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Patient & Public Engagement and Social Research: Long COVID

Report to the Joint Programme for Patient, Carer and Public Engagement in COVID Recovery

September 2022

Guy's and St Thomas' NHS Foundation Trust (including Royal Brompton and Harefield Hospitals and Evelina London Children's Healthcare) and King's College Hospital NHS Foundation Trust.

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Generously funded by Guy's & St Thomas' Charity and King's College Hospital Charity

Guy's & St Thomas' Charity &..

King's college hospital charity

Acknowledgments

We are so grateful for the people living with Long COVID who put so much time and effort into the discussions for this work. We witnessed the fatigue of Long COVID firsthand as people joined us, and we appreciated how they had worked their whole day around having the energy to take part in the 2-hour workshop sessions. We were struck by both people’s generosity with their own stories and data, their determination for a better future, their outrage at the slowness of the NHS response and the trauma of society ‘moving on’ without recognising their toll.

We are thankful for the professionals that stepped into unknown collaborative territory with open hearts and minds to discover how to support people with Long COVID.

Thank you to the People’s Academy citizens from London South Bank University who listened with care to people’s experiences and supported those in distress.

Finally, thank you to the funders of this work who had the foresight to fund a programme of work that not only contributed to a new model of care but built the capacity to deliver that along the way.

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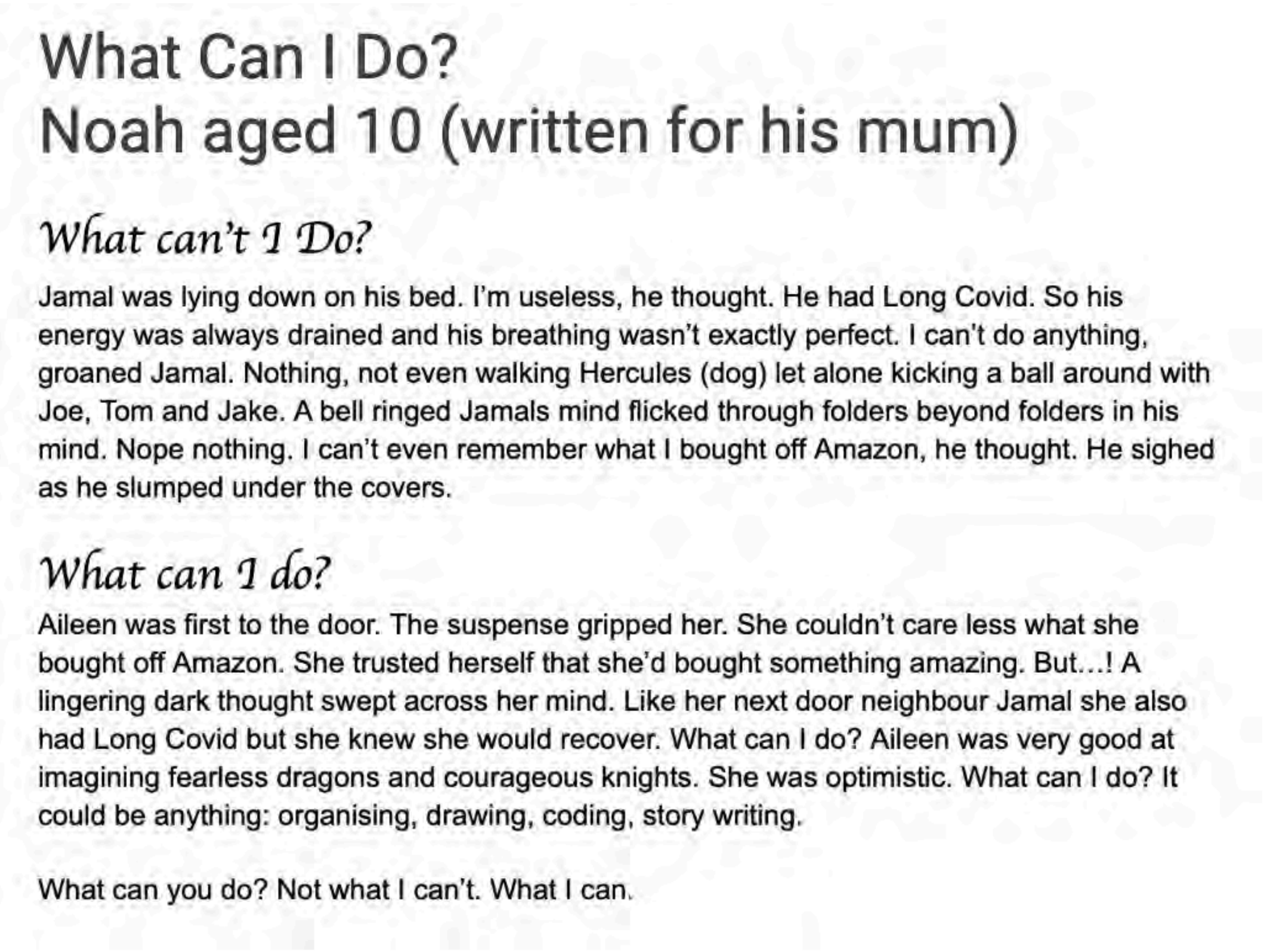
What Can I Do?

This short piece, written by a relative of a participant in the workshops shows how focusing on ‘what’s strong’ really matters to people living with Long COVID and their carers.



What Can I Do?

Noah aged 10 (written for his mum)

What can’t I Do?

Jamal was lying down on his bed. I’m useless, he thought. He had Long Covid. So his energy was always drained and his breathing wasn’t exactly perfect. I can't do anything, groaned Jamal. Nothing, not even walking Hercules (dog) let alone kicking a ball around with Joe, Tom and Jake. A bell ringed Jamals mind flicked through folders beyond folders in his mind. Nope nothing. I can’t even remember what I bought off Amazon, he thought. He sighed as he slumped under the covers.

What can I do?

Aileen was first to the door. The suspense gripped her. She couldn’t care less what she bought off Amazon. She trusted herself that she’d bought something amazing. But…! A lingering dark thought swept across her mind. Like her next door neighbour Jamal she also had Long Covid but she knew she would recover. What can I do? Aileen was very good at imagining fearless dragons and courageous knights. She was optimistic. What can I do? It could be anything: organising, drawing, coding, story writing.

What can you do? Not what I can’t. What I can.

Summary

This report gives a full account of a collaboration between Guy's and St Thomas' NHS Foundation Trust (GSTT) including Evelina London Children's Hospital and Royal Brompton and Harefield Hospitals (RBH) and King's College Hospital NHS Foundation Trust (KCH), and the communities they serve to develop a Model of Care for people living with Long COVID.

The Inquiry Questions for the Programme are:

1. What support or interventions would be helpful (e.g., clinical treatment, peer to peer support, self-management/supported self-management, advice, and guidance) and how can these services be as accessible as possible to patients?
2. How can health professionals help patients manage their symptoms, access services, and alleviate anxiety?

The approach included:

1. Desk Research, including reviewing previous commissioned research and intelligence from National Voices work on Long COVID provided as a background report
2. Mapping cohorts and inviting participants to the workshops with the help of a Design Team (a group of committed leaders from within the Trusts), through direct phone calls and messaging, through engaged local community organisations and representatives.
3. A series of coproduction workshops bringing people living with Long COVID, their cares, clinicians and allied staff from primary and secondary care, third sector organisations together

The approach resulted in the work shared in this report alongside changes in real time (during the programme) to services, ongoing collaboration of people living with Long COVID in service development, and coproduction of the videos and materials developed to support knowledge sharing.

Overall, 79 people were engaged in the Long COVID workshops of which 4 were observers, across 7 workshops.

This report provides a Model of Care for people living with Long COVID, a graphic illustration and animation of what it is like to live with Long Covid, and a set of recommendations. The materials can be found here.

Catalysing Change

Alongside the development of the Model there have been a range of immediate outputs from the workshops:

- People living with Long COVID have formed a whatsapp group to keep in touch and keep sharing.
- Some place-based groups have been established and are working with their local health professionals.
- Some of the participants have volunteered to help in the testing of the model in practice and have begun that work with the service lead.
- Prototype of educational support for patients is being put into place with people who contributed to the workshops.
- Clinicians are rewriting their clinic information booklets using the information provided in the workshop materials.

- Patients who are working shared an example email signature to include the graphic of living with Long COVID

The model development is not a static process of reporting the findings here, but the development process did contribute to the emerging New Model of Care as it is being developed in real-time, without waiting for this report. It was really helpful to have feedback from clinical leaders about how they were using the discussions and findings as they establish the Long COVID service.

Recommendations

Long COVID is both diagnosed and undiagnosed in the population, and so the scale of the problem remains unknown. The ONS[1] has reported that

"An estimated 2.0 million people living in private households in the UK (3.0% of the population) were experiencing self-reported long COVID (symptoms continuing for more than four weeks after the first suspected coronavirus (COVID-19) infection that were not explained by something else) as of 4 June 2022"

People who developed Long COVID early on in the pandemic shared their experience of having had very little support and some did not have a diagnosis. There are stages of the Long COVID experience that differ with time, services must be provided that recognise this trajectory and meet the different needs that this brings. The range of symptoms is variable and complicated. Service offers need to recognise the whole person and the variation between people.

1. The Model of Care for people with Long COVID needs to be bespoke to the whole person. It requires an approach to diagnosis that is pragmatic and enables people to access the pathway without relying on a GP referral.
2. The Long COVID Clinic as the foundation for all therapies and interventions is invaluable. This needs to be embedded in the community and provided at Borough level. There needs to be an audit to check for people who were in the clinic but have been 'lost'.
3. As the Long COVID model develops it must not increase inequalities, it must ensure that it is universally accessible. There is some experience of services developing differently in different places
4. As this is an emerging Model, health professionals need to find ways to be open to people's experience without being defensive, and learn together, in order to be able to adapt the service offer.
5. In all discussions with people living with Long COVID that are being undertaken online health professionals must have their camera on.

Primary Care should:

6. Provide a working diagnosis (a diagnosis based on symptoms rather than clinical investigations) for people who present with the symptoms of Long COVID; and identify the cohort of people with Long COVID on the GP list (as there is growing

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[1] Ayoubkhani, D. and Pawelek, P., (2022). Prevalence of ongoing symptoms following coronavirus (COVID-19) infection in the UK: July 2022. Available at https://www.ons.gov.uk/peoplepopulationandcommunity/healthandsocialcare/conditionsanddiseases/bulletins/prevalenceofongoingsymptomsfollowingcoronaviruscovid19infectionintheuk/7july2022#:~:text=An%20estimated%202.0%20million%20people,2022%20(see%20Figure%201). Accessed 25th September 2022.

evidence that there are people living with Long COVID who do not have a diagnosis and who are not accessing services).

7. Provide Long COVID specific Social Prescribing – we suggest this is a cohort for the coming Social Prescribing funding.
8. Provide Long COVID specific Care Navigators.
9. Support the development of local peer support networks, alongside Long COVID clinics (people living with Long COVID can't do the heavy lifting of setting this up).
10. Refer for talking therapies and life coaches.

The NHS should:

11. Create a trusted information service and communications campaign to educate and inform people living with Long COVID, families, carers, friends, society, employers.
12. Educate professionals, employers and society about what Long COVID is, how it manifests, and how to help.
13. Catalyse new activities that will support people with Long COVID to achieve short-term goals - this means making the demand evident and educating activity providers (sports/ yoga) on how to support people with Long COVID.
14. Make the Long COVID pathway explicit and accessible.
15. Support community Long COVID champions who can help lead community-based solutions.

Background to the Programme

This programme was commissioned by the Joint Programme for Patient, Care and Public Involvement in COVID Recovery. Established in September 2020, the Joint Programme for Patient, Care and Public Involvementin COVID Recovery is a partnership between Guy's and St Thomas' NHS Foundation Trust (GSTT) including Evelina London Children's Hospital and Royal Brompton and Harefield Hospitals (RBH) and King's College Hospital NHS Foundation Trust (KCH). It is funded, over two years, by Guy's & St Thomas' Charity and King's College Hospital Charity to ensure the involvement of patients, carers and the public in ongoing changes and the development of services necessitated by the COVID pandemic.

The programme is working with patients, carers, and the public to understand:

- Shifts in public attitudes and behaviours toward accessing care in different parts of the healthcare system and the risk that patients and the public may retract from accessing the care they need now or in the future
- How changes made, or being made, continue to affect patients, their families and carers' experiences of accessing care, using new or rapidly changing models of care
- Variations in experience of care between different protected characteristics
- How we can improve and further develop services

As part of the programme's activities, an extensive scoping, identification, and prioritisation exercise was carried out to refine the focus of the programme. This resulted in the prioritisation of the following three projects:

- Virtual access to care
- Waiting for treatment and self-management
- Long COVID

London South Bank University's Health Systems Innovation Lab and People's Academy supported the delivery of the three projects outlined above. This report is for the Long COVID Patient and Public Engagement Programme.

The Inquiry Questions for the Programme are:

- What support or interventions would be helpful (e.g., clinical treatment, peer to peer support, self-management/supported self-management, advice, and guidance) and how can these services be as accessible as possible to patients?
- How can health professionals help patients manage their symptoms, access services, and alleviate anxiety?

The deliverables include:

1. Report from the Desk Research Provided here (summary short report) and a full report provided to the Joint Programme Steering Group.
2. A Peer Network to support the development of Long COVID services and self-management. Including a network database. This has been provided and organised by borough group.
3. A co-designed model for services and self-management of Long COVID (an exemplar Model Service). This is provided here and within this report.

4. The project final report as required in the specification (Report) and a set of materials to support knowledge sharing including graphics and a video written and narrated by people living with Long COVID who contributed to the workshops, available from the programme webpage here

The Context of COVID

This programme of work was commissioned in Autumn 2021 with the plan to deliver the workshops in 2021-22. The pandemic COVID surge in the winter of 2021-22, created a significant capacity issue for the clinicians contributing to this work, and a difficulty in recruiting patients and carers to the programme. The workshops were delayed, and then provided online rather than in person to ensure everyone’s safety. The methodology was adjusted to ensure that the relational approach of co-design and co-production was built into the online space.

Methodology

Governance

Local oversight and strategic support for the project was provided to LSBU by a designated lead from GSTT as well as the Joint Programme steering group, which includes partners from South East London Clinical Commissioning Group, The Trusts' charities (GSTT Charity, KCH Charity, RBHH Charity), patient-public stakeholders, governors, Healthwatch bodies, clinical leads, transformation leads and patient and public engagement leads from the founder partners (GSTT, RBHH clinical services and KCH). Throughout the project the LSBU team met with the local project lead weekly and the steering group (every 2 months on average) to review the process stakeholders throughout.strategic

A sustainability assessment survey was conducted with the Steering Group before the workshops to identify risk areas and where there can be improvements, and after the workshops.

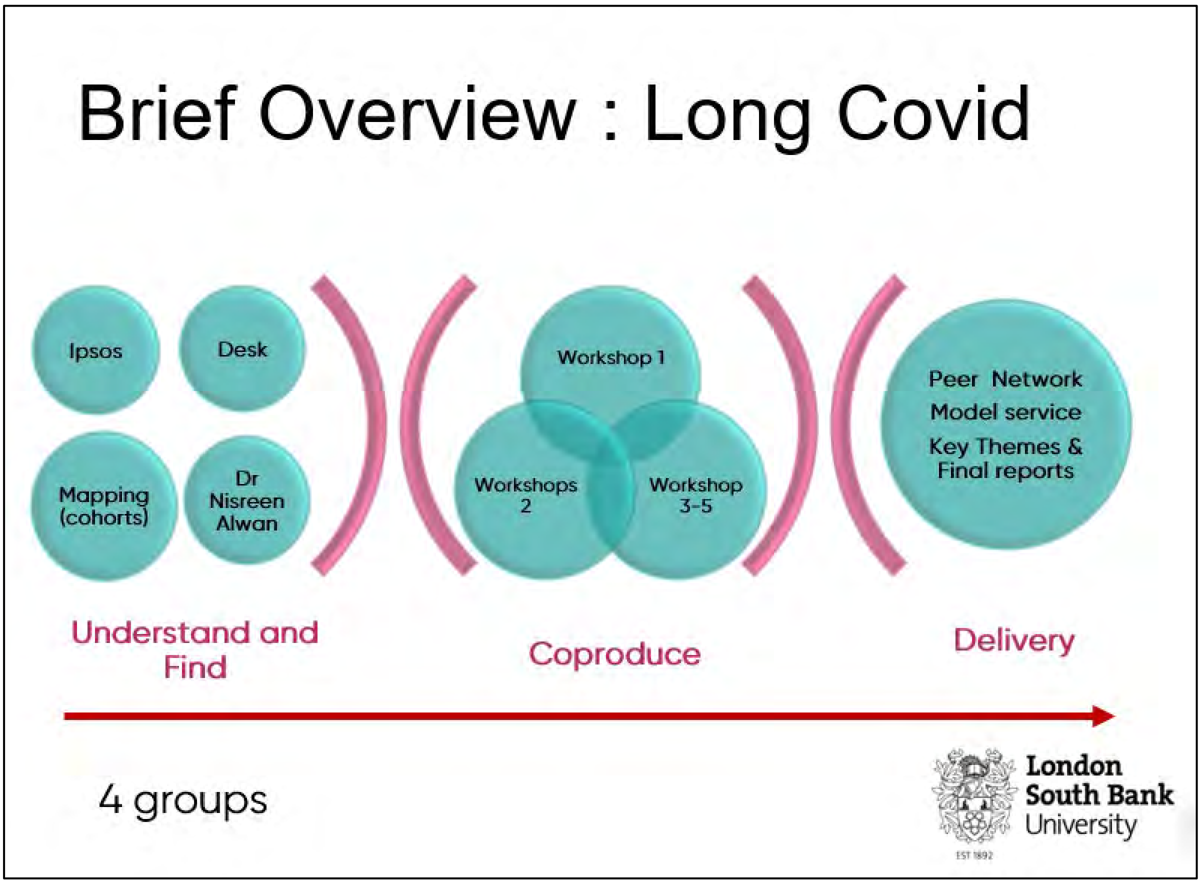
Ethical Considerations

This coproduction (service improvement) project received LSBU ethics panel approval. NHS approvals were not sought as the project is not research.

Rationale

The rationale for using coproduction is to help services move away from a paternalistic attitude whereby clinicians and managers 'know best' towards a culture that enables those jointly affected by the pandemic to help guide recovery (IHI, 2020). There is increasing evidence that co-producing change and improvement in healthcare leads to new approaches that are more likely to succeed and be sustained (IHI, 2020). The LSBU project team also involves lay members from the LSBU People's Academy who supported with various aspects of the project including the project design, running the workshops and writing the participant information in plain English.

Methodology Brief Overview



Brief Overview : Long Covid

Ipsos

Desk

Mapping (cohorts)

Dr Nisreen Alwan

Workshop 1

Workshops 2

Workshop 3-5

Peer Network
Model service
Key Themes &
Final reports

Understand and Find

Coproduce

Delivery

4 groups

London South Bank University

Figure 1: Overview of the Methodology

Understand and Find

This comprised of:

(a) Desk Research, including reviewing previous commissioned research and intelligence from National Voices work on Long COVID.
(b) Mapping cohorts and inviting participants to the workshops with the help of a Design Team.

The Desk Research[2] was delivered in both long and short form in February 2022. This provided background information and context to help shape and inform the project. One of the key insights relevant to the workshop participation was the need for local place relationships.

Key messages from the Desk Research that informed the workshops are:

- This is a unique opportunity to design an integrated asset-based model that starts in peoples' homes.

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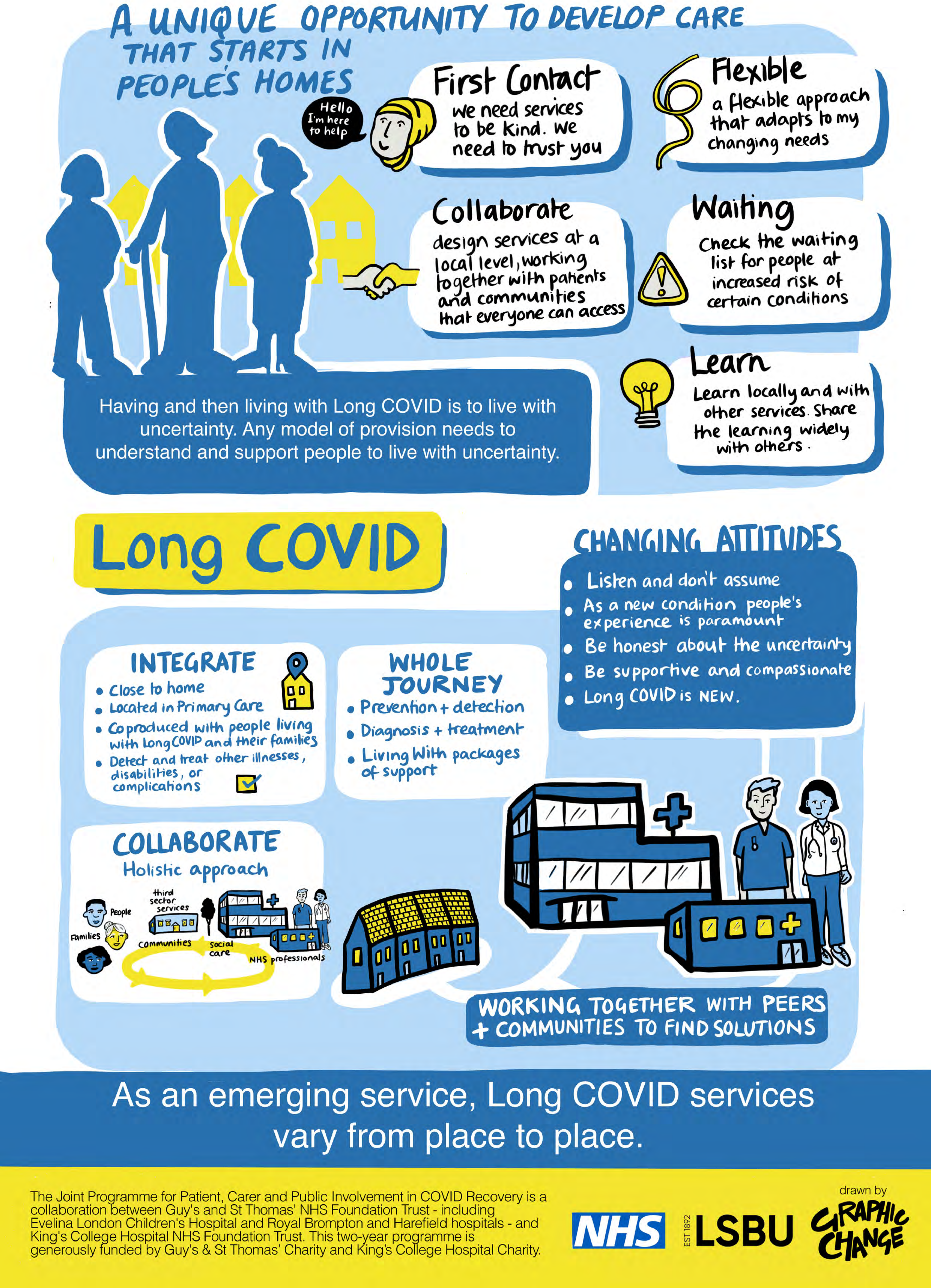
[2] Ahmed, K., Shamah, S., Malby, B. (2021) Long COVID: Summary of the Desk Research. Report for Health Systems Innovation Lab, London South Bank University December

- Health Professionals attitudes to Long COVID need addressing to move to a position of listening, belief, partnership and shared solution finding.
- Long COVID treatment support and recovery is co-dependent on community-based resources and has to be developed locally.

In addition, the Desk Research provided vital insights that informed the Model of Care as it was developed in the workshops by people living with Long COVID, by professionals, volunteers, and carers.

A summary of the Desk Research that was provided in graphic form:

Figure 2: A summary of the desk research on Long COVD to inform the workshops.



A UNIQUE OPPORTUNITY TO DEVELOP CARE THAT STARTS IN PEOPLE'S HOMES

First Contact
we need services to be kind. we need to trust you

Flexible
a flexible approach that adapts to my changing needs

Collaborate
design services at a local level, working together with patients and communities that everyone can access

Waiting
Check the waiting list for people at increased risk of certain conditions

Learn
Learn locally and with other services. Share the learning widely with others.

Having and then living with Long COVID is to live with uncertainty. Any model of provision needs to understand and support people to live with uncertainty.

Long COVID

CHANGING ATTITUDES

- Listen and don't assume
- As a new condition people's experience is paramount
- Be honest about the uncertainty
- Be supportive and compassionate
- Long COVID is NEW.

INTEGRATE

- Close to home
- Located in Primary Care
- Coproduced with people living with Long COVID and their families
- Detect and treat other illnesses, disabilities, or complications

WHOLE JOURNEY

- Prevention + detection
- Diagnosis + treatment
- Living with packages of support

COLLABORATE

Holistic approach

WORKING TOGETHER WITH PEERS + COMMUNITIES TO FIND SOLUTIONS

As an emerging service, Long COVID services vary from place to place.

The Joint Programme for Patient, Carer and Public Involvement in COVID Recovery is a collaboration between Guy's and St Thomas' NHS Foundation Trust - including Evelina London Children's Hospital and Royal Brompton and Harefield hospitals - and King's College Hospital NHS Foundation Trust. This two-year programme is generously funded by Guy's & St Thomas' Charity and King's College Hospital Charity.

drawn by GRAPHIC CHANGE

The Design Team

The Design Team was a small group of people from across GSTT and KCH who committed to help us secure participation and be ambassadors within the partner organisations. The group did this by helping:

- Sense-check the design in terms of how it will be understood by those we want to invite in (what are we trying to do).
- Identify the cohorts to take part in the workshops (who needs to do it) to be signed off by Steering Group.
- With the invitation process.

The Design Team met throughout the pre-workshop phase.

They determined that the Workshops should as far as possible, focus on building relationships in place. The workshops were provided for:

Bromley, Lambeth, Southwark, and we also provided a Mixed Borough workshop.

At this stage because of the COVID surge all workshops were re-scheduled and moved online.

Mapping Participation

For each workshop the Design Team mapped the health and care system for providing Long COVID support and determined the invitation list. The Design Team then mapped the citizen participants (public) ensuring we were able to find a diverse mix of people and referring to the programme of work specification requirements.

A full description of this process is provided at Appendix 1.

Overall, we were able to engage people who met these wide range of characteristics with the exception of homelessness and people with learning disabilities (made much harder by moving this entire process online).

The Workshops

The workshops ran from April 2022 – July 2022, with a feedback session in September.

The workshops were designed to:

- Understand the experiences and support needs of people with long COVID.
- Explore the barriers to accessing support and means of overcoming them.
- Shape the design of existing and future services
- Gathering experience and insights to understand how services should be delivered in future.
- Explore effective public messaging: how can partners ensure that the right messages are put out to patients to help them manage their symptoms, access services, and alleviate anxiety?
- Develop a network: Fostering a network of people with experience of long COVID who can potentially be involved with different aspects of the service as it develops. As well as engaging local voluntary, community and social enterprise organisations.

A summary of each workshop's findings and results are provided at Appendix 2.

Participants

A maximum of 30 people (per online workshop) was decided as the group size for each workshop to allow for discussions within the group; to give everyone time to interact; as well as having sufficient people in any virtual breakout discussions. Each workshop aimed to have an equal number of members of the public and staff. Both staff and the public were invited to attend one initial workshop and following this they could opt to attend the following workshops. We were also joined by observers from the Joint Programme Steering Group. Overall participation at the workshops was as follows:

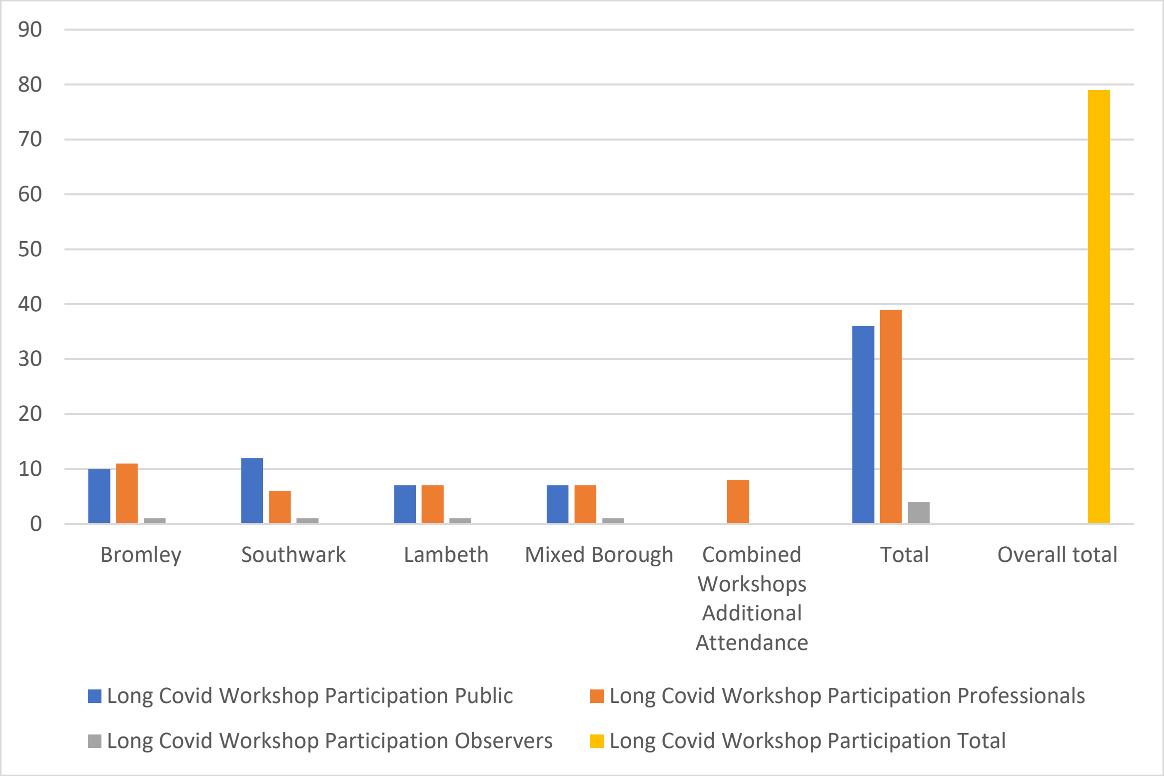


Fig 3 Participation in the workshops.

Overall 79 people were engaged in the Long COVID workshops, of which 4 were observers.

The characteristics of the public participants was as follows (not all the public were willing to share their characteristics)

Male	Female	Employed	Unemployed	Ethnic minority	Child/Teen	Adult (19-65)	Adult (65+)	Cognitive decline	Comorbidities	Digital Poverty	Carer	Disability
9	8	0	3	5	0	1	2	0	1	0	1	1
35%	31%	0%	12%	19%	0%	4%	8%	0%	4%	0%	4%	4%

Table 1 The characteristics of the public participants in the workshops (people living with Long COVID and their carers).

The professional participants came from these areas:

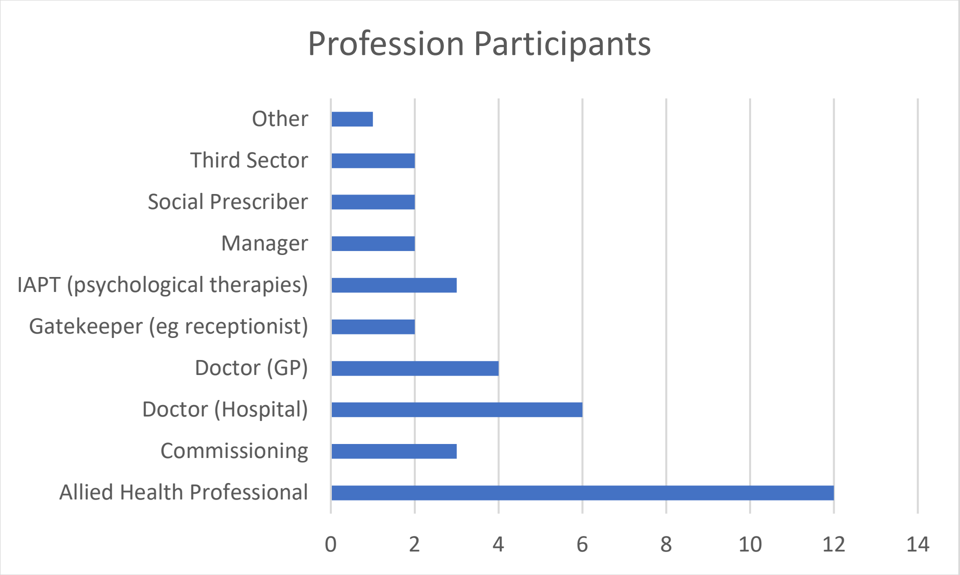


Fig 4 The Professions

Who came from these organisations:

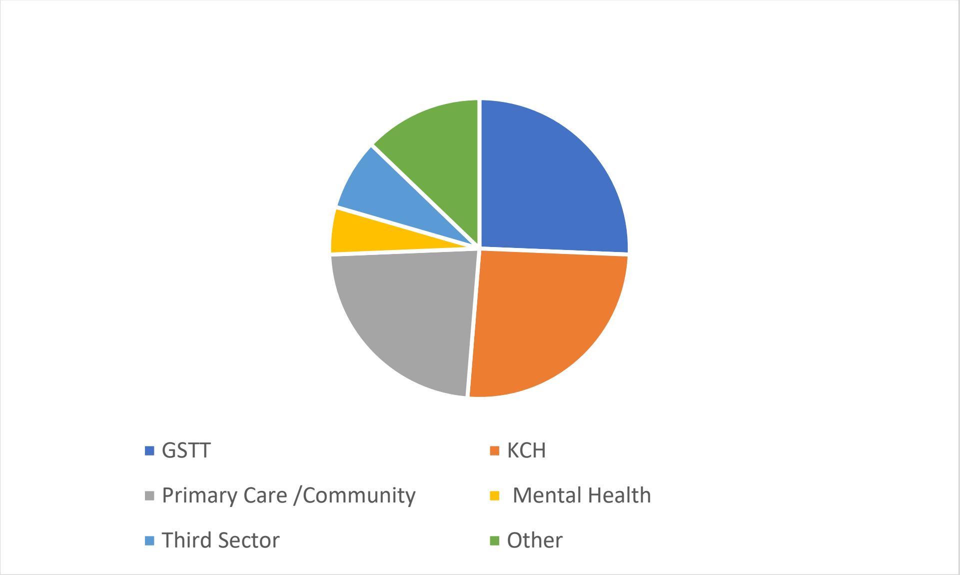


Fig 5 The organisations represented.

Organisations	
GSTT	10
KCH	10
Primary Care /Community	9
Mental Health	2
Third Sector	3
Other	5
Total	39

A full breakdown of participation by workshop is provided at Appendix 3 along with feedback from the participants.

Results of the Work

The ONS[3] has reported that

> "*An estimated 2.0 million people living in private households in the UK (3.0% of the population) were experiencing self-reported long COVID (symptoms continuing for more than four weeks after the first suspected coronavirus (COVID-19) infection that were not explained by something else) as of 4 June 2022*"

The Experience of Long COVID

This picture sets out the experience of living with Long COVID shared by the workshop participants and shows the adjustment that it takes. One of the major issues is living with the uncertainty of the impact over time – how long Long COVID will last and the effect of this. People talked of loss and grief for their normal selves, and the toll on their families and friends, from children becoming carers to mum's reframing what it takes to be a good mum if you can't do the things 'normal' mum's do with your children. The toll is very significant in terms of identity, but it can also be significant in terms of wealth and poverty as working is difficult and has consequences on the rest of the person's life.

The lack of recognition of Long COVID as a 'real condition' is an enormous hurdle for people at societal, employer and sometimes for NHS clinical professionals.

This experience is also described on the animation written and narrated by participants living with Long COVID provided here

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[3] Ayoubkhani, D. and Pawelek, P., (2022). Prevalence of ongoing symptoms following coronavirus (COVID-19) infection in the UK: July 2022. Available at https://www.ons.gov.uk/peoplepopulationandcommunity/healthandsocialcare/conditionsanddiseases/bulletins/prevalenceofongoingsymptomsfollowingcoronaviruscovid19infectionintheuk/7july2022#:~:text=An%20estimated%202.0%20million%20people,2022%20(see%20Figure%201). Accessed 25th September 2022.

Fig 6: Living with Long COVID

The Joint Programme for Patient, Carer and Public Involvement in COVID Recovery is a collaboration between Guy's and St Thomas' NHS Foundation Trust - including Evelina London Children's Hospital and Royal Brompton and Harefield hospitals - and King's College Hospital NHS Foundation Trust. This two-year programme is generously funded by Guy's & St Thomas' Charity and King's College Hospital Charity.

Living with Long COVID

NHS EST 1892 LSBU drawn by GRAPHIC CHANGE

The Journey of Long COVID

People living with Long COVID described the stages of the experience from the first few weeks right through to 1 year plus (and beyond), and with it, dwindling hope and resilience to cope.

In the First Few Weeks

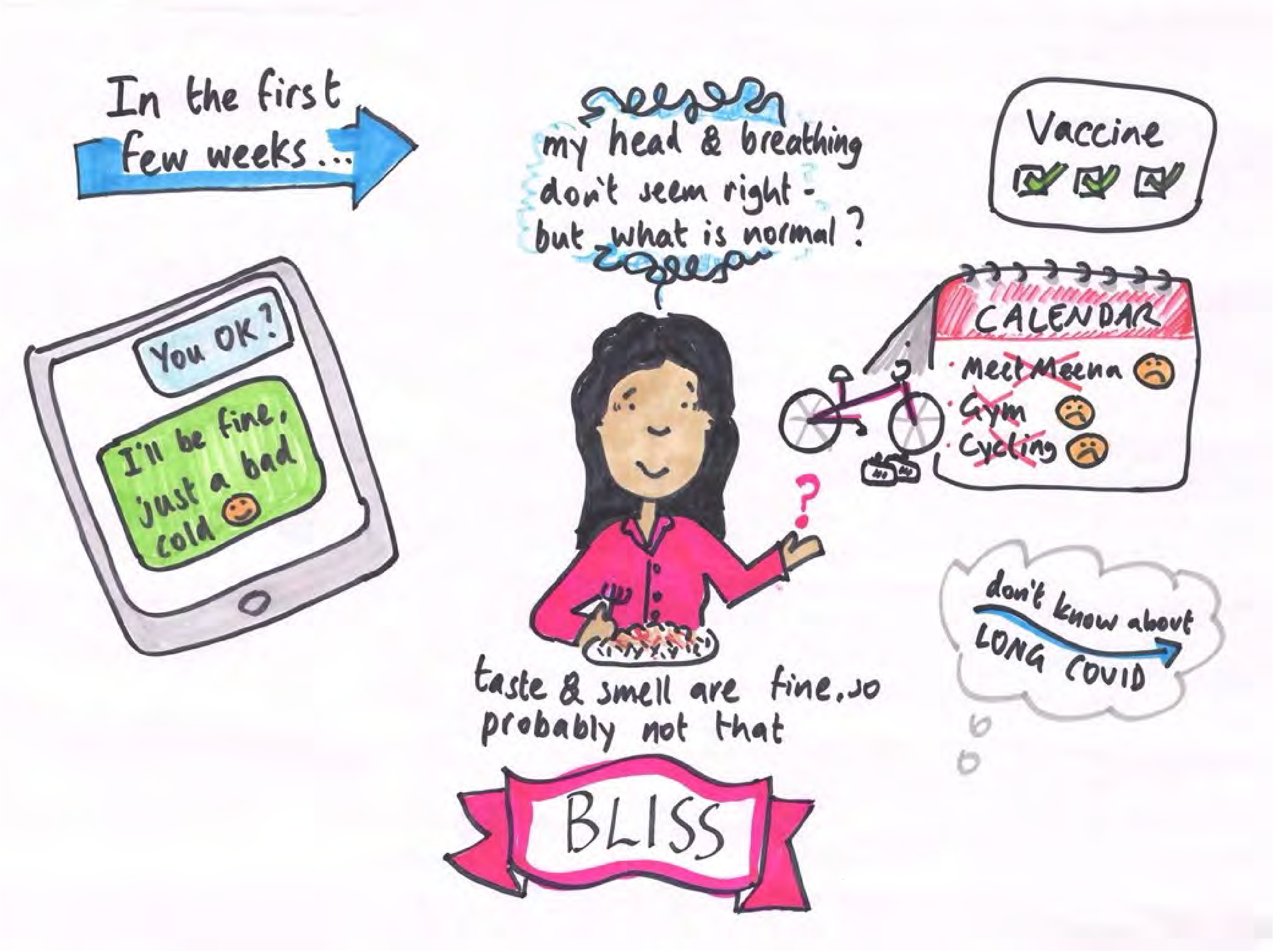


Fig 7 The Journey of Long COVID in the first few weeks

In the First Few Months

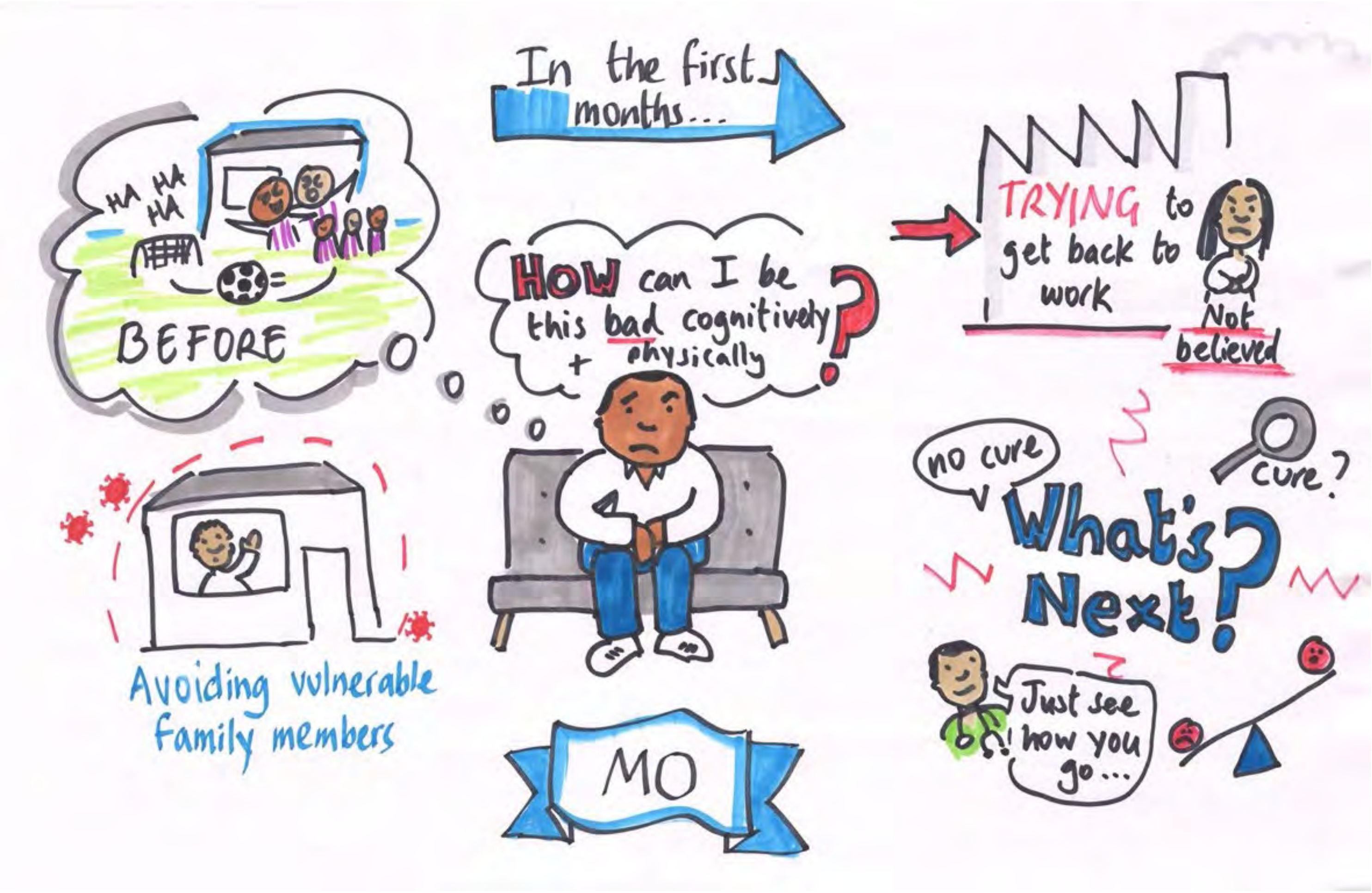


Fig 8 The Journey of Long COVID in the first few months

Now it’s a Year

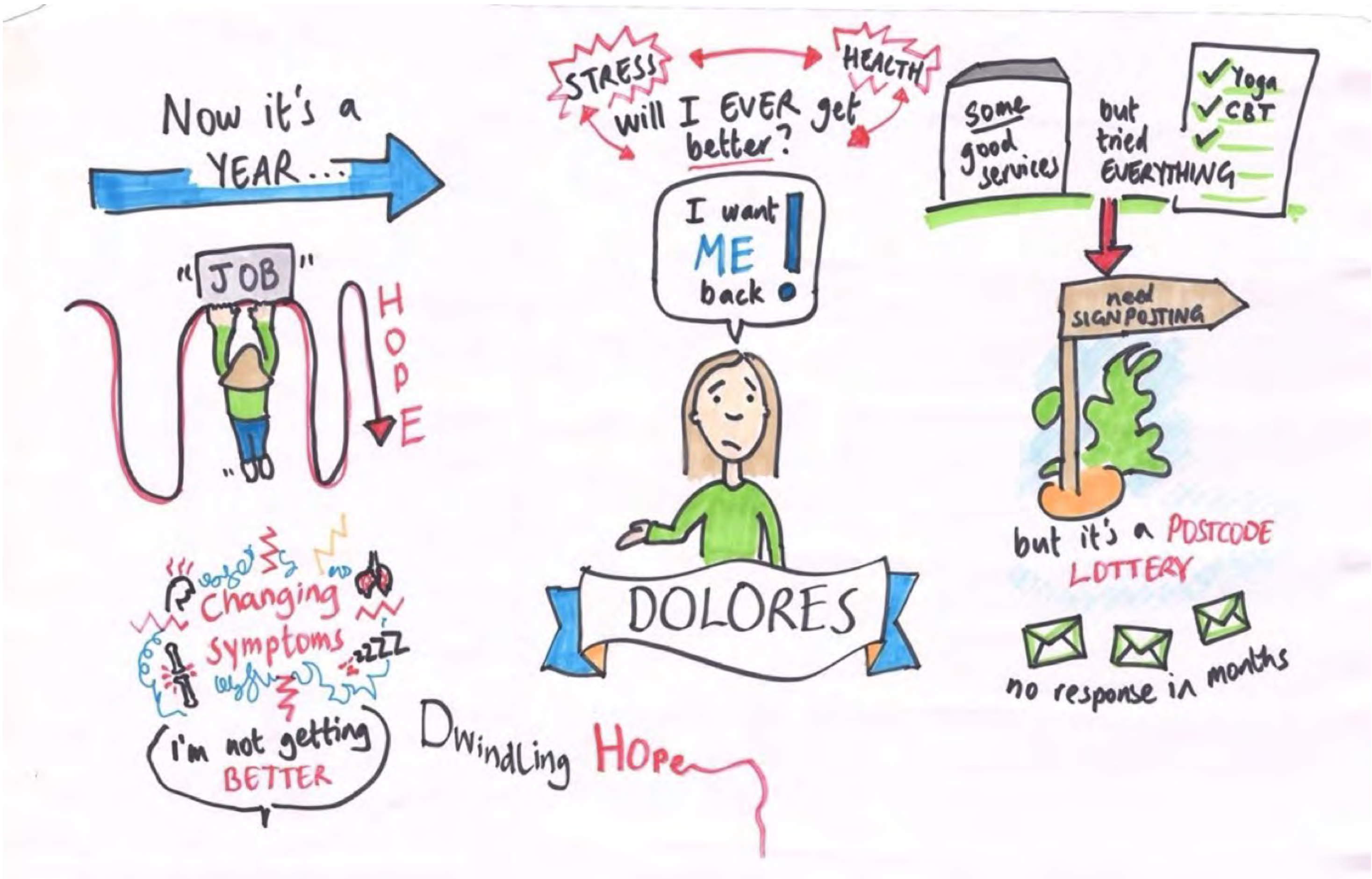
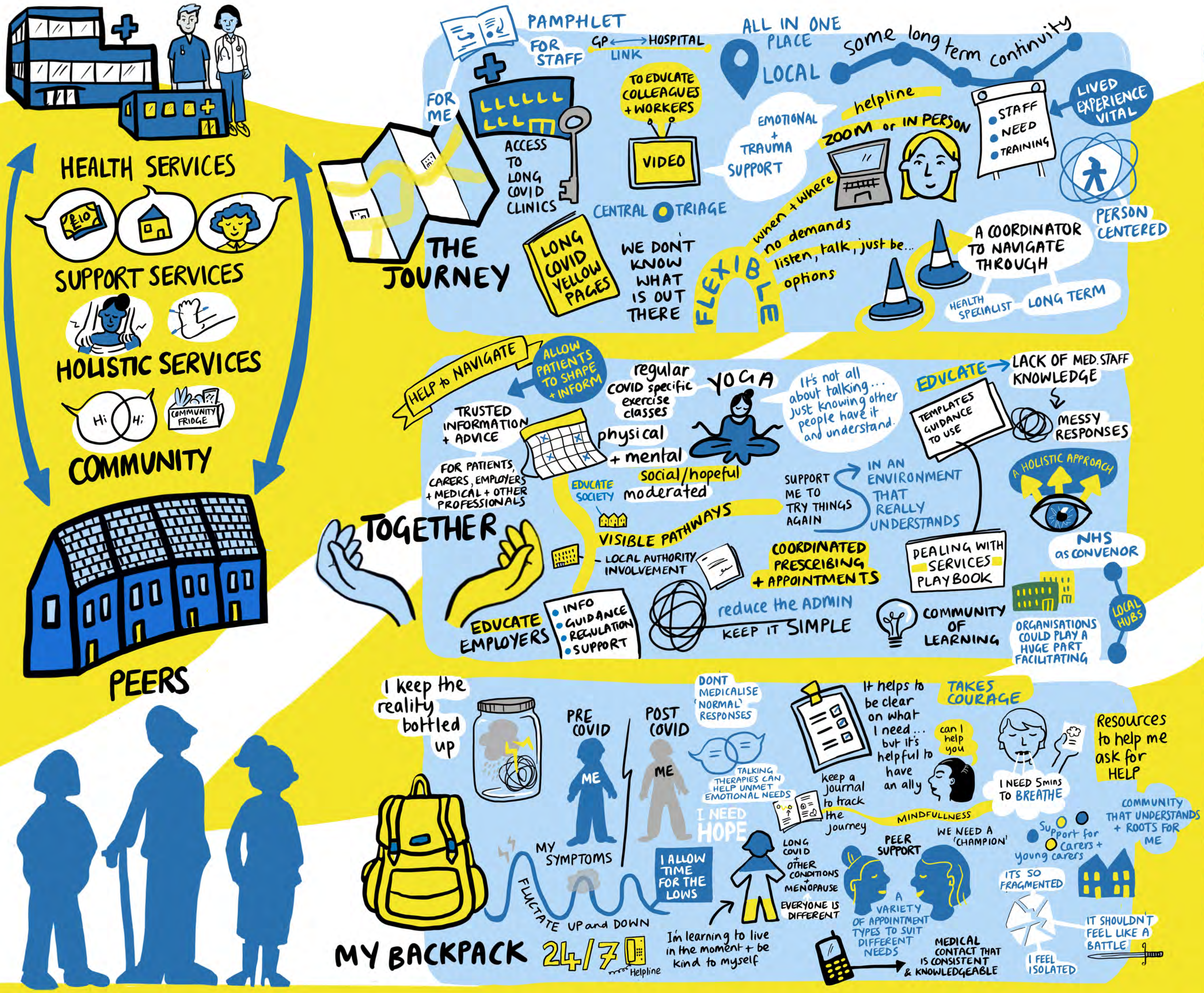


Fig 9 The Journey of Long COVID now it’s a year.

A New Model of Care for Long COVID

This new model of care designed by the workshop participants builds on the work provided in the desk research, adding to it in terms of what the community could offer alongside the NHS, and the need for societal, particularly employer, engagement with Long COVID as a chronic disease.

Fig 10 A new model of care for Long COVID



- A safe place to try things
- Talking therapies
- Long COVID clinic
- A care navigator
- Peer support activities
- Curated resources
- Reduce admin
- COVID champions connect to Social Prescribers
- All agencies understand
- GP sick-note as catalyst
- Work with employers and unions to develop pathways
- Trusted information and knowledge management
- Whole person approach
- Support with wider issues
- Patients as partner & expert
- Universal access
- Regular check ins
- Local authority involvement
- Local support clinics
- Wider education
- Carer support

A New Model of Care for Long COVID

The Joint Programme for Patient, Carer and Public Involvement in COVID Recovery is a collaboration between Guy's and St Thomas' NHS Foundation Trust - including Evelina London Children's Hospital and Royal Brompton and Harefield hospitals - and King's College Hospital NHS Foundation Trust. This two-year programme is generously funded by Guy's & St Thomas' Charity and King's College Hospital Charity.

drawn by GRAPHIC CHANGE

In My Backpack – what I can do for myself? /What we can do in communities?

Fig 11 The New Model of Care – what patients need in their backpack

People identified that some things they need come from within themselves:

- Be kind to myself.
- Set myself short term goals.
- Ask for help.
- Find an ally.
- Access to curated resources.
- Being with other people who have Long COVID to share ideas, experiences, and who understand and share the struggle.
- A place for people to meet and connect to find their own ways of supporting each other.
- Supporting others (gifting).
- Don't medicalise everything.

The Journey

Fig 12 The New Model of Care – what patients need from the NHS and services.

This is what the participants said they needed from the NHS:

- Equal and fair services across all Boroughs – not a postcode lottery.
- The Long COVID Clinic really matters, and it really helps.
- Regular contact from a coach to help with setting short-term goals.
- Staff that understand, respect, and support.
- A coordinator (care navigator) to help navigate the multiple services we access, and also to help join these up so we only go to the ones we really need. Help to understand what to expect and what we can ask for.
- A resource that tells us what is available.
- Social Prescribers that help move from listening to practical support for finances, housing and also help me connect to other people.
- Talking therapies to help with grief and loss, and to help me adapt.
- Home visits from therapies as that means we have the energy to make the most of the service (rather than the struggle of travelling).
- A joint record for all services.
- Professionals that recognise Long COVID and know how to support.

What We Have to Do Together

As Long COVID is an emerging disease, and as the attention on COVID wanes, knowledge in society is lagging behind the significant number of people now living with Long COVID. Employment practices, people's attitudes and activities that could support people with Long Covid are not aware of or informed about what it means to live with Long COVID and what the person and family/carers need. This puts people with Long COVID at a disadvantage as they try both to keep well and to secure the support they need from communities, services, and employers.

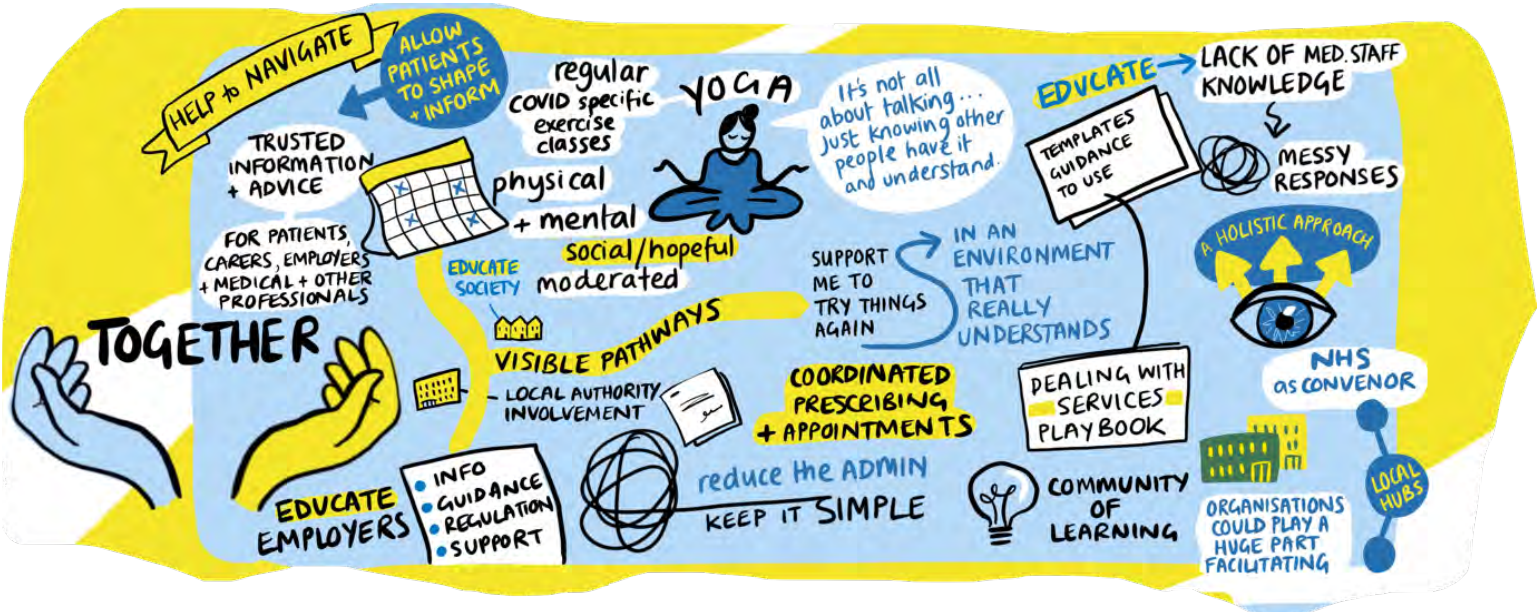


Fig 13 The New Model of Care – what patient and the NHS need to do together.

This is what patients and the NHS need to do together to support the New Model of Care:

- Educate people (society) about Long COVID, both that it exists and is a disease and what people living with Long COVID experience.
- Educate employers (much as we have done as a society about Menopause) so that they (a) recognise Long COVID as a disease and (b) put in place employment practices that enable people living with Long COVID to work.
- Educate health professionals for instance gps don't always know how to justify referrals.
- Grow Long COVID specific classes e.g., exercise, yoga as we need a lower pace than most classes can support.
- A trusted information service for patients, carers, employers, professionals.

Reflections on the Development of the Model and Networks

There were some 'stand out' moments in the workshops for the observers and delivery team.

Where to start to meet needs

A person living with Long COVID met her clinician for the first time with the video on in one of the first workshops. She said that she always had her video off because often health professionals don't have theirs on, or because she doesn't think she is really being listened to. It was a symbolic moment when we encouraged her to put her video on for the first time in the year, she had been accessing services. It dramatically changed her relationship with the work and with the people on the video conference. People need people, and video on, if it's going to be in the virtual space, has to be mandatory for this relational work – both in working with patients and the public to co-design services and in consultation on their health needs.

Humility and openness to collaboration

Where clinicians came into the discussion humble about the emerging nature of knowledge on Long COVID and willing to learn with people with lived experience, the conversations felt productive to the whole group. It was noticeable when new professionals joined into the workshops later in the work, that their defensiveness or inability to grasp the urgency of people's need for support ("It will take a long time" was not helpful feedback to people struggling to retain hope), dramatically changed the response within the group, from collaborative to adversarial. Long COVID is not the domain of the expert medical model. Humility, openness and real partnership with people living with Long COVID is vital for any new model to adapt.

The value of witnessing people's struggle

The workshops had stories of pain and suffering, of real struggle; but also had moments of laughter and enjoyment of each other's company. People valued a place to be heard, appreciated and their experience recognised and valued. Where we heard issues that were clearly harmful, we worked with the health providers to sort the issues out. This was really appreciated.

Collaborating online

Working in a collaborative space online is new to both clinicians, managers and patients and carers. We hope everyone took away some of the key principles for coproduction that can form the bedrock of online space as well as in-person space.

Impact of the Workshops – Catalysing Change

Alongside the development of the New Model of Care there were additional benefits realized during the workshops:

- Professionals joining the workshops shared the value they experience of having the time to listen to people living with Long COVID and their carers.
- People living with Long COVID have formed a whatsapp group to keep in touch and keep sharing.
- Some place-based groups have been established and are working with their local health professionals.
- Some of the participants have volunteered to help in the testing of the model in practice and have begun that work with the service lead. In addition, a prototype of educational support for patients is being put into place with people who contributed to the workshops.
- Clinicians are rewriting their clinic information booklets using the information provided in the workshop materials.
- Patients who are working shared an example email signature to include the graphic of living with Long COVID.

The Model development is not a static process of reporting the findings here, but the development process did contribute to the emerging New Model of Care as it is being developed in real-time, without waiting for this report. It was really helpful to have feedback from clinical leaders about how they were using the discussions and findings as they establish the Long COVID service

Recommendations

Long COVID is both diagnosed and undiagnosed in the population, and so the scale of the problem remains unknown. People who developed Long COVID early on in the pandemic shared their experience of having had very little support and some did not have a diagnosis. There are stages of the Long COVID experience that differ with time, services must be provided that recognise this trajectory and meet the different needs that this brings. The range of symptoms is variable and complicated. Service offers need to recognise the whole person and the variation between people.

1. The Model of Care for people with Long COVID needs to be bespoke to the whole person. It requires an approach to diagnosis that is pragmatic and enables people to access the pathway without relying on a GP referral.
2. The Long COVID Clinic as the foundation for all therapies and interventions is invaluable. This needs to be embedded in the community and provided at Borough level. There needs to be an audit to check for people who were in the clinic but have been 'lost'.
3. As the Long COVID model develops it must not increase inequalities, it must ensure that it is universally accessible. There is some experience of services developing differently in different places.
4. As this is an emerging Model, health professionals need to find ways to be open to people's experience without being defensive, and learn together, in order to be able to adapt the service offer.
5. In all discussions with people living with Long COVID that are being undertaken online health professionals must have their camera on.

Primary Care should:

6. Provide a working diagnosis (a diagnosis based on symptoms rather than clinical investigations) for people who present with the symptoms of Long COVID; and identify the cohort of people with Long COVID on the GP list (as there is growing evidence that there are people living with Long COVID who do not have a diagnosis and who are not accessing services).
7. Provide Long COVID specific Social Prescribing – we suggest this is a cohort for the coming Social Prescribing funding.
8. Provide Long COVID specific Care Navigators.
9. Support the development of local peer support networks, alongside Long COVID clinics (people living with Long COVID can't do the heavy lifting of setting this up).
10. Refer for talking therapies and life coaches.

The NHS should:

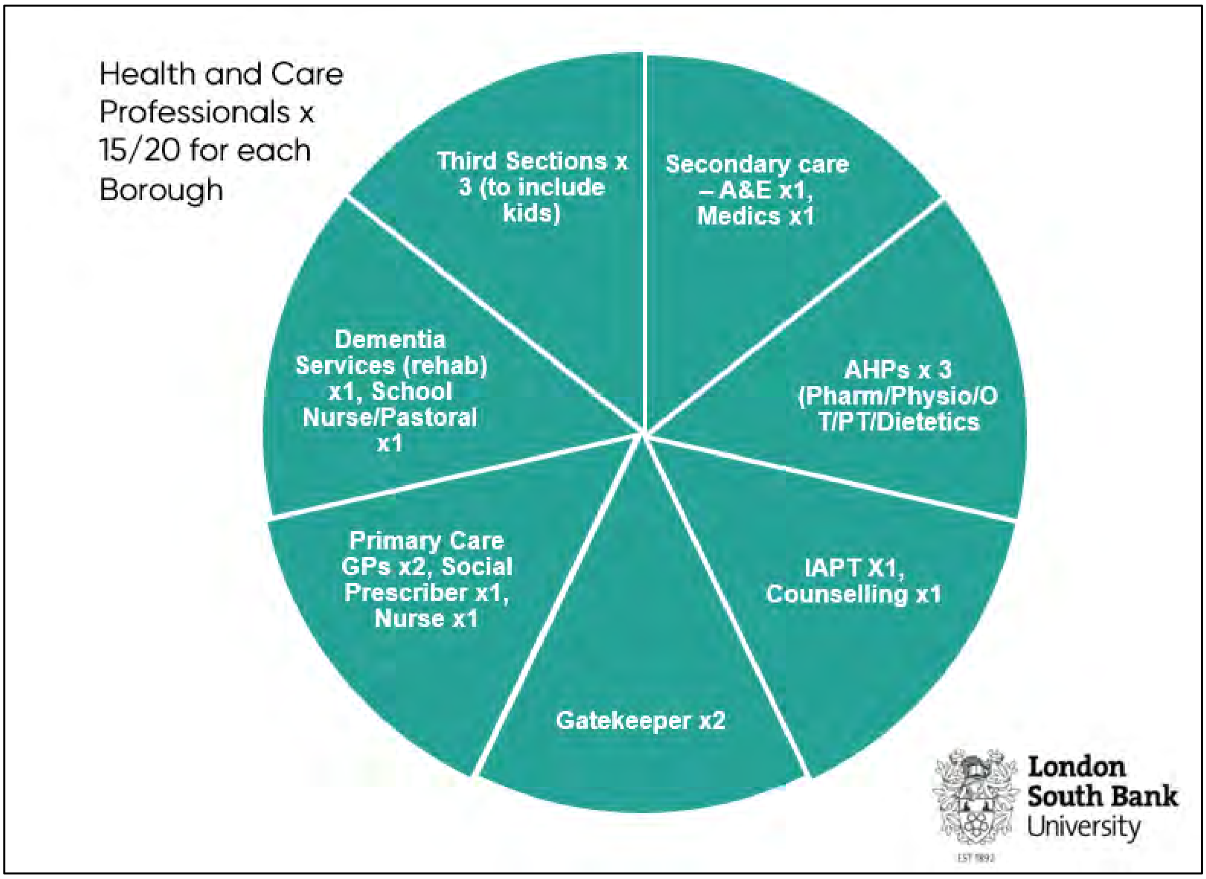
11. Create a trusted information service and communications campaign to educate and inform people living with Long COVID, families, carers, friends, society, employers.
12. Educate professionals, employers, and society about what Long COVID is, how it manifests, and how to help.
13. Catalyse new activities that will support people with Long COVID to achieve short-term goals - this means making the demand evident and educating activity providers (sports/ yoga) on how to support people with Long COVID.
14. Make the Long COVID pathway explicit and accessible.

15. Support community Long COVID champions who can help lead community-based solutions.

Appendix 1: The Methodology in Detail

Mapping Participation

Health and Care System

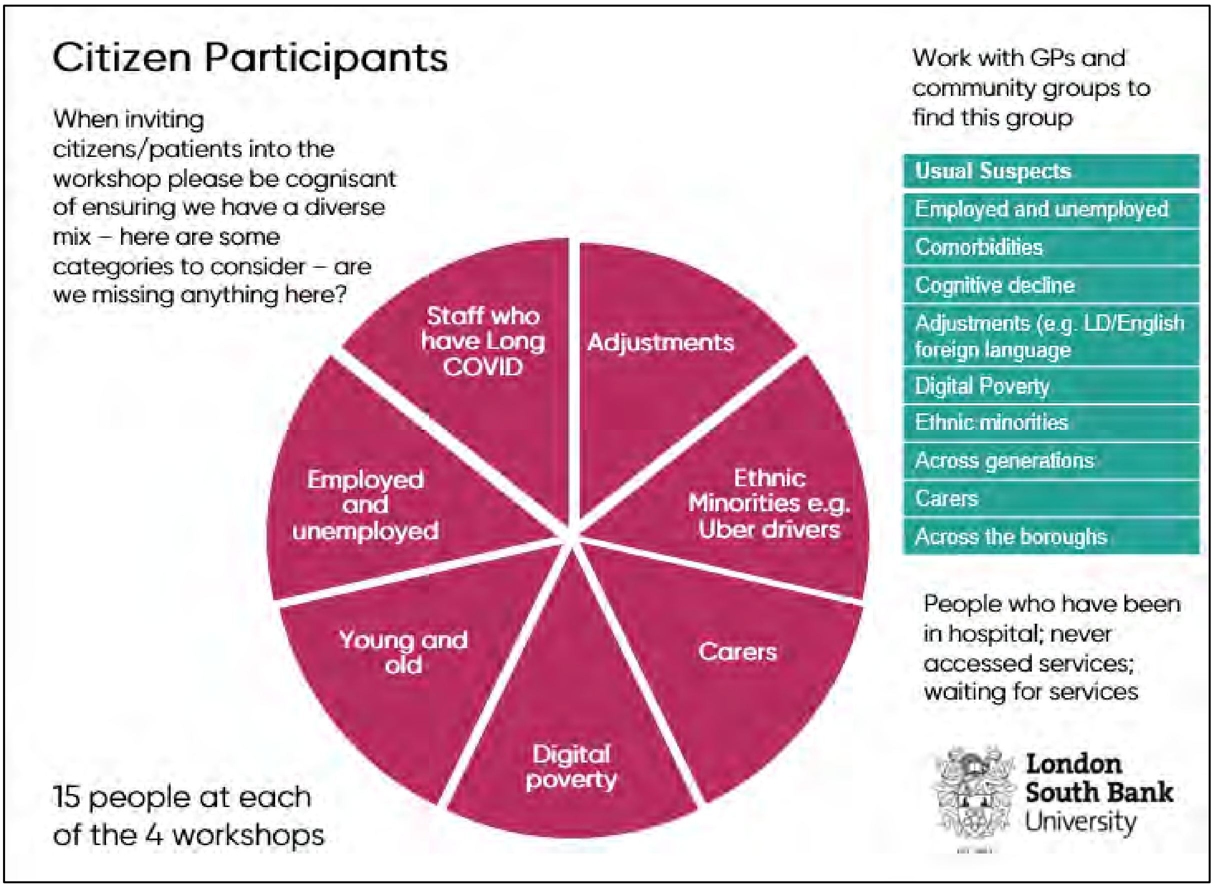


For each workshop the Design Team mapped the health and care system for providing Long COVID support and determined the invitation list.

Here is an example of the mapping.

This was then translated to a spreadsheet where the Design Team and their colleagues' identified names and contact details. These were all followed up by the LSBU team to secure participation at the events.

The Public



Citizen Participants

When inviting citizens/patients into the workshop please be cognisant of ensuring we have a diverse mix – here are some categories to consider – are we missing anything here?

15 people at each of the 4 workshops

Work with GPs and community groups to find this group

- **Usual Suspects**
- Employed and unemployed
- Comorbidities
- Cognitive decline
- Adjustments (e.g. LD/English foreign language
- Digital Poverty
- Ethnic minorities
- Across generations
- Carers
- Across the boroughs

People who have been in hospital; never accessed services; waiting for services

London South Bank University

The Design Team then mapped the citizen participants (public) ensuring we were able to find a diverse mix of people, and referring to the specification requirements of:

- Different experiences of using services, or not – Including patients who were hospitalised with COVID, patients who were supported in the community and accessed a range of services, people who have never received care or treatment for COVID, people who were initially unaware they had had COVID.
- Patients less likely to be actively engaged - Developing relationships with local community groups and leaders to support the involvement of marginalised and vulnerable communities to include:
    - People who do not speak English as their first language.
    - People with learning disabilities.
    - People from Black, Asian and minority ethnic communities.
    - People with experience of homelessness.
- Patients who experienced COVID during the different waves – For example, some wave one patients have been living with long COVID for over 2 years, as opposed to those with more recent experiences.

This was augmented by the GSTT/ KCH Database of people accessing Long COVID services.

Overall, we were able to engage people who met these wide range of characteristics with the exception of homelessness and people with learning disabilities (made much harder by moving this entire process online).

The Invitation Process

The invitation process comprised of:

a) Inviting Professionals

Design Team members from each organisation approached the teams to invite them to the workshops. They were provided with an invitation to use (Example at Appendix 1), but this is a personal process, and so the Design Team members were asked to invite people personally (by phone or in person) and follow-up with emails. All invitations had faqs and all patients/ citizens/ carers were free to withdraw at any point

b) Inviting People/ Citizens and Carers

Having mapped the range of people to invite we asked that Professionals participating also invite patients/ carers that they had contact with. We provided both invitations and easy read versions (Appendix 1). Where professionals invited patients/ carers we had a good uptake with people quickly identified and recruited and this was the best way of securing participation.

However, as not all professionals took this approach and also recruited patients through other means. The reasons for not inviting patients were related to (a) time in the consultation to do the invitation and answer any questions (b) the difficulty of asking people when working remotely (c) unclear about what they were inviting patients to. In addition, the postponement of the workshops due to the Covid surges means the Design Team and the invited clinicians lost momentum. In addition, during the workshops, we heard from clinicians about the capacity issues in their areas making participation really difficult, reducing their capacity to think about inviting patients/carers.

Therefore, we invited people in addition through more transactional means. This was much less effective in turning contacts into someone coming to a workshop. We found that thousands of touchpoints (newsletters/ social media/ flyers/ asking patient groups/ direct text messaging and phone calls) converted a few contacts into participation.

This approach included:

- Healthwatch in the Boroughs were provided with social media posts, newsletter text, easy read invitation and flyers with for their community.
- 98 VCS organisations working in and with people in communities were provided with short text information for newsletters and the flyers for each of the topic groups (Long Covid, Waiting, Virtual Access) separately with 2 weekly gaps.
- Prof Malby joined the South East London Primary Care Leaders meetings twice to invite them to workshops and to ask them to invite their patients.
- We wrote to all Social Prescribing leads asking them to invite patients and carers (provided with flyers and Easy Read invitations).
- Foundation Trust Members KCH and GSTT were sent short text and flyers.
- Southwark & Lambeth Councils Community Engagement Leads were sent text invitations, and flyers to share.
- National Voices shared all workshop flyers through their network.

- Social Media – posts to Facebook pages and posts on Twitter from GSTT, LSBU.
- Foundation for Learning Disabilities shared the Easy Reads with all their contacts; and we asked SEL community Learning Disabilities nursing teams to identify people and recruit, as was the SEL patient carer network for LD. We also asked 5 specific LD charities to support workshop recruitment.
- Finally, we also approached 89 people from the GSTT and KCH database by text (29) and phone (60). This generated 6 participants.
    - Calls lasted up to 20 mins each, recruiting between 10 and 20 people who were 'interested' and that lead to a few recruited to each workshop.
    - Some calls people wanted to talk about the issue when we rang. Maximum possible calls per person per day 20

All communication was GDPR compliant, and all patient information was held securely at LSBU. Recruiting public participants was made more difficult by the COVID surge and the lack of face-to-face contact with patients and communities.

c) Confirming Attendance

All invited staff and citizens recruited received a written invitation (printed or electronic), a Participant Information Sheet, and a consent form to decide if they wanted to take part. Those agreeing to take part and share their details were contacted by LSBU with pre-workshop information.

All participants were provided with:

1. Invitation email and letter with patient information
2. The PIS and Consent forms
3. Programme Flyer and Easy Read
4. Workshop reminder with the desk research graphic illustration
5. Calendar invite at 1-2 weeks prior
6. Joining information 5 days prior
7. Reminder and consent form 2 days prior

Consent (paper, electronic or verbal) was requested before the workshops for all participants, and a 1-hour session was built into the workshop timings to allow for real-time consent for those that had not consented prior to joining.

d) Recruiting to the follow-on workshops

At the end of each workshop, we provided the date for the next workshop, and invited all participants to join and to invite others. After taking part in the workshop, we sent an email thank you and provided the follow up workshop date and again asked all participants to invite colleagues, friends, family where they fit the criteria for the workshop.

e) Citizen reimbursement

In line with NHS and the Trusts' policies, patients and carers were provided with a voucher and information on how to claim expenses.

All invited staff and citizens recruited received a written invitation (printed or electronic), a PIS and a consent form to decide if they wanted to take part. Information did not have to be printed in hard copy and could be provided to potential participants using electronic methods (HRA and MHRA, 2018). Those agreeing to take part and share their details were contacted by LSBU with pre-workshop information. Consent (paper, electronic or verbal) was requested before the workshops for all participants, and a 1-hour session was built into the workshop timings to allow for real-time consent for those who had not consented prior to joining.

Workshop Design

Creating Readiness

As coproduction is a relational process, we designed the workshops to mirror the relational experience of face-to-face events. Key to this was a 1-hour entry session at the beginning of the first workshop where participants mingled online, met the facilitators, shared any concerns, had a cuppa, and undertook consent. As people joined the session, we checked their technology was working, checked they were consented (and if not popped them into a consent room 1:1 with LSBU staff), chatted to them about how they got to be here, and provided a breakout room for groups of 3 to get to know each other. The LSBU team includes our Peoples Academy and so all our rooms were supported by people on our team with lived experience. We came back together for 15 minutes prior to the start to informally share, chat and this also helped us identify anyone with any level of distress that needed 1:1 support.

This was an invaluable introduction and created a level of camaraderie and sharing before we started the work.

Workshop Process

Pace and Engagement

The workshops were paced to enable people with Long COVID to participate. The sessions were designed in 45 minutes blocks of discussion followed by 10-15 minutes break. We made it clear that we didn't expect people who were struggling to stay, anyone could take a break at any time and re-join when able. We had very few challenges raised throughout all the workshops. People with Long COVID took part throughout, although we were cognisant that people's concentration varied. Professionals tended to be later joining, and we had more of these participants dropping out/ coming back because of other commitments.

The workshops overall process included seeking narratives from different perspectives through listening to what participants choose to tell, rather than pre-determining all the topics or areas for improvement. An example of the workshop outline, discussion prompts, and questions can be found below. This offers a way of exploring the 'patient's' and the health professional's experiences, reflecting on current practices, and exploring the response from the system. Qualitative data was collected through narrative enquiry at the workshops for each of the 3 projects. This inquiry covered the following (from the project objectives):

- Understanding the experiences and support needs of people with long COVID.
- Exploring the barriers to accessing support and means of overcoming them.
- Shaping the design of existing and future services Gathering experience and insights to understand how services should be delivered in future.
- Exploring effective public messaging: how can partners ensure that the right messages are put out to patients to help them manage their symptoms, access services, and alleviate anxiety?

- Developing a network: Fostering a network of people with experience of long COVID who can potentially be involved with different aspects of the service as it develops. As well as engaging local voluntary, community and social enterprise organisations.

The workshops followed this overall process:

Design Principles

The design of the workshops was based on these principles in response to the Joint Programme requirements:

1. Diverse community of participants, wide participation.
2. COVID restrictions/ guidance is observed.
3. Build trusting relationships through transparency, responsiveness, accountability, inclusiveness and being consensus-oriented.
4. Recognise time limitations.
5. Act equitably.
6. Clear governance (ethics, direction, data protection).
7. Take time to act.
8. Maintaining pace, morale, energy.

And these principles for the design of the sessions in the Coproduction workshops developed by LSBU:

1. Build longer term relationships between communities and NHS services.
2. Start with Listening.
3. Respect all views.
4. Plain English and check understanding (don't assume what you said is what others have heard).

5. What is said in the room stays in the room – agree together what is shared externally.
6. We ask that people do not audio or video record or take pictures during the workshops.
7. Equal voice.
8. You own what you create.
9. Do what matters to people where it matters to people.
10. Foster relationships as a core capability so that new capacity emerges (everyone has met everyone).
11. Stay humble.
12. Starting points really matter.
13. We each participate as ourselves – no-one speaks for all patients, or 'the hospital', etc.
14. Power: the workshops are built around discussions/debates, rather than a professional-led presentation, for example. Each participant will be given the opportunity for equal contribution (power) and will be an active part of the co-production process.

In addition, these were the themes in terms of the design for all workshops

- We focus on relational work, not 'research', trigger discussion rather than a presentation.
- Create additional time for people to arrive and be welcomed (1 hr for tech set up for online sessions).
- Do more of what works.
- Online tools will be as accessible as possible, we will use Zoom and plan sessions assuming people will join from a variety of devices, including phones.
- Sessions will be designed with flexibility. We will invite and reinforce that people work at the pace and length that is comfortable for them. People will be encouraged to drop in and out of sessions as they need to.
- Documentation will be captured online using tools such as Jamboards that can be seen and added to by all participants. Jamboards will be left open with links shared so that people can review and contribute during/ after/ between sessions when the time is right for them.
- Make time for brief review after each session to ensure any actions to thank people, follow up, etc. Are assigned. The LSBU team members will de-brief after each session to take notes and check observations/messages that have been documented.
- Each workshop will have 2 facilitators, and a minimum of 1 observer to take notes plus one person leading on the technical aspects.
- We will ask that any commissioning staff attending but not participating play an active role in the sessions or take an 'observer' role, rather than act as a passive bystander. This is important so that participants and facilitators do not feel 'watched' during the sessions.
- All online participants have their names only (not role/ positions).
- There will be no recordings of the session. Notes will be taken by an observer and the facilitator and any written work from the participants will also be used to gather themes and messages as per the project objectives above.

- Offer individual check-outs for people (for all sessions) to debrief, etc. And invite feedback directly on the length and format to ensure we adapt to suit the group as much as possible.
- Online sessions will be prioritised for the group with hope to work towards a face-to-face launch session with aim to co-design a final session that all participants feel confident about in terms of accessibility and safety.

Set up (online)

- These will be held on the platform Zoom.
- We have provided information for participants on joining online and accessing IT/Wi-Fi if this is needed.
- Participants will receive copies/ online link to the Long COVID desk research poster with their invitation and encouraged to review ahead of the workshop.
- Online workshops will not be audio or video recorded but Observers will be allocated to support each breakout group to capture notes on the Jamboard.
- Online breakout groups will be designed to ensure a maximum mix of experiences and perspectives in each conversation.
- One facilitator will always remain in the 'main room' online to support any participants who struggle to be allocated to a breakout or who find themselves returning to the session due to connectivity issues. Facilitators can 'visit' breakout rooms or remain in main room.
- Tech lead will do screen share whenever we are working on virtual post-its so that everyone can see what is being discussed. If people are not able to add their own post-its to the Jamboard then they can add the comment in chat as facilitators will add as a post-it.
- People will be able to drop in and out of sessions as they need, taking additional breaks as required.

Workshop Programmes

Workshop 1 Co-discovery: Brief Summary of the Programme

Session 1: Brief introduction

Session 2: What Brought Me Here Today?

Session 3: Sharing stories of Long COVID. Tell us about your experience of Long COVID. How has it felt for you and what has helped round here?

Session 4: Asset Mapping and Reviewing the Long COVID Poster

Session 5: Review and Close

Between Workshop 1 and 2 we grouped the themes from the first workshop.

Workshop 2 Co-design: Brief Summary of the Programme

This workshop is supported by a graphic facilitator

Session 1: Brief introduction

Session 2: What is happening for you right now? / Has happened since last time?

Session 3: Reviewing the themes from Workshop 1 and moving into Journey Mapping: What you need in your backpack for your own resilience; what you need to visit on the way (services); and what the NHS and Communities need to do together.

Session 4: Reviewing the Graphic capture of the session and adjusting this.

Session 5: Working up the practical elements of a New Service Model for Long COVID

Session 6: What have I learnt? What will I do?

Between Workshop 2 and 3 we developed a graphic of the New Model of Care.

Workshop 3 Co-design: Brief Summary of Programme

Session 1: looking back what was most meaningful last time?

Session 2: Our reaction to the New Model of Care

Session 3: What does this Model mean in practice? Including feedback from Long COVID Services

Session 4: Developing Personas for the 'stages' of Long COVID

Session 5: In Borough Groups – what matters to you?

Between Workshop 3 and 4 we developed the persona graphics.

Workshop 4 Co-deliver. Building the network: Brief Summary of the Programme

Session 1: Reaction to personas and feedback from services

Session 2: Establishing Peer Networks in Boroughs

Workshop Data was collaboratively collected using Jamboards. In each session of the whole group, and in each breakout small group discussion our facilitators supported the group to populate the Jamboard with their discussions, and the data was then reviewed by the whole group during the workshop to ensure it was complete. Each workshop had a new Jamboard with a summary of the findings from the previous workshop pre-populated. Each workshop had pre-populated Jamboard pages with the questions for each session in that workshop. A summary Jamboard was populated concurrently by the facilitators to share with the Steering Group. All data was provided anonymously.

Example Workshop Design
Long COVID: Co-discovery (place-based) - Online

Time	Topic	Lead	Process	Key design issues	Logistics	Key focus for observers	Objectives covered
12.00 – 1.00	Welcoming, tech set up	ALL Becky Lucie Sandie Abby Ambra Anam Christine Charlotte Aleyah	Ensure everyone who arrives is welcomed in, asked their name, put at ease and asked to ensure their name is showing next to their picture, put at ease and encouraged to keep their camera on if possible Very brief intro to Zoom - How to make yourself heard – chat/ virtual hands up/ wave at the screen. Introduce talking stick and notion of managing equal voice. How to get in to breakout rooms. How to change the size of slides to see more people. Put into breakout rooms to 'consent' Look out for people to share why they have come at the outset of the workshop at 1	Ensure people sign consent forms Explain what information we are capturing, how and why	Multiple breakout rooms for online 1-2-1 consent Zoom intro slide Ensure we all have consent forms Ensure space feels relaxed and friendly Share links to the jamboard (see above for link) Encourage people to self-manage and feel confident about dropping in and out of sessions – ensure there is opportunity to contribute outside of sessions (on jamboards)		
1.00 – 1.05	Logistics & Principles (short intro)	Becky/ Sandie	All adults. Comfort breaks when needed. There is time to talk and listen. Explain the process. Life happens – children/ pets/ deliveries in the background.	Move quickly into citizen voice rather than Prof voice. A means to manage airtime and listening	Design principles visible	Themes from messages being shared about personal experiences	A

			Introduce notion of managing equal voice, taking turns, taking time Acknowledge context – attitude to long-COVID plus how services have emerged (highlight poster – that we have already shared - to help)	Everyone's voice in the room.		General sense about what participants 'believe' about Long COVID	
1.05 – 1.10	What Brought me here today? Introduction	Lucie	Introduce exercise – 2 people to speak, 4 mins each to speak	Model equal voice, and collaboration from the start Model airtime and listening. Run this session in the main room but explain everyone will be in breakouts for their conversation	Prime the 2 design team members to have examples to share in advance if possible		
	TECH	Ambra/ Anam	Set up breakouts for next exercise – in 3s/4s. Needs to be half staff half patients. Set time to 15 mins ALWAYS have one breakout spare in case we need a 1:1 ALWAYS have one person in the main room for latecomers/ rejoiners Post jamboard link in the Chat				
1.10 – 1.30 1.10 Breakouts	What Brought me here today? (exercise)	Lucie We will join breakout	In your breakout room share what brought you here today – why do you care about this? Make sure everyone has time to speak without interruption.	Importance of ensuring everyone has time to contribute – set up a warning for meeting	5 breakouts 3 people per breakout + one of us	Do people mention other conditions and make links to COVID	A B

15 mins in groups 5 mins back in the main room		s to help with the principles of equal voice and to help with the Jamboard	**When you have all spoken identify and write max 3 post-its on the common themes you have heard** Back in the main room we take a couple of pop-ups and link it to next session.	rooms every 5 mins so group swaps plus one that reminds them to write 3 virtual post-its Nominate one person in each group to do virtual post-its (don't all have to do it) Important to unearth attitudes to long COVID – does it exist/ is it real	Ensure mix of people in each breakout room. Post questions in chat and link to jam board Ask each group to have one person to add virtual post-its to jam board - **OR we do it.**		
	TECH	Ambra/ Abby/ Anam	Recreate breakouts in 4s – 2 people 2 staff – a new mix please set time to 20 mins Post 5 min warning for the break into breakouts at 1.45				
1.30 – 1.50 1.30 5 mins set up 1.35 – 1.50 Round One	Sharing stories of Long COVID. Tell us about your experience of Long COVID. How has it felt for you and what has helped round here? (Round 1)	Becky/ Lucie	Please tell us your story of what has worked. There will be 4 people in each breakout groups (make sure 2 citizens in each group). Roles are 2 x observer, 1 x storyteller, 1 x questioner. 12 mins per story. 3 mins to tell 3 mins for questions	Looking for the 'what works' – set up a warning every 3 mins in meeting rooms so group moves through the exercise Brief observers to ensure there is space/ time to have a deeper/ longer conversation with	**4 people per breakout** Post questions in chat and link to jam board Add virtual post-its to jam board	Observers to notice things from 'round here' to start asset mapping exercise Need listen to any links between culture and experiences	B C D E F

			3 mins feedback from observers about what was heard. THEN – 3 mins capturing the themes one per post it YOU WILL have another go after the break.	someone if needed to be able to talk something out – people can return to the 'main room' to chat to a facilitator/ observer with aim that they are able to leave with a named contact			
1.45	TECH	Ambra/ Abby/ Anam	Post 5 min warning for break Set up next breakout – same people and same time of 20 mins				
1.50 – 2.10	BREAK Everyone back into the main room 20 min break	Ambra/ Abby/ Anam Sandie/ Becky	Post link to Jamboard in Chat and page no Anyone want to stay and chat about the exercises so far? Encourage people to review/ comment on assets 'round here' that have helped – and add to map AND/ OR to look at and comment on the poster		Map of the area the jamboard for people to add post-its to – someone supporting this		A B
2.10 – 2.30	Sharing stories of Long COVID. (Exercise – round 2)	Lucie/ Becky Ambra/ Abby/ Anam	Work in breakout groups of 4 (make sure 2 citizens in each group). 2 x observer, 1 x storyteller, 1 x questioner. (Open Breakout rooms) 12 mins per story. 3 mins to tell 3 mins for questions 3 mins feedback from observers about what was heard.	Rotate roles to ensure a new voice Post questions in the chat – set up a warning in meeting rooms every 3 mins so group moves through the exercise	4 people per breakout Post questions in chat and link to jam board Add virtual post-its to jam board	Observers looking out for assets	A B

			THEN – 3 mins capturing the themes one per post it				
	TECH	Ambra/ Abby/ Anam	Set up breakout rooms in 2s Post 2 min warning at 2 mins before the end				
2.30 – 2.50 2.30 Intro to poster and map 2.35 – 2.50 Exercise	Asset mapping & reviewing the poster	Lucie	Enable people time to reflect/ process what has been heard Looking back at graphic and at post-its. In break-out groups of 4 review - What has been working/ helping round here - Who/ what has helped your experience - How much does the poster reflect your experience?	**2 people per breakout** Put graphic on jamboard slide and share in the chat 10mins: Review the graphic poster. Post anything you think it missing. What do you agree with? How much does the poster reflect your experience? 5 mins: What assets do we have in our community to support us? And think about local assets in the broadest sense - people/ places/ organisations, formal and informal support, financial, emotional	Leave map and poster online for people to add to after the session	Listen for key themes	C D E

				interventions, online and in real life)			
	TECH	Ambra/ Abby/ Anam	Post next workshop date in the chat Have slide ready with the next workshop information Take notes of the chat feedback in the next session		Slide showing dates and invitations to share with people, plus an email address to confirm someone is coming.		
2.50 – 3.00	Wrap up and next steps - who else needs to be here	Becky/ Sandie/ Christine	Thank people for their time today. Outline of future process/ timeframe. Ask people to come again and bring others – highlight that we are looking for diverse groups at the sessions Any final words of reflection about today? Post any comments in the chat	Ask people to come again and bring others – highlight that we are looking for diverse groups at the sessions Who else needs to be here and/ or how to tell others about what we are doing Add named people/ organisations to the map?	Highlight that jamboard links will stay open after the session and people can keep contributing	Listen for themes from words shared at end of session	F

Invitations to the Workshops

Flyer

Long Covid Recovery Workshop

(Lambeth)

29 March 2022 / 1 - 3pm

Online (Zoom)

Email healthlab@lsbu.ac.uk

Are you living with Long Covid? Are members of your family or friends living with Long Covid? Do join a workshop bringing people living with Long Covid and the NHS together to develop better approaches in your community. We would love it if you could come with the people who are helping you at home.

You will meet clinicians and health professionals from Guys and St Thomas, Kings Healthcare, local community and primary care services, and together discuss how to better manage Long Covid.

EST 1892 LSBU

Easy Read Invitations

Invitation from Guy's and St Thomas' and Kings College Hospital NHS Foundation Trust to help improve Long Covid services

Long COVID workshops

We want to hear from people with a learning disability or their parents who have experienced **Long Covid** (have had COVID but continue to have symptoms for many months after testing negative).

London South Bank University is working with the NHS to bring together local people and health professionals across **Lambeth, Bromley, Southwark, and South-East London.**

If you live in one of these areas and have experienced **Long Covid**, we want to hear from you.

We will run 4 online workshops:

- Lambeth – 29th March
- Bromley – 30th March
- Southwark – 31st March
- Mixed boroughs (South-East London)– 19th April

	We want to hear from lots of different people, including people with learning disabilities, about their experience accessing **Long Covid services**.
	We want to talk to you about how we can improve **Long Covid services** for patients.
	We are holding discussions **online** at the moment because of COVID.
	You will receive an **online voucher** for attending the workshops.

	If you would like to find out more or find out how you can get involved, you can email Healthlab@lsbu.ac.uk

Example Invitation Bromley

Invitation from Guy's and St Thomas' and Kings College Hospital Foundation Trust to help improve and focus on people accessing and not accessing Long COVID services

Introduction

Guy's and St Thomas' NHS Foundation Trust (including Evelina London Children's Healthcare and the Royal Brompton and Harefield hospitals) and with King's College Hospital NHS Foundation Trust, are working with patients, carers, and communities to improve quality for Long COVID.

This is an invitation to help improve and focus on people accessing and not accessing Long COVID services

London South Bank University (LSBU) has been asked to work with the NHS to bring together local people and health professionals to improve these services.

We do this through a series of discussions where everyone shares their experiences and ideas to work out what is possible in the future; and tries these ideas out in practice, to see what works. This is not just about talking; it's about doing things differently and working together. To do this we will be running a series of workshop discussions and you are invited to participate in the first workshop. If you would like to continue after this workshop, we will invite you to the future workshops.

Dates and Times

This is the date for the first workshop

	ONLINE
Bromley	30th March 2022, 12.00 – 13.00 tech check in and logistics support. You can drop in and check you have access to everything. 13.00 – 15.00 the online workshop (with a break)

At the end of the first workshop, you can sign up for the follow-up workshop 2 weeks after this first one, if you want to continue to participate.

Do I have to take part?

No. It is entirely up to you to decide. If you do not want to take part that's OK. Your decision will not affect the quality of care you receive.

What will I need to do if I take part?

- If you agree and consent, your healthcare professional will share your name and preferred contact details with LSBU so they can send you the information for the workshops. The contents of your medical records will not be shared. We also ask for information including age group, ethnicity, gender, employment status, caring responsibilities, digital technology access and disabilities for monitoring purposes.

- If you later decide not to take part you are free to withdraw at any time, without giving a reason, by contacting LSBU (see below)
- If you choose to take part, you will be asked to sign a consent form before the workshop. The consent form will be stored by the NHS and a copy of the consent form will be kept by LSBU.

Further information

For further information, please see the attached information sheet below. We will also be running some optional online 'open house drop-in' sessions to help you get ready for joining in online or face-to-face, which we will invite you to.

Please email us at this address if there is anything else you would like to know: healthlab@lsbu.ac.uk

Or telephone us and leave a message at 07909 534 296. We aim to respond within 5 working days.

Thank you,

Prof Rebecca Malby on behalf of the whole team

Christine Burke, Anam Farooq, Mary Ryan, Sandi Smith, Shani Shamah, Lucie Stephens, Kanar Ahmed

Health Systems Innovation Lab

School of Health & Social Care

London South Bank University

56 Tabard St, London SE1 4LG

Additional Information

What is this project about?

This project brings people and health and care professionals together for an honest discussion about what can be done, both by the NHS but also by people and communities.

How will we do this?

We are asking citizens experience of accessing and not accessing Long COVID services to collaborate/work with us to improve services. We can only do this by talking together and testing out our ideas.

We start in workshops which bring together 20-30 people, citizens (patients, carers) with health professionals (doctors, nurses, therapists, administrative staff, the IT services).

We need to hear everyone's experiences and ideas to work out what more is possible. We then put these ideas into practice, testing out what works. This is not just about talking, it's about doing.

Dates and Times

This is the date for the first workshop

	IN PERSON
Bromley	30th March 2022 12.00 – 13.00 tech check in and logistics support. You can drop in and check you have access to everything. 13.00 – 15.00 the online workshop (with a break)

At the end of the first workshop, you can sign up for the follow-up workshop 2 weeks after this first one if you want to continue to participate.

If you are a member of the public, you are likely to receive the invitation from someone in the health service that you know. They will ask you if they can share your contact details (email or telephone) with us here at LSBU as we are organising the workshops. This means we can send you information about the workshops beforehand.

Expenses

If you are joining a virtual workshop you will be able to claim expenses up to a maximum value of £5.

We can provide Vouchers to members of the public that join the workshops (Value £15).

If you are joining an online workshop

We use an online platform called Zoom. If you haven't used zoom before we will show you how to use zoom before the workshop starts. Let us know if you do not have a computer and we will see if we can find a computer for you to borrow. We can also help with Wi-Fi data if this is a worry for you.

The blue link will take you to some information that helps everyone to work together online:

Https://www.lsbu.ac.uk/business/research-enterprise-and-innovation/health-systems-innovation-lab/what-we-do/hsil-online-delivery

We are happy with children/ dogs/ cats and parcel delivery people in the background, we just try to keep as focused as we can on working together.

Online workshops will not be recorded.

What are the disadvantages/risks of taking part?

There are no risks involved in taking part in these workshops.

What are benefits of taking part?

We hope you will enjoy contributing to the development of services to help improve the services the NHS offer to you and people like you now and in the future. After the first workshop, if you would like to remain involved, or help your local community provide support then there will be the opportunity to keep participating.

What will happen to information collected about me?

If you agree, your contact details will be shared by your healthcare professional with the LSBU team.

The workshops are themed according to health issues e.g., people with diabetes, so you will be in a group which identifies you as someone living with this health condition, but this will only be known within the workshop. You will not be identified in any publications or shared materials outside the workshops.

The information LSBU will be given is your name and your preferred contact details (email / address / telephone). We also collect information about age group, ethnicity, gender for monitoring purposes.

LSBU will keep this information for 3 months and only use it for the purposes of this work. This information will not be shared with anyone else. You have a right to request that your personal information is deleted at any time.

The information you discuss during the workshops will be anonymised and you will not be identified in any information presented or published later on.

If you wish to withdraw from this study during a workshop the information you have provided up until you withdraw may still be used (but will be anonymised).

Confidentiality and your rights

The contents of your medical records will not be shared.

If you agree to take part in this work, you will need to sign and date a Consent Form which we will provide on the day. The form will be stored by your hospital and a copy will be kept by the researchers.

Your GP will not be informed if you take part (unless they are also at the workshop).

Results of the work

At the end of the work the ideas and solutions generated during the workshops will be shared across the NHS locally and nationally and we will enter it for publication in a health journal. LSBU are very happy to share with you with a copy of any progress summaries or publications (you can choose to be contacted with this information on the consent form).

Adjustments and accessibility

We can accommodate for any specific needs so please let us know if you require an interpreter, need any adjustments, have any access requirements or you would like to attend the workshop with someone else (e.g., a parent or carer).

Other information

Your health care professionals have not been paid for inviting you to join the workshops.

Who should I contact with questions?

You can email or call us at London South Bank University with any questions using the contact information below:

Email: healthlab@lsbu.ac.uk

Telephone: 07909 534 296 please leave a message and we will respond within 5 working days.

Thank you for reading the information sheets and for considering taking part in this work.

Thank you

Prof Rebecca Malby on behalf of the whole team,

Christine Burke, Anam Farooq, Mary Ryan, Sandi Smith, Shani Shamah, Lucie Stephens and Kanar Ahmed

Health Systems Innovation Lab, School of Health & Social Care,

London South Bank University,

56 Tabard St, London, SE1 4LG

Telephone Script for Invitations

Telephone Calls to People who are Accessing Guy’s and St Thomas’ NHS Foundation Trust Long COVID Clinic

1. You will be provided with a list of telephone numbers of patients that are using the Long COVID clinic.
2. They will be organised by Borough.
3. As a priority we need people for Lambeth for next Tuesday so please start with them.
4. The script is below followed by a set of faqs to help you answer any questions.
5. Please record if the person wants to come to the workshop if not.
6. If they do want to come, please note the person’s contact details and send them to healthlab@lsbu.ac.uk.
7. If they don’t want to come, could you find out tactfully why they don’t want too and make a note and let us know (email Becky).

SCRIPT

Good morning/afternoon. My name is _____________ and I’m calling from **London South Bank University.** Please could I speak to **[name of patient]?**

[NOTE: If the names person is not available, please do not leave a message.

NOTE: Establish safely that you are talking to the named person from list and check it is convenient to talk. If it is not convenient to talk, ask if you may call back and agree a time.]

Say that we are working with Guy’s and St Thomas’s hospital to help improve the quality of care for people who have had, or have Long COVID.

You are not calling about their health, treatment of care.

You are ringing to invite them to take part in an online workshop that brings local people together with health professionals (doctors, nurses and therapists) working in the Long COVID clinic to improve local services.

The workshop gives you the opportunity to discuss your ideas and share your experience. We will be working out to work out what is possible in the future; and will be putting these ideas into practice, to see what works.

The workshop is on

[Note: use the relevant workshop for the person you are talking too]

LAMBETH: 29th March

BROMLEY: 30th March

SOUTHWARK: 31st March

FROM ANY BOROUGH IN SOUTH EAST LONDON: 19th April

Script Cont….

The workshop starts at 1pm and run for 2 hours. There are lots of opportunities to share your story, and you will be mostly in a small online group. There is a 20 minute break in the middle. If you are finding the workshop tiring, you can take a break at anytime.

We will be online between 12.00 and 1pm to check you have everything you need to take part and to go through the consent.

Come for as much as you can/ want too.

If you would like to continue to take part after this workshop, we will invite you to the future workshops.

Please can we take a contact email address or postal address to send you the workshop information?

Do you know anyone else who has Long COVID or cares for someone who has Long COVID who you think would like to join the workshop?

[Note: If they do, please ask them to take down our email address or telephone number to pass onto this person/ people]

Thank you for agreeing to join the workshop, we will be back in touch with you tomorrow with the joining information. If you have any questions then our email is:

Healthlab@lsbu.ac.uk

And our telephone number is 07909 534 296 please leave a message and we will get back to you within 24 hours. It will be myself, or my colleague Ambra.

Thank you so much for talking to me today, I have enjoyed meeting you

[and of course, add in a nice goodbye]

Questions and Answers

Do I have to take part?

No. It is entirely up to you to decide. If you do not want to take part that's OK. Your decision will not affect the quality of care you receive.

What will I need to do if I take part?

If you agree and consent, then we will send you joining instructions for the workshop.

We also ask for information including age group, ethnicity, gender, employment status, caring responsibilities, digital technology access and disabilities for monitoring purposes.

If you later decide not to take part you are free to withdraw at any time, without giving a reason, by contacting us.

If you choose to take part, you will be asked to sign a consent form before the workshop. The consent form will be stored by the NHS and a copy of the consent form will be kept by LSBU.

Expenses

You will be able to claim expenses up to a maximum value of £5.

We can provide Vouchers to members of the public that join the workshops (Value £15).

If you are joining an online workshop

We use an online platform called Zoom. If you haven't used zoom before we will show you how to use zoom before the workshop starts. Let us know if you do not have a computer and we will see if we can find a computer for you to borrow. We can also help with Wi-Fi data if this is a worry for you.

We are happy with children/ dogs/ cats and parcel delivery people in the background, we just try to keep as focused as we can on working together.

Online workshops will not be recorded.

What are the disadvantages/risks of taking part?

There are no risks involved in taking part in these workshops.

What are benefits of taking part?

We hope you will enjoy contributing to the development of services to help improve the services the NHS offer to you and people like you now and in the future. After the first workshop, if you would like to remain involved, or help your local community provide support then there will be the opportunity to keep participating.

What will happen to information collected about me?

If you agree, I will share your contact email address with the LSBU team.

The workshop is about Long COVID, so you will be in a group which identifies you as someone living with this health condition, but this will only be known within the workshop. You will not be identified in any publications or shared materials outside the workshops.

LSBU will keep this information for 3 months and only use it for the purposes of this work. This information will not be shared with anyone else. You have a right to request that your personal information is deleted at any time.

The information you discuss during the workshops will be anonymised and you will not be identified in any information presented or published later on.

If you wish to withdraw from this study during a workshop the information you have provided up until you withdraw may still be used (but will be anonymised).

Confidentiality and your rights

The contents of your medical records will not be shared.

If you agree to take part in this work, you will need to sign and date a Consent Form which we will provide on the day. The form will be stored by your hospital and a copy will be kept by the researchers.

Your GP will not be informed if you take part (unless they are also at the workshop).

Results of the work

At the end of the work the ideas and solutions generated during the workshops will be shared across the NHS locally and nationally and we will enter it for publication in a health journal. LSBU are very happy to share with you with a copy of any progress summaries or publications (you can choose to be contacted with this information on the consent form).

Adjustments and accessibility

We can accommodate for any specific needs so please let us know if you require an interpreter, need any adjustments, have any access requirements or you would like to attend the workshop with someone else (e.g., a parent or carer).

Other information

Your health care professionals have not been paid for inviting you to join the workshops.

Appendix 2: The Individual Workshop Findings and Results

Workshop One Results

People and Professionals were asked to start with 'what works and what is needed' in terms of their experience of living with and supporting people with Long COVID. This is what emerged from this from across the 4 workshops:

Workshop One Results

What works? What is needed

Hope

Had Covid since Jan 2020, hospitalised. Still feeling really poorly - muscles hurting, hair loss, exhaustion. In the dark. No light at the end of the corridor. There's no help.

Help to cope with work, social life and coexisting co-morbidities; "Finances matter'; Acknowledging and factoring in the coexistence of Long COVID and life

Adapting to new identity

Accepting and loving self was the key for the recovery

feeling stressed, disoriented, underage son became young carer of his mum

Personal regular emotional and practical support

Kings ICU Thursday afternoon Zoom meeting - a lifeline

Lambeth talking therapy specifically for travel anxiety

trauma that comes after 'survival mode'

support for partners/family members

Getting a Diagnosis

medical care not on track with LC still no diagnostic criteria.

Services where patient are

Covid is increasing health inequalities

there is lack of joint up practice example pain clinics and LC clinics. something NHS does not do well.

Peer Support

Joined long covid facebook group. Felt like a negative place. Not getting answers or much from it. Could there be a better sort of group? Maybe someone with similar health issues.

GPs as part of the solution

Training; part of the team;

Recognition from people around me (friends, family, society)

other people can't seen/ understand what is happening with your body and mind as COVID invisible

Flexible Employment Practices

OH very helpful. Employer has expected travel as part of job. Working harder to prove herself at work doesnt want to let herself down

Support on returning to work - need help with this rather than having to find out yourself - too tiring to read and look at videos

Occupational health supported working from home. Employer not sympathetic

employers not clued up on what is lc same for public. no clear understanding on the devastating impact of LC on person and their family.

A healthy lifestyle -the usual stuff - exercise (paced), eating well, sleeping well

Getting outside for some gentle exercise

"I need to learn to breathe again. I need to get a handle on my breathing pattern."

being supporting is important if you are a partner but being kind to self as well.

Short Term Goals

support based on persons own vision of what will help them to thrive - social prescribing can help with this

Fig 14 Workshop 1 Results – What Works and What is Needed?

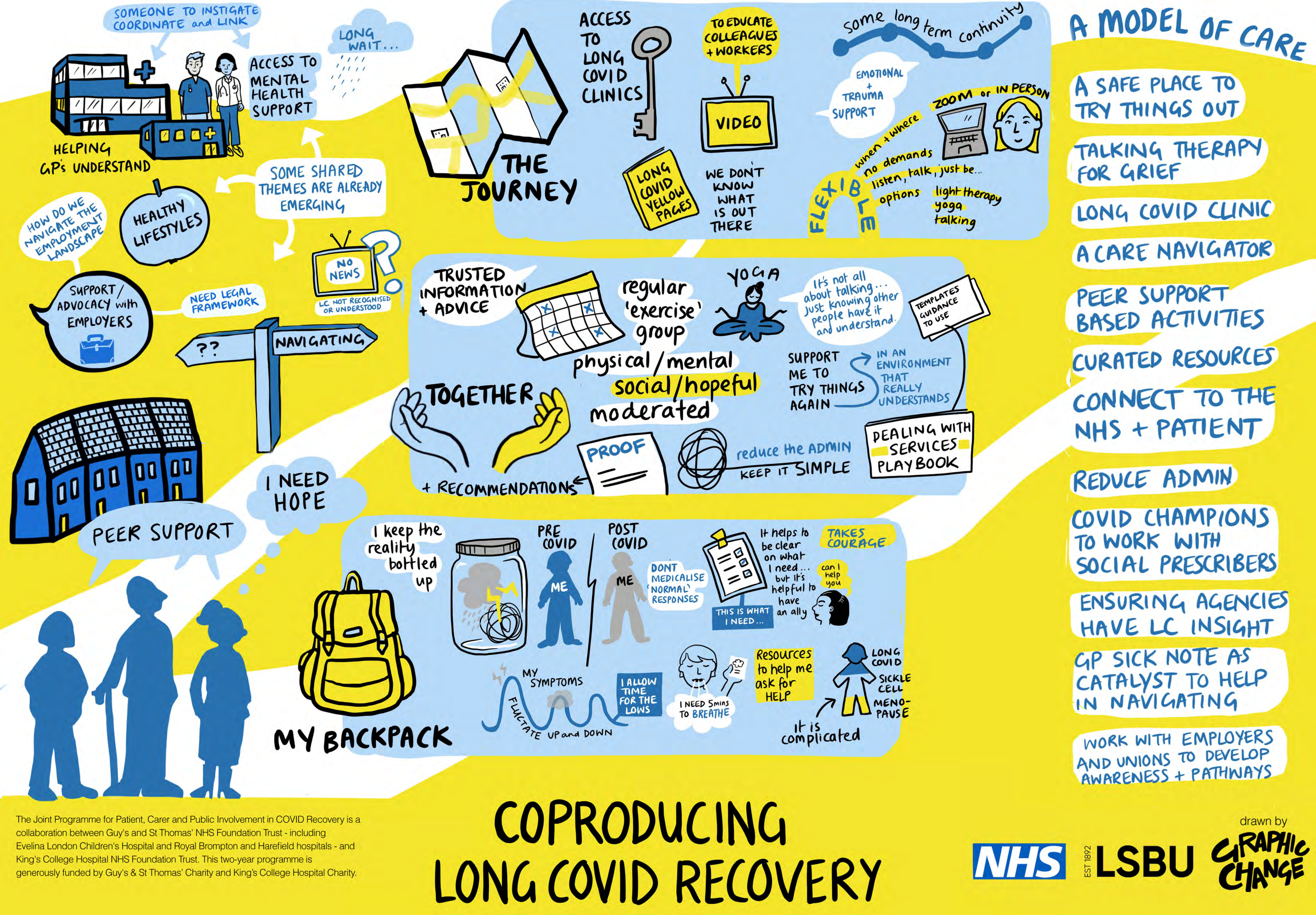
Workshop 2 Results

In each Borough workshop we explored the notion of

(a) What I need in my backpack to be resilient (that I can provide for myself, or can be sourced from family, friends, and communities
(b) What I need on my Long COVID journey from services
(c) What the Long COVID community needs to do with the NHS to help create a supportive society

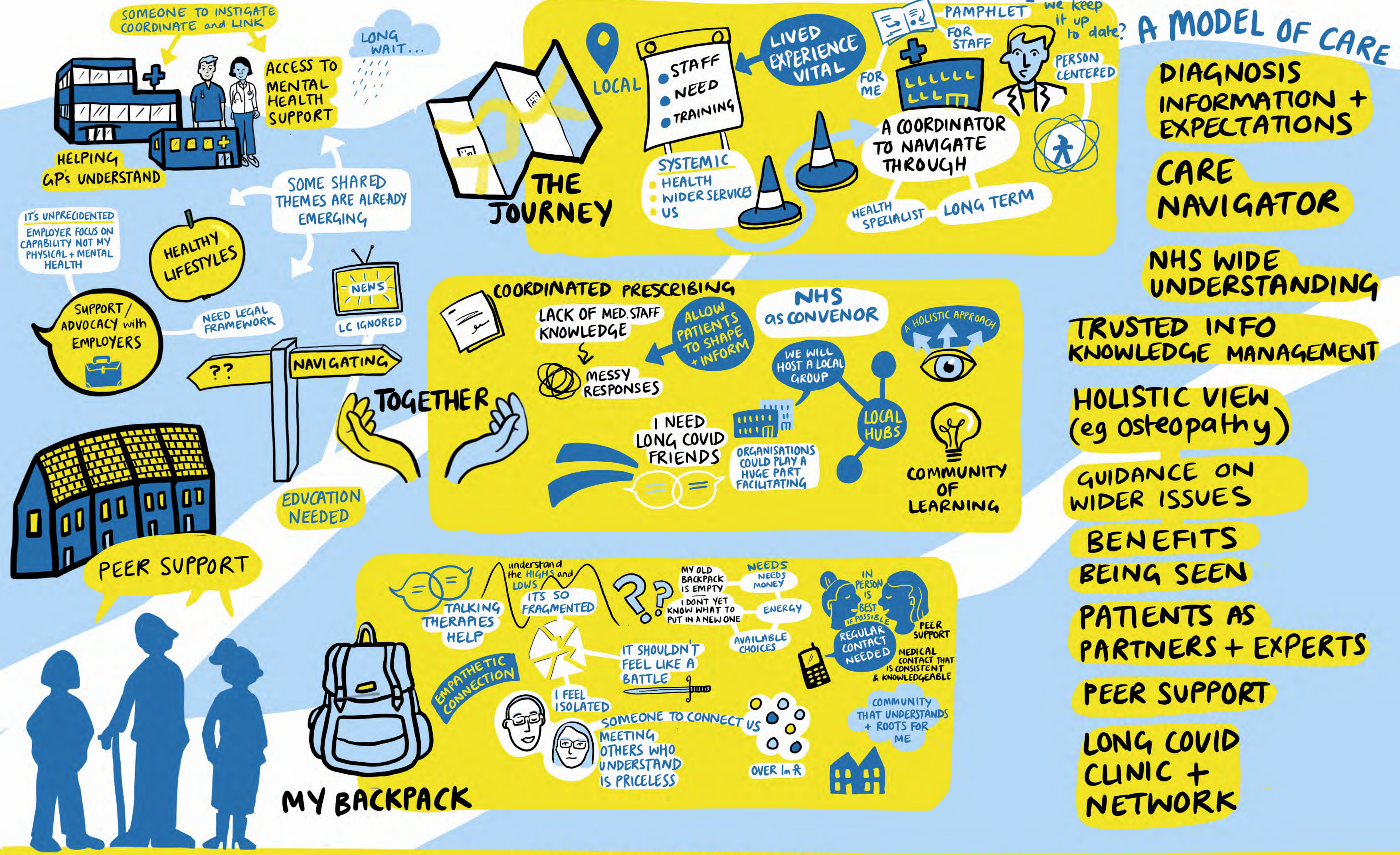
Drawings were developed from the discussions e.g., to develop the first iteration of the Model of Care diagram.

Fig 15 Lambeth workshop first draft of a new model of care



The Joint Programme for Patient, Carer and Public Involvement in COVID Recovery is a collaboration between Guy's and St Thomas' NHS Foundation Trust - including Evelina London Children's Hospital and Royal Brompton and Harefield hospitals - and King's College Hospital NHS Foundation Trust. This two-year programme is generously funded by Guy's & St Thomas' Charity and King's College Hospital Charity.

Fig 16 Southwark workshop first draft of a new model of care



The Joint Programme for Patient, Carer and Public Involvement in COVID Recovery is a collaboration between Guy's and St Thomas' NHS Foundation Trust - including Evelina London Children's Hospital and Royal Brompton and Harefield hospitals - and King's College Hospital NHS Foundation Trust. This two-year programme is generously funded by Guy's & St Thomas' Charity and King's College Hospital Charity.

COPRODUCING LONG COVID RECOVERY

NHS
EST 1892 LSBU
drawn by GRAPHIC CHANGE

The final version of this was developed over the course of the following workshops and is provided in the results section of this report.

Workshop 3 Results

The combined New Model diagram was discussed and refined further. Personas were developed for stages of the Long COVID journey over time. These are provided in the overall results section.

Workshop 4 Results

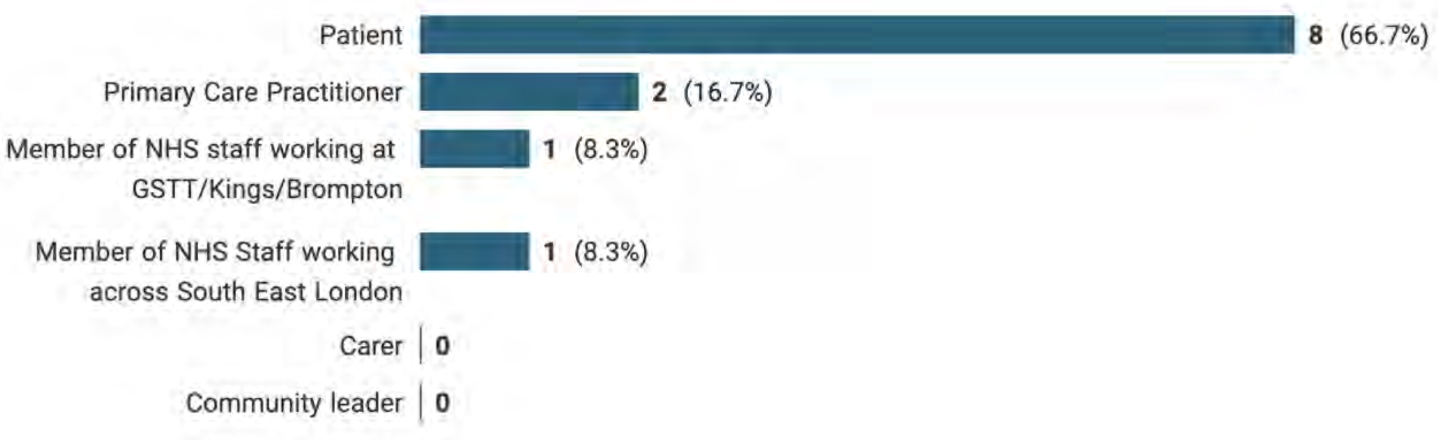
The citizens taking part have formed relationships not only with each other but also with the professionals who have joined these workshops. At this stage the citizens met in local groups. Some wanted to continue to meet beyond the lifetime of this project and have formed a whatsapp group for the whole, and peer groups in Borough. Others are seeking service development and change – and are looking for a response from GSTT and KCH in terms of what will be different as a result of this work.

Over the course of the workshops, we also developed a picture of the experience of Long COVID, this is for clinicians and people to use in consultations and to help spread the message within society about what it’s like to have Long COVID.

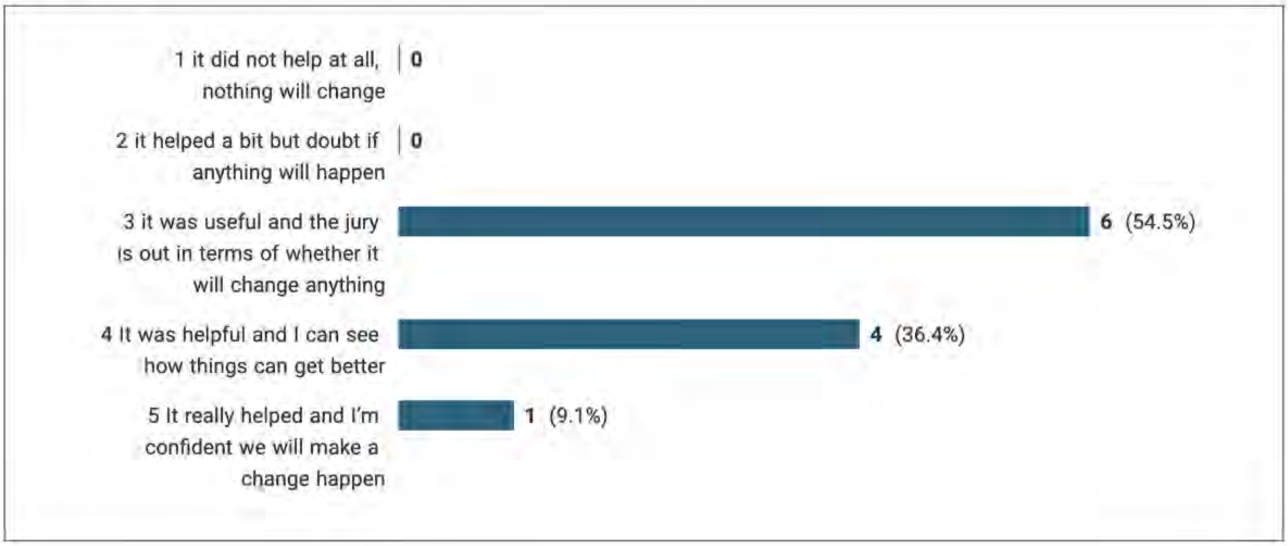
Appendix 3: Participation by Workshop

Workshop	Participation	
Long Covid	Patients	Staff
Long COVID Lambeth	5	8
Long COVID Southwark	7	6
Long COVID Bromley	7	11
Long COVID Mixed Borough	8	7
Long COVID workshop 2 Mixed Borough	5	3
Long COVID workshop 2 Southwark	6	1
Long COVID workshop 2 Lambeth	3	1
Long COVID workshop 2 Bromley	6	5
Long COVID Workshop 3 (combined all boroughs)	11	17
Long COVID Workshop 4 (combined all boroughs)	13	5

Feedback from Participants
Over the course of the workshops, we asked participants for feedback at the end of every session and used this to modify future sessions. We also provided a short feedback survey. Uptake was very low on the latter and our view is that people within the workshop felt very comfortable giving direct feedback in real time at the end of the workshop.



How well do you think the workshops helped you and the others at the workshops understand what is needed and what to provide/ support on a scale of 1-5?



Comments from participants in the survey included:

"A very educational platform in determining what patients and health care professionals needed. Excellent format especially the graphic illustrator and the leader of the workshops. Good to see the background of service development and our patients are involved and also educational re services available in South East London.

It seems we all know what needs to be done going forward but sceptical if it will come to fruition due to funding.

It is a really fantastic group to be in as the people and the professionals who join in understand what we are actually going through. What they are doing is giving long covid sufferers a voice. And there we're some brilliant ideas being bandied around about going forward which I hope could happen.

As a patient, my expectation is that this is more likely to help others than myself since it is likely to take a while to implement and I really hope I won't need it by that point!

I think clear issues have been identified which is a great place to start. But I am so very aware of the complexity and difficulty in getting any change in an area that I don't directly manage. A lot of what we have identified sits in the remit outside the NHS and so far, there is not much engagement from those who work primarily in that arena. So, its hopeful but not a given that positive change can happen. Although there are some patients that look like they might be willing to take on some of this themselves, but they still need someone to guide that energy."

We asked if there had been any impact from the first workshop, two comments stood out

"It has given me insight into how to listen to patients more and allowing patients to problem solve themselves. This will aid me in my clinical practice." Health Professional

"Yes for the first time I feel hopeful I am actually going to be going out of the country for the first time since I came out if hospital I know it will be hard and yes I will be scared but I made that decision to travel although only for 2 days it gave me satisfaction that I could do that and to me that was based on talking to the people at the workshop. I got a little bit of myself back in doing spur of the moment things which I had completely lost in myself." Person living with Long COVID.