NIHR | National Institute for Health and Care Research

Health and Social Care Delivery Research

Check for updates

Synopsis

Development and implementation of a digital health intervention in routine care for long COVID patients: a comprehensive synopsis

Henry Goodfellow[1], Ann Blandford[2], Katherine Bradbury[3], Manuel Gomes[4], Fiona Hamilton[1], William Henley[5], Fiona Stevenson[1*], Delmiro Fernandez-Reyes[6], John Hurst[7], Melissa Heightman[8], Paul Pfeffer[9], William Ricketts[9], Richa Singh[9], Hannah Hylton[9], Stuart Linke[1], Julia Bindman[1], Chris Robson[10], Sarah Walker[5] and Hadiza Ismaila[2]

[1]Research Department of Primary Care and Population Health, University College London, London, UK
[2]University College London Interaction Centre (UCLIC), University College London, London, UK
[3]Department of Health Psychology, University of Southampton, Southampton, UK
[4]Department of Applied Health Research, University College London, London, UK
[5]Department of Medical Statistics, University of Exeter Medical School, Exeter, UK
[6]Department of Computer Science, University College London, London, UK
[7]UCL Respiratory Medicine, University College London, London, UK
[8]University College London Hospitals, NHS Foundation Trust, London, UK
[9]Respiratory Medicine Service, Barts Health NHS Trust, St Bartholomew's Hospital, London, UK
[10]Living With Ltd, London, UK

[*]**Corresponding author** f.stevenson@ucl.ac.uk

In memoriam

This report is dedicated to late Professor Elizabeth Murray, the driving force behind this project. It was her vision that brought together a truly multidisciplinary group to work on it, crossing barriers between academics and healthcare professionals, patients and industry, to harness the areas of expertise necessary for success. Her loss in April 2023, following a year and half of illness, has had an impact on every aspect of the work. She is greatly missed, but her legacy of using research to make life better for patients and healthcare professionals lives on.

Published November 2025
DOI: 10.3310/GJHG0331

Abstract

Background: By July 2020, large numbers of post-COVID patients were experiencing symptoms for weeks or months, but traditional National Health Service models of rehabilitation service delivery could not meet demand.

Objectives: Design and deploy a digital health intervention to provide digitally delivered, remotely supported rehabilitation to long COVID patients on complicated and evolving pathways.

Methods: The multidisciplinary team combined established research methods based on engineering and computer science (considering safety, stability and user requirements) with those based on biomedical and health service research (considering effectiveness and population impact).

Qualitative data comprised recordings of meetings between study team members and clinicians and semistructured interviews with clinician and patient users. Quantitative data comprised referral, registration and usage rates; demographic and clinical characteristics of patients; and patient-reported outcome measures.

Results: We created a modifiable digital health intervention, 'Living With COVID Recovery™ developed by Living With Ltd', London, UK, that continues to be used by National Health Service trusts.

The digital health intervention included integration into a clinical pathway, a clinician-facing dashboard, two-way messaging and a patient-facing app with information and evidence-based treatments. We aimed to register 1000 users. By study completion on 20 December 2022, there were 9781 patients invited, of whom 7679 (78.5%) had registered, at 33 National Health Service clinics.

This synopsis should be referenced as follows:
Goodfellow H, Blandford A, Bradbury K, Gomes M, Hamilton F, Henley W, *et al*. Development and implementation of a digital health intervention in routine care for long COVID patients: a comprehensive synopsis. *Health Soc Care Deliv Res* 2025;**13**(39):1–28. https://doi.org/10.3310/GJHG0331

Limitations: Data came from patients at long COVID clinics, however data were unlikely to be representative of people with long COVID. We could not observe clinics under lockdown and had limited access to patient digital health intervention users or to people not engaging with the digital health intervention. Patient user data were incomplete, with inconsistent patient-reported outcome measure and other questionnaire data completion and no data on initial severity of disease, vaccination status, comorbidities or other individual circumstances.

Conclusions:

- Long COVID can be extremely debilitating, comparable to stage IV lung cancer in relation to fatigue and health-related quality of life. Care and rehabilitation should address the management of fatigue and reflect the impact of social disadvantage on symptom severity.
- With sufficient resources, a digital health intervention can be developed quickly and effectively using agile methodology and bringing together a genuinely multidisciplinary team, including, importantly, an industry partner.
- Digital health intervention product design and deployment are both important in getting National Health Service trusts, healthcare professionals and patients to engage with a digital health intervention. Projects should work closely with all user groups.
- Lockdown and the unmet need of a new patient group encouraged those who might otherwise have been reluctant to try a digital health intervention. Many patients and clinics accepted this digital remote support, which helped patients feel cared for while reducing strain on health services. This may encourage acceptance of other digital health intervention, although medical record integration remains a deterrent to clinics.

Future work: This research focused on the development, deployment and evaluation of a digitally enabled rehabilitation programme for long COVID. Clinical effectiveness will be assessed within the Symptoms, Trajectory, Inequalities and Management: Understanding Long-COVID to Address and Transform Existing Integrated Care Pathways (UCL, London, UK) study.

Funding: This synopsis presents independent research funded by the National Institute for Health and Care Research (NIHR) Health and Social Care Delivery Research programme as award number NIHR132243.

A plain language summary of this synopsis is available on the NIHR Journals Library Website https://doi.org/10.3310/GJHG0331.

Introduction

Rationale

The National Health Service would struggle to cope with the rehabilitation needs of large numbers of post-COVID patients

COVID-19 had already affected nearly 300,000 patients in the UK by 6 July 2020. Many remained symptomatic with breathlessness, fatigue and anxiety for weeks or months after infection. Rehabilitation could help these patients, but traditional, face-to-face (F2F) models of service delivery would struggle to cope with the volume of patients.

A digital approach was likely to be needed, but there are numerous challenges with this, including failures of deployment; anxieties around the digital divide/health inequalities; and concerns around low engagement with such programmes.

The digital health intervention (DHI) was intended to provide digitally delivered, remotely supported rehabilitation to patients on complicated and incompletely understood pathways.

Key points

The study had intended to register 1000 users, but by the study completion date, 20 December 2022, there were 9781 invited patients, of whom 7679 had registered (78.5% of those invited), at 33 NHS clinics. The DHI evolved over 11 versions during the study, expanding in response to emerging knowledge about this novel condition to cover issues, including breathlessness, anxiety, depression, brain fog and fatigue, and continues to be used and updated.

- This research focused on the development, deployment and evaluation of a digitally enabled rehabilitation programme for long COVID. The DHI has been incorporated into the STIMULATE-ICP study,[1] which will provide an assessment of clinical effectiveness.
- Long COVID can be extremely debilitating, comparable to stage IV lung cancer or severe kidney disease in relation to fatigue and health-related quality of life (HRQoL). Clinical care and rehabilitation should address the management of fatigue as the dominant symptom keeping people from living their normal lives.
- Severity of symptoms is influenced by social disadvantage, underlining the need for continued targeted interventions.
- With sufficient resource, a DHI can be developed quickly and effectively using agile methodology and bringing together a genuinely multidisciplinary team, including, in this case, clinical and non-clinical academics, healthcare professionals (HCPs), patients and, importantly, an industry partner.

- The DHI product design and deployment are both important in getting NHS trusts, HCPs and patients to engage with a DHI. DHI projects should work closely with, and respond to, all those user groups to integrate the intervention into diverse clinical pathways.
- Pandemic conditions enforced remote working and highlighted the unmet need of a new patient group. Lockdown encouraged new users of technology who might otherwise have been reluctant to try a DHI. This digital remote support has been found acceptable by many patients and by clinics with different clinical pathways, helping patients feel cared for while reducing strain on health services. This may encourage the acceptance of other DHIs.

Inability to integrate data with medical records may limit the attractiveness of DHIs.

Objectives

We aimed to develop, refine, deploy and evaluate a digitally mediated, remote, supported rehabilitation programme for patients affected by COVID-19.

The work was divided into four work packages (WPs):

> Work package 1 to determine user requirements, develop the DHI and test it against user requirements.
> Work package 2 to focus on maximising the likelihood of successful DHI deployment across different healthcare settings and generate knowledge for future DHI.
> Work package 3 to assess impact to determine the real-world costs and population impact of the DHI.
> Work package 4 to address health inequalities as a cross-cutting theme, running through WPs 1–3.

Methods

Research methods

We combined research methods common to engineering and computer science (focused on developing a product that is safe, stable and meets user requirements) with those familiar to biomedical and health service researchers (focused on effectiveness, deployment and population impact).

Thus, we applied:

- the Medical Research Council (MRC) Framework for development and evaluation of complex interventions (phases 1, 2 and 4)
- user-centred design and the ISO 9241 human–computer interaction (HCI) life cycle for intervention development
- behavioural theory and behaviour change techniques to inform content and delivery
- Normalisation Process Theory (NPT) to inform deployment
- the Joanna Briggs Institute Reviewers' Manual methods for the systematic scoping review on the digital divide.

Evaluation used qualitative and quantitative data

Qualitative data included meeting recordings and interviews with clinician and patient users.

Quantitative data included referral, registration and usage rates; demographic and clinical characteristics of patients; and patient-reported outcome measures (PROMs) for:

- HRQoL [Work and Social Adjustment Scale (WSAS) and EuroQol-5 Dimensions, five-level version]
- breathlessness (MRC dyspnoea and Dyspnoea 12 scales)
- fatigue (Functional Assessment of Chronic Illness Therapy – Fatigue)
- anxiety (Generalised Anxiety Disorder-7)
- depression (Patient Health Questionnaire-8 items)
- cognition or 'brain fog' (Perceived Deficits Questionnaire-5).

Study protocol[2]

The study was a form of 'action research': complex, contingent, evolving and improvised. We set out to deliver a product: the Living With COVID Recovery™ (LWCR) developed by Living With Ltd (LW) DHI, which was as usable, engaging, useful and effective as possible, under challenging conditions. The project aimed to achieve both research and service delivery needs on a tight timescale, needs often at odds with each other.

Note on terms

We use the terms 'long COVID' and 'post-COVID syndrome (PCS) interchangeably; 'PCS' has become the official term, but patients prefer 'long COVID'.

We value the benefits of cross-disciplinary working, but it is not without challenges: 'implementation' is an example of a term, which is used in different disciplines but may have a different focus. For example, in HCI, 'implementation' means building a product, as opposed

to designing it or deploying it. Medical sociologists refer to 'theories of implementation' to guide the planning and evaluation of the movement of interventions into practice. Meanwhile, for Health Innovation Networks[3] and Clinical Commissioning Groups, 'implementation' describes the practical steps intended to get people to adopt an intervention. For this reason, we have generally used the term 'deployment' rather than 'implementation'.

Research papers synthesised in the synopsis

1. Blandford A, Bindman J, Bradbury K, Cooper B, Costanza E, Edwards S, *et al.* Experiences of user-centred design with agile development for clinically supported self-management of long COVID. *ACM Trans Comput Hum Interact* 2025;**32**:6. https://doi.org/10.1145/3711839
2. Walker S, Goodfellow H, Pookarnjanamorakot P, Murray E, Bindman J, Blandford A, *et al.* Impact of fatigue as the primary determinant of functional limitations among patients with post-COVID-19 syndrome: a cross-sectional observational study. *BMJ Open* 2023;**13**:e069217. https://doi.org/10.1136/bmjopen-2022-069217
3. Sunkersing D, Goodfellow H, Mu Y, Ramasawmy M, Murali M, Adams L, *et al.* Long COVID symptoms and demographic associations: a retrospective case series study using healthcare application data. *JRSM Open* 2024;**15**. https://doi.org/10.1177/20542704241274292
4. Stevenson FA, Pfeffer P, Walker S, Ismaila H, Jegatheesan V, Mohammad I, *et al.* Using normalisation process theory to evaluate the implementation of a digital health intervention in community and secondary care long COVID clinics. *BMJ Open* 2024;**14**:e092824. https://doi.org/10.1136/bmjopen-2024-092824
5. Ismaila H, Blandford A, Sunkersing D, Stevenson F, Goodfellow H. Comparative insights into clinic onboarding and interaction practices for patient engagement in long COVID digital health care. *Digit Health* 2024;**10**. https://doi.org/10.1177/20552076241294101
6. Jenkins CL, Imran S, Mahmood A, Bradbury K, Murray E, Stevenson F, Hamilton FL. Digital Health Intervention design and deployment for engaging demographic groups likely to be affected by the digital divide: protocol for a systematic scoping review. *JMIR Res Protoc* 2022 Mar 18;**11**:e32538. https://doi.org/10.2196/32538
7. Wang J, Goodfellow H, Walker S, Blandford A, Pfeffer P, Hurst JR, *et al.* Trajectories of functional limitations, health-related quality of life and societal costs in individuals with long COVID: a population-based longitudinal cohort study. *BMJ Open* 2024;**14**:e088538. https://doi.org/10.1136/bmjopen-2024-088538

In addition to these research papers (RPs), we also generated a significant number of data that could be used by other researchers.

Developing the intervention

(WP 1 – development and WP 4 – health inequalities)

We created a modifiable digital health intervention, 'Living With COVID Recovery', that continues to be used by National Health Service Trusts

The DHI was delivered by LW and includes integration into a clinical pathway, a clinician-facing dashboard, two-way messaging and a patient-facing app, with information and evidence-based treatments reflecting behavioural science approaches based on psychological principles for a range of symptoms (*Appendix 2*).

The study had been intended to register 1000 users, but by the study completion date, 20 December 2022, there were 9781 invited patients, of whom 7679 had registered (78.5% of those invited), at 33 NHS clinics. The number of clinics involved fluctuated over time, with some clinics merging and new clinics adopting the DHI.

The DHI evolved over 11 versions during the study, updating content, functionality or both. It expanded to cover diverse issues characteristic of long COVID, including breathing pattern disorder (BPD), fatigue, anxiety, depression and brain fog. LW has continued to update it since the study ended and made some components available separately. By 1 May 2024, a total of 16,579 patients had been invited, of whom 13,544 had registered (81.7% of those invited), at 42 clinics.

In the absence of timely user interviews, we modified the digital health intervention to incorporate feedback from patient and public involvement, clinics and the research team

We had intended to work with patient DHI users, patients invited but not registered and patients not invited to register. However, it took longer than expected to obtain ethical clearance, and meeting data protection requirements was far more complex and took longer than we had envisaged. We could not, therefore, review user data to make further adaptations to the DHI during the project. Identifying and contacting patients for interview were also delayed until it was too late to incorporate that feedback during the project period. Instead, the time and budget were used to continue seeking feedback from our patient and public involvement (PPI) group.

Only seven clinicians, fewer than planned, responded to requests for formal interviews, but they were quick to relay requests to the developers throughout the deployment of the DHI.

We continued to modify the DHI based on those PPI and clinician inputs, alongside those from within our multidisciplinary team.

Patient-facing modifications

These include:

- Assessment module: questionnaires all in one place to increase completion rates and streamline assessment.
- Guided treatment programmes for core long COVID symptoms with integrated PROMs and goal tracking for all main symptoms.
- A fatigue and activity diary to improve understanding of the relationship between a patient's activity and their fatigue.
- Updated library content, reflecting PPI feedback and ongoing learning about the condition.
- Information videos on key areas.
- Module for carers.
- A more encouraging tone in behaviour change guidance.
- Advice on pacing for fatigue.

Clinician-facing dashboard adaptations

These include:

- ability to export data
- ability to download patient activity and responses to add to patient record
- automated reminder texts to patients as part of onboarding
- reinstating discharged patients.

Findings

People from a variety of disciplines can succeed in working and learning collectively, using an agile methodology, in a changing environment

A rich variety of disciplines, including academic, health care, PPI, behaviour change, HCI, technical and entrepreneurial, contributed to the development of the DHI. The agile methodology, of rapid prototyping and adaptation, allowed the harnessing of this expertise in the context of social disruption and the many unknowns about COVID-19. Shared purpose broke down the barriers within and between clinical and academic sectors and between them and patients and an industry partner specialising in DHI development.

This project sat at the boundary of the different investigators' knowledge and fostered unexpected opportunities for learning. Project meetings were genuinely multidisciplinary and very engaged, with people contributing, who might often have deferred to others. Learning sets emerged, including, for example, occupational therapists, physiotherapists, clinical psychologists, speech and language therapists and PPI participants. A range of academics took part, from medical student researchers to late-career professors. The PPI participants and the industry partner taught the rest of the team about the boundary between academic proposals and what works in practice with patients (see Blandford *et al.*[4]).

Digital remote support is acceptable to many people and clinics and can work across different pathways

The establishment of long COVID clinics across England was fast and ad hoc, with wide variation in HCP specialism and clinical pathway. Remote digital interventions were suddenly more acceptable as clinicians and patients wanted to minimise in-person contact. The DHI was adopted in 33 clinics across a range of settings; the number of clinics fluctuated as some clinics merged (reducing the number) and others started using the DHI. It continues to be in use at 42 clinics, with ongoing updates.

Product design must accommodate diverse patient users

Patients are not defined by clinical condition alone – their health beliefs and health literacy, demographic and individual characteristics also matter in the product design. For example, we learnt from PPI participants that they see their condition holistically, not divided by medical discipline, and the app needed to acknowledge that. We removed a core metaphor for long COVID from the DHI after it was rejected by PPI, on the grounds that it did not reflect the enormous range of possible symptoms and therefore not their experience.

The systematic scoping review recommended use of the 'universal precautions' approach[2] to the design of DHIs to help overcome the digital divide. This approach calls for developers and healthcare organisations to design DHI and deployment and communications strategies with the assumption that any patient may need support with literacy, health literacy or digital literacy and access to digital skills training, devices and data. It includes co-design with users and less reliance on text. There was some co-design of the DHI functionality with health professionals and some co-design of the text with PPI participants. From the start, the DHI content was written to be accessible for a reading age of 12 years and included video demonstrations of physical activities. More audio and video content would have been desirable, to improve access for more users, had resources been available. Attempts were made to recruit a diverse group of PPI participants, albeit with limited success. The Bart's Health Charity supported the development of a carer's module, making the DHI accessible to patients who would not have been able to use it without this help from their carers (see Blandford *et al.*[4] and Jenkins *et al.*[5]).

Working with clinics to deploy the digital health intervention

(WP 2 – deployment and WP4 – health inequalities)

The digital health intervention reached more than seven times the planned number of users, so more patients received support and more data were generated

We demonstrated that it is possible to scale an intervention of this type. The study had intended to register 1000 users, but the growing number of long COVID patients and the establishment of specialist long COVID clinics meant that by the study completion date, 20 December 2022, there were 9781 invited patients, of whom 7679 had registered (78.5% of those invited), at 33 clinics.

The scale of data collected both raised the potential for useful findings and created an unanticipated need for data management.

The DHI continues to be in use after the study period, in full and component form, and by 1 May 2024, a total of 16,579 patients had been invited, of whom 13,544 had registered (81.7% of those invited), at 42 clinics.

Findings

Designing the deployment matters as much as designing the product

Healthcare intervention studies must consider the bigger picture about deployment and impact on practice, not just the focus on the design and evaluation of a prototype. Success in implementing a DHI depends on understanding the complexity of the context, fostering cohesive teamwork for deployment and evaluating tangible changes resulting from the intervention. NPT helped us elucidate the organisational changes necessary to implement the DHI to treat long COVID, as understanding of the condition continued to evolve, and during a period of extreme organisational stress.

Digital tools to enable supported self-management must accommodate the practices of the HCPs as well as the patients, prioritise high-quality onboarding and ensure common ground between HCPs and patients. HCPs and patients will accept a DHI as an aid to human provision of care, not a replacement for it. HCPs need to see that the DHI will maintain or reduce, not increase, workload and make the NHS better and safer.

We found great diversity in the enrolment and engagement between different clinics. Clinicians onboarding patients increased patient acceptance as did completing questionnaires for initial assessment on the DHI as opposed to on paper or by e-mail. The involvement of the clinician, rather than administrative staff, to onboard patients established the DHI as part of the clinical process and built the clinical relationship. Finding the right place for onboarding in the clinical pathway matters, as completing initial assessment questionnaires on the DHI to access care, is also an effective incentive for patients to engage.

The systematic scoping review found evidence in favour of deployment that offers support with digital skills and access to devices and data. At the same time, patients who cannot be brought into the digital fold still need quality information and monitoring outside the DHI. This was supported by feedback from clinics on the difficulty of engaging people digitally when they decline technology even when it is made available. This has wider implications for policies such as 'digital first' (see Stevenson *et al.*,[6] Ismaila *et al.*[7] and Jenkins *et al.*[5]).

The creation of a new service (long COVID clinics) gave a focus for us to engage with clinicians and trusts

The clinicians in this new service were specifically dealing with long COVID: this gave them an incentive to engage with LWCR because the intervention addressed their core needs, rather than just one of many clinical conditions they might otherwise have been managing in parallel. It was also possible to bid for new money for this service, and clinical and governance systems were focused on completing processes quickly so that support could be available to patients with unmet needs.

Institutional barriers: ongoing medical record integration problems make all digital health interventions less attractive to clinicians, and trust-by-trust commissioning causes delays

Medical record integration was intended for this DHI, but we could not overcome the standard obstacles: the plethora of different information technology systems across the NHS, and concerns about data security, access and ability to make changes.

Some clinicians had concerns about impact on their clinical records. Some were concerned that the need to record data arising from the DHI outside of the medical record would add to their workload. Others were concerned that an outside body would be adding to the clinical record or, conversely, that not all care was being formally recorded.

Individual procurement, contracting and information governance processes had to be completed at each trust and this was a slow process (See Stevenson *et al.*[6]).

The intervention can stimulate change in working practices

Lockdown and the need to provide a new service to long COVID patients meant that many clinicians were willing to try a DHI, perhaps for the first time. Their experience could make them more receptive to other DHIs in the future.

The health condition and the technology crossed disciplines, bringing about new work and communication across teams in trusts as well as in the project team.

The technology has the potential to make clinical pathways more efficient – a clinician can oversee more patients per hour – as well as more flexible and patient-friendly. Monitoring and messaging could mean varying appointment intervals and communicating between appointments in response to patient messaging and extension of light-touch care beyond discharge (see Stevenson *et al.*[6]).

Impacts of long COVID on patients

(WPs 1 and 3)

Contribution to understanding of long COVID

We obtained far more symptom data than we had expected

This was because we collected much more patient data than expected, for two reasons. Firstly, since the DHI moved beyond providing the respiratory rehabilitation, we had originally expected to be necessary, to addressing the actual needs of long COVID patients presenting with complex and varied symptoms. Secondly, because the number of patients who registered on the DHI was around seven times that originally anticipated. The larger number of patients involved meant that the data collected in this study have contributed to understanding of the sequelae of COVID-19 and its management, specifically rehabilitation, to aid the longer-term recovery of long COVID patients.

Many of the long COVID patients in the study were seriously ill

They had fatigue scores worse or similar to people with cancer-related low blood counts or severe kidney disease. Many patients also reported HRQoL scores, which were lower than people with advanced cancers, like stage IV lung cancer (see Walker *et al.*[8]).

From 6 months after registering with the LWCR DHI, there was a modest reduction in the mean HRQoL impairment scores, but it was estimated that 45% of patients still had moderately severe or worse impairment. This is similar to the levels seen in patients with chronic inflammatory conditions and above the estimates for breast cancer and HIV. Levels of impairment for long COVID were higher in younger patients (aged < 50 years), female patients and patients from the most deprived areas (see Wang *et al.*[9]).

Clinical care and rehabilitation should address the management of fatigue as the dominant symptom explaining variation in functionality

A high proportion of this long COVID treatment-seeking population was of working age, with over half reporting moderately severe or worse functional limitation. There were substantial impacts on the ability to work and activities of daily living in people with long COVID. Fatigue was identified as the dominant symptom explaining the variation in functionality, suggesting that the management of fatigue should be a target for clinical care and rehabilitation.

A total of 71% of patients were female. Women tend to have more responsibilities at home and are more likely to work in caring professions, so policy-makers will need to consider the social impact of women being unable to carry out normal tasks at home and at work (see Walker *et al.*[8]).

Pain is the most commonly tracked symptom in long COVID patients

Reported intensity of pain went up rather than down over the periods of months covered by the study. Intensity of pain was positively associated with being older, female, from an ethnic minority background, living in an area affected by multiple deprivations and less educated (see Sunkersing *et al.*[10]).

We cannot evaluate impact of the digital health intervention on symptom reduction, although there are some positive signs

Our research has helped to uncover the details and trajectories of symptoms for long COVID in this population. However, the emphasis on the speed and reach of the DHI precluded the establishment of a randomised controlled trial (RCT). Our collaborators in the STIMULATE-ICP RCT[1] will evaluate the impact of the DHI on symptom reduction.

However, compared with most studies reported in the HCI literature on health technologies, the LWCR project has had demonstrable impact on patients' supported self-management. We found that over 50% of the patients, who were invited to participate in the LWCR project by July 2022, appear to have perceived some benefit: of the 7239 patients who had been invited to use LWCR by that point, 5684 registered (78.4% of those invited), and over 4600 patients read library articles and completed PROMs questionnaires (see Blandford *et al.*[4]).

Limited findings on cost implications of the digital health intervention

(WP 3)

Incorporating an industry partner into the project was an efficient use of resource and has allowed the intervention to continue beyond the research period

Paying research funds – in this case, approximately 25% of the total grant – directly to our industry partner, LW, a specialist developer of DHIs for patients and clinicians, was an effective way to get the DHI delivered to NHS clinics quickly. Our total National Institute for Health Research (NIHR) funding was £781,964.53, and £197,235.91 went to LW, including some additional funds moved to them for data management from the University College London (UCL) allocation for artificial intelligence (AI) research.

As of May 2024, more than 18 months after the project period, the DHI is in use in 42 clinics. It is now paid for by clinics, which has allowed wider deployment and ongoing development. However, it faces uncertainty, while NHS England (NHSE) formulates future spending plans.

We were unable to obtain data on cost savings in clinics, but we had anecdotal evidence from some clinicians that the digital health intervention allowed a more efficient use of resources

Informal reporting to LW suggested benefits to monitoring and resource allocation.

Efficient monitoring

- One physiotherapist was able to manage a caseload of 100 patients in the equivalent time it would take to see around 10 patients F2F, expanding clinical capacity 10-fold without the additional costs of F2F appointments.
- A respiratory assistant was able to monitor around 100 patients in 3 hours per week.

Effective monitoring and resource allocation

- A clinic found that the DHI enabled prioritisation of resource: the team could see the patients who were getting better and those who needed more help.
- That clinic also found that it enabled proactive management of the condition: the team could spot people who were declining and intervene before a 'crash'.

Economic impacts of long COVID

(WP 3)

These will be felt not just at the level of patients and their families but also by the NHS and the wider economy.

Costs to the economy of long COVID: working days lost, costs to the health service and society

On average, the monthly cost for a patient was £966 at baseline, decreasing to £851 at week 12. A societal perspective was adopted to consider a wide range of costs, including healthcare costs [e.g. general practitioner (GP) visit, psychotherapy appointment, physiotherapy session, inpatient stay and outpatient appointment] and patient costs (days off from work). Healthcare costs were calculated using days off work and healthcare utilisation data collected via a questionnaire in the LWCR app. Appropriate unit costs were applied to these data to calculate the costs for each patient. The decreases in cost at week 12 were mainly driven by the decreases in cost of days off from work (by £75 per month) rather than by healthcare costs. We adjusted the analyses for total costs at baseline in addition to the sociodemographic variables included in the WSAS/EQ-5D functional limitation models (see Wang *et al.*[9]).

Most of this long COVID treatment-seeking population were of working age, with over half reporting moderately severe or worse functional limitation. There were substantial impacts on ability to work and activities of daily living in people with long COVID.

Addressing health inequalities

(WPs 3 and 4)

We conducted a scoping review on overcoming health inequalities that can be used by other researchers and practitioners.

The 'universal precautions' approach to digital health intervention design and deployment can help to overcome health inequalities

We recommend the 'universal precautions' approach to design out the digital divide and improve digital health literacy, as described by Veinot *et al.*[11] This calls for developers and healthcare organisations to make DHI accessible by designing DHI and deployment/communications strategies with the assumption that any patient may need literacy/health literacy/digital literacy support and access to digital skills training, devices and data.

Healthcare professionals should consider the digital divide when using digital health intervention in health care or recommending them for self-management

For example, there may be barriers for patients to use digital mechanisms for making appointments. HCPs and healthcare organisations may need to provide support or

signposting for vulnerable groups to access and understand health information online or via DHIs.

Access to patient data came too late for specific analysis or qualitative research

The time taken to meet patient confidentiality and data-sharing requirements meant that we could not review user data to make further adaptations to the DHI during the project nor to contact users for interviews until late in the project.

We had also hoped to interview digital health champions (DHCs), whom we had envisaged for providing digital literacy and other support to DHI users or potential users. However, none of the clinics deployed DHCs.

The patients on the digital health intervention were representative of the patients who are seen in long COVID clinics nationally, not of all people with long COVID

We were able to examine demographic data after the relevant questionnaire became available to all patients in April 2021. Most of our patients were White, affluent and well-educated people. These patients are more likely to seek, and obtain, help than their counterparts and were therefore the ones enrolled in long COVID clinics. Without more interviews, we also lack data on why clinicians chose not to invite people and why some people did not register after invitation (see Walker *et al.*[8] and Jenkins *et al.*[5]).

Challenges

Our workforce was depleted by illness and changing employment circumstances

The main co-Chief Investigator (Co-CI), Elizabeth Murray, left UCL on grounds of ill health in December 2021 and her Co-CI, Henry Goodfellow, left academia to return to clinical practice in the summer of 2023. Fiona Stevenson took on Elizabeth's departmental and group lead responsibilities, as well as becoming Director of the Institute of Epidemiology and Health Care. Ann Blandford, responsible for two papers and supervising a third, moved from full-time to part-time employment, and several members of the research team took extended sick leave during the project. There were also changes in administrative staff and research associates.

The demands of the project outstripped its resources

The proposal was drafted and submitted before long COVID was recognised as a condition, at a time when the focus was on rehabilitation following hospitalisation. Thus, the problem being addressed turned out to be much larger, longer-term and with more impact than envisaged at the time of submission. With the workforce issues noted above, the team focused on delivering an intervention in the evolving situation, as we did not have the capacity to do both that and apply for the additional funding that we clearly needed.

So the DHI was developed efficiently, but insufficient resourcing meant that it was only possible because many of the co-investigators (Co-Is) worked significantly beyond funded hours. Some reserach publications have been delayed, and further outputs would have been possible with more research support.

Long COVID symptoms affected use of the digital health intervention and research

The DHI users could choose which PROMs to complete. We adapted the DHI to accommodate patient fatigue, minimising PROMs, but response rates on some PROMs was low, and many patients did not complete the baseline demographic questionnaire. Fatigue among the PPI participants affected our access to information from them; we made PPI review groups shorter.

Changing understanding of COVID-19/long COVID

As noted above, the project was originally planned to provide rehabilitation for patients who had been released from hospital after acute COVID-19 infection. By the end of 2020, it became clear that the real need was among patients with long COVID, few of whom had been ill enough to need hospitalisation during their initial illness.

This meant that our initial focus, on respiratory rehabilitation and overcoming acute weight loss after intensive care, needed to change to reflect the symptoms that long COVID patients' face. Although BPD continued to affect many patients, the DHI was extended to address the most common symptoms, including fatigue, pain, brain fog, anxiety and depression.

We were unable to obtain clinician and patient user interviews at the intended scale

Few clinicians responded to requests for interview, and delays in obtaining ethical and data protection clearance meant that we could only contact patients towards the end of the study.

We had not planned for the scale of data generated and data protection administration required

The DHI was far more widely adopted than we had expected, and we were not prepared for the volume of

patient data generated nor the number of data-sharing agreements required. We had not budgeted for the necessary administrative support nor a data manager.

We continued to provide the DHI beyond the planned number of users on ethical grounds. While the situation and the evidence were still evolving alongside our research, the DHI offered support to patients and clinicians in an area where little other support was available and the DHI was unlikely to do harm. During late 2020 and early 2021, we became aware that we did not have a way to capture and display the data. We needed to analyse the data to determine the most useful updates required for the DHI. We were granted permission to use grant money intended for an AI research post to instead create a digital database to store the data for analysis.

Meanwhile, data protection requirements led to research delay

Meeting data protection requirements was far more complex than we had envisaged, on two separate fronts.

Firstly, protecting patient confidentiality meant creating three classes of data: full personal data needed by the patients' HCPs; essentially anonymised data for the researchers; then pseudo-anonymised data that could be used to select potential patient research interviewees and then link to those interviewees. Splitting up those three categories and keeping them separate was a major task for LW.

Secondly, creating a Gold Standard data-sharing environment for transferring data between the NHS, LW and UCL took far longer than anticipated. We required an individual data-sharing agreement with each NHS trust; there were far more trusts involved than we had expected, and the task was a low priority for trusts who were coping with the pandemic. More than three-quarters of the way through the project, in March 2022, only five trusts had signed an agreement. UCL provided an external solicitor and an additional internal contracts officer to offer further support so that, by August 2023, there were 16 signed agreements.

We were unable to develop predictive models to help improve patient engagement: long COVID is too complex a condition

We had intended to use intelligent algorithms and machine learning to promote engagement and tailor treatment advice under clinician guidance. The first obstacle was the need to fund the database work and resultant loss of the AI research post. The second was the nature of long COVID: it was a new disease, not clearly defined, with a large variety of symptoms with varying levels of severity.

Our computer science lead, Professor Delmiro Fernandez-Reyes, ran a project with a master's student to explore the multivariate usage of the DHI data in predicting a patient's recovery parameters. This was to be the first step in building and validating a predictive model that could help clinicians to prioritise and/or select an appropriate treatment pathway for patients and thereby improve patient engagement and outcomes.

However, these models were not able to generate anything meaningful from the data, as these were too complex and there were too many unknown variables. To make sense of the data, we would need more complicated, non-linear and other deep representational models that were beyond our resources. Linking the data to the electronic health record (EHR) to attempt stratification of cohorts would help to move this forward and the STIMULATE-ICP trial[1] is currently working on that.

Limitations

Complex and evolving context contributed to data limitations

We are not aware of any prior studies where the aim was to design for people managing an emergent, complex, debilitating health condition while simultaneously deploying into clinical practice under time pressure. This unusual situation meant we had to be agile not only in terms of the development of the DHI but also in terms of the data we could collect. Data collection was, in many cases, determined by what was possible at the time rather than operating to a predefined schedule.

We will also need to ensure that the learning is transferable to a post-pandemic situation: the pandemic was an opportunity to learn and also a unique set of circumstances.

Personas based on adult London patients

Personas used to develop the DHI were based on information from hospital HCPs in London and may not be representative of experiences in other regions. We did not explicitly consider the needs of young people (< 18 years) with long COVID.

Patient and public involvement was not fully representative of the long COVID population

For example, we did not have people for whom English is not their first language despite our attempts to be inclusive. Our recruitment was almost entirely from long

COVID online support groups and mainly women volunteered. Our online information for the second round of recruitment specifically welcomed people from ethnic minority backgrounds, resulting in a slight increase and also brought slightly higher male representation.

Qualitative data limitations

Limited access to 'real users', observation in clinic or digital sceptics

The study engaged with fewer 'real users', patient and clinician, than planned or anticipated, and later in the project than we would have liked: we interviewed 14 clinicians from seven clinics and 12 patients from six clinics, with two of those clinics providing interviewees of both types. Clinical activity was largely remote during much of the project period, so we could not observe first-hand how use of the DHI was negotiated day-to-day in clinics. Participants in project meetings and in interviews were generally self-selected as supportive of the DHI. We attempted to mitigate the lack of patient user interviews through ongoing consultation with the PPI group, although we recognise that this group was not representative of the user population (see Blandford *et al.*,[4] Stevenson *et al.*[6] and Ismaila *et al.*[7]).

Varied and changing contexts of life with long COVID not accounted for

We have no information about the individual circumstances of app users beyond the demographic data collected and limited information about individual clinics' practices. What was known about long COVID, the resources available to clinics and external resources (such as online support groups, other online information resources and other local support) were all in a state of flux throughout the project period. Some app users had been living with long COVID for months or even years before they were given access to the app and had therefore already developed their own approaches to self-management. Others were themselves clinicians bringing prior expertise and knowledge. Factors such as these undoubtedly influence usage but are not visible to the analysts.

Quantitative data limitations: missing patient data

We limited ourselves to collecting only data that clinicians would normally collect to limit the burden on clinicians and patients and to increase the speed with which we could move the DHI into clinical practice, as service evaluation does not require Research Ethics Committee (REC) review. We did later add a demographic questionnaire at the request of NHSE, but we were not able to collect data on digital skills and confidence.

Inconsistent patient-reported outcome measure completion

The data collected in this study were recorded in real time by patients and were used by clinicians in their assessment and treatment. The necessity for clinically led data collection led to substantial missing data, partly due to the DHI evolving to include new features over the reported period; patients who used the DHI later in its development were able to complete more PROMs. Also, patients only completed PROMs of interest to them, and many dropped out altogether – for example, in RP 7, looking at patient trajectories, only 14% of the patients remained in the sample at week 12.

No data on initial severity of disease, vaccination status, nor comorbidities

As explained in Walker *et al.*[8]

> *The primary reason for DHI usage and associated data collection was not for research – as a result data on the severity of the initial disease or COVID-19 vaccination status were not collected within the DHI. Other studies have reported on the inconsistent relationship between severity of initial disease and severity of long COVID, therefore we did not seek to capture further patient data from other sources.*
>
> *(p. 9)*

Similarly, there were no data on comorbidities (see Walker *et al.*[8] and Sunkersing *et al.*[10]).

Potential overlap in symptom tracking responses

Patients were allowed to report their healthcare utilisation over the past 4 weeks at any time, but if they chose to do so more often than every 4 weeks, they might report on the same week or weeks more than once. Due to this possible overlap, calculating the cumulative cost might be challenging (see Wang *et al.*[9]).

As noted in Impacts of long COVID on patients, our data came from patients who are seen in long COVID clinics, probably not representative of all people with long COVID

We were able to examine demographic data after the relevant questionnaire became available to all patients in April 2021; we saw that our patient user population was not representative of the general population, nor do we know the demographic data for the population of people with long COVID, including those who are not seen in long COVID clinics.

Systematic scoping review limitations: heterogeneity of populations and limited data on digital skills

Heterogeneity of the populations studied and methods used by included studies meant that it may be hard to generalise from our findings. Few studies assessed digital health skills, and qualitative and mixed-methods studies explored the participants' motivation to use DHI, satisfaction and barriers/facilitators rather than skills and confidence.

Patient and public involvement

Aim

The aim was to identify user requirements in the context of a poorly understood condition and emerging clinical pathways. We asked PPI participants to advise around content, functionality, onboarding and clinical pathways.

Methods

All meetings took place on Zoom (Zoom Video Communications, San Jose, CA, USA). PPI participants were paid an hourly rate of £25 per hour for prework and attendance. We had 30 PPI participants involved over the course of the project.

Patient and public involvement in management

From the outset of the project, there were two PPI participants on the study steering group, actively participating in monthly meetings, and two on each of the WP management groups.

Patient and public involvement preparing digital health intervention content

Two PPI members, including one who was a co-applicant, contributed substantially by providing a PPI perspective on the delivery of the health professionals' rehabilitation recommendations, converting these into content for the DHI.

Patient and public involvement providing feedback

The wider advisory group took part in small-group discussions to provide feedback on the content and design. Some were able to access the DHI using the 'test login', but most were examining content in Microsoft Word (Microsoft Corporation, Redmond, WA, USA) documents, online or by post, rather than functionality.

Those who were able to access the DHI provided comments on functionality, and two took part in 'think aloud' sessions, explaining their thoughts as they attempted to carry out tasks.

Results

The PPI participants were involved with the research design work that was undertaken following submission of the application. The PPI perspective has been provided on all decisions on content, look, feel, functionality and navigation of the DHI.

As noted in *Key points*, PPI involvement early on provided the insight that patients experience their symptoms holistically and therefore expect their treatments to address all their symptoms in an integrated, rather than siloed, fashion. We also removed a core metaphor for long COVID from the DHI after it was rejected by PPI participants, on the grounds that it did not reflect the enormous range of possible symptoms and therefore not their experience. Ongoing PPI advice led to various changes, including in content tone – more encouragement – and the addition of advice on pacing for fatigue.

A second round of online recruitment to the PPI panel in September 2021 was led by the two PPI members of the steering group, supported by our Research Fellow.

Discussion

- We continued to use the PPI advisory group for feedback far longer into the project than expected, as ethics and data protection delays meant that we could not speak directly to DHI users until late in the project. The PPI participants brought their experience of the condition and also their existing skills to the project.
- Some PPI participants were more and less involved as their illness dictated – we reduced the length of feedback session from 1 hour to 30 minutes to accommodate fatigue and brain fog.

Reflections

Recruitment – the group was predominantly White and female, probably reflecting the composition of the online groups where we recruited them

We started by looking for PPI participants through PPI networks, including the 'Experts by Experience' group in the UCL Department of Primary Care and Population Health, the UCL Institute of Healthcare Engineering PPI support group, participating hospitals and online long COVID support groups. The original proposal was discussed with and reviewed by four PPI participants who have had COVID-19 in the community (two women from ethnic minority backgrounds, one White woman and one White man) and one PPI participant (woman from an ethnic minority background) who had been in an intensive care unit, though not for COVID. However, all the PPI participants

who agreed to join the advisory group for the study were recruited from online support groups.

This second round of recruitment did refresh the advisory group and continued to provide fresh eyes and alternative perspectives to critique the intervention. It slightly improved ethnic and gender diversity, but not as much as hoped.

We could have made our engagement processes more efficient and patient and public involvement-friendly from the start

- A standardised invitation letter and process for ongoing sessions would have saved time and confusion at the beginning.
- Some PPI participants found the complexity of the expense forms as an unnecessary burden for ill, tired people.
- Two PPI participants became embroiled in a disagreement over a weekend when project staff were not monitoring e-mail. We should have been explicit not to engage over the weekend and to refer to staff at the first sign of conflict.

Equality, diversity and inclusion

As discussed in *Impacts of long COVID on patients*, we aimed to explore equality, diversity and inclusion and the digital divide via WP 4.

Access to patient data came too late for specific analysis or qualitative research on gender or marginalised groups

The time taken to meet patient confidentiality and data-sharing requirements meant that we could not review user data to make further adaptations to the DHI during the project nor to contact users for interviews.

We had also hoped to interview DHCs, whom we had envisaged providing digital literacy and other support to DHI users or potential users. However, none of the clinics deployed DHCs.

As noted in Working with clinics to deploy the digital health intervention patients were representative of the patients who are seen in long COVID clinics nationally, not of all people with long COVID

Inclusivity

We attempted to incorporate gender and ethnic diversity into our personas for developing the DHI and to recruit a diverse PPI group – our second attempt only slightly increased male, older and ethnic minority background representation; 11 of the 30 participants opted to disclose their ethnicity: Bangladeshi 1, Indian 1, Turkish 1, White British 3, white and English 5.

We reduced the duration of PPI sessions to allow those with fatigue and/or brain fog to participate.

Guidance from clinicians was rewritten for the DHI, mainly by PPI participants, to reading age of 12 years, accessible to 80% of the UK population.

We were able to include one male speaker from an ethnic minority background in our limited selection of video resources on the DHI.

Impact and learning

What difference has been made already?

By the study completion date, 20 December 2022, there were 9781 invited patients, of whom 7679 had registered (78.5% of those invited), at 33 NHS clinics. By 1 May 2024, a total of 16,579 patients had been invited, of whom 13,544 had registered (81.7% of those invited), at 42 clinics.

Impact on clinics

The DHI provided patient access to a wide range of specialist knowledge that would not otherwise have been available at clinic level. Anecdotal evidence so far suggests that the DHI enabled clinicians to monitor patients far more efficiently than by conventional means.

Impact on patients

Compared with most studies reported in the literature on health technologies (with the exception of a few long-term projects that have had substantial funding over more than a decade), the LWCR project has had demonstrable impact on patients' supported self-management. We found that over 50% of the patients invited to participate in the LWCR project by July 2022 appear to have perceived some benefit: of the 7239 patients who were invited to use LWCR, 5684 registered (78.4% of those invited), and over 4600 patients read library articles and completed PROMs questionnaires (see Blandford *et al.*[4]).

What longer-term impact might there be?

This digital health intervention may contribute to wider provision and acceptance of digital health interventions by clinics nationally

The modifiable DHI has been developed and can be adapted to address other conditions. Clinicians in 33 NHS trusts across England and Wales have now been

exposed to a digitally delivered self-management system for patients. This may increase their acceptance of similar interventions in the future.

Lessons learnt for future research

The combination of agile methodology and a genuinely multidisciplinary team is highly effective in introducing new interventions and enabling learning

The DHI was produced and deployed rapidly, and the experience of working across boundaries can inform future research for those involved.

Normalisation Process Theory helped us understand the requirement for people to work differently at all levels of the National Health Service to implement the digital health intervention

We were able to consider the 'workarounds' people used and the necessity of champions and also the willingness to engage people across different disciplines to work together to make the implementation happen.

Working with an industry partner can be an efficient way to develop an intervention

The LW's experience in DHI development, as well as working with clinics and patients, was invaluable. This expertise was not available to us within the NHS or the universities.

Research must be adequately resourced

Requesting additional research support throughout the project would have allowed for more research and for production of outputs in a timely fashion. Such a resource would have been particularly beneficial for this project, given the importance of evidence in this novel area.

Data management should be included in digital health intervention project planning

As these interventions are likely to generate data, thought should be given to the scale of storage and nature of analysis required, to inform an appropriate strategy. Such a strategy may include specialist data management staff and/or software.

Related work, for example, things not directly funded by NIHR, *but arising from this study*

Findings about long COVID as an illness

We had not set out explicitly to study long COVID itself, but the inclusion of PROMs and other questionnaires for clinical use generated data for analysis. Among our findings, reported above, were.

- Many of the long COVID patients in the study were seriously ill.
- Clinical care and rehabilitation should address the management of fatigue as the dominant symptom explaining variation in functionality.
- Demographic factors significantly influence symptom severity, underlining the need for targeted interventions.
  pain is the most commonly tracked symptom in long COVID patients.
- *(If appropriate) Real-world impact/potential impact*.

National Health Service Trusts with limited resources in a time of national crisis were able to provide a service to patients using the digital health intervention

The DHI provided evidence-based, specialist-approved treatment at scale.

Collaborations/further funding/future work

STIMULATE-ICP[1]: Understanding long COVID to improve diagnosis, treatment and care

A trial, co-ordinated by UCL, will recruit over 4500 people with long COVID, starting with six sites in Hull, Derby, Leicester, Liverpool, London and Exeter. As well as evaluating current care, the study will include evaluation of community-based, comprehensive magnetic resonance imaging scan (using Coverscan™ developed by Perspectum, Oxford, UK) and enhanced rehabilitation (LWCR developed by LW) to inform a new integrated care pathway for people with long COVID. Within this study, another trial will test different drugs to measure effects of 3-month treatment on symptoms, mental health, return to work and other important outcomes.

What are your aspirational/preplanned dissemination or discussions to ensure the outcomes of the research are taken forward for implementation by your key stakeholders, partners and target audiences/groups?

The digital health intervention is still in use and continues to be promoted via Living With

The LWCR DHI is recommended and endorsed as a digital supported self-management tool in the NHSE guidance.[12]

New clinics joined in 2023, after the project ended, and new features continue to be added, for example:

- navigation improvements
- patient group management

- patient group messaging
- new treatment programmes, such as speech and language therapy, BPD and pain
- non-supported self-management version
- separate assessment module (questionnaires only).

Some clinics are expressing interest in separate long COVID respiratory and fatigue products.

The future of the product will now partly depend on funding decisions at NHSE.

Fatigue findings were widely reported in the press and prompted response from long COVID patients

The publication by Walker *et al.*,[8] on fatigue in long COVID patients, in June 2023, attracted significant media attention. By April 2024, it was in the top 5% of all research outputs scored by Altmetric.

Some long COVID patients wrote to the project team after reading the press reports.

> *I saw that you were interviewed by the Guardian and read your BMJ paper about long COVID. Congratulations! It's a lot of work to analyse data from that many patients, but it looks like you developed the DHI at exactly the right time to collect high quality data and get really useful results.*
> *I've been suffering with LC for 18 months now, so glad to see some decent research on it starting to appear.*
>
> *The findings are so validating for those living with this condition, and the data you and your team have collated.*
>
> *I just wanted to send you a personal thanks as you have made a massive impact regarding the long COVID community.*

Implications for decision-makers

Clinical care and rehabilitation for long COVID patients should address the management of fatigue. The research showed that fatigue is the dominant symptom keeping people from their normal lives, including full return to work. Many patients still needed time off work after 12 weeks.

Researchers are encouraged to consider broadening the range of potential collaborators to help overcome the many challenges of implementing DHIs into the NHS. This project demonstrated the effectiveness of a multidisciplinary team, incorporating academics and HCPs across disciplines and levels of seniority, as well as patient representatives and an industry partner. UCL Partners (UCLP) health innovation partnership and the Health Innovation Network (formerly Association of Health Science Networks)[3] also contributed. This combined expertise made it possible to implement and adapt the DHI under challenging circumstances.

Digital health intervention product design and deployment are equally important, and end-user input is essential to the success of both

There were three types of end-users of this DHI: patients, clinicians and service leads, and adapting the product design and deployment strategy to incorporate ongoing feedback from all of them made the DHI acceptable.

Design must accommodate not only diverse patient users, as they are not defined by clinical condition alone, but also diverse clinical pathways. Deployment is as important as product design in getting patients to engage with a DHI: the research showed an association between clinical practice and patient engagement. Digital tools to enable supported self-management need to accommodate the practices of the HCPs as well as the patients; to prioritise high quality HCP-led onboarding; and to ensure common ground between HCPs and patients (see Blandford *et al.*,[4] Stevenson *et al.*[6] and Ismaila *et al.*[7]).

The 'universal precautions' approach to both digital health intervention design and deployment can help to overcome health inequalities

The 'universal precautions' approach outlined in Veinot *et al.*[11] calls for developers and healthcare organisations to design DHI and deployment and communications strategies with the assumption that any patient may need support with literacy, health literacy or digital literacy and access to digital skills training, devices and data.

When using DHI in health care or recommending them for self-management, HCPs should be aware of the digital divide. For example, there may be barriers for patients to use digital mechanisms for making appointments. HCPs and healthcare organisations may need to provide support or signposting for vulnerable groups to access and understand health information online or via DHIs.

It had been expected that some clinics would use DHCs to help overcome barriers for patients with limited digital literacy. This did not happen, but future interventions should try to include DHCs and study the impact DHCs have on health inequalities (see Jenkins *et al.*[5]).

Funding the true cost of designing and deploying interventions, and of research, will pay dividends

The DHI development, however efficient, cannot sustainably rely on the willingness of those involved to work beyond their funded hours. Realistic funding of research that includes iterative development and testing of a DHI is essential if DHIs are the have a rapid and meaningful impact on health care. Realistic funding would also mean that all, rather than some, of the learning is made available and without delay (see Blandford *et al.*[4]).

Research recommendations

Clinical impact of this and other digital health interventions and application of this learning about digital solutions into new areas

It is likely that this type of digital health technology can be a valuable component of clinical pathways, for example, in the management of chronic, long-term intractable problems, such as mental health, in primary and community care services.

However, in the absence of a comparison group here, we have not been able to provide clear evidence of clinical impact. Further work will be needed on assessing the clinical effectiveness and cost-effectiveness if these technologies are to be taken up in ongoing patient care and self-management. The DHI is being tested in the STIMULATE-ICP trial.[1]

Deployment – what makes for effective integration with treatment pathways to work effectively for healthcare professionals and as many patients as possible?

Further exploration is needed of the barriers to, and facilitators of, DHI acceptance among trusts and HCPs at the organisation, service delivery and clinic level.

Longitudinal studies that track patient engagement over extended periods could provide a better understanding of the long-term impact of onboarding strategies and clinic–patient interactions on sustained patient engagement. Experimental studies that consider broader contextual factors could determine the causal relationships between onboarding strategies, clinic interactions and patient engagement outcomes.

A robust mixed-methods study could identify whether DHCs have an impact on health outcomes, digital skills and confidence to use DHI, and if expanding the scheme could help to overcome the digital divide with respect to DHIs.

Using artificial intelligence to promote engagement

Our models were not able to generate anything meaningful from the patient data, as these were too complex and there were too many unknown variables. To make sense of the data, we would need more complicated, non-linear and other deep representational models that were beyond our resources.

Linking the data to the EHR to attempt stratification of cohorts would help to move this forward, and the STIMULATE-ICP trial[1] is currently working on that.

Long COVID-related fatigue: its determinants, trajectories and management

Further work is needed to explore the recovery trajectories of this cohort over time and whether fatigue continues to predict the functional impairment and low HRQoL over time and also, the determinants of, and rehabilitation pathways for, long COVID-related fatigue.

Demographic determinants of long COVID trajectory and treatment

Intensity of pain was positively associated with being older, female, from an ethnic minority background, living in an area affected by multiple deprivations and less educated; further work is needed to understand why.

A total of 89% of the patients studied were White; further work is needed to understand if this was because people from the ethnic minority backgrounds fell less ill with long COVID, or less likely to be referred for treatment.

Conclusions

- This research focused on the development, deployment and evaluation of a digitally enabled rehabilitation programme for long COVID. The DHI has been incorporated into the Symptoms, Trajectory, Inequalities and Management: Understanding Long-COVID to Address and Transform Existing Integrated Care Pathways (STIMULATE-ICP) study,[1] which will provide an assessment of clinical effectiveness.
- Long COVID can be extremely debilitating, comparable to stage IV lung cancer or severe kidney disease in relation to fatigue and HRQoL. Clinical care and rehabilitation should address the management of fatigue as the dominant symptom keeping people from living their normal lives.
- Severity of symptoms is influenced by social disadvantage, underlining the need for continued targeted interventions.
- With sufficient resource, a DHI can be developed quickly and effectively using agile methodology

and bringing together a genuinely multidisciplinary team, including, in this case, clinical and non-clinical academics, HCPs, patients and an industry partner.
- The DHI product design and deployment are both important in getting NHS trusts, HCPs and patients to engage with a DHI. DHI projects should work closely with, and respond to, all those user groups to integrate the intervention into diverse clinical pathways.
- Pandemic conditions enforced remote working and highlighted the unmet need of a new patient group. Lockdown encouraged new users of technology who might otherwise have been reluctant to try a DHI. This digital remote support has been found acceptable by many patients and by clinics with different clinical pathways and so may encourage acceptance of other DHI.
- Inability to integrate data with medical records may limit the attractiveness of DHIs.

Additional information

CRediT contribution statement

Henry Goodfellow (https://orcid.org/0000-0002-0979-2839): Conceptualisation, Formal analysis, Funding acquisition, Investigation, Methodology, Supervision, Validation, Visualisation, Writing – reviewing and editing.

Ann Blandford (https://orcid.org/0000-0002-3198-7122): Formal analysis, Funding acquisition, Investigation, Methodology, Supervision, Writing – original draft, Writing – reviewing and editing.

Katherine Bradbury (https://orcid.org/0000-0001-5513-7571): Formal analysis, Funding acquisition, Investigation, Methodology, Supervision, Writing – reviewing and editing.

Manuel Gomes (https://orcid.org/0000-0002-1428-1232): Formal analysis, Funding acquisition, Investigation, Methodology, Supervision, Writing – original draft, Writing – reviewing and editing.

Fiona Hamilton (https://orcid.org/0000-0002-3126-5074): Formal analysis, Funding acquisition, Investigation, Methodology, Supervision, Writing – original draft, Writing – reviewing and editing.

William Henley (https://orcid.org/0000-0001-6273-2619): Data curation, Formal analysis, Funding acquisition, Investigation, Methodology, Supervision, Writing – original draft, Writing – reviewing and editing.

Fiona Stevenson (https://orcid.org/0000-0003-2139-2309): Supervision, Formal analysis, Methodology, Writing – original draft.

Delmiro Fernandez-Reyes (https://orcid.org/0000-0001-5070-9198): Formal analysis, Funding acquisition, Investigation, Methodology, Software, Writing – reviewing and editing.

John Hurst (https://orcid.org/0000-0002-7246-6040): Formal analysis, Funding acquisition, Investigation, Methodology, Writing – reviewing and editing.

Melissa Heightman (https://orcid.org/0000-0002-7507-2119): Funding acquisition, Methodology, Writing – reviewing and editing.

Paul Pfeffer (https://orcid.org/0000-0003-0369-2885): Conceptualisation, Funding acquisition, Methodology, Writing – reviewing and editing.

William Ricketts (https://orcid.org/0000-0002-0475-0744): Conceptualisation, Funding acquisition, Methodology, Writing – reviewing and editing.

Richa Singh (https://orcid.org/0009-0002-3239-2697): Funding acquisition, Methodology, Writing – reviewing and editing.

Hannah Hylton (https://orcid.org/0009-0002-5525-7869): Funding acquisition, Methodology, Writing – reviewing and editing.

Stuart Linke (https://orcid.org/0000-0003-2515-3946): Funding acquisition, Methodology, Writing – reviewing and editing.

Julia Bindman (https://orcid.org/0009-0001-5364-4681): Funding acquisition, Methodology, Resources, Writing – original draft, Writing – reviewing and editing, PPI (lead).

Chris Robson (https://orcid.org/0009-0007-8587-416X): Conceptualisation, Funding acquisition, Methodology, Resources, Writing – reviewing and editing.

Sarah Walker (https://orcid.org/0000-0003-4201-1093): Data curation, Formal analysis, Investigation, Writing – original draft.

Hadiza Ismaila (https://orcid.org/0009-0004-5852-1543): Formal analysis, Investigation, Writing – original draft.

Elizabeth Murray: Conceptualisation, Formal analysis, Funding acquisition, Investigation, Methodology, Supervision, Validation.

Jonathan Waywell: Data curation, Funding acquisition, Methodology, Resources.

This synopsis should be referenced as follows:
Goodfellow H, Blandford A, Bradbury K, Gomes M, Hamilton F, Henley W, *et al*. Development and implementation of a digital health intervention in routine care for long COVID patients: a comprehensive synopsis. *Health Soc Care Deliv Res* 2025;**13**(39):1–28. https://doi.org/10.3310/GJHG0331

David Sunkersing: Formal analysis, Investigation, Project administration, Writing – original draft.

Tahreem Chaudhry: Formal analysis, Investigation.

Enrico Costanza: Formal analysis, Investigation, Writing – original draft.

Jiunn Wang: Formal analysis, Investigation.

Rebecca Jaya Sudhir: Formal analysis, Investigation.

Tosan Okpako: Formal analysis, Investigation.

Aamina Mahmood: Investigation.

Jamie Scuffell: Investigation.

Shoba Poduval: Investigation.

Fred Thomas: Investigation.

Clare Casson: Project administration.

Tahreem Chaudry: Project administration.

Cherish Boxall: Project administration.

Shokraneh Oftadeh Moghadam: Project administration.

Emily Bellshaw: Project administration.

Belinda Cooper: Resources.

Georgina Palffy: Resources.

Christine Stroyan: Resources.

Vinosh Jegatheesan: Resources.

Ibrahim Mohammad: Resources.

Richard Russell: Supervision.

Kate Tilling: Supervision.

Kathrin Cresswell: Supervision.

Frances Simpson: Supervision.

Laura Bojke: Supervision.

See *Appendix 1* for acknowledgements.

Patient data statement

This work uses data provided by patients and collected by the NHS as part of their care and support. Using patient data is vital to improve health and care for everyone. There is huge potential to make better use of information from people's patient records, to understand more about disease, develop new treatments, monitor safety and plan NHS services. Patient data should be kept safe and secure, to protect everyone's privacy, and it's important that there are safeguards to make sure that those are stored and used responsibly. Everyone should be able to find out about how patient data are used. #datasaveslives You can find out more about the background to this citation here: https://understandingpatientdata.org.uk/data-citation.

Data-sharing statement

To request access to the underlying research data, please contact Professor Fiona Stevenson at f.stevenson@ucl.ac.uk. Access to anonymised data may be granted following review.

We generated a significant number of data that could be used by other researchers. Our PROMs data have already been anonymised and access may be requested. Please contact Professor William Henley W.E.Henley@exeter.ac.uk. There will be an administration fee.

Our remaining data could be made available in the future if there are resources available to anonymise and organise them. These data include records of all user interactions with the DHI, symptom tracking, diary and clinic data. There is also a demographic overview of the sample. Any interested researchers would need to get funding for the data preparation. Please contact Professor Fiona Stevenson at f.stevenson@ucl.ac.uk.

Ethics statement

The project was approved by the East Midlands – Derby REC, reference 288199, 23 July 2021, REC reference 21/EM/0160.

Ethical approval was granted to interview HCP, patients and other stakeholders, such as commissioners, at participating sites for one-to-one or group-based interviews. We also gained approval to observe clinician-patient interactions of onboarding (the process of registration and introducing patients to the app) to gain insights on how to improve the DHI.

Information governance statement

University College London is committed to handling all personal information in line with the UK Data Protection Act (2018) and the General Data Protection Regulation (EU GDPR) 2016/679. Under the Data Protection legislation UCL is the Data Processor; NHS is the Data Controller and we process personal data in accordance with their instructions. You can find out more about how we handle personal data, including how to exercise your individual rights and the contact

details for UCL's Data Protection Officer here: www.ucl.ac.uk/data-protection/reporting-breach-or-subject-access-request/contact-data-protection-team.

Disclosure of interests

Full disclosure of interests: Completed ICMJE forms for all authors, including all related interests, are available in the toolkit on the NIHR Journals Library report publication page at https://doi.org/10.3310/GJHG0331.

Primary conflicts of interest: Katherine Bradbury reports support for the present manuscript and part of her research income was funded by NIHR ARC Wessex. NIHR ARC Wessex provided some administrative support to help support this project in the first 6 months.

John Hurst reports grants or contracts from Astra Zeneca (PhD studentship) and payment or honoraria from Astra Zeneca, Boehringer Ingelheim, Chiesi, Sanofi, Takeda. John Hurst reports also participation on a Data Safety Monitoring Board or Advisory Board for Astra Zeneca. He also reports receipt of equipment from Nonin (donation of oximeters).

Paul Pfeffer reports grants or contracts from UKRI (co-investigator on on PHOSP-COVID study).

Hannah Hylton reports payment or honoraria from RCGP (lecture fees, £150).

Stuart Linke reports payment or honoraria for presenting an IAPT training seminar on managing long COVID.

Julia Bindman reports support for the present manuscript and payments from University College London for working with the patient and public involvement group and preparing content for the DHI since May 2020. Julia Bindman also reports grants or contracts from Living With (long COVID app) and other freelance content work.

Chris Robson and Jonathan Waywell are directors of the industry partner, Living With Ltd, which has a suite of DHIs used in healthcare systems, including the NHS.

Chris Robson reports support for the present manuscript and fees received from NIHR to help pay for the implementation of the LWCR product and research. Chris Robson also reports grants or contracts for STIMULATE-ICP (Symptoms, Trajectory, Inequalities and Management: Understanding Long-COVID to Address and Transform Existing Integrated Care Pathways) in accordance with the work specified in SECTION 3 being project application COV-LT2-0043, dated 12 May 2021, amending correspondence, 25 October 2021 the 'Research'. Chris Robson is also the CEO of Living With Ltd and has stock in Living With.

Copyright and credit statement

Department of Health and Social Care disclaimer

Publications

Academic presentations, webinars and videos

- Invited seminar at workshop for the cross NIHR ARCs digital health tools working group, 27 November 20 (Co-I Katherine Bradbury).
- Oral presentation at the British Thoracic Society Annual Scientific Meeting February 2021 (Co-I Hannah Hylton).
- Oral presentation at the South East Regional Meeting of the Society for Academic Primary Care January 2021 (Co-Chief Investigator Henry Goodfellow).
- Invited Plenary Panel presentation at the UK Society for Behavioural Medicine ASM January 2021 (Co-Chief Investigator Elizabeth Murray).
- Invited keynote, Conference on patient reported outcomes, Oslo February 2021 (Co-CI Elizabeth Murray).
- Invited seminar, Kings College London, March 2021 (Co-CI Elizabeth Murray).
- Seminar for the UCL IoMH Wellcome Trust PhD program in mental health; 10 March 2021. (Co-I Stuart Linke).
- Multiple presentations to interested clinical teams (October 2020–March 2021) (Co-CIs Murray and Goodfellow, plus

Chris Robson) CR alone has undertaken 51 presentations to Trusts plus 34 demonstrations in this period).

- Presentation to National IAPT series on long COVID 12.1.21 (Co-I Stuart Linke).
- Camden and Islington NHS Academic Programme 'Long COVID and Mental Health: What we are learning from a digital recovery programme' (3 February 2021). (Co-I Stuart Linke).
- Two presentations to the Digital Health Champions in North East London Foundation Trust (February and March 2021). (Co-I Fiona Hamilton).
- ARC newsletter: www.arcwx.nihr.ac.uk/news/new-approach-to-tackling-the-longlasting-symptoms-of-covid-19/
- Presentation to UCLP Innovation Network 9 February 2021 (Co-CI Elizabeth Murray).
- Wessex ARC March and July 2021.
- UCLP Innovators Network May 2021
- NHS Wales May 2021.
- London Region Long COVID Programme May 2021.
- NHSE Long COVID team May 2021.
- RCGP Round Table on Long COVID June 2021.
- UCLP Staff meeting June 2021.
- University of Surrey Annual Digital Health Seminar June 2021.
- West of England Academic Health Science Network (AHSN) August 2021.
- Care City/Living With Collaborative Workshop 5 October 21: LWCR: what can we learn from the data? (Co-CI Elizabeth Murray).
- UCLIC webinar 24 November 21 connecting patients and clinicians through the app (Co-CI Henry Goodfellow).
- Russell Group short video 1 December 21: how the app helps doctors treat more patients (Co-CI Henry Goodfellow).
- Queen's Nursing Institute COVID Expert Nurse Group 1 December 21: Digital support for patients with Long COVID (Co-CI Henry Goodfellow).
- Queen's Nursing Institute digital network 10 December 21: learnings from LWCR project
- SAPC 20 January 2022 https://t.ly/Q5FT: reasons for success with LWCR (academic contributor David Sunkersing).
- NHSE/NHS Improvement (London) 20 January 2022 overcoming inequalities in healthcare; how digital can help (Co-CI Henry Goodfellow).
- NIHR CRN N. Thames webinar 16 February 2022. Implementation and findings to date (Co-CI Henry Goodfellow) https://t.ly/MGdF
- Used as an exemplar research project presented by UCLP to senior AHSN/NHSE Improvement representatives 7 March 2022. Feedback very positive.
- Pulse Live event 26 April 2021: 30 minute talk to disseminate research findings (Co-CI Henry Goodfellow) https://t.ly/JSF9L
- NHSE and Improvement: meeting with Sarah Cooper senior long COVID programme manager. Presented results. LWCR will be included in updated Post COVID Assessment Guidelines.
- UCLP YouTube video – very positive feedback from patient using the app https://t.ly/oBhr
- Long COVID – what we know and what we need to know, 7 November 2023: UCL nationally funded researchers and people with lived experience, at the UCL Great Ormond Street Institute of Child Health: Professor Ann Blandford.
- Chris Robson (Living With) continues with regular demo presentations to increase uptake of DHI by Trusts.

Finalist for awards

- Royal College of Physicians' Excellence in Patient Care Award, 'Digital Award' 2021.
- LaingBuisson Awards 2021 - Outstanding Response to COVID in Healthcare https://t.ly/QyXF Central and North West London NHS Foundation Trust (CNWL) were finalists for use of LWCR app.
- HSJ Partnership Awards 2022: HealthTech Partnership of the Year https://t.ly/Zki5

Media

- Article in I News 14 August 2020.

- BBC South report 19 February 2021 https://vimeo.com/505587303/c719fe4b35
- Article in I News 6 March 2021 https://inews.co.uk/news/science/long-covid-digitaltreatment-programme-rolled-out-in-hospitals-to-helppatients-with-chronic-illness-900691
- Item in the SPCR newsletter March 2021 www.spcr.nihr.ac.uk/news/treatment-plan-forlong-covid

National media

- Extensive national and international media coverage of publication of Impact of fatigue as the primary determinant of functional limitations among patients with post-COVID-19 syndrome: a cross-sectional observational study.

In top 5% of all research outputs scored by Almetric, 1% of outputs of same age.

Altmetric – Impact of fatigue as the primary determinant of functional limitations among patients with post-COVID-19 syndrome: a cross-sectional observational study.

- BBC News London 2 June 2021.
- The I paper, 27 June 2021.
- BBC Look North 14 July 2021.
- Daily Mail 10 August 2021.
- The i paper, 16 September 2021.
- Guardian interview: Ami Banerjee (STIMULATE-ICP) 12 January 2022 included link to LWCR app https://t.ly/imDz

Specialist media

- UCLP newsletter August 2021 (case study of PPI excellence).
- Division of Clinical Psychology UCL Long COVID newsletter September 2021.
- ARC North Thames newsletter, May 2021
- UCL Healthcare Engineering newsletter, 2020 and 2021.
- UCLP Blog 17 March 2021: UCLPartners supports rehab app for long COVID.
- UCLP Blog 25 August 2021: Involving patients from the very beginning for COVID rehabilitation.
- Case study for NIHR Be Part of Research Campaign. Rated one of the top social media posts during the campaign, with 14,549 impressions, 199 engagements, 22 RTs and 11 likes on the @NIHRresearch Twitter (Twitter, Inc., San Francisco, CA, USA) channel on 1 June 2021.
- Hannah Hylton on PSL Blog 18 November 2021 https://t.ly/RU2J
- Henry Goodfellow video for Russell Group shared widely on Twitter (URL: https://twitter.com/RussellGroup/status/1465991700703240192; accessed 1 September 2025) and LinkedIn (URL: https://www.linkedin.com/posts/russell-group-of-universities_60-good-university-seconds-dr-henry-goodfellow-activity-6871759075227521024-EMRi; accessed 1 September 2025) 1 December 2021.
- UCL News article we've been featuring on the UCL homepage: www.ucl.ac.uk/news/2023/jun/long-covid-can-impact-fatigue-and-quality-life-worse-some-cancers

Study registration

The study is registered as Research Registry number researchregistry6173.

Funding

This synopsis presents independent research funded by the National Institute for Health and Care Research (NIHR) Health and Social Care Delivery Research programme as award number NIHR132243.

This synopsis provided an overview of the research award *Supported remote rehabilitation post Covid-19: development, deployment and evaluation of a digitally-enabled rehabilitation programme*. For other articles from this thread and for more information about this research, please view the award page (www.fundingawards.nihr.ac.uk/award/NIHR132243).

About this synopsis

The contractual start date for this research was in October 2020. This synopsis began editorial review in May 2024 and was accepted for publication in March 2025. The authors have been wholly responsible for all data collection, analysis and interpretation, and for writing up their work. The Health and Social Care Delivery Research editors and publisher have tried to ensure the accuracy of the authors' synopsis and would like to thank the reviewers for their constructive comments on the draft document. However, they do not accept liability for damages or losses arising from material published in this synopsis.

List of abbreviations

AHSN	Academic Health Science Network
AI	artificial intelligence
BPD	breathing pattern disorder
CI	Chief Investigator
DHC	digital health champion
DHI	digital health intervention
EHR	electronic health record
F2F	face-to-face
GP	general practitioner
HCI	human–computer interaction
HCP	healthcare professional
HRQoL	health-related quality of life
LW	Living With Ltd
LWCR	Living With COVID Recovery
MRC	Medical Research Council
NHSE	NHS England
NIHR	National Institute for Health Research
NPT	Normalisation Process Theory
PCS	post-COVID syndrome
PPI	patient and public involvement
PROM	patient-reported outcome measure
RCT	randomised controlled trial
REC	Research Ethics Committee
RP	research paper
STIMULATE-ICP	Symptoms, Trajectory, Inequalities and Management: Understanding Long-COVID to Address and Transform Existing Integrated Care Pathways
UCL	University College London
UCLP	University College London Partners
WP	work package
WSAS	Work and Social Adjustment Scale

References

1. Forshaw D, Wall EC, Prescott G, Dehbi HM, Green A, Attree E, *et al.*; STIMULATE-ICP trial team. STIMULATE-ICP: A pragmatic, multi-centre, cluster randomised trial of an integrated care pathway with a nested, phase III, open label, adaptive platform randomised drug trial in individuals with Long COVID: A structured protocol. *PLOS One*. 2023;**18**:e0272472. https://doi.org/10.1371/journal.pone.0272472.
2. Murray E, Goodfellow H, Bindman J, Blandford A, Bradbury K, Chaudhry T, *et al*. Development, deployment and evaluation of digitally enabled, remote, supported rehabilitation for people with long COVID-19 (Living With COVID-19 Recovery): protocol for a mixed-methods study. *BMJ Open* 2022;**12**:e057408. https://doi.org/10.1136/bmjopen-2021-057408.
3. NHS England. *The Health Innovation Network*. NHS England. URL: www.england.nhs.uk/ourwork/partrel/healthinnovationnetwork/ (accessed 21 August 2024).
4. Blandford A, Bindman J, Bradbury K, Cooper B, Costanza E, Edwards S, *et al*. Experiences of user-centred design with agile development for clinically supported self-management of long COVID. *ACM Trans Comput Hum Interact* 2025;**32**:6. https://doi.org/10.1145/3711839.
5. Jenkins CL, Imran S, Mahmood A, Bradbury K, Murray E, Stevenson F, Hamilton FL. Digital Health Intervention design and deployment for engaging demographic groups likely to be affected by the digital divide: protocol for a systematic scoping review. *JMIR Res Protoc* 2022;**11**:e32538. https://doi.org/10.2196/32538.
6. Stevenson FA, Pfeffer P, Walker S, Ismaila H, Jegatheesan V, Mohammad I, *et al*. Using normalisation process theory to evaluate the implementation of a digital health intervention in community and secondary care long COVID clinics. *BMJ Open* 2024;**14**:e092824. https://doi.org/10.1136/bmjopen-2024-092824.
7. Ismaila H, Blandford A, Sunkersing D, Stevenson F, Goodfellow H. Comparative insights into clinic onboarding and interaction practices for patient engagement in long COVID digital health care. *Digit Health* 2024;**10**. https://doi.org/10.1177/20552076241294101.

8. Walker S, Goodfellow H, Pookarnjanamorakot P, Murray E, Bindman J, Blandford A, *et al*. Impact of fatigue as the primary determinant of functional limitations among patients with post-COVID-19 syndrome: a cross-sectional observational study. *BMJ Open* 2023;**13**:e069217. https://doi.org/10.1136/bmjopen-2022-069217.

9. Wang J, Goodfellow H, Walker S, Blandford A, Pfeffer P, Hurst JR, *et al*. Trajectories of functional limitations, health-related quality of life and societal costs in individuals with long COVID: a population-based longitudinal cohort study. *BMJ Open* 2024;**14**:e088538. https://doi.org/10.1136/bmjopen-2024-088538.

10. Sunkersing D, Goodfellow H, Mu Y, Ramasawmy M, Murali M, Adams L, *et al*. Long COVID symptoms and demographic associations: a retrospective case series study using healthcare application data. *JRSM Open* 2024;**15**. https://doi.org/10.1177/20542704241274292.

11. Veinot TC, Mitchell H, Ancker JS. Good intentions are not enough: how informatics interventions can worsen inequality. *J Am Med Inform Assoc* 2018;**25**:1080–8. https://doi.org/10.1093/jamia/ocy052.

12. NHS England. *Commissioning Guidance for Post-COVID Services for Adults, Children and Young People*. NHS Englad; 2024. p. 8. URL: www.england.nhs.uk/long-read/commissioning-guidance-for-post-covid-services-for-adults-children-and-young-people/ (accessed 21 August 2024).

Appendix 1 Acknowledgements

Co-investigators

Elizabeth Murray, Co-Chief Investigator, UCL, e-Health unit, Department of Primary Care and Population Health, Institute of Epidemiology and Healthcare.

Henry Goodfellow, Co-Chief Investigator, UCL, Department of Primary Care and Population Health, Institute of Epidemiology and Healthcare.

Ann Blandford, UCL Interaction Centre (UCLIC), Department of Computer Science.

Katherine Bradbury, Southampton University, Department of Health Psychology.

Manuel Gomes, UCL, Applied Health Research, UCL Institute of Epidemiology and Health Care.

Fiona Hamilton, UCL, Department of Primary Care and Population Health, Institute of Epidemiology and Healthcare.

William Henley, Exeter University, Department of Medical Statistics, University of Exeter Medical School.

Fiona Stevenson, UCL, Department of Primary Care and Population Health, Institute of Epidemiology and Healthcare.

Delmiro Fernandez-Reyes, UCL, Department of Computer Science.

John Hurst, UCL, Department of Respiratory Medicine.

Melissa Heightman, UCLH NHS Foundation TrustPaul Pfeffer, Barts Health NHS Trust.

William Ricketts, Barts Health NHS Trust.

Richa Singh, Barts Health NHS Trust.

Hannah Hylton, Barts Health NHS Trust.

Stuart Linke, Camden and Islington NHS Foundation/ UCL, Department of Primary Care and Population Health, Institute of Epidemiology and Healthcare.

Julia Bindman, PPI (patient and public involvement) lead.

Chris Robson, CEO, Living With Ltd.

Other academic contributors

Hadiza Ismaila, Research Fellow, Department of Primary Care and Population Health, Institute of Epidemiology and Healthcare.

Sarah Walker, University of Exeter Medical School.

David Sunkersing, UCL, Department of Primary Care and Population Health, Institute of Epidemiology and Healthcare.

Tahreem Chaudhry, UCL, Department of Primary Care and Population Health, Institute of Epidemiology and Healthcare.

Enrico Costanza, UCLIC, Department of Computer Science.

This synopsis should be referenced as follows:
Goodfellow H, Blandford A, Bradbury K, Gomes M, Hamilton F, Henley W, *et al*. Development and implementation of a digital health intervention in routine care for long COVID patients: a comprehensive synopsis. *Health Soc Care Deliv Res* 2025;**13**(39):1–28. https://doi.org/10.3310/GJHG0331

Jiunn Wang, UCL, Applied Health Research, UCL Institute of Epidemiology and Health Care.

Federica Picariello, King's College London.

Rebecca Jaya Sudhir, PhD Candidate, UCL Department of Primary Care and Population Health, Institute of Epidemiology and Healthcare.

Tosan Okpako, PhD Candidate, UCL Institute of Epidemiology and Healthcare.

Vinosh Jegatheesan, UCL Medical School.

Ibrahim Mohammad, UCL Medical School.

Aamina Mahmood, UCL Medical School.

Dr Jamie Scuffell, NIHR Academic Clinical Fellow, King's College London. GP Registrar, Streatham Common Practice.

Shoba Poduval, UCL, Clinical Lecturer eHealth Unit.

Jo Dobbin, UCL, GP ACF PCPH.

Fred Thomas, Royal Free Hospital, GP ACF.

Cherish Boxall, Southampton Clinical Trials Unit.

Patra Pookarnjanamorakot, Royal Free London NHS Foundation Trust.

Other clinical contributors

Charlotte Foster, Barts Health NHS Trust.

Jane Simpson, Barts Health NHS Trust.

Heidi Ridsdale, Central and North West London NHS Foundation Trust.

Rachel Okin, Central and North West London NHS Foundation Trust.

Other contributors

Jonathan Waywell, Living With Ltd.

Belinda Cooper, PPI.

Georgina Palffy.

Christine Stroyan.

Our Patient and Public Involvement Group.

Clare Casson.

Living With COVID Recovery Independent Study Steering Committee

Richard Russell, Chair, Independent Study Steering Committee, Oxford University.

Kate Tilling, Member, Independent Study Steering Committee, Bristol University, Population Health Science Institute.

Kathrin Cresswell, Member, Independent Study Steering Committee, Edinburgh University.

Frances Simpson, Member, Independent Study Steering Committee and PPI, Coventry University.

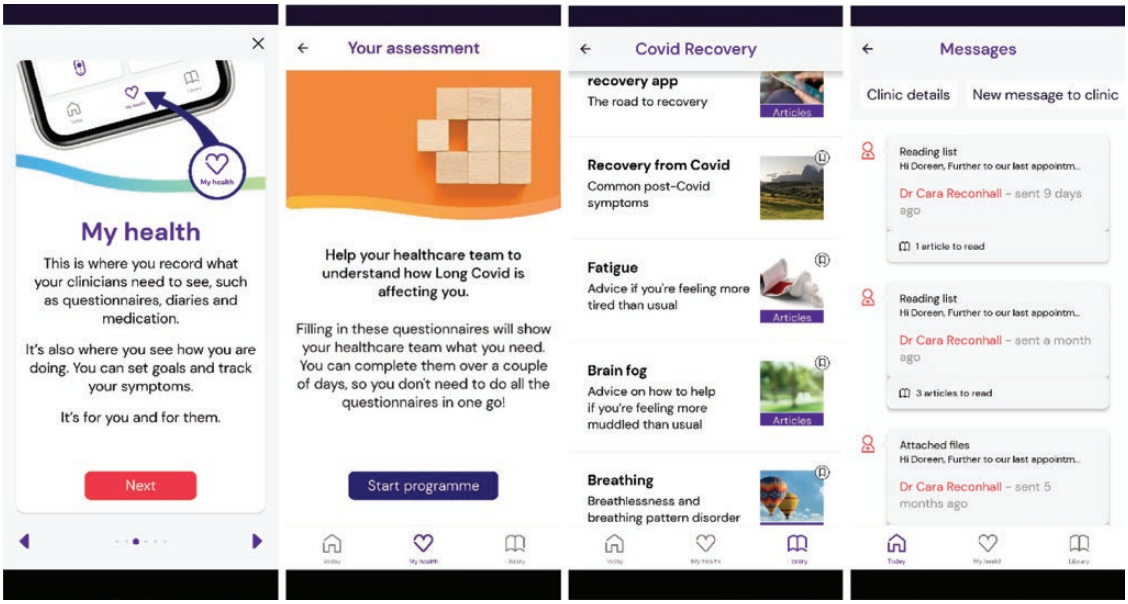
Laura Bojke, Member, Independent Study Steering Committee, York University.

Appendix 2: Sample screenshots from the digital health intervention

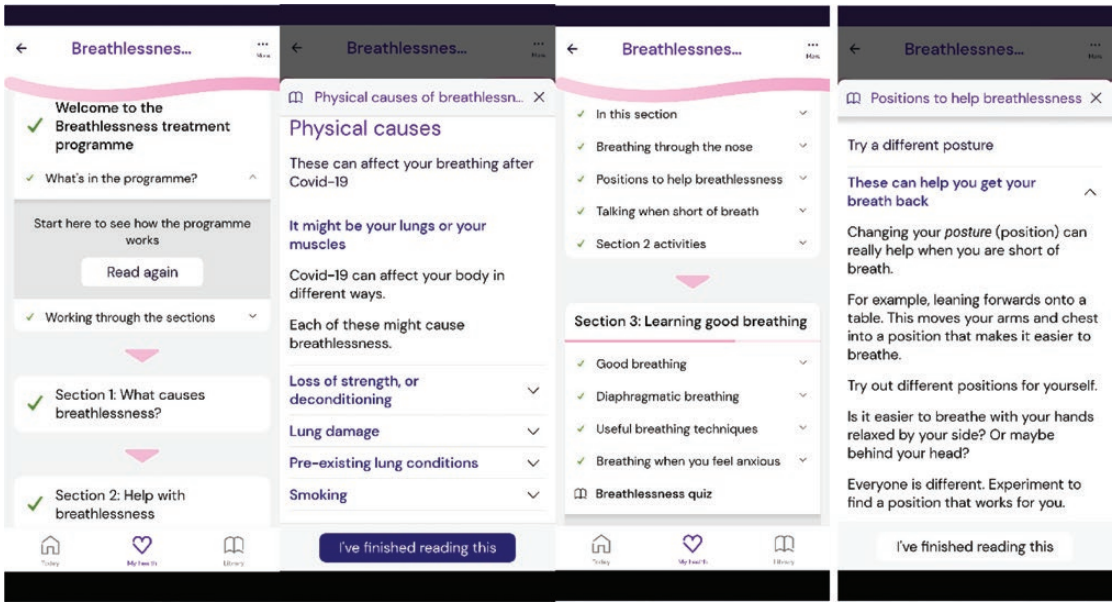
The doctor and patients in these samples are all fictitious – these screens are from dummy accounts created for demonstrating the app to clinicians.

Sample patient-facing screens

Cover pages for sample areas of the DHI: 'My health' area for patients to enter information, the 'assessment' questionnaires area, the 'Library' advice area and 'Messages' between the patient and clinician.

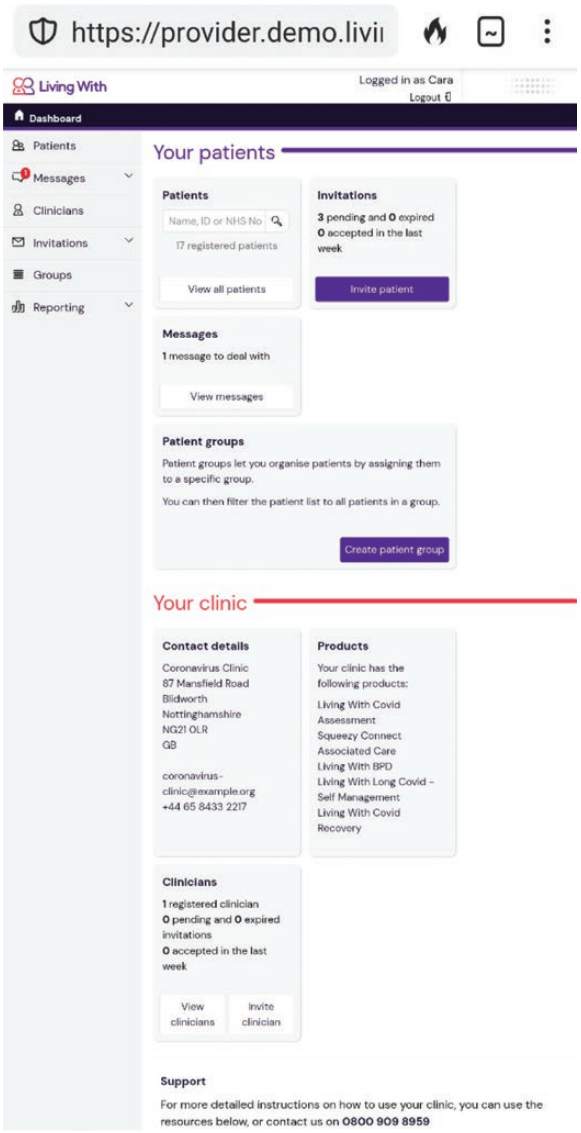


Sample screens from the Breathlessness treatment programme



Sample clinician-facing screens

Dashboard screens



Screens for an individual patient