Development and evaluation of a novel virtual agent-based app for patients with colorectal cancer: A mixed methods study

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Abstract

Background and aim: Information support is an integral part of cancer care, but its provision can be problematic in busy health settings. The aim of this project was to develop and evaluate a health app to facilitate the provision of information support in newly diagnosed patients with colorectal cancer (CRC). Instead of delivering information using text, three animated embodied virtual agents (VAs) were deployed. The VAs were formulated after patients' treating clinicians (male oncologist, female nurse and female pharmacist) to explore the role of familiarity, which has not been addressed in previous research.

Study methods: A multi-stage development process was followed for the app, which was provided to the study participants before the beginning of their treatment. A convergent parallel mixed methods design involving pre- and post-exposure questionnaires (adapted versions of the Toronto Information Needs Questionnaire and the System Usability Scale), app usage data and semi-structured interviews was deployed to evaluate the intervention.

Results and discussion: The app was acceptable by the end users and had a good degree of usability (mean System Usability Scale score=73.89). The information content was appropriate and met patients' demands to a moderate extent; this was because patients utilised other information sources (e.g., printed material) to address their needs. Incorporating supportive functions such as a medicinal calendar in addition to the information content emerged as an important aspect.

The inclusion of VAs was deemed to be appropriate. The VAs fostered a sense of presence, added trustworthiness to the information content and were perceived as more interactive than reading text. Having a VA representing a familiar clinician was favoured by most users. The vast majority of patients perceived the VAs as cartoon figures and suggested that they should be improved to look realistic in order to give the impression of having an exchange with a real person. Natural voices were preferred over synthetic speech.

Conclusion: VA-based mHealth interventions are an acceptable way of supporting patients with CRC. Appropriate consideration should be given to the requirements of the intended user audience to design acceptable interventions that reflect their needs.

Keywords: Virtual Agents, Embodied Conversational Agents, Information Support, Bowel Cancer, Mobile Healthcare

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List of abbreviations

5-FU- 5-Fluorouracil

AC- Alexandros Chatzixenitidis

AG- Alison Gifford

AI- Artificial Intelligence

AR- Augmented Reality

BD- Twice Daily

BMI-Body-Mass Index

BNF- British National Formulary

CCG- Clinical Commissioning Group

CEA- Carcinoembryonic antigen

CH-Charles Hay

COPD- Chronic Obstructive Pulmonary Disease

CRC- Colorectal Cancer

CRUK- Cancer Research UK

DTU- Day Treatment Unit

ECA-Embodied Conversational Agent

ECG- Electrocardiogram

ELM- Elaboration Likelihood Model

eMC- Electronic Medicines Compendium

EORTC - European Organisation for Research and Treatment of Cancer

FACT-C- Functional Assessment of Cancer Therapy-Colorectal

GA-Google Analytics

GCP- Good Clinical Practice

HADS- Hospital Anxiety and Depression Scale

HIV-Human Immunodeficiency Virus

HR-QoL- Health-Related Quality of Life

HRA-Health Research Authority

INQ-Information Needs Questionnaire

IRAS- Integrated Research Application System

IV- Intravenous

LASA-Longitudinal Aging Study Amsterdam

MARS- Mobile App Rating Scale

MM- Mixed Methods

MOS-Medical Outcome Study

MRC- Medical Research Council

NHS- National Health Service

NICE- National Institute for Health and Care Excellence

NIHR-National Institute of Health Research

NLP-Natural Language Processing

NS-Nicola Stoner

OB-Opeyemi Babatunde

OS- Operating System

OUH- Oxford University Hospitals

PC- Personal Computer

PCC-Patient- Centred Communication

PDA- Personal Digital Assistant

PRO-Patient Reported Outcome

PROSPERO-International Prospective Register of Systematic Reviews

QoL- Quality of Life

QUAL- Qualitative

QUAN- Quantitative

RCT- Randomised Controlled Trial

R&D- Research and Development

SC- Stephen Chapman

SCNS- Supportive Care Needs Survey

SDK- Software Developer's Kit

SMEs- Small and Medium Enterprises

SS- Semi- Structured

SSIG- Semi-Structured Interview Guide

STAI- State-Trait Anxiety Inventory

SUS-System Usability Scale

TINQ-Toronto Information Needs Questionnaire

UKONS-UK Oncology Nursing Society

VA- Virtual Agent

VLE- Virtual Learning Environment

Chapter 1: Background, Conceptual Framework and Aims

This chapter will present the background and the conceptual framework of this study. The first section will delve into the domain of information support in patients with cancer, alongside the issues experienced in this field. The second part will briefly explore the field of mobile healthcare and the third part will investigate the application of simulation in patient education. The final section will explain how these aspects were brought together to formulate the core idea of this research project, followed by its aims and objectives.

1.1. Responding to and coping with a diagnosis of cancer

"*Few words can evoke such an immediate, life-threatening reaction as the word cancer*."

(Mills and Sullivan, 1999, p.631)

Albeit the remarkable progress in the field of oncology, cancer still remains the most feared condition (Murphy et al., 2018). In a recent publication, Vrinten et al. (2017) revealed that cancer is regarded as a "*vicious, unpredictable and indestructible enemy*" (p.1070) that poses a major health concern. The authors suggested that the main fears around cancer are associated with the propinquity of the disease, the lack of strategies for preventing its onset, the implications (physical, mental and social) of the condition and ultimately, the mortality of cancer.

Considering the public views on cancer, it is reasonable to predict the impact of being diagnosed with the illness. Patients receiving a positive diagnosis of a malignant

condition can experience considerable distress and anxiety at this stage (Cardoso et al., 2016). Such feelings can stem from a sense of losing normality (Stegenga and Ward-Smith, 2009), uncertainty about the future (Sharpley, Bitsika and Christie, 2018) or even embarrassment (Iredale et al., 2006).

Patients with cancer do not only have to face the stress caused by the diagnosis of their condition, but they also have to deal with the potential effects of their imminent treatment (Adler and Page, 2008). In order to come to terms with this situation, patients can deploy several coping strategies. Among a number of copying styles, the model proposed by Lazarus and Folkman, (1984) is particularly popular in cancer research (Otaghsara et al., 2018). In their work, the authors suggested two types of coping, namely *problem-focused* and *emotion-focused coping*.

The emotion-focused approach describes an attempt to control stressful emotions through contextual cognitive reconstructions or by disregarding the stressor itself. Examples of such efforts include keeping a positive attitude (Asiedu et al., 2014), engaging in wishful thinking (Sajadian et al., 2017) and seeking spiritual support (Gall, Miguez de Renart and Boonstra, 2000). Denial, in the form of ignoring the condition (Kim et al., 2002) or refusing that cancer is there (Vos et al., 2011) is also a highly prevalent type of emotional coping.

Individuals deploying the problem-focused approach endeavour to take control over a stressful situation by modifying the stressor itself. This includes seeking social and emotional support (Kvillemo and Bränström, 2014), establishing an action plan (Miedema, Hamilton and Easley, 2007), setting goals (Clayton et al., 2005), holding discussions about the condition and day-to-day life (Elsheshtawy et al., 2014) and

seeking alternative treatments (Mosher et al., 2015). Last, but certainly not least, is seeking information about their condition and its treatment. Information-seeking is indeed an important aspect for patients dealing with cancer (Radina et al., 2011).

1.2. Information support in patients with cancer

This section will provide an overview of the information behaviour of patients with cancer. The first part will outline the most common reasons that drive patients to seek information. Then, the sources through which information is retrieved will be presented, followed by the types of information that patients wish to receive, as well as factors associated with patients' information behaviour. Finally, the issues encountered in this domain will be presented, alongside the efforts made to address them.

1.2.1. The importance and benefits of information support in cancer

Providing adequate, accurate and trustworthy information is considered to be a vital component of patient-centred care (Gattellari, Butow and Tattersall, 2001). The disclosure of information is among the highest priorities in the National Health Service's (NHS) cancer strategy, which urges healthcare professionals to ensure that the information demands of patients with cancer are met efficiently and effectively (DoH, 2000, 2007).

Effective information support can provide theoretical, as well as practical benefits. With regards to the theoretical benefits, the provision of information increases patients' understanding of their condition and treatment, which in turn enables them and even encourages them to get involved in their own care (Dy and Purnell, 2012). This can help healthcare more away from a paternalistic model and transition it in a system where

informed patients will be able to take part in treatment-related decisions (Gaston and Mitchell, 2005).

Effective information support can also exert a positive influence upon the quality of patients' care (i.e., practical benefits). A systematic review suggested that patients who had their information demands fulfilled achieved better Health-Related Quality of Life (HR-QoL) and greater satisfaction with care than those who received less effective support (Husson, Mols and van de poll-franse, 2011). Patients who received effective information support also demonstrated increased compliance with treatment and were able to effectively manage adverse events (Blödt et al., 2018).

1.2.2. Reasons for seeking information

There are several reasons that drive patients to seek health-related information. Loiselle, Lambert and Cooke (2006) suggested that the receipt of a cancer diagnosis can prompt patients to look for information in order to familiarize themselves with what that diagnosis entails. Patients can seek information in order to reduce uncertainty and achieve a sense of control over their illness (Nanton et al., 2009), as well as the effects of their upcoming treatment (Ziebland et al., 2004). Becoming knowledgeable is also important for participating in the decision-making process (Dy and Purnell, 2012).

The acquisition of knowledge also necessary for communicating with health providers, as it enables patients to discuss disease and treatment-related aspects with greater confidence (Lambert, Loiselle and Macdonald, 2009b). For some individuals, the receipt of 'positive information' is a mechanism for maintaining hope (Loiselle, Lambert and Cooke, 2006). After the end of treatment, patients can seek information in order to

resume a sense of normality either through guided advice (Tsuchiya and Horn, 2009) or by exploring the experiences of fellow patients (Mccaughan, Parahoo and Prue, 2011).

1.2.3. Sources of information

An early review revealed that patients with cancer can consult with healthcare professionals, access printed material (e.g. brochures, publications) and utilise interpersonal sources (e.g. friends, family and fellow patients) to obtain information (Rutten et al., 2005). Subsequent studies indicated the importance of the internet as a resource, the use of which increased considerably since the early 2000's (Chua, Tan and Gandhi, 2018). Mass media (e.g., radio, television, newspapers) have also been mentioned; information obtained through them is referred to as *incidental* information, since patients receive it without actively searching for it (Muusses et al., 2012).

Healthcare professionals appear to be the most preferred reference (Andreassen et al., 2006; Nagler et al., 2010; Mekuria, Erku and Belachew, 2016). Research that explored this attitude suggested that patients express high preference towards health professionals due to trust in their knowledge and expertise (Wright, Holcombe and Salmon, 2004), as well as the belief that they act in the patient's best interest (Andreassen et al., 2006).

1.2.4. Types of information

Several authors attempted to synthesise findings from this evidence base in order to provide an overview of the information that patients wish to receive, as well as to determine which information is most important to them. This includes systematic

(Rutten et al., 2005; Lim et al., 2017), scoping (Van Mossel et al., 2012) and critical reviews (Echlin and Rees, 2002).

An observation made by several authors was that patients tend to focus upon different types of information across the treatment trajectory. Prognostic and cancer-specific information appear to be important at the diagnosis/early treatment phase, but higher value is placed upon rehabilitation- related information in the post-treatment stage (Rutten et al., 2005; Lim et al., 2017). An exception to this is treatment-related information (e.g., medicines, side effects, duration of treatment etc.), which appears to be the most important type of information and is sought across all stages in the cancer care continuum.

1.2.5. Information avoidance

In the UK, a large multi-centre study suggested that almost 90% of patients with cancer wished to receive all available health-related information, regardless of whether they constituted 'good' or 'bad' news (Jenkins, Fallowfield and Saul, 2001). Yet, some patients can refrain from actively seeking information, while others might choose to avoid it altogether (Nagler et al., 2010).

Demographic factors such as age, gender, education and income can play a role in information avoidance (McCloud et al., 2013). There are also several reasons that make patients avoid cancer- related information. First, some patients can feel that they don't possess adequate intellect in order to process and understand health-related information, while others can regard information-seeking as a transgression to their role as patients (Leydon et al., 2000). The fear of receiving conflicting information or

coming across information that could compromise hope is another negating factor (Loiselle, Lambert and Cooke, 2006). Finally, some avoid seeking further information after the end of treatment, as doing so helps them towards returning to their normal lives before cancer (Lambert, Loiselle and Macdonald, 2009b).

1.2.6. Challenges in information support for patients with cancer

Although information support is accepted as an important aspect of cancer care, its delivery can be suboptimal. In fact, several reviews identified information as one of the most prominent unmet needs among patients with cancer (Harrison et al., 2009; Kotronoulas et al., 2017). As a result, patients often have to search for information on their own, which can be both burdensome and place them at risk of receiving information of questionable quality (Mills and Davidson, 2002).

A series of UK studies suggested that the limited availability of time in health environments can hinder the provision of effective information support. Stafford et al. (2001) reported that 84% of clinicians provided patients with their diagnosis and discussed treatment options in the course of 15 minutes. Manning and Dickens (2007) suggested that due to timely pressures on behalf of the clinicians, the delivery of information was performed without the chance of integration. Newell et al. (2004) demonstrated that patients also perceived time constraints as an obstacle that prevented them from receiving the information they wanted.

Poor communication is another prominent barrier. Eastman (2019) pointed out that health professionals might not necessarily possess the communication skills required in order to effectively engage with patients. Furthermore, providers can be reluctant to

discuss information, as some consider that full disclosure can diminish patients' hopes and raise anxiety (Gordon and Daugherty, 2003). Patient-related factors can also hinder the communication process. For instance, a low level of health literacy has been reported to hinder patients' understanding (Halbach et al., 2016). Moreover, patients might not clearly communicate their information demands and consequently, providers are unable to respond to address these (Neumann et al., 2011).

The relevance of information is also a major factor in providing effective support. Determining patients' demands is key towards providing appropriate counselling, but is often neglected in practice (Sainio and Eriksson, 2003). Although most patients appear to pursue as much information as possible, aspects such as the level of detail, the timing and type of information vary considerably across individuals (Leydon et al., 2000). Rood et al. (2017) proposed that the assessment of information needs should be performed on an individual basis and that a 'one size fits all' approach is not an effective way of providing information support.

1.2.7. Interventions for information support in cancer care

The issue of poor information support has been noted and a number of interventions for facilitating the provision of health information has been investigated. The findings of such studies have been summarised in several systematic reviews, which identified four types of interventions; audiotapes (Gaston and Mitchell, 2005; van der Meulen N et al., 2008), videotapes (Gysels and Higginson, 2007; van der Meulen N et al., 2008; Thygesen, Nicolaisen and Mogensen, 2015), computerised/interactive programmes (McPherson, Higginson and Hearn, 2001; Salonen, Ryhänen and Leino-Kilpi, 2014) and

written material (Gaston and Mitchell, 2005; McPherson, Higginson and Hearn, 2001; van der Meulen N et al., 2008).

A common consideration across all education techniques was the element of personalisation. Tailoring the content of these interventions was key for their success, as most authors suggested that interventions whose content was adjusted to the unique needs of each participant were more successful than those that provided general information. An important finding by Gaston and Mitchel (2005) was that audiotapes with general information in fact caused confusion to patients rather than aiding their understanding.

Another observation was that non-interactive education techniques were accompanied by several drawbacks. For instance, Gaston and Mitchell (2005) explained that oncologists might be reluctant to record their meetings with patients, as this could give rise to confidentiality issues and impede the consultation process. The same authors also argued that producing personalised written material would increase the workload of clinicians, who are under considerable time pressures in busy environments. Videotapes and recordings can also be problematic, as they can structure information in a pre-determined and linear fashion that may not be adapted to individual patients' needs (Gysels and Higginson, 2007).

Interestingly, computerised programmes and interactive technologies appeared to be unaffected by many of these issues. McPherson et al. (2001) pointed out that computer-based interventions allow users to control the amount of information, which can increase the degree of personalisation. Gysels and Higginson (2007) explained that interactive programmes can facilitate users' learning, as the content of these

interventions "*can be matched according to a patient's preferences, needs and coping style*." (p.19). In fact, the same authors concluded that interactive technologies produced, in some cases, superior results when compared to conventional methods of educating patients such as booklets and audiotapes. A subsequent review also remarked upon the favourable results of this technology in patients' knowledge, as well as the potential cost-effectiveness (Salonen, Ryhänen and Leino-Kilpi, 2014).

1.2.8. Summary

Information support is an integral part of cancer care. Yet meeting these needs still remains a challenge. Several interventions have been deployed to support patients, but most are accompanied by several drawbacks that would make their implementation challenging. In recent years, the introduction of novel technologies has opened new opportunities for reaching patients and offering support. One of these is mobile healthcare, which involves the use of mobile devices to facilitate the delivery of health services. The next section of this chapter will briefly explore the development of mHealth and its application in cancer care.

1.3. Mobile healthcare

This section will provide an overview of mHealth with a specific focus upon health apps. First, the development and application of mHealth will be briefly presented, followed by the potential benefits and limitations of this technology.

1.3.1. Definition of mobile healthcare

In an early publication, Laxminarayan and Istepanian (2000) characterised mobile healthcare (mHealth) as 'unwired e-med'. Up to date, a standardised term has not been established. This study has adopted the definition offered by the World Health Organisation's (WHO) Global Observatory, according to which mHealth is "*the medical and public health practice supported by mobile devices, such as mobile phones, patient monitoring devices, personal digital assistants (PDAs), and other wireless devices*" (WHO, 2011, p.6). Examples of mHealth interventions are presented in figure 1.1 (adopted from *Hiplink,* 2019).

Figure 1. 1: Examples of mHealth interventions

1.3.2. Development of mobile healthcare

Ali, Chew and Yap (2016) performed a review of the types of mHealth interventions used between 2007 to 2015 in three distinct periods (before 2007, 2007-2012 and 2013 onwards). According to the authors, the types of interventions used in each period

depended upon the predominant technology at the time. PDAs were the most prominent interventions before 2007, while health apps started to gain leverage until 2012 and ultimately, dominated the mHealth research scene since. This is understandable, considering that the introduction of smartphones, tablets and wearables (e.g. smart watches), as well as the increased affordability of such devices facilitated the uptake of this technology in both developed and developing countries (Al Bawab, Al Qahtani and McElnay, 2018).

In less than one decade since the introduction of commercially available health apps, more than 310,000 interventions are now available through the App and Play Stores (Larson, 2018). Indeed, the market for mHealth has witnessed an exponential growth in recent years. The current size of the global mHealth market is around $46bn (almost double in comparison with 2017), with projections estimating as much as $245bn by 2026 (Statista, 2019). The increased interest around mHealth has sparked a substantial amount of research, as well as reviews to summarise the resulting body of evidence and suggest further steps.

1.3.3. Applications of mobile healthcare

Kao and Liebovitz (2017) offered several examples of commercially available health apps and proposed six broad categories, namely "*wellness management, disease management, self-diagnosis, medication reminders, electronic patient portals and physical medicine/rehabilitation*" (p.108). These interventions provide users the opportunity to retrieve health information, keep track of symptoms and/or measurements (e.g. weight, insulin levels) and network with other users, as well as healthcare professionals. Kamel Boulos et al. (2014) also presented several examples of

health apps aimed for healthcare professionals. These apps are designed to help professionals access electronic health records, enhance communication, facilitate decision-making, manage appointments, monitor patients and assist learning.

Health apps have been applied in several therapeutic areas. Examples include diabetes (Kitsiou et al., 2017), heart disease (Giebel and Gissel, 2019), kidney disease (Stevenson et al., 2019), COPD (McCabe, McCann and Brady, 2017), HIV (Aranda-Jan, Mohutsiwa-Dibe and Svetla Loukanova, 2014) and mental health (Sucala et al., 2017). Apps have also been used to encourage healthy behaviours such as weight management and healthy eating (Müller et al., 2016) smoking cessation (Ghorai et al., 2014), promote treatment adherence (Svendsen, Andersen and Andersen, 2018), facilitate the delivery of healthcare services (Free et al., 2013) and improve sexual health outcomes among patients with long-term conditions (Karim et al., 2020)

Unsurprisingly, a considerable amount of research exploring the application of apps in the field of cancer has also been conducted. Several reviews investigated interventions targeting specific types of cancer, as well as generalised supportive tools in oncology. Cancer-specific research includes interventions for patients with skin (Choi, Cho and Woo, 2018), breast (Cruz et al., 2019), and prostate (Rincon et al., 2017) cancer, as well as paediatric cancers (Ramsey et al., 2020). Other authors summarised findings from peer-reviewed literature around the topic (Osborn et al., 2020), performed an investigation of apps that aimed to provide information support (Richards et al., 2018), or explored interventions for improving outcomes in survivors of the disease (Hernandez Silva, Lawler and Langbecker, 2019). There is also an ongoing systematic review exploring apps for screening and awareness of breast cancer (Ruco et al., 2020).

1.3.4. Potential benefits

In an early opinion paper, Tachakra et al. (2003) provided an overview of the advances in telemedicine and identified a number of benefits for mHealth. A decade after, Steinhubl, Muse and Topol (2013) remarked upon mHealth's potential to drastically transform the healthcare environment. The authors suggested that the unsustainability of healthcare's spending model in healthcare necessitates drastic solutions and proposed that mHealth can help reduce costs by limiting the number of unnecessary health visits in acute conditions, as well as by offering the capacity for effective monitoring and limit complications in chronic diseases. Later publications have also remarked upon such benefits (Kitsiou et al., 2017; Giebel and Gissel, 2019). Madanian et al. (2019) also reflected upon the opportunity of managing demanding healthcare services by integrating a large amount of data through mHealth.

One of mHealth's most prominent potential is the improvement of access to healthcare. In their report, the WHO pointed out that shortages in the health sector can limit peoples' access to care (2011); this was true not only for developing countries, but also for underserved areas in rich nations. According to the report, mHealth could potentially help patients connect with health providers in both urban and rural areas, thus improving the quality of care and eliminating unnecessary referrals. In a subsequent review of mHealth initiatives in African nations, it was suggested that the low cost and accessibility of such technologies were key factors explaining the success of these interventions (Aranda-Jan, Mohutsiwa-Dibe and Svetla Loukanova, 2014). Later studies suggested that mHealth initiatives yielded promising results in developing

(Stephani, Opoku and Quentin, 2016), as well as developed countries (Anderson-Lewis et al., 2018).

MHealth can also offer considerable benefits on an individual level. Steinhubl, Muse and Topol (2013) proposed that mHealth can grant the opportunity of effectively monitoring conditions and preventing complications, while Kamel Boulos et al. (2014) argued that it can help users receive personalised care. Later publications suggested that mHealth can improve patients' access to information (Lubberding et al., 2015), foster a sense of autonomy (Young-Afat et al., 2016), enhance their communication with health professionals (Husted et al., 2018) and promote self-management (Desveaux et al., 2018).

In addition to the potential benefits for patients, mHealth can also assist healthcare professionals. Steinhubl, Muse and Topol (2013) proposed that mHealth can help reduce clinicians' involvement in algorithmic procedures, thereby relieving them from a substantial amount of workload. The same authors explained that this would also enable them to attend more closely to their patients, which could potentially enhance their relationships; this was also apparent in a study involving HIV providers, who added that such interventions could improve the coordination of care (Swendeman et al., 2016). In a recent paper, Mesko and Győrffy (2019) added that digital interventions could help improve diagnostic accuracy and enhance the efficiency of treatments.

1.3.5. Pitfalls and limitations

A series of Cochrane reviews has pointed out that there is not enough evidence for informing policy makers, healthcare professionals and members of the public on the

effectiveness or reliability of mHealth interventions. This was because of the absence of literature around certain interventions (Badawy et al., 2017), the limited number of studies, conflicting results and a lack of a strong evidence base due to the inability to synthesise findings (Belisario José S et al., 2013). While some promising evidence is available for patients with COPD (McCabe, McCann and Brady, 2017), kidney disease (Stevenson et al., 2019) and smoking cessation (Marcolino et al., 2018), the authors advised that such results should be interpreted with caution, as aspects such as the long-term effects or cost-effectiveness of such interventions has not been determined. The same would also apply to mHealth interventions in the field of oncology.

The safety and appropriateness of such interventions is another important consideration. According to Paglialonga, Lugo and Santoro, (2018) only apps that constitute medical devices are subject to robust regulatory frameworks that demand rigorous evaluation, testing and monitoring. As most commercially available health apps do not fall under this category and are thereby not obligated to abide by the same quality standards, important concerns about their trustworthiness have been raised. A recent scoping review revealed several concerns with regards to the quality of content, including incorrect and incomplete information, incorrect output (e.g. calculations and diagnostics) and innapropriate response to users' needs (Akbar, Coiera and Magrabi, 2020). Security and privacy are also important considerations. O'Loughlin et al. (2019) pointed out that the vast majority of commercially available apps identified by their study did not have adequate security and privacy policies in place; this finding is in line with previous research. In a recently conducted survey, security and privacy were

identified as major barriers from a user perspective, indicating that developers still haven't paid close attention to this matter (Zhou et al., 2019).

1.3.6. Summary

MHealth holds considerable promise for supporting the needs of patients and the public. At the same time, it should be noted that the field of mHealth is not without concerns regarding safety and effectiveness. Such ambiguity can hinder its effective implementation, since stakeholders and policymakers are unlikely to engage and take such approaches forward (Chib, Van Velthoven and Car, 2015). It is hence important to build robust interventions and conduct high-quality research in order to build a strong evidence base, thus strengthening the potential for its effective uptake.

Another key consideration is the place of mHealth interventions in patient care. A recent review suggested that patients indeed favour the use of health apps, but they regard them as tools that can *strengthen* their relationships with providers rather than means of *replacing* them (Vo, Auroy and Sarradon-Eck, 2019). Indeed, the capabilities of health professionals "*comprise personal attributes, including attitudes, practical skills, and soft skills, which mHealth apps cannot currently replace*" (Wattanapisit et al., 2020, p.11); despite the promise of supportive interventions, the involvement of health professionals in patient care is crucial. Yet this brings us back to the issue of health professionals' limited availability. Is it possible to enhance their presence in patients' care while keeping their *actual* involvement to a minimum? Although this question suggests a paradox, simulation could potentially provide an answer.

1.4. Simulation in patient care

Simulation is defined as "*a situation in which a particular set of conditions is created artificially in order to study or experience something that could exist in reality*" (Oxfrod Dictionalry, 2021). Silva et al. (2010) presented several examples of systems in which simulation has been applied and remarked upon its potential to be used in practically any area that "*fits the concepts of simulation modelling*" (p.429). In healthcare, this term is often used in the context of professional education and student learning, with examples such as simulated patients (Dafli et al., 2019; Lee and Berge, 2011) and virtual learning environments (Humphreys, Rosenorn-Lanng and Bracegirdle, 2014).

Although the term *simulation* has rarely been used explicitly in the context of patient education and support, interventions that simulate interaction to support patients' learning and enhance their care are indeed evident. This part will briefly explore the application of simulation in patient education and support.

1.4.1. Virtual learning environments

The first example of virtual learning environments (VLEs) in patient support can be traced in the mid-90s, where Rothbaum et al. (1995) explored the efficacy of a novel treatment for acrophobia (fear of heights). In this randomised study, college students of the treatment group demonstrated significant improvements. A subsequent study by Wiederhold et al. (2002) compared a virtual reality (VR) approach to a standard treatment for fear of flying and identified significant differences suggestive of superiority in the virtual reality group, while Ku et al. (2007) showcased the benefits of a VR training course for patients with schizophrenia. Although these studies involved a

small number of participants, they demonstrated the potential of VR as a promising educative platform for patients.

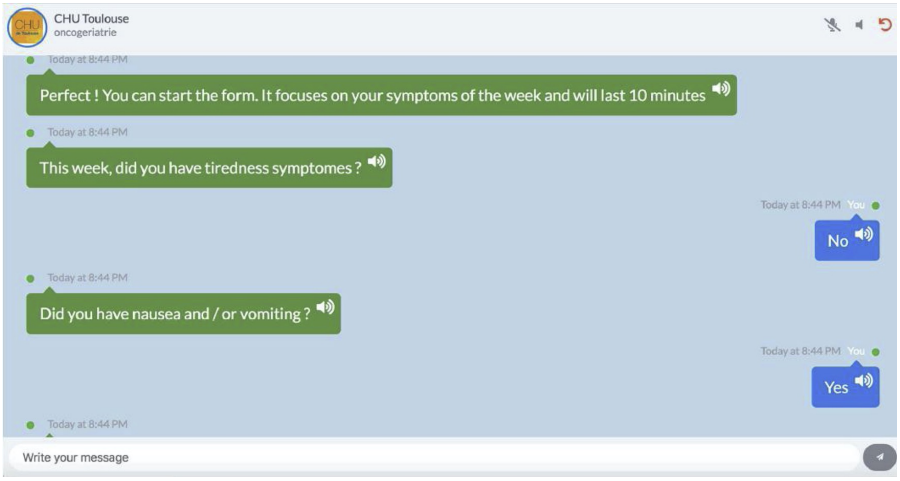
An important leap in making VR platforms readily available to patients and the public was the release of Second Life, an online augmented reality (AR) environment where users can create their avatars (i.e., a virtual representation of themselves) and interact with the avatars of other users. Using this platform, health and governmental agencies have created 3D-VLEs such as the *HealthInfo Island,* where patients and the public can receive high quality, evidence-based information (Boulos, Hetherington and Wheeler, 2007; Kamel Boulos et al., 2008). A recent study demonstrated the benefits of using Second Life to support patients with type 2 diabetes, while the potential of using this approach for other chronic conditions was also noted (Lewinski et al., 2018).

1.4.2. Chatbots and conversational agents

Chatbots be broadly described as "*computer programs that simulate conversations with users*" (Tudor Car et al., 2020) and are also known as "*conversational agents, interactive agents, virtual agents, virtual humans, or virtual assistants*" (Palanica et al., 2019). This technology made its first appearance in 1966 with ELIZA, a computer program that played the role of a psychotherapist and was capable of textual communication with users without the need of an operator (Weizenbaum, 1983). Shortly after, Kenneth Colby created PARRY, a chatbot designed to behave as a patient with schizophrenia to assist learning in young psychiatrists (Colby et al., 1972). Over time, several artificial intelligence (AI)-based programs emerged and in recent years, the introduction of systems such as Alexa (Amazon), Siri (Apple) and Google Assistant (Google) have made this technology widely available to the public (Zemčík, 2019).

Conversational agents can respond to users' textual or verbal input via text or speech; figure 1.2 (adopted by Piau et al., 2019, p.20) presents an example of an agent that provided a written reply, which was also available in audio format.

Figure 1. 2: Example of a chatbot communication interface



While some interfaces provide users with a number of fixed choices and respond in a pre-determined fashion (e.g., L'Allemand et al. 2018), others offer tailored responses according to the users' unique input; the latter is referred to as *natural language processing* (NLP) (Swartout et al., 2006). In their review, Laranjo et al. (2018) argued that there has been increased interest towards conversational agents equipped with NLP, as this allows for more sophisticated exchanges compared to interfaces with restricted user input and agent output. According to Milne-Ives et al., (2020) unconstructed NLP can simulate human interaction with considerable fidelity and give the impression of a real conversation.

Tudor Car et al. (2020) pointed out that while initially referred to simply as 'talking computers' in the field of healthcare, these interventions have grown considerably in sophistication. To date, chatbots and conversational agents have been used to support

patients in several therapeutic areas, including asthma (Rhee et al., 2014), type 2 diabetes (Griol, Carbó and Molina, 2013), mental health (Fitzpatrick, Darcy and Vierhile, 2017), medication adherence and management (Lobo, Ferreira and Ferreira, 2017) and autism spectrum disorders (Ly, Ly and Andersson, 2017). Chatbots have also been used with the general public to offer health advice (Liu and Sundar, 2018) and promote obesity management (L'Allemand et al., 2018) .

1.4.3. Embodied conversational agents

Embodied conversational agents (ECAs) are a type of conversational agents defined as "*animated computer characters that simulate face-to-face conversation with users*" (Bickmore *et al.*, 2005, p.712). As the term suggests, ECAs deploy embodiment, or at least some kind of visual representation in order to communicate with users using non-verbal ques such as facial expressions and/or gestures in addition to verbal or textual communication (Provoost et al., 2017). An example of an ECA is presented in figure 1.3 (Lisetti et al., 2013, p.194).

Figure 1. 3: Example of an ECA

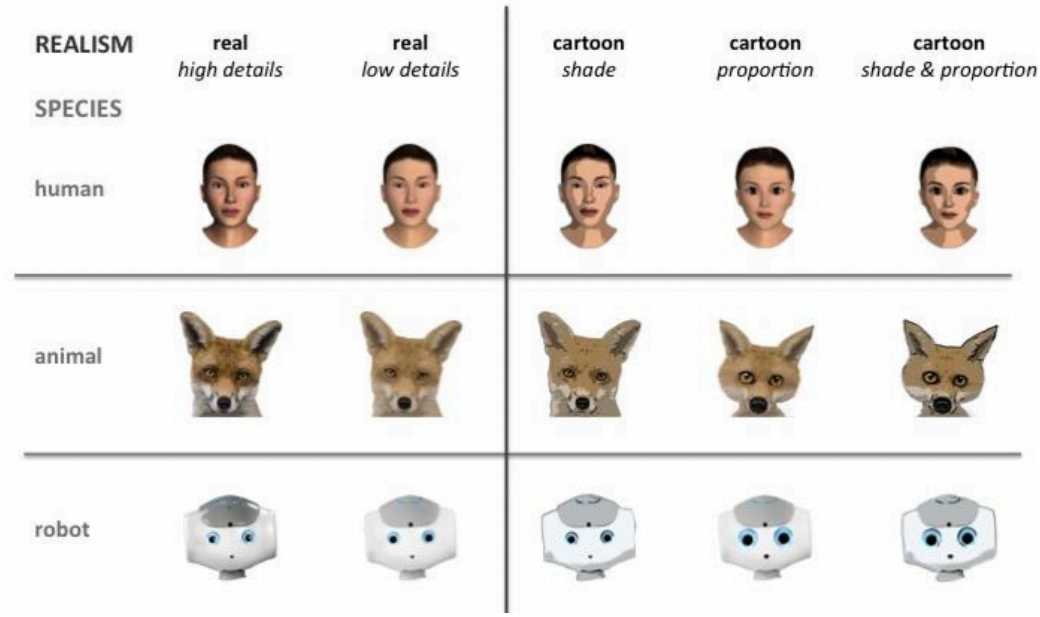
In the domain of healthcare, ECAs have been used in a number of health interventions; examples include COPD (Easton et al., 2019), diabetes (Gong et al., 2020), mental health (Lucas et al., 2017) and clinical psychology (Provoost et al., 2017). Keele University, in collaboration with the Stoke-on-Trent Clinical Commission Group (CCG) has created Manage your Health, an app that offers information and advice for a range of conditions using an ECA that portrays a healthcare professional (Keele University, 2021).

Bickmore et al. (2018) proposed that the communication channels deployed by ECAs can effectively engage users with this technology. Literature in the field of pedagogical agents has offered insight as to why this is evident. According to Lane, (2016) the *social agency theory* (Moreno et al., 2001) and in particular, the *persona effect* (Lester et al., 1997) argue that the presence of an agent in a virtual environment and the social ques derived from it can predispose users towards engaging and interacting with the interface, thereby enhancing their learning experience.

The appearance of ECAs is a central consideration (Gulz and Haake, 2006) and has two main variables. The first broadly categorises ECAs based on their appearance and is referred to as *species*, which includes "*human, animal, robots, objects, and mystical creatures*" (Straßmann and Krämer, 2017, p.414). The second variable is *realism*. Straßmann and Krämer (2017) pointed out that the term realism has been conceptualised in different ways in the field of ECAs and a universal term has yet to be agreed upon. Drawing upon previous work in the field, the authors proposed that realism is a multifaceted concept and proposed three dimensions, namely *stylisation* (degree of cartoon-likeness), *resolution* (same as above) and *detailedness* (high *versus*

low detail). Figure 1.4 (adopted by Straßmann and Krämer, 2018) provides an illustrated example of these dimensions.

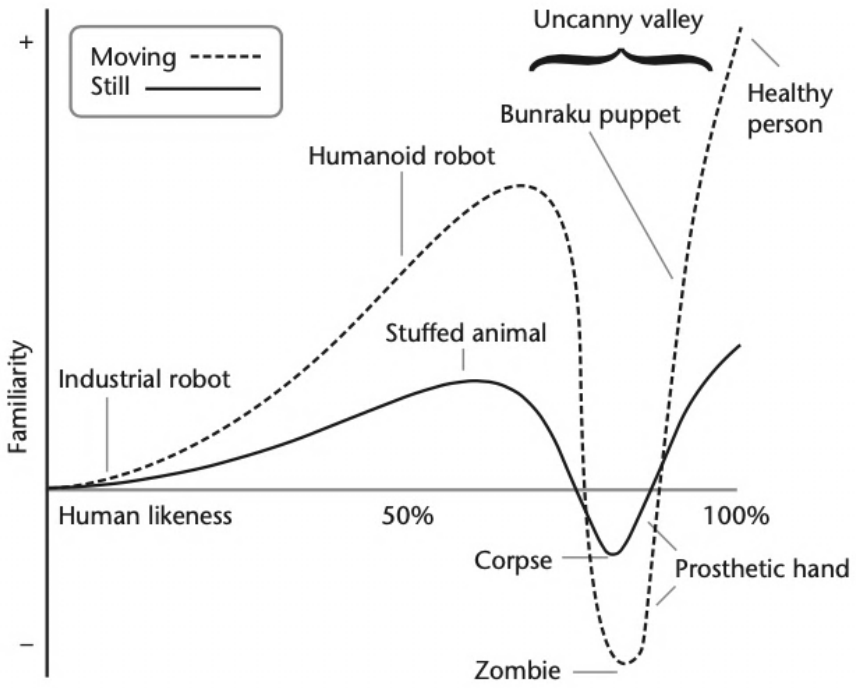
Figure 1. 4: Examples of ECA species and varying degrees of stylisation, resolution and detailedness



In their work, Ring, Utami and Bickmore (2014) demonstrated that the appearance of ECAs is highly context-specific and the perceived appropriateness of an agent depends upon the goals and setting in which this agent is used. For instance, cartoon-like characters are usually perceived as friendlier and can hence be used with a younger audience (Ring, Utami and Bickmore 2014). Yet, a professional-looking VA might be more appropriate for a task or situation where the presence of an 'expert' is required, such a health intervention (Parmar et al., 2018). Characteristics such as age and gender can also play a role; Guadagno et al. (2007) demonstrated that users can express a preference for VAs that matched their gender, while Alsharbi and Richards (2017) demonstrated that users can be more inclined towards a VA close to their age.

Another important concept in ECA's appearance is the *uncanny valley*. The uncanny valley is a theory introduced by the Japanese professor Masahiro Mori in 1970, who argued that "*a person's response to a humanlike robot would abruptly shift from empathy to revulsion as it approached, but failed to attain, a lifelike appearance*" (Mori, MacDorman and Kageki, 2012, p.98). Figure 1.5 (adopted by Geller, 2008, p.12) presents a diagrammatic illustration of the concept. As a character approaches a higher degree of human likeness, the perceiver's affinity for it will decrease dramatically in the presence of subtle non-human flaws. Motion has an additive effect on this concept, as unnatural movements can cause even greater feelings of eeriness and repulsion (i.e., steeper slope). While initially developed for use in robotics, this theory has been studied extensively in the context of VA development (de Borst and de Gelder, 2015; Ciechanowski et al., 2019; Stein and Ohler, 2018), as well a variety of scientific circles including psychology (Matsuda et al., 2012) and philosophy (Misselhorn, 2009).

Figure 1. 5: Illustration of the concept of the Uncanny valley

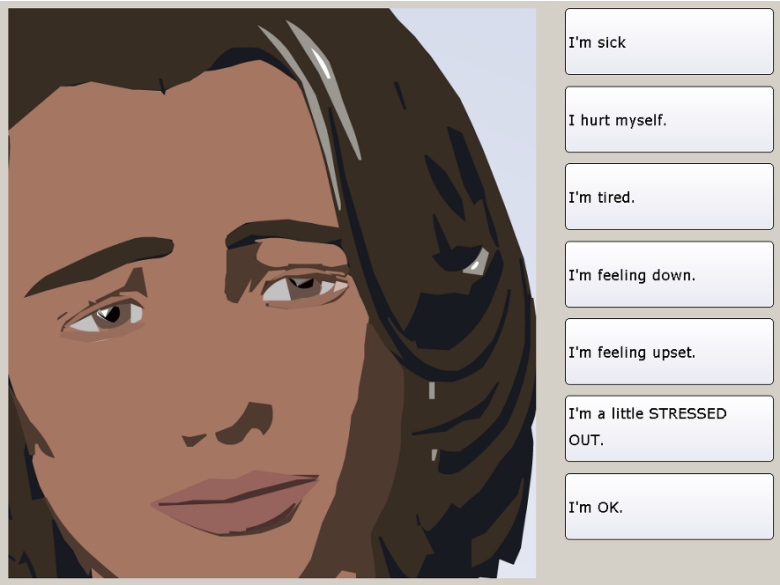


The wide exploration of Mori's theory and the abundance of empirical findings have led to the refinement of this model. In recent years, Kätsyri et al. (2015) distinguished between the original theory proposed by Mori (referred to as the n*aïve hypothesis)* and two subsequent concepts, namely the c*ategorisation ambiguity* and p*erceptual mismatch.* With regards to the former, de Borst and de Gelder (2015) pointed out that realism itself is not what gives rise to feelings of eeriness and uncanniness but rather, the difficulty to categorise an entity to a certain type (e.g., cartoon, animal, robot, human etc.). The authors argued that this is evident in characters that stand close to the dichotomy of human and non-human, as such characters are difficult to categorise. Kätsyri et al. (2015) defined perceptual mismatch as inconsistencies "*between the human-likeness levels of specific sensory cues"*, which proposes that mismatches between the naturalness of voice and image can elicit feelings of eeriness and displeasure towards a VA (Kang and Watt, 2013; Mitchell et al., 2011; Tinwell, Grimshaw and Nabi, 2015).

1.4.4. Relational agents

Bickmore and Gruber (2010) described relational agents as a category of conversational agents that are capable of establishing a relationship with users. According to the authors, this can be achieved through small talk, displays of empathy and references to previous interactions. In addition to verbal or textual output, ECAs can accomplish this by gestures and/or expressions, as shown in figure 1.6 (adopted by Bickmore and Gruber 2010, p.3).

Figure 1. 6: Example of a relational agent



The key feature of relational agents is their potential to forge a *therapeutic alliance* with users (Bickmore and Gruber, 2010). Therapeutic alliance has been defined as "*a concept that describes the trusting, collaborative nature of the transactions that occur between a patient and therapist within the context of mental health treatment*" (Corso et al., 2012, p.88) and is regarded as a key component for obtaining favourable treatment outcomes in cancer care. An early study demonstrated that this concept can also extend to other areas of healthcare and demonstrated that the trusting relationship between patients and providers can lead to improved outcomes (Reis et al., 2008)

Due to their engaging nature and potential to establish relationships with users, relational agents-especially those with an element of embodiment-have attracted considerable interest as *virtual coaches* (Bickmore et al., 2005). Examples where relational ECAs have been used to coach users include physical activity (Bickmore et al., 2005), mindfulness and meditation (Gardiner et al., 2017), nutrition (Bickmore,

Schulman and Sidner, 2013), smoking cessation (Abdullah, Gaehde and Bickmore, 2018) and disease monitoring (Klaassen et al., 2018)

1.4.5. Current state, benefits and limitations

Several publications have explored the application of virtual agents (VAs) in healthcare. This includes reviews concerned with specific fields such as mental health (Vaidyam et al., 2019), as well as healthcare as a whole (Laranjo et al., 2018; Tudor Car et al., 2020). While VAs have a long history of application in fields such as marketing and advertising, the application of this technology in healthcare appears to be relatively new, as the majority of studies have been published in the last decade (Laranjo et al., 2018). The field is currently expanding at an exponential rate, with an ever-increasing number of studies being conducted each year (Tudor Car et al., 2020).

While VAs were typically delivered through personal computers (PCs), recent years have witnessed a shift of trends towards the use of smartphones as delivery platforms for these interfaces in the domain of healthcare (Tudor Car et al., 2020). Lewis Johnson, Labore and Chiu (2004) explained that desktop computers can pose a serious limitation, as they can limit VAs' accessibility. This consideration, alongside the increased availability and uptake of smartphones (Al Bawab, Al Qahtani and McElnay, 2018) can potentially explain why researchers have begun to use handheld devises (i.e., mHealth interventions) for delivering this technology to the desired user audience.

The use of conversational agents can offer a number of potential advantages at both a systemic, as well as individual patient level. At a patient level, these interfaces provide users with a friendly environment where they can take as much time as they require to

address their needs, which is not always possible in practice (Bickmore and Gruber, 2010). Their constant availability is another major factor, as they can provide continued support and respond to users' demands at all times, thereby increasing impact (Brinkman, 2016).

At a systemic level, VAs can help facilitate the provision of information to patients, thereby preventing unnecessary visits (Bibault et al., 2019) and helping reduce consultation times (Bickmore and Gruber, 2010). Another potential advantage is the capacity for this technology to be accessible to a wide range of users. As Bickmore et al. (2010) notes, interfaces such as ECAs do not rely upon the comprehension of text, but instead simulate face-to-face conversations, which can be less daunting and more accessible to individuals with low IT or health literacy skills, thereby addressing health discrepancies.

Despite the promise of VAs, it is important to acknowledge the limitations of this technology. First, the development of these interfaces can be particularly costly in terms of time and resources, which can both hinder its effective implementation (O'Connor, 2019). Another issue is the limited evidence surrounding the use of VAs in the domain of healthcare. Tudor Car et al. (2020) pointed out that the field of VA research in the domain of healthcare is still at its infancy and that most studies conducted in the field are primarily small-scale pilot investigations, with only a few examples of randomised trials. Despite the history of application in patient education and support, the evidence base in VR and AR is also weak. Ghanbarzadeh et al. (2014) conducted a systematic review of VR in the domain of healthcare, but their work

concerned mostly education and training in healthcare professionals, with only limited examples of this technology in patient support.

1.4.6. Simulation in cancer care

In a recent article reviewing the application of digital technologies in oncology, Garg et al. (2018) noticed a paucity in publications of VAs in cancer care. A year later, Bibault et al. (2019) conducted a systematic search to identify literature regarding the use of VA-based interventions in this field, which returned only six studies.

After a brief exploration of the literature, several studies (conducted after Bibault's review) that used VAs in oncology care were identified. Examples include a support for patients with breast cancer (Chaix et al., 2019), symptom monitoring in older patients receiving chemotherapy (Piau et al., 2019), promotion of encouragement and wellbeing in survivors (Greer et al., 2019), decision aids for screening (Owens et al., 2019; Welch et al., 2020) and acquisition of patient reported outcomes (Murad Junior et al., 2020). A noteworthy observation is the lack of studies exploring the application of ECAs in the context of supportive cancer care (Ponathil et al., 2020).

1.4.7. Summary

Albeit the infrequent use of the term in the context of patient care, simulation has been applied to support patients in several areas. The field of VA research has witnessed considerable expansion in recent years, with most of the literature being published in the last decade. Despite its potential and promise, this field of research is still at its infancy. This is especially true for the field of oncology; in the most recent literature review, Tudor Car et al. (2020) still noted the need for digital health interventions to

expand to the field of cancer care. This suggests an important gap that awaits to be addressed in future research.

1.5. The conceptual framework of the project

Information support is a key component of cancer care. Considering the benefits offered by effective information support, it is necessary to ensure that patients are provided with high-quality information that are relevant to their needs. However, such support is not always provided optimally in practice (see p. 7). Several interventions have been applied to combat this issue, with computerised and digital interventions holding considerable promise for supporting patients' information needs (see pp. 8-10).

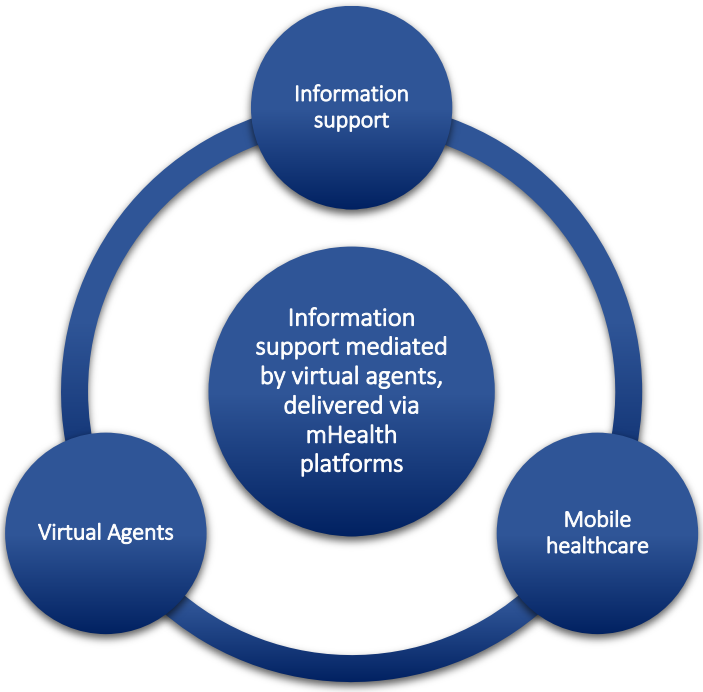
In recent years, the introduction of novel technologies has opened new opportunities for supporting patients. Health apps have attracted significant commercial as well as research interest, with a great number of commercially available interventions being available to patients and a considerable amount of research around their effectiveness and safety; despite several limitations, mHealth holds considerable promise for improving outcomes in oncology care (Osborn et al., 2020).

Albeit the potential of mHealth interventions to support patients, it is vital to consider the role of healthcare professionals in cancer care. The presence of health providers is integral, as they can inspire reassurance and help patients maintain hope, which has a positive effect upon their quality of life (Amati et al., 2019). Health professionals are the most preferred source of information as they are regarded as the most trustworthy agents, but time constraints often limit their availability in practice (see p.7).

Virtual learning and simulation could offer a solution to this matter. ECAs can constitute a viable alternative to face-to-face discussions as they can "*produce verbal and nonverbal conversational behaviours that signify understanding and mark significance, and can convey information in redundant channels of information (e.g., hand gestures, such as pointing, facial display of emotion, and eye gaze), to maximize message comprehension"* (Bickmore, Pfeifer and Paasche-Orlow, 2007). Simulations of a face-to-face exchange can be accessible even to individuals with little experience in this technology, such as older persons. As Bickmore *et al.* (2005) pointed out, engaging in face-to-face exchanges is a skill that is built early and maintained throughout one's life, which is true even for individuals with cognitive impairment.

The considerations discussed above formulated the conceptual framework of the present project, which is illustrated in figure 1.7.

Figure 1. 7: The project's conceptual framework



The central idea of this project was to deploy an ECA-based app to provide information support to patients with cancer. The ECAs of the app resembled healthcare professionals, as they are the most preferred and trusted source of information (see 1.2.3). More specifically, the ECAs were formulated after health professionals known to the users of the app. This decision was informed by a concept known as *continuity of care*, which describes the ongoing relationship between a patient and a healthcare provider (Van Walraven et al., 2010). This appears to be an important aspect in cancer care, especially in the initial stages of the care pathway (King et al., 2007) and can lead to better treatment outcomes, as well as satisfaction with care (Plate et al., 2018; Tsianakas et al., 2012). Hence, it was hypothesised that using ECAs resembling known professionals would potentially appeal to users. To date, there are no studies that deployed familiar ECAs to support patients with cancer.

Chemotherapy was the treatment of focus, as patients receiving it require a substantial degree of support (Mitchell, 2007). It was determined that the app would be designed around a specific treatment regimen instead of providing generic information about chemotherapy, as patients with cancer appear to prefer information tailored to their unique needs (see p. 9).

As several sources have suggested that patients' information demands typically peak at the early stages of the care continuum, the app was given shortly before treatment commenced (Halkett et al., 2012; Vogel, Bengel and Helmes, 2008). In order to maintain homogeneity in baseline information needs, the app was provided to patients with no previous experience with chemotherapy (i.e., newly diagnosed, chemotherapy-naïve patients).

To maintain consistency, this study focused upon patients with colorectal cancer (CRC). The rationale for this decision was twofold. First, CRC is the third most common type of cancer in both men and women, with around 42,300 new cases each year in the UK (Cancer Research UK 2020). Second, aspects such as chemotherapy, dietary changes and stomas can have a profound effect upon patients' lives, making patients with CRC an ideal group for providing continued support throughout treatment.

1.6. Aims and objectives

The aim of this project was to develop and test an ECA-based information support app for newly diagnosed, chemotherapy naïve patients with CRC. The project had three major components, namely the *developmental phase*, *pilot testing* and *main testing*. Each phase had its specific objectives.

1.6.1. Developmental stage

This phase was concerned with the development of the initial version of the intervention and the practical considerations of the project (logistics). The specific objectives included the following:

a) Identification of collaborators and recruitment centres
b) Identification of the information needs of patients with CRC
c) Acquisition of resources for developing the draft content of the app
d) Receipt of patient feedback and advice upon the draft content and functions of the app, as well as the research materials
e) Development of the pilot version of the app
f) Establishment of the pilot evaluation methodology

1.6.2. Pilot testing

The goal of the pilot study was to test the initial version of the app with real patients and validate the initial study design. The specific objectives of this phase were to:

a) assess the recruitment potential
b) establish the appropriateness of the data collection tools and study design
c) address logistical aspects
d) receive app-related feedback and recommendations for improvement
e) identify and resolve technical errors

1.6.3. Main testing

The final phase of the project was concerned with the formal testing of the updated version of the app. The goal was to provide the intervention to a large patient cohort and perform a robust evaluation. The objectives of this phase were as following:

a) establishment of the usability and acceptability of the intervention
b) users' satisfaction with information and views on the app's content
c) exploration of the app's use throughout the study period
d) exploration of patients' perspectives upon the VAs
e) exploration of emergent feedback for potential ways of improving the app

1.7. Chapter summary

Information support is an integral part of cancer care, but it is not always offered optimally in practice. MHealth could potentially address this issue, as it holds considerable promise for providing continued and high-quality services to users at any

place and any time. To further aid patients' understanding, a didactic approach involving simulation could be used. These elements were brought together to formulate the conceptual framework of this research. It was proposed that a VA-based health app for newly diagnosed patients with CRC would be developed and tested in order to explore its effects and degree of acceptability.

As discussed in p.8, achieving a good understanding of patients' needs is the first and most important step to effectively address them. Having established the population of interest (newly diagnosed patients with CRC), it was crucial to perform a formal assessment of their information needs in order to build a robust intervention towards meeting them. Hence, it was determined that a systematic review exploring the information needs of recently diagnosed patients with CRC would be undertaken. The next chapter will present the core principles underpinning systematic searches and present the findings of the aforementioned review.

Chapter 2: Systematic review and narrative synthesis

As the goal of this project was to develop and test an information support app for patients with CRC, it was vital to first understand their information demands so the content was designed according to their needs. Thus, it was determined that a structured review was necessary to further inform the research project. This chapter will outline the process undertaken for this review, present the findings and discuss how these informed the development of the app's content.

2.1. Reviews and their importance in research

While all reviews aim to identify relevant literature, analyse the retrieved body of evidence and draw conclusions, there are different types of appraisals according to the aims and objectives set by the enquirers.

A key consideration is the way in which relevant literature is identified, which is referred to as the *search strategy*. While some perform informal searches to identify studies of interest, others devise rigorous search strategies to collect all available resources. Such *systematic* searches are one of the key components of *systematic reviews*. This type of review utilises robust methods to eliminate bias and increase rigour in retrieving, appraising, synthesising and presenting all available evidence to answer a specific research question (Aromataris and Riitano, 2014). Coupled with meta-analyses, a statistical technique used to combine data across large sets of primary studies, systematic reviews are considered to produce the highest quality evidence to guide practice (Jahan et al., 2016).

Unlike systematic reviews, narrative reviews are not restricted to a single research question. Instead, the purpose of a narrative review is to gather, appraise and interpret findings from the literature around a subject area in order to produce a critical output on the topic (Ferrari, 2015). Yet narrative reviews are often regarded as inferior to systematic reviews, as the former do not always abide by the same methodological standards as the latter (Pae, 2015).

In an early editorial note, Collins and Fauser (2005) pointed out that the strengths of systematic reviews can easily turn into weaknesses if applied to a topic that needs to be examined without using strict methods and/or keeping a narrow focus. A similar view was given by Greenhalgh, Thorne and Malterud, (2018) who criticized the perceived superiority of systematic reviews and asserted that the dichotomy between them and narrative reviews is irrelevant and unproductive.

Instead of viewing systematic and narrative reviews as enemies, researchers should consider the matter at hand in order to decide upon the most appropriate review type. In the context of this project, a systematic *approach* to summarising the literature around patients' information needs was an ideal way of achieving a better understanding of their requirements. However, a meta-analysis of such data would likely be infeasible, as both the literature around this subject and the assessment measures were likely to be considerably diverse. It was hence determined that a narrative review, coupled with the core methodological components of a systematic review would be the most appropriate way forward.

To date, a systematic literature review focusing upon the information needs of newly diagnosed patients with CRC could not be identified. A recent systematic review by

Kotronoulas *et al.* (2017) identified information as an important aspect of supportive care in CRC, but it didn't go in further detail. A scoping review (Van Mossel et al., 2012) identified a large number of papers exploring the information needs of patients with CRC, but pooled data from different stages of the cancer care continuum. As the information needs can change across different stages of treatment (Kennedy and Lloyd-Williams, 2009; Pollock et al., 2008), it is likely that this review did not adequately reflect the information needs of patients with CRC at the early stages of treatment.

2.2. Aims and objectives

The aim of this review was to synthesise the body of research around the information needs of newly diagnosed patients with CRC receiving treatment for their condition. The specific objectives were to a) identify the various types of information sought by or given to these individuals and/or their caregivers, b) determine the desired volume of information and c) establish the perceived importance of specific pieces information. The present review was registered with the International Prospective Register of Systematic Reviews (PROSPERO) to prevent duplication (registration number CRD42018117833).

2.3. Methods

2.3.1. Search strategy

A review of the literature published in the last 30 years was conducted in the following databases: *Allied and Complementary Medicine Database (AMED), Applied Social Sciences Index and Abstracts (ASSIA), Cochrane Library, EMBASE, Education Resources Information Centre (ERIC), Medline, Web of Science (Social Citation Index and Science Citation Index), Cumulative Index to Nursing Allied Health Literature (CINAHL) and*

PsycInfo. A hand search of five key journals (*European Journal of Oncology Nursing, Patient Education and Counselling, Journal of Cancer Education, Colorectal Disease, Diseases of the Colon and the Rectum*) was also performed to retrieve relevant papers and screen their reference lists to identify studies that were missed from the initial search.

The search involved variations of the terms *information*, *need*, *seek*, *colorectal* and *cancer* in order to identify as many relevant studies as possible (van Mossel et al., 2012). The complete search strategy and results for each database is provided in appendix 1.

2.3.2. Inclusion and exclusion criteria

Studies were eligible for inclusion if they fulfilled the following criteria:

- Published in the English language
- Explored the information needs of patients and/or the relatives/partners/ caregivers of patients with a diagnosis of CRC who were actively receiving or were about to receive treatment at the point of the study; studies that explored the information needs of patients with various types of cancer were eligible for inclusion, as long as sub-group analysis was performed
- Conducted in Western societies (EU, UK, US, Canada, Australia, New Zealand)
- Original (primary) research studies that followed a qualitative, quantitative or mixed method design

Previous work seeking to summarise the information needs of patients with cancer (Adams, Boulton and Watson, 2009; Rutten et al., 2005; Van Mossel et al., 2012) revealed that various study designs were deployed to explore this phenomenon. Excluding any study design could therefore lead to the loss of valuable data. The present review included both qualitative and quantitative studies, as well as studies that followed a mixed method design.

Papers that pooled different types of cancer without performing a sub-group analysis of patients with CRC were excluded. Studies that explored the information needs of CRC survivors were also excluded, as the information needs of patients with cancer can change across the cancer-care continuum (Halkett et al., 2012; Matsuyama et al., 2013). Moreover, studies outside the specified geographic restrictions were excluded as cultural differences and dissimilarities in health information communication can affect the information-seeking behaviour of patients with cancer (Gaston and Mitchell, 2005; del Carmen and Joffe, 2005). Secondary research, letters and opinion papers were also excluded. Nevertheless, the reference lists of systematic reviews and scoping searches were checked to identify papers that were omitted by the search strategy.

2.3.3. Study selection

The process of title and abstract screening were performed by the lead author (AC). Studies retrieved in full text were then distributed across the review team. Five pairs of reviewers were formed, each comprised by the lead author and one member of the review team (SC, AG, NS, CH, OB). The lead author screened every article and each co-author received one-fifth of the full-text studies, which were screened independently. The results were compared within each pair to resolve any disagreements and decide

upon which articles would be included in the review. When the reviewers could not reach an agreement, the academic supervisor (SC) acted as a third reviewer; this was necessary for two studies (Bell et al., 2009; Bronner et al., 2018).

2.3.4. Data extraction and quality assessment

The data extracted from eligible studies concerned general characteristics and information needs. General characteristics included the following:

- Purpose and context (aim, setting, geographical location and outcomes)
- Methods (sampling technique, sample size, study design and data collection methods)
- Participant characteristics (gender, age, stage of condition, treatment approach and disease location).

Information needs included any mention of the following:

- Information either given to or sought by the patients and/or by their caregivers
- The desired volume of information (e.g., how much patients and/or caregivers wanted to know)
- The most important types of information (i.e., information priorities)
- Satisfaction or dissatisfaction with information

The Mixed Methods Appraisal Tool was used to determine the quality of studies that followed a mixed methods design (Pluye, 2013). As this tool examines the quality of quantitative and qualitative components separately, it was also used for determining the methodological quality of purely quantitative or purely qualitative studies.

The lead author performed the data extraction and quality assessment steps for all accepted articles. To ensure robustness in this process, each co-author received three studies at random, performed these processes independently and compared their results with those of the lead author. As there was congruity between the findings of the lead author and the co-authors, it was determined that there was no need for the co-authors to conduct further extractions and quality assessments.

2.3.5. Synthesis and presentation of findings

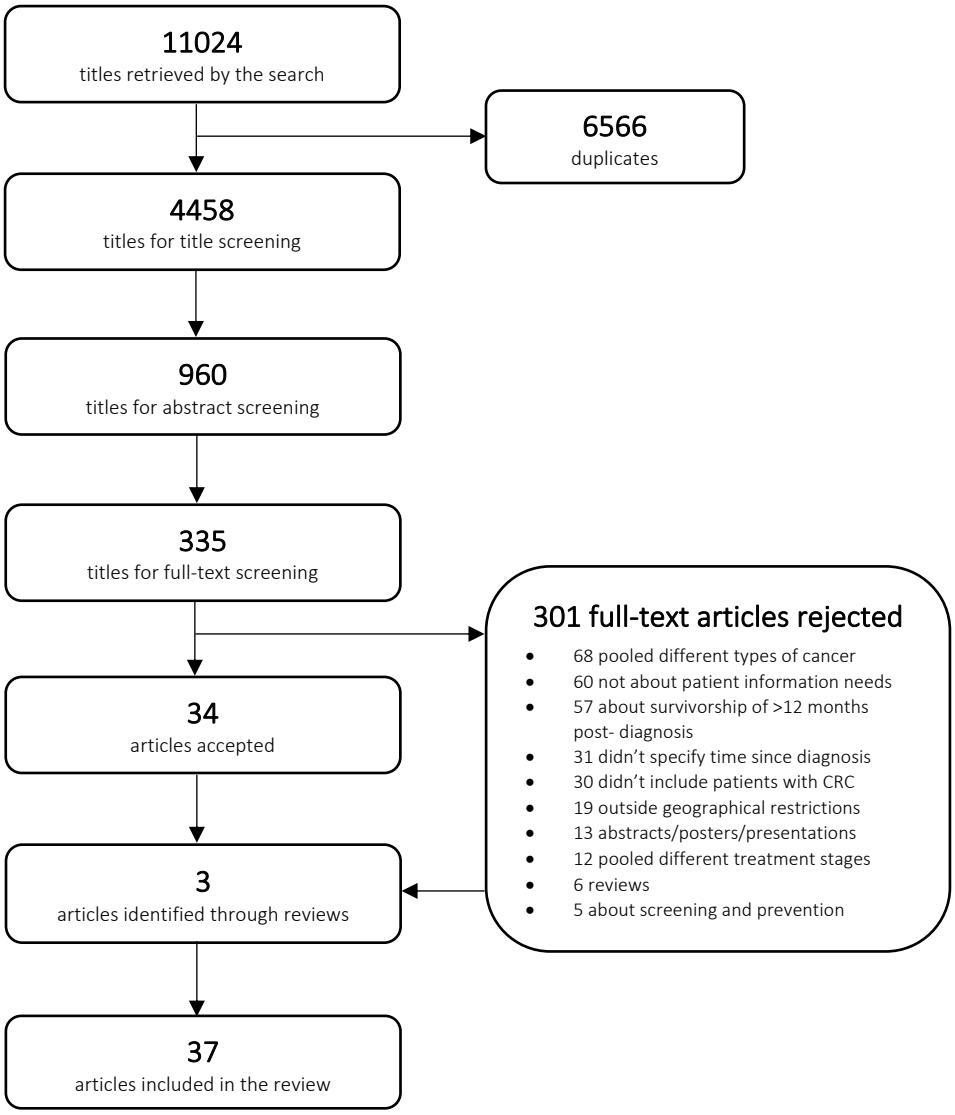
Due to the heterogeneity of the retrieved data, a meta-analysis was not possible. Instead, narrative synthesis was deployed (Popay et al., 2006).

In order to provide a concise overview of the types of information needs, this review drew upon the typology chart in van Mossel et al. (2012). In their work, the authors established ten broadly defined categories of information needs, which were then broken down in 82 subcategories. A summary table will first present which types of information appeared in each study using the ten broadly defined categories of information needs, while a more detailed table will provide an extensive account of specific pieces of information identified across studies.

2.4. Results

The search yielded 11024 titles. After the removal of duplicates, 4458 articles were screened against their titles, resulting in 960 articles for abstract screening. Following this, 335 documents were retrieved in full-text and were screened against the inclusion criteria. Ultimately, 37 articles were included in the synthesis. Figure 2.1 depicts the flow of the review process and study selection.

Figure 2. 1: Study selection process



2.4.1. General characteristics of included studies

The descriptive characterisation of the included studies is available in table 2.1. Most studies (*n*=21:37, 56.7%) were around patients' experiences with diagnosis, treatment or care. Six studies (16.2%) explored supportive interventions for patients with CRC, three (8.1%) investigated medical decision-making, one (2.7%) focused upon nutrition and one (2.7%) upon caregivers' perspectives.

Table 2. 1: Descriptive characterisation of included studies

	Purpose and Context				Methods			Participant Characteristics				
	Purpose	**Setting**	**Country**	**Study outcomes**	**Sample size and sampling technique**	**Study design**	**Data collection tools**	**Gender**	**Age**	**Disease stage**	**Type of treatment**	**Disease location**
Bailer (2001)	Patients' experiences from pre-treatment discussions and preferences for decision-making	Multi-centre (6 cancer centres)	UK (England)	1. Patients' decision-making preferences 2. Differences in a sample of older patients	337 patients, purposive sampling	Qualitative (QUAL), part of Mixed Methods (MM)	Semi-structured (SS) interviews	Not recorded	58-95 years (73.45)	Not recorded	Surgery, chemotherapy and radiotherapy	Not recorded
Bain and Campbell (2000)	Treatment experiences and differences in priorities between urban and rural patients	Multi-centre (2 cancer centres)	UK (Scotland)	1. Patients' experiences with treatment for CRC 2. Differences in attitudes and priorities between rural and urban patients	22 patients and 10 relatives, purposive sampling	QUAL	Focus groups	Not recorded	Unclear (70 to below 60)	Various but not recorded	Surgery, chemotherapy, radiotherapy, combination treatment and palliative care	Not recorded
Bain et al. (2002)	Explore how patients perceive their care	Multi-centre (outpatient clinics across Scotland)	UK (Scotland)	1. How patients with CRC perceive their care 2. Comparison of the views and experiences of urban and rural patients	39 patients and 24 caregivers, purposive sampling	QUAL	In-depth interviews	Not recorded	Not recorded	Not recorded	Surgery, Surgery + Radiotherapy, Surgery + Chemotherapy	Not recorded
Bell (2009)	Perspectives of patients on treatment	Single-centre (cancer centre)	Canada	1. Patient perceptions on adjuvant chemotherapy for CRC	8 patients, convenience sampling	QUAL	Observations (fieldnotes) and in-depth interviews	67% female	Not recorded	Not recorded	Chemotherapy only (adjuvant and palliative)	Not recorded
Boe et al. (2019)	Patients' experiences with surgery	Single-centre (district hospital)	Norway	1. Patients' experiences after completion of laparoscopic surgical resection for liver metastases	9 patients, convenience sampling	QUAL	SS interviews	44.5% female	25-85 years (no mean)	Stage 4	Surgery only	55.5% rectal, 44.5% colon
Bronner et al. (2018)	Presence of anxiety during diagnosis	Single-centre (cancer centre)	Netherlands	1. Establish patients' anxiety 2. Monitoring coping style 3. Changes in anxiety by monitoring coping style and treatment type	81 patients, convenience sampling	Quantitative (QUAN) (descriptive)	Questionnaires (STAI-6 and TMSI) plus treatment plans	34,6% female	62.5 years (9.1)	Not recorded	Chemotherapy or surgery	Not recorded
Broughton, Bailey and Linney (2004)	Patients' experiences with diagnosis and surgery	Multi-centre study (3 hospitals)	UK (England)	1. Patients' experiences following a diagnosis of CRC 2. Patients' experiences of their first follow-up visit after surgery 3. Caregivers' experiences	49 patients and 8 caregivers, convenience sampling	QUAL	SS interviews and focus groups	47% female	37-92 years (69 mean)	Not recorded	Surgery	Not recorded
Cha et al. (2012)	Nutrition in patients with CRC	Multi-centre study (3 health boards)	New Zealand	1. Patients' information needs and satisfaction with dietary information 2. Establishment of dietary patterns	29 patients, convenience sampling	QUAN (descriptive)	Questionnaire (modified version of the Food Frequency Questionnaire)	31% female	>70 (no mean or SD)	Not recorded	Surgery	Not recorded

Comb (2003)	Experiences of a stoma nurse caring for a patient undergoing surgery for CRC	Single-centre study (cancer centre)	UK (England)	1. Issues experienced by a patient undergoing surgery for CRC 2. The role of the stoma nurse throughout the patient's treatment	Single patient, convenience sampling	QUAL	Fieldnotes	Not applicable	Not applicable	Not applicable	Not applicable	Not applicable
Cuthbert et al. (2020)	Patients' supportive care needs following a diagnosis of CRC	Multi-centre (cancer centres)	Canada	1. Symptom burden and supportive needs of patients across different types of cancer 2. Differences in symptom burden and supportive needs across different types of cancer 3. Determine clinical & sociodemographic factors related to higher symptom severity	146 patients with CRC, convenience	QUAN (descriptive)	Patient records and questionnaires (ESASr and CPC)	51.2% female	64 (19-97)	44.4% local, 44.5% metastatic and 10.9% N/A	N/A (due to receive treatment)	Not recorded
Dintinjana et al. (2008)	The effects of a nutritional programme in patients during chemotherapy	Single-centre (district hospital)	Croatia	Effect of a nutritional support programme in nutrition status and frequency of symptoms during chemotherapy	388 patients, convenience sampling	QUAN (cohort)	Clinical characteristics (BMI, Appetite Loss Scale, Karnofsky Performance Status and Nottingham Screening Tool)	Not recorded	Not recorded	Not recorded	Adjuvant Chemotherapy (post-surgery) or chemotherapy alone	Not recorded
Dronkers et al. (2010)	Feasibility study for RCT of a preoperative therapeutic exercise programme	Single-centre study (cancer centre)	Netherlands	1. Feasibility of a short-term therapeutic programme for elderly patients 2. Intervention's effect on post-operative complications	42 patients, Convenience sampling	QUAN (RCT)	Questionnaires (LASA Physical Activity Questionnaire, EORTC QLQ-C30, Abbreviated Fatigue Questionnaire) and validated measures of physical activity	24.4% female	68.8 years mean control, 71.1 years mean for intervention	Not recorded	Surgery only	Colon
Harrison et al. (2011)	Patients' unmet supportive needs following discharge from surgery	Single-centre study (district hospital)	Australia	1. Unmet supportive needs 2. How patients' needs changed over a 6-month period post-surgery 3. Association between clinical factors and post-discharge unmet needs	521 patients, convenience sampling	QUAN	Records (medical and service)	41.8% female	63.8	ACPS stage A: 16.0%, B: 32.0%, C: 32.9%,D: 15.1%	Surgery only	Multiple
Houldin (2007)	Relatives' experiences	Single-centre study (cancer centre)	USA	Explore the experiences encountered by relatives following a diagnosis of colorectal cancer	14 relatives, convenience sampling	QUAL	SS interviews	28.6% female	44.92 (10.08)	Stage III or IV	Adjuvant Chemotherapy (post-surgery)	Not recorded
Houldin and Lewis (2006)	Experiences of patients with advanced CRC	Single-centre study (cancer centre)	USA	1. Patients' experiences after receiving a diagnosis of CRC 2. Coping strategies, impact on daily life and impact on family 3. Preparedness for treatment	14 patients, Convenience sampling	QUAL	SS interviews	36% female	27-67 years (11.8)	III and IV	Adjuvant Chemotherapy (post-surgery)	Not recorded
Kidd et al. (2008)	Self-care during treatment for CRC	Single-centre study (cancer centre)	UK (Scotland)	1. Self-care strategies 2. Meaning and importance of self-care 3. Changes in self-care strategies over time	11 patients, convenience sampling	QUAL	SS interviews	27% women	65.5 years mean (8.5)	91% Duke's C, 9% Duke's B	Adjuvant Chemotherapy (post-surgery)	Not recorded
Knowles (1999)	Information needs of patients	Single-centre study (university hospital)	UK (Scotland)	1. Patients' information needs 2. Factors associated with information-seeking 3. Changes in information needs during treatment 4. Sources of information	80 patients, convenience sampling	Mixed Methods (QUAN -> QUAL)	Questionnaires (EORTC QLQ-C30, STAI, INQ) and SS interviews	Not recorded	62 (10.5)	Not recorded	Adjuvant Chemotherapy (post-surgery)	77% Colon, 23% Rectal Cancer

Lithner et al. (2012)	Information provision in patients with CRC	Multi-centre study (2 university hospitals and 1 county hospital)	Sweden	1. Health-Related Quality of Life (HRQoL) 2. How patients perceive information after surgery 3. Information needs 4. Factors affecting received information	100 patients, consecutive sampling	QUAN (Prospective)	Medical records and Questionnaires (QLQ-C30, CR38 and INFO25)	45% Women	69.9 years (10.5)	I: 15% II: 41% III: 36% IV: 8%	Surgery	Multiple
Lithner et al. (2015b)	Information support and information needs after surgery	Multi-centre study (3 hospitals)	Sweden	1. Information needs after discharge 2. Experiences with information support after discharge 3. Types and volume of desired information	16 patients, purposive sampling	QUAL	SS Interviews	37.5% women	Not recorded	Not recorded	Surgery	Not recorded
Lithner, Jakobsson, et al. (2015)	Information and Health-Related Quality of Life (HRQOL) after surgery for CRC	Multi-centre study (2 university hospitals and 1 county hospital)	Sweden	1. HRQOL and perception of information 2 weeks and 1 month after discharge 2. Factors affecting perception of information	100 patients, consecutive sampling	QUAN	Medical records and Questionnaires (QLQ-C30, CR38 and INFO25)	45% Women, 55% Men	69.9 years mean (10.5)	I: 15% II: 41% III: 36% IV: 8%	Surgery	Multiple
Poland et al. (2017)	Development of patient education for enhancing recovery after CRC surgery	Multiple (hospital and patients' homes)	UK (England)	1. Understand the role of preoperative education 2. Determine the perceived value of enhanced recovery 3. Modification of existing education practices and evaluation of these changes.	97 patients and 19 caregivers, convenience sampling	QUAL	Interviews and focus groups	Not recorded.	Not recorded.	Not recorded.	Surgery	Not recorded.
Reeve et al. (2017)	Establish the most important measures of patient-centred care in patients with a recent diagnosis of CRC	Multiple sites (unclear)	USA	1. Evaluation of the patient-centred communication (PCC) survey 2. Selection of items to formulate a long and short version of the PCC measures	501 patients, convenience sampling	QUAN (survey)	Questionnaires (PCC and the Health Information National Trends Survey PCC)	51% women	66.7 (13.1)	Not recorded	Surgery, Chemotherapy or Radiotherapy	80% Colon, 17% rectal, 3% multiple sites
Reinwalds, Blixter and Carlsson (2017)	Patients' experiences following reversal of temporary ileostomy surgery for CRC	Multi-centre study (1 university hospital and 1 county hospital)	Sweden	Explore patients' experiences during the first 4-6 weeks after surgery	16 patients, consecutive sampling	QUAL	Narrative interviews		67 (median, range 33-81)	Not recorded	Surgery	Not recorded
Sanders and Skevington (2004)	Explore factors associated with patient participation in the treatment decision-making process	Single-centre study (cancer centre)	UK (England)	Establish factors associated with patients' willingness to participate in the decision-making process	49 patients, convenience sampling	QUAL	Observations and SS interviews	32.7% women	73.5% above 65, 26.5% below 65	Duke's stage B (16.3%), C 71.4%) and D (12.3%)	Surgery	57.1% Colon, 52.9% rectum
Sanders and Skevington (2003)	Explore patients' views regarding participation in medical decision-making	Single-centre study (cancer centre)	UK (England)	1. Patients' views in medical decision-making 2. Explore the exchanges between patients and oncologists	37 patients, consecutive sampling	QUAL	Observations and SS interviews	35.1% women	64.9% above 65, 35.1% below 65	Duke's stage B (5.4%), C 75.7%) and D (18.9%)	Surgery	59.4% colon, 40.6% rectum
Sawyer et al. (2008)	Experiences following surgery for CRC and perspectives on a new patient care model	Single-centre study (cancer centre)	Canada	1. Explore patients' experiences before and after surgery 2. Explore nurses' perspectives of the Milestones project and post-operative care	6 patients and 6 nurses, convenience sampling	QUAL	Telephone interviews, patient diaries and focus group (nurses)	16.7% women	66 (range 46-81)	Not recorded	Surgery	Not recorded
Scheer et al. (2012)	Decisional needs of patients with rectal cancer and gaps in recollection of consent discussions	Single-centre study (university cancer centre)	Canada	1. Describe the decisional needs of patients about undergoing surgery for rectal cancer 2. Identify gaps in patients' recollections of the discussions around informed consent	30 patients, convenience sampling	QUAL	SS interviews (based upon the Ottawa Decision Support Framework)	24:6 Male to female ratio	65 (42-89	I (33%) II (12%) III (43%) IV (10%)	Neoadjuvant chemotherapy or radiotherapy, adjuvant chemotherapy or radiotherapy and surgery	Rectal Cancer

Sierko, Werpachowska and Wojtukiewicz (2011)	Characteristics and needs of patients undergoing chemotherapy	Single-centre study (university hospital)	Poland	1. Psychological situation, 2. Social situation 3. Physical situation 4. Individual needs	50 patients, convenience sampling	QUAN (Descriptive)	Institutionally developed questionnaire	48% women	92% below 70, 8% above 70 years	Not recorded		Not recorded
Spalding et al. (2013)	Understand patients' experiences with pre-operative education for CRC and identify ways to enhance it for future patients	Single-centre study (district hospital)	UK (England)	1. Understand the pre-operative experiences of patients and caregivers 2. Ways to improve pre-operative education for future patients	97 patients, 19 caregivers and 22 professionals, convenience sampling	QUAL	Observations, SS interviews, focus groups and review of educational material	55:43 male/female ratio	69.7 (39-97)	Not recorded	Surgery	Not recorded
Taylor and Norton (2000)	Formulate the content of supportive documents for future patients	Unclear	UK (England)	1. Explore patients' information needs 2. Update information booklets according to their feedback	13 patients, purposive sampling	QUAL	Interviews and focus groups	66.7% women	42-75 years	Not recorded	Surgery alone and surgery followed by chemotherapy	Not recorded
Taylor (2001)	Patients' experiences following a recent diagnosis of CRC	Community	UK (England)	Understand patients' lived experiences and establish meanings and structures within them	8 patients, convenience sampling	QUAL	SS interviews and observations	Not recorded	Not recorded	Not recorded	Not applicable (about to receive treatment)	Not recorded
Weaver et al. (2007)	Feasibility of a symptom-tracking intervention for chemotherapy	Single-centre study (university cancer centre)	UK (England)	1. Explore the feasibility of the intervention 2. Receive feedback on the approach	6 patients, convenience sampling	MM (QUAN -> QUAL)	Usage data and interviews	33.3% women	64 (54-76)	Stage II and III	Adjuvant Chemotherapy (post-surgery)	Colon cancer
White et al. (2012)	Evaluation of a supportive care programme for patients	Community	Australia	1. Changes in supportive care needs, depression and anxiety between intervention and control 2. Reduction of symptoms and service use between intervention and control	305 patients (intervention group), convenience sampling	QUAN (RCT)	Questionnaires (SCNS, MOS and HADS) and other measures (CRC symptoms, service use)	40% women	64.86 (9.23)	Stage 1 (21%), 2 (52%), III (27%)	Surgery, Chemotherapy or Radiotherapy	Not recorded
Worster and Holmes (2008)	Pre-operative experiences of patients with CRC	Single-centre study (district hospital)	UK (England)	Patients' experiences during the first 4 weeks after discharge	20 patients, purposive sampling	QUAL	Fieldnotes and unstructured interviews	50% women	50 to 82 years (no mean)	Not recorded	Surgery	Not recorded
Worster and Holmes (2009)	The experiences of patients with CRC shortly after surgery	Single-centred study (district hospital)	UK (England)	Patients' experiences during the first 4 weeks after discharge	20 patients, purposive sampling	QUAL	In-depth face-to-face interviews (unstructured)	50% women	50 to 82 years (no mean)	Not recorded	Surgery	Not recorded
Young et al. (2010)	Acceptability and feasibility of an intervention for patients who have undergone surgery for CRC	Single-centre study (cancer centre)	Australia	1. Feasibility and acceptability of the intervention 2. Assessment of supportive care needs, anxiety and QoL	21 patients (intervention group), consecutive sampling	QUAN (Survey)	Questionnaires (SCNS, HADS and FACT-C) plus custom checklist for the study	50% women	64.5	Duke's stage A (19%), B (33%), C (24%), D (14%) and unknown (9%)	Surgery	Not recorded
Zafar et al. (2013)	Patients' preferences for chemotherapy in advanced CRC	Multi-centre study (community)	USA	1. Patients' role in decision-making 2. Quality of communication with physicians 3. Overall quality of care 4. Treatment preferences 5. Beliefs regarding treatment	702 patients, convenience sampling	QUAN	Questionnaires (ADE and other validated instruments) and medical records	38% women	73% below 75, 27% above 75 years	100% Stage IV	Chemotherapy (type unclear)	Colon (75%), rectal (20%) and colorectal (5%)

In these studies, information emerged either as a theme related to patients' experiences along the care pathway or as a factor analysed as part of assessing their quality of care. Only a small minority (*n*=5:37, 13.5%) was dedicated exclusively to the information behaviour and needs of patients with CRC (Knowles, 1999; Lithner et al., 2015b; a; Taylor and Norton, 2000).

The general characteristics of the included studies are summarised in table 2.2. A significant proportion of studies were conducted in the UK (12 in England and 4 in Scotland). The majority of the included studies (*n*=22/37, 59.5%) followed a qualitative methodology and almost half of these studies (*n*=10/22, 45.5%) deployed a combination of qualitative methods to obtain their data. Questionnaires in quantitative studies were rarely used alone.

Table 2. 2: General characteristics of included studies (n=37)

	n	%		n	%
Year of publication			Community	2	5.4
1999-2001	5	13.5	Unclear	2	5.4
2002-2004	5	13.5	**Data collection methods**		
2006-2008	7	18.9	Semi-structured interviews	7	18.9
2009-2011	6	16.2	In-depth interviews	3	8.1
2012-2015	8	21.6	Focus groups	1	2.7
2017-2020	6	16.2	Observations/Fieldnotes	1	2.7
Location			Combination (QUAL)	10	27.0
UK	16	43.2	Questionnaire	2	5.4
Europe	9	24.3	Combination (QUAN)	9	24.3
Canada	4	10.8	Patient records	2	5.4
US	4	10.8	Mixed (QUAN and QUAL)	2	5.4
Australia	3	8.1	**Treatment approach**		
New Zealand	1	2.7	Surgery only	17	45.9
Study setting			Chemotherapy only	8	21.6
Single- centre	21	56.8	Combination cohort	10	27.0
Multi-centre	13	35.1	N/A (about to receive treatment)	2	5.4

2.4.2. Methodological assessment of included studies

The complete results of the methodological quality assessment are available in appendix 2.

- *Qualitative studies:* The majority (n=14/22, 63.6%) of studies with a purely qualitative design scored above average. The most common omission, observed in 13 studies (n=13/22, 59.1%) was not giving appropriate consideration to the researchers' influence upon the findings, while seven studies (n=7/22, 31.8%) also didn't explain how the findings were related to the study's context.
- *Quantitative studies:* Only two (5.4%) of the included studies were RCTs while the remaining had either a descriptive (*n*=5/13, 38.4%) or non-RCT design (n=6/13, 46.2%). Half of the studies that followed a quantitative design scored above average, while most studies with a non-RCT design (n=4/6, 66.6%) scored below average. Although most studies that involved questionnaires (*n*=9/11, 81.8%) used validated instruments to collect their data, none of them stated whether or not their sample was representative of the population under study. Furthermore, all of these studies deployed sampling techniques that would increase selection biases such as convenience and consecutive sampling (i.e., non-probability techniques).
- *Mixed methods studies:* Studies that followed a mixed methodology scored poorly due to shortcomings in either the qualitative or quantitative compartments. While the use of mixed methods was justified and was appropriate for addressing the research objectives, none of the studies provided a robust theoretical framework for using a mixed methods approach.

2.4.3. Summary of information needs

Table 2.3 illustrates the main information categories and table 2.4 provides a detailed account of the types of information. The majority of the included studies (n=36/37, 97.3%) presented information that was both sought by and given to patients. A total of 567 mentions needs were identified, most of which were sought by patients (*n*=315:567, 55.5%).

Table 2. 3: Types and sources of information mentioned across studies

Authors	Categories of information (567 total mentions across 37 studies)										Information input		Sources of information (105 mentions in total)			
	Treatment-related information (222, 39.52%[1])	Rehabilitation-related information (133, 22.26%[1])	Disease-related information (66, 12.06%[1])	Prognostic information (62, 11.59%[1])	Coping information (32, 5.01%[1])	Interpersonal and Social information (22, 4.08%[1])	Body image/ fertility/ sexual information (14, 2.6%[1])	Medical system information (14, 2.6%[1])	Financial/legal information (2, 0.37%[1])		Information sought by patients	Information provided to patients	Healthcare professionals (57, 54.3%[2])	Printed material (19, 18.1%[2])	Media (16, 15.2%[2])	Interpersonal (13, 12.4%[2])
Bailer (2001)	•	•	•	•							•	•	•	•		•
Bain and Campbell (2000)	•			•				•				•	•			
Bain et al. (2002)	•		•	•	•			•			•	•	•			
Bell (2009)	•	•		•							•	•	•			
Boe et al. (2019)	•	•	•	•							•		•			
Bronner et al. (2018)	•	•	•	•							•	•	•	•	•	•
Broughton, Bailey and Linney (2004)	•	•	•	•	•	•		•			•	•	•	•	•	•
Cha et al. (2012)		•									•	•				
Comb (2003)	•	•	•		•		•				•	•	•	•		
Cuthbert et al. (2020)	•		•					•	•		•		•			
Dintinjana et al. (2008)	•											•	•			
Dronkers et al. (2010)	•											•	•			
Harrison et al. (2011)	•	•	•		•						•	•	•			
Houldin (2007)	•		•	•		•					•	•	•			•
Houldin and Lewis (2006)	•		•	•	•	•					•	•	•			•
Kidd et al. (2008)	•				•		•				•	•	•		•	•
Knowles (1999)	•	•	•	•		•	•				•	•	•	•		
Lithner et al. (2012)	•	•	•	•	•						•	•	•	•		
Lithner, Jakobsson, et al. (2015)	•	•	•		•			•				•	•	•		
Lithner, Klefsgard, et al. (2015)	•	•	•	•	•	•	•	•			•		•	•	•	
Poland et al. (2017)	•	•	•		•	•	•	•			•	•	•	•	•	
Reeve et al. (2017)	•	•	•	•	•	•		•			•	•	•			
Reinwalds, Blixter and Carlsson (2017)	•	•	•		•						•	•	•		•	
Sanders and Skevington (2003)	•	•	•	•		•		•			•	•	•	•		
Sanders and Skevington (2004)	•		•	•		•					•	•	•	•		•
Sawyer et al. (2008)	•	•	•								•	•	•	•	•	
Scheer et al. (2012)	•		•					•			•	•	•	•	•	•
Sierko, Werpachowska and Wojtukiewicz (2011)	•	•	•	•			•				•	•	•			•
Spalding et al. (2013)	•	•	•	•	•	•	•				•	•	•	•	•	•
Taylor and Norton (2000)	•	•	•		•	•	•				•	•	•	•	•	
Taylor (2001)	•	•	•	•	•	•	•				•		•		•	•
Weaver et al. (2007)	•	•										•	•		•	
White et al. (2012)	•	•		•			•				•	•	•	•		
Worster and Holmes (2008)	•		•	•	•	•		•			•	•	•	•		
Worster and Holmes (2009)			•	•	•			•			•	•	•	•		•
Young et al. (2010)	•	•		•	•	•	•					•	•	•		
Zafar et al. (2013)	•			•					•			•	•			

Table 2. 4: Detailed types of information mentioned across studies

N= 37 articles, 567 mentions of information needs		Mentions per category	
		n	%
Treatment-related information 222, 39.52%[1] (94.6% of articles, *n*=35/37)	Side effects of treatment/risks and benefits of treatment	25	11.3
	Tests and procedures involved in treatment	23	10.4
	General treatment-related information	23	10.4
	Surgery	21	9.5
	Treatment plan, treatment description or logistical information	21	9.5
	Medications	15	6.8
	Available treatments/treatment options	14	6.3
	Chemotherapy	13	5.9
	Purpose of treatment	10	4.5
	Treatment success	9	4.1
	How treatment works	8	3.6
	Other patients' experiences or choices about treatment	7	3.2
	Treatment referrals	6	2.7
	Reducing side effects of treatment	5	2.3
	Clinical trials	5	2.3
	Where to get information about treatment	5	2.3
	Physical limitations during treatment	4	1.8
	Progress during treatment	4	1.8
	Radiation therapy	2	0.9
	Alternative or complimentary treatments	1	0.5
	Physical activity during treatment	1	0.5
Rehabilitation-related information 133, 22.26%[1] (64.9% of articles, *n*=24/37)	Nutrition	21	15.8
	Bowel management	15	11.3
	General rehabilitation information	13	9.8
	Stoma care/ Stoma management/ Stoma formation	12	9.0
	Self-care issues during recovery	11	8.3
	Physical activity during rehabilitation	10	7.5
	Contact information for healthcare professionals	10	7.5
	Maintaining physical health or physical activity	8	6.0
	Recovery time	7	5.3
	Recognising or preventing complications following treatment	5	3.8
	Long-term post-treatment follow-up care	5	3.8
	Home care issues during recovery	4	3.0
	Immediate post-treatment follow-up care	4	3.0
	Maintaining psychological support during recovery	4	3.0
	Long-term side effects of cancer or treatment	2	1.5
	Where to get medical supplies or medical equipment	1	0.8
	Long-term side effects of cancer or treatment	1	0.8
Disease-related information 66, 12.06%[1] (72.3% of articles, *n*=27/37)	Specific diagnosis information	19	28.8
	General cancer-specific information	12	18.2
	Disease information	11	16.7
	Symptoms of cancer/management of symptoms	7	10.6
	Seeking second opinions	5	7.6
	Type of cancer/nature of disease	5	7.6
	Stage of disease	4	6.1
	Physical side effects of disease	2	3.0
	Aetiology and course of disease	1	1.5
Prognostic information 62, 11.5%[1] (62% of articles, *n*=23/37)	General prognostic information	14	22.6
	Life span or survival rate	10	16.1
	Recurrence of cancer	9	14.5
	Spread of disease or metastasis	8	12.9
	Outcome of no treatment or delayed treatment	7	11.3
	Chance of cure	6	9.7
	Effect on day-to-day activities	5	8.1
	Effect on life plan or long-term goals	2	3.2
	Expectations for future health condition	1	1.6
Coping information 32, 5.01%[1] (48.6% of articles, *n*=18/37)	General coping information	17	53.1
	Emotional reactions, emotional support, coping with cancer	11	34.4
	Support groups	3	9.4
	Community counselling or support	1	3.1
Interpersonal/ Social information 22, 4.08%[1] (37.8% of articles, *n*=14/37)	Effect on employment or work life	8	36.4
	General interpersonal/social information	8	36.4
	Effect on family, friends or caregivers	4	18.2
	Effect on social life or leisure	2	9.1
Body image/ fertility/ sexual information 14, 2.6%[1] (29.7% of articles, *n*=11/37)	Sexuality	5	35.7
	Physical appearance/physical attractiveness	5	35.7
	General body image/sexuality information	4	28.6
Medical system information 14, 2.6%[1] (32.4% of articles, *n*=12/37)	Interactions with healthcare providers	9	64.3
	Healthcare systems	3	21.4
	Experience or qualifications of physician and medical staff	1	7.1
	Available research	1	7.1
Financial/legal information 2, 0.37%[1] (5.4% of articles, *n*=2/37)	Cost of treatment, insurance coverage or other financial issues	2	100

[1] *Calculated by dividing the sum of individual items for each category by the number of total mentions of information needs (n=567)*

As the proportion of information given to patients was considerable (*n*=252:567, 44.5%), a sub-group analysis was performed (table 2.5). Although there was general congruity in terms of priorities, some noticeable differences emerged in certain categories.

Table 2. 5: Comparison of information sought by and given to patients

Information categories	Sought info (315 mentions)		Given info (252 mentions)	
	Mentions per category	$n_{articles}$	Mentions per category	$n_{articles}$
Treatment- related information	107	26/37	115	28/37
Rehabilitation- related information	72	19/37	61	17/37
Cancer-specific information	37	21/37	29	16/37
Prognostic information	42	20/37	20	9/37
Coping information	20	14/37	12	7/37
Interpersonal/ social information	18	13/37	4	3/37
Body image/sexuality information	8	8/37	6	4/37
Medical system information	10	8/37	4	4/37
Financial and legal information	1	1/37	1	1/37

Healthcare professionals received most mentions and appeared in the vast majority of the included studies (n=35/37, 94.6%). While physicians were most prominent, nurses also appeared to be an important source of information. Other types of health professionals included physiotherapists and dieticians (table 2.6).

Table 2. 6: Sources of information (105 mentions across 37 articles)

Category (n, % of total mentions)	Subcategory	Mentions per category	
		n	%
Healthcare professionals (57, 54.3%)	Physicians (e.g., doctors, surgeons, GPs)	30	53
	Nurses	19	33
	Other healthcare professionals	8	14
Printed material (19, 18.1%)	Leaflets, pamphlets, brochures, booklets	7	37
	General printed material	12	63
Media (16, 15.2%)	Internet	8	50
	General (e.g., DVDs, television)	8	50
Interpersonal (13, 12.4%)	Friends and family	8	62
	Support groups/other patients	3	23
	General	2	15

2.4.4. Satisfaction with information

17 out of 37 (45.9%) studies remarked upon patients' satisfaction with information. These studies either quantified this parameter or explored it from an in-depth perspective.

Six studies presented numerical data on patients' satisfaction with information. In most of these papers (Cha et al., 2012; Knowles, 1999; Lithner et al., 2012, 2015a), a considerable proportion of participants didn't have their information needs met. In Harrison et al. (2011), information provision accounted for almost 1/5 of unmet supportive care needs. Although satisfaction with information was not addressed explicitly in Reeve et al., (2017) all items in the domain of *exchanging information* (a measure of Patient-Centred Communication) scored a high average, indicating that patients received adequate information support during their treatment.

Eight studies that followed a qualitative design presented findings related to patients' satisfaction with information. In three studies, patients reported low satisfaction and concerns about not being adequately informed (Boe et al., 2019; Lithner et al., 2015b; Reinwalds, Blixter and Carlsson, 2017). Four studies suggested that patients were satisfied with the information they received, with only limited comments on improvement (Bailer, 2001; Poland et al., 2017; Spalding, 2013; Taylor and Norton, 2000). In Sawyer et al., (2008) participants were satisfied with the information given before surgery but reflected negatively upon the lack of post-operative information.

Two studies did not present data related to satisfaction with information, but several findings were indicative of inadequacies in this domain. In Scheer *et al*. (2012), patients were unaware of a variety of surgical outcomes, while in Broughton, Bailey and Liney, (2004) the majority of patients didn't have the opportunity to discuss post-discharge matters with their treating clinicians.

2.4.5. Desired volume/amount of information

Fourteen studies (n=14/37, 37.8%) presented findings related to the amount of information sought by patients. In the majority of these studies (n=10/14, 71.4%), there was a clear indication regarding the desired volume of information.

In three studies that presented numerical data, the majority of participants reported a desire for more information (Cha et al., 2012; Lithner et al., 2012, 2015a). In another quantitative study, only 1% of patients reported wanting less information and 17% of participants wished to know more (Bailer, 2001).

With regards to qualitative studies, three papers suggested that patients welcomed all available information (Lithner et al., 2015b; Poland et al., 2017; Spalding et al., 2013), one study pointed out that several patients would like more (Broughton, Bailey and Linney 2004), while and Bain et al. (2002) suggested that patients can't always cope with too much information. The type and timing of information appeared to play a role; in Taylor and Norton, (2000) patients expressed a wish for less pre-operative information and more post-operative advice, while Sanders and Skevington (2003) reported that some patients can feel that too much information is given at a single time point.

The remaining studies suggested that the desired amount of information can vary among participants. Two papers (Worster and Holmes, 2008; Worster and Holmes, 2009) pointed out that patients' needs can range from wanting to know as much as possible to just enough information in order to understand their condition and its treatment. A similar finding was evident in Knowles et al., (1999) where some patients reported that the information provided to them was insufficient, while others felt overloaded.

2.4.6. Most important types of information

Twelve studies (n=12/37, 32.4%) presented information that was regarded to be most important by patients. Forty-three types of information were mentioned, which were grouped in broader information categories using the same typology as table 2.3 (p. 50). Treatment-related information were most prominent (mentioned 15 times across 9 papers), followed by rehabilitation (12 mentions across 4 papers), disease (7 mentions across 6 papers) and prognostic information (5 mentions across 5 papers). Weight management and monitoring/follow-up appeared twice across two papers and interpersonal/social information appeared once.

While the aforementioned studies presented the information that was most important to patients explicitly, other papers provided indication as to which pieces were central for them. For example, in a survey-based study Lithner et al. (2012), the participants left written comments regarding the importance of treatment-related, prognostic and coping information. In Kidd et al., (2008) seeking information about treatment-related effects emerged as one of the most important coping strategies deployed by patients. Although no specific types of information appeared in Bain et al., (2002) the authors

emphasised upon the importance of disclosing 'bad news' to patients. Finally, treatment-related and prognostic information emerged multiple times in two studies that investigated the exchanges between patients and health professionals (Sanders and Skevington, 2003; Sanders and Skevington, 2004).

2.4.7. Information needs of patients' caregivers and/or family members

Five studies involved caregivers and/or family members of patients with CRC (Bain et al., 2002; Broughton, Bailey and Liney, 2004; Houldin, 2007; Poland et al., 2017; Spalding et al., 2013). Only one study involved caregivers alone (Houldin, 2007). Two studies explored the experiences of newly diagnosed patients and their caregivers (Broughton, Bailey and Liney, 2004; Houldin, 2007) and one study (Poland et al., 2017) outlined the process of developing a supportive intervention, where the authors used the perspectives of patients and caregivers in order to formulate its content. Only one study concentrated upon the domain of information support (Spalding et al., 2013), while no explicit mention of caregivers' information needs was identified in Bain et al., (2002).

Treatment-related information was again the main focus, as they appeared in all papers. Cancer-specific, as well as prognostic information was also important. The desired level of detail varied both across and within studies. In Broughton, Bailey and Liney, (2004) caregivers were not always sure about how much they wanted to know, whereas two studies (Spalding et al., 2013; Poland et al., 2017) suggested that they pursued detailed information. In Houldin, (2007) some caregivers wanted all available information, while others wished to concentrate upon positive aspects.

Across all studies, caregivers welcomed written information; in Broughton, Bailey and Liney, (2004), caregivers expressed dissatisfaction due to the lack of written information on post-discharge matters. The same authors suggested that caregivers appreciated the support offered by specialist nurses, who were regarded as the principal source of information. In Houldin, (2007) one caregiver explained being intimidated by information identified through the internet.

2.5. Discussion

2.5.1. Appropriateness of the type of review

The aim of this review was to synthesise the evidence around the information needs of patients with CRC at the early stages of treatment. As expected, the literature around patients' information needs was considerably diverse, thus making a meta-analysis of the retrieved data unfeasible. While studies that presented numerical data were identified, the variety of outcome measures and research methods (i.e., questionnaires) would not allow for the merge of this data into a single analysis. Yet, the summary typology adopted from van Mossel et al. (2012) was useful for identifying the types of information that mentioned in studies that presented findings related to information support.

A decision to conduct a meta-analysis would also result in the exclusion of qualitative studies, which accounted for more than half of the research conducted in this field. Although the quantification of patients' information needs provided an overview of their priorities, it was qualitative studies that offered invaluable insight in this domain. For example, patient satisfaction did not just depend upon delivering the desired types

and volume of information, but it was also associated with the setting (Lithner et al., 2015a; b), framing (Knowles et al., 1999; Spalding et al., 2013), timing (Houldin and Lewis, 2006) and clarity of information (Spalding et al., 2013); such factors were key in order to better appreciate how to fulfil patients' needs. Qualitative studies revealed a number of other considerations, which will be discussed in detail below.

2.5.2. Information sources

The role of health professionals in the provision of information support was significant. This was evident from the fact that they were mentioned across the vast majority of studies, as well as from explanations given by patients in qualitative papers. Kidd et al. (2008) explained that patients relied upon the knowledge and expertise of healthcare professionals in order to manage their condition and receive information on how to do so. In Reinwalds et al., (2017) patients expressed that they wouldn't trust information they came across unless they were endorsed by their treating clinicians, while Sanders and Skevington (2003) explained that the way that the way in which the oncologists communicated information played a major role in how patients got involved in the process of decision-making.

The availability of a reference point of information was another important aspect. Sanders and Skevington (2004) argued that the amount of information provided during the consultations is not always the issue but rather, it is the patients' inability to process them during that time. The availability of a reference point, as well as the repetition (Spalding et al., 2013) and endorsement (Poland et al., 2017) of information received by health providers appeared to be important for patients at that stage. Indeed, written information was the second most popular source across the identified studies. In

several papers, patients remarked upon the value of having information in writing, as it allowed them to revisit them at their own time (Knowles, 1999; Lithner et al., 2012, 2015b; Scheer et al., 2012). In Poland et al., (2017) patients welcomed an educational DVD, as it helped them interpret the information with greater accuracy. Ensuring access to such resources is hence key.

A surprising finding concerned the role of the internet as a source of information. According to Lleras de Frutos et al., (2020) the use of internet has increased exponentially in recent years, with as much as 97% of patients with cancer using it on a daily basis. However, explicit mentions of patients or caregivers using the internet to retrieve information appeared in just six papers and only two (Sawyer et al., 2008; Scheer et al., 2013) presented it as an important source. In Kidd et al., (2008) online information appeared to be important only during the early stages of treatment. Lithner, Klefsgard, et al. (2015) suggested that patients used the internet in order to confirm the information they received and learn more about their condition, while Reinwalds et al. (2017) asserted that patients turned to online information when they were not given sufficient support by healthcare professionals. One caregiver who used the internet in Houldin (2007) came across upsetting information and refrained from looking further. While it is possible that patients with CRC relied more upon their clinicians and printed resources to retrieve information, it is also likely that the use of the internet was not represented adequately in these studies. Further and more focused research is required in order to achieve a better understanding of the role of the internet in patients with CRC.

2.5.3. Information priorities and volume of information

The findings suggested congruity between the top priorities (treatment, rehabilitation, disease and prognostic information) that were mentioned explicitly by patients and the types of information that appeared mostly across the literature. Yet this finding should be interpreted with caution, due to the inability of conducting formal statistical analysis of these results.

Treatment-related information took central stage at this phase of the care continuum and rehabilitation- related information were the second most popular domain. The latter stroke as an unexpected finding, considering that this review focused upon the initial stages of treatment. This could be explained by the large number of studies that focused upon patients who received surgical treatment (*n*=17/37). As most of these studies included patients in the early post-operative phase, it is reasonable that such information was prevalent, as it was relevant at this stage.

While nutrition-related information emerged several times, there was only one study (Cha et al., 2012) dedicated to patients' needs around nutrition; furthermore, this aspect was not formally assessed or explored in any of the other studies. A similar finding was identified in van Mossel's et al. (2012) scoping review, where the authors pointed out that the nutritional needs of patients with CRC did not receive much attention by researchers. Apart from Cha's study, the search revealed only one in-depth study (James-Martin et al., 2014) that explored the information needs of survivors and patients around nutrition and exercise (which was rejected due to the inclusion/exclusion criteria), suggesting that this area still remains relatively under researched.

As mentioned in Chapter 1, some individuals might want to know as little as possible, while others can choose to avoid information altogether (pp. 6-7). Although this review did not identify any resources suggesting that patients with CRC completely avoided information, results regarding the volume of information and the desired level of detail appeared to be in line with findings from the general literature around the information behaviour of patients with cancer. This observation indicates the need for assessing the demands of individual patients in order to deliver the right volume of information and not burden them with unwanted material.

Indeed, the personalisation of information emerged as an key consideration regarding not only the volume, but also the types of information pursued by patients with CRC. This was evident in certain studies where the participants explicitly requested individualised information about their condition and treatment (Poland et al., 2017; Sawyer et al., 2008; Spalding et al., 2013). Lithner et al. (2012) remarked upon the lack of personalised post-operative education and pointed out that tailored information should be provided through this phase. The significance of providing personalised information to patients was also brought up by nurse responders in Worster and Holmes (2008). Finally, Taylor and Norton (2000) explained that printed resources should not be regarded as a replacement to the process of assessing individual patient needs and providing tailored advice according to their requirements. Instead, the authors proposed that supporting material should provide a discussion focus or act as reminders of what was discussed during the consultations.

2.5.4. Pitfalls in information support

Apart from providing an overview of the information needs of patients with CRC, the present review also identified several pitfalls in this domain. An important finding was that only a few studies (6/37, 16.2%) were dedicated exclusively to information needs and most studies presented them as a secondary finding. This was widely abundant in qualitative studies where authors attempted to explore patients' experiences with a diagnosis of CRC and/or their experiences during their treatment. In such studies, information emerged as either an important aspect of supportive care or patients described the types of information that were discussed with them. In quantitative studies, information needs and/or satisfaction with information appeared as sections in questionnaires assessing supportive needs, satisfaction with care and health-related quality of life.

A similar observation was apparent in van Mossel *et al.* (2012), where the authors pointed out that studies focusing upon patients' information demands were scarce. As mentioned in the introduction chapter (p. 1), the diagnosis of a malignant disease can exert a tremendous impact upon individuals. Studies carried out at this phase of the care continuum appeared to provide an overview of what is involved at that stage, including lived experiences, psychological responses and general supportive care needs. Perhaps this is the reason why information needs were rarely examined alone; rather, they were presented or emerged as a key part of a patient's overall care.

Due to the limited amount of evidence, it was not possible to draw definitive conclusions regarding patients' satisfaction with information. Yet, the present review identified several issues, as the majority of studies where satisfaction with information

was either assessed or emerged through the data revealed inadequacies in this domain. While poor information support caused uncertainty and worry to some, the limited or non-disclosure of information appeared to have a much more detrimental impact upon others (Bain and Campbell, 2000; Boe et al., 2018). For example, Reinwalds et al. (2017) demonstrated that the limited information on nutrition and medicines resulted in poor bowel management, while Scheer et al. (2012) pointed out that the lack of information interfered with patients' capacity of making future decisions about their care.

The review also identified some factors that had a negative influence upon the provision of robust information support. Almost half (48.6%) of the identified studies did not mention whether or not patients received written information during this stage. Patients appeared to value written accounts, as they provided the potential of revisiting aspects that were not retained or discussed during their exchanges with healthcare professionals. The lack of such point of reference was perceived negatively by some; in Lithner et al., (2015b) patients remarked upon the lack of written material (e.g. booklets, leaflets etc), which forced them to look for information themselves. As patients felt that they were not always able to process the information they retrieved or held doubts about the trustworthiness of such information, they expressed dissatisfaction and worry.

As mentioned earlier, health professionals play a key role in the provision information support. However, they can also exert a negative influence upon this process. In some papers, patients expressed concerns about having information withheld, which gave rise to fear and uncertainty (Bain and Campbell, 2000; Lithner et al., 2015b). In several studies, the lack of provision of written information by health providers stood out as a

negative, as patients expected them to offer such resources (Lithner et al., 2012; Worster and Holmes, 2009). Confusion, misunderstandings and conflicting information were also evident, which compromised patients' trust in their treating staff (Knowles et al., 1999; Worster and Holmes, 2009). Some authors also remarked upon the differences in perceptions between patients and providers. For instance, Scheer et al. (2012) noted clear disparities between patients' and professionals' information priorities. In Poland et al., (2017) clinicians were concerned that they did not spend sufficient time with patients in order to provide them the information they desired, but patients felt like they had the chance to discuss everything they wanted, indicating the differences in opinions regarding what is adequate.

2.5.5. Limitations

As mentioned in the previous section, the vast majority of studies presented information needs as a secondary finding or briefly mentioned the types of information provided to the study participants. Due to this, the present review should not be regarded as a definitive account of the information needs of patients with CRC at the early stages of the cancer care continuum. However, it can be argued that the information that appeared in these papers represent the most salient types of information sought and/or given in practice and therefore provide valuable indication as to patients' priorities.

Another limitation concerned the identification of relevant literature. In some cases, the data of interest was almost 'hidden' within articles. For instance, some authors presented the information that was given to patients as part of disclosure about an intervention they were about to receive (Dronkers et al., 2010; Weaver et al., 2007;

Young et al., 2010). These authors presented such information in the methods section of their articles, which was an unusual place to identify such data. As a result, it is likely that the present review has missed papers that contained such data, despite the robustness of the search strategy.

2.5.6. Recommendations for practice and future research

The search process identified a large number of papers (>100, including studies rejected by titles and abstracts) that focused upon the post-treatment period. This is in line with findings from other systematic reviews, where the vast majority of studies were concerned with the later stages of the cancer care continuum (Kotronoulas et al., 2017; van Mossel et al., 2012). It appears that while there is considerable interest in the post-treatment phase, the initial diagnosis and early treatment stages have not received equal attention in CRC. This indicates the need for further research concentrating upon the early stages of treatment in order to better understand the information needs of these patients during that time.

Another finding derived from the search process was that many studies included patients at various stages of the care continuum and/or involved patients with different types of cancer without performing analyses for the sub-groups in their samples. As mentioned in p. 40, the information needs of patients can change across their care pathway. Hence, pooling data from patients at different stages of treatment can potentially affect the findings and not adequately reflect the overall picture. Combining data from patients with different types of cancer can also be problematic, as differences between the information needs of patients with different forms of the condition have been previously reported (Nagler et al., 2010). Researchers should take these

considerations into account in order to achieve consistency in their samples and perform sub-group analyses if there is heterogeneity in their participant cohorts.

Although a meta-analysis of data derived from studies with a quantitative design could potentially provide a more concise overview of patients' needs, it was not possible to conduct one due to the variety of measurement tools. Authors should consider using validated and consistent data collection methods across their studies in order to enable future reviewers to summarise their findings in a robust manner. Another prominent consideration was the sample of these studies. Quantitative studies involved a limited number of participants (median 100, range 21-702), deployed non-probability sampling techniques and only half recruited participants from multiple research sites. This reveals the need for larger-scale studies with adequate samples so that findings more adequately reflect the needs of the desired patient population.

Apart from the need for more robust studies to serve the purpose of breadth, this review also indicated the need for further in-depth research on patients' information needs. While qualitative studies offered valuable insight, only two studies focused exclusively upon the information needs of patients with CRC at the early stages of treatment (Lithner et al., 2015b;Taylor and Norton, 2000). Hence, additional qualitative studies focusing on this particular aspect are required in order to build a more robust evidence base.

The present review also revealed several considerations for practice. First and foremost is the role of health providers in providing effective information support. It appears that the communication of information between patients and healthcare professionals can be problematic, which is also observed in other studies in the field of cancer care

(Parker, Aaron and Baile, 2009; Thorne et al., 2013). This could be improved by assessing the needs of individual patients and providing honest information so that patients receive adequate support throughout their care. Health providers should also take care to ensure that sufficient material is supplied to patients so they can have access to a point of reference for their queries.

2.6. Considerations for the app's content

The findings of the present review were significant not only for deciding upon specific pieces of information that would be included in the app, but also informed the general approach. Perhaps the most prominent finding of this review was that no assumptions should be made about what patients wish to know. Indeed, information demands appeared to vary across individuals and assuming that everybody wants to know as much as possible because the majority of patients has such demands would not be valid. This concerns not only the volume, but also the types of information. For instance, patients welcomed graphic information, despite the assumption that such information would upset them (Lithner et al., 2015b; Spalding et al., 2013). Henceforth, liaising with patients would be necessary in order to validate ideas and receive recommendations on what should be included in the app.

The framing of information emerged as another prominent consideration. Whilst appreciating honest advice, being left with hope was also important (Bain et al., 2002). Information should be framed in a way that preserves honesty but at the same time, does not diminish confidence; indeed, presenting information in an insensitive manner can cause uneasiness and upset patients (Bain and Campbell, 2000). The use of plain language and avoidance of technical terminology was another key consideration, as the

use of technical terms and medical jargon can potentially hinder patients' understanding (Broughton, Bailey and Linney, 2004). Being reassured about the availability of support also appeared to be important (Lithner et al., 2015b). Such aspects were key in order to formulate content that would not only cover users' information needs, but also consider salient points that would increase comfort.

Another consideration was the role of health professionals in information support. Healthcare professionals appear to be the principal source for health-related information, as they were cited in the vast majority of the included studies. Therefore, the perspectives of clinicians would also be useful for formulating the content of a supportive intervention. It was determined that physicians, as well as nurses with experience in cancer care would be consulted in order to offer their perspectives and recommendations regarding the content of the app.

2.7. Chapter summary

The review explored the information needs of patients with CRC at the early stages of treatment. While the initial goal was to provide a summary of the information needs identified in eligible studies, the narrative synthesis revealed a number of key points that were not considered prior to the conduct of the review. Perhaps the most important outcome was the necessity of consulting with the patients rather than deploying a 'one size fits all approach'. While gaining an understanding of these patients' information needs was important, involving patients with CRC in the build-up stage would be an integral part of the development of the app. The next chapter of the thesis will outline the process of developing the app that was later tested with patients in a real setting.

Chapter 3: Intervention design and development

Chapter 2 outlined the findings of a systematic review around the information needs of patients with colorectal cancer (CRC). This chapter presents the overall procedure for developing the pilot version of the project's intervention, a virtual agent (VA)-based information support app for patients with CRC. This included two main stages, namely the pre-development stage and the draft design stage. Each of these stages included a number of components, which will be discussed in detail below.

3.1. Pre-development stage

The pre-development stage was concerned with utilising input in order to build the initial version of the app, which would be tested in the pilot study. This stage included six phases, inspired by the National Health Service (NHS) guide for developing health apps (NHS Innovations South East, 2014):

a. Consultation with stakeholders
b. Familiarisation with guidelines for developing and evaluating mobile health (mHealth) interventions
c. Identification and review of commercially available apps for patients with CRC
d. Formulation of the app's draft content
e. Utilisation of clinician input on the draft content
f. Patient and Public Involvement and Engagement (PPIE)

The abovementioned phases were conducted in chronological order. The following sections will expand on each of these phases.

3.1.1. Liaison with stakeholders

Stakeholders were clinicians from the Churchill Hospital, part of the Oxford University Hospitals (OUH), who helped identify an appropriate patient population, provided access to patients and offered recommendations about the app's content. Consulting with them was also necessary in order to find out if there were any existing apps recommended to patients as a part of standard care either at a national or local level, as such apps would constitute potation competitors.

Clinicians suggested that a supportive app would be most beneficial to patients with CRC receiving chemotherapy with XELOX (Oxaliplatin and Capecitabine) for the first time. This was because XELOX is a highly emetogenic treatment, which requires extensive counselling and continued support during chemotherapy. Furthermore, CRC is a condition that can cause drastic changes (e.g., dietary, physical, emotional) to patients' lifestyles and hence these individuals require a high degree of information support in order to deal with their condition. At the time of the study, there were no alternative apps recommended as part of standard care from OUH or the NHS apps library.

3.1.2. Guidelines for developing mHealth interventions

According to Mosa, Yoo and Sheets, (2012) the development of mHealth interventions should be based upon robust frameworks; yet, van Velthoven et al. (2018) pointed out that up to date, there are no agreed standards for the development and evaluation of mHealth interventions. An exploration of the literature was therefore performed to

identify resources around the development of mHealth interventions and bring them together to construct a framework for developing this project's intervention.

The first identified resource was the NHS Guide for Developing Mobile Healthcare Interventions, which provides a thorough development process towards building high-quality health applications (NHS Innovations South East, 2014). As this guidance focuses upon the development of commercial apps, it included directions that did not apply to this project. Nevertheless, the sections concerned with the initial development process were applicable and were hence utilised.

Another useful resource was a review published by Darlow and Wen, (2016) which explored the development of mHealth interventions for patients with cancer. The authors remarked upon the importance of stakeholder engagement, as well as an understanding of patients' needs in order to formulate interventions that address their requirements. This resource also provided a theoretical perspective in the development process and offered concise directions about the methodological approach for developing mHealth interventions by presenting examples from the literature.

In order to get an appreciation of the characteristics of robust health apps, two additional resources were consulted. The first was a checklist from the Royal College of Physicians, which was designed to help healthcare professionals identify high-quality health apps (Wyatt et al., 2015). The second resource was the Mobile Application Rating Scale (MARS), a validated tool designed for researchers and developers for assessing the quality of health apps (Stoyanov et al., 2016). Both of these resources provided useful insight and were used as checklists for ensuring that the project's intervention was designed under high standards.

3.1.3. Review of existing apps for patients with colorectal cancer

In the NHS Guide for Developing Mobile Healthcare Interventions, identifying what is already available to the intended user population is defined as '*competitive analysis*' and constitutes the second step of the pre-development process. Although a competitive analysis is mainly applicable to commercial apps, this step was also of value for this research project.

Rationale and aims

Identifying commercially available apps for patients with CRC was necessary in order to find out if any similar apps were available to patients and detect potential competitors. An assessment of the features of these apps would also help identify potential pitfalls in this domain, which would inform the development process.

The objectives of this review were to a) provide an overview of the general characteristics of commercially available apps with content for CRC, b) perform an assessment of their usability and determine the quality of their content and c) compare apps with high ratings to apps with low ratings to identify differences. As user ratings are considered to be an important indicator of an app's popularity (Gomes et al., 2016), it was determined that this measure would be used to identify the most commercially successful apps, which would in turn provide indication of the aspects valued the most by users, thereby informing the development process of this project's intervention.

Methods

The major app stores (Apple store and Google Play) were searched at regular intervals from January 2017 to June 2018. As developers can use variations of medical terms in the description of their apps (Grundy, Wang and Bero, 2016; Paglialonga, Lugo and Santoro, 2018), the terms *colorectal cancer*, *bowel cancer*, *colon cancer* and *rectal cancer* were used in order to identify as many relevant apps as possible.

The apps retrieved by the search were initially screened for eligibility on the basis of their description in their respective app stores (*Table 3.1*). Apps whose description fitted any of the inclusion criteria were installed and screened again against the same criteria in order to ensure that they were relevant to patients with CRC. Apps whose description was either not clear or absent were also installed and screened against the same criteria.

Table 3. 1: Inclusion/exclusion criteria for the apps retrieved by the search

Inclusion criteria	Exclusion criteria
• Apps intended for use by patients with CRC or their caregivers • Apps with content specific to CRC • Apps with content covering multiple conditions (cancer and non-cancer) but also included a section for CRC	• Apps designed for professionals or students • Content irrelevant to CRC • Content covering multiple conditions without a section for CRC • Content not available • Apps about prevention/awareness of CRC • Apps in foreign languages

Data extraction

The following characteristics were recorded for apps that fulfilled the eligibility criteria after full screening:

- Year of release
- Origin of the app (Educational organisations, small and medium enterprises (SMEs), patient organisations, healthcare agencies, non-government agencies and individual developers)
- Classification of the app (medical, educational, health and fitness, business, news, other)
- User ratings, user reviews and number of downloads
- Purpose of the app (fundraising, promotion of healthcare professionals and practices, disease and treatment information, scientific/research news, dietary advice, physical activity, social networking, alternative treatments, treatment diary, spiritual support, miscellaneous)
- Specificity to CRC

There are two different approaches in appraising apps, namely the description-based and content-based appraisal; although the latter is more time consuming, it can allow for more reliable assessment, as app descriptions can sometimes be inaccurate or misleading (Paglialonga, Lugo and Santoro, 2018). Thus, potentially eligible apps were installed and inspected in detail in order to comment upon their quality.

The characterisation typology included two criteria, namely the quality of content and degree of usability (Giunti et al., 2018; Grundy, Wang and Bero, 2016; Nouri et al., 2018). Each of these criteria contained certain measures, which in turn included a number of parameters (*Tables 3.2 and 3.3*). Each of these parameters was coded with 0 if not present and 1 if present in accordance with previous research (Broderick et al., 2014; Caburnay et al., 2015; Ginossar et al., 2017).

Table 3. 2: Usability assessment parameters

Usability measures	Corresponding usability parameters
Organisation of content	Presence of homepage button, presence of menu button, presence of back button, presence of search function, integration with mail, integration with calendar
Display of content	Links labelled clearly, use of images, use of bold colours and contrast
Use of plan language	Use of everyday words/ avoidance of technical terminology, use of personal pronouns, use of action words, use of active voice, use of present tense, use of short sentences
Engagement of users	Printer-friendly tools and resources, inclusion of interactive content, inclusion of audio or video features
User support	Availability of user support

Table 3.3: Content assessment parameters

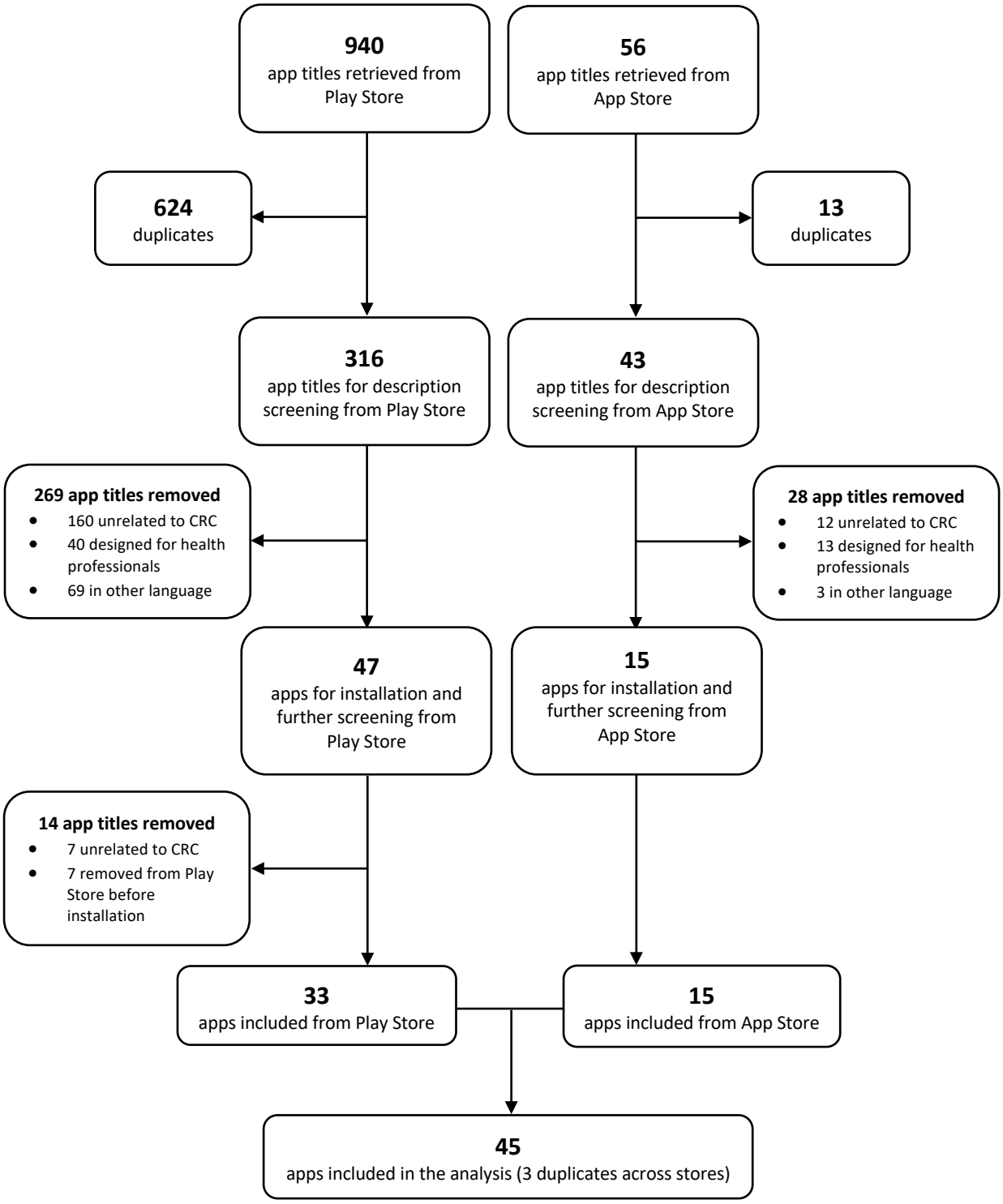
Content quality measures	Content quality parameters
Quality of information	Presence of citations, affiliation with credible organisation, accordance with guidelines and evidence base, clinical involvement
Currency of information	Content updated within the last 12 months
Authority of developer	Credibility and trustworthiness
Efficacy and impact	Results from studies, Randomised controlled trials and/or systematic reviews

Search results

The search yielded 996 hits in total. 940 apps were derived from the Play store and 56 from the Apple Store. Duplicates were removed within stores, yielding 316 apps from the Play Store and 43 from the App store. 47 potentially eligible apps were identified through the Play store and 15 thought the Apple store. Three potentially eligible apps were common across stores, which were downloaded from both stores for further inspection. In total, 62 apps were candidates for full screening. Apps from the Play Store were installed on a Samsung Galaxy A7 and apps from the Apple store were installed on an iPhone 6s Plus (both run on the latest software). After applying the exclusion criteria, seven of the potentially eligible apps from the Play Store were rejected on the basis of their content. Further seven apps from the Play store were also excluded, as they were removed from the store before they could be installed for further investigation.

Ultimately, 33 apps were kept from the Play Store and 15 apps were kept from the Apple Store (Figure 3.1). These apps were analysed in their respective store groups and were then merged to provide an overview of the apps available to patients with CRC. Three duplicates were identified, which were identical in terms of content and layout across stores.

Figure 3. 1: Screening process for installed apps



Overall Descriptive Characterisation

Table 3.4 presents the results of the overall descriptive characterisation. The vast majority of apps were available free of charge. Most of the eligible apps were tagged as 'Medical', followed by 'Health and Fitness'. The majority of apps served a single purpose. Nine interventions provided treatment-related information only, while two apps focused solely upon research news; most of these apps referred their users to websites, journals and organisations to access the latest advancements in research around CRC and its treatment. Two apps provided links to medicinal suppliers and one app was designed purely for entertainment purposes (classified as 'other').

Data on downloads, customer reviews and ratings were absent for apps derived from the Apple Store. In contrast, the Play store provided a detailed account of the number of downloads and included ratings, as well as customer reviews for most of its apps. A considerable proportion had more than 10,000 downloads and almost half of these apps received above 4 stars.

Most of the identified apps were developed by small and medium enterprises, while a considerable proportion was created by individual developers. A limited number of apps were developed by non-government agencies or educational organisations in both stores and only one app was developed by a healthcare agency in the Apple store. No apps originated from patient organisations.

Table 3. 4: Descriptive characterisation of identified apps

		iOS, n=15	Android, n=33	Total, n=45[1]
Year of release	2012	1	2	3
	2013	-	1	1
	2014	3	4	5
	2015	2	2	4
	2016	2	8	10
	2017	3	10	12
	2018	1	6	7
	Not available/ Missing	3	-	3
Origin of the app	Healthcare agencies	1	1	1
	Non-government agencies	2	1	2
	Educational organisations	1	-	1
	Small and medium enterprises	8	23	30
	Individual developers	3	8	11
Classification of the app	Medical	6	18	22
	Education	1	4	4
	Health and Fitness	4	8	12
	Business	1	-	1
	News	2	-	2
	Other	1	3	4
Price	Free	10	31	39
	£0.5-£0.99	1	-	1
	£1.00-£1.99	-	1	1
	£2.00-£2.99	2	-	2
	£3.00-£3.99	1	1	1
	£4 and above	1	-	1
Rating	1-2.0	-	1	1
	2.1-3	-	1	1
	3.1-4	-	6	6
	4.1-5	-	16	16
	Not available	15	9	21
Number of reviews	1-10	-	13	13
	11-19	-	3	3
	20-29	-	1	1
	40-49	-	1	1
	50 and above	-	6	6
	No reviews	15	9	21
Downloads	0-10	-	2	2
	11-49	-	2	2
	50-99	-	2	2
	100-499	-	4	4
	500-999	-	8	8
	more than 1000	-	7	7
	more than 10,000	-	7	7
	Not available	15	1	13
CRC Specific	Yes	4	9	11
	No	9	23	32
	Missing/Unclear	2	1	2

[1]*Three duplicates were present, which were identical in both stores*

The App store contained more apps serving multiple purposes compared to the Play store; overall, fifteen apps served multiple purposes across both stores (*Table 3.5*). The vast majority of these apps provided information about cancer and its treatment, as well as information on diet and nutrition. Information about physical activity and special exercises were also offered by than a half of these apps. Five apps included a treatment and symptom diary function, while three apps provided information about alternative treatments.

Table 3. 5: Purposes of apps for CRC

	Single purpose			Multiple purposes		
	iOS (n=8)	Android (n=23)	Total (n=30[1])	iOS (n=7)	Android (n=10)	Total (n=15[2])
Fundraising	-	-	-	2	1	2
Promotion of health professionals and practices	2	-	2	1	-	1
Disease/treatment information	1	9	10	6	9	13
Scientific/research news	2	3	5	2	1	2
Dietary advice	1	1	1	5	9	12
Physical activity/special exercises	-	-	-	6	4	8
Social networking	-	2	2	3	1	3
Treatment diary	-	3	3	2	3	5
Alternative treatments	-	2	2	2	1	3
Spiritual support	-	-	-	2	-	2
Miscellaneous	1	2	3	1	-	1
Missing	1	1	2	-	-	-

[1]One duplicate was present, which was identical in both stores; [2]Two duplicates were present, which were identical in both stores

Assessment of content and usability

The content assessment (*Table 3.6*) indicated mainly weaknesses in the quality of the apps' content. The vast majority of the apps showed no evidence of clinical involvement

or affiliation with a credible organisation. The majority of these apps also did not present any references for any medicinal claims or information provided, while the content of almost half of the apps was outdated by over a year. Almost half of the apps (48.7%) were developed by a trustworthy developer (e.g., experienced in developing health apps including a health app portfolio, endorsed by a credible organisation) and none of them was tested in a study or included in a review.

Table 3. 6: Quality of content in identified apps

Content quality measures	Content quality parameters	iOS n=15	Android n=33	Total n=45[3]
Quality of the app's content	Presence of citations	4	10[1]	13[2]
	Affiliation with credible organisation	6	4[1]	8[2]
	Accordance with guidelines and EB	1	-[1]	1[2]
	Clinical involvement	4	1[1]	4[2]
Authority of the developer	Credibility and trustworthiness	5	1[1]	4[2]
Currency of information	Updated within the last 12 months	9	15[1]	22[2]

[1] Parameter not applicable for 5 apps and unavailable for 5 apps; [2] Parameter not applicable for 1 app and unavailable for 5 apps[3]Three duplicates present, which were identical across stores

Overall, the identified apps scored either slightly above or below 50% for most usability measures (*Table 3.7*). The majority included a homepage, menu and back button and more than half of the apps used bold colours and contrast, as well as images to aid user learning. With respect to the use of plain language, most apps used one or more parameters. The most neglected usability parameter was the engagement of users, while only a few apps offered integration with calendar.

Table 3. 7: Usability assessment of identified apps

Usability measures	Usability parameters	iOS n=15	Android n=33	Total n=45[6]
User Support	Availability of user support	8	14[2]	22[2]
Use of plain language	Use of common and everyday words/avoidance of technical terms	4[1]	13[3]	18[5]
	Use of personal pronouns	4[1]	11[3]	15[5]
	Use of action words	4[1]	12[3]	16[5]
	Use of active voice	5[1]	12[3]	18[5]
	Use of present tense	5[1]	18[3]	24[5]
	Use of short sentences	5[1]	19[3]	24[5]
Display of content	Links labelled clearly	7	11[4]	19[4]
	Use of images to facilitate learning	7	14[4]	22[4]
	Use of bold colours and contrast	7	16[4]	25[4]
Organisation of content	Presence of homepage button	9	20[4]	31[4]
	Presence of menu button	9	19[4]	30[4]
	Inclusion of 'back' button	9	19[4]	29[4]
	Search and browse function	4	13[4]	17[4]
	Integration with email	4	13[4]	18[4]
	Integration with calendar	2	2[4]	4[4]
Engagement of users	Printer-friendly tools and resources	1	6[4]	7[4]
	Inclusion of interactive content	5	4[4]	8[4]
	Inclusion of audio or visual features	6	5[4]	10[4]

[1]Parameter not applicable for 1 app; [2]Parameter not available for 5 apps;[3]Parameter not applicable for 5 apps and unavailable for 5 apps; [4]Parameter unavailable for 5 apps; [5]Parameter not applicable for 6 apps and unavailable for 5 apps[6]Three duplicates present, which were identical across stores

Characteristics of high-rated apps and comparison with low-rated apps

Sixteen apps received high ratings from users (*Table 3.8*). All of these apps were derived from the Play Store; as the apps offered by the App Store did not have any ratings, they were not included in this part of the research. The majority of the highest-rated apps were classified as medical, followed by educational. Most of these apps served a single

purpose and almost half provided disease and treatment-related information. In contrast, the majority of the lowest-rated apps served multiple purposes.

Table 3. 8: General characteristics of the highest and lowest-rated apps

		High ratings (n=16)		Low ratings (n=8)	
		n	%	n	%
Number of reviews	1-10	6	37.5	7	87.5
	11-19	3	18.75	-	-
	20-29	-	-	1	12.5
	40-49	1	6.25	-	-
	50 and above	6	37.5	-	-
Downloads	100-499	-	-	3	37.5
	500-999	7	43.75	1	12.5
	more than 1000	2	12.5	4	50
	more than 10,000	7	43.75	-	-
Classification	Medical	10	62.5	4	50
	Education	2	12.5	1	12.5
	Health and Fitness	2	12.5	3	37.5
	Other	2	12.5	-	-
Purpose of the app	Disease and treatment information/ educational	7	43.75	1	12.5
	Scientific/research news	1	6.25	1	12.5
	Social networking	2	12.5	-	-
	Alternative treatments	1	6.25	-	-
	Treatment diary	1	6.25	1	12.5
	Multiple purposes	2	12.5	5	62.5
	Miscellaneous	2	12.5	-	-
Origin of the app	Non-government agencies	-	-	1	12.5
	Small and medium enterprises (SMEs)	12	75	5	62.5
	Individual developers	4	25	2	25

Usability issues were highly prevalent among the highest-ranked apps (*Table 3.9*). Only half of these apps provided user support and only a few deployed user engagement strategies. Issues regarding the display of content, as well as the use of plain language were similar in both top and low-rated apps. The only domain where the highest-rated apps appeared to perform better was the organisation of content.

Table 3. 9: Usability parameters of the highest and lowest-rated apps

Usability measures	Usability parameters	High ratings (n=16)		Low ratings (n=8)	
		n	Mean	n	Mean
Use of plain language	Use of everyday words/avoidance of technical terms	8[1]	0.62	2[2]	0.33
	Use of personal pronouns	5[1]	0.38	3[2]	0.50
	Use of action words	6[1]	0.46	3[2]	0.50
	Use of active voice	6[1]	0.46	3[2]	0.50
	Use of present tense	9[1]	0.69	5[2]	0.83
	Use of short sentences	11[1]	0.85	4[2]	0.67
Clear display of content	Links labelled clearly	6	0.38	2[3]	0.29
	Use of images to facilitate learning	8	0.50	3[3]	0.43
	Use of bold colours and contrast	10	0.63	2[3]	0.29
Organisation of content	Ease of access to homepage (homepage button)	13	0.81	3[3]	0.43
	Ease of access to a menu page (menu button)	12	0.75	3[3]	0.43
	Inclusion of 'back' button	13	0.81	3[3]	0.43
	Search and browse function	9	0.56	2[3]	0.29
	Integration with email	9	0.56	3[3]	0.43
	Integration with calendar	2	0.13	-	-
Engagement of users	Printer-friendly tools and resources	6	0.38	-	-
	Inclusion of interactive content	3	0.19	1[3]	0.14
	Inclusion of audio or visual features	2	0.13	2[3]	0.29
User Support	Availability of user support	8	0.5	4	0.5

[1] Parameter not applicable for three apps; [2]Parameter not applicable for two apps; [3] Parameter not applicable for one app

Only half of the highest-ranked apps included citations, while none of them reported clinical involvement in the developmental phase or had content formulated according to official guidelines and/or evidence base; moreover, less than half of these apps had updated their content within the last 12 months and none of them was developed by a credible source (*Table 3.10)*. The apps that received lower ratings also suffered from quality issues, as the vast majority did not include any citations, and more than half did not update their content in more than a year.

Table 3. 10: Content quality parameters of the highest and lowest- rated apps

Content quality measures	Content quality parameters	High ratings (n=16)		Low ratings (n=8)	
		n	Mean	n	Mean
Quality of the app's content	Presence of citations	6[1]	0.5	1[2]	0.17
	Affiliation with credible organisation	2[1]	0.17	1[2]	0.17
Currency of information (frequency of updates)	Updated within the last 12 months	7	0.44	3	0.38
	Updated more than 12 months ago	9	0.56	5	0.63

[1] Parameter not applicable for four apps; [2] Parameter not applicable for two apps

Discussion

The number of apps for patients with CRC has increased almost ten-fold in less than a decade (O'Neill and Brady, 2012). The purpose of this review was to assess commercially available apps for patients with CRC to inform the development process of the project's intervention. The search strategy identified 45 apps available through the major app stores, which were then screened against a set of objective measures to assess the quality of their content and usability.

Most of the identified apps deployed little usability measures for improving the user interface. The identification of these issues in the majority of the top-rated apps was an unexpected finding, since the degree of usability is a key aspect affecting users' preference for a particular app (Liew et al., 2019). This could be explained by considering that usability can be a subjective matter (Pitkänen, 2016) and therefore, the objective measures utilised by this report might have not captured usability as users envision it.

The vast majority of identified apps did not employ any strategies to engage users. Garnett et al. (2015) pointed out that the lack of engagement strategies in mHealth can potentially increase attrition rates and compromise the success of these interventions. The use of plain language was another issue, as the majority of the apps did not utilise measures to achieve it. This issue was also noted in previous research involving apps for breast cancer, where the authors pointed out that the use of inappropriate language can hinder users' understanding, which can in turn impede their experience with the interface (Ginossar et al., 2017).

More alarmingly, the findings of this review demonstrated that the content of most apps for CRC was of questionable quality. The absence of citations or references in more than half of these apps, as well as the outdated content in almost half of these interventions also raised concerns about the validity of information. The lack of expert input was also apparent. This was also evident in previous research, where authors have remarked upon the lack of expert involvement in commercially available apps for cancer (Brouard et al., 2016). Such apps have raised concerns about their safety and appropriateness and authors continuously call for improvements in this domain (Charbonneau et al., 2020).

A noteworthy finding was the identification of quality issues in the content of the highest- rated apps. In contrast with usability issues, this finding was not entirely unexpected. Singh et al. (2016) suggested that high ratings are not always indicative of quality content, which was also supported by the findings of this review. Henson et al. (2019) pointed out that users are not always able to determine the appropriateness or safety of health apps, which makes them prone to using interventions of questionable

quality that can potentially put them at risk. Although this finding might not be surprising, this certainly raises concerns about the impact of such apps, especially considering their large uptake.

At the time of this review there were no CRC- specific apps endorsed by the NHS health app library, nor any apps recommended by other official organisations such as Maggie's, Bowel Cancer.org and MacMillan. In the absence of recommendations, patients could potentially install apps that have not been assessed for safety and appropriateness by credible organisations. This has been previously proposed in Akbar, Coiera and Magrabi, (2020) who asserted that official organisations, healthcare professionals and support groups should take care to warn patients about the risks of such interventions and recommend reliable apps to ensure that patients receive appropriate advice based on robust evidence.

Another noteworthy finding was the absence of ratings and reviews for apps identified through the App store. While it could be argued that this was indicative of low popularity, the absence of data on the number of downloads would make such an assumption unsubstantiated (i.e., the App store does not provide data on the number of downloads). Yet, it can be argued that health apps in the App store did not receive as much attention as their counterparts did in the Play store. This could be explained by considering the size of the operating system (OS) market. A market analysis revealed that 85% of smartphone users owned Android devices, while only 15% possessed devices that run under iOS in 2018 (IDC, 2020). Hence, the poor uptake of these interventions could be attributed to the limited size of the target user audience rather than actual popularity.

This review has two limitations. The first is the absence of a validated instrument for assessing the identified apps. Thus far, the only validated tool for assessing health apps is the Mobile App Rating Scale (MARS), but some of its criteria rely upon subjective user accounts of the assessors and would introduce bias (Nouri et al., 2018). Wisnieski et al. (2019) pointed out that aspects such as usability can be highly subjective and therefore should be utilised with caution when attempting to assess a health app. This review hence relied upon a custom assessment typology based upon objective criteria identified from the literature in order to minimise the risk of bias whilst evaluating the retrieved apps.

The second limitation is that the review did not include generic cancer apps that could potentially be utilised by patients with CRC. The app cancer market includes more than one-thousand apps (Giunti et al., 2018). Although some apps target specific types of cancer, others provide generic services such as symptom tracking, medication reminders and glossaries and do not focus upon a particular audience. Hence, unless developers used terms related to CRC in the description of these apps, interventions that could be used by patients with CRC were inevitably missed by the search.

Summary of the competitive analysis and implications for the development process

The findings of this review suggested that the majority of the commercially available health apps with CRC-related content suffered from both usability and content- related issues. The most prominent concern was the limited degree of clinical involvement and lack of evidence-based content, which indicated the need for better quality interventions for patients with CRC. This review also demonstrated that apps with

higher ratings scored higher in both usability and content quality parameters, suggesting that these factors were likely desired by users.

In addition to addressing the original objectives, this review also revealed some problematic areas this field. Healthcare professionals and supportive organisations should consider such issues in order to direct patients to high-quality, evidence-based interventions to support their care, while developers should consider adhering by higher usability standards to optimise the interface of these apps.

3.1.4. Formulation of the draft content

The systematic review presented in Chapter 2 acted as a guideline for determining the types of information that would be included in the draft content of the app. The findings of this review were also triangulated with the results obtained from the competitive assessment (3.1.3) to identify gaps and highlight areas for improvement.

Although most areas of information support were addressed through commercially available apps to a greater or lesser extent, none of the identified apps provided information regarding the management of treatment-induced toxicity (i.e., side-effects). Yet, as the provision of information on that matter emerged as an important aspect of information support in the systematic review (p. 51), it was decided that such information should be included in the project's app. With these in mind, five broad thematic sections were drafted:

1. *Information about cancer and Treatment*: General information about bowel cancer (e.g., aetiology, incidence etc.) and the main approaches for its treatment

2. *Information about diagnostic tests*: Information about the tests that might be ordered, why they are needed and how they are performed

3. *Information on side effects*: List of side effects of XELOX and advice on how to prevent or ease them if they happen

4. *Information on medicines*: Information and advice about chemotherapy medicines and supportive chemotherapy medication

5. *Information about emotional support, help with finances and everyday life*: Information on the availability of emotional and financial support, dietary advice, help with everyday live and useful contacts during treatment

Each of these sections contained a number of questions and accompanying answers. The draft content was formulated by consulting the following resources: Cancer Research UK (CRUK), MacMillan, National Institute for Clinical Excellence (NICE), Electronic Medicines Compendium (eMC), Bowel Cancer Chemotherapy Protocols Provided by Thames Valley and the British National Formulary (BNF).

In addition to the information sections, two additional functions were proposed. The first was a search function that would enable patients identify a question within the app (i.e., a 'search and browse' function) and the second function was a section that would allow patients to keep treatment-related notes in the app. A Word version of the draft content was forwarded to the participating clinicians from OUH for review.

3.1.5. Clinician input

The clinicians' comments on the draft content concerned mainly the wording of the answers and information about supportive infrastructures available in Oxford. In addition to these comments, the clinicians proposed that the app should also contain a function referring patients to the Triage Helpline, a service for reporting chemotherapy-induced toxicity. At the time, the patient chemotherapy manuals provided by the Churchill Hospital contained a simplified version of the UK Nursing Oncology (UKONS) symptom chart, which was designed to signpost patients to the Helpline according to the severity of their symptoms (UK Nursing Oncology Society, 2016).

The clinicians suggested an interactive version of this tool, where patients could log their symptoms and, receive a custom assessment alert (according to the severity of each case) that would either instruct them to contact Triage or advise them to keep an eye on their symptoms and contact Triage if they deteriorated. The Triage function will be discussed in further detail in section 3.2.2.

After updating the draft content following the clinicians' recommendations, it was decided that advice should be sought by the targeted user audience. The following section will outline the process of obtaining input from patients with CRC as part of the project's Patient and Public Involvement and Engagement (PPIE) scheme.

3.1.6. Patient and Public Involvement and Engagement

Patient and Public Involvement and Engagement (PPIE) is about giving people the opportunity to express their opinions, views and recommendations about services they are currently receiving or will receive in the future. The implementation of PPIE is particularly beneficial in health research, since it can make projects more relevant to the needs of patients and the public (Domecq et al., 2014). Involving potential users in the development stage is also important for achieving good usability and functionality for the intended user population (Darlow and Wen 2016). The following sections will outline the design and conduct of the PPIE scheme, present the relevant findings and explain how these informed the development process of the project's intervention.

Participants

The participants of the PPIE scheme were patients with CRC receiving XELOX and were identified by the clinicians from OUH. Two patients were invited, and both accepted.

Design, conduct and ethics

The design and conduct of this PPIE was based upon the latest guidelines provided by the National Institute of Health Research (NIHR). The investigator also undertook relevant training on planning and conducting PPIE and liaised with experts from Keele University for further advice and guidance.

One month before consulting with the patients, the investigator provided two pieces of preparatory material. The first piece was a short document outlining the aims of the study and the role of PPIE in its design. This was done to help participants familiarise

themselves with the project and achieve a clear understanding of what their role involved. The second document contained the draft content of the app, which was given to the participants in order to be checked for its relevance and appropriateness.

According to the NIHR, Ethical approval was not required, as the members of the public would act as *advisors* who would help shape the project rather than study *participants*. This was confirmed with the sponsor (Research Governance of Keele University), as well as the Research and Development (R&D) department of OUH.

Theoretical framework

As obtaining individuals' experiences, perceptions and in-depth accounts is best achieved via qualitative research (Ritchie et al. 2014), it was decided that a qualitative approach was the most appropriate way forward. The method of choice was interviews, as holding a focus group was unfeasible due to the limited number of participants and logistical restrictions. The interviews were conducted in a semi-structured fashion to allow flexibility and maintain focus during the exchange between the investigator and the participants (Ritchie et al., 2014).

The investigator performed one face-to-face interview with the first participant and a Skype interview with the second participant. The interviews were recorded with the participants' permission and were transcribed verbatim. At the beginning of each interview, the investigator demonstrated '*Manage your Health*', an existing virtual agent (VA)-based app developed by Keele University to help participants understand the concept of this project's app. The investigator also presented a draft version of the proposed outline of the app using Google Power Apps.

Data analysis

The transcripts were analysed using the framework method (Ritchie *et al.* 2014). This is a type of thematic analysis whose defining characteristic is the establishment of a thematic matrix which enables researchers to move across different levels of abstraction (themes, subthemes and cases) without losing sight of the original data, thus allowing for rigorous analysis of large datasets (Srivastava and Thomson 2009; Gale et al., 2013). Due to its systematic nature, this method was used to analyse the acquired data.

After becoming familiar with the original data, a thematic framework comprised by a set of descriptive themes was formulated. Each theme was broken down to a subset of related sub-themes, each connected to one or more cases. The process was conducted in an iterative manner in order to identify as many themes as possible. The final framework was checked by an expert in qualitative research (Dr Alison Gifford) to ensure that the analysis was conducted at a high standard.

Findings

Four major discussion areas emerged, namely the use of apps in cancer care, views on the draft content, recommendations about the functions of the app and perspectives on the VAs. Each of these areas will be presented in more detail below.

The use of apps in cancer care

Both participants suggested that they would use such an intervention if it was available to them. Participant A suggested that the app would enable patients to address aspects

that were not covered during the consultations and participant B claimed that it could help revisit pieces of information that were not retained after the consultations.

Both participants remarked upon a number of potential advantages that apps can offer compared to conventional sources of information. It was suggested that an app would offer a single point of reference and provide better portability over standard information material. Participant A also explained that websites often provide conflicting answers and/or inaccurate information, which raises concerns about the reliability of information. Yet, in the case of this project's app, the information was perceived as and trustworthy, as it was formulated and checked by healthcare professionals.

> *"...it might be more accessible in a place where maybe I don't want to pull out all sorts of leaflets..."* (participant A)

Apart from their positive views around the app, the participants proposed that the age of the intended user population could potentially be a barrier for its uptake. Drawing upon the prevalence of CRC among older individuals, participant A thought that the targeted patient audience might not be inclined towards utilising such technology. Participant B shared a similar view and suggested that as older individuals did not have access to apps when they were younger, they are likely to be unfamiliar with this technology and therefore, less likely to adopt it.

> "*...there is a strong correlation between how old you are and how good you are with a lot of the technology*..." (participant A)

Despite this limitation, participant A suggested that the app would be not be applicable exclusively to patients, but it could also be used by patients' caregivers, partners or family members that might accompany them in the consultations or care for them from home. This perspective was also shared by Participant B.

> "*...if I am fairly elderly, it's likely that I'm going to be coming and bringing someone else along; maybe my daughter or my nephew who's going to be there and helping me anyway and therefore, likely to be able to be using it at that point. You might want to think that maybe this app isn't being used directly by the patient but by the person who is helping them and explaining things to them."* (participant A)

Views on the draft content

Overall, both participants were satisfied with the amount and types of information included in the content. Participant A thought that the content not only addressed information that was personally sought during treatment, but also provided information about aspects that weren't considered at the time. Participant B also reflected positively on the content and stated that it covered all relevant areas.

Suggestions about improving the content were made by both participants. Most of these comments concerned minor adjustments (e.g., rewording or rephrasing information) to improve comprehension. Participant B made a general remark upon the importance of good organisation and emphasised upon its importance. The participant thought that the proposed organisation of content was reasonable but pointed out that smaller groupings of information would improve navigation.

> *"...If I've got a menu system and I'm actively trying to search for something, I need to know where it's going to be before I can find it..."* (participant B)

While participant A made no specific comments regarding the information itself, participant B expressed several thoughts about the framing of information, proposing that statistical data associated with survival rates should be omitted, as they could potentially be daunting for some users. Another recommendation was that the content should reassure patients that nurses will be available to help at any time; this theme appeared several times throughout the interview.

Recommendations about the functions of the app

The participants made several recommendations about the functions of the app. Drawing upon the importance of being able to identify a desired query easily, participant A recommended that a '*search and browse*' function should be available so that users can quickly identify a query. The same participant also provided several technical recommendations to consider whilst developing this function.

The original idea for the name of the app (*Manage your Health*) was deemed to be an appropriate option, as it did not give away the disease it was designed for. The proposed icon of the app (a heart with an ECG line) was also mentioned in this discussion and the participant thought that it was appropriate.

> *"... the presence of this app on someone's phone tells other people things about them and so you might want to call it something that is not obvious from the name that you see on the phone screen..."* (participant A)

The inclusion of a '*treatment diary'* function was mentioned by both participants. Participant A explained that having a treatment diary in the app could help towards keeping all notes in a single place. Participant B had another rationale and explained that the inclusion of a treatment diary could potentially enable patients to record their symptoms so they can later discuss them with their care team. This participant also suggested that the treatment diary could have a function for users to log future appointments to be reminded about upcoming events.

> "*...being able to record my stuff is the thing that would make* [the app] *much more valuable... I would probably use it even without* [the generic content]*, just to keep it all in one place*." (participant B)

Security considerations emerged shortly after the recommendation of including a treatment diary. Participant A thought that usage data, as well as notes entered in the app shouldn't be shared with third parties and that patients should be reassured about this. The same participant also suggested providing users with the option of securing the app with a password.

> "*...the moment I can start entering information into it, you've now got my personal data in here and you have to be very careful about the security of that."* (participant A)

Perspectives on using virtual agents (VAs)

The participants identified some positive aspects of using VAs to deliver information. Participant A thought that visualising the content could facilitate understanding, while Participant B suggested that spoken information are likely to be helpful for older

patients, as they are likely manifest some degree of visual impairment. Participant B also proposed that having information narrated with an empathic tone could potentially appeal to senior users.

> "(…) *I could see that for other people, having it spoken to you in a reassuring voice could be a good thing."* (participant B)

Apart from their positive comments, both participants expressed doubts about this approach. Both participants were sceptical about the usefulness of spoken information over text, unless there was a need for demonstrating a procedure. Participant A expressed a preference for reading information instead of having it narrated, as reading was considered to be faster. This participant suggested that users could be given the option to either read the information or watch a clip of a VA narrating the text.

> "...*If I had to sit there and wait for it to be spoken out slowly, I would probably go and look it up on the internet or read it somewhere else*." (participant A)

The graphics emerged as an important aspect. After watching a VA clip from a previous version of Manage your Health, both participants explained that the VA resembled more of a cartoon character rather than a human being and expressed a preference for human-like VAs.

Both participants remarked upon the importance of the VA's professional appearance. Participant A explained that professional appearance was vital for conveying trustworthiness and that VAs should resemble healthcare professionals. A similar remark was made from participant B, who emphasised upon the importance of having the VAs dressed in typical medical uniforms such as white coats.

"...*if this* [information] *was being said by someone who looks like a doctor, that's going to be reassuring to me. If it looks like it's being said by my friend from home, or someone who looks a bit like them, then that's perhaps for me less valuable*." (participant A)

Participant A made no further remarks with respect to the type of health professionals that the VAs should resemble. Participant B initially thought that this wouldn't make a difference, but later stated that the type of professionals should depend upon the type of information sought through the app.

"...*the majority of nurses that I've come across during my treatment are female and you feel that they're softer. Whereas the oncologist it's very serious...* [information] *about what cancer is, the stats and all that kind of stuff, the CT scans then maybe someone looking like the oncologist or whatever but then the support and the stuff after the treatment could be quite nice coming from someone who looks like a nurse..."* (participant B)

Both participants suggested that what counts as a trustworthy VA would likely vary, as patients are likely to hold different views with respect to which people inspire trust in them. Factors such as gender and ethnicity were also likely to have an influence. Due to this, participant A suggested that users should be given the option to create their VA so it resembles characteristics of a person who inspires trust in them.

The VA demonstrated during the interviews did not resemble an individual known to the participants. When asked if the VA could look like a healthcare professional known to users, participant B thought that it wouldn't make a difference in terms of

reassurance. Yet, the participant appreciated that the concept of formulating the VAs after healthcare professionals known to users had merit.

> "(…) *it makes it more personal and reassuring and you've got the support of people who you know on the app* (…)*"* (participant B)

Participant B held a different view and explained that having information narrated by a VA formulated after a known pharmacist would not be reassuring, as the VAs response would be standardized (i.e., not personalised). Yet, the participant appreciated that this could be perceived differently by other individuals.

> "...*it's still been programmed and* [the pharmacist is] *just talking, she's not actually talking to me, she's saying the same thing to everybody else*." (participant B)

Despite this statement, the participant explained that the purpose of the app would be to provide information and not reassurance. Yet, the participant acknowledged that other patients, particularly older and those who suffer from treatment might find this useful.

Participant A provided a more detailed response to the same question, referencing a phenomenon called the *uncanny valley*. The participant explained that this a situation where a user experiences a feeling of eeriness after being presented with an almost-realistic representation of another person. The participant proposed that if the VA representing a known health professional was realistic, it could potentially improve the situation. Indeed, both participants suggested that that the VAs should look more

human-like than the one presented to them during the interviews, regardless of whether they represent a known individual or not.

> "*If it appears to me that someone is just pretending to be* [my consultant]*, then I don't trust that as much because I look at that and I say, 'Okay, you're trying to pretend to be somebody I know'.* (participant A)

Discussion

Following the formulation of the draft content of the app, it was determined that potential end users would be included to the development stage in order to provide insight as to how to make the app more accessible to the desired audience. Two patients who had previously received XELOX for CRC were interviewed as a part of the project's PPIE scheme. The findings of these interviews are discussed below.

Potential benefits

The participants identified several benefits that could be provided through the intervention. Portability was mentioned by both; this is one of the most prominent benefits of mHealth, since it can provide *"information and resources services can reach anyone, anytime, and anywhere, by removing geographical, temporal, and other barriers*" (Gagnon et al., 2016, p.212). Trustworthiness was another important factor, as the clinical involvement in the design of the content inspired trusting the information. Such perspectives confirmed several core ideas of this project and indicated the potential for applying this technology in patient care.

Potential drawbacks

Despite their positive views on the project's rationale, both participants suggested that the age of the target user audience could hinder the uptake of the intervention. This perspective was in line with the findings of several studies proposing that mHealth is less likely to be of interest to older individuals (Ernsting et al., 2019). Both participants suggested that older individuals haven't grown around information and communication technologies and might therefore be less interested in using apps, a notion which was also mentioned in Scheibe et al. (2015). Prensky (2001) refers to such users as *digital immigrants* in an attempt to describe their adaptation to the digital world.

Despite these issues, it must be noted that the poor uptake of mHealth by older individuals is not necessarily due to the lack of interest or familiarity with this technology. Conde, García-Peñalvo and Matellán-Olivera (2014) suggested that older individuals are in favour of using new technologies, but this can be eclipsed by the fact that these technologies are not always tailored to their needs, which is also evident in Scheibe et al., (2015). Therefore, novel technologies are not the issue per se; instead, the focus is considering the needs of end users whilst designing these interventions.

Content and functions of the app

The first remark concerned the level of security offered by the app. Security is a key consideration for health apps and developers need to ensure that robust measures are in place to protect sensitive user data (Nouri et al., 2018). The second recommendation concerned the ease of navigation, which is a central usability factor, especially for older individuals (Morey et al., 2019). Ensuring that future users can easily navigate through the content was regarded as an essential aspect for ensuring satisfaction and preventing attrition (Eysenbach, 2005).

Another key recommendation was the capacity to keep track of symptoms and appointments through a 'treatment calendar' function. This finding was not entirely unexpected, as interventions supporting patients with cancer can often incorporate monitoring functions to help users manage their condition (Richards and Caldwell, 2018). The incorporation of such function could also help increase engagement, as it could encourage frequent use (Baldwin et al., 2017); for the app, this could be true for after treatment commences. However, participant A implied that such functions could possibly overshadow the app's role as a repository of information. This was something that was taken into account so it could be investigated in the stages of user testing.

While the first participant provided detailed recommendations regarding technical aspects and functions of the app, the second participant offered further insight upon its content. A noteworthy comment was that survival data should be removed, as they could potentially be intimidating. Yet, a systematic review suggested that patients can in fact request information about such matters despite the daunting nature of this topic (Hagerty et al., 2005). The authors of this review pointed out that such sensitive information should be communicated, but this must be performed in a careful manner, which was also implied by participant B; this was an key consideration for amending the content.

VAs; recommendations, risks and benefits

Although participants were sceptical about the value of the VAs to them, it was suggested that using this technology for supporting older patients had its merits. This is in line with findings from the literature. In an early study, Bickmore et al., (2005) demonstrated that VAs can inspire a sense of presence and be highly acceptable by

older adults; subsequent studies also presented promising results (Vardoulakis et al., 2012; Ring et al., 2013). VAs can also be helpful for senior users who might not be able to read lines of text on screens (Chattaraman et al., 2011), which was also suggested by the PPIE participants.

Both participants suggested that the VA should resemble healthcare professionals, as they were perceived as the most appropriate agents for delivering health-related information. Another recommendation was that different types of health professionals could be used to deliver the types of information that best suits their area of expertise; this was also evident in a study by Read and Mayberry, (2000).

One suggestion was to provide users with the option of customising the app's VAs. This suggestion was due to the perception that what accounts as a trustworthy individual can vary among patients and hence, some may prefer a character of a specific gender, age or ethnicity. This was consistent with findings from the literature (Alsharbi and Richards, 2017; Guadagno et al., 2007). In online gaming, users frequently customise VAs according to their preferences to formulate a figure with favourable characteristics (Turkay and Kinzer, 2014). In the field of learning, Okita et al. (2013) proposed that altering aspects of a virtual educator such can help learners feel more comfortable, thus facilitating their learning.

Another central consideration was whether the VAs should be known to users or not. While the inclusion of familiar VAs could be of benefit to older individuals and vulnerable patients, participant A thought that having known VAs could potentially provoke a strange response and referenced the concept of the *uncanny valley*. This concept has been presented in chapter 1 (pp. 24-25) and suggests that users can

experience feelings of eeriness and repulsion towards artefacts that look or act almost like humans. This concept was considered carefully and will be discussed in further detail in 3.2.1

PPIE summary and implications for the development process

PPIE played an integral part in the development of the project's intervention. The participants provided a number of key insights for not only improving the app's usability, but also its content in order to make it more relevant to the needs of the target population. One limitation was that due to the small number of patients included in this phase, the findings might have not addressed all aspects as well as a larger sample would. Another drawback was that both participants were considerably younger than the intended user audience (<40 years); since the incidence of CRC is higher among older individuals (Cancer Research UK, 2020), participants' perspectives might have not adequately reflected the needs of potential end users. Nevertheless, their recommendations from both an IT, as well as a patient perspective, were useful for achieving a better initial understanding of the needs of patients with CRC in order to design an intervention that would be relevant to them. Participants' recommendations were implemented in the design process, which will be outlined below.

3.2. Initial design and development stage

The pre-development stage laid the foundations for building the pilot version of the intervention by receiving guidance from the literature, as well as input from clinicians and potential end users. Once these phases were conducted, the project entered its

development stage, which encompassed two main aspects: the formulation of VAs and the pilot version of the app. These will be discussed in detail in the following sections.

3.2.1. Description of the Virtual Agents

This part will present the characteristics of the VAs that were used in the pilot version of the app and provide justification for each one. These characteristics concerned the type of the VAs, the mode of communication with users and the appearance of the VAs.

Type of VAs

As discussed in chapter 1 (pp. 19-26), there are three broad types of VAs. This project focused upon embodied conversational agents (ECAs) for several reasons. First, the element of embodiment can foster a sense of presence and enhance users' learning experience; this is known as the *persona effect*, which was discussed in chapter 1 (p. 22). Second, ECAs can deploy non-verbal ques and simulate face-to-face communication with users, which can not only improve understanding, but it can also be particularly useful for older individuals (Bickmore et al., 2005). Relational agents were also considered. Yet, building such interfaces would necessitate a certain degree of artificial intelligence (AI) in order for agents to be able to form relationships with users (e.g., to remember individuals' names and refer to previous interactions), which was unfeasible in terms of time and resources.

Another aspect was whether the ECAs should be animated or static. As the former has been reported to elicit more intense emotional responses and foster a greater sense of presence than the latter (Wu et al., 2014), the app included animated ECAs.

Type of user/VA interaction

There are several ways that interactions between users and VAs can occur. As discussed in chapter 1 (p. 20), users can either choose from pre-determined items (e.g., multiple-choice questions) to receive pre-defined responses or use unconstructed textual/verbal input so that the VA responds to them in a tailored manner. The latter is defined as natural language processing (NLP), which has received increased attention due to its capacity to offer considerable advantages to such interfaces (see p. 20).

Despite the potential advantages of NLP, its implementation necessitates "*a high order of artificial intelligence technology*" (Shaked, 2017, p.84); as such resources were not available, it was not feasible to incorporate NLP in the project's intervention. Instead, the app offered users a number of pre-defined items (i.e., information queries) that were answered using pre-recorded messages. These messages were recordings of natural voices rather than synthetic speech. This was because natural voices have been reported to be more preferrable to artificial from the users' perspective (Baylor, 2011).

Appearance of VAs

Some core considerations regarding the appearance of ECAs have been presented in chapter 1 (see pp. 22-25). The concept of VA familiarity was a central consideration, which also appeared in the PPIE interviews. Participant B's comment regarding the importance of being cared for by familiar individuals across the care pathway was in line with the concept of continuity of care (see p. 32) and supported the project's idea. It was therefore determined that the app would include VAs formulated after clinicians that were known to users.

Another important consideration that emerged during the PPIE interviews was the role of the VA's static characteristics (e.g., gender, age and ethnicity) and the potential for users to customise their VA in the app. After discussing the latter with the development team, it was determined that providing this option was not viable, as it would require the formulation of new software that would push the project's timeline considerably. Instead, a range of virtual characters was used in order to increase diversity in the VAs.

Following the recommendations from participant B, a range of healthcare professional-looking VAs was used according to the types of information delivered. Three clinicians from the Churchill Hospital agreed to be represented as VAs in the app: Dr Andrew Weaver (consultant oncologist), Professor Nicola Stoner (cancer consultant pharmacist) and Ms Eliz Flanagan (senior chemotherapy nurse). Figure 3.2 illustrates these individuals in real life and figure 3.3. shows how they appeared in the app.

The final consideration about the appearance of the VAs was the degree of realism (see pp. 22-23). As the goal of this project was to provide VAs that looked like users' clinicians, it was necessary to ensure that users would recognise these individuals. Hence, the VAs of the app were realistic, high-resolution representations of the aforementioned clinicians; this was also in line with the recommendations from PPIE.

One of the most prominent concepts in the appearance of VAs is the *uncanny valley*, which also emerged during the PPIE interviews. While this theory has received much attention, work on this field has demonstrated that this effect is not always apparent as there are several examples where human-like characters and robots were considerably successful (Hanson et al., 2005). In a recent publication, Cheetham (2017) pointed out

that "*an uncanny effect is not generalizable across different individuals, stimuli, situations, tasks, and time*".

Figure 3. 2: The clinicians used to formulate the VAs (from left to right: Dr Andrew Weaver, Professor Nicola Stoner, Ms Eliz Flanagan)

Figure 3. 3: The clinicians as virtual agents (VAs) in the app

It must be noted that participant who mentioned this concept had a strong IT background, and thus approached this technology in an exhaustive and critical manner. Hence, people with more limited IT skills and/or less experience in this domain might not necessarily share the same thoughts. The concept of the uncanny valley was an important aspect that was explored further in the later stages of the project.

3.2.2. Formulation of the initial version

Having established the appearance of the VAs and the content of the app, the pilot version was developed. This section will outline the steps taken in this process.

Host platform

The software development team suggested using an existing platform developed by the School of Pharmacy of Keele University. This platform was 'Manage your Health', a VA-based app for patients with chronic conditions (Keele University, 2021).

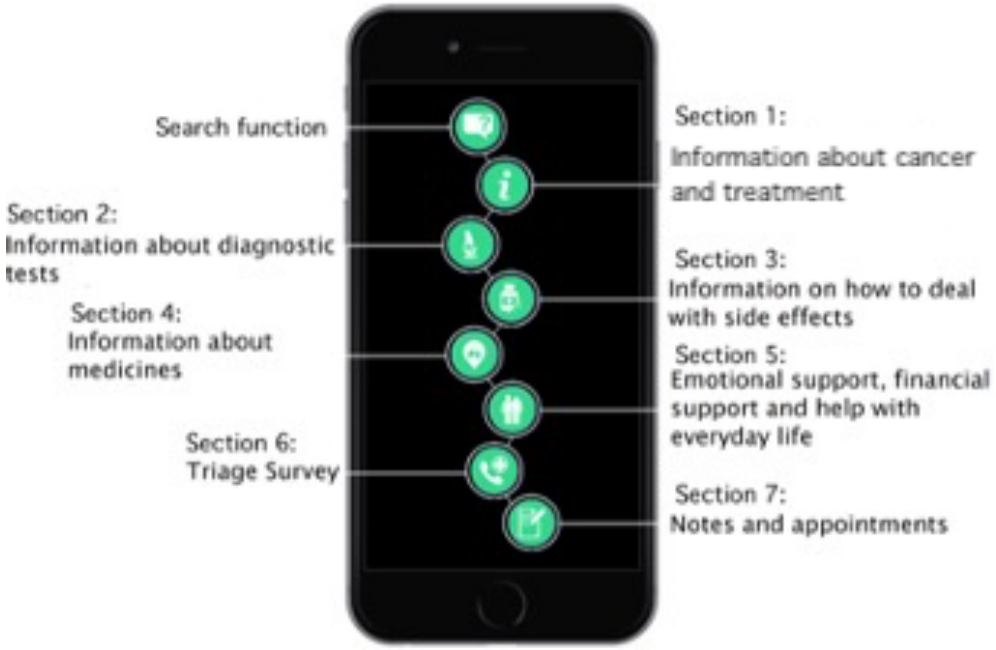
Content and functions of the app

The information content of the app was amended according to the recommendations of the clinicians' and PPIE participants. Following participant B's advice, data on survival rates were removed but a question regarding general prognostic information was included. The content was also updated to reassure and remind patients about the availability of help; this was achieved by adding statements such as '*Your doctors/nurses will help you*' or '*Your care team will ensure that…*' throughout the content.

Following PPIE participants' advice, the functions of the app were also updated. First, a search function was incorporated so that users could quickly identify a query in the app.

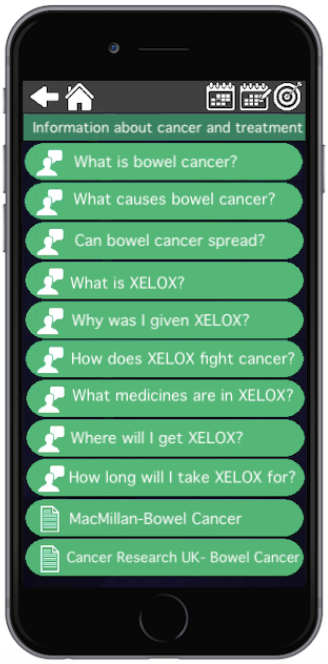
A calendar function for noting appointments and tests was also added; this function could push notifications so that patients were reminded about any upcoming events. A section where patients could keep notes was included as well. Finally, an interactive version of the Triage assessment tool was formulated following the clinicians' advice. The pilot version of the app is illustrated in figure 3.4.

Figure 3. 4: Pilot version of Manage your Health for XELOX



Each information section (sections 1-5) contained a number of items; figure 3.5. presents the outline of the first section, which was concerned with general treatment-related aspects. Patients could tap these items in order to obtain a response to each question. Items containing the chat bubble icon were VA clips, while items with the page icon contained links to external resources that referred users to official websites (e.g., Cancer Research UK, MacMillan) for further information and support.

Figure 3. 5: Outline of section 1 (Information about cancer and treatment)

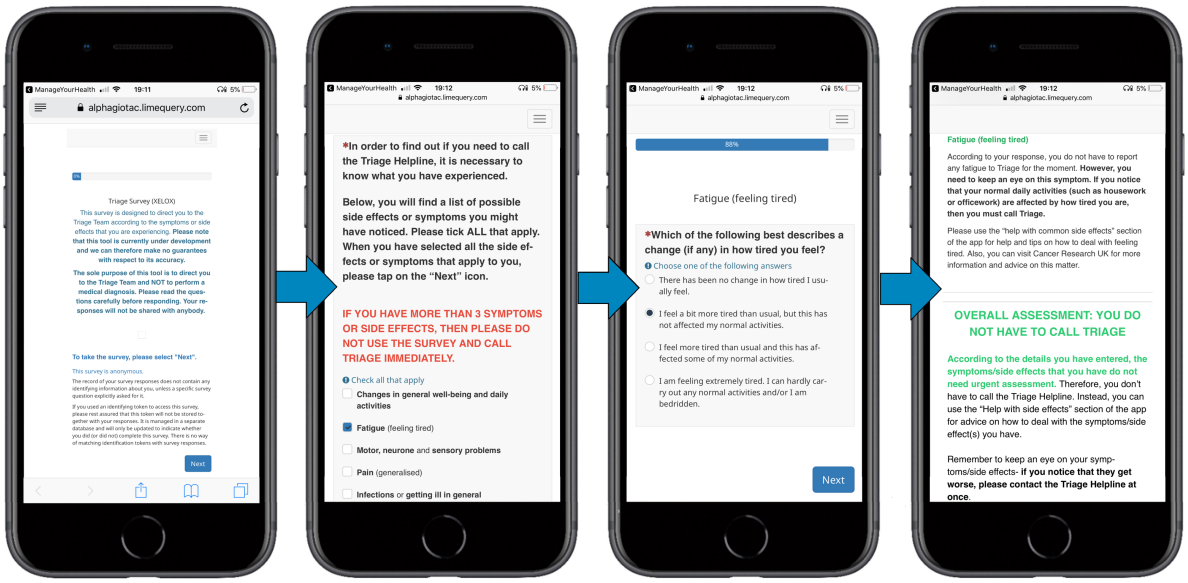


As it was not feasible to integrate the Triage function in the app, an online survey version of the tool was created and the link to it was embedded in section 6. The survey logic was based upon the Triage decision tree; in essence, the survey assessed users' symptoms and calculated an overall feedback alert that advised them on whether they had to contact Triage or not. While this function didn't constitute a diagnostic tool or medical device, ensuring safety for users was imperative. Rigorous steps were taken to safeguard that this function would be developed under the highest standards.

First, the board members of UK Oncology Nursing Society (UKONS) were contacted in order to acquire permission to use the latest clinical version of their tool as a reference in order to build the survey's logic (UK Nursing Oncology Society, 2016). Once approval was granted, a dialogue was formulated and was checked for its validity with an experienced Triage Nurse from the Churchill Hospital. The dialogue was updated and fed into Lime Survey, an online survey web application.

The first screen of the survey provided brief advice about its purpose. The second screen listed the 23 symptoms that appeared in the original Triage Tool, as well as a further option for 'other symptom or side effect not listed above'. On that screen, patients were instructed to tick the symptoms they experienced. Depending upon the items they ticked, the survey asked them some more detailed information about each symptom and calculated a score according to their responses. Depending upon the overall score, patients were either advised to contact Triage as soon as possible or monitor their symptoms and call Triage if there was any deterioration (*Figure 3.6*).

Figure 3. 6: Example of the Triage Survey



The investigator performed rigorous testing to confirm that the draft version provided the correct instructions before incorporating the survey link in the app. This involved testing all 23 symptoms separately, as well as a combination of those in order to ensure that the survey provided the correct responses. To ensure confidentiality, the survey responses were not recorded.

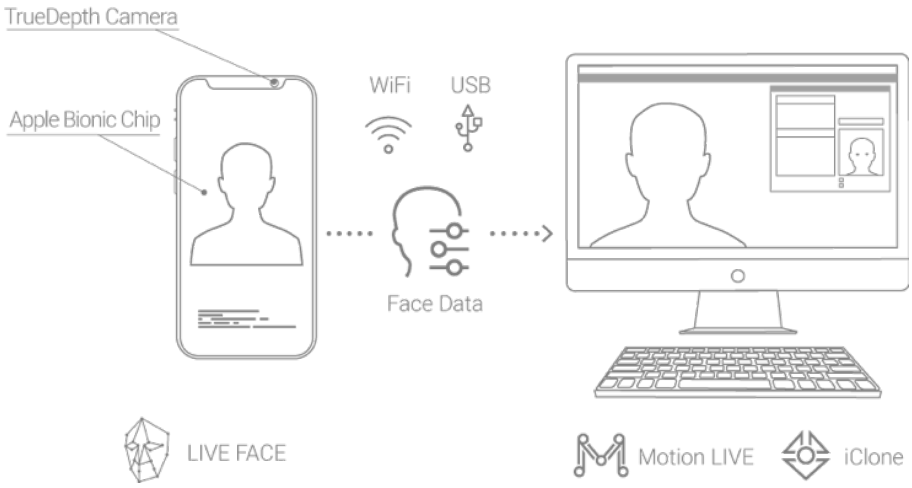
Formulation of the animations for the clinician VAs

Having established the host platform and content, the next step was to obtain audio, as well as video recordings from the clinicians in order to develop the animations. The recordings were performed at a quiet meeting room at the Churchill Hospital. In order to improve the quality of the sound recordings, a custom booth was assembled by the development team. An iPhone X was placed inside this booth using a tripod, alongside with an iPad which functioned as an autocue so that the clinicians could read the answers to the various questions.

In order to speed the animation process, facial capture technology was used instead of hand animation. This was achieved through an app called *Facial Mocap*. This app features the TrueDepth Camera which allows for the capture of a series of detailed facial movements, thus saving the need for doing these manually. In essence, Facial Mocap captured capture the clinicians' facial movements while they were reading the content and transferred this data in an animation software so that the development team could later formulate the various VA clips.

Once the recordings were obtained, the development team used Maya Autodesk®, an animation software to build the virtual characters. Once the characters were built, the team applied the data from Facial Mocap in order to synchronise the VAs' facial movements with each of the recordings (figure 3.7). Once the full set of animations was complete, the development team used Unity®, a cross- platform game engine in order to build the pilot version of the 'Bowel Cancer-XELOX' information package for Manage your Health.

Figure 3. 7: Facial Mocap app data transfer process



Security considerations

Due to developmental limitations, it was impossible to establish a two-step authentication process i.e., provide a password protection option for the app. Instead, users were advised to utilise standard security measures (e.g., password lock) to protect any sensitive information they might wish to enter in the app. In a further attempt to protect confidentiality, none of the information entered in the app (e.g., notes and appointments) were recorded or shared with another party, including OUH and Keele University. This was clearly stated in the information leaflets, the consent forms and would also be discussed with any potential participants.

3.2.3. Initial intervention testing

The goal of this phase was to identify bugs before testing the app with patients. In essence, this was an informal testing of the app before proceeding to the pilot study. The individuals involved in the initial testing phase were members of the project's supervision team, the clinicians from OUH, members of staff from the investigator's

research institute and the patients who took part in the PPIE interviews. All groups were asked to install Manage your Health, explore the content of the app and provide their feedback via email.

The overall feedback was positive. The members of staff from Keele commented positively on the layout and the content of the app, with only a few remarks concerning spelling errors, broken links or unresponsive content (e.g., animations which didn't work). Such comments were also made by the members of the supervisory team, as well as the clinicians from OUH. One academic suggested adding content that would help patients understand *why* blood tests are ordered, as the app only provided information about *how* they are performed. The patients from the PPIE group also provided positive feedback and made two key comments. The first concerned the search function, as it didn't appear to yield any relevant results when a search term was entered. The second comment was about the 'back' button at the end of the animations, as the one presented to them was not very clear and led to some confusion.

All comments were summarised and were then discussed with the software development team. The points raised were addressed promptly and the app was updated according to their feedback. In September 2018, the app was ready to be provided to patients from the Churchill Hospital in order to conduct a pilot testing of the app.

3.3. Chapter summary

This chapter outlined the process of conceptualising and developing the initial version of the project's intervention. First, a comparative analysis of commercially available apps for CRC was performed. The identification and exploration of the highest-rated apps not only provided indication regarding the features that are most popular to the desired audience, but also pointed out the need for delivering high-quality interventions to patients with CRC. The PPIE scheme offered invaluable insight as to the most salient points that should be considered from the perspective of potential end users and informed the formulation of the initial version of the app, which was then refined further before proceeding the project's pilot study.

Having formulated the initial version of the app, the next step was to test and evaluate it with real patients. According to Darlow and Wen (2016), the evaluation of mHealth interventions is best performed by involving both *qualitative* and *quantitative approaches*, which is commonly referred to as *mixed methods research*. The next chapter will discuss the core philosophical considerations surrounding these methodologies and present the theory that underpinned the evaluation process of the project's intervention.

Chapter 4: Theoretical and philosophical considerations

The previous chapter outlined the development process of the pilot version of the intervention. The aim of this chapter is to justify the approach that was utilised in order to evaluate the project's intervention (i.e., address the aims and objectives listed in chapter 1). First, the core philosophical underpinnings of research and the main approaches to empirical inquiry will be briefly presented. The chapter will then proceed to cite the research approach that was adopted for evaluating the app, as well as the author's (AC) paradigmatic stance in order to demonstrate how this choice is justified in the context of inquiry.

4.1. Philosophical underpinnings of research; ontology, epistemology and paradigmatic stances

The Oxford Dictionary defines research as "*the systematic investigation into and study of materials and sources in order to establish facts and reach new conclusions"* (Oxford Dictionaries, 2018). According to Bryman, (2016) this process is affected by the way we perceive reality, a matter that has intrigued the human mind for centuries. The philosophical study of the nature of reality is known as *ontology*. In very broad terms, there are two main ontological positions, namely realism and idealism. The former supports the existence of an external reality, which is independent of our beliefs and understandings, while the latter claims that reality is shaped entirely by the human mind and is knowable only through it (Ormston et al., 2014). Although both realism and idealism have several variants (e.g., subtle realism, naïve realism, collective idealism,

radical idealism etc.), this chapter will concentrate upon the two ends of the spectrum in order to maintain focus.

Once an ontological foundation has been laid, the next question is what counts as valid knowledge? The branch of philosophy that seeks to answer this question is referred to as *epistemology.* According to Ormston et al., (2014), there are two core epistemological positions, namely the *inductive* and *deductive* logic. Inductive logic involves generating theory through observations, while deductive logic is used to test and confirm (or reject) a given hypothesis. The same authors suggested that the main epistemological debates are associated with the acquisition of knowledge (induction *versus* deduction), the connection between the researcher and the researched (subjective *versus* objective) and finally, the accuracy of knowledge (relative *versus* absolute).

Having established their ontological and epistemological positions, researchers then formulated sets of propositions that served as guides to inquiry. These came to be known as *paradigms.* A paradigm is defined as *"an overarching philosophical or ideological stance, a system of beliefs about the nature of the world and ultimately, when applied to a research setting, the assumptive base from which we go about producing knowledge"* (Broom and Willis, 2007, p.17). Since reality and knowledge can be conceptualised differently, it is reasonable that several distinct paradigms have emerged over time. This work will concentrate upon the paradigms linked to the major research traditions.

The first main paradigm, which is commonly associated with the 'scientific method' is *positivism* (Ormston et al., 2014). This philosophical movement claims that reality is

fixed and singular, governed entirely by laws and is external to the inquirer (Bruce, Pope and Stanistreet, 2008). Positivism advocates that an accurate account of reality can be achieved (i.e., truth can be known) and that methods used in the natural sciences are suitable for examining the social world. In the early 20th century, this rigid and almost dogmatic view was succeeded by *post-positivism* (Gray, 2018), which maintained the core principles of positivism but proposed that although reality is objective, it can only be apprehended in approximation and is translated only as statistical probability (Brodsky et al., 2016).

In stark contrast with the teachings of positivism and post-positivism, there are those who argue that neither reality is singular nor knowledge is absolute but instead, they are constructed by the human mind (Ormston et al., 2014). These closely related schools of thought are known as *constructivism* and *interpretivism,* according to which reality is not an external and independent entity, but instead, "*the knower and known interact and shape one another*" (Denzin and Lincoln, 2005, p.56). Advocates of these paradigms also stress that the social world cannot be studied by the methods used in the natural sciences, as social reality is not governed in the same law-like fashion as the natural world (Ormston et al., 2014).

In summary, different ontological and epistemological views have led to the formation of distinct paradigmatic stances. Muncey (2009) suggested that these differences have underpinned the development of the research process and have led to two main research approaches, namely *quantitative* and *qualitative* research.

4.2. Qualitative and quantitative research

According to Teddlie and Tashakkori, (2010) quantitative research is the methodology traditionally associated with the positivist/postpositivist paradigm. In the field of health research, quantitative methodology has cemented its place though the use of methods and study designs such as randomised controlled trials, cohort studies and meta-analyses. Such methods aim to quantify data and make statistical inferences in order to apply findings to a wider setting (Broom and Willis, 2007). In the field of social sciences, quantitative research has exerted tremendous influence by attempting to quantify human behaviour through surveys, self-completed questionnaires and structured interviews (Denzin and Lincoln, 2005).

Qualitative research took an entirely different approach to empirical inquiry and has been characterised as a 'reformist movement' (Schwandt, 2000). Grounded in the constructivist/ interpretivist paradigms, qualitative research introduced an approach that opposed the strict doctrines of the quantitative approach and focused upon individuals' lived experiences (Ormston et al., 2014). Rather than pursuing statistical inferences and generalisation of findings, advocates of the qualitative approach deploy methods such as in-depth interviews, focus groups and participant observation in order to obtain information-rich data to achieve a holistic and in-depth understanding of the world (Brodsky et al., 2016).

In the context of this project, a qualitative approach would allow for the acquisition of in-depth perspectives, personal views and experiences, which would help to appreciate the effects of the app. Yet, quantitative data such as analytics of use, satisfaction with information and degree of usability were important in order to determine the overall

success of the intervention and perform numerical assessments across the study population. Thus, using either a quantitative or qualitative approach in isolation would provide only a partial view of the research problem and would not be sufficient to address the research objectives of this project.

Both qualitative and quantitative research have their strengths and weaknesses in relation to one another. Yet considering the goals of the present study, it appears that the question of superiority of one approach over the other is irrelevant. Instead, the interest should be focused upon the *appropriateness* of the methodological approach to address the research objectives. According to Broom and Willis, (2007) the main focus are the research questions themselves, since these will determine which approach should be utilised in order to best meet the desired objectives (i.e. breadth *versus* depth). Rather than being torn between a methodological Scylla and Charybdis, deploying a methodology that combines both quantitative and qualitative elements could help reconcile the losses from using a monomethod approach. A mixed methods approach was hence determined to be the most beneficial way fromward for this project. The following section will provide a brief overview of mixed methods research and demonstrate how this was conceptualised in this project.

4.3. Mixed methods research

Creswell (2009) noted that research methodology continually evolves and develops. One of these developments was the integration of qualitative and quantitative means in a single study, an approach that has attracted much attention in recent years and came to be known as *mixed methods research* (Tashakkori and Creswell, 2007).

The first systematic use of mixed methods can be traced in the late 1950's (Creswell and Plano Clark, 2011). At that time, the use of quantitative and qualitative *methods* in a single study resembled more of a validation process rather than a distinct *methodology* (Johnson, Onwuegbuzie and Turner, 2007). Yet, after a few decades, some began to build robust frameworks to promote the integration of research methodologies (Johnson, Onwuegbuzie and Turner, 2007; Reichardt and Cook, 1979).

Notions regarding the combination of qualitative and quantitative methodologies were introduced in close proximity with the 'paradigm wars', a period where some scholars debated the legitimacy of qualitative research over the well-established quantitative approach (Bryman, 2008). According to Scott and Briggs, (2009) the role of mixed methods research during that time resembled that of a *peacemaker*, since it encouraged researchers to deploy both quantitative and qualitative means instead of choosing sides on the 'battlefield'. Yet many objected to the notion of joining qualitative and quantitative methodologies and methods, claiming that their combination was unattainable at a philosophical level (Howe, 2004). These were referred to as purists, since they advocated the conduct of either qualitative or quantitative research in isolation (Rossman and Wilson, 1985). Despite these criticisms, mixed methods research managed to prevail. In later years, this approach witnessed considerable expansion not only in the social sciences, but also in healthcare (Halcomb, Andrew and Brannen, 2009).

In the field of mobile health (mHealth), developers are encouraged to use both qualitative and quantitative means to perform a holistic assessment of their interventions and shape them according to the needs of their intended user population

(Darlow and Wen, 2016). A later publication also proposed that complexity in mHealth calls for a mixed methods approach in order to effectively address the research objectives of such projects (Alwashmi et al., 2019). This was applicable to the present study, as it aimed to answer questions that were associated with breadth (e.g., numerical usage data on how the app was used over time), as well as depth (e.g., perspectives upon the use of virtual agents).

In summary, mixed methods started as an informal validation process, which gradually developed into a distinct approach to research (Creswell and Creswell 2018). As this approach best suited the objectives of the project, it was determined that it would be used in order to answer the research questions. At this point, it must be made clear that although mixed methods research has evolved and developed markedly, there still appears to be a lack of consensus as to what it actually *is*. Hence, before proceeding further, it is necessary to make clear how the author (AC) perceived and in term, applied mixed methods.

Mixed methods was treated as a methodological approach that has both a philosophical, as well as a practical basis for implementation (Creswell and Tashakkori, 2007). The author accepts that qualitative and quantitative methods are associated with distinct paradigms, and that although paradigms can be used together in empirical inquiry, their uniqueness needs to be respected and acknowledged. Finally, the author recognises the practical importance of deploying a mixed methods approach, as it can facilitate the communication of findings with members of his research disciplines. Considering the above, the following definition was adopted:

"*Mixed methods research is an approach to inquiry involving collecting both qualitative*

and quantitative data, integrating the two forms of data, and using distinct designs that may involve philosophical assumptions and theoretical frameworks" (Creswell and Creswell, 2018, p.4).

After presenting the author's position as to what mixed methods research is, it is necessary to demonstrate how this approach is justified in the context of inquiry. The next section will present the core philosophical arguments in mixed methods research.

4.4. Philosophical debates around mixed methods research

As mentioned earlier, mixed methods research has received criticism due to the notion that qualitative and quantitative research are incommensurable, an argument which is known as the *incompatibility thesis* (Teddlie and Tashakkori, 2003). Although this argument was raised during the paradigm wars, the issue of incommensurability still haunts this research approach (Lincoln, Lynham and Guba, 2018).

Hathcoat and Meixner (2017) proposed that the incompatibility thesis encompasses three levels of inquiry, namely "*the political (i.e., the role of evaluation in society), the technical (i.e., the methods utilized to gather information), and the philosophical (i.e., the underlying assumptions)"* (Hathcoat and Meixner, 2017, p.434). According to the authors, the philosophical dispute is mainly what perpetuates this argument. In recent years, Lincoln, Lynham and Guba (2018) argued that "*at the paradigmatic or philosophical level, commensurability between positivist and constructivist worldviews is not possible*"' (p.132). Others have suggested that incommensurability goes beyond the level of ontology and that even knowledge produced by competing paradigmatic approaches will be incompatible with each other (Bryman, 2016; Smith, 1983).

To challenge the issue of incommensurability at an ontological level, Morgan (2007) argued that if competing paradigms had clearly defined boundaries, this notion could potentially be valid. However, the existence of common ground between paradigms raises important questions about the merit of incommensurability. In more recent years, scholars have acknowledged that "*the various paradigms begin to "interbreed*"" (Lincoln, Lynham and Guba, 2018, p.164) and that qualitative and quantitative research are not "*monoliths with no interparagmatic variation*" (Johnson, 2008, pp.205–206). Indeed, it has been proposed that paradigm commensurability is possible, as long as paradigms share *"axiomatic elements that are similar or that resonate strongly"* (Lincoln, Lynham and Guba, 2018, p.174).

At an epistemological level, Sandelowski (2000) and Bergman (2010) argued that research methods pay no allegiance to particular research paradigms and hence, inquirers can freely combine qualitative and quantitative methods in their research. Other methodologists recognised that research methods are associated with paradigmatic assumptions, but argued that the epistemological gap between qualitative and quantitative research has been exaggerated, since not only qualitative methods draw influence from positivism, but also constructivism has inspired aspects of quantitative methods (e.g., Bryman 2004; Robson 2011; Alexander et al., 2008).

In any event, many academics remarked upon the value of using both qualitative and quantitative aspects to address a single research question and encouraged researchers towards adopting this approach (Albright, Gechter and Kempe, 2013; Baum, 1995; Kettles, Creswell and Zhang, 2011; Steckler et al., 1992; Östlund et al., 2011). This call has indeed not fallen on deaf ears.

Bringing together elements of quantitative and qualitative research in a single study has become increasingly popular, particularly within applied sciences such as healthcare (Alise and Teddlie, 2010). Health research, a field once dominated almost entirely by the quantitative tradition, is now a discipline where methodological plurality becomes increasingly evident (O'Cathain, 2009). As Scott and Briggs (2009) noted, clinical knowledge encompasses "*what foundational epistemology would regard as ontologically incommensurable approaches*"(Scott and Briggs, 2009, p.233), since observational data are often combined with quantitative measurements to inform decision-making (Mesel, 2013) . This reveals a great paradox for purists, considering that an entire professional community labours under otherwise falsified perceptions about what constitutes valid knowledge! The same can be argued for mHealth, since the use of mixed methods is not just evident, but also encouraged due to the complexity of the phenomena that researchers seek to investigate (Alwashmi et al., 2019; Darlow and Wen, 2016).

Considering the above, research approaches that utilise both qualitative and quantitative elements are now widespread across disciplines and produce valid knowledge. Although the dichotomy between qualitative and quantitative research appears to be less relevant in our time, the philosophical debate about incommensurability still exists (Yardley and Bishop, 2015; Bryman, 2008). Therefore, what are the philosophical foundations upon which mixed methods research rests?

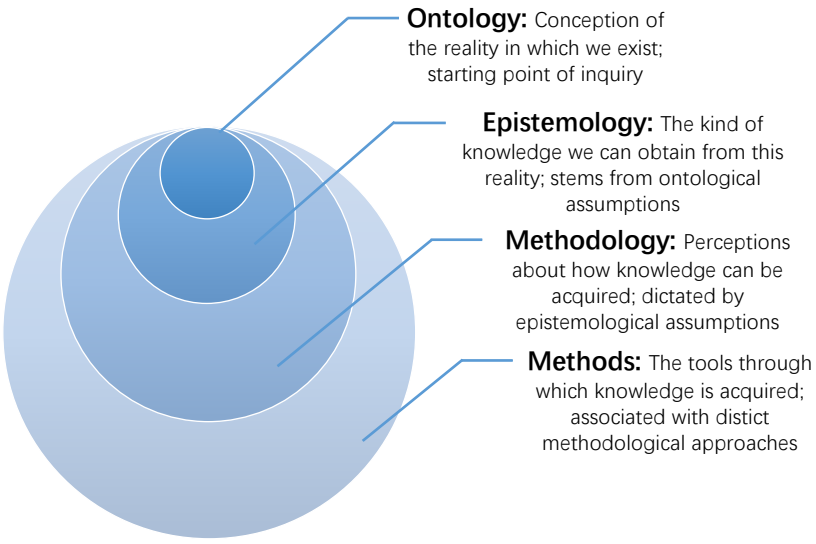
An answer to this question can be provided by the pragmatic approach to research. The following section will briefly explore pragmatism and demonstrate how it supports the conduct of mixed methods research.

4.5. Pragmatism and mixed methods research

Pragmatism is a philosophical movement founded in the early 20th century to provide solutions to issues imposed by metaphysical arguments and the conflict between competing paradigms (Sundin and Johannisson, 2005). Johnson and Onwegbuzie suggested that pragmatism can be regarded as the "*philosophical partner for mixed methods research*"" (Johnson and Onwuegbuzie, 2004, p.14), a view shared by methodologists and scholars (Morgan, 2007; Creswell and Creswell, 2018; Gray, 2018).

Feilzer (2010) argued that pragmatism objects to the traditional approach to research, which attempts to produce knowledge that best represents reality. Instead, pragmatists advocate that the focus should be to generate knowledge that best represents a phenomenon and is capable of producing meaningful actions. Gray (2018) claimed that pragmatism regards research questions as the driving force of inquiry and rejects the top-down approach (figure 4.1) proposed by other paradigms (Morgan, 2007).

Figure 4. 1: The traditional approach to empirical enquiry



Despite its popularity and contribution to mixed methods research, pragmatism has received considerable criticism. Referred to as an almost *anti-philosophical* research philosophy, pragmatism is often treated as an approach that strips research from its philosophical foundations (Robson, 2011). In addition to this, its core concept (commensurability of qualitative and quantitative research) is a matter of great dispute, since the teachings of the incompatibility thesis appear to still resonate strongly within certain research disciplines. Hence, pragmatism has often been discredited as an approach that both lacks philosophical insights and supports the unattainable proposition of combining qualitative and quantitative inquiry (Biesta, 2010).

As any other research paradigm, pragmatism is open to philosophical debate (Johnson and Onwuegbuzie, 2004). However, the criticisms of pragmatism ought to be examined carefully, as it can be argued that they appear to misinterpret and disregard several key aspects of this paradigm, which can lead to falsified claims about its illegitimacy.

To begin with, it appears that discrediting pragmatism resembles more of a combination of research agendas, funding hierarchies and discipline politics rather than genuine philosophical disagreements (Henwood, 1996; Hesse-Biber and Johnson, 2013; Lunde, Heggen and Strand, 2013; Mesel, 2013). Scott and Briggs (2009) suggested that 'basic' science, which is typically grounded in implicit epistemic assumptions, is usually favoured among the academic community and is more likely to attract funding. Hence, studies adopting a pragmatic approach (i.e., embrace methodological plurality) can potentially be placed at a disadvantage or given lower priority over research which is driven either by purely positivist/post-positivist or constructivist/interpretivist directions.

From a philosophical point of view, pragmatism bypasses the challenging issues raised by the concepts of truth and reality, accepts (from a philosophical point of view) that *"there are singular and multiple realities that are open to empirical inquiry and orients itself toward solving practical problems in the "real world""* (Feilzer, 2010, p.8). At an epistemological level, pragmatism advocates that "*knowledge is not constituted by correspondence to a given reality, but is instead reflected by an increased capacity to act on and transform experiential circumstances"* (Hathcoat and Meixner, 2017, p.436). In other words, knowledge is not something we use in order to captivate and explicate a pre-defined reality, but it is about gaining insight as to how we should respond in relation to an certain environment or given circumstances (Martela, 2015). Considering the above, pragmatism indeed positions itself clearly with respect to its philosophical assumptions regarding research. Hence, dismissing pragmatism as an 'anti-philosophical' movement due to its objections towards philosophical dogmatism indicates a rather poor understanding of pragmatism and its underlying principles.

4.6. Chapter summary and adoption of a paradigmatic stance

This chapter presented the main lines of inquiry, with particular focus upon pragmatism and mixed methods research. A mixed methods approach allows researchers to harvest the strengths of both qualitative and quantitative means in a single study and has received considerable attention due to its capacity to address multifaceted research problems. Considering the objectives of this project, it was determined that a mixed methods approach was the most appropriate way forward. Having established a methodological approach, the chapter then proceeded to demonstrate the philosophical underpinnings of this choice.

Pragmatism rejects the traditional 'top-down' approach to research and places questions at the epicentre of empirical inquiry, which enables researchers to utilise a variety of means to address their objectives (Scott and Briggs, 2009). This offers an antidote to the issue of methodological purism and liberates inquirers from operating under strict sets of metaphysical doctrines, thus allowing them to produce knowledge that can lead to meaningful actions. As Johnson (2008) argued, philosophy should be treated as a *partner* of research and not as its *dictator*. Hence, pragmatism was adopted as the research philosophy that guided the author's approach to inquiry. The following chapter will outline the methodology, as well as the methods that were used in order to evaluate the study's intervention.

Chapter 5: Evaluation methodology and methods

The previous chapter outlined the main approaches to inquiry, discussed their philosophical underpinnings and presented the author's (AC) paradigmatic stance and approach to empirical enquiry. Exploring these areas was necessary in order to provide a robust theoretical framework for the evaluation of the project's intervention and ensure congruity between the research objectives and the approach that was followed to address them. This chapter will outline the methodological approach that was followed for the evaluation of the project's intervention, alongside with the study design and research methods that were used in the pilot investigation.

5.1. Methodological considerations

The choice of methodology was informed by theoretical, as well as practical aspects. The following sections will present these in detail.

5.1.1. Theoretical aspects

The core theoretical considerations behind the choice of methodology (i.e., philosophical underpinnings) have been outlined in chapter 4. Having established the methodological approach and its potential advantage over monomethod approaches (Ritchie and Ormston, 2014), it is important to demonstrate why and how this choice of methodology would benefit this study at a theoretical level. Several authors have proposed the key reasons behind researchers' decision to undertake a mixed methods approach; drawing upon the most inclusive identified typology (Bryman, 2006), the following reasons were identified:

- *Triangulation* reflects the view that quantitative and qualitative research can be combined to triangulate findings so that they can be mutually validated. For example, a quantitative assessment of one aspect (e.g., app usability) would be validated through an investigation of in-depth user perspectives on this particular aspect.

- *Completeness* suggests that researchers can achieve a more complete account of the area of inquiry by deploying qualitative and quantitative approaches together. In the context of this project, coupling numerical findings with qualitative feedback would help acquire a more holistic understanding of the benefits and drawbacks of the intervention. Quantitative data would help understand *how* successful (or unsuccessful) the app was, while qualitative data would help clarify *why* this was so.

- *Explanation* is the concept of using findings from one research component to help explain the findings derived from the other component. This would be helpful for interpreting quantitative results using qualitative findings, as numerical data alone would not allow for fully understanding users' feedback (positive or negative).

- The concept of *unexpected results* involves the use of qualitative and quantitative research in order to understand unexpected results derived by either approach. This is in close proximity with the concept of explanation, as findings from one component can help interpret unanticipated results derived from the other strand.

5.1.2. Practical aspects

In addition to the theoretical considerations, there were several practical aspects that informed the decision of choosing mixed methods. With regards to the evaluation of

mobile health (mHealth) interventions, guidelines (e.g., Agarwal et al., 2016; Eysenbach 2011; Wyatt et al., 2015) call for a mixed methods approach, as some evaluation measures are best acquired via qualitative methods (e.g., users' or stakeholders' perspectives and recommendations for improvement), while others are best obtained through quantitative approaches (e.g., usage data). Indeed, in the guidance for developing and evaluating complex interventions, the Medical Research Council of the United Kingdom (MRCUK) suggested that a mixed methods approach can potentially benefit such projects (Craig et al., 2008).

A review exploring the application of mHealth in the field of cancer care demonstrated that the majority of studies followed a mixed approach to address their objectives (Darlow and Wen 2016). Moreover, the authors recommend that the development and evaluation of mHealth interventions should involve both quantitative and qualitative measurements, as they can provide a more complete upstanding of the effects of this technology. In a later publication, Alwashmi et al. (2019) also emphasised upon the importance of utilising a mixed methods approach to evaluate mHealth interventions at the early stages of development. Deploying a mixed method approach for the evaluation of the app was therefore in line with best practice in mHealth, which could potentially help communicate the findings of this work in this research field.

5.1.3. The research strands

The evaluation process involved a quantitative and qualitative component. These will be referred to as *strands* throughout the chapter. The quantitative strand was concerned with the first three objectives (degree of usability and acceptability, the intervention's capacity to fulfil users' information needs and use of app throughout treatment), while

the qualitative strand focused upon the last three (perspectives upon the content, attitudes towards the virtual agents and recommendations for improvement). Findings from the qualitative strand also helped enrich quantitative findings. Each strand included distinct methods, which are described in detail below.

5.2. The quantitative strand

This strand was concerned with parameters that could be readily quantified, such as satisfaction with information, degree of usability and the use of the app. In order to decide upon the most appropriate research methods for this strand, the methodologies followed by previous studies of health apps were considered.

5.2.1. Self-completed questionnaires

Surveys are a method concerned with the *"collection of quantified data from a population for purposes of description or to identify covariation between variables which may point towards casual relationships or predictive patters of influence"* (Sapsford, 2007, p.3). The main characteristic of survey research is standardisation; all participants are given a consistent set of questions, as the ultimate goal is to get a consistent set of answers from the sample. Due to their practicality (e.g., fast turnaround in data collection, acquisition of data across large samples) and cost-effectiveness, surveys were the method of choice for collecting data related with usability and information from the participant cohort (Sapsford, 2007).

For this project, the collection of survey data served the purpose of description, as the sample size was not large enough in order to establish casual relationships or draw statistical inferences. Two questionnaires were administered in total, namely a *baseline*

and a *post-exposure* questionnaire. The former was provided in order to obtain demographic data and explore the information needs of the participants before using the app, while the latter was administered after they were exposed to the intervention in order to explore the satisfaction with information (provided through the app) and establish the degree of the app's usability.

The development of questionnaires, when performed in an appropriate manner, can be a lengthy and resource- consuming process (Sapsford, 2007). Instead of developing a series of custom instruments for the aforementioned purposes, a review of the literature was undertaken in order to identify existing tools that have already been used.

5.2.2. Information needs and satisfaction with information questionnaires

The information needs of patients with cancer have been studied from both a qualitative, as well as quantitative perspective. Studies that utilised a quantitative approach deployed various questionnaires to measure and compare patients' information needs across various participant cohorts (Papadakos et al., 2015). Among these, the most thorough instrument was the Toronto Information Needs Questionnaire (TINQ), which was originally developed for patients with breast cancer (Galloway et al., 1997), but was later adopted for prostate (Templeton and Coates, 2001), lung (Hsieh, Chou and Guo, 2018) and other types of the disease (Matsuyama et al., 2013). The original version of the TINQ (Galloway et al., 1997) contains 51 items (pieces of information) and responders are asked to rate the perceived importance of each item on a 5-point Likert scale ranging from 1 (not important) to 5 (extremely

important). This tool has five subscales (disease, investigative tests, treatments, physical and psychosocial information).

O'Connor, Coates and O'Neill (2010) adopted the original version of the TINQ for patients with rectal cancer a UK treatment centre. This version contained the same subscales as the original TINQ and included a total of 53 items. The participants were asked to rate the perceived importance of these items and the extent to which these items were addressed during their treatment; in essence, patients' information needs and satisfaction with information were measured at a single time point. As the authors demonstrated that the adopted version of the TINQ was capable of making consistent measurements of CRC patients' information needs (more information about consistency are outlined in p. 143), it was decided that this tool would be used for the present study.

Since rectal and colon cancer share considerable similarities in terms of treatment, pathophysiology, diagnostic tests and supportive care, the aforementioned version of the TINQ was considered to be an appropriate instrument for exploring the information needs, as well the perceived satisfaction with information of patients with CRC in this study. This tool was checked with the patients of the project's Patient and Public Involvement and Engagement (PPIE) scheme to ensure relevance. No modifications were suggested and hence, none of the items of this questionnaire were altered.

For the present project, the original questionnaire by O'Connor was split in two; in essence, participants' information needs and satisfaction with information were assessed at different time points. The items of the baseline questionnaire were prefixed with the statement "*During my treatment, I believe/feel that it will be important for me*

to know about..." and patients were asked to state their views in a Likert scale ranging from 1 (not important at all) to 5 (extremely important). The baseline questionnaire also obtained several demographic data (age, sex, ethnicity, marital status, educational level, employment status, health literacy, time since diagnosis, previous treatment for cancer) associated with patients' information-seeking (Zeguers et al., 2012; Mayer et al., 2007; Matsuyama et al., 2013; Sainio and Lauri, 2003; Gupta et al., 2013). A single question regarding IT literacy was also included, as this has been associated with the use of apps (Rasche et al., 2018).

The Satisfaction with Information Questionnaire contained the same 53 items as the Information Needs Questionnaire (O'Connor, Coates and O'Neill, 2010) , but this time, the items were prefixed with the statement '*In my view, the app provided enough information about...*'. Again, participants were asked to state their views in a 5-point Likert scale.

Analysis of Information needs and satisfaction with information questionnaires

To decide upon the most appropriate methods for analysing the data generated by the aforementioned instruments, it is necessary to first understand the *nature* of this data. Boone and Boone (2012) pointed out that Likert-type items and Likert scales follow distinct methods of analysis, as they generate different types of data; according to the authors, a Likert scale "*is composed of a series of four or more Likert-type items that are combined into a single composite score/variable during the data analysis process. Combined, the items are used to provide a quantitative measure of a character or personality trait*". As such data would fall in the interval measuring scale, mean values can be used to determine central tendency and standard deviation can be deployed for

measuring variability (table 5.1, adopted from Boone and Boone, 2012). As these questionnaires contained Likert Scale data (O'Connor et al., 2010), it was determined that these measures would be used for analysing data derived from these questionnaires.

Table 5. 1: Data analysis methods for Likert-type and Likert scale data

	Likert-type data	Likert-scale data
Central tendency	Median or Mode	Mean
Variability	Frequencies	Standard Deviation
Associations	Kendall tau B or C	Pearson's r
Other Statistics	Chi-square	ANOVA, t-test, regression

5.2.3. Usability questionnaire

In their review of health apps used in oncology, Darlow and Wen (2016) encouraged developers and researchers towards utilising the System Usability Scale (SUS) in order to assess the degree of usability of their interventions. The SUS was originally developed by Brooke (1986) in an attempt to produce a straightforward yet reliable instrument for assessing the degree of usability in various systems. Since its release, the tool has been used widely to measure the usability of hardware, software, mobile devices, websites and applications (Bangor, Kortum and Miller, 2008; Lewis and Sauro, 2009; Peres, Pham and Phillips, 2013; Orfanou, Tselios and Katsanos, 2015). Lewis (2018) notes that despite its humble beginnings and a number of competitors (e.g., the Software Usability Measurement Inventory and the Computer Systems Usability Questionnaire), the SUS remains the most popular tool for assessing system usability in a variety of fields.

The SUS contains ten statements (items) assessing subjective user perspectives. Nine items measure usability, while one item also assess the degree of learnability. In order

to reduce the risk of bias arising as a result of the lack of attention whilst completing the scale, the SUS alternates between positive and negative statements; items 1,3,5,7 and 9 are associated with positive aspects, while items 2,4,6,8 and 10 concern negative aspects. All items are set on a 5-point Likert Scale ranging from '*strongly disagree*' to '*strongly agree*'. Due to its degree of adaptivity, applicability and reliability, the SUS was adopted in order to assess the degree of the project's intervention. To adopt this instrument for the purposes of the study, the term 'system' was replaced with 'app'.

Analysis of Usability questionnaire

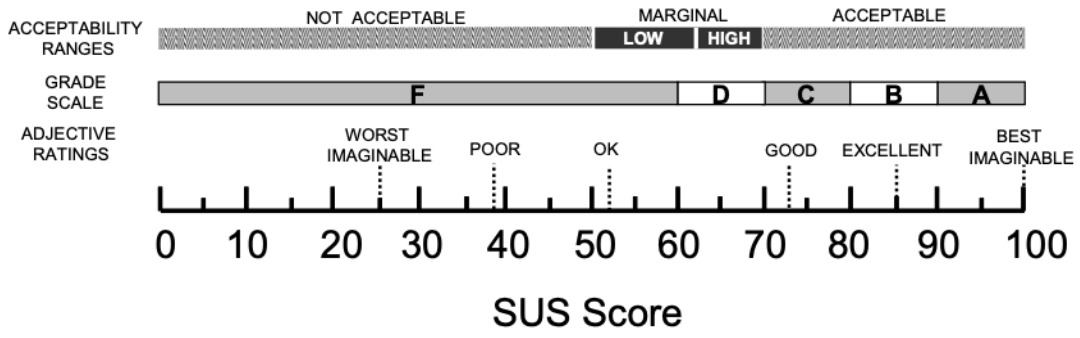
Although the items of the SUS are constructed in a Likert Scale, the SUS follows a custom scoring system. According to Brooke, (1986) the scores of each item should not be interpreted separately, as they are meaningless in isolation; instead, the purpose of the SUS is to produce a single number that represents a composite measure of an intervention's degree of usability. The author outlined the following procedure:

"*To calculate the SUS score, first sum the score contributions from each item. Each item's score contribution will range from 0 to 4. For items 1,3,5,7, and 9 the score contribution is the scale position minus 1. For items 2,4,6,8 and 10, the contribution is 5 minus the scale position. Multiply the sum of the scores by 2.5 to obtain the overall value of SU*." (Brooke, 1986)

Scores obtained from the SUS range from 0 to 100. While the author did not make further comments upon the interpretation of the overall scores, the accumulation of SUS data over the years enabled researchers to translate SUS scores in a more meaningful way. Bangor, Kortum and Miller (2009) later added an adjective rating scale

upon the SUS and proposed a comparison between adjective ratings and acceptability in relation to the average scores obtained by SUS. This is illustrated in Figure 5.1 (Bangor, Kortum and Miller, 2009, p.121) and was used as a guide in order to determine the degree of usability and acceptability of the project's intervention.

Figure 5. 1: Interpretation of SUS scores



5.2.4. Validation of self-completed questionnaires

Although validated instruments were adopted for the evaluation of the app, several modifications were implemented in order to make them fit to the study purposes. For instance, while O'Connor et al. (2010) measured information needs and satisfaction with information at a single time point, this study aimed to determine information needs at baseline and establish the satisfaction with information after the participants used the app. Furthermore, the items of the SUS were altered in order to make them relevant to the context of the study. Juniper (2009) pointed out even small changes in the wording, formatting or timing of administration can exert an effect upon the instrument's accuracy. While this does not prohibit researchers from customising validated instruments to match their unique study objectives, it certainly calls for validation before altered versions of custom tools are applied in research.

According to Tavakol and Dennick, (2011) there are two key elements to a questionnaire. The first is *validity*, which reflects the degree to which a tool can measure what it aims to measure. Face validity, the extent to which the questionnaire components are comprehensive and relevant to the responders was determined with the participants of the Patient and Public Involvement and Engagement (PPIE) group, as well as clinicians from the Churchill Hospital. As neither parties recommended any changes, the items of the questionnaire were not altered I terms of number and wording. The original sequence of items was also maintained.

The second element was *reliability*, which determines an instrument's capacity of making consistent measurements. Tavakol and Dennick (2011) proposed that reliability can be determined objectively with using Cronbach's alpha (α), which is used to establish *internal consistency*. According to the authors, "*internal consistency describes the extent to which all the items in a test measure the same concept or construct*" (Tavakol and Dennick, 2011, p.53) and should be determined prior to the administration of the instrument to ensure consistency. Cronbach's coefficient alpha ranges from 0 to 1; higher scores (i.e., values closer to 1) are indicative of higher internal consistency, with a range of 0.7 to 0.9 being generally acceptable. The alpha value for all three instruments was determined in the pilot study (Chapter 6).

5.2.5. Delivery of self-completed questionnaires

A paper version of the questionnaires was provided to the study participants at the recruitment site (Churchill Hospital) by a member of the research team. This decision was informed by considering the issue or poor response rates in internet- based

surveys, which can be attributed to the absence of human interaction during the delivery process of the questionnaire (Scott et al., 2011).

All questionnaires were provided alongside a pre-paid envelope. Patients were asked to complete them at their own time and post them to the address of the recruitment site, where they were collected by the author (AC). In order to protect participants' identities, the questionnaires were affixed with a unique identification code that allowed the author alone to identify the responder.

5.2.6. App usage data

User engagement was an significant outcome, as it would reveal the extent to which patients utilised the app and provide an overview of how the app was used during the study period. Short et al. (2018) proposed two *levels* of engagement, namely *microlevel* and *macrolevel* engagement. The former is associated with the "*moment-to-moment engagement with the intervention, including the extent of use of the intervention (eg, number of activities completed) and the user experience (eg, level of user interest and attention when completing activities*)", while the latter entails "*the depth of involvement with the behavior change process (eg, extent of motivation for changing behavior) and is linked to the behavioral goals of the intervention*." (Short et al., 2018). As the goal of this project was to provide information support without inducing changes in patients' information behaviour, the interest focused upon microlevel engagement.

In their viewpoint, Short et al., (2018) proposed that engagement can be determined by using quantitative, as well as qualitative measures. In a systematic review of mHealth and eHealth interventions, Perski et al. (2017) noted that system usage data (i.e.,

analytics of user activity) are the most common objective measure of user engagement across the literature. Short et al. (2018) later categorised usage data among the microlevel measures and emphasised upon their importance for assessing user engagement. Due to their capacity to provide a detailed and objective account of how the app was used throughout the study period, it was determined that usage data would be acquired.

Types of usage data

Short et al. (2018) proposed four categories of usage data, namely *frequency* (how often a user utilises the intervention), *intensity* (the proportion of features used in relation to the total features available to users), *time* (the duration of engagement) and *type* of interaction (passive *versus* active). The authors pointed out that using multiple categories in combination can offer greater insight with regards to engagement rather than using upon individual data categories.

In order to achieve a better understanding of how users engaged with the app, it was determined that frequency, intensity and type of engagement would be used. The duration of engagement would not add to the analysis; the content of the app included the virtual agent (VA) clips, which were fixed in terms of duration. Therefore, the following aspects were going to be measured:

- *Frequency of engagement*: The frequency of engagement refers to the number of logins and actions for each user throughout treatment. The *number of logins* and the number of actions, referred to as *tap count* were obtained for each user.

- *Intensity of engagement*: This measure helped establish the parts of the app that were visited by each user. For this project, this revealed which information sections and supportive functions of the app were visited (see figure 3.4, p. 112), as well the individual items that were accessed during these visits (i.e., VA clips and links to external resources). Another important measurement was the items viewed by each user in relation to the total items available through the app (referred to as *usage intensity*).

- *Type of engagement*: This refers to whether a user engaged with the app in an active or passive manner. *Active* use implies inputting data such as using the triage survey, making notes or setting appointments, while *passive* use entails using the app to retrieve information (e.g., watching the avatar clips, tapping on links). As the project was not concerned with clinical data (e.g., Triage assessment outcomes, symptoms, appointments etc.), it was determined that the content of user entries would not be visible to the research team. The analytics would indicate whether users visited such sections and inputted data, but they wouldn't reveal what was recorded in the app and/or the Triage survey. In this way, it was be possible to determine the proportion of active versus passive use of the app without compromising users' confidentiality.

Acquisition of usage data

The version of Manage your Health that was used in the pilot testing had its interface connected to Google Analytics (GA). GA is the most commonly used third-party data tracking service in eHealth and mHealth interventions (Crutzen, Roosjen and Poelman, 2013) and can provide information such as the time that individual users interacted

with an intervention, the pages visited and the frequency of use. As GA would provide a detailed account of the desired usage data, it was determined that it would be used for this purpose.

Analysis of usage data

In their work, Short et al. (2018) pointed out that a detailed plan of usage data analysis should ideally be established before the acquisition of data. Yet, there was no consensus with regards to the methods that should be used for analysing usage data in mHealth. Some studies used descriptive measures in order to outline how users utilised their interventions (Couper et al., 2010; Glasgow et al., 2011; Mohr et al., 2013), while others made correlations between the intensity of use and clinical endpoints such as weight reduction (Arden-Close et al., 2015) or aspects such as satisfaction with the intervention (Baltierra et al., 2016). Considering these studies, the following analysis methods would be deployed:

- *Frequency of engagement*: This included the number logins per user and the number of actions (tap count) undertaken by each user during a login. A total tap count would be presented for each user, which would be further broken down to tap count before and after the first dose of chemotherapy. Tap counts for each information section of the app would also be presented each user, which would be also broken down to before and after treatment to explore potential differences in the types of information accessed between these phases. The range (lowest and highest) mean (or median) and frequency of engagement (number of logins and tap count) would be used to summarise the findings for the participant cohort.

- *Intensity of engagement*: Proportion of unique items in relation to the total number of items provided (expressed as a percentage) for each user
- *Type of engagement*: Proportion of active *versus* passive use per user
- Correlations between the tap count and a) mean information needs, b) mean satisfaction with information and c) usability score (per user).

5.3. The qualitative strand

As mentioned earlier (p. 144), qualitative methods can also be applied for evaluating mHealth interventions. Short et al. (2018) identified three approaches namely *interviews*, *think-aloud* and *focus groups*. Think aloud entails asking users to reflect upon their experiences whilst using the intervention in real-time and capturing their perspectives at that time. This approach was not suitable for this project, as the participants of the study were going to be given the app to use in their discretion.

Focus groups have been defined as *"a form of group interview that capitalises on communication between research participants in order to generate data"* (Kitzinger, 1995, p.299). This method is fundamentally different from group interviews, as it depends upon the *interaction* between the group members (typically 6-8 strong) to address the research objectives. Participants present their personal views, but they also hear other perspectives, oppose or accept viewpoints and even refine their own, ultimately generating rich data, unlike interviews where comments are mediated exclusively by the interviewer (Finch and Lewis, 2003). In the context of this project, the limited availability of patients was a major logistical obstacle for organising a group discussion. As the study participants were going to be approached at specific time

points in their treatment (see 5.5.1 for further details), putting together a discussion group was impractical.

In qualitative research, interviewing is the most widely-used data collection method (Jamshed, 2014). Interviews enable researchers to elicit narratives in order to construct a detailed account of participants' lived experiences, which allows for achieving a thorough understanding of their perspectives (Gray, 2018). As this study was concerned with participants' perceptions around the app, this method would help obtain information- rich data towards achieving a better understanding of the reasons that encouraged or discouraged them from using the intervention. Interviewing participants was also necessary in order to obtain recommendations for improving the intervention. Hence, it was determined that interviews would be deployed to meet these objectives.

According to Ritchie et al., (2014) there are three types of interviews, namely *structured*, *semi-structured* and *unstructured interviews*. Structured interviews are commonly deployed in quantitative research, as they are highly standardised, while semi-structured and unstructured interviews find much wider application in qualitative research. With respect to unstructured interviews, Jamshed (2014) pointed out that they resemble more of a conversation rather than an interview due to the lack of a pre-defined set of questions. Semi-structured interviews on the other hand have a discussion guide, but they unfold in a conversational manner and enable the interviewees to explore matters that are significant to them. This in turn enables the interviewer to alter the order of the questions and add or omit questions according to previous findings. To maintain focus but at the same time allow for modifications in the

interview schedule, it was decided that semi-structured interviews would be deployed with study participants.

Although clinicians were already involved in the development phase of the intervention, their experiences with patients who used the intervention were key towards better understanding the effects of the app within the patient cohort. Furthermore, clinicians' views for improving the app after witnessing its effects in practice were also important. Hence, it was determined that interviews would be conducted with the clinicians of the research team. These interviews would also follow a semi-structured fashion.

5.3.1. Semi-structured patient interviews

A semi-structured interview guide (SSIG) was crafted to guide the interview process. The questions included in the guide were framed in an open-ended manner in order to allow for the acquisition of in-depth perspectives from the participants. The choice of questions was influenced not only by the research objectives, but also by relevant literature, as a degree of familiarity with a particular subject area is necessary in order to decide upon the most appropriate topics for discussion (Kelly, 2010). The SSIG included the following discussion topics:

- *General perspectives and experiences from using the app*: This topic was concerned with how the intervention was used before and after the first cycle of treatment. The purpose was to explore what the app offered to users, how it was used in relation to other sources of information and which sections were most relevant to the users.

- *Usability of the app and perspectives on the virtual agents*: As Brooke (2013) pointed out, the SUS (5.2.2) is not a diagnostic tool. This means that while it can reveal problems related to usability, it does not have the capacity of explaining why such issues exist. In this case, it was determined that in-depth accounts would help clarify any usability-related issues. The items of the SUS served as a guide for formulating open-ended questions that would allow participants to reflect upon any issues they experienced whilst using the app. After exploring this, the participants would be asked to reflect upon how the inclusion of the VA influenced the app.
- *Satisfaction with information*: While this aspect would be explored using a questionnaire, (5.2.1) this instrument wouldn't offer indication on issues such as the framing or the level of detail of the information provided. Participants would hence be asked to reflect upon aspects of the content (organisation, amount, appropriateness) and offer recommendations for improving it for future patients.
- *General recommendations for improvement*: Participants would be asked to offer any recommendations to improve the app that was given to them.
- *Overall study experience (pilot study only)*: This discussion point was concerned with the appropriateness of the study design and the research methods. Participants were asked to comment on their overall study experience in order for the CI to identify issues that had to be addressed before proceeding to the main study.

In structured interviews, the interview guide must remain unchanged, since the purpose of deploying such method is to obtain standardised responses from the participants (Stuckey, 2013). In contrast, the flow of a semi-structured interview is not determined by the guide but rather, the conversation itself is what drives the process. Furthermore, alternations can made for particular participant cases so that the SSIG can be further refined during the course of a research project. The aforementioned discussion points were going to be piloted and the SSIG would be updated by considering salient points raised by the interviewees before proceeding to the main study (Kallio et al., 2016).

5.3.2. Semi-structured clinician interviews

The semi-structured clinician interviews would be conducted at the end of the main study. This was decided in order to allow sufficient time for clinicians to interact with patients who used the app. The semi-structured clinician interview guide (available in appendix 3) included four discussion topics:

- *Experiences with patients who used the app*
- *Observed changes in patients' knowledge*
- *Observed effect on consultation time*
- *Personal views and recommendations for improvement*

5.3.3. Interview technique

Interviews can be conducted in a number of ways. The most commonly utilised interview modes (also referred to as *techniques*) are *face-to-face* and *telephone* interviews (Adhabi and Anozie, 2017). Each approach is accompanied by certain

advantages, as well as drawbacks (Opdenakker, 2006). For instance, while face-to-face interviews can be resource-consuming and time-demanding, they are capable of producing rich data and detailed accounts of participants' perceptions and thus remain the 'gold standard' in qualitative research (McCoyd and Kerson, 2006). On the other hand, telephone interviews are regarded as more time and resource-efficient, but have also received criticism regarding the depth of data they generate (Opdenakker, 2006).

Novick (2008) noted that while the effect of modality upon the interview process has been documented and examined thoroughly in the context of survey research, the differences between telephone and face-to-face interviews have not been explored in an equally extensive manner in the domain of qualitative inquiry. The author suggested that qualitative researchers might hold certain bias against telephone interviews due to potential issues arising as a result of the absence of visual and social ques (e.g., visual contact with the interviewee, body language, build of rapport). These issues concern losses in contextual, verbal and/or non-verbal data, as well as distortion of verbal data.

Apart from the theoretical considerations, there were also practical aspects that were taken into account in order to decide upon the mode of interviews. Bryman (2012) pointed out that telephone interviews might not be an appropriate choice for interviews that aim to run for a long time, as they can be more easily terminated by the interviewees when compared to face-to-face interviews. Some authors have also noted that telephone interviews can be shorter in duration, as participants tend to talk less or be less willing to 'take the stage' (Irvine, 2011; Irvine, Drew and Sainsbury, 2013).

Considering the points presented above, it was determined that face-to-face interviews were the most appropriate mode for meeting the study objectives.

5.3.4. Recording and transcription of interviews

Keeping an accurate record of interviewees' accounts was another key consideration. According to Kelly, (2010) audio recordings are the best way to document the findings of an interview. Note-taking is another way of captivating participants' responses but suffers from several important drawbacks. First and foremost is that the reconstruction of an interview through notes is highly susceptible to recall bias on the behalf of the researcher, which can compromise the quality of the results. Taking detailed notes whilst undertaking an interview can also cause disruptions, hinder the researchers' attention to the conversation and inhibit aspects of interaction such as eye contact. Hence, it was determined that audio recordings of the semi-structured interviews would be obtained, after promptly obtaining consent from the participants (6.5).

According to Opdenakker, (2006) the use of recording equipment does not mean that researchers shouldn't make *any* notes during an interview. Keeping brief notes can help track key points such as which questions were addressed and/or any issues encountered during the interviews. For each interview, the author would make brief notes of significant aspects and review them at the end of each interview in order to consider making any necessary modifications to the interview guide.

Transcription was another key consideration. While performing the transcription process would help the researcher to better familiarise himself with the data, such activity would be unfeasible considering the project's timeline. The transcription of interviews can be a particularly lengthy process; Gale et al. (2013) proposed that a 60-minute interview can produce a 15 to 30 page-long transcript. Hence, it was decided that recordings would be sent to a dedicated transcription company used by the School

of Pharmacy (Keele University). In order to compensate for the investigator's (AC) absence of involvement in the transcription process, the investigator would listen to the recordings whilst reading the transcripts.

5.3.5. Analysis of interviews

Smith and Firth (2011) proposed three categories of methods used for analysing qualitative data. The first was *socio-linguistic methods*, which are concerned with the use of language and the meanings that can be derived from it (e.g., discourse and conversation analysis). The second was *theory-developing methods*, typically involving the use of grounded theory and last (but certainly not least), the *methods used for describing and interpreting views* such as content and/or thematic analysis. Vaismoradi, Turunen and Bondas (2013) proposed that the choice of the most appropriate analytical method should be informed by study objectives, as well as how much is known in a particular field of inquiry.

Thematic analysis is a commonly deployed approach for analysing qualitative data. According to Braun and Clarke, (2006) it is a flexible tool that doesn't owe allegiance to any particular epistemological view and can is capable of producing a detailed account of the retrieved data. The *framework* approach, a particular type of thematic analysis has gained considerable momentum in the social, as well as health sciences due to its systematic nature and capacity to produce high-quality evidence (Gale et al., 2013). Framework analysis has a 'dual' analytical character, as it begins by drawing upon the established set of objectives (deductive) but then proceeds to presenting the original accounts and perspectives of the participants (inductive) (Pope, Ziebland and Mays, 2000). As these attributes were satisfactory from both a philosophical and a

methodological viewpoint, it was determined that the framework method would be deployed for the analysis of data derived from the semi-structured interviews.

Gale et al. (2013) proposed a thorough process of applying the framework method. The authors established seven distinct stages in the analysis process. The steps are described briefly below:

Step 1-Transcription: The process of transcription has already been outlined in 5.3.4.

Step 2-Familiarisation with data: During this step, the author (AC) would use the recordings, as well as the accompanying transcripts and notes to 'immerse' in the data in to achieve a holistic view of what was discussed during the interviews.

Step 3 -Coding: The author would read each transcript carefully and assign a unique label (i.e., a code) to relevant passages to describe important points. This step is not necessary for purely deductive studies; yet, as the project dealt with a relatively unmapped research area (the application of embodied conversational agents in cancer care), a certain degree of induction would help identify aspects that were not accounted for by the pre-set aims and objectives.

Step 4-Development of the analytical framework: After conducting the third step for several transcripts, the generated codes would be organised in broad categories, which would then be clearly defined in order to formulate the *analytical framework*. Several iterations (i.e., going back to the data to ensure congruity) would be performed to refine the framework before proceeding to the next step.

Step 5-Application of the analytical framework: The analytical framework would be applied to all subsequent transcripts. Essentially, the transcripts would be annotated using the codes generated in steps 3 and 4 to ensure that all relevant data were identified.

Step 6-Charting of data and formation of the framework matrix: The author would create a matrix chart for the themes and corresponding subthemes identified through the transcripts. This would reduce the volume of data so they could then be analysed. Care was would be taken to ensure that the original meanings, as well as links to the original data were retained across the matrix. According to the Gale et al. (2013), the structure of this matrix *"is visually straightforward and can facilitate recognition of patterns in the data ... through drawing attention to contradictory data, deviant cases or empty cells"* (p.117).

Step 7-Interpretation: This would be the last and most important part of the analysis. Having the entire dataset organised into the matrix would allow for the identification of core concepts, as well as the establishment of association between data and explanations of phenomena. This would be achieved through constant comparison and exploration of the transcripts.

5.3.6. Reflexivity

Darawsheh (2014) pointed out that subjectivity is an intrinsic element in the thought process of all researchers and can exert an influence upon inquiry. This is central for qualitative research, as "*qualitative researchers are not regarded as objective observers*

of social phenomena because of their social, political and cultural positioning in the worlds they study" (Walker, Read and Priest, 2013, p.38).

According to Finlay, (2002) the purpose of reflexivity is for researchers to acknowledge the personal values, beliefs and biases that influenced their research process and demonstrate how these aspects affected it. Palaganas et al. (2017) remarked upon the dual nature of reflexivity, which can be regarded as both a *concept* and a *process* and offered the following description:

> "R*eflexivity pertains to the "analytic attention to the researcher's role in qualitative research" ... As a concept, it refers to a certain level of consciousness. Reflexivity entails self-awareness (...), which means being actively involved in the research process. It is about the recognition that as researchers, we are part of the social world that we study (...). Reflexivity as a process is introspection on the role of subjectivity in the research process. It is a continuous process of reflection by researchers on their values (...) and of recognizing, examining, and understanding how their "social background, location and assumptions affect their research practice"*." (pp. 427)

Guillemin and Gillam (2004) explained that reflexivity is an ongoing process that expands across every stage of research continuum and 'saturates' it. As Smith (2006) noted, reflexivity does not just focus upon findings but is instead concerned with the entire course of inquiry including conceptualisation, design and conduct. Barrett, Kajamaa and Johnston (2020) emphasised upon the importance of keeping a reflexive account (i.e., record) throughout the course of research and continuously referring to it in order to warrant that the process is performed in the most efficient way.

It should be noted that although reflexivity is an essential component of qualitative inquiry, Finlay (1998) argued that it can also be of value in quantitative research. Ryan and Golden (2006) demonstrated how reflexivity can benefit a quantitative study while Walker, Read and Priest (2013) presented its application in a mixed methods investigation.

Albeit the significance of reflexivity, an important consideration is whether it is applied in a productive manner. The first question concerns the conceptualisation of reflexivity, or simply; do inquirers appreciate what reflexivity *is*? Barrett, Kajamaa and Johnston (2020) pointed out that the terms *reflection* and *reflexivity* are sometimes used interchangeably, but are indeed different; the authors explained that while the former seeks to "*question, evaluate and re-think practice, e.g. clinical skills*", the latter aims to "*facilitate consideration of our understanding of culture, social realities and position*" (p.10). In other words, reflexivity is about appreciating how our values, beliefs and biases shaped the way that we conduct research and influenced the interpretation of our findings. Understanding the differences of these concepts is pivotal so that reflexivity is applied effectively.

Having captured the essence of reflexivity, the next question is the *extent* to which it is applied. In an early publication, Finlay (2002) proposed that that reflexivity has its limits. Drawing upon their experiences throughout their PhD course, Mauthner and Doucet (2003) also remarked upon the limits of reflexivity and explained that while some influences (and their effects) can be uttered at the time of the study, other aspects can necessitate more time to become evident. Instead of envisioning reflexivity as a single process, the authors proposed that "*it may be more useful to think in terms of 'degrees*

of reflexivity', with some influences being easier to identify and articulate at the time of our work while others may take time, distance and detachment from the research" (p.425). This consideration is particularly valuable for newly introduced researchers in order to engage reflexively with their work, but also recognise that reflexivity can stretch beyond an individual project.

Despite the abundance of publications that describe what reflexivity entails, the lack of consensus as to *how* it is applied poses a challenge. Atkinson and Coffey (2002) pointed out that reflexivity is not a clearly defined term, the meaning of which might sometimes be unclear. In the context of this project, publications from nursing research and in particular, an article by Allen (2004) helped better appreciate how it can be applied to a project in the domain of healthcare. According to the authors, reflexivity involves three aspects, namely:

> "*a concern with how the field of study is filtered through the very particular interpretative lens of the researcher and, as such, reflects their individual history and biography as well as their theoretical perspective; an acknowledgement that in actively participating in the field, the researcher will have an effect on the phenomena being researched* (...); *and recognition that the field will have an effect on the researcher* (...)" (p.15)

Reflexivity would be an essential component of the present study. Findings derived from the qualitative compartment of this work could not be treated as factually accurate, as they would constitute an amalgamation of participants' personal accounts and the researcher's interpretation (Walker, Read and Priest 2013). It was therefore

vital for the author to demonstrate how his views and values influenced these findings in order to achieve transparency add rigour.

5.4. The relationship of the strands

After describing the research strands and the methods nested within the each one, it is now necessary to explain how the strands were related to each other. According to Creswell and Plano Clark, (2011) there are four aspects to consider, namely *"(1) the level of interaction between the strands, (2) the relative priority of the strands, (3) the timing of the strands and (4), the procedures for mixing the strands"* (p.64). These aspects constitute core decisions for all researchers undertaking a mixed methods approach and will be discussed in detail below.

- *Level of interaction between the strands*: Greene (2007), suggested two types of interaction, namely *independent* and *interactive*. An independent relationship implies that the strands are distinct and that the research questions, as well as the processes of data collection and analysis are kept separate. In this case, researchers mix the two strands at the final stages of a study. An interactive relationship on the other hand indicates that the research strands inform each other, and they are mixed before the overall interpretation step. For the present study, the research strands shared an independent relationship, as findings from one strand would not inform the design or conduct of the other. Instead, the results from each component would be merged at the last stage of the investigation (i.e., the interpretation step).

- *Relative priority of the strands*: According to Creswell and Plano Clark (2011), this aspect is concerned with the emphasis placed upon each strand and proposed three types of priorities, namely qualitative, quantitative or even priority. As participants' detailed accounts of personal experiences were more important than numerical inferences and statistical significance, the qualitative compartment was given higher priority.

- *Timing of the strands*: According to Creswell and Plano Clark (2011), the timing of the strands is "*often discussed in relation to the time the data sets are collected, but most importantly, it describes the order in which the researchers use the results from the two sets of data within a study*" (p. 66). The authors suggested three potential timings, namely *concurrent* (both sets of data are collected and analysed at the same time), *sequential* (one set of data is collected and analysed before the other) and *multiphase* (multiple phases including sequential and/or concurrent timing over a study). The qualitative and quantitative strands of this study followed a concurrent timing, as they run in parallel. Furthermore, the data from both strands were collected and analysed at the same time.

- *Procedures for mixing the strands*: The core considerations here are the point of inference (the time point when the strands are mixed in the study) and the mixing of strategies (how the strands are mixed). As the qualitative and quantitative strands shared an independent relationship, the point of inference occurred during the final stage of the study.

Having established the research strands, their relationship and the methods nested within them, it is now necessary to present how these methods were applied. The next section will present the study's design.

5.5. Study design

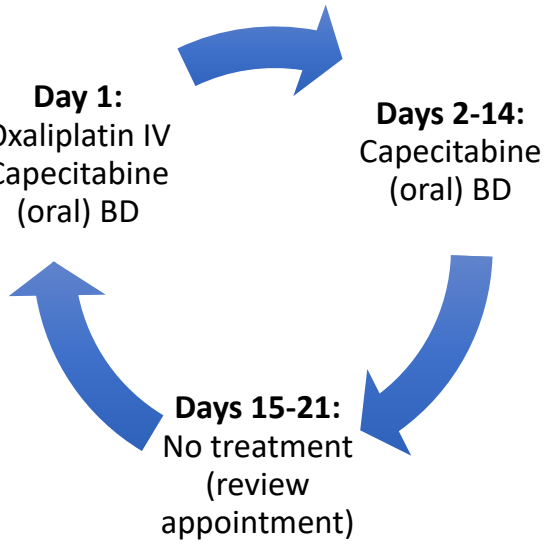
In order to prevent adding burden at a sensitive point of treatment and avoid additional hospital visits, the study design was influenced by the treatment schedules of the participating patients. Hence, before presenting the study design, it is necessary to explore the patient journey in standard care.

5.5.1. Patient journey in standard care

The pilot phase of the study involved patients with colorectal cancer (CRC) receiving chemotherapy with XELOX (Capecitabine and Oxaliplatin) for the first time. XELOX is a combination treatment, which is administered in three- week cycles. On the first day of each cycle (fig. 5.2), patients have to attend the treatment centre to be given an intravenous (IV) dose of Oxaliplatin, followed by fourteen days of oral Capecitabine taken twice daily (BD). The last week of the cycle does not involve any chemotherapy medicines.

Before the initiation of treatment, patients are seen by a consultant oncologist at the Churchill Hospital. During this appointment, the consultant explains various aspects of chemotherapy to the patients and consented them for chemotherapy. Then, patients have to attend the hospital's Day Treatment Unit (DTU) to receive their first dose of treatment. During the last week of the first treatment cycle, patients have to attend the hospital for a review appointment.

Figure 5.2: Treatment cycle with XELOX



The cycle presented above represents the average patient journey in standard care. Depending upon the availability of seats in the DTU, patients might have had to initiate their treatment earlier or later than 3-4 weeks after their pre-chemotherapy consultation. The treatment sequence can be altered according to the patient's response to the chemotherapy. For instance, patients who experience considerable toxicity may have additional treatment-free time and/or can be invited to attend a review appointment sooner. Nevertheless, as the core components of the cycle (pre-treatment phase, first dose and follow-up) are consistent for every patient receiving this regimen, the treatment schedule was used as a guide for informing the study design.

5.5.2. Provision of the intervention and administration of the data collection tools

Considering the timings discussed in 5.5.1, the following study schedule was applied:

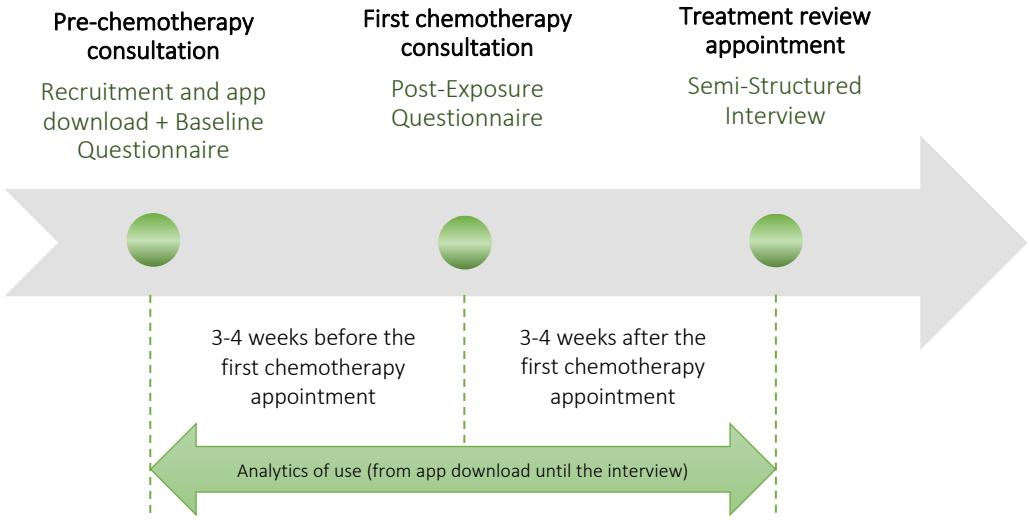
- *Recruitment, provision of the intervention and baseline questionnaire*: Potential participants were approached on the day of their pre-chemotherapy consultation

(three to four weeks before the first dose of treatment), where they were screened for eligibility and then offered a place in the study. If they agreed to take part, participants were asked to provide written consent and were then given a unique access code for the app, alongside the baseline questionnaire.

- *Pre-chemotherapy interaction phase*: During this time, the participants were free to utilise the app before their first chemotherapy appointment; usage data were collected throughout this period.
- *Provision of the post-exposure questionnaires*: Participants were given the post-exposure questionnaires (satisfaction with information and usability) to complete either at the clinic or from home. These questionnaires were provided at the DTU on the day of the first chemotherapy appointment by either the author (AC) or a member of the research team.
- *Post-chemotherapy interaction phase*: Participants were be free to utilise the app before their review appointment. During this time, usage data were also collected.
- *Semi-structured participant interviews*: On that day, participants were invited to attend a semi-structured interview after the end of their first review appointment. In order to prevent adding burden to the participants, the interviews were conducted at the Churchill Hospital upon the date of their review appointment. Patients were contacted a week in advance in order to confirm their attendance and arrange for a suitable time.

Again, this schedule depended upon the treatment schedule for each participant and was therefore affected by any alterations made in patients' treatment schedules. The overall study design is summarised in figure 5.3.

Figure 5.3: Participant study journey



Considering each individual participant journey, there was a clear quantitative phase (baseline questionnaire, post-exposure questionnaire and analytics of use) succeeded by a qualitative phase (semi-structured interviews), indicating that the quantitative and qualitative strands were conducted in a sequential manner. Yet, as this project was comprised by a series of individual participant journeys which run in parallel, quantitative and qualitative data were collected and analysed concurrently. Hence, although the quantitative and qualitative phases were conducted in a sequential manner for each participant journey, the study as a whole followed a *convergent parallel design*.

5.6. Study population and eligibility criteria

As patients with different types of cancer can potentially express unique information needs (Nagler et al, 2010), the study focused upon a single form cancer and a specific treatment approach to ensure homogeneity across the participant cohort.

All patients were recruited from the Churchill Hospital. In order to be able to enter the study, potential participants had to fulfil all of the following eligibility criteria:

- 18 years or older
- Able to provide consent to the study
- Understood written and spoken English
- Had an established diagnosis of CRC, irrespective of stage
- Eligible to receive XELOX
- Were chemotherapy-naïve (i.e., didn't receive chemotherapy in the past)
- Had (and were able to use) a smartphone or tablet that can accommodate our app (the app was compatible with both iOS and Android software). Potential candidates who didn't possess such a device were still able to take part in the study as long as a caregiver, a partner or a member of their family had an appropriate device and was willing to help.

5.7. Sample size

As there was no intention of drawing inferences from the study cohort, no formal sample size calculations were performed (Schmidt, Lo and Hollestein, 2018). Instead, the sample size depended upon the number of interviews required to reach data *saturation*, which has been defined as "*the point at which no new information or themes are observed in the data*" (Guest, Bunce and Johnson, 2006, p.59)

While the number of interviews needed to achieve data saturation cannot be determined *a priori*, it is possible to estimate an approximate figure by drawing upon existing research (Vasileiou et al., 2018). Previous qualitative studies in the field of

mHealth have demonstrated that saturation can be reached with as few as 9 (Fleming, Hill and Burns, 2017) to as many as 30 interviews (Goetz et al., 2017). It was therefore estimated that approximately 20 in-depth interviews would likely be needed for the present project. Assuming that half of the participants who used the app would agree to be interviewed, the sample size was estimated to be 40 patients; if saturation was established with fewer interviews, the researcher would seize to recruit further participants.

The above considerations concerned the sample size for the main investigation phase of the project. The sample size of the pilot investigation was 10% of the estimated sample size of the main study (i.e., 4 patients).

5.8. Sampling strategy

Teddlie and Yu (2007) grouped sampling techniques in four broad categories; *probability*, *non-probability* (also referred to as purposive), *convenience* and *mixed methods* sampling. Probability sampling is primarily deployed in quantitative research, since the ultimate goal is representativeness (Bryman, 2016). In contrast, non-probability sampling is used mostly in qualitative research, as units are selected due to the presence of specific characteristics that allow for detailed exploration of the aspects which a researcher wishes to investigate (Ritchie et al., 2014). Convenience sampling is a technique where the sample is drawn entirely according to the availability of resources (Kemper, Stringfield and Teddlie, 2003), while mixed methods sampling is generally reserved for mixed methods studies, where researchers can combine more than one sampling approach to acquire the desired sample (Teddlie and Yu, 2007).

The pilot study deployed convenience sampling, as the goal was to involve a small number of patients and therefore all individuals who fitted the inclusion criteria were eligible for inclusion irrespective of other characteristics. The sampling strategy for the main study was nested mixed methods sampling; for the quantitative strand, patients were acquired through convenience sampling while purposive sampling with maximum variation was used to obtain participants for the qualitative compartment.

5.9. Informed consent

All participants were asked to provide written informed consent (appendix 4). As this project did not involve an experimental treatment, a medical device or a surgical intervention, potential participants could provide consent on the day they were approached. All potential participants were provided with an invitation letter (appendix 5) and a participant information leaflet (appendix 6) and had the opportunity to ask any questions they might had. If potential participants needed time to consider their options, they were given the consent form, alongside with a pre-paid envelope and the information material and were contacted 2 days after the invitation to state their decision. Those who agreed to participate were given a unique access code to install the app on their device(s) of choice and asked to return a signed copy of the consent form, a completed copy of the information needs and demographics questionnaire.

Interview participants were asked to provide separate written consent for the interviews; this applied to both patients (appendix 7) and clinicians (appendix 8). The interviewer (AC) would explain the points outlined in the consent document and answer any queries before obtaining consent.

5.10. Research ethics and ethical approvals

Appropriate measures were in place to ensure that this project run in line with the Good Clinical Practice (GCP) guidelines and was conducted under high ethical standards. The project lead (AC) received appropriate training in GCP, as well as qualitative interviewing prior to approaching and interviewing participants. Expert advice was also sought by Dr Alison Gifford on interview practices.

As the project involved patients, ethical approval was required prior to the commencement of research activities that would involve study participants. The project lead (AC) liaised with Keele Research Governance and submitted the required forms through the Integrated Research Application System (IRAS). The study received ethical approval by the Health Research Authority (HRA) of England and Whales on the 4th of May 2018. The letter of HRA approval is available in appendix 9.

In the original proposal, the author stated that participants would be able to put a two-step authentication process in place (i.e., app password lock). Following further discussions with the development team, it was determined that this would not be feasible. Instead, participants would be advised to utilise their device's security measures (i.e., password lock) in order to protect any personal data that they might entered into the app, such as appointment dates and/or any notes. As this constituted a major amendment in the original proposal, a notice of substantial amendment was submitted to IRAS, which received approval on the 19th of June 2018 (appendix 10).

5.11. Chapter summary

The present chapter outlined the methodological considerations for the evaluation of the project's intervention. Instead of making a forced decision between qualitative and quantitative research, it was determined that a mixed methods approach would be followed. Each participant journey would include a quantitative phase, which would then be followed by a qualitative phase. The data collection methods of the quantitative phase were questionnaires (baseline and post-exposure) and usage data, while semi-structured interviews would be used to collect in-depth data in the qualitative phase. The order and timing of the administration of these methods were determined by considering the chemotherapy treatment cycle (XELOX). The next chapter will demonstrate how this methodology was applied to evaluate the pilot version of the app.

Chapter 6: Pilot Study

Chapter 5 presented the core methodological considerations for evaluating the project's intervention and outlined the methods for acquiring the desired study data. The present chapter will outline the conduct of the project's pilot study. The chapter will begin with an outline of the aims and objectives of this preliminary investigation and will then present the results obtained from this phase. The findings will then be discussed, followed by their implications for the main investigation.

6.1. Rationale and aims

Researchers who plan to undertake large projects or conduct studies with elaborate designs need to ensure safety and robustness prior to initiating their inquiry. According to Arnold et al., (2009) pilot studies are an excellent way of determining such aspects before proceeding to large-scale investigations. Thabane et al. (2010) referred to pilot studies as *vanguard trials* or *feasibility studies* and provided a comprehensive list of the reasons for conducting such investigations, as well as the benefits they can offer.

While some researchers use the terms *pilot* and *feasibility* interchangeably, Eldridge et al. (2016) pointed out that these are in fact distinct. According to the authors, a feasibility study is a type of research whose purpose is to determine whether or not is possible to conduct a particular project, while a pilot study is a smaller version of a large investigation whose purpose is to indicate if the various components of a large investigation can work together.

Since the question of feasibility was addressed during the Patient and Public Involvement and Engagement (PPIE) interviews, it was determined that a pilot study was going to be the next step in this project. Conducting a pilot study was necessary not only for establishing the robustness of the proposed methodology for evaluating the app, but also for providing insight as to the appropriateness of the app itself.

6.2. Objectives

Several authors have remarked upon the erroneous focus that is often placed upon hypothesis testing and assert that the objectives of pilot studies are different from those of main investigations (Arain et al., 2010; Whitehead, Sully and Campbell, 2014). This is also mentioned in the Medical Research Council's (MRC) guidance for developing and evaluating complex interventions, where the importance of understanding the context in which such interventions are applied is emphasised (Craig et al., 2008).

Considering the above, the purpose of the pilot study was not to solely perform an evaluation of the project's intervention; while receiving initial feedback from app users was an important outcome, the main focus of this investigation was to establish the robustness of the proposed methodology and study design. Hence, the specific objectives involved the following:

a) Assessment of recruitment potential
b) Establishment of the appropriateness of the data collection methods and study design
c) Determination of logistical aspects
d) App-related feedback and recommendations for improvement

e) Identification of technical errors

6.3. Methodology

The methodological considerations have been presented in chapter 5. The following sections will briefly outline the participants, the study design, the methods and the analysis plan.

6.3.1. Participants

The participants of the pilot study were chemotherapy-naïve patients with colorectal cancer (CRC) who were going to receive their first cycle of treatment with Oxaliplatin and Capecitabine (XELOX). The eligibility criteria are described in detail in chapter 5 (p. 167). All participants were recruited from the Churchill Hospital (OUH) from September 2018 to December 2018. The sample size for the pilot study was 4 patients (i.e., 10% of the target for the main study).

6.3.2. Study design and research methods

The study design and research methods are discussed in detail throughout chapter 5. The pilot study followed a convergent parallel mixed methods design, where quantitative and qualitative data were collected concurrently. The pilot study was essentially comprised by a series of individual participant journeys, which run in parallel.

Each participant was given the app approximately 3-4 weeks before the first cycle of treatment, alongside a baseline questionnaire (information needs and demographics). On the day of their first chemotherapy appointment, participants were given a set of post-exposure questionnaires (satisfaction with information and degree of usability)

and were finally invited to attend a semi-structured face-to-face interview at the Churchill hospital on the day of their review consultation. Analytics of use (i.e., usage data) were acquired for each participant from the point of download until the day of the interview. The overall study journey for each participant is depicted in figure 5.3 (p. 166).

6.3.3. Data analysis

Descriptive statistics (min, max, means and SD) were used for analysing data derived from the questionnaires exploring information needs and satisfaction with information (pp. 139-140). The scores obtained from the usability questionnaire were analysed according to Brooke's (1996) typology, which is outlined in chapter 5 (pp. 141-142). Descriptive statistics (frequencies and percentages) were be used to analyse the usage data (pp. 147-148). Data obtained from the participant interviews were analysed using the framework method. This process is described in detail in chapter 5 (pp. 156-157).

6.4. Results

Four patients were approached, all of which agreed to take part in the study. The mean age was 70.5 years and the male: female ratio was 3:1. All participants were retired and married. While health literacy was high, IT literacy was modest. Table 6.1 contains a summary of the participants' characteristics.

All four participants returned the baseline questionnaire and the System Usability Scale (SUS) and only one didn't return the satisfaction with information survey. Out of the four participants, three agreed to be interviewed at the end of their treatment cycle. The interview times ranged from 45 to 80 minutes (mean 62 minutes). The interviewees

were all male above the age of 60. The participants were coded as PS1, PS2 and PS3 for the purpose of presenting relevant quotations.

Table 6. 1: Demographic data (n=4)

	n	%		*n*	%
Age group			**Health literacy**		
50-64 years	1	25	Very high	3	75
65-74 years	3	75	High	1	25
Gender			**IT literacy**		
Male	3	75	Very comfortable	1	25
Female	1	25	Somewhat comfortable	3	75
Ethnicity			**Diagnosis**		
White (British)	3	75	<3 months	2	50
Black	1	25	3-6 months	2	50
Marital status			**Employment status**		
Married	4	100	Retired	4	100
Educational level			**Past treatment**		
Secondary education	2	50	None	3	75
Higher education	1	25	Surgery	1	25
Not disclosed	1	25			

6.4.1. Recruitment potential

Although patients were willing to participate, the number of individuals treated with XELOX was much lower than expected. According to the hospital's records, 82 patients received XELOX from April 2017 to March 2018. The team expected that six to seven new patients would be seen at the CRC department on each month, but only four patients were identified in the span of four months (September- December 2018).

Apart from the issue described above, some patients were missed due to unforeseen circumstances. At the time of the pilot study, the author contacted the oncologists one day before the colorectal clinics to check if any eligible patients would be available the following day. Yet, some patients were missed due to last-minute changes in the

chemotherapy schedule (i.e., from another treatment to XELOX) on the day of the clinics. With the exception of including only patients receiving XELOX, the remaining eligibility criteria were considered to be appropriate.

6.4.2. Appropriateness of research methods and study design

The appropriateness of methods and study design were determined by keeping fieldnotes and obtaining participants' insights. Participants were asked to express their views upon the study design and the data collection methods during the semi-structured interviews. This included three areas, namely the process of approach and invitation, the timing of the provision of the data collection tools (i.e., study design) and the perceived appropriateness of the data collection tools administered to them. The findings are presented below.

Approach and invitation to the study

Patients reported being comfortable with being approached after their pre-chemotherapy appointments, but one participant explained that this time might not be appropriate for patients in distress. The participant proposed that such patients could be contacted via phone at some other point, but also suggested that eligible patients would be more likely to agree to take part in the study if recruited face-to-face.

> *"you don't get quite the same commitment that you would get if you see somebody and then you get them to sign on the bottom line there and then and explain it to them* (...)". PS2

Study design

None of the participants thought that the study design interfered with their treatment schedules. The last patient explained that being on chemotherapy had a limiting effect upon normal activities and as a result, there was more free time that could be dedicated towards research. At the same time, the participants appreciated that other patients could potentially be overwhelmed by the study requirements and lose interest, especially if they didn't understand what benefits it could offer.

> *"...at the moment I've got the time and so I'm happy to help you. I know that you're just trying to improve things at the end of the day."* PS1

Data collection methods

The questionnaires were received well, and no comments were made with regards to the clarity of the items or the length of the surveys. One view was that certain items of the information needs and satisfaction with information questionnaires gave the impression of overlapping, but no specific items were mentioned. All questionnaires were completed from home and posted to the hospital using the pre-paid envelopes provided. One patient did not complete the satisfaction with information because the app wasn't used enough in order to be able to assess how well it addressed the items listed on the survey. With respect to the interviews, all participants felt that the interview schedule was appropriate.

While the reliability coefficient (Cronbach's alpha) was acceptable for the baseline questionnaire (0.77) and the SUS (0.85), the satisfaction with information questionnaire had a low score (0.36), which was indicative of reliability issues for this instrument.

Major issues were evident for the analytics of use, as only one set of usage data (i.e., a single user profile) was identified through Google analytics. This was because the host platform (Manage your Health) had a large number of users and the search function did not allow for identifying profiles related to the Bowel Cancer version. An attempt to identify the user profiles was performed by using the dates in which patients were enrolled, but as most of them (3/4) installed the app on different dates at their homes, it was not possible to locate them within the entire dataset of Google Analytics. As the remaining three user profiles could not be identified, it was not possible to perform a formal analysis of such data in SPSS. An informal analysis of the single user profile indicated that the patient used the app four times before receiving treatment. During these incidents, the user explored different sections of the app. Treatment-related information (Sections 2, 3 and 4) received most visits.

6.4.3. Logistical considerations

The logistical considerations included the *potential changes in the treatment cycles*, the *administration and receipt of the post-exposure questionnaires*, and the *conduct of interviews*.

Changes in treatment cycles

Fieldnotes revealed that changes in participants' treatment schedules and hospital visits were common. This included the date of the first dose of chemotherapy, as well as the

date of the initial chemotherapy review appointment. This was because of treatment-related aspects (e.g., poor response to the chemotherapy), as well as logistical issues (e.g., limited availability of seats in the hospital's day treatment unit).

Administration and receipt of questionnaires

The proposed mode of administration (i.e., provision by a member of the research team) and receipt was feasible.

Conduct of interviews

Several issues were encountered with regards to the timing and location of the interviews. These issues were associated with both the availability of patients, as well as venues for conducting the interviews. The first patient could not allocate time on the day of the review appointment and was interviewed during his second treatment appointment at the hospital's day treatment unit (DTU) instead. The second patient was also interviewed at the DTU at the second chemotherapy appointment, as the chief investigator was not able to attend the hospital on the day of the patient's review appointment.

6.4.4. App-related feedback

While some feedback regarding the app was obtained through the questionnaires (e.g., SUS and satisfaction with information), the interviews allowed for obtaining in-depth insight as to patients' views on the app. The sections below will present findings related to the app derived from the questionnaires and the semi-structured interviews.

General perspectives about the app

The participants who used the app believed that it was a valuable tool to have during their treatment. All users agreed that the app offered a good starting point where they could receive some initial information and could then utilise other resources if they wanted to examine things at greater depth. Another view was that the app was a good reference point for revising information. One participant remarked upon the portability of the app, which was also perceived to be more directed than other sources of information.

> *"...if you were starting from scratch knowing nothing, it would be quite handy, in a sense, to kind of - you know, go into it and it gives you some information and if you need more, then you think, 'Oh, I need a bit more,' and then you go and look somewhere else..."* PS3

The role of family emerged as an important theme. All participants demonstrated the app to their family members and recalled positive reactions. One participant explained that his wife encouraged him to use the app.

> "... [my wife] *encouraged me to use it more because it's more relevant to me. (…). I'm the one who is going to be taking on the consequences of it and so I tried to use it a lot prior to starting the treatment and during it."* PS1

Another participant recalled sharing the app with friends, who appeared to be fascinated about it.

> *"Yeah, friends. Just showed them, you know, especially the avatar. A lot of them were quite fascinated by that [laughter]."* PS3

Degree of usability

The overall user experience would be considered to be just above average, as the mean SUS score was slightly over 68. An SUS score above 68 indicates an average user satisfaction and marginal acceptability (high end), as shown in figure 5.1 (see p. 142)

The organisation of the content (i.e., the thematic grouping of information) was deemed to be reasonable. All participants agreed that navigating through the content was easy and did not impede the process of identifying the desired information. The degree of usability was satisfactory, as none of the users recalled having difficulties while using the app. Furthermore, none of the participants provided recommendations for improving this aspect.

> *"I think, in general, it's quite obvious how it works. I didn't find any difficulty in terms of knowing what I needed to do to get to where I needed to be in the app."*
>
> PS3

Although participants suggested that the app could be of benefit to fellow patients, they also pointed that some elderly patients might struggle with using it due to a lack of familiarity with this technology. However, they suggested that younger caregivers and family members could help patients use the app.

Information needs and satisfaction with information/content

The information needs of the patient cohort were high, with the means from each item ranging from 2.50 to 5.00. Ratings regarding the importance of each item are presented in table 6.2. The most important piece of information was knowing which side effects to

report to the doctors, followed by information regarding metastasis, recurrence, diagnostic tests and contacts for healthcare professionals. The least important piece of information was the availability of financial support, followed by information about emotional support due to concerns over physical attractiveness. In addition to questionnaire results, data on information support was also obtained from the interviews.

One participant focused upon information regarding existing issues and wasn't interested in having information about things that haven't occurred yet. Another patient explained that although theoretical information such as the aetiology of cancer was important, practical aspects such as dealing with side effects were more relevant. Focusing upon positive information avoiding unpleasant aspects was also evident. One individual reflected upon a leaflet given as part of standard care that listed all possible side effects and explained that it was particularly distressing.

> *"But it's a frightening list because you think – I couldn't even read it, there was so many things, you might as well go and drop dead than have all those things happening to you."* PS2

Patients also mentioned the sources they used to retrieve information. Two participants utilised multiple sources including the app, while the third participant relied largely upon the recommendations given by the oncologist, as well as existing knowledge.

The data obtained from the satisfaction with information questionnaire suggested that the participants were generally content with the information provided through the app (table 6.2). The means ranged from 2.33 to 4.67 and most items received an above

Table 6. 2: Information needs and satisfaction with information

	How important is for you to have each of the following types of information?					*Which of the following best describes how well the need was addressed through the app?*				
	n	Min	Max	Mean	SD	*n*	Min	Max	Mean	SD
How I will feel during or after the tests	4	4	5	4.75	0.50	3	3	5	4.00	1.00
If the bowel cancer will come back	4	4	5	4.75	0.50	3	4	4	4.00	0.00
How to prepare for my treatment	4	4	5	4.50	0.58	3	3	4	3.33	0.58
How I will feel after my treatment	4	4	5	4.50	0.58	3	4	5	4.67	0.58
Who to call if I have questions while I am still getting treatment	4	4	5	4.75	0.50	3	3	4	3.67	0.58
How bowel cancer acts in the body	4	4	5	4.50	0.58	3	3	4	3.33	0.58
If there are groups where I can talk with other people with cancer	4	2	5	3.50	1.29	3	2	5	3.67	1.53
If there are ways to prevent or ease side effects of treatment	4	4	5	4.50	0.58	3	3	4	3.67	0.58
How the illness may affect my life over the next few months	4	4	5	4.50	0.58	3	2	4	3.33	1.15
If there will be changes in usual things I can do with or for my family	4	3	5	4.50	1.00	3	2	5	3.67	1.53
If there is cancer anywhere else in my body	4	4	5	4.75	0.50	3	3	5	4.00	1.00
Who to call if I have questions after all the treatments are over	4	4	5	4.50	0.58	3	3	4	3.67	0.58
If it is known what causes bowel cancer	4	2	5	3.50	1.29	3	3	5	3.67	1.15
How the tests are done	4	3	5	4.00	0.82	3	4	5	4.33	0.58
Why do they need to test my blood	4	3	5	4.00	0.82	3	3	5	4.00	1.00
Who to talk to about treatment other to surgery/chemo/radiotherapy	4	3	5	3.75	0.96	3	3	4	3.33	0.58
How the illness may affect my life in the future	4	4	5	4.25	0.50	3	3	4	3.67	0.58
What the results of my blood tests mean	4	4	5	4.50	0.58	3	2	5	3.67	1.53
Where my family can go if they need help dealing with my illness	4	4	5	4.50	0.58	3	2	4	3.33	1.15
How to care for my wound or incision	4	3	5	4.25	0.96	3	2	5	3.67	1.53
What to do if I become concerned about dying	4	3	5	4.25	0.96	3	2	4	3.00	1.00
If I can continue with my usual hobbies and sports	4	3	5	3.75	0.96	3	2	4	3.00	1.00
If I can wear my normal clothing	4	2	5	3.50	1.29	3	3	5	3.67	1.15
Where I can get help to deal with my feelings about my illness	4	3	5	4.00	0.82	3	2	5	3.33	1.53
How to talk to my family and friends about my illness	4	3	5	4.00	0.82	3	2	5	3.67	1.53
If I have side effects, how to deal with them	4	4	5	4.50	0.58	3	2	4	3.33	1.15
The possible side effects of my treatment	4	4	5	4.25	0.50	3	4	5	4.33	0.58
What side effects I should report to the doctor or nurse	4	5	5	5.00	0.00	3	3	5	4.00	1.00
If I am prone to infection because of my treatment	4	4	5	4.50	0.58	3	2	4	3.33	1.15
How long my wound or incision will take to heal	4	4	5	4.25	0.50	3	2	4	3.33	1.15
How long will I be receiving treatment	4	4	5	4.50	0.58	3	1	4	3.00	1.73
How I will feel after the tests	4	4	5	4.25	0.50	3	3	4	3.67	0.58
Where to get help if I have problems feeling as attractive as before	4	2	3	2.50	0.58	3	1	3	2.33	1.15
How the treatment works against the cancer	4	3	5	4.00	0.82	3	3	5	3.67	1.15
If there are any special exercises I can do	4	3	5	4.00	0.82	3	2	5	3.33	1.53
The medical name for my type of cancer	4	2	4	3.25	0.96	3	2	4	2.67	1.15
If there are any physical things I should not do	4	4	5	4.25	0.50	3	2	4	3.33	1.15
If I am going to need help taking care of myself	4	3	5	4.25	0.96	3	2	5	3.33	1.53
How my treatment is done	4	4	5	4.50	0.58	3	3	5	4.00	1.00
If the treatment will alter the way I look	4	3	5	3.75	0.96	3	2	5	3.33	1.53
How to tell if the cancer has come back	4	4	5	4.50	0.58	3	4	4	4.00	0.00
Which foods I can or cannot eat	4	3	5	4.25	0.96	3	2	5	3.67	1.53
If I can take a bath or shower	4	3	5	4.25	0.96	3	2	5	3.33	1.53
What types of treatment are available	4	4	5	4.50	0.58	3	4	5	4.33	0.58
Why the doctor suggested this treatment plan for me	4	4	5	4.50	0.58	3	3	4	3.67	0.58
The reason the doctor suggests certain tests	4	3	5	4.00	0.82	3	4	5	4.67	0.58
How to prepare for the tests	4	4	5	4.25	0.50	3	4	5	4.33	0.58
What to do if I feel uncomfortable in social situations	4	2	5	3.50	1.29	3	2	4	3.00	1.00
If my illness is hereditary	4	3	5	4.00	0.82	3	3	4	3.33	0.58
If my illness/surgery/treatment will affect my relationships/sex life	4	3	4	3.25	0.50	3	2	4	3.00	1.00
If I will be able to continue with my job after my surgery/treatment	4	1	4	3.00	1.41	3	1	4	2.33	1.53
If there is any financial support available to me during my illness	4	1	4	2.25	1.26	3	2	4	2.67	1.15
If I can continue with my usual physical and social activities	4	3	5	4.00	0.82	3	1	4	3.00	1.73

average score. The means ranged from 2.33 to 4.67 and most items received score. The users were most satisfied with information regarding how they would feel after their treatment and the reasons why diagnostic tests were ordered.

The participants also reflected positively upon the information content during the interviews. The content was perceived to be straightforward and easy to understand, but at the same time inclusive and thorough; the use of language and the length of the answers were both deemed to be appropriate. Overall, the users felt that the information content was relevant to their needs and included information that they would look up themselves. One user explained that the sections related to side effects provided reassurance and help prepare for the upcoming treatment.

> *"... it was quite reassuring in some ways to see that those things* [side effects] *are common to lots of people. So, I thought that – I think that's quite a good thing about it, it does give you a bit of reassurance sometimes that you know, you're not unique." PS2*

Another view was that the app helped address information needs that were not discussed with the consultants.

> *"... I don't think this kind of erm repeats the consultant, I think it's a good thing over and above the consultant to give you general information...* [The app] *is complimentary, definitely complimentary because you can't go through what is cancer with a consultant, you've gotta go through something else. This is a good way of doing it." PS1*

Overall use of the app

Although usage data could not be acquired, the participants reflected upon the overall use of the app during the semi-structured interviews.

During the weeks before their first chemotherapy appointment, all participants briefly went through different sections of the app. The participants did this in order to familiarise themselves with the content before their treatment started. Although most of the information was not relevant at that stage, flicking through the content was useful in order to see what the app could offer for future reference.

> *"I skimmed over all the subject headings and then went into what I needed to know. It's hard to say but at a guess I probably looked at most things in detail for 50% to 60%. With the other 30% to 40% I thought, 'I know it's there; I don't really need to know it at this time, but I know where to go if I do."* PS1

After the first dose of treatment, users explained that they used the app on an 'as needed' basis. This was because once a reasonable understanding of treatment was achieved, patients didn't feel the need to use the app unless they wanted to refresh their memory. Following the administration of the first dose of chemotherapy, theoretical information (e.g., aetiology and physiology of cancer) became less relevant and the attention shifted upon practical aspects such as the management of side effects.

> *"So, at the start I looked at what it offered and then when I got into the treatment cycle I just cherry picked the bits I wanted."* PS3

Comments on the virtual agents (VAs)

Seeing the virtual clinicians for the first time provoked a humorous response in all participants. None of the participants thought that using VAs for delivering information was inappropriate; one user explained that it was simply another way of delivering information, which was acceptable in his view.

> *"I think it's quite humorous really. But the information is what's relevant at the end of the day and that's just a bit of fun."* PS1

Another participant suggested that this type of technology is likely to appeal to patients, as individuals are likely to favour this over plain text.

> *"People sort of – kind of I think people expect that these days, they don't want to just to be reading text. Especially with a subject like cancer..."* PS2

One participant believed that the clinician avatars did not add anything to the overall experience but didn't express views suggesting that their inclusion hindered the process of delivering information.

Formulating avatars after healthcare professionals was deemed to be an appropriate choice. This was because health professionals were perceived as the most appropriate agents for delivering treatment- related information. None of the users thought that the avatars should be omitted or that the characters had to be changed in order to resemble other individuals. Yet, including clips (videos) of patients undergoing diagnostic tests appeared to be important, as one patient explained that this made him more comfortable with these procedures.

"I thought they were useful at the beginning and quite reassuring and I thought that was good. They actually show people going in, having the treatment and coming out and they're not you know, it takes the fear factor away a bit I think to show those kinds of things". PS3

Recommendations for improvement

The participants made two recommendations for improving the content. The first was to include more links to external resources so that users can retrieve more detailed information; at the same time, it was proposed that the level of detail should be considered carefully, as signposting users to resources with complex information could potentially overwhelm them. Another suggestion was that the app should offer more detailed information about the processes during the first chemotherapy visit.

Only one recommendation was made for optimising usability. One user accidentally installed an information package unrelated to his condition but was unable to delete it as the app didn't offer such option. It was therefore suggested that the app should be updated so that information packages that were downloaded by mistake could be deleted.

6.4.5. Identification of technical errors

No technical errors were identified throughout the pilot study.

6.5. Discussion and implications for main study

The pilot investigation offered valuable insight regarding the feasibility of carrying out a larger-scale investigation and the integrity of the proposed evaluation methodology.

The results obtained during this phase suggested that the intervention was received well by the participants and that there was scope for testing the app with a larger patient cohort. Nevertheless, several modifications were necessary before proceeding to the main study. These modifications concerned the intervention itself, as well as certain elements of the study methods

6.5.1. Methodological considerations

Recruitment

Several authors have remarked upon the importance of recruitment and emphasised that researches should consider this carefully, as failure to do so can have a detrimental effect upon the success of any project (van Teijlingen and Hundley, 2002; Bertram et al., 2019). Although the present investigation did not suffer from commonly encountered issues such as high attrition or refusal rates, the pilot study indicated that the original choice of chemotherapy (XELOX only) would raise significant recruitment issues due to the limited number of available patients. Adjustments were hence necessary in order to obtain the desired sample and abide by the agreed timeframe.

The process of enrolling patients was deemed to be appropriate. None of the participants felt that approaching patients after their pre-chemotherapy consultations was inappropriate, but at the same time acknowledged that other patients might need to be approached at a later point, as the pre-chemotherapy appointments can be overwhelming for some. However, it was suggested that enrolling patients on site (i.e., face-to-face) can potentially make individuals prone towards committing more and would thus be beneficial to the project. While there is some evidence to suggest that

face-to-face invitation is more effective than telephone recruitment (Foss et al., 2016), attempting to recruit patients in distress would raise important ethical considerations (Wilson, Draper and Ives, 2008).

Appropriateness of study design and research methods

Testing the study schedule and the data collection tools was another important aspect of the pilot study. Overall, the participants felt that the data collection tools were appropriate; the questionnaires were received promptly and none of the participants expressed complaints regarding the clarity of the items or the length of the surveys. Yet, the reliability issues in the satisfaction questionnaire called for adjustments before proceeding to the main investigation.

One unexpected finding was that none of the patients completed the post-exposure questionnaires at the hospital, as they were anticipated to fill them whilst being at the DTU. The interview schedules were also deemed to be appropriate and addressed the study objectives at a good extent. Yet, it was determined that the guide should include more questions around VAs, as certain themes suggested that further exploration of this topic was necessary.

The most prominent methodological consideration concerned the failure in the process of acquiring the desired usage data. Although Google Analytics provided a good and concise account of user activity, there were two major issues. The first and most prominent problem was not being able to identify individual users and acquire the set of data they generated. The other major issue was the export of the usage data. Data from Google Analytics were exported as JavaScript Object Notation files, which could

not be handled by the author. Hence, it was determined that an alternative way of obtaining participants' usage data was necessary.

Logistical considerations

The pilot study offered valuable insight with regards to the logistical considerations for organising and executing a larger-scale investigation. The following changes were implemented:

- *Recruitment process:* The recruitment process could be managed entirely by the researcher (AC) and there was no need for additional personnel for this task. It was also realised that attempting to identify potential participants the day before the CRC clinics was problematic, as it could result in missing potentially eligible patients due to last-minute changes. Hence, it was determined that AC would attend all Thursday clinics in person for performing recruitment.

- *Provision of the app:* The researcher would encourage patients who agreed to participate to install the app on the day they were approached in the clinic. This was decided in order to keep a more concise record of enrolment and avoid issues encountered with identifying users in the analytics dataset.

- *Planning of treatment cycles:* The treatment schedules varied considerably for all participants. As being aware of the date and times that patients were going to attend the hospital was essential for administering the necessary data collection tools, it was determined that patients' schedules would be monitored more closely (e.g., on a weekly basis) so that any changes would be picked up on time to ensure thorough planning.

- *Conduct of interviews:* The changes in treatment cycles and the limited availability of patients indicated the need for considering alternative types of interviews. This was decided in order to avoid missing and cancelling interviews, as well for ensuring convenience for the participants, since it is a principal consideration for conducting robust interviews (McGrath, Palmgren and Liljedahl, 2019).

6.5.2. Intervention

There were two aspects to be considered in relation to the app. The first was concerned with its usability and content, while the second was associated with the VAs.

Usability and content

The mean usability score indicated that the app was acceptable, but improvements could be implemented in order to improve the overall user experience. The content appeared to address users' information needs adequately. Some recommendations were made for improving the content, but these constituted minor adjustments rather than major amendments to the initial version. The participants proposed that the app should be updated according to patient feedback, but also acknowledged that it would be impossible to cater everyone's information demands. This was due to the perception that patients' needs vary considerably, which is in line with findings from the literature (Sakamoto et al., 2017). Yet, the app appeared to be adequate at providing general information support.

Findings regarding usage patterns suggested that the app was not used frequently. As one user suggested, this could be attributed to the fact that once patients achieve a

good understanding of several aspects of their condition and its treatment, they are not likely to feel the need to use the app further unless they wish to be reminded of a particular point. Another reason that would explain this is that the app, with the exception of the Triage survey, didn't include a function that encouraged day-to-day use. Hence, it was determined that the updated version of the app should include a function that would make future users more inclined towards using the app more frequently, such as a sophisticated symptom diary. However, care was be taken in order to avoid requesting frequent input (to the app) from the participants, as doing so can potentially disengage users (Whitehead and Seaton, 2016).

Appropriateness of the VAs

The VAs appeared to be an acceptable way of delivering information to the patients of the pilot study. Although users' views regarding the role of the virtual characters varied considerably, none of the patients provided comments that raised concerns over the appropriateness of using VAs to deliver information through the app. All participants believed that the choice of formulating avatars after healthcare professionals was reasonable, which supported the initial hypothesis and indicated that there was no need to change the characters. It was hence determined that using these VAs in a larger-scale study was appropriate.

As the focus of the pilot study was to determine the feasibility of using VAs, this chapter did not offer a detailed discussion of the findings around this topic. Instead, data regarding VAs obtained during this phase will be combined with data derived from the main study, as the same animations and clinician characters were used in the main investigation phase.

6.6. Chapter summary

This chapter has presented and discussed the findings of the pilot study. This preliminary investigation indicated that there was scope for carrying out a larger-scale investigation, as the intervention appeared to be an acceptable way of providing information support to patients with CRC receiving chemotherapy for the first time. Some minor issues were encountered, but it was feasible to effectively address them before proceeding to the main investigation. The major issues were associated with recruitment, as the choice of a single chemotherapy regiment proved to be very limiting despite the initial estimations. Nevertheless, the patients approached during this phase were keen on engaging with the project and suggested that this approach was likely to interest fellow patients as well.

The pilot study indicated which changes that were necessary before proceeding to the main investigation. The following chapter will present the changes made as a result of the pilot study in detail.

Chapter 7: Revised methodology and methods for the main study

The previous chapter presented the conduct and results of the pilot investigation. This investigation revealed several methodological aspects that had to be addressed before proceeding to the main study. The present chapter will outline the alterations made to the initial approach for evaluating the project's intervention.

7.1. Study methodology

The methodological considerations regarding the evaluation of the app outlined in chapter 5 remained the same. The main study followed a convergent parallel mixed methods design with greater emphasis in the qualitative compartment. Yet, the pilot study exposed issues with recruitment, as well as several limitations in the study methods. Both of these aspects had to be addressed before proceeding to a larger-scale investigation. The following sections are going to outline the changes made to the study methods and recruitment for the main phase.

7.2. Participants, recruitment and eligibility

Focusing exclusively upon patients receiving XELOX gave rise to considerable recruitment issues. As it would have been logistically challenging to collaborate with an additional research site (e.g., identifying potential collaborators, setting up new research teams, having to travel to another location to recruit participants), it was necessary to expand the study population. As patients with different types of cancer are likely to express different information needs (Nagler et al., 2010), it was decided to keep

the research population as patients with colorectal cancer (CRC) receiving chemotherapy for the first time and expand the scope of the study to include additional chemotherapy regiments. The first regimen was FOLFOX, a combination treatment with folinic acid, 5-fluorouracil and Oxaliplatin. The second chemotherapy regimen was CAPE, a monotherapy regiment with Capecitabine which is given either alone (also known as *induction*) or in combination with radiotherapy (also known as *adjuvant*).

Another noteworthy aspect was that three new oncologists agreed to join the research team to help with recruitment. Although this would help enrol patients at a faster pace, it also meant that participants referred by these clinicians would not have members of their care team represented as VAs in the app. This was because the VAs were formulated after particular individuals (see chapter 3, pp. 109-110) and there was no time to create custom animations based on the characteristics of the new members of the research team. Although the original goal was to observe how patients would respond to a known VA only, captivating the responses of users who had information delivered by unfamiliar VAs would allow to compare perspectives between patients who had a known avatar and those who didn't. As this was considered to be an interesting domain, it was decided that differences between patients who were familiar with the VAs and users who were not would be explored in the interviews.

Apart from including patients receiving FOLFOX or CAPE, the original eligibility criteria outlined in chapter 5 (p. 167) were also applicable for the main study. All participants were recruited from the Churchill Hospital using the same enrolment process outlined in 5.5.2 (pp. 164-165).

7.3. Sample size and sampling strategy

Considerations regarding the sample size and sampling strategy have been outlined in detail in chapter 5 (pp. 167-168 and pp. 168-169 respectively). The sample size of the main investigation depended upon the number of interviews required to achieve data saturation (see p. 167 for further details) and was estimated to be 40 patients. The sampling strategy for the main study was nested mixed methods sampling; convenience sampling was deployed for the quantitative strand and purposive sampling with maximum variation was used for the qualitative component.

7.4. Intervention

The focus of the new versions of Manage your Health remained upon patients with CRC receiving chemotherapy. As feedback from the pilot study and the first Patient and Public Involvement and Engagement (PPIE) interviews was transferable to other chemotherapy regiments, the author (AC) proceeded directly to the development stage of the new information packages.

All three information packages (XELOX, CAPE and FOLFOX) contained the same thematic sections (table 7.1). The information content of most sections (1, 3,6, 7 and 8) was identical across all three packages, as it contained general information that was not related to a particular treatment schedule. Yet, the content of sections concerned with chemotherapy medicines (section 5), side effects (section 4) and unique treatment-related queries (section 2) had to be tailored for each treatment. The author inspected the chemotherapy regiments for CAPE and FOLFOX, formulated the new content and checked it with the clinicians before developing the new packages. The updated

information sections for the packages used in the main study are outlined in appendices 11 (XELOX), 12 (CAPE) and 13 (FOLFOX).

Table 7. 1: Thematic sections in XELOX, FOLFOX and CAPE

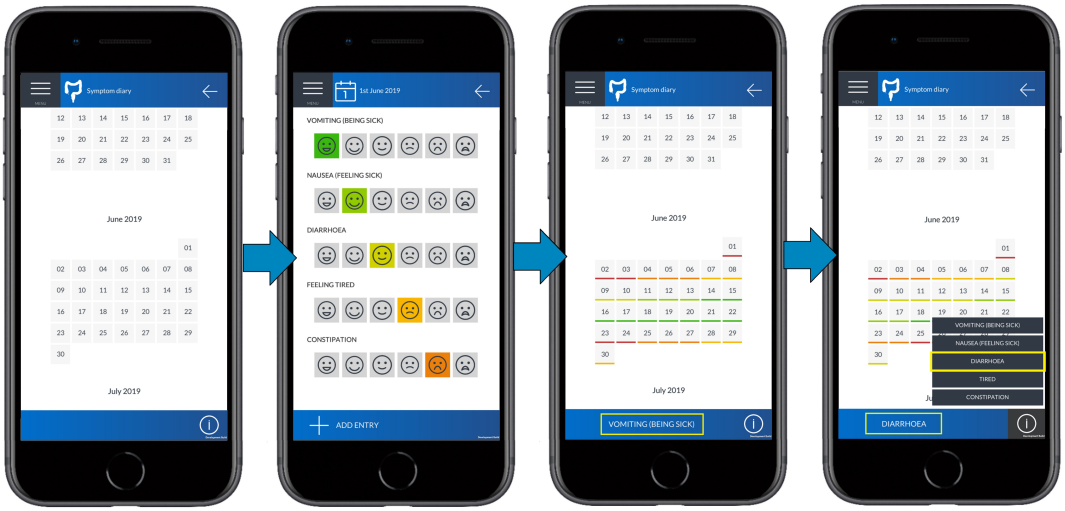
Thematic section	Section content details
Section 1: Search for a question	Enabled users to identify a query within the app
Section 2: Information about cancer and treatment	General information on bowel cancer (e.g., aetiology of the disease) and how chemotherapy medicines work
Section 3: Information about diagnostic tests	Information about why diagnostic tests are ordered and external links to demonstrate how they are performed
Section 4: Help with side effects	Outline of the potential side effects of treatment and advice how to deal with them and prevent their onset
Section 5: Help with medicines	Information and advice about chemotherapy medicines and supportive medication
Section 6: Emotional support and help with finances	Information about supportive infrastructures available in Oxford
Section 7: Triage survey	Link to the interactive version of the Triage assessment tool for reporting treatment-induced toxicity)
Section 8: Symptom diary	Record symptoms/side effects during treatment

The original version of Manage your Health had a major update planned in 2019. In March, the development team released a new version of Manage your Health which featured easier navigation (e.g., inclusion of a menu button), enhanced graphics (e.g., use of bold colours and contrast) and improved functions. This updated version was used in the main investigation phase.

While users could keep track of their symptoms through an informal notes function in the previous version of Manage your Health, the updated version provided a more sophisticated treatment diary function. For each day of their treatment, patients could

rate each symptom according to its severity and could then get an overview of the course of this symptom for over time. Figure 7.1. illustrates the diary function in detail.

Figure 7. 1: Symptom diary in Manage your Health (v.2)



Once the new information packages were prepared, the author performed preliminary testing to ensure functionality and identify potential technical problems. Some minor issues were encountered (e.g., unresponsive buttons, mute animations, typing mistakes), all of which were addressed promptly. The updated version of the app was released in May 2019.

7.5. Questionnaires

The System Usability Scale (SUS) scored well for reliability (Cronbach's alpha was 0.85) and therefore no alterations were required (p. 178). The questionnaire is available at appendix 14.

The most important consideration was the reliability issues for the satisfaction with information questionnaire. This was attributed to a printing mistake, as the instrument contained the wrong prefix. This caused confusion to the responders, as they thought

that they were given the same questionnaire twice. Hence, before proceeding to the main study, it was necessary to change the wording of the prefix to *'Which of the following best describes how well the need was addressed through the app?'*. The wording of the prefix for the baseline questionnaire was also updated for better clarity. The updated versions of the baseline and satisfaction with information questionnaires are available in appendix 15 and appendix 16 respectively.

The process of analysing the questionnaires (descriptive statistics for the information needs and satisfaction with information questionnaire and calculation of the usability score for the SUS scale) outlined in chapter 5 (pp. 139-142) remained the same.

7.6. Semi-structured interviews

Although face-to-face interviews are capable of producing information-rich data, logistical limitations can impede their planning and conduct (Opdenakker, 2006). This became apparent during the pilot study. Changes in the hospital review appointment dates or travel restrictions resulted in having to re-arrange several interviews, which was inconvenient for both the author and the participants. Additionally, moving interviews at a later time in patients' treatment could potentially result in recall bias. It was therefore decided that the interview mode should allow for more flexibility.

Advances in telecommunications have opened new opportunities for undertaking qualitative research. An early study focused upon videoconferencing and proposed that it can be a viable alternative to face-to-face interviews (Sedgwick and Spiers, 2009). Hanna (2012) later noted that developments in social media such as Skype made high-quality videoconferencing readily available to the public, which facilitated its uptake by

qualitative researchers. The same author argued that in addition to the benefit of synchronous communication, videoconferencing interviews also allow for the exchange of non-verbal ques between researchers and study participants. As discussed in chapter 5 (pp. 153), the absence of non-verbal ques in telephone interviews can potentially give rise to certain limitations; yet the use of Skype as a communication medium can help compensate for this issue.

Deakin and Wakefield (2014) proposed that in Skype interviews, rapport can be built as effectively as in face-to-face interviews. Furthermore, the authors suggested that a platform such as Skype not only allows the participants to choose a suitable time for the interviews, but it also enables them to determine the extent of engagement (i.e., audio only or video). A recent study that compared face-to-face interviews with video calling demonstrated that the former was only marginally superior to the latter and suggested that the use of videoconferencing can be justified as an alternative in qualitative studies that suffer from logistical constraints (Krouwel, Jolly and Greenfield, 2019). This was particularly applicable to the present project. As mentioned above, several interviews had to be re-arranged due to unforeseen circumstances. This not only incurred considerable cost to the researcher (e.g., additional journeys to Oxford from Keele), but also added further time upon the timeline. Considering the above, it was determined that the participants of the main study would be offered the option to conduct the interview either face-to-face or through a video or audio call. This was also applicable to the clinician interviews.

The updated version of the patient semi-structured interview guide for the main study is available in appendix 17. The interviews of the main study (both patient and clinician)

would be analysed using the framework method, which has been outlined in detail in chapter 5 (see pp. 155-157).

7.7. Usage data

As the previous method for collecting usage data proved to be problematic (see pp. 190-191 for more details), it was decided that usage data would be acquired in a different manner. The changes in the participant population also called for certain changes in the analysis of the resulting data. These alterations are discussed below.

7.7.1. Acquisition and types of usage data

Google Analytics (GA) was used in order to record usage data for the pilot study. Although GA has evolved over time, at the time of the project it was aimed more at website traffic (i.e., activity) than app reporting. The main limitation was that GA did not offer the flexibility of a real-time database for developers to structure the data in a way that best suited their objectives. For this project, this involved the identification of a user profile within the entire dataset, which was not feasible in the pilot study. Hence, it was decided that a different interface would be used for acquiring usage data.

Google Firebase, a platform specifically designed for apps offered a number of beneficial features for app monitoring, including cloud storage and methods to report usage. The Firebase features could be used by including the Firebase SDK (software developer's kit) in Unity (a cross-platform game engine). This was beneficial because all features could be grouped together as part of the same platform and could be easily accessible by the app, unlike GA. Furthermore, the Firebase utilised a data format called JavaScript Object Notation (JSON), which could be parsed fairly easily into other formats

such as Excel. Due to its flexibility and specificity for apps, Firebase was used to acquire the usage data for the main study.

The usage parameters remained the same for the main study and included the *frequency of engagement* (number of taps and logins to the app), *intensity of use* (proportion of items accessed in relation to the total number of items of the app) and *type of engagement* (active *versus* passive use). These have been described in detail in chapter 5 (see pp. 145-146).

7.7.2. Analysis of usage data

The considerations for analysing usage data have been outlined in chapter 5 (pp. 147-148). The participant sample of the main study was comprised by three sub-groups of users (FOLFOX, XELOX or CAPE). The members of each group were be given a unique version of the app, as not only the number of items in each information package varied, but also several items were unique for each package (e.g., chemotherapy medicines). Hence, sub-group analysis of usage data associated with the use of thematic information sections (sections 1-8, outlined in table 7.1) had to be performed. Three distinct datasets were developed, each corresponding to one of the treatments (XELOX, FOLFOX and CAPE).

Data regarding the frequency of engagement, the intensity of use and type of engagement were merged into a single dataset for the purpose of overall analysis. This was because such data did not depend upon the content of each information package (XELOX, FOLFOX and CAPE) *per se* and could therefore be combined to illustrate the overall picture of the participant cohort. Prior to conducting the analysis, the data was

prepared rigorously in order to ensure the reliability of the results. The steps of preparation and analysis were performed in SPSS, Version 22.

At first, the usage data for each user was merged in a single data file (in their respective treatments). Each case/row represented an action undertook at the application (i.e., a tap made by the user). To efficiently represent the layout for each treatment, including the different sections, subsections, and items (i.e., the individual animations, external links and treatment diary entries), a distinct coding was introduced for each treatment, which matched all items to a unique number. These numbers would be indicative of each section, subsection or item, as well as their original order in the app. Within each dataset developed, three additional variables were introduced. The first represented the actual use of the app, as received from the development team; for this variable, it was necessary to match the raw input to the app's layout. A distinct coding for the categories of this variable was introduced, based upon the item order within the section or subsection. The second variable corresponded to the section where each case (row) belonged. The third variable represented the stage of treatment (before and/or after the first dose of chemotherapy). The remaining information was retained in its original form.

While the initial proposal was to use descriptive statistics only, the unexpectedly large amount of usage data allowed the conduct of more sophisticated statistical analysis. Particularly, for the chi-squared (χ^2) test, the general rule of thumb is to have at least five cases per cell in the frequency crosstabulation table (Field, 2018); in the acquired dataset, this condition was met for most comparisons (XELOX and CAPE, not FOLFOX). Hence, both descriptive statistics and statistical inference were used. Within the descriptive statistical analysis and since the variables involved were categorical, frequency tables (frequency,

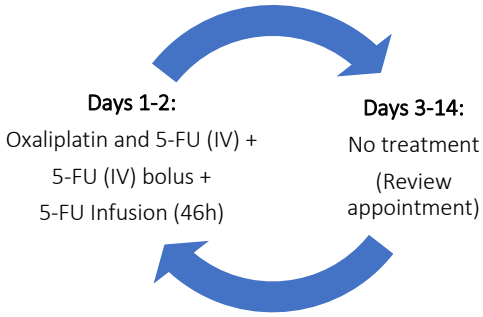
percentage), and bar charts (simple, clustered, stacked) were used (Kremelberg, 2011). Within the statistical inference analysis, the standard χ^2 test was the original choice to assess the dependency between section use and the stage of treatment (before/after the first dose of chemotherapy). In cases where the condition for a robust χ^2 test was not met (i.e., Cochran's criterion-at most 20% of the cells to have expected count less than 5), alternative standard tests were considered, particularly, the Fisher's exact test (Hae-Young, 2017). The level of statistical significance (a) was set to 0.05 in all cases.

7.8. Administration of the data collection tools

The inclusion of new chemotherapy regiments (FOLFOX and CAPE) did not cause any alterations in the original study design. Yet, the inclusion of new chemotherapy regimens affected the *timing* of the administration of the data collection tools, as each individual study journey had to be designed according to the treatment that was allocated to each patient. Hence, the treatment cycles with FOLFOX and CAPE had to be considered.

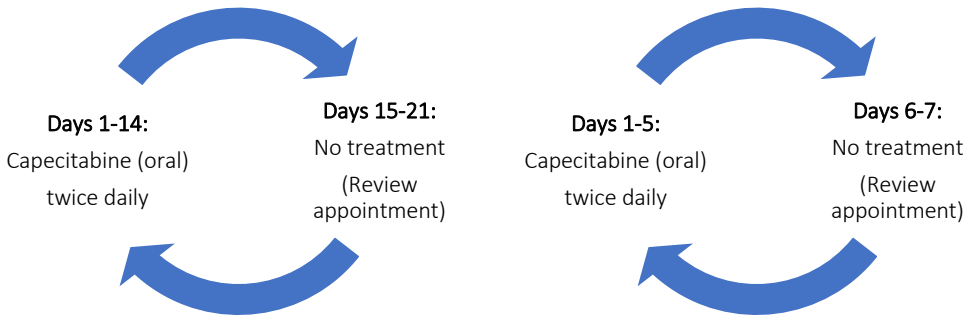
FOLFOX is a multiagent chemotherapy regimen administered in two-week cycles. On the first day of each cycle, patients attend the hospital to receive a chemotherapy pump device which delivers 5-fluorouracil (5-FU), oxaliplatin and folinic acid intravenously (IV) over two days (figure 7.2). The remaining twelve days of the cycle do not contain any chemotherapy medication. Patients then must attend a review appointment before the start of the next treatment cycle. This applies to both adjuvant and induction treatment.

Figure 7. 2: Treatment cycle of FOLFOX



CAPE is given differently depending on the type of chemotherapy (figure 7.3). The induction treatment cycle (left) follows the same pattern as XELOX (three- week cycle where treatment is given for the first two weeks). The adjuvant cycle (right) is different, as the treatment is administered in weekly intervals, where CAPE is given for the first five days of each cycle (figure 7.2).

Figure 7. 3: Treatment cycles of induction (left) and adjuvant (right) CAPE



All study participants received the app, as well as the baseline questionnaire three to four weeks before their first dose of chemotherapy, irrespective of the treatment schedule. Participants then received the post-exposure questionnaires (satisfaction with information and SUS) on the first day of their chemotherapy at the hospital's day

treatment unit; patients who received CAPE were given this questionnaire alongside their medicines by a member of the research team. All questionnaires were provided with pre-paid envelopes so that patients could complete them at their own time and send post them to the hospital. Finally, participants were invited to an interview on the day of their first review appointment. Analytics of use were obtained from the point of instalment up to the day of the first review appointment.

7.9. Ethical approval

The changes made before proceeding to the main investigation concerned both the study's population and the app. As these alterations constituted major amendments, a substantial amendment form was submitted to the Brighton and Sussex Research Ethics Committee (REC) prior to their implementation. The approval for these amendments was granted on the 5th of April 2019 (appendix 18).

7.10. Chapter summary

The present chapter outlined the changes implemented to the study's intervention, participants and methods before proceeding to the main study. In addition to patients receiving XELOX, the main study also included patients receiving chemotherapy with CAPE or FOLFOX in order to address the recruitment issues encountered in the pilot study. Users of the main study received an updated version of the app, which featured better usability features and bug fixes of the previous version. The study methods were also updated before proceeding to the main investigation to improve the acquisition of the desired data. The next chapter will present the findings of the main study.

Chapter 8: Main study results

The previous chapter outlined the amendments implemented to the app's evaluation methodology before proceeding to the main investigation. This chapter will present the results obtained from the main investigation phase of the project.

8.1. Participants

Out of 40 patients approached, 33 (82.5%) agreed to take part in the study. The main reason for not participating was the lack of an appropriate device (smartphone or tablet) that could accommodate the app, followed by the lack of time and/or interest to the study. Out of the 33 patients who provided consent, four wished to leave the study and did not install the app; reasons included a lack of interest, no perceived benefit from taking part in the study and not feeling that they could contribute to the project. The technical issues with the app that occurred during the study also led to the exclusion of six patients, as they had no access to the app during this time. Ultimately, 23 patients took part in the study. Out of these patients, 10 (43.5%) received treatment with XELOX, 5 (21.7%) received CAPE and 8 (34.8%) received FOLFOX.

The female to male ratio was 14:9. As not all participants returned the baseline questionnaire (information needs and demographics), complete demographic data were obtained for 13 out of 23 participants (56.5%). The demographic data is presented in table 8.1.

Table 8. 1: Demographic data (n=13)

Age	***n***	**%**	**IT literacy**	***n***	**%**
30-49	1	7.69	Extremely	4	30.77
50-64	6	46.15	Very	4	30.77
65-74	2	15.38	Somewhat	4	30.77
75+	4	30.77	Not at all	1	7.69
Employment status	***n***	**%**	**Health literacy**	***n***	**%**
Full time	4	30.77	Never	11	84.62
Part time	1	7.69	Some	1	7.69
Retired	6	46.15	Always	1	7.69
Unemployed	1	7.69	**Level of education**	***n***	**%**
Information refused	1	7.69	Secondary education	4	30.77
Marital status	***n***	**%**	Higher education	9	69.23
Partnered	1	7.69	**Ethnicity**	***n***	**%**
Married	9	69.23	White British	10	76.92
Divorced	1	7.69	White other	2	15.38
Widowed	2	15.38	Information refused	1	7.69
Diagnosis of cancer	***n***	**%**	**Previous treatment?**	***n***	**%**
Less than 3 months	13	100.00	No previous treatment	13	100.00

8.2. Questionnaire data

All study participants (n=23) received three questionnaires in total (one at baseline and two after treatment). Out of the 69 expected surveys (i.e., 23 baseline, 23 satisfaction with information and 23 System Usability Scale questionnaires), 29 (42%) were obtained in total. Only four patients (n=4/23, 17.39%) returned all three questionnaires. The baseline questionnaire had the highest return rate (13 out of 23, 56.5%), followed by the System Usability Scale (SUS) (9 out of 23, 39.1%) and satisfaction with information questionnaire (7 out of 23, 30.4%).

8.2.1. App usability results

Table 8.2 presents the results for the degree of the app's usability (9 responders). The majority of responders (n=7/9, 77.8%) scored above 70% in the SUS, suggesting a good degree of usability. The mean usability score was 73.89 (range 40-100, SD 16.96).

Table 8. 2: SUS scores for the main study (n=9)

	User ID								
SUS statement	User 4	User 10	User 12	User 9	User 2	User 1	User 3	User 15	User 19
I think that I would like to use this app frequently	5	4	4	4	4	4	2	3	4
I found the app unnecessary complex	1	1	4	4	2	3	4	2	2
I thought that the app was easy to use	5	5	3	4	4	4	2	4	4
I needed the support of another person in order to use the app	1	1	1	1	2	3	1	2	2
I found that the functions of the app were well integrated	5	5	3	2	4	4	1	4	4
I thought that there was too much inconsistency in this app	1	3	2	1	2	2	4	1	2
I would think that most people would learn to use this app very quickly	5	4	4	4	4	4	2	4	4
I found the app very awkward to use	1	1	4	1	2	1	4	1	2
I felt very confident using the app	5	5	3	5	4	4	3	4	4
I needed to learn a lot of things before I could get going with this app	1	1	2	3	2	1	1	2	2
SUS score	100	90	60	72.5	75	75	40	77.5	75

8.2.2. Information needs and satisfaction with information results

The results obtained for participants' information needs (13 responders) and satisfaction with information (7 responders) are presented in table 8.3. The data indicated that information needs were high, as the mean for the majority (n=50/53, 94.34%) of items was above 3. The items that received the highest scores concerned treatment-related (recurrence, metastasis, management and reporting of adverse effects and length of treatment) and dietary information.

Results regarding the satisfaction with information provided through the app suggested that participants were generally happy with the content, as the mean was 3 and above for all items. The items that received the highest mean satisfaction (4 and above) were treatment-related information (treatment options, management and reporting of

adverse events), information on diagnostic tests and information about support (support groups and contact details of healthcare professionals).

Table 8. 3: Information needs and satisfaction with information

	How important is for you to have each of the following types of information?					*Which of the following best describes how well the need was addressed through the app?*				
	n	Min	Max	Mean	SD	*n*	Min	Max	Mean	SD
How I will feel during or after the tests	13	3	5	4.08	0.86	7	2	5	3.43	0.98
If the bowel cancer will come back	13	4	5	4.92	0.28	7	3	5	3.71	0.76
How to prepare for my treatment	13	2	5	4.15	0.99	7	3	5	3.57	0.79
How I will feel after my treatment	13	2	5	4.15	0.90	7	2	5	3.86	0.90
Who to call if I have questions while I am still getting treatment	13	3	5	4.46	0.66	7	3	5	4.29	0.76
How bowel cancer acts in the body	13	2	5	4.15	0.90	7	3	5	4.00	0.82
If there are groups where I can talk with other people with cancer	13	1	5	2.77	1.36	7	2	5	4.00	1.15
If there are ways to prevent or ease side effects of treatment	13	2	5	4.54	0.97	7	2	5	3.71	1.11
How the illness may affect my life over the next few months	13	2	5	4.38	0.87	7	2	5	3.43	1.13
If there will be changes in usual things I can do with or for my family	13	2	5	3.69	1.11	7	2	5	3.71	1.25
If there is cancer anywhere else in my body	13	4	5	4.85	0.38	7	3	5	3.71	0.76
Who to call if I have questions after all the treatments are over	13	3	5	4.54	0.66	7	2	5	3.86	1.07
If it is known what causes bowel cancer	13	1	5	3.85	1.28	7	2	5	3.43	1.13
How the tests are done	13	2	5	3.85	0.90	7	3	5	4.00	0.82
Why do they need to test my blood	13	1	5	3.31	1.03	7	3	5	4.14	0.69
Who to talk to about treatment other to surgery/chemo/radiotherapy	13	2	5	3.38	0.87	7	2	5	4.00	1.15
How the illness may affect my life in the future	13	3	5	4.46	0.66	7	3	5	3.86	0.90
What the results of my blood tests mean	13	3	5	4.00	0.58	7	2	5	3.71	0.95
Where my family can go if they need help dealing with my illness	13	1	5	3.62	1.33	7	1	5	3.29	1.38
How to care for my wound or incision	13	1	5	3.77	1.64	7	2	5	3.43	1.13
What to do if I become concerned about dying	13	1	5	3.92	1.26	7	2	5	3.14	1.07
If I can continue with my usual hobbies and sports	13	1	5	3.46	1.33	7	2	5	3.43	0.98
If I can wear my normal clothing	13	1	5	2.85	1.21	7	3	5	3.57	0.79
Where I can get help to deal with my feelings about my illness	13	1	5	3.46	1.20	7	2	5	3.57	0.98
How to talk to my family and friends about my illness	13	1	5	3.46	1.33	7	2	5	3.43	1.27
If I have side effects, how to deal with them	13	3	5	4.46	0.66	7	2	5	3.57	1.27
The possible side effects of my treatment	13	3	5	4.62	0.65	7	3	5	4.00	0.82
What side effects I should report to the doctor or nurse	13	4	5	4.85	0.38	7	3	5	4.29	0.76
If I am prone to infection because of my treatment	13	3	5	4.46	0.78	7	2	5	4.14	1.07
How long my wound or incision will take to heal	13	1	5	3.92	1.32	7	2	5	3.57	0.98
How long will I be receiving treatment	13	4	5	4.77	0.44	7	1	5	3.43	1.40
How I will feel after the tests	13	2	5	4.31	0.95	7	2	5	3.57	0.98
Where to get help if I have problems feeling as attractive as before	13	1	5	2.69	1.60	7	1	5	3.57	1.40
How the treatment works against the cancer	13	2	5	3.92	1.04	7	3	5	3.86	0.90
If there are any special exercises I can do	13	1	5	3.77	1.17	7	2	5	3.57	1.13
The medical name for my type of cancer	13	1	5	3.15	1.07	7	2	5	3.86	1.07
If there are any physical things I should not do	13	3	5	4.15	0.80	7	2	5	3.43	0.98
If I am going to need help taking care of myself	13	1	5	3.54	1.05	7	2	5	3.29	1.25
How my treatment is done	13	2	5	4.08	0.95	7	3	5	3.86	0.90
If the treatment will alter the way I look	13	1	5	3.46	1.66	7	2	5	3.29	0.95
How to tell if the cancer has come back	13	2	5	4.69	0.85	7	3	5	3.71	0.95
Which foods I can or cannot eat	13	2	5	4.08	0.95	7	2	5	3.71	1.11
If I can take a bath or shower	13	1	5	3.38	1.33	7	2	5	3.29	1.11
What types of treatment are available	13	3	5	4.46	0.78	7	1	5	3.43	1.27
Why the doctor suggested this treatment plan for me	13	3	5	4.31	0.75	7	2	5	3.71	1.11
The reason the doctor suggests certain tests	13	2	5	3.92	0.95	7	2	5	3.71	0.95
How to prepare for the tests	13	3	5	4.08	0.86	7	3	5	3.71	0.76
What to do if I feel uncomfortable in social situations	13	1	5	3.00	1.63	7	2	5	3.00	1.00
If my illness is hereditary	13	1	5	4.23	1.30	7	2	5	3.14	1.07
If my illness/surgery/treatment will affect my relationships/sex life	13	1	5	3.23	1.48	7	2	5	3.14	1.21
If I will be able to continue with my job after my surgery/treatment	13	1	5	3.08	1.80	7	2	5	3.29	1.11
If there is any financial support available to me during my illness	13	1	5	2.85	1.41	7	2	5	3.71	1.11
If I can continue with my usual physical and social activities	13	1	5	3.77	1.09	7	3	5	3.57	0.79

8.3. App usage data

Unlike questionnaires where the acquisition of the desired data depended upon the response rate, Firebase provided data use accounts for the entire user cohort (23 user profiles). The following sections will present the analysis of the obtained usage data for each treatment (XELOX, FOLFOX and CAPE), as well as the overall user audience.

8.3.1. Overall user audience and correlations

Table 8.4 summarises the results obtained for the overall use of the app for each participant. As there was considerable variation in the obtained usage data, the mean value would not be an appropriate measure of central tendency (Manikandan, 2011). Hence, median values were used instead. While the median number of logins per user was 8, several users (e.g., Users 1 and 16) utilised the app much more frequently throughout the study. The median number of logins was similar for FOLFOX and CAPE (5 and 7 respectively), while a much higher median was recorded for XELOX (12). The median number of total tap counts (i.e., number of actions undertook in the app during logins) per user was 99 (range 24-881), with a considerable proportion of users (n=10/23, 43.48%) having scored lower than this. The majority of users (n=12/23, 52.17%) accessed at least 4 out of the 8 sections of the app, while several users (n=5/23, 21,73%) accessed all available sections.

Pooling data regarding the unique items accessed by users across the different information packages (CAPE, XELOX and FOLFOX) would not be valid, as each of these packages had its distinct content. However, as the usage intensity (the number of unique items accessed by the user in relation to the total items offered by the app) was

expressed as a percentage, it was possible to merge these results in a single dataset. The same applied for the percentage of active *versus* passive use of the app.

Table 8. 4: Overall app use data

User ID	Treatment	*Frequency of engagement*		Intensity of use			Type of engagement	
		Logins	Number of taps	Sections visited (out of 8)	Unique items accessed	Corresponding Usage intensity	Passive	Active
		n	*n*	*n*	*n*	%	%	%
User1	XELOX	28	583	8	64	39.26[1]	95	5
User2	XELOX	12	77	5	19	11.66[1]	84	16
User3	XELOX	12	95	8	20	12.27[1]	87	13
User4	XELOX	7	120	4	19	11.66[1]	81	19
User5	XELOX	2	92	5	21	12.88[1]	98	2
User6	XELOX	12	49	3	10	6.13[1]	96	4
User7	XELOX	10	63	3	4	2.45[1]	8	92
User8	XELOX	9	99	6	21	12.88[1]	96	4
User9	XELOX	13	344	7	33	20.25[1]	74	26
User10	XELOX	22	881	8	78	47.85[1]	94	6
User11	FOLFOX	2	156	6	39	24.53[2]	64	36
User12	FOLFOX	5	105	5	18	11.32[2]	79	21
User13	FOLFOX	5	72	5	15	9.43[2]	57	43
User14	FOLFOX	3	24	3	6	3.77[2]	92	8
User15	FOLFOX	27	388	8	39	24.53[2]	81	19
User15	CAPE	47	259	5	11	7.05[3]	10	90
User17	CAPE	3	65	5	17	10.9[3]	89	11
User18	CAPE	3	26	2	6	3.85[3]	100	0
User19	CAPE	8	103	4	14	8.97[3]	69	31
User20	CAPE	8	44	3	8	5.13[3]	95	5
User21	CAPE	19	541	8	60	38.46[3]	90	10
User22	CAPE	6	304	6	63	40.38[3]	89	11
User23	CAPE	2	55	1	9	5.77[3]	100	0

[1] out of the 163 unique items available in the XELOX information package; [2] out of the 159 unique items available in the FOLFOX information package; [3] out of the 156 unique items available in the CAPE information package

The median intensity of use was 12 (range 2.45-47.85). Most users (n=19/23, 82.6%) accessed less than a quarter of the items available through the app. The median intensity of use was similar across XELOX and FOLFOX (11 and 13 respectively), while a lower median was evident in CAPE (8). The vast majority of the participants (n=21/23, 91.3%) engaged with the app predominately in a passive manner. The figures in pages 213 and 214 provide an illustration of these results.

Figure 8. 1: Usage intensity per user

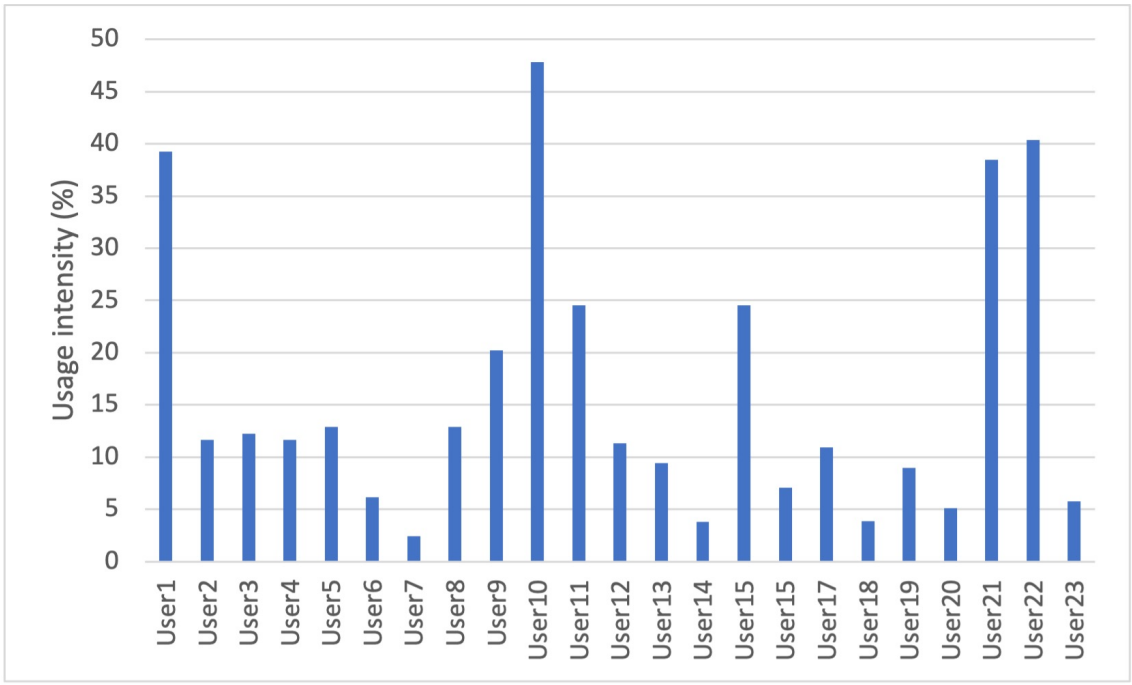


Figure 8. 2: Logins per user

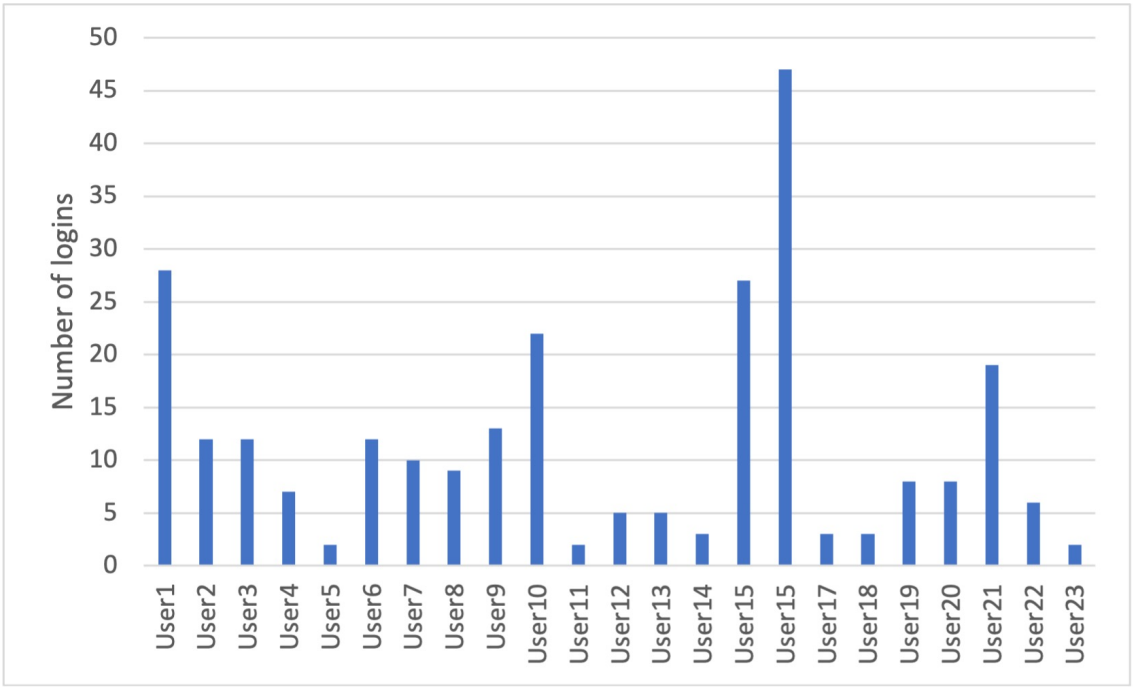


Figure 8. 3: Number of taps per user

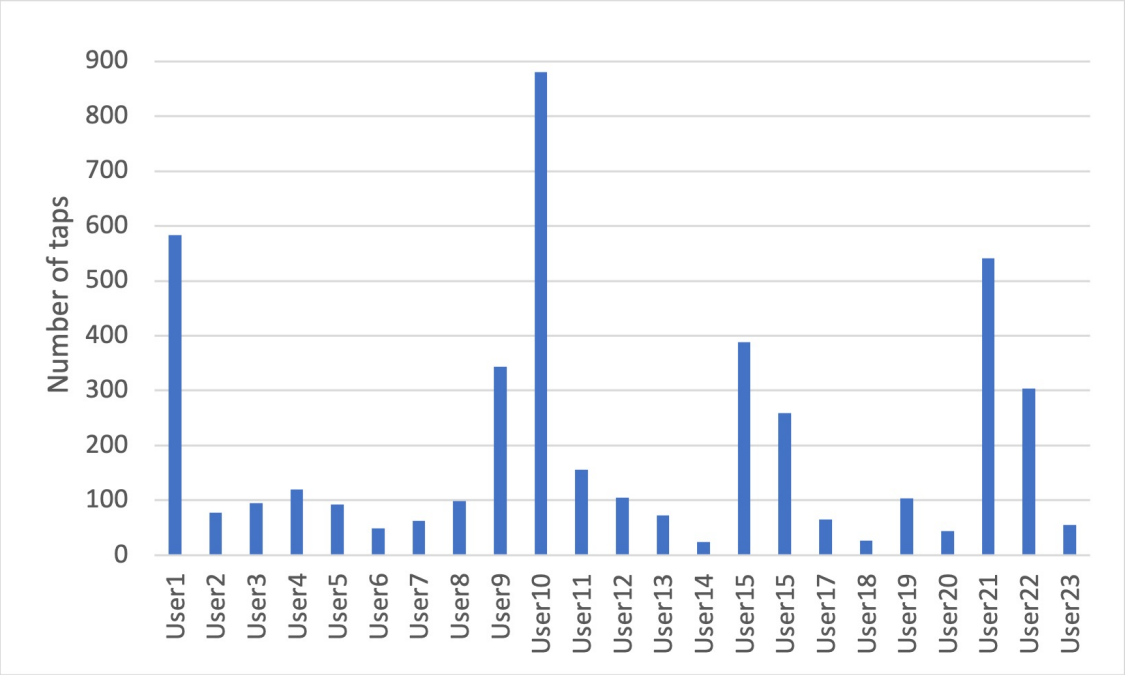
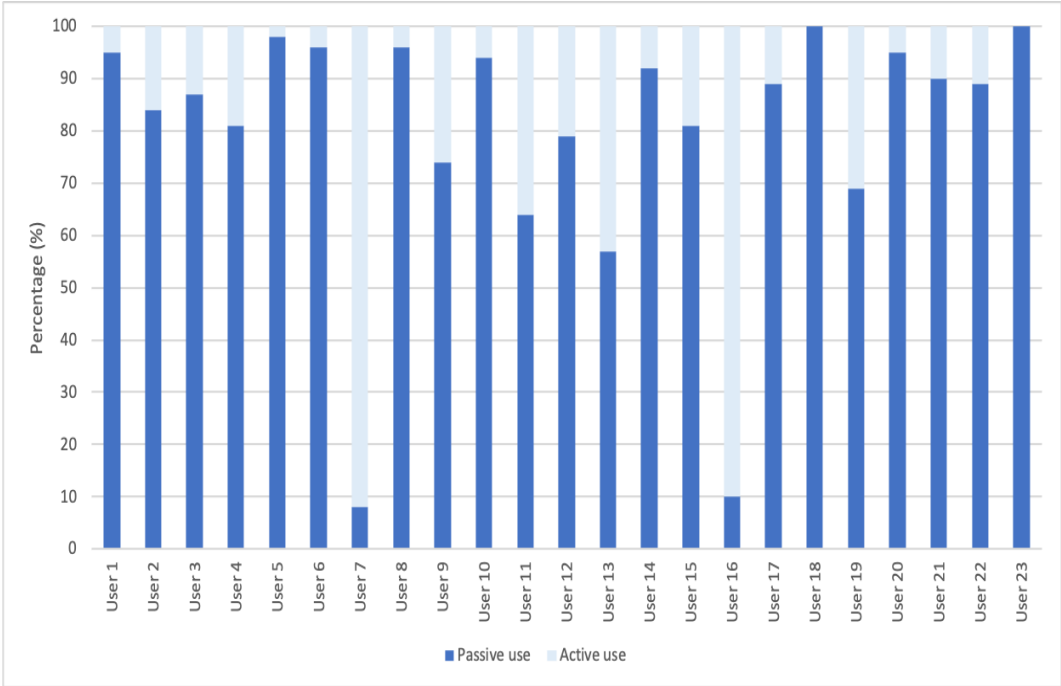


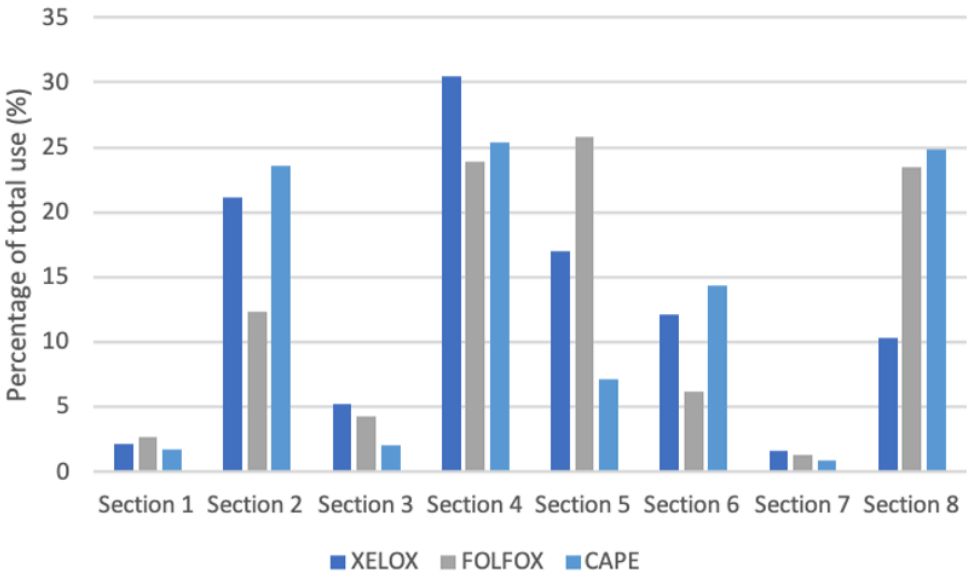
Figure 8. 4: Active versus passive use



As discussed in section 7 (pp. 202-203), making direct comparisons (e.g., tap counts) regarding the use of information sections across different information packages would be invalid, as each information package contained a different number of items. Furthermore, the information packages were not represented equally (e.g., XELOX had 10 users, while FOLFOX had 5). While comparisons between patients who received the same information packages will be presented in sections 8.4.1-8.4.3, an overall comparison of percentages was possible.

Figure 8.5 provides an illustration of the section use (as a percentage) across all information packages. The most popular section across all information packages was the management of side effects (section 4), while general treatment-related (section 2) and medicinal information (section 5) were also among the most popular domains. The treatment diary (section 8) was considerably popular for FOLFOX and CAPE.

Figure 8. 5: Section use breakdown for XELOX, FOLFOX and CAPE



Section 1-Search for a question; Section 2-Information about cancer and treatment; Section 3-Diagnostic tests; Section 4-Help with side effects; Section 5-Help with medicines; Section 6-Emotional support and help with finances; Section 7-Triage survey; Section 8-Symptom diary

Comparisons between the overall use before and after treatment were also performed. These results are illustrated in figures 8.6., 8.7 and 8.8. The first provides a visual account of the differences between the number of logins per user before and after treatment, the second presents data on the total number of taps and the third illustrates individual user profiles. Table 8.5 contains a detailed summary of these findings, which will be necessary for the sub-group analysis. A considerable proportion of participants (n=7/23, 30.4%) used the app solely before the first dose of treatment, while only one patient (n=1/23, 4.3%) used the app exclusively after treatment. The majority of users (n=15/23, 65.3%) used the app both before and after treatment.

Table 8. 5: Logins and tap counts before and after treatment

User ID	Logins before and after					Tap count before and after				
	Total logins	Logins before first dose		Logins after first dose		Total taps	Taps before first dose		Taps after first dose	
	n	*n*	%	*n*	%	*n*	*n*	%	*n*	%
User 1	28	13	46.43	15	53.57	583	231	39.6	352	60.4
User 2	12	8	66.67	4	33.33	77	53	68.8	24	31.2
User 3	12	12	100	0	0	95	95	100	0	0
User 4	7	4	57.14	3	42.86	120	55	45.8	65	54.2
User 5	2	2	100	0	0	92	92	100	0	0
User 6	12	2	16.67	10	83.33	49	5	10.2	44	89.8
User 7	10	2	20	8	80	63	7	11.1	56	88.9
User 8	9	9	100	0	0	99	99	100	0	0
User 9	13	7	53.85	6	46.15	344	155	45.1	189	54.9
User 10	22	2	9.09	20	90.91	881	278	31.6	603	68.4
User 11	2	2	100	0	0	156	156	100	0	0
User 12	5	5	100	0	0	105	105	100	0	0
User 13	5	2	40	3	60	72	21	29,2	51	70,8
User14	3	2	66.67	1	33.33	24	6	25,0	18	75,0
User 15	27	5	18.52	22	81.48	388	120	30,9	268	69,1
User 16	47	46	97.87	1	2.13	259	2	0.8	257	99.2
User 17	3	3	100	0	0	65	65	100	0	0
User 18	3	3	100	0	0	26	26	25.2	0	74.8
User 19	8	2	25	6	75	103	26	77.3	77	22.7
User 20	8	6	75	2	25	44	34	0.7	10	99.3
User 21	19	2	10.53	17	89.47	541	4	92.8	537	7.2
User 22	6	2	33.33	4	66.67	304	282	0	22	100
User 23	2	0	0	2	100	55	0	0.8	55	99.2

Figure 8. 6: Number of taps before and after treatment

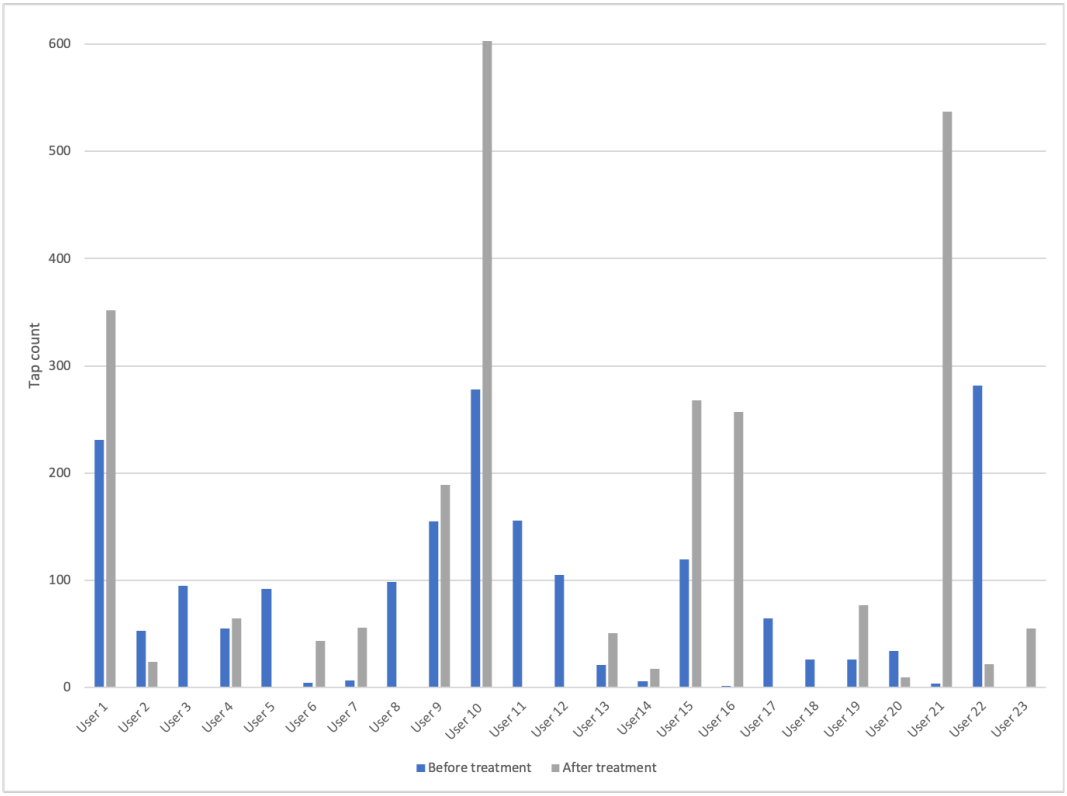


Figure 8. 7: Number of logins before and after treatment

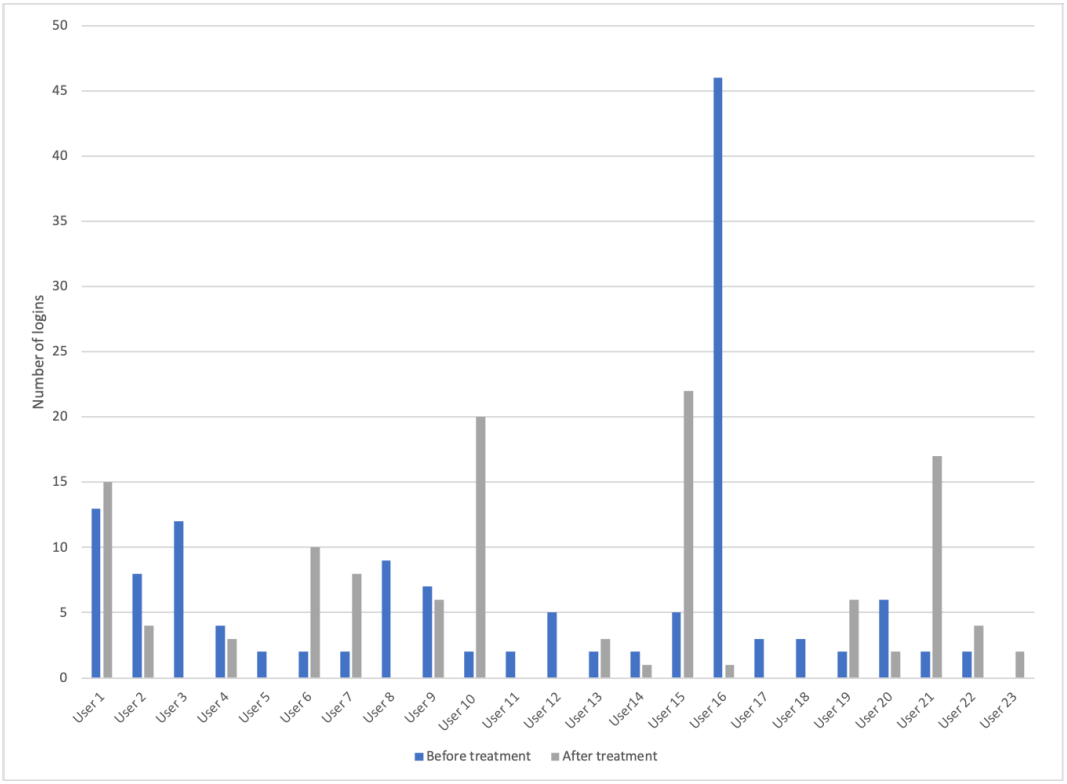
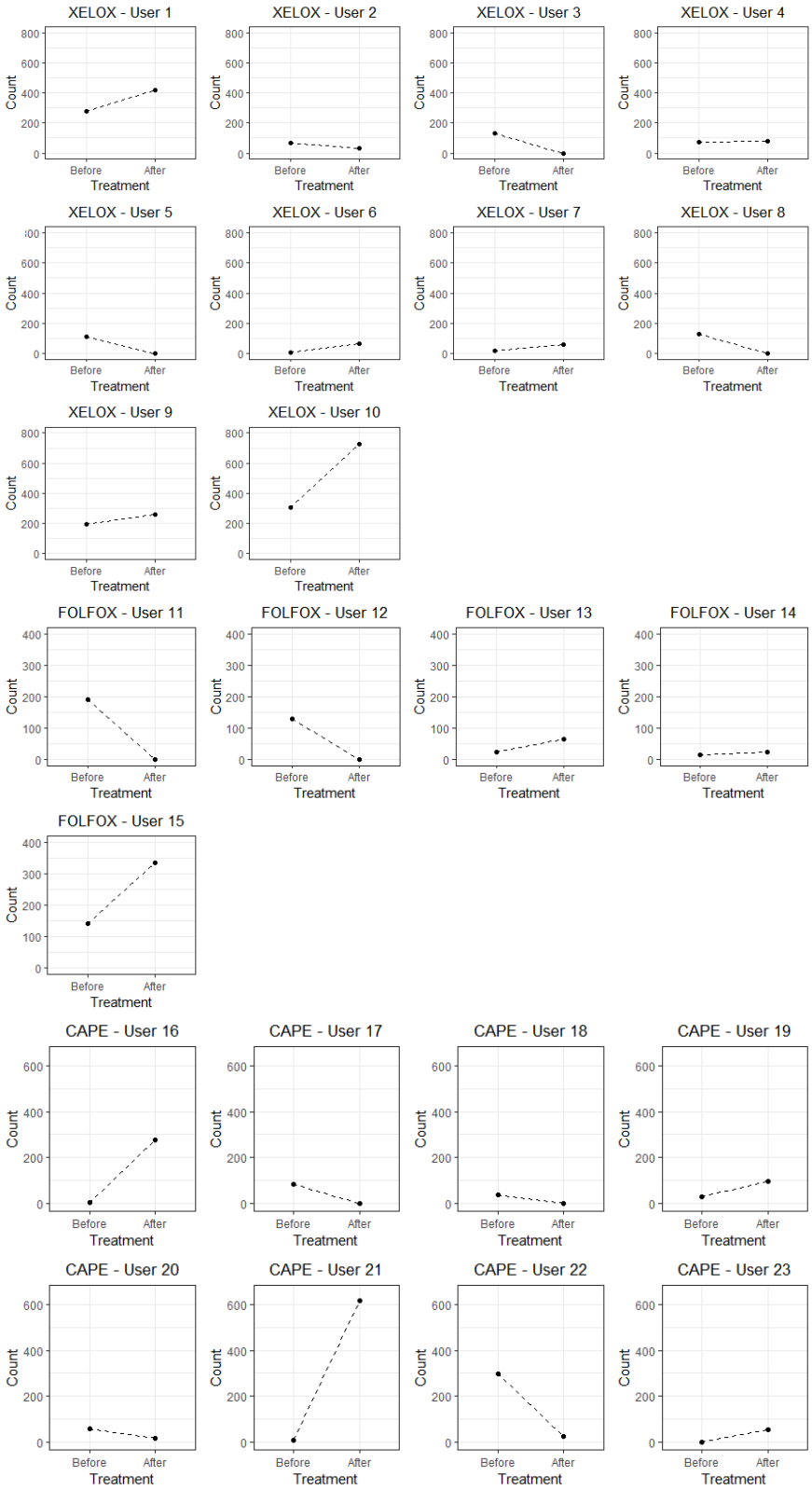


Figure 8. 8: Individual user profiles



The number of logins did not always follow the same trend as the number of taps. For example, although users 5 and 8 performed a similar number of taps (around 90), user 8 performed many more visits. Some marked differences were also observed for users 16 and 22, whose tap count and number of logins followed a completely different trend. For user 16, it appears that the user performed less logins after treatment but accessed more items during these visits; the opposite would be true for user22. Differences were also detected for users 4, 9 and 14.

Scatterplots were developed to investigate the correlations between three different sets of variables; a) mean satisfaction with information score *versus* number of taps (figure 8.9), b) mean information needs score *versus* number of taps (figure 8.10) and c) usability score (from SUS) *versus* number of taps (figure 8.11). A trend/regression line was added in each graph. In both (b) and (c), the number of taps is the dependent variable, while the mean information needs score and SUS scores are the independent variables, respectively. In both cases, a positive linear correlation is revealed, i.e., the number of taps is positively linearly dependent from the respective independent variables.The Pearson correlation coefficient for (b) is 0.372 (p-value=0.211) and 0.488 (p-value=0.183) for (c). In (a), the Pearson correlation coefficient is -0.300 (p-value=0.513), indicating negative linear dependency; this value is heavily influenced by the outlier value of user 10. In summary, the plots revealed that all correlations were weak and non-significant.

Figure 8. 9: Correlation between satisfaction with information and app use

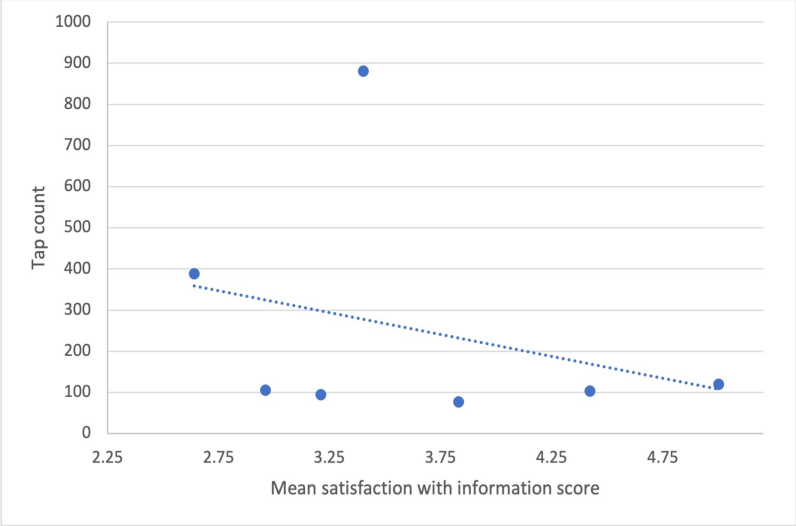


Figure 8. 10: Correlation between information needs and app use

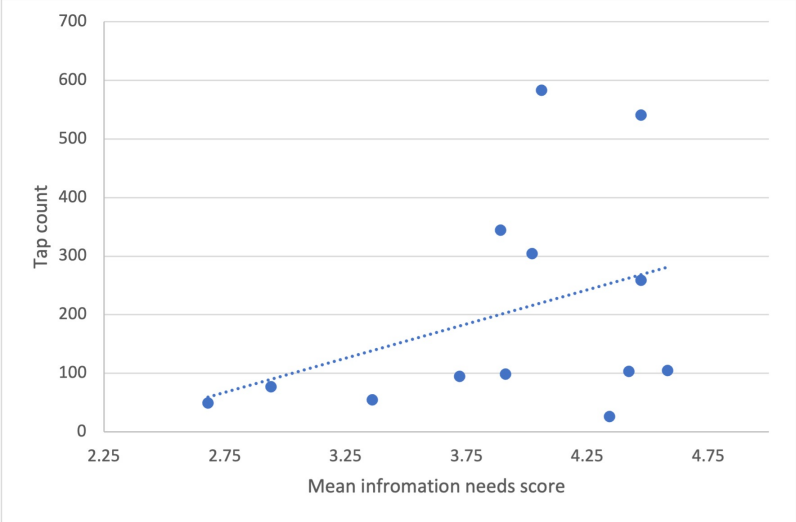
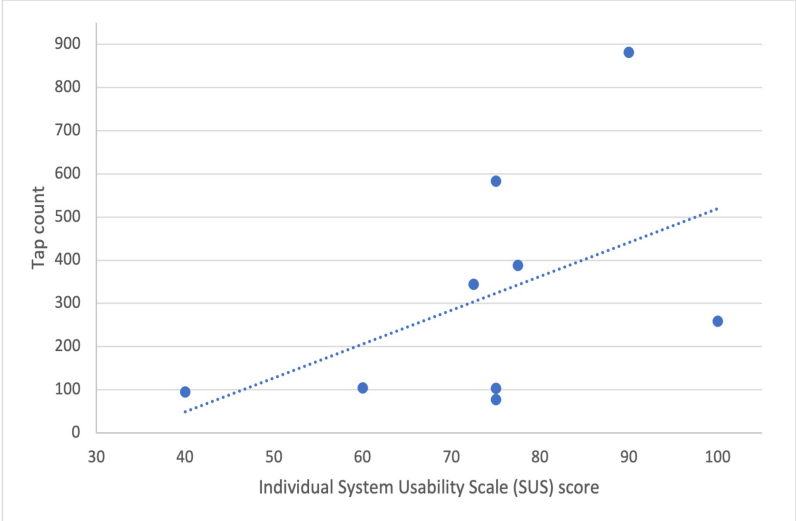


Figure 8. 11: Correlation between usability and app use



8.3.2. Section use for XELOX

Results regarding the overall use of the XELOX information package (n_{users}=10/23) are presented in table 8.4 and illustrated in figure 8.7. The total tap count for XELOX was 2403 and individual tap counts ranged from 49 to 881. As the results were considerably skewed, the median for the total tap count was used, which was 97. Two users (1 and 10) accounted for 51% of total use.

The results for section use for the XELOX information package are tabulated in table 8.6. The sections that received most visits were those associated with treatment-related information; section 4 (help with side effects) was the most popular section, followed by section 2 (information about cancer and treatment) and section 5 (help with your medicines).

Table 8. 6: Section use breakdown for XELOX

Total taps: 2403 (10 users)		
App Section	Tap count	%
Section 1 (Search for a question)	52	2.2
Section 2 (Information about cancer and treatment)	506	21.1
Section 3 (Diagnostic tests)	125	5.2
Section 4 (Help with side effects)	734	30.5
Section 5 (Help with your medicines)	409	17.0
Section 6 (Emotional support and help with finances)	291	12.1
Section 7 (Triage Survey)	39	1.6
Section 8 (Symptom diary)	247	10.3

Table 8.7 provides a breakdown of individual XELOX user profiles in relation to the thematic sections of the app. While some participants visited all sections, the majority of users (n_{users}=7/10, 70%) did not access several parts of the content. Most of these

participants (4/7) accessed more than half of the available app sections (range 4-7), while others focused almost exclusively upon a certain part of the app; for instance, more than 90% of the total use for user 7 was allocated to section 8 and 71.4% of the total use for user 6 was performed in information section 2 (information about cancer and treatment).

Table 8. 7: Section breakdown per user for XELOX

User ID	Tap summary	App Section								Total
		1	2	3	4	5	6	7	8	
User1	Tap count	26	40	31	263	112	81	10	20	583
	%	4.5	6.9	5.3	45.1	19.2	13.9	1.7	3.4	100
User2	Tap count	4	35	0	0	21	5	0	12	77
	%	5.2	45.5	0	0	27.3	6.5	0	15.6	100
User3	Tap count	2	45	14	10	10	2	3	9	95
	%	2.1	47.4	14.7	10.5	10.5	2.1	3.2	9.5	100
User4	Tap count	0	0	0	65	32	0	5	18	120
	%	0	0	0	54.2	26.7	0	4.2	15	100
User5	Tap count	0	14	20	28	28	0	2	0	92
	%	0	15.2	21.7	30.4	30.4	0	2.2	0	100
User6	Tap count	0	35	0	0	0	12	2	0	49
	%	0	71.4	0	0	0	24.5	4.1	0	100
User7	Tap count	0	0	3	2	0	0	0	58	63
	%	0	0	4.8	3.2	0	0	0	92.1	100
User8	Tap count	12	41	2	13	0	27	0	4	99
	%	12.1	41.4	2	13.1	0	27.3	0	4	100
User9	Tap count	0	79	2	100	42	32	15	74	344
	%	0	23	0.6	29.1	12.2	9.3	4.4	21.5	100
User10	Tap count	8	217	53	253	164	132	2	52	881
	%	0.9	24.6	6	28.7	18.6	15.0	0.2	5.9	100

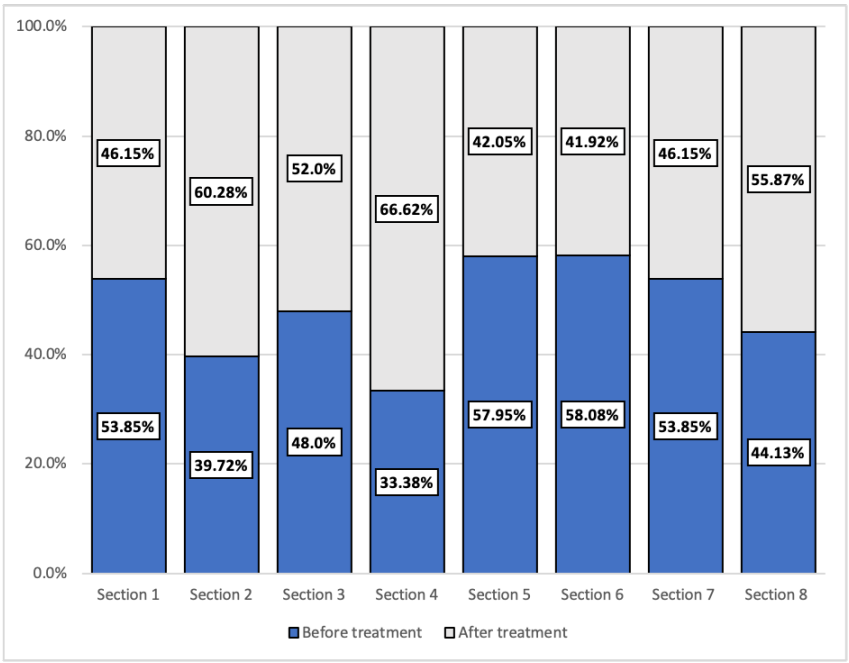
Table 8.8 presents the findings obtained for the overall use of the XELOX package before and after treatment, expressed as number of taps. The results indicated that the frequency of use was similar during the study period, with a small majority allocated after the first dose of treatment (n_{taps}=1333/2043, 55.5%, $p<0.01$). The pattern of section usage in each phase of treatment was also similar in terms of the priority given

to the different information areas. Figure 8.12 illustrates the differences for each section before and after treatment expressed as a percentage of the total tap count for each section. The most noticeable differences were observed in sections 2 (information about cancer and treatment) and 4 (help with side effects), both of which were visited mostly before treatment (60.28 and 66.62% respectively).

Table 8. 8: Section priorities before and after treatment for XELOX

App Section	Treatment phase			
	Before first dose of chemotherapy		After first dose of chemotherapy	
	Tap count (n= 1070, all XELOX users)	%	Tap count (n=1333, all XELOX users)	%
Section 1	28	2.6	24	1.8
Section 2	201	18.8	305	22.9
Section 3	60	5.6	65	4.9
Section 4	245	22.9	489	36.7
Section 5	237	22.1	172	12.9
Section 6	169	15.8	122	9.2
Section 7	21	2.0	18	1.4
Section 8	109	10.2	138	10.4

Figure 8. 12: Section use breakdown before and after treatment for XELOX



8.3.3. Section use for FOLFOX

Details regarding users who received FOLFOX (n_{users}=5/23) have been presented in table 8.4 and the user profiles have been illustrated in figure 8.7. The total tap count for FOLFOX (745) was smaller than that of XELOX (2043) and CAPE (1397). In FOLFOX, a single user (user15) dominated over the data. The median tap count was 105 (range 24-388). Usage data (see table 8.2) revealed that two users (user 11 and user 12) used the app exclusively before treatment and collectively represented more than half of the total before treatment tap count for FOLFOX (n_{taps}=231/408, 63.9%). On the other hand, user 15 accounted for the vast majority of the total after treatment tap count for the entire FOLFOX package (n_{taps}=268/337, 79.5%).

Table 8.9 presents the section breakdown (i.e. number of taps for each section) for FOLFOX .Information on medicines (section 5) and side effects (section 4) were the most visited sections. The symptom diary section (section 8) accounted for almost a quarter of the total tap count allocated to FOLFOX.

Table 8. 9: Total taps and section breakdown for FOLFOX

Total taps: 745 (5 users)		
App Section	Tap count	%
Section 1 (Search for a question)	20	2.7
Section 2 (Information about cancer and treatment)	92	12.3
Section 3 (Diagnostic tests)	32	4.3
Section 4 (Help with side effects)	178	23.9
Section 5 (Help with your medicines)	192	25.8
Section 6 (Emotional support and help with finances)	46	6.2
Section 7 (Triage Survey)	10	1.3
Section 8 (Symptom diary)	175	23.5

Table 8.10 presents the results obtained for the section breakdown per user for FOLFOX. The majority of FOLFOX users (n=4/5, 80%) accessed more than half of the available app sections, while one user (user 15) utilised the entire set of sections. User 15 was also the only user to access section 6 (emotional support and help with finances). A similar use pattern in sections 2,4,5 and 8 was observed for users 11, 12 and 15.

Table 8. 10: Section breakdown per user for FOLFOX

User ID		App Section								Total
		1	2	3	4	5	6	7	8	
User11	Tap count	0	18	2	36	44	0	2	54	156
	%	0	11.5	1.3	23.1	28.2	0	1.3	34.6	100
User12	Tap count	0	12	0	29	42	0	2	20	105
	%	0	11.4	0	27.6	40	0	1.9	19.0	100
User13	Tap count	0	9	10	22	0	0	2	29	72
	%	0	12.5	13.9	30.6	0	0	2.8	40.3	100
User14	Tap count	4	0	0	18	0	0	0	2	24
	%	16.7	0	0	75	0	0	0	8.3	100
User15	Tap count	16	53	20	73	106	46	4	70	388
	%	4.1	13.7	5.2	18.8	27.3	11.9	1.0	18.0	100

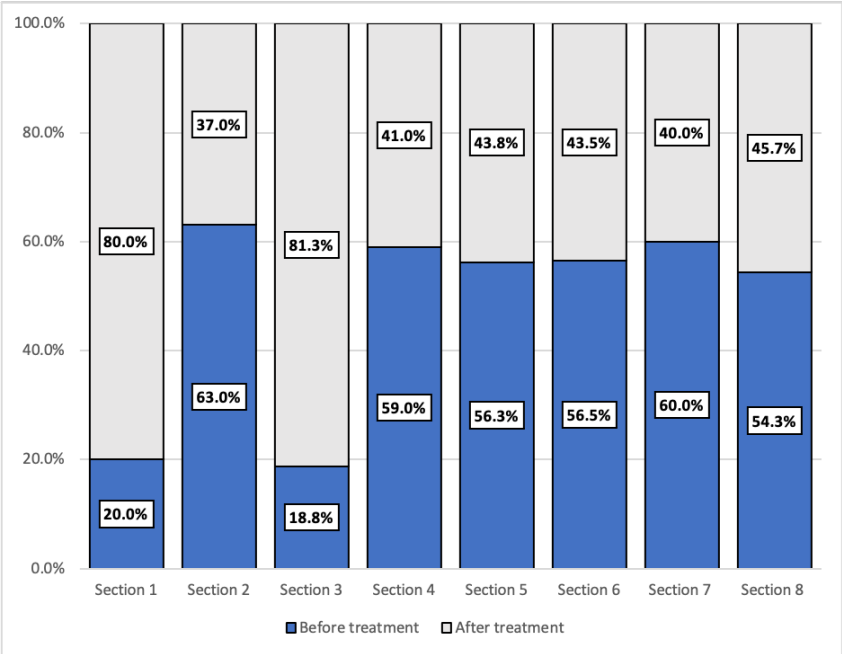
A before and after treatment section use analysis was also conducted for this treatment regimen (Table 8.11). In the case of FOLFOX, the majority of use was performed before the first dose of treatment (54,8% *versus* 45.2%). In a similar manner with XELOX, the pattern of section usage (in terms of which areas were most popular in each treatment phase) was similar before and after the initiation of chemotherapy. The exception to this was section 3, which was utilised more at the post-treatment phase.

Table 8. 11: Section priorities before and after treatment for FOLFOX

App Section	Treatment phase			
	Before first dose of chemotherapy		After first dose of chemotherapy	
	Tap count (n=408, all FOLFOX users)	%	Tap count (n=337, all FOLFOX users)	%
Section 1	4	1	16	4.7
Section 2	58	14.2	34	10.1
Section 3	6	1.5	26	7.7
Section 4	105	25.7	73	21.7
Section 5	108	26.5	84	24.9
Section 6	26	6.4	20	5.9
Section 7	6	1.5	4	1.2
Section 8	95	23.3	80	23.7

Figure 8.13 presents the differences between each section before and after treatment as a percentage of the tap counts allocated in each section. For most thematic sections, the majority of use was conducted before the first dose of treatment. Two exceptions to this were sections 1 and 3, which were used mostly after the first dose of chemotherapy.

Figure 8. 13: Section use breakdown before and after treatment for FOLFOX



8.3.4. Section use for CAPE

Table 8.4 and figure 8.7 presented the results obtained for the user profiles of the CAPE information package (n_{users}=8/23). The tap count ranged from 26 to 541, with a median value of 84. Again, certain users dominated over the dataset; users 21 and 22 accounted for more than half of the overall use in CAPE (n_{taps}=845/1397, 60.49%).

An overview of the overall section use breakdown for CAPE is provided in table 8.12. Again, treatment-related information was the most popular domain, as sections 2 and 4 accounted for almost half of the total visits (n_{taps}=684/1397, 48.96%).

Table 8. 12: Section use for CAPE

Total taps: 1397 (8 users)		
Section	Tap count	%
Section 1 (Search for a question)	24	1.7
Section 2 (Information about cancer and treatment)	329	23.6
Section 3 (Diagnostic tests)	28	2.0
Section 4 (Help with side effects)	355	25.4
Section 5 (Help with your medicines)	99	7.1
Section 6 (Emotional support and help with finances)	201	14.4
Section 7 (Triage Survey)	13	0.9
Section 8 (Treatment diary)	348	24.9

The section breakdown for each user (table 8.13) revealed that while sections 2 and 4 were used by the majority of users (7/9 and 5/9 respectively), a single user (user 16) was primarily responsible for the total use of section 8 across CAPE (n_{taps}=232/348, 66.7%). Similar to the other information packages, the majority of CAPE users (n=6/7,

85.71%) did not explore all available content; as with XELOX, some users (e.g., users 16, 18 and 20) concentrated upon a single section, while others (users 22 and 23) distributed use across multiple sections.

Table 8. 13: Section use per user for CAPE

User ID		Section								Total
		1	2	3	4	5	6	7	8	
User16	Tap count	4	6	0	15	0	0	2	232	259
	%	1.5	2.3	0	5.8	0	0	0.8	89.6	100
User17	Tap count	0	16	0	32	10	0	1	6	65
	%	0	24.6	0	49.2	15.4	0	1.5	9.2	100
User18	Tap count	0	20	0	0	6	0	0	0	26
	%	0	76.9	0	0	23.1	0	0	0	100
User19	Tap count	0	57	0	0	14	0	2	30	103
	%	0	55.3	0	0	13.6	0	1.9	29.1	100
User20	Tap count	10	32	0	0	0	0	2	0	44
	%	22.7	72.7	0	0	0	0	4.5	0	100
User21	Tap count	10	172	18	127	47	115	6	46	541
	%	1.8	31.8	3.3	23.5	8.7	21.3	1.1	8.5	100
User22	Tap count	0	26	10	126	22	86	0	34	304
	%	0	8.6	3.3	41.4	7.2	28.3	0	11.2	100
User23	Tap count	0	0	0	55	0	0	0	0	55
	%	0	0	0	100	0	0	0	0	100

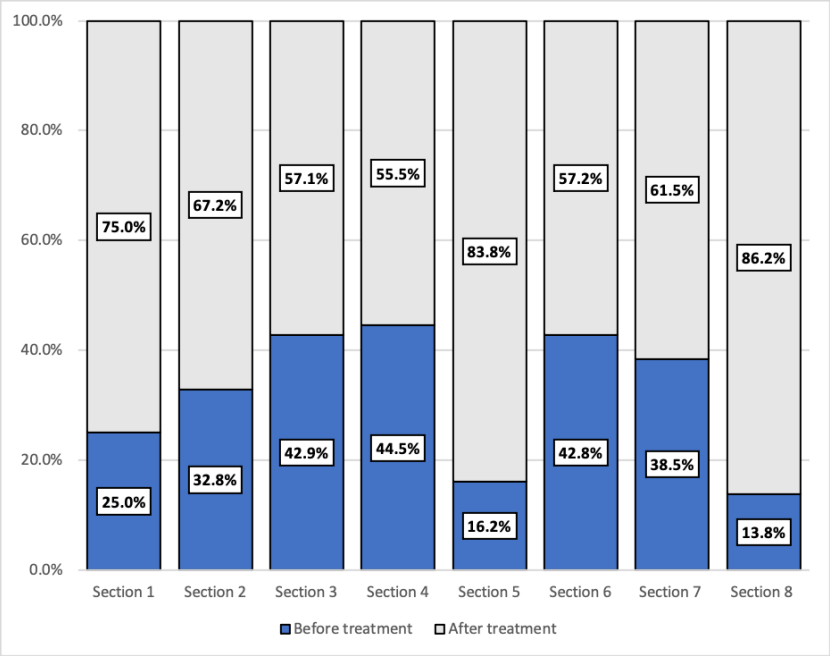
For CAPE, there was a greater difference with regards to app use in relation to the treatment phase, as the majority of use was performed after the administration of the first dose of treatment (68.2 versus 31.8%, $p<0.01$). In CAPE, there were several differences with respect to the priority given to different sections according to the phase of treatment. Section 4 was given considerably lower priority in the post-treatment phase, while sections 5 and 8 were more popular during this time (table

8.14). Figure 8.14 provides an overview of the differences within section use before and after treatment in CAPE. The most noticeable differences were observed in sections 5 (16.16% before *versus* 83.84% after) and 8 (13.79% before *versus* 86.21% after).

Table 8. 14: Section priorities before and after treatment for CAPE

App Section	Treatment phase			
	Before first dose of chemotherapy		After first dose of chemotherapy	
	Tap count (n=439, all CAPE users)	%	Tap count (n=958, all CAPE users)	%
Section 1	6	1.4	18	1.9
Section 2	108	24.6	221	23.1
Section 3	12	2.7	16	1.7
Section 4	158	36.0	197	20.6
Section 5	16	3.6	83	8.7
Section 6	86	19.6	115	12.0
Section 7	5	1.1	8	0.8
Section 8	48	10.9	31.3	31.3

Figure 8. 14: Section use before breakdown before and after treatment for CAPE



8.4. Semi-structured participant interviews

Out of 23 participants who used the app in the main study, thirteen (56.5%) agreed to be interviewed. Nine were interviewed alone, while the caregivers of patients were also involved in four interviews. Six of these interviews were conducted face-to-face at the research site and seven were conducted via video calling. All interviews were recorded and transcribed verbatim. The interview time ranged from 25 to 80 minutes (mean time 54 minutes). The patient characteristics are presented at table 8.15. As the animations remained the same across the first and second version of Manage your Health, perspectives upon the virtual agents (VAs) obtained from the pilot study were included in the main investigation.

Table 8. 15: Interview participant characteristics

User ID	Interview ID	Gender	Type of interview	Virtual Agent (VA) known?	Caregiver present?
User 1	M1	Male	Face-to-face	Yes	Yes
User 2	M2	Male	Face-to-face	Yes	Yes
User 3	M3	Male	Face-to-face	Yes	No
User 7	M6	Male	Video call	No	Yes
User 8	M7	Male	Video call	Yes	No
User 11	F1	Female	Face-to-face	No	No
User 12	M4	Male	Face-to-face	No	No
User 13	M5	Male	Video call	Yes	No
User 15	M8	Male	Video call	No	No
User 18	F2	Female	Face-to-face	Yes	Yes
User 19	F3	Female	Video call	Yes	No
User 21	F4	Female	Video call	No	No
User 22	F5	Female	Video call	No	No
PS1*	PS1*	Male	Face-to-face	Yes	No
PS2*	PS2*	Male	Face-to-face	Yes	No
PS3*	PS3*	Male	Face-to-face	Yes	No

** Participants from the pilot study*

The semi-structured interview guide is provided in appendix 17. There were five main discussion points, namely:

a) general perspectives on the app

b) app usability

c) perspectives upon the VAs,

d) information needs and satisfaction with information

e) recommendations for improvement. The following sections will present the results for each discussion point.

8.4.1. General perspectives on the app

Overall, the app received positive feedback from users. A recurring theme was its capacity as a reference point that patients could use in order to revisit information that was not retained from consultations or obtain new information that was not provided by healthcare professionals. Some participants explained that the app inspired a sense of reassurance, as it confirmed the information they received, helped them understand that what they went through was normal and that help would be available if needed. The app also helped patients prepare for their upcoming treatment, provided advice on how to make right use their medicines and prompted them to seek help when required.

> *"...So, everything is new and so this is all a big learning curve, the whole medical process. So, there's lots of questions that you can't think of asking all at the same time. So as things come into your mind you can then refer to the app to get some answers*." (M6)

Several participants reflected upon some potential benefits the app could offer. Reflecting upon their experience, users thought that the app could help other patients who were on their own during treatment. Others explained that the app could save time for the clinicians, as the patients used the app to retrieve information instead of referring to them. One participant made multiple remarks upon the potential cost-savings for the NHS, as the app could help limit the resources that patients would use in order to fulfil their information needs.

> *"... I think that would have saved the NHS some money because it meant I didn't ring anybody up and bother them [mmm] because I got the answer that I wanted, that I needed, and it was trustworthy and reliable and accurate and it helped put my mind at ease ...*" (M2)

App versus other sources of information

Several users identified a number of benefits that the app provided over other information sources. Some users explained that the app offered a greater degree of accessibility to information, as it was regarded to be more convenient, portable and allowed users to better navigate through the information they were after. The app was also considered to be more engaging and supportive than printed material and web information. The content of the app was deemed to be more targeted and reliable, especially compared with the information retrieved from the internet.

> *"... for me, the app has been designed by somebody who knows what they are talking about and is giving actual useful advice for my problem so that would be the place I would go to when I wanted some new information*." (F3)

While the app was received well, the majority of participants expressed a preference for information sources offered as part of standard care. Some users explained that printed material was more comprehensive and more usable than the app. Two users appeared to value information sources that were endorsed by the healthcare professionals, including leaflets and official websites. A recurring theme was that older patients were not used to referring to apps in general, while utilising printed material to retrieve information was a much more familiar practice. Printed material appeared to be the most common source of information among the sample, followed by health professionals and the internet.

> *"As much as computers want to take over the world and make us a paperless state, I'm afraid there will always be lists of things somewhere [yeah] [mhmm]. You, you just need something on paper."* (F3)

Just over half of the respondents had used at least one health app in the past. This included built-in health apps (e.g., iHealth), apps for weight management, fitness and NHS apps (e.g., Patient Access). When asked to compare Manage Your Heath with these, most users thought that the study's intervention offered a number of benefits over past health apps. Manage Your Health was regarded as being completely different to these apps, more reassuring and interactive.

> "*...But [Manage your Health] is way more detailed [mmm] the one that you've created, [there] is absolutely no comparison and it's basically like having, like at any time of day, like a nurse available that you could just ask questions to so it was really helpful in that respect*." (M2)

Some patients thought that Manage your Health was more targeted than previous health apps, as it was tailored to their unique treatment regimen. Yet, some participants regarded the project's app to be less specific.

> *"... I think it has its limitations, which is fair enough because it a general application...I suppose it's a bit more basic in that it's not - well, at least it didn't feel that it was... tailored to me specifically... although, working out the calories and food is different whole thing but it - I don't know, somehow it felt more - they felt a bit more personal somehow*." (F5)

One patient explained that the app was not perceived as personalised due to the lack of unconstrained user input.

> *"... I suppose it's not possible to have an app that can instantly respond to what you're telling it... it was more one way, wasn't it really? It was just erm, 'I-, if it's this, go to this.'... although it was responding to what you're clicking on, it's not responding to how you would if you were talking to it..."* (F5)

The role of family and caregivers

The majority of users shared the app with members of their family and/or their caregivers. One user also mentioned sharing it with friends and received positive feedback from them. In general, the patients were the ones who used the app mostly. In the case of M1, the patient's caregiver was the principal user of the app and encouraged the patient to use. User F1 shared the app with her partner, with whom she used it equally. One patient explained that users who might struggle with using apps could utilise help from their family environment.

"Well, there's always somebody in the family [yeah] who'll be able to help you or extended family who'll be able to help you. They might have to show them a few times, but they eventually will, will comprehend, mmm." (M3)

Overall use of the app

A similar pattern of use among the participants was identified through the interviews. The app was provided to patients and/or their caregivers a few weeks prior to their first treatment cycle with CAPE, XELOX or FOLFOX. During this time, users appeared to explore the various sections of the app in order to familiarize themselves with the content. Some participants explained that they used the app more frequently at this stage, while others explained that it was not relevant to them. The information that was sought after the most concerned the upcoming treatment, with particular emphasis upon the potential side effects of chemotherapy.

"*... when I first had the app downloaded, I went through it completely so that I could see exactly what information was contained in there so that in the future if something came into my head, I would know that I could find the information on the app*." (M7)

While patients used the app to search for general information in the pre-treatment phase, they appeared to seek more targeted information after receiving the first dose of chemotherapy.

"*... So, you look at the general picture but then later on in your treatment, you just want specific information*." (F4)

In general, the use of the app declined at the post- treatment phase.

> *"To start with, I wanted to use it all the time and now, as it's gone on, I don't really use it ... at the beginning, you want to know all the information and just visit whatever you can [mhmm] but now I'm just taking it easy, so I don't really look into anything."* (F1)

After receiving the first dose of chemotherapy, the majority of participants explained that they used the app on a 'as needed' basis in order to check any new side effects of treatment, find out whether what they experienced was alarming or remind themselves about aspects that they forgotten. A few patients used it in order to keep a record of their symptoms, while others explained that the app wasn't helpful to them at this phase, as it didn't contain any relevant information. One user explained that once being reassured that what was experienced was normal and there was no immediate risk, the app was not needed anymore.

> *"... I suppose it became erm, more personal to what I, I was experiencing physically, so that's when I used it and erm, I was getting a bit alarmed by some of the side effects."* (F5)

Phone versus tablet version

Five users had installed Manage your Health on a tablet device. Out of them, four also had it on their phone and one was using it exclusively from his tablet. Two of these users preferred the phone version, as it offered better portability.

"On my phone because I've always got my phone with me. It means going upstairs to get the iPad er, to come down, to do exactly what I can do in my phone." (M3)

The other two users preferred the tablet version, as it was easier to use the app on a large screen.

"I use the tablet more but that's because I can't see the phone properly [mhmm]. My, my eyesight is not good enough anymore, so the, the iPad was just much easier to read." (F3)

One user had the app installed on a personal tablet and had the phone version on the caregiver's phone. The caregiver explained that having the app on a personal device was a good thing, as it offered better privacy.

"...I think it's a good idea for him to have it so that he can, in private, without, if he didn't want to go through me [oh yeah], he didn't wanna worry me or something, if he's got it on his tablet, then he can access it without involving me, if he's worried about something and wants to check it direct..." (partner of M1)

Barriers to use and factors affecting use

The age of users was the most frequently mentioned barrier to use. One prominent view was that as older individuals who did not have access to apps when they were younger, they are less likely to use them as part of their everyday routine.

"... If you're used to using apps then I think it would be very easy. It's only for my generation that weren't brought up on apps; it's a whole learning curve for all of us in all sorts of apps. And yours in no harder than any others." (M7)

One argument was that apps might be more relevant to younger users.

"I think an app for younger people is very apt. ... Younger people don't read books, but they'll read er, what's on an app and I think that's very relevant for [a] younger generation." (partner of M3)

Another age-related issue was the degree of information technology (IT) literacy. Again, it was suggested that older individuals might not possess adequate IT skills, which would make the prospect of using apps challenging. Yet, several users older users explained that despite their limited IT skills, the app was not hard to use.

"I think you need to be a bit confident about using apps. I think as an older person, it's a little bit daunting at first, you think, oh it's going to be difficult, but it isn't, it's very easy, it's very straight forward." (F2)

In addition to the barriers outlined above, there were also several factors that affected the use of the app. It appeared that users who tolerated treatment well and did not suffer from much toxicity didn't need to use the app much after treatment, as they did not experience symptoms or side effects that they felt necessary to refer to the app for.

"*... So erm I'm getting through the chemotherapy itself quite well. So, I haven't felt for that reason a need to use the app*..." (M5)

In another instance, a patient who tolerated treatment well refrained from using the app in order to avoid coming across any unpleasant information.

> *"...we were focused more on us to enjoy how he was instead [of] looking for something [that] we didn't experience, [that] we didn't see in him because he was ok every single day from this first day till today I would say he didn't have chemo even, he's so good, it means err I didn't want to look for something [that] I didn't need and even I was maybe a bit scared to look for something and find something which already I didn't have...this was the main reason why err I didn't err touch [the app]...no need to go deeper because I thought we were relatively ok, good, and we were focused just, you know, to keep him going in this good, erm, err spirit..."* (M6)

The other important factor was the level of users' knowledge. A repeated finding was that patients didn't feel that the app was going to add to their knowledge, as much of their information needs were already met. As these users were already familiar with various aspects around their condition and its treatment, they did not need to use the app often.

> *"...I suppose as I already had a reasonable amount of knowledge already provided for me, I suppose I didn't need to go over as much of that, maybe, as someone else who hadn't taken onboard all the stuff - the information that you're given at the start."* (F5)

Finally, as the level of knowledge increased throughout treatment, users didn't feel the need to refer to the app.

"To start with, I wanted to use it all the time and now, as it's gone on, I don't really use it because... just at the beginning, you want to know all the information and just visit whatever you can [mhmm] but now I'm just taking it easy, so I don't really look into anything." (F1)

8.4.2. Comments on usability and content

After presenting their general perspectives upon the app, the participants were asked to comment on the usability and the content of the app. Only one user did not consider the app to be usable. This was because this user struggled with the symptom calendar function, which ultimately led to attrition.

"I stopped using [the app], and I used the booklets instead (...), just because er... I suppose - frustration, [because when] I tried to use the diaries and so on and I didn't find it usable, [I] started doubting [the] relevance of the thing and I started looking elsewhere...". (M4)

The remaining patients believed that Manage your Health was easy to use and did not require help in order to utilize the app. This was true even for certain patients with limited IT skills.

"It was very easy and I'm a complete technophobe. I'm not very good with computers and things... So, if I found it easy, you're a winner [laughter]." (F3)

Some users (both young and senior) explained that regardless of age and IT literacy, the app should be straightforward for most individuals.

> "*...if you only [use] the phone for calling someone erm, and you're not, not used to technology, then obviously it's going - it's slightly problematic but I think most people - people who are my age now are erm, coming around to the convenience of being able to use a Smartphone. So, I should think it - they would find it quite easy*." (F5)

The users also reflected positively upon the app's content. The vast majority expressed satisfaction with the content, as well as the way that the information was organized. The information within the app was considered to be reliable, straightforward and relevant to users' needs.

> *"…if you've entered the questions and you've designed the app and this is a trial, that's a really impressive job that you've done so far because it's pretty much there I think so nothing, nothing that I would change*." (M2)

While most users appeared to be satisfied with the amount of information, some expressed a desire for more in-depth explanations through the app.

> *"...I think probably on some of the questions, and I can't remember which ones, maybe the answers could've been slightly longer. They were a little bit short. Erm yeah, I think some of them could've been slightly longer answers to the question."* (M7)

8.4.3. Virtual agents

Interview data from the pilot study around this topic were incorporated into the main study's dataset. This was because the VAs of the updated version of the app were not

altered and therefore, feedback obtained from the users of the pilot study was still relevant. The details of the patients from the pilot study can be found in table 6.1 (p. 176). Ultimately, the part of VA-related analysis for the main study included 16 patients.

Six main thematic categories emerged from the interview data, namely:

- general comments,
- effect of VAs upon information,
- effect of VAs upon user experience,
- perceptions on the appearance of the VAs,
- perceived role of the VAs, and
- quality of graphics and VA realism

These categories are presented in detail below.

General comments

When patients came across the VAs for the first time, many identified a humorous element in them. Most of these users explained that the reason behind this reaction was that the VAs were perceived as cartoon versions of the treating clinicians.

> "*Erm, why would it be funny? Erm, well, I suppose because you've seen them in real life and then there's limitations to the technology, so they look - although they're similar to how they look, they're not really how they look. So, it's like erm, more of a caricature than - er, than the real thing*." (F5)

One view was that this could potentially help some to better concentrate upon the information.

"... You know, if it does raise a bit of a giggle, maybe it'll get their attention a bit more... you know [okay]. There's a, there's a positive out of it like that." (M3)

In general, the use of VAs appealed to users. Several participants made statements indicating that they were impressed by the VAs and one user (M1) mentioned receiving positive feedback from friends who saw the app. However, some explained that they were not keen on this concept, primarily due to the perceived poor quality of graphics, while others suggested using video recordings of the clinicians instead of VAs. Yet one participant pointed out that unlike videos, VAs gave the impression of interaction, which was important for engagement.

"... at least when you click on the avatar, you're drawn to it because it's talking like, 'Hi hello.' In a video, you click on it and then you think, 'Oh, I can't actually be bothered to watch this,' so then you just pause it and stop." (F1)

One prominent theme was the benefits of using verbal over written information. Three participants explained that having VAs narrating information was more appealing than having to read text.

"*The fact* [that the oncologist] *is there and he's saying something in a normal human voice and erm, I think that's – I think that's good. People sort of – kind of I think people expect that these days, they don't want to just to be reading text. Especially with a subject like cancer...*" (PS1)

Written information was sometimes perceived as tiring and confusing, while verbal information was considered easier to follow. According to some, verbal information

allowed for placing emphasis upon the most important points, which is not always possible with text.

> *"... the important part of a sentence can be emphasised in speech, but you can't emphasise it properly in a text, unless you're going to be underlining or making it big, big and even then, you can read it wrong*." (F3)

Some participants also explained that verbal information would be a suitable alternative for users with limited language skills, particularly reading, as well as users with learning difficulties. Yet, one view was that users should be given the option to choose between verbal and written information, while another suggestion was that the decision to animate the content should depend upon the complexity of information.

Effect of VAs upon information

Participants made several comments regarding the effect of VAs upon the information. A finding was that the VA made the process of information-giving less formal, which wouldn't be the case if a video recording was used instead. The humorous element of the VA also provided some relief, as conversations around cancer were deemed to be 'heavy'.

> *"I think* [the VA] *makes it better. I think it gives a bit of light relief in a heavy subject. I think it's a little bit of amusement there, erm if that's the right word [laughs].* [when asked to explain this further, the participant continued:] *Well just it makes it more real, but there's a little bit of – perhaps a little bit of humour erm added into it which makes it not quite such – I don't know – lightens it slightly*." (M7, VA familiar)

The humorous element of the VAs did not necessarily distract attention from the information.

> *"...I think you would look at it initially and have a quick laugh, but then you get down to the real point of what you're trying to get the information..."* (PS1, VA familiar)

Some users thought that the inclusion of a VA aided their understanding, which was counteracted by others who believed that the VAs didn't have an influence upon the comprehension of information. This was either because the patients were comfortable with written information or because they were not satisfied with the graphics.

> *"Obviously some people don't understand stuff when they read it. Well, I, I don't and – but someone saying it and it actually looks like a person, so you think, 'Okay, this is actually coming from someone,' it sinks in a bit more*." (F1, VA unfamiliar)

Comments regarding the influence of a familiar VA upon the information emerged as a separate theme. Some participants expressed that having a familiar VA made them listen to the information more closely.

> *"... you've had that connection with that person [the clinician representing the VA), so you listen intently to what he's saying, [mmm] yeah*." (M3, VA familiar)

Another patient who wasn't familiar with the healthcare professionals portrayed by the VAs believed that having a VA of a familiar clinician would provide better consistency and explained that this could help settle users.

> "*I would probably click on [my oncologist] because that would be your doctor explaining stuff... at least you know your doctor is giving you that information and it's not different information from different people.* [when the patient was asked what difference a familiar VA would make, the following response was obtained:] *Yeah, because [mhmm] it just settles you a bit... Settles you a bit like thinking, 'Okay, that's my doctor. They're telling me this.' It's not a different person every time, like [laughter] telling you different things*." (F1, VA unfamiliar)

One prominent theme (i.e., repeated by a lot of participants) was that information provided by a familiar VA was deemed as more reliable than having a generic VA. This was attributed to the trust that patients had upon their doctors' knowledge and expertise.

> "*And I think it gives you more of a... sense of gravitas and security that that is your doctor and so he's telling you that's the information, so you - that's it. I'll believe him, you know. I've met him. I know him.*" (F3, VA familiar)

Effect of VAs upon user experience

In addition to the influence of the VAs upon information, the participants also offered several comments regarding the effect of the VAs upon their general user experience. A repeated theme was that the VAs added a personal touch to the app. This was suggested primarily from users who were familiar with the clinicians represented by the VAs, although participants who didn't know these clinicians also brought this up.

> "*... after a few seconds, you forget it's just [an] avatar, you just think you are talking to the other person, when you are in difficult times it's important that you feel it's somebody's eyes you can talk to* ..." (M6, VA unfamiliar)

Some participants believed that the VA gave the impression of a face-to-face conversation. One patient thought that the VAs could inspire empathy, while another explained that the VA provided the impression of human contact during adversities.

> *"... the important thing is the people that are doing the speaking come across as human, ..., you can understand what they're saying and there's a bit of you know, there's a bit of empathy there. They're not sort of laying down the law to you; they're just giving you friendly advice.*" (PS1, familiar VA)

While some participants identified an interactive element in the VAs, others did not get such impression. These users explained that as there was no input from their side, they did not perceive the VA to be interactive. One of these individuals suggested that the interactive element could be introduced if users were able to speak to the VAs in order to ask questions and/or keep a record of how they felt.

> "... *if there was a little avatar that popped up, I suppose, and said, 'How are you feeling today?' or 'Isn't it marvellous you're halfway through your treatment?'...*" (F5, unfamiliar VA)

The influence of having familiar VAs emerged as a separate theme. Several users mentioned that having a familiar VA made the app more relevant to users. The most prominent theme was that having a familiar VA inspired a sense of confidence and

reassurance. This perspective was offered by users who were familiar with the VAs, as well as users who didn't know these individuals.

> "... *if you've seen* [the healthcare professional] *and if you've got the connection with* [the healthcare professional], *so his voice is reassuring, if you saw a doctor – heard a doctor and this voice, you'd think, 'Oh, well I don't know this man. He doesn't know anything about me.' That's how some people will think*." (M3, familiar VA)

One participant explained that having an established personal relationship with the oncologist upon whom the VA was based could potentially inspire a sense of security upon users.

> "... *I suppose the influence [of having a familiar oncologist] wouldn't be that great erm, for me because I didn't really have much of a relationship with them ... but if it was someone who was more affected by the disease ... and had far more appointments and had built up erm, a relationship, then I, I would guess that that would be quite - erm, quite an influence, I'd say, yeah*. [when the patient was asked to explain this further, the following response was given:] *Er, well, in the way of making you feel more secure; making you feel that you weren't quite on your own with it; and erm... that erm, there was a, a general 'we are looking after you' feeling, you know erm, even if you are at home sort of thing on your own. I would imagine that's how you would feel*." (F5, VA unfamiliar)

One view that linked with the comment above was offered by M8, who explained that despite not having extended interactions with the treating consultant, having a virtual version of this consultant made a difference and explained beginning to form a relationship with the VA. Another participant suggested that a familiar avatar can give users the impression of connecting with the real health providers, who might not always be available in practice.

> *"... you don't see your oncologist very much which I understand because they're very busy ... and they're obviously working very hard in the background, but I guess, you know, psychologically, you would think that your oncologist was talking to you maybe. I don't know. I, I, I guess... so it might be a nice touch*."
> (F4, familiar VA)

Appearance of VAs (characteristics)

The appearance of the VA was the most extensive thematic category. Three main themes emerged: a) professional appearance, b) familiarity and c) customization potential.

Users suggested that the VAs should look like health professionals. The most prominent reason was that such professionals possess the knowledge and expertise and were therefore were the most appropriate and trustworthy agents to deliver medical information. One participant also explained that this introduced a sense of realism (e.g., simulated a real-life scenario where advice would be sought by an expert). It was also suggested that fellow patient VAs would be useful for narrating patient experiences with treatment.

> *"Erm well if you're being told something about a medical issue by a doctor and that person appears to be a doctor erm you're gonna take more notice of it than if erm you deal with somebody who isn't a doctor but erm is just handing out information. ..."* (M5, familiar VA)

Another suggestion was that different types of health professionals should be used according to the types of information provided. Expertise emerged again as the most important consideration.

> *"... So, you have to have the pharmacist who does the drugs, and then you have to have the nurse who tells the patient about the personal stuff, and you have to have the oncologist and maybe you should have the surgeon as well. ... I think you should, you should show that everybody's involved*." (F4, unfamiliar VA)

Several participants explained that having different types of VAs would give the impression of having a team of healthcare professionals attending to their unique needs.

> *"But I suppose that's true of every medical condition but err, I think for the first time, having you know, being in the centre of it really, you can appreciate how there is a whole dedicated group of people with different expertise err, and different knowledge, all combining to provide the best outcome for the individual ..."* (M1, familiar VA)

The familiarity of VAs emerged as another major theme during the interviews. Out of all participants who remarked upon this, most of them expressed a preference for a

familiar VA. These users explained that having an established relationship with their clinicians made them want to see them at the app.

> *"... So, it's almost – it's not as good as* [having a conversation with the real clinician] *obviously – but it's like being able to talk to the doctor that's got control of your case or the nurse that you're used to being with or the pharmacist. So erm I think there's a value in having that relationship*." (M7, familiar VA)

The trust bestowed upon the treating clinicians was another major reason. Also, some users believed that having familiar VAs introduced a more personal and realistic element to the app.

> *"... I believe it's a big connection between your doctor who you believe is saying the truth and wants to… which wants to help you erm, to carry on as long as is possible, it means for me, 100%, seeing the same face, advice from the same face, the same nurse for example, yes, this is very important for me and I would like to carry on this way ...*" (M6, unfamiliar VA)

While some participants explicitly expressed a preference for a familiar or unfamiliar VA, others explained that this wasn't important, as they identified other priorities. Most of these users placed emphasis upon the content and thought that the mediator was not important.

> *"From my point of view, I don't mind who gives that information as long as it's correct and they're telling us the right information. It's not really that relevant. ...*" (PS2, familiar VA)

One user believed that familiarity was not important but suggested that the VAs should look like healthcare professionals.

> *"Does it really matter who, who, who it is, as long as they're wearing a white coat and a stethoscope."* (M1, familiar VA)

The quality of graphics was another reason that made familiarity irrelevant, as some users believed that the VAs did not resemble real humans.

> *"To be honest, I think it wouldn't, it wouldn't make any difference [mhmm] because it's - er, to me, it's not terribly lifelike, if I could put it in those terms."* (PS3, unfamiliar VA)

The logistical limitations of having every health professional turned into a VA for the purposes of the app was also brought up.

> *"... So, in an ideal world, I suppose every consultant oncologist would [be given] one of those scripts and erm but that's not necessarily very practical. I think getting that done would be a big ask. And erm so maybe just somebody who identifies as an oncologist, a consultant oncologist, not necessarily the treating consultant would be a good halfway house*." (M5, familiar VA)

Two users explicitly stated that they didn't want the VAs to be formulated after familiar health providers.

> "*I'd probably prefer the generic person, I mean every time I go to the doctors, I see somebody different anyway [mmm] and I think, I'd open it up and I'd think*

Jesus!! That's my doctor, that's a bit weird!! [fair enough] so probably just somebody I didn't know really." (M2, familiar VA)

The customisation potential was another discussion point. Being able to formulate a custom VA in Manage your Health was not important for some, while one user thought that this would overcomplicate the app.

"No, no. I think that would just complicate it and erm – and some people will say, 'Well what's all this about?'. I think you would undermine what you're doing." (M5, familiar VA)

The matter of gender was mentioned several times; most users thought that this was not important, but some participants explained that cultural influences or receiving information on sensitive/personal matters could potentially predispose some users towards choosing avatars that they would feel more comfortable with.

"... I think if it's something very personal, I think - and aimed at a woman, I think they would prefer to be spoken to by a woman and I expect a man would feel the same way ...". (F3, familiar VA)

Quality of graphics and VA realism

The last thematic category concerned the quality of graphics and the realism of the VAs. In general, users thought that the VAs were not realistic (i.e., they didn't accurately represent their treating clinicians). Several users expressed that the VAs were seen as cartoon/caricature versions of the actual healthcare professionals represented in the

app. This was brought up by users who were familiar with the VAs, as well as users who did not encounter them before treatment.

> *"So, I mean I referred to it as a cartoon because it's, it's not like I'm looking at you just now. It's looking at somebody that's just kind of you know - painted isn't the right word for it but you know what I mean; just kind of erm, related to certain characteristics*." (PS3, unfamiliar VA)

As mentioned in the first section, this elicited a humoristic response in most users.

> *"Erm... it's funny when you see somebody made into sort of a, a cartoon type character, you know - er, an avatar. It just, you know - 'Oh yeah!' It's, it's - it just made me giggle, didn't it?"* (F3, familiar VA)

For some, the quality of graphics did not have an impact upon their user experience. Some users explained that they paid more attention to the fact that the avatars successfully conveyed the information.

> *"... what matters is the speaking part of it. You do see somebody, okay it's not brilliant, but you see somebody and they're speaking clearly, and it gives you enough I think."* (PS1, familiar VA)

On the other hand, the graphics appeared to undermine the user experience for some. One patient explained that watching a VA that closely resembled a known person caused discomfort and eeriness.

> "*... it makes you feel a little bit queasy, when you are watching a nearly person, [mmm] it's like watching a zombie movie because you are thinking like that's*

kind of like what a person looks like but not really [mmm] yeah, it's a bit off-putting." (M2, familiar VA)

One user made a stronger comment that indicated a clear sense of repulsion towards the VAs.

"*Well, I, I think, at the moment, they're a bit scary. You know,* [they're not]*, not particularly attractive to look at [mhmm]. ... You know, you don't really want to look at them [laughter].*" (F4, unfamiliar VA)

A considerable proportion of users believed that the graphics could be improved in a future version of the app. Most of these users suggested to make the VAs more life-like.

"*Erm, I suppose more human like would be good. ... I mean it, it was the limit of the technology, wasn't it? But I suppose these days, you can get - and probably quite expensive technology to get hold of but you can get more realistic representations, can't you? So, that would be a good - that would be a plus I would think.*" (F5, unfamiliar VA)

When given the option of choosing between a realistic VA or a cartoon version of an individual, most users expressed a preference for a realistic VA.

"*... I would love to see the creation of an avatar as human as possible [mmm] yes because for me it's very important, if I want to deal with something, if I want to ask something, if I want to hear erm, advice, the best way is to see somebody's face, it's the most erm… erm beneficial for me, yes ...*" (M6, unfamiliar VA)

While most users favoured realism, others preferred to have a cartoon version of healthcare professionals.

> "*... I think it might be quite fun to hear from a cartoon because erm, children like cartoons and, and they're easy - you know, people have good associations with, with cartoons. ... this business is all a bit serious; you know. Cancer is rather serious so actually, to make it - to lighten it up a little bit, you know, a cartoon might, might not be a bad idea*." (F4, unfamiliar VA)

It was also suggested that the VAs should either be realistic or look like cartoon versions of the actual healthcare professionals.

> "*... if it was so good that you couldn't actually tell whether that was not a person speaking to you, the face, that would be fine, but when it's not quite there as a person, the way it looks like a person or it moves in a little bit of an unusual way, I would prefer it to be totally the other end of the scale and clearly not a person, like a cartoon face or something*"" (M2, familiar VA).

8.4.4. Information needs and satisfaction with information

Types and volume of information

In general, it appeared that patients actively sought information both before and after treatment. While some expressed a desire for as much information as possible, others preferred to focus upon existing issues and/or avoided information that could potentially be upsetting.

> *"... I've been trying not to err dwell on the problem and… and only look up information if I feel like I really need to know ... I don't necessarily want to flick through all the things that could go wrong and all the symptoms because then you start to believe you've actually got that thing sometimes..."* (M2)

The most important types of information concerned treatment-related matters. What seemed to concern most patients were the side-effects of their treatment and what happens during the course of chemotherapy. Cancer-specific information such as the aetiology of the disease was another important area. While some users mentioned explicit categories, others believed that the importance or relevance of information was related to the phase of treatment; in other words, information needs change across the care pathway.

> "...*I think the section, the sections were all very – they were all very good and very relevant er, in terms of the app but sometimes may not be applicable to the person at that time*..." (M3)

One prominent theme was the issue of 'information overload'. Several patients received an overwhelming amount of information during their consultations and explained that this was difficult to cope with. One participant explained that this is not only time-consuming, but it can also induce a considerable amount of stress upon patients.

> *"...I was having to take in so much information that day that erm it was – it was a bit too much in erm – in a short period of time..."* (M6)

Sources of information

Most participants utilised a variety of sources in order to retrieve information. The most prominent source was printed material (mentioned 9 times), which included leaflets from the hospital and/or supportive organizations (e.g., MacMillan). This type of information material was received well by all participants. Printed material was deemed as straightforward, inclusive, reliable and relevant to patients.

> "...*Because I'm an older person I tend to read more than use apps. But I think when I get used to working with apps then it could take the place of the reading material, but it's just a generational thing, I think*..." (M7)

Although the internet was the second most popular source, several users explained that they were cautious when looking for information online. Some explained that they often came across conflicting and/or confusing information, while two participants expressed concerns regarding the reliability of information that patients might come across on the internet.

> "...*I sometimes use the internet but erm, not that much because it's sort of, it's so vast and you know, the amount of information on there sort of can be a bit confusing*..." (M6)

Clinicians were the third most common source of information. Patients appeared to be comfortable to refer their queries to healthcare professionals and recalled having positive experiences with information exchange. Three participants stated that health providers were their most preferred source of information, as they inspired a sense of reassurance and comfort.

"I think seeing - probably erm, face-to-face with the nurse, I suppose that was reassuring. Erm, you saw her once a week on an appointment basis erm, but - although, you could see her any time and when, when the symptoms were a bit more severe erm, I did see her more often. So, I think that was the most reassuring really" (F5)

8.4.5. Recommendations for improvement

General recommendations

The users made a series of recommendations for improving the app. Some general recommendations concerned making the instalment process easier, fixing several unresponsive buttons, improving the search function and continuing with a home rather a cloud version of the app (i.e., an app that functions without the need for internet connection).

Some participants proposed implementing changes that would encourage more frequent use of the app. These patients proposed that the app could push notifications in order to encourage the user to engage with the app. These notifications included notices about appointments, reminders about taking medications and alerts about side effects. One user suggested that these notifications could be pushed via avatars instead of text.

"...it would give you a reason to check in every day as well, if you had an alarm or something... an avatar popping up on your screen on your phone saying, 'Have you remembered to take your chemo,' or 'Did you remember not to take your

chemo today because it's Saturday?' You know that sort - that's the sort of interaction I suppose that it was lacking..." (F5)

The same patient also suggested to use avatars in order to encourage patients throughout their treatment.

"*...It's, it's just saying, 'You've done really well so far. This is, you know, a milestone. This is your first week out of the way,' and, you know, all those sorts of things*." (F5)

Finally, one patient suggested that the app could include a function for tailored dietary advice, such as caloric consumption according to the user's physical activity.

"*...you know the app thought well you've done 3,000 steps today, therefore you probably don't need as much food, here's some dietary advice [mmm] or you've done 15,000 steps today, you could probably eat some more, here's some dietary advice*…" (M2)

Medicines section

Two users suggested enriching the 'Help with your Medicines' section by adding functions that would allow patients to create a personalised record for their medicines, take notes of the doses and the frequency of administration for their medicines and receive advanced alerts about running out of medicines.

"*Does it link to anything sort of within the hospital, I mean is there anything in the app that sort of, you know, if you were recording what medication you were on, on there, if you were able to do that and you were running out of it…*" (M2)

Treatment diary

The participants offered several recommendations about improving the treatment calendar. The most commonly encountered issue was the input of data, as the participants who made negative remarks didn't appear to know how to record the side effects they experienced. Another recommendation was to allow patients to record not only the intensity of the adverse event, but also the number of incidents and the time they were encountered.

> "...*if one can have - er, can add to it when it happened, the time and what have you, that would be, that would be useful, yeah, [mhmm], yeah*." (M4)

Some participants suggested that the calendar function should allow users to enter test results and measurements such as body temperature and blood pressure. Two participants suggested that the diary should provide a visual output such as a graph so that users could observe the course of a particular side effect over time. One user suggested that the treatment diary could be connected to a hospital database in order to record real-time data and that it could alert patients to call triage if they experienced any significant toxicity.

> "...*there should be like a function that's integrated with the diary and what have you. [If I log] my symptoms regularly and [this is] linked to this thing that alerts you to like contact triage and what have you*..." (M4)

One user suggested that the diary function should allow users to keep a food calendar; this user also suggested that the calendar could indicate if the consumption of any particular foods had a negative effect on patients.

Information content

Recommendations for improving the content included better explanations of side effects, improving the readability of written information, and embedding patient videos. Some users also expressed a desire for more personalised information. One indirect finding was that the information on staging was not in accordance with the hospital's staging system, which caused confusion in one patient; this piece of information should therefore be altered for future users.

8.5. Semi-structured clinician interviews

Five members of the research team took part in the interviews (table 8.16). The first member was interviewed at the research site (Churchill Hospital) and the remaining interviews were conducted remotely via Microsoft Teams due to logistical and time restrictions. All interviews were recorded with the clinicians' permission and were transcribed verbatim. There results of the semi-structured clinician interviews are outlined below.

Table 8. 16: Clinician characteristics

Clinical specialty	Gender	Participant code
Consultant Oncologist	Female	Oncologist1
Consultant Oncologist	Male	Oncologist2
Consultant Oncologist	Male	Oncologist3
Colorectal Specialist Nurse	Female	SpNurse
Consultant Cancer Pharmacist	Female	CPharmacist

8.5.1. Experiences with app users

Most clinicians could not recall specific comments made by app users but asserted that most feedback they received throughout the study was positive.

"...I couldn't tell you who it was exactly, but I mean, all the replies that I got were positive...in those patients I spoke to [were] very positive about the app. Erm, you know found it easy to use erm, straight forward from that perspective."
(Oncologist 2)

The specialist nurse presented recollections indicating feelings of reassurance and a sense of trustworthiness on the patients' behalf.

"So erm, we've had sort of feedback from patients that it's been really helpful to be able to erm, have 24-hour access to erm, the clinician's advice... They didn't elaborate much just said that it was helpful to have that on their mobile device, cause otherwise if in the middle of the night, they were worrying about symptoms, so probably look on Google and not always get the right advice so they found it reassuring to know that they just had to look at the app and they could find the right information." (SpNurse)

The consultant pharmacist recalled one incident where the app encouraged a user to contact the Triage helpline, which turned out to be necessary.

"...it sort of reinforced for me that actually the app had kept that patient safe... It may well have been that they would have used some of the paperwork we have given them and they have come to the same conclusion and it might have been the same outcome, but the patient specifically told me, in clinic, that it was due to using the app that they have contacted Triage." (CPharmacist)

The third consultant and the pharmacist, both of who appeared as VAs in the app recalled having patients mentioning that they recognized them in the app but did not

receive any further comments on how this affected the process of receiving information.

> *"...well they laughed because those that had met [the pharmacist] and myself, they made some comments about how we looked [laughed] but they did recognise us and what you know what the app was trying to do.* [when asked to explain whether this was a positive or negative aspect, the oncologist replied:] *Well, they certainly didn't say it was negative I mean they didn't specifically say it was positive [laughs] they were just amused by the actual avatar I think."* (Consultant 3)

8.5.2. Effect of the app on patients' knowledge

Some thought that the app could have exerted a positive effect upon patients' knowledge, since it offered an additive source of information that would reinforce advice provided as part of standard care and allow patients to access information at their own time. Yet, such effects did not become apparent throughout the study. Two clinicians suggested that this was due to the absence of a set of standardised measures for captivating any benefit on knowledge, as well as a 'control' group to compare findings with.

> *"...maybe it would have been better to actually formalise our thoughts and maybe we could have done a simple questionnaire on going through with a patient who was using the app and had some structured questions and going through those same questions for somebody that didn't have the app, just to see if you could tease out any differences..." (*Oncologist 3)

8.5.3. Effect on consultation time

The consultants did not observe any changes in the duration of the consultations. The first oncologist explained that the app wouldn't have any effect upon the pre-chemotherapy consultation, as the consent process involves explaining a considerable deal of information that needs to be addressed thoroughly, irrespective of patients' previous knowledge. For subsequent consultations (e.g., first chemotherapy review appointment), this consultant believed that the app could potentially help speed the process of toxicity review if patients logged their symptoms throughout treatment.

> *"...the treatment diary is actually quite useful...because it would be a, a quick glance at toxicity and seeing it objectively written down rather than trying to tease it out of somebody who doesn't specifically know what you're asking for. So, from that perspective, it might be helpful, I think, and it might sort of speed it up and just more quickly get a more accurate view of what their toxicity has been*." (Oncologist 1)

A similar remark was made by the second oncologist, who explained that the way in which patients present toxicity can add considerable time to the consultation and could potentially be improved through the app. This oncologist also thought that the app could potentially help patients prepare for their review consultations, which could in turn facilitate the process.

> *"I don't think there was a huge difference [in the duration of consultations], I think probably though, you know you were able to focus on the salient points a bit quicker in those patients that had the app. [Because] they sort of had an*

understanding of what we were going to ask them, and you know, and had a more of an idea. I mean you do get some patients who you know come in with reams and reams of paper...which often takes twice as long to do a consultation with them. Whereas you know if you've got that information already on an app, you sort of bypass that side of things." (Oncologist 2)

8.5.4. Perspectives on the app and recommendations for improvement

The clinicians presented several potential benefits that the app could provide to users. One oncologist explained that becoming knowledgeable is a common strategy that patients deploy in order to of take control over their condition and the app could potentially be of benefits in this respect.

"Anything that allows [patients] *to take some control over their disease is useful and erm, there certainly will be a subset of patients who - they like being able to be actively involved and this will allow them to do that. So I think that - I'm all for that. I think that's very useful."* (Oncologist1)

Another remark concerned was the portability offered through the app. The pharmacist explained that patients are given an excessive amount of paperwork in order to receive information, while the app could help them organise it all in one place and access it in their own time. The colorectal nurse mentioned that the app would be easily accessed in occasions where patients would need quick access to such information.

"... they might be away on holiday or visiting family and they happen to experience something that they might think is associated with their treatment erm and they have a quick of accessing the information they need." (SpNurse)

The second oncologist asserted that the app could potentially help patients better understand toxicity, which could in turn help the communication of such issues with their treating clinicians.

> *"... sometimes you get patients in clinic and you know they'll say, 'oh no, everything was fine' and then you go through the checklist and you'll suddenly find out that everything wasn't fine because they've been having all these problems. Whereas those ones that were using the app I think probably were a bit more aware of the side effects they were having because it flagged it up to them."* (Oncologist 2)

The clinicians also suggested several recommendations for improving the app. These included adding functions that would inform patients about upcoming appointments, test results and changes in medication. The most common recommendation was that the app could transmit real-time data related to toxicity (i.e., side effects that patients recorded in the app) so that the oncologists could perform closer monitoring. Yet, one oncologist pointed out the importance of objectivity in order to obtain reliable data for each individual.

> *"...it's still quite subjective, you know erm, even though they're putting in sort of relatively objective data, there's still a degree of subjectivity you know and actually having that information so that we can drum down with the patient in clinic and say, well actually that's not that severe and that is, you know normal. That would be useful so that, again it probably would help us in clinic just to be able to like I say become more erm, focused and precise with what we need to talk about*." (Oncologist 2)

The first oncologist proposed to include a section that would inform patients about the course of their cancer markers (CEA) throughout their treatment.

> *"...actually, a CEA trend - there would be quite a lot of patients who would like that because quite a lot of them will come in and ask what it is, and they follow it, and they want to know what it is, and, and, you know, want to know it's coming down. Erm, so yeah, that might be useful."* (Oncologist 1)

Another recommendation offered by the same consultant was to create a single app that would support patients across the entire cancer care continuum.

> *"...you don't want a patient to have a chemo app and then to have a separate one for surgery, and for stoma care...you'd want somebody to download a colorectal cancer app and within that app, to have everything that they might need...you know, surgeons - colorectal surgeons, liver surgeons, stoma...that would be a nice goal to get to; that this is going to look after you across your entire journey of colorectal cancer and all the appropriate people will be in here somewhere..".* (Oncologist 1)

8.6. Chapter summary

This chapter presented the findings obtained from the main investigation stage. There were two types of findings, namely quantitative and qualitative data. The former included questionnaire data (baseline information needs, satisfaction with information through the app and degree of app's usability) and analytics of app use (frequency, intensity and type of engagement, as well as section use for each treatment regimen), while the latter included results from the semi-structured interviews with the study

participants and clinicians. The next chapter will perform a discussion of these results in order to demonstrate how they addressed the objectives of the project.

Chapter 9: Discussion of main study findings

The previous chapter presented the findings obtained from the project's main study. This chapter will discuss these findings and demonstrate how they relate to the current body of literature. This chapter will also present the integration of the qualitative and quantitative data, as outlined in chapter 5 (p. 163).

Some of the specific objectives of this project focused upon the app itself, while others were specifically concerned with the VAs. The first part of this chapter will focus upon the use of the app as a whole, while the second will focus upon the virtual agents (VAs).

9.1. App-related discussion

The app-related discussion will focus upon the following aspects:

- Usability and acceptability of the app
- Overall use of the app
- Use of the app before and after treatment
- Satisfaction with information and views on the content
- Recommendations for improving the app

The study also revealed a number of issues that impeded with users' engagement, which will be discussed at the end of the section.

9.1.1. Usability and acceptability

The system usability scale (SUS), a commonly utilised tool for assessing the degree of usability in a variety of systems suggested that the intervention had a good degree of

usability, as the mean SUS score was 73.89, with most users (n=7/9) scoring above 70. Although it could be argued that the small sample size (n=9) would not adequately reflect the degree of the app's usability, Brooke (2013) suggested that the SUS can provide a reliable assessment of a system's degree of usability even with a small sample of responders (e.g., 8-12). Hence, despite the limitations in the sample size, it can be claimed that the updated version of Manage your Health was acceptable to the end users and had a good degree of usability. The interview data also backed up the SUS tool measures with regards to usability. Apart from one user who experienced issues with the symptom diary (section 8), the remaining interviewees found that the app was usable and did not experience any usage-related issues. These users were also happy with the organisation of the content.

The improvements made to Manage your Health after the pilot study had a positive effect upon the app, as higher degrees of usability (68.75 *versus* 73.89) and acceptability (marginally acceptable *versus* acceptable) were obtained in the main investigation phase. The present project is an example where the incorporation of user input led to the improvement of an intervention during the early stages of development.

The role of expert involvement in the acceptability and uptake of the intervention emerged as a noteworthy aspect. Throughout the interviews, some users explained that information on the internet and/or other apps is not necessarily checked for its validity, which is in line with findings from the literature (van Velthoven and Powell, 2017). Users made positive remarks upon the fact healthcare professionals took part in the development process, as this made them feel confident that the content of the app was

trustworthy. This was somewhat expected, given that healthcare professionals are the most trusted sources of information among patients (see Chapter 1, p. 5).

Apart from their positive influence upon the perceived trustworthiness of the content, the involvement of clinicians in the recruitment process could have made a positive contribution to the intervention's uptake. Previous studies have demonstrated that expert endorsement can exert a positive effect in the promotion and adoption of products and/or services (La Ferle and Choi, 2005; Wang, 2006). According to Shelton and Chiliya, (2014) the success of endorsement relies considerably upon perceived credibility of the endorsing source. A repeated theme throughout the interviews was that the oncologists were seen as experts that acted in the patients' best interest, which fostered a sense trust; one user explained that the app would not be used if the oncologist didn't refer them to the study. Hence, the oncologists' referrals could have played an important role in the uptake of the project's app.

9.1.2. Overall use of the app

Exploring the overall use of the app did not only help demonstrate how the app was utilised throughout the study period, but it also allowed for understanding the most salient points within the app content from user's perspective. The analytics of the use revealed the areas that were most popular among users, while qualitative data helped understand the aspects that were most important for them.

The analytics of use revealed that treatment- related information (e.g., management of side effects, information about chemotherapy medicines) were the most popular information domain across the entire study sample. This was expected, as treatment-

related information is particularly important to patients with cancer during the initial stages of the care continuum; this has been cited in the general cancer literature (Rutten et al., 2005) and is also supported by the findings of the project's systematic review (see chapter 2). Since the study participants were still early in their treatment, it was reasonable that this information domain was utilised the most in Manage your Health. Another noteworthy finding was that the information priorities of patients were similar during the entire study period. Again, this could be attributed to that patients were at the early stages of the cancer care continuum, so their priorities likely remained the same.

One key realisation was the capacity of the app to be a multivalent tool rather than simply a resource for information. Although most patients used the app for information purposes, some users appeared to place particular emphasis upon its added functions. For instance, one patient (User 12) focused upon the treatment diary; although this patient made some negative remarks about this particular function, he continuously expressed how important keeping track of his symptoms was. Whilst appreciating that Manage your Health was at an early development stage, this user strongly suggested that the diary function should be improved and ultimately be incorporated into active patient care (e.g., by sending live information about any side effects to his doctors). In general, this patient appeared to believe that added functions related to condition management and decision-making would be the most important aspect of this app and that they should be included in future versions. Similar views were also held by other users (e.g., User 21).

A similar observation was apparent after analysing the clinician (i.e., stakeholder) interviews. Healthcare professionals appeared to focus primarily upon matters that concerned patient safety. While this included patient education, with information support being an important factor, their priorities focused upon the app's capacity to 'keep the patient safe', through functions concerning symptom alerts, as well as the potential to aid the processes of monitoring and reporting of toxicity. The exception to this was the specialist nurse, whose comments largely concerned the app's capacity to provide patient support and empowerment throughout the treatment course. This was not an unexpected finding, since nurses tend to pay attention to patients' personal viewpoints rather than concentrating exclusively upon clinical outcomes (Arvidsson et al., 2010).

9.1.3. Use of the app before and after treatment

As discussed in Chapter 2 (p. 40), the information needs of patients with cancer can change across the cancer-care continuum. More specifically, these needs typically peak before treatment due to the uncertainty surrounding antineoplastic therapies, as well as a desire to prepare for their eminent treatment. Both of these reasons for seeking information appeared in the semi-structured participant interviews. Several patients reported using the intervention more intensively before treatment, while others felt that it was relevant exclusively to this stage. These findings, in conjunction with directions from the literature suggested that the majority of the app's use would have taken place before the initiation of treatment. Yet, this was not supported by the analytics of use.

The app usage data revealed that the majority of patients (n=13/23, 56.52%), performed most of their logins after the first dose of treatment. Furthermore, the total number of taps performed after treatment (n=2628/4545, 57.82%) revealed that a significant proportion of users explored the app further at that stage. Although two user profiles (users 10 and 21, see figure 8.6) dominated the tap count data, the remaining profiles indicated that a considerable number of users utilised the app more frequently after receiving the first dose of chemotherapy.

This observation can be explained in a number of ways. First and foremost is that patients were still at a very early stage of the cancer care continuum (i.e., first cycle of treatment), meaning that their information needs were still high, even after the first dose of chemotherapy. Interview data revealed that following the first dose of treatment, aspects such as the treatment-induced toxicity and the use of medications became more relevant and encouraged further and more frequent use of the app. Another consideration was the 'information overload' that was experienced by certain individuals at the pre-treatment stage. It is possible that some individuals did not use the app much before treatment due to the sheer volume of material provided to them as part of standard care, but progressively started using the app once they felt less burdened by the information.

9.1.4. Satisfaction with information and views on the content

Questionnaire data suggested that patients were generally content with the information provided through the app, as most items in the satisfaction with information questionnaire scored above average. Albeit this finding should be treated with caution due to the low response rate (see p. 209), data from the semi-structured

interviews also supported that users were generally satisfied with the app's content (see p. 240). Users expressed that the app included the right amount, types and depth of information and offered only limited comments for improving its content.

9.1.5. User engagement

Despite receiving positive feedback from users (see p. 232-233), usage data revealed that the app was used seldom throughout the study period. More than a quarter of patients (n=6/23, 26.1%) used the app only a few times before treatment and didn't return to it after receiving the first dose of chemotherapy. The interview data revealed several reasons that helped explain this phenomenon. These can be broadly categorised in *app-related* and *user-related* factors.

User-related factors

The most prevalent user-related factor was the preference for standard information material such as booklets and leaflets provided as part of usual care. This stemmed from a number of reasons. The most common reason was the perceived superiority of printed material over the app (e.g., easier to read and understand), as well as a preference for written information. For some patients, the treating clinicians were perceived as very informative and helped them to address their information needs fully. One user preferred printed material due to limited IT skills, while another expressed a clear dislike of using technological means for the purpose of exploring information; in this case, the app was used primarily by the caregiver (the patients' wife). It should also be noted that while not all users expressed a clear preference for standard information material, the vast majority explained that they utilised such sources in order to retrieve

information. As patients obtained information from such material, it is possible the app became less relevant.

The preference for conventional resources also extended upon toxicity tracking. Several patients explained that they preferred to keep a written diary of any symptoms or side effects they experienced throughout treatment, as they were more used with this practice. The age of users could have played a role here. The study sample of this project was comprised by older individuals; Anderson (2017) demonstrated that tracking health or fitness via health apps or websites was among the least popular activities undertaken by older users (undertaken by 24% of responders).

Another factor that resulted in reduced engagement was the knowledge that patients acquired throughout the care pathway. As mentioned in other studies, the information needs of patients with cancer can decrease while moving away from diagnosis, since they become more knowledgeable along the way (Hsieh, Chou and Guo, 2018; Mistry et al., 2010). This was also apparent in this project. Participants explained that as they progressed through the care pathway, they obtained a considerable deal of knowledge on their condition and treatment. As patients believed the app could not make further contributions to their knowledge past a certain point, they felt that the app was not needed, unless they came across something that they didn't experience before.

One user also refrained from seeking further cancer-related information past a certain point (see pp. 236). This could be explained by information overload, as well as an effort to resume normality by refraining from cancer-related information. In their work, Lambert, Loiselle and Macdonald (2009) demonstrated that patients with cancer can refrain from seeking information regarding their condition, as doing so helps foster a

sense of returning to their normal lives (i.e., before being diagnosed with cancer). Hence, it is possible that the aforementioned patient stopped using the app to avoid coming across further cancer information in order to resume a sense of normality.

The caregiver of participant M6 refrained from using the app in fear of coming across unwanted information (see pp. 239). This is another coping strategy employed by patients with cancer and/or caregivers; in an early qualitative study, Leydon et al. (2000) explained that avoiding unwanted or upsetting information can help maintain hope and cherish positive outcomes during treatment. It is possible that certain users stopped using the app in an attempt to keep an optimistic outlook and concentrate upon positive aspects.

Throughout the interviews, a common theme was that the app was used on an 'as needed' basis following the first dose of treatment. For some, this meant reminding themselves about aspects of treatment that might have been forgotten, while others focused on more practical aspects, such as dealing with treatment-related toxicity. Several users explained that as they tolerated the medicines well, they did not engage frequently with the app after receiving the first cycle of chemotherapy because they did not require any particular support; this was also confirmed by the analytics of use (e.g., users 3, 12, 13, 17 and 22). Therefore, it is possible that patients who tolerated their treatment well possibly didn't engage with the app as much as those who experienced adverse events and/or compactions. Unfortunately, it was not possible to investigate this with other user profiles, as not all interview participants commented on this. Furthermore, the study did not acquire data related to patients' health status and/or

quality of life in order to explore the relationship between these factors and the use of the app.

Apart from the issue of limited engagement, a noteworthy qualitative finding was that several interviewees were not aware of certain functions of the app such as the triage survey. One potential reason for this could be the lack of user training. Upon installation at the clinic, the author (AC) briefly went through the app with the participants (and caregivers when present) in order to demonstrate the sections and answer any questions they might had. Information regarding the content and functions of the app was also available in the participant information leaflet that users received upon consent. Yet, this brief training session and the supporting material might not have been adequate, as several users did not know that functions such as the Triage survey and the capacity of creating appointment alerts were available to them through the app. One factor that may have had an impact was the timing of providing the training and the supporting material. As these processes took place right after patients' first consultation with the oncologists, it is possible that patients were unable to retain the information discussed with AC.

App-related factors

The absence of engagement prompts could potentially explain the infrequent use of the app. Druce, Dixon and McBeth (2019) pointed out that the inclusion of push factors (i.e., strategies that encourage individuals towards using an intervention) are key in in increasing engagement in health apps. These strategies include, but are not limited to reminders, notifications and prompts such as text messages in order to encourage users towards entering data or check if they experienced any issues with the app. The VAs

could also help in this respect by delivering these prompts (Ring et al., 2013). If the goal of the study was to obtain high retention rates and make use of clinical data (i.e., patient reported outcomes), such techniques would potentially offer considerable benefits with regards to engagement. However, as the inclusion of push factors could potentially introduce bias and not reflect the 'natural' use of the app-which was among the most important considerations of this study-, it was decided that they would be avoided.

9.1.6. Recommendations for improving the app

The majority of participants offered detailed perspectives on how to improve the app for future users. Most of these comments and recommendations concerned the functions of the app, such as the improvement of the treatment diary, its integration with Triage and the addition of sections such as a medicinal calendar. One noteworthy finding was the limited number of comments about improving the information listed in the app. This suggested that the information content likely fulfilled patients' needs to a good degree so that no major modifications were required; this was supported by questionnaire data (i.e., satisfaction with information), as well interview findings which revealed that patients were generally satisfied with the volume and types of information available through the app.

Another key aspect was the multivalent nature of the intervention. Participants suggested that the app could be improved in order to cover several aspects of care rather than concentrating solely upon information support. Considering this, it was clear that supporting interventions in cancer should attempt to address a range of needs rather than focusing upon a particular area for support. This is particularly

applicable for interventions that aim on providing information support. This project demonstrated that focusing upon this aspect could potentially lead to attrition as patents move away from diagnosis, since the need for information support can decline as individuals progress in their treatment.

The participating clinicians also appeared to hold similar views regarding the nature of the app. While appreciating that the intervention could help patients by making them more knowledgeable around their treatment, they quickly proceeded to make suggestions on what could be included in order to aid their efforts in achieving better patient safety, such as recording patients' symptoms in real time. This was not an unexpected finding. The acquisition of patient reported outcomes (PROs) has attracted considerable attention in the field of oncology, as their use beyond clinical trials has become an increasingly attractive prospect (Toumi et al., 2019). In a recent systematic review, Lu et al. (2020) identified a number of commercially available apps able to track PROs and remarked upon the potential of using mHealth interventions for that purpose. Yet, the authors pointed out that validation of these apps would be necessary in order to ensure quality in the acquired PROs; this was also mentioned during the clinician interviews, where oncologists emphasised upon the importance of accuracy in obtaining reliable PROs.

The personalisation element emerged as another important aspect. While some users thought that the app was tailored to their needs, predominately because it referred to their chemotherapy treatment, other users believed that the app had a rather generic character. These users explained that this was because there was limited input from their side (e.g., logging personal details), as well as output from the app. This was an

unexpected finding, considering that patients were able to input data in the app and the triage survey, as well as the treatment diary functions produced individualised assessments according to the data that users entered. Yet, a comment from participant F5 helped to shed light in this (see p. 248). This comment concerned the VAs' capacity for recognising users' verbal or textual input, which is referred to as natural language processing (NLP, see p.20).

Tudor Car et al. (2020) pointed out that NLP is an important element towards the personalisation of conversational agents, since their responses are tailored according to users' input. Considering the above and the user's recommendation, it is possible that incorporating NLP to the project's intervention could have fostered a sense of personalisation, as well as the impression of a real conversation. As both of these emerged as important aspects throughout the participant interviews, the incorporation of NLP could have potentially benefited the intervention. Unfortunately, its implementation was unfeasible for practical reasons (see chapter 3, p. 108)

Apart from the recommendations obtained by participants and healthcare professionals, the present project also indicated the importance of providing adequate training before users utilise the intervention, as well as additional supportive material (such as instructional videos) to help them better understand its functions.

9.2. Virtual agents

This part will concentrate upon users' perspectives on the virtual agents (VAs) used to deliver the information through the app and discuss the following aspects:

- Appearance of the VAs

- Realism
- Uncanny valley
- Voice and embodiment
- Familiarity
- Customisation

9.2.1. Appearance

According to Straßmann and Krämer (2017), input from the intended end-user population is essential in order to successfully design engaging VAs. To the best of our knowledge, this is the first study that performed an in-depth exploration of end-user perspectives of using VAs in the context of information support for colorectal cancer (CRC). The following section will discuss findings regarding the appearance of the VAs and present how they relate to the current body of literature.

Types of VAs

As discussed in Chapter 1 (p. 21), VAs can be formulated to resemble humans, animals or other species. In the present study, the patients expressed a preference for a human-like VA but appreciated that younger users might be comfortable with other types (species) of VAs. This was in line with the findings of Sträfling et al., (2010) where university students expressed a preference and interacted longer with a zoomorphic (animal-like) VA in comparison with an anthropomorphic (human-like) agent. A later study provided a range of VAs and compared preferences among younger and senior users; the authors demonstrated that while younger users can relate to and express a preference for animals, robots and/or voice-only interfaces, older users have deemed

the inclusion of human or humanoid VAs as more appropriate (Straßmann et al., 2020). This could be attributed to the desire to co-operate with VAs in a similar manner to humans, as senior individuals stated that they wished to be able to address them in a human-like manner, such as looking them in the eyes (Straßmann and Krämer, 2017), which was also evident in the present project (see quote by M6, p. 248).

General features

General features of the VAs such as age, gender and ethnicity appeared to be received well, as none of the users remarked negatively upon them. This was expected, given that some participants had VAs formulated after their clinicians in the app (i.e., were already familiar with these characters). For users who weren't treated by the clinicians that the VAs were formulated after, this could be attributed to that patients were already familiar with the diversity in NHS staff, and were therefore comfortable with the VAs in the app.

Several studies have suggested that users can express a preference for a particular gender, for example female over male VAs (Esposito et al., 2019; ter Stal et al., 2020). Ethnicity also appeared to play a role in the determination of the most proffered VA for education purposes (Rosenberg-Kima et al., 2010). In general, users appear to express a preference for VAs that resemble individuals of their own in-group (Baylor, 2011); yet, this was not evident in this project, as none of the patients expressed a preference for specific VA features such as age and gender. Nevertheless, some participants suggested that other users might feel more comfortable with VAs that resemble their characteristics (e.g., female VAs for female users who wished to discuss sensitive matters).

It should be noted that in the present project, the VAs generally matched the participants' demographics, so it was reasonable that patients did not object to them. Yet, it is also possible that patients refrained from expressing a particular preference for factors such as age, gender or ethnicity in order to avoid being perceived in a negative way (i.e., politically incorrect) by the interviewer (AC). This is referred to as *social acceptability bias*, which has been defined as "*the general tendency of individuals to present themselves in a manner that makes them look positive with regard to culturally accepted standards of behaviour.*" (Chung and Monroe, 2003, p.292).

Professional appearance

The professional identity of the VAs emerged as a major theme throughout the interviews. Regardless of whether the clinicians in the app were known to the users or not, the majority of responders believed that the VAs should resemble the characteristics of healthcare professionals. This was because health professionals were regarded to be the most appropriate and reliable agents to deliver health-related information, as they possessed the knowledge required for this task. This is in line with findings from the literature. As discussed in chapter 1 (p. 23), the appearance of a VA depends upon the context, goals and setting in which the VA is used. A recent publication demonstrated that senior individuals pay attention to the professional occupation of VAs (Esposito et al., 2019). The same authors suggested that clothing played a role in users' preferences, which was also apparent in the present project through users' comments (e.g., see quote by M1, p. 252)

Zhang, Bickmore and Paasche-Orlow (2017) used three different types of VAs (a patient, a healthcare professional and a federal agent) to facilitate the consent process in a

research project. The results suggested that patients were more inclined towards collaborating with the patient VA and offered comments indicating that this was due to a sense of trust arising from perception that these VAs were 'on their side'. A similar finding emerged from the interviews in this project, as some users recommended including a VA that would resemble a fellow patient with CRC for sharing treatment-related experiences. One view was that exploring the experiences of patients who completed treatment would be reassuring, possibly because patients could relate to such a VA. This further endorses the context-related argument, since participants can express a preference for different VAs according to the purpose for which these VA are used.

Apart from their preferences for human VAs resembling healthcare professionals, users also had specific views for how realistic these VAs should be.

9.2.2. Virtual agent realism

As discussed in Chapter 1 (p. 22), realism (in the context of VA research) encompasses three dimensions (stylisation, resolution and detailedness). While some examined these dimensions in isolation (e.g., van Wissen, Vinkers and van Halteren, 2016), while others (e.g., McDonnell, Breidt and Bülthoff, 2012; Straßmann and Krämer, 2018) compared between different degrees of the aforementioned aspects in a single study. Although participants were not asked to comment on these dimensions explicitly in the present project, these aspects emerged after asking participants to express their views on the VAs. Patients' views concentrated upon the stylisation dimension, which refers the degree to which a VA resembles a real human being over a cartoon figure.

Preference for realistic VAs

The majority of participants in the present study expressed a preference for realistic VAs. The argument of context dependency is again applicable here, as the degree of realism makes a VA fit for purpose depending on the context in which it is being used. In their work, Ring, Utami and Bickmore (2014) suggested that cartoon figures can be perceived as friendlier in a social context, but realistic agents were deemed as more suitable for medical tasks; this was supported by a subsequent study that examined patients' preferences for a virtual health coach in chronic diseases (van Wissen, Vinkers and van Halteren, 2016).

As discussed in p. 284, older users have been reported to express a preference for human VAs. Hence, it is reasonable that these users wanted the VAs to resemble human beings as closely as possible, which can be achieved with increasing the degree of realism. Several studies have explored how varying degrees of stylisation (e.g., naturalistic, humanoid, cartoon) are perceived by individuals from different age groups and it appears that older individuals generally express a preference for realistic VAs. Two qualitative studies that explored senior individuals' views on VAs demonstrated that their participants opted for realistic VAs (Straßmann and Krämer, 2017; Tsiourti et al., 2014). Recent studies in which participants commented across a variety of VAs (ranging from cartoon to realistic) again demonstrated that older individuals were inclined towards realistic agents (Straßmann et al., 2020; Ter Stal et al., 2020).

Another aspect that could have played a role in patients' preference for more human-like VAs was the voice of the characters. The messages provided by the VAs were pre-recorded responses of the real healthcare professionals in their natural voices. In a

recent publication, Moore (2017) argued that interacting with artefacts such as robots equipped with natural human voices can make users overestimate the aptitudes of these entities (e.g. expect them to function like human beings). In the context of the present study, the naturalness of the VAs' voices potentially made users to expect that they would come across real humans in the app. This would explain why they expressed a desire for realistic VAs i.e., so congruity could be achieved between their voice and their appearance. The role of voice is discussed further in 9.2.4.

Perception of VAs

Although patients generally reflected positively upon the VAs, the majority of users did not perceive these characters as accurate (realistic) representations of healthcare professionals and suggested that they should be changed to become realistic. This view was offered by patients who were familiar with the clinicians, as well as those who weren't. The most common theme concerning the appearance of the VAs was that the agents were seen as caricatures of the actual healthcare professionals, or as patients put it, 'cartoon' versions of real people. While some patients thought that the inclusion of a cartoon figure introduced a humorous element which made the provision of information less intimidating, the majority of patients believed that the graphics should be improved so that a realistic VA with a professional appearance would deliver the information, as such an agent was regarded to be most suitable for this task.

The only identified study that used a variety of VAs in the field of cancer was Robertson et al. (2015), who tested a VA-based decision support intervention for patients with prostate cancer. In this study, the authors presented several VAs whose appearance ranged from realistic to highly stylised (cartoon) in two focus groups. The first group

expressed dislike for the cartoon version, as participants believed cartoons were disproportionate to the seriousness of the condition. Yet, the second group deemed the cartoon version as acceptable, as it was perceived to be 'softer' than the photographic agent. The authors pointed out that while it is not possible to cater the needs of every user, the risks of including a highly stylised (i.e., cartoon) VA could potentially outweigh the potential benefits for a condition such as cancer (e.g., users could potentially think that the agent was not 'serious' enough to offer advice and help).

Although the VAs used in Manage your Health were realistic, high-resolution representations of the real clinicians (see figure 3.3, p. 110) and not highly stylised versions of them, they were still referred to as cartoon versions of healthcare professionals by the study participants. Yet, none of the users made comments similar to those in Robertson et al. (2015) i.e., that the VAs were inappropriate for the task they were set out to due to a perceived lack of seriousness. This may have been because the virtual characters in Manage your Health did not bear any cartoon features such as exaggerated facial characteristics or voice exclamations. It is also possible that some patients' use of the term 'cartoon' did not necessarily reflect the meaning of the term used in VA literature, but rather referred to an artificial representation of an individual.

Despite their recommendations for improving the VAs, the majority of participants appeared to be generally satisfied with the virtual clinicians . Strasmann et al. (2020) argued that as older individuals are likely to be unfamiliar the use of VAs, they can appreciate such technology and be satisfied by it. Yet, as younger individuals are more familiar with such technologies, satisfying their demands would be more challenging. Both aspects were evident in this study. The majority of participants of this study were

older individuals and did not have any previous experience with VAs; most had positive recollections of using the VAs, while some expressed that they were 'impressed'. Younger participants held different views. One participant from the main study (user 3) and another one from the PPIE (participant A), both of which were younger than the average and were both familiar with the use of avatars expressed less satisfaction with the VA and both reflected upon the concept of the *uncanny valley*.

9.2.3. Uncanny valley

The concept of the uncanny valley has been discussed in detail in chapter 1 (pp 24-24). According to this concept, users begin to experience feelings of eeriness and repulsion when human-like interfaces approach, but are not successful at achieving lifelikeness (Mori, MacDorman and Kageki, 2012). As this project involved realistic VAs resembling familiar individuals, this theory was particularly relevant, and its potential application was hence explored.

Findings from the semi-structured interviews revealed that the uncanny valley effect was not evident across the entire participant sample. All users were presented with VAs that were realistic, high-resolution representations of healthcare professionals that portrayed them with a high degree of accuracy, but were not identical (e.g., photographic) to them (see figure 3.3, pp. 110). While feelings of repulsion were apparent among a minority of users, this phenomenon was not evident among other individuals, particularly the older patients.

Contrary to the concept of the uncanny valley, older users in this project expressed a preference for VAs with greater degrees of human likeness (i.e., realism) than the

healthcare professional avatars presented to them. This finding was not entirely unexpected, as several studies have demonstrated that senior users can express a preference for realistic VAs (p. 287). In a recent publication, Tu et al. (2019) pointed out that older users do not necessarily abide by the uncanny valley theory, given that they can opt for more realistic agents.

Such controversies are not new. As discussed in chapter 3, the concept of the uncanny valley is not necessarily generalisable (p. 111). Over the years, the accumulation of empirical findings indicating divergencies in Mori's theory have raised questions regarding the extent of its application and led to the refinement of this model (Zlotowski, Proudfoot and Bartneck, 2013). Two concepts, namely the *categorisation ambiguity* and p*erceptual mismatch* have been proposed (see Chapter 1 p. 25) and were both explored in the context of this project.

Perceptual mismatch

While mismatches between the voice and appearance of the VAs have been reported to discourage people from engaging with these interfaces (Kätsyri et al., 2015), none of the patients in the present project stated that they stopped using the app due to this. One explanation for this would be that users prioritised information support over the VAs' appearance. This emerged in some interviews, and it is also apparent in a paper by McDonnell, Breidt and Bülthoff, (2012). In this study, the authors provided a range of VAs raging from highly realistic to stylised and used natural voice to perform the required tasks. In their discussion, the authors argued that participants were so focused on the task, so that the appearance of the VA was placed in lower priority. Hence, it is possible that the participants of this study placed emphasis upon the provision of

information, and they did not allocate as much attention to the inconsistencies in the appearance of the VAs.

In a recent study, Stein and Ohler (2018) also found that inconsistences between facial proportions and vocal realism resulted in VAs being perceived as less credible and attractive Yet, these inconsistencies did not impact the agents' persuasive success. A similar finding was also present in this research, as such inconsistencies didn't hinder the perceived value or trustworthiness of the information. In the aforementioned work, the authors explained this observation through the Elaboration Likelihood Model (ELM), introduced by Petty and Cacioppo, (1984).

The ELM proposes that persuasive success relies on two routes on processing information, namely the *central* and the *peripheral*. The former route has to do with the message itself (e.g., rationality and logical merit), while the latter is associated with the source of the message (e.g., perceptions of the agent who delivers it). This model also suggests that most people will focus upon the central route, as long as they have sufficient time to process the information they received (Petty and Cacioppo, 1984). Although it is possible that this applied to the present project (i.e., patients had six to eight weeks to interact with the VAs and process the information to assess their logical merit), it should also be considered that the patients were either familiar with VA in the app or were aware that the VAs represented clinicians that worked in the hospital and collaborated with their oncologists (i.e., were part of the same team). The element of trust in these clinicians might also gave rise to the peripheral route, even if the graphics did not satisfy the users.

For human-like VAs, convincing (i.e., natural) movement and facial expressions are of critical importance (Geller, 2008). McDonnell, Breidt and Bülthoff (2012) argued that while users might be prepared to 'forgive' motion irregularities in cartoon characters, they are likely to not be as tolerant towards human-like VAs. The authors theorised that this is because humans are innately used in analysing the expressions of fellow humans, so any anomalies in motion would give rise to strong feelings of uncanniness. In the present study, although there was a good degree of coordination between the dialogue and the VAs' facial movements, the synchronisation was not identical to that of a real person. While younger users thought that facial expressions should be improved, none of the senior users remarked upon this during the interviews. One potential explanation for this is that senior individuals have been reported to not be as efficient as younger individuals at processing and evaluating facial expressions in VAs (Beer, Fisk and Rogers, 2010; Beer et al., 2015).

Categorisation ambiguity

Only a minority of users provided responses that resembled the issue of categorisation ambiguity. This could be attributed to that the majority of patients placed the VAs in the 'cartoon' spectrum. This could explain the absence of feelings of uncanniness across most users, as they appeared to be certain about which category the VAs fell into. It must be noted that users who perceived the VA as strange were younger, while users who treated the VAs as cartoon figures were older, suggest potential differences between individuals from different age groups.

9.2.4. Voice and embodiment

Although some of the participants made negative remarks upon the appearance of the VAs, there was no negative feedback regarding their voice. Several users even placed emphasis upon the voice of the VAs and even prioritised it over their appearance. This was not unexpected; in multimedia learning, voice can be of critical importance (Mayer, Dow and Mayer, 2003). In this study, voice played an integral role in older individuals' experiences with VAs, which was also in line with findings from the literature (Esposito et al., 2019b). One aspect that influenced users' perceptions was that the VAs' voices were natural. Several publications pointed out that natural voices can be favoured by users, which can explain why these were perceived well by the study participants (Baylor, 2011; Parmar et al., 2020).

One participant who was not satisfied with the appearance of the VAs suggested that the element of embodiment could be removed, and the voice could be kept instead in order to deliver the desired information. A similar proposal was evident in a review that critically appraised VAs (Campbell, Grimshaw and Green, 2009). In this work, the authors drew upon the effect of the uncanny valley and suggested that people are generally capable of recognising the artificial nature of a VA in terms of appearance and sound. The authors suggested that in order to bypass this, the element of embodiment could be removed, and communication could instead be mediated by means such as telephones and forms of textual communication (e.g., emails and text messaging) in order to 'disguise' features (e.g., voice) that might become recognised as artificial by the end users.

Although the above proposal has its merits, the findings of the present work suggested that this wouldn't necessarily align with patients' preferences. Any negative comments regarding the VA were associated with its *appearance*, not its *presence* in the app. Patients generally wanted to have embodied agents to deliver information but demanded that graphics should be improved to make them realistic. The participants of this study deemed the inclusion of the VAs to be beneficial, as it offered a sense of presence and for some, even resembled a conversation with a healthcare professional. This was in line with the findings of a systematic review, which demonstrated that the inclusion of embodied VAs induced a greater sense of social interaction in comparison with non-embodied agents (Yee, Bailenson and Rickertsen, 2007).

Distorting the voice of the VA (as proposed by Campbell, Grimshaw and Green, 2009) could also have potentially have negative consequences to some, as several participants favoured the fact that the VAs had human voice. In their work, Chérif and Lemoine (2019) demonstrated that the human voice can create a stronger sense of social presence and build greater trust in users when compared to a synthetic one. While the first observation (social presence) appeared in some interviews, the latter (trust) was more evident. Patients favoured having information delivered to them in a natural voice, while those who were familiar with the healthcare professionals represented by the VAs expressed that having their doctor's voice to explain things inspired a sense of reassurance, as they trusted their knowledge and capacity to help them get better. As one patient stated, hearing the clinician's voice on the app resulted in listening more closely to the VA.

Considering the above, using natural human voices can offer several advantages to older users. When using a natural voice, several aspects need to be considered carefully. One of them (perceptual mismatch) has already been outlined in p. 291; if a natural voice is to be used, care should be taken so that the appearance of the VA is realistic in order to match it. Another consideration is the restrictions imposed using natural voices entail, as using recordings (i.e., the only way of achieving natural voices) can limit the potential range of applications of embodied conversational agents (ECAs). For example, pre-recorded messages do not allow for the personalisation of the ECAs' responses to users, which is an important aspect of formulating successful relational agents (Campbell, Grimshaw and Green, 2009).

9.2.5. Familiarity

While the initial plan was to test these characters with patients who were treated by at least one of the healthcare professionals represented as VAs, the project also included users that were not familiar with these professionals, which allowed for an exploration of similarities and differences between these groups.

The most prominent comment from users who had their clinicians as VAs in the app was that their presence inspired a sense of reassurance. Patients appreciated having familiar clinicians in the app and explained that this was due to the trust bestowed upon them, as well as the desire to be treated by the same health professionals across their therapeutic journey. The latter resembles a dimension of *continuity of care*, which describes "*an ongoing therapeutic relationship between a patient and one or more providers"* (Haggerty, 2003, p.1220). Continuity of care plays a key role in individuals receiving treatment for cancer, as the enduring alliance between patients and

healthcare professionals can foster a sense of reassurance and security (Bakker et al., 2001; King et al., 2008). It is therefore not a surprise that patients wished to have avatars of their treating clinicians to support them through the app. Patients who weren't treated by any of the clinicians who appeared as VAs also saw merit in having their treating professionals on the app.

The aforementioned patients also received a sense of reassurance by the VAs' presence. One explanation for this emerged in an interview, where the user was aware that the VAs represented colleagues of his treating consultants working at the Churchill Hospital, which inspired a sense of reliability. Zhang, Bickmore and Paasche-Orlow (2017) demonstrated the importance of organisational affiliation in users' perceptions regarding the trustworthiness of a VA. The findings of the present project support these results, since virtual clinicians affiliated with the Churchill Hospital were regarded as reliable agents to deliver information support.

In the interviews, patients explained that they trusted their clinicians, as they deemed them to be knowledgeable and were also confident that they acted in their best interest. Being aware that their clinicians and/or members of their care team were involved in the development of the app fostered a sense of reassurance that the app provided reliable support (p. 236). For some patients, it appeared that the sense of trust extended to the familiar virtual characters, while others felt that they were looked after by their doctors through the app. This was an interesting finding, as patients were aware that these characters were virtual entities and not their actual doctors. How could they trust them or feel like they were being taken care of via an app? A potential explanation is that "*the effects of all kinds of social support are primarily a function of*

the perception of support by the one receiving it, rather than the perceptions, intentions or actual behaviour of the person providing it" (Bickmore and Schulman, 2006, pp.1–2). It is hence possible that users bestowed trust upon the VAs resembling their treating clinicians and felt that they were looked after, even if they were aware that they were artificial.

It appears that the role of VA familiarity has not received much attention within research studies, as it has been addressed in only a few publications. The first identified study was conducted by Tsiourti et al., (2014) where the authors provided a variety of static VAs ranging from highly stylised (i.e., cartoons) to highly realistic and included characters that both were known and unknown to the participants. Yet, this study had considerable methodological differences compared to the present project (e.g., not conducted in the context of healthcare, static agents and no indication as to the voice of the VAs).

Another study later explored the role of familiarity in animated VAs in the context of healthcare (van Wissen, Vinkers and van Halteren, 2016). In this experiment, the authors tested three virtual characters representing health coaches, two of which they were unknown to users and one that users were familiar with. The users rated the familiar VA as least desirable; the authors explained that this could be attributed to participants' disappointment, as the VA did not accurately represent the individual that was known to them. These findings were in contrast with the present project. While users of Manage your Health believed that the VAs could be improved to be more realistic, the preference for interacting with a familiar VA in the app was still evident.

To interpret this contradiction, it is necessary to consider the differences between the present study and the above-mentioned experiment. In van Wissen, Vinkers and van Halteren, (2016) the voice of the familiar VA did not match the voice of the individual that the VA was formulated after. This incongruity could have given rise to feelings of eeriness and uncanniness (see 9.2.3), which would make users less inclined towards using them. In the present study, the voices of the VAs were natural and matched the voices of the patients' healthcare professionals. The users reflected positively upon having a familiar voice, which inspired them towards preferring the known VAs.

Another major difference was that van Wissen, Vinkers and van Halteren (2016) used highly stylised agents with mismatching voices, whereas the VAs used in the present study were realistic, high-resolution representations of the healthcare professionals with matching natural voices. As discussed in 9.2.3, discrepancies in the VA's voice and poor graphics can have a negative effect upon users' satisfaction, as they do not provide an accurate representation of an individual. This could potentially be further aggravated if the agents portray individuals known to the users, since users are likely to be able to spot differences between the VA and the individual represented by the VA more easily. It is therefore possible that the participants in van Wissen's study expressed a dislike for the known VA, as it did not resemble the known individual with an acceptable degree of fidelity. While there were inconsistencies between the naturalness of voice and the appearance of the VAs in the present study, these mismatches were not as striking as the ones in van Wissen's study. This can also explain why users of the present project expressed a preference for familiar VAs, even if they didn't represent the actual individuals with photographic accuracy.

9.2.6. Customisation potential and ethical considerations

In virtual environments, the customisation of avatars and VAs is an integral part of the user experience (Waltemate et al., 2018). Recent reviews (e.g. Kocaballi et al., 2019; Schachner, Keller and von Wangenheim, 2020; Tudor Car et al., 2020) have explored the personalisation in ECAs and VAs' in healthcare, but focused exclusively upon agents' output according to users input (e.g. personalised responses). After a brief exploration of the literature around ECAs in healthcare, only one study where users were able to formulate their VAs was identified (Hunter et al., 2018). This study involved an intervention for supporting children with cancer, where children were able to fully customise their VA companions; users could choose between a panda bear and a penguin, as well as a range of accessories that they could pick from. Yet, views on the customisation of human-like VAs in healthcare hasn't attracted much research interest to date.

Although this project did not address this concept formally, the potential of VA personalisation emerged in some patient interviews; all responders expressed that an option of personalising their VAs would be unnecessary. While no assumptions can be made regarding how other individuals would respond to such possibility, it is important to point out that offering the option of choosing between different health providers can give rise to certain ethical dilemmas. Such issues were addressed in Graber and Graber (2011) and more recently, in Hallqvist, (2019) wherein arguments for and against the customisation of health providers in supportive interventions were presented. A prominent issue concerned the VAs' gender and ethnicity; while some patients might establish better therapeutic relations with providers that have the same characteristics

as themselves, granting the opportunity of choosing between individuals on such basis could potentially jeopardise diversity and give rise to prejudice. Instead of providing the option of personalising avatars, our proposal would be to offer a range of VAs in order to reflect the diverse character of the healthcare environment; this was also in line with findings from the interviews.

9.3. Reflexivity

The theoretical considerations around reflexivity have been presented in chapter 5 (pp. 157-160). Reflexivity can be seen as both a concept and a process and is concerned with the role and influences of the researcher in the context of inquiry (Palaganas et al., 2017). As a researcher newly introduced to qualitative research, this concept was entirely new (and somewhat foreign). My initial understanding of reflexivity mainly involved its role as a validation process and resembled that of 'tick-boxing'. Yet, my course through the PhD programme made its actual purpose and value widely clear, not only for the research process, but also myself. The following sections will demonstrate the various influences that my personal and professional journey exerted upon the conduct of my research.

9.3.1. Research 'through the looking glass'

Entering the realm of empirical inquiry was an arduous quest. Although my adventures were not as daunting as that of the protagonist in Lewis Carroll's *Alice Through the Looking Glass*, venturing into the land of qualitative research drastically altered my perspectives on how knowledge is conceptualised, captured and generated.

As a pharmacist with a master's project in organic catalysis, my training was shaped entirely by positivist/post-positivist directions, whereby knowledge is apprehended through well-established, air-tight methods and expressed as statistical probability (Brodsky et al., 2016). This created a certain perception of reality, as well as the process of research, both of which were challenged during my doctoral studies. At the early phase of the course, I took an interest upon research philosophy, with particular focus on the interpretivist/ constructivist movement and qualitative research. Exploring these domains made me envision research not just as a *microscope*, whereby a phenomenon is placed under observation in a controlled environment, but also as a *kaleidoscope*, where the same phenomenon can be looked from a different angle to reveal an entirely new picture. Drawing upon the pragmatist paradigm, I came to realise that research is not a mere *tool* used to comprehend a pre-defined reality, but instead, a *toolbox* that can be utilised in order to provide thorough answers in multiple research questions.

Re-thinking the concept of inquiry also made me reconsider the matter of subjectivity. During my undergraduate studies, I had to distance myself from the observed in order avoid 'contaminating' my findings and introducing subjectivity in my research. At the time, I regarded it as a threat with destructive potential for validity in research. As a doctoral student, I came to realise that subjectivity is an inherent characteristic of a researcher's thought process and that denying its existence would be the real threat to validity. Hence, instead of trying to eliminate subjectivity in a feeble attempt to portray an objective reality, I realised that the wisest course of action was to 'exploit' it in order to demonstrate how it affected my research, as well as the steps taken to 'contain' its impact.

9.3.2. Researcher's effect on research

There are three main aspects where I considered my effect upon the research process. First and foremost was the effect of my theoretical perceptions upon the choice of methodology, followed by my influences upon the conduct of interviews and the interpretation of qualitative findings. Below, these will be described in further detail.

Choice of methodology and research methods

In chapter 4, I presented an overview of my exploration of research philosophy. This directly influenced the choice of methodology, which in turn informed the selection of the most appropriate research methods for addressing the study's objectives. While these decisions were successful in addressing the research objectives, it is important to acknowledge how issues inherent to these methods could have affected the findings.

According to Deakin and Wakefield, (2014) the most prominent challenges associated with video conferencing is the lack of interviewee's familiarity with such technology, the encounter of technical issues and the potential of premature termination from the interviewee's behalf. The only challenge encountered in this project was experiencing technical issues (e.g., signal cuts, frozen image, sound distortion) whilst conducting two video interviews. This caused disruptions that inevitably affected the quality of the conversation. In one of these interviews, the issues were so profound that the video had to be turned off in order to continue the discussion. This had a direct impact upon the interview, as the delays resulted in terminating the interview earlier. It is also possible that the technical issues also caused frustration to the interviewee, which could have exerted an impact upon her engagement.

Apart from the aforementioned instance, the interview mode did not have an impact upon the length of interviews, as face-to-face conversations and individual videoconferences were similar in terms of duration and total amount of words. This finding is in line with Krouwel, Jolly and Greenfield, (2019) although differences in the number of themes and/or individual statements were not investigated in the present project. None of the users appeared to be unfamiliar with the use of videoconferencing and/or struggled with this interview mode; this was expected, as users' IT literacy was somewhat evident since they consented in a study that involved the use of a VA-based app.

Another consideration was the length of the information needs and satisfaction with information questionnaires (appendix 15 and 16.). These instruments were formulated after the Toronto Information Needs Questionnaire (TINQ) and provided a thorough account of patients' needs and satisfaction with information; nevertheless, it is possible that their length had a negative impact upon the return rate. Although this was not evident in the pilot study (i.e., 4/4 returned the information needs instrument, 3/4 completed the satisfaction with information questionnaire and no complaints about their length), the return rate in the main study was considerably lower (i.e., 7/23). This made me reconsider the potential risks of providing such exhaustive instruments.

Conduct of interviews

The idea of conducting interviews with patients provoked a deal of stress. Although not exploring a contingent social issue, I still had to be careful about approaching vulnerable individuals at a sensitive point of treatment. Yet, participants' willingness to engage with the project and offer structured feedback increased my comfort and made the

process flow a lot easier than I anticipated. Drawing upon my experience as a qualified pharmacist also had a favourable effect. Being experienced with patient communication, as well as aspects such as active listening and simultaneous notetaking-which are both part of the pharmacy learning and practice curriculum-equipped me with skills that facilitated the conduct of the interviews.

My occupation as a pharmacist would make me-as Bonner and Tolhurst (2002) defined-an 'inside' researcher. Although this offered several advantages, it also posed certain threats to my capacity as a researcher. For example, being familiar with aspects of information support could result in making assumptions about what was observed and refraining from pursuing clarifications. With this in mind, I took care to seek as many explanations as possible, despite any pre-existing knowledge. Another aspect was my *view* of the participants. During the first couple of interviews, I struggled to separate my professional 'instinct' from my role as a researcher and focused on the interviewees' capacity as *patients* rather than *study participants*. This could have created an excessive degree of rapport, which would in turn affect the findings (Bonner and Tolhurst, 2002). Yet, the fact that I was not involved with any clinical aspects of their care helped me to untangle myself from this confusion.

Apart from my leverage upon the interview process, another important consideration was the way that I was perceived by the study's participants. The effect of the researcher upon study participants is a well-recognised matter, especially in the domain of healthcare. Kelly (2010) pointed out that when interviewing in a healthcare setting, perceived power dynamics between providers and patients can exert a profound influence upon the interviews. These dynamics can also affect the way in that

interviewers are perceived, irrespective of their background, as responders (i.e., patients) can regard them as experts. This imbalance of power can make participants hesitant towards providing feedback that can be perceived as negative or deviant in fear that doing so can jeopardise their relationships with their providers, or even, their access to care.

Although participants knew that I was not a part of neither their clinical nor supportive care team, they were aware that I collaborated with their treating clinicians and that they were also involved in the development process of the app. It is therefore possible that they framed their responses in a positive way in order to avoid causing indirect unpleasantness to the clinicians. While participants were generally comfortable with providing negative feedback, some could have potentially responded in a positive manner in order to not 'displease' the research team.

Another aspect of my professional dimension was the role of attire upon the participants' perceptions. At the time, my dress code matched that of the male members of the clinician team (i.e., formal trousers, shirts and ties). During the first interview, the participant emphasized upon the importance of professional attire in healthcare professionals and asked a technical question about chemotherapy medicines towards the end of the interview. This made me realise the way I dressed could potentially make patients focus upon my capacity as a healthcare professional rather than a researcher who was not actively involved in their care. As discussed above, power dynamics in healthcare can affect the way that patients respond to professionals. Following the encounter with the first participant, I adjusted my clothing in order to

present myself in a more informal manner (e.g., chinos, plain t-shirts and casual blazers) in order to reduce this effect.

Another reason that could have inclined participants to provide positive feedback was my role in the development process of the app. Being aware that I was involved in the development of the intervention could have fostered the idea that my goal was the *promotion* Manage your Health rather than its *evaluation* it in the context of research. In order to avoid this, I abstained from commenting on my role as a developer and reminded participants that the purpose of the interviews was to obtain honest accounts of users' experiences rather than a glorified appraisal of the app.

Analysis and interpretation of qualitative findings

The analysis of qualitative findings was by far the most challenging part of my academic work. The in-depth interviews produced an immense amount of data, which had to be reviewed systematically, organised in a reliable manner and be interpreted in a meaningful way. Due to its systematic nature, framework analysis was chosen for this purpose. While this approach generated findings of quality, it was is also complex and laborious. This posed a significant challenge, especially considering that this was something entirely new for me. To ensure robustness, I continuously refined the initially developed framework and abided closely by the process of iteration in order to create a vigorous framework. This was performed under the watchful eye and assistance of my supervisors, whose expertise helped to increase the robustness of the analysis.

Apart from the practical challenges, my personal leverage upon the analysis of the qualitative findings was also a key aspect. At the early stages of the interpretation

process, I realised that being intimately connected with my work predisposed me towards concentrating upon positive feedback and paying less attention to negative comments. With this in mind, I took care to carefully examine negative views and deviant cases in order to captivate a reliable collective account of users' perspectives upon the intervention. The potential of biasing users was also taken into consideration whilst analysing the transcripts (see p. 305-308 for further details). While it is possible that I had an effect upon the users' responses, the presence of positive and negative feedback was indicative of honest accounts, as well as a good degree of rapport between the participants and the interviewer.

9.3.3. Research's effect on researcher

Having to leave the UK in urgent notice due to the COVID-19 pandemic and supporting the family business (pharmacy) in this volatile time forced me to temporarily put my research aside. Although this resulted in requiring additional time to complete my thesis, it also granted the opportunity of viewing my academic work away from the pressures of the academic environment. As Mauther and Douchet (2003) proposed, the realisation of certain influences can sometimes necessitate "*time, distance and detachment from the research*" (p.425). In my case, this time helped to not only appreciate my influences upon the research process, but also to understand the influence of the research process upon myself.

The most valuable outcome of my academic Odyssey was familiriasing myself with the research process. The PhD course equipped me with knowledge, as well as an array of skills that will be of the upmost importance in my future research endeavours. This includes the design of projects, the coordination of teams (academic, clinical and

developmental), the conduct of systematic reviews and experience in qualitative inquiry.

Another important aspect was a better grasp on mHealth and VAs. Before engaging with this project, one of the outmost considerations was the impact of these interventions in healthcare. Whilst appreciating the positive effects, I was concerned that such technology could potentially replace clinicians (to a greater or lesser extent). Yet, I realised that this was not the case for two reasons. Human communication is an integral part of supportive cancer care. Although this can be *supported* by mHealth interventions and VAs, it cannot be *replaced* by them. The same would be true for the app's capacity to keep track of toxicity and make assessments according to patient's input. Although such aspects could *facilitate* patient care, they could not by any means *subsidise* the role of healthcare professionals, whose non-linear reasoning is integral for making the most appropriate decisions for patients' health.

As a concluding reflexive remark, I drew upon the work of Mauthner and Doucet, (2003) who argued that there are limits to how reflexive one can be. Although strenuous efforts were made to engage reflexively with my research, I appreciate that there is still much to be learned throughout my course as a researcher in the future.

9.4. Chapter summary

The present chapter discussed the major findings of this research project, which concerned the intervention itself (app-related discussion) and the VAs (VA-related discussion) that were used to deliver the information support. The use of a mixed-methods approach was particularly helpful at conceptualising quantitative results using findings from the in-depth interviews, which also helped explain controversies and

unexpected findings. The next chapter will outline the conclusions of this research, present the strengths and limitations and point out directions for future work.

Chapter 10: Conclusions, limitations and directions for future work

The previous chapter discussed the findings of the main study. The present chapter will provide an outline of the key findings, along with their potential implications and will then proceed to the strengths and limitations of this project, followed by directions for future work.

10.1. Key findings and implications

The aim of the project was to develop and evaluate a virtual agent (VA)-based mobile health (mHealth) intervention for patients with colorectal cancer (CRC). The following objectives were set, which were addressed through a convergent parallel mixed methods design.

- Objective 1: Determination of the app's degree of usability and acceptability
- Objective 2: Satisfaction with information and views on the content
- Objective 3: Exploration of the app's use throughout the study period
- Objective 4: In-depth exploration of users' perceptions of the VAs
- Objective 5: Potential ways for improving the app

A number of insights were also offered by the systematic review (Chapter 2), as well as the competitive analysis undertook as part of the development process (Chapter 3). The following sections will summarise these insights and briefly outline their potential implications.

- Objective 1: Degree of usability and acceptability of the app

The System Usability Scale (SUS) revealed a good degree of usability and acceptability (mean SUS score 73.89), which was also supported by the interview findings (e.g., minimal negative feedback regarding usability). Users who didn't regard themselves as tech-savvy found the app easy to use and suggested that fellow patients, even those who wouldn't be very familiar with apps would find it easy to use. This project is an example where a multistage process informed by the latest directions to best practice was followed in order to build and refine an intervention for use in patient care. Future investigations can draw upon this process to develop similar interventions in the field of mHealth.

The involvement of health professionals in the recruitment process and indirect 'endorsement' of the app appeared to have exerted a positive effect upon its uptake. This finding emphasises the benefits from including healthcare professionals in the promotion of health apps and can be of potential value to future developers; this does not only include doctors, but also pharmacy, as well as nursing staff.

- Objective 2: Satisfaction with information and views on the content

The satisfaction with information questionnaire demonstrated that the app addressed patients' needs at a moderate degree. Throughout the in-depth interviews, patients reported being satisfied with the information that was available through the app, but also reported utilising a variety of other resources (e.g., printed material, healthcare professionals). In general, the app was not the principal source of information. According to users' comments, the app was seen as an additional resource that could

help endorse existing information, confirm new information and remind them of aspects that were forgotten throughout treatment.

Users reflected positively on the content of the app. This included the types of information, the organisation of the content in thematic categories, the amount of information and the level of detail. The inclusion of health professionals in the development process also increased patients' confidence regarding the quality of the content. Again, this highlights the potential benefits offered by involving healthcare professional in the development of such interventions.

- Objective 3: Use of the app throughout the study period

The interview data revealed an overall usage pattern during the study period. The participants explored various sections of the app in order to familiarise themselves with the content before treatment and used the apps on a 'as needed' basis after the first dose of chemotherapy. The usage data revealed that the degree of engagement (e.g., number of logins, tap count) varied considerably across the participant sample. Nevertheless, the majority of users accessed the app more frequently after receiving the first dose of chemotherapy. This could be attributed to that patients were still at an early phase of their care pathway, so their information needs remained high.

Throughout the interviews, it appeared that the extent of the app's use was affected by the wellbeing of the patients and how well their treatment was tolerated, with frail patients and those heavily affected by treatment being more likely to need it. This could not be examined further, as the research did not involve access to patients' health records.

- Objective 4: Users' perspectives on the VAs

Although the application of conversational agents has gained momentum in recent years, the use of embodied conversational agents (ECAs) in cancer care remains an under researched area. This project adds insight in the use of embodied VAs for supporting patients with cancer and is the first to deploy realistic VAs in oncology care. The results demonstrated that the VAs were received well by the participants and were deemed to be an appropriate way of providing patient support. It must be noted that these findings can have potential implications not only for clinical, but also for pharmacy practice, since a new type of interaction between patients and pharmacists emerged throughout the interviews.

The inclusion of the VAs fostered a sense of reassurance, facilitated the process of information- giving and had a positive effect upon the perceived trustworthiness of the content. This project included patients who had at least one of their treating clinicians represented as a VA in the app, as well as patients who were not familiar with the virtual characters. The results indicated that being familiar with the healthcare professionals represented by the VAs can play an important role. Overall, users favoured having their treating clinicians as VAs in the app, as they felt that the healthcare professionals' care extended to them through the app. This was in line with the initial hypothesis. The importance of organisational affiliation (i.e., the VAs being affiliated with the treating establishment) was also highlighted.

The most prominent comments concerned the appearance and voices of the agents. The VAs included in the app were perceived as cartoon figures and not real humans by most users. The general consensus was that the VAs should resemble healthcare

professionals, look realistic (i.e., human-like), and have natural voices. Another prominent finding was that older users do not necessarily experience the phenomenon of the *uncanny valley*, where users can manifest feelings of eeriness when encountering realistic representations of humans in virtual environments (see pp. 24-25).

The abovementioned points offer insight for developers and researchers who wish to deploy VAs in cancer care. It should be pointed out that these findings concern this particular group and should not be directly applied to other types of users. For instance, a cartoon-type ECA can be more appropriate for children with a malignant condition (e.g., Hunter et al., 2018). Developers and researchers should consider this carefully in order to design VAs according to the expectations of the intended audience to optimise the user experience.

- Objective 5: Potential ways for improving the app

The participants offered several recommendations for improving the intervention. These mainly concerned the supportive functions of the app, with only a limited number of remarks about the information content. Comments included the incorporation of a medicinal calendar section and integration of the symptom calendar function with Triage. The element of personalisation (i.e., tailored feedback according to users' input and information on their unique treatment) also emerged as a desired aspect. Healthcare professionals also provided comments on how the app could be improved and focused mainly upon its potential as a toxicity-monitoring tool. Patient-reported outcomes (PROs) emerged in most interviews.

The app's capacity as a multivalent tool rather than just an information resource was another major insight. Interventions aiming exclusively at information support are likely to be placed at a disadvantage due to the presence of 'competing' information sources and the fact that once patients become familiar with information, the intervention might cease to be utilised. This is particularly applicable for interventions with commercial intentions. This finding calls for developers to consider that supportive interventions should address a range of needs (e.g., symptom tracking, toxicity checking, coaching etc.) rather than focusing upon a single dimension of support in order to be relevant across the entire care pathway.

- Systematic review (Chapter 2)

The systematic review not only offered directions for designing the intervention, but it also made a contribution to the evidence base around the information needs of patients with a recent diagnosis of CRC. This is the first review to investigate this group of patients at the early stages of the cancer care continuum.

Treatment-related aspects were the most prominent type of information across the included studies. Patients with CRC can utilise a variety of resources to obtain information, with healthcare professionals being the most trusted and preferred source across studies. The review also identified a number of pitfalls in the provision of information support to patients with CRC; these concerned the lack of written information and issues in patient/provider communication.

The systematic review offered key insights that can be utilised by health professionals in order to optimise the provision of information support to patients with a first-time

diagnosis of CRC. This includes the information priorities (i.e., which types of information appear mostly in the literature), as well as the necessity of assessing individual needs in order to offer tailored advice.

- Competitive analysis (Chapter 3)

This was the first review of commercially available health apps for patients with CRC, which informed the development process of Manage your Health and offered insight to the quality of these interventions. The competitive analysis revealed several quality-related issues associated with the content of publicly available apps for CRC (e.g., absence of references and adherence to evidence-based practice). The poor quality of content in commercially available mHealth interventions is a common concern (Charbonneau et al., 2020), and the present project demonstrated that health apps in the field of CRC care are not free of such issues. This has implications in both a practice and policy level. Healthcare professionals, including pharmacists can help raise awareness regarding the risks of these apps, while health organisations and policymakers can draw upon these findings to call for more robust regulatory frameworks surrounding the content of these apps to ensure that patients with CRC receive high-quality advice for interventions with an evidence-based content.

10.2. Strengths of the project

The work undertaken in this project offers insight into the under-researched area of using embodied VAs to support patients with cancer. While the use of ECAs is abundant in healthcare (El Kamali et al., 2020; ter Stal et al., 2020a), their use in cancer care still remains scarce. The present study investigated the role of familiarity in embodied VAs,

another area that hasn't received much research interest. A particular strength is that unlike previous studies on the role of familiarity, the present project utilised a qualitative approach and performed formal analysis of the findings, thereby providing an in-depth understanding of users' preferences and perspectives. This study was also the first to perform qualitative comparisons between patients who had their clinicians as VAs through the app and users who didn't, thus offering insight as to similarities and differences between these groups.

The use of mixed methods was particularly beneficial for addressing the research objectives. A combination of usage parameters (e.g., number of logins, intensity of use, number of taps etc.) provided an overview of how the app was used over the study period, while questionnaires helped to quantify patients' information needs, the degree of the app's usability and patients' satisfaction with information. Qualitative data from the in-depth interviews helped to conceptualise the quantitative findings, explain controversies and most importantly, obtain exploratory views that not only increased the understanding around the effects of the intervention, but also suggested key aspects for improvement and further investigation.

Testing the intervention in a real setting was perhaps the most prominent strength of this project. While some studies (Dixon and Michaud, 2018; Reade et al., 2017) excluded users that did not engage with the intervention in a pre-defined manner, this project allowed patients to use the app as they saw fit. During the consent process, all study participants were explicitly told that there was no right or wrong way of using the app but instead, they could use it in their own discretion. Hence, instead of attempting to control the environment in which patients used the app or test it within a specific

setting (i.e., laboratory testing), this study offered insight as to how such interventions can be utilised in a real-world situation, away from the influence of the researcher.

10.3. Limitations of the project

Despite the strengths of the project, there were also several limitations. While efforts were made in order to address the issue of recruitment (i.e., the creation of two additional information packages), identifying eligible patients remained a challenge. Although widening the patient net by creating a generic app (e.g., an app for general symptom management) was considered, this was dismissed as it would eliminate the treatment-specific character of the app, which appealed to patients.

Another limitation is that the study concentrated upon the first cycle of chemotherapy. A study that expanded over a larger period of time, such as the whole treatment could potentially allow for better understanding how the app would be used over patients' therapeutic journey, thereby adding further insight as to changes in patients' information needs, as well as their relationships with the VAs.

Apart from the limitations arising from the study design, there were certain drawbacks that were innate to study techniques. These were discussed in 9.6 (Reflexivity).

The COVID-19 outbreak of 2020 also imposed considerable limitations. The first was the restricted access to the research site. Although this did not affect recruitment, it forced the researcher to conduct more asynchronous interviews (in terms of location). The pandemic also added great pressure on the NHS staff, which severely limited the clinicians' availability; as a result, some clinicians were not able to take part in the

interviews. Nevertheless, the final sample of clinicians included professionals from nursing, medicine and pharmacy so that each discipline had some representation.

10.4. Directions for future work

Alongside with its contributions, this project also highlighted several areas in which further research can be conducted. First, the systematic review indicated the need for more studies focusing upon the dimension of information support, as most papers investigated this within the general supportive framework and did not perform a detailed assessment of patients' information needs. Qualitative studies would be of particular value in this regard, as they can allow for addressing multiple aspects of information support (e.g., desired types of information, volume of information etc.) and obtain in-depth perspectives.

Findings from the main study suggested several promising areas for future work. The first would be to explore the use of hyper-realistic humanoid avatars with patients in cancer care. The majority of patients in this study regarded the VAs as cartoon figures, as they were not photo-realistic representations of the healthcare professionals they portrayed; the patients recommended that making the VAs more human-like would likely improve their user experience. A future study could use cutting-edge graphics in order to produce highly realistic VAs and perform testing in order to establish the acceptability this approach.

Another area for future exploration would be the effects of familiar and unfamiliar VAs upon users. The interview data revealed that differences are evident and that patients generally opted for having their clinicians on the app, but the project did not examine

the effects of familiarity on aspects such as intention to use or user satisfaction. A future study could test this with a larger patient sample and attempt to such explore relationships to offer further insight in that matter.

Some patients did not perceive the VAs as interactive due to restrictions in user input (e.g., patients could only choose between pre-set questions). The use of embodied VAs with natural language processing is gaining momentum in healthcare (Laranjo et al., 2018; Milne-Ives et al., 2020), but their application in oncology remains scarce. El Kamali et al. (2020) argued that since language is the cornerstone of building human relationships, the use of unrestrictive user input and language understanding in VAs can potentially increase their capacity as companions for older individuals. This would be a promising area for future exploration in cancer care. It is important to note that such studies will have to expand over long periods in order to observe how this virtual relationship unfolds with time.

10.5. Concluding remarks

The present project used a mixed method approach to evaluate a novel health app that used highly realistic, embodied VAs in the field of oncology care. Unlike previous research, the VAs used in this study represented clinicians that were known to the users. The findings of this study demonstrated that this was an acceptable approach for supporting the information needs of patients with CRC during their first cycle of chemotherapy. This project made a series of original contributions to the fields of mHealth and VA research and revealed a number of potential research areas for future studies.

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Appendices

Appendix 1: Systematic review search strategy

Cochrane Library		
Search terms		**Hits**
1	MeSH descriptor: [Consumer Health Information] explode all trees	472
2	educat* near/4 (require* or attitude* or priorit* or need* or seek* or demand* or desire* or support*):ti,ab,kw	5725
3	learn* near/4 (require* or attitude* or priorit* or need* or seek* or demand* or desire* or support*):ti,ab,kw	1485
4	advise near/4 (require* or attitude* or priorit* or need* or seek* or demand* or desire* or support*):ti,ab,kw	44
5	advice near/4 (require* or attitude* or priorit* or need* or seek* or demand* or desire* or support*):ti,ab,kw	764
6	literacy near/4 (require* or attitude* or priorit* or need* or seek* or demand* or desire*):ti,ab,kw	145
7	counseling near/4 (require* or attitude* or priorit* or need* or seek* or demand* or desire*):ti,ab,kw	1136
8	counselling near/4 (require* or attitude* or priorit* or need* or seek* or demand* or desire*):ti,ab,kw	1136
9	info* near/4 (require* or attitude* or priorit* or need* or seek* or demand* or desire* or support*):ti,ab,kw	6436
10	knowledge* near/4 (require* or attitude* or priorit* or need* or seek* or demand* or desire* or support*):ti,ab,kw	8955
11	#1 or #2 or #3 or #4 or #5 or #6 or #7 or #8 or #9 or #10	22908
12	MeSH descriptor: [Colorectal Neoplasms] explode all trees	7912
13	colorectal near/4 (neoplas* or cancer* or tumour* or tumor* or carcinoma*):ti,ab,kw	14571
14	colon* near/4 (neoplas* or cancer* or tumour* or tumor* or carcinoma*):ti,ab,kw	6108
15	Bowel* near/4 (neoplas* or cancer* or tumour* or tumor* or carcinoma*):ti,ab,kw	654
16	rectal near/4 (neoplas* or cancer* or tumour* or tumor* or carcinoma*):ti,ab,kw	3933
17	rectum near/4 (neoplas* or cancer* or tumour* or tumor* or carcinoma*):ti,ab,kw	1990
18	anal near/4 (neoplas* or cancer* or tumour* or tumor* or carcinoma*):ti,ab,kw	443
19	sigmoid* near/4 (neoplas* or cancer* or tumour* or tumor* or carcinoma*):ti,ab,kw	274
20	#12 or #13 or #14 or #15 or #16 or #17 or #18 or #19	21201
21	11 and 20	**406**
Notes: None.		

Web of science

Search terms		Hits
1	ts=(learn* near/4 (require* or attitude* or priorit* or need* or seek* or demand* or desire* or support*))	45391
2	ts=(educat* near/4 (require* or attitude* or priorit* or need* or seek* or demand* or desire* or support*))	63530
3	ts=(advice near/4 (require* or attitude* or priorit* or need* or seek* or demand* or desire* or support*))	5899
4	ts=(advise near/4 (require* or attitude* or priorit* or need* or seek* or demand* or desire* or support*))	1116
5	ts=(literacy near/4 (require* or attitude* or priorit* or need* or seek* or demand* or desire*))	2474
6	ts=(counseling near/4 (require* or attitude* or priorit* or need* or seek* or demand* or desire*))	5752
7	ts=(counselling near/4 (require* or attitude* or priorit* or need* or seek* or demand* or desire*))	5752
8	ts=(info* near/4 (require* or attitude* or priorit* or need* or seek* or demand* or desire* or support*))	138011
9	ts=(knowledge* near/4 (require* or attitude* or priorit* or need* or seek* or demand* or desire* or support*))	85640
10	#1 or #2 or #3 or #4 or #5 or #6 or #7 or #8 or #9	325389
11	ts=(colorectal near/4 (cancer* or malignan* or tumor* or tumour* or growth or neoplasm* or carcinoma*))	194165
12	ts=(colon* near/4 (cancer* or malignan* or tumor* or tumour* or growth or neoplasm* or carcinoma*))	132685
13	ts=(rectal near/4 (cancer* or malignan* or tumor* or tumour* or growth or neoplasm* or carcinoma*))	36447
14	ts=(rectum near/4 (cancer* or malignan* or tumor* or tumour* or growth or neoplasm* or carcinoma*))	5257
15	ts=(bowel* near/4 (cancer* or malignan* or tumor* or tumour* or growth or neoplasm* or carcinoma*))	10177
16	ts=(anal near/4 (cancer* or malignan* or tumor* or tumour* or growth or neoplasm* or carcinoma*))	5912
17	ts=(sigmoid* near/4 (cancer* or malignan* or tumor* or tumour* or growth or neoplasm* or carcinoma*))	2416
18	#11 or #12 or #13 or #14 or #15 or #16 or #17	314397
19	#10 AND #18	1897
Notes: All searches were performed under “advanced search”. All years were included. The search was limited to the Science Citation Index Expanded (SCI-EXPANDED)—1970-present and Social 38Sciences Citation Index (SSCI)—1970-present.		

ASSIA

Search terms		Hits
1	(colorectal* or colon* or rect* or bowel* or anal) near/4 (cancer* or malignan* or tumor or tumour or growth or neoplasm* or carcinoma*)	5439
2	SU.EXACT.EXPLODE("Colorectal cancer")	1480
3	((colorectal* or colon* or rect* or bowel* or anal) near/4 (cancer* or malignan* or tumor or tumour or growth or neoplasm* or carcinoma*)) OR SU.EXACT.EXPLODE("Colorectal cancer")	5439

4	(educat* or learn* or advice or advise or literacy or counseling or counselling or inform* or knowledge) near/4 (require* or attitude* or priorit* or need* or seek* or demand* or desire* or support*)	121947
5	SU.EXACT.EXPLODE("Health information")	3341
6	((educat* or learn* or advice or advise or literacy or counseling or counselling or inform* or knowledge) near/4 (require* or attitude* or priorit* or need* or seek* or demand* or desire* or support*)) OR SU.EXACT.EXPLODE("Health information")	124214
7	(((colorectal* or colon* or rect* or bowel* or anal) near/4 (cancer* or malignan* or tumor or tumour or growth or neoplasm* or carcinoma*)) OR SU.EXACT.EXPLODE("Colorectal cancer")) AND (((educat* or learn* or advice or advise or literacy or counseling or counselling or inform* or knowledge) near/4 (require* or attitude* or priorit* or need* or seek* or demand* or desire* or support*)) OR SU.EXACT.EXPLODE("Health information"))	1863
Note: This search terms are used in this way because a previous attempt revealed technical issues. No explode terms were identified. Duplicates are automatically removed in ASSIA. When used SU.EXACT.EXPLODE("Colorectal Cancer") and combined it with search 1, I obtained the same number of results (indicating that search 1 identified all studies under the explode term).		

EMBASE (HDAS)		
Search terms		Hits
1	educat* ADJ4 (require* or attitude* or priorit* or need* or seek* or demand* or desire* or support*).ti,ab,au	70816
2	learn* ADJ4 (require* or attitude* or priorit* or need* or seek* or demand* or desire* or support*).ti,ab,au	27516
3	advice ADJ4 (require* or attitude* or priorit* or need* or seek* or demand* or desire* or support*).ti,ab,au	8720
4	advise ADJ4 (require* or attitude* or priorit* or need* or seek* or demand* or desire* or support*).ti,ab,au	541
5	literacy ADJ4 (require* or attitude* or priorit* or need* or seek* or demand* or desire*).ti,ab,au	1547
6	counseling ADJ4 (require* or attitude* or priorit* or need* or seek* or demand* or desire*).ti,ab,au	4722
7	counselling ADJ4 (require* or attitude* or priorit* or need* or seek* or demand* or desire*).ti,ab,au	2459
8	info* ADJ4 (require* or attitude* or priorit* or need* or seek* or demand* or desire* or support*).ti,ab,au	102855
9	knowledge* ADJ4 (require* or attitude* or priorit* or need* or seek* or demand* or desire* or support*).ti,ab,au	72039
10	exp "CONSUMER HEALTH INFORMATION"/	3782
11	1 or 2 or 3 or 4 or 5 or 6 or 7 or 8 or 9 or 10	237741
12	colorectal ADJ4 (cancer* or malignan* or tumor* or tumour* or growth or neoplasm* or carcinoma*).ti,ab,au	181892
13	colon* ADJ4 (cancer* or malignan* or tumor* or tumour* or growth or neoplasm* or carcinoma*).ti,ab,au	134059
14	rectal ADJ4 (cancer* or malignan* or tumor* or tumour* or growth or neoplasm* or carcinoma*).ti,ab,au	45723

15	rectum ADJ4 (cancer* or malignan* or tumor* or tumour* or growth or neoplasm* or carcinoma*).ti,ab,au	8071
16	Bowel* ADJ4 (cancer* or malignan* or tumor* or tumour* or growth or neoplasm* or carcinoma*).ti,ab,au	13805
17	anal ADJ4 (cancer* or malignan* or tumor* or tumour* or growth or neoplasm* or carcinoma*).ti,ab,au	8303
18	sigmoid* ADJ4 (cancer* or malignan* or tumor* or tumour* or growth or neoplasm* or carcinoma*).ti,ab,au	4094
19	Exp "COLORECTAL TUMOR"/	28624
20	12 or 13 or 14 or 15 or 16 or 17 or 18 or 19	340085
21	11 and 20	2345
Note: "Colorectal Neoplasms" did not appear in thesaurus; "colorectal tumor" was used instead.		

Ovid		
Search terms		Hits
1	(educat* adj4 (require* or attitude* or priorit* or need* or seek* or demand* or desire* or support*)).mp. [mp=title, abstract, original title, name of substance word, subject heading word, keyword heading word, protocol supplementary concept word, rare disease supplementary concept word, unique identifier, synonyms]	51004
2	(learn* adj4 (require* or attitude* or priorit* or need* or seek* or demand* or desire* or support*)).mp. [mp=title, abstract, original title, name of substance word, subject heading word, keyword heading word, protocol supplementary concept word, rare disease supplementary concept word, unique identifier, synonyms]	21325
3	(advi#e adj4 (require* or attitude* or priorit* or need* or seek* or demand* or desire* or support*)).mp. [mp=title, abstract, original title, name of substance word, subject heading word, keyword heading word, protocol supplementary concept word, rare disease supplementary concept word, unique identifier, synonyms]	6165
4	(literacy adj4 (require* or attitude* or priorit* or need* or seek* or demand* or desire*)).mp. [mp=title, abstract, original title, name of substance word, subject heading word, keyword heading word, protocol supplementary concept word, rare disease supplementary concept word, unique identifier, synonyms]	1289
5	(counsel?ing adj4 (require* or attitude* or priorit* or need* or seek* or demand* or desire*)).mp. [mp=title, abstract, original title, name of substance word, subject heading word, keyword heading word, protocol supplementary concept word, rare disease supplementary concept word, unique identifier, synonyms]	5068
6	(info* adj4 (require* or attitude* or priorit* or need* or seek* or demand* or desire* or support*)).mp. [mp=title, abstract, original title, name of substance word, subject heading word, keyword heading word, protocol supplementary concept word, rare disease supplementary concept word, unique identifier, synonyms]	79929
7	(knowledge* adj4 (require* or attitude* or priorit* or need* or seek* or demand* or desire* or support*)).mp. [mp=title, abstract, original title, name of substance word, subject heading word, keyword heading word, protocol	150154

	supplementary concept word, rare disease supplementary concept word, unique identifier, synonyms]	
8	exp consumer health information/	9000
9	1 or 2 or 3 or 4 or 5 or 6 or 7 or 8	297431
10	(colorectal adj4 (cancer* or malignan* or tumo?r or growth or neoplasm* or carcinoma*)).mp. [mp=title, abstract, original title, name of substance word, subject heading word, keyword heading word, protocol supplementary concept word, rare disease supplementary concept word, unique identifier, synonyms]	139189
11	(colon* adj4 (cancer* or malignan* or tumo?r or growth or neoplasm* or carcinoma*)).mp. [mp=title, abstract, original title, name of substance word, subject heading word, keyword heading word, protocol supplementary concept word, rare disease supplementary concept word, unique identifier, synonyms]	127704
12	(rectal adj4 (cancer* or malignan* or tumo?r or growth or neoplasm* or carcinoma*)).mp. [mp=title, abstract, original title, name of substance word, subject heading word, keyword heading word, protocol supplementary concept word, rare disease supplementary concept word, unique identifier, synonyms]	51469
13	(rectum adj4 (cancer* or malignan* or tumo?r or growth or neoplasm* or carcinoma*)).mp. [mp=title, abstract, original title, name of substance word, subject heading word, keyword heading word, protocol supplementary concept word, rare disease supplementary concept word, unique identifier, synonyms]	7801
14	(bowel adj4 (cancer* or malignan* or tumo?r or growth or neoplasm* or carcinoma*)).mp. [mp=title, abstract, original title, name of substance word, subject heading word, keyword heading word, protocol supplementary concept word, rare disease supplementary concept word, unique identifier, synonyms]	8142
15	(anal adj4 (cancer* or malignan* or tumo?r or growth or neoplasm* or carcinoma*)).mp. [mp=title, abstract, original title, name of substance word, subject heading word, keyword heading word, protocol supplementary concept word, rare disease supplementary concept word, unique identifier, synonyms]	5332
16	(sigmoid* adj4 (cancer* or malignan* or tumo?r or growth or neoplasm* or carcinoma*)).mp. [mp=title, abstract, original title, name of substance word, subject heading word, keyword heading word, protocol supplementary concept word, rare disease supplementary concept word, unique identifier, synonyms]	6373
17	exp colorectal neoplasms/	198364
18	10 or 11 or 12 or 13 or 14 or 15 or 16 or 17	283994
19	9 and 18	2624
Notes: The option "Ovid MEDLINE(R) Epub Ahead of Print, In-Process & Other Non-Indexed Citations, Ovid MEDLINE(R) Daily and Ovid MEDLINE(R) 1946 to Present" was selected.		

EBSCO AMED		
Search terms		Hits
1	educat* N4 (require* or attitude* or priorit* or need* or seek* or demand* or desire* or support*)	2000

2	learn* N4 (require* or attitude* or priorit* or need* or seek* or demand* or desire* or support*)	742
3	advi?e N4 (require* or attitude* or priorit* or need* or seek* or demand* or desire* or support*)	169
4	literacy N4 (require* or attitude* or priorit* or need* or seek* or demand* or desire*)	28
5	counsel#ing N4 (require* or attitude* or priorit* or need* or seek* or demand* or desire*)	136
6	info* N4 (require* or attitude* or priorit* or need* or seek* or demand* or desire* or support*)	1718
7	knowledge* N4 (require* or attitude* or priorit* or need* or seek* or demand* or desire* or support*)	1476
8	DE "patient satisfaction"	2327
9	1 or 2 or 3 or 4 or 5 or 6 or 7 or 8	7956
10	colorectal N4 (cancer* or malignan* or tumo#r or growth or neoplasm* or carcinoma*)	507
11	colon* N4 (cancer* or malignan* or tumo#r or growth or neoplasm* or carcinoma*)	533
12	rectal N4 (cancer* or malignan* or tumo#r or growth or neoplasm* or carcinoma*)	89
13	rectum N4 (cancer* or malignan* or tumo#r or growth or neoplasm* or carcinoma*)	17
14	Bowel* N4 (cancer* or malignan* or tumo#r or growth or neoplasm* or carcinoma*)	79
15	anal N4 (cancer* or malignan* or tumo#r or growth or neoplasm* or carcinoma*)	10
16	sigmoid* N4 (cancer* or malignan* or tumo#r or growth or neoplasm* or carcinoma*)	6
17	DE "colorectal neoplasms"	356
18	10 or 11 or 12 or 13 or 14 or 15 or 16 or 17	1048
19	9 and 18	19
Notes: The terms "consumer health information" did not provide any relevant terms apart from "Patient satisfaction", which was included in the search.		

EBSCO CINAHL		
Search terms		Hits
1	educat* N4 (require* or attitude* or priorit* or need* or seek* or demand* or desire* or support*)	46744
2	learn* N4 (require* or attitude* or priorit* or need* or seek* or demand* or desire* or support*)	16412
3	advi?e N4 (require* or attitude* or priorit* or need* or seek* or demand* or desire* or support*)	4464
4	literacy N4 (require* or attitude* or priorit* or need* or seek* or demand* or desire*)	1309
5	counsel#ing N4 (require* or attitude* or priorit* or need* or seek* or demand* or desire*)	3328
6	info* N4 (require* or attitude* or priorit* or need* or seek* or demand* or desire* or support*)	58246
7	knowledge* N4 (require* or attitude* or priorit* or need* or seek* or	33190

	demand* or desire* or support*)	
8	(MH "Consumer Health Information+")	16944
9	1 or 2 or 3 or 4 or 5 or 6 or 7 or 8	161469
10	colorectal N4 (cancer* or malignan* or tumo#r or growth or neoplasm* or carcinoma*)	34293
11	colon* N4 (cancer* or malignan* or tumo#r or growth or neoplasm* or carcinoma*)	16578
12	rectal N4 (cancer* or malignan* or tumo#r or growth or neoplasm* or carcinoma*)	7342
13	rectum N4 (cancer* or malignan* or tumo#r or growth or neoplasm* or carcinoma*)	662
14	bowel N4 (cancer* or malignan* or tumo#r or growth or neoplasm* or carcinoma*)	2224
15	anal N4 (cancer* or malignan* or tumo#r or growth or neoplasm* or carcinoma*)	1466
16	sigmoid* N4 (cancer* or malignan* or tumo#r or growth or neoplasm* or carcinoma*)	600
17	(MH "Colorectal Neoplasms+")	41287
18	10 or 11 or 12 or 13 or 14 or 15 or 16 or 17	53719
19	9 and 18	1032
Notes: None.		

EBSCO ERIC		
Search terms		Hits
1	educat* N4 (require* or attitude* or priorit* or need* or seek* or demand* or desire*)	89226
2	learn* N4 (require* or attitude* or priorit* or need* or seek* or demand* or desire*)	32633
3	advi?e N4 (require* or attitude* or priorit* or need* or seek* or demand* or desire*)	695
4	literacy N4 (require* or attitude* or priorit* or need* or seek* or demand* or desire*)	4328
5	counsel#ing N4 (require* or attitude* or priorit* or need* or seek* or demand* or desire*)	2659
6	info* N4 (require* or attitude* or priorit* or need* or seek* or demand* or desire*)	28859
7	knowledge* N4 (require* or attitude* or priorit* or need* or seek* or demand* or desire*)	15832
8	(DE "health promotion")	8038
9	1 or 2 or 3 or 4 or 5 or 6 or 7 or 8	164816
10	colorectal N4 (cancer* or malignan* or tumo#r or growth or neoplasm* or carcinoma*)	77
11	colon* N4 (cancer* or malignan* or tumo#r or growth or neoplasm* or carcinoma*)	63
12	rectal N4 (cancer* or malignan* or tumo#r or growth or neoplasm* or carcinoma*)	5
13	rectum N4 (cancer* or malignan* or tumo#r or growth or neoplasm* or carcinoma*)	3

14	Bowel* N4 (cancer* or malignan* or tumo#r or growth or neoplasm* or carcinoma*)	3
15	anal N4 (cancer* or malignan* or tumo#r or growth or neoplasm* or carcinoma*)	4
16	sigmoid* N4 (cancer* or malignan* or tumo#r or growth or neoplasm* or carcinoma*)	5
17	("10 or 11 or 12 or 13 or 14 or 15 or 16")	140
18	9 and 17	38
Notes: No thesaurus terms for colorectal cancer (had generic for cancer or colorectal diseases, which were not relevant to our search). The term "neoplasms" did not include colorectal) colon or rectal) neoplasms. The terms "consumer health information" did not provide any relevant terms apart from "Health Promotion", which was included in the search.		

EBSCO PsycInfo		
Search terms		Hits
1	educat* N4 (require* or attitude* or priorit* or need* or seek* or demand* or desire* or support*)	53975
2	learn* N4 (require* or attitude* or priorit* or need* or seek* or demand* or desire* or support*)	42025
3	advi?e N4 (require* or attitude* or priorit* or need* or seek* or demand* or desire* or support*)	2933
4	literacy N4 (require* or attitude* or priorit* or need* or seek* or demand* or desire*)	2278
5	counsel#ing N4 (require* or attitude* or priorit* or need* or seek* or demand* or desire*)	6561
6	info* N4 (require* or attitude* or priorit* or need* or seek* or demand* or desire* or support*)	50371
7	knowledge* N4 (require* or attitude* or priorit* or need* or seek* or demand* or desire* or support*)	56014
8	DE "Health Promotion"	32848
9	1 or 2 or 3 or 4 or 5 or 6 or 7 or 8	222220
10	colorectal N4 (cancer* or malignan* or tumo#r or growth or neoplasm* or carcinoma*)	3002
11	colon* N4 (cancer* or malignan* or tumo#r or growth or neoplasm* or carcinoma*)	1204
12	rectal N4 (cancer* or malignan* or tumo#r or growth or neoplasm* or carcinoma*)	249
13	rectum N4 (cancer* or malignan* or tumo#r or growth or neoplasm* or carcinoma*)	49
14	bowel N4 (cancer* or malignan* or tumo#r or growth or neoplasm* or carcinoma*)	195
15	anal N4 (cancer* or malignan* or tumo#r or growth or neoplasm* or carcinoma*)	125
16	sigmoid* N4 (cancer* or malignan* or tumo#r or growth or neoplasm* or carcinoma*)	43
17	10 or 11 or 12 or 13 or 14 or 15 or 16	4251

18	9 and 17	800
Notes: No thesaurus terms for colorectal cancer (had generic for cancer or colorectal diseases, which were not relevant to our search). The terms “consumer health information” did not provide any relevant terms apart from “Health Promotion”, which was included in the search.		

Appendix 2: Quality assessment of included studies

Study design		Qualitative				Quantitative												Mixed methods			Score	
		RCTs								Quantitative non-RCT				Descriptive studies								
MMAT Criterion		1.1	1.2	1.3	1.4	2.1	2.2	2.3	2.4	3.1	3.2	3.3	3.4	4.1	4.2	4.3	4.4	5.1	5.2	5.3		
Authors	Bailey (2001)	Y	Y	Y	N																75% or ***	Y=Yes, N=No, CT= Cannot tell
	Bain and Campbell (2000)	Y	Y	Y	Y																100% or ****	
	Bain et al. (2002)	Y	Y	Y	N																75% or ***	
	Bell et al. (2009)	Y	Y	Y	Y																100% or ****	
	Boe et al. (2018)	Y	Y	Y	Y																100% or ****	
	Broughton, Bailey and Linney (2004)	Y	Y	N	N																50% or **	
	Comb et al. (2003)	Y	Y	N	N																50% or **	
	Houldin (2007)	Y	Y	N	N																50% or **	
	Houldin and Lewis (2006)	Y	Y	Y	N																75% or ***	
	Kidd et al. (2008)	Y	Y	Y	Y																100% or ****	
	Lithner et al. (2015a)	Y	Y	CT	N																75% or ***	
	Poland et al. (2017)	Y	Y	Y	Y																100% or ****	
	Reinwalds et al. (2017)	Y	Y	N	N																50% or **	
	Sanders and Skevington (2003)	Y	Y	N	N																50% or **	
	Sanders and Skevington (2004)	Y	Y	N	N																50% or **	
	Sawyer et al. (2008)	Y	Y	N	N																50% or **	
	Spalding et al. (2013)	Y	Y	Y	N																75% or ***	
	Scheer et al. (2012)	Y	Y	Y	N																75% or ***	
	Taylor and Norton (2000)	Y	Y	Y	Y																75% or ***	
	Taylor et al. (2001)	Y	Y	Y	Y																100% or ****	
	Worster and Holmes (2008)	Y	Y	Y	Y																100% or ****	
	Worster and Holmes (2009)	Y	Y	Y	Y																75% or ***	
	Dronkers et al. (2010)					Y	Y	Y	Y												100% or ****	
	White et al. (2012)					Y	N	Y	Y												75% or ***	
	Bronner et al. (2018)									CT	Y	Y	Y								75% or ***	
	Dobrila-Dintinjana, Krznarić and Guina (2008)									CT	Y	CT	CT								25% or *	
	Harisson et al. (2010)									CT	Y	Y	Y								75% or ***	
	Lithner et al. (2012)									N	Y	Y	Y								50% or **	
	Lithner et al. (2015b)									N	Y	Y	Y								100% or ****	
	Young et al. (2010)									N	Y	Y	Y								75% or ***	
	Cha et al. (2012)													N	CT	N	Y				25% or *	
	Cuthbert et al. (2019)													N	CT	N	Y				25% or *	
	Reeve et al. (2017)													N	CT	Y	N				25% or *	
	Sierko, Werpachowska and Wojtukiewicz (2011)													N	CT	N	Y				25% or *	
	Zafar et al. (2013)													N	CT	Y	CT				25% or *	
	Knowles et al. (1999)	Y	Y	Y	Y									Y	N	Y	Y	Y	Y	N	50% or **	
	Weaver et al. (2007)	Y	Y	N	N									N	N	Y	Y	Y	Y	N	25% or *	

MMAT Assessment Criteria (Pluye et al., 2011, p.2)

"*1.1. Are the sources of qualitative data (archives, documents, informants, observations) relevant to address the research question (objective)?*
1.2. Is the process for analysing qualitative data relevant to address the research question (objective)?
1.3. Is appropriate consideration given to how findings relate to the context, e.g., the setting, in which the data were collected?
1.4. Is appropriate consideration given to how findings relate to researchers' influence, e.g., through their interactions with participants?
2.1. Is there a clear description of the randomization (or an appropriate sequence generation)?
2.2. Is there a clear description of the allocation concealment (or blinding when applicable)?
2.3. Are there complete outcome data (80% or above)?
2.4. Is there low withdrawal/drop-out (below 20%)?
3.1. Are participants (organizations) recruited in a way that minimizes selection bias?
3.2. Are measurements appropriate (clear origin, or validity known, or standard instrument; and absence of contamination between groups when appropriate) regarding the exposure/intervention and outcomes?
3.3. In the groups being compared (exposed vs. non-exposed; with intervention vs. without; cases vs. controls), are the participants comparable, or do researchers take into account (control for) the difference between these groups?
3.4. Are there complete outcome data (80% or above), and, when applicable, an acceptable response rate (60% or above), or an acceptable follow-up rate for cohort studies (depending on the duration of follow-up)?
4.1. Is the sampling strategy relevant to address the quantitative research question (quantitative aspect of the mixed methods question)?
4.2. Is the sample representative of the population understudy?
4.3. Are measurements appropriate (clear origin, or validity known, or standard instrument)?
4.4. Is there an acceptable response rate (60% or above)?
5.1. Is the mixed methods research design relevant to address the qualitative and quantitative research questions (or objectives), or the qualitative and quantitative aspects of the mixed methods question (or objective)?
5.2. Is the integration of qualitative and quantitative data (or results) relevant to address the research question (objective)?*
5.3. Is appropriate consideration given to the limitations associated with this integration, e.g., the divergence of qualitative and quantitative data (or results) in a triangulation design?*"

Appendix 3: Semi-structured clinician interview guide

A Novel Health Information Support App for Patients with Cancer

Alexandros Ioannis Chatzixenitidis
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Semi-structured Clinician Interview Guide

IRAS project ID: 240263 **Version:** 1.0 **Date:** 20/02/2018

Introduction

- Introduce yourself (what you do, your role in the project)
- Ensure that participants feel comfortable having the interview. Thank them for their time and willingness to help you with your project.
- Obtain consent; briefly explain the purpose of the interview; state clearly that the interview will be recorded and transcribed by yourself; explain that he/she is able to pause or terminate the interview whenever deemed fit; if the participant is comfortable to proceed, ask them to sign the document (one copy for the study and one copy for them); begin the interview.

Patients' experiences from using the app

- Please tell me about patients' experiences from using the app.

- Did patients or patients' carers from this study mention using the app to you?

  How often did that happen?
  Was it patients or carers who mentioned it mostly and why?
  Who would you say used it mostly, patients or their carers? Why?
  What were there comments from using the app? Positive, negative or a mix of both?
  Was there a function or section that they liked or disliked in particular? Which one? Why do you think this happened?
  Can you recall any positive or negative feedback? Please tell me more.

- Throughout the study, did you mention the app to your patients and asked about their experiences?

  How often did that happen?
  Was it patients or carers who used it mostly? Why?
  What were there comments from using the app? Positive, negative or a mix of both?
  Was there a function or section that they liked or disliked in particular? Which one? Why do you think this happened?
  Can you recall any positive or negative feedback? Please tell me more.
  Do you think prompting or encouraging patients and carers to use the app made a difference? Why?

- Is there anything else that you would like to raise at this point?

Patient's knowledge

- How would you say the app influenced patients' and carers' knowledge about cancer and its treatment?

- Did you observe any improvement with respect to patients' and carers' knowledge? If yes, what makes you say that?
- Do you think that the app might confused patients and carers? If yes, what makes you say that?

- How would you compare the knowledge of patients who did and patients who didn't have the app (i.e. patients who declined participation or previous patients of yours)?

- Is there anything else that you would like to raise at this point?

Consultations

- Was there a difference in terms of overall consultation time between patients who had the app and those who didn't? If yes, why? If no, why?

- Do you think that the app played a role in this phenomenon? Why?

Personal views on the app/recommendations

- What do you think could be done differently?

- Should more features be added to the app? If yes, which ones? Why?

- Which sections should be modified or deleted from the app? Why?

- Is there anything else that you would like to raise at this point?

Conclusion

Thank the participant for his/her time and help; briefly mention how has his/her views will help your research.

Appendix 4: Consent form for the study

Developing and Testing an Avatar-Based Health Information Support App for Patients with Colorectal Cancer Receiving Chemotherapy for the First Time; A Mixed Methods Study

IRAS ID: 240263

CONSENT FORM for using the Avatar- Based App

Name of Researcher: Alexandros Ioannis Chatzixenitidis

I confirm that I have read the information sheet dated..... (version.....) for the above study and I understand what will happen with my data.	☐
I have had the opportunity to consider the information, ask questions and have had these answered satisfactorily.	☐
I understand that my participation is voluntary and that I am free to withdraw at any time without giving any reason, without my medical care or legal rights being affected.	☐
I understand that the information collected about me might be used to support other research in the future and may be shared anonymously with other researchers.	☐
I understand that relevant sections of my medical notes and data collected during the study may be looked at by authorized individuals from the regulatory authorities or the Sponsor, where it is relevant to my taking part in this research. I give permission for these individuals to have access to my records.	☐
I agree to be contacted to be invited to an interview by the researcher.	☐
I agree to take part in the above study.	☐

Name of the participant:
Date of birth:
Contact number:
Assigned username:

Participant signature:

_____ Date:

Researcher signature:

_____ Date:

Contact Information

IRAS project ID: 240263 **Version:** 3.0 **Date:** 04/05/2018

If you have any further questions or concerns about this study, please contact:
Name of researcher: Alexandros Ioannis Chatzixenitidis
Tel: 07930587130
E-mail: a.chatzixenitidis@keele.ac.uk

What if I have concerns about this research?

If you are worried about this research, or if you are concerned about how it is being conducted, you can contact the Patient Advice and Liaison Services (PALS) via telephone (01865 235855) or email (PLAS@ouh.nhs.uk).

Appendix 5: Invitation letter

Developing and Testing an Avatar-Based Health Information Support App for Patients with Colorectal Cancer Receiving Chemotherapy for the First Time; A Mixed Methods Study

Letter of Invitation

Dear Sir or Madam,

We would like to invite you to take part in our research study. Our project involves developing and testing a new type of health information support app for patients who take XELOX for bowel cancer.

Members of our research team, who are also part of your care team have identified patients who take XELOX and will approach them to present and discuss the study. The identification has been done **exclusively** by clinicians who are responsible for you; any treatment details or information are kept **strictly confidential** and will not be shared with anyone outside your care team.

Joining the study is **entirely up to you**, before you decide we would like you to understand why the research is being done and what it would involve for you. One of our team will go through the information booklet with you, to help you decide whether or not you would like to take part and answer any questions you may have. Please feel free to talk to others about the study if you wish.

The first part of the Participant Information Sheet tells you the purpose of the study and what will happen to you if you take part.

Then we give you more detailed information about the conduct of the study.

Please do ask if anything is unclear.

Keele UNIVERSITY

NHS Oxford University Hospitals NHS Foundation Trust

IRAS project ID: 240263 **Version:** 3.0 **Date:** 04/05/2018

Appendix 6: Participant information leaflet

Participant Information Leaflet

An Avatar-Based App for Patients with Colorectal Cancer

Contents of the leaflet

IRAS project ID: 240263 **Version:** 4.0 **Date:** 16/11/2018

Part 1: Summary of the study

1. What is the purpose of this study?

Several studies have suggested that patients with cancer are not always happy with the amount of information they receive. As a result, they may not be properly informed about the aspects of their condition and its treatment. Receiving accurate and understandable information is important, as it can help patients better understand aspects about their condition and treatment. In turn, this can help patients take proper (informed) decisions about their health, which is very important for their satisfaction with care.

This study will be testing a new way of delivering information to patients with bowel cancer. This is done in order for us to find out if this way appeals to patients and if it is effective at delivering patient information.

2. What does this study involve?

The present study aims to test a new type of information-giving app. This app can be installed to your smartphone, as well as your tablet (both iOS and Android software are supported). In this research, we will be testing a three-dimensional avatar representing a healthcare professional who will be giving you the information you want to get about your condition and the treatment you are receiving. An avatar is a graphical representation of a person (i.e. a digital version of an individual).

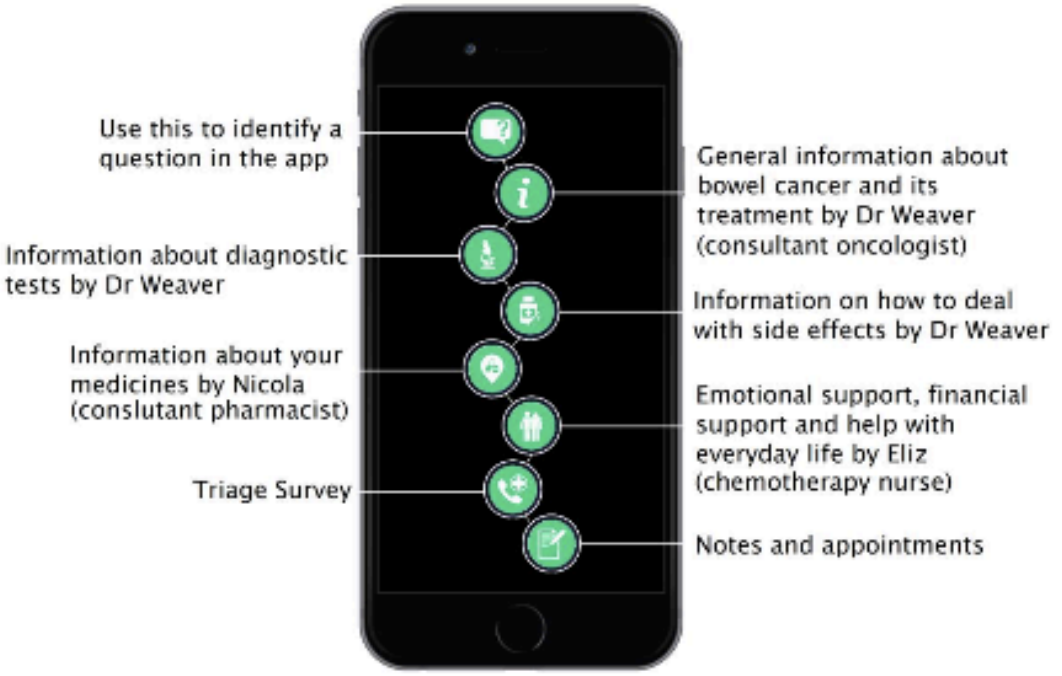
The app can be downloaded from both the Apple Store and Google play. Simply type "Manage your Health" to find it and install it in your preferred devices. You can install and access the app from more than one device, for instance both your tablet and your smartphone. The app will look like this:

Figure 1: Manage your health app

This app offers a number of information "packages", such as asthma, hypertension and diabetes. Please download the information package for COLORECTAL CANCER ONLY, as installing more could slow down the app.

This app contains eight sections. Figure 2 (Sections of the app) shows the different sections of the app at the order they appear in the app, alongside with a brief description of the content of each section.

Figure 2: Sections of the app



WARNING **PLEASE NOTE** that section 7 (Triage Survey) **DOES NOT** aim to perform a medical diagnosis. Its sole purpose is to direct you to the Triage Helpline if you have symptoms or side effects that need to be evaluated by a healthcare professional. **ALSO NOTE** that because the app is currently under development**, OUR TEAM CANNOT GUARANTEE THE ACCURACY OF THIS SECTION.** We therefore **strongly** encourage you to call the Triage Helpline if you are experiencing anything that seems irregular. The app will also remind you about this.

Our team has considered your treatment schedule and designed this study around it in order not to cause you inconvenience during your chemotherapy.

We will give you the app three weeks before your first cycle of treatment. Before you start using the app, we will ask you to complete a questionnaire that will help us understand what information you would like to get. Then, you can use the app for three weeks.

After you use the app for three weeks, you will have to visit the hospital to start your treatment. Before the first dose of treatment is given to you, we will ask you to fill in a

questionnaire exploring how easy it was to use the app and to what degree it answered your questions. After this, you will be given another two weeks to use the app further.

Two weeks after your first dose of chemotherapy, you will have to visit the hospital, so the doctors can review you to see if the treatment has worked well with you. On this day, we will invite you to attend an interview, where we would like you to reflect on your experience from using our app.

More information on how long each procedure will take is available in part 1, section 8.

3. How can I get the app?

You can download the app through the App or Android store on your phone or tablet. A member of the research team will help you with this.

If you are downloading the app from home, please visit YouTube and type "Manage your Health BC Instructions" to watch a short video with instructions on how to download the app. Alternatively, type the following link in your browser:

https://www.youtube.com/watch?v=amIzjyPGuUE

4. How might this help me and others in the future?

We are testing whether or not this app will help patients receive the information they want in an effective way. We hope that this app will:

- Help patients get their questions answered using official and validated resources thereby saving them time from searching for answers themselves
- Better prepare patients for their consultations
- Help patients save and organize any possible queries, which can help facilitate the discussions with their doctors or nurses during consultations
- Help patients receive high quality information in case they wish to find out more about their condition and its treatment
- Help patients easily share information with friends and family

If the app proves to be better at delivering information to you and other patients in the study, there is the potential to make it available to future patients.

5. What are the risks of taking part?

Due to the nature of this study (testing an app), there are no immediate risks for those who take part. Some patients might be concerned about the confidentiality of data sent through the app. Please note that the data generated through this app will be shared ONLY with the members of the research team. Furthermore, the team has taken careful steps to ensure that

the sharing of data through this app will be performed in a secure way (more information is provided in Part 1, section 8 and Part 2, section 3).

Most of the content in the app is generic and does not refer to your personal information. However, if you use the last section (treatment diary and notes) to keep notes, you will be putting personal information in the app. **As the app does not provide a password protection option, there are two potential risks if you use this section:**

- **Adding sensitive personal data in a shared device (for example, a shared tablet) means that other people using this device will be able to access your data.**

- **Adding sensitive personal data in a personal device (for example, your personal smartphone) which is not protected by a password means that other people can potentially be able to access your data should they gain access to your device (for example, if your phone is stolen)**

You are under no obligation to make notes or add personal data in the app. However, if you chose to do so, you can protect your personal data by putting several security measures in place on the device you are using the app. More information about this is provided in Part 2, section 3."

6. Who can take part?

Our study will include cancer patients with colorectal (bowel) cancer. In order to take part, you must:

- Be able to provide consent to the study
- Be 18 years or older
- Be diagnosed with colorectal cancer
- Be getting chemotherapy for the first time
- Will be able to receive chemotherapy with FOLFOX, XELOX or CAPE
- Understand English (spoken and written)
- Have a smartphone or tablet (or both) where you can install the application; if you do not possess such device, you can still take part, as long as a member of your family, a partner or a caregiver (who is willing to help you with it) has either (or both) devices.

7. Where will the study be carried out?

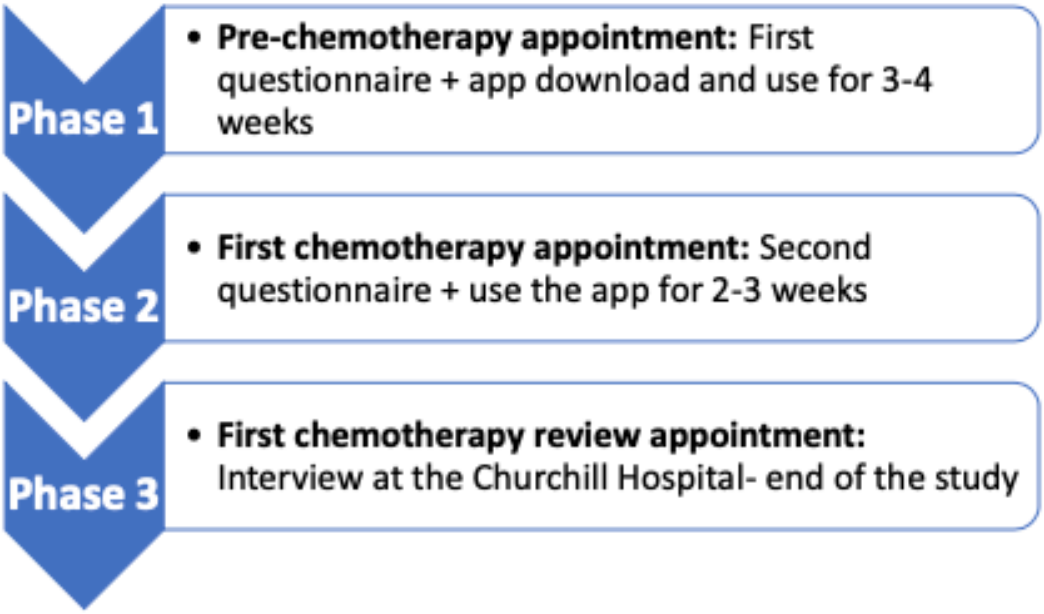
Our study will recruit patients with colorectal (bowel) cancer from the Oncology Department of Churchill Hospital (Oxford, UK). Once you provide consent, you will be granted access to the app, complete a survey and explore it in your own time from the comfort of your home.

8. How long will the study take?

We anticipate that you will be in the study for a period of FIVE to SEVEN weeks, depending upon which treatment you will receive. This is because we have designed the study around your treatment schedule in order to avoid asking you to make additional visits or disturb you at a sensitive point of your treatment. Therefore, your first cycle of treatment will determine how long you will be in the study for. Below, we discuss how this time is broken down.

The following diagram shows your journey through our study.

Figure 3: The patient journey in the study



The day of the interview will be the last day in the study. Please note that if you are not able to do the interview on the day of your first chemotherapy review appointment, we can arrange for a telephone/Skype interview or conduct this interview at your second chemotherapy appointment. The day of the interview will be the last day in the study.

Throughout your first cycle of treatment, the app will send us data about how often you used it. Please note that these data will be sent over the internet; if you are not connected to Wi-Fi, the app will use cellular data (MB) to send these over to the team. The app usage data will be sent to us while you are using the app and will only refer to how often and for how long you engaged with it. **Please note that these data will become available to the members of the research team ONLY. Furthermore, no other activity or data (unrelated to this app) will be sent to over to the research team.** To protect your confidentiality, the data generated by the app will not refer to your phone number, location or any other personal information. Instead, they will refer to your username, by which no one outside the research team will be able to identify you. Also, any information that you might enter manually (such as medical notes,

results from medical tests or a record of your symptoms) will **NOT** be sent over to us (or another party) to protect your confidentiality.

After the study ends, you will still be able to use the app throughout your treatment if you would like to. **However, please note that some contents of the app might change after a while, since new knowledge can suggest alterations to advice given currently to patients.** Therefore, some pieces of information might become irrelevant or invalid. **You will receive a notification if any major changes occur.**

Our team has taken care to design this study in a way that it won't interfere with your treatment schedule. In order to save you time, we will be giving you the questionnaires at your regular hospital visits. If however you wish to complete the questionnaires at the comfort of your home, we can give you a copy to take with you alongside with a pre-paid envelope so you can complete them from home and then post them to us.

9. What does the consent process involve?

A clinician will invite you to take part in this study. If you are interested, the clinician will explain Part I with you and answer any questions you might have. If you agree to take part, you will be asked to provide written consent during this appointment. A copy of the signed consent document will be given to you for your reference, alongside with this booklet.

If you need time to consider participation, the clinician will provide you with a copy of this booklet, two copies of the consent form and a pre-paid envelope. You will be given 48 hours to consider participation; this is done because our research is time-sensitive, and we try to avoid delays with enrolling patients to the study. The clinician will also ask for your permission so the project lead (Mr Alexandros Ioannis Chatzixenitidis) can contact you (by phone) 2 days after you were invited to the study in order to find out about your decision. If you prefer to contact the project lead yourself, please refer to section 8 of Part 2 to find his contact details.

If you agree to take part in the study, you will be asked to sign both copies of the consent fo and forward one of them to the Churchill Hospital (the second copy is for your record). The project lead will then provide you with an activation code and will help you activate the app on your device(s) of choice.

Consent in this study is voluntary. This means that <u>you</u> decide whether or not to participate in this project. This also means that even after you consented, <u>you</u> decide whether or not you want to carry on with it.

Part 2: Supportive Information

1. What if something goes wrong?

Due to the nature of this research, it is unlikely that any harm will be caused to you. However, if you are concerned about any aspect of this study, you are welcome to ask to speak with the members of the research team who will do their best to get your questions answered (please refer to Part 2, section 8 for contact details).

If you do not manage to get your questions answered or remain unhappy and wish to file a formal complaint, you can do this by contacting the Patient Advice and Liaison Service (PALS) of the Churchill Hospital (details provided below).

Patient Advice and Liaison Services (PALS)
Churchill Hospital (OUHT)
Old Road,
Headington,
Oxford,
Oxfordshire,
OX3 7LE
Contact Number: 01865 235855
Contact Email address: PLAS@ouh.nhs.uk

2. What will happen if I don't want to carry on with the study?

Participation in this study is entirely up to you. If, however you change your mind at some point, you are free to withdraw at any time, without having to explain the reasons that have lead you to this decision. A decision to withdraw from the study WILL NOT affect the care you are or will be receiving from the National Health Service (NHS) in any way.

In case you wish to leave the study, please note that data which have been generated up to the point of your withdrawal can still be used (always anonymously) for the purposes of this study. If, however you do not wish your data to be used after your withdrawal, please notify the project lead (Mr Alexandros Ioannis Chatzixenitidis) or another member of the research team about this. Please refer to Part 2, section 9 for their contact details.

In the event that you wish to withdraw your data, your questionnaire data, app usage data and interview data (both the audio files and transcripts) will be destroyed safely to protect confidentiality and ensure maximum security.

Please note that you will only be able to withdraw your data before we include them in our written report, but not after this is done. This is because your data will be 'pooled together' with other patients' data (anonymously) and it will not be possible for us to withdraw them after this happens.

3. Will my information be kept confidential?

Yes. As part of the study, we will be processing your identifiable personal data. By law we need to identify and tell you what our legal basis is for processing your information. Research is one of the University's public tasks and so we will process your non-sensitive personal data as part of that task. Where we process your sensitive personal data (e.g. health related information), we will do so for the purposes of 'scientific research' which allows us to process this information as long as we have adequate safeguards in place.

In this study, a number of different types of data will be obtained or generated. Below, our team describes the security measures put in place to ensure that this data will be kept confidential during and after the study.

A. Personal information (name, date of birth and NHS number): Your name, date of birth and NHS number will be required in order to obtain your consent for this study. The team has taken measures to ensure that these will be kept strictly confidential. Instead of using your name or any other piece of personal information on study documents (such as questionnaires), you will be given a unique username that will be used throughout the study. This username will not allow anyone (apart from the members of the research team) to trace your personal details.

The consent document will be the only document connecting your personal details with your username. It will therefore be kept in a safe location and will only be available to the members of the research team. The hard copy of this document will be stored in a locked filing cabinet at the Churchill Hospital (Oxford University Hospitals) and will be protected under the Data Protection Act, and from May 2018, the General Data Protection Regulation (GDPR). An electronic copy of this document will be sent to a secure server of Keele University, which will be accessed only by the Chief Investigator and the project lead. A copy of the informed consent document will also be given to you for your reference. We strongly recommend that you keep this document at a safe location.

Your personal identifiable data (present in the consent form) will be securely destroyed as soon as the research team has written the report for this study.

B. Health-related information: Information about your health and treatment will ONLY be accessed by members of the research team who are part of your care team and have clinical responsibility for you. The Chief Investigator, project lead and the academic supervisors from Keele University will NOT have access to such information, as they are not part of your cancer care team.

C. App usage data (generated through the app): As mentioned earlier in this document, the data generated through the app will only refer to how often you used the app and for how long you engaged with each of its sections (i.e. we will not be recording any other activity undertaken on your device). These data will be sent from the app (while you are using it) to a secure Keele University drive, where they are going to be stored electronically. This drive will be accessed only by the members of the research team, and where appropriate, the technical support staff at Keele. If the technical support staff needs to access the drive (for example, to resolve any technical difficulties), they will be able to link sets of data with their corresponding

usernames, but they won't be able to link usernames to their users, as they will NOT have access to the consent documents. *For example, they might know that user CPD93 has used the app 5 times in the last 24 hours, but they won't know who user CPD93 actually is.*

This app is owned entirely by the school of pharmacy of Keele University. No other companies or parties have been involved in the development of this app or are part of the app's ownership. Hence, all data regarding the usage of the app will be shared solely with Keele University and will be accessed ONLY by the members of the research team.

The data generated through the app (which will be anonymous) will be kept for 10 years after the end of this study (as per Keele University policy) and will then be securely destroyed.

D. Data you enter in the app: The app itself will not contain ANY of your personal information at the point of installation, but you will be able enter and store personal information such as medical test results or keep a symptom diary at the last section of the app. These pieces of information constitute health information. Therefore, they will not be sent over to the research team or used in this study. The team will only be able to see how often you used this section, but not the information you added there. The notes you enter manually in this section will be saved in the app; this means that if you delete the app from the device you installed it, the data you have entered manually will also be erased.

As discussed in part 1, section 5, the app itself does not provide password protection. This makes it possible for others to access the app and any information you might enter if they gain access to the device where the app is installed. Our team therefore strongly recommends that general security measures (such as auto-lock, PIN requirement, anti-virus protection software and tracking services) are in place, as the app will inherit them and offer better protection of your data. We also strongly recommend that you put a password protection to prevent others from accessing the contents of your phone, which will also ensure that personal data entered in the app will also be secure.

E. Responses from questionnaires and interviews: The paper questionnaires are not going to contain any identifiable information; instead, they will be coded with your unique username. These paper questionnaires will be sent to project lead at Keele University. If you don't have time to complete the questionnaires during your visits, you will be able to complete these at home and return them to the Churchill Hospital in a pre-paid envelope (provided to you upon your visits). Alternatively, you will be able to complete this questionnaire as an electronic questionnaire using Google Surveys; should you wish to do it that way, you will be provided with a link to this survey. Again, this information will be sent to the Project Lead at Keele University and will be stored in a secure Keele University server.

Your interview recordings will be kept by the project lead in a secure drive at Keele University. The transcripts of these interviews will be kept by the project lead (under the supervision of the Chief Investigator) at a password-protected Keele University computer. The data generated through questionnaires and interviews (which will be anonymous) will be kept for 10 years after the end of this study (as per Keele University policy) and will then be securely destroyed.

The University of Keele will be what's known as the 'Data Controller' for any personal data we process about you. Our full details are: The University of Keele, Keele, Staffordshire ST5 5BG. Main switchboard telephone: 01782 732000; Web site: www.keele.ac.uk. You will find full details of what information we will use; what we will do with it; how long we will keep the information; who we will share any of this information with; and how we will keep your information safe and secure in the throughout this Patient Information Booklet.

Please note that the data collected in the present study might be shared (anonymously) with other researchers and partners in the future. Sharing research data is important, as it can help towards establishing new patterns, optimise the use of good quality research data and enrich scientific knowledge. Your identity will not be disclosed to anyone outside the research team of this study.

Your rights

You have a number of rights regarding your data including a right to access the data and in some circumstances rights to restrict or delete the data. To learn more about these rights please see the Information Commissions (ICO) website (see below) or the university website at:
www.keele.ac.uk/informationgovernance/informationgovernanceforthepublic/
You will also find the contact details of the University's Data Protection Officer at the above website. You can contact the DPO to exercise any of these rights and to raise concerns with how we have dealt with your personal data.

If you are dissatisfied with our response you can complain to the Information Commissioner's Office

Information Commissioner's Office, Wycliffe House, Water Lane, Wilmslow, Cheshire SK9 5AF
www.ico.org.uk

4. What will happen to the results of this study?

The data generated by the interviews, the self-completed questionnaires and the app (data about usage only) will be used in our study in order to determine whether or not the intervention (the app) was usable and acceptable. This study is a part of the PhD project of the researcher (Mr Alexandros Ioannis Chatzixenitidis) and it is intended to be published in the future.

As discussed above, **the anonymity of the information will be retained across all stages and future publications**. Neither your name nor other personal information that could link back to you will appear through this study.

5. Who is organising and funding this study?

The present study will be conducted within the Churchill Hospital (OUH) in collaboration with the School of Pharmacy of Keele University. The research team (please refer to Part 2, section 9 for more details) will be responsible for planning, organising, setting and performing the study.

This study is funded entirely by Keele University and the Churchill Hospital (OUH).

6. How have the patients and the public been involved in this study?

Many researchers involve patients and the public in early stages of their projects in order to make their interventions and studies more relevant to their intended audience. Following this example, our team has involved patients with bowel cancer in the development stage this app. This was done in order to ensure that the information delivered through the app would be clear and understandable by patients, as well as relevant to their needs. These patients also provided recommendations on how the app should be constructed, which helped the research team make it more user-friendly.

As with any newly developed technologies, user input is necessary in order to build a successful intervention that will address the needs of its intended user population. The present study is a small project which aims to test an initial version of our app with a few patients. This is done in order to see if the app works and if you liked it, which is going to help us decide if we can carry out a larger- scale evaluation study. Also, your feedback and recommendations for improvement are vital and will be used in order to optimise our app before testing it with more patients.

7. Who has reviewed this study?

All academic research, as well as research conducted within the NHS is looked by an independent group of people, known as the Research Ethics Committee. This is done in order to ensure that all research is carried out bearing the appropriate ethical standards, thereby protecting your interests.

The present study has been reviewed and been granted favourable opinion by an NHS Research Ethics Committee, approved by the Health Research Authority (HRA) as well as the R&D Department of the Churchill Hospital (OUHT).

8. Contact details of the research team

Chief Investigator

Professor Stephen Chapman
Head of Medicines Optimisation/ Deputy Head of the School of Pharmacy
Keele University
Staffs
ST55BG
Email: s.r.chapman@keele.ac.uk

Project Lead

Mr Alexandros Ioannis Chatzixenitidis
PhD Researcher
School of Pharmacy
Keele University
Staffs
ST55BG
Email: a.chatzixenitidis@keele.ac.uk

Academic supervisors

Professor Nicola Stoner
Cancer Consultant Pharmacist
Oxford Cancer and Haematology Centre & Oxford Cancer Research Centre
Churchill Hospital (OUH)
Old Road
Headington
Oxford
OX3 7LI
Email: Nicola.Stoner@ouh.nhs.uk

Dr Alison Gifford
Postgraduate Programme Manager
Keele University
Staffs
ST55BG
Email: a.gifford@keele.ac.uk

Clinician Team

Dr Andrew Weaver
Lead Chemotherapy Clinician
Oxford Cancer and Haematology Centre & Oxford Cancer Research Centre
Churchill Hospital (OUH)
Old Road
Headington
Oxford
OX3 7LI
Email: Andrew.Weaver@ouh.nhs.uk

Ms Eliz Flanagan
Lead Chemotherapy Nurse
Cancer Consultant Pharmacist
Oxford Cancer and Haematology Centre & Oxford Cancer Research Centre
Churchill Hospital (OUH)
Old Road
Headington
Oxford
OX3 7LI
Email: Eliz.Flanagan@ouh.nhs.uk

If you have any queries, please contact the Project Lead at any time.

Appendix 7: Consent form for the patient interviews

Developing and Testing an Avatar-Based Health Information Support App for Patients with Colorectal Cancer Receiving Chemotherapy for the First Time; A Mixed Methods Study

IRAS ID: 240263
Patient name:
Patient username:
Pseudonym of choice:

CONSENT FORM for Interviews

Name of Researcher: Alexandros Ioannis Chatzixenitidis

Thank you for agreeing to be interviewed as part of the above research project. You will have already received the Participant Information Booklet for this study, which describes the purpose of the research and what you would be asked to do for the main part of the study. This consent form is necessary for us to make sure that you understand the purpose of your involvement and that you agree to the conditions of your participation.

The interview will take approximately 60 minutes. We don't anticipate that there are any risks associated with your participation, but you have the right to stop the interview or withdraw from the research at any time.

It is important for you to be aware of the following before agreeing to take part at the interview:

- Your interview will be recorded and a transcript will be produced, which will be stored at Keele University

- The transcript of the interview will be analysed by Mr Alexandros Chatzixenitidis as research investigator

- Access to the interview transcript will be limited to the researcher (Mr Alexandros Chatzixenitidis) and colleagues (**members of the research team ONLY**) with whom will might collaborate as part of the research process

- Any summary interview content, or direct quotations from the interview, that are made available through academic publication or other academic outlets will be anonymized so that you cannot be identified, and care will be taken to ensure that other information in the interview that could identify yourself is not revealed

- The actual recording will be kept in a safe location (**a secure Keele university server)** and will be accessed only by the chief investigator.

- All or part of the content of your interview may be used (anonymously) in academic papers, policy papers or news articles

By signing this form, I agree that;

1. I am voluntarily taking part in this project. I understand that I don't have to take part, and I can stop the interview at any time. ☐

2. I have read and understand the Information sheet; ☐

3. I agree to be quoted directly if my name is not published and a made-up name (pseudonym) is used. ☐

4. I agree to be quoted directly. ☐

5. I agree that the researchers may publish documents that contain quotations by me. ☐

6. I don't expect to receive any benefit or payment for my participation; ☐

7. I have been able to ask any questions I might have, and I understand that I am free to contact the researcher with any questions I may have in the future. ☐

Participant signature:

_____ Date:

Researcher signature:

_____ Date:

Contact Information

If you have any further questions or concerns about this study, please contact:
Name of researcher: Alexandros Ioannis Chatzixenitidis
Tel: 07930587130
E-mail: a.chatzixenitidis@keele.ac.uk

What if I have concerns about this research?

If you are worried about this research, or if you are concerned about how it is being conducted, you can contact the Patient Advice and Liaison Services (PALS) via telephone (01865 235855) or email (PLAS@ouh.nhs.uk).

Appendix 8: Consent form for the clinician interviews

Developing and Testing an Avatar-Based Health Information Support App for Patients with Colorectal Cancer Receiving Chemotherapy for the First Time; A Mixed Methods Study

IRAS ID: 240263
Participating clinician name:

CONSENT FORM for Interviews

Name of Researcher: Alexandros Ioannis Chatzixenitidis

Thank you for agreeing to be interviewed as part of the above research project. This consent form is necessary for us to make sure that you understand the purpose of your involvement and that you agree to the conditions of your participation.

The interview will take approximately 60 minutes. We don't anticipate that there are any risks associated with your participation, but you have the right to stop the interview or withdraw from the research at any time.

It is important for you to be aware of the following before agreeing to take part at the interview:

- Your interview will be recorded and a transcript will be produced

- The transcript of the interview will be analysed by Mr Alexandros Chatzixenitidis as research investigator

- Access to the interview transcript will be limited to the researcher (Mr Alexandros Chatzixenitidis) and academic colleagues with whom he might collaborate as part of the research process

- Any summary interview content, or direct quotations from the interview, that are made available through academic publication or other academic outlets will be anonymized so that you cannot be identified, and care will be taken to ensure that other information in the interview that could identify yourself is not revealed

- The actual recording will be kept in a safe location (accessed only by the chief investigator)

- All or part of the content of your interview may be used (anonymously) in academic papers, policy papers or news articles

By signing this form, I agree that;

1. I am voluntarily taking part in this project. I understand that I don't have to take part, and I can stop the interview at any time;	☐
2. I have read and understood the Information sheet;	☐
3. I agree to be quoted directly if my name is not published and a made-up name (pseudonym) is used.	☐
4. I agree to be quoted directly.	☐
5. I agree that the researchers may publish documents that contain quotations by me.	☐
6. I don't expect to receive any benefit or payment for my participation;	☐
7. I have been able to ask any questions I might have, and I understand that I am free to contact the researcher with any questions I may have in the future.	☐

Participant signature:

_____ Date:

Researcher signature:

_____ Date:

Contact Information

This research has been reviewed and approved by the Churchill Hospital R&D department. If you have any further questions or concerns about this study, please contact:

Alexandros Ioannis Chatzixenitidis
Tel: 07930587130
E-mail: a.chatzixenitidis@keele.ac.uk

What if I have concerns about this research?

If you are worried about this research, or if you are concerned about how it is being conducted, you can contact the Patient Advice and Liaison Services (PALS) via telephone (01865 235855) or email (PLAS@ouh.nhs.uk).

Appendix 9: HRA letter of approval

Ymchwil Iechyd a Gofal Cymru
Health and Care Research Wales

NHS
Health Research Authority

Mr Alexandros Ioannis Chatzixenitidis
Hornbeam Building (HNB 0.24)
School of Pharmacy
Keele University
ST5 5BG

Email: hra.approval@nhs.net
Research-permissions@wales.nhs.uk

04 May 2018

Dear Mr Chatzixenitidis

HRA and Health and Care Research Wales (HCRW) Approval Letter

Study title:	**Developing and Testing an Avatar-Based Health Information Support App for Patients With Colorectal Cancer Receiving Chemotherapy for the First Time; A Mixed Methods Study**
IRAS project ID:	**240263**
Protocol number:	**Not applicable**
REC reference:	**18/LO/0674**
Sponsor	**Keele University**

I am pleased to confirm that HRA and Health and Care Research Wales (HCRW) Approval has been given for the above referenced study, on the basis described in the application form, protocol, supporting documentation and any clarifications received. You should not expect to receive anything further relating to this application.

How should I continue to work with participating NHS organisations in England and Wales?
You should now provide a copy of this letter to all participating NHS organisations in England and Wales*, as well as any documentation that has been updated as a result of the assessment.

*'In flight studies' which have already started an SSI (Site Specific Information) application for NHS organisations in Wales will continue to use this route. Until 10 June 2018, applications on either documentation will be accepted in Wales, but after this date all local information packs should be shared with NHS organisations in Wales using the Statement of Activities/Schedule of Events for non-commercial studies and template agreement/ Industry costing template for commercial studies.

Following the arranging of capacity and capability, participating NHS organisations should **formally confirm** their capacity and capability to undertake the study. How this will be confirmed is detailed in the "*summary of assessment*" section towards the end of this letter.

You should provide, if you have not already done so, detailed instructions to each organisation as to how you will notify them that research activities may commence at site following their confirmation of

capacity and capability (e.g. provision by you of a 'green light' email, formal notification following a site initiation visit, activities may commence immediately following confirmation by participating organisation, etc.).

It is important that you involve both the research management function (e.g. R&D office) supporting each organisation and the local research team (where there is one) in setting up your study. Contact details of the research management function for each organisation can be accessed here.

How should I work with participating NHS/HSC organisations in Northern Ireland and Scotland?
HRA and HCRW Approval does not apply to NHS/HSC organisations within the devolved administrations of Northern Ireland and Scotland.

If you indicated in your IRAS form that you do have participating organisations in either of these devolved administrations, the final document set and the study wide governance report (including this letter) has been sent to the coordinating centre of each participating nation. You should work with the relevant national coordinating functions to ensure any nation specific checks are complete, and with each site so that they are able to give management permission for the study to begin.

Please see IRAS Help for information on working with NHS/HSC organisations in Northern Ireland and Scotland.

How should I work with participating non-NHS organisations?
HRA and HCRW Approval does not apply to non-NHS organisations. You should work with your non-NHS organisations to obtain local agreement in accordance with their procedures.

What are my notification responsibilities during the study?
The document "*After Ethical Review – guidance for sponsors and investigators*", issued with your REC favourable opinion, gives detailed guidance on reporting expectations for studies, including:

- Registration of research
- Notifying amendments
- Notifying the end of the study

The HRA website also provides guidance on these topics, and is updated in the light of changes in reporting expectations or procedures.

I am a participating NHS organisation in England or Wales. What should I do once I receive this letter?
You should work with the applicant and sponsor to complete any outstanding arrangements so you are able to confirm capacity and capability in line with the information provided in this letter.

The sponsor contact for this application is as follows:

Name: Dr Clark Crawford
Tel: 01782 733371
Email: research.governance@keele.ac.uk

IRAS project ID	240263

Who should I contact for further information?
Please do not hesitate to contact me for assistance with this application. My contact details are below.

Your IRAS project ID is **240263**. Please quote this on all correspondence.

Yours sincerely

Michael Pate
Assessor

Email: hra.approval@nhs.net

Copy to: *Dr Clark Crawford – Keele University - Sponsor contact*
Professor Nicola Stoner – Oxford University Hospital Foundation Trust – Local Collaborator
Dr Heather House – Lead NHS R&D contact.

IRAS project ID	240263

List of Documents

The final document set assessed and approved by HRA and HCRW Approval is listed below.

Document	*Version*	*Date*
Contract/Study Agreement template [Extension of Honorary Contract for Project Lead (Mr Alexandros Ioannis Chatzixenitidis)]	1.0	01 December 2017
Contract/Study Agreement template [Delegation of Sponsorship Function]		04 April 2018
Evidence of Sponsor insurance or indemnity (non NHS Sponsors only) [Insurance Policy of Keele University]	1.0	31 July 2017
HRA Schedule of Events	1	19 April 2018
HRA Statement of Activities	1	04 May 2018
Interview schedules or topic guides for participants [Participant Interview Guide]	1.0	20 February 2018
Interview schedules or topic guides for participants [Clinician Interview Guide]	1.0	20 February 2018
IRAS Application Form [IRAS_Form_05042018]		05 April 2018
Letter from sponsor [Confirmation of Sponsorship]		04 April 2018
Letters of invitation to participant [Invitation Letter]	1.0	20 February 2018
Non-validated questionnaire [Information Needs and Demographics Questionnaire]	1.0	20 February 2018
Non-validated questionnaire [Satisfaction with Information Questionnaire]	1.0	20 February 2018
Non-validated questionnaire [App Usability Questionnaire]	1.0	20 February 2018
Participant consent form	2	02 May 2018
Participant information sheet (PIS) [Participant Information Booklet (PIB)]	1.0	20 February 2018
Participant information sheet (PIS)	2	02 May 2018
Research protocol or project proposal [Study Protocol]	1.0	04 April 2018
Summary CV for Chief Investigator (CI) [Chief Investigator CV]	1.0	
Summary CV for student [Student CV]	1.0	04 April 2018
Summary CV for supervisor (student research) [Professor Nicola Stoner Research CV]	1.0	10 January 2018
Summary CV for supervisor (student research) [Professor Stephen Chapman CV]	1.0	
Summary CV for supervisor (student research) [Dr Alison Gifford Research CV]	1.0	01 March 2016
Summary of any applicable exclusions to sponsor insurance (non-NHS sponsors only) [Medical Malpractice - Keele University Combined University Policy]	1.0	19 July 2017
Summary, synopsis or diagram (flowchart) of protocol in non technical language [Pilot Study Schema]	1.0	04 April 2018
Summary, synopsis or diagram (flowchart) of protocol in non technical language [Main Study Schema]	1.0	04 April 2018

IRAS project ID	240263

Summary of assessment

The following information provides assurance to you, the sponsor and the NHS in England and Wales that the study, as assessed for HRA and HCRW Approval, is compliant with relevant standards. It also provides information and clarification, where appropriate, to participating NHS organisations in England and Wales to assist in assessing, arranging and confirming capacity and capability.

Assessment criteria

Section	Assessment Criteria	Compliant with Standards	Comments
1.1	IRAS application completed correctly	Yes	No comments
2.1	Participant information/consent documents and consent process	Yes	Following REC favourable opinion, the information sheet and consent form were updated via a non-substantial amendment to bring them in line with HRA assessment standards.
3.1	Protocol assessment	Yes	No comments
4.1	Allocation of responsibilities and rights are agreed and documented	Yes	A Statement of Activities and Schedule of Events will form the agreement between the sponsor and participating sites.
4.2	Insurance/indemnity arrangements assessed	Yes	No comments
4.3	Financial arrangements assessed	Yes	No direct funding to site, although Keele University will be providing all of the study materials, as per the Statement of Activities.
5.1	Compliance with the Data Protection Act and data security issues assessed	Yes	No comments
5.2	CTIMPS – Arrangements for compliance with the Clinical Trials Regulations assessed	Not Applicable	No comments
5.3	Compliance with any applicable laws or regulations	Yes	No comments

IRAS project ID	240263

Section	Assessment Criteria	Compliant with Standards	Comments
6.1	NHS Research Ethics Committee favourable opinion received for applicable studies	Yes	No comments
6.2	CTIMPS – Clinical Trials Authorisation (CTA) letter received	Not Applicable	No comments
6.3	Devices – MHRA notice of no objection received	Not Applicable	No comments
6.4	Other regulatory approvals and authorisations received	Not Applicable	No comments

Participating NHS Organisations in England and Wales

This provides detail on the types of participating NHS organisations in the study and a statement as to whether the activities at all organisations are the same or different.

One participating NHS organisation. Therefore, one site type.

The Chief Investigator or sponsor should share relevant study documents with participating NHS organisations in England and Wales in order to put arrangements in place to deliver the study. The documents should be sent to both the local study team, where applicable, and the office providing the research management function at the participating organisation. Where applicable, the local LCRN contact should also be copied into this correspondence.

If chief investigators, sponsors or principal investigators are asked to complete site level forms for participating NHS organisations in England and Wales which are not provided in IRAS, the HRA or HCRW websites, the chief investigator, sponsor or principal investigator should notify the HRA immediately at hra.approval@nhs.net or HCRW at Research-permissions@wales.nhs.uk. We will work with these organisations to achieve a consistent approach to information provision.

IRAS project ID	240263

Principal Investigator Suitability

This confirms whether the sponsor position on whether a PI, LC or neither should be in place is correct for each type of participating NHS organisation in England and Wales, and the minimum expectations for education, training and experience that PIs should meet (where applicable).
A local collaborator should be in place at the participating site, and this person has been identified as Dr Nicola Stoner. GCP training is not a generic training expectation, in line with the HRA/HCRW/MHRA statement on training expectations.

HR Good Practice Resource Pack Expectations

This confirms the HR Good Practice Resource Pack expectations for the study and the pre-engagement checks that should and should not be undertaken
The taking of consent and face-to-face interviews will require a Letter of Access for researchers not already holding a contract with a participating site. Evidence of standard DBS and OH clearance would be expected.

Other Information to Aid Study Set-up

This details any other information that may be helpful to sponsors and participating NHS organisations in England and Wales to aid study set-up.
The applicant has indicated that they do not intend to apply for inclusion on the NIHR CRN Portfolio.

Appendix 10: Approval of the first substantial amendment

NHS
Health Research Authority

London - Brighton & Sussex Research Ethics Committee
Health Research Authority
Ground Floor, Skipton House
80 London Road
London
SE1 6LH

20 June 2018

Mr Alexandros Ioannis Chatzixenitidis
Hornbeam Building (HNB 0.24)
School of Pharmacy
Keele University
ST5 5BG

Dear Mr Chatzixenitidis

Study title:	**Developing and Testing an Avatar-Based Health Information Support App for Patients With Colorectal Cancer Receiving Chemotherapy for the First Time; A Mixed Methods Study**
REC reference:	**18/LO/0674**
Protocol number:	**Not applicable**
Amendment number:	**SA1**
Amendment date:	**12 June 2018**
IRAS project ID:	**240263**

Thank you for submitting the above amendment, which was received on 18 June 2018. I can confirm that this is a valid notice of a substantial amendment and will be reviewed by the Sub-Committee of the REC at its next meeting.

Documents received

The documents to be reviewed are as follows:

Document	*Version*	*Date*
Notice of Substantial Amendment (non-CTIMP) [AmendmentForm_ReadyForSubmis]	SA1	12 June 2018
Participant information sheet (PIS) [Participant information booklet (PIB) (v.3)]	3	07 June 2018
Participant information sheet (PIS) [Participant information booklet (PIB) (v.3CLEAN)]	3	07 June 2018
Research protocol or project proposal [StudyprotocolA.Chatzixenitidis (v.2)]	2	07 June 2018
Research protocol or project proposal [StudyprotocolA.Chatzixenitidis (v.2CLEAN)]	2	07 June 2018

Notification of the Committee's decision

The Committee will issue an ethical opinion on the amendment within a maximum of 35 days from the date of receipt.

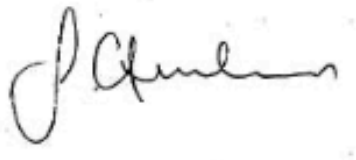
R&D approval

All investigators and research collaborators in the NHS should notify the R&D office for the relevant NHS care organisation of this amendment and check whether it affects R&D approval for the research.

We are pleased to welcome researchers and R & D staff at our Research Ethics Service Committee members' training days – see details at http://www.hra.nhs.uk/hra-training/

18/LO/0674:	**Please quote this number on all correspondence**

Yours sincerely



Jake Chambers
REC Assistant

Email: nrescommittee.secoast-brightonandsussex@nhs.net

Copy to: *Professor Nicola Stoner, Churchill Hospital (OUHT)*

Appendix 11: Layout of the XELOX information package

Section 2: Information about cancer and treatment	
Animation button: What is cancer?	Cancer is a condition where cells in our body get damaged multiply without control. To watch a video explaining what cancer is, visit the link below when I finish talking. YouTube link: https://www.youtube.com/watch?v=2g5nJfKoIqE&t=3s
Animation button: What causes cancer?	Although we know what cancer is, we are not sure as to what triggers it. Research suggests that cancer is due to genetic factors such as family history, as well as environmental factors such as air pollution, chemicals, smoking, an unhealthy diet and excessive alcohol consumption.
Animation button: Has the cancer left its original site and spread in my body?	If you are told that you have stage four, advanced or metastatic colorectal cancer, this means that the cancer has spread to other parts of your body. If you are unsure about the stage of your condition, you can ask your doctor about this. YouTube link: https://www.youtube.com/watch?v=2NKaGDNm8ls
Animation button: What are the treatment options for cancer?	The general treatment options for bowel cancer are surgery, chemotherapy, radiotherapy or a combination of these. In some cases, doctors suggest clinical trials, where experimental treatments are given.
Animation button: I will be given chemotherapy with XELOX. How does this treatment fight bowel cancer?	In order for tumours to grow and spread, cancer cells need to divide and multiply. XELOX fights tumours by preventing this from happening. Since cancer cells are not able to multiply and some of them die, the tumours will stop growing and will gradually shrink, which is important for treatment.
Animation button: What medicines does XELOX contain?	Your treatment contains two medicines called Oxaliplatin and Capecitabine. Capecitabine comes as a tablet and you will be taking it at home. Oxaliplatin will be given to you at the hospital as a drip over two hours.
Animation button: Is there any preparation	Yes. Before or on the day that you will be given Oxaliplatin at the hospital, a qualified person will take a blood sample to check if it is okay for you to take the medicine. Also, before you get oxaliplatin at the hospital, a nurse will give you some anti-

before I get XELOX?	sickness medication.
Animation button: How will I feel during and after my treatment at the hospital?	There is no single answer to this question, since patients tolerate the treatment differently and we can't now until you have it. Generally speaking, patients can get sickness or feel generally worn out after they get Oxaliplatin. Don't worry, a nurse will be with you to help.
Animation button: If XELOX cures my cancer, what are the chances of it coming back?	There is no definite answer to this question, as the risk of the cancer coming back is different for each patient. However, bear in mind that your doctor will arrange for regular check-ups after your treatment is finished to check for signs indicating returning cancer. If you are concerned about this, please discuss this with your oncologist.
Animation button: How can I tell if the cancer has come back?	If cancer has returned and progressed, you might get symptoms similar to those that you got before your first diagnosis. However, bear in mind that your doctor will arrange for regular check- ups after your treatment is finished, so it is very unlikely that the cancer will return without your doctors knowing it. If you are concerned about this, please discuss this with your oncologist.

Section 3: Diagnostic tests for cancer	
Animation button: What is a CT scan and why I might have one?	CT stands for Computerised Tomography, which is performed using a CT scanner. A CT scanner will take detailed images of the inside of the body, which is done to diagnose cancer and monitor your condition. A CT scan also helps doctors decide upon further tests or future treatment. To see how a CT scan is done, tap on the link below when I finish talking. YouTube link: https://www.youtube.com/watch?v=tS4a6I4-Yjo&t=43s
Animation button: What is a PET scan and why I might have one?	PET stands for Positron-Emission Tomography, which is performed using a PET scanner. A PET scan is used to diagnose cancer and determine its stage. It also helps doctors decide which treatment is best for you and see how well your current treatment works. To see how a PET scan is done, tap on the link below when I finish talking. YouTube link: https://www.youtube.com/watch?v=lk-VzATcv4M&t=4s
Animation button: What is an MRI scan and	MRI stands for Magnetic Resonance Imaging. This is performed by an MRI scanner, which uses a powerful magnet to create an image of the inside the body. An MRI scan helps doctor locate tumours, determine their size and find out if the cancer has

why I might have one?	spread. To see how an MRI scan is done, tap on the link below when I finish talking. YouTube link: https://www.youtube.com/watch?v=NUbifL_MAro
Animation button: What is an ultrasound scan and why I might have one?	An ultrasound scan uses sound waves to build an image of the inside of the body and it is used to locate a tumour or determine if the cancer has spread. To see how an ultrasound scan is done, tap on the link below when I finish talking. YouTube link: https://www.youtube.com/watch?v=vTLvg6XR9Tc
Animation button: What are X-Rays and why are they performed?	X-Rays use high energy rays to build an image of the inside of the body. Patients with bowel cancer will have this to find out if the cancer has spread to another part of the body. To see how X-Rays are performed, tap on the link below when I finish talking. YouTube link: https://www.youtube.com/watch?v=l3YqLAbs5lg
Animation button: What is a PET-CT scan and why I might have one?	A PET-CT scan combines a PET and a CT scan. It is used to monitor your condition and determine how well your treatment is working. The procedure of carrying out a PET-CT scan is the same with this of a PET scan. To see how a PET scan is done, tap on the link below when I finish talking. YouTube link: https://www.youtube.com/watch?v=lk-VzATcv4M&t=4s
Animation button: Why do doctors order blood tests?	Doctors order blood tests to check your general health and markers that indicate cancer. To watch a video explaining this in detail, tap on the link below when I finish talking. YouTube link: https://www.youtube.com/watch?v=bqSt7wLxCDQ

Section 4: Side effects of XELOX	
Subsection 1: Common, less common and uncommon side effects of XELOX	
Animation button: What is the risk of getting the very common side effects of XELOX? (Animation)	Imagine a group of 10 people going on a field trip. Out of them, at least one will leave because of feeling unwell. We cannot know which one this will be, but older individuals or those with a medical condition are more likely to leave. The same is true for chemotherapy. There is no way to tell who will get side effects, but the risk is generally higher in older patients or people with pre-existing medical conditions. However, your doctors will make sure to minimise the risk of you getting such side effects.
Very common side effects (more than 1 in 10 people) (text)	• Blood disorders: Decreased red blood cells, decreased number of neutrophils, decreased number of cells responsible for blood clots, decreased number of white blood cells, decreased number of lymph cells (if they occur, these will be picked in blood tests) • Metabolic and nutrition disorders: Loss of appetite, high or low blood sugar, decreased potassium and sodium levels in the blood • Nervous system disorders: Peripheral sensory neuropathy, sensory disturbance, taste disturbances, Headaches

	• Respiratory, thoracic and mediastinal disorders: Difficulty in breathing, cough • Gastrointestinal disorders: Feeling sick, being sick, tummy pain, mouth soreness, constipation, diarrhoea • Liver problems: Liver function test abnormalities (picked up in blood tests) • Skin disorders: Palmar-plantar erythro-dysesthesia syndrome (hand-foot syndrome), skin disorders, hair loss • Musculoskeletal disorders: Back pain • General disorders and administration site conditions: Feeling tired, fever, pain, injection site reaction, nosebleeds
Animation button: What is the risk of getting the common side effects of XELOX?	Imagine that 100 people are at a town fair on a warm summer day. Out of them, a maximum of ten people will feel it's too hot, while the rest will be comfortable in that temperature and enjoy their time. In a similar manner, common side effects can affect a maximum of 10 out of 100 patients. However, bear in mind that the possibility of not getting them is higher than the like hood of experiencing them.
Common side effects of XELOX (up to 10 in 100 people) (text)	• Infections and infestations: Herpes viral infection, nose and throat infection, lower or upper respiratory tract infection, neutropenic sepsis • Blood disorders: Blood creatinine increase, severely low number of neutrophil blood cells (if they occur, these will be picked in blood tests) • Metabolism and nutrition disorders: Dehydration, weight loss • Nervous system and psychiatric disorders: Sleepiness, pins and needles, dizziness, problems with coordination, meningism, sleeplessness, low mood • Eye disorders: Increased tearing, eye infections, visual disturbances • Vascular disorders: Blood clots in veins, bleeding, painful redness, deep vein thrombosis, pulmonary embolism, increased blood pressure • Respiratory disorders: Runny nose, hiccups • Gastrointestinal disorders: Gastrointestinal bleeding, stomach pain, indigestion, flatulence, dry mouth, gastro esophageal reflux, rectal bleeding • Liver problems: Jaundice (yellowing of the skin due to a blockage in the liver) • Skin disorders: Rash, redness, dry skin, skin hyper-pigmentation, nail disorder, excessive sweating • Musculoskeletal disorders: Pain in extremity, back pain, joint pain, bone pain • Kidney and urinary disorders: Blood in urine, difficulty in urination

	• General disorders and administration site conditions: Leg swelling, general feeling of discomfort, chest pain
Animation button: What is the risk of getting the uncommon side effects of XELOX?	Imagine that 1000 people are attending a concert at the Royal Albert Hall. Out of them, only ten will leave because they feel unwell, while the 990 will remain at the venue to watch the performance. In a similar manner, uncommon side effects can affect up to 10 in 1,000 patients. There is no guarantee that you won't get any of these side effects, but we know that the risk of experiencing them is very low.
Uncommon side effects of XELOX (up to 10 in 1000 people) (text)	• Infections and infestations: Sepsis, urinary tract infection, skin infections, tonsillitis, throat infection, oral candidiasis, influenza, gastroenteritis, fungal infections, tooth abscess • Blood disorders: Decreased number of all blood cells (if it occurs, it will be picked up in blood tests) • Immune system disorders: Hypersensitivity • Metabolic and nutrition disorders: Diabetes, malnutrition, increased triglycerides, metabolic acidosis • Nervous system and psychiatric disorders: Difficulty in speech and writing, memory impairment, problems with coordination, syncope (passing out), balance and sensory disorder, confusion, panic attack, decreased libido, nervousness • Eye and ear disorders: Visual acuity reduced, double vision • Ear and labyrinth disorders: Vertigo, ear pain • Heart and vascular problems: Myocardial infarction (decreased blood flow in the heart muscle), atrial fibrillation, irregular heartbeat, deep vein thrombosis, low blood pressure, hot flush, peripheral coldness • Respiratory disorders: Pulmonary embolism, spitting blood, asthma • Gastrointestinal disorders: Intestinal obstruction, bloating, inflammation in the bowel, stomach or oesophagus, difficulty in eating), abdominal discomfort, gastroesophageal reflux, blood in stools, lack of movement in the bowels • Liver problems: Liver failure, cholestatic hepatitis • Skin disorders: Blistering, skin ulcer, hives, sensitivity to light, swelling face, intense redness • Musculoskeletal disorders: Joint swelling, facial pain, stiffness, weakness • Kidney and urinary disorders: Kidney swelling, urinary incontinence, night urination • Reproductive system and breast disorders: Vaginal haemorrhage • General disorders and administration site conditions: Swelling, Chills, -influenza-like illness, lipoma (fatty lump on the skin)

Animation button: What is the risk of getting the rare side effects of XELOX?	Imagine that 10,000 people are going to Wembley stadium to watch a football match. Out of them, ten will leave because they feel unwell, while the rest will stay to watch the game. In a similar manner, rare side effects can affect up to 10 in 10,000 patients. Although we cannot guarantee that you won't get any of these side effects, we know that the risk of experiencing them is extremely low, so you are very unlikely to get them.
Rare side effects of XELOX (less than 1 in 100 people) (text)	• Blood disorders: Immunoallergic thrombocytopenia, haemolytic anaemia • Nervous system disorders: Toxic leukoencephalopathy (brain damage), slurred speech • Eye disorders: Lacrimal duct stenosis, corneal disorders, keratitis, visual field disturbances, damage of optic nerve, transient vision loss • Ear and labyrinth disorders: Transient loss of hearing • Cardiac disorders: Ventricular fibrillation, QT prolongation, slow heartbeat, constriction of blood vessels , • Respiratory disorders: Interstitial lung disease, pulmonary fibrosis • Gastrointestinal disorders: Colitis including clostridium difficile diarrhoea, pancreatitis • Skin disorders: Cutaneous lupus erythematosus, severe skin reactions such as Stevens-Johnson Syndrome and toxic epidermal necrolysis
Subsection 2: Help with side effects	
Part 1: Help with very common side effects	
Animation button: Loss of appetite	You might find it helpful to eat small portions of food and have snacks instead of large meals. Also, don't fill up your stomach with fluids before you eat. Remember, if you don't feel like eating one day, you can make up for the calories the next day. If you lose your appetite and become worried about losing weight, let your GP or nurse know. They can recommend some high calorie drinks that can help you not lose weight.
Animation button: Diarrhoea	If you have diarrhoea after your treatment, let your doctor or nurse know. They can recommend or prescribe medicines to help you. While being on treatment, make sure to drink plenty of fluids. Diarrhoea makes you lose a lot of water from your body, so you need to replace it to stay hydrated. Ideally, aim for 8 glasses of water a day. If you find this hard, you can try things such as drinking flavoured water or eating water- rich fruits and vegetables, such as cucumbers, courgettes, and watermelons.
Animation button: Nausea (feeling sick) and vomiting (being sick)	To ease or prevent feeling sick, try to eat small portions of food throughout the day. Also, avoid eating heavy, spicy or fatty foods, as they might make you feel sick. Fizzy drinks can also help. Ginger, either as tea, ginger ale or crystalized stem ginger is a natural alternative that some patients find useful. Finally, if you

	don't feel like eating, you can try sipping high calorie drinks, such as smoothies and milkshakes.
Animation button: Mouth sores and ulcers	Clean your mouth and wash your teeth every morning and evening, as well as between meals. If you are prescribed a mouthwash, use it as advised. If you notice that it stings, let your GP or nurse know. They might change it or advise you to dilute it with water. Avoiding certain foods and drinks will also help reduce the irritation in your mouth. Avoid spicy, sour or salty foods, alcohol and acidic drinks like orange juice.
Animation button: Numbness or tickling in fingers and toes	If the weather gets cold, wrap up warm and keep your fingers and toes warm by wearing gloves, warm shoes and warm socks. Avoid cold drinks and cold food if you know that it makes things worse. Also, be careful when you use hot water, as you might not feel how hot it is and burn yourself. Finally, I recommend that you moisturise your hands and feet with a cream.
Animation button: Soreness, redness and peeling on palms and soles	Keep your hands and feet cool and avoid hot water. If your hands or feet get swollen, avoid tight fitting gloves or socks. If your hands or feet become scaly, you can use a moisturising cream. Go for a non-perfumed cream, as they are less likely to irritate your skin.
Animation button: Feeling tired (Fatigue)	There are some things you can do to feel more energised. For example, maintain a healthy sleep pattern and make sure to take rest during the day. A healthy diet and mild exercise will also help you. You might find it useful to keep a diary of how you are feeling each day. This can help you make notes of what might make you feel better or worse. You can use the "My Notes" section of the app to do this.
Animation button: Breathlessness and looking pale (due to decreased number of white blood cells and/or red blood cells)	Chemotherapy can reduce the number of red blood cells, which can make you feel breathless and look pale. If you feel breathless, you must contact the Triage Helpline straight away. They will order some tests to check the levels of red blood cells in your blood. If the levels are very low, you might get a blood transfusion, which will help you be less breathless and look less pale.
Animation button: Taste disturbances (changes in taste)	This is a temporary side effect which resolves soon after treatment. If it happens, it is important to not put yourself off food, but instead experiment to find out what you like. You can try things such as adding spices and sauces to your food to make it tastier. For more information and tips about this, follow the link below this message.
Animation button: Constipation	To prevent or ease constipation, sure to drink plenty of fluids. Ideally, aim for 8 glasses of water a day. If you find this hard, you can try things such as drinking flavoured water or eat water- rich

	fruits and vegetables, such as cucumbers, courgettes, and watermelons. Also, eat as much fruits and vegetables as you can, as they can help your bowel movements. Some mild exercise such as walking will help as well.
Animation button: Tummy pain	Tummy pain is a common side effect, but it is something that needs to be assessed at once if it happens. If you get any pain in your tummy, you need to call the Triage assessment team as soon as possible.
Animation button: Hair thinning or hair loss	You might notice that your hair becomes thinner or falls out while you are on chemotherapy. However, in most cases this is a temporary effect and your hair is likely to grow back once treatment is finished. If you are concerned about this, please talk to your nurse keyworker. Cancer Research UK and MacMillan can also support you with this and provide a range of advice. Their contact information can be found at the 'useful contacts' section of the app.
Animation button: Skin problems	Your skin might become more sensitive during treatment, so it's important to avoid things such as unprotected exposure to sunlight, strong cleansing products and chlorinated water. If your skin becomes dry, use a non-perfumed cream to moisturise. Also, you need to watch out for skin rashes. If your skin becomes red, itchy and irritated or if you have an existing rash that has become worse, you will need to call Triage straight away.
Animation button: Reaction at the site of the injection (Oxaliplatin only)	Sometimes patients get redness, itchiness, pain and swelling around their central lines while having their medicines. At the hospital, a nurse will keep an eye on you and take appropriate action if this happens. If you get this at home while using the infusion pump, you need to call Triage immediately.
Animation button: Pain (chest pain, pack pain, generalised pain the body)	Pain caused by no apparent reason such as injury is something that needs to be assessed at once. If you notice any new pain or existing pain becomes worse and persists or interferes with your normal activities, you need to call Triage as soon as possible. If you get any chest pain, you need to call 999 immediately.
Animation button: Headaches	To prevent headaches, it is important to stay hydrated and rest during the day. Relaxation techniques can also help, as reducing stress can prevent headaches. If you get headaches, you might find it useful to use the 'my notes' section of the app to note what makes headaches better or worse. If headaches persist or become worse, please let your GP know, as they can recommend medicines that can help.
Part 2: Help with common side effects	
Animation button: Weight loss	Please keep a regular track of how much you weight and let your doctors know if you start to lose too much, as they can find out why this happens and help you maintain your normal weight. Cancer Research UK and MacMillan also provide a range of advice about how to maintain your weight through eating

	healthily. Please visit the links below this message for more information.
Link button:	MACMILLAN LINK FOR DIETARY ADVICE
Link button:	CANCER RESEARCH UK LINK FOR DIETARY ADVICE
Animation button: Sleeplessness (Insomnia)	] If you have trouble sleeping, let your pharmacist or GP know. They can make changes to your existing medicines to reduce this side effect or recommend medicines that can help you sleep. There are also plenty of things that can help with sleeping difficulties. Please visit the link below this message for more information.
Link button:	MACMILLAN LINK FOR ADVICE ON SLEEPLESSNESS
Animation button: Depression – low mood	Patients can sometimes feel very sad, which is completely normal. If this persists or becomes worse, then it could be a sign of depression. Please remember that help will always be available if you feel like this. This includes the members of your care team, as well as experts who can help you with your feelings. Patient support groups are also available. Please visit the 'emotional support' section of the app for more information.
Animation button: Dizziness	Keeping hydrated is key for preventing dizziness, so make sure to drink plenty of fluids throughout the day. If you get dizziness for the first time or if you feel dizzier than you usually do, you need to call Triage straight away.
Link button:	CANCER NET LINK FOR TASTE DISTURBANCES
Animation button: Eye problems (runny eyes, eye irritation, eye infections)	Chemotherapy can cause eye problems such as dryness, irritation or excessive tearing. If you notice any of these, please let you doctor, pharmacist or nurse know, as they can recommend products that can help. However, if you notice any changes in your vision such as reduced eyesight, blurred or double vision, or if you get any pain in your eyes, you need to call Triage straight away.
Animation button: Bloating	Chemotherapy can slow down the movement of food across the digestive tract, which can make you feel overly full after a meal. To prevent this or ease it if it happens, make sure to drink plenty of fluids and avoid food that you cannot digest easily. Some mild exercise such as walking can also help. For more information and tips, please visit the links below this message. Please note that if bloating becomes painful, you need to call Triage straight away.
Link button:	LINK FOR ADVICE AND TIPS ON BLOATING
Link button:	LINK FOR FOODS AND RECIPES TO REDUCE BLOATING
Animation button: Dry mouth	Mouth dryness is temporary and resolves soon after treatment. To ease it if it happens, it is important to drink plenty of fluids throughout the day. Also, try eating moist foods, vegetables and add gravy or sauces to your meals to moisten them. Maintaining good oral hygiene also helps; use a soft toothbrush and rinse your mouth with water throughout the day. If your mouth becomes too dry, please let your doctor or nurse know, as they can recommend products that can help.

Animation button: Infections (generalised or respiratory) and getting/feeling ill (fever, cough, runny nose, sore throat)	Chemotherapy medicines can weaken the immune system, and this can increase the risk of you getting ill. This is a common side effect of XELOX. If your temperature is higher than normal or if you feel you are getting ill, you MUST contact the Triage Helpline IMMEDIATELY. If you have an infection, your doctor or nurse will prescribe you antibiotics. You will have them as either tablets, which can be taken at home, or as an injection, which is given at the hospital.
Animation button: Heartburn	Spicy, fatty or oily foods are not digested easily and can cause or worsen heartburn. Alcohol, caffeine and acidic juices can also make this worse, so it's best to avoid them as well. There are also several non- prescription medicines that can help. Please speak to your doctor or local pharmacist to make sure that it's safe to take them.
Animation button: Hyperhidrosis (excessive sweating)	This can be caused by the treatment, but it can also be a sign of infection. If you notice excessive sweating, keep a regular track of your temperature and call Triage at once if it is higher or lower than normal. If sweating is caused by the medicines and not an infection, your doctor can recommend medicines that can help.
Part 3: Help with uncommon side effects	
Animation button: General advice about uncommon side effects	In most cases, the uncommon side effects of Capecitabine are important and need to be assessed by the Triage team as soon as possible. After this message is finished, please read through the list below and call Triage at once if you have any of the side effects that appear on that list.
List of uncommon side effects that need to be reported to Triage at once: (text)	• Joint swelling, bone pain, stiffness, muscular weakness • Incontinence, blood in wee, having to wake up at night to wee • Vaginal haemorrhage (unexpected blood flow from the vagina) • Tummy pain, blood in stools • Severe skin problems (blisters, ulcers, sensitivity to light, swelling in the face) • Jaundice (skin turning yellow because of liver problems) • Heart problems (changes in the way your heart beats, high or low blood pressure) • Severe breathing problems (being unable to breathe properly or finding it hard to breathe) • Spitting blood (also known as haemoptysis) • Memory/cognitive disorders (problems with movement, coordination and speech, memory problems, confusion) • Visual problems (clarity of vision reduced, double vision) • Vertigo (feeling that everything around you is spinning),

	• Infections (urinary tract infection, skin infections, tonsillitis, pharyngitis, fungal infections, influenza, gastroenteritis, tooth abscess) • Lipoma (small, fatty lumps on the skin)
Part 4: Help with rare side effects	
Animation button: Loss of hearing or Loss of vision	These are rare side effects and develop gradually rather than all of the sudden. If you notice any problems with your vision or hearing, please report them to your doctor or Triage as soon as possible. They can help stop your hearing or vision from deteriorating and reverse any damage made by chemotherapy.
Ringing in your ears (tinnitus)	This is a very uncommon common side effect, which affects 1 out of 100 people. Ringing in your ears is also known as tinnitus. This often gets better after treatment. If you experience ringing in your ears, let your doctor or nurse know.

Section 5: Help with side effects	
Subsection 1: Chemotherapy medicines	
Animation button: Oxaliplatin (drip)	Oxaliplatin will be given to you as a drip over two hours at the hospital at the first day of each chemotherapy cycle.
Animation button: Capecitabine (tablets)	Capecitabine comes as a tablet, which you will get for the first two weeks of each chemotherapy cycle.
Animation button: How should I take the Capecitabine tablets?	Capecitabine should be taken twice daily. Swallow the tablet whole, after food or a meal. It is important to eat something before you take it, as the medicine works best with food.
Animation button: What happens if I miss a dose of Capecitabine?	If you forgot to take a Capecitabine tablet, do not take two together. Please call your doctor or pharmacist for instructions on what to do.
Animation button: What happens if I vomit after I take Capecitabine?	If you vomit IMMEDIATELY and you can still see the tablet, you should take another tablet an hour after. If you vomit later, even 5 minutes after you took the tablet, DO NOT take another dose. Please contact your doctor for information on what to do.
Animation button: If I get side effects, from XELOX, how long will they last for?	XELOX can have short term side effects that can last for weeks, and long-term side effects that can last for several months. Please note that all side effects get better after the treatment is finished. Your care team will also help you deal with them.
Subsection 2: Chemotherapy supportive medication	
Anti-diarrhoea medication	
Animation button: General information about anti-diarrhoea medicines	If you get diarrhoea during your treatment, let your doctor or nurse know. They can prescribe Codeine or recommend a medicine called Loperamide, which is available to buy over the counter.

Animation button: Loperamide	Loperamide comes as a capsule. Only take it if it is recommended by your doctor, nurse or the Triage Helpline. The usual dose is two capsules at first, and then one capsule after each loose stool, if required. Take no more than 8 capsules a day.
Animation button: Codeine	Codeine comes as either tablets or syrup. Let your doctor or nurse which one you prefer. Please note that this medicine might make you sleepy. Avoid driving, operating machinery and drinking alcohol when you have it.
Mouth care and mouthwashes	
Animation button: General information about mouth care	If your mouth becomes sore, there is a number of things that the doctor or nurse might recommend. Remember to brush your teeth and clean your mouth regularly to prevent your mouth from becoming sore.
Animation button: Salt water mouthwash	This is used to prevent your mouth from becoming sore. You can make this at home by adding one teaspoon of salt in a glass of lukewarm water. Use this to clean your mouth after food. Remember to rinse out with water afterwards.
Animation button: Aspirin mouthwash	This is used to relieve soreness in your mouth. Only use this if it has been recommended by your doctor or nurse. You can make this at home by adding two tablets of soluble aspirin in a glass of water. Wait for them to dissolve and then use this as a gargle. It is very important to take care not to swallow this.
Animation button: Difflam mouthwash	This is used to relieve soreness in your mouth. Difflam mouthwash is available to buy over the counter, but only use it if it has been recommended by your doctor or nurse. Use one tablespoonful three times a day to rinse your mouth. If it stings, you can mix one tablespoonful of Difflam with one tablespoonful of water and use it as regular.
Animation button: Difflam oral spray	This is used to relieve soreness in your mouth. This is available to buy over the counter, but only use it if it has been recommended by your doctor or nurse. Please ask your doctor or pharmacist for an appropriate dose.
Medicines for constipation	
Animation button: General information about medicines for constipation	Chemotherapy can cause constipation to some patients. If this happens, let your doctor or nurse know, as they can recommend or prescribe a laxative. Note that you must not self-medicate with laxatives and you should use them only if they have been prescribed or recommended by your doctor or nurse.
Animation button: Macrogol	This is available to buy over the counter. Only use it if it is recommended by your doctor or nurse. Macrogol comes as sachets, which are dissolved in water. Please ask your doctor or pharmacist for an appropriate dose.
Animation button: Senna	This is available to buy over the counter. Only use it if it is recommended by your doctor or nurse. Senna comes as tablets, granules or a syrup. Senna is taken at night, ideally before

	bedtime. Please ask your doctor or pharmacist for an appropriate dose.
Non-prescription painkillers	
Animation button: General information about over the counter painkillers	There are several over the counter painkillers you can take during your chemotherapy. Always ask your doctor or nurse before you start taking such medicines, as some of them are not suitable for all patients.
Animation button: Paracetamol (over the counter)	Paracetamol is a common painkiller and it is available over the counter. Make sure that you don't exceed the recommended daily dose, which is 8 tablets a day. Also take care not to mix paracetamol- containing products together.

Section 6: Emotional support, help with finances and everyday life	
Subsection 1: Emotional support	
Animation button: Are there any groups where I can talk with other people with cancer?	Yes, there are. Talk to your keyworker, such as your Specialist Nurse to get more information on how to contact such groups. Alternatively, you can contact MacMillan or Maggie's for local support groups. You can also link up with fellow patients through Beating Bowel Cancer.org. Contact information for these organizations can be found on the "Useful contacts" section.
Animation button: Where can my family go if they need help dealing with my illness?	This is something that MacMillan or Maggie's can help you with, as they have great experience in this respect. Their contact information can be found on the "useful contacts" section.
Animation button: How to talk to my family and friends about my illness?	Same as above
Animation button: Where can I get help to deal with my feelings about my illness?	This is something that your keyworker, such as your Specialist Nurse will help you with. This is also something that MacMillan or Maggie's can help you with. Their contact information can be found on the "useful contacts" section.
Animation button: What to do if I become concerned about dying?	If you become concerned about dying, please talk to any healthcare professional that looks after you. This includes your GP, as well as any member of your cancer care team. This is something that Maggie's or MacMillan can also help you with. Contact information for both can be found on the "useful contacts" section.
Animation button: Where can I get help if I don't feel as attractive as before?	This is something that MacMillan or Maggie's can help you with, as they have great experience in this respect. Their contact information can be found on the "useful contacts" section.

Animation button: What to do if I feel uncomfortable in social situations?	Same as above
Subsection 2: Financial support / help with finances	
Animation button: Will there be any financial support available to me during my illness?	Yes. MacMillan can provide advice and help you with your finances. Pending what is available in local Trusts, something like a citizens' advice bureau will be available. This will assist you in applying for benefits and has plenty of information for patients who are already receiving benefits or tax credits. Contact details are provided in the "Useful contacts" section.
Subsection 3: Help with diet and everyday life	
Animation button: Who to call if I have questions while I am still getting treatment?	You can refer your questions to your consultant or nurse keyworker after treatment. Your consultant or nurse have provided you with a 24-hour emergency number if you have an urgent question or if you need to report a side effect or complication of treatment.
Animation button: Who do I have to call if I have any questions after the treatment is finished?	You will still be able to refer your questions to your consultant or nurse keyworker after treatment. Maggie's and MacMillan can also help you. Keep a list of these questions so you can re-visit them when you want. You can use the "My Notes" section of the app to create your custom questions and have them all saved in one place.
Animation button: Who to talk to about alternative treatments?	This is something that your consultant, nurse or pharmacist can help you with. Refer to them for further information about this.
Animation button: How may the illness affect my life over the next few months?	This is different for each patient and will depend on the stage of your condition, as well as how well you will tolerate your treatment. You can discuss this with any member of your medical care team.
Animation button: How may the illness affect my life in the future?	This is different for each patient and will depend on the stage of your condition, as well as your general health state. You can discuss this with your consultant or your nurse Keyworker.
Animation button: Will there be changes in usual things I can do with or for my family?	Same as above.
Animation button: Will I be able to continue with my usual hobbies and sports?	Patients are generally able to continue with their usual activities and hobbies. In some cases, you might need to make several modifications, which can be either temporary or permanent. This will depend on how well you tolerated chemotherapy and how well it worked. The members of your care team will discuss this with you.

Animation button: Will I be able to continue with my usual activities (physical/ social/professional)?	Same as above
Animation button: Will the illness or treatment affect my relationships/sex life?	Chemotherapy can have some effect on your sex life. However, we cannot know until after you have had several doses of the medicines. Your doctor or nurse will provide a range of advice at different stages of treatment.
Animation button: Are there any physical things I should not do/avoid?	Generally, there are no physical things that you should avoid. However, if you had recent surgery for your condition, you must avoid stooping or lifting weights for several weeks after surgery. Your surgeon will provide more advice about this.
Animation button: Are there any special exercises I can do?	Patients are highly encouraged to maintain normal activity and perform mild exercise. With respect to special exercises, this would depend on your symptoms and on whether or not you had previous surgery for bowel cancer. Your surgeon or surgical nurse will provide you with information about this.
Animation button: Am I going to need help taking care of myself?	This will depend upon your symptoms and how you tolerate treatment, both of which will determine the level of care required, as well as its duration. If you are concerned about this, ask your doctor or nurse keyworker for further information.
Animation button: Will I be able to take a bath or shower?	Generally, yes. If you are concerned about needing help during showering or advice around how to shower if you have a stoma, ask your doctor or nurse keyworker for further information.
Animation button: Are there any foods I should avoid during treatment?	Yes. This is because chemotherapy can cause side effects that can make your mouth, stomach and tummy more sensitive. Generally, you should avoid fatty, spicy or heavy foods, as these can irritate your stomach or tummy. Sour foods and drinks, as well as alcohol should also be avoided if your mouth becomes sore.
Animation button: After treatment is finished, will I be able to return to my normal eating habbits?	Patients should avoid some foods and drinks because chemotherapy can cause side effects which can affect the mouth, stomach and tummy. However, these side effects are usually temporary and disappear after treatment. Hence, you will be able to gradually return to your normal eating habits.
Animation button: Can I wear normal clothing?	Yes, you should be able to wear normal clothing before and after treatment. If you have a stoma, you might find it helpful to prefer clothing that is easily unbuttoned and does expose the area around the stoma bag.

Animation button: Will treatment alter the way I look?	Side effects such as looking pale, weight or hair loss can change the way you look, but these do not occur in every patient. Moreover, such side effects usually resolve after treatment, so even if you get them, you are likely to go back to the way you looked before treatment.
Animation button: How long will it take for my incision or wound to heal?	If you had surgery, the skin wound takes 7-10 days to heal. You will be given plenty of information about this on discharge by your surgeon and your surgery nurse.
Animation button: Am I prone to infection because of my treatment?	Yes. XELOX makes you more susceptible to infections, meaning that you are at higher risk of getting ill. Your doctor and nurse will tell you what you need to do to do to protect yourself from infections.
Animation button: How should I care for my wound or incision?	You will be given advice, information and material about how to care for your wound or incision by a specialist nurse in wound care. You will also be referred to district nurses if required.
Animation button: Will I be able to continue my job after my treatment?	Generally, the answer is yes. Your doctor will discuss this with you in order to decide if it is safe and when it is safe for you to return to work.

Appendix 12: Layout of the CAPE information package

Note: Sections 1, 3, 6, 7 and 8 were the same as XELOX.

Section 2: Information about cancer and treatment	
Animation button: What is cancer?	Same as XELOX
Animation button: What causes cancer?	Same as XELOX
Animation button: Has the cancer left its original site and spread in my body?	Same as XELOX
Animation button: What are the treatment options for cancer?	Same as XELOX
Animation button: I will be given chemotherapy with Capecitabine. How will it fight cancer?	Cancer tumours are made by cancer cells. In order for tumours to grow and spread, cancer cells need to divide and multiply. Capecitabine fights tumours by preventing this from happening. Since cancer cells are not able to multiply and some of them will die, the tumours will stop growing and will gradually shrink, which is important for treatment.
Animation button: What medicines does my chemotherapy contain?	Your chemotherapy contains a single medicine, which is called Capecitabine. Capecitabine is given in cycles of treatment, each lasting for three weeks. Capecitabine comes as tablets, which you will take twice daily for the first two weeks of each chemotherapy cycle.
Animation button: Is there any preparation before I get Capecitabine?	Your doctors will order some blood tests in order to make sure that it is safe to take Capecitabine. Once the results are back, your doctor will tell you when your treatment will start.
Animation button: Do I need to be at the hospital for my treatment?	Dome chemotherapy regiments contain medicines that need to be given at the hospital. However, your treatment does not contain such medicines, so you don't need to worry about this. Capecitabine comes as tablets, which you will take from home.
Animation button: If Capecitabine treats my cancer, what are the	Same as XELOX

chances of it coming back?	
Animation button: How can I tell if the cancer has come back?	Same as XELOX

Section 4 (Help with side effects)	
Subsection 4.1.: Side effects of CAPE	
Part 1 Button Very common side effects (more than 1 in 10 patients)	Animation button: How likely am I to get a very common side effect? - Same as XELOX *(Text) List of very common side effects:* • Loss of appetite • Diarrhoea • Nausea (feeling sick) and vomiting (being sick) • Mouth problems (sore mouth) • Pain in your stomach • Numbness or tickling in fingers and toes • Soreness, redness and peeling on palms and soles • Feeling tired (Fatigue) • Feeling ill (Asthenia)
Part 2 Button Common side effects (up to 10 in 100 patients)	Animation button: How likely am I to get a common side effect? -Same as XELOX *(Text) List of common side effects:* • Cold sores (herpes viral infection) • Breathlessness and looking pale (due to decreased number of white blood cells and/or red blood cells) • Weight loss • Sleeplessness (Insomnia) • Depression – low mood • Headaches • Dizziness • Taste disturbances (changes in taste) • Eye problems (runny eyes, eye irritation, eye infections) • Thrombophlebitis (formation of blood clots) • Constipation • Tummy pain • Bloating • Changes in liver function

	• Skin problems (rash, dry skin, skin inflammation) • Hair thinning or hair loss • Pain (chest pain, pack pain, generalised pain the body) • Infections (generalised or respiratory) and getting/feeling ill (fever, cough, runny nose, sore throat)
Part 3 Button Uncommon side effects (up to 10 in 1,000 patients)	Animation button: How likely am I to get an uncommon side effect? Same as XELOX *(Text) List of uncommon side effects:* • Joint swelling, bone pain, stiffness, muscular weakness • Kidney problems (incontinence, blood in wee, having to wake up at night to wee) • Vaginal haemorrhage (unexpected blood flow from the vagina) • Gastrointestinal problems (tummy pain, discomfort, blood in stools) • Severe skin problems (blisters, ulcers, sensitivity to light, swelling in the face) • Jaundice (skin turning yellow because of liver problems) • Heart problems (changes in the way your heart beats, high or low blood pressure) • Severe breathing problems (being unable to breathe properly or finding it hard to breathe) • Spitting blood (also known as haemoptysis) • Memory/cognitive disorders (problems with movement, coordination and speech, memory problems, confusion) • Visual problems (clarity of vision reduced, double vision) • Vertigo (feeling that everything around you is spinning), • Infections (sepsis, urinary tract infection, skin infections, tonsillitis, pharyngitis, fungal infections, influenza, gastroenteritis, tooth abscess) • Lipoma (small, fatty lumps on the skin) • Blood problems (changes in the composition of blood, which doctors will pick up from blood tests) • Metabolic disorders (diabetes, low potassium levels, high triglyceride levels, which doctors will pick up from blood tests) • Mood disorders (anxiety, low sexual drive) • Ear pain
Part 4 button Rare side effects (up to 10 in 10,000 patients)	Animation button: How likely am I to get a rare side effect? - Same as XELOX *(Text) List of rare side effects:*

		• Severe eye problems (lacrimal duct stenosis, corneal disorders, keratitis and punctate keratitis) • Severe heart problems (ventricular fibrillation, QT prolongation, torsade de pointes, Bradycardia, Vasospasm) • Severe liver problems (hepatic failure, cholestatic hepatitis) • Severe skin problems
Subsection 4.2.: Help and advice on dealing with side effects		
Part 1 Button Help with very common side effects	Animation button: Loss of appetite	Same as XELOX
	Animation button: Diarrhoea	Same as XELOX
	Animation button: Nausea (feeling sick) and vomiting (being sick)	Same as XELOX
	Animation button: Mouth sores and ulcers	Same as XELOX
	Animation button: Pain in your stomach	Same as XELOX
	Animation button: Numbness or tickling in fingers and toes	Same as XELOX
	Animation button: Soreness, redness and peeling on palms and soles	Same as XELOX
	Animation button: Feeling tired (Fatigue)	Same as XELOX

	Animation button: Feeling ill (Asthenia)	Same as XELOX
Part 2 Button Help with common side effects	Animation button: Cold sores (herpes viral infection)	Same as XELOX
	Animation button: Breathlessness and looking pale (due to decreased number of white blood cells and/or red blood cells)	Same as XELOX
	Animation button: Weight loss	Same as XELOX
	Link button: Link for MacMillan	Same as XELOX
	Link button: Link for Cancer Research UK	Same as XELOX
	Animation button: Sleeplessness (Insomnia)	Same as XELOX
	Link button: Link for MacMillan	Same as XELOX
	Animation button: Depression – low mood	Same as XELOX
	Animation button: Headaches	Same as XELOX
	Animation button: Dizziness	Same as XELOX

	Animation button: Taste disturbances (changes in taste)	Same as XELOX
	Link button: Link for Cancer Net	Same as XELOX
	Animation button: Eye problems (runny eyes, eye irritation, eye infections)	Same as XELOX
	Animation button: Constipation	Same as XELOX
	Animation button: Tummy pain	Same as XELOX
	Animation button: Bloating	Same as XELOX
	Link button: Link for Cancer Research UK	Same as XELOX
	Link button: Link for Stanford Health	Same as XELOX
	Animation button: Dry mouth	Same as XELOX
	Animation button: Skin problems (rash, dry skin, skin inflammation)	Same as XELOX
	Animation button: Hair thinning or hair loss	Same as XELOX
	Animation button:	Same as XELOX

	Pain (chest pain, pack pain, generalised pain the body)	
	Animation button: Infections (generalised or respiratory) and getting/feeling ill (fever, cough, runny nose, sore throat)	Same as XELOX
Part 3 Button Help with uncommon side effects	Animation button: General advice for uncommon side effects- Same as XELOX List of uncommon side effects that need to be reported to Triage at once: • Joint swelling, bone pain, stiffness, muscular weakness • Kidney problems (incontinence, blood in wee, having to wake up at night to wee) • Vaginal haemorrhage (unexpected blood flow from the vagina) • Gastrointestinal problems (tummy pain, discomfort, blood in stools) • Severe skin problems (blisters, ulcers, sensitivity to light, swelling in the face) • Jaundice (skin turning yellow because of liver problems) • Heart problems (changes in the way your heart beats, high or low blood pressure) • Severe breathing problems (being unable to breathe properly or finding it hard to breathe) • Spitting blood (also known as haemoptysis) • Memory/cognitive disorders (problems with movement, coordination and speech, memory problems, confusion) • Visual problems (clarity of vision reduced, double vision) • Vertigo (feeling that everything around you is spinning),	

Section 5: (Help with your medicines)	
Subsection 1: Chemotherapy medicines	
Animation button: Capecitabine (tablets)	Same as XELOX

Animation button: How should I take the Capecitabine tablets?	Same as XELOX
Animation button: What happens if I miss a dose of Capecitabine?	Same as XELOX
Animation button: What happens if I vomit after I take Capecitabine?	Same as XELOX
Animation button: If I get side effects, from XELOX, how long will they last for?	Same as XELOX
Subsection 2: Chemotherapy supportive medication- Same as XELOX	

Appendix 13: Layout of the FOLFOX information package

Note: Sections 1, 3, 6, 7 and 8 were the same as XELOX.

Section 2: Information about cancer and treatment	
Animation button: What is cancer?	Same as XELOX
Animation button: What causes cancer?	Same as XELOX
Animation button: Has the cancer left its original site and spread in my body?	Same as XELOX
Animation button: What are the treatment options for cancer?	Same as XELOX
Animation button: I will be given chemotherapy with FOLFOX. How does this treatment fight bowel cancer?	In order for tumours to grow and spread, cancer cells need to divide and multiply. Your chemotherapy contains three medicines, which work in combination to fight cancer. Oxaliplatin prevents cancer cells from multiplying, while 5-fluorouracil works by killing them. Folinic acid is not a chemotherapy medicine, but it is given to boost the effects 5-fluorouracil, so it can kill more cancer cells. All these effects make tumours stop growing and gradually shrink, which is important for treatment.
Animation button: What medicines does FOLFOX contain?	Your chemotherapy is known as FOLFOX and contains three medicines. These are Oxaliplatin, folinic acid and 5 fluorouracil, also known as 5-FU. These medicines are given as cycles of treatment, each lasting for 14 days. To find out more about these, please use the 'help with your medicines' section of the app.
Animation button: Is there any preparation before I get FOLFOX?	Same as XELOX
Animation button: How will I feel during and after my treatment at the hospital?	Same as XELOX

Animation button: If FOLFOX cures my cancer, what are the chances of it coming back?	Same as XELOX
Animation button: How can I tell if the cancer has come back?	Same as XELOX

Section 4 (Help with side effects)	
Animation button: Meet the Oncologist (Andrew) Same as XELOX	
Subsection Button: Side effects of FOLFOX	
Part 1 Button Very common side effects (more than 1 in 10 patients)	Animation button: How likely am I to get a very common side effect? - Same as XELOX ***List of very common side effects*** *(grouped according to the system they can affect)* • **Blood disorders:** Bruising, decreased production of blood cells, decreased red blood cells, decreased white blood cells, decreased neutrophils, decreased lymph cells, decreased number of cells responsible for blood clots • **Gastrointestinal side effects:** Tummy pain, loss of appetite, constipation, diarrhoea, difficulty in swallowing, feeling or being sick, heartburn, mouth soreness, redness and pain around the anus • **Immune system disorders:** Allergy/allergic reaction to the medicines, reaction at the site you got your injection or drip (redness, pain, swelling, itchiness), fever, weakening of the immune system, increased risk of infections • **Skin problems:** Hair thinning or hair loss, Palmar-plantar erythrodysaesthesia syndrome (hand-foot syndrome), sensitivity to light • **General disorders and administration site conditions:** Asthenia (feeling Ill), back pain, bleeding (nose bleeds), delayed wound healing, fatigue (feeling tired), pain (generalised) • **Heart problems:** Ischemic ECG abnormalities (changes in the way your heart works) • **Respiratory system problems:** Cough, difficulty in breathing

	• **Metabolic disorders:** Increased blood sugar, increase in liver enzymes, weight gain, decreased levels of potassium and sodium • **Nervous system problems:** Headaches, peripheral sensory neuropathy (nerve damage), sensory disturbances (changes affecting your vision, taste, hearing etc.)
Part 2 Button Common side effects (up to 10 in 100 patients)	Animation button: How likely am I to get a common side effect? - Same as XELOX *List of common side effects* • **Blood disorders:** Febrile neutropenia and neutropenic sepsis (manifests with symptoms similar to those of the flu like fever, chills and/or sweating, sore throat, cough, diarrhoea) • **Gastrointestinal side effects:** Dyspepsia (difficulty in digesting food), gastro-oesophageal reflux (heartburn), gastrointestinal haemorrhage (bleeding across the gastrointestinal tract, which makes stools darker than normal), hiccups, rectal bleeding • **Skin problems:** Flushing (redness), skin exfoliation (peeling of the skin at hands and feet), nail disorder (nails becoming soft and/or brittle, discoloration in nails), skin rash (skin becoming dry, red, scaly and/or itchy) • **General disorders and administration site conditions:** Joint and/or bone pain, dehydration, hyperhidrosis (excessive sweating), meningism (manifests with neck stiffness, sensitivity to light and headaches) • **Heart problems:** Deep vein thrombosis (which manifests with pain, swelling, redness and itchiness in one of your legs, usually the calf), hypertension (high blood pressure) • **Eye problems:** Conjunctivitis (eye infections), visual disturbances (blurred vision, double vision, reduced eyesight, decreased tolerance to light) • **Respiratory system problems:** Pulmonary embolism (similar symptoms to deep vein thrombosis plus fever, sweating, dizziness and/or rapid heartbeat), rhinitis (blocked or runny nose), upper respiratory tract infections (manifest with blocked nose, cough, difficulty in breathing, sore throat and/or fever) • **Nervous system disorders:** Depression (low mood), dizziness, insomnia (sleeplessness), motor neuritis (difficulty in coordinating your movements, including the movement of the eyelid) • **Urinary disorders:** Dysuria (discomfort while weeing), haematuria (presence of blood in urine), changes in how often you wee

Part 3 Button Uncommon side effects (up to 10 in 1,000 patients)	Animation button: How likely am I to get an uncommon side effect? - Same as XELOX *List of uncommon side effects* • Gastrointestinal side effects: *Ileus* (decrease in the movement of the bowels), *intestinal obstruction* (blockage in your intestines which manifests with constipation and tummy pain), *dehydration* (lack of water in the body), *gastrointestinal ulceration* (ulcers across the gastrointestinal tract) and bleeding • Immune system disorders: *Sepsis* (severe form of infections) • Skin problems: *Hyperpigmentation of the skin* (darkening of the skin), *depigmentation near the veins* (lightening of the skin around the veins) • Heart problems: *Arrhythmia* (irregular heartbeat), *myocardial infarction* (known as heart attack, which manifests with chest pain, shortness of breath and dizziness), *myocardial ischemia* (decreased blood flow in the heart, which gives symptoms similar to those of myocardial infarction), *myocarditis* (damage of the heart's muscles, which gives symptoms similar to those of myocardial infarction), *hypotension* (low blood pressure) • Ear problems: *Ototoxicity* (problems to your ears, which can cause ringing in your ears or affect your hearing) • Metabolic disorders: *Damage to your kidneys* (which will manifest through changes in your wee), *damage to your liver* (if they become severe, they can manifest as yellowing of the skin and the white of the eyes) • Nervous system disorders: *Nervousness, nystagmus* (feeling sleepy), *symptoms of Parkinson's disease* (such as tremor in hands, loss of memory etc.), *euphoria* (intense feeling of happiness or excitement) • Fertility problems: *Problems with spermatogenesis* (producing sperm cells) *in men and ovulation disorder in women*
Part 4 button Rare side effects (up to 10 in 10,000 patients)	Animation button: How likely am I to get a rare side effect? - Same as XELOX *List of rare side effects* • Blood disorders: Haemolytic anaemia, immunoallergic thrombocytopenia • Gastrointestinal side effects: Colitis (inflammation of the blows), including clostridium difficile • Immune system disorders: Generalized allergic reactions, anaphylaxis, and anaphylactic shock.

	• **Heart problems:** Cerebral ischaemia (decreased blood flow to the brain) , intestinal ischaemia (decreased blood flow to the bowels), peripheral ischemia (decreased blood flow across the body), Raynaud's syndrome (decreased blood flow in the body, which usually makes fingers and toes go white), thromboembolism (manifests with chest pain, shortness of breath and dizziness), thrombophlebitis/vein tracking (manifests as veins hardening and going darker in colour, limb pain, swelling in arms and/or legs) • **Ear problems:** Deafness • **Eye problems:** Optic neuritis (damage of the eye nerves), gradual loss of vision • **Respiratory system problems:** Interstitial lung disease, pulmonary fibrosis (gives symptoms such as persistent and intense cough, difficulty in breathing etc.) • **Metabolic disorders:** Pancreatitis (damage of the pancreas), increase of T4 (total thyroxin), increase of T3 (total triiodothyronine). • **Nervous system disorders:** Dysarthria (difficulty in speech, slurred speech), reversible Posterior Leukoencephalopathy syndrome	
Subsection 4.2.: Help and advice on dealing with side effects		
Part 1 Button Help with very common side effects	Animation button: Tummy pain	Same as XELOX
	Animation button: Loss of appetite	Same as XELOX
	Animation button: Constipation	Same as XELOX
	Animation button: Diarrhoea	Same as XELOX
	Animation button: Difficulty in swallowing and/or breathing.	Same as XELOX
	Animation button: Feeling or being sick	Same as XELOX
	Animation button: Heartburn	Same as XELOX
	Animation button: Mouth soreness	Same as XELOX
	Animation button: Reaction at the site you have your	Same as XELOX

	injection, drip or infusion	
	Animation button: Increased risk of infections	Same as XELOX
	Animation button: Hair thinning or hair loss	Same as XELOX
	Animation button: Palmar-plantar erythrodysaesthesia syndrome (hand-foot syndrome)	Same as XELOX
	Animation button: Asthenia (feeling Ill)	Same as XELOX
	Animation button: Fatigue (feeling tired)	Same as XELOX
	Animation button: Pain (local or generalised)	Same as XELOX
	New Animation button: Breathlessness /Difficulty in breathing	Same as XELOX
	Animation button: Headaches	Same as XELOX
	Animation button: Taste disturbances (changes in taste)	Same as XELOX
	Link button: Link for Cancer Net	Same as XELOX
Part 2 Button Help with common side effects	Animation button: Skin problems	Same as XELOX
	New Animation button: Hyperhidrosis (excessive sweating)	Same as XELOX
	Animation button: Eye problems	Same as Capecitabine
	Animation button:	Same as XELOX

	Depression (low mood)	
	Animation button: Dizziness	Same as XELOX
	Animation button: Insomnia (sleeplessness)	Same as XELOX
	NEW Link button: Link for MacMillan	Same as XELOX
Part 3 Button Help with uncommon side effects	Animation button: Ringing in your ears	Same as XELOX
	Animation button: Feeling tired and/or sleepy	Same as XELOX
	New Animation button: Problems affecting fertility (both men and women)	Same as XELOX
Part 3 Button Help with rare side effects	Animation button: Pain (chest pain or generalised pain)	Same as XELOX
	New Animation button: Loss of hearing or Loss of vision	Same as XELOX

Section 5: Help with side effects	
Subsection 5.1: Chemotherapy medicines	
Animation button: What is the difference between FOLFOX-4 and FOLFOX-6?	FOLFOX-4 and FOLFOX-6 are two different ways of getting your treatment, but they both contain the same medicines. In Folfox-6, you get a long infusion of 5-FU over 2 days, while in Folfox 4, you get two slower infusions of 5-FU, each lasting for 22 hours. In both schedules, the treatment cycle lasts for 14 days and you only get chemotherapy medicines for the first two days.
Animation button: Where will I get my treatment?	Oxaliplatin and folinic acid will be given to you at the hospital. If you have a catheter or a port, you will be able to take 5-FU from home through a chemotherapy pump. However, if you have neither of those, you will need to stay at the hospital for the first two days of each chemotherapy cycle. Your doctor will discuss this with you.
Animation button: If I get side effects, from FOLFOX, how long will they last for?	Same as XELOX
Subsection 2: Chemotherapy supportive medication- Same as XELOX	

Subsection 3: Your chemotherapy pump	
Animation button: What is a chemotherapy pump?	A chemotherapy pump is a device that delivers a steady amount of chemotherapy medicines to your blood over several hours. The pump is a small device and will be given to you with a bag or belt holster, so you can carry it with you.
Where do I get a chemotherapy pump and how do I use it?	Your chemotherapy pump will be prepared for you at the hospital on the first day of each cycle. A pharmacist will check the medicines that go in and a nurse will set it up and attach it to your catheter or port through a tube. The nurse will also give you instructions and printed material on how to use your pump from home.
Will I be able to carry out normal activities while using the chemotherapy pump?	You should be able to carry out your normal activities while having your treatment through the pump. However, please avoid activities that may cause pulling of the tube, such as exercise and playing with children or pets. Also, when taking a bath or shower, avoid getting the catheter dressing wet and do not let the pump go underwater.
How to take care of my pump at home?	Please always keep the pump in the pouch supplied by the hospital. Please do not expose the pump to extreme temperatures and protect it from light, as both can affect the way the device works and damage the medicine.
How can I check if my chemotherapy pump is working properly?	The chemotherapy pump contains a balloon filled with the medicine. Over time, this balloon will shrink gradually to deliver the medicines to your body. The nursing staff will show you how to check that this is done correctly. Please remember to check the pump every 8 hours to make sure that the balloon is shrinking at the correct pace and call Triage at once if you notice something wrong.
What should I do if I notice a spillage or leakage of the medicines from the pump?	Before you go home, your nurse will provide you with special equipment and a set of written instructions on what to do in the event of a spillage or leakage of medicines from the pump. Please follow these instructions to clear any spillage and report to Triage as soon as you do so.

Appendix 14: System Usability Scale

App Usability Questionnaire

Thank you for agreeing to help us with our research. Here, we provide you with a **TWO** (**2**) page-long questionnaire. We expect that this should take **no longer than 10 minutes to complete**.

Please attempt to answer **ALL** questions.

All your responses, as well as your personal details will be kept confidential.

Please DO NOT write your name or any other personal information (e.g. NHS number, home address, personal email etc.) **anywhere on this document.** Instead, please use your assigned username. This is done in order to maintain confidentiality and protect your anonymity in the study.

If you have any queries or are unsure about a question, please ask for help from the member of staff who provided this questionnaire to you.

PLEASE WRITE YOUR USERNAME IN THE BOX PROVIDED BELOW. This is the username provided to you when you signed up for the study to unlock the app.

If you have forgotten your username, please refer to the member of staff who gave you this questionnaire to help you retrieve it.

Date: ☐☐/☐☐/ 20☐☐

Keele UNIVERSITY

NHS Oxford University Hospitals NHS Foundation Trust

App Usability Questionnaire

The questionnaire below aims to understand how easy it was for you to use the app. For questions 1-10, please indicate your response by ticking the appropriate box.

1. I think that I would like to use this app frequently

Strongly disagree	Disagree	Neither agree nor disagree	Agree	Strongly agree

2. I found the app unnecessary complex

Strongly disagree	Disagree	Neither agree nor disagree	Agree	Strongly agree

3. I thought that the app was easy to use

Strongly disagree	Disagree	Neither agree nor disagree	Agree	Strongly agree

4. I needed the support of another person in order to use the app

Strongly disagree	Disagree	Neither agree nor disagree	Agree	Strongly agree

5. I found that the functions of the app were well integrated

Strongly disagree	Disagree	Neither agree nor disagree	Agree	Strongly agree

6. I thought that there was too much inconsistency in this app

Strongly disagree	Disagree	Neither agree nor disagree	Agree	Strongly agree

7. I would think that most people would learn to use this app very quickly

Strongly disagree	Disagree	Neither agree nor disagree	Agree	Strongly agree

8. I found the app very awkward to use

Strongly disagree	Disagree	Neither agree nor disagree	Agree	Strongly agree

9. I felt very confident using the app

Strongly disagree	Disagree	Neither agree nor disagree	Agree	Strongly agree

10. I needed to learn a lot of things before I could get going with this app.

Strongly disagree	Disagree	Neither agree nor disagree	Agree	Strongly agree

Information Needs and Demographics Questionnaire

Thank you for agreeing to help us with our research. Here, we provide you with a **FOUR** (**4**) page-long questionnaire. We expect that this should take **no longer than 25 minutes to complete**.

Please attempt to answer **ALL** questions.

All your responses, as well as your personal details will be kept confidential.

Please DO NOT write your name or any other personal information (e.g. NHS number, home address, personal email etc.) **anywhere on this document.** Instead, please use your assigned username. This is done in order to maintain confidentiality and protect your anonymity in the study.

If you have any queries or are unsure about a question, please email the project lead (Alexandros.Chatzixenitidis@ouh.nhns.uk) at any time.

PLEASE WRITE YOUR USERNAME IN THE BOX PROVIDED BELOW. This is the username provided to you when you signed up for the study to unlock the app.

If you have forgotten your username, please email the project lead (Alexandros.Chatzixenitidis@ouh.nhns.uk) at any time.

Date: ☐☐/☐☐/ 20☐☐

Keele UNIVERSITY

NHS Oxford University Hospitals NHS Foundation Trust

Information needs of patients with Bowel Cancer

Our team is interested in knowing the types of information that you need.

How important is it for you to have each of the following types of information?	**1= Not important 2= Slightly important 3=Moderately important 4= Very important 5= Extremely important**				
	1	**2**	**3**	**4**	**5**
How I will feel during or after the tests	☐	☐	☐	☐	☐
If the bowel cancer will come back	☐	☐	☐	☐	☐
How to prepare for my treatment	☐	☐	☐	☐	☐
How I will feel after my treatment	☐	☐	☐	☐	☐
Who to call if I have questions while I am still getting treatment	☐	☐	☐	☐	☐
How bowel cancer acts in the body	☐	☐	☐	☐	☐
If there are groups where I can talk with other people with cancer	☐	☐	☐	☐	☐
If there are ways to prevent or ease side effects of treatment	☐	☐	☐	☐	☐
How the illness may affect my life over the next few months	☐	☐	☐	☐	☐
If there will be changes in usual things I can do with or for my family	☐	☐	☐	☐	☐
If there is cancer anywhere else in my body	☐	☐	☐	☐	☐
Who to call if I have questions after all the treatments are over	☐	☐	☐	☐	☐
If it is known what causes bowel cancer	☐	☐	☐	☐	☐
How the tests are done	☐	☐	☐	☐	☐
Why do they need to test my blood	☐	☐	☐	☐	☐
Who to talk to about treatment other than surgery/chemo/radiotherapy	☐	☐	☐	☐	☐
How the illness may affect my life in the future	☐	☐	☐	☐	☐
What the results of my blood tests mean	☐	☐	☐	☐	☐
Where my family can go if they need help dealing with my illness	☐	☐	☐	☐	☐

How important is it for you to have each of the following types of information?	1= Not important 2= Slightly important 3=Moderately important 4= Very important 5= Extremely important				
	1	2	3	4	5
How to care for my wound or incision	☐	☐	☐	☐	☐
What to do if I become concerned about dying	☐	☐	☐	☐	☐
If I can continue with my usual hobbies and sports	☐	☐	☐	☐	☐
If I can wear my normal clothing	☐	☐	☐	☐	☐
Where I can get help to deal with my feelings about my illness	☐	☐	☐	☐	☐
How to talk to my family and friends about my illness	☐	☐	☐	☐	☐
If I have side effects, how to deal with them	☐	☐	☐	☐	☐
The possible side effects of my treatment	☐	☐	☐	☐	☐
What side effects I should report to the doctor or nurse	☐	☐	☐	☐	☐
If I am prone to infection because of my treatment	☐	☐	☐	☐	☐
How long my wound or incision will take to heal	☐	☐	☐	☐	☐
How long will I be receiving treatment	☐	☐	☐	☐	☐
How I will feel after the tests	☐	☐	☐	☐	☐
Where to get help if I have problems feeling as attractive as before	☐	☐	☐	☐	☐
How the treatment works against the cancer	☐	☐	☐	☐	☐
If there are any special exercises I can do	☐	☐	☐	☐	☐
The medical name for my type of cancer	☐	☐	☐	☐	☐
If there are any physical things I should not do	☐	☐	☐	☐	☐
If I am going to need help taking care of myself	☐	☐	☐	☐	☐
How my treatment is done	☐	☐	☐	☐	☐
If the treatment will alter the way I look	☐	☐	☐	☐	☐
How to tell if the cancer has come back	☐	☐	☐	☐	☐
Which foods I can or cannot eat	☐	☐	☐	☐	☐
If I can take a bath or shower	☐	☐	☐	☐	☐
What types of treatment are available	☐	☐	☐	☐	☐

How important is it for you to have each of the following types of information?	1= Not important 2= Slightly important 3=Moderately important 4= Very important 5= Extremely important				
	1	2	3	4	5
Why the doctor suggested this treatment plan for me	☐	☐	☐	☐	☐
The reason the doctor suggests certain tests	☐	☐	☐	☐	☐
How to prepare for the tests	☐	☐	☐	☐	☐
What to do if I feel uncomfortable in social situations	☐	☐	☐	☐	☐
If my illness is hereditary	☐	☐	☐	☐	☐
If my illness/surgery/treatment will affect my relationships/sex life	☐	☐	☐	☐	☐
If I will be able to continue with my job after my surgery/treatment	☐	☐	☐	☐	☐
If there is any financial support available to me during my illness	☐	☐	☐	☐	☐
If I can continue with my usual physical and social activities	☐	☐	☐	☐	☐

Several studies have suggested that factors such as age, marital and educative status are associated with cancer patients' information needs. In our study, we will also aim to explore if there is a relationship between these factors and your desire for information. Therefore, it is important for us to know these characteristics in order to be able to establish possible relationships. For questions 1-10, please tick each box as appropriate.

Q.1 Which of the following age groups are you in?

- 18-29 years old ☐
- 30-49 years old ☐
- 50-64 years old ☐
- 65-74 years old ☐
- 75 years and above ☐
- Prefer not to say ☐

Q2. What is your gender?

- Male ☐
- Female ☐
- Prefer not to say ☐

Q3. What I your ethnicity?

- White (British) ☐
- White (Other) ☐
- Black ☐
- Asian/Chinese ☐
- Other/Prefer not to say ☐

Q4. What is your marital status?

- Single ☐
- Partnered ☐
- Married ☐
- Divorced ☐
- Widowed ☐
- Other/ Prefer not to say ☐

Q5. Which is the highest level of education you have attended?

- Primary Education (Primary School) ☐
- Secondary Education (Secondary School) ☐
- Higher Education (University) ☐
- Prefer not to say ☐

Q6. What is your employment status?

- Employed (full time) ☐
- Employed (part time) ☐
- Claiming State Benefits ☐
- Retired ☐
- Unemployed ☐
- Prefer not to say ☐

Q7. How often do you need to have someone help you when you read instructions, pamphlets, or other written material from your doctor or pharmacy?

- Never ☐
- Rarely ☐
- Sometimes ☐
- Often ☐
- Always ☐
- Prefer not to say ☐

Q8. How comfortable are you with using smartphone or tablet apps?

- Extremely comfortable ☐
- Very comfortable ☐
- Somewhat comfortable ☐
- Not comfortable ☐
- Not comfortable at all ☐

Q9. When you were first diagnosed with cancer?

- Less than 3 months ago ☐
- 3 to 6 months ago ☐
- 6 to 12 months ago ☐
- More than 12 months ago ☐

Q10. Have you had any other treatment for cancer in the past?

- No, I am getting cancer treatment for the first time ☐
- Yes, I had surgery for cancer in the past ☐
- Yes, I had radiotherapy for cancer in the past ☐
- Yes, I had both surgery and radiotherapy for cancer in the past ☐

Satisfaction with Information Questionnaire

Thank you for agreeing to help us with our research. Here, we provide you with a **THREE** (**3**) page-long questionnaire. We expect that this should take **no longer than 25 minutes to complete**.

PLEASE NOTE that this questionnaire looks very similar to the first one you completed when you entered the study. However, this questionnaire is entirely different. Please read this carefully and contact Alexandros.Chatzixenitidis@ouh.nhs.uk if you have any queries.

Please attempt to answer **ALL** questions.

All your responses, as well as your personal details will be kept confidential. Please DO NOT write your name or any other personal information (e.g. NHS number, home address, personal email etc.) **anywhere on this document.** This is done in order to maintain confidentiality and protect your anonymity in the study.

THE FOLLOWING BOX IS FILLED WITH YOUR USERNAME. This is to help us identify your responses. This is the username provided to you when you signed up for the study to unlock the app.

Please fill the date below

Date: ☐☐/☐☐/ 20☐☐

Keele UNIVERSITY

NHS Oxford University Hospitals NHS Foundation Trust

Satisfaction with Information Questionnaire

Our team is interested in knowing if the app addressed your information needs during your first cycle of chemotherapy.

Which of the following best describes how well the need was addressed through the app?	**1= Very poorly 2= Poorly 3= Moderately 4= Good 5= Excellently**				
	1	2	3	4	5
How I will feel during or after the tests	☐	☐	☐	☐	☐
If the bowel cancer will come back	☐	☐	☐	☐	☐
How to prepare for my treatment	☐	☐	☐	☐	☐
How I will feel after my treatment	☐	☐	☐	☐	☐
Who to call if I have questions while I am still getting treatment	☐	☐	☐	☐	☐
How bowel cancer acts in the body	☐	☐	☐	☐	☐
If there are groups where I can talk with other people with cancer	☐	☐	☐	☐	☐
If there are ways to prevent or ease side effects of treatment	☐	☐	☐	☐	☐
How the illness may affect my life over the next few months	☐	☐	☐	☐	☐
If there will be changes in usual things I can do with or for my family	☐	☐	☐	☐	☐
If there is cancer anywhere else in my body	☐	☐	☐	☐	☐
Who to call if I have questions after all the treatments are over	☐	☐	☐	☐	☐
If it is known what causes bowel cancer	☐	☐	☐	☐	☐
How the tests are done	☐	☐	☐	☐	☐
Why do they need to test my blood	☐	☐	☐	☐	☐
Who to talk to about treatment other than surgery/chemo/radiotherapy	☐	☐	☐	☐	☐
How the illness may affect my life in the future	☐	☐	☐	☐	☐
What the results of my blood tests mean	☐	☐	☐	☐	☐
Where my family can go if they need help dealing with my illness	☐	☐	☐	☐	☐

Which of the following best describes how well the need was addressed through the app?	**1= Very poorly** **2= Poorly** **3= Moderately** **4= Good** **5= Excellently**				
	1	**2**	**3**	**4**	**5**
How to care for my wound or incision	☐	☐	☐	☐	☐
What to do if I become concerned about dying	☐	☐	☐	☐	☐
If I can continue with my usual hobbies and sports	☐	☐	☐	☐	☐
If I can wear my normal clothing	☐	☐	☐	☐	☐
Where I can get help to deal with my feelings about my illness	☐	☐	☐	☐	☐
How to talk to my family and friends about my illness	☐	☐	☐	☐	☐
If I have side effects, how to deal with them	☐	☐	☐	☐	☐
The possible side effects of my treatment	☐	☐	☐	☐	☐
What side effects I should report to the doctor or nurse	☐	☐	☐	☐	☐
If I am prone to infection because of my treatment	☐	☐	☐	☐	☐
How long my wound or incision will take to heal	☐	☐	☐	☐	☐
How long will I be receiving treatment	☐	☐	☐	☐	☐
How I will feel after the tests	☐	☐	☐	☐	☐
Where to get help if I have problems feeling as attractive as before	☐	☐	☐	☐	☐
How the treatment works against the cancer	☐	☐	☐	☐	☐
If there are any special exercises I can do	☐	☐	☐	☐	☐
The medical name for my type of cancer	☐	☐	☐	☐	☐
If there are any physical things I should not do	☐	☐	☐	☐	☐
If I am going to need help taking care of myself	☐	☐	☐	☐	☐
How my treatment is done	☐	☐	☐	☐	☐
If the treatment will alter the way I look	☐	☐	☐	☐	☐
How to tell if the cancer has come back	☐	☐	☐	☐	☐
Which foods I can or cannot eat	☐	☐	☐	☐	☐
If I can take a bath or shower	☐	☐	☐	☐	☐

Which of the following best describes how well the need was addressed through the app?	**1= Very poorly 2= Poorly 3= Moderately 4= Good 5= Excellently**				
	1	**2**	**3**	**4**	**5**
What types of treatment are available	☐	☐	☐	☐	☐
Why the doctor suggested this treatment plan for me	☐	☐	☐	☐	☐
The reason the doctor suggests certain tests	☐	☐	☐	☐	☐
How to prepare for the tests	☐	☐	☐	☐	☐
What to do if I feel uncomfortable in social situations	☐	☐	☐	☐	☐
If my illness is hereditary	☐	☐	☐	☐	☐
If my illness/surgery/treatment will affect my relationships/sex life	☐	☐	☐	☐	☐
If I will be able to continue with my job after my surgery/treatment	☐	☐	☐	☐	☐
If there is any financial support available to me during my illness	☐	☐	☐	☐	☐
If I can continue with my usual physical and social activities	☐	☐	☐	☐	☐

Appendix 17: Semi-structured participant interview guide

A Novel Health Information Support App for Patients with Cancer

Alexandros Ioannis Chatzixenitidis
PhD student
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Semi-structured participant interview guide

IRAS project ID: 240263 **Version:** 2.0 **Date:** 18/11/2018

INTERVIEW GUIDE

Introduction

1. Introduce yourself (what you do, your role in the project)
2. Ensure that participants feel comfortable having the interview. Thank them for their time and willingness to help you with your project.
3. Obtain consent; briefly explain the purpose of the interview (them reflecting on their experiences with using the app, the degree of the app's usability, the extent to which they were satisfied with the information support through the app and their recommendations for improvement); reassure patient about confidentiality; state the expected duration of the interview; state clearly that the interview will be recorded and transcribed by yourself; briefly explain what will happen to the results of the study; explain that he/she is able to pause or terminate the interview whenever deemed fit; if participant is comfortable to proceed, ask them to sign the document (one copy for the study and one copy for them); begin the interview.

Main interview

a. Could you tell me more about your experience from the app?

   i. How familiar are you with using apps in general?
   ii. Have you used another health app in the past? What was it about?
   iii. How would you compare your past experiences with the app you used now? What was done differently?

b. Compared to other ways of getting information, which one would you say you preferred and used most? Why?

c. Did you download the app to more than one devices?

   i. On which one would you say you used it mostly and why?

d. How often would you say you used the app?

e. How did you use the app over time?

   i. In terms of overall use, did this change over time? Why?
   ii. Did you use different sections before and after treatment? Why?
   iii. How do you think you might use it in the future? Why?

f. Which section of the app did you use or enjoy the most? Why? (take a note)

g. Which section of the app did you use or enjoy the least? Why? (take a note)

Usability of the app and experiences with avatars

a. How easy or hard it was to use the app?

i. What made it hard for you to use the app? (take a note)
ii. Was there something that facilitated the use of the app (i.e. made it easier for you to use it)?

b. Did you need another person's assistance to use the app?

i. To what extent did you need his/her assistance? Why?

c. Who would you say used the app mostly?

i. Was it you or a member of your family? Who? How often did they use it?
ii. Did you use it together with him/her?

d. Could you tell me how the avatar influenced the app? Do you think it made things easier or harder?

i. Was any of the clinician avatars known to you? How did this influence things?
ii. What do you think about the appearance of the avatars? What would you change, if anything?

e. Did you have to learn things or do some training before using the current app?

i. What were these? How easy or hard was it to achieve these?

f. How do you think that other fellow patients might find the app?

i. Do you think they will find it easy or hard to use? Why?

Satisfaction with information

a. How much would you say the app helped you get answers to your questions?
b. What did you think of the organization and amount of information? (take a note)
c. What questions did you have that were not answered by the avatar? (take a note)
d. In your view, were there questions where the avatar's answer could have been improved?
e. Which ones? (take a note)

Recommendations for improvement

a. Do you have any recommendations for improving the app?

i. Do you think that something should be changed? (refer to what they said in 1f, 2a, 3b and 3d)
ii. In your opinion, is there something that should be added to the app?
iii. In your opinion, do you think that there is something that should be deleted from the app?
iv. Is there anything else you can think of?

Overall study experience

a. Could you tell me more about your overall experience in our study? Do you think that something should be done differently? How did you find the questionnaires and the interviews? Do you think they should be changed? How?
b. Are there any other issues that you would like to raise at this point?

Conclusion

1. Thank the participant for his/her time and help; briefly mention how has his/her views will help your research
2. Encourage patients to contact you or any other member or the research team for any questions they might have
3. In case you wish clarifications (i.e. cannot make sense of what was transcribed, need additional info etc.), ask them if they will be willing to be contacted.

Appendix 18: Approval of the second substantial amendment

NHS
Health Research Authority

London - Brighton & Sussex Research Ethics Committee

Health Research Authority
Ground Floor, Skipton House
80 London Road
London
SE1 6LH

Tel: 0207 104 8002

05 April 2019

Mr Alexandros Ioannis Chatzixenitidis
Hornbeam Building (HNB 0.24)
School of Pharmacy
Keele University
ST5 5BG

Dear Mr Chatzixenitidis

Study title:	**Developing and Testing an Avatar-Based Health Information Support App for Patients With Colorectal Cancer Receiving Chemotherapy for the First Time; A Mixed Methods Study**
REC reference:	**18/LO/0674**
Protocol number:	**Not applicable**
Amendment number:	**Substantial Amendment 2**
Amendment date:	**18 November 2018**
IRAS project ID:	**240263**

Thank you for submitting the above amendment, which was received on 04 April 2019. I can confirm that this is a valid notice of a substantial amendment and will be reviewed by the Sub-Committee of the REC at its next meeting.

Documents received

The documents to be reviewed are as follows:

Document	*Version*	*Date*
Covering letter on headed paper	SA2	08 February 2019
Interview schedules or topic guides for participants [Semi-Structured Participant Interview Guide]	2.0(tracked)	18 November 2018
Interview schedules or topic guides for participants [Semi-Structured Participant Interview Guide]	2.0	18 November 2018
Non-validated questionnaire [Information Needs and Demographics Questionnaire]	2.0 (tracked)	29 November 2018
Non-validated questionnaire [Information Needs and Demographics Questionnaire]	2.0	29 November 2018

Non-validated questionnaire [Satisfaction with Information Questionnaire]	2.0(tracked)	29 November 2018
Non-validated questionnaire [Satisfaction with Information Questionnaire]	2.0	29 November 2018
Notice of Substantial Amendment (non-CTIMP)	Substantial Amendment 2	18 November 2018
Other [Main Study Schema and timeline]	2.0(tracked)	18 November 2018
Other [Main Study Schema and timeline]	2.0	18 November 2018
Other [Pilot Study Schema and Timeline]	2.0 (tracked)	18 November 2018
Other [Pilot Study Schema and Timeline]	2.0	18 November 2018
Participant information sheet (PIS) [Information Booklet]	4.0 (tracked)	16 November 2018
Participant information sheet (PIS) [Information Booklet]	4.0	16 November 2018
Research protocol or project proposal	3.0	18 November 2018
Research protocol or project proposal	3.0(tracked)	18 November 2018

Notification of the Committee's decision

The Committee will issue an ethical opinion on the amendment within a maximum of 35 days from the date of receipt.

R&D approval

All investigators and research collaborators in the NHS should notify the R&D office for the relevant NHS care organisation of this amendment and check whether it affects R&D approval for the research.

HRA Learning

We are pleased to welcome researchers and research staff to our HRA Learning Events and online learning opportunities– see details at: https://www.hra.nhs.uk/planning-and-improving-research/learning/

18/LO/0674: **Please quote this number on all correspondence**

Yours sincerely

Ewa Grzegorska
Approvals Administrator

Email: NRESCommittee.SECoast-BrightonandSussex@nhs.net

The Committee will issue an ethical opinion on the amendment within a maximum of 35 days from the date of receipt.

R&D approval

All investigators and research collaborators in the NHS should notify the R&D office for the relevant NHS care organisation of this amendment and check whether it affects R&D approval for the research.

We are pleased to welcome researchers and R & D staff at our Research Ethics Service Committee members' training days – see details at http://www.hra.nhs.uk/hra-training/

18/LO/0674:	**Please quote this number on all correspondence**

Yours sincerely

Jake Chambers
REC Assistant

Email: nrescommittee.secoast-brightonandsussex@nhs.net

Copy to: *Professor Nicola Stoner, Churchill Hospital (OUHT)*