Co-Designing Patient-Centred Technology for Chronic Kidney Disease: Supporting the Patient Journey

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Declaration of Authenticity and Author's Rights

‘This thesis is the result of the author’s original research. It has been composed by the author and has not been previously submitted for examination which has led to the award of a degree.’

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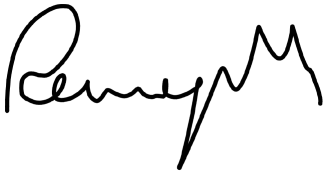

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Published Work

Research from this thesis has been published at the following venues. Contributions by the author are described for each.

1. Meiklem, R., Stevenson, K., Richarz, S., Kingsmore, D.B., Bouamrane, M.M., Dunlop, M. and Thomson, P., 2021, August. Advanced kidney disease patient portal: implementation and evaluation with haemodialysis patients. In *Human-Computer Interaction–INTERACT 2021: 18th IFIP TC 13 International Conference, Bari, Italy, August 30–September 3, 2021, Proceedings, Part II* (pp. 175-196). Cham: Springer International Publishing.
2. Richarz, S., Greenwood, S., Kingsmore, D.B., Thomson, P.C., Dunlop, M., Bouamrane, M.M., Meiklem, R. and Stevenson, K., 2021. Validation of a vascular access-specific quality of life measure (VASQoL). *The Journal of Vascular Access*, p.11297298211046746.

3. Meiklem, R., Stevenson, K., Richarz, S., Kingsmore, D., Bouamrane, M.M., Dunlop, M. and Thomson, P., 2022. Patients' and Clinicians' Perspectives on the Acceptability of Completing Digital Quality of Life Questionnaires During Routine Haemodialysis Clinics: A Mixed-Methods Study. In *MEDINFO 2021: One World, One Health–Global Partnership for Digital Innovation* (pp. 752-756). IOS Press.
4. Kingsmore, D., Meiklem, R., Stevenson, K., Thomson, P., Bouamrane, M. and Dunlop, M., 2022. A national co-design workshop of a mobile-based application for vascular access as a patient decision aid. *The Journal of Vascular Access*, p.11297298221091140.

I was the principal study designer and investigator of articles 1, 3, and 4. This included analysis of results and subsequent write-up. I was also responsible for the creation and maintenance of artefacts such as prototypes of various fidelity and software forming mobile applications used in studies described in articles 1 through 3.

Article 4 was an exception where Professor Kingsmore led the writing of the article and also produced artefacts (i.e. prototype designs) through a codesign process, as well as myself.

The study of Paper 2 was primarily led by Richarz, where I conducted the study described in Chapters 5 and 6 in parallel. I contributed to this work through participation in meetings discussing the work, expert input into questionnaire design, and creation and maintenance of mobile based app artefact for hosting a quality-of-life questionnaire.

Article 1 is discussed in Chapters 5 and 6, and Article 3 in Chapter 6 regarding questionnaire design and timed responses of participants. Article 4 discusses the results of the interactive symposium hosted at an online national conference, described fully in Chapter 8.

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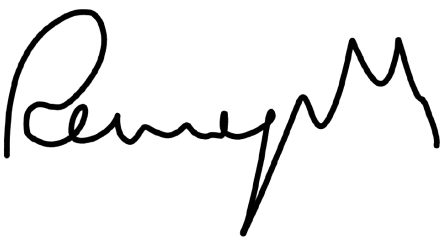

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I am very thankful to Steven Blom at ReturnToLife, a local charity carrying out work to support people living with chronic kidney disease. They were very helpful in aiding us recruit patient participants for the workshops conducted. I also thank all our participants involved in this research, especially during such a strange and stressful period in healthcare. Their engagement and contribution highlighted important needs for our prototypes to meet and informed our designs.

I would also like to express my appreciation to the members of the DHaWG research group and my student peers within the Computer and Information Sciences department, for their advice, feedback, and friendship over the last four years. Special thanks to Dr Linda Lapp, Olivia Foulds and David Kernaghan for their feedback and input throughout the PhD, and of course the encouragement, support and laughs.

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Abbreviations and Terms

CKD – Chronic kidney disease

QEUH – Queen Elizabeth University Hospital, Glasgow

QoL – Quality-of-life

RRT – Renal replacement therapy

HD – Haemodialysis

VA – Vascular access

HCI – Human-computer interaction

mHealth – Mobile health

UCD – User-centred design

PAR – Participatory Action Research

AR – Action Research

VASQoL – Vascular access-specific quality of life

eVASQoL – Electronic VASQoL application

SUS – System Usability Scale

MDG – Multidisciplinary group

PRO – Patient reported outcome

PROM – Patient reported outcome measure

ePRO – Electronic patient reported outcome

ePROM – Electronic patient reported outcome measure

Abstract

Chronic kidney disease (CKD) patients endure their chronic condition, in addition to complicated treatment pathways and trajectories, high treatment burden and great volumes of information which is not always applicable to their individual situations. There are calls for more patient-centred care, with greater patient involvement in treatment decisions and routine collection of patient outcomes. Digital health innovations have the potential to address these points, but poorly designed or implemented interventions can increase treatment burden, and many fail to reach implementation, described as "pilotitis" in the literature. This thesis explores the use of a Participatory Action Research approach to designing CKD interventions, involving multidisciplinary stakeholders and patients in the design process. First a scoping review on implemented technology-based and patient-centred interventions for high treatment burden populations was conducted, with results providing factors for promoting patient-centredness in technological interventions. A multidisciplinary group of domain experts from academia and medicine was then formed, to identify issues within the community, provide initial design requirements and guide development of a prototype intervention. This prototype would be implemented and evaluated after 6 weeks use by CKD patients in routine care, as part of a vascular access-specific quality-of-life measure (VASQoL) validation study. This resulted in a System Usability Scale (SUS) evaluation and qualitative feedback from 26 CKD patients as well the feedback and observations of a clinical researcher. This evaluation identifies further design requirements as well as the idiosyncratic needs of dialysing CKD patients, such as situational impairment and perceived value of technology. The focus then shifted to patient education, with iterative design and feedback on prototype designs with the MDG, clinical stakeholders and CKD patients in online and in-person workshops, and an interactive symposium. Through multidisciplinary co-design and iterative development, the research produced extensive design requirements and prototype systems for CKD patient education and decision-making aids.

Chapter 1: Introduction

This chapter will introduce the reader to the research context and the research questions to address gaps in the existing knowledge. It will also summarise the contributions made and provide the thesis statement, providing an overview of the thesis.

1.1. Context and Background

Chronic kidney disease (CKD) carries a substantial global health burden with high associated economic costs to health systems and a substantial impact on quality-of-life (QoL) (Cleary & Drennan, 2005; Fukuhara et al., 2003; Hill et al., 2016). Worldwide prevalence rates have increased by 29.3% since 1990 and CKD is an important risk factor for comorbidities, such as cardiovascular disease (Bikbov et al., 2020), diabetes and hypertension (MacRae et al., 2021). With the function of the kidneys impaired, renal replacement therapy (RRT) is required but the treatment options and care trajectories for CKD patients are often complex and can vary greatly between individuals, as well as over time. The three main modalities of RRT are kidney transplantation, peritoneal dialysis, and haemodialysis (HD).

HD treatment in particular places patients under a high treatment burden, due to the intense and intermittent nature of the procedure performed 3 times a week, lasting between 4 to 5 hours per session. Treatment burden has been defined as 'the work placed upon a patient as a result of their healthcare and the impact upon their wellbeing' (Gallacher et al., 2018). "Work" refers to both 'the treatment' as well as the process of 'self-care' for a condition, including attending clinical appointments, monitoring one's health, doing exercise as part of a treatment or recovery programme, or taking medications (Eton et al., 2012; Gallacher et al., 2011). Excessive levels of treatment burden can result in reduced QoL and adherence to treatment, which in turn can increase the risk of hospitalisation and mortality (Eton et al., 2012; Gallacher et al., 2011; Gallacher et al., 2018). Furthermore, patients' reduced engagement with treatments can result in an intensification of treatment, thus further aggravating the treatment burden for patients.

For example, HD treatment is life-prolonging but can be likened to an aeroplane flight – busy periods at the start and end of sessions with safety procedures, checks and actions to be completed, with a long period of restricted movement and activity in between (Noble, 2015). Outside of treatment, patients must also carefully manage their health while enduring restrictions in diet, fluid intake, activities and monitor their vascular access for any irregularities or complications, alongside everyday life and responsibilities. The intense

schedule of HD can also have a substantial impact on families and social relationships (Stenvinkel, 2010).

One of the key decisions that is required is the choice of how HD is delivered – vascular access (VA). Most importantly, this key decision must be made at a time of illness, in a pressurised situation, potentially with limited time for professional input. Currently, this is often delivered in an environment with time-limited consultations, paper-based generic information, and unstructured internet information. This is time-consuming, inefficient and can confuse patients. Patient education is a key element of effective treatment, self-management and improving the overall health of CKD patients (Young et al., 2011). However, patients must endure a high level of "information work" or information processing, having to first recognise what they need to know, find a resource which provides what they need and then begin trying to understand the information and then make sense of it in terms of their own personal circumstances and situation (Burgess et al., 2019). This process can be delayed by various barriers, such as high emotions from dealing with the diagnosis and declining health or information overload, but the process of deciding and starting treatment carries on as required. Patients can take a passive role in their treatment and often make meaning of information in the context of their personal health too late. For example, after starting treatment, patients realise the decision is not personally viable but are now at a stage where other options may be limited or no longer viable. Following the Montgomery Judgement (Montgomery v Lanarkshire health board (Campbell, 2015)), the emphasis of medical decisions and information provision has now shifted from what the clinician considers relevant to what the patient feels is relevant to them. This can be understood as needing to tell patients everything, no matter how relevant or likely it may be to their situation or not. It is often difficult to tailor to an individual's needs and levels of understanding, as well as how their situation which may change, making the attainment of fully informed consent difficult.

In addition, there is no routine mechanism to digitally collect real-time patient experiences or outcomes of dialysis. In 2017, Oliver et al. conducted a mixed-methods national appraisal of HD VA provision in Scotland, highlighting substantial variation in the use of different VA modalities between Scottish renal units, with patients reporting frustration and dissatisfaction with their personal experiences of treatment (Oliver et al., 2017). The appraisal recommended better staff education, multidisciplinary focus on patient care, clinical pathway optimisation and improved measurements of clinical and patient outcomes to improve VA service quality and facilitate safer and more effective, patient-centred care. In the following year, Murray et al. published an analysis of the first 365 days of HD for 144 patients, noting the VA patients use can be a factor in how their treatment journeys are shaped (Murray et al., 2018). The work

calls for personalised access solutions, where the VA that best represents the lowest cumulative burden (patient as well as nephrology, surgery and imaging services) is pursued, in the context of QoL and life expectancy. In short, there is a need for greater patient involvement in treatment decisions regarding VA provision.

Within the human-computer interaction (HCI) literature, there is increasing recognition that hospitalised patients, such as CKD patients undergoing regular HD treatment, are poorly supported in patient-provider communication or accessing and managing health information and resources. This is not for a lack of wanting to engage, but lacking the tools that enable patients to do so (Mishra et al., 2018). Therefore, there is potential for a technology-based and patient-centred intervention to address the recommendations set out in the literature and support CKD patients in their treatment. However, failure to consider and include the needs of patients, and other stakeholders, results in failure to meet expectations and secure engagement and endorsement (Irizarry et al., 2015; Korhonen et al., 2016; Sadeghi et al., 2017).

1.2. Research Gap

CKD patients endure their chronic condition, in addition to complicated treatment pathways and trajectories, great volumes of information which is not always applicable to their individual situations and high treatment burden. There are calls for greater patient involvement in treatment decisions, routine collection of patient outcomes and patient-centred care. Digital health innovations have the potential to reduce the burden of treatment, but poorly designed or implemented interventions may have the opposite effect.

There is always a need for further design requirements and information when developing and evaluating patient-facing technologies (Sadeghi et al., 2017). However, “pilotitis” is very common in the digital health literature, a frustrating phenomenon where many of the interventions discussed in publications and studies never reach implementation (Huang et al., 2017), and so it is difficult to consider how the lessons provided by these interventions will carry over into real-world settings with real patient users and wider scopes. Recommendations from the case studies examined by Huang et al. include prioritising interoperability with existing systems as well as focusing on the perceptions, attitudes and needs of stakeholders through participatory approaches. Particular efforts should also be made to include hospital inpatients as primary stakeholders in respect to the quality and safety of their care (Haldar et al., 2019).

Literature concerning implemented interventions, such as those described earlier (Haldar et al., 2019; Irizarry et al., 2015; Sadeghi et al., 2017) and later in Chapter 4, can offer further

insight into understanding the needs of the patient in the context of their treatment, and how the implementation of technologies can be done effectively with reference to barriers encountered and factors for success. Finally, these technology-based interventions can also demonstrate what factors promote patient-centredness, and also those that impair it.

To summarise, there is a need for work that demonstrates the development, implementation and evaluation of patient-centred and technology-based interventions for CKD patients, with clear patient and other stakeholder involvement. There is a demand for design requirements for CKD, and other high treatment burden populations.

This thesis therefore explores the development of technology-based and patient-centred interventions that address key issues in the CKD context. The overarching co-design methodology inspired by Participatory Action Research (described in detail in Chapter 3) will allow the "community of interest" i.e. clinicians, nurses and patients, to lead the processes in developing, evaluating and implementing such interventions. This will ensure the technologies produced are designed to the unique needs and problems as they are identified by those who endure them first-hand, and are patient-centred.

1.3. Research Questions and Thesis Statement

Existing patient-centred and technology-based interventions for CKD and similar high treatment burden populations must first be reviewed. However, implemented technologies offer the most insightful lessons and examples. Therefore the first research question is:

- **RQ 1:** What patient-centred, technology-based interventions have been implemented to support patients with high treatment burden?

Reviewing existing interventions will inform how they support patients in their treatment, as well as identify potential barriers and facilitators for engagement and implementation. These interventions also need to demonstrate patient-centredness and what factors determine how well they achieve this. This requires RQ1 to be split into two sub-questions:

- **RQ 1.1:** What is the range of technological interventions that have been developed specifically for patients with high treatment burden?
- **RQ 1.2:** What factors of technological intervention can promote 'patient-centredness'?

However, the focus of this thesis is CKD and the community of interest within that context. In order to design patient-centred technology-based interventions for CKD treatment, the processes should seek to gather design requirements and other key lessons for such systems. This thesis will aim to compile this information and answer the second research question:

- **RQ 2:** What do haemodialysis patients and other stakeholders need from a technology-based intervention to support the CKD treatment journey?

While addressing these research questions, the following thesis statement was established:

- **Thesis Statement:** A Participatory Action Research inspired co-design approach for CKD interventions leads to novel insights from multidisciplinary stakeholders and technologies with great perceived value from both patient and clinician.

1.4. Contributions to Knowledge

This research has made the following contributions to knowledge:

- A novel scoping review on existing implemented patient-centred and technology-based interventions, supporting high treatment burden patients, was conducted. As a result, characteristics of patient-centredness and common barriers and facilitators to the implementation of such interventions were identified – publication in progress, estimated 2023.
- The proposal of a Participatory Action Research (PAR) inspired co-design approach in a digital health context and the development of patient-centred and technology-based intervention(s) to support CKD patients). The approach placed the "community of interest" i.e. patients, nurses and clinicians, at the head of research efforts to resolve problems they identified and face in the CKD treatment context – see (Meiklem et al., 2021) and (Kingsmore et al., 2022)
- Design requirements for intervention(s) to support CKD patients, used in subsequent study to produce the eVASQoL implemented and evaluated with CKD patients in a clinical setting. Initial requirements were produced with a multidisciplinary group (MDG) of medical and academic experts and can be used as a basis for future work – see (Meiklem et al., 2021) and (Richarz et al., 2021).
- Identification of idiosyncratic facilitators to successful implementation of digital data collection in the context of dialysing patients, namely ease of input, perceived value of engagement, sense of privacy via independent use, and barriers such as condition-related accessibility and situational impairment. – see (Meiklem et al., 2021) and (Richarz et al., 2021).
- Insight into the design of digital QoL questionnaires and their content following analysis of CKD patient response times, feedback and clinical use observations of digital QoL questionnaire completion – see (Meiklem et al., 2022).

- A series of co-design workshops with surgeons, nephrologists, dialysis nurses and CKD patients and caregivers to evaluate and inform the design of a patient education and decision-making aid intervention. These sessions resulted in insights and design requirements from various stakeholder groups from across the UK and highlighted the benefit of online and remote qualitative methods for research with participants with high treatment burden or very demanding schedules.

A list of literature and other outputs during the course of this thesis can be found in the Published Work section, including the roles and contributions of the authors in the articles.

1.5. Thesis Overview

As described prior, this thesis explored the potential for technology-based and patient-centred interventions to support CKD patients in their care as high-treatment burden patients. Chapter 2 will cover related work, in respect to CKD and digital health. Chapter 3 provides more details on the overarching methodology and discusses the methods utilised throughout this thesis. Chapter 4 includes the scoping review of existing implemented patient-centred and technology-based interventions supporting high treatment burden patients, to highlight the barriers and facilitators to successful implementation. Chapter 5 describes the development and refinement of a prototype patient portal within the MDG. The finalised prototype is then implemented into a clinical setting as part of a validation study for a vascular access specific and quality of life (electronic VASQoL) measure with 101 patients using the eVASQoL for up to 6 weeks in a Glasgow dialysis centre.

Chapter 6 discusses the implementation and evaluation of the eVASQoL, with a SUS (System Usability Scale) evaluation (Brooke, 1996) and qualitative feedback from 26 CKD patients as well the feedback and observations of a clinical researcher. This evaluation identifies further design requirements as well as the idiosyncratic needs of dialysing CKD patients, such as situational impairment and perceived value of technology. Chapter 7 details the MDG initialising three low-fidelity prototypes for supporting patient education, before presenting two refined high-fidelity prototypes to online workshops with 3 surgeons, 4 nephrologists and 5 dialysis nurses from across the UK. Feedback and discussion from medical staff workshops then inform a final, refined prototype presented to 14 patients and 1 caregiver in further online and in-person workshops, and a mini-symposium at a national online conference. Chapter 8 details the findings and feedback from patients and other stakeholders on this final prototype.

Chapter 9 summarises the development through the thesis and the key functionalities of the interventions discussed, with emphasis on how they have evolved and changed. This chapter will also present a final comprehensive list of the design requirements collected throughout

this work. Finally, Chapter 10 discusses the primary findings of this thesis, in addition to strengths, limitations and future work in this context and others.

Chapter 2: Related Work

This chapter presents related and relevant work to this thesis, namely in the domains of chronic kidney disease (CKD) and digital health, as well as literature from the human-computer interaction (HCI) community. Literature described here will also be referenced throughout the thesis, highlighting key findings and supporting decisions taken when planning and conducting the research.

2.1. Chronic Conditions and Treatment Burden

Treatment burden is a major contribution to the decreased quality of life (QoL) of patients with chronic conditions. Gallacher et al. define treatment burden as the "work placed upon the patient as a result of their healthcare and the impact on their well-being", which encompasses both the treatment itself and self-care required by the patient (Gallacher et al., 2011; Gallacher et al., 2018). Their initial work in 2011 discusses chronic heart failure, aiming to understand the treatment burden or "work" of patients with chronic heart failure and comorbidities. Another common trait of chronic conditions is comorbidities (e.g. CKD is an important risk factor cardiovascular disease (Bikbov et al., 2020; Stenvinkel, 2010), diabetes and hypertension (MacRae et al., 2021)), which may present further work for the patient, requiring management of another condition and its associated treatment burden. Gallacher et al. give the example of patients attempting to manage multiple primary and secondary appointments across different days for different medical needs, referring to this as a disease-centred approach. This approach ultimately results in a further treatment burden, which then potentially contributes to higher nonattendance rates at appointments and wasting resources. This highlights the potential for excessive treatment burden to result in nonadherence, which in turn requires further intensification of treatment and associated treatment burden.

Eton et al. (2012) provide a similar definition for treatment burden in their work with patients with one or more chronic health conditions. They describe it as "the workload of healthcare as well as its impact on patient functioning and well-being", referencing medication-taking, keeping appointments and monitoring health, diet and exercise (Eton et al., 2012) and also highlight the consequences of greater treatment burden, nonadherence and intensification of treatment in response.

These themes of non-adherence and workload of chronic conditions is discussed by May et al., where they note the need for "minimally disruptive medicine" for those living with chronic conditions and comorbidities (May et al., 2009). They describe a lack of coordination between

different clinics and clinicians dealing with different medical conditions as fractured care, with negative outcomes such as increased costs, side effects and unintended medication interactions, with burden of treatment expanding and overwhelming patients. To resolve this, they propose four principles for minimally disruptive medicine: (1) establishing weight of the burden, (2) encourage coordination in clinical practice, (3) acknowledge comorbidity in clinical evidence and (4) prioritise from patient perspective. These principles, especially the fourth, are echoed by Gallacher et al. where they propose patient-centred approaches to care, rather than disease-centred (Gallacher et al., 2011). However, in order to provide such care and minimally disruptive medicine, the weight of the treatment burden needs to be better understood.

2.1.1. Chronic Kidney Disease and Haemodialysis

In the context of CKD, renal replacement therapy (RRT) is required to replace the function of the failing kidney(s), with three main modalities of treatment: kidney transplantation, peritoneal dialysis, and haemodialysis (HD). The work of this thesis will focus primarily on the third modality, HD treatment.

While life-prolonging, HD places a great burden upon the patient, requiring the receival of frequent and intense dialysis treatment and also managing their health outside of treatment. Noble (2015) compares the activity of dialysing to the process of an aeroplane flight, highlighting the numerous safety procedures, preparations and other actions which must be completed at the start and end of treatment. Between these steps, there is a period of 4 to 5 hours of inactivity, where the patient is limited in ability and movement due to the cannulated needles that allow blood to be exchanged with the machine via a vascular access (VA) modality.

The intense schedule of HD can also have a substantial impact on families and social relationships (Stenvinkel, 2010), limiting time that can be spent elsewhere. Alongside frequent treatment, patients must also carefully manage their health. This includes restrictions in diet, fluid intake, medical appointments and medication, physical activities and also closely monitor their VA for any irregularities or complications. This is all completed alongside everyday life, commitments and responsibilities (e.g. families or careers). HD can also lead to further conditions and ailments. Vision impairment from eye diseases such as diabetic retinopathy are common amongst CKD patients, with recommendations from for eye screening for patients, multidisciplinary collaboration and other methods of dialysis which reduce the increase of intraocular (within the eyeball) pressure during HD treatment, such as peritoneal dialysis (Nusinovici et al., 2019). Carpal tunnel syndrome is also common amongst HD patients, with

HD causing deposits of a protein called amyloid to build up around the tendons within the forearm and carpal tunnel (Fujita et al., 2019). This causes pressure on a nerve within the carpal tunnel and results in numbness, tingling or weakness in the hand and arm.

Depression is also a notable mental health problem for this cohort, as is anxiety (Cukor et al., 2007). Zalai et al. describe three main types of factors that contribute to depression in CKD. These include (1) biological factors, such as toxins, chronic inflammation, pain and other physical symptoms (fatigue, insomnia, appetite, etc.), (2) psychological factors, due to change from healthy to sick, burden of symptoms, fear of treatment and uncertainty of the future, along with negative experiences of healthcare, and (3) sociodemographic factors, such as gender, race, age and employment status, with younger patients often more distressed than their older peers (Zalai et al., 2012). They conclude by noting the psychological distress the burden of CKD places on patients in early stages of the disease, which some may learn to cope with, while others struggle. The lived experience of patients with routine HD were also investigated by Hagren et al., with patients expressing encroachment of time and space as a result of their condition. This may be something carers are not aware of creating emotional distance and vulnerability in patients, having to accept HD treatment is a lifeline, with the restrictions it brings and the end of life itself eventually (Hagren et al., 2005). Patients desire to live as normally as possible but realise that this is almost impossible.

2.1.2. Vascular Access and Care Pathways

VA provision is a key decision for patients and is influenced by clinical evidence, patient factors and prevailing configuration of the renal service. For example, some modalities appear more convenient than others, with central venous catheters (CVC) being quick to insert and start using via minimally invasive procedures. In contrast, arteriovenous fistulae (AVF) require surgical procedures, and several weeks to mature before use, if successful. This would present CVC more positively as an option, but AVF patients who start HD treatment experience less hospitalisation, procedures, imaging activities and financial cost than those who started with a CVC (Murray et al., 2018). The important decision around VA is one often made when patients are unwell, with limited time and opportunity for input from their healthcare team.

The balance between the decision-making factors described above is also not always equal. Oliver et al. undertook a national appraisal within Scotland of HD VA provision in 2017, to better understand the variations between renal centres in VA provision and find opportunities for improvement. Through interviewing different individuals (minimum of 1 nephrologist, surgeon, radiologist, VA nurse and adult patient per unit) and collecting VA-related clinical data from all Scottish renal units across a 6-week period, they reported four themes

summarising their insights into VA service provision: (1) patient experience, (2) access creation, (3) access maintenance, and (4) service performance and development needs. Their work indicated a need for clearly described and adequately resourced clinical pathways for VA creation, use and maintenance, with instances of pathways being circumvented or chosen based on clinician perceived speed or attitude towards VA modalities described. To conclude, Oliver et al. recommend a patient-centred approach for the assessment of VA services, judging quality through patient factors such as hospital experiences, perceived utility and impact on daily routine (i.e. treatment burden). Similar recommendations were reported a year later by Murray et al., with a suggestion for delivering personalised access solutions in the modern pursuit of HD access modalities. They demonstrated trends across 144 patients' first 365 days of HD, following their shifts between VA modalities and the procedures, clinical events and hospitalisations incurred. Both works describe the experience and treatment of patients as a journey shaped by the VA they use, and within the context of the patient's quality of life and life expectancy, the lowest cumulative burden of treatment should be targeted (Murray et al., 2018). However, measuring and communicating outcomes such as this effectively to patients presents further challenges.

2.2. Digital Health

Digital health as a concept has grown and evolved with time, with the term now including many categories of technology such as mobile health (mHealth), health information technologies, wearables and telehealth and telemedicine (Guo et al., 2020). The field is driven by advancements in technology, such as wearables and Internet of Things (IoT) as well as events in the health domain, with a recent example of the COVID-19 global pandemic driving uptake in teleconsultation to avoid risk of infection from face-to-face meetings (Cummins & Schuller, 2020).

Applying digital technology to a problem in the health domain is not always a perfect and immediate solution, however. Mair et al. discuss the potential of digital transformation to resolve challenges faced by healthcare systems, but warn of shifting more workload to patients, ultimately adding to treatment burden instead of lessening it. They also consider the potential for digital health to widen health inequalities, where interventions such as may provide benefits for some while limiting others (Mair et al., 2021). In an example of teleconsultation, there may be reduced treatment burden associated with attending frequent appointments (such as travel, time required or taken off work, accessibility of buildings, expenses, etc.) but assumes patients' access to resources like broadband and Wi-Fi at home, and ability to use the system. They conclude by warning that digital and remote healthcare that

does not consider financial, language, literacy, cognitive, physical and social limitations may render patients vulnerable to digital inequality and loss of wellbeing from further treatment burden.

A review of qualitative studies on patients' perceptions of mHealth highlighted similar factors, with a need for greater personalisation of mHealth applications and the content provided by them, especially where a patient may be managing a complex condition or multiple comorbidities (Vo et al., 2019). Another review on patient portals also highlighted personalisation as an important factor for adoption of technology (Irizarry et al., 2015). Patients, while being empowered by mHealth, also consider their healthcare providers as the first point of contact and only view applications as a back-up or support for the patient-provider relationship. Vo et al. reinforce this by noting mHealth is a complementary tool, not a substitute for care. Finally, there is often an assumption that the introduction of new technology presents barriers for older users and that they will struggle to engage and use these systems, or by preference chose not to. This would be problematic for the digital health context, where some populations are often naturally older (such as CKD patients (Ronsberg et al., 2005)). Work has shown use of modern technologies such as tablet devices as satisfactory for older adults in health settings (Gitlow, 2014) and older users can perform just as well as their younger peers when using touch-screen devices (Schneider et al., 2008). However, as Mair et al. warn, failing to consider the limitations of patients, including older adults, risks excluding them from the potential benefits of digital health technologies and exposes them to inequalities in their care.

2.2.1. Implementing Digital Health Technology

Within the literature, there is a large volume of evaluated digital health interventions. However, these interventions are often limited in scale, focusing on small populations and are very narrow in focus, a phenomenon termed as "pilotitis" by those frustrated by it (Huang et al., 2017). The implementation of digital health technology into a health setting can be difficult and challenging, especially when trying to secure engagement and endorsement by patient and clinician respectively. Huang et al. state implementers need to focus on the perceptions, attitudes and needs of stakeholders as much as on the technology itself, as well as the factors that influence engagement at different levels of an institution.

The literature has also been criticised for a lack of design guidelines and systematic evaluations. Sadeghi et al. discussed this from the perspective of patient portals, noting how systems that are so important and potentially costly to hospitals need design requirements evaluated in objective and user-centred approaches. Patient-facing technologies always have

a need for further requirements if they are to meet patient expectations, which will contribute to adoption and usage (Sadeghi et al., 2017). Involving patients in the design and evaluation of technologies aimed to support them should always be encouraged, where systems are often designed "top-down" and adapted from technology where the clinicians are the primary stakeholders. Approaches from the "bottom-up" and involving patients can identify unique needs of patients that established technologies are failing to meet, and ensure their success amongst the patients they aim to support, demonstrated in work addressing patient portals for hospital inpatients (Haldar et al., 2019).

Patient experiences of care, and technology that delivers it, are also important to consider. Korhonen et al. (2016) conducted a meta-synthesis of patients' experiences of care and describe preconditions for the realisation of dignified and good care, in the context of technology. Positive experiences can be formed by ensuring technology is easy to use, safe and somehow benefits patients (e.g. relieving symptom burden, saving time and effort, etc.). Negative experiences and emotions towards technology can result from a lack of information or not being heard or included in decision-making, which in turns makes patients less willing to engage and use technology. They reiterate the importance of the healthcare provider, namely nurses, who provide information and guidance, repeat and interpret information, support the patient and their family and are often the ones to implement complex and demanding technology in a competent manner.

While patients should be considered as experts in their own care and be included in the design, implementation and evaluation of digital health to support themselves, clinicians and other healthcare providers are also important stakeholders in the proposed interventions. Patients' experiences are rich, valuable, and very personal, however patients may not fully understand the scientific background of their condition and treatment (Nisha et al., 2016). Clinicians have an expert knowledge of the health context from scientific and public health reports, as well as years of experience and field observations (Song et al., 2021). Understanding the processes and workflow of a healthcare setting and providers working within it is important when implementing a new intervention into the environment.

Securing engagement and endorsement from clinicians is also vital to patient adoption of technology, and the opposite can also be true. Irizarry et al. (2015) review the literature on patient portal technology and discuss factors for introducing new portals successfully, noting they may be met with perceived increases in workload by clinicians and require changes in workflow by the entire healthcare team. However, studies where clinicians believed portals encouraged increased patient engagement and provided additional information for

consultations relieved concerns. Therefore, perceived usefulness from both patient and provider perspective needs to be considered and technology designed to meet these expectations to ensure adoption.

The work of Blomqvist et al. presents an example of a multidisciplinary approach to health care in a renal context. They describe how a participatory action research (PAR) project brings patients, renal unit nurses, a hospital manager and a researcher together to form patient-centred care, combing the lived experience of patients with professional expertise of staff. They describe the need for low intensity but long-term development work by the group due to the uneven workloads, with four areas identified for improvement. While these areas were not new concepts to the core staff members, the patient experts provided a different understanding from their own, allowing for realisations and "revolutions" in areas they had been immersed for years (Blomqvist et al., 2010). This work and the others described in this section highlight the importance of considering and understanding the needs and expectations of both patients and providers in order to secure adoption and endorsement by all.

2.2.2. Patient Education and Information Seeking

Patient education is a key element of improving overall health of a patient, and is true in the context of CKD as well (Young et al., 2011). It is also an important component of patient-centred care, allowing patients to ask questions, raise concerns and needs regarding their care and provides patients with self-management skills and knowledge to manage CKD-related risks (Narva et al., 2016). Health literacy is an important factor in the success of patient education and can be defined as "the cognitive and social skills that determine the motivation and ability of individuals to gain access to, understand and use information in ways that promote and maintain good health" (Rowlands et al., 2013). Traditional examples of patient education resources i.e. printed materials such as leaflets, posters and brochures, often require high levels of health literacy (Tuot et al., 2013) and reading ability (Morony et al., 2017), while almost a quarter of the CKD population are noted as having low levels of health literacy. Moroney et al. also discuss the benefits of visual aids, supplementing textual information and attracting patients to materials, however if embellishing (i.e. not adding to explanation or related to textual information) they offer no support in comprehension (Houts et al., 2006) and can become distracting instead (Griffin & Wright, 2009).

Limited health literacy and unsuitable materials for CKD patients are not the only issues facing patient education. Narva et al. discuss various patient, provider and system barriers in the context of CKD patients in the United States, such as the complex nature of CKD information, limited time for providers and a lack of decision support tools. The complexity of the CKD

treatment pathways described earlier poses challenges in how providers provide information. This information provision process is now often required to be comprehensive and complete, even if not relevant to the individual patient e.g. Montgomery v Lanarkshire case in the UK (Campbell, 2015), in order for a state of full informed consent to be achieved. For CKD patients, there is a great volume of information work and seeking to carry out, before attempting to understand and make sense of information as described by Burgess et al. (2019). Their work, titled "Tricky to get your head around", discusses the information work of those manging CKD in the UK, describing an information journey where patients shift between phases of "learning" and "living with" their condition. This includes a process of sense making, where an individual reaches a conceptual understanding of a topic, before meaning making can occur. i.e. personally applying the information to their own health context. They also present classifying patients as low- or high-monitor information workers, where the latter represents patients who form routines of frequent information-seeking and desire to know their current health information. In contrast, low-monitor workers are patients who master an understanding of the basics of CKD and treatment but then reduce the information work activities in their day-to-day lives, depending on healthcare providers to manage further information for them.

Burgess et al. go on to highlight how many resources are design to support sense making, rather than meaning making, resulted in patients feeling overwhelmed from the overload of information and the intense emotions of being diagnosed and living with a chronic condition. Work with bone marrow transplant patients also reported patients becoming overwhelmed where clinician perspective of the treatment trajectory is far different from that of patients and their caregivers (Büyüktür & Ackerman, 2017). The authors described patients and caregivers as living through a series of crises and transitions, with a great deal of emotional work to handle and being overwhelmed where having too much information at certain periods or not having the information they needed at the right time.

Digital health interventions have the potential to overcome the limitations of traditional resources and support the process of CKD patients' education about their condition, by transforming static information resources e.g. leaflets into flexible and interactive alternatives, such as websites, patient forums or patient portals. However, there is still the potential for a digital divide to occur where digital resources are implemented poorly. For example, Burgess et al. note how patients categorised as high-monitor information workers utilise patient portal resources to stay informed of blood test results and current health information and use this information in collaborative discussions with their clinicians. Patients seen as low-monitor

information workers may be unlikely to take advantage of these digital information resources as they require sustained participation from the individual. While these resources can be more dynamic and adaptive than traditional counterparts, they can also require considerable work to utilise and maintain for patients. Instead, reducing focus on purely technical solutions and considering collaboration with other people may be another suitable strategy for low-monitor individuals (Burgess et al., 2019). The peer influence in decision-making for CKD patients is well understood, and highlights the importance of patient peers as another potential resource for patient education (Morton et al., 2010; Taylor et al., 2016). Through collaborating with others, such as nurses and patient peers, CKD patients can overcome education barriers and enable meaning making of information about their condition and treatment.

To summarise, a single "one size fits all approach" is inappropriate and as suggested by Burgess et al., a system of both digital and physical information resources is needed to ensure the individual requirements of patients are well met. Given the earlier discussion on designing and implementing digital health, multidisciplinary involvement should be considered to ensure this is possible and done so effectively.

2.2.3. Using Digital Patient-Reported Outcome Measures

Patient-reported outcomes (PROs) can be understood as "any report of the status of a patient's health condition that comes directly from the patient, without interpretation of the patient's response by a clinician or anyone else" (FDA, 2006). Collection of PRO data enables patients to engage with their care, a key element of ensuring patient-centred care. For example, Oliver et al. called for improved measurements of clinical and patient outcomes in their appraisal in 2017, as part of recommendations to improve VA service quality and facilitate safer and more effective, patient-centred care. Traditionally, PROs were collected using patient-reported outcome measures (PROMs) in paper formats, incurring significant administrative burden, missing or incomplete data and errors in data entry (Aiyegbusi, 2020).

Aiyegbusi discusses hosting PROMs digitally to monitor and deliver healthcare, with patients able to report PROs via mobile devices (also referred to as electronically i.e. ePROs and ePROMs), allowing for "real time" feedback on treatment and health status. They also highlight how ePROMs would also allow for robust analysis and reporting of PRO data in clinical trials, with data available in exportable formats with digital validation resulting in fewer errors and occurrences of missing or incomplete data. When reporting via a computer systems, also known as a patient-computer interview (Bachman, 2003), patients can proceed at their own pace, the questions posed are consistent and have been also shown to be more honest in providing complete and sensitive information than if reporting to a clinician.

However, digital transformation of PROMs to enable ePRO collection must be done carefully. Consistency between paper and digital formats is vital to ensure the validity of the measure is not compromised. Visual design of questions is important, with inconsistent formats and layouts with user's experience and expectations resulting in negative consequences i.e. confusion, incorrect responses and longer response times (Christian et al., 2009). Longer response times may indicate greater engagement and consideration for individual questions (Lenzner et al., 2010), but longer questions (e.g. more syllables) can also be responsible for greater time taken as well. Aiyegbusi notes suitable ePROM interfaces should be designed with consideration for user-friendliness and usability, much like any user-facing system. This requires adequate assessments of system interfaces and improvements to reduce attrition in use during clinical trials and increase chances for their adoption in clinical practice outside the trial setting. Patients who already engage in their healthcare will likely benefit greatly from such systems but those who do not or are less digitally able may experience further work and burden, disadvantaging them (Mair et al., 2021; Vo et al., 2019). Like many other areas of digital health, the design and implementation of digital PROMs needs to be done so with consideration for both patient and clinician needs in order to ensure both can reap benefits from continued engagement.

Chapter 3: Methodology

This chapter will describe the overarching methodological approach used to guide the research, alongside justifications and advantages to using such an approach. The chapter will also describe and explain methods utilised in individual studies of this research, including the iterative development and evaluation of prototypes, and the use of a framework during the thematic analysis of feedback. Other methods included collecting and analysing questionnaire completion time data and codesign workshops to inform patient information guide design. The rationale for these methodology choices will be given as well.

3.1. Methodology Criteria

Certain criteria were prioritised when considering a suitable approach and methodology for this work. The community of research interest in this contact was those who received and delivered renal replacement therapy (RRT) for chronic kidney disease (CKD) i.e. patients and healthcare providers such as nephrologists, surgeons and nurses. The supervision team of the author was multidisciplinary and included one such stakeholder, providing the opportunity to work closely with the community of research interest. Therefore, the selected methodology should allow for and encourage working with the intended target users. In addition, the specific population of CKD patients and healthcare providers would present its own unique context, challenges and requirements to overcome. A suitable methodology should not be bound to a specific population or specification of intervention. Finally, the methodology should be recognisable and accepted in the HCI domain.

To address problems experienced by a specific population, there are various methodologies that are viable. Many of these come under the terms co-design, defined as "creativity of designers and people not trained in design working together in the design development process" (Sanders & Stappers, 2008). The terms co-design and co-creation are often confused (Sanz et al., 2021), but the latter is a broader term applied from material to the metaphysical as defined by Sanders and Stappers. Co-design approaches should allow stakeholders to participate in the design process as partners, rather than passive subjects like that of user-centred design (UCD). UCD is an acceptable methodology, considering the user (i.e. patient) at each stage of the design process through prototyping and user testing to ensure the end-product meets their needs and can often ensure user engagement (McCurdie et al., 2012). However, co-design takes this a step further, by including users and stakeholders in the design process and equipping them with the tools to express their perspectives and perceptions (David et al., 2013). Co-design is a popular term that can be applied to activities or research methods

(e.g. workshops, storyboards, interviews, prototyping, etc.) that allow for collaboration with users, often without a guiding methodology or framework. The previously described methodologies are also targeted at single system or service design, rather than tackling more complicated or numerous issues within a community.

Participatory Action Research (PAR) combines the approaches of Action Research (AR) and Participatory Research (Khanlou & Peter, 2005). The former, AR, forms strategies from research findings to address problems and issues experienced by a community through a cyclic planning, action, and evaluation process. A new plan is formed on the completion of the evaluation, restarting the cycle. Participatory Research however focuses on issues experienced by rarely engaged participants, with people in the community controlling the research (Watters et al., 2010).

PAR sees participants and researchers working together throughout all stages and sharing power between the two (Baum et al., 2006). Researchers engage with the community to address a problem or challenge they experience with their participation producing a sustainable and helpful result. The cycles of the PAR methodology also lend themselves well to user-centred development and evaluation of technologies, with development, implementation, evaluation and analysis of technology echoing the stages of AR, with iterative development strategies building on the findings and learnings of the previous cycle (Hayes, 2011). Therefore, this methodology would be selected as inspiration for the co-design processes within this work.

3.2. Overview of PAR

PAR is a methodology that differs from most other research methodologies, which often seek to simply research or investigate. Similar to AR, changes for the community are positive and real-world, and knowledge is developed by solving the problem i.e. “knowing by doing” (Hayes, 2014). The participation of the community of research interest requires them to be equally and collaboratively involved, providing a topic or question to guide the research. This needs to be research efforts created with the people who have real-world problems – not for, about or focused on them. Such research is explicitly interdisciplinary and collaborative in nature and this characteristic of PAR shifts the typical power dynamic, with the researcher performing as a “tool” or “research coach” for facilitating change and giving the participant the roles of owner, director, and expert in the research project. PAR is particularly useful where disadvantages or differences in power exist between groups, empowering members to improve their situation (Reason & Bradbury, 2005).

This also provides an opportunity for informal learning to occur in the various stakeholders, such as citizens learning about research processes or researchers gaining insight into experiences of living with an illness (Danley & Ellison, 1999). As a partnership with members of the community of interest had been already established in prior studies and work (i.e. nephrologists, vascular access nurses and transplant and vascular access surgeons), the PAR methodology was not only appropriate for this research but also already beginning to unfold and would ensure ongoing and future work would continue to be completed with the community members closely involved and guiding the research, with all involved parties learning from one other.

PAR has been effectively utilised when working with groups and communities who experience systematic disadvantages, such as Indigenous communities (Madden et al., 2014; Siew et al., 2013), Black women (Mehra et al., 2002), refugees (Talhouk et al., 2018) and people with disabilities (Balcazar et al., 1998). Madden et al. in particular note Indigenous populations have a history with research where studies were of dubious value to the participants and wanted to ensure the Aboriginal women were treated as experts about their lived experiences (Madden et al., 2014). In the case of these groups, PAR offered an opportunity for underrepresented individuals to take ownership of research that would benefit them and shifted the balance in power. The methods of the PAR approach have also been shown to encourage participation by offering the opportunity for immediate change and benefits (Madden et al., 2014; Mehra et al., 2002), with flexibility and quick reactions to feedback maintaining engagement and enthusiasm (Mugwanya et al., 2012). Given the established connection to the community of interest in this work, PAR would be an effective methodology that will maintain and develop this relationship.

3.3. Use In Related Work

In the field of HCI, AR typically uses the design, development, and deployment of technology or intervention as an action that enacts change and produces knowledge through learning. The cyclic nature of PAR is also well-suited to the iterative development seen in user-centred design, as previously highlighted. Contemporary HCI methods such as Participatory Design (PD) (Schuler & Namioka, 1993), Scandinavian (Cooperative) Design (Ehn & Kyng, 1987) and other forms of user-centred design and research consist of methods, motivations and planning which is similar to that of AR, while not explicitly pursued as such.

PRISMA (Participatory Action Research In Software Methodology Augmentation) was presented as an amalgamation of “hard” software development and “soft” PAR research, a

community-based approach to software engineering for rural communities, seeking to deliver software development alongside social change (Siew et al., 2013).

In the health domain, patient-centred care has become a priority in recent years and can be considered similar to a user-centred design approach in HCI. However, patient-centred care can often be planned by professionals without patient involvement. Again, PAR overcomes the traditional researcher and participant roles by encouraging participants to become active and take ownership of the research, enacting the change they want (Glasson et al., 2006; White & Verhoef, 2005) and empowering patients, such as with those living with chronic illness (Hagey, 1997), and forming relationships to enable future collaboration (Gross et al., 2018). Blomqvist et al. asked the question "What happens when you involve patients as experts?", carrying out a PAR project at a renal failure unit, involving multiple disciplines including patients, nurses and a hospital manager (Blomqvist et al., 2010). This project shares the community of interest for the work detailed in this thesis and demonstrates the suitability of a PAR methodology in the context of kidney disease patients and professionals. Notable lessons included management of uneven workloads of those involved in the unit by conducting low intensity but long-term research, a recorded shift in attitudes from professionals towards the expert patients and the success of implementing changes to practices in the unit and planning future ones. Another example of work in the community of interest was conducted by Madrid (Madrid, 2007), with child patients and caregivers to produce an adaptable patient information manual. The manual began as a request from one child patient, with regular opportunity for input from patients and their caregivers to ensure it met their needs and expectations. The participatory process resulted in patients feeling more secure in their treatment and improving their self-care, due to feeling pro-active and well-supported by others involved in the treatment process.

3.4. Influence on Research

The methodology of AR such as PAR is open-ended and iterative, demanding the flexibility to change as the project unfolds over time (Hayes, 2011). This was especially true where opportunities arose for research and involvement with the wider community of interest, such as presenting work and collecting data as part of a national kidney disease conference or scaling back where current methods were inappropriate such as face-to-face meetings with vulnerable patients during a global pandemic. These opportunities and insights were only possible through close relationships and work with community members.

Both quantitative and qualitative methods are applicable, with Hayes (Hayes, 2011) noting AR does not allow for methods that would distance the researcher from the problems and questions

of the community, such as those that seek to ensure “objectivity” or avoid “contamination”. Research in HCI has begun to shift towards participatory methods in recent years and often shares issues and methods with AR, such as working closely with partners, engaging in fieldwork and iterative design and development.

While this work originally sought to conduct co-design in a manner true to the PAR approach, restrictions as a result of the COVID-19 pandemic and pragmatic design decisions, the approach was adapted rather than applied outright. Therefore, the PAR approach inspired co-design processes in this work, leading to the selection and use of methods that encouraged participation and involvement of stakeholders, suitable to PAR and familiar to HCI researchers. Efforts were made to make use of qualitative methods such as workshops, observations, and semi-structured interviews with individuals. Care was taken to not rely on purely quantitative methods or evaluation methods which were of importance to the HCI community but of little value to the community of interest. Instead, quantitative measures would complement qualitative methods, with the focus placed on what the people involved in the research had to say.

The involvement of stakeholders also resulted in their contribution to and production of output, such as prototype designs and demonstrations used in online workshops (where contributions such as these occur, they will be credited appropriately). In these cases, the researcher became like a “coach” and collaborator (Blomqvist et al., 2010), as noted within the concept of PAR, and stakeholders became more acquainted with HCI and its methodologies. For example, consultant surgeons Kingsmore and Stevenson work operated as both within the scope of both participant and supervisor, or the researcher was an active participant in multidisciplinary group meetings (Chapter 5). Likewise, working closely with stakeholders also provided insight into the medical domain and literature, with their experience and expertise valuable in writing output appropriately for their peers and the domain, finding relevant literature and understanding the processes of clinical research.

The generalisation of results is often sought for in the HCI community. However the focus on problems experienced by a community, at a “grassroots” level, within PAR research often means the results of resolving these local problems are not directly applicable to others and can be viewed as a limitation (Reuter et al., 2020). Approaches like PAR instead offer transferability of knowledge rather than the generalisation of results, where the methods in how the result was achieved can be transferred to other problems and contexts with adjustments if there is transparency in how the work was completed and reported.

3.5. Decision Aid Development Methodologies

As the work completed in this thesis progressed and the priority of challenges or issues to address shifted it became clearer that there was a need for an intervention to support patients in making informed decisions regarding RRT i.e. a patient decision aid. This specification did not occur until the final stages of this work (Chapters 7 and 8) and as such, many stages of the work were not conducted in a methodology explicitly designed for development of decision aids (DAs). CKD patients will face decisions many times throughout the course of their illness and treatment, and DAs can prove effective interventions to guide patients in decision-making (Murray et al., 2009). However, like most patient-centred interventions, DAs are also subject to various barriers to effective use. These barriers are similar to those later identified in the literature review and workshops (Chapters 4, 7 and 8), notably sociodemographic factors, patient engagement, values and beliefs, social influences and the communication and comprehension of information (Cassidy et al., 2018) A review by Davis and Davidson also highlighted issues with DAs not being fully evaluated at time of writing and delivery format i.e. lengthy handbook formats vs interactive online resources (Davis & Davison, 2017).

The International Patient Decision Aid Standards (IPDAS) also recommends patient DAs user-tested and open to scrutiny (Coulter et al., 2013). This is primarily due to the potential harm a poorly design patient DA can cause and other negative implications that can arise (e.g. less likely to advance shared decision-making, lack of engagement and endorsement from clinicians) (Coulter et al., 2013). However, certain elements of DA and technology development are shared. A review into the development process of patient DAs by Coulter at al. (Coulter et al., 2013) found key common features included: scoping and design, development of prototype, "alpha" testing iteratively stakeholders, "beta" testing in real-world field tests and production of final version for further evaluation or use. A conceptual framework for the development and evaluation of DAs for clinical trial participation also followed a cyclic process of development, feasibility and piloting, evaluation and implementation (Gillies & Campbell, 2019). These are not unlike the steps often seen for the development of technology-based interventions and similarities can be drawn to steps already taken in this work i.e. alpha testing with our multidisciplinary group before beta field-tests with patients or piloting before attempting formal implementation.

DA development also calls for extensive documentation throughout the development process. Tools such as the SUNDAE Checklist (Standards for UNiversal reporting of patient Decision Aid Evaluations) (Sepucha et al., 2018) can assist in ensuring research is reported effectively,

understandable and of high quality. Patient DAs are defined within the SUNDAE Checklist as evidence-based interventions designed to:

- help patients make informed and deliberated choices regarding healthcare options.
- provide accurate and unbiased information on options and relevant outcomes.
- aid patients in clarifying their values and treatment preferences.
- guide steps of decision-making and deliberation

While the intervention at the focus of this research does fulfil some of the roles specified, it was not explicitly designed as a patient DA in initial stages and instead was proposed to support the patient throughout treatment with various other functionalities. Therefore, the SUNDAE Checklist was not directly applicable to evaluations of the intervention discussed at the time the research was conducted.

However, reporting output from this work similar to how the SUNDAE Checklist specifies ensures the research is understandable, high quality and can be transferred to other populations or domains. The effort to do so was taken with all research output during this work and is good practice in any field. Producing understandable and high-quality output also ensures that in a mixed audience such as that of this work (i.e. HCI and medical domains), readers from one field can understand and follow the work without requiring an explicit understanding of the other field(s).

In short, while the initial work was not focused on producing a DA intervention and did not follow an appropriate development methodology as such, the shift of the scope highlights the ever adapting and evolving process of the researcher and community of research interest tackling the issues experienced by the community. Future work will take into consideration the expected protocols of DA development and evaluation.

3.6. Overall Thesis Methodology

The work conducted as part of this thesis was completed in three main stages, with the PAR methodology inspiring the co-design approaches throughout, albeit with differing methods at each stage. These are demonstrated in Figure 3.1, detailing the typical PAR cycles of planning, acting, evaluation and analysis. Each unique stage of work is discussed below and further detail on the output and results of each study will be discussed in later relevant chapters. Cycle 1 (Chapter 5) focuses on the work within the MDG to identify key functionalities and develop a prototype to evaluate in Cycle 2. This stage implements the prototype into routine dialysis treatment for 6 weeks with patients, with researcher observations before a usability evaluation and interviews with patients and clinicians (Chapter 6). Finally, Cycle 3 sees the co-design of

patient education and decision aid prototypes, repeating the cycle multiple times through sessions within the MDG, clinical stakeholders and patients (Chapters 7 and 8).

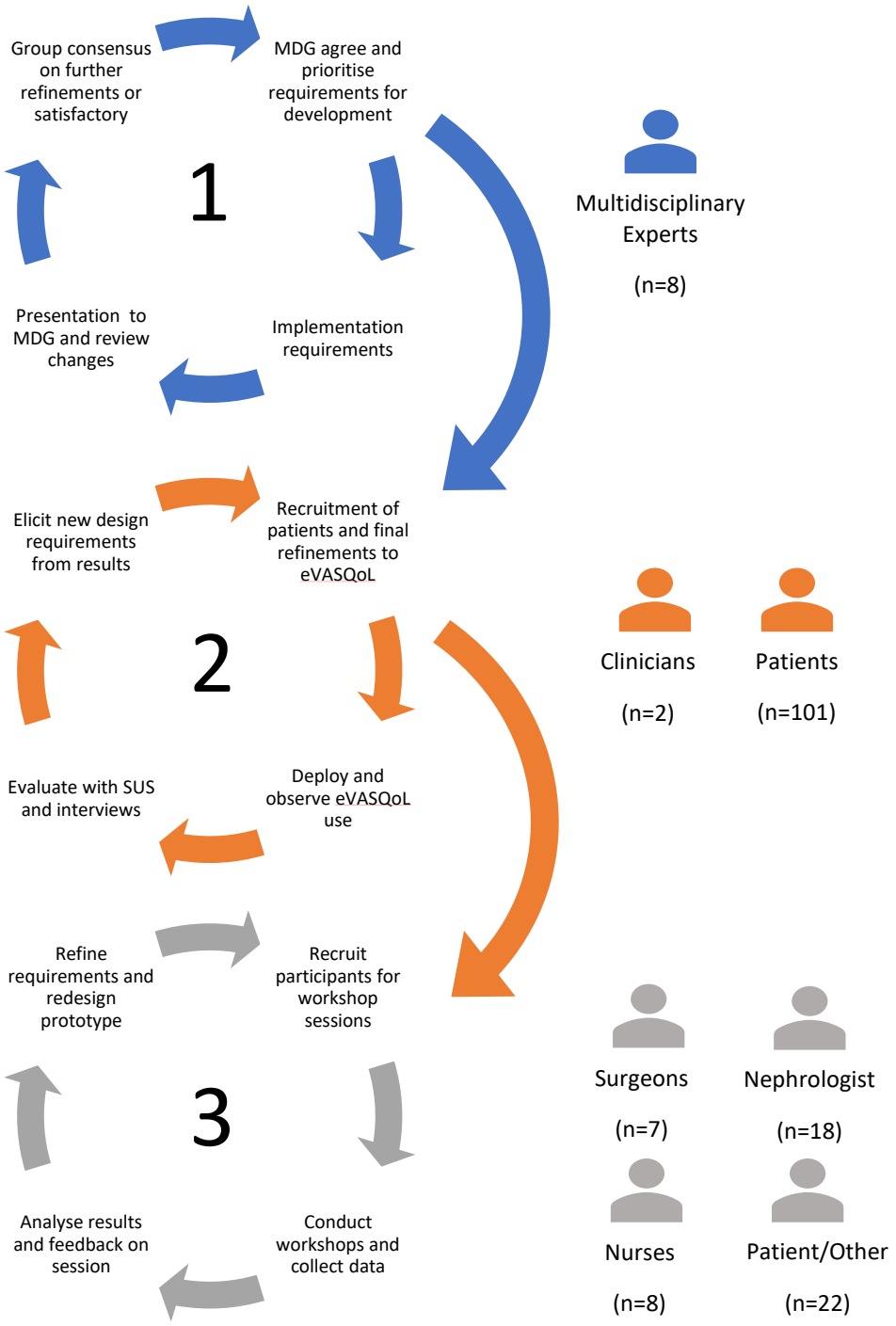


Figure 3.1: The stages of a PAR-inspired cyclic approach, with relevant methods and participant numbers

3.6.1. Developing and Refining Prototype with a Multidisciplinary Group

The work was initially concerned with the refinement and development of the haemodialysis patient portal (HDPP) prototype from earlier work (Bouamrane et al., 2019). This prior research resulted in the author establishing relationships with stakeholders in the community of interest (i.e. nurses, nephrologists and vascular access and transplant surgeons) and beginning to understand the context of the problems they experienced. A multidisciplinary group (MDG) was established, consisting of clinical professionals and academics, including the author. This team would meet regularly (monthly in-person, then fortnightly online from March 2020 onwards) to discuss progress and current focus of research, with the clinical professionals identifying goals (e.g. preparing digital prototype for VASQoL study (Richarz et al., 2021)) and issues, and sharing experience and knowledge of the CKD context while the researchers shared their expertise of human-computer interaction, digital health and suitable methods to achieve the shared goals. Knowledge exchange occurred between the two parties as they shared and became familiar with the domain of the other. Here the principles of the PAR approach could be seen in practice, with all parties sharing power and responsibility for the work being carried out.

While it would have been beneficial to include patients and nurses regularly in MDG meetings, the burden and workload (Blomqvist et al., 2010) these groups are placed under as a result of treatment (receiving and providing respectively) would have made it difficult to ensure their regular attendance. The MDG agreed these stakeholder groups were vital to the success of any proposed change and their involvement should be sought when appropriate and via appropriate methods (e.g. formal evaluation of produced prototypes, co-design workshops on patient information needs, etc.). As previously mentioned, the COVID-19 global pandemic restricted the suitability of some methods, notably face-to-face patient interviews and evaluations with the author. These were later postponed indefinitely under the advice of the clinicians within the MDG, as they were concerned the vulnerable patients would be under enough burden with attending regular treatment during a global pandemic and national lockdown. Therefore, methods were adjusted to consider patient safety and health, as well as the increased workload on health services and staff as a result of COVID-19.

3.6.2. Implementation and Evaluation in a Real-World Setting

The next step was the implementation and evaluation of the refined intervention via a validation study for the VASQoL (Richarz et al., 2021). While recognised as an opportunity for patients to engage with the research, national social distancing measures arising from the COVID-19 global pandemic presented challenges to traditional evaluation methods and the

collection of data. For example, the author was unable to physically attend dialysis clinics and engage with patients due to these restrictions. Clinical members of the MDG could do so however, as they would be providing regular treatment as part of the interaction and were also running the VASQoL validation study in parallel. This presented an opportunity to investigate the clinicians' opinion of the deployed technology and elicit their observations and experiences of patients using the system with minimal disruption in the clinic setting. This work was completed as a case study (see Chapter 6 for details of the methodology).

Flexibility was required throughout this study, as it became apparent during the early stages of deployment of an electronic VASQoL (eVASQoL) that patients found interacting with the system difficult as a result of situational impairment and disease-related accessibility issues i.e. sensitivity of fingers and touchscreen devices (Fujita et al., 2019). Rather than cancel or continue the study with patients' becoming frustrated with using the prototype, steps were taken to improve the situation through updating the system to appear consistently across device orientation changes and the provision of styluses to overcome touch sensitivity issues.

3.6.3. Co-Design of Patient Information Resource with MDG and Medical Professionals

The final set of studies focused on the design of an interactive patient pathways information guide. A key component of the system described during the initial design requirements was the need for an "interactive treatment guide and patient care pathways". While a basic implementation was a feature of the prototype developed with the MDG, the feature had not changed very much over time from this point, unlike the collection of QoL data or capture of vascular access data.

It was determined the iterative and collaborative development of a design for the interactive information guide would be appropriate. This was completed through a series of co-design workshops, initially within the MDG but expanding to surgeon, nephrologist and dialysis nurse groups, with participants from across the UK. Again, this was only possible through the relationship with the community of interest, with clinical members of the MDG utilising their network of peers, established careers and contacts to aid recruitment from across the UK.

It is important to note that during the initial co-design stages of this work, members of the MDG produced their own prototype designs at initial stages and one individual, Professor Kingsmore, later produced a second refined low-fidelity prototype utilised in the stakeholder co-design workshops, before creating another prototype for use in subsequent studies. This is an example of the positive impact of a PAR-inspired approach and the close relationship of

the multidisciplinary group, where an individual inexperienced in designing systems was able to produce their own prototype designs after inclusion and discussion in similar exercises.

3.6.4. Evaluation Workshops with CKD Patients (and UKKW Symposium)

As described, the prototypes designed by the MDG and reviewed by medical staff stakeholders were refined by Kingsmore to a single high-fidelity prototype. This prototype was then presented to patient participants for review in co-design workshop sessions. Following the prior series of co-design workshops, changes were made. For example, initial feedback from medical staff stakeholders suggested that patients would be better reviewing a more refined design due to concerns over how the content of a unvalidated and incomplete prototype would impact on their well-being, given the impact their condition and treatment can have on their lives (e.g. symptom burden such as lack of sleep, decreased sexual drive, pain and fatigue alongside psychological factors including change in self-image, roles and uncertainty of future and health) (Cukor et al., 2007; Hagren et al., 2005; Zalai et al., 2012).

An initial co-design workshop with patients then highlighted issues with the delivery of the sessions and so adaptations were made to streamline and reduce the burden of the activities for patients i.e. reviewing the prototype in stages, more guided and structured discussions in regard to time constraints and given the opportunity to share personal experiences before reviewing the prototype. The final change was designed to allow patients to share their personal experiences of treatment, before then asking them to consider the wider and more general experience of other patients, which was a difficult stage to reach in the first group of patients. This was not encountered with other stakeholders and while surgeons, nephrologists and nurses will have a uniform approach to treatment, patients often only have their own unique and deeply personal experience to refer to and reflect upon. These experiences while valuable cannot always be easily interpreted into design requirements or feedback for the wider community.

The relationships within the MDG also provided an opportunity to engage with a larger and varied audience through a mini-symposium at UK Kidney Week 2021 (UKKW), an accessible online national conference open to patients, industry, and healthcare providers. This required flexibility yet again, with the format of the workshops needing to be adjusted to better suit the wider audience of the mini-symposium and a more restricted time frame for co-design activities. The conference also provided the opportunity to display the progress of the research (i.e. refined prototype design) to the community of interest, including interested parties who had been involved in earlier stages of research.

3.7. Methods and Practices

3.7.1. Software Development Process

Throughout the development of the system(s) (i.e. a HDPP) produced in this research, a software specification document was maintained. The document laid out important statements for the HDPP, such as its purpose, the current scope of the project, the functional and non-functional design requirements of the HDPP, potential use cases and additional materials. This document was updated and maintained, with a new version required after each significant change and evaluation of the system or one of its components. This would allow for logging of significant updates to the system and its design requirements, while also grounding the development of the HDPP within the key issues that gave it purpose and the scope of the project. These statements were flexible and could change to reflect the needs of the community partners with each iteration, but also stark reminders of what the development and evaluation of the system needed to achieve at each iteration.

As discussed earlier, the system was designed in iterative cycles, again keeping with the overarching methodology inspired by the cyclic PAR approach, with iterations consisting of eliciting and prioritising design requirements with community partners, development, and implementation of the HDPP before evaluation with community partners and other stakeholders, concluding in the analysis of the evaluation methods to provide insight for the next iteration. These cycles often occurred at a very detailed level, such as updating the interface of a component and reviewing within the MDG at bimonthly meetings as per the request of a community partner, rather than aiming to implement many changes and design requirements in one iteration.

3.7.2. Internet-mediated or Virtual Qualitative Research

Several of the methods listed in this chapter required transition from traditional physical meetings to an online format, requiring some modification and adaptation. Research such as this can be referred to as Internet-mediated, or virtual qualitative research (if qualitative in nature). This was a result of the introduction of the social distancing guidelines and restrictions within the United Kingdom as of March 2020 in response to the COVID-19 pandemic, which impacted face-to-face meetings and research. Conducting research in this manner allowed adherence to public health guidance and the continuation of high-quality research (Dodds & Hess, 2020). Online research methods are described as extensions of their traditional counterparts (Lobe & Morgan, 2021) but can overcome traditional challenges such as cost, location and participant populations who are normally difficult to recruit and assemble e.g. highly specialised individuals with restricted schedules (Stewart & Shamdasani, 2017).

The teleconferencing platform Zoom was utilised to continue regular MDG meetings to continue but as the COVID-19 pandemic and restrictions changed over time, it became clear the Zoom sessions were more feasible and effective than physical meetings between members with commitments and limited schedules. This would be the same for future research involving participants outside the group and so further utilisation of the platform was considered. The adaptations of these traditional methods will be reported as transparently as possible, to ensure they are transferable in this and other domains of research.

3.7.3. Qualitative Methods

The qualitative methods included in this work collected and analysed data in various forms. This included discussions from one-to-one interviews and co-design workshops, observations of participants and images of activities completed by participants. The analysis of qualitative data is also described below.

Semi-Structured Interviews and MDG Group Discussions. Semi-structured interviews (SSIs) were employed during the implementation and evaluation of the prototype HDPP, to elicit feedback from patients and clinicians. Interviews with patients were conducted by clinicians at the time and focused on patients' opinions of the VASQoL content and using the HDPP, while the author interviewed the clinical research fellow primarily responsible for delivering the HDPP to patients and assisting them during the VASQoL validation study to elicit their observations of patients and opinions on paper vs digital data collection. SSI scripts prompted discussion with questions but did not seek to guide participants to answers and allowed open discussion around a topic, with further prompts where the discussion did not flow as easily. SSIs may require more effort and time than structured interviews but the probing and open-ended nature of questions employed supplement other standardised approaches i.e. System Usability Scale (SUS) (Brooke, 1996) and allow researchers to follow interesting and useful topics in conversation or query interesting findings (Adams, 2015).

Open discussions were also a key part of the MDG sessions, with several members engaging in discussions and topics across a single meeting. These were audio-recorded, and notes were taken to allow for the formation of minutes afterwards to:

- keep a record of the key topics or points raised by group members.
- state any actions or responsibilities members were to carry out as result of meeting.
- update absent members.
- allowing the opportunity to amend or add information to the record.

Case Study Methodology. Case studies are an established research methodology within psychology and sociology and have now been appropriated by other disciplines such as law, medicine, and political science. Case studies are a recognised qualitative approach where the researchers explore one or more bounded systems (i.e. the case or context) over time (Creswell & Poth, 2016) or more simply, "an intensive study about a person, a group of people or a unit, which is aimed to generalize over several unit" (Gustafsson, 2017). A case study design can suit complex cases (i.e. eVASQoL deployment with HD patients during treatment, as described in Chapter 6) that warrant a deeper understanding and investigation. The collection of various data from multiple sources allows for much richer design requirements and considerations for the system in question and others.

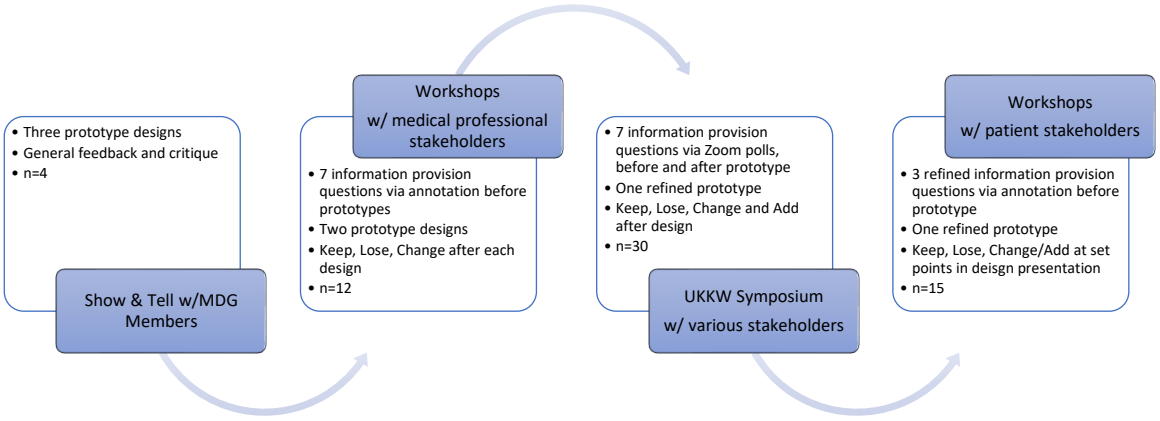


Figure 3.2: Changes in methods and delivery of co-design workshops

Co-design Workshops and Symposium. Workshop sessions consisted of co-design techniques, namely high-fidelity prototype probes, showcased as a narrated video clip. Co-design can be defined as a methodology for active engagement of a broad range of people (i.e. researchers and stakeholders) involved with an issue or process in the design and sometimes implementation of a solution (Burkett, 2012). Co-design (or participatory design) workshops have been utilised in digital health and mHealth settings with great success, bringing stakeholders together to co-create ideas (Lupton, 2017; Ozkaynak et al., 2021). The group interaction of workshops lends the method well to co-design, where discussion between

participants is encouraged, such as questioning one another or commenting on others' views and opinions. These interactions are just as useful as responses to open-ended questions and prompts from the researcher and would be not be possible in a one-to-one interview setting.

The co-design workshops intended to review prototype designs, alongside gathering feedback, design requirements and experiences of patient information provision. Figure 3.2 demonstrates the shift in methods and delivery as three stages, adapting for different settings (i.e. workshop with 6 or fewer participants versus a mini-symposium with 30+ attendees) and audiences (medical professionals with a uniform approach to treatment versus patients who have a personal experience of treatment). Each change to the methods and materials employed was informed by the previous workshops and members of the MDG present during sessions. For example, following the initial patient workshop, the format of the sessions was shifted to allow participants to begin discussions early in the activities and unburden themselves of points, issues or experiences they wish to share, to avoid them resurfacing in later discussions (Adams & Cox, 2008).

Further co-design methods employed during the workshops included an adaptation to the classic "post-it note" exercise, where participants would normally write a response on some kind on a physical note and attach it to a collective whiteboard or flipchart. As the co-design workshops were conducted online via Zoom teleconferencing, the screen-sharing feature was utilised to have participants annotate on a "board" i.e. shared PowerPoint presentation slide. Figure 3.3 demonstrates a screenshot of a completed board exercise. Open discussion was also encouraged during these exercises after annotation was concluded, with participants asked to elaborate on their submissions or comment about others. In the one in-person workshop with patients (see Chapter 8), these methods were readjusted for a physical setting, with participants annotating and note-taking on printouts of slides.

In total, participants completed six tasks in the workshops. They answered three sets of questions about patient information needs in the first half of the sessions, before being shown two probes and providing feedback on each, one after the other. The final task was more informal, as participants were invited to have an open discussion about the workshop themselves and topics raised once the other tasks were completed. The "sticky note" annotation board technique sought to gather responses from participants about the current information needs and practices of kidney patients, with responses typed and placed onscreen next to prompts.

Annotation exercises were also used to elicit feedback on the probes shown, through the "Keep, Lose, Change" (KLC) co-design exercise (Frohlich et al., 2014; Mcgee-Lennon et al.,

2012), with screenshots shown to allow for reflection and recall back to elements of the probes. Each category was given a column and participants would place their comment in the relevant column e.g. under the heading “Keep”, a participant placed the text: “Like the interactive nature”. The KLC technique was later adapted for the UKKW symposium, with the opportunity for interactive exercises such as those in the workshop settings limited by time constraints. Instead, the chat feature of Zoom was utilised, with participants asked to provide feedback via messages to a dedicated host, structured by the relevant heading and then the feedback e.g. “Keep the people diagrams”.

Another category was also added, “Add”, to allow participants to consider additional features outside the confines of what was shown via the probe in addition to “Change”, which suggested changing something already existing in the prototype rather than proposing something completely novel. However, in the final sessions, this was modified to “Change or Add”, as there was notable overlap in how participants interpreted the categories. Adapting the “Change” category to include “Add” reduced confusion while still expanding the scope for design requirements (KLCA i.e. Keep, Lose, Change or Add).

The delivery of the questions had to vary between mediums as well. This first occurred when transitioning the methods from workshops to a symposium format. Co-design workshops were relaxed, had fewer participants, and allowed longer discussion of open-ended questions, while the UKKW event was limited to one hour and so questions were close-ended and given limited response times to ensure the presentation and data collection proceeded to schedule with many participants present. For example, Figure 3.3 displays the original layout of the “Keep, Lose, Change” exercise, whereas the UK Kidney Week event carried out the same exercise with one-minute windows to respond to each category in addition to the category “Add”, one at a time.

Shifting format and delivery was also required with a shift from two single-feature prototype designs to a more detailed and refined single design, with questions of the KLCA technique asked during pauses in a video demonstration of the prototype with patient workshops. This was an effort to minimise the burden of the task for patient participants and collect feedback on several features or functions of the proposed design. The changes in structure were the result of the first session with patients, where the review of the prototype proved difficult for participants as they struggled to recall the entire design and raise points or feedback on all the features demonstrated in a single exercise. The visuals for the activity were also adapted, to include clear colour-coded sections for the three categories (see Figure 3.3 for comparison).

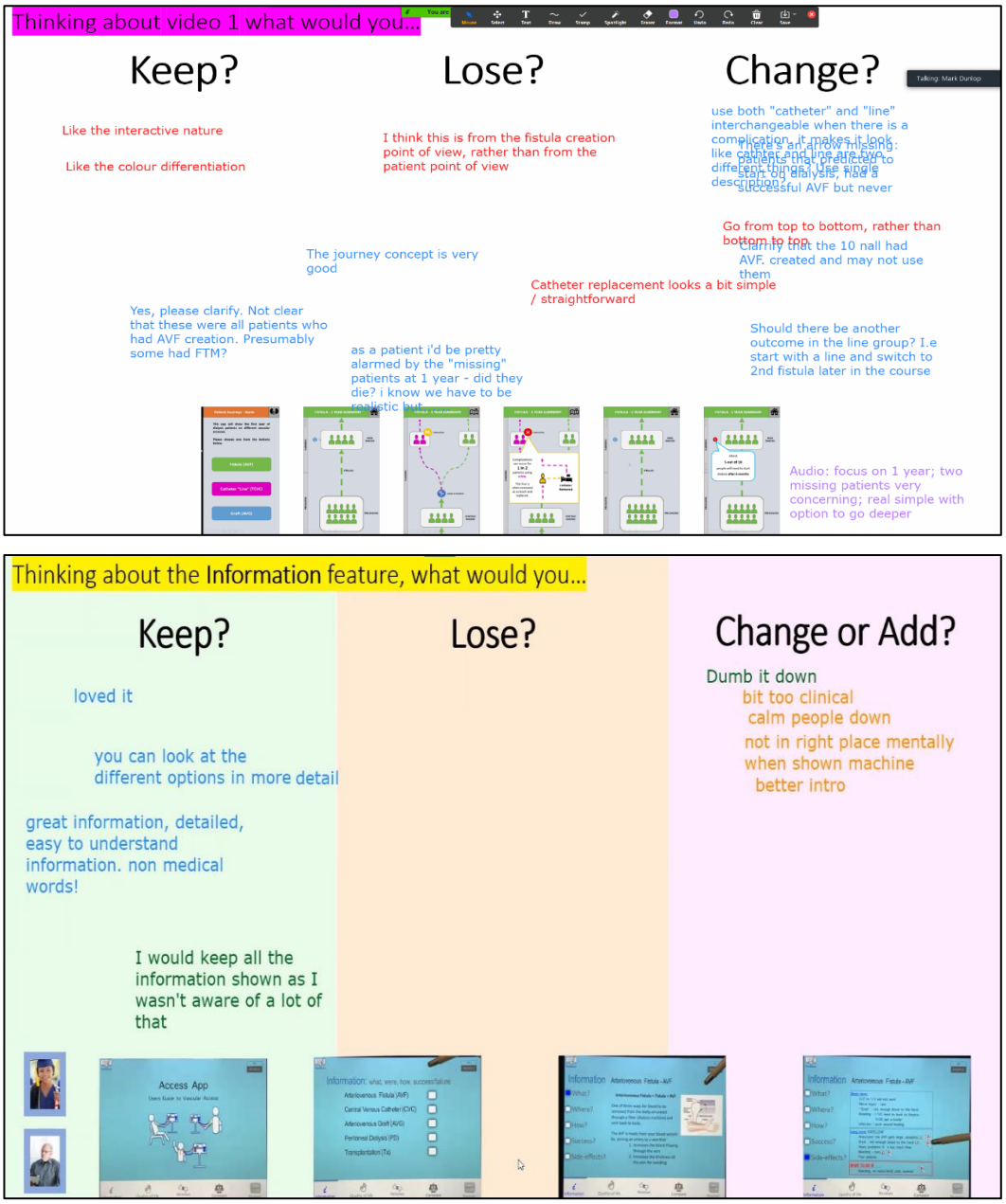


Figure 3.3: Original and final version slide designs for “Keep, Lose, Change” exercise in Zoom workshops

Thematic Analysis. Thematic analysis of qualitative data was conducted numerous times, on transcribed discussions from MDG group meetings, semi-structured interviews with patients and clinicians and co-design workshops with various stakeholders. All thematic analysis was conducted via a framework approach (Gale et al., 2013; Kaplan & Maxwell, 2005) with the use of one of two frameworks, a health information systems quality assessment framework (Bouamrane et al., 2012) or a qualitative meta-synthesis of patients' experiences of technology in care by Korhonen et al. (Korhonen et al., 2016). The former was employed during the analysis of feedback and discussion of an early system (Chapter 6), to synthesise common and

recurring themes and design considerations for future iterations of development. The latter was modified as below and utilised in the scoping literature review and co-design workshops on patient information needs and patient pathway visualisation, where the "patient-centredness" of the framework lends itself to the focus on patient-centred interventions in both exercises (Chapters 4, 7 and 8).

The process of thematic analysis involved repeated listening and reading to ensure accuracy (of transcribed data e.g. audio recording of co-design workshop) and understanding of the data. Instances of data that were consistent with or related to themes of utilised framework were coded using the NVivo qualitative data analysis software (Dhakal, 2022) to the relevant concept. The coded data within each concept was then examined separately and where suitable, synthesised into recurring themes and topics to create original subthemes. These coding processes were subject to input from peers and reviewed as part of frequent MDG meetings.

Within this process, some concepts and themes of the framework by Korhonen et al. were expanded with rebranded names or new themes, after Chapter 4 and the scoping review was conducted. They are listed below:

- Safe - under the concept of Technology, this theme was rebranded as *Appropriate* due to inclusion of themes that were not explicitly about physical safety but still relevant to patient wellbeing.
- Round-the-clock Telephone Support – under the concept of Support, the term "Telephone" was removed to rebrand the theme as *Round-the-clock Support*. This would allow for inclusion of other modern methods of 24/7 communication such as videocalls and messaging through various means.
- Respect of Human Rights – the concept was redescribed as *Patient-Centredness*, as the encompassed themes aligned with the new title and reflected the elements of technology-based interventions that make them patient-centred. Identifying these attributes within interventions were a key goal for the analysis of the scoping review and subsequent analyses on the systems produced as part of this thesis.
- *Treatment burden* – added as a new theme under rebranded *Patient-Centredness*, after recurring codes related to positive effects of interventions on treatment burden of patient were identified. This included reduced costs and expenses of remote patients accessing healthcare or avoiding unnecessary hospitalisation, as well as potential for increased burden from interventions. This theme was not as common in later analyses.

- *Quality of life* – also under the concept of *Patient-Centeredness*, several examples of QoL measures resulted in codes related to measuring and improved patient QoL. This theme was not as common in later analyses.
- *Barriers* – under the concept Technology, a new theme was included to encompass codes that described barriers to the adoption and/or use of technologies, such as technical difficulties, attitudes towards technology and study design.
- *Motivations* – also under the Technology concept, codes describing various motivations for implementing and using technology were given a new theme. These included altruism, community-spirit and immediate perceived benefits such as reduced travel time to access health.

3.7.4. Quantitative Methods

Evaluation Methodology. The evaluation methodology consisted of various methods and techniques, the most prevalent being stakeholder feedback collated from observations, interviews, meetings, and workshops. These qualitative methods were supplemented by recognised quantitative measures, such as the System Usability Scale (SUS) (Brooke, 1996, 2013). While formally recognised measures such as these are of importance to the HCI community and less so to the community of interest, they do allow for comparison between systems, notably in this case iterations or different presentations of the same system. The results of these evaluation tools can support the findings of quantitative methods and highlights areas of concern to focus on in qualitative efforts.

Zoom Polls. As discussed in earlier sections, the opportunity to present at UKKW presented challenges in adapting the workshop methodology to a wider audience in a more limited time frame. The elicitation of participants' opinions on the current information needs and behaviours of patients via the qualitative "sticky note" annotation was not feasible for an anticipated audience of thirty or more individuals in terms of time and effort (i.e. effort for participants to use the annotation feature to write on a screen and effort for the author to organise a single board on which many participants have posted text, often overlapping).

Instead, a quantitative method was employed, using Zoom's polling feature to post questions to the audience with Likert-scale responses, reducing the effort and time required to complete the task given. The UKKW event consisted of four polls in total: (1) demographics questionnaire, (2) patient information sources, (3) current information provision, (4) potential information provision (after viewing prototype probe). The last two polls were informed by the scoping review findings, whereas the second poll aimed to capture the information the first three tasks in the workshops sought to elicit. A key benefit of collecting quantitative data live

during a session was the ability to process the completed poll responses immediately and demonstrate the results during the session, as a radar plot diagram (Figure 3.4).

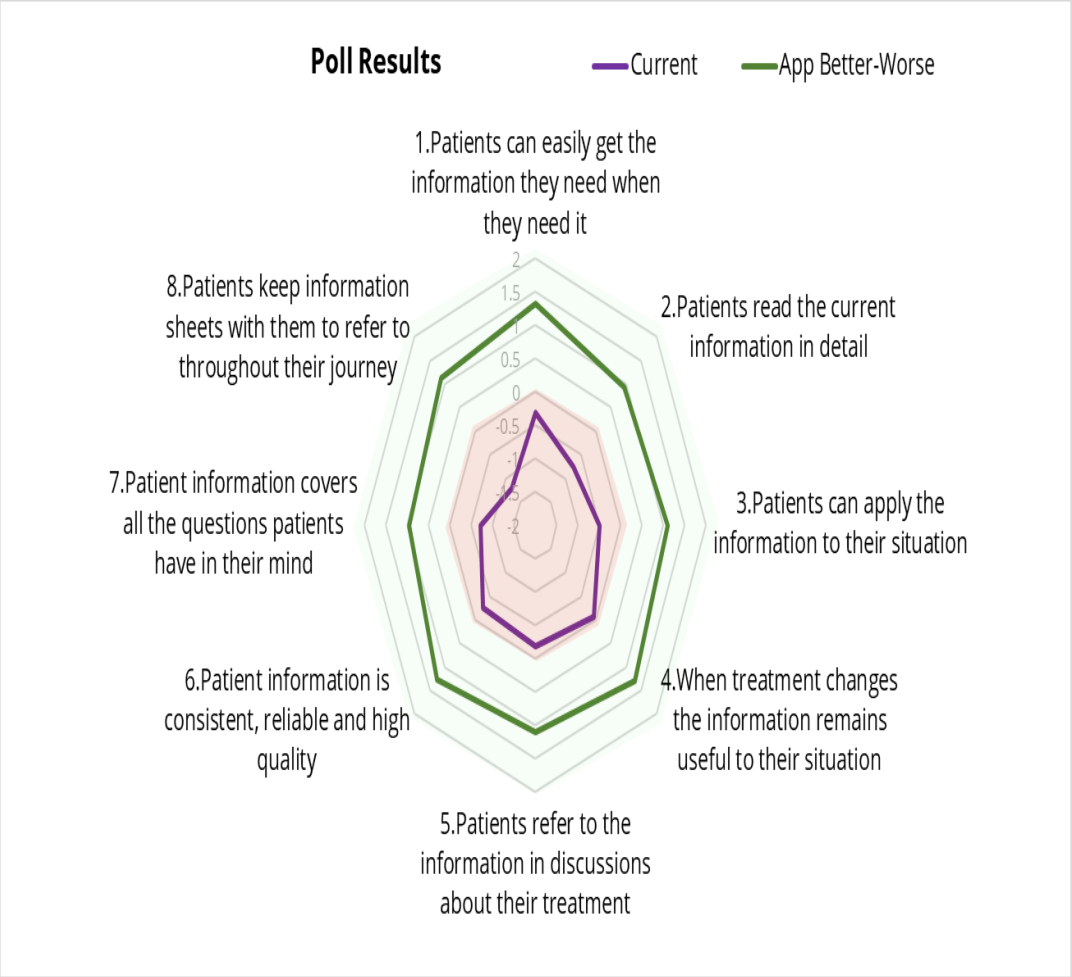


Figure 3.4: Example of radar plot displayed at mini-symposium at UK Kidney Week. Comparing Poll 3 (current information provision i.e. purple line) and Poll 4 (expected impact of the app on information provision i.e. green line) responses from participants during the session

3.8. Conclusion

The work completed as part of this thesis aimed to follow a Participatory Action Research (PAR) methodology and as such involved working collaboratively with stakeholders such as clinicians, nurses and patients. Restrictions from the COVID-19 pandemic and pragmatic design decisions meant a true PAR methodology was not conducted, but the co-design processes carried out were inspired by PAR principles. This included the formation and continued engagement of the multidisciplinary group, evolving to the stage where participants began to better understand and produce their own contributions within the work. Iterative work with this group produced a refined prototype application which was later deployed and

evaluated in a real-world setting. Further effort was given to patient information provision as well, via workshops to produce an appropriate and effective intervention through co-design. The work described consisted of qualitative methods such as co-design workshops, semi-structured interviews, and group discussions. These rich sources of information underwent thematic analysis and were supplemented with quantitative methods and measures (e.g. SUS, Likert scale responses, etc.) to better highlight the themes and topics raised.

Chapter 4: Scoping Literature Review

This chapter covers the procedure, results and analysis of the scoping review conducted to provide an overview of the literature and guide the research of the thesis. This will also include justifications for methodological decisions such as inclusion and exclusion criteria of articles. This chapter provides responses to the first research question proposed in section 1.3 and its sub-questions, namely lessons and insights gathered from existing technologies and methods, that are then carried into the later research completed within this thesis.

4.1. Introduction

Treatment burden has been defined as 'the work placed upon a patient as a result of their healthcare and the impact upon their wellbeing' (Gallacher et al., 2018). "Work" refers to both 'the treatment' as well as the process of 'self-care' for a condition, including attending clinical appointments, monitoring one's health, doing exercise as part of a treatment or recovery programme or taking medications (Eton et al., 2012; Gallacher et al., 2011). Treatment burden is distinct from the 'burden of illness', where the illness directly impacts the patient through symptoms, fatigue, pain or discomfort. Excessive treatment burden can result in lower quality of life and reduced adherence to treatment, which in turn can increase the risk of hospitalisation and mortality (Eton et al., 2012; Gallacher et al., 2011; Gallacher et al., 2018). Paradoxically, patients' reduced engagement with treatments can in turn trigger in reaction an intensification of treatment, thus further aggravating the treatment burden for patients.

In order to avoid these negative consequences, there has in recent years been an increased interest in the concept of "minimally disruptive medicine", i.e. the provision of care and services that are designed to minimise the treatment burden of patients while furthering their healthcare goals (May et al., 2009). With this recognition of treatment burden, there is also an increased interest in objectively measuring treatment burden by means of disease-specific measures (Sav et al., 2017).

4.2. Objective and Research Question

This scoping review is complementary to these efforts aiming to identify and alleviate the burden of treatment for patients, focusing specifically on technological interventions developed for patients with high treatment burden. There have been no reviews conducted to date on this topic and thus the present work makes an important contribution to the advancement of the state of research in the field of treatment burden research. Scoping reviews can be particularly useful to identify emerging patterns in the literature or mapping multi-dimensional and potentially loosely defined concepts such as 'eHealth' or 'cloud-computing'

or potentially extremely large research domains such as ‘digital technology and nursing care’ or ‘electronic prescribing’ for example (Griebel et al., 2015; Krick et al., 2019; Pagliari et al., 2005; Williams et al., 2021). This mode of investigation is particularly useful for researching emerging technology innovations, where identifying broad trends is key, as opposed to systematic reviews aiming to underpin the development of policies or clinical guidelines with evidence grading (Bouamrane, Macdonald, et al., 2011).

This scoping review is thus guided by the following main research question:

- **RQ 1:** What patient-centred, technology-based interventions have been implemented to support patients with high treatment burden?

In considering this research question, the following objectives were specifically considered:

- **RQ 1.1:** What is the range of technological interventions that have been developed specifically for patients with high treatment burden?
- **RQ 1.2:** What factors of technological intervention can promote ‘patient-centredness’?

4.3. Methods

A scoping review methodology, first advocated by Arksey and O'Malley (2005) (Arksey & O'Malley, 2005) and further refined by Levac et al. (2010) (Levac et al., 2010) was followed. The review was conducted using the following 6 stages: (1) identifying the research question, (2) identifying relevant studies, (3) selecting relevant studies, (4) mapping and charting the data, (5) thematic synthesis and (6) consultation with experts. Four clinicians with expertise in surgery (general, transplant and vascular surgery), nephrology, vascular access and renal services provided domain expertise throughout the review design and each subsequent iterative step, and are co-authors of this review (Kingsmore, Richarz, Stevenson, Thomson).

4.4. Data sources

The database search included the following 3 electronic databases: (1) Medline, (2) ACM Digital Library and (3) Inspec, (Engineering Research Database, Institution of Engineering and Technology (IET)). By searching these databases, a wider view of the literature was possible, from both medical and computer science sources. Complementary searches were subsequently conducted on Google Scholar as a means to expand the search space and increase the recall of relevant studies (Bouamrane, Macdonald, et al., 2011). This was done so by screening the first 100 results, then screening the subsequent 20 results unless no relevant article was found within the current 20 articles. The literature searches were carried out in June 2020 initially and updated later in Dec 2021 and the subqueries used to form the query for

these searches are described in Table 4.1. The reference lists of included studies were also scrutinised to identify additional potentially relevant studies.

Table 4.1: Queries and Search Terms

Subquery	Search Terms	Overarching Concepts
P1	"high treatment burden" OR “treatment burden” OR “medication burden” OR “treatment impact”	Synonyms of high treatment burden
P2	"haemodialysis" OR "dialysis" OR "chemotherapy" OR "radiotherapy" OR "transplants"	Treatments with high associated burden
P3	"advanced" OR "severe"	Descriptive terms associated with high treatment burden conditions
P4	"cancer" OR “heart failure” OR "COPD" OR “chronic obstructive pulmonary disease” OR “chronic kidney disease”	Health conditions or diseases typically associated with high treatment burden
P5	"digital health" OR "mHealth" OR “eHealth” OR “telemedicine” OR “telehealth” OR “telecare” OR “app”	Technology-based interventions and keywords
P6	“PROM” OR “patient reported outcome measures” OR “patient diary” OR “electronic patient diary” OR “self reporting” OR “patient feedback”	Patient-centred interventions
Query	P1 AND P2 AND P3 AND P4 AND P5 AND P6	Amalgamation of all subqueries

4.4.1. Eligibility Criteria

The search included scientific papers that were published between 1995 and 2021, describing empirical / implementation studies available in English.

4.4.2. Inclusion Criteria

- Primary studies describing the implementation of technology driven, patient-centred interventions for high treatment burden populations (as defined in the introduction).

- Interventions and technology where patients are "pro-active" users, for example, technologies which enable patients to:
    - actively communicate with healthcare providers.
    - provide feedback.
    - input or record clinical measures, patient recorded outcomes (PROs/PROMs) or other data.
- The study population are adult (18+) patients.

4.4.3. Exclusion Criteria

- Studies of interventions which are not patient-centred.
- Studies of interventions of populations who are not high-treatment burden patients.
- Studies of interventions which are not technology-driven e.g. paper-and-pen forms.
- Studies of technology interventions which have not been implemented in practice (i.e. proof-of-concept studies or prototype development not implemented in practice).
- Studies of interventions where patient is monitored for limited period (e.g. post-operative monitoring).
- Studies of interventions where patients are not “pro-active” users but “passive” users (e.g. sensor providing feed-back to clinicians but not the patient).
- Study is not a primary study, such as secondary analysis of exiting datasets or systematic reviews.
- Study is an opinion piece or review without a clearly defined methodology.
- Studies of non-adult patients i.e. under 18 years of age.
- Studies published earlier than 1995.
- Articles unavailable in English.

4.5. Study Selection

The review team consisted of seven researchers with expertise in medicine, computer science and medical informatics. Each abstract was reviewed independently by two reviewers. Conflicts between reviewers were resolved by consensus during online team meetings using Zoom and including all authors, which took place between July 2020 and December 2021. Details of the number of abstracts screened, full texts screened, full texts included and excluded are detailed in the PRISMA flow-chart provided in Figure 4.1.

4.6. Data Extraction & Thematic Analysis

A data extraction instrument was iteratively developed by the review team, piloted and further refined using a sample of the included studies. After piloting the data extraction instrument, items included for extraction were: first author, title, year of publication, patient population, healthcare setting, study design, study location (country), and intervention-specific information: intervention description, main functions, platform or delivery method, data collected, primary / secondary outcomes measures, results, and key findings. Thematic analysis was performed using a framework approach (Gale et al., 2013; Kaplan & Maxwell, 2005), with the thematic framework developed using prior work conducted as part of a qualitative meta-synthesis of patients' experiences of technology in care by Korhonen et al. (Korhonen et al., 2016). In this review, Korhonen et al. sought to explore patients' experience of technology in care and identified 5 key dimensions that significantly affected patients experiences: respect of human rights, support, uniqueness, technology and competence (Korhonen et al., 2016). The first concept of respect of human rights was renamed "patient-centredness", considered more appropriate for the purpose of this review, and then a thematic framework was iteratively developed fusing the five overarching themes of patient-centredness, support, uniqueness, technology and competence.

4.7. Results

4.7.1. Overview of Included Studies

A total of 1099 records were retrieved for this review, including 848 from the database searches (Medline: n=517; ACM: n=154; Inspec: n=177) and 251 from complementary searches. After removing duplicates, 1085 abstracts were screened and n=96 articles met the eligibility criteria for full text screening, from which 39 full texts were included for data extraction and thematic analysis (Absolom et al., 2019; Ashley et al., 2013; Basch et al., 2005; Basch, Artz, et al., 2007; Basch et al., 2016; Basch, Iasonos, et al., 2007; Basch et al., 2009; Berry et al., 2011; Berry et al., 2014; Coombs et al., 2020; Crafoord et al., 2020; Evenski et al., 2020; Ferrer-Roca & Subirana, 2002; Fjell et al., 2020; Gallar et al., 2007; Hauth et al., 2019; Huang et al., 2020; Jacobs et al., 2018; Judson et al., 2013; Kargalskaja et al., 2020; Kearney et al., 2009; Kennedy et al., 2021; Kuo et al., 2020; Maguire et al., 2021; McCann et al., 2009; Meiklem et al., 2021; Mitchell & Disney, 1997; Mitchell et al., 2000; Ngo et al., 2020; Ruland et al., 2010; Rumpsfeld et al., 2005; Sicotte et al., 2011; Velikova et al., 2004; Warrington et al., 2016; Whitten & Buis, 2008; Wood et al., 2020; Wood et al., 2017; Wright et al., 2003; Zini et al., 2019) (see Figure 4.1, PRISMA flow-chart for process).

During full-text screening, 57 articles were excluded for various reasons. The most common justification (n=18) was the intervention(s) described were not patient-centred and patients were "passive" users (e.g. sensors reporting to clinician, but not patient). Many excluded articles described interventions which had not yet been implemented (n=14) or were still in pilot phases or simply protocols (n=7), and 4 were not technology-based. Studies describing patients who were post-treatment or not defined as high treatment burden were also excluded (n=5) alongside 2 which were non-primary (secondary analysis of existing data) and 1 study which was of a limited period (i.e. failed to run as long as originally planned). Finally, 4 full-text articles could not be accessed or made available and 2 were unavailable in English.

Of the 39 included studies, 29 described interventions were designed for oncology patients, notably those receiving chemotherapy or radiotherapy (Absolom et al., 2019; Ashley et al., 2013; Basch et al., 2005; Basch, Artz, et al., 2007; Basch et al., 2016; Basch, Iasonos, et al., 2007; Basch et al., 2009; Berry et al., 2011; Berry et al., 2014; Coombs et al., 2020; Crafoord et al., 2020; Evenski et al., 2020; Ferrer-Roca & Subirana, 2002; Fjell et al., 2020; Hauth et al., 2019; Jacobs et al., 2018; Judson et al., 2013; Kargalskaja et al., 2020; Kearney et al., 2009; Kennedy et al., 2021; Kuo et al., 2020; Maguire et al., 2021; McCann et al., 2009; Ngo et al., 2020; Ruland et al., 2010; Velikova et al., 2004; Warrington et al., 2016; Wright et al., 2003; Zini et al., 2019). Another 8 studies focused on chronic kidney disease patients receiving haemodialysis or peritoneal dialysis (Gallar et al., 2007; Huang et al., 2020; Meiklem et al., 2021; Mitchell & Disney, 1997; Mitchell et al., 2000; Rumpsfeld et al., 2005; Sicotte et al., 2011; Whitten & Buis, 2008) and 2 studies reported interventions for cystic fibrosis patients (Wood et al., 2020; Wood et al., 2017).

The focus of all the included studies was a technology-based intervention, with several types and examples of technologies described. 11 of the interventions were described as web-based or websites (Absolom et al., 2019; Ashley et al., 2013; Basch et al., 2005; Basch, Artz, et al., 2007; Basch et al., 2016; Basch, Iasonos, et al., 2007; Berry et al., 2014; Hauth et al., 2019; Judson et al., 2013; Kargalskaja et al., 2020; Kennedy et al., 2021), 8 were delivered via teleconferencing technology (Evenski et al., 2020; Gallar et al., 2007; Mitchell & Disney, 1997; Mitchell et al., 2000; Rumpsfeld et al., 2005; Sicotte et al., 2011; Whitten & Buis, 2008; Wood et al., 2017) and a further 9 were delivered via a dedicated device, such as a touch-screen computer, handset or personal digital assistant (PDA) (Basch et al., 2009; Berry et al., 2011; Kearney et al., 2009; Kuo et al., 2020; Maguire et al., 2021; McCann et al., 2009; Ruland et al., 2010; Velikova et al., 2004; Wright et al., 2003). There were also 4 interventions which were telephone-based (Coombs et al., 2020; Ferrer-Roca & Subirana, 2002; Kennedy et al.,

2021; Warrington et al., 2016) and 8 were described as mobile applications (Crafoord et al., 2020; Fjell et al., 2020; Huang et al., 2020; Jacobs et al., 2018; Meiklem et al., 2021; Ngo et al., 2020; Wood et al., 2020; Zini et al., 2019).

The interventions also varied in purpose and how they primarily supported or facilitated patient-centred care: 24 facilitated the self-reporting of disease or treatment-related symptoms (Absolom et al., 2019; Basch et al., 2005; Basch, Artz, et al., 2007; Basch et al., 2016; Basch, Iasonos, et al., 2007; Basch et al., 2009; Berry et al., 2014; Coombs et al., 2020; Crafoord et al., 2020; Fjell et al., 2020; Hauth et al., 2019; Judson et al., 2013; Kargalskaja et al., 2020; Kearney et al., 2009; Kuo et al., 2020; Maguire et al., 2021; McCann et al., 2009; Ngo et al., 2020; Ruland et al., 2010; Warrington et al., 2016; Wood et al., 2020; Wright et al., 2003; Zini et al., 2019), 6 facilitated self-reporting of PROMs (Ashley et al., 2013; Berry et al., 2011; Kennedy et al., 2021; Meiklem et al., 2021; Velikova et al., 2004; Zini et al., 2019) and 9 facilitated telemedicine via consultations between remote patients and clinicians (Evenski et al., 2020; Ferrer-Roca & Subirana, 2002; Gallar et al., 2007; Mitchell & Disney, 1997; Mitchell et al., 2000; Rumpsfeld et al., 2005; Sicotte et al., 2011; Whitten & Buis, 2008; Wood et al., 2017). There were 7 examples of interventions designed to deliver personalised/tailored information or recommendations for patients (Coombs et al., 2020; Crafoord et al., 2020; Fjell et al., 2020; Huang et al., 2020; Jacobs et al., 2018; Kargalskaja et al., 2020; Maguire et al., 2021) and 3 examples of clinical reading reporting (Huang et al., 2020; Kargalskaja et al., 2020; Zini et al., 2019).

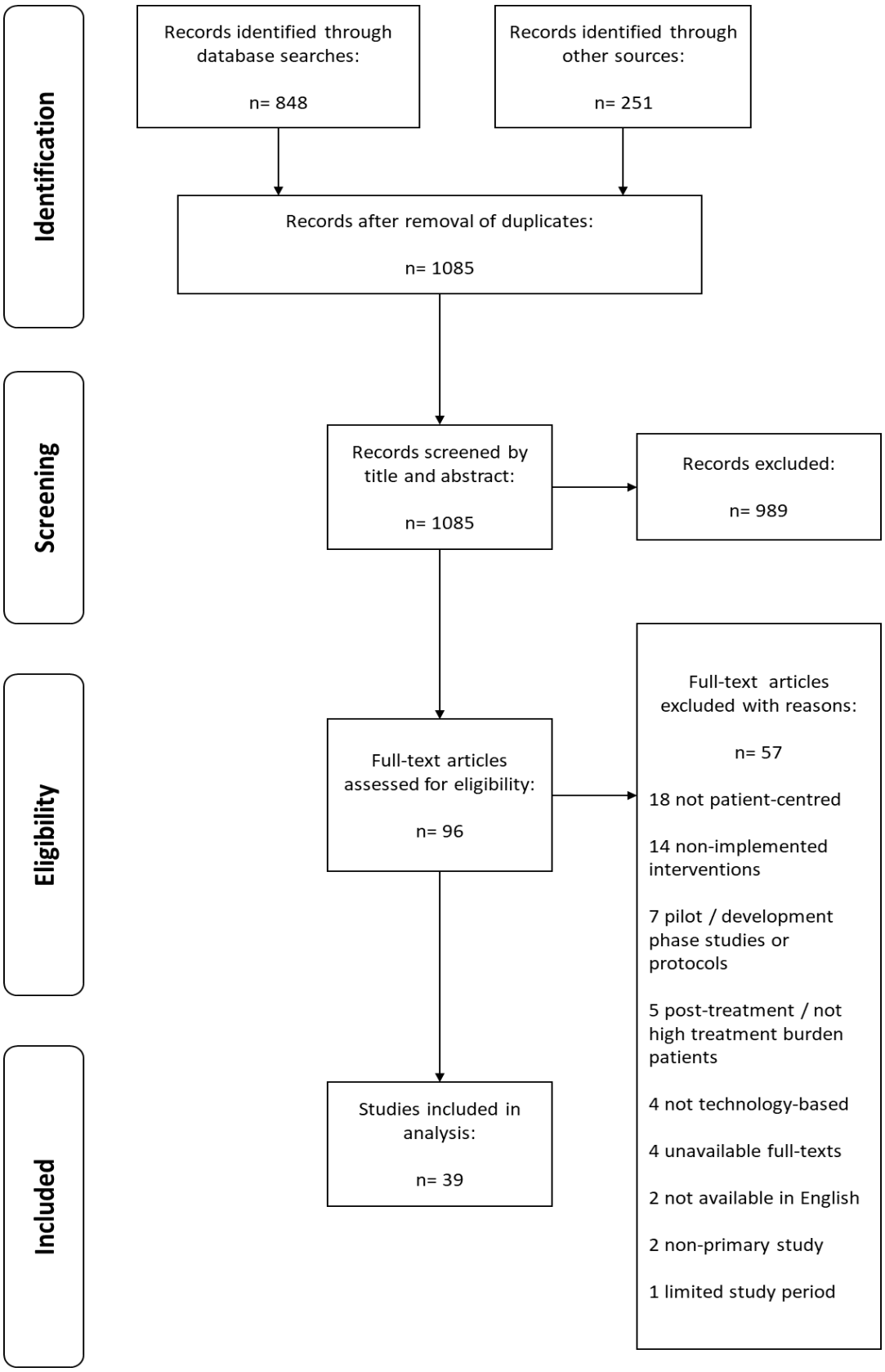


Figure 4.1: Scoping Review PRISMA Flow-chart

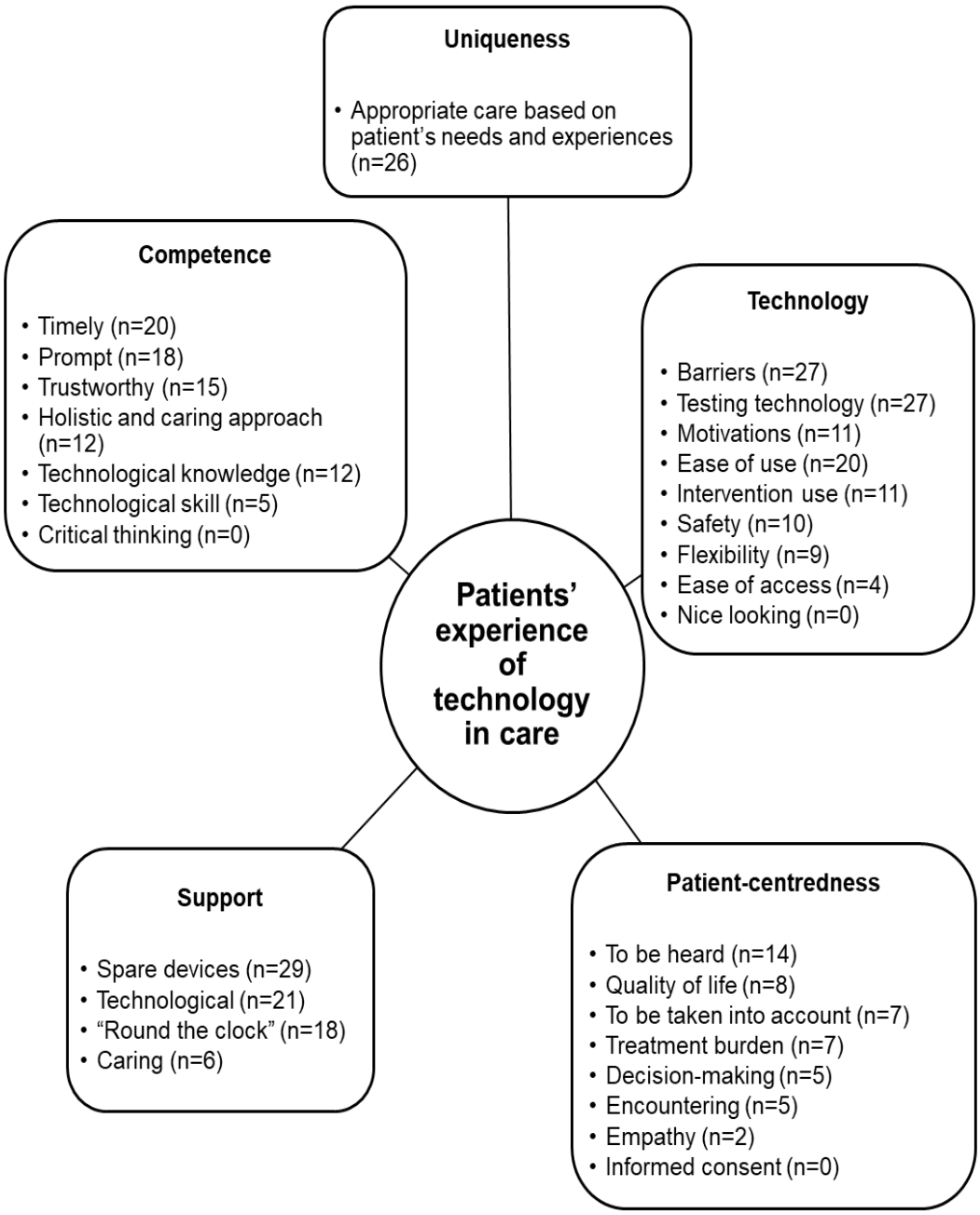


Figure 4.2: Diagram of Concepts and Themes Identified from 39 Papers with Prevalence

4.7.2. Thematic Analysis

A high-level concepts map of the included studies along with their relation to the thematic framework developed (Korhonen et al., 2016) is provided in Figure 4.2. Each concept is discussed in detail in the following sections.

Patient-centredness. Originally named respect of human rights by Korhonen et al., this precondition included various concepts including “to be heard”, “to be taken into account”, informed consent, decision-making, patient education, empathy and encountering, which are key elements of patient-centred practices. It was notable that informed consent was not a topic of discussion in any study. One study discussed the impact on shared decision-making between patients and clinicians as unaffected (Velikova et al., 2004) while 4 studies did demonstrate PRO data informing medical decision-making solely by clinicians (Basch et al., 2005; Judson et al., 2013; Kearney et al., 2009; Mitchell & Disney, 1997). However, all included studies recruited patients at stages after decisions had been made and thus neither of these concepts would be relevant. The concepts “to be taken into account” and “to be heard” (understood to refer to how patients’ data is incorporated into treatment, and how patient opinions and concerns are taken into consideration respectively) were also not often achieved in the context of the reviewed studies. Study design was suggested as a possible cause in one study (Absolom et al., 2019), while other studies did not explicitly require review and use of PRO data by clinicians (Basch et al., 2005; Basch, Iasonos, et al., 2007; Berry et al., 2011; Kennedy et al., 2021; Kuo et al., 2020; Ngo et al., 2020; Wright et al., 2003) or left it to their judgement (Velikova et al., 2004). Importantly, the lack of utilisation of PROs lead to a reduction in patients’ perception of value of engaging with interventions and their data (Basch, Iasonos, et al., 2007; Berry et al., 2011; Jacobs et al., 2018; Meiklem et al., 2021) and a sense of little or no impact on their healthcare (Absolom et al., 2019; Wright et al., 2003). Oddly and in contrast to the patient experience, clinicians found systematic patient reporting was very useful and valuable (Absolom et al., 2019; Basch et al., 2016; Wright et al., 2003), and graphical summaries (Kargalskaja et al., 2020) or prioritisation of symptoms to discuss in clinical encounters (Kennedy et al., 2021; Ruland et al., 2010) was another benefit. It is likely that optimal integration would require both parties to clearly engage in the exchange.

While 6/39 studies (Absolom et al., 2019; Berry et al., 2014; Coombs et al., 2020; Crafoord et al., 2020; Jacobs et al., 2018; Ruland et al., 2010) explicitly facilitated patient education, other systems also facilitated the delivery of patient education despite it not being their primary function, providing education and training remotely (Fjell et al., 2020; Huang et al., 2020; Kargalskaja et al., 2020; Maguire et al., 2021; Mitchell & Disney, 1997; Ngo et al., 2020; Whitten & Buis, 2008; Zini et al., 2019). 4 studies reported an improvement in communication and discussion (Basch et al., 2005; Basch, Artz, et al., 2007; Crafoord et al., 2020; McCann et al., 2009), and others suggested implemented interventions provided information which initiated and supported communication (Berry et al., 2011; Berry et al., 2014; Hauth et al., 2019; Jacobs et al., 2018; Judson et al., 2013) and a sense of reassurance (Crafoord et al., 2020;

Huang et al., 2020; Judson et al., 2013; McCann et al., 2009; Meiklem et al., 2021; Mitchell et al., 2000; Ngo et al., 2020). There were few examples of intervention impact upon encountering (e.g. consultation between patient and clinician), however attendance at physical appointments (Wood et al., 2020) and focus of consultations improved (Gallar et al., 2007) in two examples. The improved focus of consultations was a result of prior symptom reporting and advice provided by the intervention, allowing for reflection and prioritisation of discussions.

The concept of empathy was only reported within 2 studies (Ferrer-Roca & Subirana, 2002; Jacobs et al., 2018) where staff displayed understanding and support of patients' situations. The lack of this concept in the included literature may be attributed to the focus of these studies on the implementation and evaluation of interventions, and less so on the empathy of healthcare staff towards patients. Concerns for traditional care and the patient-provider relationship were also raised (Meiklem et al., 2021; Whitten & Buis, 2008; Wood et al., 2020), which interventions must be shown to support and are not seen to completely replace or negatively impact. Interestingly, the opposite also applies, that there may be negative consequences of interventions becoming unavailable upon study completion, leaving patients with feelings of being alone and no longer meeting healthcare professionals frequently (Crafoord et al., 2020).

Treatment burden and quality of life (QoL) were added to the original concepts after recurring themes pertaining to both were identified in the literature. One study reported reduction in symptom burden (Maguire et al., 2021) and others reported improved QoL and care (Berry et al., 2014; Ferrer-Roca & Subirana, 2002; Jacobs et al., 2018; Ruland et al., 2010; Velikova et al., 2004; Warrington et al., 2016; Wood et al., 2017), with QoL measures being a common feature of the interventions listed. Treatment burden was not explicitly stated in the included studies or formally measured, but examples of the positive effects of interventions on patients' treatment burden were identified. For patients in remote locations geographically, reduced costs and expenses were recorded where patients did not need to travel to a central hospital or clinic, with interventions facilitating improved access to treatment (Mitchell & Disney, 1997; Wood et al., 2020). Finally, the reduction of hospitalisation and emergency treatment is a notable benefit for both patients and healthcare systems (Berry et al., 2014; Gallar et al., 2007; Mitchell et al., 2000; Warrington et al., 2016) and the reporting of symptoms and ability to monitor changes in health of remote patients can be effective in reducing patient treatment burden and improving their outcomes, as well as utilising healthcare services effectively by avoiding unnecessary hospitalisation and identifying symptoms and complications earlier

(Berry et al., 2014; Gallar et al., 2007; Mitchell & Disney, 1997; Mitchell et al., 2000; Warrington et al., 2016; Wood et al., 2020). However, one study noted that the intervention itself could become another burden of their treatment (Wood et al., 2017).

Support. The support precondition was broken down into four types of support required for technology-based interventions: technological, caring, round the clock and spare devices.

Three types of technological support were identified: patient training, staff training and support to access interventions and resolving issues. Patient training was most common, with various approaches and deliveries identified. This included physical materials such as custom user manuals (Absolom et al., 2019; Mitchell et al., 2000; Zini et al., 2019), wallet-sized instruction cards (Basch et al., 2005), barcodes attached to appointment cards (Wright et al., 2003) or written instructions (Crafoord et al., 2020; Fjell et al., 2020). Training of patients (Absolom et al., 2019; Basch et al., 2005; Basch et al., 2016; Basch, Iasonos, et al., 2007; Crafoord et al., 2020; Fjell et al., 2020; Jacobs et al., 2018; Judson et al., 2013; Kearney et al., 2009; Kennedy et al., 2021; McCann et al., 2009; Mitchell et al., 2000; Ngo et al., 2020; Wright et al., 2003; Zini et al., 2019) was also often delivered prior to or during the first use of an intervention. Those that provided training via brief teaching sessions in-clinic ranged from five to fifteen minutes in length (Basch et al., 2005; Basch, Iasonos, et al., 2007; Judson et al., 2013; Wright et al., 2003), while others described training occurring in dedicated meetings with healthcare staff that the patient was familiar with or would normally encounter regarding their health (Jacobs et al., 2018; Kearney et al., 2009). Staff training typically focused on educating staff on how to utilise the intervention or its data in treatment (Ashley et al., 2013; Evenski et al., 2020; Velikova et al., 2004; Warrington et al., 2016). One study also reported costs of training in a summary of total annual costs associated with the implementation of an intervention, but did not specify if only staff or staff and patients received training (Rumpsfeld et al., 2005). The last form of technological support demonstrated was support for patients attempting to access interventions or resolving issues encountered during use. This took various forms, including assistance from friends and family (Ashley et al., 2013), e-mails or dedicated helpline (Basch et al., 2005; Ngo et al., 2020) or a dedicated individual such as an education navigator (Jacobs et al., 2018) or researcher (Meiklem et al., 2021). This support was a key aspect of interventions aimed at independent use by patients, without which individuals would have been unable to engage fully with the interventions (Ashley et al., 2013).

Caring support was the least reported concept, with only two themes identified: reassurance from monitoring and dedicated support services. Reassurance from monitoring was reported

in 4 studies (Crafoord et al., 2020; Huang et al., 2020; McCann et al., 2009; Mitchell et al., 2000), and while the interventions in question differed in technology and population, they provided reassurance to patients at home by providing monitoring and attention from healthcare professionals. Dedicated support services included specific individuals which patients were able to meet with (Jacobs et al., 2018) or automated call centre to redirect calls (Ferrer-Roca & Subirana, 2002), providing patients with an accessible and reliable source of support. Round the clock telephone support was primarily provided through telephone calls (Absolom et al., 2019; Ferrer-Roca & Subirana, 2002; Warrington et al., 2016; Wood et al., 2017), and alerting systems for both patients and clinicians (Basch et al., 2005; Basch, Artz, et al., 2007; Basch et al., 2016; Basch, Iasonos, et al., 2007; Coombs et al., 2020; Crafoord et al., 2020; Fjell et al., 2020; Hauth et al., 2019; Judson et al., 2013; Kearney et al., 2009; Maguire et al., 2021; McCann et al., 2009; Wood et al., 2020). Most interventions however did encourage the patient to initiate contact if reported symptoms were severe or health was deteriorating, as alerts were not always responded to immediately (Absolom et al., 2019; Basch et al., 2005; Basch, Artz, et al., 2007; Basch et al., 2016; Basch, Iasonos, et al., 2007; Coombs et al., 2020; Crafoord et al., 2020). Whilst necessary, such disclaimers could undermine the potential reassurance from monitoring systems.

Studies were considered to provide support via spare devices where they provided patients with a dedicated device to access the intervention, Examples included in-clinic computers, devices and teleconferencing equipment (Basch et al., 2005; Basch, Artz, et al., 2007; Basch et al., 2016; Basch, Iasonos, et al., 2007; Basch et al., 2009; Berry et al., 2011; Berry et al., 2014; Evenski et al., 2020; Kuo et al., 2020; Meiklem et al., 2021; Mitchell & Disney, 1997; Ruland et al., 2010; Rumpsfeld et al., 2005; Sicotte et al., 2011; Velikova et al., 2004; Whitten & Buis, 2008; Wood et al., 2017; Wright et al., 2003) or dedicated devices and equipment for patients to use from home (Crafoord et al., 2020; Gallar et al., 2007; Jacobs et al., 2018; Kearney et al., 2009; McCann et al., 2009; Mitchell et al., 2000; Ngo et al., 2020; Zini et al., 2019). One study specifically provided dedicated devices for clinicians (Maguire et al., 2021). In the 12 studies that did not provide a spare or dedicated device (Absolom et al., 2019; Ashley et al., 2013; Coombs et al., 2020; Ferrer-Roca & Subirana, 2002; Fjell et al., 2020; Hauth et al., 2019; Huang et al., 2020; Judson et al., 2013; Kargalskaja et al., 2020; Kennedy et al., 2021; Warrington et al., 2016; Wood et al., 2020), limitations in participation and intervention use were often experienced. For example, it was acknowledged the calls diverted to doctors by a call-centre (Ferrer-Roca & Subirana, 2002) cost ten times that of ordinary phone calls and this was not acceptable for public sector healthcare if it appeared that only patients able to afford the service could contact their doctor. Another study (Ashley et al., 2013) reported 71%

(n=234/329) of those who refused participation in the study cited nonparticipation was due to IT reasons (such as no computer or Internet access or a dislike of computers), as the study required accessing the intervention online from home. However, reasons for declining such as these are not always simply due to participant's attitudes and personal preferences. Deprivation in particular was found to be negatively associated with accessing interventions (Ashley et al., 2013; Ferrer-Roca & Subirana, 2002) e.g. costs of Internet access or devices. The lack of provision of spare devices in these studies has demonstrated barriers patients experience accessing technology-based interventions, which need to be considered to prevent the exclusion of patients and denying them access to an intervention which could support their healthcare.

Table 4.2: Patient-centredness

Patient-Centredness		
Concepts	**Themes**	**Present in Papers**
To Be Taken into Account		
Patient perceptions of PRO data utilisation		(Absolom et al., 2019; Meiklem et al., 2021)
Clinician utilisation of PRO data		(Berry et al., 2011; Velikova et al., 2004; Wright et al., 2003)
Benefits of systematic reporting and utilisation		(Absolom et al., 2019; Basch et al., 2016; Kennedy et al., 2021; Wright et al., 2003)
To Be Heard		
Improved communication and discussion		(Basch et al., 2005; Basch, Artz, et al., 2007; Crafoord et al., 2020; McCann et al., 2009)
Providing information to support and initiate communication		(Basch, Artz, et al., 2007; Berry et al., 2011; Hauth et al., 2019; Jacobs et al., 2018; Judson et al., 2013)
Reassurance		(Crafoord et al., 2020; Huang et al., 2020; Judson et al., 2013; McCann et al., 2009; Meiklem et al., 2021; Mitchell et al., 2000; Ngo et al., 2020)
Prioritising symptoms for discussion		(Kargalskaja et al., 2020; Ruland et al., 2010)
Informed Consent		
No examples identified		

Decision-Making	
Patient-clinician decisions unaffected	(Velikova et al., 2004)
PRO data used in clinician decision-making	(Basch et al., 2005; Judson et al., 2013; Kearney et al., 2009; Mitchell & Disney, 1997)
Patient Education	
Provide recommended information and advice	(Absolom et al., 2019; Berry et al., 2014; Coombs et al., 2020; Crafoord et al., 2020; Jacobs et al., 2018)
Facilitated the delivery of patient education	(Fjell et al., 2020; Huang et al., 2020; Kargalskaja et al., 2020; Maguire et al., 2021; Mitchell & Disney, 1997; Ngo et al., 2020; Ruland et al., 2010; Whitten & Buis, 2008; Zini et al., 2019)
Empathy	
Staff displayed understanding and provided support	(Ferrer-Roca & Subirana, 2002; Jacobs et al., 2018)
Encountering	
Increased attendance to physical consultations	(Wood et al., 2020)
Focused consultations	(Gallar et al., 2007)
Concerns for replacement of traditional care and patient-provider relationship	(Meiklem et al., 2021; Whitten & Buis, 2008; Wood et al., 2020)
Decreased communication post-study	(Crafoord et al., 2020)

Quality of Life	
Improved QoL and care	(Berry et al., 2014; Ferrer-Roca & Subirana, 2002; Jacobs et al., 2018; Maguire et al., 2021; Ruland et al., 2010; Velikova et al., 2004; Warrington et al., 2016; Wood et al., 2017)
Treatment Burden	
Reduction of hospitalisation and emergencies	(Basch et al., 2016; Hauth et al., 2019; Mitchell et al., 2000; Wood et al., 2020; Wood et al., 2017)
Reduced costs and expenses e.g. travel and accommodation	(Mitchell et al., 2000; Wood et al., 2020)
Improved treatment access	(Gallar et al., 2007; Mitchell & Disney, 1997)
Added burden of intervention	(Wood et al., 2017)

Table 4.3: Support

Support		
Concepts	**Themes**	**Present in Papers**
Technological		
Patient training and education for intervention		(Absolom et al., 2019; Basch et al., 2005; Basch, Artz, et al., 2007; Basch, Iasonos, et al., 2007; Crafoord et al., 2020; Fjell et al., 2020; Jacobs et al., 2018; Judson et al., 2013; Kearney et al., 2009; Kennedy et al., 2021; McCann et al., 2009; Mitchell et al., 2000; Ngo et al., 2020; Wright et al., 2003; Zini et al., 2019)
Staff training and education for intervention and data		(Ashley et al., 2013; Evenski et al., 2020; Rumpsfeld et al., 2005; Velikova et al., 2004; Warrington et al., 2016)
Intervention access and resolving issues		(Ashley et al., 2013; Basch et al., 2005; Jacobs et al., 2018; Meiklem et al., 2021; Wright et al., 2003)
Caring		
Dedicated support services for patients		(Ferrer-Roca & Subirana, 2002; Jacobs et al., 2018)
Reassurance from monitoring		(Crafoord et al., 2020; Huang et al., 2020; McCann et al., 2009; Mitchell et al., 2000)
Round the Clock		

Telephone support	(Absolom et al., 2019; Coombs et al., 2020; Ferrer-Roca & Subirana, 2002; Ngo et al., 2020; Warrington et al., 2016; Wood et al., 2017)
Patient and clinician alerting systems	(Basch et al., 2005; Basch, Artz, et al., 2007; Basch et al., 2016; Basch, Iasonos, et al., 2007; Crafoord et al., 2020; Fjell et al., 2020; Hauth et al., 2019; Judson et al., 2013; Kearney et al., 2009; Maguire et al., 2021; McCann et al., 2009; Wood et al., 2020)
Spare Devices	
Provision of device by study	(Basch et al., 2005; Basch, Artz, et al., 2007; Basch et al., 2016; Basch, Iasonos, et al., 2007; Basch et al., 2009; Berry et al., 2011; Berry et al., 2014; Crafoord et al., 2020; Evenski et al., 2020; Gallar et al., 2007; Jacobs et al., 2018; Kearney et al., 2009; Kuo et al., 2020; McCann et al., 2009; Meiklem et al., 2021; Mitchell & Disney, 1997; Mitchell et al., 2000; Ngo et al., 2020; Ruland et al., 2010; Rumpsfeld et al., 2005; Sicotte et al., 2011; Velikova et al., 2004; Whitten & Buis, 2008; Wood et al., 2017; Wright et al., 2003; Zini et al., 2019)

Uniqueness. The concept of uniqueness in the context of the framework was solely described as "appropriate care based on patients' needs and experiences". The most common example of this being addressed by the interventions reported was provision of appropriate feedback or responses to PROs. Responses included advice on reported symptoms (Absolom et al., 2019; Berry et al., 2014; Coombs et al., 2020; Crafoord et al., 2020; Kargalskaja et al., 2020; Kearney et al., 2009; McCann et al., 2009; Warrington et al., 2016), tailoring content and questionnaires (Absolom et al., 2019; Jacobs et al., 2018; Ruland et al., 2010) and feedback on treatment or abnormal parameters (Huang et al., 2020). Many studies included PRO and symptom-reporting interventions recording serious or worsening symptoms and conditions, reporting the change in health to a healthcare professional in real-time (Basch et al., 2005; Basch, Artz, et al., 2007; Basch et al., 2016; Basch, Iasonos, et al., 2007; Coombs et al., 2020; Crafoord et al., 2020; Ferrer-Roca & Subirana, 2002; Fjell et al., 2020; Hauth et al., 2019; Judson et al., 2013; Maguire et al., 2021; Warrington et al., 2016; Wood et al., 2020). Many interventions such as these were also required to instruct patients to contact their clinician immediately as they could not guarantee an alert would be responded to immediately.

Studies also reported how patient-reporting and clinician alerts lead to changes in treatment, (Basch et al., 2005; Gallar et al., 2007; Kargalskaja et al., 2020) and resources were also better utilised, through avoiding hospitalisations (Rumpsfeld et al., 2005) or increased clinic attendance (Wood et al., 2020) with beneficial impact on safer and effective treatment or having a positive effect upon patient care (Ruland et al., 2010). However, the impact of these interventions upon treatment plans may be context-specific and not appropriate to generalise. For example, one study (Sicotte et al., 2011) stated there was no intention of reducing the number of transfers from a dialysis centre to hospital, as the remote location of patients and limited opportunity for transfer via air required immediate transfer at the earliest sign of serious complications. Instead maintaining quality of care was prioritised. This highlights the need for appropriate endpoints or goals for interventions upon implementation.

Failure to meet the individual needs and preferences of patients often resulted in reduced intervention uptake and engagement, noted in 5 studies (Jacobs et al., 2018; Kennedy et al., 2021; McCann et al., 2009; Meiklem et al., 2021; Warrington et al., 2016). This was primarily experienced where the intervention had a limited scope (e.g. breast cancer information provision (Jacobs et al., 2018)) and failure to meet the needs of individual patients and became a hinderance or additional burden to patients and staff, reducing any potential benefits of the intervention for these individuals. For example, one side effect of chemotherapy referred to as

"chemo brain" (difficulty in learning, concentrating, etc.) made adoption of new technologies challenging for patients (Ngo et al., 2020). Only one study (Meiklem et al., 2021) made efforts to adapt their intervention to better meet patients' needs mid-deployment, specifically situational and condition specific impairments identified in haemodialysis patients utilising touchscreen tablets (e.g. introduction of styluses and updating user interface).

Table 4.4: Uniqueness

Uniqueness		
Concepts	**Themes**	**Present in Papers**
Appropriate Care Based on Patients' Needs and Experiences		
Appropriate response or feedback to PROs		(Absolom et al., 2019; Basch et al., 2005; Basch, Artz, et al., 2007; Basch et al., 2016; Basch, Iasonos, et al., 2007; Berry et al., 2014; Coombs et al., 2020; Crafoord et al., 2020; Ferrer-Roca & Subirana, 2002; Fjell et al., 2020; Hauth et al., 2019; Huang et al., 2020; Jacobs et al., 2018; Judson et al., 2013; Kargalskaja et al., 2020; Kearney et al., 2009; Maguire et al., 2021; McCann et al., 2009; Ruland et al., 2010; Warrington et al., 2016; Wood et al., 2020)
Changes to treatment		(Basch et al., 2005; Gallar et al., 2007; Kargalskaja et al., 2020; Ruland et al., 2010; Rumpsfeld et al., 2005; Wood et al., 2020)
Failed to meet complex health needs or personal preference		(Jacobs et al., 2018; Kennedy et al., 2021; McCann et al., 2009; Meiklem et al., 2021; Ngo et al., 2020; Warrington et al., 2016)

Technology. The original framework provided various requirements for patient-centred technology, such as easy to use, safe, flexible, nice looking, easy access and testing of technology. In this context, nice looking was understood to ascertain to evaluation of the user interfaces of implemented technologies, but there were no examples of this in any of the included texts. This may have been underreported as other measures were prioritised in this context, such as ease of access and usability. The former was only explicitly addressed in 4 studies, with 2 reporting (Ashley et al., 2013; Coombs et al., 2020) patients' ease of access and the others pertaining to ease of access for clinicians, (e.g. inclusion of PRO data within electronic health records (Absolom et al., 2019) or implementation of equipment in existing workspaces (Mitchell & Disney, 1997)). Ease of use was much more frequently reported, with several studies stating usability was evaluated through user feedback, custom instruments, or

qualitative feedback (Absolom et al., 2019; Ashley et al., 2013; Basch et al., 2005; Basch, Artz, et al., 2007; Basch, Iasonos, et al., 2007; Berry et al., 2011; Crafoord et al., 2020; Jacobs et al., 2018; Kennedy et al., 2021; McCann et al., 2009; Meiklem et al., 2021; Ngo et al., 2020; Ruland et al., 2010; Wright et al., 2003; Zini et al., 2019). Task automation was another indication of ease of use, noted by 5 studies (Ashley et al., 2013; Coombs et al., 2020; Jacobs et al., 2018; McCann et al., 2009; Meiklem et al., 2021). However only 2 of the 15 (Meiklem et al., 2021; Wood et al., 2020) reported usability via a validated measure i.e. the System Usability Scale (SUS) (Brooke, 1996) while others (Absolom et al., 2019; Jacobs et al., 2018) stated usability testing was conducted but without reference to a formal measure, instrument or methodology. While user feedback from both patient and clinician users can be very insightful, a lack of validated tools and measures makes it difficult to compare with other systems. This however may be irrelevant as most of these interventions are designed for specific high treatment burden populations or to support unique tasks and processes and therefore cannot be easily compared with others or generalised to the wider community.

User satisfaction was measured in 4 studies through their own survey or questionnaire (Evenski et al., 2020; Warrington et al., 2016; Zini et al., 2019) or a modified formal measure (Wood et al., 2017) i.e. the Telehealth Satisfaction Scale (Tess) (Morgan et al., 2014). User acceptance testing was reported at early stages or in prior work, with studies also reporting other outcomes, often with smaller cohorts of patients and other stakeholders, such as clinical staff (Basch, Artz, et al., 2007; Jacobs et al., 2018; Wood et al., 2020) or members of a research team (McCann et al., 2009). One study chose to only test with clinical staff through early validation (Kearney et al., 2009), while other studies reported testing of interventions with staff on usability (Berry et al., 2014), satisfaction (Rumpsfeld et al., 2005) and perceived effectiveness or usefulness (Kennedy et al., 2021; Meiklem et al., 2021; Mitchell & Disney, 1997; Velikova et al., 2004; Wright et al., 2003).

Other methods for testing of technology included evaluation of integration and quality of technology-based interventions, such as evaluating its administrative burden (Ashley et al., 2013) or assessing the quality of information produced or collected by the intervention (Ashley et al., 2013; Berry et al., 2011; Gallar et al., 2007; Mitchell & Disney, 1997; Mitchell et al., 2000; Velikova et al., 2004; Wood et al., 2017; Wright et al., 2003). Practically, there were 2 reports that highlighted audio-visual quality as the interventions applied were based on AV communication. The conclusions of these reports seem related to the practical geographical network rather than the type of intervention itself, with one reporting to be of an acceptable standard when used to facilitate remote monitoring of dialysis patients (Gallar et al., 2007;

Mitchell et al., 2000) whereas another study (Wood et al., 2017) reported the audio quality of telehealth clinics was the only item patients scored below average, attributed to a delay in voice audio.

Quality of information was also discussed where patient-reported data was utilised in consultations or patient management (Ashley et al., 2013; Berry et al., 2011; Sicotte et al., 2011; Velikova et al., 2004; Warrington et al., 2016; Whitten & Buis, 2008; Wright et al., 2003), for example integration with existing patient registry data (Ashley et al., 2013), identification of issues or topics for discussion in consultation (Berry et al., 2011; Velikova et al., 2004; Wright et al., 2003) or confirmation of clinician's knowledge of patient problems (Wright et al., 2003). The impact of technology was also evaluated through the direct benefits of its implementation, such as decrease in medication changes (Sicotte et al., 2011), reduced hospitalisations (Rumpsfeld et al., 2005; Warrington et al., 2016) and streamlining referral processes (Warrington et al., 2016). While benefits such as reduced hospitalisation and medication are positive results to demonstrate, a lack of obvious changes or improvements does not always suggest an ineffective intervention. As previously mentioned, one study (Sicotte et al., 2011) highlighted there was no change in patients' health conditions between pre- and post-study periods, yet they noted the purpose of the study was not to improve patients' health but to maintain the recognised standards of quality already in place. This approach suggests that systems should be evaluated on their ability to improve quality of care while also maintaining existing standards and the need to consider appropriate endpoints for interventions. Finally, traditional paper-and-pen methods and measures (Ashley et al., 2013; Basch et al., 2005; Basch, Iasonos, et al., 2007; Meiklem et al., 2021; Wright et al., 2003; Zini et al., 2019) were also present in the included studies, justifications including attempts to keep feedback on the system distinct from the technology-based system itself (Ashley et al., 2013) or to reduce burden of participation (Meiklem et al., 2021).

Economic evaluations were only conducted by 2 studies (Ferrer-Roca & Subirana, 2002; Rumpsfeld et al., 2005) (another made note of costs but did not demonstrate these in their own work (Ashley et al., 2013)). While there was no immediate savings made from the implementation of the interventions in their study period (Ferrer-Roca & Subirana, 2002; Rumpsfeld et al., 2005), it is important to note there were other clear immediate benefits in reducing time spent traveling (for both patients and doctors), time spent in hospital and avoiding emergency hospitalisations. This also suggests the scope of the economic evaluations were limited, requiring more appropriate timescales.

User safety in the use of technology was a common theme, with methods including password protection (Absolom et al., 2019; Ashley et al., 2013; Hauth et al., 2019; Kennedy et al., 2021; McCann et al., 2009), firewalls (Basch et al., 2005; Basch, Artz, et al., 2007), physical restrictions on equipment such as being attached to a trolley (Wright et al., 2003) and automatically logging out users after a set period of inactivity (Basch, Artz, et al., 2007). Privacy was also a concern, notably with teleconferencing in shared spaces such as clinics or wards (examples of solutions included provision of headsets (Wright et al., 2003) and quiet private spaces (Rumpsfeld et al., 2005)). Interestingly reliability was also discussed by 2 studies, measured through successful linkage of patient PROs and registry data (Ashley et al., 2013) or demonstration of teleconsultation success (Gallar et al., 2007).

The flexibility of technology is was addressed in several ways. Adaptable systems were considered those which were reported to provide tailored content or refined questions (Absolom et al., 2019; Jacobs et al., 2018; Ruland et al., 2010), facilitate other activities besides those intended (Mitchell & Disney, 1997; Mitchell et al., 2000) or with some degree of flexibility in design (Basch, Artz, et al., 2007). Flexibility was also demonstrated where interventions allowed patients to control the pace, notably being able to complete PROs and other measures in their own environment i.e. at home or stopping and revisiting the intervention when they chose to (Ashley et al., 2013; Jacobs et al., 2018; Judson et al., 2013; Kennedy et al., 2021; Ngo et al., 2020; Zini et al., 2019).

Intervention use was often the focus of included studies and described as adherence or compliance. Attrition of participants was common, as would be expected with populations living with chronic health conditions, with death and changes in health or treatment often cited for decreases in use (Ashley et al., 2013; Basch et al., 2016; Basch, Iasonos, et al., 2007; Judson et al., 2013; Kearney et al., 2009; Ruland et al., 2010). However, one study noted compliance rates were maintained until shortly before death (Judson et al., 2013), with later stage cancers associated with higher compliance, along with greater age, white ethnicity, and higher education levels. Certain patient characteristics were associated with reduced compliance and intervention use (i.e. greater age and lack of technology experience was often associated with refusal or withdrawal from studies (Ashley et al., 2013; Berry et al., 2011; Gallar et al., 2007; Wood et al., 2017) and intervention usage (Basch et al., 2005; Basch, Artz, et al., 2007; Basch, Iasonos, et al., 2007; Wright et al., 2003)) and deprivation was negatively associated with accessing interventions (Ashley et al., 2013; Ferrer-Roca & Subirana, 2002) i.e. cost of Internet access or telephone calls. One report (Basch, Artz, et al., 2007) stated prior computer experience was significantly associated with greater compliance, whereas male and younger

patients were noted by another (Wright et al., 2003). Other work reported greater compliance survey completion with clinicians than patients (Basch et al., 2009). However, high rates of compliance with patient participants were also logged by some studies (Ashley et al., 2013; Basch et al., 2005; Coombs et al., 2020; Hauth et al., 2019; Jacobs et al., 2018; Judson et al., 2013; Kennedy et al., 2021; Wood et al., 2020; Wood et al., 2017). For example, work concerned with patients living with cystic fibrosis saw an increase in number of clinics attended per patient (Wood et al., 2017) and a mobile app for monitoring symptoms demonstrated better weekly intervention usage than earlier work (Wood et al., 2020). Another study demonstrated high adherence in both older and younger adults, credited to the intervention facilitated via a telephone call, rather than a smartphone app or another platform that required Internet access (Coombs et al., 2020).

Studies employed various methods to retain patient adherence to intervention use. Regular reminders (Ashley et al., 2013; Hauth et al., 2019), simple set-up (Hauth et al., 2019) and integration of the intervention into the patient's daily routine (McCann et al., 2009) or treatment (Meiklem et al., 2021) proved most successful. However, diminished impact of regular reminders at later stages suggests some care should be taken in determining when they are most effectively employed (Ashley et al., 2013), instead providing reminders where intervention use has not been observed for a period of time (Wood et al., 2020). Key design choices were cited for successful sustained use, such as widely accessible or multiple platforms (Coombs et al., 2020; Kennedy et al., 2021) or pacing recommended information resources (Jacobs et al., 2018), but altruism of patients was also an unexpected reason for regular survey completion. This suggests while the design of the intervention and use of reminders at appropriate periods can increase compliance, it may purely be the patient's own altruistic intentions that spur engagement.

Barriers to intervention use was a supplementary addition based on studies that highlighted common problems or issues which prevented effective intervention implementation and uptake by study participants. Technical difficulties or IT-related problems were common amongst studies, including difficulty accessing technology or Internet (Ashley et al., 2013; Basch et al., 2005; Basch, Iasonos, et al., 2007; Berry et al., 2011; Gallar et al., 2007; Judson et al., 2013; Kennedy et al., 2021; McCann et al., 2009; Mitchell & Disney, 1997; Mitchell et al., 2000; Ngo et al., 2020; Rumpsfeld et al., 2005; Wood et al., 2017; Wright et al., 2003) or a dislike for computers (Ashley et al., 2013; Berry et al., 2011; Judson et al., 2013; Wright et al., 2003). Negative attitudes towards computers can be difficult to resolve, but a lack of experience or confidence using technology does not always impact on successful intervention

use (McCann et al., 2009). These problems are often associated with older, less experienced, or deprived patients, and the expectation is often such problems will resolve themselves over time as technology and the Internet grow in prevalence (Ashley et al., 2013; Basch et al., 2005; Basch et al., 2009). However, while this may hold true, alternatives should always be provided where the technology-based intervention is inappropriate or unwanted (Ashley et al., 2013; Coombs et al., 2020; Meiklem et al., 2021). Studies where interventions were self-completed reported patients forgetting to log in to interventions and staff failing to remind or administer interventions to patients, giving rise to a need for personalised reminders (Basch, Iasonos, et al., 2007; Basch et al., 2009; Judson et al., 2013; McCann et al., 2009; Wright et al., 2003). For example, one study reported 73% of patients "forgot, were too busy or did not feel like self-reporting" and reflected upon the "add-on" nature of the study intervention (Judson et al., 2013) as the study was not part of regular clinical workflow.

One important aspect of this highlights that the technical ability to collect information that previously was not recorded may lead to better care but must be viewed as an improvement by the participants. However, integration into regular workflows can be difficult and the demonstrated compliance in clinical trials may differ from that of routine data collection, with regular support from research staff unavailable in a busier care environment (Wright et al., 2003).

Other reasons for non-engagement related to inability to access interventions. IT-related issues were common (Ashley et al., 2013; Basch et al., 2005; Basch, Iasonos, et al., 2007; Berry et al., 2011; Ferrer-Roca & Subirana, 2002; Gallar et al., 2007; Jacobs et al., 2018; Judson et al., 2013; Kennedy et al., 2021; McCann et al., 2009; Mitchell & Disney, 1997; Mitchell et al., 2000; Ngo et al., 2020; Rumpsfeld et al., 2005; Wood et al., 2017; Wright et al., 2003). Data collection via digital mediums (e.g. websites, mobile apps, etc.) can be limited by such issues (Basch et al., 2005). There were differing aspects that led to the exclusion of potential participants including: no experience of tablet devices (Zini et al., 2019), home Internet access or prior e-mail experience (Jacobs et al., 2018), and connecting and transferring data over networks (Gallar et al., 2007; McCann et al., 2009; Rumpsfeld et al., 2005). Teleconferencing interventions also often encountered issues, such as the practicalities of hosting video conferencing within dialysis units (e.g. video conferencing units had to placed next to haemodialysis machines due to space constraints and so the noise of the machines was picked up during calls (Rumpsfeld et al., 2005)). Practical issues were also reported in a case study with a home dialysis patient, with several efforts required to implement teleconferencing equipment effectively in the home (Mitchell et al., 2000) (e.g. position and lighting for video

quality, height of unit, delays in connection audio, etc.). This case study also demonstrated a dynamic approach to guides may be required, with the manufacturers guide being inappropriate and requiring production of a training guide and policy and procedures manual by staff and patients working together.

In order to avoid practical issues such as those discussed, extensive and comprehensive testing of technology is required before implementation into practice, to minimise risk of losing engagement with repeated failures and shortcomings (Rumpsfeld et al., 2005).

Other than technology itself being a barrier to accessing interventions, sometimes other factors prevented intervention and healthcare access which may not always be anticipated. For example, 10% of videoconferences between haemodialysis patient and nephrologist failed where a nephrologist was unavailable, and cancellations were very common on Saturdays (25%) (Rumpsfeld et al., 2005). In another study, two patients were unable to access the Web-based intervention as they had no upcoming appointments in-clinic (Basch et al., 2005). Changes in health are common in the chronic patient populations that such interventions are designed for and yet they were often a barrier to intervention use. Patients were described as "older, frailer and more symptomatic" (Basch et al., 2016), and often reported being too ill, sick, or distressed as justifications for refusal to participate or failing to submit symptom reports (Basch et al., 2005; Basch et al., 2016; Basch, Iasonos, et al., 2007; Basch et al., 2009). Attrition of participants was also often due to disease progression or death (Ashley et al., 2013; Basch et al., 2005; Basch et al., 2016; Basch, Iasonos, et al., 2007; Basch et al., 2009; Berry et al., 2011; Jacobs et al., 2018; Judson et al., 2013; Kearney et al., 2009; Kennedy et al., 2021; Kuo et al., 2020; Maguire et al., 2021; Ruland et al., 2010; Velikova et al., 2004; Wright et al., 2003).For those who were unable to access and use an intervention independently, there was concerns that additional burden was placed upon family and friends to support them (Ashley et al., 2013) and an inefficient and time-consuming intervention would add to existing treatment burden rather than provide reprieve (Wood et al., 2020). One answer to this was to highlight the importance of the perceived usefulness or value of interventions (Basch et al., 2005; Basch, Iasonos, et al., 2007; Jacobs et al., 2018; Meiklem et al., 2021). Patients will also often prioritise other aspects of their life over their health, demonstrated by delays in reporting symptoms to avoid hospital admittance and keep social plans instead (Warrington et al., 2016), as well as interruptions in use (Ashley et al., 2013), preferring to call when their preferred physician is available (Ferrer-Roca & Subirana, 2002) or patients being "too busy" to regularly complete reports (Basch et al., 2005; Basch et al., 2009; Berry et al., 2011; Jacobs et al., 2018). In some cases, time constraints were responsible for failing to report regularly via interventions

e.g. before clinic appointments (Basch, Iasonos, et al., 2007) or when patients were treated as a hospital inpatient and experienced competing demands during their stay (Wright et al., 2003). This is common where patients were required by interventions to self-report, but they do not expect noncompletion of assessments to impact negatively on their medical consultations or treatment delivery (Absolom et al., 2019; Wright et al., 2003).

Study design was blamed in one randomised control trial, which resulted in clinicians seeing very few patients with PRO data per week and subsequently forgot the data was available for use in consultations (Absolom et al., 2019). To resolve this issue, amendments in training were made. This perceived underutilisation of patient reported information was present in other studies however, but it was often the case while clinicians were provided information they were not required to review or utilise them as part of the study design (Basch et al., 2005; Basch, Iasonos, et al., 2007; Berry et al., 2011; Wright et al., 2003). 2 studies (Fjell et al., 2020; Maguire et al., 2021) required healthcare professionals to respond to generated alerts within given timeframes (e.g. 1 hour if severe) and another (Velikova et al., 2004) required clinicians to review and discuss patient submitted data, unless data was explicitly irrelevant to treatment or the patient's major health problems. The analysis of the latter study suggested the explicit use of patient reported information during medical encounters was associated with clinically significant improvement in the well-being of the patient. These findings support the use of PROs and similar information in care, while demonstrating how a lack of perceived value results in patient discontinued use and engagement.

Finally, while there are several barriers to successful technology-based intervention implementation and use, there were examples of various motivations which can be useful resources when implementing interventions into practice. Studies demonstrated support for full implementation of interventions (Ashley et al., 2013; Basch et al., 2005; Basch, Iasonos, et al., 2007; McCann et al., 2009; Mitchell et al., 2000; Velikova et al., 2004) and 3 studies found clear support for technology-based interventions over traditional paper-and pen (Ashley et al., 2013; Meiklem et al., 2021; Wood et al., 2017), highlighting there is support for technology-based interventions despite difficulties with technology and patients. Patients demonstrated they had a "desire to use" the interventions provided (Basch et al., 2005; McCann et al., 2009; Mitchell et al., 2000; Warrington et al., 2016; Whitten & Buis, 2008), and others cited altruism and a sense of community (Ashley et al., 2013; Jacobs et al., 2018; McCann et al., 2009) for participation in studies. High recruitment rate was accredited to the immediate perceived benefit of reduction in travel required for healthcare (as most participants were required to travel hours by plane or car to in-person clinics for management of their cystic

fibrosis) in one study (Wood et al., 2017). These motivations are positive findings and despite the numerous barriers listed, indicate there is potential in delivery patient-centred interventions through technology and the various barriers can be resolved or overcome with appropriate measures and forethought.

Table 4.5: Technology

Technology		
Concepts	**Themes**	**Present in Papers**
Nice Looking		
No examples identified		
Ease of Access		
Ease of access for patients and staff		(Absolom et al., 2019; Ashley et al., 2013; Coombs et al., 2020; Mitchell & Disney, 1997)
Ease of Use		
Formal evaluation		(Absolom et al., 2019; Ashley et al., 2013; Basch et al., 2005; Basch, Artz, et al., 2007; Basch, Iasonos, et al., 2007; Berry et al., 2011; Crafoord et al., 2020; Jacobs et al., 2018; Kennedy et al., 2021; McCann et al., 2009; Meiklem et al., 2021; Mitchell & Disney, 1997; Ngo et al., 2020; Ruland et al., 2010; Wood et al., 2020; Wright et al., 2003; Zini et al., 2019)
Automation and ease of tasks		(Ashley et al., 2013; Coombs et al., 2020; Jacobs et al., 2018; McCann et al., 2009; Meiklem et al., 2021)
Safety		
Reliability		(Ashley et al., 2013; Gallar et al., 2007)
Privacy		(Rumpsfeld et al., 2005; Wright et al., 2003)
Security		(Absolom et al., 2019; Ashley et al., 2013; Basch et al., 2005; Basch, Artz, et al., 2007; Hauth et al., 2019; Kennedy et al., 2021; McCann et al., 2009; Wright et al., 2003)

Flexibility	
Adaptable	(Absolom et al., 2019; Basch, Artz, et al., 2007; Jacobs et al., 2018; Mitchell & Disney, 1997; Mitchell et al., 2000; Ruland et al., 2010)
Patients set pace (e.g. start, stop)	(Jacobs et al., 2018; Judson et al., 2013; Kennedy et al., 2021; Wright et al., 2003)
Testing of Technology	
Patient user evaluation (usability, satisfaction, acceptance testing)	(Absolom et al., 2019; Basch, Artz, et al., 2007; Crafoord et al., 2020; Evenski et al., 2020; Jacobs et al., 2018; Kennedy et al., 2021; McCann et al., 2009; Meiklem et al., 2021; Ngo et al., 2020; Warrington et al., 2016; Wood et al., 2020; Wood et al., 2017; Zini et al., 2019)
Staff evaluations (validation, effectiveness, usefulness)	(Berry et al., 2014; Jacobs et al., 2018; Kearney et al., 2009; Kennedy et al., 2021; Meiklem et al., 2021; Mitchell & Disney, 1997; Rumpsfeld et al., 2005; Velikova et al., 2004; Wood et al., 2020; Wright et al., 2003)
Evaluation of integration and quality of intervention	(Ashley et al., 2013; Berry et al., 2011; Gallar et al., 2007; Mitchell & Disney, 1997; Mitchell et al., 2000; Rumpsfeld et al., 2005; Sicotte et al., 2011; Velikova et al., 2004; Warrington et al., 2016; Wood et al., 2017; Wright et al., 2003)
Costs and economic evaluations	(Ferrer-Roca & Subirana, 2002; Rumpsfeld et al., 2005)
Paper-and-pen response/feedback methods	(Ashley et al., 2013; Basch et al., 2005; Basch, Iasonos, et al., 2007; Meiklem et al., 2021; Wright et al., 2003; Zini et al., 2019)
Intervention Use	

Adherence and compliance	(Ashley et al., 2013; Basch et al., 2005; Basch, Artz, et al., 2007; Basch et al., 2016; Basch, Iasonos, et al., 2007; Basch et al., 2009; Coombs et al., 2020; Crafoord et al., 2020; Fjell et al., 2020; Hauth et al., 2019; Jacobs et al., 2018; Judson et al., 2013; Kearney et al., 2009; Kennedy et al., 2021; Maguire et al., 2021; McCann et al., 2009; Ruland et al., 2010; Wood et al., 2020; Wood et al., 2017; Wright et al., 2003)
Barriers to Intervention Use	
Technical difficulties	(Ashley et al., 2013; Basch et al., 2005; Basch, Iasonos, et al., 2007; Basch et al., 2009; Berry et al., 2011; Gallar et al., 2007; Judson et al., 2013; Kennedy et al., 2021; McCann et al., 2009; Mitchell & Disney, 1997; Mitchell et al., 2000; Ngo et al., 2020; Rumpsfeld et al., 2005; Wood et al., 2017; Wright et al., 2003)
Lack of reminders	(Basch, Iasonos, et al., 2007; Basch et al., 2009; Judson et al., 2013; McCann et al., 2009; Wright et al., 2003)
Unable to access intervention, information, and healthcare	(Ashley et al., 2013; Basch et al., 2005; Basch, Iasonos, et al., 2007; Berry et al., 2011; Crafoord et al., 2020; Ferrer-Roca & Subirana, 2002; Gallar et al., 2007; Jacobs et al., 2018; Judson et al., 2013; McCann et al., 2009; Mitchell & Disney, 1997; Mitchell et al., 2000; Rumpsfeld et al., 2005; Wood et al., 2017; Wright et al., 2003)
Burden of intervention	(Ashley et al., 2013; Wood et al., 2020)
Perceived usefulness or value	(Absolom et al., 2019; Basch et al., 2005; Basch, Iasonos, et al., 2007; Berry et al., 2011; Crafoord et al., 2020; Jacobs et al., 2018; Meiklem et al., 2021; Wright et al., 2003)
Patient health changes or deteriorates	(Ashley et al., 2013; Basch et al., 2005; Basch et al., 2016; Basch, Iasonos, et al., 2007; Basch et al., 2009; Berry et al., 2011; Jacobs et al., 2018; Judson et al., 2013; Kearney et al., 2009; Ruland et al., 2010; Velikova et al., 2004; Wright et al., 2003)

Time and prioritising other aspects of life	(Ashley et al., 2013; Basch et al., 2005; Basch, Iasonos, et al., 2007; Basch et al., 2009; Berry et al., 2011; Ferrer-Roca & Subirana, 2002; Jacobs et al., 2018; Warrington et al., 2016; Wright et al., 2003)
Age and familiarity with technology	(Ashley et al., 2013; Basch et al., 2005; Basch, Artz, et al., 2007; Basch, Iasonos, et al., 2007; Berry et al., 2011; Coombs et al., 2020; Gallar et al., 2007; McCann et al., 2009; Wood et al., 2017; Wright et al., 2003)
Motivations	
Desire to use	(Basch et al., 2005; McCann et al., 2009; Mitchell et al., 2000; Warrington et al., 2016; Whitten & Buis, 2008)
Support for implementation of intervention	(Ashley et al., 2013; Basch et al., 2005; Basch, Iasonos, et al., 2007; McCann et al., 2009; Meiklem et al., 2021; Mitchell et al., 2000; Velikova et al., 2004)
Technology preferred over paper	(Ashley et al., 2013; Meiklem et al., 2021; Wood et al., 2017)
Immediate reduction of treatment burden	(Wood et al., 2017)
Altruistic and patient community	(Ashley et al., 2013; Jacobs et al., 2018; McCann et al., 2009)

Table 4.6: Competence

Competence		
Concepts	**Themes**	**Present in Papers**
Timely		
Earlier diagnosis		(Basch et al., 2009; Ferrer-Roca & Subirana, 2002; Fjell et al., 2020; Hauth et al., 2019; Kargalskaja et al., 2020; Kearney et al., 2009; Mitchell et al., 2000; Wood et al., 2020; Wood et al., 2017)
Efficient use of time		(Basch et al., 2005; Hauth et al., 2019; Ruland et al., 2010; Velikova et al., 2004; Wood et al., 2020)
Real-time responses and information		(Basch et al., 2005; Basch, Iasonos, et al., 2007; Coombs et al., 2020; Crafoord et al., 2020; Fjell et al., 2020; Hauth et al., 2019; Kearney et al., 2009; Maguire et al., 2021; McCann et al., 2009)
Frequent reporting		(Basch et al., 2009; Judson et al., 2013; Ruland et al., 2010)
Patients delay treatment		(Warrington et al., 2016)
Time constraints		(Basch, Iasonos, et al., 2007; Kennedy et al., 2021)
Technological Knowledge		
Patient experience and access to technology		(Basch et al., 2005; Basch, Artz, et al., 2007; Basch et al., 2016; Basch, Iasonos, et al., 2007; Hauth et al., 2019; Jacobs et al., 2018; Judson et al., 2013; McCann et al., 2009; Wright et al., 2003; Zini et al., 2019)
Increasing prevalence of technology		(Hauth et al., 2019; Jacobs et al., 2018; McCann et al., 2009; Meiklem et al., 2021; Wood et al., 2020)

Technological Skill	
Patient familiarity with intervention delivery platform	(Berry et al., 2014; Hauth et al., 2019; Judson et al., 2013; McCann et al., 2009; Wood et al., 2020)
Prompt	
Earlier or delayed treatment intervention	(Basch et al., 2005; Basch, Artz, et al., 2007; Ferrer-Roca & Subirana, 2002; Kargalskaja et al., 2020; Kearney et al., 2009; McCann et al., 2009; Ruland et al., 2010; Wood et al., 2020; Wood et al., 2017)
Immediate feedback to PROs	(Absolom et al., 2019; Basch et al., 2005; Basch et al., 2016; Basch, Iasonos, et al., 2007; Coombs et al., 2020; Crafoord et al., 2020; Fjell et al., 2020; Huang et al., 2020; Judson et al., 2013; Kargalskaja et al., 2020; Kearney et al., 2009; McCann et al., 2009)
Clinicians instructed to review alerts	(Fjell et al., 2020; Kearney et al., 2009; Maguire et al., 2021; McCann et al., 2009)
Patient responsible for follow-up on alert	(Absolom et al., 2019; Basch et al., 2005; Basch et al., 2016; Basch, Iasonos, et al., 2007; Coombs et al., 2020; Crafoord et al., 2020; Judson et al., 2013; Kargalskaja et al., 2020; Kennedy et al., 2021)
Trustworthy	
Patients trust in treatment and staff	(Huang et al., 2020; Kearney et al., 2009; Meiklem et al., 2021; Warrington et al., 2016; Wright et al., 2003)
Staff trust in reliability and quality of data and information	(Absolom et al., 2019; Basch et al., 2005; Basch et al., 2016; Basch et al., 2009; Gallar et al., 2007; Meiklem et al., 2021; Mitchell & Disney, 1997; Mitchell et al., 2000; Rumpsfeld et al., 2005; Sicotte et al., 2011; Wright et al., 2003)

Missing or incomplete data	(Basch et al., 2009; Judson et al., 2013; Warrington et al., 2016)
Critical Thinking	
No examples identified	N/A
Holistic and Caring Approaches	
Impact of intervention	(Basch et al., 2016; Crafoord et al., 2020; Gallar et al., 2007; Maguire et al., 2021; Meiklem et al., 2021; Mitchell et al., 2000; Ruland et al., 2010; Sicotte et al., 2011; Velikova et al., 2004)
Observed changes in care management	(Basch, Iasonos, et al., 2007; Ruland et al., 2010; Velikova et al., 2004)
Multidisciplinary approach	(Jacobs et al., 2018; Wood et al., 2017)
Expected standard of care met	(Sicotte et al., 2011)

Competence. Competence included timely, prompt, technological skill, technological knowledge, trustworthy and "holistic and caring approach". Critical thinking was also listed by the original framework, but no examples were identified in the included studies.

Regarding timely, various themes were identified, some focusing on positive changes in behaviour and outcomes. For example, earlier diagnosis was facilitated by interventions in various studies (Basch et al., 2009; Ferrer-Roca & Subirana, 2002; Fjell et al., 2020; Hauth et al., 2019; Kargalskaja et al., 2020; Kearney et al., 2009; Mitchell et al., 2000; Wood et al., 2020; Wood et al., 2017) and benefits to earlier detection and intervention included increased patient QoL and reduction in high-cost emergency care visits and patient anxiety (Ferrer-Roca & Subirana, 2002), as well as an increase in patient contentedness (Hauth et al., 2019), sense of support and access to healthcare (Mitchell et al., 2000). Reporting and identifying severe symptoms, concerns and changes in health earlier also allowed for more efficient use of time by clinicians, by removing the need to identify problems in consultations and allowing discussion to focus on reported areas (Basch et al., 2005; Hauth et al., 2019; Ruland et al., 2010; Velikova et al., 2004). Interventions were also better received where they do not require significant time to use, such as a mobile app-based intervention which only required 2 minutes to complete a weekly report (Wood et al., 2020). The benefit of the immediate availability of digital data from electronic PROMs and reporting was also showcased, with earlier warnings allowing for improved response times and automated alerts, with interventions providing "real-time" communication between patients and clinician (Basch et al., 2005; Basch, Iasonos, et al., 2007; Coombs et al., 2020; Crafoord et al., 2020; Fjell et al., 2020; Hauth et al., 2019; Kearney et al., 2009; Maguire et al., 2021; McCann et al., 2009). The alerting facility provided by some interventions allowed patients to feel secure that their symptoms were being registered by someone, as did real-time response after reporting (McCann et al., 2009). Patients reported more severe grades of symptoms earlier and more frequently than clinicians (Basch et al., 2009) and frequent reporting by patients is beneficial for clinicians, providing insight into their health between visits (Judson et al., 2013) and patterns over time (Ruland et al., 2010). Despite the examples of benefits of technology-based and patient-centred interventions in respect to time, there are also existing barriers that diminish the impact of such interventions. Patients may delay contact with their hospital, despite adverse symptoms and justify this behaviour with upcoming scheduled appointments and wanting to keep social and family plans, prioritising these over their health (Warrington et al., 2016) . On the other hand, one study (Basch, Iasonos, et al., 2007) noted only one of five nurses reported frequently making management changes based on patient-reported information, with insufficient time to act upon or discuss the information the most cited reason. Potential benefits of a patient engaging in an intervention can be undone if there are insufficient resources for clinicians and staff on the other side, such as time to review and act on patient-reported data.

Interventions were found to influence prompt behaviours, namely the earlier or delayed provision of treatment interventions in response to earlier diagnosis or identification of symptoms or changes to

health (Basch et al., 2005; Basch, Artz, et al., 2007; Ferrer-Roca & Subirana, 2002; Kargalskaja et al., 2020; Kearney et al., 2009; McCann et al., 2009; Ruland et al., 2010; Wood et al., 2020; Wood et al., 2017). Immediate feedback to PROs was also recorded in several studies, but where an immediate response or review of moderate or severe alerts could not be guaranteed, the responsibility was often placed upon the patient to contact their healthcare team despite an alert being made (Absolom et al., 2019; Basch et al., 2005; Basch et al., 2016; Basch, Iasonos, et al., 2007; Coombs et al., 2020; Crafoord et al., 2020; Judson et al., 2013; Kargalskaja et al., 2020; Kennedy et al., 2021). Only 4 studies explicitly required review of alerts (Fjell et al., 2020; Kearney et al., 2009; Maguire et al., 2021; McCann et al., 2009) and as mentioned previously, patients felt reassured by the quick response times of healthcare providers when reporting (Kearney et al., 2009; McCann et al., 2009) – the concept of trustworthy that reflected both the view of the patient and the clinician. High patient satisfaction was demonstrated by a streamlined triage system, along with high confidence in staff knowledge and capabilities (Warrington et al., 2016). It was noted however that there was support to include quality of life assessment in routine care from staff or patients (Wright et al., 2003), suggesting compliance will improve as the assessments are integrated into practice and staff become more familiar with interpreting results. Trust from clinicians'' viewpoint was often seen in terms of the reliability and quality of information produced by interventions. Collecting data directly from patients removes potential for third party bias, ensuring data is captured consistently and limiting risk for interpretation and inconsistency between individuals (Basch et al., 2005; Meiklem et al., 2021). In addition, patients reported symptoms earlier and more frequently than clinicians (Basch et al., 2009). There are also examples of clinicians and staff citing patient-reported data as useful and relevant (Absolom et al., 2019; Basch et al., 2016; Kennedy et al., 2021; Wright et al., 2003) and praising the quality of picture or video in videoconferencing technology for facilitating consultation and evaluation of remote dialysis patients (Gallar et al., 2007; Mitchell & Disney, 1997; Mitchell et al., 2000; Rumpsfeld et al., 2005; Sicotte et al., 2011), especially when compared to traditional telephone consultations (in one study, a senior nephrologist commented how the intervention in question "met its greatest challenge, to show its legitimate clinical role" (Mitchell & Disney, 1997)). However, there were also examples where interventions and their data were less useful or relevant, notably where data was inconsistent, incomplete, or missing (Basch et al., 2009; Judson et al., 2013; Warrington et al., 2016). One study (Judson et al., 2013) highlighted the risk of non-random missing data, especially in individuals who are hard to reach, while another (Warrington et al., 2016) discussed the completeness of data in the study, noting staff did not always complete the standardised assessment fully (i.e. in most cases, where the form completed by staff was graded as poor, it was found the staff had used the form for notetaking rather than a decision-support tool as intended). In this case, this was attributed to time-constraints during phone calls, lack of training for new staff and the forms not covering confusion or medication queries when reported. There is also the issue of the patient-provider relationship to consider. Underutilised or unused patient data implies no perceived value for patients [18, 21, 33, 41] and patients disengage with the intervention. This reduces the availability and

value of reported data to clinicians, resulting in it being underused or not referred to at all and this confirms patients' perceptions there is no benefit or gain from using such interventions.

Technological knowledge and technological skill were two similar concepts. Knowledge was understood as the patients' access to and experience with technology, whereas skill referred to how familiar patients were with the platform or medium delivering the intervention. Experience and access to technology has been touched on in other sections prior to this one, with most studies choosing to measure this by surveying patients on their Internet, e-mail and computer access or usage (Basch et al., 2005; Basch, Artz, et al., 2007; Basch et al., 2016; Basch, Iasonos, et al., 2007; Hauth et al., 2019; Jacobs et al., 2018; Judson et al., 2013; McCann et al., 2009; Wright et al., 2003). The growing prevalence of technology was raised, usually in response to an unwillingness or lack of confidence from patients in technology usage (Hauth et al., 2019; Jacobs et al., 2018; McCann et al., 2009), or cited as the success of compliance (Wood et al., 2020). The growing prevalence and progression of technology will limit the patient cohort that is unable to or not willing to use electronic PROMs (Hauth et al., 2019), reflecting the recommendations made in earlier sections of this review to avoid such exclusion. Technological skill was noted in some studies, suggesting younger patients were more accustomed to web-based instructions than their older peers (Berry et al., 2014). Other studies recruited patients based on their prior experience with certain technologies such as e-mail (Hauth et al., 2019; Judson et al., 2013), tablet devices (Zini et al., 2019) or smartphones and mobile apps (Wood et al., 2020), which could have been seen as a possible barrier to recruitment by requiring prior experience or access to these technologies. The opposite effect was demonstrated by one study however, where despite a majority of patients citing frequent use and confidence with various types of technologies, 84% had never used a personal digital assistant (PDA) before (McCann et al., 2009). This was later reported as not having any impact on their success with using the PDA-based intervention, highlighting that while skill and confidence with certain platforms and technologies is useful for patients, a well-designed system should be as usable for a novice as it is for an experienced user.

Finally, the last concept of holistic and caring approach was reported indirectly through examples. Interventions often had an impact in one way or another, such as improvements in health and care through reduced emergency visits or hospitalisation (Basch et al., 2016), improved support (Mitchell et al., 2000; Ruland et al., 2010) and improvements in patient outcomes and health-related quality of life (Basch et al., 2016; Maguire et al., 2021; Velikova et al., 2004). Telehealth for remote dialysis patients in particular allowed for a reduction in burden associated with distance (Sicotte et al., 2011) and need for home visits by staff (Gallar et al., 2007). Impact was also demonstrated through observed changes in patient management, such as changes in medication, lifestyle recommendations and arranging new consultations (Basch, Iasonos, et al., 2007). One study reported patients gaining a sense of independence and privacy from completing QoL measures independently (Meiklem et al., 2021). Other studies also reported sensitization of clinicians, where patient self-reporting led to clinicians addressing significantly

more symptoms and problems (Ruland et al., 2010) or increased awareness of emotional problems (Velikova et al., 2004). The latter study also reported the experience of having health-related QoL profiles available for patients within intervention groups may have influenced similar behaviour within the control group, suggesting patient-reported PRO interventions may have a place in communication training programs for improving and maintaining clinician communication skills.

Multidisciplinary approaches were primarily required for patients who had to manage multiple health conditions and conflicting or contrasting information from multiple specialists (Jacobs et al., 2018; Wood et al., 2017). One study differed from others (Sicotte et al., 2011), where authors stated they sought to demonstrate how telehealth was able to maintain the quality of care according to best practice standards. They emphasised that the lack of differences in patients' health condition between pre- and post-study was expected and demonstrated the maintained recognised standards rather than a lack of improvement in patients' health. Again, this reinforces how patient-centred and technology-based interventions should not seek to simply replace existing systems or standards but supplement, support and maintain them instead. Care must also be taken in how these systems can impact patients if removed, as patients may feel alone and unable to contact clinicians frequently without the support of the intervention (Crafoord et al., 2020).

4.8. Discussion

4.8.1. Objectives of Review

This scoping review set out to discover what patient-centred and technology-based interventions have been implemented to support patients with high treatment burden and to map the literature on such interventions, identifying topics of interest for the human-computer interaction and digital health communities. Several interventions implemented into practice with patients were identified and the key principles or "lessons learned" in their development, evaluation, and implementation reported. Framework analysis with the preconditions set out assisted in understanding how the approach of various technology-based interventions delivering patient-centred support to high treatment burdens, and where they did not meet the specified preconditions. From the analysis, key themes and recurring concepts were identified, discussed below.

4.8.2. Problems with Technology

The most prevalent technology-related issue reported was "IT issues" or "technical difficulties", where the technology hosting the intervention was unreliable or failed. Transmission issues were noted in both telemedicine and PRO reporting interventions, such as use of ISDN (Integrated Services Digital Network) lines during peak times (Gallar et al., 2007), rural mobile phone reception (McCann et al., 2009) and limited transmission rate within the study site (Rumpsfeld et al., 2005). One study reported multiple technical difficulties in two separate study sites, such as data loss and program corruption as result of program updates to existing systems at one site and eight days of poor network function at

another (Wright et al., 2003). Another reported a mobile app behaving poorly after updates which caused frustration (Ngo et al., 2020).

Recommendations: Intensive testing in the intended site (e.g. clinic, patient home, etc.) at expected times of use before implementation into routine practice is proposed, to avoid clinician frustration and loss of support for the intervention (Rumpsfeld et al., 2005). This would also identify the limits and faults in the technologies used, reducing the potential for unexpected faults and errors during implementation and subsequent impact on intervention effectiveness (McCann et al., 2009; Wright et al., 2003).

4.8.3. Accessing a Technology-Based Intervention

Inability to access or fully use the intervention was common. Problems identified included:

- Ten percent of videoconferences between haemodialysis patient and nephrologists failed because a nephrologist was unavailable for consultation (Rumpsfeld et al., 2005).
- Cost of accessing a telephone support intervention implied only patients who could afford the service would be able to access it (Ferrer-Roca & Subirana, 2002).
- Provision of intervention based on upcoming clinic attendance resulted in two participants not being able to access the system at all throughout the study (Basch et al., 2005).
- Technology-based intervention was highlighted as a possible barrier to data collection in populations unfamiliar with technology (Ashley et al., 2013; Ferrer-Roca & Subirana, 2002).
- Failure to provide a "spare device" through a clinic computer or dedicated patient device (Absolom et al., 2019; Ashley et al., 2013; Ferrer-Roca & Subirana, 2002; Hauth et al., 2019; Warrington et al., 2016; Wood et al., 2020).
- Exclusion of twenty seven percent of approached patients from study due to no home internet access (Judson et al., 2013).
- Patient inability to access and use intervention independently (e.g. requires help from family, placing burden unto them) (Ashley et al., 2013).
- Situational impairment during treatment or impairment as result of treatment (Meiklem et al., 2021; Ngo et al., 2020).

The association between age and deprivation with lower Internet and computer use with study results indicating a negative association between deprivation and patient questionnaire completions is important (Ashley et al., 2013). Concerns exist that those who are less 'digitally able' due to resources, literacy, physical or social limitation could be further disenfranchised or have additional burden placed on their care if such issues are not considered in the design and implementation processes of health technology research (Mair et al., 2021).

Recommendations: While increasing familiarity with computers and technology in patient populations and prevalence of technology over time was proposed as one solution (Ashley et al., 2013; Basch et al.,

2005), other steps must be taken. Conventional and familiar methods (e.g. paper-and-pen or telephone reporting) should be offered as alternatives until such a prevalence of technology is reached and even then, should be available for those who do not engage with digital health (Ashley et al., 2013; Coombs et al., 2020; Meiklem et al., 2021). Other solutions include patient training sessions (Basch et al., 2005; Basch, Artz, et al., 2007; Basch et al., 2016; Crafoord et al., 2020; Fjell et al., 2020; Judson et al., 2013; Kearney et al., 2009; McCann et al., 2009; Ngo et al., 2020; Wright et al., 2003; Zini et al., 2019), custom instruction manuals (Absolom et al., 2019; Mitchell et al., 2000; Velikova et al., 2004; Zini et al., 2019) or support for intervention access and resolving issues. The provision of a dedicated education navigator for patients to contact regarding use of intervention (Jacobs et al., 2018) or a helpline (Basch et al., 2005).

4.8.4. Patients' Attitudes and Experiences of Technology

A major barrier was patients' dislike of technology (Ashley et al., 2013; Berry et al., 2011; McCann et al., 2009; Wright et al., 2003), alongside older age and deprivation with lower Internet and computer experience (Ashley et al., 2013). It was noted compliance of submitting QoL assessments was better in younger and economically advantaged patients, with concerns those who would benefit the most from the regular assessments were the most likely to refuse (Gallar et al., 2007; Wright et al., 2003). It was suggested older patients' refusal was from "fear of innovations", with computer-inexperienced patients described as "older, frailer and symptomatic" than their computer-experienced peers (Basch et al., 2016). Three other studies confirmed that prior computer and Internet experience was associated with greater adherence to PRO reporting interventions (Basch et al., 2005; Basch, Artz, et al., 2007; Basch, Iasonos, et al., 2007).

Recommendations: System design that was simple overcame patients' reports of inexperience and lack of confidence with personal digital assistant (PDA) technologies, with "initial anxieties diminished within the first days of use" (McCann et al., 2009), produced from multiple early testing phases with patients (end-users). This suggests a simplistic and well-informed system design with patient involvement in early stages can support patients in overcoming their inexperience and allows patients to access and use interventions effectively, which is expected good practice when designing systems for any population.

4.8.5. Changes in Patients' Health

The health of the patient may be a barrier to intervention use with some patients as "older, frailer and more symptomatic" (Basch et al., 2016). and being too ill, sick, or distressed to submit symptom reports (Basch et al., 2005; Basch, Iasonos, et al., 2007; Basch et al., 2009). Similar problems were found for refusal to participate and attrition of participants in other studies (Berry et al., 2011; McCann et al., 2009; Velikova et al., 2004; Wright et al., 2003), interestingly with a decline in compliance rates within a month of death (Judson et al., 2013). This is unfortunately common within research involving patients

with chronic illnesses, with declining health and death often considered when recruiting an appropriate number of participants.

Interestingly, patients whose health improved or did not change also demonstrated discontinued use of interventions. In a population of breast cancer patients, patients who did not experience significant physical effects as a result of their illness or treatment found the intervention and its tailored information for their illness less helpful (Jacobs et al., 2018), while patients completing PRO forms reported they perceived no benefit reporting if they are well (Basch, Iasonos, et al., 2007) or their symptoms have not changed since their previous report (Basch et al., 2009).

Recommendations: Considerations for the health-related and situational impairments for patients are required when designing for systems, and adaptations to overcome issues should be to prevent exclusion where a patient may otherwise be able to engage (Meiklem et al., 2021). Empathy and understanding for the varying or declining health of patients is also important (Ferrer-Roca & Subirana, 2002; Jacobs et al., 2018).

4.8.6. Perceived Value

The theme of perceived benefit was very common amongst the identified studies investigating patient reporting interventions, with varying factors described influencing patients' perceptions. These included:

- Patients' priorities were unrelated to the targeted health condition (e.g. other illnesses or family deaths) (Jacobs et al., 2018).
- Improvements or no change in health therefore no perceived value in reporting (Basch, Iasonos, et al., 2007; Basch et al., 2009).
- Lack of perceived value of interventions as a reason for discontinued use (Basch et al., 2005; Basch, Iasonos, et al., 2007; Jacobs et al., 2018; Meiklem et al., 2021).
- Patients do not expect noncompletion of QoL assessments to impact on their medical consultations or prevent treatment delivery (Absolom et al., 2019; Wright et al., 2003).
- Increased perceived value upon study completion and loss of access to intervention (Crafoord et al., 2020).

Health care technology interventions should not increase burden of care or reduce patient capacity. Understanding the effectiveness of healthcare technology interventions in either reducing treatment burden or increasing patient capacity is key to effective implementation of proposed technologies (Mair et al., 2021).

The perception reported information was not essential to treatment or was underutilised by healthcare staff was demonstrated in one study where it was noted clinicians reviewed data but did not overly refer to it (Absolom et al., 2019). This was attributed to the chosen study design of a randomised controlled

trial, which resulted in clinicians seeing very few patients with PRO data per week and subsequently forgot the data was available. Only 5 of the 39 included studies did note clinicians were required to review and/or act upon PROs as part of the study (Absolom et al., 2019; Basch et al., 2005; Basch, Iasonos, et al., 2007; Berry et al., 2011; Wright et al., 2003).

Recommendations: It is essential that the training provided for the intervention includes meaningful, re-enforced encouragement of clinicians to use available data and patients to bring up their reports in discussion till this becomes routine (Absolom et al., 2019; Velikova et al., 2004). In the one study where clinicians were required to review and discuss patient submitted data (unless data was explicitly irrelevant to treatment or the patient's major health problems), analysis suggested the explicit use of health-related QOL (HRQOL) information during medical encounters was associated with clinically significant improvement in the well-being of the patient (Velikova et al., 2004). These findings suggest the use of HRQOL information in care are important for patient outcomes, as opposed to patients only completing questionnaires.

4.8.7. Reliable and High-Quality Sources of Data

A key benefit of collecting data directly from patients is the removal of a third-party bias, ensuring data is captured consistently and limiting risk for interpretation and inconsistency between individuals (Basch et al., 2005) e.g. patients reporting to nurses who then record data in system. Other benefits include:

- Earlier reporting of symptoms, with greater severity and more frequently than clinicians (Basch et al., 2009).
- Earlier diagnosis and treatment changes as result of patient reported information (Ferrer-Roca & Subirana, 2002; Fjell et al., 2020; Hauth et al., 2019; Kargalskaja et al., 2020; Kearney et al., 2009; Wood et al., 2020).
- Patient reported data was considered more useful and relevant, as cited by clinicians and healthcare staff (Absolom et al., 2019; Basch et al., 2016; Kennedy et al., 2021; Wright et al., 2003).

However, these findings indicate a potential problematic relationship between patient perceptions and clinician utilisation of patient reported data. As discussed earlier, patients often fail to report frequently due to no perceived benefit of doing so, which reduces the availability and perceived value of reported data to clinicians, resulting in it being underused or not referred to at all. This in turn confirms the patients' perceptions there is no benefit or gain from using such interventions. However, patients are not solely responsible for incomplete or missing data. For example, staff often failed to complete a standardised grading assessment of symptoms reported via a telephone triage system by cancer patients (Warrington et al., 2016). In most cases, where the form completed by staff was graded as poor, it was found the staff had used the form for notetaking rather than a decision-support tool as intended. This

was attributed to time-constraints during phone calls, lack of training for new staff and the forms not covering confusion or medication queries when reported.

While the issue of infrequent reporting was exclusive to interventions facilitating PRO reporting, several telemedicine interventions, notably those providing video consultation for dialysis patients, met and surpassed clinician and nurse expectations. This included the ability to view and evaluate physical treatment methods via high quality video, such as catheter exit sites (Gallar et al., 2007) and fistula appearance (Mitchell et al., 2000). In one study, a senior nephrologist commented the intervention "met its greatest challenge, to show its legitimate clinical role" (Mitchell & Disney, 1997) and nurses felt regular videoconferencing calls were a direct replacement to telephone calls and extra time spent on these calls averted the patient needing to travel for unnecessary treatment (Mitchell et al., 2000). Patients were reported to have received intensive and personalised clinical monitoring, while health providers were able to access higher quality of support than available via a telephone conversation (Sicotte et al., 2011). These studies were all conducted in regions where travel for potentially unnecessary treatment can be lengthy and costly, and these benefits reduce patients' treatment burden drastically.

Recommendations: This reciprocal patient-provider relationship is important, with commitment needed from staff, alongside experience and training, in order for patients to benefit fully (Wright et al., 2003). Ongoing staff training was recommended for completed forms to be used to their full potential, an important consideration for any intervention where staff interact with it directly or information produced by patient reports, especially when implementing into regular work practices and shifting from an experimental setting.

4.8.8. Other Patient Priorities

Finally, referring to the examples of priorities shifting from specific health conditions (Jacobs et al., 2018), it is noteworthy that patients will prioritise other aspects of their life over their health or have life events which require adjusting priorities. This was demonstrated by patients' delay in reporting symptoms (Warrington et al., 2016), as they were keen to avoid earlier hospital admittance and keep social plans instead. Other studies found patients' use of reporting interventions was interrupted (Ashley et al., 2013) or they were "too busy" to complete reports (Basch et al., 2005; Basch et al., 2009; Berry et al., 2011; Judson et al., 2013). Time constraints were also problematic, such as reporting before clinic appointments (Basch, Iasonos, et al., 2007) or in the case of in-ward patients, who experienced a lot of competing demands during their hospital stay (Wright et al., 2003).

A common problem was patients forgot to report data, which some interventions aimed to resolve through reminders along with implementation into routine workflows (Judson et al., 2013). However, this proved unsuccessful where staff tasked to remind patients failed to do so (Basch, Iasonos, et al., 2007) or patients felt reminders were generic and not personalised (Basch et al., 2009).

Recommendations: Success in maintaining adherence was demonstrated where the intervention was able to fit into patients' routines or did not impose additional burden (Ashley et al., 2013; McCann et al., 2009), particularly in patient cases where non-compliance, loneliness or major healthcare or social problems have been observed (Gallar et al., 2007).

4.8.9. Motivations

The topic of adherence or compliance with the intervention provided was common among the included papers. It was clear that patient uptake and continued use of such interventions is never guaranteed, due to various factors and barriers. While there are several barriers to successful intervention implementation and use, there were examples of motivations expressed by patients which can be useful resources when implementing interventions into practice.

5 studies demonstrated that patients had a "desire to use" the interventions provided (Basch et al., 2005; McCann et al., 2009; Mitchell et al., 2000; Warrington et al., 2016; Whitten & Buis, 2008) and 3 captured altruism and a sense of community as motivations for patient participation in the study (Ashley et al., 2013; Jacobs et al., 2018; McCann et al., 2009). However, such altruism outside of a study setting is not potentially less sustainable.

While no study formally measured burden of treatment, evidence of reduced treatment burden was demonstrated and can be a driving force for intervention uptake. For example, one study suggested the most likely explanation for their high recruitment rate was the immediate perceived benefit of reduction travel required for healthcare, as most participants were required to travel hours by plane or car to in-person clinics for management of their cystic fibrosis (Wood et al., 2017). These motivations support the earlier discussion of how perceived value or benefit encourages patients' use and adherence to interventions, and how patients can very quickly lose interest where there is no perceived benefit for themselves or their peers.

4.9. Conclusion

This scoping review identified examples of patient-centred and technology-based interventions, and valuable lessons and insights into how implementation of such interventions can be done successfully, in both patient and clinician perspectives. While technology is seen as the ultimate solution, it can exclude patients who cannot access or utilise technology-based interventions as easily as their peers and add to their existing treatment burden (Mair et al., 2021). Patients may have other goals and priorities than their health and will abandon interventions which fail to continually support them throughout their treatment or have no perceived benefit, as will healthcare providers. The relationship between patient and healthcare provider should be taken into consideration during the design and implementation phases, ensuring both parties will benefit from the other's involvement and have the necessary continued support throughout the use of the intervention.

It is possible that other relevant studies and interventions have been unidentified by our search queries through misclassification under MEsH terms or publication in smaller but non-listed journals. However, there is no formal classification of high treatment burden conditions or treatments, therefore we believe our inclusion of terms and synonyms of treatment burden and chronic health conditions was adequate. Scoping reviews are also not systematic and should not be expected to map the entire literature. They are characterised by the identification of broad themes and common approaches across high volumes of published research and work (Rumrill et al., 2010) and are useful tools for "scoping" the body of literature on a topic and provide clear indications of the volume of research and studies available, before asking more specific questions via a systematic review approach (Munn et al., 2018). In addition, the themes arising from this review were consistent across the range of interventions performed which suggests the common problems with patient-centred and technology-based interventions have been identified.

To summarise, this scoping literature review lists various technology-related and human-related barriers, with note of recommendations and solutions, where reported by the various studies. The findings of this review should inform ongoing and future development and implementation of patient-centred and technology-based interventions supporting high treatment burden patient populations, with particular attention to the barriers to implementation use and adherence. The key relationship between patient and staff significantly influences these interventions, emphasising the importance of co-design and both parties should be able to effectively use and benefit from the interventions' implementation into routine practice.

Chapter 5: Multidisciplinary Investigation of CKD Support Priorities

This chapter describes the early stages of the research conducted in this thesis, namely conceptualising and prioritising issues to address, with a multidisciplinary group (MDG) (see Figure 5.1). This work builds on the lessons and recommendations learned from the scoping review of Chapter 4 and addresses part of the second research question by working with and gathering needs and wants from medical professional stakeholders.

- **RQ 2:** What do haemodialysis patients and other stakeholders need from a technology-based intervention to support the CKD treatment journey?

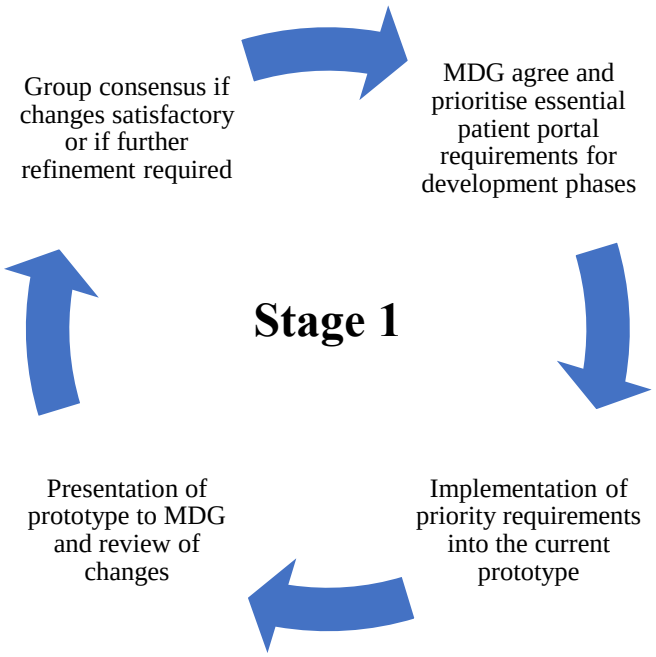


Figure 5.1: Stage 1 of cyclic approach and relevant methods

By involving medical staff and academics, the systems produced have will have a great perceived value of engagement and should overcome potential patient familiarity or confidence issues, by informing the design of systems with the experience and knowledge of experts. These experts include stakeholders from the community of interest, and justifications will be given for selection of participants and methods employed at this stage. The outputs include prioritised design requirements and a prototype mobile application for implementation described in the subsequent Chapter 6.

5.1. Introduction

As informed from the scoping review of the previous chapter, technology-based interventions can often fail to secure both patient and provider engagement for various reasons. Both need to see a value in the use and support of the technology, otherwise both can disengage if one party feels there is no benefit. Well-informed system design was another recommendation, to overcome potential issues as a result of patient unfamiliarity or lack of confidence with technology. To ensure such systems to support patients with high treatment burden effectively and meet these recommendations, an understanding of the medical domain and practices is required. This knowledge can be found in healthcare providers, such as consultants and nurses, through experience and professional training and education. These stakeholders or members of the community of interest can lead the direction of research and address issues they experience and understand in their context.

Therefore, a multidisciplinary group (MDG) was formed to address two objectives: (1) identify priorities for addressing issues within the CKD context and (2) further refine and expand on a set of start high-level requirements (Bouamrane et al., 2019). The group of domain experts met on a regular basis and from meeting minutes, agreed objectives and design requirements were elicited. As needs and requirements were identified and prioritised, a prototype mobile application would also be developed and reviewed by the group, either undergoing evaluation and review as a group during a meeting or through individual testing and review by individuals.

This stage of research consists of this cycle repeating until the prototype reached a state where MDG members agreed it was of suitable quality to implement and evaluate as part of a validation study for a VA-specific QoL measure i.e. VASQoL (Richarz et al., 2021), in a real-world clinical setting with patients. Part of this work was published in 2021 (Meiklem et al., 2021) following this evaluation, detailing how seven domain experts provided feedback and further design requirements for the patient portal during 33 regular meetings between February 2019 and November 2020. Meetings continued to occur after this period and so this chapter will provide additional results to the publication.

5.1.1. High-level Design Requirements

As described, starter high-level design requirements (see Table 5.1) from a feasibility study (Bouamrane et al., 2019) were used as a basis for the work described in this chapter. The feasibility study sought to act on recommendations from a Scottish national appraisal of HD VA provision (Oliver et al., 2017). This work builds on these requirements, refining and adding idiosyncratic design requirements would be required to produce an effective system to support CKD patients.

Table 5.1. High-level formal requirements for Haemodialysis Patient Portal (Bouamrane et al., 2019)

Requirement Description	Related Themes (Justifications)
Capture of Quality of Life (QoL) measure	• Information Quality: Inadequate Or Missing Data. • Individual Impact: Improving Patients. • Outcomes Measures.
Capture of Important Clinical Events	• Information Quality: Inadequate Or Missing Data.
Capture of Vascular Access data	• Information Quality: Inadequate Or Missing Data.
Data Linkage between various data sources	• Information Usage: Measuring Care Quality and Generating New Insights on Treatments.
Data Processing: providing new insight into treatment impact	• Information Usage: Measuring Care Quality and Generating New Insights on Treatments. • Individual Impact: Improving Patients Outcomes Measures. • Organisational Impact: Developing Optimal Care Pathways.
Interactive treatment guide & patient care pathways	• Information Usage: Measuring Care Quality and Generating New Insights on Treatments. • User Satisfaction: Simplifying and Clarifying Treatment Options for Patients. • Individual Impact: Improving Patients Outcomes Measures.
System should be well designed, have high accessibility and usability to aid users with varying ability and experience	• Information System Quality: Importance of Good and Simple Design. • User Satisfaction: Simplifying and Clarifying Treatment Options for Patients.

5.2. Methods

5.2.1. Description of MDG Meetings and Attendees

A MDG was formally convened in early 2019, consisting of medical professionals and senior academics, with expertise in nephrology, vascular and transplant surgery, Medical Informatics and HCI (Human-Computer Interaction). These meetings occurred monthly in-person from February 2019 until March 2020. At this time, COVID-19 social distancing measures were enforced, and the UK went into a lockdown, so after a brief hiatus, subsequent meetings occurred from April 2020 via the Zoom teleconferencing platform every two weeks (where possible) until September 2020 where the user

evaluation study commenced (MDG meetings continued for the remainder of the research however, primarily as supervision meetings).

Five of these experts were medical professionals, while the remaining two were senior academics with expertise in Medical Informatics and HCI. The researcher also actively participated in these sessions as a collaborator (Blomqvist et al., 2010), with expertise falling under HCI and Mobile Usability. Medical experts were able to advise on what was required in practice and how to integrate the patient portal into routine care with patients. The academic experts provided expertise on system design, development, and implementation on both the patient portal prototype and the VASQoL measure design. The details of participants' expertise are provided in Table 5.2.

Table 5.2. Domain Expert Professions, Expertise and Sex

Participant ID	**Profession/Expertise**	**Sex**
CR	Consultant, Renal Transplant Surgery	F
CV	Consultant, Vascular and Transplant Surgery (honorary professor)	M
CN	Consultant Nephrologist	M
CRF	Clinical Research Fellow	F
DN	Dialysis Nurse	F
AM	Senior Academic ('associate professor' level), Medical Informatics	M
AU	Senior Academic ('associate professor' level), Mobile Usability and Human-Computer Interaction	M
Researcher	Academic (Post-Doctoral Candidate), Human-Computer Interaction and Mobile Usability	M

Initial meetings began by outlining general needs and prioritising issues to address, before starting co-design processes and producing requirements, with some early concepts for functionalities sketched out by members of the group. These early requirements were the basis of a web-based prototype patient portal, becoming the focus of discussion and feedback once a first iteration was completed. During meetings, this prototype would be discussed and reviewed after demonstration, either through the web-based application or a mobile application on a tablet device, at later stages.

Sessions were audio recorded and transcribed, alongside written notes which were summarised and distributed to all members (present or not) after each meeting by the researcher. Written notes and transcriptions were reviewed for discussions regarding the prototype systems and any recommendations, suggestions, critiques, or requests based on the current prototype were extracted as design requirements. This was straightforward given meetings would typically conclude with a

summary of agreed actions or tasks to be completed by members, including prioritised adjustments or additions to the prototype. Prioritisation of requirements was agreed by the group, with consideration for length of time to complete proposed requirement and whether or not previous agreed priorities were now of satisfactory implementation.

5.2.2. Justifications for Research Methods

This work focused on eliciting user needs and system design requirements from domain (medical) experts alongside academic experts, with expertise in medical informatics, mobile usability and HCI. The domain experts understand the context well and given their knowledge of the field (through scientific and public health reports, as well as experience in field observations i.e. providing treatment to patients (Nisha et al., 2016), and the experts in technology-related fields assist in transforming information into design requirements for a system (Song et al., 2021). The work of Song et al. (Song et al., 2021) showcases similar choices to this research, where a clinician-led and experience-based design approach is used to establish user needs before testing with the population of interest, similar to formative research (Beran et al., 2018).

CKD patients are undoubtedly experts in their condition and treatment and are a valuable source of user needs and design requirements. However, they can be described as having a micro-view of the domain, given that their experience of CKD and treatment is very personal and unique to them. Patients are also often not fully aware of the scientific background of their condition and it can be challenging for patients to fully conceptualise their needs and wants from mobile health (Song et al., 2021). CKD patients can be considered "vulnerable" due to the burden of their care and experience emotional, physical and psychological problems as a result of their condition (Almutary et al., 2013; Sein et al., 2020). This was particularly reinforced by the group members CR and CV following the COVID-19 pandemic, where they requested considerations for patient evaluations of the prototype system at the time be put on hold to prevent adding additional stress on an already very vulnerable and high-risk group (Bell et al., 2020). The intended system would be patient-facing and so was developed with the goal of conducting a formal evaluation with patients when appropriate, discussed in the following chapter.

Domain experts belong to the community of interest and through regular meetings as a group drive the direction of the research, with the academic experts bridging the gap between their experience and expertise of the context and formal design requirements for the system. The process of scheduled MDG meetings and iterative development is similar to the Agile method of project management, with "sprints" of small tasks to be completed within the fixed window between meetings to review the progress and developments (e.g. every 4 weeks, then 2 weeks after March 2020) (Hidalgo, 2019). While no formal analysis was conducted, the tasks and goals of the next "sprint" were defined and agreed in each meeting and shared with the group members in the minutes afterwards to allow for further review or amendment. This would ensure that "sprints" goals were achievable and of relevance to the current

issues within the MDG, and meetings between domain experts with varying timetables and commitments were productive, without delaying development by conducting formal transcription and analysis processes.

5.3. Results

The outcomes of this work were primarily the elicitation, prioritisation and refinement of design requirements from the expert led MDG sessions. A side-effect of this work was the production of a mobile app prototype designed primarily to host the VASQoL measure (referred to as eVASQoL), after several iterations of development and evaluation within the MDG. Table 5.3 encapsulates design requirements that were produced as a result of MDG discussions. These are split into the various aspects of the system, such as the QoL data capture and patient pathway visualisation functionalities as well as characteristics of the overall system e.g. accessibility and usability. Each design requirement is also described as functional or non-functional. The former describes *what* a system will do and the latter *how* it does this, or these can also be understood as what makes the system *useful* and what makes it *usable* (Eckhardt et al., 2016).

5.3.1. Prioritisation of Requirements

Given the variety of issues identified and addressed by the MDG in the form of design requirements, prioritisation was required in order to ensure development between group meetings was achievable and significant. This resulted in the MDG primarily focusing on the cannulation recorder, capture of QoL and clinical data and the patient pathway visualisation. These three were also listed in the starter high-level requirements, however as Table 5.3 shows, these were expanded upon with additional requirements described for each functionality. These key functionalities are each described further in subsequent sections. Other requirements were also prioritised and addressed by the MDG, such as defining hardware and platform choices (i.e. essential to progression of work by MDG) or ensuring the system was robust and accessible, through iterative review and testing within the group.

Conflicts did occur between group members in priorities and requirements but were resolved via the group coming to a consensus during frequent meetings. For example, as the work progressed and the VASQoL measure was refined, the clinical experts within the group sought for it and the other requirements related to QoL data collection to be refined and expanded upon further over the other key functionalities. At the time this was agreed in order to have a system robust enough for implementation and evaluation as part of the impending VASQoL validation study. Another conflict existed between the clinical and academic experts on the choice of hardware and platform to design for – the clinical side had a preference for familiar Apple devices, while the academics had experience with the more accessible Android devices for development purposes (discussed further in 5.3.3).

Table 5.3: Formal Design Requirements Identified by MDG Members (Type: F = functional, NF = non-functional)

Aspect	Design Requirement Description	Type	Source (MDG Member Initials)
QoL and Clinical Data Capture	Capture of SF-36, EQ5D-5L and VASQoL data	F	CV, CR
	Clinical events capture (i.e. changes in dialysis status and vascular access)	F	CV, CR
	Recording user response times to QoL questionnaires	F	CR, AU
	User progression visible throughout	F	AU
	Review input before submission	F	CV, CR
	VASQoL administered across 3-4 times in a week (initial schedule for validation study)	F	CV
	Adapt questionnaire based on user data i.e. skip VASQoL Q2a if not dialysing	F	CV, CR
Cannulation Recorder	Coloured and labelled markers for arteriovenous and venous needle sites	F	CV
	Error handling for attempts to mark a cannulation outside of graft area	F	CV
	Selection of graft configuration and location	F	CV
	High quality images	NF	CV, AM, AU
	Transforming captured data to heatmap	F	CV, AM
	Storing and retrieving cannulation data to and from database	F	CV
	Update markers to more precise icon	F	CV
	Loading graft configuration and previous cannulations by default	F	CV
	Snap placed markers to nearest portion of graft area if within proximity	F	CV
	Mark flow on graft image	F	CV
	Load previous cannulations in weekly increments	F	CV, CR, CRF
	Include body in image of graft (i.e. arm or leg outline), but remove medical detailing	F	DN, CV
Pathway Visualisations	Patient information: Provision and access to tailored patient information	F	CV, CR, CN
	Navigation through set timeframes via slider	F	CV, AM

Aspect	Design Requirement Description	Type	Source (MDG Member Initials)
	Displaying likely outcomes and complications at common timepoints	F	CV, CN
	Display number of patients remaining on chosen access/diverted to different access	F	CV, CN
Data flow & Storage	Background data syncing and submission	F	CV, AU
	Retrieval of data from database for review and analysis	F	CV, CR
	Confirmation of data submission for clinician	F	CRF, CR
Hardware	Android platform and device(s) for initial prototype	F	AU
	Device specification (i.e. screen ratio 4:3, 10.1 inch screen, etc.)	F	AU
	Case for device to protect from falls/accidents and robust enough for medical sanitisation	F	CV, CR
Robust System	MDG testing and checks following updates	F	AU
Accessibility & Usability	Tutorial or demo mode for new users	F	CV, CR
	Timely and appropriate feedback from interactions	F	CRF, CR
	Designing with and for users with little to no experience of technology and living with a chronic health condition	NF	CV, CR, CRF, AU

5.3.2. Development Tools and Environment

To allow for flexibility early in development, the prototype was designed as a web-app, using HTML, JavaScript and CSS coding to construct the system, and PHP scripts to manage storing data from application to a MySQL database. The MDG had established that the system would be delivered on a dedicated tablet devices during regular dialysis sessions and stored on the ward/clinics, ensuring that the look and feel of the system would be consistent for users and would provide all patients with the opportunity to access the system. The target platform of the system was initially undecided and so the web-app allowed for flexibility, using the Apache Cordova environment to generate native mobile applications from the core web-app (Bosnic et al., 2016).

5.3.3. Considerations for System and Platform

Several design requirements were concerned with the whole system rather than a particular functionality. It was decided that the targeted platform would be Android tablet devices, after recommendations from AU due to ease of development compared to Apple devices, initially selected due to preference and familiarity by the medical professionals (CV, CR and CN). AU also suggested that the device would need to have a screen ratio of 4:3 and screen size of 10.1 inches, so it would be large enough for patients to view and hold comfortably. CV and CR also suggested the device would also need to fit a case robust enough for accidental damage (e.g. drops or falls from hospital beds or chairs) and regular medical sanitation. The potential for home use was considered for future iterations of the work, however the group agreed the scope of the system was for in-clinic use, where consistent devices could be provided to patients during their regular and lengthy dialysis sessions and managed by the staff of the clinic.

The storage and retrieval of data collected from patients needed to be robust and secure, including handling of network connection issues with background data syncing once a connection is re-established (CR and AU). Data retrieval would also be essential, in a format that would allow analysis and review by clinicians, alongside confirmation of users submitting data for clinicians such as CR and CV. AU recommended the system would also need to undergo testing within the MDG to ensure all functionalities behaved as expected after updates and refinements. Tutorial or demo modes were requested to allow for demonstration and familiarisation in a safe setting by clinicians such as CV and CR, as were appropriate and timely feedback form the system following user interactions (CRF and CR found the original system alerts on the device used in development were not sufficient and requested custom alerts be implemented).

Finally, CR, CV, CRF and AU considered the need for a highly usable and accessible system, given its intended user population is typically older and frailer (Basch et al., 2016). However, high usability and accessibility is a generic design requirement of any system, and the literature has shown that the

stereotype that older patients will struggle with technology is not always true (Coombs et al., 2020). Regardless, the web application was validated using the web tools Lighthouse (*Lighthouse overview - Chrome Developers*) and Wave (*Wave Web Accessibility Evaluation Tools*) on a Google Chrome browser. Both tools did not detect critical errors or faults and in the case of Lighthouse, the pages received scores of 90 or above, indicating overall good levels of accessibility. Potential issues such as coding errors were also identified and resolved with these technologies.

Deprivation and lower experience of technology can also be responsible for patients' difficulties accessing and using systems, as can outright dislike of technology (Ashley et al., 2013; Berry et al., 2011; Judson et al., 2013; Wright et al., 2003). Patients who are less "digitally able" due to a lack of resources, literacy, physical or social limitation could can experience additional burden placed on their care if these issues are not considered in the design and implementation processes of health technology research (Mair et al., 2021), and a well-informed and simple design can overcome a lack of experience and confidence in using technologies and is expected good practice in with any population (McCann et al., 2009).

5.3.4. Capture of QoL Measures and Clinical Data

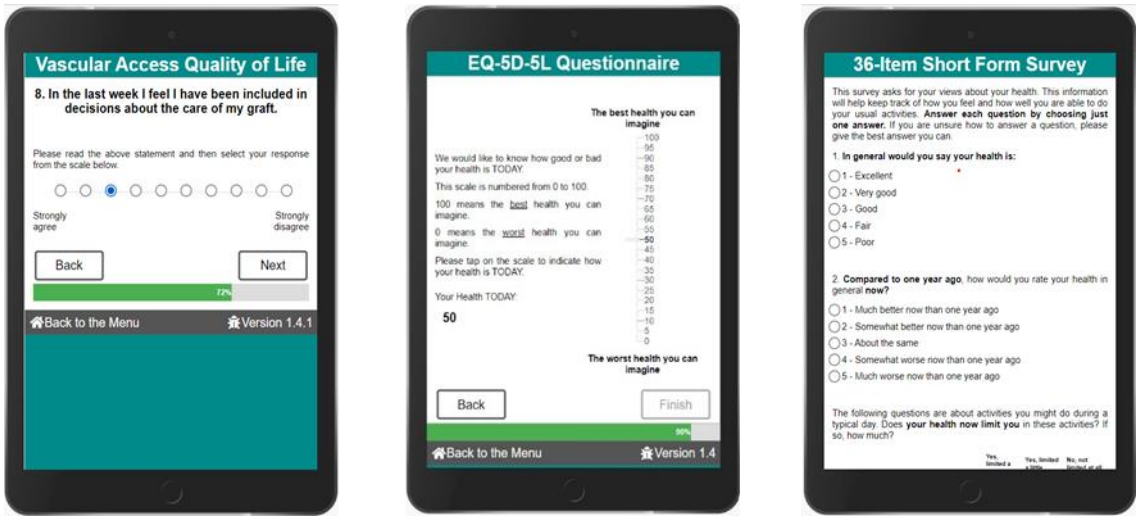


Figure 5.1: Screenshots of QoL Measures (left to right): VASQoL, EQ-5D-5L and SF-36

One of the starter high-level requirements (Bouamrane et al., 2019), capture of QoL data was established and refined early on within MDG meetings, focusing on the capture of data for the VASQoL measure (Richarz et al., 2021). This measure was in development in parallel with the proposed system and so would require validation against established QoL measures. This resulted in the additional requirement for the capture of the clinical standard Short Form 36-Item Health Survey (SF-36) (Ware Jr, 1999) and EQ-5D-5L (Herdman et al., 2011) measures, alongside the VASQoL measure, as requested by CV and CR. Figure 5.1 shows the original VASQoL design, alongside the standardised

and validated EQ-5D-5L and SF-36, implemented as per specification. In order to maintain the validity of the QoL measures, they were implemented to be as true to the original as possible (SF-36) or per specification of licensing requirements (EQ-5D-5L). This resulted in little opportunity for the user interface of these measures to be informed by the group discussions.

These questionnaires would require validation and error handling, especially given the requested functionality for reviewing input prior to submission. CV and CR specified this would require the system to allow for users to progress back through completed questions and change answers if they desired, while handling the changes in score, and submitted time for the question. The system would also need to include prevention of progress or submission if no response recorded for current question. CV and CR noted the system would also be handling changes in questionnaire design from question to question e.g. the eVASQoL skips Q2a if the patient is not currently dialysing with their selected access, and the EQ-5D-5L shifts from a Likert scale to numerical scale from Q5 to Q6 (see Figure 5.2).

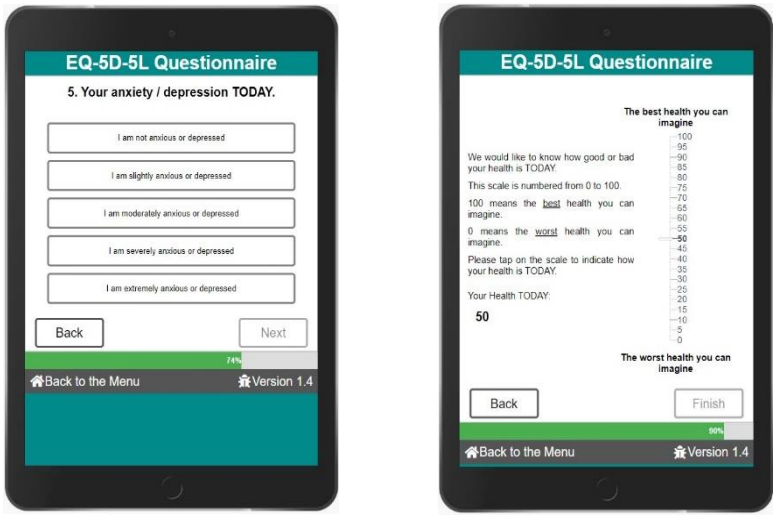


Figure 5.2: Screenshots of EQ-5D-5L Q5 and Q6, highlighting the change in question design.

In addition to capture of QoL data, clinical event data was another high-level design requirement, also refined by CR and CV. This would comprise of patient-reported changes in dialysis status or vascular access and would hopefully provide insights into changes and trends in patient responses when tracking reported QoL over time (e.g. QoL changing when a patient can no longer using their fistula due to a clot and instead using a line). The clinical data would also be used to customise the VASQoL question to the patient completing it (i.e. if dialysing show Q2a, or skip if otherwise, and replacing placeholder text in the questions with the selected VA – see Figure 5.3).

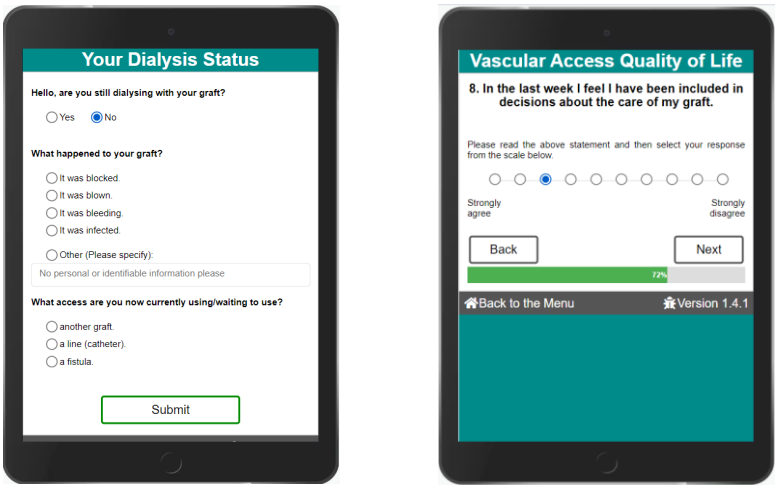


Figure 5.3: Screenshots of VA clinical event capture and VASQoL measure

Further metadata was also desired through recording of user response times to each questionnaire by CR and AU, for later analysis of the time spent on each questionnaire and its questions by patients, as well to review if repeated use of the system lead to improved completion times (the following chapter on the discusses the findings of said data). AU was aware patients may become frustrated answering lengthy questionnaires (sometimes all three in one session) and suggested to include a visible progress tracker, to indicate the current progress and remaining tasks to reach the goal. This manifested as a progress bar to indicate progress through the VASQoL and EQ-5D-5L questionnaires, as both are viewed one question on page at a time, whereas the SF-36 presents all 36 questions in a single page. The SF-36 differs in this aspect due to the need to maintain the integrity of both validated measures (and in compliance with the license agreement for EQ-5D-5L), therefore the digital implementations of both had to reflect the original or approved versions. CV also proposed potentially splitting the VASQoL completion across three separate entries, to minimise the burden for patients. This requirement would be considered at a later stage given the upcoming validation of the VASQoL and necessary completion intervals for comparison.

5.3.5. Cannulation Recorder

The cannulation recorder functionality required a great level of detail and therefore has the most listed design requirements at this stage. In regard to marking cannulation sites, CV specified the functionality required:

- Markers colour-coded (blue for venous (V), red for arteriovenous (A)).
- Markers labelled in type and order of most recent e.g. 1V, 1A, 2V, 2A, etc.
- Marker icon should be indicating precise/accurate location i.e. arrow or pin instead of cross icon.
- Appropriate error-handling if selected site is within/out with a graft area (use of “heatmap” image underlying graft image to determine if within area).
- Adjusting location of a marker to graft area if placed near graft area of image.

- Graft configuration and location selection e.g. three common “shapes” in right or left arm or leg.
- Storage and retrieval of cannulation points accurately.
- Load previous cannulation points and display from start, in weekly increments i.e. 3 pairs of points per week (agreed by CV and CRF as well).

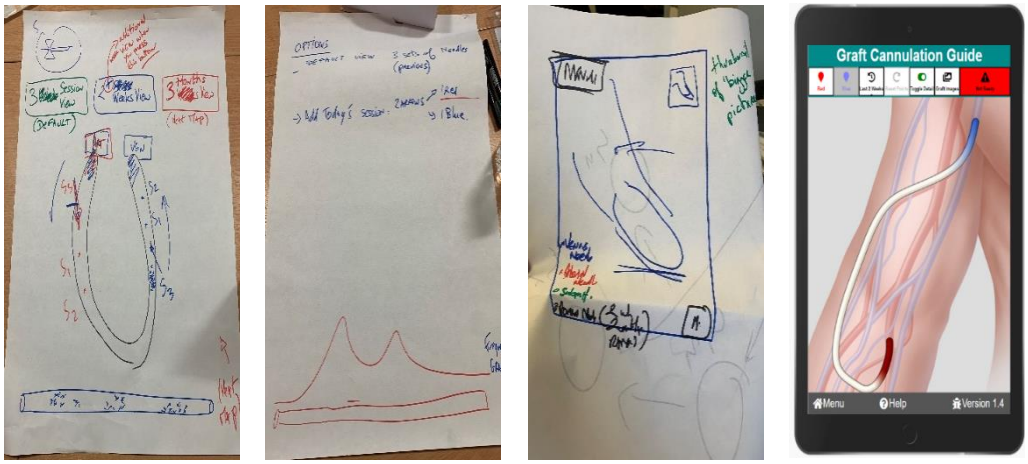


Figure 5.4: Three concept sketches by CV and final design of graft cannulation recorder

CV initially drew out sketches of during an in-person meeting of what they pictured the interface of the system would like with these design requirements in mind (Figure 5.4), assisting in focusing the development of the user interface. Discussions also covered the specification for the images used in the cannulation recorder. These were originally a cross-section of an arm, detailing the veins and arteries within, with the graft marked as well. Before further images were commissioned by CV, it was requested they be of high quality across all devices, (AU and AM specified 2000 by 1500 pixels minimum, ideally 4000 by 3000 pixels for a very high resolution and portrait PNGs with transparent backgrounds). DN and CR requested these the removal of medical detail such as muscle, bone, etc. from the images as this was not required for the cannulation recorder and may be off-putting to patients. Other specifications by CV included marking the flow of blood within the graft and including the details of the limb within the image i.e. the arm or leg, so it would be recognisable to patients. Finally, the system should be able to produce a “heatmap” of cannulation sites from recorded data, to aid in identifying overused areas of the graft, potentially leading to complications and surgery to correct. CV and AM both agreed on the merit of having such data visualised in this way as a method to review the cannulation of grafts over time.

5.3.6. Pathway Visualisations

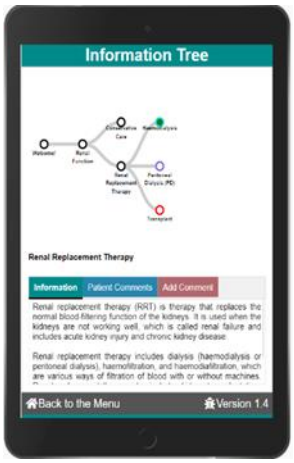


Figure 5.5: Screenshot of pathway visualisation feature

The initial description of this functionality was "interactive treatment guide and patient care pathways" leaving much to the imagination in terms of design and implementation. CV had originally presented the idea of a "London Underground" style map, with different train lines representing treatment options and the stops along the routes key procedures or milestones patients could expect. This concept would allow patients to see their treatment as a journey and view the different routes they may take as they progressed.

Therefore, CV, CR and CN noted the system would need to provide and allow access to information tailored to patients, taking into account their circumstances and variables (e.g. prior vascular access, need for renal replacement therapy, age, etc.). As discussions continued over the course of meetings, the concept of likely routes and alternatives through typical patient pathways arose, with CN and CV providing considerations and design requirements based on their experiences of patient education.

Patients' routes and likely outcomes can vary at different stages of the treatment, and so the functionality would need to allow traversal through different key timepoints: 3, 6 and 12 months, as the first 365 days of treatment are important for determining future treatment options (AM suggested using a sliding diagram to show the change at each stage). The complications, changes, and odds of these occurring vary at different stages as previously mentioned and so this would need to be listed as well. Communicating risk can be a difficult task and so it was proposed by CV and CN that each route would start with 10 patients, from which the odds of success or complications could be assessed e.g. 6 of 10 patients who start on a fistula still use their fistula after 12 months. This information should be communicated via visual data such as restroom icons (i.e. male and female people symbols) for ease of understanding.

5.4. Discussion

This early stage of the research focused on the further conceptualisation and development of a prototype system. Through regular MDG meetings consisting of domain experts and academics in digital health and HCI fields over two years, design requirements were elicited and refined over many meetings alongside iterative development and evaluation of a prototype patient portal mobile app.

(a) Sign In (b) Pathway Visualisation (c) Cannulation Recorder

(d) VASQoL Measure (e) SF-36 Survey (f) EQ-5D-5L Measure

Figure 5.6: Screenshots of Final Prototype

Through this process, this prototype was robust enough to be implemented into a medical setting with patients as part of another study (Richarz et al., 2021). This can be attributed to the thorough and iterative development process with medical experts, given their input and feedback based on scientific and public health reports and years of experience and field observations with patients (Song et al., 2021). The inclusion of academics specialising in HCI, and medical informatics assisted in bridging the gap between these suggestions and formal design requirement in discussions, such as the need for high quality images being translated into a specified image size and specification for future commissions.

Song et al. (Song et al., 2021) note how patients may not fully understand the scientific aspects of their condition and treatment (Nisha et al., 2016) and therefore a clinician-led approach to define initial needs is an effective method and ensures when patients are involved they can interact with something tangible and concentrate on what they need from the system under review. Forming the MDG also had unmeasurable benefits, such as building rapport and familiarity with the community of interest as well as their domain, with knowledge exchange occurring over discussions (e.g. knowledge of and writing for medical publications, HCI methods and outcomes, etc.).

Certain design requirements listed in Table 5.3 are generalisable to potentially any other user-facing system. These include accessibility considerations like system feedback being clear and timely following an interaction and considering the typical user may be older, frailer (Nisha et al., 2016) but more importantly, inexperienced, which can impact their desire and ability to engage (Ashley et al., 2013; Basch et al., 2005; Basch, Artz, et al., 2007; Basch et al., 2016; Basch, Iasonos, et al., 2007). Others may be applicable to similar mobile health interventions for other health conditions and patient populations outside the scope of CKD. Many of the design requirements for specific functionalities are functional and are less generalisable to other mobile health systems, such as those required for marking a cannulation site on an image of a graft.

The cannulation recorder was the feature with the most design requirements at this stage, given the number of interactions and behaviours the system needed to provide to facilitate the novel functionality. It is important to note that not all of the design requirements listed were implemented in the final prototype produced by the MDG, due to time constraints and prioritisation within cycles, particularly when development pivoted around the VASQoL validation study (Richarz et al., 2021). This focused heavily on the refinement of the QoL data collection and clinical events capture functionality in later stages, while other functionalities received less attention. However, this is an effective strategy given the opportunity the study allowed for the prototype to be used over a longitudinal period, in a real-world setting with patients during their treatment. Focusing on one aspect of the design requirements ensures a thorough evaluation of the targeted solution and then allows prioritisation of other problems or challenges once complete, rather than trying to formally assess and refine multiple functionalities and ideas at once. The other functionalities were continually improved across later studies (e.g. the co-design workshops of Chapters 7 and 8 focuses primarily on the patient pathway visualisations).

This work also addressed some of the issues raised by the scoping review. Accessing technology-based interventions may rely on the patient having internet access (Judson et al., 2013) and/or a suitable device of their own at home (Ashley et al., 2013), and so provision of a dedicated device for use in-clinic ensures all patients have the opportunity to access the intervention. The accessibility of the system was also considered acceptable using automated tools Lighthouse and Wave, but in-person use and manual checks will also inform this in the following stage. Perceived value was ensured from the medical

professional perspective by working with such stakeholders in this iterative development, and the planned implementation with patients in a real-world setting will provide opportunity to gauge their perceptions of the value the eVASQoL can offer, as well as test how well it performs in its expected use, to identifying issues and problems ahead of wide-scale routine use.

5.5. Strengths and Limitations

The approach of this work has both strengths and limitations. The cohort involved was not large and were recruited from a single location (i.e. Glasgow, Scotland). However, at this stage a smaller and concentrated multidisciplinary group was effective in providing initial needs and design requirements, which will be expanded upon as the scope widens to patients in real-world settings and eventually national scale recruitment. Establishing primary needs within the community of interest, by capitalising on experts with a wider view and experience of the context, prepares for more refined research with the intended population (i.e. CKD patients) at later stages. The high-level design requirements were sourced from a feasibility study (Bouamrane et al., 2019) that recommends the capturing of the idiosyncratic design requirements inherent to the patient are essential for success, and so this approach will allow these to be elicited in the user evaluation now that primary needs are established.

The community of interest (i.e. consultants and nurses) influenced and determined the direction of the research. The lack of formal transcript analysis may be criticised, however given the varying timetables and commitments of the MDG members, treating sessions as group meetings over formal group sessions or interviews allowed for prioritisation of design requirements for following meetings in app development and more frequent meetings as a group. Formal meetings and transcriptions potentially could have resulted in than meeting less often after transcribing, analysing and attempting to implement many design requirements in one iteration.

5.6. Conclusion

This chapter saw the first stage of the co-design processes, namely the formation of a MDG with both members of the community of interest i.e. clinicians and nurses, and academic experts, in order to identify and prioritise issues to address with technology-based solutions. Through frequent meetings of the MDG, these members directed and informed efforts in identifying, prioritising, and implementing design requirements for a system to support CKD patients. This work partly answers the second research question, by establishing what medical professional stakeholders need from a technology-based intervention.

This resulted in a side-effect of producing a system that met underlying clinical needs, as well as identifying key issues experienced within the context of CKD. Working with the MDG also addressed recommendations raised in the scoping review of the previous chapter, such as providing access to technology for patients, designing to overcome attitudes and experiences of technology and based on

staff experience and knowledge, designing a system that holds a great perceived value for clinicians and will fit in with patients' existing treatment routine, minimising burden.

The prioritisation of design requirements continues in the subsequent chapters, with Chapter 6 detailing the implementation and evaluation of the QoL and clinical data collection, as well as detecting new and possibly unique needs from CKD patients. Chapters 7 and 8 further the patient treatment pathway visualisations, expanding on the established requirements of this chapter.

Chapter 6: Real-World Evaluation with Patients in Clinical Setting

This chapter details the implementation and evaluation of the eVASQoL prototype produced in Chapter 5, as part of a parallel study to standardise the VASQoL measure. The multidisciplinary group (MDG) identified and prioritised key functionalities, including the capture of clinical event and quality-of-life (QoL) data, which this chapter will focus upon. The work followed a case study approach, and was carried out in a real-world setting, aligning with the principles of PAR, and first introduces the work to patients. They and clinicians contribute to the evaluation, resulting in quantitative and qualitive data collected from multiple sources. This chapter further builds on the efforts of the previous two chapters, namely the recommendations from the scoping review by testing in the expected use case and environment. The design requirements elicited from the experience and knowledge of non-patient stakeholders are refined and expanded with design requirements elicited from patient feedback and clinician observations, notably accessibility considerations as a result of situational impairment and patients' medical condition. This chapter also provides answers to RQ2 from the patient perspective, complimenting that of the medical professionals in the previous chapter. and contributing to the literature a study focused on dialysis patients completing QoL measures during routine treatment with a technology-based intervention, not identified in the scoping review.

6.1. Introduction

Following on from the previous, this chapter details the user evaluation of the prototype eVASQoL system and implementation into a clinical setting i.e. a dialysis clinic. The prototype was produced from the iterative development with the multidisciplinary group (MDG) detailed in Chapter 5. The eVASQoL was evaluated with patients in a clinical setting, in parallel with the validation of a vascular access specific quality of life (VASQoL) (Richarz et al., 2021). Despite challenges arising from the suitability of traditional evaluation methods in a COVID-19 world, a case study (Creswell & Poth, 2016) approach and multiple sources of data resulted in a formal evaluation of the prototype implemented, along with feedback and design requirements from both patient users and clinician observations. Early issues with patients' health-related accessibility were resolved with flexibility in the methods to ensure the research could continue without frustrating patients further and that both studies would continue without disruption.

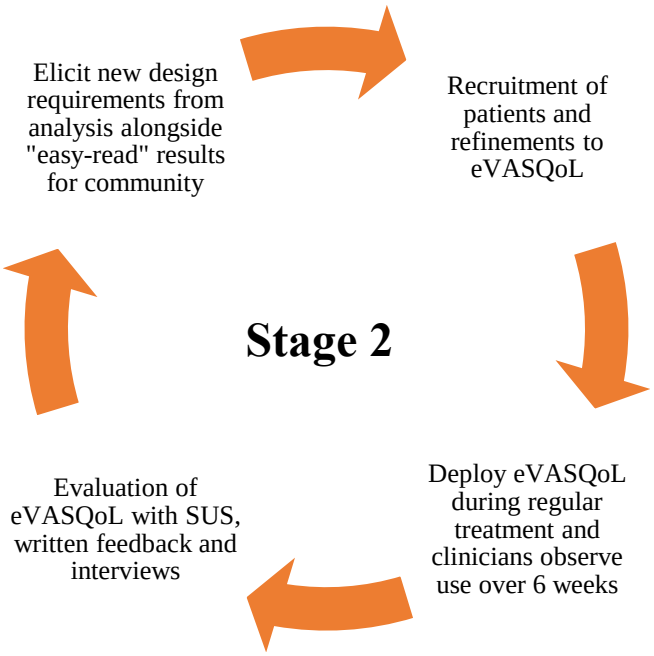


Figure 6.1: Stage 2 of cyclic co-design approach and relevant methods

The aim of this study was primarily to assess if the previous multidisciplinary approach of Chapter 5 can produce a system appropriate for implementation into a real-world setting i.e. during HD treatment in a hospital environment. Other goals included gathering feedback from both patient and clinician to further inform the design of the prototype and similar systems, supplementing the design requirements already elicited from the MDG of clinical staff and academics, as well as investigating the response times of each questionnaire used in the parallel VASQoL study, for insight into what questions patients spent greater time answering, or vice versa. The study would also address some of the recommendations formed in the scoping review of Chapter 4: by testing the system in a real-world setting and its expected use case, this work can (1) identify problems with the technology, (2) issues where patient's health changes, (3) the quality of data collected, (4) the priorities of patients and (5) their motivations. This study also contributes to the literature, as the review did not identify studies where a CKD cohort completed patient-reported outcome measures (PROMs) measures during treatment. Finally, the results of the chapter will help answer the second research question from the patient perspective, having already gathered insight from medical professionals in the previous chapter.

- **RQ 2:** What do haemodialysis patients and other stakeholders need from a technology-based intervention to support the CKD treatment journey?

This evaluation resulted in a formal System Usability Score (SUS) (Brooke, 1996) evaluation, alongside design requirements for further development of CKD technology-based interventions and the digital VASQoL questionnaire, based upon patient feedback (written and interviews) alongside clinician observations of patients' use over 6-week periods. The feedback and design requirements produced focus heavily on how the idiosyncratic needs of CKD patients need to be addressed, namely the

accessibility considerations required due to their impairments as a result of treatment, both physical and situational. This highlights the value of employing domain experts as a primary source, with the concepts of what the system needs to do already captured and implemented before evaluating with CKD patients to discover how it can do these things effectively. Other important themes to carry forward include the need to consider the perceived value of engaging with mobile health technologies for a patient, the benefits of digital over paper for this population, both physically and emotionally. Capturing this information alongside idiosyncratic requirements (Bouamrane et al., 2019) for the population are vital for the following work.

6.2. Methods

The work within this chapter was conducted as a case study design (Creswell & Poth, 2016), detailing the eVASQoL development and deployment within the context of a HD patient population. A case study design was selected as the complexity of the case (i.e. eVASQoL deployment with HD patients during treatment) warranted a deeper understanding and investigation, and the collection of various data from multiple sources (detailed below) allows for much richer design requirements and considerations for the system in question and others. This choice of study design takes inspiration from the "real-world elements" of a PAR approach (Hayes, 2014), especially given that in this case the researcher had to direct the study via the clinical researchers and patients.

As part of the VASQoL validation, participants had to complete the VASQoL and EQ-5D-5L questionnaires on 4 occasions over a 6-week period (weeks 1, 2, 4 and 6) while the SF-36 questionnaire was completed twice (weeks 1 and 6). In addition, response time data was automatically collected and recorded with patient completion of QoL measures and is analysed alongside qualitative feedback regarding the content of the measures. These timings were recorded alongside the given response scores for all three questionnaires via secure transfer to a SQL database hosted by the University of Strathclyde, alongside an anonymous identifier unique to each participant.

While the previous stage of the research gathered and refined initial needs for the system from medical and academic experts, the work of this chapter sought to evaluate the eVASQoL, through qualitative feedback from patients alongside a usability evaluation. The study coordinator was also enlisted to provide qualitative feedback based on their observations during the study. Both sources are explained in detail in the following sections on participant recruitment, data collection and data analysis.

6.2.1. Recruitment of Participants

Patient Participants. Ethical approval for this study was provided by the University of Strathclyde Computer and Information Sciences departmental ethics committee (ID 1061) and the Greater Glasgow and Clyde (NHS GGC) health board (GN19RE634). Informed consent was obtained from all patients prior to participation.

The culmination of the efforts of the MDG produced a prototype mobile application (referred to as the eVASQoL within this chapter), which was used to collect data for a validation study of the VASQoL measure (Richarz et al., 2021) for patients requiring HD. This provided an opportunity to evaluate the system with patients in a clinical setting. Therefore, the study detailed in this chapter was designed as part of this work, in collaboration with members of the MDG. A quota sampling technique was employed for the recruitment of patients to complete digital questionnaires and cognitive interviews, with the intent to recruit a diverse population in terms of age, primary renal disease, vascular access history and mix of vascular access modalities.

Due to the COVID-19 pandemic at the time of the study, data was collected by clinical researchers, two medical professionals with extensive experience of HD and familiarity with patients, Richarz and Stevenson. This also prevented patient contact with additional individuals outside those providing their treatment. Social distancing guidelines were adhered to throughout including limited access to hospital facilities during national restrictions in response to the COVID-19 pandemic. I, the principal investigator, co-designed the VASQoL study and took up a role of technical support for Richarz and Stevenson, informing them of successful submissions to the database and making ad hoc changes to the app if required, for the duration of the study.

Inclusion criteria for the VASQoL study were (1) patients with chronic kidney disease and (2) undergoing or about to undergo regular HD treatment. Participants who met these inclusion criteria were approached and recruited from five regular dialysis units in the NHS GGC health board to participate in the study over a 6-week period. Patient participant numbers and characteristics are described below for both forms of evaluation.

Patient Usability Evaluation. A total of 26 out of 101 patients (25%) using the eVASQoL for QoL data collection provided an SUS evaluation (Brooke, 1996). The SUS was used to measure system usability and the original questionnaire and questions were not modified. Paper questionnaires were chosen over digital ones to reduce the burden of participation for patients. The clinical researchers distributed the SUS to patients and aided with comprehension or acted as a scribe for participants where appropriate (e.g. writing arm being used for cannulation during dialysis, impaired vision, etc.). Patients were also encouraged to record any comments or feedback they felt was important about the system in a blank space below the SUS questions on the paper questionnaire.

As described above, the COVID-19 situation and approach of utilising clinical researchers limited the number of patients they were able to recruit for SUS completion during HD sessions, as well as overall participant numbers reducing over time due to attrition and lack of compliance with the study. Clinical researchers were also under additional workload as result of the pandemic, and patients were under additional stress and already completing multiple measures frequently over 6-weeks. Therefore, adding further burden for both was minimised. It is widely accepted that the SUS measure is valid with smaller

sample sizes (recommendations for at least 12 participants) (Tullis & Stetson, 2021), reducing the need for participants and overall burden on patients and clinicians.

Table 6.1: SUS Evaluation: Participant Characteristics

Patient Characteristics	Values	N (total = 26)
Sex	Male	9
	Female	17
Age	< 65 years	15
	65 + years	11
Length of Time on HD	Pre-HD	2
	< 1 year on HD	13
	1+ years on HD	11
Occupation	Studying or working	6
	Retired	13
	Not working	5
	Unknown/Incomplete	2
SIMD	Level 1 (Most deprived)	5
(Scottish Index of	Level 2	10
Multiple Deprivation)	Level 3	4
	Level 4	4
	Level 5 (Least deprived)	3

Of the 26 participants, 35% were male (9/26) and patient ages ranged from 28 – 85, with 58% under 65 years of age (15/26). Half of patients (13/26) were in their first year receiving haemodialysis (HD) treatment, with two pre-HD and the remainder having received HD for over a year. There were 2 occurrences of incomplete data where patients did not provide their occupation, but otherwise the collected data was complete (Table 6.1). Deprivation was also recorded via the Scottish Index of Multiple Deprivation (SIMD) (Executive, 2006). This is a common measure for clinicians to collect and is often routine in care data collection, however it also holds relevance for HCI as the literature has

indicated that high levels of deprivation are associated with reduced access to and engagement with health technology (Ashley et al., 2013; Ferrer-Roca & Subirana, 2002).

Patient Comments and Semi-Structured Interviews. Of the 26 participants in the SUS evaluation, just over half provided written feedback via a comment on the SUS form (14/26). A total of 19 patients were also interviewed as part of the validation study and provided feedback on their experience using the eVASQoL as part of the validation study. These interviews lasted on average 45 minutes and were conducted by one clinical research fellow coordinating the validation study. The transcripts of these interviews were then thematically analysed by the researcher separately from the VASQoL study.

QoL Response Time Data. The eVASQoL recorded a timestamp for each questionnaire when started and when a response was provided for each question. This was updated if the participant reviewed a question and then selected a different response. Anonymized patient demographic data was later merged through data linkage with the SQL database of responses and anonymous patient identifiers.

Researcher Interviews. The two clinical researchers who administered the questionnaires during the study were also interviewed after the completion of quantitative and qualitative data collection, to gain an understanding of their observations of patients' interactions with the eVASQoL and each QoL questionnaire during dialysis treatment. These interviews were conducted remotely over Zoom, audio recorded and subsequently transcribed for analysis as mentioned above.

6.2.2. Data Collection

Patient Feedback and Evaluations. The eVASQoL was used to complete QoL measures at intervals during their regular dialysis treatment. This required patients to access the eVASQoL via an Android application on one of two dedicated Samsung Galaxy Tab A tablets. The Android development environment was decided in the previous chapter, due to ease of app development and deployment, and the 10.1-inch screen size compromised screen size for viewing the interface and ease for patients holding the tablet with one hand (see previous chapter for more details). The clinical researchers delivered the devices to the patient during HD treatment and supported patients if required. Patients were required to complete the following three tasks: (1) update their VA modality and dialysing status, (2) complete the QoL data collection and (3) log out and leave feedback if appropriate.

The three questionnaires (Short Form 36-Item Health Survey (Ware Jr, 1999), EQ-5D-5L (Herdman et al., 2011) and the VASQoL measure (Richarz et al., 2021) under validation) were accessed via three separate buttons from the main menu, with only the relevant questionnaire accessible according to the scheduling of reporting. Other non-relevant questionnaires were made inaccessible until required (e.g. the SF-36 was not available if the latest submission was completed within 25 days of the current date, as the questionnaire is designed for monthly use) to reduce unnecessary effort and data. As discussed

in the previous section, response time data was collected and recorded automatically as patients completed the three QoL measures.

Table 6.2: QoL Measure Responses: Participant Characteristics

	Total Sample	**SF-36**	**EQ-5D-5L**	**VASQoL**
Sex n (% of total 101)				
Male	55 (54)	50 (57)	43 (59)	36 (57)
Female	46 (46)	38 (43)	30 (41)	27 (42)
Age (yrs)				
Mean (standard deviation)	59 (16)	59 (16)	60 (15)	59 (17)
Range	21-88			
Age Group				
< 65 years	58	48	40	38
65+ years	43	40	33	25
Scottish Index of Multiple Deprivation (SIMD)				
1 (Most deprived)	39	32	25	22
2	18	16	13	12
3	11	10	9	8
4	17	15	13	10
5 (Least deprived)	16	15	13	11

Patients were asked to participate in the SUS evaluation upon completion of their final VASQoL study visit and final use of the eVASQoL application, having used the portal up to 4 times over 6 weeks for QoL data collection. Qualitative feedback was also gathered from a separate cohort of patients as part of the VASQoL study interviews.

Researcher Interviews. The questions sought to elicit their experience working with patients and collecting patient data in paper and digital formats, alongside their views of the prototype and their observations of patients' interactions with the eVASQoL. The interviews lasted between 20 to 41 minute and were conducted remotely over Zoom, audio recorded and subsequently transcribed.

6.2.3. Data Analysis

Thematic Analysis of Qualitative Data. Transcripts and notes from patient and clinical researcher interviews were analysed by the researcher, using the Health Information Systems Quality Assessment Framework (Bouamrane et al., 2012), which is derived from DeLone and McLean's Model of Quality In Information Systems (DeLone & McLean, 1992). The framework consists of six dimensions for ensuring information quality in health information systems, with potential issues, solutions and benefits provided for each: (1) eHealth information system quality, (2) information quality, (3) information usage, (4) user satisfaction, (5) individual impact and (6) organizational impact.

For example, the first dimension eHealth information system quality, is defined as the performance of information processing. Potential issues include a mismatch between system functionalities and clinical work processes or ambiguity of coding standards and errors or variability in assignment of codes. The proposed solutions to these issues are co-design of systems with stakeholders to closely match clinical practices (i.e. regular MDG meetings prior to deployment) and automated validity checks. The latter is a theme discussed in the following results section, highlighted by the clinical research fellow. A feasibility study within this setting (Bouamrane et al., 2019) also used this relevant framework in thematic analysis, and it was thus used to allow for consistency and comparison.

A transcript of each interview was read alongside audio to ensure consistency in transcription, before being indexed and coded using the NVivo software tool (Dhakal, 2022) before charting of codes in respect to the six dimensions detailed by the framework (Bouamrane et al., 2012). Finally, themes were synthesized from the charted codes, providing insight into the impact of the prototype on treatment and patients and new or refined design requirements.

System Usability Scale (SUS) Quantitative Data. The SUS questionnaire (Brooke, 1996) data was used to calculate an overall average usability score and averages for individual questions as well, to allow for insight into the different aspects of the SUS questionnaire and how patients responded to these in respect to the eVASQoL. For example, the Question 2, "I found the system unnecessarily complex", is of relevance to a system that does not wish to impose further burden upon a high-treatment burden population such as HD patients.

QoL Response Timing Data. Anonymized patient demographic data was later merged through data linkage with the anonymous identifiers and the QoL measure data. Using the timestamps collected, the order of completion and length of time spent on each question was then calculated. To investigate each questionnaire, patients who did not complete the questionnaire at required intervals were filtered from the dataset, leaving only those who completed the SF-36 twice and the EQ-5D-5L and VASQoL four times in the 6-week period. Table 6.2 demonstrates the attrition of completion and submission across the three measures, with only 88 (SF-36), 73 (EQ-5D-5L) and 63 (VASQoL) of the initial 101 participants completing the measures as required.

From these filtered datasets, data was separated into intervals e.g., the EQ-5D-5L dataset was split into datasets for entries in weeks 1, 2, 4 and 6. This allowed comparison between intervals, such as calculating the difference in completion time between intervals.

6.3. Results

The results of this work are described as follows: (1) SUS scoring, (2) analysis QoL questionnaire responses, (3) thematic analysis of patient and researcher interviews and (4) refined set of design requirements for the prototype PROM system.

6.3.1. System Usability Scale (SUS) Scores

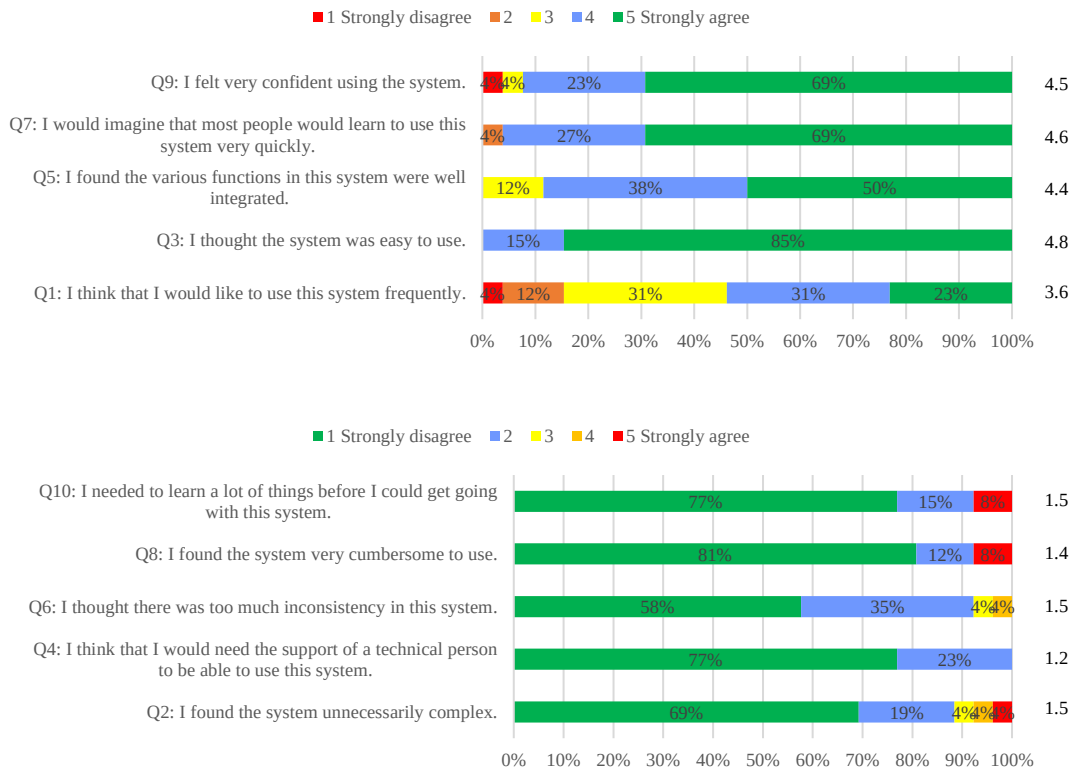


Figure 6.2: Distribution of Responses and Mean Scores (range 1 to 5) for SUS Questions (n=26). Upper chart displays odd numbered questions with positive statements, lower shows even numbered questions with negative statements.

The overall average usability score was 86.9 (range 72.5 and 100 / 100) which can be considered as a "good" score (Bangor et al., 2009). Figure 5.2 shows the distribution of response scores (Strongly disagree to strongly agree, 1 to 5) by each question. It is important to note that the odd numbered questions (Questions 1, 3, 5, 7, 9) are scored low to high, with 5 being the highest score possible and 1 the lowest. The opposite is then true for even numbered questions (Questions 2, 4, 6, 8, 10). For example, Question 3 has a very high average score of 4.8 and Question 4 a low average score of 1.2 but

this indicates that patients agreed they found the system easy to use and disagreed that they think they required support from a technical person to use the system (Questions 3 and 4 respectively).

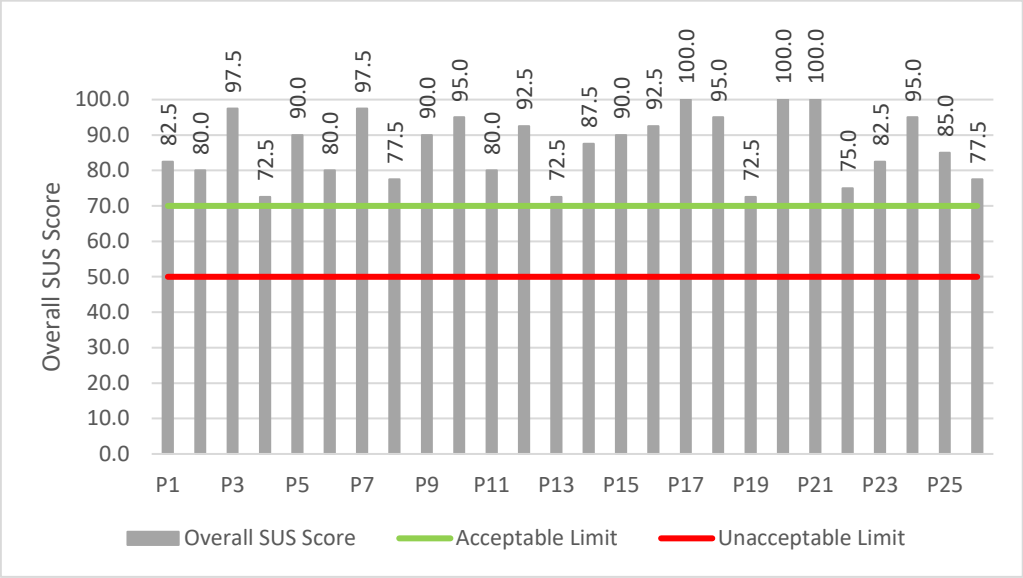


Figure 6.3: SUS Score by Participant, with acceptability ranges

Interpreting the scores for each question requires a calculation, to convert the scores from 0 to 40, to 0 to 100. The overall score is calculated by (1) subtracting 1 from the scores of odd-numbered questions (Q1, 3, 5, 7, 9), (2) subtracting the scores of even-numbered questions (Q2, 4, 6, 8, 10) from 5, (3) taking the sum of the new values and (4) multiply the sum by 2.5.

For example, P1's score was calculated like so:

$$= \big((Q1 - 1) + (5 - Q2) + (Q3 - 1) + (5 - Q4) + (Q5 - 1) + (5 - Q6) + (Q7 - 1) + (5 - Q8) + (Q9 - 1) + (5 - Q10)\big) * 2.5$$

$$= \big((\mathbf{3} - 1) + (5 - \mathbf{1}) + (\mathbf{5} - 1) + (5 - \mathbf{2}) + (\mathbf{4} - 1) + (5 - \mathbf{1}) + (\mathbf{4} - 1) + (5 - \mathbf{1}) + (\mathbf{4} - 1) + (5 - \mathbf{2})\big) * 2.5$$

= **82.5**

Figure 5.3 shows calculated SUS score for each participant, with the minimum score of 72.5 placing the system in the "high" acceptability range i.e. above 70, with scores between 70 and 50 noted as "marginally acceptable", and unacceptable if below 50 (Bangor et al., 2009; Bangor et al., 2008). While a small number of patients found the system presented a challenge and was considered "unnecessarily complex" (8% agreed or strongly agreed with statement Question 2) or required prior learning before use (8% strongly agreed with Question 10), the tablet-based system performed well and was of an acceptable standard to most patients, suggesting the co-design process was successful in producing a system which met the needs and expectations of stakeholders.

5.1.1. QoL Questionnaires Response Analysis

To determine if there was evidence of a learning curve or boredom, the total time to complete each questionnaire was compared between Weeks 1 and 6. There were no trends in relation to response times either overall, or by patient characteristics including age (under 65, 65 and over) or deprivation category (Scottish Index of Multiple Deprivation (Executive, 2006), most deprived vs least deprived).

The time taken to complete the questionnaires varied widely (the median time for SF-36, EQ-5D-5L and VASQoL was 392, 91 and 149 seconds, respectively). The longest time recorded was almost half an hour (1794 seconds or 29.9 minutes) by a patient completing the SF36, whereas the shortest time recorded was 17 seconds for completing the EQ-5D-5L (see Table 6.3).

Table 6.3: Time for Questionnaire Completion

Measure	**Time for completion (seconds)**			
	Median	**IQR**	**Min**	**Max**
SF-36	392	282 – 540	85	1794
EQ-5D-5L	91	68 – 117	17	1118
VASQoL	149	110 – 226	35	888

As well as overall completion time, the time spent completing individual questions of each questionnaire was reviewed. Given the widely differing number of questions, the percentage of the total completion time each question took was calculated and thus allows for comparison across all three questionnaires (Figures 6.4, 6.5 and 6.6). It had been postulated that for all three questionnaires, the first question would require more time than most others for familiarization with the presentation of the question and the response choices. However, each questionnaire differed widely in the times taken to complete each question.

The response time for the VASQoL questions were all similar, except for Question 8, which had higher response times, after Question 1. The VASQoL does not have a change in response range or layout as the other two measures do. Question 8 asks patients to select a response to the statement: “In the last week I feel I have been included in decisions about the care of my line / fistula / graft”, focusing on the patients’ perception of their care and relationship with healthcare providers, but other distractions cannot be dismissed (e.g. nurses attending to patient or equipment, tea trolley, etc.). The greater response time may also imply greater engagement and consideration for the response, as it can be generally assumed the time taken to answer a survey question is reflective of the cognitive effort to form an answer (Lenzner et al., 2010).

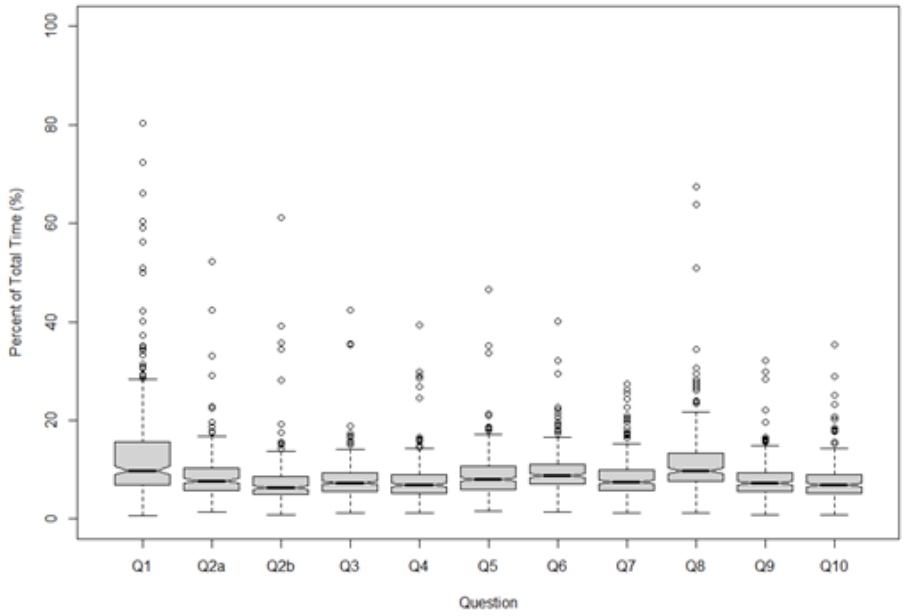


Figure 6.4: VASQoL Question Completion Time

The SF-36 question response times were longer for Questions 3, 13, 17, 20, 23, 32 and 33. These questions characterized by differing response ranges and layout (e.g., Question 2 is presented as one singular question using a 5-point Likert scale whereas Question 3 is the start of a grid of ten questions all using a 3-point Likert scale under one shared question or domain). Where the visual layout of questions is inconsistent with previous experiences and expectations of the respondent, they can become confused, enter incorrect or unintended answers and overall may take longer to respond (Christian et al., 2009).

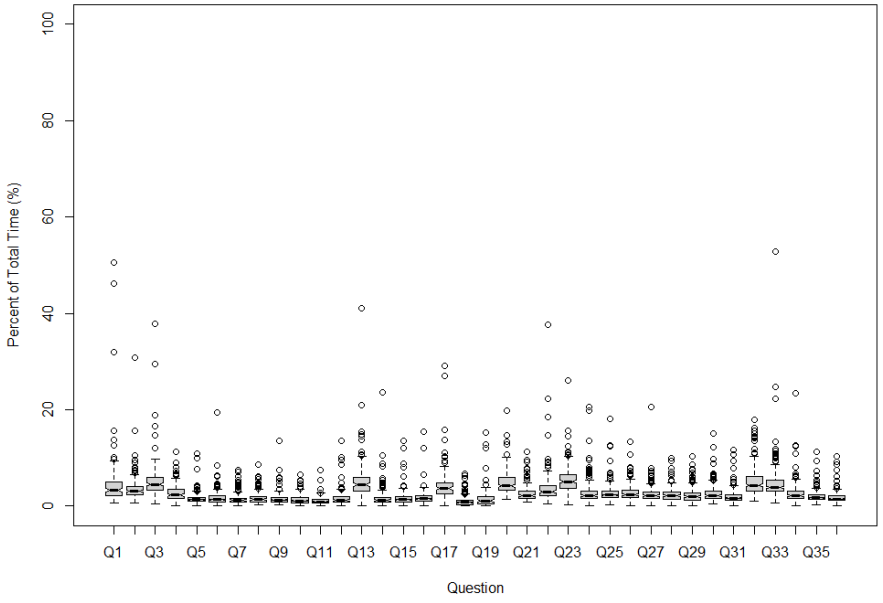


Figure 6.5: SF-36 Question Completion Time

Interestingly there was a consistent reduction in response times for the EQ-5D-5L as the patient completes the questions, except for Questions 3 and 6 (the latter being the visual analogue scale). Notably, Question 6 is the only question from all three measures where the median is greater than 20% of total time taken. Question 6 does include a significant change in layout and question format (shifting from 5-point Likert to an analogue scale of 0 to 100). Question 3 is longer in length than the other five text-based questions and asks patients to select a response regarding the problems about carrying out usual activities which is broader than the other questions covering several "activities" which may be important individually (e.g., family and work may be impacted very differently). The former characteristic has been found to cause delays in responses, with more syllables per question requiring greater time to process (Lenzner et al., 2010).

Considering the additional response times Question 3 of the EQ-5D-5L and Question 8 of the VASQoL, the context of these questions may be considered "emotionally loaded" or more abstract. For example, the VASQoL (Question 8) requires the patient to consider their engagement in their care and the relationship with their healthcare providers, while the EQ-5D-5L (Question 3) asks about several aspects of the patient's life in a single question.

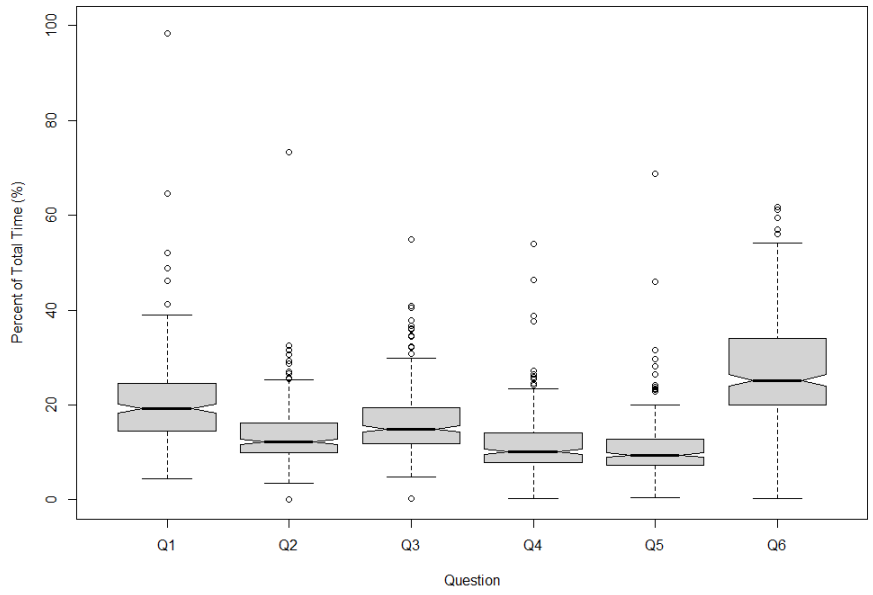


Figure 6.6: EQ-5D-5L Question Completion Time

6.3.2. Thematic Analysis of Qualitative Feedback

Following the Health Information Systems Framework derived from DeLone and McLean (Bouamrane et al., 2012; DeLone & McLean, 1992) design requirements were elicited from two sources: patient feedback via comments and interviews following study implementation, and researcher observations during implementation. Findings are described according to the six dimensions of the framework.

T1: eHealth Information System Quality. The topic of information systems quality was described in discussions of paper versus digital mediums. For example, when asked during interviews if they would

prefer paper alternatives to the digital eVASQoL, most patients preferred the tablet-hosted questionnaires (11/19) or had no preference (5/19), while three would have preferred paper. Both the researcher and patients noted the completion of the tablet-based questionnaires was easier and more feasible than using pen-and-paper during dialysis sessions with only one hand available and restricted movement. This is an important and previously unidentified observation as dialyzing with a fistula − particularly if in the dominant hand − makes writing difficult whilst receiving dialysis treatment but it did not limit the use of the eVASQoL.

"I think it's easier to place a tablet on your legs and use a pen or stylus, even with your non-dominant hand, you can do that…So I think it's much more convenient to use a tablet, especially for the one-handed patients." – Researcher 1

However, it was clear from both the patient and researcher interviews that provision of traditional alternatives should be made for those who may be inexperienced or unwilling to use technology. This suggests that while there are benefits to digital PROM data collection for this population, there is a need to provide traditional alternatives when appropriate (Absolom et al., 2019; Ashley et al., 2013; Burgess et al., 2019).

"I personally would prefer to do it on the app. And for people who, if you are going to do the questionnaire for people who are on dialysis it is actually quite hard to write. Some people have their fistula in their dominant hand, I don't fortunately, but even just writing can be awkward but some people are a bit funny about computers. So I don't know, you maybe have to do a bit of both." - Interview P8

"We had some trouble at the beginning but actually its quite good, a good thing to use it. I really liked it, I liked to work with the app or with the tablet." – Researcher 1

Overall, the interviews revealed patients found the eVASQoL to be usable. This reflects the results of the SUS evaluation, where scores indicated the app was "easy to use" and patients did not think the support of a technical person was required to use the system. There was discussion amongst patients that it may be easier for younger and more experienced patients, but some inexperienced patients also praised the ease of use of the eVASQoL, as did the clinical researcher.

T2: Information Quality. Discussions of quality of information focused on accuracy, honesty and relevance to the patient. The researcher interviews also revealed further benefits of the digital system over traditional data methods. Firstly, the validation processes of the system reassured the researcher that any completed questionnaires were complete and automatically stored securely, mitigating the risk of missing or incomplete data from human error (i.e. incomplete questions only detected after participant has completed study or transcribing paper responses to digital formats).

"And the other thing is the feedback, if you miss a question, it doesn't store…for paper forms, I won't realize until they missed a question or something…" – Researcher 1

Secondly, there was also a common theme of independence amongst the patient comments provided, praising the ability to complete the QoL questionnaires independently and provide honest responses. These comments suggest patients can be uncomfortable discussing their health and QoL with others or feel unable to provide honest answers. Thus, the ability to self-complete the QoL measures via the eVASQoL app provided a "safe space", with no pressure from other individuals to respond in a certain manner. This positive feedback suggests that provision of systems like the eVASQoL encourage patient activation and engagement in their care, which would otherwise be difficult to achieve through purely direct communication with their healthcare team.

"I really enjoyed using the tablet system. I also preferred being on my own to do it so I could put honest answers." – SUS P3

"I like being left to complete it. I feel I can be more honest than if I am asked a question directly." – SUS P6

This important aspect of patient feeling better equipped to disclose sensitive information to a "computer" has also previously been highlighted in other work on computer-mediated patients' medical questionnaires (Bachman, 2003; Bouamrane, Rector, et al., 2011). Another common theme amongst patients was the desire to provide open responses rather than selecting from a numerical range on a Likert scale, noting that they would be able to provide different answers to questions or add information to justify responses. The numerical nature of the EQ-5D-5L Question 6 scale was also discussed, as Researcher 1 observed patients found identifying with a number more difficult, with similar observations made during the VASQoL and the 10-point Likert scale. Researcher 2 supported this when noting patient feedback on the use of statement to anchor responses in the EQ-5D-5L (Questions 1-5). Both researchers were aware patients had shown a preference for open-ended responses but noted that open-ended responses are harder to analyse. One patient agreed with the researcher interviewing them that analysing open responses were more comfortable but could be more difficult to analyse, noting the opposite was true for the Likert scale responses. This discussion highlights the need to consider the balance between what is easier for the user to answer and what is easier for the researcher to analyse.

"Statement anchoring – patients fed back they found that easier to complete. They could identify which statement they could apply to them." – Researcher 2

"It's so much easier to give open answers and give everything that's on your mind. It's harder to link to a number. It'd be harder to analyse open answers… So, for an obvious evaluation it is easier just to have a range, of course, but I totally understand that it is more comfortable to give free answers." – Researcher 1

"Yes, I mean, I get that it is easier to calculate but it is harder to answer sometimes. See, I don't think you are always going to get a more accurate, in that sense, because people are just going to go, I suppose, do you know what I mean…" – Interview P16

The interviews primarily focused on confirming the patient's understanding of what each question was trying to elicit, often referring to the use of language. While it appeared most questions were easily understood, there were some instances where patients had difficulty in interpreting the question or required further information. Patients found some questions in the SF-36 less relevant, in contrast to the EQ-5D-5L and VASQoL, which were described as "relevant, practical simple questions". This was attributed to patients understanding the question in context to their situation i.e., a patient living with a chronic condition and high treatment burden. Researcher 2 noted a "ceiling effect" in responses reflected this fact as well, potentially due to the generic nature of the SF-36 questions. Both discussed how some questions naturally required more time for reflection. For example, patients often paused on the VASQoL Q8 (which questions the patient on if they feel involved in their care) to verify their input with the researcher assisting them. Patients' situations also appeared to determine their response time to the final two questions of the VASQoL, focusing on interference with work and/or study and hobbies and interests. This indicates the nature of the questions may require additional time, for both reflection and verifying responses in respect to the individual's circumstances.

"Whenever they think about things, they think about context in terms of their situation." – Researcher 2

T3: Information Usage. The theme of communication between patient and healthcare provider was identified in patient comments, with patients indicating they wished for staff to review their responses. However, while there was potential for the eVASQoL to support patient-provider communication, it was of little value to patients if their responses were not reviewed. These findings reflect those of Absolom et al. (Absolom et al., 2019), where the perceived value of an intervention and collection of patient-reported outcome measure (PROM) data was doubted by patients when data was not referred to during clinical counters. While both this study and the VASQoL validation study did not utilize PROM data clinically, a clear sentiment was reported by patients that they only found benefit in reporting data through the eVASQoL where it is viewed and utilized by healthcare providers. This utilization of data will need to be visible in future implementations, through referral in discussions or other means to retain engagement from patients.

"Useful for nightshift or twilight shift to communicate with doctors - no use if nobody looks at it." – SUS P15

"I would like the VA [vascular access] team to know my answers." – SUS P16

Similar behaviour was also noted by researchers conducting the study, with patients keen to participate at Week 1 but enthusiasm waning as the 6-week study progressed. A possible key factor in those that

took widely differing times to complete the questions (outliers) was interruptions from medical interventions, dialysis machines or nurses and distractions such as snacks and tea trolleys, televisions, or phone calls, which were often positively received by patients according to Researcher 1.

"There are lots of reason for distraction. Every distraction is welcome. They would just put the tablet away and do something different." – Researcher 1

While this is discouraging, it demonstrates dialysis patients are willing to try and engage with something new if it distracts them from their lengthy sessions, as long as it does not add to their existing burden. There were opposing comments, notably SUS Patient 14 felt "perfectly able" when communicating with healthcare providers and were the only participant to respond they strongly disagreed that they would like to use the system frequently. This suggests for patients who are confident in their ability to communicate and discuss their healthcare, interventions such as the eVASQoL are seen unnecessary and as a possible hinderance to their patient-provider relationship and communication. However, patients with reduced health literacy and ability to interact and engage with healthcare providers (such as those from financially deprived backgrounds (Palumbo et al., 2016)) may find tools such as the eVASQoL of great support and enable them.

"I feel I am perfectly able to communicate with nurses, doctors, when I need to. I am also quite able to understand what is being said to me when discussing my health." – SUS P4

T4: User Satisfaction. Both patients and the researcher enjoyed using the system during the study. There were accessibility obstacles to overcome early on during the study, notably concerning patients' ability to utilize touchscreen input.

"What made a difference, a huge difference, is using like a pen [stylus]. They are not that precise without a pen. They sometimes miss a field." – Researcher 1

"Awkward because in dominant hand but much easier than writing - difficult to add written comment with non-dominant hand - a voice recognition function could help with things." – SUS P14

Considerations were made for accessibility issues during the development of the system, as clinical experts provided this insight. Early observations by the study coordinators highlighted the scale of the issue of touch input and HD patients. Decreased sensitivity or sense of pressure in patients' fingers, credited to carpal tunnel syndrome symptoms or neuropathy (Fujita et al., 2019), appeared to result in incorrect gestures being registered and the system providing an incorrect response to the intended input (i.e. patients press on elements such as buttons for a longer length of time and the touch gesture is read as a "long press" instead of a click event). This caused frustration amongst patients and prevented them from completing the tasks required of them without difficulty. Immediate action was taken to remedy this by providing styluses alongside the tablet devices, which improved the touch input and accuracy of

patients' input. Designing for potential medical conditions to avoid dependency on a stylus to mediate such issues should be considered in future work.

Another common barrier was the impaired vision of patients, with the clinical research fellow required to support those unable to view the tablet and user interface clearly. However, there was no apparent impact on the study due to impaired vision due to support being provided by researchers. Impaired vision can be common in this population (Nusinovici et al., 2019), especially in diabetic or elderly patients receiving HD long-term (Gonda et al., 1978). Therefore, the addition of alternative output and input methods (e.g. text-to-speech and speech-to-text) should be considered and may also be well-received by other users i.e. those who experience issues with touch input.

"I totally underestimated, there are a lot of visually impaired patients." – Researcher 1

Other issues arose from the interface and questionnaire designs for the three measures. To maintain the validity of the QoL measures, they were implemented into the tablet without modification to their original presentation as possible. In the case of the SF-36, this meant all 36 questions were presented on a single screen. Compared to the other measures, this made it difficult for patients to focus on individual questions (Researcher 1 described having to scroll the screen for the patient so the current question was positioned at the top of the screen). The limitations of the one-page questionnaire also caused issues where scrolling caused text to go offscreen, notably where the question was part of a group under the one domain or heading. In contrast the EQ-5D-5L and VASQoL were preferred for their question-per-page layout and shorter length. The EQ-5D-5L was particularly praised for implementing large buttons onscreen for displaying 5 responses (Questions 1-5), which visually changed colour when selected, rather than simplistic radio buttons as seen on the VASQoL Likert scales. The previous chapter describing the design requirements elicited from the MDG stated a need for timely and appropriate feedback from interactions, and so the feedback given was taken forward when redesigning the digital version of the VASQoL measure.

"It's [SF-36] not question by question, confusing to focus on one question, the way its presented is very difficult." – Researcher 1

"They [participants] liked the big boxes [EQ-5D-5L]. They liked when they hit it, it changed colour and they knew it had been recorded. It was big visual feedback." – Researcher 2

The design of the questions not only varied by QoL measure but also by question in each measure. differing in length and question design. There was discussion about how this influenced patient response times. Again, the SF-36 was problematic, with question format changing often i.e., 3-point Likert to 5-point Likert scales, creating a "unstructured" questionnaire (Researcher 2). The EQ-5D-5L had a similar issue where the final question (Question 6) shifted from choice of 5 responses to simple statement to an analogue scale, with sudden changes in layout and the addition of instructions on how to respond to the

scale contributing to additional time spent on the question. A more consistent question design displayed one-by-one may prove to be a more accessible approach.

T5: Individual Impact. Patients highlighted how the eVASQoL and the QoL questionnaires caused them to consider their healthcare and their role in their care. There was a request for the addition of further information on how to leave comments following questionnaire completion and inclusion of a question to elicit patient preferences.

"Would like to be able to expand on other aspects of care or problems. Instructions of how to leave comments at the end." – SUS P14

"I think adding…asking a question that sticks in your head: what is the preference of the dialysis patient? I mean, at the end of the day it doesn't fall into the preference because this is your lifeline. If this one [current vascular access] fails you need to end up with this one [other vascular access]." – Interview P3

The earlier theme of providing honest responses also supports this activation of patients, as they feel they can provide honest answers and engage with their health independently. There was a request for better explanation of some questions, which should be considered carefully in order to continue facilitating the independent completion of the questionnaires. This also connects back to the usability of the system, where the need for explanation of a question or instruction suggests the support of a technical individual is required and reduces system usability.

"I liked being able to fill it in and then have people ask me about it. I don't like bringing things up myself. I don't talk about it much." – SUS P8

"Most relevant to me are the health questions. Fill in the vascular access one if I have problems (haven't had with this line)." – SUS P21

While all interview patient participants expressed positive relationships with staff or confidence in their ability to communicate and participate in care decisions, some suggested that some of their peers could have reservations. Patients were also at times unsure whether some of the questions should be interpreted in the context of their clinical treatment or their personal life in general. Even though some of the VASQoL questions were more generic than others, the "confines of dialysis" still affected how they responded as part of the reality of their day-to-day life.

"*Yes, but I think maybe, have you been asked about your care, that kind of thing maybe. Some people probably come in and maybe they don't want to ask, maybe they are afraid or frightene*d." *–Interview P1*

"That question, I think is, the last question [Question 7, VASQoL] there is, if you are satisfied with life in general? I think that is a hard question to answer. You have to say it within the confines of being on dialysis. You know, my life would be completely different if I didn't have to come here three times a week." – Interview P8

Similar notions were expressed by other patients when discussing how their vascular access impacted aspects of life, such as relationships (Question 6), hobbies, social activities, or things they enjoy (Questions 5 and 9) or work and/or study (Question 10). Patients felt they did not see their vascular access as an interference to these aspects of life as they had already accepted prioritizing their health over such things, often noting the alternative was simply death. The emotionally loaded nature of these questions may need to be considered carefully and handled appropriately by medical staff if required.

"It is awful at having a fistula but I don't know how else you would say it "interfered", because if it was going to interfere with your hobbies, if your hobby was weight lifting, do you know what I mean? It is definitely interfering with it but it is not. You would weight it up, wear a fistula or die." – Interview P16

"The thing is, the alternative to getting this is death so how can I be unhappy about it really?" – Interview P21

T6: Organizational Impact. The eVASQoL proved to be an effective and usable method for collecting patient-reported outcome measure (PROM) data from patients, praised by both patients and researcher. There were benefits over paper data collection (e.g. accessibility for dialyzing patients, validation of data and reducing risk of human error) but considerations should be made for those who may not wish to engage with digital methods or are unable to. This population is typically older (Ronsberg et al., 2005), and while there is an expectation that the prevalence and familiarity with technology will grow with time, this subpopulation of users should be supported, either through the accessibility of the system or by providing alternatives (Absolom et al., 2019; Ashley et al., 2013; Burgess et al., 2019) e.g. pen-and-paper if requested or providing support through scribing. The need for supported use would require further investigation in following work, to warrant how both patients and healthcare providers feel towards the concept.

"Like I said, there are some patients who just can't do it by themselves. They just have no experience [with the technology]." – Researcher 1

6.3.3. Formal Design Requirements

A set of formal design requirements was previously collated from iterative review and feedback from experts (see previous chapter). These were refined and expanded following patient usability evaluations and interviews, as well as researcher observations of the system implementation. They are classified as functional and non-functional, the former describing what a system will do and the latter how it does

this (Eckhardt et al., 2016) (these can also be understood as what makes the system useful and what makes it usable).

After the commencement of the VASQoL validation study, it became clear some emerging design requirements were of high priority and resolving these were critical to the patients' effective and continued use of the system. Early observations reported that dialysis patients struggled with touch gestures using the tablet devices, with a reduced sense of pressure or sensitivity in their fingers impacting their ability to tap buttons onscreen (i.e. too much pressure indicated a long-press gesture, highlighting the text of the button rather than registering a click event as intended).

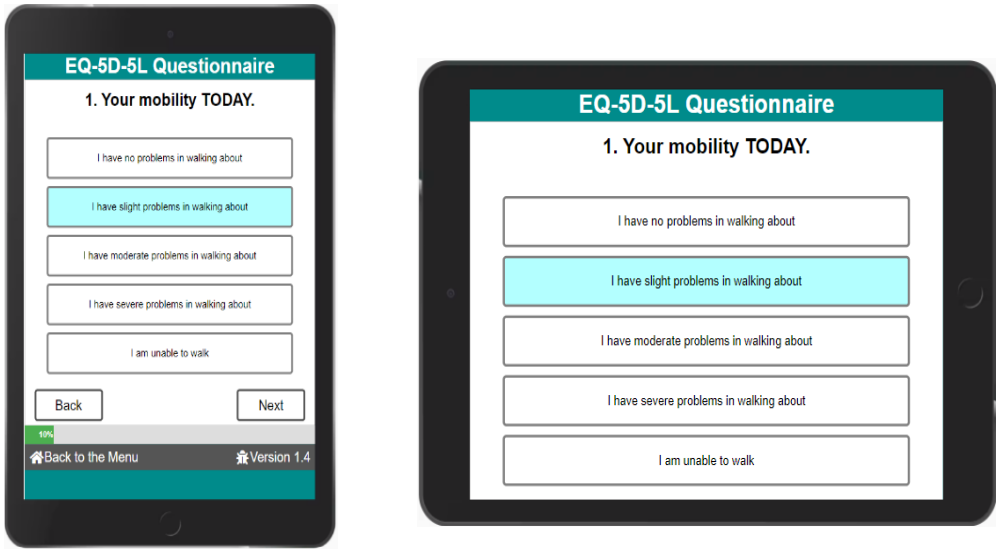


Figure 6.7: Screenshots of EQ-5D-5L layout change on orientation, highlighting offscreen positioning of navigation buttons

To avoid interrupting the study and increasing frustration for patients, rubber-tipped styluses were acquired and provided alongside the tablets for the remainder of the study. This option minimised disruption to the study and it was found patients enjoyed using the styluses. This was later resolved programmatically after the study concluded by disabling the "user-select" property of the user interface elements.

Other modifications to reduce system complexity and patient frustration included the disabling of the user feedback functionality (which prompted patients during logging out to leave feedback) and modifying the size of the EQ-5D-5L user interface elements so all content was available onscreen regardless of, device screen orientation. In this case, patients were disorientated when navigation buttons were not visible in landscape orientation without scrolling (see Figure 6.7). This may seem easily resolved by rotating the screen to the portrait orientation, but for a patient dialyzing with a fistula or graft, they are unable to both hold the tablet and touch the screen with one hand and rely on tablet being positioned upright to interact with it. Overall, this setback caused flow disruption but did not

impede submission of responses. Otherwise, the systems key functionalities and user interface elements remained unchanged for the duration of the study.

Table 6.4: Formal Design Requirements First Identified by Patients and Observations

Aspect	Requirement Description	Type
QoL Data Capture	Include statement anchors for Likert scales	Functional
	Large buttons for response options (versus radio buttons)	Functional
	One question layout/onscreen	Functional
	Consistent question format/design throughout questionnaire e.g. Likert, scale, etc.	Non-Functional
	Careful and clear wording of questions/instructions	Non-Functional
	Perceived value of contributing PROM to system for patient	Non-Functional
Accessibility and Usability	Account for CKD population health-related issues i.e. touch-input issues, impaired vision	Non-Functional
	Alternative input and output options e.g. speech-to-text, text-to-speech	Functional
	Correct handling of accidental long-press events e.g. longer timespan, ignore action	Functional
	UI must be consistent between device orientation changes	Non-Functional
	Option to increase/decrease font size as required	Functional
	Adequately spaced and sized UI elements	Non-Functional
	Minimal steps or actions required to reach goals	Non-Functional
	Accessible and clear system feedback (e.g. replace system alerts with custom “pop-up” messages, buttons highlighted, etc.)	Functional

Capture of QoL Data. Patient interviews discussed the VASQoL questions as part of its validation, focusing on the context of the questions themselves. Interviews with the researchers conducting the study provided insight into how the patients interacted with the digital questionnaires, such as the preference for the large buttons for responses of the EQ-5D-5L and their clear visual feedback when selected or difficulties encountered when trying to complete the 36 items of the SF-36 on a single page, especially where questions varied in context and design (e.g. 3-point Likert scales and 5-point scales, individual questions or grids, etc.). Suggestions for the design and implementation of the VASQoL measure going forward are detailed below, and Figure 6.8 demonstrates the original interface alongside the updated version.

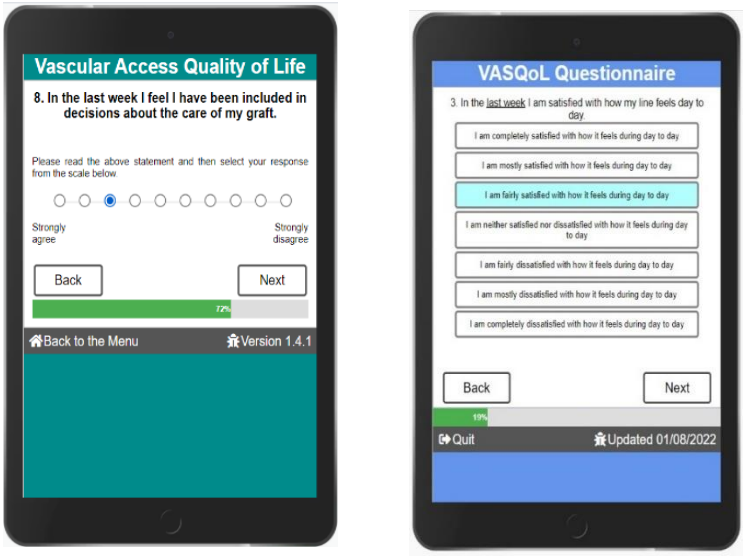


Figure 6.8: Screenshots of original and updated VASQoL question interface, after feedback

Key changes include:

- Use of statement anchors with responses
- Large buttons for responses in place of radio buttons
- Ensure perceived value of contributing via PROM submission i.e. acknowledgement, response or actions from clinicians as result of submitting data

Considerations for System Accessibility Usability. As described above, the implementation of the prototype into a real-world setting with patient users revealed various accessibility problems unique to the population. These focus on the physical issues of the patients' condition and treatment present, such as restricted use of cannulated arms, decreased sensitivity in fingers when input is required via touch and vision impairments which are common. Recommendations to refine the system to ensure it is accessible and usable for its intended user population include:

- Alternative and adapted input options for users e.g. text-to-speech, styluses
- Alternative output to visual e.g. audio, text-to-speech
- Accounting for errors in touch-input e.g. taps which result in long-presses
- Consistent user interface and layout between device orientation changes
- Adequate spacing between and size of user interface elements to avoid errors in selection (e.g. custom alerts/pop-ups for system feedback)
- Minimise steps and actions require to complete tasks or reach goals i.e. confirmation pop-ups

Future work towards the design of a non-touch and mixed-input interface for this user population would be of interest given the issues identified in this case study.

6.4. Discussion

This work sought to determine if the previous multidisciplinary approach could produce a system appropriate for implementation into a real-world setting i.e. during HD treatment in a hospital environment. The system was evaluated with patients, achieving an above average SUS score and gathered rich design requirements from both patient feedback and investigator observations. The in-depth thematic analysis of qualitative data supplemented the quantitative SUS scores and the framework utilized in a feasibility study with solely domain experts participants (Bouamrane et al., 2019) proved to be suitable in this work.

The delivery of the QoL measures digitally via the eVASQoL app benefitted patients and allowed them to complete the tasks given without issue, overcoming situational impairment where traditional paper-and-pen questionnaires would have been difficult to complete. The clinical researchers also noted the validation of the digital data collection reduced human error and streamlined the process. However, observations also confirmed that younger patients were often more comfortable and adept at using the tablets than their older peers, with patients raising concerns others may simply chose not to engage with the technology due to personal preferences. While the growing prevalence of technology is often cited as an eventual solution to this issue (Ashley et al., 2013; Basch et al., 2005; Basch, Iasonos, et al., 2007), conventional alternatives should be provided alongside the digital options to prevent patients from becoming excluded from healthcare (Ashley et al., 2013; Burgess et al., 2019). While the validation of the measure itself was published separately from this work (Richarz et al., 2021), the process also provided insight into its digital implementation, and how the design can be refined to produce a more accessible and usable tool for patients and clinicians.

Otherwise, a highly usable prototype resulted in the engagement and activation of patients, promoting a sense of independence, and providing a private space for reporting their health and satisfaction with treatment. Interestingly patients reported that they felt they could be more honest via the tablet app than in a face-to-face conversation and felt it was a way to initiate discussion, confirming previous findings in the sphere of computer-mediated patient medical questionnaires research (Bachman, 2003; Bouamrane, Rector, et al., 2011). The perceived value of the system indicates it met the needs and expectations of patients (Sadeghi et al., 2017) and was also a motivator for engagement for both patients (as demonstrated by their feedback) and clinicians (Irizarry et al., 2015), which has been difficult to secure with similar systems as noted in the section on related work.

While this work did not utilize the collected PROM data or influence participants' treatment in any manner, the system will need to demonstrate this value or risk losing patient engagement, as made clear by patients' feedback. Systems such as the eVASQoL need to acknowledge patient input and demonstrate engagement from the other side, such as read receipts of submitted data, where an action in response may be delayed e.g. follow-up appointment with consultant. Studies which enforced

providers to respond to patient reports (Fjell et al., 2020; McCann et al., 2009; Velikova et al., 2004) demonstrated satisfied patients and in the case of Velikova et al., clinically significant improvement of patient well-being. Implementation of functionalities such as this may reassure patients their input matters and prevent perceived value and engagement deteriorating. However, this also potentially adds more tasks to existing workloads of NHS staff, and so there may need to be a compromise between managing patient expectations and staff workloads to ensure neither side loses sense of value from the exchange of data.

The positive reception of the eVASQoL through implementation with HD patients showed clear support for future work in this field. This case study of the eVASQoL evaluation with HD patients during treatment identified unique accessibility issues, idiosyncratic with this user population. This included an example of situational impairment, already highlighted by Mishra et al. (Mishra et al., 2018), which in turn can lead to patients preferring horizontal orientation for the tablet devices and identifying issues with the eVASQoL user interface. Considerations were made for such issues in selection of a suitable device and the design and layout of the user interface but still required refinement to improve the accessibility of the system with HD patients, such as adaptive layouts with orientation changes and use of a stylus to overcome touch sensitivity difficulties. While some actions were taken during the study to remedy this (e.g. the introduction of styluses), the eVASQoL will need to take these issues into consideration in future iterations, such as accounting for longer presses to achieve a click event, spacing user interface elements or ensuring the shift in screen orientation does not result in additional actions to complete tasks (i.e. scrolling down to view offscreen buttons). Condition-specific accessibility issues were also captured, including vision impairment which is common within this population. These findings will hopefully inform future work with this population and demonstrate the benefits of the in-depth analysis and description this case study has produced.

6.5. Strengths and Limitations

While the approach was appropriate and sufficient, limitations were noted. At the time, the study was conducted under a national lockdown and other COVID-19 restrictions during the global pandemic in 2020 and great care had to be taken for patient safety as chronic kidney disease patients are classed as vulnerable (Bell et al., 2020). This prevented a non-medical researcher attending the medical facilities, so data collection was reliant on healthcare professionals already working in the hospital. A single usability measure was employed in a paper format as clinicians felt additional measures e.g. the NASA-TLX (Hart & Staveland, 1988) would have placed an excessive burden upon patients and the clinical researchers during an already difficult period. The use of a paper medium for the SUS evaluation avoided presenting patients with another digital questionnaire after 6 weeks of tablet-based questionnaires. The case study was conducted in only one setting, so replication studies are planned as part of future development cycles.

Considerations for future work include further refinement of the existing system following this evaluation and implementation into routine practice, potentially at national and international levels. Most importantly, piloting this within a routine clinical setting such as monthly haemodialysis clinic reviews will be important as where there is lack of perceived value, the intervention is less likely to become normalised into routine practice (Bouamrane, Osbourne, et al., 2011; Jacobs et al., 2018). Further work with HD patients to address and resolve barriers to engagement and use of the eVASQoL is also required, notably those arising from situational impairment and condition-specific challenges, such as vision impairments and touch input difficulties. The design requirements elicited in this work will provide direction for further refinements of both this system and similar technologies.

6.6. Conclusion

This chapter covered the second stage of the co-design processes, focused on the implementation and usability evaluation of the multidisciplinary co-designed digital PROM, eVASQoL. CKD patients were introduced to the eVASQoL and contributed towards its development and refinement following testing in its expected use case and environment, as per the recommendation made in Chapter 4. This case study with HD patients using the application over 6-week periods during their regular dialysis treatment proved an effective evaluation and indicates the system is usable and of "good" quality, with an average SUS score of 86.9 based on responses from 26 patients. This work also yielded rich and important design requirements to consider, with data and positive feedback from both patients and a clinical researcher familiar with the domain. The input from patients at this stage compliments the contributions of the non-patient stakeholders of the previous chapter and provides further answers to the second research question from the patient perspective.

Important lessons for the research community include: (1) CKD patients' need for perceived value of engagement from systems (i.e. where clinicians reciprocate), (2) addressing their condition-related and situational-impairment accessibility needs (i.e. vision impairment, limited use of cannulated arm and reduced touch sensitivity) to allow them to use such interventions independently which (3) can promotes a sense of independence and privacy when completing PROMS and (4) the benefits and ease-of-use from collecting PROM data digitally for both clinician and the CKD patient population. Insights and considerations such as these are required to produce a system fit for purpose and accessible by its target end-users (Aiyegbusi, 2020), while also addressing some recommendations of the scoping review of Chapter 3, such as identifying perceived value and how patients' health (i.e. situational and condition-related impairment) may impact their usage of the intervention.

A PROM-capturing intervention implemented into routine care with a CKD cohort had not been described by studies captured in the literature review of Chapter 4, highlighting the novel contribution of this work that demonstrates the successful deployment and evaluation of a QoL reporting system with a CKD patient cohort, marked by treatment and disease burden, comorbidity, and age, within a

clinical setting. This work also produced a refined set of design requirements, including those idiosyncratic to the context of CKD patients, such as situational impairment while dialysing and difficulty in utilising touch screens as a result of their treatment. It also provides considerations for the design and formats of digital QoL questionnaires, based on the response times and feedback of patients completing three different measures over 6 week periods. Finally, the chapter demonstrates the highlights the value of employing domain experts as a primary source, capturing the key concepts of what the system needs to do before implementing with the patient population to discover how it can do these things effectively.

Chapter 7: Design and Evaluation of CKD Patient Education Resource with Medical Professionals

This chapter details the co-design of a patient education resource, with a wider stakeholder audience than that of the previous studies conducted by the author. Having addressed the need for clinical and patient-reported data collection, the focus of the MDG could now change to addressing the issue of patient education and decision-making within the context of CKD, first identified in Chapter 5. The outcomes of this work will also contribute to answering the second research question, focusing on the needs of system to support patient education and decision-making.

- **RQ 2:** What do haemodialysis patients and other stakeholders need from a technology-based intervention to support the CKD treatment journey?

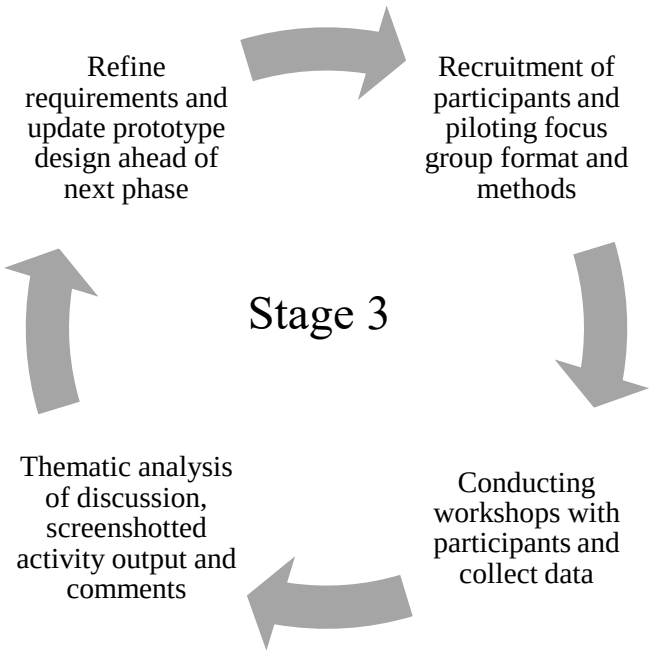


Figure 7.1: Stage 3 of cyclic co-design approach and relevant methods

Initial designs for a visualisation of patient pathways and treatment outcomes are reviewed by the MDG, informing the design of two prototypes later used in co-design workshops with clinical staff from outside the MDG and across the UK. Keeping with the iterative co-design approach employed throughout (see Figure 7.1), the group processes and discussions of these sessions provides a new set of design requirements for a CKD patient education and decision-making aid, as well as insight into the process of informing patients based on participants' experiences. This process also allowed for the review and refinement of the prototypes prior to being viewed by patients in the subsequent chapter.

7.1. Introduction/Background

A key element of effective treatment, self-management and improving the overall health of chronic kidney disease (CKD) patients is patient education (Young et al., 2011), but the literature suggests there are several issues pertaining to CKD patients, patient education and information regarding treatment options and pathways. It is not uncommon for CKD patients to have limited levels of health literacy (Narva et al., 2016), defined as "the cognitive and social skills that determine the motivation and ability of individuals to gain access to, understand and use information in ways that promote and maintain good health" (Rowlands et al., 2013). Patients endure a high level of information work, having to first recognise what they need to know, find resources that provide what they need, try to understand the information and finally attempt to make sense of it in terms of their own personal circumstances and situation (Burgess et al., 2019). This process can be delayed by barriers, such as high emotions from dealing with the diagnosis or information overload but the process of deciding and starting treatment will continue as renal function declines. Patients may adopt a passive role in their treatment and often make meaning of information in the context of their personal health after starting treatment, realising the decision is not personally viable but at a stage where other options may be limited or no longer viable (Burgess et al., 2019). Healthcare providers also face barriers, notably time constraints and challenges communicating the complexity of CKD treatment, with a lack of tools to support effective education and communication (Narva et al., 2016). Patient information resources (notably printed material such as leaflets, brochures, posters, etc.) are designed to support patient education and self-management activities required for effective care but often require a high level of health literacy (Tuot et al., 2013) or reading ability (Morony et al., 2017), when almost a quarter of the CKD patient population are noted to have low health literacy. Visual aids such as images and graphics can supplement information, attract patients to materials and aid in their understanding, especially for low literacy readers (Morony et al., 2017). However, if these images are unrelated to the text or embellishing (i.e. not related to text or aiding in explanation), they provide no benefit to comprehension (Houts et al., 2006) and such graphics can be distracting for older readers (Griffin & Wright, 2009).

Issues in patient education such as these can provide opportunity for technology-based interventions. For example, the complexity of the patient treatment pathway was discussed in Chapter 5 during the identification of design requirements with a multidisciplinary group (MDG) of experts, resulting in a proposal for an interactive treatment guide. The proposed solution would map and visualise patient care pathways and treatment in an accessible format to overcome the issues stated. While technology-based interventions can be effective methods of overcoming the barriers described, they can impose further work for patients who already struggle (Burgess et al., 2019; Mair et al., 2021), detracting from any perceived value of engagement and ultimately will be abandoned. For example, Burgess et al. (Burgess et al., 2019) describe how "low-monitor" patients (who can be less engaged than their peers in their care and may practice information avoiding behaviours) often do not engage with resources that require

sustained participation from the individual (e.g. online health portal or forums). They propose collaboration with others with backgrounds to answer patients' questions as a potential solution for less engaged, rather than rely on a purely technical solution for individuals. This echoes the recommendation from the scoping review (Chapter 4) for technology to be accessible, as inability to access technology independently further adds to the burden of the patient (and their support network e.g. family (Ashley et al., 2013)). Technology also needs to adapt for changes in patients' health, as demonstrated by the MyPath intervention (Jacobs et al., 2018), where breast cancer patients found the tailored information provided by MyPath less helpful or relevant when they did not experience significant physical symptoms.

Therefore, the aim of this work was to produce a patient education resource that could support CKD patients in both independent and collaborative uses, progressing the concept first identified in Chapter 5 by the MDG. This would be achieved in three phases, summarised below:

1. Conceptualising designs within MDG to further understand the context and gather initial design requirements.
2. Reflection on patient education and high-fidelity pathway visualisation prototype design evaluations with non-patient stakeholders outside of the MDG.
3. Reflection on experiences of information provision and refined prototype evaluations with patient and caregiver stakeholders.

This chapter will describe the first two phases; this includes the conceptualisation work within the MDG to produce early design requirements and two high-fidelity prototypes, before evaluation with healthcare providers outside the MDG to inform further design requirements for a refined high-fidelity prototype. The evaluation of this prototype i.e. the third and final phase, will be discussed in the following chapter. Justifications for this approach are provided in the following section.

7.2. Methods

Co-design workshops with stakeholders were identified as a viable method for this study. Co-design (or participatory design) workshops have been utilised as effective methods in similar digital health and mHealth work and bring stakeholders together to co-create ideas (Lupton, 2017; Ozkaynak et al., 2021). Group processes engage participants in research activities and allowing them to guide the research going forward with their input (Chiu, 2003). The data collected is primarily that of discussions between participants, with the researcher enabling and facilitating the supportive environment. They are also responsible for encouraging differing points of view and should recognise and value the viewpoints of all participants, providing all an opportunity to communicate (MacDonald, 2012). Patient-centred care and interventions such as the systems this research thesis can particularly benefit from elements of action research, bringing the patient participant and their perspective into the research process and outputs alongside that of the researcher (White & Verhoef, 2005).

End-user participants (i.e. CKD patients) will be the final group of participants to be included in this work (in subsequent Chapter 8) and while this may contradict basic user-centred design approaches, the decision was made with the best interests of patient participants in mind. CKD patients can often suffer from depression, due to the impact of both their disease and treatment on their lives (e.g. symptom burden such as lack of sleep, decreased sexual drive, pain and fatigue alongside psychological factors including change in self-image, roles and uncertainty of future and health) (Cukor et al., 2007; Hagren et al., 2005; Zalai et al., 2012). Exposing patients to unfinished and unvalidated content regarding their treatment and disease may be triggering or difficult for them to engage with. The nature of the workshops would also require patients to reflect on potentially distressing and difficult experiences of treatment, so minimising any further distress was vital. Therefore, it was decided that the early prototypes of this research may be inappropriate to demonstrate to patients without first refining the prototypes and the content within them with medical professional participants' input.

7.2.1. Multidisciplinary Group Members

As a result of the ongoing work of this thesis, the University of Strathclyde had formed a strong collaboration with the Queen Elizabeth University Hospital (QEUH), Glasgow. This was in the form of a multidisciplinary group (MDG) consisting of digital health, management science and human-computer interaction academics and clinical experts including nephrologists, vascular and transplant surgeons and research fellows. Participation was discussed beforehand during regular fortnightly supervision meetings, with four individuals (3 male, 1 female) confirming their participation in workshops. Participants recruited were of varying age, level of education, employment positions, and degrees of computer literacy. However, these participants are regarded as "experts" in their fields, with professions as listed later in Table 7.1. Participants were all involved in ongoing CKD mobile health interventions and analytics, but are associated with one or more of the following various institutions or faculties:

- Department of Computer and Information Sciences, University of Strathclyde, Glasgow
- Usher Institute, College of Medicine and Veterinary Medicine, University of Edinburgh, Edinburgh
- Glasgow Renal and Transplant Unit, Queen Elizabeth University Hospital, Glasgow

Although potential participants were already aware of the study, they were all contacted through email with full details of the study including a patient information sheet before requesting participation.

7.2.2. Workshop Participant Recruitment

Participation in the studies was completely voluntary. No pressure or incentive was applied to encourage participation. Ethical approval was granted by the departmental ethics committee for Department of Computer and Information Sciences, University of Strathclyde (ID numbers: 1131, 1319, 1582 and 1791).

Medical professional participants, namely vascular surgeons, nephrologists, and dialysis nurses were primarily recruited via distribution word of mouth via peers within the MDG and via their regular multidisciplinary meetings.

7.2.3. Materials and Methodologies Employed

MDG and Show-and-Tell Session. MDG participants had previously discussed possible visualisations for patient pathways in regular MDG meetings and the concept had been raised in earlier work (Bouamrane et al., 2019; Meiklem et al., 2021). They were all provided with a dataset of haemodialysis patients and changes in their vascular access (VA) use during their first year of haemodialysis (sourced from previous study (Murray et al., 2018), see Figure 7.2).

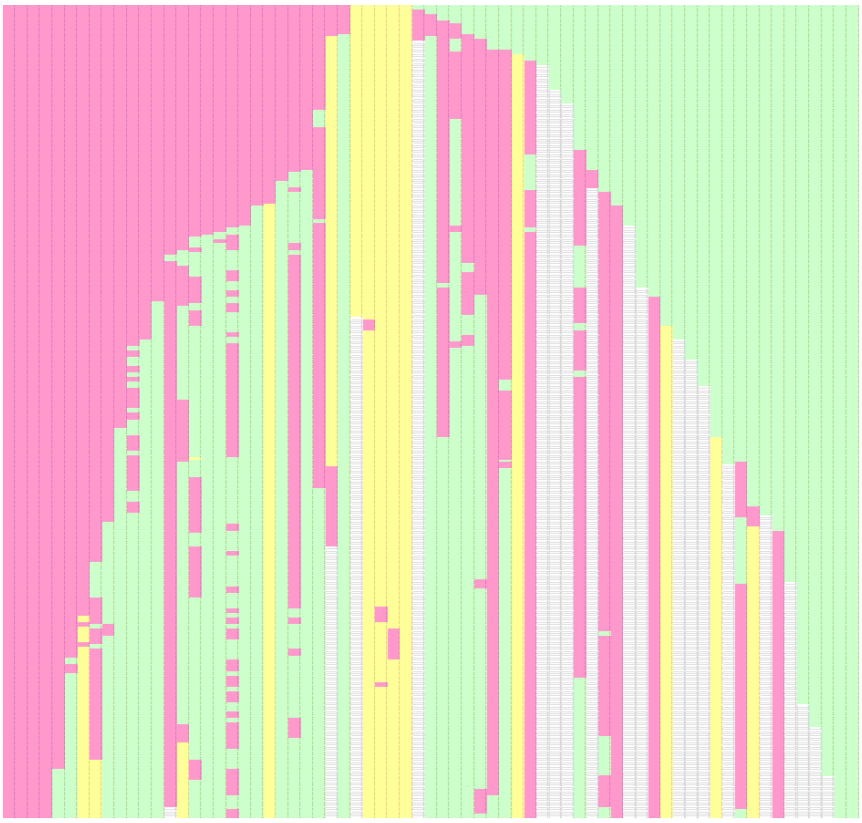


Figure 7.2: Sample of 365 days on RRT data provided to MDG members.
Patients are plotted horizontally across top of diagram and VA for each day plotted vertically downwards from Day 1 to 365. Pink = CVC (line), yellow = AVG (graft), green = AVF (fistula), grey/blank = censored (death or change in renal replacement therapy (RRT) modality e.g. transplant).

Participants were instructed and provided a brief on creating visualisations prior to the study. Instructions specified visualisations should show:

- all the various vascular VA methods included in the dataset provided (i.e. fistula, graft, catheter)
- movement of patients between VA methods and justifications (e.g. patients shifting from a fistula to a catheter because of an infection).

- number or proportion of patients who start with each access and how many are using access after 365 days

MDG participants were informed they could use various mediums and techniques, from paper and pen sketches to digital designs. The only constraint was they must be able to show and present their visualisation effectively over a videoconference call e.g. a PowerPoint slide or a digital image. The videoconference platform Zoom was used to host a "show-and-tell" workshop. Participants were asked one by one to present their visualisation to the others via the screen sharing function, followed by an opportunity for others to give feedback and thoughts or ask questions. The first author (Meiklem) was responsible for facilitating this session and ensuring all participants had the opportunity to present their visualisation and engage in the discussion, as well as limit time spent on one individual visualisation and prevent one or more individuals controlling or leading the session. Participants made use of the chat feature and Internet access to share relevant publications and other information sources in real-time, and annotations on screen-sharing to make changes or recommendations to visualisations. Participants were not required to submit a design to attend. Three designs were submitted at this stage (see Figures 7.3, 7.4 and 7.6 in the Results section).

Workshops: Stakeholder Opinion on Patient Education Experiences and Prototype Evaluations. Following the initial session within the MDG, two high-fidelity prototypes for a patient education application (focusing on visualising treatment pathways) were produced based on design requirements elicited from discussions and reference to the designs showcased within the session (Figures 7.7 and 7.8). To evaluate these prototypes, co-design workshops of stakeholder groups were chosen, utilising the high-fidelity prototypes as probes. Group interactions lend the method well to co-design with discussion between participants encouraged, including questioning one another or commenting on others' views and opinions. Co-design workshops are an established method in qualitative research and can be held online via videoconferencing platforms such as Zoom, with various co-creation tools and functionalities available that can replace the whiteboard and flipcharts used during in-person sessions (Cesário & Nisi, 2021). The groups consisted of participants in the same role (i.e. surgeon, nephrologist and dialysis nurse) and would aim to stay within 4-6 individuals where possible (including researchers) (Dodds & Hess, 2020). All attending participants were asked to complete a demographic questionnaire prior to the session.

To further inform the context of the proposed intervention, experiences of patient education were elicited through open-ended questions and prompts in a "post-it" note exercise. The first two exercises asked in the contexts of patients first beginning and then changing treatment: (1) what patients want to know, (2) where patients find information and (3) what should patients know then (i.e. at the stage being discusses). The third exercise then asked for someone about to start treatment, what would be the one thing participants would want them to know (i.e. key or important information). These exercises sought

investigate the participants' experiences of CKD patients accessing and understanding information, both when beginning treatment and during ongoing treatment. This was an opportunity to gather design criteria without bias from being exposed to the prototypes and allowed participants to understand the setting of the work. The exercises also allowed participants a chance early in the session to unburden themselves of points, issues or experiences they wished to share, to avoid them resurfacing in later discussions focusing on the prototype probes (Adams & Cox, 2008). Participants were free to discuss these prompts in their groups, either audibly or in the chat feature, while adding "post-it notes" to the shared screen via the annotation feature of Zoom.

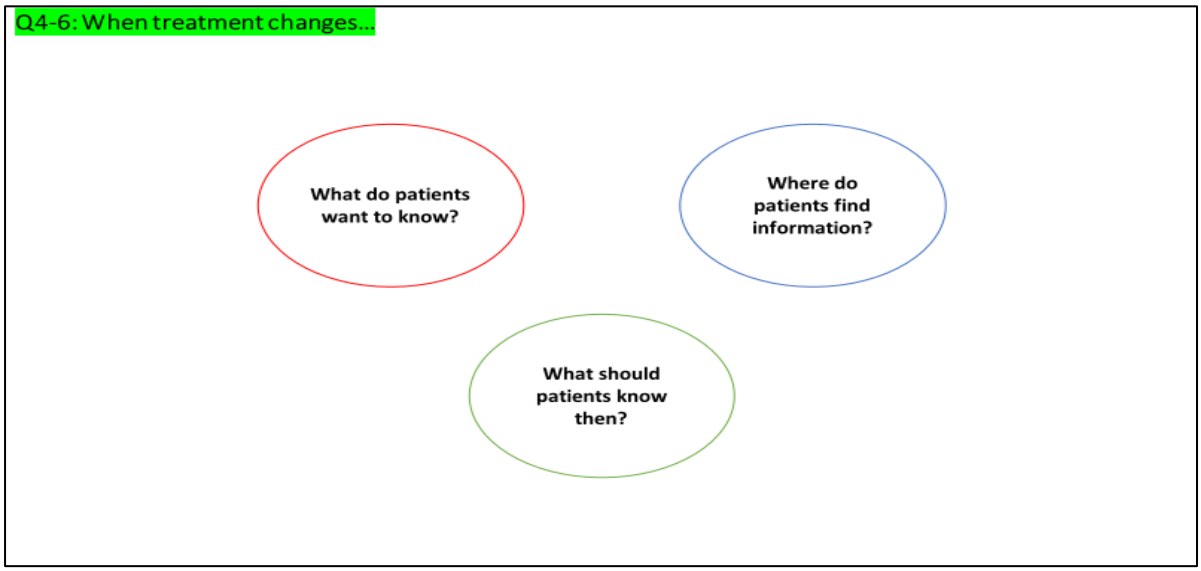


Figure 7.3: Screenshot of PowerPoint slide with second set of prompts

Following the previous phase, participants were then shown narrated video demonstrations of the two prototypes. Following each demonstration, participants were asked to provide feedback or discuss the prototype shown openly. To prompt feedback, participants were shown three prompts: "Keep, Lose, Change", and asked to annotate on slides under the relevant headings as well as discuss. As both are high-fidelity prototypes formed via slideshow presentation software, participants were provided opportunities to revisit the designs or see demonstrations again.

7.3. Results

7.3.1. Participant Demographics

The MDG "show-and-tell" session consisted of n=4 members, from which two prototypes were produced and used as probes in further stakeholder workshops. These members included a general consultant and transplant surgeon (P1, female), a vascular consultant and renal transplant surgeon (P2, male), and two senior lecturers, experienced in mobile usability and HCI (P3, male), and digital health and health systems respectively (P4, male).

There were four stakeholder workshops in total: one for surgeons (n=3), one for nephrologists (n=4) and two for nurses (n=3 and n=2 respectively). The average age of the cohort was 46 years (range 41 to 59), over three quarters (81%) were female and the average number of years of experience with CKD patients was 18.4 (range of 7 to 38 years).

Table 7.1: Demographics for Participants of Co-design Workshops

Workshop (Stakeholder Role)	Participant ID	Sex	Age (yrs)	Self-described Occupation	Experience with CKD Patients (yrs)
S1 (Surgeons)	S1	M	46	General, Transplant and Access Surgeon	10
	S2	M	43	Consultant Transplant and Vascular Access Surgeon	9
	S3	F	41	Consultant Vascular Access and Renal Access Surgeon	7
Ne1 (Nephrologists)	N1	F	44	Nephrologist	15
	N2	F	41	Consultant nephrologist	15
	N3	M	42	Consultant nephrologist	12
	N4	F	41	Medical consultant	13
Nu1 (Nurses)	Nu1	F	44	Vascular Access Clinical Nurse Specialist (CNS)	22
	Nu2	F	48	Renal Vascular Access Clinical Nurse Specialist (CNS)	23
	Nu3	F	59	Renal Vascular Access Clinical Nurse Specialist (CNS)	38
Nu2 (Nurses)	Nu4	F	52	Vascular Access Nurse	27
	Nu5	F	51	Senior Charge Nurse	30

7.3.2. MDG Prototype Designs

The MDG "show-and-tell" session resulted in three designs being pitched to the group. Two were static low-fidelity designs, one designed digitally (Dunlop, P3) and the other via traditional paper-and-pen (Meiklem), while the third design was a high-fidelity prototype, designed using slideshow presentation software (Kingsmore, P2).

The first shown was the high-fidelity prototype by Kingsmore (Prototype 1, see Figure 7.4), which had taken the brief provided and gone a further step to produce a design that was able to demonstrate the provided dataset more dynamically than that of the other two. Kingsmore had much more experience

and familiarity with the topic and therefore could interpret and expand on the data shown in more detail. As a result, Prototype 1 resembled a completed system, with multiple pages and seemingly interactive elements, such as navigation buttons. It demonstrated the use case of investigating possible treatment outcomes after inputting variables such desired start time, transplant potential and preferred timescale for starting treatment. Prototype 1 also displayed likelihood of outcomes in fractions (e.g. 2/10, 4/10) and utilised visual elements to convey further information, such as icons (i.e. red question mark) or width of the flow arrows between treatment outcomes (arrow becomes wider as odds of complication increase from 2 in 10 to 4 in 10).

Figure 7.4: Screenshots of high-fidelity Prototype 1 produced by Kingsmore.

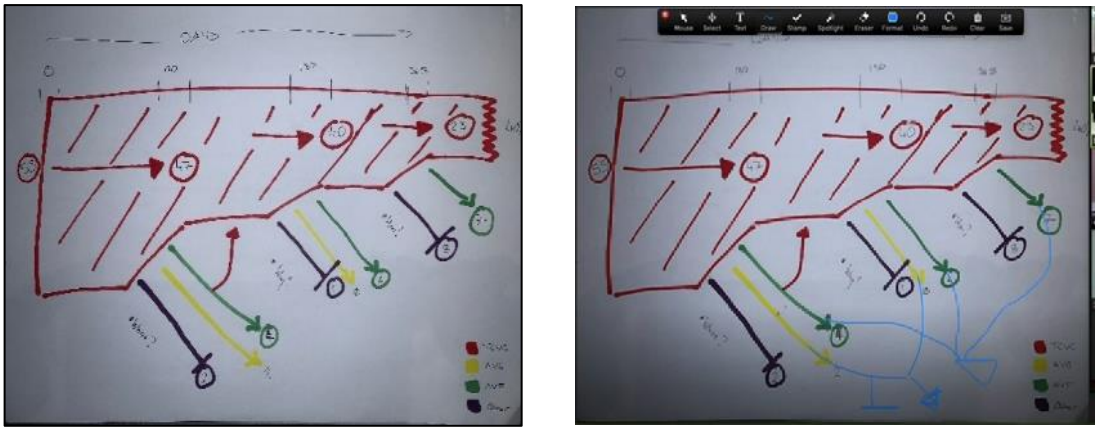


Figure 7.5: Screenshots of Prototype 2 produced by Meiklem and annotations.

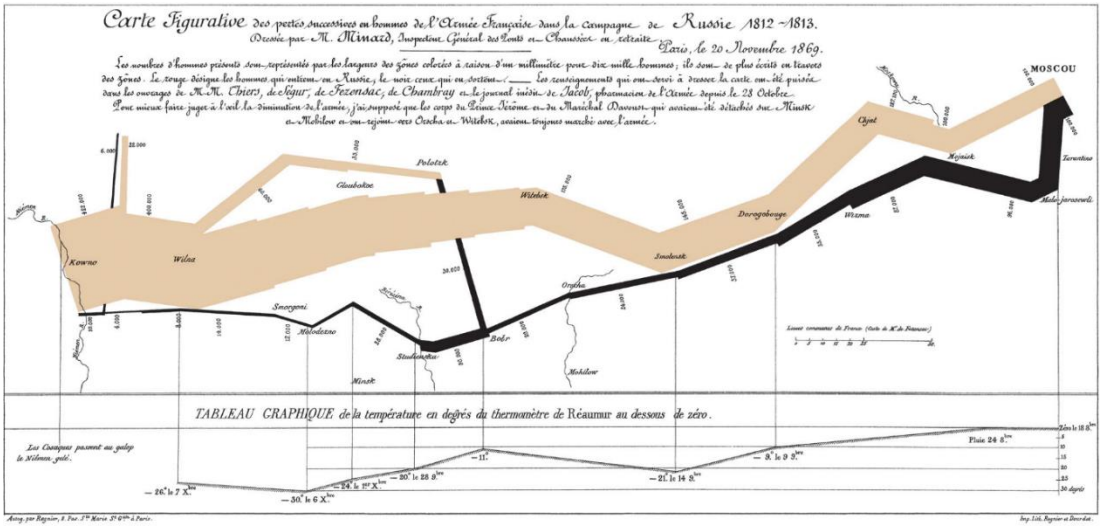


Figure 7.6: Charles Minard's map from 1861 “Carte figurative des pertes successives en hommes de l'Armee Française dans la campagne de Russie 1812–1813” or “Napoleon’s March on Moscow”.

In contrast, Dunlop and Meiklem produced single page static designs, attempting to convey the dataset in a single visualisation. Prototype 2 by Meiklem (see Figure 7.5) was inspired by *“Carte figurative des pertes successives en hommes de l'Armee Française dans la campagne de Russie 1812–1813”,* or “Napoleon's March on Moscow” by Charles Minard from 1861 (Figure 7.6). The Minard map was able to display many variables and demonstrated the size of the army on different paths through the width of the bands, which Prototype 2 seeks to replicate. The graph displays the number of patients using the selected treatment as width with annotations at key time points and branching paths below for different VA or other outcomes (i.e. transplant or death), with some cycling back to the original treatment.

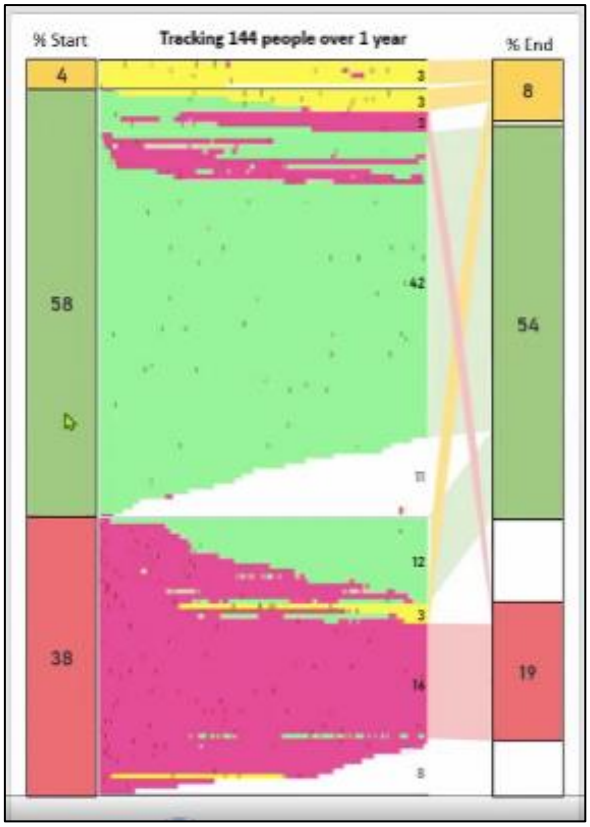


Figure 7.7: Screenshot of Prototype 3 produced by Dunlop.

Prototype 3 by Dunlop was also a single static design, opting to show the number of patients starting on the different VA through percentages and changes in colour to represent where a patient shifted in their modality, much like the original dataset. Towards the end of the year, the visualisation shows the new percentages of patients on each access and then redirects these respective colours so the viewer can see the percentage of the total for patients starting and ending on each access. This final section resembles a Sankey diagram, with ribbons of colour overlapping to reach the right section.

7.3.3. Refined Prototype Designs

Finally, Kingsmore and Meiklem produced two further prototypes (Prototype 4 and Prototype 5 respectively, see Figures 7.8 and 7.9) in presentation software (Keynote and PowerPoint respectively) following the MDG discussion – both high-fidelity in nature to allow the workshop participants to perceive the probes as mobile applications, with icons for navigation (e.g. home buttons) as well as other shared elements. Both took the concept of a patient journey from Prototype 1 forward, with Prototype 5 presenting this from bottom-to-top, and Prototype 4 vice versa. They both also utilised restroom icons (i.e. male and female people symbols) to represent the likelihood of outcomes, with each icon representing one patient. Changes in icon number or colour represent changes in outcomes or treatment modality. Finally, both prototypes demonstrated changes in likelihoods at different time points, notably 3, 6 and 12 months.

Figure 7.8: Screenshot of Prototype 4 produced by Kingsmore.

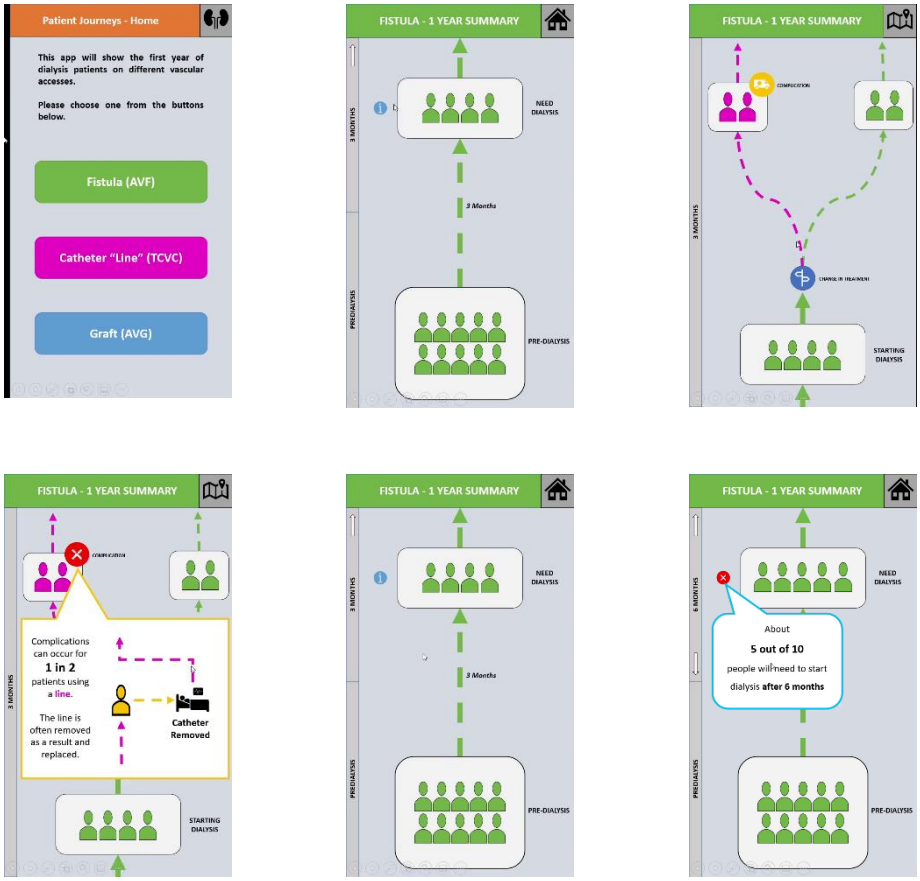


Figure 7.9: Screenshot of Prototype 5 produced by Meiklem.

To promote discussion, the prototypes did differ in some respects. Prototype 4 continued the approach of Prototype 1 by including potential input options to calibrate the information shown (i.e. Where are you now? How far do you want to go? Is there a transplant option? What way do you want to go (access)?) and would use these variables to demonstrate the likelihood of all VA being available and successful in 1 year, not just the chosen modality. However, Prototype 5 had a menu limited to three

options (graft, fistula or line) and only focused on the access chosen than provide an overview of all possible modalities. Prototype 5 also made use of icons to indicate further information (e.g. signpost for change in pathway or ambulance for possible complications) to supplement the visual data, rather than text.

7.3.4. Framework Analysis

This section details the results of the framework (Korhonen et al., 2016) analysis, compiling the topics discussed by the participants under five key concepts defined by the modified framework (competence, patient-centredness, support, technology and uniqueness) and the themes they each encompass. This framework was also utilised during the scoping review of patient-centred and technology-based interventions supporting patients with high treatment burden, and its use again at this stage will allow comparison with the other systems from the literature and how the five concepts were fulfilled. The framework used at this stage reflects the additions and modifications made during the scoping review (fully described in section 3.7.3 under heading Thematic Analysis).

The transcript and outputs from each workshop were analysed together rather than separately, to identify common themes and ideas from all stakeholders, while also identifying where some stakeholders provided unique themes and concepts or did not address those common in the other groups. To analyse each workshop session separately would provide rich and unique results but attempting to synthesise all of these outputs into design requirements the community as a whole require would prove more complex also.

The process of thematic analysis involved repeated listening and reading to ensure accuracy (of transcribed data e.g. audio recording of co-design workshop) and understanding of the data. Instances of data that were consistent with or related with themes of utilised framework were coded using the NVivo software (Dhakal, 2022) to the relevant concept. The coded data within each concept was then examined separately and where suitable, synthesised into recurring themes and topics to create original subthemes. Original themes and other amendments to the original framework will be defined as such.

Table 7.2 details a summary of design requirements and app functionalities with their source and related themes from the framework analysis, in the following section.

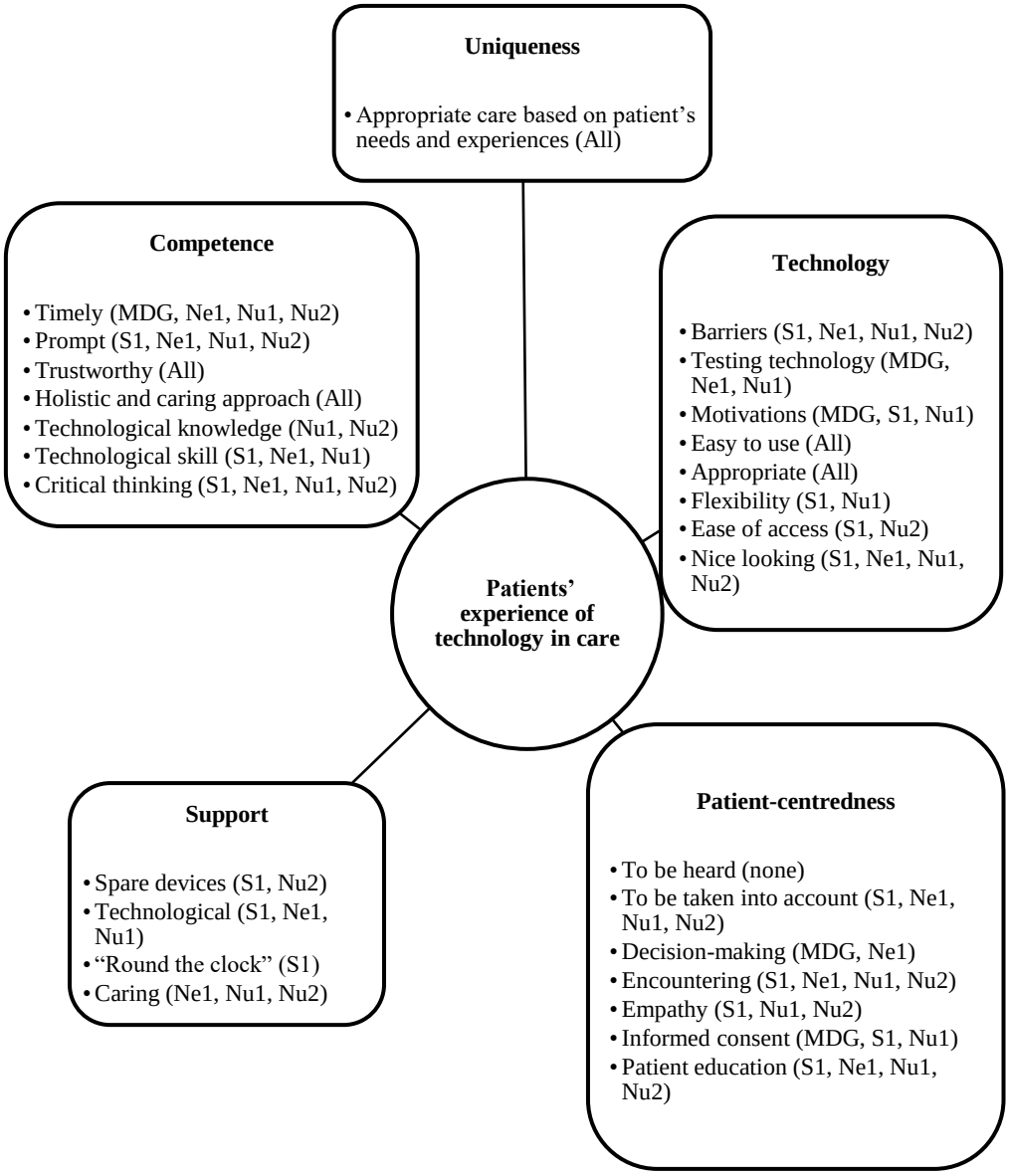


Figure 7.10: Prevalence of themes across workshops

7.3.4.1. Competence

The theme of competence covers a range of views related to how care delivered in the context of technology can be competent. This includes aspects of care such as timely, technological knowledge and skill, critical thinking, promptness, holistic and caring approaches and trustworthiness.

Timely: Timely refers to the provision of information and care in a timely manner. In the workshops, this primarily concerned nurse participants preparing patients for possible outcomes and complications with early workup and discussions. This included making patients aware their kidney function may deteriorate and starting dialysis will be required, with earlier workup and plenty of time to prepare. This was first discussed in the MDG session, where P1 noted patients tended to cope better with known potential risks, rather than unexpected problems (e.g. routine maintenance appointments versus acute or urgent admissions).

"The other thing is that actually, people cope better with things they've been aware of as potential risks as opposed to the things which come unexpectedly." – MDG Member P1

The timeline of the prototypes' treatment journey was also the focus of discussion around long-term planning, as the timescales displayed were often criticised or questioned. Nurse participants discussed similar experiences and suggested the patients would be more interested in overall outcomes, than those at various stages such as 3, 6 or 12 months and that they may interpret these outcomes literally or as certainties, so generalisations and approximations need to be made clear.

"I think so. I think so because they can then choose what they want to look at and that's where, where would it be in six months or a year."

"As long as they don't take it literally you know." – Nurses 4 and 5

Technological knowledge: Technological knowledge refers to knowledge of technology and its uses within care. For example, online and technology-based sources of patient information included search engines (i.e. Google), websites and PatientView, a patient portal where patients primarily review test results. However, Nurse 4 was not aware of any online information resources they would recommend to patients and doubted there was a single reliable resource, as patients often encountered the "worst case" or inappropriate information online (such as bulbous fistula images, representing the worst-case outcomes).

"Some don't even have smartphones, all they use the phone for is making phone calls and they very rarely text, never mind anything else. So they're not going to pick up an iPad and or a smartphone and do the app because they won't have it." – Nurse 3

"As to where they find information, I also think some of the younger patients, that we see now… they do actually all and do research on Dr Google and things and get information from there, which quite often isn't correct, and they'll find images that are horrendous." – Nurse 2

Nurse 2 noted this behaviour more common in younger patients, who are more familiar with online resources, with most patients being less familiar with technology and therefore unlikely to access and utilise resources like the proposed prototypes. This raised concerns about how the proposed intervention would be received and utilised by the typical demographic of CKD patients.

Technological skill: Technological skill refers to any skills utilising technology in a care setting. Again, the potential lack of skills in the user demographic was discussed, with concern over how much interaction was required to utilise the app fully, particularly with complicated gestures such as swiping and clicking various user interface elements. When probed about the complexity of the refined prototypes interfaces, Nephrologist 1 noted that some level of interaction would be required, as "that's how apps work". Nurses 2 and 3 also shared this sentiment, noting that those who will use the application would likely be familiar with technology and such interactions.

"No, I think the people that will use this app will be used to the technology where you do take that, buttons and go to different places to see things and come back in and out." – Nurse 2

Despite the general feeling that less familiar and older patients would struggle to engage with the proposed systems, participants noted younger and more professional patients would be interested. Nurse 2 in particular considered the growing familiarity with technology and how patients would become more familiar with the intervention if implemented. However, as previously discussed, this cannot be seen as a final solution and alternatives must be made available as well (Ashley et al., 2013; Basch et al., 2005; Basch et al., 2009).

"I think that depends on your patient demographic. I think if you've got young professional patients coming in, that's going to be really interesting to them." – Surgeon 3

Critical thinking: Critical thinking was primarily concerned with examples of adapting treatment and information delivery to individual patients. Stakeholder participants explained having to determine treatment options based on patient's characteristics and variations, which requires medical investigation to determine the suitability of VA modalities and often surveillance as well. Even then, they are unable to predict how a patient will respond to dialysis until they start. Those already established on dialysis are more limited in their options and so earlier workup and planning are recommended to avoid reaching such situations. This highlights the difficulty in delivering relevant information to an individual patient, and why CKD information provision often needs to be broad and generic initially without knowing certain variables.

"So I think in those cases which is a judgment of course you know, depends on who you have in front of you in clinic. In those cases I prefer to explain the basics. Even if it's about the risks I stick to the basics like you know very basic stuff: you may bleed, it may get infected, it may fail, it may not work as expected." – Surgeon 2

Nephrologist 2 stated patients will often have a "Plan A" and "Plan B"; however the latter is typically expected by providers to be put into place eventually, and for younger patients, having a plan spanning 20 to 30 years can be reassuring. Again, the delivery of information too requires some critical thinking and tailoring to the individual patient, with one surgeon choosing to keep to the basic and practical information of treatment in initial discussions, to prevent patients from becoming overwhelmed. The implications for the intervention proposed are the need to provide broad information in a basic and understandable format, before progressing to more specific and detailed levels of information.

"It's a little harder at that stage as their options are often trickier so I think it's also about earlier work up and earlier discussions than we often embark on." – Nephrologist 2

"I think it's a hard thing [reaction to dialysis] to predict other than you know, looking at it. But again I've seen throughout my career different experience of unique starts to dialysis. Just looking at the numbers, you need to start dialysis...." – Nurse 5

Prompt: The theme of prompt could be considered to be concerned with immediate response or reaction to a change in care or information, in contrast to the themes described earlier regarding preparation over time. The best example of this from Nephrologist 1, where a patient may "crash-land", requiring immediate renal replacement therapy and a prompt and effective response from providers in.

"Yeah and also you know if somebody's "crash-landed", you know what are their options? What's going to work for them straight away?" – Nephrologist 1

Other examples of prompt focused on provoking or prompting patients. For example, patients should be questioning their consultants in consultations or nurses in the clinic about treatment, encouraged and provoked by providing new and broader information via the intervention.

"But this is this the whole thing about this app is it needs to provoke questions and hopefully answer quite a lot of questions as well. But the idea is that you have that conversation in the clearance clinic or in haemodialysis with your patient, they go and use the app and they come back armed with the questions that they want to ask." – Nephrologist 4

Surgeon 1 noted patients often ask more questions about the practical implications of their treatment, such as how to handle emergencies (e.g. bleeds from VA, not feeling the "buzz" in their graft", etc.) and the appropriate response or support to contact in these situations, while Surgeon 3 also described patients asking questions about the need to change their treatment where a lack of communication or

information occurred. Other suggestions included how the intervention could prompt patients to be aware of monitoring their symptoms and VA, as part of their self-care. Therefore, a resource such as the proposed system should provide patients with the information to provoke their own follow-up questioning and self-care activities.

"But I think patients, and maybe I'm being a bit paternalistic here, patients probably want to know: what happens if I get what do I do if I get a big bleed? Um what do I do if the fistula clots off or I can't feed the pulse in my graft anymore?" – Surgeon 1

Holistic and caring approach: Several subthemes were discussed which together form a holistic and caring approach. The preference and priorities of patients need to be considered, with treatment built around the individual. For example, factors such as preferred treatment times (e.g. due to responsibilities as a parent) or leisure activities, namely swimming, should be factors in decision-making and included in information resources. The MDG session discussed this around the topic of the Montgomery Judgement (Montgomery v Lanarkshire health board (Campbell, 2015)), a landmark case that saw the emphasis of medical decisions and information provision shifting from what the clinician considered relevant to what the patient feels is relevant to them. This was described as needing to tell patients everything, no matter how relevant or likely it may be to their situation. This resulted in suggestions for the intervention to include ways of factoring in preferences to the information displayed, such as toggling whether the patient is willing to attend frequent observations and maintenance and demonstrating the trade-off clearly.

"So you know the important things to patients are you know: is this going to affect my work, for example, is this going to affect me going swimming on holidays …these kind of things and I think having that sort of almost like a separate page with quite, you know answering some questions about access, like me." – Nephrologist 4

Patients place great value on their lifestyle being maintained or minimally disrupted by the VA they receive and so, some patients opt for the modality they are familiar and comfortable with over something new or more viable in the long term (e.g. the practical ease of a line versus the potential effectiveness of a fistula). Nurses 4 and 5 also discussed patients feeling unwell and how they considered this to be normal or their baseline until they began treatment, surprised at how good they felt in a few weeks. They also noted how female patients preferred VA that could be concealed below skirts, reducing the impact on their body image. Points like these should also be included in information resources, to highlight the positives of RRT and how quality of life can be improved.

However, patients established in treatment and certain VA modes are more limited in their options at the later stages and can often have operation fatigue or reservations based on prior negative experiences, as well observations and interactions with other patients during treatment. Again, earlier work up with

patients, notably utilising information regarding failure rates and impact one treatment modality may have on the viability of others should be clearer in early stages of information provision.

"Because they've got operation fatigue, who wants to put themselves into constant surgery? it's just constant trauma for them." – Nurse 2

Patients also have support networks which need to be considered and respected. Family should be included in discussions to keep the social circle informed, which can also encourage live kidney donor transplantation, and the concept of the intervention would allow patients to take something home to their families, to discuss or investigate information together. Patient peers also need to be considered carefully, as patients will see and observe their peers regularly, often witnessing their negative complications and treatment, which will impact their own perceptions. However, Nurse 2 did note younger patients often found it hard to relate to their typically older dialysis peers. During the nurses workshop, the topic of child-to-adult patient transitions was also raised, where they discussed the need to tailor their information to an individual who may have lived with the condition for many years already but now must take on the responsibility and understanding of their condition as an adult, as the parent would have done. Patient peer opinions or testimonials should be included as possible sources of information in the intervention, with the potential to allow subgroups of patients (i.e. younger patients, child patients transitioning to adult, etc.) to find experiences of others they can relate to.

Tailoring communication is the final subtheme but was first mentioned in the MDG session, with providers needing to consider a patient's understanding and intake of information. Topics such as risk are difficult to explain and so some providers try to discuss these at the most basic level, but overall find their delivery is not standardised given the level of detail in the information. P1 described patients not understanding or assessing odds and risks well (e.g. 2 in 10 patients will develop a complication) and so visual representations were viewed as more effective, such as counts of restroom icons where 2 of the 10 people are coloured differently to demonstrate the frequency. Further talks also noted the issue with current resources, namely paper leaflets, where each treatment modality is described independently of others and so, it is difficult to see how they differ and interact. The surgeons group reiterated this discussion and noted quoting numbers as "pointless" if it appeared the patient was unable to understand the meaning behind them. This again reiterates the need for a source of information patients can investigate and interpret in their own time.

"We provide a whole lot of really detailed information it's not done in a very standardized way we're not very good at talking to patients from different backgrounds, so they then go out and find their own sources of information." – Surgeon 1

Trustworthy: The topic of trust was raised often, typically by providers who emphasised the need to build and maintain trust with their patients. Surgeon participants cited managing expectations of patients to maintain a positive relationship while nurses discussed the relationship or bond they build through

frequent contact with patients, described as closer and more trusting. This relationship can be vital for effective patient-centred care and so technology must supplement it, and not seek to replace it. Nephrologist 4 commented on this point by recommending that it was not the interventions place to tell patients what their prognosis was, and that patients should still be having discussions with their providers if such an intervention was implemented.

"You got to manage their expectations at the start otherwise it's going to be a disaster. They lose faith and they're potentially going to be in your service or you're in their service for 20 years. And if you lose if you lose the fight at the start because your 1.8-millimetre wrist fistula fails, it's not going to be a happy relationship." – Surgeon 1

Providers are also aware that patients will trust first-hand accounts from their peers over the presumed "sugar-coated" information provided by clinical and nursing staff. Nurse participants stressed finding the balance between being honest, without "sugar-coating", but also not terrifying patients with the reality of treatment. The subject of death needs to be included and not omitted from information as well as the positives and negatives of all treatment options. The surgeon participants also discussed this at length, with reference to the legal requirement to explain all available options as a result of the Montgomery v Lanarkshire health board (Campbell, 2015). This will require the intervention to provide information in a similar format, ensuring content is balanced and all positives and negatives are clearly described.

"I also think, we talk to patients -it's really important to be honest with them, not sugar-coat and not make it terrifying, at the same time." – Nurse 2

Finally, as discussed prior, patient peers can sway patients' decisions and perceptions of treatment, even with established patients and their compliance with treatment. This was compared to how reviews of a product inform the decision to purchase or not and raised the suggestion for including peer reviews and testimonials within patient education resources.

7.3.4.2. Patient-centredness (originally Respect of Human Rights)

The concept of "respect of human rights" refers to how technology-based care respects the dignity of patients. This includes patients being able to be taken into account and be heard, encounter and receive empathy from their providers and other aspects of patient-centred care such as informed consent, decision-making and patient education.

Patient education: This theme was the most discussed topic across all workshops, which is not surprising given the purpose of the proposed intervention. The difficulty with patient education is the personal needs and individuality of each patient, with differences in circumstances (i.e. slow decline or "crash-landing" into renal replacement therapy, need for investigations and operations to gauge factors such as the size of veins, etc.). Learning styles and preferences also make delivering the large volume

of standardised information in a suitable and effective manner for each patient difficult. Even so, providers must also make the patient aware that while an outcome may be likely for many people like them, it may not be the case for them. Some patients will also be unable or unwilling to intake large volumes of information and instead choose to rely on their consultants' experience, while others may have other priorities, such as maintaining their lifestyle. Therefore, staff often need to adjust and tailor how they educate patients based on their understanding and retention of information, such as describing the outcomes of risks rather than quoting numbers to older frailer patients.

"I mean the vast majority of the information I give to somebody in clinic they haven't a baldy notion about that. If you try and recall it when they leave the clinic and the vast majority of information that patients forget…" – Surgeon 1

This strategy was also proposed for the content of the app, with a simple overview and summaries initially shown with options to investigate further if the patient wished to do so. Referred to as "drilling down" in detail, this would allow patients to build on a basic level of understanding and information but did not overwhelm them by trying to provide it all at once. Nurses, nephrologists and surgeons noted the benefit of a multidisciplinary and dynamic process to information provision, as long as the information was given was consistent across sources. The pathway elements of the prototypes were praised for showing treatment as a journey, a relatable concept for patients to consider how their treatment will have steps, stages and changes in route as they progress, rather than a "snapshot", posed as a one-off solution or cure to their condition.

"The idea, the thought I had was to have it fairly skeletal centrally, let people build up according to what way they wanted to see it." – MDG Member P2

In terms of the content provided, participants noted patients would often look for practical information and ask how their treatment will impact their lifestyle, such as their career or hobbies. Some questions asked by patients may seem specific or narrow in scope (e.g. how long an access will last, what happens if they get a bleed, etc.) but concern the areas of their treatment and life they place value upon or have responsibility to act. Participants noted it was best to prepare patients with respect to these factors and consider the best VA modality to fit with their lifestyle. Caring for VA was also a suggested topic to add, notably the practical things patients can do outside of dialysis to monitor their access and ensure it continues functioning as expected.

Meanwhile, the content of Prototypes 4 and 5 shown to staff participants was heavily critiqued as overly negative, with additional information on complications and little else. Other examples of inappropriate and unbalanced content were unfamiliar language and terminology (e.g. referring to lines as catheters, use of abbreviations or VA as 'treatment') and overuse of numbers and mathematical symbols (i.e. greater than '>' and less than '<'). Nurses described issues with online sources of information, with patients often encountering graphic images of fistulas or viewing information which may be

inconsistent with what they are told. Patients may experience similar biased sources with patient peers, typically seeing the disfigurement and complications of fistulas on dialysis while the complications of other VA are less obvious.

"For me there's the language. Because we're talking about grafts, we're talking about fistulas but we're writing things on the screen like AVF, AVG, TX. We're talking in a medical language on the screen, not in patient language." – Nurse 2

Suggestions to improve the content of the prototypes included including summaries of the pros and cons of each VA, even if one is less viable than another, and also including mortality risks. Nurse 3 commented on the limited content of the prototypes, noting further practical information should be included to explain what complications could occur and what will happen as a result of the given complication (i.e. procedures, outcomes, etc.). There would also need to be disclaimers noting the generalisable nature of information, given the variety of circumstances and factors that influence a patient's treatment, including how they start renal replacement treatment (i.e. slow decline with preparation or "crash-landing") and previous VA and treatment (e.g. operation fatigue). Preparation and planning are important elements of the patient education journey but with patients who require immediate renal replacement therapy, time is limited, and it is less effective. Where possible, early workup and warning of possible outcomes can reduce patient frustration and manages their expectations, given how providers cannot exactly predict how any one individual will progress once they start dialysis. Alternative plans are also useful but are expected to eventually be utilised rather than considered as purely alternatives. Stakeholder participants spent time discussing how interested patients would be in the possibility of when they would start dialysing (e.g. 3 in 10 people with a fistula start dialysis after 3 months), often agreeing patients would not need several options to select from and would prefer a general timescale, such as 1 year.

"I think in the patient journey, it's always helpful to have Plan A and Plan B because they're always going to need their Plan B and even if you don't need it for 20 years, it's always good to have a Plan B!" – Nephrologist 2

The use of visual representations of risk and outcomes in Prototypes 4 and 5 was praised, with the icons of patients helping aid understanding of how likely or unlikely outcomes are in place of numbers or percentages. Some critique was given to the colour choices for VA, with green being applied to fistulas and red for lines, possibly subliminally influencing the patient with the common association green is good and red is bad. The pathways themselves were generally appreciated as a representation of the patient journey but some preferred the final summary or overview than trying to follow the pathways as they moved along a timeline.

There was a large amount of value given to patient peers as a resource, given how much they can influence a patient in their decision-making and even compliance with treatment. As discussed, patients

can also infer information simply from viewing their peers and Nurses 2 and 3 agreed the prototypes needed some element of patient testimonial to retain perceived value.

"So, sometimes as Nurse 2 was saying, they do Google but a lot of times its word of mouth. I know before COVID, when patients are predialysis and they got shown round the dialysis unit, they would speak to patients and ask them, how it was for them: what it's like on dialysis? What the surgery was like, and they would take everything in, they'd be looking at machines, they'd be looking at people's access. So a lot of from patients as well and people that they know outside." – Nurse 1

Given the overall opinions regarding effective patient education, the concept of the intervention was welcomed by the participants of the workshops. It would act as a further source for patients to refer to and prompt them to question their healthcare team and would meet the need for a validated resource that providers could refer patients to. The interactive nature of a digital resource overcomes the physical limitations of paper-based information, with many static pages required to convey the same information as a single screen. There was discussion around the merit for a medical education tool version as well during the surgeons' workshop, giving the intervention further support.

"Yeah I know it's great, fantastic thinking of vascular access in this sort of way. It's forgotten about a lot of the time and this is a great initiative, so welcome." – Surgeon 1

To be taken into account (*and to be heard*): Patient involvement and input were discussed in regard to the delivery of healthcare, namely the further evaluation of the prototypes shown to participants. Nephrologist 4 recalled patient involvement in the design of a new dialysis unit, citing those involved as insightful.

"I think you need to get some patient views on it. I don't think it would do any harm, you know they'd be the ones that would be telling you 'Yes I can use it, that information is too blunt, that information is too harsh, I don't want to know that, or I do…'" – Nurse 3

"Yeah, absolutely we've got -so we've got a couple of patients involved in the new [location] rebuild, our build and the design of the unit and stuff and two patients in particular have been really really insightful" – Nephrologist 4

The nursing participants also inquired about patient involvement in the design and evaluation of the app, and their involvement was vital to secure engagement. This discussion was primarily centred around the inclusion of patient peer reviews and testimonials, but the participants also agreed that the content of the prototypes may need tempered before presentation to patients, as justified in the methodology. Surgeon 3 gave an example of where patients had not been informed about their change in dialysis, also highlighting the basic need to consider how patients will perceive change and keeping them informed.

"The reason I put that "why do I need to change", I come across that quite frequently in the cohort who come from PD [peritoneal dialysis] to hemo [haemodialysis]. So I do all of the scanning and planning so they come to see me as a first stop. And there's a couple of nephrologists here recently departed who were not awfully good at telling the patients so I very frequently got asked "why am I stopping PD, why do I need a hemo option" and so in that context it can be helpful". – Surgeon 3

"To be heard" was not a theme which was identified within this set of discussions but as this would likely come from the patient perspective (while "being taken into account" would be completed by clinical and nursing staff), this is not unexpected.

Decision-making: As described, the decision-making process for renal replacement therapy can be a complex and difficult decision, given the multiple options and routes of treatment available. The topic was first discussed during the MDG session, with the group debating over the intervention's purpose as a "calculator" that takes patient characteristics as input to determine the treatment and outcomes they will likely encounter, or as a support tool that provides a more generic overview. P4 noted that using any form of predictive modelling may work well for populations, but not for individuals, and therefore a disclaimer should be stated that the information shown was not unique to the individual but rather a patient similar to them.

"Yeah, I think we need to make that very clear that you know, prediction is not based upon that specific patient, but is a model of what would happen to a patient similar to themselves if you see what I mean." – MDG Member P4

The exercise of designing visualisations from the dataset also demonstrated the non-linear nature of CKD treatment, as patients often varied from VA modality despite what they started using. This was raised again later by Nephrologist 4, commenting on how patients can also change their minds and are not fixed on one path. The key outcome from the MDG discussion was that all possible pathways need to be available to the viewer, so they can see how each varies and the trade-offs each has. These discussions highlighted the potential the intervention could have in early discussions between patients and providers, encouraging shared decision-making with emphasis on the patient's preferences and desired outcomes.

"And I think also that you can change your mind as well. And I think that's important you know you're not fixed down one route." – Nephrologist 4

Informed consent: Primarily discussed by the surgeon participants, informed consent can be viewed as a dynamic process. Patients can be informed by different clinical and nursing staff prior to providing consent and will take input from other sources such as patient peers. Some patients will struggle to intake and retain information post-consultation, (especially risks and numbers as mentioned previously), so repeating information over time can be more effective. For example, Surgeon 3 described how they would inform patients of basics over multiple consultations, going into further and

complete detail at the time of the decision and then taking consent. However, Surgeon 2 noted this is not an option for themselves and their patients, due to the population size of their health board and limited staff resources. This variability in practice was also discussed, with the participants agreeing they aim to deliver the same treatment and care but do so in different ways.

"I think at that at the point of formal consent it's a bit different but at the point that you're looking at and undeciding options. My view is there's no point in quoting numbers at patients because it means nothing to them, they're the vast majority." – Surgeon 3

"Yeah but imagine you know if you consult someone for something extreme and extremely rare okay? But you have to mention in the consent form at the last minute just before they go into the operating theatre and they suddenly say: "what are you talking about?" You know so, that's so I totally agree with you, your approach I'm just you know stating the other side." – Surgeon 2

"I mean by the time a lot of these things have been covered, I completely agree. I think everybody has in their own way written that information giving is a dynamic process." – Surgeon 1

There was also the topic of the Montgomery v Lanarkshire health board case (Campbell, 2015) , from which consultants are legally required to explain all options fully to the patient to reach informed consent. The same would need to be true for any health information resource that would aim to support this decision-making and informing consent stages of treatment. This may result in patients selecting treatment which is not viable in the long-term but has benefits that suit them and their lifestyle. Decisions such as these would not be possible without shared decision-making and fully informing patients, again highlighting the potential for such an intervention to help facilitate these activities. Nurse participants also stressed how the content of the prototypes needed to include both negatives and positives, to allow patients to make such fully informed decisions.

"You can't make a choice unless you know the positives and the negatives. For some people that line is the positive. You may have no veins to help make a fistula and end up with eight operations! [laughs]" – Nurse 2

Empathy: The topic of empathy was often detected in discussions with nurses, who have the most contact with patients. This frequent contact allows nurses to build very close and trusting relationships with their patients. Other clinical staff participants also expressed empathy for patients, understanding their expectations and aiming to maintain the relationship they had. Returning to nurses' relationships with patients, they described patients' fear of dying and the difficult perspective for younger patients amongst their older peers.

"For younger people like that it's quite terrifying as well, because they walk into dialysis units and see lots of older people and suddenly they're having to be dealing with the fact that I could spend 12 hours a week with a lot of older people." – Nurse 2

Nurses cited trying to ease patients into treatment in order to reduce their anxiety and fear, giving them positive experiences at the start of treatment. They also aimed to reassure patients and remind them of the positives of their treatment, stating how dialysis and renal replacement is a journey, along which the patient will find they feel better over time. Resources such as the intervention could consider how to support patients in a similar manner, with emphasis on the journey aspect of dialysis and how to find support.

"You know the patient's nervous, you're nervous for them." – Nurse 5

Encounters: Encounters, referring to discussions or consultations between patient and healthcare provider, are most common and frequent between nurses and patients in dialysis units or wards as previously described. The relationship formed from this frequency of encounters is built on conversation and getting to know one another personally. Low-clearance (pre-dialysis) clinics were also discussed often, where patients with declining renal function attend often to discuss their condition and learn more about their treatment options with various staff, such as a nephrologist, specialist nurse and nutritionist.

"And I think we've got a great opportunity because we're seeing the patients so frequently. And we always, before we had a low clearance clinic, when we were established over [ward], when we had sort of community dialysis, we ran low clearance clinic alongside home hemo [haemodialysis] and PD clinic. So we gave a lot of the information before we had a CKD nurse." – Nurse 5

"We got to the stage during COVID and where they've been in, all these patients because we're having such difficulty getting access, the first time I met them was going into theatre." – Surgeon 1

The number of encounters patients have with clinical staff can vary given the variability of practice across units, typically due to limited resources or in recent years, social distancing as a result of the COVID-19 pandemic. However, Surgeons 1 and 3 agreed that the patient should be aware that the process of renal replacement therapy is a journey, and they will eventually meet again at some stage. Finally, nephrologist participants were keen to also include family and caregivers in consultations, not only to keep the wider social circle and support network informed but also to promote the idea of live donor transplantation.

"But the average number of visits in our cohort, in South London is -you know from, let's say the original discussion to theatre is one. So they only come once. We see them, that's it. You're having this, we'll book you in, goodbye. We'll see you after the procedure. You know if it's unsuccessful, we'll talk again about other options." – Surgeon 2

Again, these discussions highlight the value of the patient-provider relationship and how these encounters and relationships should not be replaced by technology but supplemented and supported by it. Sites with limited resources i.e. opportunities for consultations could benefit from the potential of the proposed app, supporting and preparing patients between their encounters with providers.

7.3.4.3. Support

Patient-centred and technology-based care requires technological support for patients, with spare devices on standby or available. Patients will also require other forms of support via their providers, such as round-the-clock support (e.g. telephone) and traditional caring support.

Spare devices on standby: To supply spare devices means to enable patients to access technology where they may not have the means to access it themselves. Nurse 4 cited not having equipment as the main barrier to utilising and delivering the proposed app in practice, while Nurse 5 pointed out they already have possibly suitable equipment used on the wards, namely tablet devices (utilised during social distancing periods to allow family members to contact patients) which patients are familiar with. Other suggestions included the need to make the application available on a variety of devices and platforms, as well as constantly available in dialysis units and clinics.

"You're talking to the nurses constantly and you do talk about your own lives, what's happening and where you've been and what they're doing for relationships -you get quite a close relationship, and I can still think of dialysis patients long gone. I still think about it regularly because we have that bond." – Nurse 2

"Make it readily available for all possible let's say platforms. Tablet, phones, laptops, whatever. I think this information should be at all times available in the dialysis units, and the clinics generally speaking you know advanced kidney care clinics, pre-dialysis access clinics, it should be available." – Surgeon 2

Round-the-clock (*telephone*) support: Originally focused on telephone support, this theme was expanded to consider all forms of round-the-clock support available to patients. This theme was not discussed at length however, outside of discussions by surgeons around patients' concerns over who to contact in the case of emergencies with their VA, such as bleeds or clots.

"What happens during a declot? How many times am I going to have to be declotted? What phone number should I phone if the buzz goes in my graft? What happens if I have a massive bleed? What's a, what's a massive haemorrhage going to look like and how do I manage it? Who do I phone?" – Surgeon 1

Caring support: Caring support could be received by patients from clinical and nursing staff as well as their peers and family. Nurses discussed at length the level of contact they have with patients, as well as the bond and relationships they build over time. They saw themselves as the first people patients see

as their life is about to make the major change of beginning dialysis, and so would make effort to ease patients into treatment. As previously mentioned, experienced nurses would be paired with new patients if appropriate and dialysis would be slowly increased in frequency and cannulation. Patients will also rely on their peers as a source of support as well as information, and so this must be considered as well. Again, technology cannot replace these relationships and so should seek to encourage and support them where possible.

"In a dialysis unit, now that you get to know your nurses incredibly well. It's so much of a different relationship than if they have with us as vascular access nurses or even that you have a nursing on a ward because you get to know the nurses on a dialysis unit well as they get to know you. And if you're there a year on year on year, you watch their kids grow up, you watch what happens in their lives, you chat. You actually get a very different relationship and it's a lot of a lot closer, more trusting-"– Nurse 2

Technological support: The conversation around technological support focused on supporting patients in the use of a technology-based intervention. This role could be taken on by anyone, such as family members, caregivers, friends, nursing and clinical staff and even general practitioners or practice nurses. This would require the intervention to be usable and accessible to not only patients and medical professionals, but anyone who may be unfamiliar with the specific contexts of CKD and VA modalities.

"But if there's something that you know, this is something the nursing staff on dialysis potentially could help them with when they're there or a family member or something, so I think having this kind of thing is really important." – Nephrologist 4

"If patients don't understand it then it was it would be an easy, the nurses could go online and go through it with them um any kind of health care professional could go through with them and have a chat." – Nurse 1

7.3.4.4. Technology

According to the framework, care in the context of technology requires technologies to be easy to access, safe or secure, flexible in their use and be well tested, aesthetically pleasing and have ease of use. These themes are discussed below, alongside barriers and motivations to use of technology, original themes identified previously in the scoping review of Chapter 4.

Easy access: The ease of access to technology was discussed in regard to both inside and outside of the clinic (i.e. home). Nurse 4 and Surgeon 2 both suggested the app should be made always available to patients at clinics and therefore equipment should be available as well (see section prior for provision of spare devices).

"Not having the equipment. Do you know, if you put it on an iPad or something like that to make it for the patient. And so we could take them to take it to the patient. If you didn't have the equipment that would probably be the biggest barrier." – Nurse 4.

On the other hand, the proposed intervention would also need to be accessible from home as well, not just for the patient's benefit but also for their families or caregivers, who may not be able to attend consultations and stay informed of the patient's health.

"So would it be available to the patients from home? Because that point of the patients might not be interested, but their family would. The family that are interested and engaged might not necessarily be at those consultations." – Surgeon 3

Easy to use: Ease of use was commonly discussed, with topics such as the flow of the designs shown and how users were guided through the function. For example, Prototype 4 flowed top-to-bottom and was preferred than the bottom-up flow of Prototype 5. Overall, both refined designs received positive feedback, but Prototype 4 was seen as more informative, "straightforward" and the tasks and goals were easier to understand than the intuitive elements of Prototype 5. This level of interaction required by the user was a common topic across all workshops. While most considered the interactions demonstrated in the workshops to be acceptable for any mobile application, Surgeon 1 noted Prototype 4 led the user through the process and this flow was more effective than expecting the user to be bold and click various elements with no explanation to discover information.

I think the second video [Prototype 4] for me was a lot more user friendly than the first [Prototype 5]. I think the way that it was led through the journey um was a bit more organic. I'm not sure that I'd want to click loads of different things to find out different things." – Surgeon 1

Consistency was also discussed often, in reflection to both user interface elements and language and terminology. Suggestions to improve ease of use included consistent and familiar user interface elements (e.g. the use of an X icon might be interpreted as "close" the app and restarting the process), explaining terms and abbreviations when used and accessibility considerations, notably text-to-speech output. The visual representation of data and risks, notably the coloured patient icons first described in the MDG session, were praised and considered easier to understand than just numbers.

Finally, a recurring subtheme occurred in all groups regarding the level of detail of information, with participants agreeing that those who sought further information would look for it and interact with the app further, "drilling down" from the initial "skeletal" and simple overview or interface initially displayed, intended for those who were less inquisitive and engaged. This was preferred to attempting to deliver all information at once, at the risk of overwhelming the patient and causing them to disengage. These points all suggest that further refinements should continue in reference to Prototype 4, with a

clear process and flow leading the user through information while still allowing investigation and information seeking for those who may desire to do so.

"I really like the revealing. That's – the going, like at the beginning, 3 months, six months. It's nice to show the data like that. The way you talked about that it's actually quite accessible." – MDG Member P3

Flexible: The concept of flexibility was considered to include alternative uses or outcomes of the proposed app. Touched upon earlier, these included medical education (Prototypes 4 and 5), use outside of the renal setting (i.e. home) and supporting families of patients with information.

"I think it's a phenomenal resource for medical education. Yeah, I think it is just brilliant for medical education." – Surgeon 1

"Yeah I think even a GP doctor or someone that could pick up and talk to them about it if they're there for anything else you want to talk to." – Nurse 2

Nice looking: The aesthetics are the designs shown were not often discussed but points were made about the styling and colour of the user interface, often regarding colours, with one reference to how appropriate colours can support users with dyslexia by Nurse 4. Colour choices were also critiqued by Nurses 2 and 3 for VA modes**,** namely red for lines and green for fistulas. While they commented that the positive green colour for fistulas was good for encouraging their uptake, the red for lines painted a negative perception, which may not be ideal if that is the only option for the patient. As previously mentioned, the visual representations of data and risk were positively received, as were the pathways representing the patient journey.

"Especially with COVID just now we've got red, amber and green. Very much in people's head, red's bad." – Nurse 3

Testing of technology: This subtheme was originally described as allowing patients to test the technology in a safe and positive environment (e.g. walkthroughs and demonstrations with healthcare staff, described prior) but was expanded to include feedback on the methodology and materials used in the workshops as well. While this work did not involve patients at this stage, patient involvement was discussed and promoted by participants, with some having experience of patients being involved in designing the services they access (i.e. rebuild and design of dialysis unit as described by Nephrologist 4). Nurse 2 noted that patients will engage with resources their peers endorse or utilise, so the intervention could not progress without some level of patient input. There was concern the content of Prototypes 4 and 5 were too blunt and unrefined for patients to review. Nurses 1 and 2 raised this issue and suggested refining the design and considering the stage of treatment potential patient participants may be at, before seeking their involvement.

"You don't want to confuse them."

"I think the rough version might confuse them…yeah I think it needs to be a bit more refined before you ask patients." – Nurses 1 and 2

***Appropriate* (Safe):** The original theme of Safe was adapted to Appropriate, shifting the scope solely from the physical safety of technology (e.g. electrical shock or discharge, potentially harming patient) to include the appropriateness of the technology and its content, with the latter becoming the focus of many discussions. The primary issue discussed was the graphic nature of images of VA such as bulbous fistulas or cannulation. Nurse 2 described unmoderated online resources such as Google can return incorrect information with images of worst-case examples, which frightens patients and may not reflect the reality of their treatment. The prototypes did not contain any images, but this later inclusion will require consideration.

"But you'll get lots of different views on Google as well. I mean, google what a fistula is and you'll see something extremely abnormal to something that's perfectly normal." – Nurse 2

Other issues included the content of the prototypes being unbalanced, with a focus on the negatives rather than the positives of different VA. Prototypes 4 and 5 were critiqued as having a very negative view of VA types, with no incentive for the patient to click anywhere as the primary information was complications. More positive content was requested, namely the benefits of each VA, to fully inform patients and ensure no one modality was more promoted than the other. Mortality risk was also to be included, rather than avoiding the truth through omission, as patients need to be aware there are outcomes that are unfavourable and will see throughout treatment that their peers can become worse and may die. This was first raised during the MDG session by P3, who felt categorising those that left the dataset paths as "transplant or death" was not appropriate and the omission of a clear statement of death as an outcome in the final summary of Prototype 5 was heavily critiqued.

"Right, I think that's something that needs to be separated, that's what I care about. I suppose transplant -no, yeah, I think I'd worry about that." – MDG Member P3

Less sensitive topics included technology not replacing patients' relationships with providers (i.e. the intervention should not offer the prognosis of the patient), content being too clinical for patients, and the applicability of the information to individual patients. The final topic was concerned with how existing resources and information can be inapplicable to the individual patient, notably how generalised information or predictive modelling should be clearly stated as such and how what happens to many may not occur to a single patient.

"Again the prognosis for many is not great on dialysis…like I hope that's been discussed by their pre-dialysis, I don't think it's the point of an app to tell them their prognosis." – Nephrologist 2

Barriers: An additional theme first conceptualised in the scoping literature review (Chapter 4) (also utilising the framework by Korhonen et al. (Korhonen et al., 2016)), barriers to uptake of and engagement with technology were also identified in this study. Discussions focused on the age and familiarity with technology of the patient demographic, with participants assuming older and frailer patients would struggle with any technology-based intervention or would simply prefer to not engage with it, while younger and more "professional" (i.e. educated) patients would be keen to utilise the app.

"I think that depends on your patient demographic. I think if you've got young professional patients coming in, that's going to be really interesting to them." – Surgeon 3

Implications for the intervention and similar technologies are the need to design for the least familiar and skilled users, regardless of age and health, with considerations for accessibility needs of the user population. For example, CKD patients can have treatment-related accessibility issues, such as impaired vision (Gonda et al., 1978; Nusinovici et al., 2019) or reduced sensitivity in their fingers, making touch screens difficult to interact with and situational impairment while dialysing (see previous chapter).

When questioned on what would stop them utilising something like the prototypes shown, Nurse 4 added the biggest barrier to overcome was the availability of technology i.e. having the equipment in clinics or wards available for use, already touched upon in the earlier sections regarding spare devices and ease of access.

And also, half of our patients are not going to follow any kind of type of app anyway. So that they're kind of pretty old, frail and you know everything is going to be hard for them." – Nephrologist 3

Motivations: Like the subtheme of Barriers, this additional concept was included after examples of motivators for engaging with technology were detected in discussions. Surgeons 1 and 2 appreciated the concept of a single resource and expressed a desire for better information provision, citing the prototypes as a step in the right direction. The intervention also overcame the limitations of physical paper resources, by presenting information in a single format or view and effectively showing how the different VA modalities interact and compare.

"-rather than having screeds of writing about the different options. So most patient information leaflets are just paragraphs of writing with no pictures in it. Whereas this is a much more visual guide. And I think that's helpful for a lot of folk." – MDG Member P1

Finally, as discussed previously, technology is becoming more prevalent in day-to-day life and healthcare, and so the concept of the proposed intervention was considered appropriate given the shift in recent years. This of course does not mean it should be seen as a "one size fits all" solution and consideration should be taken for those who cannot or will not engage with technology, with alternatives available (Ashley et al., 2013).

"But I think as people are coming in and moving forward particularly the way we are with technology now actually I think it's got more of a future in it. Do you know do you know what I'm trying to say?" – Nurse 2

7.3.4.5. Uniqueness

The concept of uniqueness refers to the appropriateness of care, based on the patients' needs and experiences. This is the only theme under the concept, but the analysis revealed many subthemes related to how care can be tailored to the individual, including long-term health and goals as well as adjusting for patients' tolerance for information intake and the burden of treatment.

Appropriate care based on patient's needs and experiences: This theme covers a range of factors which can influence and changed the care or the delivery of care to patients to better meet their needs. The most common topic was how the patient's long-term health, and their priorities were factors in decision-making. For example, nurses noted patients prefer their lines for various reasons (e.g. hands are free during dialysis, no pain or direct cannulation, immediately usable and less time spent disconnecting) despite the fact fistulas are seen as the "gold standard" for dialysis adequacy. However, this is not always an option for those with weak veins, and fistulas require more time to mature and to disconnect from dialysis, and patients must actively monitor their fistula, adding to the existing burden of dialysis. Patients can also be influenced by their experiences of VA or treatment, positive and negative, with patients often confused why the access they have that works needs to be changed to something that is unfamiliar but more viable.

"Right, the thing is if you actually had the beginning, what people were at, not just that they use the line, what they thought they were signing up for, will give you that idea that…" – MDG Member P2

This was also noted during the MDG session, as P2 pointed out that while the designs submitted showed patients' VA over 365 days, it did not capture their intent for treatment i.e. not everyone who wanted a fistula started with one. Operation fatigue can also be a factor in their decision-making, alongside the experiences of their peers or even family in the case of shared conditions. These factors can be very influential to patients and so need to be included in patient information resources.

"They probably take more from people already on dialysis then the medical professional and nursing professional per se, because they will believe a person on dialysis and has gone through it, as opposed to, they might think medical staff and nursing staff are sugar-coating it, making it look better than it actually is, so to do tend to believe their peers more..." – Nurse 3

"I think again that's an individual thing because there's a slow decline over years, so they gain knowledge over years and a lot of people that happens quite quickly. Again that happens differently for different people." – Nurse 2

Patients will differ in priorities and how they intake the information about their condition, with some actively seeking complete information on all options while others are satisfied to hear about the best option for them, from their clinician. Difficulties can occur when patients chose to disengage and ignore their condition (often out of fear), or in one example, may be transitioning from a child to an adult patient and now have to handle their condition and the responsibility associated with it. Surgeon participants also expressed difficulty in adjusting the delivery of information for patients, with a need to explain all the options and risks fully to someone who may not necessarily be able to take all of that in. Where possible, Surgeon 2 keeps to the basics and outcomes of risks and meet the patient prior to obtaining informed consent, allowing them time between consultations to process and consider what they have been told.

"So trying to know what every patient should, every patient's different and I think the dynamic process is as much what they want to know as much what we need to go." – Surgeon 1

This can be especially difficult where resources such as staff and consultation time are unavailable given the variability across health boards (as noted by Surgeon 3 and discussed in earlier sections), or patients may "crash-land" and need to start treatment immediately. These patients have less time to reach a fully informed state while their peers who have been in decline may have had more work-up and preparation from their healthcare team. A resource such as the intervention could aid patients at these key sense-making and meaning-making moments, being utilised before, during and after consultations to provide information and support patients in their learning and become informed.

"And actually, different people want to know different things and different levels. I mean some people you meet want to know the ins and outs of everything straight away and other people just want to know what's happening next. And sometimes people just want to say: I want you tell them what best option is." – Nurse 2

Nurse participants described easing patients into dialysis, by pairing experienced nurses with new patients if possible and cannulating with smaller needles initially, to give the patient a positive initial experience. While it is harder to implement such empathetic measures into a digital intervention, the key points from these themes are the need to allow patients to engage and explore the information provided as they chose, as well as including information on factors they find important such as lifestyle changes and ongoing self-care in order to ensure they can determine the choice that best suits them.

7.3.5. Reflection on Themes and Scoping Review Recommendations

Some of the themes identified in the thematic analysis were also noted during the scoping review of Chapter 4. Accessing technology was a common issue considered by stakeholders, namely the provision of technology or equipment to patients and issues where independent use of the technology may not be possible. The literature has shown failure to provide access to technology through provision of devices

can exclude those who may benefit most from the intervention (Mair et al., 2021), while the allocation of a dedicated individual to support patients' use of the technology (Jacobs et al., 2018) may be preferred to relying on the burden being taken up by patients' family or support network (Ashley et al., 2013). The attitudes of patients towards technology were not discussed as commonly in the co-design workshops as the literature reported, but there were similar concerns that the typical CKD patient may be unfamiliar and inexperienced with technology. There was also a sense that the engaged and familiar patient users would be comfortable with the level of interaction required by the prototypes, echoing the sentiment in the literature that as the prevalence of technology increases, issues with familiarity would be less common (Basch et al., 2005).

Patient priorities, changes in patient health and reliable and high-quality data were also themes that occurred within the workshops, when the content of the prototypes was discussed. Patients' priorities may place medical outcomes lower than elements they value such as hobbies, career or longevity and so the information of the prototypes needs to include such topics. Changes in health also affect how patients view the information provided, as it may no longer be relevant to their situation or their familiarity with one mode of treatment may cause them to disregard other options. Finally, the stakeholders also described the legal need to present all options and outcomes clearly, as well as the need for honesty in information provision. Patient peers are regarded as very valuable and reliable sources of information, similar to the reliability and usefulness of patient-reported data in the literature (Absolom et al., 2019; Basch et al., 2016; Kennedy et al., 2021; Wright et al., 2003).

The concept of perceived value for patients was not clearly described by the workshops, however the stakeholders expressed their high regard for the concept of the proposed system and the difficulties in information provision it could potentially overcome or resolve. The MyPath intervention (Jacobs et al., 2018) was the only intervention of the reviewed literature that focused on information provision, similar to the prototypes reviewed in this work. Within their study, Jacobs et al. found the perceived value of their intervention decreased where the information provided did not align with patients' priorities, which changed with health or life events (e.g. family death). This highlights again the importance of the relevance of the information provided by such systems and ensuring that the content does align with what patients value and wish to know, as well as providing the required medical information as well.

7.3.6. Design Requirement Elicitation

In addition to the themes elicited via the framework analysis above, design requirements were also gathered directly from both the discussions and the Keep, Lose, Change or Add exercises posed to stakeholder participants upon reviewing a demonstration of Prototypes 4 and 5 (see Figure 7.11). Some of these comments may overlap with points made during the discussions, as the participants would often discuss the annotations made by others.

Prototype 4 was primarily praised for its "algorithmic approach" or flow, as described previously, and the limited number of interactions or buttons available e.g. "Next" and "Continue", which aided in creating an easy-to-follow flow throughout. The use of restroom icons here was again praised as well and the concept of a journey being shown throughout. Prototype 4 saw critique for its "pastel" colour scheme, and overuse of clinical terminology and abbreviations such as "AVF" for fistula. Changes suggested included:

- additional information to explain common abbreviations and terms such as "surveillance" through pop-ups or expanding sections
- adding more practical information e.g. "what do I do if I bleed?", "What do I do if I clot?"
- showing positives and negatives for each VA
- include steps and procedures prior to starting dialysis
- patient peer testimonials
- images of people and treatment

Prototype 5 saw positive feedback for its inclusion of restroom icons and display as a patient journey, as well as the simplicity of the layouts and the final summary page, interactive nature and clear distinct colours for VA modalities (e.g. pink for line, green for fistula, etc.). However, the simplistic design held it back at times, where comments were made for clearer options and labelled elements e.g. coloured lines for different VA. There was some discussion around dropping the 3-month stage of information by Nurses 4 and 5, as they felt this would not be of much interest to patients as the 6- and 12-month summaries. Prototype 5 only displayed VA modalities as options for investigation and so requests to include transplant and peritoneal dialysis were also made. Further suggestions for improvement included:

- the lack of explanation for the missing patients in the final year summary (i.e. death)
- inconsistent terminology (switching between catheter and line often, referring to changing VA as changing treatment, etc.)
- flow of bottom-to-top to top-to-bottom
- more additional information besides complications i.e. showing positives and negatives for each VA, expanding on what complications may be, etc.
- navigation via buttons or arrows instead of swiping

The summarised design requirements are listed in Table 7.2 below, with their source themes and whether or not they were discussed by the different stakeholder groups.

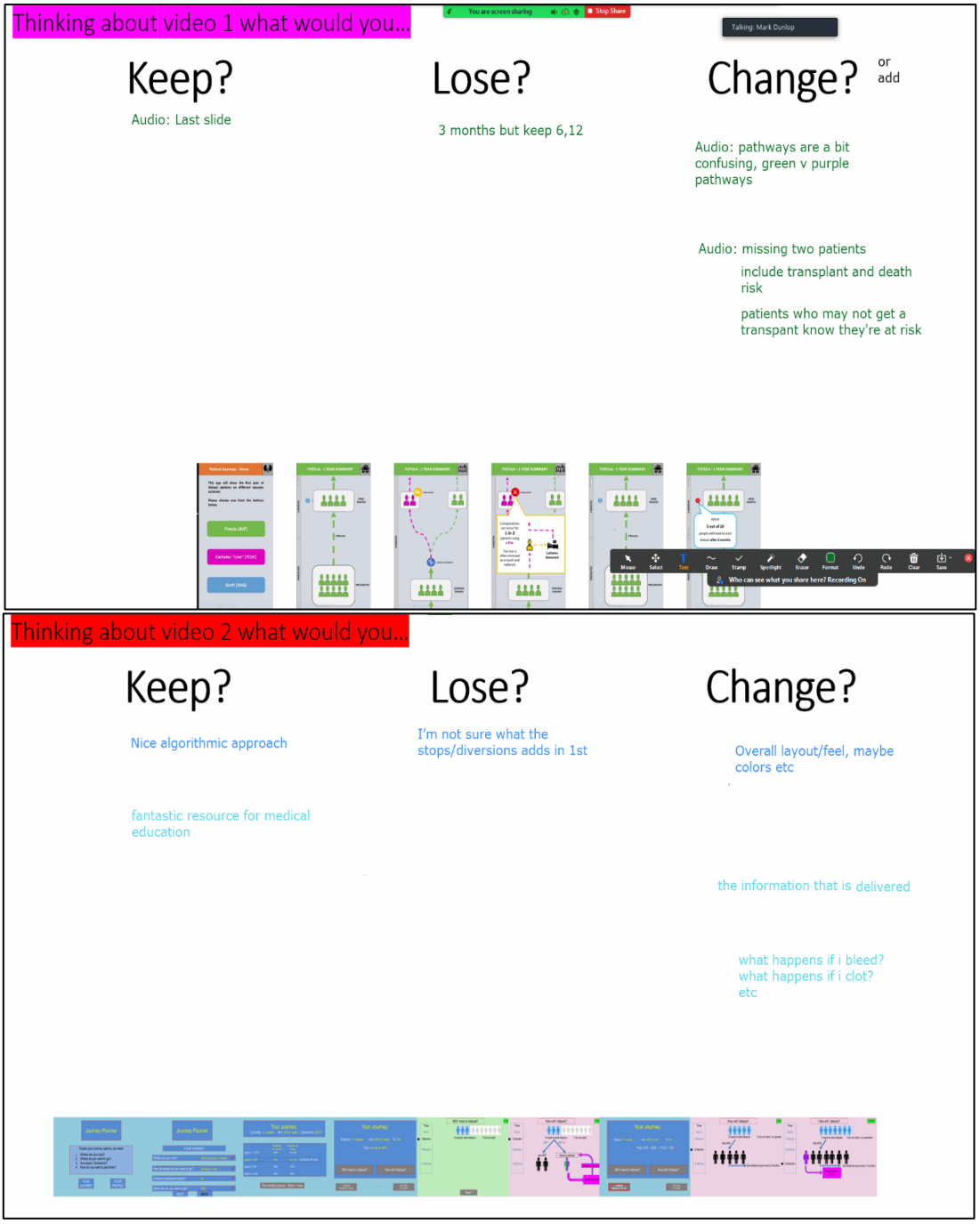


Figure 7.11: Screenshots of Keep, Lose, Change exercise slides and participant responses.

Table 7.2: Design Requirements for App with Sources and Themes

App Functionality and Design Requirements	Source Theme(s)	MDG	Surgeons	Nephrologists	Nurses
Complete information including subject of death	- Competence (Trustworthy) - Patient-centred (Patient education) - Technology (Appropriate)	✓	✓	✓	✓
Simple overview but then allow user to "drill down" in detail	- Patient-centred (Patient education) - Technology (Easy to use)	✓		✓	✓
Disclaimer of generalisations	- Patient-centred (Patient education) - Technology (Appropriate)	✓		✓	✓
Visual representations of risk i.e. patient icons	- Patient-centred (Patient education) - Technology (Easy to use, Nice looking)	✓		✓	✓
Consistent and familiar terminology and language (e.g. "line" instead of catheter, avoid use of symbols such as <, >, etc.)	- Patient-centred (Patient education)		✓	✓	✓
Highly accessible with functionalities to support users e.g. text-to-speech/audio content	- Technology (Easy to use)	✓			✓
Include pre-dialysis stages and steps i.e. intention	- Patient-centred (Patient education)	✓			✓
Include practical information or a "What Can I Do" section, with emergency contact information	- Competence (Prompt) - Patient-centred (Patient education) - Support (Round-the-clock)		✓		✓
Positive and negative information, summarised	- Patient-centred (Informed consent		✓		✓

App Functionality and Design Requirements	Source Theme(s)	MDG	Surgeons	Nephrologists	Nurses
	- Patient education) - Technology (Appropriate)				
Overall summaries prioritised over timepoints	- Competence (Timely) - Patient-centred (Patient education)			✓	✓
Page and pathways should flow top-to-bottom	- Technology (Easy to use)			✓	✓
Widely available and supported on various platforms and devices	- Support (Spare devices on standby) - Technology (Easy access)		✓		
Consistent and familiar user interface e.g. consistency in icons and their related action, arrow buttons to move forward or back, etc.	- Technology (Easy to use)		✓		
Minimal and simple interactions e.g. no swiping to move left or right	- Competence (Technological skill)			✓	
Explanations of common terms and abbreviations (e.g. AVF = arteriovenous fistula)	- Technology (Easy to use)			✓	
Appropriate and balanced colour choices (e.g. green vs red) for specific VA modes i.e. fistula vs line	- Patient-centred (Patient education) - Technology (Nice looking)				✓

7.4. Discussion

The intent of this stage of the research was to utilise co-design workshops and activities to investigate the opinions and experiences of medical professionals regarding CKD patient education, as well as conceptualise and evaluate prototype designs for the visualisation of treatment pathways. A total of 5 sessions to review prototype designs took place online over Zoom, with a total of 16 participants. From these sessions, 5 designs for a digital patient education tool were produced (3 static images and 2 interactive prototypes, shown as pre-recorded demonstrations). These were supplemented with a set of design requirements for such patient education systems, all informed by stakeholders including surgeons, nephrologists, and dialysis nurses.

The most prominent theme of patient education was the concept of "drilling down" in detail, where a simple overview of the content providing users the opportunity to access further information was preferred to attempting to encompass all possible information in one view. It is not uncommon for CKD patients to have limited levels of health literacy (Narva et al., 2016; Rowlands et al., 2013) and giving this choice ensures those who would seek further information the option to do so, while avoiding overwhelming those who do not (Büyüktür & Ackerman, 2017). This can be seen with focus of the workshop discussions shifting purely from the patient pathways to visualising the idea of the patient journey. This original concept was found to be a positive idea amongst stakeholders but given the volume and variety of patient's information needs, a single all-encompassing solution may not be effective. Instead, the visualisation of the pathways was best received where it provided an overview of what to expect from the selected treatment, with the ability to investigate or refine information available further, but not enforced. The use of patient restroom icons to communicate risk was also met positively, visually describing risk rather than written as "1 in X" (Freeman, 2019).

Again, supplementary information and alternatives should be available as well (e.g. frequencies and percentages), given how health literacy may impact patients understanding of various icon types (Zikmund-Fisher et al., 2014). It was also made clear that patients would give much greater weight to their peers' experiences than other sources, based on the opinions of the workshop participants. Peer influence is understood as a major factor in decision-making and education for CKD patients (Morton et al., 2010; Taylor et al., 2016) and so should be included in digital interventions aimed at supporting decision-making and patient education resources. Therefore, further iterations of prototypes will aim to include some form of peer testimonial functionality before evaluation with CKD patients.

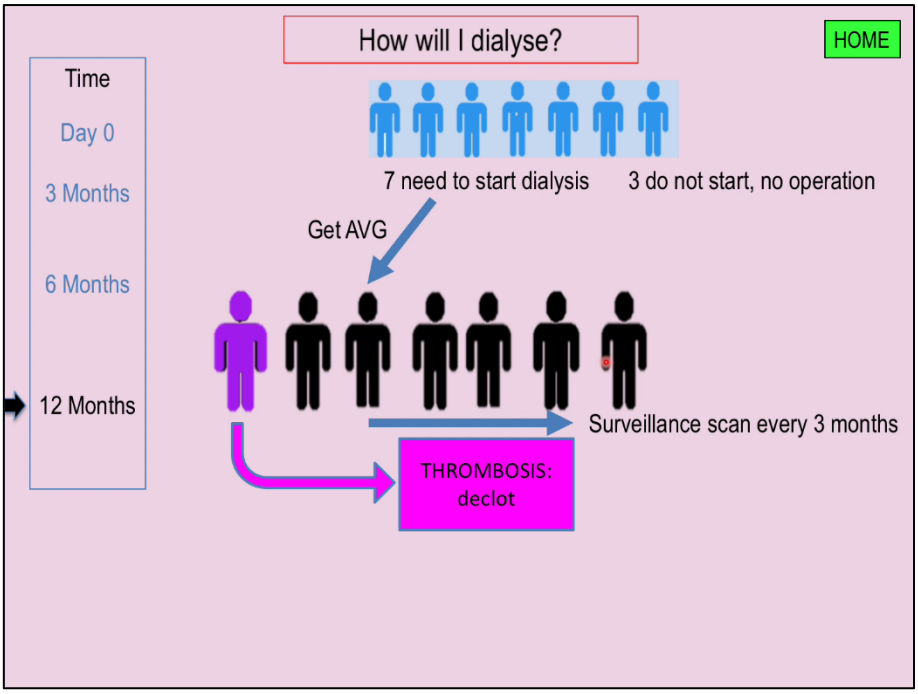


Figure 7.12: Screenshot of Prototype 4, highlighting use of icons to show odds of success or risk of complication. After 1 year, out of 10 patients, 7 will start with a graft and 1 will have a complication. 3 out of 10 will not need to start.

It is also interesting how the different roles of healthcare providers differed in how they interacted with the patient throughout their education and treatment journey. There was a sense that despite their intent to fully inform the patient at their stage, the next provider interaction may find a patient is ill-informed or unprepared. This is not surprising given the anecdotes of patients not retaining information and the need for multiple and consistent interactions from multiple disciplines. This may be attributed to the delay in patients interpreting information in their own context, such as that described by Burgess et al. (Burgess et al., 2019). This includes the concepts of sensemaking and meaning making, where the latter is achieved once patients understand the information provided in their own personal context. Their work also highlighted the benefits of collaboration and how it must be considered in the design of information resources, especially to ensure the expertise of differing people is not lost within a purely technical intervention. This was raised in discussions under the theme of preserving the patient-provider relationship, honed through many encounters and conversations. It is a common concern that new technologies in healthcare settings may replace this relationship (Meiklem et al., 2021; Whitten & Buis, 2008; Wood et al., 2020) and so steps must be taken to ensure that the intervention conceptualised in this work supplements these existing relationships, by acting as a resource for both providers and patients.

The thematic analysis of the discussions also highlighted providers' efforts to provide patient-centred care, through examples of unique and tailored care. This is evident in the two overarching themes of Patient-centredness and Uniqueness – the former described provider efforts and considerations while

the latter focused on experiences and examples of tailored care based on patients' needs at the time. Interestingly, Uniqueness is the only theme which does not offer any explicit design requirements. This is possibly due to the specific examples of patient-centred care, which are actions completed by the providers themselves. This reiterates the importance of considering the fundamental design of the intervention we propose, and ensuring it is at its core widely accessible and adaptable for all, rather than all-knowing and complicated. Again, the idea of "drilling-down" through levels of information allows for flexibility in information provision and enables the patient to explore as they wish. It has become clear that no single intervention can effectively provide all the information an individual patient may possibly require throughout their journey, as any prediction modelling or information will need to be clear on its limited applicability to individuals versus populations. Instead, the intervention should aim to provide thorough and balanced information (i.e. positives and negatives of different modalities, including the outcome of death) to inform the patient, so they are then prompted to ask their own questions to their healthcare provider.

Another common concern was the suitability of such technology for older patients, who are often stereotyped as being averse to technology or simply less technologically skilled and experienced than their younger peers. In contrast, participants also discussed the appeal of technology for the younger, professional patient – the "ideal" user. The use of tablet technologies (like the proposed prototypes) has been found to be satisfactory with older adults in health settings however (Gitlow, 2014), and older adults can perform as well as their younger peers when using touch-screen devices (Schneider et al., 2008). Characteristics such as age, deprivation and experience with Internet and computer technologies are associated with compliance to technology use or refusal to partake (Ashley et al., 2013; Basch et al., 2005; Basch, Artz, et al., 2007; Basch et al., 2016; Basch, Iasonos, et al., 2007) as is dislike of technology (Ashley et al., 2013; Berry et al., 2011; McCann et al., 2009; Wright et al., 2003). Often the response is that the increasing prevalence of technology will resolve this issue over time. Instead, technology should be designed to be familiar and simple (McCann et al., 2009), alongside providing supported use, training and instructions should be offered (Absolom et al., 2019; Basch et al., 2005; Basch, Artz, et al., 2007; Basch et al., 2016; Crafoord et al., 2020; Fjell et al., 2020; Judson et al., 2013; Kearney et al., 2009; McCann et al., 2009; Mitchell et al., 2000; Ngo et al., 2020; Velikova et al., 2004; Wright et al., 2003; Zini et al., 2019) and alternatives offered for those who may still be unable or unwilling to engage with technology (Ashley et al., 2013; Coombs et al., 2020; Meiklem et al., 2021). Otherwise, the risk is those who would benefit the most from the intervention fail to access it and any benefits (Gallar et al., 2007; Wright et al., 2003).

7.5. Strengths and Limitations

This study consists of various strengths and limitations. As the research progressed, issues and pitfalls were identified within the methods employed. These are summarised below, with the modifications made to resolve the issues arising further:

- Participants unable to annotate text on Zoom shared screen on tablets and smartphones.
    - Resolved: Utilising chat functionality to record responses or verbal response transcribed by researcher (Workshop 3 onwards)
- Participants spent more time on one question while unaware of other prompts.
    - Resolved: Fixed timings and instructions from researcher to ensure all questions had appropriate amount of time to respond to (Workshop 3 onwards)

While these issues are problematic, we believe by choosing to proactively make efforts to address and iteratively resolve these throughout the research allowed for subsequent sessions to improve and be delivered effectively, rather than continue with methods and materials which were ineffective. For example, participants accessed the sessions via different devices, with different user interfaces and functionality for different platforms (e.g. tablet device vs a laptop or desktop computer). This challenge was met with the decision to decide at the beginning of sessions what would be the optimum way to conduct the sessions based on the participants attending, rather than continue with participants unable to participate equally (e.g. one talking while others annotate, allowing the individual to dominate the group).

The timing of this research amidst a global pandemic also posed challenges, given the need to mitigate physical methods and adapt to online and remote sessions. While this had benefits such as greater accessibility for participants who were limited by time and distance, the online delivery possibly excludes participants who cannot attend or would prefer not to do so online. This poses a consideration for future work, where a choice between physical and online workshops should be offered to ensure no single cohort is excluded by the preference of another.

Taking inspiration from the PAR methodology throughout this thesis directed focus on the community of interest and as such, lead to the modifications made to the traditional methods described previously, for the benefit of the community. Another strength "coach" or collaborator role of the researcher, which enabled Kingsmore to be an active contributor in the study throughout all stages by producing high-fidelity prototypes despite no previous training or background in designing systems before the research began.

Finally, the lack of patient involvement in this study regarding a patient education resource could be seen as controversial, as first discussed in the Methods (section 7.2). However, involving solely providers at an earlier phase allowed for an expert opinion on the appropriateness of the prototypes before moving to patient participants, particularly around sensitive content regarding their life-prolonging treatment and chronic condition (e.g. topic of death). A similar approach was taken in the previous research as well (Chapters 5 and 6) and doing so ensures patient participants see an informed and refined prototype, and can focus on what they need from the intervention that already contains the functionalities required by the medical domain. The next phase of this work will seek to recruit CKD

patient participants for the evaluation of this further refined prototype and gather their input into the intervention as stakeholders and end-users.

7.6. Conclusion

The contributions of this chapter include two stages of patient education prototype designs, alongside a set of design requirements for a technology-based patient education and decision-making aid, and insights into the process of CKD patient education including the relationship between patient and providers, technology and seeking information, and the delivery and receipt of patient-centred care. This work demonstrates effective co-design exercises conducted online and remotely, and how stakeholders such as Kingsmore are able to produce their own patient education prototypes, through participating in several co-design activities and learning from the "coach" researcher.

This study sees the progression of the previous conceptualisation work completed within Chapter 5 and expands the scope to national levels, recruiting various professional stakeholders from across the United Kingdom. It also addresses the second research question in regard to what medical providers require from a patient-centred and technology-based intervention, from the new perspective of a patient education and decision-making resource. Important themes to continue in future work include the flexibility of information provision, through "drilling down" in detail and use of alternatives to text-based information (i.e. communicating risk through graphics) and how technology can supplement and support existing multidisciplinary and holistic approaches to patient education and care, without seeking to answer all potential questions or problems.

The following chapter will look to build upon the outputs of this work by evaluating a further refined and more informed prototype with CKD patients and supplementing the existing design requirements for such CKD patient education interventions with those from the patient user perspective.

Chapter 8: Design and Evaluation of CKD Patient Education Resource with Patients and Multidisciplinary Symposium

This chapter continues the work carried out in Chapter 7 taking the elicited design requirements and feedback of clinical staff co-design workshops to produce a single refined high-fidelity prototype to present to both online and in-person patient workshops, and a multidisciplinary national kidney disease conference. The methods of the prior sessions are adapted and refined for these sessions, allowing for elicitation of further design requirements and the patient perspective of information provision, while still enabling the community of interest. The outcomes of these studies will also contribute to answering the second research question, expanding on the needs already established by medical provider stakeholders with those from patients and caregivers.

- **RQ 2:** What do haemodialysis patients and other stakeholders need from a technology-based intervention to support the CKD treatment journey?

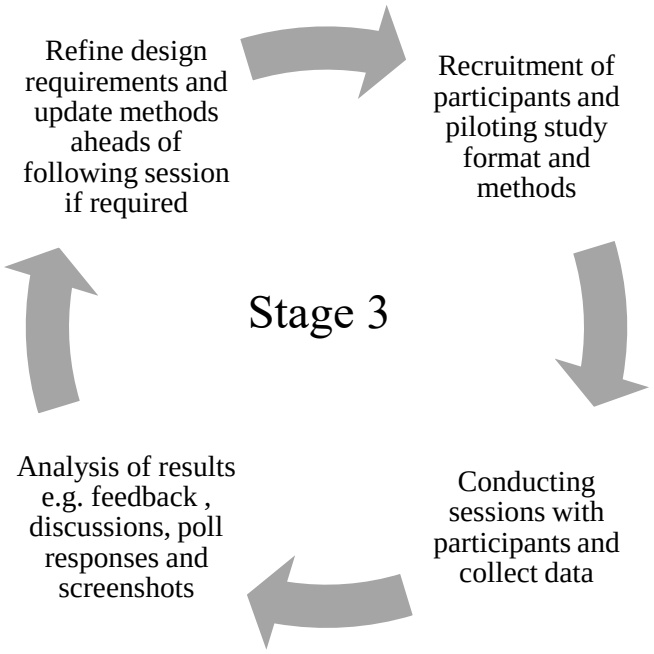


Figure 8.1: Stage 3 of cyclic co-design approach and relevant methods, applied for conference symposium, online and in-person workshops

8.1. Introduction/Background

Patient education is essential for effective treatment, self-management and improving the overall health of chronic kidney disease (CKD) patients (Young et al., 2011), however several issues exist in the

context of CKD patient education. These include limited levels of health literacy (Narva et al., 2016), and high levels of information work in making meaning and sense of information in the individual's context (Burgess et al., 2019). Decision-making is often required at times of emotional duress and is pressured by continuing worsening health and declining renal function. Existing patient information resources (primarily printed material e.g. leaflets, brochures, posters, etc.) are designed to support patient education and self-management activities but often require a high level of health literacy (Tuot et al., 2013) or reading ability (Morony et al., 2017), while almost a quarter of the CKD patient population have low health literacy. Visual aids such as images and graphics supplement information, attract patients to materials and aid in their understanding, especially for low literacy readers (Morony et al., 2017). However, images that are unrelated to the text provide no benefit (Houts et al., 2006)and embellishing (i.e. not related to text or aiding in explanation) graphics can be distracting for older readers (Griffin & Wright, 2009).

The prior chapter explored the opportunity for technology-based interventions to support CKD patient education, focusing on an interactive treatment guide, as described initially in Chapter 5. Following co-design workshops with domain experts and medical professionals, a set of design requirements were formed for a refined and informed prototype. The refined prototype may address the clinical needs of information provision but risks imposing further work on patients (Burgess et al., 2019; Mair et al., 2021) and as stated by medical professionals in the previous chapter, should not seek to hold all the answers, and replace the existing relationships and exchanges patients have with their clinicians, peers and family.

Therefore, the aim of this work was to continue the design of patient education resource that would support CKD patients in both independent and collaborative uses, progressing the concepts first identified in Chapters 5 and 7. This included conceptualising designs within MDG to further understand the context and gather initial design requirements, followed by reflection on patient education and high-fidelity pathway visualisation prototype design evaluations with non-patient stakeholders outside of the MDG. Now, this stage will further the work through reflection on experiences of information provision and a refined prototype evaluation in co-design workshops with patient and caregiver stakeholders, as well as a wider audience at a national conference via an interactive symposium.

8.2. Methods

The work of this chapter continues to follow the iterative co-design approaches conducted throughout the thesis as a whole and utilised in the previous chapter. Co-design (or participatory design) workshops have been utilised in digital health and mHealth settings with great success, bringing stakeholders together to co-create ideas (Lupton, 2017; Ozkaynak et al., 2021) and group processes such as workshops allow participants to guide the research and engage them in activities to do so.

Conducting workshops remotely over Zoom allows for groups of stakeholders to come together and share experiences across distances, without the expense of travel and time, while also adhering to

COVID-19 social distancing guidelines (which were still relevant during the early stages of this work). However, the requirement of using technology like Zoom to access the sessions may exclude those who are inexperienced with or unwilling to use the medium. To avoid exclusion of participants, and where appropriate (i.e. after social distancing guidelines relaxed), the option to attend an in-person session was provided to participants.

It is recognised that CKD and its treatments have a significant negative impact on patients' lives through symptom burden (e.g. lack of sleep, decreased sexual drive, pain and fatigue) alongside psychological factors including change in self-image, roles and uncertainty of future and health (Cukor et al., 2007; Hagren et al., 2005; Zalai et al., 2012). Patient participation was sought on a prototype derived from insights and feedback about the patient education process, provided by the previous round of workshop sessions with multidisciplinary stakeholders.

An additional opportunity also arose during this phase of research to conduct an interactive session at the UK Kidney Week (UKKW) symposium (Kingsmore et al., 2022). UKKW is the largest event for nephrology in the UK, devoted to all topics and research in all fields of nephrology. For the first time, entry to the 2021 UKKW was opened to professions other than nephrology, and CKD patients. In addition, it was held online allowing for widely varying interactive sessions easily accessible to a broader audience. This exercise was conducted prior to the commencement of the workshops with patients and caregivers.

Participation in the studies was completely voluntary. No pressure or incentive was applied to encourage participation. Ethical approval was granted by the departmental ethics committee for Department of Computer and Information Sciences, University of Strathclyde (ID numbers: 1131, 1319, 1582 and 1791).

8.2.1. UK Kidney Week Symposium Attendees

Registration was free for patients or through renal unit registration, thus minimizing the costs for attending. This allowed a unique opportunity to present and obtain feedback on a scale that would be impossible with traditional work-shop dynamics. A pre-scheduled lunchtime workshop was allocated to the presentation of the prototype (see Figure 8.2 in later section describing prototype in detail) and the conference was held remotely over Zoom due to COVID-19 guidelines.

Ensuring a diverse audience was felt critical to an effective session. Several advertising strategies were employed. Firstly, direct contacts were approached through email 'keep-the-date' fliers shared at 2 weeks and 3 days before the session, to 150 potential participants from the conference delegate list. Secondly, social media was used to disseminate the session with Twitter feeds of organisers, UK renal charities and regional patient groups.

Attendees of the conference were able to join the scheduled session and were briefed on the study at the beginning of the session. Due to the public nature of the session, participants were also free to leave

the session at any given time. Any attendee under 18 years of age was instructed to not participate in the data collection or other activities.

8.2.2. Workshop Participant Recruitment

Adult (i.e. over 18 years of age) CKD patients, patient carers or supporters (family, friends, and patient charities) were recruited through distribution of study information on online social media platforms such as Facebook and Twitter, primarily through the principal investigator's own personal accounts. Charities supporting dialysis and CKD patients were also contacted to request their assistance in distributing study information, notably a local renal charity called ReturnToLife. ReturnToLife has aided recruitment in previous studies and has been contacted directly to confirm their participation in this recruitment. Once the charity had confirmed their assistance in recruitment, they were provided with all necessary materials and information, primarily a poster that could be shared online or printed and displayed. The poster listed the principal investigator's contact details included so interested participants can contact the researcher directly if they wish to take part or request further information such as participant information sheets, etc., and the charity was not required to interact with or manage participants after the recruitment stage.

8.3. Materials and Methodologies Employed

8.3.1. UKKW Symposium: Adapted Methods

Given the large attendance and limited time in the conference symposium slot, data collection was adapted to make more effective use of the 30-minute time slot. Kingsmore and Meiklem presented the session to reduce aural fatigue while Dunlop managed Zoom-related tasks (i.e. launching polls, collating messages and formatting results). This session utilised Zoom's polling feature to collect demographic data and perceptions around patient education, both before and after the demonstration of the prototype in real-time. To attempt onscreen annotation and/or verbal discussions as done in the workshops with an audience of 30+ participants would not have been feasible and difficult to coordinate.

In total, four polls were conducted (1) a demographics poll to collect participants age, gender, and roles (e.g. patient, nephrologist, nurse, etc.), (2) overall opinion on current patient information sources and satisfaction with these, (3) 8 questions on issues with technology-based interventions (identified from findings of scoping review in Chapter 4, see Table 8.2 for questions). A 6-minute video demonstration of the prototype was then shown, following which (4) participants were re-asked the same 8 questions to determine if proposed intervention would improve or worsen identified issues, and if such an intervention would be useful. A 5-point Likert response scale was used to grade the strength of feeling to statements made (strongly agree to strongly disagree, weighted 2 to -2 respectively).

The chat feature was used to collect more open-ended feedback, namely during the "Keep, Lose, Change and Add" exercise that followed the polling, and to allow questions at the end of the session.

While this approach may have produced less detailed and rich data than the workshop discussions, it demonstrated the ability to have a large audience review a prototype live and remotely. Another benefit of collecting data in a quantitative manner rather than qualitative was the researchers were able to analyse and showcase the results of the participants feedback during the session itself.

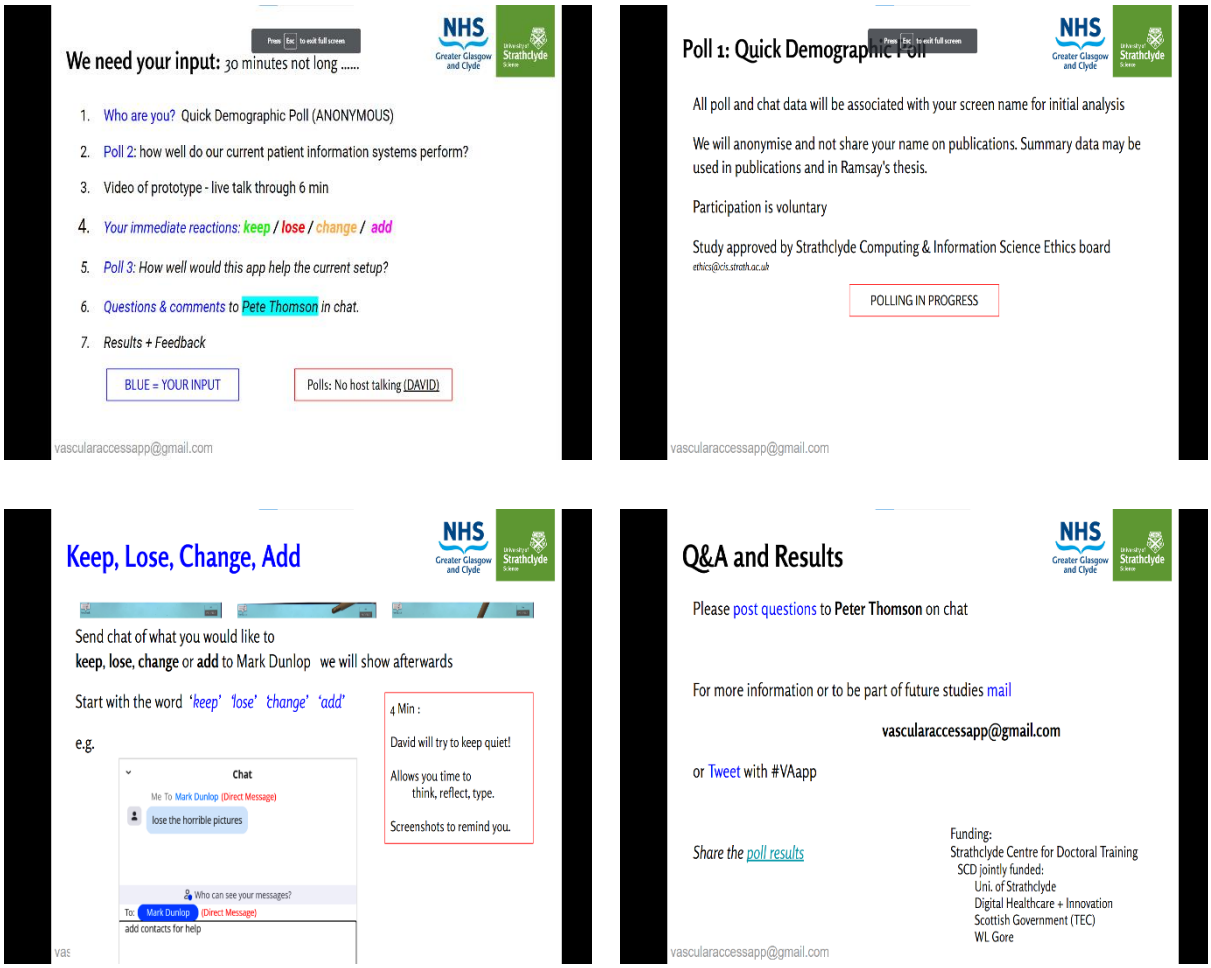


Figure 8.1: Samples of UKKW slides

The addition of "Add" as a category was proposed to create a fourth category for feedback outside the scope of the prototype shown. The original "Keep, Lose and Change" refer to elements of the existing system but the inclusion of "Add" allowed participants a space to list elements that where related to the prototype displayed or entirely new concepts or ideas. However, there was an overlap in feedback in the "Change and "Add" categories from the UKKW exercise following this change and for the workshop sessions that occurred afterwards, the exercise was refined to house both under "Change / Add" as a single category.

8.3.2. Workshops: Stakeholder Patient Education Experiences and Prototype Evaluations

Following the underlying work of the previous chapter, a final high-fidelity prototype for a patient education application was produced by Kingsmore, based on design requirements elicited from discussions and reference to the designs showcased to medical professional stakeholders (see previous chapter). To evaluate the prototype, workshops of CKD patients (as well as caregivers or charities) were conducted, utilising the high-fidelity prototype as a probe.

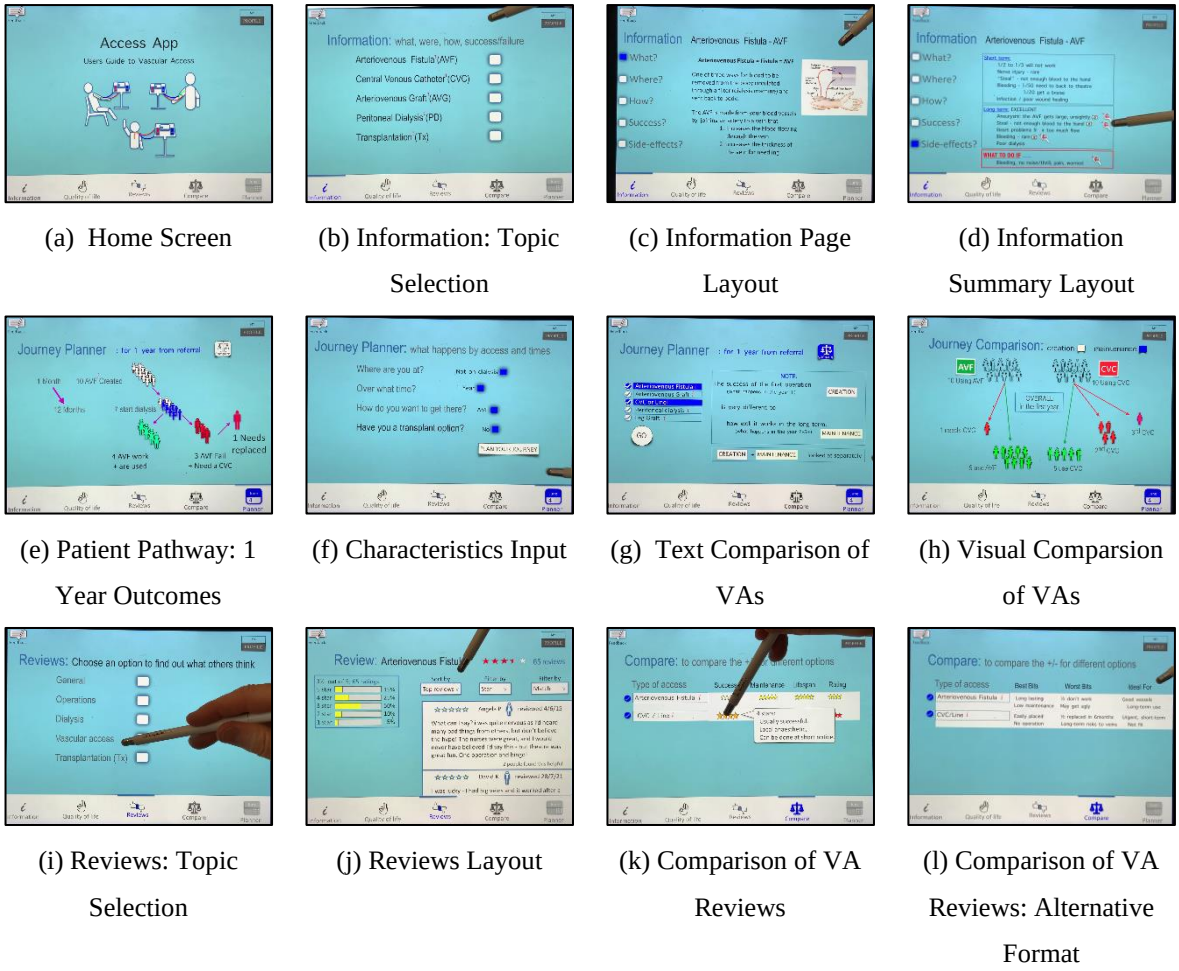
These were primarily held online via the videoconferencing platform Zoom, with various co-creation tools and functionalities utilised to recreate the whiteboard and flipcharts used during in-person sessions (Cesário & Nisi, 2021). At request, in-person workshops were held for those unable or unwilling to engage in online sessions and would recreate the online methods in the traditional physical formats (i.e. paper and pen). These groups would aim to stay within 4-6 individuals where possible (including researchers) (Dodds & Hess, 2020) and all attending participants were asked to complete a demographic questionnaire prior to the session.

Experiences of patient education were elicited through open-ended questions and prompts in a "post-it" note exercise. This exercise sought investigate the participants' experiences of accessing and understanding information, both when beginning treatment and during ongoing treatment. This exercise also allowed participants to begin discussions early in the activities and unburden themselves of points, issues or experiences they wish to share, to avoid them resurfacing in later discussions (Adams & Cox, 2008) focusing on the prototype probe. Participants were free to discuss these prompts in their groups, either audibly or in the chat feature, while adding "post-it notes" to the shared screen via the annotation feature of Zoom or their own paper printouts where in-person. Once these exercises were completed, participants were then shown a narrated video demonstration of the prototype.

Following the demonstration, participants were asked to provide feedback or discuss the prototype shown openly. To prompt feedback, participants were shown three prompts: the traditional "Keep, Lose, Change/Add" (KLCA), following refinement after the UKKW event, and asked to annotate on slides under the relevant headings as well as discuss. As before, the high-fidelity prototype was formed via a digital slideshow, so participants were provided opportunities to revisit the designs or see demonstrations again.

8.3.3. Summary of High-Fidelity Prototype Probe

Following the workshops with medical professional stakeholders, Kingsmore took the lead in further refining the high-fidelity prototypes into one final design, taking the feedback and design requirements from the workshops and implementing it. This resulted in the previously single function prototypes expanding to include multiple key functionalities: information pages, patient reviews, VA comparison and treatment journey planner.



(a) Home Screen

(b) Information: Topic Selection

(c) Information Page Layout

(d) Information Summary Layout

(e) Patient Pathway: 1 Year Outcomes

(f) Characteristics Input

(g) Text Comparison of VAs

(h) Visual Comparsion of VAs

(i) Reviews: Topic Selection

(j) Reviews Layout

(k) Comparison of VA Reviews

(l) Comparison of VA Reviews: Alternative Format

Figure 8.2: Screenshots from prototype demonstration video

Information Pages. The previous prototypes (Chapter 7) focused solely on the visualisation of patients' treatment journeys, with supporting information minimal and mostly focused on complications that may occur. The information pages functionality begins by offering a selection of content to review, focusing on individual VA modalities or renal replacement therapies (i.e. peritoneal dialysis and transplant) with their common abbreviations listed as well. Each is broken into five sections:

- What – description of treatment modality
- Where – physical location of treatment modality e.g. fistula in elbow or wrist
- How – the procedure(s) required to receive treatment via modality selected and how they are conducted
- Success – short-term and long-term rates of success and possible steps if failure occurs
- Side-effects – short-term and long-term side-effects or complications, with a practical information section for referral event of emergencies

The textual information is summarised and concise where possible, and sections include diagrams or animations to better describe processes or procedures. Further information can be accessed through

tapping icons such as the magnifying glass (i.e. more detail) and camera (i.e. photographic images related to content).

Treatment Journey Planner. The pathway visualisations or "Planner" functionality was the primary focus of this work, with each prototype iteration refining the concept further. The final version requires user input to determine the pathway it displays, namely: dialysis status (on dialysis or not dialysing), length of time from referral (1, 2 or 5 years), preferred access (fistula, graft or peritoneal dialysis – these choices were requested to be expanded and listed in familiar terms and not abbreviations in previous evaluations) and if there is a transplant option. Confirming the given parameters, the user interface shifts to display the selected timeline from referral.

For example, if a fistula over 1 year was selected, 10 patient icons are displayed at 1 month with a note of 10 fistulas being created, alongside how 7 have started dialysis at 12 months. From the cohort of 7, a breakdown is shown to indicate if patients change from their fistula (and any subsequent steps) or continue via their fistula. During this pathway visualisation, an icon for the Comparison tool is displayed as well to allow patients to reflect on their chosen access versus those also available. On selection of one or more other accesses to compare against, a note is displayed to remind patients the success of the first procedure (year 1, creation) can be very different to how well access performs in the long-term (years 2 to 5+, maintenance) and so the two periods are treated as two comparisons. On confirmation, the user interface updates to display 10 patient icons and assigns one access to the left and the other to the right of the icons. Two options, creation and maintenance, can be toggled between to show the pathways at the selected stage for both accesses. From the original 10 icons, outcomes are displayed using colour-coded patient icons and arrows to indicate changes in access (red, orange, yellow) or continuation of using the original (green), one side at a time. After both animations have finished, the pathway updates to display a final summary for both accesses and their outcomes. At any point, patients can reset the Planner by tapping the icon in the menu bar.

Patient Reviews. The patient reviews functionality was an addition based on the frequent theme of patients valuing their peers' experiences. Similar to the Information functionality, Reviews first displays five topics for users to select from (i.e. general, operations, dialysis, VA, transplantation), which expand into specific topics (e.g. VA encompasses fistulas, grafts, and lines). A small red "*i*" icon beside terms can be tapped to provide more detail on definitions or explanations of terms. Once a topic is selected, reviews and other metadata is displayed. This includes an average rating (out of 5 stars), count of reviews, rating distribution (e.g. 15% gave 5 stars, etc.) and individual reviews. The reviews are displayed as a list, each with review text and a rating, author name, gender icon and review date. The icon of a male or female figure can be clicked to reveal further details about the reviews author such as age, when they started renal replacement therapy and how. A count of upvotes from other users is also

displayed if applicable. Above this list view were options to sort or filter the shown reviews by characteristics (e.g. by rating, age group, gender, treatment history, etc.)

VA Comparison. To better summarise and allow comparison of different VA modalities, a comparison functionality was also included. The previous series of workshop sessions noted the need for pros and cons of each modality to be made clearer, as well the issues of information resources discussing each in relation to others. In a table format, users can select two or more VA and/or treatment modalities (fistula, graft, line, peritoneal dialysis and leg graft), and then review and compare the selected options under the headings "Success", "Maintenance", "Lifespan" and "Rating" via a 5-star rating system, with 5 stars being coloured gold and lower values (e.g. 2 stars) coloured red. Tapping on a star rating would reveal further information about the rating in a pop-up textbox. Swiping from the right side of the comparison table would reveal summarised comparisons under headings "Best Bits", "Worst Bits" and "Ideal For". In this view, the visual ratings are replaced with brief points to highlight the positives and negatives of the accesses selected, along with a suggestion for what situation or circumstances the modality would possibly best fit.

8.4. Results

8.4.1. UKKW Participant Demographics

Table 8.1: Demographics for Participants of UKKW

Participant Characteristics		Individuals (total n = 30)
Gender	Male	19
	Female	11
Role/Specialty	Nephrology	14
	Surgical	4
	Nursing	3
	Patient	2
	Other	7
Age Group	18-30	1
	31-40	10
	41-50	10
	51-60	8
	61-70	1

The n=30 participants who completed the demographics poll showed variation in all aspects: nephrology was the leading specialty represented (n=14), (surgical n=4, nursing n=3, patients n=2, other roles represented n=7). The age distribution showed a predominance of ages between 31-50 (n=20,

68%), with 9 being older and 1 younger; 19 were male (63%) and 11 were female. Table 8.1 details the complete data.

8.4.2. UKKW Poll Responses and Analysis

8.4.2.1. Sources of Information and Satisfaction

Figure 8.3 demonstrates the percentage of responses to the second poll, with three questions:

1. How do patients get information? (multiple choice)
2. What is the best? (single choice)
3. These methods are good enough and no further information is needed (5-point Likert, Strongly agree to strongly disagree)

The responses to the poll on information sources saw 'Verbal' as the most cited source (90%) and considered the best (n=14, 48%). All other sources were considered poor with less than 25% rating them satisfactory despite wide use. For example, the internet was cited by 80%, patient peers ('other patients') 75% and paper leaflets the least, at 60%. Other than verbal, the sources were not regarded highly and less than 25% felt they were the best source.

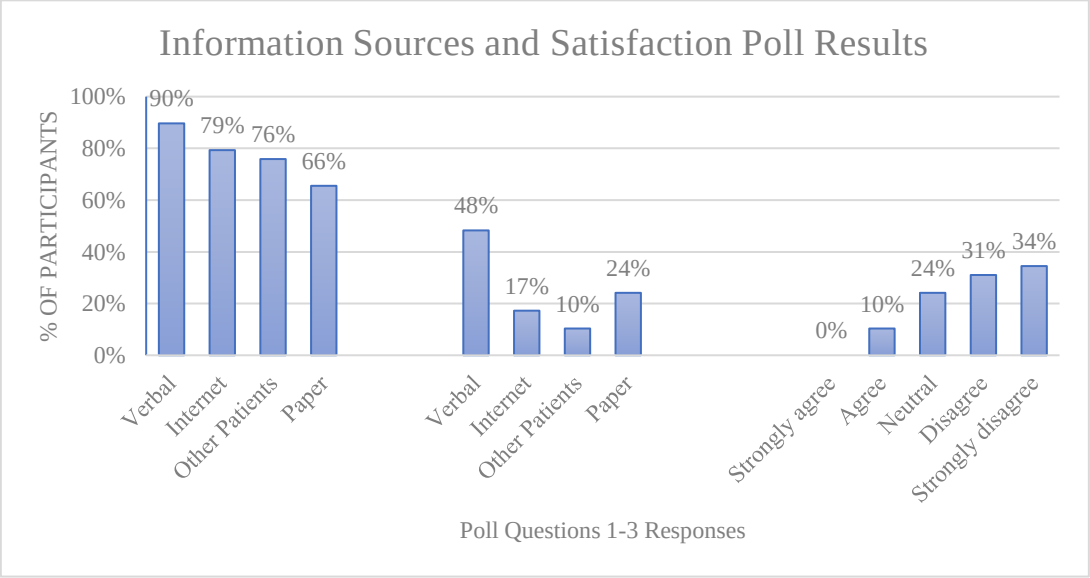


Figure 8.3: Bar chart of Information Source Poll Questions and Responses (left to right: Q1. How do patients get information? (multichoice), Q2. What is the best? (single choice) and Q3. These methods are good enough and no further information is needed (strongly agree to strongly disagree)).

When posed the statement "current sources are satisfactory, and no other information source is needed", only 10% of participants agreed and none strongly agreed, while over half (65%) disagreed or strongly disagreed. These results highlight the issues with existing paper information materials and the need for a better resource, as well as the perception verbal (i.e. consultations) is the best and any proposed new source should not aim to replace it.

8.4.2.2. Current Information Provision Poll

The eight aspects of interventions were based on the findings of the scoping review in Chapter 4, resulting in the eight questions listed below along with the relevant theme:

1. Patients can easily get the information they need when they need it. (Accessibility)

2. Patients read the current information in detail. (Engagement)

3. Patients can apply the information to their situation. (Applicability)

4. When treatment changes the information remains useful to their situation. (Relevance)

5. Patients refer to the information in discussions about their treatment. (Informed Consent)

6. Patient information is consistent, reliable and high quality. (Quality of Information)

7. Patient information covers all the questions patients have in their mind. (Breadth of Information)

8. Patients keep information provided with them to refer to throughout their journey. (Longevity)

All questions saw negative overall scores for current information provision, with the poorest performing being Q8 (longevity of information), suggesting patients struggle with maintaining sources throughout treatment.

Table 8.2: Table with Results of Information Provision Poll

Questioned Posed and Scoping Review Theme Addressed	Strongly Agree (2)	Agree (1)	Neutral (0)	Disagree (-1)	Strongly Disagree (-2)	No Comment	Mean Score
Q1: Accessibility	1	2	12	13	0	-	-0.32
Q2: Engagement	0	3	4	18	3	-	-0.75
Q3: Applicability	0	0	21	17	10	-	-0.49
Q4: Relevance	0	10	6	12	0	-	-0.07
Q5: Informed Consent	0	6	10	9	1	2	-0.19
Q6: Quality of Information	0	7	7	12	1	1	-0.26
Q7: Breadth of Information	0	3	6	15	4	-	-0.71
Q8: Longevity	0	1	2	12	9	4	-1.21

Only 1 response was rated as 2 i.e. strongly agree out of 28 others, for Q1 (patients can easily get information when they need it), while there were primarily neutral (n=12) and negative responses (n=13). Most participants thought patients did not read information in detail (Q2, 70% disagree or strongly disagree) and there was uncertainty if patients could apply information to their situation (Q3, n=21 responded neutral) however n=27 disagreed with the statement, and none agreed. A small portion

agreed that information was “consistent, reliable and high quality” (Q6, n=7) but less than half of responses felt “information covers all the questions patients have” (Q7, n=9).

Overall, the order of worst to least poor was:

1. Q8 – Longevity (“keeping information with them”), score of -1.21
2. Q2 – Engagement (“reading the information in detail”), score of -0.75
3. Q7 – Breadth of Information (“covering all questions patients have”), score of -0.71
4. Q3 – Applicability (“applying information to their situation”), score of -0.49
5. Q1 – Accessibility (“easily get information”), score of -0.32
6. Q6 – Quality of Information (“consistent, reliable and high quality”), score of -0.26
7. Q5 – Informed Consent (“refer to treatment in discussions”), score of -0.19
8. Q4 – Relevance (“treatment changes and information remain relevant”), score of -0.07

Questions 8, 2, 7 and 3 were the highest scored, indicating the main faults of current information provision as patients failing to keep information throughout the journey for referral, reading it in detail, and applying the information to their own situation, as well as the information failing to cover the breadth of questions patients may have.

8.4.2.3. Potential of Intervention on Information Provision Poll

Following the prototype demonstration, responses to a poll on the impact of the prototype on information provision were collected. Overall, mean scores were much improved with 7 of 8 overall answers positive the intervention could make the aspect better (see Table 8.3).

Table 8.3: Table with Results of Prototype Impact Poll

Questioned Posed	Much Better (2)	Better (1)	Neutral (0)	Worse (-1)	Much Worse (-2)	No Comment	Mean Score	Difference in Mean Score
Q1: Accessibility	11	16	0	1	0	1	1.32	+1.64
Q2: Engagement	2	21	4	0	0	2	0.93	+1.68
Q3: Applicability	8	17	3	1	0	-	1.10	+1.59
Q4: Relevance	10	16	2	0	0	3	1.29	+1.36
Q5: Informed Consent	6	19	3	0	0	2	1.11	+1.30
Q6: Quality of Information	12	10	5	0	0	2	1.26	+1.52
Q7: Breadth of Information	3	21	2	1	0	6	0.93	+1.64
Q8: Longevity	7	15	4	0	0	3	1.12	+2.33

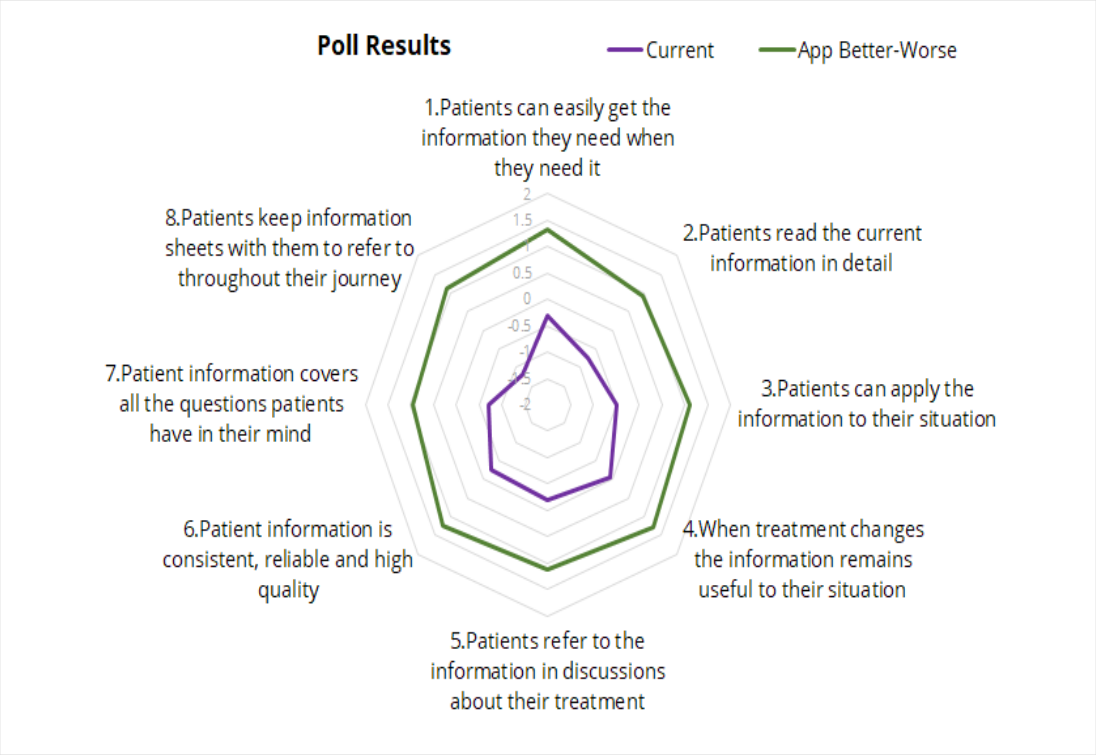


Figure 8.4: Radar Plot of Mean Scores for each question from 1st and 2nd polls, shown during UKKW.

Only Q7, "covers all questions patients may have", remained below the positive mean score (0.73). However, change from the current provision of information was positive for all aspects, the greatest impact on "keeping information to refer to through their [patients] journey" (Q8), rated as the lowest scoring aspect in the prior poll. The concept of the prototype had the greatest positive impact on "ease of access to information" (Q1, 1.32), "useful in response to changes in situation" (Q4, 1.29) and "consistent, reliable and high quality information" (Q6, 1.26). The positive change in scores was analysed during the session and participants were shown Figure 7.4 to highlight how their input had improved with the introduction of the prototype.

An additional question was also posed to determine if "an app like this would be useful", resulting in an overwhelming positive response, with 55% of participants strongly agreeing and the remainder agreeing (45%). Both polls demonstrate the need for an intervention to support patients in their information provision and use, with clear potential improvements to problem areas and positive reception from the different stakeholder roles present.

Table 8.4: Participant Characteristics for Co-design Workshops

Workshop	Participant ID	Sex	Age (yrs)	Dialysis Status	Experience (yrs)
P1 (Online)	Patient 1	M	74	Previously received dialysis	1
	Patient 2	F	64	Previously received dialysis	10
	Patient 3	F	54	Previously received dialysis	3
	Caregiver 1	M	64	*Patient spouse/caregiver*	3
P2 (Online)	Patient 4	M	33	Currently receives dialysis	12
	Patient 5	M	54	Previously received dialysis	3
	Patient 6	F	23	Currently receives dialysis	2
P3 (Online)	Patient 7	M	68	Currently receives dialysis	2
	Patient 8	M	66	Currently receives dialysis	6
	Patient 9	F	49	Currently receives dialysis	3
	Patient 10	F	26	Previously received dialysis	1
P4 (In-person)	Patient 11	M	65	Currently receives dialysis	35
	Patient 12	F	66	Previously received dialysis	4
	Patient 13	M	62	Currently receives dialysis	5
	Patient 14	F	26	Currently receives dialysis	6

8.4.3. Patient Workshop Participants Demographics

Patient participants (n=14) attended four co-design workshops (n=3, n=3, n=4 and n=4 respectively) following the UKKW symposium session. Half were female (50%), the average age was 52 years (range 23 to 74 years) and the average number of years' experience of dialysis was 6.6 years (range of 1 to 35 years). Of the patient participants, just under half had received dialysis previously (42%) while the remaining were currently receiving dialysis. In addition, a patient caregiver also attended the first session (male, 64 years, 3 years' experience of dialysis), alongside their patient spouse who also participated.

8.4.4. Framework Analysis

This section details the results of the framework (Korhonen et al., 2016) analysis, compiling the topics discussed by the workshop participants under the five key concepts of the framework: competence, patient-centredness, support, technology and uniqueness, each with its own aspects. This framework was previously utilised during both the scoping review of patient-centred and technology-based interventions supporting patients with high treatment burden (Chapter 4) and the analysis of the workshops with medical professional stakeholders (Chapter 7). Consistent use of the specified

framework allows comparison with not only the literature but also the findings of the previous workshop sessions and examines how the prototype and functionalities fulfilled the five concepts. Any original themes that occurred as a result of this or earlier analysis that are added to the framework will be clearly defined as such (e.g. *Barriers* and *Motivations* within the Technology concept, first identified in the scoping review – see section 3.7.3 Thematic Analysis for full details).

The process of thematic analysis involved repeated listening and reading to ensure accuracy (of transcribed data e.g. audio recording of co-design workshop) and understanding of the data. Coding was completed using the NVivo software (Dhakal, 2022). The transcriptions and outputs of all patient sessions were analysed together rather than separately, to identify common themes and ideas, while also identifying where some individuals or groups provided unique themes and concepts which may have not occurred in other sessions. Analysis of each group separately would provide richer and more unique results but would then be more difficult to synthesis into design requirements that meet the wider needs of the whole community.

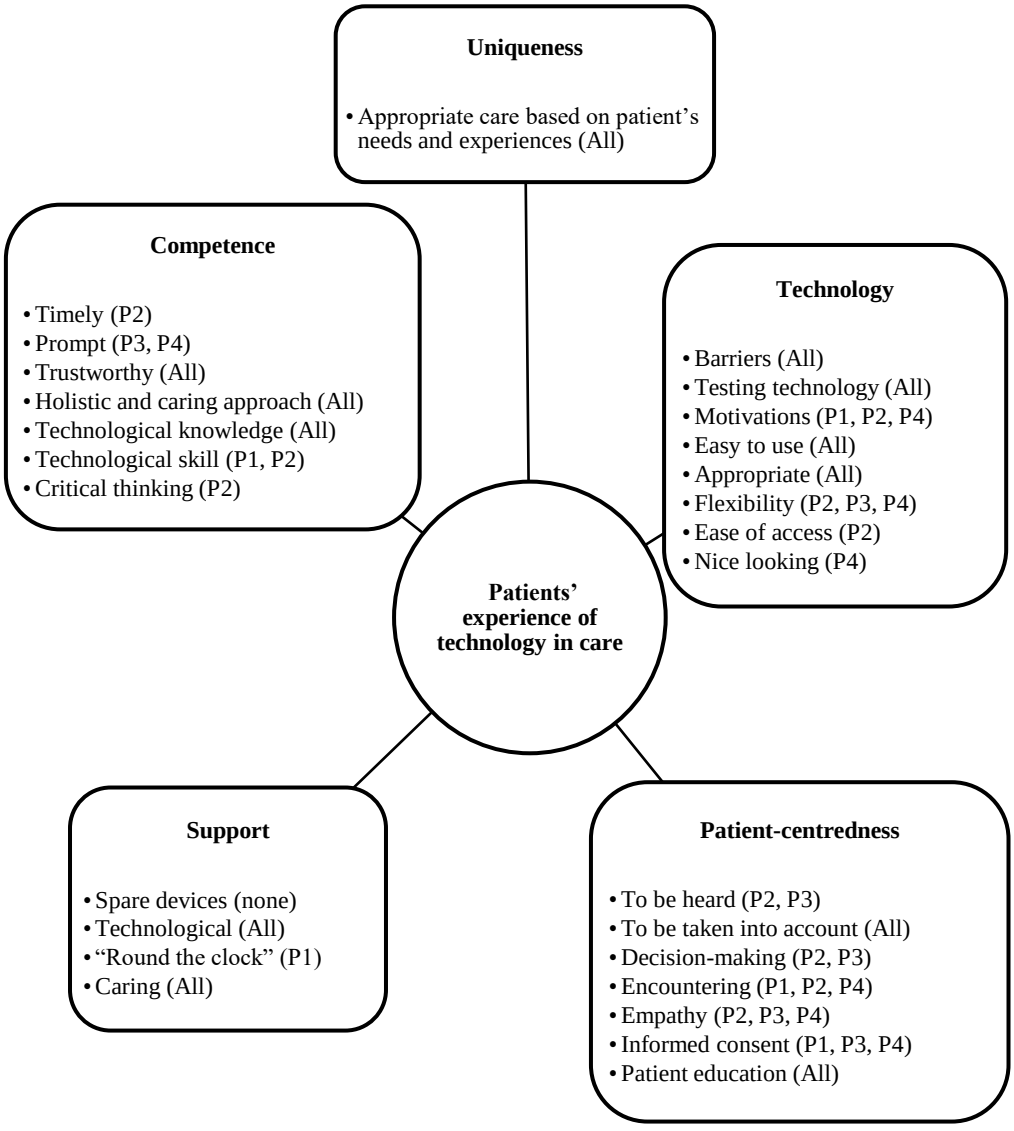


Figure 8.5: Prevalence of themes across workshops

8.4.4.1. Competence

Timely: The provision of information and care in relevance to time. Patient participants discussed needing to take time to process and understand information, partly due to the volume of information they needed to absorb.

" I think, talking about it, but I know that's a lot of time. Just for someone starting I think it's a lot. It's quite daunting to have all that information." – Patient 4

This is further hindered if they are pressured due to deteriorating kidney function and the emotional burden of their condition. For example, Patient 4 noted that talking with a healthcare provider was one of the best methods of getting information, but this requires a great deal of time. Other participants added the prototype could be a useful tool to utilise to understanding information in their own time, whether when first deciding treatment or once settled, even during lengthy dialysis sessions itself.

"I feel like a way to do that is probably sit down with the family and like show them this, in this way. And they would be able to take that and kind of go over all the information themselves in their own time." – Patient 6

Technological knowledge: This theme covered the participants' knowledge of technology and its uses within care settings as patients. Participants discussed various technology-based resources, such as search engines (i.e. Google), kidney disease websites, social media platforms (notably Facebook groups and pages) and video platforms like YouTube or TikTok. PatientView was also discussed but is primarily utilised to view test results and other personal clinical data. However, the appropriateness of these resources was also raised, as some are not relevant to the patient (e.g. American versus British or NHS websites).

"Most of the- when you go on the Internet you don't know whether you're on an American site or a British site right? And the thing you usually do when you go on to [kidney website], it told you that you had 6 years to live!" – Patient 8

Caregiver 1 noted they often relied on resources from other countries when supporting Patient 3 in home dialysis, often referring to YouTube videos, and felt the resources provided by the NHS were lacking in comparison. In contrast to the stereotype of older adults, they desired to see more technology being utilised in their care, if it meant they would be able to communicate with providers and receive support more effectively. Patient 11 also challenged the stereotype, knowing patients older than himself who regularly accessed technology, through public services at local libraries.

"It [accessing technology as a barrier] shouldn't be, I know two elderly ladies. From dialysis with me. I'm in my late sixties and so I don't consider myself elderly but they're in their late 80s. Both of

them go to the library at least twice -a fact, if they're not on dialysis, they go to the library. Yeah, and they love going to the library. Access to PC. Every Glasgow library has PC." – Patient 11

Participants also discussed familiarity with technology, with some citing they themselves wanted nothing to do with modern technology (e.g. social media, smartphones, mobile applications) while many of the participants noted that the majority of CKD patients would struggle with technology or would be unfamiliar with it, in reference to the fact the cohort is typically older and frailer than general populations. Younger patients like Patient 6 understood their older patient peers may not engage with social media but found they were able to find content they could relate to, such as other patients sharing their "dialysis stories" online on the platforms. Patients 2, 12 and 14 also described using Facebook groups centred on dialysis for information and support. However, information and experiences discussed in these communities could often be very specific or personal and they had learned not to compare their condition against that of others, again raising the issue of relevance of information to the individual.

"I know from previous sessions with P6 some of the stuff she brought to the conversation about social media and things like that can help, that… there's going to be a group of people who find this very natural and there's going to be a group of people who will find it very difficult, I think." – Patient 5

These discussions demonstrate the variety of patients present within the workshops and how their needs and preferences differed. For the intervention to be of relevance and use to this varied user population, it will need to be flexible in approach to information provision.

Technological skill: Similar to the previous theme, this one refers to any skills patients describe when utilising technology. Such skills were often noted from those who expressed familiarity with technology. For example, social media platforms were used to share experiences and support patient peers, and researching online sources produced many different views, as described earlier.

"So I joined various different dialysis and transplant [Facebook] groups. And the information you get on that, it works in two different ways. If you've got people on the group who are knowledgeable, then they correct incorrect [information]…" – Patient 2

Patient 5 picked up on the level of effort required to utilise the prototype, concerned that the generally older CKD population would struggle if expected to swipe or tap elements to find more information. Patient 6 proposed supported use or training sessions with staff could allow less skilled patients the opportunity to engage with the technology, which Patient 5 agreed would need to be available.

"I'm concerned about how complicated it may be getting. Swiping. Click, clicking on ratings to see a pop up with more explanation. I reckon -I don't know what the average is age is of someone getting a fistula but if it's 60 years old, then I think you do need to think about demographics." – Patient 5

"Patient 5 is right. Like some people might not be able to like use the technology, which is why maybe a nurse could go through like half an hour of dialysis to teach them how to use it, or something." – Patient 6

They continued the discussion by noting the best impact would be made by making the intervention readily available to patients – those skilled and familiar with technology would be able to make use of the features while others might need the assistance and support from staff. Participants in the fourth session shared similar opinions on the availability of the technology. These points again highlight the variation in patient characteristics and the challenge of designing a usable system that all can benefit from, with the possibility that the best solution for inexperienced and unfamiliar users is using it with someone else assisting. This reflects the recommendations of Burgess et al., who considered collaboration between patients and others more effective for less engaged patients than a purely technological intervention (Burgess et al., 2019).

Critical thinking: Patient participants described critical thinking in reference to applying information to their own context. Peer experiences were highlighted as a vital source of information by the previous workshops, and so the patient reviews feature was included in the prototype shown. However, as noted above, patients must interpret the experiences of patient peers and gauge the applicability that information had to their own circumstances.

This included considering other health conditions they lived with and how they interacted with the context of CKD (e.g. Patient 6 found it hard to compare with peers due to sepsis originally triggering their condition, and Patient 12 explained their condition was result of an autoimmune disease). Despite questions around the reliability of the reviews that could be included in the feature, participants (notably those of the second and fourth sessions) agreed that they felt most people would be able to make their own judgements on the relevance of their peers' experiences and would utilise the information how they wished.

"No, I think everyone can tell like, a review if someone's like -if there's like 100 people saying: yeah the fistula is great, and then there's one person saying: I had such a bad experience. It's like Amazon, you know, like you mentioned, if you see 100 people saying this product's great and then there's one person goes like "I don't like it" then you'll trust the 100 people, it's just normal like, I think. A lot of will be able to kind of judge for themselves." – Patient 6

"People use it different ways. People will just look at what is rated the highest or people's best experience, but other people will then go in and look through want to look through every review just to know what your experiences." – Patient 4

"You just gotta accept the fact that everybody looks at things differently." – Patient 11

Prompt: The theme of prompt was only identified in a discussion with Patient 3, who reflected on when they had experienced a complication with their VA (i.e. they had not been aware of the possible complication and expressed that they wished they had been aware of it at the time, through more information at an earlier stage).

"…these were things I hadn't really thought about asking the doctor, so I didn't really have much information on that." – Patient 3

The theme was further discussed where participants reflected on not knowing to ask questions, without first knowing about the topic (e.g. only becoming aware of the complication when it happened). These examples highlight the need for patients to be prepared either through earlier work up and thorough discussions with their providers, or by being prompted to ask questions of their providers. The latter is an opportunity for a resource such as the prototype to be utilised, giving patients broad and general information so they are aware of potential outcomes or are prompted to follow-up with their providers.

"But I think preparation and knowledge is power, and I think that's two of the main things I would say." – Patient 12

Holistic and caring approach: The theme of holistic and caring approach covers various subthemes. Participants expressed the need for a gentle approach to starting dialysis, citing fear and anxiety with beginning treatment and a life-changing activity (i.e. facing the idea of a foreign body being inserted into their body, cannulation with needles, the dialysis wards and machines, etc.), and looking for reassurance from providers. Patient 8 commented that patients sometimes need to visit the ward and see the dialysis machine several times to fully comprehend the process, reflecting the comments in the previous workshops around repeating information over time to ensure it was understood and taken in.

"Now see at that time, your mind isn't in the right place so you'll no take in what's happening. You'll maybe need to be shown the machine a few times. No a few times, you'll no have time for that but eased into it a wee bit easier." – Patient 8

Holistic and caring approaches to care must also take the patients' preference and priorities into consideration, as these will influence patients' decision-making. For example, Patient 5 noted when they started dialysis, they opted for the modality that was the most viable long-term in order to be around for their young family, rather than the most convenient at the time. In contrast, Patient 6 was dealing with the impact of sepsis and dialysis became "constant" throughout the process, with them only now beginning to learn and understand CKD fully. Patients 11 and 13 both prioritised continuing to work, and Patient 14 was primarily concerned with feeling better, all aiming to keep their lives as similar to how they were before their disease. For a resource like the prototype, this requires information provision to be flexible, adaptable to different circumstances and situations and relevant throughout the patient's journey i.e. the longevity of the information.

"And I was interested in initially which options were available to me and what the advantages and disadvantages of each of them were. Not in, not only in terms of in medically, how many times a week you did dialysis, but things like: will it have an impact my working life? I've always worked and so –I did it up at the [hospital] and I went. I worked until 7:00 o'clock at night. And then come straight, yeah, finished at 1:00 in the morning, went home, went to bed. Back up at 7:00 and went to work again, which is important to me." – Patient 11

Patients 6 and 14 were also able to provide the unique perspective of being a younger patient (e.g. Patient 6 started dialysis when they were 20 years old). They discussed the difficulty in relating to older peers, and saw the patient reviews feature as very progressive, giving them a resource where they could find experiences more similar to their own. Age is another factor in how care can be delivered, as older patients will have different experiences and priorities to that of their younger peers. The role of the prototype is to give patients the information they need in a format that allows them to easily make meaning of it in their own context.

"I didn't know that there were younger people that could even be on dialysis up until six months ago. I thought I was just like the only case in Scotland [laughs.] So like I mean like I feel like it's so -it's very progressive idea, I feel like it's really good." – Patient 6

Trustworthy: Trust was typically identified in examples of the relationship between patient and provider. Patient participants expressed faith in their healthcare teams and described the reassurance they felt from their staff. This was often attributed to patients viewing consultants as the expert in discussions or in the case of Patient 8, placing responsibility on them due to their roles and knowledge.

"And I'm quite happy to say: look I don't know, I will never know a fraction of what you know, you tell me what you think is best. And I have the confidence to go with that." – Patient 1

"I know for a fact they doctors never put anything into me that wasn't for best of my health, so you want to go that way, although you can say: 'you want this, you want that', at the end of the day you are guys that are doing it and you are the guys who should know." – Patient 8

Peer influence and testimonies were regarded by providers as one of the key influences on patients' decision-making, as they often highly value the lived experience of peers. However, Patient 8 raised how patient peers can also be a source of disinformation, due to personal opinions and experiences both negative and positive, questioning how a new patient can trust their peers and be sure they can apply their information to their own situation. This again brings up the topic of patients needing to navigate their sources carefully and make their own judgements on if the information is relevant to their own situation.

"Also, when you're talking, a lot of disinformation comes from when you're waiting to go in your dialysis session. You're actually in a corridor with people who, let's say they're no very happy with the doctors. They'll no tell you [consultants] that, but they'll tell me that. And that's when you get a lot of this disinformation." – Patient 8

Finally, Patient 6 mentioned they felt the diagrams and animations used in the prototype "sugar-coated" what actually happens in the process of VA provision and treatment. A similar theme was described by nurses in the previous chapter, who tried to be honest when discussing treatment and avoid sugar-coating the reality (while also not distressing patients).

"I think it looks less gory but I think that, like it hides, it kind of sugar coats what we're really going..." – Patient 6

In this case, Patient 6 thought realistic photographic images would be more suitable, preparing the patient for the reality of dialysis. The subject of photos was raised in the prior staff workshops, but the topic of appropriateness of photographic images will be discussed further in the following section. Discussions such as these show there is a balancing act in information provision, between providing the whole truth as it is and delivering information in such a way patients are not overwhelmed or distressed. For technologies such as the intervention proposed, this is best achieved by letting patients decide how much they wish to see.

8.4.4.2. Patient-centredness (originally *Respect of Human Rights*)

Patient education: Given the individuality of each patient's treatment, the participants had different experiences and discussions around the subject of patient education. For example, Patients 9 and 10 had attended staff-led workshops on VA, but felt the information given was too generic or broad, lacking detail on specific points and Patient 10 was left unsure which option was the best for them afterwards.

"I think it was a similar one [workshop]. I think it, I think it was a doctor that talked about the different -peritoneal and the haemodialysis and like how they were done… but again, similar to Patient 9 I think, I felt that you needed to know pros and cons for both because I even after the workshop I wasn't quite so sure which one was the best, personally for myself." – Patient 10

Patients will look for practical information about how their treatment will impact their lifestyle, including elements like careers and hobbies, and where the expectation of treatment does not align with the reality, patients cited frustration. Patient 1 recalled feeling unprepared for the day-to-day commitments of peritoneal dialysis such as dedicating a room to storage of and managing medical supplies, which outweighed the perceived benefits. Other factors also determine the best-fit for each patient and how they will approach learning about CKD and treatment, such as other health conditions they may have, limited options and sometimes purely preference, including opting for the option recommended by their consultant or preferring to separate dialysis from their everyday life. Patients 4,

9 and 14 commented when starting the level of information was daunting or overwhelming and can be too complicated to express through images. Patient 9 added that given the volume of information shown in the visuals, they then sought understandable information, such as a percentage or summary of outcomes.

"I probably wouldn't have taken very much and like I was really overwhelmed by it all. It's quite daunting and I think I just went for what I thought would have been the quickest and maybe easiest option. ...I didn't really want it in the house, you know, I would -I like the idea of just coming home and being able to forget about it." – Patient 14

When posed a question on focusing more on the practical and simplified outcomes of different modalities, patients felt that although the information needed was becoming more complex, this was acceptable given the complexity of the decision they needed to make. Therefore, this information should be included and emphasised to ensure patients are fully aware of what is involved with each option as well potential complications. This also needs to be delivered in a way patients can choose to intake a large volume or can find the easy-to-read summaries as they prefer.

"It's I know I know it feels like it's like getting more complex, the more things you change and stuff but it is a complex decision to make." – Patient 6

The visual elements of the prototype were a topic of discussion by participants, with the restroom icons being praised for communicating risk more effectively. However, some felt that the diagrams and animations demonstrated were not adequate and wished for other formats, like video and photo images. The photographic content in particular was debated, as some participants like Patient 6 felt they would rather see the reality of treatment and be prepared for it, already experiencing such graphic sights in their treatment. However, others disagreed on the acceptability of this and felt that graphic or sensitive images should censored and only shown if the user chose to see them (discussed in detail later under Technology (Appropriate)).

"Yeah cuz I think you can see it better. What you've been through and then other people can kind of see it as well." – Patient 10

The patient reviews feature was also well-received, especially by younger patients like Patients 4, 6, 10 and 14. While most confirmed they valued hearing their peers' experiences, some struggled to find relatable experiences or patient peers of a similar demographic in their "sphere" at clinic, and so the concept of the patient reviews would allow them to seek out experiences and information from others similar to themselves. All participants had experience of engaging with peers and learning from their experiences, whether this was directly provided or second-hand, such as seeing other patients in clinic have complications or disfigured fistulas. In contrast to the findings of the previous chapter that patient peers were highly valued, Patient 8 had found in their experience that patient peers' opinions were largely negative and too personal (Patients 9 and 10 also agreed with this opinion) and could often be a

source of disinformation. Despite these issues, most patients felt the reviews functionality was very useful, with patients using it capable of discerning biased reviews and extracting the information they need, such as overall ratings or reading in more detail to find specific elements of interest in reviews (e.g. swimming or bathing). Requests for further filtering of data were made, such as more refined age groups or by race.

"I think this is actually really good, because what I was saying before was you read all these places, or you talk to patients but you're only getting sort of in your sphere, or in your dialysis ward or whatever, people's experiences. So you might not get people of your demographic but I think this is really good that you can match with people the same as you." – Patient 4

The topic of overly negative or unbalanced information was also present when discussing the content of the journey and treatment pathways. Patients 6 and 13 felt there were primarily negatives i.e. complications and there were more of these for one VA than the other when comparing both. They were concerned that this would encourage patients to choose one over the other, without knowing the potential pros as well as cons of both. Terminology was also critiqued at stages, with clinical terms and procedures described as jargon and off-putting for unfamiliar patients. Participants understood there would be an element of clinical information required but expressed this needed to be easier to understand. The explanation feature shown in the information feature was highlighted as a good solution to this problem.

"You know, there's so much jargon [medical terminology] again, but you, you've covered it." – Patient 13

Finally, the concept of the app was welcomed by all participants. They appreciated the idea of a "one-stop-shop" or single resource that could be relied upon, especially for preparing themselves for what to expect (rather than learning as changes occur, such as the potential of a transplant arising), using it with family so they are all informed and being able to read in detail or just skim over what they felt was relevant.

"I think it's a good idea, especially at the end there, when you said you could take it home for the family." – Patient 8

"Access. Access to the information you want, as opposed to reading a damn book that is either too short or too long." – Patient 13

The point of preparing and planning was described as difficult but important by patients, with Patient 5 noting the long-term plan is not always the priority when their health is so poor, and they need to immediately start treatment. In this case, having key time stages and overall summaries are both appreciated, giving patients the opportunity to mentally prepare based on the expected or potential outcomes described. Overall, these comments show the development of the intervention is heading in

the right direction and the need for such a tool, albeit with further refinements to the format of content, such as including realistic images, practical information and more clearly demonstrated pros and cons.

"This is what we've all been craving all of us, myself, Patient 1, Caregiver 1…I mean by the sound of it as well. We all came into this blind. And you have no idea what's ahead of us you've no idea what to expect and you're going along and you're learning as you go along." – Patient 2

To be heard: The previous set of workshops did not identify any examples of "to be heard" – this was attributed to the fact this is a theme patients would express rather than their providers. Patients 5 and 8 described examples of feeling unable to input into their treatment or feeling like there was no debate despite their preferences (e.g. Patient 5 did not wish to use a fistula due to their fear of needles). Patient 6 raised a different issue within being heard, focusing on the unfamiliarity the general population has with CKD and appreciated the reviews functionality for allowing patients to share their experiences and stories.

"It's such a hard disease to deal with, but like also people don't know where that no one knows about it, nobody knows what anyone's going through. I didn't know that there were younger people that could even be on dialysis up until six months ago." - Patient 6

To be taken into account: Patients being taken into account in decisions and discussions was a theme which was promoted in the providers workshops, but there were examples from participants feeling dissatisfied with decisions, where they were not fully informed of why changes had to occur. Patient 8 in particular believed that their input did not matter, and it was the responsibility of the clinical staff to make the correct decision.

"And then I think the whole essence of dialysis has to be taken around that individual and that's where the real big personal system comes in, I think." – Patient 9

"That's a huge thing for me, you know that. Control is the biggest thing for me, to have control and to be able to see it before… actually I don't think that's a real want to go down or tell me more about this, so that I can make the choice, myself, and you're not making that choice for me." – Patient 2

On the other hand, for some patients, there was a sense of control to be gained from being fully informed and having the ability to decide for themselves. Examples of this included frequent checking of PatientView, to monitor clinical outcomes such as potassium levels. When posed if being able to opt-in to track their health and journey through the prototype would be useful, those already confident in such behaviours responded yes, but were aware others may not be comfortable sharing data in this way.

Decision-making: As described by Patient 6, the process of decision-making for CKD and treatment is a complex, with many options and routes of treatment differing in viability given characteristics often

outside the patient's control. Participants often felt that they were not given a choice in their consultations or were very limited in the available options.

"Because I don't know if you have a choice, and I still don't know if you have a choice, you know between the fistula or the whatever. But I'm saying why do I need to come off of this? I'd rather have this, given what I said earlier about the disfigurement and that, you know, personally I would keep the line. But that wasn't given as an option." – Patient 7

Decision-making also needs to take into account the priorities of the patient (e.g. some patients will value being able to have a bath, leg grafts for body image concerns, long-term viability for a young family, etc.). This reflects the need for shared decision-making within CKD, with the clinician sharing their medical expertise and experience and the patient (and caregivers) sharing their values and concerns to achieve a decision that balances medical risk and benefits with patient preference (Charles et al., 1999). To better support shared decision-making, tools such as the prototype could be utilised as decision aids, potentially leading to improved decisional outcomes for CKD patients (Frazier et al., 2022).

"It's a balance between how prescriptive you want to be with the flow of this. Because you may want to say: 'Here's things you'd want to consider...', instead of do you enjoy having a bath, is that a big thing for you? Then, can you have a bath with some of the access types? Because that could, you know I'm not saying that will make, that's not this sole decision-making point – but someone may want to know." – Patient 5

Informed consent: This topic was chiefly discussed by surgeon participants in the previous workshops, with references to the Montgomery v Lanarkshire case (Campbell, 2015) changing the way in how fully informed consent is achieved by the patient. With the possibility of all and any treatment option being relevant to the patient, providers are tasked with making patients aware of all options and outcomes, with thorough explanation. Patient participants reiterated the need to view the positives and negatives of all options, similar to nurse participants previously. However, they found the prototype a great resource to aid their understanding and become fully informed, stating they wish they had information like this at the time of their decision to assist in making a fully informed choice.

"It wasn't a choice. Having this [prototype] and looking at this, I can make a more informed choice. And I think, from that point of view, this is a great thing for new people coming on to dialysis to give them that information and that's what it's about, it's about the informed aspect." – Patient 2

Empathy: Participants discussed their fears, typically present at the start of their treatment journey, with anxiety around the idea of having a foreign body inside them and becoming familiar with the wards and machines or even overcoming a phobia of needles when cannulation was to be required. Patients did also reflect on how they wished staff at the time had been more compassionate, given the life-changing activity they had begun. This was attributed to the two differences in perspective – patients

are unfamiliar to CKD and inexperienced, while staff have years of experience and are much more familiar and accustomed to processes and events which patients may find distressing. Moving forward, the intervention should aim to include more practical information about treatment and show patients what to expect, to better prepare them and ease their anxieties.

"Definitely, you know it's having a -it's a big life changing activity, you know it's huge and I think - please there's no disrespect here at all. But I think when you're in a certain profession it's a matter of fact, and I don't mean that cheekily." – Patient 9

Encounters: Encounters were considered as discussions or consultations between patient and their healthcare provider. Participants focused on the level of information given in consultations, often struggling to recall or understand it fully afterwards.

"Sometimes when you've been seen by the doctors, they use medical terms that you don't understand. And we look at each other and we don't ask at the time, because it's so much." – Caregiver 1

Low-clearance (pre-dialysis) clinics were also discussed before, where patients with declining renal function can attend to discuss their condition and learn more about their treatment options with specialist providers, such as a nephrologist, specialist nurse and nutritionist. The low-clearance clinics were appreciated by patients, but Patient 5 noted how after they started dialysis, they felt as if they never saw their doctor again afterwards. Patient 13 also described noting different levels of competency between staff and began to understand that each member of staff was different in their expertise. They gave the example of how only one staff member discussed mental health with them, 10 months after starting treatment. Inconsistencies between encounters and individuals was also noted during the providers workshops. These issues within encounters with staff provide opportunity for the intervention to provide support for patients between consultations and meetings, by giving them a resource they can consult after consultations to research discussed topics or to prepare and prompt questions to be raised with their clinician.

"I spoke to the medical staff. The people at [hospital]… Because I come from a management background as well and look at the staff at the [hospital] and I'd see they all had a certain level of competency, but then they were all different." – Patient 13

8.4.4.3. Support

Spare devices on standby: The topic of spare devices was not raised in patient participant discussions – this may be due the assumption they would be able to access the intervention on their own devices or one would be provided. Patients in the fourth session considered this further when prompted about barriers to accessing the intervention but overall did not seem to consider this a concern. Given the discussions from the previous chapter and within the literature on the subject, provisions should be

made for those who may not be able to access the intervention regardless, to prevent a "digital divide" occurring.

Round-the-clock (*telephone*) support: This theme was expanded to consider all forms of round-the-clock support available to patients in addition to telephone support. The only example was raised by Patient 3 and Caregiver 1, in regards to home dialysis and accessing support if complications arose. They liked the concept of videoconferencing to show nurses the issue, rather than attempt to explain and relay instructions over telephone (this has been utilised for home dialysis in other studies but usually to resolve the issue of patients living in remote areas from their primary hospital or unit (Mitchell & Disney, 1997; Mitchell et al., 2000; Sicotte et al., 2011)). Caregiver 1 supports Patient 3 in their home dialysis and commented on using online resources, primarily YouTube, to troubleshoot problems that occur, like air embolisms (clots). They felt there was little in similar content provided by the NHS, relying on content from other countries. The scope of the intervention will include home dialysis patients and should also support them in delivering their own treatment, in addition to information provision.

"You go to YouTube and there's a lot of foreign videos showing what to do if you get an embolism [clot] or that, but there's nothing NHS provided to say, this is what you should do." – Caregiver 1

Caring support: Caring support was recognised as support from others, such as providers or family of patients.

"Well… one thing that happens when you go on dialysis is that when you're at a low clearance clinic, you're seeing a nephrologist very regularly, you see a nutritionist and you see a specialist nurse who prepares you for dialysis. And then you go on a dialysis ward and unless you ask, you never see your doctor again." – Patient 5

While most participants recalled positive experiences regarding individual clinicians or nurses who supported them, others felt more could be done to put patients at ease when starting the life-changing treatment, such as introductions to the wards, clinics and machines used in dialysis. Patient 5 recalled they lost frequent contact with their clinician once they began dialysis, having received a great deal of support in the low-clearance clinic.

Patient peers were also discussed as support, whether in-person or online (e.g. Facebook groups) and were a source of reassurance. P6 suggested a similar forum space for patients as a potential feature for the intervention, in addition to the patient reviews. Finally, Patients 6, 9, 10 and 12 all noted the potential the intervention had for supporting patient families as well as patients themselves, allowing them to review information together and help patients make sense of information with input from family members as well. These comments highlight where existing support networks are lacking and can be

supplemented with by technology such as the intervention. The same is also true for relationships that are already effective if the introduced technology is not treated as a replacement.

"You do talk to other patients when you're on dialysis and when you're meeting other patients round about and they… they are often the ones to give you the reassurance. It's all very well a doctor saying to you, "Look this is normal, going to do that", but…" – Patient 2

Technological support: A common topic discussed by participants centred around that there would be patients who would struggle with a technology-based intervention, and therefore some form of support would be needed. This was proposed through supported use, with a clinician, nurse or family member directly using the intervention with the patient as well as initial training, demonstrations, or walkthroughs of it in use.

"I have nothing to do with Twitter, Face-ate, YouTube. Nothing like- an app. You canny get an app on that phone!" – Patient 1

"I think it's a good idea, especially at the end there, when you said you could take it home for the family. As I said, older people will be terrified of that. As soon as they see stick men they go into a panic, but if they could sit down and somebody next to them could explain it to them, you know it'd be a lot better." – Patient 8

These suggestions have been implemented in other studies (Basch et al., 2005; Kearney et al., 2009) alongside custom user manuals (Mitchell et al., 2000), or providing a dedicated individual (Jacobs et al., 2018) or helpline (Basch et al., 2005) to support users in accessing and using the technology. Providing support in this way enables less skilled or able users to benefit as much as their technology-familiar peers, in addition to other practices such as generally high usability and accessibility.

8.4.4.4. Technology

Easy access: Easy access to technology was briefly discussed by some patient participants. Patient 5 first raised the subject, noting that the best impact would be experienced by making the prototype readily available to patients and thought that the intervention would be immediately available at clinic and home, via the Internet. While other comments were made in later groups around availability of technology and access, the literature has shown lack of provision can often exclude patients who have the most to gain from potential benefits and impose further burden (Mair et al., 2021).

"Well, I think the best impact, for this, is just to make available to people. …When you say access at home sorry I was assuming this was on the Internet, and I could just use this whenever I wanted whenever I wanted to start. Is that not the plan"? – Patient 5

While implementations of technology often need to be staggered to ensure issues that arise are dealt with effectively, Patient 5's comments highlight the need to make interventions easily accessible, by

providing dedicated devices in-clinic and making them compatible with a variety of platforms and settings such as the patient's home, and other environments.

Easy to use: The perceived ease of use of the prototype by patients focused on various elements. The consistency of user interface elements was raised by Patients 4 and 5, questioning the choice of icons (e.g. magnifying glass for additional information) and suggesting the repeated use of icons to convey additional information or features throughout the system, rather than just the information pages.

"Press the magnifying glass -is a magnifying glass, the best UI construct to use for that?

That's what I was going to say about. I was about to write the magnifying glass is confusing but…" - *Patients 5 and 4*

Patient 5 also commented on the level of interaction required to complete tasks, such as when swiping was demonstrated to move between the comparison functionality summaries. They were worried expecting the user to complete actions like these made the prototype more complicated and tasks more difficult to complete. The common concern regarding the use of technology with the typically older user population of CKD patients was raised again, with Patient 5 noting younger patients more familiar with modern technology and behaviours (e.g. swiping a touchscreen) would find the system far easier to operate than their older and less familiar peers. These comments highlight the need to design for the least experienced and able user, often achieved through simplicity and familiarity.

Finally, comments were also made that the system was easy to follow and made sense, particularly the final summary of the pathways functionality. This suggest the core concept of this work, the patient pathway visualisations, have reached a stage where they are able to effectively communicate the treatment journey and potential outcomes.

"On first sight on the presentation, it looks great. You know, it makes sense, it looks fairly straightforward." – Patient 2

"Yeah, I think I would have looked at it. And I think the good thing about it is it's really easy to read and understand." – Patient 14

Flexible: Flexibility was considered to include alternative uses or outcomes of the proposed intervention, such as utilisation by patient caregivers and family members. This theme has been touched on previously and indicates the potential for families to be better informed in their loved one's condition, as well as aid them in their decision-making process.

"Our family, especially my son, actually probably more my son… it would have been helpful for him. You know, he was in his mid-20s when I was diagnosed and he was actually in the RAF at the time. So something like that would have been good for him to be able to look at instead of sitting away, you know…" – Patient 12

Participants were also asked how they would feel if they were able to opt into tracking their health as a journey. Patients 4, 6, 9 and the participants of the final session all responded positively to this concept, citing a better sense of control and being more informed about their specific situation, as well as allowing others to see their journey as a whole more clearly.

"I think it's important and with the reference to the family as well, there will be things that you know if you know when you go into any sort of clinical environment your head goes into mush sometimes, you know? You forget questions. And I think it's really interesting points of view from the family members, who know you more than anything." – Patient 9

Nice looking: While Patient 13 made critical comments on the graphical quality of the prototype, they understood this was a prototype and would eventually improve. No other patient participants made comment on the aesthetics of the prototype – this may be due to the focus being on the content and functionalities instead and the aesthetics being less of a concern for this stakeholder group at this stage.

"No, it's great. It's absolutely -the only criticism but that's not, isn't criticism. The design just now, just the graphics together. And always pay attention to more images you know? Well that's great." – Patient 13

Testing of technology: Participants did not explicitly discuss the methodology of evaluating of the prototype but rather demonstrated a desire to interact with it further. Patient 5 had to leave their session early but was positive in feedback to the concept of the prototype and volunteered to participate in future evaluations such as reviewing the user interface and providing more feedback, as did Patient 13.

"Yes, definitely I, in principle I like it. But I would like a bit more detail about it, you know if you want proper feedback then I need to be able to play with it and look at it in more detail. You know seven minutes isn't long enough to give you enough feedback about an app."- Patient 2

Patient 2 expressed a desire to interact with the prototype as a mobile application and spend more time reviewing the functionalities. This was partly due to their critique of the demonstration being a single 7-minute video clip that they found passed by very quickly, which led to adjustments in subsequent workshops. The willingness of patients to be involved in designing interventions to support themselves is always welcome and should be encouraged in order to ensure the systems are effective and well-received by the target users, by designing with them, not for them.

***Appropriate* (Safe):** The original theme of Safe was renamed to Appropriate in Chapter 4, expanding the scope of safety to include the appropriateness of the technology and its content, rather than just physical safety implications (e.g. electric shocks from equipment). Patient participants primarily debated the appropriateness of including realistic images of VA and dialysis – while some felt it was necessary to prepare new patients for the reality of treatment (e.g. bruising, bleeding large quantities of blood, scarring and cannulation) and were comfortable now having lived through these moments, others

cited still not wishing to see that type of content without warning, noting once seen it cannot be forgotten. Patients suggested censoring or hiding such images, in a manner similar to social media platforms and posts with possibly upsetting images, allowing the user to choose whether they saw it or not.

"Oh, but once you do you [view images], you can't unsee can you?" – Patient 5

"Possibly just thinking, people like my wife… The thought of seeing something on television, she looks away. Even though she gave me a kidney [laughs]. She just, she doesn't like stuff like that. But that website and that app, click here to see a diagram. Click here you see a photo. She's got the option." – Patient 11

Another topic was concerned with how existing resources and information can be inapplicable to the patient, notably the personal experiences of patient peers or content from other countries (e.g. YouTube videos or websites). As discussed, younger patients can struggle to find peers similar to themselves and having the patient reviews feature was appreciated, to allow sharing and discovery of experiences with peers like themselves. To create a single resource with content that is appropriate for everyone is very difficult based on feedback from patients. Therefore, the best solution may be to include the information that is deemed as sensitive and allow patients to make the choice in if and how they view it and give enough information to prompt discussion with their clinicians.

"What I would say is, that although you're comparing things there. My kidney disease is completely different to someone with polycystic kidneys…so you can't generalise everything. And that's the hard thing." – Patient 12

***Barriers*:** Barriers to technology was an additional theme within the Technology concept first identified in the scoping literature review (Chapter 4, also utilising the framework by Korhonen et al. (Korhonen et al., 2016)), and similar examples were also identified in the previous chapter.

"I think older people may struggle with it to be honest." - Patient 7

As touched upon already, patient participants also had concerns older and frailer patients would struggle or not wish to engage with the prototype. These comments were typically followed by suggestions for supported use, with family or a provider aiding them to utilise the intervention. The potential barrier of accessing technology was also raised but overall patients did not seem concerned that this would pose an issue, either through the availability of technology (e.g. public libraries) or they possibly assumed the provision of a device.

"I think the app is a great idea. I think it's well overdue and I appreciate, no disrespect, the older generation may struggle, a little bit, but I think if it's given a bit of help via the medical staff, first and foremost, maybe that would be an option." – Patient 9

***Motivations*:** This second additional theme (also identified in Chapter 4) includes examples of motivators for engaging with technology, such as the perceived value of a single resource and a desire for better information provision.

"I would have loved this, back in the day. Just one place to go and then skim over stuff that you think, 'Not really that relevant to me'..." – Patient 5

Participants viewed the prototype as a positive step in the right direction regarding information provision, especially with the ability to choose how much detail they went into and find information from peers similar to themselves through the patient review functionality. Patients also saw benefit in contributing to the information i.e. submitting patient reviews, to help inform others. These motivations for patients are promising for the potential of the intervention and highlight the elements that should be prioritised in future development and refinement to secure engagement from patients.

"I would willingly share because if it's going to help everybody else that's coming along. That's what happened, you know, people shared with me. And helped me go through it." – Patient 12

8.4.4.5. Uniqueness

Appropriate care based on patient's needs and experiences: There were several examples of how the delivery of care was tailored to the individual patient. Factors in decision-making normally concern the patient's long-term health and how their priorities fit in around this. Some patients value preserving their lifestyles and opt for the treatment options that they perceive as minimal disruptive, such as dialysing at home, and making them feel better day-to-day and allowing them to continue their life as it was prior to their treatment. Participants also spoke about the negative impact of VA on body image, viewing worst-case examples of fistulas via online results and patient peers. Wanting to avoid disfigurement, this often influenced their decision-making (similar comments were made also about transplant scarring). Patient 9 preferred having the option to have a "superhero" graft, which they felt disrupted their body image less than a fistula, citing it as very important for her as a female.

"And was for me a much better option, and I wish I'd known about that and years ago. Mainly for a female's point of view, because for me, I had my fistula tied off because it was so bulbous. And for me, that that was a big thing at 38, 39-year-old female and so, for me, this superhero graft I know it's only -you see it differently when you're ill but it's really big thing for female I think you know?" – Patient 9

Likewise, Patient 13 noted he felt he had to continue working, as that was his role as a man, until he became too ill to continue. These priorities and preferences can change though, as Patient 4 reflected on their body image concerns when they were younger and first beginning treatment, but now they did not value this as much as they had done, having had positive experiences of three fistulas. Patient 14

was initially worried and objected about dialysing at home, looking to separate their secure space from the process of dialysis, but over two years became confident enough to change from in-clinic to home dialysis, now the preferred method.

"Because men like to think we're different. We're brought up to believe we're tough, we're hard, we're strong. And if you can't work, you should be in hospital. So of course that, so you just work because that's what's important." – Patient 13

Participants discussing their personal experiences of VA or treatment, positive and negative, were often frustrated when the access they were familiar with was no longer viable. This reflected the comments of nurse participants in the prior workshops, noting it was harder to get established patients to change away from their familiar VA. In contrast, patients like Patient 5 valued longevity of their treatment over feeling better and fear of needles, due to having a young family and wishing to be around for as long as possible. The decision is complicated further by factors outside the patient's control such as other illnesses, limiting their options and time to choose. For example, Patient 6 found informing themselves about their new CKD condition less of a priority while trying to manage the unexpected change to their life from another major health condition (i.e. sepsis), and Patient 13 described always having concerns over cancer, which triggered their dialysis treatment after their kidney was removed. These factors can influence patients heavily and so may need to be included in patient information resources, even if they may not be relevant to every individual.

"I think you use it as a baseline [prototype]. Yes, it gives you a lot of information and things, but there's still a whole lot of stuff that you need to discuss in a personal one-to-one. It doesn't answer every single question that you - You know, because, you know, we're all different. We've all got different questions. You know and affects us all in different ways." – Patient 12

Overall, it is difficult to determine what each patient wants and needs to navigate their journey through CKD and treatment. Providers do their best to support patients in this difficult transition, but gaps can occur in this process, where the intervention could supplement and support patients in their decision-making and throughout their journey. As mentioned earlier, elements of patient preferences and practical information should be included with clinical information to aid patients' sense-making of the information in their context. Information should be delivered at a level that is accessible to those who cannot or will not seek further information, while allowing those who are active in their information seeking to "drill down" in detail.

"You can pick out what you think is a bit, but you know basically before you, you're on dialysis… you have a certain lifestyle and once you're on dialysis you're going to have a different lifestyle. And the sooner you accept and adjust to a new way of life. Looking forward, not back, then the more you'll get out of your new cycle of life." – Patient 1

8.4.5. KLCA and Design Requirement Elicitation

Design requirements were elicited from the discussions and themes above, as well as directly from both the discussions and the Keep, Lose, Change or Add exercises posed to both workshop and UKKW symposium participants upon reviewing demonstrations of the prototype. Discussion continued during these exercises in workshop sessions and so some points may reflect those raised in the analysis. During the UKKW symposium, participants were asked to submit each category one at a time, due to constraints on time and given the larger attendance.

Under Keep, most participants noted all key functionalities shown i.e. the information pages, patient reviews, VA comparison and the journey planner should be retained. Other positive feedback included use of people icons and other visual elements to represent outcomes and the figures for creation and maintenance of VA. However the category Lose saw the patient reviews critiqued for potential bias in reviews and the star ratings applied to them, as well as the journey planner and journey comparisons. Clinical terms were also flagged (e.g. AVF) as was colour choices (both aesthetically i.e. background and for specific VA). Finally, one comment described the comparisons as too complicated and another suggested the feedback feature removal – this was included as a manner to leave feedback for the prototype but the participant considered patients may think this was linked to their renal unit instead.

Change was similar to Lose – often due to participants describing what to change about the issues raised already. These included removing ratings from reviews while retaining testimonials or stories from patients, modifying language or terms with patient input and colours for one example of a third line – this was coloured pink while the prior was purple. Other suggestions included adding photographic images and allowing patients to expand on complications like other terms.

Add was the most responded to category during the UKKW session. Key suggestions of features or elements included:

- information about local clinics, clinicians, and instructions on who and where to report to
- images of patients, complications and procedures to accompany information already included.
- interaction between patients based on reviews.
- including data sources for patient journey outcomes and granting patients access if requested.

Other additions posed included information on topics such as death, home therapies, other modalities and types of transplant, risk of VA change and monitoring or surveillance, as well as a notes section for patients, clinical trial or study participation information, welcome packs for newly diagnosed patients, and explaining key terms outside of the information pages. One suggestion made was to allow patients to monitor their VA by uploading images and work with providers, similar to the graft cannulation functionality first described in Chapter 5.

While the UKKW exercise for Keep, Lose, Change and Add was successful at eliciting design requirements, the limitations of the symposium format meant that some comments could not be further explained, such as "change all – too complicated". Comments like this are very broad and hard to understand without context, which the limited session did not allow for. The co-design workshops however allowed discussion between participants and researchers about the comments made. Following participant feedback in the first workshop with patients, the exercise was adapted and restructured so Keep, Lose, Change /Add (KLCA) was posed for each separate key functionality, which also ensured the context of the comments would be clear.

The first functionality to be demonstrated was the Information feature. This was praised for being comprehensive and described as a "one-stop-shop". The key aspect was the ability to "drill down" in detail, allowing patients to review as much as they wished, starting with brief explanations, and explaining key terminology as well in non-clinical terms. The latter was not necessarily the same perception for all, as some still requested it be made more "patient-friendly" and explained in simple terms as possible. The choice of icon i.e. magnifying glass was also raised but only once.

Suggestions included the addition of what to expect, and practicalities of treatment (e.g. peritoneal dialysis requires time to managing supplies for treatment or a walkthrough of treatment and dialysis machines) and the controversial addition of photographic images and videos but censored so only viewed at the user's discretion (e.g. graphic or triggering).

Second was the Patient Reviews and Access Comparison features, which were very well received and so comments for Keep often described the feature as "perfect" or "great" rather than identify a single aspect. The navigation and use of gestures to interact were critiqued however, such as swiping or clicking on elements without prompt. Suggested changes or additions to resolve this included a demonstration or walkthrough feature, as well as other new features like a live chat between patients or adding further age categories i.e. under 20 years old.

The Patient Pathway and Journey Planner was the last feature shown. The final summary aspect was the highlighted aspect of the feature, with a comment to move this to the start of the process under Change/Add. Other comments included the other sections of the planner animation being too technical and complicated, and suggestions to be able to review more than just the flow of the patients in treatment. Suggestions included adding written information and also simplifying the information to just percentages.

The summarised design requirements are listed in Table 8.5, amalgamating the KLCA responses of the UKKW symposium and workshop with requirements identified through discussions in workshops as well. Requirements also identified in healthcare provider sessions are listed as such.

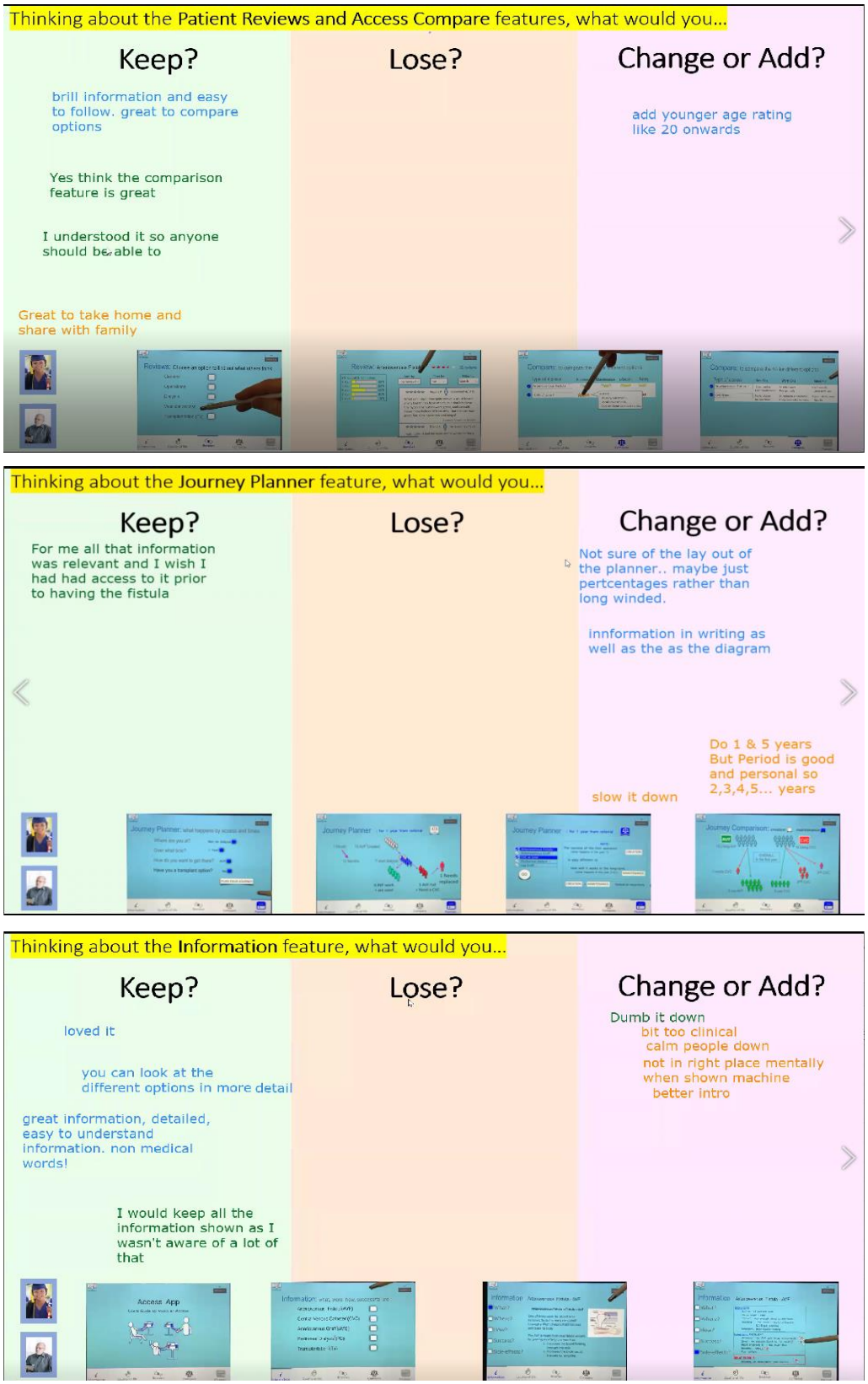


Figure 8.6: Screenshots of KLCA exercise slides and participant responses during workshops. Includes persona reminders at the far left and prototype screenshots at bottom of slides.

Table 8.5: Design Requirements for App with Sources and Themes

App Functionality and Design Requirements	**Source Theme(s)**	**UKKW**	**Patient Groups**	**Previously Identified?**
Visual representations of risk i.e. patient icons and pathways	- Patient-centred (Patient education)	✓	✓	✓
Explanations of common terms and abbreviations (e.g. AVF = arteriovenous fistula)	- Patient-centred (Patient education) - Technology (Easy to use)	✓	✓	✓
Inclusion of realistic/photographic images and video content	- Competence (Trustworthy), Patient-centred (Patient education)	✓	✓	✓
Complete information including mortality and other topics (e.g. transplant types), as well as welcome packs for new patients	*UKKW Comment*	✓		✓
Highly accessible with functionalities to support inexperienced and frail users e.g. familiar UI and simpler interactions	Technology (Easy to use, Barriers)		✓	✓
Practical and day-to-day information	- Patient-centred (Patient education, Empathy)		✓	✓
Simple overview but then allow user to “drill down” in detail	- Patient-centred (Patient education), Uniqueness		✓	✓
Positive and negative information well summarised	Patient-centred (Patient education, Informed consent)		✓	✓
Chat or forum for patients to share and discuss	- Support (Caring support)	✓	✓	
Local information e.g. clinic, consultants, contact information	*UKKW Comment*	✓		

App Functionality and Design Requirements	Source Theme(s)	UKKW	Patient Groups	Previously Identified?
Clinical data sources and download	*UKKW Comment*	✓		
Notes section	*UKKW Comment*	✓		
Clinical trial information and participation	*UKKW Comment*	✓		
Avoid complicated gestures or interactions (i.e. swiping)	- Competence (Technological skill) - Technology (Easy to use)		✓	
Filtering patient reviews by further age groups and other attributes (e.g. race)	- Competence (Holistic and caring approach)		✓	
Inclusion of patient-centred factors in information (e.g. hobbies, long-term, body image)	- Patient-centred (Patient education, decision-making) - Uniqueness		✓	
Readily available for use in and out of clinic	- Competence (Technological skill), Support (Spare device on standby), Technology (Easy to use)		✓	
Video consultations and support for home dialysis	- Support (Round-the-clock)		✓	
Option to view summarised information in place of visual data	- Patient-centred (Patient education)		✓	
Tracking journey or inputting data	- Patient-centred (To be taken into account) - Technology (Flexible)		✓	
Censoring of content based on user preference	- Patient-centred (Patient education) - Technology (Appropriate)		✓	

8.5. Discussion

This stage of work continued that of the previous chapter, by demonstrating a refined prototype to a wider audience at a national conference as well as CKD patients and caregivers in co-design workshop sessions. During the UKKW symposium 30 attendees of various roles and age contributed to the exercises, while a total of a total of 14 patients and 1 caregiver participated in the workshop sessions to review the prototype, 3 over Zoom and 1 in-person. These participants informed a further set of design requirements, supplementing those gathered from medical professionals and experts with needs and wants of the patient perspective. This required the incorporation of various methods and adaptations to online formats, including live polls, results and qualitative feedback with an audience of 30 or more participants at a national conference.

There were several overlaps with the themes identified by patient participants and UKKW attendees with those recorded in the previous set of workshops with medical professionals and experts (see Table 8.5). Patients also shared concerns that the general CKD population would be older and less familiar with technology but proposed supported use and availability of the intervention as methods for overcoming these issues. The visual representation of risk and outcomes was well received by all stakeholders, and there was a shared call for explanation of clinical terms and simpler language as well as the inclusion of photographic images to demonstrate treatment and procedures "realistically". The latter was a point of discussion within the workshops, with some patients pushing for images that showed the graphic nature of treatment, such as bulbous fistulas or bleeds that can occur, having become familiar with such sights as part of treatment. On the other hand, some felt they would not want to be exposed to such sights and would prefer the choice of choosing to view a censored image if they wished. This contrast highlights the differences between patients' preferences and tolerance in relation to information, which often makes CKD patient education and information provision difficult to generalise, in addition to varying health literacy (Narva et al., 2016; Rowlands et al., 2013). Resources such as the proposed intervention that provide patients with choices and the ability to control how they learn, through censoring images or "drilling down" in detail from simple overviews, can support patients in understanding and making sense of information at their own rate, without becoming overwhelmed (Büyüktür & Ackerman, 2017).

Of course, the patient perspective also provided new insight and feedback about the prototype and information provision. Peer influence was regarded very highly by medical professionals

in the previous sessions, and is understood to factor heavily into decision-making and education for CKD patients (Morton et al., 2010; Taylor et al., 2016). Therefore, the functionality was included and presented to patient participants. While most participants cited observing their peers and/or valuing their input, a small portion noted the opinions and experiences their peers shared could be overly negative and biased. Similar concerns were raised during the UKKW session in respect to the patient reviews functionality, with concerns testimonials could be biased and unreliable. However, patient participants responded overwhelming positively towards the concept of the review functionality, notably due to the ability to read the experiences of peers similar to themselves (e.g. younger patients) and were confident in their ability to discern information relevant to them, from experiences shared by their peers.

The previous set of co-design workshops saw the single concept of a patient pathway visualisation being expanded into a more refined intervention with distinct functionalities that provided information from different perspectives and formats – summarised textual information, patient peer reviews, comparisons of VA characteristics and visual representations of treatment outcomes and risks. All were praised for their approaches to information provision, and each received feedback or critiques. These functionalities would not have been produced without the earlier input from medical providers based on their experience of patient education and allowed patient participants to review a more refined prototype and provide further feedback and input on the various deliveries of information. By bringing both parties into the design of this intervention, the medical expertise and experience of clinicians and nurses formed the foundations of the intervention and its information, while patients' experiences and perspective of information provision inform and refine the delivery of content.

8.6. Strengths and Limitations

This work demonstrated various strengths and limitations. The UKKW session was a unique opportunity to conduct research with a wider and varied audience but posed challenges. The online symposium slot limited the available time and so exercises such as polling and KLCA were restricted to a few minutes at most to allow the session to progress as planned, potentially limiting the number of responses. The open nature of the session allowed attendees to join and leave the session freely and as mentioned earlier (section 8.3.5), the data collected was either quantitative or limited in context if qualitative. However, given the number of participating attendees and quality of the data, the UKKW can be viewed as successful. This demonstrates

the feasibility of running an interactive session with a large cohort in an online format, including polling, the demonstration of a prototype and displaying live results to the attendees.

The workshops contrasted the UKWW session, by collecting richer qualitive information from a smaller cohort of patient participants. Like the previous chapter, issues and pitfalls were identified with the methods employed within the workshops. These included:

- Difficulty recalling prototype details for KLCA exercise after lengthy video
    - Resolved: Breaking prototype demonstration into three shorter clips focusing on unique functionalities, followed by KLAC exercises (Workshop 2 onwards)
- Difficulty considering perspective of potential users (i.e. patients)
    - Resolved: Addition of personas prior to demonstrations of prototype and headshot images include on review slides (Workshop 2 onwards)

Again, adapting the methods of the co-design workshops was undertaken to ensure that further sessions were effective and avoid frustrating participants with ineffective or difficult tasks. The online format of the first three sessions allowed for participants to join remotely and removed the need for travel, particularly beneficial for a user population under a restrictive schedule of treatment. This also reduced the risk for a population at greater risk from COVID-19 (Bell et al., 2020) by mitigating physical methods. However, solely utilising the Zoom platform may result in recruitment of participants who are confident with engaging with the technology and limit the participation of others who are not. Therefore, at the request of the participants, the fourth session was hosted with a cohort of patients who did not wish to take part over Zoom, at a stage where social distancing was relaxed, and the meeting would be appropriate. A choice between physical and online workshops should be offered to ensure no single cohort is excluded by the preference of another. There is also the potential for bias through engaged patients opting to take part in such sessions more so than their less engaged peers, as there is with any participant recruitment. Based on feedback from patients, the most effective way to include the opinions of this subgroup of less engaged patients is to make the intervention readily available to allow them to use it and provide feedback at their discretion.

The continuation of co-design processes throughout this thesis focused efforts on the community of interest and resulted in modifications made to traditional research methods described previously, for the benefit of the community. With researchers taking a “coaching” role, stakeholders were enabled and involved in the research, with Kingsmore designing and demonstrating the refined prototype based on the output of the prior workshops (Chapter 7). Finally, concerns over a lack of patient involvement in the previous chapter were resolved by the inclusion of patients at this stage. Patients were able to view a refined and informed

prototype, limiting the potential to cause distress or trigger patients emotionally, and with functionalities required by the clinical stakeholders established, allowing them to focus on what they needed from the intervention as the end-users.

8.7. Conclusion

The contributions of this chapter include a high-fidelity patient education prototype design, with a further set of design requirements for technology-based patient education and decision-making aids for CKD patients, sourced from patients and caregivers. This work gives insights into the patient perspective of CKD patient education, such as their relationship with both healthcare providers and their patient peers, what factors may matter to patients in their decision-making and how their individuality requires patient education to be flexible and adapt to their needs and abilities. Co-design exercises have again been demonstrated as effective in both in-person and online remote formats, including a live symposium with a large audience engaging in interactive exercises with little preparation. Kingsmore was also able to produce the high-fidelity prototype utilised in the sessions, after participation in co-design sessions and learning from the principal investigator, acting as a "coach".

This study sees the continuation of the work first proposed in Chapter 5 and initialised in Chapter 7. The CKD patient and caregiver perspectives compliment the expertise and experience of medical professionals, with an overwhelming positive reception for such interventions to support patients in their education and decision-making. The conference symposium exercise also allowed for the prototype and the progress of the work completed by the MDG to be showcased to a national audience, while gathering feedback and insight from multidisciplinary participants in a single session. The results of this work provide further answers to the second research question, giving insight into what CKD patients need from a patient education and decision-making support tool, after establishing the clinical need from medical professionals in the previous chapter.

Key themes to continue in future work include the flexible approach of "drilling down" in detail of information, the use of graphical information (i.e. restroom icons and pathways), and the inclusion of realistic (and potentially graphic) images and patient review functionalities reflecting the reality of treatment. Implementation of a patient education and decision-making support intervention should that is readily available and accessible for CKD patients will also be necessary, to examine how less engaged patients may utilise the technology and identify potential problems with the use of such technology in its intended setting.

Chapter 9: Software Requirements Specification

This chapter will describe the system conceptualised and developed throughout this work, and summarise its intended purpose and how it is expected to perform. This will be discussed in an overview of the system and how it has adapted and changed over course of this research, as described in the Methodology (Chapter 3). Finally, the chapter will list the complete design requirements and their respective sources. More details on the evaluation of the system and methods employed are included in relevant chapters prior.

9.1. Overview of System and Intended Users

The purpose of the proposed system was to improve communication between chronic kidney disease (CKD) patients and healthcare providers. To achieve this, three key functions were selected to address issues known to the community:

- Patient information – assist patients in accessing and understanding information about the options, outcomes and potential risks of different vascular access (VA) modalities. The intent was adequate information to support patient decision-making would demonstrate a decrease in catheter (also known as a "line") use by highlighting the benefits of other VA modalities versus catheters (the focus of Phase 3/Chapters 7 and 8).
- Graft cannulation recording – optimise the cannulation of grafts by nurses by digitally recording previous cannulation points for each patient for review. Over-cannulation of grafts can result in a need for replacement grafts and at the time of proposal, the only effective record of cannulation is the patient's memory (primarily focused on in Phase 1/Chapter 5).
- Collection of PROMs – facilitate the collection of patient-reported outcome measures (PROMs) for later review by patient and healthcare provider, specifically related to VA i.e. the VASQoL measure (Richarz et al., 2021). This would allow the collection of how patients' quality of life is impacted by VA modalities and complications resulting from their VA (the focus of Phase 2/Chapter 6).

The system would support CKD patients undergoing haemodialysis (HD) treatment, ranging in experience from patients new to HD, to those established in treatment but requiring a change in VA or experiencing a complication of HD. The system would have various intended use cases, including (1) initial consultation with a healthcare provider (2) use in outpatient clinics or HD units while dialysing and (3) home use but with a limited or a "lite" version of the system.

Patients have variable experience with computer and information technology (IT). Difficulties with or negative attitudes towards IT are often associated with older and less experienced patients (Ashley et al., 2013; Basch et al., 2005; Basch, Artz, et al., 2007; Basch, Iasonos, et al., 2007; Berry et al., 2011; Gallar et al., 2007; Wood et al., 2017; Wright et al., 2003), as well as those who live with deprivation (Ashley et al., 2013; Ferrer-Roca & Subirana, 2002). Patients also vary in physical ability and health, as patients living with chronic conditions can be "older, frailer and more symptomatic" (Basch et al., 2016). The user evaluation of the prototype system with patients (Chapter 6) also revealed touch-input difficult where they have lost sensitivity in their fingers and experience impairments of vision, common in diabetic patients or elderly patients receiving long-term HD (Gonda et al., 1978; Nusinovici et al., 2019). Situational impairment of HD patients was also identified, occurring when the arm is used for cannulation of a graft or fistula (limiting use to one hand while sitting or lying back) making completion of written or typed tasks more challenging.

It was also considered the system may be used by caregivers supporting patients in its use or healthcare providers in different use cases, such as consultants delivering information on treatment options such as VA and nurses cannulating grafts. Healthcare provider users would be very experienced in HD and VA, and much more likely to be computer literate.

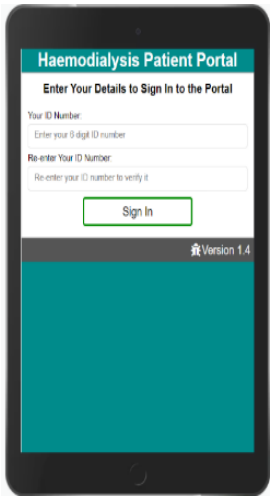
9.2. Iterative Development with Multidisciplinary Group

Work prior (Bouamrane et al., 2019) to this thesis established the feasibility of the proposed system by designing and evaluating a prototype with domain experts i.e. two consultant surgeons, a nephrologist, a research fellow, a research assistant and three senior academics experienced in digital health and human-computer interaction (HCI). Following this work, a multidisciplinary group (MDG) was formed. The goal of the MDG was the development and refinement of a prototype system, to a stage where it could be evaluated with patients in practice i.e. dialysis clinics. This was achieved via cycles of development, evaluation within the MDG and prioritization of feedback to inform the next development stage. Full details on the methods are described in Chapter 5.

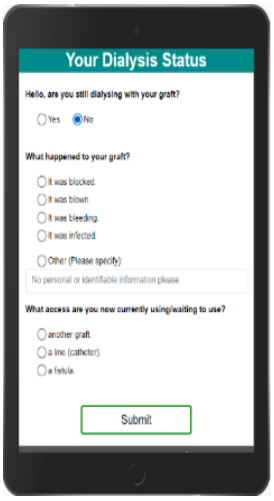
The efforts of the MDG resulted in the elicitation of a variety of functionalities and design requirements, primarily the capture of PROMS and clinical events, recording the cannulations of graft and patient pathway information. Other requirements captured at this stage concern hardware and security considerations alongside the usability and accessibility of the prototype. While the prototype aimed to refine and build on the design requirements gathered, the priority of the development was led by the MDG member's consensus alongside the need to ensure the prototype was robust and capable of hosting QoL measures as part of the VASQoL

validation study (Richarz et al., 2021) (SF-36 (Ware Jr, 1999) and EQ-5D-5L (Herdman et al., 2011)). Therefore, the graft cannulation recorder and PROM capture functionalities received further attention than the patient pathway information visualisations at this stage, which were functional but limited in topics and information. Before the initiation of the evaluation of the prototype (Meiklem et al., 2021) (and the VASQoL validation), the system incorporated the following (see Figure 9.1 for screenshots):

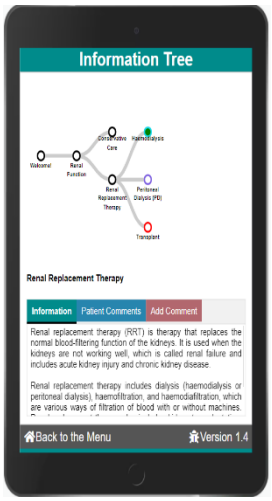
- Clinical event capture upon login (logging changes in vascular access and justifications e.g. fistula blew so patient now using line)
- Hosting and submission of VASQoL, SF-36 and EQ-5D-5L measure responses
- Graft cannulation recorder functionality
- Patient pathway information with limited topics and interactions



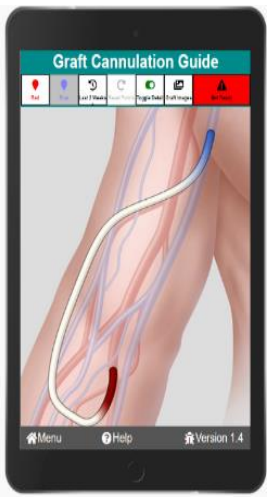
(a) Sign In Screen



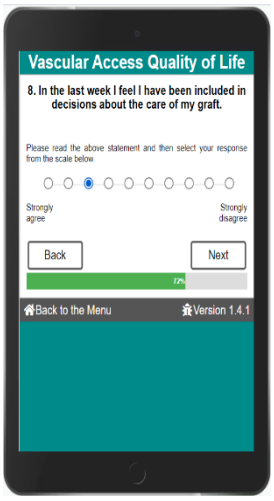
(b) Clinical Events



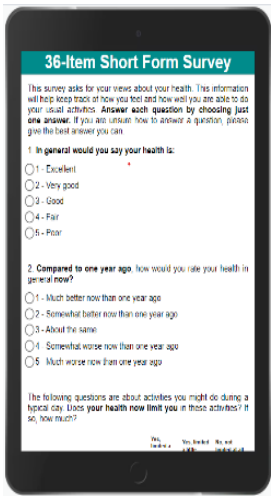
(c) Patient Information Tree



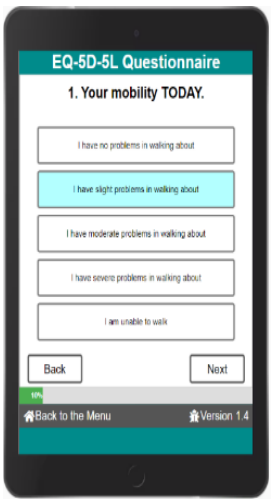
(d) Cannulation Recorder



(e) VASQoL Measure



(f) SF-36 Survey



(g) EQ-5D-5L Measure

Figure 9.1: Screenshots of Prototype after MDG Development

9.3. Implementation into Dialysis Clinic with User Evaluations

The prototype produced through the efforts of the MDG was utilised as a part of the validation process for the VASQoL measure (Richarz et al., 2021), hosting and collecting the necessary QoL measures and their responses. The opportunity to evaluate the system with patients in a real-world setting (i.e. dialysis units and clinics) and gather further design requirements from their perspective as end-users.

Early into the commencement of the study, ad-hoc changes were made to incorporate design requirements arising from patient usage of the prototype. This primarily focused on patient difficulties with touch screen input due to health-related issues and consistency in interface layout between device orientations, given patients' preference when dialysing with one free hand. Short-term fixes were applied, such as the provision of touch styluses and redesigning interface layouts, to ensure patients were able to continue using the prototype without experiencing further frustration or difficulties.

This study produced further design requirements, notably focusing on the digital collection of PROMs and the accessibility and usability of the prototype, given health-related and situational impairments of dialysing users e.g. issues with touch-screen due to carpal tunnel syndrome or neuropathy symptoms (Fujita et al., 2019). While some of these design requirements were generic and applicable to most systems, others were idiosyncratic and essential to the effective refinement and further implementation of the prototype system in future work. This version of the prototype underwent refinement to redesign the VASQoL digital questionnaire functionality while removing other features to streamline the system to produce a dedicated VASQoL application for use in future work regarding the VASQoL measure (see Figure 9.2 for refined prototype following user evaluation).

9.4. Patient Pathway Information, Co-Design Workshops and Interactive Symposium

Following the user evaluation and VASQoL validation, the focus turned toward the requested patient pathways information functionality (Chapters 6 and 7). Patient education is an important element of effective treatment and so stakeholders from all sides were sought to provide input on prototype designs. The prototypes of this study ultimately saw a redesign of the original concept formed by the MDG, prioritising the various aspects of the patient education functionality over PROM collection and graft cannulation recording. Initially arising from three sketches of pathway visualisations, two more refined pathway visualisation prototypes were produced by Kingsmore (consultant surgeon and member of the MDG) and I

to present to non-patient stakeholders (i.e. nurses, nephrologists, surgeons). Following these workshops, an interactive prototype was designed solely by Kingsmore based on collated feedback, to present to a wide audience at the UK Kidney Week symposium and to patient participants in further workshops. This final prototype shifted from solely displaying a representation of likely treatment pathways and outcomes to incorporating requested elements of patient education into their functionalities e.g. a patient reviews feature similar to online marketplace review sections (see Figure 9.3). This highlights the shift in priority of the MDG throughout the research and how working with the community of interest results in individual problems being addressed in order to achieve an overall goal.

The design requirements collected from the workshops primarily focused on different aspects of patient education which emerged during the discussions: information pages, patient reviews and visualisations of treatment pathways and journey planners. The information available in the resource pages needed to be more practical, comprehensive (i.e. risk of death, possible benefits as well as drawbacks, etc.) and controllable based on the user's preference i.e. censoring of sensitive but realistic images of treatment. Patient reviews should allow further filtering based on more refined age groups and lifestyle terms such as sports or hobbies, while the visualisation of patient pathways is needed to refine visual data and colour choices while also factoring patient characteristics into the approximate outcomes. Overall system requirements were also identified, which while generic were necessary for an effective system:

- minimal and simple interactions
- widely available and supported
- highly accessible with alternative input methods, consistent and familiar interfaces) and others more unique to the context, such as explanations of common terms and abbreviations e.g. AVF, line, graft
- simple overviews which can be expanded upon in a "drill-down" approach to information

9.5. Overview of Key Functionalities

This section will cover each of the key functionalities of the system in more detail and how they have progressed from original concepts to their final and current versions.

9.5.1. PROM Capture

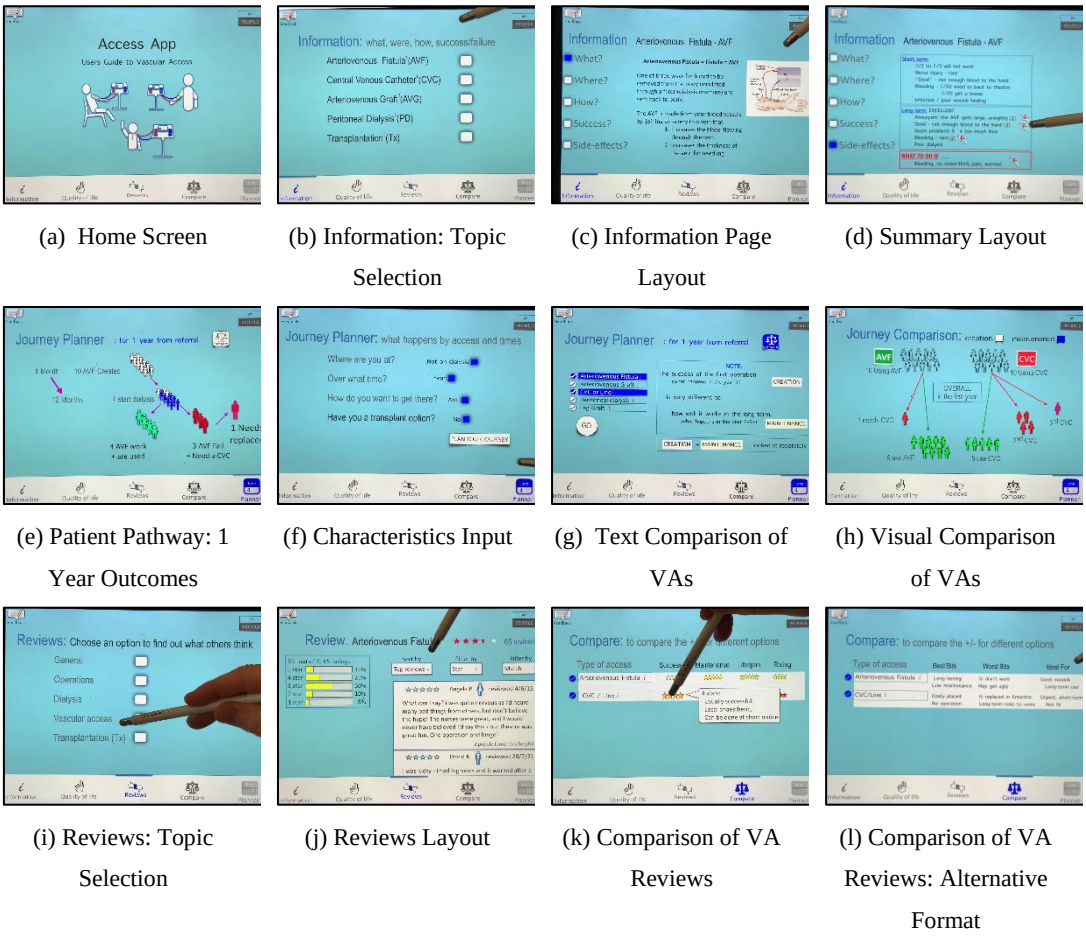
The capture of PROM data was prioritised in early discussions due to the parallel work by the Queen Elizabeth University Hospital staff to produce and validate the VASQoL measure (Richarz et al., 2021). This work also benefitted from the formation of the MDG and often

sessions would be utilised for both the prototype system and the discussion and review of the VASQoL wording and structure. Given the predetermined format of the validated QoL measures required for the validation study, the implementation of each measure needed to be robust and accurate to the original to preserve validity for comparison (and as per licensing specification in the case of the EQ-5D-5L). The system needed to capture each response and time taken to respond for each question for all three measures (see Chapter 5) and send the data to the SQL database hosted on a University of Strathclyde server for later analysis. The VASQoL was the only original and dynamic questionnaire of the three, substituting placeholder text in the questions with the user's VA and removing question 2a if the user was not registered as dialysing (values stored in Local Storage on sign-in), as the question would not be relevant. Considerations were made for security given the option to an open-text comment at the end of the VASQoL questionnaire, such as server-side scripts to remove dangerous and harmful characters from the String of text e.g. single quotes (‘’) in text can "break" SQL queries used for submitting data to the database and can be used to perform harmful SQL injections.

(a) Sign In Screen (b) Vascular Access Capture (c) Updated VASQoL

Figure 9.2: Screenshots of Refined Prototype (Updated VASQoL App) after User Evaluation

Following the feedback and design requirements elicitation after user evaluation with patients, the VASQoL measure was adapted – this involved the shift from Likert-scale radio buttons to large buttons with statement anchors (similar to the EQ-5D-5L layout for questions 1 through 5). This can be seen in Figure 9.2.



(a) Home Screen (b) Information: Topic Selection (c) Information Page Layout (d) Summary Layout

(e) Patient Pathway: 1 Year Outcomes (f) Characteristics Input (g) Text Comparison of VAs (h) Visual Comparison of VAs

(i) Reviews: Topic Selection (j) Reviews Layout (k) Comparison of VA Reviews (l) Comparison of VA Reviews: Alternative Format

Figure 9.3: Screenshots of Final Prototype (Demonstration Video) designed by Kingsmore

9.5.2. Graft Cannulation Recorder

The graft cannulation recorder functionality received attention primarily during the development with the MDG. To address inefficient cannulation of arteriovenous grafts, the consultants of the MDG desired a formal way to record cannulation sites to prevent the same sites being overused and eventually causing damage to the graft. This would require a visual representation of the patient's graft and the ability to mark cannulation site for both venous and arterial needles on the image. This should cover as much of the screen possible to allow for accuracy in marking sites. Previous recordings would be viewable on the same image to highlight areas which should be avoided. Considering a graft can be one of three common configurations, and located in either arm or leg, this would require 12 possible representations and all images were requested to be of high quality.

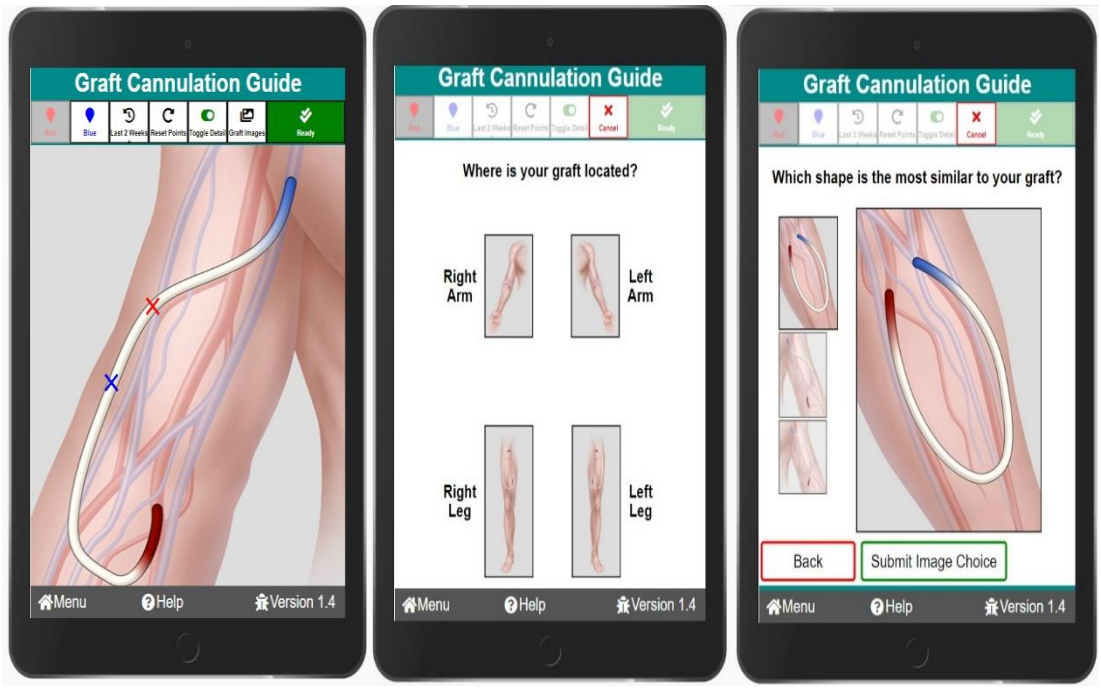
Figure 9.4 demonstrates the final version of the graft cannulation guide, where a user with a predefined graft location and configuration is shown their graft. While the image dominates much of the visible screen, a menu was also required to allow toggling between:

- markers for venous and arteriovenous (red and blue)

- reviewing previous points (if any) three pairs at a time and resetting the view
- the graft image with arm and medical detail or a simple view of the graft image

The menu also allows reselection of graft configuration and location, as well as submission of two points if both are placed. Previous iterations saw the menu offscreen and accessible through a button at the base of the image however this increased the number of steps in order to complete the task and its complexity (e.g. opening menu, selecting marker colour, close menu, place marker, open menu, submit, etc.). Therefore, having the menu accessible on the same screen as the image proved more efficient.

Validating if the user had touched to place a marker on an area of the image that was part of the graft presented a unique challenge, especially as all the images varied from one another. For each configuration and location, three images exist: (1) a detailed image of the graft with the body and anatomy visible, (2) a simple image of the graft shape with nothing else shown and (3) a green heatmap of the image marking where the graft area is. Using the JavaScript Canvas object, these three images are drawn and stacked atop one another, with the heatmap not visible while the other two are toggled between. A fourth transparent Canvas object covers the top layer, on which the markers are drawn and gives the appearance they are marked on the image shown below. When a touch is registered on the upper-most layer, the coordinates are captured. These coordinates are used to sample the selected location on the heatmap layer. The RGB values of the pixel at this location are compared to the known RGB values of the grey background of the heatmap (R: 221, B: 221, G: 221) – if they match then the selection is invalid, and no marker is placed on the top layer. If they do not match the given values, this indicates an area of the green graft heatmap has been tapped and so the relevant marker is drawn at the coordinates on the top layer.



(a) Main View with Markers (b) Graft Location Selection Options (c) Graft Configuration Selection

(d) Help and Instructions (e) Alternate View with Markers Placed

Figure 9.4: Overview of Graft Cannulation Recorder Functionality

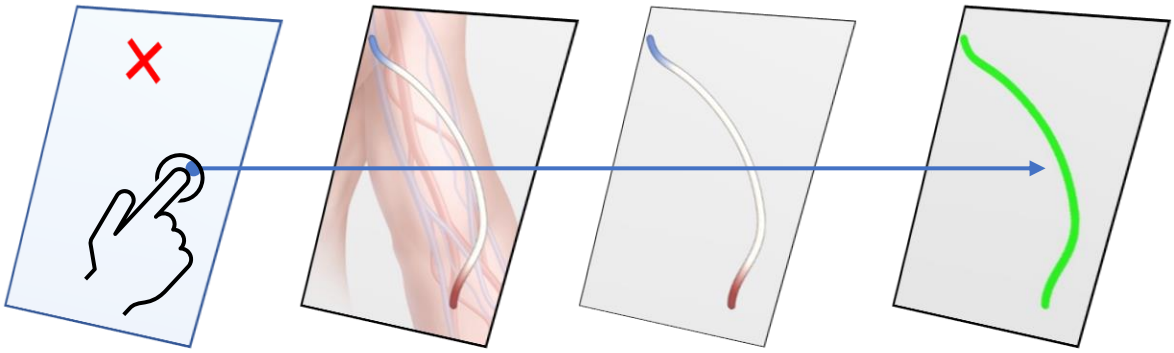


Figure 9.5: Validating cannulation markers using coordinates of canvas layered over images (left to right; canvas, detailed image, simple image, graft area heatmap)

9.5.3. Patient Pathway Visualisation (Patient Education)

The initial concept presented by Kingsmore for the visualisation of patient treatment pathways was described as accessing information via a "London Underground map" of treatments and outcomes. This analogy also included inputting a "destination and preferred route" (preferred treatment modality and state) and being aware of "delays or changing lines" (complications and possible changes to modality as a result). The initial pathway visualisation aimed to recreate the concept of a journey with branching paths, utilising JavaScript library D3 (Data-Driven Objects) (Bostock, 2021) to build the visual out of Node and Link objects. Each Node stores a name for itself, information on the topic and comments, as part of an early concept for patient feedback on the topics discussed. Tapping a parent Node would produce any child Nodes and doing so again to the same parent or any other Node higher in the tree would collapse these child Nodes again. The information of the selected Node was then displayed in a scrollable portion below the visual, with tabs to navigate between comments and information.

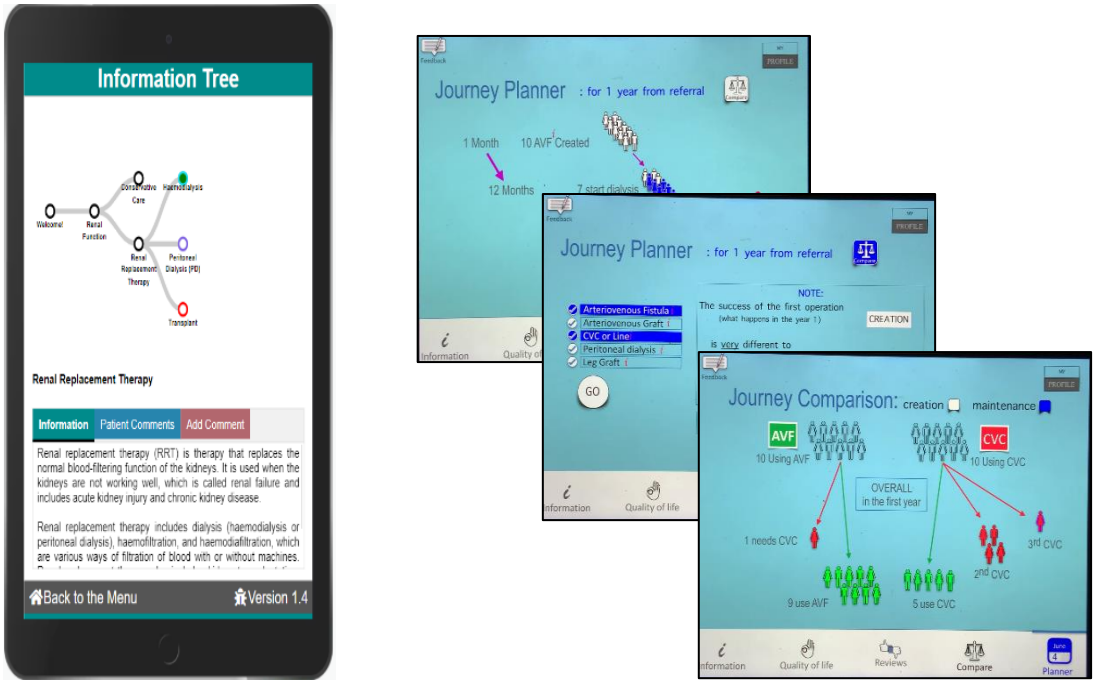


Figure 9.6: Comparison of initial and final patient pathway design and concept

The concept of the pathway visualisations was visited again after the culmination of the user evaluations. Based on data of patients first 365 days of treatment (Murray et al., 2018), three different designs were produced for static images of the outcomes of the patients included in the data. While all three varied in medium and design (e.g. paper sketch of "Napoleon's March" (Friendly, 2002), digitally created Sankey diagram and Keynote prototype demonstration, see Figure 9.7). Following the discussion of each diagram (as reported in Chapter 7), two refined prototypes were produced using presentation software to simulate the interactivity of mobile app. These prototypes focused on displaying the pathways for a selected vascular access, both sharing the concept of representing changes in treatment and outcome via patient icons to represent the portion of patients who have remained on their treatment or changed. However, feedback from medical professionals at this stage suggested the singular visualisation would not be able to effectively display all the desired information (i.e. information summaries, typical pathways and outcomes/complications, patient reviews and comparing VA). The final prototype was produced solely by Kingsmore and sought to address the requirements gathered thus far by designing an app dedicated to patient education, with the other functionalities previously discussed less prominent. Given the volume of information patients take on as part of their process of reaching informed consent, assigning different

sources of information to their own functionalities may be more appropriate than an all-encompassing and all-knowing single visualisation.

9.6. Design Requirements of System

Table 9.1 details the collated design requirements alongside their original chapter of detection and sources. Not all design requirements were implemented by the completion of this thesis and its work, however many will be in ongoing work. For example, following the workshops with patients, work has begun to add the functionality to toggle the VASQoL questionnaire between languages for wider studies with multiple centres in various countries. In addition, this set of design requirements will be taken forward to procurement for future work. The team at QEUH are leading a procurement exercise to develop software based on the lessons from this research for clinical use, based on the understanding gained in the projects completed as part of this thesis.

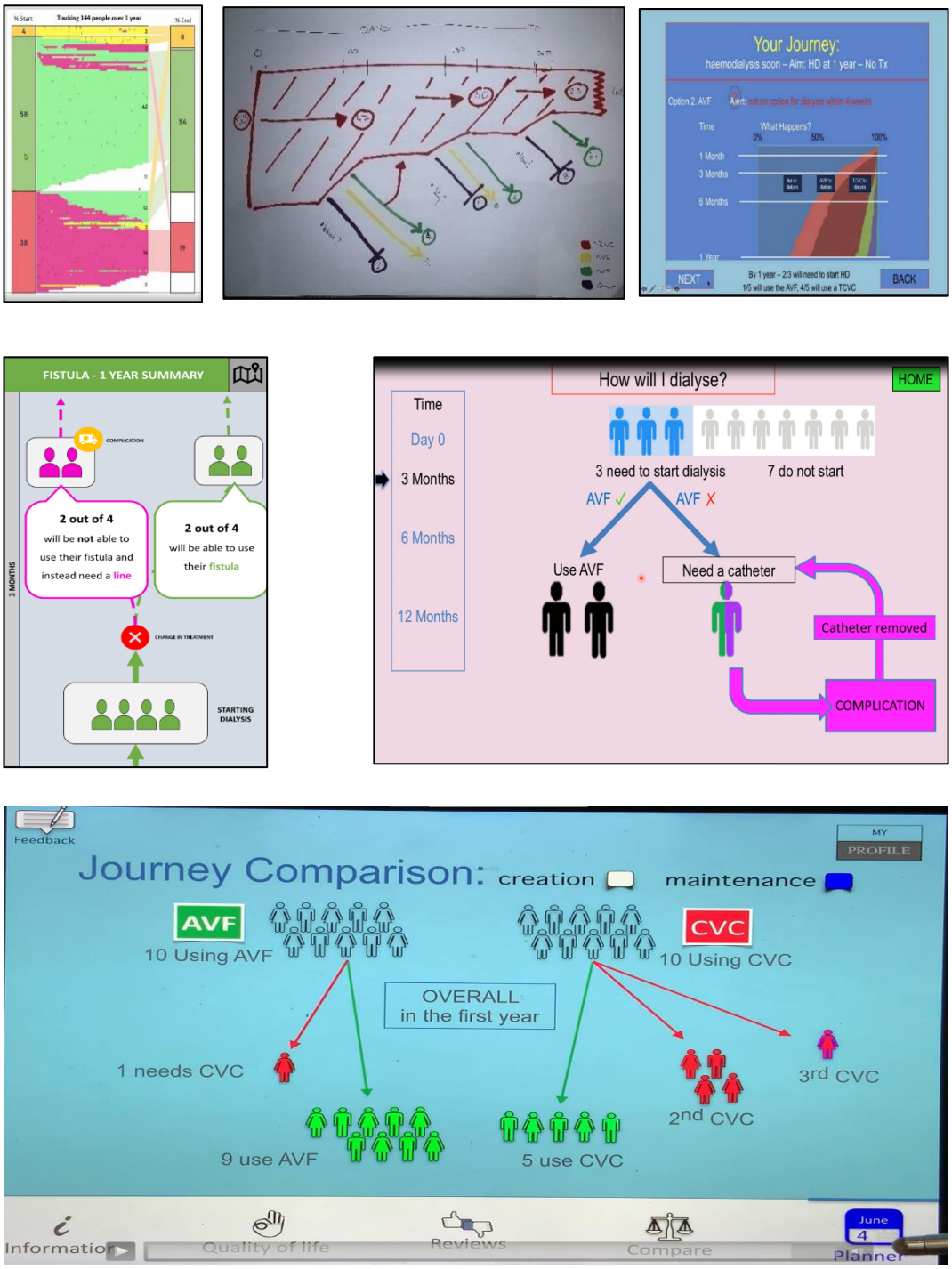


Figure 9.7: Progression of prototyping for patient pathways with MDG and stakeholders

Table 9.1: Overall Design Requirements for mHealth for Supporting CKD Patient

Aspect	Requirement Description	First Identified	Source(s)
PROM Data Capture	Capture of SF-36, EQ5D-5L and VASQoL data	Chapter 5	MDG (Medical experts)
	Clinical events capture (i.e. changes in dialysis status and vascular access)	Chapter 5	MDG (Medical experts)
	Recording user response times to QoL questionnaires	Chapter 5	MDG (Medical experts)
	User progression visible throughout	Chapter 5	MDG (HCI experts)
	Review input before submission	Chapter 5	MDG
	VASQoL administered across 3-4 times in a week	Chapter 5	MDG (Medical experts)
	Include statement anchors for Likert scales	Chapter 6	Clinical use observations
	Large buttons for response options (versus radio buttons)	Chapter 6	Clinical use observations
	One question layout/onscreen	Chapter 6	Clinical use observations
	Consistent question format/design throughout questionnaire e.g. Likert, scale, etc.	Chapter 6	Clinical use observations
	Careful and clear wording of questions/instructions	Chapter 6	Patient interviews
	Perceived value of contributing PROM to system for patient	Chapter 6	Patient interviews
Cannulation Recorder	Coloured and labelled markers for arteriovenous and venous needle sites	Chapter 5	MDG (Medical experts)
	Error handling for attempts to mark a cannulation outside of graft area	Chapter 5	MDG (Medical experts)
	Selection of graft configuration	Chapter 5	MDG (Medical experts)
	High quality images	Chapter 5	MDG (HCI experts)
	Transforming captured data to heatmap	Chapter 5	MDG (Medical experts)
	Selection of graft location	Chapter 5	MDG (Medical experts)

Aspect	Requirement Description	First Identified	Source(s)
	Storing and retrieving cannulation data to and from database	Chapter 5	MDG (Medical experts)
	Update markers to more precise icon	Chapter 5	MDG (Medical experts)
	Loading graft configuration and previous cannulations by default	Chapter 5	MDG (Medical experts)
	Snap placed markers to nearest portion of graft area if within proximity	Chapter 5	MDG (Medical experts)
	Mark flow on graft image	Chapter 5	MDG (Medical experts)
	Load previous cannulations in weekly increments	Chapter 5	MDG (Medical experts)
	Include body in image of graft i.e. arm or leg outline	Chapter 5	MDG (Medical experts)
	Menu visible on same screen/pane as graft image	Chapter 6	MDG (Medical experts)
	Align placed markers in centre of graft area	Chapter 6	MDG (Medical experts)
Pathway Visualisations	Patient information: Provision and access to tailored patient information	Chapter 5	MDG (Medical experts)
	Personalisation of information to user and their circumstances	Chapter 5	MDG (Medical experts)
	Navigation through set timeframes via slider	Chapter 5	MDG (Medical experts)
	Displaying likely outcomes and complications at common timepoints	Chapter 5	MDG (Medical experts)
	Display number of patients remaining on chosen access/diverted to different access	Chapter 5	MDG (Medical experts)
	Incorporate restroom icons to explain frequency	Chapter 7	MDG (Medical experts)
	Prioritise the first 365 days of dialysis	Chapter 7	MDG (Medical experts)
	Overall summaries prioritised over timepoints	Chapter 7	Nephrologists, Nurses, Patients / Carers

Aspect	Requirement Description	First Identified	Source(s)
	Include pre-dialysis stages and steps	Chapter 7	Nurses
	Disclaimer of generalisations	Chapter 7	Nephrologists, Nurses
	Visual representations of risk i.e. patient icons	Chapter 7	Nephrologists, Nurses, Patients / Carers
	Appropriate and balanced colour choices (e.g. green vs red) for specific vascular access	Chapter 7	Nurses
	Page and pathways should flow top-to-bottom	Chapter 7	Nephrologists, Nurses
	Ability to input details and track health over time	Chapter 7	Patients
	Patient information: Include practical information or a "What Can I Do" section, with emergency contact information	Chapter 7	Surgeons, Nurses, Patients/Carers
	Patient information: Complete information including risk of death	Chapter 7	Surgeons, Nephrologists, Nurses, Patients / Carers
	Patient information: Inclusion of photographic images	Chapter 7	Patients / Carers
	Patient information: Censorship of graphic images, toggle on/off as chosen	Chapter 7	Patients / Carers
	Patient information: Positive and negative information, summarised	Chapter 7	Surgeons, Nurses, Patients/Carers
	Patient information: Consistent and familiar terminology and language (e.g. "line" instead of catheter, avoid use of symbols such as <, >, etc.)	Chapter 7	Surgeons, Nephrologists, Nurses, Patients / Carers
	Patient reviews: Filtering by further age groups	Chapter 7	Patients / Carers

Aspect	Requirement Description	First Identified	Source(s)
	Patient reviews: Filter by tags (e.g. lifestyle terms such as swimming, bathing, sports, etc.)	Chapter 7	Patients / Carers
	Patient reviews: Patient chat functionality	Chapter 7	Patients / Carers
Data flow and Storage	Background data syncing and submission	Chapter 5	MDG (Medical and HCI experts)
	Retrieval of data from database for review and analysis	Chapter 5	MDG (Medical and HCI experts)
	Confirmation of data submission for clinician	Chapter 5	MDG (Medical experts)
Hardware	Android platform and device(s) for initial prototype	Chapter 5	MDG (HCI experts)
	Device specification (i.e. screen ratio 4:3, 10.1-inch screen, etc.)	Chapter 5	MDG (HCI experts)
	Case for device to protect from falls/accidents and robust enough for medical sanitisation	Chapter 5	MDG (Medical experts)
Robust System	MDG testing and checks following updates	Chapter 5	MDG (HCI experts)
	Correct handling for open text responses that include single quotes (and other special characters)	Chapter 6	MDG (HCI experts)
Accessibility and Usability	Tutorial or demo mode for new users	Chapter 5	MDG (Medical experts)
	Timely, clear and appropriate feedback from interactions	Chapter 5	MDG (Medical and HCI experts), Clinical use observations

Aspect	Requirement Description	First Identified	Source(s)
	Accounting for a typically older, frailer and inexperienced user population	Chapter 5	MDG (Medical and HCI experts), Surgeons, Nephrologists, Nurses, Patients / Carers
	Replace system alerts with custom pop-up messages	Chapter 6	Clinical use observations
	Minimal steps or actions required to reach goals	Chapter 6	MDG (Medical experts)
	Adequately space UI elements	Chapter 6	Clinical use observations
	UI must be consistent (between device orientations and functionalities) and adequately spaced	Chapter 6	Clinical use observations, Patients / Carers, Surgeons
	Option to increase font size as required	Chapter 6	Clinical use observations
	Account for user touch-input issues and handle accidental long-press actions	Chapter 6	Clinical use observations
	Easy-read updates and output	Chapter 6	MDG (HCI experts)
	Translations into other languages	Chapter 7	MDG (Medical experts)
	Minimal and simple interactions e.g. no swiping to move left or right	Chapter 7	Patients / Carers
	Widely available and supported on various platforms and devices	Chapter 7	Surgeons
	Highly accessible with functionalities to support users e.g. text-to-speech/audio content	Chapter 7	Patient feedback, Nurses
	Explanations of common terms and abbreviations (e.g. AVF = arteriovenous fistula)	Chapter 7	Nephrologists

Aspect	Requirement Description	First Identified	Source(s)
	Simple overview but then allow user to “drill down” in detail	Chapter 7	MDG, Nephrologists, Nurses, Patients / Carers

Chapter 10: Discussion

This thesis focused on investigating the application of mobile health technologies to support chronic kidney disease (CKD) patients. The purpose of this chapter is to summarise the conclusions of the prior chapters and discuss these in relation to answering the research questions presented in section 10.1 below. The outcomes and findings of these chapters will also be tied back to the wider literature. Finally, the limitations of this work will be presented alongside considerations and opportunities for future work.

10.1. Response to Research Questions

The efforts of this research have been completed in alignment with the goals of the posed research questions:

RQ 1: What patient-centred, technology-based interventions have been implemented to support patients with high treatment burden?

- **RQ 1.1:** What is the range of technological interventions that have been developed specifically for patients with high treatment burden?
- **RQ 1.2:** What factors of technological intervention can promote 'patient-centredness'?

RQ 2: What do haemodialysis patients and other stakeholders need from a technology-based intervention to support the CKD treatment journey?

Through a scoping review of the literature, RQ1 was answered along with its subsequent questions. RQ2 was answered by the investigator after following a co-design methodology inspired by Participatory Action Research, as described in previous chapters. The findings will be discussed below in relation to the research questions.

10.1.1. Response to Research Question 1

RQ1 sought to explore the range of technology-based and patient-centred interventions designed and to support high treatment burden patient populations. The purpose of the scoping literature review in Chapter 4 was to identify technology-based and patient-centred interventions which had been implemented into practice. The search included 1099 records, of which 39 articles were included for full-text analysis. These articles described the design and implementation of patient-centred and technology-based technologies.

Research question 1.1 focused on considering the range and types of interventions implemented for high treatment burden populations. These were identified within the scoping

review stage, with many examples of purpose and functionality to facilitate or deliver patient-centred care. Self-reporting of disease or treatment-related symptoms was the most common purpose of interventions reported, typically in populations of oncology patients regarding levels of toxicity. A small number also facilitated self-reporting of PROMs and even fewer enabled the reporting of clinical readings.

Remote monitoring and consultations between remote patients and clinicians enabled by telemedicine were more common within remote cystic fibrosis and dialysis populations, where accessing a hospital requires travelling a great distance or over difficult terrain (Mitchell & Disney, 1997; Mitchell et al., 2000; Sicotte et al., 2011; Wood et al., 2020; Wood et al., 2017). Finally, patient education interventions were also included, designed to deliver personalised or tailored information or recommendations. However these were limited in scope to supporting oncology patients, indicating a gap in the literate for an implemented patient education resource for CKD patients.

While all these interventions varied in patient population and delivery, they shared the purpose of supporting high treatment burden patients in a patient-centred manner. The thematic framework analysis sought to answer research question 1.2, utilising the preconditions for the realisation of dignity and good care in the context of technology, as specified by Korhonen et al. (Korhonen et al., 2016). The analysis allowed for the synthesisation of the articles and the themes of the framework to create a summary of common issues the high treatment burden patients experienced with technology-based interventions. Recommendations to resolve and prevent these issues were also listed in the chapter as a result of the synthesis of articles. The main characteristics to achieve patient-centredness within technology-based interventions are described below.

Reliable – can the technology be relied upon?

The most common issue related to the technology aspect of the interventions discussed was patients encountering “IT issues” or “technical difficulties”, where the technology had failed to deliver the support expected or was unreliable in use. Unusable or unreliable technologies are frustrating for not only for patients but also clinicians, risking loss of their support and endorsement (Rumpsfeld et al., 2005). One study demonstrates this where an update to a mobile application-based intervention caused the system to behave poorly, resulting in frustration towards a previously well-received intervention (Ngo et al., 2020). These issues are not always necessarily a result of the intervention or its hardware, however. A prime example was transmission issues within telemedicine and self-reporting interventions due to external factors, such as poor mobile reception in rural areas (McCann et al., 2009) or limited or

impacted (e.g. peak times) transmission rates (Gallar et al., 2007; Rumpsfeld et al., 2005; Wright et al., 2003). Intensive testing within the intended context of use (e.g. a patient's home or hospital ward, at expected use times, etc.) should be carried out before implementation to minimise the potential of unexpected faults and errors, which subsequently lead to reduced effectiveness and uptake (McCann et al., 2009; Wright et al., 2003) .

Accessible – how can the intervention be accessed?

Many studies reported participants who were either unable or partially able to access interventions. This attributed to several reasons, varying between domains and intervention type, but most commonly were deprivation and familiarity with technology. The impact of deprivation is not always obvious when described in studies, but it is important that it is recognised how patients with greater deprivation levels will struggle to access technology-based interventions. This can be simply due to immediate costs (e.g. expensive telephone calls (Ferrer-Roca & Subirana, 2002)), or a lack of home Internet access (Judson et al., 2013) or a dedicated device (Absolom et al., 2019; Ashley et al., 2013; Ferrer-Roca & Subirana, 2002; Hauth et al., 2019; Warrington et al., 2016; Wood et al., 2020), with some studies not providing one as part of their protocol. Where a medical intervention is not readily accessible or available to patients creates disparities and potentially places further burden on the patient, particularly those who are less "digitally able" (Mair et al., 2021). Interventions should be designed and implemented with these issues in mind, especially within study protocols where samples of the participants may be excluded by not providing a dedicated device such as an in-clinic computer or an access method (e.g. home Internet, e-mail address, etc.).

Being unable to access and use technology may also lead to unfamiliarity with it as well, but is more commonly attributed to age (Ashley et al., 2013). A common suggestion to these issues is that, with time, the prevalence of technology will breed further familiarity with technology and devices. However, this is not an appropriate answer for those who currently need the support these interventions can provide (and those who may never willingly use technology) and so, traditional alternatives (e.g. paper-and-pen) must be provided alongside the technology-based intervention. Patients using these interventions should also have access to ongoing support such as training, bespoke user manuals and technical support from dedicated staff or helplines.

Usable – can patients use the technology?

As described previously, the design of technology-based interventions should be well-informed (Mair et al., 2021), as should any system. Patients will have their own attitudes and

experiences of technology and was cited as a major barrier to intervention uptake and engagement in many studies (Ashley et al., 2013; Berry et al., 2011; McCann et al., 2009; Wright et al., 2003). Technology-based interventions should be designed to allow those with the least experience and skill opportunity to access and use them effectively. Good and simplistic designs, informed by involving patients during early design and testing phases, can aid patient users in overcoming their inexperience of technology and lack of confidence (McCann et al., 2009).

Adaptable – does the intervention and support change with the patient?

Within the context of the diseases and high treatment burden populations covered by the included articles, changes in patients' health were common barriers to their use of technology. Patients can be described as "older, frailer and more symptomatic", eventually becoming too ill or distressed to engage with interventions (Basch et al., 2005; Basch et al., 2016; Basch, Iasonos, et al., 2007; Basch et al., 2009). Unfortunately, attrition of participants is common when researching these populations, as declining health and death can occur. However, patients whose health improves or does not change can also discontinue using interventions. This may be due to finding the provided support unhelpful in their current situation (Jacobs et al., 2018) or having no perceived benefit from engaging when they feel well, or their condition has not changed since the last time (Basch, Iasonos, et al., 2007; Basch et al., 2009). Empathy and understanding for the implications of patients' health is another important part during the design of technology, and considerations must be made for health-related and situational impairments to allow patients of all stages to access support.

Valuable – does the intervention demonstrate value for patients and clinicians?

The perceived value of an intervention for a patient can vary depending on the context. For example, remote consultation through videoconferencing offers the patient reduced expenses in travel costs and time (especially in remote communities or difficult environments (Mitchell et al., 2000; Sicotte et al., 2011)), while self-reporting of PROs allows clinicians to monitor patients' conditions and prioritise key issues during consultations. While no study formally measured burden of treatment, evidence of reduced treatment burden was demonstrated and can be a driving force for intervention uptake. For example, one study suggested the most likely explanation for their high recruitment rate was the immediate perceived benefit of reduction travel required for healthcare, as most participants were required to travel hours by plane or car to in-person clinics for management of their cystic fibrosis (Wood et al., 2017). This perceived value can be easily lost however, especially where the patients feel their efforts are not matched by their clinicians or the intervention increases the burden upon the patient or

diminishes their capacity (Mair et al., 2021). The former is very common among self-reporting interventions, where patients perceive that PROs are not essential to their treatment or that they will be underutilised or ignored by clinicians. Only 5 of the 39 included studies stated that clinicians were required to review PROs as part of their design (Absolom et al., 2019; Basch et al., 2005; Basch, Iasonos, et al., 2007; Berry et al., 2011; Wright et al., 2003), despite explicit use of health-related quality of life information during consultations being associated with clinically significant improvement of patient well-being (Velikova et al., 2004). This highlights the need for clinician training to re-enforce and encourage the use of available data reported by patients, until it becomes part of routine.

On the other hand, there is the clinician perspective of value to consider as well. Self-reporting through digital interventions removes bias and inconsistency that may occur through interpretation by individuals and allows data to be captured consistently (Basch et al., 2005). Other benefits include early reporting of symptoms by patients, with greater severity and frequency than clinicians (Basch et al., 2009), which can result in earlier diagnosis and treatment changes (Ferrer-Roca & Subirana, 2002; Fjell et al., 2020; Hauth et al., 2019; Kargalskaja et al., 2020; Kearney et al., 2009; Wood et al., 2020). This presents a relationship between patient and clinician that impacts the perceived value of an intervention – where one fails to contribute, the other sees less value in the system and does the same, leading to both abandoning the intervention. This reciprocal patient-provider relationship is important, with commitment needed from staff, alongside experience and training, in order for patients to benefit fully (Wright et al., 2003). Again, ongoing staff training is an important consideration for any intervention where staff interact directly with the intervention or information produced by patient reports, especially when implementing into regular work practices and shifting from experimental settings.

Burdensome – does the intervention add to the patient's existing burden?

The purpose of these technology-based interventions was to support high-treatment burden patients, which may involve directly reducing the burden they experience. Where such a reduction in burden is obvious to patients (e.g. reducing travel time and costs by replacing in-person clinics with telemedicine (Wood et al., 2017)), the perceived value and uptake of the system can increase. However, such interventions may instead add to the existing burden of the patients. Patients have their own priorities and goals in terms of their healthcare and personal lives, which can impact how they engage with interventions. They also may forget, be interrupted (Ashley et al., 2013) or too busy to engage with interventions (Basch et al., 2005; Basch, Iasonos, et al., 2007; Basch et al., 2009; Berry et al., 2011; Judson et al., 2013;

Wright et al., 2003) or in some cases, chose to not engage to avoid unwanted consequences e.g. missing social plans due to hospital admission following symptom reporting (Warrington et al., 2016). Those which do not align with patients' priorities are often ignored or abandoned, especially where they impose additional burden and demand time and effort from the patient. Considerations should be made during the design and implementation of interventions, targeting introduction into established routines and processes which can reduce additional burden upon the patient burden (Ashley et al., 2013; McCann et al., 2009).

10.1.2. Response to Research Question 2

Research question 2 investigated the needs of haemodialysis patients and other stakeholders from a technology-based intervention, designed to support patients in their treatment journey. While the characteristics identified in research question 1 are important for ensuring the design of an intervention for high treatment burden populations is patient-centred, each population (including haemodialysis patients) has its own idiosyncratic needs and requirements inherent to their condition (Bouamrane et al., 2019). While patients can be viewed as experts in their condition and treatment, this is based on their own personal and unique experiences of care, giving them a micro-view of the domain. Patients are also often unaware of the scientific background of their treatment and condition, which can mean conceptualising their needs and wants from mobile health can be challenging (Song et al., 2021). Therefore, to fully understand the needs of patients and how technology-based interventions can support them in their treatment, the perspective and experience of the clinicians delivering the treatment would also be important. Input from experts in medical informatics and digital health would further bridge the gap between the experiences and expertise of medical experts and technological design requirements. The original intended methodological approach of participatory action research (PAR) was selected to ensure all stakeholders had an opportunity to be involved and lead the research to resolve their problems and issues, with the aid of the researcher as a "coach". While this was not formally conducted (due to restrictions as result of COVID-19 pandemic and pragmatic design decisions), the principles of PAR inspired co-design processes throughout the thesis. This allowed for the needs of haemodialysis patients to be captured from various sources with different methods, building upon the previous iteration of knowledge and intervention design at each stage.

The initial development cycles with the multidisciplinary group (MDG) of medical and digital health experts produced three key areas the intervention needed to provide support for: (1) capture of vascular access specific quality of life data, (2) recording graft cannulation sites and (3) a visualisation of the patient journey and possible outcomes. Table 9.4 of the previous chapter provides a complete list of the design requirements for this instance of a technology-

based and patient-centred intervention, with views from patients, caregivers, clinicians, nurses and academic experts. Key requirements specific to the population will be summarised in Table 10.1, with relevant sources.

The requirements described may focus on three distinct functionalities previously listed, but they also demand each be designed with a high degree of usability and awareness of patient's physical accessibility needs. This includes considerations for issues with physical touch input and situational impairment when dialysing and other condition or treatment-related impairments, such as vision. Complicating the system interface and process a patient needs to complete in order to achieve their goal must also be avoided, with simpler and consistent designs proving more successful (McCann et al., 2009) and enabling patients to use the intervention independently, giving them an opportunity to be honest about their treatment experience with a sense of privacy from clinicians and nurses.

The need for simplicity also applies to the delivery of information and the display of content, with all stakeholders agreeing on the "drill-down" approach for detail, giving the patient user the choice in how much information they need to face and intake – the inquisitive can burrow deeper down in detail and information, while the overview and simple summaries at the base level is available for those less confident or unready to engage. This approach does not mean to make light of a very complicated and difficult condition however, and the information displayed must be comprehensive and unbiased – this applies to not only the concise positives and negatives of each treatment modality but also the visual information through colour choices (e.g. red is associated with "bad") and included images. The latter divided participants in discussions, with some requesting more realistic albeit graphic images of treatment while others would wish these images were hidden until they chose to view. Similar sentiment can be found towards the information their peers provide, on the topic of patient reviews on their experiences of treatment, versus the expertise of their clinician. The repeating theme is choice: by giving patients choice in how they access information (and how much), they are able to personalise their own education, without being limited or overwhelmed by one singular format or resource. This does not mean the intervention should be all-knowing and replace clinician consultations or nurse interactions, but instead act as a resource to supplement them, for preparation beforehand or to follow-up with afterwards.

Table 10.1: Final Summarised Design Requirements for mHealth Supporting CKD Patient

Design Requirement	Identified By
Capture of both patient-reported outcomes and clinical events, with confirmation of submission	Medical experts
Patient-reported data should be accessible for review by clinicians, and acted upon	Medical and HCI experts, Patients
Questionnaires should be simple and consistent in design with single-question pages, large elements for input (e.g. buttons) and clear and concise statements to select as responses, with progress visible	Patients, Clinical researcher, HCI experts
Capture of graft cannulation data and review of previous cannulation sites	Medical experts
Patients should be able to select a graft template image in a similar area and configuration to their own	Medical experts
Provision of patient education and decision support information, which can be tailored to patient's situation and prior circumstances, at select timepoints.	Medical experts
Patient information must be comprehensive and complete, with both negative and positive points for each route of treatment, including the potential outcome of death and practical information for emergencies. Generalisations should be made clear as well.	Surgeons, Nephrologists, Nurses, Patients, Caregivers
Patient information should be displayed and communicated through visual aids where suitable, including restroom icons to describe risk and graphic and realistic images. Colour choices should be carefully considered (e.g. red suggests negative or bad) and the concept of a journey should flow top-to-bottom.	Medical experts, Nephrologists, Nurses, Patients, Caregivers
Language used in patient information should be clear, concise and familiar to the patient e.g. line versus catheter, or otherwise explained if commonly used.	Surgeons, Nephrologists, Nurses, Patients, Caregivers
Collection and display of patient reviews to assist patients in sharing and understanding experiences of others, with options to filter based on characteristics and important terms (e.g. lifestyle and hobbies).	Patients, Caregivers

The intervention should allow patients to complete tasks and reach goals in as few steps as possible, with timely and appropriate feedback to actions.	Medical and HCI experts, Clinical researcher
The intervention should be simplistic and consistent in design, with simple overviews and features that "drill down" in detail and minimal complexity e.g. swiping gestures, for a unfamiliar and frailer users.	All
The intervention should account for disease-specific and situational-impairments, with modifications for impaired touch and visual abilities of patients.	Clinical researcher, Nurses, Patients

Finally, similar to the findings of the scoping review, perceived value was very important where patients were required to engage and use interventions often (Absolom et al., 2019). For example, SUS Patient 15 from Chapter 6 directly described the need for responses from their clinicians to demonstrate the potential benefit of communication via submitting PROMs, otherwise they saw no value in contributing. While this phase of implementation was for research purposes only, the implementation directly into routine treatment and the inclusion of both patients and clinicians early in development may promote further engagement and endorsement from all sides, ensuring the intervention is continually beneficial for both patient and clinician.

10.2. Discussion of Key Findings

10.2.1. Perceived Value of Engaging with Technology

Perceived value can be considered as the key factor in the adoption of mHealth interventions, alongside trust and perceived ease of use (Pan & Zhao, 2018). Perceived value will vary in the context of the intervention, but the work of Pan and Zhao lists the following qualities of an mHealth intervention as valuable: (1) meets basic accessibility, usability and security needs, (2) encourages patient-centredness (3) facilitates better and more secure communication and (4) supports personalised management from clinicians. These qualities have been described at different stages of this work, such as the sense of privacy and being able to be honest patients felt when completing the digital VASQoL measures independently (better and more secure communication) or the ability to "drill down" in detail and change the format of patient education information (encouraging patient-centredness).

However, there is still the user to consider, namely the patient, and how their own experiences and views determine their own perception of an intervention's worth. For example, the literature suggests mHealth technologies can complement and benefit those who are regarded as highly engaged in their care and self-management (Vo et al., 2019), while their less engaged peers may struggle and find additional burden instead of support. To contrast, during the VASQoL validation study, SUS participant P4 expressed they felt very confident in their ability to communicate and understand information regarding their health. This suggests even highly engaged patients, such as P4, may find the introduction as new technology a perceived risk rather than beneficial, based on their own attitude towards technology. As previously mentioned, these patients need to be listened to and offered alternatives (i.e. paper-and-pen), rather than expected to eventually adopt the technology as prevalence grows over time (Ashley et al., 2013). Within this work and related literature, the greatest risk patients perceive is the

detriment or replacement of the patient-provider relationship and communication by new technologies (Whitten & Buis, 2008; Wood et al., 2020). To highlight the possible benefits over this perceived risk, interventions need to demonstrate how they supplement and support the existing processes and relationships.

During the scoping literature review and evaluation of the VASQoL with patients, the theme of perceived value of engagement with technology was raised for both the patient and clinician perspectives. For one intervention, the perceived value can differ for a patient to that of the clinician. For example, the VASQoL study demonstrated clinician appreciation for a streamlined and automated collection of patient-reported data, while patients listed benefits including: an increased sense of independence, privacy and being able to be honest in their responses, ease of tablet and stylus input versus traditional paper-and-pen methods when dialysing, and communication with providers when face-to-face is not always possible (i.e. night dialysis). In the same setting, the two differed on the format of the responses, with clinicians preferring the Likert-scale for analysis ease while patients felt open-ended responses would be more informative and allowed them to share details of their concerns. Ultimately, both agreed there was benefit in the digitally collecting PROs, whether it be automation and validation of data or being able to complete independently. While different, both views matter equally and need to be answered to encourage continued engagement. The scoping review identified examples of a relationship between patient and provider perceived value, where if one is not met and the relevant user does not continue engaging, the other sees no perceived value and also abandons the intervention. This was often due to study design (e.g. withdrawal of intervention after study, limited patient group with PRO data, no obvious consequence for non-reporting or use of PRO data). This sentiment was described again during the validation of the VASQoL measure, where two participants (SUS P15 and P16) noted they wanted their healthcare team to review their responses, otherwise the intervention was of no use. Studies which enforced providers to respond to patient reports (Fjell et al., 2020; McCann et al., 2009; Velikova et al., 2004) demonstrated satisfied patients and in the case of Velikova et al., clinically significant improvement of patient well-being.

To promote engagement with a new intervention, both parties need to clearly gain from contributing their time and effort into the technology, otherwise neither can truly benefit and the intervention may be abandoned (Basch et al., 2005; Basch, Iasonos, et al., 2007; Jacobs et al., 2018). Therefore, considerations in both study and intervention design such as these may reassure patients their input matters and prevent perceived value and engagement deteriorating early in their introduction with the intervention in question.

10.2.2. Design Considerations for Interventions (and Studies) with CKD Patient Populations

A feasibility study (Bouamrane et al., 2019) for a patient portal technology in the context of CKD treatment specified that for technology-based interventions to be successful at supporting CKD patients in their care, they would need to address idiosyncratic design requirements. This referred to not only the functional needs of patients and other stakeholders, but accessibility and usability problems unique to the population.

While the work described in previous chapters varied in functionality at different stages, certain accessibility and usability requirements were identified that impact how CKD patients can interact with and use technology in a broader context. A common condition-specific accessibility consideration is vision impairment or eye diseases, noted during implementation with patients. Sometimes referred to as ocular morbidity, patients with CKD are at greater risk due to factors such as underlying conditions and risk factors for CKD (e.g. hypertension, diabetes) and CKD treatment itself (Gonda et al., 1978; Nusinovici et al., 2019). Vision impairments can present significant challenges for individuals in accessing their health care, particularly via technologies which do not consider their needs. During the implementation of the eVASQoL in Chapter 6, the clinical researcher reflected on the prevalence of visual impairments patients in the study exhibited, having supported them when using the tablet-based intervention. These issues did not appear to impact on the study itself, however. Designing for the visually impaired user not only benefits them but can be helpful for non-disabled users as well (Kim et al., 2018) and so by adhering to guidelines such as those proposed by Kim et al., the interventions deployed have a higher chance of supporting a wider variety of patients regardless of their impairment. Some design requirements captured during this work regarding vision impairment, such as alternative input methods to touch or text-to-audio output, will be important in further work.

It was also established early in the VASQoL study that patients were struggling to use the touch screen of the tablet effectively, due to a reduced sensation in their fingers. This resulted in longer presses on the screen which caused unwanted actions such as highlighting the text of a button when they wanted to press the button itself. The clinicians of the MDG suggested this touch impairment was attributed to carpal tunnel syndrome or neuropathy symptoms (Fujita et al., 2019), and immediate action was taken to ensure the patients could continue to participate in the study without frustration, by supplying styluses with the tablet devices. While the introduction of styluses remedied these issues, the system should not rely on additional hardware to be usable and so steps were taken to ensure patient's touch input was correctly

handled, by disabling long-presses and highlighting of user interface elements, as well as adjustments to make these larger and more easily targeted by patients (e.g. the refinement of the VASQoL digital design from small and closely positioned radio buttons to reflect the large and stacked buttons of the EQ-5D-5L design).

The situational impairment of CKD patients during dialysis treatment was first identified during the VASQoL validation study, where patients dialysing are limited in their movements (otherwise they risk disrupting treatment if their cannulations are disturbed). Those who are dialysing through their arm particularly face challenges where the cannulated arm cannot be used whether their dominant arm or not. This was demonstrated by patients choosing to prop tablets up in their laps and use their free arm to engage with the screen, which was preferable to attempting to complete a paper version one-handed. However, this then posed issues where the devices were dominantly used in this context – horizontal orientation was preferred as it was more stable, but the user interface was designed for portrait. While modifications were made to resolve these issues (i.e. ensuring user interface was consistent across orientations), the community should be mindful of this situational impairment and design accordingly – again if not for the benefit of the dialysing patient, for the wider user group also.

Many of these design implications would have not been identified without implementation with patients in a real-world, clinical setting. While the posed challenges for both the participants and study progress, taking action to resolve them earlier meant the study could continue to progress without patients growing frustrated. Encountering issues such as these during a study are not uncommon – the scoping review found similar examples which often went unresolved and were considered limitations throughout the study (Gallar et al., 2007; Ngo et al., 2020; Wright et al., 2003). However, by choosing to act and remedy these issues, the research described previously was able to continue, while both contributing valuable lessons and solutions to the community and ensuring the study was completed with minimum disruption or detriment. Future work involving technology-based interventions and deployment into real-world settings should allow for technical issues in early implementation and treat this stage not as a setback but as an opportunity to correct any unforeseen issues prior to formal study commencement.

10.2.3. Suitability of Co-design for Patient-Centredness

Throughout the work detailed in this thesis, the Participatory Action Research (PAR) methodology inspired co-design processes and principles guided the individual studies completed. The principles of PAR seek to put the community of interest (i.e. stakeholders) at the helm of the research while the researcher plays a “coach” role, to aid the community in

understanding and resolving their problems. In the context of mHealth, employing action research methods like PAR is useful for creating and implementing patient-centred and sustainable interventions (Gerhardt et al., 2017). The concept of sustainability refers to "pilotitis", a frustrating phenomenon where many of the interventions in literature never reach implementation (Huang et al., 2020). With consideration for PAR and utilising co-design in this work, interventions were developed and implemented into real-world settings, evaluated and reviewed by patient users, alongside the involved clinicians and domain experts, providing valuable insight for the HCI and medical communities. While unfortunate that a PAR approach could not be fully realised in this work, given the timing of the work during the global COVID-19 pandemic and subsequent pragmatic design decisions as a result, the co-design processes inspired by PAR have shown to be effective.

A key benefit noted during this work was the relationship and rapport developed with the community interest. Regular meetings as a multidisciplinary group (MDG) allowed for regular communication and familiarisation with one another's domains and expertise. Collaboration occurred and allowed both clinician and researcher to conduct studies during the difficult stages of the COVID-19 pandemic, while minimising the burden and risk to patients, such as during the VASQoL validation. While hard to measure, there was evidence of knowledge exchange and teaching between the medical staff and the academic experts involved. The most notable was Kingsmore's ability to design and develop high-fidelity prototype interventions for use in workshop sessions, following time spent with the researcher and learning about prototyping through mediums such as PowerPoint. The other common example was the bridging of clinical staff expertise and needs to design requirements and specifications by HCI and medical informatic experts. This mix of stakeholders also revealed the various perceptions of value the intervention(s), such as how in Chapter 6 patients valued the privacy and communication the VASQoL application offered while clinicians saw the automation of data collection and validation as a key benefit. As previously discussed, there must be a perceived value for both patient and clinician in order to ensure continued engagement or endorsement, which is not always obvious without involving both in the development and evaluation processes.

The regular contact of the MDG was described in Chapter 5, and this continued throughout the work detailed afterwards. Progress from all members in their respective tasks was reported often and goals of the group could be prioritised and refined to ensure the problems identified were being addressed. For example, the work of Chapter 5 primarily focused on the graft cannulation recorder functionality being developed, but with the approval of the validation

study of the VASQoL, efforts of the group were focused on the refinement of the VASQoL wording and its digital implementation. Once this key functionality and solution was satisfactory, the group could instead turn to the design and implementation of a patient pathways guide and education resource. This prioritisation approach is favoured by methodologies such as PAR, as the community of interest can see progress and solutions come into place one at a time, rather than pulling multiple threads at once to try and resolve many problems. Patients are often unaware of the scientific background of their treatment and condition (Song et al., 2021)., and so the early involvement of clinical staff in the MDG and development cycles allowed for the necessary medical background and requirements to be established prior to patient involvement, as well as verification of the appropriateness of interventions designed to face patients, as noted during Chapter 7.

Finally, patient involvement is required for any intervention that will be patient-facing and claims to be patient-centred. While not involving patients early in development cycles of interventions (i.e. Chapters 5 and 7), subsequent evaluations focused on patient feedback to inform and refine the established requirements provided by medical and academic experts. While clinicians have the expertise and experience of dealing with many patients, each patient provides their own unique perspective of care and ultimately will be the one interacting with the interventions. This approach allowed for the development of interventions that met both the needs of the clinicians and the staff, from their perspectives as service providers and receivers. For example, clinicians described the requirement of fully informing the patient in order to achieve fully-informed consent, which means all available options and outcomes must be discussed (e.g. Montgomery v Lanarkshire (Campbell, 2015)). This translated to the patient education intervention of Chapters 7 and 8 needing to cover all treatment modalities in an unbiased manner (i.e. highlighting pros and cons of each method). However, patient participants in later workshops of Chapter 8 had different experiences of achieving a fully informed state. They highlighted the need for information from other perspectives such as patient peer reviews or being able to choose how they interacted with the information provided (e.g. levels of detail or censorship of graphic content).

10.3. Overall Strengths and Limitations

This thesis is not without potential limitations. The greatest impact was a result of the COVID-19 pandemic, which saw the United Kingdom enter a national lockdown in March 2020 and made conducting research difficult, particularly with a population such as CKD patients, classed as vulnerable and high-risk (Bell et al., 2020) and under a great deal of stress. While this resulted in the desired PAR methodology not being fulfilled, and earlier evaluation

interviews with patients being abandoned, it resulted in the refinement and adoption of remote methods of research, complying with guidance at the time (Dodds & Hess, 2020) and a more accessible co-design approach for participants such as CKD patients and medical staff, who have restrictive and regular treatment routines or demanding working schedules. During the patient co-design workshops, by which the national situation had changed, in-person studies were also utilised where the participant preferred, as not to exclude potential participants. The evaluation of the VASQoL prototype with patients was conducted during a period of lockdown and social distancing, so only employed a single suability measure, the System Usability Scale (Brooke, 1996). This was decided as clinicians felt additional measures would have placed an excessive burden upon patients and the researchers during an already difficult period and with non-medical researchers unable to attend the site, data collection was reliant on healthcare professionals and clinical researchers. The SUS is a measure which does not require many participants to produce a valid result and so would minimise the burden on patients and clinicians alike.

The scoping review of Chapter 4 sought to explore the literature on the range of technology-based and patient-centred interventions implemented with their respective high treatment burden patient populations. The scoping review protocol is not as extensive as a systematic review and so the database searches were limited to Medline, ACM and IET databases as well as Google Scholar for complementary searches. There is the potential that key literature was missed that may have been significant to the findings of the review and subsequent prototypes and study designs. In addition, the scope of the search was subject to the inclusion and exclusion criteria, which excluded studies not available in English and may have impacted identification of further literature in other regions or countries. The definition of high treatment burden was stated as ‘the work placed upon a patient as a result of their healthcare and the impact upon their wellbeing’ (Gallacher et al., 2018), as there is no verified categorisation of high treatment burden conditions, and so the researchers sought out similar treatment burden populations to that of CKD, which may have missed further key literature.

Finally, the methods of the VASQoL validation and prototype evaluation study, along with that of the co-design workshops, saw changes made in response to feedback from participants. These included refinements made to the prototypes interface and the addition of styluses to reduce patient participation and the workshop materials being adapted to minimise participant burden. While this may seem unorthodox and inconsistent, these decisions were made to maximise the effectiveness of the research being carried out and reduce the burden or frustration on the participant and allowed the studies to continue without disruption. These

positive changes could not have been possible without the partnership between researchers and clinicians, due to close relationships formed during the multidisciplinary group. As described, this approach inspired by the PAR methodology leant itself well to the context and allowed for experts in different roles and backgrounds to come together to produce effective patient-centred prototypes, as well as share knowledge and skills with thee researcher assuming a "coach role". For example, Kingsmore produced high-fidelity prototypes using presentation software for use as materials in the workshops and mini symposium, as a result of being involved in the research processes and understanding how needs are translated into design requirements. The community of interest was able to drive the focus of the research, which resulted in each distinct functionality being developed and refined independently. This may have been unconventional and different from the original single patient portal concept but allowed for each issue to be addressed and solutions produced thoroughly.

10.4. Future Work

The scope of the work in this thesis calls for future work and further research, both to fulfil identified gaps in the research and to see through the early work started here is implemented into routine care formally. This will ensure any perceived value these early systems have shown does not diminish as demonstrated by those withdrawn at study conclusion (Crafoord et al., 2021).

The scoping review to address RQ1 identified limited literature on implemented interventions for CKD populations, namely focused on teleconsultations for remote dialysis centres or patients. The patient education and decision-making resource investigated in Chapters 7 and 8 shows potential for further work to produce a prototype with further patient and clinician input, before implementing into practice supporting both new and established CKD patients in their care and decision-making. Completing such an implementation and evaluation would contribute to and expand the literature. The graft cannulation tool discussed in Chapter 5 will also require further evaluation and refinement before implementation as a tool for patients and nursing staff.

To ensure the prototype systems do not fall to the "pilotitis" mHealth technologies can become victim to (Huang et al., 2020), work is underway to roll out a refined VASQoL mobile application to different trial sites, including outside the United Kingdom and will require the delivery of the application in multiple languages. This requires a thorough forward and backwards translation process of both the VASQoL questionnaire and the applications contents, to ensure consistency in meaning across countries.

In addition, the set of design requirements produced within this thesis to answer RQ2 will be taken forward to procurement for future work. The team at Queen Elizabeth University Hospital in Glasgow are leading the procurement exercise to develop software based on the lessons from this research for clinical use, based on the understanding gained in the projects completed as part of this thesis. Other design requirements identified in prior stages will also need implemented to demonstrate the inclusion of patient feedback, as well as further design requirements only identified from making the technology available to patients from a variety of populations and locations.

Finally, there is potential to take the methods and lessons of this thesis and apply them to other domains outside of CKD. Co-design processes (inspired by PAR) have demonstrated how technology-based and patient-centred interventions can be produced while also aligning with clinical practice and supplementing established relationships. Such approaches could be applied to resolve issues within other high-treatment burden populations (e.g. oncology patients) or other areas of healthcare where there is disconnect between the clinical outcomes and patient experience.

10.5. Final Conclusions

The design requirements for patient-centred and technology-based interventions to support CKD patients in their high-treatment burden care have been produced throughout this thesis and included studies.

A novel scoping literature review was conducted to review existing implemented systems for CKD and other high treatment burden populations, highlighting common pitfalls with introducing such technologies and factors for successful implementation and adoption. Through the formation of a multidisciplinary group consisting of medical staff and academic experts, a prototype design of a patient portal mobile application was iteratively developed and refined to answer key issues as identified by the community of interest. These issues were then addressed individually, while contributing to the wider understanding of the context and the needs community of interest.

The implementation and evaluation of a PROM data collection application (Richarz et al., 2021) in a real-world clinical setting with 26 patients and 1 clinical researcher (Meiklem et al., 2021) identified idiosyncratic facilitators to successful implementation of technologies in the context of dialysing patients. These included ease of input, perceived value of engagement, a sense of privacy via independent use, and barriers such as condition-related accessibility and situational impairment. Insight was also gathered into the design of digital QoL questionnaires

by analysing response times, feedback and clinical observations of digital QoL questionnaire completion (Meiklem et al., 2022).

The iterative design and refinement of patient treatment pathway and information visualisations through 8 co-design workshops with various stakeholder groups and a live interactive symposium at a national conference (Kingsmore et al., 2022). This series of studies resulted in insights and design requirements from various stakeholder groups from across the UK and highlighted the benefit of online and remote qualitative methods for research with participants with high treatment burden or very demanding schedules, such as CKD patients and clinicians.

The results of these studies have demonstrated the value technology-based interventions can provide for CKD patients and clinicians in their care, such as offering resources for patient education and decision-making support or improving communication between both by collecting the PROMs digitally. Interventions such as these should be patient-centred in design, while clearly demonstrating value for patient and clinician and how they can support existing relationships, not replace. There is also the consideration that those who cannot or will not engage should always be offered alternatives or support as to not exclude them from potential benefits. The work of this thesis has provided the HCI community and medical domains with intrinsic design requirements for future technology-based interventions with CKD populations, and the suitability of the co-design approaches and methods to successfully developing and implementing patient-centred interventions and the studies within which they are deployed.

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Appendix A: Scoping Review Data Extraction Table

First Author	Year of Publication	Patient Population	Healthcare Setting	Study Design	Location	Intervention Description	Main Functions	Platform/ Delivery Method	Data Collected 1. Patient characteristics 2. Clinical characteristics/measures 3. In-session control/monitoring (treatment) 4. Symptoms 5. Lifestyle/behaviour change 6. QoL assessment 7. Usage of intervention 8. Usage of medical services (and costs if included)
Absolom, K	2019	Cancer (breast, gynaecologic, colorectal) patients undergoing chemotherapy	Tertiary	Mixed-methods: Iterative phases of co-design phase with professionals and usability phases with stakeholders (professionals and patients) over four years and a case study.	United Kingdom	Web application (eRAPID) facilitating PRO symptom reporting and self-management advice provision and integration with EHR	(a) Self-reporting symptoms from home (b) Immediate feedback or advice based on symptoms	Website/web application, home computer	4, 8
Ashley, L	2015	Cancer (breast, colorectal, prostate) patients	Secondary	Longitudinal: Completion of PROMs at intervals	United Kingdom	ePOCs System; QTool. Facilitates PROM recording through web-based questionnaires	(a) Self-reporting of PROMs (b) Linking self-reported PROMs to registry data	Website	1, 6, 7
Basch, E	2005	Cancer (gynaecologic) patients beginning chemotherapy (all female)	Tertiary	Longitudinal: Patient satisfaction of voluntary use of intervention in treatment and nurse feedback, over 8 week observation period (n=80)	United States	STAR (Symptom Tracking and Reporting), web-based interface facilitating symptom PRO reporting	(a) Self-reporting at clinic or remotely (b) Severe or worsening symptom warning to responsible clinical team	Website/web application (STAR), clinic waiting area computer and home computer	1, 4, 7
Basch, E	2007	Cancer (gynaecologic, lung, others?) patients undergoing chemotherapy	Tertiary	Longitudinal: Considerations with professionals and user acceptance testing with patients, baseline paper survey and follow-up, single-center feasibility study (n=60)	United States	Web portal facilitating symptom PRO symptom reporting and reviewing	(a) Self-reporting and reviewing toxicity symptoms from home (b) Severe or disabling symptoms warning sent to responsible clinical team	Website/web application, home computer or touchscreen computer in clinic waiting area	1, 4, 7

Basch, E	2007	Cancer (gynaecologic, lung, others?) patients undergoing chemotherapy	Tertiary	Longitudinal: Patient satisfaction of voluntary use of intervention in treatment and nurse feedback, over 8 months (n=107)	United States	STAR (Symptom Tracking and Reporting), web-based interface facilitating symptom PRO reporting	(a) Self-reporting at clinic or remotely (b) Severe or worsening symptom warning to responsible clinical team	Website/web application , clinic waiting area computer and home computer	1, 2, 4, 6, 7
Basch, E	2009	Cancer (lung) undergoing chemotherapy	Tertiary	Longitudinal: patients and clinicians reporting at sequential office/clinic visits, up to 28 months (or until death)	United States	Patient toxicity reporting prior to clinician reporting during consultation	(a) Self-reporting toxicity symptoms at clinic before consultation	Touchscreen tablet at clinic	1, 2, 4, 6
Basch, E	2016	Cancer (metastatic breast, genitourinary, gynaecologic, lung) undergoing chemotherapy	Tertiary	RCT: (intervention vs standard care, computer-experienced subgroup) n=766, over 4 years	United States	STAR (Symptom Tracking and Reporting), web-based interface facilitating symptom PRO reporting	(a) Self-reporting at clinic or remotely (b) Severe or worsening symptom warning to responsible clinical team	Website/web application (STAR), home computer and kiosk in clinic	1, 2, 4, 6, 7, 8
Berry, D.L.	2011	Cancer (medical or radiation treatment)	Tertiary	RCT: compare the likelihood of discussion of SQLIs in an intervention group	United States	Electronic QoL (ESRA-C) used in clinic visits	(a) Completion of ESRA-C questionnaire (b) Generation of graphical summary for clinician	Touch-screen, notebook computer in clinic	1, 2, 5, 6, 7
Berry, D.L.	2014	Cancer (various) patients starting new treatment	Tertiary	RCT: compare typical assessment vs intervention use and impact on symptom distress	United States	Electronic QoL (ESRA-C II) used in clinic visits and at home	(a) Provide tailored care instructions/information (b) Facilitate symptom reporting	Touchscreen clinic computer or Web-based version from home computer	1, 4, 5, 6
Coombs, L.A.	2020	Cancer (various) patients	Secondary	RCT: intervention vs usual care (control)	United States	Automated telephone-based symptom reporting and coaching for intervention group	(a) Facilitate reporting of symptoms (b) Provide symptom care strategies via DSS (c) Alert nurses if moderate or severe logged	Telephone call	1, 2, 4, 7
Crafoord, M.T.	2020	Cancer (breast, chemo and prostate, radio) patients	Secondary	Two RCTs: intervention vs usual care	Sweden	Smartphone app Interaktor, for symptom reporting during treatment and afterwards (2-3 weeks)	(a) Facilitate reporting of symptoms (b) send alerts to nurse	Personal smartphone (provided if required) via app	1, 2, 4, 7

							(c) remind patients to report if out with normal nurse hours (d) reminders to read self-care advice (breast cancer only)		
Evenski, A.	2020	Oncology (orthopaedic (bone)) patients	Secondary	Cross-sectional: satisfaction survey with patients using tele-oncology service (n=15)	United States	Telehealth services for orthopaedic oncology patients	(a) Facilitate regular meetings with remote oncologist and patient	On-site telehealth service (not stated)	1, 5, 7
Ferrer-Roca, O.	2002	Oncology patients	Secondary	Longitudinal: Comparison of outreach visits and hospital visits with year before service introduced and that with the service running for four years	Spain	Non-supervised call centre rerouting patient calls allowing 24hr contact with doctor	(a) Route incoming patient calls automatically to doctor's mobile or office phone	Telephone call	1, 2, 3, 7, 8
Fjell, M.	2020	Cancer	Secondary	RCT	Sweden	Mobile application, Interaktor, for symptom reporting	(a) Facilitate symptom reporting (b) Provide self-care advice (c) Send SMS alerts to nurses if severe symptoms (d) Review previous reports	Smartphone or tablet	1, 2, 4, 6, 7
Gallar, P.	2007	Home peritoneal dialysis patients	Tertiary	Cohort study: Comparison of long-term stable patients with telemedicine (alternate months of tele- and physical consultations) support with vs those without over 2 years	Spain	Teleconsultations via videoconferencing equipment installed in patients' home (not in-session)	(a) Facilitate teleconsultation between patient at home and clinician at hospital	Videoconferencing equipment (Falcon, Vcon) installed in patients home television and hospital (software allowed control of patient camera)	1, 6, 7, 8
Hauth, F.	2019	Oncology (Pelvic, thoracic, head and neck, upper gastrointestinal) patients receiving radiotherapy and radiochemotherapy	Tertiary	Longitudinal: Patient acceptance of intervention in treatment over 6 months (n=21)	Germany	Web application (PROMetheus) facilitating ePROM symptom, side effect and QoL reporting	(a) Self-reporting during and after treatment	Website/web application via home computer, smartphone or tablet	1, 2, 4, 7

							(b) Severe or worsening symptom warning to responsible clinical team (c) E-mail reminder sent weekly		
Huang, R.	2020	Home dialysis	Secondary	Longitudinal	Australia	Mobile application for remote patient monitoring (RPM) for home HD patients	(a) Patients log HHD data (b) Feedback for patients or alerts (c) Share patient messages and emotions with care team	Smartphone or tablet	1, 2, 3, 7
Jacobs, M.	2018	Cancer (breast) patients in rural populations	Secondary	Longitudinal: Deployment of intervention in rural community over 7 months, evaluated with patient interviews and useage logs (n=12)	United States	Mobile health application, MyPath, providing personalised recommendations from vetted set of health information	(a) Provide personalised recommendations based on treatment and diagnosis (offline and online) (b) Elicit patient information needs via survey and update content accordingly and prompt contacting clinic if distress levels high	Tablet device (Verizon Ellipsis 8), kept by patient	1, 5, 7
Judson, T.J.	2013	Cancer (lung, gynaecologic, genitourinary, breast) receiving chemotherapy	Tertiary	Longitudinal: Reporting of symptomatic toxicity between visits to clinic, within RCT methodology	United States	STAR (Symptom Tracking and Reporting), web-based interface facilitating symptom PRO reporting	(a) Self-reporting at clinic or remotely (b) Severe or worsening symptom warning to responsible clinical team	Website/web application (STAR), home computer and kiosk in clinic	1, 4, 6, 7
Kargalskaja, I. G.	2020	Cancer	Secondary	Longitudinal	Russia	ONCONET platform	(a) Collect symptoms and readings from patients (b) Provide relevant information based on symptoms (c) Attach results or contact clinician	Web-based	2, 7

Kearney, N.	2009	Cancer (lung, breast, colorectal) chemotherapy patients	Tertiary	RCT: intervention vs control	United Kingdom	Advanced symptom management system (ASyMS©); mobile-based symptom tracking	(a) Self-reporting remotely (b) Severe or worsening symptom warning to responsible clinical team	Mobile phone/PDA	1, 4, 7
Kennedy, F .	2021	Cancer	Secondary	Longitudinal	United Kingdom	Online or telephone-based PROM data collection	(a) Collect PROMs (b) Paper reports included to upcoming appointments	Telephone call or online via computer or in-clinic computer	1, 2, 4, 7
Kuo, J. C.	2021	Cancer	Secondary	RCT	Canada	PROM data collection via handled pocket computer	(a) Report symptoms (b) Report graphical summary	Handheld pocket computer	1, 2, 4
Maguire, R.	2021	Cancer	Secondary	RCT	Europe (multisite)	Symptom reporting via ASyMS, with access to tailored self care advice	(a) Report symptoms (b) Access to tailored advice (c) Alerts sent to hospital clinicians	Smartphone or tablet, dedicated clinician handsets	1, 2, 4,
McCann, L.	2009	Cancer (lung, breast, colorectal) chemotherapy patients	Tertiary	RCT: intervention vs control	United Kingdom	Advanced symptom management system (ASyMS©); mobile-based symptom tracking	(a) Self-reporting remotely (b) Severe or worsening symptom warning to responsible clinical team	Mobile phone/PDA	1, 4, 7
Meiklem, R.	2021	Haemodialysis	Secondary	Case study: patients using app in multiple centres in health board	United Kingdom	QoL questionnaires via app on dedicated tablet device during HD	(a) Completion of QoL measures	Tablet device (Samsung Tab A), kept on ward	1, 2, 6, 7
Mitchell, J. G.	1997	Remote dialysis patients	Tertiary	Cross-sectional: satisfaction survey with staff using tele-renal services to treat remote patients	Australia	Clinic teleconferencing equipment	(a) Facilitate teleconsultation between patient at satellite unit and staff at hospital during dialysis	Teleconferencing equipment (rolling units for patient use, desktop units for staff use)	7
Mitchell, J. G.	2000	Home haemodialysis patient	Tertiary	Case study: patient (n=1) using telemedicine during home dialysis and to access support, with	Australia	Home telemedicine equipment used routinely during home treatment and on request for support	(a) Facilitate teleconsultation between patient at home and staff at hospital during home dialysis	Home teleconferencing equipment	1, 5, 7, 8

				nurses attitudes to intervention (n=2)			(b) allow access to support if requested (c) patient education and interviews		
Ngo, V.	2020	Cancer	Secondary	RCT	United States	mHealth app for managing healthcare and contacting clinicians	(a) Review care plan (b) contact details for care team (c) symptom assessment surveys (d) library of health information (e) calendar and journal/note taking (f) secure messaging and video chat	Tablet (Galaxy Tab Pro 8.4 SM-T325), kept by patients	1, 7
Ruland, M.	2010	Cancer (leukemia or lymphoma) patients beginning treatment (inpatients or outpatients)	Secondary, Tertiary	RCT: control vs intervention	Norway	Interactive tailored patient assessment (ITPA)	(a) Facilitate self-reporting of symptoms (b) Tailor questions asked based on responses (c) Send summary to clinician	ITPA via touch-screen tablet before consultation	1, 4, 5
Rumpsfield, M.	2005	Haemodialysis patients	Tertiary	Longitudinal: 8 month observations with economic analysis and nurse satisfaction	Norway	Teleconsultations via videoconferencing equipment for patients at satellite dialysis centre and staff at main hospital	(a) Facilitate consultations between nephrologist and patient (b) Educational events	Videoconferencing units (Vision 6000) and medical tele-equipment e.g. ultrasound, stethoscope	1, 7, 8
Sicotte, C.	2011	Haemodialysis patients in native communities	Tertiary	Pre-post design: to compare health and care utilisation of patients (n=19) receiving tele-haemodialysis over 2 years (12 months pre, 12 months post)	Canada	Tele-haemodialysis; videoconferencing between remote nephrologist and patient during treatment at local centre at one site and videoconferencing for weekly patient reviews at other site	(a) Facilitate "telerounds" with remote nephrologist communicating with patient and nurse present (b) Videoconferencing between remote and local medical staff to review patients	Mobile teleconferencing unit	1, 2, 7

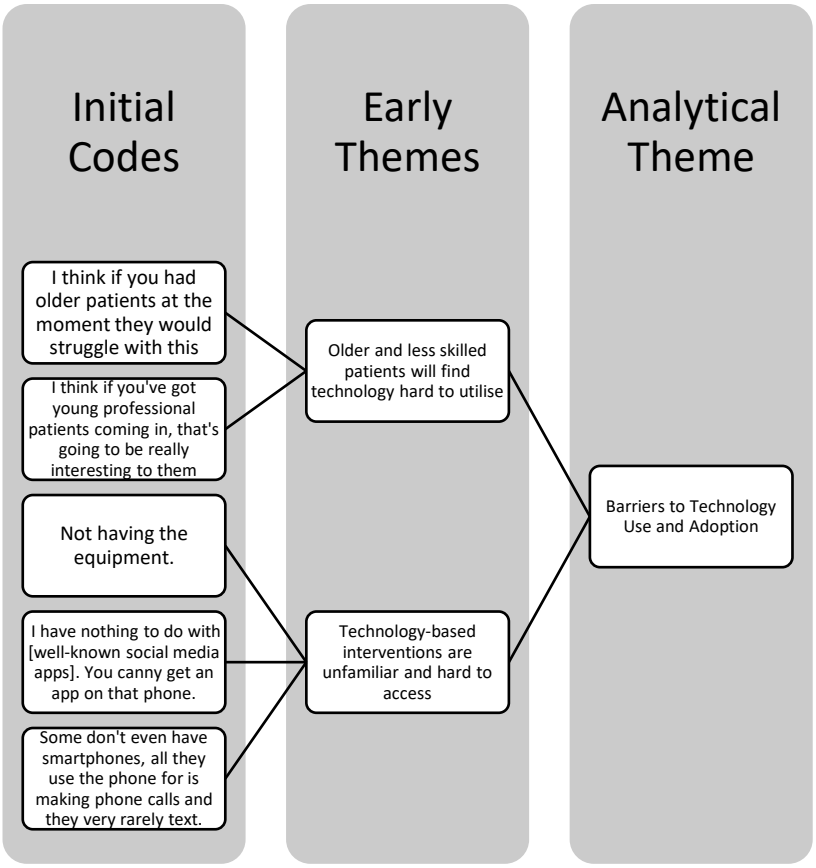
Velikova, G.	2004	Cancer (breast, gynaecologic, renal, bladder, sarcoma, melanoma and other) patients	Tertiary	RCT: Intervention and feedback vs intervention vs control, evaluate if patient well-being and process of care changes, as well as medication changes and patient satisfaction	United Kingdom	HRQoL Questionnaire, with a group of patients' data being provided for use in consultation	(a) Collection of HRQoL responses (b) Visualisation of HRQoL data for consultation purposes	Touchscreen tablet at clinic	1, 6, 7
Warrington, L.	2016	Acute oncology patients	Tertiary	Longitudinal: audit over 2 years	United Kingdom	Nurse-led tele-triage system for patient symptom assessment	(a) Facilitate reporting of symptoms (b) Nurse provides advice based on grading assessment of symptom severity	Telephone call	1, 2, 4, 7
Whitten, P.	2008	Haemodialysis patients in rural communities	Tertiary	Longitudinal: Evaluation of intervention use with clinical outcomes and user perceptions via telephone surveys with patients and providers (n=34, 4) after 13 months, in three clinics	United States	Tele-haemodialysis; videoconferencing between remote nephrologist and patient during treatment at local centre	(a) Facilitate regular meetings with remote nephrologist and patient as required (b) Facilitate patient and professional educational events	Videoconferencing equipment on cart	1, 2, 7
Wood, J.	2017	Cysticfibrosis patients	Secondary	Longitudinal: telehealth clinics provided over 12 months, measuring satisfaction and uptake and patient outcomes	Australia	Teleclinic for CF patients	(a) Facilitate teleconsultations with remote multidisciplinary team	Teleconferencing equipment at clinic	1, 2, 5, 7, 8
Wood, J.	2020	Cysticfibrosis patients	Secondary	Cohort study: Single-centre (intervention vs usual care, n =29, 31)	Australia	Smartphone app facilitate reporting of symptom changes; nurse contacts patient if worsened symptoms reported	(a) Facilitate reporting of symptom changes (b) Remind patient via text message if no report submitted for a week	Personal smartphone via app	1, 2, 4, 6, 7
Wright, E.P.	2003	Cancer (various) patients	Secondary. Tertiary	Longitudinal: two studies to investigate feasibility and compliance of QoL intervention, one with cohort over 6 months and second with all patients over 12 week period	United Kingdom	QoL questionnaires via touchscreen computer	(a) Facilitate QoL questionnaire and collect responses (b) Print out summary of responses afterwards	Touch-screen computer at clinic	1, 6, 7

Zini, E. M.	2019	Cancer	Secondary	Longitudinal	Italy	HeNeA mobile app collects symptom, clinical measures and PROMS, allows contact with clinicians and provides healthcare education, support and management	(a) collect symptom, readings and PROM data (b) provide education material and self-care advice (c) tracking costs related to healthcare (d) maps with pharmacy and radiotheraphy units (e) peer support via dedicated social networks (f) contact staff and attach reports	Tablet (Android)	1, 2, 4, 6, 7

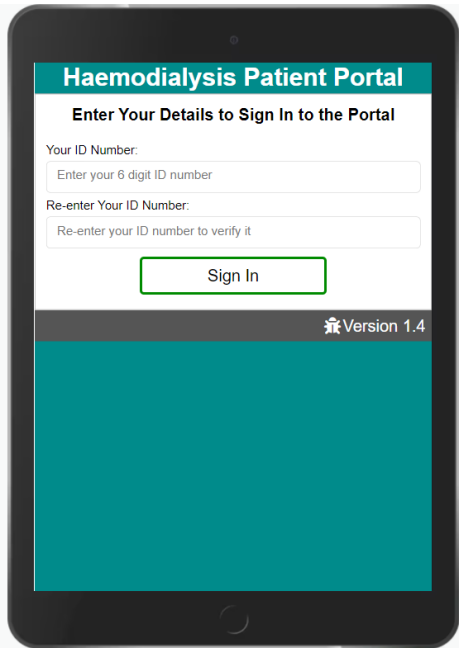
Appendix B: Thematic Analysis Protocol

1. Familiarise with the data by reading over transcription and listen to audio. Check transcription is accurate, repeat as necessary.
2. Generate codes by reviewing transcript with one concept at a time, as per framework specifies. Repeat until all concepts completed.
    - Coding process subject to peer input and review as part of frequent meetings of MDG.
3. For each concept, collate codes into early themes.
4. Merge and rename themes where appropriate.
5. Review themes to ensure relevant and valid.
    - Any conflicts/difficulty addressed by group.
6. Where several occurrences of same overarching theme appear across multiple concepts or established themes, look to potentially including as a separate theme.
    - Example: Including Barriers in the Technology concept of Korhonen et al. after scoping review

See diagram for an example of process of steps 2 through 4.



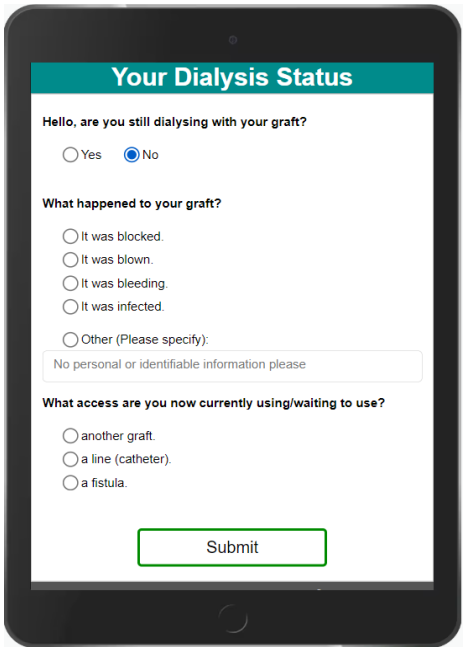
Appendix C: Screenshots of First Prototype / eVASQoL



Sign In Screen

User enters anonymous 6-digit identifier twice in order to access functionalities.

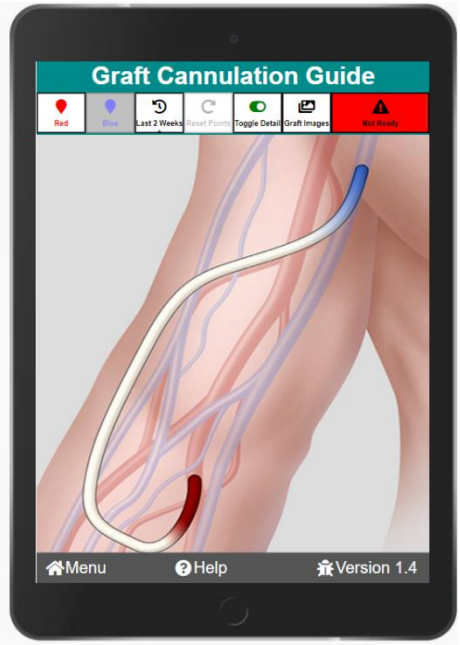
If app can confirm identifier exists within remote database, user's details are retrieved and app begins sign-in process.



Clinical Events Capture

User completes questions to determine if there is a change in their vascular access.

If No (using the same access as the previous log-in), they continue to main menu.
If Yes (a change has occurred), details on what happened (i.e. clinical event) and details of new access are recorded before continuing.

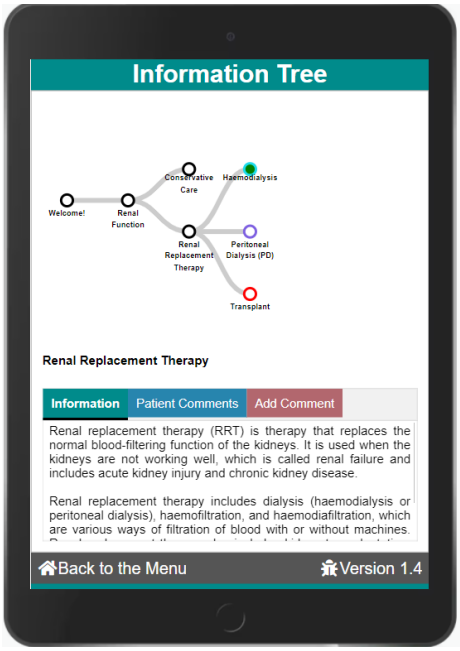


Cannulation Recorder

User is shown an image of a graft in reference to veins and arteries in a limb. Previous submissions are recovered from the database.

Tapping on the graft places one of two markers to indicate cannulation sites. Only when both markers are placed, can the responses be stored to the database. User can toggle between markers, graft images (hides medical detail), show markers from previous cannulations and edit graft image (configuration and location).

Disabled/removed for VASQoL validation (Chapter 6).

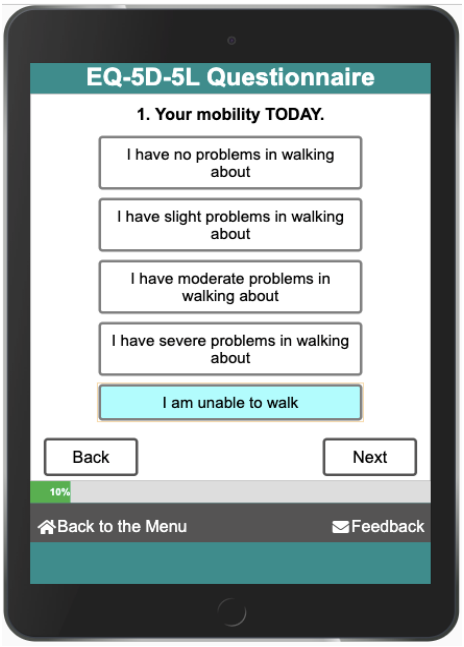


Patient Information Tree

User interacts with tree formed of nodes, each with its own summary of information and potentially child nodes, indicated by a coloured centre. Nodes expand and collapse on touch.

Prepared patient comments are viewable in relevant tab but adding comment functionality not implemented.

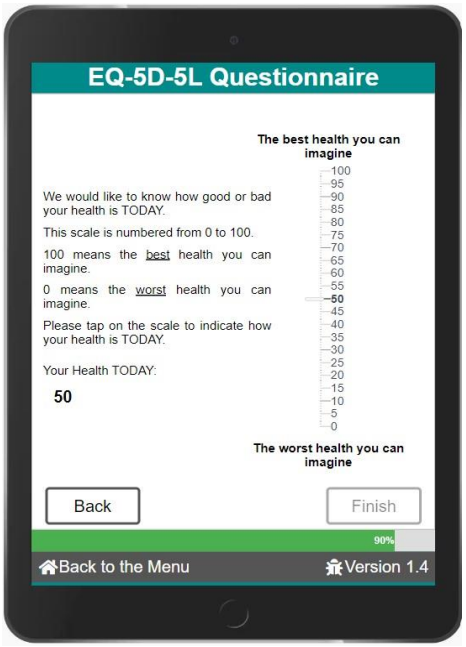
Disabled/removed for VASQoL validation (Chapter 6).



EQ-5D-5L QoL Measure

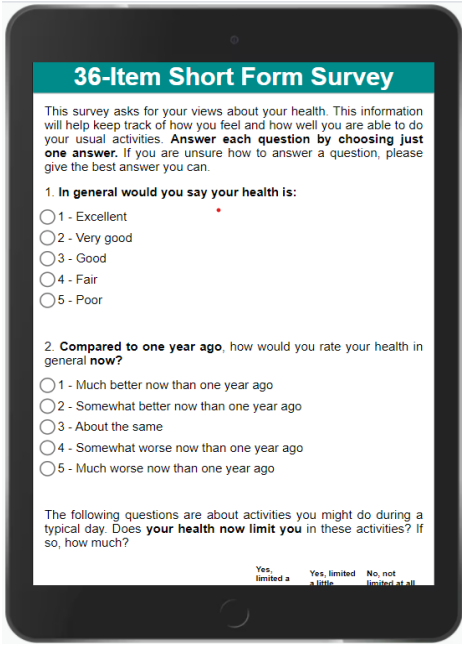
The user is guided through the EuroQoL EQ-5D-5L questionnaire one question at a time.

Tapping buttons to select a response highlights the selected button for Likert scale Questions 1 to 5.



For Question 6, the view changes and users select an overall score from the numerical scale.

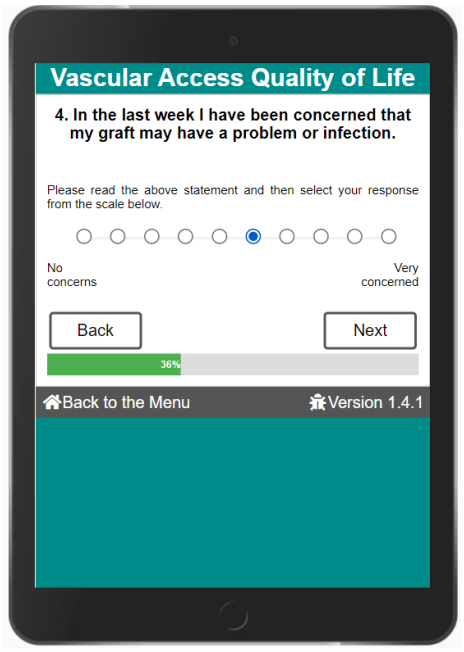
Questions can be reviewed but progression forward is not possible without a response for the current question. The progress bar increases as the question number does.



SF-36 QoL Measure

The user works through all 36 questions of the SF-36 questionnaire on one scrollable screen.

Input is recorded through radio buttons for each question. On submission attempt, any unanswered questions are flagged with red error messages, and submission is not completed until all radio button groups are checked.

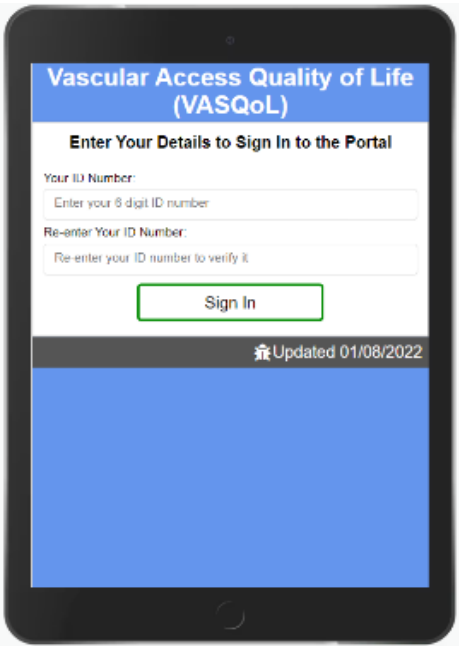


VASQoL Measure

The VASQoL questionnaire is displayed one question at a time, with Likert-scale response through radio buttons. The second question is skipped if the user has responded as not using their vascular access to dialyse.

Progression is not possible unless a response is provided. Reviewing questions is possible. The progress bar increases as the user completes the questionnaire.

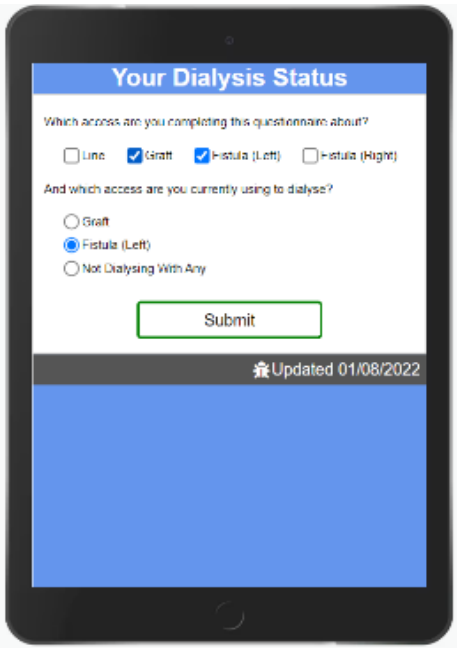
Appendix D: Screenshots of Refined eVASQoL



Sign In Screen

User enters anonymous 6-digit identifier twice in order to access functionalities.

App no longer verifies with database, and instead records given identifier to submit with vascular access and VASQoL responses.



Vascular Access Capture

User completes selects which vascular access(es) they are completing the VASQoL questionnaire about. They must also select which of their selected options is currently being used for dialysis (or if none are being used).

The number of accesses determines the number of times the VASQoL is completed.

Updated following VASQoL validation (Chapter 6).

VASQoL Measure

The VASQoL questionnaire is displayed one question at a time but refined to 7-point Likert-scale response through large buttons.

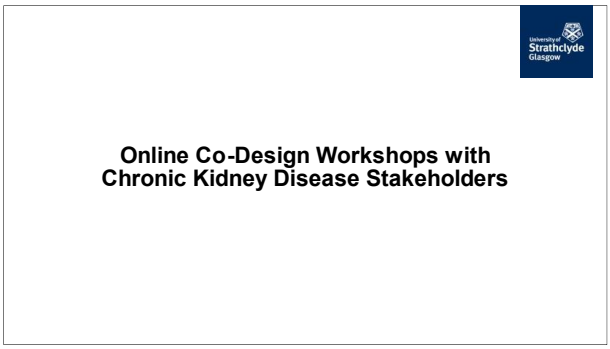
Buttons are highlighted once a response is selected.

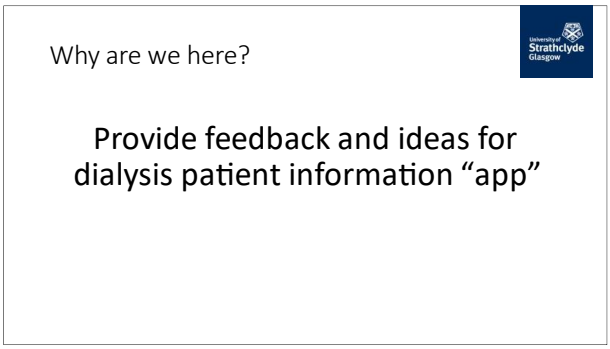
The second question is skipped if the user has responded as not using their vascular access to dialyse.

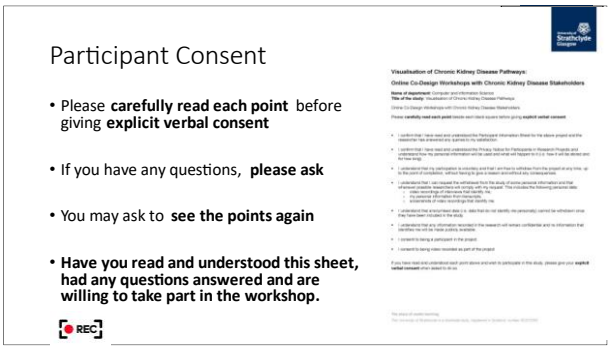
Progression is not possible unless a response is provided. Reviewing questions is possible. The progress bar increases as the user completes the questionnaire.

Updated following VASQoL validation (Chapter 6).

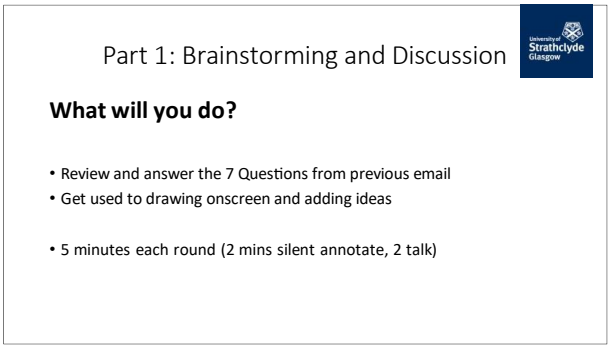
Appendix E: PowerPoint Slides used in Co-Design Workshop Sessions w/Medical Professionals







Part 1: Introductory Slides and Consent Confirmation

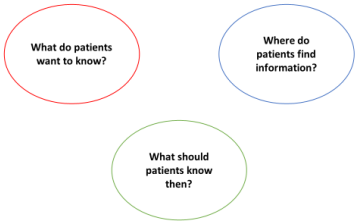


Part 2: Experiences of Patient Education Questions

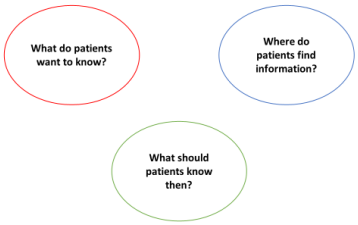
Practice Slide

Try using Annotate to add to the slide.

Q1-3: When deciding treatment...

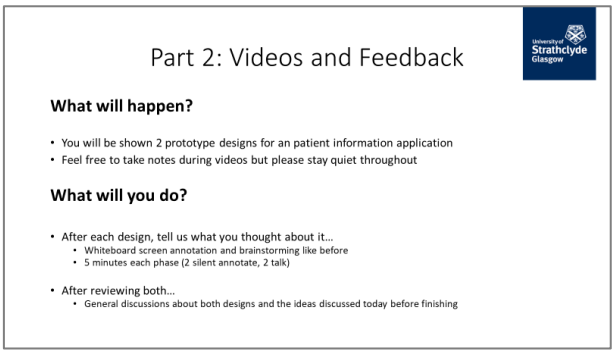


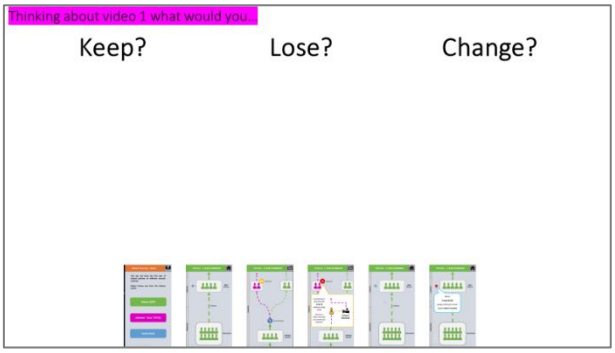
Q4-6: When treatment changes...

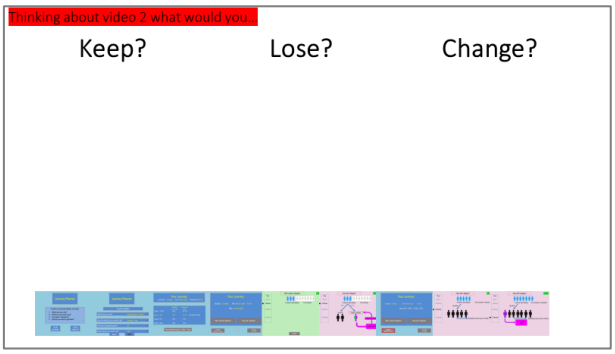


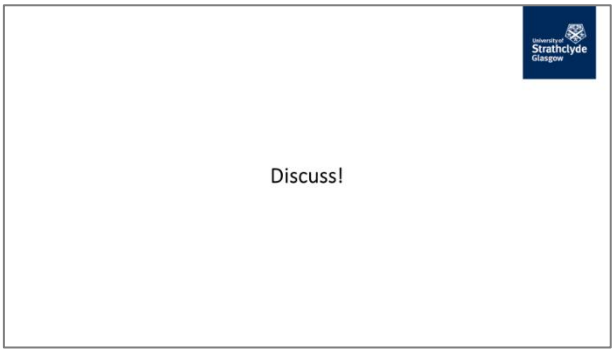
Q7: For someone about to start treatment...

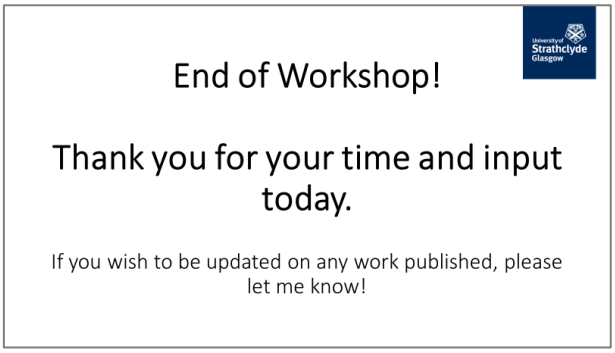
Part 3: Reviewing Prototypes and KLC Exercise





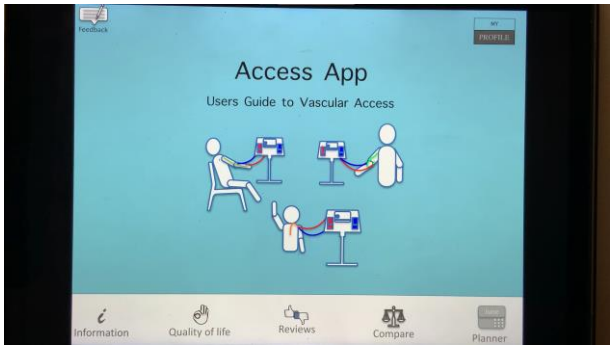


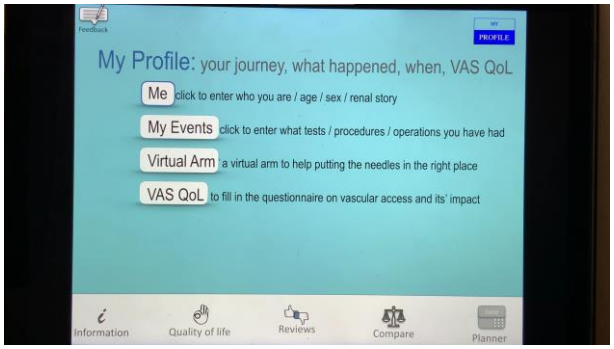




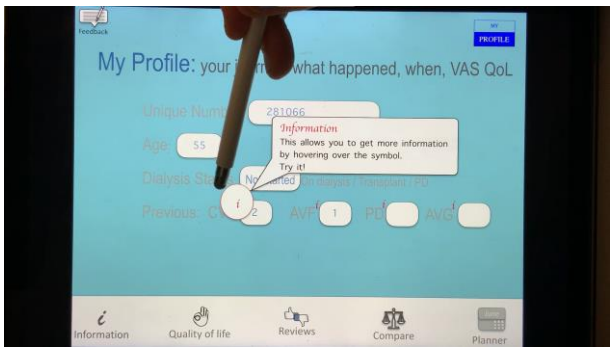
Part 4: Final Discussions and Conclusion

Appendix F: Screenshots of Final Patient Education Prototype Video by Kingmsore

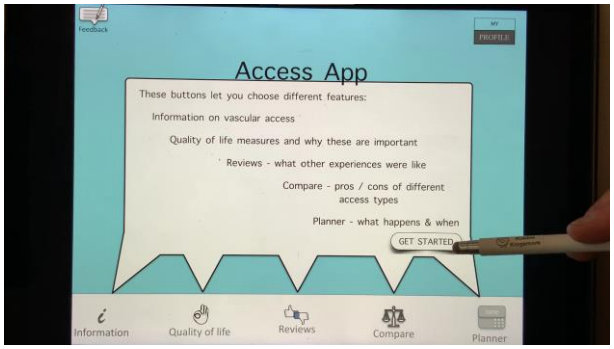


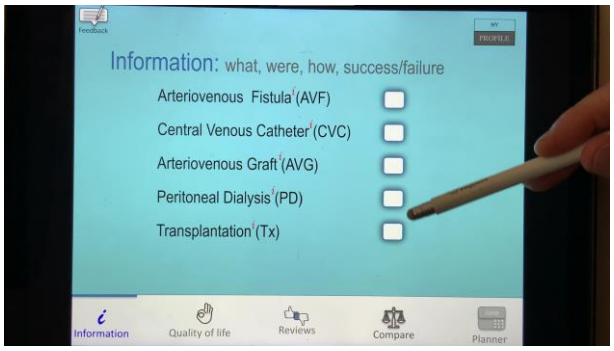


Part 1: Main Menu and Overview

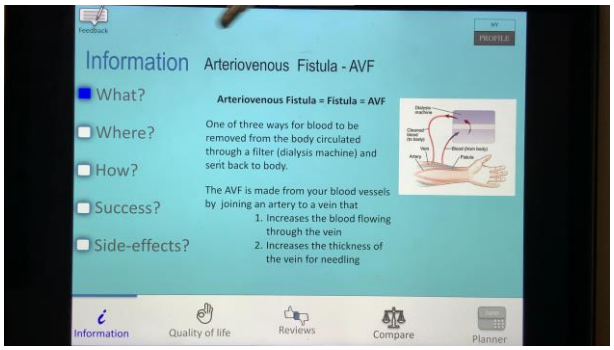


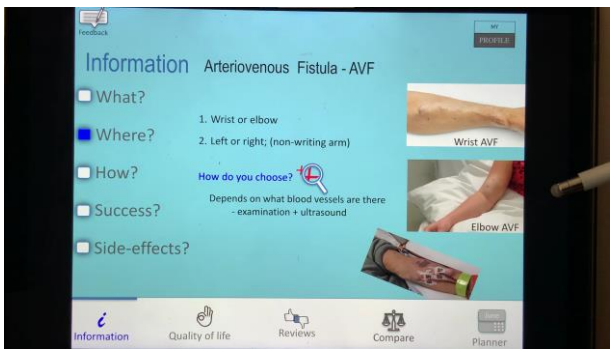
Here the information icon "i" is demonstrated in reference to abbreviated VA terms.



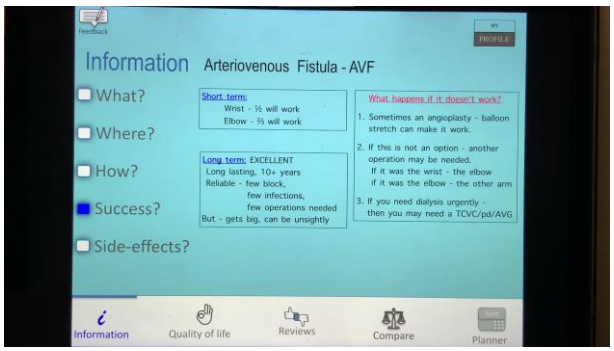


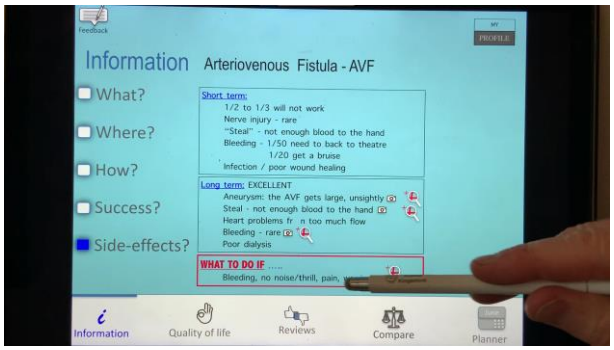
Part 2: Information Pages



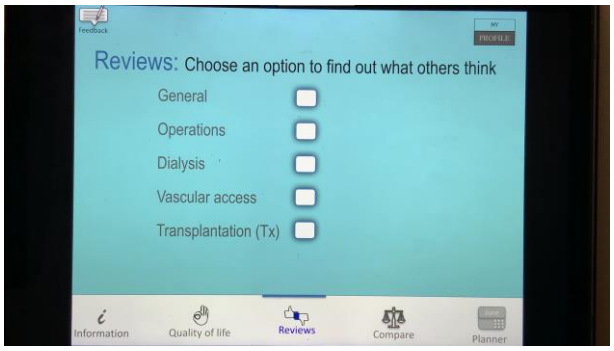


Here the magnifying glass icon signifies more details or information is available.

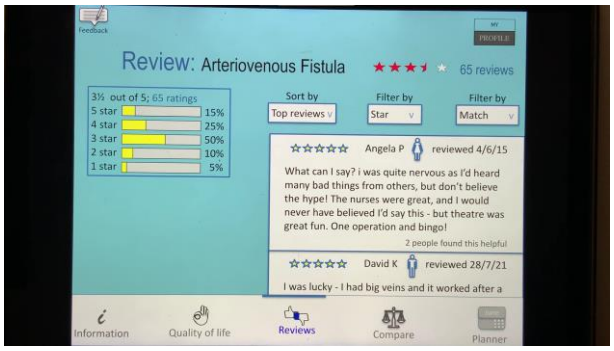




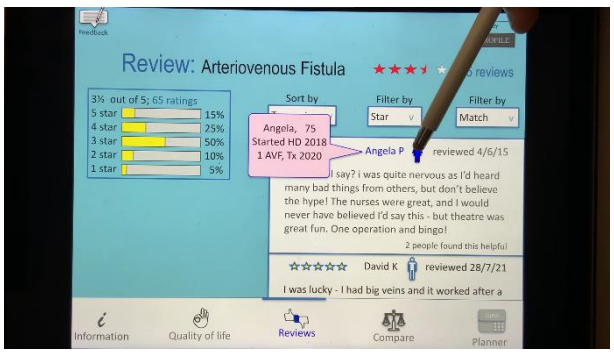
Camera icons indicate a related image is available but allows user to choose if they wish to view it or not.



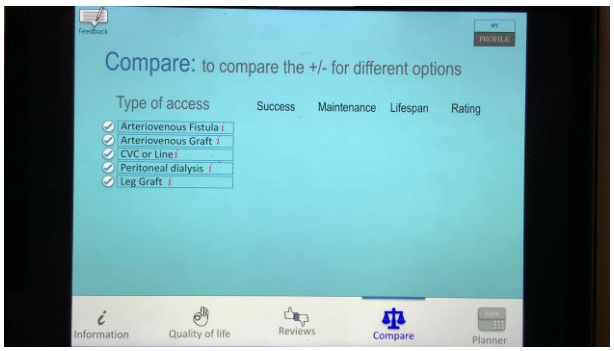
Part 3: Patient Reviews



The reviews can be sorted or filtered by rating or characteristics like age group.

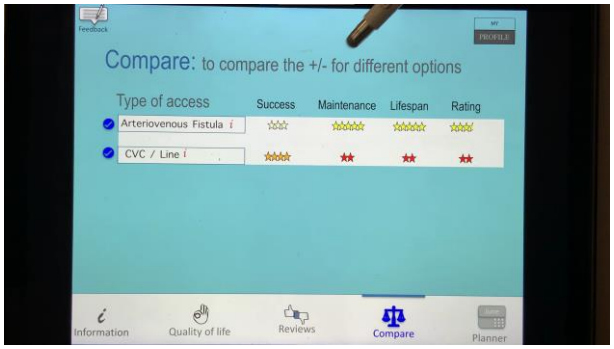


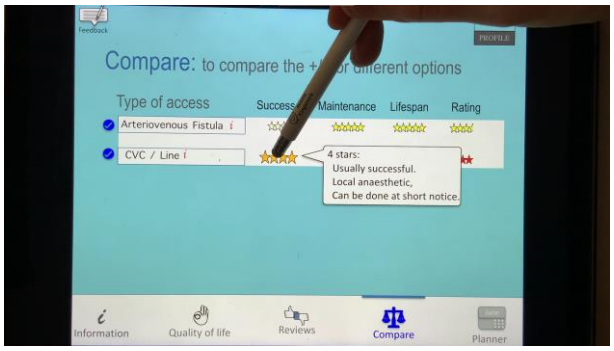
User can select elements to discover more details, such as the age, and VA experience of other patients who have left reviews.



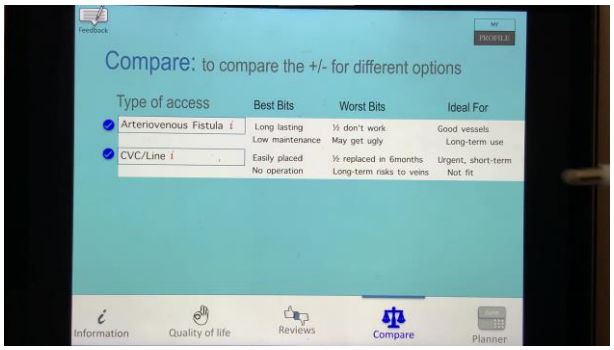
Part 4: VA Comparison

Two or more VA can be selected to view how they compare in a variety of categories.

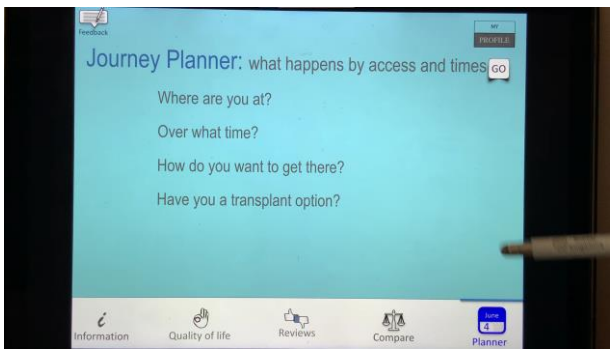




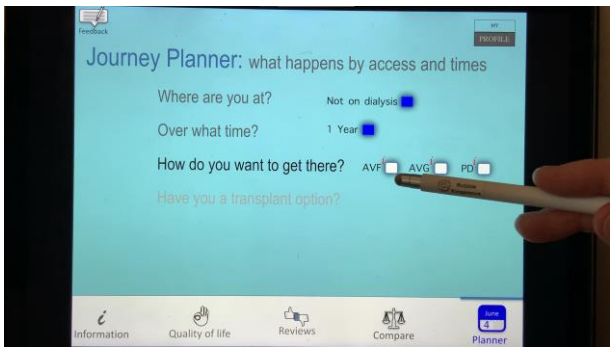
Elements like ratings can be tapped to reveal more information.



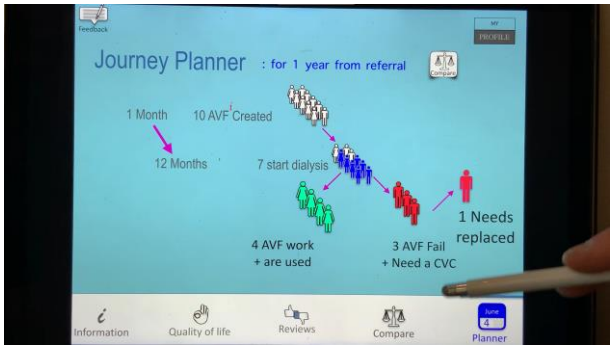
A summary of the comparison can be viewed when the table is swiped.



Part 4: Journey Planner

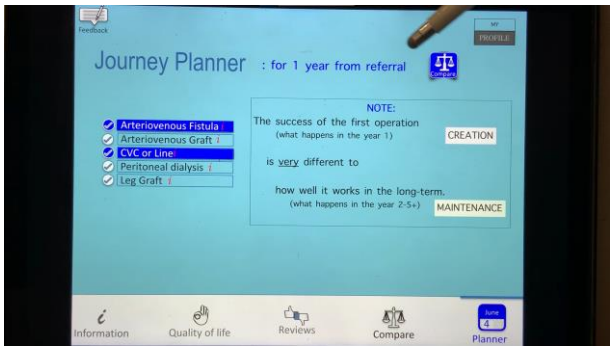


User selects responses to the four options to generate the visualisation of the expected treatment journey.

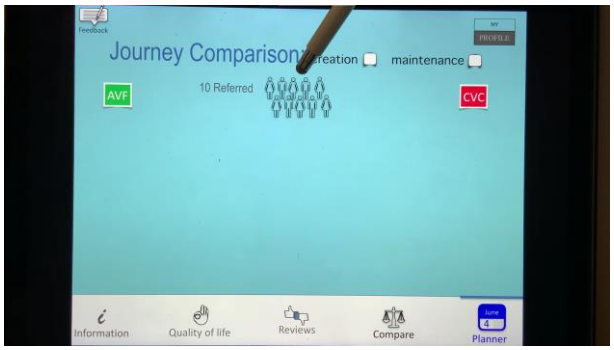


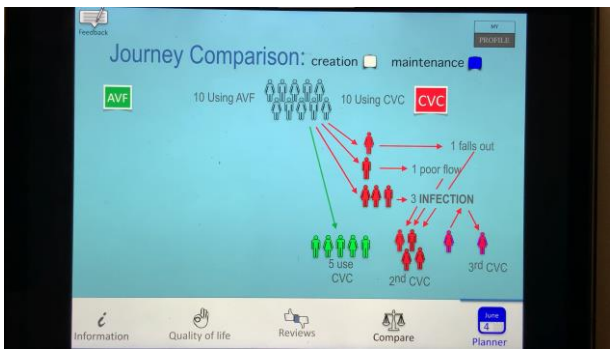
The expected journey for the options selected is displayed with potential complications and changes.

A compare icon signifies that a comparison with other VA options is available.

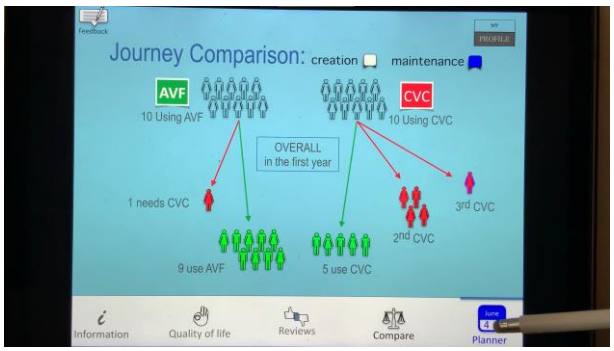


Selected VA options can be compared on creation or maintenance.





Expected outcomes are shown for each VA one at a time, then a summary is displayed.



Appendix G: PowerPoint Slides used in Co-Design Workshop Sessions with Patients and Caregivers

Part 1: Introductory Slides and Consent Confirmation

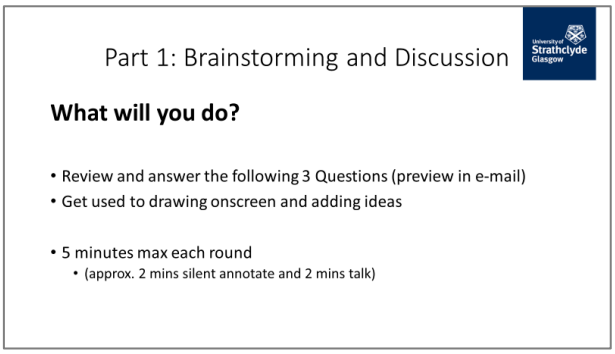
Online Co-Design Workshops with Chronic Kidney Disease Stakeholders

Why are we here?

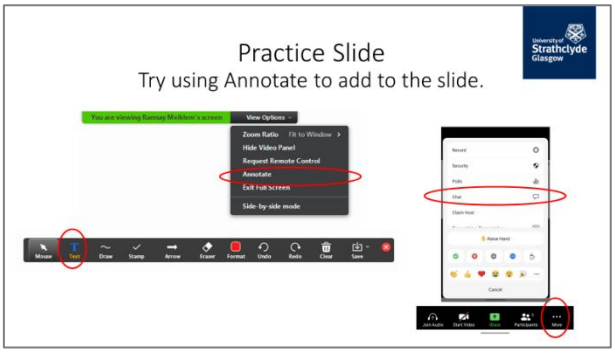
Provide feedback and ideas for dialysis patient information "app"

Participant Consent

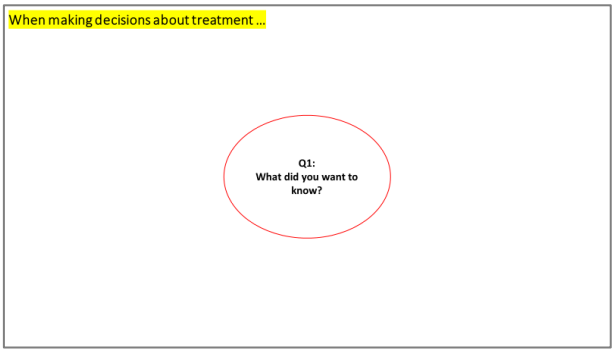
- Please **carefully read each point** before giving **explicit verbal consent**
- If you have any questions, **please ask**
- You may ask to **see the points again**
- **Have you read and understood this sheet, had any questions answered and are willing to take part in the workshop.**



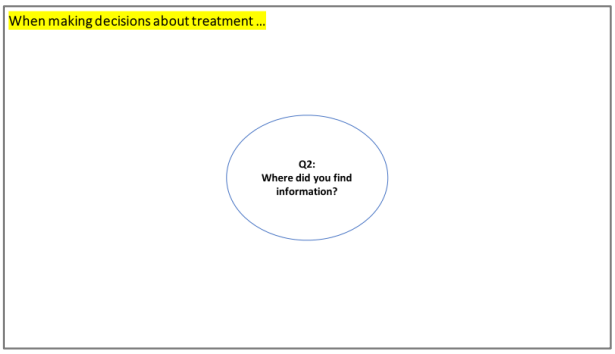
Part 2: Experiences of Patient Education Questions

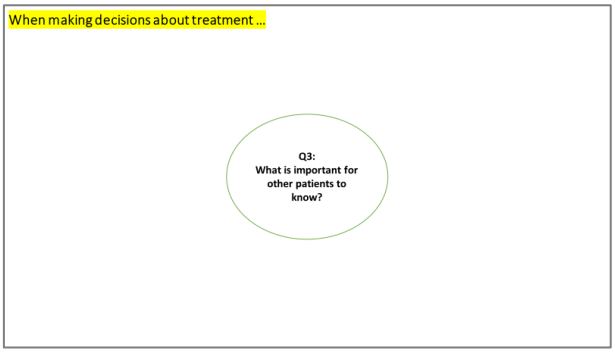


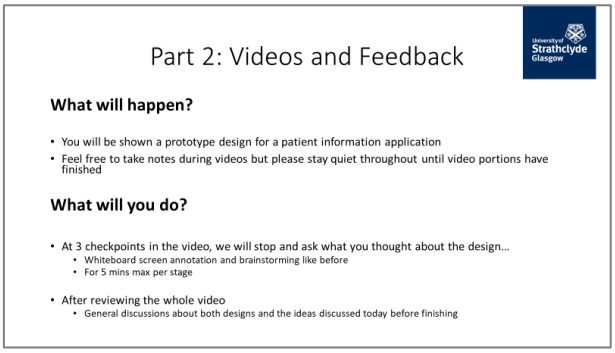
Note annotation slide now includes updated Zoom user interface for accessing the chat functionality on mobile devices.

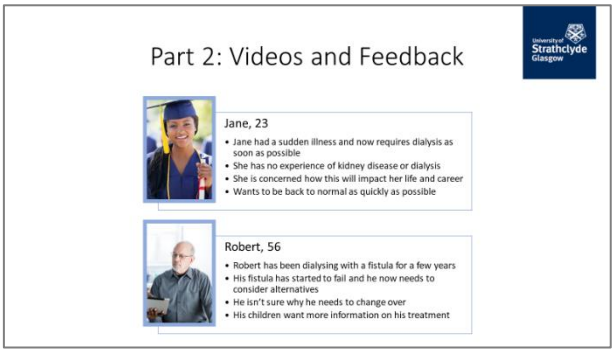


Questions are now asked in context of both starting and changing treatment.



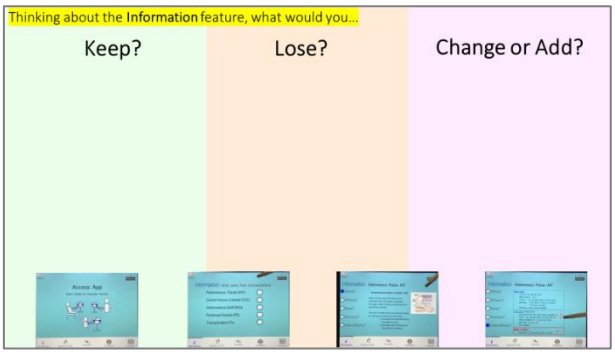


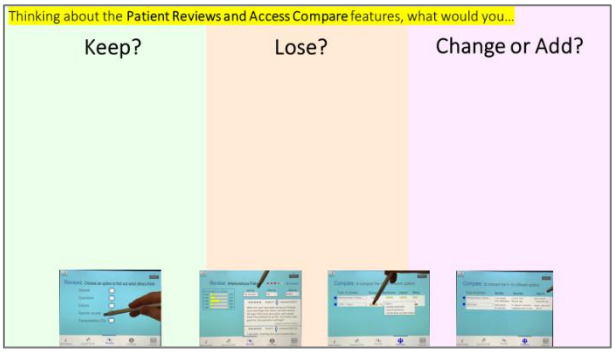


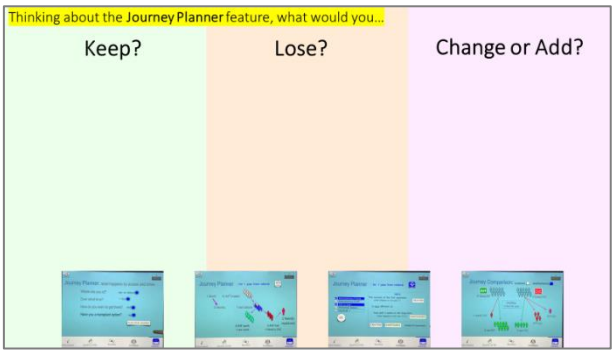


Part 3: Reviewing Prototypes and KLC Exercise

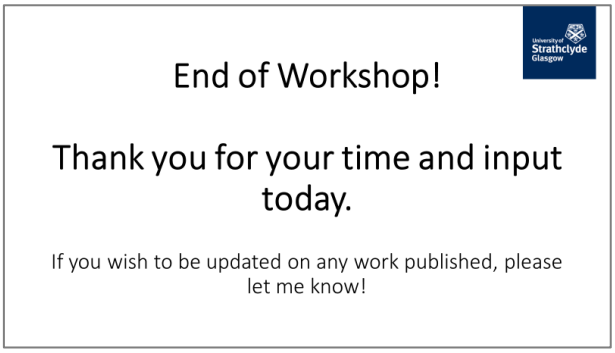
Inclusion of patient personas to encourage patient participants to consider how others may engage with the prototype as well.





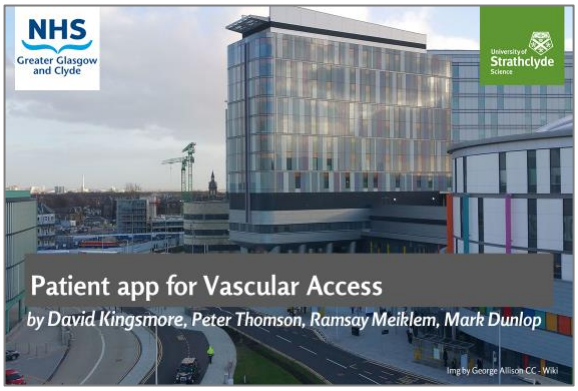


Keep, Lose, Change or Add slides now have colour coded sections to organise annotated responses better.



Part 4: Final Discussions and Conclusion

Appendix H: PowerPoint Slides used in UKKW Session



Part 1: Introductory Slides and Context

We need your input: 30 minutes not long .....

1. Who are you? Quick Demographic Poll (ANONYMOUS)
1. Poll 2: how well do our current patient information systems perform?
1. Video of prototype - live talk through 6 min
1. *Your immediate reactions: **keep** / **lose** / **change** / **add***
1. *Poll 3: How well would this app help the current setup?*
1. *Questions & comments to **Pete Thomson** in chat.*
1. *Results + Feedback*

BLUE = YOUR INPUT

Polls: No host talking (DAVID)

vascularaccessapp@gmail.com

What is the problem we are trying to fix?

High quality information empowers people.
With poor information they cannot make effective choices;
and without information
they have no real choices at all.

BUT

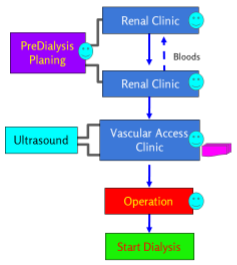
Better information, better choices, better health. Putting information at the centre of health. Department of Health

National Patients Survey:
½ of patients were not involved as much as they wanted
in decisions about their care

Care Quality Commission (Undated) National summary of the results for the Inpatients Survey

vascularaccessapp@gmail.com

Vascular Access Planning: the '*service*' view .....



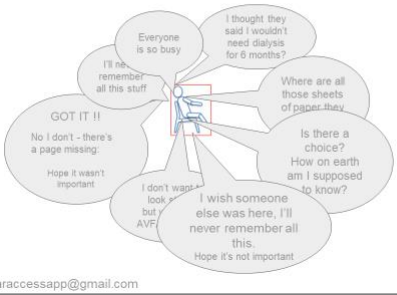
Well planned

1. Information - verbally
   : from doctors
   : from Pre-Dialysis nurses
   : Vascular Access Clinic
1. Patient Information Sheets:

= Fully engaged patients

vascularaccessapp@gmail.com

Vascular Access Planning: can we do better?



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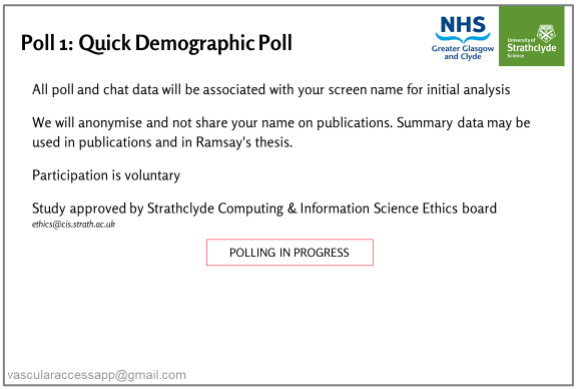
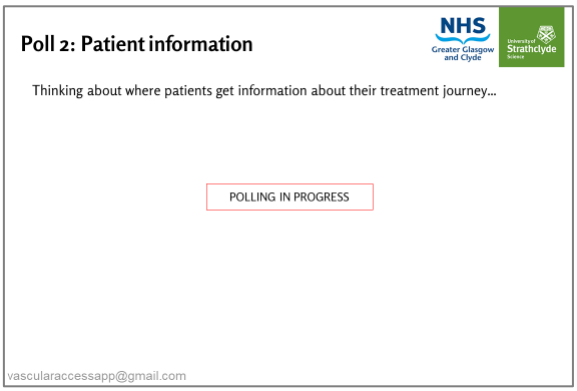
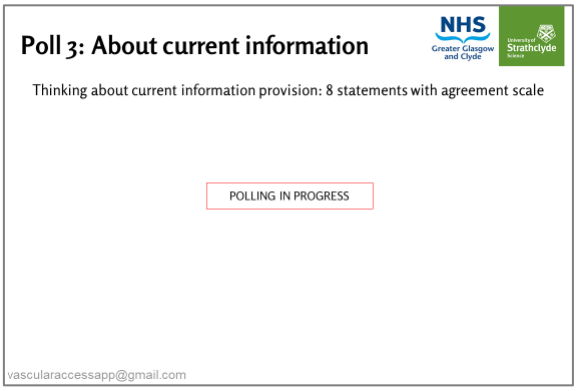


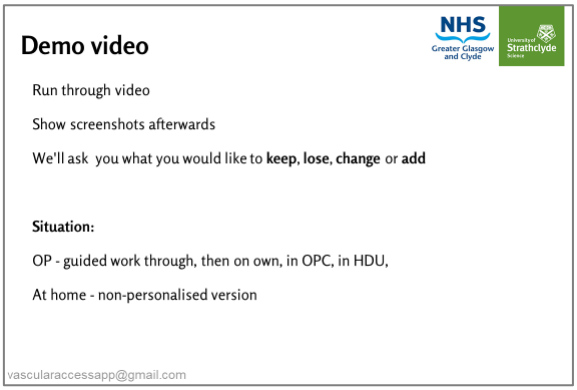


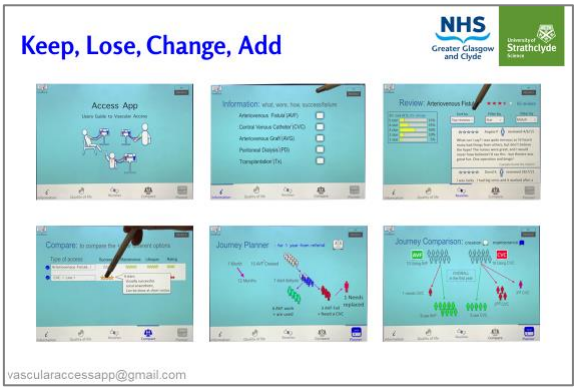


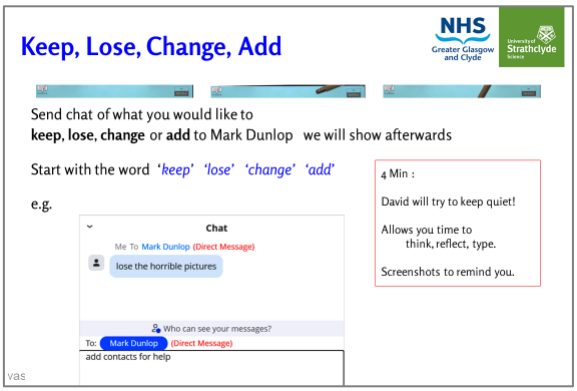
Part 2: Polling Questions

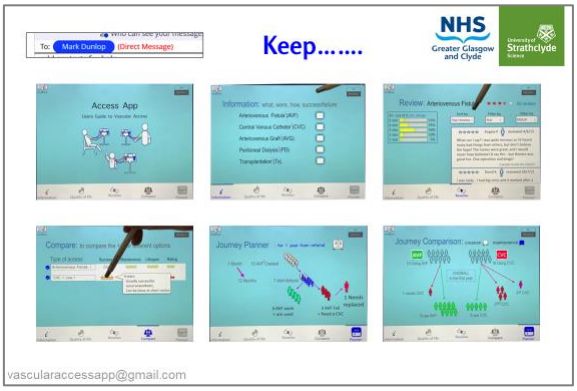
These slides were shown while polling was conducted, with a poll window appearing in the user interface of the Zoom application.

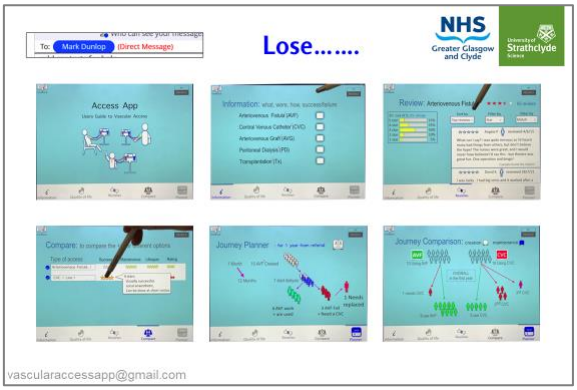
Part 3: Prototype Demo, KLCA and Poll

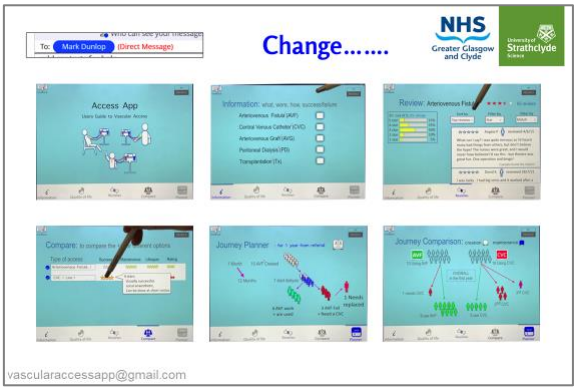


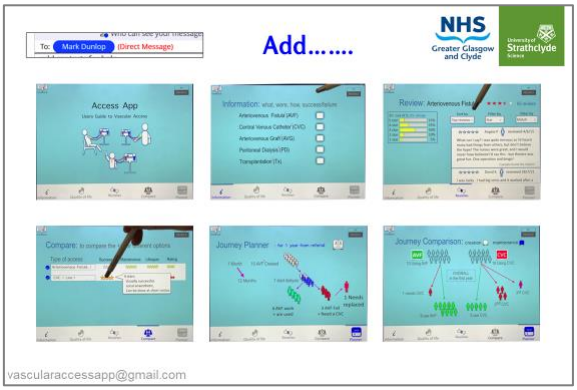


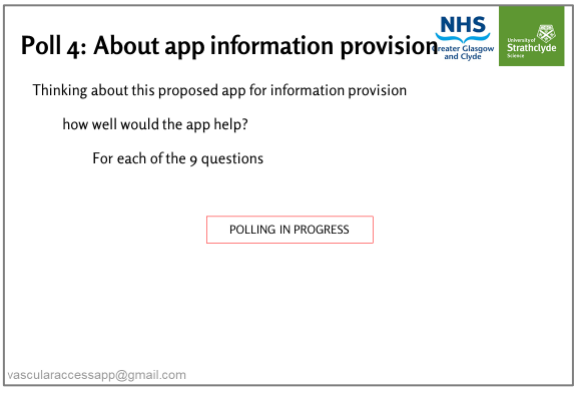


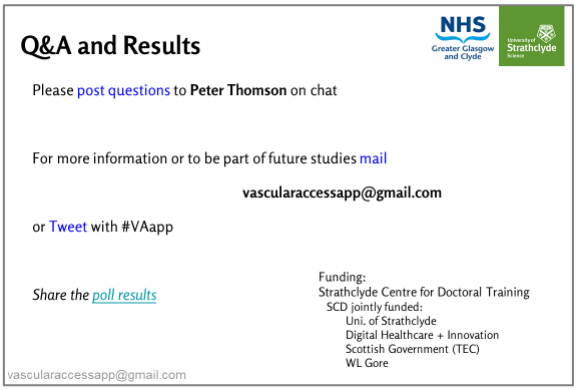



Lose……
NHS Greater Glasgow and Clyde
University of Strathclyde
Access App
vascularaccessapp@gmail.com


Change……
NHS Greater Glasgow and Clyde
University of Strathclyde
Access App
vascularaccessapp@gmail.com


Add……
NHS Greater Glasgow and Clyde
University of Strathclyde
Access App
vascularaccessapp@gmail.com


Poll 4: About app information provision
NHS Greater Glasgow and Clyde
University of Strathclyde
Thinking about this proposed app for information provision
how well would the app help?
For each of the 9 questions
POLLING IN PROGRESS
vascularaccessapp@gmail.com



Part 4: Results and Conclusion

The poll results were generated automatically following the download of poll results via a script in a Google Sheets document. The radar plot of results was then accessed via a hyperlink on the slides.