, the tactics Johnny employed in response to experiencing this medication-related issue moved Johnny once again into the complex domain, introducing a new medication-related issue with latent potential to result in MRH. It is unclear if this situation ever came to the attention of his care team.

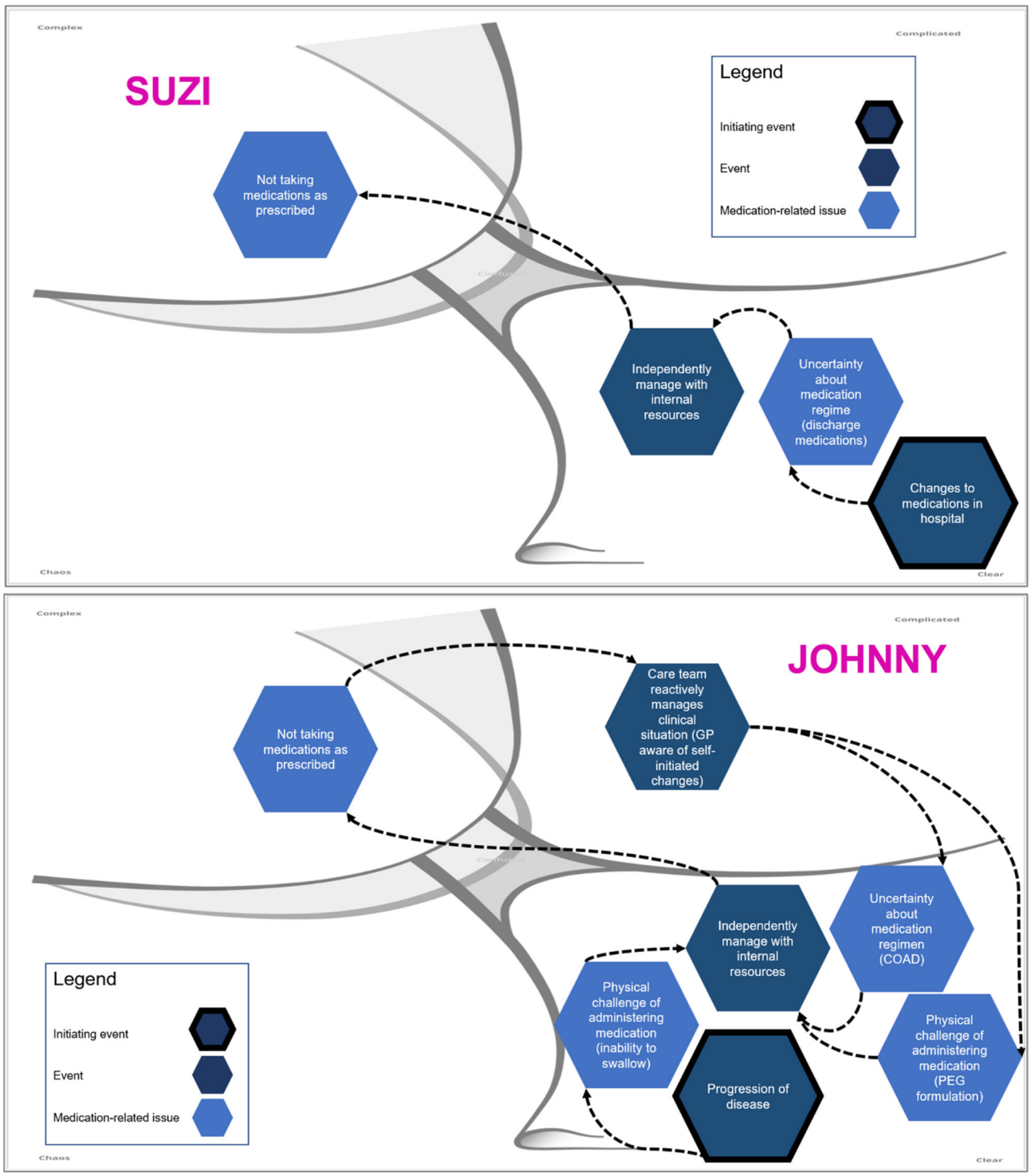


Figure 27: A case comparison of Suzi and Johnny

Johnny and Suzi's cases demonstrate the nuance of what is often reductively described as non-adherent behaviour. The common thread between these cases is that Johnny and Suzi's behaviour resulted from their ability to recognise a medication-related issue and respond to it in the way that they thought was appropriate; by promptly managing it with resources that were already present in their patient world. In Suzi's case, her behaviour reflected her complex feelings toward her care team, informed by prior experiences. She did not see the value of seeking help and openly disclosing information to her care team when she had not provided her with explicit instructions on how to do so or why it was

important. In Johnny's case, he was merely doing what he thought was right at the time, openly disclosing his behaviour to his care team at a later date. He was aware that the issue he was facing required prompt action, but he was not aware that his resultant actions inadvertently placed him at risk of experiencing MRH by delaying the time for his care team to ensure his prescribed medication regimen was appropriate for his needs.

6.4.2 Medication experience is improved by timely and appropriate response

Patients and their care providers can only actively respond to issues that they are aware of. Thus, visibility of medication-related issues directly influences the tactics employed by patients and those who care from them, impacting the likelihood of MRH and negative medication experience. To explore this further we will once again use the Cynefin Framework, as illustrated in Figure 28. Before continuing, we must acknowledge that this discussion is based upon the assumption that in most cases, achieving an appropriate response to a medication-related issue requires input from the care team, either in the form of active management or endorsed parameters for self-management. Within Figure33, "positive tactics" that make medication-related issues more visible to the care team or promote efficacy in self-management behaviours are illustrated by the green dotted lines while "negative tactics" that make it less likely that the care team is able to promptly recognise and respond to a medication-related issue have been illustrated by the blue dotted lines.

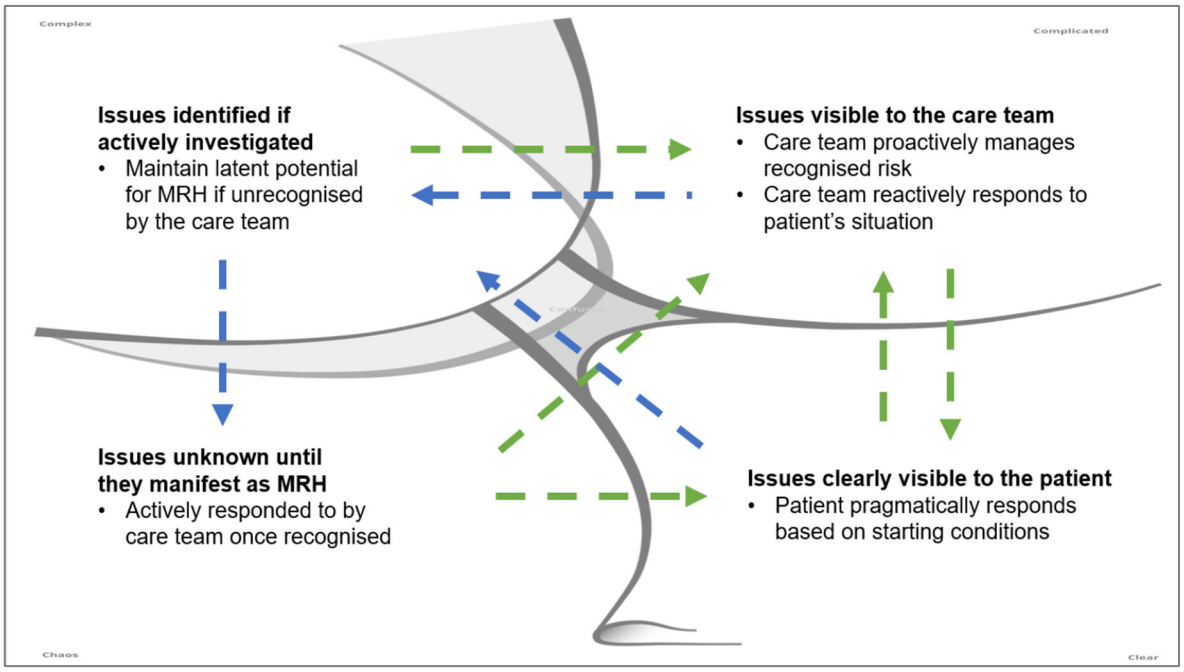


Figure 28: Responses to medication-related issues in relation to their visibility

6.4.2.1 Patients respond pragmatically to issues they are aware of

When patients encounter a medication-related issue that fits within the clear domain they can be expected to respond pragmatically, doing what they think is best to resolve it unless otherwise instructed. The tactics an individual will employ will be shaped by their starting conditions and entrained patterns of behaviour. In some cases, patients will manage the issue independently with resources already present within their patient world, instigating what they consider to be an appropriate course of action. If this action is undertaken within parameters of self-management that have been endorsed by the prescriber, this self-initiated action will result in timely and appropriate management of the issue, minimising MRH. However, if this action is undertaken outside the knowledge of the prescriber, this self-initiated response can introduce a new medication-related issue that shifts their situation to the complex domain, represented in Figure 33 by the blue dotted line. While well intended, this type of self-initiated response can inadvertently place the patient at increased risk of experiencing MRH by delaying the timeliness of an appropriate response.

6.4.2.2 Care teams actively manage issues they are aware of

When patients encounter a medication-related issue that fits within the complicated domain they are reliant on the response of their care team. If the care team is aware of a tangible medication-related issue, such as an experience of MRH or a practical issue with implementing the medication regimen, they can be expected to respond reactively to the patient's situation by implementing an approach they believe to be appropriate. The sooner the issue is made visible to the care team, the sooner they can initiate a response. Hence, any action that moves an issue into the complicated domain by making it visible to the care team is represented in Figure 33 by a green dotted line.

If the care team is aware of issues of drug-related risk, they may implement proactive tactics to minimise MRH, by bringing in further expertise or by proceeding with caution and implementing active surveillance. In some cases active surveillance is undertaken by the patient themselves under the instruction of the care team. This moves the issue from the complicated to the clear domain as illustrated by the green dotted line.

6.4.2.3 Unrecognised issues maintain latent potential for MRH

In circumstances where pro-active tactics like active surveillance are not employed, or when the management approach implemented by the care team is not appropriate to meet the patient's needs, the medication-related issue goes unmanaged. This moves the issue from the complicated to the complex domain as illustrated by the blue dotted line. Medication-related issues within the complex domain will likely go unnoticed until they reach a threshold that triggers a response from the patient or their care team. In many

cases, this will only occur once there is a tangible manifestation of the issue, which in many cases will be clinical signs and symptoms of MRH, moving the issue into the chaotic domain as illustrated by the blue dotted line. It is only through initiatives that actively seek to uncover medication-related issues that these unrecognised issues can be brought into the complicated domain, making the issue visible to the care team so that it can be appropriately managed prior to resulting in MRH, as illustrated by the green dotted line.

6.5 Chapter Summary

This chapter has described the tactics employed by patients and their care providers in response to the medication-related issues encountered throughout the cancer journey. It has shown that when patients are aware of a medication-related issue they tend to act pragmatically, enacting behaviours that they believe are appropriate for the situation at hand. For some, this means managing themselves with resources already present within their patient world. Other times this will involve actively bringing in resources from the system of care. If patients are unaware that they are experiencing a medication-related issue they are reliant on the tactics employed by their care providers and those that are embedded within the system of care. While there are some proactive management tactics utilised at both an individual and organisational level, they are not consistently applied across all parts of the system of care. As such, many medication-related issues go unnoticed until they manifest as clinically significant MRH. When this occurs, care providers can be expected to act reactively, managing the clinical situation at hand. The combination of tactics employed impacts the timely and appropriate management of medication-related issues. Achieving this timely and appropriate management is challenged in circumstances where medication-related issues lack visibility, when patients are not armed with the ability to undertake active surveillance, and when patients are not provided with clear escalation pathways to help manage their concerns.

6.6 Summary of findings: Part A

This chapter has concluded Section Two, Part A, which has provided a deeper understanding of how cancer diagnosis and treatment impacts the nature of reality in the patient world: how the workload and capacity changes, the types of medication-related issues encountered, and the ways in which medication-related issues are responded to by patients and their care team. Within this thesis, the purpose of building this understanding is to enable us to recognise the needs of people living with cancer. By doing so, we can identify actions that can be taken within the system of care to better meet those needs.

Healthcare need is defined as the potential for a patient to benefit from a healthcare service (Stevens & Gillam, 1998). The findings of Part A have indicated that people who

are independently using medicines prior to a cancer diagnosis have a need for healthcare services that assess and positively challenge their starting conditions and services that increase the visibility of medication-related issues throughout the cancer journey.

This research has shown that a patients' starting conditions are foundational to their medication experience throughout cancer diagnosis and treatment, comprised of their level of activation, baseline capacity, and pre-existing workload associated with medicine use. These starting conditions can be expected to persist unless actively challenged. It logically follows that people with cancer could benefit from interventions that assess and positively challenge their starting conditions by engaging patients to be more activated in their care, bolstering capacity and reducing workload.

This research has also shown that achieving a positive medication experience and minimising MRH by achieving a timely and appropriate response to a medication-related issue requires the issue to first be recognised by the patient or their care team. This suggests people with cancer can benefit from health interventions that increase visibility of medication-related issues encountered throughout their cancer journey. There are two types of health interventions that could achieve this, illustrated by the green arrows in Figure 29: interventions that make issues more visible within the patient world, and interventions that make issues more visible within the system of care.

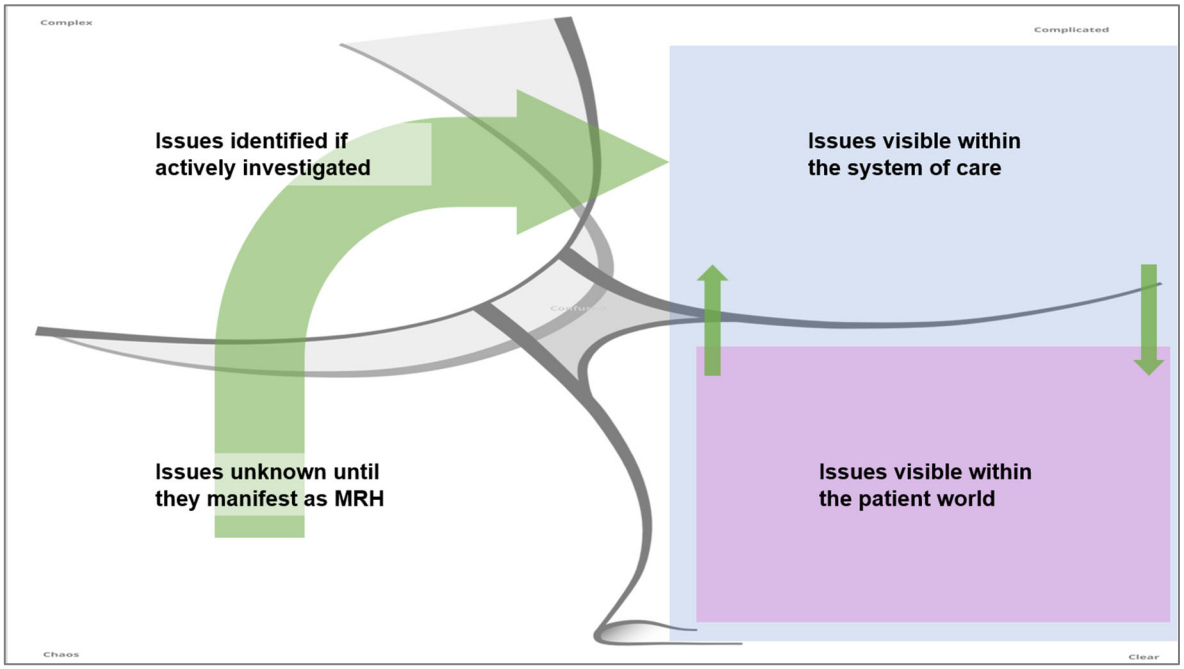


Figure 29: Increasing visibility of medication-related issues

The first are interventions that make medication-related issues more visible within the patient world, represented by the downward green arrow that spans the complicated and clear domain. These types of interventions support patients to be more effective in their

self-management by bringing issues into the clear domain. This allows the patient to recognise they have encountered a medication-related issue and promptly respond to it, either through an endorsed self-management approach, or by seeking help through openly disclosing it to the care team.

The second are interventions that make medication-related issues more visible within the system of care, represented by the upward green arrow that spans the complicated and clear domains, and the upward curved arrow extending from the chaotic to the complicated domain. These interventions increase the care team's visibility of medication-related issues by bringing issues into the complicated domain. This allows the care team to recognise the patient has encountered a medication-related issue and promptly respond to it. As described above, this visibility can be improved through the patient's willingness to seek help and openly disclose information to their care team. Visibility can also be improved through actions taken within the system of care, such as the use of decision support tools and expertise that brings attention to medication-related issues, and active investigation by a skilled HCP that bring issues from the complex to the complicated domain. Active investigation can also help to identify early signals of medication-related issues that have manifested as MRH which, if left unrecognised, will persist until they reach a clinical threshold that triggers a reactive response from the patient or their care team.

In the next Chapter, we move to Part B, analysing the system of care that supports the medication management of Australians living with cancer. It begins by looking further into how proactive tactics to manage medication-related issues are applied within that system of care, starting with the types of PC-MMS available to Australians undergoing cancer diagnosis and treatment.

PART B – THE SYSTEM OF CARE

Section Two Part A presented and interpreted the research findings to improve our understanding of the ways in which cancer diagnosis and treatment alter the nature of reality in the patient world, by examining the impact on workload and capacity, the types of medication-related issues encountered, and the strategies employed by patients and their HCPs in response to such issues. In Part B, I shift our focus to the research findings that address objective 2, analysing the system of care that supports the medication management of Australians living with cancer as illustrated by Figure 30. First, in Chapter Seven we will present and discuss the findings of the scoping review, examining the cancer literature to describe the types of PC-MMS initiatives that have been empirically studied in cancer and how they compare with the generic PC-MMS programs available in Australia (i.e. the HMR and MedsCheck programs). Building on this understanding, Chapter Eight will characterise a series of archetypal roles of MMS providers will be described, drawing from the findings of the pharmacist interview study. Finally, in Chapter Nine we will examine the constraints placed on MMS providers as they deliver care within existing service models.

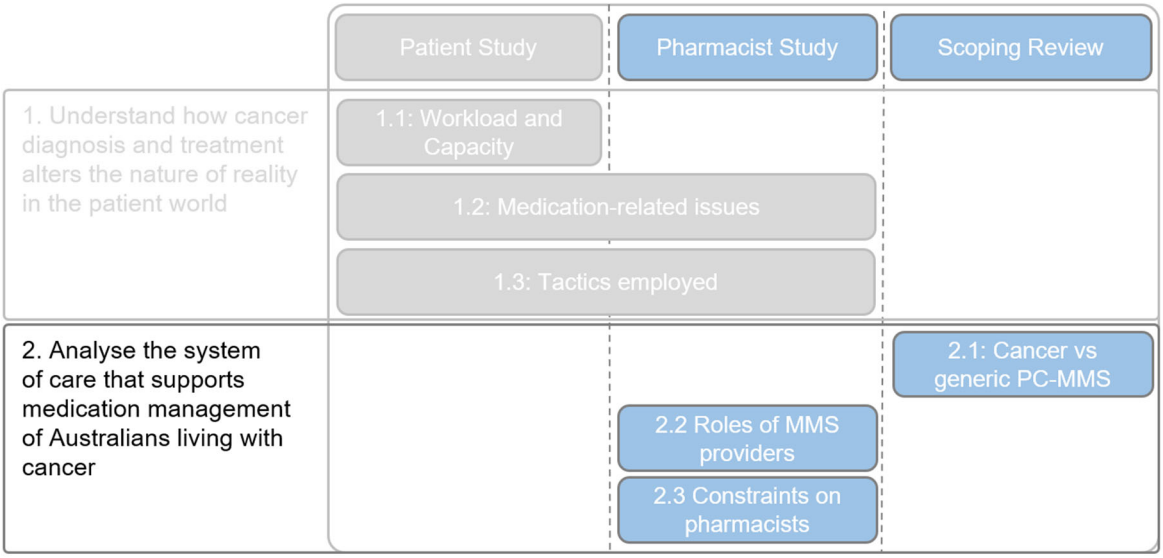


Figure 30: Research activities mapped to objective 2

7 CANCER VS GENERIC PC-MMS

7.1 Chapter introduction

This chapter takes a turn from the research presented thus far, shifting to the look at the results of the scoping review. These findings address Objective 2.1: Critically compare the empirical evidence assessing PC-MMS in non-hospitalised adult cancer populations with generic community-based services. As detailed in Chapter Three, the aim of this review was to critically compare the empirical evidence assessing PC-MMS in non-hospitalised adult cancer populations with generic community-based services available in Australia; the HMR and MedsCheck programs introduced in Chapter Two. The critical comparison is facilitated through the use of an analytical framework based upon elements of the business model canvas. The purpose of the literature review in the context of the thesis is to gain insight into the types of PC-MMS initiatives that are developed and implemented within cancer services at a local level and how they compare with PC-MMS that are available through generalist HMR and MedsCheck providers. As detailed in Chapter Three, this is based on the assumption that in order to secure ongoing funding, locally developed innovations in practice are typically based on interventions that have been reported in the literature.

7.2 The nature of included studies

The study flowchart is outlined in Figure 31. Full text review was undertaken on 37 papers. After applying inclusion and exclusion criteria 16 papers were included in the review, the details of which can be found in Appendix II. Multiple geographic regions were represented within the included papers, with six from Germany, five from the US, and one each from Finland, Taiwan, Italy, Spain, and the UK. The included papers reported 19 experimentally evaluated PC-MMS initiatives. Eleven papers reported findings from randomised controlled trials. It is worth mentioning that the search results included many Pharmacist-led interventions. However, the vast majority did not even make it to the full text review because they did not include a comparator or did not meet the inclusion criteria due to the absence of an objective outcome measure or patient reported outcome measure using a validated tool.

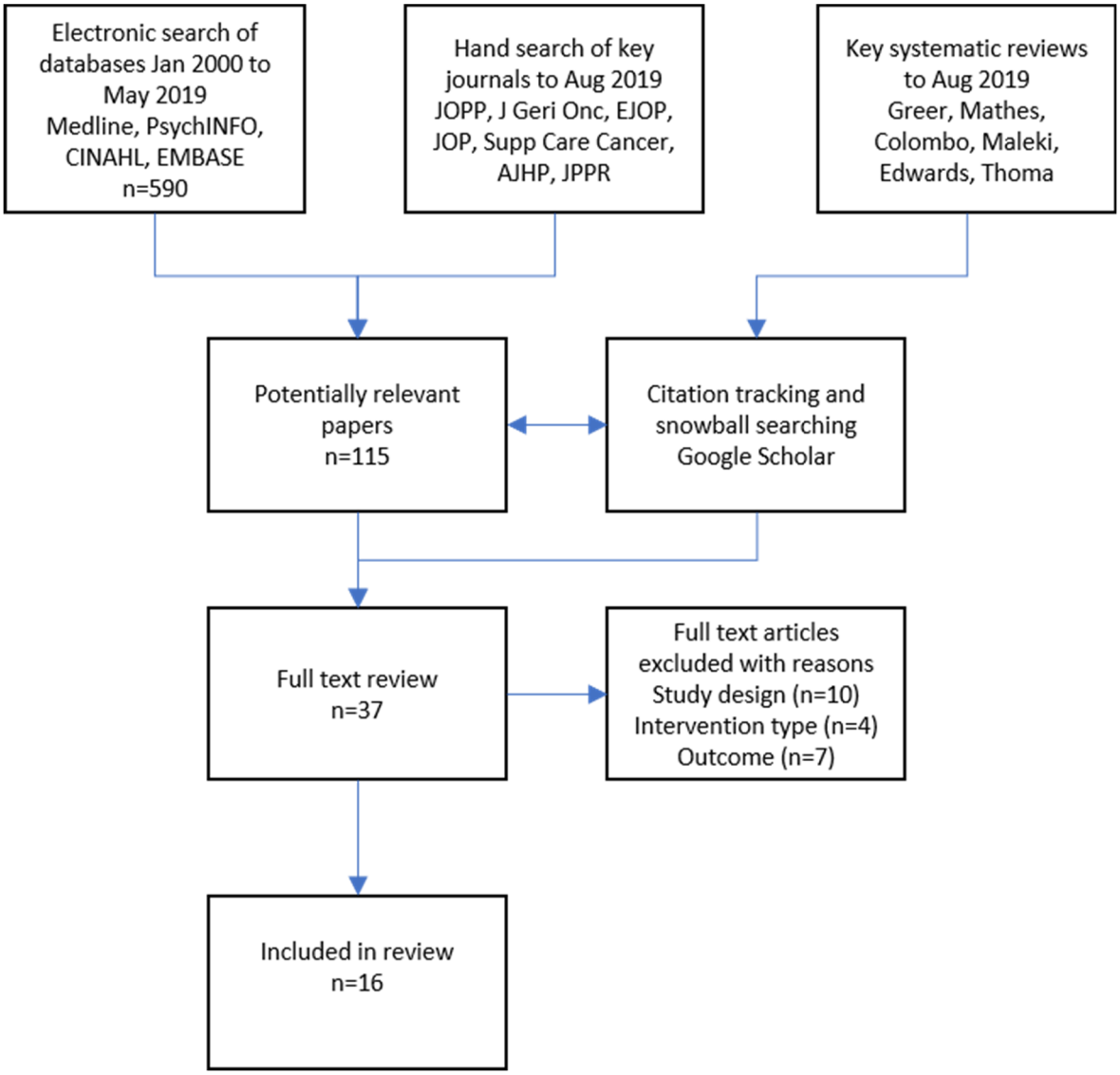


Figure 31: Flowchart of studies included in the review

All included studies used a control group as a comparator, 12 of which described the control group as receiving usual, conventional, or standard care. There was variation in what was considered standard care. Some papers were not explicit, stating simply that standard care was the absence of the intervention or that it occurred prior to the introduction of the intervention. Others were more explicit in detailing the care received by the control group, such as Schneider et al who detailed the elements of standard chemotherapy education provided to controls which included disease-specific patient education notebook and personal instruction on their treatment by a healthcare provider. In Krolop et al's study, the control group received standard care plus two modules of their PC-MMS intervention. In Read et al's study comparing a pharmacy technician-led to control, the control group received standard care plus a medication history interview. Koller et al's control group received what they referred to as standard care with increased

attention. Syrjala utilised a similar approach, providing what could be referred to as a sham intervention to the control group.

7.2.1 Features of reported PC-MMS initiatives

The following section provides a summary of the features of reported PC-MMS initiatives mapped to elements of the business model canvas. Details of the included studies can be found in Appendix II.

7.2.1.1 Target populations

A variety of patient populations were targeted by PC-MMS initiatives. Ten studies targeted patients with specific cancer types. Eleven targeted patients prescribed specific medications, including chemotherapy agents, and three targeted patients experiencing a specific symptom. Women using aromatase inhibitors or starting parenteral chemotherapy for breast or ovarian cancer were targeted in four studies. People experiencing pain were targeted in three studies, and nine studies targeted people prescribed oral chemotherapy, specifically tyrosine kinase inhibitors and capecitabine. Inclusion and exclusion criteria were detailed in all but one paper (Kekäle et al.). Of the 15 papers that detailed their inclusion and exclusion criteria, only two did not exclude people based upon a language barrier. Other studies excluded people based upon cognitive function, psychological illness, and life expectancy less than six months.

7.2.1.2 Value proposition

PC-MMS initiatives reported in eleven studies intended to improve adherence to cancer-related medicines. Nine were concerned with adherence to oral chemotherapy agents and two with aromatase inhibitors. Seven studies reported PC-MMS initiatives designed to support the self-management of specific cancer-related conditions. Three studies provided interventions to improve symptom management and supportive care relating to chemotherapy, with one study focusing specifically on nausea and vomiting. Self-management of pain was the focus of three papers. Ribed and colleagues paper was the only study to report outcomes intended to demonstrate that the PC-MMS initiative being studied offered value to the patient in terms of improving the safety and efficacy of the overall medication regimen (Ribed et al., 2016), despite the identification of DTPs being noted as a part of the intervention in an additional five papers.

7.2.1.3 Recruitment

All studies included in the review recruited patients from hospital sites or settings where specialist cancer care was being provided, either as hospital-based clinics or specialty practices held within the community. For thirteen PC-MMS initiatives, patients were recruited directly by a member of the research team. The remaining three PC-MMS

initiatives recruited patients indirectly through the referral from collaborating oncologists who screened patients for eligibility criteria. Each of these studies was conducted in Germany, involving a pharmacist-led intervention, suggesting that this may reflect local practice.

7.2.1.4 Patient relationships

The degree of patient interaction involved in the PC-MMS initiatives reported in the included studies ranged from automated assistance through to repeated contacts. Five studies involved zero or limited personal contact with patients, utilising automated processes to support self-management and adherence, either through mail outs or information and communication technology. Three PC-MMS initiatives involved a one-off face to face consultation between a clinician and patient, focused on education and self-management. Eleven PC-MMS initiatives provided repeated contact with the patient through a combination of face-to-face consultations and remote support, offering a degree of continuity in personal assistance.

7.2.1.5 Key resources

Fourteen of the PC-MMS initiatives reported in the included studies explicitly required the ongoing use of specialist HONC human resources. Six initiatives were delivered by specially trained nurses, with one also involving specialist physicians. Six initiatives were delivered by specialist pharmacy resources, with five delivered by pharmacists and one by a specially trained pharmacy technician. Gebbia et al's study was noted to be delivered by specialist cancer clinicians but did not specify which discipline (Gebbia et al., 2013), while Lin and colleagues note the intervention was delivered by a trained research assistant but failed to detail their qualification (Lin et al., 2006). Involvement of specialist HONC clinicians was also implicit in the development of resources utilised in PC-MMS initiatives involving automated delivery of patient educational materials and support such as the three PC-MMS initiatives that utilised information and communication technology and the two studies that utilised the postage system.

7.2.1.6 Key partnerships

It was not routine for key partnerships to be explicitly noted within the papers included in the review, but many were implied through the patient recruitment strategies and resources that were utilised, specifically the relationships with cancer care sites which were utilised for recruitment in all included studies and collaborating oncologists who screened for eligibility criteria in those studies utilising indirect modes of recruitment. Two studies noted specialist pharmacies as a site of recruitment in addition to other specialist sites of patient care. Liekweg noted relationships with primary care-based oncologists

(Liekweg et al., 2012), but none of the included studies detailed involvement of other primary care clinicians.

7.2.1.7 Patient care activities

Majority of the PC-MMS reported fit the MUR classification. As outlined in Table 9, seven studies focused on symptom or condition-specific management which included addressing aspects of medication taking behaviour and six focused exclusively on patient's medication taking behaviour relating specific medications. Three studies examined interventions that could be classified as medication Table 9 outlines the details of the included studies and maps elements of the interventions against the common elements of PC-MMS available in the community. Of the thirteen interventions classified as MURs, all but one detailed the provision of educational materials to the patient regarding their condition, medicines and managing their side effects. Provision of educational materials were the only elements that MUR-type interventions consistently met the requirements of the community-based MUR programs. Only three interventions explicitly detailed that they considered all of the patient's medicines and identified DTPs, five explored attitudes and beliefs about medicines, three provided the patient with documentation in the form of a medication list or care plan, and two facilitated communications with other care providers to resolve DRPs. A number of MUR interventions provided evaluation elements of care which exceeded the community-based MUR programs. Six interventions actively monitored and recorded patient outcomes and eight provided ongoing evaluation of progress in meeting goals of therapy. Five interventions provided some form of ongoing support.

Of the three interventions classified as MMR, all explicitly detailed most of the elements defined by the community-based MMR standards, but none detailed all eleven elements. The most common uncertainty was concerning documentation of the patient medication and care plan. It was unclear if the intervention examined by Simons et al explored attitudes and beliefs about medicines or addressed medication management skills.

Table 12: Summary of PC-MMS initiatives reported by included studies

PC-MMS Classification		Patient population	Included studies
Medication Use Reviews (MUR)	Symptom/condition management	Supportive care for people receiving parenteral chemotherapy	(Liekweg et al.; Read et al.)
		Supportive care for people taking oral chemotherapy	(Spoelstra et al.; Spoelstra et al.)
		Pain management	(Koller et al.; Lin et al.; Syrjala et al.)
	Medication taking behaviour	Aromatase inhibitors	(Hadji et al.; Ziller et al.)
		Oral chemotherapy	(Gebbia et al.; Kekäle et al.; Krikorian et al.; Schneider et al.)
Medication management review (MMR)		Medication management in people taking oral chemotherapy	(Krolop et al.; Ribed et al.; Simons et al.)

7.3 Discussion: Objective 2.1

7.3.1 Generic PC-MMS complement cancer-specific PC-MMS

This review asked how the empirically investigated cancer-specific PC-MMS compare to the generic PC-MMS which are available in many community settings and the results show that there are some obvious differences between the two with regards to the ways in which the service providers connect with their target populations, and the patient care activities undertaken.

Unlike the generic PC-MMS programs which tend to be initiated and conducted in primary care, all cancer-specific PC-MMS were initiated in specialist care, provided by specialist healthcare providers or research staff, and had a value proposition that specifically targeted cancer-related concerns. It is not clear if this strategy to initiate and conduct PC-MMS within specialist care is intentional, or simply a pragmatic approach to aid recruitment. It is well understood that communication across the primary-specialist interface from care is far from optimal (Dossett et al.; Grunfeld & Earle; Lizama et al., 2015). Introducing cancer-specific PC-MMS, which are initiated and conducted within specialist care, has the potential to exacerbate these issues by further isolating the primary care provider from the patient's ongoing management. The alternative perspective is that people with cancer may have reduced contact with their primary care providers during acute cancer treatment, creating a barrier to accessing generic community PC-MMS.

Almost all cancer-specific PC-MMS excluded people who did not speak the native language, and many excluded those with cognitive impairment, psychological illness or had a prognosis of less than six months. Yet these vulnerable populations are the very

people have the greatest need for support in their medication management. Excluding vulnerable populations from empirically tested interventions may make the process of research easier, but it does not reflect true clinical practice, where any individual deemed capable of self-administering medications is called upon to do so. This may also skew the results, with potential to underestimate the effect.

Only the three cancer-specific PC-MMS classified as MMR consistently addressed the core elements of patient assessment detailed in Chapter Two, indicating that they were less comprehensive than HMRs. Of the 13 MUR initiatives, just three explicitly detailed that they considered participants overall medication regimes and worked to identify DTPs and five explored participants' attitudes and beliefs about medicines. This is important for any intervention designed to improve medication-outcomes, particularly those intending to influence medication taking behaviour. As described in Chapter Two, multiple systematic reviews have examined factors that influence medication adherence in cancer populations (Irwin & Johnson, 2015; Lin et al., 2017; Mathes et al., 2014; Puts et al., 2014; Verbrugghe et al., 2013). All have demonstrated that medication adherence should be considered a complex, multifaceted phenomenon, where many interrelated factors influence an individual's medication taking behaviour. These include attitudes and beliefs toward medicines, depression and emotions, and the complexity of the medication regimen. In their recent ethnographic study, Lau and Kriegbaum argue that a person's decision making about whether they will adhere to a prescribed treatment is so individual that the best approach is to ensure their needs and concerns are being considered and addressed at the point of prescribing (Lau & Kriegbaum).

In their 2014 systematic review investigating the association between health literacy and adherence, Ostini and Kairuz argue that different patient groups may require different types of interventions strategies (Ostini & Kairuz). Those with lower health literacy are more likely to display unintentional non-compliance (i.e. they intent to take the medicine but something gets in the way) and are more likely to respond to interventions that target knowledge and support. People with higher health literacy on the other hand are more likely to display intentional non-adherence (i.e. a rational decision not to take the medicine as prescribed) and may respond better to prescribers involving them in shared decision making. In looking at the assessment processes utilised by most cancer-specific PC-MMS it suggests that there is an emphasis on strategies to address unintentional non-compliance. Few cancer-specific PC-MMS have been evaluated to address intentional non-adherence by understanding participants overall medication experiences and how this influences their medication taking behaviour. Deeper understanding of this overall medication experience could be useful to inform proactive strategies to prevent non-adherence and poor medication outcomes.

Cancer-specific PC-MMS excelled in their provision of specifically designed educational materials. Most study interventions provided participants with both verbal and written information regarding their drug treatment and managing potential adverse effects. While providing individuals with information about their medicines and managing effects is considered a core element of community PC-MMS, it is unlikely that the detail of the information relating to cancer-specific therapies provided by a generalist care provider will be as thorough as that which is provided by an oncology specialist. The importance of this in real life appears to be based on assumption rather than data. It is unknown if the effectiveness of an education program relates to the availability of the educational materials or the specific expertise of the care provider. This is one of the major criticisms of complex interventions, that you cannot decipher which elements of an intervention contribute to its success (Greenhalgh et al., 2015). To the best of our knowledge, the potential to utilise generalist providers by supporting them to with specialist resources has shown promise (Jiwa et al.; Johnson et al., 2015) but is yet to be extensively researched.

Cancer-specific PC-MMS were less consistent in addressing participants broader medication management skills than community PC-MMS. Very few provided patients with clearly documented medication lists or documented goals of therapy in a care plan. Only five cancer-specific PC-MMS communicated with other care providers to resolve any identified DTPs the patient was experiencing. The three interventions described as MMR were the most likely to address the care plan elements of the patient care process, but none met all criteria of the community-based programs. Documentation of medicines-related information is important for two reasons. Firstly, clear documentation of a person's overall medication regimen promotes self-efficacy of individuals, helping them to understand the management of their conditions and providing them with a communication tool that they can use in their interaction with different care providers. Secondly, clear, accurate and up to date documentation helps to transfer medicine-related information between care providers across different episodes of care, reducing medication errors associated with transcription errors and incomplete medication reconciliation (Tam et al., 2005). Even in circumstances where a patient is receiving all their care from a single cancer centre, it can be expected that they will interact with multiple care providers who will likely ask them about their medication history. In their study of medication errors in the cancer outpatient setting, Walsh and colleagues found that 7.1% of adult visits were associated with a medication error, and 20% of these were associated with medicines used in the home setting (Walsh et al.).

Ongoing evaluation of outcomes and progress is one part of the patient care process where cancer-specific PC-MMS potentially exceed the community-based PC-MMS, with 13 of 16 interventions offering some form of formal follow up. Community-based MUR

programs do not typically mandate the provision of ongoing follow up. MMR programs are expected to provide ongoing evaluation, but even they may not provide the same level of continuity of care as the cancer-specific interventions. In each of the cancer-specific PC-MMS the same provider who conducted the initial assessment provided the ongoing monitoring and evaluation of progress, which is a key point of difference from the Australian HMR program which utilises a collaborative team approach. It is not known if one model of care is superior to the other, however it does present a potential issue in considering if such interventions can be translated to other settings of care. Indeed, this concern was highlighted by Nieuwlaat in their 2014 Cochrane review examining interventions to enhance medication adherence, suggesting complex interventions that relying upon specialised resources and personal to deliver the intervention have limited capacity to be implemented into real life settings (Nieuwlaat et al., 2014).

Another major difference between cancer-specific PC-MMS and community-based PC-MMS is that the vast majority of cancer-specific PC-MMS relied almost exclusively on the use of specialist resources. This presents a major challenge for cancer services who are being required to meet an increasing demand for oncology services relating to the ageing population and increased survival rates with a finite pool of resources (Chalkidou et al., 2014). The result is a relative scarcity of resources and an imperative to carefully consider how specialist cancer resources are allocated and utilized.

7.3.2 Strengths and limitations

This literature review presents the first ‘real world look’ at the overall landscape of patient-directed MMS in non-hospitalised cancer populations. By critically comparing the elements of the patient care process addressed by empiric cancer-specific MMS against community-based MMS this review challenges the assumptions that underpin this body of evidence.

Being a scoping literature review utilising a narrative approach to analysis, the findings are inherently based upon the interpretation of the researchers. Best attempts have been made to be transparent in the process to promote rigour as detailed in Chapter Three, but ultimately it is an interpretive act. Best attempts were made to identify the available evidence, but the broad range of terms and keywords that is used within the literature proved that to be challenging. Of the 16 included studies there were 58 different keywords used, only 7 were used in multiple papers (range 1 to 6).

7.3.3 Recommendations for Future Research

As has been suggested by prior systematic reviews, future research on MMS in non-hospitalised cancer would benefit from greater rigour in study design, methodology and reporting. But determining the effectiveness of cancer-specific MMS requires more than increasing the research output of methodologically rigorous studies where the control comparator is usual oncology care. Community-based MMS are evidence-based and readily available. At the very least, they should provide the yardstick by which cancer-specific MMS are measured. Better still would be to develop novel models of care which utilise these resources. If the strength of cancer-specific MMS lies in the development of cancer-specific content, perhaps there is an opportunity to make this content available to the community-based services? If the strength of the community-based services is their comprehensive assessment and documentation of an individual's overall medication management, then perhaps there is an opportunity to make this more available to the specialist services?

What is unknown, is how people with cancer currently utilise community-based MMS. Further research exploring people with cancer's overall medication experience, and the MMS they access throughout their cancer journey would be an important first step to understanding their medication-related needs and how they are currently being met, something this thesis seeks to address.

7.4 Chapter Summary

This chapter has detailed the empirical evidence examining PC-MMS initiatives in non-hospitalised adults who are living with cancer, providing an indication of the types of PC-MMS initiatives that may be made available to Australians living with cancer in addition to the generic HMR and MedsCheck programs. It has shown that cancer-specific PC-MMS programs are most likely to be MUR type interventions sitting within specialist settings of care. These types of initiatives tend to have clear value propositions, assisting patients in specific aspects of their cancer-related care, such as their oral chemotherapy or supportive care. While these types of interventions may be effective in optimising cancer-related aspects of care in people managing cancer as a sole condition, they are not designed to enhance the overall medication experience in the same way that generic PC-MMS programs are. As such, cancer-specific PC-MMS interventions can be thought of as adding complementary value to generic PC-MMS initiatives. In the next Chapter, we take a closer look at the complementary value offered by MMS providers working in specialist cancer settings and generalist providers by examining the archetypal roles of MMS providers delivering care to people living with cancer.

8 ROLES OF MMS PROVIDERS

8.1 Chapter Introduction

Chapter Seven described the types of PC-MMS initiatives reported in the cancer literature and how these compare with the generic PC-MMS programs that are already available to Australians living with cancer, demonstrating the complementary value that specialist and generalist PC-MMS initiatives offer people living with cancer. This chapter presents and interprets the findings that address Objective 2.2: Characterise the roles of MMS providers within the system of care. This chapter draws solely from the pharmacist interview study to characterise the roles undertaken by Australian MMS providers within the system of care. Five archetypal roles are identified: the Auditor, the Expert, the Teacher, the Intelligence Officer, and the Coach. These roles tended to align with whether the MMS initiative was prescription-focused or patient-centred.

Table 13: Themes identified associated with Objective 2.2

Major theme	Sub-themes
PF-MMS roles	The Auditor
	The Expert
	The Teacher
PC-MMS roles	The Intelligence Officer
	The Coach

8.2 PF-MMS roles

The Auditor, the Expert, and the Teacher are each roles undertaken as part of PF-MMS initiatives. The value of these roles primarily relates to risk management, helping to create more robust healthcare services by minimising the occurrence of MRH associated with error, accident, and miscommunication.

8.2.1 The Auditor

The role of the Auditor is to identify and mitigate drug-related risk, and to reduce the opportunity for medication-related error or accident. The Auditor role is undertaken once a medicine has been prescribed and is associated with clear and measurable outcomes which are often referred to as interventions. Auditing is in built into the dispensing process of prescribed medicines and is the defining role of pharmacists involved in medication supply and as such, the role is routinely undertaken by specialist HONC pharmacists, general hospital pharmacists, and dispensing community pharmacists. The Auditor role

was noted to be a primary role of specialist HONC pharmacists, with the validation and ordering of chemotherapy described as a core duty across each of the nine hospitals:

> *Getting the chemo verified is my absolute priority. Because if I don't verify them the patient is not going to get treatment*. – Pharmacist 11, Ambulatory HONC pharmacist

Pharmacists working in large metropolitan hospitals also described undertaking the role of auditor for patients who receive their care in country services:

> *We have a lot of involvement in country chemotherapy where the verification happens off site, so here. And then they either order their own chemo or we get our production unit to send it across.* – Pharmacist 19, Ambulatory HONC pharmacist

When the patient is first initiated on chemotherapy, the process of validation often includes consideration of a patient's supportive care requirements:

> *Making sure the patients are receiving the appropriate care first in terms of their cancer treatment. So are they on the right, given the right chemotherapy for their condition…validate all the chemotherapy that they'll get after it's been prescribed by the physician or doctor…not letting the little things fall through the gaps…so they're on the right dose of their antifungal prophylaxis or if they've just recently been restarted on their steroids, do they need blood sugar control, do they need to restart certain prophylactic medications, so I'm keeping an eye on their immunosuppressant dose, are they taking it as the consultant wants them to take it, and are they able to manage all the things happening from the clinic, have they received all the messages from the consultant about what they're supposed to be doing with their medication management.* – Pharmacist 10, Inpatient/ambulatory HONC pharmacist

Auditing of the broader medication regimen through medication history and reconciliation occurs less frequently, most commonly on admission to and discharge from hospital, and during the first cycle of chemotherapy. While this process of medication history and reconciliation involved utilising the patients as a source of information, the interventions associated with these processes were predominantly focused on behind-the-scenes aspects of care, such as identifying prescribing errors or drug interactions. When undertaken by specialist HONC pharmacists, medication reconciliation was typically linked to the first cycle of chemotherapy, often occurring after the chemotherapy had been prescribed:

> *If I'm talking to people getting their history of what medication they're on the decision to have chemo has already been made, and they're here usually for their first treatment…usually I'll start with trying to get a good summary review, but probably on subsequent cycles it's a bit hit and miss* – Pharmacist 13, Ambulatory HONC/palliative care pharmacist

> *In terms of patient-wise we do try and see all of our cycle one's. They're the ones where we can actually do a history. In doing that we catch any interactions or any issues right from the start* – Pharmacist 19, Ambulatory HONC pharmacist

> *Ideally, we would like to do the history before they have treatment but that just, it often doesn't work that way. So if they're an outpatient or a day patient it's often done on the day of. Um, occasionally if we can identify patients that are coming in for treatment we'll make a phone call, but a lot of that depends on staffing and time. So that's the ideal even to make a phone call and take a history over the phone. Otherwise it's the day of, and the same for any inpatients admitted, it's on admission.* – Pharmacist 15, Inpatient/ambulatory HONC pharmacist

Within some hospitals, a thorough medication history was also undertaken by the surgical pharmacist as part of the pre-admission process of preparing for surgery:

> *We have pre-admission pharmacists, so often their medication history has been documented by the pre-admission pharmacist when they've had surgery* – Pharmacist 15, Inpatient/ambulatory HONC pharmacist

The extent of clinical pharmacy review for patients undergoing surgical procedures was noted to vary according to the nature of the procedure and the nature of the patient's usual medication regimen:

> *I guess it depends on how long the patient's in as to whether they get those full reviews or if they're seen as sort of a simpler surgical procedure, so not in as long, not on many medications related to the admission and don't get seen.* – Pharmacist 11, Ambulatory HONC pharmacist

Pharmacist 11 describes how the timing of undertaking a patient history interview after the chemotherapy has already been prescribed presents challenges to delivering optimal patient care:

> *It's always done once the treatment's been planned, which I don't like. I would prefer it to be done before the patient even saw the doctor. Um, it sometimes is done before the patient comes in for treatment, which is ideal, which is sometimes when they have their education sessions with the nurses. I prefer doing it then because then if I identify interactions, we can have them stopped before the*

> *patient's there with the chemo flowing through their arm and I'm saying, "you can't take this". Otherwise it is when they're being treated* – Pharmacist 11, Ambulatory HONC pharmacist

Medication history and reconciliation was also linked to standard hospital-based processes of care, predominantly inpatient admission. Pharmacist 16 described how this provided greater consistency for patients receiving chemotherapy while admitted as an inpatient compared to those receiving it in an ambulatory clinic:

> *For inpatients routinely, definitely…every inpatient definitely gets seen so before chemo starts and gets a full work up* – Pharmacist 16, Inpatient/ambulatory HONC pharmacist

Patients with haematological malignancies were noted to be more likely to experience an inpatient admission, impacting their likelihood of having a thorough medication history and reconciliation occur prior to initiating new treatment:

> *Some patients might be a new diagnosis, like they've come in with a fracture, they've been found to have myeloma, and then they'll start treatment while they're an inpatient. So then we'll do a history and everything before they start treatment. Others, um, the majority of people who start chemo as an outpatient, we usually don't do a history until the day that they come for their treatment. But the aim will be to see all those cycle one patients, to do a history and report any interactions and highlight any issues and things like that. But usually it happens on the day of treatment unfortunately, not beforehand, which would be great* – Pharmacist 17, Inpatient HONC pharmacist

The auditor role is also undertaken by pharmacists as part of the dispensing process that occurs in both the hospital and community settings:

> *If I take yesterday for example, there were three interactions with oncology patients where there were interactions between an antibiotic. The classic antibiotic and statin interaction [antibiotic prescribed by oncology]* – Pharmacist 7, Ambulatory HONC/Community pharmacist

8.2.2 The Expert

The Expert role is an advisory role undertaken during the process of selecting and deciding on pharmacotherapy when the prescriber seeks out the advice of a clinical specialist or pharmacist regarding a specific query regarding drug-related risk. To utilise this role the prescriber must recognise that a potential medication-related issues exists that is either beyond their scope of expertise or beyond their capacity to understand within

the available timeframe. As such, it is most commonly utilised in contexts where there is an established culture of collaborative practice and existing relationships between HCPs such as hospitals and HONC units.

Within the hospital setting, the Expert role was most commonly described in relation to patients with commonly encountered comorbidities (e.g. HIV, diabetes, cardiovascular disease), patients demonstrating clinical manifestations of an adverse drug reaction (e.g. steroid induced psychosis), and patients taking medicines that made the prescriber feel concerned about drug interactions. HONC pharmacists undertaking expert roles were most often called upon to research potential drug interactions, meaning that much of their expert role occurred behind the scenes from the patient perspective, through interaction with other HCPs:

> *One of the doctors asked me to look into what medication would be most appropriate out of two for the treatment of prostate cancer. The patient had a massive list of mainly cardiac medications, all had interactions with the two options of treatment for prostate cancer – Pharmacist 11, Ambulatory HONC pharmacist*

> *There was an HIV patient recently…and they wanted to start cisplatin and they wanted to see if there were any interactions with that. So if there are any unusual drugs that the doctors don't commonly see they'll just give us a call and say, "can you look this up for me?" – Pharmacist 19, Ambulatory HONC pharmacist*

Within the hospital setting, the Expert role was also initiated through referral to the HONC pharmacist from the pharmacy dispensary if they identified a potential issue as part of the supply process. This was considered an important avenue for patients with cancer who were not receiving services that did not receive extensive clinical pharmacy services, such as radiotherapy and outpatients:

> *Outpatients dispensary and all that know who to contact if they need to, you know there's a referral base there so. Because if you've got a myeloma, you know a patient goes on oral thalidomide for example and they need something they'll page me, and I'll go and speak to the patient. We have that sort of system in place.* – Pharmacist 10, Inpatient/ambulatory HONC pharmacist

Community pharmacists are also called upon to fulfil the Expert role in relation to the selection of over-the-counter medicines. In the case of Schedule 3 medicines, it is a legal requirement for the pharmacist to be involved. In the case of other self-selected medicines the pharmacist's involvement depends upon the need for their expert input being recognised by the patient or pharmacy assistant who is often the first point of contact that a patient has within the community pharmacy:

> *She was actually dehydrated, and she had asked one of the assistants for oral dehydration solution and when they asked one of the questions like are you taking medications etc and she told them she was on chemo the assistant called me to be involved* – Pharmacist 6, Community pharmacist

8.2.3 The Teacher

The Teacher role is concerned with providing the patient sufficient information to ensure they can enact the self-care behaviours that are required of them. In doing so, the Teacher makes complicated or confusing information easier for the patient to understand. This role is routinely fulfilled in relation to the supply of medicines that require self-administration throughout the cancer journey. It is also routinely undertaken to prepare patients for the self-care activities associated with parenteral chemotherapy administered by HCPs. Instructional education occurs less consistently for other medicines administered by HCPs, whether they be newly initiated medicines or alterations to usual medicines that occurs in the hospital setting.

In each of the specialist cancer services, patient education about chemotherapy was the primary responsibility of the chemotherapy nurses, with pharmacists and doctors also contributing:

> *They have a cancer care coordinator, and they actually hand the patient leaflets, and they do counselling, quite often our nurses will focus more on that* – Pharmacist 13, Ambulatory HONC/palliative care pharmacist

> *Patients will usually get the information or similar information two or three times. So the doctor usually goes through, albeit quite briefly usually, the nursing staff and the pharmacist will usually come and do more education as well. But yeah, nursing staff are mainly responsible for doing the whole thing. Like it takes about an hour for a new patient. I'll sit down with them while they're having their chemotherapy and I'll go through everything* – Pharmacist 17, Inpatient HONC pharmacist

HONC pharmacists each described routine involvement in educating patients about medicines upon discharge from hospital, and reinforcing education about their chemotherapy side effects and supportive care medications within the ambulatory setting:

> *We see the patients and counsel on discharge medicines, also on side effects of the treatment and what to expect.* – Pharmacist 2, Ambulatory HONC/Community pharmacy

> *Wherever possible, counselling the patients when they come for chemo…I'll come along and reinforce the side effects, go through the meds…So if it's [oral chemotherapy] dispensed from here then I will, I mean I'm trying, yeah probably not so formally, but I'm trying to explain the oral chemo*– Pharmacist 13, Ambulatory HONC/palliative care pharmacist

> *They'll often ask for a lot of info about the tablets they're taking. And usually yeah, so whenever somebody has a first diagnosis, I usually try to get in there in the first 24 to 48 hours that they come in, just introduce myself, who I am, if they have any questions they can ask them* – Pharmacist 18, Inpatient HONC pharmacist

Community-based pharmacists also described undertaking the teacher role as part of routine practice, either associated with the supply of medications or as part of undertaking PC-MMS:

> *Like someone who is palliative, and it's just often providing education to the family or loved ones about what each medication is for, so that when they're looking after them at home, like how does clonazepam act and things around you know managing constipation… like dose of opioids* – Pharmacist 5, Accredited/GP practice pharmacist

> *I see a lot of people who have just come out of hospital and those individuals have a very poor understanding of what's happened to them while they've been in hospital. And oftentimes will ask lots and lots of questions and I'll explain how their medicines have changed or they did this to them or whatever, and you kind of explain to them what's been going on…They often don't take that information in in that sort of very clinical environment in the hospital* – Pharmacist 9, Accredited/GP practice pharmacist

8.3 PC-MMS roles

The Intelligence Officer and the Coach are roles undertaken as part of delivering PC-MMS initiatives. The value of these roles primarily relates to the facilitation of more informed decision-making, helping to build a more resilient healthcare service by making it more likely that desired behaviours will be enacted and medication-related issues be identified and responded to rapidly.

8.3.1 The Intelligence Officer

Like the Expert, the Intelligence Officer is an advisory role. But unlike the Expert that focuses on a specific prescribing issue associated with drug-related risk, the Intelligence Officer provides support to the prescriber in their clinical decision-making by increasing

their access to information that may not otherwise be readily available or easy to comprehend. Three aspects of this role were described: acting as the Informant, the Go-between, and the Sense-maker.

8.3.1.1 The Informant

Pharmacists undertaking PC-MMS described their role in bringing new information to the prescriber or care team, often relating to the patient's medication taking behaviour in the home setting:

> *Often what's on the specialist referral, on the GP referral, it doesn't match what the patient is actually doing at home. 99% of the time it does not match what the patient is doing at home* – Pharmacist 1

> *A woman in her sixties was feeling generally quite unwell. She actually described what that meant for her. She couldn't understand why. So after quite a prolonged conversation realised that she took her SSRI on an intermittent basis*– Pharmacist 2, Accredited pharmacist

In other circumstances, Pharmacists identified areas of concern that needed to be brought to the attention of the care team which were not specifically medication-related, such as their overall disease control or their general social environment:

> *I've seen a person who his diabetes was out of control, his daily blood sugar levels were just all over the place, he was not getting on top of things himself, so I was able to phone the clinic there and then and get him in to see his GP that day because they were totally unaware of what was going on*. – Pharmacist 2, Accredited pharmacist

Sometimes this information was directly related to the pharmacist being able to visit the patient in their home environment, which may otherwise be unseen by HCPs:

> *You will discover things about them that they have never told their GP, like I mean, I often tell the GP about their home environment* – Pharmacist 9, Accredited/GP practice pharmacist

> *I did an HMR when I followed an old lady into the kitchen when the lounge was perfectly clean and tidy, and she'd already had a pack provided by the pharmacy, so it looked like she was doing really well, but she did have some dementia, I followed her into the kitchen, and it was like a bomb had hit the place from there onwards. And yeah, I ended up coming out, I went through her pantry and everything, you know all the medications in there, I came out with two shopping bags of out-of-date stuff. Because she was just buying stuff that she wasn't using and just hoarding* – Pharmacist 12, Accredited/community pharmacist

8.3.1.2 The Go-Between

Pharmacists undertaking PC-MMS also described their role in acting as a go-between within the broader care team, whether that be acting as a conduit between the GP and other HCPs, or between the patient and their HCPs. The role of the pharmacist in facilitating progress within a context of tension between the GP and specialist was noted by multiple participants:

> *The urologist was trying to manage this patient's cardiovascular disease and there were arguments between, because he took them off one drug…and the cardiologist was trying to put them on a different drug, and they were arguing between themselves, and the poor patient was in the middle and the doctors [GP] in the middle saying "I don't know what to do now".* – Pharmacist 4, Accredited pharmacist

> *The piggy in the middle in some ways…with the GP you can hedge your bets, I'll always give them different options as to what they need to be doing and let them know that I've sent my report through to whoever the specialist is to try and help guide them through that process. And I'll always offer to speak to specialists, which I have done on occasion, to speak to them personally, go back and see the patient, on a kind of free service basis because I think it's important to offer that follow up.* – Pharmacist 9, Accredited/GP practice pharmacist

In other circumstances, pharmacists described their role in bringing the team together to work toward common goals:

> *I was the go-between, between the GP and the specialist whereby they both had differing opinions on how the patient was to be treated… yeah I had to be the go between specialist and GP and decide what we were going to do moving forward…Well while the specialist had very good reason as to why he wanted certain medications reduced he in fact didn't realise the GP had increased the dose because the GP hadn't spoken to the specialist, and the specialist had a very good reason why he wanted a reduction in dose and so I worked with the specialist because she was going to be seeing him and then I had to let the GP know what was being capped and why it was being capped* – Pharmacist 8, Accredited/Community pharmacist

> *I might see someone with MS who mainstream medicines failed them and you know I'll sort of, they've been working with a naturopath and I'll kind of you know work with them and, often you know they work with naturopaths and there's kind of no structure to how they approach it and the GP has got no idea of what's going on and there's not a strong evidence base, but on occasions I've been able to kind*

> *of work out a plan, a structured plan that they can at least implement and then the GP knows exactly what's going on* – Pharmacist 5, Accredited/GP practice pharmacist

In some situations, the PC-MMS acts as the go-between for the patient and their HCP, acknowledging patient experiences that had either been dismissed or overlooked by other members of the care team:

> *I remember her telling me this story which has really stuck with me, "At the moment I can see a steering wheel and I can see two little people sitting on the steering wheel taking to one another." So she was hallucinating on apixaban, well she was hallucinating full stop. I looked at all of her medications, the only difference in her treatment regime was that she'd be changed from warfarin to apixaban. So I said to her "I think you need to stop the apixaban and we need to put you on something else." Her specialist didn't believe her. So I sent my report to the specialist, I sent it to the GP, and lo and behold the apixaban is stopped and the hallucinations go away. But because this hasn't been reported in the literature because the reports about it had only just come out, the GP, the specialist didn't believe her. And it's like, she's not mad, do you know what I mean? This is a perfectly lucid lady who is seeing things that are not there.* – Pharmacist 9, Accredited/GP practice pharmacist

8.3.1.3 The Sense-Maker

Pharmacists undertaking PC-MMS often described acting in a sense-making role, bringing disparate sources of information together to join the dots and get to the bottom of concerns and confusing situations. Reconciling conflicting information following an admission to hospital was a scenario described by multiple participants, something that was time consuming to resolve:

> *Patient gets discharged from hospital, goes to see the GP…English is a second language, and the discharge summary is full of errors…and the patient thinks they're doing one thing, but it's not consistent with the discharge summary, and the discharge summary it just doesn't even make sense... So the GP says, "I don't know what's going on here, can you help?". And so I go to the patient's home and it's still difficult to work out. The patient's pretty sure that they're doing what's the right thing to do…apparently the granddaughters told him to do this, and he's pretty confident he's doing the right thing. He's a smart guy…I'd actually done an HMR for this man's wife before and he's very involved in her care…I'd seen her twice before so I actually knew that he was pretty sharp…he was discharge from a [hospital] so I figure out what ward he was on, contacted the clinical pharmacist and she was then able to say yes, this is what's happening, pretty much what he*

> *was doing was right…and she said oh yeah, "I'll send you the MedProf". And I said, "Well the GP hasn't seen the MedProf", and the patient didn't have a MedProf. And once I got the MedProf it all made sense. He was pretty much doing the right thing. But what had happened was the clinical pharmacist, the discharge summary was a dog's breakfast… the clinical pharmacist had given the granddaughters who spoke English the MedProf but because he didn't speak English, they didn't give it to their grandfather. But they had given it to the community pharmacy, and they hadn't given it to the GP. So basically between the clinical pharmacist and the community pharmacist, they'd worked it out, but the GP had no idea what was going on, and the discharge summary certainly didn't shed any light on it. Anyway, I was able to join up the dots, contact the community pharmacy, there were sort of some minor changes to one or two drugs that needed to be made, but I liaised with the GP, got a new medication history for the GP, sent it to the community pharmacy, it was all good, and also some suggestions to the granddaughters that they keep the GP in the loop.*- Pharmacist 5, Accredited/GP practice pharmacist

In some cases, gaining a deeper understanding of these messy situations was the reason for the GP referral to the PC-MMS pharmacist:

> *He [GP] threw his hands up and said "Look, I need to get [the Pharmacist] involved here because I don't know what's happening"…she was going in for a colonoscopy or an endoscopy and they told her to stop her one of the fibrin drugs and put her on aspirin and nicorandil...She had very very complicated angina and [the Gastroenterologist] told her to stop that …and the problem is that if you stop that abruptly you're likely to get a rebound ischaemic attack. Moreover, she was on that, she was on perhexiline, on the nitrates, and neither the doctor nor the patient knew whether she should be on nicorandil and perhexiline, so they ended up she just didn't have any of them and she was wondering why she was going through the nitrate spray like it was going out of fashion. And the doctor threw his hands up and said, "well I don't know what she should be on"...and the specialist was off skiing in Switzerland somewhere, the GP had no idea so decided not to do anything which I thought was really quite dangerous…I ended up having to ring up the gastroenterologist as well…I thought "I must be missing something, there must be something that they know that I don't". So I rung them up and they said, "no I didn't tell her to stop that". And this woman's not stupid. So I didn't say "look, you could've killed the woman" I just said, "ok thanks very much" and I went back and told her "Look, go back on it straight away"* – Pharmacist 4, Accredited pharmacist

Multiple participants described their role in making sense of messy situations that other HCPs did not necessarily have the time to get to the bottom of:

> *One gentleman that when I went to his house the first time there was a note on the front door saying "Sorry, I'm in hospital can we reschedule?". So I go back and arrange to go back and see him a week later and he tells me he's been in hospital four times in the past month with blood noses that he couldn't stop. So looking at his medicines list he was on warfarin, he was on aspirin, he was on clopidogrel. They were all started by his cardiologist, and he had, you know, reasons to be on that. But each time he went to hospital he didn't see the cardiologist again, they just saw him, fixed him up and sent him home after a couple of days and didn't ever cease any of the drugs that were contributing to his nose bleeds. So while I was at the house I said "who is your cardiologist? I'm going to ring them and see whether you actually need to be on all of these because they're obviously not following it up in the hospital if you're still on them all. So I did, I rang the cardiologist, got to speak with him straight away which was really good and yeah, so he stopped the antiplatelets, so just kept him on the warfarin*. – Pharmacist 1

In other circumstances, the ability of the pharmacist to make sense of the situation was a result of an interaction with the patient that was focused specifically on their medicines and allowed their story to unravel:

> *I had one gentleman who was taking alendronate and he stopped taking it in the winter months. And I said to him, "Why are you not taking alendronate?", and he said "Well, it's too cold". And I said, "What do you mean it's too cold?" And he said "Well it says on the label that I have to stand upright for half an hour after I take the medication. I'm not getting out of bed at 6:30 in the morning and staying upright because it's too cold".* – Pharmacist 9, Accredited/GP practice pharmacist

Taking time to make sense of the mess was also described by pharmacists undertaking PC-MMS within the community pharmacy setting:

> *I had a lady the other day who had um bought all her medication in [to the community pharmacy] because she felt that she wasn't getting good control for her rheumatoid arthritis, and it was discovered that she had been taking frusemide instead of prednisolone… she's mislabelled her own bottles thinking that her frusemide was her prednisolone. So it turns out she was not getting the effectiveness then* – Pharmacist 8, Accredited/Community pharmacist

8.3.2 The Coach

The Coach is concerned with equipping and enabling patients to be more effective in their self-management by supporting learning and skill development to a level that is commensurate with their capability. Pharmacists who practiced within a haematology unit described fulfilling this type of role in relation to patients undergoing bone marrow transplants:

> *Understanding why they're on certain medications, the transplant patients that they're able to take all the medications, they understand how each one, what each one is supposed to do and not to take them if we're checking for levels, um, that they're tolerating all of the medications as well…in the day centre it's more because they're coming to get their chemotherapy you're sort of seeing more if they tolerating it, if their symptoms are ok, then it's much more of a brief contact, whereas the haematology patients, especially the ones who've had a bone marrow transplant, going through everything that they should be on, it takes a lot more time,* - Pharmacist 10, Inpatient/ambulatory HONC pharmacist

> *Helping the patient manage all this information that they're going to get, and all these medications that they're going to start, and dealing with the side effects as well,* - Pharmacist 17, Inpatient HONC pharmacist

More tailored education and ongoing coaching interventions were also described in relation to oral chemotherapy, delivered by a combination of nursing and pharmacy staff:

> *I educate all new patients on their supportive medications and oral chemotherapy…our procedure that we have written for here that is just not always followed is that they should come to me first so I can then provide that education, have a look at their medications, and we then have what we call an oral chemo book which the nurses have, and they'll ring patients like once a week to see how they're going with their treatment*. – Pharmacist 11, Ambulatory HONC pharmacist

Hospital-based pharmacists also described being opportunistic, undertaking coaching roles as needed within routine education sessions:

> *Part of our education as well would be that when we're doing that medication history and review, if I know that someone's got type 2 or maybe type 1, we don't get that many type 1's but we get many type 2 diabetics and I tell them you know to monitor, well make sure that (a) they're monitoring their sugars, and (b) maybe ask them to monitor them a bit more frequently. To record their results and if they are consistently running high, usually to feed back with the GP in the outpatient setting is who we would usually get them to check in with. But yeah, that would be*

part of their education when they start their first cycle – Pharmacist 17, Inpatient HONC pharmacist

Pharmacists undertaking PC-MMS described acting in a coaching role for patient and carers, supporting them to be more effective in their self-management through improved knowledge about their medicines and confidence in communicating with care providers. In some cases, this is achieved by helping them develop skills in communicating with HCPs and better equipping them to participate in decision-making:

I give them a blank [medication list] so they can practice writing the names out themselves as well, so they've got one to keep on their fridge at home in case the ambulance comes, and one to keep in their wallet or handbag if they're out at any time in case they suddenly get caught out and end up in hospital. Someone needs to know what medicines they're taking. So, um, but that's the first step because I feel that then empowers them as the patient to then discuss their medicines with whomever they're seeing. So I will ask the patient "when do you next see the specialist? Can you ask the specialist about this medicine and how long you need to continue it for?" …My role is very much to empower the patient to ask their health professionals about their medicines and, um, to continually consider the benefits of the medicines. - Pharmacist 1

I think one of the main roles is helping people to understand why they are taking them and to empower them to take responsibility for their own health decisions. And so therefore they can determine whether something is appropriate for themselves to take. – Pharmacist 2, Accredited pharmacist

In other circumstances, the coaching aspect entailed providing patients with realistic expectations about their medicines, with goals of care that aligned to their current life situation:

I often feel that it's my role, not to scare patients, I don't want to scare patients, I do want to encourage them in compliance, but just to put a bit of reality in around some of the medicines…sometimes they might think that a medicine is guaranteed to do something. I think the worst ones that I've seen is antidepressants. So antidepressants, yep, they've taken it for three years or so, you know, and I'm looking at it going "escitalopram, OK, you've got a dose here of 30mg, the maximum dose is 10mg" … And I don't think that people, they just go "oh well that's for my depression" and they just assume the fact that they're taking something for something that it's worked. They don't realise that not all drugs work all the time for all people. So I feel that sometimes it's my role just to sort of step in there and say "they're not always effective every time" – Pharmacist 1

Pharmacists also play a role in providing patients and carers with confidence in communicating with their care providers, advocating on their behalf if needed:

> *My job is to afford you abilities and confidence to be a speaker for your own right. So you go to the doctors and say "look, these are what my concerns are, how can we address them?" And so that's what I do. If it's urgent I'll ring them up, if it's not I'll write a letter, I'll give a note to the patient*. – Pharmacist 4, Accredited pharmacist

> *I think in our current generation of geriatric population there's a lot of "well I just do whatever the doctor tells me…they make those decisions" so there is an element where people don't know because they have given that to the clinician, and they trust that that is correct. And don't feel comfortable questioning that as well.* – Pharmacist 14, Palliative care/accredited pharmacist

8.4 Discussion: Objective 2.2

This chapter has characterised five roles undertaken by MMS providers, each of which offers distinct but complementary value to patient care. The roles of Auditor, Expert and Teacher were strongly evident in HCPs that adopt a prescription-focused approach with a focus on risk management. The roles of Intelligence Officer and Coach were most evident in HCPs that adopt a patient-centred approach with a focus on facilitating more informed decision-making by patients and prescribers.

8.4.1 Prescription-focused roles are concerned with risk reduction

The Auditor, Expert and Teacher roles are primarily concerned with medication safety, defined by the International Pharmaceutical Federation as "freedom from preventable harm with medication use"(FIP, 2020). The Auditor monitors risk, the Expert advises on risk management, and the Teacher seeks to reduce risk through patient education.

8.4.1.1 The Auditor monitors risk

As has been described, the Auditor role is demonstrated by HCPs who actively assess medication regimens against agreed standards as part of routine processes of care. This is illustrated using the Cynefin Framework in figure 32. Auditing processes are represented by the red dotted line, monitoring the compliance of medication regimens with defined medication protocols (within the clear domain) and alignment with established clinical guidelines (within the complicated domain). Auditors are systematically inserted into healthcare systems when it is recognised that there is a high degree of medication-related risk, such as the prescribing of chemotherapy or during a transition of care. The Auditor's role assists the care team by proactively monitoring for medication-related

issues and advising on appropriate management strategies. Auditing is broadly recognised as a core role of pharmacists, and this role is embedded into processes of care undertaken in healthcare settings in relation to the supply of prescribed medicines and the movement of patients into and out of healthcare institutions.

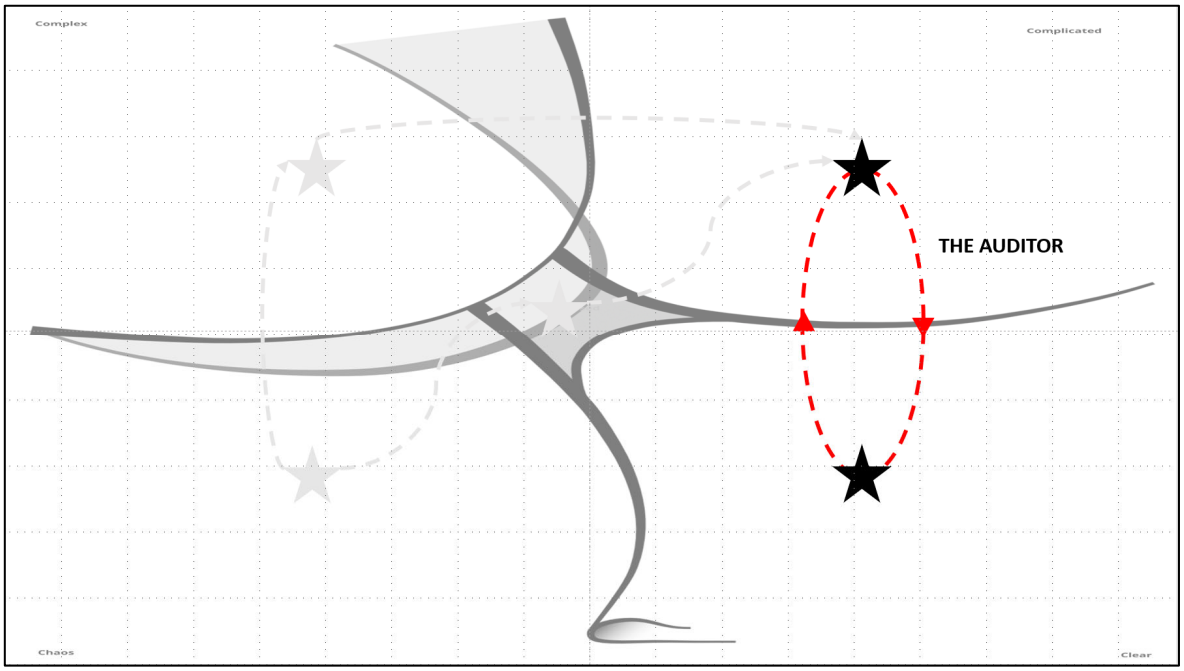


Figure 32: The Auditor role

By using the Cynefin model, it is easy to understand why the Auditor role is strongly evident in pharmacists who practice within ordered environments where there is strong clinical governance, such as hospitals. It is more difficult for pharmacists to undertake the Auditor role when they are practicing in more complex environments, such as those who are supporting patients at home. While community pharmacists regularly undertake the Auditor role for patients who are prescribed medicines that they dispense, their ability to fulfil this role in relation to an anti-cancer medicine will be impaired due to their inability to access relevant regarding both the patient's clinical status and the treatment protocol.

8.4.1.2 Experts advise on risk management

The Expert role is demonstrated when there is a medication-related issue that requires a level of analysis or expertise to identify and manage it appropriately. When considered using the Cynefin Framework, the role of the Expert fits within the complicated domain, as illustrated in figure 33. Utilising the Expert requires some type of referral pathway to be enacted, where someone who is involved in the patient's care acknowledges the potential for a medication-related issue that could benefit from the input of a pharmacist or other suitably skilled HCP. These referral pathways are illustrated by the dotted lines. Path A represents a referral for investigation of a medication-related issue that has been

identified through routine process of care. An example of this is a prescriber who has asked a pharmacist to investigate a potential drug interaction after receiving an alert from the electronic prescribing software. Path B represents a situation where a patient's medication regimen is recognised as having a high degree of risk, such as a prescriber requesting a pharmacist review for a patient who is known to use a range of herbal and complementary medicines and is requiring chemotherapy. Path C represents a situation where there is uncertainty regarding a patient's clinical condition and medication-related causes need to be considered as part of the differential diagnosis, such as a prescriber asking a pharmacist to investigate if a symptom could be the result of an adverse drug reaction.

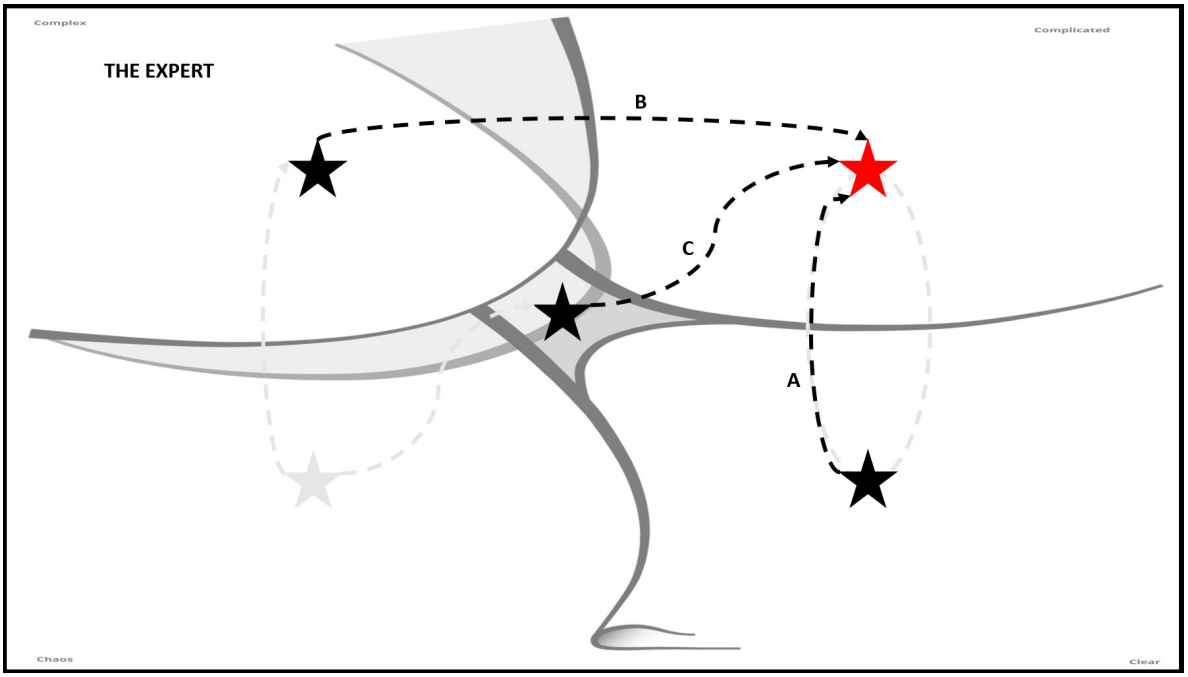


Figure 33: The Expert role

The Expert role offers greatest value when brought into patient care at the point of prescribing. Hence, utilisation of the Expert is most likely to occur in settings where the system enables the identification of medication-related issues through clinical decision support tools, and where there is an established culture of collaborative practice. This level of collaboration can be more difficult to achieve within the community-setting than hospital-based practice due to the greater challenges in building inter-professional relationships and more restrictive remuneration models.

8.4.1.3 Teachers seek to reduce risk

The Teacher role is demonstrated when HCPs endeavour to make confusing or complicated medication-related information clearer for patients, enabling them to implement their medication regimen as prescribed. This role is illustrated using the Cynefin Framework by the red dotted line in figure 34. While the goal of the Teacher is

always to make information clearer for the patient, the starting point and process may vary. In some cases, it may involve a straightforward process such as translating or decoding complicated medical terminology into a plain language explanation as represented by path A. In other cases, the starting point may be one of confusion, as represented by path B, where the HCP must first establish a level of situational understanding prior to instructing the patient.

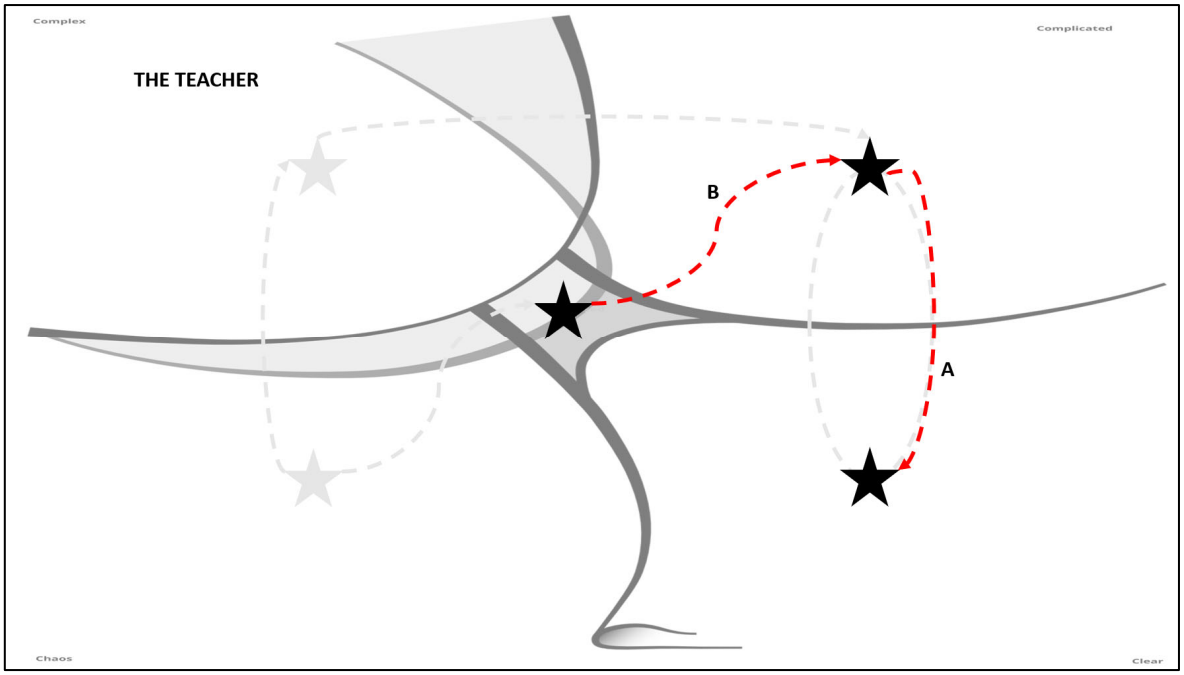


Figure 34: The Teacher role

The Teacher role is routinely demonstrated by medical practitioners, nurses, and pharmacists as part of the supply of prescribed medicines that are to be self-administered by the patient. It also commonly occurs in relation to the self-care activities associated with undergoing parenteral chemotherapy. The patient-facing nature of the Teacher role offers obvious relevance to the patient in circumstances where they have some uncertainty about their medication. By comparison, the Auditor and Expert roles are more likely to occur behind the scenes from the patient perspective, meaning that the value of these roles is not necessarily recognised by the patient unless something goes wrong.

8.4.2 Patient-centred roles focus on resilience

The Information Officer and Coach roles help to build resilience in healthcare service by supporting patients and prescribers to make better informed decisions and increasing the visibility of medication-related issues. This offers particular benefit in settings where risk cannot be eliminated or controlled, as occurs with the self-administration of medicines. The effectiveness of HCP undertaking the Information Officer and Coach roles depends upon the therapeutic relationship. This may be more easily achieved in consultations that

are conducted within the home or within healthcare settings that afford sufficient time and physical space for a focused consultation and relationship to develop. As such, these roles are most commonly undertaken in settings where the HCP is formally responsible for delivering a PC-MMS initiative that is supported by a model of care and remuneration model, like the community-based HMR and MedsCheck programs. Because of this, these roles are less commonly encountered by people who are undergoing cancer diagnosis and treatment.

8.4.2.1 Intelligence Officers illuminate medication-related issues

The Intelligence Officer role is demonstrated when an HCP elicits and interprets sources of evidence beyond that which is routinely available, such as the patient's medication experience. This role is illustrated using the Cynefin Framework in figure 35 by the red dotted line. Path A represents the actions of the Informant; discovery of obviously relevant medication-related information that is otherwise unknown to the healthcare team. By identifying this type of complex behavioural issue, the HCP can then act as the Sense-Maker, applying expertise to make sense of the clinical situation and identify suitable management strategies, as represented by path B. Path C also represents the identification of information that is unknown to the healthcare team, but where the relevance is uncertain. An example of this is the identification of a possible but highly improbable adverse drug reaction. In some cases, this information may be dismissed, and it will remain uncertain. In others, the information may be considered and incorporated into a management strategy, as represented by path D. Paths C and D can also represent the actions of the Go-Between, where the HCP is brought into a situation to help resolve known conflict and related confusion.

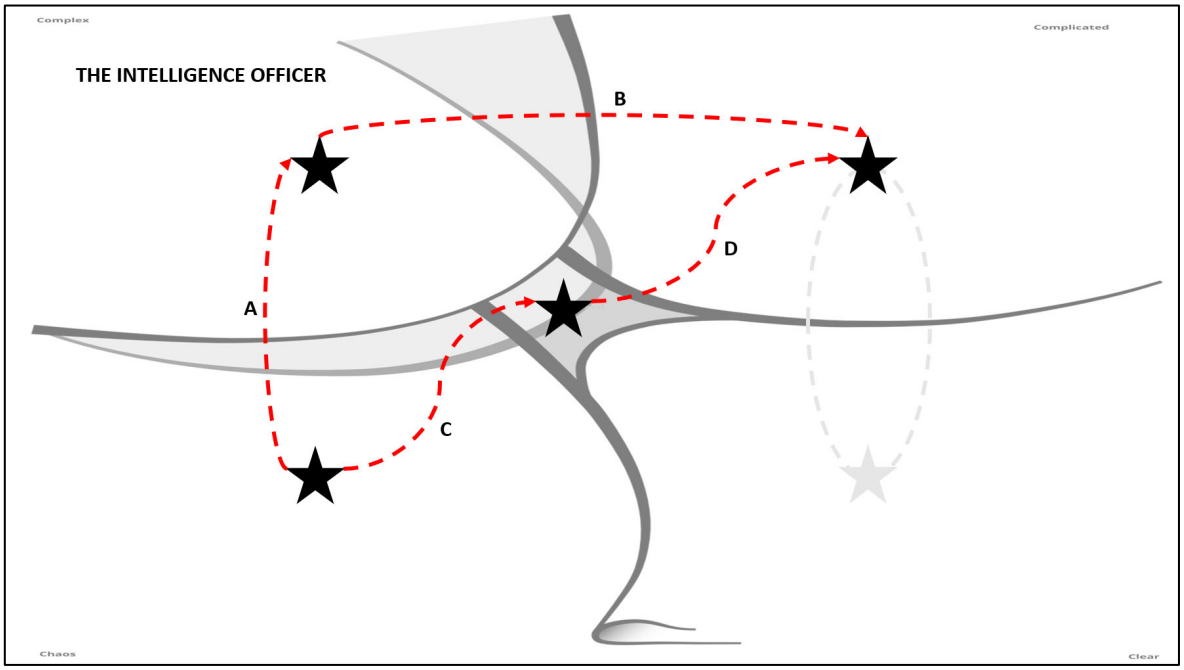


Figure 35: The Intelligence Officer role

Eliciting new information through exploration of the patient's medication experience (i.e. path A and path C) requires HCPs who can establish a strong therapeutic relationship and listen to the patient's story. Identifying relevant medication-related issues (i.e. path B and D) requires HCPs who have advanced knowledge of pharmacotherapeutics and are able to make connect multiple sources of information which may be disparate in nature. Thus, fulfilling the role of the Intelligence Officer requires HCPs who are not only adequately skilled, but also have sufficient time and resources available.

8.4.2.2 Coaches promote efficacy in self-management

The Coach role is demonstrated by HCPs who support patients to be more effective in their activities of medication management, moving beyond instructional education to skill development. This role is illustrated using the Cynefin Framework in figure 36 by the red dotted line. Similar to the Intelligence Officer, paths A and B may relate to the discovery of information that is otherwise unknown to the healthcare team so that it can be appropriately managed, but in this case, it is a result of the patient being encouraged to self-disclose information relating to their behaviours without fearing judgement. For example, suggesting to patients "this is something your doctor would really like to know" when talking about a missed dose of medication. Path C represents the role of the Coach in empowering patients to ask questions of their care providers when they face uncertainty rather than remaining passive.

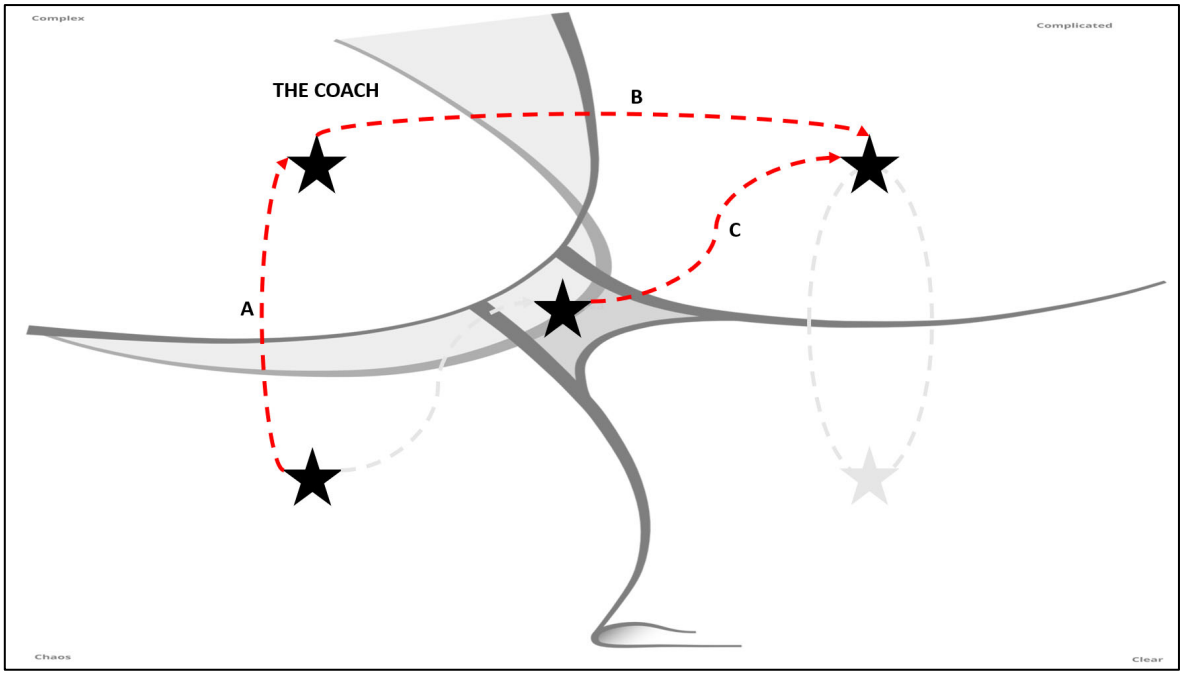


Figure 36: The Coach role

Unlike the Teacher role that is primarily focused on the patient's ability to fulfil the logistical work associated with medication use, the Coach addresses the social and intellectual workload of using medicines. Coaching helps the patient to be a more effective

member of their healthcare team and feel more equipped for the journey ahead by delivering care and support that is commensurate to the patient's need. Effective coaching is built upon a strong therapeutic relationship, allowing the patients concerns to be heard and providing support to resolve medication-related issues that may otherwise go unrecognised. For someone who has low activation this could be as simple as ensuring they have a medication history documented in their electronic health record, are able to use their medicines as prescribed, know what medication-related issues to look out for and how to respond if one is encountered. A patient with a higher level of activation may be more interested in furthering their knowledge or assistance with interpreting information. Within hospital-based settings the coaching role may be fulfilled within tailored education programs that are specific to aspects of care, such as oral chemotherapy, supportive care, or self-management of a specific condition. Within the community-setting coaching roles are formally fulfilled by MMS providers participating in the MedsCheck and HMR programs, and informally[51] by primary care providers as they build ongoing relationships with patients and upskill them gradually over time. Coaching is about building the patient's effectiveness in medication management, meaning that specialist cancer knowledge is not a prerequisite for the HCP, although they may benefit from access to specialist support if fulfilling this role for patients undergoing parenteral chemotherapy.

8.4.3 PF-MMS and PC-MMS offer complementary value

The knowledge contributed by this chapter builds on Cipolle, Stand and Morley's differentiation in the value offered by PF-MMS and PC-MMS initiatives (Cipolle et al., 2012) introduced in Chapter Two) by characterising five archetypal roles that are undertaken by MMS providers: the Auditor, the Expert, the Teacher, the Intelligence Officer, and the Coach. These roles offer complementary value to patient care.

8.4.3.1 PF-MMS roles: A Safety-I approach

PF-MMS roles add layers of defence that are embedded within the system of care, relating to medication supply and activities associated with transfers to and from institutional settings. As such, it can be anticipated that all people undergoing cancer diagnosis and treatment will regularly encounter these roles throughout their cancer journey. They fit within the conventional approach to medication safety also known as *Safety I* (Hollnagel et al., 2015).

In their 2015 White Paper, Hollnagel, Wears and Braithwaite describe Safety I as an approach to safety that is focused on avoiding things from going wrong (Hollnagel et al.,

[51] Informally because it may not be remunerated by a specifically funded model of care

2015). As introduced in Chapter One, this conventional approach is underpinned by Reason's Human Error, commonly referred to as the *Swiss Cheese Model*. Reason's model introduced a systems-based approach to safety, identifying two sources of incidents: active failures and latent conditions. Based on an understanding that "*we cannot change the human condition, but we can change the conditions under which humans work*", the focus of the model is to change the design of the system to proactively alter latent conditions by introducing layers of defences, barriers and safeguards that target behaviours at individual, team, task, workplace and the institutional levels (Reason, 2000). This error and risk management is enabled by establishing a safety culture within an organisation, encouraging those who encounter risks or incidents to report them without fear of consequence (Reason, 2000). The purpose of this incident monitoring is to facilitate organisational learning which is used to identify ways to improve the robustness of the system, preventing future occurrences of errors and incidents (Reason, 2000). A central tenet of this approach is that understanding the past behaviour of a system enables prediction of its future behaviour. While this may hold true within ordered environments, such as hospitals or within organisational settings, we now understand through the developments in complexity science that the same predictability and relationships between cause and effect do not exist within complex contexts like primary care.

8.4.3.2 PC-MMS roles: A Safety-II approach

PC-MMS roles help to uncover medication-related issues that would otherwise go unnoticed, bringing them from the complex and chaotic domains into the ordered environment where they can be appropriately managed. They offer value by making it more likely that things will go right; increasing the visibility of medication-related issues and supporting patients and their care providers to make better informed decisions. This builds resilience in healthcare service, fitting within a *Safety II* approach to medication safety (Hollnagel et al., 2015).

Hollnagel, Wears and Braithwaite define Safety II as a system's ability to succeed, viewing safety as an emergent property of a system in which things go right (Hollnagel et al., 2015). In contrast to the Safety I approach to medication safety which is primarily concerned with creating a *robust* system that maintains the level of MRH at an acceptable level, Safety II is about building a *resilient* system that make it easier for quality use of medicines to be achieved (Hollnagel et al., 2015). An important aspect of the Safety II approach is the role of active surveillance and proactive monitoring where initiatives are put in place to ensure that in the instances when things do go wrong, they are rapidly identified and responded to in a way that requires smaller effort and reduces the severity of consequences.

8.4.3.3 Complementary value

Whether resilience-based approaches to safety should be seen as a replacement of Safety I or as complementary remains a matter of debate within the field of safety management. This thesis takes the position that the two approaches are complementary, and that Safety II broadens the opportunity to enhance medication safety by providing an approach that is better suited to complex contexts. Jones et al arrived at a similar conclusion in their qualitative study of procedural violations in UK community pharmacies (Jones et al., 2018). They found that community pharmacists often face situations where they are required to exercise professional judgement because the context does not fit within pre-defined procedures. In most cases, these diversions from recommended practice were taken to preserve patient safety and enable things to go right. However, on some occasions diversions were taken to preserve efficiency, something that is actively promoted in community pharmacy through the use of performance targets (Jones et al., 2018). This demonstrates one of the risks that can be inadvertently introduced by Safety I approaches that utilise management by objectives; that processes of care can be perverted to preference the meeting of targets over the needs of the patient.

As illustrated in figure 37, PF-MMS initiatives offer discrete value increasing the care team's visibility of medication-related issues through expert analysis or audit and providing patients with drug or condition specific instruction on desired behaviours, such as how to undertake active surveillance of a common side effect for a prescribed medicine. PC-MMS initiatives are more generalised, increasing visibility of medication-related issues to the care team through active investigation and coaching of patients to facilitate more open disclosure of medication-related information. In addition to this, PC-MMS offer value in positively challenging the patient's starting conditions, by making a holistic assessment of their medication-related needs that considers their level of activation and capacity.

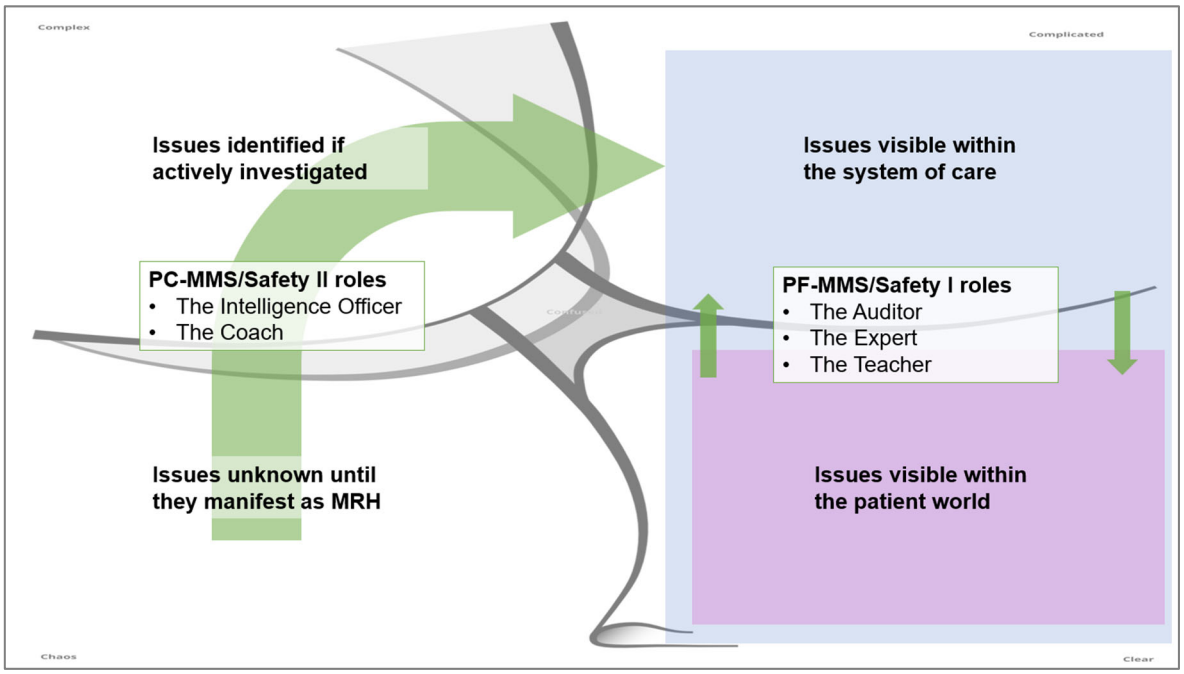


Figure 37: PF-MMS and PC-MMS roles offer complementary value

8.5 Chapter Summary

This chapter has described five archetypal roles that MMS providers undertake within the system of care. The prescription-focused roles of Auditor, Expert and Teacher roles are commonly seen in healthcare environments and are embedded into activities associated with medication supply and transitions into and out of institutional settings. They fit within the conventional approach to medication safety focused on risk reduction, or *Safety I* and are routinely encountered by people undergoing cancer diagnosis and treatment. The patient-centred roles of Intelligence Officer and Coach are built upon strong therapeutic relationship and are most likely in settings that facilitate that, such as formal PC-MMS initiatives. They fit within a contemporary approach to medication safety concerned with building resilience in the system, or *Safety II*. Because these roles are most commonly demonstrated by MMS providers practicing within the community setting, they are less commonly encountered by people undergoing cancer diagnosis and treatment. In the next Chapter, we shift focus slightly to look more closely at the ways in which the system of care influences the types of encounters people with cancer can expect to have with their HCPs, by looking at the ways in which the system constrains the behaviour of pharmacists responsible for providing MMS, and how these constraints impact their ability to contribute to the timely and appropriate management of medication-related issues.

9 CONSTRAINTS ON PHARMACISTS

9.1 Chapter Introduction

In the previous Chapters, the system of care was characterised in terms of the types of PC-MMS initiatives available and archetypal roles undertaken by MMS providers, primarily pharmacists, delivering care to Australians living with cancer. This chapter presents the findings that address Objective 2.3: Describe the constraints placed on pharmacists who provide MMS available to people living with cancer. It draws on the findings from the pharmacist study which were interpreted as three themes: time and place, capacity to provide PC-MMS, and pharmacist relationships with other HCPs.

Table 4: Themes identified associated with Objective 2.3

Major theme	Sub-themes
Time and place	After diagnosis, within a hospital (HONC)
	Any time, within the home (Accredited)
	Any time, if you ask for it (Community)
Capacity to provide PC-MMS	Need to prioritise PF-MMS within the hospital
	Remuneration for HMRs that is blind to complexity
	Perception of value within a business strategy
Pharmacist relationships with other HCPs	An accepted member of the MDT
	Seen as a competitor rather than collaborator

9.2 Time and place

All pharmacists face constraints relating to time and place. HONC pharmacists have input into patient care after a diagnosis has been made, usually within a hospital environment. Accredited pharmacists have input episodically throughout a patient's journey and provide care within the patient's home, but only if a referral has been made. Community pharmacists also have input throughout a patient's journey, but only if the patient initiates contact through engagement within the community pharmacy.

9.2.1 After diagnosis, within a hospital (HONC)

HONC pharmacists practice within hospital environments, which brings with it a well-established medical model of care that creates clear boundary conditions. HONC pharmacists will not be involved in a patient's care unless they are under the care of a HONC medical team. In cases where diagnosis of cancer is the cause of admission (e.g. acute haematological malignancy) the HONC pharmacist will have input to patient care early in the cancer trajectory:

> *Whenever somebody has a first diagnosis [of acute leukaemia] I usually try to get in there in the first 24 to 48 hours that they come in, just introduce myself, who I am, if they have any questions they can ask them* – Pharmacist 18, Inpatient HONC pharmacist

For the majority of patients for whom diagnosis takes weeks to months, HONC pharmacist input will not begin until after a formal cancer diagnosis has been made.

> *They all have a diagnosis when they come to us, it's not just a "Oh it's a potential cancer", this is definitely cancer.* – Pharmacist 10, Inpatient/ambulatory HONC pharmacist

As such, the input of HONC pharmacists is restricted in time and place. In terms of time, it is unlikely that an HONC pharmacist will be involved in a patients care in the earliest stages of their cancer journey. In terms of place, the involvement that an HONC pharmacist does have with a patient will likely be associated with care provided within a hospital, either due to admission or ambulatory anti-cancer treatment.

9.2.2 Any time, within the home (Accredited)

Accredited pharmacist can have input into the care of people living with cancer at any stage of the cancer trajectory provided they receive a referral from an approved service provider. HMRs can be referred at any phase of the cancer journey, but pharmacist experience suggests that they infrequently occur during the diagnosis and treatment phase. Of the seven pharmacists conducting medication reviews funded through the HMR program, none of them received referrals for people actively receiving parenteral chemotherapy:

> *Occasionally they're still undergoing radiotherapy but predominantly, well the majority that I see they would be at least twelve months out.* – Pharmacist 1

> *I'm not aware of having seen anybody that has been undergoing acute treatment.* – Pharmacist 2, Accredited pharmacist

> *I can't actually think of one where it's active treatment* – Pharmacist 12, Accredited/community pharmacist

> *I don't see any, I've never seen any [people undergoing acute chemotherapy] I don't think* – Pharmacist 5, Accredited/GP practice pharmacist

For several pharmacists, the interview was the first time they had really thought about the absence of referrals for this population, providing with an opportunity to reflect on the needs of this patient population:

> *Isn't that funny, now you ask the question, you kind of think they'd [people undergoing cancer treatment] be the kind of people we'd be targeting but they're not the ones that… I've obviously done reviews on people who have had chemotherapy and come out the other side, but not people actively receiving chemo*. – Pharmacist 9, Accredited/GP practice pharmacist

At the time the interviews were conducted, GPs were the only approved referral source for HMRs. There was a perception amongst pharmacists that the lack of HMR referrals for this patient population reflected a reduced level of contact with the GP as the patient underwent an intensive treatment schedule and regular hospital admissions or outpatient visits:

> *A lot of patients don't see their GP or their community pharmacy much during their acute treatment* – Pharmacist 15, Inpatient/ambulatory HONC pharmacist

This perception of reduced GP involvement was also reflected in the experiences of HONC pharmacists, who spoke of the challenges the disenfranchisement of the GP during acute cancer care posed to the timely resolution of medication-related issues:

> *Oncologists are generally quite good but they're also very busy, so they don't have time to look after every single aspect of medication. So they often want the GP to [manage a medication-related issue], but sometimes the patients then aren't seeing their GPs very often cause they're like "I've got cancer and I'm constantly seeing my oncologist" so working out who is the best person to speak to about those issues can be quite complicated.* – Pharmacist 11, Ambulatory HONC pharmacist

Another perspective was that medication review for people undergoing cancer diagnosis was best left to the specialists. This was mostly associated with a perception that the majority of medication-related needs would be associated with chemotherapy:

> *[GPs] don't feel competent, in my opinion, treating cancer… Cancer is actually treated by specialists so why do I need to send an HMR for these patients because they're already being dealt with by a specialist?* – Pharmacist 4, Accredited pharmacist

Accredited pharmacists undertake their consultations within the home setting. This physical environment is outside the control of the pharmacist, changing with every patient encounter. But while the environment may be foreign to the pharmacist, it is familiar and comfortable to the patient, providing the pharmacist with an enhanced opportunity to build a therapeutic relationship relationships. This, along with the capacity to undertake a lengthy consultation, assists the pharmacist in fulfilling PC-MMS roles, such as the

Intelligence Officer role that identifies medication-related issues that are buried within the patient's medication experience, as Pharmacist 2 explains:

> *I go out to somebody's place. I'll usually spend about an hour sitting with them…Even if I go out there and they go "I have no idea why you're here I think this will be a waste of time" I'm still often there for around an hour. And I think it takes a long time sometimes to unravel what is going on, what may be their actual concern. For example, I can sit there for three quarters of an hour, and they go "No no no I'm not on anything else, I just take this" and then you know in the last five minutes they bring all this other stuff out of the cupboard. And so I take a deep breath and start all over again…* – Pharmacist 2, Accredited pharmacist

9.2.3 Any time, if you ask for it (Community)

Community pharmacists are highly accessible health practitioners able to build direct relationships with patients without the need of a referral. As such, a person with cancer can access a community pharmacist throughout the entirety of their cancer journey. In some cases, this relationship may pre-date the formal cancer diagnosis, allowing the pharmacist to provide input from the very start of the patient's cancer journey:

> *With prostate cancer that happens more often because they will find out they have prostate cancer and they'll walk up and say, "Oh I've just been diagnosed on Thursday", the doctor's written up a script for an injection straight away and like they're usually you know, a bit shaken. – Pharmacist 12, Accredited/community pharmacist*

Community pharmacists not only provide support to the patient, but also their family unit who are often impacted by the cancer diagnosis. This supportive relationship may even extend beyond the patient's death, as the community pharmacy continues to support the family members in their bereavement:

> *We had a couple, oh this is probably a few years ago now that he died, and they were like, they were one of my favourite couples, they were lovely…and she still comes in, but he passed away from a brain tumour, and he had it a couple of times and got better and, but I suppose also moral support for the person that's left. Like we all attended the funeral and things like that – Pharmacist 12, Accredited/community pharmacist*

Despite the relationships that community pharmacists can build with regular customers, their involvement in the patient's cancer care journey requires an initial conversation about cancer, which can be challenging. Community pharmacists described experiencing more hesitation from patients when it came to engaging in conversations about cancer than

compared with other chronic conditions. In some cases, community pharmacists perceived that patients seemed overwhelmed or overloaded by their cancer care:

> *People with cancer feel that their medication is only for a short time, and it marks a very traumatic time in their life, and so the less the need to talk about it to anybody, I think, this is the attitude I get. They just want to get it over, get it done, get it fixed, put it behind me, move forward* – Pharmacist 8, Accredited/Community pharmacist

In other cases, it was perceived that the reluctance to talk about cancer related to social stigmas:

> *People have no problem telling you they've got diabetes or they've had a heart attack. But it's different when they've got cancer, they don't talk about it openly at all. Yeah, I think it probably compares a bit to mental health, that it is still a topic that people don't like to talk about.* – Pharmacist 12, Accredited/community pharmacist

9.3 Capacity to provide PC-MMS

Pharmacists were constrained in their capacity to provide PC-MMS in different ways. HONC pharmacists were constrained by the need to prioritise scarce resources toward essential PF-MMS initiatives relating to chemotherapy and transitions of care. Accredited pharmacists were constrained by defined business rules that impacted viability of delivering care to patients with complex needs. Community pharmacists faced similar constraints, as well as being constrained by perceptions of the value that PC-MMS offer the community pharmacy as a business.

9.3.1 Need to prioritise PF-MMS within the hospital

HONC pharmacists require additional training to undertake the PF-MMS roles specific to the provision of systemic cancer therapies. This results in a finite pool of pharmacists who are responsible for ensuring the core pharmacy service requirements are met in the areas where there is the greatest degree of drug-related risk: chemotherapy and transitions of care into and out of the hospital. As Pharmacist 16 explains, this means that not all areas of HONC practice are regularly serviced by an HONC pharmacist:

> *I think it's just resources to be honest. So I guess how we allocate resources…I'd love to allocate more resources to ambulatory settings, like continuity of care, transition points, palliative care…* - Pharmacist 16, Inpatient/ambulatory HONC pharmacist

As explained in Chapter Two, there is high demand for cancer services. In practice, this translates to a high throughput of patients and constant workload. To meet service expectations HONC pharmacists prioritise their workload. One way in which they do this is through normalised approaches to prioritisation, such as limiting the Teacher role to patients undergoing their first cycle of chemotherapy:

> *always our priority is to first cycle patients and then follow up for cycle two but depending on what yeah, you don't always get to see patients but coming back for cycle three or four, you don't get to spend much time with them* – Pharmacist 15, Inpatient/ambulatory HONC pharmacist

While it can be expected that patients will interact with an HONC pharmacist for their first cycle of treatment, it is less likely that they will be afforded the same opportunity if they experience any changes to their chemotherapy treatment regimen:

> *I don't see every patient if they change treatment, it just depends on what treatment they change to, how long it's been since they started, because of the numbers that we get* – Pharmacist 11, Ambulatory HONC pharmacist

HONC pharmacists independently manage their workload on a day-to-day basis, with little time available to spend with patients. For those working in ambulatory care their contact with patients is likely to be episodic and primarily focused on the initial cycle of chemotherapy:

> *It's hard because of that minimal contact that we have, so it's hard to follow [more general medication-related issues] up. It's really just check the [chemotherapy] script, next one, check the script…I would say about 90% of the day is checking scripts.* – Pharmacist 19, Ambulatory HONC pharmacist

This limited patient contact time restricts HONC pharmacist's capacity to build a therapeutic relationship and restricts their ability to fulfil the PC-MMS roles of Coach and Intelligence Officer. As Pharmacist 11 explains, this constrains HONC pharmacists ability to identify and resolve more complex medication-related issues:

> *It's not too common [to identify someone with general problems with medication management], but I wonder if it's because I'm not spending enough time with them, due to time constraints.* – Pharmacist 11, Ambulatory HONC pharmacist

9.3.2 Remuneration for HMRs that is blind to complexity

Accredited pharmacists providing medication reviews under the HMR model are remunerated in a fixed fee for service model. This means that the pharmacist gets paid the same amount regardless of whether it was a standard or complex case. While each of the accredited pharmacists interviewed was resistant to allowing the remuneration model

to impact the time spent on their patient consultation and report writing, the impact on their willingness to follow up on resolution of medication-related issues was more variable. Some pharmacists, like Pharmacist 9, willingly offered follow up for those who needed it:

> *I'll always offer to speak to specialists, which I have done on occasion, to speak to them personally, go back and see the patient, on a kind of free service basis because I think it's important to offer that follow up.* – Pharmacist 9, Accredited/GP practice pharmacist

At the time of interviews there was no remuneration available for follow up after the initial patient assessment. Because of this, some pharmacists considered follow up outside of their scope:

> *…I don't get paid for that. And um the amount that I do get paid for the HMR, I think I work quite hard for that money. So I actually have to be quite careful not to do too much work outside of that remuneration because that's actually how I make my living.* – Pharmacist 2, Accredited pharmacist

The result of the fixed fee remuneration model results is that pharmacists must accept a lower margin or potential loss when receiving referrals for patients with higher levels of needs. To protect the ongoing viability of their business model, pharmacists who take on complex cases may self-impose limits on the number of cases they take on, as Pharmacist 5 does:

> *I don't really want to do more than 15 a month… it takes up so much time and I don't have time to do other stuff that's better paid* – Pharmacist 5, Accredited/GP practice pharmacist

9.3.3 Perception of value within a business strategy

MedsChecks are also remunerated through a fixed fee for service, paid to the community pharmacy who at the time of interview were able to claim a maximum of 10 episodes per month. But unlike HMRs, MedsChecks can be initiated without a referral from an approved service provider, enabling community pharmacies to target specific populations of need in alignment with their overall business strategy. This feature of the MedsCheck model was leveraged by Pharmacist 7, who practiced within a community pharmacy that was co-located and serviced a private hospital with an oncology unit. Within that service, MedsChecks were utilised as a method of providing oncology patients with a higher standard of care. This was pursued in spite of the fact that they were only able to claim for a proportion of these episodes, because it was recognised as an opportunity to build ongoing patient relationships through delivering higher value services:

> *In terms of oncology [MedsChecks], it makes us no money. It costs money to provide that. However if we are genuinely interested in improving, there's real value there.* – Pharmacist 7, Ambulatory HONC/Community pharmacist

Pharmacist 7 was the only community pharmacist who pursued MedsChecks as part of their business strategy and regularly offered them to people living with cancer. The other community pharmacists all described MedsChecks as rarely utilised in cancer populations.

9.4 Pharmacist relationships with other HCPs

Relationships with other HCPs constrain pharmacists in their ability to contribute to patient care. As explained in Chapter Two, Australian pharmacists do not have the authority to initiate changes to prescribed medications. Any changes in drug therapy are ultimately the prescriber's decision. HONC pharmacists and pharmacists affiliated with GP practices are aided by their acceptance as a member of the MDT, while community-based pharmacist must overcome the perception of being seen as a competitor rather than collaborator.

9.4.1 An accepted member of the MDT

HONC pharmacists are an accepted part of the cancer MDT. The strength of the professional relationships the HONC pharmacist is able to build by being part of this team is a key enabler for fulfilling the Expert role, allowing them to develop low-friction referral pathways that can be initiated by any member of the cancer MDT, not just prescribers:

> *Often the issues are brought to you kind of by the nursing staff or the doctors who see them in the clinic beforehand, before they get their chemo* – Pharmacist 10, Inpatient/ambulatory HONC pharmacist

The rapport and trust the HONC pharmacist is able to build within the cancer MDT and other hospital specialists not only enables their involvement in the patient's care, but also the acceptance of their input:

> *The ones [specialists] who are here, having built that rapport, if they can see that there might be an issue, they will either refer, so they'll often trust what I come to them with – Pharmacist 11, Ambulatory HONC pharmacist*

The only pharmacist who was regularly fulfilling PC-MMS roles for people with active cancer was Pharmacist 14 who was employed by a hospital division to provide HOMR. Like the HONC pharmacists, being part of the MDT enabled development of a locally defined model of care with low friction referral pathways, able to accept referrals from any member of the multidisciplinary team.

Several accredited pharmacists described being able to build a collaborative relationship with the GP practice more generally, enhancing their ability to contribute to patient care by being accepted as a member of the MDT:

> *I have a really good relationship, not just with the doctors but also the [GP] practice staff.* So *there have been times where in the past I may have felt like I haven't had a relationship close enough where I can just ring them up and say "hey, I'm really concerned about patient a, b, c". So I would normally just write a report and send it to them, and that's not as good as just getting them on the phone …* – Pharmacist 4, Accredited pharmacist

9.4.2 Seen as a competitor rather than collaborator

While community pharmacists may be able to identify medication-related issues by working directly with patients, often times the resolution of those issues depends on their relationship with the prescribers, as Pharmacist 6 describes:

> *Some of the things that I was able to recommend to her without the prescriber being involved, the GP and specialist, but the other things I let the GP know, and the specialist… it's been really good that the specialist and the GP have been willing to work with the patient to see things in a different light… it shows that sometimes doctors and specialists do actually take on board what pharmacists are saying, especially when it's in the interest of the patient* – Pharmacist 6, Community pharmacist

In the case of issues identified as part of a MedsCheck, resolution of issues often fits within the scope of the GP. Some community pharmacists recognise this and, like accredited pharmacists, put effort into building strong collaborative relationships, as described by Pharmacist 8:

> *…absolutely, you have to be part of the team. You know, I can't sort them out without the GP being on board and listening to my suggestions and working as a team.* – Pharmacist 8, Accredited/Community pharmacist

Building collaborative relationships with GPs can be particularly challenging for community pharmacists. Broader issues between the professional groups has resulted in a "turf war" where pharmacists are seen as a competitors rather than a collaborator in patient care, as Pharmacist 9 explains:

> *… they [GPs] see the pharmacist taking roles off the practice, and the vaccinations and pathology and things like that and they see it as pharmacists interfering as opposed to working with the GPs for the better care of the patient* – Pharmacist 9, Accredited/GP practice pharmacist

Pharmacist 7, who practised in a community pharmacy attached to a private hospital and GP clinic described how the different perceptions of community versus hospital pharmacy directly impacted their ability to efficiently resolve issues encountered in practice:

> *The scenario gets difficult when they're not a patient of the GP clinic here, because then you hit those traditional barriers of community pharmacy. And if I was to ring up and say that I was from a community pharmacy you get thrown the "oh we'll get back to you". As long as I put "hospital" in the statement of where I'm calling from there's a much more immediate response*. – Pharmacist 7, Ambulatory HONC/Community pharmacist

A similar experience was shared by Pharmacist 12 who regularly encountered GPs who were resistant to the input of pharmacists because they are perceived as "meddling" rather than an active collaborator in care:

> *If I see people in community that I know are having problems [with their medications]…I sort of know which doctors will do an HMR, which ones won't…I have personally gone to see [GPs] and handed out information and stuff, but you know, you haven't got past the receptionist, and they've said, "no the doctors don't want you meddling with their stuff" – Pharmacist 12, Accredited/community pharmacist*

Several pharmacists described how they work at overcoming these negative perceptions on the ground level, like Pharmacist 6 who purposely brings each interaction back to centre on the needs of the patient:

> *I've talked to doctors who maybe don't want to listen to the issues that we have going on after having spent time with the patient, I always point out to them that the end result and the outcome that we're looking for is that there's a benefit for the patient…*– Pharmacist 6, Community pharmacist

Other pharmacists described how MedsChecks provided an opportunity to help patients resolve issues in spite of the GP's resistance:

> *There's lots of doctors in our area that won't do it [an HMR] and then we'll offer a MedsCheck and see what we can do with that and help people*. – Pharmacist 12, Accredited/community pharmacist

9.5 Discussion: Objective 2.3

9.5.1 Describing the constraints within the system of care

This chapter has shown how the actions and behaviour of pharmacists providing MMS initiatives are influenced by constraints that exist within the system of care. One way of

describing these constraints is through terms such as external/internal, rigid/flexible, governing/enabling, and containing/connecting.

9.5.1.1 External/internal constraints

External constraints are boundary conditions that are put upon the pharmacists, such as the model of care, the allocation of departmental resources, and the patient care environment. While pharmacists may be able to provide input that shapes these conditions over time, they are generally accepted as a pre-determined aspect of day-to-day practice. Internal constraints are common behaviours that emerge from individual pharmacists in response to their conditions, such as the prioritisation of workload demonstrated by HONC pharmacists. While the precise ways in which HONC pharmacists prioritise their workload may vary between individuals, the shared conditions result in normalised behaviours such as prioritising the verification of chemotherapy ahead of other activities in order to meet service goals.

9.5.1.2 Rigid/flexible constraints

Rigid constraints are those that are resistant to change. Like external constraints, rigid constraints are boundary conditions that are put upon the pharmacist. The remuneration model for HMRs and MedsChecks is a rigid external constraint; while it is possible to change it, it must occur through the Community Pharmacy Agreement which as explained in Chapter Two, is negotiated every five years. Flexible constraints are able to change in response to local conditions. Whether or not they are able to be directly influenced by individual pharmacists depends on whether they are external or internal in nature. For example, the physical environment in which patient care occurs for HMRs (the home) is different for every patient, but the pharmacist has little direct influence on it. By contrast, an individual pharmacist is able to make independent decisions on how they build relationships with other HCPs.

9.5.1.3 Governing/enabling constraints

Governing constraints are those that govern the actions of HCPs, including the laws, professional competency standards, policies, and protocols that pharmacists are expected to abide by. While many governing constraints are universal to all pharmacists (e.g. legislation) HONC pharmacists are subject to additional governing constraints imposed by their organisations, such as the restrictions on which pharmacists are able to verify chemotherapy, or the standards for performing a medication history. Enabling constraints provide guidance but allow individual pharmacists greater autonomy in their decision-making. The HMR and MedsCheck models of care are enabling constraints, in that they set out the business rules but still allow pharmacists or business entities to define their individual practices. Accredited pharmacists are able to establish their own channels for

HMRs referrals, such as building a relationship with a GP practice, or developing their own templates for written reports. Similarly, community pharmacists are able to target customer segments for the MedsCheck program by identifying target populations of need.

9.5.1.4 Containing/connecting constraints

Containing constraints reinforce boundary conditions by providing clear demarcations of scope. The setting of care acts as a containing constraint for all pharmacists. HONC pharmacists are contained within their organisation, community pharmacists within their pharmacy premises, and accredited pharmacists by the referrals they are able to receive as part of the HMR model of care. Connecting constraints are the linkages and networks that form within the system of care. The professional relationships that pharmacists build enable them to respond to their local conditions. HONC pharmacists relationships with medical teams and other departments within the hospital, in particular the cancer MDT, enable them to create low friction referral pathways, increasing their opportunity to identify and resolve medication-related issues. Accredited pharmacists' relationships with GPs and their practices enable them to develop a more sustainable business model, increasing their ability to add value to patient care. Community pharmacists' relationships with patients enables them to create a direct channel that is not reliant on referrals, providing opportunity to offer patient care services that leverage their accessibility.

9.5.2 Understanding constraints to identify actions that can be taken

Within a system, constraints represent an opportunity for change. By manipulating constraints, we can influence the disposition of the system and the outcomes that it produces. Hence, understanding the constraints placed on the pharmacists responsible for providing MMS to Australians living with cancer is critical to identifying feasible actions that can be taken to result in improved medication experiences. To explore this further we will once again use the Cynefin Framework, illustrated in figure 38. A detailed version of the Cynefin map on which this diagram was based can be found in Appendix I.

The constraints mapped to the clear domain represent actions that can be initiated from the top-down at a policy level. Such actions are highly desirable because they enable broad scale change. But achieving change in these types of constraints requires investment of time and resources, resulting in a longer time horizon for any effects to be realised. Constraints mapped to the complicated domain represent actions that can be initiated from the top-down at an organisational level. Such actions can be expected to result in change for patients within that organisation's regional area. Initiating actions at an organisational level also requires investment of time and resources, but to a more moderate degree than system wide reform. Constraints mapped to the complex domain represent actions that can be initiated from the bottom-up at an operational level. These

actions result in localised change but offer the advantage of requiring lower investments in time and resources, resulting in a shorter time horizon to effect.

9.6 Chapter Summary

This chapter has described a range of constraints that influence the actions of pharmacists providing MMS to Australians living with cancer. Some of these constraints are imposed on pharmacists from the top-down, while others are internally derived, emerging from the bottom-up. This chapter has also explained how understanding these constraints helps to identify the feasibility of actions that can be taken within the system of care to improve medication experience. Actions to alter top-down constraints produce broad scale change but take time and resources to elicit effect. By contrast, actions that influence bottom-up constraints produce local change and can elicit effects within short time frames with limited resource requirement.

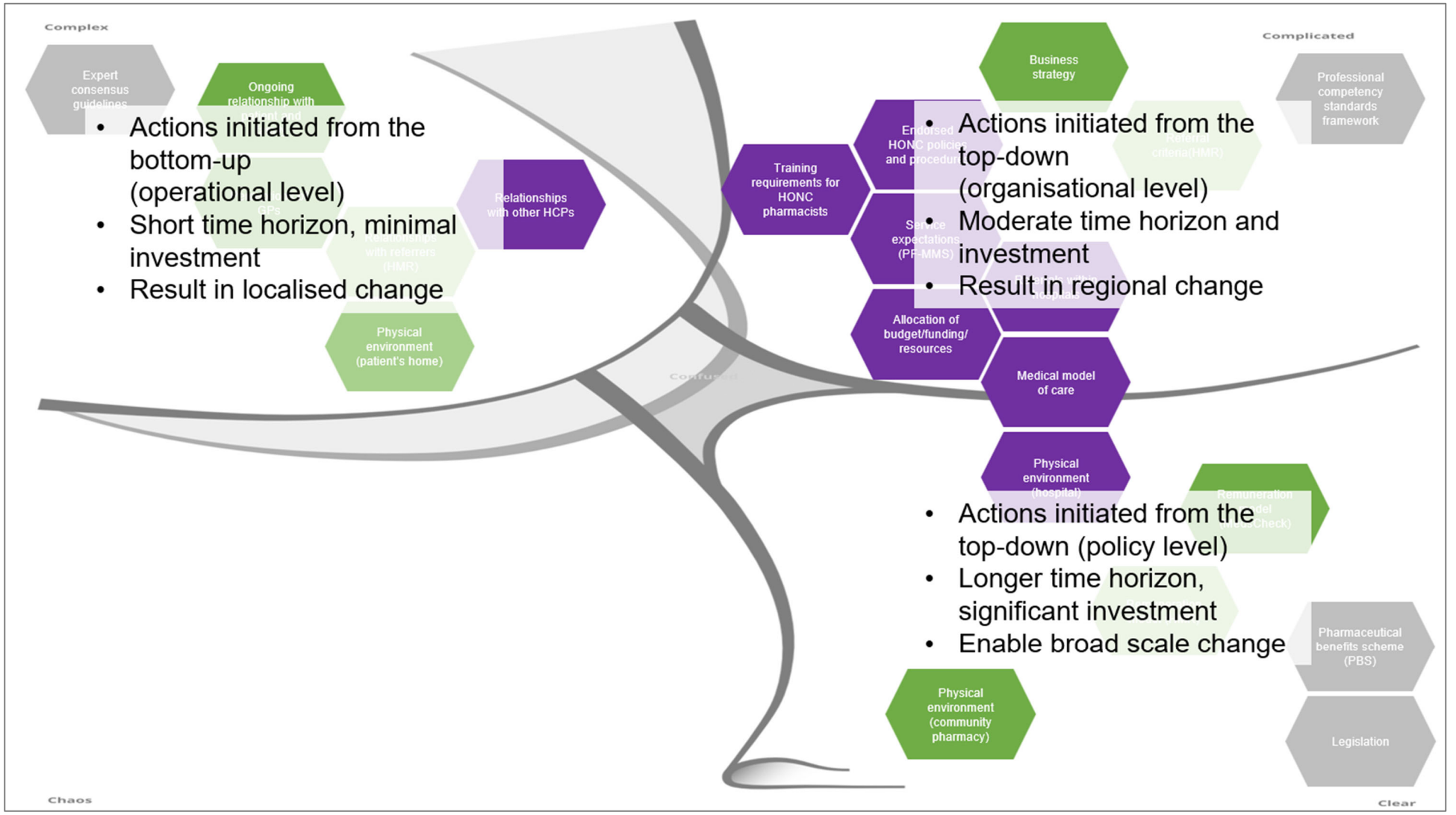


Figure 38: Feasibility of actions within the system of care

9.7 Summary of findings: Part B

The findings presented in Part B show that a variety of resourced PF-MMS and PC-MMS initiatives are available to Australians living with cancer, indicating that there is a viable industry of MMS providers within the Australian healthcare system. However, not all of these initiatives are equally accessible to the cancer population. As illustrated by Figure 44, accessibility of MMS initiatives varies according to the type of MMS provider. This research has focused on three key types of MMS provider within the industry: community pharmacists, accredited pharmacists and specialist providers (including HONC pharmacists).

Community pharmacists are accessible to patients throughout the entirety of their cancer journey, sometimes continuing their relationship with the family into the bereavement phase after the patient themselves has died. They routinely offer PF-MMS initiatives which are embedded into practice in association with the supply of prescription medications and patient-requested supply of some over the counter medicines. Community pharmacies are able to provide MedsCheck services as a MUR style PC-MMS initiative, but not all do. People who are independently using medicines throughout cancer diagnosis and treatment would qualify for a MedsCheck service, but we know from the findings presented in Chapter Nine that they are not consistently targeted as a population who could benefit from the service.

Accredited pharmacy services are also accessible to patients throughout the entirety of their cancer journey. They are able to provide comprehensive MMR style PC-MMS initiatives if initiated by a referral from an approved service provider. People who are independently using medicines throughout cancer diagnosis and treatment would qualify for the HMR program, but we know from the findings presented in Chapter Nine that accredited pharmacists do not commonly receive referrals for people who are undergoing cancer diagnosis and treatment.

Specialist providers routinely offer PF-MMS initiatives which are embedded into practice in association with the supply of medicines and movements into and out of hospital, restricting their input into patient care to later in the cancer journey after a formal cancer diagnosis has been made. PF-MMS initiatives are seen as core pharmacy services within specialist settings, where they are prioritised and formalised through policies and procedures. Specialist providers may also offer cancer-specific PC-MMS initiatives to people with a formal cancer diagnosis. As detailed in Chapter Seven, PC-MMS initiatives delivered by specialist providers tend to be MUR style interventions that offer discrete value propositions relating to a defined aspect of the patient's cancer journey, such as

adherence to oral chemotherapy or an aspect of supportive care. Specialist providers are less likely to dedicate cancer-specific resources to PC-MMS initiatives that consider the patient's broader medication management. While HONC pharmacists have the capability to offer these initiatives, as described in Chapter Nine, the high demand on a limited pool of specialist resources creates conditions of scarcity that limit their capacity to deliver PC-MMS to people living with cancer.

This chapter brings Section Two to its conclusion. As we progress to Section Three, attention is turned to the ways in which the research findings can be used to identify feasible actions that can be taken within the system of care to improve the medication experience of people who are independently using medicines throughout cancer diagnosis and treatment.

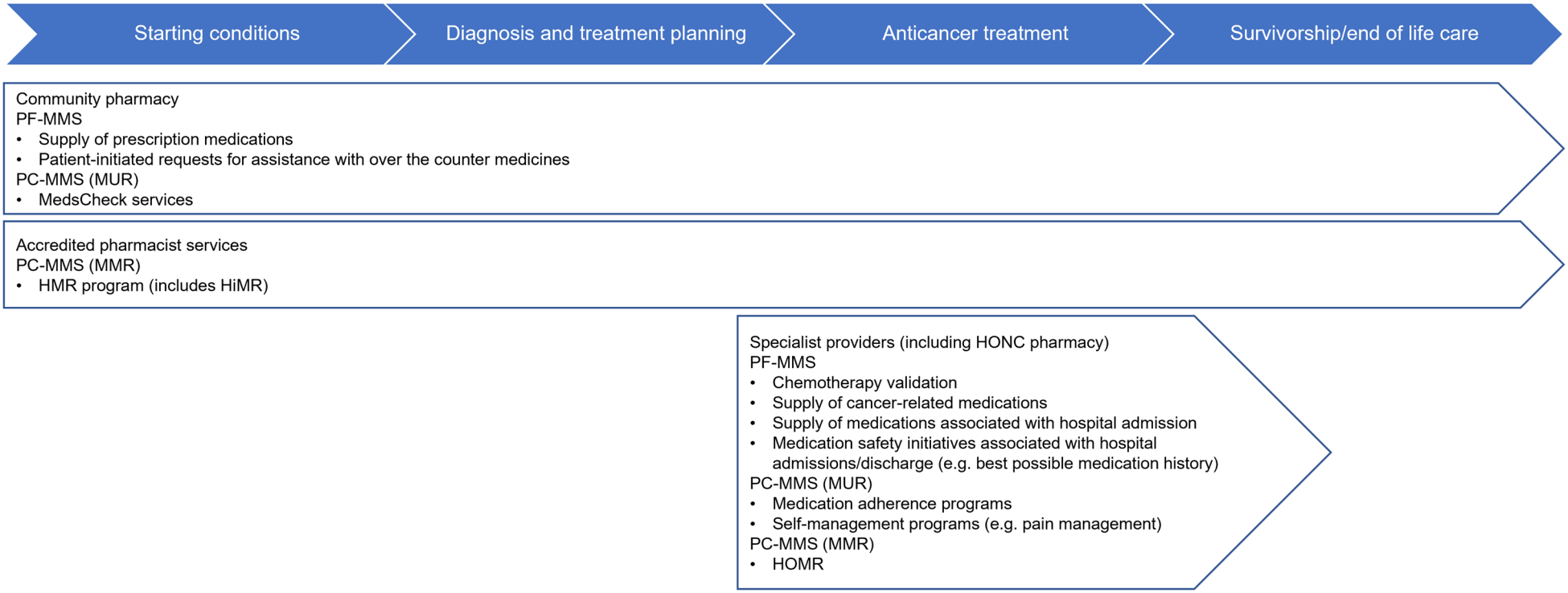


Figure 39: Accessibility of MMS providers aligned to the cancer journey

SECTION THREE – THE INSIGHTS

Section One: The Foundation	• Chapter One - Introduction • Chapter Two – Literature review • Chapter Three - Methodology

Section Two: The Findings	• Part A: The Patient World
	  • Chapter Four: Work and capacity
	  • Chapter Five: Medication-related issues
	  • Chapter Six: Tactics employed
	• Part B: The System of Care
	  • Chapter Seven: Cancer vs generic PC-MMS
	  • Chapter Eight: Roles of MMS providers
	  • Chapter Nine: Constraints on pharmacists

Section Three: The Insights	• Chapter Ten: Identifying feasible actions • Chapter Eleven: Reflection and concluding remarks

10 IDENTIFYING FEASIBLE ACTIONS

10.1 Chapter Introduction

Section Two presented and interpreted the research findings in line with the research objectives, describing how cancer diagnosis and treatment impacts the nature of reality in the patient world, and analysing the system of care that supports medication management of Australians living with cancer. The third and final section uses this knowledge to identify actionable insights. This chapter makes further sense of the research findings by looking at how they address the overarching research question: *What feasible actions can be taken within the system of care to improve the medication experiences of people who are independently using medicines throughout cancer diagnosis and treatment?*

10.2 Normative vs expressed need for PC-MMS

The research findings discussed thus far demonstrate that people with cancer can benefit from initiatives. In healthcare terms, this translates to an identifiable need for MMS (Stevens & Gillam, 1998). This research has shown that in addition to the already well recognised need for PF-MMS initiatives that reduce MRH associated with risk, people with cancer also have a need for PC-MMS initiatives that positively challenge their starting conditions and increase visibility of medication-related issues throughout the cancer journey. According to Bradshaw's taxonomy of need, this can be described as a *normative need* for PC-MMS (Bradshaw, 1972). But, as we will go on to discuss, this normative need for PC-MMS is not commonly translating to an *expressed need* for these initiatives within cancer populations.

Bradshaw defines expressed need as needs that are demonstrated when consumers take action to address their self-identified needs (Bradshaw, 1972). The research findings from Part B help us to identify if there is an expressed need for MMS amongst Australians living with cancer by understanding what MMS initiatives are available to them, and by providing an indication of how they are currently utilising these services. In the case of PF-MMS, the service funders (the Commonwealth and State Governments) can be considered the primary consumer, in that the initiatives create value for them by reducing risk. This thesis has shown there is evidence of expressed need for PF-MMS initiatives within cancer populations. As described in Chapter Two, PF-MMS initiatives are a core component NSQHS Standard Four which, as indicated in Chapter Eight has seen PF-MMS roles embedded into the system that supports the medication management of people with cancer, built into the dispensing process associated with the supply of all prescribed medicines. PF-MMS initiatives specific to the use of chemotherapy are also routinely implemented in

specialist settings, where they are prioritised as a core pharmacy service as detailed in Chapter Nine. Notably, while there is evidence of expressed need for PF-MMS, the same is not the case for PC-MMS.

This research indicates there is low utilisation of PC-MMS by people who are undergoing cancer diagnosis and treatment. In part, this could be considered a result of lack of access to PC-MMS initiatives within the specialist setting of care. As detailed in Chapter Seven, the PC-MMS initiatives offered by specialist providers tend to be MUR type initiatives that focus on specific aspects of cancer care, such as oral chemotherapy or symptom management. These initiatives are not universally available across all specialist providers, suggesting that the organisations responsible for allocating resources within specialist settings do not consider specialist PC-MMS to be a service worth prioritising. This suggests an absence of expressed need for specialist PC-MMS at the service funder level.

When we consider the Commonwealth funded PC-MMS initiatives of the HMR and MedsCheck programs, we see that they are readily available to people living with cancer throughout the entirety of their cancer journey, indicating there is an expressed need for these initiatives at the service funder level. However, this research also shows that these initiatives are not commonly utilised by the cancer population during the diagnosis and treatment phase. This suggests that patients and their referring medical practitioners (in the case of HMRs), do not accept that the value being offered by generic PC-MMS is worthy of their effort. Increasing utilisation of PC-MMS by people who are independently using medicines throughout cancer diagnosis and treatment requires more than simply resources available to deliver PC-MMS within the system of care. Consumers of these services must be willing and able to engage with them.

10.3 Actions that can be taken

In strategic management terms, this mismatch between normative and expressed need is described as a problem of product-market fit, a concept that was introduced in Chapter Two.

The concept of product-market fit is more than a useful analogy for improving the system of care, it is a practical tactic to identify insights that can bring about change. There are three ways of improving product-market fit: change the choice of market, iterate on the product or service, or refine the business model (Osterwalder et al., 2014). Changing the market (or patient population) is clearly not an option as the purpose of this thesis is to find feasible ways to improve the experience of people who are independently using medicines through cancer diagnosis and treatment. Iterating on the product or service is an option but may not

be particularly feasible in our current environment, in that it is unlikely to be an action that is able to be implemented within a short to medium term time horizon. Refining the business model of existing PC-MMS providers is feasible in that it is able to effect change within a short time horizon with limited investment of resources.

The following section will focus on the approach considered the most feasible: iterating on the business models of PC-MMS providers. To understand this more, let us revisit the concepts associated with strategic management that were introduced in Chapter Two. That Chapter described three levels of corporate decision: strategic, management and operational. Each of these will be discussed in turn.

10.3.1 Strategic level – recognising the business opportunity

Increasing uptake of generic PC-MMS requires strategic level decision makers to recognise that intentionally targeting cancer population represents viable business opportunity. Within the corporate world, strategic level decision making is concerned with attaining competitive advantage; the ways in which a business achieves better performance than the competitors within their industry, indicated by profit and market share (Porter, 1998). Competitive advantage occurs when the value created by a business for its customer is greater than what it costs to produce it, either through lowering the costs or by differentiating, providing customers with a unique offering (Porter, 1998). To a large extent this holds true within the industry of PC-MMS providers. As explained in Chapter Two, providers of generic PC-MMS (MedsCheck, HMR, HiMR) are predominantly privately operated SMEs, including community pharmacies, and accredited pharmacists acting as sole traders or attached to another small business (e.g. general practice). Increasing utilisation of MedsCheck and HMRs therefore requires private service providers to recognise that better meeting the needs of people with cancer aligns with their business strategy. While the requirement to demonstrate profit may not directly translate to publicly funded specialist PC-MMS (cancer-specific MUR, HOMR), the current fiscal environment means there is an expectation that all health services remain viable and are able to create more value than it costs to fund the services. As such, the same underlying principle applies; increasing uptake of PC-MMS initiatives amongst people with cancer requires the strategic level decision-makers within the organisations responsible for providing PC-MMS to consider these initiatives worthy of prioritising. To explore this, let us take a closer look at the key service providers that exist within the industry.

10.3.1.1 Direct to consumer (D2C) service providers

PC-MMS that can be accessed directly by a consumer (or patient) are referred to as *direct-to-consumer* businesses (D2C) (Osterwalder & Pigneur, 2010). Community pharmacies

represent a D2C provider of PC-MMS, able to provide MedsChecks directly to patients without any medical involvement. Services that include an accredited pharmacist as part of the multi-disciplinary team also effectively provide D2C services, with referrals occurring as an internal business process. This includes HMRs provided by a pharmacist associated with a general practice, HMR/HiMR provided by a pharmacist associated with a private cancer centre, and HOMR provided by pharmacists who are part of a specialist MDT.

Like all businesses, community pharmacies, general practices and specialist teams working within a larger health institution, have a target market. Within healthcare, this tends to be the population within the local geographical area. For general practices and community pharmacies who provide generalist care, a proportion of this local population will be undergoing cancer diagnosis and treatment. As has been explained, there is evidence that these patients could benefit from a MedsCheck or HMR during the early phase of their cancer journey, representing a distinct market segment that is currently under-served. The same can be said for private cancer centres who exclusively care for people who are diagnosed with cancer. Again, there is evidence that their patients could benefit from an HMR/HiMR as they progress through their cancer journey, representing a market segment who have needs that are currently going unmet. In business terms, this is an unrealised competitive advantage for who seek to compete on service rather than cost.

Providing HMRs and MedsChecks to people managing cancer and chronic conditions is not going to be seen as an attractive business proposition for providers who seek to compete on cost. As described in Chapter Nine, providing patients who have complex needs with the comprehensive care they require results in a high overhead within the current remuneration model of MedsCheck and HMR programs that provides a fixed fee for service and caps the number of services able to be claimed each month. As such, providing these services is unlikely to be profitable as a standalone activity. But for those who seek to differentiate by providing a high standard of service it is a different story. Better serving the needs of people living with cancer enables general practices, community pharmacies and specialist cancer centres to build stronger relationships with their patients. By doing so, they can make it more likely that the patient continues their relationship with the business as they progress through cancer treatment into the survivorship or end of life phase, increasing the customer lifetime value. Providing positive patient experiences also serves to improve the reputation of the business, effectively functioning as a marketing device. As such, providing generic PC-MMS throughout the early stages of the cancer journey, even at a high overhead, presents an opportunity for service-oriented general practices, community pharmacies and private cancer centres to create value for both the patient and the business.

10.3.1.2 Business-to-business (B2B) service providers

There is no doubt that many of the accredited pharmacists who are practicing independently also seek to serve the needs of their patients, but when it comes to the way their businesses are structured, their reliance on referrals for ongoing business means they are effectively functioning as a *business-to-business* (B2B) service provider. As such, to secure ongoing referrals for HMRs, the service must be perceived as creating value for the referring business, whether that be a medical practice who provides direct referrals, or a community pharmacy who acts as a broker for those referrals. In line with the previous discussion, whether increasing uptake of HMRs amongst people living with cancer will be seen as an attractive proposition will depend on the strategy of both the accredited pharmacist and the referring business. As above, the alignment with businesses pursuing a service-oriented strategy is clear, with PC-MMS providing opportunity to create value for both the referring business and the accredited pharmacists. While businesses that have a cost driven strategy may be reluctant to pursue greater uptake of PC-MMS as a D2C service, they may view outsourcing of PC-MMS as a potential value add; an opportunity to provide higher levels of service to their customers without having to absorb a substantial overhead. And for independent accredited pharmacists who seek to pursue a focused business strategy, purposefully increasing the uptake of generic PC-MMS by people living with cancer presents an opportunity to carve out a niche and build reputation and expertise in a more specialised area of practice while still leveraging Commonwealth funded service models.

10.3.2 Management level – target initiatives to specific customer segments

Increasing uptake of generic PC-MMS requires managerial decision-makers within organisations providing PC-MMS to refine business models to target value propositions toward specific customer segments. Business models form at an organisational level as a result of localised decision making. As such, they can be considered an emergent property of the system of care, emerging from the bottom-up. But while a business model is not a direct result of decisions made at a policy level, actions taken from the top-down do constrain the ways in which they can be refined.

Providers of the publicly funded PC-MMS programs that are currently available to Australians living with cancer (MedsCheck, HMR/HiMR, HOMR) operate within a *third-party funded enterprise model*[52] where the service is provided to the patient without any out-of-pocket expense and paid for by the Government. This creates constraints in several elements of the business model, which were described in Chapter Nine, including the

[52] "Products and services are paid for by a third party, which might be a donor or the public sector" (Osterwalder et al. 2014)

remuneration model and business rules that specify the key activities that must be undertaken, and which HCPs can act as approved service providers. But while providers of generic PC-MMS initiatives may be constrained in their business models, that is not to say there is not any opportunity for refinement. One method of refining a business model is to target value propositions to specific customer segments (Osterwalder & Pigneur, 2010). To explore how this could be achieved, let us consider the strengths, weaknesses, opportunities, and threats of PC-MMS initiatives offered by the three service providers that have been the focus of this research: specialist providers, accredited pharmacists and community pharmacies. Understanding these differences helps us to position these initiatives in relation to one another, as illustrated by Figure 40.

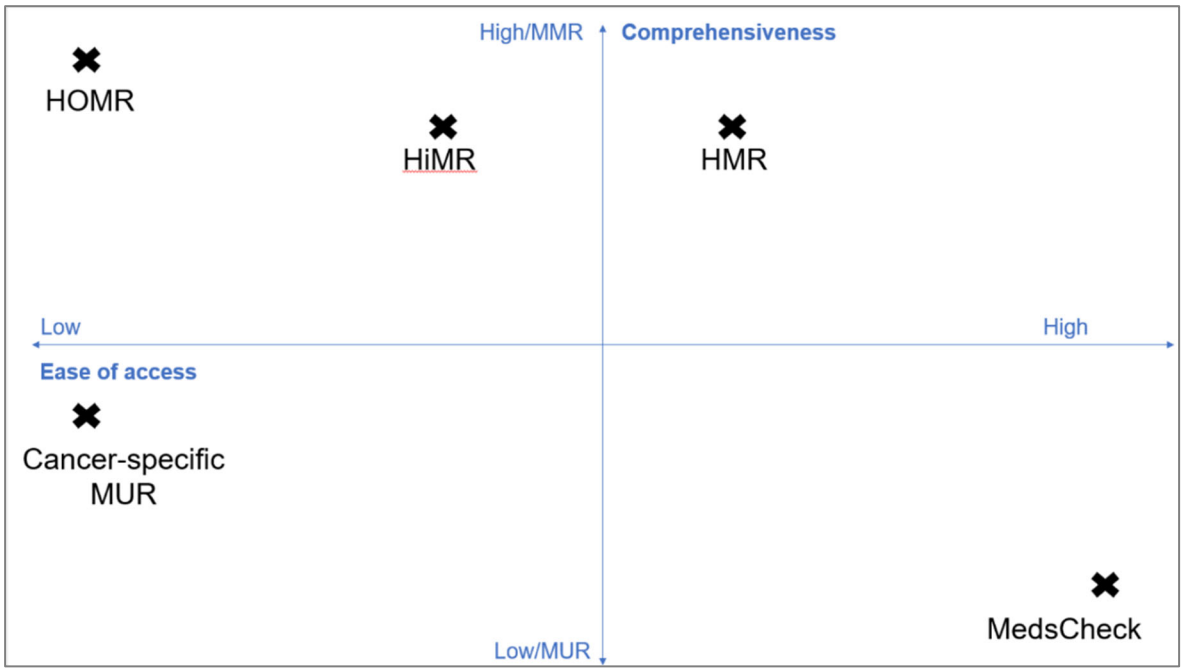


Figure 40: Positioning of existing PC-MMS initiatives

10.3.2.1 Specialist PC-MMS offer targeted value during cancer treatment

A major strength of PC-MMS initiatives offered by specialist providers (cancer-specific MURs and HOMR) is that they are delivered by an HCP who has specialist knowledge of cancer care and is part of the cancer MDT. This increases MMS providers access to relevant information and reduces the overhead associated with collaborative care. HOMRs are comprehensive MMR type initiatives undertaken by an accredited pharmacist employed by the hospital, likely an accepted member of the specialist unit's MDT (e.g. HONC, palliative care, geriatrics). As detailed in Chapter Seven, other cancer-specific MUR type initiatives tend to be less comprehensive but highly targeted, providing specific value such as improving the adherence of oral chemotherapy, or better management of the effects of cancer and its treatment. Specialist initiatives can be funded under the hospital activity-

based funding model (introduced in Chapter Two). This affords some flexibility when it comes to the model of care, allowing specialist PC-MMS providers to locally develop referral pathways and define key activities, but limits their accessibility to non-admitted patients of public hospitals. As a result, these services are not readily accessible by patients who receive cancer treatment in private hospitals which, in Australia, accounts for around half of chemotherapy same-day admissions (AIHW, 2021). Furthermore, for patients to access these services they must be under the care of a specialist team, meaning they are not accessible early in the cancer journey. An obvious threat to specialist PC-MMS initiatives relates to availability of resources. As detailed in Chapter Nine pharmacists with expertise in HONC are a scare commodity who which results in limited capacity to undertake PC-MMS initiatives. With these considerations in mind, there is an opportunity to utilise cancer-specific MUR initiatives to target patients in the treatment phase who could benefit from coaching on discrete aspects of care, while HOMR can target patients in the treatment phase who require comprehensive investigation that may be beyond the scope of generalist accredited pharmacists.

10.3.2.2 Accredited PC-MMS coach and actively investigate issues

The major strength of PC-MMS initiatives offered by accredited pharmacists (HMRs and HiMRs) is that they are Commonwealth funded initiatives that provide personalised coaching and comprehensive review of the patient's overall medication-related needs. While these initiatives are available throughout the cancer journey, there are limitations in accessibility due to the need for a referral from an approved medical practitioner. Engagement in HMRs/HiMRs therefore requires both the patient and their referring medical practitioner to recognise the value offered by the service which, as explained above, can be expected to vary depending on the providers overarching strategy. The generic nature of these services may serve as a weakness in this regard, in that it may be difficult for patients and medical practitioners to identify the benefits at a time when cancer is the primary focus of care. Restrictive remuneration models and prescribed business rules further threaten utilisation of these services in people who are managing a chronic condition in addition to cancer, due to the high overhead associated with taking on complex cases. With these considerations in mind, there is an opportunity to utilise HMRs to target patients early in their cancer journey, at a time when the GP is still coordinating the patients overall care. An early intervention HMR presents an opportunity to better prepare the patient for the journey ahead, by positively challenging their starting conditions in ways that help the patient to recognise the value of maintaining a relationship with their GP as they progress through their cancer journey. HiMR presents an opportunity to ensure patients have sufficient capacity to fulfil the work of using medicines in the home environment without consuming specialist resources

that could be better utilised elsewhere. It also presents an opportunity for private hospitals to extend their services without absorbing the cost.

10.3.2.3 Community pharmacy PC-MMS: accessible before diagnosis

The major strength of PC-MMS initiatives offered by community pharmacists (MedsChecks) is that they are Commonwealth funded initiatives that are readily accessible to the patient throughout the entirety of their cancer journey before they have received a formal cancer diagnosis. Because they do not require a referral from a medical practitioner, community pharmacies are uniquely placed to provide early intervention to patients regardless of where they are receiving care. The most obvious weakness of MedsChecks is that they are an MUR type intervention which is less comprehensive than the MMR type HMR/HiMR/HOMR, and their generic nature makes them less targeted than cancer-specific MURs. As with HMRs, the restrictive remuneration model does not adequately compensate for the overhead associated with taking on complex cases, presenting a threat to the uptake of MedsChecks in people managing a coexisting chronic condition and cancer. Community pharmacies are SMEs which must remain financially viable and as such will not dedicate resources toward MedsChecks for cancer patients and risk taking on a potential liability unless they consider it a sound business opportunity. However, unlike accredited pharmacists who have episodic relationships with the patients that are facilitated through the medical practitioner, community pharmacies have an opportunity to use MedsChecks to strengthen their ongoing relationships patients, which as discussed earlier could result in an increase in the lifetime value of that customer. With these considerations in mind, there is an opportunity to utilise MedsChecks to target patients at the earliest point in their cancer journey, when they are facing a suspected diagnosis of cancer. This presents an opportunity to provide practical support to patients at a time when they are feeling emotionally and cognitively overloaded before they have been connected to a cancer MDT. By assessing the patient's starting conditions the community pharmacy can identify simple actions that better prepare them for the journey ahead, such as the provision of a medication list, connection with the cancer council, or referral for an HMR to provide more comprehensive support. By containing a tight scope on activities undertaken in a cancer MedsCheck, community pharmacies will be able to provide improved care to patients without incurring the same overhead and financial risk.

10.3.3 Operational level – communicate value to consumers

Increasing uptake of PC-MMS in cancer populations requires operational decision-makers within organisations providing PC-MMS to effectively communicate the value offered by these initiatives so that they are willing to engage with services. The ways in which PC-MMS providers communicate this value to their customers is known as marketing.

10.3.3.1 Marketing of PC-MMS initiatives

In relation to PC-MMS, marketing encompasses all of the activities, institutions and processes that make patients and referring medical practitioners aware of the ways in which they would benefit from engaging with the service. Ethical marketing puts people first, taking an empathetic position that considers the value created from the perspective of the customer rather than the service provider (Laczniak & Murphy, 2010). Hence, to increase consumers' willingness to engage with PC-MMS, service providers must start by recognising who they are as people and the circumstances they are in.

Broadly speaking, the target consumers we are trying to engage with PC-MMS are people who have been independently using medicines to manage at least one chronic condition for some time and are now undergoing cancer diagnosis and treatment. But as we established in Section One Part A, this patient population is not a homogenous group, meaning there will be variations in how the value proposition of PC-MMS is perceived by different individuals. To identify how the value proposition can be effectively communicated to different audiences, lets break this population down into smaller sub-populations, also known as *customer segments*.

While there are many possible ways of identifying customer segments, we will focus on the segments that were identified in Section One Part A, by grouping patients according to their level of activation and baseline capacity. This type of segmentation based on how shared characteristics may give rise to common beliefs and behaviours is referred to as *psychographic* segmentation (Raj et al., 2023). Our starting point will be to consider four fictional personas that differ in terms of their level of activation and baseline capacity but have the same demographic factors of age, gender, and number of medicines. These personas, illustrated in figure 41, have intentionally been exaggerated into stereotypes for illustrative purposes. This is not to suggest that patients be reduced into four stereotyped categories in practice, it is intended as an exercise to explore how different types of people will have different perceptions of an offer to engage in a MedsCheck or HMR and therefore require a more nuanced approach. Let us start by introducing the four personas: Compliant Connie, Passive Paula, Best-intentions Betty, and Expert Edie. An informal writing style has been used to describe these personas to help facilitate a real-world perspective rather than an academic one.

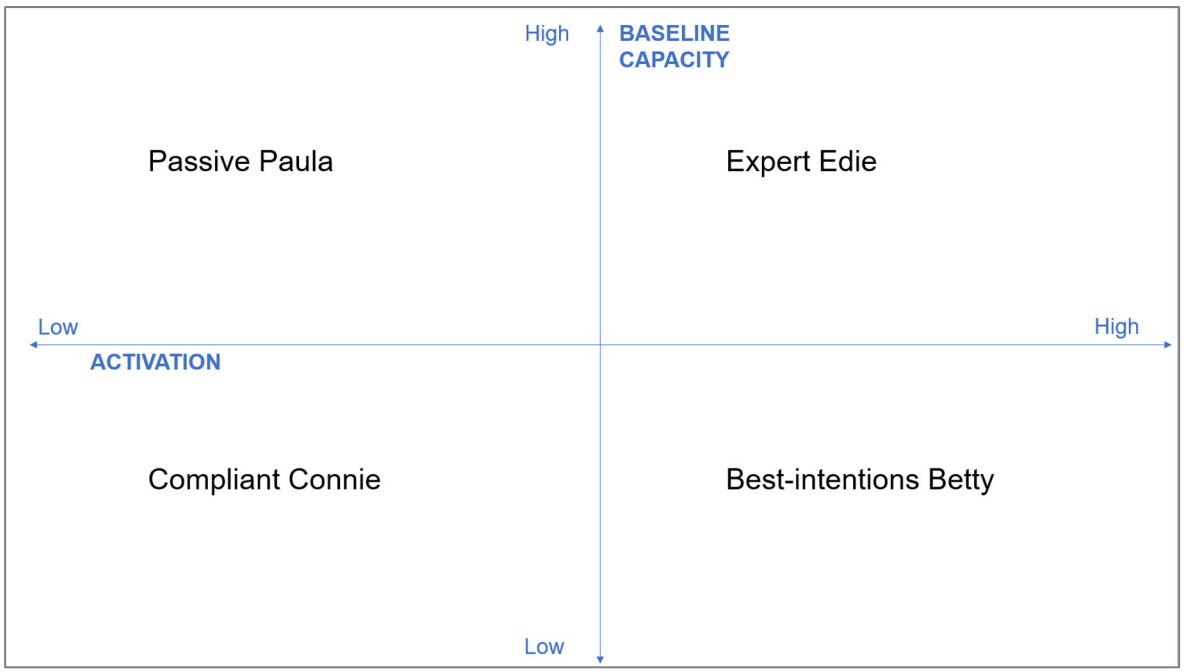


Figure 41: Personas represent distinct customer segments

Compliant Connie (65yo female, 5 medicines) – low activation, low capacity

Connie lives alone and has an elderly mother living close by in an aged care facility who she visits every Monday, Thursday, and Saturday morning without fail. Connie has a quiet lifestyle funded by her aged care pension and has been using medicines regularly since being diagnosed with diabetes five years ago. Every day feels like a struggle for Connie, but she has long accepted that as her lot in life. Connie visits her GP practice when she needs a new prescription or has a problem that won't go away. She knows doctors are busy and doesn't want to bother them if she doesn't have to. Connie gets her medicines from the discount pharmacy nearby the supermarket. She does what she's told, no questions asked.

Passive Paula (65yo female, 5 medicines) – low activation, high capacity

Paula lives with her husband Rob and has two adult children who live close by. Paula retired from working as a high school teacher five years ago after suffering a heart attack, which saw her go from zero to five prescribed medications in a matter of weeks. Since then, she has managed to stay out of hospital by following her doctor's instructions as best she can. Nowadays Paula doesn't think too much about her health, she just does what is necessary to keep things ticking over as usual, visiting her cardiologist every 6 months, and seeing her GP when she needs a prescription. Paula's been visiting the same GP for over 20 years now and has formed a good relationship with the girls at the local pharmacy over the past 5 years. Paula trusts them and is sure they'll tell her what she needs to know.

Best intentions Betty (65yo female, 5 medicines) – high activation, low capacity

Betty lives alone with her dog Charlie. Things have gotten difficult for Betty over the last few years as she's had to cope with the loss of her husband Bob while managing her own health, but she feels like she's been coping just fine thanks to her routines. Every Sunday Betty uses her medication list to pack her dosette and set things up for the week ahead, including folding the laundry and cooking up a small roast dinner for lunches in the coming days. Betty hasn't been able to find a regular GP since her longstanding doctor retired 18 months ago, but it's been hard to go outside the local area since Bob died as Betty doesn't have a driver's licence. These days if Betty has a problem, it's easier to ask Doctor Google than make a GP appointment.

Expert Edie (65yo female, 5 medicines) – high activation, high capacity

Edie has recently moved into a retirement village attached to a supported care facility after the death of her husband George. She enjoys an active lifestyle and has been enjoying the social aspects of living in a community. Since being diagnosed with rheumatoid arthritis in her forties, Edie has taken an active role in her health and likes to be in control or at the very least included in decisions that are made about her health. She credits this active involvement and her naturopath Lisa with why her arthritis has been so well controlled. Edie has a regular GP who she trusts, and a dedicated rheumatologist, but her past experiences have taught her that doctors still get things wrong at times despite their good intentions. To compensate for this, Edie takes personal responsibility for making sure her healthcare providers understand her needs and will soon set them straight if she suspects otherwise.

10.3.3.2 Effective marketing of PC-MMS treats different people differently

Now that we have got to know our four personas, let us use them to consider different groups of people may perceive a pharmacist or GP's offer of a MedsCheck or HMR differently amidst facing a cancer diagnosis. Recognising these differences enables us to better market PC-MMS to people undergoing cancer diagnosis and treatment by tailoring messages to target different customer segments. The following sections describe four generalised approaches that could be used to achieve this, illustrated in figure 42: support, engage, empower and equip.

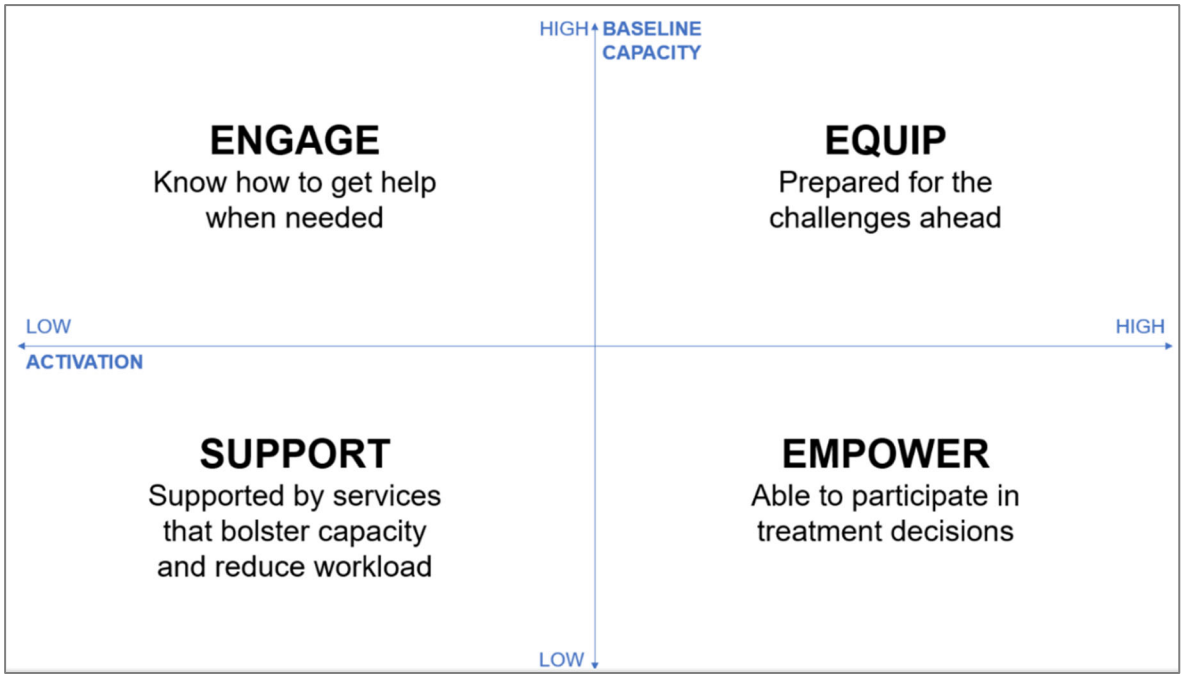


Figure 42: Marketing to target specific customer segments

Support the Compliant Connie's

Patients like Connie who have low activation and low baseline capacity are likely to be struggling before their cancer journey even begins, meaning they could benefit from the supports offered by PC-MMS. However, this may not be something that they are able to recognise or willing to admit, meaning they might not be immediately receptive to the typical marketing approach of PC-MMS that use phrases like "assist you with managing", "make sure your medicines are safe", "make sure you are taking your medicines correctly" to describe the value offered by these initiatives. But because people like Connie are compliant in nature, they will likely respond positively to recommendations made by a trusted HCP, meaning they may be accepting of an HMR initiatives that requires referral by a medical professional. This same level of trust will not necessarily extend to the community pharmacist offer of a MedsCheck, which may result in refusal. One mechanism to overcome this is to achieve a level of endorsement that legitimises the pharmacy's offer of support. A government program for cancer specific MedsCheck in the same vein as the diabetes MedsCheck could help to provide this imprimatur. Another mechanism that could be employed at a local level is to make the value of the MedsCheck more explicit to the patient. Community pharmacists seeking to engage patients with low activation and low capacity should inform patients that a cancer diagnosis is likely to make it more difficult for them to manage their medications in the weeks and months ahead. A MedsCheck helps to improve their cancer journey by making sure they are support during this difficult time by reducing the work required of them and bolstering their capacity to undertake the work.

Engage the Passive Paula's

For people like Paula who have low activation and high baseline capacity, the significance of a cancer diagnosis provides an opportunity to better engage them in their healthcare. Unlike Connie who follows doctor's recommendation without question, the Paula's of the world need to be convinced that something is relevant to warrant their investment of time. As far as their medications are concerned, people like Paula feel that they are managing quite well and are therefore reluctant to accept any offers of help or assistance. But even though people like Paula feel comfortable with keeping the status quo, they are not immune to experiencing issues as they progress in their cancer journey. Trouble may arise when a medication-related issue is encountered that cannot be appropriately managed through their usual tactics of utilising the resources that exist within their patient world, such as calling on informal support networks. It is therefore important that people like Paula are instilled with the capability and confidence of being able to access help if they need it. This could be as simple as providing them with the contact details of who to contact if they have any concerns. Offers of PC-MMS initiatives to patients with low activation and high capacity should focus on alerting patients to the challenges they may encounter in the weeks and months ahead. By engaging people like Paula early in their cancer journey and encouraging them to communicate more openly with their care team it helps to increase the visibility of medication-related issues, making it more likely that they will be appropriately responded to in a timely manner, positively impacting their medication experience.

Empower the Best-intentions Betty's

For people like Betty who have high activation and low baseline capacity, a cancer diagnosis may make them feel disempowered as their will to be involved as an active participant in the care team is constrained by their capacity to do so. The idea of accepting an offer to "help manage your medicines" is likely to make someone like Betty feel even more disempowered, an offer that is not necessarily worth accepting. Instead, offers of PC-MMS to the Betty's of the world need to enable them to maintain a sense of control and participation in their healthcare decisions. Offers of PC-MMS initiatives to patients with high activation and low capacity should focus on empowering them by directing them toward trustworthy information resources and providing opportunities to build their knowledge in a supported environment. By getting the Betty's of the world to accept offers to provide them with the types of assistance they want early in their cancer journey, it may then be possible to provide them with support in other areas of need as their journey progresses, positively impacting their medication experience.

Equip the Expert Edie's

For people like Edie who have high activation and high baseline capacity, a cancer diagnosis introduces a likelihood that they will experience acute reductions in physical and cognitive capacity as they progress in their cancer journey. As such, like Paula, it is important that people like Edie know where to seek help if and when they need it. Edie's confidence in medication management makes it unlikely that anyone would suggest someone like her participate in a PC-MMS initiative. Indeed, an offer to "assist you in managing your medicines" would not be well received by someone like Edie, who would likely find it condescending and irrelevant to their needs. But that is not to say that people like Edie would not benefit from PC-MMS. By equipping the Edie's of the world for the journey ahead of them, they can progress through their cancer diagnosis and treatment alert to the challenges they may encounter, with the knowledge of how to respond to them appropriately through effective self-management, positively impacting their medication experience.

10.3.4 Changing the environment to create favourable conditions

So far, this discussion has been concerned with the actions that can be initiated from the bottom-up to improve the uptake of generic PC-MMS in cancer populations by improving product-market fit. In this final section we will look at actions that can be taken from the top-down at the policy level, either through decision-makers within Government or by professional bodies that interact with Government and are able to influence the providers of PC-MMS. Policy-level decisions shape the environment in which providers of PC-MMS act. As such, actions of policymakers can be used to intentionally shift the disposition of the system of care to make it more likely that a provider of PC-MMS initiatives will take the actions detailed above. This concept is coherent with the principles of complexity.

As introduced in Chapter Two, a feature of complex systems is that they consist of networks of interconnected elements, where decision-making is distributed and responsive to local conditions, resulting in structures that emerge from the bottom-up. Whilst it is not possible to control the actions of local actors in a complex system, it is possible to influence their disposition. So it goes, that actions taken from the top-down cannot control the ways in which the independent SMEs that provide generic PC-MMS go about operating their businesses, but they can make it more likely they will see people with cancer as a target customer segment that is worth actively engaging with.

In this section we will discuss three policy-level actions that could enable increased uptake of MedsCheck and HMR amongst people with cancer at a broader scale. These enablers have been illustrated in figure 43: internal marketing of the value of PC-MMS in cancer,

funding of a cancer MedsCheck program that sits outside of existing service caps, and establishment of structures that support the provision of care to people with complex needs.

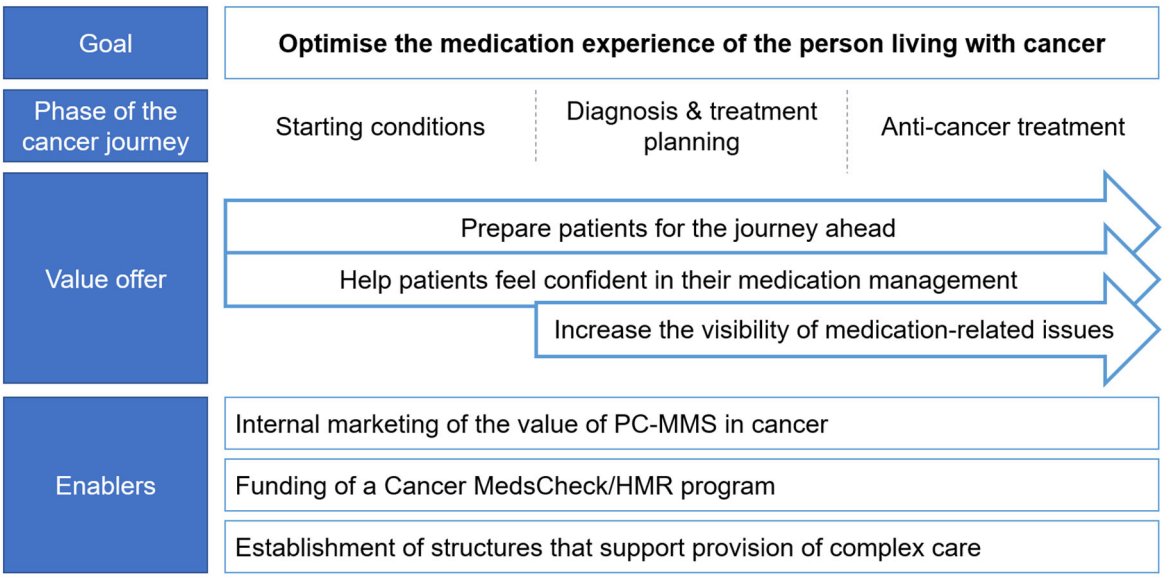


Figure 43: Optimising the medication experience of people living with cancer

10.3.4.1 Internal marketing of the value of PC-MMS in cancer

Increasing the uptake of PC-MMS in cancer populations requires an adequate supply of service providers who are willing to actively engage with this patient population despite the constraints placed upon them by the system of care. As has been discussed, providers of Commonwealth funded PC-MMS initiatives are primarily privately owned SMEs who must be able to maintain a viable business model to continue to provide services. In practical terms, this means that these independently functioning business must be convinced that actively seeking to increase uptake of PC-MMS initiatives in cancer populations will create more value for their business than it will cost. Professional associations and pharmacy banner groups can help communicate this message through internal marketing activities that make it known that providing better services to people living with cancer provides service-oriented businesses with an opportunity to better serve the needs of a currently underserved market segment. This is an action that can be undertaken with modest investment of resources, and one that could be initiated within a short time horizon.

10.3.4.2 Funding of a Cancer MedsCheck and HMR program

Establishing Cancer MedsChecks and HMR as discrete programs that fit under the broader umbrella of Commonwealth funded medication management programs could enable increased uptake of PC-MMS within cancer populations by facilitating improved supply of service providers and help to increase demand by patients and their referring medical practitioners. As explained in Chapter Two providers of MedsChecks and HMRs are

remunerated on a fixed fee for service basis, with monthly limits on the number of service episodes they can claim. These service caps are applied ubiquitously, they are not adjusted according to the needs of the service provider's patient population, nor do they take into account the provider's scope of practice. As such, there is currently no incentive for service providers to take on patients whom they perceive as having more complex needs, such as patients with cancer and coexisting chronic conditions. Setting up Cancer MedsChecks and HMRs as discrete programs that could be claimed outside of existing service caps and remunerated at an appropriate rate could help to overcome this and encourage service providers to actively pursue this currently underserved market segment.

In addition to facilitating increased supply, establishing a discrete Cancer MedsChecks and HMR program could also help to create increased demand, improving product-market fit. Centrally defining a more targeted service model could help to establish a clear value proposition that can be readily communicated to consumers. It could also allow individual service providers to enjoy the benefits of economies of scale through centralised marketing activities. The downside of a centrally defined service model is that it requires an investment of resources, either allocated within the existing the Community Pharmacy Agreement, or negotiated as part of the next agreement. This means establishing a Cancer MedsCheck and HMR program is only feasible within a longer time horizon.

10.3.4.3 Structures that enable collaboration

By creating systemic structures that facilitate the collaboration required to provide care to people with complex needs, policymakers can help to improve PC-MMS providers' willingness to offer these initiatives to the cancer population. As has been discussed, there is a high overhead associated with delivering PC-MMS to people who are managing chronic condition throughout cancer diagnosis and treatment that constrains both PC-MMS service providers and referring medical practitioners in their willingness to participate in activities of collaboration. Actions that reduce this overhead, such as the investment in information technology and infrastructure that facilitates secure interprofessional communication across boundaries of care, can help to shift this constraint and build more collaborative practice. As with the establishment of Cancer MedsCheck and HMR programs, creation of these structures requires significant investment of resources, meaning that these actions are only feasible to be implemented on a longer time horizon.

10.4 Chapter Summary

This chapter has explained how the research findings address the overarching research question, identifying feasible actions that can be taken within the system of care to improve the medication experience of people who are independently using medicines throughout cancer diagnosis and treatment. It has argued that the most feasible action to take is to make better use of the PC-MMS resources that already exist within the system of care, by increasing uptake of generic PC-MMS across the cancer population and targeting specialist PC-MMS toward those who require more comprehensive or specialist care. Increasing uptake of HMR and MedsChecks in cancer populations requires us to actively address the lack of product-market fit that exists. This can only be achieved if the privately operated SMEs that provide these services recognise this underserved market segment. Actions taken at a policy level can augment this distributed decision making by creating favourable conditions that promote the value proposition of PC-MMS in cancer and establish structures that foster collaborative practice. In the Eleventh and final Chapter of the thesis, we will close with a brief reflection on the originality of this research and its significance, both to the broader community and to myself, the researcher

11 CONCLUSION AND FINAL REMARKS

11.1 Chapter Introduction

This chapter brings the thesis to its conclusion. At this point, the argument has been made. This chapter is about reflecting on this research, it's limitations, and the original and significant contribution that it makes.

11.2 Summary of findings

This thesis contributes knowledge to reduce the vast gap in the literature that was introduced in Chapter Two by providing insight into the medication experience of people with cancer, by better understanding the MMS initiatives available to support the overall medication management of people living with cancer, and by identifying ways in which policymakers can influence the locally developed corporate constraints the shape the delivery of MMS in practice within the system of care. The findings of the three research activities have been presented and discussed throughout the thesis in relation to the two primary objectives being addressed: understanding how cancer diagnosis and treatment alters the nature of reality in the patient world, and analysing the system of care that supports the medication management of Australians living with cancer. This section provides a final summary of those findings.

11.2.1 Objective 1: Understanding how cancer diagnosis and treatment alters the nature of reality in the patient world

Chapter Four has shown how cancer diagnosis and treatment creates imbalances in workload and capacity that while difficult predict, can be anticipated at times where work associated with medicines is acutely increased, such as the peri-operative period, treatment planning and chemotherapy administration. Whether or not these imbalances result in medication-related issues appears dependent on their normalised workload, baseline capacity and level of activation, which have been described as the starting conditions. These starting conditions may serve as an asset or liability as the person progresses through their cancer journey, influencing their likelihood to experience medication-related issues and the tactics employed in response.

The types of medication-related issues encountered by people who are independently using medicines to manage a chronic condition throughout cancer diagnosis and treatment are described in Chapter Five, with the patient and pharmacist perspectives on these issues

discussed side by side. It shows that while healthcare practitioners may consider medication-related issues to be events associated with underlying drug-related risk, practical challenges of using medicines, or other multifactorial problems, they are experienced by patients as tangible or emotional events that can occur at any stage throughout the cancer journey. As such, they can easily go unnoticed by the patient unless they manifest as an episode of MRH.

Whether or not a medication-related issue results in MRH depends on the tactics employed by the patient and their care team. These tactics were examined in Chapter Six. This showed that when patients are aware that they are experiencing a medication-related issue they can expect to act pragmatically, enacting behaviours that they believe to be appropriate for the situation at hand. However, if patients are unaware they are experiencing a medication-related issue they are reliant on that issue being identified and responded to by their care team. Timely and appropriate management, and the subsequent minimisation of MRH, is therefore more likely to be achieved in situations where medication-related issues are visible, when patients are equipped to undertake active surveillance and have clear pathways for escalating their concerns.

11.2.2 Objective 2: Analysing the system of care that supports the medication management of Australians living with cancer.

There are a variety of MMS initiatives available to Australians living with cancer. In addition to the generic Commonwealth funded programs detailed in Chapter Two, specialist initiatives may also be available. The scoping review in Chapter Seven suggests that MMS initiatives developed specifically for the cancer population tend to be MUR type interventions targeted to specific aspects of cancer care such as chemotherapy or supportive care. These types of interventions alone may be insufficient to meet the pharmaceutical care needs of people who are concurrently using medicines to manage a chronic condition. For this population, cancer-specific and generic MMS programs should be considered to offer complementary value.

Adding to the argument that cancer-specific and generic MMS programs offer complementary value is Chapter Eight, which characterised five archetypal roles that MMS providers undertake within the system of care. The PF-MMS roles of Auditor, Expert and Teacher were described in relation to MMS providers practicing throughout the healthcare system, including specialist cancer settings. The PC-MMS roles of Intelligence Officer and Coach, however, were primarily described in relation to settings where MMS providers are able to build strong therapeutic relationships, such as primary care or areas of practice where continuity of care was able to be achieved (e.g. longer stay haematology admissions).

Despite having a health system in which a range of complementary MMS initiatives are available, there is a perception that people who are living with cancer are not utilising PC-MMS initiatives to the same extent as other chronic condition populations. Chapter Nine explores how the system of care could be contributing to this, describing some of the constraints that are placed upon pharmacists who provide the MMS that are available to people living with cancer. Within the hospital setting, pharmacists may be capable of providing PC-MMS once a formal cancer diagnosis has been made, but they typically lack the capacity to do so. Community pharmacists are readily accessible throughout the entirety of the cancer journey, but face constraints relating to perception of value. While accredited pharmacists possess both the capacity and capability to deliver PC-MMS but are constrained by the need for a referral and a remuneration model that is blind to complexity.

11.3 Conclusion

This thesis set out to identify feasible actions that can be taken within the system of care to improve the medication experience of Australians undergoing cancer diagnosis and treatment. What it has found is something that in hindsight seems quite obvious; there is an opportunity to improve care simply by making better use of the resources we already have. The HMR and MedsCheck programs are funded programs that are readily available to people living with cancer throughout their cancer journey. Increasing utilisation of these services early in the cancer journey can help to positively challenge the starting conditions of people living with cancer and increase the visibility of medication-related issues. By doing so we can reduce the load on specialist MMS providers as the patients progress through diagnosis and treatment, enabling specialist PC-MMS to be targeted toward those patients with specialist or complex care needs. This research offers practical understanding that can effect change within a short time horizon with minimal investment of resources. It is this practicality that gives the research its significance, allowing us to move beyond understanding of the problem to offer actionable insights. These insights have been sensitive to the perspective of those who are best positioned to take immediate actions that can effect change: the private businesses that provide HMRs and MedsChecks. By using the lens of strategic management, I have shown that taking action to better meet the needs of people living with cancer would not only result in a social good, but also represents a viable business opportunity for those providing these services. People with cancer use multiple medicines and require ongoing care from primary care providers, making them a currently underserved market segment. It is therefore in everyone’s best interest to improve this.

11.4 Final remarks

It would be remiss of me to end this thesis without acknowledging that this was not the research finding I set out to find. As explained in the opening Chapter of this thesis, the last thing on my mind when I set about undertaking this PhD was that my findings would promote the role of the pharmacist. If anything, I was actively trying to avoid any type of pro-pharmacist rhetoric. But the results are too obvious to ignore. We know that people will face challenges relating to their medications as they go through a cancer diagnosis and treatment, so why not prepare them for the journey ahead? Simple actions like providing someone with a medication list they can give to their doctors, making them aware of who to call if they face an issue, and giving them confidence to raise their concerns with their doctor could change the course of their cancer journey. These actions do not require any specialist knowledge of cancer care, they can be opportunistically undertaken by any HCP who engages with the patient in the early part of their cancer journey. But community pharmacies and general practices and specialist cancer centres have an opportunity to proactively offer this service to patients in their care. They can do this now, within their existing resources.

Undertaking this research was not without its problems, some of which were described in Chapter Three. But perhaps the biggest personal challenge has been accepting the lengthy time it has taken me to complete this thesis, which has been an ongoing battle between will, ego, and the need to accept life circumstance. There is no doubt that part of this challenge was due to my bravado in taking on qualitative research in the first place. Admittedly, I was completely naïve to the effort required for every aspect of undertaking qualitative research. But while it has been a steep learning curve that has seen me pushed far out of my comfort zone, I have no regrets. In fact, I have already tasted the fruits of this labour, able to apply the skills and knowledge I have gained through this PhD to my work in the implementation of the voluntary assisted dying legislation in South Australia. One of the risks of taking an extended time to complete a PhD is that the opportunity to make an original contribution to knowledge may disappear within your grasp as others seek to reduce the gap in literature. While it is to my advantage, I am somewhat saddened to say that the gap in the literature relating to medication experience in cancer remains as vast today as it did when I first set out on writing my literature review. The opportunities for further research in this area are broad and much needed.

When I set out to conduct this research, my primary goal was to effect change that would result in better outcomes for Australians living with cancer. I can make the argument, and as an accredited pharmacist I can implement the actions required to create change for patients within my sphere of influence. But effecting change on a broad scale requires actions of

policymaker that make this problem known, and for the SMEs that provide these services to heed the call to action. Australians living with cancer need more than promises of a better future, they require actions that will give them a better today.

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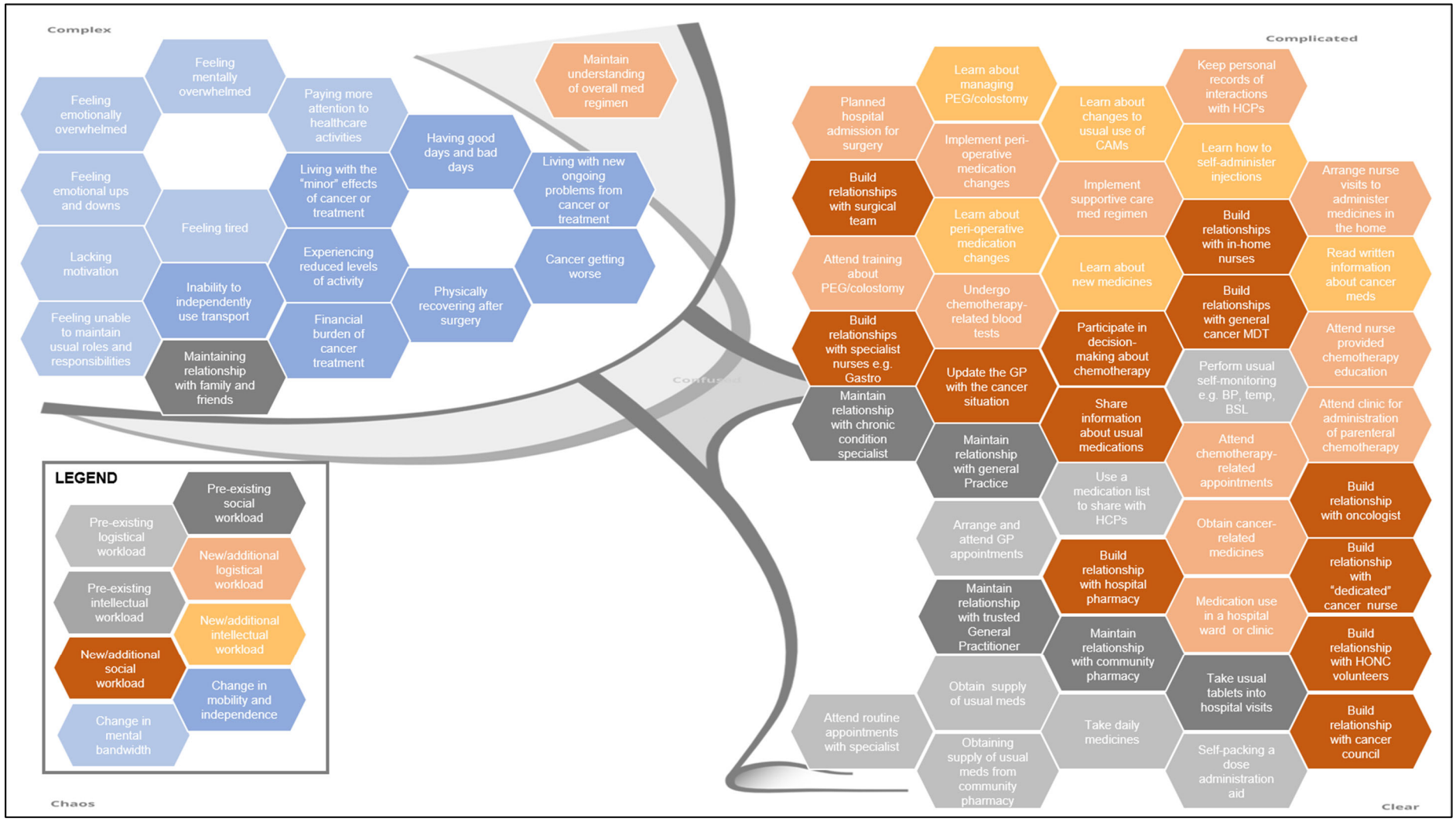
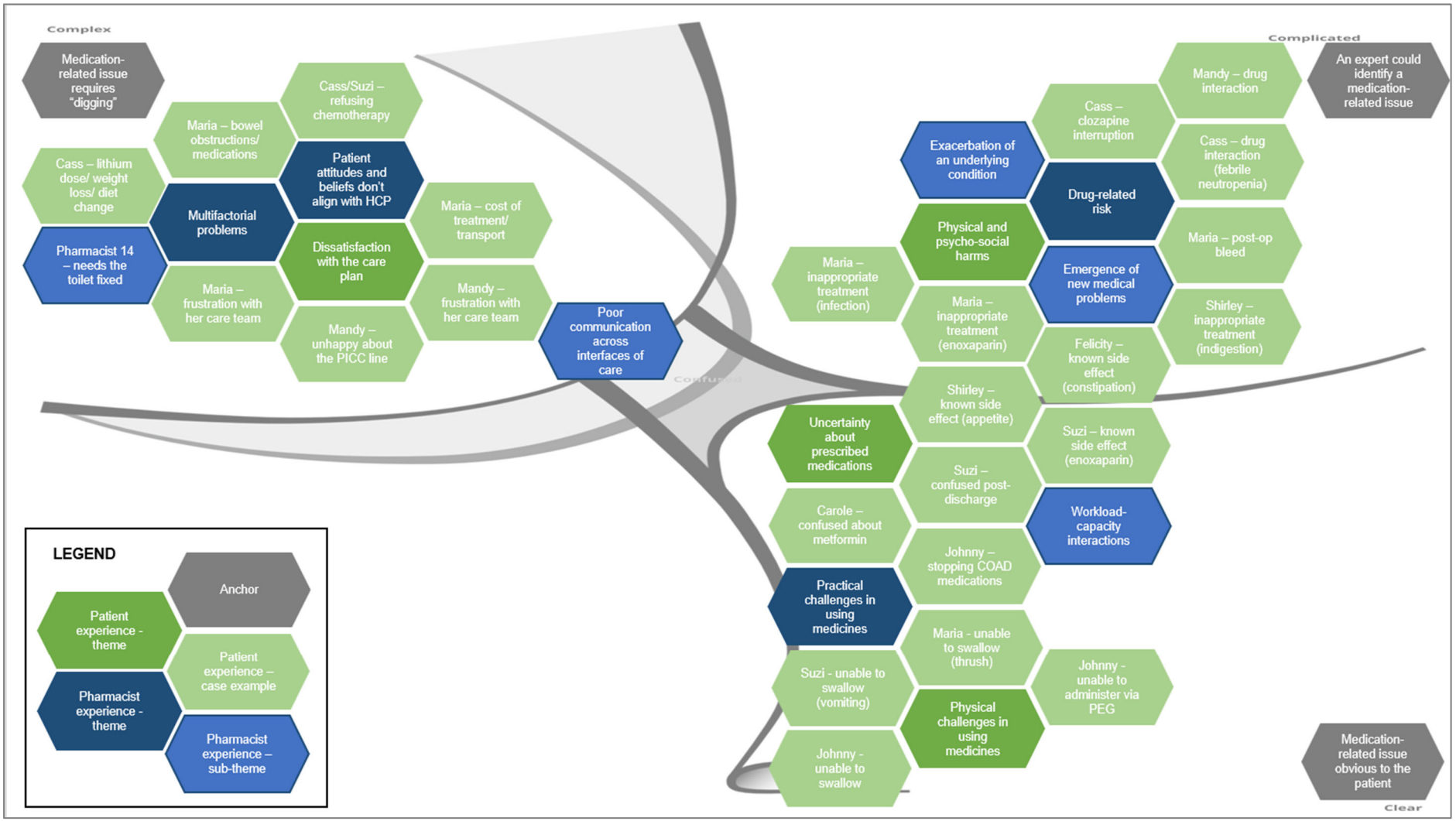
APPENDICES

Appendix I: Cynefin Maps

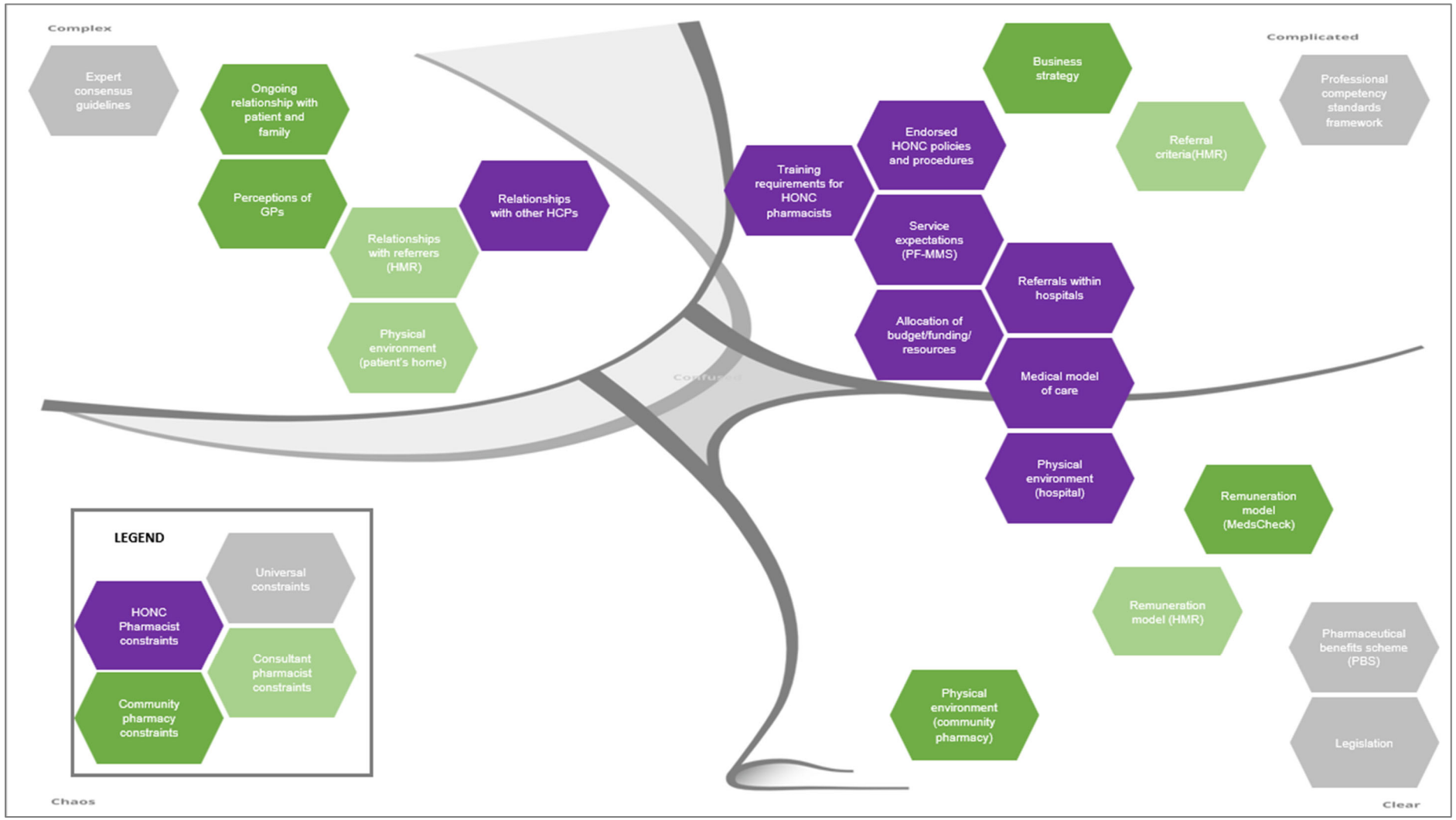
Cynefin map of the work activities, and factors influencing capacity as they exist within the patient world



Cynefin map of the types of medication-related issues encountered by participants and pharmacists



Cynefin map of constraints on Pharmacists providing MMS to people with cancer



Appendix II: Details of studies included in scoping review

Author, Year, Country, Study design	Target population (Customer Segments)	Value Proposition	Channels (Recruitment)	Customer relationship	Key Resources	Key Partnerships	Key Activities	Assessment			Care Plan						Evaluation		
								Considers all medicines?	Explores attitudes & beliefs about medicines?	Identifies DTPs?	Educates patient about medicines/condition?	Educates patient about managing side effects?	Addresses medication management skills?	Provides patient with medication list?	Communicates with other care providers to resolve DRPs?	Establishes & documents goals of therapy in care plan?	Monitors and records actual patient outcomes?	Evaluates progress in meeting goals of therapy?	Support available prn
Liekweg, 2012, Germany, NRT	Adults with a diagnosis of breast or ovarian cancer receiving chemotherapy	Improve self-management of nausea and vomiting	Indirect via six academic and community-based outpatient clinics and two primary care oncologists	Continuity in personal assistance	HONC pharmacist, written patient education resources, self-management resources	Collaborating oncologists and cancer care centres	Regular appointments with pharmacist providing pharmaceutical care. Medication systematically documented, algorithm for evidence-based antiemetic prophylaxis and treatment, patient education regarding optimal use of supportive medication, prevention and management of adverse effects. Monitored for 6 cycles	Y	U	Y	T	T	U	U	U	U	U	U	U
Read, 2007, UK, RCT	Adults receiving IV chemotherapy for breast cancer	Improve self-management of supportive care	Direct within a single medical day case unit	One-off personal assistance	HONC pharmacy technician	Participating cancer care centres	Patients attended a pharmacy technician-led outpatient clinic prior to seeing the consultant oncologist outpatient clinic, recorded a full drug history, potential drug interactions, the need for supply of support medications.	Y	U	Y	U	U	U	U	Y	N	N	N	N
Lin, 2006, Taiwan, RCT	Adults diagnosed with cancer experiencing cancer pain and currently taking oral analgesics	Improve self-management of pain	Direct, within oncology outpatient clinics of two hospitals	Continuity in personal assistance	Trained research assistant, patient education materials	Participating cancer care centres	The pain education intervention consisted of a Pain Education Booklet . The research assistant provided the pain education intervention to patients with family carers, conducted in private. Follow-up visits with research assistant at 2 and 4 weeks after the pain education to raise questions and reiterate education	N	Y	N	T	T		N	N	N	N	Y	Y
Syrjala, 2008, US, RCT	Adults with cancer diagnosis, disease-related persistent pain expected to live at least 6 months	Improve self-management of pain	Direct, within six oncology outpatient clinics	One-off personal assistance; Self-management	HONC nurses and physicians, professional support training and resources, patient education resources (print and video), self-management resources	Participating cancer care centres	Pain training consisting of watching a video, nurse assisted education with written material, 'things to tell your doctor' assessment checklist; follow up phone call after 72 hours to reinforce training	N	Y	N	T	T	N	N	Y	N	N	N	N
Koller, 2015, Germany, RCT	Adults with cancer diagnosis experiencing persistent cancer-related pain expected to live at least six months	Improve self-management of pain	Direct, within a single oncology outpatient clinics	Continuity in personal assistance	Specialist Nurse, dose administration aid, patient education materials	Participating cancer care centres	PRO-SELF© plus pain control program based on three key strategies: provision of information using academic detailing, skills building and ongoing nurse coaching. Delivered in six visits and four phone calls over ten weeks.	N	Y	N	T	T	T	N	N	Y^	Y	Y	U
Spoelstra, 2015, US, RCT	Adults prescribed oral chemotherapy for a solid tumour	Improve adherence to oral chemotherapy and improve self-management of symptoms	Direct, from a specialist pharmacy and two community cancer centres	Automated assistance; Self-management	Automated phone system, Patient education materials, self-management resources,	Participating cancer care centres	Symptom management toolkit, daily text messages and weekly texts for symptoms from an automated phone system for adherence over 8 weeks	N	N	N	G	G	Y	N	N	N	Y	Y	U
Spoelstra, 2013, US, pilot RCT	Adults prescribed oral chemotherapy for a solid tumour	Improve adherence to oral chemotherapy and improve self-management of symptoms	Direct, within a community oncology program, a private oncology practice and a comprehensive cancer centre	Automated assistance; Self-management; Continuity in personal assistance	AVR system, patient education resources, self-management resources, +/- HONC nurse	Participating cancer care centres	8 week intervention of weekly calls from Automated voice response (AVR) phone system and use of symptom management toolkit (SMT) +/- nurse strategies via phonecall to manage unresolved symptoms and/or improve adherence	N	N	N	G	G	Y	N	N	N	Y	Y	U
Hadji, 2013, Germany, RCT	Adults prescribed an aromatase inhibitor for a hormone receptor positive breast cancer	Improve adherence to oral cancer medication	Direct, within 109 breast cancer centres	Automated assistance	Written materials, low cost gift items (e.g. dose administration aid, lip care), logistics staff	Participating cancer care centres	Written educational materials: nine letters and brochures via mail in first year, monthly reminders, incentives.	N	N	N	G	U	U	N	N	N	N	N	N

Author, Year, Country, Study design	Target population (Customer Segments)	Value Proposition	Channels (Recruitment)	Customer relationship	Key Resources	Key Partnerships	Key Activities	Assessment			Care Plan							Evaluation		
								Considers all medicines?	Explores attitudes & beliefs about medicines?	Identifies DTPs?	Educates patient about medicines/condition?	Educates patient about managing side effects?	Addresses medication management skills?	Provides patient with medication list?	Communicates with other care providers to resolve DRPs?	Establishes & documents goals of therapy in care plan?	Monitors and records actual patient outcomes?	Evaluates progress in meeting goals of therapy?	Support available prn
Ziller, 2013, Germany, RCT	Adults prescribed an aromatase inhibitor for a hormone receptor positive breast cancer	Improve adherence to oral cancer medication	Direct, within a single hospital	Automated assistance; Continuity in personalised assistance	Specialist nurse, written patient education materials	Participating cancer care centres	Letter group - patients received a personalized, motivational reminder letter, informative content in combination with written educational materials at regular intervals; Telephone group - patients contacted by a study nurse at regular interviews, reminded, informed and motivated about medicines, followed up over 12 months	N	N	N	T	T	Y	N	N	N	N	Y	Y
Gebbia, 2013, Italy, NRT	Adults prescribed erlotinib for advanced non small cell lung cancer	Improve adherence to oral chemotherapy	Direct, via five oncology units	Continuity in personal assistance	Specialist HONC clinicians (unspecified), written patient education materials	Participating cancer care centres	Oral antitumor treatment monitoring program provided by HONC clinicians (unspecified). Patient and caregiver extensively informed about drug characteristics and expected side effects and received a written prescription and written instructions about management of side effects and follow up visits over 2 months	?	?	N	T	T	N	N	N	N	Y	N	Y
Kekale, 2016, Finland, RCT	Adults prescribed a tyrosine kinase inhibitor for chronic myeloid leukaemia	Improve adherence to oral chemotherapy	Direct, within eight secondary and tertiary care hospitals	One-off personal assistance; Automated assistance	HONC nurse, patient education resources (written, video, website), automated phone system	Participating cancer care centres	One-on-one education session with a nurse delivering content in audiovisual, verbal and written formats, automated daily text message reminders	N	?	N	T	T	Y	N	N	N	N	Y	Y
Schneider, 2014, US, RCT	Adults prescribed oral chemotherapy for breast, colorectal, renal cell carcinoma, hepatocellular carcinoma, multiple myeloma, chronic leukemia	Improve adherence to oral chemotherapy	Direct, from a comprehensive cancer centre and a hospital	Continuity in personal assistance	Specialist nurse, education resources, self-management support resources	Participating cancer care centres	Standard chemotherapy education plus a personalized assessment and tailored intervention plan developed by an advanced practice nurse, weekly phone calls for the first month then twice a month for 6 months or until they completed their medication	Y	P	Y	T	T	Y	U	U	Y^	Y	Y	U
Krikorian, 2019, US, RCT	Adults with a diagnosis of cancer prescribed oral chemotherapy	Improve adherence to oral chemotherapy	Direct, from a single haematology-oncology outpatient service	Continuity in personal assistance	Specialist pharmacist, patient written education material, professional support resources, self-management support resources	Participating cancer care centres	Pharmacist intervention: 30 to 40 minute counselling session, followed by 10 minute follow-up telephone call 3 to 5 days later. Follow up consultations with the pharmacist repeated at 4 weeks and 8 weeks	U	Y	N	T	T	Y	Y	N	Y^	Y	Y	U
Krolop, 2013, Germany, NRT	Adults prescribed oral capecitabine	Improve adherence to oral chemotherapy	Indirect via oncologist referral in two oncology outpatient wards and one oncology practice	Continuity in personal assistance	Specialist pharmacists, written patient education material	Collaborating oncologists and cancer care centres	Three modules of medication management. All patients received module 1 (basic pharmaceutical care) and module 2 (adverse event management). Patients identified as initially non-adherent received module 3 (adherence support). Personal follow-up at least once per cycle, up to six cycles.	Y	Y	Y	T	T	Y	U	Y	Y	Y	Y	Y
Simons, 2011, Germany, NRT	Adults prescribed oral capecitabine for breast or colorectal cancer	Improve adherence to oral chemotherapy	Indirect via oncologist referral three hospital sites (two departments of internal medicine and one department of obstetrics and gynaecology) and three ambulatory oncology practices	Continuity in personal assistance	HONC pharmacists, self-management resources, education resources	Collaborating oncologists and cancer care centres	Intensified pharmaceutical care service consisting of written and spoken information. Initial consultation included information about capecitabine and adverse event management, education about individual treatment regimen, importance of adherence, detailed medication history and written dosing schedule; contact at least once during each cycle for up to six cycles.	Y	U	Y	T	T	U	Y	Y	U	Y	Y	U
Ribed, 2016, Spain, NRT	Adults diagnosed with an onco-hematologic tumour starting oral chemotherapy	Improve safety of drug therapy, improve adherence	Direct via outpatient pharmacy within a single hospital	Continuity in personal assistance	HONC pharmacists, professional support resources, education resources	Participating cancer care centres	Three clinical interviews with pharmacist: beginning of treatment to inform patient about medication and adverse effects, medication history, schedule follow up; 1 month to detect and manage side effects, revise dose adjustments, reinforce literacy and adherence; 6 months reinforce adherence and managing long-term side effects	Y	Y	Y	T	T	Y	U	Y	U	Y	Y	U