Understanding the needs and preferences of patients with cancer regarding an app to help them to meet their information needs: development of the 'Ask Us' cancer app

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Summary

Patients with cancer, and their relatives, often have unmet information needs during the course of their illness. Within the NHS, there has been a shift from inpatient to outpatient cancer care, which has meant that patients are receiving less direct, regular supervision from their clinicians. The introduction of Smart technology has presented an opportunity to deliver interventions to patients, and their relatives, remotely. The aims of this thesis were to: (1) understand the needs and preferences of patients with cancer regarding an app to help them to meet their information needs in non-inpatient settings, and (2) to develop an app for patients, which may also be used by relatives, based on their identified needs and preferences.

A qualitative study with patients and their relatives identified several barriers to information-gathering and understanding that occur during and between patient-clinician consultations, which lead to unmet information needs. Patients and their relatives reported that an app intervention, which could help them to overcome these barriers and enable them to meet their information needs, would be useful. A qualitative study with cancer clinicians explored their opinions on the value of this type of app and clinicians appeared to be supportive of its development and use in consultations. The 'Ask Us' app was then designed and user-tested with patients in the community. Patients perceived the app to be a useful and acceptable intervention to help them to meet their information needs. A range of benefits were reported by patients and some barriers to app use were highlighted. Overall, the 'Ask Us' app appears to be a feasible intervention to support patients with cancer in the community.

Contents

List of Abbreviations

AMSTAR -A Measurement Tool to Assess Systematic Reviews

APEASE - affordability, practicability, effectiveness/cost-effectiveness, acceptability, side-effects/safety and equity

CASP - Critical Appraisal Skills Programme

CNS – Cancer Nurse Specialist

CSM – The common Sense Model of self-regulation of health and illness

CTU – Clinical trials unit

HBM – Health belief model

Health-ITUEM - The Health IT Usability Evaluation Model

HRQOL – Health related quality of life

IP – Intellectual property

IOM – Institute of Medicine

MRC – Medical Research Council

NHS - National Health Service

PACMAD - The People At the Centre of Mobile Application Development model

PAM – Patient Activation Measure

PDA – Personal digital assistant

PRISMA - Preferred Reporting Items for Systematic reviews and Meta-Analyses

PROSPERO - International Prospective Register of Systematic Reviews

QPL – Question prompt lists

RCT – Randomised controlled trial

TAM – Technology acceptance model

TPB – Theory of planned behaviour

UHW – University Hospital Wales

WCISU – Welsh Cancer Intelligence Surveillance Unit

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Chapter 1

Introduction

It is estimated that one in two people in Great Britain will develop some form of cancer during their lifetime (Ahmad, Ormiston-Smith, & Sasieni, 2015). In 2014, 357,000 new cases of cancer were diagnosed in the UK and the incidence rate is increasing (Cancer Research UK, 2014). However, survival rates have doubled in the UK in the last 40 years and so for many, cancer has become a chronic condition with which they live for many years. Subsequently, there has been a shift from inpatient to outpatient and community cancer care (i.e. non-inpatient settings), where patients are required to manage their condition at home, away from regular supervision by clinicians. This change in care requires patients to take a more active role in their treatment and survivorship. Patients are often faced with an uncertain future, unfamiliar tests and procedures, treatment options, treatment-related side-effects and lifestyle changes. In order to take a more active role in their care, and to cope with and manage these changes to daily life, patients require relevant information (Hibbard & Gilbert, 2014; Jefford & Tattersall, 2002). Consequently, recent government initiatives and National Health Service (NHS) plans, such as the National Cancer Strategy and Cancer Delivery Plan, have highlighted information provision as one of their key priorities (Department of Health (DOH), 2011; 2013; Welsh Government, 2016).

1.1 The importance of information for patients with cancer and variation in patients' information needs

A need can be described as, "*a wish to receive support with an experienced problem*" (Osse, Vernooij-Dassen, de Vree, Schadé & Grol, 2000, p.901), therefore an information need can be described as the more specific desire for informational support. The dominant view of what constitutes a need, in a culture geared towards increasing patient involvement, is that need is self-assessed by the patient themselves (Boberg et al., 2003; Tamburini et al., 2000). This is in comparison to a previous view, where a patient's need was defined by a healthcare professional (Krishnasamy, Wilkie & Haviland, 2001; Walters, Iliffe, Tai & Orrell, 2000).

Mills and Sullivan (1999) outlined six functions and benefits of information for patients with cancer following a review of the literature, which included gaining a sense of control, reduction of anxiety, increased adherence to treatment, more realistic expectations, increased feelings of safety, and promotion of self-care and participation. There is also evidence to suggest that information provision leads to health

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improvements and improved health-related quality of life (Husson, Mols & van de Poll-Franse, 2011). Studies across the UK, USA, North America and Australia have shown that most patients want as much information on their condition as possible, whether good or bad (Butow, Dunn, Tattersall & Jones, 1994; Jenkins, Fallowfield & Saul, 2001). For example, a UK study of 2231 patients found that 87% of patients stated that they wanted detailed information on their cancer, with no difference in information needs between curative or palliative patients (Jenkins et al., 2001). Reviews of the literature suggest that patients generally want information on the extent of the disease, likelihood of cure and prognosis, available treatments, side-effects of treatment, self-care and return to normal life (Bilodeau & Degner, 1996; Luker et al., 1995; Mills & Sullivan, 1999). Other, less urgent, information needs include the impact of cancer and/or treatment on social activities, family and friends, mental wellbeing and sexual activity, and the risk of family and friends getting cancer (Bilodeau & Degner, 1996; Luker et al., 1995). It is important to note that an information need is separate from other types of needs, such as emotional or practical needs. However, information related to emotional or practical issues can enable patients to meet their other needs. For example, access to information on services that provide psychological support enables patients to contact those services and meet their emotional needs. For the purpose of this thesis, the term 'information need' therefore refers to the need for any cancer-related information, such as information about the disease itself, treatment, emotional support services, practical support services and so on, which in turn, may help patients to meet a range of needs throughout their cancer.

Cancer-related information seeking by patients and survivors has generally increased over time which likely reflects the increased access to information, however patients' information-seeking has been shown to vary between and within patients (Leydon et al., 2000; Rutten et al., 2016). A number of demographic factors, such as age, gender, education and income, as well as the type of cancer, have been associated with variation in information needs and information-seeking (Morrison et al., 2012; Nagler et al., 2010; Rutten et al., 2016). Studies have previously suggested that patients who are younger, female, and have a higher education level and income, are more likely to have greater information needs and seek more information than patients who are older, male, less educated and of lower income (Morrison et al., 2012; Rutten et al., 2016). Inequality in access to information resources, such as the Internet, perceived loyalty to clinicians and avoidant coping strategies in order to maintain hope have accounted for some of these findings (Leydon et al., 2000; Rutten et al., 2016). However, some recent studies suggest that the effects of demographic factors on

cancer patients' information-seeking may be reducing, as the acceptance and use of newer information resources, such as the Internet, becomes more widespread throughout older generations and more accessible to patients of lower socioeconomic status (Katz, Roberge & Coulombe, 2014). Patients' information needs also appear to vary throughout the cancer journey, however they are typically highest following diagnosis and then generally decrease over time (Rutten et al., 2005; 2016). Finally, information-seeking generally remains consistent throughout the cancer journey and into survivorship, regardless of time since diagnosis, which suggests that both cancer patients and survivors require long-term information support (Morrison et al., 2012; Rutten et al., 2016).

1.2 Patients' unmet information needs

Unfortunately, research suggests that the information needs of cancer patients are not always met. Up to 93% of cancer patients across the US, Europe and the UK report having unmet information needs (Boberg et al., 2003; Cox, Jenkins, Catt, Langridge & Fallowfield, 2006; Faller et al., 2016; Harrison, Young, Price, Butow & Solomon, 2009). Similarly, the Wales Cancer Patient Experience Survey revealed that a significant number of patients across Wales declared unmet information needs (Quality Health, 2014). Patients have generally reported a lack of basic information related to their type and stage of cancer, treatment, and other important information, such as the long-term consequences of treatment, available support services, necessary lifestyle changes and how to manage their finances. As well as limiting patients' ability to participate in their care, unmet information needs are associated with a lower quality of life, increased anxiety and depression, and dissatisfaction with care (Faller et al., 2016; Husson et al., 2011).

Research has highlighted several reasons for cancer patients' unmet information needs. Firstly, previous studies have identified barriers to information exchange within patient-clinician consultations. Clinicians may underestimate patients' information needs, overestimate the amount of information they give or patients may feel uncertain about what to ask, feel unable to ask questions, particularly patients with serious or life-threatening diseases, or forget to ask a particular question during consultations (Boberg et al., 2003; Jefford & Tattersall, 2002; Jenkins et al., 2001). Additionally, some patients forget or misunderstand the information they receive from the clinician or have difficulty assimilating the information due to anxiety or decreased cognitive performance caused by the disease or treatment (Hogbin & Fallowfield, 1989; Ley, 1988; Jepson & Chaiken, 1990; Maguire & Faulkner, 1988). Secondly, many patients

find it difficult to identify reliable information resources and relevant information between consultations. Some patients struggle to find the information that they need on the Internet and may also be misled by inaccurate information from websites or misinterpret the information (Eysenbach, 2003; Kiley, 2002). Similarly, other common sources of information, such as family and friends, the media, and social media or chat forums, cannot be relied upon for accurate information (Rutten, Arora, Bakos, Aziz, & Rowland, 2005).

1.3 Sources of information for patients

Despite these issues in consultations, it is widely acknowledged that clinicians are patients' most valued source of information (Mills & Sullivan, 1999; Rutten et al., 2016). However, patients commonly seek information from a variety of additional sources outside of the healthcare service, including the Internet, printed materials, the media, interpersonal sources (e.g. friends and family, support groups), and organisational and scientific sources (e.g. cancer charities, medical journals) (Rutten et al., 2005; 2016). A recent survey of breast cancer patients' use of information sources in Ireland reported that the most common information resources included cancer clinicians (95%), leaflets (69%) and websites (59%), while other printed media (42%), books (41%) and medical journals (in print and online) (31%) were less popular (O'Brien et al., 2015). Additionally, although this study did not report the percentage of patients that used their Smartphones to search for illness-related information, 47% of patients perceived a Smartphone app to be a useful medium to learn from, or communicate with, their healthcare team.

Comparison of several surveys demonstrate the increasing popularity of new web-based information resources due to increased access to devices and availability of information websites and apps (Kempf et al., 2016; O'Brien et al., 2015; Rutten et al., 2005; 2016). For example, a survey of cancer outpatients in France found that half of patients had used websites and a quarter had used apps to search for health information (Kempf et al., 2016). In contrast, the amount of patients that report using printed materials or the media as a first source of information on their condition has decreased (Rutten et al., 2016).

The acceptance and use of new web-based technologies appear to be influenced by several demographic factors. Surveys of cancer patients across Europe, the US and Canada have shown that patients who are younger, urban-dwelling, more educated, and employed are significantly more likely to accept and perceive websites, apps and

text messaging as useful forms of education and communication with their clinicians compared to older, rural-dwelling, less educated and unemployed patients (Katz et al., 2014; O'Brien et al., 2015; Rutten et al., 2016). Authors concluded that the acceptance of new technology as an information resource for patients with cancer is expanding as expected along generational trends and over time, use of these media as a resource of cancer-related information will increase. Given the benefits of information for patients with cancer, it is prudent to develop web-based information resources in order to cater for the increasing number of patients that prefer to access information in this way.

Despite the increasing popularity of web-based technology, a review by Rutten and colleagues (2016) found that the percentage of patients reporting clinicians as their first source of information has increased over time, which suggests that although new web-based information resources are becoming more popular and are likely to replace traditional resources of information, clinicians are still patients' first and preferred source of information. The continued reliance on clinicians for information may be an indicator of the complexity of the information environment and patients' need for guidance in understanding the available information, particularly among those who are male, older, and socioeconomically disadvantaged, as these patients are especially likely to rely on clinicians as a key source of information (Rutten et al., 2016). It is therefore important to develop interventions to support information exchange and understanding in patient-clinician consultations.

1.4 The information needs of patients' families

It is now acknowledged that a cancer diagnosis also has a significant negative impact on patients' close family and friends, who experience similar levels of distress to patients following their diagnosis (Long et al., 2016; Revenson & Pranikoff, 2005). Reasons for the similar levels of distress include worrying about the patient's future, feeling like 'helpless observers' and the burden of becoming an informal caregiver, due to the shift to outpatient cancer care (Davis-Ali, Chesler & Chesney, 1993; Lambert, Girgis, Lecathelinais & Stacey, 2013). As a result, the concept of cancer has evolved into that of a 'family disease' (Harrison, Haddad & Maguire, 1995). Family and friends of patients have become more physically and emotionally involved in patients' care and are expected to perform duties, such as managing symptoms and treatment side-effects, providing emotional and informational support, communicating with clinicians, organising finances and transport, alongside playing a key role in patients' medical decision making (Long et al., 2016). Despite this increasing responsibility, most do not receive assistance and have a short time to gather the relevant information that they

need to care for the patient (Revenson & Pranikoff, 2005; Soothill et al., 2001). Similar to patients, previous reviews have indicated that relatives are dissatisfied with the information that they receive and require more information in order to cope with the impact of cancer, both on themselves and the patient (Deeken, Taylor, Mangan, Yabroff, & Ingham, 2003; Kitrungrote & Cohen, 2006). The demanding responsibilities and unmet information needs of a caregiver further contributes to the negative impact of cancer on their wellbeing and compromises their ability to provide effective care for the patient (Lambert et al., 2012; Long et al., 2016). It is therefore important to meet the information needs of patients' relatives in order to maintain their wellbeing and optimise patients' care. Recent cancer policies, government and health organisations now encourage the development of interventions that consider and support patients' relatives, as well as the patient (DOH, 2011; 2013; Welsh Government, 2016). For these reasons, relatives of patients will be involved the development of an app for this PhD thesis.

1.5 Information interventions for patients and their families

Various types of interventions have been developed in an attempt to meet cancer patients' information needs, including paper-based written information, audiotapes of consultations, telephone helplines, teaching and counselling services and multimedia resources, such as DVDs (Mills and Sullivan, 1999). Reviews of such interventions have generally reported a small but positive effect on at least one patient outcome, including increased knowledge of their condition, increased recall of the information provided, increased satisfaction with their care, improved symptom management or improved psychological well-being (Mills & Sullivan,1999; McPherson, Higginson & Hearn, 2001). However, many of these interventions are expensive to develop and run, and require staff for delivery. While paper-based printed information has generally been the most effective and efficient method of delivering information to patients, not all information has been found to be evidenced-based, easy to read or tailored to the patients' individual needs. For example, one study of patients who had undergone a hysterectomy in the UK found that only 14% of written information provided was based on the patients' needs, 26% of the leaflets were illegible, and 80% of hospitals did not follow printing guidelines, which meant the leaflets were difficult to read (Scriven & Tucker, 1997). Written information also needs to be pitched at the correct educational level to ensure full patient understanding (Foltz & Sullivan, 1996). Authors have suggested that information interventions should be used as a supplement to cement verbal information from clinicians, particularly due to the emotive nature of cancer (Cortis & Lacey, 1996; Hinds, Streater & Mood, 1995).

Consequently, many interventions have been developed to support cancer patients' information-gathering in consultations, which include face-to-face or multimedia coaching, decision aids, audio recordings of consultations, and question prompt lists (QPL) (Brown, Butow, Dunn & Tattersall, 2001; Street, Voigt, Geyer, Manning & Swanson, 1995; Tattersall & Butow, 2002). The most cost-effective and useful intervention appears to be the QPL, where patients select questions they wish to ask their clinician from a pre-chosen list of relevant questions, which facilitates tailored information-gathering (Dimoska, Tattersall, Butow, Shepherd & Kinnersley, 2008). Reviews of the use of QPL for cancer consultations have suggested positive effects on patient-clinician communication, question-asking and recall of information (Brandes, Linn, Butow & Weert, 2015; Dimoska et al., 2008). However, these effects have been small and studies suggest that in order to have a larger effect, a QPL needs to be paired with a second intervention, such as coaching, prior to consultations, which increases the total cost of the intervention.

Recently, more comprehensive, psycho-educational interventions have been developed for patients with cancer in response to a growing awareness of their unmet psychological needs, in addition to their informational needs (Faller et al., 2013). Psycho-educational interventions are typically multi-method interventions that often include education, coping skills training, stress management and psychological support (Fawzy & Fawzy, 1994). In comparison, information-only interventions are typically shorter in duration and lower in intensity (Faller et al., 2013). A large systematic review of RCTs of psycho-educational interventions reported small but significant positive effects on anxiety, depression and quality of life, with effects on quality of life shown to be sustained in the long term (Faller et al., 2013). Conversely, no effects on these outcomes were found for information-only interventions. This review suggests that intervention developers should seek to develop more comprehensive interventions that aim to support patients' psychological needs, as well as their informational needs.

Due to the cost of staff-delivered interventions, efforts have turned to the development of computer- and web-based psycho-educational interventions (also known as 'e-health' interventions), which are low cost and wide-reach (Slev et al., 2016). A meta-review of such interventions reported an increase in patients' knowledge of their condition, as well as their ability to acquire and use information appropriately (Slev et al., 2016). Although more studies are needed to investigate the effects of these

interventions on health status, this review demonstrates the potential of technology to deliver comprehensive interventions to cancer patients remotely.

Due to an awareness that cancer often affects both the patient and family caregiver, which are usually spouses, there has been an increasing number of dyadic interventions developed over the last decade which have aimed to support both patients and their caregivers by delivering interventions jointly (Northouse et al., 2010). Interventions have been in the form of psychoeducation, skills training or therapeutic counselling and have included content such as information on caring for the patient, maintaining relationships, caregiver self-care and addressing their informational and psychological needs (Lambert, Levesque & Girgis, 2016; Northouse, Katapodi, Song, Zhang & Mood, 2010). Modes of delivery for this type of intervention have included clinicians, self-directed, telephone and the Internet, however web-based interventions are becoming increasingly popular due to the lower cost, higher sustainability and ease of access compared to other types of interventions (Lambert et al., 2016; Northouse et al., 2010). Systematic reviews and meta-analyses of studies of dyadic interventions for patients with cancer and their caregivers have provided some evidence for small but beneficial effects on aspects of quality of life (e.g. physical, psychological and relationship well-being) for both the patient and caregiver (Badr & Krebs, 2013; Northouse et al., 2010). Reported benefits for caregivers of this type of intervention have included reduced burden, improved ability to cope, increased self-efficacy and increased quality of life (Northouse et al., 2010). For these reasons, it is prudent to consider the development of interventions that may be used by both patients and their families. However, it must be noted that many dyadic interventions have been patient-focused. For example, many of the interventions reviewed by Northouse and colleagues (2010) primarily focused on patient care, whereas self-care for the caregiver tended to be a secondary focus. Furthermore, only two studies in this review conducted caregiver groups in which caregivers could interact openly with other caregivers without the presence of patients. It is therefore possible that the full effects of dyadic interventions on caregivers are unknown. Indeed, of the nine of 29 studies in this review that were of interventions for caregivers only, findings suggested that these interventions resulted in a more positive appraisal of caregiving benefit (Northouse et al., 2010). Authors suggested that these interventions may have been better able to focus on caregivers' own needs and enabled them to reflect on their role as caregiver. These studies suggest that some studies of dyadic interventions may have limited exploration of the caregivers' opinions in favour of the opinions of patients.

Furthermore, it is known that patients with cancer and their caregivers may participate in dyadic-level coping in an attempt to protect their relationship during times of stress (Hagedoorn et al., 2000). One such relationship-focused coping strategy is known as protective buffering, which has been defined as, *"hiding one's concerns, denying one's worries, concealing discouraging information, preventing the patient from thinking about the cancer, and yielding in order to avoid disagreement"* (Hagedoorn et al., 2000, p. 275). Studies have suggested that dyads typically engage in protective buffering to avoid further burdening or worrying their partner or because they are uncertain about how best to support their partner (Kuijer et al., 2000). Dyadic interventions may therefore produce different effects on patients and their caregivers compared to individual interventions, particularly for the caregivers who participate in patient-focused interventions. It is therefore important to consider the effects of protective buffering on the part of the patient and caregiver when developing and evaluating a dyadic intervention.

1.6 The introduction of Smart technology

The introduction of Smart technology has provided a new platform to deliver interventions to patients remotely. Smart devices, such as Smartphones and tablet computers, are called so due to their advanced capabilities in comparison to older devices. For example, old generation mobile phones served the sole purpose of sending and receiving communications in the form of text messages and voice calls, whereas the new generation of mobile phones, that are made today, have dramatically enhanced power and capabilities, and an increasing list of software applications (known as 'apps'). Smartphones are typically equipped with a touchscreen interface, customised apps, Internet access, digital cameras, music players, GPS systems and much more. Most mobile phones that are made and sold today can be described as Smartphones, as even the cheapest, less advanced mobile phones available (e.g. the Tesco Mobile IMO Dash mobile phone) offer the same types of functions as the most expensive and advanced Smartphones on the market (e.g. an Apple iPhone 7). Similarly, a tablet computer can be described as a wireless, portable personal computer with a touchscreen interface that is larger than a Smartphone but smaller than a notebook computer. Tablets are typically used for the same functions as Smartphones but do not have the capability to make conventional telephone calls (though calls may be made via apps that use the Internet, such as Viber).

An app can be described as a software programme that runs on a technological device, such a computer. However, the term app has become specifically associated

with software that runs on a Smartphone or tablet. Apps make use of the capabilities of Smartphones and tablet computers, described above. Many companies have created apps so that it is easy for consumers to find and use their services. For example, it is now commonplace for people to use apps daily for communication with family and friends, banking, shopping, emailing, gaming or consulting the news and weather (Ofcom, 2016). Smart devices typically come with some basic apps installed and other apps are available to download via their respective app stores, either for free or for a small fee. Once downloaded to a device, an app is stored on the home screen and can be accessed quickly by tapping on the app icon.

Approximately 93% of adults in the UK now personally own or use a mobile phone, of which 71% specify that they own a Smartphone (Ofcom, 2016). Additionally, around 66% of adults report using their Smartphone to access the Internet (Ofcom, 2016). No other device has had such a commercial and societal impact as the Smartphone and the relentless innovation of such devices means that ownership and use are continuing to rise. Similarly, over two thirds of adults in the UK now own or have access to a tablet computer (Deloitte, 2016). Although ownership and use of Smartphones and tablets is continuously rising across all demographic groups, there are still some notable differences (Ofcom, 2016). Recent statistics showed that around twice as many 16-24 and 25-34 year olds in the UK own a smartphone (90% and 91% respectively) compared to those aged over 55 (42%) (Ofcom, 2016). Additionally, those of the highest socioeconomic status were more likely to own a Smartphone than those of the lowest socioeconomic status (76% and 62%, respectively). Similar trends for tablet devices were reported. Contrary to popular belief, some studies suggest that minority ethnic populations are more likely than non-minority ethnic populations to use their Smartphones to access health information (Fox & Duggan, 2012; Smith, 2013). This may be due to the fact that these populations are less likely to have access to home computers and broadband, which means that Smartphone-based interventions could have greater reach than other web-based interventions (Smith, 2013). Similarly, acceptance and use of this technology by older adults, who may be less familiar with this technology than younger adults, is rapidly increasing (Zickuhr & Madden, 2012). Smart technology interventions have the potential to benefit healthcare due its wide reach to patients at the point of need and enabling access to tailored healthcare to those in resource-poor settings or those facing access barriers to traditional healthcare.

Similar statistics of Smart device ownership and use have been reported in cancer patient populations (Girault et al., 2015; O'Brien et al., 2015). One survey of patients with breast cancer reported that 97% of patients owned a mobile, of which 69% specified a Smartphone, and 83% reported using their mobile phone several times a day, in comparison to a computer by 52% (O'Brien et al., 2015). Over half of these patients used their phones for 'Smart' activities, such as accessing websites (53%), emailing (51%) or planning or scheduling (49%). An intervention delivered via an app therefore has the potential to reach a large number of patients with cancer remotely, at a lower cost compared to traditional healthcare interventions (Blake, 2008; Boulos et al., 2011). Subsequently, the UK government has encouraged the integration of new technology into traditional healthcare services (Liddell, Adshead & Burgess, 2008).

1.6.1 The use of Smart technology for the management of chronic conditions
Interventions that run on mobile devices, including Smart technology, have been developed to facilitate the self-management of many chronic conditions, including diabetes, heart disease and asthma (Cafazzo, Casselman, Hamming, Katzman, & Palmert, 2012; Klasnja & Pratt, 2012; Seto et al., 2012; Rhee, Allen, Mammen, & Swift, 2014). Studies have found that they may improve patients' biological markers of disease, quality of life, communication with clinicians and family, and adherence to medication, and achieve these positive patient outcomes whilst reducing health service costs (Charpentier et al., 2011; Gammon et al., 2005; Park Howie-Esquivel, Chung & Dracup, 2014; Seto et al., 2012). Following the early indicators of the effectiveness of this type of intervention for other chronic conditions, there has been development of mobile interventions to support patients with cancer. Existing reviews show that the majority of studies are of mobile interventions that support patients during the treatment phase of cancer, with fewer interventions developed to assist prevention, diagnosis, follow up and survivorship (Davoodi, Mohammadzadeh, & Safdari, 2016; Nasi, Cucciniello, & Guerrazzi, 2015; Odeh, Kayyali, Nabhani-Gebara & Philip, 2015). Previous searches of Apple and Android app stores in 2013 indicated that although there is a large number of publically available apps that provide information on cancer, only 55% of these apps provided scientifically validated data, and none appeared to have been systematically developed and evaluated (Bender, Yue, To, Deacken & Jadad, 2013; Nasi et al., 2015; Pandey, Hasan, Dubey & Sarangi, 2013). For these reasons, it was considered prudent to develop an app intervention to help patients with cancer to meet their information needs throughout their illness.

1.7 Involving clinicians in the development of interventions for patients

Although the development of information and communication technologies has rapidly increased within the health service over recent years, they do not yet appear to have become established or commonplace within clinical practice (May, Mort, Williams, Mair & Gask, 2003). A main barrier to the successful implementation of such interventions appears to be a lack of involvement of clinicians in the development and testing stages (Mannan, Murphy & Jones, 2006). Studies that have involved clinicians have reported that clinicians found it difficult to incorporate such technology within their existing practices and other barriers included issues with the content and design of systems, training and confidentiality (Gibson, Aldiss, Taylor, Maguire & Kearney, 2009; Maguire, McCann, Miller, & Kearney, 2008). The perceptions of clinicians are essential to ensure the successful implementation of any new technological interventions that will be used by their patients in clinical practice, such as an app. Additionally, it is important that clinicians review and approve interventions to be used by patients, as patients trust the opinions their clinicians and are therefore likely to trust their endorsement of interventions. For these reasons, cancer clinicians will be involved in the development of an app for this PhD thesis.

1.8 Frameworks to guide development and evaluation of an app intervention
1.8.1 The Medical Research Council (MRC) framework
The MRC framework is a general guide for the development and evaluation of complex interventions to improve health and will be used to guide intervention development for this thesis (Craig et al., 2008). This framework advocates a systematic, phased approach to intervention development and evaluation to ensure researchers fully understand, define and document the development process in order to successfully evaluate the intervention and enable replication, evidence synthesis and wider implementation. Four phases of development and evaluation are outlined, though these may not follow a linear sequence in practice (Figure 1).

During the first phase, 'development', researchers are encouraged to identify the evidence base, relevant theories, model processes and outcomes of the intervention. The development phase of an app intervention for this thesis is reported from Chapters 2 to 6, using primary and secondary data. The second phase, 'feasibility and piloting', encourages initial testing of the acceptability and feasibility of the intervention, prior to a full scale evaluation. A field testing study of the app intervention for this thesis is reported in Chapter 7. Although a feasibility study need not be a scale model of a future evaluation, this study was considered a field testing study and not a feasibility

study as the study did not aim to determine the required sample size for a full-scale evaluation.

The third phase, 'evaluation', involves assessing the effectiveness and cost-effectiveness of the intervention and developing an understanding of the change processes involved. Following evidence of an acceptable, feasible and effective intervention, the final phase of development, 'implementation', is carried out, which involves surveillance and monitoring of the intervention through long term follow up.
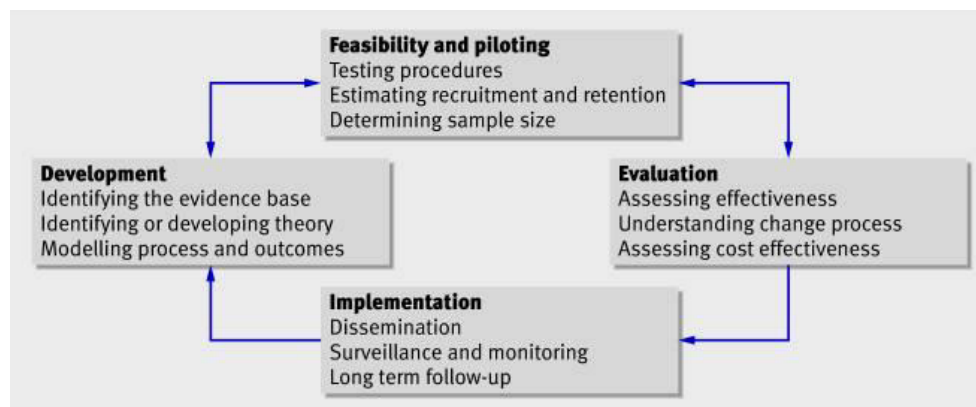
Figure 1: *Key elements of the MRC framework for development and evaluation of complex interventions [source: Craig et al., 2008].*

1.8.2 Frameworks for the development and evaluation of app interventions

A scoping review of early-phase studies of app development for chronic conditions revealed that many studies have employed a user-centered, phased approach or philosophy, similar to the MRC framework (Craig et al., 2008), which includes the iterative involvement of patients in the development and user-testing stages, as well as consultation with clinicians, using qualitative research methods, such as interviews and focus groups (Cafazzo et al., 2012; Whittaker, Merry, Dorey & Maddison, 2012). Additionally, with the growing body of literature on digital health interventions, specific models and frameworks to guide development and evaluation of mobile interventions have been developed. These specific frameworks serve to increase rigor of such studies and facilitate the translation of literature into replicable and evidence-based mobile interventions that can be systematically evaluated, used and adapted to health care settings. It is important to use such frameworks to guide intervention development if studies are to contribute to the evidence base on which interventions (and components) are effective, for which population groups, and in which settings, to achieve desired outcomes.

The MRC framework (Craig et al., 2008) therefore provides a suitable overarching framework for the early-phase development of an app intervention for this thesis, whereas a framework that is specific to the development and evaluation of mobile interventions will be most useful following results of a field testing study, when more detailed information of the intervention has come to light, such as its potential outcomes. However, several specific models and frameworks for the design and development of app interventions were taken into consideration in this thesis, where appropriate. These include the 'person-centred' approach for digital health-related behaviour change (Yardley, Morrison, Bradbury & Muller, 2015), the Chronic Disease mHealth App Intervention Design Framework (Wilhide III, Peeples, & Kouyaté, 2016), the Technology Acceptance Model (TAM) (Davis, 1989; Venkatesh & Bala, 2008), the Health IT Usability Evaluation Model (Health-ITUEM) (Brown, Yen, Rojas & Schnall, 2013) and the People At the Centre of Mobile Application Development (PACMAD) model (Harrison, Flood & Duce, 2013). The CONSORT-EHEALTH checklist, an adapted checklist to improve the reporting standards and level of detail provided specifically for randomised and non-randomised trials of web- and mobile-based interventions, was also used to guide the reporting of the studies in this thesis (Eysenbach, 2012).

1.9 Aims and objectives of this thesis

The primary aims of this thesis were: (1) to understand the needs and preferences of patients with cancer regarding an app to help them to meet their information needs in non-inpatient settings, and (2) to develop an app intervention for patients, based on identified needs and preferences, which may also be used by relatives. Based on existing literature, it was hypothesised that an app could help patients with cancer, and their relatives, to meet their information needs by facilitating information-gathering and understanding during and between consultations with clinicians.

There were six objectives of this PhD:
(1) Identify how mobile devices have previously been used to help patients with cancer to meet their information needs in non-inpatient settings.
(2) Identify potentially relevant theory related to the impact of and self-management of cancer.
(3) Explore patients' (and their relatives') needs and preferences regarding an app to help them to meet their information needs and the reasons for these perceptions.

(4) Explore cancer clinicians' opinions on the value of an app for patients with cancer and their relatives, their preferences for app features and reasons for these perceptions.

(5) Design an app intervention based on the identified needs and preferences of patients and their relatives and opinions of clinicians.

(6) Conduct a field test of the app with patients in the community to assess its acceptability and feasibility in practice.

Each phase of work presented in this thesis was guided by two phases of the MRC framework (Craig et al., 2008). Phase one, which involved the development of the intervention, included a systematic review of the use of mobile devices to help patients with cancer to meet their information needs, a review of potentially relevant theories related to the impact and self-management of cancer, and a qualitative exploration of patients' and their relatives' information needs and experiences of information exchange in consultations, as well as their preferences regarding an app intervention. A qualitative exploration of cancer clinicians' views on these topics was also conducted. An app was then created based on the findings of this body of work. Phase two consisted of user-testing an initial version of the app in a discussion group of patients, followed by final refinements of the app to produce a final version. A field testing study was then conducted with a sample of patients to test the acceptability and feasibility of the app in a real life setting. Figure 2 presents an outline of the work conducted for this thesis according to the phases of MRC framework and aims of the PhD.
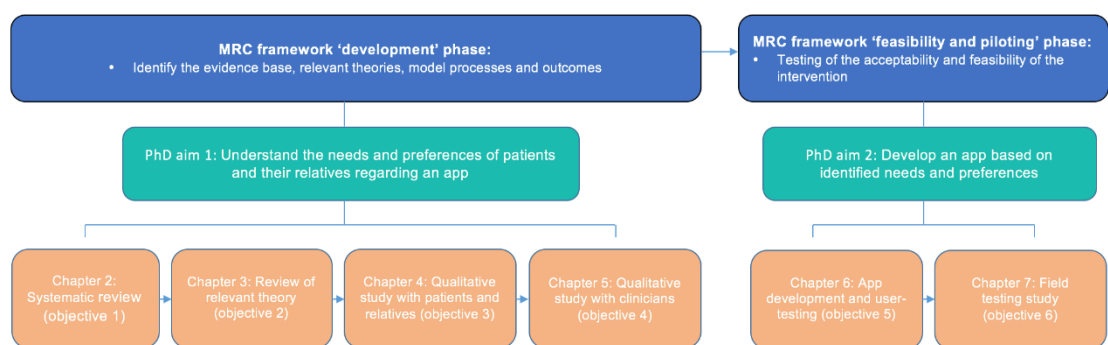
Figure 2: *An outline of the work presented in this thesis, according the aims of the PhD and phases of the MRC framework*.

1.10 Thesis structure

Chapter 2

Chapter 2 describes a systematic review of the literature which identified how mobile devices had previously been used to help patients with cancer to meet their information needs in non-inpatient settings. This review was conducted to establish the need for an app that enables patients to meet their information needs and the acceptability and feasibility of this type of intervention.

Chapter 3

Chapter 3 presents a review and critical appraisal of a selection of health behaviour models, theories and approaches that are relevant to the impact of cancer on patients and their self-management of the condition. This review was conducted to gain theoretical understandings of patients' experiences of cancer, the type of app that might best support them and the changes that may be expected as a result of this type of intervention.

Chapter 4

Chapter 4 presents the findings from a qualitative interview study with cancer patients and their relatives. Interviews explored patients' information needs and experiences of information exchange with clinicians in cancer consultations, and their needs and preferences regarding an app that aims to help them to meet their information needs.

Chapter 5

Chapter 5 presents findings from a qualitative interview study with cancer clinicians, including cancer nurse specialists, oncologists and surgeons. Interviews explored clinicians' experiences of information exchange with patients in consultations and their opinions on the value of an app for patients with cancer. This study also explored clinicians' preferences for app features.

Chapter 6

Chapter 6 describes the systematic process that was used to create an app intervention for patients with cancer, based on findings from Chapters 2-5 and consultation with a digital software team and clinical supervisors. This chapter also reports on 'in-house' testing of the app and user-testing with a group of patients. The final design and content of the app is presented.

Chapter 7

Chapter 7 reports findings from a field testing study, which involved a sample of patients using the app in community settings, running up to and during a consultation with their clinicians. Qualitative interviews explored patients' experiences of using, and opinions on, the app, including the acceptability and feasibility of the app, the usefulness of the app features, and the perceived benefits and disadvantages of, and barriers to, using the app in practice. This chapter also reports on the findings of software-logged app activity data.

Chapter 8

Chapter 8 summarises the key findings of this thesis, in relation to relevant literature, and highlights its novel contributions to existing knowledge. Methodological strengths and limitations of this thesis are discussed. Suggestions for further research are provided and the potential evaluation and implementation of the app are discussed.

Chapter 2
The use of mobile devices to help patients with cancer to meet their information needs in non-inpatient settings: a systematic review

2.1 Chapter overview

This chapter presents a systematic review of literature that was conducted to identify how mobile devices, such as mobile phones and tablets, have previously been used to help patients with cancer to meet their information needs in non-inpatient settings. Non-inpatient settings include at home, in the community, outpatient settings and consultations. Several existing systematic and scoping reviews have previously explored the general use of mobile devices for patients with cancer (Bender et al., 2013; Davis & Oakley-Girvan, 2015; Davoodi et al, 2016; Hesse, Beckjord, Rutten, Fagerlin, & Cameron, 2015; Nasi et al., 2015; Odeh, Kayyali, Nabhani-Gebara, & Philip, 2015; Pandey et al., 2013). Findings from these reviews showed that mobile interventions have been developed for a range of purposes, including for the prevention, detection, and management of cancer, however most interventions have aimed to support patients during the treatment phase of cancer, with fewer interventions developed to assist prevention, diagnosis, follow up and survivorship. There has not yet been a review that identifies how mobile interventions have been used to help patients with cancer to meet their information needs in non-inpatient settings.

2.1.1 Aims of the present study

The aim of the research described in this chapter is to conduct a novel systematic review to identify and critically evaluate literature that describes the use of mobile interventions to enable cancer patients to meet their information needs in non-inpatient settings, and to describe the effects and feasibility of this type of intervention. The findings of this review will be used to inform the development of an app intervention for patients with cancer.

2.2. Systematic review methods

A systematic review involves five stages in order to be deemed 'systematic', which include: (1) a fixed, clearly defined and prospectively developed research question, (2) identification of relevant studies, (3) a quality appraisal of included studies, (4) a summary of the evidence, and (5) interpretation of the findings (Khan, Kunz, Kleijnen, & Antes, 2003). All stages are required to be double checked by a second independent coder to reduce any potential bias during selection of the included studies, quality

appraisal and data analysis (Khan et al., 2003). Due to the efforts taken to reduce potential bias and the transparency of the methods used, systematic reviews are regarded as the highest level of evidence (Khan et al., 2003). It is this systematic approach that distinguishes this type of review from others, such as scoping reviews. Systematic review methodology was selected for the present review to provide a high strength summary of the evidence.

2.3 Method

This systematic review followed the PRISMA guidelines for the conduct of systematic reviews (Moher, Liberati, Tetzlaff, & Altman, 2009). The review was registered on the International Prospective Register of Systematic Reviews (PROSPERO) to prevent duplication (registration number: CRD42014010614). At all stages of the search, data extraction and quality appraisal, 10% of studies were double checked for consistency by another PhD student. All discrepancies were resolved through discussion.

2.3.1 Search strategy

A systematic search of titles and abstracts was conducted in MEDLINE (1946-2017), EMBASE (1947-2017) and PsychINFO (1806-2017) databases in January 2017. Advice was sought from a subject librarian on developing a suitable search strategy. Search terms focused on three concepts of the review question: *'mobile devices', 'information needs'* and *'cancer'* (Appendix 1). Terms relating to the same concept were combined using the Boolean operator 'OR' and different concepts were combined using 'AND'. Duplicates were electronically removed using the OVID de-duplicate function prior to review of abstracts. Titles and abstracts of citations were screened for appropriate studies. References of included articles were searched for further studies. The aim of this review was to assess data on the effects and feasibility of this type of intervention, provided by empirical studies. Prior to the search, it was therefore decided that grey literature would not be searched as these studies are not peer-reviewed and are unlikely to contain empirical data.

2.3.2 Inclusion criteria

Identification of studies included a four stage process of identification, screening, eligibility and inclusion (Moher et al., 2009) (Figure 3). In order to be as inclusive as possible, there were no restrictions on study methodology or date of publication, however searches were limited to include only human studies and those written in English. Included studies were required to meet the following criteria:

<blockquote>
<dl>
<dt>i.</dt>
<dd>Interventions delivered by a mobile or handheld device (e.g. mobile phone, personal digital assistant)</dd>
<dt>ii.</dt>
<dd>Primary participants are patients with cancer who are currently undergoing treatment</dd>
<dt>iii.</dt>
<dd>Interventions are for use in non-inpatient settings, or non-inpatient *and* inpatient settings</dd>
<dt>iv.</dt>
<dd>Interventions attempt to meet patients' cancer-related information needs</dd>
</dl>
</blockquote>

Only those participants who currently had cancer were included in this review as cancer survivors may have different information needs to those who are currently undergoing treatment for cancer. The aim of this thesis is to develop an app to support patients following a diagnosis of cancer, when their information needs are greatest and an intervention may have the greatest impact on their adjustment and self-management of their condition (Rutten et al., 2005). Additionally, this review will include interventions that are used to support patients in non-inpatient settings, as this is where patients are now primarily managed for the majority of their time during their illness and require additional support.

2.3.3 Exclusion criteria

Studies were excluded from the review based on the following criteria:

<blockquote>
<dl>
<dt>i.</dt>
<dd>Non-human studies</dd>
<dt>ii.</dt>
<dd>Studies not written in English</dd>
<dt>iii.</dt>
<dd>Studies not published in peer-reviewed journals</dd>
<dt>iv.</dt>
<dd>Studies not relevant to the research question</dd>
<dt>v.</dt>
<dd>Studies that do not provide sufficient information on the mobile intervention/disease type to be adequately reviewed</dd>
<dt>vi.</dt>
<dd>Studies that only provide a description of the intervention/creation of the intervention</dd>
<dt>vii.</dt>
<dd>Studies of only health professional/caregiver perceptions of a mobile intervention for patients with cancer</dd>
<dt>viii.</dt>
<dd>Studies of cancer survivors who have ceased treatment</dd>
<dt>ix.</dt>
<dd>Use of mobile intervention is in inpatient settings only</dd>
<dt>x.</dt>
<dd>Interventions are a method of data collection only and not interactive (e.g. used to collect questionnaire data)</dd>
<dt>xi.</dt>
<dd>Interventions do not focus on provision or exchange of information to support self-management (e.g. weight loss interventions)</dd>
</dl>
</blockquote>

xii.   Studies conducted in lower income countries

xiii.   Not an original research study (e.g. review articles)

xiv.   Conference abstracts or articles

Many studies were excluded for multiple reasons, however only one main reason was documented (Figure 3).

2.3.4 Data extraction and synthesis

Data were extracted onto a template under the following headings; research identification (authors, year of publication, country of study sample, study population), intervention (intervention type, mobile device type), research methods (study design, method, data analysis), outcome measures, principal findings, and quality appraisal. Due to a lack of suitable data, a meta-analysis was not conducted. A narrative synthesis was performed and organised by common themes found across studies (Popay et al., 2006).

2.3.5 Quality appraisal

Included studies were assessed for methodological quality using the Critical Appraisal Skills Programme (CASP) checklists for quantitative and qualitative research (CASP, 2014) (Appendix 2). The quality of each study was assessed according to each domain included in the checklists, including methodology, design, recruitment, data collection, data analysis, ethical issues, reporting of findings and contribution to research. The overall quality of the studies was categorised as good, medium or poor. This review will focus on the findings of studies that are appraised as 'good' or 'medium' quality, however studies that are appraised as 'poor' quality will also be referenced where appropriate.
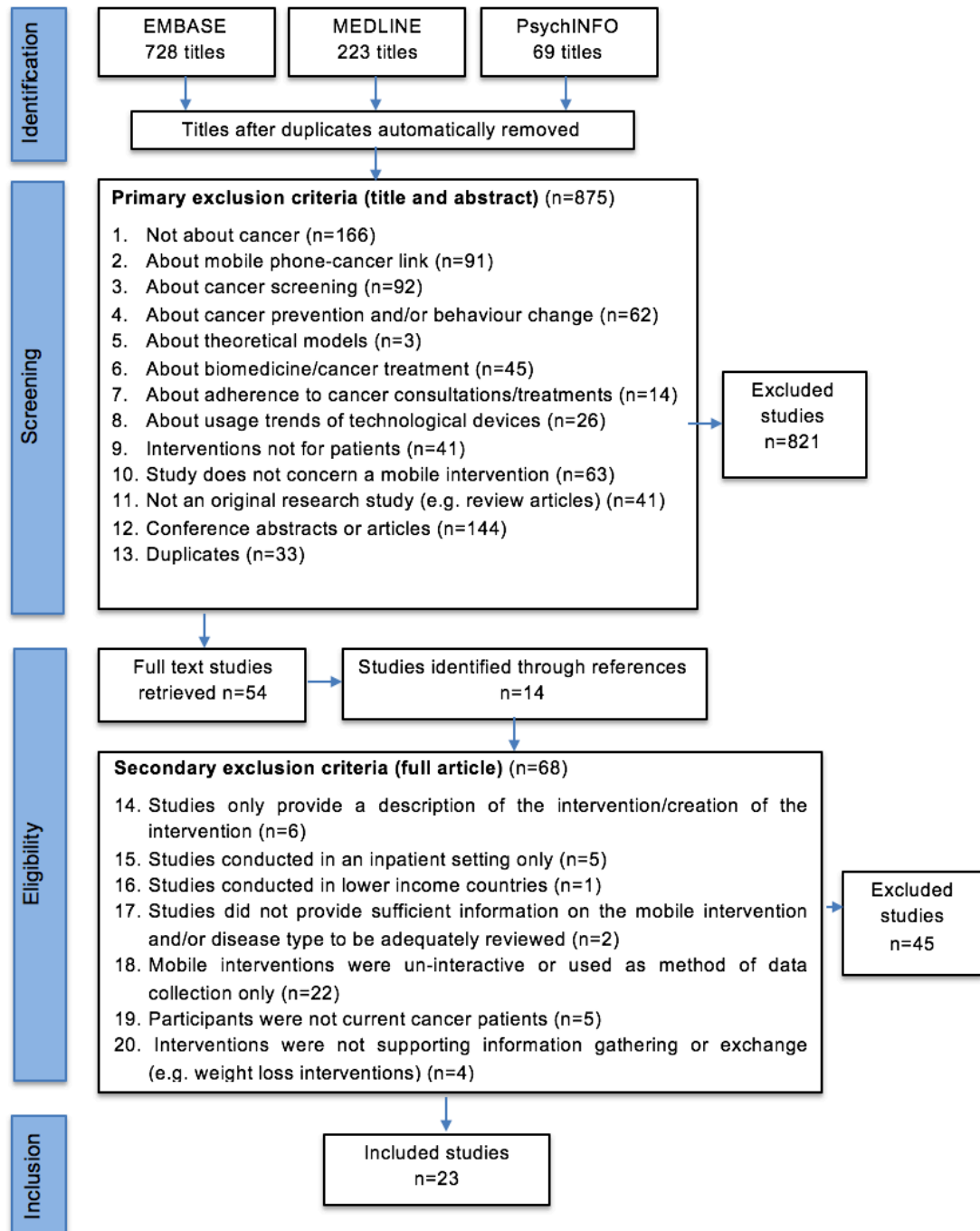
Figure 3: *PRISMA flowchart.*

2.4 Results

Searches during the identification stage generated 1,020 citations. A total of 54 articles were considered appropriate for eligibility screening and an additional 14 articles were identified through references. The full-texts of these 68 articles were screened using the secondary inclusion and exclusion criteria, which resulted in the exclusion of a further 45 articles.

2.4.1 Description of studies

A total of 20 studies were described by the 23 included articles (Table 1). Within these 20 studies, 14 different interventions were identified. The Advanced Symptom Management System (ASyMS) was used in six studies (described by nine of the 22 articles) and the Cancer Care Home Telehealth intervention (CCHT) was used in two studies (described by two of the 22 articles). The remaining 12 articles described 12 separate intervention studies. Of the 23 articles, there were 13 early-phase feasibility studies, one full RCT, three pilot RCTs, three process evaluations, one matched-case control study, a secondary qualitative analysis of data generated by a RCT included in this review and an analysis of software-logged data from a feasibility study included in this review. Sample sizes of patients ranged from n= 4-125, with 13 studies consisting of 25 participants or less. Two studies were categorised as good quality, 12 were of medium quality and nine were of poor quality.

2.4.2 Sample characteristics

Patients with a wide range of cancer types were included in studies. A total of 17 studies were of adult patients and three studies were of adolescent patients. Ages of adult patients ranged between 24-87 years and ages of adolescent participants ranged from 8-18 years. Six studies reported the race and/or ethnicity of participants; in four studies, the vast majority of participants were white with a minority of black participants (three of which specified African American), one study reported a majority of Hispanic-White participants and the remaining study reported a majority of Chinese participants. Nineteen studies included non-inpatient participants only. Nine studies provided participants with a mobile device on entry to the study, a further four studies provided devices for participants but participants needed to have a telephone landline in order to participate, two studies required participants to own a mobile device and five studies failed to report whether participants were required to own a mobile device in order to participate in the study or whether a device was provided for the study period. It is also worth noting that one study that provided a mobile device for participants only included those who were 'able and willing' to use a mobile device and another study excluded participants if they had poor proficiency with the device.

2.4.3 Description of the interventions

Ten interventions were run on mobile phones; nine of which used Smartphones. One intervention that required participants to use their own mobile phone for the study included both Smartphones and non-Smartphones (Yap et al., 2013). Four interventions were run on tablets and two were run on a Personal Digital Assistant (PDA; a palmtop computer that functions as a personal organiser but also provides access to the Internet). A further four interventions were run on 'handheld devices' which were attached to the participant's telephone line. Studies that used a handheld device did not report the functions of this type of mobile device, however these devices are typically the most limited device type in terms of functions. Studies published from 2013 onwards used more advanced Smartphones and tablets that are commonly used today, such as iPhones and iPads.

All interventions were for patients use only and did not aim to support relatives simultaneously. Two interventions primarily aimed to directly increase patients' knowledge; one intervention provided information on patients' upcoming surgical operation and one intervention educated patients on cancer-related pain-coping skills. One further intervention study primarily aimed to improve patients' communication of symptoms to clinicians in consultations, thereby facilitating information exchange. The primary aim of the remaining seventeen intervention studies was to improve the monitoring and management of treatment-related symptoms. These interventions provided treatment-related self-care information following patients' symptom reports and/or included a system where clinicians would be alerted to contact patients and exchange symptom-related information in order to manage severe symptoms. One of these seventeen interventions also provided cognitive and behavioural skills training in non-pharmacological pain management strategies. Study periods ranged from five days to six months, however some study periods may have been longer due to the individual duration of participants' treatment, which were not reported.

Table 1: *Characteristics of included studies.*

Study	Author	Study population	Intervention	Methods	Outcome measures	Principal findings	Quality score
1	Kearney et al., 2009	112 adult patients. Breast, lung or colorectal cancer. Mean age 56 years. UK. No information on race/ethnicity.	Mobile phone, symptom-monitoring for four weeks of chemotherapy (12-16 weeks). Provision of device unknown.	Quantitative, RCT. Logistic regression.	Incidence, severity and distress of six chemotherapy-related symptoms (nausea, vomiting, fatigue, mucositis, hand/foot syndrome, diarrhoea).	Significantly lower reports of fatigue (p=0.04) and higher reports of hand/foot syndrome (p=0.031) in intervention vs control group. Reports of severity (p=0.033) and distress (p=0.028) associated with hand/foot syndrome were also significantly higher in intervention vs control group.	Medium
	McCann et al., 2009	53 adult patients from the intervention arm of Kearney et al. (2009). Breast, lung or colorectal cancer. Mean age approx. 55 years. UK. No information on race/ethnicity.	""	Mixed methods, process evaluation. Semi-structured questionnaires, semi-structured interviews. Descriptive statistics, thematic content analysis.	Patients' perceptions of the intervention	Patients had positive expectations and experiences of study participation. Some patients (n=13, 36%) experienced some issues when sending symptom reports, however this was rare. Patients found the technology and intervention to be acceptable and were all felt comfortable using it. Most patients reported a perceived improvement in symptom management (n=33, 91%) and patients commented that it had improved communication with their clinicians. Patients also perceived that the alerting facility gave them a sense of reassurance.	Medium

	Forbat et al., 2009	12 adult patients from intervention arm of Kearney et al. (2009). Colorectal and breast cancer. Mean age 50 years, age range 38-66 years. UK. No information on race/ethnicity.	""	Qualitative, secondary analysis. Semi-structured interviews. Foucauldian approach with focus on surveillance and power.	Patients' perceptions of the intervention	Patients perceived that the system improved access to and increased communication with clinicians. Patients found the alerting facility reassuring and suggested the system empowered patients to become more active and created a sense of control.	Medium
2	Maguire et al., 2005	10 adult patients. Breast and lung cancer. Age range 44-74 years. UK. No information on race/ethnicity.	Mobile phone, symptom-monitoring for two weeks. Provision of device unknown.	Mixed methods, process evaluation (from pilot RCT). Semi-structured questionnaires, semi-structured interviews. Descriptive statistics, thematic content analysis.	Patients' perceptions of the intervention	Patients had positive experiences of study participation. Most patients (n=3, 75%) felt comfortable using the intervention and no patients reported any technical issues. All patients (n=4, 100%) perceived that the intervention improved their management of their symptoms and communication with their clinicians. Patients commented that they felt reassured due to being monitored by clinicians.	Poor
3	Kearney et al., 2006	15 adult patients. Lung and colorectal cancer. Age range 24-77 years. UK. No information on race/ethnicity.	Handheld device, symptom-monitoring for two cycles of chemotherapy (approx. 6-8 weeks). Access to home	Mixed methods, feasibility study. Semi-structured questionnaires, semi-structured interviews, software log of activity (reported in McGee and Gray (2005)).	Patients' perceptions of the intervention	Patients had positive experiences of study participation. All patients commented that they felt comfortable using the device. Most patients perceived an improvement in symptom monitoring and self-management (n=10, 91%) and communication with their clinicians (n=8, 73%). Patients also commented that the intervention empowered them	Medium

		telephone line required.		Descriptive statistics, thematic content analysis.		to feel more confident in managing symptoms by improving their knowledge and confidence.	
	McGee et al., 2005	""	""	Software log of activity, descriptive statistics.	Software-logged activity; modem events, questionnaire events, and information access events.	All but one patient (n=17, 94%) had difficulty trying to connect and send session data to the server but attitudinal data did not reflect this. Symptom questionnaire use, access to self-care advice and use of information pages greatly varied. All but one patient accessed these facilities at some point during the trial.	Medium
4	Aldiss et al., 2011	4 adolescent patients. Non-Hodgkins lymphoma and osteosarcoma. Age range 13-15 years. UK. No information on race/ethnicity.	PDA, symptom-monitoring for one cycle of chemotherapy (2 weeks). Mobile device provided.	Mixed methods, pilot RCT. Semi-structured questionnaires, interviews. Narrative summary of results due to small number of participants.	Patients' perceptions of the intervention	Patients commented that communication had improved with their clinicians and that the self-care advice was acceptable. One patient felt the intervention was helpful in monitoring symptoms, however one patient suggested that a longer time period was needed to capture the real-time symptom experience.	Poor

5	McCall et al., 2008	21 adult patients receiving palliative care. Breast, prostate, oral, respiratory, GI/colorectal, gynaecology, myeloma, unknown primary cancers. Mean age 64 years, age range 40-87 years. UK. No information on race/ethnicity.	Mobile phone, symptom-monitoring for 30 days. Provision of device unknown.	Mixed methods, feasibility study. Questionnaires, semi-structured interviews. Descriptive statistics, thematic analysis.	Patients' perceptions of the intervention	Patients had positive experiences of study participation. All patients felt comfortable (n=6, 46%) or very comfortable (n=7, 54%) using the intervention, however some required assistance from family members due to poor physical state (n=5, 38%). Most patients (n=9, 69%) felt the intervention improved symptom monitoring and communication of symptoms to their clinicians. Patients commented that the self-care advice, graphs and information provided by the intervention was fairly useful.	Poor
6	Chumbler et al., 2007a	125 adult patients. Lung, head and neck, colorectal, other cancers. Mean age 63 years. US. No information on race/ethnicity.	Handheld device, symptom-monitoring for six months. Access to home telephone line required.	Quantitative, matched-case control study. Electronic medical records. Multivariate regression.	Number of preventable service uses (unplanned clinical visits) and cancer-related service uses (expected clinical visits) over a six-month period	There was significantly lower use of preventable services in the intervention vs control groups (p=0.01). There were also significantly higher rates for use of some expected, cancer-related services in the intervention vs control groups (p=0.01), except for clinic visits, where patients in the intervention group had significantly fewer expected clinic visits compared to controls (p=0.01).	Medium

| 7 | Chumbler et al., 2007b | 48 adult patients. Lung, head and neck, colorectal, other cancers. Mean age 64 years. US. 91% White, 9% African American. | Handheld device, symptom-monitoring for six months. Access to home telephone line required. | Quantitative, feasibility study. Questionnaires, medical records. Descriptive statistics, linear mixed regression. | Patients' cooperation with the intervention (adherence) and health-related quality of life during cancer treatment | Mean cooperation rate was 84% (range 4-100%) and this remained high over the six month period. No variables were significantly associated with patient cooperation. There was a significant 6.45-point increase in HRQOL score between baseline and end of treatment (95% CI, 65-11.88). Patients who reported nervousness/worry symptoms during treatment experienced an average of 8.86 points significant increase in HRQOL (95% CI, 2.08-15.64). | Good |
| 8 | Post et al., 2013 | 60 adult patients. Breast cancer. Mean age 51 years. US. 84% White, 16% African American. | PDA, symptom communication with clinicians, for 160 days (around 5 months). Provision of device unknown. | Mixed methods, pilot RCT. Questionnaires, focus groups, and interviews. Descriptive statistics, random-effects linear regression, qualitative analysis. | Effects of the intervention on pain, fatigue and depression symptoms, patients' and healthcare professionals' perceptions of the intervention and patients' HRQOL and communication self-efficacy | Intervention group reported significantly lower average pain severity over time compared to the control group (p=0.02). Patients and healthcare professionals reported positive experiences of the intervention. Mean pre-post decreases in HRQOL were generally higher among intervention group. Pre-post changes in communication self-efficacy were equivalent. | Poor |

9	Weaver et al., 2007	6 adult patients. Colon cancer. Age range 54-76 years, median age 64 years. UK. No information on race/ethnicity.	Mobile phone, symptom-monitoring for two cycles of chemotherapy (approx. 6-8 weeks). Mobile device provided.	Mixed methods, feasibility study. Informal interviews. Descriptive statistics, narrative summary of results due to informal nature of interviews.	Number of alerts generated and reasons for alerts/responses to alerts, patients' perceptions of the intervention	Data entry compliance was 98%. There were 91 alerts, 54 red and 37 amber; 54% of the red alerts were data delay and transmission problems. All patients (n=6) had positive experiences of study participation and found the intervention simple to use. All patients commented that they felt reassured due to their symptoms being monitored and all felt involved and responsible for their care.	Poor
10	Yap et al., 2013	68 adult patients. Breast, GI, head & neck, lung, lymphoma, ovarian, cervical, bladder cancers. Median age 50 years. Singapore. 68% Chinese, 25% Malay, 3% Indian, 2% other.	Mobile phone, symptom-monitoring for five days. Access to own mobile device required.	Mixed methods, feasibility study. Semi-structured telephone questionnaire. Descriptive statistics, Pearson's chi-squared and Fisher's exact tests, qualitative analysis.	Study feasibility measured by patients' adherence to the intervention, patient satisfaction and number of pharmacists' interventions	Patients found the intervention acceptable. A total of 44 patients (73%) were adherent over five days of monitoring. Adherence was significantly higher among smartphone users vs. basic phone users (p=0.001). Most patients (n=54, 90%) of patients were comfortable with the duration of the intervention, especially smartphone users (p=0.017) and adherent patients (p=0.038), however 15% (n=9) found the intervention too difficult or complicated. Over half of patients (n=37, 62%) found the SMS advice useful, especially those with lower education (p=0.003) and chemo-naive patients (p=0.045). Most patients (n=43, 72%) agreed that the service made it easier to contact pharmacists.	Medium

11	Head et al., 2011	44 adult patients. Head and neck cancers. Mean age 59 years. US. 91% White, 9% African American.	Handheld device, symptom-monitoring for the duration of treatment, average 70 days (around 10 weeks). Access to home telephone line required.	Mixed methods, process evaluation (from a RCT). Interviews, telephone questionnaires. Descriptive statistics, correlation analysis, descriptive qualitative analysis.	Feasibility of the intervention, patient perceptions, satisfaction and acceptance, and long-term impact of intervention	Patients completed the intervention over 86% (average of 70 days) of the expected days of use with a median and modal percentage use of 94% and 100%, respectively. Most patients (n=37, 85%) had a positive experience using the device and 80% (n=35) were satisfied with the intervention. Patients commented that the intervention provided needed information and improved management of their condition. Significant positive correlations were found between percentage use of the intervention and the physical (p=0.048) and emotional (p=0.042) well-being scores during treatment. A long-term follow up survey showed that 65% (n=13) patients felt they had better care as a result of the intervention	Medium
12	Stinson et al., 2013	14 adolescent patients. ALL, AML, Ewing's sarcoma, non-Hodgkin's lymphoma, osteosarcoma, rhabdomyo-sarcoma, other. Mean age 13 years. Canada. No information on race/ethnicity.	Mobile phone, pain-related symptom-monitoring for two weeks. Mobile device provided.	Mixed methods, feasibility study. Semi-structured questionnaires. Descriptive statistics, t tests.	Feasibility and patients' perceptions of the intervention	Patients found the app to be acceptable. Almost all (n=12, 86%) liked the app and 11 (79%) patients found the app easy to use. All bar one patient (n=13, 93%) reported that the app did not interfere with their daily activities. The mean rate of adherence was 81% and there were no differences in adherence across the day, time of week or between week one and week two of the study period.	Poor

13	Weaver et al., 2014	26 adult patients. Breast, colorectal cancers. Mean age 57 years. UK. No information on race/ethnicity.	Mobile phone, symptom monitoring for approx. five cycles of chemotherapy. Mobile device provided (participants required to be able to use device).	Mixed methods, feasibility study. Questionnaires, interviews. Descriptive statistics, thematic analysis.	Toxicities and treatment., management of toxicities, summaries of advice generated by the app, number of alerts, perceptions of the intervention.	Ten patients were advised to be admitted to hospital by the nurse to be treated for severe toxicities. A total of 1,954 alerts were generated, a median of 103 alerts per patient, however only 25% of these were genuine toxicity alerts. Patients commented that real-time monitoring made them feel safe and were reassured by the fast response of the nurse. Patients also commented that their confidence to self-manage their toxicities had improved.	Medium
14	Somers et al., 2015	25 adult patients. Breast, lung, colorectal, prostate cancers. Mean age 53 years. US. 76% White, 24% Black.	Tablet, pain coping skills. Four sessions (30-45 minutes). Mobile device provided.	Mixed methods, feasibility study. Questionnaires, qualitative data collection method not specified. Descriptive statistics, paired sample t-tests.	Pain severity, physical functioning, physical symptoms, psychological distress, self-efficacy for pain management, pain catastrophizing.	Patients rated the intervention as good or excellent (n=13, 62%), were very satisfied (n=14, 67%) or mostly satisfied (n=7, 33%) with the programme and all received the information and skills that they wanted. Most patients (n=19, 92.5%) said that it helped their pain management. Patients reported significantly decreased pain severity (p=0.009), physical symptoms (p=0.001), psychological distress (p<0.001) and pain catastrophising (p=0.005) following the intervention. The mean score on pain self-efficacy also increased but was not of statistical significance.	Poor

15	Sundberg et al., 2015	9 adult patients. Prostate cancer. Mean age 69 years. Sweden. No information on race/ethnicity.	Mobile phone, symptom monitoring for two weeks. Mobile device provided.	Mixed methods, feasibility study. Focus group, interviews. Descriptive statistics, content analysis.	Software logged data, patient perceptions of ease of use and feasibility	A total of 59 symptom alerts were sent and patients commented that they found the alert system to be helpful. The self-care advice was accessed by most patients (n=8, 85%), and those who did found it useful. Only some patients commented that they accessed links for further information but all patients suggested the potential usefulness of this function. No technical problems were experienced during the study. All patients found the app easy to use and understand. Patients commented that symptom reporting via a mobile device was acceptable and they felt reassured.	Medium
16	Maguire et al., 2015	16 adult patients. Lung cancer. Mean age 64 years. UK. No information on race/ethnicity.	Mobile phone, symptom monitoring for duration of radiotherapy treatment plus one month post-treatment. Provision of device unknown.	Mixed-methods, feasibility study. Semi-structured questionnaires, semi-structured interviews. Descriptive statistics, t-tests, Mann-Whitney U tests, 1-way ANOVA tests, Kruskal-Wallis tests, Fisher Exact tests, Wilcoxon signed ranks tests, McNemar tests, thematic	Perceptions of the feasibility and acceptability of the intervention, anxiety, self-care self-efficacy, well-being, quality of life, physical symptom distress.	All or nearly all patients (n=10, 100%) reported that they never or very rarely experienced problems in using the mobile device. All (n=9, 100%) felt that the intervention helped to manage their symptoms and communicate with their doctors and nurses. Patients commented that they felt reassured by the monitoring of symptoms by healthcare professionals and felt that the intervention reduced their uncertainty on whether to contact their clinician if needed. No statistically significant improvements in patient anxiety, wellbeing, self-care, or self-efficacy were found.	Good

analysis.

17	Dawes et al., 2015	20 adult patients, 18 of which had colorectal cancers. Median age 58 years. US. No information on race/ethnicity.	Tablet computer, symptom monitoring for 6-24 days, depending on time between operation and clinic visit. Mobile device provided (participants excluded for poor proficiency).	Mixed methods, feasibility study. Questionnaires. Descriptive statistics, qualitative data was summarized narratively.	Compliance with data entry, symptom monitoring, patient perceptions of the intervention.	Compliance with the intervention was 63% (ranging from 26-100% over 166 of the 265 monitored days). Post-operative monitoring of patients appeared feasible and provided more detailed and complete information to the clinical team. Patients commented that the intervention was helpful, aided in their recovery and improved communication and the relationship with their clinicians.	Poor
18	Besse et al., 2016	9 adult patients. GI, lung, pancreatic, urogenital cancers, osteosarcoma, unknown/other cancers. Mean age 58 years. Netherlands.	Mobile phone, pain monitoring for four weeks. Access to own mobile device required.	Quantitative, feasibility study. Questionnaires. Paired t-tests.	Quality of life, satisfaction with the intervention, pain course and treatment adaptations.	Patients were satisfied with the intervention and did not consider it too burdensome, time consuming or an intrusion of their privacy. Most patients (n=7, 78%) considered the telephone response and therapeutic advice given by the researcher if their pain was clinically significant as useful. Overall, pain scores decreased significantly (p=0.047) and quality of life increased but was not of statistical	Medium

		No information on race/ethnicity.				significance.	
19	Fortier et al., 2016	12 adolescent patients. Leukemia, tumours of the central nervous system. Mean age 12 years. US. Hispanic-White (75%).	Tablet, pain monitoring for ten days. Mobile device provided.	Quantitative, feasibility study. Questionnaires. Descriptive statistics, Wilcoxon signed rank tests.	Patient perceptions of content and usability, general symptom assessment, pain assessment, pain-related coping strategies.	Patients were highly satisfied with the app and perceived it to be useful. Pain and appetite disturbances were the most frequently reported symptoms. Nine symptom rating entries from three patients triggered an alert to a healthcare professional, eight of which were due to pain. Patients who experienced pain reported that the pain-related skills training were useful, in particular the positive self-talk, belly breathing and distraction techniques.	Poor
20	Foley et al., 2016	39 adult patients. Breast cancer. Median age in intervention group 54 years. Ireland. No information on race/ethnicity.	Tablet, information provision prior to surgery. One week. Mobile device provided.	Quantitative, pilot RCT. Questionnaires. Mann-Whitney tests, Fischer's Exact tests.	Mental adjustment to cancer, anxiety, depression, familiarity with technology, satisfaction with information.	Anxiety was significantly lower in the control group at 7 days post operation (p=0.029). There was a significant difference in the intervention group in 1 of the 5 domains of mental adjustment to cancer, pre-operative fatalism, which is a mal-adaptive coping response (p=0.004). Information satisfaction was similar between groups and overall, both groups rated the information they received as either good or excellent.	Medium

2.4.4 Themes

Findings from the narrative synthesis were organised into two main themes: (1) acceptability of the interventions, which included the subthemes of perceived usefulness, perceived ease of use, and adherence to interventions, and (2) benefits of the interventions, which included the subthemes of symptom management, patient empowerment, reduced anxiety, patient-clinician communication and health-related quality of life.

Theme 1: Acceptability

Subtheme 1a: Perceived usefulness

The mobile interventions were perceived as useful by the majority of patients, particularly the self-care advice provided in response to symptom entries (Besse et al., 2016; Forbat, Maguire, McCann, Illingworth, & Kearney, 2009; Fortier, Chung, Martinez, Gago-Masague & Sender, 2016; Head et al., 2011; Kearney et al., 2006; Maguire et al., 2005; 2015; McCall et al., 2008; McCann et al., 2009; Sundberg et al., 2015; Weaver et al., 2014; Yap et al., 2013). Qualitative interviews with patients who took part in a RCT reported that the information provided them with expectations for their treatment, reminded them to watch for symptoms and suggested helpful home remedies (Head et al., 2011). Qualitative interviews from another RCT showed that patients also felt positively about the real-time, fast response of the clinician-alerting facility (McCann et al., 2009). However, interviews from a feasibility study found that some patients felt that the depth of the information available was insufficient and repetitive (Kearney et al., 2006) and two feasibility studies revealed variation in use of the self-care advice/information pages (Maguire et al., 2015; McGee & Gray, 2005, Sundberg et al., 2015). Yap and colleagues (2013) reported that whilst over half of patients (62%) found a mobile phone, symptom-monitoring intervention useful, patients with lower education and chemotherapy-naïve patients rated the intervention significantly more useful than those with higher education (75% vs 35%) or those who had received chemotherapy before (82% vs 53%).

Subtheme 1b: Perceived ease of use

Almost all patients reported that they found the mobile interventions easy to use, regardless of age, type or stage of cancer and experience with technology (Besse et al., 2016; Head et al., 2011; Kearney et al., 2006; Maguire et al., 2005; 2015; McCall et al., 2008; Post et al., 2013; Stinson et al., 2013; Sundberg et al., 2015; Weaver et al., 2007). For example, Head and colleagues (2011) reported that all 44 patients from the intervention arm of a RCT reported a handheld device to be very easy (85%) or easy (15%) to use and a feasibility study reported that although 66% of 18 patients had little prior computer experience, at post-study all 11 patients who had received the intervention reported that they felt comfortable

using the handheld device (Kearney et al., 2006). Interviews and questionnaires findings from an RCT and feasibility study suggested that daily use of a mobile phone intervention did not impact on patients' daily routines or privacy and was not perceived as burdensome or too time-consuming (Besse et al., 2016; McCann et al., 2009). The majority of patients experienced no or very few technical problems with their mobile devices, however those who did tended to encounter problems with Internet connection or practical problems with the device itself (Maguire et al., 2005; McCall et al., 2008; McCann et al., 2009; McGee & Gray., 2005; Post et al., 2013; Weaver et al., 2007; 2014).

Subtheme 1c: Adherence to mobile interventions

Studies generally reported high adherence rates to the mobile interventions, regardless of the length of the study (Besse et al., 2016; Chumbler et al., 2007b; Dawes et al., 2015; Head et al., 2011; Post et al., 2013; Somers et al, 2015; Stinson et al., 2013; Weaver et al., 2007; 2014; Yap et al., 2013). A pilot RCT of 44 patients reported that patients used a handheld device consistently for an average of 10 weeks (Head et al., 2011). For the longest study period included in this review, up to six months, Chumbler and colleagues (2007b) reported that the mean adherence of 48 patients to daily dialogues with a care coordinator was 84%, with a decrease in adherence as treatment progressed. One study suggested that adherence might be affected by the type of device used or experience with this type of technology (Yap et al., 2013). Yap and colleagues (2013) reported that adherence was significantly higher among Smartphone users compared to basic mobile phones users (87.2% vs 47.6%). The most common reasons reported for non-adherence to interventions were hospitalisation, forgetfulness and technical problems (Head et al., 2011; Post et al., 2013).

Theme 2: Benefits of the interventions
Subtheme 2a: Symptom management

The majority of patients perceived the mobile interventions to be helpful in monitoring their treatment-related symptoms. Additionally, studies highlighted that mobile interventions are able to capture patient information and outcomes that are not captured via conventional reporting, such as questionnaires (Dawes et al., 2015; Fortier et al., 2016; Kearney et al., 2006; Maguire et al., 2005; McCall et al., 2008; Somers et al, 2015; Sundberg et al., 2015; Weaver et al, 2014). However, a RCT of 112 breast, lung and colorectal cancer patients showed mixed results (Kearney et al., 2009). Authors hypothesised that a real-time, symptom monitoring intervention would facilitate better measurement of six chemotherapy-related symptoms, resulting in more timely interventions. Although two out of six monitored symptoms were significantly different between groups, there were significantly lower reports

of fatigue and significantly higher reports of hand/foot syndrome in the intervention vs. control group. There was some evidence to suggest that symptom-monitoring interventions have the potential to reduce the unnecessary use of healthcare services by improving symptom management (Besse et al., 2016; Chumbler et al., 2007a; Weaver et al., 2014). For example, a matched case-control study of 125 patients investigated the effects of a handheld device intervention by measuring patients' unexpected and expected use of cancer-related services over six months (Chumbler et al., 2007a). Findings showed that the intervention group had significantly lower use of unexpected care services and significantly higher use of most expected care services, however contrastingly, patients in the intervention group had significantly fewer expected clinic visits compared to controls. Authors suggested this contrasting result is possibly due to patients resolving issues with the care coordinator prior to an expected clinic visit thereby reducing the need for the visit.

The majority of symptom-monitoring intervention studies further reported that patients perceived that the interventions had led to improved symptom management (Besse et al., 2016; Dawes et al., 2015; Head et al., 2011; Maguire et al., 2005; 2015; McCann et al., 2009; Somers et al., 2015; Weaver et al., 2014). Head and colleagues (2011) found that 52% of patients reported that they were much better and 44% somewhat better at managing their condition as a result of a handheld, symptom-monitoring intervention. A more recent feasibility study reported that the mean pain score of participants from the start to end of a feasibility study decreased non-significantly, but when measured using the European Organisation for Research and Treatment of Cancer Quality of Life Questionnaire (EORTC QLQ-C30), the mean pain score decreased significantly from 56 to 35 (Besse et al., 2016). Furthermore, two studies reported that patients were admitted to hospital as a result of a real-time symptom monitoring intervention, which resulted in proactive management of those patients' symptoms (Besse et al., 2016; Weaver et al., 2014).

Subtheme 2b: Patient empowerment
Some studies suggested that remote monitoring of symptoms empowered patients to participate in their care and better manage their condition due to increased knowledge of their condition and symptom management strategies provided by the mobile interventions (Dawes et al., 2015; Fortier et al., 2016; Head et al., 2011; Kearney et al., 2006, Weaver et al, 2015). In qualitative interviews with 11 lung and colorectal cancer patients, patients explained that this type of intervention had increased their understanding of their symptom-related problems and consequently, their confidence in their abilities to manage symptoms (Kearney et al., 2006). Furthermore, Weaver and colleagues (2014) reported that patients felt more in control of their care and had increased confidence to self-manage their condition

at home as a result the intervention. Similarly, Somers and colleagues (2015) showed that 95% of participants reported that the intervention helped them to understand the experience of pain and 90% of participants felt the intervention had taught them skills that improved their pain coping, however an observed increase in pain self-efficacy following the pain-related coping skills intervention was not significant.

Subtheme 2c: Reduced anxiety

The majority of studies reported that patients perceived clinicians' surveillance of, and response to, their symptoms as reassuring, however there were some mixed findings for the effects of information on levels of anxiety (Foley et al., 2016; Forbat et al., 2009; Kearney et al., 2006; Maguire et al., 2005; 2015; McCall et al., 2008; McCann et al., 2009; Sundberg et al, 2015, Weaver et al., 2007; 2014). Qualitative interviews with 12 patients from a process evaluation of an RCT of a mobile phone, symptom-monitoring intervention reported that patients felt secure in the knowledge that clinicians were being alerted about their symptoms (McCann et al., 2009). Results from a secondary analysis of these interviews suggested that patients viewed their surveillance as liberating, freeing them of the worry of making a decision to contact clinicians themselves (Forbat et al., 2009). In contrast, a feasibility of a mobile symptom monitoring intervention reported no change in anxiety levels (Maguire et al., 2015). Conversely, a pilot RCT study of a tablet-based information provision intervention found that there was a significant difference in pre-operative fatalism in the intervention group and anxiety was significantly lower in the control group at seven days post operation (Foley et al., 2016). This suggests that increasing patients' knowledge on patients' treatment could potentially increase rather than reduce their anxiety. However, authors reported that some women were anxious about using a tablet device with which they were unfamiliar and this may have increased their anxiety. Additionally, the follow up period was short at 7 days post-surgery.

Subtheme 2d: Patient-clinician communication

Many patients perceived that communication with clinicians had improved or their relationship had strengthened as a result of the interventions (Aldiss et al., 2011; Dawes et al., 2015; Forbat et al., 2009; Head et al., 2011; Maguire et al., 2005; 2015; Weaver et al., 2007). A post-study questionnaire of 44 patients from a RCT of a handheld, symptom-monitoring intervention found that 65% of patients were more satisfied with the communication with their clinicians (Head et al., 2011). In a secondary qualitative analysis of patient interviews from a RCT of a mobile phone, symptom-monitoring intervention, Forbat and colleagues (2009) reported that patients felt the intervention gave them easier access to cancer specialists, as well as increasing the amount of communication with clinicians.

Authors suggested that easier access to clinicians may change the dynamic of the traditional hierarchical models of healthcare to a more patient-centred model, as clinicians are more responsive to the patients' reports and needs. Furthermore, two feasibility studies found that as the intervention prompted clinicians to contact the patients, patients' uncertainty about contacting whether to contact their clinicians when needed was reduced and they felt less 'bothersome' to their clinicians (Maguire et al., 2015; Weaver et al., 2007).

Subtheme 2e: Heath-related quality of life (HRQOL)

Studies reported mixed findings of the interventions on patients' HRQOL (Besse et al., 2016; Chumbler et al., 2007b; Head et al., 2011; Maguire et al., 2015; Post et al., 2013). A RCT of 44 patients using a handheld device during treatment periods, which required patients to report symptoms three to five times daily, reported that significant positive correlations were found between usage of the intervention and physical well-being and emotional well-being scores during treatment (Head et al., 2011). A feasibility study of 48 patients using a handheld device to answer daily symptom questions from a care coordinator found a clinically significant improvement of 6.3 points in patients' HRQOL between baseline and six months (Chumbler et al., 2007b). This study suggested that a symptom-monitoring intervention could reassure patients who are anxious during treatment thereby maintaining their HRQOL. In contrast, although one feasibility study reported a non-significant increase in quality of life following a pain-monitoring intervention (Besse et al., 2016), one feasibility study reported no change in wellbeing (Maguire et al., 2015), however both studies suffered from small sample sizes. Negative findings were also reported by Post and colleagues (2013). Their pilot RCT study of 60 patients using a PDA device, where patients reported symptoms weekly during treatment periods and viewed videos on how to communicate their symptoms to their clinicians prior to their consultations, found that patients' HRQOL were not significantly different between groups. Furthermore, the pre-post treatment decrease in HRQOL was generally greater among the intervention group. Authors suggested that this result might be due to the intervention drawing attention to the symptoms experienced by patients in the intervention group. However, due to the methodological differences between studies, such as study design, measurement of HRQOL and intervention intensity (e.g. intervention functions, interaction with patient and duration of intervention), meaningful comparison of these studies is not possible, though it is possible that intervention intensity is partly responsible for these mixed findings.

2.5 Discussion

This is the first systematic review to identify and evaluate literature that describes the use of mobile interventions to enable cancer patients to meet their information needs in non-inpatient settings, and to describe the effects and feasibility of this type of intervention.

2.5.1 Summary of the evidence

The primary aim of the majority of intervention studies included in this review was to improve the monitoring and management of patients' treatment-related symptoms, which included the provision of self-care information and interactive information exchange with clinicians. Although these interventions attempted to educate patients in some way, the information and skills provided were solely related to their treatment. Two further intervention studies primarily aimed to increase patients' treatment-related knowledge and one intervention study aimed to improve communication and exchange of information between patients and their clinicians. There were no interventions that primarily aimed to meet patients' full range of information needs by increasing their general knowledge and understanding of their condition. Additionally, all interventions were for patient use only and did not aim to support relatives simultaneously.

Based on studies included in this review that were appraised as medium or good quality, there was moderate evidence to suggest that this type of technology and intervention was acceptable to patients with cancer, regardless of age, experience with technology, cancer type or stage of cancer. Similarly, there was moderate evidence to suggest that patients perceived the mobile interventions to be useful, particularly the self-care advice and the fast response from clinicians, and one study suggested that patients with lower education or chemotherapy-naïve patients could benefit more from this type of intervention than their counterparts. Studies of medium and good quality also reported that patients found the mobile interventions easy to use and non-intrusive on their daily routine, with few technical problems encountered, and that adherence to interventions was generally high, however there was considerable variation in usage of the different intervention components within and between studies. Reported benefits of the interventions from medium to good quality studies included improved symptom monitoring and management, patient empowerment and improved clinician-patient communication, however mixed findings were reported for patients' anxiety and HRQOL. Overall, findings between studies of good, medium and poor quality were largely consistent.

2.5.2 Findings in the context of other literature

A plethora of mobile interventions have been developed to support patients with range of chronic conditions remotely, such as diabetes, heart disease, asthma and mental illnesses,

the majority of which primarily aimed to improve patients' self-management behaviours, such as adherence to treatment and monitoring of their condition (De Jongh, Gurol-Urganci, Vodopivec-Jamsek, Car & Atun, 2008; Klasnja & Pratt, 2012). The findings of the present review are consistent with previous literature that has found mobile technology to be an acceptable platform to deliver interventions to patients with other chronic conditions, regardless of the patients' type of disease, age, gender and experience with technology (Cleland, Caldow & Ryan, 2007; De Jongh et al., 2008; Holtz, & Lauckner, 2012; Logan et al., 2007; Wang et al., 2014). Generally, the majority of patients included in good, medium and poor-quality studies of the present review found mobile interventions easy to use and engaging, regardless of the type of device used (e.g. mobile phone, PDA) or age of the patient. Furthermore, very few barriers were reported by patients; a minority experienced minor technical issues when connecting to the server to transfer information and some forgot or were unable to complete symptom diaries due to hospitalisation. The finding that few technical problems were experienced is in contrast to previous literature, where many patients have cited technical difficulties as a barrier to use and satisfaction with the intervention (Cleland et al., 2007; Harrison et al., 2014; Holtz, & Lauckner, 2012; Wenze, Armey & Miller, 2014). One review of mobile interventions for patients with diabetes reported that 67% of 21 studies reported technical issues (Holtz & Lauckner, 2012) and some patients have found these types of issues frustrating and dissatisfying (Cleland et al., 2007). The contrasting finding of the present review may be due to the fact that many interventions for other chronic conditions, such as diabetes and asthma, require additional technological devices to monitor symptoms, which would increase the likelihood of technical errors. In contrast, mobile interventions for patients with cancer included in the present review required a mobile device only.

Adherence rates to mobile interventions included in good, medium and poor-quality studies included this review were generally high throughout the study periods, which were up to six months, however engagement appeared to decrease over the course of the intervention. These patterns mirror those of studies of mobile interventions for other chronic conditions, which included study periods of up to a year in duration (De Jongh et al., 2008; Logan et al., 2007; Wenze et al., 2014). However, despite generally high rates of adherence for this type of intervention, there appeared to be considerable variation in the usage of the different intervention components within and between studies included in the present review. In 2008, Abraham and Michie developed a taxonomy of behaviour change techniques (BCT), which included standard definitions of the techniques included in behaviour change interventions. This taxonomy enabled intervention developers to use a common language with which to systematically categorise intervention content, particularly complex interventions with

multiple components. This process allows intervention developers to trial and measure the effects of individual components and compare different versions of interventions, in order to create the most optimal version through an iterative, on-going process (West, Aiken & Todd, 1993). All studies in the present review failed to code intervention content using this taxonomy and so it was not possible to identify and attribute success to active components. As a result, it will be difficult for future researchers to replicate effective interventions and a challenge to identify the most effective BCTs for this type of intervention for patients with cancer. It is therefore important that future intervention developers code interventions in order to develop effective interventions for patients with cancer and enable a more systematic evaluation (Michie, van Stralen, & West, 2011).

Patients appeared to recognise the benefits of real-time symptom monitoring interventions, such as increased knowledge and confidence to participate in self-care, which appeared to result in improved management of symptoms. Mobile technology enables patients to keep a real-time record of symptoms, which improves the accuracy of symptom appraisal and management and enables clinicians to better identify and understand patterns of symptoms (Baggott et al., 2012; Moskowitz & Young, 2006). The capability of this technology to capture patient-reported outcomes in real-time may be of clinical importance as it promotes timely intervention. This could reduce the amount of preventable hospitalisations, as suggested by three medium-quality studies included in this review. Previous studies of the effects of mobile symptom-monitoring or adherence interventions on symptoms of other chronic conditions have shown similar findings, including improved symptoms, such as an increased blood glucose control, and increased self-management behaviours, such as better adherence to treatment (Angeles, Howard, & Dolovich, 2011; Baron, McBain, & Newman, 2012; De Jongh et al., 2008; Holtz, & Lauckner, 2012). As a result, some patients with other chronic conditions have reported fewer clinic visits or hospital admissions following a use of mobile intervention (Angeles et al., 2011; De Jongh et al., 2008).

Some medium-quality studies included in the present review suggested that mobile interventions have the potential to empower patients by equipping them with the knowledge and confidence they need in order to participate more effectively in their care. Similarly, although not directly measured, studies of mobile interventions for other chronic conditions have provided some evidence for increases in patient empowerment, due to observed increases in knowledge and self-management behaviours (Angeles et al., 2011; De Jongh et al., 2008; Holtz, & Lauckner, 2012; Wang et al., 2014).

In the present review, studies of good and medium quality reported that patients perceived clinicians' monitoring of their symptoms to be reassuring. Similar findings have been reported in studies of symptom-monitoring interventions for other chronic conditions, where patients described feelings of security, felt that they had not been forgotten and were receiving good care outside of hospital and clinic (Wang et al., 2014). Additionally, studies of good and medium quality in the present review reported that symptom-monitoring and management interventions appeared to improve patient-clinician communication, due to increased and easier access to clinicians and the reduction of patients' uncertainty of whether to contact them. Similarly, patients with other chronic conditions, such as asthma and diabetes, have also reported increased and improved communication with their clinicians as a result of mobile interventions (Cleland et al., 2007; Harrison et al., 2014). Mobile interventions offer an inexpensive way to bridge the gap between patients and clinicians and increase their contact at a time when patients require more support following a shift from inpatient to outpatient cancer care.

Studies in the present review reported mixed findings on the impact of mobile interventions on patients' HRQOL and anxiety, however few studies included in this review measured these outcomes. Studies of medium and good quality provided evidence to suggest that symptom-monitoring and management interventions could reassure patients and reduce their anxiety. For some patients, having more knowledge on their condition might reduce their anxiety due to preparedness for treatment-related side effects, resulting in a better experience and the development of realistic expectations of the future. Conversely, one study of medium quality in the present review provided evidence to suggest that information might increase some patients' anxiety by drawing attention to their condition, unknown symptoms or the risks of treatment. Previous research from the nursing and palliative care field, as well as theories of coping with a chronic condition such as cancer, including the Common Sense Model (CSM) of self-regulation of health and illness (Leventhal, Nerenz & Steele,1984) and Moos and Schaefer's model of a life crisis and framework of coping (1984), have distinguished between two types of coping, namely approach coping and avoidance coping. Approach coping involves actively confronting the diagnosis, gathering information and taking action, whereas avoidance coping involves minimising the importance of the diagnosis and includes strategies such as denial or wishful thinking in an attempt to maintain hope. Although approach coping is generally regarded as the most adaptive form, studies have found that the usefulness of coping strategies for cancer patients depend on the fit between the demands of their situation and selected coping strategy (Christensen et al., 1994; Lerman et al., 1990; Park et al., 2001). For example, avoidant coping strategies strategies may be useful in certain situations for some cancer patients, such as during

chemotherapy where active coping strategies may draw attention to the negative consequences of treatment (Lerman et al., 1990). Furthermore, studies have shown that denial and wishful thinking may help an individual through various stages of the illness and treatment by allowing them time to process distressing information at a more manageable rate (Rabinowitz & Peirson 2006). The usefulness of mobile interventions that aim to help patients with cancer to meet their information needs will likely depend on an individuals' unique situation and preferred coping style at particular points during their illness trajectory.

The majority of studies in the present review failed to report the race and ethnicity of participants and all studies failed to consider the potential differences in cancer experience and information needs between groups and the possible implications of these differences for this type of intervention. On one hand, some studies have suggested the absence of a dramatic difference in information needs between minority and majority groups with cancer in the UK and US and many studies have reported that most patients across groups prefer to have information on their condition from their healthcare provider (Guidry, Aday, Zhang & Winn, 1998; Kumar et al., 2004; Rutten et al., 2005). For example, a study of 82 Asian and 220 White British cancer patients in Leicestershire, which included Indian, British Asian, Bangladeshi and Pakistani patients, reported that a high percentage of Asian patients wanted to know the specific name of their cancer (93.8%), week-by-week progress (86.4%), the chance of cure (84.0%), all possible treatment options (87.7%) and all possible side effects (85.2%), which were comparable to findings of White British patients (Kumar et al., 2004). Conversely, studies have reported that some patients of black and ethnic minority groups, such as African American and Chinese, have different experiences of cancer, different needs and use different information sources compared to majority groups (Elkan et al., 2007; Matthews, Sellergren, Manfredi & Williams, 2002; Randhawa & Owens, 2004; Talosig-Garcia & Davis, 2005; Wills & Wootton, 1999). For example, a qualitative study of African American patients with cancer reported a number of barriers to medical information seeking and treatment participation, such as fatalistic beliefs about cancer, historical mistrust of the medical community, religious beliefs that God would ultimately take care of them, concerns about burdening the family and embarrassment of the stigma associated with cancer in their culture (Matthews et al., 2002). Patients with these types of beliefs are unlikely to want extensive information on their condition and may perceive this type of intervention as threatening (Matthews et al., 2002). Patients in this study also valued lived experience of cancer and so relied heavily on family and friends for information on their condition. It is therefore important that future studies explore the use and impact of this type of intervention for patients from black and ethnic minority groups.

Finally, some studies of good and medium quality in the current review provided some evidence for increased HRQOL and other studies of good and medium quality suggested no effect. Few studies that have measured the impact of mobile devices on patients' quality of life or emotional disturbances for other chronic conditions have also reported mixed findings (Kirwan, Vandelanotte, Fenning & Duncan, 2013; Kristjánsdóttir et al., 2013). However, some of these studies have highlighted the potential of Smartphones to specifically increase patients' awareness of stress and emotional well-being, by recording moods during both health and illness, and deliver therapeutic interventions accordingly, which has led to reduced anxiety (Kristjánsdóttir et al., 2013; Morris et al., 2010). Mobile interventions offer a new opportunity to increase patients' access to psychological support and deliver psychological interventions remotely at a time when patients are vulnerable.

Although findings of this review are largely positive, it highlighted the fact that the majority of the interventions included involved a significant amount of monitoring and interaction from clinicians. Studies that have explored clinicians' perceptions, some of which are included in this review, have reported mixed opinions on the acceptability and feasibility of symptom-monitoring interventions (Kearney et al., 2006; Maguire et al., 2008; McCall et al., 2008). This type of intervention may place an additional burden on clinicians during a time when they are already stretched.

2.5.3 Quality of studies

The large number of early-phase studies in this field means that many studies included in the present review used an uncontrolled design. The current evidence for the effectiveness and feasibility of mobile interventions to support cancer patients is therefore limited. Although these studies highlighted the potential benefits of such interventions, RCTs are needed to support the findings of this review. Additionally, most included studies included in this review were critically appraised as poor or medium quality, which further limits the conclusions that can be drawn from these studies. Limitations of some studies included small sample sizes, samples limited to single cancer types, under-reporting of response rates and details of participants who were lost to follow up, and short study periods. Other limitations included the failure of studies to explore the opinions of patients with negative views and the cost of this type of intervention. Additionally, some studies only included participants who had access to their own device or were already able to competently use a mobile device. This inclusion criterion may have biased findings, as those who participated in these studies may have had more favourable perceptions of mobile interventions than those who were unable to participate. However, findings across studies of good, medium and poor quality were generally consistent and conclusions of this review were drawn only from good and medium

quality studies. Finally, many studies relied on self-reported data which may have been affected by recall or the Hawthorne effect (Merrett, 2006), where participants may have changed their behaviour due to knowingly being observed.

2.5.4 Strengths and limitations of this review

The AMSTAR checklist (A Measurement Tool to Assess Systematic Reviews; https://amstar.ca/Amstar_Checklist.php) was used to assess the quality of this systematic review. Strengths of this review include an '*a priori*' design, study selection and data extraction was conducted by two independent reviewers, multiple databases and references of included studies were searched, study characteristics were reported, and the studies were critically appraised on their quality, which was taken into account when drawing conclusions. However, the present review has several limitations. A meta-analysis was not conducted as the included studies did not have suitable data to aggregate. A narrative synthesis was considered to be a suitable alternative method to explore the findings of these studies. Other limitations include poor indexing of studies, which may have limited the number of studies included in this review, and a high number of potential studies was found through searching the references of included studies. Finally, this review did not report on the perceptions and experiences of healthcare professionals that participated in some studies.

2.5.5 Implications for policy and practice

This review has several implications. Firstly, it established that a wide range of patients with cancer perceived mobile devices to be an acceptable medium to provide interventions remotely. Secondly, this type of intervention appears to have the potential to provide a range of benefits for patients, clinicians and the healthcare service. Specifically, findings of this review suggested that symptom-monitoring interventions that provide treatment-related information to patients have the potential to improve patients' self-management of their condition and provide clinicians with a better understanding of patients' symptom experiences, whilst improving the patient-clinician relationship. This may lead to earlier detection of treatment-related side-effects and timely intervention, which could reduce costs for the healthcare system. This type of intervention also has the potential to sustain or improve patients' well-being during a time where they typically experience a decrease.

Importantly, this review established that, to date, mobile interventions have only attempted to meet a single type of information need (e.g. treatment-related symptom information, coping skills), which has typically been achieved indirectly. There are currently no app interventions that primarily aim to meet patients' full range of information needs in non-inpatient settings, an intervention which may be used by both patients and their relatives. Additionally, the

majority of interventions required monitoring and interaction with clinicians, which may place unrealistic demands on an already stretched healthcare service. Few mobile interventions have been developed to be used independently by patients in non-inpatient settings. Development of such an intervention would support the initiatives of UK governments and health organisations to empower patients to take a more active role in their care by increasing support for patients in non-inpatient settings and harnessing the power of technology in order to do so (DOH, 2011; 2013).

2.5.6 Conclusion

This is the first systematic review to identify how mobile devices have previously been used to help patients with cancer to meet their information needs in non-inpatient settings and evaluate the effects and feasibility of this type of intervention. The majority of mobile interventions developed for patients with cancer so far have been to enable clinicians' surveillance of patients remotely in the form of symptom-monitoring interventions. Despite promising findings, this type of intervention seeks only to increase patients' knowledge of their treatment side-effects. Currently, there no app interventions that primarily aim to meet patients' full range of information needs in non-inpatient settings, which may be used independently of clinicians, and no app interventions have been developed for use by both patients and their relatives. Nevertheless, mobile devices appear to be an acceptable platform to deliver interventions remotely to patients with cancer. However, this review highlighted the early stage of the research that is being conducted in this area, which limits the conclusions that can be drawn. Following on from the early-phase feasibility studies, RCTs are needed to support the findings of this review, further determine the effectiveness of this type of intervention to improve patient outcomes and to support the transfer of interventions into standard practice.

Chapter 3

Models, theories and approaches relevant to patients' experiences of cancer and self-management of their condition

3.1 Chapter overview

This chapter describes and critically appraises a selection of health behaviour models, theories and approaches that are relevant to being diagnosed and living with cancer. The purpose of the chapter is to gain theoretical understandings of how the illness might impact patients, the issues they might face and the type of app that might best support them. Theories related to patients' self-management of a chronic condition, and the reasons for selection of these theories, will be described and critically evaluated in the context of cancer. This chapter will help to inform the development of an app intervention for patients with cancer.

3.2 Introduction

As described in Chapter 1, the MRC framework for developing and evaluating complex interventions in healthcare highlights the importance of identifying relevant theories to gain a deeper understanding of the behaviour to be targeted by an intervention and the changes that may be expected (Craig et al., 2008). This first phase of the MRC framework provides insight into the processes that are likely to underlie the targeted behaviour prior to intervention development, which allows the intervention to be designed specifically to address these processes (Craig et al., 2008).

Previous studies, as described in Chapter 1, have provided evidence of the unmet information needs of patients with cancer, and their relatives, and the negative impact of these unmet needs. A systematic review of mobile interventions for patients with cancer, presented in Chapter 2, highlighted the potential benefits of interventions that were delivered to patients remotely by Smart technology. It was therefore anticipated that an app would be developed to enable patients with cancer to meet their full range of information needs in non-inpatient settings. Prior to developing an intervention, it is important to explore the views and opinions of the intervention users to develop an understanding of their needs and the type of intervention that they anticipate to be most useful (Yardley et al., 2015). A review of relevant health behaviour models, theories and approaches related to the impact and self-management of a chronic condition was conducted in order to develop an understanding of the experiences of cancer patients and their relatives, the issues they might face and the type of app that might best support them. It was assumed that these theories might also be relevant for

relatives, as well as patients, due to their shared experienced of cancer (Harrison et al.,1995).

Theories selected for inclusion in this chapter refer to the concepts of coping, adjustment and self-management. Coping has been defined as, *"the thoughts and behaviors a person uses to regulate distress, manage the problem causing distress and maintain positive well-being"* (Folkman & Greer, 2000, p. 11), and this concept overlaps with, and has often been hypothesised to predict, adjustment to illness (Brown, King, Butow, Dunn, & Coates, 2000; Sharpe, & Curran, 2006). Adjustment has similarly been described as a response to a change to circumstance, such as a cancer diagnosis, that allows an individual to become more suitably adapted to the change Brennan, 2001; Sharpe, & Curran, 2006). Earlier definitions tend to refer to a desirable outcome to signify adjustment, such as emotional equilibrium, quality of life, or social functioning (Brennan, 2001; Sharpe, & Curran, 2006). More recently, adjustment is viewed as a disease-specific and on-going process, which is separate to the desired outcome, and desired outcomes of adjustment should include aspects relevant to physical, social and psychological adjustment (Hoyt & Stanton, 2012). The concept of self-management has come to encompass the concepts of coping with cancer and adjustment, and is described as, "*the individual's ability to manage the symptoms, treatment, physical and psychosocial consequences and lifestyle changes inherent in living with a chronic condition. Efficacious self-management encompasses the ability to monitor one's condition and to effect the cognitive, behavioural and emotional responses necessary to maintain a satisfactory quality of life. Thus, a dynamic and continuous process of self-regulation is established.*" (Barlow, Wright, Sheasby, Turner & Hainsworth, 2002, p178).

Definitions of coping, adjustment and self-management all share a focus on the need of an individual to return to and maintain a status quo, the importance of coping with and managing the physical, social and psychological effects of a chronic condition and an individual's self-efficacy to successfully adopt and carry out suitable coping strategies and self-management behaviours (de Ridder, Geenen, Kuijer, & Middendorp, 2008). Additionally, when reviewing theories for inclusion in this chapter, it was apparent that similar elements permeate the models and theories related to coping with a chronic illness and patients' self-management of the disease (e.g. appraisal, coping responses, self-management behaviours). The term self-management will therefore be used as an over-arching term throughout this thesis to encompass patients' coping with, and adjustment to cancer, and self-management of

the disease, however the terms will be referred to separately in this chapter, as originally referred by authors of the theories. It is also useful to note the difference between the terms 'theory' and 'model'. A theory is described as explanatory and predictive, and is used to guide selection of appropriate research methods and predict behaviour to guide intervention development. A model is descriptive and often a simplified version of a theory that outlines simplified cause and effects of key aspects of behaviour (Gabrenya, 2003).

A number of core models of health psychology, such as the Health Belief Model (HBM) (Becker, 1974) and Theory of Planned Behaviour (TPB) (Ajzen, 1991), are potentially relevant to the development of an app for cancer patients due to their focus on behaviour change, however these models typically require a high level of specificity in identifying the target behavior. At this point in app development, it is prudent to allow for the consideration of a broad domain of behaviours. Additionally, these models lack a prescribed role for an individual's emotional response to an illness and have therefore failed to account for the complex set of processes involved in adjustment to cancer (Sharpe, & Curran, 2006). For these reasons, the HBM and TPB were not included for discussion in this chapter.

3.2.1 Aims of this chapter

The aim of this chapter is to review and critically evaluate health behaviour models, theories and approaches that might be relevant to the impact and self-management of a chronic condition, such as cancer. This chapter will discuss how each theory may be used to inform the development of an app intervention to help to meet patients' information needs in non-inpatient settings.

3.3. Models relevant to the impact and self-management of a chronic condition

3.3.1 The Common Sense Model (CSM) of self-regulation of health and illness

The CSM (Leventhal, Nerenz & Steele,1984) (Figure 4) attempts to explain how an illness is inferred, understood and acted upon and is a useful model to explain how patients might come to understand and cope with a diagnosis of cancer. The CSM posits that, following a diagnosis, individuals aim to develop an understanding of their condition based on the need to maintain equilibrium and return to a state of 'normality' (which in the case of cancer is cure or management of the disease). Leventhal and colleagues (1984) assume an individual to be a problem solver who is actively involved in the management of their health by responding to a health threat, such as cancer, with a dual, parallel process of cognitive processing (i.e. identifying, understanding and

responding to the health threat) and emotional processing (i.e. the emotional response to the health threat and coping strategies to manage emotions).

There are three key constructs of the CSM, which include: (1) interpretation of the illness (making sense of the diagnosis), (2) the coping response to the illness (an attempt to regain a state of normality), and (3) appraisal of the coping response (assessment of the success of the coping strategies used). The CSM posits that following a cancer diagnosis, patients actively construct representations of the illness, termed 'illness cognitions', by using their existing knowledge of cancer and accessing their implicit beliefs. Illness cognitions provide a framework for understanding and coping with the illness and are constructed according to five dimensions:

(1)   Identity (the label given to the illness)
(2)   Consequences (possible short-term and long-term physical, emotional, social and economic effects of the illness)
(3)   Causes (perceptions of the cause of the illness)
(4)   Timeline (perceptions of the timeframe of the development and duration of the illness)
(5)   Curability/controllability (perceptions of whether the illness can be cured or managed)

Illness cognitions enable the individual to give meaning to the illness and adopt suitable coping strategies, which are suggested to have the ability to influence health outcomes. If and when new information about the illness comes to light, the relevant illness cognitions can be amended. Simultaneously, the model posits that a health threat, such as a cancer diagnosis, will result in an emotional response from the individual, such as fear, anxiety and/or depression.

This model refers to two broad coping 'styles': approach coping and avoidance coping (Roth & Cohen, 1986). Approach coping involves confronting the diagnosis, gathering information and taking action, and includes strategies such as taking medication, venting emotions and going to the doctor. Avoidance coping involves minimising the importance of the diagnosis and includes strategies such as denial or wishful thinking. Approach coping is generally regarded as the most adaptive form. Once the individual has adopted a coping style, the coping response is appraised. If appraised as unsuccessful, the coping response can be amended or individuals may revisit their initial illness cognitions. The feedback loop between the interpretation, coping and

appraisal stages is therefore self-regulatory. This model implies that maladaptive illness cognitions (i.e when an illness is represented as serious, chronic or uncontrollable) could be addressed and modified by interventions in order to achieve improved health outcomes.

It is worth noting that the match between a person's beliefs about their illness and reality is important in determining their adjustment to illness, which is known as the goodness-of-fit or reality-matching hypothesis (Christensen, Smith, Turner, & Cundick, 1994; Park, Folkman, & Bostrom, 2001). If a person's illness is uncontrollable, beliefs about controllability of the cure or the progression of the illness might be unhelpful. Instead, patients could use other coping strategies that distract from the illness and focus on aspects of their illness that they *can* control, such as monitoring and preventing treatment-related side-effects (Sharpe & Curran, 2006).
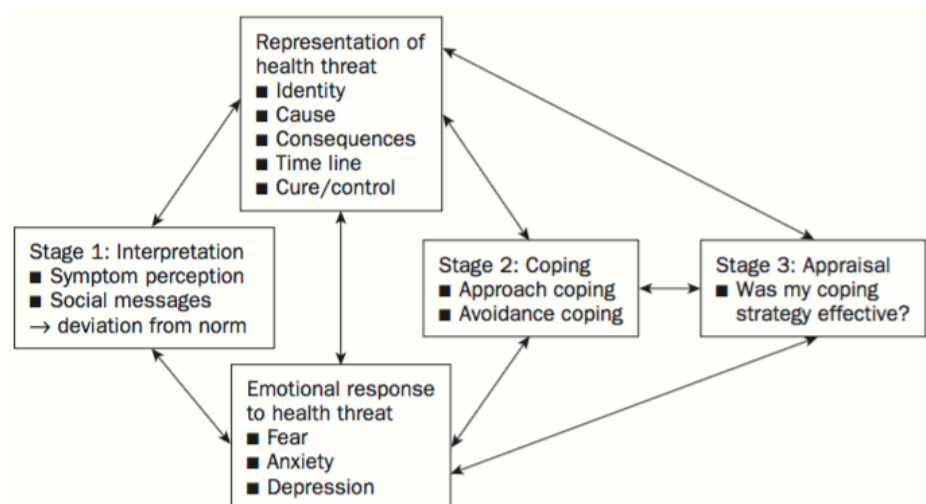
Figure 4: *The common sense model of illness self-regulation (adapted from Ogden, 2012, p221).*

There is much support for the central constructs of the CSM. In studies of cancer patients, maladaptive illness cognitions have been associated with poorer self-efficacy to manage their condition and treatment-related problems (Foster, Cotterell, Breckons & Fenlon, 2012), poorer self-management behaviours, such as passive coping (Hopman & Rijken, 2015), and poorer health outcomes, such as lower quality of life, higher symptom burden, psychological distress and higher rates of mortality (Ashley, Marti, Jones, Velikova & Wright, 2015; Gray et al., 2014; Thong, Kaptein, Vissers, Vreugdenhil, & van de Poll-Franse, 2016). Similarly, studies of women with breast cancer have shown that those who respond with an avoidant coping style report increased distress compared to those who respond with approach coping (Low, Stanton, Thompson, Kwan & Ganz, 2006; Rozema, Völlink, & Lechner, 2009). The CSM proposes that information available to cancer patients plays a key role in the formation of illness cognitions about their condition and some studies have shown that patients' information needs vary as a function of adjustment to cancer (Mulcare et al., 2011). Many studies suggest that interventions that aim to restructure cancer patients' maladaptive illness perceptions by enabling patients to obtain relevant and accurate information may help patients to gain a better understanding of their illness and consequently, achieve better adjustment to cancer in the long term (Fischer et al., 2013; Hirsch et al., 2009; Husson et al., 2013).

For the purpose of this thesis, the CSM provides insight into how patients with cancer might come to understand their illness, how it is interpreted and effects of this understanding on their experience of cancer (i.e. their adopted coping strategies). This model describes the type of information that cancer patients might need in order to develop an understanding of their illness, such as information on the identity of the disease, and its consequences, causes, timeline and curability/controllability. An app could help patients with cancer to achieve an accurate understanding of their illness by enabling them to gather this specific information and construct adaptive illness cognitions. In turn, this might promote adoption of suitable coping strategies and adjustment to the illness. An app could also promote adjustment to cancer by directly including app features which enable the adoption of an approach coping style.

3.3.2 Moos and Schaefer's (1984) crisis theory of coping with an illness
Similar to the CSM, Moos and Schaefer (1984) developed a theory to understand the impact of a diagnosis of a serious illness, such as a cancer, which they described as a life 'crisis' due to its representation of a turning point in a person's life (Figure 5). Moos

and Schaefer (1984) further distinguished between the types of coping strategies that may be adopted during illness and the strategies that individuals might find most useful. Their framework of coping therefore provides further insight into how patients with cancer might manage their illness.

As in the CSM (Leventhal et al., 1984), individuals are regarded as self-regulators who attempt to return to a stable state. Following a diagnosis of a chronic illness, crisis theory describes how changes in the following domains may occur: identity (e.g. from breadwinner to patient), location (e.g. from work/home to hospitalisation), role (e.g. from independent to dependent), social support (e.g. isolation from friends due to the illness), and the future (e.g. from a planned future involving children or travel to an uncertain future). The ensuing coping process includes three processes, including: (1) cognitive appraisal, (2) carrying out adaptive tasks, and (3) adopting coping skills. Cognitive appraisal involves the individual assessing the seriousness and impact of the illness, much like Leventhal's illness cognitions (Leventhal et al., 1984). Following appraisal, individuals may use a variety of seven adaptive tasks in order to cope with the illness. These are divided into three illness-related tasks: (1) dealing with pain and other symptoms, (2) dealing with the hospital environment and treatment, and (3) developing and maintaining relationships with clinicians, and four general tasks: (4) preserving an emotional balance, (5) preserving self-image and a sense of competence and mastery, and (6) sustaining relationships with family and friends, and (7) preparing for an uncertain future.

Following use of these adaptive tasks, the framework of coping posits that individuals select from three types of coping strategies, which include: (1) appraisal coping, (2) problem-focused coping, and (3) emotion-focused coping. Appraisal coping involves attempts to achieve an understanding of the illness and includes three sets of skills: (1) logical analysis and mental preparation, which enables the individual to manage a situation by turning it into small manageable events, (2) cognitive redefinition, which involves the acceptance of the illness and its reality and redefining the situation in a positive way, and (3) cognitive avoidance and denial, which involves denying or minimising the seriousness of the illness. Alternatively, problem-focused coping involves facing the illness and performing constructive tasks to manage it, which includes: (1) seeking information and support to build knowledge and achieve an understanding of the illness, (2) taking problem-solving action, which can involve learning procedures or behaviours in order to manage the illness (e.g. keeping a chemotherapy symptom diary), and (3) identifying alternative rewards, which involves

planning of events or goals that provide shorter-term satisfaction. Finally, emotion-focused coping involves managing emotions evoked by the illness in order to maintain an emotional balance, and includes: (1) affective coping, which involves efforts to maintain hope when facing a serious illness, (2) emotional discharge, which involves venting negative emotions, and (3) resigned acceptance, which involves coming to terms with the outcomes of the illness. The types of tasks and coping skills an individual uses following a diagnosis is expected to affect health outcomes, such as psychological adjustment, well-being and quality of life. Finally, this framework distinguishes between two types of equilibrium: health adaptation and maladaptive equilibrium. Health adaptation is expected to lead to maturation and involves the use of adaptive tasks and constructive coping skills, with the desired outcome being coming to terms with reality. In contrast, maladaptive equilibrium is expected to lead to deterioration.
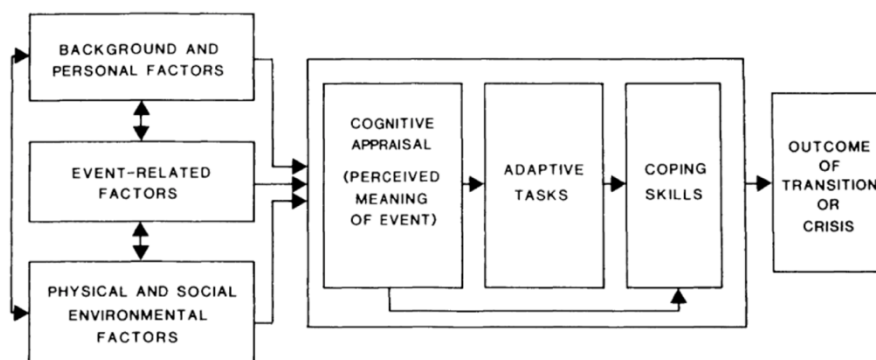
Figure 5: *Moos and Schaefer's model of a life crisis and framework of coping (taken from Moos, 2013, chapter 1, p20).*

There is much overlap between Moos and Schaefer's (1984) description of coping and that described by the CSM (Leventhal et al., 1984). It is worth noting that as a result of this overlap, coping strategies that involve an individual's acceptance of the illness and active attempts to deal with the situation are generally referred to as 'active', 'adaptive', 'approach', 'problem-focused' or 'monitoring' strategies within the literature, and coping strategies that involve trying to avoid dealing with the illness and distancing from the situation are referred to as 'avoidant', 'maladaptive' or 'blunting' strategies.

Moos and Schaefer's crisis theory (1984) and the framework of the coping have gained considerable support from the literature. Studies have shown that patients with cancer

use a variety of these coping strategies throughout their illness (Heim, Augustiny, Schaffner & Valach, 1993). Overall, studies have tended to report that active coping strategies are beneficial for cancer patients' clinical and psychological outcomes, whereas avoidant strategies are generally associated with negative effects. For example, active coping has been associated with higher quality of life, positive psychosocial adaptation to cancer, improved psychological well-being and positive health behaviours compared to avoidant coping (Heim, Valach & Schaffner, 1997; Kershaw, Northouse, Kritpracha, Schafenacker & Mood, 2004; Manne et al., 1994). However, despite these overall trends for either coping style, there is a body of literature that has shown that illness-related information is not necessarily helpful at all time points during their illness or for all patients and/or their carergivers.

In support of the goodness-of-fit hypothesis described in section 3.3.1 (Christensen et al., 1994; Park et al., 2001), studies have found that the usefulness of coping strategies for cancer patients depends on the fit between the demands of their particular situation and selected coping style. For example, Lerman and colleagues (1990) found that although active coping strategies were more beneficial during hospitalisation, avoidant coping strategies, such as denial, were positively associated with better adaptation during chemotherapy treatment. Patients who used active coping strategies experienced more anxiety and nausea symptoms before and during chemotherapy, whereas those who used avoidant coping strategies experienced less anxiety and depression and less nausea during and following treatment. These findings suggest that avoidant coping strategies may be useful in certain situations for patients with cancer, where active coping strategies may draw attention to the situation. Other studies in this body of literature that have focused on two further coping styles, 'monitoring' and 'blunting', have shown that some patients with cancer might not benefit from obtaining illness-related information (Folkman & Lazarus, 1980; Lazarus & Folkman, 1984; Miller, 1996). 'Monitoring' is described as attention to, scanning for, and amplification of threatening cues and involves the extent to which individuals are alert for and sensitised to the negative, potentially painful, or dangerous aspects of information and experience (Miller, 1995, p168.). In contrast, 'blunting' is described as the avoidance of threatening cues and involves the extent to which individuals distract themselves from such information (Miller, 1995, p168). Research suggests that patients who adopt a monitoring coping style tend to actively seek out information about their condition and are highly sensitive to it, whereas those with a blunting coping style try to avoid or minimise threatening information (Miller 1979a; 1979b). Studies have reported that patients tend to have better physical, psychological

and behavioural outcomes when the information they receive about their condition is tailored to their particular coping style (Miller, 1995). For patients who adopt a blunting coping style, mobile interventions that attempt to provide information to patients with cancer may result in increased anxiety.

For the purpose of this thesis, Moos and Schaefer's (1984) framework for coping provides further insight into the changes that might occur for patients following a diagnosis of cancer and the types of activities, tasks and issues that they are faced with. An app could help patients to complete some of these tasks, for example, by including an app feature that facilitates the development and maintenance of relationships with clinicians. This framework of coping further outlines the different types of coping strategies that could be incorporated into app features. For example, an app feature that includes links to credible information websites may facilitate information-gathering and therefore serve as a problem-focused coping strategy. Alternatively, an app feature that includes links to information on local cancer support groups may enable patients to attend these groups, share their stories and vent emotions, which would serve as an emotion-focused strategy (i.e. emotional discharge).

3.3.3 Taylor's (1983) theory of cognitive adaptation

There is a general trend for patients with cancer to suffer with psychological distress throughout the course of their illness, with the highest distress typically reported prior to a first treatment and a gradual decrease thereafter (Munro & Potter, 1996; Stiegelis et al., 2003). In contrast, some studies have shown that many patients show a sense of psychological well-being that is comparable to healthy individuals (Andrykowski & Hunt, 1993; Breetvelt & Van Dam, 1991). Several theories have been used to interpret these findings, such as the response-shift theory (Sprangers & Schwartz, 1999) or Helson's adaptation theory (Helson, 1964). Instead, Taylor's theory of cognitive adaptation (Taylor, 1983; Taylor, Lichtman & Wood, 1984) was selected for discussion in this chapter, as it has been popular in explaining these findings due to its concepts of adaptive cognitions, such as self-esteem, control and optimism, which can be targeted by interventions (Stiegelis et al., 2003).

Similar to the CSM (Leventhal et al., 1984) and crisis theory (Moos & Schaefer, 1984), the theory of cognitive adaptation regards the individual as self-regulatory. In contrast, it proposes that adjustment (i.e. cognitive adaptation) depends on the ability of an individual to develop, sustain and modify illusions throughout their illness, which are

described as positive interpretations of reality (e.g. interpreting the cause of cancer to be stress-related, when there may be little evidence for the real cause), in order to buffer against threats or setbacks. The desired outcome is therefore cognitive adaptation and not reality orientation, as suggested by the previous theories, as reality orientation may be detrimental to adjustment.

Three processes are believed to be central to achieving cognitive adaptation and include: (1) a search for meaning, (2) a search for mastery, and (3) a process of self-enhancement. A search for meaning involves searching for the causes, consequences and implications of the illness in order to understand and give the illness meaning, and to predict and control the environment. This concept is similar to Leventhal's illness cognitions (Leventhal et al., 1984) and cognitive appraisal described by Moos and Schaefer (1984). A sense of mastery can be achieved by making efforts to control the disease (and believing the illness is controllable) by using psychological techniques, such as having a positive attitude or meditating, and behavioural techniques, such as changing diet, controlling side-effects of treatment or gathering information on the illness.

This theory further suggests that individuals will attempt to rebuild their self-esteem that was lost or decreased following a diagnosis of a chronic illness through a process of self-enhancement. This process was described with social comparison theory (Festinger, 1954), which suggests that individuals compare themselves to those who are worse off in order to increase their self-esteem (e.g. a woman who undergoes a lumpectomy compares herself favourably to a woman who had a mastectomy). Finally, the theory of cognitive adaptation suggests that illusions are maintained throughout the course of the illness as individuals are able to amend the goals and focus of their illusions when they are challenged (e.g. a reoccurrence of cancer when the individual believed they could control whether the cancer would come back).

Studies testing the theory of cognitive adaptation are limited, however the available evidence provides support (Aspinwall & Taylor, 1992; Helgeson, 1999). For example, Taylor and colleagues (1984) reported that patients with breast cancer who were able to find meaning in their illness felt a sense of control and restored their self-esteem, and consequently showed better adjustment compared to patients who did not hold these perceptions. In a longitudinal study of cancer patients and a reference group of health individuals, cancer patients reported greater levels of optimism and self-esteem compared to those without the disease and this was maintained for three months post-

treatment (Stiegelis et al., 2003). Authors suggested that the fact that patients reported greater levels of optimism and self-esteem provides support for social comparison theory or evidence that patients are able to focus on positive aspects of their lives in order to protect their self-esteem and optimism for the future. It is possible that social comparison, or benefit-finding, counteracts distress during cancer (Affleck, Tennen, & Apter, 2001). Further studies in patients with a poorer prognosis also provide evidence that patients attempt to adapt cognitively (Taylor, 1983; Taylor & Armor, 1996).

For the purpose of this thesis, the theory of cognitive adaptation offers insight into the processes and types of psychological and behavioural techniques that could be targeted to help to maintain cancer patients' psychological well-being throughout their illness. Additional to app features that would enable patients to develop an understanding of their illness (i.e. a search for meaning), this theory suggests the consideration of app features that will help patients to foster a sense of control (i.e. mastery) and self-esteem. For example, an app feature that allows patients to record and monitor treatment-related symptoms, such as a diary, might enable patients to gain a sense of control through their illness, whereas an app feature that enables patients to meet other patients might facilitate opportunities for self-enhancement and increase self-esteem.

3.3.4 Self-efficacy theory

In the theories of coping with chronic conditions described so far, there is an inherent assumption that increasing an individual's knowledge and understanding of their illness will lead to behaviour change, such as executing suitable coping strategies. However, previous research has long established that this relationship is complex and there are often disparities between an individual's knowledge and their actual health-related behaviours (Gollwitzer & Sheeran, 2006; Schwarzer, 2008). For example, self-management education interventions for patients with chronic conditions, such as diabetes, have been found to increase patients' knowledge without altering their behaviours (Atak, Gurkan & Kose, 2008). This phenomenon has come to be known as the 'knowledge-behaviour gap' (Sligo & Jameson, 2000).

Studies have shown that self-efficacy, described as an individual's belief that they are capable of executing a specific behaviour that will lead to a desired outcome (Bandura, 1996), mediates some of the relationship between knowledge and health behaviour change (Atak, Gurkan & Kose, 2008; Rimal, 2000). Furthermore, within the cancer literature, studies have established the association between higher self-efficacy and

positive adjustment to cancer, as well as an increase in self-care behaviours (Lev, 1997; Lev, Paul & Owen, 1999). The concept of self-efficacy permeates the theories that have been described so far in this chapter, as patients select and execute what they perceive to be effective coping strategies in order to adjust to their illness. For these reasons, the concept of self-efficacy will be discussed in more detail using Bandura's theory of self-efficacy (1996).

Perceived self-efficacy is believed to be a central mechanism for behaviour change (Bandura, 1996). As well as having the relevant knowledge, this theory posits that an individual needs to believe that they are capable of executing and maintaining a behaviour (e.g. coping strategies, self-care behaviours) in order to devote the necessary effort for them to succeed. Perceptions of self-efficacy are thought to be based on four sources of information, which include: (1) personal experience of success, (2) vicarious experience of success, (3) verbal persuasion about their own capabilities and (4) emotional arousal. These sources of information are thought to be mediated by an individual's cognitive appraisal. For example, success of a behaviour is more likely to increase self-efficacy if it appraised as due to skill rather than due to chance, whereas success that is hard to achieve may not alter one's self-efficacy due to the implied low ability. Additionally, Bandura (1996) distinguished between self-efficacy and outcome expectancies. Outcome expectancies are defined as an individual's beliefs about whether the specific behaviour will lead to the desired outcome. An individual's self-efficacy and outcome expectancies are thought to influence the maintenance of behaviours, and the amount of effort invested and persistence, when confronted with adverse experiences.

In support of self-efficacy theory, studies have shown the association between a higher degree of self-efficacy with increased self-care behaviours and decreased physical and psychological symptoms in cancer patients (Lev, 1997). Interventions were therefore developed to increase cancer patients' self-care self-efficacy and were based on the premise that patients must develop an understanding of the relationship between the behaviour and their desired outcome, and be provided with the knowledge of how to modify the behaviour and believe that they are capable of executing the behaviour (Bandura, 1996). Such interventions have been shown to successfully increase self-care self-efficacy and behaviours for patients with cancer and other chronic illnesses, as well as increase quality of life and reduce symptom distress (Lev et al., 2001; Lorig, Sobel, Ritter, Laurent & Hobbs, 2001). For example, psycho-educational interventions that aim to increase cancer patients' control over their psychological states by teaching

coping skills have been shown to increase patients' execution of these skills and consequently, their quality of life (Cunningham, Lockwood & Cunningham, 1991; Cunningham & Tocco, 1989).

For the purpose of this thesis, self-efficacy theory provides further insight into why patients might lose a sense of control over their lives following a cancer diagnosis and ways in which self-efficacy may be increased by an intervention to promote self-management behaviour. An app intervention could be used to help increase patients' perceived sense of control over their lives and self-care self-efficacy by including app features that target the described sources of self-efficacy outlined by Bandura (1996), such as a feature that enables patients to meet other patients who are self-managing their condition (i.e. vicarious experience).

3.3.5 Health literacy

As well as knowledge and confidence to execute self-management behaviours, patients with chronic conditions also require the relevant skill set to take an active role in their healthcare (Hibbard et al., 2004). The particular skills that patients need to navigate their health and healthcare came to be known as 'health literacy'. Recent studies lend support to the 2004 Institute of Medicine (IOM) definition of health literacy as a skills-based construct: '*the degree to which individuals have the capacity to obtain, process, and understand basic health information and services needed to make appropriate health decisions',* (Kindig, Panzer, & Nielsen-Bohlman, 2004, p.37). This body of literature has provided further insight into the underlying processes of, and barriers to, patients' self-management of chronic conditions, such as cancer, and is another piece in the knowledge-behaviour gap puzzle.

In support of the important role of health literacy in the self-management of chronic conditions, such as cancer, studies of patients with various chronic conditions have found low health literacy to be associated with patients' low knowledge of their condition and poor self-management skills (Gazmararian, Williams, Peel & Baker, 2003; Williams, Baker, Honig, Lee & Nowlan, 1998). For example, patients with low health literacy demonstrate an inability to read and understand instructions, which means that they have a limited ability to prepare for consultations and tests, and have poor understanding and recall of information from consultations (Poon et al., 2004; Wilson et al., 2010). Similarly, patients with low health literacy may fail to understand self-care advice, which means that they are more likely to be hospitalised or make medication errors (Williams et al., 1995). This body of literature has also highlighted

the most likely mechanism through which health literacy might impact health outcomes. Individuals with low health literacy find it more difficult to access and understand health information, which results in decreased knowledge of their health, reduced health prevention behaviours and poor adherence to medication (Bennett, Chen, Soroui & White, 2009; Von Wagner, Steptoe, Wolf & Wardle, 2009).

The study of health literacy is particularly relevant in the context of cancer as newly diagnosed patients receive large amounts of information, which contain unfamiliar medical terms. Additionally, patients are often involved in choosing a treatment option along with their clinician and are required to adhere to a treatment regime, which requires an understanding of the treatment process and attendance of follow-up consultations with clinicians. Studies have suggested that health literacy plays an important role in the successful treatment and outcomes of cancer. For example, one prospective, population-based study of patients with cancer suggested that patients with higher health literacy were more likely to receive chemotherapy than their counterparts (Busch, Martin, DeWalt & Sandler, 2015). Furthermore, studies have shown that low health literacy has a direct impact on information-seeking; patients with low health literacy are less likely to seek printed information as they struggle to understand it and/or lack interest in reading (Von Wagner, Semmler, Good & Wardle, 2009).

Early health literacy interventions typically focused on simplifying medical language and improving readability of information resources in order to improve understanding of health information, however whilst showing some improvement, these interventions provided limited or mixed results (Davis et al., 1998; Gerber et al., 2005). Other interventions have focused on enhancing communication in the patient-clinician consultation, including presenting important information first, providing concise information whilst avoiding jargon, explaining medical terms, encouraging question-asking and checking understanding, all of which have been shown to increase patient understanding and recall (Ley, 1989). However, due to the current demands placed on the health system, consultations are often rushed and clinicians may not be able to identify those with low health literacy and forget to present information in this way. Consequently, patients often have to rely on written information, which is unlikely to be understood by those with low health literacy (Manning & Dickens, 2006).

More recently, interventions have focused on the relationship between cognition (i.e. processing speed, working memory and long-term memory) and health literacy due to

the association of the two on existing health literacy measures (Baker, Wolf, Feinglass, & Thompson, 2008) and the impact of cognitive ability on health outcomes (Insel, Morrow, Brewer, & Figueredo, 2006; Singh-Manoux, Ferrie, Lynch, & Marmot, 2005). A study of information recall for colorectal screening information found that although levels of health literacy were predictive of recall of information, cognitive ability accounted for much of the association, where those with poorer cognitive abilities recalled less information than their counterparts (Wilson et al., 2010). These findings have been supported by other similar studies, which have highlighted the potential usefulness of scientific learning principles when developing an intervention to help patients to meet their information needs, such as keeping the working memory demands low, sequencing and segmenting of the content, using a slow pace of learning and 'chunking' of information to improve recall and understanding (Kandula et al., 2009; Sobel et al., 2009).

For the purpose of this thesis, the health literacy literature highlights the importance of developing patients' skills to navigate their health and healthcare, such as enabling them to understanding cancer-related terminology, the written and verbal information that they are provided in consultations (or gather from other sources, such as the Internet) and the processes involved with their treatment. In terms of intervention development, recent studies encourage consideration of cognitive factors when designing interventions, in order to improve patients' ability to obtain and understand health information and enable performance of self-management behaviours (Wilson et al., 2010). These studies also suggest that such educational tools are best used as supportive interventions for those with limited health literacy, perhaps in the presence of clinicians, rather than relying on the intervention alone to provide information for patients (Wilson et al., 2010).

However, the concept of health literacy suffers from a limitation that has led to the development of the broader concept of 'patient activation' (Hibbard et al., 2004). Researchers argue that although a good predictor of health outcomes for patients, the concept of health literacy is a skills-based construct only and does not encompass the motivational aspect that is also crucial for behaviour change (Hibbard, Stockard, Mahoney & Tusler, 2004; Smith et al., 2013). Additionally, other measures of motivation, such as self-efficacy, tend to focus on specific behaviours, such as smoking (Smith et al., 2013).

3.3.6 Patient activation

Developed by Hibbard and colleagues (Hibbard et al., 2004), patient activation is described as a behavioural concept that includes the core components that are necessary for execution of self-management behaviours, defined as, '*an individual's knowledge, skill and confidence for managing their health and healthcare'* (Hibbard & Mahoney, 2010, p.1). Importantly, this concept encompasses an individual's motivation, as well as their knowledge, skills and beliefs about their ability to self-manage their condition (i.e. self-efficacy), and the likelihood that they will put these beliefs into action. The Patient Activation Measure was developed in order to measure these constructs (Hibbard et al., 2004).

Assuming that patients already have the skills to obtain the health information that they want (i.e. an adequate level of health literacy) but have low motivation, studies suggest that they may feel less able to self-manage their condition due to low confidence, have passive communication skills and less engagement in health behaviours (Hibbard & Cunningham, 2008; Hibbard & Mahoney, 2010). Patients with high levels of activation are expected to understand and feel capable of fulfilling their role in their care and as a result, are more likely to engage in preventive (e.g. screening, regular check ups), treatment (adherence to medications) and healthy behaviours (e.g. healthy diet, not smoking) (Hibbard & Greene, 2013). Patient activation has proven to be a changeable construct by tailored interventions and so a framework for understanding patients' capabilities, beliefs and behaviours at different levels of activation was developed to guide intervention development. This framework enables developers to tailor interventions to an individual's needs and levels of activation. Four levels of patient activation are described, ranging from low to high activation (Figure 6).

Four levels of patient activation	
Level 1	Individuals tend to be passive and feel overwhelmed by managing their own health. They may not understand their role in the care process.
Level 2	Individuals may lack the knowledge and confidence to manage their health.
Level 3	Individuals appear to be taking action but may still lack the confidence and skill to support their behaviours.
Level 4	Individuals have adopted many of the behaviours needed to support their health but may not be able to maintain them in the face of life stressors.

Figure 6*: The four levels of patient activation (from Hibbard & Gilburt, 2014, p9).*

Patient activation has been found to be a better predictor of health outcomes compared to other predictors, such as demographic variables, including socioeconomic status, education, ethnicity, age and gender, which suggests that patient activation is not just a reflection of these factors (Smith et al., 2013). With regards to chronic illnesses, such as cancer, higher activation levels are associated with self-management behaviours, such as adherence to treatment, condition monitoring and obtaining regular care, which are evident across a diverse range of patients and conditions (Kansagara, Ramsay, Labby & Saha, 2012; Ryvicker, Peng, & Feldman, 2012). Consequently, studies have associated higher patient activation levels with better clinical outcomes (e.g. lower blood pressure and cholesterol), and decreased health service costs due to lower rates of health service use (e.g. hospitalisations, re-admissions following discharge, visits to accident and emergency departments) (Greene & Hibbard, 2012). Importantly, patient activation is associated with improved experiences of care. Highly activated patients appear to have the skills and confidence to create more productive interactions with their clinicians and are more adept at getting their clinicians to meet their needs (Alexander, Hearld, Mittler & Harvey, 2012; Hibbard & Gilburt, 2014). As a result, more activated patients report better quality communication with clinicians and more contact outside of consultations than less activated patients (Alexander et al., 2012).

In contrast, those with low levels of activation typically misunderstand their role in their care, have little confidence in their abilities to contribute to their healthcare, possibly due to experience of failing to manage their health in the past, and so have become passive and would rather not think about their health (Hibbard & Mahoney, 2010). Less activated patients are also less likely to prepare questions for consultations, to ask if they don't understand what the doctor has said and understand the treatment guidelines for their condition (Fowles, Terry, Xi, Hibbard, Bloom & Harvey, 2009; Rogvi, Tapager, Almdal, Schiøtz & Willaing, 2012).

In order to engage the patients with low levels of activation, interventions must be tailored to their level of activation and patients should be encouraged to conduct a succession of smaller tasks to enable the individual to experience success, in order to increase their confidence and motivation, and progress to a higher level of activation. An example of such an intervention is where a specially trained medical assistant meets with less-activated patients prior to a consultation (Hibbard, Greene & Overton, 2013). The assistant helps the patient to formulate questions for their clinician in order to organize their priorities and get the most from the consultation. Following the

appointment, the patient revisits the assistant to discuss the consultation, where the assistant ensures that the patient understands the information provided and the patients' treatment plan is reviewed.

For a range of chronic conditions, such as diabetes and hypertension, studies of tailored interventions have reported increases in levels of patient activation (Deen, Lu, Rothstein, Santana, & Gold, 2011; Parchman, Zeber & Palmer, 2010; Solomon, Wagner & Goes, 2012). These interventions have typically focused on fostering patients' sense of responsibility for their health and the development of skills and confidence. Encouraging the use of strategies that stimulate autonomous motivation is also important so that patients begin to make choices for themselves and self-initiate the desired behaviours. Consequently, patients' sense of control and responsibility for their health are expected to increase with their level of activation (Ryan & Deci, 2000). Although there is a vast amount of recent studies that specify a 'patient activation' intervention for a variety of chronic conditions, there appears to be limited new studies that specify this type of intervention in cancer care. However, one systematic review of this type of intervention for patients with cancer reported positive effects on symptom distress, uncertainty, communication and quality of life, with some potential evidence for survival, though studies in this review pre-dated or did not use the PAM measure and so do not specifically refer to 'patient activation' (McCorkle, et al., 2011).

For the purpose of this thesis, this body of literature outlines the mechanisms by which interventions could improve cancer patients' engagement in their care. With regards to the knowledge-behaviour gap, the concept of patient activation highlights the importance of considering both patients' levels of knowledge and their illness-related skill set, as well as their confidence and motivation to engage in self-management behaviours, when developing behaviour change interventions to promote action-taking. This research further highlights the advantages of tailoring interventions to patients' levels of activation, particularly for those with the lowest levels of activation, in order to facilitate engagement with the intervention and encourage progression to a higher level of activation and thus achieve better outcomes.

3.4 Discussion
This chapter aimed to select, describe and critically appraise a selection of models, theories and approaches that are particularly relevant to the impact and self-management of cancer. The purpose of this exercise was to develop an understanding of patients' experiences of cancer, the issues that they might face and the type of app

that might best support them, in order to inform the development of an app intervention.

Discussion of the CSM (Leventhal et al., 1984), crisis theory (Moos & Schaefer, 1984) and the theory of cognitive adaptation (Taylor, 1983) highlighted parallels between central constructs, such as the Leventhal's interpretation stage (Leventhal et al., 1984) with Moos and Schaefer's cognitive appraisal (1984) and Taylor's (1983) search for meaning, and the coping stages of each model and theory. Overall, these models and theories suggest that cancer is a traumatic experience which disrupts an individual's 'normal' life, leading to a perceived loss of control. Viewed as a problem-solver, the individual has a need to regain perceived sense of control over their lives in some way and re-establish normality. Individuals are hypothesised to achieve this by developing an understanding of their illness, and consequently, executing suitable coping strategies. Coping strategies may be adaptive or maladaptive, depending on the situation and strategy used. Taylor's (1983) theory of cognitive adaptation further describes the impact of cancer on an individual's sense of control and self-esteem and the types of behavioural and psychological strategies that could be used to maintain these throughout the course of the illness. Overall, these theories on coping with a chronic illness advocated prominent role for illness-related knowledge in the self-management of, and adjustment to, a chronic illness, such as cancer. However, this chapter noted the disparities that are often found between an individual's knowledge and their actual health-related behaviours in health research (Gollwitzer & Sheeran, 2006; Schwarzer, 2008). Consequently, the roles of other constructs that are required for the execution of health behaviours were discussed, including self-efficacy and health literacy. Finally, this chapter introduced the concept of patient activation, which acknowledges that there are several important constructs that are required in order for patients to engage in self-management behaviours, including an individual's knowledge, skills, confidence and motivation. Consideration of these theoretical frameworks and approaches leads to the conclusion that information-only interventions, which aim to help patients with cancer to meet their information needs, will not necessarily lead to behaviour change. Although this type of intervention might increase patients' knowledge of their condition, other intervention components are likely required to enable patients to take a more active role in their health and healthcare.

A further limitation of knowledge – and interventions that aim to help patients with cancer to meet their information needs – is that it may not necessarily be beneficial at

all time points throughout a cancer journey or for all types of patients and their caregivers. It is important that intervention developers, and cancer clinicians, are aware of this body of literature so as not to prescribe the use of information interventions for those patients who may actually suffer consequences, such as increased anxiety, as a result of this type of intervention.

3.4.1 Implications of this review

Together, the health behaviour models, theories and approaches described in this chapter suggest that an app could be used to enable patients to develop an adaptive representation of their illness (i.e. illness cognitions), and promote the adoption of adaptive coping strategies. Furthermore, an app could be used to develop patients' cancer-related health literacy and subsequently, their knowledge, skills and confidence to participate in their care, which could increase patients' levels of activation and lead to better health outcomes. It is hypothesised that these outcomes may be achieved by an app intervention that facilitates information-gathering and understanding of this type of information, and an app that incorporates features that develop patients' skills and confidence to gather information. However, it is important that clinicians and intervention developers are aware that this type of intervention will not be suitable at all time points and for all patients with cancer and their caregivers.

3.4.2 Conclusion

This chapter reviewed and critically appraised a selection of health behaviour models, theories and approaches that are particularly relevant to the impact and self-management of cancer, and described how each may be useful for the development of a novel app intervention to help patients with cancer to meet their information needs in non-inpatient settings. Each of the models, theories and approaches discussed in this chapter appear to account for a piece of the puzzle regarding the impact of cancer on patients and successful self-management of the disease, and so each will be considered when developing of an app intervention. Consideration of these theories during development, alongside consultation with patients and their relatives, could lead to the development of an app that has the potential to improve patients' (and relatives') self-management of their condition, including their psychological coping, performance of self-care behaviours and participation in their care. Following interviews with patients and their relatives regarding their needs and preferences for an app, this selection of models, theories and approaches will be used to interpret findings and guide development of selected app features.

Chapter 4

The needs and preferences of patients with cancer regarding an app to help them to meet their information needs: a qualitative interview study with patients and their relatives

4.1 Chapter overview

This chapter reports a novel qualitative interview study that explored the views of patients and their relatives on their experiences of cancer, including their information needs and information exchange with clinicians in consultations, as well as their needs and preferences regarding an app intervention. This study was used to gain an understanding of the type of app that would be most useful and the potential uptake and possible outcomes of this type of intervention, including the benefits and disadvantages of, and barriers to, app use. Data from semi-structured interviews were analysed using thematic analysis. The implications of these findings for the creation of an app intervention are discussed.

4.2 Introduction

As described in Chapter 1, many patients with cancer and their relatives report having unmet cancer-related information needs (Faller et al., 2016; Kitrungrote & Cohen, 2006). The introduction of Smart technology has provided a new opportunity to deliver interventions to patients and their relatives remotely. A systematic review of the literature conducted for this thesis, described in Chapter 2, identified the need for an app intervention to help patients, and their relatives, to meet their full range of information needs in non-inpatient settings. Prior to creating an intervention, the MRC framework (Craig et al., 2008) for the development of complex interventions in healthcare encourages researchers to identify the evidence base, relevant theories, model processes and outcomes. The evidence base and relevant theories for this type of intervention were described in Chapters 1- 3. Next, it is important to determine the views of users of the intervention in order to further establish the evidence base and identify the potential processes and outcomes of this type of intervention.

Furthermore, frameworks and approaches that were created to guide the development and evaluation of digital health interventions highlight the importance of the psychosocial context (Glasgow, 2007; Yardley et al., 2015). For example, the 'person-based' approach developed by Yardley and colleagues (2015) advocates a two-step developmental process, the first of which involves conducting iterative, in-depth qualitative research with a varied sample from the target user population at every

stage of intervention development, including planning, usability testing, feasibility testing and implementation stages. This provides a deep understanding of the views of various types of users to tailor the intervention accordingly and continually improve the intervention throughout these stages. Additionally, this information helps the researcher to anticipate the potential uptake of the intervention and its possible outcomes, including the potential benefits and disadvantages of, and barriers to the intervention. This process ultimately enables development of interventions that are more relevant and engaging for its users and helps to circumvent or minimise common issues in digital intervention research, such as low uptake and adherence (Kohl, Crutzen & de Vries, 2013). Following identification of the type of intervention required by users, the second step in the 'person-based' approach is to identify the objectives of the intervention and the key features (i.e. app features) which are required to achieve each objective.

4.2.1 Aims of the present study

To date, no study has sought to understand the needs and preferences of patients with cancer, and their relatives, regarding an app that aims to help them to meet their full range of cancer-related information needs in non-inpatient settings. The primary aim of this study was to explore the value of an app for patients with cancer and to establish the type of app required. This included exploration of their information needs and experiences of information exchange in consultations with clinicians, and their preferences for an app and its features. Specifically, the perceived acceptability of an app, desired app features and the potential benefits and disadvantages of, and barriers to, an app were explored, as well as the types of patient and the time at which they might find this intervention most useful. A secondary aim of this study was to explore the views of relatives in order to establish the value of an app which may be used by both the patient and their relatives.

4.2.2 Qualitative methods

Qualitative methods enable a more personal response from individuals compared to quantitative methods and so a qualitative method was chosen for this study to allow the candidate to gain a more in depth understanding of a phenomenon from the perspective of the individuals affected (Green & Thorogood, 2013). Qualitative methods, such as in-depth semi-structured interviewing, are also best suited when the subject matter is a sensitive topic, such as cancer (Smith, 2007). A sensitive topic can be defined as one having the potential to cause physical, emotional or psychological distress to participants or the researcher (Elmir, Schmied, Jackson & Wilkes, 2011).

Semi-structured interviews were chosen to allow participants the freedom to bring up other issues that they felt were relevant and allow the candidate the freedom to deviate from the topic guide to further explore any issues raised (King & Horrocks, 2010). Although interviews on sensitive topics have the potential to cause some discomfort, studies have shown that generally, interviewees perceive the interview process to be beneficial (East, Jackson, O'Brien, & Peters, 2010; Gysels, Shipman & Higginson, 2008). Participants may feel empowered by having their stories and opinions listened to and feel a sense of purpose, and being valued, by contributing their experiences to research (East et al., 2010; Gysels et al., 2008). There is also evidence that many participants find sharing their thoughts to be therapeutic, as they undergo a reflective process of their experiences, which provides them with a sense of closure and relief (East et al., 2010; Elmir et al., 2011).

Multi-perspective interviews, where several different groups of participants are interviewed on the same topics (i.e. patients, their relatives and clinicians) were chosen for this study in order to produce a richer understanding than single perspective interviews (Kendall et al., 2009). This research method allowed the candidate to explore the similarities and differences in participants' perceptions, understand their relationships and generate a consensus of suggestions for app features (Kendall et al., 2009). As well as having their own unmet information needs, relatives were interviewed as they are often present during consultations and it was anticipated that some patients might be too elderly, unwell or may not wish to use an app, in which case their relative may wish to use the app on the patient's behalf.

Patients and relatives were offered the opportunity to be interviewed together if they wished to do so. This was done to aid recruitment of participants who would not be likely to take part in research alone. Joint interviews offer the benefit of participants building on each other's answers, which may prompt them to explore topics that they may not have thought about themselves and describe their shared experiences (Gysels et al., 2008; Kendall et al., 2009). Other authors have considered how joint interviews can sometimes constrain the discussions, as it is difficult to get a full account from both participants on the same topic and some participants may withhold information that might cause distress for one another, known as 'protective buffering' (Hagedoorn et al., 2000; Kendall et al, 2009). These issues can lead to joint and separate interviews with patients and their caregivers providing different results. The

topics of the interview guide were carefully considered in order to minimise these potential issues (Kendall et al, 2009).

Thematic analysis was selected to analyse interviews, as this method helps to provide insights by moving from a broad reading of the data to reporting patterns and themes, followed by their interpretation (Braun & Clarke, 2006). The thematic analysis conducted was not considered purely inductive, nor deductive. Instead, it can be considered a blend of both approaches. Inductive approaches are those that start from the data and search the data for patterns that suggest general laws, ultimately aiming for theory generation. In contrast, deductive approaches start with hypotheses that are derived from a theory which are then tested against a body of data that was gathered to test the hypotheses. However, many researchers argue that in practice, all research incorporates elements of both inductive and deductive logic. For example, Murphy and Dingwall (2003) argue that researchers are unable to analyse data with a completely blank slate as there are always theories and assumptions that shape the way in which we read and interpret the data. Similarly, they argue that theories and hypotheses do not come ready formed and researchers select particular theories to test and may have preconceived ideas about how to test them. The polarisation of inductive and deductive approaches is unhelpful and it is important to acknowledge that qualitative methodology can be a blend of both logics.

4.3 Methods
4.3.1 Participants

Maximum variation sampling, a type of purposeful sampling strategy in which cases are selected on the basis of the study population characteristics and study objectives, was used to allow for divergent views to emerge (Patton, 2002). Patients were recruited from cancer clinics within University Hospital Wales (UHW) and Velindre hospital. Clinics at UHW provided access to more recently diagnosed patients who were waiting to have or had undergone surgical treatment, whereas clinics at Velindre hospital provided access to patients who were undergoing chemotherapy, radiotherapy, hormone therapy treatment or were in remission. Initially, patients were recruited from colorectal and urological cancer clinics at UHW and breast and gynaecological cancer clinics at Velindre hospital. These four cancer types were chosen in order to have a variety of some of the most common cancers in the participant sample (Welsh Cancer Intelligence Surveillance Unit (WCISU), 2015). A decision was made to include a varied sample of patients, including:

     i.   Patients undergoing surgery, radiotherapy, chemotherapy or hormone therapy for cancer

     ii.   A range of cancer types: breast, gynaecological, colorectal and urological

     iii.   Women and men

     iv.   Patients older than 60 years and patients younger than 60 years

Patients' eligibility for the study was assessed by cancer nurse specialists (CNSs) at the clinics using the following inclusion and exclusion criteria:

Inclusion criteria:
  i.   Male or female
  ii. Aged 18 or above
  iii. Receiving neoadjuvant, adjuvant, radical or palliative treatments
  iv. At least 2 weeks after diagnosis (to allow patients time to come to terms with their diagnosis)
  v. Able to give informed consent

Exclusion criteria:
  i.   Patients who do not have an estimated life-expectancy of at least 12 months.
  ii. Patients who the clinician deems to be unsuitable for the research (for example in a current state of crisis or have their own significant health or social problems, unable to provide informed consent, or other reason for not being approached about the study).

Although lung cancer is the third most common cancer in the UK, the majority of patients (72-76%) with this cancer are diagnosed at a late stage, either stage III or IV (National Cancer Intelligence Network (NCIN), 2016; Information Services Division (ISD) Scotland, 2016; Northern Ireland Cancer Registry (NICR), 2016). Diagnosis of lung cancer at these later stages is associated with poor survival rates. For example, it is estimated that less than 20% of patients diagnosed at stage IV will survive their cancer for a year or more (Cancer Research UK, 2017). Patients with lung cancer who are diagnosed at a late stage and have poorer prognoses may have different needs and preferences regarding an app, compared to patients with cancers who are diagnosed at earlier stages with better prognoses. The candidate and supervisory team also had concerns about the potential impact of study participation on those patients with lung cancer (and other cancers) who had poor prognoses and this issue was raised by, and discussed with, the NHS ethics committee. A decision was made to

avoid recruitment of patients with lung cancer for this study and at this early phase of development of the app. For the same reasons, recruitment of any patient with less than 12 months life expectancy was also avoided. The candidate and supervisory team acknowledged that this decision may be perceived as gatekeeping. However, it was anticipated that a wider range of patients, including those with rare cancers and/or poorer prognoses, could be recruited for future studies of the app at a later stage of development to explore the potential differences and similarities in need or preferences regarding an app, compared to other patients with cancer.

4.3.2 Patient recruitment

CNSs that took part in qualitative interviews (see Chapter 5) were asked to assess patients' eligibility and recruit patients for the present study. Two CNSs from each of the breast, colorectal, gynaecological and urological cancer clinics agreed to help. The CNSs were provided with a total of 15 information packs per clinic to distribute to eligible patients, which contained an invitation letter printed on the relevant cancer clinic headed paper and signed by the lead clinician (Appendix 3), an information sheet (Appendix 4), reply form (Appendix 5) and pre-paid envelope addressed to the candidate at Cardiff University. Pre-paid envelopes and headed and signed invitation letters were used to increase response rates (Edwards et al, 2002). As relatives were being recruited through patients, an invitation letter (Appendix 6) and an information sheet addressed to relatives (Appendix 7) were included in patients' information packs. The candidate kept in contact with the CNSs to track how many information packs were distributed to patients in order to determine the response rate.

Recruitment using this method was slow, possibly because most patients were recruited from UHW clinics, where they had been diagnosed fairly recently and were perhaps emotionally unprepared to participate in research. The candidate's clinical supervisor contacted the clinical trials unit (CTU) manager at Velindre hospital to help with recruitment. Patients having treatment at Velindre hospital have typically had more time to come to terms with their diagnosis, are likely to be familiar with their treatment regime and have more spare time, as their treatment often takes several hours, which means they may be more willing to participate in research. The CTU manager at Velindre was provided with information packs and asked to recruit patients with colorectal, gynaecological, and urological cancers (an adequate sample of patients with breast cancer had already been successfully recruited). The candidate kept in contact with the CTU manager to track how many information packs were distributed to patients.

4.3.3 Recruitment of relatives

Information sheets given to interested patients asked if they had a relative or close friend who would participate in the study. Relatives (or friends) were asked to indicate their interest in the study by ticking a box on the patient's reply form and include their contact details. Once received, the candidate contacted the patient to arrange an interview time that was suitable for both the patient and their relative. Relatives' eligibility for the study was assessed using the following criteria:

Inclusion criteria:
  i. Male or female
  ii. Aged 18 or above
  iii. Close family member (or friend) of a patient receiving neoadjuvant, adjuvant, radical or palliative treatments, as specified under patient sample inclusion criteria
  iv. Able to give informed consent

Exclusion criteria:
  i. Relatives (or friends) of patients with an estimated life expectancy of less than 12 months.
  ii. Relatives (or friends) of patients who the clinician deems to be unsuitable for the research (for example in a current state of crisis or have their own significant health or social problems, unable to provide informed consent, or other reason for not being approached about the study).

4.3.4 Procedure

The CNSs or CTU manager described the study to eligible patients and invited them to participate by providing them with an information pack. All written information was tested using a readability formula to ensure that it was easy to read (http://www.readabilityformulas.com/free-readability-formula-tests.php). Interested patients returned the reply form to the candidate in the prepaid envelope detailing their contact information. The candidate telephoned or emailed interested patients to answer any questions about the study and to arrange an interview in their own homes, at a time convenient for them. Participants were offered reimbursement of their travel expenses if they wished to have the interview at another location. At the time of the interview, patients and relatives were each provided with a consent form to sign and a further opportunity to ask questions about the study (Appendices 8-9). The candidate

explained that the interview was confidential and that only the candidate and lead supervisor would have access to the data. Participants were informed of how the data would be anonymised, stored securely and kept for 15 years at Cardiff University, after which it will be deleted. Demographic information was then collected from participants by questionnaire prior to the start of the interview (Appendices 10-11). Relatives were given the option of having an interview jointly with the patient or separately. Where a relative was present, the interview would be directed at the patient as the patients' views were most important to the study, however the relative would be asked for their views and opinions where appropriate. Interviews were audio-recorded with permission and audio-files were sent electronically to a reputable company for transcription by uploading the files to a secure server used by the transcription company. Audio-recordings were transcribed verbatim, which means that a full transcript of everything that was said in each interview was provided (including common terms, such as 'ums' and 'ers', and sometimes repetitive 'I mean', 'sort of', 'you know' etc). All contractions were typed as said (e.g. don't and couldn't) and 'ums' and 'ers' retained within the script. Any information that could identify participants in the interview was anonymised on the transcript. A confidentiality agreement was required from the transcription company to ensure that participant data and information was protected. Once the completed transcripts were provided to the candidate, the candidate listened to the audio-recordings whilst reading the transcripts to check for accuracy.

4.3.5 Data management
Transcripts and audio-recordings were securely stored on a Cardiff University password-protected server in accordance with the Data Protection Act 1998. This server is password-protected and confidential. All consent forms, transcripts and audio-recordings will be kept securely for 15 years according to Cardiff University research data policies. Following this time, all data will be destroyed.

4.3.6 Interview topic guide
A semi-structured interview topic guide was used (Appendix 12). Two separate interview schedules were originally created for patients and relatives, however as all participants chose to be interviewed together, the patient interview topic guide was used and relatives' opinions were sought where appropriate. Studies included in and findings of the systematic review (i.e. to identify gaps in the evidence base), and other relevant literature on the use Smart technology to deliver interventions in healthcare, informed the development of the topic guide. The topic guide was reviewed by the candidate's supervisors and amendments to the topic guide were made following

comments. The topic guide was then piloted on two post-graduate students at Cardiff University to ensure simple language was used and leading questions were not asked. The main topics covered at interview were: information needs, communication with clinicians in consultations, experience with Smart technology, perceived acceptability of an app for patients with cancer, desired app features, and the perceived benefits and disadvantages of, and barriers to, this type of intervention. At the beginning of the interviews, the candidate briefly explained the type of app that might be useful (i.e. one to help with their information needs) and described examples of types of app features in order for them to imagine what types of features are possible to include in an app. For participants who were unfamiliar with apps, the candidate briefly explained what an app is and showed them an example on a Smartphone.

4.3.7 Analysis

Patients were interviewed until data saturation was reached to ensure that adequate data were collected and the views of patients were represented. Data saturation was considered to have occurred when no new themes were identified for at least the final three interviews. Data were managed using the qualitative analysis software package NVivo (NVivo, 10). Interview transcripts were analysed using thematic analysis (Braun & Clarke, 2006). Each anonymised transcript was read several times for familiarity, actively searching for, and noting, meanings and patterns. Initial codes were generated from each data item and mind maps were created to identify the links between codes and possible overarching themes. Codes were then organised into meaningful subthemes and main overarching themes. Themes were reviewed and refined by reviewing each data item within a theme to ensure coherence. All themes were reviewed for validity in relation to the dataset as a whole, to ensure the final thematic framework accurately reflected the dataset. Finally, themes were defined and refined to reflect the essence of the theme. Five transcripts were independently analysed by the candidate's supervisor, Dr Fiona Wood, who has extensive experience of qualitative research, in order to reduce the potential bias of subjectivity associated with coding and facilitate interpretation of findings. Discrepancies were resolved through discussion.

4.3.8 Researcher values and relationship to participants

It is important to reflect upon the personal values of the researcher, and the relationship between the researcher and the participant, when conducting qualitative research. The researcher requires an awareness of these how these might influence responses during an interview and interpretation of the findings. Firstly, I was aware

that I had not experienced living with cancer and so may not fully understand participants' experiences or the psychosocial context. Secondly, during interviews, I was conscious of how I may be perceived by participants. Some participants may have perceived me to be of a higher social standing due to my role as a researcher from a reputable university and may have been conscious that I was in contact with some of their cancer clinicians. I was aware of how this might influence participants' trust and openness during the interview and so made every effort to build rapport prior to the interview to make the participant feel comfortable. I assured participants that the interviews were confidential, that their views and opinions would not be discussed with their clinicians and any data published as a result of this study would be anonymised and could not be linked back to them in any way.

4.3.9 Ethical Issues

NHS ethical approval and R&D approval from each of the sites was granted (14/WA/0066, Appendices 13-15).

4.4 Results

Twenty three interviews were conducted with 32 participants in their own homes between November 2014 and February 2015. All relatives chose to be interviewed jointly with the patient. The average length of the interviews was 43 minutes (range 16-75 minutes).

4.4.1 Sample characteristics

Patient participants

A total of 130 information packs were distributed to eligible patients: 40 were distributed to urological cancer patients, 30 to colorectal cancer patients, 30 to gynaecological cancer patients and 30 to breast cancer patients. A total of 33 patients returned a reply form indicating interest in participating. Out of the 33 patients who responded and contacted, 23 participated and completed the study (overall response rate 17.7%). Four patients did not answer the telephone or respond to emails, four stated that they were not well enough to participate at the time, one patient was on holiday, and one patient declined to participate in the study. Characteristics of patient participants are presented in Table 2. The most common age category was 56-65 years (n=8). There were 12 females (52%) and 11 males (48%). The most common cancer type was colorectal (n=10, 44%) and the rest of the sample was made of up gynaecological (n=5, 22%), breast (n=4, 17%), urological (n=3, 13%) and other (n=1, 4%) cancers. The response rate of patients from each cancer type was 7.5% (3/40) for

urological cancer patients, 13.3% (4/30) for breast cancer patients, 16.6% (5/30) for gynaecological cancer patients and 33.3% (10/30) for colorectal cancer patients. Time since diagnosis ranged from 3-6 months to over 5 years and the most common time since diagnosis was 1-2 years (n=8). Level of education was collected as a proxy of socio-economic status. Nearly three-quarters of participants were educated to at least secondary level (n=17, 74%) and over a quarter were educated to degree level (n=6, 26%). All participants were white Caucasian. Seventeen out of 23 patients (74%) reported that they owned (or co-owned) a Smart device (Smartphone or tablet). Patients and relatives tended to own their own Smartphones and share a tablet device with their partner.

Table 2: *Patient sample characteristics.*

ID	Age	Gender	Cancer type	Time since diagnosis	Education level
P1, Jim	66-75	M	Urological	2-4 years	GCSE/O levels
P2, Vicky	18-25	F	Gynaecological	3-6 months	Diploma
P3, John	66-75	M	Colorectal	1-2 years	None specified
P4, Michael	66-75	M	Colorectal	2-4 years	Degree
P5, Pam	56-65	F	Breast	3-6 months	Post-graduate degree
P6, David	66-75	M	Colorectal	3-6 months	None specified
P7, Julie	56-65	F	Colorectal	2-4 years	Degree
P8, Mandy	56-65	F	Gynaecological	5 years +	Degree
P9, Moira	85+	F	Colorectal	1-2 years	None specified
P10, Sue	66-75	F	Other	1-2 years	None specified
P11, Dawn	46-55	F	Gynaecological	2-4 years	GCSE/O levels
P12, Kay	46-55	F	Breast	1-2 years	Missing data
P13, Lynne	56-65	F	Gynaecological	2-4 years	Degree
P14, George	66-75	M	Colorectal	1-2 years	Post-graduate degree
P15, Albert	76-85	M	Urological	1-2 years	Diploma
P16, Ralph	56-65	M	Colorectal	6 months -1 year	None specified
P17, Jackie	46-55	M	Colorectal	6 months -1 year	Degree
P18, Martin	56-65	M	Colorectal	2-4 years	GCSE/O levels
P19, Paula	36-45	F	Breast	1-2 years	NVQ/HNC/HND
P20, Beryl	56-65	F	Gynaecological	1-2 years	Degree
P21, Nerys	66-75	F	Breast	5 years +	GCSE/ O levels
P22, Clive	76-85	M	Colorectal	2-4 years	None specified
P23, Paul	56-65	M	Urological	3-6 months	GCSE/O Levels

Relative participants

Fourteen patients (42% of 33 patients) returned a reply form indicating a relative's interest in participating in the study. Of those 14 nominated relatives, nine did not wish to participate in the study as they were nominated by patients that did not participate in the study. Five relatives agreed to participate in the study (response rate 36%). During the patient interviews, four extra relatives volunteered to participate in the study, resulting in a total of nine relative participants. Characteristics of participants are presented in Table 3. Two thirds of relatives were spouses or partners of the patients (n=6) and the majority were educated to at least secondary level (n=7). All participants were white Caucasian. All relatives reported that they owned (or co-owned) a Smart device.

Table 3: *Sample characteristics of relatives.*

ID	Age	Gender	Relationship to patient	Educational level
R1, Sadie	66-75	F	Wife of P1, Jim	NVQ/HNC/HND
R2, Geraint	18-25	M	Boyfriend of P2, Vicky	Diploma
R3, Helen	56-65	F	Wife of P3, John	GCSE/O levels
R4, Stella	36-45	F	Daughter of P4, Michael	A levels
R5, Susan	56-65	F	Partner of P5, Pam	Post-graduate degree
R6, Lucille	46-55	F	Daughter of P6, David	GCSE/O levels
R7, Sarah	36-45	F	Daughter of P6, David	NVQ/HNC/HND
R8, Maude	56-65	F	Wife of P6, David	Other
R9, Henry	Missing data	M	Husband of P9, Moira	None specified

4.4.2 Interview themes

From the interviews, two key themes were identified: (1) information needs, and (2) opinions on an app for patients with cancer. Subthemes will be discussed in detail below. Figure 7 presents the full theme hierarchy in the format of a flowchart. Patient participants are identified with 'P' and relatives with 'R', followed by their identification numbers in Tables 2 and 3, respectively, and a pseudonym. The interviewer is identified with 'I'. Where irrelevant, text was removed from quotes and denoted by {…}. Square brackets within the quotes represent inserted text to clarify the content. Exemplar transcripts are included in appendices 16 to 19.

Figure 7: Flowchart of themes from interviews with patients and relatives.

Theme 1: Information needs

- Subtheme 1: Information-seeking as a coping mechanism
- Subtheme 2: Unmet information needs
- Subtheme 3: Barriers to information exchange in consultations
- Subtheme 4: Sources of cancer-related information

Theme 2: Opinions on an app for patients with cancer

- Subtheme 1: Anticipated acceptability
  - Subtheme 1a: Anticipated uptake
  - Subtheme 1b: Anticipated ease of use
- Subtheme 2: Suggested app features
  - Subtheme 2a: Features that support patients' self-management of their condition
  - Subtheme 2b: Features that facilitate information-exchange in consultations with clinicians
  - Subtheme 2c: Features that increase access to patient support
  - Subtheme 2d: Features that increase access to support for relatives
- Subtheme 3: Anticipated benefits of app use
- Subtheme 4: Potential disadvantages of app use
- Subtheme 5: Potential barriers to app use

Theme 1: Information needs

This theme reflects the views of patients and their relatives on the use and importance of information during cancer and their experiences of cancer consultations. Key subthemes related to information needs were: information-seeking as a coping mechanism, unmet information needs, barriers to information exchange in consultations and sources of cancer-related information.

Subtheme 1: Information-seeking as a coping mechanism

Both patients and relatives described a cancer diagnosis as a shocking, upsetting and overwhelming experience. Cancer was talked about as a shared experience, particularly by patients and their spouses, who felt cancer impacted them equally.

> P13, Lynne (55-65 years, gynaecological cancer) - …Of course to be told you've got cancer you know, your whole world crashes around you.
>
> R5, Susan (56-65 years, partner of P5, Pam – …you lose total control of your whole lives you know it's all about, you know hospital appointments, we've got a diary with hospital appointments you know, it's....and the first couple of weeks it was just hospital appointments.
>
> R8, Maude (56-65 years, Wife of P6, David) – I mean the terrible thing that we went through was that ((David)) was diagnosed and it was a shock and it was, I mean it probably worried me I think more than ((David)).

As a result, the majority of patients and their relatives reported that they had wanted in depth information on their condition following diagnosis and talked about their information-seeking and learning about their condition as if it was a coping mechanism. Having information enabled them to prepare themselves for treatment, relieved some of their anxiety and helped them to regain a sense of control over their lives (e.g. Appendix 16 (transcript for P5 Pam and R5 Susan), lines 673-815; Appendix 17 (transcript for P3 John and R3 Helen), lines 189-194).

> R5, Susan (56-65 years, partner of P5, Pam) - …Anything and everything we could get our hands on we read…we wanted to know the type, you know, we wanted to know what was going to happen, how you were going to do that.

> P20, Beryl (56-65 years, gynaecological cancer) - I suppose we want to know more, I suppose I'm a bit of a controlling person, I've always been a controlling person over my own life and know I still want to be that controlling person, so that's why I want information …to try to, or to trick myself into thinking that I have some control.

A minority of participants only wanted the minimum amount of information necessary, directly from their clinicians only, and explained that this was because they knew that this information was accurate. In contrast, the Internet was viewed by this group of participants as a source of unreliable and potentially threatening information, which increased their anxiety.

> P19, Paula (36-45 years, breast cancer) – I think I was very lucky because with the experts that I dealt with they only gave me the information I needed and nothing else, because if you do go to the Internet and you do search you get bombarded with too many bad scenarios that might not be your case, so from start I can tell you, from my diagnosis I've never, ever tried to investigate anything on the Internet at all.

Subtheme 2: Unmet information needs

Some patients and relatives did not appear to be satisfied with the information they had received during the illness and it was apparent that some patients were provided with more information from their clinicians than others (e.g. Appendix 16 (transcript for P5 Pam and R5 Susan), lines 152-229, lines 398-408; Appendix 19 (transcript for P13 Lynne), lines 267-291). Participants recalled a range of unmet information needs, including information on treatment-related side effects, cancer support services, lifestyle changes (e.g. diet, exercise and smoking), survival and recurrence rates, alternative therapies, managing finances, psychological support and logistical issues, such as parking at the hospital. One patient recalled that she had not had her surgery explained to her, which left her with many questions that she felt too embarrassed about to ask.

P22, Clive (76-85 years, colorectal cancer) -… I had to search [for information] I did, with a few friends asked friends, and they said well so and so had it have a chat with them, you know things like that, that's the way I had to go around it

P13, Lynne (56-65 years, gynaecological cancer) –…After my operation …nobody spoke to me at all, because um it's a bit sort of I suppose it might sound a bit personal you know when you've had your womb removed it's stupid ((laughs)). Things like, cos I had everything removed, I know this is very specific to womb cancer, but womb, cervix and you think stupid things like well okay, so is there just a big hole there now?
I - Yes, so you had questions?
P13, Lynne – Yeah, but very sort of you know...not even specifically related to the disease, but what had happened to my body?
I –…So no one spoke to you about that sort of thing?
P13, Lynne – No, no one mentioned um sex, and you know, was it okay?

Subtheme 3: Barriers to information exchange in consultations
The unmet information needs of patients (and their relatives) appeared to be primarily due to barriers to communication of information in consultations, which are briefly described. Many patients reported that they found it difficult to concentrate in consultations due to anxiety and/or the effects of chemotherapy on their cognitive abilities (e.g. Appendix 16 (transcript for P5 Pam and R5 Susan), lines 1813-1826). Some patients were conscious of the amount of time that they spent with or contacting clinicians due to an awareness of their heavy workloads (e.g. Appendix 19 (transcript for P13 Lynne), lines 340-345) or reported that clinicians and nurses were hard to reach when they needed information (e.g. Appendix 18 (transcript for P19 Paula), lines 541-546; Appendix 19 (transcript for P13 Lynne), lines 205-211 and 373-375).

P20, Beryl (56-65 years, gynaecological cancer) - …You just completely forget what you've gone in [to the consultation] for, sometimes you forget what you're saying half way through your saying it. If you've got treatment, it really affects your short-term memory. I can be halfway through a sentence and I don't know the end of the sentence…it's, it's a real issue.

Some participants perceived a power imbalance, where they believed that their clinician was of superior authority. Furthermore, some patients reported that they did not understand some of the medical terminology used by clinicians in consultations or the cancer information resources that they were provided.

> P13, Lynne (56-65 years, gynaecological cancer) – … You know me being me I kept apologising and he [the clinician] said, "It's alright, I understand, you know", because you know there is the white coat syndrome as well isn't there? Where you go in and everything in your mind goes blank
> I - What do you mean by the white coat syndrome?
> P13, Lynne – The whole thing of you know, as soon as you go into a medical professional setting, maybe more someone of my age who is used to, I mean I'm still surprised when a doctor comes up to me in hospital and says, "I'm Luke I'm one of the doctors", I expect it to be, "I'm Dr so, and so", ((laughs)) and there's that sort of you know, it's a doctor…! And I know it's silly, but uh…and when I go to the GP, I take a list with me because you do, you've got that sort of, again, you're afraid of wasting time, and you've got that oh it's a doctor!

> P2, Vicky (18-25 years, gynaecological cancer) – Yeah they give us different leaflets, for different sorts of things you know
> I – Did you look at those, or did you...?
> P2, Vicky– No. I've read quite a few but there are words I don't quite understand {…}
> I –Okay, so you said there's quite a few words that you didn't really understand?
> P2, Vicky– Yeah I don't know what they mean to be honest
> R2, Geraint (18-25 years, boyfriend of P2, Vicky) - No, they're doctors' words and they…they're not simple for a layman like myself.

It appeared that these barriers meant patients sometimes forgot to ask or lacked confidence to ask questions and struggled to digest and recall information from consultations.

Subtheme 4: Sources of cancer-related information
Generally, it appeared that the cancer consultant was patients' and relatives' primary and most valued source of information, as this information was trusted and specific to their condition.

P2, Vicky, (18-25 years, gynaecological cancer) – Sometimes I try not to Google because like, it's not all reliable. So when I want information, if anywhere, I ask my doctor.

P13, Lynne (56-65 years, gynaecological cancer) – um well mainly from the doctor I'd get it [information]. I didn't really, I would sort of look at websites, but I didn't really trust you know? I wanted it from the mouths of the professionals

Most patients and relatives also tended to gather information from other sources, most commonly from the Internet, though some found it difficult to identify relevant and reliable information online (e.g. Appendix 18 (transcript for P19 Paula), lines 16-22). Other sources included other cancer patients, cancer charities and family and friends, support groups and social media. No patients reported having previously used an app for cancer and only one relative reported using the NHS app to look up health information about her partner's cancer (e.g. Appendix 17 (transcript for P3 John and R3 Helen), lines 842-860).

I - …Is there any reason why you haven't used the Internet?
R2, Geraint (18-25 years, boyfriend of P2, Vicky) - Well we have looked a little bit in the beginning, but now we get information from the hospital. Everybody's different, the treatment for everybody is different...and different chemo's are for different treatments for particular people as well
I – So you find that the information on the Internet is too general, the doctors can give more specific information? Is that correct?
P2, Vicky - Yeah more specific.

Theme 2: Opinions on an app for patients with cancer and their families
This theme reflects the needs and preferences of patients and their relatives regarding an app and their views on the potential outcomes of this type of intervention. Key subthemes were: anticipated acceptability, suggested app features, anticipated benefits, potential disadvantages, and anticipated barriers.

Subtheme 1: Anticipated acceptability
Subtheme 1a: Anticipated uptake

The majority of patients and relatives anticipated that they would have used an app during cancer, if it was available, in order to learn more about the illness. Participants believed that other patients would also find this type of app to be useful.

> P11, Dawn (46-55 years, gynaecological cancer) - I find that what I wanted was to know as much as I could...I wanted to understand it [the cancer], so um, so I'd find it [the app] really useful.

> I – …And what about friends, friends and family of the patients?
> P5, Pam (56-65 years, breast cancer) – Yes I'm sure
> R5, Susan (56-65 years, partner of P5, Pam) – I would've been on it [the app]
> P5, Pam– Everybody wants to help
> R5, Susan – Absolutely

Some participants anticipated that younger patients would be more experienced with Smart technology and therefore more likely to use an app compared to older patients, who may be more inclined to use traditional methods to source information, such as asking a friend or the doctor.

> I - So the type of app we've talked about, do you think that patients would want to use this app?
> P8, Mandy (56-65 years, gynaecological cancer) – I don't know if older people would
> I – Okay and why do you think that?
> P8, Mandy – Um, I don't think they use phones as much as, like your generation do, it's like you have to be glued to them you can't leave them...you gotta have them. I think I grew up looking up information, so I do see the Internet as a means of finding information but, I also like asking people things. But I think, because younger generations have grown up with phones and tablets and things then possibly you'll make more use of them, whereas I think maybe older people might ask things first, be told about them and maybe have a look at them.

Patients recalled how each phase of cancer prompted new questions for them and the need for new information. Participants therefore believed that an app would be useful for all types of cancer and all phases of the disease, including diagnosis, pre-treatment, during treatment, post-treatment and remission. Patients expected an app to

be most useful following diagnosis, as they recalled having the greatest need for information at this point.

> I – …What about the different stages of cancer, do you think it would be useful for diagnosis, or treatment, or post treatment …or do you think it could be used throughout all of these stages?
> P12, Kay (46-55 years, breast cancer) – All of it I think, because obviously you're diagnosed, "What happens next?" Like the treatments, "What happens next?" You know?

> P20, Beryl (56-65 years, gynaecological cancer) - …it was just, I'd say diagnosis was the big one, I needed loads and loads and loads of information then

Subtheme 1b: Anticipated ease of use
Most patients and relatives anticipated that they, and future patients, would find a cancer app easy to use, as the majority of the general population already use and are familiar with apps. Furthermore, participants believed that apps are intuitive to use.

> R2, Geraint (18-25 years, boyfriend of P2, Vicky) - Yeah I'd think it would be fairly easy, as long as the information is accessible and you haven't got to go through like about 20 sub-headings to get the information that you need.

> P1, Jim (66-75 years, urological cancer) - Most apps I would suspect, they're not too difficult to use, but whether they're focused on what you're looking for…but the use of the app, I suspect the average person these days, if they're using other apps, will find out [how to use it].

Some participants with no or limited experience with Smart technology suggested that they would need some initial training on how to use an app but anticipated that they would be able to learn how to use fairly easily.

> P15, Albert (76-85 years, urological cancer) – I might like a little training, perhaps one session but uh, because as I say, I've never used one I wouldn't know how to start with it…I would soon pick it up I think.

Subtheme 2: Suggested app features

Overall, suggestions for app features by patients and their relatives indicated that they primarily wanted an app that would help to increase their knowledge of the illness and meet their full range of information needs. Relatives reported that they wanted the same app features as the patient. Some participants found it difficult to think of app features and instead, listed the types of information that they had previously wanted. The most commonly suggested features were organised into the four themes: (1) Features that support patients' self-management of their condition, (2) features that facilitate information exchange in consultations with clinicians, (3) features that increase access to patient support, and (4) features that increase access to support for relatives.

Subtheme 2a: App features that support patients' self-management of their condition
Patients and relatives suggested features that would facilitate patients' self-management of cancer, such as self-care behaviours for symptoms and treatment-related side effects. The majority of participants desired an informational feature that would contain the types of cancer-related information that they had wanted previously, as described in section '*Subtheme 2: Unmet information needs'*. Participants wanted information that was specific to their cancer and imagined this feature to be like an 'Ask Jeeves' website, where you would perhaps write a specific question in the app and immediately get the information you need (Appendix 17 (transcript for P3 John and R3 Helen) lines 876-899).

> P11, Dawn (46-55 years, gynaecological cancer) – Well the sort of information that I wanted was um symptoms, um oh, what am I saying? Right someone's got cancer, you've been told you've got colon cancer, like myself, um the sort of thing I wanted to find out was how curable is it? Um....treatments, I wanted to know what sort of treatment I was having.

> P10, Sue (66-75 years, other cancer) - I think the sort of information I got admittedly from that book which people might pick up um, the one thing with the chemotherapy, was probably the worst part of it was going to be the incredible tiredness, and I think things like that, the down side as well as the good side needs to be pointed out.

Some participants suggested including links to credible cancer information websites as they reported that they found it difficult to navigate the Internet and identify reliable information, due to the large amount of websites and information available.

P14, George (66-75 years, colorectal cancer) – It [the app] could be used to direct them [patients] towards websites that contain that information, so you could use it as a roadmap, that I suspect could be useful.

P17, Jackie (46-55 years, colorectal cancer) – … but to direct you to relevant things, rather than the masses of information out there which could contain all sorts of irrelevant things… {…} to point people in the right direction for the right answers, rather than give the answers… yeah signpost and direct people.

Some participants suggested that a treatment-related symptom diary feature would be useful, as some of them benefited from keeping a paper diary. Participants described how it helped to predict how they would feel at certain times during their treatment and helped them to plan ahead to prevent or remedy symptoms, and organise their diet and social calendar. Participants also explained that they felt reassured by knowing when symptoms were likely to occur.

P19, Paula (36-45 years, breast cancer) - …Uh like I told you when you start chemo, it's really good for you to have a report, a detailed report of symptoms, how you feel. So throughout the cycles, not only for yourself to prepare yourself for what's coming as well, for the nurses because they ask you, they ask you at every clinic, "How are you feeling?" "How did it go?" If you don't write it down I can tell you, you will forget. If the app has um a way so that you could personalise your own link and then you can actually have a diary, so instead of writing, I got to the stage where I'd forgotten completely I thought oh I'll remember, I'll remember, well if you've got…because it's much easier with technology so instead of writing… it's much easier if you've got it there so when you do go to the nurse you can easily pop it up and say, "Look that day I went though that, this was a different symptom, or this one might've been a bit more graphic than the other time you know" that would be, that would be quite useful.

Subtheme 2b: App features that facilitate information exchange in consultations with clinicians

Patients and relatives suggested app features that would facilitate information exchange in consultations and their understanding of the information provided, in an attempt to overcome the barriers experienced in consultations (described in section 4.4.2.1.3). Some patients recalled writing question prompt lists (QPL) for consultations

during their illness to remind them to ask questions (e.g. Appendix 19 (transcript for P13 Lynne), lines 465-472). Conversely, many patients that had not used a QPL reported that they had forgotten to ask questions. As a result, many participants suggested including a QPL feature and many anticipated that it would be the most useful feature for patients.

> P19, Paula (36-45 years, breast cancer) - I think if the app does that, you know gives you a list of questions that would be useful for you to ask so you can write them down… I think it's extremely useful because at least you've got your mind set to ask the questions if you've got any… If I had any questions when I got home, I'd have to ring back and say, "Look I don't understand this", you know so I think if the app does that, that's really good.

> P3, John (66-75 years, colorectal) - …When we saw the doctor he called us in on New Years day so I knew there was something wrong when he called us and then he said, "Anything you want to ask me?" Well of course you're stunned and there is nothing you can think of to ask... it would be useful to have questions that you hadn't thought of at the time.

Participants suggested including a glossary feature that provides definitions of cancer terms to enable patients to understand the information that they are provided in consultations, as they recalled times when they did not understand the terminology used by clinicians or in information resources, such as leaflets.

> R6, Lucille (46-55 years, daughter of P6, David) - …They want a doctors' dictionary on there [the app] ((laughs))… they said, when she give us the form she said, "There's gonna be loads of things that you don't understand because the words are about that long", …it's assuming you understand them isn't it?

> P14, George (66-75 years, colorectal cancer) - I don't class myself as to being of superior intellect, but I'm not a fool and um, I understand, but I suspect Mr Average might say to himself, "Well I don't know what that means". So the app would be useful for him, um....
> I – Well one of the things that we're thinking about including is including a glossary of medical terms. Do you think that would be useful for patients?
> P14, George – To be honest with you yes, for the average person, uh and I think that would be useful and explain what that means to them, because I think

an awful lot of people would be to a degree, a little bit in awe of what the doctor is saying because they're not trained as uh doctors they wouldn't understand completely, and maybe there's a slight reluctance to say to the doctor, "Well explain that more fully, be more open with me" because of that if you like, power differential, between the patient and the doctor, so having the ability to go to an app afterwards, provided you remember what all the big words were.

Subtheme 2c: App features that increase access to patient support
Patients and relatives suggested app features that would raise awareness of and increase patients' access to other types of support, such as psychological and social support. Some participants suggested including links to local cancer support services, such as psychological support services and help with managing finances, and cancer charity websites that already contain some links to these services. It was hoped that this would raise awareness of and increase access to some of the services that participants found helpful during their illness (e.g. financial benefits advisor for patients who were unable to work).

> R2, Geraint (18-25 years, boyfriend of P2, Vicky) – …Yeah and then also they employ a McMillan advisor, she is fantastic, she helped us a lot
> I - Oh that's good
> P2, Vicky (18-25 years, gynaecological cancer) – That's one thing I reckon would be good to put on here is like numbers for people like, money wise, because we've struggled to find all the help…like what type of benefits to go on and even if you just put the McMillan Advisor's number on it [the app].

> P8, Mandy (56-65 years, gynaecological cancer) –…I think there's a lot of things the app could help to link up a bit. You know, there is a lot of stuff [cancer services] out there, putting it in one place would probably, I would've thought would be helpful, so that people haven't got...I kind've stumbled across things by accident, like I didn't realise that Macmillan did the complimentary therapy services thing, but there's also links to sort of art therapy and all sorts of things that are there, and they're there for families as well and I didn't know they were there initially.

Many participants recalled how they exchanged information with other cancer patients, both face-to-face at hospitals and online (e.g. information on remedies for treatment side effects), which they described as invaluable. Some patients therefore suggested

including a social feature or links to existing social forums or media, as they recalled the informational and emotional benefits of meeting other patients.

> P2, Vicky (18-25 years, gynaecological cancer) – …Because on the page on Facebook, there was a woman she just, her cancer came back and she was like, "What's the chances of me even beating it this time, who beats cancer twice?" and a woman commented on it, "I've beat cancer 3 times and I'm in remission", and that woman, you could see like she was commenting on it saying, "Oh my God thank you, that's made me feel so much better", and any little help like that. Even with the groups on there, even if you're not from their area, it doesn't matter – they're there for you. I think it's really good with social media now and um maybe you could incorporate that into your app?
> I – Yeah, do you think that would be a good idea?
> R2, Geraint (18-25 years, boyfriend of P2, Vicky) – Yeah …certain social media sites and that sort of thing, like I know [hospital] has a Facebook page, and the ovarian page is where she's with that sort of thing, like having that support base is better than like, I can support her as much as I can, but it's nothing compared to someone who's been through it, or going through it, you know they can talk about certain things that I can't talk about with her because it doesn't matter how hard I try, I can't understand what she's going through...

> R3, Helen (56-65 years, wide of P3, John) - We found that when we used to go down there (hospital), other patients with similar cancers or receiving chemotherapy and you talk and that always helped to find out their experiences, how they dealt with certain side effects and if that would be, if you could have that on an app I think it would be you know a help.

Patients also suggested including links to information on online or local support groups to meet patients as they found it difficult to locate information on these services.

> I – So what sort of things would you like the app to do?
> P11, Dawn (46-55 years, gynaecological cancer) - Um, I think support side of it is very important, to give the information about support, um support groups, cos that's what I couldn't find, I couldn't find any support groups. It was only about last year I found a support group near home.

Subtheme 2d: App features that increase access to support for relatives

Some relatives, as well as patients, suggested some additional features that would be useful specifically for relatives. Some relatives explained that they had wanted someone to talk to during the patient's illness for emotional support, such as another relative in a similar situation, who was outside of the family so as not to burden the patient.

> R8, Maude (56-65 years, Wife of P6, David) – I mean the terrible thing that we went through was that ((David)) was diagnosed and it was a shock and it was, I mean it probably worried me I think more than ((David)) I was you know, the fear of the future, I don't know what other people think, but it certainly did worry me and in the beginning I thought, my mind was all over the place and then someone said, "Get in touch with these nurses", and I couldn't do that because it's [the cancer] not that bad...you know, I would've at that stage and they never said anything at the hospital "Would I like someone to talk to?"… I would've liked to have that, to have someone to talk to at that stage, and nothing was offered.

Participants therefore suggested including an in-app feature that would enable relatives to talk with other relatives, or links to information on local support groups that they could attend (online or face-to-face).

> R3, Helen (56-65 years, wife of P3, John) - I tell you what I think would be helpful as well is if there was something on there for family, immediate partners where you could share experiences, or maybe chat to other people, because if you know what I mean. I've been strong for (P3, John) and doing everything for (P3, John) but then you get those moments when I'm on my own, and you do think down the wrong way and you get worried, and have concerns and then I don't want to go to him with it.

Patients and relatives also suggested including a feature that provides information on how relatives can best support the patient, in order to provide informed care. For example, one patient explained that a friend who had previously had cancer was able to help her in more useful ways due to her experience of the illness.

> P5, Pam (56-65 years, breast cancer) – All my friends have said, "What can I do to help you?" all of them, um they don't know how to deal with me
> R5, Susan (56-65 years, partner of P5, Pam)– We just say "meet us for coffee"

P5, Pam - I think but if they...there's a lovely website…um 'not another bunch of flowers.com'. This woman, she's had three breast surgery's and uh she's fed up of getting flowers, she wants useful gifts and I think that would be, if they [relatives and friends] had some ideas about how to alleviate... they might not feel so helpless, because they all want to do is help, don't they?

R5, Susan – …and don't bring another bunch of flowers!

P5, Pam – I mean a friend of mine with breast cancer sent me a bra, now she obviously knew exactly what I was going through, because my bras don't fit.

Subtheme 3: Anticipated benefits of app use

Patients and relatives anticipated several potential benefits of an app that would help patients to meet their information needs. The most commonly anticipated benefit of this type of app was a more informed patient. As a result of increased access to reliable and relevant information, participants anticipated that future patients would have a better understanding of their condition and the information provided in consultations.

P5, Pam (56-65 years, breast cancer) - …You go in with a bit more information, you feel more comfortable, you can ask them questions and the answer won't confuse you because you know the rudiments of it like.

R2, Geraint (18-25 years, boyfriend of P2, Vicky) - I think it will prompt a conversation between a nurse and a patient, it will give the patient questions, um you know which gives them more information and uh, I wouldn't say it will level the playing field, cos I don't think there is an app that can go into that much detail you know than a nurse's expertise, but it will definitely give the patient a better idea of what is going on.

A more informed patient was expected be able to identify treatment side effects and treat them accordingly, which may prevent complications and potentially improve their quality of life. For example, one patient and her partner reported that her lack of knowledge on the importance of monitoring her temperature during treatment almost lead to her hospitalisation.

P5, Pam (56-65 years, breast cancer) - …On the Sunday night when I was feeling like death I took my temperature and it was 37.5 so I took it with another thermometer and it was 37.4, because 37.5 is the magic number [the threshold] I went to bed, in the morning I took my temperature and it was 37.9

R5, Susan (56-65 years, partner of P5, Pam) – …and I said, "It's about time now you rang"

P5, Pam –…but because I didn't want to go in, 'Its 37.4, I don't want to go in". If I had understood the very important aspect of that, I would have gone in to hospital that night.

A more informed patient was also expected to have lower levels of anxiety throughout their illness due to having a better understanding and more realistic expectations of their prognosis and treatment.

P7, Julie (56-65 years, colorectal cancer) - I think uh, give information on treatment, be specific about what's involved with chemotherapy because people are afraid of chemotherapy and if it was explained to them beforehand they might not be as afraid. Explain about what happens with radiotherapy, as again, people are afraid of it.

There was some evidence to suggest an app could help patients to increase their confidence in actively participating in their care and communicating with their clinicians. For example, one patient described that patients would be 'armed' with a question prompt list.

I –What benefits do you think there might be for patients using this type of app?
P20, Beryl (56-65 years, gynaecological cancer)– Well it might help them, it might help them get some confidence, within the system, because if they, you know if it opens up questions and answers session when they go [to clinic] it's going to make them more confident next time isn't it? It's going to help encourage their relationship with their practitioners, so you know with their doctors, so....
I –…Do you think it would help or hinder communication with clinicians?
P20, Beryl – Oh no I'm sure it would help… because it would open a dialogue {…} I think it does well for confidence and self-esteem and opening up relationships, which can only be a good thing I think

R4, Stella (36-45 years, daughter of P4, Michael)- …I mean the thing is, it's [the app] going to inform the patient far more um than, um so they're going to be going to their appointments you know far more armed and prepared with questions.

Participants also highlighted the benefits of Smart technology. Accessing cancer-related information and resources via an app was expected to be less burdensome compared to searching through the printed leaflets and booklets, which are provided at diagnosis. Additionally, participants highlighted that patients would be able to access an app independent of time and location.

> P2, Vicky (18-25 years, gynaecological cancer) - You have these pile of booklets off them and when you see all that you're like, "Oh have I really got to read all that?", so if you've got an app there it's easier then isn't it. It's like you haven't got to carry everything around, and say you're in an appointment, you can just pull the app up on your phone and just read up on it, rather than carrying all these massive books with you.

Subtheme 4: Potential disadvantages of app use

A minority of participants were concerned that some patients might become anxious if they misinterpret information on an app or are misinformed by inaccurate information.

> I - Do you see any problems at all with this app being used in practice?
> P14, George (66-75 years, colorectal cancer) – One point that might manifest itself would be Joe Bloggs getting the wrong end of the stick, when they've been diagnosed with a particular condition, their research make take them away from the condition to something else, and maybe anxiety could set in as a result of that, because they've over researched it perhaps and um, frighten themselves because they've got so much information about perhaps a condition which is similar to theirs, but not theirs and then they'll put themselves in a place where they don't want to be. That could be counterproductive health-wise, if you like call it misinformation, because they've misinformed themselves, by using the app.

Additionally, a small number of participants also worried that patients actively using an app in a consultation might distract them from the conversation with the clinician.

> P10, Sue (66-75 years, other cancer) - …In my case it [the app] would hinder communication...because you're looking at this [the app] and you're not looking at them [the clinician] and you're just reading a list.

Subtheme 5: Anticipated barriers to app use

The majority of patients and relatives reported that they did not foresee any barriers to an app for cancer patients working in practice. However, the most commonly anticipated barrier was patients' age and experience with Smart technology. Some participants anticipated that many older patients would lack the knowledge and experience to be able to use an app, in comparison to younger patients, who typically use apps every day.

> P13, Lynne (56-65 years, gynaecological cancer) – …If you said to me there's this app called such and such then I'd just go and look at it and find it out for myself, like my dad bless him who's 82 and he plays around with his laptop um he wouldn't know like to look at the little words and to click on them and things and explore an app you know? …When somebody of your generation finds it, oh that sounds patronising but imagine that um you know, there are some people they still don't know what an app is.

In support of these views, a minority of patients in the present study anticipated that they would be unlikely to use an app as they preferred traditional methods to gather information, such as asking a nurse or a friend.

> I - Do you think if you had a Smartphone or tablet that you would use, or try to learn to use the app?
> P10, Sue (66-75 years, other cancer) - Probably not, I would probably still ring the nurses.

Access to Smart devices, in terms of cost or access to the Internet to be able to use an app, was also highlighted as a barrier by participants, though patients who do not own a Smart device were expected to have access to one via family or friends.

> P13, Lynne (56-65 years, gynaecological cancer) – ...the only barrier I can think of is that some people do not have any access to the Internet and I suppose that's something that you just have to accept you know that's not a reason for not producing something, but that's the only barrier that I can see, in that people, there are people who don't have internet access.

Some participants anticipated that a minority of patients will only want minimal information on their condition in an attempt to minimise their anxiety, and so believed

that this group of patients would be less likely to use an app that primarily aims to meet patients' information needs. These views are supported by comments from a minority of patients in the present study who appeared to have an avoidant coping approach.

> P5, Pam (56-65 years, breast cancer) - …I can't have enough information, but I know from my experience people don't want a lot of information
> R5, Susan (56-65 years, partner of P5, Pam) - Then they're not going to use the app are they? They won't, they'll go...or they may open it and they may see a little bit and they'll go, "Okay that's as far as I want to go".

> P17, Gerald (46-55 years, colorectal cancer) -…it [the app] may help some people… people who want to know the ins and outs of everything, but not somebody like me who doesn't want to know the ins and outs of everything.

A minority of participants were concerned about the accuracy of information sourced from an app, however they suggested that future patients would trust an app if it was endorsed by their clinicians or affiliated with a reputable cancer charity. Similarly, some patients who were less familiar with Smart technology were concerned about the confidentiality and security of any personal information required by an app.

> P19, Paula (36-45 years, breast cancer) – It all depends how the app runs, it all depends the basis, or what it's based on, um for me when I think of the Internet as a reliable source, can I trust it or not? You know if it makes sense
> I – Okay, so how reliable the app is?
> P19, Paula – How reliable it is. For example, if you told me that the app had a support or background from the cancer research, I would be more than happy to you know to look up anything that I would read, or that I would obtain from the app was accurate and that I could rely on, for me that would be 'the' thing reliability, where it comes from, what's the basis, can I trust it personally?

> P3, John (66-75 years, colorectal cancer) –…as long as it keeps confidentiality, which is I think absolutely imperative, I mean certain things slip past the old uh marker at times, um, yeah I think that's generally that's the most important thing confidentiality is not in any way breached, you know.

4.5 Discussion

This is the first study to explore the needs and preferences of patients with cancer and their relatives regarding an app that aims to help them to meet their full range information needs in non-inpatient settings. The primary aim of this study was to explore the value of an app for patients and to establish the type of app required, as well as the acceptability of an app and its potential outcomes. A secondary aim of this study was to explore the views of relatives on an app which may be used by themselves, as well as the patient. Findings highlighted the importance of information for both patients and their relatives in order to cope with and effectively self-manage the illness. Barriers to information exchange and understanding in consultations, and identification of reliable information sources between consultations, appeared to largely contribute to unmet information needs for patients and their relatives. This was reflected in the type of app and features desired. Suggestions for app features indicated the need for an app that supports patients to retrieve the information that they need from their short time in consultations, facilitates understanding of this information, and collates the large amount of cancer-related information and support services that are available to helps patients and their relatives to navigate through them. Participants anticipated that this type of app would be useful for all types of cancers and phases of the disease, particularly following diagnosis. The potential benefits of this type of app identified by patients and their relatives appeared to outweigh the few potential disadvantages, and the potential barriers to app use are likely to be temporary or can be minimised with consideration of these findings during app development and implementation.

The findings that a cancer diagnosis is a traumatic experience for both the patients *and* their relatives, and that information-gathering appeared to be used as a coping strategy to regain a sense of control, are consistent with findings of previous studies (Ranchor et al., 2010; Hinds et al., 1995). These findings suggest that an app intervention that facilitates information-gathering has the potential to promote better psychological adjustment for both patients and their relatives and are consistent with several overlapping theories related to coping with a chronic illness, such as the CSM (Leventhal et al., 1984), crisis theory (Moos & Schaefer, 1984*),* the theory of cognitive adaptation (Taylor, 1983) and self-efficacy theory *(*Bandura, 1996).

Patients and their relatives recalled a range of unmet information needs, which appeared to be largely due to barriers to information exchange and understanding in consultations and barriers to finding reliable information sources outside of

consultations. These findings are consistent with previous studies on communication in medical consultations and patients' preferences for information resources (Chapman, Abraham, Jenkins & Fallowfield, 2003; Shea–Budgell, Kostaras, Myhill & Hagen, 2014; Slort et al., 2011). The patient activation framework might be a useful framework to provide further insight into these issues (Hibbard et al., 2004). For example, many participants in the present study appeared to lack the skills (i.e. unable to identify reliable information on the Internet), knowledge (i.e. limited understanding of cancer upon first diagnosis, clinicians' use of medical terminology in consultations) and confidence (i.e. lack of confidence to ask questions in consultations) to self-manage their condition. It was important to explore these issues in the present study as participants' needs and preferences regarding an app were based on their experiences. Additionally, confirmation that these barriers still exist provides evidence to support the development of an app that enables them to overcome these barriers and meet their information needs in non-inpatient settings.

Patients' and relatives' desire for an app that would help them to meet their information needs reflected their experiences of barriers to information-gathering and understanding during and between consultations. Firstly, participants suggested app features that would facilitate patients' self-management of their condition in non-inpatient settings (e.g. at home), such as an informational feature that would provide detailed information on their condition, such as their treatment and related side effects. This type of information is required for the performance of self-care behaviours, which in turn might prevent hospitalisations (Ream & Richardson, 1996). Participants also suggested including links to reliable cancer information websites to help them to navigate the Internet and source accurate information. As the Internet is now a common health information resource, studies have highlighted the importance of guiding patients and educating them on how to filter accurate health information online (Eysenbach, 2003; Gerber & Eiser, 2001). However, information needs can vary throughout a patient's illness, as well as between patients with different types of cancers (e.g. common versus rare cancers) and between patients at different stages of cancers (e.g. stage I versus stage IV). Information needs may also vary between patients and their relatives. If an app was to include an information feature, it would therefore require the ability to be tailored to each individuals' information needs in order to be able to offer something more than the most general, early advice. For example, a question prompt list feature would enable patients and their relatives to create their own tailored list of questions to help them to obtain information in consultations that meets their own individual information needs.

Secondly, patients and relatives suggested app features that would enable them to overcome the barriers to information exchange in consultations. For example, it was hoped that a QPL would prevent patients from forgetting to ask important questions. As described in Chapter 1, reviews of the use of paper-based QPLs for cancer consultations have suggested small but positive effects on communication, question asking and recall of information (Brandes et al., 2015; Dimoska et al., 2008). A glossary of cancer terms was also suggested by participants in the present study, in the hope of enabling patients to develop an understanding of cancer-related information provided in consultations or information resources, rather than relying on clinicians to explain terminology. In contrast, previous research has focused mainly on improving clinicians' communication of information in lay terms in consultations (Ley, 1989).

Thirdly, patients and relatives highlighted other negative consequences of a cancer diagnosis, such as financial and psychological issues, and suggested that an app could be used to collate information on the available cancer services for patients to raise awareness of and signpost them to the relevant support when needed. Similarly, patients suggested including a feature than enables contact with other patients for emotional support. This finding is consistent with previous studies on the benefits of social support during cancer (Dukes Holland & Holahan, 2003) and theories related to coping with a chronic illness, such as the CSM (Leventhal et al., 1984), crisis theory (Moos &Schaefer, 1984) and the theory of cognitive adaptation (Taylor, 1983). These theories suggest that talking with other patients may act as an emotion-focused coping strategy, used to restore the patient's emotional balance which is offset by the illness, or used as a mechanism to boost self-esteem. An app intervention that increases patients' access to other types of support, such as emotional or social support, may further facilitate their adjustment to their illness.

Relatives in the present study appeared to agree with and suggested the same types of app features as the patient, which may be due to their comparable information needs. However, all relatives participated in joint interviews with the patient and so it is possible that relatives perceived that they were there to validate the patients' voice, which may have precluded their own unique experience and desires for app features (Kendall et al, 2009). Furthermore, relatives (and patients) may have chosen to not to disclose and discuss their own specific experiences and desires for app features if they

felt that this information might upset or burden the patient. Protective buffering may have led to artificial findings, where the experiences discussed and app features suggested where those that were felt to be appropriate in the presence of partners (Hagedoorn et al., 2000). Despite this possibility, there was some evidence to suggest that relatives (and patients) felt comfortable to discuss their own experience, as relatives told of their desire for emotional support from other relatives in a similar situation during the patients' illness and for information on how they could provide more informed support for the patient. These findings are supported by a growing body of literature that shows the negative impact that a lack of information and support can have on the well-being of relatives and on the patient's care (Hours, Rusenas, Simmonds, & Hueford, 1991; Soothill et al., 2003). Overall, patients and relatives suggested app features that can be thought of as a 'toolkit' that would enable them to overcome the barriers to information-gathering and understanding that they have faced during and between consultations with clinicians.

The majority of patients and relatives in the present study anticipated that an app would be an acceptable intervention, which they perceived could be useful for patients with all types of cancer, through all phases, particularly following diagnosis. This was due to their on-going need for new information as they progressed throughout their cancer and treatment. Based on patients' and relatives' perceptions in this study, it would be prudent to explore the usefulness of this type of app in a field testing study with a wider range of patients, including those with different types of cancers and at different stages of their illness. Exploring the use of an app with a range of patients might highlight whether certain populations might benefit more from this type of intervention (i.e. those recently diagnosed).

Patients and relatives also expected that an app would be intuitive and easy to use. These findings are a positive preliminary indicator of the potential uptake of the app upon implementation and are consistent with patients' expectations for other types of mobile interventions for other chronic conditions (Bostock et al., 2009; Pinnock, Slack, Pagliari, Price & Sheikh, 2006; Seto et al., 2010). However, the samples of this study included a majority of patients and relatives with higher levels of education compared to the general population. Studies have shown that those with lower levels of education (e.g. those educated to secondary school or college level) are less likely to engage with web-based activities for their health, such as downloading health information to a mobile device, communicating with a doctor via email or tracking personal health information online (Kontos et al., 2014). Participants included in this study may

therefore have had more favourable perceptions of an app that would enable them to perform web-based activities, compared to their less educated counterparts. This may have led to artificially inflated findings of the acceptability of this type of intervention.

Some participants in the present study expected that older patients would be less likely to use an app compared to younger patients, and consistent with these expectations, a minority of older patients in the current study did not anticipate that they would use an app, instead preferring more traditional methods of information gathering. In contrast to these expectations, studies show that actually, many older patients are willing to learn to use a new technology if they think that it will benefit them (Joe, & Demiris, 2013; Parker, Jessel, Richardson, & Reid, 2013). Other perceived barriers to app use included access to Smart devices, the perceived reliability and security of information, and an avoidant coping approach. Access to Smart devices is likely to be temporary barrier as ownership of Smart devices is increasing rapidly in the UK across all demographic groups (Deloitte, 2016; Ofcom, 2016). Patients who do not currently own a Smart device will likely have access to one via family and friends. Affiliation with a reputable organisation and development of an app that does not require personal information will reduce concerns about reliability and security of information. A minority of patients in the present study appeared to have an avoidant coping style and therefore anticipated that they would not want to use an app to learn more about their illness. However, other useful features, such as links to information on psychological support, might still be of use for this group of patients.

The most commonly anticipated benefit of this type of intervention was a more informed patient, which in turn, was expected to lead to a range of other benefits, such as increased quality of life, reduced anxiety and a sense of empowerment. Though anticipations of the outcomes of this type of intervention depended on the app features that were suggested, studies have provided evidence for these types of benefits as a result of improved communication with clinicians in consultations and increased access to information outside of consultations (Chumbler et al., 2007a; Street, Makoul, Arora & Epstein, 2009; Ussher, Kirsten, Butow & Sandoval, 2006). It is anticipated that relatives of patients might also experience some of these benefits by using the same app features, due to their comparable information needs with patients. As the majority of patients diagnosed with cancer are experiencing a disease for the first time, they are unlikely to have the knowledge or skills to actively participate in their care. Suggestions that this type of app might increase users' knowledge of their condition, and

participation in consultations, might indicate that this type of app has the potential to increase patients' levels of activation (Hibbard et al., 2004).

Finally, two potential disadvantages of using this type of app were suggested, including increased patient anxiety and poorer communication with clinicians in consultations. The risks of these potential consequences may be minimised by including only reputable information resources and avoiding active engagement with the app during communication in consultations (i.e. use as a reference and not to type notes). Overall, the anticipated benefits of this type of intervention appeared to outweigh the potential disadvantages.

Currently, there does not appear to be evidence of an existing, similar app intervention that has been successfully implemented into routine cancer practice. Participants in the present study did not report use or awareness of any cancer-specific apps during their illness. As described in Chapter 2, the development of Smart technology for use by patients in cancer care is in its infancy and so the majority of apps are in an early phase of development. Additionally, it is well known that a gap exists between the identification of beneficial research findings and the application in clinical practice in cancer care (Adesoye, Greenberg, & Neuman, 2016). Furthermore, as highlighted by patients and relatives in this study, the information and resources that patients receive upon diagnosis, and throughout their cancer, is not standardised and varies greatly between clinicians, clinics and hospitals. One way to implement this type of intervention into practice would be to make it available on the NHS digital apps library. This is a resource of evidence-based digital tools to help patients with a range of conditions to manage their health. Currently, the apps library contains only one app for cancer, called 'OWise', which enables patients to keep track of their treatment and wellbeing, including fatigue, appetite, pain and other issues to spot trends to help improve their care. Patients can also record conversations with their clinician to listen back to in your own time. However, the app is specified for patients with breast cancer only and would not be useful for patients with other types of cancers.

In contrast, a handful of studies have explored the implementation of question prompt lists into clinical practice within the cancer setting (e.g. Dimoska et al., 2012; Glynn-Jones et al., 2006). While these studies generally reported positive findings on the acceptability and feasibility of this type of intervention, they highlighted the challenges of implementing new interventions into practice. For example, one study aimed to distribute a question prompt list to 300 cancer patients in a UK oncology clinic over one

year (Glynne-Jones et al., 2006). A research nurse distributed the question prompt list to patients as they arrived for their consultation and patients were surveyed following the consultation. Despite efforts to ensure that all patients received the question prompt lists, only 85% (n=254) of patients received them. Additionally, some patients felt the doctor was busy and did not want to take up too much of their time by using the question prompt list. Nevertheless, 65% of patients (n=195) felt that the intervention was 'very helpful' and one-third of the patients were able to ask more questions about their disease as a result. A similar study was conducted across four cancer centres in Australia (Dimoska et al., 2012). This study also reported that only 64% of 606 patients received a question prompt list. Of those offered a question prompt list, 91% accepted and post-consultation, 89% reported reading the question prompt list and, of these, 44% referred to the question prompt list during the consultation at least once. These findings highlighted the importance of implementation studies as the delivery and use of this intervention in practice was less than optimal.

4.5.1 Study strengths and limitations

The varied samples of patients and relatives are a strength of this study, however there are several limitations to consider. Firstly, the study had a low response rate for both patient and relatives and the samples included high numbers of Smart technology owners and a majority with higher educational levels. Additionally, information on the key characteristics of those who declined to participate was not collected and the different cancer sites had varying response rates. Specifically, the lowest response rate was from patients with urological cancer, which contrasts to patients with colorectal cancer, who had the highest response rate. The samples included in this study, particularly the patient group, may therefore not be representative of the general population. Due to these limitations, the sample may have included those with more favourable perceptions of an app than those who chose not to participate. For example, those who declined to participate may have not been familiar with Smart technology or liked the idea of an app for patients with cancer. Similarly, patients who do not own Smart technology were likely to be less familiar with it and may therefore have had more negative perceptions of this technology. Finally, the low response rate from patients with urological cancer, as well as a fairly low response rate from patients with breast and gynaecological cancers, might indicate differences in opinion of the acceptability and feasibility of an app between cancer sites. For example, patients with urological cancer, which includes kidney, bladder, prostate, testicular, and penile cancers, are more likely to be older male patients and studies have shown that this

population group are less likely to engage in health information-seeking and other related web-based activities (Kontos et al., 2014). It is therefore possible that these limitations artificially inflated the positive findings of this study. Participants included in this study may also have had different needs and preferences regarding an app compared to their counterparts.

A further limitation of this study is that all participants were White Caucasian. While some studies suggest little evidence for a digital divide by race/ethnicity (Kontos et al., 2014), some report that patients of black and ethnic minority groups, such as African American and Chinese, may have different experiences of cancer, and use different information sources, compared to majority groups, and may therefore have different needs and preferences regarding an app (Elkan et al., 2007; Matthews et al., 2002; Randhawa & Owens, 2004).

The sample size of the relatives group was small and all relatives participated in joint interviews with the patients. Additionally, some relatives included in this study volunteered to participate at the time of the patient's interview. It is therefore possible that relatives perceived that they felt they were present to validate the patients' voice (Kendall et al., 2009). Joint interviews may have also prevented relatives (or patients) from discussing important issues that they might have talked about in a separate interview (i.e. protective buffering) (Hagedoorn et al., 2000). These limitations may have led relatives to agree with the views of the patient, however this risk was minimised as much as possible by careful development of the topic guide.

Finally, providing examples of types of app features that participants might find useful prior to beginning the interview might have influenced responses due to social desirability. The risk of this bias was minimised as the prior to the interview, the candidate explained that all opinions were valued, both positive and negative, in order to develop an app that would be most useful for future patients and their families.

4.5.2 Future research

Future studies could investigate the views of certain minority populations of patients, such as those with negative perceptions of an app, those who do not own or have experience with Smart technology and those with lower levels of education or health literacy (Kontos Blake, Chou & Prestin, 2014; Neter & Brainin, 2012). This will help to determine the barriers to use of this type of intervention for these population groups and ways to overcome them, and identify possible strategies to increase engagement

of these patients and their families. Furthermore, the present study excluded those patients under 18 years of age. Interventions identified for adolescent patients by the systematic review in Chapter 2 were gamified apps. For this reason, it was hypothesised that this population may have different needs and/or preferences regarding an app for cancer. For the same reason, patients with less than 12 months to live were not included in this study. Further studies are required to explore the perceptions of these subgroups of patients. Further research is also needed with patients with urological, breast and gynaecological cancers, as these cancer sites had a lower response rate compared to patients with colorectal cancers in the present study. Finally, individual interviews with relatives of patients with cancer are required in order to support the findings of this study.

4.5.3 Implications

The findings of this study have several implications for the development of an app. Firstly, this study identified the psychosocial context of patients and their relatives which appeared to have shaped their needs and preferences regarding an app to meet their information needs. Specifically, findings confirmed that barriers to information exchange and understanding during consultations with clinicians, and identification of reliable information sources outside of consultations, still exist for patients with cancer and their families. This study also presented evidence to support the knowledge that information-gathering may used as an adaptive coping strategy. Together, these findings indicate the need for an app intervention to help patients and their relatives to overcome these barriers and enable them to meet their information needs. Secondly, this study presented novel findings on the needs and preferences of patients with cancer and their relatives regarding the development of an app. Preferences for app features can be used to develop intervention objectives and inform the selection of app features that are required to achieve these objectives (Yardley et al., 2015).

Views of patients and their relatives on the usefulness and acceptability of this type of intervention for a wide range of patients may be interpreted as a positive preliminary indicator of the potential uptake of the app upon implementation (Craig et al., 2008; Yardley et al., 2015). However, these findings must be interpreted with caution due to the low response rate of the study. This study also identified the potential outcomes of this type of intervention, including the benefits and disadvantages of, and barriers to app use, which may be considered during app development in order to optimise its uptake, usability and usefulness (Craig et al., 2008; Yardley et al., 2015).

This study highlighted how several health behaviour models, theories and approaches related to the impact and self-management of a chronic illness were useful to explain some of the findings, including the CSM (Leventhal et al., 1984) crisis theory (Moos & Schaefer, 1984), theory of cognitive adaptation (Taylor, 1983) and the patient activation framework (Hibbard et al., 2004). These theories may be use to inform development of an app intervention and selection of app features. Finally, this study added to the preliminary body of work conducted for this thesis so far, which follows the MRC framework for the development of complex interventions (Craig et al., 2008). Specifically, findings of this study provided further insight into the theories that may be relevant for such an intervention, the processes that may underpin the intervention (i.e. the issues faced by patients and the app features suggested to overcome these) and potential outcomes of this type of intervention (i.e. the potential benefits and disadvantages).

4.5.4 Conclusion

This study was the first to explore the needs and preferences of patients with cancer, and their relatives, regarding an app that aims to help them to meet their information needs in non-inpatient settings. Patients and their relatives highlighted the importance of having information and its use as a coping strategy to regain a sense of control over their lives. However, barriers to information exchange and understanding during consultations with clinicians and identification of reliable information sources outside of consultations appeared to lead to unmet information needs. These findings led to discussions of the types of app features that patients and relatives would find useful. Specifically, an app that enabled patients and their relatives' to develop an understanding of and subsequently self-manage the condition was required, including features to support information exchange and understanding in consultations and features to increase access to support for both patients and their relatives. Overall, patients and their relatives considered an app to be an acceptable medium to receive interventions to support them through cancer. However, the findings of this study must be interpreted with caution due to a low response rate and other limitations. Nevertheless, the potential outcomes of this type of intervention were highlighted and the benefits of an app appeared to outweigh the few possible disadvantages and barriers to app use.

Chapter 5

The views and opinions of cancer clinicians regarding an app to help patients with cancer and their relatives to meet their information needs: a qualitative interview study

5.1 Chapter overview

This chapter reports a novel qualitative interview study that explored the views of cancer clinicians on the value of an app for patients and their relatives. This study was used to gain an understanding of the type of app that clinicians anticipate to be most useful for patients and their relatives, and the potential uptake and possible outcomes of this type of intervention, including the benefits and disadvantages of, and barriers to, app use. This study was used to identify whether clinicians would support the use of an app in cancer care and assess their training needs in relation to the app. Data from semi-structured interviews were analysed using thematic analysis. The implications of the findings for the creation of an app are discussed.

5.2 Introduction

As well as in depth exploration of the issues faced by the key users of an intervention, it is important to gain an understanding of the context in which an app intervention would be used and potential influences on the intervention (Murray et al., 2016, Yardley et al., 2015). Findings from Chapter 4 reported suggestions of features by patients and their relatives to include in an app that would help them to meet their information needs. These suggestions included features that would be used in consultations with their clinicians, such as a QPL. It is therefore important to explore clinicians' perceptions of the acceptability of this type of app, as their support is key to the its successful implementation in consultations (Murray et al., 2016).

Technology is fast becoming integrated into the healthcare service and there are many apps now available to assist clinicians with their clinical tasks, such as information gathering, clinical decision-making and medical education and training (Divall, Camosso-Stefinovic & Baker, 2013; Ozdalga, Ozdalga & Ahuja, 2012; Wallace, Clark & White, 2012). Studies have shown that the majority of clinicians have positive opinions on the use of such technology in healthcare, however some clinicians are still reluctant to use this technology in clinical practice (Bostock et al., 2009; Ozdalga et al., 2012; Wallace et al., 2012). Unease about new technology in healthcare includes concerns about patient data protection, the impact of technology on the patient-clinician relationship, and the integration of technology into clinical practice, as well as

the accuracy of intervention content (Moodley, Mangino & Goff, 2013; Mickan, Tilson, Atherton, Roberts & Heneghan, 2013). Early-phase studies of mobile interventions to support patients with cancer in non-inpatient settings, such as feasibility studies and pilot RCTs, have revealed mixed opinions from clinicians that use mobile technology in clinical practice (Kearney et al., 2006; Maguire et al., 2008; McCall et al., 2008). For example, a survey of 28 nurses involved with a mobile chemotherapy symptom-monitoring intervention found that 67% perceived the intervention to be time-consuming and 57% found it to be a challenging experience (Maguire et al., 2008). Additionally, post-study interviews revealed that nurses felt the intervention had impacted on their workload. However, despite this initial experience, the majority of nurses could see the potential benefits of such an intervention. Involving clinicians prior to the development of an app intervention for patients and their relatives provides an opportunity to identify and minimise the potential barriers to its implementation in a clinical context (Maguire et al., 2008; Murray et al. 2016).

Clinicians also have a potential role in encouraging the uptake of an app for patients with cancer following a diagnosis, as patients value the opinions of their clinicians and trust them as a source of reliable information (Hall et al., 2002; Rutten et al., 2016). Furthermore, second to patients themselves, clinicians have an awareness of their patients' needs and can provide further insight into the type of app and features that would most beneficial.

5.2.1 Aims of the present study

To date, no study has sought to understand the views of cancer clinicians regarding the development of a novel app intervention that aims to help patients with cancer and their relatives to meet their information needs in non-inpatient settings. This study aimed to explore clinicians' views of information exchange in consultations and the type of app that they anticipate to be most useful for patients. Specifically, the perceived acceptability of an app, useful app features and the potential benefits and disadvantages of, and barriers to app use were explored, as well as the types of patient and the time at which they might find this intervention most useful. Views on whether clinicians would support the use of an app in cancer care and their perceptions of their training needs in relation to the app were also established.

5.2.2 Qualitative methods

Semi-structured interviews were used to explore the views of clinicians and thematic analysis was conducted to analyse interview findings. Reasons for choosing this

method and details of the analysis are similar to those discussed in Chapter 4, section 4.2.2.

5.3 Methods

5.3.1 Participants

Maximum variation sampling, a type of purposeful sampling strategy in which cases are selected on the basis of the study populations' characteristics and on the study objectives, was used to allow for divergent views to emerge (Patton, 2002). Clinicians were recruited from colorectal and urological cancer clinics at UHW and breast and gynaecological cancer clinics at Velindre and the sample aimed to include consultant surgeons, consultant oncologists, cancer nurse specialists and trainee clinicians.

5.3.2 Recruitment

Lead clinicians were contacted by the candidate's clinical supervisors to arrange for the candidate to attend multi-disciplinary team (MDT) meetings at each of the cancer clinics to present the study and invite clinicians to participate. Interested clinicians were encouraged to contact the research student via telephone or email. Following this, clinicians were provided with an information pack, including an invitation letter, information sheet, and reply form via email (Appendices 20-22). All interested clinicians chose to contact the candidate directly by email instead of returning a reply form. The candidate contacted interested clinicians to answer any questions about the study and arrange an interview at their clinic, at time convenient for them. It was not possible to attend an MDT meeting in all cancer clinics, in which case the lead clinician of the clinic was asked to email his/her colleagues to invite clinicians to participate in the study and to contact the candidate if interested. As a result of this recruitment method, it was not possible to determine the response rate.

5.3.3 Procedure

At the time of the interview, clinicians were provided with a consent form to sign and a further opportunity to ask questions about the study (Appendix 23). The candidate explained that the interview was confidential and that only the candidate and lead supervisor would have access to the data. Participants were informed of how the data would anonymised, stored securely and kept for 15 years at Cardiff University, after which, it will be deleted. Demographic data were then collected by questionnaire prior to the start of the interview (Appendix 24). The interviews were audio-recorded with permission. Audio-files were sent electronically to a reputable company for transcription by uploading the files to a secure server used by the transcription

company. Audio-recordings were transcribed verbatim, as described in Chapter 4. Any information that could identify participants in the interview transcripts was anonymised. A confidentiality agreement was required from the transcription company to ensure that participant data and information was protected. Once the completed transcripts were provided to the candidate, the candidate listened to the audio-recordings whilst reading the transcripts to check for accuracy.

5.3.4 Data management

Transcripts and audio-recordings were securely stored on a Cardiff University password-protected server in accordance with the Data Protection Act 1998. This server is password-protected and confidential. All consent forms, transcripts and audio-recordings will be kept securely for 15 years according to Cardiff University research data policies. Following this time, all data will be destroyed.

5.3.5 Interview topic guide

A semi-structured interview topic guide was used (Appendix 25). Findings from interviews with patients and their relatives, and other relevant literature, informed the development of the topic guide. The topic guide was reviewed by the candidate's supervisors and amendments to the topic guide were made following comments. The main topics covered at interview were information provision in consultations, clinician-patient communication in consultations, experience with Smart technology, perceived acceptability of an app, perceived benefits and disadvantages of, and barriers to app use, useful app features for patients and their relatives and clinicians' training needs in relation to the app. At the beginning of the interviews, the candidate briefly explained the type of app that might be useful (i.e. one to help with patients' information needs) and described examples of types of app features to help clinicians to imagine what types of features would be possible to include an such an app.

5.3.6 Analysis

Participants were interviewed until data saturation was reached to ensure that adequate data were collected and the views of participants were represented. Data saturation was considered to have occurred when no new themes were identified for at least the final three interviews. Data were managed using the qualitative analysis software package NVivo (NVivo, 10). Interview transcripts were analysed using thematic analysis (Braun & Clarke, 2006), which has been described in Chapter 4, section 4.2.2. Four transcripts were independently analysed by the candidate's supervisor, Dr Fiona Wood, who has extensive experience of qualitative research, to

reduce the potential bias of subjectivity associated with coding and facilitate interpretation of findings. Discrepancies were resolved through discussion.

5.3.7 Ethical issues

NHS ethical approval and R&D approval from each of the sites was granted (14/WA/0066, Appendices 13-15).

5.4 Results

Twenty interviews were conducted with 22 clinicians between June 2014 and November 2014. Four CNSs chose to be interviewed in pairs stating time constraints in clinic as their reason, however the remaining clinicians participated in individual interviews. The average length of the interviews was 27 minutes (range 20-39 minutes).

5.4.1 Sample characteristics

Characteristics of participants are presented in Table 4. All participants reported that they owned a Smart device (Smartphone or tablet).

Table 4: *Sample characteristics of clinicians.*

Participant ID	Gender	Occupation	Cancer clinic
C1 (Onc)	Female	Oncologist	Gynaecology
C2 (Onc)	Male	Oncologist	Breast
C3 (Onc)	Female	Oncologist	Breast
C4 (PCC)	Female	Palliative care consultant	All types
C5 (CNS)	Female	Cancer nurse specialist	Breast
C6 (TOnc)	Male	Trainee oncologist	Gynaecology
C7 (CNS)	Female	Cancer nurse specialist	Gynaecology
C8 (CNS)	Female	Cancer nurse specialist	Gynaecology
C9 (CNS)	Female	Cancer nurse specialist	Colorectal
C10 (CNS)	Female	Cancer nurse specialist	Colorectal
C11 (Sur)	Male	Surgeon	Colorectal
C12 (Onc)	Male	Oncologist	Colorectal
C13 (TSur)	Female	Trainee surgeon	Colorectal
C14 (Onc)	Male	Oncologist	Gynaecology
C15 (TSur)	Male	Trainee surgeon	Urology
C16 (Sur)	Male	Surgeon	Colorectal
C17 (TSur)	Male	Trainee surgeon	Urology
C18 (CNS)	Female	Cancer nurse specialist	Urology
C19 (Sur)	Male	Surgeon	Urology
C20 (CNS)	Female	Cancer nurse specialist	Urology
C21 (CNS)	Female	Cancer nurse specialist	Urology
C22 (TSur)	Male	Trainee surgeon	Urology

5.4.2 Interview themes

From the interviews, three key themes were identified and included: (1) information exchange in consultations, (2) relatives' information needs, and (3) opinions on an app for cancer patients and their relatives. Subthemes will be discussed in detail below. Participants are identified with 'C' followed by their identification numbers and abbreviations of occupations listed in Table 4 (e.g. C1(Onc) is Clinician 1, oncologist). The interviewer is identified by 'I'. Where irrelevant, text was removed from quotes and denoted by {…}. Square brackets within the quotes represent inserted text to clarify the content. Exemplar transcripts are included in appendices 26 to 29.

Figure 8: Flowchart of themes from interviews with clinicians.
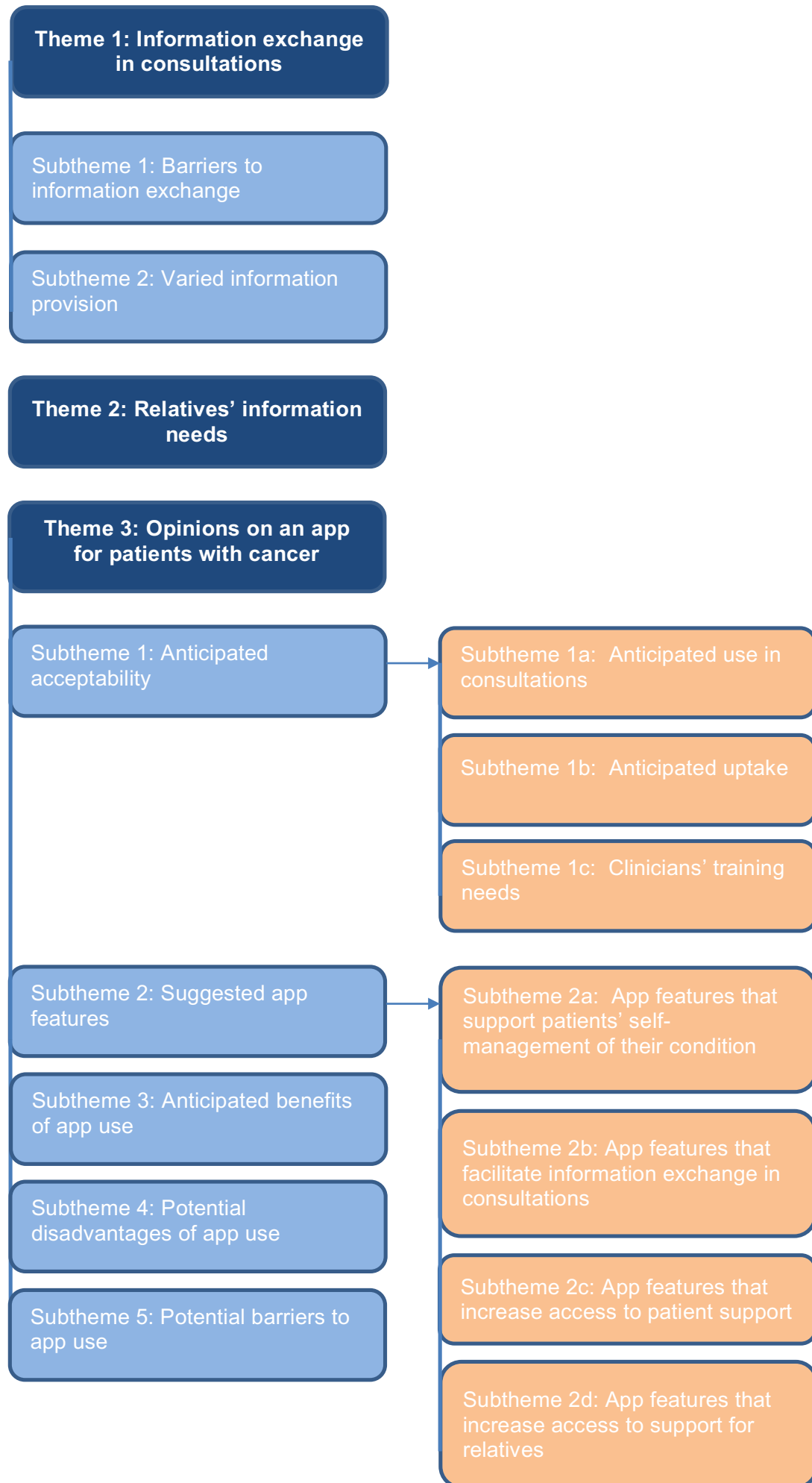
Theme 1: Information exchange in consultations

This theme reflects the views of clinicians on their experiences of information exchange with patients in cancer consultations. Key subthemes included barriers to information exchange and varied information provision.

Subtheme 1: Barriers to information exchange

Participants reported several barriers to information exchange that they experience during consultations. Clinicians reported that anxiety as a result of the cancer diagnosis was the one of the most common barriers they experienced. Anxiety caused patients to struggle to concentrate, digest and recall the information provided and as well as forget to ask questions, particularly during the first few consultations after diagnosis. Additionally, clinicians reported many cases where patients appeared to have made themselves more anxious by searching for information on their condition on the Internet, where they had been misinformed.

> C15 (TSur) - Most of them [the patients] are really anxious actually that's the, that's the main problem. When they come in for the consultation... and many times it happens that whatever we say doesn't register in the mind. Especially at the first consultation.

> C22 (TSur) -… you say something big like cancer and they start to drop off and don't, don't think of anything else, and I think that's a major barrier …we always ask at the end of consultations, do you have any questions. Invariably, the answer's no, or they'll have one question. And I think when they leave the consultation and leave the room, they'll think damn I should have asked that question…

> C16 (Sur) - I've had a few of the sort of more IT literate patients come extremely anxious into clinic saying I've read this forum where some patient was saying, "This is a disaster don't let any surgeon do this operation", and they've got completely the wrong information, they've been talking about completely the wrong operation and you know and you're already starting on a really back foot with those patients.

Another frequently reported barrier was an avoidant coping approach adopted by the patient. Clinicians reported that a minority of patients do not wish to have information

on their condition, and instead, prefer the minimum amount of information that they need to undergo treatment.

> C16 (Sur) - I think the, first and probably the most difficult one is the patient who doesn't want to know, and you do get that not infrequently. And that's a big problem because you get the patient who is happy to have an operation but doesn't want to know about the operation and about the consequences of surgery and the potential complications of surgery, that's a problem because you are obliged to discuss that with them.

Many clinicians reported that some patients lack a basic understanding of cancer and its treatment, which limits the amount of information that they can provide to patients. Additionally, some clinicians reported that they, and other clinicians, do not always communicate information to patients in layman's terms, which may limit patients' understanding of the information provided. Clinicians also suspected that some patients may too embarrassed to tell them if they have not understood the information, which may lead to further unmet information needs.

> C22 (TSur) - I mean, I'm always conscious to keep it in as simple terms as possible, but you can go a little bit more into the technicalities with someone who knows about the subject. At the very other end of the spectrum, you have people who know nothing about the subject and, if that's the case, then you want to just try and spell it out as simply as possible. But then you can't get the details in there.

> C13 (TSur) - Something I try hard not to do but I have seen it as a trainee where consultants don't necessarily use lay terminology… and even if you try hard not to slip up, I've done it myself, consciously trying to avoid it so I think that can be an issue.
> I - So patients' technical understanding…
> C13 (TSur)- Yes so you use terms they are not understanding and they may not pick up on it or tell you, they are embarrassed and think they should know about it.

Clinicians felt that the short amount of time allocated consultations limits opportunities to check patients' concerns and understanding of the information and some felt it was not sufficient for patients to fully understand and memorise the information. Clinicians

also reported an awareness that some patients may be conscious of the time they spend in consultations due to clinicians' busy schedules.

> C22 (TSur) - I think the main thing is you've got a very small window in your clinic, often a busy clinic to tell somebody some life changing news, so it's difficult to convey, you know, you would like to spend as much time as you can with that patient, so they really understand what's going on and what their options are and if they have questions at that time and things, but it's difficult because of the time frame.

> C5 (CNS)– um, sometimes I think maybe the clinics are really busy so the patient perceives the doctor is very busy {…} they sense that sometimes, but certainly with all our consultants they do allow enough time for every patient, but you know in a busy clinic the patient's are aware of other patients sat there.

Subtheme 2: Varied information provision

Clinicians reported that their awareness of these barriers to information exchange in consultations means that vary the amount and type of information that they provide to patients. Patients who are perceived to be less anxious and more knowledgeable tend to receive more information from clinicians than those who are perceived to be more anxious and less knowledgeable, as these patients are perceived to be less likely to cope with, understand and recall the information.

> C9 (CNS)- … it depends on the individual really, the patient's needs, some patients have got more than others, some patients can cope better than others and just assess it individually isn't it, how shocked they are at the initial consultation. If they're composed then we give them more information in the next outpatients, it's all pretty by ear really.

> C18 (CNS) - Well in my view you have to try to establish a nice rapport, work out what they might be able to understand and how much they'd be able to understand in one sitting, that's what I would say. Erm so you have to gauge the person and you have to ask them what they want to know and invite them to ask questions.

In an attempt to increase patient understanding and recall of important information, clinicians reported that they only provide patients with the basic information and will

provide further information if the patient asks for it. Some clinicians described a staged approach of information-giving, where they tell the patient more information about their condition and treatment at each consultation to give them time to digest it.

> C16 (Sur) - I think there's two boxes I'd say, I'd say there's information about the cancer and the surgery which every patient needs to be told, I think you can put things in that, like you know {…} stage of cancer, erm prognosis to some extent, but then there's a whole huge amount of information which you put in another box, for me anyway which is I can tell the patient this stuff if they want to know it. So I don't see it as being compulsory to tell them stuff but depending on each consultation, depending what the patient's cognitive ability is and whether they want to know this stuff or not there's a huge amount of stuff which we can tell them if they want to know it. But I think there's a core information which we have to tell the patient.

> C19 (Sur) - …in the clinic, doctors have to think about that on the spot. So actually, "I think that's a bit much, that's enough now, I am going to step back a bit, and let's look at it again once you've had time to have a think".

Written information and the format in which it is provided to patients also varied between clinicians, for example, some reported that they provide links to cancer information websites, whereas others reported that they provide information leaflets.

> C19 (Sur) - We might give them information booklets which describe ... Prostate Cancer UK website, is very good {…}. But in some appointments, er, we might, if we have got a reasonable screen, we might show them, "this is the Prostate Cancer UK website" {…}. But we don't do that very often I don't think, and obviously there are issues around availability of computer screens and showing patients, er, it's not straightforward.

Theme 2: Relatives' information needs

This theme reflects clinicians' views of and concern for relatives of patients. Many clinicians reported that relatives of patients often ask their own questions in order to fulfil their own information needs. Clinicians reported that relatives often still want information in cases where the patient themselves does not wish to have extensive information on their condition.

C3 (Onc) - …Often it's the relatives that come with the questions.

C16 (Sur) - …Sometimes we get relatives phoning us up wanting to speak to us about, you know …from different areas of the family.

C5 (CNS) –…Quite a lot of the time uh, the other family members will ask the questions that, that particular patient doesn't.

One clinician suggested that relatives of patients are often more anxious than the patient themselves, as they feel that they are unable to help the patient when they are unwell.

C12 (Onc) - Um, relatives will often feel that, strangely enough, relatives often feel more stressed than some of the patients, because they feel useless, they feel they can't do anything.

Theme 3: Opinions on an app for cancer patients and their relatives

This theme reflects clinicians' views on the value of an app for patients and their relatives, and the type of app that they anticipate to be useful. Key subthemes were: anticipated acceptability, suggested app features, anticipated benefits, potential disadvantages, and anticipated barriers.

Subtheme 1: Anticipated acceptability

Subtheme1a: App use in consultations

Most clinicians reported that they do not currently use Smart technology with their patients in consultations, however two clinicians had used apps to assist them in explaining a patient's condition to them but had not jointly used it with a patient in a consultation. Most clinicians anticipated that it would be acceptable for patients to use an app for their cancer in consultations, as many patients already bring printed information or written question lists, and some use their Smartphones to make notes during consultations.

C14 (Onc) - …There's a few kind of apps erm that are useful, like a Figo app.
I - What does that do?
C14 (Onc) - Erm, it tells erm, it's got all the different gynae cancers, what are the different stages and what the treatments erm… complications and stuff.
I - And is that for clinicians?

C14 (Onc) - Erm, yeah more aimed at that.

I - Do you ever use it with patients, do you ever sort of…?

C14 (Onc) - Hmm, I haven't done yet actually.

C19 (Sur) - … I mean, patients bring bits of paper, articles, all sorts of things. I mean, I think the patient population is changing {…} …you know, it's just a screen with information on it really isn't it? {…} So I think, you know, the delivery is not critical…in terms of what the response would be to them bringing it in and discussing it. {…} …the patients write things down quite a lot now. If they, I think if they did something on the app as opposed to the writing it down, I don't think it makes any difference.

C16 (Sur) - I mean often patients will bring out erm a notebook with questions they've written down at home so I can't see how it's different {…} it's just a slightly technological way of doing the same thing.

In contrast, two participants suggested that some older clinicians might perceive patients' use of an app in consultations to be socially unacceptable and will 'resist' the use of this type of technology in consultations.

C22 (TSur) – …Um there are still, I'm sure the old guard who will have to be moved out in the next ten years as well, and they might er, they might have a big resistance to it.

Subtheme 1b: Anticipated uptake

Clinicians anticipated that many patients with cancer, and their relatives, would want to use an app to help to meet their information needs, however many also expected that younger patients would more likely to use an app compared to older patients, as they are more familiar and experienced with Smart technology.

C11 (Sur) - I mean, it's difficult because a lot of these patients are elderly so, and I know a lot of elderly people do use tablets and Smartphones, but I don't think it's as prevalent as maybe in the younger age groups, so you know. I think certainly for some people it [the app] would be very useful {…}. You know, I think apart from, you know, the very elderly, I think most, a lot of people are starting to use the technology, you know, in their 70s and 80s, so I think it will apply to most groups.

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Consequently, some clinicians anticipated than an app intervention would be particularly useful for cancers that more commonly affect younger patients, such as testicular or cervical cancer, though most anticipated that an app would be useful for all types of cancers.

> C19 (Sur)- …If you look at the, sort of, if you can imagine in your own mind the, sort of, age of the patients with different cancers. So testes cancer would be affecting quite a young male population, um, peak incidence in the late teens, early twenties. So that group would probably be quite familiar with Smartphones and apps. Er, many cancers, of course, affect the elderly population.

Most clinicians anticipated that an app would be useful throughout all phases of the cancer journey (i.e. diagnosis, treatment, remission), as each phase brings new questions for patients. Some expected that an app that aims to help patients and relatives with their information needs would be most useful following diagnosis, as patients appear to have the largest need for information at this point.

> C12 (Onc) - I think it [the app] could be suitable for all, I don't think there is any ...routes {…} …I don't think there are any groups that it shouldn't be considered for.

> I - So you mentioned that an app might be most useful in the first month following diagnosis. Could you tell me why you think that might be the case?
> C22 (TSur) - Because I think in the first month, a majority of people who get a diagnosis, try and gather as much information as they can. The way they normally do that is with Google and with friends, both of which are pretty unreliable at best. Um you know, some people might be lucky and they come across the correct information, but some people might not and so I think it's important that in that time period, they get the correct information {…}. Um I think, you know, once you are six months down the line, maybe you would have to have another app or you know, a year down the line, for the chronic proportion of their disease. Um but at that point generally, people know enough, they've gained enough information about their disease, that they aren't looking for new stuff any more.

Alternatively, some clinicians expected that an app would be most useful for patients who are in remission and are being followed-up, as these patients often have questions about long-term side effects of their cancer or treatment and recovery but are not in regular contact with their clinicians.

> I - so you mentioned that, erm ... perhaps this app could be useful for sort of post treatment and follow up …can you just elaborate a bit on that?
>
> C14 (Onc) - Well like I said you can look out for possible problems, erm ... I think you know you can prompt who to call if you had a problem like that. {…} Erm … you could prompt, well I suppose it might get annoying but you could prompt the app to sort of check on you every morning, just to how are you feeling this, have you got any symptoms, but that could get annoying {...} but I suspect it's a lot of being able to look at possible problems that a patient might be experiencing and then whether they should then, erm ... initiate something you know.

Subtheme 1c: Clinicians' training needs

Clinicians did not anticipate that they would require extra training in how to deal with possible changes in communication with patients in consultations as a result of an app, as they already deal with more active patients who bring printed information or written question lists. Many clinicians reported that instead, they would like to know the content of the app.

> I - Do you feel that clinicians would require training in how to deal with more active patients as a result of this type of app?
>
> C14 (Onc) – Erm, I wouldn't have thought so, but they will need to know what is on the app and what's on the … you probably will have to allow the clinician to look into what is actually in the app and how the app works so that they understand.

Subtheme 2: Suggested app features

Overall, clinicians' suggestions for app features indicated that an app that would help patients, and their relatives, to meet their information needs was anticipated to be a useful intervention. Some clinicians found it difficult to think of potential app features and instead, listed the types of information that patients request in consultations (see below). The most commonly suggested app features were organised into four themes: (1) features that support patients' self management of their condition, (2) features that

facilitate information exchange in consultations, (3) features that increase access to patient support, and (4) features that increase access to support for relatives.

Subtheme 2a: App features that support patients' self-management of their condition
Clinicians suggested features that would facilitate patients' general self-management of cancer, including information, organisation and communication features. Many clinicians described the types of information most commonly requested in consultations by patients. Clinicians suggested including information on the types of cancers and their investigations, treatment options, the potential side effects of treatment, symptoms caused by the cancer, recovery and potential long-term effects. Other suggested information included lifestyle (such as guidelines on diet, exercise and smoking), clinical trials, psychological support, cancer support services, genetic risk, transport to appointments, palliative care and cancer survival rates.

> I – I know there are loads of things that an app could do, but are there any features that you think might be useful?
> C21 (CNS) – Yeah erm, well definitely anatomy…things like why the investigations have been carried out, why we need to carry out extra tests, information about treatments, possible side effects and what psychological support is out there as well because I think that's often missed really and, erm, and probably information on how to look after yourself as well you know. I mean smoking cessation, diet, stuff like that. Because a lot of patients ask that.

Clinicians suggested including links to credible cancer information websites to signpost patients to reliable information, as they were aware that patients can often struggle to find reliable information outside of consultations, particularly on the Internet, where some patients had been misinformed.

> C5 (CNS) – …I think if the patients are getting good information, so you know if this app is directing them to the right sites and everything, so it's specific to them, then lots of patients go on the Internet and Google breast cancer and you get millions of hits back and they don't know what is good information and what is bad information, so I think if this [the app] is going to tailor, or point them in the right direction, the clinicians would be up for that totally.

C14 (Onc) - …So maybe if we had an admin signpost you are in the right place and perhaps even signpost you to the correct, erm … websites that you read through and information that would be really useful.

Some clinicians felt that an app could help patients to organise their care, as they explained how patients are faced with many appointments, various tests and multiple treatment visits. Some clinicians suggested linking the app to the calendar feature on a Smart device to remind patients of upcoming appointments, as many forget to attend. Additionally, some clinicians suggested including a medication log for patients to record their medication, and some suggested a feature to remind patients to follow rehabilitation guidelines upon discharge.

C13 (TSur) - …I mean I really like the idea of the prompts and the diary and reminders, I mean patients forget so maybe a day in advance to just remind them and then it reduces our DNAs [Did Not Attend]. Or a week before, "Have you asked your boss for that time off? Have you booked transport?" Or something like that. You get text messages from your bank appointments don't you? Why not for your cancer appointments? And then if it's changed [the appointment], so act maybe as a diary manager… they get a lot [of appointments] in a two-week period because they've got to be managed.

C13 (TSur) - So what about a prompt that you get, I don't know, 4 weeks, how you deal with cardiac rehabilitation. You know, "Have you done your three times a week walk round the block? If not why? Have you got any of the following symptoms? If you have speak to your GP". You know and it sort of acts as a little pop up reminder, you can even have it so if it does actually pop up on your phone and sort of say, and you could set it so if you wanted to sort of achieve so much you could sit there with the patient say what I'd like you to do is this, and you set it with them, and then they've got a reminder.

Clinicians suggested a feature that could store clinician contact details to enable patients and their relatives to contact their clinician quickly when they need to do so, as they explained that patients often forget their designated nurse or consultant or lose their contact details. Clinicians also suggested including the contact numbers of cancer charities as they provide many useful services for their patients, which many other patients are not aware of, and so could be used to provide extra support.

C13 (TSur) - The name of the clinicians that are looking after them, half the time they can't remember…contact details for their clinicians, that would be really useful. Summary of, you know, this is your diagnosis, this is your consultant, this is the number, the name of the nurse specialist, this is the name of the stoma nurse, these are their contact details, these are their email addresses, this is the secretary's number. Everything they need there without having… because they come in with reams of paper scrawled and they can't remember anything.

C22 (TSur)- …Perhaps local phone numbers for specialist nurses or specialist departments…just having contact numbers so that if their relative becomes unwell or they have particular questions and need to get hold of someone urgently there's a quick reference contact or phone number or email or something that they can have access to.

C18 (CNS) - …Erm, relevant information on how to find help, you know how to get extra support like erm, like a forum …or group support …or MacMillan numbers, Tenovus numbers.

Subtheme 2b: App features that facilitate information exchange in consultations
Clinicians suggested app features that would facilitate information exchange in consultations and patients' understanding of information, in an attempt to overcome some of the reported barriers in consultations (described in section 5.4.2.1.1**).** Many clinicians were aware that patients forget to ask questions in consultations and that this can lead to unmet information needs. Participants suggested including a question prompt list feature to remind patients to ask questions during consultations.

C15 (TSur) - I mean many patients come and say to us, they're once, first at the initial the shock, of the diagnosis, got cancer. So nothing, they can't think about anything else. Um so if they can formulate some questions, they won't forget to ask, and they can keep their Smartphone in front of the consultation, and keep ticking the boxes. That um, that'll be useful actually for them, so they don't forget anything.

C6 (TOnc) - Erm, I mean you could have a subset of questions or you know like erm you know you could fill in a form and it goes to the nurses or something.

Many clinicians reported that they often use anatomical diagrams or images in consultations to help patients to understand the information they are given, such as diagrams showing the location of the cancer and how operations will be performed. Clinicians suggested a feature that includes anatomical diagrams and images that could be used by clinicians to facilitate the communication of information to patients in consultations.

> C14(Onc) - …Sometimes pictorially its better, erm ... I think with gynae as well is particularly difficult especially if you are dealing with different organs, which you may not be familiar with. So having pictures really helps. And, erm, trying to explain what we are trying to do in terms of the operation as well, sometimes having a diagram actually makes a difference. And there are some apps where you could then look at your staging pictorially, that might be helpful to include in an app.

Subtheme 2c: App features that increase access to patient support
Clinicians suggested including app features that would increase patients' awareness of and access to patient support, as they explained that this information is provided secondary, if at all, to information on their type and treatment of cancer. Some clinicians reported that they sometimes fail to provide information on the psychological support available to patients, such as support groups, due to limited time in consultations. Clinicians also suggested a feature that enables patients to meet one another, particularly those with the same issues, either online via a blog or face to face via a support group.

> C17 (TSur) - I think your suggestion of links to other support groups is a very good one perhaps with, you know, sort of online links that would take you to the website for example. Um, local support groups as well as national groups. And, yeah, that's probably it. I think more of the supportive side that perhaps we… we can't really spend a huge amount of time on. Because I think we're quite good at treating the disease and talking about the scientific part of the disease if the patients wish but it's the, like the supportive aspect that we can't provide enough time for that I think would be of greatest benefit to a patient.

> C14 (Onc) - Err, I don't know if you could have, if you could use, it has like some sort of community so you know you can contact other people with the same problem.

Subtheme 2d: App features that increase access to support for relatives

Clinicians anticipated that features that would be useful for the patient would also be useful for the patient, due to their comparable information needs, however clinicians suggested some additional features that would be useful for relatives. Due to the impact of a diagnosis on relatives, clinicians suggested including links to family support groups and reputable cancer charities that also provide psychological support for patients' families and friends.

> I - Do you think there's any features that would be useful for the relatives or friends…?
>
> C19 (Sur) - I'm not sure there's anything over and above that would be unique for their purposes ...as opposed to over and above what would be helpful for the patient.

> C22 (TSur)- Um I guess in the same way that you have emotional support for the patients in so far as support groups and things, perhaps you could also get family support groups or carer support groups popping up on the app, so that would be quite useful.

Clinicians also suggested including links to information for relatives on how they can best support the patient during their illness, including information on how to help with the patient's diet, changing of a stoma bag or practical information, such as how to get to the hospital.

> C18 (CNS) - I think support them [the patients], what they [relatives] could do to make their [patient's] life easier... transport to hospitals and how they are going to get to appointments. Especially for chemotherapy if they go every day and then get there, helping and supported in that. What can they do to jolly them along, what can they do psychologically to help them through. There is a lot out there. And then the patients' relatives feel they are doing something to help, so yes, just information about progress, how long it takes to get there, where do you park, how much is the car park, this sort of thing.

Subtheme 3: Anticipated benefits of app use

Clinicians anticipated several potential benefits of an app that would help patients to meet their information needs. The most commonly anticipated benefit of an app was a more informed patient. Clinicians suggested that an app could provide patients with a better understanding of cancer prior to consultations, which would enable to have a more detailed discussion with them. Additionally, clinicians expected that a more informed patient might develop more questions to ask.

> C21 (CNS - I think it would have benefits in that the patient would be more prepared …and therefore understand more about their own disease erm before their consultations, which would help. Erm, there may be, it may be that they ask more questions as a result of it.

> C20 (CNS) - …You know if patients are coming in and they've looked at that, they know they know what the process is, they know what, you know potentially is available to them and it leads for a sort of much more informed discussion really.

> C7 (CNS) - But I suppose it enhances their, it enhances the information that they've got so it enables them maybe to ask the right questions.
> C8 (CNS) -Hmm.
> C7 (CNS) -To get more information that is useful.
> C8 (CNS) - Yeah. And maybe not leave a consultation without asking the questions isn't it, you know because they know exactly what they should be asking.

It was also anticipated that a QPL feature would encourage patients to think of questions that they may not have thought of. Some clinicians anticipated that this type of app could lead to more informed relatives.

> C21 (CNS) - I think erm it would really give them tips on how to prepare for a consultation…You know giving them ideas sort of what questions would be good to ask.

> I - What about for the family do you think there would be any benefits of this type of app for them?

C1 (Onc) – Well for the family I think the same thing, it gives them more information and it points them in the right direction if they're trying to get more information.

A minority of clinicians further anticipated that an increase in knowledge of their condition could provide patients with an increased sense of control over their lives and reduce their anxiety. A more informed patient was expected to have more realistic expectations throughout their illness, which would enable them to plan ahead and exert some degree of control over their condition.

I - …What do you think the benefits would be in the long term for the patients? C1(Onc) – It just gives them more control, um I think when they have more control, feel more control that helps them because it's their lack of control, their lack of being able to plan, their lack of, things just happening around them and at least if you know what's happening, so many patients come in and say, "Even though you kind've given me bad news, I feel better leaving than I did coming because I know what's happening and I know you've got a plan."

C17 (TSur) - I think it would, um, help them to learn more about it and not be alarmed by certain symptoms, um, to know what to look out for if their disease is progressing, if they develop new symptoms because a lot of people with cancer think that every little ache and pain is related to their disease and… and sometimes, you know, if… if they read about it perhaps or learned a bit more about it then they might not be too concerned at certain things.

Clinicians also anticipated that this type of app could improve communication between patients and clinicians in consultations. Clinicians anticipated that a question prompt list feature would act as an agenda for the consultation, which would facilitate a more structured discussion and encourage patients to communicate their concerns. In turn, clinicians suggested that this might improve the efficiency of the consultation and increase clinicians' confidence that they have met the patients' information needs.

I - What benefits do you think there might be for clinicians if patients are using this sort of app? C4 (PCC) – Well I think clearer communication actually you know, knowing you're following the patient's agenda and what their problems are enables you to you know, clarify things quicker and to answer questions better.

I - What kind of benefits do you think there might be for the clinicians if patients are using this app?

C11 (Sur) - Er, as I say, hopefully it could form a very clear structure for a consultation em, which, you know, means it's probably more time efficient. Em, you know, and again, consultations can be quite long sometimes, particularly when you're trying to get the complex situation across, so I think, you know, there are benefits in terms of time.

Clinicians also recognised the additional benefits of an intervention delivered via an app, such as access to information independent of time and location, which means patients can digest information in their own time, where they are comfortable. Clinicians anticipated that accessing information via an app less burdensome compared to searching through printed information leaflets, which can often be lost.

I - Do you think patients would want to use this sort of thing?

C18 (CNS) - I think they'd be open to the suggestion. Otherwise they have got reams and reams of paperwork. That's the positive I can see from this. It's not having reams of paperwork because it becomes overwhelming. They get too much information at the same time, and with an app I presume they can pick out the bits they want and only access what they are interested in rather than be bombarded with too much jargon and stuff.

Subtheme 4: Potential disadvantages of app use

A minority of clinicians were concerned that an app for patients could potentially increase their workload, and perhaps the length of consultations, by encouraging patients to contact clinicians (via a contacts feature) or encouraging them to ask questions in consultations (via a question prompt list feature). Despite the potential increase in consultation length, clinicians believed that the advantages of such an app would outweigh this potential disadvantage.

C17 (TSur) - It probably would increase our workload…they'd have more questions, they'd probably want to spend more time with us as a result.

C12 (Onc) – Um, they can potentially, obviously, slow down consultations, so then you make them longer. Er, we have to bear that in mind. But I think in the

end of you have a quality consultation, in the end it probably speeds things up overall. As well as improves the quality of that consultation.

C21 (CNS) - …It may be that they ask more questions as a result of it so obviously there may be time... but overall I think you know that's, that's, the benefits outweigh the disadvantages there.

A small number of clinicians were concerned that an app might hinder communication during consultations by distracting patients, who may then miss information. Some clinicians also suggested that an app might reduce patients' non-verbal communication that enables clinicians to assess whether patients have understood the information.

C12 (Onc) - I think there are certain patients who will want to scroll through the app consistently through the, um, through the consultation and you have got to be a little bit cautious of that. One, that they are actually paying attention to the answers you are giving, rather than just the app.

I - Do you think clinicians would be happy for patients to use this app in a consultation?
C15 (TSur) – If it doesn't divert the consultation because they are constantly looking at the app, and they won't be able to listen what we say, and they may even miss it. So I presume that's the downside of it actually…I don't, I personally don't like um, somebody sitting in front of me and they're just on the Smart phone ticking boxes, not listening to what I say, because a lot of it…face to face, eye contact on the person, and from the eye contact I can see whether the patient has understood it or not.

Subtheme 5: Anticipated barriers to app use
Clinicians anticipated several potential barriers to use of this type of app in practice. The main anticipated barrier was patients' age and prior experience with Smart technology, where many clinicians believed that many older patients would lack the knowledge and experience with Smart technology to be able to use or want to use an app. Clinicians further explained that older patients might have problems with physically using an app due to poor eyesight and/or dexterity but this might be overcome by using a tablet device rather than a Smartphone, which has a larger screen.

> C22 (TSur) - I think in general and it is a vast generalization, the cancer patients tend to be the older patients and the older patients tend not to be able, quite so versed, in using iPhones and apps and Smartphones and all that sort of stuff. So I think at the moment you might not get a great uptake. Give it ten years and I think yeah, I think everyone will be using it and the people who are in their sixties, seventies now who are then going on in to get cancer in their eighties and things… it'll be very useful for.

> C13 (TSur) - Well the problems with the patients is as we've discussed before you've got the patients that really aren't IT or technologically advanced enough to be able to use it, you do have the very practical problems with patients of this age group because their eyesight's often poor, erm they can… their dexterity might not be that good…you know on an iPhone rather than an iPad.

Despite these concerns, clinicians reported that there are many older patients who use Smart technology and anticipated this issue to be temporary. Clinicians suggested that relatives and friends could use the app on behalf of the patients that are unable or do not wish to use an app.

> C13 (TSur) - Not everyone is going to want to take it [the app] up, but it may be that it increases over the next 10 or 20 years as everybody understands it. {…} I mean I'd argue that if they [the patients] don't then their relatives will. So I don't think there's a particular, and you would be amazed at the age who actually come in and use, you know their sitting there with their Kindles and their iPads and stuff.

Another potential barrier identified by clinicians was access to Smart devices. Some clinicians were concerned that older patients might not own a Smart device and others highlighted that some patients might not be able to afford a device. Clinicians anticipated that the majority of patients will own a Smart device in the future and that those patients who do not currently own a Smart device are likely to have access to one via family or friends.

> C20 (CNS) - It would be sort of potentially a barrier you know for the older ones who may not have the equipment or want the equipment … but then again may have family members that would be willing.

C18 (CNS) - You could be out in the clinic and people with their apps and then the man next door says I haven't got one of those, where can I get one of those, it will cost you £300. So that will be a barrier, price. I don't know, yes, but we are talking about future generations here really aren't we, we are talking 10 years in the future where people will all have one. So it is not such, so really it's not a massive barrier because everybody will have one.

Some clinicians were worried about the confidentiality of patients' information on an app and suggested including password protection and/or limiting the amount of sensitive patient information stored on an app.

C14 (Onc) - I think, erm, storage of information, erm sensitive information is the main issue I think. Erm, if they have a Smart Phone or, erm ... you know, erm ... a tablet that isn't locked then potentially if you put sensitive information on it it could be easy to view, so you might need to put a password onto your app.

Finally, some clinicians indicated that a minority of patients appear to have an avoidant coping approach and do not wish to have extensive information. As such, this type of patient was not anticipated to want to use this type of app.

C5 (CNS) - One thing I guess I would say is that you're always going to get the patient that will do everything, and you're always going to get the patient that will do nothing {…} there are those patients that will use everything and everything that they can access they will do …and others won't, you know?

5.5 Discussion

This is the first study to explore the views of cancer clinicians regarding the development of a novel app intervention that aims to help patients with cancer and their relatives to meet their full range of information needs in non-inpatient settings. The aim of this study was to understand the views of clinicians on the value of this type of intervention and to establish the type of app that clinicians anticipate to be most useful for patients. This study also aimed to explore the acceptability of an app for patients, and its potential outcomes, and identify whether clinicians would support the use of an app in clinical practice and their training needs in relation to the app. Findings identified several barriers to information exchange in consultations, and information-gathering outside of consultations, which appear to contribute to patients' unmet information needs. These issues were reflected in the type of app and features

suggested by clinicians, which indicated the need for an app to enable patients, and their relatives, to meet their information needs by facilitating information-gathering and understanding during and between consultations. Clinicians anticipated that many patients and their relatives would want to use an app for cancer care, however they expected older patients to be less likely to use an app. An app was expected to be a useful intervention for all types of cancers and phases of the disease, particularly around diagnosis and remission, and for cancers that commonly affect younger patients. Clinicians appeared to be supportive of its use in consultations and did not perceive a need for specific training in relation to the app. The identified potential benefits of this type of app appeared to outweigh its few potential disadvantages, and anticipated barriers to its use in practice were considered temporary or minor issues which could be minimised by consideration of these findings during app development. The findings of this study largely mirror the views of patients and relatives described in Chapter 4.

Findings of this study identified clinicians' awareness of the barriers to information exchange with patients in consultations, including limitations of their own communication skills, such as the use of complicated medical terminology, and limitations on the patients' behalf, such as anxiety. The views of clinicians on the barriers that exist within consultations were consistent with those of patients and relatives described in Chapter 4, and with previous studies of clinicians' perceptions of issues in consultations (Légaré, Ratté, Gravel, & Graham, 2008; Slort et al., 2011). This study further identified that clinicians' awareness of these barriers lead them to vary the information that they provide to patients, depending on their display of anxiety and level of understanding in the consultation, which is consistent with previous findings (Mills & Sullivan, 1999). These findings, and those from Chapter 4, indicate that patients might benefit from an app intervention that helps them to develop a basic understanding of cancer and the related terminology *prior* to consultations, which will enable them to understand more of the information that they are given by clinicians and guide clinicians to provide further information, if desired. Additionally, patients might benefit from an app that also enables them to become more active *during* consultations by prompting question-asking, to make their information needs clear to the clinician, instead of passively relying on the clinician to relay information. It is important for patients to voice their concerns and provide adequate information for their clinicians in order for clinicians to formulate the correct diagnoses and prescribe or amend treatment for patients (Waitzkin, 1985).

Clinicians' awareness of the barriers to communicating and understanding information in cancer consultations, as well as knowledge of the difficulties that patients have when trying to find reliable information outside of consultations (i.e. on the Internet), were reflected in their suggestions for app features. Clinicians' suggestions of app features were consistent with the four types of app features suggested by patients and relatives, however clinicians reported several additional app features, including a contacts feature and features to help patients to organise their care.

Clinicians were aware of the impact of a cancer diagnosis on the relatives of patients and the lack of available support, and as a result, perceived that an app would be a valuable intervention to enable relatives to fulfil their own information needs. Like patients and their relatives, clinicians expected relatives to find use in the same app features as the patients, with some additional app features just for relatives, including links to family support groups and information on how to provide informed care for the patient.

Only two clinicians reported that they had previously used an app to assist them with patients in consultations, however all clinicians owned a Smart device and were familiar with this technology. This finding is likely due to the lack of availability of patient-facing apps that are reliable and developed by researchers or health organisations (Bender et al., 2013; Pandey et al., 2013), as an increasing number of clinicians use apps for a wide variety of work-related tasks (Ozdalga et al., 2012). Importantly, clinicians appeared to be supportive of the development of an app to help patients and relatives to meet their information needs, which is likely due to their appreciation of the difficulties faced by clinicians and patients during and between consultations, as well as the negative psychological impact of cancer on patients and their families. Most clinicians in the current study anticipated that they would find it acceptable for patients to use an app for their cancer in consultations, as they told how patients already bring Smart devices or paper-based tools to consultations to facilitate the consultation process. Consequently, clinicians did not feel that they would require extra training to support an app for patients. Instead, clinicians suggested brief training on the content of the app to have an awareness of the information resources and tools being used by their patients. As clinicians are familiar with Smart technology, this training could be delivered via a brief, in-app tutorial. These findings are encouraging as the views and support of clinicians are key to the successful implementation of an app and its use by patients (Maguire et al, 2008; Murray et al., 2016). These findings are consistent with previous studies that reported clinicians' positive perceptions and

expectations for other types of mobile interventions for other chronic conditions (Bostock et al., 2009; Pinnock et al., 2006; Seto et al., 2010).

A novel finding of this study, in comparison to findings in Chapter 4, is that some clinicians anticipated that an app would be particularly useful for patients in remission. In support of this, research suggests that some patients who have completed their treatment still want information on their treatment, its long term side-effects, self-care and rehabilitation (Mistry, Wilson, Priestman, Damery & Haque, 2010; Rutten et al, 2005). An app has the potential to bridge the gap for those patients who have recently ceased to have supervision from clinicians and regular appointments.

Clinicians anticipated many patients would want to use an app to help to meet their information needs, however younger patients who are more familiar with Smart technology were expected to be more likely to use an app, compared to older patients. Clinicians appeared to be more concerned about the impact of this potential barrier on uptake of the app compared with patients and their relatives, which may be due to the fact that the majority of their cancer patients are of an older age. This led clinicians to anticipate that an app might be most useful for cancers that most commonly affect younger patients, such as testicular cancer. However, clinicians recognised that patients' age and prior experience with Smart technology is only a temporary potential barrier.

Other potential barriers to app use identified by clinicians included access to Smart technology and the security and confidentiality of patients' information on an app, which were also concerns of patients and their relatives. Previous studies of clinicians' anticipations of mobile interventions for a range of other chronic conditions have identified patients' age, access to Smart technology, and confidentiality of information as concerns (Bostock et al., 2009; Pinnock et al., 2006; Seto et al., 2010). However, the ways in which these types of barriers may be circumvented, or minimised, have been outlined in Chapter 4.

A number of clinicians in the present study identified a potential issue for the implementation of the app in consultations; some clinicians were concerned that an app might hinder communication during consultations by distracting patients, which in turn, might reduce the non-verbal cues that clinicians use to assess patients' understanding and cause patients to miss important information. It was further anticipated that a number of older clinicians might also resist this change in

consultations. These findings are unsurprising as previous studies have reported that some clinicians perceive the use of a Smartphone in clinical settings to be unprofessional due to the association of mobile technology with social contact (Koehler, Vujovic & McMenamin, 2013; Koehler, Yao, Vujovic & McMenamin, 2012). Two theories of new technology adoption are useful to explain the findings of the present study. Firstly, the Technology Acceptance Model (TAM) (Davis, 1989; Venkatesh & Bala, 2008), arguably the most widely used model to explain the adoption of new technology in healthcare, suggests that if clinicians are exposed to an app and perceive it to be useful and easy to use, they are likely to accept its use by patients. Clinicians with negative perceptions of apps in the present study, and older clinicians, may be less familiar with this technology, hence their negative perceptions. Secondly, the diffusion of innovation theory (Rogers, 2003) describes the process that occurs as people adopt a new innovation, such as an idea, product, or practice and has been used widely in healthcare research (Putzer & Park, 2010). At its simplest, the theory describes the process of adoption using five categories of 'adopters'. Firstly, there are an initial few, termed 'innovators' who are open to the new innovation and adopt its use. The innovators spread the word about the new innovation, which leads to more and more people, termed the 'early innovators and the 'early majority', to adopt the innovation. The innovators, early adopters and early majority lead to the development of a 'critical mass'; over time, they become the majority who have adopted the new innovation. The new innovation will then diffuse amongst the population until a saturation point is achieved, which involves the adoption of the innovation by the 'late majority' and finally, the 'laggards'. Sometimes, a sixth group of 'non-adopters' is included in the model. The findings in the present study suggest that currently, there is a critical mass of clinicians who are open to the idea of the use of an app by patients in consultations. Over time, it is likely that those clinicians with concerns will become familiar with apps as they are used by patients and their colleagues, eventually leading them to perceive such technology as useful and easy to use, and become late adopters. Older clinicians are likely be the last group to accept the use of an app in consultations, i.e. the laggards (Putzer & Park, 2010).

Models of the doctor-patient relationship, and the evolution of this relationship, may provide further insight into the anticipated resistance to change in consultations by some clinicians. A paternalistic model of the doctor-patient relationship dominated prior to the last two decades, which was characterised by 'hard-line beneficence' and imbalanced interaction (Hellin, 2002; Kaba & Sooriakumaran, 2007). This model of the relationship was analogous to the parent-infant relationship; the doctor's role was to

act in the patient's best medical interest, which involved making decisions that were silently complied with by the patient. A 'good patient' was regarded as one submissively accepted the passive role of the infant (Hellin, 2002). Over the last 20 years, critics have challenged this model and proposed a more active role for the patient, reduced clinician dominance and mutual participation (Kaba & Sooriakumaran, 2007). It is characterised by shared power and responsibility between the patient and clinicians, with recognition of the patients' needs and preferences, and involves behaviours such as encouraging the patient to voice their opinions and concerns, listening, and offering or engaging in collaboration (Mead & Bower, 2000). This model is known as the patient-centred approach and has become the predominant model in medical practice today (Kaba & Sooriakumaran, 2007). The findings of the present study provided evidence of paternalistic care by some clinicians, who told how they make decisions about the level of information that they provide to the patients without explicitly informing and involving patients in this decision. Additionally, it is possible that older clinicians prefer a paternalistic approach for cancer care as they were trained in the era of paternalism. An app that empowers patients and activates them in consultations, for example, through use of a question prompt list, has the potential to facilitate a power shift and create a more patient-cantered consultation. Clinicians in favour of a paternalistic approach may therefore resist an app being used in their consultations in order to protect their preferred model of care.

The most commonly anticipated benefit of an app that aims to enable patients to meet their information needs was a more informed patient, which is consistent with the expectations of patients and relatives. Clinicians further highlighted the benefits that they themselves might receive as a result of this type of intervention, including a more structured and therefore efficient consultation, and more confidence that they have dealt with patients' concerns. Some previous studies of the use of paper-based QPL in cancer consultations have reported a decrease in consultation lengths, however the evidence is generally mixed (Brown, Butow, Dunn & Tattersall, 2001; Dimoska et al., 2008).

In contrast, some clinicians were concerned that this type of app would lead to an increased workload, if an app was to increase patient contact and question-asking. Some previous studies of clinicians' perceptions of their involvement in mobile symptom-monitoring interventions for patients with cancer have reported issues such as an increased workload or technical issues to be problematic in clinical practice (Kearney et al., 2006; Maguire et al., 2008; McCall et al., 2008). However, these

interventions were used equally by the clinicians and patients, whereas a patient-facing app that is used independently of the clinician would limit the potential impact on clinicians' workloads. Additionally, clinicians in the present study believed that the advantage of a better quality consultation might outweigh the potential increase in workload. Subsequently, studies of digital and paper-based interventions that are patient-facing and used *during* allocated consultation time have been found to be acceptable by clinicians (Dimoska et al., 2012; Politi, Adsul, Kuzemchak, Zeuner, & Frosch, 2015).

5.5.1 Study strengths and limitations

A strength of this study is that it recruited a varied sample of clinicians, including a variety of roles, settings, patient types, career lengths and genders. Although not recorded, the sample included a mix of ethnicities, however there is little evidence for a digital use divide by this characteristic (Kontos et al., 2014). Furthermore, the sample size was sufficient for this type of qualitative inquiry and data saturation was reached. However, this study has several limitations to consider. It was not possible to calculate the response rate for this study nor collect key characteristics of those who declined to participate. Additionally, all clinicians were Smart technology owners. The sample may therefore not be representative of the general population and may have included clinicians with more favourable perceptions of an app than those who chose not to participate. However, statistics suggest that ownership of Smart technology among clinicians is pervasive, where up to 90% of healthcare professionals own a Smart device, and new technologies will continue to be integrated into healthcare services (Chase, 2013; Wallace et al., 2012). It is therefore likely that the majority of clinicians will have favourable attitudes to the use of technology in healthcare. Joint interviews with four clinicians may have prevented these participants from discussing important issues that they might have talked about in a separate interview, however the majority of interviews were conducted individually at length. Finally, providing examples of types of app features that might be useful for patients prior to beginning the interview may have influenced responses due to social desirability. The risk of this bias was minimised as the prior to the interview, the candidate explained that all opinions were valued, both positive and negative, in order to develop an app that would be most useful for future patients and their families.

5.5.2 Future research

Future studies are encouraged to investigate the views of the minority of older clinicians who may find app use in consultations to be socially unacceptable, as

reported by clinicians in the present study. This will help to further determine the barriers to use of this type of intervention and explore ways to overcome them in order to increase the chances of successful implementation of this type of app in clinical practice.

5.5.3 Implications

The findings of this study have several implications for the development of an app for patients with cancer and their relatives. Firstly, this study provided further evidence of the psychosocial context that underpins the needs and preferences of patients and their relatives regarding an app, as clinicians corroborated the presence of barriers to information exchange and understanding during consultations, and difficulties that patients have when trying to find reliable information outside of consultations. Additionally, clinicians highlighted the importance of developing interventions that enable relatives to meet their own information needs in order to optimise the patients' care.

Secondly, exploration of the views of clinicians on the type of app that they anticipate to be useful for patients and relatives provides further justification for the development of an app that enables patients and relatives to meet their information needs by facilitating information exchange and understanding in consultations and identification of reliable information sources outside of consultations. Additionally, clinicians suggested further app features that were not suggested by patients and relatives. These additional suggestions can be considered during app development.

Importantly, this study suggests that clinicians would be support of an app in practice, which provides further justification for its development. Findings identified further possible barriers to the uptake of the app, such as an increased workload for clinicians and older clinicians' perceptions of the acceptability of app use in consultations. These potential barriers may be considered during app development in order to optimise its uptake, usability and usefulness (Craig et al., 2008; Yardley et al., 2015).

Finally, this study adds to the preliminary body of work conducted for this thesis so far, which completes the first phase of intervention development outlined by MRC framework (Craig et al., 2008). Consideration of the findings of this body of work suggest that it is prudent to begin development of an app intervention that aims to meet the information needs of patients and their relatives, followed by exploratory research on the acceptability and feasibility of this type of intervention.

5.5.4 Conclusion

This was the first study to explore the views of cancer clinicians regarding an app that aims to help patients with cancer and their relatives to meet their information needs in non-inpatient settings. Clinicians provided further insight into the psychosocial context that underpins needs and preferences of patients and their relatives for an app intervention. Findings indicated the need for an app that facilitates information exchange and understanding during consultations and identification of reliable information sources outside of consultations. Clinicians also highlighted the importance of developing interventions that support relatives, as well as patients, in order to optimise the patients' care. Exploring the views of clinicians proved a useful exercise, as this led to the identification of further app features and potential outcomes that were not identified by patients and relatives in Chapter 4. Clinicians appear to be supportive of the development of an app and its use in consultations and did not perceive a need for specific training in relation to the app. Overall, the potential benefits of this type of intervention appeared to outweigh clinicians' few minor concerns.

Chapter 6

The design and user-testing of an app for patients with cancer and their relatives

6.1 Chapter overview

This chapter reports on the systematic process used to create an app for patients with cancer and their relatives. This was an iterative process consisting of several stages, including selection and development of app features and content, design of the app interface in consultation with a digital software company, and user-testing with a sample of patients and their relatives, which informed the final version of the app.

6.2 Introduction

As described in Chapter 1, the first phase of the MRC framework (Craig et al., 2008) for the development of complex interventions in healthcare encourages identification of the evidence base, relevant theories, model processes and outcomes of the intervention prior to development. Chapter 2 described a systematic review that reported preliminary evidence for the potential effectiveness of mobile interventions in supporting patients with cancer remotely. Additionally, this review identified a gap for an app intervention that aims to enable patients with cancer and their relatives to meet their information needs in non-inpatient settings. Chapter 3 reviewed relevant health behaviour models, theories and approaches related to the impact and self management of a chronic illness, such as cancer, in order to gain insight into the possible underlying processes and outcomes of such an intervention. Chapter 4 described qualitative research that provided further evidence that indicated the need for an app intervention to enable patients and their relatives to meet their information needs. Qualitative research with patients and relatives also highlighted the possible processes (and features) through which this may be achieved and identified the potential outcomes of this type of intervention (i.e. the benefits and disadvantages). These findings were supported by further qualitative research with cancer clinicians (Chapter 5). Following completion of this initial body of work in line with the first phase of the MRC framework, it was decided an app intervention for patients and their relatives should be created.

Next, the 'person-based' approach to development of digital interventions (Yardley et al., 2015) and other relevant frameworks, such as the Chronic Disease mHealth App Intervention Design Framework (Wilhide III et al., 2016), suggest determining the objectives of the intervention and the key features which are required to achieve each objective. Guidelines also suggest that the prototype intervention should be tested with

a sample of users to elicit their perceptions and reactions to intervention elements, including the content and design (Brown, Yen, Rojas & Schnall, 2013; Yardley et al., 2015). User-testing of the intervention provides an opportunity to optimise the usability and acceptability of the intervention for future users prior to implementation (Yardley et al., 2015). A range of user-testing models and qualitative and quantitative research methods have been employed in previous research (Harrison et al., 2013; Zhang & Adipat, 2005). Studies have typically used think aloud techniques, where a sample of users are given a list of tasks to complete in front of the researcher while discussing their thoughts and opinions (Klasnja, Hartzler, Powell, Phan & Pratt, 2010; Mirkovic, Kaufman & Ruland, 2014; Yardley et al., 2015). This provides researchers with the opportunity to understand how users actually interact and use the intervention in practice.

The Technology Acceptance Model (TAM) (Davis, 1989) (and its relevant extensions; Venkatesh & Bala, 2008) is another useful model to consider prior to developing an app intervention and testing its usability. The TAM was originally developed to predict the adoption and use of new information technology in the workplace and there has been much empirical support for the model (Adams, Nelson & Todd, 1992; Agarwal & Karahanna, 2000). More recently, the TAM has been used to predict individuals' adoption and use of newer information technologies, including Smart devices (Kim, & Park, 2012). At its most basic level, the TAM posits that an individual's behavioural intention to use a new information technology is determined by two beliefs, including its perceived usefulness and perceived ease of use (Davis, 1989). It is therefore important that these two concepts are prioritised during creation and testing of the app. With regards to an app for patients with cancer, perceived usefulness could be described as the extent to which a person believes that the app will help to meet their information needs and ease of use could be described as the extent to which a person believes that using an app will be free of effort (Ventakesh & Bala, 2008).

The Health IT Usability Evaluation Model (Health-ITUEM) for evaluating mobile health technology (Brown et al., 2013) was informed by the TAM and other relevant frameworks (Folmer & Bosch, 2004; Shneiderman & Plaisant, 2010) and offers intervention developers a framework of concepts to consider when assessing the usability of a digital health intervention. A similar user-testing model, the People At the Centre of Mobile Application Development (PACMAD) model (Harrison et al, 2013), was also useful to consider prior to user-testing of the app.

6.2.1 Aims of this chapter

This chapter reports on these next two steps in the systematic development of the app, including how the intervention objectives were determined from the synthesis of users' (i.e. patients and their relatives) and key stakeholders' (i.e. clinicians) perceptions and the process of user-testing to inform a final version of the app prior to field testing (described in Chapter 7). The aim of this chapter was to describe the systematic development of an app for patients with cancer, and their families, including: 1) The design of the app interface, 2) the selection of app features to include in an app and development of app feature content, and 3) the user-testing of the app with a sample of patients and their relatives.

6.3 App design

Digital Morphosis was selected to develop the app as they are a reputable, local software company and had experience of creating user-friendly apps. Additionally, they had previously worked with Tenovus Cancer Care and the Division of Population Medicine at Cardiff University. In order to create an app within the project budget, Digital Morphosis explained that the app would be created as a website to run on an app platform, as this would cost far less than creating a 'real' native app. A search of the Apple app store identified five apps that had similar features to the type of app desired by patients, described in Chapter 4. These five apps were shown to Digital Morphosis to provide the team with an idea of the types of apps that were currently available:

- Breast Cancer: Beyond The Shock
- Pain Diary: CatchMyPain
- Pocket Cancer Care Guide
- The Simplyhealth Back Care app
- Macmillan's 'My Organiser'

Design principles outlined in Apple's 'IOS human interface guidelines' (Apple, inc., 2010) were followed by Digital Morphosis during the app design and build. The guidelines facilitated the creation of a user-friendly and intuitive app, the navigation of which would be familiar to regular app users. It was important to create an app that was simple and easy to use for those patients who lack experience of using Smart technology. The app was created to run on any Smartphone and also run on tablet devices as they have a larger screen for users who have poorer physical health

(Charness & Boot, 2009). The candidate met with the digital team to discuss the initial findings from the qualitative interviews with patients, relatives and clinicians. Potential app layouts, colour schemes and fonts were discussed and decided upon in consultation with Digital Morphosis. It was decided that each app feature would have a separate tab on the home screen and an icon would be used to indicate the purpose of each feature. A Tenovus Cancer Care colour scheme of blue, orange and turquoise was chosen to indicate the affiliation of the app with a reputable Welsh cancer charity, which, it was hoped, would increase users' engagement with and trust of the app. A contract was drawn up between Digital Morphosis and Cardiff University detailing issues such as Intellectual Property (IP) rights, confidentiality, fees and payment. The app and all IP are owned by Cardiff University, however the app includes a Digital Morphosis logo at the bottom of the home page to highlight the company's involvement.

Digital Morphosis created an initial version of the app which focused on design rather than content and the candidate then met with the digital team to review the app. The initial version of the app was satisfactory though some minor changes were requested. The content for the app was then sent to the digital team to input into the app. The name of the app was decided in consultation with the supervisory team, which was then approved by Tenovus Cancer Care. 'Ask Us' was chosen, as it highlights the question prompt list feature and encourages patients and relatives to ask their clinicians for information if they want more information. Additionally, this name is in line with other services provided to patients by Tenovus Cancer Care, such as their choir group, called 'Sing with Us', and their writing group, called 'Write with Us'.

A second version of the app that included the requested changes and app content then underwent 'in-house' testing by the candidate and supervisory team. 'In-house' testing is recommended in order to iron out any potential issues prior to user-testing with real users (Kirwan et al., 2013). The team were asked to use each app feature and report any suggestions for improvements or confusion and difficulties. Several minor changes were requested and were amended accordingly by the digital team.

6.4 App feature selection and content
6.4.1 Method
Findings of interviews with patients, relatives and clinicians, described in Chapters 4 and 5, were used to determine the most and least popular suggested app features. Suggested app features were evaluated using the APEASE criteria (Michie, Atkins, &

West, 2014), which involved reviewing each feature for its affordability, practicability, effectiveness/cost-effectiveness, acceptability, side-effects/safety and equity. Final selection of app features involved a discussion between the candidate and project supervisors based on how potential app features would help to achieve the objectives of the intervention (Yardley et al., 2015).

6.4.2 Results

Intervention objectives

Synthesis of the findings of interviews with patients, their relatives, and clinicians indicated the need for an app intervention that enables patients with cancer and their relatives to meet their full range of information needs in non-inpatient settings. It was suggested by participants that this could be achieved by facilitating information exchange and understanding between and during consultations with clinicians. More specifically, patients, their relatives and clinicians desired an app that included four types of features:

(1) Features that support patients' self management of their condition
(2) Features that facilitate information exchange in consultations
(3) Features that increase access to patient support
(4) Features that increase access to support for relatives

It is important to create an app that is perceived as useful by patients and their relatives in order to increase the likelihood of adoption of the app (Davis, 1989; Venkatesh & Bala, 2008). An app feature to support each of these objectives was therefore included in the app. It was anticipated by the supervisory team that an app that included features to support each of the above intervention objectives could be useful for patients with different types of cancer, mirroring the views of patients, relatives and clinicians. For example, following a diagnosis of any type of cancer, it is likely that most patients will have to self-manage their condition during treatment, face barriers to information exchange and understanding during and between consultations, and may want to access further support for their condition, as told by patients, relatives and clinicians in qualitative interviews in Chapters 4 and 5. A decision was therefore made to create a non-specific cancer app that could help patients to overcome these generic issues. Where possible, app features would be designed so that they to be tailored to the individual and their specific condition.

Theoretical underpinning

Qualitative interviews suggested that the common sense model (CSM) of self-regulation of health and illness (Leventhal et al., 1984), crisis theory (Moos & Schaefer, 1984) and the theory of cognitive adaptation (Taylor, 1983) may explain why many patients and their relatives (i.e. those with an active/monitoring coping style) appeared to use information-seeking as a coping mechanism. Furthermore, the framework of patient activation (Hibbard et al., 2004) provides insight into how meeting patients' information needs might help them to develop the skill set and mind set needed to actively self-manage their condition. These theories, in combination with the qualitative data, were used as evidence to support the development of an app that aims to enable patients and their relatives to meet their information needs and develop their skills and motivation to better self-manage their condition.

Summary of app feature suggestions from qualitative interviews

Analysis from the qualitative interviews indicated that app features could be organised into four themes, as described in the 'intervention objectives' section. The most popular app feature suggestions are displayed in Table 5. Each theme is described below.

Features that support patients' self management of their condition:

The majority of patients listed the types of information that they wanted during their illness in order to help them self-manage their condition, which were reiterated by clinicians. Patients and clinicians highlighted the difficulty in identifying reliable information on the Internet and suggested including links to signpost patients to credible cancer websites. Other suggestions to support patients' self management of their condition included a symptom-monitoring feature to help patients record and monitor their symptoms during treatment, a contacts feature to store clinician and cancer charity contact details in order to increase access and encourage contact, and features to help patients organise their care, such as a reminder feature to prompt attendance of appointments.

Features that facilitate information exchange in consultations:

A question prompt list (QPL) feature was the most popular suggestion in this category. Many patients reported that they forgot or lacked confidence to ask questions in consultations and therefore suggested including a QPL feature to prompt question-asking and facilitate communication with clinicians. Participants anticipated that this would be the most useful feature of all to help patients to meet their information needs. Participants also suggested features to facilitate patients' understanding of information in consultations as some patients struggled to understand the terminology used by

clinicians. Patients and relatives suggested including a glossary of cancer terms and clinicians suggested including anatomical images to explain the location and nature of the cancer and/or treatment to the patient.

Features that increase access to patient support:

Features that enabled patients to talk with other similar patients was the most popular suggestion in this category. Patients reported the informational and emotional benefits of meeting other patients with cancer during their illness. Patients, their relatives and clinicians suggested including links to information on patient support groups and/or a feature to enable patients to connect with one another or links to online forms/social media platforms. Many patients also found cancer charities to be a useful source of information on the support services available to patients, such as psychological support and finances, and therefore suggested including links to cancer charity websites and links to local cancer support services to increase patients' awareness of these services.

Features that increase access to support for relatives:

A feature that provides information on how the relatives can support the patient was the most popular suggestion in this category. Patients and relatives reported that relatives were unsure of how they could help the patient during their illness and therefore suggested including information on how to support them effectively. Participants also described the impact of a cancer diagnosis on relatives and therefore suggested features to increase access to support specifically for relatives, such as a feature to connect them with other relatives of cancer patients.

Table 5: *Assessment of popular app features suggested by patients with cancer, their relatives and clinicians using the APEASE criteria (affordability, practicability, effectiveness/cost-effectiveness, acceptability, side-effects/safety and equity).*

App feature suggestions	A	P	E	A	S	E	Outcome
Features that support patients' self-management of their condition							
Self-management related informational needs							
Informational feature providing information such as treatment side-effects, types of treatment and risks, and types of cancer and staging.	√	X	√	√	√	√	Building an in-app feature that contains all of this information was not practical due to the huge amount of information available. It would also be duplicating the efforts of reputable cancer charities, such as Macmillan, and health organisations such as the NHS. Alternatively, an app could include a feature that contains links to specific topics of information that already exist on credible cancer information websites.
Signposting							
Links to credible cancer information websites	√	√	√	√	√	√	Possible feature.
Increasing access to clinicians							
Contacts feature to include clinician contacts details (and contact details of relevant health and cancer charity organisations)	√	√	√	√	√	√	Possible feature.
Symptom monitoring							
Treatment-related symptom diary	√	X	X	√	√	X	There is already a wealth of literature examining the effectiveness of this type of intervention for patients with cancer. Additionally, this feature would not directly help to meet the aim of the intervention which is to help patients to meet their full range of unmet information needs.

Organisation of care							
Reminder function for appointments, medication log, prompts for adherence to rehabilitation guidelines	√	√	X	√	√	√	Patients can already programme reminders and alerts using the 'Reminders' feature on their Smart device. Additionally, this type of feature would not directly help to meet the aim of the intervention which is to meet patients' information needs.
Features to facilitate information exchange in consultation with clinicians							
Increasing communication of information needs							
Question prompt list	√	√	√	√	√	√	Possible feature.
Increasing patient understanding of information provided							
App feature to view anatomical images/diagrams	√	X	√	X	X	√	This type of feature might not be acceptable to all patients as images might cause distress. Additionally, the app aimed to be non cancer-specific.
Glossary of cancer terms	√	√	√	√	√	√	Possible feature.
Features to increase access to patient support							
Signposting							
Links to cancer charity websites	√	√	√	√	√	√	Possible feature.
Links to local cancer services (e.g. psychological support, help with finances)	√	X	√	√	√	√	This feature was not practical as all local services would have to be included and this would decrease the ease of use of the app. Additionally, some support services are already signposted via cancer charity websites. Alternatively, an app could include a feature that contains links to existing, specific topics of information within cancer charity websites.
Social support							
Feature to connect patients with one another or links to existing forums/social media	X	X	X	√	X	√	An in-built app feature to connect patients online via a chat forum could potentially pose a risk to patients' safety/well-being. This

							type of feature would therefore have to be monitored to ensure patient safety, which is not practical. Alternatively, the app could include links to local patient support groups to enable patients to meet in person in a safe environment.
Links to information on patient support groups (online or face to face)	√	√	√	√	√	√	Possible feature.

Features to increase access to support for relatives of patients

Information needs

Informational feature providing information on how relatives can help the patient effectively	√	X	√	√	√	√	Building an in-app feature that contains this information was not practical due to the large amount of information available. It would also be duplicating the efforts of reputable cancer charities, such as Macmillan, and health organisations such as the NHS. Instead, an app could include a feature that contains links to existing information for relatives on cancer charity websites.

Increasing support for relatives

Feature to connect relatives with other relatives of cancer patients	X	X	X	√	X	√	An in-built app feature to connect relatives online could potentially pose a risk to their safety/well-being. This type of feature would therefore have to be monitored to ensure safety, which is not practical. However, the app could include links to online of face-to-face support groups for relatives to enable relatives to meet in person in a safe environment.
Links to information on support groups (online or face to face)	√	√	√	√	√	√	Possible feature

Results of application of the APEASE criteria

Assessment of the most popular app features suggestions with the APEASE criteria resulted in the following possible app features per theme:

(1) Features that support patients' self management of their condition:
   i.   Links to credible cancer information websites
   ii.   Links to specific topics of self management-related information within credible cancer information websites
   iii. Contacts feature to store clinician contact details (and contact details of relevant health and cancer charity organisations)

(2) Features that facilitate information exchange in consultations:
   i.   QPL
   ii.   Glossary of cancer terms

(3) Features that increase access to patient support:
   i.   Links to patient support groups (online or face to face)
   ii.   Links to reputable cancer charity websites
   iii. Links to specific topics of support-related information within reputable charity cancer websites

(4) Features that increase access to support for relatives of patients:
   i.   Links to information on how relatives can support the patient within reputable cancer charity websites.
   ii.   Links to support groups for relatives (online or face to face)

Selected app features

The project team discussed these possible features and how to incorporate as many as possibly whilst maintaining ease of use. Four app features were selected, including: (1) a QPL, (2) a glossary of cancer terms, (3) a resources feature, and (4) a contacts feature. The selected app features, their aim in relation to the objectives of the intervention, reasons for their selection and a description of the development of their content are described below.

Question prompt list feature:

A QPL is a structured list of questions selected from a range of possible questions by the patient to increase patient participation by prompting question-asking, in order to

acquire the information that they need (Dimoska et al., 2012). The aim of this feature was to facilitate information exchange in patient-clinician consultations. It was anticipated that this feature would help patients to increase their knowledge and develop an accurate understanding of their condition by obtaining reliable and specific information from their cancer clinician. As described in Chapter 3, theories related to coping with cancer posit that accurate illness-related information helps patients to develop illness cognitions, which in turn, facilitates the adoption of adaptive coping strategies and promotes psychological adjustment (Leventhal et al., 1984, Moos & Schafer, 1984).

Findings from qualitative interviews with patients with cancer, relatives and clinicians highlighted several barriers to information exchange and understanding in consultations, such as patients' poor memory and concentration, lack of confidence to ask questions and a busy clinic environment, which meant that many patients did not always ask their clinician questions to obtain the information that they needed. Studies on the effects of paper-based QPLs have suggested that this type of intervention has the potential to circumvent these issues in cancer consultations (Brandes et a., 2015; Brown et al., 2001). A QPL aids patients' memories and concentration by helping them to think about what questions they want to ask and reminding them to ask questions when in consultations. This feature will also have the benefit of allowing patients to add questions to their list as soon as they think of them, which will prevent them from forgetting which questions they wish to ask. Additionally, this feature could be useful for patients who lack the skills and confidence to ask questions in consultations (i.e. those with low health literacy) by helping them to prepare a question list and prompting them to participate in the consultation (Hibbard et al., 2004; Joseph-Williams, Edwards & Elwyn, 2014; Kinnersley et al., 2007). Indeed, studies suggest that an app might be best used as a supportive intervention in the presence of clinicians for those with limited health literacy, rather than relying on the using the app alone (Wilson et al., 2010).

Findings from qualitative interviews with patients with cancer and their relatives also suggested that clinicians are still patients' most valued source of information, despite the increasing trend of seeking information on the Internet. It is therefore important to include a QPL as this feature will facilitate patients' information gathering in consultations and enable patients to obtain information that is reliable and specific to their condition.

Content for the QPL feature was developed using findings from the qualitative interviews, the CSM of illness self-regulation of health and illness (Leventhal et al., 1984) and existing paper- and app-based QPLs. This was followed by a review of the final included questions by clinical supervisors. General, and frequently asked, questions were chosen for this feature. As described in Chapter 3, the CSM model proposes that individuals actively construct representations of the illness, termed 'illness cognitions' which have five dimensions, as described in Chapter 3, section 3.3.1. Questions that addressed each of the five dimensions of illness cognitions were therefore devised for the QPL app feature in an attempt to enable patients to develop an accurate and adaptive understanding of their illness.

Next, findings from interviews with patients, their relatives and clinicians on patients' and relatives' information needs were considered and questions that would help them to address these specific information needs were also included in the final QPL feature. Existing cancer-specific QPLs were then extracted from relevant literature and were searched for any additional, relevant questions (Dimoska et al., 2008). An app-based QPL from Pocket Cancer Care Guide app was also searched for relevant questions. During this process of creating and collating potential questions for a QPL app feature, any questions deemed relevant and useful were added to a list of possible questions and duplicate questions were removed. Questions were then grouped into five categories: (1) after your cancer diagnosis, (2) treatment, (3) support, (4) family and friends, and (5) remission. This list of questions was sent to clinical supervisors (one consultant oncologist and one general practitioner) for review. Supervisors were asked to add any useful questions that were not already on the list and suggest the deletion of questions, if appropriate. The final list of questions consisted of the same five categories and a total of 62 questions. A function was then added to enable patients to add their own questions to their question list. Patients might use this function if the question they wish to ask is not already available within the categories Additionally, this functions allows patients with all types of cancer to tailor the app feature to their condition as they are able to add specific questions about their own cancer or treatment.

Glossary of cancer terms:
The aim of the glossary feature was to facilitate information exchange in patient-clinician consultations and understanding of information sought during and between consultations. When diagnosed with cancer, patients are exposed to a new medical language about their illness. It is the role of their clinician to explain using terms that

the patient understands. Qualitative interviews confirmed that some patients do not understand medical terminology used by clinicians in consultations and other cancer information resources, and cancer terms are not always explained to patients. These findings are also supported by previous research (Lobb, Butow, Kenny & Tattersall, 1999; Chapman et al., 2003). Additionally, patients may be embarrassed that they do not understand the terminology and are afraid of being 'found out' if they ask for explanations (Parikh, Parker, Nurss, Baker & Williams, 1996). If patients do not understand the information provided by their clinicians, they are likely to have a poor understanding of their condition, poor recall of information, decreased satisfaction with their care, and lower adherence to treatment (Ley, 1989; Siminoff, 1992). Consequently, clinical outcomes, such as survival time and quality of life, can be negatively affected (Siminoff, 1992). Taken together with the other issues in consultations described by patients, such as a power imbalance with clinicians, patients appeared to have low levels of activation (Hibbard et al., 2004). The patient activation framework (and field of health literacy) suggests that it is important that patients have the required knowledge, skills and confidence in order to increase their levels of activation. For these reasons, a glossary app feature was included in the app to help patients, and their relatives, to learn the meaning of cancer-related terms used in consultations and information resources. It was hoped that patients could build up their cancer-related vocabulary in their own time or chose to look up certain words as and when needed in order to facilitate patients' understanding of cancer-related terminology in consultations and information resources. This in turn, might increase their confidence to participate in consultations. The QPL feature could then help to motivate and activate patients by prompting them to ask for information in consultations.

Content was developed using existing glossaries from apps and websites (listed below). The initial list of terms comprised 495 terms, however this number was not feasible to include in the glossary. The following types of terms were excluded to reduce the initial list of terms:

   i.   Specific drug names
  ii.   Pre-diagnosis test procedures
 iii.   Terms relating to specific cancer types
 iv.   Vaccinations

The second draft of glossary terms was reviewed by the two clinical supervisors to ensure that all terms were useful for patients' understanding of their condition and to ensure the readability of the definitions. No further terms were added to the list following clinical review, however some definitions were simplified. The final list included 179 terms related to the following topics:

i. Types of treatment and related procedures/investigations
ii. Non-specific cancer types/phases (e.g. advanced, malignant, hormone-resistant)
iii. Possible side-effects of cancer and treatment
iv. Types of clinicians
v. Anatomy and biology
vi. Non-specific drug types (e.g. anti-emetic drugs)
vii. Mental health
viii. Lifestyle (e.g. balanced diet)
ix. Clinical trials

The final list of terms was organised alphabetically. Terms and definitions for the final glossary were extracted from the following resources and permission was obtained from Cancer Research UK as most of the definitions were extracted from their website:

i. Pocket Care Cancer Guide app
ii. Breast Cancer Glossary app
iii. http://www.cancerresearchuk.org/about-cancer/utilities/glossary/
iv. http://www.cancer.org/cancer/cancerglossary/index
v. https://www.cancer.gov/publications/dictionaries/cancer-terms
vi. http://www.cancerindex.org/medterm/medtm3.htm
vii. http://www.cancer.net/navigating-cancer-care/cancer-basics/cancer-terms-cancer-basics

Resources feature:
The aims of the resources feature were to support patients' self management of their condition, to increase access to patient support, and to increase access to support for relatives. The majority of patients and relatives requested an informational feature to access cancer-related information so that they could obtain information independently of their clinicians. However, it was decided that this type of feature would not be feasible, due to the huge amount of information available, nor practical, as it would be

duplicating efforts by reputable cancer charities and health organisations. Instead, the candidate decided to include an app feature that enabled patients to obtain information from consultations via a QPL feature, as described above, and a resources feature that enabled patients to obtain existing information outside of consultations. The resources feature included links to credible cancer information websites, such as health organisations (e.g. NHS) and cancer charities, and links to specific topics of information within these websites for faster access to information.

Information-seeking was described as a coping mechanism by patients and their relatives, therefore a resources feature that enables patients to actively gather information via the Internet in non-inpatient settings, independently of clinicians, could promote better adjustment to the illness (Leventhal et al., 1984; Moos & Schaefer, 1984; Taylor, 1983). In support of this, previous research on cancer patients' Internet use for information-seeking suggests a positive impact on their sense of control and psychological well-being (Bass et al, 2006; Lee, Gray & Lewis, 2010).

Additionally, patients, relatives and clinicians reported on the difficulty of finding reliable cancer-related information on the Internet and some reported that they had been misinformed by inaccurate or irrelevant information. A recent study suggested that up to 80% of cancer patients now search for information about cancer on the Internet and use of the Internet can affect patients' clinical decisions (Castleton et al, 2011). The resources feature was included in order to help patients to navigate the Internet and filter out accurate information. Furthermore, access to accurate information is associated with improved clinical outcomes, increased adherence to treatment, better disease management and decreased anxiety (Galloway et al, 1997; Kessels, 2003; Mossman, Boudioni & Slevin, 1999). A further reason for including the resources feature was to enable patients' and relatives to build a more in depth understanding of their condition outside of consultations, which might increase their levels of activation (Hibbard et al., 2004).

Patients, relatives and clinicians also reported a lack of awareness of available support services and suggested including links to these services in order to raise patients' awareness of them. Additionally, a recent systematic review of RCTs of psycho-educational interventions, which are typically multi-method interventions that support both patients' information and psychological needs, reported small but significant positive effects on anxiety, depression and quality of life (Faller et al., 2013). In contrast, information-only interventions failed to show effects on these outcomes. This

review therefore suggests that intervention developers should seek to develop more comprehensive interventions that aim to support both patients' information and psychological needs. For these reasons, the resources feature also included links to information on patient and relative support services, such as support groups, help with finances and psychological support.

A list of clinician-recommended websites was compiled from interviews with clinicians. Recommendations included reputable cancer charity websites, health organisation and general health information websites. Websites that were for specific cancer types were excluded. Administrators of the websites that were to be included in the app were contacted and permission was granted to include the website links. Links to the following websites were included in the resources feature:

   i.   www.nhs.uk
   ii.   www.tenovuscancercare.org.uk
   iii. www.macmillan.org.uk
   iv.   www.cancerresearchuk.org
   v.   www.mariecurie.org.uk
   vi.   www.patient.info

The most common topics of information needed by patients and relatives during their illness, as reported in Chapter 4, were searched for within the websites listed above. Where possible, links to these specific information topics (e.g. chemotherapy side effects) were included in the resources feature to enable patients, particularly those who are unfamiliar with Smart technology and websites, to easily locate and access the information they need. A 'coping with cancer section' included links to local patient support groups and information on psychological well-being to facilitate access to patient support. Similarly, a 'support for family and friends' section included links to information specifically for relatives on how to support the patient and links to support groups. Links to the following topics of information and support services were included:

   i.   Chemotherapy side effects
   ii.   Radiotherapy side effects
   iii. General anaesthetic side effects
   iv.   Coping with cancer
   v.   Support groups
   vi.   Support for family and friends

vii.   Maintaining a healthy lifestyle

viii.   Financial information

ix.   Information on clinical trials

<u>Contacts feature:</u>

The aims of the contacts feature were to support patients' self-management of their condition and to increase access to patient support. During interviews with clinicians, a 'contacts' feature was suggested in order to encourage patients and their relatives to save the contact details of their clinicians to facilitate easier access to clinicians, however few patients or relatives suggested this type of feature. This may be due to the fact that many patients are reluctant to contact their clinicians outside of consultations for fear of unnecessarily 'bothering' them (Maguire et al., 2015; Weaver et al., 2007). In support of this, interviews described in Chapter 4 described patients' awareness of a pressured healthcare service. However, with the shift from inpatient to outpatient cancer care, patients spend most of their time at home self-managing their condition. It is therefore important that patients have access to, and feel able to, contact their clinicians in order to prevent hospitalisations or unnecessary anxiety (Besse et al., 2016; Maguire et al., 2015). During clinician interviews, there was also support for the inclusion of contact telephone numbers of cancer charities in an app in order to provide extra support for patients in cases of emergency. Research has suggested that patients use a range of information sources and cancer services to obtain different types of information on cancer, such as the Internet to obtain factual information, whereas emotional support was more likely to be sought via telephone helplines (Hardyman, Hardy, Brodie & Stephens, 2005). Including a range of services and sources of information in an app for patients would enable patients to benefit from each type, such as personal communication when using telephone helplines and anonymity when using the Internet. A contacts feature was therefore included in the app to enable patients to save clinician contact details and access the helplines for reputable cancer charities.

The contacts feature was designed by Digital Morphosis. Up to five contacts can be input and saved into the contacts feature and each contact includes the name, telephone number and email address. The telephone helplines of the following organisations were listed (including two out of hours contacts for emergencies), with details of the telephone line operation times and costs:

i.   Tenovus Cancer Care

ii.   Cancer Research UK

iii.   Macmillan

iv.   Marie Curie Cancer Care

v.   NHS Direct Wales (out of hours)

vi.   Samaritans (out of hours)

<u>Additional features:</u>

The 'Ask Us' cancer app also included useful technical features. As highlighted in the qualitative interviews, one of the main benefits of an app is the ability to use it independent of time and location. Although many community settings now offer free wifi, the location and connection are not always guaranteed. The QPL, glossary and contact features were designed to be used offline, without the use of Internet connection. This provides patients with the flexibility to use the app when on the move. However, the resources feature, which provides links to websites, does require Internet connection, although it is expected that patients would prefer to use this feature when at home, where they have time to read the information.

The ability to use most of the features of the app offline is a unique advantage that sets it apart from similar tools that are available for patients with cancer. For example, existing glossaries of cancer terms that are available on cancer websites, such as Cancer Research UK, require the Internet to access them. Additionally, patients require the knowledge and experience to access the particular website via an Internet browser on a Smartphone (or tablet) and then locate the glossary within that website. This would be a difficult task for patients who lack experience with Smart technology. Instead, the 'Ask Us' cancer app glossary is located on the homepage of the app to enable fast and easy access for patients of all abilities. Similarly, the resources feature offers patients fast and easy access to topics of cancer information within existing websites, such as Macmillan. Some clinics or websites may offer patients paper-based QPLs to use and some patients have reported that they wrote questions for their consultation on a blank piece of paper. However, there is a risk of losing a paper-based QPL and forgetting to take it to the consultation. As most people now carry Smartphones with them when in community settings, it makes sense to use an app-based QPL that cannot be lost and or forgotten. Finally, the contact feature provides fast access to telephone numbers for emergency care or further cancer-related information and these numbers may be telephoned directly from the app. This saves patients the time of having to look up the organisations telephone number and typing it manually into their phones.

As described in section 6.3, there are a number of apps for patients with cancer that offer similar features as the 'Ask Us' cancer app, which were found through the Apple app store. However, as described in Chapter 1, previous searches of Apple and Android app stores in 2013 indicated that only 55% of the publically available apps which provided information on cancer provided scientifically validated data, and none appeared to have been systematically developed and evaluated (Bender, Yue, To, Deacken & Jadad, 2013; Nasi et al., 2015; Pandey, Hasan, Dubey & Sarangi, 2013). Additionally, the features included in the 'Ask Us' cancer app were suggested by patients, their relatives *and* clinicians and were further screened using the APEASE criteria, in consultation with researchers and clinicians. This rigorous process created a unique combination of app features and only included information and sources that were accurate and reputable. For example, the Pocket Cancer Care guide offers a QPL feature and a glossary feature, as well as a 'care guide' feature, however the glossary includes a huge list of cancer-specific terms which appears to decrease its ease of use. Additionally, this app does not include links to credible cancer information websites that were desired by many patients. Similarly, Macmillan's 'My Organiser' app offers patients an appointment feature, medication log and a contacts feature. However, the appointment feature was not very popular amongst patients and their relatives in qualitative interviews described in Chapter 4, and Smartphones already have an inbuilt calendar feature that patients could use to record dates of consultations. Furthermore, although a medication log might be desired by some patients, it was not popular enough amongst patients in qualitative interviews for this thesis to be included in the app. Other features, such as the resources feature, were anticipated to be of more use. In summary, the 'Ask Us' cancer app provides patients with faster and easier access to a unique combination of useful cancer-related tools and services, that are available via one platform, by taking advantage of the benefits offered by Smart technology.

6.5 User-testing discussion group
6.5.1 Method
A sample of patients and their relatives were invited to a discussion group to user-test the app and assess the design, its ease of use and content. Research has shown that user-testing with just five participants can reveal up to 85% of usability issues (Nielsen, 1993; Nielsen & Landauer, 2000). A discussion group offers the benefit of prompting participants to think about issues that they may not have thought about individually and provides the opportunity to build upon one another's opinions and the ability to reach a

consensus for suggested app modifications, much like a focus group (Kitzinger, 1995). As a result, a discussion group with around 5-6 participants was considered a suitable method to identify any issues with the app at this early stage in app development. The discussion group would not be audio-recorded as it would be a followed by an in-depth field testing study consisting of semi-structured interviews covering much of the same topics, such as perceived acceptability, usefulness and ease of use. The aim of the discussion group was to iron out any issues and optimise the app prior to field testing.

Participants

A small sample of patients and relatives that participated in qualitative interviews (Chapter 4) who consented to being contacted for further research were invited to participate in a user-testing session. Purposive sampling was used to recruit a varied sample of participants, including:

    i.   Participants that had positive views of an app for patients
   ii.   Participants that had negative views of an app for patients
  iii.   Participants that were familiar with Smart technology and apps
  iv.   Participants that were unfamiliar with Smart technology and apps
   v.   Women and men
  vi.   Participants above and below the age of 60

Recruitment

Selected participants were contacted by telephone or email to participate in the user-testing session and were sent an information sheet about the session by email (Appendix 30). Participants were informed that they would receive a £20 Marks & Spencer voucher for their time and could be reimbursed for their travel expenses. The date and time selected by the majority of participants was then selected and participants were notified.

Procedure

The candidate began the discussion group by introducing herself and the participants to one another. The session was explained to participants and they were given an opportunity to ask questions. Written informed consent was given by each participant (Appendix 31). Demographic information was then collected by questionnaire (Appendix 32). A short PowerPoint presentation that included a brief overview of the PhD project and findings of the qualitative interviews with patients, their relatives, and clinicians was given, followed by a demonstration on how to use the app. Participants

were then provided with iPads and/or downloaded the app to use on their Smartphones and were asked to explore the app by using each of its features, reading the content, and completing the following tasks:

(1) Question prompt list feature: create a question prompt list and add questions to the list.
(2) Glossary feature: search for a term in the glossary.
(3) Resources feature: select a link from the resources feature and obtain information.
(4) Contacts feature: add a contact and save it.

After 30 minutes, the candidate used a topic guide to facilitate a group discussion of participants' views and opinions of the app. Throughout this discussion, participants kept the Smart devices so that they could continue to explore and refer to the app. Once the session had finished, the participants were debriefed about next steps for the app.

Topic guide

A semi-structured topic guide was used to facilitate the user-testing session (Appendix 33). This allowed the candidate to cover certain topics of interest but also allowed participants the freedom to discuss other topics of importance (Harrell & Bradley, 2009). Findings from previous chapters and usability testing models, including the Health-ITUEM (Brown et al., 2013) and the PACMAD model (Harrison et al., 2013) informed the development of the topic guide. These models encourage the consideration of concepts such as effectiveness (whether users can successfully complete a set task), learnability (whether users are able to use the app within less than five minutes), satisfaction (the perceived level of comfort and affect towards the app), and error prevention (how well a user can complete tasks without making errors or experiencing technical problems). The topics of the discussion group were grouped into three themes, including (1) the design (layout, colours, font, icons and placement of features), (2) navigation (the ease of which users navigate through the app), and (3) content (understanding of app content and perceived usefulness).

Analysis

The discussion group was recorded by the candidate by taking written notes. Any positive comments, confusion, difficulties and recommended modifications for the app

were noted. A consensus of themes and recommendations was created from the results.

6.5.2. Results

Sample characteristics

Nine patients and three relatives were contacted to participate in the discussion group (Table 6). Four patients and one relative (daughter) agreed to participate and completed the discussion group (response rate 42%). Four out of five participants were educated to at least degree level. Of the seven participants who did not take part in the session, three participants were on holiday, two participants did not respond to the contact made, one participant did not wish to participate in further research, and one participant could not attend the date of the session.

Table 6: *Participant characteristics*

Participant type	Age	Gender	Cancer type	Time since diagnosis	Education level
Patient	66-75	M	Colorectal	1-2 years	Post-graduate degree
Patient	66-75	M	Colorectal	2-4 years	Degree
Patient	56-65	F	Gynaecological	5 years+	Degree
Patient	56-65	F	Gynaecological	1-2 years	Degree
Relative	36-45	F	N/A	N/A	A levels

Themes

Design

Participants were satisfied with the overall design of the app and described it as 'laymen-friendly'. Participants were satisfied with the readability of the app and anticipated that it would be suitable for all patients. Most participants liked the colour scheme. One participant suggested increasing the size of the font and another two participants suggested changing the font to a more 'friendly' font such as Comic Sans to make it easier to read.

Navigation

The app appeared to be effective as all participants were able to successfully complete the tasks set. Participants appeared to use the app with ease on both a Smartphone and tablet device, which demonstrated the learnability of the app. There did not appear

to be any differences between usability of the app on each device. Participants were able to navigate easily between and within the app features, using both menus, and were able to use each feature successfully. Participants did not experience technical errors during the user-testing session, however some participants suggested modifications for some app features, which are described below.

(1) QPL feature: Some participants reported that navigation through the QPL feature was not intuitive. Participants had to create a consultation list and title and then progress to the categories of questions where they could browse individual questions and add them to a list. Participants suggested that it would be more intuitive to have immediate access to the categories of questions and be prompted to create a consultation list only once they have selected questions that they would like to add.

(2) Glossary feature: One participant noticed that once a term had been searched for and found in the glossary, it was not highlighted. This participant suggested including highlighting of the search term to increase ease of use.

Content

Participants were satisfied with the app features and their content and perceived all features to be useful for future patients. Participants particularly liked the QPL feature, anticipating that it would possibly be the most useful feature for patients. Participants commented that the questions within the QPL feature were comprehensive and covered all the concerns that they had during their earlier experience of cancer. Participants were satisfied with the terms and definitions in the glossary, however one participant wanted to add cancer-specific terms. Participants commented on the usefulness of the website links and were impressed with the amount of information available via the links, particularly the links for individual topics, such as chemotherapy. Two participants suggested adding links to local information, such as parking at the hospital and complimentary therapies available at Velindre NHS Trust. Participants were satisfied with the contacts feature and no suggestions for changes were made. Finally, all participants suggested that the app should be available in Welsh.

Post user-testing app modifications

The findings of the discussion group were reviewed by the candidate and supervisors and the following modifications were made:

(1*)* A function was added to the app that allowed users to change the font to two different sizes – normal and large, in increase its ease of use.

(2) The layout of the QPL feature was amended to provide users with immediate access to question categories. Additionally, selected questions were added automatically to a consultation list called 'Question list 1'.

(3) The glossary feature was amended so that the definition of the main searched term now appears highlighted and at the top of the list of results.

Screenshots of the final version of the app can be found in Appendix 34.

6.6 Discussion

The aim of this chapter was to describe the systematic development of a novel app intervention for patients with cancer and their relatives, including the design of the app interface, the selection of app features to include in an app and development of app feature content, and the user-testing of the app with a sample of patients and their relatives. Data from qualitative interviews with patients, their relatives and clinicians were used to decide what type of app patients and their families would find useful based on their needs within their psychosocial context. From these findings, objectives of an app intervention were developed. Findings from these qualitative interviews in combination with assessment of suggested app features using the APEASE criteria (Michie et al., 2014), review of relevant literature and consultation with the supervisory team, led to the systematic selection of four features to include in an app that would meet the objectives of the intervention. Selected features included a QPL, glossary of cancer terms, resources feature and contacts feature. The design of the app was created by Digital Morphosis and the candidate and supervisors guided its development through an iterative process. Development of the content of the app features was also an iterative process which was refined by the candidate and supervisory team. Content was created by using existing, credible information resources, where appropriate, such as health information and cancer charity websites. 'In-house' testing of the app was conducted by the candidate and supervisory team, followed by a user-testing discussion group with a sample of patients and relatives. The design and testing of other app interventions for cancer patients and patients with other chronic conditions have followed a similar format of development prior to field testing studies (Aldiss et al., 2011; Cafazzo et al., 2012; Mirkovic et al., 2014; Stinson et al., 2013).

The discussion group found the app to be useful and easy to use and were satisfied with the overall design and content. As suggested by the Technology Acceptance Model (TAM) (Davis, 1989), an individual's behavioural intention to use a new information technology is determined by its perceived usefulness and perceived ease of use. However, these findings must be interpreted with caution as the sample was highly educated. Education level, a proxy of socioeconomic status, has been shown by some studies to be predictive of the use of web-based technologies across the health care and health information-seeking domains (Kontos, Blake, Chou & Prestin, 2014; Neter & Brainin, 2012). For example, one study analysed data from the National Cancer Institute's 2012 Health Information Trends Survey (HINTS) of 3959 adult Internet users and found that adults with lower levels of education had significantly lower odds of engaging in a range of health-related web-based activities, including searching for health-related information online, downloading health information to a mobile device, using email or the Internet to communicate with a doctor, tracking their personal health information online and using a website to help track diet, weight, and physical activity (Kontos et al., 2014). The divides among those less educated indicate possible issues of health literacy and eHealth literacy, which is described as the ability to seek, find, understand, and appraise health information from electronic sources and apply knowledge gained to addressing or solving a health problem (Neter & Brainin, 2012; Norman & Skinner, 2006a; 2006b). It is possible that, with higher education levels, participants in the present user-testing discussion group were more engaged in their health and had higher levels of eHealth literacy. As a result, these participants may have found the 'Ask Us' cancer app easier to use and perceived it to be more useful compared to patients with lower levels of education. However, these studies have further identified that those with lower levels of education were more likely to use social media for their health compared to those with higher levels of education (Fox & Duggan, 2013; Kontos et al, 2014). Similarly, the Pew Internet & American Life Project's 2013 Health Online study (Fox & Duggan, 2013) reported that non-Hispanic blacks (35%) and Hispanics (38%) were more likely to report using their mobile phone to access health information, compared to non-Hispanic Whites (27%). Individuals with lower education levels may therefore engage with the health care system in a different way, which may primarily be through the use of mobile phones and so an app for patients with cancer might be a way of reducing this digital divide. Nonetheless, further user-testing with a sample that is more representative of the population, including patients and relatives with lower levels of education, is needed in order to add weight to the present findings.

Suggested modifications from the user-testing session were discussed by the candidate and supervisory team and agreed changes were made to create the final version of the app. This was conducted in an attempt to optimise the usability and acceptability of the app prior to field testing (Yardley et al., 2015).

6.6.1 Strengths and limitations

The development of the 'Ask Us' cancer app was a systematic and thorough process. Selection of features for the app was determined by synthesis of qualitative of research conducted with key users (i.e. patients, relatives) and stakeholders (i.e. clinicians) of the intervention, review of relevant literature, application of the APEASE criteria and consultation with digital and supervisory teams. The app went through two rounds of user-testing, including in-house testing with the supervisory team and a sample of 'real' users, and user-testing was guided by existing usability models and frameworks (Brown et al., 2013; Harrison et al., 2013). However, there are several limitations to consider. Firstly, the sample size of the user-testing discussion group was small and four out of five participants were educated to degree level or higher, which may have artificially inflated findings on perceived ease of use and usefulness. Secondly, participants had also previously taken part in qualitative interviews for this thesis and so may have felt invested in this research. This sample may therefore have provided more favourable opinions of the app, compared to those who declined to participate or new participants who had not previously taken part in research for this thesis. However, efforts were made to include a varied sample of users for the discussion group, including those who displayed negative opinions and those who displayed positive opinions of an app during qualitative interviews. Additionally, participants were provided with a monetary incentive to participate so it possible that the participants' views were influenced by a desire to be polite, as well as to be supportive of the candidates' PhD and development of an app for future patients and their relatives (a form of social desirability bias). However, prior to start of the user-testing session, the candidate explained that both positive and negative opinions would help in the future development of the app.

6.6.2 Implications

This chapter outlines the systematic process involved in developing an app intervention to help patients with cancer to meet their information needs and will therefore be of use to intervention developers in the wider cancer intervention field. The findings from the user-testing study provide preliminary evidence for the uptake of an app for cancer patients, though these expectations are currently limited to those

with higher education levels and experience of Smart technology. Finally, the work outlined in this chapter enables progression to a field testing study, contributing to the second phase of the MRC framework, 'feasibility and piloting', which involves initial testing of the acceptability and feasibility of the intervention in real life settings.

6.6.3 Conclusion

This chapter describes the development and user-testing of a novel app intervention that aims to help patients and their relatives to meet their information needs in non-inpatient settings. Four features were selected for inclusion in the 'Ask Us' cancer app, including a QPL, glossary of cancer terms, resources feature and contacts feature. An iterative process of in-house testing of the design and content of the app led to the creation of an initial prototype, which was then user-tested in a discussion group with patients and their relatives. The app was found to be useful and easy to use by the discussion group and patients and their relative were largely satisfied with the design and content of the app. However, further user-testing is required with less educated patients and relatives to support these findings. Minor improvements were made following the user-testing discussion group, which informed the final version of the app.

Chapter 7

Exploring the acceptability and use of the 'Ask Us' cancer app in community settings: a field testing study

7.1 Chapter overview

This chapter reports a mixed methods field testing study that explored the views of patients with cancer on their experiences of using the 'Ask Us' cancer app. The purpose of this study was to assess the acceptability and feasibility of the app in a real life setting and understand whether it would be useful to patients in practice. A secondary purpose was to guide further development of the app content, where needed. This study also reports on app activity data that was collected during the study to identify patterns of app use and compare with qualitative findings. The implications of these findings for the future development of the app are discussed.

7.2 Introduction

The second phase of the MRC framework (Craig et al., 2008) for the development of complex interventions in healthcare, 'feasibility and piloting', encourages initial testing of the acceptability and feasibility of the intervention, prior to a full scale evaluation. A field testing study serves as an opportunity to explore the potential outcomes of an intervention and identify any problems that may occur in the context in which it will be used. For example, the 'Ask Us' app includes a QPL feature that is intended for use during a consultation with clinicians and so it is important to explore the use of the app in this context and identify possible barriers to successful implementation (Murray et al., 2016, Yardley et al., 2015). Furthermore, it enables examination of uncertainties that may have been identified during the development process (e.g. whether potential barriers to the uptake of the app identified in Chapters 4 and 5 occur in practice). Finally, following modification of the intervention after user-testing, the 'person-based' approach (Yardley et al., 2015) to intervention development encourages a mixed-methods evaluation to check that the modifications have been successful in achieving an acceptable and easy to use intervention. A mixed-methods evaluation, such as qualitative interviews and recording of app activity data, is useful for a field testing study as this approach enables validation of users' explicit perceptions (McGee & Gray, 2005). The 'person-based' approach highlights the importance of gaining an in-depth understanding of how users may view and engage with the intervention in practice and which elements of the intervention may be useful or even rejected, in order to make the intervention more attractive to users and more feasible prior to implementation (Yardley et al., 2015).

7.2.1 Aims of the present study

The aim of the present field-testing study was to assess the acceptability and feasibility of the 'Ask Us' cancer app. This study explored the views and opinions of patients with cancer after using the app prior to, and during, a consultation with their clinician. Specifically, the acceptability of this type of intervention, patients' use of the app, the most and least useful features, and the benefits and disadvantages of, and barriers to, the app were explored. As the app may also be used by relatives, patients were asked about the opinions of their relatives on the app. A secondary aim was to guide further development of the app content, where needed. App activity was recorded and used to provide further insight into patients' use of app features and to compare with patients' perceptions.

7.2.2 Qualitative methods

Qualitative methods were chosen to gain in-depth understanding of patients' perspectives and experiences of using an app for cancer care (Green & Thorogood, 2013). As described in Chapter 4, qualitative methods, such as semi-structured interviews, are best suited when the subject matter is a sensitive topic, such as cancer, but also when the purpose is exploratory (Smith, 2007). Further reasons for selecting qualitative semi-structured interviews, such as the freedom of participants to bring up other issues that they felt were relevant, have been discussed in Chapter 4, section 4.2.2. Thematic analysis was selected to analyse interviews as this method helps to move from a broad reading of the data to reporting of patterns and themes, followed by their interpretation (Braun & Clarke, 2006). Further description of this approach has been discussed in Chapter 4, section 4.2.2.

7.2.3 Software-logged app activity data

Patients' use of the app, illustrated by app activity data, was also recorded and available for analysis. This provides insight into how patients engage with the app and further information on which elements of the app features are preferred.
Collection and analysis of this data also provides an opportunity to validate patients' perceptions or highlight potential discrepancies between the data sets (McGee & Gray, 2005).

7.3 Methods
7.3.1 Participants

Maximum variation sampling, a type of purposeful sampling strategy in which cases are selected on the basis of the study populations' characteristics and study objectives, was used to allow for divergent views to emerge (Patton, 2002). Participants were recruited from Velindre Hospital where patients typically undergo chemotherapy, radiotherapy, hormone therapy treatment or are in remission. Following discussions with supervisors, it was decided that a sample of approximately ten patients would be sufficient for this field testing study. Initially, patients were recruited from the clinical trials unit (CTU) as this provides access to a large number of patients who are often familiar with research and this method was most successful when recruiting patients for the qualitative interviews with patients described in Chapter 4. Recruitment of patients from breast, gynaecology, colorectal and urological cancer clinics at Velindre Hospital was also conducted where necessary, in order to meet the recruitment target. These four cancer types were chosen in order to have a variety of some of the most common cancers in the participant sample (WCISU, 2015) and to provide continuity with sampling methods used in Chapters 4 and 6 of this thesis. Within those cancer types, an attempt was made to include a varied sample of patients with cancer, including:

i. Patients undergoing surgery, radiotherapy, chemotherapy or hormone therapy for cancer
ii. A range of cancer types: breast, gynaecological, colorectal and urological
iii. Women and men
iv. Patients older than 60 years and patients younger than 60 years

Patients' eligibility for the study was assessed by the CTU manager or lead clinicians from the cancer clinics using the following inclusion and exclusion criteria:

Inclusion criteria:
i. Male or female
ii. Aged 18 or above
iii. Receiving neoadjuvant, adjuvant, radical or palliative treatments
iv. At least 2 weeks from diagnosis (in order to give patients time to come to term with their diagnosis)
v. Able to give informed consent

Exclusion criteria:
i. Patients who do not have an estimated life-expectancy of at least 12 months

ii.   Patients who the clinician deems to be unsuitable for the research (for example in a current state of crisis or have their own significant health or social problems, unable to provide informed consent, or other reason for not being approached about the study).

7.3.2 Patient recruitment

The CTU manager from Velindre Hospital who helped to recruit patients for qualitative interviews described in Chapter 4 was contacted and invited to help with recruitment of patients for the present study. Initially, 25 study information packs were distributed to eligible patients in the CTU, of which 15 were given during consultations, and 10 were posted to patients who had upcoming clinic appointments. Information packs contained an invitation letter printed on the relevant cancer clinic headed paper and signed by the lead clinician (Appendix 35), an information sheet (Appendix 36), reply form (Appendix 37) and pre-paid envelope. Pre-paid envelopes and headed and signed invitation letters were used to increase response rates (Edwards et al., 2002). All written information was tested using a readability formula to ensure that it was easy to read (http://www.readabilityformulas.com/free-readability-formula-tests.php). Response to this method of recruitment was lower than anticipated but could be explained by poor health of patients on clinical trials. A further 33 study packs were provided to lead clinicians at breast, gynaecology, colorectal and urological cancer clinics in order to recruit additional patients. The candidate kept in contact with the CTU manager and the clinicians to track how many information packs were distributed to patients, in order to determine the response rate.

7.3.3 Procedure

Interested patients were encouraged to return a reply form to the candidate in the prepaid envelope detailing their contact information. The candidate telephoned or emailed the patients to answer any questions about the study and arranged to meet them, at their homes or in clinic, to download the app to their Smart device and provide a brief training session on how to use the app, which involved demonstrating each feature once. Participants were asked to sign a consent form prior to the research student downloading the app onto their Smart device to consent to app activity being recorded and stored by Google Analytics (Appendix 38) and were given an opportunity to ask questions about the study. Demographic information was then collected by questionnaire (Appendix 39). Participants provided the date of their next consultation with their clinician and agreed to use the app prior to this date and during the consultation. The candidate then arranged an interview with each participant following

their consultation, in their own homes, at a time convenient for them. Participants were offered reimbursement of their travel expenses if they wished to have the interview at another location. Informed written consent for the interview was given immediately prior to the interview (Appendix 40) and participants were provided with a further opportunity to ask questions about the study. The candidate explained that the interview was confidential and that only the candidate and lead supervisor would have access to the data. Participants were informed of how the data would anonymised, stored securely and kept for 15 years at Cardiff University, after which, it will be deleted. The interviews were audio-recorded with permission. Audio-files were sent electronically to a reputable company for transcription by uploading the files to a secure server used by the transcription company. Audio-recordings were transcribed verbatim, as described in Chapter 4. Any information that could identify participants in the interview transcripts was anonymised. A confidentiality agreement was required from the transcription company to ensure that participant data and information was protected. Once the completed transcripts were provided to the candidate, the candidate listened to the audio-recordings whilst reading the transcripts to check for accuracy.

7.3.4 Data management

Transcripts and audio-recordings were securely stored on a Cardiff University password-protected server in accordance with the Data Protection Act 1998. This server is password-protected and confidential. All consent forms, transcripts and audio-recordings will be kept securely for 15 years according to Cardiff University research data policies. Following this time, all data will be destroyed.

7.3.5 Interview topic guide

A semi-structured interview topic guide was used (Appendix 41). Findings from Chapters 2, 4, 5 and 6 informed the development of the topic guide. The topic guide was reviewed by the candidate's supervisors and amendments to the topic guide were made following comments. The topic guide was then piloted on two post-graduate students at Cardiff University to ensure simple language was used and leading questions were not asked. The main topics covered at interview were:

    i.   Usefulness of the training session
   ii.   Acceptability of the app
  iii.   Actual use of the app (times, frequency, location)
  iv.   Most and least useful app features

    v.   Benefits of and barriers to app use

   vi.   Communication in consultations

  vii.   App development

7.3.6 App activity data

Google Analytics software was used to record and store app activity data (https://www.google.co.uk/analytics/). The following app activity was recorded:

     i.   Total number of app sessions (number of times participants access the app)

    ii.   Average duration of an app session (time engaged with the app)

   iii.   App feature page views (number of times each feature was accessed)

   iv.   App feature events (use of each app feature), including:

        a. Number and type of questions added to consultation lists in the question list feature

        b. Visits to home pages of cancer information websites and specific topics of information within websites in the resources feature

        c. Searches conducted using the search bar for cancer-related terms in the glossary

        d. Storing of contacts details of clinicians in the contacts feature

7.3.7 Analysis

Qualitative data were managed using the qualitative analysis software package NVivo (NVivo, 10). Interview transcripts were analysed using thematic analysis (Braun & Clarke, 2006), as described in Chapter 4, section 4.3.6. Two transcripts were independently analysed by the candidate's supervisor, Dr Fiona Wood, who has extensive experience of qualitative research, to reduce the potential bias of subjectivity associated with coding and facilitate interpretation of findings. Discrepancies were resolved through discussion. App activity data was analysed using descriptive statistics as the small sample size precluded any meaningful statistical analyses.

7.3.8 Researcher values and relationship to participants

The potential influence of personal values of the researcher and the relationship between the research and the participant on data collection and interpretations of findings for this study have been previously discussed in Chapter 4, section 4.3.7. Additionally, it was important make clear to participants that the app did not intend to replace their regular care in any way. Participants were informed that if they had any concerns regarding their health during the study that they should contact their clinician

immediately and not wait for their upcoming consultation. This information was stated in a disclaimer on the first page of the app, to which patents had to agree.

7.3.9 Ethical issues

NHS ethical approval and R&D approval from Velindre NHS Trust was granted for this study (15/WA/0161, Appendices 42-43).

7.4 Results

Interviews were conducted with eight participants in their own homes between May and October 2016. The average length of the interviews was 18 minutes (range 12-23 minutes).

7.4.1 Sample characteristics

A total of 58 study information packs were distributed to eligible patients, of which nine patients returned a reply form indicating interest in participating in the study. All nine patients agreed to participate (response rate 15.5%), however only eight completed the study. One participant was not able to be reached to conduct the interview following their consultation. Participant characteristics are presented in Table 7. Five participants were ages 56 or over and half were female. The sample was made up of patients with urological (n=3), colorectal (n=2), breast (n=2) and gynaecological (n=1) cancers and all participants were undergoing treatment for their cancer. Time since diagnosis ranged from 1-3 months to over 5 years and five participants were a year or less since diagnosis. All participants were educated to at least secondary level, with three participants educated to degree level or more. Six participants downloaded the app to a Smartphone and two downloaded the app to a tablet device. The amount of time that participants were able to use the app (from initial download of the app to their device to interview following the consultation) ranged from 4 days to 11 weeks, as this depended on whether they had a suitable upcoming consultation.

Table 7: *Participant characteristics.*

ID	Age	Sex	Cancer type	Time since diagnosis	Education	App use	Device
P1, Lucy	26-35	F	Gynae	1-3 months	Diploma	1 week	Smartphone
P2, Keith	56-65	M	Urological	6 months-1 year	A Levels	4 days	Tablet
P3, Rachel	36-45	F	Breast	1-2 years	Degree	8 weeks	Smartphone
P4, Mark	56-65	M	Urological	5 years+	GCSE/O Levels	8 weeks	Smartphone
P5, Josie	66-75	F	Colorectal	1-2 years	A Levels	2 weeks	Tablet
P6, Karen	36-45	F	Breast	3-6 months	Post-grad degree	1 week	Smartphone
P7, Albert	66-75	M	Colorectal	3-6 months	GCSE/O Levels	5 weeks	Smartphone
P8, Thomas	66-75	M	Urological	3-6 months	NVQ/HNC/HND	11 weeks	Smartphone

7.4.2 Interview themes

From the interviews, three key themes were identified: (1) acceptability of the app, (2) participants' use of the app, and (3) the benefits of, and barriers to, app use. Subthemes will be discussed in detail below. Patient participants are identified with 'P', followed by their identification numbers listed in Table 7 and a pseudonym. The interviewer is identified with 'I'. Where irrelevant, text was removed from quotes and denoted by {…}. Square brackets within the quotes represent inserted text to clarify the content.

Theme 1: Acceptability of the app

Subtheme 1a: Ease of use

Participants were satisfied with the design of the app, including its layout, colour and font and perceived it to be was a user-friendly design. Most reported that they felt comfortable using the app following the brief training session. Participants who used the app on a Smartphone and those who used it on a tablet device reported that they found the app easy to navigate and were able to use the features with ease. As a result of the simple design, most participants anticipated that patients would find the app easy to use, including those who lack experience with apps, such as older patients.

> P2, Keith (56-65 years, urological cancer) – Erm, design wise it's fine, it does what it needs to do. It's user friendly so there was nothing in there that would make it difficult to … to use. {…} It's very very user friendly and very very easy to navigate even for somebody that's not that well up with modern technology. I think once its explained to them and once they are shown how to go through it, I think it will be very easy to follow.

> P4, Mark (56-65 years, urological cancer) - As I say it's, it's, this is the basic app, but it's very good as I say for people who are not quite as tech savvy as you might be and the buttons are there. {…} I mean it was very easy to use and … you know, it was quick.

Subtheme 1b: Technical problems

All but one participant reported that they did not experience any technical problems with the app. One participant explained that when he added questions to a consultation list the questions would disappear, however no other participant reported this issue.

I – Did you have any technical problems at all?

P3, Rachel (36-45 years, breast cancer)- No, no problems at all, no.

I - Did you have any technical problems? So first of all we couldn't find the app could we?

P7, Albert (66-75 years, colorectal cancer) - No we could not.

I - What about after that, did you have any problems?

P7, Albert - Well when it come on mine [Smartphone] it was alright and I did load the question onto it but I can't seem to find it now, do they drop off or …?

I - Oh we'll have a look at it now.

P7, Albert - Okay, I can't find it on there. I did put a question on there but …

I - But you couldn't find the question list?

P7, Albert - I couldn't find, I couldn't find the question, I know the question I was going to ask but I can't, I couldn't find it again.

Subtheme 1c: Relatives' views on the app

Some patients reported that their partners had had a look at the app but hadn't use it with them, either because the patient was busy or had not used it much themselves. One patient reported that her daughter thought the app was 'good' and easy to use.

P6, Karen (36-45, breast cancer) – Erm I think [husband] had a quick look at t just visually but didn't use it.

I – Okay. Did he have any comments at all?

P6, Karen – Erm no, I don't think so.

I – Did any of you relatives or friends have a look at the app? Did any of them use it with you?

P5, Josie (66-75, colorectal cancer) – My, my daughter.

I - Okay, and what did she think of it?

P5, Josie - She thought it was really good.

I - Oh that's good. Did she find it easy to use?

P5, Josie – Yes she is computer literature, so she found it very easy and she said how straightforward it was too.

Subtheme 1d: Suggestions for improvement

With regards to existing app features, one participant suggested expanding the glossary to include cancer specific terms and one suggested creating a separate

feature for relatives to make it easier to access. Some participants reported that initially, they found it confusing that there was no 'Back' button to exit the app features and instead had to scroll down to the bottom of the page and click 'Done'.

> I - Okay so overall how did you find the app, how did you get on with it?
>
> P6, Karen (36-45, breast cancer) - Okay, erm I thought it was fine, I mean it was pretty easy to navigate I think once I got the hang of sort of putting questions in and how to sort of go back yeah.
>
> I - Yeah, what do you mean when you say you had to go back?
>
> P6, Karen - So erm, so when I was putting questions in, because on this you've got sort of a 'Back' key there which takes you out of the app rather than pressing the 'Done', I'd forgotten there was a 'Done' button.
>
> I - Right okay yeah.
>
> P6, Karen- Yeah so once I got that sorted it was fine.

Some participants suggested additional app features that they thought would be useful for future patients, including a feature to write notes from consultations, a feature to organise and prompt attendance at clinic appointments, a treatment-related symptom diary feature, a feature to send a question list to their clinician prior to a consultation and a feature signposting to meditation resources.

> I - …What about any other features you might have thought of while you were using the app?
>
> P4, Mark (56-65 years, urological) - Erm … the only other thing would be like a diary section perhaps… just to keep track of, erm ... symptoms and appointments, erm ... you know just like a simple calendar. You know, I have one on my phone anyway but it gets overtaken with social events and things like that, so maybe having a specific hospital one.

Theme 2: Participants' use of the app

Subtheme 2a: Frequency, time and location of app use

Participants reported that they tended to use the app at any time when they wanted information but mostly prior to their consultations with clinicians. Participants reported that they mostly used the app at home but also when out in the community or at cancer clinic if they needed information or wanted to note down a question for a consultation.

> I - So how often did you use the app?

P4, Mark (56-65 years, urological) - Erm ... certainly a few days before I would have my clinical appointments. So about every three weeks to write down questions, but like I say I did use it to contact MacMillan and that was just sporadically you know whenever I felt the need to know something, yeah certainly every three weeks just before I am due in for a chemo.

I - And when did you use it? Was there any typical time of day or…

P4, Mark - Usually in the evening yeah, when our kids are in bed and I sat down to think about what I wanted to ask the oncologist I was using the the app then.

Subtheme 2b: App use during consultations

Three participants reported that they used the app *during* a consultation with their clinician to ask questions about their condition, two used the app immediately *prior* to a consultation to remind themselves of their questions, one planned to use it prior to her consultation but forgot to charge her phone so was unable to use it, one was unable to use it to prepare for a consultation as he felt he didn't have questions to ask but also had experienced a technical issue with the QPL feature and suggested that if he did have questions, he would write them down. One participant did not use the app to prepare for his consultations due to lack of experience with Smart technology and preference for traditional methods (i.e. pen and paper). Of those participants who used the app during a consultation, all reported that they felt comfortable with the experience, though one participant also felt that it was 'weird' and not the norm.

I - So you, you used the app in the consultation and you said the nurse responded well to it and that was okay?

P6, Karen (36-45, breast cancer) - Yeah, that's fine yeah, yeah.

I - Erm were you comfortable using it in the consultation?

P6, Karen - Erm yeah, I mean I did feel a bit weird taking my phone out and going, "Oh I'm just going to use this", erm but I don't think it was a massive issue.

P7, Albert (66-75 years, colorectal cancer - I know in my own mind what questions I wanted to ask…. You know I'm quite intelligent… you know I'm quite intelligent and erm if I need to ask a question I generally write them down, if there's numerous questions you want to ask you sort of write them down, but I didn't erm because there was not many questions I wanted to ask.

Participants who used the app in a consultation with their clinician reported that they did not find it to be distracting and suggested that their clinician responded positively to the experience, with some commenting that they thought the app was a good idea.

> I - And did you find it distracting using the app in the consultation?
>
> P4, Mark (56-65 years, urological) – No, its just two buttons and you are in really isn't it, so it didn't bother me. I think times have changed and they actually say how well organised I am so it's just …another addition to being organised. Having everything to hand, and to make her [clinician] job easier rather then hassling her two days later saying, "I forgot to ask you this" … I have got it all there, on the question list.

> I - And how did the doctor react to you taking the app into the consultation?
>
> P2, Keith (56-65 years, urological cancer) - Very positively.
>
> I - Oh that's good, erm ... did he mention anything at all, did you find they were more helpful or less helpful?
>
> P2, Keith - Erm…no I mean they thought it was a very good idea.
>
> I – Yeah…
>
> P2, Keith – But they were more concerned with, erm…actual treatment than…anything else because obviously that's what they are there for.

Subtheme 2c: Most and least popular app features

In general, participants perceived the app to be useful and found at least some of the app features to be useful for themselves. As a result, participants did not feel that any features should be removed from the app. Most participants reported that they found the QPL feature to be the most useful of all the features, followed by the resources and glossary features. It was suggested that this was because participants have regular consultations with clinicians and have questions to ask at each stage throughout their cancer journey. The majority of participants reported that they used the QPL feature to prepare for consultations and although they felt that the categories of questions were comprehensive, they liked that they could also add their own questions.

> I - What are the most useful features on the app?
>
> P4, Mark (56-65 years, urological) – Erm, the question lists for me.
>
> I - And why was that?
>
> P4, Mark - Well because we have clinics every three weeks so every.. you know before chemo you have … you go into the nurses on the Tuesday, so I

have always got questions to ask. So I did, erm … I used some of the loaded questions and added a few of my own, so I did use that.

I - What were the most useful features for you on the app, I mean you mentioned the links and the question prompt list…

P2, Keith (56-65 years, urological cancer) - Probably the questions because …you have these things [questions] and you might write them down on a piece of paper and then you will forget the piece of paper or you just want to get the questions, the fact you have got them all there in front of you [on an app] … then you can just open up that [app] page and you can go through them with the doctor or the nurse or whoever that might be … I think that's a very good feature, and the fact … also the fact that you can add in your own questions … you know you are not confined to the questions that are there … the fact that you can add your own in is a good feature.

Participants reported that they found the resources feature to be informative and the links to specific topics of information to be particularly useful, as this made it easier to navigate the cancer information websites and find the specific information they wanted. Two participants reported that this feature was informative even though they had been diagnosed with their cancer for a few months, as there was so much to learn about their condition.

I - So going onto the features, what do you think were the most useful features on the app?

P7, Albert (66-75, colorectal cancer(- I would think the information contained in the resources section.

I – Okay, why do you think that was the most useful for you?

P7, Albert - Well it was just handy to know, you know what different organisations do, how they can help, and just information about cancer in general really. So it was all in the same section.

I - And was that useful to you even at this point [of your cancer]?

P7, Albert- Yeah I read quite a bit.

I - What do you think were the most useful features of the app?

P1, Lucy (26-35 years, gynaecological cancer) - Erm the questions I liked and the fact you could upload your own questions as well, and the side effects [in

the resources feature], you know you have the side effects of chemotherapy and radiotherapy already there and …

I - In the resources section?

P1, Lucy - Yeah in the quick reference [links to specific topics of information] that was good. So you can, you can find them they were there for you.

I - Yes sort of straight away.

P1, Lucy – So yeah to have it there as a quick reference so you can just click on, you know, I think is brilliant. I mean even now that I'm halfway through [her treatment], I'm still looking at side effects of it you know.

Fewer participants reported that they had searched for words in the glossary following their consultations and though they reported that it helped to improve their knowledge of cancer-related terms. The contacts feature appeared to be the least popular. The majority of participants reported that they did not find the contacts feature as useful as other features and explained that this was because they already knew their important contacts. In contrast, one patient explained that it was useful to have the contact details of cancer organisations in one place and storing their clinician details meant that they could access them easily in case of an emergency, even when out in the community.

I - The glossary of cancer terms, did you use that?

P2, Keith (56-65 years, urological cancer) - I did that yeah, that is very very helpful. Because you know doctors and nurses tend to use these words assuming everybody knows what they mean …and I can understand that but obviously people don't often ... sometimes they don't know and they are not confident enough to ask. So if they can use that to find out what those things mean … and following it through that will help a lot of people.

I - And what about least useful features, why were those do you think the ones that weren't so …?

P1, Lucy (26-35 years, gynaecological cancer) - Erm what I didn't use was the erm, what was it called …?

I - Was it the contacts section?

P1, Lucy - The contacts yeah, the groups and, but then I think that's because of where I am in the treatment, I already know those [contacts].

P5, Josie (66-75 years, colorectal cancer)- Erm some of the extra support [the contacts feature] where it says you could get in touch with people, I found that was excellent.

I - Okay so you mean where you add the contacts. Did you use that? Do you think other patients might use it?

P5, Josie - I actually put the numbers in.

I - Oh that's good erm and why did you save them, why do you think it was useful?

P5, Josie - If you're not very well sometimes you need to, I don't keep my phonebook with me all the time but if I'd got those phone numbers if I'm out and about or if anything happens I've automatically got those numbers that I need to get in touch with straight away.

Theme 3: Benefits of and barriers to app use

Subtheme 3a: Increased question-asking

Participants reported that the question list feature served as a memory aid as they were able to add questions and store them when needed, independent of time and location, which prevented them from forgetting important questions. Participants also reported that this feature reminded them of the questions that they wanted to ask prior to their consultation and for those who used this feature *during* a consultation, participants reported that it prompted them to ask the questions. Participants perceived that using the QPL resulted in them asking more questions than they normally would during their consultation. Some participants further suggested that the QPL helped to improve communication with their clinicians in consultations, as it prompted them to actively participate in discussion.

P3, Rachel (36-45 years, breast cancer) - …Like you know, I'd suddenly think of something, because you've got the phone with you all the time … so I'd suddenly think of a question or something and think, "uUh-oh, jot that down", it'll remind me then when I go and see the specialist.

I - And did you find that helped …

P3, Rachel - Yes, yeah.

I - … you preventing forgetting questions?

P3, Rachel - That's right, yeah. Because you do tend to get a bit forgetful when you're in with the … consultant or whatever. You've got such a short space of time… to, to sort of think of what you want to say…

I - What sort of benefits did you get from using the app? Erm, for example, erm some of the things patients have said are increase in knowledge, or confidence maybe to ask questions, or erm better communication with their doctors and nurses.

P3, Rachel - Better communications, definitely. I mean because you've got the questions you want to ask there; you can look at them quickly before you go into the room … remember what you, you know …

I - Okay, that's good. Erm, so do you think the app, going back to the consultation, you said you think it'd improved communication. Erm, how did the app make a difference to how you talked to the doctors and nurses?

P3, Rachel - Well it, it just helped me to, to remember things to ask, really.

I – Okay so you used the app in the consultation with the doctor…

P2, Keith (56-65 years, urological cancer) – Yes only to refer to the questions that I stored in the…

I – Okay and how did that go? Did you find it useful?

P2, Keith– Yes, like I said, it's a good memory aid because you might write them down and try to remember them but non of those things are going to work. So with the app, you have got them right in there in front of you.

I – Do you think the app made a difference in how you talked to the doctors and nurses?

P2, Keith - Only in that you have got the information right there in front of you so you can… you don't need to try and think back to remember what you want to say, it's all there for you, so it is a good memory aid definitely.

Subtheme 3b: Increased knowledge

Some participants perceived an increase in cancer-related knowledge as a result of using of the app, particularly from using the resources and glossary features. Participants reported that they appreciated that the links included in the resources feature were to reputable cancer information websites as this reduced the burden of having to search through a huge amount of information on the Internet.

P1, Lucy (26-35 years, gynaecological cancer) - …Yeah, yeah but you know all the information on there was, like they're trusted sites for a start so it's not just you know typing into Google and God knows what you're going to read, so it was nice that it was trusted McMillan and that the Patient, I did use the Patient

one because I had erm a really bad stomach so I used that and put in my symptoms. Erm and I had a rash one night and I was like … go through that erm, so all that is there and you do gain knowledge from it all.

I – Okay so how did you find using the app in general?

P2, Keith (56-65 years, urological cancer) -…Very easy to navigate and very very informative.

I - Oh good okay, erm ... so what do you mean informative? Was there anything in particular, any particular feature or … ?

P2, Keith – What I particularly liked was the links to the specific web pages, the websites. Because there is loads of information on there particularly about, erm ... the effects of the various treatments … which I think would be very very helpful to a lot of people even though they are given the information at the beginning of their treatment… it's so much information, that it's got to be able to … you can sit in front of a PC and find the websites … but if you are guided through to the relevant ones… it's so much better.

Additionally, some participants suggested that the resources and glossary features increased their understanding of their condition by enabling them to understand the medical terms used and information provided by clinicians in consultations. One participant reported that this increased his confidence in consultations.

I - Okay. So erm, so you said you used the app leading up to the consultation with the doctor, erm do you think the app made a difference in how you talked to the doctors and nurses?

P1, Lucy (26-35 years, gynaecological cancer) - Only in the fact that you're more knowledgeable about the wording and things like that so that's always good because it makes you a bit more confident then and you can understand what they're saying {…}

I - So what do you mean, so you said you're confident about the wording, do you mean you feel confident that you can ask a couple of questions in the right way?

P1, Lucy - Yeah and you're understanding them as well, so.

Subtheme 3c: Reduced anxiety

Some participants suggested that an increase in cancer-related knowledge reduced their anxiety as they were able to develop expectations of their condition with regards

to treatment. One patient explained that reading about potential side-effects of treatment enabled her to prepare for such effects and provided reassurance that this was a normal part of the treatment, which in turn reduced her anxiety.

> I - Yeah and how does it help you by reading about the side effects?
>
> P1, Lucy (26-35 years, gynaecological cancer) - It prepares you mentally and it confirms that all you're feeling is normal and other people have felt that way, because when you're feeling you know, pretty rundown you do question whether it's just …you know but I know …they say this is part of it, it just puts your mind at rest.
>
> I - Yeah that it's normal.
>
> P1, Lucy - Yeah but other people you know, and it is part of the treatment.

In contrast, an avoidant coping approach, and subsequent preferences for information, appeared to be a barrier to app use for two participants. These participants reported that they did not want to have further information on their condition beyond that provided by their clinician, as they felt that this information was sufficient. One participant further explained that this approach enabled him to minimise the anxiety caused by his illness.

> I - What sort of benefits do you think you might get, if you had used this app previously, do you think you might have benefited at all?
>
> P8, Thomas (66-75 years, urological cancer) - No. It's information, isn't it?
>
> I - Yeah.
>
> P8, Thomas - The, the information I've been given is pretty good.
>
> I - Right, okay, so you feel like you've had enough information?
>
> P8, Thomas - Yeah. I don't want it to ruin my life… if I was sat at home worrying about it all the time … I might have a big file on it and all that. I'm just carrying on as normal.
>
> I - Yeah. Okay, so for you then, you wouldn't want all these extra bits and bobs reminding you about it all the time, so you've got the information you need and that, that's enough, is that what you're saying?
>
> P8, Thomas - Yeah. I think I'm in very good hands, I'm not worried about it. And, I, I'm just going along with the treatment. I've not questioned it at all. Erm, because I don't know anything about it, really. But I'm very confident in the people who are looking after me.

Subtheme 3d: Time since diagnosis

No participants reported experiencing any disadvantages as a result of using the app, however some barriers to app use were highlighted. Some participants reported that time since diagnosis was a barrier to the usefulness of the app features. The majority of participants felt that the app would be more useful for more recently diagnosed patients than themselves, as they had already met most of their information needs by gathering information following their diagnosis. Participants suggested presenting the app as early as possible to newly diagnosed patients would maximise its benefits.

> I - So in general how did you find the app?
>
> P5, Josie (66-75 years, colorectal cancer) - I would've found it much more beneficial last year then I had this year, when I was first diagnosed.
>
> I - Okay and why is that?
>
> P5, Josie - Because most of the things that I found on the app I'd already worked out and had sorted for myself previous. …that would've been very useful last year.
>
> I - Okay and do you think that is?
>
> P5, Josie - Because to be honest when you're diagnosed, number one you don't take in what people tell you. Then you won't believe what people are telling you. And then when you can actually sit down and look at things yourself you then begin to take it in a lot better and there are certain things are on there then that would've been beneficial if I'd been able to say what happens now, what is going on. So last year it would've been wonderful.
>
> I -Have you got any concerns about the app at all?
>
> P3, Rachel (36-45 years, breast cancer) - No, I mean erm the sooner they [patients] get the app the better though.
>
> I - Right, okay.
>
> P3, Rachel - You know, as soon as they, you know, as you're diagnosed if possible, you know, make it available that people know about it. You know, the sooner you've got the app obviously the easier … it makes it right from day one.
>
> I - Yeah. So do you, do you think patients would get more use out of it as soon as they're diagnosed?
>
> P3, Rachel - Well I mean they'll still get a use out of it even if you're, you're in my stage where I'm you know, later stages but er I'm sure that if, it's when you first get diagnosed is when you've got questions.

Subtheme 3e: Experience with Smart technology

A lack of experience with Smart technology and apps appeared to be a barrier to app use for some participants. As mentioned previously, three older participants were not initially able to locate the app on their home screen of their Smart device in order to use it, though two participants later reported that they had located the app and were able to use it. However, one participant required a second visit from the candidate in order to locate the app and was provided with a second training session. This participant had the app for the longest period of time (11 weeks) as he was not using the app in consultations but said that he intended to do so. This participant later reported that he had hardly used the app throughout the study period and chose not use the app during a consultation. Instead, he reported that he would use the app to refer to questions but write the questions down. However, this participant anticipated that he would use the app in the future if he was able to learn and practice using it.

> I - So going back to when I showed you how to use the app, did you feel comfortable using it once you'd been shown how to use it?
>
> P5, Josie (66-75 years, colorectal cancer) - Yes, yes.
>
> I - And have you got much experience with apps?
>
> P5, Josie - No I don't use them very often so.
>
> I -How did you feel using it sort of on your own running up to the appointment was that okay?
>
> P5, Josie - That was fine.
>
> I - Did you have any problems?
>
> P5, Josie - No, no other than when I couldn't find it.
>
> I - And then you managed to find it?
>
> P5, Josie- Yes because erm I actually, like I said when you sit down quietly and think things through …
>
> I - Yeah you have chance to look through and …
>
> P5, Josie - … then I suddenly found, "Oh right if I go on this one", so browse it and it automatically came up.
>
> I - Oh good.
>
> P5, Josie - So it was, it was just where we had hidden it. Well it seemed to have got hidden.

I - …So you would prefer to use the app and then write, you'd prefer to write the questions down on paper? So why do you think you wouldn't use the actual app in a consultation?

P8, Thomas (66-75 years, urological cancer) - I'm not well used to using this …except for making phone calls.

I - Yeah. Yeah. So you'd prefer to write it down?

P8, Thomas - Yeah.

Subtheme 3f: Patients' perceptions of the acceptability of app use in consultations

A further barrier to app use for some participants appeared to be their perceptions of the acceptability of using an app in consultations with clinicians. Some participants reported that they used the app immediately *prior* to, instead of *during,* the consultation due to fear of being perceived as rude by their clinician. These participants felt that using a Smartphone in a consultation was anti-social and not the norm. One participant suggested that they would feel comfortable using an app in a consultation with a nurse but not a consultant, which suggests a perceived power imbalance with consultants. Participants suggested that they would feel comfortable using the app in a consultation in future, if they were to obtain permission and the clinician explicitly approved use of the app.

> P6, Karen (36-45 years, breast cancer) - …It kind of feels a bit, a bit weird in a way because I think sometimes texting and things like that seems quite antisocial if you're in an interaction with someone. So I suppose it's about getting that shift of its fine to be looking at your phone and typing whereas when I'm making notes really quickly it's easier to maintain eye contact.

> I - So let's talk about why you didn't choose to take the app into the consultation…
> P3, Rachel (36-45 years, breast cancer) - Well it's just a little bit rude having a phone open in front of the, you know, when the consultations starting I took it in with me, the phone … I didn't actually open the app until … you know, and then I'd open it… it depends what and who you're talking to I think. If it's just the nurses or whatever I've always got it open and I'm… doing, doing the blood pressure and they're doing, jotting that down and …
> I - Oh, okay, but you won't use the app with the doctors?

> P3, Rachel - The specialist not so much, no, no, it's a little bit, you know, they're doctors and you feel a little bit intimidated.

7.4.3 App activity data results

App activity was recorded over a period of approximately four months, from when the app was downloaded by the first participant to the day of the interview of the final participant.

App sessions and durations

A total of 415 app sessions were recorded, which might suggest that the app was used frequently by participants. However, this number could be artificially inflated due to events such as participants exiting and re-entering the app during use or entering the app and not using individual features. The average app session duration was 1m 43s and participants viewed an average of five pages per session, which suggests engagement with the app for a sustained period of time.

Most and least popular app features

The question list feature appeared to be the most popular feature with 158 page views, which was three times that of the other features. The resources and glossary features appeared to be of similar popularity, with 42 and 36 page views respectively. The contacts feature appeared to be the least popular feature with 29 page views. However, it is possible that the page views of the question prompt list reflect participants' flicking back and forth between the six pages of question categories plus consultation list pages, whereas all other features have just one page to view.

Question prompt list feature events

Use of the QPL feature appeared to be high. A total of 57 questions were added from the categories of questions to consultation lists, however the data does not indicate how many participants created a question list for a consultation or how many consultation lists were made. Of the questions added, 42 were added from the pre-set categories of questions and 15 were created and added by participants themselves, however the data does not indicate how many participants added pre-set questions or created their own. Of the pre-set questions selected, 26 were selected from the 'treatment' category, eight were selected from the 'after your cancer diagnosis' category, five were selected from the 'support' category, two were selected from the 'remission' category and one was selected from the 'family and friends' category. Of the 15 questions that were created and added to consultation lists by participants, five

questions were related to treatment, three were related to further tests/investigations, two were related to symptoms, two were about diet and lifestyle, one was about the cancer diagnosis, one was about finance and one was a duplicate. The majority of these questions were cancer-specific questions that were not available on the prescribed list of questions, however one question was available but the participant worded it differently. One question about travelling during treatment was not on the prescribed list of questions and could be added in the future. These results suggest that participants only add their own questions if they are not available in the suggested categories of questions.

Resources feature events

Links to external cancer information websites in the resources feature were accessed a total of 23 times. Links to the home pages of cancer information websites were accessed ten times and links to specific topics of information, such as 'information on chemotherapy', were accessed 13 times. Of the links to the home pages of cancer information websites, www.patient.info and www.macmillan.org.uk were accessed four times each, and www.tenovuscancercare.org.uk and the NHS website were accessed once each. Of the links to individual topics of information, links for information on chemotherapy or radiotherapy side effects were accessed six times, links for information on clinical trials were accessed four times and links for information on finances were accessed three times. However, the data does not indicate how many participants accessed links.

Glossary feature events

Searches performed within the glossary appeared to be very low. Four cancer-related terms were searched for in the glossary by inputting the text in the search bar, however the data does not indicate how many participants searched for terms in this way. Three out of four of these terms were cancer-specific terms and were not available in the glossary. It was not possible for the app to record manual searches by scrolling downwards through the glossary.

Contacts feature events

Only one participant added and saved a contact within the app. It was not possible for the app to record participants' use of the contact numbers listed.

7.3.5 Validation of qualitative findings

In qualitative interviews, participants' suggested that their preferred app feature was the QPL. App activity data supports participants' reports as the QPL feature displayed the highest number of page views and a high number of events. However, the number of page views may have been artificially inflated due to the number of pages within the feature to view, as suggested above, and it is unclear how many participants used the QPL feature. Second to the QPL feature, qualitative findings suggested that the resources and glossary features were of similar popularity, with slightly fewer participants reporting that they had found the glossary useful. App activity data supports participants' reports as the resources and glossary features received a similar number of page views, with the glossary feature receiving slightly less views, both of which were less than the page views of the QPL. Participants reported that they found the links to specific topics of information to be particularly useful, which is supported by a slightly higher number of links accessed compared to links to the main homepage of websites. Some participants reported that they had searched for words in the glossary following their consultations, which is supported by activity data that showed four terms were searched for. Qualitative findings suggested that the contacts feature was the least popular feature, which is supported by app activity data that showed only one contact was added to this feature.

7.5. Discussion

This chapter described a field testing study of the 'Ask Us' cancer app, which is the first app developed to specifically enable patients (and their relatives) to meet their full range of information needs in non-inpatient settings. The aim of this study was to explore the acceptability and feasibility of the app in real life settings, which was determined by exploration of patients' views and opinions after using the app prior to, and during, a consultation with their clinician. The acceptability of this type of intervention, including their relatives' opinions on the app, their use of the app, the most and least useful features, and the benefits and disadvantages of, and barriers to, this type of intervention were explored. A secondary aim of this study was to guide further development of the app content, where needed. App activity data was used to provide further insight into patients' use of app features and to compare with patients' perceptions. Findings indicated that the majority of patients found the app to be acceptable and most found it easy to use, however there was variation in patients' perceptions of the acceptability of using an app during a consultation with their clinician and some older patients had initial difficulty learning to use the app. The QPL was perceived to be the most useful app feature, followed by the resources and glossary features, and the contacts feature was perceived as the least popular feature. App

activity data appeared to corroborate patients' perceptions of app use. Patients reported several benefits of using the app, including increased question-asking in consultations, increased knowledge on their condition and reduced anxiety. Nonetheless, the app generally appeared to be a feasible intervention to help this sample of patients to meet their information needs. The identification of some of the barriers to use of the app in real life settings is useful for the future development of the app, as this information can be used to circumvent or minimise these issues prior to implementation. Finally, there were few minor suggestions for an improved version of the app.

Findings from this study suggested that the 'Ask Us' cancer app was an acceptable intervention to help a variety of patients to meet their information needs in non-inpatient settings, including those of differing ages, genders and cancer types. Most patients found the app easy to use, regardless of the device type, and only one patient experienced a minor technical issue that could be amended during further development of the app. However, the sample consisted of patients with higher levels of education compared to the general population. As described in Chapter 6, section 6.6.1, individuals with higher levels of education may have higher levels of health literacy and eHealth literacy, compared to their counterparts (Kontos et al., 2014; Neter & Brainin, 2012). This means that the present sample may have been more familiar with, and engaged in, using this type of technology for their health, leading to inflated findings of ease of use and perceived usefulness.

Three older patients had initial difficulty when first using the app, however a novel finding of this study is that two of these participants quickly learned to use the app without further assistance. These preliminary findings are encouraging as they suggest that an app could be a useful platform to deliver interventions to all types of cancer patients, including those who lack experience with technology, such as older patients. In support of this, participants anticipated that patients who have less experience with apps would be able to learn to use the app due to its simple design and navigation. This finding is consistent with previous studies that have found Smart devices to be an acceptable platform through which to deliver interventions remotely to a variety of patients with cancer (Somers et al., 2015; Stinson et al., 2013; Sundberg et al., 2015; Yap et al., 2013).

Overall, patients found at least some of the features to be useful for themselves during the study period. The QPL feature appeared to help patients to prepare for their

consultations, the resources feature enabled patients to access reliable information that they needed outside of consultations, and the glossary helped patients to learn the definition of new cancer terms following consultations. The contacts feature was perceived to be the least useful feature due to the fact that the majority of patients in the present study were at least three months post diagnosis and already knew their important contacts. In contrast, patients still found the other features useful as they still had regular consultations and were still learning about their illness and the related cancer terms. Time since diagnosis was explicitly reported as a barrier to app use by some patients in the current study and therefore suggested presenting the app to patients as soon as possible in order to maximise the benefits of the app. This is supported by a previous study of patients' use of mobile interventions for patients with cancer found the intervention was more useful for those who had not received chemotherapy before (Yap et al., 2013). It also well established that patients' information needs are highest following diagnosis (Mistry et al., 2010). Nonetheless, the present study found that the app was generally perceived as useful and easy to use, which are positive preliminary indicators of the uptake of the app in practice (Davis, 1989).

This study was not able to gain insight into relatives' opinions on the app as most patients reported that they had not used the app with their partner, for various reasons. This is likely due to the short period of time that some patients had to use the app, as well as the fact that some patients reported that time since diagnosis was a barrier to their own app use, which would also likely be a barrier for relatives.

Under half of participants used the QPL app feature *during* a consultation, however those that did reported that they felt comfortable using the app during their consultation, did not find it distracting and perceived that their clinicians responded positively to them using the app. QPLs are intended to be used and referred to *during* consultations to prevent patients from relying on their memory to ask questions (Brandes et al., 2015; Dimoska et al., 2008), and so it is encouraging that patients had a positive experience. Additionally, a positive response to the app from clinicians is key to the successful uptake and implementation of the app (Murray et al., 2016). However, the present study identified three barriers to use of the app in practice. Firstly, fear of being perceived as rude by clinicians and use of the app distracting from non-verbal communication in consultations prevented some patients from using the app *during* their consultation. The finding that some patients have negative perceptions of the use of Smart devices in consultations is novel, however previous studies have similarly

reported that some clinicians, and the general population, may perceive the use of a Smartphone by clinicians in clinical settings to be unprofessional due to the association of mobile technology with social contact (Koehler et al., 2013; Koehler et al., 2012). Fortunately, patients' negative perceptions of app use in consultations is likely to be a temporary barrier as these perceptions are anticipated to diminish over time as use of Smart devices increases (Koehler et al., 2013). Alternatively, patients in the present study suggested that they would feel comfortable using an app in consultations if they were to obtain the clinicians' permission.

Lack of experience with Smart technology also proved to be an initial barrier for some patients, one of which required a second training session. This finding is unsurprising as studies have suggested that older people might need more time to learn due to being more error-prone as a result of sensory, motor and cognitive changes (Conci, Pianesi & Zancanaro, 2009). Though the brief training session provided for patients prior to app use in the present study appeared to be sufficient, some older adults will likely need further on-going support while they become familiar with the app. This could be provided in the form of manual instructions and a task list to keep costs down (Conci et al., 2009; Tang, Leung, Haddad & McGrenere, 2013). Alternatively, relatives of patients may use the app on behalf of patients who are unable to use the app (McCall et al., 2008). Finally, a further novel finding is that a minority of patients appeared to have an 'avoidant' coping approach and did not perceive the app to be of benefit to them as they did not wish to have further information on their condition, beyond that provided by their clinician. It appears that this was an attempt to minimise anxiety and so an app that is seen to provide information may be perceived as a threat to this type of patient. This finding can be explained by theories of coping with a chronic illness, such as the CSM of health and illness (Leventhal et al., 1984) or crisis theory (Moos & Schaefer, 1984). A previous qualitative interview study with patients with cancer supports these findings, as it reported how some patients avoid too detailed or 'unsafe' information in order to maintain hope and as normal a life as possible (Leydon et al., 2000).

Importantly, no patients reported experiencing any negative consequences as a result of using the 'Ask Us' cancer app. This finding, along with feasibility studies and RCTs of other mobile interventions for cancer patients reported in Chapter 2, is a preliminary indictor of the safety of this type of app. Furthermore, several perceived benefits of the app were identified. Due to the nature of this study, it is unclear which components of the intervention are responsible for these perceived benefits, however findings provide

preliminary evidence for the QPL, resources and glossary features. The finding that some patients perceived an increase in question-asking and/or knowledge of cancer-related information may be indicative of increased levels of activation and patients taking a more active role in their care (Hibbard et al., 2004). It is possible that the features included in the app are working to increase patients' knowledge of their condition, their skills and confidence in order to participate more effectively in their care. Additionally, the finding that the app may have reduced some patients' anxiety could be explained by psychological theories of coping with a chronic illness, such as the CSM (Leventhal et al., 1984), which suggests information-gathering may help to construct adaptive illness cognitions to promote better adjustment to the illness.

Few app modifications were suggested by patients in the present study, which might indicate patients' overall satisfaction with the app design and content. It was thought that navigation of the app could be made easier by including a 'Back' button to exit features quickly and the creation of a separate feature for relatives to make it easier to access related information was suggested. Some patients suggested additional app features that they thought would be useful for future patients, however these features had been previously suggested by patients, relatives or clinicians in Chapters 4-6, and were either unpopular or were excluded by the APEASE criteria.

App activity data appeared to support patients' perceptions on use of the app. Data suggested that patients engaged frequently in the app, for a sustained period of time and the number of page views and feature events support patients' perceptions on their engagement the app and preferences for features. App activity data also highlighted that questions related to treatment and links to information on treatment-related side effects were popular with patients. This finding provides further support for presentation of the app immediately following a patients' diagnosis and prior to the start of treatment. However, app activity data findings should be interpreted with caution. It is possible that the number of app sessions was affected by non-engaged activity (i.e. entering and exiting the app without engaging) and the number of participants that used each feature, and the total use of each feature could not be determined.

7.5.1 Study strengths and limitations
A strength of this study is that it recruited a varied sample of patients, with several types of common cancers, different types of treatment (or remission), varied times since diagnosis and a mix of ages and genders**.** However, this study has several

limitations to consider. Firstly, the sample size was small, however analysis of data indicated that similar views were being expressed by the majority of participants and a decision was made to halt data collection. Secondly, the study had a low response rate, information on the key characteristics of those who declined to participate in the study was not collected and one participant did not complete the study. Those that declined to participate or did not complete the study may have had less favourable perceptions of an app than those who chose not to, or could not, participate. For example, they may have had limited experience with apps and may not have found the app as easy to use as those included in the present sample. Thirdly, participants had to own or have access to a Smart device to participate in the study. Individuals who already own Smart devices are likely to be more familiar with them than those who do not own such technology. The positive findings of the present study may therefore have been artificially inflated by recruiting a sample of patients who already owned a Smart device. Similarly, the participants in this sample mostly had high levels of education, which further increases the possibility that findings of the acceptability and feasibility of the app were inflated. Additionally, the sample included were White Caucasian. Further testing of the app is required with a sample that is more representative of the population, including patients with lower levels of education, those who do not own their own Smart device, and those of black and minority ethnic groups in order to support the present findings.

It is also possible that the participants' reported views may have been influenced by their desire to be polite and supportive of the candidates' PhD (a form of social desirability bias), however prior to beginning the interviews the candidate explained that both positive and negative opinions would help in the future development of the app. Similarly, participants were aware that their app activity was being recorded. This data may have been subject to the Hawthorne effect, where participants alter their behaviour due to their awareness of being 'observed' (Merrett, 2006). However, steps were taken to minimise this potential bias. At the start of this study, participants were instructed to use the app as and when they wish and that there were no obligations for them to use the app in any particular way.

A further limitation of this study is that participants used the app for different periods of time prior to their upcoming consultation date, which may have affected their opinions and experiences of the app. For example, some patients may not have used the app for long enough in order to experience potential benefits. Similarly, only one patient in the current study had been recently diagnosed with cancer within the last three

months, all other patients are likely to have met most of their information needs after three months which would limit the usefulness of the app for these patients. Finally, this study was unable to explore relatives' opinions on the app through patients.

7.5.2 Future research

Following from this field testing study, the MRC framework for the development of complex interventions encourages a feasibility study, followed by a pilot evaluation (Craig et al., 2008). A feasibility study would look to explore issues additional to the acceptability and feasibility of the app, including adherence, delivery, recruitment and retention (Craig et al., 2008). Outcome variables and suitable measures for a pilot evaluation would then be selected from the findings of this study. Ideally, a pilot evaluation would include randomisation and a control arm to allow assessment of the size of the effect. This study would provide a basis for calculating the sample sizes required for a definitive, controlled evaluation of the app. Given the limitations of the sample in the present study, further research should include a sample of patients that better reflect the general population, including those with lower levels of education, those who do not own Smart technology and patients from black and ethnic minority groups. Additionally, a future sample of patients should include more recently diagnosed patients in order to further explore the full range of potential benefits of this type of app. Although this study has reported the benefits experienced by patients and the most and least popular app features, further research is needed to determine the active components of the app (Yardley et al., 2015). Additionally, the current study did not include relatives of patients, therefore a future study would explore the usefulness and benefits of the app for this group. Finally, future studies may seek to determine which app features might be more useful for patients who are further along in their cancer journey.

7.5.3 Implications

This study presents some preliminary evidence to suggest that the 'Ask Us' cancer app may be a useful, acceptable and feasible intervention to support patients with cancer of various ages, gender and cancer types, in non-inpatient settings, though these findings are limited to this sample. It is likely that some older patients with a lack of experience with Smart technology will require on-going support when first learning to use an app.

Patients' perceptions of the usefulness of the app features, suggestions for improvement of the app, and the findings from the analysis of app activity data can be used to further to optimise the usefulness, acceptability and feasibility of the app prior

to implementation (Yardley et al., 2015). Additionally, app activity data highlighted patients' patterns of use the app features. This information can be used to improve our understanding of how patients engage with and use this type of app.

The perceived benefits of the app reported by patients in this study suggest that the app may be helping patients to meet their information needs by facilitating information exchange in consultations (i.e. increased question-asking and increased understanding of information provided in consultations) and information-gathering outside of consultations (i.e. increased cancer-related knowledge). The present study provides preliminary evidence that suggests that the app achieved some of the intervention objectives set out in Chapter 6. Furthermore, this study provides some evidence to suggest that the app may have increased patients' levels of activation (Hibbard et al., 2004) and/or improved their psychological coping with their illness (Leventhal et al., 1984; Moos & Schaefer et al., 2984). This information may be used to explore of the active components and mechanisms of the app and to design a full feasibility and then pilot evaluation (Yardley et al., 2015).

Importantly, this study did not indicate that patients experienced any negative consequences as a result of using the app, which contrasts to patients', relatives' and clinicians' anticipations described in Chapters 4 and 5, that the app might lead to increased anxiety and poorer communication in consultations. The present study also identified some barriers to app use that were experienced in a real life setting. Time since diagnosis and patients' perceptions of the acceptability of app use in consultations were not initially anticipated to be barriers by patients, their relatives and clinicians in Chapters 4 and 5, which highlights the usefulness of conducting a field testing study. This information can can be considered prior to implementation in order to further optimise the usefulness and feasibility of the app (Craig et al., 2008). Finally, this study adds to the growing body of evidence on the potential acceptability, feasibility and benefits of interventions for patients with cancer delivered remotely via mobile technology.

7.5.4 Conclusion

This study presents some preliminary evidence to suggest that an app that enables cancer patients to meet their information needs might be an acceptable and feasible intervention for the majority of patients with cancer. The majority of patients perceived the app to be useful, easy to use and reported that clinicians responded positively to app use in consultations. Findings suggested that the preferred features of the app,

including the QPL, resources and glossary app features, have the potential to enable patients to meet their information needs by facilitating question-asking in consultations with clinicians and information-gathering outside of consultations. App activity data appeared to corroborate patients' preferences. Benefits including increased question-asking, increased cancer-related knowledge and reduced anxiety were reported as a result of using the app, though further research with a larger sample of very recently diagnosed patients is required to establish the full range of potential benefits. Importantly, no negative consequences of using the app were reported and minimal problems were experienced during the study period. Some barriers to app use were identified, though these barriers can be minimised if taken into consideration prior to future implementation of the app. However, several limitations of the study, including the higher levels of education of the sample, requirement to own a Smart device to participate and low response rate to the study, may have artificially inflated findings. Further field testing with a sample that better reflects the general population is required to support the present findings.

Chapter 8
 General discussion

8.1 Chapter overview

This chapter presents an overview and critical reflection of the PhD findings and a discussion of how findings from each study were used to develop an app intervention to help patients and their relatives to meet their information needs. Findings are discussed in relation to theory and existing knowledge, and the novel contributions of this thesis are highlighted. The strengths and limitations of the methodology used throughout the PhD are discussed and the implications of findings for future development of the app and research are outlined.

8.2 Thesis findings and novel contributions

This PhD aimed to: (1) understand the needs and preferences of patients with cancer regarding an app to help them to meet their information needs in non-inpatient settings, and (2) develop an app intervention based on identified needs and preferences, which may also be used by relatives. Based on existing literature, it was hypothesised that an app would help patients with cancer to meet their information needs by facilitating information-gathering and understanding during and between consultations with clinicians. There were six objectives of this PhD:

(1) Identify how mobile devices have previously been used to help patients with cancer to meet their information needs in non-inpatient settings.
(2) Identify potentially relevant theory related to the impact and self-management of cancer.
(3) Explore patients' and relatives' needs and preferences regarding an app to help them to meet their information needs and the reasons for these perceptions.
(4) Explore cancer clinicians' opinions on the value of an app for patients with cancer and their relatives, their preferences of app features and reasons for these perceptions.
(5) Design an app intervention based on the identified needs and preferences of patients and their relatives and opinions of clinicians.
(6) Conduct a field test of the app with patients in the community to assess its acceptability and feasibility in practice.

The MRC framework for the design of complex interventions in healthcare was used as an over-arching framework to guide the work presented in this thesis (Craig et al., 2008) (Figure 2), specifically, phases one, 'development' and two 'feasibility and piloting' of the framework. The findings and novel contributions of each chapter of this thesis are discussed below and presented in Table 8.
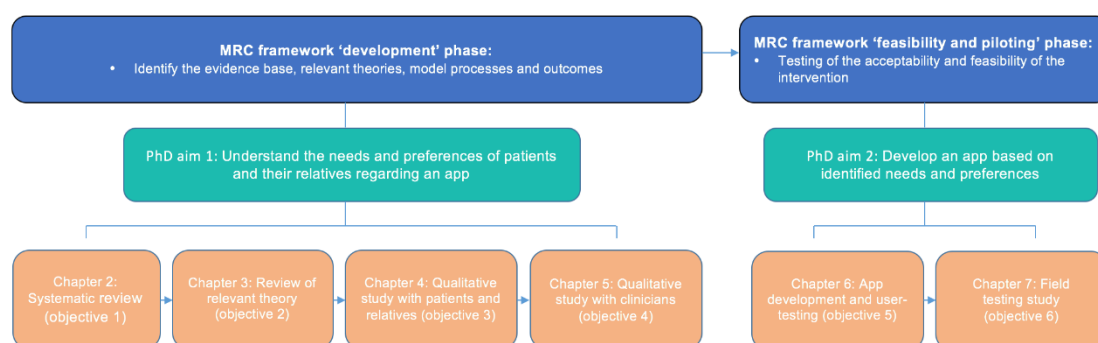
Figure 2 (from Chapter 1): *MRC framework phases and the aims and objectives of this PhD.*

8.2.1 A systematic review of existing mobile interventions for patients with cancer

Previous reviews have been conducted to explore the use of mobile interventions for cancer, including from cancer prevention to survivorship (e.g. Bender et al., 2013; Davis & Oakley-Girvan, 2015; Davoodi et al., 2016), however the systematic review conducted for this thesis was the first to identify how mobile devices have been specifically used to help patients with cancer to meet their information needs in non-inpatient settings. This review made several novel contributions to the wider cancer intervention field. Firstly, this review found that mobile devices appeared to be an acceptable platform to deliver interventions to remotely to a range of patients with cancer, including a variety of ages, genders, nationalities and familiarity with technology. Secondly, the potential benefits of this type of intervention were highlighted, including improve symptom management, patient empowerment, reduced anxiety, improve patient-clinician communication and increased health-related quality of life. In contrast, the review pointed out one study that reported the information intervention appeared to have increased some patients' anxiety by drawing attention to negative aspects of their condition (Foley et al., 2016), which drew attention to the literature on monitoring and blunting coping styles (Miller, 1995) and the goodness-of-fit hypothesis (Christensen et al., 1994; Park et al., 2001).

A fourth novel finding of this review is that it identified how so far, the majority of mobile interventions have been designed to enable remote surveillance of patients with cancer in the form of symptom-monitoring interventions. This type of intervention has sought only to increase patients' knowledge of their treatment side-effects and so highlighted a a gap for an app intervention that enables patients to meet their full range of information needs (i.e. any cancer-related information) in non in-patient settings.

Finally, this review identified that the majority of intervention studies had failed to report the race and ethnicity of participants, and those that did, failed to explore the effects of the interventions on these groups. As the UK is an expanding multi-cultural society, it is important that intervention developers explore the acceptability and perceived usefulness of interventions among minority groups, as they may have different experiences of cancer, and subsequently, needs and preferences for interventions (Matthews et al., 2002).

8.2.2 Models, theories and approaches relevant to patients' experiences of cancer

A review of relevant theory related to the impact and coping with cancer was conducted for this thesis. A selection of health behavior theories, models and approaches were identified as applicable to the context of the development of a novel app intervention to help patients with cancer to meet their information needs, including the Common Sense Model (CSM) of illness self-regulation (Leventhal et al., 1984), crisis theory (Moos & Schaefer, 1984), the theory of cognitive adaptation (Taylor et al., 1983), self-efficacy theory (Bandura, 1996) and the concepts of health literacy (Kindig et al., 2004) and patient activation (Hibbard et al., 2004). It was clear that there were common constructs that permeated these theories, such as appraisal and self-efficacy, and that they shared a focus on the empowerment of the patient and the potential role of mobile interventions in enabling patients to take a more active role in their care. However, this review outlined how there appeared to be an inherent assumption within this body of literature that knowledge would lead to behavior change, ignoring the 'knowledge-behaviour' gap that has been widely noted in research studies (Sligo & Jameson, 2000). Nevertheless, each of these theories useful provided insight into the many constructs required to effect behaviour change, including knowledge, skills, confidence and motivation. The framework of patient activation incorporated each of these concepts and is therefore likely to be the most useful for the future development of an app that aims to activate patients in their care (Hibbard et al., 2004).

The point of 'goodness-of-fit' in relation to knowledge was returned to in this chapter. The CSM (Leventhal et al., 1984) and crisis theory (Moos & Schaefer, 1984) and supporting literature suggested that 'approach' or 'active' coping leads to improved psychological adjustment for patients with cancer. However, in practice, a body of literature has shown how a minority of patients with cancer do not benefit from obtaining illness-related information (Folkman & Lazarus, 1980; Lazarus & Folkman, 1984; Miller, 1996). Research has since presented the conclusion that patients tend to have better physical, psychological and behavioural outcomes when the information they receive about their condition is tailored to their particular coping style (Miller, 1995). It is important that intervention developers, and cancer clinicians, are aware of this goodness-of-fit and do not prescribe the use of information interventions for those who may suffer consequences as a result of this type of intervention, such as increased anxiety (Christensen et al., 1994; Park et al., 2001). Finally, this review of relevant theory identified the potential outcomes of an app that facilitates patients' information-gathering, for those patients who prefer an active coping style, including improved psychological adjustment by enabling the development of adaptive illness cognitions and suitable coping strategies, and increasing patients' knowledge, skills and confidence to participate in their care (i.e. activation), which may ultimately lead to better health outcomes.

8.2.3 Patients' and relatives' needs and preferences regarding an app for cancer

The systematic review conducted for Chapter 2 included studies of adolescent patients, however the interventions for this group were gamified apps (e.g. Stinson et al., 2013). It was therefore anticipated that this population might have different needs and preferences regarding an app and so a decision was made to develop an intervention for adult patients with cancer only. A qualitative interview study was conducted to explore patients' and relatives' needs and preferences regarding an app to help them to meet their information needs. This study made several contributions to the wider cancer intervention field. Firstly, this study identified the context of patients' and relatives' needs and preferences regarding an app for cancer. Findings revealed that, despite advances in understanding of doctor-patient communication, barriers to information exchange and understanding during and between consultations with cancer clinicians still exist for patients and their families today, mirroring previous literature on doctor-patient communication in consultations (Ford, Fallowfield, & Lewis, 1996; NHS, 1993; Chapman et al., 2003; Shea–Budgell et al., 2014; Slort et al., 2011). These barriers created the need for four broad types of app features, including features that supported patients' self-management of their condition, facilitated information

exchange in consultations with clinicians and increased access to support for both patients and their relatives. These findings are of particular value to the wider cancer intervention field as they describe a range of patients' (and relatives') needs, and the underlying context, which could guide researchers to design interventions that are of more value to patients, compared to interventions that are designed using a theory-driven, deductive approach without direct involvement of its target users.

Secondly, this study identified that most patients and relatives anticipated an app to be an acceptable platform through which to deliver an intervention, which provided preliminary evidence for the potential uptake of an app for cancer upon implementation. However, several limitations of this sample, such as the low response rate, high numbers of Smart technology owners and a majority with higher educational levels, meant that the positive findings on the acceptability and potential usefulness of the app should be interpreted with caution. It is possible that these limitations introduced bias to findings and artificially inflated the findings. Additionally, the sample used in this study was not representative of the general cancer patient population; the perceptions of many subgroups of patients with cancer are still unknown. For example, a limitation of this sample was that all patients were White Caucasian; patients of black and ethnic minorities may be less likely to find such an intervention acceptable depending on their beliefs about cancer and may consequently differ in their needs and preferences regarding an app (Matthews et al., 2002). Similarly, adolescent patients, patients with lung cancer, rare cancers and those with less than 12 months life expectancy were not included in this sample due their potentially different needs and preferences regarding an app. Future studies will be required to explore the perceptions of subgroups of the cancer population in order to provide a more realistic indictor of the uptake of an app intervention for cancer that enables patients to meet their information needs. Notwithstanding these limitations, the favourable views of patients and relatives are consistent with several studies on patients' perceptions and expectations for other types of mobile interventions for other chronic conditions (Bostock et al., 2009; Pinnock et al., 2006; Seto et al., 2010).

Thirdly, this study highlighted the positive perceptions of relatives on an app for patients and caregivers. However, the sample size for relatives was small and all chose to participate in joint interviews with patients, which may have led to participants engaging in protective buffering, where they withold information so as not to burden or upset one another (Hagedoorn et al., 2000; Kuijer et al., 2000). These limitations mean that it is possible that the unique experience of relatives has been missed and so a

further study of individual interviews with relatives is required to support the these findings (Kendall et al., 2009). Nevertheless, the fact that all relatives of patients with cancer chose to participate in joint interviews when given the choice is of value to the wider cancer intervention field. Researchers are advised to conduct a number of individual interviews with relatives who are not offered a joint interview, as well as dyadic interviews, in order to compared findings.

Fourthly, this study identified the potential benefits of this type of intervention for patients with cancer and their relatives, which included a more informed patient, increased quality of life, reduced anxiety, a sense of empowerment and more convenience. Potential disadvantages were also identified and included increased anxiety and poorer communication in consultations. Finally, several potential barriers to app use were anticipated by patients and relatives and included patients' age and experience with Smart technology, access to Smart devices, the perceived reliability and security of information, and an avoidant coping approach. Previous studies of patients' anticipations of mobile interventions for a range of other chronic conditions, such as asthma and heart failure, have identified patients' age (and prior experience with Smart technology), increased anxiety and access to Smart technology as concerns (Bostock et al., 2009; Pinnock et al., 2006; Seto et al., 2010). However, an avoidant coping approach may be a potential barrier that is specific to the context of cancer due to the life-threatening nature of the disease. Concerns about the reliability and security of information on an app also appeared to be specific an intervention that aims to meet patients' information needs. However, although these findings provided an insight into the potential outcomes of this type of intervention, research has shown that dyadic interventions, which may be used jointly by the patient and their caregiver, may produce different effects on patients and their caregivers compared to individual interventions, particularly for the caregivers who participate in patient-focused interventions (Northouse et al., 2010). Future studies of this type of intervention should therefore consider testing the effects of the app on patients and their caregivers separately.

Finally, although not a novel finding, this study confirmed previous findings on the role of information-seeking for patients with cancer (Ranchor et al., 2010; Hinds et al.,1995) and theories of coping with a chronic illness (Leventhal, et al., 1984; Moos & Schaefer, 1984) as it reported how information-gathering was used as an adaptive coping strategy by the vast majority of patients and their relatives. Furthermore, this study reported how a minority of patients appeared to adopt avoidant coping strategies

where they preferred a minimum amount of information, from their clinician only, and did not use the Internet in order to avoid threatening information, which supports the literature on the goodness-of-fit of opposing coping strategies, such as monitoring and blunting (Christensen et al., 1994; Miller, 1995; Park et al., 2001). Based on these findings, it was hypothesised that this subgroup of patients would be unlikely to benefit from using an app intervention that facilitates information-gathering (Folkman & Lazarus, 1980; Lazarus & Folkman, 1984; Miller, 1996).

8.2.4. Clinicians' views and opinions of an app for patients with cancer and their relatives

A similar qualitative interview study was conducted to explore patients' and relatives' needs and preferences regarding an app from the perspective of cancer clinicians, as second to patients themselves, clinicians know what is best for the patient. This study also made several contributions to the wider cancer intervention field. Firstly, this study identified that clinicians' views on the barriers to information exchange and understanding for patients during and between consultations were consistent with patients' and relatives' perceptions. As a result of their awareness of the communication issues in cancer consultations, this study reported how clinicians suggested the same four types of app features as patients and their relatives and anticipated this type of app to be useful. Although previous studies that have demonstrated that some clinicians are aware of some of these issues (Légaré et al., 2008; Slort et al., 2011), this is the first study that has demonstrated full agreement between patients, their relatives and clinicians about the communication issues faced in today's cancer consultations. These findings are useful for the wider cancer intervention field as they may be used to guide efforts in developing new interventions to facilitate doctor-patient communication in cancer consultations.

Secondly, this study identified that clinicians were supportive of the development of an app for cancer care and did not anticipate that they would need additional training for implementation of an app. This finding is consistent with previous studies that reported clinicians' positive perceptions and expectations for new technology in healthcare, including other types of mobile interventions for chronic conditions (Bostock et al., 2009; Pinnock et al., 2006; Seto et al., 2010).

Thirdly, this study highlighted the concerns of some clinicians regarding an app intervention; some clinicians were concerned that an app used in consultations could distract patients and hinder communication and others anticipated that some older

clinicians might resist this new technology. Relevant theories were used to explain these findings, including the Technology Acceptance Model (TAM) (Davis, 1989; Venkatesh & Bala, 2008), the diffusion of innovation theory (Rogers, 2003) and models of the doctor-patient relationship, including paternalism and the shift to patient-centered care (Hellin, 2002; Kaba & Sooriakumaran, 2007). The present findings suggest that currently, there is a critical mass of clinicians that would find app use by patients in consultations to be acceptable, and over time, the remaining clinicians will become 'late adopters' and 'laggards', as they were not opposed to the app (Rogers, 2003). However, an app might not be perceived as useful by a minority of clinicians who adopt a paternalistic approach with their patients as this type of intervention acts to facilitate patient-centered care by empowering the patient, causing a power shift.

Finally, this study identified the potential outcomes of an app that enables patients to meet their information needs, anticipated by clinicians. The anticipated benefits of this type of intervention were consistent with patients' and relatives' views, however clinicians also anticipated that there may be improved communication between patients and their clinicians, as well as possible benefits for clinicians themselves, as a result of the app. These findings demonstrate the usefulness of multi-perspective interviews to the wider cancer intervention field, as different groups of key stakeholders may foresee potential outcomes that others may not have anticipated. Another example of this benefit of multi-perspective interviews is that clinicians appeared to be more skeptical of the uptake of the app compared to patients and relatives. This may be due to the fact that clinicians consult a wide range of patients, such as patients with an avoidant coping approach and older patients who are unfamiliar with technology, who may therefore have less favourable perceptions of an app, whereas patients and relatives included in the studies in this thesis were mostly technology owners and had an active coping approach. Clinicians also anticipated the same types of potential barriers and disadvantages to this type of app as patients and relatives, however clinicians additionally suggested that this type of intervention might increase clinicians' workloads. Previous studies of clinicians' anticipations of mobile interventions for a range of other chronic conditions have identified patients' age, access to Smart technology and increased workload as some of their concerns (Bostock et al., 2009; Pinnock et al., 2006; Seto et al., 2010).

8.2.5 The design and user-testing of an app for patients with cancer and their relatives

The findings of Chapters 2-5 motivated and justified the design of an app intervention for patients with cancer and their relatives. Chapter 6 reported on the systematic process that was used to create the 'Ask Us' cancer app, which consisted of an iterative process and several stages, including development of the intervention objectives, selection and development of app features and content, design of the app interface and a user-testing discussion group with a sample of patients and their relatives to inform the final version of the app. The 'Ask Us' app consisted of a QPL, a glossary of cancer terms, a resources feature and a contacts feature. Although there are several similar apps for patients with cancer currently available, such as the Pocket Care Cancer Guide or Macmillan's 'My Organiser', the 'Ask Us' cancer app has several unique advantages. Firstly, the app provides patients with fast and easy access to a unique combination of cancer-related tools and services, which were perceived to be of great value by patients, relatives and clinicians. Secondly, these useful features can be accessed via one platform and are available to use without access to wifi by taking advantage of the benefits of Smart technology. Findings from the discussion group showed that patients and their relatives perceived the app to be useful and easy to use and only minor modifications were made following the discussion group, which created the final version of the app. However, limitations of the methodology of the user-testing study means that these findings may have been artificially inflated. For example, the sample was more highly educated compared to the general population. Education level, a proxy of socioeconomic status, has been shown by some studies to be predictive of the use of web-based technologies across the health care and health information-seeking domains (Kontos, Blake, Chou & Prestin, 2014; Neter & Brainin, 2012). The current sample may therefore have perceived the app to be more useful and easier to use compared to patients with lower education levels. More in depth user testing with patients of a range of education levels is required to add weight to the findings of this study.

8.2.6 The acceptability and use of the 'Ask Us' cancer app in community settings

Following 'in-house' user-testing, a mixed-methods field testing study was conducted to test the app in real life settings. This study provided several contributions to existing knowledge on the implementation of an app intervention into routine cancer care. Findings of this study suggested that overall, patients found the app to be an acceptable platform through which to receive an intervention, however several barriers were identified that would need consideration prior to future implementation of the app. Firstly, although most patients found it easy to use, some older patients with a lack of experience with Smart technology had initial difficulty when learning to use the app and

one patient appeared dis-interested in the app throughout the entire study period. This finding generally contrasts with previous studies, which have claimed this type of intervention to be acceptable for a wide range of patients, including different ages and patients who were receiving palliative care (McCall et al., 2008; Somers et al., 2015; Stinson et al., 2013; Sundberg et al., 2015; Yap et al., 2013). These studies may have failed to report the initial difficulties of older patients when learning to use the intervention, if they eventually used it successfully. The present field testing study highlights the fact that some older patients might need more time to learn to use the app compared to younger patients who are more familiar with this technology, which is expected due to them being more likely to be error-prone as a result of sensory, motor and cognitive changes (Conci et al., 2009).

Secondly, this study revealed how some patients were concerned about the acceptability of using an app during a consultation with their clinician and wanted permission from the clinician to use the device. It is possible that finding indicates patients' perceptions of a paternalistic relationship with their clinician, however as anticipated by the diffusion of innovation theory (Rogers, 2003), it is likely that this will be a temporary issue until the widespread adoption of Smart technology in health care becomes common place (Koehler et al., 2013). Importantly, this barrier was not initially anticipated by patients, their relatives or clinicians in early qualitative interviews, which highlights the usefulness of testing the app in the context in which it will be used (Yardley et al., 2015). In contrast, this study confirmed the previous expectations of patients, relatives and clinicians in qualitative interviews that a minority of patients who appeared to have an avoidant coping approach did not perceive the app to be of benefit to them as they did not wish to have further information on their condition. Importantly however, this study found that there were no perceived disadvantages for any patient as a result of having access to the app, which is a preliminary indicator of its safety.

Thirdly, this study identified some of the outcomes of this type of intervention in practice. Several perceived benefits of using the app were reported by patients, including increased question-asking in consultations, increased knowledge on their condition and reduced anxiety. These findings might suggest that the app is helping patients to meet their information needs by facilitating information exchange in consultations (i.e. increased question asking and increased understanding of information provided in consultations) and information-gathering outside of consultations (i.e. increased cancer-related knowledge), as outlined in the intervention

objectives. These findings suggest that the app could be increasing patients' levels of activation (Hibbard et al., 2004), as well as improving psychological coping with their condition (Leventhal et al., 1984, Moos & Schaefer, 1984). Overall, the app appeared to be an acceptable and feasible intervention in real life settings, however these findings were restricted to particular subgroups of patients. The sample included included Smart-technology owners, most of whom had higher educational levels compared to the general population. It is possible that patients included in this study found the app more acceptable, easier to use and more useful compared to their counterparts and so further field testing with a sample of patients with lower education levels is required to add weight to present findings (Kontos et al., 2014).

Nevertheless, this study identified patients' preferences for the selected app features and patterns of app use. The QPL feature was identified as the most popular app feature, followed by the resources and glossary features, and the contacts feature was identified as the least popular. Most patients suggested that the app features would have been more useful if presented early after their diagnosis as they felt their information needs were greatest at this point. For example, it was anticipated that the glossary feature will be useful when patients are attending consultations, which is mostly between diagnosis and during treatment, and the contacts feature will mostly be useful at diagnosis, when patients are first meeting their team of clinicians. However, the QPL and resources features were suggested to be useful even for patients who had been diagnosed with their cancer for a few months due to the need for new information as their disease or treatment progressed. Figure 9 illustrates the potential usefulness of each feature throughout around diagnosis, treatment and remission, based on these findings reported in this study. Finally, app activity data appeared to corroborate patients' perceptions of app use and suggested that patients engaged in the app frequently, and for a sustained period of time.

Figure 9: Perceived usefulness of app features throughout the stages of cancer.
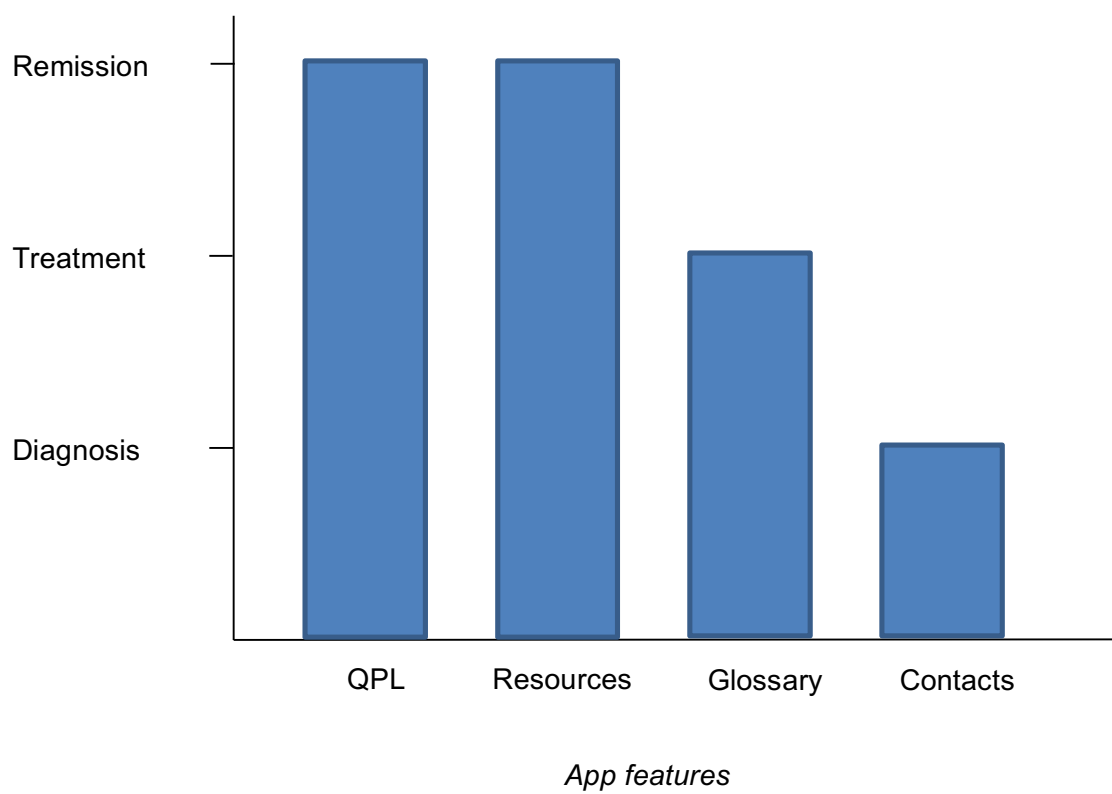
App features

Table 8: *Novel contributions of this thesis.*

Chapter	Study design	Primary aims	Contribution to research
2	Systematic review	Identify how mobile devices have previously been used to help patients with cancer to meet their information needs in non-inpatient settings.	• Most interventions were symptom-monitoring interventions which sought only to increase patients' knowledge of their treatment side-effects. The review highlighted a gap for an app intervention that aimed to enable patients and their relatives to meet their full range of information needs in non in-patient settings. • Mobile devices appeared to be acceptable platform to deliver interventions remotely to a range of patients with cancer and potential benefits of this type of intervention included improve symptom management, patient empowerment, reduced anxiety, improve patient-clinician communication and increased health-related quality of life. • One study highlighted how information interventions are unlikely be suitable for all patients and might increase anxiety for those who adopt an avoidant/blunting coping style. • Most studies failed to report race/ethnicity and so it is possible that unique experiences of minority groups were missed.
3	Scoping review	Review of theory relevant to the impact and self-management of cancer.	• The CSM, crisis theory, theory of cognitive adaptation, self-efficacy theory and the concepts of health literacy and patient activation were identified as relevant theories for the development of an intervention to help patients with cancer to meet their information needs. • This chapter also discussed the limitations of knowledge in this context and how the usefulness of an information intervention depends of the 'goodness-of-fit' between the demands of the situation and selected coping style.
4	Qualitative interview study	Establish patients' (and relatives') needs and preferences for an app and the underlying psychosocial context.	• This study identified the underlying context of patients' and relatives' needs and preferences regarding an app; barriers to information exchange and understanding during and between consultations appeared to lead to unmet information needs. • Patients and relatives desired four types of app features, including features that: (i) supported patients' self-management of their condition, (ii) facilitated

			information exchange in consultations with clinicians, (iii) increased access to patient support, and (iv) increased access to support for relatives. • Patients and their relatives reported positive views on the potential usefulness and acceptability of this type of intervention. • Potential outcomes of this intervention were identified. Perceived benefits of this type of intervention included a more informed patient, increased quality of life, reduced anxiety and a sense of empowerment. Potential disadvantages of this type of app included increased anxiety and poorer communication, and anticipated barriers to app use in practice included patients' age and experience with Smart technology, access to Smart devices, the perceived reliability and security of information, and an avoidant coping approach.
5	Qualitative interview study	Establish clinicians' perspectives regarding an app for patients and relatives.	• This study identified that clinicians' views were consistent with those of patients and relatives on the barriers to information exchange and understanding during consultations. • Clinicians supported the development of an app that aims to help patients with cancer and their relatives to meet their information needs and suggested the same four types of app features as patients and relatives. • Clinicians did not anticipate that they would need additional training for the implementation of the app. • Clinicians' views of the perceived benefits, possible disadvantages, and barriers to this type of intervention were largely consistent with those of patients and relatives', although clinicians were also concerned about an increase in workload.
6	App development	Describe the systematic development of an app and assess its usability in-house	• Patients and their relatives perceived the app to be acceptable, useful and easy to use during a user-testing discussion group.
7	Mixed-methods field testing study	Assess the acceptability and feasibility of the app in a real life setting and understand whether it	• Most patients perceived the app to be acceptable, though some older patients had initial difficulties when first learning to use an app. • The QPL feature appeared to be the most popular app feature and the contacts feature was least popular. App activity data appeared to corroborate

		would be useful to patients in practice.	patients' perceptions of app use and suggested that patients engaged in the app frequently and for a sustained period of time. • Perceived benefits of using the app included increased question-asking in consultations, increased knowledge on their condition and reduced anxiety, which might indicate increasing levels of patient activation. • There were no reports of any disadvantages as a result of using the app, however time since diagnosis, experience with Smart technology, perceptions of the acceptability of app use in consultations and an avoidant coping approach were perceived by some as barriers to app use. • Overall, the app appeared to be feasible in practice for particular groups of patients, such as those who are familiar with technology and an active/monitoring coping style.

8.3 Theoretical underpinning

In Chapter 3, several models, theories and approaches relevant to the impact and self-management of cancer were identified as potentially useful for the development of an app intervention to help patients and their relatives to meet their information needs. Broadly, the CSM (Leventhal et al., 1984), crisis theory (Moos & Schaefer, 1984), and theory of cognitive adaptation (Taylor, 1983) provided insight into patients' responses to a cancer diagnosis, its impact, and the process of psychological coping. Self-efficacy theory (Bandura, 1996), health literacy (Kindig et al., 2004) and patient activation (Hibbard et al., 2004) provided insight into the determinants of patients' engagement with their care and self-management of their condition. However, it was apparent that similar elements permeate the models, theories and approaches (e.g. appraisal, coping responses, self-management behaviours). Additionally, the term 'self-management' has come to be used in the literature as one that encompasses both patients' coping with, and adjustment to, cancer and self-management of the disease. As such, it was anticipated that each of these models and theories could be useful for providing insight into patients' and relatives' experiences of cancer and inform the development of an app intervention.

Findings from the qualitative study with patients and relatives reported in Chapter 4 suggested that theories of coping with cancer, such as the CSM, crisis theory and theory of cognitive adaptation, were useful in understanding their needs and preferences regarding an app, and the underlying psychosocial context. These theories, particularly the CSM and crisis theory, were useful to explain the initial impact of a cancer diagnosis (i.e. perceived loss of control) and patients' and relatives' use of information-gathering as a coping mechanism. Approaches relating more to the self-management of cancer, particularly patient activation, were a useful framework to provide further insight into the barriers of information exchange and understanding in consultations and identification of information sources outside of consultations. For example, it was apparent that many participants lacked the skills (i.e. unable to identify reliable information on the Internet), knowledge (i.e. limited understanding of cancer upon first diagnosis, clinicians' use of medical terminology in consultations) and confidence (i.e. lack of confidence to ask questions in consultations) to self-manage their condition. This selection of models, theories and approaches also provided insight into patients' and relatives' suggestions for app features. For example, suggestion of

features such as question prompt list and a glossary of cancer terms might suggest that patients were attempting to increase their knowledge, skills and confidence to enable them to self-manage their condition more effectively. Similarly, suggestion of features such as connecting with other patients might suggest that patients would use this feature as an emotion-focused coping strategy or a mechanism of self-enhancement to increase their self-esteem.

The CSM and crisis theory were considered particularly useful during development of the app due to their frameworks of coping strategies. Features that could be used as adaptive coping strategies to promote better psychological adjustment were selected for inclusion in an app. For example, use of the resources feature could be considered a problem-focused strategy as patients can use this feature to actively gather information to answer questions, when needed. Similarly, links to local support groups provide an opportunity for patients to adopt an emotion-focused strategy, such as venting their emotions to other patients. The patient activation framework was also considered particularly useful during app development and was used to guide the selection of features that would help to increase patients' knowledge (e.g. QPL, glossary of cancer terms, resources feature, contacts feature), skills (e.g. resources feature, QPL), and confidence (e.g. QPL, glossary of cancer terms, contacts feature) to self-manage their condition in non-inpatient settings. It was therefore hypothesised that an app that facilitates patients' information-gathering could promote better psychological adjustment to cancer by enabling them to develop adaptive illness cognitions and adopt problem-focused coping strategies. Furthermore, an app that aims to increase patients' knowledge of their condition and their skills and confidence to participate in their care could increase patients' levels of activation and lead to better health outcomes. However, as discussed in Chapter 3, based on the goodness-of-fit hypothesis (Park et al., 2001), it is anticipated that the intervention will be suitable only for those patients with an active/monitoring coping style. Patients with an avoidant/blunting coping style are unlikely to use, nor benefit, from this type of intervention.

Findings from the field testing study of the app provided further insight into the theories that may be most relevant to this type of intervention. Reported benefits experienced by patients, including increased knowledge and question-asking in consultations might suggest that the app increased patients' levels of activation and so the patient

activation framework might be useful for this aspect (Hibbart et al., 2004). Furthermore, some patients reported that they experienced reduced anxiety as a result of using the app. This finding might indicate that the app was useful for psychological coping with the condition, as anticipated by the CSM (Leventhal et al., 1984) and crisis theory (Moos & Schaefer, 1984). However, as the development of the app for this PhD project was largely exploratory, these studies cannot yet confidently determine the most or least useful theories. Additionally, as the app is a multi-feature, complex intervention, it is likely that elements of each of these models, theories and approaches discussed throughout this thesis will be relevant for its future development and evaluation.

8.4 Study methodology strengths and limitations

8.4.1 Systematic review

A systematic review method was used in this thesis to identify studies of existing mobile interventions that aimed to help patients with cancer to meet their information needs in non-inpatient settings. Systematic reviews are regarded as the highest level of evidence due to the efforts taken to reduce potential bias and the transparency of the methods used. The aim of this review was to assess data on the effects and feasibility of this type of intervention, provided by empirical studies, and conduct a formal assessment of the quality of the methodologies used. In contrast, scoping review methodology allows for the inclusion of grey literature and interventions of lower quality. Although grey literature may include useful studies that were subject to publication bias, these studies are not peer-reviewed. Additionally, double coding at each stage of the search, study selection and data extraction is not compulsory for scoping review methodology and so allows for potential bias at each stage. Additionally, this methodology does not include a formal assessment of included studies and so has the potential for conclusions to be drawn on methodological flawed evidence or untrustworthy studies. Some systematic reviews extend the search to include grey literature to be as inclusive as possible, however the aim of this review was to assess data on the effects and feasibility of this type of intervention, provided by empirical studies. Prior to the search, it was therefore decided that grey literature would not be searched as these studies are not peer-reviewed and are unlikely to contain empirical data. Finally, due to the small number of studies and lack of suitable data, a meta-analysis was not conducted for this review.

8.4.2 Qualitative methods

Qualitative methods were selected for this thesis to enable an in-depth exploration of the psychosocial context of patients' and relatives' needs and preferences regarding an app intervention to meet their information needs, as well as clinicians' views on the value of such an app. Face-to-face interviews were used to facilitate a personal response to these topics in order to provide a deep understanding of an individuals' experiences and views. This method was considered suitable for exploration of a sensitive subject, such as cancer. Furthermore, semi-structured interviews enabled the investigation of pre-determined topics but also allowed the candidate the freedom to deviate from the topic guide to further explore any interesting issues raised by the participants.

Although qualitative, semi-structured interviews were most suitable for these studies, there are limitations to consider. Firstly, qualitative methodology is criticised for its lack of generalisability. As qualitative methods provide in depth understandings of individuals on a case-by-case basis, findings may not be generalisable to the general population. For example, patients included studies in this thesis were those that had one of the most common types of cancers, including colorectal, urological, breast and gynaecological cancers. As these cancers are more common, there are more support services available for these cancer types. Additionally, more common cancers tend to be diagnosed sooner and have better treatment outcomes compared to rarer cancers, such as pancreatic cancer, which tend to be diagnosed later and have poorer prognoses. Patients with other cancers may therefore have different needs and preferences for an app compared to those included in this qualitative study.

Secondly, qualitative methods are criticised for the potential influence of researcher bias on the analysis and interpretation of findings. It is argued that qualitative research is so personal to the researcher (e.g. their epistemology, values, experiences) that they may select, analyse and interpret data in ways that favour their own view. The third criticism of qualitative research is therefore the potential lack of reproducibility, as one research might produce different findings to another. However, practicing reflexivity throughout the data collection, analysis and interpretation of research enabled the candidate to minimise this potential bias. Additionally, double coding was conducted during data analysis of the qualitative studies included in this thesis.

Measures were also taken to prevent any social desirability bias affecting the findings. Prior to interviews, I explained to participants that there were no 'right' or 'wrong' answers to questions and that both positive and negative opinions were useful to inform the development of an app for patients and their families. I explained the importance of their honesty in developing an app that would be useful to future patients and their families. Additionally, I assured participants that all data would be anonymised and could not be linked back to them in any way, which was particularly important for patients and relatives when discussing the care provided by their clinicians.

I was also aware of how I may be perceived by participants (patients and their relatives), as a doctoral researcher from a reputable university. In order to reduce any potential influences of my own social standing during interviews, I made efforts to build rapport with participants and dressed appropriately to make them feel comfortable. I have never received a diagnosis of and lived with cancer which this means that I may never fully understand the impact of this disease and the needs and views of patients and their relatives that participated in the studies.

Other methods that could have been used in place of the qualitative studies include focus groups or observations. However, a focus group would have precluded any in-depth exploration of patients' and relatives' psychosocial context, which was required in order to understand their needs and preferences regarding an app and the type of app that would be most useful to them. Additionally, patients and relatives may feel self-conscious talking about such personal issues in a focus group, and providing information on their information technology skills or issues. Observations of patients' and their relatives may have provided further insight into living with cancer on a daily basis and the different ways in which an app could help to support them. This method circumvents the self-report bias that is a potential risk with face-to-face interviews. However, semi-structured interviews allowed the exploration of large breadth and depth of information in a short space of time and this method was considered most suitable for the aims and objectives of this thesis.

Finally, joint interviews with patients and relatives may have precluded exploration of the unique experiences of relatives. Firstly, it is difficult to get a full account from each participant in a joint interview and secondly, relatives may have engaged protective

buffering, where they censor information so as not to burden or upset the patient (Hagedoorn et al., 2000; Kuijer et al., 2000). Similarly, patients may have withheld relevant information to protect their relatives.

8.4.3 Frameworks and approaches to guide the development of an app

The MRC framework (Craig et al., 2008) for the development of complex interventions in healthcare was considered suitable to use as an overarching framework to guide the early phase, exploratory work conducted for this thesis. This framework advocates a systematic, phased approach that enabled the candidate to develop the evidence base for the intervention, as well as evidence for the use of theories, intervention processes and outcomes. The advantage of using such an approach is that development of an intervention is guided by evidence and tailored according to findings, which enables the creation of an intervention that is useful and engaging for its users, as well as acceptable and feasible.

However, the MRC framework is not without its limitations. Firstly, it has been criticised for being too closely tied with the development of pharmacological interventions, for which significant resources are provided. In contrast, public health interventions and/or those that do not involve the generation of intellectual property do not often have the resources to follow the rigorous development and evaluation process of the MRC framework, which ultimately ends in a full RCT (Lakshman et al., 2014). Secondly, although the RCT is held as the gold standard method for evaluation, this method is not always practical or appropriate for complex interventions in healthcare (De Silva et al., 2014). For example, as described below in section 8.3.5, researchers have argued that the timeline of an RCT is incompatible with web- and mobile-based interventions as technology rapidly advances (Mohr, Cheung, Schueller, Brown & Duan, 2013). Furthermore, the RCT is limited to identifying the efficacy of an intervention, that is whether an intervention 'works', and is usually conducted in closed systems where the intervention is typically isolated from other extraneous influences. However, the effects of interventions can be very dependent upon factors such participant characteristics, setting, and the way in which it is implemented. Trial methodology does not account for the translation of interventions into practice where they are delivered in open systems, and is not sufficient to understand what works, for whom and under what circumstances (Bonell, Fletcher, Morton, Lorenc & Moore, 2012; Pawson and Tilley, 1997; Sayer 2000). Researchers have therefore argued that the MRC framework does

not sufficiently account for the role context in shaping implementation and causal processes (Bonell et al., 2012; De Silva et al., 2014). However, new MRC guidance has endorsed the integration process evaluation within RCTs of complex interventions, with the use of qualitative data collection and analysis focused that is focused on the interactions between mechanisms, context and outcomes, termed 'realist RCTs' (Moore et al., 2015). Thirdly, researchers have argued that greater attention is required to early phase piloting and development work for behavior change interventions, including the involvement of key stakeholders, than is advocated in the MRC framework (Yardley et al., 2015). For this reason, the person-based approach (Yardley et al., 2015) was selected to complement the MRC framework to guide the work in this thesis as this approach highlights the importance of understanding and accommodating the perspective of the people who will use the intervention and the context of the intervention in which it will be delivered (e.g. consultations with clinicians). Similarly, the field of psychology has accumulated psychological principles that can be used to change determinants of behaviour, such as knowledge, attitudes, subjective norms and self-efficacy (Sheeran, Gollwitzer, & Bargh, 2013). These principles have been codified into taxonomies to facilitate coding and description of behaviour change interventions, such as Abraham and Michie's Behaviour Change Technique (BCT) taxonomy (Abraham & Michie, 2008). However, the codification of principles into a taxonomy suffers from the same limitation as the MRC framework; it does not acknowledge the fact that methods of behavior change are only effective under specific conditions (Schaalma & Kok, 2009). Researchers have highlighted the need for more systematic evidence regarding context, i.e. about which methods work in relation under which conditions (Peters, De Bruin & Crutzen, 2015).

Due to the growing number of mobile interventions for being developed for healthcare, researchers have also designed specific frameworks to guide development and evaluation of this particular type of intervention. The advantages of using a more specific framework for mobile interventions includes increasing the rigor of such studies and facilitating the translation of literature into replicable and evidence-based mobile interventions that can be systematically evaluated, used and adapted to health care settings. The Chronic Disease mHealth App Intervention Design Framework (Wilhide III et al., 2016), the Technology Acceptance Model (Davis, 1989), the Health IT Usability Evaluation Model (Health-ITUEM) (Brown et al., 2013), and the People At the Centre of Mobile Application Development (PACMAD) model (Harrison et al., 2013)

were selected to guide the design of the app and testing of its usability. For example, an 'in house' user-testing discussion group, followed by a field testing study where the app is used in real life settings, were considered the most appropriate methods to test the acceptability and feasibility of the intervention at this early point in app development. As described by the MRC framework (Craig et al., 2008), intervention development is an iterative process and so several user testing sessions will likely be required over time as improved versions of the app evolve. A more in-depth and resource-intensive user-testing study, such as a think aloud study, would be a suitable method further down the line when there is more certainty of the core features of the app as this type of study is more resource-intensive.

8.4.4 App design and user-testing

A common-sense process was used to collate and synthesis the evidence on suggested app features. Following synthesis of findings from Chapters 4 and 5, a digital software team was also consulted on the types of app features that would be feasible to build and include in an app and the APPEASE criteria (Michie et al., 2014) was considered a suitable method to screen potential app features for inclusion. Additionally, discussions with the supervisory team on the selection process helped to reduce the potential influence of researcher bias on the interpretation of findings.

A discussion group was conducted to user-test the app, with the aim of ironing out any issues and to optimise the app prior to field testing. Research has shown that user-testing with just five participants can reveal up to 85% of usability issues (Nielsen, 1993; Nielsen & Landauer, 2000) and a discussion group offers the benefits of prompting participants to think about issues that they may not have thought about individually and providing participants with the opportunity to build upon one another's opinions (Kitzinger, 1995). As a result, this method enables a consensus to be reached on suggested app modifications, much like a focus group (Kitzinger, 1995). For these reasons, a discussion group with 5-6 participants was considered a suitable method to conduct user-testing of the app to identify any issues at this early stage in app development. However, the usefulness of this method hinges upon recruitment of a suitable sample. The present sample suffered from several limitations, such as higher educational levels and previous participation for research in this thesis, which may have reduced the validity of the findings.

8.4.5 Mixed-methods field testing

A mixed-methods field testing study, including semi-structured qualitative interviews and recording of app activity data, was considered an appropriate method to explore patients' experiences of using the app in practice. As described in section 8.4.2, face-to-face interviews were used to facilitate a deep understanding of individuals' experiences and views on using the app running up to and during a consultation with their clinician. Semi-structured interviews enabled the investigation of pre-determined topics of app use but also allowed the candidate the freedom to deviate from the topic guide to explore any interesting issues raised by the participants. Recording of app activity data was considered a useful addition to semi-structured interviews as this method provided further insight into patients' actual use of the app, including patterns of app use and the way patients engaged in the app. This mixed-methods approach offered the advantage of comparing the data sets and validating or highlighting the differences between recorded app activity data and patients' explicit perceptions of the app. However, there were limitations to this approach.

Firstly, conducting face-to-face interviews with participants on their opinions on the acceptability and feasibility of the app has the potential to introduce social desirability bias. Participants may have responded favourably to interview questions in order to please the interviewer. Steps were taken in order to limit this possible bias. Prior to the start of this study, the candidate explained to participants that all opinions on the app, both positive and negative, were essential in order to develop the most useful app for future patients.

Secondly, although semi-structured interviews provided in depth information on a range of pre-determined topics of interest, not all topics were explored equally with participants. For example, some participants had much to say about some app features but little to say about others. The addition of a questionnaire for this study may have be useful as it would ensure a breadth of information was collected on all topics, whereas interviews provided in-depth information on certain topics.

Thirdly, participants were aware that their app activity was being recorded. This data may have been subject to the Hawthorne effect, where participants alter their behaviour due to their awareness of being 'observed' (Merrett, 2006). Participants in the current study may have used the app differently to what they may do in 'real life' as

they knew the candidate would be able to see their app activity data. However, steps were taken to minimise this potential bias. At the start of this study, participants were instructed to use the app as and when they wish and that there were no obligations for them to use the app in any particular way.

A further limitation is that relatives and clinicians were not included in this field testing study and it is important to assess the acceptability and feasibility of an intervention with its key users. However, it is possible that this type of dyadic intervention will have a different effect on patients and relatives due to protective buffering and so it is important to test the intervention with each group separately, as well as jointly (Kuijer et al., 2000).

8.5 Strengths and limitations of sampling methods

Maximum variation sampling, a type of purposeful sampling strategy in which cases are selected on the basis of the study populations' characteristics and on the study objectives was considered appropriate as this method allows for divergent views to emerge (Patton, 2002). The studies aimed to recruit patients of different cancer types, treatment types, time since diagnosis, ages, and genders. It was important to gather opinions from a range of patients in order to determine the type of app that would be most useful. However, most patients (and relatives) included in this study had higher education levels and were owners of Smart technology and these factors may have artificially inflated findings of the acceptability and perceived usefulness of the app. A more representative sample of the cancer patient population is therefore required to support the findings of the studies included in this thesis. Additionally, patients recruited from the clinical trials unit at Velindre Hospital are more likely to be already participating in research and so may have more favourable opinions towards any interventions compared to patients recruited from the cancer clinics at Velindre and University Hospital Wales.

Opportunistic recruitment methods involving snowball sampling via patients were used to invite relatives to participate in the interview study. This method was considered useful for engaging participants who may otherwise not have been included in the study. Some relatives also volunteered to participate in interviews at the time of interviewing the patient. However, these sampling methods may have lead to recruitment of relatives who had more favourable opinions of Smart technology, which

may have artificially inflated the perceived acceptability of an app intervention for patients' caregivers, and may also have led relatives to believe that they were there to validate the patients' experiences. As a result, the unique experiences of relatives may have been missed.

Maximum variation sampling was used to recruit clinicians for this thesis, however opportunistic methods, involving snowball sampling via clinicians, were later used to increase the response rate (Patton, 2002). Again, it is possible that clinicians that participated in the study had an interest in, and more favourable opinions of, Smart technology.

Maximum variation sampling was also used in the user-testing discussion group, however, as these participants had already taken part in research for this thesis, they may have had a vested interest in the app and therefore more favourable opinions than those who declined to participate. Additionally, the monetary incentive may have introduced bias as participants may have felt obligated to give positive feedback on the app. However, as in the qualitative studies, the candidate outlined the importance of honest feedback and the usefulness of a range of opinions.

A new sample of patients were recruited for the field testing study in this thesis. This prevented the possible bias that may have been introduced by using patients that had participated in the qualitative interview study. Initially, maximum variation sampling was used in order to gather a range of opinions of the use of the app in practice (Patton, 2002). However, the response rate was particularly low for this study and so this led to the use of convenience sampling. Those included in the study may have had more favourable opinions of Smart technology than those who declined, however nurses that were helping with recruitment informed the candidate that many patients at the CTU where they were recruited were poorly from participation in a clinical trial. The low response rate might also reflect patients' concerns about what is being asked of them (i.e. to learn something new) and or the burden it might place on them while they are undergoing treatment for cancer (i.e. having two visits from a researcher and having to use an app). It is possible that the studies have included participants who are more well and able to use an app during their cancer than those who declined to participate, and therefore inflated the feasibility of this type of intervention for patients with cancer in practice.

8.6 Recommendations for further evaluation

This section will outline the future for the intervention, including suggestions for feasibility and pilot testing, evaluation, and consideration of future implementation, as outlined by the MRC framework (Craig et al., 2008). The role of the intervention in relation to current policy initiatives will also be discussed.

8.6.1 App refinements and intervention mapping

Findings from the field testing study indicated some possible changes that could be implemented in order to improve the app prior to further testing. Additionally, the 'person-based' approach encourages researchers to carry out intervention mapping of behavioural determinants and behaviour change techniques (Yardley et al., 2015). The relevant theories outlined in this thesis could be used to map the behaviour determinants of the intervention and the behaviour change taxonomy could be used to code the specific behaviour change techniques embedded within the app (Abraham & Michie, 2008). At this stage, the person-based approach also suggests creating a logic model describing the hypothesised mechanisms of action of intervention (Yardley et al., 2015). However, as discussed in section 8.4.3, this process should consider the context in which the app will be used in relation to its causal mechanisms, in order to overcome the constraints of overly prescriptive frameworks and taxonomies.

8.6.2 Feasibility testing

Preliminary findings from a field testing study suggested that the 'Ask-Us app' is acceptable, however, further testing is required prior to pilot testing. Firstly, although the MRC framework suggests that a feasibility study need not be a scale model of a future evaluation, it should estimate the sample size required for a larger study and assess appropriate methods for recruitment (Craig et al., 2008). This would include estimates of the number and type of patients that would be eligible for the intervention and the willingness of clinicians to help identify eligible participants, as well as the response rate of the recruitment methods. Additionally, the study would be conducted across multiple sites to assess the feasibility in several locations.

Secondly, it is important to test the acceptability and feasibility of the intervention with samples of its key users. The 'Ask Us' app has been developed to be be used by both patients and relatives, therefore a feasibility study would recruit a sample of relatives to

use the app. It would be prudent to recruit dyads but also patients and relatives who plan to use the intervention individually in order to explore whether the intervention produces different effects on dyads compared to individuals. This study should also explore the perspectives of clinicians, particularly on the acceptability and feasibility of patients using the app during their consultations, as it is important to gain an understanding of the context in which the app is used and the potential influences on the intervention (Murray et al., 2016; Yardley et al., 2015). Clinicians' support is key to the successful implementation due to their role in encouraging patients' use of the app, particularly during consultations.

Thirdly, a feasibility study should assess the acceptability and suitability of the methods used. As suggested previously, it would be beneficial to used a mixed-methods approach that includes semi-structured interviews for in-depth assessment, a questionnaire to ensure breadth of information and app activity data to provide further insight into app use and compare this data to patients' explicit perceptions. For example, comprehension and usefulness of questions asked in qualitative interviews could be explored by conducting separate focus groups with samples of patients and relatives on the interview topic guide. Similarly, patterns of missing data or multiple responses on the questionnaire could be observed and explored with participants upon completion. Amendments of these methods could then be made accordingly. Finally, a feasibility study should record the time taken to recruit participants and the time required for older patients to learn to use the app, in order to estimate the time scale required for a larger pilot study.

Upon completion of feasibility testing, potential changes to improve the app that may have come to light during the study may be discussed with the project team. This allows for a more refined version of the app to be used during pilot testing. Additionally, barriers that were identified during the feasibility study may be considered and ways to circumvent or minimise these barriers can be implemented. If the feasibility study provides more evidence for the perceived usefulness of the app features, a think aloud study, where users use the app and talk through the process with a researcher, could be used to elicit and observe user reactions to each intervention element (i.e. app feature) (Yardley et al., 2015). This study would enable the iterative modification of the app in order to optimise its acceptability and feasibility prior to a pilot evaluation. Specific frameworks for evaluating the usability of mobile interventions in healthcare

may be used to guide the think aloud study. These frameworks might include the Health-ITUEM (Brown et al., 2013) and the PACMAD model (Harrison et al, 2013).

8.6.2 Pilot testing

Following completion of feasibility testing, the MRC framework encourages pilot testing of the intervention across multiple sites (Craig et al., 2008). A pilot study is designed to replicate a larger controlled trial on a smaller scale and is conducted to ensure that methods and study procedures run as intended, such as recruitment of participants, intervention implementation, and completion of baseline and follow up measures. A pilot study should also be randomised to allow assessment of the size of the intervention effects. This will enable the calculation of the sample size required for the main, larger controlled trial. Importantly, outcome measures for the main trial will be piloted during this study to provide preliminary insights into the intervention effects. Patients and their relatives would be randomised to one of two arms: an intervention arm where patients and relatives would receive the app following a diagnosis of cancer, and a control arm, where no intervention is received. In the intervention arm, patients and relatives would use the app running up to, and during, a consultation with their clinician, which would be audio-recorded. Again, it is important that dyads and individuals are recruited to the study to explore whether the intervention has different effects on each group. App activity data would be recorded by Google Analytics. The primary outcome would be levels of activation, with levels of anxiety as a secondary outcome (and proxy measure of psychological coping). Measures could include the State-Trait Anxiety Inventory form, a valid and reliable self-report measure of anxiety levels that has previously been used in mobile interventions for patients with cancer (Spielberger, 1983), and the Patient Activation Measure (PAM) questionnaire (Hibbard et al., 2004), which is the most commonly used measure, which has been found to be a scientifically valid and reliable tool to measure patient activation. The potential effectiveness of the app to improve patients' levels of activation and anxiety will be determined by analysing the differences between pre- and post-intervention PAM and anxiety scores. Audio-recordings of consultations would be transcribed *verbatim* and analysed using thematic content analysis. A subset of consultations would be further analysed with in-depth discourse analysis to gain an understanding of how changes in patient-clinician communication occur. App activity data, in combination with anxiety scores, PAM scores and audio-recordings, will help to determine the probable active components of the intervention.

8.6.3 Controlled evaluation

A larger, controlled evaluation could then be considered if pilot testing indicated that the intervention, study methods and procedures were acceptable and feasible. The MRC framework suggests the evaluation is in the form an RCT including the measures used in the pilot study, however completion of RCT can require years to validate the intervention, by which time technology may have advanced and cancer care and patients' requirements for an app may have changed. Researchers have argued that the timeline of an RCT is therefore incompatible with web- and mobile-based interventions (Mohr et al., 2013). A methodologic framework, Continuous Evaluation of Evolving Behavioral Intervention Technologies (CEEBIT), has been developed as an alternative method to support the evaluation of web- and mobile-based interventions (Mohr et al., 2013). The CEEBIT methodology works by taking advantage of the ability of mobile interventions to collect and transmit outcome and use data in real-time, thereby enabling the evaluation of multiple interventions or evolving versions of the same intervention provided by one deployment system (e.g., a clinical care organisation or commercial marketplace). By using real-time data, this method enables the identification and elimination of interventions, or older versions of a single intervention, that demonstrate poorer outcomes, and the entering of new interventions, or updated versions of a single intervention, at any time. This process facilitates the continuing evolution of a digital intervention, thereby providing patients with continually improving care. Irrespective of choice of method, a controlled evaluation would involve multiple national sites (e.g. Wales and England), and ideally international sites, in order to assess the generalisability of the findings. If the intervention is found to be effective, intervention implementation could be then considered.

8.7 Intervention implementation: consideration and challenges
8.7.1 Encouraging the adoption of the 'Ask Us' cancer app

The findings of the field testing study conducted for this PhD thesis highlighted the potential barriers to the successful implementation of the app in practice, including time since diagnosis, experience with Smart technology, patients' perceptions of the acceptability of app use in consultations and an avoidant coping approach. These findings highlighted the importance of presenting the app to patients at the earliest opportunity following diagnosis, in order for them to maximise the benefits of the intervention. Patients may be provided with information leaflets, booklets or websites

by the consultant or cancer nurse specialist when diagnosed in a consultation. A leaflet about the 'Ask Us' app and the benefits of using it could be created and presented to patients and relatives during this consultation. Alternatively, the 'Ask Us' app could be made publically available to download from the Tenovus Cancer Care website.

The field testing study also highlighted that some patients, most likely older patients, will lack knowledge and experience with Smart technology and so may require training in how to use the app. An in-app tutorial of how to use the app would be an inexpensive way to provide this training. However, older individuals might need more extensive training and time to learn to use the app. This could be provided in the form of manual instructions and a task list to keep costs down (Conci et al, 2009; Tang et al., 2013). Indeed, a previous study of older adults learning to use Smart technology found that they preferred to learn by trial and error (with on screen instructions) or by paper manual (Tang et al., 2013), both of which are cheap to implement. Alternatively, relatives of patients may use the app on behalf of patients who are unable to use the app (McCall et al., 2008). Similarly, for the minority of individuals that might not own a Smart device, they may access the app by using it on a relatives' device.

A further potential barrier to implementation of the app in practice is patients' perceptions of the acceptability of using an app during consultations with clinicians. The QPL feature of the app is intended to be used to prompt patients to ask questions during consultations. Findings from the field testing study in this thesis suggested that it would be useful to make clinicians aware of the app and its purpose so that they might encourage its use if patients present it at consultations. Patients in the field testing study suggested that they would feel comfortable using the app if their clinician approved of it and gave their permission. An information leaflet could be created and distributed to clinicians detailing the purpose of the app.

Some individuals might not be able to, or want to use, this type of technology due to being too poorly, or having preference of traditional methods of information-gathering or an avoidant coping approach (Leydon et al., 2000). However, relatives might use the app on the patients' behalf if they are too poorly to use it themselves. Additionally, this app was developed as a tool for those patients who want, and will benefit from, information on their condition. It is intended to supplement existing information

resources and interventions and to encourage patients to retrieve accurate and reliable information from their clinicians.

Finally, long-term maintenance of the app must be considered prior to wide scale implementation. It is anticipated that the app would be publically available to download from the Tenovus Cancer Care website and maintained by their information technology services. Additionally, the NHS has recently launched a website called the Digital Apps Library, which contains trusted apps that patients can use for their health and care (https://apps.beta.nhs.uk) (see section 8.7.2). Currently, there is only one app for cancer patients listed, the 'OWise Breast Cancer App', which enables patients to track their treatment and wellbeing. To be listed on this website, an app must be available in either Apple, Google or Microsoft App Stores as the library does not host apps, it only provides links to the stores. Additionally, an app must be approved by the NHS following submission of sufficient evidence of its effectiveness, safety and usability (i.e. a controlled trial) (more information can be found here https://apps.beta.nhs.uk/about-us/).

8.7.2 Policy considerations

The development of an app that enables patients and their relatives to meet their information needs in non-inpatient settings follows the objectives set out by the UK Government and National Health Service plans, such as the National Cancer Strategy and Cancer Delivery Plan, which highlighted information provision as one of their key priorities (DOH, 2011; 2013; Welsh Government, 2016). Additionally, the development of an app that may be useful for relatives, as well as patients, supports the objectives of recent cancer policies, the NHS and cancer organisations, which encourage the development of interventions that consider and support patients' families (DOH, 2011; 2013; Welsh Government, 2016).

The UK government has encouraged the integration of mobile interventions into traditional healthcare services since the early 2000's (DoH, 2006; Liddell et al., 2008). However, key reviews over the last few years, such as NHS Five Year Forward (NHS England, 2014) and the Wachter review (Wachter, 2016), have highlighted the importance of, and urgent push for, digitisation in the NHS, in order for it to continue to provide a high level of healthcare at an affordable cost. In 2016, Jeremy Hunt stated that more than £4 billion had been set aside to support digital and technology projects

in the NHS, including £1.8 billion to meet the ambition of a paperless NHS (Honeyman, Dunn & McKenna, 2016).

The Next Steps on the NHS Five Year Forward View report (NHS, 2017) outlines the commitment of the organisation to support the implementation of healthcare apps that enable patients to manage their health remotely. In April 2017, the NHS launched two new digital platforms, NHS Digital Apps Library for patients and clinicians and a 'mobile health space' for app developers on www.developer.nhs.uk. The apps have been designed and tested to support the self-management and prevention of health related conditions. The NHS Apps Library have created a Digital Assessment Questionnaire and review process that enables app developers to provide information and evidence for the safety and effectiveness of the apps. This process is currently being tested. Once an app assessment has been completed, it will go through a pre-assessment process at NHS Digital to determine if the app is suitable. If it qualifies, the developer will be invited to take part in the self-assessment by answering the digital assessment questions. This will then be reviewed by subject matter experts, who are specialists in various fields (e.g. clinical safety, data security). If an app successfully satisfies the assessment criteria, it will go through a process that will lead to publication on the NHS Apps Library.

8.8 Conclusion

The body of work completed for this PhD thesis identified patients' (and their relatives') needs and preferences regarding an app to help them to meet their information needs, and the psychosocial context that underpinned these perceptions. This thesis also provided insight into clinicians' perceptions of the value of an app for patients and their relatives and the type of app that they anticipated to be useful. The 'Ask Us' cancer up was created on the basis of these findings and was found to be an acceptable platform to deliver interventions to patients in non-inpatient settings, although further exploration is required with a sample that is more representative of the general cancer patient population to add weight to these findings. This type of intervention has the potential to provide a range of benefits to a variety of patients and preliminary findings did not indicate any disadvantages of app use. Potential barriers that were identified were mostly considered temporary, due to the rapid diffusion of new technology in the general population and healthcare, and can be considered and minimised prior to implementation. There is potential for this intervention to be listed on the NHS Digital

Apps Library to provide patients and relatives with free access to the app. The work conducted for this PhD project, and the creation of the 'Ask Us' cancer app, support the recent policies and objectives set out by the government and NHS in the UK to enable patients and their families to take a more active role in their care and to harness the power of health information technology in order to do so.

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