



Digital Health to Improve Australians Experience of Care: The case of melanoma post-treatment care

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ABSTRACT

Improving access to care *is not enough* if it is not effectively delivered. Ineffective care is a result of poor adherence to evidence-based guidelines by healthcare providers, which reflects either a lack of knowledge of the guidelines or non-compliance regardless of the knowledge. Ineffective care originates from the provision of unsuitable interventions that do not meet client-specific needs. Further, poor quality healthcare services have proven to slow progress to achieve better health outcomes and substantially increase the societal and economic burden of diseases. To address this and ensure high-quality care, actions must occur at the organisational, system and individual levels.

To achieve optimal care, it is essential to provide healthcare services that constantly meet client-specific needs, which vary widely per individual. Scientific evidence indicates that to assess a client's needs, it is crucial to consider factors such as sociodemographic, psychological, health conditions, as well as accounting for barriers to accessing adequate care services. Of notable importance, social and cultural environments impact a client's experience of care as they influence knowledge, perception, satisfaction and therefore needs. Hence, there is no single approach to optimal care.

The emergence of digital technologies has played a critical role in the advancement of the healthcare sector. Digital health is used as a time and cost-effective solution to overcome the numerous challenges faced by health systems that limit the provision of high-quality care. These include geographical inaccessibility, overcrowded and understaffed hospitals, delayed provision of care, low adherence to clinical protocols and guidelines, and costs to patients.

Therefore, digital health's primary goal is to achieve better health outcomes through engaging with individuals at all touch-points throughout their patient journey, from the initial diagnosis to final treatment and recovery, and supporting clinicians in their practices to help them provide the most effective care.

While research has extensively discussed the *'WHY'* and *'WHAT'* of digital health implementation, the *'HOW'* has often been overlooked. Indeed, a large body of literature showcases digital health opportunities and challenges in various settings. Still, a critical research gap remains in demonstrating best practices to support digital health adoption and integration. The current research aimed to address this gap in the literature by making a case for providing a user-informed digital health model to improve Australians' experience of melanoma post-treatment care.

Recent findings by the current authors reveal that to deliver optimal melanoma care through technology, it is critical to understand the user's specific needs and consider individual characteristics in the design of solutions. Therefore, the current exploratory study captured information about the experience of care from a melanoma patient's perspective and attitude toward digital health interventions. The data were collected through an online questionnaire developed based on clinical recommendations from melanoma guidelines and findings from a published systematic review (Rollin, Ridout & Campbell, 2018).

The access to, and satisfaction with, melanoma post-treatment care of 95 patients were investigated, as well as their attitude toward digital health. Overall, 30% expressed difficulties accessing care due to geographical barriers, cost and time pressure. A majority presented signs of distress and desire for more educational and psychosocial support. The data also identified significant associations between access and psychological distress. Overall, participants reported positive attitudes toward the use of digital health, particularly if it can improve their quality of life. Overall, the findings showed that adapted uses of digital health in melanoma post-treatment care could increase self-management and healthy behaviour; reduce psychological distress and social isolation; enable timely access to healthcare providers and communication, and support collaboration between clinicians. However, the study also reported a substantial lack of knowledge and awareness about technologies made available to melanoma patients.

Recommendations on where to start and how we could encourage digital health uptake to provide high-quality, effective and adequate care are proposed. To achieve this, a patient-

centred, integrated and collaborative model for melanoma post-treatment care based on needs assessment has been recommended.

The thesis concludes on a call to action for healthcare stakeholders to ‘upgrade’ the existing melanoma healthcare system in Australia to a technology-enabled system which is based on clients’ needs, but driven by healthcare expert clinicians and service providers.

DECLARATION

I, Audrey Rollin, certify that to the best of my knowledge and belief, it does not incorporate any material which to a substantial extent has been submitted for any degree or other purposes.

I certify that the intellectual content of this thesis is the product of my own work and that all the assistance received in preparing this thesis and sources have been acknowledged.

Signature:

Audrey Rollin

Date:

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ABBREVIATIONS

AIHW	Australian Institute of Health and Welfare
AR	Augmented reality
ASR	Aged-standardised rate
CM	Cutaneous melanoma
DALYs	Disability-adjusted life years
eHealth	Electronic health
FoCR	Fear of cancer recurrence
GP	General practitioner
HIMSS	Healthcare Information and Management Systems Society
HIT	Health information technology
HCP	Healthcare provider/professional
HDI	Human Development Index
ICT	Information and communication technology
IT	Information technology
LVC	Live video call
mHealth	Mobile health
MoC	Model of care
NMSC	Nonmelanoma skin cancer
OECD	Organisation for Economic Co-operation and Development
QoL	Quality of life
RPG	Role-playing games
SSE	Skin self-examination
SES	Socioeconomic status
TSSE	Total self-skin examination
UV	Ultraviolet
VBC	Value-based care
VBHC	Value-based healthcare
VR	Virtual reality

WBG

World Bank Group

WHO

World Health Organisation

CHAPTER 1

INTRODUCTION

Overview

This chapter provides a broad background of the impacts of poor quality and inadequate care on patients, healthcare providers (HCPs), the Australian healthcare system and melanoma patient care. It then gives an overview of the opportunities and challenges for implementing digital health in Australia, and the priority to rethink and transform the national healthcare system to reduce the societal and economic burden of chronic disease, with the disease focus on melanoma post-care as the priority of this thesis research. A large body of evidence suggests that digital health is a cost-and-time effective solution to provide healthcare enmass through interoperable, scalable and adaptable systems. While scholars have extensively discussed the *'WHY'* and *'WHAT'* of digital health implementation, the *'HOW'* has often been overlooked.

Established on a client-centred approach, the current study elaborates on cutaneous melanoma as a case study to illustrate how technological interventions' implementation, use, and adoption can benefit its end-users. The author then provides a rationale for exploring digital health with melanoma post-treatment care and the thesis' aims. The chapter concludes with an outline of the thesis and how the present study is an essential first step in establishing evidence-based digital transformation and implementation of an optimal model of melanoma post-treatment care in Australia.

Background

In a recent report (2018), the World Health Organisation (WHO), the World Bank Group (WBG) and the Organisation for Economic Co-operation and Development (OECD)

urged governments, health system leaders, policymakers, clinicians and patients to scale up healthcare services ‘quality’ and no longer just focus on ‘quantity’ of service provision

High-quality healthcare refers to “*the right care, at the right time, in the right place, and by the right care provider*” (WHO, WBG & OECD, 2018). While *high-quality* care is a result of effective, safe, client-centred, timely, equitable, integrated and efficient care, *poor quality* healthcare involves unsafe, inaccurate, inadequate, unnecessary and inefficient practices (WHO, 2018a). Ultimately, poor quality healthcare can severely increase the societal and economic burden at the individual, community and country level. It also considerably increases costs on health systems (OECD, 2017), led by duplicate services, more costly treatments and avoidable hospital admissions. Besides, empirical evidence highlights that healthcare service quality is associated with patient satisfaction, health outcomes, and, therefore, quality of life (QoL) (Choi et al., 2005; WHO, WBG & OECD, 2018).

Given this, stakeholders in healthcare, including governments, policymakers, clinicians and patients, must implement and adopt interventions to expand quality healthcare services. These interventions include:

- Measures to support HCPs to achieve the most effective care, including clinical decision support systems, information and education, to augment their technical knowledge and ability to communicate and collaborate with other professionals and clients. Indeed, there is strong evidence that quality of care is associated with the capacity to access skilled and adequately supported HCPs (WHO, WGB, OECD, 2018);
- Initiatives to engage through improved health literacy and adoption of client-centred care. It has long been established in public health that promoting healthier and more adaptive behaviour, and enhancing patient experience and effective utilisation of health services, have direct positive impacts on national and global economies, as well as improving world health outcomes (WHO, 2018b);

- Changes in clinical practices and healthcare structure. Evidence-based practice illustrates that quality care must be underpinned by collaborative and shared-model healthcare (Schouten et al., 2008).

Keeping the above interventions in mind, digital health plays a key role in suggesting and supporting new ways to deliver timely, high-quality care services, at an affordable cost (WHO, OECD & WBG, 2018; Murray et al., 2016). Innovation’s adoption is led by its potential benefits, user-friendliness and readiness (Greenhalgh et al., 2017; Lennon et al., 2017; Tolf et al., 2020):

- To increase the management of chronic diseases with the use of clients self-management technologies such as mobile health (mHealth) interventions (i.e., self-education, self-monitoring) (Klonoff, 2013; WHO, 2011);
- To facilitate quick and convenient access to healthcare by clients with the use of telehealth (i.e., virtual consultation, electronic communication) (Marshall et al., 2018)
- To manage workload pressures on general practitioners (GPs) through teleconsultations and clinical-decision support systems. (Salisbury et al., 2020; Klonoff, 2013).

While a large body of evidence suggests that digital health is an effective solution to provide healthcare enmass through interoperable, scalable and adaptable systems, non-adoption and abandonment of technologies by end-users is common (Wade et Hiller, 2014; Sligo et al., 2017). Digital health has proven slow to become accepted and integrated into health systems (Lennon et al., 2017). Furthermore, the misalignment between the cadence of traditional research and fast-paced innovations gives rise to the digital health paradox “*no evidence, no implementation — no implementation, no challenge*” (Guo et al., 2020). This adds to the challenges of providing timely and robust evidence of digital health best practices to meet end-user expectations.

The current thesis proposes ways of bridging the research-practice gaps in healthcare and innovative solutions to the aforementioned challenges with melanoma management in Australia. Melanoma has been identified as a good exemplar because:

- (1) It is classified as a chronic illness that has a significant societal and economic burden (Urban et al., 2021);
- (2) There is evidence showing strong dissatisfaction with patient management care (McInnes et al., 2008; Oerlemans et al., 2012; Mitchell et al., 2014);
- (3) There are gaps in the melanoma digital health literature that should be addressed (Rollin et al., 2018).

Thesis aims

The primary aim of this doctoral thesis is to address the quality gaps in healthcare services, specific to melanoma patients, using digital health to reduce the social and economic burden in Australia. To this end, the specific aims of this research are to:

- (1) Have a comprehensive view of the current melanoma post-treatment care pathway in Australia in order to identify determinants of access and melanoma patients (un)met needs, and therefore, to improve their experience of care;
- (2) Conduct a systematic review of digital health in melanoma post-treatment care in Australia. Thus to report on the current use of technologies in this specific setting and identify gaps in the literature;
- (3) Using data collected from a clinical population of recovering melanoma patients, provide a user informed digital health model for melanoma patient care using evidence-based benefits to increase access to, and quality of care via integration of existing digital options.

Thesis outline

This introduction provides a broad scope overview of direct and indirect impacts associated with existing provisions of inadequate and poor-quality care at individual and system levels by identifying key patient challenges to inform best practice and evidence-based digital health interventions.

With the above thesis aims outlined, three primary components form the development of the present thesis. Chapters 2-4 will review the literature on digital health and melanoma care; Chapters 5 and 6 describe the scientific reliability and validity of the current study; Chapters 7 and 8 detail the data collected and discuss the study's results real-world implications.

- Chapter 2 — *Digital health for melanoma post-treatment care* outlines the global digital transformation of healthcare systems, underpinned by its opportunities and challenges. The objective is to provide a comprehensive illustration of the Australian digital health landscape in melanoma post-treatment care. It articulates how technological innovations may change the ways healthcare services are accessed and delivered. Notably, it highlights the lack of empirical evidence for the management of melanoma internationally.
- Chapter 3 — *Understanding melanoma* provides background information on cutaneous melanoma, including its epidemiology, societal and economic burden and clinical management guidelines. Importantly, it highlights patients' dissatisfaction with, and poor quality of, supportive care, which technological interventions could address.
- Chapter 4 — *Melanoma post-treatment care in rural and remote Australia: Systematic review* (Rollin, Ridout & Campbell, 2018) is a peer-reviewed scholarly publication comprising an analysis of the literature. The review procedure is first described for study eligibility criteria, search method, article selection (PRISMA), data extraction, and narrative synthesis of findings. Data

from the identified studies are then presented in a table, including information about available digital health technologies for melanoma patients and their direct (positive and negative) outcomes. The systematic review discusses four gaps that have been identified in the literature. The study concludes with suggestions for future research.

- Chapter 5 — *Rationale for methodology* presents the background and reasoning for the research methodology, including challenges accessing melanoma post-treatment care and the benefits of using digital health to improve health outcomes. The methodology's rationale is based on the published systematic review findings (Rollin et al., 2018) and previous literature. This chapter explains the current study's sample selection, participants' characteristics collected and measures, and concludes with a summary of the twenty-five hypotheses identified.
- Chapter 6 — *Method* describes the study design and research approach, including sample selection, recruitment procedures, data collection and analysis methods developed and used to generate a snapshot of melanoma patients' attitudes towards digital interventions in Australia. The study was a questionnaire structured into two sections. The first section aimed to analyse the current state of melanoma post-treatment care in Australia and the barriers to accessing this care. The second section's objective was to understand melanoma patients' attitudes toward digital health interventions in post-treatment care.
- Chapter 7 — *Results* presents the current study findings, reporting demographics of the overall sample and their access to post-treatment care. It also investigates digital health's potential benefits to increase the provision of healthcare services and improve QoL. Finally, the main analysis aims to identify the factors impacting patients' experience of care and determinants of digital health uptake. The implications of the current study's findings are discussed in Chapter 8.

- Chapter 8 — *Discussion*'s primary objective is to propose an innovative model of melanoma post-treatment care based on empirical evidence to provide high-quality care through the use of digital health interventions. The proposed model is underpinned by a patient-centred and value-based care approach. To this end, a comprehensive illustration of the current Australian melanoma model of post-treatment care is designed. It showcases the challenges encountered by melanoma patients and their impacts on individuals and the health system. A second part discusses the substantial role of digital health to address these issues, but most importantly, how to implement and encourage the use of technologies to provide optimal care and reduce the overall burden of melanoma in Australia. The discussion is supported by previous literature referred to in Chapters 2-4 of the thesis. The implications of the current study for future directions of both melanoma post-treatment care in Australia and digital health and research at the intersection of these two fields are then proposed. The thesis concludes with some perspectives on how the Australian model of melanoma post-treatment care could be digitally-enhanced to deliver optimal care to patients and be used as an adjunct service by clinicians to support them in their daily practice.

CHAPTER 2

DIGITAL HEALTH FOR MELANOMA POST-TREATMENT CARE

Overview

Chapter 2 aims to provide a comprehensive illustration of the Australian digital health landscape in melanoma post-treatment care. It will also demonstrate how digital health implementation may transform the melanoma patient ecosystem. To achieve this, a clear definition of the concept of digital health is provided, with discussion of its various applications and functions.

This chapter outlines the emergence of digital health, its opportunities and encountered challenges. It provides a global perspective of digital health and reviews the digital transformation of the Australian healthcare system. It identifies three factors that influence uptake and adoption/integration of digital health by patients and HCPs:

1. Technological revolutions that push forward the health sector;
2. The rising costs of healthcare;
3. Public health crises.

The chapter concludes with an overview of the implementation of digital health interventions in melanoma care, highlighting the lack of empirical evidence for management of melanoma. A review of existing digital health literature provides the basis for how the Australian model of melanoma care could benefit from a digitally-enhanced solution.

This thesis specifically focuses on technology used by patients rather than clinicians to reduce the scope of the research. It defines ‘digital health’ as the application of organised

knowledge and skills in various forms such as devices, procedures, and systems, developed to solve a health problem and improve clients' quality of life.

Part 1 — Digital health

The term 'digital health' has become an accepted neologism, despite the lack of an agreed-upon definition, and little consensus on the taxonomy of digital health technologies. 'Digital health' is therefore, an umbrella term. The following terms are often used to describe 'digital health', or in place of 'digital health', when there are actually acute differences in their technical meanings, i.e., digital medicine; digital therapeutics; eHealth; connected health; health information technology (HIT); telehealth; telemedicine; mHealth; virtual care. All can be, and often are, commonly and interchangeably used to describe the application of technology in healthcare services, and the accompanying functions of healthcare technology.

Given this current interchangeable-terms basis, there are currently many definitions of 'digital health'. With no key, authoritative discipline or professional entity agreeing to one definition, there are obvious wide-ranging issues for health communication and patient outcomes.

Australians associate 'digital health' with the digitalisation of healthcare systems. For example, ICT infrastructure such as MyHealthRecords, e-prescription, as well as the limited use of teleconsultation to gather patient information (Walsh et al., 2017). Of notable importance, the Australian perspective of digital health has been criticised for being too narrow (Turner, 2020), with the utilisation of technology to collect, store and analyse data often lacking (Turner A, 2020). This, despite evidence demonstrating that it can significantly improve treatment and enable precision medicine and personalised care (NHS, 2021).

The following sections discuss some current definitions, applications and functions of digital health, highlighting this complexity.

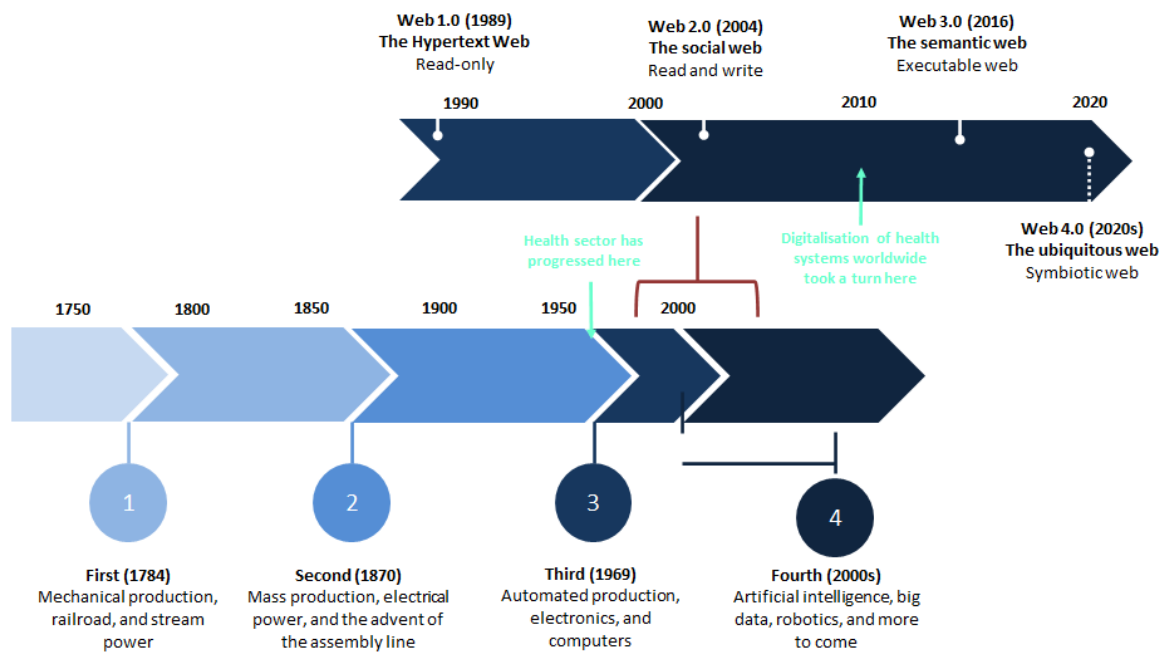
Section 1: The evolutionary concept of digital health

Historically (Rowlands, 2019), digital health was limited to the distribution of information through hardware, software telecommunications and electronic platforms (e.g., emails, patient admission systems, electronic health records). Since its introduction in the early 1960s, there has been a rapid growth of digital technology, with the concept of digital health now quickly evolving due to different application uptake beyond administrative records.

Digital health is associated with the development of the World Wide Web, i.e., Web 2.0 (aka. ‘social web’) (Lupton, 2017), and is the outcome of innovation change with the adoption of information and communication technologies (ICT) in health systems (Rowlands, 2019). It is embedded in the fourth industrial revolution (Figure 1), characterised by rapid transformations due to, and within, information technology, data volume and ubiquity, as well as increased computer processing power (Otokiti, 2020). It has been suggested that the driving force of digital health is its capacity to collect, store, and analyse extensive amounts of health (and medical) data (Vayena et al., 2018), which can be exploited for multiple purposes, including research, security, commercial and governmental (Lupton, 2017).

Figure 1

Digital health as an 'era'



Note. Adapted from (Murray, 2016); (Choudhury, 2014)

While it has been widely accepted that digital health aims to increase QoL and wellbeing using various technologies, there is currently no consensus on a definition for 'digital health'. Generally, digital health has been broadly defined as a term encompassing a wide range of technology from ICT to big data and genomics that aids in decision making. Table 1 provides an overview of some selected definitions of digital health.

Table 1*Overview of the current description of digital health*

Authors	Date	Definition
Bhavnnani et al	2016	<i>“Digital health is defined as information technologies that can be applied in three aspects including digital patients, digital devices, and digital clinics.”</i>
Lupton	2017	<i>“The term ‘digital health’ refers to a wide range of technologies directed at delivering healthcare, providing information to lay people and helping them share their experiences of health and illness, training and educating healthcare professionals, helping people with chronic illnesses to engage in self-care and encouraging others to engage in activities to promote their health and wellbeing and avoid illness.”</i>
Chu et al.	2018	<i>“Digital health is thought to spark innovation in health care by providing better tools and solutions which empowers the end-users, patients and providers.”</i>
Sharma et al.	2018	<i>“Broadly defined, digital health describes using digital information, data, and communication technologies, to collect, share, and analyse health information for purposes of improving patient health and health care delivery.”</i>

Adjekum et al.	2018	<i>“Digital health broadly refers to the use of information and communication technologies to improve human health, health care services, and wellness for both individuals and populations.”</i>
Rivas	2018	<i>“Digital health, which broadly refers to the convergence of digital tools with health and healthy living.”</i>
World Health Organisation	2019	<i>“The term digital health is rooted in eHealth, which is defined as “the use of information and communications technology in support of health and health-related fields. Mobile health (mHealth) is a subset of eHealth and is defined as the use of mobile wireless technologies for health. More recently, the term digital health was introduced as “a broad umbrella term encompassing eHealth (which includes mHealth), as well as emerging areas, such as the use of advanced computing sciences in ‘big data’, genomics and artificial intelligence.”</i>
Food and Drug Administration	2020	<i>“The broad scope of digital health includes categories such as mobile health (mHealth), health information technology (IT), wearable devices, telehealth and telemedicine, and personalized medicine.”</i>
Australian Institute of Health and Welfare	2020	<i>“Digital health is an umbrella term referring to a range of technologies that can be used to treat patients and collect and share a person’s health information, including mobile health and applications, electronic health records, telehealth and telemedicine, wearable devices, robotics and artificial intelligence.”</i>

The Healthcare Information and Management Systems Society (HIMSS) reviewed current definitions of digital health in the literature (empirical and grey), from 2014 to 2020 (Snowdon, 2020). As a result, twenty-two papers were identified and broadly defined digital health in terms of:

- Type and use of digital technologies;
- Improvement of healthcare (e.g., using a holistic view of patients; upskilling clinicians; evidence-based therapeutic interventions; monitoring; personalised care; etc);
- Strategy for health system transformation toward patient-centric, democratisation of care.

The HIMSS conclusion, combined with the information outlined in the previous section of this thesis, highlights the complexity of digital health and the variability of perspectives that change across disciplines and fields. However, it also clearly showcases digital health's unique goal: to improve health system performance for both HCPs and patients.

Section 2: Technologies and applications

'Digital health' is characterised by all technologies used and implemented by HCPs and patients for health and medical purposes. It is an umbrella term referring to a range of technologies and applications that are used in eHealth, mHealth, telehealth and gamification, each defined below:

- **eHealth** (aka. electronic health) is defined as "*the use of ICT in support of health and health-related fields*" (WHO, 2016a). At its origin, eHealth was used by both patients and HCPs to communicate at distance and to share and look for information using electronic platforms (e.g., emails, electronic health records, web-based platforms). However, the term eHealth has evolved to include a broader range of technologies such as mHealth, telehealth and digital gamification tools (Srivastava et al., 2015).

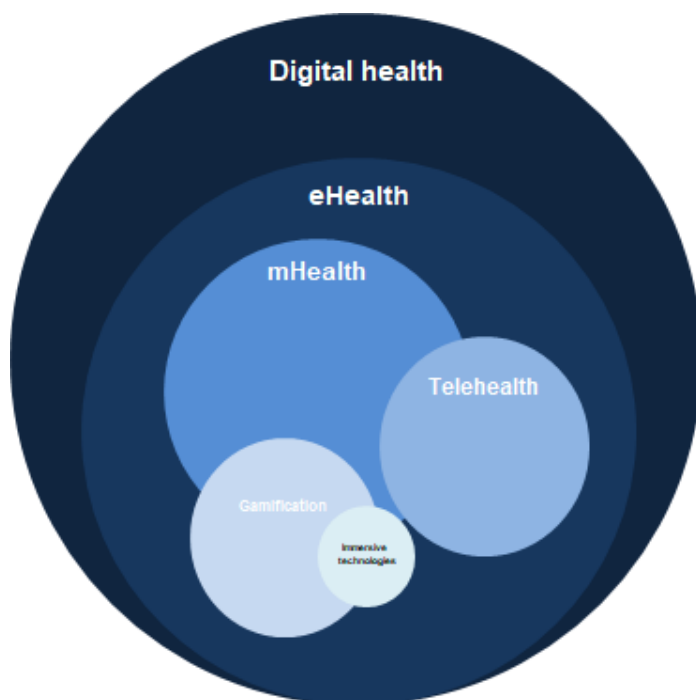
- **mHealth** (aka. digital mobile health) is a subset of eHealth and refers to “the use of mobile wireless technologies for public health” (WHO, 2011; 2018) (e.g., wearables, text messages, mobile apps, and handheld imaging devices). mHealth technologies have created a new, convenient communication channel between providers and patients which influence healthcare delivery and services (Rowland et al., 2020). Further, mHealth — particularly mobile apps — has the potential to empower patients through increased knowledge and promotion of self-management and health monitoring (Irfan Khan et al., 2018). However, research has reported strong safety, privacy, quality of content, and regulatory concerns for mHealth (Chao et al., 2017).
- **Telehealth** is the *“delivery of healthcare services, where patients and providers are separated by distance. Telehealth uses ICT for the exchange of information”* (WHO, 2016b). It involves the delivery of synchronous and asynchronous care through remote telecommunications and virtual technologies (e.g., videoconferencing, e-consultation, store-and-forward platforms) (Mechanic et al., 2020). The use of telehealth has been thought of as a time- and cost-effective solution, leading to increased communication and information sharing for, and between, patients and HCPs, as well as improved coordination between HCPs (Moffatt & Eley, 2010; Center for Disease Control and Prevention, 2020; Monaghesh & Hajizadeh, 2020).
- **Gamification** (aka. serious games) in health is an umbrella term for *“the use of video game elements in non-gaming systems [such as healthcare] that aim to improve user experience and user engagement”* (Pereira et al., 2014). Examples of gamification include online challenges, RPGs - also known as role-playing games, quizzes, simulations and adventures games. Increasingly, serious games are recognised as a therapeutic method promoting behaviour change to treat and educate patients, resulting in increased patient empowerment and engagement in their care (Rondon et al., 2013). Gamification is also used to train and upskill healthcare professionals (Meijer et al., 2018). However, research has showcased

the lack of scientific evidence toward gamification's effectiveness (Meijer et al., 2018; Maganty et al., 2018), which can explain HCPs' reluctance to use games as a therapeutic solution (Hammedi et al., 2017).

- **Immersive technologies** refer to the use of multi-sensorial stimulation like virtual reality (VR) and augmented reality (AR) in healthcare (Wiederhold et al., 2018; Hoffman et al., 2000). VR and AR technologies have predominantly been implemented in treatment for psychological and physiological pain, anxiety, phobias, stress disorders, social readaptation and stress management (Wiederhold et al., 2016). Immersive technologies have also been used in some physical therapies and mindfulness programs (Smith et al., 2020). Further, there is scientific evidence that VR and AR can provide medical education to HCPs and support them in their day-to-day practice (Wiederhold et al., 2018; Pottle, 2019).

Figure 2

Digital health ecosystem



Of notable importance, the terms digital health and eHealth fundamentally differ when referring to their respective semantics of ‘digital’ and ‘electronic’. Electronic refers to any device that uses electrons (Merriam-Webster, n.d., definition 1 and 2), whereas digital is defined by the collection, storage and transition of information (aka data) from various systems and devices (Collins,n.d., definition 6a). This means that almost every ‘digital’ device is ‘electronic’, but not all ‘electronic’ devices are ‘digital’.

Part 2 — The global digitalisation of healthcare

The first signs of technology-enabled healthcare delivery date back to the 1960s, where telephone and telegraph networks were used to deliver healthcare to remote locations (FDA, 2020). However, neither the medical curriculum nor the policies and healthcare guidelines reflected upon this technological development (Druss & Marcus, 2005). It is only in the 2010s, that the digitalisation of healthcare took a turn as worldwide healthcare systems became financially unsustainable (Meskó et al., 2017), and patients were empowered with the use of information found online and therefore want to take an active part in making decisions about their care (Lupton, 2013; Meskó et al., 2017). Since then, healthcare systems have rapidly evolved with the implementation of digital technologies to improve healthcare delivery. The global digital transformation of healthcare has the potential to enable a more effective, collaborative, multidisciplinary and cross-organisational system that facilitates increased availability and accessibility to health services.

Section 1: The emergence of digital health

Digital health is argued as a necessary evolution to improve health outcomes and healthcare systems (Murray et al., 2016), whilst engaging with individuals at all touch-points throughout their patient journey, from initial diagnosis to final treatment and recovery (Global Digital Health Industry (2019 to 2027) - Market Trajectory & Analytics, 2020). It aims to overcome challenges faced by health systems (Alami et al., 2017), such as geographical inaccessibility, overcrowded and understaffed hospitals, delayed provision of care, low adherence to clinical protocols, and costs to patients.

Health and medical needs for digital health

Estimates released by WHO reported that by 2020 noncommunicable diseases were expected to represent 57% of the global burden of disease and 75% of deaths (WHO, 2002). Arguably current healthcare models are not able to support this societal burden (Schofield et al., 2019). The use of digital health technology has been proposed as a solution to develop an interoperable and scalable system to deliver healthcare enmass (Raghupathi & Kesh, 2009).

However, its adoption is compounded with the constant need for improvement, efficiency, availability, utilisation and cost-effectiveness of the healthcare sector (Chu et al., 2018; Geiser & Gross, 2017; Mehl & Labrique, 2014; Michie et al., 2017) to ensure optimal care.

The potential of digital health in primary healthcare has been extensively investigated globally. Research reveals that the use of digital technologies in healthcare can:

- Improve QoL including clinical diagnosis and treatment (Morton et al., 2017);
- Increase access to care through remote, timely and cost-effective care delivery (Murray et al., 2016);
- Enhance health literacy which enables patient empowerment and improved communications with HCPs (von Schuckmann et al., 2017);
- Encourage self-management and health monitoring (Morton et al., 2017; Michie et al., 2017);
- Promote healthy and adaptive behaviour (Michie et al., 2017);
- Reduce psychological distress (Fu et al., 2020).

Due to its scalability and relative low-cost interventions, digital health has been accepted as a cost-effective solution to numerous health systems challenges.

Public health crises motivators for Digital Health

While there are substantial needs for digital health worldwide, the uptake of digital health technologies to support public health systems has been rather unsatisfactory (Petracca et al., 2020).

However, public health crises have influenced rapid and abrupt adoption of digital health. With the past epidemic events (e.g., SARS outbreaks, Ebola, Swine Flu, etc.), the world has witnessed a remarkable surge in digital health adoption, with a scale-up of telehealth (Ohannessian et al., 2020; Gunasekeran et al., 2021). Pandemics like COVID-19 have driven a significant uptake in digital health and an unparalleled shift to teleconsultations in some

medical practices (Lonergan et al., 2018), as a direct result of the infectious status of this disease outbreak and the public health crisis and measures to limit the transmission of the virus in communities (Gunasekeran et al., 2021). Collectively, these factors have driven rapid changes in demand and need, capacity (i.e., overcrowded hospitals and lack of clinical/medical staff) and ways of delivering care, which have been addressed by the deployment of digital health and new models of care (Gunasekeran et al., 2021). COVID-19 resulted in a technological disruption of the healthcare system (Milne & Costa, 2020), and therefore the digital health industry. Global estimates reported that the digital health market is expected to witness a 37.1% spike in growth in the year 2021 and to reach US 505.4 billion by 2025 — up from US 86.4 billion in 2018 (Global Digital Health Industry (2019 to 2027) - Market Trajectory & Analytics, 2020).

Additionally, it has been argued that an effective response to public health crises is communication between governments, HCPs, scientists, media and communities (Cowper, 2020). Research has also highlighted the substantial role of public education in community engagement and the implementation of national mitigation strategies against infectious disease outbreaks (Jalloh et al., 2020). Given this, online information and social media have been widely used during global pandemics to collect and share validated data to support surveillance of public health threats (Wang et al., 2020), control the spread of misinformation (WHO, 2020; 2020a), and promote adaptive behaviour (Young, 2020).

Section 2: Digital health challenges

Driven by unconventional players and transcending geographical, cultural and regulatory boundaries, emerging technologies disrupt the healthcare ecosystem and the delivery of its services (Alami et al., 2017). To explain the slow uptake of digital health, many studies (Petracca et al., 2020; Weinstein et al., 2014; Magrabi et al., 2019; Alami et al., 2017; Salibury et al., 2015) discussed the barriers to the adoption of health-related technologies, including numerous challenges such as the poor and slow adaptation of regulations and governance systems to rapid technology changes; the implementation of appropriate reimbursement schemes of digital health services; user experience of adopting technologies,

lack of compliance with the use of technologies and arduous involvement of HCPs; as well as, the development of integrated systems and coexistence with analog pathways.

For the purpose of this thesis, the present chapter focuses on two subsets of digital health challenges — (1) the importance of customising digital solutions to an individual, and (2) the problematic of digital health literacy — as their impacts have proven to be determinant of digital health adoption.

Customised to individuals

Previous literature outlines the importance of taking into consideration an individual's personal characteristics for optimal adoption of digital health (Hall & Murchie, 2014). Specifically, a person's information technology (IT) capabilities, demographic characteristics (e.g., age, gender), cultural beliefs, socioeconomic status (SES), and health condition and/or disability may influence the use of, and attitudes toward digital health (Rollin et al., 2018; Lupton, 2017; van Dijk & Hacker, 2003; Cheng et al., 2020), and may pose health inequalities if a digital health option is provided to individuals without considering these factors. Therefore, a patient-centred approach is required to allow the personalisation and customisation of digital health interventions (Valardo et al., 2017).

Digital health literacy

Digital health has the potential to both promote health literacy or be a barrier (Dunn & Hazzard, 2019). Health literacy relates to how people access, understand and use health information to make appropriate health decisions (Parker & Ratzan, 2012). Subsequently, digital health literacy relates to '*the ability to seek, find, understand, and appraise health information from [digital] sources and apply the knowledge gained to addressing or solving a health problem*' (Norman & Skinner, 2006). Therefore, people who are 'digitally health literate' are often more active and engaged with their health care. Given this, digital health literacy can lead to improved prevention, awareness of healthier behaviours, and overall improvement in health outcomes as it can aid with proactive clients who will better assist

clinicians and allied health with data in determining treatment and/or recovery (Sørensen et al., 2012).

Digital health options can lead to increased access for some clients to services, provide transparency of information, and improve communication between patients and HCPs (Dunn & Hazzard, 2019). However, some studies report that people with low levels of digital health literacy are less likely to use online health information and tools (e.g., apps, patient portals) (Mackert et al., 2016; Davis et al., 2015). As a result, digital health may lead to a wider healthcare gap between disadvantaged (e.g., low-socioeconomic) and advantaged communities (e.g., well-educated) (Smith & Magnani, 2019).

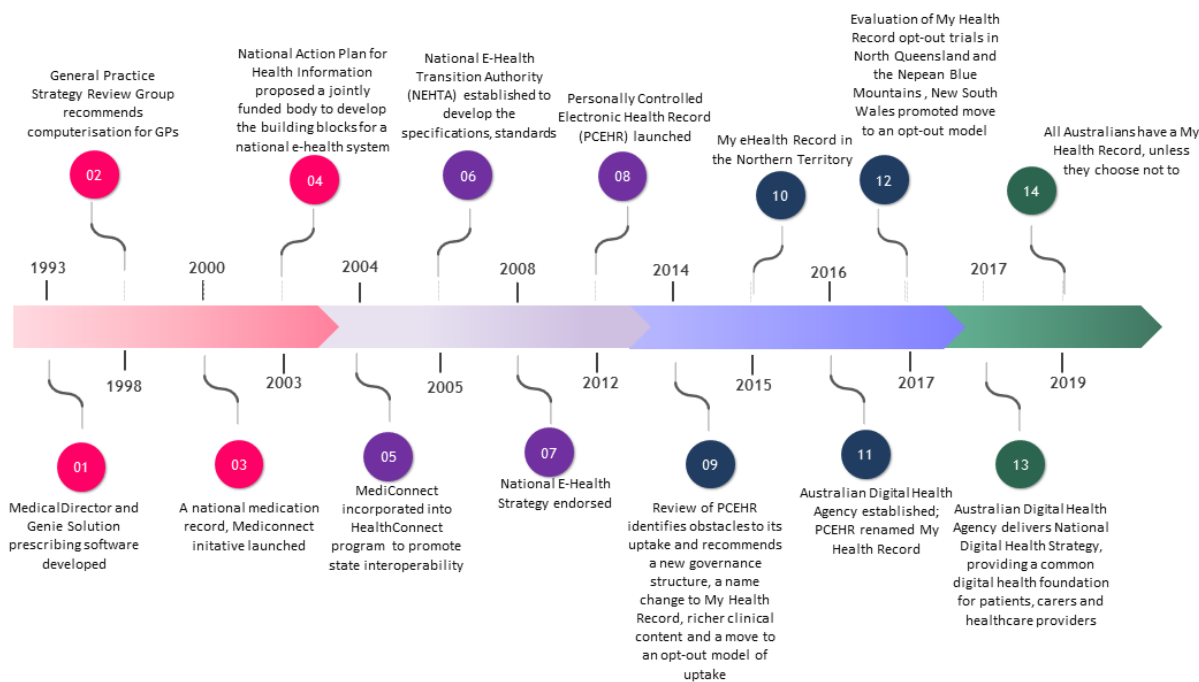
Given these existing challenges across diverse populations, research continually argues for the necessity to better understand and address individual needs and preferences for digital health to implement new strategies that would deliver optimal health to patients depending on their sociodemographics (Chu et al., 2018).

Section 3 — Digital health in Australia

Australia is one of the global leaders (ranked 6th in 2018) in digital health research, producing 4.4% of all scientific work (Gupta et al., 2018). Since 1993, the country has witnessed a digital health transformation in how healthcare is provided and patient experience (Hambleton & Aloizos, 2019). The accelerated development of the digital health industry in Australia can be explained by the country's vast distances and highly urbanised population, which increase difficulties for accessing healthcare services, workforce shortage amongst healthcare professionals, especially in rural and remote areas (Productivity commission, 2005); and the national growth of health expenditures (between 2000–01 and 2017–18, total spending on health increased from \$91 billion to \$185 billion) (AIHW, 2020a) which is exacerbated by inefficiencies and waste in healthcare provision (Schofield et al., 2019). Given this, advancements in digital health can enable the decentralisation of healthcare resulting in more available and affordable health services.

Figure 3

Australia's digital health journey



Note. adapted from Hambleton & Aloizos, 2019

Health landscape in Australia

The emergence of digital health in Australia has been driven by stretched services and the demands of its ageing population living longer with higher levels of chronic disease (47%) (ABS, 2018). Chronic disease was estimated to represent nearly 40% of the national healthcare expenditure (AIHW, 2014a). This is compounded with the difficulties of providing healthcare in a vast geographical landscape (AIHW, 2018a, 2018b, 2019a, 2019b).

Furthermore, the adoption of technology in Australia has been thought of as a solution to overcome Australians' dissatisfaction with access to care, waiting times, and cost limitations (Jolly, 2011). Uptake of technology will also better facilitate coordination between HCPs.

Australian Government National estimates (ABS, 2020) revealed that between 2019-20:

- 23% of Australians felt they waited longer than acceptable to see a specialist;
- 17% saw at least 3 HCPs for the same condition;
- 15% experienced issues related to a lack of communication between HCPs.

Similar findings were released in 2017 by the Australian Digital Health Strategy Agency evaluating patients' engagement with their health (Australian Digital Health Agency, 2017). Results illustrated that:

- 45% of Australians experienced cost, travel and waiting time limitations which impacted their access to healthcare;
- Almost four million Australians see more than three different HCPs for the same condition.

Attitudes toward digital health in Australia

As previously outlined, people's IT capabilities and willingness to use digital technologies significantly influence the adoption of digital health. Recent data shows a net majority of Australians have access to digital technologies, and many already integrate them into their health care management. The data indicated that:

- 86% of households have internet access at home (ABS, 2018);
- Almost 91% of Australians own or have access to a smartphone (Drumm et al., 2017; ABS 2018; Deloitte 2019);
- 73% of Australians seek health-related information online. Of those, 69% are aged over 65 (Research Australia 2017; ADHA 2017);
- 77% of Australians would like their doctor to suggest health websites (ADHA 2017);
- 84% of Australians go online first to seek health-related information (Carnabuci, 2020).

In addition, 2020 Medicare data shows that at the start of the COVID-19 pandemic, ten million telehealth services have been delivered to more than 3.2 million people across Australia (The Department of Health, 2020). In comparison, 2016 data reported that 75,545 telehealth services were provided to over 144,400 patients (The Department of Health, 2016). This increase in telehealth uptake well-illustrates the potential of digital health to provide safe care to Australians.

Australia's National Digital Health Strategy

In 2017, the Australian government implemented a digital health strategy for a better, more sustainable and safer healthcare system. *Australia's National Digital Health Strategy* focuses on increasing access to care delivery, and quality of care, for all Australians at a cheaper cost (Australian Digital Health Agency, 2020). However, the rapid evolution of new technologies, associated costs and required training for healthcare professionals may represent a significant barrier to adoption.

Part 3 — Digital health and its role with Melanoma

With cases of melanoma, digital health has predominantly been used to promote early detection and prevention of recurrence through the adoption of technologies like ICT, mHealth and Live Video Call (LVC) platforms. In 2019, a scoping study (unpublished) of the technologies currently available for melanoma management was completed. Results are summarised in Table 2.

Table 2*Current technologies available in melanoma care*

Technologies	Early-detection/ surveillance	Supportive care	
		Informative	Psychological
Algorithm-based tools	x		
LVC	x	x	
Mobile applications	x	x	x
Mobile teledermoscopy	x		
Online communities		x	x
Serious video games		x	
Store-and-forward systems	x	x	
Videos		x	x
Virtual Reality (VR)		x	x
Websites		x	x

Previous literature (Rollin et al., 2018) revealed that digital health for melanoma management has the potential to improve self-management, promote positive behaviour with the patient, enhance access to melanoma care, increase health literacy and communication, reduce patient and healthcare costs, as well as decrease psychological distress.

Section 1: Technologies and applications

Mobile apps

Mobile apps are the most commonly used technologies in melanoma care. It is well-established that mobile apps can increase cost-effectiveness, efficiency and convenience in melanoma surveillance (Rat et al., 2018; Ngoo et al., 2018). However, the benefits of mobile

apps to enhance supportive care, particularly informational and psychological support, are yet to be determined.

In 2020, a precursor analysis of the mobile apps currently available for melanoma patients was carried out. The objective was to identify how mobile apps were used, and what they were being used for.

Thirty applications were identified. Of those, twenty-seven aimed to promote early detection, with a majority of the twenty-seven focusing on self-monitoring, whereas only one was dedicated to supportive care for pain management.

In line with the literature (Rat et al., 2018), these findings highlight the predominant role of mobile apps in self-monitoring to promote early detection, provide patients with tools (e.g., digital skin maps, photo libraries, reminders) and knowledge (e.g., ABCDE method for evaluation). Consequently, mobile apps are often used to easily and quickly identify any changes or new lesions and timely share information with HCPs.

Despite the positive aspects, the use of mobile apps is not risk-free for melanoma patients. There is little evidence of the safety and efficacy of mobile apps, and several studies (Rat et al., 2018) report that mobile apps may lead to delays in seeking medical advice.

Telehealth

Originally, telehealth (also called teledermatology) was developed as a convenient, cost-and-time effective solution for the ageing population, lack of healthcare providers (i.e., dermatologists) (Coates SJ et al., 2015; Brinker et al., 2018; Rat et al., 2018), and unnecessary follow-up exams (Lapinsky, 2007). Telehealth technologies including store-and-forward and live-video-conferencing, have been principally used for melanoma diagnosis to provide remote access and timely information, as well as improve accuracy in diagnosis. For instance:

- **Store-and-forward systems** have allowed patients to send information (images or text) about new lesions or mole changes to clinicians for review;

- **Teleconference platforms** have been used by clinicians to receive second opinions from specialists based anywhere in the world (Osman, 2019) from “virtual colleagues” (Osman, 2019).

Web-based resources

Web-based resources, including web-based apps and websites, have been predominantly used to increase melanoma literacy and awareness. Increasingly, melanoma patients turn to health-related websites to look for complementary information (Damude et al., 2017). A 2014 study identified that 90% of melanoma patients were using the internet to seek information (Hamilton et al., 2015), compared to 39% in 2005 (Damude et al., 2017). It has been suggested that providing patients with information related to melanoma disease, prevention, treatment, and coping strategies can increase their decision-making and self-management.

A 2018 study (Alshaikh, 2018) analysed the content and quality of thirty-one melanoma websites. The findings reported that most of the websites provided the definition of melanoma (97%), mole recognition using the ABCDE method (97%), treatment options (91%) and diagnosis (87%). Information about preventive behaviour was sometimes missing (>70%) and content about risk factors varied (>80%). Nevertheless, the study reported issues with the quality of information delivered and lack of scientific evidence.

Moreover, a systematic search of the literature reported a lack of scientific evidence about web-based resources for emotional and social support in melanoma. However, research indicated that the vast quantity of information found online can sometimes create psychological distress to melanoma patients who can feel overwhelmed by the volume (Hall & Murchie, 2014).

Online communities

Online communities, such as forums and social media, can improve disease management by creating a safe space where patients can interact with clinicians and other

patients (Colera, 2013). However, only a few studies have investigated the benefits of online communities in melanoma care.

Previous literature indicates that online communities give melanoma patients an easy and costless way to obtain information, coping strategies, reassurance from peers and social support (Maganty et al., 2018). Online narratives reinforce social norms and encourage preventive behaviour (e.g., sun protection, skin self-examination) to reduce risks of recurrences or new primary melanomas (Smita, 2018; Coups et al., 2018). Facebook, for instance, is a place to read, share and react. It enables patients to engage and connect with other peers which may result in change behaviour and promote positive attitudes and practices (Coups et al., 2018).

In addition, online communities can decrease psychosocial distress, and online support groups can be used as a therapeutic solution to help patients cope with anxiety, social withdrawal and denial (Maganty et al., 2018; Banerjee et al., 2018; Hinyard & Kreuter, 2007). Further, part of the driving influence which motivates people to seek health information online is the need for reassurance and second opinions (Hall & Murchie, 2014). Data reveals that almost 20% of melanoma patients use online communities to seek social support (Banerjee et al., 2018).

Moreover, research indicates that online communities can reduce the geographical gap between clinicians and melanoma patients through increased communications (Maganty et al., 2018). For example, clinicians can use online communities to answer questions asked by patients and share educational materials more easily with a broader audience.

Online videos

Online videos and platforms such as YouTube have real potential for information sharing, and studies show that melanoma patients are more receptive to video-based content than traditional media (Damude, 2017; Idriss, 2009). Online videos have proved to be an effective, convenient and easily accessible way to raise public awareness about melanoma and reinforce patient knowledge about disease-specific information, particularly for skin self-examination.

However, no study has analysed the type of video content shared online related to melanoma to date. Given this, an unpublished analysis has been conducted to assess video content on melanoma on YouTube of the thirty most viewed videos on this topic. The findings revealed that:

- 50% of videos were sharing informational and educational content. Of those, 65% provided instructions about melanoma symptoms and mole recognition.
- 33% were testimonies of melanoma patients sharing their journey.
- 13% showed medical interventions such as mole surgery removal processes);
- 6% were public health awareness campaigns.

In addition, the use of educational videos in melanoma care has the potential to lessen emotional and psychological distress (Orringer et al., 2005). Indeed, videos demonstrating how to perform self-examination can build patient confidence and motivation to self-manage their cancer (Damude et al., 2017; Roman, 2016).

Gamification

Over the last decade, there has been some interest in measuring the benefits of gamification (Maganty et al., 2018; Idriss, 2009). Previous literature has looked at the potential therapeutic benefits of serious video games in melanoma care (Loescher et al., 2010). Key findings reveal that, like video content, game-based learning is a more effective and preferred educational tool than printed media (e.g., pamphlet, brochure, booklets, etc.).

To date, scientific evidence on the use and potential of immersive technologies like VR and AR in melanoma settings is lacking.

Section 2: Digital health in melanoma post-treatment care in Australia

A recent study (Rollin et al., 2018) about digital health in melanoma post-treatment care revealed a knowledge gap in the literature. Although the previous findings show that digital health can lead to increased access to management care and improved supportive care — using ICT, mHealth, telehealth, gamification technologies — to date, there is no scientific evidence of the specific patient-reported benefits.

Conclusion

Digital health, which refers to the use of technologies (software and hardware) to deliver value-based care, is a dynamic concept that evolves as new technologies arise. The rapid pace of change in technologies generates difficulties in measuring the benefits of digital health in mid and long-term adoption. Thus most studies are brief snapshots of technology implementation for a specific health or health systems problem at a specific point in time (Patrick et al., 2016).

Although digital health aims to improve human health and health systems, it can increase healthcare disparities between individuals (due to demographic factors, including SES differences, cultural and geographical disparities). This highlights the essential need to consider a patient's unique circumstances and characteristics to ensure optimal digital healthcare.

While it is well-established that the use of technologies can increase access to care and improve QoL for patients suffering from chronic disease, this chapter identifies a lack of empirical evidence about the potential of digital health to enhance melanoma management care in Australia in the mid-to-long term. Client-centred research is arguably one of the most valuable approaches in aiding in the iterative adoption and growth of digital health. By understanding the forms and functions of digital health, measures of use, uptake, and effectiveness on melanoma management, we can begin to map a digital health care model that is population and demographic-specific for melanoma patients.

CHAPTER 3

UNDERSTANDING MELANOMA

Overview

This chapter provides a clinical description of cutaneous melanoma management and its global burden. The first section gives an overview of melanoma clinical management, including information about diagnostics, treatments and post-treatment care. A majority of the clinical background provided is cited from the Australian *Clinical practice guidelines for the diagnosis and management of melanoma* (Cancer Council Australia, 2019).

The thesis focus is on post-treatment care. Given this, the following review refers specifically to the care and services available to patients who have been treated with melanoma. It will highlight specific gaps and needs as outlined by the literature.

The second section of this chapter provides a snapshot of the melanoma global burden. It begins with epidemiological data from around the globe, with specific reference to Australia, and refers to current data around incidence, mortality and survival rates, as well as risk factors. The economic impacts of melanoma are also discussed.

Melanoma clinical management

Cutaneous melanoma is the most common type of melanoma (95-97%) (Stretch & Varey, 2016). Cutaneous melanoma develops on the skin, on areas particularly exposed to the sun. In men, the most common sites for melanoma are the chest and back; in women, the legs are the most affected (Stanienda-Sokół et al., 2017).

There are eight types of melanoma: superficial spreading melanoma, nodular melanoma, acral-lentiginous melanoma, lentigo malignant melanoma, amelanotic and desmoplastic melanomas, ocular melanoma and metastatic melanoma.

For convenience, cutaneous melanoma, also known as melanoma of the skin, has been abbreviated to ‘melanoma’.

Melanoma diagnosis

Melanoma is diagnosed histopathologically (Schadendorf et al., 2018), with clinicians’ treatment decision-making depending on the histological classification, as well as risk calculation. If melanoma is diagnosed, a skin biopsy is used to provide an accurate assessment of depth and other histological features to determine its stage, and to allow planning of further management (e.g., surgical therapy) (Watts et al., 2020). If not diagnosed at an early-stage, melanoma can rapidly become life-threatening once it metastasizes (Brouwers et al., 2019).

Stagings and classification

Melanoma staging provides information about a patient’s risk of disease-mortality. It also enables clinicians to develop an appropriate treatment plan to deliver optimal care to a patient.

The 8th edition of the American Joint Committee on Cancer (AJCC) classification of melanoma (Gershenwald et al., 2017) is the most widely used classification. **Table 1** represents the melanoma clinical prognostic established by the 8th edition of the AJCC. The classification includes:

- Tumour thickness and ulceration (**T** stage; Breslow scale);
- Lymph node involvement (**N** stage);
- Presence of metastasis (**M** stage)

These are referred to as ‘TNM Markers’.

Tumour thickness is known to be the most crucial criterion for assessing prognosis and subsequent treatment (Breslow, 1970). In addition to standard anatomic TNM markers, the 8th edition AJCC considers nonanatomic factors, such as melanoma history and other risks, that could further increase staging.

The 8th edition of the AJCC establishes a framework for developing robust and iteratively refined clinical prognostic models, which is used to enhance clinical decision-making. Importantly, it provides accurate risk stratification and facilitates understanding the broader melanoma landscape (Gershenwald et al., 2017).

Table 3
AJCC Clinical prognostic stage groups (TNM)

When T is...		And N is...	And M is...	Then the clinical stage group is...
Tis	In-situ	N0	M0	0
T1a	<0.8mm thickness, no ulceration	N0	M0	IA
T1b	0.8–1mm thickness (<0.8mm with ulceration)	N0	M0	IB
T2a	>1-2mm thickness, no ulceration	N0	M0	IB
T2b	>1-2mm thickness with ulceration	N0	M0	IIA
T3a	>2-4mm thickness, no ulceration	N0	M0	IIA

T3b	>2-4mm thickness with ulceration	N0	M0	IIB
T4a	>4mm thickness, no ulceration	N0	M0	IIB
T4b	>4mm thickness with ulceration	N1b & N1c	M0	IIC
Any T		≥ N1*	M0	III
Any T		Any N	M1**	IV

*Note. *≥ N1 with N1a-c, N2a-c, N3a-c ** M1 with M1 a-d*

More information on lymph node classification and metastasis classification can be found here: <https://acsjournals.onlinelibrary.wiley.com/doi/full/10.3322/caac.21409>

This is an adaptation of the Pathological stage group according to the American Joint Committee on Cancer eighth edition staging manual, 2017.

Melanoma Screening

Melanoma prognosis depends on the stage of disease at diagnosis, making early detection critical (Watts et al., 2020). Timely discovery of melanoma leads to significantly reduced mortality rates (Curiel-Lewandrowski et al., 2012), as melanoma can be more effectively treated and cured with simple and inexpensive therapies in the early stages (Doran et al., 2015).

There are several different screening techniques including:

- **Whole-body skin examination** supported by dermoscopy and other imaging techniques, preferably performed by an experienced physician (Mar et al., 2018).
- **Examination with the naked eye** which assesses the so-called A (asymmetry), B (irregular borders), C (inhomogeneous colour), D (diameter ≥ 5 mm) and E

(change in size, shape, color, elevation) criteria which point to suspicious lesions (ABCDE rule) (Melanoma Institute Australia, 2021). This technique can easily be performed by patients themselves, their relatives and caregivers.

Although regular screening enables early detection of melanoma, to date there is no scientific evidence that it reduces melanoma mortality (Schadendorf et al., 2018; Stang et al., 2018; 2016). Rather, regular screening has been argued to lead to an overdiagnosis of thin melanomas, with no effect on patient survival rates (Janda et al., 2020).

Melanoma treatment

There are many treatment options available, but treatment decisions rely on prognostics. The most common treatment for early-stage (localised) melanoma, is surgery which includes simple procedures (biopsy or local excision).

In the case of more advanced melanoma, patients may require treatments such as radiation, targeted therapies, immunotherapy or chemotherapy. However, these treatments can cause side effects (e.g., pain, fatigue, depression, neurological problems, etc.), which may lead to a reduced quality of life.

Melanoma post-treatment

Patients should be provided with a treatment summary and care plan, which outlines medical follow-ups required; strategies to manage any side effects of treatment (psychological and physiological); and necessary actions for suspected recurrence. It should also include information on how to access a range of health professionals such as psychologists, nurses, social workers (Cancer Council, n.d.).

Follow-Up

Ideally, routine follow-up for melanoma patients should be conducted in a scientifically proven cost-effective manner.

The main purpose of follow-up is to detect new primary melanomas or recurrences, thus quickly resulting in early diagnosis and treatment leading to decreased mortality rates, reduced medical costs and increased quality of life (Barbour et al., 2018).

The clinical follow-up routines of melanoma patients aim to (Garbe et al., 2016):

1. Identify tumour recurrence progression at the earliest stage, as well as additional primary melanomas through history and physical examinations;
2. Identify needs and offer psychosocial support;
3. Provide education on prevention, skin self-examination for the patient and his relatives/caregivers;
4. Administer and monitor adjuvant therapy.

Guidelines for follow-up are typically only based on opinions of experts worldwide because there have been no valid randomized trials comparing different follow-up schedules and patient survival (Barbour et al., 2018). Follow-up recommendations also vary widely by country and population (Watts et al., 2015; Dummer et al., 2012; Cromwell et al., 2012).

Physicians determine the frequency and extent of follow-up schedules based on the primary tumour characteristics (melanoma staging) and patient-specific needs (Swetter et al., 2018). Generally, the first 5 years following surgery are the most important; 90% of all metastases occur during this time period (American Cancer Society, 2021). In addition, patients who have had a history of melanoma have an increased risk of a second primary melanoma, adding increased importance to regular clinical examinations. Follow-up schedules can be structured as follows:

- **Stage 0:** every 6 to 12 months for 1-2 years, annually thereafter.
- **Stages IA-IIA:** 6 to 12 months for 2-5 years, at least annually thereafter.
- **Stages IIB and higher:** 3-6 months for the first 2 years, then at least 6 for 3-5 years, and at least annually thereafter.

Self-examination

The fact that melanoma patients should be taught the importance of, and how to conduct, total skin self-examination has been well-established (Marciano et al., 2014).

Skin self-examination and mole monitoring are essential to prevent development of a new primary melanoma or recurrence. A majority of recurrences are self-detected (Francken et al., 2008). In Australia, patients detect up to 75% of recurrences, compared to other countries which can be as low as 20% (Dancey et al., 2005; Francken et al., 2008; Garbe et al., 2003). This data indicates significant differences in patients' individual ability to detect recurrences (Poo-Hwu et al., 1999). Multiple tools are available to help people conduct skin self-examinations to identify and monitor new moles, lesions, and skin changes. A comprehensive list of the technologies can be found in the '*Digital health in melanoma care*' chapter.

Supportive care services

The Australian *Optimal cancer care pathway for people with melanoma* (Cancer Council, n.d., p.5), defines supportive care as: "*an umbrella term used to refer to services, both generalist and specialist, that may be required by those affected by cancer. It addresses a wide range of needs across the continuum of care and is increasingly seen as a core component of evidence-based clinical care.*"

Supportive care helps patients and their relatives/caregivers cope with the impact of the disease, from diagnosis and treatment to cure, continuing illness, or death and bereavement (Harrison et al., 2009). Supportive care encompasses seven domains of needs: (1) physical, (2) psychological, (3) emotional, (4) social, (5) spiritual, (6) practical and (7) informational (Fitch, 2000). These needs vary across the different stages of the patient journey, but all aim to improve patients' quality of life (Moghaddam et al., 2016).

Unmet supportive care needs can lead to ineffective coping, increase psychological distress and reduce quality of life (Okediji et al., 2017). Furthermore, patients with unmet supportive care needs may delay seeking medical advice, leading to a worsening physical condition and associated increases in medical costs, as well as poorer survival rates and reduced

quality of life (Loquai et al., 2013; Sanson-Fisher et al., 2000). In melanoma, unmet needs generally occur in the informational domain, followed by psychological and social domains (Fu et al., 2020).

Informational support

Melanoma-specific information includes facts and recommendations about diagnosis, treatment and survival rates, disease evolution, recurrence, risk factors and prevention, skin self-examination, the disease's impact on life, psychological and social support, and where to seek help (Cancer Council, n.d.).

Information tailored to patients' needs can reduce anxiety, improve compliance with therapy, and increase the feeling of personal control, thereby improving coping with the disease itself and quality of life (Husson et al., 2013; Lamers et al., 2016; McInnes et al., 2008).

Over the past four decades, development of educational materials has improved melanoma awareness and prevention. Indeed, campaigns in Australia such as the 1980s '*Slip-Slop-Slap*' (Cancer Council, 1981) enabled today's population to be better informed about how to identify and prevent melanoma than populations of the past (Montague et al., 2001).

Furthermore, many studies report patient education as one of the strongest predictors of implementation of appropriate and thorough skin self-examination (McLoone et al., 2013; Kasparian et al., 2010).

Psychosocial support

Australian estimates indicate that 30% of melanoma patients have unmet psychological needs (Cassileth et al., 1983; Kneier et al., 2003) associated with numerous debilitating physical and psychological effects for patients and burden on caregivers (Cheung et al., 2018). Both disease- or treatment-related effects may include reduced general health status and quality of life, pain, insomnia, loss of appetite, fatigue, psychological distress, poor work productivity and financial hardship as well as relationship and family stress. Psychological distress

encompasses fear of cancer recurrence, depression, anxiety, treatment-related morbidity, concerns related to conducting skin self-examination, reduced self-esteem, and impaired cognitive and social functioning. Moreover, patients treated with immunotherapy may experience other immune-specific adverse events such as arthralgia and inflammation of major organs and systems (Bayer et al., 2017).

Global research shows a crucial need to focus on helping cancer survivors, including melanoma patients, cope with life beyond their treatment (Oliveria et al., 2013). However, psychological aspects of melanoma are often overlooked by physicians (Fischbeck et al., 2015). Since 1994 scientific evidence has emerged that melanoma patients require more psychosocial support than they're currently receiving and are dissatisfied with their psychological care (Brandberg et al., 1994; Bonevski et al., 2000; McInnes et al., 2008; Oerlemans et al., 2012; Mitchell et al., 2014; Fischbeck et al., 2015).

Fear of melanoma recurrence is one of the most prevalent psychological distresses reported by patients (Costa et al., 2016; Thewes et al., 2012; Kasparian et al., 2009; Gibertini et al., 1992; Zabora et al., 2001). It is often associated with other psychological side-effects related to melanoma, impaired social and emotional functions (Dieng et al., 2018), and is also associated with lower quality of life (Simard et al., 2013). A recent study investigated sensitivity of preference-based quality of life measures for economic evaluations in early-stage melanoma in Australia (Dieng et al., 2018). Findings indicated that the loss of utility attributable to fear of cancer recurrence is an important issue, outlining a need for interventions to reduce fear of cancer recurrence.

It is well-established that emotional and social support are key components of care (Kasparian et al., 2009), with psychological intervention associated with superior survival and recurrence rates (Kasparian, 2013), and decreased psychological burden in people with melanoma. (Awzy et al., 1993). Nevertheless, psychological needs in melanoma are often overlooked, with research suggesting that clinical guidelines should include psychosocial and psycho-educational interventions for patients.

To date, there is no strong evidence that psycho-educational and psychological interventions are cost-effective for melanoma patients. Given this, there is an important need to evaluate the economic impacts of psychological interventions in melanoma, just as they have been evaluated for other types of cancer. A 2016 systematic review identified only eight economic evaluations of psychological interventions in cancer. Of those, only one focused on melanoma (Dieng et al., 2016). A more recent study (2018) (Dieng et al., 2019), reported that psycho-educational interventions have the capacity to reduce fear of cancer recurrence and provide cost-effective returns for both patients and the healthcare system.

Melanoma guidelines

The purpose of evidence-based clinical guidelines is to achieve early diagnosis whenever possible, inform on the most effective treatment options, therefore minimise the financial burden on the health system (Cancer Council Australia, 2019). Clinical guidelines have been developed worldwide to provide physicians with guidance and recommendations on the most optimal patient care pathway and to ensure the provision of standardised and sustainable models of care (Cochrane et al., 2010; Institute of Medicine (US) Committee on Standards for Developing Trustworthy Clinical Practice Guidelines et al., 2011).

Melanoma guidelines typically cover processes and timeframes for melanoma diagnosis and management, including biopsy and staging information, treatment options, and follow-up schedule recommendations. Guidance on the provision of melanoma supportive care (e.g., educational and psychological interventions) is sometimes overlooked.

The management of melanoma is, therefore, subject to country-specific healthcare systems and policies. A thorough search found nine guidelines (Steeb et al., 2020) published between 2015 and 2021 in Australia, France, Germany, Scotland, Spain, the United Kingdom and the United States. **Table 4** shows the content covered in the identified guidelines.

Table 4

International guidelines for melanoma management (2017-2019)

Guidelines Title	Year	Authors
<i>Guidelines of care for the management of primary cutaneous melanoma</i>	2019	Swetter et al. (USA)
<i>Clinical practice guidelines for the diagnosis and management of melanoma</i>	2019	Cancer Council Australia (Australia)
<i>Diagnostik, Therapie und Nachsorge des Melanoms</i>	2019	AWMF, DKG & DKH (Germany)
<i>Cutaneous melanoma</i>	2017	Scottish Intercollegiate Guidelines Network: SIGN (Scotland)
<i>SEOM clinical guideline for the management of malignant melanoma</i>	2017	Berrocal et al. (Spain)
<i>French updated recommendations in Stage I to III melanoma treatment and management</i>	2017	Guillot et al. (France)
<i>Diagnosis and treatment of melanoma. European consensus-based interdisciplinary guideline – Update 2016</i>	2016	Garbe et al. (Europe)
<i>Cutaneous melanoma: ESMO Clinical Practice Guidelines for diagnosis, treatment and follow-up</i>	2015	ESMO (International)
<i>Melanoma: assessment and management</i>	2015	National Institute for Health and Care Excellence: NICE (UK)

The global burden of melanoma

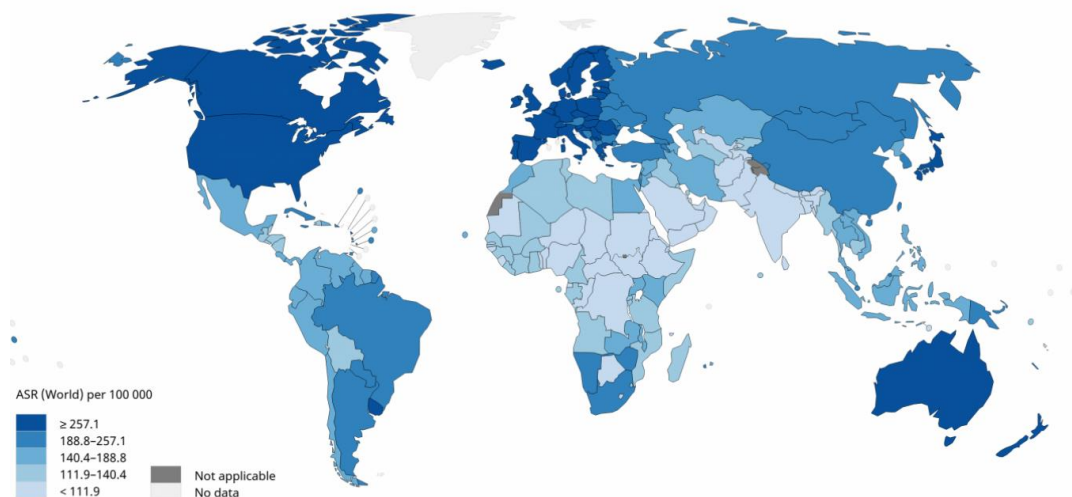
Incidence, mortality and survival

Worldwide

Melanoma ranks among the 20 most commonly diagnosed cancer entities globally (Steeb et al., 2020). The incidence of primary melanoma continues to increase steadily each year (Institute of Medicine, 2011; Wróbel et al., 2019). Worldwide, 324,635 (1.7%) of all newly diagnosed cancers (excluding non-melanoma skin cancer) are cases of melanoma, and 57,043 cancer deaths are due to melanoma annually (Globocan, 2020). In 2015, the worldwide average age-standardised incidence rate (ASR) for melanoma was 5 cases for 100,000. The incidence rate of melanoma significantly varies between countries, and higher incidence rates are usually reported in high-income/developed countries (Globocan, 2020). Countries with a very high human development index (HDI) reported an ASR incidence rate at 10.2 versus 0.76 for countries with low HDI. However, the mortality-incidence ratio (MIR) is higher in low HDI countries (MIR low HDI $\approx 0,67 >$ MIR very high HDI $\approx 0,17$) (Globocan,2020). Figure 4 represents the worldwide ASR incidence rate of cutaneous melanoma in both men and women in 2020.

Figure 4

Estimated age-standardised worldwide incidence rate of cutaneous melanoma in both men and women in 2020



Note. WHO, International Research on Cancer, 2020

Datasource: GLOBOCAN 2020

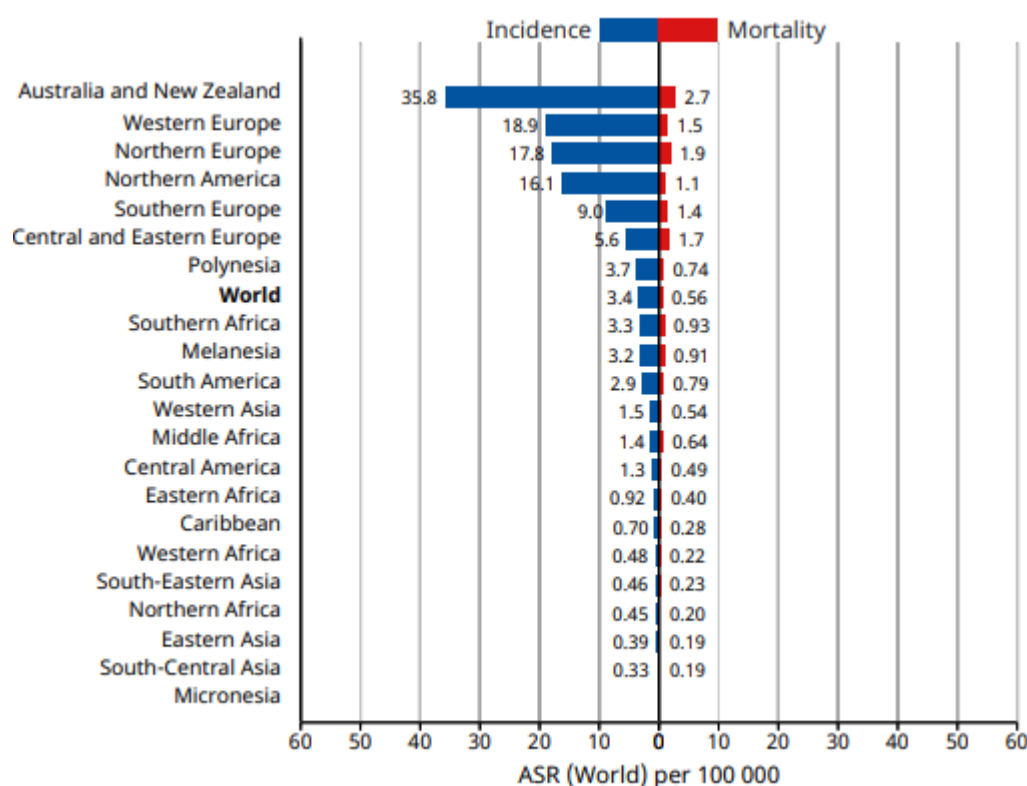
The global melanoma incidence rate increased by 39% (95% CI, 33%-43%) between 2006 and 2016. Of the 39% increase, 15% was due to a variation in the population age structure, 12% was because of population growth, and 11% was triggered by a change in age-specific incidence rates (Global Burden of Disease Collaborative Collaboration, 2018).

Age-cohort period analysis (1982 - 2011) of melanoma incidence in Australia, New Zealand, Norway, Sweden, the United-Kingdom (UK), and the white population of the United States (US) revealed that incidence increased about 3% annually and will further increase until at least 2022 in Norway, Sweden, the UK and US. Conversely, since 2005, the melanoma incidence rate has been decreasing in Australia by -.07% per year, and New Zealand is projected to decline in the next few years (by 2023) (Whiteman et al., 2016).

Melanoma mortality rates, as with incidence, differ widely by country, and trends are influenced by geography, ethnicity, age, and sex. Graph 1 represents the worldwide ASR incidence and mortality rates of cutaneous melanoma in both sexes in 2020.

Graph 1

Estimated ASR worldwide incidence and mortality of cutaneous melanoma in men and women in 2020



Note. WHO, International Research on Cancer, 2020

Datasource: GLOBOCAN 2020

The 5-year relative survival from melanoma can be influenced by many factors such as demographics (e.g., age and gender), tumour type, cancer stages at diagnosis, treatment availability (Crocetti et al., 2015), and varies across ethnicity and countries.

Australia

Australia remains a country with one of the highest levels of melanoma, with an incidence rate ten times that global level (Karimkhani et al., 2017). The prevalence of melanoma in Australia is due to high levels of ambient ultraviolet (UV) radiation, a cultural

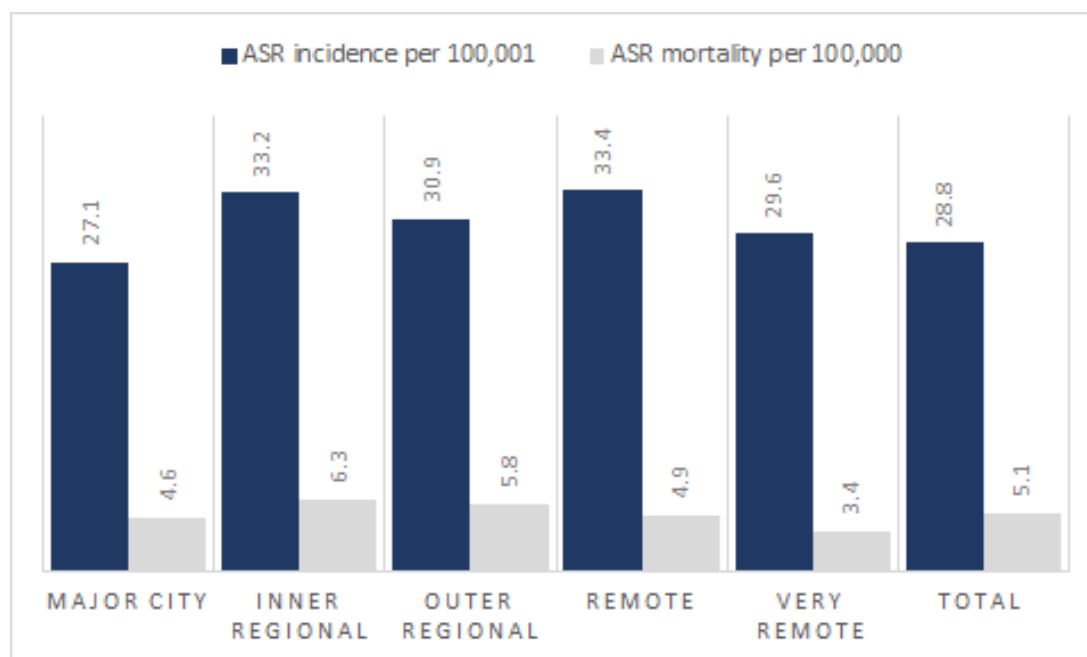
emphasis on outdoor activities and tanning (Olsen et al., 2016; Sneyd et al., 2013, Fabbrocini et al., 2010).

Melanoma is the fourth most commonly diagnosed cancer in Australia [5]. Projected data indicates that in 2020, there will be 16,221 new cases of melanoma and 1,375 deaths. In 2020, 1 in 13 men and 1 in 21 women was expected to be diagnosed with melanoma. Melanoma is also the most common cancer among young Australians between 15-39 years old, making up 20% of all cancer cases in this age group. Although melanoma represents only 2% of all skin cancers, it often leads to premature death and is responsible for most skin cancer deaths (AIHW, 2015; 2017).

The Australian Institute of Health and Welfare (AIHW) reported that the incidence of new cases of melanoma was significantly higher in regional areas than in major cities (AIHW, 2013). The median ASR incidence for nonindigenous Australians with CM is 32 per 100,000 across regional, rural and remote areas and 27 per 100,000 in major cities. In comparison, the median worldwide ARS mortality for CM is 5.4 per 100,000 across regional, rural and remote areas and 4.6 per 100,000 in major cities (Graph 2).

Graph 2

Age-standardised incidence and mortality rates of cutaneous melanoma by remoteness status



Note. Adapted from (AIHW, 2013).

This disparity has been explained by the difficulties experienced by rural people in accessing skin cancer diagnosis, as their detections (especially among men) are likely to be later, by which time their condition is likely to be exacerbated (Coory et al., 2006). Moreover, other geographical aspects such as access to health services, clinical practices, and medical care management need to be considered to fully evaluate survival rates, especially after an initial diagnosis and treatment for CM (Coory et al., 2006).

Risk factors

Risk factors for melanoma include ultraviolet radiation by sun exposure and subsequent sunburns, bed tanning, personal and family history of cutaneous melanoma, phenotypic characteristics (e.g. fair hair, eye and skin colour), gene mutation, and high socioeconomic status (Jiang et al., 2015). Generally, individuals are considered at very high risk of primary

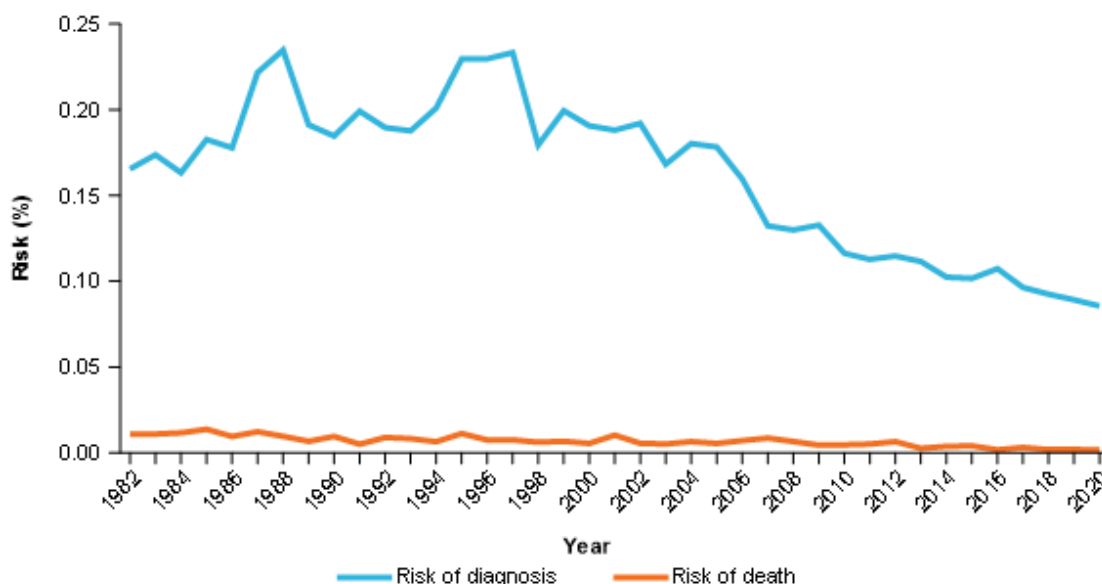
melanoma if they carry a genetic mutation that predisposes them to melanoma, have previously been diagnosed with melanoma or have a strong family history (Marsden et al., 2010).

Recent estimates also revealed that elderly and male populations accounted for the greatest burden from melanoma (Karimkhani et al., 2017).

An Australian commentary (2020) about risk of melanoma by age and time (AIHW, 2021) explained the declining risk for younger populations with increased education and awareness over time. As a result, older people lived most of their lives in a less ‘sun smart’ environment within the general population. Given this, estimates show that in 2020 the risk of being diagnosed with melanoma had decreased by half since 1997 (Figure 5).

Figure 5

Melanoma incidence and mortality risk by the age of 30 per person (1882 - 2020)



Note. Incidence risk for 2017–2020 and mortality risk for 2019 – 2020 are based on projections. Datasource: AIHW Australian Cancer Database 2016 and National Mortality Database

Melanoma incidence rates are about 60% higher in men than in women, while death rates are more than double for males (Siegel et al., 2017). Behavioural and biological factors have explained this gender disparity. Generally, men tend to have worse sun protection behaviours and reduced skin screening (Pettigrew et al., 2016), therefore have the largest disparity for mortality, which has been observed in both Europe and Australia (Siegel et al., 2017). This group reflects older ages, as well as a later stage at diagnosis and more unfavourable prognostic indicators in men than women.

As such, better predict and reduce late diagnosis, risk prediction models and risk stratification tools have been developed to identify individuals at risk of melanoma (Usher-Smith et al., 2014).

Economic impacts of melanoma

In addition to being a public health issue, melanoma has an economic impact on individuals and communities. The cost of melanoma care is increasing due to the rising incidence and mortality rates and the cost of melanoma therapies (Buja et al., 2018). Hence, the approval of new therapies raises questions about whether global healthcare systems still have the funding capacity to account for these increases in costs (PBS, 2016). Therefore, estimated the economic burden of this disease is essential to enable policymakers to allocate appropriate resources.

Medical costs

Health economic studies on melanoma indicate that cost-saving theoretically results from averting one case of melanoma, demonstrating the monetary value of educational campaigns and early detection.

To assess the economic burden of melanoma, methods included: (1) the evaluation of melanoma-related direct costs and (2) the measurement of melanoma-related indirect costs (Buja et al., 2018). Indirect costs include productivity losses associated with morbidity and

premature death, while direct costs relate to management of the disease, including diagnosis, treatment and follow-up cost (Rollin et al., 2018).

A recent study assessed the patient direct cost for melanoma care for all disease management phases (including diagnosis, medical therapy, surgical therapy, 1-year follow-up care, supportive care and relapse) and illness staging in Italy (Buja et al., 2018). The disparity in expenditure between in-situ melanoma and stage 4 is significant, ranging from EUR 149 to EUR 66,950. The cost relating to each management phase varied considerably per disease stage. The dramatic difference in cost between stages shows that early detection has the potential to reduce melanoma-related expenses while reducing the need for treatment. Similar findings have been reported in other studies (Doran et al., 2015; Elliott et al., 2017).

Melanoma treatment represents a significant cost for the Australian Healthcare System. National estimates indicate that health system costs increased from approximately AUD 30 million in 2001 (8885 new cases) to AUD 201 million in 2017 (~13,000 new cases). Overall, melanoma treatment was estimated at AUD 10,716 (95% CI: AUD 9,953 to AUD 11,516) per patient (Elliott et al., 2017), although treatment costs for advanced melanoma may be 21% to 70% more expensive compared to early stages (in situ, stage I and II). Also, in 2014 AUD 9.4 million was claimed through Medicare for melanoma-related services (AIHW, 2016).

Another study compared the lifetime direct and indirect costs of 150,000 cases of melanoma and non-melanoma skin cancer (NMSC), in New South Wales. The direct costs related to management of the disease including diagnosis and treatment to follow-up, and indirect costs included productivity losses associated with morbidity and premature mortality. In 2001, estimates of lifetime costs were AUD 44,796 for melanoma and AUD 2459 for NMSC. Direct cost accounted for 72% of costs (AUD 10,230 for melanoma and AUD 2336 for NMSC), and indirect costs accounted for 28% of total cost per year (AUD 34,567 for melanoma and AUD 123 for NMSC) (Doran et al., 2015).

To describe the impact of the disease on populations beyond the traditional epidemiological measures of incidence and mortality rates, further metrics need to be considered (Karimkhani et al., 2017). One health economics method evaluates disability-

adjusted life years (DALYs), which combine both morbidity and mortality metrics (GBD 2015 Disease and Injury Incidence and Prevalence Collaborators, 2016). This method captures the adverse health effects for melanoma patients, preventing them from living in full health, including health effects related to diagnosis, treatment, follow-up, and disease progression (Bell & Cust, 2018). The authors suggest that by identifying populations with the highest melanoma burden and investigating policy and practice interventions that are likely to be the most effective, we may start to lessen the melanoma burden (Bell & Cust, 2018). In 2016, Australian DALYs was 136.8 (ASR) for both sexes compared to 21.8 (ASR) globally (GBD, 2016).

Summary

In Summary, melanoma counts amongst the most prevalent cancers globally and in Australia. Melanoma's epidemiological threat and economic burden widely vary across countries and ethnicities. Global research has found that early detection can mitigate risk of melanoma. Data also revealed that on average 75% of new or recurrent melanomas are detected by patients themselves, highlighting the need to arm patients with adequate knowledge and support. After reviewing the literature on melanoma patients' needs and access to post-treatment care, several studies showcased that melanoma patients did not receive the support they needed. As a result, patients were reported worsening physical and emotional conditions, resulting in increases in medical costs, as well as poorer survival rates and reduced quality of life.

The gaps identified in the literature give rise to an opportunity for digital health to reduce the individual and societal burden of melanoma in Australia. Further research is needed to evaluate factors influencing the implementation, use and adoption of digital health in this specific setting. Of importance, the following considerations are: (1) the rapid evolution of melanoma treatment, which includes the use of technology and the increase of early detection, may supersede the previous findings (Buja et al., 2018); (2) melanoma-related costs change significantly per country (Krensel et al., 2018). Given this, it is essential to take into

consideration these factors as key variables when looking at cost-effectiveness of digital health technologies.

CHAPTER 4

PUBLISHED SYSTEMATIC REVIEW: DIGITAL HEALTH IN MELANOMA POST- TREATMENT CARE IN RURAL AND REMOTE AUSTRALIA

Review of Use of Digital Health in Melanoma Post-Treatment Care for Rural and Remote Communities

Abstract

Background: The melanoma incidence and mortality rates in rural and remote communities are exponentially higher than in urban areas. Digital health could be used to close the urban/rural gap for melanoma and improve access to post-treatment and support care services.

Objective: To understand how digital health is currently used for melanoma post-treatment care and determine its benefits for Australian rural and remote areas.

Methods: A systematic search of PubMed, Medline, Google Scholar, Scopus was conducted in March 2018. Findings were clustered per type of intervention and related-direct outcomes.

Results: Five studies met the inclusion criteria, but none of them investigated the benefits of digital health for melanoma post-treatment care in rural and remote areas of Australia. A number of empirical studies demonstrated consumers' acceptance toward digital intervention for post-treatment care. Findings did not take into consideration individual, psychological and socioeconomic factors, even though studies show their significant impacts on melanoma quality of aftercare.

Conclusions: Digital interventions may to be used as an adjunct service by clinicians during melanoma post-treatment care, especially in regions that are lower-resourced by practitioners and health infrastructure, such as rural and remote Australia. Technology could be used to

reduce the disparity in melanoma incidence, mortality rates and accessibility to post-treatment care management between urban and rural/remote populations.

Keywords: Digital health; eHealth; Technology; Melanoma; Post-treatment care; Support care services; Rural areas; Remote communities; Patient centric; Oncology

Introduction

Australia remains a country with one of the highest levels of melanoma. In 2015, the worldwide average age-standardised incidence rate (ASR) for melanoma was 5 cases for 100,000, however the rates for Australia and New Zealand are over ten times that level (Table 1) (Karimkhani et., 2015). Melanoma treatment represents a significant cost for the Australian Healthcare System that has increased dramatically in the past two decades, from approximately AU\$30 million in 2001 to AU\$201 million in 2017 (Sneyd et al., 2013).

Table 1. Worldwide ranking: average age-standardised incidence rate for melanoma

Rank	Country	Age-standardised incidence rate for melanoma
1	New-Zealand	54/100,000 (95% CI 39–73)
2	Australia	54/100,000 (95% CI 41–78)
3	Norway	26/100,000 (95% CI 18–32)
4	Sweden	26/100,000 (95% CI 20–35)
5	The Netherlands	25/100,000 (95% CI 17–30)

Cutaneous melanoma (CM) is the fourth most commonly diagnosed cancer in Australia (Fabbrocini et al., 2010) and the most common cancer among young Australians (15-39 years old). Although Melanoma represents only 2% of all skin cancers (Elliott et al., 2017), it often leads to premature death (Elliott et al., 2017) and is responsible for a majority of skin cancer

deaths (AIHW, 2017a). Compared to metropolitan populations, Australia's rural and remote communities experience inequities in access to care (AIHW, 2017b), leading to a higher incidence and mortality within 5 years. The median incidence ASR for Non-Indigenous Australians with CM is 32 per 100,000 across rural and remote areas and 27 per 100,000 in major cities. In comparison, the median worldwide ARS mortality for CM is 5.4 per 100,000 across rural and remote areas and 4.6 per 100,000 in major cities (AIHW, 2015).

Melanoma treatment plans depend on (a) prognostic factors which are largely defined by the American Joint Committee on Cancer (AJCC) staging system (Thomas et al., 2015), and (b) individual characteristics which will allow the clinicians to determine the type of Melanoma and the risk for recurrences. For example, patients previously treated for primary CM are at higher risk of recurrences and developing new primary melanomas and skin lesions (AIHW, 2013). However, early-detection can reduce mortality rates, as melanoma can be more effectively cured with simple and cheap treatments in the early stages (Jershenwald et al., 2018). In 1996, Berwick and colleagues reported that Total Self Skin-Examination (TSSE) may decrease melanoma mortality by 63% (Marsden et al., 2010) and a 2003 study found that regular Self Skin-Examination (SSE) could significantly reduce the likelihood of a tumour >1 mm thick at diagnosis (Buja et al., 2018). It has been suggested that early detection is one factor influencing the disparity between urban-rural survival rates, but other aspects such as access to health services, clinical practices and medical care management need to be taken into consideration to fully evaluate survival rates, especially after an initial diagnosis and treatment for CM (Berwick et al., 1996).

In 2017, the Australian Institute of Health and Welfare estimated that 14,000 new melanoma cases would be diagnosed. However, there are only 775 registered dermatologists in Australia (only 260 of which are melanoma specialists), and very few of them are easily accessible to people living in rural and remote areas (Australian College of Dermatologists, 2017). There are several infrastructure, cost and access limitations which impact on the provision of health services for people. This is further compounded by the lack of training for future dermatologists and GPs in remote areas.

It has been suggested that technology-based training and telehealth could help combat this disparity by bringing health services to rural and remote areas (Carli et al., 2003). A number of studies have evaluated the benefits of e-health and the level of acceptance for digital intervention in the early-detection of cutaneous melanoma (Coory et al, 2006; DoH, 2017; Fabbrocini et al, 2011). Benefits of telemedicine and tele-dermatology include increased access to healthcare services, reduced travel and waiting times and cost-effectiveness (DoH, 2017). A 2006 study reported that patients prefer telemedicine if it can provide quicker access to their physicians. However, a qualitative review found that patients' attitude toward technology is only positive if the tool is personalised and adapted to the recipients' needs and characteristics (Coory et al., 2006). In addition, available evidence suggests that telemedicine is not only beneficial for patients, but for Healthcare professionals (HCP) too. A prior study reported that General Practitioners (GPs) appreciate using tele-dermatology when they need to refer to dermatologists' expertise in order to obtain a second opinion (Hall et al., 2014).

In order to structure post-treatment plans, physicians must refer to the Clinician Guidelines. A recent study showed that clinicians working with rural populations are less likely to properly apply guidelines when it comes to educating patients towards surveillance and supportive care (Loiselle et al., 2013). For example, patients living in rural areas were less likely to be provided with patient education material (86% compared to 89% in urban areas) or encouraged to conduct SSE (86% compared to 81%). There are also concerns that oral educational information provided by clinicians may not be effective, with a recent study finding that only 5% of melanoma patients were able to correctly reproduce all four key characteristics of their tumour (Murchie et al, 2015). These results suggest a need for better quality and greater consistency in providing information to patients.

An area of post-treatment care that is often neglected across all populations is psychosocial support. Psychological distress, including worry, anxiety and fear for disease recurrences and death, are common for survivors (Qureshi et al., 2006; Al-Qirim, 2003). However, only 1% of specialists suggested patients see a psychologist as part of their post-treatment plan, despite an entire chapter of the clinician guidelines being devoted to psychosocial issues related to melanoma.

Although reviews have evaluated the effectiveness of technology for melanoma early detection, no studies have directly highlighted the benefits of e-health on melanoma post-treatment care for rural communities. Qualitatively researchers have examined the different forms of treatment and care between rural and urban populations (Read et al, 2018) and the care needs among rural cancer patients (Damude et al., 2017). However, these studies did not focus on melanoma post-treatment care.

It is unclear from the published literature the level and utility of technology support available to patients with melanoma living in remote areas. The primary aim this systematic review was to examine how technology is currently used and accepted by physicians and patients with melanoma, and to determine if there has been any implementation of such systems in rural and remote areas of Australia. With this focus, the researchers seek to identify areas of weakness and bring to light hypotheses on how technology could be used as an adjunct service during post-treatment care of CM, to aid physicians in designing follow-up care plans for patients with CM based on their needs and personal characteristics.

Methods

Databases and Search strategy

The overall aim of this systematic review was to investigate digital health acceptance and its current use among people treated for melanoma. Our primary aim was to better understand digital health benefits among rural and remote populations for CM. However, given the impact of CM across all of Australia's population, literature around digital health and CM that impacted urban and regional areas was incorporated as well. This was done to ensure broad inclusion of digital health practice for CM post-treatment care. The databases selected were searched using keyword combinations related to digital health and melanoma post-treatment care as outlined in Table 2. For the current systematic literature review, four databases (PubMed, Medline, PsycInfo, Scopus) were searched in March 2018.

Table 2. Databases search strategy

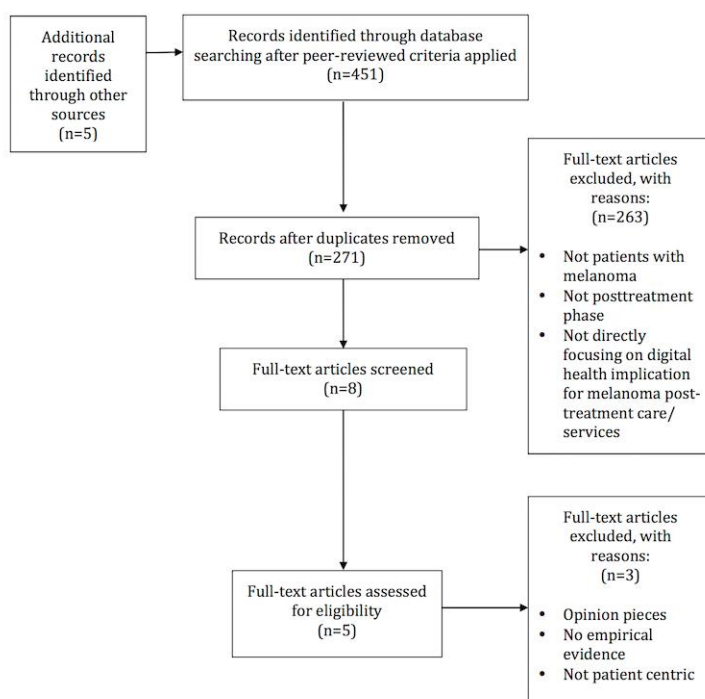
	Keywords combination
1	(telehealth OR telemedicine OR teledermatology OR "online services" OR ehealth OR e-health OR eHealth) AND (Melanoma)

Study selection

The search was limited to peer-reviewed papers. Search results identified 451 papers which were exported in a excel document. After duplicates were removed 271 articles remained.

The search strategy involved two screening phases. Each article was screened based on exclusion criteria to remove irrelevant articles from the initial selection of 271 articles. For the second phase, only studies that were based on empirical evidence and used a patient-centric approach were retained for the final systematic literature review. Figure 1 presents the selection overview based on the PRISMA flowchart.

Figure 1. PRISMA flowchart of the systematic literature review



Data extraction

Data was extracted from the relevant papers using the following classification: (1) Sources (country, year of study intervention), (2) participant characteristics (gender, residential area, mean ages, patient illness conditions, level of education, socioeconomic background), (3) study design, (4) study intervention, and (5) research focus (Multimedia Appendix 1).

Results

Origin

Two of the studies were from Scotland, with the others from The Netherlands, Canada and US. All studies were from before 2015 except for the study from The Netherlands, which was from 2016.

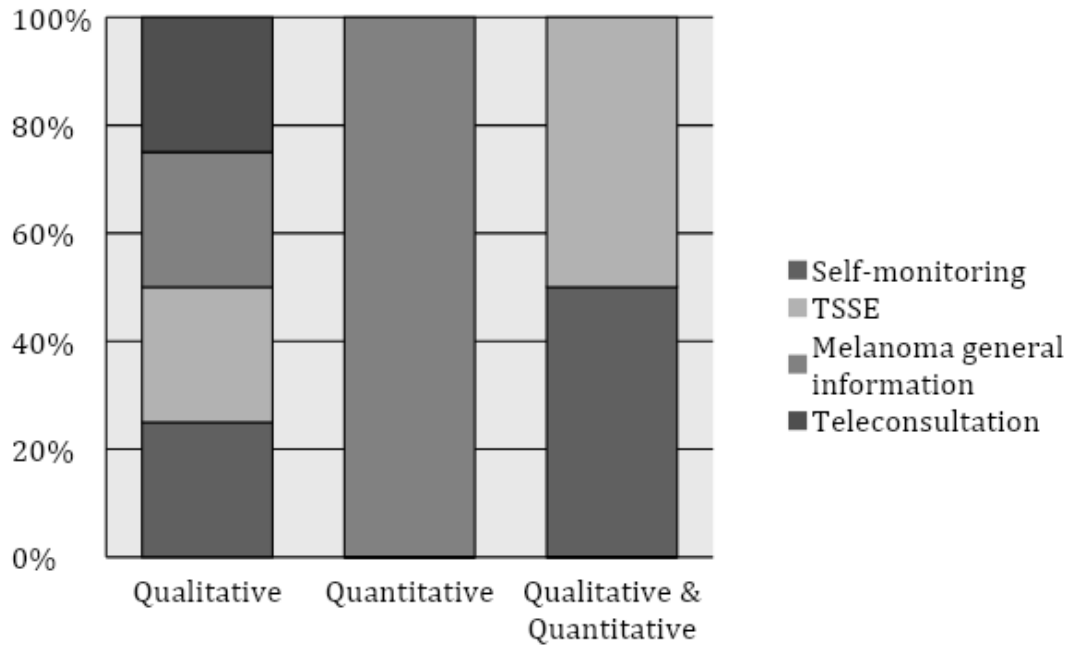
Participant characteristics

Four of the studies consisted of patients with melanoma only. The remaining study recruited patients with a history of melanoma and psoriasis, or collateral cancer. A majority of the authors referred to the patient's illness condition in their sample description. The gender distribution of studies was mostly homogeneous (47% to 60% of males) and the mean age range was 53 to 66 years of age. None of the studies used 'residential area' as an independent variable. Two studies used residential area as a patient characteristic, but did not mention it in their findings. Two studies reported socioeconomic criteria in their findings and three featured level of education.

Study design and intervention

Before investigation, all published research informed participants of the objectives of the studies. Three of the five studies were qualitative and used semi-structured interviews either face-to-face or over the phone. The interviews were recorded by the researchers, transcribed verbatim, coded and reviewed by one or several co-researchers in order to cluster by themes/concepts of the participants' answers. The quantitative studies assessed the perception and preferences of dermatology patients about the use of technology for self-monitoring and TSSE (Coory et al., 2006), a web-based platform (OIN™) to deliver information about melanoma (DoH, 2017), and store-and-forward teleconsultation (Kasparian, 2013). The latter used a Willing-To-Pay (WTP) approach in order to investigate dermatology patients' preferences. One study used both qualitative and quantitative methods to assess the feasibility and acceptability of a digital intervention for self-monitoring and the participants' attitude to perform TSSE. Another quantitative study used an online questionnaire in order to capture participants' knowledge of melanoma and TSSE, and their preferences. Figure 2 displays the study design distribution with regards to the research main focus areas.

Figure 2. Distribution of the papers according to the study design and the main focus area



Research focus areas

Table 2: Direct outcomes on post-treatment care per type of intervention

Direct Outcomes for:	Type of Intervention
TSSE – Positive findings	
Provides reassurance to patients (Coory et al., 2006)	Report sent by phone to clinicians including photographs; Self-monitoring supportive tools
Convenient: Avoids in-person clinical visit if not necessary (Coory et al., 2006)	Report sent by phone to clinicians including photographs;
Reduces the number of people who might forget about TSSE (Coory et al., 2006)	Reminder sent by text message or email

Promotes early detection (Coory et al., 2006)	Report sent by phone to clinicians including photographs
Behaviour change: empowers patients' confidence to perform TSSE (Fabbrocini et al., 2011; Kasparian, 2013)	Self-monitoring supportive tools; YouTube videos explaining how to perform TSSE
Reinforces TSSE (Fabbrocini et al., 2011)	Self-monitoring supportive tools
TSSE - Negative findings	
HCPs based their opinion on pictures only (Coory et al., 2006)	Clinicians' feedback sent by text message or email
TELECONSULTATION – Positive findings	
Convenient: - Reduces travel and saves time (Coory et al., 2006; Fabbrocini et al., 2011) - Quick access to Clinicians (Coory et al., 2006; Kasparian, 2013)	Skype or teleconference, store-and-forward telemedicine
TELE-CONSULTATION - Negative findings	
Patients' desire to discuss F-2-F with clinicians (Coory et al., 2006)	Skype or teleconference
Patients' skin required to be examined by clinicians (Coory et al., 2006)	Phone
CLINICIANS' SUPPORT AND COORDINATION – Positive findings	
Accuracy in the diagnosis (Coory et al., 2006)	Three-way consultation via a video or Skype link from the GPs' room
Convenient: Time and travel saved (Coory et al., 2006)	Remote point of contact: nurse specialist' opinion to be provided via store-and-forward system

CLINICIANS' SUPPORT AND COORDINATION – Negative findings	
N/A	N/A
INFORMATIVE AND SUPPORTIVE DISPLAYS – Positive findings	
Promotes early detection (Coory et al., 2006; DoH, 2017)	Web-based app tailored information delivered about their own conditions; Skin map
Reduces patients' stress (DoH, 2017)	Web-based app tailored information delivered about their own conditions; Skin map
Improves patients' decision-making in treatment (DoH, 2017)	Web-based app tailored information delivered about their own conditions
Ease of communication: - Content is more adapted to the patients' level of understanding (DoH, 2017) - Supporting oral/written information delivered to the patients (Murchie et al., 2015)	Web-based app tailored information delivered about their own conditions; YouTube videos explaining how to perform TSSE
Reduce/control the content load (Coory et al., 2006; DoH, 2017)	Web-based app tailored information delivered about their own conditions
INFORMATIVE AND SUPPORTIVE DISPLAYS – Negative findings	
Don't want to be associated with other patients. Makes them feel sicker than they are (Coory et al., 2006)	Online peer support (i.e. Forum, group chat)
Do not replace the oral and written information provided by clinicians (Murchie et al., 2015)	YouTube videos explaining how to perform TSSE

Discussion

Principal Results

The primary aim of this review was to identify the different use of digital health for melanoma post-treatment care, including its benefits and weaknesses. Patients perceived digital health as an added value to their post-treatment care (Coory et al., 2006, DoH, 2017, Fabbrocini et al., 2011, Murchie et al., 2015, Kasparian, 2013). However, a majority of the studies reported the benefits of digital interventions to prevent recurrence and promote early detection [Coory et al., 2006, DoH, 2017, Murchie et al., 2015]. None of the selected studies investigated the benefits of digital health for melanoma post-treatment care in rural and remote areas. This gap in the digital health literature gives thought to a very specific niche in telemedicine that needs to be explored further, given this is an at-risk population (Fabbrocini et al., 2010). Thus, it is crucial to understand how digital health could help clinicians to provide better care and quality of life (QOL) for people treated with melanoma, especially in regions where after-care resources are limited or no existent, such as in rural and remote areas of Australia.

Patients' individual characteristics

The current review found some evidence for the efficacy of digital interventions for melanoma post-treatment care. Key findings identified that clinicians need to take into consideration patients' individual characteristics in order to provide personalised follow-up plans, tailored information and quality of care (Coory et al., 2006, Kasparian,2013]. It is clear that IT capabilities, patient age, illness condition, level of incomes and residential areas influence clinician and patient decision-making in the post-treatment plan. One study by Hall and Murchie found that participants who were familiar with technology and not living close to hospitals, were more likely to have a positive attitude toward telemedicine for self-monitoring and performing TSSE (Coory et al., 2006). Querish and colleagues also reported that 73% of the participants are more willing to pay when telemedicine was giving them faster access to the clinicians. Among this sample, 55% had an income inferior, or equal to US\$50,000 p/a (Kasparian, 2013). Other studies that investigated consumers' perception toward tele-medicine found that people with 'technology anxiety' were less likely to use technology for specific care

(Bird et al., 2015). In contrast, young populations may be more inclined to trust digital health interventions, as they are more familiar with technology (Yu et al., 2016).

Patients' acceptance

In order to efficiently use personal consumer technology in melanoma post-treatment care, it is crucial to understand patients' acceptance toward digital intervention. Several of the studies reviewed illustrated a shift from 'passive' recipients to 'active' patients for their own care (DoH, 2017), which led to proactive health behaviour change and positive attitudes toward early-detection. Simple measures such as receiving a reminder to perform TSSE by text message or email, having access to informative videos, or using smartphone apps for self-monitoring, reduced anxiety and reinforced TSSE (Coory et al., 2006, Fabbrocini et al., 2011, Murchie et al., 2015). These technologies could also be used to address the need for better quality and greater consistency in information provided to melanoma patients (Murchie et al., 2015).

The study by Quereshi and colleagues reported that patients' attitude toward telemedicine was generally positive if it showed convenience (58% well willing to pay up to US\$125P), but almost universally positive if it gave a quicker access to their clinicians (95% of the patients were willing to pay up to US\$500) [25]. The study by Horsham and colleagues emphasised that survivors showed positive attitude towards a digital health application that allowed them to monitor quality of life and provided tailored information and advice (Yu et al., 2016).

While these findings demonstrated that patients were generally receptive toward digital health for melanoma post-treatment care, no studies to date have focused on rural and remote communities' views. Nevertheless, a few studies have already highlighted people's acceptance toward telemedicine in Australian rural and remote communities for cancer more broadly. In their studies, Sebesan and colleagues reported the benefits of tele-oncology in rural and remote areas for cancer care (Martinez-Donate et al., 2013, Werner & Karnieli, 2003). The main benefits of this telehealth system included travel time saved and better access to specialist care. In addition, studies have shown that telehealth may lead to financial benefits and improved quality of care in distant communities (Werner & Karnieli, 2003, Horsham et al., 2016).

Patients' psychological and social needs

In this systematic review, there was a lack of empirical evidence with regards to the benefits of digital health for support and psychological care services, in order to provide better QOL. These studies mainly focused on early-detection, including self-monitoring and TSSE. However, a previous systematic review suggested that 30% of patients with melanoma reported psychological distress (Sabesam et al., 2012), which interfered with QOL, medical cost, risk of recurrence and mortality rates (Sabesam et al., 2012, Moffatt and Eley, 2010). Likewise, Oliveria and colleagues found that patients treated with melanoma showed direct psychosocial concerns related to conducting skin self-examination; anxiety associated with new recurrence and sun exposure; familial concerns; financial constraints and maintenance of health insurance benefits (Kasparian et al., 2009). Emotional support and reassurance is considered a key component of care (Sabesam et al., 2012, Sabesam et al., 2012, Moffatt and Eley, 2010, Kasparian et al., 2009, Cassileth et al., 1983, Kneier, 2003, Oliveira et al., 2013), with psychological intervention associated with superior survival and recurrence rates, and decrease of distress (Kneier, 2003). Clinicians should therefore take into consideration the psychosocial impact on patient outcomes when designing post-treatment plans.

The economic burden of melanoma treatment in Australia

Melanoma early detection reduces mortality rate and results in simple treatments for lower cost (Fischbeck et al., 2015). A 2017 study (Sneyd & Cox, 2013), estimated the mean cost to the Australian health system for melanoma treatment to be AU\$10,716 per patient. However, treatment cost for advanced melanoma may be 21% to 70% more expensive than for early stages (in-situ, stage I & stage II). Doran and colleagues compared the direct and indirect costs of melanoma and non-melanoma skin cancer (NMSC) in 2010 (Fawzy et al., 1993). The direct costs related to the management of the disease, including diagnosis and treatment to follow-up, and indirect costs included productivity losses associated with morbidity and premature mortality. Estimates of direct lifetime cost per case were AU\$10,230 for melanoma and AU\$2,336 for NMSC; and total indirect cost per case AU\$34,567 for melanoma and \$123 for NMSC.

Moreover, additional studies have reported an urban-rural disparity in term of accessing health care and mortality rate (Buja et al., 2018, Read et al., 2018). Yu and colleagues reported that

socioeconomic factors may impact people's decision-making in selecting their healthcare provider (Read et al., 2018). The study showed a difference in provider performance based on patients' income. Rural populations with lower-income received poorer care from HCPs, compared to patients living in urban areas.

The comparatively lower cost of delivering support care services via digital health initiatives, in addition to reduced treatment costs associated with promoting early detection (Carli et al., 2003, Coory et al., 2006, DoH,2017) would go some way to improving access to health care and reduce urban/rural inequity.

Limitations

This systematic literature review presents several limitations. First, most of the studies used small samples ($n \geq 20$). It is evident that digital health research regarding melanoma post-care treatment is still in its early stages of investigation. Second, few studies were identified as focusing on the psychosocial and health economic side of post-care treatment, as melanoma studies are primarily focused on early-detection, and those that did used retrospective measurement of consumer attitudes towards telemedicine. Third, melanoma treatment plans depend on individual characteristics, including the disease staging. Only one of the studies used staging as a participant characteristic. Finally, although the authors were primarily interested in rural and remote areas of Australia, the lack of studies conducted in these areas meant that studies for this review were drawn from across the world, and their conclusions may not necessarily generalise to the Australian rural and remote context.

Overall, the current systematic review provides findings about patients' perceptions toward telemedicine and digital interventions already used by clinicians and patients. However, in order to have a complete review of digital health benefits for melanoma post-treatment care, it would have been necessary to look at HCP's acceptance toward such technological interventions.

Conclusion

The study of digital health has become an area of focus in primary health care, as it can help clinicians in their practice and support patients in improving and monitoring their quality of

life. While there is research interest in using digital health in early detection of melanoma, there is an urgent need to explore the potential for benefits of digital health in melanoma post-treatment care for specific needs and intervention, particularly for rural and remote populations who are lagging behind in terms of post-care treatment quality and availability. This current literature review also highlights the importance of considering individual, psychosocial and socioeconomic characteristics in future developments in this area.

Although our findings showed positive outcomes with regards to using technology during post-treatment care, there were also some limitations in using digital health. Patients believe that technology can't replace clinician provided written and oral information, follow-up visits, or clinical interventions (Murchie et al., 2015). To summarise, digital health shows potential to be used as an adjunct service by clinicians during melanoma post-treatment care, especially in regions that are lower-resourced by practitioners and health infrastructure, such as regional and remote Australia.

Implication for further research

Future research needs to explore the potential for digital health within rural and remote areas for melanoma post-treatment care in order to reduce the mortality rate disparity in between urban and rural population. In addition, it will be interesting to consider how digital health implementation may transform the patients' ecosystem, and the cost-effectiveness of this solution for both patients and the healthcare industry.

Interdisciplinary studies in behavioural psychology and health economy can add new insights to the healthcare industry in term of benefits and services that digital health can bring to melanoma patients care in rural and remote areas.

CHAPTER 5

RATIONALE FOR METHODOLOGY

Overview

Chapter five presents a background and rationale for the research methodology, including challenges accessing melanoma post-treatment care and the benefits of using digital health to improve health outcomes.

A recent systematic review on melanoma post-treatment care (see Chapter 4) suggests that digital health has the potential to improve access and quality to healthcare delivery for melanoma patients if it's personalised and adapted to one's needs. However, none of the studies reviewed focused on the Australian population.

In addition to understanding Australian melanoma patients' needs, it is essential for this study to identify factors that influence access to melanoma care. Global research discusses the negative impact of socioeconomic status and health literacy on the overall access to care. However, there is little melanoma-specific evidence for this, highlighting critical knowledge gaps. The melanoma literature also highlighted further limitations to accessing care included psychological distress.

This chapter also explains the current study's sample selection, participants' individual characteristics collected and measures, and concludes with a summary of the twenty-five hypotheses identified.

Note for the reader: From this chapter onward, 'rural and remote' areas of Australia are referred to as 'rural' areas of Australia

Background

Digital health encompasses a broad range of technologies and interventions, which all aim to benefit health outcomes (Lupton, 2017; Bhavnani et al., 2016; Rivas, 2018). Chapter 2 gives a comprehensive analysis of the technologies available to patients and their application to melanoma post-treatment care.

After reviewing the literature, researchers found that to date, there is little evidence demonstrating the benefits of digital health in melanoma post-treatment care. A recent study by this author (see Chapter 4) identified only five papers investigating the use of digital health in melanoma post-treatment care and patients' attitudes toward digital interventions (Rollin, Ridout & Campbell, 2018).

The findings revealed that:

- Patients perceive digital health as adding value to their post-treatment care;
- Digital health in melanoma post-treatment care enables increased access to care;
- Digital health is predominantly used to prevent recurrence or new primary melanoma and promote early detection;
- Psychological and health economic benefits of digital health in post-treatment care are often overlooked.

In addition, the systematic review suggested that digital health may be used as an adjunct service to reduce the urban-rural disparity in accessibility to melanoma post-treatment care to rural populations, and ultimately incidence and mortality rates. However, to date, there is no scientific evidence showing that digital health can solve this inequity. Further investigations would, therefore, be necessary to understand the attitudes of patients from rural Australia toward the use of digital health in melanoma post-treatment care.

At the conclusion of the systematic review (Rollin et al., 2018), researchers highlighted the urgent need to understand how digital health could help clinicians to provide better, quicker

and cheaper care for melanoma patients, more particularly for people who have limited access to healthcare services (e.g., rural populations). It also emphasised the importance of considering an individual's characteristics (e.g., age, illness condition, residential and SES) when measuring patients' needs and access to care, as well as evaluating their attitudes toward digital health.

Furthermore, while the systematic review showed that the use of digital health varies greatly between countries, it revealed that to date, there had been no Australian studies focusing on the use of digital health in melanoma post-treatment.

Research method

While there is research interest in the use of digital health in melanoma care, the current study is the first to investigate the benefits of digital health in melanoma post-treatment care in Australia using a holistic patient-centred care approach.

Initially, the study intended to understand the needs and attitudes of melanoma patients living in rural Australia and compare rural and urban populations. However, after scanning the collected data and completing preliminary analyses, it was decided to broaden the scope of the study and redefine the research question as per below.

To answer the thesis research question "*Could technology help improve melanoma post-treatment care in patients who face barriers to accessing health care?*", researchers conducted an exploratory study using a mixed-method (quantitative and qualitative) design to:

1. Identify current challenges met by melanoma patients during their post-treatment care;
2. Identify components and predictors of access to post-treatment care;
3. Identify how digital health can improve the provision and quality of care;
4. Identify if, and how, the benefits of digital health in melanoma post-treatment care differs between patients.

Melanoma post-treatment care challenges

The National Health Performance Framework has defined access to care as people being able to '*obtain healthcare at the right place and right time irrespective of income, physical location and cultural background*' (NHPC, 2002). Access to care encompasses five dimensions (Levesque et al., 2013):

1. **Approachability** (awareness of the existence of services, how to reach them and the effect they have on one's health);
2. **Acceptability** (social or cultural factors that affect the use of services);
3. **Availability** (ability to reach the service both physically and in a timely manner);
4. **Affordability** (ability to pay for services);
5. **Appropriateness** (ability to engage in care that is of a reasonable quality).

Moreover, it is well-established that, unfortunately, not all patients benefit from the same level of access to healthcare services (Riley, 2012). Barriers to accessing care can occur in any or all of these domains (Corcadden et al., 2019), and vary by location, disease and patient characteristics (Shukla et al., 2020).

In melanoma post-treatment care, challenges and limitations to access healthcare services are often related to geographical, social and financial (Yu et al., 2016), factors as well as health literacy (Wu et al., 2020).

Socioeconomic status

Although SES is often discussed as a limitation to healthcare delivery in melanoma publications, a systematic search revealed important knowledge gaps regarding the impact of SES on melanoma management care.

In the Australian literature on melanoma management of care, only one study (Coory et al., 2006) investigated the urban-rural differences in survival. At the conclusion of the study, researchers suggested that the disparity may reside in the differences in access to services and variation in management practices. Further investigations are still required to test the validity of this hypothesis.

A 2020 review of the various modelling approaches used by researchers to analyse barriers to healthcare access in Australia (Shukla et al., 2020) revealed that most of the focus has been on cancer-related studies and understanding accessibility among the rural and urban population. However, of the 127 identified studies, none was specific to melanoma.

Moreover, the Australia Institute of Health and Welfare states that on average, Australians living in rural (and remote) areas have poorer access to, and use of, health services, compared with people living in urban areas. This rural-urban disparity has been explained by lifestyle differences, geographic isolation and a lower level of education and income (AIHW, 2019). Also, rural communities are likely to face several infrastructure, cost, and access limitations that impact the provision of health services. This is further compounded by the lack of training for future dermatologists and general practitioners in these more remote areas (The Department of Health, 2017).

AIHW reports (AIHW, 2020) also show that socioeconomic factors such as travel distance to healthcare facilities, residential status, level of income and education are predictors of health and wellbeing in Australia. Lower SES can lead to reduced quality of care delivery and hence poorer patient outcomes. The following are examples of patient outcomes associated with lower socioeconomic status:

- (1) **Reduced access** — people living farther from healthcare infrastructure report lower rates of usage than those who live closer (Kelly et al., 2016; Barbieri & Jom, 2019; Harrold et al., 2014).
- (2) **Poorer quality** — rural areas suffer from a limited, and inferior quality of, health services compared to urban areas (Weinhold & Gurtner, 2014).

- (3) **Increased psychological distress** — low-income levels are strongly associated with high psychological distress and poor mental health (Lazzarino et al., 2013). The higher level of distress in disadvantaged communities has been explained by several factors including financial hardships (aka. financial stress), fewer inter- and intra-personal resources to manage stressful events, adverse life conditions.

Health literacy

Health literacy relates to how people access, understand and use health information in ways that benefit their health. It is often correlated with SES. Poor health literacy is more prevalent among low-educated, low-income, minorities and rural populations (Friis et al., 2016; Stormacq et al., 2019). Research also reveals that health literacy can decline under stressful circumstances and due to illness (White et al., 2008; Davis, T. et al., 2002).

Health literacy is also positively correlated with health outcomes. Low patient literacy can lead to decreased self-management, medication adherence, decision-making and communication with healthcare providers, financial hardships, psychological needs and delays in seeking help and medical advice. Subsequently, poor health literacy can result in poor overall health and increased mortality.

Therefore, to improve melanoma post-treatment care, it is essential to understand better the factors influencing patients' access to and readability of melanoma-related information.

Unmet supportive care

As mentioned in Chapter 3, melanoma patients' unmet needs, particularly in supportive care, can lead to ineffective coping, increased emotional distress and a reduced quality of life (Kasparian, 2013; Fu et al., 2020). And, although there is no strong scientific evidence specific to melanoma patients, broader studies suggest that failure to meet patients' needs can lead to delays in seeking medical advice resulting in a worsening physical condition (Loquai et al.,

2013). Ultimately, unmet needs can increase medical costs for the patient (and healthcare system) and lead to poorer survival rates and quality of life (Davies et al., 2018).

Benefits of using digital health in melanoma post-treatment care

It is well-established that digital health can improve health outcomes by (1) supporting clinicians in their practices to deliver better quality care (Hall & Murchie, 2014); (2) increasing access to healthcare services (Hall & Murchie, 2014; Murchie et al., 2015, Qureshi et al., 2006); and (3) putting health back into people's hands; (Loiselle et al., 2013; Murchie et al., 2015).

As outlined in Chapter 4, five studies discussed the direct outcomes of digital health in melanoma post-treatment. Benefits of using technologies include:

- Increased access (i.e., convenience);
- Quicker access;
- Remote access (i.e., teleconsultation);
- Effective communications with HCPs;
- Timely information;
- Self-management support;
- Increased patient empowerment;
- Reinforced positive behaviour (e.g., skin self-examination);
- Cost-effectiveness (e.g., travel, medical);
- Time-effectiveness (e.g., travel, medical);
- Improved health literacy;
- Greater reassurance;
- Reduced psychological distress.

In addition, the devices and interventions identified in the systematic review were as per Table 5.

Table 5*Devices and digital interventions in melanoma post-treatment care*

Devices	Interventions
Mobile phone text messages	Clinicians to send reports/feedback to patients Patients to send reports to clinicians Reminder to conduct skin self-examination
Mobile camera	Patients to send photographs of moles, skin lesions
Emails	Clinicians to send reports/feedback to patients Reminder to conduct skin self-examination
Self-monitoring supportive tools	Help patients to conduct skin self-examination
YouTube videos	Educational content on how to conduct skin self-examination
Skype/teleconference	Teleconsultation Three-way consultation with a specialist, during a GP consultation
Store-and-forward platforms	HCPs to share information with patients
Web-based apps	To provide educational and tailored information
Online peer support	To share information and experiences with other patients
Digital skin map	To help patients track their moles and skin lesion changes

The review of digital health for melanoma care outlined the importance of considering patients' individual characteristics (e.g., IT capability, patient age, illness condition, level of income and remoteness) to provide personalised and quality care through digital health. It also highlighted the need to understand patients' attitudes and willingness to use technology into their care to ensure optimal adoption of digital health (Rollin et al., 2018).

Sample selection

Previous scientific papers have discussed the increasingly central role of technology in healthcare (Lupton, 2013; Meskó et al., 2017) and how it can help overcome the challenges in creating equal access across a country as vast as Australia (AIHW, 2020a). Studies showed that whether technology is used to monitor and manage health follows some clear demographic, economic, social and spatial/geographic patterns (Senecal et al., 2018).

Because the highest melanoma incidence and mortality rates are in rural communities (Chapter 3), the prominent discrepancy in healthcare delivery between rural and urban communities, and to allow for comparative analysis, researchers ensured that at least half of the sampled participants came from rural Australia.

Therefore, the targeted participant group were adults living in rural and urban areas of Australia who have been treated for cutaneous melanoma. In addition, to give a representative snapshot of melanoma patients living in Australia, there was interest in capturing a demographically diverse sample. This sample included participants diagnosed with either primary or recurrent melanomas and patients at different stages of the disease (in-situ, stage I, II, III, IV).

Finally, the sampling procedure was nonprobabilistic, since no list of Australian melanoma patients was available.

Individual characteristics

While previous studies have investigated the role and adoption of digital health in melanoma post-treatment care, none considered individual characteristics and socioeconomic factors. Therefore, the current study aimed to investigate possible associations between patients' individual characteristics and the use of digital health interventions in melanoma post-treatment care.

A key finding of the systematic review was that to provide personalised and quality care, clinicians should consider patients' characteristics including illness condition; age; IT capabilities; level of education; annual income; residential areas; etc. However, the importance of this information has often been overlooked whilst evaluating the benefits of digital health in melanoma care.

The current study, therefore, collected patient information relating to: (1) demographics (age, gender); (2) socioeconomic status (ABS, 2011) (residential areas, travelled distance to follow-up visits, employment status, annual income); and (3) illness condition (primary or recurrent melanoma, melanoma thickness, surgical interventions).

Measures

To the best of the researchers' knowledge, there was no pre-existing tool available to:

- Assess the challenges met by patients to access healthcare;
- Measure a patient's current use of digital health technology;
- Measure a patient's willingness to use digital health.

Therefore, non-standardised questions were devised by the research team to collect data on the above, based on clinical recommendations from melanoma guidelines (refer to the '*Melanoma*' chapter). For instance, Guidelines of care for the management of melanoma reported that clinicians determine follow-up schedules based on the primary tumour characteristics (melanoma staging) and patient-specific needs. Given this, questions investigating follow-up frequency, clinical interventions and melanoma characteristics were included. In addition, the questionnaire was based on findings from previous studies on melanoma unmet needs and knowledge gaps identified in the literature (refer to Chapters 2, 4). Research revealed that unmet needs generally occur in the informational, psychological, and social domains (Fu et al., 2020). Therefore, questions related to the nature, amount, and quality of information received by patients (including related to psychological care) were asked better to understand the levels of supportive care available to patients.

Questions to address patients' use of technologies were based on a systematic review of digital health in melanoma post-treatment care in Australia (Rollin et al., 2018). The selection of the specific digital health technologies that participants were asked about was restricted to technologies that:

- Have been identified in the digital health and melanoma literature;
- Are available to patients themselves to manage their health.

As a result, the questionnaire asked participants about SMS, emails, mobile phone cameras, mobile apps, websites, web-based apps, digital skin maps, YouTube videos, Facebook and other social media platforms, online forum discussions, telehealth platforms (including skype), teledermoscope, self-monitoring supportive tools, store-and-forward telemedicine, virtual reality, augmented reality and serious video games.

The use of electronic management systems such as electronic health records and patient admission systems were outside of the scope of this study.

The current study also asked participants specific questions about non-digital aspects of their care (e.g., provision of disease information at time of diagnosis, follow-up visit frequency, and conduct of TSSE) to compare real-world management practice with the Australian recommended guidelines (Cancer Council, 2019) for the management of melanoma.

Summary

In summary, the current study aimed to answer the following research questions: *Would technology help improve melanoma post-treatment care in patients who face barriers to accessing health care?*

1. *What are the current challenges and limitations that melanoma patients experience in their post-treatment care?*

- Melanoma patients living in rural areas will report poorer access to, and satisfaction with, their care than those living in urban areas (**H1**);
- Melanoma patients who need to travel longer distance to follow-up visits will report poorer access to, and satisfaction with, their care than those living closer (**H2**);
- Melanoma patients coming from lower socioeconomic backgrounds will report poorer access to, and satisfaction with, their care than those coming from higher socioeconomic backgrounds (**H3**);
- Melanoma patients living in rural areas will experience psychological difficulties related to melanoma more frequently than those living in urban areas (**H4**);
- Melanoma patients who need to travel longer distance to follow-up routines will experience psychological difficulties related to melanoma more frequently than those living closer (**H5**);
- Melanoma patients coming from lower socioeconomic backgrounds will experience psychological difficulties related to melanoma more frequently than those coming from higher socioeconomic backgrounds (**H6**);
- Melanoma patients who face difficulties in accessing their follow-up visits frequently, will report more psychological needs than those who don't experience them as often (**H7**);
- Melanoma patients who express lower satisfaction with the amount of information received at the time of diagnosis, will report more psychological needs than those who don't experience them as often (**H8**);
- Melanoma patients who express lower satisfaction with the quality of information received at the time of diagnosis, will report more psychological needs than those who don't experience them as often (**H9**);

2. How melanoma patients currently use digital health in their post-treatment care?

- The younger melanoma patients are the more likely they are to use technology in their post-treatment care (**H10**);

- Female patients are more likely to use technology for their post-treatment care than male patients (**H11**);
- Patients who have a more advanced condition, will be less likely to use technology in their post-treatment care than those at an earlier condition (**H12**);
- Patients from lower socioeconomic backgrounds will be less likely to use technology in their post-treatment care than those from higher socioeconomic backgrounds (**H13**);

3. *To what extent would melanoma patients be willing to use technology in melanoma post-treatment care?*

- The younger melanoma patients are, the more willing they will be to use technology to increase access to post-treatment care (**H14**);
- The younger melanoma patients are, the more willing they will be to use technology to improve their quality of life (**H15**);
- Female patients will be more willing to use technology to increase access to post-treatment care than male patients (**H16**);
- Female patients will be more willing to use technology to improve their quality of life than male patients (**H17**);
- Patients at a more advanced condition will be more willing to use technology to increase access to post-treatment care than those at an earlier condition (**H18**);
- Patients at a more advanced condition will be more willing to use technology to improve quality of life than those at an earlier condition (**H19**);
- Patients from a lower socioeconomic background will be less willing to use technology to increase access to post-treatment care than those from a higher socioeconomic background (**H20**).
- Patients from a lower socioeconomic background will be less willing to use technology to improve quality of life than those from a higher socioeconomic background (**H21**);
- Patients reporting higher psychological distress will be associated with a greater willingness to incorporate technology to access melanoma post-treatment care than those with lower psychological distress (**H22**);

- Patients reporting higher psychological distress will be associated with a greater willingness to incorporate technology to improve quality of life than those with lower psychological distress (**H23**);
- Patients experiencing difficulties to access follow-up visits will perceive greater benefits of incorporating technology to increase access to melanoma post-treatment care, than those reporting less difficulties to follow-up visits (**H24**);
- Patients experiencing difficulties to access follow-up visits will perceive greater benefits of incorporating technology to improve quality of life, than those reporting less difficulties in achieving quality of life (**H25**).

CHAPTER 6

METHOD

Overview

This chapter describes the study design and research method, including sample selection, recruitment procedures, data collection and analysis methods. The questionnaire was designed to collect data about current and future uses of digital health in melanoma post-treatment care to generate a snapshot of melanoma patients' attitudes towards digital interventions in Australia.

The questionnaire contained two sections. The first section aimed to analyse the current state of melanoma post-treatment care in Australia and the barriers to accessing this care. The objective of the second section was to understand melanoma patients' attitudes toward digital health interventions in their post-treatment care, including clinical routine visits/follow-up and supportive care services. The study's end-goal was to propose a digitally-enhanced model of melanoma post-treatment care based on the identified patient needs.

An initial sample of ninety-five melanoma patients answered the questionnaire developed for this study. All ninety-five respondents completed the first section of the survey; however, twenty-two dropped out before completing the second section, resulting in a reduced sample of seventy-three.

To analyse the data, researchers utilised qualitative, quantitative and statistical analysis methods. In addition, ArcGIS was used to generate data about distance travelled by patients to their follow-up appointments. At the conclusion of the study, all participants received a study debrief via email.

Participants

A total of one hundred and twelve participants took part in the study. Of these, one hundred and five were approached online via Facebook, and seven were recruited in-person by healthcare professionals (e.g., general practitioners, doctors specialised in skin cancers, dermatologists).

Of the one hundred and twelve, thirty-two respondents dropped out of the study before the end of the questionnaire, and one did not meet the inclusion criteria. In addition, ninety-five people completed the first section of the survey (sample 1). Of those, seventy-three people completed the full survey (sample 2). The researchers theorised that the difference between the number of responses to section one and section two was due to the length of the questionnaire. As a result, the first set of analyses was conducted on the full sample ($n = 95$), and the second was performed on a constrained sample ($n = 73$). Refer to '*Data analysis*' for further details.

All participants were adult patients previously diagnosed with, and treated for, melanoma and living in Australia. The mean age of the initial sample was 51.9 years old ($SD=12.8$). The majority of participants were female ($\sim 75\%$), and more than half of the respondents (60%) were living in rural/remote areas of Australia. The average distance travelled to attend follow-up appointments was 115km. Full details of the participants' characteristics are provided in the 'Results' chapter.

The study was fully approved by the Human Research Ethics Committee of the University of Sydney (protocol number 2018/903) on 7 December 2018 (Appendix A).

Design

The purpose of this study was to (1) identify unmet needs to improve the patient experience in posttreatment care for melanoma and (2) to understand how digital health may be used as an adjunct service to increase access to and the quality of care. As such, a descriptive research design was adopted to achieve these aims, with Spearman's correlations, ANOVA and

multiple pairwise comparison analyses used to determine relationships between the variables measured. In addition, to verify the reliability of results, researchers ran a Welch's t-test investigating if there were any individual differences (e.g., demographic, satisfaction with care) between participants who completed the whole survey (sample 1) and those who did not (sample 2).

The first section of the survey captured information about melanoma patient demographics, satisfaction and accessibility to post-treatment care (e.g., quantity and quality of the information received, doctors' recommendations, the frequency of follow-up visits, etc.). The second section of the survey collected information about patients' knowledge and attitudes towards digital interventions in melanoma post-treatment care.

The objective was to measure the degree of correlation between individual characteristics between patients' needs and their access to melanoma care. Further, patients' attitudes toward digital health in melanoma post-treatment care was also surveyed.

Independent variables:

1. Demographic factors (gender, age)
2. Socioeconomics factors (remoteness, annual income, employment status, level of education)
3. Residential area (rural/urban)
4. Illness condition (recurrence, tumour thickness)
5. Access to follow-ups (frequency, barriers, satisfaction)
6. Access to information (nature, quantity, quality, satisfaction)
7. Psychological implications

Dependent variables:

1. Access
2. Satisfaction
3. Attitudes toward digital health (current and future use)

Measures

As described in the ‘*Rationale for methodology*’ chapter, the survey was designed to address the gaps in the literature regarding digital health in melanoma post-treatment care identified by Rollin et al. (2018). In addition to capturing individual-specific information (*sociodemographic* and *illness condition*), the questionnaire consisted of two sections: (1) individual post-treatment care access and (2) melanoma patients’ attitudes towards digital health to manage their health in posttreatment care.

The measures were as follows:

- *Individual characteristics*: The aim was to capture individual characteristics including gender, age, residential area, level of education, employment and annual income, as well as illness condition including surgical interventions, melanoma thickness, recurrence. Additionally, to estimate an individual’s travel time, participants were asked to provide information about their postcode and the location of doctor/hospital. To get a comprehensive image of the participants’ personal situations, a series of eleven questions were asked.
- *Individual post-treatment care access*: The first section of the survey aimed to assess participants’ melanoma post-treatment plans to identify unmet needs and potential areas of improvement. The data collected allowed researchers to measure their access to melanoma care, including frequency, accessibility and quality. Individuals were asked to answer questions about:
 - *Access to follow-up visits*: Three questions generated data about frequency and factors impacting access to care (travel and waiting time, cost of travel and medical visits, and taking time off from work).
 - *Access to information*: Four questions asked about the nature, quality, quantity of, and satisfaction with, the information provided by healthcare professionals at diagnosis. This included information on

treatment, disease evolution, skin self-examination, psychological implications due to disease, available support groups, and recommendations to see a specialist (i.e. psychologist, counsellor, nurse specialising in melanoma care). To rate patients' satisfaction with the amount and quality of information received, researchers used a scale of satisfaction from 1 (very dissatisfied) to 5 (very satisfied).

- *Psychological needs*: One question collected information about how patients were coping with their illness. The information was obtained through a question listing the psychological implications related to melanoma. A scale of frequency rated from 'never' to 'always' has been used to assess the participants' individual's needs and wants.
- *Attitude toward digital interventions*: Section two aimed to understand how digital health could be used within melanoma post-treatment care. Questions asked about the current use of technology, as well as potential future digital solutions that could be implemented within post-treatment care to (1) increase access to care and (2) improve quality of life.

A total of five questions were asked of the participants: three close-ended (quantitative) and two open-ended questions (qualitative).

- *Current use of digital technology in melanoma care*: The first question evaluated the current use of technology in melanoma care. Participants were asked about their experience with the fourteen technologies identified for melanoma post-treatment care in the literature (Rollin et al., 2018). The objective was to understand if melanoma patients were using digital technology as described in the literature, using three indicators: 'Yes', 'No', or 'I have never heard of it'.

- *Willingness to use digital health in melanoma care*: The second and third questions focused on melanoma care and how technology in general could increase both access and quality care. These questions were not constrained to the technology found in the melanoma treatment literature but referred to healthcare-related technology found in other conditions, such as serious games, virtual reality and augmented reality. Researchers used a Likert scale rated from 1 (very unlikely) to 5 (very likely) to ascertain participants' willingness to use digital health in melanoma care.
- *Benefits of using digital health from a patient perspective*: To understand how technology could benefit patients in their care, two open-ended questions were asked. The first question captured their general perception of digital health in melanoma care, including follow-up visits and supportive care. The second question focused on the impact of technology on increasing access to melanoma care.

Procedure

Participants were recruited on social media through melanoma support groups and via skin cancer organisations in Australia or through healthcare professionals (doctors, dermatologists, melanoma clinics). Melanoma support groups and skin cancer organisations shared a hyperlink on their Facebook page that took the subjects to a secure survey website (Redcap).

To facilitate the promotion of the survey, all groups and individuals who agreed to share the study were provided promotional materials, including flyers and informational templates including a short description of the study, the participant inclusion criteria and the human ethics approval number (Appendix B). Participants who were invited by their treating doctor either received a hyperlink via email or completed the survey offline while in the waiting room before

their follow-up visit. The first page of the survey contained the *Participant Information Statement* (Appendix C) and the *Consent Statement*.

At the conclusion of the survey, participants were asked to provide their email addresses if they wished to receive information related to the study.

Data analysis

In this study, the authors evaluated the use and benefit of technology in melanoma post-treatment care. First, they assessed melanoma patients' (un)met needs and satisfaction with their individual post-treatment care. Second, they investigated how digital health technology could be efficiently integrated into the melanoma model of care to improve quality care and, therefore, health outcomes and quality of life for melanoma patients.

Preliminary analysis

Quantitative analysis: To measure melanoma patient satisfaction with care and (un)met needs and assess the potential benefits of digital health in melanoma post-treatment care. Researchers utilised descriptive statistics, non-parametric tests (Spearman's correlation), MANOVA tests and pairwise comparison methods. Refer to Appendix D for complete statistical analysis.

Qualitative analysis: A summative content analysis method was used to analyse the qualitative data gathered in the current study. To do so, researchers developed a coding scheme based on recurrent keywords and themes. To minimise biases, coding was undertaken by two researchers and any disagreements were resolved by consensus. Results were reported and clustered in a table (Appendix E).

Mapping visualisation and geospatial analysis: To define the variable 'residential area', researchers used the RRMA classification (1991) (The Department of Health, 2021; AIHW, 2004) to identify if participants were living in 'rural' or 'urban' Australia. Researchers

decided to combine rural and remote areas for this study as remote was underrepresented (n=3). To measure the approximate travelled distance for follow-up visits, researchers mapped the ‘*personal postcodes*’ and ‘*doctor/clinic postcodes*’ information in ArcGis. ArcGis is a geospatial information management system that enabled the creation of an interactive map representative of the route used by the subject for their follow-up visit and analysis of the approximate distance travelled (+/-10km).

Main analysis

The primary objective was to understand any relationships between demographic characteristics, individual psychological needs, access to post-treatment care and digital health adoption, to verify the hypotheses described in the ‘*Rationale for methodology*’ chapter. To achieve this, the researchers completed several Spearman’s correlations and MANOVA analyses on multiple variables. Table 6 refers to the seven relationships that were investigated in this study. Full details of the analysis can be found in Chapter 6.

Table 6

Summary of relationship investigated

Dependent variables		Independent variables
Demographic characteristics	↔	Access to post-treatment care
Demographic characteristics	↔	Psychological implications
Access to post-treatment care	↔	Psychological implications
Demographic characteristics	↔	Current use of digital health
Demographic characteristics	↔	Current use of digital health
Access to post-treatment care	↔	Willingness to use digital health
Psychological implications	↔	Willingness to use digital health

CHAPTER 7

RESULTS

Overview

This chapter presents the results of the current study. Demographics of the overall sample are discussed with patients' needs, access to, and appreciation of care investigated. The potential benefits of integrating digital health to improve melanoma post-treatment care are also looked at.

At least one in five participants experienced difficulties in accessing their follow-up appointment. In addition, more than one-in-two reported strong psychosocial needs and required better supportive care.

Analyses on the current use of digital health show that although most participants know about the different technologies available for melanoma care, only a small portion currently uses them. Nevertheless, the vast majority of the sample had a positive attitude toward digital health interventions. The main perceived benefits of using technology in melanoma care were increased access to care, increased psychosocial support and patient's empowerment. Participants mentioned that technology would improve their access to care if it was more accommodating and provided better communications and quicker access.

Finally, correlational analyses attempted to identify factors that may influence patients' satisfaction with their care, as well as barriers to accessing follow-up visits and patients' willingness to use technology to improve their care. The implications of the current study's findings are discussed in Chapter 8.

Preliminary analyses

Participant demographics

The initial sample consisted of 95 melanoma patients (23 males and 72 females) ranging in age from 31–81 years ($M = 51.85$, $SD = 12.78$), with the majority living in rural Australia (62.8%). Two-thirds of the sample were currently employed (65.3%), and the majority had at least a diploma or TAFE level of education (72.7%) and an annual income lower than AUD 80,000 (69.5%).

The majority of the participants were first-time diagnosed patients (73.7%). Overall, 24.2% of the melanomas were less than one millimetre thick, 34.7% between one and four millimetres, and 23.2% greater than four millimetres. Regarding primary/surgical management, 31.6% reported undergoing a sentinel lymph node (SNL) biopsy as part of their treatment. Still, the majority (60.4%) did not recall the type of procedure they had had. Refer to Table 7 for complete descriptive statistics.

Table 7

Participants demographic characteristics

Individual characteristics	Total number (n:95)	Frequency in %
Gender		
Female	72	75.8%
Male	23	24.2%
Age		
30 – 39	21	22.1%

40 – 49	24	25.3%
50 – 59	23	24.2%
60 – 69	18	18.9%
70 – 79	5	5.3%
80 – 89	3	3.2%
Missing	1	1.1%
<hr/>		
Residential area (geographical remoteness)		
Urban	35	37.2%
Rural	59	62.8%
Missing	1	1.1%
<hr/>		
Level of education		
Less than Year 12	12	12.6%
Year 12	14	14.7%
Diploma or TAFE	28	29.5%
Undergraduate	26	27.4%
Postgraduate	15	15.8%
<hr/>		
Employment		
Full time	37	38.9%
Part-time or Casual	25	26.3%

Not employed	33	34.7%
Annual income (per \$1000k pa)		
> 20	13	13.7%
20 <50	26	27.4%
50 < 80	27	28.4%
80 < 110	14	14.7%
110 < 140	8	8.4%
140 < 170	4	4.2%
170 < 200	1	1.1%
200 <	2	2.1%
Surgical intervention		
High-resolution ultrasound	5	5.3%
Tattoo and high-resolution ultrasound	2	2.1%
SNL biopsy	30	31.6%
I don't know	57	60.0%
Missing	1	1.1%
Breslow thickness		
Less than 1mm	23	24.2%
1mm < 4mm	33	34.7%

Greater than 4mm	22	23.2%
I don't know	17	17.9%
<hr/>		
Recurrence		
Yes	25	26.3%
No	60	73.7%
<hr/>		

Reliability of measures

As mentioned in Chapter 6, the survey contained two separate sections. The initial sample (n=95) completed at least the first section of the survey. Twenty-two participants from this initial sample dropped out before the end of the study, resulting in a reduced sample of 73 for the second section of the survey. Therefore, it is essential to keep in mind that the results reported in section two were based on a restricted dataset.

To verify the reliability of results, researchers ran a Welch's t-test investigating if there were any individual differences (e.g., demographics, satisfaction with care) between participants who completed the whole survey (*sample 1*) and those who did not (*sample 2*). Overall, the findings showed no statistical difference between the two samples (see Appendix D).

Section 1: Patients access to melanoma post-treatment care

Individual post-treatment care

As addressed in Chapter 6, it was of interest to assess participants' current melanoma post-treatment care, as well as identify (un)met needs and potential areas of improvement. Data collected included the frequency of follow-up visits, as well as accessibility and quality of information and care services.

Follow-up frequency and satisfaction

The median frequency for follow-up visits was 4.19 times per year ($SD = 1.887$). Almost all the participants visited their doctors at least once per year for a follow-up appointment, with only two (2.1%) responding that they did not attend any follow-up appointments.

Overall, participants were satisfied with the frequency of their follow-up (85.3%). Only 12.6% felt the need to have more visits, and a small number (2.1%) would have liked to decrease the frequency of their visits. Table 8a-b provides full details of the descriptive statistics.

Table 8

Follow-up appointments frequency

Follow-up visits frequency (pa)

Never	2	2.1%
Once	20	21.1%
Twice	24	25.3%
Three times	4	4.25%
Four times	23	24.2%
Five times	1	1.1%
> Five times	21	22.1%
Total	95	100%

Table 9*Follow-up appointments frequency and satisfaction*

Are you satisfied with the frequency of your follow-up?

No, liking fewer	2	2.1%
Yes, Liking as is	81	85.3%
No, liking more	12	12.6%
Total	95	100%

It was of importance to understand if there was any relationship between illness condition and number of annual follow-up visits. The only significant association was a moderate positive correlation between recurrence and follow-up frequency ($r = .460, p < .001$), meaning patients with recurrent melanoma tended to have less frequent follow-up appointments than first-time diagnosed patients. Of note, the findings reported no correlation between tumour thickness and how often patients saw their doctors ($r = .157, p < .129$).

As a vast majority of participants (85.3%) reported being satisfied with the number of follow-up visits, there were not enough dissatisfied responses to analyse whether there was a correlation between the frequency of follow-up appointments and satisfaction with the number of visits.

Doctors' recommendations to see specialists

A majority of patients (67.4%) were not advised to see any specialists at the time of diagnosis. Of those who were, 18.9% of the patients were advised to see a nurse outside of their follow-up appointments, 11.6% were advised to see a psychologist, 8.4% a counsellor and 4.2% a psychiatrist. Other specialists that a small number of patients were recommended to see included dermatologists, endocrinologists, dieticians, and physiotherapists.

Access to care services

As discussed in Chapter 5, ‘access to care’ includes three different components: (1) distance travelled, (2) barriers to accessing follow-up visits, and (3) access to information.

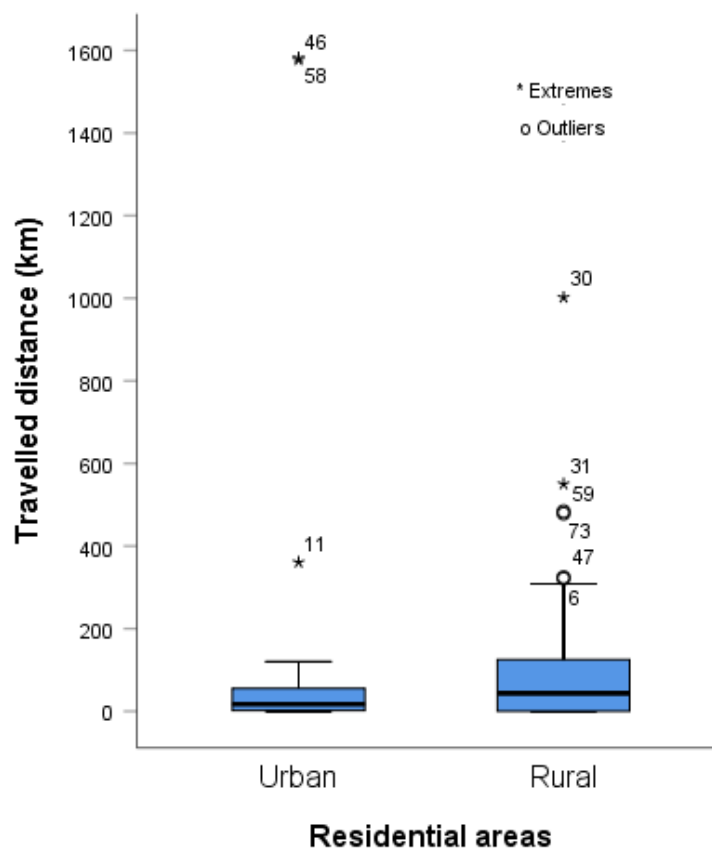
Distance travelled to attend follow-up appointments

The travelled distance ranged from 0km to 1,582km ($M = 114.5$, $SD = 263.0$). The majority (54.8%) of sampled patients travelled at least 30km to their follow-up appointments, with 10.5% travelling between 10km and 30km, and 33.7% less than 10km.

Not surprisingly, participants living in urban areas tended to live closer to their follow-up clinics/health centres than those from rural areas. Figure 6 shows that the distance travelled varied more in rural settings than in urban areas, although the two furthest outliers were from urban areas.

Figure 6

Distribution of travelled distance per residential area

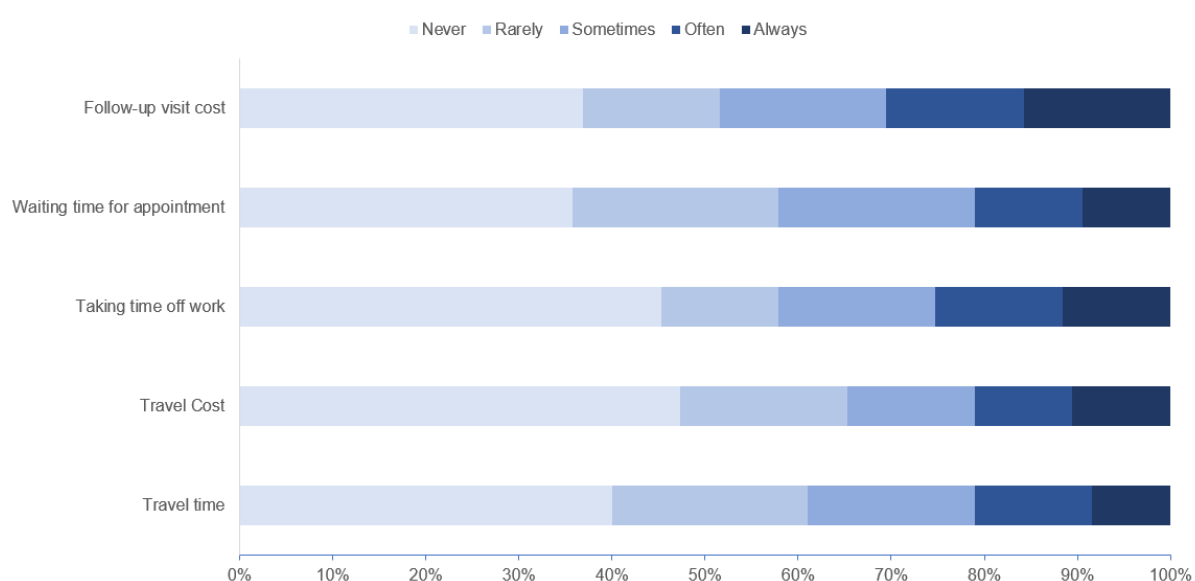


Barriers faced by patients to access their care

Figure 7 shows the distribution of responses regarding the barriers faced by melanoma patients to access their follow-up visits. A majority of participants reported being never, or rarely, impacted by any of the surveyed factors (51.6-65.3%). The most prevalent barriers were follow-up cost (often - always: 30.5%) and taking time off work (often - always: 25.3%). Also, melanoma patients expressed similar levels of limitations regarding travel time (often - always: 21.1%), travel cost (often - always: 21.1%) and long waiting time to get an appointment (often - always: 21.1%).

Figure 7

Limitations to access follow-up visits experienced by melanoma patients (n=95)



Access to information and supportive care

Table 10 and Figure 8 show the breakdown of responses regarding the nature of information received at the time of diagnosis and the participants' satisfaction with the quantity and quality of received information. Regarding the type of information received, Table 3 shows that melanoma treatment information (87.4%) was received by most patients at the time of diagnosis, with many also receiving information regarding total skin self-examination (70.5%) and disease evolution (52.6%). In contrast, few patients received information related to psychological support, with only 20.0% and 29.5% receiving information related to social group support and melanoma-associated psychological impacts, respectively.

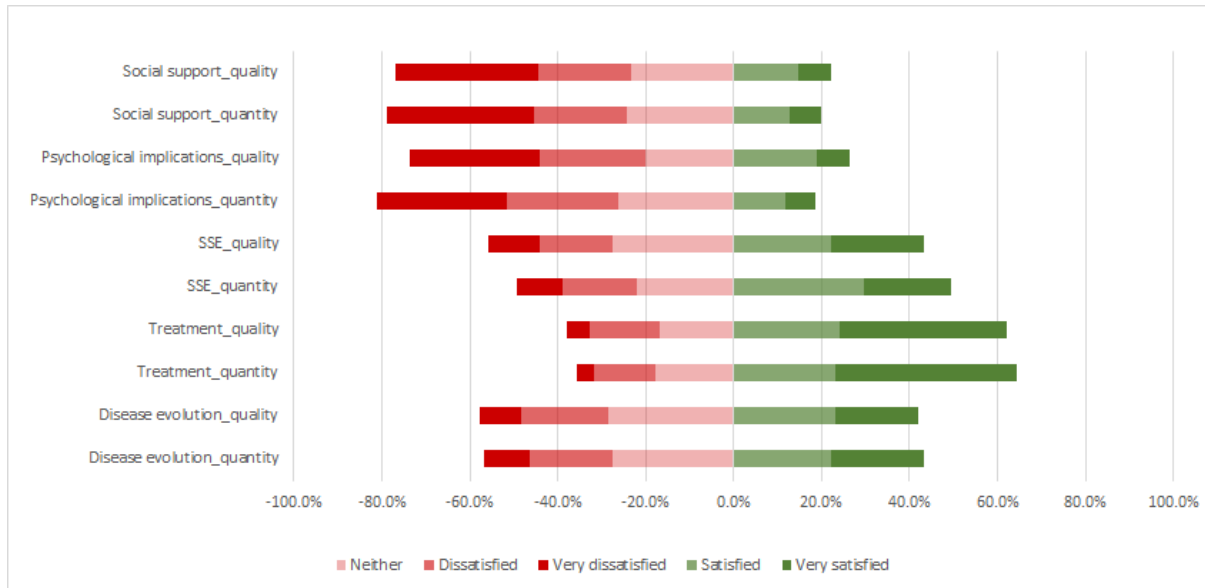
Table 10*Information received at the time of diagnosis*

Type of information:	Did you receive information?		
	Yes	No	Don't recall
Melanoma disease evolution	52.6%	35.8%	11.6%
Melanoma treatment	87.4%	10.5%	2.1%
Total skin self-skin examination	70.5%	27.4%	2.1%
Psychological implications	29.5%	66.3%	4.2%
Social group support	20.0%	76.8%	3.2%

Figure 8 shows the distribution of responses regarding patients' satisfaction with both the amount and quality of received information at the time of diagnosis. The lowest levels of satisfaction were received regarding information least communicated at the time of diagnosis. That is, melanoma patients were least satisfied with the quantity and quality of information related to psychological implications (quantity: 18.7%; quality: 26.3%) and social support (45.3%; 44.3%). Conversely, a majority of patients were satisfied with the quantity and quality of information about melanoma treatment (64.3%; 62.1%). Responses for skin self-examination and disease evolution were more evenly spread.

Figure 8

Satisfaction with quantity and quality of received information

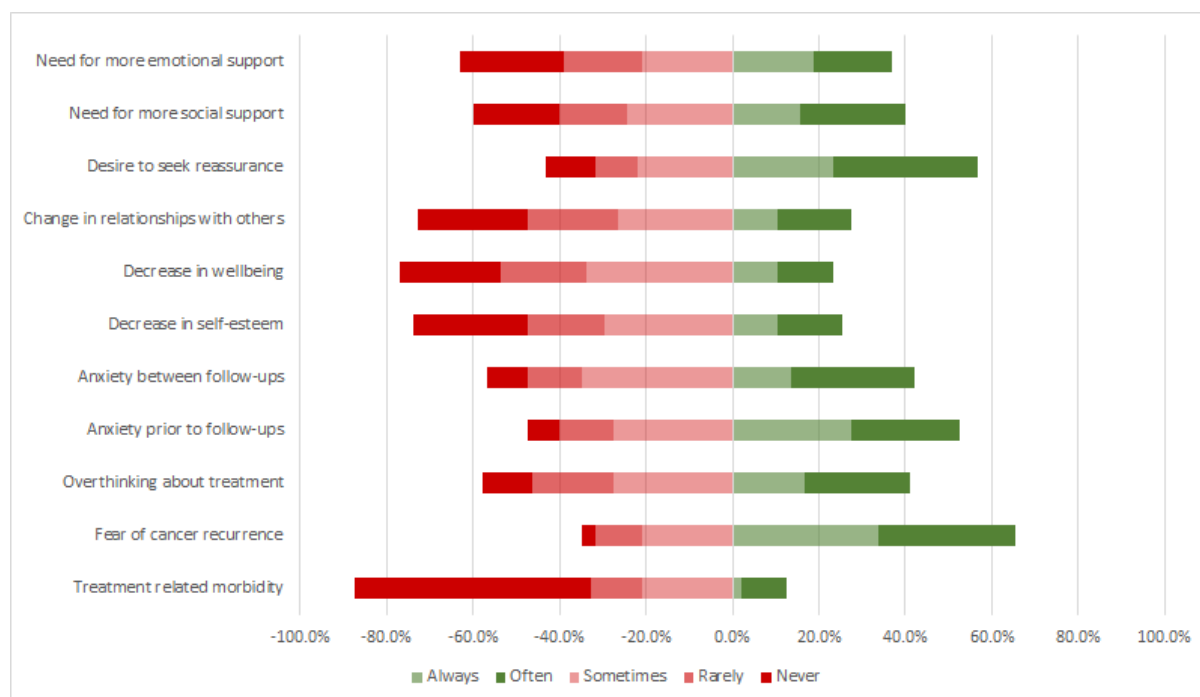


Psychological impacts

The first section of the questionnaire also aimed to understand the impacts of melanoma on patient wellbeing and associated psychological needs. Figure 9 shows the frequency distribution of responses regarding impacts on psychological health and wellbeing.

Figure 9

Melanoma impact on psychological health and wellbeing



Results indicated that a majority of melanoma patients often or always experienced fear of recurrence (65.3%), desire to seek reassurance (56.8%), and anxiety prior to follow-up (52.8%). Many also reported often, or always, feeling anxious between follow-ups (42.1%), overthinking about treatment (41.1%), and expressed needs for more social support (40.0%) and emotional support (36.8%). Some said that melanoma changed their relationships with others (27.4%), decreased their self-esteem (25.3%) or wellbeing (23.2%).

Few patients mentioned experiencing fear of treatment-related morbidity (12.6%). Given this, it is crucial to keep in mind that the latter result may be due to a lack of understanding of the clinical definition of treatment-related morbidity (i.e., death due to medical treatment).

These results, combined with data about access to information, suggest that supportive care is often lacking in melanoma patient treatment plans, underpinning an urgent need for clinicians and other healthcare providers to address this issue.

Patients' knowledge and current use of digital health

Table 11

Knowledge and use of technology for melanoma

	Have heard* of the technology to manage their care		Currently using** the technology to manage their care		
	Yes	No	Frequency	Yes	No
SMS	83.6%	16.4%	61	41.0%	59.0%
Email	84.9%	15.1%	62	45.2%	54.8%
Mobile phone camera	84.9%	15.1%	62	35.5%	64.5%
Mobile apps	79.5%	20.5%	58	25.9%	74.1%
Websites	93.2%	6.8%	68	58.8%	41.2%
Web-based apps	78.1%	21.9%	57	21.1%	78.9%
Digital skin map	83.9%	16.4%	61	26.2%	73.8%
Youtube videos	84.9%	15.1%	62	29.0%	71.0%
Facebook	89.0%	11.0%	65	56.9%	43.1%
Online forums	89.0%	11.0%	65	43.1%	56.9%
Teleconference platforms	82.2%	17.8%	50	6.7%	93.3%
Tele-dermoscope	67.1%	32.9%	49	6.1%	93.9%

Self-monitoring supportive tools	74.0%	26.0%	54	22.2%	77.8%
Store-and-forward platforms	63.0%	37.0%	46	13.0%	87.0%

Note.

*Participants who answered ‘yes’ or ‘no’ to this question were counted as ‘have heard’ (n = 73).

** Results excluded participants who have not heard of x technology

Most participants responded that they had heard of the various technologies listed in the survey (at least 70% for 12 of 14 technologies). However, only two of the technologies (websites and Facebook) had been used in melanoma post-treatment care by more than 50% of those who had heard of them.

Overall, digital health adoption was relatively low. Basic web-based platforms such as websites, email and Facebook were the three technologies most used by melanoma patients regarding their care. More advanced digital health technologies such as teleconsultation and teledermoscope were the least used.

Section 2: Individual’s attitude toward digital health

Patient willingness to integrate digital health within their care

As discussed in Chapter 6, the survey used a scale of likelihood to calculate patients’ willingness to integrate digital health in melanoma post-treatment care to increase: (1) access to care; and (2) improve quality of life.

Figures 10-15 illustrate the breakdown of responses to these questions by the reduced section 2 sample of 73, grouped by type of digital health technology. For most technologies, the response patterns for willingness to use technology to increase access to care and improve quality of life were similar.

Figure 10

Patient willingness to use ICT in melanoma post-treatment care

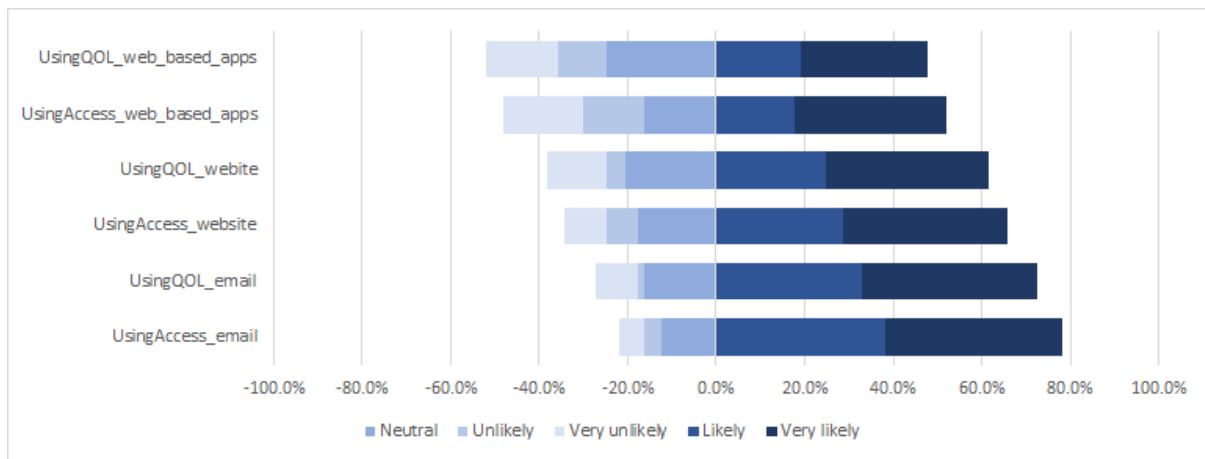


Figure 11

Patient willingness to use mHealth technologies in melanoma post-treatment care

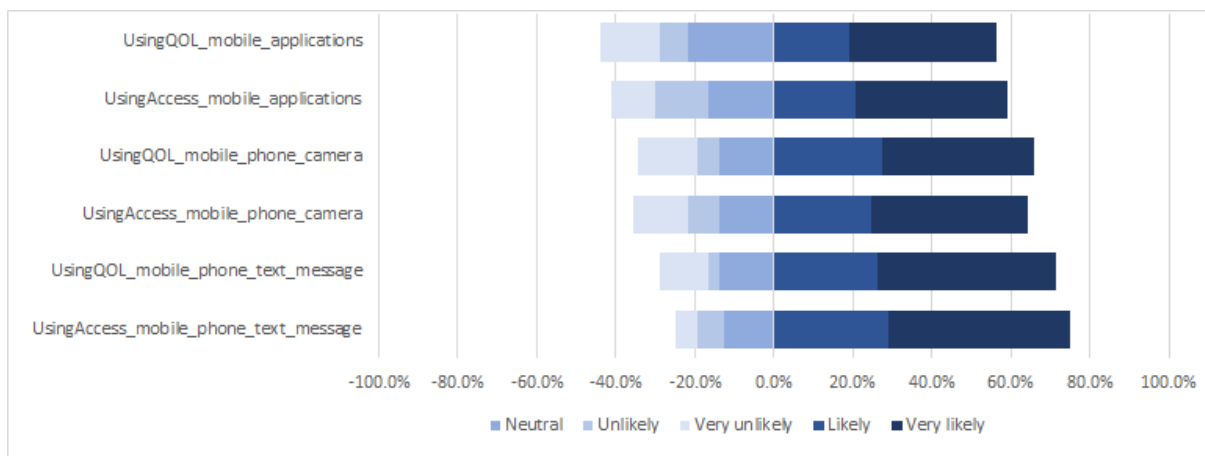


Figure 12

Patient willingness to use online communities in melanoma post-treatment care

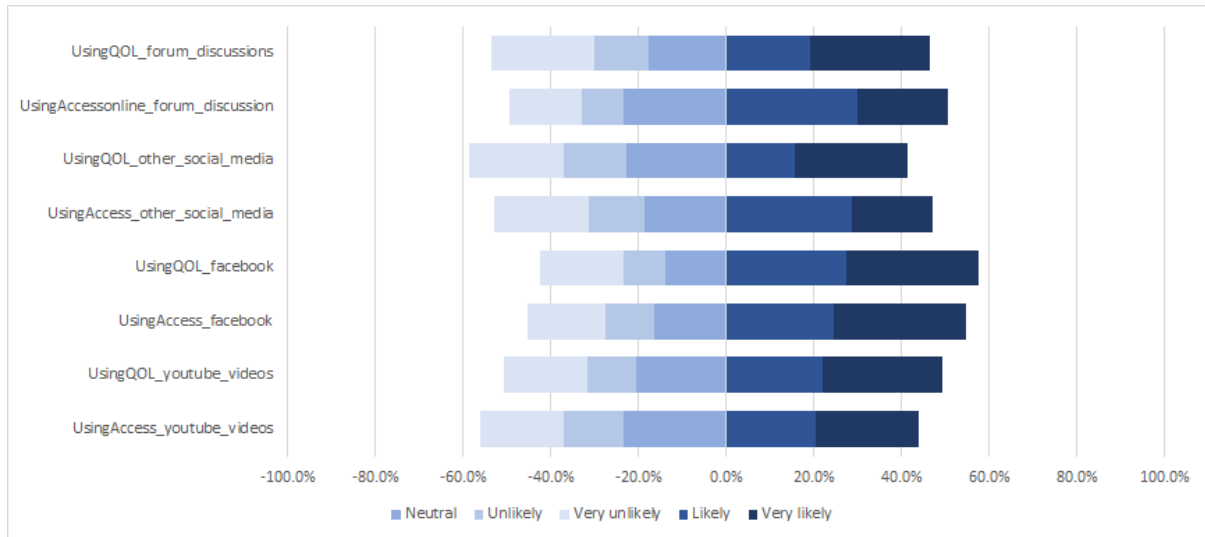


Figure 13

Patient willingness to use self-monitoring technologies in melanoma post-treatment care

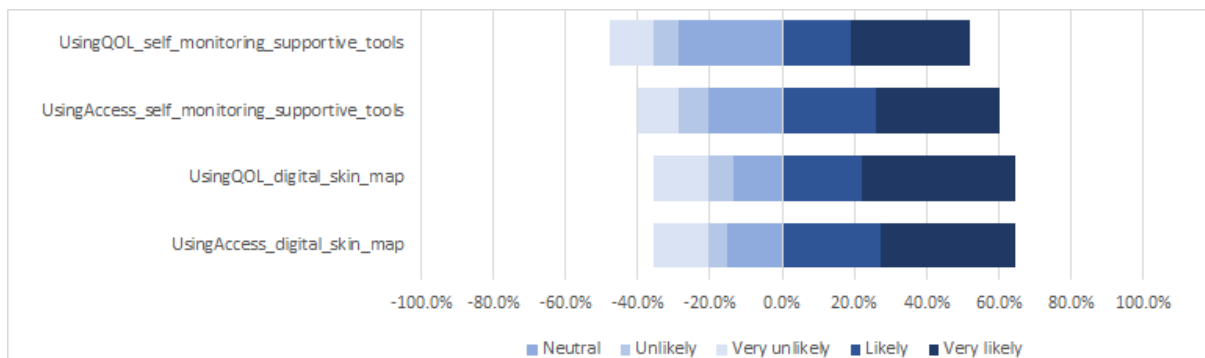


Figure 14

Patient willingness to use telehealth technologies in melanoma post-treatment care

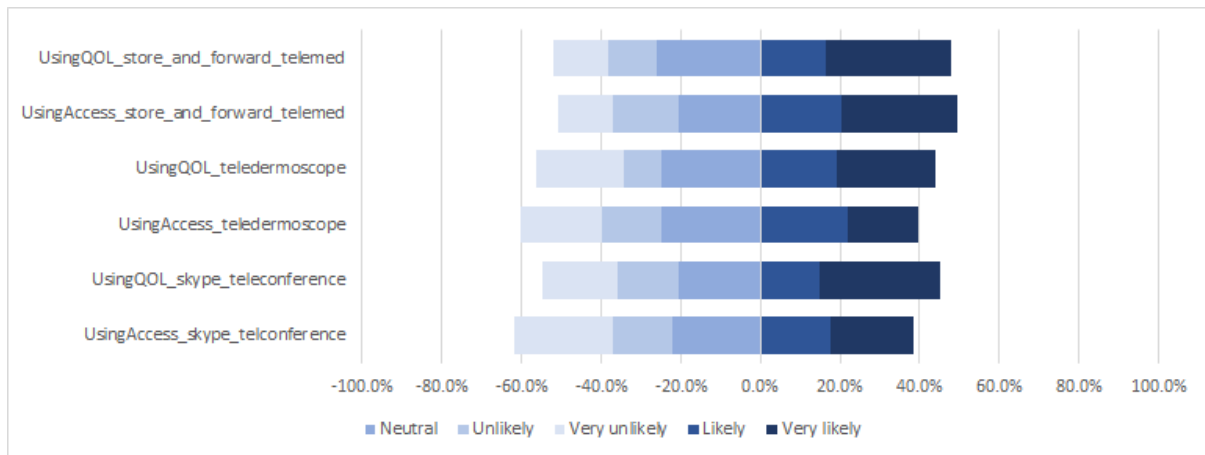
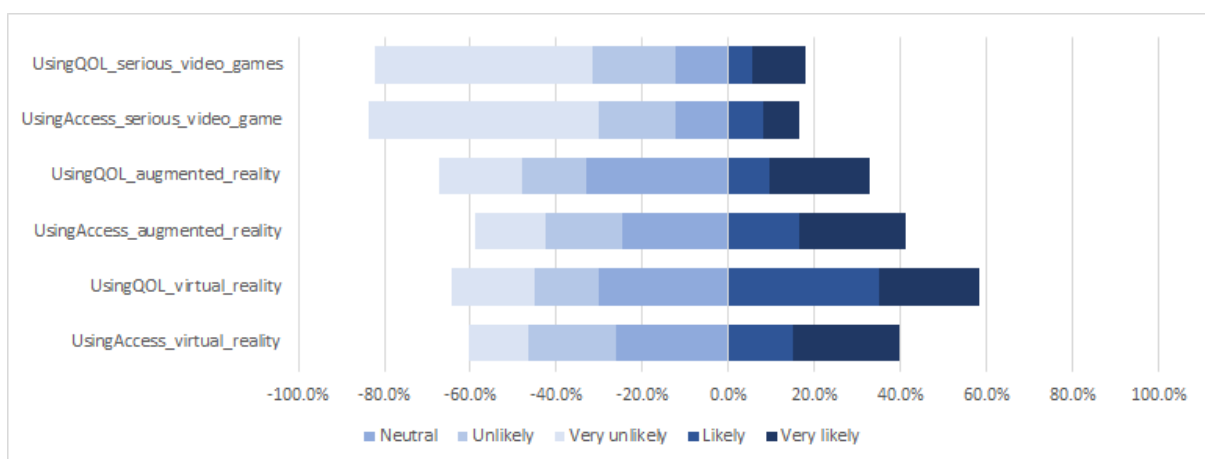


Figure 15

Patient willingness to use gamification and immersive technologies in melanoma post-treatment care



The findings suggest that, overall, melanoma patients are willing to use digital health to increase their access to care and improve their quality of life. However, the difference in distribution between the figures suggests that patients' attitude toward digital health widely differs by technology offered/available.

Figures 10 and 11 show that all mobile technologies and ICT technologies (with the exception of web-based apps) received a great level of acceptance by participants for increasing access to care (52.1 – 78.1%). Figure 10 shows that email and texts sent via mobile phone were the digital interventions most likely to be used to increase access to care and quality of life. In contrast, acceptance of gamification for increasing access to care was very low (16.4 – 41.1%, see Figure 15). However, 58.3% of participants were likely, or very likely, to be open to using Virtual Reality to improve their quality of life.

Self-monitoring interventions, including digital skin mapping, were also well-accepted by participants (52.1 – 60.3%, see Figure 13). Of interest, only around half of the participants are willing to use social media to manage their care (41.4% - 57.5%), with Facebook and online forums ranking the highest.

The above findings suggest that participants have similar attitudes towards telehealth support technologies (see Figure 14). It is important to note that of the support technologies provided, teleconsultations ranked the lowest for both increased access to care and quality of life.

Benefits of using digital health

As discussed in Chapter 6, participants answered two open-ended questions to understand their perception of (1) digital health benefits in melanoma care, including follow-up visits and supportive care; and (2) the impact of technology increasing access to melanoma care.

Table 12 provides a list of the most extracted codes and the emergent themes from summative content analysis of responses to the first open-ended question. The findings show that most melanoma patients (49/73, 67.1%) perceived benefits in using technology within their overall melanoma care, while 16/73 (21.9%) did not see any benefits.

The positive responses identified three prominent themes: increased access to care, psychological support, and patient empowerment. Two other less common themes were identified: promoting early detection and increasing quality of care.

Table 12

Results to the question: 'What benefits do you think using technology could bring to your melanoma care?'

Participants' reply	Frequency	Percentage
Yes	49	67.1%
Increased access to care	22	44.9%
Increase quality of care	6	12.2%
Patient's empowerment	17	34.7%
Psychosocial support	19	38.8%
Promote early detection	8	16.3%
Unsure	6	8.2%
No	16	21.9%
Missing	2	2.7%

Note. N=73.

Theme 1: Increased access to care

Many participants thought that technology would benefit them by giving them quicker, cheaper and easier access to care:

“Not having to travel to specialists. Skype would be so helpful... it’s hard travelling while having a shake and bake etc....takes so much effort and time. [...]I feel so isolated and stuck and just like an outcast because I am not in a big city. It’s a bit of effort getting on a plane for a half-hour appointment, buying plane tickets, paying the hotel, going to hospital, seeing doctors.”

Participants also saw benefits in using technology for the convenience of being able to receive health care services at any time:

“Support at your fingertips.”

“Could provide support outside of a clinical environment.”

Communicating more efficiently with healthcare professionals was also identified as one of the benefits of technology to increase access to care:

“To answer questions or concerns as they come up, to help overcome time delays in reviews.”

Theme 2: Psychological support

The second most prominent theme was ‘psychosocial support’, which included psychological support (e.g., reassurance, anxiety management) and online-group support:

“It could help manage anxiety and expectations. Specialists most often only deal with the medical side, not the reality of emotions and feelings.”

“Reassurance without the cost. Provide information/knowledge. Alleviate anxiety.”

“Online forums talking about the disease, and learning what could help through talking to other melanoma patients.”

“I find a Facebook support group very useful and informative.”

A link between cheaper and quicker access to care and peace of mind was also identified:

“Reassurance without the cost. Provide information/knowledge. Alleviate anxiety.”

“Help ease any concerns between monthly appointments.”

Theme 3: Patient empowerment

The other central theme was that digital health technology could add value to melanoma care by increasing patient empowerment. For example, providing better access to information and educational support (e.g., melanoma, mole recognition) and awareness about TSSE and self-monitoring would enable patients to have greater control over their care.

“Timely information.”

“Allow me to learn more about what to look out for.”

“Recognition and monitoring.”

“Give control to consumers.”

Theme 4: Promote early detection

Some respondents reported that technology would specifically benefit them by promoting early detection, allowing them to learn more about mole recognition and/or use their mobile phones to track mole changes. Ultimately this would increase their confidence in performing TSSE and therefore improve melanoma early detection.

“I think it would make me feel more confident that my skin checks were accurate.”

“Phone Apps that can help track skin changes that we could use would be great.”

“Use of cameras to check moles.”

Others also mentioned that technology could benefit them by sending reminders to self-monitor.

Theme 5: Increase patient care quality

Only six participants commented explicitly on how technology could add value by increasing the quality of the care they receive. These responses included providing better diagnostics, better access to specialists, better ways of sharing information, and improved communications between clinicians and patients.

“Not having to travel to specialists. Skype would be so helpful [...] takes so much effort and time. Surely a doc here could do blood pressure etc before Skype with a specialist...”

“Easy communication between patient and medical staff to check in with patients.”

“Providing accurate visual records.”

Table 13 provides a list of the most extracted codes and the emergent themes for the second open-ended question. The below findings show that most melanoma patients (42/73, 57.5%) perceived benefits in using technology to increase their access to care, while 12/73 (16.4%) did not see any benefits.

Three key themes emerged amongst the positive responses: ‘more accommodating’, ‘better communication’ and ‘quicker access’. 16.7% of patients mentioned better detection and diagnosis, while less than 10% mentioned that technology would increase their access to care by making it cheaper.

Table 13

Results to the question: ‘How do you think technology could increase your access to care?’

Participants' reply	Frequency	Percentage
Yes	42	57.5%
<i>Quicker access</i>	20	47.6%
<i>Cheaper access</i>	4	9.5%
<i>More accommodating</i>	27	64.3%
<i>Better communication</i>	25	59.5%
<i>Better detection and diagnosis</i>	7	16.7%
Unsure	14	19.2%
No	12	16.4%
Missing	5	6.8%

Note. N=73.

Theme 1: More accommodating

Participants reported that technology would increase their access to care by providing more convenient care tailored to their individual needs.

“To be able to contact your doctor outside of your appointment times could help to ease any stress.”

“Allow frequency to suit individual needs.”

“More time manageable.”

Theme 2: Better communication

The second most prominent theme was ‘better communication’, with comments referring to improved communication between clinicians and patients through eHealth platforms and teleconsultations, and the ability to receive more timely and tailored information.

“Phoning, texting or emailing telling me of changes.”

“I’ve just started using a Zoom meeting place to keep in contact with an environmental group, and it’s a great way to communicate. Definitely would be interested in accessing care through that way....”

“Provide up to date treatment advances, advise more timely reporting of scan results.”

“To be able to contact your doctor outside of your appointment times could help to ease any stress.”

Other responses within this theme mentioned that technology could help them find adequate information online, increase their knowledge and allow them to connect with other melanoma patients.

“Finding the info we need.”

“Provide more information about the latest treatments.”

“It would arm me with a deeper knowledge.”

“Widen access to other melanoma patients.”

Theme 3: Quicker access

The respondents mentioned that digital health technology could improve their care by providing quicker access. This included responses about using teleconsultations to enable remote access, getting assistance sooner, easing the process to make an appointment and receiving results in a more timely manner.

“I could save a lot of travelling time.”

“Provide on-time care and prevent time delays in travel and unnecessary time off work.”

“Speed, frequency & affordability of access.”

“Direct follow up for concerns using technology would be ok to check on side effects and other minor concerns, but we still need one on one meetings.”

Theme 4: Better detection and diagnosis

Some respondents reported that technology could benefit them by improving the diagnostic process – promoting early detection through increasing surveillance, and enabling remote monitoring.

“Good reminder tools to check your skin.”

“Earlier diagnosis. Early diagnosis seems to be the only successful treatment for melanoma.”

“Would support self-examination.”

Theme 5: Cheaper access

While cheaper and quicker access are related given they often involve teleconsultations and remote access, a small number of patients explicitly mentioned cost savings as a way that technology would increase their access to care.

“Not having to travel.”

“Could have saved so much. Wish the powers to have compassion and bring in Skype appointments.”

“More cost-effective.”

Main analyses

The objective of the main analysis was to understand relationships between demographic characteristics, access to post-treatment care, psychological needs, and attitude toward digital health to answer the formerly identified research question: “*Could technology help improve melanoma post-treatment care in patients who face difficulties in accessing health care?*”.

To this end, several Spearman correlations and MANOVA analyses were conducted on multiple variables to verify the hypotheses described Chapter 5.

Demographic characteristics and access to post-treatment care

Researchers tested the hypotheses regarding associations between demographic characteristics and access to post-treatment, specifically:

- Melanoma patients living in rural areas will report poorer access to, and satisfaction with, their care than those living in urban areas (**H1**);
- Melanoma patients who need to travel longer distance to follow-up visits will report poorer access to, and satisfaction with, their care than those living closer (**H2**);
- Melanoma patients coming from lower socioeconomic backgrounds will report poorer access to, and satisfaction with, their care than those coming from higher socioeconomic backgrounds (**H3**).

Spearman’s correlation analyses attempted to understand whether access to melanoma post-treatment care (which includes access to facilities, information and clinician recommendations) varied based on demographic characteristics such as residential status (rural vs urban), distance to the follow-up clinic, and socioeconomic factors (level of education and annual income). As employment was a categorical variable, it was analysed using MANOVA rather than correlation analysis. Results are summarised in Table 14.

Table 14

Correlations between demographic characteristics and access to melanoma post-treatment care services

		Individual characteristics				
		Socioeconomic factors				
		Residential area	Travelled	Level of education	Annual incomes	Employment
Received information about:						
	disease evolution	r(83)=-.117, p=.29; r(83)=-.009, p=.93; r(84)=-.286, p=.006; r(84)=-.226, p=.035 (F(2,77) = .713, p=.493)				
	melanoma treatment	r(92)=-.022, p=.85; r(92)=-.084, p=.42; r(93)=-.034, p=.74; r(93)=-.064, p=.54; (F(2,77) = 1.592, p=.210)				
	self-skin examination	r(92)=-.063, p=.55; r(92)=-.038, p=.718; r(93)=-.067, p=.52; r(93)=-.044, p=.67; (F(2,77) = .349, p=.706)				
	melanoma psychological implications	r(90)=-.037, p=.77; r(90)=-.006, p=.95; r(91)=-.107, p=.313; r(91)=-.105, p=.321 (F(2,77) = .638, p=.531)				
	social group support	r(91)=-.106, p=.316; r(91)=-.100, p=.34; r(92)=-.014, p=.898; r(91)=-.085, p=.421 (F(2,77) = 2.546, p=.085)				
Satisfaction with the amount of information received on:						
	disease evolution	r(94)=-.131, p=.209; r(94)=-.125, p=.23; r(95)=-.208, p=.04; r(95)=-.116, p=.263 (F(2,90) = .826, p=.441)				
	melanoma treatment	r(94)=-.078, p=.45; r(94)=-.080, p=.44; r(95)=-.053, p=.61; r(95)=-.044, p=.67 (F(2,90) = .186, p=.831)				
	self-skin examination	r(93)=-.009, p=.93; r(93)=-.016, p=.88; r(94)=-.153, p=.14; r(94)=-.054, p=.60 (F(2,90) = .896, p=.412)				
	melanoma psychological implications	r(94)=-.019, p=.858; r(94)=-.150, p=.14; r(95)=-.051, p=.62; r(95)=-.069, p=.50 (F(2,90) = .383, p=.683)				
	social group support	r(93)=-.081, p=.43; r(93)=-.160, p=.12; r(94)=-.064, p=.54; r(94)=-.064, p=.54 (F(2,90) = .894, p=.413)				
Satisfaction with the quality of information received on:						
	disease evolution	r(94)=-.151, p=.14; r(94)=-.158, p=.12; r(95)=-.192, p=.06; r(95)=-.090, p=.38 (F(2,90) = .040, p=.961)				
	melanoma treatment	r(94)=-.113, p=.280; r(94)=-.030, p=.77; r(95)=-.038, p=.71; r(95)=-.016, p=.875 (F(2,90) = .326, p=.723)				
	self-skin examination	r(93)=-.062, p=.56; r(93)=-.009, p=.92; r(94)=-.170, p=.10; r(94)=-.057, p=.58 (F(2,90) = .706, p=.496)				
	melanoma psychological implications	r(94)=-.100, p=.340; r(94)=-.131, p=.20; r(95)=-.091, p=.38; r(95)=-.088, p=.38 (F(2,90) = .052, p=.946)				
	social group support	r(93)=-.037, p=.72; r(93)=-.113, p=.28; r(94)=-.091, p=.38; r(94)=-.014, p=.89 (F(2,90) = .394, p=.675)				
Received clinicians recommendations for:						
	psychologist	r(94)=-.054, p=.60; r(94)=-.014, p=.89; r(95)=-.095, p=.38; r(95)=-.056, p=.55 (F(2,92) = .451, p=.638)				
	psychiatrist	r(94)=-.058, p=.58; r(94)=-.208, p=.04; r(95)=-.114, p=.271; r(95)=-.193, p=.06 (F(2,92) = 1.395, p=.253)				
	councillor	r(94)=-.073, p=.48; r(94)=-.000, p=1; r(95)=-.068, p=.51; r(95)=-.072, p=.48; (F(2,92) = 1.048, p=.355)				
	nurse	r(94)=-.062, p=.55; r(94)=-.169, p=.103; r(95)=-.023, p=.82; r(95)=-.095, p=.38 (F(2,92) = .900, p=.410)				
	others	r(94)=-.033, p=.75; r(94)=-.038, p=.71; r(95)=-.146, p=.157; r(95)=-.087, p=.40 (F(2,92) = .132, p=.876)				
	none	-	-	r(95)=-.064, p=.54; r(95)=-.126, p=.225 (F(2,92) = 1.836, p=.165)		
to facility care (e.g. clinic, hospital):						
	travel time to follow-up visits	r(94)=-.126, p=.225; r(94)=-.350, p<.001; r(95)=-.017, p=.86; r(95)=-.126, p=.22 (F(2,35) = .944, p=.399)				
	travel cost to follow-up visits	r(94)=-.120, p=.250; r(94)=-.312, p=.002; r(95)=-.090, p=.38; r(95)=-.177, p=.08 (F(2,35) = .678, p=.514)				
	taking time off work	r(94)=-.062, p=.55; r(94)=-.257, p=.012; r(95)=-.036, p=.73; r(95)=-.001, p=.99 (F(2,35) = 3.23, p=.049)				
	long waiting time for appointment	r(94)=-.029, p=.78; r(94)=-.192, p=.064; r(95)=-.049, p=.63; r(95)=-.045, p=.66 (F(2,35) = .777, p=.467)				
	follow-up visit direct cost	r(94)=-.019, p=.85; r(94)=-.184, p=.076; r(95)=-.096, p=.35; r(95)=-.056, p=.58 (F(2,35) = 1.064, p=.356)				
	other impacts	r(93)=-.120, p=.254; r(93)=-.035, p=.83; r(93)=-.304, p=.06; r(93)=-.077, p=.66 (F(2,35) = .225, p=.793)				

Residential areas (rural vs urban)

Direct access to facilities

There was no correlation between residential areas and factors identified as barriers to follow-up appointments.

Access to information

There was no correlation between residential areas and type of information received, nor satisfaction with the amount and quality of information received at the time of diagnosis.

Travelled distance

Direct access to facilities

Patients who live the farthest from their clinical appointments were more likely to experience difficulties related to travel time ($r = .350, p < .001$), travel cost ($r = .312, p = .002$), and having to take time off work ($r = .257, p = .012$).

Access to information

The findings showed that the farther patients needed to travel to their clinical appointments, the less likely they were to receive a recommendation to see a psychiatrist ($r = -.208, p = .044$).

Socioeconomic status

Direct access to facilities

There were no significant correlations between factors limiting access to follow-up appointments and the highest level of education attained, nor annual incomes. The results also showed that taking time off work to attend follow-ups differed significantly by employment status ($F(2,35) = 3.39; p = .049$), with a pairwise comparison showing that those in full-time employment were more likely to need to take time off work ($M = 2.78$), than those without employment ($M = 1.94, p = .039$). Given this, there was no significant difference between those in full-time compared to part-time employment, nor those in part-time compared to no employment. No other aspects of access to care significantly differed by employment status.

Access to information

Patients who had attained a higher education level were less likely to receive information related to disease evolution at time of diagnosis ($r = .286, p = .008$), and more likely to express dissatisfaction with the quantity of information received ($r = -.208, p = .043$), but not the quality. Similarly, patients with higher annual incomes were less likely to receive

information on disease evolution at the time of diagnosis ($r = .226, p = .039$). However, the results showed no correlation between employment status and access to information, nor annual income and satisfaction with the amount, or quality, of received information.

Overall, socioeconomic factors did not have a major impact on access to post-treatment care. Patients coming from higher socioeconomic backgrounds were more likely to be unsatisfied with quality of information received at the time of diagnosis, and those who are employed may face more additional difficulties to access their follow-up appointments if it requires taking time off work.

Demographic characteristics and psychological implications

The study hypothesised that demographic characteristics will be associated with melanoma-related psychological implications, specifically:

- Melanoma patients living in rural areas will experience psychological difficulties related to melanoma more frequently than those living in urban areas (**H4**);
- Melanoma patients who need to travel longer distance to follow-up routines will experience psychological difficulties related to melanoma more frequently than those living closer (**H5**);
- Melanoma patients coming from lower socioeconomic backgrounds will experience psychological difficulties related to melanoma more frequently than those coming from higher socioeconomic backgrounds (**H6**).

Spearman's correlations and MANOVA analyses were conducted. Results are summarised in Table 15.

Table 15

Correlations between demographic factors and melanoma-related psychological impacts

Psychological implications	Individual characteristics				
	Residential area		Socioeconomic factors		
	distance		Level of education	Annual incomes	Employment
Treatment related morbidity	r(94)=.087, p=.405	r(94)=.282, p=.006	r(95)=-.007, p=.944	r(95)=-.043, p=.679	(F(2,40) =.587, p=.560)
Fear of cancer recurrence	r(94)=-.224, p=.030	r(94)=.139, p=.180	r(95)=-.062, p=.552	r(95)=.179, p=.082	(F(2,40) =1.451, p=.246)
Ovethinking about treatment	r(93)=-.034, p=.744	r(93)=.246, p=.018	r(94)=-.097, p=.353	r(94)=.091, p=.382	(F(2,40) =1.422, p=.253)
Anxiety prior to follow-up	r(94)=-.154, p=.138	r(94)=.103, p=.323	r(95)=-.018, p=.860	r(95)=-.018, p=.861	(F(2,40) =1.753, p=.186)
Anxiety between follow-up	r(93)=-.099, p=.343	r(93)=.223, p=.032	r(94)=-.062, p=.553	r(94)=.074, p=.481	(F(2,40) =1.186, p=.316)
Decrease self-esteem	r(93)=.023, p=.830	r(93)=.285, p=.006	r(95)=-.016, p=.879	r(94)=-.059, p=.572	(F(2,40) =2.737, p=.077)
Decrease in general wellbeing	r(94)=.011, p=.917	r(94)=.275, p=.007	r(95)=.009, p=.931	r(95)=-.043, p=.677	(F(2,40) =.071, p=.932)
Change in relationships	r(94)=-.041, p=.696	r(94)=.284, p=.005	r(95)=.002, p=.984	r(95)=-.020, p=.848	(F(2,40) =.065, p=.937)
Desire to seek reassurance	r(94)=-.065, p=.534	r(94)=-.004, p=.975	r(95)=-.091, p=.381	r(95)=-.028, p=.786	(F(2,40) =1.284, p=.288)
Need for more social support	r(94)=-.009, p=.934	r(94)=.181, p=.082	r(95)=-.019, p=.853	r(95)=-.092, p=.375	(F(2,40) =1.273, p=.291)
Need for more emotional/psychological support	r(94)=-.055, p=.601	r(94)=.168, p=.105	r(95)=-.014, p=.895	r(95)=-.055, p=.596	(F(2,40) =1.309, p=.281)
Others	r(43)=-.034, p=.827	r(43)=.260, p=.092	r(43)=.060, p=.702	r(43)=-.144, p=.357	(F(2,40) =.227, p=.798)

Table 14 shows some associations between distance travelled and how patients were coping psychologically with melanoma. The further patients needed to travel to their clinical appointments, the more likely they were to report psychological needs from melanoma, including changes in relationships with others ($r = .284, p = .005$), reduced self-esteem ($r = .285, p = .006$) and wellbeing ($r = .275, p = .007$), as well as treatment-related morbidity ($r = .282, p = .005$) and overthinking about treatment ($r = .246, p = .018$). There was also a significant correlation between residential area and melanoma-related fear of cancer recurrence, with patients living in urban areas more likely to express fear of melanoma recurrence than those living in rural areas ($r = -.224, p = .030$). No other psychological implications significantly differed by demographic status.

Access to post-treatment care and psychological implications

The hypotheses that melanoma patients' access to post-treatment care will be associated with how they cope psychologically with the illness, with:

- Melanoma patients who face difficulties in accessing their follow-up visits frequently will report more psychological needs than those who don't experience them as often (**H7**);

- Melanoma patients who express lower satisfaction with the amount of information received at the time of diagnosis will report more psychological needs than those who don't experience them as often (**H8**);
- Melanoma patients who express lower satisfaction with the quality of information received at the time of diagnosis will report more psychological needs than those who don't experience them as often (**H9**).

To understand if there was a link between access to melanoma post-treatment care (including follow-up visits and access to information) and the psychological impacts of melanoma, MANOVA analyses were completed. Results are reported in Table 16 and Tables 17, 18.

Table 16

Correlations between barriers to access facility care and melanoma-related psychological impacts

Psychological implications	Access to facility care limitations				
	Travel time	Travel cost	Time off work	Waiting time	Follow-up cost
Treatment related morbidity	r(95)=.484, p<.001	r(95)=.485, p<.001	r(95)=.310, p=.002	r(95)=.221, p=.031	r(95)=.248, p=.016
Fear of cancer recurrence	r(95)=.363, p<.001	r(95)=.279, p=.006	r(95)=.224, p=.029	r(95)=.02, p=.051	r(95)=.247, p=.016
Ovethinking about treatment	r(94)=.502, p<.001	r(94)=.506, p<.001	r(94)=.288, p=.005	r(94)=.344, p=.001	r(94)=.323, p=.001
Anxiety prior to follow-up	r(95)=.293, p=.004	r(95)=.303, p=.003	r(95)=.274, p=.007	r(95)=.310, p=.002	r(95)=.349, p=.001
Anxiety between follow-up	r(94)=.407, p<.001	r(94)=.419, p<.001	r(94)=.346, p=.001	r(94)=.412, p<.001	r(94)=.447, p<.001
Decrease self-esteem	r(94)=.499, p<.001	r(94)=.482, p<.001	r(94)=.403, p=.001	r(94)=.397, p<.001	r(94)=.399, p<.001
Decrease in general wellbeing	r(95)=.529, p<.001	r(95)=.465, p<.001	r(95)=.440, p<.001	r(95)=.451, p<.001	r(95)=.418, p<.001
Change in relationships	r(95)=.437, p<.001	r(95)=.477, p<.001	r(95)=.436, p<.001	r(95)=.349, p=.001	r(95)=.454, p<.001
Desire to seek reassurance	r(95)=.233, p=.003	r(95)=.233, p=.003	r(95)=.112, p=.279	r(95)=.115, p=.266	r(95)=.270, p=.008
Need for more social support	r(95)=.390, p<.001	r(95)=.420, p<.001	r(95)=.416, p<.001	r(95)=.347, p=.001	r(95)=.421, p<.001
Need for more emotional/psychological support	r(95)=.446, p<.001	r(95)=.438, p<.001	r(95)=.402, p<.001	r(95)=.329, p=.001	r(95)=.417, p<.001

Table 17

Correlations between satisfaction with the amount of information received at time of diagnosis and melanoma-related psychological impacts

Psychological implications	Satisfaction with the amount of information received				
	Disease evolution	Treatment	Self-skin examination	Psychological	Social support group
Treatment related morbidity	r(95)=-.060, p=.562	r(95)=-.040, p=.702	r(94)=-.126, p=.225	r(95)=-.033, p=.751	r(94)=-.084, p=.422
Fear of cancer recurrence	r(95)=-.182, p=.078	r(95)=-.099, p=.342	r(94)=-.040, p=.701	r(95)=-.314, p=.002	r(94)=-.328, p=.001
Ovethinking about treatment	r(94)=-.042, p=.689	r(94)=-.051, p=.626	r(94)=-.041, p=.693	r(94)=-.211, p=.041	r(93)=-.144, p=.168
Anxiety prior to follow-up	r(95)=-.167, p=.105	r(95)=-.196, p=.057	r(94)=-.084, p=.421	r(95)=-.395, p<.001	r(94)=-.319, p=.002
Anxiety between follow-up	r(94)=-.217, p=.036	r(94)=-.276, p=.007	r(94)=-.033, p=.750	r(94)=-.431, p<.001	r(93)=-.466, p<.001
Decrease self-esteem	r(94)=-.193, p=.062	r(94)=-.306, p=.003	r(94)=-.056, p=.591	r(94)=-.335, p=.001	r(93)=-.258, p=.012
Decrease in general wellbeing	r(95)=-.207, p=.044	r(95)=-.205, p=.046	r(94)=-.152, p=.142	r(95)=-.349, p=.001	r(94)=-.230, p=.026
Change in relationships	r(95)=-.143, p=.166	r(95)=-.244, p=.017	r(94)=-.157, p=.130	r(95)=-.286, p=.005	r(94)=-.175, p=.092
Desire to seek reassurance	r(95)=-.028, p=.784	r(95)=-.127, p=.221	r(94)=-.020, p=.849	r(95)=-.287, p=.005	r(94)=-.206, p=.047
Need for more social support	r(95)=-.201, p=.051	r(95)=-.279, p=.006	r(94)=-.115, p=.269	r(95)=-.447, p<.001	r(94)=-.425, p<.001
Need for more emotional/psychological support	r(95)=-.186, p=.071	r(95)=-.256, p=.012	r(94)=-.091, p=.382	r(95)=-.438, p<.001	r(94)=-.356, p<.001

Table 18

Correlations between satisfaction with the quality of information received at time of diagnosis and melanoma-related psychological impacts

Psychological implications	Satisfaction with the quality of information received				
	Disease evolution	Treatment	Self-skin examination	Psychological	Social support group
Treatment related morbidity	r(95)=-.103, p=.321	r(95)=-.021, p=.839	r(94)=-.122, p=.241	r(95)=-.023, p=.822	r(94)=-.002, p=.983
Fear of cancer recurrence	r(95)=-.138, p=.182	r(95)=-.079, p=.444	r(94)=-.005, p=.964	r(95)=-.268, p=.009	r(94)=-.332, p=.001
Ovethinking about treatment	r(94)=-.041, p=.696	r(94)=-.033, p=.750	r(94)=-.062, p=.553	r(94)=-.196, p=.059	r(93)=-.198, p=.057
Anxiety prior to follow-up	r(95)=-.178, p=.085	r(95)=-.199, p=.053	r(94)=-.005, p=.963	r(95)=-.406, p<.001	r(94)=-.375, p<.001
Anxiety between follow-up	r(94)=-.248, p=.016	r(94)=-.262, p=.011	r(94)=-.059, p=.573	r(94)=-.450, p<.001	r(93)=-.406, p<.001
Decrease self-esteem	r(94)=-.245, p=.017	r(94)=-.289, p=.005	r(94)=-.099, p=.344	r(94)=-.350, p=.001	r(93)=-.322, p=.002
Decrease in general wellbeing	r(95)=-.220, p=.015	r(95)=-.191, p=.064	r(94)=-.164, p=.114	r(95)=-.338, p=.001	r(94)=-.278, p=.007
Change in relationships	r(95)=-.172, p=.096	r(95)=-.166, p=.107	r(94)=-.156, p=.132	r(95)=-.300, p=.003	r(94)=-.222, p=.031
Desire to seek reassurance	r(95)=-.052, p=.614	r(95)=-.155, p=.133	r(94)=-.002, p=.982	r(95)=-.268, p=.009	r(94)=-.251, p=.015
Need for more social support	r(95)=-.206, p=.045	r(95)=-.281, p=.006	r(94)=-.126, p=.226	r(95)=-.433, p<.001	r(94)=-.477, p<.001
Need for more emotional/psychological support	r(95)=-.200, p=.052	r(95)=-.260, p=.011	r(94)=-.117, p=.263	r(95)=-.445, p<.001	r(94)=-.421, p<.001

Table 16 illustrates significant correlations between negative psychological implications related to melanoma and perceptions of barriers to attending follow-up appointments. This means that the more patients experienced difficulties accessing their care (travel time/cost, waiting time, follow-up cost, taking time off work), the more likely they were to report the various psychological impacts they were asked about.

There were similar patterns regarding patient satisfaction with the amount (see Table 17) and quality (see Table 18) of received information at the time of diagnosis, especially for information related to melanoma-associated psychological impacts and the existence of social

group support. The only factor that did not psychologically impact patients was information about total skin self-examination. Overall, the more dissatisfied a patient was with the quantity and quality of information received, the more likely they were to experience a negative psychological impact.

Secondary research questions

In addition to identifying the gaps in post-treatment care and associated factors, the current project aimed to investigate potential digital solutions to overcome these issues. As previously mentioned in Chapter 5, it was essential to understand how melanoma patients have used technology to date, and if this varied by individual characteristics, to inform how technology intake to improve melanoma care can be increased. Table 11 presents summary data for current digital health adoption.

It is important to note that these results relate to the restricted sample ($n = 73$), as explained in the ‘*Reliability of measure*’ section.

Current use of digital health in post-treatment care

The hypotheses tested whether individual characteristics such as demographics, socioeconomic status and illness condition will impact how patients currently use digital health in their post-treatment care, specifically:

- The younger melanoma patients were, the more likely they are to use technology in their post-treatment care (**H10**);
- Female patients are more likely to use technology for their post-treatment care than male patients (**H11**);
- Patients who have a more advanced condition will be less likely to use technology in their post-treatment care than those at an earlier condition (**H12**);

- Patients from lower socioeconomic backgrounds will be less likely to use technology in their post-treatment care than those from higher socioeconomic backgrounds (**H13**).

Spearman’s correlation analyses were used to investigate if patients’ current use of technologies in melanoma post-treatment care was associated with demographic characteristics and illness conditions. As employment was a categorical variable, it was analysed using MANOVA rather than correlation analysis. Results are summarised in Table 19 and Table 20.

Table 19

Correlations between individual characteristics and current use of digital health

Technology currently used	Individual characteristics			
	Demographics		Illness condition	
	Age	Gender	Melanoma thickness	Cancer recurrence
Mobile phone text message	r(60)=-.036, p=.784	r(61)=.151, p=.245	r(50)=-.159, p=.269	r(61)=-.151, p=.245
Email	r(61)=-.038, p=.769	r(62)=.023, p=.857	r(51)=-.382, p=.006	r(62)=-.241, p=.059
Mobile phone camera	r(61)=.283, p=.027	r(62)=.025, p=.848	r(51)=-.036, p=.804	r(62)=.129, p=.317
Mobile applications	r(57)=-.036, p=.787	r(58)=.076, p=.571	r(48)=-.221, p=.131	r(58)=-.055, p=.697
Websites	r(67)=.082, p=.508	r(68)=.069, p=.576	r(56)=-.020, p=.886	r(68)=.040, p=.747
Web-based apps	r(56)=.067, p=.622	r(57)=.060, p=.655	r(46)=-.057, p=.707	r(57)=-.050, p=.712
Digital skin map	r(61)=.097, p=.455	r(61)=.068, p=.602	r(51)=-.011, p=.937	r(61)=-.092, p=.480
Youtube videos	r(62)=-.109, p=.398	r(62)=-.029, p=.820	r(50)=-.189, p=.189	r(62)=-.137, p=.290
Facebook	r(65)=-.321, p=.009	r(65)=-.008, p=.951	r(53)=-.220, p=.113	r(65)=.008, p=.708
Online forum discussion	r(65)=-.316, p=.010	r(65)=.119, p=.347	r(53)=-.324, p=.018	r(65)=-.224, p=.073
Teleconference platform/teleconsultation	r(60)=.068, p=.608	r(60)=.292, p=.024	r(49)=-.133, p=.364	r(60)=-.154, p=.239
Teledermoscope	r(49)=-.265, p=.066	r(49)=.215, p=.137	r(40)=-.014, p=.934	r(49)=-.067, p=.649
Self-monitoring supportive tools	r(54)=-.233, p=.090	r(54)=.066, p=.054	r(46)=-.250, p=.094	r(54)=-.116, p=.405
Store and forward telemedicine	r(45)=.000, p=1.000	r(46)=-.083, p=.543	r(39)=-.369, p=.021	r(46)=-.265, p=.075

Table 20

Correlations between socioeconomic status and current use of digital health

Technology currently used	Socioeconomic status				
	Travelled distance	Residential area	Level of education	Annual incomes	Employment
Mobile phone text message	r(60)=.097, p=.459	r(60)=-.012, p=.929	r(61)=.030, p=.818	r(61)=.001, p=.994	(F(2,70) =.274, p=.761)
Email	r(61)=-.047, p=.719	r(61)=.130, p=.317	r(62)=.045, p=.730	r(62)=-.063, p=.626	(F(2,70) =2.071, p=.134)
Mobile phone camera	r(61)=-.023, p=.857	r(61)=.318, p=.012	r(62)=-.059, p=.649	r(62)=.022, p=.864	(F(2,70) =.824, p=.443)
Mobile applications	r(57)=.121, p=.370	r(57)=.452, <.001	r(58)=-.211, p=.112	r(58)=-.231, p=.081	(F(2,70) =4.986, p=.009)
Websites	r(67)=.155, p=.209	r(67)=.028, p=.822	r(68)=.081, p=.509	r(68)=.008, p=.950	(F(2,70) =1.345, p=.267)
Web-based apps	r(56)=.147, p=.280	r(56)=.156, p=.252	r(57)=-.144, p=.284	r(57)=.073, p=.587	(F(2,70) =.548, p=.580)
Digital skin map	r(61)=-.192, p=.138	r(61)=.283, p=.027	r(61)=.151, p=.244	r(61)=-.009, p=.947	(F(2,70) =1.598, p=.210)
Youtube videos	r(62)=.055, p=.670	r(62)=-.177, p=.168	r(62)=-.238, p=.063	r(62)=.052, p=.689	(F(2,70) =1.041, p=.358)
Facebook	r(65)=.047, p=.711	r(65)=.113, p=.370	r(65)=-.194, p=.121	r(65)=-.047, p=.708	(F(2,70) =5.462, p=.006)
Online forum discussion	r(65)=-.177, p=.159	r(65)=.206, p=.099	r(65)=-.073, p=.561	r(65)=-.032, p=.799	(F(2,70) =2.410, p=.097)
Teleconference platform/teleconsultation	r(60)=.021, p=.871	r(60)=.074, p=.574	r(60)=-.008, p=.952	r(60)=.049, p=.708	(F(2,70) =1.055, p=.354)
Teledermoscope	r(49)=.134, p=.359	r(49)=.146, p=.316	r(49)=.145, p=.320	r(49)=.040, p=.784	(F(2,70) =.769, p=.467)
Self-monitoring supportive tools	r(54)=-.065, p=.642	r(54)=.282, p=.039	r(54)=.047, p=.736	r(54)=-.163, p=.240	(F(2,70) =.101, p=.904)
Store and forward telemedicine	r(45)=.112, p=.465	r(45)=.347, p=.020	r(46)=.050, p=.742	r(45)=.233, p=.118	(F(2,70) =.266, p=.768)

Demographic characteristics

The results illustrate that use of some technologies differed by age. Specifically, the older patients were, the less likely they were to use mobile cameras ($r = .283, p = .027$), facebook ($r = .321, p = .009$,) and online forums ($r = .316, p = .010$). Additionally, Table 11 showed that the only significant correlation between gender and current use of technology was for teleconsultation, with women more likely to utilise teleconsultations than men ($r = .292, p = .024$).

Illness conditions

Patients with deeper melanoma were more likely to use some technologies, namely email ($r = -.382, p = .006$), online forum discussions ($r = -.324, p = .018$), and store and forward telemedicine ($r = -.369, p = .021$). Recurrence didn't seem to impact how melanoma patients currently use digital health within their care.

Socioeconomic status

The results showed that patients' current use of digital health in melanoma care is affected only by residential area and employment status. Patients living in rural areas were

significantly less likely to currently use the following technologies than those living in urban areas: mobile camera ($r = .318, p = .012$), mobile apps ($r = .412, p < .0005$), digital skin map ($r = .283, p = .027$), self-monitoring tool ($r = .282, p = .039$), store and forward telemedicine ($r = .347, p = .020$). In addition, current use of mobile applications ($F(2,70) = 4.986, p = .009$) and Facebook ($F(2,70) = 5.462, p = .006$) differed significantly by employment status. A pairwise comparison revealed that the current use of mobile apps and Facebook were significantly lower for those working part-time/casual (Facebook: $M = 1.29, p = .009$; mobile apps: $M = 1.76, p = .021$) and full-time (Facebook: $M = 1.48, p = .048$; mobile apps: $M = 1.85, p = .031$) compared to those without employment.

Willingness to use digital health in melanoma post-treatment

Individual characteristics and future use of technology

Hypotheses that individual characteristics such as demographic, socioeconomic status and illness condition will be associated with patient willingness to use digital health in their post-treatment care were tested, specifically:

- The younger melanoma patients are, the more willing they will be to use technology to increase access to post-treatment care (**H14**);
- The younger melanoma patients are, the more willing they will be to use technology to improve their quality of life (**H15**);
- Female patients will be more willing to use technology to increase access to post-treatment care than male patients (**H16**);
- Female patients will be more willing to use technology to improve their quality of life than male patients (**H17**);
- Patients at a more advanced condition will be more willing to use technology to increase access to post-treatment care than those at an earlier condition (**H18**);
- Patients at a more advanced condition will be more willing to use technology to improve quality of life than those at an earlier condition (**H19**);

- Patients from a lower socioeconomic background will be less willing to use technology to increase access to post-treatment care than those from a higher socioeconomic background (**H20**).
- Patients from a lower socioeconomic background will be less willing to use technology to improve quality of life than those from a higher socioeconomic background (**H21**).

To test these hypotheses, Spearman’s correlations were carried out, and MANOVA was used on employment. Tables 21-24 is a summary of the data generated by the analyses.

Table 21

Correlations between individual characteristics and benefits of using technology to increase access to melanoma post-treatment care

Technology to increase access to care	Individual characteristics			
	Demographics		Illness condition	
	Age	Gender	Melanoma thickness	Cancer recurrence
Mobile phone text message	r(72)=-.143, p=.231	r(73)=.140, p=.238	r(73)=-.098, p=.410	r(60)=.111, p=.399
Email	r(72)=-.182, p=.126	r(73)=.042, p=.725	r(73)=-.088, p=.461	r(60)=.100, p=.447
Mobile phone camera	r(72)=-.311, p=.008	r(73)=.137, p=.248	r(73)=-.065, p=.583	r(60)=.071, p=.591
Mobile applications	r(72)=-.382, p=.001	r(73)=.164, p=.166	r(73)=-.069, p=.562	r(60)=.048, p=.718
Websites	r(72)=-.347, p=.003	r(73)=.105, p=.375	r(73)=.013, p=.916	r(60)=.123, p=.350
Web-based apps	r(72)=-.395, p=.001	r(73)=.061, p=.610	r(73)=-.051, p=.666	r(60)=.001, p=.996
Digital skin map	r(72)=-.218, p=.066	r(73)=.203, p=.086	r(73)=.027, p=.823	r(60)=-.109, p=.406
Youtube videos	r(72)=-.212, p=.074	r(73)=.130, p=.275	r(73)=.002, p=.985	r(60)=.017, p=.898
Facebook	r(72)=-.393, p=.001	r(73)=.043, p=.720	r(73)=.105, p=.375	r(60)=.252, p=.052
Other social media platform	r(69)=-.316, p=.008	r(70)=.115, p=.342	r(70)=.191, p=.114	r(59)=.138, p=.296
Online forum discussion	r(72)=-.360, p=.002	r(73)=-.029, p=.810	r(73)=.019, p=.876	r(60)=.158, p=.228
Teleconference platform/teleconsultation	r(72)=-.308, p=.009	r(73)=.085, p=.476	r(73)=.197, p=.096	r(60)=.045, p=.732
Teledermoscope	r(72)=-.298, p=.011	r(73)=.119, p=.317	r(73)=.184, p=.119	r(60)=-.061, p=.642
Self-monitoring supportive tools	r(72)=-.219, p=.065	r(73)=.267, p=.022	r(73)=-.095, p=.422	r(60)=.051, p=.701
Store and forward telemedicine	r(72)=-.188, p=.114	r(73)=.289, p=.013	r(73)=-.034, p=.775	r(60)=.001, p=.996
Virtual reality	r(72)=-.213, p=.073	r(73)=.141, p=.235	r(73)=-.022, p=.851	r(60)=-.039, p=.766
Augmented reality	r(72)=-.192, p=.107	r(73)=.107, p=.367	r(73)=.004, p=.974	r(60)=-.015, p=.910
Serious video games	r(72)=-.351, p=.002	r(73)=-.074, p=.533	r(73)=.188, p=.112	r(60)=.028, p=.831

Table 22

Correlations between socioeconomic status and benefits of using technology to increase access to melanoma post-treatment care

Technology to increase access to care	Socioeconomic status				
	Travelled distance	Residential area	Level of education	Annual incomes	Employment
Mobile phone text message	r(72)=-.065, p=.588	r(72)=.022, p=.857	r(73)=.262, p=.025	r(73)=.086, p=.470	(F(2,67) =1.020, p=.366)
Email	r(72)=.088, p=.462	r(72)=-.156, p=.192	r(73)=.246, p=.036	r(73)=.160, p=.175	(F(2,67) =1.128, p=.330)
Mobile phone camera	r(72)=.248, p=.036	r(72)=-.127, p=.289	r(73)=.236, p=.042	r(73)=.221, p=.060	(F(2,67) =1.806, p=.172)
Mobile applications	r(72)=.245, p=.038	r(72)=-.100, p=.404	r(73)=.294, p=.012	r(73)=.285, p=.014	(F(2,67) =3.163, p=.049)
Websites	r(72)=.081, p=.501	r(72)=-.135, p=.258	r(73)=.258, p=.027	r(73)=.204, p=.083	(F(2,67) =2.359, p=.102)
Web-based apps	r(72)=.138, p=.249	r(72)=-.101, p=.398	r(73)=.301, p=.010	r(73)=.293, p=.012	(F(2,67) =3.584, p=.033)
Digital skin map	r(72)=.360, p=.002	r(72)=-.109, p=.363	r(73)=.205, p=.082	r(73)=.184, p=.119	(F(2,67) =.255, p=.776)
Youtube videos	r(72)=.155, p=.194	r(72)=.060, p=.618	r(73)=.224, p=.057	r(73)=.040, p=.736	(F(2,67) =1.927, p=.154)
Facebook	r(72)=.204, p=.086	r(72)=.003, p=.981	r(73)=.177, p=.134	r(73)=.153, p=.196	(F(2,67) =2.636, p=.079)
Other social media platform	r(69)=.259, p=.031	r(69)=.129, p=.290	r(70)=.044, p=.721	r(70)=.078, p=.522	(F(2,67) =3.527, p=.035)
Online forum discussion	r(72)=.281, p=.017	r(72)=.014, p=.910	r(73)=-.038, p=.748	r(73)=.099, p=.404	(F(2,67) =.865, p=.426)
Teleconference platform/teleconsultation	r(72)=.279, p=.018	r(72)=-.056, p=.639	r(73)=.222, p=.060	r(73)=.178, p=.132	(F(2,67) =1.784, p=.176)
Teledermoscope	r(72)=.202, p=.089	r(72)=.022, p=.854	r(73)=.264, p=.024	r(73)=.150, p=.206	(F(2,67) =.250, p=.780)
Self-monitoring supportive tools	r(72)=.189, p=.112	r(72)=-.068, p=.568	r(73)=.243, p=.038	r(73)=.151, p=.203	(F(2,67) =.536, p=.588)
Store and forward telemedicine	r(72)=.195, p=.100	r(72)=-.133, p=.264	r(73)=.338, p=.003	r(73)=.215, p=.068	(F(2,67) =.450, p=.640)
Virtual reality	r(72)=.115, p=.334	r(72)=.021, p=.863	r(73)=.355, p=.002	r(73)=.234, p=.047	(F(2,67) =.838, p=.437)
Augmented reality	r(72)=.165, p=.167	r(72)=.021, p=.859	r(73)=.290, p=.013	r(73)=.240, p=.041	(F(2,67) =.391, p=.678)
Serious video games	r(72)=-.019, p=.872	r(72)=-.025, p=.834	r(73)=.100, p=.398	r(73)=.196, p=.114	(F(2,67) =3.832, p=.027)

Table 23

Correlations between individual characteristics and benefits of using technology to increase quality of life

Technology to increase quality of life	Individual characteristics			
	Demographics		Illness condition	
	Age	Gender	Melanoma thickness	Cancer recurrence
Mobile phone text message	r(72)=-.324, p=.006	r(73)=.151, p=.203	r(73)=-.067, p=.572	r(60)=-.019, p=.884
Email	r(72)=-.264, p=.025	r(73)=.088, p=.457	r(73)=-.043, p=.718	r(60)=.091, p=.490
Mobile phone camera	r(72)=-.379, p=.001	r(73)=.137, p=.248	r(73)=-.064, p=.592	r(60)=.069, p=.602
Mobile applications	r(72)=-.378, p=.001	r(73)=-.172, p=.145	r(73)=-.035, p=.767	r(60)=.049, p=.711
Websites	r(72)=-.459, p<.001	r(73)=.007, p=.953	r(73)=.058, p=.625	r(60)=.128, p=.330
Web-based apps	r(72)=-.452, p<.001	r(73)=.115, p=.334	r(73)=-.039, p=.745	r(60)=-.037, p=.781
Digital skin map	r(72)=-.352, p=.002	r(73)=.154, p=.192	r(73)=-.028, p=.816	r(60)=-.015, p=.912
Youtube videos	r(72)=-.346, p=.003	r(73)=.060, p=.612	r(73)=.043, p=.716	r(60)=.095, p=.469
Facebook	r(72)=-.361, p=.002	r(73)=.009, p=.938	r(73)=.106, p=.374	r(60)=.198, p=.130
Other social media platform	r(69)=-.423, p<.001	r(70)=-.028, p=.817	r(70)=.115, p=.343	r(59)=.151, p=.255
Online forum discussion	r(72)=-.395, p=.001	r(73)=-.015, p=.902	r(73)=.086, p=.471	r(60)=.153, p=.243
Teleconference platform/teleconsultation	r(72)=-.438, p<.001	r(73)=.087, p=.462	r(73)=.188, p=.111	r(60)=.156, p=.234
Teledermoscope	r(72)=-.336, p=.004	r(73)=.061, p=.608	r(73)=.287, p=.014	r(60)=.065, p=.622
Self-monitoring supportive tools	r(72)=-.407, p<.001	r(73)=.055, p=.646	r(73)=.030, p=.803	r(60)=.062, p=.640
Store and forward telemedicine	r(72)=-.300, p=.010	r(73)=.116, p=.329	r(73)=.091, p=.444	r(60)=.152, p=.247
Virtual reality	r(72)=-.311, p=.008	r(73)=.052, p=.663	r(73)=.153, p=.197	r(60)=.091, p=.491
Augmented reality	r(72)=-.370, p=.001	r(73)=.016, p=.896	r(73)=.194, p=.099	r(60)=.107, p=.414
Serious video games	r(72)=-.449, p<.001	r(73)=-.238, p=.042	r(73)=.076, p=.525	r(60)=.009, p=.945

Table 24

Correlations between socioeconomic status and benefits of using technology to increase quality of life

Technology to increase quality of life	Socioeconomic status				
	Travelled distance	Residential area	Level of education	Annual incomes	Employment
Mobile phone text message	r(72)=.169, p=.155	r(72)=-.039, p=.748	r(73)=.159, p=.180	r(73)=.154, p=.195	(F(2,67) =1.218, p=.302)
Email	r(72)=.144, p=.229	r(72)=-.159, p=.182	r(73)=.142, p=.231	r(73)=.178, p=.132	(F(2,67) =1.029, p=.363)
Mobile phone camera	r(72)=.236, p=.046	r(72)=-.074, p=.536	r(73)=.177, p=.135	r(73)=.213, p=.070	(F(2,67) =2.784, p=.069)
Mobile applications	r(72)=.297, p=.011	r(72)=-.087, p=.465	r(73)=.217, p=.065	r(73)=.307, p=.008	(F(2,67) =4.587, p=.014)
Websites	r(72)=.151, p=.206	r(72)=-.131, p=.272	r(73)=.158, p=.182	r(73)=.194, p=.099	(F(2,67) =4.687, p=.012)
Web-based apps	r(72)=.205, p=.084	r(72)=-.135, p=.258	r(73)=.231, p=.049	r(73)=.247, p=.035	(F(2,67) =5.831, p=.005)
Digital skin map	r(72)=.266, p=.024	r(72)=-.179, p=.133	r(73)=.158, p=.183	r(73)=.180, p=.016	(F(2,67) =1.855, p=.164)
Youtube videos	r(72)=.104, p=.383	r(72)=.021, p=.858	r(73)=.181, p=.126	r(73)=.063, p=.597	(F(2,67) =2.183, p=.121)
Facebook	r(72)=.185, p=.119	r(72)=-.006, p=.962	r(73)=.104, p=.379	r(73)=.069, p=.562	(F(2,67) =2.053, p=.136)
Other social media platform	r(69)=.192, p=.115	r(69)=.093, p=.447	r(70)=.007, p=.951	r(70)=.065, p=.593	(F(2,67) =4.290, p=.018)
Online forum discussion	r(72)=.220, p=.064	r(72)=-.042, p=.726	r(73)=.123, p=.299	r(73)=.078, p=.513	(F(2,67) =2.795, p=.068)
Teleconference platform/teleconsultation	r(72)=.291, p=.013	r(72)=-.065, p=.588	r(73)=.168, p=.156	r(73)=.126, p=.290	(F(2,67) =2.924, p=.061)
Teledermoscope	r(72)=.180, p=.131	r(72)=-.093, p=.438	r(73)=.195, p=.098	r(73)=.036, p=.761	(F(2,67) =1.797, p=.174)
Self-monitoring supportive tools	r(72)=.131, p=.274	r(72)=-.047, p=.217	r(73)=.214, p=.069	r(73)=.200, p=.090	(F(2,67) =.818, p=.446)
Store and forward telemedicine	r(72)=.200, p=.093	r(72)=-.118, p=.323	r(73)=.393, p=.012	r(73)=.290, p=.040	(F(2,67) =1.014, p=.368)
Virtual reality	r(72)=.248, p=.036	r(72)=-.041, p=.734	r(73)=.088, p=.458	r(73)=.202, p=.087	(F(2,67) =1.479, p=.235)
Augmented reality	r(72)=.000, p=1.000	r(72)=-.041, p=.733	r(73)=.119, p=.316	r(73)=.236, p=.044	(F(2,67) =2.661, p=.077)
Serious video games	r(72)=.279, p=.122	r(72)=-.041, p=.730	r(73)=-.018, p=.878	r(73)=.170, p=.151	(F(2,67) =4.792, p=.011)

Demographic factors (age and gender)

Increasing access to care

There were significant correlations between age and willingness to use technology to increase access to care for the following technologies only: mobile phone camera ($r = -.311, p = .008$), mobile apps ($r = -.382, p = .001$), websites ($r = -.347, p = .003$), web-based apps ($r = -.395, p = .001$), Facebook ($r = -.393, p = .001$) and other social media ($r = -.316, p = .008$), online forum discussion ($r = -.360, p = .002$), teleconference platforms ($r = -.308, p = .009$), tele-dermoscope ($r = -.298, p = .011$) and serious video games ($r = -.351, p = .002$).

In addition, the results showed that females were more likely to use self-monitoring supportive technologies ($r = .267, p = .022$), and store and forward telemedicine ($r = .289, p = .013$) to increase access to care.

Improving quality of life

The findings showed that patients' willingness to use technology within their care was significantly associated with their age, particularly when improving their quality of life. For

each technology shown in Table 23, the younger patients were, the significantly more likely they were to integrate technology within their post-treatment care positively. The results also showed only one significant correlation between gender and benefits of using technology to improve quality of life, with males more likely to integrate serious video games into their care than females ($r = -.238, p = .042$). Overall, willingness to integrate digital health technology in melanoma care to improve quality of life was not linked to patients' age and gender.

Illness condition

The results show no significant correlations between cancer recurrence or melanoma thickness and patients' willingness to use technology within their care (except teledermoscope, which was positively correlated with melanoma thickness). This means that overall melanoma stages, and cancer recurrence, do not appear to influence patients' attitudes toward digital health interventions.

Socioeconomic status

The results illustrate that patients' willingness to use various technologies to increase their access to care and improve their quality of life was associated with travelling further to attend their follow-up appointments. It was also associated with having higher annual income and education levels. Employment status impacted on willingness to use mobile, web-based and gaming technologies. Residential area was the only socioeconomic factor not associated with patients' willingness to use any digital health technology.

Increasing access to care

The further patients lived from their clinic/hospital, the more willing they were to use digital skin mapping ($r = .360, p = .002$), online discussion forums ($r = .281, p = .017$), social media other than Facebook ($r = .259, p = .031$), mobile phone camera ($r = .248, p = .036$) and mobile phone apps ($r = .245, p = .038$) to increase their access to care.

In addition, the results showed that educated patients were more willing to use digital solutions such as virtual reality ($r = .355, p = .002$), store and forward telemedicine ($r = .338, p = .003$), web-based apps ($p = .010, r = .301$), mobile application ($r = .294, p = .012$), augmented reality ($r = .290, p = .013$), ect. to increase their access to care.

Regarding annual incomes, the more patients earned per year, the more willing they were to use web-based apps ($r = .293, p = .012$), mobile phone apps ($r = .285, p = .014$), augmented reality ($r = .240, p = .041$) and virtual reality ($r = .234, p = .047$) to increase their access to care.

The findings also reported that employment status affected patients' willingness to use mobile apps ($F(2,67) = 3.163, p = .049$) and web-based apps ($F(2,67) = 3.584, p = .033$), as well as social media others than Facebook ($F(2,67) = 3.527, p = .035$) and serious video games ($F(2,67) = 3.832, p = .027$). Pairwise comparisons revealed that patients working part-time/casual were more willing to use mobile apps ($M = 4.12, p = .034$), web-based apps ($M = 4.12, p = .010$), social media others than Facebook ($M = 3.88, p = .030$) and serious video games ($M = 2.65, p = .022$) compared to those with no employment. Notably, the same comparisons between those not employed and those employed full-time were not significant.

Improving quality of life

The further patients lived from their clinic/hospital, the more willing they were to use teleconsultation/skype ($r = .231, p = .013$), augmented reality ($r = .289, p = .022$), digital skin map ($r = .266, p = .024$), virtual reality ($r = .248, p = .036$) and mobile phone camera ($r = .236, p = .046$) to improve their quality of life.

Melanoma patients that have attained a higher level of education were more inclined in use store and forward telemedicine ($r = .393, p = .012$) and web-based applications ($r = .231, p = .049$).

The results also showed that patients with higher annual incomes were more willing to use mobile apps ($r = .307, p = .008$), digital skin map ($r = .280, p = .016$), web-based apps (r

= .247, $p = .035$), store and forward telemedicine ($r = .240$, $p = .040$) and augmented reality ($r = .236$, $p = .044$) to improve their quality of life.

Finally, results of employment status were also related to patients' perception toward digital health adoption to improve quality of life. Statistically significant results were found for the following technologies: mobile apps ($F(2,67) = 4.587$, $p = .014$) and web-based apps ($F(2,67) = 5.831$, $p = .005$), websites ($F(2,67) = 4.687$, $p = .012$) as well as social media other than Facebook ($F(2,67) = 4.290$, $p = .018$) and serious video games ($F(2,67) = 4.792$, $p = .011$). Pairwise analyses reported that both patients working full-time and part-time/casual were more willing than those without employment to use mobile apps ($M = 4.06$, $p = .006$; $M = 3.94$, $p = .035$), web-based apps ($M = 3.70$, $p = .008$; $M = 3.94$, $p = .005$), websites ($M = 4.04$, $p = .013$; $M = 4.18$, $p = .014$) and serious video games ($M = 2.48$, $p = .018$; $M = 2.53$, $p = .032$), whereas only patients with part-time/casual employment had greater willingness to integrate social media other than Facebook into their care ($M = 3.63$, $p = .034$). There were no significant differences between full-time and part-time/casual employment regarding willingness to use any of the technologies to improve their quality of life.

Psychological distress and future use of digital health

Researchers completed Spearman's correlations to verify the hypothesis that:

- Patients reporting higher psychological distress will be associated with a greater willingness to incorporate technology to access melanoma post-treatment care than those with lower psychological distress (**H22**);
- Patients reporting higher psychological distress will be associated with a greater willingness to incorporate technology to improve quality of life than those with lower psychological distress (**H23**).

Results illustrate significant association between psychological distress and willingness to use technology in their care and more specifically, to improve quality of life. Refer to Matrix 1-6 (indicators: orange: $p > .05$; dark green: $.05 > p > .010$; light green: $p < .010$).

Significant correlations between psychological distress and patient willingness to integrate technology to increase access to melanoma care were found. Overall, the more melanoma patients experienced psychological impacts, the more willing they were to use technology within their post-treatment care. The strongest correlations were for anxiety between follow-ups, need for more social support, and change in relationships with others. Conversely, decrease in self-esteem was the factor least impacting future technology adoption.

eHealth technologies

Matrix 1

Correlations between psychological impacts and willingness to use eHealth technologies in melanoma post-treatment care

		Treatment related morbidity	FoCR	Overthinking about treatment	Anxiety prior to follow-ups	Anxiety between follow-ups	Decrease in self-esteem	Decrease in general wellbeing	Change in relationships with others	Desire to seek reassurance	Need for more social support	Need for emotional/psychological support
Digital health technology to increase access to care												
Email	Correlation r	0.030	.299*	0.200	0.189	0.181	0.116	.257*	0.154	.266*	.300**	.270*
	Sig. (2-tailed)	0.799	0.010	0.090	0.109	0.126	0.327	0.028	0.192	0.023	0.010	0.021
	N	73	73	73	73	73	73	73	73	73	73	73
Websites	Correlation r	0.071	.328**	0.216	.249*	.285*	0.164	.269*	.258*	.270*	.330**	.305**
	Sig. (2-tailed)	0.553	0.005	0.067	0.034	0.015	0.165	0.021	0.027	0.021	0.004	0.009
	N	73	73	73	73	73	73	73	73	73	73	73
Web-based apps	Correlation r	0.083	0.211	.234*	.286*	.305**	0.195	.319**	.294*	.274*	.318**	.313**
	Sig. (2-tailed)	0.486	0.073	0.046	0.014	0.009	0.098	0.006	0.012	0.019	0.006	0.007
	N	73	73	73	73	73	73	73	73	73	73	73
Digital health technology to increase quality of life												
Email	Correlation r	-0.008	.244*	0.114	0.200	0.202	0.106	.316**	0.192	.332**	.333**	.284*
	Sig. (2-tailed)	0.944	0.038	0.337	0.090	0.086	0.371	0.007	0.104	0.004	0.004	0.015
	N	73	73	73	73	73	73	73	73	73	73	73
Websites	Correlation r	0.169	.360**	.350**	.398**	.441**	.267*	.462**	.423**	.427**	.443**	.451**
	Sig. (2-tailed)	0.152	0.002	0.002	0.000	0.000	0.023	0.000	0.000	0.000	0.000	0.000
	N	73	73	73	73	73	73	73	73	73	73	73
Web-based apps	Correlation r	0.070	.279*	.237*	.356**	.364**	0.150	.354**	.303**	.326**	.359**	.337**
	Sig. (2-tailed)	0.556	0.017	0.044	0.002	0.002	0.204	0.002	0.009	0.005	0.002	0.004
	N	73	73	73	73	73	73	73	73	73	73	73

Matrix 1 illustrates different psychological impacts were positively associated with patients' willingness to use websites and web-based technologies in melanoma care (with few significant results regarding use of email). Moreover, patients with higher levels of psychological distress were more likely to use eHealth technologies to improve quality of life than access to care.

Increasing access to care

The adoption of ICT technologies to increase access to care was more likely to be accepted by patients who recorded a frequent reduction of general well-being, desire to seek reassurance, and need more social and emotional support. The results also showed that treatment-related morbidity and decreased self-esteem did not affect patients' attitudes toward websites, web-based apps, and emails.

Improving quality of life

Significant correlations were found between patients' experience of psychological impacts and willingness to use ICT technologies to improve their quality of life. In contrast to results for improving access to care, willingness to use websites to improve quality of life was impacted by decreased self-esteem and overthinking about treatment.

mHealth (aka. Mobile Digital Health) technology

Matrix 2

Correlations between psychological impacts and willingness to use mHealth technologies in melanoma post-treatment care

		Treatment related morbidity	FoCR	Overthinking about treatment	Anxiety prior to follow-ups	Anxiety between follow-ups	Decrease in self-esteem	Decrease in general wellbeing	Change in relationships with others	Desire to seek reassurance	Need for more social support	Need for emotional/psychological support
Digital health technology to increase access to care												
Mobile phone text message	Correlation r	0.020	0.221	0.125	0.122	0.105	0.026	0.121	0.078	.317**	.302**	0.213
	Sig. (2-tailed)	0.865	0.060	0.291	0.302	0.377	0.827	0.306	0.513	0.006	0.009	0.070
	N	73	73	73	73	73	73	73	73	73	73	73
Mobile phone camera	Correlation r	0.054	.284*	0.187	.263*	.335**	0.172	.306**	.291*	0.220	.296*	.307**
	Sig. (2-tailed)	0.647	0.015	0.113	0.024	0.004	0.146	0.008	0.012	0.061	0.011	0.008
	N	73	73	73	73	73	73	73	73	73	73	73
Mobile applications	Correlation r	-0.003	.267*	0.179	.290*	.331**	0.139	.275*	0.229	0.224	.289*	.298*
	Sig. (2-tailed)	0.982	0.022	0.129	0.013	0.004	0.240	0.018	0.051	0.057	0.013	0.010
	N	73	73	73	73	73	73	73	73	73	73	73
Digital health technology to increase quality of life												
Mobile phone text message	Correlation r	-0.052	0.199	0.100	.240*	0.224	0.136	.294*	0.147	.360**	.332**	.252*
	Sig. (2-tailed)	0.663	0.091	0.398	0.040	0.057	0.251	0.011	0.213	0.002	0.004	0.032
	N	73	73	73	73	73	73	73	73	73	73	73
Mobile phone camera	Correlation r	-0.001	.265*	0.196	.295*	.285*	0.167	.349**	0.211	.292*	.327**	.300**
	Sig. (2-tailed)	0.996	0.024	0.097	0.011	0.015	0.159	0.002	0.073	0.012	0.005	0.010
	N	73	73	73	73	73	73	73	73	73	73	73
Mobile applications	Correlation r	0.026	.272*	0.167	.327**	.342**	0.123	.281*	0.222	.268*	.310**	.301**
	Sig. (2-tailed)	0.827	0.020	0.157	0.005	0.003	0.300	0.016	0.059	0.022	0.008	0.010
	N	73	73	73	73	73	73	73	73	73	73	73

Matrix 2 illustrates patients who experienced higher psychological impacts were willing to integrate mHealth technologies within their care to improve their quality of life rather than to increase access to care.

Increasing access to care

The results illustrate that patients who reported a frequent need for social support were more likely to integrate mHealth technologies into their care. Willingness to use mobile apps and mobile phone cameras were both significantly correlated with the following variables: fear of cancer recurrence, anxiety prior and between follow-ups, reduced wellbeing, and the need for more emotional support and change in relationships with others. Results show no

correlation between how frequently patients experienced treatment-related morbidity, overthinking about treatment, and decreased self-esteem using mHealth technologies.

Improving quality of life

Results also illustrate that patients who experienced needs for more social and emotional support, desire to seek reassurance, reduced well-being and anxiety before follow-ups, were more likely to integrate mHealth technology into their care to improve their quality of life. Similarly, increasing access to care, treatment-related morbidity, overthinking about treatment, decreased self-esteem, and changes in relationships with others did not significantly impact how much patients were willing to use mHealth in their care.

Social media

Matrix 3

Correlations between psychological impacts and willingness to use social media in melanoma post-treatment care

		Treatment related morbidity	FoCR	Overthinking about treatment	Anxiety prior to follow-ups	Anxiety between follow-ups	Decrease in self-esteem	Decrease in general wellbeing	Change in relationships with others	Desire to seek reassurance	Need for more social support	Need for emotional/psychological support
Digital health technology to increase access to care												
Youtube videos	Correlation r	0.153	0.070	0.112	0.031	0.109	-0.026	0.105	0.195	0.041	0.102	0.097
	Sig. (2-tailed)	0.196	0.555	0.346	0.797	0.358	0.827	0.378	0.097	0.732	0.389	0.413
	N	73	73	73	73	73	73	73	73	73	73	73
Facebook	Correlation r	.265**	.374**	.414**	.307**	.369**	0.210	.342**	.402**	.313**	.368**	.357**
	Sig. (2-tailed)	0.024	0.001	0.000	0.008	0.001	0.074	0.003	0.000	0.007	0.001	0.002
	N	73	73	73	73	73	73	73	73	73	73	73
Other social media platform	Correlation r	.363**	0.201	.278*	0.121	.314**	0.181	.290*	.410**	0.092	0.165	0.197
	Sig. (2-tailed)	0.002	0.094	0.020	0.320	0.008	0.134	0.015	0.000	0.447	0.171	0.102
	N	70	70	70	70	70	70	70	70	70	70	70
Online forum discussion	Correlation r	.234*	0.154	.352**	0.223	.310**	.237*	.359**	.376**	.311**	.356**	.335**
	Sig. (2-tailed)	0.046	0.194	0.002	0.058	0.008	0.044	0.002	0.001	0.007	0.002	0.004
	N	73	73	73	73	73	73	73	73	73	73	73
Digital health technology to increase quality of life												
Youtube videos	Correlation r	0.123	0.080	0.130	0.109	0.137	0.013	0.182	0.186	0.114	0.197	0.196
	Sig. (2-tailed)	0.299	0.501	0.273	0.359	0.247	0.912	0.123	0.115	0.338	0.094	0.097
	N	73	73	73	73	73	73	73	73	73	73	73
Facebook	Correlation r	0.214	0.201	.270*	0.219	.281*	0.161	.296*	.324**	0.219	.267*	.272*
	Sig. (2-tailed)	0.070	0.089	0.021	0.062	0.016	0.175	0.011	0.005	0.062	0.023	0.020
	N	73	73	73	73	73	73	73	73	73	73	73
Other social media platform	Correlation r	.344**	0.204	.339**	.259*	.335**	.238*	.371**	.358**	.246*	.322**	.365**
	Sig. (2-tailed)	0.004	0.090	0.004	0.030	0.005	0.047	0.002	0.002	0.040	0.006	0.002
	N	70	70	70	70	70	70	70	70	70	70	70
Online forum discussion	Correlation r	.269*	0.138	.279*	.339**	.330**	.298*	.413**	.373**	.360**	.453**	.444**
	Sig. (2-tailed)	0.021	0.245	0.017	0.003	0.004	0.011	0.000	0.001	0.002	0.000	0.000
	N	73	73	73	73	73	73	73	73	73	73	73

Matrix 3 illustrates that patients with higher levels of psychological distress were more willing to primarily use Facebook and online forum discussions to increase their access to care. However, to improve their quality of life, they would rather use other social media platforms in addition to online forum discussions. Notably, patients' willingness to watch YouTube videos was not significantly associated with any psychological impacts. Furthermore, the findings revealed that fear of cancer recurrence was not correlated with patients' willingness to use social media, except Facebook, to increase access to care ($r = .374, p = .001$).

Increasing access to care

Regarding social media, the results showed that there were positive correlations between experiencing all psychologically impacts they were asked about (excluding reduced self-esteem) and their willingness to use Facebook. However, these results differed for other social media. Only patients who reported higher scores of treatment-related morbidity, overthinking about treatment, anxiety between follow-ups, decrease in general wellbeing and change in relationships with others were willing to integrate social media other than Facebook and YouTube into their care. Willingness to use online forum discussions were significantly correlated with all psychological impacts except for fear of cancer recurrence and anxiety before follow-ups. Finally, the findings show that there were no significant correlations between YouTube videos and psychological impacts.

Improving quality of life

Overall, results showed that most kinds of psychological distress were significantly correlated with patients' willingness to use social media (but not YouTube) in melanoma care to improve quality of life. The exceptions were treatment-related morbidity and overthinking about treatment, which were not significantly correlated with patients' attitudes towards social media.

Self-monitoring tools

Matrix 4

Correlations between psychological impacts and willingness to use self-monitoring technologies in melanoma post-treatment care

		Treatment related morbidity	FoCR	Overthinking about treatment	Anxiety prior to follow-ups	Anxiety between follow-ups	Decrease in self-esteem	Decrease in general wellbeing	Change in relationships with others	Desire to seek reassurance	Need for more social support	Need for emotional/psychological support
Digital health technology to increase access to care												
Digital skin map	Correlation r	0.057	.254*	0.141	.250*	.311**	0.151	.247*	.247*	0.157	.251*	.238*
	Sig. (2-tailed)	0.632	0.030	0.233	0.033	0.007	0.202	0.035	0.035	0.185	0.032	0.042
	N	73	73	73	73	73	73	73	73	73	73	73
Self-monitoring tools	Correlation r	0.097	.246*	0.164	0.213	.243*	0.140	0.229	.275*	0.216	.286*	.239*
	Sig. (2-tailed)	0.412	0.036	0.166	0.070	0.038	0.237	0.052	0.019	0.066	0.014	0.042
	N	73	73	73	73	73	73	73	73	73	73	73
Digital health technology to increase quality of life												
Digital skin map	Correlation r	0.025	.368**	.242*	.416**	.390**	0.212	.354**	.312**	.277*	.372**	.354**
	Sig. (2-tailed)	0.835	0.001	0.039	0.000	0.001	0.071	0.002	0.007	0.018	0.001	0.002
	N	73	73	73	73	73	73	73	73	73	73	73
Self-monitoring tools	Correlation r	0.161	.346**	.323**	.413**	.416**	.262*	.381**	.316**	.335**	.462**	.418**
	Sig. (2-tailed)	0.174	0.003	0.005	0.000	0.000	0.025	0.001	0.006	0.004	0.000	0.000
	N	73	73	73	73	73	73	73	73	73	73	73

Matrix 4 shows that patients who expressed frequent psychological distress were more willing to use self-monitoring technologies within their care to improve their quality of life than solely increasing access to care.

Increasing access to care

Findings illustrate significant correlations between patients' willingness to use self-monitoring technologies and fear of cancer recurrence, change in relationships with others, as well as needs for social and emotional support. Patients' attitudes towards digital skin maps were also positively associated with anxiety prior to follow-ups and self-report of reduced wellbeing.

Improving quality of life

Results revealed that patients with high psychological needs (except for treatment-related morbidity and decreased self-esteem) are likely to have positive attitudes towards self-monitoring tools for improving their quality of life.

Telehealth technologies

Matrix 5

Correlations between psychological impacts and willingness to use telehealth technologies in melanoma post-treatment care

		Treatment related morbidity	FoCR	Overthinking about treatment	Anxiety prior to follow-ups	Anxiety between follow-ups	Decrease in self-esteem	Decrease in general wellbeing	Change in relationships with others	Desire to seek reassurance	Need for more social support	Need for emotional/psychological support
Digital health technology to increase access to care												
Teleconsultation	Correlation r	0.229	0.152	0.144	0.133	.235*	0.108	0.204	.269*	0.143	0.185	0.128
	Sig. (2-tailed)	0.051	0.200	0.225	0.261	0.045	0.365	0.084	0.021	0.227	0.118	0.281
	N	73	73	73	73	73	73	73	73	73	73	73
Teledermoscope	Correlation r	0.146	0.136	0.122	0.187	.238*	0.141	0.162	0.180	0.190	0.165	0.114
	Sig. (2-tailed)	0.218	0.251	0.302	0.113	0.043	0.233	0.171	0.127	0.107	0.163	0.338
	N	73	73	73	73	73	73	73	73	73	73	73
Store and forward telemedicine	Correlation r	0.083	.316**	0.198	.232**	.298*	0.153	0.205	.237*	.244*	.313**	0.213
	Sig. (2-tailed)	0.486	0.006	0.094	0.048	0.011	0.196	0.081	0.043	0.038	0.007	0.071
	N	73	73	73	73	73	73	73	73	73	73	73
Digital health technology to increase quality of life												
Teleconsultation	Correlation r	.263*	0.225	0.217	.368**	.403**	.245*	.361**	.287*	.262*	.356**	.327**
	Sig. (2-tailed)	0.025	0.056	0.065	0.001	0.000	0.036	0.002	0.014	0.025	0.002	0.005
	N	73	73	73	73	73	73	73	73	73	73	73
Teledermoscope	Correlation r	0.153	0.216	0.135	.351**	.320**	0.161	.231*	0.097	.233*	0.222	0.189
	Sig. (2-tailed)	0.197	0.066	0.253	0.002	0.006	0.175	0.049	0.412	0.047	0.059	0.108
	N	73	73	73	73	73	73	73	73	73	73	73
Store and forward telemedicine	Correlation r	.254*	.348**	.290*	.383**	.405**	.256*	.366**	.308**	.238*	.391**	.354**
	Sig. (2-tailed)	0.030	0.003	0.013	0.001	0.000	0.029	0.001	0.008	0.043	0.001	0.002
	N	73	73	73	73	73	73	73	73	73	73	73

Matrix 5 illustrated that willingness to use tele-health support technologies was significantly correlated with psychological implications to improve quality of life, over increased access to care.

Increasing access to care

Patients who felt psychologically impacted by melanoma were willing to use store-and-forward platforms to increase their access to care, especially for fear of cancer recurrence ($r = .316, p = .006$), need for more social support ($r = .313, p = .007$), anxiety prior ($r = .232, p = .048$) and between follow-ups ($r = .298, p = .011$), desire to seek reassurance ($r = .244, p = .038$) and change in relationships with others ($r = .237, p = .043$). Willingness to use teleconsultations was only significantly greater in people with higher levels of anxiety between follow-ups ($r = .235, p = .045$) and those experiencing changes in their relationships with others as a result of melanoma ($r = .269, p = .021$). The use of tele-dermoscopes was only linked to how often patients experienced anxiety between follow-up also ($r = .243, p = .043$).

Improving quality of life

Significant correlations between patients willingness to use store-and-forward platforms and all psychological impacts listed were reported. In addition, teleconsultations were more likely to be adopted by individuals who experienced higher levels of most types of psychological distress (the exceptions were for fear of cancer recurrence and overthinking about treatment). Teledermoscope was associated with fewer psychological implications (only anxiety prior and between follow-ups, decreased general well-being, and desire to seek reassurance).

Gamification

Matrix 6

Correlations between psychological impacts and willingness to use gamification and immersive technologies in melanoma post-treatment care

		Treatment related morbidity	FoCR	Overthinking about treatment	Anxiety prior to follow-ups	Anxiety between follow-ups	Decrease in self-esteem	Decrease in general wellbeing	Change in relationships with others	Desire to seek reassurance	Need for more social support	Need for emotional/psychological support
Digital health technology to increase access to care												
Virtual reality	Correlation r	0.150	.277	.340**	.242*	.292	0.129	0.226	0.229	.298*	.299*	0.213
	Sig. (2-tailed)	0.205	0.018	0.003	0.039	0.012	0.277	0.055	0.051	0.010	0.010	0.070
	N	73	73	73	73	73	73	73	73	73	73	73
Augmented reality	Correlation r	0.166	.245	.314**	0.187	.252	0.122	0.195	0.198	0.216	.245*	0.150
	Sig. (2-tailed)	0.159	0.037	0.007	0.114	0.032	0.303	0.098	0.092	0.067	0.037	0.206
	N	73	73	73	73	73	73	73	73	73	73	73
Serious video games	Correlation r	0.133	0.004	0.048	-0.039	0.079	0.079	0.006	0.063	0.013	0.095	0.026
	Sig. (2-tailed)	0.262	0.973	0.688	0.744	0.506	0.505	0.962	0.595	0.913	0.426	0.826
	N	73	73	73	73	73	73	73	73	73	73	73
Digital health technology to increase quality of life												
Virtual reality	Correlation r	0.213	0.207	0.193	0.226	.290	0.152	.300**	0.191	0.163	.251*	0.186
	Sig. (2-tailed)	0.071	0.079	0.102	0.055	0.013	0.199	0.010	0.105	0.168	0.032	0.115
	N	73	73	73	73	73	73	73	73	73	73	73
Augmented reality	Correlation r	.243	0.183	0.174	0.209	.282*	0.137	.285*	0.190	0.107	0.224	0.184
	Sig. (2-tailed)	0.038	0.122	0.142	0.076	0.016	0.249	0.015	0.108	0.369	0.057	0.119
	N	73	73	73	73	73	73	73	73	73	73	73
Serious video games	Correlation r	0.112	0.092	0.071	0.037	0.102	0.003	0.112	0.035	0.071	0.110	0.048
	Sig. (2-tailed)	0.347	0.440	0.553	0.755	0.392	0.982	0.344	0.772	0.549	0.355	0.685
	N	73	73	73	73	73	73	73	73	73	73	73

Matrix 6 illustrated that willingness to use serious video games, and immersive technologies was not significantly correlated with psychological implications. Nevertheless, unique to other technologies surveyed, patient willingness to use gamification and immersive technologies showed greater association with psychological impacts to increase access to care than improve quality of life.

Increasing access to care

Results show that patients who were impacted by fear of cancer recurrence, overthinking about treatment, anxiety between follow-ups, desire to seek reassurance and expressing stronger need for more social support, were more willing to integrate immersive

technologies (virtual and augmented reality) into their post-treatment care. However, there was no correlation between the adoption of serious video games for increasing access to care and psychological impacts.

Improving quality of life

Overall, the willingness to use immersive technologies were mostly unrelated to patients' psychological needs. However, patients were more likely to be willing to use virtual reality to improve their quality of life if they experienced more frequent episodes of anxiety between follow-ups ($r = .290, p = .013$), reduced wellbeing ($r = .300, p = .010$) and a need for more social support ($r = .251, p = .032$). Willingness to use augmented reality was significantly correlated with treatment-related morbidity ($r = .243, p = .038$), anxiety between follow-ups ($r = .282, p = .016$) and reduced wellbeing ($r = .285, p = .015$) only. As with increasing access to care, there were no significant correlations between willingness to use serious video games to improve quality of life and any psychological implications.

Access to post-treatment care and willingness to use technology

The study tested the hypothesis that:

- Patients experiencing difficulties to access follow-up visits will perceive greater benefits of incorporating technology to increase access to melanoma post-treatment care than those reporting less difficulties to follow-up visits. (**H24**);
- Patients experiencing difficulties to access follow-up visits will perceive greater benefits of incorporating technology to improve quality of life than those reporting less difficulties in achieving quality of life (**H25**).

Results of Spearman's correlation analyses are presented in Tables 25-26.

Results illustrate overall that patients were willing to use technology within their care if it is a time and cost-effective solution., Moreover, specifically, if it enables them to improve their quality of life.

Increasing access to care

Table 25

Correlations between access to facility care barriers and benefits of using technology to increase access to care

Technology to increase access to care	Access to facility care limitations				
	Travel time	Travel cost	Time off work	Waiting time	Follow-up cost
Mobile phone text message	r(73)=.098, p=.408	r(73)=.057, p=.634	r(73)=-.024, p=.838	r(73)=.086, p=.472	r(73)=.201, p=.088
Email	r(73)=.218, p=.064	r(73)=.050, p=.672	r(73)=.088, p=.457	r(73)=.177, p=.135	r(73)=.205, p=.082
Mobile phone camera	r(73)=.225, p=.055	r(73)=.147, p=.214	r(73)=.125, p=.291	r(73)=.235, p=.045	r(73)=.413, p<.001
Mobile applications	r(73)=.231, p=.049	r(73)=.047, p=.693	r(73)=.214, p=.069	r(73)=.204, p=.084	r(73)=.324, p=.005
Websites	r(73)=.209, p=.076	r(73)=.095, p=.423	r(73)=.176, p=.136	r(73)=.081, p=.495	r(73)=.282, p=.016
Web-based apps	r(73)=.284, p=.015	r(73)=.104, p=.383	r(73)=.239, p=.042	r(73)=.162, p=.170	r(73)=.302, p=.009
Digital skin map	r(73)=.321, p=.006	r(73)=.228, p=.053	r(73)=.187, p=.113	r(73)=.155, p=.189	r(73)=.351, p=.002
Youtube videos	r(73)=.135, p=.253	r(73)=.136, p=.250	r(73)=.014, p=.907	r(73)=-.012, p=.918	r(73)=.123, p=.299
Facebook	r(73)=.409, p<.001	r(73)=.304, p=.009	r(73)=.148, p=.211	r(73)=.161, p=.173	r(73)=.191, p=.105
Other social media platform	r(70)=.227, p=.058	r(70)=.221, p=.067	r(70)=.083, p=.492	r(70)=.047, p=.699	r(70)=.099, p=.416
Online forum discussion	r(73)=.325, p=.005	r(73)=.282, p=.016	r(73)=.230, p=.050	r(73)=.082, p=.488	r(73)=.158, p=.182
Teleconference platform/teleconsultation	r(73)=.220, p=.061	r(73)=.142, p=.229	r(73)=.244, p=.037	r(73)=.025, p=.835	r(73)=.198, p=.094
Teledermoscope	r(73)=.176, p=.136	r(73)=.114, p=.338	r(73)=.249, p=.034	r(73)=.065, p=.584	r(73)=.207, p=.079
Self-monitoring supportive tools	r(73)=.372, p=.020	r(73)=.247, p=.035	r(73)=.132, p=.264	r(73)=.086, p=.472	r(73)=.340, p=.003
Store and forward telemedicine	r(73)=.392, p=.012	r(73)=.231, p=.050	r(73)=.155, p=.192	r(73)=.108, p=.363	r(73)=.246, p=.003
Virtual reality	r(73)=.393, p=.012	r(73)=.170, p=.152	r(73)=.171, p=.148	r(73)=.158, p=.181	r(73)=.246, p=.036
Augmented reality	r(73)=.319, p=.006	r(73)=.199, p=.091	r(73)=.210, p=.075	r(73)=.143, p=.227	r(73)=.191, p=.105
Serious video games	r(73)=-.046, p=.700	r(73)=.013, p=.910	r(73)=-.032, p=.787	r(73)=.059, p=.620	r(73)=-.067, p=.573

Table 25 illustrates that the further melanoma patients needed to travel, the more willing they were to use technology to improve their quality of life. The results revealed that patients' attitudes toward the use of mobile phone text messages, emails, YouTube, social media platforms (other than Facebook) and serious video games were not associated with barriers to accessing melanoma care facilities. Follow-up costs were correlated with mHealth technologies, self-monitoring supportive technologies (including digital skin maps) and virtual reality; travel time with mobile and web apps, self-monitoring supportive technologies (including digital skin maps), store-and-forward telemedicine, as well as virtual and augmented reality. Notably, patients' willingness to use teleconsultation was only associated with the need to take time off work.

Improving quality of life

Table 26

Correlations between access to facility care barriers and benefits of using technology to increase access to care

Technology to improve quality of life	Access to facility care limitations				
	Travel time	Travel cost	Time off work	Waiting time	Follow-up cost
Mobile phone text message	r(73)=.266, p=.023	r(73)=.136, p=.250	r(73)=.183, p=.120	r(73)=.277, p=.018	r(73)=.303, p=.009
Email	r(73)=.293, p=.012	r(73)=.127, p=.285	r(73)=.237, p=.044	r(73)=.171, p=.147	r(73)=.231, p=.049
Mobile phone camera	r(73)=.320, p=.006	r(73)=.165, p=.163	r(73)=.292, p=.012	r(73)=.333, p=.004	r(73)=.356, p=.002
Mobile applications	r(73)=.298, p=.010	r(73)=.105, p=.376	r(73)=.297, p=.011	r(73)=.245, p=.036	r(73)=.312, p=.007
Websites	r(73)=.325, p=.005	r(73)=.181, p=.126	r(73)=.264, p=.024	r(73)=.179, p=.129	r(73)=.283, p=.015
Web-based apps	r(73)=.343, p=.003	r(73)=.135, p=.254	r(73)=.304, p=.009	r(73)=.240, p=.041	r(73)=.344, p=.003
Digital skin map	r(73)=.405, p<.001	r(73)=.213, p=.071	r(73)=.338, p=.003	r(73)=.269, p=.022	r(73)=.360, p=.002
Youtube videos	r(73)=.230, p=.050	r(73)=.108, p=.364	r(73)=.123, p=.298	r(73)=.116, p=.329	r(73)=.130, p=.273
Facebook	r(73)=.386, p=.001	r(73)=.252, p=.031	r(73)=.159, p=.179	r(73)=.142, p=.232	r(73)=.118, p=.319
Other social media platform	r(70)=.347, p=.003	r(70)=.197, p=.103	r(70)=.240, p=.046	r(70)=.091, p=.453	r(70)=.113, p=.353
Online forum discussion	r(73)=.344, p=.003	r(73)=.206, p=.080	r(73)=.358, p=.002	r(73)=.195, p=.097	r(73)=.245, p=.037
Teleconference platform/teleconsultation	r(73)=.408, p<.001	r(73)=.193, p=.101	r(73)=.400, p<.001	r(73)=.295, p=.011	r(73)=.295, p=.011
Teledermoscope	r(73)=.270, p=.021	r(73)=.061, p=.608	r(73)=.361, p=.002	r(73)=.317, p=.006	r(73)=.186, p=.115
Self-monitoring supportive tools	r(73)=.378, p=.001	r(73)=.218, p=.063	r(73)=.260, p=.027	r(73)=.374, p=.001	r(73)=.373, p=.001
Store and forward telemedicine	r(73)=.473, p<.001	r(73)=.253, p=.031	r(73)=.294, p=.012	r(73)=.348, p=.003	r(73)=.318, p=.006
Virtual reality	r(73)=.395, p=.001	r(73)=.173, p=.143	r(73)=.344, p=.003	r(73)=.304, p=.009	r(73)=.196, p=.097
Augmented reality	r(73)=.387, p=.001	r(73)=.158, p=.181	r(73)=.380, p=.001	r(73)=.289, p=.013	r(73)=.159, p=.179
Serious video games	r(73)=.092, p=.437	r(73)=-.005, p=.964	r(73)=.025, p=.836	r(73)=.147, p=.216	r(73)=-.094, p=.430

Table 26 shows that overall, patients' willingness to use digital health technologies to improve their quality of life was significantly correlated with the extent to which they were facing difficulties in accessing their follow-up visits. Not surprisingly, patients who reported to be more limited by travel time, having to take time off work, follow-up costs, and long waiting time to get an appointment were more likely to have a positive attitude toward digital health. However, travel cost was only significantly associated with willingness to use Facebook ($r = .252, p = .031$) and store-and-forward telemedicine ($r = .253, p = .031$).

Summary

The following is a summary of the current study results as they relate to the hypotheses set out in the ‘*Rationale for methodology*’ chapter.

1. *Overall, residential areas and socioeconomic status (with the exception of distance travelled) were not determinants of access to melanoma post-treatment care. However, psychological distress, distance travelled and barriers to access medical centres were significantly associated with better access.*
- **H1 was not supported** — Overall, melanoma patients living in rural areas benefited from the same level of access to post-treatment care as those living in urban areas.
 - **H2 was partially supported** — Distance travelled was a predictor of access to follow-up visits. Still, it did not influence the amount, nor the patients’ satisfaction with, the information received from clinicians at the time of diagnosis.
 - **H3 was not supported** — Socioeconomic status did not impact patients’ access to melanoma post-treatment care.
 - **H4 is not supported** — Residential area was not a predictor of psychological difficulties encountered by melanoma patients after treatment (with the exception of fear of cancer recurrence).
 - **H5 was supported** — Patients who were required to travel farther to attend their follow-up appointments expressed higher levels of psychological distress than those living closer to their follow-up centre.
 - **H6 was not supported** — Socioeconomic status did not influence how patients psychologically cope with melanoma.

- **H7 was supported** — Patients who frequently faced difficulties in accessing their follow-up visits expressed higher psychological needs than those who didn't experience these difficulties as often.
- **H8 was partially supported** — Patients reporting dissatisfaction with the amount of information related to psychological implications, support groups available, and melanoma treatment reported greater psychological difficulties than those that were satisfied with the received information.
- **H9 was partially supported** — Patients reporting dissatisfaction with the quality of information related to psychological implications and available support groups reported greater psychological difficulties than those satisfied with the received information.

2. *Current use of technology was not related to individuals' characteristics.*

- **H10 was not supported** — Age was not a strong determinant of patients' current use of digital health into melanoma care (with some exceptions such as mobile phone cameras, Facebook and online forums).
- **H11 was not supported** — There was no difference in current use of digital health between genders.
- **H12 was not supported** — Melanoma patients with more advanced conditions used digital health as much as those with a less advanced condition.
- **H13 is partially supported** — Overall, socioeconomic status was not a predictor of the current use of technology by melanoma patients. However, people living in urban areas used certain technologies more than those living in rural areas.

3. *Overall, patients' age, psychological distress and barriers to accessing care were strong predictors of willingness to integrate digital health within their care, especially to improve*

quality of life. Surprisingly, socioeconomic status barely influenced patients' willingness to use digital health, except for education and distance travelled.

- **H14 was mostly supported** — The younger patients were, the more willing they were to use social media and mHealth to increase their access to melanoma care.
- **H15 was supported** — The younger patients were, the more willing they were to use all types of technologies to improve their quality of life.
- **H16 was partially supported** — Overall, there was no gender difference regarding willingness to use technology to increase access to care. However, women were more willing to use self-monitoring supportive tools and store-and-forward platforms.
- **H17 was not supported** — Female patients were as willing as male patients to use digital health to improve their quality of life.
- **H18 was not supported** — Illness condition was not a predictor of willingness to use digital health to increase access to melanoma post-treatment care.
- **H19 was partially supported** — Illness condition was associated with patients' willingness to use technology within their care to improve their quality of life, except for teledermoscope. Patients diagnosed with deeper tumour thickness were more willing to use teledermoscope within their care to improve their quality of life compared to those diagnosed with less thick tumours.
- **H20 was partially supported** — Higher socioeconomic status was a determinant of patient willingness to use digital health to increase access to melanoma post-treatment care for some factors and technologies. Level of education and travel distance were the factors that most impacted patient willingness to integrate digital health (especially mobile and web apps) within their care.

- **H21 was partially supported** — Higher socioeconomic status was associated with patients' willingness to use digital health within their care to improve their quality of life for some factors and technologies. Employment status, level of education and travel distance were the factors that most impacted the patient willingness to integrate digital health (especially mobile and web apps) within their care.

Note that for both H20-21, results show that rural populations shared the same level of willingness as urban populations to integrate digital health within their care.

- **H22 was partially supported** — Patients reporting higher psychological distress were somewhat more willing to use technology to increase their access to care compared to those reporting lower psychological distress.
- **H23 was supported** — Psychological distress was a strong determinant of willingness to use digital health to improve quality of life. Patients reporting higher psychological distress were more willing to use technology to increase their access to care compared to those reporting lower psychological distress.
- **H24 was partially supported** — Patients who were frequently impacted by travel time and follow-up cost were somewhat more willing to use digital health, particularly mHealth technologies, compared to those who reported fewer difficulties accessing their follow-up care.
- **H25 was partially supported** — Patients facing more difficulties accessing their follow-up visits (except travel costs) were more willing to use digital health to improve their quality of life except for travel costs.

CHAPTER 8

DISCUSSION

Overview

The primary aim of the current study was to use exploratory research practices to obtain user experience information on how to guide the delivery of high-quality and evidence-based care for people treated with melanoma. The study aimed to inform quality improvement initiatives across melanoma post-treatment care through digital health interventions.

The overall purpose of this work is to propose an Australian digitally-enhanced melanoma model of post-treatment care, which is underpinned by a patient-centred and value-based care approach. This was undertaken using a quantitative and qualitative survey to assess patients' access to, and satisfaction with, existing melanoma post-treatment care in Australia, as well as patients' attitudes toward, and perception of, digital health.

This study identifies substantial gaps in the management of melanoma, demonstrating the necessity to re-think, re-organise, and transform the Australian healthcare system and improve coordination between clinical services. While a broad range of digital health technologies and interventions have been proposed, the extent of user acceptance and interest and successful real-world implementation of these technologies in melanoma settings remained unclear.

It was predicted that patients' individual characteristics (demographics, SES, illness condition) would be strong determinants of melanoma post-treatment care and digital health uptake. However, the study reveals that individual needs, i.e., psychological distress, cost, and time pressures, are of most significant importance to the patient experience of care, and

therefore should be focused upon as the driving force for improving digital health implementation in melanoma post-treatment care in Australia.

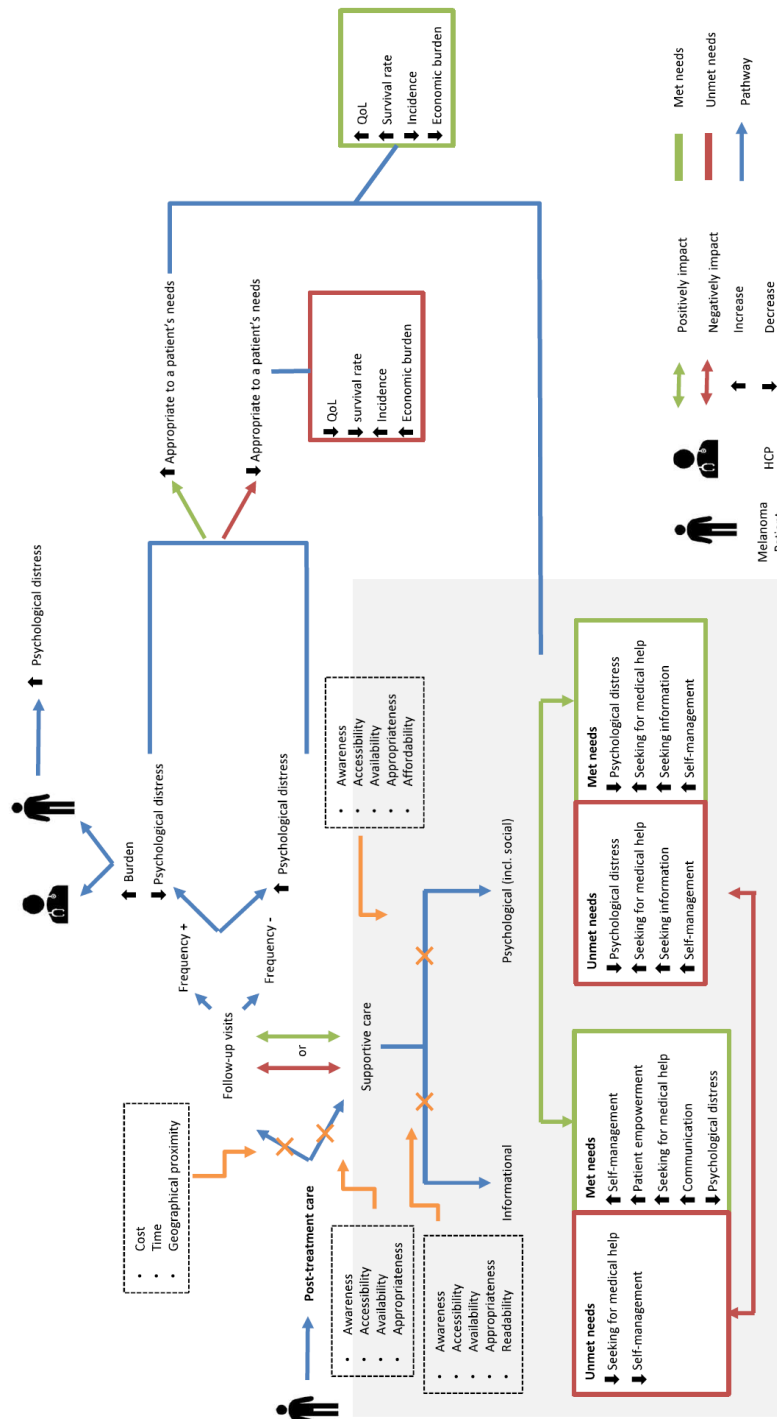
The following chapter discusses the results of the current study in detail. The discussion is supported by previous literature referred to in the melanoma and digital health fields. The implications of the present study for future directions of both melanoma post-treatment care in Australia and digital health, as well research at the intersection of these two fields, are then proposed. The thesis concludes with some thought on how the Australian model of melanoma post-treatment care could be digitally-enhanced to deliver optimal care to patients and be used as an adjunct service by clinicians to support them in their daily practice.

PART 1 — Melanoma patients (un)met needs

Given the complexity of this exploratory research, a graphical summary of the study's findings has been illustrated to clearly represent the patient-reported melanoma post-treatment care pathway in Australia. It highlights specific barriers encountered by patients for accessing health services and expected outcomes as to whether appropriate care is obtained or un-obtained (Figure 16).

Figure 16

Current research, patient reported Australian melanoma post-treatment care pathway



As illustrated in Figure 16, in order to curb the societal and economic burden of melanoma treatment in Australia, post-treatment care must be designed to meet patients' individual needs. While melanoma post-treatment care should include both *follow-up visits* (to identify early signs of recurrences or new lesions and monitor patients overall health) and *supportive care* (to help individuals coping with their illness and to assist them in participating more actively in their decision-making), the current study identified a major lack of access to psychological, social and informational support.

Access has often been defined in timeliness, distance and cost (Corscadden et al., 2017). However, in support of previous findings, this study confirms that access *must* be a fit between patient needs and the services that meet those needs (Corscadden et al., 2017; Levesque et al., 2013). Insufficient and/or inadequate healthcare services can exacerbate psychological distress for patients and worsen illness leading to reduced health outcomes. Consequently, poor quality and inappropriate melanoma care will increase health costs for both patients and the Australian healthcare system due to more extensive and costly treatments.

In addition, this study provides evidence that to deliver optimal post-treatment care for patients, both access to supportive care and follow-ups must satisfy patients' needs and meet their demands, as one impacts another. The current results reinforce existing findings indicating that (1) failure to meet patient, supportive care needs can delay seeking of medical advice and negatively affect therapeutic compliance; (2) ongoing follow-up care provides an opportunity for clinicians to identify and address the psychological and social unmet needs of melanoma patients. This is done by referring them to a specialist or providing adapted options and information tailored to their specific needs.

Supportive care is increasingly seen as a core component of evidence-based clinical care (Cancer Council, n.d.). Building on the current study's data, post-treatment plans should be co-designed with patients. It should fully integrate supportive care to deliver optimised patient outcomes and promote better health through the adoption of *patient-centred care*, *value-based care* (VBC) and *quality care*.

Therefore, this study's findings elaborate on patients' perceptions of the current model of melanoma post-treatment care in Australia. It provides thoughts on re-organising and transforming the national healthcare system to improve clients' QoL, increase survival, decrease incidence rates of melanoma, and ultimately reduce its economic burden.

As outlined in Chapter 6, the current study investigated participants' melanoma post-treatment plans, including data about access to follow-up visits and supportive care, including informational and psychosocial needs. The objective was to identify patients' (un)met needs and areas of improvement in melanoma management care.

Empirical evidence of the graphical summary is detailed in the following section, which discusses (un)met needs identified in melanoma post-treatment care, including access to, and satisfaction with, follow-ups and supportive care. Section 2 reviews solutions and mechanisms to assure continuous and quality care for melanoma patients.

Section 1: Access to post-treatment care

To provide evidence-based guidance on where governments, health system leaders, policymakers and HCPs should marshal their efforts to improve healthcare quality, the current study investigated melanoma patients' use and satisfaction with melanoma care services. Barriers and predictors for access to post-treatment care were identified, and existing gaps in the current Australian model of supportive care.

The current study used a patient-centred, holistic approach to care, including access to clinical care through follow-up visits, access to information, and psychological and social services. While ongoing follow-up care provides an opportunity for clinicians to address the unmet needs of melanoma patients, the current study identified several factors limiting the provision of timely, effective and integrated post-treatment care.

1. Access to follow-up visits

Variations in the *burden of cancer*' resulting from individual disparities is often overlooked. Given this, there is a lack of interventions to address this reality (Abbott et al., 2017). Therefore, it has been suggested that understanding barriers to receiving ongoing cancer care will be critical to advancements in patient engagement and improved health outcomes (Chegini et al., 2020). In line with this previous finding, the current study identified two subsets of melanoma patients at higher risk of suffering from healthcare disparities: geographic and psychological.

Frequency of follow-ups

On average, sampled patients were meeting their doctors four times a year (SD:1.887) for follow-up visits, which is higher than the average schedule (3-6 monthly) recommended in the Australian *Clinical practice guidelines for the diagnosis and management of melanoma* (Barbour et al., 2021). In addition, the current study identified that approximately 15% of melanoma patients surveyed reported dissatisfaction with their follow-up frequency, with a majority expressing a desire to see their doctors more often.

As mentioned, follow-up is an essential component of post-treatment care. Its purpose is to detect new skin cancers early and monitor for recurrence. It also has the potential to provide reassurance to patients experiencing psychological distress related to their illness (Barbour et al., 2021; Murchie et al., 2007). Controversially, some studies revealed that these consultations can also be a source of anxiety and a burden for both patients and clinicians (e.g., cost, time, workload etc.) (Lim et al., 2018; Turner RM et al., 2011). Nonetheless, there is scientific evidence that shorter timelines between follow-ups may reduce patients' distress and increase their well-being and QoL (Cancer Council, n.d.). Based on this rationale, frequency of follow-up visits should be personalised and adapted to patients' needs.

Paradoxically, more frequent follow-up visits can either decrease or increase anxiety in patients, and vice-versa, less regular follow-ups have proven not to be detrimental for overall survival rates (Barbour et al., 2021). For physicians, this demonstrates the importance of

designing follow-up plans that are not only based on clinical inputs but also on patients' individual needs (i.e., psychological) and characteristics (e.g., socioeconomic status).

Barriers to access follow-up visits

The current study investigated the type of barriers to follow-up visits experienced by patients. The data revealed that over 35% of patients reported cost or time limitations. Of those, 30% mentioned being strongly impacted by follow-up costs, and 25% said they were limited by taking time off work. Over 20% mentioned travel time or cost as barriers and the long waiting time to get an appointment. In line with previous findings (Turnock, 2001), this study shows that the ability to obtain healthcare services may be influenced by many factors, including healthcare services availability/proximity, direct and indirect costs, and waiting time. Unremarkably, geographical proximity has been shown to increase timely utilisation of health services (LaVeka et al., 2004; Leonard et al., 2009; Bauer & Groneberd, 2016), exhibiting better health outcomes (Gorey et al., 2009; Grzybowski et al., 2011; Laditka et al., 2009; Macinko et al., 2011; Kelly et al., 2016; Barbieri & Jorm, 2019).

Previous research indicates that, across all cancer types, patients (and caregivers) experience 'financial toxicity' (Thom et al., 2020). Financial toxicity encompasses two components: the measurable financial impact of treatment (e.g., out-of-pocket copayments, medications, lost wages); and the psychosocial impact resulting from the adverse financial outcomes (e.g., lower QoL, financial distress). Financial toxicity is a household phenomenon, and its effects on patients can be debilitating (Gordon et al., 2017). Financial pressures on the affordability of medical care include the risk of job loss and the need to take time off from work during cancer treatment (Gordon et al., 2017).

Increasing costs associated with cancer treatments also affect affordability. Meaning, costs incurred by healthcare services can strongly influence whether or not treatment and follow-up care can be translated into routine care (Tuttle et al., 2015). Financial toxicity can also delay help-seeking and lead to reduced treatment compliance, which in-turn can decrease clinical outcomes and QoL (Witte et al., 2019). Although previous literature highlights the negative impacts of financial toxicity on QoL for other cancer types (Gordon et al., 2017), to

the author's knowledge, there's been only one melanoma-specific study investigating financial distress on patients (Thom et al., 2020). The latter describes the negative associations between financial toxicity and QoL.

Prior research also identifies that people who live farther away from healthcare facilities use them less than those who live closer (Barbieri & Jorm, 2019; Arcury et al., 2005; Pagano et al., 2007; Littenberg et al., 2006; Sibley et Weiner, 2011; Chan, 2006), an effect also known as the '*distance decay*' association (Haynes, 2003; Goddard & Smith, 1998). As a result of longer travel distances and time to attend healthcare facilities, patients often experience worsened health outcomes (Kelly et al., 2016; Barbieri & Jorm, 2019).

In the current study, 20% of patients mentioned being affected by travel-time, whereas most participants (55%) travel more than 30km ($M = 210$, $SD = 57$) to their follow-up appointments. These results may be explained by Australia's size and demographic distribution, as well as the local population's acceptance of long-distance commutes as part of their daily routine (ABS, 2016). Given this, the current study validates that cultural, environmental, and lifestyle influences (i.e., urban vs rural) are important predictors of health and wellbeing that influence patterns of access to care and health management (Hernandez et al., 2006; Sherman et al., 2005; Kwan & Weber, 2010).

Socioeconomic impacts on access

In contrast to previous literature (Hashmi et al., 2018), the current analysis found that, overall, SES does not play a role in influencing access to follow-up visits. Indeed, except for travel distance, factors such as residential areas, employment status, level of income, and education don't appear to impact access to clinical care in Australia.

It was predicted that patients living in rural areas would experience more difficulty accessing follow-up appointments. Several studies described significant obstacles to effective cancer care encountered by rural populations (Abbott et al., 2017; Grimison et al., 2013; McGrail et al., 2015). Indeed, barriers to health and medical care faced by people in rural areas have been extensively studied (Zhao et al., 2013; McGrail et al., 2015; Thomas et al., 2015; Yu et al., 2016; AIHW, 2019). Existing results show that geographical barriers are often associated

with the inconvenience of travelling long distances to access effective care. Similarly, the urban-rural disparity has been explained due to diverse factors, including geographical and financial barriers.

- **Geographical barriers:** the density of specialists and GPs in rural areas is significantly lower than in urban settings (Charlton et al., 2015; Wakerman & Humphreys, 2012); moreover, rural populations tend to lack access to medical infrastructure and services (McGrail et al., 2015);
- **Financial barriers:** the cost associated with healthcare delivery and the lower socioeconomic status in rural areas compounds the above barriers (Cheek et al., 2016; AIHW, 2019).

In contrast, the current analysis revealed that *residential areas* (urban vs rural) and *barriers to accessing follow-ups* were not associated in Australia. Whereas most patients living in rural Australia required more travel than the others, individuals living in urban areas are more likely to *feel* impacted by distance despite shorter travel times.

Access to care and psychological distress

In line with other studies findings, the results of this study showed strong positive correlations between distress and barriers to follow-ups and difficulties accessing healthcare services often leading to higher psychological distress. This can be explained by critical factors such as lack of clinical support and strategies to cope with melanoma psychologically.

Follow-up visits are an essential part of a melanoma post-treatment plan, as previously discussed. It is a unique opportunity for clinicians to detect recurrent melanoma early and ensure the patient receives appropriate support. However, previous findings revealed that little attention is paid to patients' emotional wellbeing during follow-up consultations (Francken et al., 2005), and shows that when psychological distress increases, it causes:

- Risk of delays in patients seeking medical advice for melanoma.
- Decreased adherence to treatment regimes.

- Reduced conscientiousness pertaining to skin screening and other preventative behaviours.

Psychological distress, therefore, results in increased rates of melanoma recurrence, mortality, and medical costs. Therefore, to ensure better health outcomes (clinical and psychological) in melanoma, it is essential to increase both opportunity and ease of access to healthcare facilities/services.

Socioeconomic status and psychological distress

The present results show that SES does not necessarily impact psychological distress related to melanoma. The findings indicate that geographical proximity is the only factor that influences how patients psychologically cope with melanoma. Indeed, the farther patients needed to travel to see a doctor, the more likely they were to report psychological distress, including changes in relationships, reduced self-esteem and wellbeing, treatment-related morbidity and overthinking about treatment. Also, patients from rural areas are more exposed to fear of cancer recurrence than urban patients.

In summary, the data illustrates that those who live farther away from healthcare facilities have lower usage rates after adjustment for individual needs than those who live closer. Patients with insufficient access to health care services may experience higher psychological distress than those with better access. Therefore, it was not surprising to observe a strong positive correlation between travel distance and psychological distress.

2. Access to supportive care: informational and psychological

Unmet supportive care needs reflect the disparity between the support that one perceives as necessary and the received support (Moghaddam et al., 2016). For decades, scholars have reported patient dissatisfaction with the amount and nature of information received and available psychological support (Brandberg et al., 1994; Bonevski et al., 2000), yet the issue is still to be addressed. Indeed, several studies showcased that melanoma patients

often report specific emotional, psychosocial and informational needs, but ways to address them are not identified (Bird et al., 2015).

Health literacy (unmet information needs)

As discussed in Chapter 5, health literacy relates to people's access, understanding and use of information in ways that benefit their health. The information needs of persons living with chronic medical conditions like melanoma cannot be underestimated because the nature, quantity, quality, accessibility and readability of information is critical for the optimal management and improved QoL (Kugbey et al., 2019). While information accessibility and readability are crucial to health literacy, the current study focused simply on information's nature, quantity, and quality.

Further, health literacy has been found to influence several aspects of patients' health, such as physical and emotional function, the utilisation of healthcare services, individual decision-making and self-care management (Berkman et al., 2011). Health literacy has been argued to be the core of communication challenges in cancer care (Institute of Medicine US Committee on Health Literacy, 2004). Low health literacy has often been associated with reduced HCP-patient communication, poor understanding of illness and adherence to treatment, and a higher risk of relapse in cancer patients. In melanoma, data reveals significant correlations between patient communication and SSE (Rodriguez et al., 2017).

In 2016, the Australian government released a report — *Optimal cancer care pathway for people with melanoma* (Cancer Council, n.d.) — promoting quality care and patient experience through effective communication, as effective, clear, consistent and adequate communication is better for patients. Moreover, as discussed in *Chapter 3*, national guidelines (Cancer Council Australia, 2019) highlight the importance of providing patients with a treatment summary and care plan, including information on diagnostic tests performed, tumour characteristics, treatments and strategies to manage comorbidity in their post-treatment care planning.

Given this, while the current study found that surveyed patients predominantly receive information about melanoma treatment and total skin self-examination (TSSE) (87_70%), more than half of them reported not receiving information about melanoma evolution (53%), nor knew the surgical intervention they received (60%). Furthermore, a majority did not learn about melanoma-related psychological impacts (30%) and/or social support groups available (20%).

These findings highlight the urgent need to increase HCP-patient communication. These results are consistent with previous research illustrating cancer patients have consistently demonstrated a strong desire to receive complete and clear information, as well as emotional support from their doctor at the time of diagnosis (Schofield et al., 2003).

Besides patient access to information, satisfaction with the information received (quantity and quality) is equally crucial. However, the current study revealed that more than one in two patients are not satisfied with the *amount* and *quality* of the information received at the time of diagnosis, about disease evolution (57_58%), TSSE (49_56%), psychological implications (81_74%) and available social support groups (79_77%).

The current analysis reports significant correlations between satisfaction with the information received and patients' levels of distress. Patients who are dissatisfied with the amount and quality of information received about melanoma treatment, psychological implications, and social support groups are likely to experience greater psychological distress, especially for those reporting insufficiency with the quality of information. Oncology studies show that satisfaction with health-related information is associated with increased QoL and decreased levels of psychological distress (Husson et al., 2010; Ong et al., 2000). Interestingly, levels of satisfaction toward TSSE information were not associated with patients' distress.

These results align with previous studies referring to information need as one of the greatest areas of unmet psychosocial needs for patients with melanoma (Kasparian, 2013). Patients are often dissatisfied with the *quality* and *quantity* of information they receive (Thorne et al., 2005). This study supported previous research (Brandberg et al. 1994; Kasparian, 2013),

which revealed that, compared with those who were satisfied, dissatisfied patients reported significantly higher levels of psychological distress (e.g., anxiety, depression).

From these findings, the current study proposes that:

- Clinicians focus on direct medical outcomes (i.e., decreased incidence and mortality rates through early detection) and often neglect the benefits of improved health literacy. This demonstrates a need to better inform clinicians about the role of health literacy in patient care, and provide them with tools to improve communication with patients;
- Increased availability and access to melanoma-related information through various media (e.g., brochure, pamphlet, VR, video, online, social media) could support clinicians in their daily practice, generating increased and better health communication and patient education.

While not part of the scope of the present study, it's important to note that prior research has also identified that patients often do not understand the information that they are provided, highlighting the lack of appropriateness and readability of information (Graham and Brookey, 2008), (Weiss, 2007). This may be addressed by delivering information tailored to personal needs and individual's characteristics.

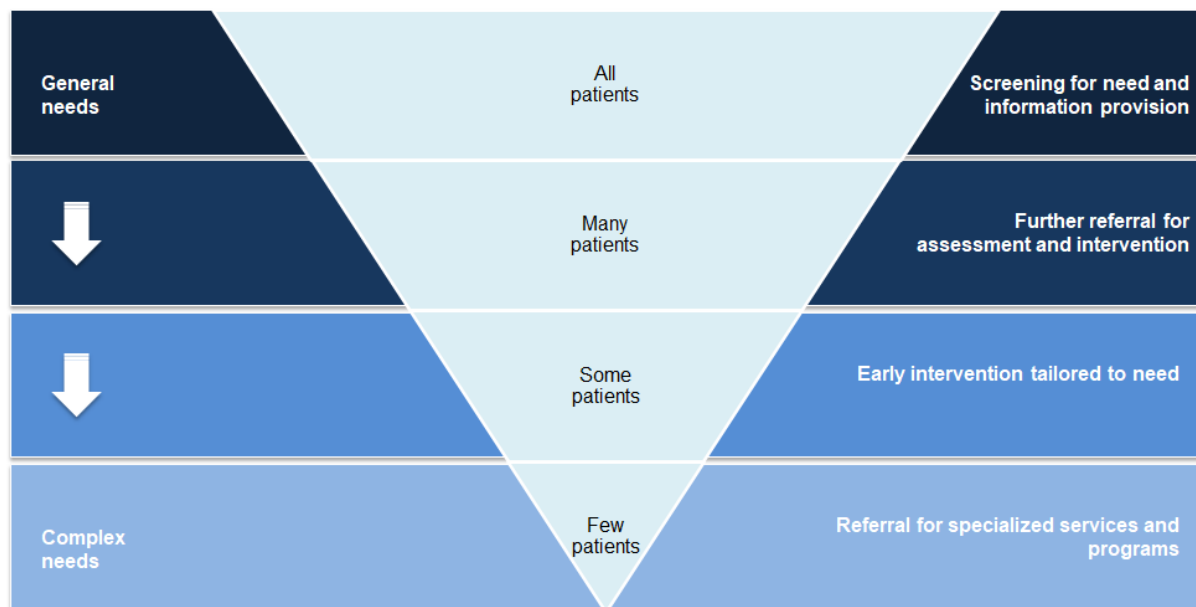
Health literacy has proved to be correlated with SES. Research demonstrates that patients most at risk for poor health literacy are from rural areas, undereducated and/or from low-income status (Friis et al., 2016; Stormacq et al., 2019). However, the current results demonstrated that SES might not influence access to, and satisfaction with, information received. Therefore, the predominant issues about information needs are identified as availability and accessibility.

The aforementioned results indicate that information needs to be personalised and tailored to one's needs. Fitch's (2000) model of supportive care (Supportive Cancer Care Victoria, 2011) recognises that effective, efficient allocation of resources is required to respond to a specific population's diversity of needs. This model underpins the importance of making

information available to patients and argues that all patients require general information, whereas only a few will require specialised interventions (Figure 17).

Figure 17

Provision of information based on patient needs



Note. Adapted from Fitch's 2000 model, Supportive care pyramid of needs

Unmet psychological needs

Melanoma patients' psychological needs are one of the least satisfying supportive care needs (Bonevski et al., 2000). Melanoma treatment can lead to numerous debilitating physical and psychological effects on patients, including treatment-related morbidity, pain, fatigue, anxiety, depression, low self-esteem, financial toxicity, as well as relationship and family stresses (Cheung et al., 2018; Bayer et al., 2017; Oliveria et al., 2013). Combined, these can lead to reduced overall health status, wellbeing and QoL.

The current study supported findings in existing i.e. literature (Okediji et al., 2017; Kasparian, 2013; Fu et al., 2020), highlighting many domains of unmet needs. The results of the current study showed that FoCR (62%) remains a major concern for people treated for

melanoma, and patients often suffer from high anxiety (40_50%), revealing strong desires to seek reassurance (56%). In addition, on average, one in three surveyed patients reported overthinking about treatment (39%) and desire for more emotional (38%) and social (35%) support. 26% mentioned that melanoma changed their relationship with others, 24% said it decreased their self-esteem, and 22% reported that the experience of having melanoma negatively affected their overall wellbeing.

As mentioned in Chapter 3, supportive care plays a vital role in melanoma post-treatment care. It encompasses multiple needs of patients (i.e., psychological, emotional, social, practical, informational) (Fitch, 2000), which are individual-specific and vary across the stages of the cancer journey (Moghaddam et al., 2016). Research also shows evidence that unmet supportive care needs of patients with melanoma can lead to ineffective coping, increased emotional distress and reduced QoL. Failure to meet patient needs may also lead to delays in seeking medical advice leading to worsening physical conditions in some patients and associated increases in medical costs, as well as poorer survival rates (Loquai et al., 2013; Sanson-Fisher et al., 2000). Hence, the importance of effectively identifying and establishing strategies to mitigate unmet needs is well-established for improving patient outcomes into the future.

In theory, follow-up appointments provide a unique opportunity for clinicians to address melanoma patients' unmet needs. However, this study is consistent with previous findings (McLoone et al., 2013), highlighting limitations to patient satisfaction with their individual care. With this, the risk of providing inadequate care.

The link between information and psychological needs

The association between *informational needs* and *psychological health* has been well-established in previous studies. Research shows that patients who receive information according to their preferences report greater emotional, social, and physical wellbeing. It also reports that providing information that fits individual patient needs can reduce psychological distress, increase patient satisfaction with their care, and improve QoL (Fallowfield et al., 1994; Husson et al., 2013; Lamers et al., 2016; McInnes et al., 2008).

Indeed, patients reporting poorer satisfaction with the quantity and quality of information received at the time of diagnosis were more likely to report stronger psychological distress than those reporting higher satisfaction.

These results reiterate the crucial need to improve communication about the impact of melanoma on mental health and supportive care services available for patients (e.g., peer support groups). With this, the current study showed that less than half of patients surveyed received information related to melanoma psychological implications (66%) and social group support (77%). At the same time, the majority were dissatisfied with the amount (55_55%), and quality (54_54%) of information received.

Moreover, depending on the needs of the patients, referral to appropriate health professionals and/or organisations should be considered. However, patients are not always aware of what their options are. While more than one in three patients (36%) experienced difficulties psychologically coping with melanoma, a majority of the surveyed patients (67%) were not referred to a specialist (e.g., psychologists, melanoma nurses, counsellors, etc.). Given this, there is a discrepancy (29%) between the number of patients reporting psychological distress versus the number referred to appropriate mental health professionals.

If replicated in the broader melanoma community, this gap indicates that a significant number of patients are not getting the customised treatment they need and are at risk of their overall health being negatively affected as a result. This gap also represents an opportunity for interventions that could meet these needs, improve health outcomes, and ultimately represent a cost-effective strategy for improving melanoma care.

Therefore, the aforementioned data reinforces the critical need and argument to provide information and communication tailored to patients' individual needs.

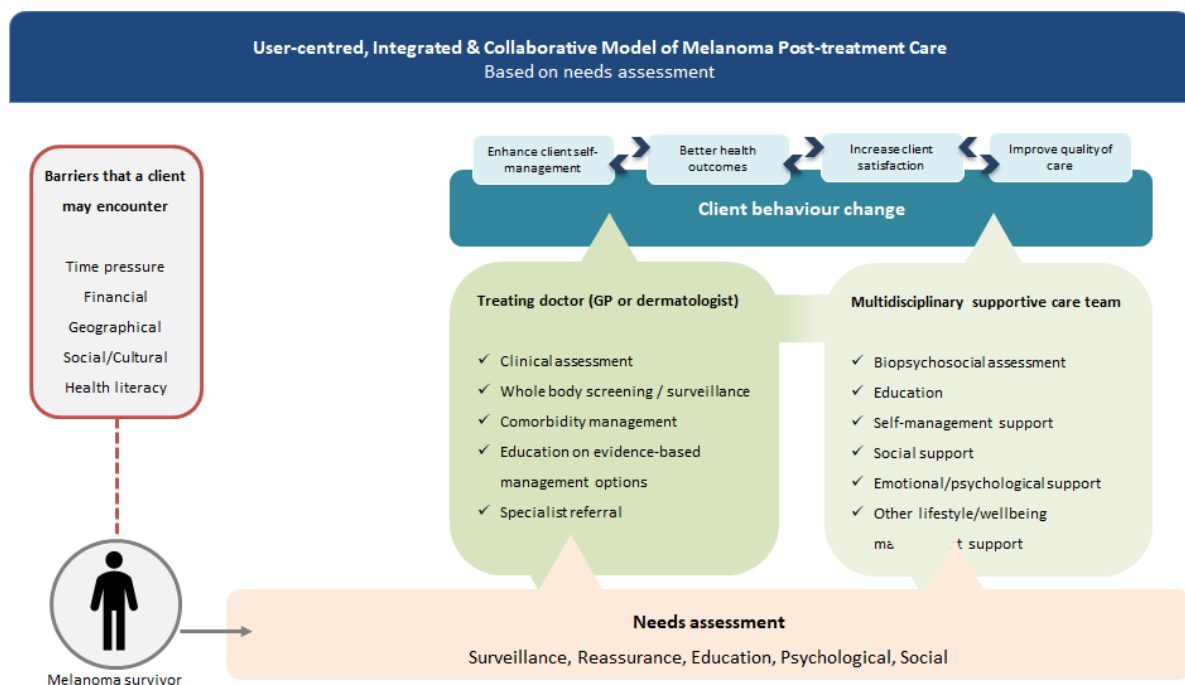
Section 2: A patient-centred model for melanoma patients to receive high-quality post-treatment care

Model of care (MoC) broadly defines how health services are delivered, outlining best practice care and services through the different stages of a condition. It ensures people get the right care, at the right time, by the right team and in the right place (ACI, 2013). To achieve the most efficient and effective care, MoC must embrace patient-centeredness and ensure equitable and integrated health coverage. Optimal MoC must therefore identify an area of need and understand the root of the problem to address the issue.

As of the conclusion of this study, no authoritative model has been offered for melanoma post-treatment care. Building on the current findings, a model is proposed for melanoma post-treatment care centred around optimal care for patients (Figure 18).

Figure 18

User-centred, Integrated & Collaborative Model of Melanoma Post-treatment Care



The proposed model is rooted in a user-centred, integrated and collaborative approach to healthcare supported by a multidisciplinary team. Importantly, the type of interventions undertaken is based on a client's needs assessment conducted by the treating doctor during follow-ups and/or a supportive care team (e.g., allied health professionals, social workers, nurses, specialists, etc.) rather than individual characteristics. Effective care enables positive behaviour change and leads to improved quality care and, therefore, patients' satisfaction with

their experience of care. Arguably, a cost-and time-effective model of melanoma care should encourage patients to engage in their care through co-developed post-treatment care plans, supported self-management, improved health literacy and increased efficient communication with HCPs.

The proposed model is established on evidence-based practice. Shared follow-up and use of multidisciplinary teams (Satisivam et al., 2014) (i.e., specialists, GPs, allied health) in other cancers and melanoma has been successfully trialled in Australia (Lim et al., 2018). It has proven to accommodate the needs of patients in a timely and effective way. For instance, patients' clinical risk factors influenced follow-up options, as well as psychosocial and logistic considerations (Rychetnik et al., 2012; Lim et al., 2018).

Efficient communication between HCPs and with patients is at the forefront of the model of melanoma post-treatment care suggested in this thesis. However, according to the current results, there is insufficient and inadequate communication between clinicians and melanoma patients today. Given this, melanoma management guidelines should encourage clinicians to undertake continuing professional development (CPD) training to improve communication skills and assist them in effectively providing information, client-centred care, shared decision-making, and adequate support to patients. These would increase the efficiency of healthcare services, providing patients with better support and optimal melanoma pathways, which increases melanoma relative survival rates, DALYs, and ultimately reduces incidence rates.

Finally, the proposed post-treatment care services delivery model is based on needs assessment and positions supportive care as equally crucial as follow-up visits. However, the study's results suggest that today, supportive care is often lacking in melanoma patient treatment plans, underpinning an urgent need for clinicians and other HCPs to address this. Adequate supportive care has proven to provide better health outcomes to patients with chronic diseases (Fu et al., 2020). It can reduce stress, improve wellbeing and QoL, provide support and connection to patients. Therefore, psychosocial evidence-based interventions, such as cognitive behavioural therapy, psycho-education, and support groups, should be made available to melanoma patients to improve QoL. Unfortunately, these interventions come at an

extra cost in the current Australian Healthcare System and can lead to an increased burden (e.g., financial toxicity, psychological distress, etc.) on patients.

The *Patient-centered, Integrated & Collaborative Model of Melanoma Post-treatment Care* places quality at its foundation. However, to develop and implement such a model, changes in clinical practice at the front line are required. This means that measures to support HCPs at any time of the transition need to take place. Challenges such as financial, technical, workflow and staffing also need to be considered. Arguably, there remains an opportunity for digital health to be used as an adjunct service by HCPs to support them in their practice to deliver the most effective care.

Figure 19 offers an evidence-based perspective on enablers and outcome factors of VBHC for melanoma post-treatment care. This perspective is supported by three years of research in NSW with various melanoma populations. Founded on data generated from the current study, it identifies digital health as an enabler of VBHC for melanoma post-treatment care. It recognises technologies that are the most likely to provide better patient outcomes and value to the Australian health system (refer to Part 2, Section 1 of the discussion for details). Moreover, this perspective illustrates the benefits for a client, underpinned by digital health interventions and their impact on health and society. In summary, it demonstrates that digital health can support and enhance the model above of melanoma post-treatment care at the condition that clients' needs and preferences inform its implementation. Building on this finding, a digitally enabled model of melanoma post-treatment care would help HCPs provide a better experience of care for patients through improved access and QoL, which would increase health outcomes and ultimately reduce the economic burden of melanoma in Australia.

Part 2 of this chapter provides the scientific rationale supporting this perspective and discusses the results of the current study regarding melanoma patient attitudes toward digital health and factors that may influence their use of technologies in post-treatment care.

Section 1: Melanoma patients use of digital health

The data generated from the current study reveals that digital health adoption is relatively low amongst melanoma patients (6%-59%). Findings show basic web-based platforms, including websites (59%), Facebook (57%) and email (45%), are the technologies that people most use during their melanoma patient journey. In contrast, what are considered by clients to be more advanced digital health technologies, such as teleconsultation (7%) and teledermoscopy (6%), were the least used. Compared to the data generated about patient knowledge of technologies (Table 10, Chapter 7), these results are significantly low and unexpected, given the evidence-based benefits discussed in Chapter 2.

Willingness to use digital health technologies

The data within the current study reports that, overall, patients are willing to use digital health technologies to increase access to melanoma care and enhance QoL. However, the results show a significant difference in distribution between the different technologies, suggesting that patient attitudes toward digital health differ according to technologies offered/available. This finding suggests there are features within technologies that people respond more positively to, leading to these preference patterns - possibly relating to the type of interventions, user experience, familiarity with technology and time- and cost-pressure factors. Further investigation into qualifying the potential outcomes and attributes of technology that are popular with and comfortable for melanoma patients will facilitate the customised design and implementation of technology and digital health tools to produce better results and health outcomes for this specific group.

Overall, the current study identifies that melanoma patients are open to digital health interventions to increase access to post-treatment care and improve QoL. Results report that a majority of patients are willing to use ICT platforms like emails (78_73%) or websites (66_62%); mHealth technologies including SMS (75_71%), mobile camera (64_66%) and mobile apps (59_56%); as well as self-monitoring tools (60_52%) and digital skin maps (64_64%).

The current research indicates that a minority of patients surveyed would accept telehealth as a solution to increase *access to care* (38-49%) and *improved QoL* (44-48%). The data also provides evidence to increase access to post-treatment care patients are more willing to use store-and-forward platforms (49%) and teledermoscopy (40%) compared to LVC (38%). However, more patients are eager to use LVC (44%) if it improves QoL.

Therefore, *the difference in distribution between technologies* suggests that people are often more inclined to use digital tools that they are already familiar with and/or use in their day-to-day lives.

Of note, the present study also identified an opportunity for social media platforms like Facebook (58%), and online communities (51%), as well as VR (58%), which could improve

QoL, suggesting that these technologies are underutilised in practice areas (Harkin et al., 2020). Compared to more commonly used technologies like mobile apps, social media, or telehealth, patients reported a greater willingness to include VR in their melanoma treatment plan to improve QoL.

Building on previous findings, this result suggests that patients are more receptive to interactive and gamified technologies. Evidence-based interventions demonstrated that VR could increase patient knowledge and empowerment, and engagement with their care. The use of VR in melanoma could promote early detection and therefore reduce anxiety between consultations. Scientific evidence is already established that immersive therapies, including mindfulness programs, can support patients with a chronic disease reduce psychological distress (Russel et al., 2018). The current analysis reveals that patients who experience more difficulties accessing follow-up visits due to travel time and distance, long waiting times and taking time off work are more willing to use VR to manage their health. Similarly, patients reporting higher psychological distress are more likely to show positive attitudes toward VR interventions to manage their health. However, to date, there is no empirical evidence about the use of VR in melanoma diagnosis/management and its benefits. Thus, the aforementioned results only highlight an opportunity for VR interventions that could increase the accessibility and affordability of melanoma post-treatment care through immersive therapy and the delivery of psychoeducational programs like game-based learning.

Furthermore, the current data identified that while demographic factors like age and gender do not influence preferences toward VR interventions, patients surveyed of higher socioeconomic class reported stronger willingness to use immersive technologies. This result can be explained by the expensive cost associated with this type of technology. This information needs to be considered to accurately personalise the health technologies according to the melanoma patient and drive better outcomes.

While the above results show positive attitudes regarding immersive technologies, the current study also identifies low acceptance/interest for serious video games. A minority of patients surveyed were willing to use serious video games in their post-treatment care (i.e., access to care: 16%; improve QoL: 18%). However, a recent study (Maganty et al., 2018)

indicates melanoma patients enjoy online game-based learning more than written education material. This can be explained by the association between patient age and willingness to use serious video games. Indeed, the current analysis is consistent with previous studies (Johnson et al., 2016), demonstrating that young populations are more likely to use serious video games to manage their health than older populations.

Of further consideration are the current study's results about patient willingness to use technology. Findings indicate that patients' willingness to use technologies are significantly higher than the data assessing current use of digital health in melanoma post-treatment care (*Part 2, Section 1*). This difference suggests that patients don't know (1) what technologies are available, (2) how to use them and/or (3) their potential benefits.

This disparity may also result from poor digital health literacy, which has been defined as "*the ability to seek, find, understand, and appraise health information from [digital] sources and apply the knowledge gained to addressing or solving a health problem*" (Norman et al., 2006). Unremarkably, previous literature reveals that people with low digital health literacy are less likely to use online health information and digital health technologies (Jayasinghe et al., 2016).

The disparity between current use and willingness to use technology, particularly to improve QoL, represents an opportunity to incentivise HCPs to encourage uptake. The benefits to melanoma patients are discussed in *Section 2*. This measure may benefit melanoma patients living farther away from healthcare infrastructure or experiencing cost and time limitations.

Section 2: Digital health benefits in melanoma care

The present study attempts to understand the potential benefits of digital health in melanoma post-treatment care to optimise patient outcomes by answering two questions:

1. What benefits do patients think they will achieve using technology in their melanoma care?
2. What do patients think technology could do to increase their access to care?

This knowledge will inform HCPs (and health policymakers) on optimal ways to implement digital health to optimise melanoma patient outcomes. The results of the qualitative analysis (*Tables 5-6*) indicate that a majority (67%) of patients believe digital health can add value to their melanoma care. Yet, almost one in three patients don't think (22%) or are unsure (8%) that digital health can add value to their melanoma care.

The current analysis demonstrates an unavoidable overlap between the different identified benefits. As showcased in Part 1 of the discussion, access to care is significantly associated with psychological distress, with time and cost limitations interfering with how much access patients have. In addition, the current findings highlight that better access to post-treatment care is often linked to improved supportive care and QoL.

Increasing access to melanoma care

While the benefits of digital health to melanoma patients are uncertain, the present data illustrate that increased access to care is the primary predictor of digital health uptake (57%). Indeed, it is well-established that, to be accepted by patients, digital health should accommodate their individual needs and enable quicker access to healthcare services (Coory et al., 2006; Hall & Murchie, 2014; Murchie et al., 2015).

Furthermore, findings reveal numerous time, cost and infrastructure limitations to access follow-up visits. These barriers can therefore explain patients' positive attitudes toward, and perceptions of, digital health. As outlined in the *Rationale for methodology* chapter, access encompasses five dimensions: (1) approachability, (2) acceptability, (3) availability, (4) affordability and (5) appropriateness.

The results of the qualitative analysis suggest that there is a real opportunity for digital health to improve appropriateness and availability of care. Nevertheless, while almost one in three melanoma patients experience financial difficulties (direct and indirect costs) related to their illness and treatment, patients surveyed don't think that the use of technologies could increase access through more affordable care.

Importantly, patients value good communication and personalised/tailored care as essential needs that must be met to increase access to melanoma care through technology.

Appropriateness and availability

In line with previous literature (Rollin et al., 2018), the current study identifies that patients think that digital health can increase their access to care if it is, first and foremost, thought of as an *accommodating solution* (64%). To achieve this, digital health must provide melanoma patients with convenient care tailored to their individual needs (e.g., adapted follow-up schedule, timely access to HCPs, etc.). Further, almost half of those who believe that digital health can increase access to care think that using technologies could provide them with quicker access (48%).

As outlined in Part 1, 15% of patients surveyed reported dissatisfaction with their follow-up visit frequency, wishing to see their doctors more often. Therefore, digital health — specifically telehealth interventions — would enable patients to timely receive virtual care, adjusted to their schedule (i.e., work, family constraints), which in turn may reduce their anxiety between appointments.

The results also suggest that teleconsultations have strong potential to improve availability of care. This could be achieved by enabling patients to reach healthcare services remotely in a timely and cost-effective manner and would be especially effective for those living farther away from their doctors or would otherwise be required to take time off work.

The analysis also suggests that digital health technologies could increase access to care by creating an opportunity for patients to check side effects and other minor concerns with HCPs directly. This could reduce long waiting times for setting an appointment and overcome the cost and time constraints of in-person consultations.

Of importance, the data indicates that increased access to care through the delivery of digital health can provide reassurance to melanoma patients and reduce psychological distress, such as anxiety between visits, FoCR.

Better communication

The current data indicates that digital health should enhance communication between HCPs and patients (60%). It has long been established that better communication can improve both clinical care and supportive care (it can help meet a patient's information and psychological needs) (EdCan, 2021). In line with existing studies on digital health for the management of chronic disease (Rollin et al., 2018; Horsham et al., 2016), the current research shows that:

- Digital health — particularly ICT and telehealth technologies — can deliver *efficient communication* between HCPs and patients by providing timely information such as results.
- Digital health interventions can *improve patient knowledge* by providing adequate and tailored information and being utilised as an adjunct service by HCPs to meet patients' needs. As mentioned in Part 1, patients lack knowledge about their illness and how to cope with it; are dissatisfied with the nature and quality of the information received from their doctors at diagnosis. Previous research on melanoma suggests that technologies like ICT, mobile apps, videos and social media can be used to address the need for better quality and greater consistency in the information provided to patients (Damude et al., 2017).
- Digital health can *reduce social isolation* by connecting patients (and carers) with other melanoma patients via online communities. Indeed, the current study highlights that almost one in three patients required more social support and mentioned that melanoma changed their relationships with others. As outlined in the *Digital health* chapter, online communities — such as social media and discussion forums — have the potential to improve patients' engagement with their care by creating a safe space where they can interact.

These findings also reflect that better communications for-and-between HCPs and patients via digital health can reduce psychosocial distress and significantly improve reassurance by decreasing social isolation, improving health literacy and reducing the HCP-patient communication gap.

Affordability

A small number of patients (10%) explicitly mentioned cost savings so that technology would increase their access to care. This finding suggests that patients don't see monetary value in using technologies. However, costs associated with the melanoma patient journey can limit access to care by 20-30% of patients.

Enhance supportive care

As outlined in Part 1 and reported in previous literature, unmet supportive care needs reflect the disparity between the support that one perceives as necessary and the support received (Moghaddam et al., 2016). The current study confirms the existing findings, demonstrating the need to address the lack of supportive care to improve melanoma patient health outcomes and QoL.

Notably, the present analysis reveals an opportunity for digital health interventions that could address the unmet informational and psychological needs of patients.

Psychosocial support

Of the patients surveyed, 39% mentioned that digital health would improve psychosocial support. In support of previous literature, the current analysis indicates that providing information and testimonies from other patients online can increase patient engagement in their care, provide reassurance, and help them psychologically cope with their illness (Colera, 2013; Maganty et al., 2018).

In addition, the current results confirm the benefits of using online communities and social media to improve patient outcomes. Patients surveyed clearly stated social media and online communities as valuable sources of information, which would address their psychological and information needs.

Furthermore, the current results confirm previous findings that online narratives can reinforce social norms and promote adaptive behaviour (Coups et al., 2018). As a result, digital health will improve patients' confidence in conducting TSSE and increase their willingness to participate in their care. Moreover, similar to a recent study (Banerjee et al. 2018), the current analysis finds that online communities and social media also can address social isolations by facilitating connection and interaction with other melanoma patients (Banerjee et al., 2018).

Critically, this study reports that digital health — particularly online communities — can be used as adjunct therapies by patients during post-treatment care as “*clinicians often deal with the medical side, not the reality of emotions and feelings*” (ID 64).

Patients surveyed also reported that the adoption of digital health can provide patients with peace of mind while reducing financial toxicity and improving timely access to healthcare services and information. However, further research needs to be done to calculate the potential cost benefits to melanoma patients and the healthcare system.

Patient's empowerment

Supporting the results of existing studies, the current findings illustrate a need for melanoma patients to be more active in managing their illness (Loiselle et al., 2013). With the present study, 35% of patients believed there was further potential for digital health to increase self-empowerment related to their melanoma care. As outlined in Chapter 2, technologies can lead to patient empowerment by providing better access to online information and educational support about preventive behaviours and risk factors (e.g., TSSE, sun exposure). Similar findings were reported in previous research (Damude et al., 2017), showing that eHealth technologies such as online videos can supplement oral and written information delivered by

clinicians. Gamification and immersive technologies also offer the potential to support patients in their health management.

The current data indicates that digital health can give more control to patients, enhancing engagement in their care and improving self-management. As outlined in Chapter 2, mHealth technologies such as mobile apps, mobile cameras and digital skin maps can support patients' health management.

A majority of the existing studies highlighted that digital health is predominantly used to promote early detection and report the main benefit of digital interventions is to prevent recurrence (Rollin et al., 2018). However, in the current study, a minority of patients report improving detection and promoting self-monitoring as benefits of digital health. In line with findings discussed in Part 1, these results suggest that melanoma patients are already satisfied with the support they have related to early detection and prevention of recurrence. Given this, it is recommended that digital health be thought of as a solution to help patients psychologically cope with their illness through improved knowledge and emotional and social support.

Improved quality of care

The current study reports that a minority of patients (12%) think that digital health can increase their quality of care. The qualitative data indicate that digital health may improve patient outcomes by encouraging collaboration between HCPs and remote access to specialists.

These findings suggest that overall, patients think that digital health can benefit them if it:

- Provides them with more convenient care tailored to their individual needs;
- Increases supportive care through emotional and social support, as well as access to adequate information;
- Gives them more control to self-manage their health.

Consequently, the adoption of digital health in melanoma post-treatment care could reduce FoCR, anxiety and social isolation, as well as increased reassurance and confidence.

Section 3: Predictors of digital health adoption

As outlined in Chapter 4, it was reported that existing studies about digital health in melanoma care did not consider the individual characteristics of patients in their analysis. As a result, the published review highlighted the importance of considering these factors to optimise digital health and provide better care and QoL.

In contrast to previous literature, the current study reveals that, overall, individual characteristics (demographics, SES, illness condition) do not influence the current use of digital health but can interfere with patient willingness to use technologies. The data reveal that patient age, psychological distress and barriers to accessing care significantly influence patient willingness to implement digital health in melanoma post-treatment care, particularly to improve QoL.

Notably, the results also identify that SES is not significantly associated with patient willingness to use technologies in melanoma care. Instead, education level attained, and distance to services are two SES factors that influence the uptake of digital health.

Demographic status

Compared to existing findings (Werner & Karnieli, 2003; Horsham et al., 2016; Hall & Murchie, 2014; Murchie et al., 2015), the present study reveals that demographic factors — like gender and age — are not strong determinants of digital health uptake. Nonetheless, the results do show that older patients are more likely to use online communities to manage their health.

Given this, a patient's age plays an essential role in willingness to use technologies in their post-treatment care. This factor seems to primarily affect people's willingness to use technologies that help improve QoL. These results translate to the following insight: the

younger a person is, the more willing to use digital health. These results align with existing findings (Horsham et al., 2016), which indicate that young patients are often more familiar with technology (meaning, those with digital skills and IT capability). Furthermore, the current study posits that young populations may be more inclined to trust digital health interventions (Horsham et al., 2016).

Illness condition

The current use of digital health technologies was not influenced by one's illness condition (i.e., severity of illness, including melanoma stage and recurrence). There were some exceptions, specifically that less severe conditions were correlated with patients' use of emails, online discussion forums and store-and-forward platforms. These results suggest that patients with a thinner melanoma are more likely to already communicate with their doctors via emails or sharing information using store-and-forward media compared to those with a more advanced stage. The data also identified that patients diagnosed early are more inclined to use online forum discussions.

In contrast, the study highlighted that patients diagnosed with a deeper tumour thickness are more willing to use teledermoscopy to improve QoL than those diagnosed with a thinner melanoma. This finding aligns with a recent empirical study investigating patient attitudes toward mobile teledermoscopy (Kong et al., 2020). The study reported that over 96% of melanoma patients would be inclined to use mobile teledermoscopy to self-monitoring lesions between follow-up visits.

Socioeconomic status

In contrast to previous findings by (Smith & Magnani, 2019), the current study illustrates that, overall, SES was not a key predictor of current use or uptake of digital health by melanoma patients. Data generated from this study reveals some correlations between SES and willingness to use technologies. Level of education and distance travelled are the factors interfering the most with patient willingness to use digital health. The findings also indicate

more significant potential for digital health interventions if they increase access to healthcare services rather than improve QoL.

Level of education

Current analysis reveals that patients who have attained a higher level of education are more often more willing to use digital health (except for online communities) to increase their access to healthcare services. However, the results also show no correlation between education and the potential for digital health to improve QoL. This lack of association between level of education and willingness to use digital health to improve QoL may be explained by the difference in QoL perceptions which varies between various social and cultural environments (Mielck et al., 2014). In support of this, several studies have highlighted that low education is associated with low health-related QoL (Wan Puteh et al., 2019; Aminde et al., 2020). Therefore, this suggests that although a patient with low education may *objectively* present poor QoL, it may not perceive it as such. Conversely, a patient with higher education may *objectively* present a moderate QoL but perceive it as low.

Geographical barrier

In contrast to previous literature findings (Hall & Murchie, 2014; Murchie et al., 2015), the current use of technologies is not influenced by distance travelled to follow-up visits. However, patients surveyed living farther away from their doctors present a greater willingness to implement mHealth technologies and teleconsultations into their care and use online communities.

The findings also reveal that patients who experience difficulties accessing healthcare services are more willing to use digital health to improve QoL rather than increase access to care. These results suggest that:

- Patients are sufficiently satisfied with their access but see the potential for technology to improve their QoL;

- Barriers experienced by patients to access healthcare services are directly associated with QoL.

With either of these two approaches, there remains an opportunity for digital health interventions, which could make patient life easier and better.

Moreover, the current study shows that patients who face difficulties accessing healthcare services are more willing to implement digital health in their post-treatment care to improve QoL. Technologies they are more likely to adopt are ICT, mHealth, telehealth and those enabling self-monitoring. This suggests that patients want to increase access to care through increased control/engagement in their care and improved communication with HCPs.

Furthermore, building on findings previously reported in this chapter, results indicate that travel costs are not likely to predict digital health uptake, reinforcing the idea that patients don't perceive digital health as a solution that could bring them cheaper access.

Residential areas

It was predicted that differences in residential areas would correlate with patient digital health use in melanoma post-treatment care. However, the present data illustrate that patients' residential areas are not strong predictors of digital health uptake in melanoma. The only significant correlations identified in this study are for technologies that can enable self-monitoring interventions. Notably, urban populations report a stronger interest in using digital health compared to rural patients.

This study also indicated that rural communities share the same level of willingness to integrate digital health within their care as urban populations. It suggests that rural and urban patients have similar attitudes toward utilising technologies to manage their health and patient experience.

As discussed in Part 1 of this chapter, melanoma patients living in rural areas report the same level of access to, and satisfaction with, current post-treatment practices as those living

in urban areas. However, as outlined in Chapter 3, rural communities in Australia have less access to healthcare services due to infrastructure and medical resource limitations.

Combined, these findings suggest that rural populations should not be treated any differently than urban communities when implementing digital health strategies and infrastructure in Australia.

Psychological health

It was predicted that melanoma patients who experience more significant psychological distress are more willing to implement digital health to manage their health. In line with findings previously described in the discussion, this study suggests that patients reporting high levels of distress are more inclined to adopt technology to improve QoL and increase their overall access to post-treatment care.

The results show that to increase their access to healthcare services and QoL, melanoma patients with psychological distress (e.g., FoCR, anxiety prior and between medical appointments) and those reporting psychosocial needs (i.e., desire for more reassurance, social and emotional support) are more willing to use digital health to manage their health. Therefore, melanoma patients are more inclined to use technologies that could help them to:

- Connect and interact with other patients (e.g., via online forum discussions, Facebook);
- Communicate and share timely information with HCPs (e.g., via emails, mobile phone texts and cameras, store-and-forward platforms);
- Receive adequate information and psychoeducation materials to improve their knowledge on melanoma and teach them coping strategies (e.g., via websites, web-based apps, VR)
- Self-monitor/manage their illness (e.g., via mobile phone cameras, apps and other self-monitoring tools).

Patients who reported that melanoma reduced their wellbeing and impacted their relationships are willing to use technologies in similar patterns. However, patient distress and

psychosocial needs did not determine an individual's willingness to use YouTube, serious video games, AR and teledermoscopy.

An individual's psychological health significantly influenced patient willingness to implement teleconsultations in their melanoma care to improve QoL. Conversely, this was not the case when increasing access to healthcare services was the proposed outcome. This suggests that patients see more significant potential for digital health to meet their psychological needs to improve QoL and wellbeing. If HCPs made greater use of telehealth technologies, the psychological and psychosocial outcomes could be improved for melanoma patients. However, trials and further study is required to quantify and qualify these outcomes in melanoma settings.

Section 4: Access to digital health by melanoma patients

It has been shown that digital health can vastly improve health outcomes for patients suffering from chronic diseases (Hewitt et al., 2020; Kerr et al., 2019; Cahn et al., 2018) when used as adjunct services by HCPs, and by patients to improve their access to information, HCPs and other support.

As previously outlined in the discussion, patients exhibit positive attitudes toward the use of digital health in their melanoma post-treatment care. However, this study reveals a vast disparity between *patient knowledge* and *patient use* of technologies. To encourage digital health implementation for optimal care, it is essential to identify what factors are interfering with digital health uptake and strategies to reduce this gap.

Similarly, to measure access to 'traditional' healthcare services, the research refers to the *five dimensions of access* (Lavesque et al., 2013) to investigate access to digital health in post-treatment care.

1. **Approachability** (awareness of the existence of services, how to reach them and the effect they have on one's health);
2. **Acceptability** (social or cultural factors that affect the use of services);

3. **Availability** (ability to reach the service both physically and in a timely manner);
4. **Affordability** (ability to pay for services);
5. **Appropriateness** (ability to engage in care that is of a reasonable quality).

Approachability and availability

The current results show that most patients (roughly 70% for 12 out of 14 technologies inquired about) know about the various technology options. Still, only 2 of the technologies (websites and Facebook) have been used in melanoma post-treatment care by more than 50% surveyed. This discrepancy between what patients “know about” and “do” suggests that:

- Patients may not be aware that these technologies can be used in melanoma care settings;
- Patients may not know how they can integrate these technologies into their melanoma post-treatment care;
- Patients have heard of these technologies but may not be aware of where and how to access them (e.g., mobile apps);
- Patients may not know how to use these technologies. For instance, due to a lack of education or IT capabilities;
- Patients ignore how these technologies can improve their experience of care and health outcomes.

These results also suggest that HCPs aren’t using them, promoting their use to patients, or communicating them as options to patients. Given this, researchers posit that:

- HCPs aren’t aware of the potential digital health options or benefits;
- HCPs workload doesn't allow them to learn how to efficiently use or educate their patients on how to apply these technologies to their melanoma care.

Acceptability

As previously discussed in this chapter, data generated from the current study reports that rural patients are more likely to use technologies enabling self-monitoring and timely sharing of information with HCPs compared to urban patients. Also, the data reveals that SES was not a predictor of access to healthcare services. These findings suggest that people living in urban areas may accept these technologies *less*, despite knowing about their existence. Further research would need to be carried to understand why urban populations may be less inclined to use digital health to manage their melanoma care in Australia.

Affordability

As outlined in the *Digital Health in melanoma care* chapter, more than 85% of households have internet access, and more than 91% of Australians have access to a smartphone.

With this finding, it is arguable that the digital health technologies investigated in the current study are all accessible either online or via mobile phones (with teledermoscopy being the exception). It suggests that the affordability of the technologies is most likely not a predictor of the know-use disparity.

Appropriateness

The data discussed in this section (Part 2, Section 4) were based on technologies previously identified in the digital health and melanoma care literature, which have all been scientifically proven to benefit patients with melanoma to a certain extent (Rollin et al., 2018). However, the right technology still requires to be available to, and accessible by, an individual at the right time to fit with a client-specific needs to improve health outcomes.

Better digital health uptake

These findings suggest that the disparity between *patient knowledge* and *patient use* of digital health in melanoma care is not because of lack of technology options but most likely relates to access, awareness, and education problems. This suggests that patients need to be:

- Informed about technologies available/offered;
- Educated on how to use digital health efficiently;
- Taught about digital health potential and benefits.

One solution would be to standardise the training of clinicians in digital technologies capabilities to educate patients about digital health interventions in melanoma post-treatment care.

Conclusion — Toward a digitally-enhanced model of melanoma post-treatment care in Australia

To date, there is no authoritative model of melanoma post-treatment care to support clinicians in their daily practice to deliver evidence-based interventions for melanoma post-treatment care. Given this, the current study identifies, for some patients, a lack of access to effective and appropriate healthcare services and dissatisfaction with supportive care. In addition, the above findings provide strong evidence that Australia needs to develop and implement an optimal health model for melanoma post-treatment care that is based on needs assessment in which policymakers, health system leaders and clinicians consider the following information to expand access to high-quality care:

- Geographical proximity, cost, and time pressures are the most significant barriers that limit melanoma patients to access their follow-up care;
- Social and cultural environments do influence patients' perception of geographical isolation and, as such, shape their individual needs;
- Poor access to post-treatment care leads to higher psychological distress;
- In melanoma, supportive care often does not meet patients' needs.

Building on empirical findings, a client-centred, integrated and collaborative model of melanoma post-treatment care for Australians has been proposed in this thesis (Figure 18).

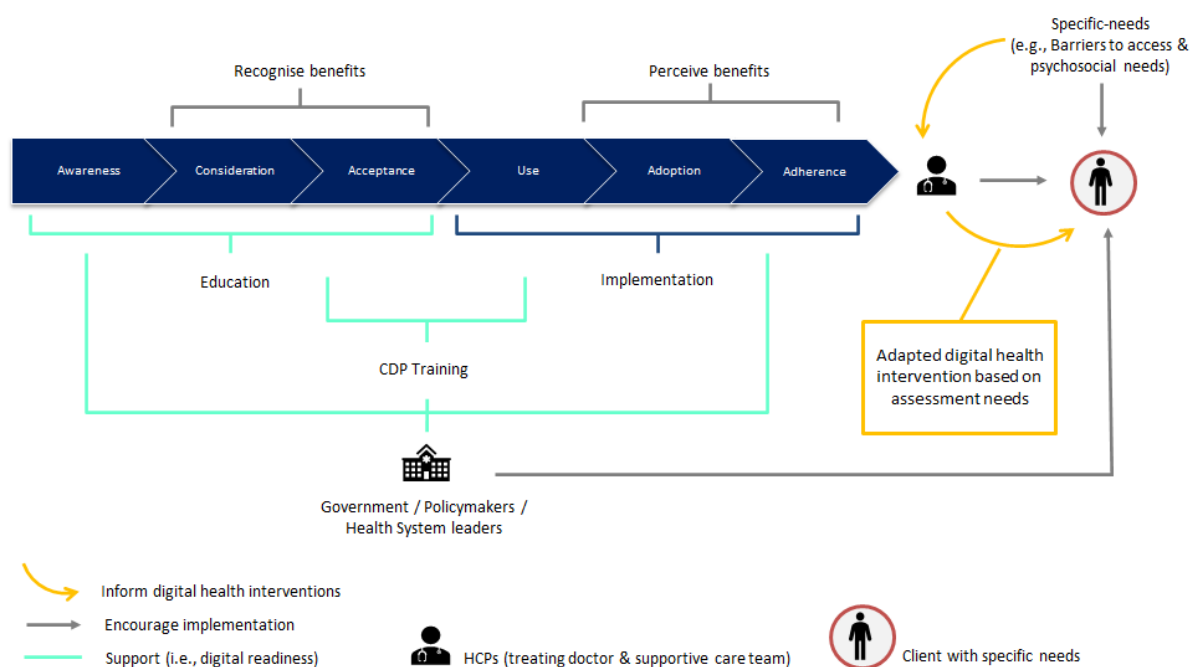
Moreover, while this thesis confirms that digital health has substantial potential to meet melanoma patients' needs and improve supportive care, its application, development, and adoption have been impeded by a lack of initiative to advance change. To optimise its implementation, further depth of information and education are required for both patients and HCPs. Remarkably, while digital health must fit in with client-specific needs to improve health outcomes, clinicians play a critical role in adopting technologies.

Given this, consideration of three critical questions for the implementation, utilisation and adoption of digital health for melanoma post-treatment care is required:

1. What measures and strategies should be considered to enhance digital health uptake amongst patients?
2. How to boost clinicians' adherence to digital health?
3. How to support clinicians in the digitalisation of melanoma post-treatment care?

Figure 20

Implementation of melanoma Digital Health care model based on user-centred needs Framework



The recommended digital health framework (Figure 20) for melanoma post-treatment care highlights the critical roles of HCPs and the national health system (i.e., government, policymaker and health system leaders) to inform and support the implementation of digital health to deliver optimal care for melanoma patients. It includes three key recommendations that support the aforementioned model of melanoma post-treatment care.

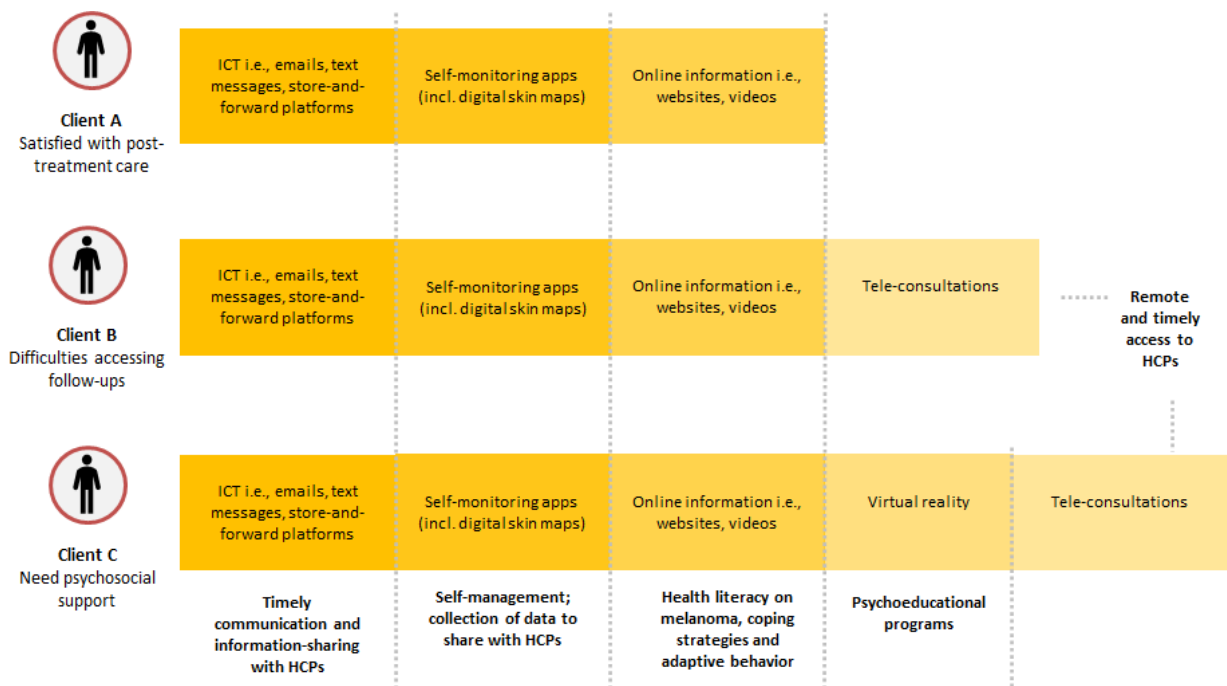
- Digital health interventions are based on a needs assessment of a client to ensure personalised and effective care;
- Identifying and recognising evidence-based benefits to enhance acceptance, willingness to use and adherence to digital health;
- Efficient communication between the different stakeholders and education are critical for the implementation of digital health.

Empirical evidence supporting this framework is discussed in the following sections of the discussion.

Section 1: Personalised digital health

Figure 21

Evidence-based digital health interventions to support clinicians in their practices



Based on the data generated by the study, Figure 21 provides recommendations to clinicians toward implementing digital health interventions based on identified needs and

clients' preferences for certain technologies. First and foremost, findings discussed in this chapter identify that it is essential to establish constant communication between HCPs and patients and improve information-sharing to support effective care delivery regardless of their needs. Indeed, inadequate and delayed communication can create anxiety and reduce health outcomes. Second, self-monitoring tools show great potential to support HCPs in their practice and deliver better care for patients. In addition to enhancing patients empowerment and engagement in their care, mobile tracking and monitoring technologies can increase treatment accuracy and quality care (i.e., precision medicine) by using the data generated. Third, this study identifies a significant poor level of knowledge and people's satisfaction with information received at the time of diagnosis, resulting from the high workload of HCPs and aptitude to communicate with their patients efficiently. Given this, this study argues that online information should be made available to patients, particularly as this study provides scientific evidence that poor health literacy can reduce psychological health and QoL.

Moreover, HCPs and particularly supportive care teams are encouraged to integrate telehealth in their daily practice to provide remote and timely care to patients who face access, time, and financial constraints. Finally, the current study reveals that melanoma patients are interested in exploring VR to address their psychological needs and improve their QoL. Given this finding, further research should be undertaken to investigate how HCPs could adopt VR to deliver optimal care for melanoma patients and measure its benefits.

Meeting patient needs

Melanoma patients are (to a certain extent) willing to integrate digital health into their health routine to increase their access to post-treatment care, mainly if it makes their life easier and improves QoL. Critically, patients' attitudes toward digital health vary according to technologies or platforms. Patient's individual needs have explained the difference between people's preferences for specific technologies (e.g., their communication preferences, informational needs, social or psychological or practical needs and wants), time and cost pressures, as opposed to demographic characteristics and SES.

Therefore, this research confirms the findings from the published systematic review in Chapter 4 (Rollin et al., 2018). It argues that digital health can reduce the burden of melanoma treatment/management for patients and the healthcare system if digital health and associated technologies are personalised to one's needs and for specific interventions.

Improving psychological support

To increase the use of technologies amongst melanoma patients, it is essential to provide them with evidence-based information on the benefits derived from digital health interventions and address how it can improve their QoL and reduce the melanoma burden. The following are examples of how digital technologies can benefit melanoma based on their specific needs.

- Measures of patients' willingness to use digital health to increase their access to healthcare services and improve QoL, compounded by results from the correlations between willingness to use technologies and patients' reported psychological distress (*Matrixes 1-6, Results chapter*), indicate that digital health has a real potential to help meet psychosocial needs of melanoma patients and would improve their overall experience of care and enable shared decision-making processes.
- In addition, as previously discussed, geographical proximity is a determinant of health and patients who experience more significant difficulties accessing healthcare services report higher psychological distress. Patients surveyed expressed positive attitudes toward using technologies that can help obtain support from other patients and improve their knowledge about melanoma and coping strategies.
- Moreover, psychological interventions such as tele-counselling should also be considered for regions where mental health treatment options, programs and facilities are minimal or absent. Arguably tele-counselling (a.k.a. telepsychology) has proven to be an effective solution to help clinicians counter

disparities in access to mental health services in underserved communities (Cooper et al., 2019).

Nevertheless, further study is required to comprehend digital health interventions cost-benefits (both direct and indirect) and the effect on a patient's QoL.

Section 2: Toward a value-based healthcare approach

Healthcare systems have recently witnessed a transition to value-based healthcare (VBHC) to facilitate and optimise healthcare delivery. The transition to VBHC, which aims to improve health outcomes and quality of services, measured against the cost spent on providing care to patients (PalliAged n.d.), has been supported using innovative technologies (Zhang et al., 2019).

As outlined in Part 1, Australia's current model of melanoma post-treatment care has numerous limitations, including:

- Patient's individual needs are often overlooked by clinicians, which reduce patients satisfaction;
- Time and cost pressures;
- Minimal supportive care which results from a lack of resources or clinicians' awareness about individuals needs or the effects of supportive care on patient outcomes.

The findings discussed in Part 2 represent an opportunity for digital health to be used as an adjunct service to help clinicians (1) to design post-treatment care plans for patients based on one's personal needs; (2) in their daily practice, generating increased and better health communication and to supplement information delivered to patients. (3) Digital health could also support clinicians in their practice by using the data generated from the technologies to remotely monitor a patient's health and adjust post-treatment care plans. To achieve this, it is critical to develop and implement digital solutions that are integrated and can coexist with pre-existing technology infrastructures and platforms. To date, scientific evidence identifies a lack

of uniformity amongst systems in use and inconsistency with data captured (Australian Digital Health Agency, 2019).

Furthermore, his study indicates that digital health interventions, especially telehealth, can upskill clinicians and improve clinical performances. Implementing technologies in clinical practices represents an opportunity to advance the transition toward a collaborative model of post-treatment care. The current results suggest that by improving coordination and communication between HCPs (e.g., between GPs, nurses, psychologists and specialists), digital health may provide cost and time benefits to patients and HCPs and more effective care, specifically to increase supportive care.

Given this evidence, this research proposes that digital health interventions can be utilised to develop a model of care that is agile and adjustable to patients, which may lead to reduced melanoma incidence and mortality rates, and ultimately decrease the economic burden of melanoma in Australia. However, further research needs to be undertaken to measure the *cost-effectiveness* of digital health in melanoma post-treatment care to the healthcare system.

Section 3: Identified challenges to the implementation of digital health in melanoma post-treatment care

Although the current study confirms that digital health has substantial potential to improve patient experience of care, especially supportive care, numerous challenges need to be addressed to implement it in melanoma post-treatment care efficiently.

Firstly, as outlined in the discussion, the current data reveal a significant lack of awareness and education amongst the melanoma community about technology options (the range, type and application to melanoma care) and benefits. This needs to be addressed to encourage digital health uptake in the future. However, patients' awareness of these technologies does not necessarily mean they know that they can use them to manage their melanoma care, nor that they would be proficient enough to use these technologies. Although this study does not directly address the question of digital health literacy, previous studies highlight its increasing importance for healthcare consumers (van der Vaart & Drossaert,

2017). The studies show that people's skills to search, select, appraise, and apply online health information and healthcare-related digital applications can affect their health and healthcare quality. Conversely, poor digital health literacy can lead to adverse outcomes (Hsu et al., 2014; Neter & Brainin, 2012).

Secondly, implementation of digital health into primary healthcare settings remains a prolonged process (Thiel et al., 2019), with one of the significant barriers being the lack of HCPs' knowledge and awareness of the technologies on offer and the skills to use them (Ross et al., 2016). Many studies have highlighted the insufficiency of digital health literacy amongst HCPs and a need to implement digital health in healthcare education (Poncette et al., 2020). In addition, there are questions as to what meaningful user data generated from technologies can have for clinical insights and interventions (Aungst & Patel, 2020).

Finally, it has been suggested that the driving force of digital health is its capacity to collect, store, and analyse an extensive volume of and ubiquitous health and medical data (Otokiti, 2020). To capitalise on this, there are some imperatives for policymakers and regulators to address data privacy and data custodians. Given this, to date, there is no unique standardised framework for digital implementation and adoption. To implement digital health in melanoma post-treatment care, there remains a need for a systemic shift in the healthcare system.

Limitations of the current study

In considering the strengths of the current study, some limitations must be acknowledged. First, these findings are specific to Australia's unique geographical and cultural features and cannot fully be extrapolated worldwide. Australia is a vast country with a clearly defined remoteness structure. Therefore, the same study in a different country may generate different data and outcomes, particularly for distance-related questions. Data indicate that people easily commute more than 1 hour in Australia and up to 5 hours to access healthcare facilities. In Europe, rare are those travelling more than half an hour (Wess et al., 2020). Perception of distance varies by country, population and culture.

Secondly, this study refers to ‘rural’ as a single unit. In contrast, several types of rural populations are sparsely settled or densely settled, with research showing differences in travel behaviour between them. A 2015 study investigating the travel behaviour of rural residents in relation to geographic barriers when accessing primary healthcare found that compared to people living farther away from healthcare services, residents were more willing to travel longer distances (McGrail et al., 2015).

In addition, researchers use distance travelled to assess geographical proximity to healthcare services (e.g., follow-up visits). Comparatively, it may have been more accurate to use travel time instead, as 10km in urban areas can take less time than in rural or remote settings.

Of consideration may be that current data generated about patients' willingness to use certain technologies may be biased based on patient knowledge. For instance, less than 70% of patients surveyed have heard of teledermoscopy or store-and-forward tools, which may explain the low rate of patient willingness to use these technologies to manage their health.

Finally, some limitations were associated with the findings related to teleconsultations, as this survey was done before COVID 19, which disrupted healthcare and resulted in a significant increase in technology use by patients and clinicians, particularly for teleconsultations.

Future directions

This exploratory research analysed discrepancies in the utilisation of, and satisfaction with healthcare services between health service advantaged (e.g., urban population) and disadvantaged (e.g., rural population) melanoma communities of Australia. Its main aim was to determine how patients and HCPs could adjunctly use digital health to provide optimal care and improve QoL in Australia. While the results are very encouraging, showing low associations between sociodemographic factors (with geographical proximity for exception) and access to melanoma post-treatment care, social and cultural factors play substantial roles

in a patient's perception of melanoma care. Given this, much more research is required in this area to validate and build upon these findings.

The above discussion has highlighted that patients facing difficulties accessing melanoma post-treatment care are more likely to develop psychological distress. According to research by Kasparian et al. (2009), 30% of Australians treated for melanoma present psychological signs that would require clinical attention. This study has illustrated positive attitudes from melanoma patients — especially those facing barriers to accessing their follow-up visits who also experienced high psychological distress — toward the use of technologies to manage their illness. Future research should focus on clinical trials assessing health benefits and patient-reported outcomes measures from services that provide a holistic framework involving psychological support via digital tools.

As of the conclusion of this study in 2021, no study has investigated the cost-effectiveness of digital health in melanoma care. Given this, research has stated that technological interventions are a cost-saving solution to the economic burden of melanoma. Health economic analyses, therefore, would be necessary to assess the cost-effectiveness of digital health for melanoma patients and health systems both in the initial stage of rollout (the more expensive start-up process for training of clinicians and clients, as well as for technical UX iterative changes) to the greater long term economic benefits over the coming decade.

Additionally, the above findings have suggested that HCPs play an essential role in implementing and patient adoption of digital health. Given this, further studies, collaborative workshops and focus groups with GPs, dermatologists, nurses and other HCPs involved in melanoma care should be completed to build engagement and social licence.

This research work is a crucial first step in establishing an evidence base for the translation of a digitally enhanced model of post-treatment care for Australians with melanoma, which may inform other disease and chronic health conditions in Australia to scale universal healthcare for immediate and future generations.

APPENDICES

Appendix A: Ethics approval

Appendix B: Recruitment promotional materials

Appendix C: Participant information statement

Appendix D: Supporting data

Appendix E: Digital health in melanoma post-treatment care in rural and remote Australia

Appendix F: Full survey

Appendix A: Ethics approval



Research Integrity & Ethics Administration
HUMAN RESEARCH ETHICS COMMITTEE

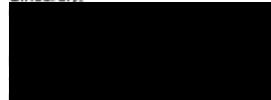


- Ethics approval is dependent upon ongoing compliance of the research with the *National Statement on Ethical Conduct in Human Research*, the *Australian Code for the Responsible Conduct of Research*, applicable legal requirements, and with University policies, procedures and governance requirements.
- The Ethics Office may conduct audits on approved projects.
- The Chief Investigator has ultimate responsibility for the conduct of the research and is responsible for ensuring all others involved will conduct the research in accordance with the above.

This letter constitutes ethical approval only.

Please contact the Ethics Office should you require further information or clarification.

Sincerely,



Associate Professor Rita Shackel
Chair
Human Research Ethics Committee (HREC 3)

The University of Sydney of Sydney HRECs are constituted and operate in accordance with the National Health and Medical Research Council's (NHMRC) [National Statement on Ethical Conduct in Human Research \(2007\)](#) and the NHMRC's [Australian Code for the Responsible Conduct of Research \(2007\)](#)

Appendix A: Ethics approval (cont'd)



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Appendix A: Ethics approval (cont'd)



Research Integrity & Ethics Administration
HUMAN RESEARCH ETHICS COMMITTEE

Tuesday, 7 May 2019

Dr Andrew Campbell
Disability and Community; Faculty of Health Sciences
Email: andrew.campbell@sydney.edu.au

Dear Andrew,

Your request to modify this project, which was submitted on 04 April 2019, has been considered.

This project has been approved to proceed with the proposed amendments.

Protocol Number: 2018/903
Protocol Title: How could technology help meet the treatment and psychosocial needs of melanoma patients living in rural areas of Australia?
Annual Report Due: 07 December 2019

Documents Approved:

Date Uploaded	Version Number	Document Name
04/04/2019	Version 1	Message to share online (Screenshot - Document 1)

Special Condition/s of Approval

- It is a condition of approval that all necessary approvals are sought from social media administrators (i.e. Facebook) and kept on file prior to the study being shared. You do not need to send a copy of these permissions to the Ethics Office.

Please contact the ethics office should you require further information.

Sincerely,



Dr Clifton Chan
Chair
Modification Review Committee (MRC 1)

The University of Sydney of Sydney HRECs are constituted and operate in accordance with the National Health and Medical Research Council's (NHMRC) [National Statement on Ethical Conduct in Human Research \(2007\)](#) and the NHMRC's [Australian Code for the Responsible Conduct of Research \(2007\)](#)

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ABN 15 211 513 484
CRICOS 90026A

Appendix B: Recruitment promotional materials

Flyer Research Study



Contact information:

To find out more about this study and eligibility, please contact:

- Audrey Rollin
- Audrey.rollin@sydney.edu.au

Use the link to participate in the research study:

<https://redcap.sydney.edu.au/surveys/?s=XRLP4DJADY>



THE UNIVERSITY OF
SYDNEY

Digital Health For Melanoma Care In Rural Areas Of Australia

The study is being carried out by Mss Audrey Rollin (PhD candidate).

The purpose of this research is to investigate digital health for melanoma care in rural regions of Australia with a goal of understanding how technology could help improving access to care and melanoma patients' quality of life.

To participate in this research, you must:

- Be diagnosed with melanoma
- Be 18 years old or older
- Live in rural area

Participation in this study

Involves:

- Answer online survey questions
- A time commitment of 8-10 minutes

Appendix B: Recruitment promotional materials



Audrey Rollin

4 avril 2019 · 🔒



Been affected by melanoma and want to participate in a survey? It should only take 5-8 minutes to complete. Be assured that all answers you provide will be kept strictly anonymous.

Audrey Rollin is a PhD candidate in Health Sciences from The University of Sydney. This research project focuses on digital health for melanoma care in rural regions of Australia with a goal of understanding how technology could help improving access to care and melanoma patients' quality of life.

The ethical aspects of this study have been approved by the HREC of the University of Sydney 2018/903.

To complete the survey you have to meet the following requirements:

- cutaneous melanoma patient from stage 0 to IV,
- living in Australia, and
- over the age of 18.

<https://redcap.sydney.edu.au/surveys/?s=XRLP4DJADY>



Appendix C: Participant information statement



School of Disability & Community Faculty of
Health Sciences

ABN 15 211 513 464

CHIEF INVESTIGATOR Dr Andrew Campbell
Senior Lecturer

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Digital health for melanoma patients in rural areas of Australia

PARTICIPANT INFORMATION STATEMENT

(1) What is this study about?

You are invited to take part in a research study about investigating digital health for melanoma care in rural regions of Australia with a goal of understanding how technology could help improving access to care and melanoma patients' quality of life.

This Participant Information Statement tells you about the research study. Knowing what is involved will help you decide if you want to take part in the research. Please read this sheet carefully and ask questions about anything that you don't understand or want to know more about.

Participation in this research study is voluntary.

By giving your consent to take part in this study you are telling us that you:

- ✓ Understand what you have read.
- ✓ Agree to take part in the research study as outlined below.
- ✓ Agree to the use of your personal information as described.

You will be given a copy of this Participant Information Statement to keep.

(2) Who is running the study?

The study is being carried out by Miss Audrey Rollin (PhD Candidate). Audrey is conducting this study as the basis for the degree of Doctor of Philosophy (PhD) at The University of Sydney. This will take place under the supervision of Dr Andrew Campbell.

(3) What will the study involve for me?

As a participant in this study, you will be asked to answer an online survey questions including both direct and open questions. For some questions, a short video explicative will be available. If you are interested there will be an option to request a summary of the findings that will be emailed to you at the conclusion of the research.

(4) How much of my time will the study take?

Appendix C: Participant information statement (cont'd)

Answering to the survey questions should take between 5 to 8 minutes.

(5) Who can take part in the study?

Anyone 18 years or older who have been diagnosed with cutaneous melanoma and living in rural regions of Australia. Under this rational we will be accepting those who are diagnosed with in-situ cutaneous melanoma, stages I-II-II and IV. You must be able to understand and speak English without a translator. If you have any concerns about your eligibility please email the researcher.

(6) Do I have to be in the study? Can I withdraw from the study once I've started?

Being in this study is completely voluntary and you do not have to take part. Your decision whether to participate will not affect your current or future relationship with the researchers or anyone else at the University of Sydney.

If you decide to take part in the study and then change your mind later, you are free to withdraw at any time. You can do this by informing the investigator at any stage during either session, or at any time via email. Once you have completed the first session you will have 28 days to withdraw from the study.

If you decide to withdraw from the study, we will not collect any more information from you. Please let us know at the time when you withdraw what you would like us to do with the information we have collected about you up to that point.

(7) Are there any risks or costs associated with being in the study?

Aside from giving up your time, we do not expect that there will be any risks or costs associated with taking part in this study.

(8) Are there any benefits associated with being in the study?

We cannot guarantee that you will receive any direct benefits from being in the study.

(9) What will happen to information about me that is collected during the study?

During this study your responses to surveys will be collected. There will be NO audio or visual recordings taking place during the study. If you consent to participating in this study, collected data will be examined in order to publish the results in an appropriate scholarly journal. Your information will be stored in such a way that you cannot be identified. All information will be securely stored in digital form, and will be destroyed after 5 years. No third party will be given unrestricted access to any data collected.

By providing your consent, you are agreeing to us collecting personal information about you for the purposes of this research study. Your information will only be used for the purposes outlined in this Participant Information Statement, unless you consent otherwise. Your information will be stored securely and your identity/information will be kept strictly confidential, except as required by law. Study findings may be published, but you will not be individually identifiable in these publications.

We will keep the information we collect for this study, and we may use it in future projects. By providing your consent you are allowing us to use your information in future projects. We don't know at this stage what these other projects will involve. We will seek ethical approval before using the information in these future projects.

Appendix C: Participant information statement (cont'd)

(10) Can I tell other people about the study?

Yes, you are welcome to tell other people about the study.

(11) What if I would like further information about the study?

When you have read this information, Audrey Rollin (PhD candidate) will be available to discuss it with you further and answer any questions you may have. If you would like to know more at any stage during the study, please feel free to contact Audrey via email at audrey.rollin@sydney.edu.au

(12) Will I be told the results of the study?

You have a right to receive feedback about the overall results of this study. You can tell us that you wish to receive feedback by submitting your email and ticking at the end of the online survey. This feedback will be in the form of a brief lay summary of the findings. You will receive this feedback after the study is finished.

(13) What if I have a complaint or any concerns about the study?

Research involving humans in Australia is reviewed by an independent group of people called a Human Research Ethics Committee (HREC). The ethical aspects of this study have been approved by the HREC of the University of Sydney 2018/903. As part of this process, we have agreed to carry out the study according to the *National Statement on Ethical Conduct in Human Research (2007)*. This statement has been developed to protect people who agree to take part in research studies.

If you are concerned about the way this study is being conducted or you wish to make a complaint to someone independent from the study, please contact the university using the details outlined below. Please quote the study title and protocol number.

The Manager, Ethics Administration, University of Sydney:

- Telephone: +61 2 8627 8176
- Email: human.ethics@sydney.edu.au
- Fax: +61 2 8627 8177 (Facsimile)

This information sheet is for you to keep

Appendix D: Supporting data

Section 1: Individual characteristics

What is your gender?

		Frequency	Percent	Valid Percent	Cumulative Percent
Valid	Male	23	24.2	24.2	24.2
	Female	72	75.8	75.8	100.0
	Total	95	100.0	100.0	

What is your age?

		Frequency	Percent	Valid Percent	Cumulative Percent
Valid	6	1	1.1	1.1	1.1
	31	2	2.1	2.1	3.2
	32	2	2.1	2.1	5.3
	33	2	2.1	2.1	7.4
	34	1	1.1	1.1	8.4
	35	1	1.1	1.1	9.5
	36	5	5.3	5.3	14.7
	37	4	4.2	4.2	18.9
	38	1	1.1	1.1	20.0
	39	3	3.2	3.2	23.2
	40	1	1.1	1.1	24.2
	41	1	1.1	1.1	25.3
	42	2	2.1	2.1	27.4
	43	2	2.1	2.1	29.5
	44	4	4.2	4.2	33.7
	46	4	4.2	4.2	37.9
	47	4	4.2	4.2	42.1
	48	2	2.1	2.1	44.2
	49	4	4.2	4.2	48.4
	50	1	1.1	1.1	49.5
	51	2	2.1	2.1	51.6
	52	2	2.1	2.1	53.7
	53	3	3.2	3.2	56.8
	54	1	1.1	1.1	57.9
	56	3	3.2	3.2	61.1
	57	6	6.3	6.3	67.4
	58	4	4.2	4.2	71.6
	59	1	1.1	1.1	72.6
	60	3	3.2	3.2	75.8
	61	2	2.1	2.1	77.9
	63	2	2.1	2.1	80.0
	64	2	2.1	2.1	82.1
	65	1	1.1	1.1	83.2
	66	2	2.1	2.1	85.3
67	2	2.1	2.1	87.4	

68	1	1.1	1.1	88.4
69	3	3.2	3.2	91.6
71	1	1.1	1.1	92.6
72	1	1.1	1.1	93.7
73	1	1.1	1.1	94.7
74	1	1.1	1.1	95.8
76	1	1.1	1.1	96.8
80	2	2.1	2.1	98.9
81	1	1.1	1.1	100.0
Total	95	100.0	100.0	

Residential area (based on 'What is your postcode?')

		Frequency	Percent	Valid Percent	Cumulative Percent
Valid	Urban	35	36.8	37.2	37.2
	Rural	59	62.1	62.8	100.0
	Total	94	98.9	100.0	
Missing	n.a.	1	1.1		
Total		95	100.0		

Distance travelled distribution

	N	Minimum	Maximum	Mean	Std. Deviation
Distance travelled	94	0	1582	114.47	263.022
Valid N (listwise)	94				

What is the highest attained level of education?

		Frequency	Percent	Valid Percent	Cumulative Percent
Valid	Less than Year 12	12	12.6	12.6	12.6
	Year 12	14	14.7	14.7	27.4
	Diploma or TAFE	28	29.5	29.5	56.8
	Undergraduate	26	27.4	27.4	84.2
	Postgraduate	15	15.8	15.8	100.0
	Total	95	100.0	100.0	

Are you currently employed?

		Frequency	Percent	Valid Percent	Cumulative Percent
Valid	Full time	37	38.9	38.9	38.9
	Part-time or Casual	25	26.3	26.3	65.3
	No	33	34.7	34.7	100.0
	Total	95	100.0	100.0	

What is your annual income bracket

		Frequency	Percent	Valid Percent	Cumulative Percent
Valid	Less than 20K	13	13.7	13.7	13.7
	20K<50K	26	27.4	27.4	41.1
	50K<80K	27	28.4	28.4	69.5
	80K<110K	14	14.7	14.7	84.2
	110K<140K	8	8.4	8.4	92.6
	140K<170K	4	4.2	4.2	96.8
	170K<200	1	1.1	1.1	97.9
	More than 200K	2	2.1	2.1	100.0
Total	95	100.0	100.0		

Section 2: Post-treatment care and health information

What is the thickness of your melanoma?

		Frequency	Percent	Valid Percent	Cumulative Percent
Valid	Less than 1mm	23	24.2	24.2	24.2
	1mm<4mm	33	34.7	34.7	58.9
	Greater than 4mm	22	23.2	23.2	82.1
	4	17	17.9	17.9	100.0
Total	95	100.0	100.0		

Is it a recurrent stage?

		Frequency	Percent	Valid Percent	Cumulative Percent
Valid	0	70	73.7	73.7	73.7
	Yes	25	26.3	26.3	100.0
	Total	95	100.0	100.0	

Have you received information about disease evolution?

		Frequency	Percent	Valid Percent	Cumulative Percent
Valid	Yes	50	52.6	59.5	59.5
	No	34	35.8	40.5	100.0
	Total	84	88.4	100.0	
Missing	I don't know	11	11.6		
Total		95	100.0		

Have you received information about melanoma treatment?

		Frequency	Percent	Valid Percent	Cumulative Percent
Valid	Yes	83	87.4	89.2	89.2
	No	10	10.5	10.8	100.0
	Total	93	97.9	100.0	
Missing	I don't know	2	2.1		
Total		95	100.0		

Have you received information about TSSE?

		Frequency	Percent	Valid Percent	Cumulative Percent
Valid	Yes	67	70.5	72.0	72.0
	No	26	27.4	28.0	100.0
	Total	93	97.9	100.0	
Missing	I don't know	2	2.1		
Total		95	100.0		

Have you received information about psychological implications?

		Frequency	Percent	Valid Percent	Cumulative Percent
Valid	Yes	28	29.5	30.8	30.8
	No	63	66.3	69.2	100.0
	Total	91	95.8	100.0	
Missing	I don't know	4	4.2		
Total		95	100.0		

Have you received information about social group support?

		Frequency	Percent	Valid Percent	Cumulative Percent
Valid	Yes	19	20.0	20.7	20.7
	No	73	76.8	79.3	100.0
	Total	92	96.8	100.0	
Missing	I don't know	3	3.2		
Total		95	100.0		

Have you been recommended to see a psychologist?

		Frequency	Percent	Valid Percent	Cumulative Percent
Valid	No	84	88.4	88.4	88.4
	Yes	11	11.6	11.6	100.0
	Total	95	100.0	100.0	

Have you been recommended to see a psychiatrist?

		Frequency	Percent	Valid Percent	Cumulative Percent
Valid	No	91	95.8	95.8	95.8
	Yes	4	4.2	4.2	100.0
	Total	95	100.0	100.0	

Have you been recommended to see a counsellor?

		Frequency	Percent	Valid Percent	Cumulative Percent
Valid	No	87	91.6	91.6	91.6
	Yes	8	8.4	8.4	100.0
	Total	95	100.0	100.0	

Have you been recommended to see a nurse?

		Frequency	Percent	Valid Percent	Cumulative Percent
Valid	No	77	81.1	81.1	81.1
	Yes	18	18.9	18.9	100.0
	Total	95	100.0	100.0	

Are you satisfied with the amount of information received about disease evolution?

		Frequency	Percent	Valid Percent	Cumulative Percent
Valid	very dissatisfied	10	10.5	10.5	10.5
	Dissatisfied	18	18.9	18.9	29.5
	Neither	26	27.4	27.4	56.8
	Satisfied	21	22.1	22.1	78.9
	Very Satisfied	20	21.1	21.1	100.0
	Total	95	100.0	100.0	

Are you satisfied with the amount of information received about treatment?

		Frequency	Percent	Valid Percent	Cumulative Percent
Valid	very dissatisfied	4	4.2	4.2	4.2
	Dissatisfied	13	13.7	13.7	17.9
	Neither	17	17.9	17.9	35.8
	Satisfied	22	23.2	23.2	58.9
	Very Satisfied	39	41.1	41.1	100.0
	Total	95	100.0	100.0	

Are you satisfied with the amount of information received about TSSE?

		Frequency	Percent	Valid Percent	Cumulative Percent
Valid	very dissatisfied	10	10.5	10.6	10.6
	Dissatisfied	16	16.8	17.0	27.7
	Neither	21	22.1	22.3	50.0
	Satisfied	28	29.5	29.8	79.8
	Very Satisfied	19	20.0	20.2	100.0
	Total	94	98.9	100.0	
Missing	System	1	1.1		
Total		95	100.0		

Are you satisfied with the amount of information received about psychological implications?

		Frequency	Percent	Valid Percent	Cumulative Percent
Valid	very dissatisfied	28	29.5	29.5	29.5
	Dissatisfied	24	25.3	25.3	54.7
	Neither	25	26.3	26.3	81.1
	Satisfied	11	11.6	11.6	92.6
	Very Satisfied	7	7.4	7.4	100.0
	Total	95	100.0	100.0	

Are you satisfied with the amount of information received about social group support?

		Frequency	Percent	Valid Percent	Cumulative Percent
Valid	very dissatisfied	32	33.7	34.0	34.0
	Dissatisfied	20	21.1	21.3	55.3
	Neither	23	24.2	24.5	79.8
	Satisfied	12	12.6	12.8	92.6
	Very Satisfied	7	7.4	7.4	100.0
	Total	94	98.9	100.0	
Missing	System	1	1.1		
Total		95	100.0		

Are you satisfied with the quality of information received about disease evolution?

		Frequency	Percent	Valid Percent	Cumulative Percent
Valid	very dissatisfied	9	9.5	9.5	9.5
	Dissatisfied	19	20.0	20.0	29.5
	Neither	27	28.4	28.4	57.9
	Satisfied	22	23.2	23.2	81.1
	Very Satisfied	18	18.9	18.9	100.0
	Total	95	100.0	100.0	

Are you satisfied with the quality of information received about treatment?

		Frequency	Percent	Valid Percent	Cumulative Percent
Valid	very dissatisfied	5	5.3	5.3	5.3
	Dissatisfied	15	15.8	15.8	21.1
	Neither	16	16.8	16.8	37.9
	Satisfied	23	24.2	24.2	62.1
	Very Satisfied	36	37.9	37.9	100.0
	Total	95	100.0	100.0	

Are you satisfied with the quality of information received about TSSE?

		Frequency	Percent	Valid Percent	Cumulative Percent
Valid	very dissatisfied	11	11.6	11.7	11.7
	Dissatisfied	16	16.8	17.0	28.7
	Neither	26	27.4	27.7	56.4
	Satisfied	21	22.1	22.3	78.7
	Very Satisfied	20	21.1	21.3	100.0
	Total	94	98.9	100.0	
Missing	System	1	1.1		
Total		95	100.0		

Are you satisfied with the quality of information received about psychological implications?

		Frequency	Percent	Valid Percent	Cumulative Percent
Valid	very dissatisfied	28	29.5	29.5	29.5
	Dissatisfied	23	24.2	24.2	53.7
	Neither	19	20.0	20.0	73.7
	Satisfied	18	18.9	18.9	92.6
	Very Satisfied	7	7.4	7.4	100.0
	Total	95	100.0	100.0	

Are you satisfied with the quality of information received about social group support?

		Frequency	Percent	Valid Percent	Cumulative Percent
Valid	very dissatisfied	31	32.6	33.0	33.0
	Dissatisfied	20	21.1	21.3	54.3
	Neither	22	23.2	23.4	77.7
	Satisfied	14	14.7	14.9	92.6
	Very Satisfied	7	7.4	7.4	100.0
	Total	94	98.9	100.0	
Missing	System	1	1.1		
Total		95	100.0		

How often do you experience treatment related morbidity?

		Frequency	Percent	Valid Percent	Cumulative Percent
Valid	Never	52	54.7	54.7	54.7
	Rarely	11	11.6	11.6	66.3
	Sometimes	20	21.1	21.1	87.4
	Often	10	10.5	10.5	97.9
	Always	2	2.1	2.1	100.0
	Total	95	100.0	100.0	

How often do you experience Fear of Cancer Recurrence?

		Frequency	Percent	Valid Percent	Cumulative Percent
Valid	Never	3	3.2	3.2	3.2
	Rarely	10	10.5	10.5	13.7
	Sometimes	20	21.1	21.1	34.7
	Often	30	31.6	31.6	66.3
	Always	32	33.7	33.7	100.0
	Total	95	100.0	100.0	

How often do you experience overthinking about treatment?

		Frequency	Percent	Valid Percent	Cumulative Percent
Valid	Never	11	11.6	11.7	11.7
	Rarely	18	18.9	19.1	30.9
	Sometimes	26	27.4	27.7	58.5
	Often	23	24.2	24.5	83.0
	Always	16	16.8	17.0	100.0
	Total	94	98.9	100.0	
Missing	System	1	1.1		
Total		95	100.0		

How often do you experience anxiety prior to follow-ups?

		Frequency	Percent	Valid Percent	Cumulative Percent
Valid	Never	7	7.4	7.4	7.4
	Rarely	12	12.6	12.6	20.0
	Sometimes	26	27.4	27.4	47.4
	Often	24	25.3	25.3	72.6
	Always	26	27.4	27.4	100.0
	Total	95	100.0	100.0	

How often do you experience between follow-ups?

		Frequency	Percent	Valid Percent	Cumulative Percent
Valid	Never	9	9.5	9.6	9.6
	Rarely	12	12.6	12.8	22.3
	Sometimes	33	34.7	35.1	57.4
	Often	27	28.4	28.7	86.2
	Always	13	13.7	13.8	100.0
	Total	94	98.9	100.0	
Missing	System	1	1.1		
Total		95	100.0		

How often do you experience decrease in self-esteem?

		Frequency	Percent	Valid Percent	Cumulative Percent
Valid	Never	25	26.3	26.6	26.6
	Rarely	17	17.9	18.1	44.7
	Sometimes	28	29.5	29.8	74.5
	Often	14	14.7	14.9	89.4
	Always	10	10.5	10.6	100.0
	Total	94	98.9	100.0	
Missing	System	1	1.1		
Total		95	100.0		

How often do you experience decrease in general well-being?

		Frequency	Percent	Valid Percent	Cumulative Percent
Valid	Never	22	23.2	23.2	23.2
	Rarely	19	20.0	20.0	43.2
	Sometimes	32	33.7	33.7	76.8
	Often	12	12.6	12.6	89.5
	Always	10	10.5	10.5	100.0
	Total	95	100.0	100.0	

How often do you experience change in relationship with others?

		Frequency	Percent	Valid Percent	Cumulative Percent
Valid	Never	24	25.3	25.3	25.3
	Rarely	20	21.1	21.1	46.3
	Sometimes	25	26.3	26.3	72.6
	Often	16	16.8	16.8	89.5
	Always	10	10.5	10.5	100.0
	Total	95	100.0	100.0	

How often do you experience Desire to seek reassurance?

		Frequency	Percent	Valid Percent	Cumulative Percent
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Valid	Never	11	11.6	11.6	11.6
	Rarely	9	9.5	9.5	21.1
	Sometimes	21	22.1	22.1	43.2
	Often	32	33.7	33.7	76.8
	Always	22	23.2	23.2	100.0
	Total	95	100.0	100.0	

How often do you experience need for more social support?

		Frequency	Percent	Valid Percent	Cumulative Percent
Valid	Never	19	20.0	20.0	20.0
	Rarely	15	15.8	15.8	35.8
	Sometimes	23	24.2	24.2	60.0
	Often	23	24.2	24.2	84.2
	Always	15	15.8	15.8	100.0
	Total	95	100.0	100.0	

How often do you experience need for more emotional support?

		Frequency	Percent	Valid Percent	Cumulative Percent
Valid	Never	23	24.2	24.2	24.2
	Rarely	17	17.9	17.9	42.1
	Sometimes	20	21.1	21.1	63.2
	Often	17	17.9	17.9	81.1
	Always	18	18.9	18.9	100.0
	Total	95	100.0	100.0	

How often are your follow-up visits?

		Frequency	Percent	Valid Percent	Cumulative Percent
Valid	Never	2	2.1	2.1	2.1
	1/year	20	21.1	21.1	23.2
	2/year	24	25.3	25.3	48.4
	3/year	4	4.2	4.2	52.6
	4/year	23	24.2	24.2	76.8
	5/year	1	1.1	1.1	77.9
	more than 5/year	21	22.1	22.1	100.0
	Total	95	100.0	100.0	

Are you satisfied with the frequency of your follow-up visits?

		Frequency	Percent	Valid Percent	Cumulative Percent
Valid	Yes	81	85.3	85.3	85.3
	No, more	12	12.6	12.6	97.9
	No, less	2	2.1	2.1	100.0
	Total	95	100.0	100.0	

How often travel-time has impacted on your access to care?

		Frequency	Percent	Valid Percent	Cumulative Percent
Valid	Never	38	40.0	40.0	40.0
	Rarely	20	21.1	21.1	61.1
	Sometimes	17	17.9	17.9	78.9
	Often	12	12.6	12.6	91.6
	Always	8	8.4	8.4	100.0
	Total	95	100.0	100.0	

How often travel-cost has impacted on your access to care?

		Frequency	Percent	Valid Percent	Cumulative Percent
Valid	Never	45	47.4	47.4	47.4
	Rarely	17	17.9	17.9	65.3
	Sometimes	13	13.7	13.7	78.9
	Often	10	10.5	10.5	89.5
	Always	10	10.5	10.5	100.0
	Total	95	100.0	100.0	

How often takin time off work has impacted on your access to care?

		Frequency	Percent	Valid Percent	Cumulative Percent
Valid	Never	43	45.3	45.3	45.3
	Rarely	12	12.6	12.6	57.9
	Sometimes	16	16.8	16.8	74.7
	Often	13	13.7	13.7	88.4
	Always	11	11.6	11.6	100.0
	Total	95	100.0	100.0	

How often long waiting time between appointments has impacted on your access to care?

		Frequency	Percent	Valid Percent	Cumulative Percent
Valid	Never	34	35.8	35.8	35.8
	Rarely	21	22.1	22.1	57.9
	Sometimes	20	21.1	21.1	78.9
	Often	11	11.6	11.6	90.5
	Always	9	9.5	9.5	100.0
	Total	95	100.0	100.0	

How often follow-up cost has impacted on your access to care?

		Frequency	Percent	Valid Percent	Cumulative Percent
Valid	Never	35	36.8	36.8	36.8
	Rarely	14	14.7	14.7	51.6
	Sometimes	17	17.9	17.9	69.5
	Often	14	14.7	14.7	84.2
	Always	15	15.8	15.8	100.0
	Total	95	100.0	100.0	

Section 3: Attitudes toward digital health

Have you ever used SMS within your melanoma care?

		Frequency	Percent	Valid Percent	Cumulative Percent
Valid	Yes	30	31.6	32.6	32.6
	No	46	48.4	50.0	82.6
	Never heard	16	16.8	17.4	100.0
	Total	92	96.8	100.0	
Missing	System	3	3.2		
	Total	95	100.0		

Have you ever used email within your melanoma care?

		Frequency	Percent	Valid Percent	Cumulative Percent
Valid	Yes	33	34.7	35.9	35.9
	No	45	47.4	48.9	84.8
	Never heard	14	14.7	15.2	100.0
	Total	92	96.8	100.0	
Missing	System	3	3.2		
Total		95	100.0		

Have you ever used mobile camera within your melanoma care?

		Frequency	Percent	Valid Percent	Cumulative Percent
Valid	Yes	30	31.6	32.6	32.6
	No	49	51.6	53.3	85.9
	Never heard	13	13.7	14.1	100.0
	Total	92	96.8	100.0	
Missing	System	3	3.2		
Total		95	100.0		

Have you ever used mobile apps within your melanoma care?

		Frequency	Percent	Valid Percent	Cumulative Percent
Valid	Yes	19	20.0	20.7	20.7
	No	55	57.9	59.8	80.4
	Never heard	18	18.9	19.6	100.0
	Total	92	96.8	100.0	
Missing	System	3	3.2		
Total		95	100.0		

Have you ever used website within your melanoma care?

		Frequency	Percent	Valid Percent	Cumulative Percent
Valid	Yes	51	53.7	54.8	54.8
	No	34	35.8	36.6	91.4
	Never heard	8	8.4	8.6	100.0
	Total	93	97.9	100.0	
Missing	System	2	2.1		
Total		95	100.0		

Have you ever used web-based apps within your melanoma care?

		Frequency	Percent	Valid Percent	Cumulative Percent

Valid	Yes	14	14.7	15.2	15.2
	No	58	61.1	63.0	78.3
	Never heard	20	21.1	21.7	100.0
	Total	92	96.8	100.0	
Missing	System	3	3.2		
Total		95	100.0		

Have you ever used digital skin map within your melanoma care?

		Frequency	Percent	Valid Percent	Cumulative Percent
Valid	Yes	21	22.1	22.8	22.8
	No	57	60.0	62.0	84.8
	Never heard	14	14.7	15.2	100.0
	Total	92	96.8	100.0	
Missing	System	3	3.2		
Total		95	100.0		

Have you ever used YouTube within your melanoma care?

		Frequency	Percent	Valid Percent	Cumulative Percent
Valid	Yes	21	22.1	22.8	22.8
	No	57	60.0	62.0	84.8
	Never heard	14	14.7	15.2	100.0
	Total	92	96.8	100.0	
Missing	System	3	3.2		
Total		95	100.0		

Have you ever used Facebook within your melanoma care?

		Frequency	Percent	Valid Percent	Cumulative Percent
Valid	Yes	50	52.6	54.3	54.3
	No	33	34.7	35.9	90.2
	Never heard	9	9.5	9.8	100.0
	Total	92	96.8	100.0	
Missing	System	3	3.2		
Total		95	100.0		

Have you ever used online discussion forums within your melanoma care?

		Frequency	Percent	Valid Percent	Cumulative Percent
Valid	Yes	36	37.9	39.1	39.1
	No	46	48.4	50.0	89.1

	Never heard	10	10.5	10.9	100.0
	Total	92	96.8	100.0	
Missing	System	3	3.2		
Total		95	100.0		

Have you ever used LVC within your melanoma care?

		Frequency	Percent	Valid Percent	Cumulative Percent
Valid	Yes	5	5.3	5.4	5.4
	No	72	75.8	78.3	83.7
	Never heard	15	15.8	16.3	100.0
	Total	92	96.8	100.0	
Missing	System	3	3.2		
Total		95	100.0		

Have you ever used teledermoscope within your melanoma care?

		Frequency	Percent	Valid Percent	Cumulative Percent
Valid	Yes	4	4.2	4.3	4.3
	No	55	57.9	59.8	64.1
	Never heard	33	34.7	35.9	100.0
	Total	92	96.8	100.0	
Missing	System	3	3.2		
Total		95	100.0		

Have you ever used Self-monitoring tools within your melanoma care?

		Frequency	Percent	Valid Percent	Cumulative Percent
Valid	Yes	18	18.9	19.6	19.6
	No	53	55.8	57.6	77.2
	Never heard	21	22.1	22.8	100.0
	Total	92	96.8	100.0	
Missing	System	3	3.2		
Total		95	100.0		

Have you ever used store-and-forward platforms within your melanoma care?

		Frequency	Percent	Valid Percent	Cumulative Percent
Valid	Yes	7	7.4	7.6	7.6
	No	52	54.7	56.5	64.1
	Never heard	33	34.7	35.9	100.0
	Total	92	96.8	100.0	

Missing	System	3	3.2		
Total		95	100.0		

How likely would you be to use SMS to improve your access to care?

		Frequency	Percent	Valid Percent	Cumulative Percent
Valid	Very unlikely	8	8.4	9.2	9.2
	Unlikely	7	7.4	8.0	17.2
	Neither	9	9.5	10.3	27.6
	Likely	25	26.3	28.7	56.3
	Very likely	38	40.0	43.7	100.0
	Total	87	91.6	100.0	
Missing	System	8	8.4		
Total		95	100.0		

How likely would you be to use email to improve your access to care?

		Frequency	Percent	Valid Percent	Cumulative Percent
Valid	Very unlikely	8	8.4	9.1	9.1
	Unlikely	5	5.3	5.7	14.8
	Neither	10	10.5	11.4	26.1
	Likely	31	32.6	35.2	61.4
	Very likely	34	35.8	38.6	100.0
	Total	88	92.6	100.0	
Missing	System	7	7.4		
Total		95	100.0		

How likely would you be to use mobile camera to improve your access to care?

		Frequency	Percent	Valid Percent	Cumulative Percent
Valid	Very unlikely	11	11.6	12.6	12.6
	Unlikely	8	8.4	9.2	21.8
	Neither	10	10.5	11.5	33.3
	Likely	23	24.2	26.4	59.8
	Very likely	35	36.8	40.2	100.0
	Total	87	91.6	100.0	
Missing	System	8	8.4		
Total		95	100.0		

How likely would you be to use mobile apps to improve your access to care?

		Frequency	Percent	Valid Percent	Cumulative Percent
Valid	Very unlikely	9	9.5	10.3	10.3
	Unlikely	13	13.7	14.9	25.3
	Neither	13	13.7	14.9	40.2
	Likely	19	20.0	21.8	62.1
	Very likely	33	34.7	37.9	100.0
	Total	87	91.6	100.0	
Missing	System	8	8.4		
Total		95	100.0		

How likely would you be to use website to improve your access to care?

		Frequency	Percent	Valid Percent	Cumulative Percent
Valid	Very unlikely	9	9.5	10.2	10.2
	Unlikely	6	6.3	6.8	17.0
	Neither	16	16.8	18.2	35.2
	Likely	24	25.3	27.3	62.5
	Very likely	33	34.7	37.5	100.0
	Total	88	92.6	100.0	
Missing	System	7	7.4		
Total		95	100.0		

How likely would you be to use web-based apps to improve your access to care?

		Frequency	Percent	Valid Percent	Cumulative Percent
Valid	Very unlikely	14	14.7	16.3	16.3
	Unlikely	11	11.6	12.8	29.1
	Neither	15	15.8	17.4	46.5
	Likely	17	17.9	19.8	66.3
	Very likely	29	30.5	33.7	100.0
	Total	86	90.5	100.0	
Missing	System	9	9.5		
Total		95	100.0		

How likely would you be to use digital skin map to improve your access to care?

		Frequency	Percent	Valid Percent	Cumulative Percent
Valid	Very unlikely	14	14.7	16.1	16.1
	Unlikely	4	4.2	4.6	20.7
	Neither	12	12.6	13.8	34.5
	Likely	25	26.3	28.7	63.2
	Very likely	32	33.7	36.8	100.0
	Total	87	91.6	100.0	
Missing	System	8	8.4		
Total		95	100.0		

How likely would you be to use YouTube to improve your access to care?

		Frequency	Percent	Valid Percent	Cumulative Percent
Valid	Very unlikely	18	18.9	20.7	20.7
	Unlikely	14	14.7	16.1	36.8
	Neither	18	18.9	20.7	57.5
	Likely	18	18.9	20.7	78.2
	Very likely	19	20.0	21.8	100.0
	Total	87	91.6	100.0	
Missing	System	8	8.4		
Total		95	100.0		

How likely would you be to use Facebook to improve your access to care?

		Frequency	Percent	Valid Percent	Cumulative Percent
Valid	Very unlikely	14	14.7	16.1	16.1
	Unlikely	10	10.5	11.5	27.6
	Neither	15	15.8	17.2	44.8
	Likely	21	22.1	24.1	69.0
	Very likely	27	28.4	31.0	100.0
	Total	87	91.6	100.0	
Missing	System	8	8.4		
Total		95	100.0		

How likely would you be to use other social media to improve your access to care?

		Frequency	Percent	Valid Percent	Cumulative Percent
Valid	Very unlikely	16	16.8	19.3	19.3
	Unlikely	11	11.6	13.3	32.5
	Neither	16	16.8	19.3	51.8
	Likely	24	25.3	28.9	80.7
	Very likely	16	16.8	19.3	100.0
	Total	83	87.4	100.0	
Missing	System	12	12.6		
Total		95	100.0		

How likely would you be to use online discussion forums to improve your access to care?

		Frequency	Percent	Valid Percent	Cumulative Percent
Valid	Very unlikely	14	14.7	16.3	16.3
	Unlikely	9	9.5	10.5	26.7
	Neither	20	21.1	23.3	50.0
	Likely	25	26.3	29.1	79.1
	Very likely	18	18.9	20.9	100.0
	Total	86	90.5	100.0	
Missing	System	9	9.5		
Total		95	100.0		

How likely would you be to use LVC to improve your access to care?

		Frequency	Percent	Valid Percent	Cumulative Percent
Valid	Very unlikely	21	22.1	24.4	24.4
	Unlikely	13	13.7	15.1	39.5
	Neither	18	18.9	20.9	60.5
	Likely	17	17.9	19.8	80.2
	Very likely	17	17.9	19.8	100.0
	Total	86	90.5	100.0	
Missing	System	9	9.5		
Total		95	100.0		

How likely would you be to use teledermoscope to improve your access to care?

		Frequency	Percent	Valid Percent	Cumulative Percent
Valid	Very unlikely	18	18.9	20.9	20.9
	Unlikely	12	12.6	14.0	34.9
	Neither	21	22.1	24.4	59.3
	Likely	20	21.1	23.3	82.6
	Very likely	15	15.8	17.4	100.0
	Total	86	90.5	100.0	
Missing	System	9	9.5		
Total		95	100.0		

How likely would you be to use self-monitoring tools to improve your access to care?

		Frequency	Percent	Valid Percent	Cumulative Percent
Valid	Very unlikely	11	11.6	12.6	12.6
	Unlikely	6	6.3	6.9	19.5
	Neither	16	16.8	18.4	37.9
	Likely	23	24.2	26.4	64.4
	Very likely	31	32.6	35.6	100.0
	Total	87	91.6	100.0	
Missing	System	8	8.4		
Total		95	100.0		

How likely would you be to use store-and-forward to improve your access to care?

		Frequency	Percent	Valid Percent	Cumulative Percent
Valid	Very unlikely	14	14.7	16.1	16.1
	Unlikely	12	12.6	13.8	29.9
	Neither	17	17.9	19.5	49.4
	Likely	19	20.0	21.8	71.3
	Very likely	25	26.3	28.7	100.0
	Total	87	91.6	100.0	
Missing	System	8	8.4		
Total		95	100.0		

How likely would you be to use VR to improve your access to care?

		Frequency	Percent	Valid Percent	Cumulative Percent
Valid	Very unlikely	15	15.8	17.2	17.2
	Unlikely	16	16.8	18.4	35.6
	Neither	21	22.1	24.1	59.8
	Likely	14	14.7	16.1	75.9
	Very likely	21	22.1	24.1	100.0
	Total	87	91.6	100.0	
Missing	System	8	8.4		
Total		95	100.0		

How likely would you be to use AR to improve your access to care?

		Frequency	Percent	Valid Percent	Cumulative Percent
Valid	Very unlikely	17	17.9	19.5	19.5
	Unlikely	15	15.8	17.2	36.8
	Neither	20	21.1	23.0	59.8
	Likely	15	15.8	17.2	77.0
	Very likely	20	21.1	23.0	100.0
	Total	87	91.6	100.0	
Missing	System	8	8.4		
Total		95	100.0		

How likely would you be to use serious video games to improve your access to care?

		Frequency	Percent	Valid Percent	Cumulative Percent
Valid	Very unlikely	47	49.5	54.0	54.0
	Unlikely	16	16.8	18.4	72.4
	Neither	10	10.5	11.5	83.9
	Likely	7	7.4	8.0	92.0
	Very likely	7	7.4	8.0	100.0
	Total	87	91.6	100.0	
Missing	System	8	8.4		
Total		95	100.0		

How likely would you be to use SMS to improve your QoL?

		Frequency	Percent	Valid Percent	Cumulative Percent
Valid	Very unlikely	12	12.6	15.4	15.4
	Unlikely	3	3.2	3.8	19.2
	Neither	10	10.5	12.8	32.1
	Likely	19	20.0	24.4	56.4
	Very likely	34	35.8	43.6	100.0
	Total	78	82.1	100.0	
Missing	System	17	17.9		
Total		95	100.0		

How likely would you be to use email to improve your QoL?

		Frequency	Percent	Valid Percent	Cumulative Percent
Valid	Very unlikely	10	10.5	12.8	12.8
	Unlikely	2	2.1	2.6	15.4
	Neither	12	12.6	15.4	30.8
	Likely	24	25.3	30.8	61.5
	Very likely	30	31.6	38.5	100.0
	Total	78	82.1	100.0	
Missing	System	17	17.9		
Total		95	100.0		

How likely would you be to use mobile camera to improve your QoL?

		Frequency	Percent	Valid Percent	Cumulative Percent
Valid	Very unlikely	12	12.6	15.6	15.6
	Unlikely	6	6.3	7.8	23.4
	Neither	10	10.5	13.0	36.4
	Likely	20	21.1	26.0	62.3
	Very likely	29	30.5	37.7	100.0
	Total	77	81.1	100.0	
Missing	System	18	18.9		
Total		95	100.0		

How likely would you be to use mobile apps to improve your QoL?

		Frequency	Percent	Valid Percent	Cumulative Percent
Valid	Very unlikely	12	12.6	15.6	15.6
	Unlikely	7	7.4	9.1	24.7
	Neither	16	16.8	20.8	45.5
	Likely	14	14.7	18.2	63.6
	Very likely	28	29.5	36.4	100.0
	Total	77	81.1	100.0	
Missing	System	18	18.9		
Total		95	100.0		

How likely would you be to use website to improve your QoL?

		Frequency	Percent	Valid Percent	Cumulative Percent
Valid	Very unlikely	12	12.6	15.4	15.4
	Unlikely	4	4.2	5.1	20.5
	Neither	16	16.8	20.5	41.0
	Likely	18	18.9	23.1	64.1
	Very likely	28	29.5	35.9	100.0
	Total	78	82.1	100.0	
Missing	System	17	17.9		
Total		95	100.0		

How likely would you be to use web-based apps to improve your QoL?

		Frequency	Percent	Valid Percent	Cumulative Percent
Valid	Very unlikely	13	13.7	16.9	16.9
	Unlikely	9	9.5	11.7	28.6
	Neither	19	20.0	24.7	53.2
	Likely	14	14.7	18.2	71.4
	Very likely	22	23.2	28.6	100.0
	Total	77	81.1	100.0	
Missing	System	18	18.9		
Total		95	100.0		

How likely would you be to use digital skin maps to improve your QoL?

		Frequency	Percent	Valid Percent	Cumulative Percent
Valid	Very unlikely	12	12.6	15.6	15.6
	Unlikely	6	6.3	7.8	23.4
	Neither	11	11.6	14.3	37.7
	Likely	16	16.8	20.8	58.4
	Very likely	32	33.7	41.6	100.0
	Total	77	81.1	100.0	
Missing	System	18	18.9		
Total		95	100.0		

How likely would you be to use YouTube to improve your QoL?

		Frequency	Percent	Valid Percent	Cumulative Percent
Valid	Very unlikely	15	15.8	19.5	19.5
	Unlikely	11	11.6	14.3	33.8
	Neither	15	15.8	19.5	53.2
	Likely	16	16.8	20.8	74.0
	Very likely	20	21.1	26.0	100.0
	Total	77	81.1	100.0	
Missing	System	18	18.9		
Total		95	100.0		

How likely would you be to use Facebook to improve your QoL?

		Frequency	Percent	Valid Percent	Cumulative Percent
Valid	Very unlikely	15	15.8	19.5	19.5
	Unlikely	9	9.5	11.7	31.2
	Neither	10	10.5	13.0	44.2
	Likely	21	22.1	27.3	71.4
	Very likely	22	23.2	28.6	100.0
	Total	77	81.1	100.0	
Missing	System	18	18.9		
Total		95	100.0		

How likely would you be to use other social media to improve your QoL?

		Frequency	Percent	Valid Percent	Cumulative Percent
Valid	Very unlikely	16	16.8	21.6	21.6
	Unlikely	12	12.6	16.2	37.8
	Neither	16	16.8	21.6	59.5
	Likely	12	12.6	16.2	75.7
	Very likely	18	18.9	24.3	100.0
	Total	74	77.9	100.0	
Missing	System	21	22.1		
Total		95	100.0		

How likely would you be to use online discussion forums to improve your QoL?

		Frequency	Percent	Valid Percent	Cumulative Percent
Valid	Very unlikely	18	18.9	23.4	23.4
	Unlikely	10	10.5	13.0	36.4
	Neither	14	14.7	18.2	54.5
	Likely	15	15.8	19.5	74.0
	Very likely	20	21.1	26.0	100.0
	Total	77	81.1	100.0	
Missing	System	18	18.9		
Total		95	100.0		

How likely would you be to use LVC to improve your QoL?

		Frequency	Percent	Valid Percent	Cumulative Percent
Valid	Very unlikely	15	15.8	19.5	19.5
	Unlikely	12	12.6	15.6	35.1
	Neither	16	16.8	20.8	55.8
	Likely	11	11.6	14.3	70.1
	Very likely	23	24.2	29.9	100.0
	Total	77	81.1	100.0	
Missing	System	18	18.9		
Total		95	100.0		

How likely would you be to use teledermoscope to improve your QoL?

		Frequency	Percent	Valid Percent	Cumulative Percent
Valid	Very unlikely	17	17.9	22.1	22.1
	Unlikely	8	8.4	10.4	32.5
	Neither	19	20.0	24.7	57.1
	Likely	14	14.7	18.2	75.3
	Very likely	19	20.0	24.7	100.0
	Total	77	81.1	100.0	
Missing	System	18	18.9		
Total		95	100.0		

How likely would you be to use self-monitoring tools to improve your QoL?

		Frequency	Percent	Valid Percent	Cumulative Percent
Valid	Very unlikely	10	10.5	13.0	13.0
	Unlikely	6	6.3	7.8	20.8
	Neither	22	23.2	28.6	49.4
	Likely	14	14.7	18.2	67.5
	Very likely	25	26.3	32.5	100.0
	Total	77	81.1	100.0	
Missing	System	18	18.9		
Total		95	100.0		

How likely would you be to use store-and-forward to improve your QoL?

		Frequency	Percent	Valid Percent	Cumulative Percent
Valid	Very unlikely	11	11.6	14.3	14.3
	Unlikely	10	10.5	13.0	27.3
	Neither	20	21.1	26.0	53.2
	Likely	12	12.6	15.6	68.8
	Very likely	24	25.3	31.2	100.0
	Total	77	81.1	100.0	
Missing	System	18	18.9		
Total		95	100.0		

How likely would you be to use VR to improve your QoL?

		Frequency	Percent	Valid Percent	Cumulative Percent
Valid	Very unlikely	15	15.8	19.5	19.5
	Unlikely	12	12.6	15.6	35.1
	Neither	23	24.2	29.9	64.9
	Likely	9	9.5	11.7	76.6
	Very likely	18	18.9	23.4	100.0
	Total	77	81.1	100.0	
Missing	System	18	18.9		
Total		95	100.0		

How likely would you be to use AR to improve your QoL?

		Frequency	Percent	Valid Percent	Cumulative Percent
Valid	Very unlikely	15	15.8	19.5	19.5
	Unlikely	12	12.6	15.6	35.1
	Neither	25	26.3	32.5	67.5
	Likely	7	7.4	9.1	76.6
	Very likely	18	18.9	23.4	100.0
	Total	77	81.1	100.0	
Missing	System	18	18.9		
Total		95	100.0		

How likely would you be to use serious videos games to improve your QoL?

		Frequency	Percent	Valid Percent	Cumulative Percent
Valid	Very unlikely	40	42.1	51.9	51.9
	Unlikely	15	15.8	19.5	71.4
	Neither	9	9.5	11.7	83.1
	Likely	4	4.2	5.2	88.3
	Very likely	9	9.5	11.7	100.0
	Total	77	81.1	100.0	
Missing	System	18	18.9		
Total		95	100.0		

Appendix E: Digital health in melanoma post-treatment care in rural and remote Australia

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Review

Digital Health in Melanoma Posttreatment Care in Rural and Remote Australia: Systematic Review

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Abstract

Background: The melanoma incidence and mortality rates in rural and remote communities are exponentially higher than in urban areas. Digital health could be used to close the urban/rural gap for melanoma and improve access to posttreatment and support care services.

Objective: The aim of this review was to understand how digital health is currently used for melanoma posttreatment care and determine the benefits for Australian rural and remote areas.

Methods: A systematic search of PubMed, Medline, PsycINFO, and Scopus was conducted in March 2018. Findings were clustered per type of intervention and related direct outcomes.

Results: Five studies met the inclusion criteria, but none investigated the benefits of digital health for melanoma posttreatment care in rural and remote areas of Australia. Some empirical studies demonstrated consumers' acceptance of digital intervention for posttreatment care. The findings did not take into consideration individual, psychological, and socioeconomic factors, even though studies show their significant impacts on melanoma quality of aftercare.

Conclusions: Digital interventions may be used as an adjunct service by clinicians during melanoma posttreatment care, especially in regions that are less-resourced by practitioners and health infrastructure, such as rural and remote Australia. Technology could be used to reduce the disparity in melanoma incidence, mortality rates, and accessibility to posttreatment care management between urban and rural/remote populations.

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KEYWORDS

digital health; eHealth; technology; melanoma; posttreatment care; support care services; rural areas; remote communities; patient-centric; oncology

Introduction

Australia remains a country with one of the highest levels of melanoma. In 2015, the worldwide average age-standardized incidence rate (ASR) for melanoma was 5 cases for 100,000. However, the rates for Australia and New Zealand are over ten times that level (Table 1) [1]. The high incidence of melanoma

in Australia and New Zealand—whose populations consist primarily of transplanted, fair skinned, northern Europeans—is due to high levels of ambient ultraviolet (UV) radiation. Exposure of the skin to UV radiation is a well-known risk factor for melanoma [2-3]. Melanoma treatment represents a significant cost for the Australian Health Care System that has increased dramatically in the past two decades, from approximately Aus \$30 million in 2001 to Aus \$201 million in 2017 [4].

<http://www.jmir.org/2018/9/e11547/>

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(page number not for citation purposes)

Appendix E: Digital health in melanoma post-treatment care in rural and remote Australia (cont'd)

Table 1. Worldwide ranking of the average age-standardized incidence rate for melanoma.

Rank	Country	Age-standardized incidence rate for melanoma (95% CI)
1	New Zealand	54/100,000 (39-73)
2	Australia	54/100,000 (41-78)
3	Norway	26/100,000 (18-32)
4	Sweden	26/100,000 (20-35)
5	The Netherlands	25/100,000 (17-30)

Cutaneous melanoma (CM) is the fourth most commonly diagnosed cancer in Australia [5] and the most common cancer among young Australians between 15-39 years old. Although melanoma represents only 2% of all skin cancers [6], it often leads to premature death [6] and is responsible for a majority of skin cancer deaths [7]. Compared to urban populations, Australia's rural and remote communities experience inequities in access to care [8], leading to a higher incidence and mortality within 5 years. The median incidence ASR for nonindigenous Australians with CM is 32 per 100,000 across rural and remote areas and 27 per 100,000 in major cities. In comparison, the median worldwide ASR mortality for CM is 5.4 per 100,000 across rural and remote areas and 4.6 per 100,000 in major cities [9].

Melanoma treatment plans depend on (1) prognostic factors which are primarily defined by the American Joint Committee on Cancer staging system [10], and (2) individual characteristics which will allow the clinicians to determine the type of melanoma and the risk for recurrences. For example, patients previously treated for primary CM are at higher risk of recurrences and developing new primary melanomas and skin lesions [11]. However, early detection can reduce mortality rates, as melanoma can be more effectively cured with simple and inexpensive treatments in the early stages [12]. In 1996, Berwick and colleagues [13] reported that total skin self-examination (TSSE) might decrease melanoma mortality by 63%. In 2003, the study by Carli et al [14] found that regular skin self-examination (SSE) could significantly reduce the likelihood of a tumor >1 mm thick at diagnosis. It has been suggested that early detection is a factor influencing the disparity between urban and rural survival rates, but other aspects such as access to health services, clinical practices, and medical care management need to be taken into consideration to fully evaluate survival rates, especially after an initial diagnosis and treatment for CM [15].

In 2017, the Australian Institute of Health and Welfare estimated that 14,000 new melanoma cases would be diagnosed. However, there are only 775 registered dermatologists in Australia (only 260 of which are melanoma specialists), and very few of them are easily accessible to people living in rural and remote areas [16]. There are several infrastructure, cost, and access limitations which impact on the provision of health services for people. This is further compounded by the lack of training for future dermatologists and general practitioners (GPs) in remote areas.

It has been suggested that technology-based training and telehealth could help combat this disparity by bringing health services to rural and remote areas [17]. Many studies have evaluated the benefits of eHealth and the level of acceptance

for digital intervention in the early detection of cutaneous melanoma [18-20]. Benefits of telemedicine and teledermatology include increased access to health care services, reduced travel and waiting times, and cost-effectiveness [19]. A 2006 study by Qureshi et al [21] reported that patients prefer telemedicine if it can provide quicker access to their physicians. However, a qualitative review found that patients' attitudes toward technology are only positive if the tool is personalized and adapted to the recipients' needs and characteristics [18]. Also, available evidence suggests that telemedicine is not only beneficial for patients, but for health care professionals (HCP) too. For example, a previous study by Al-Qirim [22] reported that GPs appreciate using teledermatology when they need to refer to a dermatologists' expertise in order to obtain a second opinion.

In order to structure posttreatment plans, physicians must refer to the clinician guidelines. A recent study [23] showed that clinicians working with rural populations are less likely to properly apply guidelines when it comes to educating patients towards surveillance and supportive care. For example, patients living in rural areas were less likely to be provided with patient education material (86% compared to 89% in urban areas) or encouraged to conduct SSE (86% compared to 81%). There are also concerns that oral educational information provided by clinicians may not be useful. A study by Damade et al [24] found that only 5% of melanoma patients were able to reproduce all 4 critical characteristics of their tumor correctly. These results suggest a need for better quality and greater consistency in providing information to patients.

An area of posttreatment care that is often neglected across all populations is psychosocial support. Psychological distress, including worry, anxiety, and fear of disease recurrences and death, are common for survivors [25,26]. However, only 1% of specialists suggested patients see a psychologist as part of their post-treatment plan, despite an entire chapter of the clinician guidelines being devoted to psychosocial issues related to melanoma [23].

Although reviews have evaluated the effectiveness of technology for melanoma early detection, no studies have directly highlighted the benefits of eHealth on melanoma posttreatment care for rural communities. Researchers have qualitatively examined the different forms of treatment and care between rural and urban populations [27] and the care needs among rural cancer patients [28]. However, these studies did not focus on melanoma posttreatment care.

It is unclear from the published literature the level and utility of technology support available to patients with melanoma living

Appendix E: Digital health in melanoma post-treatment care in rural and remote Australia (cont'd)

in remote areas. The primary aim of this systematic review was to (1) examine how technology is currently used and accepted by physicians and patients with melanoma, and (2) to determine if there has been any implementation of such systems in rural and remote areas of Australia. With this focus, the researchers seek to identify areas of weakness and bring to light hypotheses on how technology could be used as an adjunct service during posttreatment care of CM, to aid physicians in designing follow-up care plans for patients with CM based on their needs and personal characteristics.

Methods

Databases and Search Strategy

The overall aim of this systematic review was to investigate digital health acceptance and its current use among people treated for melanoma. Our primary aim was to better understand digital health benefits among rural and remote populations for CM. However, given the impact of CM across all of Australia's population, literature around digital health and CM that impacted urban and regional areas was incorporated as well. This was done to ensure broad inclusion of digital health practice for CM posttreatment care. The databases selected were searched using keyword combinations related to digital health and melanoma posttreatment care. Specifically, we used the keyword combination "telehealth" OR "telemedicine" OR "teledermatology" OR "online services" OR "ehealth" OR

"e-health" OR "eHealth" AND "melanoma." For the current systematic literature review, 4 databases (PubMed, Medline, PsycINFO, Scopus) were searched in March 2018.

Study Selection

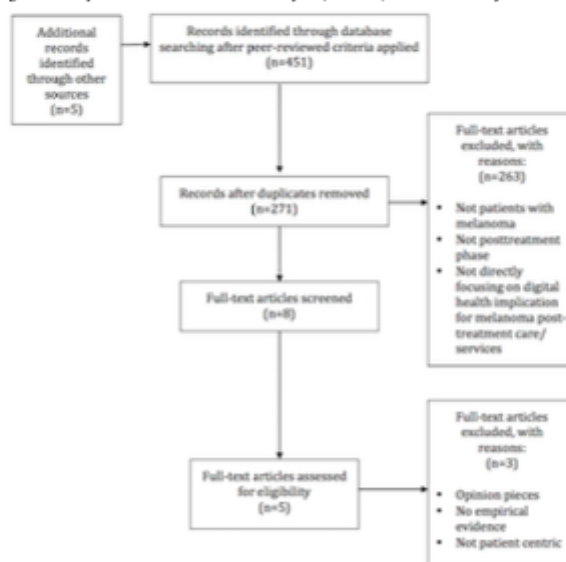
The search was limited to peer-reviewed papers. Search results identified 451 papers which were exported into a Microsoft Excel document. After duplicates were removed, 271 articles remained.

The search strategy involved 2 screening phases. Each article was screened based on exclusion criteria to remove irrelevant articles from the initial selection of 271 articles. For the second phase, only studies that were based on empirical evidence and used a patient-centric approach were retained for the final systematic literature review. Figure 1 presents the selection overview based on the Preferred Reporting Items for Systematic Reviews and Meta-Analyses (PRISMA) flowchart. A PRISMA checklist is shown in Multimedia Appendix 1.

Data Extraction

Data was extracted from the relevant papers using the following classification: (1) sources (country, year of study intervention), (2) participant characteristics (gender, residential area, mean ages, patient illness conditions, level of education, and socioeconomic background), (3) study design, (4) study intervention, and (5) research focus (Multimedia Appendix 1).

Figure 1. Preferred Reporting Items for Systematic Reviews and Meta-Analyses (PRISMA) flowchart of the systematic literature review.



Appendix E: Digital health in melanoma post-treatment care in rural and remote Australia (cont'd)

Results

Origin

There were 5 studies in total. Two (40%) of the studies were from Scotland, with the other 3 (60%) from the Netherlands, Canada, and the US. All studies were from before 2015 except for one (20%) study from the Netherlands, which was from 2016.

Participant Characteristics

Four of the 5 (80%) studies consisted of patients with melanoma only. The remaining study (20%) recruited patients with a history of melanoma and psoriasis, or collateral cancer. A minority, 2 of the 5 (40%) authors referred to the patient's illness condition in their sample description. The gender distribution of studies was mostly homogeneous with 47%-60% males and a mean age ranging from 53-66 years. None of the studies used "residential area" as an independent variable. Two (40%) studies used residential area as a patient characteristic but did not mention it in their findings. Also, 2 (40%) studies reported socioeconomic criteria in their findings and 3 (60%) featured level of education.

Study Design and Intervention

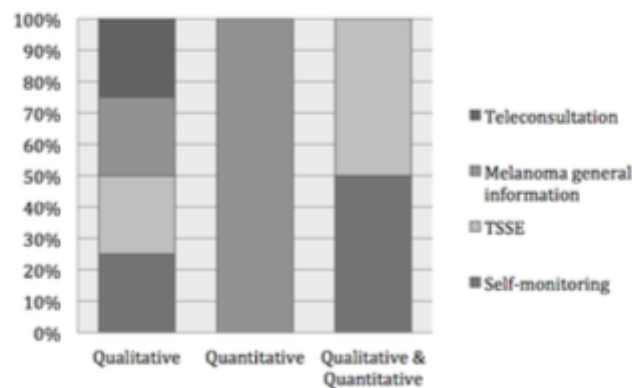
Prior to the investigation, all published research participants were informed of the objectives of the studies. Three of the 5

(60%) studies [18,19,21] were qualitative and used semistructured interviews either face-to-face or over the phone. The interviews were recorded by the researchers, transcribed verbatim, coded and reviewed by 1 or more coresearchers in order to cluster by themes/concepts of the participants' answers. The 3 (60%) qualitative studies assessed the perception and preferences of dermatology patients about the use of technology for self-monitoring and TSSE [18], a Web-based platform (Oncology Interactive Navigator) to deliver information about melanoma [19], and store and forward teleconsultation [21]. The latter used a willingness-to-pay approach in order to investigate dermatology patients' preferences. One (20%) study [20] used both qualitative and quantitative methods to assess the feasibility and acceptability of a digital intervention for self-monitoring and the participants' attitude to perform TSSE. One quantitative study [24] used an online questionnaire in order to capture participants' knowledge of melanoma and TSSE, and their preferences. Figure 2 displays the study design distribution with regards to the research main focus areas.

Research Focus Areas

Table 2 presents the positive and negative outcomes of using technology for melanoma posttreatment care of each selected study by type of intervention. The studies reviewed were classified under four intervention categories: (1) total skin self-examination; (2) teleconsultation; (3) clinicians' support and coordination; and (4) informative and supportive displays.

Figure 2. Distribution of the papers according to the study design and the main focus area. TSSE: total skin self-examination.



Appendix E: Digital health in melanoma post-treatment care in rural and remote Australia (cont'd)

Table 2. Direct outcomes on posttreatment care per type of intervention.

Direct outcomes	Type of intervention
Total skin self-examination	
Positive findings	
<ul style="list-style-type: none"> Provides reassurance to patients [18] 	<ul style="list-style-type: none"> Report sent by phone to clinicians including photographs Self-monitoring supportive tools
<ul style="list-style-type: none"> Convenient Avoids in-person clinical visit if not necessary [18] 	<ul style="list-style-type: none"> Report sent by phone to clinicians including photographs
<ul style="list-style-type: none"> Reduces the number of people who might forget about total skin self-examination [18] 	<ul style="list-style-type: none"> Reminder sent by text message or email
<ul style="list-style-type: none"> Promotes early detection [18] 	<ul style="list-style-type: none"> Report sent by phone to clinicians including photographs
<ul style="list-style-type: none"> Behavior change Empowers patients' confidence to perform total skin self-examination [20,21] 	<ul style="list-style-type: none"> Self-monitoring supportive tools YouTube videos explaining how to perform a total skin self-examination
<ul style="list-style-type: none"> Reinforces total skin self-examination [20] 	<ul style="list-style-type: none"> Self-monitoring supportive tools
Negative findings	
<ul style="list-style-type: none"> Health care professionals based their opinion on pictures only [18] 	<ul style="list-style-type: none"> Clinicians' feedback sent by text message or email
Teleconsultation	
Positive findings	
<ul style="list-style-type: none"> Convenient Reduces travel and saves time [18,20] Quick access to clinicians [18,21] 	<ul style="list-style-type: none"> Skype or teleconference Store and forward telemedicine
Negative findings	
<ul style="list-style-type: none"> Patients' desire to discuss face-to-face with clinicians [18] 	<ul style="list-style-type: none"> Skype or teleconference
<ul style="list-style-type: none"> Patients' skin required to be examined by clinicians [18] 	<ul style="list-style-type: none"> Phone
Clinicians' support and coordination	
Positive findings	
<ul style="list-style-type: none"> Accuracy in the diagnosis [18] 	<ul style="list-style-type: none"> Three-way consultation via a video or Skype link from the general practitioner's room
<ul style="list-style-type: none"> Convenient Time and travel saved [15] 	<ul style="list-style-type: none"> Remote point of contact Nurse specialist' opinion to be provided via store and forward system
Negative findings	
<ul style="list-style-type: none"> Not applicable 	<ul style="list-style-type: none"> Not applicable
Informative and supportive displays	
Positive findings	
<ul style="list-style-type: none"> Promotes early detection [18,19] 	<ul style="list-style-type: none"> Web-based app tailored information delivered about their conditions Skin map
<ul style="list-style-type: none"> Reduces patients' stress [19] 	<ul style="list-style-type: none"> Web-based app tailored information delivered about their conditions Skin map
<ul style="list-style-type: none"> Improves patients' decision-making in treatment [19] 	<ul style="list-style-type: none"> Web-based app tailored information delivered about their conditions

Appendix E: Digital health in melanoma post-treatment care in rural and remote Australia (cont'd)

Direct outcomes	Type of intervention
<ul style="list-style-type: none"> Ease of communication Content is more adapted to the patients' level of understanding [19] Supporting oral/written information delivered to the patients [24] 	<ul style="list-style-type: none"> Web-based app tailored information delivered about their conditions YouTube videos explaining how to perform a total skin self-examination
<ul style="list-style-type: none"> Reduce/control the content load [18,19] 	<ul style="list-style-type: none"> Web-based app tailored information delivered about their conditions
Negative findings	
<ul style="list-style-type: none"> Don't want to be associated with other patients Makes them feel sicker than they are [18] 	<ul style="list-style-type: none"> Online peer support (ie, forum, group chat)
<ul style="list-style-type: none"> Do not replace the oral and written information provided by clinicians [24] 	<ul style="list-style-type: none"> YouTube videos explaining how to perform a total skin self-examination

Discussion

Principal Results

The primary aim of this review was to identify the different use of digital health for melanoma posttreatment care, including its benefits and weaknesses. Patients perceived digital health as an added value to their posttreatment care [18-21,24]. However, a majority of the studies reported the benefits of digital interventions to prevent recurrence and promote early detection [18,19,24]. None of the selected studies investigated the benefits of digital health for melanoma posttreatment care in rural and remote areas. This gap in the digital health literature gives thought to a very specific niche in telemedicine that needs to be explored further, given this is an at-risk population [5]. Thus, it is crucial to understand how digital health could help clinicians to provide better care and quality of life (QoL) for people treated with melanoma, especially in regions where aftercare resources are limited or nonexistent, such as in rural and remote areas of Australia.

Patients' Individual Characteristics

This review found some evidence for the efficacy of digital interventions for melanoma posttreatment care. Key findings identified that clinicians need to take into consideration patients' characteristics in order to provide personalized follow-up plans, tailored information, and quality of care [18,21]. It is clear that information technology (IT) capabilities, patient age, illness condition, level of incomes and residential areas influence clinician and patient decision-making in the posttreatment plan. One study by Hall and Murchie [18] found that participants who were familiar with technology and not living close to hospitals were more likely to have a positive attitude toward telemedicine for self-monitoring and performing TSSE [18]. Querish and colleagues [21] also reported that 73% of the participants are more willing to pay when telemedicine was giving them faster access to the clinicians. Among this sample, 55% had an income inferior, or equal to US \$50,000 per annum. Another study [29] investigating consumers' perception toward telemedicine found that people with "technology anxiety" were less likely to use IT for specific care. In contrast, young populations may be more inclined to trust digital health interventions, as they are more familiar with technology [30].

Patients' Acceptance

In order to efficiently use personal consumer technology in melanoma posttreatment care, it is crucial to understand patients' acceptance toward digital intervention. Several of the studies reviewed [18,20,24] illustrated a shift from "passive" recipients to "active" patients for their care [19], which led to proactive health behavior change and positive attitudes toward early detection. Simple measures such as receiving a reminder to perform TSSE by text message or email, having access to informative videos, or using smartphone apps for self-monitoring, reduced anxiety, and reinforced TSSE [18,20,24]. These technologies could also be used to address the need for better quality and greater consistency in information provided to melanoma patients [24].

The study by Quereshi and colleagues [21] reported that patients' attitude toward telemedicine was generally positive if it showed convenience (58% well willing to pay up to US \$125), but almost universally positive if it gave a quicker access to their clinicians (95% of the patients were willing to pay up to US \$500). The study by Horsham and colleagues [30] emphasized that survivors show a positive attitude towards a digital health application that allowed them to monitor QoL and provided tailored information and advice.

While these findings demonstrated that patients were generally receptive toward digital health for melanoma posttreatment care, no studies to date have focused on rural and remote communities' views. Nevertheless, a few studies have already highlighted people's acceptance toward telemedicine in Australian rural and remote communities for cancer more broadly. In their studies, Sebesan and colleagues [31,32] reported the benefits of teleoncology in rural and remote areas for cancer care. The main benefits of this telehealth system included travel time saved and better access to specialist care. Also, studies [32,33] have shown that telehealth may lead to financial benefits and improved quality of care in distant communities.

Patients' Psychological and Social Needs

In this systematic review, there was a lack of empirical evidence with regards to the benefits of digital health for support and psychological care services, in order to provide better QoL. These studies mainly focused on early detection, including

Appendix E: Digital health in melanoma post-treatment care in rural and remote Australia (cont'd)

self-monitoring and TSSE. However, a previous systematic review [34] suggested that 30% of patients with melanoma reported psychological distress, which interferes with QoL, medical cost, risk of recurrence, and mortality rates [35,36]. Likewise, Oliveria and colleagues [37] found that patients treated with melanoma showed (1) direct psychosocial concerns related to conducting skin self-examination, (2) anxiety associated with new recurrence and sun exposure, (3) familial concerns, and (4) financial constraints and maintenance of health insurance benefits. Emotional support and reassurance are considered a key component of care [34-40], with psychological intervention associated with superior survival and recurrence rates, and decreased distress [39]. Clinicians should, therefore, take into consideration the psychosocial impact on patient outcomes when designing posttreatment plans.

The Economic Burden of Melanoma Treatment in Australia

Melanoma early detection reduces the mortality rate and results in simple treatments for lower cost [41]. A 2017 study [2], estimated the mean cost to the Australian health system for melanoma treatment to be Aus \$10,716 per patient. However, treatment cost for advanced melanoma may be 21% to 70% more expensive than for early stages (in situ, stage I and stage II). Doran and colleagues [42] compared the direct and indirect costs of melanoma and nonmelanoma skin cancer (NMSC) in 2010. The direct costs related to the management of the disease, including diagnosis and treatment to follow-up, and indirect costs included productivity losses associated with morbidity and premature mortality. Estimates of direct lifetime cost per case were Aus \$10,230 for melanoma and Aus \$2336 for NMSC; and total indirect cost per case Aus \$34,567 for melanoma and Aus \$123 for NMSC.

Moreover, additional studies [15,27] have reported an urban and rural disparity in term of accessing health care and mortality rate. Yu and colleagues [27] reported that socioeconomic factors may impact people's decision-making in selecting their health care provider. The study showed a difference in provider performance based on patients' income. Rural populations with lower-income received poorer care from HCPs, compared to patients living in urban areas.

The comparatively lower cost of delivering support care services via digital health initiatives, in addition to reduced treatment costs associated with promoting early detection [17-19] would go some way to improving access to health care and reduce urban/rural inequity.

Limitations

This systematic literature review presents several limitations. First, most of the studies used small samples ($n < 20$). It is evident that digital health research regarding melanoma postcare treatment is still in its early stages of investigation. Second, few studies were identified as focusing on the psychosocial and

health economic side of post-care treatment, as melanoma studies are primarily focused on early detection, and those that did use a retrospective measurement of consumer attitudes towards telemedicine. Third, melanoma treatment plans depend on individual characteristics, including the disease staging. Only one of the studies used staging as a participant characteristic. Finally, although the authors were primarily interested in rural and remote areas of Australia, the lack of studies conducted in these areas meant that studies for this review were drawn from across the world, and their conclusions may not necessarily generalize to the Australian rural and remote context.

Overall, the current systematic review provides findings of patients' perceptions toward telemedicine and digital interventions already used by clinicians and patients. However, in order to have a complete review of digital health benefits for melanoma post-treatment care, it would have been necessary to look at HCP's acceptance of such technological interventions.

Conclusion

The study of digital health has become an area of focus in primary health care, as it can help clinicians in their practice and support patients in improving and monitoring their QoL. While there is research interest in using digital health in early detection of melanoma, there is an urgent need to explore the potential for benefits of digital health in melanoma post-treatment care for specific needs and intervention, particularly for rural and remote populations who are lagging behind regarding postcare treatment quality and availability. This literature review also highlights the importance of considering individual, psychosocial and socioeconomic characteristics in future developments in this area.

Although our findings showed positive outcomes with regards to using technology during post-treatment care, there were also some limitations in using digital health. Patients believe that technology cannot replace the clinician provided written and oral information, follow-up visits, or clinical interventions [24]. To summarize, digital health shows potential to be used as an adjunct service by clinicians during melanoma posttreatment care, especially in regions that are less-resourced by practitioners and health infrastructure, such as regional and remote Australia.

Implication for Further Research

Future research should explore the potential for digital health within rural and remote areas for melanoma posttreatment care in order to reduce the mortality rate disparity in between urban and rural populations. Also, it will be interesting to consider how digital health implementation may transform the patients' ecosystem and the cost-effectiveness of this solution for both patients and the health care industry.

Interdisciplinary studies in behavioral psychology and health economy can add new insights to the health care industry in term of benefits and services that digital health can bring to melanoma patients care in rural and remote areas.

Acknowledgments

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Appendix E: Digital health in melanoma post-treatment care in rural and remote Australia (cont'd)

Conflicts of Interest

None declared.

Multimedia Appendix 1

Preferred Reporting Items for Systematic Reviews and Meta-Analyses (PRISMA) Checklist.

[\[PDF File \(Adobe PDF File\), 67KB-Multimedia Appendix 1\]](#)

Multimedia Appendix 2

The consumer-technology relationship and digital interventions for melanoma posttreatment care.

[\[XLSX File \(Microsoft Excel File\), 15KB-Multimedia Appendix 2\]](#)

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Appendix E: Digital health in melanoma post-treatment care in rural and remote Australia (cont'd)

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Abbreviations

ASR: age-standardized rate
CM: cutaneous melanoma
GPs: general practitioners
HCP: health care professional
IT: information technology
NMSC: nonmelanoma skin cancer
QoL: quality of life
SSSE: skin self-examination
TSSE: total skin self-examination
UV: ultraviolet

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Appendix F: Full survey

Using technology to help meet the treatment and psychosocial needs of melanoma patients living in rural areas of Australia

Dear participant,

Thank you for agreeing to take part in this survey investigating digital health for melanoma care in rural regions of Australia with a goal of understanding how technology could help improving access to care and melanoma patients' quality of life.

This survey should only take 5–8 minutes to complete. Be assured that all answers you provide will be kept strictly anonymous.

Before starting the survey, please take 5 minutes to read the 'Participant Information Statement'.

If you would like to know more at any stage during the study, please feel free to contact Audrey via email at audrey.rollin@sydney.edu.au.

Many thanks,
Audrey Rollin
(PhD candidate)

Appendix F: Full survey (cont'd)

Section 1: Individual characteristics

In this section we seek to identify individual characteristics. Please answer the questions by ticking the option corresponding to your personal situation. All information provided will remain confidential.

~~CONFIDENTIAL~~

What is your gender?

**must provide value*

- Male
- Female
- Transgender
- Other
- Prefer not to say

Please specify "other":

What is your age?

**must provide value*

What is your postcode?

**must provide value*

What is the highest attained level of education?

**must provide value*

- Did not complete school to Year 12
- Completed school to Year 12
- Diploma or TAFE certificate
- Undergraduate degree
- Postgraduate degree

Are you currently employed?

**must provide value*

- Yes, full-time
- Yes, part-time/casual
- No

What is your annual income bracket?

**must provide value*

- Less than \$20,000
- \$20,001 to \$50,000
- \$50,001 to \$80,000
- \$80,001 to \$110,000
- \$110,001 to \$140,000
- \$140,001 to \$170,000
- \$170,001 to \$200,000
- More than \$200,000

Do you own a car?

**must provide value*

- Yes
- No

Have you had any of the following surgical interventions in relation to your melanoma?

- High resolution ultrasound of draining nodes
- Tattoo and high resolution ultrasound

Appendix F: Full survey (cont'd)

Please specify "others":

How satisfied were you about the quantity of information received from your clinician related to the below items?

**must provide value for all items*

To answer this question you need to use the scale of satisfaction rated from 1 to 5 with:

- 1=very dissatisfied
- 2=dissatisfied
- 3=neither satisfied nor dissatisfied
- 4=satisfied
- 5=very satisfied

	1	2	3	4	5
Disease evolution	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Treatment	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Self Skin-Examination	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Psychological implication due to disease	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Social group support	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

How satisfied were you about the quality of information received from your clinician?

**must provide value for all items*

To answer this question you need to use the scale of satisfaction rated from 1 to 5 with:

- 1=very dissatisfied
- 2=dissatisfied
- 3=neither satisfied nor dissatisfied
- 4=satisfied
- 5=very satisfied

	1	2	3	4	5
Disease evolution	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Treatment	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Self Skin-Examination	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Psychological implication due to disease	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Social group support	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

Please indicate how often you experienced the following items since being diagnosed with Melanoma.

**must provide value for all items*

	Never	Rarely	Sometimes	Often	Always
Treatment-related morbidity (i.e. Pain due to drugs)	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Fear of Cancer Recurrence (FCR)	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Fearful thoughts about treatment	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

4

3

Appendix F: Full survey (cont'd)

Anxiety prior to follow-up visits	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Anxiety between follow-up visits	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Decrease in self-esteem	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Decrease in general wellbeing	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Change in relationships with others	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Desire to seek reassurance from follow-up visits	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Need for more social support	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Need for emotional/ psychological support counselling	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Others	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

Please specify "others":

How often are your follow-up visits? <i>*must provide value</i>	<input type="checkbox"/> Never
	<input type="checkbox"/> 1 time per year
	<input type="checkbox"/> 2 times per year
	<input type="checkbox"/> 3 times per year
	<input type="checkbox"/> 4 times per year
	<input type="checkbox"/> 5 times per year
	<input type="checkbox"/> More than 5 times per year
Are you satisfied with the frequency of your follow-up visits? <i>*must provide value</i>	<input type="checkbox"/> Yes
	<input type="checkbox"/> No, I would like more frequent follow-up visits
	<input type="checkbox"/> No, I would like less frequent follow-up visits

Please indicate how often the following factors have impacted on your access to care?
**must provide value for all items*

	Never	Rarely	Sometimes	Often	Always
Time of travel for follow-up visits	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Cost of travel for follow-up visits	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Taking time off from work for follow-up visits	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Long waiting time to get an appointment for follow-up visits	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Cost for follow-up visits	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Others	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

Please specify "others":

Appendix F: Full survey (cont'd)

Section 3:

In this section we seek to understand how digital intervention could be used within melanoma care. You will be asked to answer questions about the current use of technology as well as potential future digital solutions that could be implemented within your treatment and follow-up care.

Have you ever used any of the following technology for melanoma care (i.e. monitoring the disease, Skin Self-Examination, consultations, find psychological help, etc.)?

**must provide value for all items*

	Yes	No	I have never heard of it
Mobile phone text message	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Email	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Mobile phone camera	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Mobile apps	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Websites	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Web-Based apps (note: a web-based app is a software program that runs on a web server. It must be accessed through a web browser)	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Digital skin map	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
YouTube videos	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Facebook	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Online Forum discussion	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Skype/teleconference platform	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Teledermoscope	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Self-monitoring supportive tools (note: a self-monitoring supportive tool is a tool that allow you to monitor your health condition over time, e.g. the evolution of your moles)	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Store-and-forward telemedecines (note: store-and-forward telemedicine is technology that collects clinical information and sends it electronically to another site for evaluation)	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

Appendix F: Full survey (cont'd)

How likely would you be to use the following technology to increase your access to care as a melanoma patient?

**must provide value for all items*

To answer to this question you need to use a scale of probability rated from 1 to 5 with:

1=very unlikely

2=unlikely

3=neither unlikely nor likely

4=likely

5=very likely

	1	2	3	4	5
Mobile phone text message	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Email	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Mobile phone camera	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Mobile apps	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Websites	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Web-Based apps (note: a web-based app is a software program that runs on a web server. It must be accessed through a web browser)	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Digital skin map	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
YouTube videos	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Facebook	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Online Forum discussion	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Skype/teleconference platform	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Teledermoscope	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Self-monitoring supportive tools (note: a self-monitoring supportive tool is a tool that allow you to monitor your health condition over time, e.g. the evolution of your moles)	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Store-and-forward telemedecines (note: store-and-forward telemedicine is technology that collects clinical information and sends it electronically to another site for evaluation)	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Virtual Reality (note: Virtual Reality is the use of computer technology to create a simulated environment.)	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Augmented Reality (note: Augmented Reality is an enhanced version of reality created by the use of technology to overlay digital information on a real world environment)	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Serious video games	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Others	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

Appendix F: Full survey (cont'd)

Please specify "others":

How likely would you be to use the following to increase your quality of life as a melanoma patient?

**must provide value for all items*

To answer to this question you need to use a scale of probability rated from 1 to 5 with:

1=very unlikely

2=unlikely

3=neither unlikely nor likely

4=likely

5=very likely

	1	2	3	4	5
Mobile phone text message	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Email	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Mobile phone camera	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Mobile apps	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Websites	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Web-Based apps (note: a web-based app is a software program that runs on a web server. It must be accessed through a web browser)	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Digital skin map	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
YouTube videos	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Facebook	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Online Forum discussion	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Skype/teleconference platform	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Teledermoscope	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Self-monitoring supportive tools (note: a self-monitoring supportive tool is a tool that allow you to monitor your health condition over time, e.g. the evolution of your moles)	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Store-and-forward telemedecines (note: store-and-forward telemedicine is technology that collects clinical information and sends it electronically to another site for evaluation)	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Virtual Reality (note: Virtual Reality is the use of computer technology to create a simulated environment.)	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Augmented Reality (note: Augmented Reality is an enhanced version of reality created by the use of technology to overlay digital information on a real world environment)	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Serious video games	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Others	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

Appendix F: Full survey (cont'd)

Please specify "others":

What benefits do you think using technology could bring to your melanoma care (i.e. follow-up care and support care services)? If none please answer "none".

**must provide value*

How do you think technology could increase your access to care?

**must provide value*

You have successfully completed the survey. Please provide your email address below if you would like to receive information on the results of the study and/or agree to be contacted by the researchers for complementary information.

Please provide your email address:

Do you agree to be contacted for complementary information? Yes

No

Do you wish to receive information on the results of this study when completed? Yes

No

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