Experiences of user-centred design with agile development for clinically supported self-management of Long Covid

Designing for clinically supported self-management of Long Covid

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ACM 1557-7325/2025/1-ART
https://doi.org/10.1145/3711839

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The aim of the study reported here was to reflect and report on lessons learned from adapting HCI methods to fit into an agile development process delivering a digital intervention for people managing Long Covid. During the project, we maintained a record of all activities and interim design products. Subsequently, selected records were analysed qualitatively. Challenges included engaging patients managing this complex, debilitating health condition and fitting the digital intervention into different and evolving patient pathways provided by clinics. The key contributions of this paper are a description of the clinically supported self-management app, Living With Covid Recovery, and of adapted methods for user-centred design and testing; narratives on engaging diverse clinics integrating a digital health intervention in their care pathways; reflections on designing for diverse users; implications for design of future technologies for supported self-management; and insights into multidisciplinary working that are rarely discussed within HCI.

CCS CONCEPTS • Human-centered computing ~ Human computer interaction (HCI) ~ HCI design and evaluation methods ~ User studies • Human-centered computing ~ Interaction design ~ Interaction design process and methods ~ User centered design • Software and its engineering ~ Software creation and management ~ Software development process management ~ Software development methods ~ Agile software development • Applied computing ~ Life and medical sciences ~ Consumer health

Additional Keywords and Phrases: HCI methods, UCD, agile software development, healthcare technology, digital health intervention, DHI, clinically supported self-management, Long Covid

1 INTRODUCTION

Human computer interaction (HCI) should inform the effectiveness and user experience of health technologies at scale. The research question addressed in this study is what can be learned from the experience of applying HCI methods in a time-critical, real-world situation with very limited access to the intended users. Such practical experiences are rarely discussed in the literature, yet they are essential if HCI is to make an impact in complex and challenging situations. This study is based on the development and deployment of a digital health intervention (DHI) for clinically supported self-management of Long Covid called Living With Covid Recovery (LWCR). The study covers the period May 2020 to July 2022 – i.e., the period of this research project, although service delivery is ongoing.

The aims of the overall project were to develop, deploy and evaluate a clinically supported self-management DHI for patients affected by Covid-19. Forms of evaluation include health economics and patient outcomes as well as user interaction [53]; the focus of the study reported here is on interaction design and evaluation of the patient-facing app.

The key components and users of LWCR are illustrated in Figure 1. The clinical team have access to a dashboard that enables them to view data on all the patients under their care and send messages to individual patients. Patients (or their representatives) have access to the LWCR app that enables them to share data with their clinic by completing health questionnaires, submitting patient diaries, exchanging messages and more, and to access clinically validated information about their condition (see section 5 for a full description). Patients and clinicians may also interact through other channels, as determined by their clinic. As for all clinical conditions, there is a patient pathway that each patient follows, from initial contact with presenting symptoms to final discharge from the service; this is discussed in section 6.3.

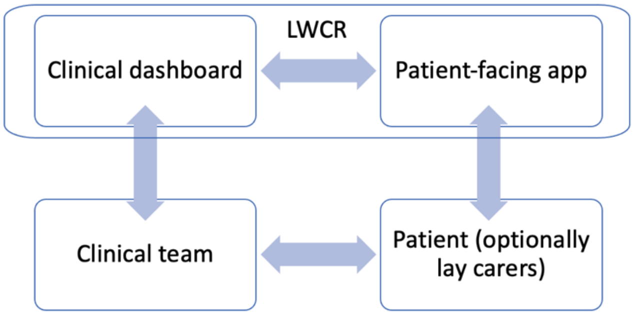

Figure 1: Overview of Living With Covid Recovery (LWCR) system

In this paper, as well as presenting the design of the LWCR app, we report on key HCI methods applied in the iterative design, evaluation and deployment of the app. We present an account of challenges, activities, insights, decisions and findings from the project. We reflect on successes and limitations of designing for diverse users on the care pathways offered by different clinics[1], and draw out implications for design. We hope that our experiences will advance the field of HCI methods for designing and evaluating impactful health technologies for clinically supported self-management and enable others to build on our successes and learn from our mistakes.

To set the context, we first summarise the early evolution of Covid-19 and Long Covid and the origins of LWCR (section 2) and present relevant prior work (section 3). In section 4 we present the methods applied in this study. Section 5 presents the design rationale for the LWCR app and an overview of its initial and final iterations. Section 6 focuses on the application of HCI methods within the longitudinal development process. Sections 7 and 8 comprise a discussion and conclusions from this study.

2 BACKGROUND: COVID-19, LONG COVID AND THE ORIGINS OF LWCR

Covid-19 emerged as a recognised new virus of concern on 31st December 2019 [77]. The World Health Organisation declared that Covid-19 represented a pandemic on 11th March 2020. In the UK, a national lockdown was introduced on 23rd March 2020; other countries responded similarly. The healthcare system in the UK was reconfigured rapidly to address the demands of Covid-19. This initially focused on the acute phase of the disease, and on minimising transmission.

By late April 2020, it was becoming evident to medical professionals that there was a rapidly growing population of patients who had been hospitalised with Covid-19 and had recovered well enough to be discharged into the community but would need ongoing care [75]. Clinical teams did not have the capacity to manage every Covid-19 patient through their recovery as they would have done previously: they recognised the need for a DHI to support them as healthcare professionals, although at this point they did not realise how long some people's symptoms would persist or recognise the particular characteristics of Long Covid.

Based on their prior experience of working with researchers and clinicians, a Small or Medium-sized Enterprise (SME) called Living With (https://www.livingwith.health/) proposed a collaboration between healthcare professionals (HCPs[2]) at three London hospitals and a team at UCL to develop and deploy such a DHI. Living With had a track record of developing behaviour change interventions for long-term conditions (e.g., oesophageal cancer [74]), and an existing platform that would form the basis for LWCR. The original design concept focused on cardio-pulmonary rehabilitation following severe, acute Covid infection, but the focus shifted through the summer of 2020 to rehabilitation for Long Covid.

The term "Long Covid" was first used around May 2020: by this time, it was clear that some people who had contracted Covid-19 were experiencing longer-term symptoms including fatigue, breathlessness and anxiety.

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[1] We use the terms "clinic", "clinical service" and "service" interchangeably, reflecting the fact that although services are commonly referred to as clinics, many of them were delivered as remote services, without physical premises.

[2] In this paper, we use the terms "HCP" and "clinician" almost interchangeably, recognising that there are some HCPs who are not qualified clinicians but work in supporting roles.

Long Covid was recognised by patients some time before it was acknowledged by HCPs [13]. Different people experienced different symptoms; also, people who had never been hospitalised, and might have had mild Covid-19 symptoms, were experiencing debilitating longer-term symptoms: it was all poorly understood. The lack of early recognition created additional challenges for, and prejudice experienced by, patients. The condition is often referred to as Post Covid Syndrome (PCS), but we use the more familiar term "Long Covid" throughout this paper.

A team was convened by Professor Elizabeth Murray (EM) to: develop a DHI to address the problem as understood in May 2020; obtain funding to resource the development; and conduct research to better understand patients' needs for rehabilitation following Covid-19 and what support a DHI could provide, for both HCPs and patients. EM described the challenge in an email; we include a verbatim extract to illustrate how simple the vision appeared at the outset:

> EM (19/5/20): The current plan is to [focus] on what's needed for the Minimum Viable Product, i.e. breathlessness, fatigue, nutrition and anxiety. Living With have templates, which we are sort of expecting to just drop the content into. The plan is to get something up and viable asap, and then refine / revise it heavily, according to user feedback.

Early work was largely *pro bono*, supported by discretionary funds from UCL, Barts Health National Health Service (NHS) Trust investigators and Living With. In September 2020, research funding was awarded for the project. By this time, a first version of the LWCR app (a "minimal viable product", as described in section 5.2) had been launched.

In December 2020, NHS England announced funding for over 60 Long Covid clinics nationwide [55]. These were staffed by clinical specialists (doctors, nurses and Allied Health Professionals) who were seconded from their existing roles, often on a part-time basis, to form new teams focusing on the assessment and management of Long Covid. Patients were referred to these services by their General Practitioners. The guidance on how to organise these services was not detailed, so each developed and evolved its own practices, based on the local context and individual personalities. Many of these clinics became our primary clinical users of LWCR, "prescribing" it for their patients. Participating clinics used LWCR free of charge during the period of research as part of their service delivery for Long Covid.

By July 2022, there had been nine further releases of LWCR (app, platform[3] or both – Appendix A.1) and LWCR had been deployed into 35 NHS Long Covid clinics with 380 individual clinicians registered to use it. The number of registered patients had grown from 32 (August 2020) to 5684 (July 2022) (Appendix A.2). Over the course of this project, the discourse evolved from managing patients who were discharged from hospital following severe Covid-19 through recovering from Long Covid to effectively managing the condition (e.g., [29]), as it became increasingly evident that people recover at very different rates.

In parallel with the work reported here, other teams were working on DHIs for Long Covid. For example, Thomas-Purcell et al [76] conducted a study with 20 older people that included assessing the potential of an existing self-management app to be adapted for Long Covid, but do not report on the adaptation or deployment. Rinn et al [65] present a scoping review of DHIs for Long Covid; the eight studies that met their inclusion criteria all reported on interventions that involved digital means of communication, providing peer or clinician support. They conclude that "evidence so far suggests that patients should be provided with digital interventions to overcome their symptoms and reintegrate into everyday life, including work". However, none of the studies involved clinician-supported patient self-management that is directly comparable with LWCR.

3 BACKGROUND: USER-CENTRED DESIGN FOR DIGITAL HEALTH INTERVENTIONS

To set the context for this study, we briefly review prior research on HCI for health and wellbeing; design processes for developing DHIs; designing for diverse users; and studies on multidisciplinary working across HCI and health.

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[3] "platform" includes the clinical dashboard and underpinning infrastructure.

3.1 HCI for health and wellbeing

HCI has many potential roles in the design and evaluation of DHIs [7]. Many studies in HCI for health and wellbeing have focused on particular theories, applications or user groups. For example, a 2020 special issue of this journal focused on “reimagining women’s health”, covering themes including sense-making and menstruation [27] and designing for the uncertainties of motherhood [22].

There is a growing body of research in HCI that addresses the needs of people managing chronic and debilitating conditions and how to ensure their voices are heard. For example, Nunes et al [58] present an overview of self-care technologies for individuals managing chronic conditions. The impact of fatigue is discussed by Massimi et al [49] in the context of technology for end-of-life care, while Wilson et al [83] present an approach to co-designing with people with aphasia. Massimi et al [49] focused on the way that needs and capabilities change for the different people involved (those who are bereaved, the dying, etc.) and emphasise ethical concerns about working with the living while maintaining respect for the deceased. In contrast, Wilson et al [83] emphasise the need to adapt and innovate methods to give a voice to their participants.

Bowler et al [10] and Davies et al [20] worked with people managing Chronic Fatigue Syndrome (CFS) to understand their needs for flexible time scheduling and self-management (respectively). Although Bowler et al [10] were designing for people managing CFS, in their main study they worked with participants who expressed a need for managing uncertainty, whether or not they were managing a health condition. Davies et al [20] conducted three studies, all remote and asynchronous, with 24-52 people who were managing CFS. They discuss the ethics of working with people managing chronic fatigue, the risk of exacerbating symptoms, and the steps they took to minimise the risk – most notably, through their data gathering methods. Their studies focused on independent self-management and not on the design of a particular app but on user needs, such as support for pacing (avoiding excessive fatigue).

As well as being debilitating, Long Covid is inherently complex and poorly understood. In this regard, it shares features in common with co-morbidities and rare diseases. Li et al [45] report on the testing of a mobile app to support individuals managing multiple chronic conditions, specifically type 2 diabetes with arthritis or depression; they highlight usability concerns including visual aesthetics, broader user experience and the specifics of supporting people in setting goals. MacLeod et al [46] interviewed 19 people with rare diseases and highlight people’s need to communicate effectively with family, peers and professionals, particularly about their lived experiences. In both these examples, the focus is on the individual’s responsibility for self-management and valuing their expertise, rather than on supported self-management.

Most studies reporting on design and evaluation processes for health technologies have worked with relatively small numbers of engaged users. For example, Hayes et al [33] describe the design and evaluation of Estrellita, a tool to support parents of pre-term babies. For the design, they drew on prior research that identified user requirements, and they involved HCPs in cooperative design and the parents of full-term babies in early evaluation studies. The main study reported in their paper involved deployment of the resulting system for four months with seven families of pre-term babies, with a comparable control group. They note that “Too often iterative design is only used at the start of the design phase and stops at the deployment stage”, arguing that it is essential to investigate, and design for, the realities of use in context.

The issue of “pilotitis” [42] – where products are prototyped and tested at small scale but stall before having large scale impact – is rarely discussed in HCI. Stawarz et al [73] and Doyle et al [22] are unusual in reporting on the longitudinal use of digital systems for clinician-supported therapy. Stawarz et al focused on psychotherapy for depression, using a “blended” approach where the first therapy session was in-person and the subsequent eight sessions (and any intermediate support) were online. They involved 17 patients and three therapists. Therapists were able to tailor access to resources for each patient. Stawarz et al note the value placed on the initial face-to-face session for developing rapport, and that the blended approach required each therapist to receive training and to adapt their usual approach to exploit the functions of the platform. Doyle et al [22] report on a year-long study of ProACT, a digital intervention designed to support people managing multiple long-term conditions. They recruited 120 participants from Ireland and Belgium and conducted a Proof of Concept trial to study people’s long-term engagement with ProACT. They report that most participants engaged well with the intervention, but do not discuss the roles of formal carers in supporting people, or whether or not they had to adapt their practices to engage with ProACT.

Previous examples of HCI design and deployment at scale include SilverCloud and Monarca, both interventions for mental health. SilverCloud originated with foundational research and a future research agenda on talk-based mental health therapies [19]. The design, design rationale and early evaluation are described by Doherty et al [21]. That evaluation involved users of a university counselling service. More recent papers (e.g., [39]) have evaluated the delivery of SilverCloud as a clinical service, focusing on quantitative measures of effectiveness.

In parallel, MONARCA was developed as an android-based personal monitoring system for people with bipolar disorder. Bardram et al [5] describe the design and development process for MONARCA, which involved both clinicians and patients in regular collaborative design workshops over a period of a year. Their focus is largely on the technical design and early formative evaluation. Subsequent clinical trials are summarised by Faurholt-Jepsen et al [25] and the system has been commercialised as Monsenso (https://www.monsenso.com/). For both these examples, the focus shifted over several years from user-centred design to deployment at scale.

SilverCloud and MONARCA are rare in there being evidence in the academic literature of them having progressed from an early design concept into routine clinical practice. Mamykina et al [48] review their experiences of progressing from early design innovation to larger-scale clinical trials of two applications for diabetes self-management. They highlight the importance of designing in anticipation of the need to have a system that will remain operational for the time taken to complete a clinical trial, typically several years. They also highlight the importance of designing for diverse users, who need to be recruited and retained for the duration of a trial, and of designing systems that enable people to stop using them "gracefully" as users' needs change. Their focus is on apps for self-management without ongoing clinician support, and on enabling clinical trials.

It is widely recognised in healthcare that patients managing long term conditions need support to do so effectively (e.g., [1, 44]). Adriaans et al [1] define supported self-management as "the systematic provision of education and supportive interventions by health care professionals to increase patients' skills and confidence in managing their health problems"; they present a systematic review of 19 randomised controlled trials of what they call "digital self-management support tools" for people managing cancer. They summarise the key functions of the tools in their review as support for symptom management, clinical assessments, information provision, communication between patients and carers and a diary function. Similarly, in their description of ProACT, Doyle et al [22] describe functions including tracking of multiple symptoms, providing education on relevant health conditions, helping people understand how symptoms and conditions relate to each other and sharing data and data analytics with professionals. These are exceptions: most studies in HCI focus on patient self-management, without explicit discussion of how clinical practice needs to adapt to provide effective support for people learning to self-manage.

Similarly, although the need to design for the context of use is sometimes discussed (e.g., [34]), and many qualitative studies describe the context of use (e.g., [62]), few explicitly discuss how the context of use has to be adapted to make best use of a novel technology. Traditionally, HCI research has focused on the tasks of the individual user, and while it has long been recognised that tasks evolve over time [14], this has mostly been discussed as an emergent phenomenon rather than intentional design of the work system. Alternatively, as described by Stawarz et al [73], people are expected to adapt to the technology.

Health services research, in contrast, has largely ignored the power of design to shape the adoption and use of technology; for example, Normalisation Process Theory [50] considers a "complex intervention" as a change in clinical practice that might or might not include digital tools, but does not question the design of those tools, while the NASSS framework [30] proposes an approach to predicting the likely success of new technology adoption in healthcare based on layers of complexity, but does not discuss the interplay between technology design and the design of the larger work system.

We are not aware of any prior studies in HCI where the aim was to design for people managing an emergent, complex, debilitating health condition whilst simultaneously deploying into clinical practice.

3.2 Design processes for digital health interventions: person-based and agile

Research into design processes for DHIs has often drawn on individual teams' experiences of doing such design. For example, Elwyn et al [23] propose a process map for the design of health websites that involves phases of content specification, creative design and tailoring to the intended users. However, their discussion on how to engage intended users through this process is non-specific.

Emphasising the need to involve users early in design, Gkatzidou et al [28] describe a focus-group-based study to gather user requirements for a DHI for sexually transmitted infections. A later study [24] established that eligible users engaged well with the resulting system. However, there is no discussion of the detailed design process.

Yardley et al [84] present the Person Based Approach, which engages intended users through four stages of intervention development: planning; design (providing principles); development, evaluation and iteration; and deployment "in the wild", including evaluation through clinical trials. Blandford [8] draws on the Person Based Approach together with established practices in HCI design to propose a five stage model involving problem identification and planning; conceptual design; iterative design and evaluation; development and testing; and deployment and diffusion. Although there is iteration between those stages, the model did not anticipate a situation where deployment took place in parallel with all the earlier stages, employing agile methods.

Although not discussed explicitly at the project outset, LWCR development followed an agile process. There is an extensive literature on both agile in general and the integration of user-centred methods with agile processes. For example, Salah et al [68] included 71 papers in a systematic literature review describing the integration of agile and user-centred design (UCD) methods. Agile methods are iterative and incremental, involving "sprints" between review points, but classic agile methods do not include specific stages of requirements gathering or user testing. Requirements gathering and other preparatory activities are often included as a "Sprint 0", and "design sprints" (e.g., [38]) have been proposed as a method to incorporate design ideation and prototyping with user testing in rapid cycles. Nevertheless, Salah et al [68] list challenges including maintaining effective communication between developers and usability professionals and scheduling user testing to fit with development cycles. They note that "simplicity in the UI [user interface] does not always align with simplicity in the implementation". There are no prior accounts of UCD with agile development for DHIs.

Of particular relevance to the LWCR project is an earlier project involving Living With as the developers. That earlier project [74] focused on the development of an app to support patients and their clinical teams in managing oesophageal cancer. Systematic literature reviews, focus groups and interviews with both patients and HCPs were used in planning and gathering user requirements. Patient representatives and healthcare professionals were involved in co-design sessions and workshops to develop a minimum viable product. This was tested in a pilot study with target users and further refined. Thus, the project applied established HCI methods, but the details are not reported from an HCI perspective.

One technique used in the LWCR project (as described below) was to represent user requirements through personas and scenarios; Although personas and scenarios are widely used in design [17], [67], their use in digital health projects is not widely reported. Vincent and Blandford [80] present the rationale and evidence behind the development of a set of personas for medical device design, but the focus is on personas for health professionals and hospital patients rather than for people self-managing. Williams et al [82] report on an interactive workshop involving designers and healthcare practitioners in developing personas for people living with HIV, where the evidence behind the personas came from earlier qualitative research so the focus was on engaging healthcare staff with the design process. Similarly, Kwon et al [41] report on the use of personas to help clinicians empathise with patients in the interpretation of Patient Reported Outcome Measures (PROMs) data. There is little evidence of clinicians being involved in the design of personas for patients.

Design elements of LWCR drew on behaviour change techniques. There has been a growing focus on behaviour change within the HCI literature (e.g., [64]) as well as in the design of digital interventions for health and wellbeing; for example, Mohr et al [52] present a Behavioural Intervention Technology Model that links theory and practice in designing a digital behaviour change intervention comprising five considerations:

- Why? – the aims of the intervention, both clinical and usage.
- How (conceptual)? – relevant Behaviour Change Techniques (BCTs).
- What? – elements of the proposed intervention, such as information delivery and notifications.
- How (technical)? – the characteristics of the proposed intervention, such as the platform and the physical appearance.

- When? – the workflow, such as the frequency of events and what might trigger them.

Bradbury et al [11] propose a similar model; both Mohr et al and Bradbury et al emphasise the importance of identifying the components of the intervention and how they are expected to shape the required outcome for people engaging with the intervention. Within HCI, the outcomes measured have traditionally been immediately measurable, such as short-term user satisfaction, efficiency and effectiveness. Smith et al [71] highlight that these are proximal outcomes, whereas for health and wellbeing applications we should also be concerned with distal outcomes – notably long-term behaviour change that enables people to self-manage and positive health outcomes, whether that be health improvement or slowing the decline of a long-term condition.

3.3 Designing for diverse users

Patients managing any health condition are diverse, so mantras such as testing with five users [56] are never going to be adequate. Cooper [17] discusses the need to design for particular users and to focus functionality on user needs. One of his examples (p.124) is users of different vehicles such as “soccer moms” and “junior executives”. He argues that the buyer of a car can reflect on their situation and their different requirements and identify a suitable vehicle for their needs, and that an important role for the car salesperson is to help match people with products. However, there are no similar “market segments” for digital health interventions. Indeed, a commonly voiced concern is that some people may be particularly disadvantaged by a growing reliance on digital technologies for care delivery; Jenkins et al [40] highlight both sociodemographic factors (e.g., age, ethnicity) and literacy factors that contribute to the “digital divide”. Both health literacy and digital literacy need to be considered in design.

There is preliminary research on individual differences in managing health conditions (e.g., [18], [70]), with a focus on how people engage with health information; the main differentiators are people who avoid health information; those who comply with what is required of them; and those who actively seek out new information. However, there is little guidance on how to design effectively to address the needs of different groups.

Conversely, “inclusive design” [16] focuses on designing for all; this typically involves designing for as large a population as possible, based on physical, cognitive and other abilities. It requires that a development team make trade-offs that might make an application less attractive or engaging to one segment of society to make it accessible to a broader population of people. While there are various toolkits to help design in an inclusive way, such as those described by Cremers et al [16], these do not effectively address all the challenges of accommodating individual differences in health literacy, motivations and health-related behaviours.

In summary, there is limited prior literature on which we could draw to optimise the design of LWCR for diverse users.

3.4 Multidisciplinary working in HCI and health

The development of any DHI requires multidisciplinary working.

A few studies have been conducted on multidisciplinary working in health technology projects. For example, Vermeulen et al [79] conducted an interview study with 25 members of development teams involved in the design of four different telecare products. Participants represented end-users, health professionals, engineers, managers and researchers. They focused on barriers and facilitators to working together and delivering a product. The main barrier they report is people speaking “different languages”. Other issues such as projects running over time or over budget may be exacerbated by multidisciplinary team working but are not specific to such projects. They report a consensus that having multi-disciplinary teams was essential to success for the projects studied.

Ayobi et al [4] report on a study that involved multidisciplinary co-design of a self-care technology for managing type 1 diabetes. The co-design project extended over 18 months, and 17 project members including people managing T1D, researchers and industry representatives participated in retrospective, reflective interviews. Ayobi et al highlight that individuals managing T1D experienced difficulties in thinking about needs other than their own and that they had diverse needs and practices. They also highlight the challenges HCI and AI researchers experienced in translating between co-design outputs and practical technology implementation and of bridging their different research methods and priorities. They also report that industry partners expressed frustration about the constraints imposed by academic data sharing regulations. The data sharing regulations led the team to re-design planned activities so that research could be conducted alongside industrial development in a loosely coupled way rather than directly involving all participants in co-design activities. Highlighted benefits of the multidisciplinary project included learning from each other, both across disciplines and within (particularly for people managing T1D, learning from each other).

Drawing on more general experiences of multidisciplinary team working, Blandford et al [7] identify differences in culture and expectations between HCI and health researchers in the research and development of digital behaviour change interventions. As well as differences in language (e.g., whether "implementation" refers to the development of technology or its deployment into clinical practice), they highlight differences in what is valued (e.g. user experience or clinical outcomes) and expectations about the frequency and purpose of design iterations.

Agapie et al [2] also draw on multiple experiences in their study interviewing 17 HCI academics in US universities who had experience of collaborating with health researchers. They highlight various challenges faced by HCI researchers such as experiencing limited availability of clinicians, conflicting research/career goals, the need to navigate complex requirements of ethics boards, a lack of familiarity with the culture and practices of clinical trials, the logistical challenges of deploying novel technologies in health contexts and balancing participant confidentiality with research rigour. Where research was led by HCI with health collaboration, they highlight challenges of engaging the necessary healthcare professionals; where a project was clinically led, they highlight the risk of HCI being treated as a service role.

Beyond the specifics of HCI-health collaborations, Leigh Star and Griesemer [72] introduce the concept of "boundary objects" that support multidisciplinary working. They argue that to collaborate effectively, people from different disciplines need shared "objects" that they can each view from their different perspectives, and that people need to negotiate adequately shared meanings to collectively make progress while also advancing each individual perspective. Such shared objects can also serve as focuses for complementary research outcomes.

In our discussion below, we compare our experiences with those presented by others and on the role of "boundary objects" in supporting our collaboration.

4 METHOD

As noted above, the aim of this study was to explore what can be learned from the experience of applying HCI methods in a time-critical, real-world situation with very limited access to the intended users to enhance an agile development process. It is a form of action research [32], in the sense that a small HCI team worked with the intervention development team and devised, conducted and documented small studies that informed subsequent development cycles.

Over the study period, a large corpus of data was systematically collected, including: recordings, transcripts or notes of all project meetings; documentation of every HCI-related study; anonymised transcripts of every interview with users (patients and clinicians); log data of every patient interaction with the LWCR app; and project correspondence. For the analysis reported here, we extracted the data that was most obviously pertinent to the study aims. For some stages the analysis was in-depth and is described in more detail in the relevant sections of this paper. For others, it involved identifying and extracting data that encapsulated important points in the development process, and is thus simply reporting what was done, drawing on the representations (e.g., personas, meeting notes, diaries) that were generated at the time.

In the following subsections, we present our ways of working in the project; while these primarily supported the aim of delivering the LWCR digital intervention into clinical practice, they also delivered the corpus of data that was analysed for this study.

4.1 Public and Patient Involvement (PPI)

The project involved substantial input and engagement from Public and Patient Involvement (PPI) representatives. The UK National Institute for Health Research [57] defines PPI as "an active partnership between patients, carers and members of the public with researchers that influences and shapes research". Majid et al [47] discuss incorporating principles of PPI in conducting interviews and workshops with people with experience of bipolar disorder, focusing on their self-tracking experiences. They focus on people having greater involvement in the research process than might be usual for study participants involved in requirements gathering or user testing. More generally, in health services research, PPI representatives are not necessarily the intended users of a particular user interface but are people with expertise that informs the design of research.

PPI members served three roles in this project: guiding the research; authoring material; and evaluating both material and the interaction design. The first of these is a standard UK PPI role; the other two are extensions. All PPI representatives were paid for their time, following national guidelines.

Throughout the project, we engaged with a varying number of PPI representatives. 30 individuals played important roles over the course of the project – from attending one or two meetings to leading user studies and writing content for the LWCR app. People joined and moved on as individuals' circumstances and our needs for PPI input changed. We aimed for demographic and clinical diversity in our PPI representatives and recruited through several different sources. These included PPI networks such as the "Experts by Experience" group in the UCL Department of Primary Care and Population Health and the UCL Institute of Healthcare Engineering PPI support group, but mainly through online Long Covid support groups.

A PPI Advisory Group with 8 participants maintained oversight of the whole project and of the constituent work packages. Each work package research team had two PPI members contributing to the design, conduct, interpretation and dissemination of the research. Some of the PPI were expert patients and could point us towards resources that they had found helpful.

We made adaptations to our process to enable patients with Long Covid to contribute to their fullest. For instance, we quickly realised that our discussion groups were too long and made them shorter to reduce fatigue.

4.2 Team structure and activities

Figure 2 illustrates the approximate structure of the development team, though the organization evolved dynamically over time. At the core was the software development team, working at Living With, whose day-to-day activities were largely invisible to the broader intervention development team except through the versions of the LWCR app delivered and through the two Living With representatives (CR, JW) who participated in research team meetings. The core research team involved in the LWCR app development met weekly; as well as the members of Living With, this team comprised clinicians (HG, SL); PPI representatives (JB, BC); HCI representatives (AB, EC); and a behavioural scientist (KB). The project steering committee (which had oversight of the entire research programme including clinical, economic, large-scale deployment and intervention development) met every 4-6 weeks and involved the entire project team with additional clinicians and PPI representatives. Clinicians from early clinics and further PPI representatives were directly involved in designing and evaluating functions of LWCR on an *ad hoc* basis (responding to needs and opportunities). At the outermost level, we sought to engage with patients who were using the LWCR app as part of their clinical care and clinicians from long covid clinics that had adopted LWCR to support their care delivery to evaluate LWCR with a broader pool of users.

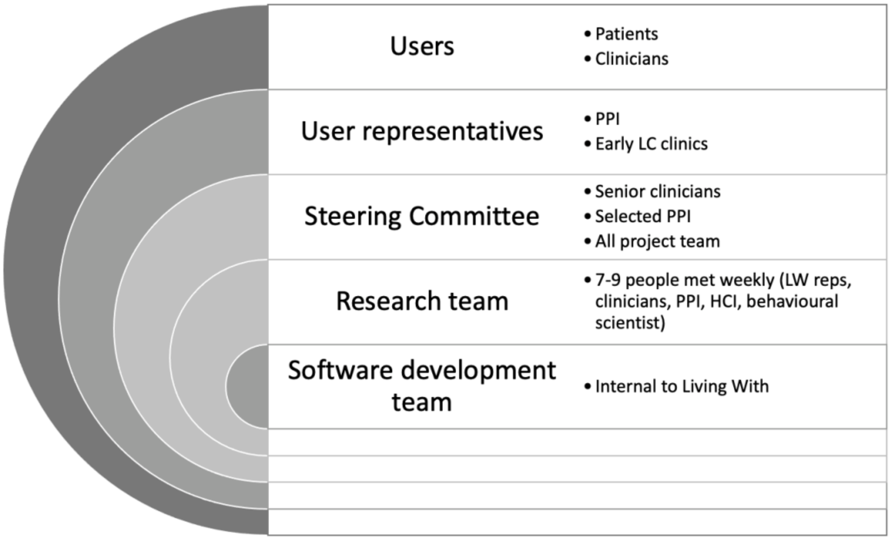

Figure 2: the overall structure of the development team

We did not explicitly explore individuals' motivations for participating in the project, but some clear differences emerged; Living With representatives most obviously focused on delivering a product that was acceptable to clinicians and for which there would be a sustainable (financially viable) development strategy; clinicians were concerned about patient outcomes, and often wanted to gather as much data as possible about patients; PPI were patient advocates and generally wanted the project to help patients recover; HCI and behaviour change specialists focused primarily on user interaction design and less on the clinical content. For all team members, the LWCR app served as a boundary object, in the sense outlined in section 3.4: all focused on it but brought their different interests and expertise to it.

4.3 Ethical and regulatory considerations

In the UK, Health Research Authority ethical clearance is required for research involving patients; an application for ethical clearance can be considered by any recognised HRA ethics committee. Ethical clearance was granted for involving users in this study by the UK Health Research Authority East Midlands - Derby Research Ethics Committee on 23rd July 2021 (REC reference: 21/EM/0160).

Users were required to give informed consent to having anonymised data used for research in the terms and conditions of using the LWCR app and could choose whether to consent to being approached to participate in an interview. Most consented to be approached for interview too.

Even after we had obtained ethical clearance, we were faced with data protection barriers. In brief: patient identifiable data was made available through LWCR to the clinic managing that patient; researchers had access to anonymised data. Interviewing a patient would make them identifiable; data protection specialists took the view that the university needed to set up a separate data sharing agreement with every clinic to have access to patient identifiable data even for patients who had given consent for their identifiable data to be shared with researchers. It took a further nine months to set up the necessary data sharing agreements with multiple trusts; by March 2022, agreements had been signed and countersigned with ten NHS trusts, so that patients could be approached to participate in an interview study.

We also had to be mindful of patient safety and medical device regulations throughout. All design decisions and patient-facing documents were subject to a risk assessment and clinical sign-off. This limited the scope to be creative and adventurous in the project but ensured that Living With complied with relevant regulations and standards so that it was possible to have an impact on patient wellbeing from the earliest possible point in the project.

4.4 An overview of the development process for LWCR

As noted above, the development process followed an agile methodology. This involved three-weekly sprints and approximately quarterly releases. The overall project flow is illustrated in Figure 3, which summarises key events and activities. The events are described in Table 1.

Table 1: Events shown in Figure 3

Month	Event label	Event
May 2020	Start	Unfunded project start.
Aug 2020	1st	First version of LWCR app released to 32 patients (“minimum viable product”), including five questionnaires.
Oct 2020	Fund	Funded project start. 2nd app release.
Dec 2020	Clinic	First NHS Long Covid clinics announced by UK Department of Health and Social Care. 3rd LWCR app release included symptom tracker and additional questionnaire.
Feb 2021	4th	4th app release with additional questionnaires.
April 2021	5th	5th app release includes Anxiety programme.
May 2021	Meta	Data warehouse implemented (Metabase).
July 2021	Ethics	Ethical clearance obtained for patient interviews.
Oct 2021	6th	6th app release included seven further programmes.
Jan 2022	7th	7th app release.
March 2022	DP	Data protection issues resolved so that we could approach patients for interview.
April 2022	8th	Final app release within project period.
July 2022		Project end

As noted above, the list of LWCR releases (both app and platform) is included in Appendix A.1.

From May 2021, Living With made anonymised clinic and patient data from LWCR available to the team via Metabase, an online data analytics platform (https://www.metabase.com/). This enabled us to track user engagement, loosely defined, and behaviours at a generalised level throughout the second half of the project, and evidence from Metabase was used alongside other sources of information to inform design thinking and prioritise system updates. Where statistics on usage are reported in this paper (e.g., Appendix 2), the data has been extracted from Metabase, and relates to activity up to 15th July 2022.

Activities are summarised in Table 2; all are described in more detail in following sections of this paper.

Table 2: Activities shown in the project timeline

Activity label	Where discussed (section)
Working on library content	5.3.3.
Conversations with HCPs for personas	5.1.2.
Occasional expert reviews	6 (intro).
First programme developed	5.3.4.
More programmes developed	5.3.4.
Focus groups	6.1.
Patient diary developed	5.3.5.
Clinician interviews	6.4.
"Being Doreen" autoethnography	6.2.
Fantasy timeline developed	6.3.
Patient interviews	6.4.

In parallel with the HCI-related activities, there were other activities such as inviting clinics to use the service and participate in the research, conducting an economic evaluation of the intervention, and studying the process of implementing the intervention across multiple services. These are beyond the scope of the current paper.

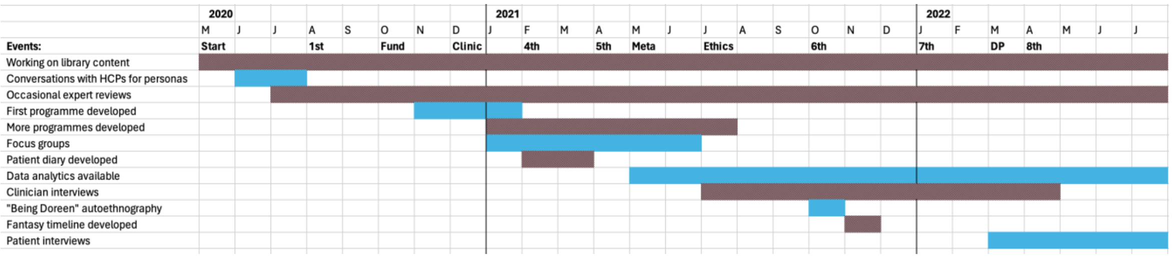

Figure 3: Overview timeline for the project to July 2022, focusing on activities discussed in this paper.

4.5 LWCR team working with clinics

The LWCR team worked with clinics in a variety of ways over the course of the project. Many early adopters were actively involved in the design of the LWCR system whereas later adopters were more focused on deployment in their clinic, including local configuration requirements. Members of the project team, including both Living With staff and clinicians, built relationships with all participating clinics, both before they signed up to use LWCR and subsequently. Staff from early adopter clinics also talked with staff from later clinics to share their experiences and build trust. In practice, levels of engagement were variable and maintaining engagement with overworked clinicians was often difficult.

Early clinics shaped the design of functions such as the Patient Activity Diary, programmes and our view of the care pathway, all described below. They joined our weekly meetings during the development of relevant functions and signed off to approve functions once completed. We also validated functions with a wider group of clinicians.

Some later clinics had already established care pathways before commissioning LWCR. How seamlessly LWCR could be incorporated into these clinics' pathways depended on how well aligned the design of their pathway and that of LWCR were. It also depended on how confident staff were in their digital skills, and whether they saw benefits in adopting LWCR. Resource limitations meant that it was not possible to develop strong working relationships with all clinics, and the scope for adapting LWCR to work seamlessly with different clinics was limited. There needed to be co-adaptation between clinics' care pathways and LWCR.

Every clinic received training in how to use LWCR to support their clinical practice, including how to respond to messages and review Patient Reported Outcome Measures (PROMs), symptom reports and diaries. However, we relied on the individuals who received training to train colleagues; sometimes this worked well, but some HCPs missed out.

5 THE DESIGN RATIONALE AND DESIGN OF LWCR

The vision for LWCR was that HCPs would "prescribe" LWCR to eligible patients, patients would be encouraged to take responsibility for following tailored self-management advice, and HCPs would monitor progress and intervene as necessary. System safety was managed carefully throughout.

The term "supported self-management" is often used to refer to the digital tool as the support (e.g., [35]). We refer to supported self-management to mean self-management supported and overseen by a clinical team, where the DHI is the principal channel that enables clinicians to support and oversee a patient's self-management.

While digital tools, including the LWCR app, can provide support, our decision at the time of this study was that the LWCR app would only be available with clinical supervision. We decided for two reasons against making it available for independent self-management:

- The first was that both literature (e.g., [59]) and previous experience within the team had shown that patients engage more with DHIs when they are part of their clinical care rather than independent interventions (e.g., [54]).
- The second was for safety reasons: at the time we started designing LWCR, nobody knew how the disease would affect people in the long term. With so much unknown, our view was that a healthcare professional had to check that it was safe for the patient to use the LWCR app and oversee their care.

In this section, we present the three key inputs that shaped the design of the initial patient facing LWCR app (Minimum Viable Product, MVP) followed by a summary of its key functions. Following the release of the MVP, and as our understanding developed, we refined the personas and scenarios that guided subsequent design iterations; we illustrate these then present the final (July 2022) version of the LWCR app and describe selected functions in more detail.

5.1 Key inputs to design

The three key inputs to the design of the MVP were: the existing Living With DHI infrastructure; personas and scenarios that were developed in the early months of the project; and established theory, most notably on behaviour change interventions.

5.1.1 The foundational DHI infrastructure.

The foundational DHI infrastructure developed by Living With before this project included a dashboard for health professionals and an app for patients. The system architecture and reusable components had been developed for diverse clinical conditions (e.g., rheumatoid arthritis, pelvic health, oesophageal cancer). App functions included messaging from HCPs to patients, mechanisms for the patient to record their weight, set themselves goals and complete questionnaires, and a library of information articles. Building on this earlier infrastructure enabled us to deploy the MVP within about 10 weeks of Long Covid first being recognised as a clinical condition.

5.1.2 User requirements, personas and scenarios developed from interviews with HCPs and medical students.

The second main source of input into the design of the LWCR app was a set of personas and scenarios, developed before the first product release; although these had little influence on the design of the minimum viable product, they shaped later thinking.

At the time when a design team would normally be gathering user requirements, the users' needs were poorly understood and only HCPs within the team had direct access to a limited pool of patients.

There were several reasons for not gathering early requirements from real users: we did not yet have ethical clearance to interview users; patients were anticipated rather than there being many yet; and the patients who had already been discharged from hospital were struggling with their health and wellbeing and had little capacity to support research.

To better understand the anticipated users and develop personas to inform design, we interviewed three consultants (specialists in respiratory disease) from different hospitals and two medical students from one hospital. These students had been employed to make follow-up calls to patients six weeks after discharge to check on their progress. Detailed notes were taken during these five telephone interviews. Extracts from these notes are included in Appendix A.3. The consultants provided a broad overview of the situation as they were experiencing it and the different ways that they were monitoring and managing patients post-discharge. The medical students provided detailed descriptions of different types of patients they had spoken with which formed the basis for our personas.

Initially, we developed five personas based on the information from the medical students:

- Amid is managing chronic illness; he might respond face-to-face but doesn't deal well with a phone call. He might use an app such as LWCR with support from a relative.
- Stefan is younger, thought of himself as invincible, professional, wants to get well quickly, very engaged.
- Inge is aged 80+ and was very healthy before Covid. She is "well preserved" and getting regular exercise. She reports feeling better now.
- Darren is younger, has recovered and is experiencing no further symptoms. He just wants to get on with his life and sees little value in even entering data into the LWCR app, never mind using it longer-term.
- Betty is an essential worker who believes she caught Covid at work. She has recovered well enough, physically, to return to work, but has poor mental health.

For each persona, we described their demographics, their experience with Covid-19, and their likely engagement with an app such as LWCR, as illustrated by the persona for Amid, below. This persona exemplifies our aim to mitigate the digital divide by considering factors such as access, confidence, skills, etc. and the possibility of having support from family members as well as HCPs. Our vision was that people who are not necessarily digitally literate could still benefit from the LWCR app.

This is the initial persona developed for Amid (4th June 2020):

Amid: Demographics:

- Age: 60
- Male
- Moved to the UK when he was a young man, but most of his extended family are in India. Has lived in a small terraced house in North London for many years.
- Lived with wife of 38 years, Meera, until she died of Covid a month ago.
- Has two children, Zara and Jay, who both live nearby, each with their own young family.
- He worked in a small factory until about 10 years ago, but stopped work due to health conditions, and lives on a very small income.
- His English is functional, but limited, and he often relies on his children (particularly Jay) to deal with complex matters (e.g., finance) for him.

Experience of Covid-19:

- Amid was admitted to hospital when his Covid symptoms were making breathing frighteningly difficult for him. He was given oxygen and fluids and pulled through without going to the Intensive Care Unit.
- Amid is used to being ill. He has been managing kidney disease, chronic obstructive pulmonary disease (COPD) and diabetes for many years and has high blood pressure. He has struggled for some time with walking any significant distance. Before Covid, he could go to the most local shops in his neighbourhood and had dialysis 3 times a week at a local dialysis centre, but never ventured further.
- Because of the long-term conditions, he is used to being isolated from society and reliant on family members. He is now very withdrawn, grieving for Meera (he couldn't be with her when she died), really struggling to function without her, both physically and emotionally. Zara takes him by car to his dialysis sessions now; he struggles with the journeys.
- His children are supporting him (while also managing their own families) in every way they can. They want him to move in with one of them, but he can't face the upheaval.
- Physically, he is very breathless and tired.
- Emotionally, he is depressed and not motivated to help himself much.

Engagement with an app such as LWCR:

- Amid is not going to use an app unaided. However, Zara and Jay find it really helpful to track his symptoms and to know what they should be encouraging him to do and what to expect.
- The app has got the data from the hospital electronic health record (EHR).
- It is Zara who enters all the initial data into the app, logging in with her father's details.
- Based on the existing and new data, the app makes two recommendations: to aim to walk to the nearest shop again within a month (on a planned physiotherapy programme)[4] and to engage in Cognitive Behavioural Therapy (CBT).
- Zara and Jay don't have time to use the app every day, but they manage to enter data about twice a week. They are managing to get Amid to engage with the CBT occasionally, but he is struggling to do his physiotherapy exercises.

Following discussion in the team, we shelved the personas for Inge, Darren and Betty, as we did not perceive them as being key users of the LWCR app, beyond perhaps completing initial questionnaires that would show that they did not need supported self-management. This was helpful in clarifying the scope of the project as it made it more explicit who we were not designing for as well as who we were.

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[4] NB: clinical advice on fatigue management has changed since this persona was developed.

By this point (mid-June 2020), it was becoming widely recognised that Long Covid was a major concern, and that we were not simply dealing with post-Covid rehabilitation of people who had been hospitalised. Also, we realised that we should be designing for carers of people like Amid, who were likely to use the LWCR app with or on behalf of the patient. We therefore developed two further personas:

- Brenda is aged around 60; she was moderately fit prior to Covid, but not particularly focused on her health. She is now experiencing a variety of symptoms that are more persistent than expected.
- Zara is Amid's daughter. She lives near her father and grew up in the UK, so English is her first language. Although her life has been badly impacted by the Covid in the family and the loss of her mother, she is not having to manage Long Covid herself.

In addition, the team at Living With needed scenarios of use to inform their development work. The scenarios developed at this stage were non-specific as the team did not yet have a well-formed view of what was needed, or indeed possible, as illustrated in the following scenario of use (21st June 2020) for Amid.

Engagement with an app such as LWCR:

- Amid is sent a letter from the hospital when staff there had reviewed his questionnaire responses and determined that he needs both physical and mental health interventions to support his recovery.
- The letter includes a QR code to download an app "Living with Covid Recovery" (LWCR) to an IOS or Android phone and a link to an alternative secure website that provides an equivalent interaction. The letter also contains a unique code that Amid must enter, along with his NHS number, to access the app / website. Amid has no idea what his NHS number is, but Zara finds it on a scrap of card in a drawer in the kitchen.
- LWCR has access to selected data from the hospital EHR, including the data from the Amplitude questionnaire (a post-Covid questionnaire administered by the hospital post-discharge). In turn, data entered into LWCR is automatically transferred to the hospital care record.
- Zara and Jay discuss whether they're going to bother with the app since Amid has neither a smart phone nor a computer so cannot use the app unaided.
- They agree that they would find it really helpful to track his symptoms and to know what they should be encouraging him to do and what to expect.
- Based on the initial data, the app makes some recommendations (which can be viewed as text or in a brief video from a physiotherapist at the hospital): to aim to walk to the nearest shop again within a month (on a planned physiotherapy programme), to engage in CBT, and to adjust his diet to prioritise more fresh fruit and vegetables.
- Zara and Jay don't have time to use the app every day, but they manage to enter data 3-4 times a week. Each accesses the app from their mobile phone, logging in using Amid's credentials. They are managing to get Amid to engage with the CBT, and even to do his physiotherapy exercises on most non-dialysis days. They reason that getting to his dialysis sessions (even with a wheelchair) is a significant effort for him.

5.1.3 Behavioural Intervention Techniques.

Since the LWCR app required patients to change their behaviours as well as engaging with their clinics, our third source of input was prior work on behavioural intervention techniques.

Michie et al [51] present a taxonomy of 93 Behaviour Change Techniques; many of these (e.g., policy changes) are unsuited for implementation within a DHI, but a subset are relevant, including goal setting and review; self-monitoring; and social support. We drew more directly on some of the BCTs described by Mohr et al [52]:

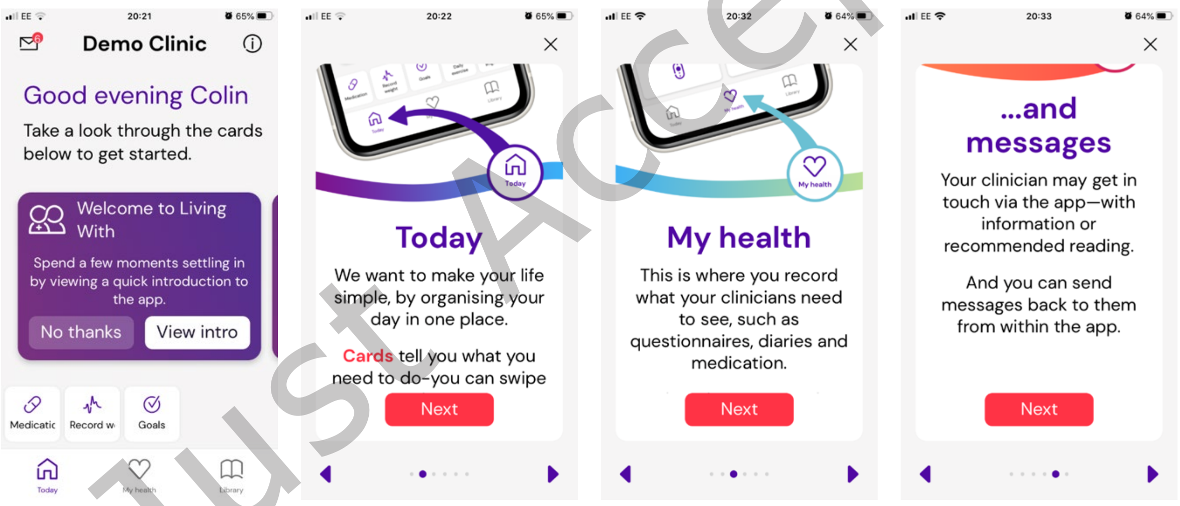
- It was important for people to understand their condition and how best to manage it (though understanding of this was evolving throughout the project), so providing **educational resources** and keeping them updated was a high priority. Articles were made available through the library and programmes, as described below.
- We wanted to motivate people to make progress and to feel that they were progressing, so **goal setting** was included as a stand-alone function and later within programmes.

- To help people track their progress and better understand what factors (such as activities and events) influenced their symptoms, and to provide information to clinics to support their patients, **monitoring** was implemented. This was done through questionnaires, diaries and symptom tracking, all described below.
- To help people feel engaged and informed, we implemented **feedback** to users in various forms, mostly linked with monitoring.
- Throughout, we recognised the importance of **motivating** users. The programmes in the LWCR app were linked to established psychological treatment programmes. We also relied significantly on clinics to motivate their patients to use the LWCR app effectively.

5.2 The LWCR minimum viable product

The first version of LWCR, deployed on 1st August 2020, comprised three main functions: messaging to support communication between HCP and patient; a set of questionnaires that patients were asked to complete, with results automatically shared with their clinical team; and a library of information resources developed specifically for recovery from pneumonia and critical care illness. The home page featured "cards" pointing the user towards suggested actions with the LWCR app. See Figures 4 and 5.

Patient Reported Outcome Measures (PROMs) were the primary source of outcome data and all LWCR app users were encouraged to complete several questionnaires at the beginning and periodically throughout the project. These had a dual purpose: to provide information to their HCPs to support their care management through triage, assessment and monitoring, and as aggregated data to provide a baseline [81] from which measures of progression could be compared.



Good evening Colin

Take a look through the cards below to get started.

Welcome to Living With

Spend a few moments settling in by viewing a quick introduction to the app.

We want to make your life simple, by organising your day in one place.

Cards tell you what you need to do–you can swipe

This is where you record what your clinicians need to see, such as questionnaires, diaries and medication.

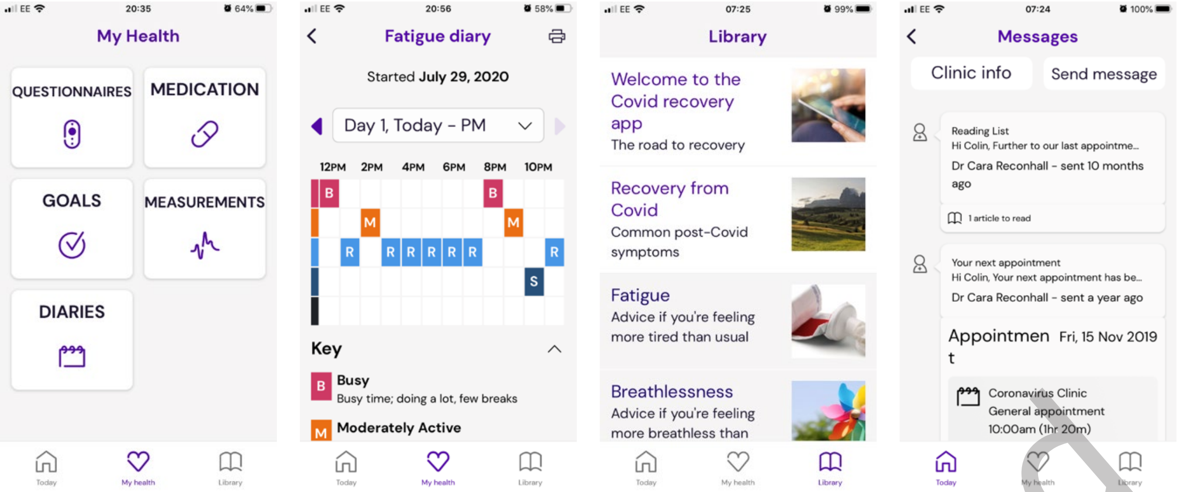
...and messages

Your clinician may get in touch via the app—with information or recommended reading.

And you can send messages back to them from within the app.

Figure 4: Illustrative screen shots from the early version of the LWCR app (taken from the demo / test version that was used by the team), showing the "Today" screen and the introductory explanation of it; also the descriptions of the "My health" area and messages with the clinic, accessed via the "letter" icon, top-left of the "today" screen. © Living With.

The questionnaires were chosen to solicit PROMs on the symptoms expected to be most clinically important while also minimising the demands on app users in completing them. All but one of the clinical questionnaires were validated PROMs to measure the severity of symptoms associated with recovery from pneumonia and critical care illness, such as breathlessness, fatigue and anxiety. A one-item questionnaire on Covid recovery was not validated but was requested by HCPs; Appendix A.4 summarises descriptions of all questionnaires. Initially, five questionnaires were included. Users were invited to set up a schedule for completing questionnaires (weekly, fortnightly or monthly) so that they and their clinical team could monitor progression over time. Six further questionnaires were added at different stages through the project. Patients' responses to questionnaires are a focus for a parallel study on the evolving health experiences of patients managing Long Covid but not for the HCI study reported here.



B Busy
Busy time; doing a lot, few breaks

M Moderately Active

Welcome to the Covid recovery app
The road to recovery

Recovery from Covid
Common post-Covid symptoms

Fatigue
Advice if you're feeling more tired than usual

Breathlessness
Advice if you're feeling more breathless than

Reading List
Hi Colin, Further to our last appointme...
Dr Cara Reconhall - sent 10 months ago
1 article to read

Your next appointment
Hi Colin, Your next appointment has be...
Dr Cara Reconhall - sent a year ago

Appointment Fri, 15 Nov 2019
Coronavirus Clinic
General appointment
10:00am (1hr 20m)

Figure 5: more detailed screen shots from early versions of the LWCR app (August and October 2020 releases). These illustrate: what functions were available under "My Health"; an example of the fatigue diary interaction; an overview of library contents; and an example of interactions within the "Messages" function. © Living With.

Other functions that had been developed previously by Living With such as medication reminders, a diary and a function to set and manage goals were also available in the LWCR app. Although they were not considered central to the design concept for the LWCR app, we thought these additional functions might be useful to some users. Some of these functions were subsequently included more explicitly in patient pathways, as described below.

5.3 Refined scenarios and final version of LWCR

In describing the evolution of the LWCR app over the two years of the project, we first present refinements to the scenarios of use discussed in section 5.1.2 then give an overview of the final (July 2022) version of the LWCR app and describe in more detail three key functions developed over the course of the project: library material, programmes, and a Fatigue Activity Diary.

5.3.1 Refinements to the scenarios of use.

Through the autumn of 2020, we grappled with what was needed and how to work with the Long Covid services that were being planned and set up across the UK [55]. We developed richer scenarios of use for our three key patient groups (Zara with Amid, Stefan and Brenda), loosely based on the design of the minimum viable product that had been released by this time, as illustrated through the scenario developed for Zara, Amid's daughter. Note that at this time the importance of pacing (to avoid Post Exertional Malaise) had not yet been recognised.

This scenario was developed for Zara on 8th November 2020:

- It's Zara who first uses LWCR: she takes home the letter so that she can try it out first in her own home. She downloads the app to her phone and briefly surfs through the various areas, feeling a little overwhelmed by all the apparent expectations. This includes skim-reading some of the articles in the library. She reads a message from Amid's clinician that is asking him to complete various questionnaires, listing them in likely priority order. The message briefly explains why he's being asked to do these things and how important it is to get baseline data.
- The next time she visits Amid, they complete the most important of the PROM questionnaires together. They agree that, as guided by the clinician, the most important ones to complete first are the single Covid Recovery question, fatigue (FACIT), breathlessness (D12) and depression (PHQ-8) questionnaires. They agree to leave others for a later date. The app will flag these up when they next log in.
- For each questionnaire, the app presents an interpretation of what that score means for Amid, suggests some of the articles in the library to read, suggests some kinds of goals to set (such as

agreeing some things that he enjoys doing and some activity goals), and suggests maintaining a fatigue diary.

- In this first session, Zara and Amid just read a couple of the articles and discuss what would give him pleasure that he's not doing at the moment. They agree that he would enjoy nurturing a few herbs on his window sill so Zara promises to bring him the necessary pots, seeds, etc. when she next visits. She enters this as a sub-goal in the goals section of the app, and also completes a simple "happiness rating" for Amid.
- On the next visit, 2 days later, Zara brings the herb kit along and they work together to set it up. They log in to LWCR, which first asks how he's getting on with the herb garden goal. Zara can enter that they have set it up (i.e., completed the first sub-goal). She can enter a simple rating of whether he's feeling happier, less happy or about the same compared with two days ago.
- LWCR then suggests that they follow up on the fatigue PROM from the first visit by reading the fatigue information, giving tips on how Amid can learn to manage his fatigue, and starting to complete the fatigue diary. Zara and Amid discuss what he'd really like to achieve (being able to get out to the shops on his own again) and what that means for the next few days (being able to make himself a drink at least 3 times a day). They set this as a sub-goal.
- On visit 3, LWCR first asks about the herb garden. Although Amid has watered his plants once, they haven't obviously started sprouting, so there isn't any visible change. This is reported to the app, and they also complete the happiness rating again.
- Amid is complaining of breathlessness, so Zara reads the main information on breathlessness from the LWCR library. They haven't followed up on the breathlessness information from the first visit yet, so LWCR suggests that they review his data entry from that date and consider whether things have changed significantly or not. If they are a lot worse, it recommends that he should complete the questionnaire again and also message the hospital to ask what he might do about it. He doesn't like to cause a fuss, so he doesn't do these things and resists Zara doing them either.
- LWCR reminds them about the fatigue diary. They complete it together, based on Amid's rather sketchy memory of the past two days.
- On visit 4, since a week has passed since first using the app, LWCR issues a reminder to complete the single Covid Recovery question. Amid is complaining of tightness in his chest. Zara has noticed that there's an area in the app for recording new symptoms, and this one seems important enough that she feels she should report it. She just enters free text to note this. Because this is a new symptom, LWCR suggests that now might be a good time to first complete the anxiety questionnaire (GAD-7). They do this. As with previous questionnaires, this provides a link to the relevant information in the library and also information about managing anxiety.
- At the next review session, his clinical team note that he seems to be deteriorating a little and has a new symptom. A clinician calls or messages him.
- After a month, Amid is still depressed, but there are fewer really bad days, and he seems to be getting better. He still can't walk to the shop, but he's struggling less with the dialysis visits. Looking back over the data from the month, Zara is encouraged to see the progress. The herbs are growing well.
- After a further three months, Amid has a final hospital review and is formally discharged. He receives a letter from the hospital with a discharge summary that notes his latest data and reasons for discharge. The letter also encourages him to keep using the app for as long as he finds it helpful, suggesting that he should be aiming to be able to go up a single flight of stairs without being out-of-breath, and to be able to walk to his local park with no rests on the way (though he can sit on a bench and enjoy himself when he gets there).
- Zara continues to use LWCR with Amid, focusing now on the mental health support and gradually tailing off on all the other components. LWCR makes it clear that the app data is for their personal use only: although it is still being uploaded to the hospital record, it is no longer being reviewed by the clinical team. There's a link to show what to do if they have further concerns.

Although the personas and scenarios were influential in guiding the LWCR app development, we did not implement all the functions proposed in the various scenarios (section 7.2.5).

5.3.2 *Overview of the LWCR app (July 2022 version).*

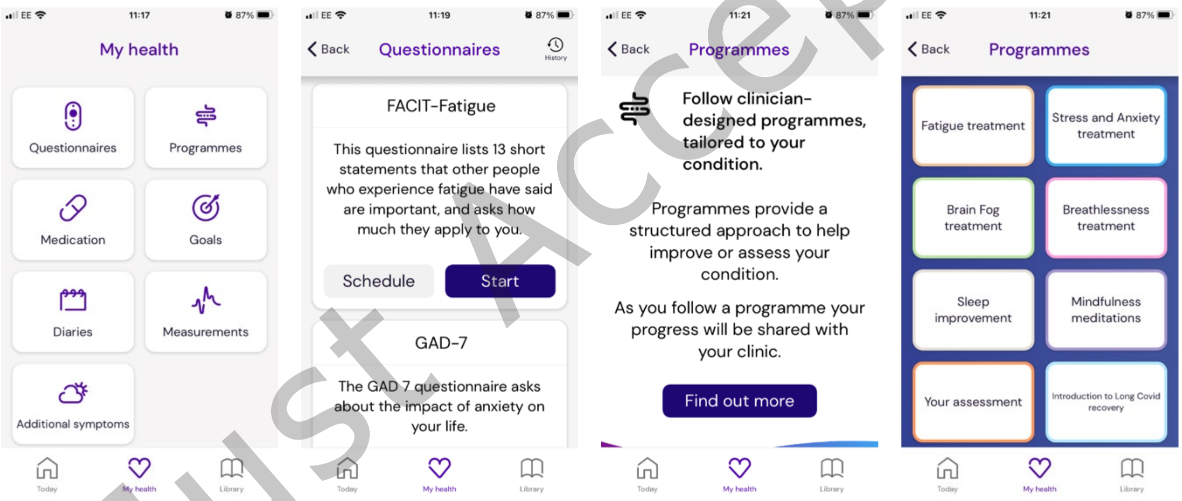
By the end of the project, several new functions had been added to the LWCR app based on requests from clinicians and PPI, as illustrated in Figure 6. No functions had been removed.

As noted above, the number of questionnaires was expanded from five to 11. Some clinics and patients suggested that we should expand the set of questionnaires even further to cover additional symptoms of Long Covid. We were reluctant to add to the burden of completing questionnaires, so we addressed this by adding a symptom tracker; this proved useful for identifying other important symptoms such as pain, for which Living With have subsequently developed a programme.

As the understanding of Long Covid developed, it became clear that demand would grow and patients would benefit from more guidance on self-management. To address this, HCPs in the team proposed that we should draw on established clinical practice in various specialisms and develop programmes that patients could follow. These built on functions that already existed in the LWCR app including some, such as goal setting, that had previously served no clear role. Programmes are described in more detail below (section 5.3.4).

Inevitably, as understanding of Long Covid evolved, it was necessary to update library articles and to add to the set of articles, as described below.

Finally, the existing fatigue diary did not provide clinicians (particularly physiotherapists) with the details they wanted to support them in guiding patients, so we worked with a small team of physiotherapists to understand their requirements and develop a Fatigue Activity Diary, as described in section 5.3.5.



This questionnaire lists 13 short statements that other people who experience fatigue have said are important, and asks how much they apply to you.

The GAD 7 questionnaire asks about the impact of anxiety on your life.

Follow clinician-designed programmes, tailored to your condition.

Programmes provide a structured approach to help improve or assess your condition.

As you follow a programme your progress will be shared with your clinic.

Figure 6: Screenshots from the LWCR app (July 2022) showing extensions in the "My Health" area, example questionnaires with descriptions, and information about the eight available programmes. © Living With.

In the following sub-sections, we outline considerations in designing three functions of the LWCR app: the library content, treatment programmes, and the Fatigue Activity Diary. We have chosen these three as they raised the most important issues from an HCI perspective. Other functions (such as goal setting and symptom tracking) are discussed in terms of their evaluation in section 6.4.

5.3.3 *Library content: information and advice for patients to browse in the LWCR app.*

The purpose of the library was to provide easily accessible and trusted information about Long Covid and strategies for managing it. The content of the library was developed, and largely maintained, by PPI representatives with expertise in writing for a lay audience (JB and BC, paid as consultants). This was based on information from clinical specialists. 22 PPI members were involved in providing feedback on the content of articles through focus group discussions. Of particular note was PPI guidance on physical activity, which emphasised pacing and avoiding Post Exertional Malaise before this was widely recognised in the medical community. Each discussion was time-limited to avoid overloading people. Material was signed off for clinical accuracy by a suitably qualified HCP. By July 2022, the library contained 92 articles, typically of around 100 words, with longer articles split into separate sections that were also no more than 100 words each. Articles are written for ages 12 and below to make it easier for people with brain fog or limited English literacy to comprehend.

As a team, we faced three notable challenges in developing and maintaining library content. Firstly, the understanding of Long Covid was evolving over the period of the project; secondly, Long Covid causes variable symptoms that are unique to each patient so that treatment plans were not suitable for all patients, particularly in relation to physical activity and fatigue; and thirdly patients had very different levels of health literacy (e.g., many were HCPs). Hence, providing content relevant to all patients was difficult.

As the understanding of Long Covid evolved, our library content was updated to reflect the latest scientific findings. While the team continued to update the library as frequently as possible, this was resource-intensive, and we had to trade off the costs and benefits of this.

5.3.4 Programmes: guided information and activities in the LWCR app.

Through the summer of 2020 it was becoming increasingly apparent that the NHS did not have the capacity to provide the level of care that HCPs would provide for people with similar symptoms under less pressured circumstances. There was minimal follow-up support to guide patients through the stages of rehabilitation for each symptom. Therefore, we decided that the LWCR app needed to provide more explicit support for patients than the first version did.

The first programme to be developed was on “Stress and Anxiety”, based on an established cognitive behavioural therapy (CBT) clinical protocol in UK mental health services. This focus was chosen because, as well as it being an important topic, a mental health specialist (SL) was involved in the weekly team meetings and had the resources and capacity to develop the first prototype. Drawing on his experience of delivering rehabilitation programmes through in-person therapy sessions, SL drafted a first version of an online “Stress and Anxiety” programme as a set of PowerPoint slides to guide the software developers. This version emphasised developing a personal “tool kit” of practical self-management strategies. This was iteratively refined based on low-fidelity prototypes that were tested by PPI in two think-aloud sessions involving people who could access the LWCR app and three small group sessions that reviewed sample texts. Living With extended the system architecture to accommodate programmes with content of different types. Programmes allowed patients to use the LWCR app in a structured way, providing a pathway through library articles, questionnaires, goal setting, etc. This was well received by early clinics.

Based on the design of the “Stress and Anxiety” programme, we implemented programmes for other symptoms including fatigue, breathlessness and sleep management. For each programme, we needed leadership from HCPs with specific expertise. This required us to involve HCPs beyond the original team. By utilising the experiences and suggestions of different Long Covid clinics, we were able to develop a breadth of programmes rapidly. By July 2022, seven further programmes had been developed, reviewed and included, as shown in Figure 6. Five were therapy programmes addressing different symptoms of Long Covid; the remaining two were an overall introduction to both Long Covid and the LWCR app, and an assessment programme that packages up the questionnaires that users were asked to complete. Each therapy programme typically included articles to read from the library, activities to perform (either using the LWCR app or external to it), goals to set and report on, and quizzes to enable people to test their understanding.

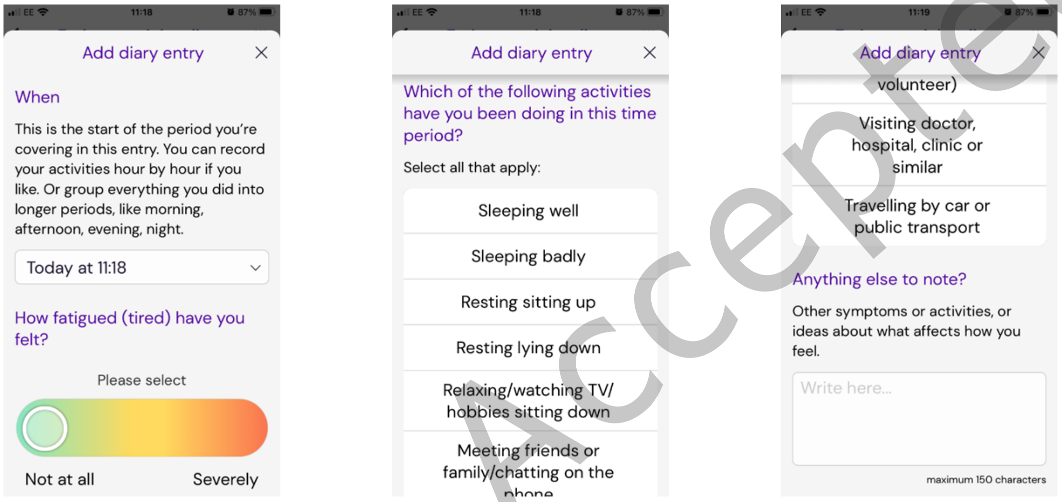
Face-to-face, such a therapy programme would be delivered over several weeks, with patients being recommended activities to perform between sessions. Initially, no such natural pacing was built into the online version. We debated what to call each session, avoiding words such as “week” that would imply a particular pace that might not suit every user. We finally settled on “section”.

However, reviewing anonymised user activity traces (which became available to the team from May 2021), it became evident that some users were working through an entire programme in an hour or two. It is very unlikely that someone working through a programme without time to complete off-line activities, such as maintaining a reflective diary for several days, would realise much benefit from it. Adding guidance text at the beginning of the programme did not change behaviours significantly. By July 2022, the latest version of the programme implemented “tunnelling”, so that all users are guided from one step to the next, reducing user freedom to explore within a programme, and pacing, such that people are required to wait between sections, and hopefully engage with the activities recommended in their current section.

5.3.5 *Diaries for patients to complete and share with healthcare professionals.*

Physiotherapists involved in rehabilitation have traditionally encouraged patients to maintain diaries of activities and impact on fatigue, to identify what activities are most effective for rehabilitation. These are typically developed locally, and structured to capture the information physiotherapists require. The LWCR app included an existing fatigue diary that had been developed for people managing Rheumatoid Arthritis, as illustrated in Figure 5 (second screen from left). However, HCPs reported that they needed more details of people's activities for a diary to be useful to them.

We took examples of activity diary templates from different clinical services, picked out the common features of them and adapted them to an online form that would, in the longer term, make it possible to present a visualisation of activities and corresponding fatigue levels over time (Figure 7). This diary was based on the requirements of health professionals, based on their experience of running clinics, and evaluated by PPI representatives (section 6.1).


Add diary entry

When

This is the start of the period you're covering in this entry. You can record your activities hour by hour if you like. Or group everything you did into longer periods, like morning, afternoon, evening, night.

Today at 11:18

How fatigued (tired) have you felt?

Please select

Not at all / Severely

Add diary entry

Which of the following activities have you been doing in this time period?

Select all that apply:

- Sleeping well
- Sleeping badly
- Resting sitting up
- Resting lying down
- Relaxing/watching TV/ hobbies sitting down
- Meeting friends or family/chatting on the phone

Add diary entry

- volunteer)
- Visiting doctor, hospital, clinic or similar
- Travelling by car or public transport

Anything else to note?

Other symptoms or activities, or ideas about what affects how you feel.

Write here...

maximum 150 characters

Figure 7: Screenshots from the LWCR app (July 2022) showing the "fatigue activity diary". © Living With.

6 HCI IN THE DEVELOPMENT PROCESS

In this section, we present key HCI studies that were conducted alongside the agile development process. Other methods including expert review were also applied, iteratively, but since these are standard methods we do not discuss them further. We present our principal methods in approximately chronological order: how PPI representatives contributed to testing of the LWCR app; an autoethnography; the design of the patient pathway; selected insights from the clinician and patient interviews; and an overview of the data analytics.

6.1 PPI Involvement in evaluating the LWCR app

As well as their role in shaping the research and assessing material for inclusion in the library (section 4.1), PPI were involved in testing various interactive functions of the LWCR app.

A couple of PPI panel members did not have access to a smart phone or the confidence to use one; although these people commented on text documents of proposed library material, they could not assess the interaction design.

Twelve PPI participated in a focus group (Feb 2021) to test particular tasks in the LWCR app. The chosen tasks focused on completing the anxiety questionnaire, reviewing material on brain fog, and using the prototype Fatigue Activity Diary. While most participants found the device tasks relatively straightforward, some had to imagine themselves into the situation if they were not experiencing a particular symptom. This study helped to identify usability "nits" (localised usability issues that could be addressed relatively quickly) but larger-scale recommendations for changes tended to be broad and difficult to action. The exception to this was the Fatigue Activity Diary.

The focus group highlighted usability difficulties (e.g., in editing or deleting a diary entry); further requirements (e.g., to be able to get an overview of diary entries to reflect on their activities and progress); issues of motivation (what's the value of completing diary entries?); fear of feeling overwhelmed by the demands of completing diary entries, given their brain fog and fatigue; and concerns about privacy. Some of these issues could be acted on, but others depended on how different HCPs were going to use the diary.

Since clinics were using the diary information in different ways, it was not feasible to include specific details of how diary information would be used, which would have addressed some of the concerns PPI representatives expressed. This might be different from individuals maintaining their own personal diaries to note and reflect on their activities, feelings and progress. This highlighted a potential tension between what the clinics required of a diary and what individual patients required, and people's motivations to maintain a diary for themselves or for their clinical team.

Others were invited to participate in a retrospective think-aloud study (June 2021), in which they worked through the Stress and Anxiety programme within one session reporting on how they had used it. Only two PPI were available for this. One had been using the LWCR app, including that programme, for several weeks. She reported finding the programme easy to navigate, clear and relevant, and valued it being structured. She had been setting herself goals and performing tasks as advised by the LWCR app. She highlighted many features of the programme that she had found helpful and also areas for improvement, such as adding audio. She also emphasised the importance of patients listening to their bodies and only doing what they felt able to at any given time, and of providing reassurance to people. She also emphasised individual differences: that people are presenting with different symptoms, and that different things will work for different people. The other PPI study participant was, indeed, different. She had not used the programme previously and struggled to find it in the LWCR app. She treated the programme like the library and specifically reported that she wanted to choose what content to go to. She focused largely on visual content and text that stood out (e.g., bold or italics). Although she was excited about the programme, she wanted to stay in control and not use the programme as designed; she reported finding material reassuring, but in debrief there was little evidence that she has internalised much content. The contrast between these two PPI members illustrates the challenge of designing for diverse users.

PPI members (JB, BC, SE) were involved in leading, as well as participating in, these evaluation activities and helped analyse this data as they were well placed to interpret feedback from other PPI. PPI members JB and BC then revised content in response to feedback. This illustrates contributions of PPI as core team members as well as representative users.

As well as the team explicitly seeking feedback, we received unsolicited feedback from both users and non-users of LWCR. Of note was email feedback from a member of the PPI panel (9/11/21); their theme of how some clinics used LWCR and how this was experienced by patients was also raised by patients who participated in interviews later in the development process (section 6.4).

> Anon: Someone, preferably a medic, should explain what the app is for and what the benefits of using it are. […] Newspaper articles had led me (and I suspect others) to expect that the longcovid clinics would mean face to face time with specialists, so being sent off with just an app, was a huge disappointment. […] LWCR has a huge amount of helpful, clear and usable information, concisely presented and even I managed to work my way through lots of it. But its usefulness is constrained by how good/proactive ones GP and Health Authority is.

Another example of useful PPI feedback was on a resource we prototyped called the "vicious flower" which drew on existing practices in mental health therapy to communicate the interdependencies between symptoms. Through the early months of the project, understanding of Long Covid was evolving rapidly. It was becoming evident that the condition manifests in different ways for different patients, and that most patients had multiple interrelated symptoms. We thought it might be helpful to communicate this explicitly. In a team meeting, SL proposed the notion of a "vicious flower":

> SL (23/11/20): "In psychology we have a nice concept of the vicious flower, in which all the different things are petals around the flower and you work on one petal at a time."

By the following week, SL had sketched out and expanded on this idea, as illustrated in Figure 8 and in the following extract from a meeting transcript.

> SL (30/11/20): "This is a sort of way of drawing these things together into what in psychology we call the vicious flower and I've put fatigue at the middle. And you can see that each of these petals around it are like positive feedback loops because they make it worse. So what we need to be doing as a treatment model [...] is tackling each of these different ones to try and help the fatigue and to reduce the impact of those things on the fatigue. [...] At the bottom, on the stem of the flower, you've got other kind of shoots and things which may be more causal and the line in the middle shows what's kind of current, what we're working on, and what might be in people's histories. That's a bit more kind of speculative: inflammation is one that [colleague] talks about a lot. Stress, pre-existing conditions, a lot of social factors and maybe genetic contributions."

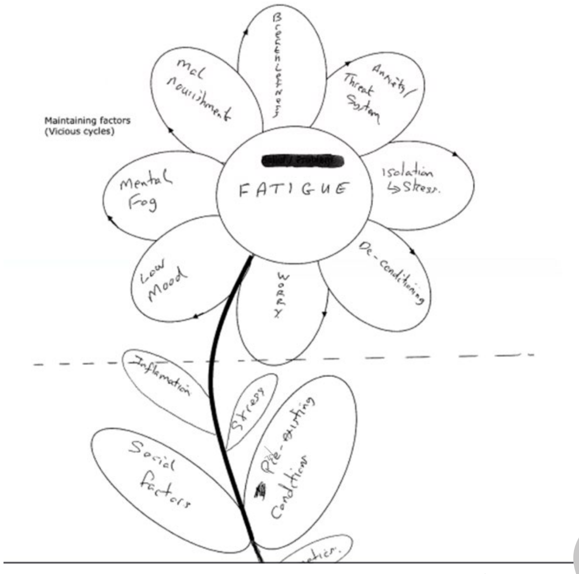


Figure 8: An early sketch of the "vicious flower": see transcript (SL, 30/11/20) for explanation.

As a team, we found these ideas helpful, and we thought that patients might find them helpful too. However, when we tested this concept with PPI representatives, their responses were almost unanimously negative. They felt that this did not reflect the variety of their symptoms. We therefore removed any reference to the "vicious flower" from the next design iteration, though we tried to include notes about interdependencies between symptoms where appropriate throughout the LWCR app. The proposal and rejection of the "vicious flower" is an example of an HCI design decision that could be tested, in a relatively cheap and timely way, through PPI feedback.

6.2 Autoethnography: Being Doreen

LWCR was designed to be used over an extended period of time (weeks or months), one or more times a week, depending on individual patient needs and how their condition evolved. We considered it important to get some understanding of what this felt like: what was the experience of using it repeatedly? How might experience evolve over time?

Because of the burden of self-managing Long Covid, we did not ask any PPI or patients to record their experiences of LWCR over time – e.g., through a diary study. Conversely, we recognised that asking people who were not managing Long Covid to use the LWCR app over an extended period of time and to either conduct a longitudinal think-aloud or maintain a diary of their usage over time was artificial and a poor use of limited project resources.

To obtain insights into usage over time at minimal cost, one member of the project team (AB) conducted an autoethnography [63] using the LWCR app for 18 consecutive days (13-30 October 2021). The aim was not to report on personal lived experiences (e.g., [37]), but to gain empathy with the experiences of users of the LWCR app, in a similar style to that reported by O'Kane et al [60]. By this time, the name of the demo clinic user had been changed from Colin to Doreen so this was dubbed "being Doreen". Since AB had no personal experience of Long Covid, and did not have support from a clinic, the strategy adopted in using the LWCR app was to be guided by the "cards" presented on the home screen (Figure 4, left) rather than to choose activities proactively based on personal experiences; we expected some real users to interact proactively and others to be guided by their HCP and the LWCR app cards.

AB maintained a think-aloud over the 18 sessions of use, which lasted between 6 and 31 minutes, with a mean duration of 15 minutes (total duration 4h 31m). The think-alouds were transcribed using an automated transcription service and notes were then made of user experience and usability issues encountered. 180 notes were made covering the 18 days of usage (minimum 2 notes for a day, maximum 25 notes).

The 180 notes were collaboratively synthesised into 96 usability issues and classified by three members of the project team (AB, KB, HG) based on the area of the LWCR app they affected (e.g., questionnaires, diaries, goals, programmes), the class of the issue, and our assessment of the priority for fixing. We inductively identified 18 classes of issue with the LWCR app as summarised in Appendix A.5. For example, these included "niggles" (localised problems that could be easily fixed), "flow", which highlighted problems with the flow of the interaction across sessions, and "overwhelmed", which was the emotional response to high cognitive load or having too many tasks to do.

Examples of situations where "Doreen" felt overwhelmed included:

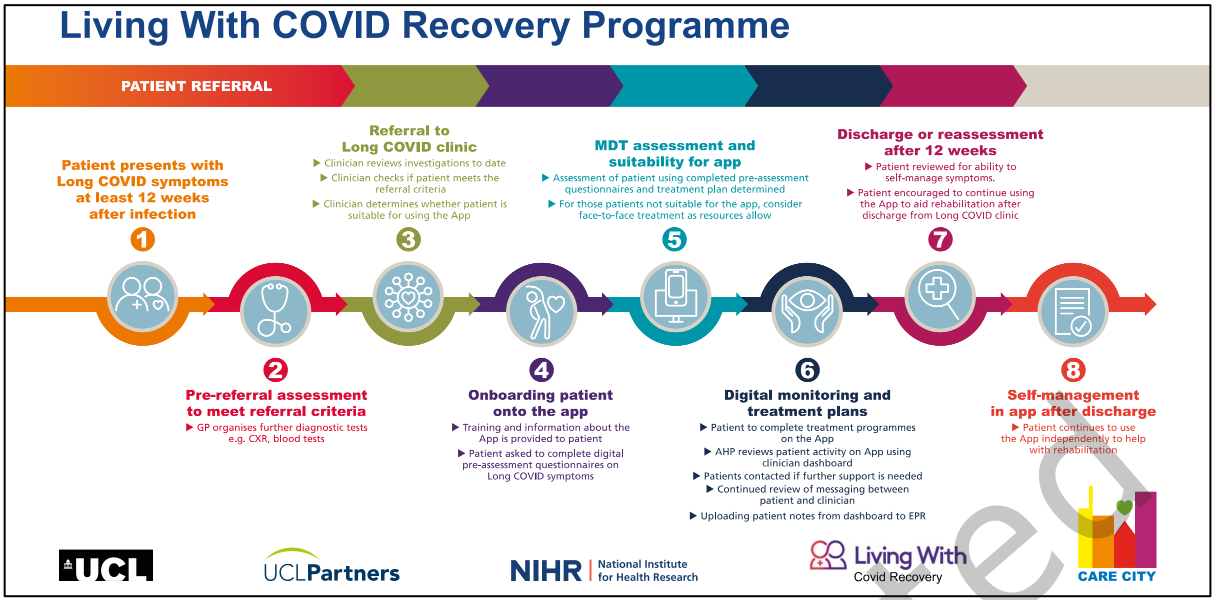
> Doreen note (Day 1): [there is] scope for getting lost every time one goes to articles.
> Doreen note (Day 2): I was feeling cognitively overloaded and lost by this point. I pressed "Home" to get out of being lost.
> Doreen note (Day 4): I got lost again!
> Doreen note (Day 9): Cards create many things to do in parallel. Overwhelming.
> Doreen note (Day 10): Completing a "questionnaire" about covid recovery sounds daunting but it's actually only one question.
> Doreen note (Day 18): Holding things in my head about future things to do. Would need notebook to externalise these but bookmarks would be easier.

Given that some LWCR app users were reporting feeling overwhelmed, "being Doreen" helped identify design features that contributed to this, as well as other potential areas for improvement of the LWCR app.

The issues identified were discussed and prioritised with the development team, taking into account both how easy and how important each was to fix (and, indeed, whether it was obvious what the "fix" might be). We considered feeling lost or overwhelmed and the lack of pacing in programmes at that time to be critical issues. Both were addressed in subsequent releases.

6.3 The patient pathway: creating fantasy timelines

A further set of considerations, which we put in the "too hard" bucket for a long time, was how clinicians and patients would jointly interact with LWCR over the time that a patient was under the care of a clinic. The key reasons for this seeming "too hard" were that we knew how much variability there was in the ways that clinical teams were using LWCR and that individual patients were engaging with the LWCR app. The LWCR app was designed to support patients with a variety of symptoms and approaches to self-management. Support from the clinic was a key intervention ingredient, so it was important to make explicit what good support might look like. Documents providing guidance to services on how to manage patients were developed and shared with participating services. The guidance covered technical onboarding and monitoring in some detail, but little about how to support users in their self-management, as illustrated in an overview diagram from November 2021 (Figure 9).



Living With COVID Recovery Programme

PATIENT REFERRAL

1 Patient presents with Long COVID symptoms at least 12 weeks after infection

2 Pre-referral assessment to meet referral criteria
- GP organises further diagnostic tests e.g. CXR, blood tests

3 Referral to Long COVID clinic
- Clinician reviews investigations to date
- Clinician checks if patient meets the referral criteria
- Clinician determines whether patient is suitable for using the App

4 Onboarding patient onto the app
- Training and information about the App is provided to patient
- Patient asked to complete digital pre-assessment questionnaires on Long COVID symptoms

5 MDT assessment and suitability for app
- Assessment of patient using completed pre-assessment questionnaires and treatment plan determined
- For those patients not suitable for the app, consider face-to-face treatment as resources allow

6 Digital monitoring and treatment plans
- Patient to complete treatment programmes on the App
- AHP reviews patient activity on App using clinician dashboard
- Patients contacted if further support is needed
- Continued review of messaging between patient and clinician
- Uploading patient notes from dashboard to EPR

7 Discharge or reassessment after 12 weeks
- Patient reviewed for ability to self-manage symptoms.
- Patient encouraged to continue using the App to aid rehabilitation after discharge from Long COVID clinic

8 Self-management in app after discharge
- Patient continues to use the App independently to help with rehabilitation

Figure 9: The proposed patient pathway for LWCR.

The key phase of LWCR app use is summarised in stage 6 of this pathway:

- Patient to complete treatment programmes on the App.
- [Clinician] reviews patient activity on App using clinician dashboard.
- Patients contacted if further support is needed.
- Continued review of messaging between patient and clinician.
- Uploading patient notes from dashboard to EPR [electronic patient record].

However, there was no guidance on what use of the LWCR app might entail. For example, how was a patient to be guided on which programme(s) to follow? how long was a patient expected to take on a programme? How many programmes might they do in parallel? When, and how often, should they be completing questionnaires? When and how would a completed Fatigue Activity Diary inform their care? We debated such questions at length, both within the team and with other clinical colleagues.

As well as the practical need to provide clearer guidance, a clinical trial involving LWCR was planned [26]; that trial design planned to measure improvements in patients' symptoms over three months. To be part of a clinical trial, it was essential that there be a standardised care pathway that covered the three months to be tested in the trial.

Figure 10 shows an example "fantasy care pathway". The details of the text are not important; the principles were that:

- The timeline covered 12 weeks from onboarding (i.e. getting the patient started on the LWCR app and in care) to discharge, after which the patient could continue to use the LWCR app, but with no further clinical care; this was consistent with the guidance given to clinics at this time.
- The clinic was expected to monitor and respond to patient messages at least weekly, and to have a mid-point assessment with the patient (at 6 weeks) as well as initial assessment and review/discharge. This would be supported by messages to the patient.
- Patients were expected to complete the set of PROM questionnaires every 6 weeks, and to maintain a Fatigue Activity Diary between the first and second clinical assessments, for discussion with their clinician at the second assessment.
- Patients were expected to have therapy programmes recommended by their clinical team, and to complete just one or two programmes over the 12 week period, with the possibility of completing more, or repeating them, after they had been discharged.
- Their use of library articles was "ongoing", depending on their individual needs and interests.

- Both “cards” on the home page and pop-up notifications to the patient would serve as reminders and motivation to continue engaging with the LWCR app for as long as needed.
- Goal setting and symptom tracking were both considered “discretionary”.

Week	Clinic R/Vs	Messages to Pt	Patient PROMs for clinic	Programme	Articles	App / carousel	Goals	Symptom tracking
-	Referral							
0	Assessment for using app							
1	Onboarding	Welcome		Intro		Welcome. Introductory programme		
1.5		Reminder of r/v	Complete assessments	Assessment	Ongoing	Assessment programme	Discretionary	Discretionary
2	Assessment and treatment plan	post r/v support				Encourage patient to read articles and commence a programme (suggested focus fatigue, but other if patient prefers). Also FAD?		
2.5			FAD	Fatigue 1		Reminder twice a week about next session. Reminder **3 times a day** about FAD		
3	Dashboard Review	post r/v support	FAD	Fatigue 2		Ditto		
3.5			FAD	Fatigue 3		Ditto	May be prompted by programmes	
4	Dashboard Review	post r/v support	FAD	Fatigue 4		Ditto		
4.5				Fatigue 5		Reminder twice a week about next session.	Goals are hard to do well	
5	Dashboard Review	post r/v support		Fatigue 6		Reminder twice a week about next session.	See separate note	
5.5		Reminder of r/v	Complete assessments	Fatigue 7		Reminder twice a week about next session.		
6	In-depth review of assessments and FAD	post r/v support		Fatigue 8		Reminder twice a week about next session.		
6.5				Fatigue 9		Reminder twice a week about next session.		
7	Dashboard Review	post r/v support		Fatigue 10		Reminder twice a week about next session.		
7.5						Congratulate about programme completed. Encourage reflection. Encourage to consider whether another programme would be helpful		
8	Dashboard Review	post r/v support		Anxiety 1		Reminder twice a week about next session.		
8.5			other questionnaires as discussed with clinician	Anxiety 2		Reminder twice a week about next session.		
9	Dashboard Review	post r/v support		Anxiety 3		Reminder twice a week about next session.		
9.5				Anxiety 4		Reminder twice a week about next session.		
10	Dashboard Review	post r/v support		Anxiety 5		Reminder twice a week about next session.		
10.5				Anxiety 6		Reminder twice a week about next session.		
11	Dashboard Review	post r/v support		Anxiety 7		Reminder twice a week about next session.		
11.5		Reminder of r/v	Complete assessments	Anxiety 8		Reminder twice a week about next session.		
12	Discharge or reassessment	post r/v support		Anxiety 9		Reminder twice a week about next session.		
12.5	Encourage patient to continue rehab		Self-management	Anxiety 10		Reminder twice a week about next session.		
						Congratulate about programme completed. Encourage reflection. Encourage to consider whether another programme would be helpful		
				Brain fog 1		Reminder twice a week about next session.		
				Brain fog 2		Reminder twice a week about next session.		
				Brain fog 3		Reminder twice a week about next session.		
				Brain fog 4		Reminder twice a week about next session.		
				Brain fog 5		Reminder twice a week about next session.		
						Congratulate about programme completed. Encourage reflection. Encourage to consider whether another programme would be helpful		
				Breathlessness 1		Reminder twice a week about next session.		
				...etc.		Reminder twice a week about next session.		

Figure 10: A fantasy care pathway illustrating one possibility (November 2021).

Having subsequently analysed clinician and patient interview data, this idealised pathway bears little relationship to the lived reality of either clinical practice or patient experience. This is discussed further below.

6.4 Interviews with HCPs and patients

In the second year of the project, semi-structured interviews were conducted with HCPs from seven Long Covid services and 12 patients – i.e., users of LWCR.

6.4.1 Method.

The main aim of the HCP interviews was to improve patient care by understanding how LWCR was being used in each service, to inform updates to LWCR and to share best practices of use across services. All 35 services using LWCR were invited to participate in interviews; HCPs from seven services agreed to this. The interviews were conducted between July 2021 and April 2022. In three cases, multiple clinicians (2-4) from the same service participated in a group interview. Where more than one member of a clinical team participated, they presented a united front, commonly either reinforcing or embellishing a point made by a colleague or deferring to a colleague with greater expertise on a particular topic. Thus, we treated them as group interviews (rather than, for example, focus groups where we would expect people to provide contrasting perspectives). Therefore, for this analysis, we did not distinguish between individuals representing the same service. In this paper, where illustrative quotations are used, HCPs are referred to by a clinical service code that indicates the order in which they were interviewed: C1-C7.

Patient interviews aimed to better understand patients’ experiences of Covid, Long Covid, their management and their experiences with the LWCR app: what had worked well and opportunities for improvement. We aimed to recruit a representative sample of patients who were diverse on various criteria. In practice, we recruited patients who had registered 6-12 weeks previously in December 2021-January 2022. Participants were stratified into two groups:

- A: people who had used LWCR at least once a week up to the time they were identified as potential interviewees (“high engagement”).
- B: people who had used it less than once a week but more than five times in total over the same period (“low engagement”).

The response rate was low and slow: of 239 people invited, only 12 agreed to be interviewed, and interviews took place up to 8 months after they had registered to use the LWCR app. Interviews took place between March and August 2022. Participation was voluntary, and participants were not compensated for their time. One recording failed so the analysis focused on the remaining 11 participants. Ten of those analysed were female; year of birth ranged from 1956 to 1990; education level ranged from school leaver (few qualifications) to degree or post-graduate study; 8/11 participants were of white ethnicity; and 8/11 were classified as “high engagement". Where illustrative quotations are used, participants are referred to by a code that denotes their engagement level and the order in which they were interviewed: B1, A2… A11 (so, for example, the first participant was classified as "low engagement" and the second as "high engagement"). Patients were asked to review the LWCR app to prepare for their interviews, so that they could recall its functions and what they had used in the past. Some clearly took this "homework" seriously and had detailed notes with them for their interviews.

HCP and patient interviews were analysed separately (HCP interviews first). Both analyses were qualitative and inductive, so no pre-defined codes were used; rather, codes were derived from the data. NVivo was used to support coding. Analysis was conducted by AB and discussed with the research team. Although coding was inductive, the analyses were shaped by our focus on people's experiences of using LWCR. For HCPs, the key themes identified were: how LWCR integrated with their care pathway; clinicians' perceptions of their patients and how they use the LWCR app; and their views on functions in the LWCR app. For patients, the key themes were aligned as far as possible with those of the HCPs: perceptions and experiences of using the LWCR app; their awareness and use of different app functions; explicit and implied user requirements for app revisions; and their experiences of their Long Covid clinics and how LWCR was integrated with their care. Two themes that were identified as being major influences on clinicians' and patients' experiences of LWCR were how LWCR fitted into the care pathways of different clinics and how patients were onboarded onto the LWCR app.

For the purposes of this paper, we focus on a subset of the findings, namely how clinicians reported that LWCR fitted into their care pathways, clinicians' and patients' perspectives on key app functions, and specifics about onboarding and the need for common ground between clinicians and patients.

These interviews were conducted too late in the project to inform the design within the project period but have informed subsequent developments.

6.4.2 How LWCR fitted into care pathways.

As noted above (section 2), NHS England was responsible for setting up clinics but did not provide clear guidance on care pathways, so different clinics created their own care pathways. Some were only offering a virtual service (no face-to-face care) and clinics had varying numbers of consultations with patients. Some discharged patients after a fixed number of weeks (e.g., 12) whereas others discharged patients when they had recovered sufficiently or seemed disengaged from care. Also, many clinics had very long waiting lists and patients would be put on the LWCR app but not seen by a clinician for several months.

Even within the seven clinical services that participated in interviews, there was substantial variability in how they used LWCR. At one extreme, C2 were quite dismissive of LWCR and expressed the view that every patient had complex needs that needed individualised care.

> C2: The app is there as part of the service, but capacity, our ability to work with patients on a one to one basis, and our ability to offer rehab, work on breathing pattern dysfunction, you know, more individualised care, has greatly increased. Because the app was not going to meet those needs.

At the other extreme, C6 organised group sessions for patients, with a 2-month programme of weekly session based on LWCR information and functions to facilitate supported self-management. The structure of the programme was built around the themes covered in the LWCR app. The team were committed to making the LWCR app work for their patients:

> C6: we're just onto 16 groups it's on now since the beginning of the year. Some are running focused very much around using the app and the app as support. […There's…] much more buy-in […] with the app. [… Before the groups…] it was very hit and miss whether people were actually using it anyway. Whereas now because we're doing it through the groups and, you know, mass education on what it is, we do joke that we are not on commission for this app, although I really do think we should be

C6 was unusual in presenting a vision of how they are integrating LWCR with their service. For example, C7 did not directly discuss how they used the app; C5 emphasised support and partnership without being specific about what that meant in practical terms; and C1 expressed the view that it helped patients to feel cared for early on:

> C1: we can get them onboarded on to the app. And get them to feel like they're in – rather than just sitting at home for eight weeks waiting for an appointment. Hopefully they feel engaged [...] the number of calls that we get about, "I was referred and I haven't heard anything," have almost vanished.

C3 described it as an "add on" to treatment and emphasised adaptability and patients taking ownership:

> C3: we've taught them how to manage: in essence we're saying now this is what you need to do.
> C3: It allows them to be accountable or to feel accountable to us as clinicians. And feel that they are being looked after.

C4 also emphasised the value of patients taking ownership of their health, particularly regarding Long Covid as a potentially long-term condition:

> C4: in the past it's been very much, sort of, patients go to clinicians to tell them what to do and in this sense we're saying, here are all the tools, we're here to coach you through it, we're here to say, maybe have a think about this, or, why don't you do this, or, have you considered doing ... And they can get in touch with us whenever they like if they've got questions, and that I think is the unique, kind of, what this brings to a service where, actually, with long term conditions we've not really had an opportunity like it to the same degree.

C4 recognised the risk of patients feeling fobbed off with the app, and emphasised the value of tracking data:

> C4: rather than actually allowing the patients to think, oh, you're just planting me on some software where I'm going to sit and play about on my phone, if they actually understand the data that you can collect for us to actually understand what is going on with their symptoms in real time. As well as that, if they can see visually what is going on with their symptoms themselves.

6.4.3 Perspectives on app functions.

Analysis of the interview data gave us richer perspectives on the various LWCR app functions than earlier forms of evaluation.

6.4.3.1 Library.

Common feedback on library articles, from various sources, was that we should provide library material in multiple modalities (audio, video, pictures) as well as text; by July 2022, we had developed and included some such material, but preparing this was very resource intensive.

In interviews, HCPs commented on the quality of the information resources: e.g., in discussing how they use LWCR with patients, C3 explained:

> C3: I then talk around it as a huge, huge resource and I talk about the resources being implemented from you guys [...], and it's established with many different very experienced clinicians. And that all the resources are in there and they're building new ones which come in on a very regular basis. [...] lots of patients have said the resources have been excellent.

Most patients interviewed reported valuing and trusting the information resources, based on the fact that they were clinically validated and recommended by their clinics; e.g.:

> A3: you're inundated with information [...] But because I got yours from the long Covid clinic, then I was OK and happy doing it with a bona fide one, shall we say. [and] everything's all in one place.

The fact that the LWCR app was being regularly updated was also valued by patients. A2 pointed out that this meant there was often new material available, giving them a reason to remain engaged:

> A2: you've just said something really important. You've said the app is being developed and that's really good to know, so I mustn't think oh I've done this bit and that's it because there will be more added to it, so you've got to keep your eye on the ball so to speak.

In contrast, clinician C2 felt that the resources were presented at too low a level for their patients, many of whom had a medical background. While no patient participants made exactly the same point, one noted that they had become an "expert patient" before being given access to the LWCR app:

> B1: I'd done so much research before that I didn't really need to look at all of the information on the app as much. But if you're new to it it would be really good to have it all in one place from a reliable source.

Only two of the patients interviewed expressed any concerns about the way information was presented. The first concern related to the fact that understanding of Long Covid is still evolving and that it could be "damaging" to include information in areas that were not yet well understood. The second concern related to the inability of an app to adapt to what stage of recovery someone is at:

> B7: the sort of exercises and things that were being suggested were not suitable for someone who was suffering from fatigue, exhaustion, having difficulty breathing. […] the app wasn't realistic to what a person was up to. It just had no timescale.

Given the current state-of-the-art, the second concern should be addressed by clinicians guiding patients towards material that is appropriate to their stage of recovery. This point was made by clinician C2:

> C2: there were a lot of patients that we were putting provisos on them following any sort of suggested exercise plan until we knew it was safe for them to exercise.

6.4.3.2 Programmes.

There were few substantive comments about programmes from either clinician or patient interviews; this may be because many of the clinician interviews took place before the programmes had become a major feature of LWCR. Also, clinicians may not have been signposting patients towards programmes effectively. As C4 noted:

> C4: I've certainly pointed people in those directions but I haven't had the feedback. And, to be honest, I also haven't gone through them.

Most patient interviewees also showed little awareness of programmes. The only participant who had clearly followed several programmes was A5. They discussed them at length. In particular, they commented on the different levels of integration with the LWCR app, and were rather dismissive of using external tools such as pencil and paper:

> A5: One of the interesting things I think about the programmes, is that it seems to me as though they're written by different people, which obviously it would be because people have different specialisms. But also they have different levels of integration in the app. So some of the programmes are very integrated in the app and have lots of kind of within app functions. And others seem to link to like other sites, like NHS or the breath works or whatever. So I think the within app functions are actually probably the most useful ones, the ones like the fatigue one which has a fatigue diary, was, you know, was really interesting because it has that kind of immediate feedback. It has that function. Whereas others, oh, they're just really irritating when they say "Oh get a piece of paper," or "Keep a diary of this".

6.4.3.3 Fatigue Activity Diary.

At the times of their interviews, only a couple of the clinics reported asking their patients to maintain diaries. They highlighted how they use diaries to better understand patients' experiences. C4 emphasised the importance of patients tracking their own symptoms regularly so that they could remember from day to day – for example, their fatigue levels – and noted how having longitudinal data supported their conversations:

> C4: it allows us to, sort of, have really structured conversations with people from the start, so if someone has been on the app for two weeks and they've started to fill out measures your conversation is going to already be more productive than if they haven't and you're starting from the beginning. […] And then, generally, patients all engage much better and think, actually, this is quite helpful.

In contrast, C2 made it clear that they did not make use of patient diaries, but noted that:

> C2: I only had one patient use it but when they used it they used the activity diary just brilliantly.

C3 noted individual differences: between patients for whom self-tracking was a "selling point" for LWCR, those who did not want to self-track, and those for whom it could become compulsive, and hence negative:

> C3: Some absolutely have loved tracking symptoms […] that's how you sell it to them. […] then there's [those who say] I don't want to do that. I don't want to keep focusing every day or every four days, or whatever on my symptoms. […and there are those who] you almost don't want them to concentrate on symptoms. So, I don't want them to keep reporting that to me, and actually I think that's probably not the right way to manage them.

Only a few patient participants reported experiences of the diaries function of the LWCR app. A8 reported that diary keeping, presumably at the request of their clinic, was onerous, while A6 explicitly stated that they kept a diary at the request of their clinic but did not seem to find it personally useful. In contrast, participant B1 reported keeping a diary for personal reflection. B1 wanted to be able to track all their symptoms in one place so as to better understand cause and effect:

> B1: I tried to track the symptoms but I actually found that the spreadsheet I'd made myself was a bit more comprehensive. You know, like, I feel like in the app you can, sort of, track your fatigue but then I think I need to track all of my symptoms in the same place and also track my activities next to it so I can see which activities trigger which symptoms.

In summary, the few people (clinicians and patients) who commented on the diary function had different perspectives on it, depending on whether they regarded the diaries as being kept for self-tracking or primarily to support clinician-patient conversations. For the former, diaries need to support people in tracking multiple symptoms and activities over time. For the latter, they need to achieve a good balance between simplicity and utility.

6.4.3.4 Questionnaires (PROMs).

Patients were encouraged to submit questionnaires to their clinic to track progress over time, though reporting requirements were not standard across clinics.

While some clinicians commented extensively on how useful the questionnaire responses were for themselves, they also noted how burdensome they could be for patients. E.g.:

> C3: some of them say the questionnaires can be quite burdensome because there are a lot. […] I do say do it over a number of days, a number of weeks, it doesn't matter.

In addition, C1 and C3 felt that they didn't provide all the information that they required as a clinic. C1 wanted the questionnaires to include a post-traumatic stress disorder (PTSD) score, and C3 wanted the questionnaires to include the depression-related Personal Health Questionnaire PHQ9, which has an additional question about suicidal thoughts, rather than PHQ8.

Various clinicians recognised the value of detecting trends in the data over time for clinic staff monitoring questionnaire responses, and also the value for patients to see their own improvements; e.g.:

> C7: I actually do tell them it's a bit like a diary and to use it as such because you can then reflect on where you were, you know, six weeks ago.

Patients were invited to complete the questionnaires as their first activity with the LWCR app. Consequently, all the patient interviewees had experience of them. However, several patients questioned their value; e.g.:

> A3: I think just being a bit clearer on […] what you actually want with the questions and things like that, which is I think would help people a lot.
>
> B9: after the first couple of times, I just thought, "What a waste of time." It was asking me the same questions, I haven't improved in over two years, why are you asking?

A5 explained that they didn't think the questionnaires were capturing the experience of Long Covid well:

> A5: I don't think those questionnaires are really measuring […] the Long Covid experience and recovery very well, to be honest. […] I think they are again a bit of a weak link in terms of, you know, indicating recovery factors over time.

This point was also made by clinician C2:

> C2: [patients say] the breathlessness questionnaire […] doesn't report that my lungs are burning or that my body sometimes forgets to breathe. […Patients] felt very frustrated, particularly in the early days, that the questionnaire did not cover their cardiac symptoms. […] A lot of our patients are getting sort of IBS symptoms.

Participant A3 raised various points of difficulty about completing questionnaires (e.g., about interpreting particular questions). As the questionnaires had been chosen as validated and standardised questionnaires, we had not conducted this kind of testing on them. Indeed, the clinicians in the team would not have accepted non-validated questionnaires.

Most of the questionnaires were originally designed for other conditions and had been included because they were expected to be relevant for Long Covid in the early months of the project. Once included, clinicians in the team were reluctant to remove any as this would have limited our ability to track changes over time.

6.4.3.5 Symptom tracking.

The only participant who commented at length on the symptom tracker was B1, and this was linked with their desire to be able to track many symptoms together (section 6.4.3.3). The only other participant who discussed the symptom tracker (A5) wanted to share their symptom tracking with their clinic, rather than just using it for self-monitoring and reflection:

> A5: I put those [symptoms] in and then it started telling me about monitoring them myself and I thought, "What?" I've just spent all this time filling in this stupid section and it's of no relevance to anyone whatsoever and all it's doing is giving me an opportunity to just make myself feel better about it over time. […] I just thought it was a complete waste of my time.

Symptom tracking data was shared with clinics, but this patient clearly was not aware of that, illustrating that patients, and maybe clinics, were not always aware of how data might be used.

6.4.3.6 Messaging.

Messaging was a key function designed for communication between clinics and patients. All seven clinics that participated in interviews highlighted the value of messages as a means of communication.

At the time of their interviews, four of the 11 patient participants were unaware of the messaging function. A further participant (B1) was aware of the function but unsure where messages would go and, therefore, reluctant to send messages.

A6 had discovered the messaging function relatively recently and used it successfully:

> A6: it was two months ago I sort of like used it for the first time and then I used it again, […and clinicians are responding…] within maybe 24 hours as well so I think they are pretty good on there.

In contrast, A5 discovered, and introduced their clinical team to, the messaging function, but got little response from them:

> A5: I've sent messages and the person who I've been meeting […said…] she's never seen them […Eventually…] I have had a message from her through the app on something she was going to refer me to and she had to quickly tell me what the situation was with it. And she did message me through the app. But there's lots of messages that I sent them that, to be honest, haven't been answered.

Conversely, A11 reported long-term effective communication with their clinical team via LWCR:

> A11: I'd hate to think where I would be if I didn't have this app on my phone to speak about how I'm feeling. […] If I'm feeling really low, or if I'm feeling unwell, I literally just go on it and then I just have a quick chat. […] Yeah, so it might take them a day, a day and a half to get back to me, but they do get back to me, and it's comforting to know that somebody's there.

6.4.3.7 Goal setting and monitoring.

Another function of the LWCR app that the team considered important for behaviour change was goal setting and monitoring. Only A5 and A6 discussed the goals function of the LWCR app. Both had negative perceptions of it, regarding goal setting as unhelpful and an "obsession":

> A6: it was hard to think, you know, well what is my goal? My goal is basically to try and get my health back to how it was beforehand and the concentration and everything.
>
> A5: [There] is this obsession with goals. […] it's quite dispiriting when you're constantly being told to set yourself goals, in the sense that […] there's an assumption that that is going to be the thing to sort everything out.

6.4.4 Onboarding and finding common ground.

One theme identified through the interviews was the importance of clinicians and patients having common ground – i.e., both understanding what the other could see and do. For patients, this was particularly evident in their questioning about where data they submitted went and what was done with it. This should have been addressed through onboarding, but this clearly did not always happen. Also, clinician C4 had identified data they could see that was not available to patients at the time:

> C4: I love being able to see the graphs of people's scores going up and down. From what I gather from patients they can't see that and I don't know if that's true or not but I think a lot of people would really enjoy and benefit from seeing those movements of their numbers in the way that we do. [...] I look at it and talk about it but I hadn't quite realised that they didn't see it.

For clinicians, the lack of common ground was particularly evident in their awareness of what patients could see and do. Clinicians did not automatically have access to the patient-facing app and had little time to familiarise themselves with each upgrade. Some clinicians reported addressing this by requesting a fake patient identity so that they could experience the patient view of the LWCR app, e.g.:

> C1: The only thing that was frustrating is that as a clinician you can't see what the articles are so [...] we created me another patient, so that I can then go in on my phone and read what they are. And our clinical psychologist in particular was really, really stressed about what on earth you might be telling people because you weirdos in London could be writing all sorts of stuff. So once we got that down and I was able to screenshot her stuff and send it, she was really, really delighted.

A second theme was the importance of effective onboarding. Onboarding was both a clinical process, introducing patients to the clinical service and doing a first assessment, and a process of getting patients set up on the LWCR app:

> C4: it shouldn't be an admin person onboarding people onto the app, actually, it should be a clinical conversation that doesn't necessarily need to be a qualified member of staff but should be somebody that comes from the rehab team themselves.

Three perspectives on onboarding were discussed by different clinicians: technical (the process of getting access to the LWCR app), educational (ensuring that patients knew what was available in the LWCR app and how to use it) and motivational (encouraging people to use the LWCR app). Ismaila et al [36] discuss in more detail what constituted effective onboarding and engagement between clinics and patients.

Few patient participants had experienced any form of onboarding beyond being sent a link to the LWCR app; they almost all felt that they needed more training in how to use it effectively, with one suggesting having access to repeat training, to accommodate brain fog. Only one patient felt that the within-app introduction was adequate, though many of the participants had worked out how to use the LWCR app well.

6.5 Reviewing data from the data warehouse (Metabase)

As noted above, Living With set up a data warehouse for anonymised data gathered from the LWCR app, which was available from May 2021. The volume of data available was large and it proved difficult to interpret this data rapidly in any depth. During the project period, the main use of this data was to review what functions were being used and for how long.

We noted some unexpected behaviours, such as individuals who read the 92 library articles several hundred times (1531 times in one case), but these generally did not lead us to take any immediate action as we did not have contextual information to help with interpreting such data. The one exception was data on the use of programmes: as noted above, early data on programmes showed that some individuals were completing programmes in a single session of a couple of hours, which is unlikely to be clinically effective, so we implemented design changes as outlined above (section 5.3.4).

7 DISCUSSION

We have reported on the design and deployment of a novel healthcare service for managing Long Covid, focusing on the design and evaluation of the patient-facing app. Some of the issues raised by this study are specific to the situation we found ourselves in: designing a system for supported self-management for a condition that was not even recognised as such at the time the study started, and conducting research alongside service delivery. However, many of the issues are pertinent to other projects where HCI researchers are working in multidisciplinary teams to deliver novel health technologies that are intended for use in clinical practice at scale.

We revisit our key contributions in relation to existing literature, reflect on strengths and limitations of the study, highlight key points for other researchers and practitioners working on related projects and outline future work, for both LWCR and the research community.

7.1 Key contributions

The key contributions are organised by the five themes outlined above.

7.1.1 LWCR as an exemplar tool for clinically supported patient self-management.

The design of LWCR draws on prior work and theory so it is not unique in terms of the functions available for individuals to support self-management. Other systems such as SilverCloud [21] include functions similar to the programmes implemented in LWCR and others [1, 22] have highlighted the implementation of functions such as self-tracking, goals and information provision. We have made a minor contribution in adapting established methods to a new clinical context that addresses both physical and mental health issues for people managing an unusually complex set of symptoms related to a poorly understood condition. Our major contribution is in addressing **clinically supported** self-management.

Little prior work in HCI on self-management has discussed the integration of clinical support. One of the few exceptions is the work of Stawarz et al [73], who involved three clinicians in their study of the delivery of a mental health therapy over several weeks. They noted that the clinicians had to adapt their usual way of working to the technology, but do not discuss this in detail. Conversely, health services researchers (e.g., [30]) have studied complex interventions in healthcare but do not consider the design of any DHI involved. We believe our study on integration of clinical support across multiple clinics with self-management to be unique. No previous study has reported on working with 35 clinics, each with its own clinical pathway, involving 380 clinicians and delivering a DHI that is integrated with those diverse pathways. We outline the challenges we encountered in section 7.1.3.

In terms of app functions, we drew on prior literature on Behaviour Change Techniques (BCTs), as described in section 5.1.3. The functions of "education", "monitoring" and "feedback" were generally well received and extensively used. We partly relied on clinics to "enhance motivation", and patients' experiences of this were variable. Motivational considerations were built into the design of programmes but would ideally have been included more explicitly in introductory material too.

The BCT of "goal setting" was notable in that few people used this function and the feedback from patient interviews was generally negative. Existing literature (e.g., [3]) suggests that face-to-face interventions including goal setting can be effective for people managing fatigue, while Chevance et al [15] highlight the need to take a more nuanced approach to goal setting in DHIs. Li et al [45] report that their participants valued the goal-setting functionality in their app for managing multiple long-term conditions. There is a need for more focused research on how theory and BCTs can be implemented effectively for particular problems and situations.

7.1.2 Adapted methods for user-centred design and testing.

Most HCI methods involve data gathering with the intended users of a new technology [66]. As discussed above, a few researchers (e.g., [20, 83]) have explicitly discussed tailored strategies for working with people with debilitating health conditions, while others have worked with healthy surrogates (e.g., [10]) or with small numbers of users (e.g., [33]). Majid et al [47] discuss following PPI principles in their research design while recruiting participants through normal channels. In the LWCR study, we engaged with an unusually large number of PPI representatives, recruited via relevant channels, to inform the research design and to design and test information resources and engage in user testing. These PPI representatives were surrogates for the intended users. While engaging a small number of PPI representatives to inform design is a common practice in the UK, we believe this study to be unusual in the breadth and depth of PPI engagement. Beyond being sensitive to fatigue and brain fog, the patient interviews and the analysis of this data followed common practices in qualitative research in HCI.

We also adapted established methods to "put ourselves in the users' shoes" to gather data where it was neither practical nor ethical to involve users of the LWCR app. Medical students who had had in-depth conversations with patients in the early months of the Covid pandemic were particularly helpful in developing personas. While others (e.g., [41]) have reported using personas to help clinicians to better understand patients' needs, we are not aware of previous studies that have engaged clinicians to develop personas of patients. While interviews with patients (if that had been possible) or PPI representatives might have given greater detail, it would have been disproportionally resource-intensive for the team and added to the patients' burden. Thus, our approach to involving clinicians in the rapid development of personas at low cost is novel. We believe this was only effective because the clinicians had had in-depth conversations with patients about their experiences – in this case, of Covid.

LWCR is not designed for short-term use, but for an extended "journey" with the patient. While there are reports of longitudinal evaluations of various wellbeing technologies (e.g., [78]), those reports are generally of studies taking place over a month or less, for wellbeing apps, with a focus on broad user experience rather than usability or interaction experiences that would inform design. The "Doreen" study provided valuable insights into interaction experiences over time, even though it also has clear limitations. Autoethnography as an evaluation method is becoming more widely recognised and used in HCI, often in preparation for other methods such as diary studies (e.g., [43]). We are not aware of other studies where the purpose of an autoethnography was to evaluate an existing system to inform the next iteration of design in a situation where it was not feasible to involve real users in a longitudinal study.

The methods chosen were selected as being rapid, to fit within the development cycles of an agile process; low-cost, as we were working with limited resources; and ethically responsible, given that our users were all managing a new debilitating condition with limited NHS resources due to the ongoing pandemic.

As discussed in section 3.1, most digital health interventions for which there is a documented process in the HCI literature (e.g., SilverCloud, Monarca) were developed using user-centred design methods, with deployment only taking place after years of careful research. We believe that the application of an agile development methodology where research was being conducted in parallel with deployment and service delivery is novel in the development of digital health interventions. Such an approach would not be possible for systems where the risks outweighed the potential patient benefits, but where possible it enables developers to engage with, and design for, the realities of use in context as suggested by Hayes et al [33].

7.1.3 Designing for diverse clinics.

While prior work (e.g., [31]) has highlighted the issue that different clinics adopt DHIs in diverse ways, we are not aware of any prior studies that focus on designing for diverse clinics. The LWCR study reported here did not set out to focus on this either, but was forced to do so by circumstances, as Long Covid clinics were established and became our primary "customer" for LWCR. This is therefore a significant novel contribution of this project. We discuss implications for design and design practice in section 7.3.

7.1.4 Designing for diverse users.

Although we tried to design for diverse users, this remained a challenge throughout the project. The personas we developed represented diverse users; the writing team reviewed library articles rigorously with PPI to ensure they were comprehensible to people with low health literacy and with brain fog; and the various LWCR app functions were intended to accommodate the needs of individuals with different clinical needs and symptoms. However, individuals who did not receive strong guidance from their clinics found themselves feeling overwhelmed by the available options.

Cooper's [17] recommendation to focus functionality on particular user needs does not readily apply to the design of technology for managing a complex health condition. The developers of ProACT [22] take a similar approach to ours in terms of providing a range of functions to accommodate diverse symptoms, but they do not explicitly discuss designing for diverse users; furthermore, the participants in their study were self-selecting volunteers whereas the users of the LWCR app were patients selected by their clinicians.

One aspect of diversity that was evident in our study but has not been discussed explicitly by others is health literacy: in aiming for inclusivity, the LWCR app was reported to be less useful than hoped for people with high health literacy, notably HCPs. This relates specifically to the design of the information resources, rather than other app functions or interaction design. Another aspect highlighted by one patient was stage of recovery; while others have discussed the importance of understanding the patient journey (e.g., [12], [85]), we are not aware of any studies that have designed specifically to support the patient journey over extended time periods.

This study has raised important issues about designing for diversity in healthcare interventions that we summarise below (section 7.3.7).

7.1.5 Multidisciplinary working.

As others (e.g., [4,79]) have noted, a project such as this would not be possible without multidisciplinary working. Developing a tool to support management of a complex condition like Long Covid requires a multi-disciplinary team of a scale that is rare in HCI projects.

The LWCR project was led by clinicians and their perspectives dominated. Although HCI and behavioural science were included from the outset, they were treated as "nice to have" rather than essential, though they were influential in the design. Because the project was focusing on service delivery as well as research, there were times when all roles focused more on service than research – not just HCI, as suggested by Agapie et al [2]. Also, we did not experience the differences in language that some others report (e.g., [79]), probably because most team members had prior experience of working across disciplinary boundaries.

The LWCR app served as a central boundary object, with different team members focusing on different aspects of it while all accepting the app as the key means of supporting patients managing Long Covid. From a software developer perspective, it instantiated decisions about functions to be used by patients; from a PPI perspective, it encapsulated clinically validated information for consumption by patients and other tools (e.g., diaries, symptom tracker) that would be valuable to patients in self-management; from a clinical perspective, it was a tool to gather patient information to both support patient care and gather research data to better understand Long Covid; from an HCI perspective it provoked questions about how patients would use and experience it; and from a behavioural science perspective the primary question was how it would or could support behaviour change.

In principle, the care pathway should also have served as a boundary object; in practice, as a team, we did not achieve sufficient clarity on "stage 6" of the pathway (section 6.3) for it to serve this role.

Two differences were identified that have not been discussed in prior literature. One was the status of patient questionnaires (PROMs): it mattered to clinicians (and to national health policy makers) that patients would complete these at defined intervals and that the set of questionnaires would remain consistent to support research into patients' experiences of Long Covid. HCI professionals would have preferred to make it easier for patients to focus on the questionnaires that mattered most to them individually, to reduce the burden on patients and improve their user experience. A second was expectations of clinics: clinicians in the team tended to focus on the role of clinics in caring for patients whereas HCI professionals focused more on the role of the LWCR app in supporting self-management. These differences in perspectives merit further research to manage interdisciplinary differences in future projects.

7.2 Strengths and limitations of the study

This was not a classic HCI digital health study with a well-defined problem, engaged participants, strong user representation and clear evaluation questions. The study is better characterised as complex, evolving and improvised. While we believe that this is a strength of the project, given the circumstances of designing for an unknown disease with no established clinical pathway, it resulted in limitations from an HCI research perspective. For example, we engaged with fewer "real users" than planned. Our contribution is not a single analysis of carefully collected data, but multiple complementary analyses of a large body of data gathered over the course of a project that aimed to achieve both research and service delivery needs on a tight timescale. Nevertheless, our systematic approach to gathering project data from the outset has enabled us to provide a detailed account of the design, development, evaluation and deployment of LWCR that is unusual in the HCI literature. Further, we have triangulated findings from different sub-studies; for example, we could compare the perspectives of clinicians and patients through interviews and relate the findings from "being Doreen" with feedback from PPI representatives and interviews.

In this section, we reflect on the strengths and limitations of this study, including what worked well and where we would have done things differently if we had our time again.

7.2.1 Resourcing.

The project was under-resourced, particularly in terms of dedicated staff: there was only one full-time researcher funded to work on user needs, evaluation and implementation into clinical practice. Nearly all team members, including PPI, were juggling their work on this project with many other demands on their time (clinical, academic, health- and life-management, etc.). There were two main reasons for this: we anticipated that funders and reviewers would have limited understanding of what is required for such a project, so we were conservative in the resources requested; and, at the time of applying for funding, the scale of the challenge was not obvious. We initially anticipated having fewer than 1000 patients and fewer than ten clinics over two years. We neither planned nor requested resources for the number of clinics and patients who made use of the service within the project period.

Without spare capacity to apply for additional funding, the project remained under-resourced. This affected our ability to gather or analyse user data; to address all the identified needs in a timely way; and to work effectively with diverse clinics. Conversely, strengths of the project included the commitment of the entire team to having a positive impact on patients' experiences; the opportunity to adapt methods to the needs of an evolving situation; and engagement with many more clinics and patients than envisaged.

7.2.2 An agile process.

This situation violated many of the assumptions behind a classic user-centred design (UCD) process, such as there being an understood problem and a known population of users. It is hard to imagine how a traditional UCD process (section 3.2) could have been followed in this situation without many false starts. An agile process enabled us to respond rapidly to changing contexts in terms of both the understanding of Long Covid and the care pathways LWCR needed to align with. It also enabled us to achieve rapid impact at scale. However, the various user studies and interviews highlighted areas of the design, such as complexity that can result in people feeling overwhelmed, that were difficult to change without starting again. Also, we faced many of the documented challenges of integrating UCD with agile development. For example, it took several months to resolve some usability issues after they had been reported.

7.2.3 The design of the LWCR app and integration with clinics.

The LWCR app has both strengths and limitations.

In terms of functions, information provided in the library was generally well received; it was validated, updated, comprehensible and relevant to those managing Long Covid. The main criticism of it was that it was too basic for those with high health literacy.

Programmes provided a structured way for people to engage with the LWCR app and usage logs suggest that they have been well received. We have not had capacity to evaluate their clinical effectiveness.

The PROM questionnaires were generally accepted as a necessary part of care, but some people expressed frustration that they did not enable people to articulate the lived experience of Long Covid well. The symptom tracker that was introduced in response to this concern was well used by a subset of patients. Similarly, diaries were welcomed by some but others found them onerous and yet others wanted a more sophisticated diary that would allow them to track more contextual factors and their impact on health outcomes. More work is needed to make these various tracking features valuable to a broader user population, as well as to their clinics.

The biggest criticisms (and concern for the research team) were that the variety of functions made available through the LWCR app made it feel overwhelming for some, and that there were sometimes mixed messages regarding the roles of the app and the clinical service.

It was sometimes difficult to balance the requirements of HCPs (what data they wanted to receive from patients) with the desires of patients (e.g., to be able to report what mattered most to them). A message that came through strongly from patients and PPI was the desire to be treated as individuals, to have meaningful engagement with their HCPs, and not to be "fobbed off" with an app. This is in line with our decision to focus on clinically supported self-management rather than independent app use.

Given the variability in people's recovery times, it would have been helpful to actively teach people about self-management and to measure people's abilities and confidence in self-managing. Since we did not anticipate patients having to self-manage in the long term when the project started, we did not include a questionnaire on self-management (e.g., the Partners in Health scale, [6]). This was an opportunity missed and would be important to consider in any future project of this kind.

One requirement that was highlighted by a few interviewees and PPI was representing the "lived experience" of Long Covid. This might be through patients' recorded stories or a forum. At the time this was raised, there were other online resources that addressed this requirement, albeit disconnected from LWCR, and we chose not to divert our limited resources to this. However, this is potentially a valuable area to address in the future.

In summary, while we are aware of areas where the LWCR app could be, and is being, improved, it was generally well received, was welcomed by many clinicians who were tasked with providing support for people managing Long Covid, and had a positive impact on the lives of many people struggling with Long Covid.

7.2.4 Adapting for different clinics.

The LWCR steering committee involved clinicians from three hospitals who were managing Covid patients following discharge from hospital. Although each hospital managed patients differently post-discharge, they worked together to agree requirements for LWCR. As the situation changed (with Long Covid being recognised and Long Covid clinics being set up), some of the hospital staff took on roles at the clinics and other staff at "early adopter" clinics got involved in the project in a form of co-design [69] of new functions – notably the Fatigue Activity Diary, some programmes and new library content. As more clinics joined the programme, each with their own ideas, resources and priorities, the pool of healthcare professionals highlighting different requirements grew – sometimes helpfully, sometimes distractingly. For example, as noted in section 6.4.3.4, clinics with psychology support wanted patients to complete the PHQ9 questionnaire rather than PHQ8. This meant that development time had to be dedicated to making such configurations possible to support different clinic requirements. This distracted from other priorities such as dealing with known usability issues.

Early clinics had more input into the design of LWCR than later clinics did, so it typically fitted their requirements better. As described above (section 6.4.2), some clinics designed their Long Covid services around LWCR whereas others treated it as an optional add-on. If we had anticipated the level of uptake of LWCR, we would have involved more clinics early on to design a product that met diverse clinics' needs as well as patient needs better. In addition, we should have provided more directive guidance to clinics on how to exploit LWCR effectively, particularly on how to onboard patients onto the app and how to engage with patients through LWCR. If we had had more resources we would have developed more comprehensive training materials so that when new staff joined a clinic they could get up-to-speed rapidly.

We found that some patients had high enough digital literacy to benefit from the app with minimal support from their clinic; conversely, there were patients (e.g., those with very complex needs and some with low digital literacy) for whom no DHI would be helpful; there were, however, also many patients who would have benefitted from greater support in using a DHI, and better integration of such an intervention into their care pathway. These groups are summarised, in a simplified way, in Table 3.

Table 3: Simplified summary of alignment between clinics and patients.

		Clinic	
		Integrating DHI with care	**Marginalising DHI**
Patient	**High autonomy and competence**	Effective use and satisfied users	Competent but frustrated users
	Low autonomy or competence	Effective use and satisfied users	Unable to use effectively
	Not suited to use DHI	Reliant on clinical service only	Reliant on clinical service only

The study is based in England and Wales, so the model of healthcare delivery may not readily translate to other countries. Nevertheless, the general principle that care is delivered in subtly different ways by different providers is probably universal, so the issues we have highlighted about accommodating different care pathways are likely to translate internationally.

We are not aware of any previous projects that have designed for supported self-management involving a large number of care providers with different requirements.

7.2.5 Scenarios.

With the wisdom of hindsight, the scenarios we developed were naïve in terms of their understanding of Long Covid. However, while the personas continued to be referenced throughout the project, the scenarios served only a short term role in getting started and were then implicitly embodied in the app.

We did not implement all functions outlined in the early scenarios; for example, Brenda wanted to manage her diet better, and the scenario included suggested recipes and a function to generate a shopping list from that. This was never implemented because the LWCR app became function-heavy, such that users risked feeling overwhelmed by it, and our priority became to streamline functions rather than adding more.

Some functions from the scenario proved too difficult to implement – most notably, seamless integration with hospital and clinic care records. Others were under-ambitious: the programmes that were subsequently developed (section 5.3.4) provided a more structured user experience than was anticipated at the time scenarios were developed.

It would almost certainly have been helpful to update and extend the scenarios to reflect our changing understanding and to provoke earlier discussion about the details of LWCR fitting the clinical pathway (section 6.3).

7.2.6 Involving and representing users.

Every HCI sub-study had limitations (fewer users than planned, diverse in their outlooks, later in the project than we would have liked, etc.). Personas were based on information from hospital HCPs in London and may not be representative of experiences in other regions. Although we tried to be inclusive in our recruitment, our participants were not fully representative of the target users (e.g., few people for whom English is not their first language). On the other hand, the need to conduct meetings remotely meant that it was easier to involve researchers, practitioners and PPI who were geographically distributed; also, the clinics subscribing to the service, and hence the patients using it, are geographically distributed across England and Wales.

It would have been beneficial to conduct patient interviews earlier in the development process. To do this, we would have needed to get ethical clearance and data sharing agreements in place earlier. With greater resources, we would have explored alternative ways of recruiting and compensating patients to gather perspectives from a more diverse range of users.

Personas to represent users for design were a powerful tool. Although our core personas (section 5.1.2) were diverse, they were not as diverse as real users (or PPI) were found to be. With greater resources, we would have embellished the existing personas with more details about motivations, coping styles and literacies, and developed a small number of additional personas, based on empirical findings, to support the team in designing to support diverse users better.

DHIs have the potential to widen health inequalities, due to differential access to devices and data, and different levels of skills, motivation and trust among potential users. We aimed to mitigate the digital divide [40] at the design stage through the use of personas representing a broad population of potential users (section 5.1.2), public and patient involvement (section 4.1), providing video content where possible, reviewing all articles with PPI, and iterative user testing. LWCR was implemented on basic smartphones to make it accessible to people who did not have access to computers or more sophisticated smartphone functions.

In summary, while we would ideally have worked more with diverse LWCR users earlier in the project, there were various barriers to doing so and PPI made substantial contributions to partly plug the gap.

7.2.7 Mixing research and service delivery.

The disparate aims of research and service delivery were often at odds with each other: service delivery needed to be rapid and as safe and clinically effective as possible, whereas research needs would have been better addressed through a slower, more deliberative and rigorous process. Yet the main insights in this study have come from addressing the realities of delivering a product (LWCR) that was as usable, engaging, useful and effective as possible into clinical practice under challenging circumstances. Conversely, the fact that there was urgent clinical demand for LWCR made the path to deployment smoother than it might be for other clinical conditions.

7.2.8 *Impact on practice.*

A commercial partner (Living With) was a core part of the team and committed to the project from the outset. This was essential for delivering a product and service at scale and remains essential for ensuring that the LWCR product is sustainable and has impact beyond the lifetime of the project. Such models of collaboration are rare and do not fit neatly into the remit of any UK funder, being neither pure research nor service delivery. If user-centred digital health projects are to move beyond the pilot stage in a timely way, there is a need to rethink funding models and to be much bolder than we were in articulating the different ambitions of such a project.

A strength of this study is that, compared with most studies reported in the HCI literature on health technologies (with the exception of long-term projects such as those described in section 3.1), the LWCR project has had greater demonstrable impact on patients' supported self-management. Of the 7239 patients who were invited to use LWCR within the project period, 5684 registered (78.4% of those invited) and over 4600 patients read library articles, completed PROMs questionnaires and used other functions of LWCR. In other words: over 50% of the patients invited to participate in the LWCR project used it in a substantive way even though they were not self-selecting (as is the case for many studies of DHIs).

7.2.9 *Team working.*

The core development team involved HCI specialists, clinicians, PPI representatives and representatives from Living With. They had weekly meetings online throughout the project, and rapidly learned to work well together. Steering committee meetings took place every 4-6 weeks. This allowed us to be flexible and make decisions quickly with input from the whole team. This, in turn, allowed us to design at speed and maintain high quality. The multidisciplinary team had most of the necessary skills. We would have benefited from more expertise in data regulation and data analytics from the outset; these were added once we recognised the need.

The input, and active engagement, of clinicians was essential to the success of this project. Clinicians with different skills (particularly respiratory, physiotherapy and mental health) contributed substantively throughout the project. Their experience in early clinics was rapidly translated into design outcomes in the product, exploiting the agile development process that was led by Living With.

7.3 Implications for design and design processes

In this section we draw out guidance for researchers and practitioners developing digital interventions for clinically supported self-management, based on our experiences as reported above. The guidance is summarised in Table 4 and discussed in the following sub-sections.

Table 4: Guidance for researchers and practitioners developing and deploying DHIs for clinically supported self-management

Area	Guidance
Planning for long term impact	Design for deployment into clinical practice
	Design for research as well as service delivery
	Ensure sustainability
	Plan training for clinicians
Designing for clinicians and patients	Ensure clinicians and patients have adequate common ground
	Onboard patients effectively
	Design for individual differences
	Design for self-management
	Balance economies of scale with local factors
HCI methods	Select and adapt UCD methods
	Involve patient representatives
	Use personas and scenarios effectively
Valuing expertise	Integrate different kinds of expertise

7.3.1 *Design for deployment into clinical practice.*

If a product is to be deployed at scale it is important to plan for scaling up from the outset. Articulate your development process as far as possible but be prepared to adapt as you learn about the problem, contexts and users for which you are designing. Plan for iterations and improvements over time.

Aim to deploy as early as possible with real users in clinical care and plan care pathways as early and clearly as possible but be prepared to adapt to new clinical settings. Care pathways include both the broad process of patient management and the details of how both clinicians and patients are expected to use the digital intervention.

Be aware of, and comply with, all relevant regulations and standards regarding safety, data management, ethics and patient confidentiality. The details of these are out of scope for this paper.

1.1.17.3.2Design for research as well as service delivery.

Advances in healthcare rely on learning from past experiences. Pseudonymised or anonymised health data has great value for learning about both clinical conditions and effective patient management. This is described by Blandford [8] in terms of a health data lifecycle, in which identifiable health data is used within care pathways involving health professionals and patients while pseudonymised data is aggregated and analysed to generate new knowledge at a population level about health conditions and the impacts of different interventions on health and wellbeing.

In planning data management, consider how data might be used for both research and service delivery while maintaining patient confidentiality and obtaining informed consent from patients for any research uses of data.

From a patient perspective, this dual purpose can be obscure; make it very clear to patients (as well as clinicians) how data is managed for both individualised care and research.

7.3.3 Ensure sustainability.

There are many aspects to ensuring sustainability of any digital health intervention – for example, ensuring there is a market that supports financial viability [86] and that there is capacity to maintain software as systems evolve. Of particular note in the LWCR project was the need to review and update library content regularly. Understanding of Long Covid was changing unusually rapidly; for any DHI, it is important to ensure that information is reliable and reflects current thinking on condition management.

7.3.4 Plan training for clinicians.

Supported self-management tools expect clinicians to provide meaningful support, which requires them to know what the patient has access to. Plan clinician training from the outset. It is not sufficient to provide training for a clinic (or other care provider) just once or to assume that new staff will learn from existing colleagues, particularly where there is high staff turnover.

Consider developing a package to train every new HCP who joins any clinic on how to get the most out of a DHI and how to support their patients in using it. This includes providing clearer guidance about onboarding patients, and guiding patients on prioritising their interactions with the DHI. Also make it easy for those HCPs who want to review a patient-facing app to access it directly, including all app updates.

7.3.5 Ensure clinicians and patients have adequate common ground.

As well as clinicians being aware of what information is made available to patients (or their representatives), patients need to be aware of what information is available to their clinical team and what the team will do with that data. Doing this effectively requires clarification between clinicians and intervention developers. Stawarz et al [73] note that the clinicians in their study had to adapt their ways of working to conform to the design of the intervention. In the case or LWCR, it might have been better to allow clinics to configure the intervention to clearly inform patients on what to expect when using the LWCR app – e.g., that messages would be responded to within a certain number of days, that questionnaire data would be reviewed prior to the first clinical consultation and then at particular points until discharge, that diary data is reviewed before the second consultation but is subsequently for the individual to reflect on, or similar. In our limited experience, it is unlikely that all clinics would agree to work in the same way with a DHI, so consider adaptability in design and deployment.

7.3.6 Onboard patients effectively.

A key aspect of getting patients engaged with a DHI is how they are onboarded. As noted in section 6.4.4, onboarding is both a clinical process (assessing patients' care needs) and a process of enabling and encouraging patients to use the DHI. There are at least four aspects to this: enabling people to access the DHI technically, helping them understand how to use it effectively, giving people reasons to use it (motivating them) and setting expectations on how their app use will support their care. Address all these aspects – either by their clinical team or through the DHI.

7.3.7 Design for individual differences.

Patients are diverse: not just in their backgrounds, health beliefs, coping strategies, etc. but also in their health experiences and illness stage. Achieving a balance between providing different functions to address different needs while avoiding a DHI becoming overwhelming can be challenging.

Ideally, it would be possible to tailor each DHI instantiation to the needs of a particular user and clinical team, and to make the app adaptive to an individual user's evolving needs. Where this is not possible, consider how people will be guided to access the features that are most relevant to them. This might be through features of the DHI[5] or through guidance to clinicians on how to support and direct their patients.

Not all patients are suited to use a DHI, for various reasons, but effective use relies on both good interaction design and effective integration with the care service.

7.3.8 Design for self-management.

Self-management is a transferrable skill that is rarely taught explicitly [9]. Some of the patients interviewed in this study highlighted the value of having learned to self-manage (e.g., through earlier illness experiences). Although we did not include specific education in self-management in LWCR, we believe that DHIs would benefit from doing so – probably woven through the intervention rather than as a separate unit.

7.3.9 Balance economies of scale with local factors.

One of the purported benefits of DHIs is that they provide economies of scale. However, they can only do this if the same DHI can be deployed across multiple healthcare settings with minimal adaptation. This can be challenging in practice as care providers have typically evolved different practices based on local factors.

For a project where early potential care providers are already known, it is important to understand their existing practices and requirements, and identify both the common requirements and those areas where adaptation is needed across providers. Apply good UCD practices for patients, clinicians and clinical services.

7.3.10 Select and adapt UCD methods.

Digital health interventions designed for long-term and evolving use pose challenges in evaluation: if they are for use by people with debilitating conditions, it is important to be sensitive to people's capabilities and mindful of risks from over-exertion, as discussed by Davies et al [20]. This might involve working with surrogate users such as PPI representatives or taking clinical advice on how to work with representatives of the user population.

Most digital health interventions are designed to be used over an extended period of time, and it is important to evaluate use over time. Longitudinal methods such as diary studies can be insightful but may impose a disproportionate burden on people who are managing a long-term and debilitating condition. Adaptations such as the autoethnography described above (section 6.2) can deliver valuable insights while avoiding burden on the intended users but also work with users, to understand their needs and capabilities. For this, short interviews and observations can be highly informative.

7.3.11 Involve patient representatives.

Patient representatives such as PPI can provide invaluable insights but, like patients, they are diverse in their abilities and priorities. Indeed, this diversity is a strength; for example, in our study, some PPI members did not have access to smart phones, forcing us to accommodate their involvement in ways that were not reliant on personal ownership of such a phone. On the one hand, this means that it is important to involve a range of representatives; on the other hand, involving many representatives can result in each individual feeling that their voice is not heard. It requires commitment, and the investment of significant project resources, to maintain engagement with a good pool of patient representatives and ensure that they feel valued.

7.3.12 Use personas and scenarios effectively.

Personas and scenarios can be very useful for keeping in mind the needs of people who are very different from the design team. As far as possible, personas should be evidence-based. Ideally, this will include interviews with

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[5] Subject to complying with the relevant medical device regulations – a topic that is beyond the scope of this paper.

representative users (e.g. [20]), but other sources of information can also be used. We found the input of medical staff who had close contact with patients to be invaluable, but other sources might include family members or close friends. It is important to include consideration of other health conditions (co-morbidities), digital literacy, health literacy, physical and cognitive capabilities, lifestyle, values and expectations. Specifics might vary depending on the purpose of the DHI.

It is good practice to develop scenarios with different focuses – e.g., on how an individual might use a digital intervention and on how they might fit usage into their lives. One set of scenarios we overlooked, but would have been helpful, is how an intervention for supported self-management fits in the clinical pathway, how clinicians and patients are expected to communicate, both via the intervention and through other channels, and staff attitudes towards digital (including their capacity and baseline knowledge/experience).

7.3.13 Integrate different kinds of expertise.

Different kinds of expertise are needed to design effective and engaging DHIs. Determine how the different kinds of expertise – in clinical requirements, technology, data management, user experience, behaviour change, regulatory requirements, care delivery, etc. – will be sourced and integrated in an efficient and effective way. Also recognise and accommodate disciplinary differences in practices, language, values, etc. (e.g., [7]).

7.4 Future work

This project has highlighted many areas for future work, some linked directly with LWCR and others more general, relating to the design of patient-facing apps for clinician-supported self-management. In this section, we summarise ongoing work to ensure the sustainability of LWCR beyond the research reported here and propose a future research agenda for clinically supported self-management at scale.

7.4.1 Long-term sustainability of LWCR.

Beyond the period of this project, the intervention has become a commercial offering, for which a funding model is being developed to ensure sustainability of the intervention, drawing on the lessons learned from the research phase of the project.

The product has also been developed further, including: a carer module (based on both the “Zara” persona and HCPs’ experiences); a version of the app for self-management without direct clinical support; an assessment-only version that changes into the full product after the patient has been assessed; and three further programmes developed (on pain management, speech and language therapy, and pulmonary rehabilitation). Further changes are still planned, including availability in languages other than English, tailored towards particular ethnic groups, and more specialised versions of the app tailored to patients with particular sets of symptoms.

LWCR would ideally be integrated with hospital and GP electronic health records (EHRs), but data integration across health service providers has been a matter of concern and research for decades without any satisfactory resolution to date [8].

In terms of research, anonymised app data is a useful resource for better understanding Long Covid and patients’ healthcare needs in the longer term. An ongoing project involving LWCR is studying areas for improvement in care delivery.

7.4.2 A future research agenda for clinically supported patient self-management with DHIs.

Many of the limitations discussed in section 7.2 highlight areas for future research. These can be collectively summarised as understanding and adapting to diverse patients’ needs and integrating the app into clinical service delivery in a way that works smoothly and effectively for HCPs and as many patients as possible.

If supported self-management facilitated by DHIs is to become a widespread model of care, HCI researchers need to work with health services researchers to better understand how to design both patient-facing apps and clinical services (e.g., supported by dashboards) that achieve a suitable balance between clinician and patient autonomy and standardised care delivery to achieve economies of scale.

Although patients are not defined by their health conditions, those conditions often affect their capabilities. Future work should aim to better understand individuals’ different behaviours, kinds of engagement and clinical outcomes, and causal relationships between these; also on what individual attributes shape people’s interactions and engagement with DHIs and how to design to support diverse users.

Further research is also needed on better addressing digital inequalities. Whereas the designers of business technologies can assume a minimum level of digital literacy and the availability of support and training for users within an organisation and the designers of entertainment technologies have limited moral obligation to be inclusive, the designers of patient-facing health technologies should be aiming to make their products as accessible and usable as possible, so as not to exacerbate the "digital divide". Future research should aim to better understand digital exclusion and strategies for minimising it.

Another area of future research is how to measure engagement and clinical effectiveness. As summarised by Perski et al [61], there are many possible ways of measuring engagement with a digital behavioural change intervention, but none is obviously the ideal measure. Similarly, in terms of clinical effectiveness, there are many possible measures based on clinical questionnaires (PROMs), reported symptoms, or other considerations such as ability to self-manage [6].

In terms of design being informed by theory: our approach was informed by the literature on behaviour change techniques. Most of these translated well into the design of LWCR, but a question hangs over goal setting and monitoring. There is a need for further research on how goal management can be implemented effectively in DHIs.

User-centred digital health projects more generally need to review how best to engage users in the process of design, evaluation and deployment, particularly when those users are managing a debilitating health condition.

8 CONCLUSIONS

Small-scale, focused studies are essential to give depth of insight across a range of health conditions and interaction styles. However, if HCI researchers only ever conduct such studies, following "textbook" methods, we are unlikely to move beyond user requirements, theory development and pilot studies. Those are necessary but not sufficient to make a meaningful clinical impact.

In this paper we have reported on a ground-breaking project that created a new digital health intervention from a minimum viable product through to large scale impact in two years for a poorly understood and complex new clinical condition. This was achieved by conducting research across multiple academic and non-academic disciplines alongside rapidly expanding service delivery. This approach worked due to shared goals and boundary objects, mutual respect and a willingness to learn from each other, so that collectively we have made advances that none of us could have achieved alone. Throughout the project our understanding of what we were doing evolved significantly and we adapted traditional HCI methods to fit the situation we found ourselves in. We worked at speed and scale to better support patients and HCPs. Rigour was achieved through triangulating across methods and through iterative cycles involving different forms of evaluation with clinicians, surrogate patients, and patients.

The project has highlighted that patients are not defined by their clinical condition, and that it is essential that design accommodates diverse patient users. It has also highlighted that DHIs that enable clinician-supported self-management need to not only ensure common ground between HCPs and patients but consider the clinical context such as onboarding protocols and the clinical pathway.

The project presented here has limitations, including those described above, but it also illustrates an approach that is making a real difference to clinical practice, leading to substantive impact at scale.

ACKNOWLEDGEMENTS

First and foremost, this paper is dedicated to Professor Elizabeth Murray. Elizabeth was the driving force behind this project. Her vision, energy and commitment were second to none. She approved the inclusion of the email extract quoted in section 2 before her untimely death on 7th April 2023. The team miss her enormously.

We are indebted to all the PPI representatives who contributed to the project in diverse ways and to LWCR users (patients and HCPs) who agreed to be interviewed. Also to the many HCPs who provided material and ideas, including the team at KCL who drafted the fatigue programme and the medical students (Camila Nagoda Niklewicz and James Robertson) whose early input informed the user personas. Clare Casson (project administrator) kept us all on track. Hadiza Ismaila provided excellent feedback on an early draft of this paper and Helena Mentis and anonymous reviewers gave really useful guidance on how to improve the submission

– particularly making it less messy and more useful! The Living With staff who developed LWCR supported our research efforts even as they were rushing to deliver the next release.

Funding statement: This study is funded by the National Institute for Health and Care Research (NIHR) Cross-programme [HS&DR] Covid-19 [project reference NIHR132243]. The views expressed are those of the authors and not necessarily those of the NIHR or the Department of Health and Social Care. This report is independent research supported by the NIHR ARC North Thames, NIHR ARC Wessex and NIHR ARC West.

Access to data: To request access to the underlying research data, please contact Prof Fiona Stevenson f.stevenson@ucl.ac.uk

9 AUTHOR CONTRIBUTIONS STATEMENT

AB led the HCI workstream and the writing of this paper. KB led on behaviour change and co-led the health inequalities and digital divide workstream with FH. EC led on data analytics. JB led on the authoring of library articles and coordinated the team of PPI representatives. BC authored library articles. SE helped coordinate PPI focus groups. JRH, HH, MH, PP and WR provided timely input from their clinical perspectives. SL led the work on stress and anxiety. CR led the Living With team and negotiations with participating clinics. DS interviewed patients. HG led the development work, interviewed clinicians, and co-led the overall project. AB, JB, KB, BC, EC, SL, CR, DS and HG met weekly to advance the development and evaluation work. All authors participated in the project steering committee and contributed to the writing of this paper.

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APPENDIX 1 TABULATED RELEASE DATES

Release date	App / platform version	Key features of release (N.B. these are for Covid Recovery specific features)
August 2020	Platform v.9.0.0	• Implement Enrolment invitation reminder email • Implement Enrolment invitation expiry reminder email • Allow for assignment to Clinician when inviting a Patient • New dashboard layout • Allow for an Individual patient view with an overview of the latest interventions • Review results from the implementation of all questionnaires included in the app such as FACIT-Fatigue or GAD-7 questionnaires • View results from the Daily Physical Activity assessment • View results from Covid Recovery outcome measure • Add reading list for Covid Recovery package • Content: Put Covid Recovery content live
August 2020	App v.9.02 & 9.03	• Implemented welcome cards and also all tasks complete cards for the today screen • Implemented Today cards to track assessments and other scheduled data • Today’s assessments • Today’s medication • Today’s weight • Today’s active diaries • Today’s messages • Implemented app introduction on first use • Patient discharge message now placed on today's screen • Implemented questionnaires • MRC Dyspnoea questionnaire • Dyspnoea-12 (D-12) questionnaire • FACIT-Fatigue questionnaire • GAD-7 questionnaire • Implemented Daily Physical Activity assessment • Implemented Covid Recovery questionnaire (assessment) • Edited weight screen to allow Kg and grams to be separated • Reminder to the patient about the non-monitoring message by the clinic before sending a message implemented • Confirm all text/background colour combos conform to WCAG 2.0 AA or better • Content: D-12 wording changes
October 2020	App v.9.1.0 & 9.1.1	• Implemented entering weight in imperial units • Today's goals and tasks added • Implemented PHQ-9 questionnaire (assessment) • Implemented Access a file shared by a clinician through the app • Implemented notification troubleshooter • Content: Add explanatory text to Goals screen
December 2020	Platform v.10.0.0	• View a Patient list by latest interventions (activities) • Monitor my patient’s symptoms • Patient files uploaded and sent through the message function on the app are scanned for viruses • Implemented CBT diary monitoring • Monitor a patient's 7-column thought diary • Add EQ-5D-5L to Covid Recovery

		• View results from PHQ-8 outcome measure • Made PHQ-8 and Symptom tracking available in COVID product
December 2020	App v.10.0.0	• Implemented Add appointment to calendar functionality in messaging • Implemented Track a custom symptom • View historic custom symptom trackers • Implemented Link from questionnaire result to article • Implemented PHQ-8 questionnaire (assessment) • Content: • Inconsistent diaries terminology edit/amend • Update descriptions of PHQ-8 and PHQ-9
February 2021	Platform v.10.2.0	• Implement view results from PDQ-5 outcome measure • Implement graph for: • GAD-7 assessment • PHQ-8 assessments • PHQ-9 assessments • Implement export patient data functionality • Implement view results from WSAS outcome measure • Implement view patient's predicted outcomes • Implement export covid recovery patient data
February 2021	App v.10.1	• Implemented PDQ-5 questionnaire (assessment) • Make it clear diaries must be finished to be shared • Implemented WSAS questionnaire (assessment) • Make it clear fatigue diary is always saved • Implemented a way to record demographic information
April 2021	Platform v.10.3.0	• View patient demographic information • Make demographic questionnaire available • View service use information • Sort patients by FACIT-Fatigue • Covid Clinic Consent Agreement (opt-in consent) • Add symptom tracker to products • Implement Password protection for patient export file • Implement graph for FACIT-Fatigue assessment • Demographics - View detailed ethnicity
April 2021	App v.11.0.0	• Implement program feature • Allow for a way to manage a condition using a mixture of reading and questionnaires • Complete a programme reading task • View programme task as a today card • Link to a programme from article • Today card notification for assessments that should be completed on first use • Implemented Record service use • Demographics - Ask about detailed ethnicity • Implemented Anxiety Programme • Content: Update intro text for Daily Physical Activity assessment
May 2021	Platform v.10.4.0	Datawarehouse implementation covers: • Patient data • Clinician data • Clinic data • Patient demographics data • Assessment data • Simple diary data

		• Weight data Content: • Update Covid Content
October 2021	Platform v.11.0.0	• Reinstate discharged patient • Review a patient's Fatigue Activity Diary • patient status data is now in the data warehouse • Patient behaviour data is now in the data warehouse Content: • Covid Reading List Update
October 2021	App v.12.0.2	• Display reinstated status to the patient after readmission • Prompt to set up a schedule on assessment completion • Intro Programme for Covid Recovery • Included Clinic info and profile information in the app • Implemented Fatigue programme for Covid recovery • Implemented Breathlessness programme for Covid Recovery • Implemented Mindfulness programme for Covid Recovery • Implemented Brain fog programme for Covid Recovery • Implemented Sleep programme for Covid Recovery • Implemented Fatigue Activity Diary Content: • Add missing description for Mindfulness & Assessment programmes
November 2021	Platform v.11.1.0	• Message data is now in the data warehouse • Add registration date to the clinician's list on Clinic Management • Made patient invite process easier • Re-invite from patient overview • Add graphs to all applicable assessments Content: • Covid Reading List Update
December 2021	Platform v.12.0.0	• View patient's programme progress • See the latest programme progress on the patient list • Add or change NHS Number • Clinician can now pick programme product option for individual patients
January 2022	App v.14.0.2	• The app can now share programme progress with the clinic • Patient names are now included in diary PDFs
April 2022	Platform v.13.0.0	• Additional patient details, as well as SMS data, are available in the data warehouse • View 3 month adherence on the patient list • Symptom tracker data now available in the data warehouse • Add D-12 to the patient outcomes list • Provide patient exercise records online • Covid assessment programme now can use PHQ-9 • Add PHQ-9 to Covid Recovery product as an option
April 2022	App v.15.0.1 and 15.0.2	• COVID assessment programme can now use the PHQ-9 assessment • The app now reminds patients to do diary entries if scheduled • The app now presents information from answering PHQ-9 assessment questions • App stops reminding users if a single programme task has been completed that day • Programmes now mentioned on all done today card • Updated PHQ-9 warning screen content • Changed diary notification content • Updated email address links within the app

		• Added CSO, DPO and design statement to all apps • App remembers username from the last login

APPENDIX 2 NUMBER OF PATIENTS

Figure 11 shows the number of patients registered to use the app over the first two years. Number of patients includes those invited up to 15th July 2022 who then registered by 5th August 2022. By 5th August, 954 of these patients had been discharged from the service. The average time from registration to discharge for these patients was 180 days.

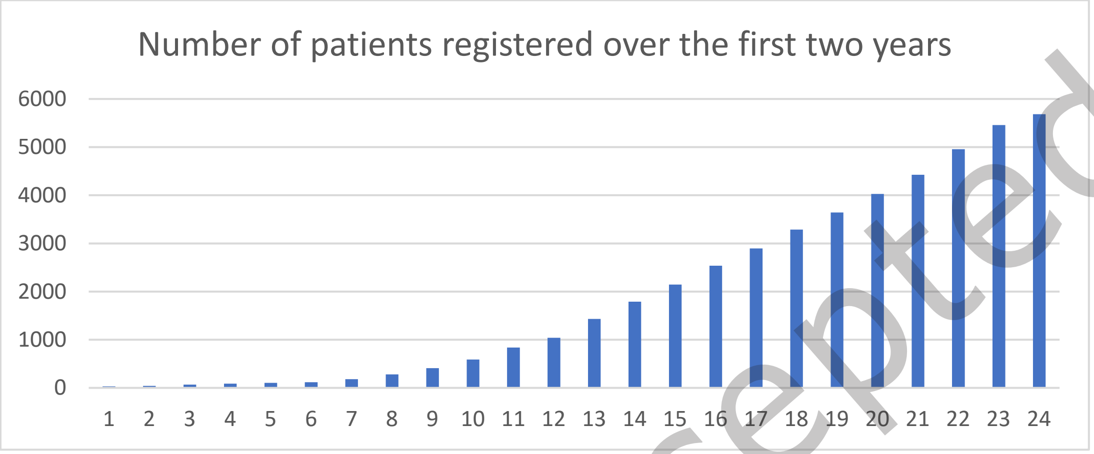

Figure 11: Number of patients registered over the first two years (NB final month is only to 15th July).

APPENDIX 3 EXTRACTS FROM NOTES WITH CLINICIANS

Consultants were all based at different hospitals; both medical students were at the same hospital.

C1 (Consultant) 1/6/20:

- It’s apparent that survivors of Covid have a lot of ongoing health needs. Some are on a recovery trajectory (variable, we don’t know much about it). Other are developing long-term complications.
- This is happening NOW – we’re at the peak of the 6 weeks. Need excellent solution now.
- There is no rehab at all at the moment.
- Recovery in the community is the responsibility of the GP but primary care isn’t functioning normally at the moment.

C2 (Consultant) 1/6/20:

- Patients who don’t improve remain the responsibility of the hospital.
- They are administering an “Amplitude” questionnaire (online) at 12 weeks. Based on the data gathered through this questionnaire, a decision is made on whether a patient is severe and needs to be recalled to a clinic or whether they can be discharged with advice.
- Further care is a “holding pattern”, with periodic follow-ups for patients who don’t recover as expected.
- Also use longitudinal data to better understand what “normal recovery” looks like and ideally flag up on a clinician dashboard when things are very abnormal for a particular patient.

C3 (Consultant) 2/6/20:

- For patients who were seen in the Emergency Department but not then admitted to hospital, there is a phone follow-up at two weeks. For those about whom there is concern, they are invited to a F2F consultation at 6 weeks (once they are no longer infectious).
- The hospital have seen 150 people in 3 weeks. Originally, this was in a lorry; it’s now moving to outpatients.
- Once GPs found out that the hospital were doing these reviews, they started getting GP referrals.

- In these F2F meetings, they have a conversation, measure clinical parameters (including imaging), do an exercise test (sit-to-stand), take a blood sample (to measure for antibodies and inflammatory markers).
- People outside hospital have experienced protracted illness at home, have been frightened that they would die, and are really relieved to see someone. 1/3 have elevated GAD/PHQ (stress and anxiety) due to stress of lockdown and fear of symptoms.
- Physio shares 3-4 leaflets (about different aspects of recovery) with patients, and some are referred to IAPT (Improving Access to Psychological Therapies) services.
- Blood tests are showing that 1/3 have high inflammatory markers (which is resulting in fatigue).
- Patients are really pleased to be able to *see* someone. Many of these are people for whom English is not their first language.
- We need to determine who needs to be seen and who could use an app.
- The people who've been on wards often feel like winners – they beat the odds and are grateful to be alive. Some others (who couldn't get the level of care that they expected) are very angry about how the government / NHS could have let this happen to them.
- Symptoms mentioned include breathlessness, fatigue, postural dizziness, muscle weakness, anxiety, depression, poor sleep.
- Many patients are freaked out about how long recovery takes.

M1 (Medical student) 1/6/20:

M1 identified 2 main "types" of patients, and a further couple of groups who don't quite fit those types. They suggested that an app would have to offer different levels of detail to different people (maybe three levels, from brief to very detailed).

Type 1: person with chronic illness who "can't be bothered with the phone call"

- This person is used to being ill. They have pre-existing conditions. They are breathless and anxious.
- They may have a language barrier, and therefore struggle with understanding the caller.
- They are typically older (50+).
- Because of the long-term conditions, the patient may be used to being isolated from society and reliant on family members.
- Some calls are taken by a son or daughter in this situation, who responds on behalf of their parent.

Type 2: younger, used to being "invincible"

- This person is 30-50 years old. Having Covid-19 has had a big impact on their lives. They are anxious and frustrated and hyper-aware of their symptoms.
- An example might be someone who was high-performing before Covid and are now experiencing fatigue, breathlessness and anxiety (probably linked with each other in a negative feedback loop).
- This person might be highly educated and wants to know all their medical details (all data recorded about them, including admission information). They want to feel invincible again.
- They are reporting complaints about different parts of their body – eyes, chest, cognition (ability to think and make decisions): they might be feeling confused.
- They want guidance on questions like step count (i.e. being proactive about recovery).
- They can't believe they became so ill. It has made them feel vulnerable and hyper-aware, and they need reassurance.
- They might have been furloughed from their job.

Type 3: Everything is OK now

The third type wants to get the questionnaire over as quickly as possible. They are young, and feel fine, and just want to get on with their lives.

Type 4: Older and doing OK

The fourth type is people who are 80+, who feel that they are doing fine. They may still have some symptoms but aren't anxious about it.

M2 (Medical student) 5/6/20

M2 described "personas" in a different way that gave additional details, though some map well to those described by M1:

Demographic 1: corresponds closely with M1’s Type 2:

- Young(ish), previously very fit, experienced real breathing difficulties and been very ill.
- Now dealing with a delayed return to fitness, and shocked at how long this is taking.
- They have ongoing psychological issues: these people are showing signs of PTSD and anxiety.
- Their mood tends to be OK. They aren’t experiencing anything particularly distressing, but still very fatigued.
- They earlier experienced a raging fever, and now feel burnt out.
- They are trying to get back on their bikes (or back into running, or whatever) and are feeling very fatigued.
- This is a relatively small group of people.

Demographic 2: corresponds closely with M1’s Type 1:

- People with multi-morbidities, often older (40-70+) – e.g., people with kidney disease, chronic lung disease, heart problems.
- Their Covid might not have been particularly serious, but their other health conditions weren’t properly managed during the early weeks of Covid.
- They are deconditioned from their time in hospital, and are typically still not exercising.
- They are of mixed ethnic backgrounds.
- There are similar numbers of men and women.
- Most have high blood pressure.

Demographic 3: corresponds closely with M1’s Type 4:

- These people are aged 80+ and were very healthy before Covid. They were “well preserved” and getting regular exercise.
- Covid was an immediate and terrible threat to them.
- They report being better now.
- They don’t typically remember their admission because Covid caused confusion. Thus, they are not traumatised by the experience (because they have little or no recollection of it).
- The main symptom now is breathlessness (with a little fatigue).
- These people are now staying at home. They are unsure whether they are allowed to leave the house, and are unsure whether they might get Covid again, or pass it on to others.
- Thus, they are deconditioned, and don’t feel able to exercise as they would have done previously.
- Although their moods are typically OK, they are becoming vulnerable to falls and lack of social interaction.

Demographic 4: Essential workers:

- These people feel that they are in danger and are frightened.
- They are suffering from mood problems, particularly depression. They are also experiencing a lack of motivation.
- They may have forced themselves to go back to work.
- It is hard for them to do things that would help them to relieve the stress, such as going out or seeing family.

APPENDIX 4 QUESTIONNAIRES INCLUDED IN THE APP

Questionnaire	**Measures**	**Number of questions**
MRC Dyspnoea	Degree of breathlessness related to activity.	1
Dyspnoea-12	Overall score of breathlessness severity.	12
Covid Recovery	This asked: “Which of the following phrases best describes how you are getting on?” with five possible responses ranging from “I cannot do any of the normal activities that I could do before Covid” to “I can do all the normal activities that I could do before Covid”.	1
Functional Assessment of Chronic Illness Therapy - Fatigue (FACIT-F)	Self-reported fatigue and its impact upon daily activities and function.	13
Generalized Anxiety Disorder scale (GAD-7)	Screening tool and severity measure for anxiety.	7
Work and Social Adjustment scale (WSAS) *	Measures perceived ability to work and engage with others.	6

EQ-5D-5L *	Measures key experiences of health from different perspectives.	6
Perceived Deficits Questionnaire, 5 item version (PDQ-5) *	Measures the degree to which individuals perceive themselves as experiencing cognitive difficulties (“brain fog”).	5
Demographic *	Records basic demographic information.	5
Patient Health Questionnaire depression scale (PHQ-8)[6] *	A diagnostic and severity measure for current depressive disorders.	8
Health Service Use *	Patient-reported use of health services and working days list in preceding four weeks	6

Questionnaires marked with an asterisk* were not included in the minimum viable product (August 2020) but were added later.

APPENDIX 5 CATEGORIES OF ISSUES FROM “BEING DOREEN”

Clinic	About relationship between app and clinic or expectations of the clinic.
Cognitive load	Putting excessive cognitive load on user. Related to "overwhelmed", which is often the emotional response to high cognitive load.
Comprehension	Speak the patient's language!
Confusion	Got confused because of the interface design
Flow	Problems with the overall flow of the interaction across sessions
Improvement	Potential areas for improvement of the app - new features
Interaction	Issues with the way the user interacts with the app (local to a particular feature).
Navigation	Difficulties with navigating between screens.
Niggles	Local problems that can probably be fixed with an edit to the code or an article text that doesn't have wider ramifications.
Overwhelmed	Emotional response to high cognitive load or a sense of having too many tasks to do.
Pace	Dissonance between messages about how quickly the user should move through programmes or otherwise manage their Long Covid.
Physical-digital	Potential issues about how the user is expected to use a notebook alongside the app
Query	Miscellaneous queries from AB relating to user experience or self-management issues.
Reminders	Comments about the use of a separate alarm and app notifications and places where users might well forget things.
Self-management	Features that fail to support the user in self-managing between interactions with the clinic.
UX	Miscellaneous user experience issues that don't fit in a more specific category.

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[6] Some clinics requested PHQ9, which has an additional question about suicidal thoughts.