Development and evaluation of an interactive avatar-based educational application to improve heart failure patients' knowledge and self-care behaviours

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LIST OF ABBREVIATIONS

AIHW	Australian Institute of Health and Welfare
BNP	B-type natriuretic peptide
CALD	culturally and linguistically diverse
CG	control group
CINAHL	Cumulative Index to Nursing and Allied Health Literature
DHFKS	Dutch Heart Failure Knowledge Scale
DSMP	Diabetes Self-Management Profile
ECG	electrocardiogram
EF	ejection fraction
HF	heart failure
HFmEF	heart failure mid-range ejection fraction
HFpEF	heart failure with preserved ejection fraction
HFrEF	heart failure with reduced ejection fraction
ICD	implantable cardiac defibrillator
IG	intervention group
IT	information technology
JBI	The Joanna Briggs Institute
JBI SUMARI	The Joanna Briggs Institute System for the Unified Management Assessment and Review of Information
NT–proBNP	N-terminal pro–B-type natriuretic peptide
NYHA	New York Heart Association (NYHA) functional classification
PAR	participatory action research
PC	desktop computer
PICF	Participant Information and Consent Form
PND	paroxysmal nocturnal dyspnoea
QOL	quality of life
RCT	randomised controlled trial
SAC HREC	The Southern Adelaide Clinical Human Research Ethic Committee
SCHFI	Self-Care of Heart Failure Index
US	United States
WHO	World Health Organization

SUMMARY

Background: Self-care is an essential part of heart failure (HF) management to prevent avoidable hospitalisation and achieve optimal patient outcomes. Avatar-based technologies to support patient education are an innovative approach for patients with low literacy or low health literacy, or for whom English is a second language. The use of avatar technologies for patient education has shown benefits in improving knowledge, self-care behaviours and quality of life in patients with chronic diseases.

Aims: This study aimed to develop and evaluate an interactive avatar-based application to improve knowledge and self-care of patients with HF.

Methods: The systematic review is used to examine the use of avatar-based technology in patient education, and to evaluate its effects on the knowledge and self-care behaviours of patients with chronic disease. A mixed methods design is adopted, involving participatory action research and feasibility evaluation using pre-post comparison methods.

Results: The findings of systematic review showed that avatar-based technology in patient education can have a positive effect on a wide range of healthcare outcomes. The intervention can improve knowledge, self-care behaviours and self-efficacy in patients with chronic diseases. There was limited evidence on improvement in health-related quality of life, adherence to medication and no study has evaluated its effects on readmission.

Six HF patients, two of their family members and 15 cardiovascular and information technology experts were involved in the design and development of the avatar-based education application through two cycles of development and critical reflection. After one cycle of development and critical reflection, the application was updated to improve user experience of the avatar's characteristics and the application's illustrations, presentation of information, concepts and random quizzes.

Subsequent to the application update, 13 participants (67 ± 13 years, 76.9% male) were recruited to assess the application's feasibility to improve knowledge and self-care behaviours of patients with HF. After using the application, there was a significant improvement in HF knowledge (p = 0.020),

self-care maintenance (p = 0.027) and self-care confidence p = 0.002). Self-care management did not significantly improve (p = 0.113). Overall satisfaction with the revised avatar application was high at 90%. No particular characteristics were found to correlate with improved HF knowledge and self-care behaviours.

Conclusion: An avatar-based application is feasible to improve HF knowledge and self-care behaviour. Using a participatory approach in development the application is acceptable and valuable to meet appropriate user experience and health-related outcomes.

DECLARATION

I certify that this thesis does not incorporate without acknowledgement any material previously submitted for a degree or diploma in any university, and 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.

Signed:…… ……..

Parichat Wonggom

Date:…….23 April 2019……..……

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CHAPTER 1: BACKGROUND AND SIGNIFICANCE OF THE STUDY

1.1 Chapter overview

This chapter contains an overview of the author's interest in this field and a background to the study, its significance and main purpose, its research questions, aims and objectives, and a brief description of the research approach and structure of this thesis.

1.2 Introduction

Heart failure (HF) poses an especially heavy public health burden and is a new epidemic of cardiovascular disease (Liu & Eisen 2014). It is an increasingly common and burdening illness, especially among older people, and is a major cause of mortality, morbidity and poor quality of life (QOL) worldwide (Australian Institute of Health and Welfare [AIHW] 2011; Go et al. 2013). Despite advances in the medical, pharmacological and surgical treatment of HF, outcomes remain poor with high mortality and hospitalisation (Mozaffarian et al. 2015; Yancy et al. 2013).

Self-care is a core feature of health programs to prevent exacerbation of HF (Ditewig et al. 2010; Lainscak et al. 2011). Optimal outcomes following patients with HF have been observed to result from effective self-care (Boyde et al. 2011; Ditewig et al. 2010; Fredericks et al. 2010). As a result, self-care educational interventions have been developed and evaluated to improve patients' self-care behaviours (Jaarsma et al. 2013).

This thesis presents the conceptual underpinnings for, and the development and preliminary evaluation of an intervention designed to improve knowledge and self-care behaviours of patients with HF. This chapter describes the burden of HF, the role of self-care in prevention of HF, the use of information technology (IT) in patient education and health literacy, and an avatar-based intervention that assists with patient education.

1.3 Definition of heart failure

1.3.1 Heart failure

HF is a complex clinical syndrome that results from underlying structural abnormality of the heart and cardiac dysfunction from ventricular filling or ejected blood (Atherton et al. 2018; Yancy et al. 2013). Common causes of HF include ischaemic heart disease, hypertension and idiopathic dilated cardiomyopathy (Atherton et al. 2018). These common precursors to HF result in systolic ventricular dysfunction, which is usually myocardial disease. However, there are many reasons for abnormalities of ventricular diastolic function; these abnormalities may occur in the valves, pericardium, endocardium, heart rhythm or conduction and can cause HF (McMurray et al. 2012a). The manifestation of HF has typical symptoms (e.g., breathlessness, swelling of ankles and fatigue) and signs (e.g., elevated jugular venous pressure, pulmonary crackles and displaced apex beat) (McMurray et al. 2012a). Therefore, HF is a multifaceted clinical syndrome with serious effects on health.

1.3.2 Heart failure with reduced ejection fraction or with preserved ejection fraction

The measurement of left ventricular ejection fraction has historically been used to determine HF (McMurray et al. 2012a). Ejection fraction (EF) is the percentage of blood pumped out of the right and left ventricles with each contraction which is the stroke volume divided by the end-diastolic volume (McMurray et al. 2012a). A normal EF ranges from 50% to 70% (Atherton et al. 2018; Yancy et al. 2013). Therefore, EF is considered important in the classification of patient with HF.

HF with reduced EF (HFrEF), or systolic HF, is defined as HF with clinical symptoms, with or without signs of HF, and the EF is < 50% (Atherton et al. 2018). HF with preserved ejection fraction (HFpEF), or diastolic HF, is variably classified and more difficult to define (Atherton et al. 2018; Krum et al. 2011; McMurray et al. 2012a; Yancy et al. 2013). Therefore, HFpEF is defined as HF with clinical symptoms, with or without signs of HF, and EF is ≥ 50%. In addition, the classification of HFpEF requires objective evidence of either relevant structural heart disease or diastolic dysfunction without an alternative cause (Atherton et al. 2018). In addition, the 2016 European Society of Cardiology

define HF with mid-range EF (HFmEF) as a clinical syndrome presenting with typical HF signs and/or symptoms, and the EF 40-49% (Ponikowski et al. 2016).

1.3.3 Acute and chronic heart failure

De novo acute HF, or decompensated chronic HF, is usually defined as acute HF with signs of acute pulmonary oedema resulting from increased arterial blood pressure and cardiogenic shock (Chatti et al. 2007). Acute decompensation of chronic HF usually leads to a hospital admission (McMurray et al. 2012a). The study presented in this thesis focuses on the syndrome of chronic HF, and not on aspects of acute HF. Therefore, the term 'heart failure' in this thesis refers to the chronic state of HF. Chronic HF is defined differently depending on the context. For the purpose of this project, the definition adopted for chronic HF is that used by the National Heart Foundation of Australia and Cardiac Society of Australia and New Zealand (2018, p. 1136):

> Heart failure is a **complex clinical syndrome** with **typical symptoms and signs** that generally occur on **exertion**, but can also occur at **rest** (particularly when **recumbent**). It is secondary to an **abnormality of cardiac structure or function** that **impairs the ability of the heart to fill with blood at normal pressure** or **eject blood sufficient** to fulfil the needs of the metabolising organs.

1.3.4 Heart failure classification

Table 1.1 presents the New York Heart Association's (NYHA) functional classification of HF, based on the severity of its symptoms and its limitations on physical activity (McMurray et al. 2012a), while Table 1.2 presents the American Heart Association's classification of HF on the basis of stages of HF disease (Yancy et al. 2013).

Table 1.1 New York Heart Association's functional classification of heart failure based on severity of symptoms and limitation in physical activity

Class I	No limitation of physical activity. Ordinary physical activity does not cause undue breathlessness, fatigue or palpitations.
Class II	Slight limitation of physical activity. Comfortable at rest, but ordinary physical activity results in undue breathlessness, fatigue or palpitations.
Class III	Marked limitation of physical activity. Comfortable at rest, but less than ordinary physical activity results in undue breathlessness, fatigue or palpitations.
Class IV	Unable to perform a physical activity without discomfort. Symptoms at rest can be present. If any physical activity is undertaken, discomfort is increased.

Source: McMurray et al. (2012a p. 1794).

Table 1.2 The American Heart Association's classification of stages of heart failure

Class A	No objective evidence of cardiovascular disease. No symptoms and no limitation in ordinary physical activity.
Class B	Objective evidence of minimal cardiovascular disease. Mild symptoms and slight limitation during ordinary activity. Comfortable at rest.
Class C	Objective evidence of moderately severe cardiovascular disease. Marked limitation in activity due to symptoms, even during less than ordinary activity. Comfortable only at rest.
Class D	Objective evidence of severe cardiovascular disease. Severe limitations. Symptoms are experienced symptoms even at rest.

Source: Yancy et al. (2013, p. e155).

1.4 Burden of heart failure

1.4.1 Incidence and prevalence

Over the last decade, HF has become a global pandemic affecting an estimated 26 million people worldwide (Ambrosy et al. 2014); one in five individuals have a lifetime risk of developing HF (Liu & Eisen 2014). The prevalence, incidence and mortality of HF have progressively increased over the

past 25 years (Liu & Eisen 2014), and it is predicted that its prevalence will increase 46% by 2030 (Yancy et al. 2017).

Therefore, it is useful to review some international figures. Figure 1.1 shows the prevalence of HF in the United States (US) across sex and age (Mozaffarian et al. 2015), where the disease affects from 2009 to 2012 over 5.7 million people and is increasing at a rate of 870,000 new cases per year based on data from 2005-2011. These figures are concerning given the ageing US population (Mozaffarian et al. 2015).

Image removed due to copyright restriction.

Source: From Mozaffarian et al, (2015, p.275)

Figure 1.1 Prevalence of heart failure by sex and age in the US population (National Health and Nutrition Examination Survey 2009–2012)

In Europe, the trend of increasing incidence and prevalence of HF in the older population is also evident. The incidence rises from 2.1 per 1000 among those aged 50, to 8.2 per 1000 among those aged 67; the prevalence of HF among those aged younger than 65 is 0.6 per 1000, and among those aged older than 65, this prevalence rises to 28 per 1000 (Guha & McDonagh 2013).

In Australia, 480,000 people aged 18 years or older, representing 2.1% of the adult population, are diagnosed with HF (Chan et al. 2016), and two-thirds of adults with HF (72,800) were aged 65 years and over (Australian Institute of Health and Welfare (AIHW) 2018). Moreover, there is a higher incidence of oedema and HF among female adults (n = 165,700) than in male adults (n = 109,500), particularly in female adults aged 85 years or older (National Heart Foundation of Australia 2013). Consistent with this, the Australian Health Survey in 2011-2012 revealed that the prevalence of oedema and/or HF increases according to age, with 3.9%, 8.0% and 12.2% among those aged 65–74 years, 75–84 years and over 85 years, respectively, having experienced HF (Nichols et al. 2014). This is a concern, given that the Australian population is projected to increase from 31 to 43 million people by 2056, and around 23–25% of this population will be aged 65 and older (Australian Bureau Statistics 2011).

1.4.2 Hospitalisation

In the US, HF is a leading cause of hospitalisation among adults older than 65. Annually, more than one million patients are hospitalised with a primary diagnosis of HF (Mozaffarian et al. 2015). In the decade from 2000 to 2010, the rate of hospitalisation for HF in the US has remained essentially unchanged (Figure 1.2). In 2010, the number of people hospitalised for HF was approximately 1.8 million, not including 676,000 presentations to the emergency department and 236,000 to the outpatient department for HF (Hsiao et al. 2010).

Following a diagnosis of HF, hospitalisations become reportedly common: 83% of diagnosed patients were hospitalised at least once, and 43% hospitalised at least four times after HF diagnosis (Dunlay et al. 2009). Moreover, patients hospitalised for HF are at high risk of all-cause rehospitalisation, with a readmission rate of 25% within a month of discharge from the hospital (Krumholz et al. 2009). There is a high rate of all cause readmission among patients with HF; one US study showed that readmission rates ranged from 11% to 32% for patients with HF (Epstein, Jha & Orav 2011).

Image removed due to copyright restriction.

Source: From Mozaffarian et al, (2015, p.276)

Figure 1.2 Number of hospital discharges for heart failure broken down by sex of the patient (US: 1980–2010). Hospital discharges include people discharged alive, dead or whose status is unknown.

In Australia, 1.6% of all hospitalisations (173,000 individuals) were rehospitalisations due to HF and cardiomyopathy (Atherton et al. 2018). Among the patients rehospitalised for HF and cardiomyopathy, 40% had HF and cardiomyopathy as primary diagnosis and the overall hospitalisation rates were 1.5 times higher among male relative to female patients. However, the highest rate of increase was reported for patients with HF aged 85 years or more, who are 2.4 times more likely than those aged 75–84 years to be hospitalised (Australian Institute of Health and Welfare [AIHW] 2017).

This increasing trend of hospitalisations occur alongside another trend, which is that of a steady decrease in the average duration of hospitalisations among patients with a principal diagnosis of HF or cardiomyopathy. Among those with HF or cardiomyopathy who were hospitalised for at least one night, the average length of stay decreased from 11.2 days in 1993–94, to 8.9 days in 2007–08 (AIHW 2011). In 2013, the median length of stay for such hospitalised patients for HF was 6 days in New South Wales and the Australian Capital Territory (Newton et al. 2016). Variations in patient mix,

available resources and admitting speciality could be explain some of factors that may influence on the length of stay.

1.4.3 Mortality of heart failure

Cardiovascular diseases are the number one cause of death worldwide (World Health Organization [WHO] 2014). In 2012, 17.5 million people died of cardiovascular diseases (WHO 2014). Although the likelihood of survival after a diagnosis of HF has improved over time, the death rate remains high: approximately 40–50% of people diagnosed with HF die within 5 years (Gruszczynski et al. 2010). Moreover, these patients also experience increasing rates of hospitalisation and up to 40% die within one year of the first hospitalisation (Liu & Eisen 2014).

HF is life-threatening and usually associated with poor survival (AIHW 2011; Ambrosy et al. 2014). In Australia, 4,055 deaths in 2007 had HF or cardiomyopathy as the underlying main cause, and nearly 90% of HF or cardiomyopathy deaths occurred among those aged 75 and over. Age-specific death rates were higher among males than females across all age groups, except among those aged 85 years and over (AIHW 2011); and Indigenous Australians are reported to have morbidity and mortality rates from HF that are higher than their non-Indigenous counterparts (Woods et al. 2012).

1.4.4 Health-related quality of life

HF is an important cardiovascular problem in its own right, being associated with substantial disability, impaired health-related quality of life (HRQOL) and diminished survival (Krum & Abraham 2009). HF significantly impairs HRQOL, especially in the areas of physical functioning and vitality (Heo et al. 2008; Lesman-Leegte et al. 2009). A study based on a US population, more than half of the patients diagnosed with HF reported shortness of breath, lack of energy, pain, drowsiness or dry mouth (Bekelman et al. 2007). The psychological and functional status of these patients were also found to be strongly affected (Bekelman et al. 2007; Ramos et al. 2014).

As patients with HF report experiencing a range of severe symptoms and symptom burden, target interventions have sought to decrease the frequency, severity, distress and overall symptom burden of the disease and improve HRQOL (Zambroski et al. 2005). It is important to assess the HF patient's perception of health and identify interventions to improve this perception, because women and older

patients have relatively worse perceptions of their QOL in both physical and mental domains (Ramos et al. 2014). Worse HRQOL was found to be associated with hospital admissions, and 35% of patients with HF underwent a first emergency prehospitalisation, with 17.8% of those who underwent such prehospitalisation having died by the six-month follow-up (Rodríguez-Artalejo et al. 2005).

1.4.5 Economic burden of heart failure

HF imposes a significant economic burden on Western healthcare systems that is expected to further increase in the future with an ageing population (Braunschweig, Cowie & Auricchio 2011; Cook et al. 2014). Hospitalisations comprise the largest portion of treatment costs, and HF is responsible for 1–2% of all healthcare expenditure in most Westernised economies (Braunschweig, Cowie & Auricchio 2011). According to reported analyses, the overall economic cost of HF in 2012 was estimated at U$108 billion per annum, with direct and indirect costs accounting for approximately 60% (U$65 billion) and 40% (U$43 billion) of the total cost, respectively (Cook et al. 2014).

In the US, the total cost (including indirect costs) of HF exceeded U$31 billion in 2013. Over half of this total was expended on direct medical care, with the cost for physician office visiting the clinic being U$1.8 billion (Heidenreich et al. 2013). Based on 2012 data, the total cost of HF is projected to increase almost 127% to U$70 billion by 2030 (Heidenreich et al. 2013).

In Australia, the annual cost of HF has been estimated at over A$2.7 billion, with hospital care being the largest item of expenditure (Chan et al. 2016). The development of symptoms that worsen over an extended period of time, leading to low HRQOL and declining physical ability, along with hospital admissions that often recur, are costly for health services (McMurray et al. 2012a). A significant proportion of this cost is associated with HF readmissions that can be prevented by best-practice management, including evidenced-based, multidisciplinary and patient-centred care that can lead to better health outcomes (Page et al. 2014).

1.5 Diagnosis of heart failure

1.5.1 Physical assessment

Initially, a thorough history and physical examination should be performed on the patient presenting with HF symptoms and/or signs, to identify cardiac and non-cardiac disorders. In terms of history,

the factors to assess include duration of illness, weight gain, signs and symptoms (Yancy et al. 2013). More specific signs of HF include elevated jugular venous pressure, displacement of the apical impulse, hepatojugular reflux and third heart sounds (a gallop rhythm). Additionally, typical symptoms are breathlessness, exertional dyspnoea, orthopnoea and paroxysmal nocturnal dyspnoea (PND), reduced exercise tolerance, fatigue, tiredness and ankle swelling (Atherton et al. 2018; McMurray et al. 2012a; Yancy et al. 2013).

1.5.2 Clinical investigations

Initial clinical investigation is necessary in any patient suspected of having HF (Atherton et al. 2018). The purpose of investigating for HF is to make a clinical diagnosis, determine the mechanism, identify a cause, identify exacerbating and precipitating factors, guide therapy and determine prognosis (Atherton et al. 2018; McMurray et al. 2012a; Yancy et al. 2013). A minimum investigation should involve an electrocardiogram (ECG), chest X-ray, echocardiogram, measurement of plasma electrolyte and full blood count, invasive haemodynamic monitoring, coronary arteriography and endomyocardial biopsy (Atherton et al. 2018; McMurray et al. 2012a; Yancy et al. 2013).

1.6 Management of heart failure

1.6.1 Pharmacological management of heart failure

The goals of HF treatments are to relieve symptoms and signs, prevent future hospital admissions and improve likelihood of survival (McMurray et al. 2012a; Yancy et al. 2013). Patients with HF were prescribed multiple medications based on different symptoms and signs, severity or contributing factors. The average number of totally medications HF was 8±3 per person (Custodis et al. 2016). The CHECK-HF registry in 34 Dutch HF outpatient clinics from 10,910 patients with the diagnosis of HF reported that HFrEF patients were prescribed with loop diuretics (81%), renin-angiotensin-system inhibitors (84%), beta blocker (86%), mineralocorticoid-receptor antagonists (56%), and Ivabradine (f)-channel inhibition (Brunner-La Rocca et al. 2018). ACE inhibitors and beta blocker should be used in all patients with a reduced EF (McMurray et al. 2012a; Yancy et al. 2013). With appropriate medical therapy, patients with left ventricular EF of 30% or less can reasonably expect to survive more than one year after diagnosis (Yancy et al. 2013). Additionally, diuretics for patients with HFrEF who show

evidence of fluid retention, unless contraindicated, can improve symptoms (McMurray et al. 2012a; Yancy et al. 2013).

An additional goal of HF medication therapy is to educate patients about their condition (McMurray et al. 2012a; Yancy et al. 2013). Based on electronic health records for 55,312 patients with HF reported that adherence to medication regime in HF was associated with reductions in emergency department visits, hospital admissions, length of stay, and all-cause mortality rate (Hood et al 2018). Further, the level of HF medication-associated knowledge was low and decreased from the time of hospital admission to the outpatient clinic because of the inappropriate of structured health education during hospital admission and during outpatient clinic (Custodis et al 2016). Therefore, it is important to follow medication regime or assess the patients' understanding of their medications in HF for improving health outcomes.

1.6.2 Nonpharmacological interventions for heart failure

The nonpharmacological interventions are defined as the complex strategies of managing people with HF for improving patient health outcomes and system of care (Atherton et al. 2018; McMurray et al. 2012a; Yancy et al. 2013). Patients with HF are required to have a good understanding of HF, ability to self-manage, and adhere to complex regimes including taking medications as prescribed, monitoring signs and symptoms of HF, and collaboration with a health care team (Atherton et al. 2018). Nonpharmacological interventions for HF such as a nurse-led self-management program, multidisciplinary HF diseases management programs, telemonitoring, and a multimedia educational intervention have been developed and implemented for enhancing patients in self-management and decision-making in managing their HF (Atherton et al. 2018; Boyde et al. 2018; Inglis et al. 2017; McMurray et al. 2012a; Yancy et al. 2013).

The prevention of hospitalisation is important for patients and healthcare systems. Management of HF involves preventing and detecting the disease early, slowing its progression, relieving its symptoms, minimising its exacerbations and prolonging survival (Atherton et al. 2018). In the first stage, HF may be masked by many other conditions, such as hypertension, lipid disorders, obesity, diabetes mellitus, tobacco use and known cardiotoxic agents. Therefore, these conditions should be

treated or controlled (Bibbins-Domingo et al. 2009; Yancy et al. 2013). Patients with HF should receive specific education to facilitate self-care (Atherton et al. 2018; McMurray et al. 2012a; Yancy et al. 2013), such as education in understanding how to monitor their symptoms and weight fluctuations, restrict their sodium intake, take their medication as prescribed and maintain physical activity (Atherton et al. 2018; McMurray et al. 2012a; Riegel et al. 2009c; Yancy et al. 2013). Further, exercise training and cardiac rehabilitation can be useful for improving functional capacity, HRQOL and mortality (Austin et al. 2008; Davies et al. 2010).

1.7 Self-care by patients with heart failure

Self-care is defined as a naturalistic decision-making process that is employed by people to make decisions in real situations to maintain physiological stability and to respond to symptoms when they occur (Riegel, Dickson & Faulkner 2015). Self-care in HF is a method of improving HF outcomes, and consists of self-care maintenance, self-care management and self-care confidence.

Self-care maintenance requires patients to heed the advice of healthcare providers to take medication, eat a low-sodium diet, engage in preventive behaviours and to monitor signs and symptoms. Further, self-care management requires that patients are able to recognise and evaluate symptoms, and implement and evaluate treatment (Riegel et al. 2009c).

Patients, their caregivers and families can manage and mitigate worsening of symptoms if they understand the basic principles of HF management and learn to monitor the symptoms and signs of deterioration on a daily basis (Albert 2016; Riegel, Dickson & Faulkner 2015; Srisuk et al. 2017). Regardless of whether patients are enrolled in a specific management program, it is important that they understand the importance of self-care and the availability of support from organisations (Atherton et al. 2018). In addition, patients with HF should have an awareness of the importance of self-management in basic daily functioning, such as monitoring the level of water and salt intake, as well as nutrition intake, and the importance of daily exercises (Atherton et al. 2018; Yancy et al. 2013).

Adequate patient education with special emphasis on adherence and self-care components of a management program for HFrEF and HFpEF patients (McMurray et al. 2012a), along with exercise, may improve HRQOL (Yancy et al. 2013). Interventions that focus on specific self-care behaviours may be more effective than general educational programs (Casimir et al. 2014; Ditewig et al. 2010).

1.8 Patient educations

1.8.1 Teaching self-care

Knowledge is an important influence on patient self-care behaviour. Patient education is necessary for the effective management of HF symptoms (Gruszczynski et al. 2010). Knowledge is important for developing skills, and performing routine self-care maintenance behaviours requires assistance and support, and helps patients to learn how to manage their health status (Riegel et al. 2009c). Learning and acquiring knowledge of HF symptoms is associated with improved self-care; therefore, educational interventions patients with HF should focus on skills to assess, recognise and respond to HF symptoms to improve HF self-care (Lin et al. 2016).

In addition, educating HF patients about the symptoms and signs of HF may encourage positive lifestyle changes that can lead to lowered readmission rates and reduced care costs (Atherton et al. 2018; Płotka et al. 2017). However, patients with HF are likely to encounter difficulties with integrating self-care recommendations into their lifestyle due to experience and skills, motivation, habits, cultural beliefs and values, functional abilities and cognitive abilities, confidence, support and access to care, and emotional reaction (Dickson & Riegel 2009; Harkness et al. 2015; Jaarsma et al. 2017); healthcare providers should be more understanding and acknowledge the patient's difficulties and point of view. Such educational interventions would need to apply self-care strategies in an individualised way to encourage the patient to develop the appropriate self-care skills (Harkness et al. 2015).

The goal of patient-centred self-care education is to take an individualised approach to inform and increase a patient's knowledge and self-care capabilities to achieve the following desired outcomes: improved knowledge of HF; improved self-care behaviours; improved QOL and reduced readmissions (Casimir et al. 2014). Written discharge instructions or educational material given to

the patient, family members and/or caregiver, during the hospital stay or at discharge, is an essential component of transition care (Yancy et al. 2013). Essential topics of patient education that should be covered include skills and self-care behaviours in relation to specific signs and symptoms (Boren et al. 2009; McMurray et al. 2012a).

Presently, psychosocial support through family or caregivers is key to successful self-care in patients with HF (Buck et al. 2015; Graven & Grant 2014; Sacco et al. 2014). Social support is a vital resource and used as part of their everyday coping strategies (Graven & Grant 2014; Sacco et al. 2014). Family or carers should be actively involved in treatment and care planning decisions throughout the educational processes and interventions (Cene et al. 2015; Sobanski, Jaarsma & Krajnik 2014; Stromberg 2013). Education programs for family or those who provide social support have demonstrated for improvements in HF knowledge and self-care behaviours, enhancing quality of life, and reducing readmissions (Clark et al. 2014; Srisuk et al. 2017; Wingham et al. 2015). Therefore, it is recommended that the development of more effective HF interventions should include family and carers.

In addition, a multidisciplinary approach is very important to ongoing reinforcement and continual assessment of the patient's specific needs for effective management of their care, because this approach consists of a bunding of interventions and a multidisciplinary team specialised in HF (Casimir et al. 2014). Patients with HF should receive specific education to facilitate HF self-care behaviours (Friedman et al. 2011; Riegel et al. 2009c; Yancy et al. 2013). Promotion of effective self-care, combined with optimal medical management, is critical to improving patient outcomes.

Patients should be educated about their underlying condition, beneficial lifestyle changes, the purpose and function of their medicine, possible side effects of therapy, signs of deterioration in their condition and the importance of adherence to therapy (National Heart Foundation of Australia 2013). Patient-centred education has been found to reduce HF readmissions and enhance HF–related knowledge, self-care behaviours and QOL (Ditewig et al. 2010; Fredericks et al. 2010).

A lack of knowledge of HF and self-care, especially about the importance of medical and dietary adherence (Rogers et al. 2000; Rucker-Whitaker et al. 2006), daily self-weighing (Riegel & Carlson

2002), symptom recognition (Horowitz, Rein & Leventhal 2004), help-seeking behaviour (Rodriguez et al. 2008) and a misconception about HF symptoms leading to failure to understand the relationship between disease and symptoms, were prominent factors that were found to be barriers to self-care (Eldh, Ehnfors & Ekman 2006; Horowitz, Rein & Leventhal 2004; Ming et al. 2011; Riegel & Carlson 2002; Rodriguez et al. 2008; Sheahan & Fields 2008). Moreover, many patients with HF were found to be incapable of incorporating their knowledge into their daily lives because they lack the ability to apply the practical skills they learned (Dickson & Riegel 2009; Eldh, Ehnfors & Ekman 2006; Granger et al. 2009). Regarding patients are often provided with printed informational materials they can read; however, a mismatch often exists between the reading levels of those materials and the reading skills and health literacy levels of the intended audience.

For instance, a lack of knowledge about the importance of low dietary sodium intake was found to be an independent risk factor for a hospital readmission rate of three times over 90 days in an urban setting (Kollipara et al. 2008). Further, deficient knowledge about dietary sodium is an identified pathway through which low health literacy in patients with HF leads to adverse outcomes (Kollipara et al. 2008). Important factors related to insufficient knowledge about HF included lack of symptom recognition and ways of self-care, hopelessness and psychological problems, so these resulted in limited patients' abilities for an effective self-care (Siabani, Leeder & Davidson 2013). Conversely, adequate care programs that employ effective educational methods are able to build patients' self-care skills (Siabani, Leeder & Davidson 2013).

1.8.2 Educational content for teaching self-care

The educational topics and content of HF self-management programs that should be incorporated for HF self-care are divided into four categories: (i) knowledge and self-management (diagnosis and prognosis, pathophysiology of how congestive HF affects the body, aims of treatment, management and symptoms, medication review and discussion of side effects, knowing when to access/call the general practitioner, communication with the physician, follow-up assessment or reinforcement); (ii) social interaction and support (social interaction and support, stress, depression); (iii) fluids management (sodium restriction, fluid balance, daily measurement of weight and ankle circumference, self-monitoring and compliance in relation to fluids); and (iv) diet and activity (dietary

assessment and instructions, physical activity and exercise, alcohol intake, smoking cessation) (Boren et al. 2009; Siabani, Leeder & Davidson 2013). However, multiple barriers exist that prevent optimal learning about self-care behaviours.

Additionally, educational interventions can be employed to enhance self-care behaviours by adapting the method of communicating information to address the needs of the individual patient (Dickson, Lee & Riegel 2011; Harkness et al. 2015). Based on a mixed methods study of symptom perception in 36 patients with chronic HF in US, many patients with HF (mean age 64 years) are poor at interpreting and managing HF symptoms such as fluid retention, and need high-quality social support to make appropriate decisions (Riegel et al. 2018).

1.8.3 Barriers to learning self-care

Self-identified barriers to self-care are associated with shortcomings of the self-care programs, such as unskilled health educators (Albert et al. 2002; Eldh, Ehnfors & Ekman 2006) or a gap in the knowledge of healthcare providers or misinformation in the self-care instructions (Lainscak, M. et al. 2011), the provision of instructions that are too general in situations that required specific instructions (Dickson, Deatrick & Riegel 2008), inappropriately planned educational programs (Boren et al. 2009) and lack of assessment of self-care educational programs with the short- and long term outcomes (Lainscak et al. 2011). Furthermore, multiple intrinsic barriers have been identified including impaired cognition, poor understanding of health information and inadequate health literacy (Cajita, Cajita & Han 2016; Cameron et al. 2010; Dickson, Lee & Riegel 2011; Hawkins et al. 2016). Of particular importance in improving self-care is overcoming health literacy issues in the learning process.

1.9 Health literacy

The definition of health literacy is that used by the Australian Commission on Safety and Quality in Health Care (2014, p. 10):

> Individual health literacy is the skills, knowledge, motivation and capacity of a person to access, understand, appraise and apply information to make effective decisions about health and health care and take appropriate action.

According to the eHealth literacy Lily model, there are the six literacy types including traditional literacy, information literacy, media literacy, scientific literacy, computer literacy, and health literacy

(Norman & Skinner 2006). Health literacy is the junction between general literacy, health, and health care but also can incorporate aspects of the other types of literacies to varying degrees (Kickbusch 2001). Additionally, computer literacy is essential skill to adapt to new technologies and software which both absolute and relative access to health resources (Norman & Skinner 2006). Health literacy goes beyond the narrow concept of health education and health-oriented behaviour and communication, and addresses the environmental, political and social factors that determine health (World Health Organization 2015).

A previous systematic review of the health literacy among patients with HF reported that thirty-nine per cent of patients with HF have low levels of health literacy (Cajita, Cajita, & Han 2016). Health literacy influences a patient's capacity for self-care; low levels of health literacy among patients with HF have been found to be a fundamental barrier to their effective self-care (Berkman et al. 2011; Cajita, Cajita & Han 2016; Riegel et al. 2009c). Further, worse HRQOL was also found to be associated with low levels of literacy (Macabasco-O'Connell et al. 2011). Conversely, adequate health literacy has been associated with greater knowledge about HF; therefore, inadequate health literacy entails less knowledge about HF (Cajita, Cajita & Han 2016; Chen et al. 2013; Macabasco-O'Connell et al. 2011). Patient-centred aspects of an educational intervention should consider the varying levels of literacy among different ethnic groups and hence, their specific needs for support and information (Casimir et al. 2013).

Therefore, low levels of literacy may influence the ability to acquire essential knowledge about HF and self-care skills, leading to more HF exacerbations, higher burden of symptoms, poorer QOL, increased risk of hospitalisation for ambulatory and emergency and death (Macabasco-O'Connell et al. 2011; McNaughton et al. 2013; Riegel et al. 2009c; Rodríguez-Artalejo et al. 2005; Wolf et al. 2007; Wu et al. 2013). Given the importance of self-care to improve the health outcomes associated with HF, novel approaches are required to overcome the barrier of low health literacy.

1.10 Using information technology in patient education

1.10.1 Information technology for patients with low literacy

Patient education that employs interactive technology and serious game platforms have been found to overcome low health literacy by using visual and auditory signals to promote knowledge about the disease and hence improve patient health outcomes (Annaim et al. 2015; Charlier et al. 2016).

Internet-enabled systems are adopting different technological trends and exploiting advantage of the available infrastructure to enable providers (healthcare professionals) and consumers (patients and their families) to access cutting edge technologies. Some of the trends that are driving the evolution of healthcare services are the maturity of the technology, availability of the internet, development of home health monitoring devices to remotely monitor patients' health and the acceptance of the standards and procedures to protect the patient's' privacy and confidentiality (Alaoui et al. 2003; Or, Tao & Wang 2016).

Face-to-face and online interventions have produced encouraging results in terms of behavioural change in patients (Andrade et al. 2015). Telehealth is a specific form of disease management that can help to improve the self-care abilities of patients. Sophisticated technology such as videoconferencing and telephone line transmission of information, such as weight, blood pressure and electrocardiography, have been effectively used to reduce hospitalisation and length of stays (Clarke, Shah & Sharma 2011; Inglis et al. 2015). Patients exposed to technology-enhanced practice have demonstrated benefits in HRQOL and improved self-management of chronic heart disease in the early post-discharge stage of care (Brennan et al. 2010). The internet is an extremely powerful tool for the transmission of data and knowledge, and the question is whether this technology can be used effectively to educate patients. If yes, employing the internet adds an important, new, low-cost dimension to continuing medical education of healthcare providers as well as educating patients (Dubner et al. 2007).

There are a number of educational interventions for patients with inadequate health literacy to improve their knowledge of disease and self-care. Research has found that knowledge, self-efficacy, daily weight measurements (DeWalt et al. 2006) and medication adherence (Murray et al. 2007;

Noureldin et al. 2012) can be improved by educational interventions for patients with HF who also have inadequate levels of health literacy. However, the beneficial effects of the intervention were not found to endure beyond the period of the intervention itself (Murray et al. 2007).

1.10.2 Using information technology for patients with heart failure

The quality and amount of information provided to patients and healthcare providers should be evaluated and improved, because nurses may not be properly educated in HF self-management and must be provided with the right information (Albert et al. 2002; Lainscak, M. et al. 2011). Moreover, traditional patient education strategies such as booklet, brochure and video do not support the development of self-care skills in patients with HF (Dickson & Riegel 2009).

The widespread use of information and communication technology tools and resources offers an innovative and potentially beneficial avenue for increasing levels of physical activity in patients with HF. Information and communication technologies, including internet-and mobile-based communications, social media platforms, and self-monitoring health devices, can serve as a means to broadly promote increasing levels of physical activity to improve health outcomes among the population of patients with HF (Franklin 2015). A variety of educational interventions have been developed to assist patients with HF to maintain their own health, develop self-care behaviours and decrease readmissions. A multimedia educational intervention which included watching the DVD and a one-to-one discussion with a specialist HF nurse was found to have reduced all-cause unplanned readmissions (Boyde et al. 2018).

In addition, structured telephone support and telemonitoring are effective in reducing the risk of all-cause mortality and chronic HF–related hospitalisations in patients with chronic HF. They also improve QOL, reduce costs, and facilitate evidence-based prescribing (Inglis et al. 2010; Inglis et al. 2015; Or, Tao & Wang 2016).

At present, human-like avatars are used in patient education in an attempt to improve engagement and the learning experience in chronic diseases, such as cancer, depressive disorder, diabetes mellitus, overactive bladder and cardiac disease (Andrade et al. 2015; Bedra et al. 2013; Hoffman et al. 2014; Johnson et al. 2013; Pinto et al. 2013). However, no studies have investigated the

effectiveness of avatar-based technology patient education in HF despite encouraging results in other chronic disease conditions.

1.11 The avatar-based intervention for patient education

An avatar is defined as an animation of a human or embodied conversation agent that is designed to enhance interaction in the digital environment or virtual cyberspace (Falloon 2010). Human interactions with human-like avatars identify these representations as realistic, credible, attractive, with potential for similar if not more social interactions than avatars that do not appear human-like (Nowak, Hamilton & Hammond 2009). Avatar characteristics influence the perceptions of those whom they represent in a process that is remarkably similar to the way physical bodies influence a person's perception of bodies in the real world. For example, an avatar-based intervention embedded in an online self-management program was found to improve the HRQOL and elaborate on overactive bladder symptoms in women (Andrade et al. 2015).

To date, researchers have mostly studied avatar-based applications in chronic disease, and have demonstrated that these applications have a positive impact on knowledge, self-care behaviours and self-efficacy of patients (Andrade et al. 2015; Bedra et al. 2013; Clark et al. 2015; Hoffman et al. 2014; Johnson et al. 2013; Pinto et al. 2013). However, avatar-based applications in patients with HF have not been studied to date.

1.12 Aims of this PhD project

This project aims to develop and evaluate an avatar-based educational intervention designed to improve the knowledge of patients with HF and support their self-care behaviours in relation to HF. A feasibility study is subsequently conducted to evaluate the impact of an avatar-based intervention on the following health-related outcomes:

- knowledge of HF
- self-care behaviours
- the avatar-based application satisfaction

1.12.1 Objectives

This project has three objectives:

1. critically review current evidence on interventions to improve HF patients' knowledge and self-care behaviours
2. develop an avatar-based educational application to teach HF patients self-care
3. evaluate the effectiveness of the application on patients' knowledge and self-care behaviours

1.13 Structure of this thesis

Chapter 1 focused on the significance of this research, by defining and describing HF and its health burden on the world and Australia, its diagnosis and management. It also outlined the importance of self-care and patient education for health outcomes, and the potential for technology to assist with educating patients with low literacy, low health literacy as well as patients with HF. The chapter introduced the aim of the thesis and outlined its objectives.

Chapter 2 reviews current studies on the use of avatar-based technology to educate patients and to improve their knowledge of chronic disease and self-care behaviours, and outlines a conceptual framework for self-efficacy and self-care in the context of patients with HF. This chapter will be presented in the form of a published manuscript accepted for publication. The title of the manuscript 'Effectiveness of avatar-based technology in patient education for improving chronic disease knowledge and self-care behaviour: a systematic review'.

Chapter 3 provides an overview of the research methodology, which is mixed methods and entails two phases of research. Study I, a participatory action research (PAR), developed an avatar-based application. Study II, a feasibility study, examined the effect of the developed avatar-based application on knowledge, self-care behaviour, and the avatar-based application satisfaction. In addition, this chapter also discusses the management of the study and its ethical issues.

Chapter 4 reports the findings of the study in the form of amanuscript. The title of the manuscript 'Development and feasibility testing avatar-based education application in HF'.

Chapter 5 discusses the findings and conclusions, including the limitations of the study, and identifies their implications for policy, practice and future research.

Thesis flowchart	Publications
Chapter 1 **Study Background and Significance** Why is heart failure self-care important?	
Chapter 2 **Literature Review** - What are the current research interventions to improve self-care knowledge and behaviours? - What is the best conceptual framework for the thesis?	Wonggom, P, Tongpeth, J, Newman, P, HuiYun, D & Clark, R 2016, 'Effectiveness of using avatar-based technology in patient education for the improvement of chronic disease knowledge and self-care behavior: a systematic review protocol', *JBI Database of Systematic Reviews and Implementation Reports*, vol. 14, no. 9, pp. 3-14. Wonggom, P, Kourbelis, C, Newman, P, Du, HY & Clark, RA 2019, 'Effectiveness of avatar-based technology in patient education for improving chronic disease knowledge and self-care behavior: a systematic review, *JBI Database of Systematic Reviews and Implementation Reports*, vol. 17, no. 6, pp. 1101-29.
Chapter 3 **Methodology** What research design is best suited to develop and design an app for teaching?	
Chapter 4 **Results** - How can HF and IT experts and consumer participation develop an avatar-based educational application to teach heart failure patients self-care? - What is the effectiveness of an avatar-based educational application for improving patients' knowledge and self-care behaviours?	Wonggom, P, Du, H, Burdeniuk, C, Kelman, S, Wight, J, Bellchambers, T, Nolan, P, Barry, T & Clark, RA, (submitted), 'Development and feasibility testing avatar-based education application in heart failure', *European Journal of Cardiovascular Nursing.*
Chapter 5 **Conclusions and Implications** - What are the findings and conclusions? - What are the limitations of the study? - What are the implications for policy, practices and research?	

CHAPTER 2: REVIEW OF THE LITERATURE AND CONCEPTUAL FRAMEWORKS

2.1 Chapter overview

This chapter reviews the use of avatar-based applications to improve knowledge and self-care behaviours of patients with chronic disease. A systematic review is a review that methodically integrates existing research evidence on a specific research question, using careful sampling and data collection procedures that are spelled out in advance in a protocol (Polit & Beck 2013). It is from rigorous integration of research evidence on a topic through systematic review of the research findings to date, that healthcare practice can be evidence-based.

The systematic review for this project aimed to examine the use of avatar-based technology in patient education, and to evaluate its effects on the knowledge and self-care behaviours of patients with chronic disease. Therefore, the review sought to identify current studies in this area and evidence on the effectiveness of patient education, using avatar technology, on knowledge and self-care behaviours of patients with chronic disease. The protocol employed for the systematic review has been published in *JBI Database of Systematic Reviews and Implementation Reports* in 2016 (see Appendix 1). The subsequent reported findings of the systematic review has been submitted to the same journal in June 2018 and published. The submitted findings are provided here in this chapter. Its publication details are as follows:

Wonggom, P, Kourbelis, C, Newman, P, Du, HY & Clark, RA 2019, 'Effectiveness of avatar-based technology in patient education for improving chronic disease knowledge and self-care behavior: a systematic review, *JBI Database of Systematic Reviews and Implementation Reports*, vol. 17, no. 6, pp. 1101-29, doi: 10.11124/JBISRIR-2017-003905.

Table 2.1 Status of the Manuscripts

Study and article title	Publication status*
Effectiveness of using avatar-based technology in patient education for the improvement of chronic disease knowledge and self-care behaviour: a systematic review protocol	Published
Effectiveness of avatar-based technology in patient education for improving chronic disease knowledge and self-care behavior: a systematic review	Published

Note: *Status as at 17 July 2019

Wonggom, P, Kourbelis, C, Newman, P, Du, HY & Clark, RA 2019, 'Effectiveness of avatar-based technology in patient education for improving chronic disease knowledge and self-care behavior: a systematic review, *JBI Database of Systematic Reviews and Implementation Reports*, vol. 17, no. 6, pp. 1101-29, doi: 10.11124/JBISRIR-2017-003905.

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Authorship and Guarantor

Effectiveness of avatar-based technology in patient education for improving chronic disease knowledge and self-care behavior: a systematic review

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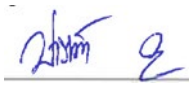

Signed April 23 2019

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2.2 Effectiveness of avatar-based technology in patient education for improving chronic disease knowledge and self-care behavior: a systematic review

2.2.1 Abstract

Objective: To examine the effectiveness of patient education, using avatar technology, on knowledge and self-care behaviours of patients with chronic disease.

Introduction: Chronic disease is a major problem worldwide. Patients with chronic disease who engage in self-care and self-management of their illnesses have better health outcomes, fewer hospitalisations and complications. Presently, information and communication technologies are used to support self-care and to improve health outcomes. Within this body of literature, research into avatar technology for patient education is growing rapidly. Evidence to date has not been systematically reviewed to determine the effectiveness of patient education, using avatar technology, on patients' knowledge and self-care behaviours in relation to their chronic disease.

Inclusion criteria: This review included studies on children and adults who received avatar-based patient education intervention. The comparator included usual care or other forms of programs. The identified outcomes were knowledge; self-care behaviour; self-efficacy; HRQOL; readmission and medication adherence. Eligible experimental designs included randomised and non-randomised control trials, quasi-experimental, prospective and retrospective, and before and after studies.

Methods: Seven databases (Medline, CINAHL, PsycINFO, Cochrane Central Trials Register of Controlled Trials, ProQuest, Web of Science, Scopus) and three other trial registries (World Health Organization, Clinicaltrials.gov and Australian New Zealand Clinical Trials Registry) were systematically searched for studies published between January 2005 and March 2017. Papers selected for retrieval were assessed by two independent reviewers for methodological validity prior to inclusion in the review, using the standardised critical appraisal instrument from the Joanna Briggs Institute System for the Unified Management Assessment and Review of Information (JBI SUMARI). Data were extracted from selected papers, including specific details about the interventions, populations, study methods and outcomes relevant to the review question and specific objectives, using the standardised data extraction tool from JBI SUMARI. Due to the heterogeneity of the studies

selected for inclusion, statistical pooling and meta-analysis was not possible. Results were tabulated and data were narratively synthesised.

Results: Nine publications from eight studies were included in this review (n = 752). Three of the eight studies were randomised controlled trials and five were non-randomised experimental studies. The overall quality of the included studies was moderate; there was low risk of bias in the randomised controlled studies and moderate risk of bias in the quasi-experimental studies. Four of the eight studies showed that patients who participated in avatar-based education demonstrated a statically significant improvement in knowledge ($p < 0.05$). Three studies showed improvement in self-care behaviours and self-efficacy. Three of the eight studies examined health-related quality of life and adherence to medication, but the results were not statistically significant ($p > 0.05$). Of the eight studies identified for inclusion in the review, none investigated the effectiveness of avatar-based patient education on reduced rate of readmission.

Conclusions: Avatar-based technology in patient education can have a positive effect on a wide range of healthcare outcomes. The intervention can improve knowledge, self-care behaviours and self-efficacy in patients with chronic diseases. There was limited evidence on improvement in health-related quality of life, adherence to medication and no study has evaluated its effects on readmission.

Keywords: avatar; chronic disease; knowledge; patient education; self-care behaviours

2.3 Summary of findings

Avatar-based patient education intervention compared to usual care or other interventions for chronic disease

Patient or population: Chronic disease

Setting: Hospital or community

Intervention: Avatar-based patient education intervention

Comparison: Usual care or others

Outcomes	Anticipated absolute effects (95% CI)		Relative effect (95% CI)	№ of participants (studies)	Certainty of evidence (GRADE)^	Comments
	Risk with usual care or others	**Risk with avatar-based patient education intervention**				
Knowledge assessed with: investigator-developed instrument, Diabetes Knowledge Instrument, the modified HF knowledge questionnaire, PedCarbQuiz. **Follow-up period:** 1 to 6 months	2 RCTs demonstrated statistically significant benefits from the intervention. 2 pre-post studies suggested a benefit from the intervention on disease-related knowledge.			622 (2 RCTs, 4 pre-post studies)	⨁⨁⨁◯ MODERATE [a]	
Self-care behaviours assessed with: the Summary of Diabetes Self-care Activities, Self-Care Heart Failure Index, Diabetes Self-Management Profile questionnaire **Follow-up period:** 1 to 6 months	2 pre-post studies suggested benefits from the intervention on self-care behaviour, including improved physical activity and foot care behaviour.			119 (4 pre-post studies)	⨁◯◯◯ VERY LOW [a,b,c]	
Self-efficacy assessed with: the Self-efficacy Scale, cognitive interview, the Diabetes Empowerment Scale–Short Form **Follow-up period:** 1 to 6 months	1 RCT demonstrated statistically significant benefits; 2 pre-post studies showed the intervention improved participants' self-efficacy in stoma care and diabetes self-care.			499 (2 RCTs, 2 pre-post studies)	⨁⨁⨁◯ MODERATE [a]	1 RCT compared a virtual-world educational intervention with a face-to-face intervention; both groups showed significant improvements in self-efficacy at follow-up.
Health-related quality of life (HRQOL) assessed with: EuroQol:EQ-5D, Pediatric Quality of Life Scale, SF-12 **Follow-up period:** 1 to 6 months	All 3 RCTs suggested the intervention had no benefits for HRQOL.			618 (3 RCTs)	⨁⨁◯◯ LOW [a,c]	Different questionnaires were used, including generic QOL questionnaire and HRQOL questionnaire.
Readmission: not assessed	–		–	–	–	

Avatar-based patient education intervention compared to usual care or other interventions for chronic disease

Patient or population: Chronic disease

Setting: Hospital or community

Intervention: Avatar-based patient education intervention

Comparison: Usual care or others

Outcomes	Anticipated absolute effects (95% CI)		Relative effect (95% CI)	№ of participants (studies)	Certainty of evidence (GRADE)^	Comments
	Risk with usual care or others	**Risk with avatar-based patient education intervention**				
Adherence to medication assessed with: investigator-developed instrument, the Chronic Disease Compliance Instrument; Medication Adherence Scale; Medication Event Monitoring System **Follow-up period:** 1 to 6 months	1 RCT demonstrated statistically nonsignificant benefits from the intervention for diuretic medication adherence; 2 RCTs suggested no benefit for adherence to medication.			618 (3 RCTs)	⨁⨁⨁◯ MODERATE [c]	

*__The risk in the intervention group__ (and its 95% confidence interval) is based on the assumed risk in the comparison group and the **relative effect** of the intervention (and its 95% CI). **CI:** confidence interval

^ **GRADE Working Group grades of evidence**

High certainty: We are very confident that the true effect lies close to that of the estimate of the effect

Moderate certainty: We are moderately confident in the effect estimate: The true effect is likely to be close to the estimate of the effect, but there is a possibility that it is substantially different

Low certainty: Our confidence in the effect estimate is limited: The true effect may be substantially different from the estimate of the effect

Very low certainty: We have very little confidence in the effect estimate: The true effect is likely to be substantially different from the estimate of effect

[a] The heterogeneity of populations, interventions and comparators affecting the inconsistency of the results.

[b] All single-group pre-post studies with no comparators.

[c] Estimate of effects are not precise. Narrative synthesis was performed.

2.4 Introduction

Chronic disease is a major problem worldwide. There are four main types of chronic disease: cardiovascular disease (myocardial infarction and cerebrovascular events), cancer, chronic respiratory disease (chronic obstructed pulmonary disease and asthma) and diabetes (WHO 2014). Annually, 38 million people die from a chronic disease (WHO 2014). From 2011 to 2025, the financial burden of chronic disease is expected to increase from US$12 billion to US$7 trillion (WHO 2014). In addition, between 10 and 50% of hospitalisations due to chronic diseases are potentially preventable (Kanel & Vrbin 2010).

Patients can play an integral role in the management of their chronic diseases (Janevic et al. 2011; The Center for Managing Chronic Disease 2015). Self-care is the process of maintaining health through health-promoting practices in both healthy and ill states, including self-care maintenance, self-care monitoring and self-care management (Riegel, Jaarsma & Strömberg 2012). Patients with chronic disease who engage in self-care and self-management of their illnesses have better health outcomes, fewer hospitalisations and complications (Van Hecke et al. 2017). Patients can limit worsening of symptoms when they understand the principles of chronic disease management and learn to undertake simple interventions (Dickson et al. 2013; Kennedy, Rogers & Bower 2007).

The ability of the patient to control his/her illness through an effective therapeutic plan is significantly influenced by social and behavioural factors (Clark, Gong & Kaciroti 2014; Riegel, Jaarsma & Strömberg 2012). However, impaired cognition, poor understanding of health information and illiteracy often prevent effective self-care behaviours (Cameron et al. 2010; Vaughan Dickson, Lee & Riegel 2011).

A key predictor of successful behavioural change is self-efficacy, which is the confidence in one's ability to carry out self-monitoring and to implement appropriate actions to care for oneself. Bandura's conceptual framework of self-efficacy is often referenced to describe the relationship between self-confidence and the development of self-care behaviours (Bandura 1977).

The concept of self-efficacy has been adopted in chronic disease management in an attempt to educate and change habits. Self-efficacy is a powerful predictor of self-care performance (Martin

2007). According to Bandura, there are three factors of human interaction that influence self-efficacy: behavioural, personal and environmental factors (Bandura 1977). If patients have higher self-efficacy, they will be more likely to display self-care behaviours (Frost et al. 2015; Jongen et al. 2015). With chronic disease, this means that not only will they adhere to treatment recommendations, they will also maintain these behaviours.

A number of chronic disease education programs are based on Bandura's theory that self-efficacy improves knowledge, self-care skills, QOL and psychological health (Farrell, Wicks & Martin 2004; Hughes et al. 2015; Kim et al. 2015). Self-efficacy may also influence how individuals with chronic disease perceive their cognitive functioning over time (Hughes et al. 2015).

Literacy is the ability to read and write, including the skills to access knowledge through technology and the ability to read and comprehend complex instructions (United Nations Educational, Scientific and Cultural Organization 2006). In 2013, the number of illiterate adults worldwide was estimated to be 757 million (United Nations Educational, Scientific and Cultural Organization Institute for Statistics 2015).

Literacy is an important factor in understanding how to engage in self-care, self-manage illness and access the healthcare system, as most educational instruction is presented in print form. Therefore, low literacy is a fundamental barrier to effective self-care (Gazmararian et al. 2003; Wolf et al. 2007). For example, inadequate literacy can affect the patient's ability to read instructions on a medicine bottle and this may lead to the exacerbation of illness, a higher burden of symptoms, poorer QOL and an increased risk of hospitalisation and premature death (Macabasco-O'Connell et al. 2011; Riegel et al. 2009a; Rodríguez-Artalejo et al. 2005). Any patient-centred educational intervention to teach self-care for chronic disease needs to consider a variety of delivery formats to account for low literacy and for patients for whom English is a second language (Casimir et al. 2014).

While literacy is a person's ability to read and write, health literacy is defined as the ability to read and understand health information and materials for performing self-care and making effective health decisions (Wayne 2009). Health literacy influences a patient's self-care ability. Adequate health

literacy is associated with greater knowledge about the disease and better health outcomes (Chen et al. 2013).

For individuals with a chronic illness, having an adequate level of health literacy is essential for obtaining and understanding the health information and services they need to engage in managing and making decisions about their own health (Berkman et al. 2011; Zamora 2011). Berkman et al. (2011) reported, in a systematic review, an association between low levels of health literacy, poor health outcomes and poorer utilisation of healthcare services (Berkman et al. 2011).

Patient education interventions have been developed to improve knowledge and self-care skills in patients with low health literacy (DeWalt et al. 2006). However, printed educational materials and traditional patient education have had only minor beneficial effects on health outcomes; the information contained in such materials has been found to be insufficient for a positive effect on patient outcomes (Dickson & Riegel 2009; Giguère et al. 2012).

Presently, information and communication technologies can serve as a means to support self-care and to improve health outcomes (Azevedo et al. 2015; Franklin 2015). Technology-assisted interventions have been shown to be efficacious in improving self-management and health status. Emerging technologies have been positively linked to improved patient engagement (Georgeff 2014; Heapy et al. 2015; Lorig et al. 2006). Real or simulated experiences, as well as the process of debriefing, also enhance learning. Therefore, technology has the potential to be part of the learning environment for teaching self-care for chronic disease (Georgeff 2014).

An avatar is defined as a movable online manifestation or animation of a person used to enhance interaction in a virtual-reality environment or in virtual cyberspace (Graffigna, Barello & Riva 2013). Avatar-based educational technologies enable users to actively participate in the creation of a unique online persona and allow educators to easily present an activity that would otherwise be difficult to read or demonstrate with a static picture (Peterson 2005). Therefore, avatar technology is particularly useful for patients with low literacy and low health literacy.

In addition, avatar technology has been developed for collaborative or simulation-based education, which is a contemporary intuitive approach to distance teaching and an important tool in modern education practices (Falloon 2010; Phillips et al. 2010). Virtual activities are experienced as being more interactive than real-world teaching activities (Duncan, Miller & Jiang 2012). Avatar-based technologies that support education are now widespread and on the increase (Duncan, Miller & Jiang 2012).

The use of avatar technology for patient education aids in chronic disease management such as cancer, diabetes and depression for improving knowledge, self-care behaviours and QOL (Bedra et al. 2013; Johnson et al. 2013; Pinto et al. 2013). Findings from related studies demonstrate positive outcomes in clinical practice. For example, an avatar-based intervention embedded into an online self-management program improved overactive bladder HRQOL and symptoms in women (Andrade et al. 2015). In another study, an avatar-based interactive application improved knowledge and stoma care self-efficacy in hospitalised patients with a new ileostomy (Bedra et al. 2013). Avatar technology also reduced depressive symptoms over time in a group of young adults (Pinto et al. 2013) and prevented smoking relapse in hospitalised cancer patients (Krebs et al. 2009).

A preliminary search in the *JBI Database of Systematic Reviews and Implementation Reports,* the Cochrane Library, Cumulative Index to Nursing and Allied Health Literature (CINAHL) and PubMed found no systematic reviews on the use of avatar-based technology for patient education, nor evaluation of its effect on outcomes such as knowledge and self-care behaviours for chronic disease management. Therefore, this review has been undertaken to determine the effectiveness of patient education, using avatar technology, on knowledge and self-care behaviours to manage chronic disease.

This review was conducted according to an a priori published protocol (Wonggom et al. 2016).

2.5 Review question

The question of this review is, what is the effectiveness of using avatar-based technology in patient education intervention to improve knowledge and self-care behaviours for chronic disease?

2.6 Inclusion criteria

2.6.1 Participants

The current review considered studies that included patients with any chronic disease. For example, cardiovascular diseases, chronic respiratory diseases, type 1 or type 2 diabetes or any form of cancer (WHO 2014). In addition, it considered studies of patients in any age group (children and adults), race, ethnicity and gender.

2.6.2 Intervention

The current review considered studies that investigated the effectiveness of using avatar technology in patient educational interventions. In the first encounter (orientation to the technology), the avatar technology will have been delivered by a nurse, physician and/or allied health educator via an iPad, other tablet device, computer or mobile phone in a hospital or in the community. Patients will then continue to use/view the technology at home.

2.6.3 Comparator

The published protocol for this systematic review specified that the comparator would be only usual care and paper-based materials. However, due to the low number of studies found and variations in usual care, other types of educational and/or information programs were included as comparators in this review.

2.6.4 Outcomes

The current review considered studies that included the following outcomes. Primary outcomes were knowledge and self-care behaviours, and secondary outcomes included self-efficacy, HRQOL, readmission and adherence to medication.

2.6.5 Types of studies

The current review considered both experimental and quasi-experimental study designs, including randomised controlled trials (RCT), non-randomised controlled trials, before and after studies, and interrupted time-series studies. In addition, analytical observational studies, including prospective and retrospective cohort studies, case-control studies and analytical cross-sectional studies, were

considered for inclusion. This review also considered descriptive observational study designs including case series, individual case reports and descriptive cross-sectional studies for inclusion.

Studies published in the English language and published from January 2005 to March 2017 were considered for inclusion in this review. This review excluded publications in languages other than English, due to limited resources for translation.

2.7 Methods

This systematic review was conducted in accordance with the Joanna Briggs Institute (JBI) methodology for systematic review of effectiveness evidence (JBI 2014) and with an a priori protocol (Wonggom et al. 2016). The title of the review has been registered in PROSPERO 2016: CRD42016052987.

2.7.1 Search strategy

The objective of the search strategy was to find both published and unpublished studies. A three-step search strategy was utilised to search the literature from January 2005 to March 2017, as this is the period during which these technologies began making an impact on teaching and learning outcomes (Baker, Wentz & Woods 2009). In addition, this review excluded all qualitative studies on this topic, as the aim was to determine the effectiveness of using avatar technology in patient education.

An initial limited search of PubMed and CINAHL was undertaken, followed by analysis of the words contained in the title, abstract and the index terms used to describe the articles. A second search, using all identified keywords and index terms, was undertaken on 24 March 2017.

The databases that were searched included:

- MEDLINE
- CINAHL
- PsycINFO
- Cochrane Central Trials Register of Controlled Trials
- ProQuest
- Web of Science

- Scopus.

The databases and/or registries that were searched to identify unpublished studies included:

- WHO International Clinical Trial Registry Platform
- Clinicaltrials.gov
- Australian New Zealand Clinical Trials Registry.

Finally, the reference lists of all reports and articles selected for critical appraisal were searched for additional studies. The full search strategy is provided in Appendix 2.

2.7.2 Study selection

Following the search, all identified citations were imported into Endnote and duplicates were removed. Titles and abstracts were screened by two independent reviewers for assessment against the inclusion criteria for the review (PW & CK). The full text of potentially eligible studies was retrieved and assessed in detail against the inclusion criteria by two independent reviewers (PW & CK). The details of studies that met the inclusion criteria were imported into the Joanna Briggs Institute's System for the Unified Management, Assessment and Review of Information (JBI SUMARI). Full-text studies that did not meet the inclusion criteria were excluded, and reasons for their exclusion are provided. Any disagreement about the inclusion and/or exclusion of a study between the reviewers were resolved through discussion or with a third reviewer (RC).

2.7.3 Assessment of methodological quality

Eligible studies were critically appraised by two independent reviewers (PW & CK), using the standardised critical appraisal instruments from the JBI for randomised controlled trials (RCTs) and non-randomised experimental studies (See Appendix 3). The RCTs that were selected for the systematic review had to have responded 'yes' to seven of the 13 questions on the critical appraisal tool for inclusion. The non-randomised experimental studies selected had to have responded 'yes' to a minimum of five of the nine questions on the critical appraisal tool. Any disagreement between the two reviewers were resolved through discussion, with a third reviewer (RC).

2.7.4 Data extraction

Data was extracted from studies included in the review by two independent reviewers (PW & CK), using the standardised JBI data extraction tool. The data extracted included specific details about the interventions, populations, study methods and outcomes of significance to the review question and its specific objectives. Any disagreement between the reviewers were resolved through discussion or with a third reviewer. The authors of papers were contacted to request missing or additional data (RC).

2.7.5 Data synthesis

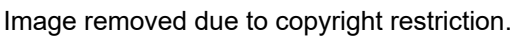
Statistical pooling of quantitative data and meta-analysis was not possible because of heterogeneity across the studies with regard to the study population, duration of intervention, outcome measurements and data analysis. The findings are presented and discussed in a narrative form, accompanied by tables and figures to aid data presentation where appropriate.

2.8 Results

2.8.1 Study inclusion

A comprehensive search of the literature identified 2,891 records. In addition, 387 records were identified through other sources. After removing duplicates, 2,547 records were evaluated by their titles and abstracts. After a review of the titles and keywords, 2,535 records were excluded and 12 full-text articles were retrieved for further review, as additional information beyond the abstracts was required to determine whether the article met the inclusion criteria for the review. After reviewing the full-text articles, three were excluded for not meeting the inclusion criteria (See Appendix 4).

Nine articles (from eight studies) were appraised for methodological quality and included in the review. No articles assessed for methodological quality were excluded. Figure 2.1 outlines the search results, and the study selection and inclusion process. The characteristics and findings of the included studies were described in Section 2.8.3. Appendix 4 provides a list of excluded studies and reasons for their exclusion.



Source: Moher et al. (2009, p.3).

Figure 2.1 Search results and the study selection and inclusion process

2.8.2 Methodological quality

A total of nine articles were included for appraisal of methodological quality. All nine were determined to be of adequate quality with adequate reporting of at least 50% of the applicable questions in the

critical appraisal tools. The overall quality of the included studies demonstrated moderate and low risk of bias for RCTs and moderate risk of bias for quasi-experimental studies. See Tables 2.2 and 2.3 for details of the assessment of methodological quality.

All three RCTs (four articles) scored 10 out of 13 (77%) for quality assessment (Beale et al. 2007; Kato et al. 2008; Rosal et al. 2014; Strömberg, Dahlström & Fridlund 2006). All three studies (100%) were performed using true random assignment to treatment groups (Q1); allocation to treatment groups were concealed (Q2); both groups were similar at baseline (Q3); the control and treatment groups received identical treatment other than the intervention (Q7); and the outcomes were measured in the same way (Q10) and the reliable way (Q11) for both groups. The follow-up was completed (Q8), and appropriate statistical analysis was used (Q12) in the three studies. All three studies had an appropriate trial design (Q13). Given the nature of the patient education intervention, blinding of the participants or the researchers was not possible in all three studies (0%) (Q4 and Q5) (Beale et al. 2007; Kato et al. 2008; Rosal et al. 2014; Strömberg, Dahlström & Fridlund 2006). All three studies reported blinding of outcome assessors (100%) (Q6) (Beale et al. 2007; Kato et al. 2008; Rosal et al. 2014; Strömberg, Dahlström & Fridlund 2006). For all three studies, it was unclear if participants were analysed in the groups to which they were randomised (Q9) (Beale et al. 2007; Kato et al. 2008; Rosal et al. 2014; Strömberg, Dahlström & Fridlund 2006). However, all studies described reasons for loss at follow-up.

As stated above, although blinding of the participants was not possible for this type of intervention, all the studies took reasonable measures to blind the outcome assessors and, therefore, minimised the risk of distorted results.

In terms of data analysis, in all three studies it was unclear whether all participants enrolled in the studies were included in the analyses of the groups to which they were randomised; however, the authors of each of the three RCT provided information on the reasons for loss at follow-up. The difference between the intervention group (IG) and the control group (CG) was small, in terms of the number of participants lost at follow-up and the reasons for the loss. Therefore, the author judged that although insufficient reporting limited the studies' ability to meet the criteria for Question 9, it is

unlikely to have compromised the way in which the study methodology was conducted. Overall, the three studies scored above seven out of 13 (> 50%) and were therefore, considered of acceptable quality for inclusion.

For quasi-experimental studies, all five studies met at least five of the nine criteria (50% quality score) for quasi-experimental studies (Bedra et al. 2013; Clark et al. 2015; Johnson et al. 2014; Joubert et al. 2016; Ruggiero et al. 2014). All five studies (100%) were considered to have met the criteria for having a clear 'cause' and 'effect' (Q1). All of the five studies were single-group pre- and post-test studies (Q4) (Bedra et al. 2013; Clark et al. 2015; Johnson et al. 2014; Joubert et al. 2016; Ruggiero et al. 2014) therefore, were considered to have characteristics similar to comparison groups (Q2), received similar treatment/care (Q3), with results from multiple measurements compared (Q5) (Bedra et al. 2013; Clark et al. 2015; Johnson et al. 2014; Joubert et al. 2016; Ruggiero et al. 2014). Three of the five studies had follow-up at six months (Johnson et al. 2014; Joubert et al. 2016; Ruggiero et al. 2014). With regard to completion at follow-up (Q6), all participants had complete follow-up in only one study (33%) (Joubert et al. 2016). Two studies (66.66%) lost participants at follow-up, and the reasons were not adequately described (Johnson et al. 2014; Ruggiero et al. 2014). Three studies (60%) reported measurement of outcomes that were performed consistently in the same way throughout the studies (Q7) and in a reliable way by trained researchers (Q8) (Bedra et al. 2013; Clark et al. 2015; Ruggiero et al. 2014). Only one study (20%), a brief report, did not provide detail on statistical analysis (Q9) (Bedra et al. 2013).

Table 2.2 Critical appraisal of eligible randomised controlled studies

Study	Q1	Q2	Q3	Q4	Q5	Q6	Q7	Q8	Q9	Q10	Q11	Q12	Q13	Total
Strömberg, Dahlström & Fridlund (2006)	Y	Y	Y	N	N	Y	Y	Y	U*	Y	Y	Y	Y	**10/13**
Beale et al. (2007). / Kato et al. (2008)	Y	Y	Y	N	N	Y	Y	Y	U*	Y	Y	Y	Y	**10/13**
Rosal et al. (2014)	Y	Y	Y	N	N	Y	Y	Y	U*	Y	Y	Y	Y	**10/13**
Total (%)	**100**	**100**	**100**	**0**	**0**	**100**	**100**	**100**	**0**	**100**	**100**	**100**	**100**	

Y = Yes, N = No, U = Unclear.

JBI critical appraisal checklist for RCTs:

Q1: Was true randomisation used for assignment of participants to treatment groups?
Q2: Was allocation to treatment groups concealed?
Q3: Were treatment groups similar at baseline?
Q4: Were participants blind to treatment assignment?
Q5: Were those delivering treatment blind to treatment assignment?
Q6: Were outcome assessors blind to treatment assignment?
Q7: Were treatment groups treated identically other than the intervention of interest?
Q8: Was follow-up complete, and if not, were strategies to address incomplete follow-up utilised?
Q9: Were participants analysed in the groups to which they were randomised?
Q10: Were outcomes measured in the same way for treatment groups?
Q11: Were outcomes measured in a reliable way?
Q12: Was appropriate statistical analysis used?
Q13: Was the trial design appropriate, and any deviations from the standard RCT design (individual randomisation, parallel groups) accounted for in the conduct and analysis of the trial?

* = Author contacted, no response nor further information received.

Table 2.3 Critical appraisal of quasi-experimental studies (non-randomised experimental studies)

Study	Q1	Q2	Q3	Q4	Q5	Q6	Q7	Q8	Q9	Total
Bedra et al. (2013)	Y	Y	Y	N	Y	NA	Y	U	U	**5/9**
Ruggiero et al. (2014)	Y	Y	Y	N	Y	U	Y	Y	Y	**7/9**
Johnson et al. (2014)	Y	Y	Y	N	Y	U	N	U	Y	**6/9**
Clark et al. (2015)	Y	Y	Y	N	Y	NA	Y	Y	Y	**7/9**
Joubert et al. (2016)	Y	Y	Y	N	Y	Y	U	Y	Y	**7/9**
Total (%)	**100**	**100**	**100**	**0**	**100**	**33**	**60**	**60**	**80**	

Y = Yes, N = No, U = Unclear, NA = Not applicable.

JBI critical appraisal checklist for quasi-experimental studies (non-randomised experimental studies):

Q1: Is it clear in the study what is the 'cause' and what is the 'effect' (i.e., there is no confusion about which variable comes first)?
Q2: Were the participants included in any of the comparisons similar?
Q3: Were the participants included in any comparison receiving similar treatment/care, other than the exposure or intervention of interest?
Q4: Was there a control group?
Q5: Were there multiple measurements of the outcome, both pre and post the intervention/exposure?
Q6: Was follow-up complete and if not, were differences between groups in terms of their follow-up adequately described and analysed?
Q7: Were the outcomes of participants included in any comparisons measured in the same way?
Q8: Were outcomes measured in a reliable way?
Q9: Was appropriate statistical analysis used?

2.8.3 Characteristics of included studies

This review considered studies that investigated the effectiveness of using avatar technology in patient educational interventions delivered by a nurse, physician and/or allied health educator via a tablet computer, computer or mobile phone in a hospital or in the community, and in which patients were able to continuously use the technology at home. The review aimed to examine the use of avatar technology compared to other methods of patient education. Table 2.4 lists and describes the research using avatar-based technology in patient education.

2.8.3.1 Methods

The eight studies reviewed included two RCTs (Beale et al. 2007; Kato et al. 2008; Strömberg, Dahlström & Fridlund 2006), one pilot randomised controlled trial (Rosal et al. 2014); four single-group pre-post studies (Bedra et al. 2013; Clark et al. 2015; Johnson et al. 2014; Ruggiero et al. 2014) and one prospective multicentre pilot study (Joubert et al. 2016).

2.8.3.2 Country/Setting

Seven of the eight studies were single-centre studies conducted in Sweden (Strömberg, Dahlström & Fridlund 2006), US (Bedra et al. 2013; Johnson et al. 2014; Rosal et al. 2014; Ruggiero et al. 2014), France (Joubert et al. 2016) and Australia (Clark et al. 2015). One multicentre RCT was conducted in US, Canada and Australia (Beale et al. 2007; Kato et al. 2008).

2.8.3.3 Sample size

The total sample size of the studies reviewed was 752 participants. The number of study participants ranged from 15 (in a study of an educational intervention for ileostomy care) (Bedra et al. 2013) to 375 (the ‘Re-Mission’ study) (Beale et al. 2007; Kato et al. 2008).

2.8.3.4 Demographics

Six of the eight studies involved adult participants (Beale et al. 2007; Bedra et al. 2013; Clark et al. 2015; Johnson et al. 2014; Kato et al. 2008; Rosal et al. 2014; Ruggiero et al. 2014; Strömberg, Dahlström & Fridlund 2006), one study involved children with diabetes mellitus (aged 11 to 18) (Joubert et al. 2016) and one study involved young adults with cancer (age 13 to 29) (Beale et al.

2007; Kato et al. 2008). Overall, four studies involved patients with diabetes mellitus (Johnson et al. 2014; Joubert et al. 2016; Rosal et al. 2014; Ruggiero et al. 2014), two studies each of patients with HF (Clark et al. 2015; Strömberg, Dahlström & Fridlund 2006) and cancer (Beale et al. 2007; Kato et al. 2008) and another study patients with ileostomy (Bedra et al. 2013).

2.8.3.5 Intervention/Follow-up

The avatar-based technology in patient education has been described in various terms, based on the method used to deliver the intervention or the program used to develop the educational tool. The methods used to deliver the intervention include the tablet computer (Bedra et al. 2013; Clark et al. 2015) and desktop computer (PC) (Beale et al. 2007; Johnson et al. 2014; Joubert et al. 2016; Kato et al. 2008; Rosal et al. 2014; Ruggiero et al. 2014; Strömberg, Dahlström & Fridlund 2006). The avatar-based interventions included three interactive multimedia education programs (Bedra et al. 2013; Clark et al. 2015; Strömberg, Dahlström & Fridlund 2006), three virtual-world educational programs (Johnson et al. 2014; Rosal et al. 2014; Ruggiero et al. 2014) and two educational computer games (Beale et al. 2007; Kato et al. 2008). The two computer games were developed for children with diabetes (Joubert et al. 2016) and young adults with cancer (Beale et al. 2007; Kato et al. 2008).

Follow-up varied greatly between studies, and the data collection at follow-up aimed to detect changes in short-term outcomes (knowledge and self-care behaviours) and long-term outcomes (self-care behaviours, self-efficacy, HRQOL, readmission, adherence to medication). The follow-up period was six months in four studies (Johnson et al. 2014; Joubert et al. 2016; Ruggiero et al. 2014; Strömberg, Dahlström & Fridlund 2006) and three months in two studies (Beale et al. 2007; Kato et al. 2008).

2.8.3.6 Outcome/Instruments

The outcomes measured in the studies are presented in Table 2.3. Primary outcomes were knowledge and self-care behaviours, and secondary outcomes included self-efficacy, HRQOL, readmission and adherence to medication.

Table 2.4 Characteristics and findings of the studies

Publication/ Country	Method	Population	Sample size (n)	Intervention/Comparator	Follow-up (mths)	Result/Instrumentation
Randomised Controlled Trials						
Beale et al. (2007) - USA - Canada - Australia	RCT	Cancer Age: 13–29 years Mean age: 15.79 (± 2.62) years	375	Intervention: the Re-Mission educational video game in addition to a commercial video game Exposure: 1 hour per week for 3 months Comparator: commercial video game	3	**Knowledge** (investigator-developed instrument) 1- and 3-month follow-up. IG v. CG: $F(1,302) = 4.07$, $p = 0.04$ Factor associated with increase in knowledge: Credibility and Knowledge: $r(142) = –0.20$, $p = 0.016$ Playing time and Knowledge: $F = 5.33$, $p = 0.02$, $f = 0.018$
Kato et al. (2008) - USA - Canada - Australia	RCT	Cancer Age: 13–29 years Mean age: 66% ≤ 16 years	375	Intervention: the Re-Mission educational video game in addition to a commercial video game Exposure: 1 hour per week for 3 months Comparator: commercial video game	3	**Knowledge** (investigator-developed instrument) 3-month follow-up: IG v. CG: $p = 0.035$ Baseline: IG: 0.59 (mean), CG: 0.60 (mean) 1-month follow-up: IG: 0.65 (mean), CG: 0.63 (mean) 3-month follow-up: IG: 0.66 (mean), CG: 0.63 (mean) **Self-efficacy (the Self-efficacy Scale)** 3-month follow-up: IG v. CG: $p = 0.011$ Baseline: IG: 155.9 (mean), CG: 156.6 (mean) 1-month follow-up: IG: 158.0 (mean), CG: 157.9 (mean) 3-month follow-up: IG: 164.1 (mean), CG: 158.8 (mean) **Adherence to medication** (the Chronic Disease Compliance Instrument; the Medication Adherence Scale; Medication Event Monitoring System) General medication adherence: IG v. CG: $p = 0.503$ Antibiotic adherence: IG: ↑ 16% Oral chemotherapy adherence: IG v. CG: $p = 0.002$ **QOL** (Pediatric Quality of Life Scale) 3-month follow-up: IG vs CG: $p = 0.112$ Baseline: IG 64.2 (mean), CG 62.5 (mean) 1-month follow-up: IG: 65.5 (mean), CG 63.5 (mean) 3-month follow-up: IG 69.1 (mean), CG 66.3 (mean)
Rosal et al. (2014) USA	Pilot RCT	Diabetes mellitus type 2 Age ≥ 18 years	89	Intervention: an open-air virtual-world forum	4	**Adherence to medication** (investigator-developed instrument) • IG v. CG: $p = 0.298$ • IG: ↑1.2%, $p = 0.035$

Publication/ Country	Method	Population	Sample size (n)	Intervention/Comparator	Follow-up (mths)	Result/Instrumentation
		Mean age: 52 (± 10) years		Exposure: 90 minutes of groups sessions per week over an 8-week period Comparator: a face-to-face group session		**QOL** (SF-12) • IG v. CG: $p = 0.113$ • IG: ↑1.4%, $p = 0.599$ • CG: ↑6.6%, $p = 0.02$ **Diabetic self-efficacy** (cognitive interview) • IG v. CG: $p = 0.268$ • IG: ↑12.7%, $p < 0.001$ • CG: ↑17.1%, $p < 0.001$
Strömberg, Dahlström & Fridlund (2006) Sweden	RCT	Heart failure Age: 32–91 years Mean age: 70 (± 11) years	154	Intervention: Interactive multimedia program with CD-ROM in addition to standard care Comparator: the Standard care	6	**Knowledge** (investigator-developed instrument) 1-month follow-up (change): • IG: ↑ 0.99 (mean) • CG: ↑ 0.54 (mean) • IG v. CG: 95% CI [–0.03, 0.92], $p = 0.07$ 6-month follow-up (change): • IG: ↑0.77 (mean) • CG: ↑0.29 (mean) • IG v. CG: 95% CI [0.03,0.91], $p = 0.03$ **Adherence to medication** (investigator-developed instrument) Adherence to diuretic therapy 1-month follow-up: IG v. CG, $p = 0.01$ 6-month follow-up: IG v. CG: (not significant) Women (39%) v. Men (25%), $p = 0.05$ No between-group difference in: • planned medical appointments • resting during the day • ↓ activity if short of breath • low salt **Health-related quality of life** (EuroQol:EQ-5D) 1-month follow-up: IG v. CG: 95% CI [–0.07, 0.09], $p = 0.87$ 6-month follow-up: IG v. CG: 95% CI [–0.08, 0.06], $p = 0.81$
Quasi-experimental studies						
Bedra et al. (2013) USA	A single-group pre-post study	Ileostomy Age: unreported	15	Intervention: Avatar-based interactive ileostomy computer-assisted education program	None	**Knowledge** (not reported in paper and no response from the author) 27.8 ± 3.4 to 31.3 ± 1.5, $p < 0.002$

Publication/ Country	Method	Population	Sample size (n)	Intervention/Comparator	Follow-up (mths)	Result/Instrumentation
		Mean age: 51 years		Comparator: none		**Self-efficacy** (not reported in paper and no response from the author) 78.4 ± 22.7 to 92.7 ± 14.1, $p < 0.05$
Clark et al. (2015) Australia	A mixed-method (action research and single-group pre-post study)	Heart failure Age ≥ 18 years Mean age: 61 (± 10) years	20	Intervention: Avatar-based education resource through a tablet resource Comparator: None	None	**Heart failure knowledge** (the modified HF Knowledge questionnaire) ↑ 20.8% knowledge **Self-care behaviour** (Self-Care Heart Failure Index) ↑ 95% self-confidence ↑ 26.1% self-maintenance ↑ 1.9% self-management
Johnson et al. (2014) USA	Single-group, pre-mid- and post-test study	Diabetes mellitus type 2 Age: 21–75 years Mean age: 54 years	20	Intervention: A virtual environment for type 2 diabetes education available for 6 months Comparator: None	6	**Diabetes knowledge** (the Assessment Diabetes Knowledge) 6-month follow-up: $t_{10} = 0.70$, $p = 0.77$ **Self-efficacy** (the Diabetes Empowerment Scale–Short Form) 3-month follow-up: ↑ $t_{13} = 2.3$, $p = 0.036$ 6-month follow-up: ↑ $t_{11} = 2.73$, $p = 0.02$ **Self-management behaviours** (the Summary of Diabetes Self-Care Activities) 6-month follow-up: • foot care behaviour, $t_{11} = 2.54$, $p = 0.03$ • dietary, $t_{11} = –0.69$, $p = 0.50$ • exercise, $t_9 = –0.76$, $p = 0.46$ • blood sugar testing, $t_{11} = 0.70$, $p = 0.50$
Joubert et al. (2016) France	A prospective multicentred pilot study	Diabetes mellitus type 1 Age: 11–18 years Mean age: 13.7 (± 2.1) years	38	Intervention: Web-based serious educational video game for self-management of a flexible insulin therapy method for 6 months Comparator: None	6	**Knowledge** (the PedCarbQuiz) Total score at 6-month follow-up: ↑ 31.6 ± 4.9 to 36.0 ± 4.0, $p < 0.05$ Carbohydrate recognition 1-month follow-up: not significant 6-month follow-up: not significant Insulin titration: 1-month follow-up: ↑, $p < 0.01$ 6-month follow-up: ↑, $p < 0.0001$ Carbohydrate quantification knowledge: 1-month follow-up: not significant

Publication/ Country	Method	Population	Sample size (n)	Intervention/Comparator	Follow-up (mths)	Result/Instrumentation
						6-month follow-up: ↑, $p < 0.001$ **Self-care behaviour** (the Diabetes Self-Management Profile questionnaire) Baseline: 59.1 ± 9.9 1-month follow-up: 60.2 ± 9.8 (not significant) 6-month follow-up: 60.0 ± 10.0 (not significant)
Ruggiero et al. (2014) USA	A single-group repeated measure study	Diabetes mellitus type 2 Age ≥ 8 years Mean age: 55.2 (± 9.6) years	41	Intervention: Immerse into a virtual-world Diabetes Island self-care educational program including 10 real-time formal presentation sessions Comparator: None	6	**Self-care behaviours** (the Summary of Diabetes Self-care Activities) 6-month follow-up: • ↑ summary score, $p = 0.03$ • ↑ physical activity-rev, $p = 0.04$ • General diet-rev, $p = 0.09$ • Specific diet-rev, $p = 0.91$ • Exercise, $p = 0.12$ • Self-testing, $p = 0.46$

Note: IG: intervention group; CG: control group; ↑: statistical increase in outcome measured; significance $p \leq 0.05$.

2.8.4 Review findings

Table 2.4 summarises the results of the reviewed studies using avatar-based technology in patient education. A summary of the primary and secondary outcomes was summarised below.

2.8.4.1 Knowledge

Six of the eight studies examined the effects of avatar-based technology on the patient's knowledge, including two RCTs (Beale et al. 2007; Kato et al. 2008; Strömberg, Dahlström & Fridlund 2006), three single-group pre-post studies (Bedra et al. 2013; Clark et al. 2015; Johnson et al. 2014) and a prospective study (Joubert et al. 2016).

The two RCTs reported that the use of an interactive multimedia program with CD-ROM plus standard care (Strömberg, Dahlström & Fridlund 2006), and the Re-Mission educational video game plus a commercial video game intervention (Beale et al. 2007; Kato et al. 2008), improved disease-specific knowledge at one-, three- and six-month follow-up (Beale et al. 2007; Kato et al. 2008; Strömberg, Dahlström & Fridlund 2006). In the study involving patients with HF, the interactive multimedia program with CD-ROM plus standard care resulted in a statistically significant improvement in knowledge (measured by an investigator-developed instrument) at the six-month follow-up among the IG participants, compared to those in the CG, who only received the standard care (95% CI = 0.03–0.91, $p = 0.03$) (Strömberg, Dahlström & Fridlund 2006). The RCT investigating the effect of an educational video game plus a commercial video game on young adults with cancer found that the intervention led to a statistically significant improvement in knowledge (measured by an investigator-developed instrument) at the three-month follow-up in the IG compared to the CG, who only received a commercial video game *(*$F[1,302] = 4.07$, $p = 0.04$) (Beale et al. 2007; Kato et al. 2008).

Of the four quasi-experimental studies, three showed positive intervention effects on chronic disease knowledge in single-group pre-post studies (Bedra et al. 2013; Clark et al. 2015; Joubert et al. 2016). Bedra et al. (2013) reported that those who received the avatar-based interactive ileostomy computer-assisted education program showed statically significant improvement in knowledge of ileostomy, in a single-group pre-post study without follow-up (27.8 ± 3.4 to 31.3 ± 1.5, $p < 0.002$).

Clark et al. (2015) demonstrated that the provision of an avatar-based educational resource through a tablet in a single-group pre-post study without follow-up, resulted in an increase in HF knowledge scores by 20.8% on the modified HF Knowledge questionnaire (Clark et al. 2015). Johnson et al. (2014) found that the virtual environment for type 2 diabetes education in a single group pre-mid post-test study with six months follow-up did not result in a statistically significant increase in overall diabetes knowledge over time ($t_{10} = 0.70$, $p = 0.77$) (Johnson et al. 2014); however, there were significant improvement in insulin titration knowledge immediately after receiving intervention ($p < 0.01$) and at six-month follow-up ($p < 0.001$), and increased knowledge of carbohydrate quantification at six-month follow-up ($p < 0.001$) on the PedCarbQuiz (Joubert et al. 2016).

2.8.4.2 Self-care behaviours

Four of the eight studies investigated the effects of using avatar-based technology in patient education on self-care behaviours (Clark et al. 2015; Johnson et al. 2014; Joubert et al. 2016; Ruggiero et al. 2014). Three single-group pre-post studies measured self-care behaviours of patients with diabetes mellitus (Johnson et al. 2014; Joubert et al. 2016; Ruggiero et al. 2014), and one of patients with HF (Clark et al. 2015).

Two of the four single-group pre-post studies showed that those who received a virtual-world educational intervention demonstrated statistically significant improvement in self-care behaviour and skills at six-month follow-up, based on the Summary of Diabetes Self-Care Activities (Johnson et al. 2014; Ruggiero et al. 2014). Ruggiero et al. (2014) demonstrated that physical activity following immersion in a virtual-world Diabetes Island self-care educational program showed statistically significant improvement (with mean [SE] of 3.9 [0.31] at baseline to 4.5 [0.33] at six-month follow-up, $p = 0.04$) (Ruggiero et al. 2014). Johnson et al. (2014) reported that people with diabetes mellitus who received a virtual-world environment educational intervention also showed statistically significant improvement in foot care behaviour at six-month follow-up ($t_{11} = 2.54$, $p = 0.03$) (Johnson et al. 2014).

Using the Self-Care Heart Failure Index (SCHFI) to evaluate self-care behaviour skills, Clark et al. (2015) found that there was a 95% increase in self-care confidence, 26.1% increase in self-care

maintenance and 1.9% increase in self-care management by people living with HF who received avatar-based education resource through a tablet (Clark et al. 2015).

One prospective multicentred pilot study reported that a web-based serious educational video game intervention did not result in changes to the participants' diabetes self-management behaviours, based on the Diabetes Self-Management Profile questionnaire at six-month follow-up (from 59.1 ± 9.9 to 60.0 ± 10.0) (Joubert et al. 2016).

2.8.4.3 Self-efficacy

Four of the eight studies assessed the effects of avatar-based technology on patient self-efficacy: one RCT (Kato et al. 2008), one pilot RCT (Rosal et al. 2014) and two single-group pre-post studies (Bedra et al. 2013; Johnson et al. 2014), of patients with cancer, diabetes mellitus and ileostomy.

The RCT investigating the effect of the Re-Mission educational video game plus a commercial game on young adults with cancer, demonstrated that the intervention led to statistically significant greater improvements in self-efficacy (on the Self-efficacy Scale) in the IG compared to the CG who were exposed only to the commercial game, at three-month follow-up (mean [SD]: 155.9 [22.3] to 164.1 [23.4] for the IG and 156.6 [21.3] to 158.8 [23.5] for the CG), $p = 0.011$) (Kato et al. 2008).

Two of the four single-group pre-post studies found that the avatar-based interactive computer-assisted educational program and a virtual-world environment educational intervention resulted in statistically significant improvement in self-efficacy (Bedra et al. 2013; Johnson et al. 2014). Bedra et al. (2013) found that those participants who only received the avatar-based computer-based intervention, without follow-up or comparator, also improved in their scores on self-efficacy of stoma care, from 78.4 ± 22.7 to 92.7 ± 14.1 ($p < 0.05$) (Bedra et al. 2013), and Johnson et al. (2014) found that a virtual environment educational program improved diabetes self-care at six-month follow-up, based on the Diabetes Empowerment Scale–Short Form ($t_{11} = 2.73$, $p = 0.02$).

Rosal et al. (2014) reported that an open-air virtual-world forum intervention did not result in a statistically significant difference in diabetic self-efficacy (measured by a cognitive interview) between the IG and the CG, who received face-to-face group sessions (mean difference: 4.58 for

the IG and 5.90 for the CG, $p = 0.268$) (Rosal et al. 2014). Both the intervention and the control groups improved in diabetic self-efficacy at four-month follow-up; however, the self-efficacy of CG patients had improved significantly more than that of IG patients (17.1% for the CG and 12.7% for the IG, $p < 0.001$) (Rosal et al. 2014). In this pilot RCT study, the intervention (virtual-world group sessions) were compared with face-to-face group sessions (Rosal et al. 2014).

2.8.4.4 Health-related quality of life

Three of the eight studies examined the effects of avatar-based technological education on QOL-related health metrics (Kato et al. 2008; Rosal et al. 2014; Strömberg, Dahlström & Fridlund 2006).

Two RCTs (using an interactive multimedia program plus the standard care, and an educational intervention videogame plus a commercial videogame) and one pilot RCT (using open-air virtual-world groups sessions) reported that their interventions did not result in statistically significant improvement in patients' QOL over time (Kato et al. 2008; Rosal et al. 2014; Strömberg, Dahlström & Fridlund 2006).

However, Kato et al. (2008) demonstrated that patients in the IG exposed to the Re-Mission educational video game plus a commercial video game showed more improvement in mean QOL scores relative to the CG patients, who only received a commercial video game, at the one-month follow-up (mean of 0.59 to 0.65 for the IG and 0.60 to 0.63 for the CG) and at the three-month follow-up (mean of 0.65 to 0.66 for the IG and 0.63 to 0.63 for the CG) (Kato et al. 2008).

2.8.4.5 Readmission

None of studies included in the systematic review assessed the effects of avatar-based technology in patient education on readmission.

2.8.4.6 Adherence to medication

Three of the eight studies investigated the effects of avatar-based education on patients' medication adherence (Kato et al. 2008; Rosal et al. 2014; Strömberg, Dahlström & Fridlund 2006).

Two RCTs demonstrated that an educational video game plus a commercial video game, and virtual-world group session interventions, did not lead to statistically significant improvements in medication adherence between the IG and CG groups (Kato et al. 2008; Rosal et al. 2014).

Kato et al (2008) reported that there was no significant difference in the general cancer medical adherence (measured by the Medication Adherence Scale) between the participants with cancer in the IG who received an educational video game plus a commercial video game, and the participants with cancer in the CG who only received a commercial video game, at three-month follow-up (mean [SD] of IG at baseline at 2.9 [1.1] to 2.9 [1.1] at 3 months for the IG and 2.9 [1.1] at baseline to 3.0 [1.1] at 3 months for the CG, $p = 0.503$) (Kato et al. 2008). In this study, the IG showed greater improvement in antibiotic adherence (an increase by 16%) and oral therapy medical adherence compared to the CG ($p = 0.002$) (Kato et al. 2008).

The study involving patients with diabetes mellitus showed that there was no difference between the IG, who received open-air virtual-world forum group sessions, and the CG, who received face-to-face group sessions, with regard to pre-post change in self-reported medication adherence (percentage change: 86.9 to 88.1 for the IG, and 88.1 to 79.5 for the CG, $p = 0.298$), whereas the IG showed an improvement in diabetic medication adherence by 1.2% (Rosal et al. 2014).

Only one RCT, employing an interactive multimedia program with CD-ROM plus the standard care intervention, demonstrated a statistically significant increase in adherence to diuretic medication in the IG compared to the CG, who only received the standard care, at one-month follow-up ($p = 0.01$), using an investigator-developed instrument. However, there was no difference between groups at six-month follow-up (Strömberg, Dahlström & Fridlund 2006). Additionally, subgroup analysis revealed that women (39%) were more compliant with diuretic therapy than men (25%) at six-month follow-up (Strömberg, Dahlström & Fridlund 2006).

2.9 Discussion

The objective of this review was to investigate the effectiveness of using avatar-based technology in patient education versus that of usual care, in improving chronic disease knowledge and self-care behaviours. An extensive search of the literature was conducted and identified 12 articles for

inclusion in a full-text review. Following this, eight studies (nine publications) meeting the inclusion criteria for methodological quality were included in the systematic review.

Synthesising the results across these identified research studies in the review was challenging because of the heterogeneity of the methods and the technology used, and the way outcomes were measured.

The differences in the definitions of avatar-based patient education reflect the various ways in which health education was being delivered. The definition of the CG also differed, as some studies involved usual care (Strömberg, Dahlström & Fridlund 2006) and others compared avatar-based intervention with another intervention, such as a commercial video game (Beale et al. 2007; Kato et al. 2008) or a face-to-face group session (Rosal et al. 2014). The definition of avatar-based technology has been explained in varied terms. The outcomes were measured by validated and reliable measures or alternatively, investigator-developed instruments.

To sum up, avatar-based interventions demonstrated positive outcomes. The research on these interventions showed significant improvements in knowledge, self-care behaviours and self-efficacy of patients with chronic disease. However, there was lack of evidence that avatar-based patient education enhanced health metrics related to QOL or improved medication adherence in patients with chronic diseases. The effects of such a technology on patients' readmission rates were not examined by any of the studies reviewed.

2.9.1 Knowledge

The findings of this systematic review demonstrated that using avatar-based technology in patient education may be beneficial in improving patients' disease-related knowledge and self-care behaviours. All six studies revealed that intervention yielded positive results with regard to improving disease-specific knowledge (Beale et al. 2007; Bedra et al. 2013; Clark, R et al. 2015; Joubert et al. 2016; Kato et al. 2008; Strömberg, Dahlström & Fridlund 2006).

Annaim et al. (2015) and Charlier et al. (2016) reported that interactive media technology is a potential tool to educate patients on health conditions (Annaim et al. 2015; Charlier et al. 2016).

Avatar-based technology can increase knowledge and self-management skills in patients with chronic conditions, because it is able to account for differing levels of health literacy using visual and auditory signals, and promote disease knowledge and affect patient health outcomes. The avatar-based application can provide flexible learning environments within which patients can learn about their medical condition in a dynamic and personalised setting. Additionally, the application is able to adapt the content to the educational level, personal interest and specific disease of the patient (Annaim et al. 2015).

A systematic review and meta-analysis previously undertaken by Friedman et al. (2011) found that certain teaching strategies and methods of delivery had positive effects on patient education, and it was recommended that IT use pictures and illustrations to enhance learning and understanding in patients with low health literacy (Friedman et al. 2011). Additionally, the use of multiple teaching strategies with patient-specific information should be used, rather than general information (Friedman et al. 2011). Therefore, interactive IT in patient education could be recommended and introduced to deliver health information.

2.9.2 Self-care behaviours and adherence to medication

Avatar-based patient education has been shown to improve self-care behaviours and skills in patients with diabetes mellitus and HF. The intervention has enhanced self-care activities such as daily weighing, diet control, physical activity and foot care (Johnson et al. 2014; Ruggiero et al. 2014). Joubert et al (2016) reported that use of the serious game improved insulin titration and carbohydrate quantification in children with type 1 diabetes, and likewise, Lo et al. (2011) reported that a multimedia education program improved overall self-care attitudes and behaviour among patients with a stoma in the postoperative period.

However, these interventions did not significantly improve adherence to medication in cancer or diabetes patients. This finding could be due to the fact that it is possible that patients with long-term chronic illness are less likely to adhere to a medication regime because of fatigue and they may resent the medication's unpleasant side effects. (Brown & Bussell 2011). The healthcare provider should tailor the information for the individual affected by chronic disease, to encourage responsible

behaviours regarding prescribed medications and reduce the risk of non-adherence (Napolitano et al. 2015). Moreover, people who received more education on their chronic disease or adhered to their medications, were more likely to remember to take their medicines (Brown & Bussell 2011).

Vollmer et al. (2011) demonstrated that an intervention based on health IT using speech recognition software increased and promoted adherence to inhaled corticosteroids among individuals with asthma.

In conclusion, additional research on avatar-based technology could be undertaken to determine how best to enhance the reach and effectiveness of such interventions in promoting self-care behaviour skills and maintaining medication adherence.

2.9.3 Self-efficacy

Three of the four studies reviewed, showed that using avatar-based technology in patient education significantly improved patients' self-efficacy (Bedra et al. 2013; Johnson et al. 2014; Kato et al. 2008). This finding could be due to the characteristics of the intervention. The intervention delivered health information in various virtual environments that included the bookstore, grocery store, restaurant, pharmacy and gym. Interactive avatar-based ileostomy education also demonstrated strong potential as a useful resource to inform patients about ileostomy care and how to improve their self-efficacy (Bedra et al. 2013).

The study by Rosal et al. (2014) compared the effect of educational virtual-world group sessions with face-to-face group sessions on diabetic self-efficacy. Both the IG and CG showed significant improvement in self-efficacy ($p < 0.001$ for both groups). This study result suggested that the virtual-world and face-to-face interventions had similar effects on self-efficacy. However, the virtual-world intervention has the potential to reach a wider geographically diverse population.

2.9.4 Health-related quality of life

While the three studies that investigated HRQOL found that it did not improve significantly following intervention (Kato et al. 2008; Rosal et al. 2014; Strömberg, Dahlström & Fridlund 2006), all three studies observed a trend of improvement. This finding could be due to the possibility that study

participants had high levels of HRQOL at baseline. In addition, the duration of follow-up may have been insufficiently long to detect changes in QOL (Cocks et al. 2012).

In addition, HRQOL is a multidimensional subjective concept, and the measures used in the studies reviewed might not have been comprehensive enough to show a significant change (Megari 2013). In this review, generic and specific questionnaires were used to assess changes in QOL. Given the advantages and disadvantages of generic and specific instruments, the questionnaires might not have been sufficiently sensitive, precise or comprehensive in measuring the effectiveness of interventions (Cocks et al. 2012).

Other studies employing game-based virtual reality for people with chronic illness, including those with stroke and HF, have found improvements in HRQOL (Jaarsma et al. 2015; Shin, Park & Jang 2015).

2.9.5 Readmission

None of the studies included in the systematic review explored the effects of avatar-based patient education on readmission. The current literature suggests that improved disease-related knowledge and self-care behaviours would lead to a reduction in readmission rate for a number of health conditions, such as HF (Boyde et al. 2018) and diabetes (Drincic et al. 2017). One systematic review of computer-based learning programs found that HF discharge education was effective in reducing readmission (Carr et al. 2013).

Based on our review, we cannot conclude on the effectiveness of avatar-based patient education in reducing readmission rates. Healthcare providers considering the use of avatar-based technology as an alternative tool to standard care, should be aware that there is currently no evidence to support the effectiveness of such an intervention. As readmission is an important clinical outcome, it is recommended that future studies of avatar-based patient education interventions include readmission as an outcome measure.

The findings of this systematic review have shown that avatar-based technology is an effective strategy to improve knowledge, self-care behaviours and self-efficacy of patients with chronic illness.

From a systematic review undertaken previously by Annaim et al. (2015) and Charlier et al. (2016), the use of interactive education technology and serious game interventions improved patients' knowledge and self-care behaviour and skills (Annaim et al. 2015; Charlier et al. 2016). However, as clinical outcomes were not measured in any of the studies reviewed, it is unclear whether changes in patient knowledge and self-care behaviours that are attributable to avatar-based education, will have effects on clinical outcomes. The paucity of studies shows a gap in research on the use of avatar-based technology to educate patients with chronic conditions.

2.10 Limitations of the review

This systematic review had some limitations. The lack of eligible studies may have been a consequence of the search strategy itself. With the avatar-based technology patient education review, our searches were designed to be sensitive, but the search strategy was still designed to answer a specific research question. As the RCT filter was not applied to the search, this review has identified all types of studies.

The actual concept of an avatar itself presented some interesting challenges, as our preliminary searches using the term alone resulted in quite limited finds. Consequently, we ended up with a relatively broad search term for the concept to cover alternative terms that may have been used to describe what we understood as an avatar. Interestingly, authors have defined the term 'avatar' differently, such as animation, virtual reality, virtual environment, video game, interactive computer program and a commercial game. Although we conducted a comprehensive search across electronic databases, eligible studies might still have been missed if avatar-based technology was not defined or described as such in these studies.

The inclusion criteria were restrictive and may have limited the number of RCTs in this review. While most single-group studies in this review demonstrated positive outcomes, without a comparison group the validity of their causal inferences is weak.

In addition, this review included only studies published in English, which means that potential eligible studied published in other languages were excluded.

2.11 Conclusions and recommendations

Avatar-based technology for patient education can have a positive effect on a wide range of healthcare outcomes. Its intervention can improve knowledge, self-care behaviours and self-efficacy in patients with chronic conditions. Based on the findings of this review, there was limited evidence that its use improves HRQOL and adherence to medication, and no evidence on its effect on readmission rates.

2.11.1 Recommendations for practice

The following preliminary suggestions can be made:

- Avatar-based technology in patient education is an effective method to deliver health information.
- Avatar-based interventions should be considered to support education of patients from rural and remote locations where access to face-to-face interventions are limited.

2.11.2 Recommendations for research

- Future evaluations of avatar-based patient education, in RCTs with appropriate power, are needed to establish its effectiveness.
- Future research should explore how avatar-based patient educational interventions can be tailored to the characteristics and needs of different patient groups.
- Important clinical outcomes, such as readmission rates, should be considered in future studies to evaluate the effectiveness of the intervention.

2.12 Acknowledgements

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2.13 Funding

No funding was received for the systematic review.

2.14 Conflicts of interest

The authors disclose that there were no conflicts of interest.

2.15 Conceptual framework of the study

Health behaviour theories and models have been applied in prediction, explanation and understanding not only health behaviours, but also providing a basis upon which programs for improving health are able to develop and evaluate.

Self-monitoring and adherence to treatment recommendations are two important aspects of self-care in HF and interrelated concepts. Self-monitoring consists of monitoring, interpretation and response; therefor, better self-monitoring indicates better self-care behaviour. In this chapter, two commonly used theoretical models were briefly introduced: Bandura's social cognitive theory and Riegel's HF self-care theory.

2.15.1 Bandura's self-efficacy theory

The evidence from the literature review indicates that a great deal of emphasis is focused on self-efficacy including self-management interventions and the development of models. Thus, for development of an appropriate model of this study, it is essential to understand self-efficacy theory. The concept of self-efficacy exists is centred to Bandura's social cognitive theory (Bandura 1977).

Self-efficacy is defined as 'the conviction that one can successfully execute the behaviour required to produce the outcome' (Bandura, Adams & Beyer 1977, p.193). The further definition has been described to an individual's 'beliefs about their abilities to exercise control over events that affect their lives' (Bandura 1989, p.1175) and 'beliefs in their capabilities to mobilize the motivation, cognitive resources, and courses of action needed to exercise control over task demands' (Bandura 1990, p.316). Self-efficacy is associated with the attitudes, abilities and cognitive skills of a person; therefore, it varies from person to person (Bandura 1977).

The level of self-efficacy has a great effect on how a person perceives situations and responds to different circumstances. Especially, an increase in self-efficacy improves skills to understand tasks, construct and evaluate the course of actions, set proximal goals and motivate engagement in activities (Bandura 2006). There are two cognitive components that characterise self-efficacy: efficacy expectations and outcome expectations (Bandura 1977). In other words, to achieve

outcomes, confidence in ability (efficacy expectation) and the belief that behaviour results in success (outcome expectation) are required (Bandura 1982).

In some circumstances, there is no association between efficacy and outcome expectations. This occurs where the outcome is loosely connected to the level or quality of the performance or when it is anticipated that an action will not result in a specific outcome, (Bandura 1986). Bandura (1977) also argued that self-efficacy is multifaceted, and proposed four factors that influence judgement of one's capabilities: mastery experience, role modelling, social (verbal) persuasion and emotional states. The source of self-efficacy is shown in Figure 2.2.

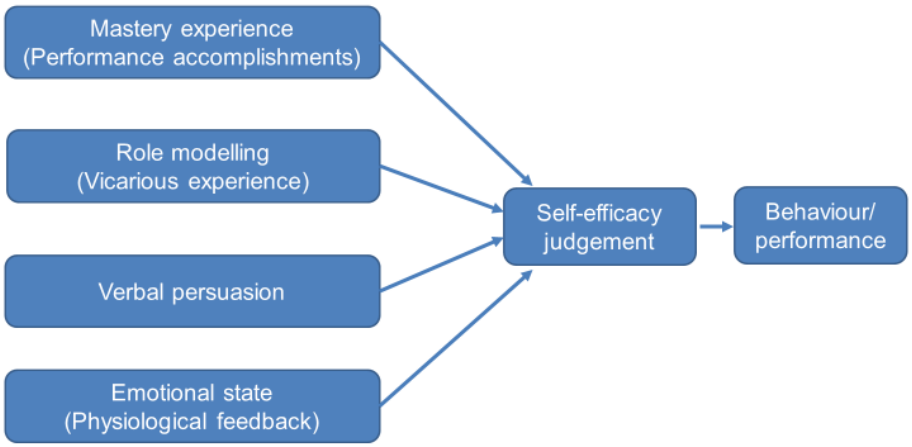


Figure 2.2 The sources of self-efficacy

The first factor, mastery experience (performance accomplishments), refers to the successful experience of performing a task which develops and is achieved by learning through personal experience (Bandura 1977). Once a person becomes successful in performing a difficult task, self-efficacy increases. Mastery experience is considered the most effective factor influencing self-efficacy (Bandura 2006), and is also the most commonly incorporated component in interventions designed to strengthen efficacy expectations in older adults.

The second factor, role modelling (vicarious experience), relates to a learning experience that occurs through role modelling and/or observation of actions (Stretcher et al. 1986). The models perform a set of behaviours that demonstrate a certain principle, rule or response. Alternatively, observing and

attending a successful model who has overcome a complicated task can improve a person's expectations of mastery (Bandura, Adams & Beyer 1977). A powerful model in this setting must be seen as an individual who overcame barriers through a determined effort rather than with ease (Bandura, Adams & Beyer 1977). Role modelling is impacted by various conditions. For example, if an individual has not been presented to the behaviours or has had minor introduction to it, role modelling is probably going to have a more noteworthy effect. Effective behaviours likewise happen when clear rules for performance have not been clarified (Smith & Liehr 2018).

The third factor is verbal persuasion, which is an easy and available method and has been widely applied in education as well as by healthcare providers (Stretcher et al. 1986). Further, the evidence suggests that verbal persuasion is effective in enhancing recovery from chronic illness (Smith & Liehr 2018). Persuading people through verbal suggestion supports them to believe they can manage effectively to a specific task that has overcome them previously (Bandura 2006). It is argued that verbal persuasion will increase self-efficacy through effective communication and feedback, to guide a person through the task or to motivate them to make their best effort (Stretcher et al. 1986). This factor is likely to be weaker than other sources of self-efficacy (Bandura 1977).

The fourth factor is emotional state (physiological feedback) that shapes judgement of one's capacities. It is considered that people are more likely to experience failure when they are very tense and agitated. For example, those who experience severe anxiety prior to talking publicly find that their self-efficacy decreases (Bandura 2006). Likewise, if patients with HF are fearful of a cardiac event when they exercise, an exceptionally emotional state related to that fear may influence action and reduce confidence in the capacity to display the action.

Physiological factors play an important role in managing with stressors, physical achievements and health functioning. Therefore, interventions can be employed to change individual physiological feedback to help people adapt to physical sensations and in turn, enhance self-efficacy and improve performance. The proposed interventions involve visualising mastery to eliminate emotional reaction to a given situation (Bandura, Adams & Beyer 1977), enhance physical status (Smith & Liehr 2018) and alter the interpretation of bodily states (Schnoll et al. 2011). Improved self-efficacy in adults is

an effective and persistent factor in enhancing competence (Stretcher et al. 1986). Patients with high self-efficacy are more willing to learn and focus on accomplishing goals. People with low self-efficacy are more likely to avoid performing a task (Bandura 2006).

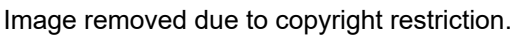
Similar to other clinical and psychosocial problems, the behaviour of heart disease patients can be predicted employing self-efficacy theory (Chen et al. 2014). The evidence indicates that self-efficacy demonstrates an optimistic view that supports improve people's behaviour. Further, it has been revealed that self-efficacy has a strong effect on patient with HF behaviour in terms of developing self-management skills and overcoming obstacles (Barnason, Zimmerman & Young 2012; Chen et al. 2014; Riegel, Lee & Dickson 2011). HF patients with a higher level of self-efficacy have been shown to manage their condition better in terms of performing daily activities such as weighing themselves, doing physical activity and avoiding salt in their diets (Riegel, Lee & Dickson 2011; Yehle et al. 2013). In contrast, patients who had lower or no self-efficacy performed ineffectively because they did not believe they could make a difference (Chen et al. 2014; Yehle et al. 2013).

Therefore, a significant body of research has established an important association between self-efficacy and patient-related outcomes (Chen et al. 2014; Warren-Findlow, Seymour & Huber 2012).

2.15.2 Riegel's heart failure self-care theory

Self-care is defined as a naturalistic decision-making process that effects actions to maintain physiological stability, facilitate the perception of symptoms and direct the management of symptoms. There are three processes of self-care: self-care maintenance, symptom perception and self-care management (Riegel, Dickson & Faulkner 2015).

First, self-care maintenance is treatment adherence and healthy behaviours. Second, symptom perception involves symptom monitoring and recognition in addition to body listening, symptom interpretation and labelling. Third, self-care management is the reaction to symptoms when situations happen. All three processes have an autonomous and a consultative element (Riegel, Dickson & Faulkner 2015). The diagram of the self-care process is presented below (Figure 2.3).



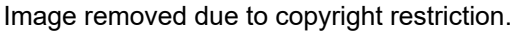
Source: From Riegel, Dickson & Faulkner (2016, p.227)

Figure 2.3 The diagram of self-care process

Self-care decisions by patients with HF are influenced by the naturalistic decision-making circumstances of the person, problem and environment, and are also influenced by knowledge, skills, experience and values. Effective self-care decisions may impact by the person's characteristics, problem manifestations and even the environment (Riegel, Dickson & Faulkner 2015). The decision rules depend on individual experience and accessible practical information. Therefore, a similar condition may make a different decision if the setting and available information are different.

Decisions about HF self-care are performed daily, and naturalistic decision-making is implemented at each stage of the self-care process. Factors influencing a decision about self-care include knowledge, skill and compatibility with personal values. The significance of knowledge in HF is that it is a determinant of self-care, particularly self-care with respect to dietary sodium restriction and adherence to medication (Lainscak et al. 2011; Macabasco-O'Connell et al. 2011; Strömberg, Dahlström & Fridlund 2006). As a result, knowledge is one important factor affecting self-care: skills in both decision-making and acting on the decision, are required to carry out successful self-care behaviours. In addition, the chosen action or behaviour must be compatible with one's values. The link between the situational characteristics, the factor influencing the decision-making process and self-care action, are illustrated in Figure 2.4.

In conclusion, self-care appears to be a direct process proceeding from maintenance, to symptom perception, to management. In this conception of self-care behaviour, the management of symptoms is the highest, most refined self-care behaviour requiring the most knowledge and skills.



Source: From Riegel, Dickson & Faulkner (2016, p.228)

Figure 2.4 The link between the situational characteristics, the factor influencing the decision-making process and self-care action

2.16.3 Conceptual framework of avatar-based applications in education

The conceptual framework of avatar-based educational applications is based on the concept of self-efficacy as positioned within Bandura's self-efficacy and in Riegel's heart failure self-care theory. The elements of an avatar-based educational intervention consist of literacy, health literacy, patient engagement, language and culture. The intervention specifically aims to improve knowledge, self-efficacy and self-care behaviour.

However, the successful development of an avatar-based application must be informed by andragogical principles and understanding, knowledge of adult learning, and sensitivity to low literacy and culturally and linguistically diverse (CALD) needs of communities.

Avatar education interventions are innovative technologies to communicate and deliver health information using interactive animation and provide the patient with a multi-modal option for learning.

The conceptual framework of an avatar-based educational application is illustrated in Figure 2.5, and the concept of an avatar-based application is shown in Figure 2.6.

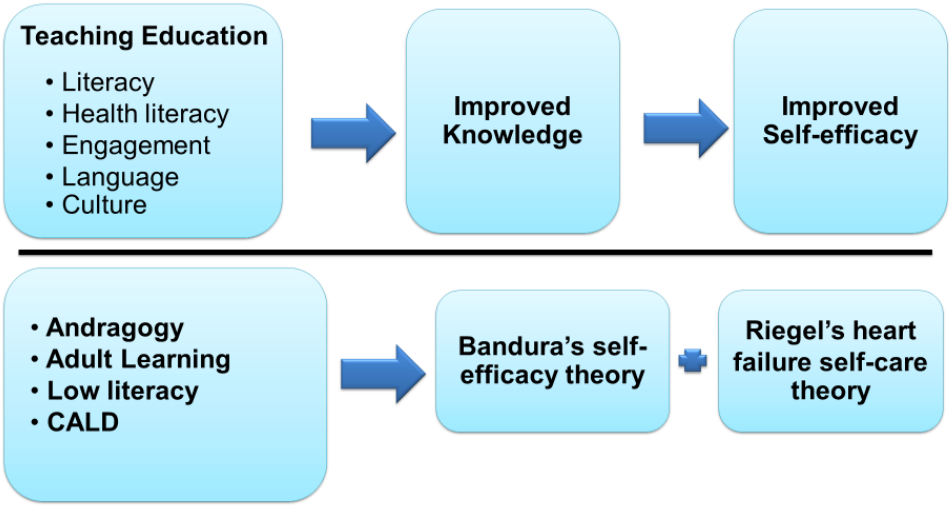


Figure 2.5 The conceptual framework of an avatar-based educational application

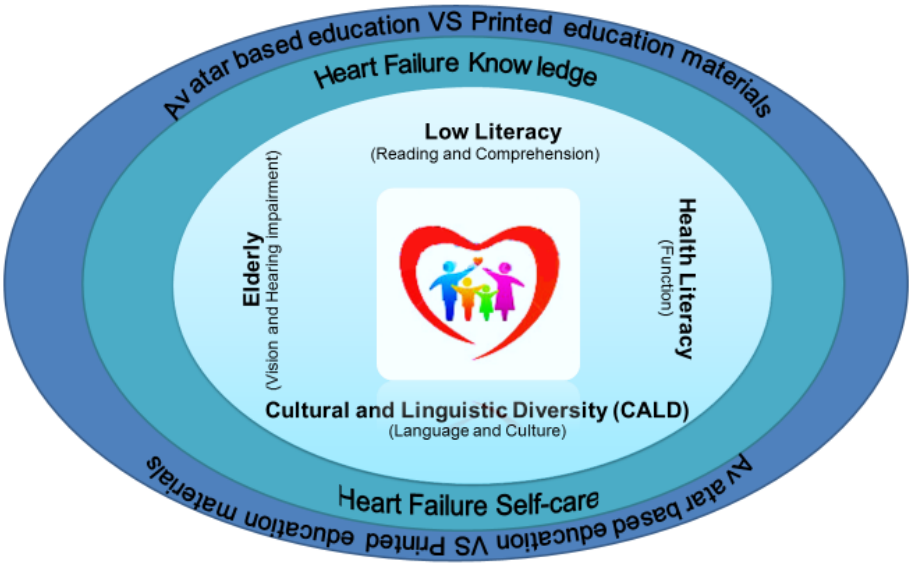


Figure 2.6 The concept of an avatar-based educational application

2.16 Chapter summary

The findings of this systematic review showed that avatar-based technology is an effective strategy to improve knowledge, self-care behaviours and self-efficacy of patients with chronic disease. The paucity of studies shows a gap in research on its use in education of patients with chronic conditions. Avatar-based technology is a sophisticated tool that would allow the development and delivery of

health information to patients so that they can gain more knowledge and self-care behavioural skills. The conceptual framework of an avatar-based educational application is based on the concept of self-efficacy, as proposed by Bandura's self-efficacy and Riegel's HF self-care theories. The educational elements of an avatar-based intervention consist of literacy, health literacy, patient engagement, language and culture, although its specific aims are to improve knowledge and self-care behaviour skills.

Thesis flowchart	Publications
Chapter 1 **Background and significance of the study** Why is heart failure self-care important?	
Chapter 2 **Literature review** - What are the current research interventions to improve self-care knowledge and behaviours? - What is the best conceptual framework for the thesis?	Wonggom, P, Tongpeth, J, Newman, P, HuiYun, D & Clark, R 2016, 'Effectiveness of using avatar-based technology in patient education for the improvement of chronic disease knowledge and self-care behavior: a systematic review protocol', *JBI Database of Systematic Reviews and Implementation Reports*, vol. 14, no. 9, pp. 3-14. Wonggom, P, Kourbelis, C, Newman, P, Du, HY & Clark, RA 2019, 'Effectiveness of avatar-based technology in patient education for improving chronic disease knowledge and self-care behavior: a systematic review, *JBI Database of Systematic Reviews and Implementation Reports*, vol. 17, no. 6, pp. 1101-29.
Chapter 3 **Methodology** What research design is best suited to develop and design an app for teaching?	
Chapter 4 **Results** - How can HF and IT experts and consumer participation develop an avatar-based educational application to teach heart failure patients self-care? - What is the effectiveness of an avatar-based educational application for improving patients' knowledge and self-care behaviours?	Wonggom, P, Du, H, Burdeniuk, C, Kelman, S, Wight, J, Bellchambers, T, Nolan, P, Barry, T & Clark, RA, (submitted), 'Development and feasibility testing avatar-based education application in heart failure', *European Journal of Cardiovascular Nursing.*
Chapter 5 **Conclusions and Implications** - What are the findings and conclusions? - What are the limitation of the study? - What are the implications for policy, practices and research?	

CHAPTER 3: RESEARCH METHODOLOGY

3.1 Chapter overview

This project aims to develop and evaluate an avatar-based education intervention to improve knowledge and support self-care in patients with HF. To achieve the goals of this project the sequential exploratory mixed method design was used, involving the collection of qualitative data first, then quantitative data. This chapter presents the research methodology employed in this study. First, PAR was used to develop an avatar-based educational application to equip patients with HF with knowledge about their disease and skills in self-care. Second, a feasibility study was used to evaluate the effectiveness of the avatar-based application on patients' knowledge and self-care behaviours.

3.2 Introduction

The rationale for improving knowledge and supporting self-care behaviours in patients with HF has been explained in Chapter 1. PAR is a method for improving practices and involves action, evaluation and critical reflection based on the evidence gathered, followed by changes in the implementation of practice (Klein 2012). The process of PAR consists of the continual evolution of these four essential components of the process, which represents a self-reflective spiral or loop that is repeated depending on the scope, purpose and outcome of the research (Kemmis 2009). In this project, PAR involves two cycles and three steps of action and reflection involving multidisciplinary collaboration of various experts and consumer reviews in the phase of developing an avatar-based application.

A feasibility study is a commonly used approach to evaluate complex interventions and services. Accordingly, a feasibility study was conducted to evaluate the effectiveness of the avatar-based application on knowledge and self-care behaviours on patients with HF.

3.3 Study I: Participatory action research

3.3.1 Rationale for the participatory action research

PAR is a method of collaborative research that seeks to create self-critical communities as a basis for change. The principle of PAR can be identified in projects conducted in different settings including

education (Hagevik, Aydeniz &Rowell 2012), mental health (Katsikitis et al. 2017), nursing (Fredericks et al. 2013) and primary health care (Cordeiro & Soares 2018); however, its application in the culture of healthcare organisations and the context of healthcare services require further consideration. Regarding, the primary purpose of the PAR process is to impact social changes with a specific action as the ultimate goal of better formulating health care deliver by an individual's feelings, views, and patterns of participants (MacDonald 2012). In addition, a key reason PAR has had a powerful effect on nursing practice is its ability to examine afresh the high degree of autonomy that is more often enjoyed by healthcare professionals and patients, to assess patient-centred problems, action plans and their implementation and evaluate the outcomes (Williamson, Bellman & Webster 2011).

PAR processes allow healthcare researcher to target individual groups to involve in action and self-reflection in the practical solutions to solving issues (Bradury 2016). These processes emphasis on critical reflection by employing engagement and collaboration through individual group members (Kemmis, McTaggart & Nixon 2013). Therefore, the application of PAR to nursing and healthcare practice to change practices or generate new theories about the role of nurses in healthcare services is appropriate.

The spiral of cycles of self-reflection include planning, acting and observing, reflecting and replanning has become the dominant component of PAR for collaborative between multidisciplinary team and patient to make changes in the practices (Kemmis, McTaggart & Nixon 2013). The key important features of self-reflective spiral of PAR are a social process, participatory to engage people in examining their understanding and interpreting in the social learning process, practical and collaborative the social interaction, reflexive to help people to investigate for changing their actions and transform evident to actual practices (Kemmis, McTaggart & Nixon 2013). These features summarize some of the principal features of PAR. As a result, PAR has an orientation to construct knowledge co-production from practice and requires researchers to collaborate with different groups of consumers, practitioners or healthcare providers (Bradury 2016; Stapleton 2018).

Peer teaching is defined as the involvement one or more people teaching other people in specific area or knowledge and contribute to the belief for its benefits on cognitive level, affective level and peer learning (William & Fife 1988). The concept of peer teaching was used to develop the avatar-based educational application. Turner and Shepherd (1999) stated that the justifications for adopting peer teaching include: 1) a credible source of information, 2) empowerment of the people involved, 3) information sharing and advice, 4) achievement of greater success than if professionals delivered the health information; 5) positive role models; 6) acceptability of new information and 7) reinforcement of learning through continuing contact (Turner & Shepherd 1999).

In this project, PAR was conducted in the development of an avatar-based patient educational application to obtain feedback from technology specialists, patients and their families, and from cardiovascular specialists about its technical specifications and guidelines, its features and the information in the application.

3.3.2 Aim

This study aims to improve disease-related knowledge and self-care behaviours of patients with HF, by engaging them in the development of an avatar-based educational application about HF.

3.3.3 Objective

The objective is to develop an interactive avatar-based educational application through the participation of cardiovascular experts, IT experts and consumers.

3.3.4 Participatory action research plan in this study

The evidence suggests that IT can assist with self-care behaviours (Greenwood et al. 2017; Inglis et al. 2015). In addition, IT interventions can describe improvements in knowledge, QOL, reduce readmission rates and associated costs, and in turn, these benefits help patients to use the IT (Inglis et al. 2015; Or, Tao & Wang 2016).

To address the research objectives, the cycle of PAR was employed. The PAR represents a multidisciplinary collaboration that includes experts in HF and in IT, as well as consumer groups and the Heart Foundation Australia. The development or action component of the PAR in this project

involved two cycles of PAR and three stages of action and reflection. Feedback from three participant groups informed the development of the application.

3.3.5 Development of avatar-based educational application

3.3.5.1 Study design

The PAR method was used to develop the application. PAR is a collaborative and participative approach to a problem that supports self-critical reflection to improve practice and outcomes (Bradbury & Lifvergren 2016; Kemmis, McTaggart & Nixon 2013; Wicks & Reason 2009). This PAR represents a multidisciplinary collaboration that actively engages cardiovascular research and IT experts and consumer groups in individual reflection and feedback on the components of the HF educational tool. In this study, the action research involves iterative cycles of planning, acting, observing, reflecting and replanning (Kemmis & McTaggart 2005).

3.3.5.2 Development of the application: Participatory action research

The development component of the PAR involves two cycles and three stages of action and reflection by participants in the study (Figure 3.1). Three participant groups were recruited, namely, 1) consumers with a confirmed diagnosis of HF who were able to use a smartphone and who spoke English; 2) cardiovascular experts consisting of cardiologists, cardiac nurses, a cardiac nurse practitioner and cardiac research academics and 3) IT experts. A focus group discussion and individual interview methods were conducted to obtain, review, and reflect on feedbacks on the development of the application.

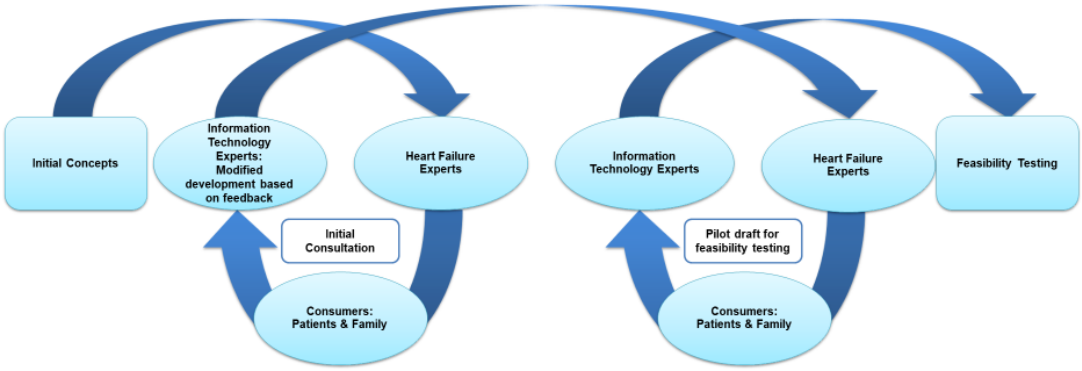


Figure 3.1 The action research cycles of developing the avatar-based application

3.3.5.2.1 Step one: content development

The content of the avatar-based application was developed by a panel of clinical and research experts, and drew on evidence-based medical information from a well-known and highly reliable resource, the National Heart Foundation of Australia's booklet, *Living Well with Heart Failure* (National Heart Foundation of Australia 2016).

Cardiovascular experts were engaged to review the content storyboard and question bank through a focus group discussion. Their participation in action and reflection related to the content storyboard and question bank, and their contributions informed the design of the avatar character, picture, language, voice, content, user-friendliness and expected benefits. The cardiovascular experts consisted of two cardiologists, five HF nurse educators, seven cardiovascular researchers and a PhD candidate.

Based on the expert panel's recommendations, cardiovascular researchers developed the content of the avatar application in a storyboard with a question bank using PowerPoint. The content storyboard consisted of four main sections: 1) understanding HF, 2) looking after yourself, 3) things to do every day and 4) emergency action plan. Each main section included subsections. For example, section four includes an HF action plan and a heart attack action plan.

The questions in the question bank were used for a quiz at the start of the application and after completing each subsection. The question at the end of each subsection was randomly selected from the question bank each time the participant reviews that section. The storyboard and question bank were subsequently presented to consumers, including six patients with HF and two family members of HF patients for comment.

Audio recording and field notes were used to collect data. Revisions to the storyboards were made on the basis of comments by the patients and their families, and then presented to the IT experts for development of the application.

3.3.5.2.2 Step two: application development

The avatar application was developed by a team of IT experts. The storyboard content was translated into multiple application screens that incorporated interactive components to segue between each other, based on user input. The avatar technology platform was developed by a commercial application development company. The avatar application responds to varying speech, facial expressions, body gestures and touch-based interaction. In creating an avatar, the consumers are able to customise to their own characteristics; for example, hair, eyes, skin colour and eyeglasses. This customisation feature encourages user engagement. Speech by the avatar was recorded by a voice actor and dynamically recomposed to match the behaviours of the avatar. To enable a consistently engaging experience, the application was developed for tablets with either IOS or Android platform.

3.3.5.2.2 Step three: consumer review

Five patients with HF and one family member were recruited from an HF outpatient clinic to review the first storyboard version of the avatar-based application. The time taken by each patient to review the application was recorded. The relevance of the avatar character, the application's design, images, language, visual presentation as well as the size of the print on screen, the buttons on the touch screen, audio quality and content of the health information, were reviewed through an individual feedback session between the participants and the researchers. Audio recording and field notes were used to collect data during the interview.

In this development process, further changes to the design were suggested to make the application more accessible for people from different languages and cultural backgrounds. However, in this study only an English version was developed; therefore, only patients who could communicate in English were recruited for the development of this application.

Following the above three steps of content and application development and consumer review, the application was reviewed by researchers and presented to IT experts. This stage consisted of a report from the researchers, including comments from the consumer groups and recommendations for revision. Both the content and technological aspects of the application were modified by the cardiovascular and IT experts. Two cycles of review and an update of the application occurred before the avatar-based application was finalised. Table 3.1 presents the semi-structured questions that were asked during the development of the avatar-based education application.

3.3.5.3 Data collection

The avatar-based education application was developed and revised through each PAR cycle. Within each action research cycle, cardiovascular and IT experts provided their feedback through a focus group discussion meanwhile patients with HF and their family members reflected their views through individual interview method.

3.3.5.3.1 Designing focus group and individual interview question

For the focus group open-ended and semi structured questions were used to encourage open discussion, refection, and flexibility. These questions based on the literature relationship of the aspects of designing and development the avatar-based education technology in patient education. Topic themes were used to construct the questions including the contents of HF and aspects of the avatar-based application. Probing approach was used to gain more details and using closed or directed questions were avoided.

3.3.5.3.2 Recruiting and preparing for participants

A total 15 cardiovascular and research experts were involved in avatar-based application development from a HF outpatient clinic at a public hospital, the Integrated Cardiovascular Clinical Network, and the National Heart Foundation were recruited through a focus group discussion. Two IT experts were recruited from a commercial application development company. Six patients with HF

and two family members of patients with HF were recruited from a HF outpatient clinic at a public hospital using individual interview

3.3.5.3.3 Focus group and individual interview confirmation

Once the group was organised, each participant was telephoned and/or sent an email to confirm their interest and availability. Participants were also informed of the time and location of the focus group meetings via phone or email. A written confirmation letter to the recruits through an email and call to remind participants two days before the scheduled time were performed.

3.3.5.3.4 Time management

The focus group discussion was 1-2 hours. Participants were invited to attend 15 minutes prior to the actual start time for allowing for filling out necessary paperwork and having a bite to eat and setting into the group.

3.3.5.3.5 Place

The researchers arranged a comfortable room in a convenient location at local health facilities based on the participating group. The room had a door for privacy, a table and chairs to seat a circle up to 10 people including observers and the moderator.

3.3.5.3.6 Offer an incentive

Refreshments were provided during the focus group discussion and individual interview. A car park ticket was provided to participants.

3.3.5.3.7 Recording procedure and consent

Audio recording and field notes were used in data collection during the meeting to record the conversations and help the researchers recall the conversations at a later time. The participating group discussion and individual interview were recorded and these recordings were stored in a locked filing cabinet in the researcher's office. Electronic data was stored and maintained kept on the university network computer, which is password protected and only accessible to identified researchers.

The participants were asked to read the participant information and consent form, and the researcher verbally explained this research involvement and answered any questions. Once the participant

original written inform consent was signed and returned, the audio recording device was only be used if participants gave permission to have the conversation recorded. These audio recordings were transcribed verbatim. Table 3.1 presents the semi-structured questions that were asked during the development of the avatar-based education application.

Table 3.1 Semi-structured questions for the development of the avatar-based educational application

Question	Theme
1. What do you think about the character/avatar within the application?	Design
2. What do you think about the pictures within the application?	Picture
3. How about the language used within the application?	Language
4. What do you think about the audio of the application?	Voice
5. How about the contents of the application?	Content
6. What do you think the size of the print on screen?	User-friendliness
7. What do you think about the buttons on the touch screen?	User-friendliness
8. Overall, how do you feel about using the application?	Satisfaction
9. Do you think this application would be useful to you?	Benefit
10. What aspects of the application do you like the most?	Application development
11. What aspects of the application you don't like? How would you like it to be changed?	Application development
12. What other things do you think could be improved in the next version of the application?	Application development
13. Any other comments for our research team to consider.	Application development

3.4 Study II: feasibility study

3.4.1 Rationale for a feasibility study

A feasibility study is a type of research done prior to a main study and is used to estimate important limitations that may aid in the design of a main study (Arian et al. 2010; Polit & Beck 2018). Feasibility studies are routinely performed in many clinical areas including critical care (Arnold et al. 2009), mental health (Kuyken et al. 2013), cardiovascular trials (Cossette et al. 2016; Tongpeth, Du & Clark 2018). A feasibility study is used to determine the viability of an idea, such as ensuring a study is legally and technically feasible as well as economically justifiable. The purposes of a feasibility study

consist of testing study procedures, validity of tools, estimation of recruitment rate, and estimation of parameters such as the variance of the outcome variable to calculate sample size (Arian et al. 2010; Thabane et al. 2010).

The purposes of our feasibility testing were to assess the feasibility of the steps that need to take place as part of a pragmatic RCT including determining recruitment rates, investigating the length of time to review the application or fill out all the survey forms, assessing personnel and data management issues at participating centres, and evaluating application safety. Further, to pilot the avatar-based educational application in the real practice, which was an important preliminary research step for testing the effectiveness of the application on knowledge of HF and self-care behaviour skills.

3.4.2 Objective

The objective of the feasibility study was to evaluate the avatar-based educational application, including its acceptability to its intended users (patients with HF) and its effects on their knowledge and self-care behaviours.

3.4.3 Participants

Patients with an HF diagnosis attending a public HF outpatient clinic in South Australia were invited to evaluate the application. The inclusion criteria for participants in the study II were: 1) patients with a confirmed diagnosis of HF, 2) attendance at the HF outpatient clinic, 3) ability to use a smartphone and 4) ability to speak English. The exclusion criteria were that the patients 1) have a major and uncorrected hearing loss, 2) are ‘clinically unstable’ (‘clinically unstable’ was defined as patients who do not achieve the five normal vital signs based on heart rate, systolic blood pressure, respiratory rate, oxygen saturation and temperature) and normal mental status and ability to eat for at least 24 hours prior to enrolling in the study 3) have cognitive impairment and 4) refused to give informed consent.

3.4.4 Study procedure

Participants were asked to complete the Dutch Heart Failure Knowledge Scale (DHFKS) and the Self-Care Heart Failure Index (SCHFI) before and after they reviewed the educational application,

and also asked to indicate whether the application would make a difference to their knowledge about HF and self-care behaviours. After reviewing the application, participants were asked to rate their level of agreement with a number of statements about their perception of the clarity, content and technical quality of the application.

3.4.4 Instruments

The three questionnaires used in Study II were in Appendix 5. Two validated questionnaires were used to evaluate HF patients' knowledge of their disease and their self-care behaviours. A third questionnaire, regarding participants' satisfaction with the avatar-based application, was developed by the researchers.

The Dutch Heart Failure Knowledge Scale

The patient's knowledge about HF was measured by the DHFKS, which consists of 15 multiple choice items. The scale has a minimum score of zero points (no knowledge) and a maximum score of 15 points (maximum knowledge). Cronbach's α of the DHFKS was reported to be 0.62 (van der Wal et al. 2005)

The Self-Care of Heart Failure Index

The self-care behaviours of the patient wth HF were assessed by the SCHFI (version 6.2), which is a survey consisting of 22 questions. Each of the three components of the index has been tested for reliability (maintenance component: coefficient alpha = 0.553; confidence component: coefficient alpha = 0.827; management component: coefficient alpha = 0.597). The possible range of total score on the index is 0 to 100. A score ≥ 70 has been suggested to indicate adequacy of self-care (Riegel et al. 2009b).

The avatar-based application satisfaction questionnaire

The avatar-based application satisfaction questionnaire was adapted from previous research on surveys measuring satisfaction with educational materials (Clark et al. 2015; Wakefield et al. 2008). It consists of 15 Likert-scale items that refer to the avatar's design, audio, visual quality, content,

usefulness and user-friendliness. Open-ended questions in the questionnaire were used to gain feedback about the application.

3.5 Data analysis

Qualitative data from the focus group discussion and individual patient interviews were analysed by identifying the common themes. Thematic analysis is the most common process of identifying, analysis and reporting patterns or themes within qualitative data to emphasize organization and rich description of the data set (Braun & Clarke 2006; Vaismoradi, Turunen & Bondas 2013). The Braun and Clarke's six phase process for thematic analysis was used to analyse the collected data from the focus group discussions and the individual patient interviews including becoming familiar with the data, generating initial codes, searching for themes, reviewing themes, defining and naming themes, and producing the report (Braun & Clarke 2006).

After completing data collection, focus group discussions and individual patient interviews were transcribed verbatim to feel familiar with the content of the data and to identify overt patterns or repeated information from one or more interview. Following the completion of the transcription process, generation of the initial codes from the data set was conducted, these were based on the research question of the development of the avatar-based educational application. The codes were organised into broader themes for specific to this research question. A review of the themes was conducted to modify and develop the final themes. The themes regarding the development of the avatar app were presented in the final analysis. After the final themes were reviewed, the process of describing the components of an effective avatar-based education application were presented as six categories (Braun & Clarke 2006; Maguire & Delahunt 2017; Vaismoradi, Turunen & Bondas 2013).

Demographics and clinical characteristics of the participants were described using descriptive statistics including means and standard deviation or frequencies and percentage. Scores on the DHFKS and SCHFI were analysed using non-parametric tests, as they did not meet the assumption of normality under the Kolmogorov–Smirnov test. Pre-post comparisons of the DHFKS and SCHFI scores were performed using Wilcoxon signed-rank tests. Effect size was calculated and reported the power of the study. A bivariate correlation analysis of the sociodemographic and clinical

characteristics, and the level of HF knowledge and self-care behaviours, were conducted using Fisher's exact test. The level of significance was set at 0.05 for all tests in the analysis, with two-sided *p* values.

3.6 Ethical consideration

The ethical principles on which this study was conducted are based on the National Health and Medical Research Council's National Statement on Ethical Conduct in Human Research (2007). Ethics approval for this study was granted by the Southern Adelaide Clinical Human Research Ethics Committee (SAC HREC), Adelaide, South Australia (OFR#350.16-HRC/16/SAC/315) (See Appendices 6 and 7). Overall project coordination was undertaken at the College of Nursing and Health Sciences at Flinders University. The investigation conforms with the principles outlined in the Declaration of Helsinki. Written informed consent was obtained from all participants (See Appendices 8 to 10).

The key ethical issue in this study related to the vulnerability of participants who have heart conditions. To minimise coercion of participants, the medical and nursing staff first approached patients in one HF outpatient clinics. The research nurse was then introduced to individuals who expressed their willingness to participate. The research nurse explained the study procedure and provided the patient with the Participant Information and Consent Form (PICF). The research nurse read the form out aloud and explained the study in detail to potential participants so that they could provide informed consent. Participants were reminded that they could withdraw at any time during the study and that withdrawal from the study will not affect their current or future treatment. Once the patient agreed to participate in the study, they were asked to sign the written consent form.

Confidentiality was ensured by replacing the participant's name with a numerical code on all study documents. Data linking the identity of each participant to his/her participant code were kept separately and removed prior to analysis. Data collected throughout this study were stored in a locked filing cabinet in the researcher's office. Electronic data were stored and maintained on the university network computer, which is password protected and only accessible to identified researchers.

The researchers intend to publish and present the study results in high-impact peer-reviewed journals, conferences and research seminars. Only de-identified aggregated data will be presented. The researchers will provide feedback to key stakeholders such as the Department of Health South Australia by presenting outcomes at seminars and conferences.

3.6 Chapter summary

This chapter presented the methodology of the two studies in this project. A mixed-method approach was adopted: a PAR and a feasibility study. The PAR aimed to develop an interactive avatar-based educational application through the collaboration of HF experts, people with HF and their families, and IT experts. Upon development, a feasibility study was undertaken to investigate the effectiveness of the developed application on patients' knowledge and self-care behaviours. The results of the two studies will be reported in the next chapter.

Thesis flowchart	Publications
Chapter 1 **Background and significance of the study** Why is heart failure self-care important?	
Chapter 2 **Literature review** - What are the current research interventions to improve self-care knowledge and behaviors? - What is the best conceptual framework of the thesis?	Wonggom, P, Tongpeth, J, Newman, P, HuiYun, D & Clark, R 2016, 'Effectiveness of using avatar-based technology in patient education for the improvement of chronic disease knowledge and self-care behavior: a systematic review protocol', *JBI Database of Systematic Reviews and Implementation Reports*, vol. 14, no. 9, pp. 3-14. Wonggom, P, Kourbelis, C, Newman, P, Du, HY & Clark, RA 2019, 'Effectiveness of avatar-based technology in patient education for improving chronic disease knowledge and self-care behavior: a systematic review, *JBI Database of Systematic Reviews and Implementation Reports*, vol. 17, no. 6, pp. 1101-29.
Chapter 3 **Methodology** What research design is best suited to develop and design an app for teaching?	
Chapter 4 **Results** - How can HF and IT experts and consumer participation develop an avatar-based educational application to teach heart failure patients self-care? - What is the effectiveness of an avatar-based educational application for improving patients' knowledge and self-care behaviours?	Wonggom, P, Du, H, Burdeniuk, C, Kelman, S, Wight, J, Bellchambers, T, Nolan, P, Barry, T & Clark, RA, (submitted), 'Development and feasibility testing avatar-based education application in heart failure', *European Journal of Cardiovascular Nursing*.
Chapter 5 **Conclusions and Implications** - What are the findings and conclusions? - What are the limitation of the study? - What are the implications for policy, practices and research?	

CHAPTER 4 RESULTS

4.1 Chapter overview

This chapter reports the findings of the study in the form of a manuscript that has been submitted to the peer-reviewed journal, *European Journal of Cardiovascular Nursing*. The citation of the submitted manuscript is as follows:

Wonggom, P, Du, H, Burdeniuk, C, Kelman, S, Wight, J, Bellchambers, T, Nolan, P, Barry, T & Clark, RA (submitted), 'Development and feasibility testing of an avatar-based education application for in heart failure', *European Journal of Cardiovascular Nursing.*

This chapter is based on this manuscript and reports on the development of an interactive avatar-based educational application designed to teach patients with HF about their disease and self-care behaviours.

Wonggom P, Du H, Burdeniuk C, Kelman S, Wight J, Bellchambers T, Nolan P, Barry T & Clark RA (submitted), 'Development and feasibility testing of an avatar-based education application for in heart failure', *European Journal of Cardiovascular Nursing.*

[Impact Factor: 2.651]

Authorship and Guarantor

Development and feasibility testing avatar-based education application in heart failure

Parichat Wonggom RN, BNS, BPH, MNS	**Contribution** **Concept and design** **Analysis and interpretation of data** **Drafting the article and critical revision for important concepts** **Final approval of submitted manuscript**
Huiyun Du RN, PhD	Contribution Analysis and interpretation of data Revision of content Final approval of submitted manuscript
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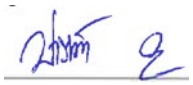
Sue Kelman RN, BN, MN	Contribution Revision of content Final approval of submitted manuscript
Justin Wight	Contribution Revision of content Final approval of submitted manuscript
Troy Bellchambers	Contribution Revision of content Final approval of submitted manuscript
Paul Nolan PhD	Contribution Analysis and interpretation of data Revision of content Final approval of submitted manuscript

Tracey Barry RN, BN	Contribution Revision of content Final approval of submitted manuscript
Robyn A Clark RN, PhD, FAHA	Contribution Analysis and interpretation of data Revision of important content Final approval of submitted manuscript

Candidature Parichat Wonggom



Signed 23 April 2019

Guarantor

I certify the fidelity of the authorship and act as guarantor for all data.

Signed 23 April 2019

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4.2 Development and feasibility test of an avatar-based educational application for heart failure patients

4.2.1 Abstract

Background: Self-care is important for preventing avoidable hospitalisation and achieving optimal patient outcomes. Interactive patient educational technology has been developed to promote self-care and to improve knowledge and health outcomes of heart failure patients.

Aims: To develop and evaluate an interactive avatar-based educational application to improve the knowledge and self-care behaviours of patients with heart failure.

Methods: Participatory action research and feasibility test using pre-post comparison methods.

Results: Six HF patients, two HF family members and 15 cardiovascular and IT experts were involved in the design and development of the avatar-based educational application through two cycles of development and critical reflection. After each cycle of development and critical reflection, the application was revised to improve user experience of avatar characteristics, illustration, concepts and random quizzes.

Subsequent to the revision of the educational application, 13 participants (67 ± 13 years, 76.9% male) were recruited to assess the application's feasibility for improving HF knowledge and self-care behaviours. After using the application, there was a significant improvement in HF knowledge (median [IQR]: 80.0 [70.0 – 93.3] to 86.7 [76.7 – 96.7], $p = 0.020$), self-care maintenance (82.5 [70.0 – 82.5] to 85.0 [77.5 – 96.3], $p = 0.027$) and self-care confidence (75.0 [72.9 – 91.7] to 100.0 [95.9 – 100.0], $p = 0.002$). Self-care management did not significantly improve (62.5 [72.7 – 91.7] to 75.0 [29.2 – 93.8], $p = 0.113$). Overall of the participants' satisfaction with the revised avatar application was high at 90%.

Conclusion: An avatar-based educational application is feasible for improving HF knowledge and self-care behaviours among patients with HF. Employing a PAR method is important in the design and development of applications to improve user experience and health-related outcomes.

Keywords: avatar-based education, application, knowledge, self-care behaviours, action research, heart failure

4.2.2 Introduction

HF is a global pandemic affecting an estimated 26 million people worldwide. Further, the prevalence of HF is expected to increase by 46% from 2012 to 2030 (Benjamin et al. 2018; Savarese & Lund 2017). The increasing prevalence of HF will be a major cause of health expenditure, mortality, morbidity and reduction in HRQOL (Benjamin et al. 2018). Engaging in self-care behaviour results in lower rates of hospitalisation, better QOL and lower mortality (Lee et al. 2018). Therefore, effective self-care behaviours will reduce preventable rehospitalizations and lower the healthcare costs of HF.

Health literacy is defined as the capability of people to understand health information and services and take appropriate health decisions and actions in their lives (Australian Commission on Safety and Quality in Health Care [ACSQHC] 2014). Over half of Australians (60%) have low health literacy (ACSQHC 2014), and almost half (47%) of the European population have limited health literacy (Sørensen et al. 2015). Lower levels of health literacy are associated with limited knowledge of, access to and use of, healthcare services for HF, and with reduced health outcomes for patients (Berkman et al. 2011; Cajita, Cajita & Han 2016). Accounting for the health literacy of patients is crucial when developing and delivering educational interventions (Cajita, Cajita & Han 2016). Multiple strategies that incorporate patient-specific information should be used, rather than general information, to serve the patient's needs (Cajita, Cajita & Han 2016; Friedman et al. 2011).

An avatar is defined as an animation of a human or embodied conversation agent that is designed to enhance interaction in the digital environment or virtual cyberspace. Avatar technology can express emotion, perform various gestures and actions and assist users to actively participate in the technology (Peterson 2005).

Avatar-based patient educational technology has shown positive outcomes in chronic diseases such as cancer, diabetes and HF, in terms of improving the knowledge, self-care behaviours and self-efficacy of patients (Annaim et al. 2015; Clark et al. 2015; Kato et al. 2008; Rosal et al. 2014). Previous research findings also suggest the benefits of applying a participatory approach and patient engagement in developing educational interventions (Cajita et al. 2017; Fredericks et al. 2013).

Therefore, the primary aim of this study was to develop an avatar-based educational application for patients with HF using a participatory research approach. Subsequent to achieving the primary aim, the final application was tested for feasibility in improving HF knowledge and self-care behaviours in a small cohort of patients with HF.

4.2.3 Aim and objectives

This study aims to improve the HF patient's knowledge and self-care behaviours through consumer engagement in the development of an avatar-based educational application.

4.2.3.1 Objectives

The objectives of the study are:

1. to develop an interactive avatar-based education application through participation of HF experts, IT experts and consumers
2. to undertake a feasibility evaluation of the educational application to assess its acceptability and its effects on HF patients' knowledge and self-care behaviours
3. to describe the association between the sociodemographic and clinical characteristics of the patients and their HF knowledge and self-care behaviours.

4.2.4 Methods

4.2.4.1 Design

This study involved two phases. First, a PAR method was used to develop the application. Subsequent to the development of the application, a single-group pre- and post-test design was employed to evaluate the feasibility and acceptability of the application.

PAR is a collaborative and participative approach that supports self-critical reflection to improve practice and outcomes (Bradbury & Lifvergren 2016; Kemmis, McTaggart & Nixon 2013; Wicks & Reason 2009). The current study involved a multidisciplinary collaboration that includes HF and IT experts and consumer groups to actively engage in individual reflection and feedback on the components of an educational application. In this study the action research involves two cycles of planning, acting, observing, reflecting and replanning (Kemmis & McTaggart 2005).

4.2.4.2 Development of the application

The development component of the study, a PAR research, involved two cycles and three stages of action and reflection by participants in the study (Figure 4.1). Three participant groups were recruited: 1) consumers with a confirmed diagnosis of HF who could use a smartphone and who spoke English, 2) cardiovascular experts consisting of cardiologists, cardiac nurses, a cardiac nurse practitioner and cardiac research academics and 3) IT experts. A focus group discussion and individual interviews were used to review, reflect on and provide feedback on the application.

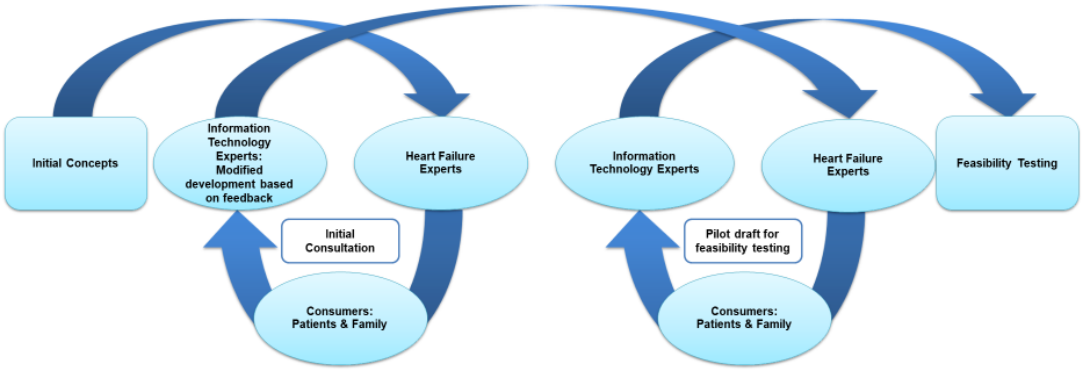


Figure 4.1 The action research cycles of developing the avatar-based application

4.2.4.2.1 Stage one: content development

The content of the application was developed by the cardiovascular researchers using evidence-based information from the National Heart Foundation of Australia's booklet, *Living Well with Heart Failure* (National Heart Foundation of Australia 2016). The cardiovascular experts engaged in reviewing the content storyboard and question bank through a focus group discussion. Their participation in action and reflection on the content storyboard and question bank were relevant to the avatar character's design, picture, language, voice, content, user-friendliness and expected benefits.

The cardiovascular expert panel consisted of two cardiologists, five HF nurse educators, seven cardiovascular researchers and a PhD candidate. Based on the recommendations of the expert

panel, cardiovascular researchers developed the content of the avatar application in a storyboard and question bank using Microsoft PowerPoint 2016.

The content storyboard consisted of four main sections: 1) understanding HF, 2) looking after yourself, 3) things to do every day and 4) emergency action plan. Each main section included subsections; for example, section four includes an HF action plan and a heart attack action plan. Questions randomly selected from the question bank were used in a quiz at the start of the application and after completing each subsection.

The storyboard and question bank were subsequently presented to consumers, including six HF patients and two family members of HF patients from a public HF outpatient clinic in South Australia for comment. Audio recording and field notes were used in the data collection. The storyboard was revised based on consumers' comments, and then presented to the IT experts for development of the application.

4.2.4.2.2 Stage two: application development

The avatar application was developed by a team of IT experts. The storyboard content was translated into multiple application screens that incorporated interactive interface components that segued between each other based on user input. The avatar technology platform was developed by a commercial application development company. The avatar application responds reactively with varying speech, facial expressions, body gestures and touch-based interaction. To increase consumer engagement, the avatar's characteristics could be customised by users. For example, the hair, eyes and skin colour, and eyeglasses could be customised accordingly. Figure 4.2 shows an example of the IT expert's work with developing the avatar. The avatar's voice was recorded by a voice actor and dynamically recomposed into the behaviours of the avatar. The application was developed for tablets with either an IOS or Android platform.

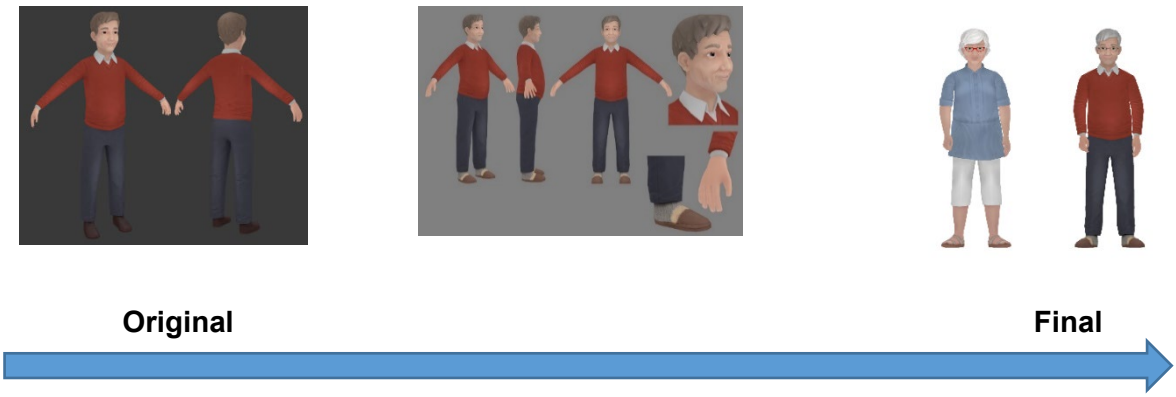


Figure 4.2 An example of the development of the avatar

4.2.4.2.3 Stage three: consumer review

The first version of the storyboard for the avatar-based application was presented to people with HF and their family members for comment. In reviewing the potential application, five participants with HF and one family member were recruited from an HF outpatient clinic. In this study, only an English version was developed. Therefore, only patients who could communicate in English were recruited for the development of this application.

The time taken by each consumer to review the application was recorded. The relevance of the character of the avatar, the applications' design, images, language, visuals, as well as the size of the print on screen, the buttons on the touch screen, audio quality and health content were reviewed through an individual feedback session between the consumers and the researchers. Audio recording and field notes were used for data collection during the interview.

After the three stages of content and application development, and consumer review, the application was reviewed by researchers and presented to IT experts for revision. This stage consisted of a report from the researchers, which outlined the comments from the consumer groups and recommendations for revision. Both the content and technology aspects of the application were modified by the cardiovascular and IT experts. Two cycles of review and update of the application took place to develop the final avatar-based application. The screenshots and dialogue of the avatar-based application are presented in Appendix 11.

4.2.4.3 Evaluation of the application's feasibility and acceptability

Once the final application was developed, it was reviewed by a group of HF patients to assess its acceptability and usefulness in improving self-care behaviours. Thirteen patients with diagnosed HF attending a public HF outpatient clinic in South Australia were invited to evaluate the application.

4.2.4.3.1 Participants

The inclusion criteria for participants in the review group were: 1) patients with a confirmed diagnosis of HF, 2) attendance at the HF outpatient clinic, 3) ability to use a smartphone and 4) ability to speak English. The exclusion criteria were that the patients: 1) had major and uncorrected hearing loss, 2) were clinically unstable. 'Clinically unstable' was defined as patients who do not achieve the five normal vital signs (i.e., heart rate, systolic blood pressure, respiratory rate, oxygen saturation and temperature) and normal mental status and ability to eat for at least 24 hours prior to enrolling in the study, 3) had cognitive impairment and 4) refused to give informed consent. This was an unfunded PhD feasibility study power of sample size has not been reported. Patients volunteered or were invited to participate from the HF clinic during the time frame of the study. This convenience sample was also a limitation.

4.2.4.3.2 Study procedure

The DHFKS and the SCHFI were used with participants before and after they reviewed the educational application, to evaluate if the application would make a difference to their knowledge about HF and self-care behaviours. After reviewing the application, participants were asked to rate their level of agreement with a number of statements about their perception of the clarity, content and technical quality, to indicate their level of satisfaction with the application.

4.2.4.3.3 Instruments

Semi-structured questions were used in the focus group discussion and individual patient interviews to encourage open discussion of opinions and views.

Two validated questionnaires were used to evaluate HF patients' knowledge and self-care behaviours. A third questionnaire regarding the participant's satisfaction with the avatar-based application was developed by the researchers.

The Dutch Heart Failure Knowledge Scale

The patient's knowledge of HF was measured by the DHFKS, which consists of 15 multiple choice items. Cronbach's α of the DHFKS was 0.62. The scale has a minimum score of zero points (no knowledge) and a maximum score of 15 points (maximum knowledge) (van der Wal et al. 2005).

The Self-Care of Heart Failure Index

The HF patient's self-care behaviours were assessed by the SCHFI (version 6.2), which is a survey consisting of 22 questions. Each of its three components has been tested for reliability (maintenance component: coefficient alpha = 0.553, confidence component: coefficient alpha = 0.827 and management component: coefficient alpha = 0.597). The possible range of total score for the index (i.e., across maintenance, confidence and management) is 0 to 100. A score of ≥ 70 has been used to indicate adequacy of self-care (Riegel et al. 2009b).

The avatar-based application satisfaction questionnaire

The avatar-based application satisfaction questionnaire was adapted from previous research on surveys measuring satisfaction with educational materials (Clark et al. 2015; Wakefield et al. 2008). The satisfaction questionnaire consists of 15 Likert-scale items that refer to the avatar's design, audio, visual quality, content, usefulness and user-friendliness. Open-ended questions were included to gain feedback about the application.

4.2.5 Ethical considerations

The study was approved by the SAC HREC, Adelaide, South Australia (OFR#350.16-HRC/16/SAC/315). All researchers have Good Clinical Practice accreditation, and the study was conducted using good clinical practice principles. The investigation conforms with the principles outlined in the Declaration of Helsinki. Written informed consent was obtained from all participants.

4.2.6 Data analysis

Qualitative data from the focus group discussion and individual patient interviews were analysed by identifying common themes.

The demographic and clinical characteristics of the participants were described using descriptive statistics included means and standard deviation or frequencies and percentage. Scores on the DHFKS and SCHFI were analysed using non-parametric tests, as they did not meet the assumption of normality under the Kolmogorov–Smirnov test. Pre-post comparisons of the DHFKS and SCHFI scores were performed using Wilcoxon signed-rank tests. Effect size was calculated and reported the power of the study. A bivariate correlation analysis between sociodemographic and clinical characteristics and the level of HF knowledge and self-care behaviours were conducted using Fisher's exact test. The level of significance was set at 0.05 for all tests in the analysis, with two-sided *p* values.

4.2.7 Results: findings from development of the application

A total of 15 cardiovascular and research experts were involved in developing the avatar-based application. Their mean age (±SD) was 43.8 ± 10.1 years and the experience in the cardiovascular field ranged from 8 to 29 years.

4.2.7.1 Cardiovascular expert and consumer feedback

The components of an effective avatar-based educational application were divided into six categories: 1) provision of information on the specific disease and the patient's needs, 2) appropriate aspects of design and functionality, 3) flexible learning environments and accessibility, 4) elder-friendliness, 5) engagement and enjoyment and 6) usefulness. The feedback on each component follows. A summary of the feedback on the development of the avatar-based application is presented in Box 1.

Box 1 A summary of feedback during the development of the avatar-based application

Positive feedback

- The avatar characters were good, funny and reflective of older people with heart failure.
- The pictures, language, audio and content were clear, precise and easy to understand.
- The navigation was easy to use and follow.
- The size of the print on screen and button was large enough for easy reading and pressing.
- The application was good for refreshing knowledge and reinforced the need to update knowledge regularly.
- The application is great for use at home.
- The application would be great and useful for people newly diagnosed with heart failure.

Opportunities and challenges

- Consideration needs to be made for avatars for younger patients.
- More options are required to customise the female avatar to appear feminine.
- The duration taken to complete the educational application was quite long.
- There should be an ability to pause and repeat a sentence.
- There should be written information on screen for those patients with hearing difficulty.

4.2.7.1. Provision of information on the specific disease and patient's needs

The expert panel and consumers stated that the content relating to HF and to the needs of the patients and healthcare providers were precise, informative and clear. Examples of screenshots from the application are shown in Figure 4.3.

4.2.7.1.2 Appropriate aspects of application design and functionality

The expert panel and consumers stated that the 'how to use' instructions in the application for novices were good. The application was described as easy to use, read and navigate. The size of the print screen was easy to read, and the buttons were sufficiently large and appropriate for elderly people. Realistic pictures were useful and clear to illustrate information about nutritional and health effects, such as swelling.

However, feedback on the first version of the application suggested the pictures chosen should be those that were more relevant; for example, to present information about swollen legs. The speech

was natural, varied in tone and similar to face-to-face communication in real life. Content was structured to provide a single message for each image, using simple, plain language (Figure 4.3).

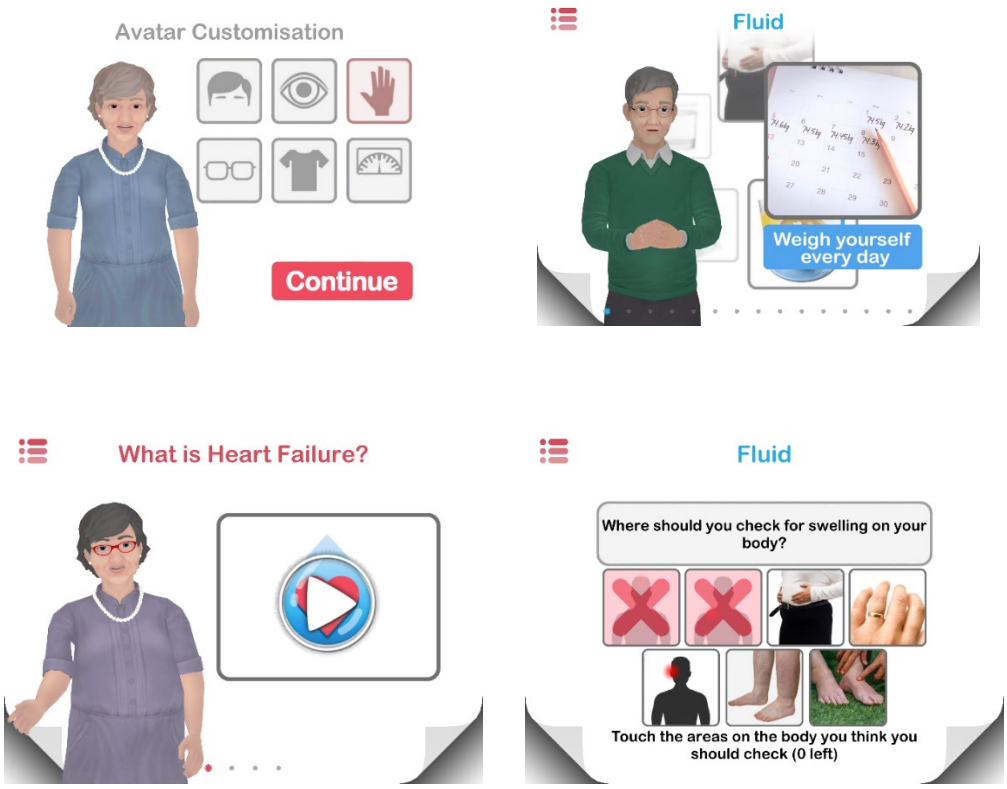


Figure 4.3 Examples of screenshots from the avatar-based educational application

4.2.7.1.3 Flexible learning environments and accessibility

The application can be installed on a tablet, either on an IOS or Android platform, and does not require the internet to operate. The avatar-based educational application was provided to participants to use in their own time and at a location convenient for them. Consumers stated that the entire application took quite long to complete (one hour). Therefore, the application was modified to contain independent subsections with a random question at the end of each subsection, so that consumers could complete individual sections at times that suited them.

4.2.7.1.4 Elder-friendliness

The visual layout and the design of the avatar-based application were considered by the cardiovascular experts, consumers and IT experts to be appropriate for elderly participants. The visual presentation was straightforward and clear. The font size was large enough for older readers, and adequate white space around the text was considered restful for the eyes and easier for reading. Realistic images that were simple to understand at a glance were located near the text. Captions

were used to reinforce the graphics' main points. Graphics were placed throughout to balance text and white space. Embedded video and animations were used to capture and maintain participant attention.

4.2.7.1.5 Engagement and enjoyment

Cardiovascular experts suggested that the avatar character should have an older appearance with facial wrinkles, a friendly face, grey hair, pale complexion with a bloated stomach. Cardiovascular experts and consumers described the avatar character as good, funny, friendly and reflective of older people who have HF. Participants had an opportunity to customise their own avatar characteristics, including 1) eyeglasses, 2) hair colour, 3) skin colour, 4) clothing and 5) weight.

Other suggested changes included having a young avatar character and more options to customise the female avatar to look more feminine (i.e., jewellery, lipstick, different-coloured clothing and choice of hairstyle).

The application was designed using a variety of strategies to encourage interaction and enjoyment. After the presentation of information in each session, there was a range of quizzes and activities to check participant understanding. These quizzes and activities included choosing healthy foods to place in a shopping trolley, answering yes/no questions and arranging a heart attack action plan in the correct sequence. Additionally, a video and animation of the heart was used to explain HF and the participants liked the video for encouraging them to understand what HF was (Figure 4.3).

4.2.7.1.6 Usefulness

The expert panel and consumers stated that the application was useful. They noted its value in reinforcing and refreshing knowledge about HF, enhancing confidence in using technology and supporting new learning about the importance of self-care behaviours, such as weighing oneself daily.

4.2.7.2 Information technology experts' response

IT experts ensured that the main design components of the application included avatar characteristics that clearly represented older people with HF, and a variety of interactive activities based on gaming. They also ensured that the application was easy to navigate and accessible.

4.2.8 Results: findings from feasibility and acceptability evaluation of the application

4.2.8.1 Participant characteristics

Thirteen participants were recruited to evaluate the application's feasibility and acceptability. Their median age was 67.0 ± 13.2 years; 76.9% were male and 69.2% were living with their spouse. Regarding education, 61.6% of the participants had attained at least certificate level and 61.5% were retired. HFpEF was the most prevalent HF condition (53.8%) among the participants. Approximately 39% of the participants had been diagnosed with HF in the previous year, and the same percentage of participants had lived with the condition for two to five years. The most common cause of HF in the group was non-ischaemic heart disease, and 46% of the group had at least three comorbidities. Demographic and clinical characteristics of the study patients are shown in Table 4.1.

Table 4.1 Demographic and clinical characteristics of the study patients

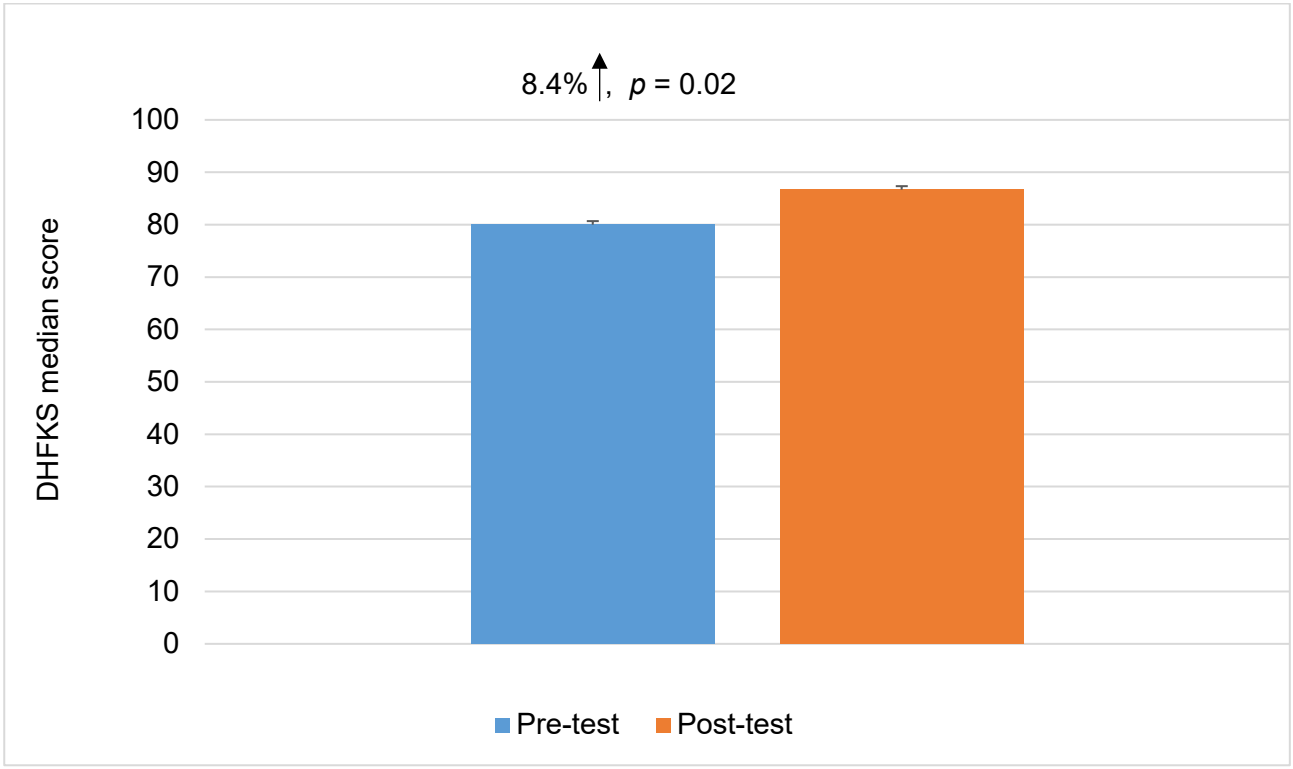
Characteristics	Descriptive statistics (n = 13)
Age, median (SD)	67.0 (13.2)
Sex, n (%)	
Male	10 (76.9)
Female	3 (23.1)
Marital status, n (%)	
Single	2 (15.4)
Married	8 (61.5)
Widowed	3 (23.1)
Living status, n (%)	
Alone	4 (30.8)
Spouse	9 (69.2)
Education level, n (%)	
No school	1 (7.7)
Primary school	2 (15.4)
Trade	2 (15.4)
Certificate	6 (46.2)
Degree	2 (15.4)
Country of birth, n (%)	
England	5 (38.5)
Australia	8 (61.5)
Occupation, n (%)	
Retired	8 (61.5)
Employed	2 (15.4)
Unemployed	3 (23.1)
Type of HF, n (%)	
HFrEF	5 (38.5)
HFmEF	1 (7.7)
HFpEF	7 (53.8)
HF (number of years), n (%)	
≤ 1 year	5 (38.5)
2–5 years	5 (38.5)
≥ 6 years	3 (23.0)
Aetiology of HF, n (%)	
Ischaemic	4 (30.8)
Non-ischaemic	9 (69.2)
NYHA classification, n (%)	
I	6 (46.2)
II	6 (46.0)
III	1 (7.70)
HF medication, n (%)	
ACEI	7 (53.8)
Beta blockers	11 (84.6)
ARB	4 (30.8)

Characteristics	Descriptive statistics (n = 13)
Diuretic	12 (92.3)
Anticoagulants	11 (84.6)
Lipid-lowering agents	6 (46.2)
Charlson Comorbidity Index, n (%)	
≤ 2, n (%)	7 (53.9)
3– 4, n (%)	5 (38.5)
≥ 5, n (%)	1 (7.7)
Comorbidities, n (%)	
Myocardial infarction	5 (38.5)
Peripheral vascular disease	1 (7.7)
Cerebrovascular disease	2 (15.4)
Chronic pulmonary disease	4 (30.8)
Peptic ulcer disease	2 (15.4)
Diabetes	5 (38.5)
Renal disease	2 (15.4)

Note. ACEI: angiotensin-converting-enzyme inhibitor; ARB: angiotensin II receptor blockers; HF: heart failure; HFrEF: heart failure reduced ejection fraction; HFmEF: heart failure mid-range ejection fraction; HFpEF: heart failure preserved ejection fraction; NYHA: New York Heart Association; SD: standard deviation.

4.2.8.2 Heart failure knowledge

There was a statistically significant improvement in the pre- to post-test scores of HF knowledge (median [IQR] from 80.0 [70.0 – 93.3] to 86.7 [76.7 – 96.7], $p = 0.020$) (Table 4.2), with a 8.4% increase in HF knowledge (Figure 4.4).

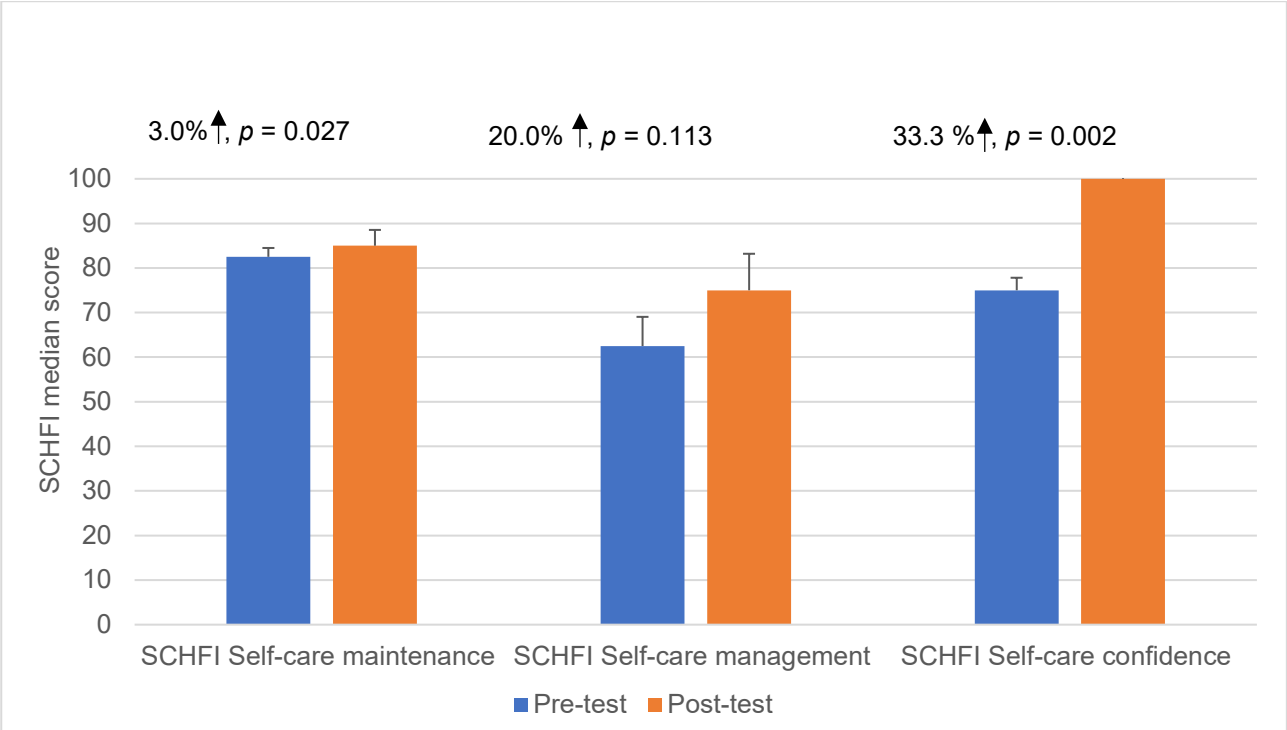


DHFKS: Dutch Heart Failure Knowledge Scale

Figure 4.4 Change in knowledge of heart failure on the Dutch Heart Failure Knowledge Scale

4.2.8.3 Self-care behaviours

There was a significant improvement in self-care maintenance behaviours and confidence. The self-care behaviour scores are presented in Table 4.2. After intervention, 3.0% increase in self-care maintenance was found (from 82.5 [70.0 – 82.5] to 85.0 [77.5 – 96.3), $p = 0.027$) along with a 33.3% increase in self-care confidence (from 75.0 [72.9 – 91.7] to 100.0 [95.9 – 100.0], $p = 0.002$). However, there was no statistically significant improvement in self-care management (62.5 [72.7 – 91.7] to 75.0 [29.2 – 93.8], $p = 0.113$) (Figure 4.5).



SCHFI: Self-Care Heart Failure Index

Figure 4.5 Change in behaviour on the Self-Care of Heart Failure Index

Table 4.2 Changes in knowledge and self-care behaviour scores

	Pre-test (n=13)		Post-test (n=13)		*r*	*p*-value[a]		% change
	Median	IQR	Median	IQR				
Knowledge (0–15) DHFKS score (range 0–100)	12.0 (80.0)	10.5–14.0 (70.0–93.3)	13.0 (86.7)	11.5–14.5 (76.7–96.7)	-0.46	0.020	↑	8.4
Self-care maintenance SCHFI score (range 0–100)	82.5	70.0–82.5	85.0	77.5–96.3	-0.43	0.027	↑	3.0
Self-care management SCHFI (range 0–100)	62.5	31.3–83.3	75.0	29.2–93.8	-0.31	0.113	↑	20.0
Self-care confidence SCHFI (range 0–100)	75.0	72.9–91.7	100.0	95.9–100.0	-0.60	0.002	↑	33.3

Note. DHFKS: Dutch Heart Failure Knowledge Scale; IQR: interquartile range; SCHFI: Self-Care Heart Failure Index.
↑ indicates statistical increase in outcomes measured; significance $p \leq 0.05$.
[a] Wilcoxon signed-rank test.

4.2.8.4 The association between sociodemographic and clinical characteristics and the level of HF knowledge and self-care behaviours

Age, sex, marital status, living status, educational level attained, occupation and comorbidities were not associated with the level of HF knowledge and self-care behaviours pre- test scores (Table 4.3). Self-care confidence data were not computed due to a constant score. However, after the intervention, there was a significant improvement in HF knowledge. A score of 70% or greater was considered to be adequate self-care behaviours for each sub-scale. The pre-test median score for self-care maintenance and self-care confidence in this study was >70% at in the pre-test, however the score still improved significantly following the avatar intervention. The pre-test median score for self-care management was 62.5% this did not show improvement in the pre-test post-test.

Table 4.3 Relationship of demographic and clinical variables with heart failure knowledge and self-care behaviours

Sociodemographic and clinical characteristics	**Pearson correlation coefficient**		
	Knowledge	**Self-care behaviours**	
		Self-care maintenance	Self-care management
Age	0.014 (p = 1.000)	0.014 (p = 1.000)	0.066 (p = 1.000)
Sex	0.965 (p = 0.423)	0.709 (p = 1.000)	0.660 (p = 0.559)
Marital status	0.430 (p = 1.000)	2.176 (p = 0.295)	0.014 (p = 1.000)
Living status	0.410 (p = 1.000)	0.410 (p = 1.000)	0.034 (p = 1.000)
Education level	0.133 (p = 1.000)	0.133 (p = 1.000)	0.627 (p = 0.592)
Country of birth	0.410 (p = 1.000)	1.051 (p = 1.000)	1.040 (p = 0.559)
Occupation	6.278 (p = 0.099)	2.438 (p = 0.487)	4.952 (p = 0.175)
Comorbidity	0.014 (p = 1.000)	2.758 (p = 0.192)	0.066 (p = 1.000)

4.2.8.5 The avatar-based application satisfaction

Participants' satisfaction with the avatar-based application is shown in Figure 4.6. Overall satisfaction with the revised avatar application was high at 89.2%. The participants stated that the application delivered health information that was easy to understand. All participants indicated that the

application was easy to use including clear speech and large print size. The participants reported that the application delivered concise information and was easy to follow. It assisted them to understand their medical health problems, learn new knowledge, and educate them to read nutrition information and weigh themselves every day. However, participants indicated that the length of time to complete the application was too long.

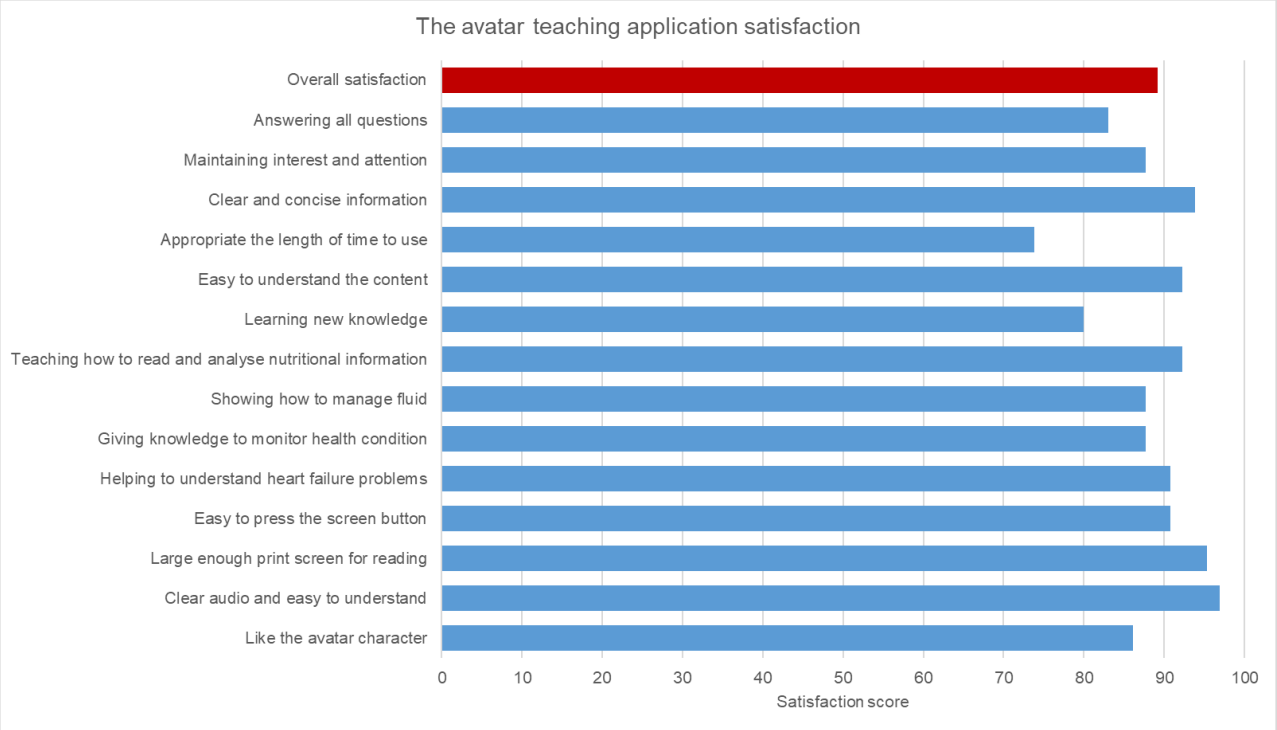


Figure 4.6 The avatar-based application satisfaction

4.2.9 Discussion

An evidence-based, avatar-based teaching application was successfully developed and delivered to HF patients with the aim of improving their knowledge of HF and self-care behaviours. There were three main findings in this study. First, a PAR method resulted in the development of this powerful application. Second, its application was found to be feasible in that it improved HF knowledge and most self-care behaviours in a small cohort of patients with HF. Last, overall satisfaction among participants who used the developed application was very high.

A PAR method was employed in this study, utilising best practice and engaging consumers (HF patients), the healthcare workforce (cardiovascular experts) and IT experts in developing the application. The current study's findings support previous research that a PAR method is effective

for developing IT-based patient interventions to address patients' self-management needs and enhance confidence with using technology (Cajita et al. 2017; Clark et al. 2015; Tongpeth & Clark 2018). Thus, an engagement and collaboration approach between clinical researchers and consumers should be employed in the application development process to design an application that provides information about a specific disease and patient's needs.

The results of the feasibility test indicated that the avatar-based application increased HF patient's knowledge and enhanced self-care maintenance and confidence. This finding is similar to the results of previous studies that have employed an action research approach to examine the potential of avatar-based technology in healthcare services (Clark et al. 2015; Tongpeth, Du & Clark 2018).

However, the avatar-based application in the current study did not result in changed self-care management skills. This finding could be due to the short-term follow-up period for self-evaluation.

A high level of participant engagement among the study participants was also recognised. This is corroborated by the level of participant satisfaction with the application, and adds credibility to the participatory action approach. This study not only improved HF knowledge and self-care behaviours of patients with HF, but also demonstrated that patients with HF were highly satisfied with the avatar-based application as a learning tool.

Avatar-based technology for patient education is rapidly developing. It is very scalable. As the application was designed with usability in mind, particularly by the elderly, it is appropriate for elderly participants. Notwithstanding, the average duration of time taken to complete the activities in the application took an hour. We have modified the application to break it down into smaller chunks so that patients can complete individual sessions at different times. Therefore, the activities in the final version of the application are likely to be quicker to complete.

4.2.10 Limitations

This study has some limitations. The initial version of the design and development of the avatar-based application was only available in the English language, so access by people with CALD

backgrounds is limited. Future research should be considered to translate the application into multiple languages.

The limitations of the feasibility and acceptability tests are based on the fact that the test group was a small sample and recruited at a single centre. As a result, the generalisability of the study's findings is limited. Future research with a larger number of participants, across multicentred settings, should be implemented to address these issues.

Validated and reliable tools were used to measure outcomes of self-care behaviours; however, the SCHFI was not utilised to detect changes in self-care management skills in this study because the evaluation occurred immediately after exposure to the educational application. To address this concern, a longer follow-up period would be required to evaluate changes in self-care behaviour skills and knowledge retention.

4.2.1.11 Conclusion

This study applied a PAR to develop a self-administered avatar-based educational application for people with HF. Its findings indicate that using a participatory approach to develop the intervention is acceptable and beneficial to ensure that appropriate self-management and information needs of the patient with HF are taken into account, so that the application is appropriate and ready for use. An avatar-based patient education technology is a feasible learning tool to support and enhance patient's HF knowledge and self-care behaviours, particularly for people with low health literacy, CALD backgrounds or people with limited access to HF service.

4.2.1.12 Implications for practice

- Collaboration and engagement between multidisciplinary teams and consumers should be employed in the design and development of education materials for patients with chronic diseases.
- Avatar-based technology in patient education is an effective method to deliver health information to people with HF.
- The interactive avatar-based technology intervention may increase accessibility to healthcare information for patients from rural and remote locations.
- An avatar-based educational application should be considered as an alternative educational tool for improving patients' knowledge of their disease and self-care

behaviours.

- Interactive patient education technology has the potential to overcome low health literacy through multimedia and culturally sensitive development and design of the visual, audio or video format of education materials.

4.2.1.13 Conflict of interest

The authors declare that there is no conflict of interest.

4.2.1.14 Acknowledgement

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Huiyun Du is supported by Establishment Grant and a Tom Simpson Trust Fund.

4.2.1.15 Funding

This study was supported by a Heart Foundation Future Leader Fellowship (APP ID. 100847), Establishment Grant, a Tom Simpson Trust Fund, and Faculty of Nursing, Khon Kaen University Scholarship.

Thesis flowchart	Publications
Chapter 1 **Background and significance of the study** Why is heart failure self-care important?	
Chapter 2 **Literature review** - What are the current research interventions to improve self-care knowledge and behaviours? - What is the best conceptual framework for the thesis?	Wonggom, P, Tongpeth, J, Newman, P, HuiYun, D & Clark, R 2016, 'Effectiveness of using avatar-based technology in patient education for the improvement of chronic disease knowledge and self-care behavior: a systematic review protocol', *JBI Database of Systematic Reviews and Implementation Reports*, vol. 14, no. 9, pp. 3-14. Wonggom, P, Kourbelis, C, Newman, P, Du, HY & Clark, RA 2019, 'Effectiveness of avatar-based technology in patient education for improving chronic disease knowledge and self-care behavior: a systematic review, *JBI Database of Systematic Reviews and Implementation Reports*, vol. 17, no. 6, pp. 1101-29.
Chapter 3 **Methodology** What research design is best suited to develop and design an app for teaching?	
Chapter 4 **Results** - How can HF and IT experts and consumer participation develop an avatar-based educational application to teach heart failure patients self-care? - What is the effectiveness of an avatar-based educational application for improving patients' knowledge and self-care behaviours?	Wonggom, P, Du, H, Burdeniuk, C, Kelman, S, Wight, J, Bellchambers, T, Nolan, P, Barry, T & Clark RA (submitted), 'Development and feasibility testing avatar-based education application in heart failure', *European Journal of Cardiovascular Nursing.*
Chapter 5 **Conclusions and Implications** - What are the findings and conclusions? - What are the limitation of the study? - What are the implications for policy, practices and research?	

CHAPTER 5 CONCLUSIONS AND IMPLICATIONS

5.1 Chapter overview

This thesis has demonstrated the justifications for, and conceptual approach to participatory action research in the design and development of an interactive avatar-based educational application to improve knowledge and self-care behaviours of patients with HF. A feasibility study using pre- and post-test methods was performed to evaluate the effect of the application on knowledge, self-care behaviours and satisfaction. The previous chapter presented the findings and discussions of the effect of avatar-based application intervention on patient outcomes. This chapter will provide a summary of the key findings and insight gained in the study, the limitations of the research, the implications for practice, policy and research, and the study's conclusion.

5.2 Key findings and new knowledge

The key findings of this thesis are as follow.

1. There was a lack of large RCTs to establish the effectiveness of an interactive avatar-based educational application.
2. The use of an interactive avatar-based educational application in patient education is innovative.
3. This is the first research study of a novel and interactive avatar-based educational application in HF.
4. An avatar-based educational application was very effective for patients with HF.
5. As avatar-based educational applications are patient-centred, they have the potential to improve patient education.
6. Avatar-based educational application is a feasible strategy to effectively improve HF patients' self-care behaviour and outcomes.
7. People with HF engaged with and enjoyed using an avatar-based educational application.
8. Carefully developed technology-based education programs can be feasible among older people. Elderly people were confident using IT associated with the avatar-based educational application.

5.2.1 There was a lack of large randomised controlled trials to establish the effectiveness of an interactive avatar-based educational application

Our systematic review reported that there were only three RCTs and five non-randomised experimental studies that determined the effectiveness of avatar-based patient education technology on knowledge and self-care behaviours in chronic disease management (Wonggom et al. 2019). The paucity of studies in this field shows a gap in research on the use of avatar-based technology education of patients with HF; therefore, future evaluations of the use of avatar-based technology in patient education require RCTs with appropriate power (Wonggom et al. 2019).

5.2.2 The use of an interactive avatar-based educational application in patient education is innovative

Using avatar-based application technology can provide flexible learning environments in which patients can learn about their medical condition in a dynamic and personalised setting. Additionally, the application was able to adapt the content based on educational level, personal interests and specific diseases. This means that avatar-based educational application is able to translate evidence into practice in the context of the individual patient. Therefore, employing an avatar-based technology is innovative in patient education. In addition, the technology was more engaging and motivating than printed educational materials, and supported learning through audio and visual aids.

5.2.3 This is the first research study of a novel and interactive avatar-based educational application in HF

Our study is novel in that it is the first to have developed and tested an interactive avatar-based education application for patients with HF. No previous studies have investigated the effectiveness of avatar-based technology patient education in HF. Current evidence on the effectiveness of avatar-based technology in patient education to improve chronic disease knowledge and self-care behaviours is very limited. From the available research on avatar-based technology, it can be concluded that the intervention had a positive effect on knowledge, self-care behaviours and self-efficacy in chronic diseases.

5.2.4 An avatar-based educational application was very effective for patients with HF

Our avatar-based education application was designed and developed using simple and plain language, large-sized font and button, realistic pictures, with a single message for each image. It was also designed to be easy to navigate, have varied speech tone, captions, embedded video and animations, with various quizzes and activities. Therefore, an avatar-based technology was particularly useful for patients with HF as a result of the listed components.

5.2.5 As avatar-based educational applications are patient-centred, they have the potential to improve patient education

Avatar-based educational technology is likely to be a method of the future in patient education. Printed and traditional educational materials such as booklet, brochure, video, and face-to-face intervention demonstrated only minor benefits for health outcomes (Dickson & Riegel 2009; Giguère et al. 2012). As a consequence of insufficient information, a mismatch often exists between the information in these materials and the reading skills and health literacy levels of the intended audience (patients). Applying PAR is an acceptable and appropriate method for designing and developing interactive technology for patient education. In this study, an avatar-based educational application provided patient-specific information that patients wanted to know rather than general information and met patients' needs and experience in an optimal way. The collaboration and engagement of multidisciplinary teams and consumers must be employed in the co-design and development of educational materials for patients to actively involve in self-critical reflection and feedback.

5.2.6 Avatar-based educational application is a feasible strategy to effectively improve HF patients' self-care behaviour and outcomes.

The results from a feasibility pre-post study demonstrated positive improvements in knowledge and self-care behaviours of patients with HF; therefore, our study suggested that the use of avatar-based technology in patient education is a feasible effective method to deliver health information to people with HF.

5.3.7 People with HF engaged with and enjoyed using an avatar-based educational application

Patients with HF reported a high level of overall satisfaction (90%) with the application resulting from a high level of engagement and enjoyment during its use. Participants enjoyed customising their own avatar and prompted to do random quizzes after completing each sub-section. The application was designed to encourage user interaction and enjoyment. Patient learning was scaffolded using a range of quizzes and activities to check understanding of the delivered content. The quizzes and activities included choosing healthy foods to place in a shopping trolley, answering yes/no questions, and arranging a heart attack action plan in the correct sequence.

5.2.8 Carefully developed technology-based education programs can be feasible among older people. Elderly people were confident using IT associated with the avatar-based educational application.

The visual and the design aspects of the avatar-based application were considered appropriate for elderly participants, including the large font size, the use of adequate white space around the text, realistic images, captions, a single message restricted to each image, the use of simple and plain language and embedded video and animations. These design aspects were included because a high proportion of patients with HF are likely to be elderly (average age of HF patients: 77 ± 13 years) (Newton et al. 2016). Given the high level of satisfaction among the patients with HF using the application (median age: 67 ± 13 years), our study has demonstrated that elderly patients were confident with using this technology.

5.3 Limitations

While this thesis was carefully researched, planned and executed, it is important to acknowledge its limitations. As the initial version of the avatar-based application was only made to be available in the English language, it was only trialled on English-speaking patients. The length of time to complete all sections of the application in one session was quite time-consuming (60 minutes). Future versions of the application will attempt to deconstruct the content into smaller bite-sized learning components.

The limitations of the feasibility and acceptability test consist of a small sample size and a single-centre recruitment; consequently, its results are likely to have limited generalisability. Validated and reliable tools were used to measure the outcome of self-care behaviours; however, the SCHFI was not utilised to detect changes in self-care management skills in this study as post-intervention measurements were taken immediately after use of the application. HF patients with current experience with technology are more likely to volunteer in this study, so it would be beneficial to involve patients early in the design and development of the avatar-based education application. This study recruited all patients with a confirmed diagnosis of HF to assess the feasibility of the application; this is an important preliminary research step for testing the avatar-based education application. However, this means that the number of years that the patient has had HF will affect changes in knowledge and self-care behaviours relating to HF. Varying previous experience of HF is likely to be a factor affecting the effectiveness of the application, and should be examined in future evaluations. Unfortunately, no patients from CALD backgrounds volunteered to participate in this study; therefore, there was limited generalisability to CALD populations.

5.4 Implications

5.4.1 Implications for practice

The results of this study have several implications for practice. First, avatar-based patient educational technology was piloted in the real world and showed positive outcomes in terms of improving knowledge and developing self-care skills and behaviours in patients. Second, employing a participatory approach to develop the educational intervention is acceptable and beneficial, as it ensures appropriate user involvement in the design and development of the intervention. Third, The use of an avatar-based application to support patient education is an innovative method of educating people with HF and those in rural areas where access to HF specialist support is limited. Fourth, avatar-based technology is feasible as an alternative educational tool to deliver health information to people with HF.

5.4.2 Implications for policy

Avatar-based educational applications are effective because they provide the patient with information about disease specific information that they can use to modify their health behaviour and

practice. Avatar-based technology will deliver word-perfect evidence-based health education that is tailored to their individual needs and health circumstances. This educational application has the potential to replace or supplement the traditional information found in booklets, brochures intended to educate patients and their families. For patients from cultural and linguistically diverse groups, consideration should be given to translate avatar-based educational applications into multiple languages. It is a potentially cost-effective method to provide and update health education, and can easily increase access to healthcare information.

5.4.3 Implications for research

This thesis presented the development and feasibility of an interactive avatar-based educational application to improve the knowledge and self-care behaviours of patients with HF. Future research studies can be undertaken to improve our understanding of this important area of HF research. First, future research should consider translating the avatar into multiple languages for use by CALD populations. Second, avatar-based educational applications are self-administered, so the application should be provided on a tablet or on the patients' personal device for use any time and at any location convenient for them. Third, a pragmatic RCT with larger number of participants, recruited across multiple centres with longer follow-up periods, may uncover additional and stronger intervention effects. Fourth, future research into avatar-based educational tools for younger patients should be considered, with younger avatar's characteristics and more options to customise female avatars so that they appear feminine. Additional modifications could also examine options for reducing the duration taken to complete the application, information on screen for those patients with limited hearing abilities, and information tailored for people who are newly diagnosed with HF. Fifth, future research should consider evaluating the effectiveness of the application for other health outcomes, such as readmission, mortality, length of hospital stays and HRQOL.

5.5 Conclusion

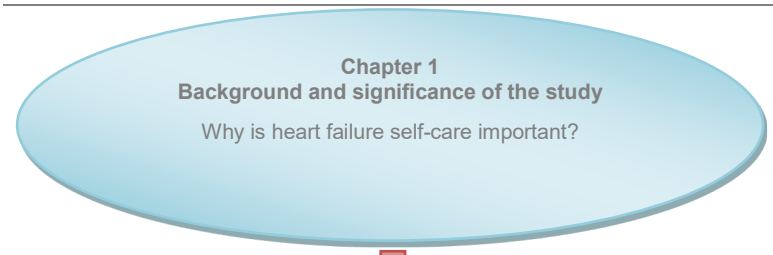
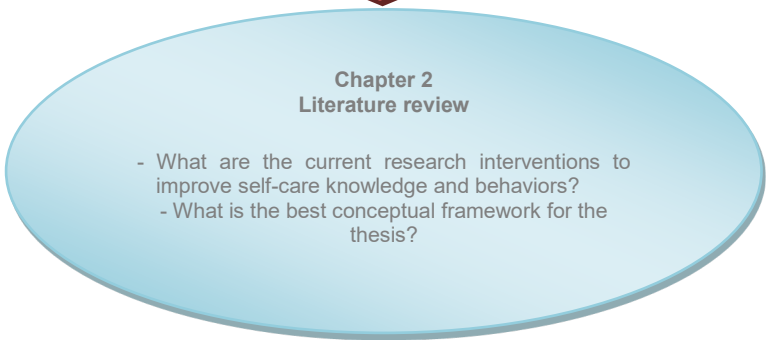
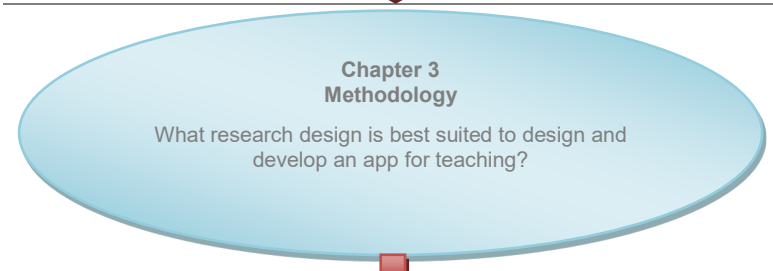
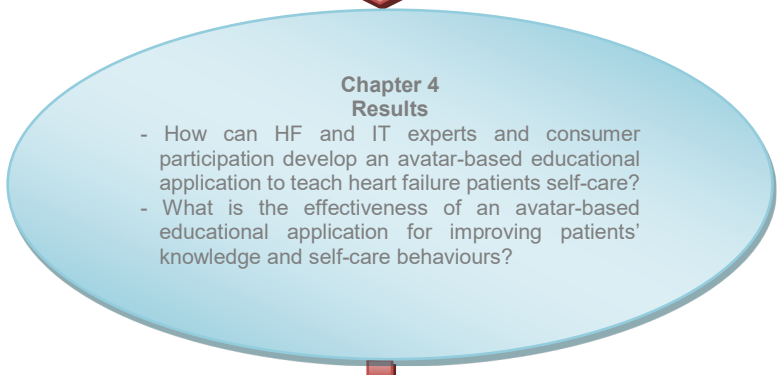
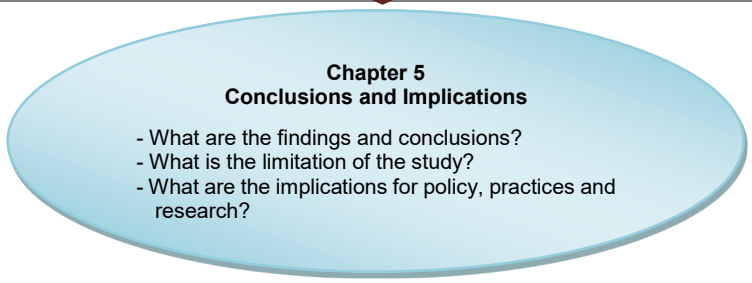
HF guidelines recommend that it is necessary to educate patients and their family members to improve their knowledge about HF and self-care skills, and to reduce preventable rehospitalisations (Atherton et al. 2018). Such patient education should be provided at a level appropriate to their health literacy. Presently, there is a rapid development of technological interventions to support patient self-

care and improve health outcomes. This study has demonstrated that applying a PAR approach in the design and development of an avatar-based educational application is feasible and beneficial for patient health outcomes. We have created male and female avatars that embody patients with HF as conversation agents to deliver HF health information with varying speech, facial expressions, body gestures and touch-based interaction. This avatar-based application would be very scalable for any other disease or healthcare system, and was specifically designed for usability by the elderly.

The avatar-based patient educational technology is feasible for supporting and enhancing the HF knowledge and self-care behaviours especially of people with low health literacy. Therefore, an interactive avatar-based educational application is a novel approach to deliver HF health messages to patients with HF.

Although the results from the pre-post feasibility study demonstrated positive improvement in HF knowledge and self-care behaviours; a pragmatic randomised controlled trial to evaluate the effectiveness of an avatar-based education application would confirm the findings here. Our research team is conducting a pragmatic randomised controlled trial study (Wonggom, Du & Clark 2018), and currently recruiting participants at three HF outpatient clinics in three public hospitals in South Australia, and the study results will be published in a high-impact peer reviewed journal in 2020.

This thesis has reported detailed information on the development and evaluation of an interactive avatar-based educational application for patients with HF. Its results are useful to guide the development and delivery of patient education through innovative healthcare education technology that seeks to improve HF knowledge and self-care behaviours.

Thesis flowchart	Publications
	
	Wonggom, P, Tongpeth, J, Newman, P, HuiYun, D & Clark, R 2016, 'Effectiveness of using avatar-based technology in patient education for the improvement of chronic disease knowledge and self-care behavior: a systematic review protocol', *JBI Database of Systematic Reviews and Implementation Reports*, vol. 14, no. 9, pp. 3-14. Wonggom, P, Kourbelis, C, Newman, P, Du, HY & Clark, RA 2019, 'Effectiveness of avatar-based technology in patient education for improving chronic disease knowledge and self-care behavior: a systematic review, *JBI Database of Systematic Reviews and Implementation Reports*, vol. 17, no. 6, pp. 1101-29.
	
	Wonggom P, Du H, Burdeniuk C, Kelman S, Wight J, Bellchambers T, Nolan P & Clark RA (submitted), 'Development and feasibility testing avatar-based education application in heart failure', *European Journal of Cardiovascular Nursing.*
	

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APPENDICES

Appendix 1: Published works

Published papers

Wonggom, P, Tongpeth, J, Newman, P, Du, H, & Clark, R 2016, 'Effectiveness of using avatar-based technology in patient education for the improvement of chronic disease knowledge and self-care behavior: a systematic review protocol', *JBI Database of Systematic Reviews and Implementation Reports*, vol. 14, no. 9, pp. 3-14. doi:10.11124/jbisrir-2016-003083.

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UNIVERSITY of York
Centre for Reviews and Dissemination

NHS
National Institute for
Health Research

PROSPERO International prospective register of systematic reviews

Effectiveness of using avatar-based technology in patient education for the improvement of chronic disease knowledge and self-care behavior: a systematic review protocol

Parichat Wonggom, Jintana Tongpeth, Peter Newman, HuiYun Du, Robyn Clark

Citation

Parichat Wonggom, Jintana Tongpeth, Peter Newman, HuiYun Du, Robyn Clark. Effectiveness of using avatar-based technology in patient education for the improvement of chronic disease knowledge and self-care behavior: a systematic review protocol. PROSPERO 2016:CRD42016052987 Available from http://www.crd.york.ac.uk/PROSPERO_REBRANDING/display_record.asp?ID=CRD42016052987

Review question(s)

The objective of this review is to investigate the effectiveness of using avatar-based technology in patient education for the improvement of knowledge and self-care behaviors for chronic disease.

Searches

The search strategy aims to find both published and unpublished studies. A three-step search strategy will be utilized and has been adapted from the Joanna Briggs Institute Reviewers Manual (2014 edition) guidelines. An initial limited search of MEDLINE and CINAHL will be undertaken, followed by an analysis of the text words contained in the title and abstract and of the index terms used to describe each article. A second search using all identified keywords and index terms will then be undertaken across all the included databases. Third, the reference list of all the identified reports and articles will be searched for additional studies. Studies published in English from 2005 to present will be considered for inclusion in the review, as this is the timeframe in which these technologies have begun to make an impact on teaching and learning outcomes. This review will exclude publications in languages other than English, as there are no facilities available for translation. In addition, this review will exclude all qualitative studies on this topic, as the aim is to determine the effectiveness of using avatar technology in patient education.The databases to be searched include:PubMed, CINAHL, PsycINFO, Cochrane Central Trials Register of Controlled Trials ProQuest, Web of Science and Embase.The search for unpublished studies will include:TROVE, Networked Digital Library of Theses and Dissertations, PQDT Open, World Health Organization, National Institute for Health and Care Excellence, Clinicaltrials.gov, Open-Grey and Google Scholar.Initial keywords to be used will be:Chronic disease, heart diseases, diabetes mellitus, cerebrovascular disorders, asthma, pulmonary disease chronic obstructive, cancer, avatar, user-computer interface, gaming, computer simulation, three-dimension, virtual environment, patient education, health education, consumer health information, knowledge, self-care behaviors, self-efficacy, quality of life and medication adherence.

Types of study to be included

The current review will consider both experimental and epidemiological study designs including randomized controlled trials, non-randomized controlled trials, quasi-experimental studies, before and after studies, prospective and retrospective cohort studies, case-control studies and analytical cross-sectional studies for inclusion. If there is a lack of the best evidence in this area (randomized controlled trials), this review will also consider descriptive epidemiological study designs including case series, individual case reports and descriptive cross-sectional studies for inclusion to report on current best evidence in relation to the effectiveness of using avatar technology in patient education for the field of chronic disease.

Condition or domain being studied

Chronic disease is a major problem worldwide. There are four main types of chronic disease, including cardiovascular disease, cancer, chronic respiratory disease and diabetes. Chronic disease patients who engage in self-care and the self-management of their illnesses have better health outcomes, fewer hospitalizations and complications. Presently, information and communication technologies can serve as a means to promote the principles of self-care and to improve health outcomes. The use of avatar technology for patient education aids in chronic diseases for improving

knowledge, self-care behaviors and Quality of life. Therefore, this review will search for evidence to determine the effectiveness of patient education, using avatar technology, on knowledge and self-care behaviors in chronic disease.

Participants/ population

The current review will consider studies that include patients with any chronic diseases. For example, cardiovascular diseases, chronic respiratory diseases, type 1 or type 2 diabetes or any form of cancer.1 In addition, this review will consider for inclusion studies evaluating patients of all ages (children and adults), races, ethnicities and genders.

Intervention(s), exposure(s)

The current review will consider studies that investigate the effectiveness of using avatar technology in patient education interventions. In the first encounter (orientation to the technology), the avatar technology will have been delivered by a nurse, physician and/or allied health educator via an iPad, other tablet device, computer or mobile phone in a hospital or in the community. Patients will then continue to use/view the technology at home.

Comparator(s)/ control

The current review will consider studies that use usual care and paper-based education materials.Usual care in the chronic disease field includes standard medical care via outpatient or specialist clinics, education through printed materials and/or verbal information from a physician or nurse.48 Care from a family physician or general practitioner, self-management programs, mainstream community services and generic telephone advice are also included. Self-management programs for usual care in chronic disease normally provide education using adult learning principles. These education programs may utilize a variety of education formats such as audio, video and written delivered in group and individual sessions.49 Other computer/internet-based program that do not use an avatar will not be used as comparators.

Outcome(s)

Primary outcomes

The current review will consider studies that include the following outcomes as measured by valid and reliable instruments.

Knowledge is defined as a theoretical or practical understanding of health information acquired through experience or education. There are many tools in the chronic disease field that measure knowledge including: the Michigan Diabetes Knowledge Test, which is used to measure diabetes knowledge through a 14-item scale questionnaire; the Dutch Heart Failure Knowledge Scale, which measures the knowledge of heart failure patients through a 15-item self-administered questionnaire; the Bristol chronic obstructive pulmonary disease (COPD) Knowledge Questionnaire designed to measure knowledge of COPD through a 20-minute self-administered instrument comprising 13 domains, each consisting of five statements with response choices and the Cancer Knowledge Test, which is used to measure knowledge about cancer and its treatment through 18 multiple-choice questions.Self-care behavior is defined as the process of maintaining health through the use of health-promoting practices and the self-management of illness in both healthy and ill states. There are many tools in the chronic disease field that measure self-care behaviors including the European Heart Failure Self-care Behavior Scale, which measures heart-failure-related self-care behaviors through a nine-item questionnaire and the Summary of Diabetes Self-care Activities Measure, which is used to assess diabetes self-management through a brief self-report questionnaire

Secondary outcomes

Self-efficacy is defined as the use of individual management to educate and change one's habits. There are several tools that can potentially be used to measure self-efficacy including the Self-Efficacy for Diabetes Scale, which measures the perception of one's ability to manage diabetes in medical, general and diabetes-specific situations through a 34-item questionnaire and a six-point scale, and the Exercise Self-Regulatory Efficacy Scale, to measure the self-regulatory efficacy of individuals with COPD to exercise through a 16-item questionnaire with a level of confidence ranging from 0 (not at all confident) to 100% (highly confident).Health-related QoL (HRQoL) is defined as the overall impact of a medical condition on the physical, mental and social wellbeing of an individual. Examples of tools used to measure HRQoL in the chronic disease field include: the Medical Outcome Study 36-item Short Form Health Survey, which is designed to measure the health status of individuals through a combination of a physical component summary and a mental component summary, including 36 questions in a self-administered questionnaire with scores for each dimension ranging from 0 to 100; the Minnesota Living with Heart Failure Questionnaire, which

measures the effects of symptoms, functional limitations and psychological distress on individual QoL through 21 questions on a scale from 0 to 5 and the St. George's Respiratory Questionnaire, which is a disease-specific QoL assessment tool validated for both COPD and asthma through 50 items containing 76 weighted responses.Re-admission is defined as a subsequent acute admission for the same patient within 30 days of discharge of the initial admission, with at least one day between the discharge and the new admission. In this review, re-admission includes both emergency and elective admissions to hospitals and unplanned general physician units as measured by a medical self-report form.Adherence to medication is defined as patients taking medications as prescribed by their healthcare providers with respect to timing, dosage and frequency. Medication adherence can be measured through: the Medication Adherence Questionnaire, also known as the Morisky-4 or morisky medication adherence scale-4 (MMAS-4) scale; the Brief Medication Questionnaire, which measures adherence to medication in diabetic patients, through a self-report tool for screening adherence and barriers to adherence, and includes a five-item scale and the Hill-Bone Compliance Scale to measure adherence to hypertension medication through a 14-item scale in three subscales with each item being measured through a four-point Likert-type scale.

Data extraction, (selection and coding)
Data will be extracted from papers included in the review by two independent reviewers using the standardized data extraction tool from JBI-MAStARI. The data extracted will include specific details about the interventions, populations, study methods and outcomes of significance to the review question and specific objectives.

Risk of bias (quality) assessment
All quantitative papers on avatar technology patient education in the field of chronic disease selected for retrieval will be assessed by two independent reviewers for methodological validity prior to inclusion in the review using standardized critical appraisal instruments from the Joanna Briggs Institute Meta-Analysis of Statistics Assessment and Review Instrument (JBI-MAStARI). Any disagreements that arise between the reviewers will be resolved through discussion or with a third reviewer.

Strategy for data synthesis
Quantitative data will, where possible, be pooled in a statistical meta-analysis using JBI-MAStARI. All results will be subject to double data entry. Effect size expressed as an odds ratio (for categorical data) or weighted mean differences (for continuous data) and their 95% confidence intervals will be calculated for analysis. Heterogeneity will be assessed statistically using the standard Chi-squareD measure and will also be explored through subgroup analyses based on the different study designs included in this review.

Analysis of subgroups or subsets
Where statistical pooling is not possible, the findings will be presented in narrative form including tables and figures to aid in the presentation of the data where appropriate.

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Reference and/or URL for protocol
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Stage of review
Ongoing

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13 December 2016

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13 December 2016

Stage of review at time of this submission	Started	Completed
Preliminary searches	No	No
Piloting of the study selection process	No	No
Formal screening of search results against eligibility criteria	No	No
Data extraction	No	No
Risk of bias (quality) assessment	No	No
Data analysis	No	No

Appendix 2: Full search strategy

Searches conducted 2005 to 24 March 2017

Medline

Search	Query
1	Video Games/
2	Computer Graphics/
3	User-computer interface/
4	Computer-assisted instruction/
5	computer simulation/
6	Avatar*.tw.
7	Conversation* Agent*.tw.
8	Virtual Agent*.tw.
9	Intelligent Agent*.tw.
10	Virtual Environment*.tw.
11	virtual realit*.tw.
12	Simulat* Environment*.tw.
13	Computer* Agent*.tw.
14	embodi* agent.tw.
15	3D Simulat*.tw.
16	gaming.tw.
17	Second Life.tw.
18	Virtual Represent*.tw.
19	Three-dimension* Simulat*.tw.
20	or/1-19
21	Patient Education as Topic/
22	Health Education/
23	Health communication/
24	Consumer Health Information/
25	Inpatients/ed [Education]
26	Outpatients/ed [Education]
27	Health Literacy/
28	Health Knowledge, Attitudes, Practice/
29	Attitude to health/
30	Self care/
31	Patient Compliance/

Search	Query
32	Medication Adherence/
33	Health Behavior/
34	self efficacy/
35	quality of life/
36	Patient Participation/
37	((health or patient* or outpatient* or inpatient* or client* or consumer*) adj3 (educat* or inform* or instruct* or train* or advice or advis* or coach* or learn* or teach* or involv* or engag* or intervention* or evaluat* or literac* or knowledg* or attitude* or complian* or behav* or participa* or trust* or communicat* or decision* or perception* or engag* or involv* or support* or empower* or disempower* or motiv* or perspective* or view* or "self efficacy" or "self care" or collaborat* or experience* or perspective* or concern* or adher* or nonadher* or belief*)).tw.
38	"self care".tw.
39	("quality of life" or QOL).tw.
40	(medication adj2 adher*).tw.
41	or/21-40
42	chronic disease/
43	exp heart diseases/
44	exp Diabetes Mellitus/
45	exp Neoplasms/
46	exp cerebrovascular disorders/
47	exp asthma/
48	exp pulmonary disease chronic obstructive/
49	exp Hypertension/
50	(non-communicable disease* or noncommunicable disease*).tw.
51	(chronic adj2 (disease* or ill* or condition* or disorder* or health*)).tw.
52	((disease* or failure*) adj1 (kidney* or liver)).tw.
53	((disease* or disorder*) adj1 thyroid).tw.
54	(COPD or ((disease* or disorder*) adj1 pulmonary)).tw.
55	((heart or cardiac or cardiovascular or coronary) adj1 (disease* or disorder* or failure)).tw.
56	diabetes.tw.
57	(cancer* or neoplasm*).tw.
58	asthma.tw.
59	(hypertension or hypertensive or high blood pressure).tw.

Search	Query
60	or/42-59
61	20 and 41 and 60
62	limit 61 to yr="2005 -Current"

CINAHL

Search	Query
S1	(MH "Video Games")
S2	(MH "Computer Graphics")
S3	(MH "User-Computer Interface")
S4	(MH "Computer Assisted Instruction")
S5	(MH "Computer Simulation")
S6	TI avatar* OR AB avatar*
S7	TI "Conversation* Agent*" OR AB "Conversation* Agent*"
S8	TI "Virtual Agent*" OR AB "Virtual Agent*"
S9	TI "Intelligent Agent*" OR AB "Intelligent Agent*"
S10	TI "Virtual Environment*" OR AB "Virtual Environment*"
S11	(MH "Virtual Reality") OR TI "virtual realit*" OR AB "virtual realit*"
S12	TI "Simulat* Environment*" OR AB "Simulat* Environment*"
S13	TI "Computer* Agent*" OR AB "Computer* Agent*"
S14	TI "embodi* agent*" OR AB "embodi* agent*"
S15	TI "3D Simulat*" OR AB "3D Simulat*"
S16	TI gaming OR AB gaming
S17	TI "Second Life" OR AB "Second Life"
S18	TI "Virtual Represent*" OR AB "Virtual Represent*"
S19	TI "Three-dimension* Simulat*" OR AB "Three-dimension* Simulat*"
S20	S1 OR S2 OR S3 OR S4 OR S5 OR S6 OR S7 OR S8 OR S9 OR S10 OR S11 OR S12 OR S13 OR S14 OR S15 OR S16 OR S17 OR S18 OR S19
S21	(MH "Patient Education+")
S22	(MH "Health Education+")
S23	(MH "Consumer Health Information")
S24	(MH "Patients+/ED")
S25	(MH "Health Literacy")
S26	(MH "Health Knowledge")
S27	(MH "Attitude to Health")
S28	(MH "Patient Attitudes")
S29	(MH "Self Care+")
S30	(MH "Patient Compliance")
S31	(MH "Medication Compliance")
S32	(MH "Health Behavior")
S33	(MH "Self-Efficacy")
S34	(MH "Quality of Life+")

Search	Query
S35	(MH "Consumer Participation")
S36	TI (((health or patient* or outpatient* or inpatient* or client* or consumer*) N3 (educat* or inform* or instruct* or train* or advice or advis* or coach* or learn* or teach* or involv* or engag* or intervention* or evaluat* or literac* or knowledg* or attitude* or complian* or behav* or participa* or trust* or communicat* or decision* or perception* or engag* or involv* or support* or empower* or disempower* or motiv* or perspective* or view* or "self efficacy" or "self care" or collaborat* or experience* or perspective* or concern* or adher* or nonadher* or non-adher* or belief* or "quality of life" or QOL))) OR AB (((health or patient* or outpatient* or inpatient* or client* or consumer*) N3 (educat* or inform* or instruct* or train* or advice or advis* or coach* or learn* or teach* or involv* or engag* or intervention* or evaluat* or literac* or knowledg* or attitude* or complian* or behav* or participa* or trust* or communicat* or decision* or perception* or engag* or involv* or support* or empower* or disempower* or motiv* or perspective* or view* or "self efficacy" or "self care" or collaborat* or experience* or perspective* or concern* or adher* or nonadher* or non-adher* or belief* or "quality of life" or QOL)))
S37	TI ((medication* N2 (adher* or nonadher* or non-adher*))) OR AB ((medication* adj2 (adher* or nonadher* or non-adher*)))
S38	S21 OR S22 OR S23 OR S24 OR S25 OR S26 OR S27 OR S28 OR S29 OR S30 OR S31 OR S32 OR S33 OR S34 OR S35 OR S36 OR S37
S39	(MH "Chronic Disease")
S40	(MH "Heart Diseases+")
S41	(MH "Diabetes Mellitus+")
S42	(MH "Neoplasms+")
S43	(MH "Cerebrovascular Disorders+")
S44	(MH "Asthma+")
S45	(MH "Pulmonary Disease, Chronic Obstructive+")
S46	(MH "Hypertension+")
S47	TI (("non-communicable disease*" OR "noncommunicable disease*")) OR AB (("non-communicable disease*" OR "noncommunicable disease*"))
S48	TI ((chronic N2 (disease* or ill* or condition* or disorder* or health*))) OR AB ((chronic N2 (disease* or ill* or condition* or disorder* or health*))) OR TI ((COPD or ((disease* or disorder*) N1 pulmonary))) OR AB ((COPD or ((disease* or disorder*) N1 pulmonary)))

Search	Query
S49	TI (((heart or cardiac or cardiovascular or coronary) N1 (disease* or disorder* or failure))) OR AB (((heart or cardiac or cardiovascular or coronary) N1 (disease* or disorder* or failure)))
S50	TI diabet* OR AB diabet* OR TI asthma* OR AB asthma*
S51	TI (cancer* or neoplasm*) OR AB (cancer* or neoplasm*)
S52	TI (hypertension or hypertensive or "high blood pressure") OR AB (hypertension or hypertensive or "high blood pressure")
S53	S39 OR S40 OR S41 OR S42 OR S43 OR S44 OR S45 OR S46 OR S47 OR S48 OR S49 OR S50 OR S51 OR S52
S54	S20 AND S38 AND S53 Limiters - Published Date: 20050101-20171231

PsycInfo

Search	Query
1	Video Games/
2	Computer-assisted instruction/
3	computer simulation/
4	Avatar*.tw.
5	Conversation* Agent*.tw.
6	Virtual Agent*.tw.
7	Intelligent Agent*.tw.
8	Virtual Environment*.tw.
9	virtual realit*.tw.
10	Simulat* Environment*.tw.
11	Computer* Agent*.tw.
12	embodi* agent*.tw.
13	3D Simulat*.tw.
14	gaming.tw.
15	Second Life.tw.
16	Virtual Represent*.tw.
17	Three-dimension* Simulat*.tw.
18	or/1-17
19	Client education/
20	Health Education/
21	Health Literacy/
22	Health knowledge/
23	Health attitudes/ or Client attitudes/
24	Self care/
25	Treatment Compliance/
26	Health Behavior/
27	self efficacy/
28	quality of life/
29	Patient Participation/
30	((health or patient* or outpatient* or inpatient* or client* or consumer*) adj3 (educat* or inform* or instruct* or train* or advice or advis* or coach* or learn* or teach* or involv* or engag* or intervention* or evaluat* or literac* or knowledg* or attitude* or complian* or behav* or participa* or trust* or communicat* or decision* or perception* or engag* or involv* or support* or empower* or disempower* or motiv* or perspective* or view* or "self

	efficacy" or "self care" or collaborat* or experience* or perspective* or concern* or adher* or nonadher* or non-adher* or belief* or "quality of life" or QOL)).tw.
31	(medication* adj2 (adher* or nonadher* or non-adher*)).tw.
32	or/19-31
33	chronic illness/
34	exp Diabetes Mellitus/
35	exp Neoplasms/
36	exp cerebrovascular disorders/
37	exp asthma/
38	exp Hypertension/
39	(non-communicable disease* or noncommunicable disease*).tw.
40	(chronic adj2 (disease* or ill* or condition* or disorder* or health*)).tw.
41	(COPD or ((disease* or disorder*) adj1 pulmonary)).tw.
42	((heart or cardiac or cardiovascular or coronary) adj1 (disease* or disorder* or failure)).tw.
43	diabet*.tw.
44	(cancer* or neoplasm*).tw.
45	asthma*.tw.
46	(hypertension or hypertensive or high blood pressure).tw.
47	or/33-46
48	18 and 32 and 47
49	limit 48 to yr="2005 -Current"

Cochrane Central Register of Controlled Trials

Search	Query
#1	(Avatar* or "Conversation* Agent*" or "Virtual Agent*" or "Intelligent Agent*" or "Virtual Environment*" or "virtual realit*" or "Simulat* Environment*" or "Computer* Agent*" or "embodi* agent*" or "3D Simulat*" or gaming or "Second Life" or "Virtual Represent*" or "Three-dimension* Simulat*"):ti,ab,kw
#2	((health or patient* or outpatient* or inpatient* or client* or consumer*) near/3 (educat* or inform* or instruct* or train* or advice or advis* or coach* or learn* or teach* or involv* or engag* or intervention* or evaluat* or literac* or knowledg* or attitude* or complian* or behav* or participa* or trust* or communicat* or decision* or perception* or engag* or involv* or support* or empower* or disempower* or motiv* or perspective* or view* or "self efficacy" or "self care" or collaborat* or experience* or perspective* or concern* or adher* or nonadher* or non-adher* or belief* or "quality of life" or QOL)):ti,ab,kw
#3	(medication* near/2 (adher* or nonadher* or non-adher*)):ti,ab,kw
#4	#2 or #3
#5	("non-communicable disease*" or "noncommunicable disease*" or cancer* or neoplasm* or hypertension or hypertensive or "high blood pressure" or diabet* or asthma*):ti,ab,kw
#6	(chronic near/2 (disease* or ill* or condition* or disorder* or health*)):ti,ab,kw
#7	(COPD or ((disease* or disorder*) near/1 pulmonary)):ti,ab,kw
#8	((heart or cardiac or cardiovascular or coronary) near/1 (disease* or disorder* or failure)):ti,ab,kw
#9	#5 or #6 or #7 or #8
#10	#1 and #4 and #9 Publication Year from 2005 to 2017

Proquest

(ti(((Avatar* OR "Conversation* Agent*" OR "Virtual Agent*" OR "Intelligent Agent*" OR "Virtual Environment*" OR "virtual realit*" OR "Simulat* Environment*" OR "Computer* Agent*" OR "embodi* agent*" OR "3D Simulat*" OR gaming OR "Second Life" OR "Virtual Represent*" OR "Three-dimension* Simulat*"))) OR ab(((Avatar* OR "Conversation* Agent*" OR "Virtual Agent*" OR "Intelligent Agent*" OR "Virtual Environment*" OR "virtual realit*" OR "Simulat* Environment*" OR "Computer* Agent*" OR "embodi* agent*" OR "3D Simulat*" OR gaming OR "Second Life" OR "Virtual Represent*" OR "Three-dimension* Simulat*")))) AND ((ti(((health OR patient* OR outpatient* OR inpatient* OR client* OR consumer*) NEAR/3 (educat* OR inform* OR instruct* OR train* OR advice OR advis* OR coach* OR learn* OR teach* OR involv* OR engag* OR intervention* OR evaluat* OR literac* OR knowledg* OR attitude* OR complian* OR behav* OR participa* OR trust* OR communicat* OR decision* OR perception* OR engag* OR involv* OR support* OR empower* OR disempower* OR motiv* OR perspective* OR view* OR "self efficacy" OR "self care" OR collaborat* OR experience* OR perspective* OR concern* OR adher* OR nonadher* OR non-adher* OR belief* OR "quality of life" OR QOL))) OR ab(((health OR patient* OR outpatient* OR inpatient* OR client* OR consumer*) NEAR/3 (educat* OR inform* OR instruct* OR train* OR advice OR advis* OR coach* OR learn* OR teach* OR involv* OR engag* OR intervention* OR evaluat* OR literac* OR knowledg* OR attitude* OR complian* OR behav* OR participa* OR trust* OR communicat* OR decision* OR perception* OR engag* OR involv* OR support* OR empower* OR disempower* OR motiv* OR perspective* OR view* OR "self efficacy" OR "self care" OR collaborat* OR experience* OR perspective* OR concern* OR adher* OR nonadher* OR non-adher* OR belief* OR "quality of life" OR QOL)))) OR (ti((medication* NEAR/2 (adher* OR nonadher* OR non-adher*))) OR ab((medication* NEAR/2 (adher* OR nonadher* OR non-adher*))))) AND ((ti(("non-communicable disease*" OR "noncommunicable disease*" OR cancer* OR neoplasm* OR hypertension OR hypertensive OR "high blood pressure" OR diabet* OR asthma*)) OR ab(("non-communicable disease*" OR "noncommunicable disease*" OR cancer* OR neoplasm* OR hypertension OR hypertensive OR "high blood pressure" OR diabet* OR asthma*))) OR (ti((chronic NEAR/2 (disease* OR ill* OR condition* OR disorder* OR health*))) OR ab((chronic NEAR/2 (disease* OR ill* OR condition* OR disorder* OR health*)))) OR (ti((COPD OR ((disease* OR disorder*) NEAR/1 pulmonary))) OR ab((COPD OR ((disease* OR disorder*) NEAR/1 pulmonary)))) OR (ti(((heart OR cardiac OR cardiovascular OR coronary) NEAR/1 (disease* OR disorder* OR failure))) OR ab(((heart OR cardiac OR cardiovascular OR coronary) NEAR/1 (disease* OR disorder* OR failure))))) Additional limits - -Date: After 01 January 2005

Scopus

(((TITLE-ABS((Avatar* OR "Conversation* Agent*" OR "Virtual Agent*" OR "Intelligent Agent*" OR "Virtual Environment*" OR "virtual realit*" OR "Simulat* Environment*" OR "Computer* Agent*" OR "embodi* agent*" OR "3D Simulat*" OR gaming OR "Second Life"))) AND ((TITLE-ABS((health or patient* or outpatient* or inpatient* or client* or consumer*) W/3 (educat* or inform* or instruct* or train* or advice or advis* or coach* or learn* or teach* or involv* or engag* or intervention* or evaluat* or literac* or knowledg* or attitude* or complian* or behav* or participa* or trust* or communicat* or decision* or perception* or engag* or involv* or support* or empower* or disempower* or motiv* or perspective* or view* or "self efficacy" or "self care" or collaborat* or experience* or perspective* or concern* or adher* or nonadher* or non-adher* or belief* or "quality of life" or QOL))) OR (TITLE-ABS(medication* W/2 (adher* or nonadher* or non-adher*)))) AND PUBYEAR > 2004) AND (TITLE-ABS(("non-communicable disease*" OR "noncommunicable disease*" OR cancer* or neoplasm* OR hypertension or hypertensive or "high blood pressure" OR diabet* OR asthma*)) AND PUBYEAR > 2004)) OR (((TITLE-ABS((Avatar* OR "Conversation* Agent*" OR "Virtual Agent*" OR "Intelligent Agent*" OR "Virtual Environment*" OR "virtual realit*" OR "Simulat* Environment*" OR "Computer* Agent*" OR "embodi* agent*" OR "3D Simulat*" OR gaming OR "Second Life"))) AND ((TITLE-ABS((health or patient* or outpatient* or inpatient* or client* or consumer*) W/3 (educat* or inform* or instruct* or train* or advice or advis* or coach* or learn* or teach* or involv* or engag* or intervention* or evaluat* or literac* or knowledg* or attitude* or complian* or behav* or participa* or trust* or communicat* or decision* or perception* or engag* or involv* or support* or empower* or disempower* or motiv* or perspective* or view* or "self efficacy" or "self care" or collaborat* or experience* or perspective* or concern* or adher* or nonadher* or non-adher* or belief* or "quality of life" or QOL))) OR (TITLE-ABS(medication* W/2 (adher* or nonadher* or non-adher*)))) AND PUBYEAR > 2004) AND ((TITLE-ABS((heart or cardiac or cardiovascular or coronary) W/1 (disease* or disorder* or failure)) AND PUBYEAR > 2004) OR (TITLE-ABS(COPD or ((disease* or disorder*) W/1 pulmonary)) AND PUBYEAR > 2004) OR (TITLE-ABS(chronic W/2 (disease* or ill* or condition* or disorder* or health*)) AND PUBYEAR > 2004)))

Web of Science

Search	Query
#11	#9 AND #8 AND #1 Refined by: PUBLICATION YEARS: (2016 OR 1998 OR 2014 OR 2009 OR 2015 OR 2008 OR 2013 OR 2007 OR 2011 OR 2000 OR 2012 OR 2005 OR 2010)
#10	#9 AND #8 AND #1
#9	#7 OR #6 OR #5 OR #4
#8	#3 OR #2
#7	TOPIC: (((heart or cardiac or cardiovascular or coronary) NEAR/1 (disease* or disorder* or failure)))
#6	TOPIC: ((COPD or ((disease* or disorder*) NEAR/1 pulmonary)))
#5	TOPIC: ((chronic NEAR/2 (disease* or ill* or condition* or disorder* or health*)))
#4	TOPIC: (("non-communicable disease*" OR "noncommunicable disease*" OR cancer* or neoplasm* OR hypertension or hypertensive or "high blood pressure" OR diabet* OR asthma*))
#3	TOPIC: ((medication* NEAR/2 (adher* or nonadher* or non-adher*)))
#2	TOPIC: (((health or patient* or outpatient* or inpatient* or client* or consumer*) NEAR/3 (educat* or inform* or instruct* or train* or advice or advis* or coach* or learn* or teach* or involv* or engag* or intervention* or evaluat* or literac* or knowledg* or attitude* or complian* or behav* or participa* or trust* or communicat* or decision* or perception* or engag* or involv* or support* or empower* or disempower* or motiv* or perspective* or view* or "self efficacy" or "self care" or collaborat* or experience* or perspective* or concern* or adher* or nonadher* or non-adher* or belief* or "quality of life" or QOL)))
#1	TOPIC: ((Avatar* OR "Conversation* Agent*" OR "Virtual Agent*" OR "Intelligent Agent*" OR "Virtual Environment*" OR "virtual realit*" OR "Simulat* Environment*" OR "Computer* Agent*" OR "embodi* agent*" OR "3D Simulat*" OR gaming OR "Second Life" OR "Virtual Represent*" OR "Three-dimension* Simulat*"))

Appendix 3: Appraisal instruments

Checklist for Randomized Controlled Trials (2016) by Joanna Briggs Institute. Source: https://joannabriggs.org/critical-appraisal-tools

Removed due to copyright restriction.

Checklist for Randomized Controlled Trials (2016) by Joanna Briggs Institute. Source: https://joannabriggs.org/critical-appraisal-tools

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Checklist for Randomized Controlled Trials (2016) by Joanna Briggs Institute. Source: https://joannabriggs.org/critical-appraisal-tools

Removed due to copyright restriction.

Appendix 4: Studies excluded on full text

Fortier, MA, Chung, WW, Martinez, A, Gago-Masague, S & Sender, L 2016, 'Pain buddy: A novel use of m-health in the management of children's cancer pain', Computers in Biology and Medicine, vol. 76, pp. 202-14.
Reason for exclusion: No measure of outcomes.

Greer, MZ, 2009. Effect of a cd-rom game to teach school-age children about asthma. *Dissertation Abstracts International Section A: Humanities and Social Sciences,* 70**,** 1630.
Reason for exclusion: This is a dissertation, which is not a peer reviewed paper and therefore may be less scientifically rigorous than those that are peer reviewed.

Meppelink, CS, Van Weert, JC, Haven, CJ & Smit, E. G. 2015. The effectiveness of health animations in audiences with different health literacy levels: an experimental study. *Journal of Medical Internet Research,* 17**,** e11.
Reason for exclusion: No measure of outcomes.

Appendix 5: Instruments used to collect data (pre- and post-test)

FLUID WATCHERS

Flinders UNIVERSITY

CELEBRATING 50 years OF INSPIRING ACHIEVEMENT

Participant ID

Section 1: General Information

Patient profiles information and Medical record

1. Gender	Female ☐	Male ☐
2. Date of birth	DD/MM/YYYY	
3. Country of birth		
4. Aboriginal or Torres Strait islander origin	No ☐	Yes, Aboriginal ☐
	Yes, Torres Strait Islander ☐	
5. Language spoken at home	English ☐	
	Other ☐ *(please specify)*	
	Both English & other ☐	
6. Marital status *(please tick one box only)*		
Single	☐	
Married	☐	
Defacto	☐	
Separated	☐	
Divorced	☐	
Widowed	☐	
7. Living status	Living alone ☐	
	Living with spouse, carer or relative(s) ☐	
	Living with other ☐ please specify_____	
8. Current occupation		
9. Private health insurance		
10. Highest level of education *(please tick one box only)*		
No school certificate or other qualification	☐	
School or intermediate certificate (or equivalent)	☐	
High school or leaving certificate (or equivalent)	☐	
Trade/apprenticeship (e.g. hairdresser, chef)	☐	
Certificate/diploma (e.g. child care, technician)	☐	
University degree or higher	☐	

FLUID WATCHERS

Flinders UNIVERSITY | CELEBRATING 50 years OF INSPIRING ACHIEVEMENT

Participant ID

Development and evaluation of an interactive avatar-based education application for improving heart failure patients' knowledge and self-care behaviours

Preliminary Evaluation: Pre-test

- **Section 1:**
  The Dutch Heart Failure Knowledge Scale
- **Section 2:**
  The Self-Care of Heart Failure Index

FLUID WATCHERS

Flinders UNIVERSITY

CELEBRATING 50 years OF INSPIRING ACHIEVEMENT

Participant ID

Section 1: The Dutch Heart Failure Knowledge Scale

Patient interview

The Dutch Heart Failure Knowledge scale

Please tick for the best answer

1. How often should patients with severe heart failure weigh themselves?
   - ☐ Every week
   - ☐ Now and then
   - ☐ Every day

2. Why is it important that patients with heart failure should weigh themselves regularly?
   - ☐ Because many patients with heart failure have a poor appetite
   - ☐ To check whether the body is retaining fluid
   - ☐ To assess the right dose of medicines

3. How much fluid are you allowed to take at home each day?
   - ☐ 1.5 to 2.5 litres at the most
   - ☐ little fluid as possible
   - ☐ As much as possible

4. Which of these statements is true
   - ☐ When I cough a lot, it is better not to take my heart failure medication
   - ☐ When I am feeling better, I can stop taking my medication for heart failure
   - ☐ It is important that I take my heart failure medication regularly

5. What is the best thing to do in case of increased shortness of breath or swollen legs?
   - ☐ Call the doctor or the nurse
   - ☐ Wait until the next check-up
   - ☐ Take less medication

6. What can cause a rapid worsening of heart failure symptoms?
   - ☐ A high-fat diet
   - ☐ A cold or the flu
   - ☐ Lack of exercise

7. What does heart failure mean?
   - ☐ That the heart is unable to pump enough blood around the body
   - ☐ That someone is not getting enough exercise and is in poor condition
   - ☐ That there is a blood clot in the vessels of the heart

8. Why can the legs swell up when you have heart failure?
   - ☐ Because the valves in the blood vessels in the legs do not function properly
   - ☐ Because the muscles in the legs are not getting enough oxygen
   - ☐ Because of accumulation of fluid in the legs

9. What is the function of the heart?
   - ☐ To absorb nutrients from the blood
   - ☐ To pump blood around the body
   - ☐ To provide the blood with oxygen

10. Why should someone with heart failure follow a low salt diet?
    - ☐ Salt promotes fluid retention
    - ☐ Salt causes constriction of the blood vessels
    - ☐ Salt increases the heart rate

11. What are the main causes of heart failure?
    - ☐ A myocardial infarction and high blood pressure
    - ☐ Lung problems and allergy
    - ☐ Obesity and diabetes

12. Which statement about exercise for people with heart failure is true?
    - ☐ It is important to exercise as little as possible at home in order to relieve the heart
    - ☐ It is important to exercise at home and to rest regularly in between
    - ☐ It is important to exercise as much as possible at home

13. Why are water pills prescribed to someone with the heart failure
    - ☐ To lower the blood pressure
    - ☐ To prevent fluid retention in the body
    - ☐ Because then they can drink more

14. Which statement about weight increase and heart failure is true?
    - ☐ An increase of over 2 kilograms in 2 or 3 days should be reported to the doctor at the next check-up
    - ☐ In case of an increase of over 2 kilograms in 2 or 3 days, you should contact your doctor or nurse
    - ☐ In case of an increase of over 2 kilograms in 2 or 3 days, you should eat less

15. What is the best thing to do when you are thirsty?
    - ☐ Suck an ice cube
    - ☐ Suck a lozenge
    - ☐ Drink a lot

Applied from:
van der Wal, M. H. L., T. Jaarsma, D. K. Moser and D. J. van Veldhuisen (2005). "Development and Testing of the Dutch Heart Failure Knowledge Scale." European Journal of Cardiovascular Nursing 4(4): 273-277.

FLUID WATCHERS

Flinders UNIVERSITY

CELEBRATING 50 years OF INSPIRING ACHIEVEMENT

Participant ID

Section 2: The Self-Care of Heart Failure Index

Patient interview

The Self-Care of Heart Failure Index

Think about how you have been feeling in the last month or since we last spoke as you complete these items.

SECTION A:

Listed below are common instructions given to persons with heart failure. How routinely do you do the following?

Item	Never or rarely	Sometimes	Frequently	Always or daily
1. Weigh yourself?	1	2	3	4
2. Check your ankles for swelling?	1	2	3	4
3. Try to avoid getting sick (e.g., flu shot, avoid ill people)?	1	2	3	4
4. Do some physical activity?	1	2	3	4
5. Keep doctor or nurse appointments?	1	2	3	4
6. Eat a low salt diet?	1	2	3	4
7. Exercise for 30 minutes?	1	2	3	4
8. Forget to take one of your medicines?	1	2	3	4
9. Ask for low salt items when eating out or visiting others?	1	2	3	4
10. Use a system (pill box, reminders) to help you remember your medicines?	1	2	3	4

SECTION B:

Many patients have symptoms due to their heart failure. Trouble breathing and ankle swelling are common symptoms of heart failure.

In the past month, have you had trouble breathing or ankle swelling? Circle **one**.

0) No

1) Yes

11. If you had trouble breathing or ankle swelling in the past month

(Circle **one** number)

Item	Have not had these	I did not recognize it	Not Quickly	Somewhat Quickly	Quickly	Very Quickly
How quickly did you recognize it as a symptom of heart failure?	N/A	0	1	2	3	4

Listed below are remedies that people with heart failure use. If you have trouble breathing or ankle swelling, how likely are you to try one of these remedies?

(Circle **one** number for each remedy)

Item	Not likely	Somewhat likely	Likely	Very likely
12. Reduce the salt in your diet	1	2	3	4
13. Reduce your fluid intake	1	2	3	4
14. Take an extra water pill	1	2	3	4
15. Call your doctor or nurse for guidance	1	2	3	4

16. Think of a remedy you tried the last time you had trouble breathing or ankle swelling,

(Circle **one** number)

Item	I did not try anything	Not Sure	Somewhat Sure	Sure	Very Sure
How sure were you that the remedy helped or did not help?	0	1	2	3	4

SECTION C:

In general, how confident are you that you can:

Item	Not Confident	Somewhat Confident	Very Confident	Extremely Confident
17. Keep yourself free of heart failure symptoms?	1	2	3	4
18. Follow the treatment advice you have been given?	1	2	3	4
19. Evaluate the importance of your symptoms?	1	2	3	4
20. Recognize changes in your health if they occur?	1	2	3	4
21. Do something that will relieve your symptoms?	1	2	3	4
22. Evaluate how well a remedy works?	1	2	3	4

Applied from:

Riegel, B., C. S. Lee, V. V. Dickson and B. Carlson (2009). "An Update on the Self-Care of Heart Failure Index." The Journal of cardiovascular nursing 24(6): 485-497.

FLUID WATCHERS

Flinders UNIVERSITY | CELEBRATING 50 years OF INSPIRING ACHIEVEMENT

Participant ID

Development and evaluation of an interactive avatar-based education application for improving heart failure patients' knowledge and self-care behaviours

Preliminary Evaluation: Post-test

- **Section 1:**
  The Dutch Heart Failure Knowledge Scale
- **Section 2:**
  The Self-Care of Heart Failure Index
- **Section 3**:
  Patient satisfaction questionnaire

FLUID WATCHERS

Flinders UNIVERSITY

CELEBRATING 50 years OF INSPIRING ACHIEVEMENT

Participant ID

Section 1: The Dutch Heart Failure Knowledge Scale

Patient interview

The Dutch Heart Failure Knowledge scale

Please tick for the best answer

1. How often should patients with severe heart failure weigh themselves?
   - ☐ Every week
   - ☐ Now and then
   - ☐ Every day

2. Why is it important that patients with heart failure should weigh themselves regularly?
   - ☐ Because many patients with heart failure have a poor appetite
   - ☐ To check whether the body is retaining fluid
   - ☐ To assess the right dose of medicines

3. How much fluid are you allowed to take at home each day?
   - ☐ 1.5 to 2.5 litres at the most
   - ☐ little fluid as possible
   - ☐ As much as possible

4. Which of these statements is true
   - ☐ When I cough a lot, it is better not to take my heart failure medication
   - ☐ When I am feeling better, I can stop taking my medication for heart failure
   - ☐ It is important that I take my heart failure medication regularly

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   - ☐ Wait until the next check-up
   - ☐ Take less medication

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   - ☐ A cold or the flu
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   - ☐ Because of accumulation of fluid in the legs

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   - ☐ To absorb nutrients from the blood
   - ☐ To pump blood around the body
   - ☐ To provide the blood with oxygen

10. Why should someone with heart failure follow a low salt diet?
    - ☐ Salt promotes fluid retention
    - ☐ Salt causes constriction of the blood vessels
    - ☐ Salt increases the heart rate

11. What are the main causes of heart failure?
    - ☐ A myocardial infarction and high blood pressure
    - ☐ Lung problems and allergy
    - ☐ Obesity and diabetes

12. Which statement about exercise for people with heart failure is true?
    - ☐ It is important to exercise as little as possible at home in order to relieve the heart
    - ☐ It is important to exercise at home and to rest regularly in between
    - ☐ It is important to exercise as much as possible at home

13. Why are water pills prescribed to someone with the heart failure
    - ☐ To lower the blood pressure
    - ☐ To prevent fluid retention in the body
    - ☐ Because then they can drink more

14. Which statement about weight increase and heart failure is true?
    - ☐ An increase of over 2 kilograms in 2 or 3 days should be reported to the doctor at the next check-up
    - ☐ In case of an increase of over 2 kilograms in 2 or 3 days, you should contact your doctor or nurse
    - ☐ In case of an increase of over 2 kilograms in 2 or 3 days, you should eat less

15. What is the best thing to do when you are thirsty?
    - ☐ Suck an ice cube
    - ☐ Suck a lozenge
    - ☐ Drink a lot

Applied from:
van der Wal, M. H. L., T. Jaarsma, D. K. Moser and D. J. van Veldhuisen (2005). "Development and Testing of the Dutch Heart Failure Knowledge Scale." European Journal of Cardiovascular Nursing 4(4): 273-277.

FLUID WATCHERS

Flinders UNIVERSITY | CELEBRATING 50 years OF INSPIRING ACHIEVEMENT

Participant ID

Section 2: The Self-Care of Heart Failure Index

Patient interview

The Self-Care of Heart Failure Index

Think about how you have been feeling in the last month or since we last spoke as you complete these items.

SECTION A:

Listed below are common instructions given to persons with heart failure. How routinely do you do the following?

Item	Never or rarely	Sometimes	Frequently	Always or daily
1. Weigh yourself?	1	2	3	4
2. Check your ankles for swelling?	1	2	3	4
3. Try to avoid getting sick (e.g., flu shot, avoid ill people)?	1	2	3	4
4. Do some physical activity?	1	2	3	4
5. Keep doctor or nurse appointments?	1	2	3	4
6. Eat a low salt diet?	1	2	3	4
7. Exercise for 30 minutes?	1	2	3	4
8. Forget to take one of your medicines?	1	2	3	4
9. Ask for low salt items when eating out or visiting others?	1	2	3	4
10. Use a system (pill box, reminders) to help you remember your medicines?	1	2	3	4

SECTION B:

Many patients have symptoms due to their heart failure. Trouble breathing and ankle swelling are common symptoms of heart failure.

In the past month, have you had trouble breathing or ankle swelling? Circle **one**.

0) No

1) Yes

11. If you had trouble breathing or ankle swelling in the past month

(Circle **one** number)

Item	Have not had these	I did not recognize it	Not Quickly	Somewhat Quickly	Quickly	Very Quickly
How quickly did you recognize it as a symptom of heart failure?	N/A	0	1	2	3	4

Listed below are remedies that people with heart failure use. If you have trouble breathing or ankle swelling, how likely are you to try one of these remedies?

(Circle **one** number for each remedy)

Item	Not likely	Somewhat likely	Likely	Very likely
12. Reduce the salt in your diet	1	2	3	4
13. Reduce your fluid intake	1	2	3	4
14. Take an extra water pill	1	2	3	4
15. Call your doctor or nurse for guidance	1	2	3	4

16. Think of a remedy you tried the last time you had trouble breathing or ankle swelling,

(Circle **one** number)

Item	I did not try anything	Not Sure	Somewhat Sure	Sure	Very Sure
How sure were you that the remedy helped or did not help?	0	1	2	3	4

SECTION C:

In general, how confident are you that you can:

Item	Not Confident	Somewhat Confident	Very Confident	Extremely Confident
17. Keep yourself free of heart failure symptoms?	1	2	3	4
18. Follow the treatment advice you have been given?	1	2	3	4
19. Evaluate the importance of your symptoms?	1	2	3	4
20. Recognize changes in your health if they occur?	1	2	3	4
21. Do something that will relieve your symptoms?	1	2	3	4
22. Evaluate how well a remedy works?	1	2	3	4

Applied from:

Riegel, B., C. S. Lee, V. V. Dickson and B. Carlson (2009). "An Update on the Self-Care of Heart Failure Index." The Journal of cardiovascular nursing 24(6): 485-497.

FLUID WATCHERS

Flinders UNIVERSITY

CELEBRATING 50 years OF INSPIRING ACHIEVEMENT

Participant ID

Section 3: Patient satisfaction questionnaire

Patient interview

Please tick whether you agree or disagree with the following.

	Item	Strongly Disagree	Disagree	Do Not Agree Nor Disagree	Agree	Strongly Agree
1.	I liked the Avatar (the character within the app)	1	2	3	4	5
2.	The audio of the app was clear and easy enough for me to understand	1	2	3	4	5
3.	The size of the print on screen was large enough for easy reading	1	2	3	4	5
4.	It was easy to press the buttons on the screen	1	2	3	4	5
5.	The app has helped me to understand of my medical health problems	1	2	3	4	5
6.	I would be happy to use the app to monitor my health	1	2	3	4	5
7.	The app has shown me what to do when I have too much fluid	1	2	3	4	5
8.	The app taught me how to read and analyse nutritional information	1	2	3	4	5
9.	I learnt something that I was not taught about before	1	2	3	4	5
10.	The content was hard to understand	1	2	3	4	5
11.	It takes too long to use the app	1	2	3	4	5
12.	The information was clear and concise	1	2	3	4	5

Item	Strongly Disagree	Disagree	Do Not Agree Nor Disagree	Agree	Strongly Agree
13. The app maintained my interest and attention	1	2	3	4	5
14. The app answered all my questions	1	2	3	4	5

Overall, how satisfied are you with this app?

Not at all					Indifferent					Highly
0	1	2	3	4	5	6	7	8	9	10

What do you like about this app?

What you did not like about this app?

Do you have any further comments about this app? How could this app be improved?

……

……

……

……

……

……

Adapted from:

Clark, R., B. Fredericks, N. Buitendyk, M. Adams, J. Howie-Esquivel, K. Dracup, N. Berry, J. Atherton, S. Johnson and R. Clark (2015). "Development and feasibility testing of an education program to improve knowledge and self-care among Aboriginal and Torres Strait Islander patients with heart failure." Rural and remote health 15(3231).

Wakefield, B. J., C. L. Bylund, J. E. Holman, A. Ray, M. Scherubel, M. G. Kienzle and G. E. Rosenthal (2008). "Nurse and patient communication profiles in a home-based telehealth intervention for heart failure management." Patient Educ Couns 71(2): 285-292.

Appendix 6: Ethics approval letters

Office for Research

Flinders Medical Centre
Ward 6C, Room 6A219
Flinders Drive, Bedford Park SA 5042
Tel: (08) 8204 6453
E: Health.SALHNOfficeforResearch@sa.gov.au

Government of South Australia
SA Health
Southern Adelaide Local Health Network

Final approval for ethics application

You are reminded that this letter constitutes **ethical** approval only. **Ethics approval is one aspect of the research governance process.**
You must not commence this research project at any SA Health sites listed in the application until a Site Specific Assessment (SSA), or Access Request for data or tissue form has been authorised by the Chief Executive or delegate of each site.

11 October 2016

Professor Robyn Clark
School of Nursing and Midwifery
Flinders University
Sturt Road
BEDFORD PARK SA 5042

Dear Professor Clark

The Southern Adelaide Clinical Human Research Ethics Committee (SAC HREC EC00188) have reviewed and provided ethical approval for this application which appears to meet the requirements of the *National Statement on Ethical Conduct in Human Research.*

Application Number: OFR # 350.16 - HREC/16/SAC/315

Title: Development and evaluation of an interactive avatar based education application for improving heart failure patients' knowledge and self-care behaviour

Chief investigator: Professor Robyn Clark

Approval Period: 11 October 2016 to 11 October 2019

Public health sites approved under this application: Noarlunga Hospital

The below documents have been reviewed and approved:

- Cover Letter Dated 8 August 2016
- Heart Failure story Board Example Dated 26 July 2016
- Evaluation Survey v4.0 Dated 7 July 2016
- HoD letter Dated 27 July 2016
- LNR Fluid Watchers HREC/16/SAC/315 dated 5 October 2016
- Participant Feedback Questionnaire v4.0 Dated 3 August 2016
- PICF Fluid Watchers Phase 1 Development v6.0 Dated 4 October 2016
- PICF Fluid Watchers v6.0 Phase 1 Survey v6.0 Dated 4 October 2016
- PICF Fluid Watchers v6.0 Phase 1 Expert Panel v3.0 Dated 4 October 2016
- Response to reviewers dated 30 September 2016

TERMS AND CONDITIONS OF ETHICAL APPROVAL
As part of the Institution's responsibilities in monitoring research and complying with audit requirements, it is essential that researchers adhere to the conditions below and with the *National Statement chapter 5.5.*

Final ethical approval is granted subject to the researcher agreeing to meet the following terms and conditions:

1. The approval only covers the science and ethics component of the application. A SSA will need to be submitted and authorised before this research project can commence at any of the approved sites identified in the application.

2. If University personnel are involved in this project, the Principal Investigator should notify the University before commencing their research to ensure compliance with University requirements including any insurance and indemnification requirements.
3. Compliance with the *National Statement on Ethical Conduct in Human Research* (2007) & the *Australian Code for the Responsible Conduct of Research* (2007).
4. To immediately report to SAC HREC anything that may change the ethical or scientific integrity of the project.
5. Report Significant Adverse events (SAE's) as per SAE requirements available at our website.
6. Submit an annual report on each anniversary of the date of final approval and in the correct template from the SAC HREC website.
7. Confidentiality of research participants MUST be maintained at all times.
8. A copy of the signed consent form must be given to the participant unless the project is an audit.
9. Any reports or publications derived from the research should be submitted to the Committee at the completion of the project.
10. All requests for access to medical records at any SALHN site must be accompanied by this approval email.
11. To regularly review the SAC HREC website and comply with all submission requirements, as they change from time to time.
12. Once your research project has concluded, any new product/procedure/intervention cannot be conducted in the SALHN as standard practice without the approval of the SALHN New Medical Products and Standardisation Committee or the SALHN New Health Technology and Clinical Practice Innovation Committee (as applicable) Please refer to the relevant committee link on the SALHN intranet for further information.

Kind Regards

A/Professor Bernadette Richards
Chair, SAC HREC

Office for Research

Flinders Medical Centre
Ward 6C, Room 6A219
Flinders Drive, Bedford Park SA 5042
Tel: (08) 8204 6453
E: Health.SALHNOfficeforResearch@sa.gov.au

Government of South Australia
SA Health
Southern Adelaide Local Health Network

Final approval for ethics application

You are reminded that this letter constitutes **ethical** approval only. **Ethics approval is one aspect of the research governance process.**
You must not commence this research project at any SA Health sites listed in the application until a Site Specific Assessment (SSA), or Access Request for data or tissue form has been authorised by the Chief Executive or delegate of each site.

11 October 2016
(Amended 19 December 2016)

Professor Robyn Clark
School of Nursing and Midwifery
Flinders University
Sturt Road
BEDFORD PARK SA 5042

Dear Professor Clark

The Southern Adelaide Clinical Human Research Ethics Committee (SAC HREC EC00188) have reviewed and provided ethical approval for this application which appears to meet the requirements of the *National Statement on Ethical Conduct in Human Research.*

Application Number: OFR # 350.16 - HREC/16/SAC/315

Title: Development and evaluation of an interactive avatar based education application for improving heart failure patients' knowledge and self-care behaviour

Chief investigator: Professor Robyn Clark

Approval Period: 11 October 2016 to 11 October 2019

Public health sites approved under this application: Noarlunga Hospital

The below documents have been reviewed and approved:

- Cover Letter Dated 8 August 2016
- Heart Failure story Board Example Dated 26 July 2016
- Evaluation Survey v4.0 Dated 7 July 2016
- HoD letter Dated 27 July 2016
- LNR Fluid Watchers HREC/16/SAC/315 dated 5 October 2016
- Participant Feedback Questionnaire v4.0 Dated 3 August 2016
- PICF Fluid Watchers Phase 1 Development v7.0 Dated 25 October 2016
- PICF Fluid Watchers v6.0 Phase 1 Survey v7.0 Dated 26 October 2016
- PICF Fluid Watchers v6.0 Phase 1 Expert Panel v4.0 Dated 25 October 2016
- Response to reviewers dated 30 September 2016

TERMS AND CONDITIONS OF ETHICAL APPROVAL
As part of the Institution's responsibilities in monitoring research and complying with audit requirements, it is essential that researchers adhere to the conditions below and with the *National Statement chapter 5.5.*

Final ethical approval is granted subject to the researcher agreeing to meet the following terms and conditions:

1. The approval only covers the science and ethics component of the application. A SSA will need to be submitted and authorised before this research project can commence at any of the approved sites identified in the application.
2. If University personnel are involved in this project, the Principal Investigator should notify the University before commencing their research to ensure compliance with University requirements including any insurance and indemnification requirements.
3. Compliance with the *National Statement on Ethical Conduct in Human Research* (2007) & the *Australian Code for the Responsible Conduct of Research* (2007).
4. To immediately report to SAC HREC anything that may change the ethical or scientific integrity of the project.
5. Report Significant Adverse events (SAE's) as per SAE requirements available at our website.
6. Submit an annual report on each anniversary of the date of final approval and in the correct template from the SAC HREC website.
7. Confidentiality of research participants MUST be maintained at all times.
8. A copy of the signed consent form must be given to the participant unless the project is an audit.
9. Any reports or publications derived from the research should be submitted to the Committee at the completion of the project.
10. All requests for access to medical records at any SALHN site must be accompanied by this approval email.
11. To regularly review the SAC HREC website and comply with all submission requirements, as they change from time to time.
12. Once your research project has concluded, any new product/procedure/intervention cannot be conducted in the SALHN as standard practice without the approval of the SALHN New Medical Products and Standardisation Committee or the SALHN New Health Technology and Clinical Practice Innovation Committee (as applicable) Please refer to the relevant committee link on the SALHN intranet for further information.

Kind Regards

Dr Josephine Harris
Deputy Chair, SAC HREC

Appendix 7: Site-specific assessment approval letter

Office for Research

Flinders Medical Centre
Ward 6C, Room 6A219
Flinders Drive, Bedford Park SA 5042
Tel: (08) 8204 6453
E: Health.SALHNOfficeforResearch@sa.gov.au

Government of South Australia
SA Health
Southern Adelaide Local Health Network

22 November 2016

Professor Robyn Clark
School of Nursing and Midwifery
Flinders University
ADELAIDE SA 5001

Dear Professor Clark

HREC reference number:	HREC/16/SAC/315 **350.16**
SSA reference number:	SSA/16/SAC/387
Project title:	Development and evaluation of an interactive avatar based education application for improving heart failure patients' knowledge and self-care behaviour
Ethics approval:	11 October 2016 to 11 October 2019
Site:	Noarlunga Health Service
Subject:	Site Specific Assessment Review

Thank you for submitting an application for authorisation of this project.

On the basis of the information provided in your Site Specific Assessment submission, I am pleased to inform you that authorisation has been granted for this study to commence.

This authorisation is based on the following documents:

Site Specific Assessment AU/16/72B9212 dated 26 October 2016

SAC HREC approval letter dated 11 October 2016

PICF Fluid Watchers Phase 1 Development v6.0 4 October 2016

PICF Fluid Watchers Phase 1 Survey v6.0 4 October 2016

PICF Fluid Watchers Phase 1 Expert Panel v3.0 4 October 2016

Prof Robyn Clark, Principal Investigator CV 13 July 2016

HREC reviewed documents listed on the approval letter are accepted as part of the site authorisation.

The SSA reference number should be quoted in any correspondence about this matter.

If University personnel are involved in this project, the Principal Investigator should notify the University before commencing their research to ensure compliance with University requirements including any insurance and indemnification requirements.

Should you have any queries about the consideration of your Site Specific Assessment form, please contact Dawn Jennifer on 8204 6453.

Yours sincerely

Professor Villis Marshall
Director, Office for Research

Appendix 8: Participant information and consent form, individual patient interview (consumers)

Participant Information Sheet/Consent Form

Non-Interventional Study - *Adult providing own consent: application development*

Noarlunga Health Service

Title	Development and evaluation of an interactive avatar based education application for improving heart failure patients' knowledge and self-care behaviours– *phase I (development)*
Short Title	Fluid Watchers
Coordinating Principal Investigator/ Principal Investigator	Professor Robyn Clark Dr Huiyun Du Parichat Wonggom
Associate Investigator(s) (if required by institution)	
Location (where CPI/PI will recruit)	Noarlunga Health Service

Part 1 What does my participation involve?

1. Introduction

You have been invited to take part in this research study 'Development and evaluation of an interactive avatar based education application for improving heart failure education.' This research project aims to develop an interactive education tool for assisting people to learn more about heart failure and self-care.

This Participant Information sheet/Consent Form tells you about the research project. It explains what participation in this research project involves and understanding what is involved will help you to decide whether you want to take part in this research.

Please read this information carefully and ask questions about anything that you do not understand or want to know more about. Before deciding whether to take part in this study, you are welcome to talk about it with a relative, friend or local doctor.

Participation in this research is voluntary. If you do not wish to take part, you do not have to. If you decide you want to take part in the research project, you will be asked to sign the consent section. By signing this, you are telling us that you:

- Understand what you have read.
- Consent to take part in the research project.
- Consent to allow us the use of your personal and health information as described.

You will be given a copy of the Participant Information Sheet/Consent Form to keep for your records.

2. What is the purpose of this research?

Heart failure can be a burdensome illness. Managing multiple medications and following recommendations from your healthcare providers can be complex and challenging. You have been given booklets and phamplets to read about how you can better take care of yourself. However, reading and understanding medical information can be time consuming, daunting and difficult. In this research study, our research team aims to develop an interactive education tool that provides information about heart failure and things you can do to feel better, by using animations, videos, and voice, and without complex medical language. We would like you to participate in this development process to provide your opinion about the content, audio-visuals, and the user friendliness of the tool.

3. What does participation in this research involve?

If you agree to participate in this study, you will be asked to sign the Consent Form.

We would like to see you twice to ask you some questions about the education tool. It is anticipated that 2 sessions will run for approximately 30 minutes.

During the first meeting with a researcher, you will be asked to review the draft of our education tool, and provide your opinions of the contents, audio-visuals, and any other ideas you may have.

An audio recording device will be used during the meeting to record the conversations and help the researchers recall the conversations at a later time. The audio recording device will only be used if you give your permission to have the conversation recorded.

Your opinions will be used to help the research team to develop and refine the education tool. The revised education tool will be presented to you during your second meeting with the researcher. You will be asked to comment on the revised education tool. A free copy of the tool will be given to you when it is completed at the end of this study.

If you would like to view the individual interview meeting notes, please let one of the researchers know, and we will be very happy to send you a copy. Your participation in this study will not interfere with your current medical treatment

There is no cost associated with participating in this research project.

4. Do I have to take part in this research project?

Participation in this research study is voluntary. If you do not wish to take part, you do not have to. If you decide to take part and later change your mind, you are free to withdraw from the study at any stage.

Your decision to take part in this research study will not affect your routine treatment, your relationship with those treating you or your relationship with Noarlunga Health Service.

5. What if I withdraw from this research project?

You are free to withdraw from the study at any time without consequence. Please note, since the data collected during meetings will not be individually identifiable; we will not be able to identify or remove information provided by you from this study.

6. What are the possible benefits of taking part?

Your participation will help the researchers to develop a simple and interactive education tool. Viewing the education tool during this study may help you to gain a better understanding of heart failure and to better manage your heart condition.

7. What are the possible risks and disadvantages of taking part?

We do not foresee any physical or emotional risks from taking part in this research. We hope, it will actually be fun.

8. How will my confidentiality be protected?

Data collected through this research project is not individually identifiable and will be stored in a locked cabinet in the researcher's office within the School of Nursing & Midwifery building, Flinders University and will only be accessible to the researchers listed at the beginning of this document.

Any identifiable information that is collected about you during this study, including the Consent Form, will remain confidential and locked in a filing cabinet in the researcher's office within the School of Nursing & Midwifery, Flinders University. Your identification will be disclosed only with your permission or as required by law.

Part 2 How is the research project being conducted?

9. What will happen to information about me?

Any information or comments provided by you will be collected in a de-identified form.

The survey will be stored in a locked filing cabinet in the researcher's office within the School of Nursing and Midwifery, Flinders University. Electronic data will be kept on the Flinders University network computer in the School of Nursing and Midwifery, Flinders University, which is password protected. All study-related data will only be accessible to the researchers listed at the beginning of this document.
After completion of the study, audio files will be deleted, and the paper-based data will be stored for five years and destroyed by means of shredding. After five years, the electronic data files will also be deleted from the Flinders University network computer.

10. Complaints and compensation

If you suffer any injuries or complications as a result of this research project, you should contact the study team as soon as possible and you will be assisted with arranging appropriate medical treatment. If you are eligible for Medicare, you can receive any medical treatment required to treat the injury or complication, free of charge, as a public patient in any Australian public hospital.

11. Who has reviewed the research project?

All research in Australia involving humans is reviewed by an independent group of people called

a Human Research Ethics Committee (HREC). This study will be carried out according to the National Statement on Ethical Conduct in Human Research (2007). This statement has been developed to protect the interests of people who agree to participate in human research studies

This research project has been approved by the HREC of Southern Adelaide Local Health Network (approval number HREC 350.16).

12. Who should I contact if I have concerns about the conduct of this study?

The person you may need to contact will depend on the nature of your query. If you want any further information concerning this project or if you have any medical problems which may be related to your involvement in the project (for example, any side effects), you can contact the principal study doctor on 08 8177 1599 or any of the following people:

Clinical contact person

Name	*Robyn Clark*
Position	*Professor, School of Nursing and Midwifery, Flinders University*
Telephone	*8 82013266*
Email	*Robyn.clark@flinders.edu.au*

For matters relating to research at the site at which you are participating, the details of the local site complaints person are:

Complaints contact person

Name	*Villis Marshall*
Position	*Director, Office for Research*
Telephone	*8204 6061*
Email	*Health.SALHNOfficeforResearch@sa.gov.au*

If you have any complaints about any aspect of the project, the way it is being conducted or any questions about being a research participant in general, then you may contact:

Reviewing HREC approving this research and HREC Executive Officer details

Reviewing HREC name	*Southern Adelaide Clinical*
HREC Executive Officer	*Damian Creaser*
Telephone	*8204 6453*
Email	*Health.SALHNOfficeforResearch@sa.gov.au*

Local HREC Office contact (Single Site -Research Governance Officer)

Name	*Dawn Jennifer*
Position	*Research Governance Officer*
Telephone	*8204 6453*
Email	*Health.SALHNOfficeforResearch@sa.gov.au*

Consent Form - *Adult providing own consent: application development*

Title	Development and evaluation of an interactive avatar based education application for improving heart failure patients' knowledge and self-care behaviours– *phase I (development)*
Short Title	Fluid Watchers
Coordinating Principal Investigator/ Principal Investigator	Professor Robyn Clark Dr Huiyun Du Parichat Wonggom
Associate Investigator(s) (if required by institution)	
Location (where CPI/PI will recruit)	Noarlunga Health Service

Declaration by Participant

I have read the Participant Information Sheet or someone has read it to me in a language that I understand.

I understand the purposes, procedures and risks of the research described in the project.

I have had an opportunity to ask questions and I am satisfied with the answers I have received.

I freely agree to participate in this research project as described and understand that I am free to withdraw at any time during the project without affecting my future health care.

I understand that I will be given a signed copy of this document to keep.

☐ (Please tick if you agree) I agree to have the conversations recorded during the individual interview meetings.

Name of Participant (please print) _____

Signature_____Date_____

Declaration by Study student /Senior Researcher†

I have given a verbal explanation of the research project, its procedures and risks and I believe that the participant has understood that explanation.

Name of Study student/
Senior Researcher† (please print) _____

Signature_____Date_____

† A senior member of the research team must provide the explanation of, and information concerning, the research project.

Note: All parties signing the consent section must date their own signature.

Form for Withdrawal of Participation - *Adult providing own consent: application development*

Title	Development and evaluation of an interactive avatar based education application for improving heart failure patients' knowledge and self-care behaviours– *phase I (development)*
Short Title	Fluid Watchers
Coordinating Principal Investigator/ Principal Investigator	Professor Robyn Clark Dr Huiyun Du Parichat Wonggom
Associate Investigator(s) (if required by institution)	
Location (where CPI/PI will recruit)	Noarlunga Health Service

Declaration by Participant

I wish to withdraw from participation in the above research project and understand that such withdrawal will not affect my routine treatment, my relationship with those treating me or my relationship with Flinders Medical Centre

Name of Participant (please print) _____

Signature_____Date_____

Declaration by Study student/Senior Researcher†

I have given a verbal explanation of the implications of withdrawal from the research project and I believe that the participant has understood that explanation.

Name of Study student/
Senior Researcher† (please print) _____

Signature_____Date_____

† A senior member of the research team must provide the explanation of and information concerning withdrawal from the research project.

Note: All parties signing the consent section must date their own signature.

Appendix 9: Participant information and consent form, focus group discussion (cardiovascular experts)

Government of South Australia
SA Health

Flinders UNIVERSITY

Participant Information Sheet/Consent Form

Non-Interventional Study - *Adult providing own consent: expert panel / focus group*

Noarlunga Health Service

Title	Development and evaluation of an interactive avatar based education application for improving heart failure patients' knowledge and self-care behaviours– phase I (*focus group*)
Short Title	Fluid Watchers
Coordinating Principal Investigator/ Principal Investigator	Professor Robyn Clark Dr Huiyun Du Parichat Wonggom
Associate Investigator(s) (if required by institution)	
Location (where CPI/PI will recruit)	Noarlunga Health Service

Part 1 What does my participation involve?

1. Introduction

You have been invited to take part in this research study 'Development and evaluation of an interactive avatar based education application for improving heart failure education.' This research project aims to develop an interactive education tool for assisting people to learn more about heart failure and self-care.

This Participant Information sheet/Consent Form tells you about the research project. It explains what participation in this research project involves and understanding what is involved will help you to decide whether you want to take part in this research.

Please read this information carefully and ask questions about anything that you do not understand or want to know more about. Before deciding whether to take part in this study, you are welcome to talk about it with a relative, friend or local doctor.

Participation in this research is voluntary. If you do not wish to take part, you do not have to. If you decide you want to take part in the research project, you will be asked to sign the consent section. By signing this, you are telling us that you:
- Understand what you have read.
- Consent to take part in the research project.
- Consent to allow us the use of your personal and health information as described.

You will be given a copy of the Participant Information Sheet/Consent Form to keep for your records.

2. What is the purpose of this research?

Heart failure can be a burdensome illness. Managing multiple medications andfollowing recommendations from your healthcare providers can be complex and challenging. You have been given booklets and phamplets to read about how you can better take care of yourself. However, reading and understanding medical information can be time consuming, daunting and difficult. In this research study, our research team aims to develop an interactive education tool that provides information about heart failure and things you can do to feel better, by using animations, videos, and voice, and without complex medical language. We would like you to participate in this development process to provide your opinion about the content, audio-visuals, and the user friendliness of the tool.

3. What does participation in this research involve?

If you agree to participate in this study, you will be asked to sign the Consent Form.

We would like to see you twice to ask you some questions about the education tool. It is anticipated that 2 sessions of focus group meeting will run for approximately one hour.

During the first focus group meeting with a researcher, you will be asked to review the draft of our education tool, and provide your opinions of the contents, audio-visuals, and any other ideas you may have.

An audio recording device will be used during the meeting to record the conversations and help the researchers recall the conversations at a later time. The audio recording device will only be used if you give your permission to have the conversation recorded.

Your opinions will be used to help the research team to develop and refine the education tool. The revised education tool will be presented to you during your second meeting with the researcher. You will be asked to comment on the revised education tool. A free copy of the tool will be given to you when it is completed at the end of this study.

If you would like to view the focus group meeting notes, please let one of the researchers know, and we will be very happy to send you a copy. Your participation in this study will not interfere with your current medical treatment

There is no cost associated with participating in this research project.

4. Do I have to take part in this research project?

Participation in this research study is voluntary. If you do not wish to take part, you do not have to. If you decide to take part and later change your mind, you are free to withdraw from the study at any stage.

5. What if I withdraw from this research project?

You are free to withdraw from the study anytime without consequence. Please note, since the data collected during focus group meetings will not be individually identifiable; we will not be able to identify or remove data provided by you from this study.

6. What are the possible benefits of taking part?

Your participation will help the researchers to develop a simple and interactive education tool. Viewing the education tool during this study may help you to gain a better understanding of heart failure and to better manage your heart condition.

7. What are the possible risks and disadvantages of taking part?

We do not foresee any physical or emotional risks from taking part in this research. We hope, it will actually be fun.

8. How will my confidentiality be protected?

Data collected through this research project is not individually identifiable and will be stored in a locked cabinet in the researcher's office within the School of Nursing & Midwifery building, Flinders University and will only be accessible to the researchers listed at the beginning of this document.

Any identifiable information that is collected about you during this study, including the Consent Form, will remain confidential and locked in a filing cabinet in the researcher's office within the School of Nursing & Midwifery, Flinders University. Your identification will be disclosed only with your permission or as required by law.

Part 2 How is the research project being conducted?

9. What will happen to information about me?

Any information or comments provided by you will be collected in a de-identified form.

The survey will be stored in a locked filing cabinet in the researcher's office within the School of Nursing and Midwifery, Flinders University. Electronic data will be kept on the Flinders University network computer in the School of Nursing and Midwifery, Flinders University, which is password protected. All study-related data will only be accessible to the researchers listed at the beginning of this document.
After completion of the study, audio files will be deleted, and the paper-based data will be stored for five years and destroyed by means of shredding. After five years, the electronic data files will also be deleted from the Flinders University network computer.

10. Complaints and compensation

If you suffer any injuries or complications as a result of this research project, you should contact the study team as soon as possible and you will be assisted with arranging appropriate medical treatment. If you are eligible for Medicare, you can receive any medical treatment required to treat the injury or complication, free of charge, as a public patient in any Australian public hospital.

11. Who has reviewed the research project?

All research in Australia involving humans is reviewed by an independent group of people called

a Human Research Ethics Committee (HREC). This study will be carried out according to the National Statement on Ethical Conduct in Human Research (2007). This statement has been developed to protect the interests of people who agree to participate in human research studies

This research project has been approved by the HREC of Southern Adelaide Local Health Network (approval number HREC 350.16).

12. Who should I contact if I have concerns about the conduct of this study?

The person you may need to contact will depend on the nature of your query. If you want any further information concerning this project or if you have any medical problems which may be related to your involvement in the project (for example, any side effects), you can contact the principal study doctor on 08 8177 1599 or any of the following people:

Clinical contact person

Name	*Robyn Clark*
Position	*Professor, School of Nursing and Midwifery, Flinders University*
Telephone	*8 82013266*
Email	*Robyn.clark@flinders.edu.au*

For matters relating to research at the site at which you are participating, the details of the local site complaints person are:

Complaints contact person

Name	*Villis Marshall*
Position	*Director, Office for Research*
Telephone	*8204 6061*
Email	*Health.SALHNOfficeforResearch@sa.gov.au*

If you have any complaints about any aspect of the project, the way it is being conducted or any questions about being a research participant in general, then you may contact:

Reviewing HREC approving this research and HREC Executive Officer details

Reviewing HREC name	*Southern Adelaide Clinical*
HREC Executive Officer	*Damian Creaser*
Telephone	*8204 6453*
Email	*Health.SALHNOfficeforResearch@sa.gov.au*

Local HREC Office contact (Single Site -Research Governance Officer)

Name	*Dawn Jennifer*
Position	*Research Governance Officer*
Telephone	*8204 6453*
Email	*Health.SALHNOfficeforResearch@sa.gov.au*

Consent Form - *Adult providing own consent: expert panel / focus group*

Title	Development and evaluation of an interactive avatar based education application for improving heart failure patients' knowledge and self-care behaviours– phase I (*focus group*)
Short Title	Fluid Watchers
Coordinating Principal Investigator/ Principal Investigator **Associate Investigator(s)** (if required by institution)	Professor Robyn Clark Dr Huiyun Du Parichat Wonggom
Location (where CPI/PI will recruit)	Noarlunga Health Service

Declaration by Participant

I have read the Participant Information Sheet or someone has read it to me in a language that I understand.

I understand the purposes, procedures and risks of the research described in the project.

I have had an opportunity to ask questions and I am satisfied with the answers I have received.

I freely agree to participate in this research project as described and understand that I am free to withdraw at any time during the project without affecting my future health care.

I understand that I will be given a signed copy of this document to keep.

☐ (Please tick if you agree) I agree to have the conversations recorded during the focus group meetings.

Name of Participant (please print) _____

Signature_____Date_____

Declaration by Study student /Senior Researcher†

I have given a verbal explanation of the research project, its procedures and risks and I believe that the participant has understood that explanation.

Name of Study student/
Senior Researcher† (please print) _____

Signature_____Date_____

† A senior member of the research team must provide the explanation of, and information concerning, the research project.

Note: All parties signing the consent section must date their own signature.

Form for Withdrawal of Participation - *Adult providing own consent: expert panel / focus group*

Title	Development and evaluation of an interactive avatar based education application for improving heart failure patients' knowledge and self-care behaviours– phase I (*focus group*)
Short Title	Fluid Watchers
Coordinating Principal Investigator/ Principal Investigator	Professor Robyn Clark Dr Huiyun Du Parichat Wonggom
Associate Investigator(s) (if required by institution)	
Location (where CPI/PI will recruit)	Noarlunga Health Service

Declaration by Participant

I wish to withdraw from participation in the above research project and understand that such withdrawal will not affect my routine treatment, my relationship with those treating me or my relationship with Noarlunga Health Service

Name of Participant (please print) _____

Signature_____Date_____

Declaration by Study student/Senior Researcher†

I have given a verbal explanation of the implications of withdrawal from the research project and I believe that the participant has understood that explanation.

Name of Study student/
Senior Researcher† (please print) _____

Signature_____Date_____

† A senior member of the research team must provide the explanation of and information concerning withdrawal from the research project.

Note: All parties signing the consent section must date their own signature.

Appendix 10: Participant information and consent form, pre- and post-intervention measurement

Government of South Australia
SA Health

Flinders UNIVERSITY

Participant Information Sheet/Consent Form

Non-Interventional Study - *Adult providing own consent: consumer review*

Noarlunga Health Service

Title	Development and evaluation of an interactive avatar based education application for improving heart failure patients' knowledge and self-care behaviours – *phase II (evaluation)*
Short Title	Fluid Watchers
Coordinating Principal Investigator/ Principal Investigator	Professor Robyn Clark
Associate Investigator(s) (if required by institution)	Dr Huiyun Du Parichat Wonggom
Location (where CPI/PI will recruit)	Noarlunga Health Service

Part 1 What does my participation involve?

1. Introduction

You have been invited to take part in this research study 'Development and evaluation of an interactive avatar based education application for improving heart failure education.' This research project aims to develop an interactive education tool for assisting people to learn more about heart failure and self-care.

This Participant Information Sheet/Consent Form tells you about the research project. It explains what participation in this research project involves and knowing what is involved will help you decide whether you want to take part in this research.

Please read this information carefully and ask questions about anything that you do not understand or want to know more about. Before deciding whether to take part in this study, you are welcome to talk about it with a relative, friend or local doctor.

Participation in this research is voluntary. If you don't wish to take part, you don't have to. You will receive the best possible care whether you take part or not.

If you decide you want to take part in the research project, you will be asked to sign the consent section. By signing this, you are telling us that you:
• Understand what you have read.
• Consent to take part in the research project.
• Consent to allow us the use of your personal and health information as described.

You will be given a copy of the Participant Information Sheet/Consent Form to keep for your record.

2. What is the purpose of this research?

Heart failure can be a burdensome illness. Managing multiple medications and following recommendations from your healthcare providers can be complex and challening. You have been given booklets and phamplets to read about how you can better take care of yourself. However, reading and understanding medical information in a traditional booklet can be time consuming, daunting and difficult. In this research study, our research team aims to evaluate an interactive education tool that provides information on heart failure and self-care by the use of animation, videos, and voice, and without complex medical language.

We would like you to review and evaluate this tool and provide your opinions of the content, audio-visuals and user friendliness through a survey.

3. What does participation in this research involve?

If you agree to participate in this study, you will be asked to sign the Consent Form. Participation in this research involves the trial use of a newly developed education tool and completing a survey.

You will be asked to use a newly developed education tool via a tablet. It will take approximately 10 minutes of your time to go through the education tool. Before, and after you use the education tool, a research nurse will ask you some questions about heart failure. After using the education tool, you will be asked to complete a survey, which will ask for your opinions of the audio-visuals, content and user friendliness of the tool. It will take you approximately 30 minutes in total, to participate in this study.

The researcher will be available to answer any questions, you may have about the tool and/or the surveys. Your opinions will be used to help the research team to develop and refine this education tool.

4. Do I have to take part in this research project?

Participation in this research study is voluntary. If you do not wish to take part, you do not have to. If you decide to take part and later change your mind, you are free to withdraw from the study at any stage.

Your decision to take part in this research study will not affect your routine treatment, your relationship with those treating you or your relationship with Noarlunga Health Service.

5. What if I withdraw from this research project?

You are free to withdraw from the study at any time without consequence. Please note, since the data will be collected and stored in a de-identified form, once the survey is submitted, we will not be able to re-identify it or remove it from this study.

6. What are the possible benefits of taking part?

Your participation will help the researchers to evaluate a simple and interactive education tool. Viewing the education tool during this study may help you gain a better understanding of heart failure, and to better manage your heart failure.

7. What are the possible risks and disadvantages of taking part?

We do not foresee any physical or emotional risks from taking part in this research.

8. How will my confidentiality be protected?

Data collected through this research project is not individually identifiable. Completed surveys will be stored in a locked cabinet in the researcher's office within the School of Nursing & Midwifery building, Flinders University and will only be accessible to the researchers listed at the beginning of this document.

Any identifiable information that is collected about you during this study, including the Consent Form, will remain confidential and locked in a filing cabinet in the researcher's office within the School of Nursing & Midwifery, Flinders University. Your identification will be disclosed only with your permission or as required by law.

Part 2 How is the research project being conducted?

9. What will happen to information about me?

Any information or comments provided by you will be collected in a de-identified form.

The survey will be stored in a locked filing cabinet in the researcher's office within the School of Nursing and Midwifery, Flinders University. Electronic data will be kept on the Flinders University network computer in the School of Nursing and Midwifery, Flinders University, which is password protected. All study-related data will only be accessible to the researchers listed at the beginning of this document.
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10. Complaints and compensation

If you suffer any injuries or complications as a result of this research project, you should contact the study team as soon as possible and you will be assisted with arranging appropriate medical treatment. If you are eligible for Medicare, you can receive any medical treatment required to treat the injury or complication, free of charge, as a public patient in any Australian public hospital.

11. Who has reviewed the research project?

All research in Australia involving humans is reviewed by an independent group of people called a Human Research Ethics Committee (HREC). This study will be carried out according to the National Statement on Ethical Conduct in Human Research (2007). This statement has been developed to protect the interests of people who agree to participate in human research studies

This research project has been approved by the HREC of Southern Adelaide Local Health Network (approval number HREC 350.16).

12. Who should I contact if I have concerns about the conduct of this study?

The person you may need to contact will depend on the nature of your query. If you want any further information concerning this project or if you have any medical problems which may be related to your involvement in the project (for example, any side effects), you can contact the principal study doctor on 08 8177 1599 or any of the following people:

Clinical contact person

Name	*Robyn Clark*
Position	*Professor, School of Nursing and Midwifery, Flinders University*
Telephone	*8 82013266*
Email	*Robyn.clark@flinders.edu.au*

For matters relating to research at the site at which you are participating, the details of the local site complaints person are:

Complaints contact person

Name	*Villis Marshall*
Position	*Director, Office for Research*
Telephone	*8204 6061*
Email	*Health.SALHNOfficeforResearch@sa.gov.au*

If you have any complaints about any aspect of the project, the way it is being conducted or any questions about being a research participant in general, then you may contact:

Reviewing HREC approving this research and HREC Executive Officer details

Reviewing HREC name	*Southern Adelaide Clinical*
HREC Executive Officer	*Damian Creaser*
Telephone	*8204 6453*
Email	*Health.SALHNOfficeforResearch@sa.gov.au*

Local HREC Office contact (Single Site -Research Governance Officer)

Name	*Dawn Jennifer*
Position	*Research Governance Officer*
Telephone	*8204 6453*
Email	*Health.SALHNOfficeforResearch@sa.gov.au*

Consent Form - *Adult providing own consent: consumer review*

Title	Development and evaluation of an interactive avatar based education application for improving heart failure patients' knowledge and self-care behaviours - *phase II (evaluation)*
Short Title	Fluid Watchers
Coordinating Principal Investigator/ Principal Investigator	Professor Robyn Clark Dr Huiyun Du Parichat Wonggom
Associate Investigator(s) (if required by institution)	
Location (where CPI/PI will recruit)	Noarlunga Health Service

Declaration by Participant

I have read the Participant Information Sheet or someone has read it to me in a language that I understand.

I understand the purposes, procedures and risks of the research described in the project.

I have had an opportunity to ask questions and I am satisfied with the answers I have received.

I freely agree to participate in this research project as described and understand that I am free to withdraw at any time during the project without affecting my future health care.

I understand that I will be given a signed copy of this document to keep.

Name of Participant (please print) _____

Signature _____ Date _____

Declaration by Study student /Senior Researcher†

I have given a verbal explanation of the research project, its procedures and risks and I believe that the participant has understood that explanation.

Name of Study student/
Senior Researcher† (please print) _____

Signature _____ Date _____

† A senior member of the research team must provide the explanation of, and information concerning, the research project.

Note: All parties signing the consent section must date their own signature.

Form for Withdrawal of Participation - *Adult providing own consent: consumer review*

Title	Development and evaluation of an interactive avatar based education application for improving heart failure patients' knowledge and self-care behaviours -*phase II (evaluation)*
Short Title	Fluid Watchers
Coordinating Principal Investigator/ Principal Investigator	Professor Robyn Clark Dr Huiyun Du Parichat Wonggom
Associate Investigator(s) (if required by institution)	
Location (where CPI/PI will recruit)	Noarlunga Health Service

Declaration by Participant

I wish to withdraw from participation in the above research project and understand that such withdrawal will not affect my routine treatment, my relationship with those treating me or my relationship with Noarlunga Health Service

Name of Participant (please print) _____

Signature _____ Date _____

Declaration by Study student/Senior Researcher†

I have given a verbal explanation of the implications of withdrawal from the research project and I believe that the participant has understood that explanation.

Name of Study Student/
Senior Researcher† (please print) _____

Signature _____ Date _____

† A senior member of the research team must provide the explanation of and information concerning withdrawal from the research project.

Note: All parties signing the consent section must date their own signature.

Appendix 11: Screenshots and dialogue of the Fluid Watchers App

FLUID WATCHERS

This app does not replace your doctor or nurse.

If you have any questions or concerns about your condition, please contact your doctor or nurse.

Avatar Customisation

Continue

Index

Return To App

Acknowledgements

Avatar Creation

Quit App

Understanding Heart Failure

Looking After Yourself

Things to do Every Day

Emergency Action Plan

Introduction Quiz

Introduction Quiz

Introduction Quiz

You should skip your heart failure tablets if you're coughing a lot.

YES NO

Touch 'YES' to agree, or 'NO' to disagree.

Introduction Quiz

Heart failure is when the heart cannot pump enough blood around the body.

YES NO

Touch 'YES' to agree, or 'NO' to disagree.

Introduction Quiz

Eating a low-salt diet can reduce fluid build-up in your body and help your heart.

YES NO

Touch 'YES' to agree, or 'NO' to disagree.

Introduction Quiz

Heart failure and a heart attack are the same thing.

YES NO

Touch 'YES' to agree, or 'NO' to disagree.

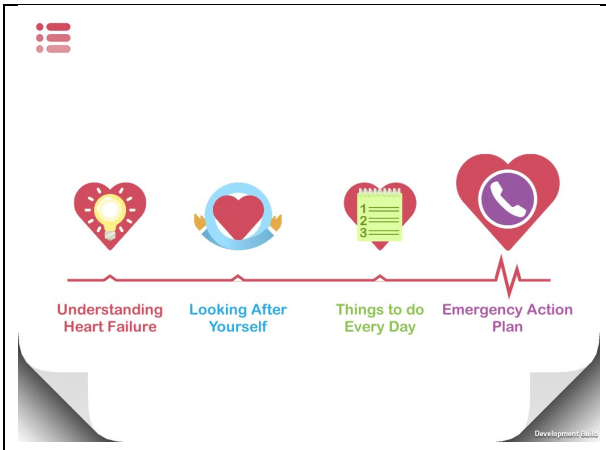
Quiz Results

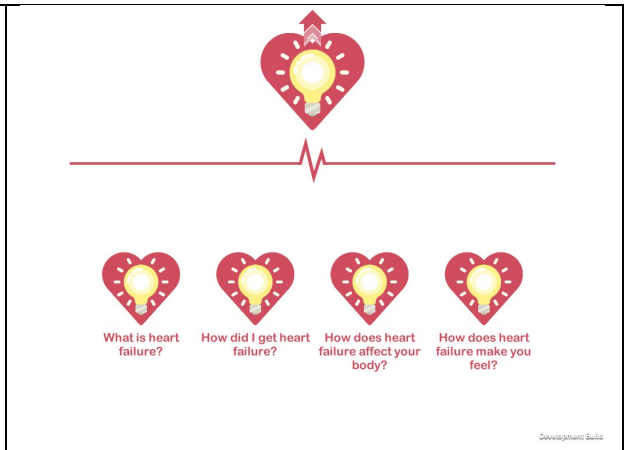
Total Score:

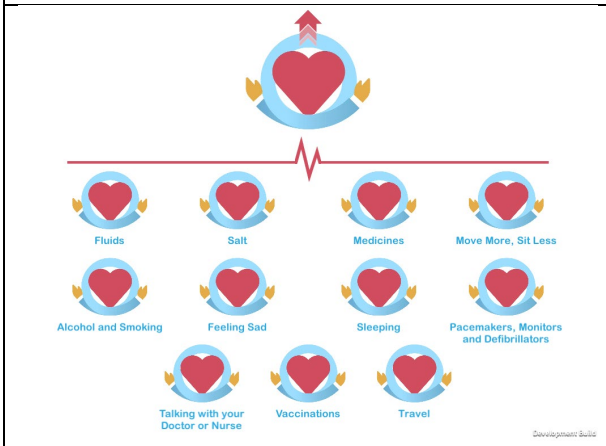
3/4

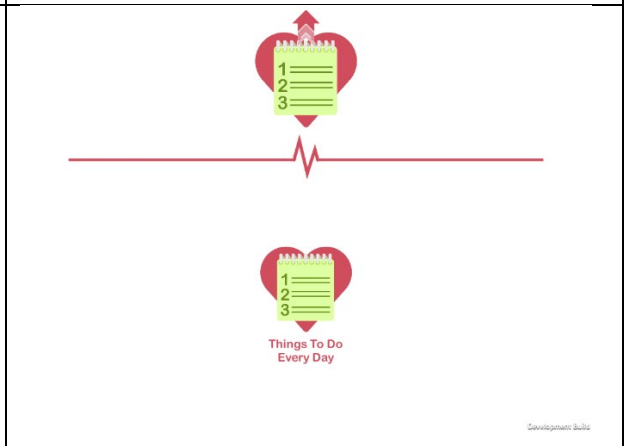
Well done

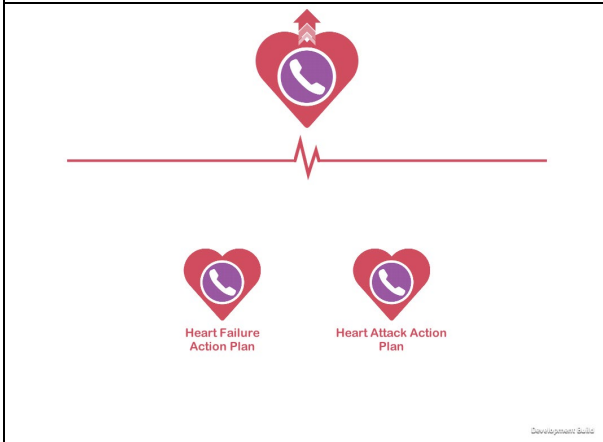
When you're ready, swipe left to continue

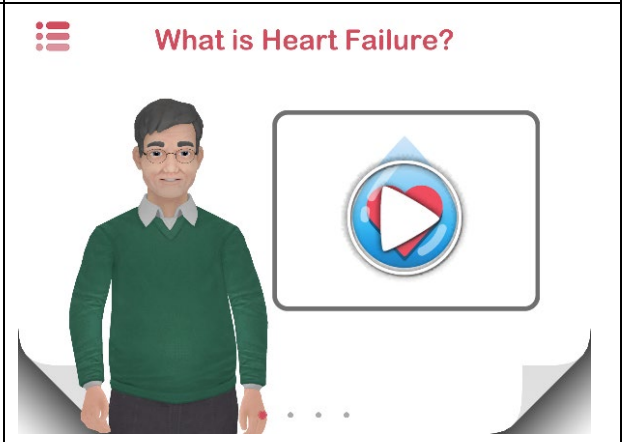

Understanding Heart Failure
Looking After Yourself
Things to do Every Day
Emergency Action Plan

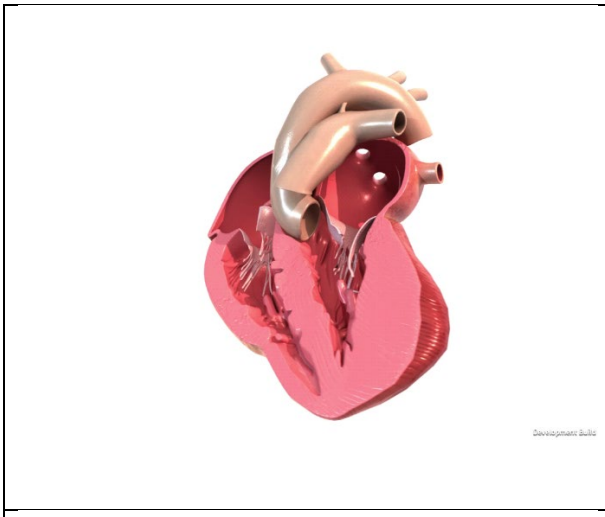

What is heart failure?
How did I get heart failure?
How does heart failure affect your body?
How does heart failure make you feel?

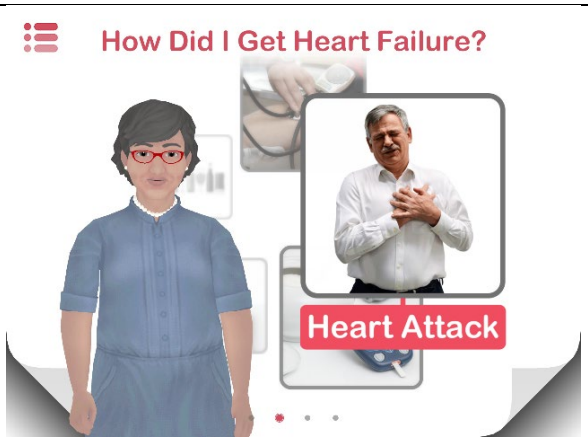

Fluids
Salt
Medicines
Move More, Sit Less
Alcohol and Smoking
Feeling Sad
Sleeping
Pacemakers, Monitors and Defibrillators
Talking with your Doctor or Nurse
Vaccinations
Travel


Things To Do Every Day

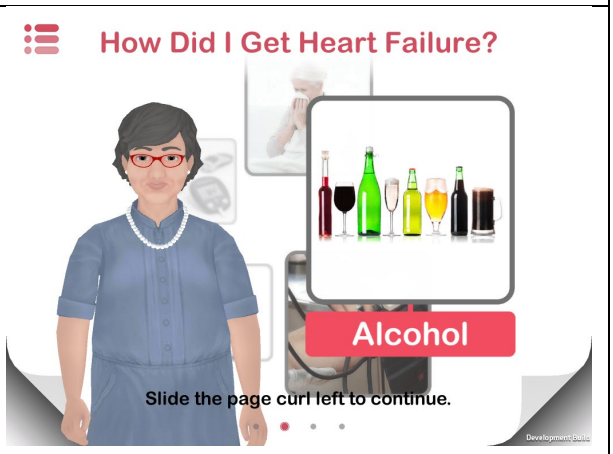

Heart Failure Action Plan
Heart Attack Action Plan

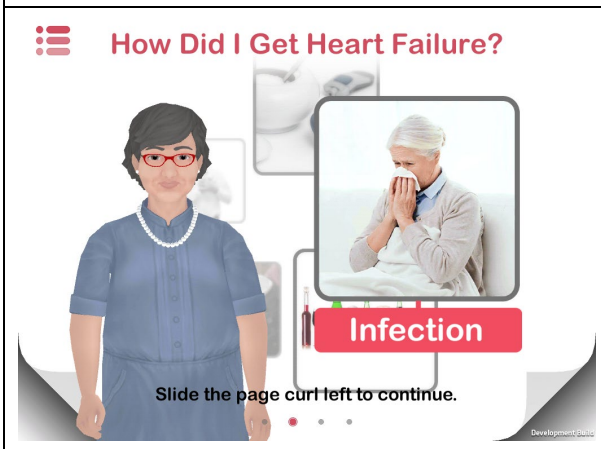

What is Heart Failure?



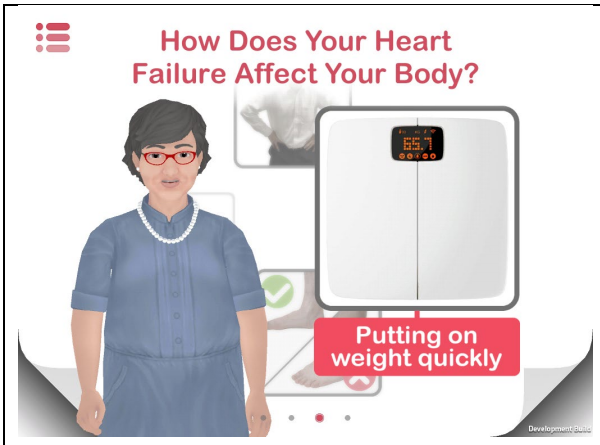

How Did I Get Heart Failure?
Heart Attack

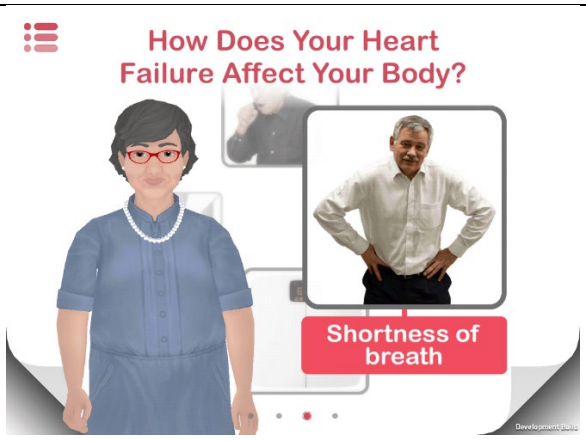

How Did I Get Heart Failure?
High Blood Pressure


How Did I Get Heart Failure?
Alcohol
Slide the page curl left to continue.


How Did I Get Heart Failure?
Infection
Slide the page curl left to continue.

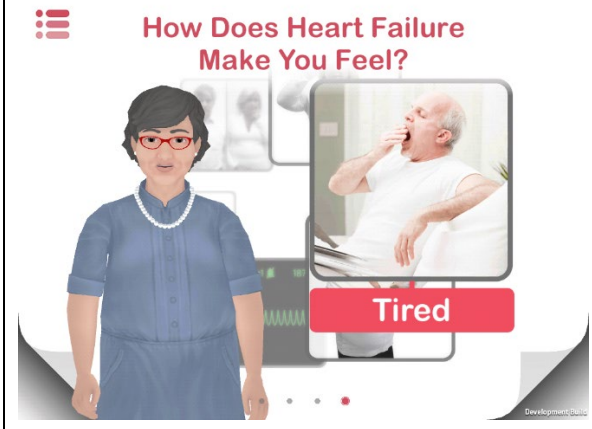

How Did I Get Heart Failure?
Other Causes
Slide the page curl left to continue.


How Does Your Heart Failure Affect Your Body?
Putting on weight quickly


How Does Your Heart Failure Affect Your Body?
Shortness of breath

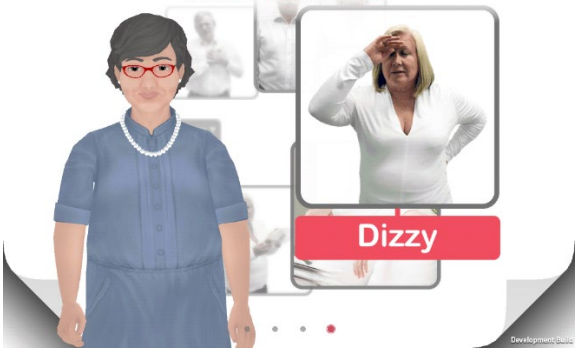

How Does Your Heart Failure Affect Your Body?
Coughing
Slide the page curl left to continue.


How Does Your Heart Failure Affect Your Body?
Swollen ankles or legs
Slide the page curl left to continue.

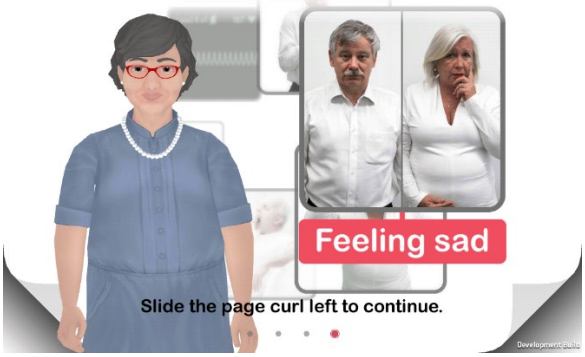

How Does Heart Failure Make You Feel?
Tired


How Does Heart Failure Make You Feel?
Loss of appetite

How Does Heart Failure Make You Feel?



How Does Heart Failure Make You Feel?



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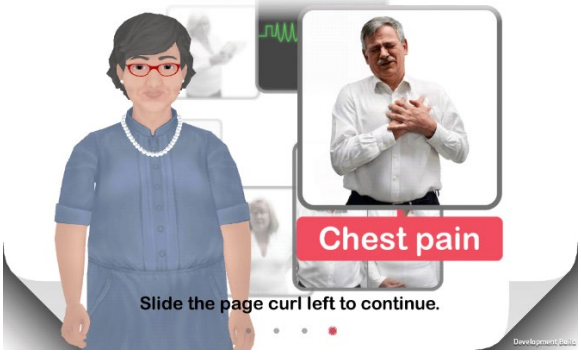
How Does Heart Failure Make You Feel?



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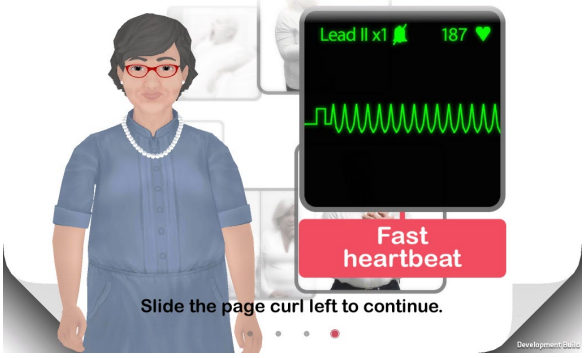
How Does Heart Failure Make You Feel?



Slide the page curl left to continue.

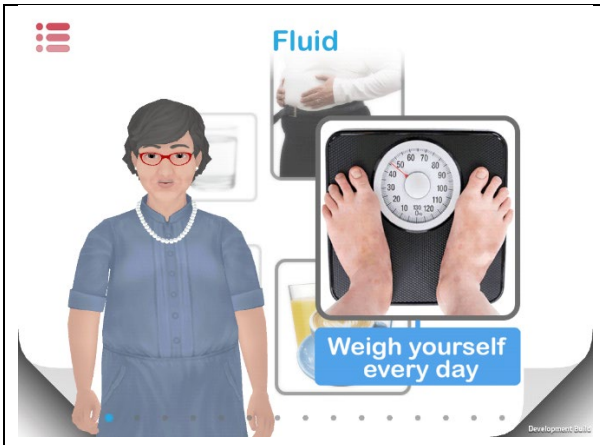
Understanding Heart Failure

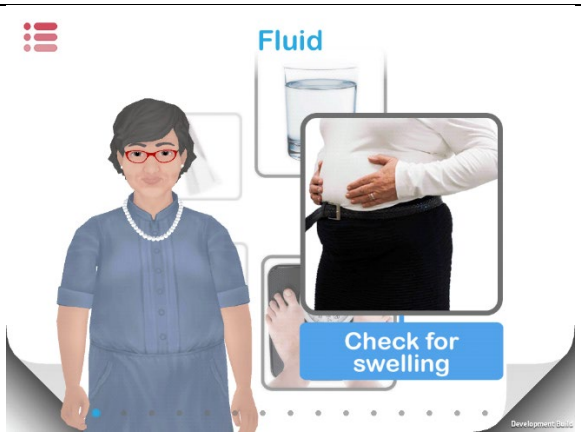
Heart failure can make your belly look fat.

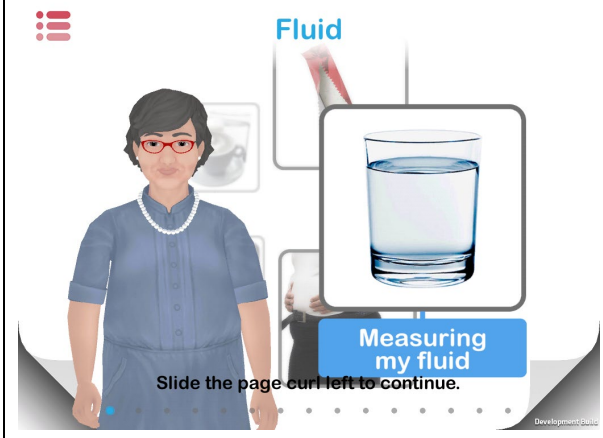
YES

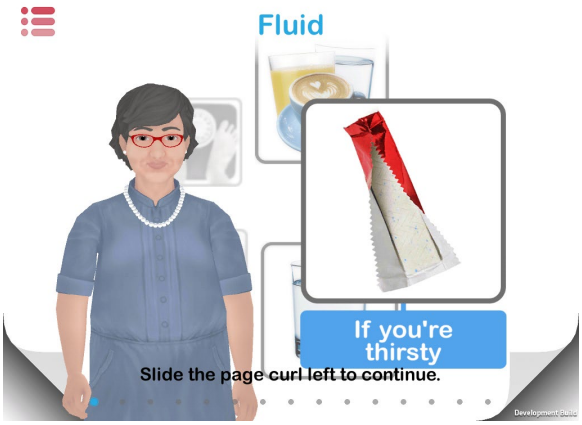
NO

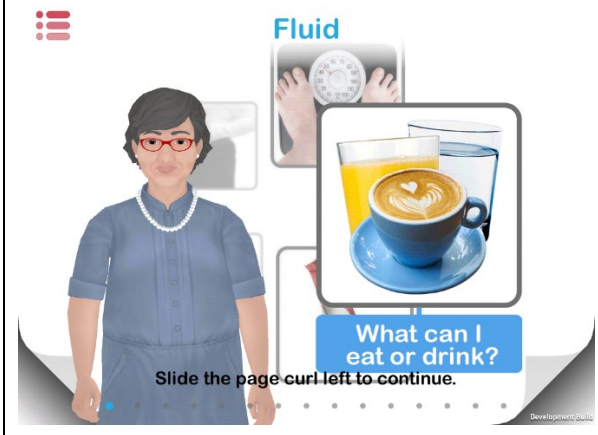
Touch 'YES' to agree, or 'NO' to disagree.

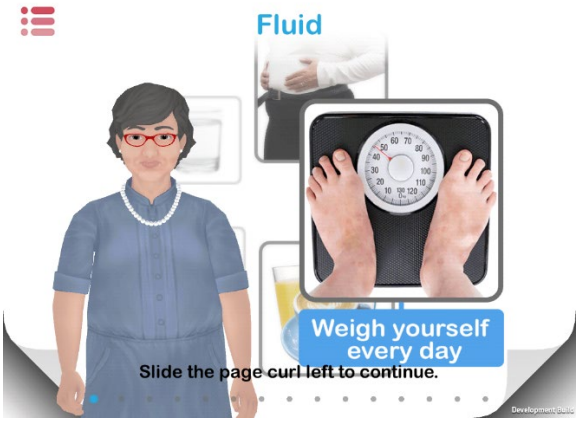

Fluid
Weigh yourself every day


Fluid
Check for swelling


Fluid
Measuring my fluid
Slide the page curl left to continue.


Fluid
If you're thirsty
Slide the page curl left to continue.


Fluid
What can I eat or drink?
Slide the page curl left to continue.


Fluid
Weigh yourself every day
Slide the page curl left to continue.

Making a Fluid Plan

Breakfast	Porridge Orange juice	200mL 250mL
Morning Tea	A cup of coffee	200mL
Lunch	Soup Drinking water	200mL 200mL
Afternoon tea	Herbal tea	150mL
Dinner	Ice cream	200mL
Bedtime	Drinking water with tablets	100mL

Fluid

Heart failure can lead to rapid gain of weight due to fluid build-up in our body.

YES

NO

Touch 'YES' to agree, or 'NO' to disagree.

Fluid

Where should you check for swelling on your body?

Touch the areas on the body you think you should check (1 left)

Salt

Salt

Nutrition Information

Serving Size: 12g
Servings Per Package: 20 NET 240g

	Qty per Serve	Qty per 100g
Energy	187kJ	160kJ
Protien	0.2g	1.8g
Fat - Total	0.1g	0.6g
- Saturated	0.0g	0.3g
Carbohydrate	10.7g	89.4g
- Sugars	3.0g	25.1g
Sodium	47mg	388mg
Calcium	31.4mg	262mg
Magnesium	9.1mg	76mg
Phosphorus	2.5mg	21mg
Potasium	140.7mg	1173mg

Salt

Nutrition Information

Serving Size: 12g
Servings Per Package: 20 NET 240g

	Qty per Serve	Qty per 100g
Energy	187kJ	160kJ
Protien	0.2g	1.8g
Fat - Total	0.1g	0.6g

Salt

Energy	187kJ	160kJ
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Sodium	47mg	388mg
Calcium	31.4mg	262mg
Magnesium	9.1mg	76mg
Phosphorus	2.5mg	21mg

Salt

Is this food a good choice for people with heart failure?

YES

Nutrition Information

Serving Size: 12g
Servings Per Package: 20 NET 240g

	Qty per Serve	Qty per 100g
Energy	187kJ	160kJ
Protien	0.2g	1.8g
Fat - Total	0.1g	0.6g
- Saturated	0.0g	0.3g

NO

Touch 'YES' to agree, or 'NO' to disagree.

Is this food a good choice for people with heart failure?

Nutrition Information

Serving Size: 12g
Servings Per Package: 20 NET 240g

	Qty per Serve	Qty per 100g
Energy	187kJ	160kJ
Protien	0.2g	1.8g
Fat - Total	0.1g	0.6g
- Saturated	0.0g	0.3g

NO

Touch 'YES' to agree, or 'NO' to disagree.

Salt

Swipe foods that are low in salt into your trolley.

Medicines

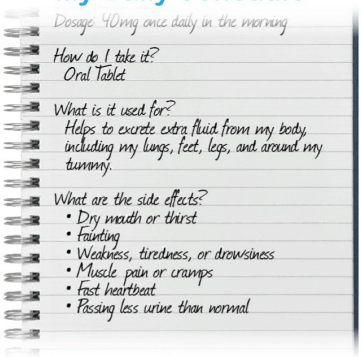
Do's and don'ts

Medicines

Slide the page curl left to continue.

My Daily Schedule

My Daily Schedule



Medication

It is ok to skip your water pills when you are going shopping.

YES NO

Touch 'YES' to agree, or 'NO' to disagree.

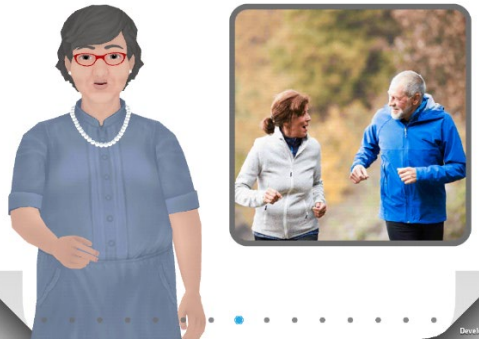
Medication

It is ok to skip your water pills when you are going shopping.

NO

Touch 'YES' to agree, or 'NO' to disagree.

Move More, Sit Less



Move More, Sit Less

Move More, Sit Less

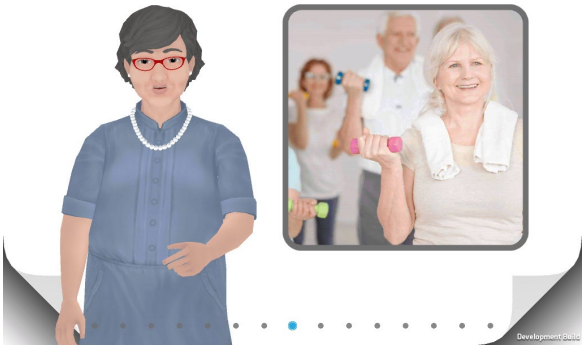
Move More, Sit Less

Move More, Sit Less

Move More, Sit Less

Move More, Sit Less

Move More, Sit Less



Move More, Sit Less

Being active is good for your heart.

YES

NO

Touch 'YES' to agree, or 'NO' to disagree.

Alcohol and Smoking

Alcohol and Smoking

Alcohol and Smoking

Smoking can make your heart failure symptoms worse.

YES

NO

Touch 'YES' to agree, or 'NO' to disagree.

Alcohol and Smoking

Smoking can make your heart failure symptoms worse.

YES

Touch 'YES' to agree, or 'NO' to disagree.

Feeling Sad

Feeling Sad

Feeling Sad

Feeling Sad

Feeling Sad

If you feel sad for more than two weeks, you need to tell your doctor.

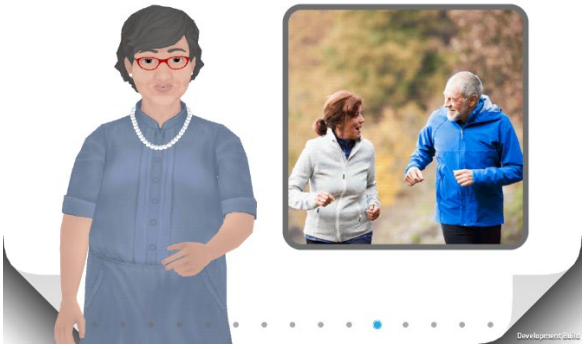
YES

NO

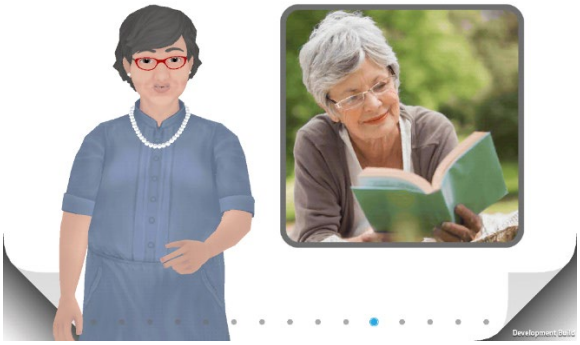
Touch 'YES' to agree, or 'NO' to disagree.

Sleeping

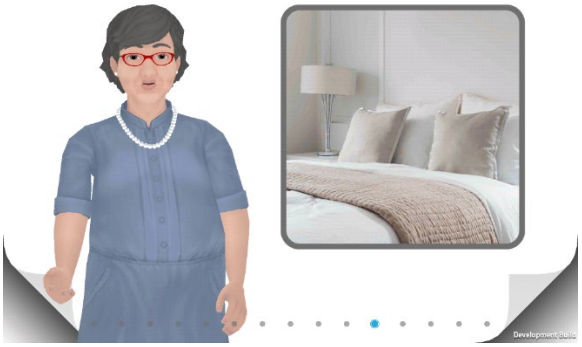
Sleeping



Sleeping



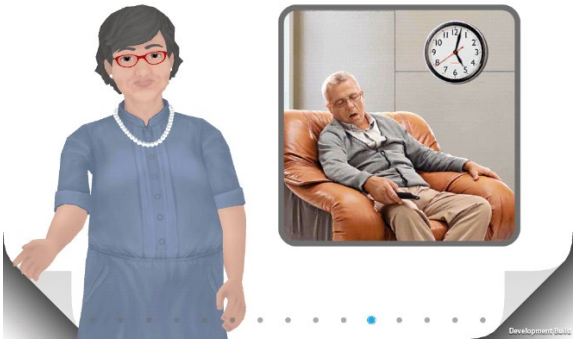
Sleeping



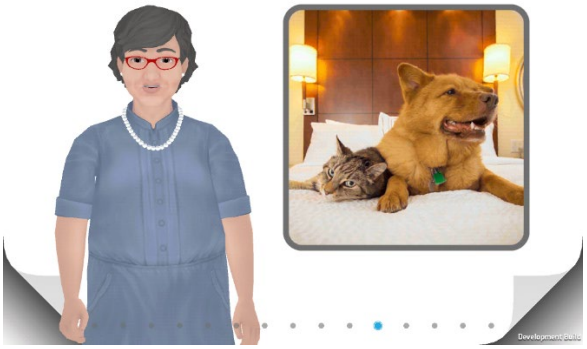
Sleeping

Sleeping

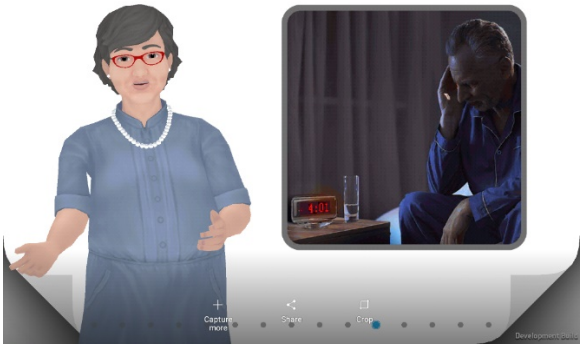
Sleeping



Sleeping

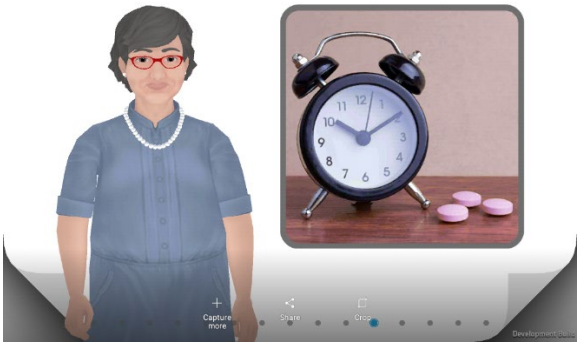


Sleeping

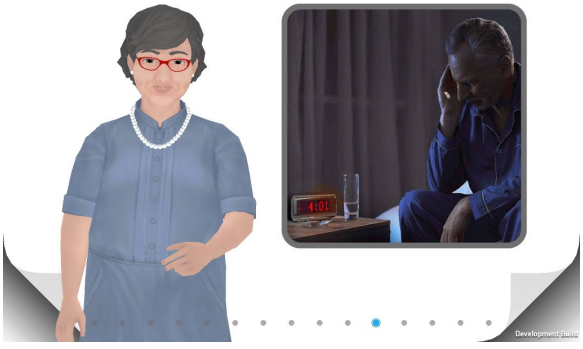


Sleeping

Sleeping



Sleep Apnoea



Sleep Apnoea

Sleep Apnoea

Sleeping

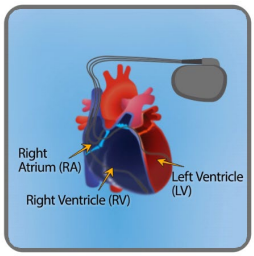
It's important to get up and go to sleep at the same time each day.

YES

NO

Touch 'YES' to agree, or 'NO' to disagree.

Pacemakers, Monitors and Defibrillators



Pacemakers, Monitors and Defibrillators

Pacemakers can help us with our shortness of breath and fluid build-up.

YES

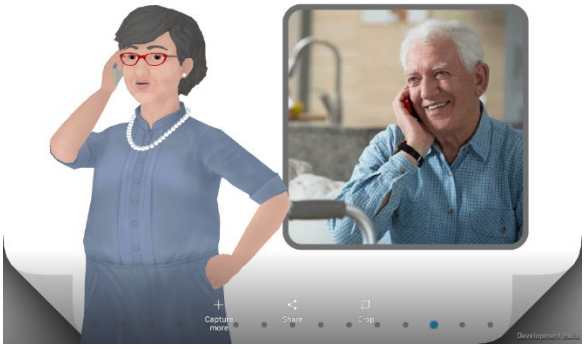
NO

Touch 'YES' to agree, or 'NO' to disagree.

Talking with your Doctor or Nurse

Talking with your Doctor or Nurse

Talking with your Doctor or Nurse



Talking with your Doctor or Nurse

Talking with your Doctor or Nurse

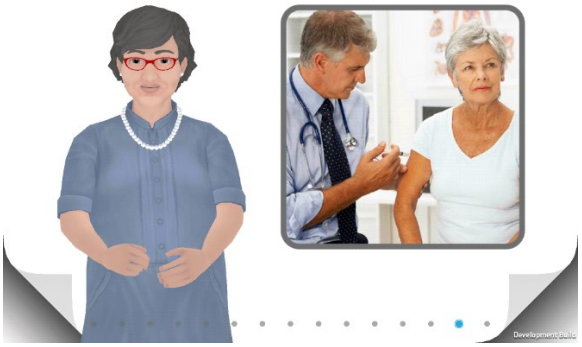
It's ok to ask for an urgent appointment with your GP if you feel unwell.

YES

NO

Touch 'YES' to agree, or 'NO' to disagree.

Vaccinations



Vaccinations

People with heart conditions are more likely to have health complications if they get the flu.

YES

NO

Touch 'YES' to agree, or 'NO' to disagree.

Travel

Travel

Travel

Slide the page curl left to continue.

Things to do Every Day

Things to do Every Day

Weigh yourself every morning.

Things to do Every Day

Take all of your prescribed medicines.

Things to do Every Day

Monitor your fluid intake.

Things to do Every Day

Eat heart-healthy foods and exercise.

Things to do Every Day

Enjoy yourself!

Things to do Every Day

Have too much fluid.

DO

DON'T

Touch 'DO' to agree, or 'DON'T' to disagree.

Slide the page curl left to continue.

Self-check Plan

Self-check Plan

- No new or worsening shortness of breath, or new cough.
- Physical activity level is normal for you.
- No new swelling, feet and legs look normal to you.
- Your weight is stable.
- No sign of chest pain.

Self-check Plan

Self-check Plan

- Dry, hacking cough.
- Worsening shortness of breath with activity.
- Increased swelling of legs, feet and ankles.
- Weight gain of more than 1kg in a 24 hour period.
- Discomfort or swelling in the abdomen.
- Trouble sleeping.

Self-check Plan

Self-check Plan

- Frequent dry, hacking cough.
- Shortness of breath at rest.
- Increased discomfort or swelling in the lower body.
- Weight gain of more than 1kg in a 24 hour period.
- New or worsening dizziness, confusion, sadness, or depression.
- Increased trouble sleeping, cannot lie flat.

Heart Attack Warning Signs





Heart Attack Warning Signs


Pain

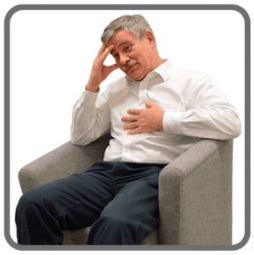

Cold Sweat


Dizziness


Nausea


Shortness of Breath

Heart Attack Action Plan



Heart Attack Action Plan

Heart Attack Action Plan

Heart Attack Action Plan

Heart Attack Action Plan

Emergency Action Plan

When we have chest pain, we should...

TALK to someone.
CALL 000 for an ambulance.
STOP what you are doing.
TAKE your angina medicine.

1:
2:
3:
4:

SUBMIT

Drag the elements on the left into the correct order on the right, then press Submit.

Emergency Action Plan

When we have chest pain, we should...

1: STOP what you are doing.
2: CALL 000 for an ambulance.
3: TALK to someone.
4: TAKE your angina medicine.

SUBMIT

Drag the elements on the left into the correct order on the right, then press Submit.

Emergency Action Plan

When we have chest pain, we should...

1: STOP what you are doing.
2: TALK to someone.
3: TAKE your angina medicine.
4: CALL 000 for an ambulance.

SUBMIT

Drag the elements on the left into the correct order on the right, then press Submit.

Emergency Action Plan

Which pain points are possible warning signs of a heart attack?

Touch the pain points that are possible warning signs (5 left)

Contact a Doctor or Nurse

Contact a Doctor or Nurse

Acknowledgements

Developed by

Powered by

Return To Index

Navigation statements

Swipe the Page Curl left to continue

Swipe the page curl right to go back

Swipe the page curl in the bottom left to go back

Swipe the page curl in the bottom right to continue

Swipe the carousel up or down to see more options

Touch an image to learn more about it.

Touch a button to make a selection

Touch a symbol to make a selection

Did you know that at any time, you can access the menu in the top left corner of the screen? From there you can access any Chapters of the app quickly or even change what I look or sound like. You can also go there to exit the app to.

Arrange these activities in the correct order.

Can you arrange these in the correct order?

Drag and drop them to where they should be.

Quiz-commencing statements (recorded June 2018)

• Shall we do a quick quiz to test the knowledge you've learnt in this chapter?

• Congratulations. We're at the end of this chapter. Let's do a quiz to see what you've learned.

• Let's do a quick quiz to see what you learned in the last chapter.

• We're now reached the end of this section. Are you ready for a quick quiz to test your knowledge?

• I hope you're learning lots of useful information. Let's do a quiz to find out!

• Are you ready to take a short quiz to test what you've just learnt in this section?

• So much to learn! Let's do a quiz to see how you're going.

• Hopefully there hasn't been information overload. Let's do a quick quiz to see what you've learned!

Quiz question success – generic statements

Yes!
Good job
That's correct
Correct!
Spot on!
You're right.
Well done.
You're doing a great job.
Excellent.
Keep up the good work.
Congratulations.
Very good.
Great!

Quiz question fail – generic statements

Sorry, that's not correct.
No, not this time.
Oh no, that's not correct
Hmmm. Not quite right.

Quiz category: success/fail

Don't worry too much about your score – that's why I'm here to help
Don't be too concerned – going through this app at your own pace will help.
There's room for a bit of improvement. Hopefully I can help!
Well done, that score is good.
Excellent work. What a great result!
Full marks. Good job.

Slide #	Section	Screen heading	Dialogue	Additional Dialogue
0	Splash #0		This app does not replace your doctor or nurse. If you have any question or concern about your condition, please contact your doctor or nurse.	
1	Splash #1 welcome	Fluid watchers		
2	Splash #2 continue		Touch continue to continue from where you left off or New to choose an avatar and start from the beginning again.	Are you sure?
3				
4	Intro 2 Avatar creation (Gender) Tutorial – Making a selection		Who would you like to talk to today?	
5	Intro 3 Avatar creation (Race)		Swipe up or down to choose another avatar	
6	Intro 4 Avatar creation (Customisation #1)		Do you want to customise your character? • Hair colour • Eye colour • Skin colour • Glasses • Clothing colour • Weight	
8	Intro 11 Avatar Welcome		Hi, I'm Bob/Mary and I have heart failure. I don't normally introduce myself that way but I heard that you've been diagnosed with it too. It's been five years since my doctor first told me and I remember what a shock it was to hear those words. I didn't know how I was going to go, but here I am, alive and well, and ready to share all the things I've learnt along the way.	
9	Menu Introduction		You can find all the information we've put together by touching the icon on the top left corner of your screen – this brings up the menu. Let's get started by tapping it now.	
10	Menu		This is the main menu. It can be used to jump straight to a topic you're interested in via the index.	

			There's also a list of acknowledgements for those involved in the creation of the app and also a button to quit too. AVATAR ALT 01: Also, if you're getting sick of me, you can change how I look and sound in Avatar creation. AVATAR ALT 02: Also, if you're getting sick of me, you can also change how I look in Avatar creation. When you're ready, tap the 'return to app button' and we can continue.	
9 part 02	Menu Introduction		Right, so you can either use the menu to navigate to what you want to learn, or just start here and work your way through. You already know you can swipe the page curl in the bottom right to go forwards, but if you miss anything or want to go back, you can swipe the one in the bottom left corner in the opposite direction to go back. When you're ready, swipe the page curl left to continue	
11	Acknowledgements			
12	Intro 13	Introduction Quiz	I'm going to take you through a little quiz about heart failure. Touch the tick if you think the statement is correct, or the cross if you think it's false. Don't worry if you don't know all the answers – I'm here to help – but I think you might be surprised by how much you already know.	
13	Quiz	Quiz		

Slide	Section	Screen Heading	True Dialogue	False Dialogue
Q1	Introduction Quiz			
Q2		Heart failure is when the heart cannot pump enough blood around the body.		
Q3		Heart failure and a heart attack are the same thing.		
Q4		You should skip your heart failure tablets if you're coughing a lot.		
Q5		Eating a low-salt diet can reduce fluid build-up in your body and help your heart		
Slide #	Section	Screen heading	Dialogue	Additional Dialogue
14	Quiz Results			
14a				
14b				
14c				
14d				
14e				
15	Understanding Heart Failure #1 - Intro	Understanding Heart Failure	I am going to talk about the most important things you need to know about heart failure in four sections. First, Understanding Heart Failure, second, Looking after yourself, third, Things to do every day and fourth the most important one, I am going to talk about an Emergency Action Plan. Let's get started with Understanding Heart Failure.	
16	Understanding Heart Failure #2.1 – What is heart failure? (Pre-video)	What is heart failure?	I like things simple and this is the simplest explanation I have read: Heart failure is when your heart can't pump blood around your body that well anymore. Take a look at this video to see if it helps you to understand.	

17	Understanding Heart Failure #2.2 – What is heart failure? (Video)		Our heart beats around 60 to 100 times a minute when it's healthy. With each heartbeat, the heart's pumping chambers circulate oxygen-rich blood to the rest of the body. Heart failure is an ongoing medical condition where the heart cannot pump blood around the body as well as it should. The heart's pumping chambers can become larger and/or thicker and either can't squeeze or can't relax as well as they should. This means that the oxygen and nutrient-rich blood isn't delivered efficiently to the rest of the body. This makes you feel tired. At the same time, the body may also retain excess fluids to compensate for the reduced blood flow. This may cause swelling in the legs and around the belly. Although it is called heart 'failure', it doesn't mean that your heart is about to stop, it just means that your heart is not pumping as effectively as it should. Coronary heart disease such as a heart attack, high blood pressure or viruses can lead to heart failure. The good news is that heart failure can be managed effectively. Talk to your doctor or nurse if you have any questions or concerns about your condition – your healthcare team is there to help you look after yourself and feel well.	
18	Understanding Heart Failure #2.3 – What is heart failure? (post-video)	What is heart failure?	Do you have any questions? Note them down and if I don't answer them in the next sections, you can ask your doctor or nurse at your next appointment. Now, let's look at what causes heart failure.	

19	Understanding Heart Failure #3 – How did I get heart failure #1	How did I get heart failure?	We can get heart failure in many ways. 15 years ago I had a heart attack. But I also had high cholesterol, high blood pressure, diabetes, and I really enjoyed a few too many glasses of wine each day. All of this was a bit too much for my heart. When you see a section like this, you can swipe up or down to different topics or if you want to know about them, just tap them.	Swipe the carousel up or down to discover another cause or tap on an image to learn more
19a		Heart attack	After a heart attack, some areas of the heart muscle can be damaged. The healthy muscle then has to work harder to compensate. This can eventually lead to heart failure.	
19e		Other Causes	There are other causes of heart failure, such as drug use, other conditions like diabetes and lung disease. If you would like to know more, please do talk to your doctor or nurse.	
Slide #	Section	Screen heading	Dialogue	Additional Dialogue
23	Looking After Yourself	Looking after yourself	Which topic would you like to start with? Simply tap on the topic and we will get started. In this section, I'll talk you through some of the important ways you can look after yourself.	
25			Let's talk about fluid. Our heart can't circulate blood around our body properly and so fluid can build up. This can make you put on weight and you might find that parts of your body, like your ankles or legs start to swell. It's important to know how much fluid you should drink each day and learn how to recognise the signs of fluid build-up.	Swipe the carousel up or down to learn more about Fluids, or swipe the page curl left to continue
25a		What can I eat or drink?	It's so important that we watch what we eat and drink. It's one of the great ways we can take care of ourselves. Here are some drinks and foods you need to count as part of your fluid intake. Fruit juice, water, milk, soup, soft drinks, tea, coffee, jelly, alcohol, watermelon, ice, ice-cream – these are all considered fluids.	

			Some drinks, like coffee and coke in particular, can influence your blood pressure and make your heart race so it's important to not have more than one coffee or cola a day. We should also avoid energy drinks and electrolyte replacement drinks; they are often high in caffeine or salt content. Believe it or not, I've found that decaf coffee and a good old glass of water are great alternatives. I've been doing this for ten years now and I don't actually miss much at all. I still enjoy the food and drinks I like, but just in moderation. It's a good idea to keep a food and drink diary, this helps make it easier to talk to your nurse or doctor about your diet. For most of us with heart failure, our fluid allowance varies between 1 and 1.5 litres. Your doctor or nurse will tell you how much you can drink each day.	
Q12	Fluids Quiz			
Q13		Heart failure can lead to a build-up of fluid in the body		No, this one is actually true. Heart failure can lead to excess fluid that makes our legs, feet or stomach swell. It's important that you check your body for swelling and if your shoes, socks or belt get tight, you should call your doctor or nurse.
Slide #	Section	Screen heading	Dialogue	Additional Dialogue
28	Looking After Yourself #4 – Salt #1	Salt	Our body needs salt, but not too much. Many foods contain salt naturally. Foods are high in salt are processed. Processed foods are any foods that come in tins or packets so best to avoid these and eat fresh whenever you can	
29	Looking After Yourself #5 – Salt #2	Nutrition information	On food label salt is referred to as sodium. Look for amount per 100 grams. Can you see how much sodium is in this food? First, look at the quantity per 100 grams . Then find the sodium level. This food has 388 milligrams of sodium per 100 grams of the food. For people with heart failure, like to you and I, we need to avoid food with more than 120 milligrams of	Swipe up or down to view the label or swipe the page curl left to continue

			sodium per 100 grams. So, whatever's in this package is too high in salt and not good for us.	
31		Quiz		
Slide	Section	Screen Heading	True Dialogue	False Dialogue
Q19	Salt Quiz			
Q23		Swipe foods that are low in salt into your trolley	Well done. As you already know, fresh fruits, lemon juice, garlic, herbs and spices are low in salt.	No, that's not right – try again. Food such as ham, bacon, sausages, hamburgers, pizza, hot chips, noodles, potato chips, many Asian food, pasta and fried chicken are high in salt.
36		Quiz		
Slide	Section	Screen Heading	True Dialogue	False Dialogue
Q29	Move more, sit less Quiz			
Q30		It is important for heart failure patients to stay active doing the things they enjoy.	That's true. Being active strengthens your heart and gives you more energy.	Hmmm … no, this is true. Moving more and sitting less will help your heart become stronger and give you more energy.
Slide #	Section	Screen heading	Dialogue	Additional Dialogue
43	Looking After Yourself #14 – Pacemakers, monitors and defibrillators	Pacemakers, monitors and defibrillators	Heart failure can lead to some heart muscle problems, where the electrical signals travel too slowly through the muscles and your heart doesn't squeeze and release properly. I had this problem and my doctor recommended a pacemaker to make me feel better. This might be the case for you too. If not, then feel free to skip this section by swiping the page curl left. For me, I had a biventricular pacemaker implanted that is designed to help the lower chambers of my heart, or ventricles, work better. A pacemaker can help you with some of your symptoms like shortness of breath and fluid build-up. I have regular check-ups to make sure it's working correctly and the electrical impulses from the pacemaker can be changed if needed – it's just like tuning a radio.	

			Some heart failure patients also have an implantable cardiac defibrillator (ICD). This is used in people who have a high risk of developing dangerous heart rhythms that can lead to cardiac arrest and death. An ICD can identify a life-threatening heart rhythm and deliver an electrical shock to return it to normal.	
Slide	Section	Screen Heading	True Dialogue	False Dialogue
Q48	Pacemakers, Monitors and Defibrillators Quiz			
Q49		Pacemaker can help our heart to maintain regular rate and be a better pump		No, this is actually true. A pacemaker is designed to help the heart maintain a regular rate by making the lower chambers of your heart work better.
Slide #	Section	Screen heading	Dialogue	Additional Dialogue
47	Looking After Yourself #16 –	Vaccinations	When we have heart failure, we have a higher risk of developing complications from other illnesses like the flu and infections, like pneumonia. The good news is that there are vaccinations against these illnesses and they are free for us! Talk to your doctor or nurse about getting the flu vaccine each year and keeping your pneumococcal vaccine up to date. The flu vaccine, called Fluvax, doesn't contain the live flu virus and won't give you the flu, but you may experience flu-like symptoms; this is normal.	
48		Quiz		
Slide	Section	Screen Heading	True Dialogue	False Dialogue
Q58	Vaccinations Quiz			
Q59		The Fluvax will give me the flu.	No, the Fluvax won't give you the flu, but you can experience flu-like symptoms. Don't let this stop you getting the vaccine each year – the flu can have serious consequences for your health.	You're right – the flu vaccine won't give you the flu.
Slide #	Section	Screen heading	Dialogue	Additional Dialogue

49	Things to do every day #1 – Intro	Things to do every day	We can help ourselves feel better by managing our condition. Here are a few things you need to do every day.	
50	Things to do every day #2 – Things		The first thing you should do each day is weigh yourself. Just remember the four Ws. Wake Wee Weigh And Write So, weigh yourself in the morning when you wake up, after going to the toilet, wearing the same clothes – or none at all, and check for any swellings. Keep a record of your weight and notice any changes. For example, if you are developing a new cough, coughing more often or coughing more at night and needing more pillows to sleep. Take all of your prescribed medicines. Monitor your fluid intake, and don't go over your daily limit. Remember even when things are going well, it is still import to eat heart healthy foods and stay active. And last but not least - enjoy yourself!	
Slide #	Section	Screen heading	Dialogue	Additional Dialogue
52	Emergency action plan #1 – Intro	Emergency action plan	Our last topic is about emergency action plans. Things can happen unexpectedly and it's important that you know what to look for and what to do	
53	Emergency action plan #2 – Heart failure Self-Check Plan-GREEN	Green zone-Excellent	Good news, if you are in the green zone, it means you're doing well. Keep up the great work and continue your daily weight checks, taking your medications and eating a healthy, low-salt diet. Tap on the icons to learn what check for each day. • No new or worsening shortness of breath or new cough • Physical activity level is normal for you • No new swelling, feet and legs look normal for you	

			• Check weight stable • No sign of chest pain	
56	Emergency action plan # 5 – heart attack action plan	New screen with heart attack signs and symptoms STOP TALK TAKE CALL	Even though we have heart failure, we can still have a heart attack and it's important to know what to do if you have chest pain or any other symptoms of a heart attack Signs and symptoms listed here are the warning signs of heart attack. If you experience any of these 1. immediately stop what you are doing and rest and check the time … if the pain has does not go away in 10 minutes while you are resting you will need to take action 2. tell someone if you are at work or home what is happening and what time your pain started … if you are alone call and tell someone close to you that you are having pain … If rest alone does not bring rapid or effective relief, take a dose of your angina medicine. If the angina is not relieved within 5 minutes, take another dose. If any of your symptoms are severe, get worse quickly, or have lasted more than 10 minutes … 3. CALL triple zero (000) and chew an (300 mg) aspirin, unless you have an allergy to aspirin or your doctor has told you not to take it. Ask for an ambulance immediately. Don't hang up. The operator will be able to help you. • Tap on the icons to learn what those symptoms are. Pain, pressure, heaviness or tightness in your chest, arm(s), back, jaw, neck, shoulder(s) • nauseous • a cold sweat • dizzy	

			• short of breath	
57		Quiz		
Slide	Section	Screen Heading	True Dialogue	False Dialogue
Q68	Emergency action plan Quiz			
Q69		If you develop a new cough from your medication… you should contact to your GP.		When the unexpected happens, it's important to get in touch with your health care team. If you develop a cough you should make an urgent appointment with your GP so they can assess your condition.
Slide #	Section	Screen heading	Dialogue	Additional Dialogue
58	Contact #1	Contact a doctor or nurse	You've done it! We're now at the end of the app. Is there anything else you'd like to know? If I haven't answered all of your questions you can contact your doctor or nurse and they'll help you out. The health information service also provides free information on heart health, nutrition, and a healthy lifestyle. You can call the Heart Foundation's helpline 13 11 12 or visit their website. You can also come back and visit me any time – I'd be happy to refresh your memory on all things heart health and check in on how you're going.	Turning the page here will take you back to the beginning.