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**LSBU**

# **Patient & Public Engagement and Social Research: Waiting for Treatment and Self-Management**

**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.

## **Authors**

Prof R Malby, Mary Ryan, Hai Saint, Sandie Smith, Lucie Stephens

## **Contact**

[healthlab@lsbu.ac.uk](mailto:healthlab@lsbu.ac.uk)

[engagement@gstt.nhs.uk](mailto:engagement@gstt.nhs.uk)

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**Guy's &  
St Thomas'  
Charity  
&..**



## Acknowledgments

We are so grateful for the people who are waiting for treatment and care, who contributed their experience and stories in the spirit of collaboration and to secure improvements in services. Some people were living in very difficult personal circumstances, were in pain, and were struggling. Despite this people were supportive of the efforts the NHS was making to reduce waiting lists and focused their attention on the issues in workshops on how waiting can be better supported.

We were struck by both people's generosity with their own stories and data, their clarity about what they needed, their frustration at the difficulty of getting the support they need to manage whilst they wait, and at the uncertainty of waiting.

We are thankful for the professionals that stepped into unknown collaborative territory with open hearts and minds to discover how to support people who are waiting. Of course, clinicians and managers came into the workshops concerned about how they would be judged. They listened with compassion, and where there were serious concerns, they expediated solutions for individuals quickly.

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 the design of better solutions for people waiting, but also built relationships to support those solutions along the way.

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## 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 waiting for treatment and self managing.

The Inquiry Questions for the Programme are:

1. What is it that people need to know about waiting?
2. What will help people as they wait?
3. How will we ensure waiting is safe? How can we (NHS and people) ensure no one is forgotten or left behind?
4. How can the NHS partners promote, support, and enable effective self-management?

The approach included:

1. Desk Research, including reviewing previous commissioned research and intelligence from National Voices work on the pandemic and waiting times.
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 on the waiting list for a range of specialities, their cares, clinicians and allied staff from primary and secondary care, and third sector organisations together resulting in participants volunteering to help in the testing of the innovations in practice supporting the Waiting List transformation team.

Overall, 51 people were engaged in the 7 Waiting for Treatment and Self-Management workshops of which 3 were observers.

This report provides recommendations, an animation and a set of personas (character profiles that can be used to design services). The materials can be found here.

### **The Impact of Waiting**

Waiting places 3 types of burden on people (McGill et al, 2020; The Health Foundation, 2021):

- a) Burden on quality of life: physical health, mental health and wellbeing
- b) Burden on their financial stability (impact on their job)
- c) Burden on their social context, including caring responsibilities and relationships

All three of these burdens need to be taken into consideration when prioritizing the waiting list, otherwise the burden will fall unequally, increasing inequalities in people's health outcomes.

## Recommendations

The recommendations came from the patients, carers, staff and other professionals who participated in the workshops. The details on 'how to' behind these recommendations are provided in the section on the personas provided in the body of the report.

1. Waiting List prioritisation should be adjusted for social context and personal circumstances. Be clear about prioritisation and ensure that it reflects the impact waiting has on people's personal circumstances.

People who are waiting are in fact enduring a new chronic disease. The NHS's prioritisation based purely on clinical need has undertones of the COVID pandemic crisis response, which whilst helpful in the first stages of the waiting list crisis now needs to be adapted to reflect the wider needs of people who wait. Waiting is not fair and waiting prioritised by clinical condition has the potential of increasing inequalities. For example, people on zero-hour contracts are penalised over those who can for instance take sick leave, and those same people tend to have poorer personal circumstances. Being poor on the waiting list is harder and has knock on effects that endure beyond the immediacy of their clinical condition. People wanted clear transparent criteria for prioritisation that is followed. These are the recommendations from the participants in the workshops:

2. Make sure that support to people on the Waiting List is provided equitably and universally.

The support for people waiting should be consistent and fair, not varied by where you live.

In the workshops people wanted waiting to be fair for all. There were experiences of people living in some localities getting different support services than others for instance the role social prescribing or care navigation played in different Primary Care Networks (PCNs).

3. Provide regular updates to people waiting in terms of what's next and the timescales, and what to do if they deteriorate. Living with uncertainty makes waiting harder.

"Regular" to patients is not every 3 months. People need to be assured and reassured.

4. Provide a one-stop phone line (one call that's all) for patients to access if they are worried and need information about their waiting time.

Provide a safe waiting care plan shared between the person, GP, and hospital that includes any red flags, how to manage deterioration, and where to go for help.

5. Help people navigate the whole system of waiting. Provide Care Navigators.

For those struggling to navigate their own care on the waiting list, provide support through care navigators who will 'hold the hand' of the person waiting and their family, being an advocate, educator and administrator. This is not the receptionist who signposts alternative appointments (a model that has been advanced in primary care).

6. People need support to help themselves. Provide dedicated Health and Wellbeing Coaches.

People understood the need to help themselves but needed the tools to do so, provided by someone that can guide them.

7. Enable Peer Support.

Initiate and provide a space for peer support groups to form locally. People will contribute, but they need help to get them going. The focus should be on waiting safely and healthily as possible. It should not be disease specific.

8. Provide family counselling for people who are traumatised by the COVID experience and struggling to cope on the waiting list as a result.

Check-in with families and carers to see how they are managing whilst their loved one waits.

9. In relation to measuring what matters to people who are waiting please see section on Measuring People's Experience in this report.

Critically any feedback provided by people waiting should be analysed and shared back with those same people. What is measured can also in itself support people, for example asking people to measure their self-management interventions will draw those people's attention to those interventions.

## 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, Carer and Public Involvement in 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 experiences 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 Waiting for Treatment and Self-Management Patient and Public Engagement Programme.

The Inquiry Questions for the Programme are:

1. What is it that people need to know about waiting?
2. What will help people as they wait?
3. How will we ensure waiting is safe? How can we (NHS and people) ensure no one is forgotten or left behind?
4. How can the NHS partners promote, support, and enable effective self-management?

The deliverables include:

1. The first report of the key themes and messages from the desk research, a summary report is provided [here](#) and the full report was provided to the Joint Programme Steering Group.

2. A network of people contributing to coproducing and championing solutions to ensure safe waiting and effective self-management (a self-selecting list of people who want to continue contributing). This has been provided as a database to the Joint Programme.
3. A report of the Co-discovery Stage setting out the key findings secured between people and services; the solutions to be trialed (report using accessible language and imagery); and a set of change ideas prototyped. This was provided as a Jamboard.
4. A report from the review workshop to inform Joint Programme partners about how best to secure safe waiting and self-management (incorporated in this report).
5. Project final report as required in the specification (report) and a set of materials to support knowledge sharing including graphics and a video, available from the programme webpage [here](#).

A summary of the work and findings is provided as an animation video available online [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 (GST 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 and ensure input and support from strategic stakeholders throughout.

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 Codesign (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.

## Brief Overview:

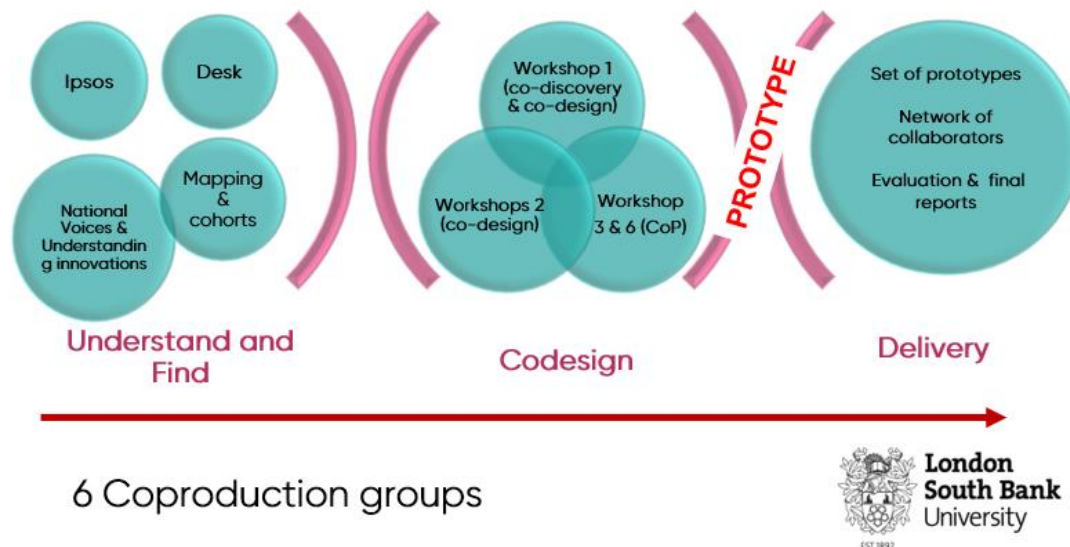


Figure 1: Overview of the Methodology

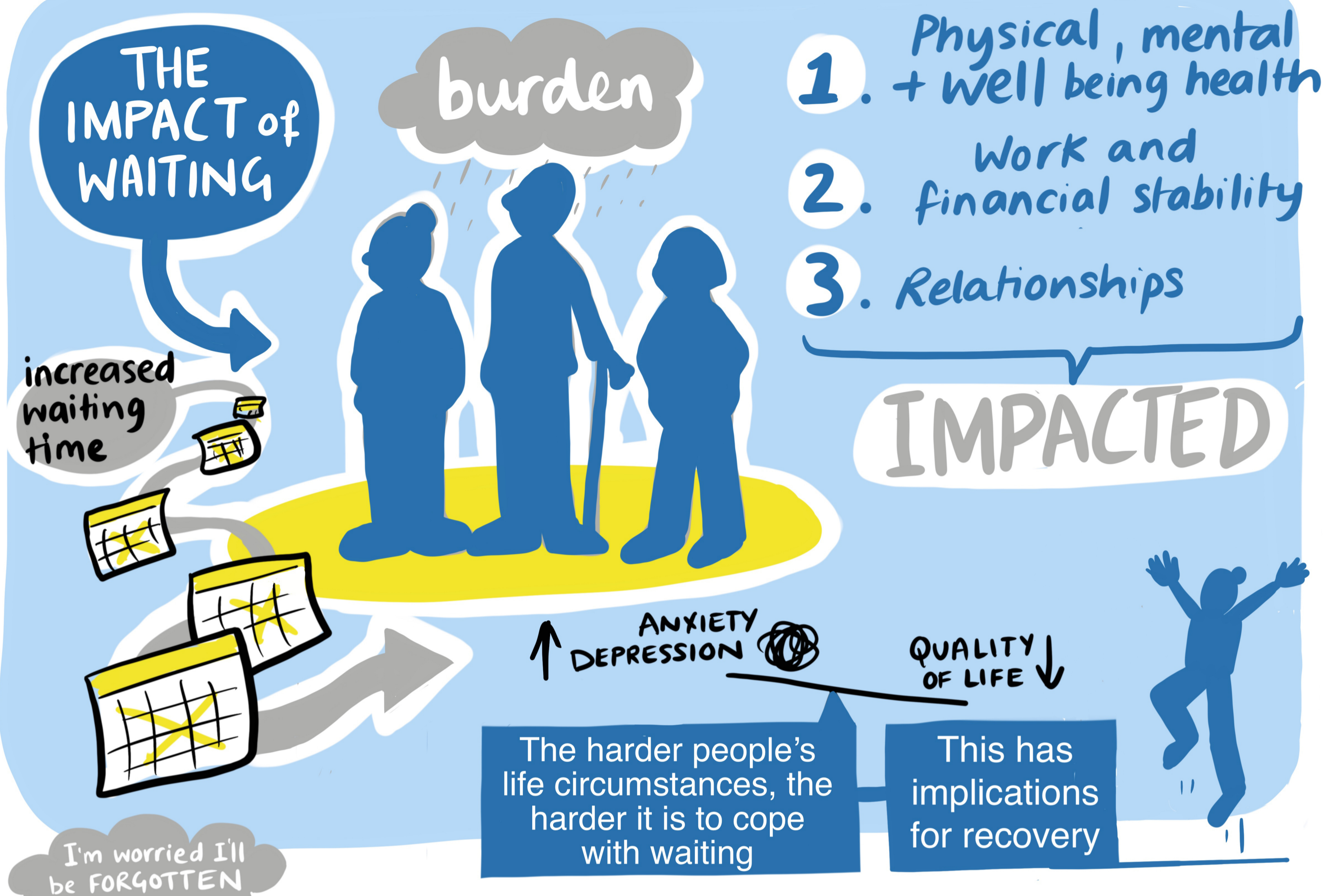
### Understand and Find

This comprised of:

- Desk Research, including reviewing previous commissioned research and intelligence from National Voices work on the pandemic and waiting times.
- Mapping cohorts and inviting participants to the workshops with the help of a Design Team.

The **Desk Research** was delivered in both long and short form in February 2022. This provided background information and context to help shape and inform the project.

Key messages from the Desk Research are provided in Appendix 1 and summarised in this graphic provided in the report:



## WHAT PEOPLE NEED

- Acknowledge my concerns
- Keep me informed about the wait + anticipated dates
- Help me manage my condition while I wait
- Give me access to support services + peer support

## WHAT CAN BE DONE



## WAITING

## The Design Team

The Design Team was a small group of people from across GSTT and KCH who committed to helping us secure participation and to being 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.

The discussions in the Design Team generated some hypotheses from the Design Team members about the need for information. They had the view that if people knew how long they would be waiting they would make choices about their health management, possibly choosing alternatives or managing their symptoms differently.

The design team categorised the Waiting List information to ensure that the workshops accessed the full range of patient experience as follows:

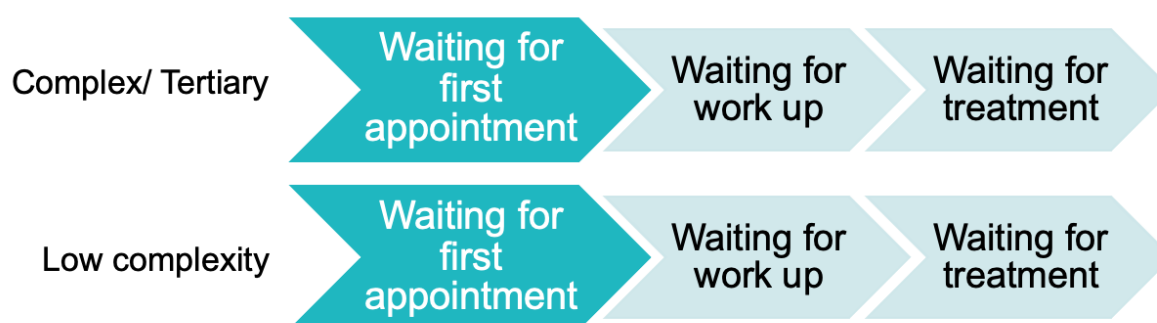


Figure 3: Design Team categories of waiting list patients

The clinical groups chosen by the Design Team were:

Complex/ Tertiary	
Waiting for first appointment	Cardiology
Waiting for work up	Frailty
Waiting for treatment	Orthopedics
Low Complexity	
Waiting for first appointment	Cancer
Waiting for work up	Vascular
Waiting for treatment	Ophthalmology

Table 1 Clinical groups chosen by the Design Team

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

## **Mapping Cohorts**

For each workshop the Design Team mapped the health and care system for providing support to people on the Waiting List and determined the invitation list. They then mapped the citizen participants (patients and carers) ensuring they were able to find a diverse mix of people and referring to the specification requirements.

A full description of this process is provided at Appendix 2

The Design Team intent was to identify these cohorts of patients through the clinics, but this yielded a very short list of people. This was augmented by the GSTT/ KCH Waiting list Database for the cohorts identified, and wide-ranging publicity for the workshops (see the invitation process provided in Appendix 2).

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).

## **Recruitment Issues**

The workshop on frailty was replaced with Children and Young People. However, this also proved a challenge in terms of securing participation. The first workshop elicited no attendance from children and young people or their families. The LSBU team were invited to attend a family support group in Lambeth with the Evelina London's patient and public engagement lead. The 9 people who joined this had complex and challenging needs from a range of services. As the stories shared were very personal, and their situations in some instances required a rapid response from the Trust, we did not address the questions identified for the workshops, taking a compassionate listening approach. Evelina London subsequently followed through with those families that needed immediate support.

## The Workshops

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

The workshops were designed to:

1. To develop a shared picture of what is needed (understand)
2. To develop 'readiness' for collaborating to find solutions (attitude)
3. To design solutions that you can test (ownership) that improve inequalities (fairness)
4. To catalyse safe waiting (improve)
5. To design the measures to review the success of these solutions (feedback – what counts)
6. To consider how to spread equably across the partnership (share)

The workshop design and detailed information on the workshop programmes is provided in 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:

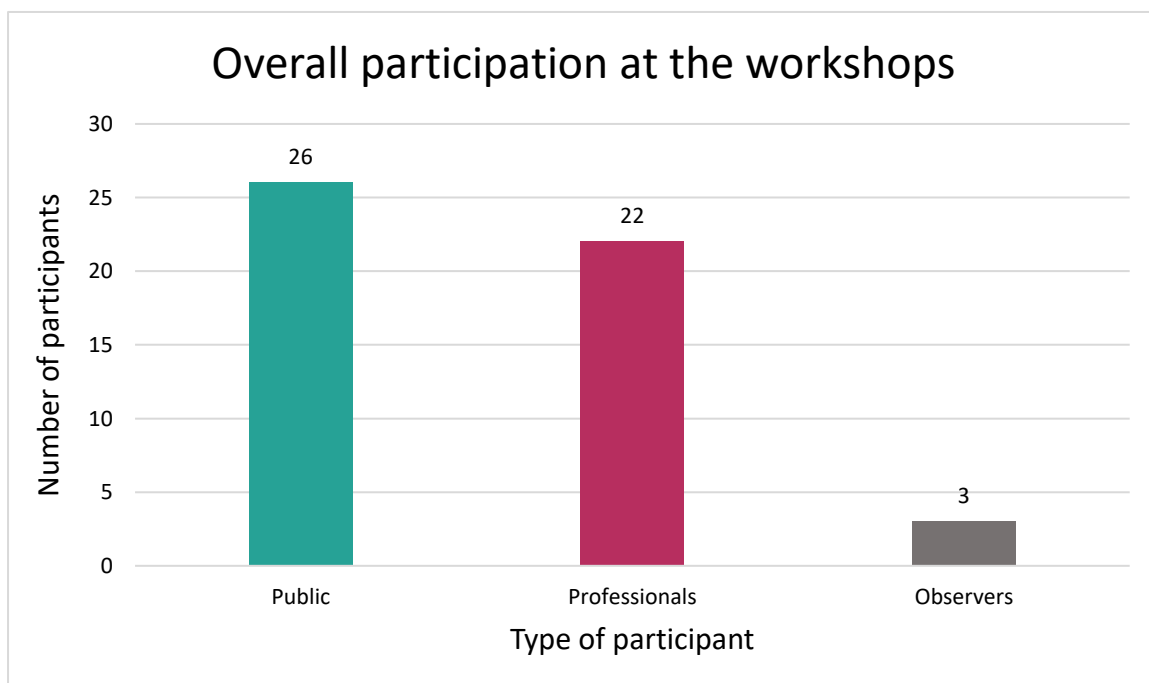


Fig 4 Overall participation in the workshops



Fig 5 Participation in each of the workshops

Overall, 51 people were engaged in the Waiting for Treatment and Self-Management workshops of which 3 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
6	29	15	5	11	0	24	3	0	8	0	2	0
17%	81%	42%	14%	31%	0	67%	8%	0	22%	0	6%	0

Table 2 Characteristics of the public participants



Fig 6 Professions participating

Who came from these organisations:

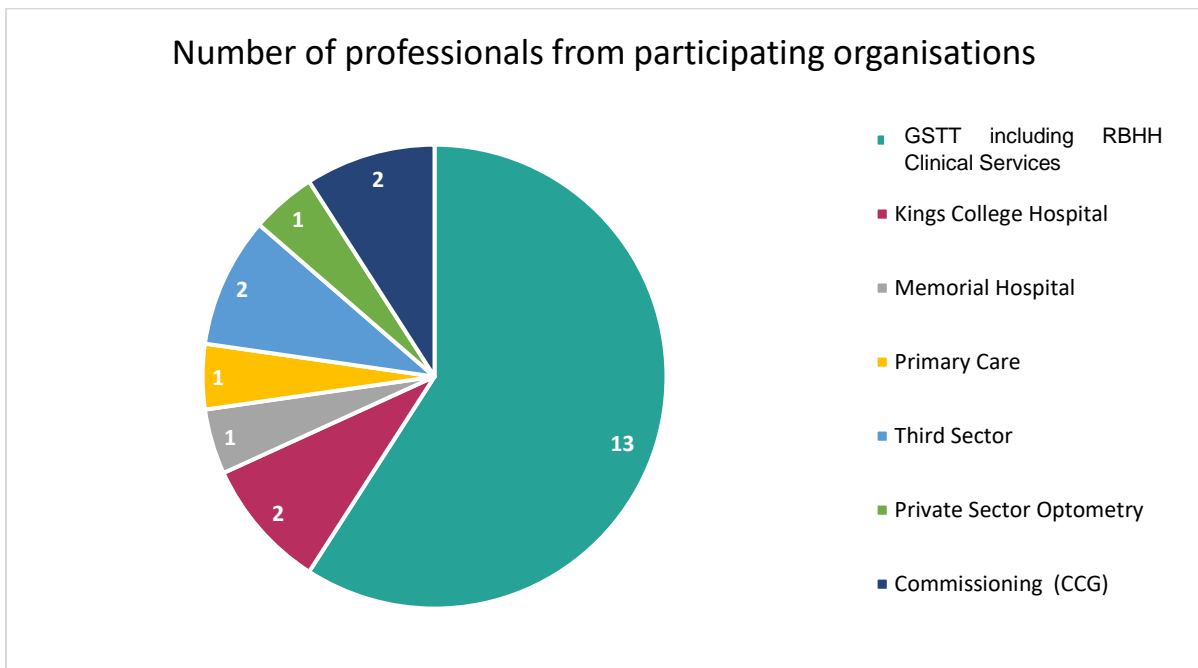


Fig 7 Number of professionals from participating organisations



## Organisations

GSTT	13
KCH	2
Memorial Hospital	1
Primary Care	1
Third Sector	2
Private Sector Optometry	1
Commissioning (CCG)	2

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

# Results of the Work

## Improvement Ideas

People and Professionals were asked to start with 'what works' in terms of their experience of living with and supporting people who are waiting. This is what emerged from across the 5 condition specific workshops:

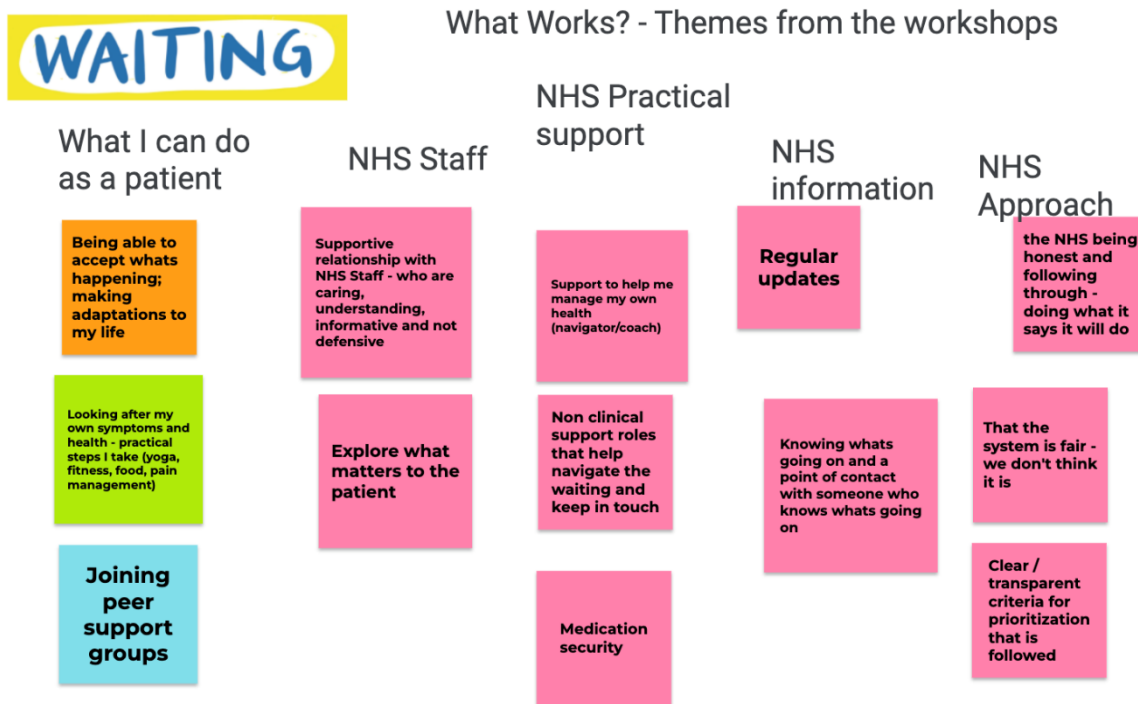


Fig 8 What works? Themes from the workshops

It was clear that where people were informed and knew what was happening next with appointments booked even if that was not an immediate appointment, they didn't feel like they were waiting, they felt like they were being looked after. Where people had little information about what was happening, they experienced this as waiting.

People experienced waiting as a health condition in its own right and wanted a coordinated and informed approach.

From here we moved into the key areas for improvement and generated 9 ideas for solutions:

1. **Health and Wellbeing Coach** dedicated to supporting people who are waiting to manage their symptoms, and a **Care Navigator** to help unscramble the jargon and to advocate, navigate, talk through what is happening and what next for the person waiting (note this is not a receptionist in a GP surgery signposting alternative provision but a care coordinator role).
2. **A Safe-Waiting Care Plan** coproduced by the hospital, the person and the GP. Waiting is in itself a condition and needs managing (a pathway) to help the person live as well as possible whilst they are waiting.

3. **Information** to explain the waiting journey including videos, website, booklets, easy reads, with all the information people would find useful including who to contact if you are deteriorating or concerned.
4. **Where Am I?** A way to check progress on the waiting list including how much longer you need to wait, with a triage helpline to speak to someone if you are worried. This needs to be a single point of contact (one call that's all).
5. **Adjustments.** Change things so that appointments are there for people who really need them – conditions and contexts change as people wait and need to be taken into consideration.
6. **Local peer support groups.** People to talk to who are also waiting which should be geographically based rather than disease based. People enjoyed talking to others who were waiting and picking up tips in the workshops but didn't want to keep talking to people with the same condition as themselves.
7. **Family counselling.** People talked about the trauma of COVID and how families have not recovered, which compounds the difficulty waiting experience. The person waiting is not the only one affected by waiting, it impacts the person's whole support network (friends and family) and they need support too.
8. **Make the waiting fair** so everyone gets the best support and it's not a postcode lottery
9. **Better integrated communication** between NHS services (primary and secondary care) as it feels like the NHS 'drops the ball' at the point of handover.

We asked the GSTT Director of Elective and Diagnostic Recovery to review the ideas and join us at the next workshop. Together (the professionals and people waiting, along with the waiting list transformation lead worked through the list to see what was already happening and where there needed to be more work from this group.

Areas where there is work ongoing that can be better informed by the work from this programme / group	Areas where the waiting list transformation team need specific advice and will invite people from this group into their current improvement activity	Areas where there needs to be development and a case for change and investment
4. Where Am I 5. Adjustments 8. Making the waiting fair 9. Better integrated processes	3. Information	1. Health and Wellbeing Coach and Care Navigator/ Ambassador/ Coordinator 2. Safe Waiting Care Plan 6. Local peer support groups 7. Family Counselling

Table 3 Categorising the suggested areas of improvement

Here you can see how the categories were developed. Numbers relate to the table above and the diagram below.

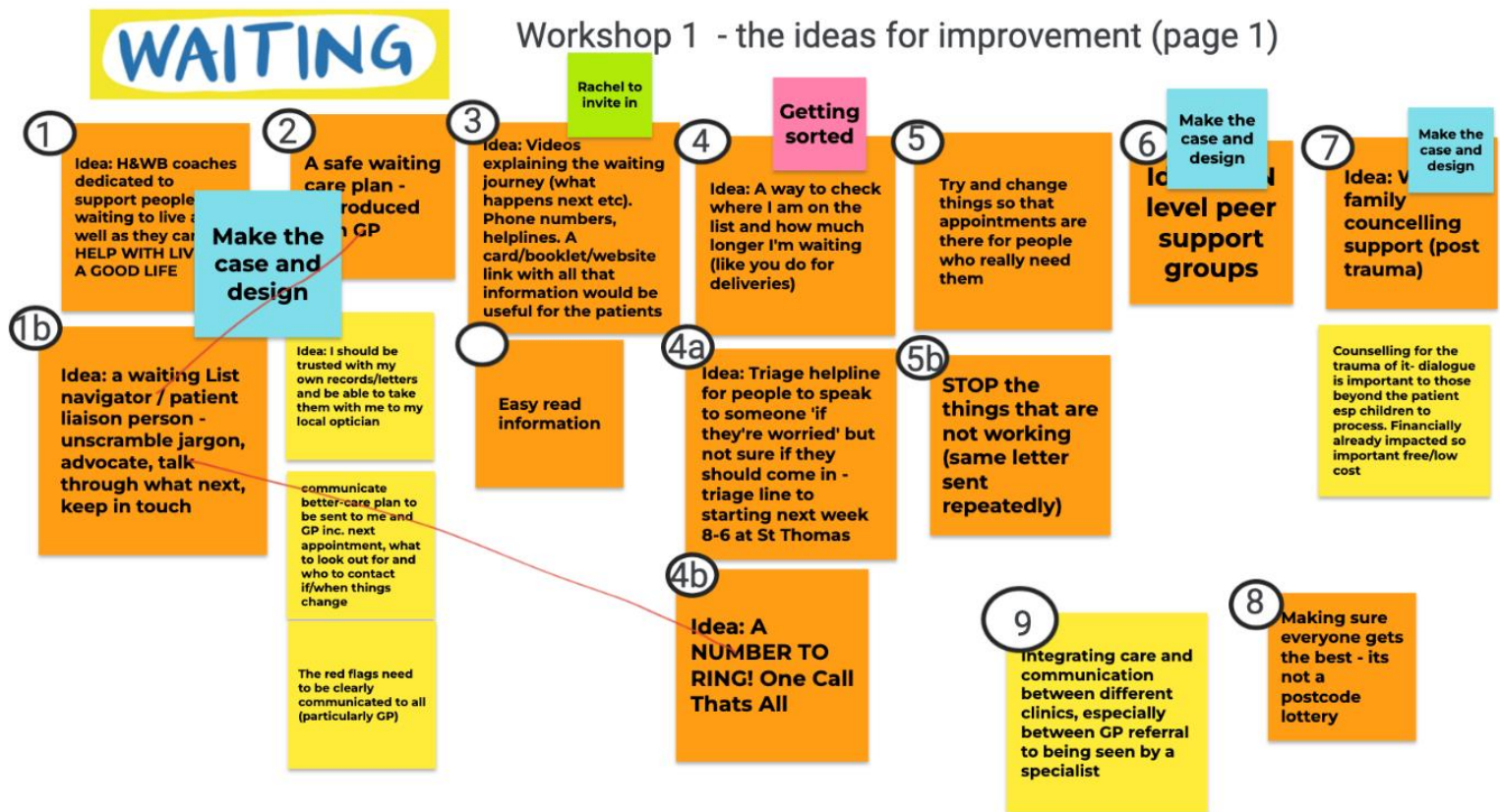


Fig 9 Workshop 1 Ideas for Improvement and how these were categorised.

The participants went onto developing the personas and the approach needed for the solutions where there needed to be development, and they wanted to make a contribution. Personas are used in design thinking as a way of exploring the impact of an improvement idea. Personas are fictional characters but made from the experience of the creators, in this case patients, carers and professionals. The participants developed personas for these ideas for improvement:

1. Health and Wellbeing Coach and Care Navigator/ Ambassador/ Coordinator
2. Information
3. Knowing where I am on the list
4. Local peer support groups
5. Making the waiting fair – everyone to get the best.

The personas were to capture the person’s experience of waiting and demonstrate why the solution posed would help.

The group also discussed these areas in terms of what is needed:

1. Safe Waiting Care Plan
2. Integration
3. Family Counselling

Persona: Jim needs a Care Navigator and a Health and Wellbeing Coach



Fig 10: Persona: Jim who needs a Care Navigator and a Wellbeing Coach

Jim is in his 70s. Isolated from family with little support network.

He is not affluent and not up to date with options available.

He feels alone and uncared for and doesn't like to make a fuss or 'rock the boat.'

Jim is waiting for a knee operation and in a lot of pain – he is feeling depressed.

His mobility is severely restricted so he can't get out and about and this is affecting his mental health

Jim is a private individual; he'd love someone to help him but doesn't know who or how to ask. He feels stuck, a bit lost, and doesn't know who to contact.

Here are some quotes from Jim:

**Quotes**

- support network
- embarrassed to ask for help
- feels lost, not knowing who to contact
- General health also suffering
- 'Has everything come to this?'
- "I'd love someone to help me but I don't want to ask"
- Care Navigator needs to be proactive
- Care Navigator needs to be pointed at patients by the primary contact, either GP or hospital
- Care Navigator needs to be a 'lynch pin' between primary care and social prescribing

Fig 11 What Jim might say

This is what Jim needs from a Health and Wellbeing Coach:

## What Do We Need from a Health and Wellbeing Coach?

- Talk through what I can do to help myself (lifestyle)
- Check in to see how I am doing
- Help me live as well as I can whilst I'm waiting
- Counselling skills, empathic, approachable. Person-centred coaching approach. Enabling agency in their patients.
- We need a blueprint and education path for establishing the profession that is legitimate yet flexible. Service users must be involved in their education.
- Not to be confused with private coaching services that use similar language.
- A knowledgeable, empathic partner with holistic knowledge to be a companion for a patient's healthcare journey.
- Must be able to communicate with clinical staff appropriately to help with care co-ordination.
- Encouraging experienced service users to train to become H&W coaches
- Having time to develop deep long-term relationships with patients. Knowing the broader issues in their lives not just their conditions
- 
- 

Fig 12 What Jim needs from a Wellbeing Coach

This is what Jim needs from a Care Navigator:

This is not the sort of care navigator we are seeing in some general practice which is a receptionist that signposts. This group explored a more active advocate role which better represents the language of Care Navigation, something that is more akin to the Macmillan nurse who cares, advocates, navigates. There was concern that there are so many roles and that this could be combined with the coach role.



Fig 13. What Jim needs from a Care Navigator



Mrs Lost needs information about 'what next'?



Fig 14 Persona: Mrs. Lost needs information about 'what next'.

Mrs. Lost is 82. She has no computer experience and no family to support her. English is her second language. She has little self-confidence and is hearing impaired with poor eyesight. She finds it difficult to trust technology and has limited understanding of her condition.

*"I am concerned that the longer I wait the worse I get, and will you be able to fix me, and it will cost more and take me longer to recover. Will I have to wait as long for the next treatment?"*

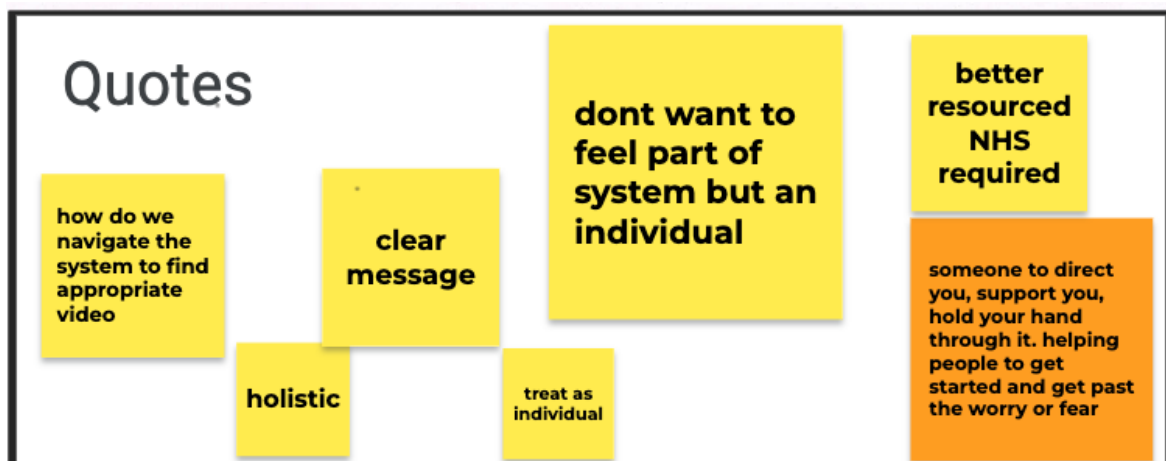


Fig 15 What Mrs Lost might say

Mrs Lost needs these key areas to be addressed in the information provided:



Fig 16 What Mrs Lost needs to be addressed

Josephine Bloggs needs a way to check where she is on the waiting list

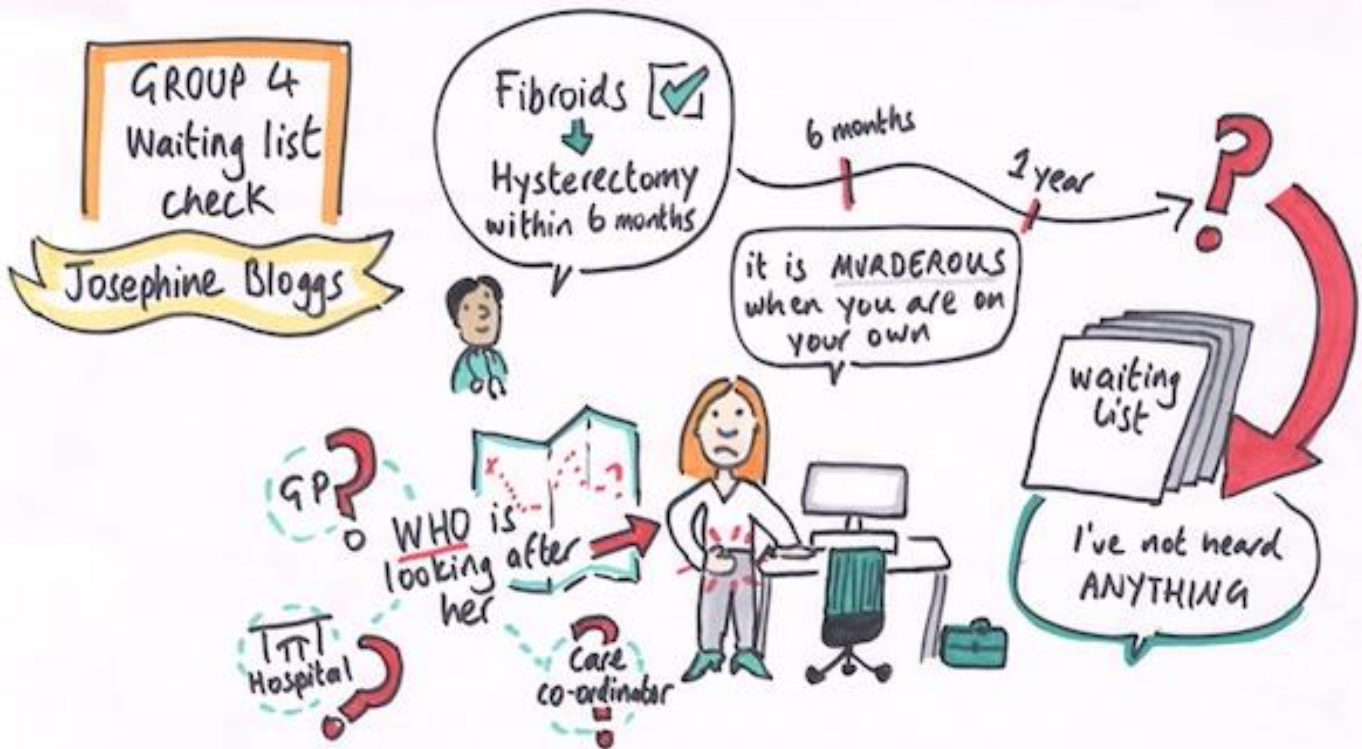


Fig 17. Persona: Josephine Bloggs needs a way to check where she is on the waiting list.

Josephine Bloggs is a 48-year-old woman who has had fibroids for 7 years.

She was being managed by a GP but now needs a hysterectomy as previous treatments have been unsuccessful.

She is suffering with heavy periods, stress, difficulty when she goes out – physically unwell, anaemic, ongoing/chronic, pain, feeling depressed whilst waiting. It is not life threatening but she needs support/advice/someone to listen to her.

She has been waiting for more than expected (her letter said 6 months), it has now been more than a year and she has not heard anything.

She needs advice, surgery. It is not clear who is looking after her: the surgical, gynae team or GP?

It would be helpful to understand who can support her- the hospital team or GP? Someone needs to assess this or be a care coordinator.

This is what she needs:

She is on a waiting list, but the wait is tough and has passed the 6 months, not phoned or contacted again. She needs a number to call. She needs reassurance and realistic expectations.

GP/Clinical Nurse Specialist or other person could offer her a regular appointment to review her or a coordinator who she can check in with and understand where she is on the list, and if she is getting worse to escalate this/understand if she is stable.

She needs a care plan and a lifestyle change - 'it is murderous when you are on your own'. Someone to ring you up, find out what your problems are and support you with some lifestyle advice including diet and sleep. Access to things like television/something to watch/do if this is not available to her, or help navigating online advice. Space to spell out worries. Apps may also help.

*"My periods are terrible - they are affecting my quality of life, my work and my energy levels"*

*"I'm still waiting, I'm in pain"*

Josephine Bloggs needs to know where she is on the list but also needs advice in the meantime to help her self-manage (cope) and wait safely.



Figure 18. What Josephine Bloggs needs to know

## Muriel Antoinette needs a local peer support group

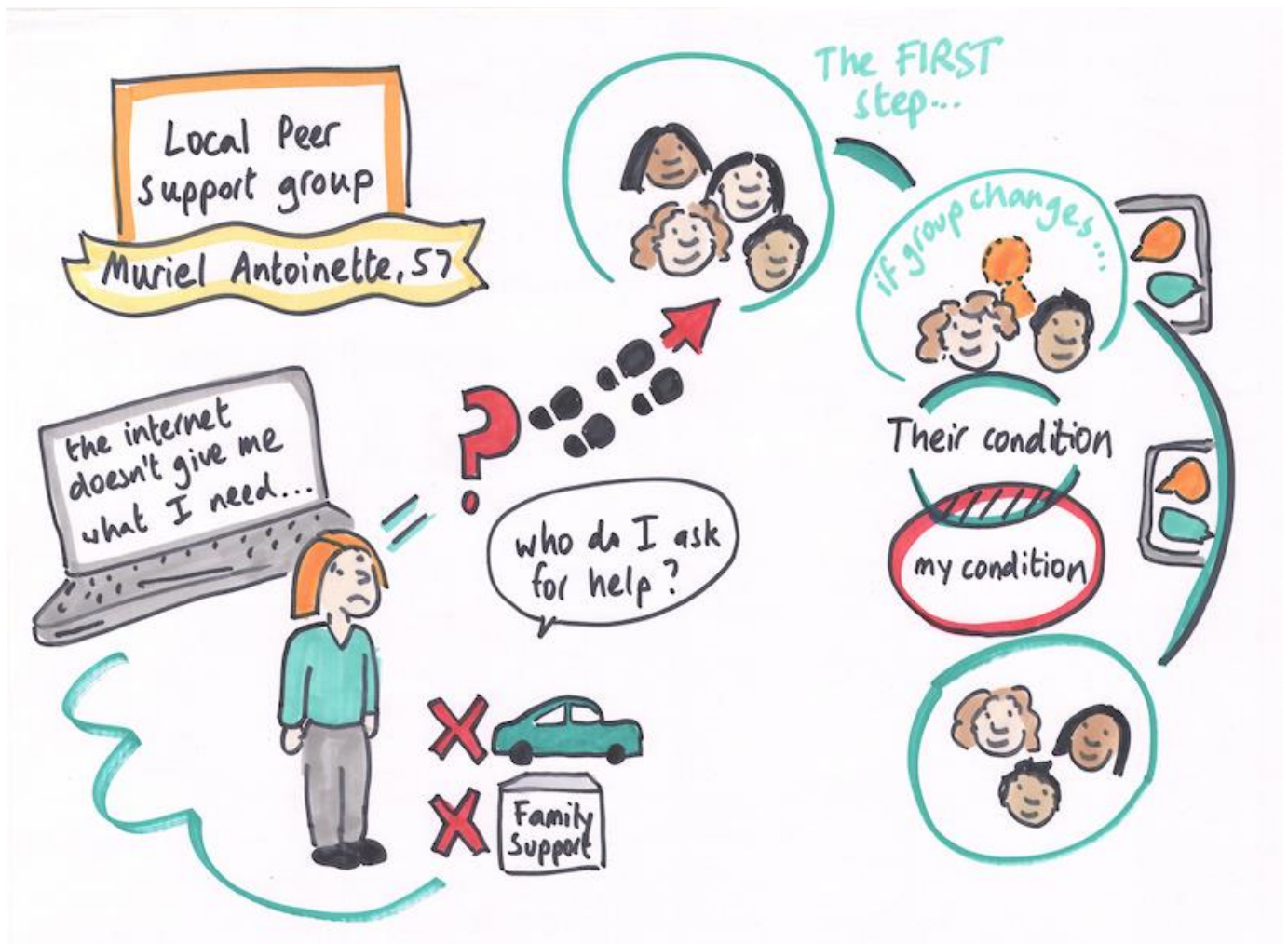


Figure 19. Persona: Muriel Antoinette needs a local support group

Muriel Antoinette is 57. She is not tech savvy, and the internet doesn't give the connection sought. She needs support with the first stage of social outreach. She doesn't know who to ask for help and her condition doesn't quite fit the standard support groups. She has family support to pick up the slack. She needs to communicate with the same people from one session to the next.

*"I need to feel listened to".*

In terms of how best to provide Peer Support this is what she needs:

*"My peer supporters are friends, and we meet on WhatsApp we keep in touch daily and support each other. it really works."*

*"It is extremely helpful and keeps you from being lonely. It is a core need and can become a core support system that would not be there ordinarily. Supporting each other as communities is crucial as a ritual routine that can do magic."*

These are the key features of good peer support groups



Figure 20: The key features of a peer support group

Miss Everybody needs everyone to get the best there is



Fig 21 Persona: Miss Everybody needs everyone to get the best there is.

Care and treatment should be person centered not a lottery in terms of who you are or where you are. These are the key features of a person-centered approach:



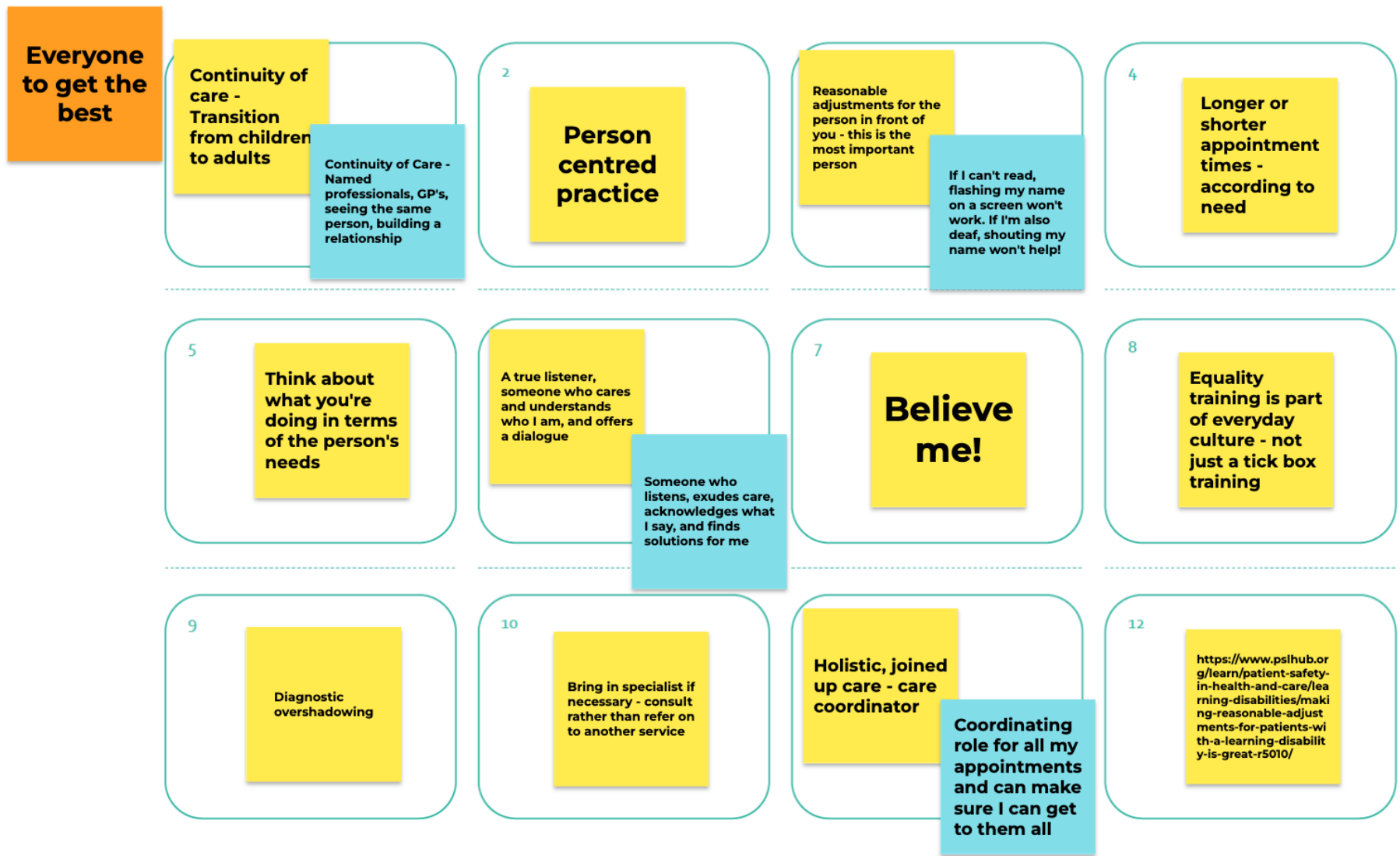


Fig 22 The key features of a person-centered approach

## Areas for Improvement

There were three further areas where the group did not develop personas for but put together what is needed – A safe waiting care plan, Integration and Family Counselling

### Safe Waiting Care Plan

This shared care plan needs to be patient held and include:

1. What is coming next
2. What to look out for and who to contact when things change
1. The red flags so everyone knows (person, hospital, GP)

## What Needs To be Covered in a (Patient Held) Safe Waiting Care Plan?

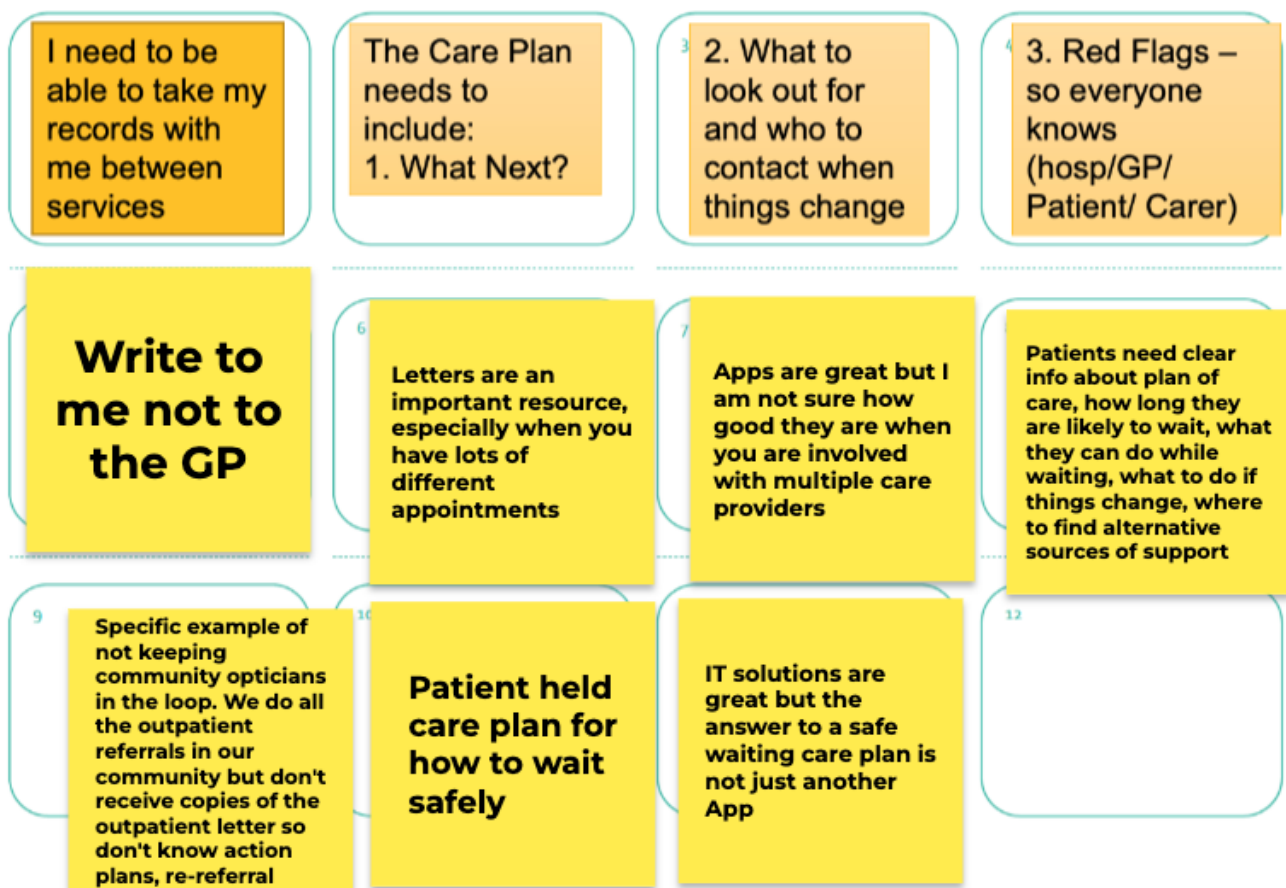


Fig 23: What needs to be covered in a patient held safe waiting care plan

## Integration

This was a real issue for ophthalmology with the following issues:

- A missing link between the ophthalmologist and the hospital where there needs to be a way of sharing and communicating information safely, while also enabling clinicians to be able to see referral letters. The GP needs to be part of this process, but currently they seem to be outside it. The patient seems to have to link everything together. Some services are still using paper referrals!
- If a patient misses an appointment, they have to be re-referred which is a waste of time and effort.
- There are variations in appointment process between boroughs which makes it hard to navigate.
- The NHS is not making the most of opticians who could provide triage for a group of boroughs linked to a Primary Care Network (PCN).

## Family Counselling

*"My problem impacts my children but there is no support for them."* Everyone who is caring for someone waiting needs dedicated support from statutory or voluntary sector organisation.

There was also experience of COVID trauma where people told stories of loved ones dying because as a carer, they didn't know what to do when they deteriorated. People who have been in situations like that and are caring again for someone waiting need emotional and personal support.

*"Family therapy helped me understand how to do the best I could".*

The personas and additional ideas for improvement are for the Trusts to utilise in the ongoing design of the Waiting services.

## Measuring People's Experience

Alongside developing solutions and ideas for improvement, this programme of work also invited participants to consider how best to measure the experience of waiting.

The purpose of getting feedback is twofold:

- Firstly, to secure feedback in order to make adjustments to a service – making it better as it's being developed and implemented
- Secondly, to see if it is making the difference it was expected to make – the impact.

We asked these two questions of workshop participants:

1. What Do We Need to Measure in terms of the Patient and Carer Experience (in order to adapt as we go along)?
  - Patient satisfaction with the service overall.
  - The impact of waiting on what I can do, including my social and work context, my ability to be independent, the impact on carers.

- Call handling: Response times on telephones; how long it takes for issues to be resolved; call handling quality
- Measuring deterioration: How many people escalated their concerns, needed additional help, and had to be 'moved up' the list.
- Communication: how often people are getting the communication that relates to their preference; how often are they contacting the service before they get the information they need; how often they are contacted by the service with information on wait times.
- Measures that support people to be more active in their care (this one is an active intervention) asking people to keep a record of what they are doing for themselves. For example, the Macmillan cancer journey book.

For this issue people also fed back about the process of collecting evidence/ measures:

- The results should be available and fed back to those that contributed.
- The measures should not just be surveys but should include qualitative interviews.

## 2. What do we need to measure in terms of the impact on patients and carers? (Impact Measures)

This is what the group said:

- Hours/ days lost because of waiting
- The mental and emotional impact of waiting
- The loss of function because of waiting
- The avoidable harms from waiting which includes knowing if people have died because they have been waiting.

The participants from the Trusts found these really useful as they develop their waiting list management process. It forms part of the recommendations from this report.

## Impact of the Workshops – Catalysing Change

Alongside the report and recommendations including the development of the personas and improvement ideas; there were other benefits realised by participants. Some of the people who were waiting were able to secure answers to their individual questions; some of the participants have volunteered to help in the testing of the innovations in practice supporting the Waiting List transformation team.

## Recommendations

The details on 'how to' behind these recommendations are provided with the personas in the section above.

1. Waiting List prioritisation should be adjusted for social context (e.g., poverty) and personal circumstances (e.g. finances). Be clear about prioritisation and ensure that it reflects the impact waiting has on people's personal circumstances.

People who are waiting are in fact enduring a new chronic disease. The NHS's prioritisation based purely on clinical need has undertones of the COVID pandemic crisis response, which whilst helpful in the first stages of the waiting list crisis now needs to be adapted to reflect the wider needs of people who wait. Waiting is not fair and waiting prioritised by clinical condition has the potential of increasing inequalities. For example, people on zero-hour contracts are penalised over those who can for instance take sick leave, and those same people tend to have poorer personal circumstances. Being poor on the waiting list is harder and has knock effects that endure beyond the immediacy of their clinical condition. People wanted clear transparent criteria for prioritization that is followed.

2. Make sure that support to people on the Waiting List is provided equitably and universally.

The support for people waiting should be consistent and fair, not varied by where you live.

In the workshops people wanted waiting to be fair for all. There were experiences of people living in some localities getting different support services than others for instance the role social prescribing or care navigation played in different PCNs.

3. Provide regular updates to people waiting in terms of what is next and timescales, and what to do if you deteriorate. Living with uncertainty makes waiting harder.

"Regular" to patients is not every 3 months. People need to be assured and reassured.

Provide a one-stop phone line (one call that's all) for patients to access if they are worried and need information about their waiting time.

4. Provide a safe waiting care plan shared between the person, GP and hospital that includes any red flags, how to manage deterioration, where to go for help.
5. Help people navigate the whole system of waiting. Provide Care Navigators.

For those struggling to navigate their own care on the waiting list, provide support through care navigators who will 'hold the hand' of the person waiting and their family, being an advocate, educator and administrator. This is not the receptionist who signposts alternative appointments (a model that has been advanced in primary care).

6. People need support to help themselves. Provide dedicated Health and Wellbeing Coaches.

People understood the need to help themselves but needed the tools to do so, provided by someone that can guide them.

7. Enable Peer Support.

Initiate and provide a space for peer support groups to form locally. People will contribute but they need help to get them going. The focus should be on waiting safely and healthily as possible. It should not be disease specific.

8. Provide family counselling for people who are traumatised by the COVID experience and struggling to cope on the waiting list as a result.

Check-in with families and carers to see how they are managing whilst their loved one waits.

9. In relation to measuring what matters to people who are waiting please see section on Measuring People's Experience in this report.

Critically any feedback provided by people waiting should be analysed and shared back with those same people. What is measured can also in itself support people, for example asking people to measure their self-management interventions will draw those people's attention to those interventions.

# Appendix 1: Key Messages from the Desk Research

Ahmed, K., Shamah, S., Malby, B. (2021) Waiting for Treatment and Self Management: Summary of the Desk Research. Report for Health Systems Innovation Lab, London South Bank University December

## Key Messages from the Desk Research.

People are fearful that they will be forgotten, particularly when communication is lacking whilst people wait.

1. As people wait over the 'norm', anxiety, as well as illness and disability, may increase.
2. People's ability to cope with waiting is correlated to their resilience. Resilience is correlated to life circumstances and factors such as poverty, insecure finances, caring responsibilities, or employment. Once on the waiting list, people from more deprived communities are more likely to cancel or postpone their care (NHS Confed, 2021). Training people to cope is not the answer.
3. Supporting people who are waiting requires a care process, and therefore resources. This may include providing supportive physical care (e.g., physiotherapy or pain management), emotional care, information (resources to inform self-management; information about the waiting process), and access to services to support financial and employment security.

## The Impact of Waiting

1. Waiting places 3 types of burden on people (McGill et al, 2020; The Health Foundation, 2021):
  - a. Burden on quality of life: physical health, mental health and wellbeing
  - b. Burden on their financial stability (impact on their job)
  - c. Burden on their social context, including caring responsibilities and relationships
2. Waiting also has implications for recovery (e.g., surgical) and on other services.
3. During waiting, people can get worse, get better, or stay the same - and therefore the need for intervention can change whilst waiting (The Health Foundation, 2021).

## What People Need

People who are waiting need the following to help them manage their condition and anxiety:

1. Acknowledgement of concerns
2. Periodic communication about wait-list position and anticipated procedure date
3. Tailored prioritization according to need and circumstances
4. Advice on identification and management of 'red flags'

5. Contact details for concerns and confidence that they will be responded to
6. Information to help them manage their condition as they wait
7. Access to and information about relevant supportive services (including non-medical services)
8. Peer support

### **Addressing inequalities**

1. Once on the waiting list, people from more deprived communities are more likely to cancel or postpone their care (NHS Confed, 2021).
2. Waiting list management should factor in the impact of waiting on other circumstances, such as poverty, employment, caring responsibilities, learning disabilities, and mental health.
3. There is also a concern about 'hidden' waiters and those from at-risk groups, particularly people who may present with a non-cancer referral with an underlying cancer diagnosis, which may be identified at a more advanced stage.

### **Next steps**

1. Active management of waiters (telephone/other contact to assess context, deterioration, and provide information) improves the self-reported quality of care, which can also be assumed to have a positive impact on outcomes.
2. Waiting list management needs to be coordinated across primary and secondary care. Waiting implies no resource, but safe waiting does need resourcing.
3. Waiting will increase inequalities. People experiencing health inequalities will have the same issues with waiting as they do with inequitable access (e.g., ability to take time off work). Waiting list management must include an adjustment assessment. Waiting list prioritisation must be fair, paying attention to specific considerations (such as impact on caring responsibilities or employment) (Nuffield Trust, 2021; The Health Foundation, 2021).
4. Self-management support needs to be co-designed with people and delivered in a way that suits them, supported by access to NHS services that can help people wait (therapy, pain management, mental health), and is able to assess the need to escalate. Self-management should also be an integral part of, rather than an alternative to, ongoing care (Nuffield Trust, 2021).
5. Information and guidance should also be provided (including 'red flags', safe waiting, peer support, and preparing for intervention/surgery).

The full desk research report can be found [here](#)



## References

McGill, N., Crowe, K. and Mcleod, S. (2020) "Many wasted months": Stakeholders' perspectives about waiting for speech-language pathology services, *International Journal of Speech-Language Pathology*, 22 (3), pp. 313-326.

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The Health Foundation (2021). Waiting for care. Understanding the pandemic's effects on people's health and quality of life. Available online at: <https://www.health.org.uk/publications/long-reads/waiting-for-care> accessed 16/11/21

# Appendix 2: Further Information on The Methodology

## Mapping

### Mapping the Health and Care System

For each workshop the Design Team mapped the health and care system for providing support to people on the Waiting List, and determined the invitation list as follows:

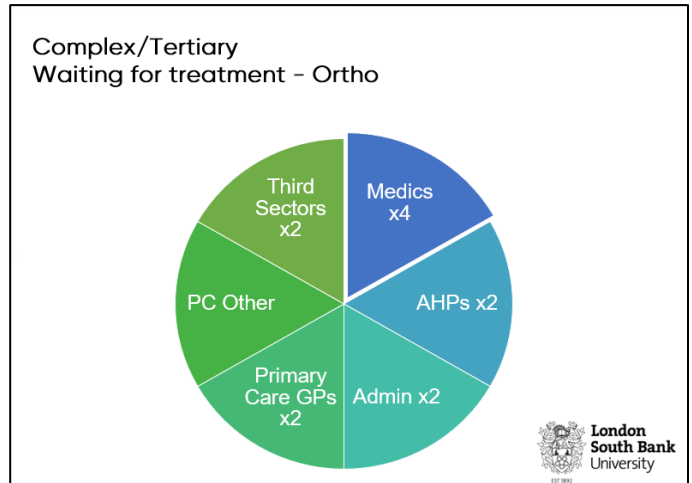
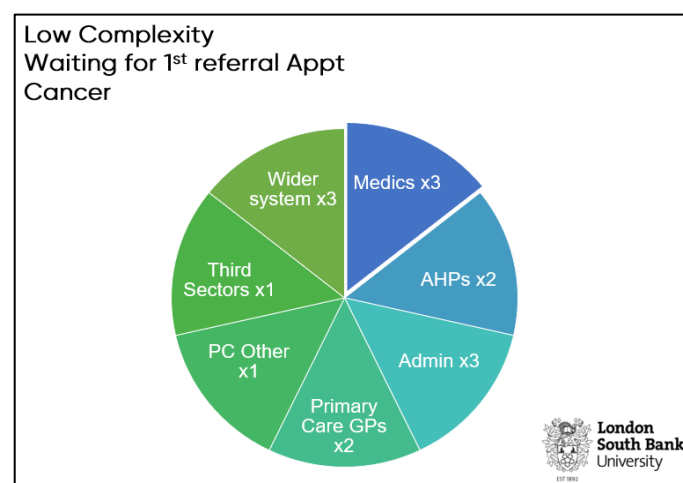
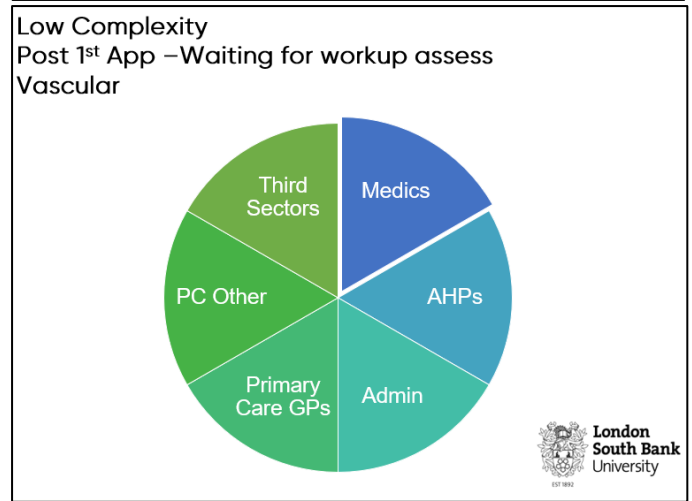
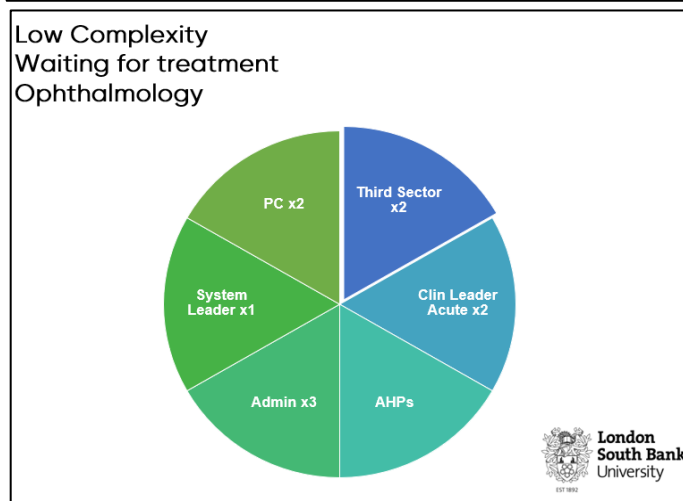
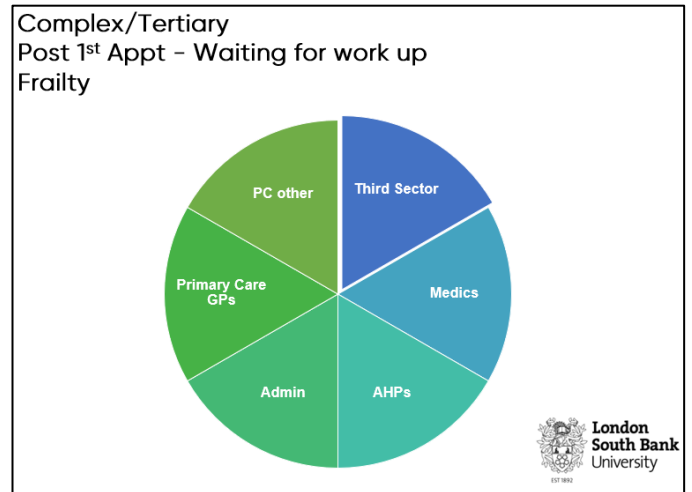
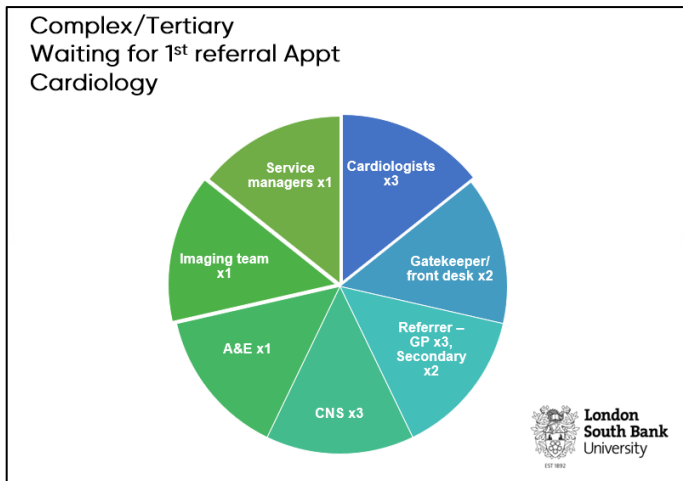


Fig 24 Mapping the Health and Care System

This was then translated to a spreadsheet where the Design Team and their colleagues identified names and contact details for the invitations. The Design Team then invited the professionals, and these invitations were all follow-up by the LSBU team to secure participation at the events.

The design team members for Frailty and Vascular were unable to continue working on this project in Spring 2022 and pulled out due to overwhelming workload, these two workshops were replaced with one other key area of children and young people.

### Mapping the Citizen Participation

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

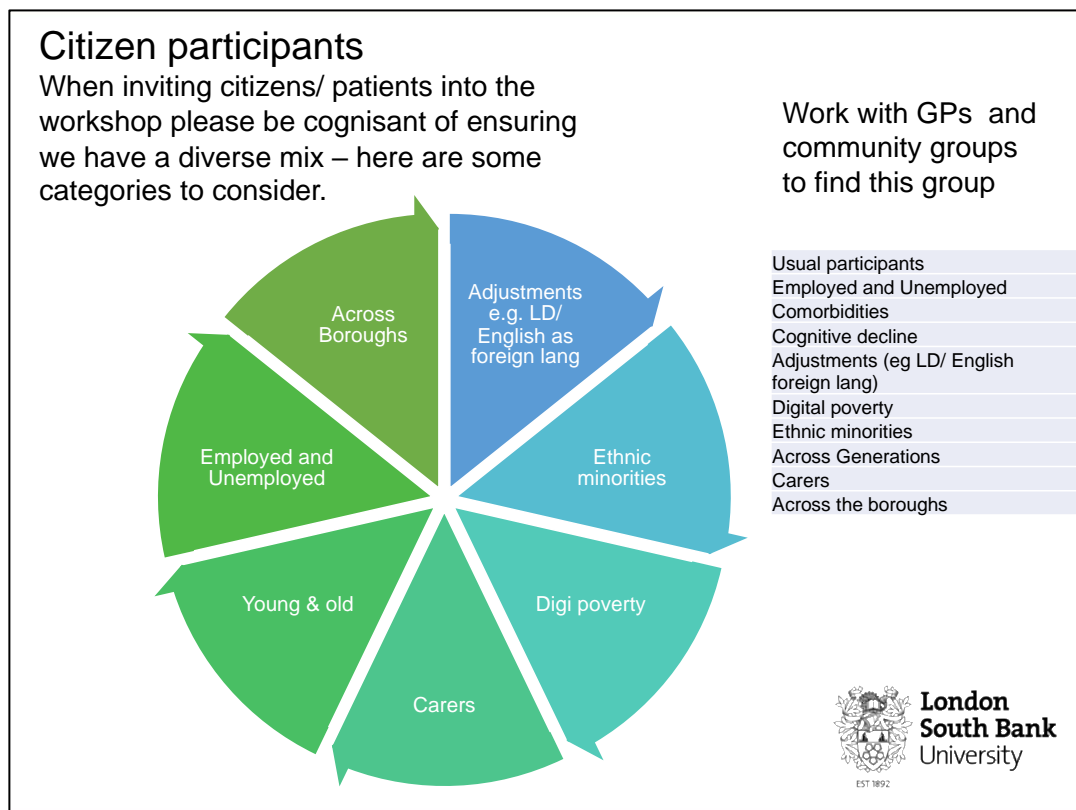


Fig 25 Mapping the citizen participants

- “Users of different services: It will be important to capture the expectations and experiences of a broad spectrum of patients and carers, including children, young people and their families, and people at different stages of the patient journey. The focus needs to be on services that are experiencing the greatest pressure in terms of backlogs during COVID recovery. It is noted that the South East London Acute Provider Collaborative (part of the Integrated Care System) is focusing on the following seven areas: oral surgery,
- ophthalmology, ear, nose and throat, gynaecology, trauma and orthopaedics, urology and general surgery. However, there is a wider range of services (see Figure 1 above) that are affected, e.g., therapies and allied health services.
- Seldom heard and marginalised groups and communities. This includes exploring the likely impact of changes on people who may experience more challenges in accessing services and care in the changing system. This also includes those who are the least engaged and not just those who regularly engage with patient involvement activities.

We have prioritised the following frequently under-represented groups and communities to work with:

- people from Black, Asian and minority ethnic communities
  - people who do not speak English as their first language
  - people with learning disabilities
  - people with experience of homelessness
- Infrequent users of services, as their needs need to be understood and supported alongside frequent service users.
  - Paid and unpaid carers, as they have a key role to play in supporting patients to navigate services.
  - Patients with long term conditions, complex conditions, and multiple service users. It is likely these populations will be using different services simultaneously, so it will be important to understand whether they know what to do in different situations.

The populations in scope should cover Bromley, Lambeth and Southwark (i.e., the local populations GSTT and KCH predominantly serve) as well as non-local patients who access specialist care from across Southern and South East England, as well as other parts of the country (i.e., national or regional specialist services) provided by the partners including RBHH" (Project Specification 2021, unpublished)

## **The Invitation Process**

The invitation process comprised of the following:

### **(a) Inviting Professionals.**

Design Team members from each organisation approached the teams to invite to the workshops. They were provided with an invitation to use (example below), 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 we had to recruit 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 meant the Design Team and the invited clinicians lost momentum. During the workshops, we heard from clinicians about the capacity issues in their areas making participation difficult, reducing their capacity to think about inviting patients/carers.

We therefore also invited people 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, the easy read invitation, and flyers 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 the 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 for 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 (LD) shared the Easy Reads with all their contacts; and we asked SEL community Learning Disabilities nursing teams were asked 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 276 people from the GSTT and KCH database by text (62), email (124) and phone (90). This generated 8 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 PIS and a consent form to decide if they wanted to take part. Those agreeing to take part and sharing 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 provided 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, 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.

### **Workshop Design**

The workshops were designed to:

7. To develop a shared picture of what is needed (understand)
8. To develop 'readiness' for collaborating to find solutions (attitude)
9. To design solutions that you can test (ownership) that improve inequalities (fairness)
10. To catalyse safe waiting (improve)
11. To design the measures to review the success of these solutions (feedback – what counts)
12. To consider how to spread equably across the partnership (share)

#### **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 who may have conditions that would limit their energy levels to participate. The sessions were designed in 45 minutes 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 little of this throughout all the workshops. All participants

took part throughout. 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 in Appendix 3. 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 (Gregory, 2010). 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):

- To explore people's (citizens and staff) experiences of services.
- To understand what best practice looks like when delivering services. This will involve working with patients, carers and clinicians to agree best practice requirements.
- To develop a set of patient experience measures which capture 'what matters' to patients, carers and families.
- To explore how to align the patient experience measures with service delivery i.e. – What does this mean for service delivery?
- To investigate barriers to service improvements and how to overcome these, by understanding the views and needs of patients, carers, families, and staff.
- To facilitate conversations within the organisation(s) to explore and test solutions and improvements.

The workshops followed this overall process:



Fig 26 the workshop 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 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/WIFI if this is needed.
- Participants will receive copies/ online link to the [Waiting for Treatment and Self-Management 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 max 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 waiting and self-management

Tell us a time when you have been waiting for care and how you managed your condition

Session 4: Reviewing the Waiting for Treatment and Self-Management Poster

Session 5: Generating potential solutions. What would help?

What ideas do we have for what is needed to support people 'waiting'?

Session 6: Review and Close

Between Workshop 1 and 2 we grouped the themes from the first workshop, and reviewed the solution ideas with Director of Operations for Cancer and Surgery Clinical Group who is leading on Waiting List transformation

### **Workshop 2 Co-design: Brief Summary of the Programme**

Aims: Design Prototypes

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 prioritising the list of solutions.

Session 4: Working up the solutions: picking a solution topic to join and working with the group on developing a persona.

Session 5: Working up the practical elements of the solution – what would 'better' look like?

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

Between Workshop 2 and 3 we developed the personas as graphic representations.

### **Workshop 3 Co-design: Brief Summary of Programme**

Aims: Co-design of solutions and Metrics

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

Session 2: Our reaction to the Personas.

Session 3: What is needed to improve the waiting experience.

Session 4: Measuring What Matters.

What should the NHS measure in terms of the patient experience of waiting?

## Session 5: What Next?

After Workshop 3 we developed the themes and shared these by emails, with some 'top tips' provided from patients added to the Jamboard

**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

### ONLINE - Lot 2: Waiting and Self-Management

Time	Topic	Lead	Process	Key design issues	Logistics	Key focus areas for observers	Objectives covered
12.00	Welcoming	ALL	<p>Ensure everyone who arrives is welcomed in, asked to ensure their name is showing, put at ease and encouraged to keep their camera on it possible.</p> <p>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.</p>	<p>Ensure people sign consent forms</p> <p>Explain what information we are capturing, how and why</p>	<p>Multiple breakout rooms for online 1-2-1 consent</p> <p>Ensure room is already set up so everyone can focus on attendees</p>		
13.00	Logistics & Principles (short intro) LSBU	Becky/ Sandie	<p>All adults. Comfort breaks when needed. There is time to talk and listen. Explain the process.</p> <p>Life happens - children/ pets/ deliveries in the back ground.</p> <p>Introduce notion of managing equal voice</p>	<p>Move quickly into citizen voice rather than Prof voice.</p> <p>A means to manage air time and listening</p> <p>Everyone's voice in the room.</p>	Design principles visible		

13.05 – 13.10	What Brought me here today? (introduction)	Lucie	Introduce exercise - 3 pop up/ example (stand up) short responses (set up in advance – 1 citizen, 1 clinician, 1 manager) 3 mins each	Model equal voice, and collaboration from the start Model air-time and listening. Questions to focus on – What am I proud about in the current context and what am I sorry about  Run this session in the main room but explain everyone will be in breakouts for their conversation	Prime the 3 being examples in advance	Key themes	A
13.10 – 13.25	What Brought me here today? (exercise)	Lucie	On tables time to share what brought you here today – why do you care about this? Make sure everyone has time to speak without interruption.  When you have all spoken identify and write max 3 post-its on the common themes you have heard	Importance of ensuring everyone has time to contribute – set up a warning every 5 mins so group swaps plus one that reminds them to write 3 virtual post-its  Questions to focus on – What am I proud about in the current context and what am I sorry about  Nominate one person in each group to do virtual post-its (don't all have to do it)	<b>3 people per breakout</b>  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	Key themes – any contrast between citizens/ clinicians, etc	A B
13.25	Our Purpose today	GSTT – intro by Becky/ Sandie	Welcome more than presentation Short introduction on what we are wanting to achieve through	Welcome from Joint Programme Brief presentation by LSBU	PowerPoint presentation with shared screen	People's body language in response to the presentation	A B D E F

			this process and what part today plays	Introduction to observers (get people to wave on screen)			
13.30	Sharing stories of waiting for care and how you managed your condition (introduction)	Becky/Sandie	5 mins Introduction to Appreciative Inquiry approach (storytelling to find out what works) We want stories both from citizens and from health staff Citizen and member of design group demonstrate (2 mins each) – focus on being personal/human	Listening for what works so we can build on that in our Charter Run this session in the main room but explain everyone will be in breakouts for their conversation	Post questions in the chat and show 1 slide explaining what we want them to do		A B D F
13.35 – 13.50	Sharing stories of waiting and self-management Tell us a time when you have been waiting for care and how you managed your condition (round 1)	Christine	Work in 4s (make sure 2 citizens in each group). 2 x observer, 1 x storyteller, 1 x questioner.  20 mins per story. 5 – 10 mins to tell 5 mins for questions 5 mins feedback from observers about what was heard.  THEN – 5 mins capturing the themes one per post it (one person nominated to add to jamboard)	Looking for the 'what works' – set up a warning in workshop groups every 3 mins so group moves through the exercise  Brief observers to ensure there is space/ time to have a deeper/ longer conversation with someone if needed to be able to talk something out – with aim that they are able to leave with a named contact	<b>4 people per breakout</b>  Post questions in chat and link to jam board  Group nominate someone to add virtual post-its to jam board	Key themes from stories	B C D E F
13.50 – 14.05	Comfort break		Have some music queued up if people want to stay in the main room		Ensure a couple of breakout rooms available if people want to talk in		A B

					detail to solve an issue		
14.05 – 14.20	Sharing stories of Waiting and Self-care Tell us a time when you have been waiting for care and how you managed your condition (round 2)	Christine	Work in 4s (make sure 2 citizens in each group). 2 x observer, 1 x storyteller, 1 x questioner.  20 mins per story. 5 – 10 mins to tell 5 mins for questions 5 mins feedback from observers about what was heard.  THEN – 5 mins capturing the themes one per post it (one person nominated to add to jamboard)	Looking for the what works  – set up a warning in workshop groups every 3 mins so group moves through the exercise  Brief observers to ensure there is space/ time to have a deeper/ longer conversation with someone if needed to be able to talk something out – with aim that they are able to leave with a named contact	<b>4 people per breakout</b>  Post questions in chat and link to jam board  Add virtual post-its to jam board	Key themes from stories	A B
14.20 – 14.25	Mapping Themes	Lucie	Affinity Map of the themes Working with whole group in the main room	Putting the post-its on the jamboard and clustering. Whole group review	Discuss/ agree 'key theme' names for groups – facilitator posts on jamboard	Key themes from discussion – any tensions	C E
14.25 – 14.	How does this relate to what we have found?  What ideas do we have for what is needed to support	Becky/ Sandie	In breakout groups of 4 look at the graphic we have provided – what are we adding?  Waiting will be better/ safer when..... And Generate ideas for solutions – things that would help that you can contribute to	Building out from the desk research – bringing the new information we have together to contribute Principle: You Own what you create  What did you see/ hear/ what resonates? What surprises you?	<b>2 people per breakout</b> Put graphic on jamboard slide and share in the chat Post question in the chat, Waiting will be better/ safer when.....	Key themes from discussion – any tensions	D

	people 'waiting'		Back to whole group to share the ideas	Generating prototype ideas	And send a reminder to all groups towards the end of the session. Send time reminders to breakout groups		
14.55 - 15.00	Wrap up and what Next	Becky/ Sandie	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	Ask people to come again and bring others – highlight that we are looking for diverse groups at the sessions	List of following dates and invitations to share with people, plus an email address to confirm someone is coming		F



## Materials to Support the Invitation Process and the Workshops

(a) Workshop Flyer

The flyer is a vertical rectangle with a dark blue top half and a red bottom half. The title 'Waiting for Treatment and Self-Management Workshop' is written in large, bold, pink letters across the top. Below the title is a decorative horizontal line of white diagonal slashes. The main text is in white, starting with a question: 'Are you or members of your family or friends waiting for treatment and care for any of these services?'. This is followed by a bulleted list of medical services: Cardiology, Cancer, Ophthalmology, Orthopaedics, and Children and Young People. Below the list is a paragraph of text: 'Do join a workshop bringing people Waiting for Treatment and Self-Management 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.' Another paragraph follows: '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 Waiting and Self-Management services.' At the bottom left is the LSBU logo with 'EST 1892' written vertically to its left. At the bottom right is a white arrow pointing right with the text 'TIMES AND DATES' written in a handwritten style below it. At the very bottom of the flyer, there is a small white footer containing the file name '125-2122-SCH-HSC-Waiting for treatment workshop flyer.indd 1' on the left and the date and time '30/03/2022 10:30' on the right.

# Waiting for Treatment and Self-Management Workshop

Are you or members of your family or friends waiting for treatment and care for any of these services?

- Cardiology
- Cancer
- Ophthalmology
- Orthopaedics
- Children and Young People

Do join a workshop bringing people Waiting for Treatment and Self-Management 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 Waiting and Self-Management services.

EST 1892 **LSBU**



TIMES AND DATES 

125-2122-SCH-HSC-Waiting for treatment workshop flyer.indd 1 30/03/2022 10:30

Fig 27 the Workshop Flyer

(b) Easy Read Invitation

**Invitation from Guy's and St Thomas' and Kings College Hospital to help improve Waiting for treatment and Self- Management services**

	<p><b>Waiting for treatment and Self-Management services</b></p> <p>We want to hear from people with a learning disability or their parents who have experienced Waiting for treatment. This is when you are on a waiting list for a long time to see a doctor, nurse or therapist.</p>
	<p>London South Bank University is working with the NHS to bring together local people and health professionals.</p>
	<p>We want to hear from you if you are waiting for treatment and care for any of these services:</p> <ul style="list-style-type: none"><li><input type="checkbox"/> Cardiology</li><li><input type="checkbox"/> Cancer</li><li><input type="checkbox"/> Orthopaedics</li><li><input type="checkbox"/> Ophthalmology</li><li><input type="checkbox"/> Children and Young People</li></ul>
	<p>We want to hear from lots of different people, including people with learning disabilities, about their experience with Waiting for Treatment.</p>

### C) Example Invitation Cancer – Waiting for first appointment

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

#### Cover letter for health professionals

We are inviting you to a workshop to improve services with and for people who are waiting for treatment. We will be sharing some key messages from our background research and working together with local people (who access your services) to make improvements.

This is a personal invitation, coming from a colleague in the Trust who really values you and your work, and thinks you would make a valuable contribution.

Below is the first workshop date. Please do confirm with them OR email us at [healthlab@lsbu.ac.uk](mailto:healthlab@lsbu.ac.uk) to let us know if you can take part.

ONLINE	
CANCER – WAITING FOR FIRST APPOINTMENT	21st April 2022, 11:45 – 15:00

#### Inviting people who use your services, and members of the public.

If you are a clinician and you can come to the relevant workshop, we would really like you to invite a patient/ local citizen to join you. Could you do that?

We are looking for a real mix of people (age, gender, ethnicity, borough, adjustments).

It is easy to invite someone – just ask them at an appointment/ clinic and you share the information attached (we will provide you with printed copies).

Please ask your invitee for consent to share their contact details with us so we can stay in touch with information about the workshop. Their name and contact information will not be shared with anyone else. If your invitee changes their mind about attending, and lets you know, please pass this on so we can remove their details from our system.

All the information you provide will be shared securely with LSBU. Please email your invitees details to [gst-tr.engagement@nhs.net](mailto:gst-tr.engagement@nhs.net) as follows:

1. Workshop name, date and time
2. Their name and preferred contact details.
3. Their characteristics as follows (this information is only used for monitoring purposes so we can be sure we have diverse participation)
  - o Gender – please state
  - o Employed/Unemployed/Retired please state:
  - o Ethnicity -please state if known
  - o Child 0-12 years
  - o Teenager 13-18 years
  - o Adult 19-65 years
  - o Adult 65+ years
  - o Comorbidities (Y/N)

- Physical disability Y/N
- Learning disability Y/N
- Carer (Y/N)
- Digital Access (can access online) Y/N

1.

Further information on the project and printable information for the public can be found on the following pages.

## Invitation from Guy's and St Thomas' and Kings College Hospital to help improve services with and for people who are waiting for treatment.

### 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 Waiting for Treatment and Self-Management

This is an invitation to help improve services with and for people who are waiting for treatment.

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	
CANCER – WAITING FOR FIRST APPOINTMENT	21st April 2022, 11:45 – 15:00

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](mailto: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

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 waiting for treatment and self-management 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

ONLINE	
CANCER – WAITING FOR FIRST APPOINTMENT	21st April 2022, 11:45 – 15:00

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?**

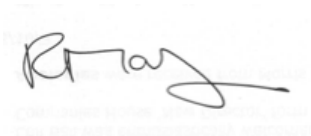
You can email or call us at London South Bank University with any questions using the contact information below:

Email: [healthlab@lsbu.ac.uk](mailto: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

A handwritten signature in black ink, appearing to read 'Rebecca Malby', is positioned above a faint, light-colored rectangular stamp or watermark.

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



## (d) Telephone Script for Invitations

### Telephone Calls to People who are Accessing Guy's and St Thomas' Long COVID Clinic

1. You will be provided with a list of telephone numbers of patients that are on the waiting list
2. The script is below followed by a set of FAQs to help you answer any questions
3. Please record if the person wants to come to the workshop if not
4. If they do want to come, please note the person's contact details and send them to [healthlab@lsbu.ac.uk](mailto:healthlab@lsbu.ac.uk)
5. 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 are waiting for treatment and care.

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]

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 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](mailto: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**

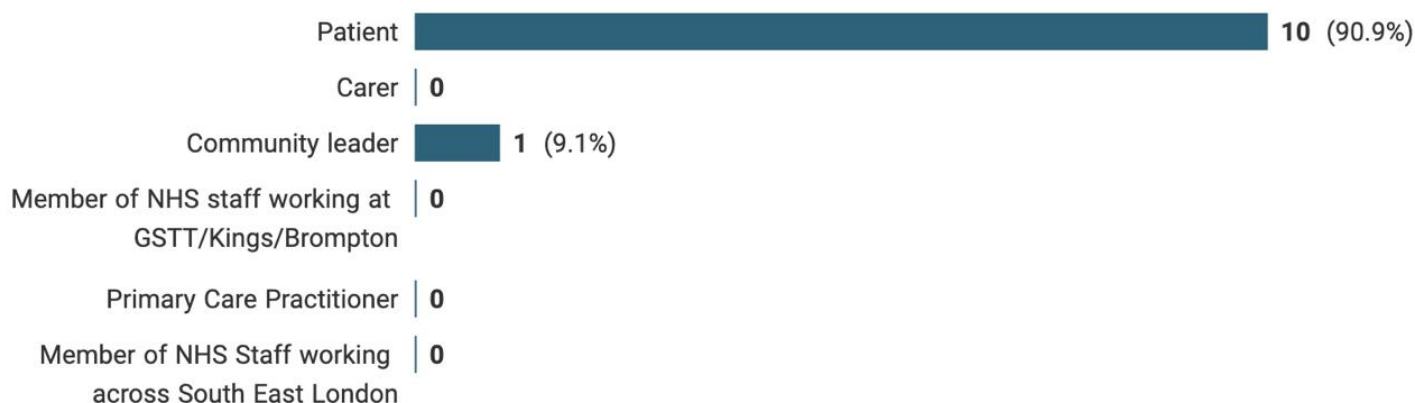
Your health care professionals have not been paid for inviting you to join the workshops.

## Appendix 3: Participation by Workshop

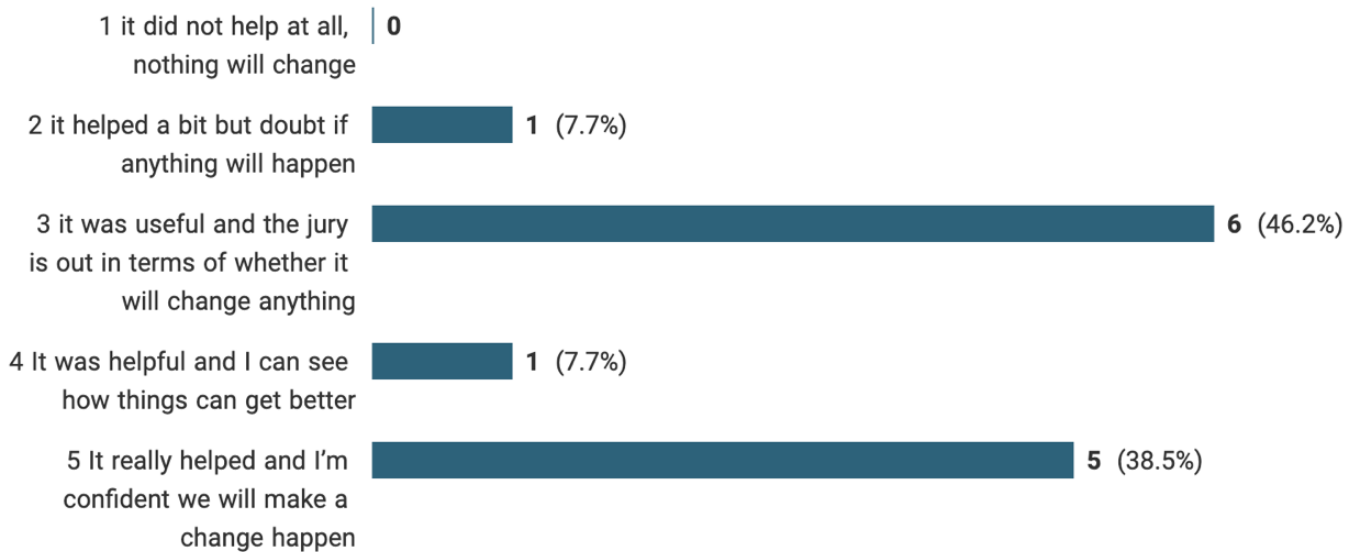
Waiting for treatment and self-management	Patients	Staff
Waiting for treatment and self-management (cardiology)	2	6
Waiting for treatment and self-management (cancer)	6	6
Waiting for treatment and self-management (Opth)	5	4
Waiting for treatment and self-management (Ortho)	6	4
Waiting for treatment and self-management (Children)	0 and then 9 through Lambeth Parent Forum additional workshop	6
Waiting for treatment and self-management Workshop 2	16	10
Waiting for treatment and self-management Workshop 3	11	6

### Feedback from Participants

Over the course of the workshops, we both asked participants for feedback at the end of every session and used this to modify future sessions and 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.



Question 1: 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? (Most responses after the first workshop)



Really good to add ideas and share ideas
When people collaborate and discover that many have shared experiences and then they come up with solutions it can be very powerful in driving change
My appointments with Professor Rinaldi were all on time, then I received a letter informing me of a phone consultation 6 days after my CT scan, I never received the call, and this is the third time this has happened, on one hand very good the other disappointing.
Seeing is believing
There need to be much better systems of communication so that patient enquiries are actually dealt with and processed in a timely manner. Just to receive some sort of acknowledgement from admin staff would be a huge improvement.

Question 2: Is there anything else you would like to comment on?

Great initiative
I like the idea of expanding a 'patient coach' programme.
On the right path - keep going
Nobody ever seems to want to take responsibility for communication failures! But the teams are probably overwhelmed and have to divert precious resources into producing endless statistics for the Government.
Does anyone actually know quite what is going on? It appears to me as a patient that everyone is doing their best but seems to be ships that pass in the night.

Question 3: Has taking part in the workshop led to anything for you? For instance, something you are doing differently based on the conversations/ meeting with other people from the workshop outside/ changing the way you provide a service?

Spreading the word
It has made me feel more connected with others that have or are still sharing similar experiences
It's opened my eyes up to the many different departments that operate within the NHS and how all the links in the chain need to work together.
I got to meet the Matron of the eye department at my hospital, so at least I now have a real person to refer things to.