Joint Programme for Patient and Public Engagement

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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.

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

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3 issues 3 approaches

1. Virtual Access – Co-discover
2. Waiting for Treatment and Self Care – Co-design
3. Long COVID - Coproduction

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.

Virtual Access to Care

https://www.lsbu.ac.uk/business/research-enterprise-and-innovation/health-systems-innovation-lab/what-we-do/patient-carer-and-public-involvement-in-covid-recovery/virtual-access-to-care

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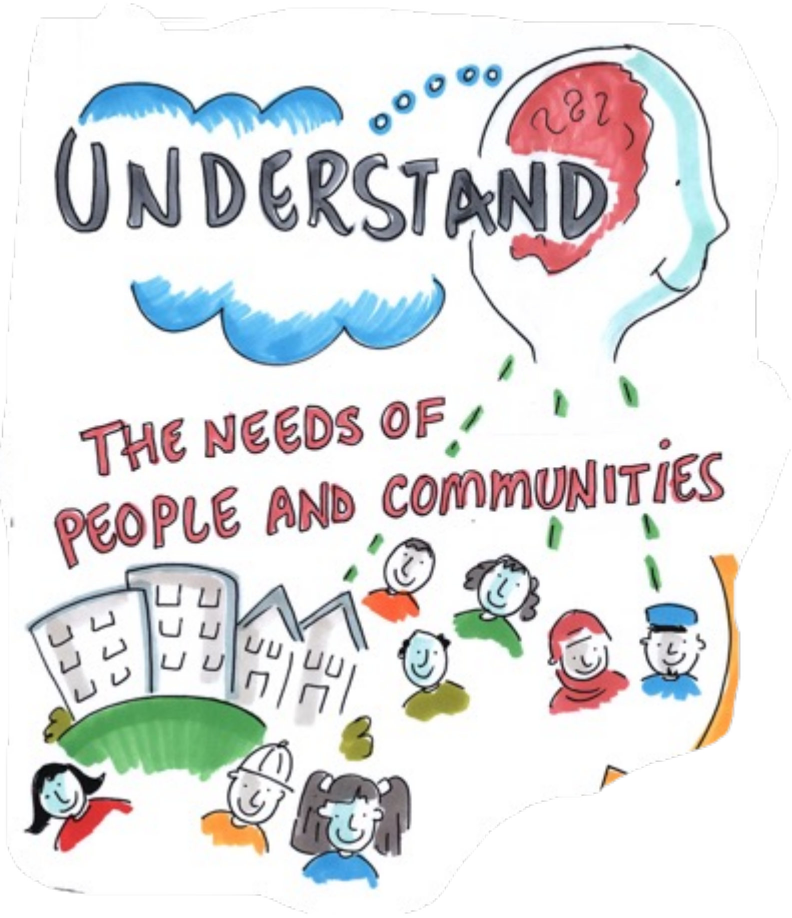
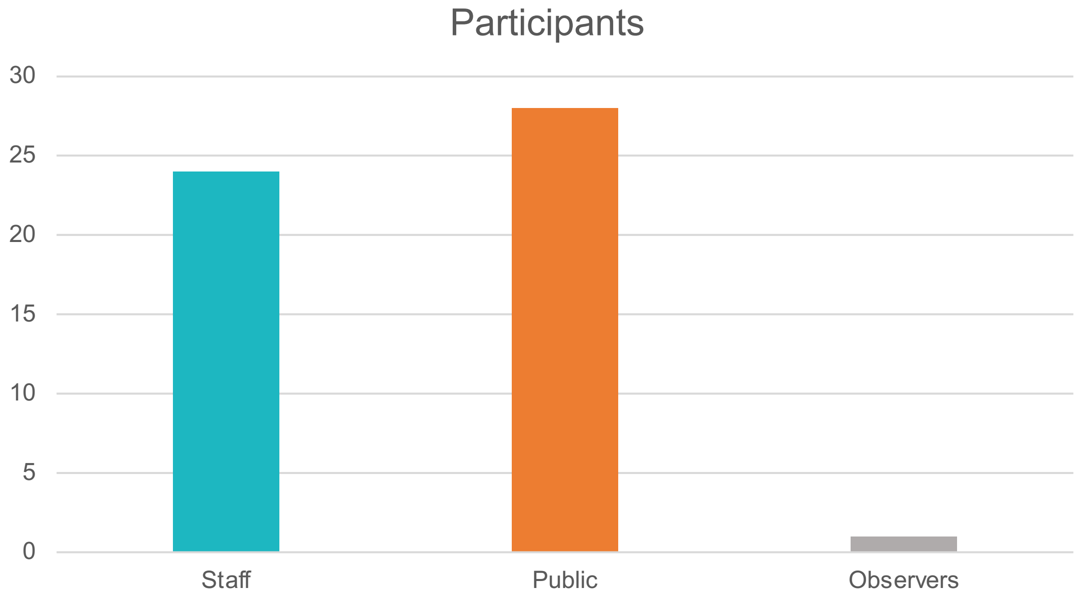
Understand and Get Feedback to Improve

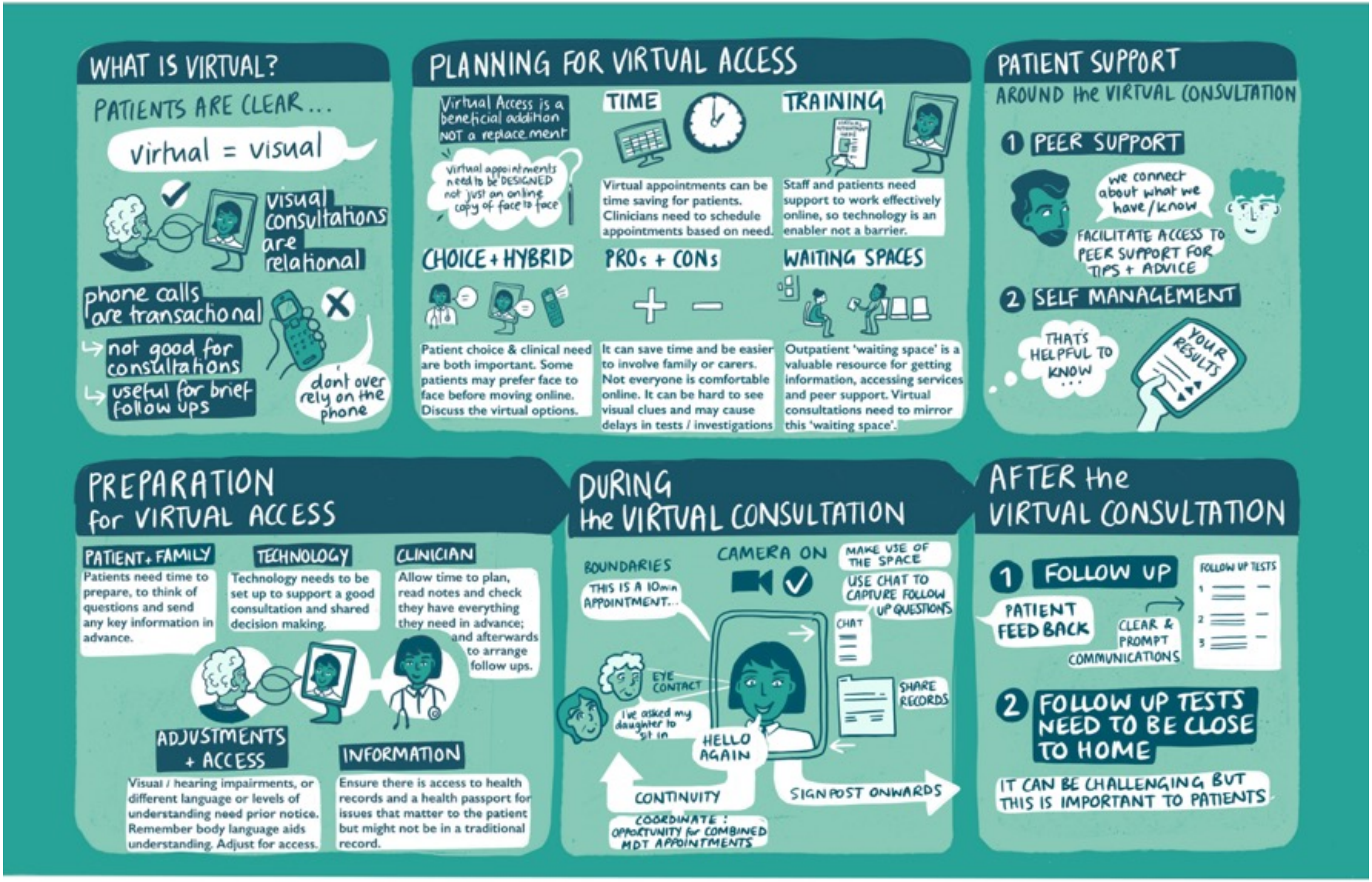


Services where we see people repeatedly	
Interstitial Lung Disease	
Services that are using virtual access now but could revert back to being held to face to face	
HIV	Renal
Services with remote digital monitoring	
Irritable Bowel Disease	
Services with long waiting lists	
Trauma and Orthopaedics	Urology
The virtual pioneers – those services that are pioneering virtual access	
A mix of specialties including dermatology, endocrinology and cardiovascular	

Virtual Access Who Came?

Overall, 53 people were engaged in the Virtual Access to Care workshops of which 3 were observers.





WHAT IS VIRTUAL?

PLANNING FOR VIRTUAL ACCESS

TIME

Virtual appointments can be time saving for patients. Clinicians need to schedule appointments based on need.

TRAINING

Staff and patients need support to work effectively online, so technology is an enabler not a barrier.

CHOICE + HYBRID

Patient choice & clinical need are both important. Some patients may prefer face to face before moving online. Discuss the virtual options.

PROs + CONs

It can save time and be easier to involve family or carers. Not everyone is comfortable online. It can be hard to see visual clues and may cause delays in tests / investigations

WAITING SPACES

Outpatient 'waiting space' is a valuable resource for getting information, accessing services and peer support. Virtual consultations need to mirror this 'waiting space'.

PATIENT SUPPORT

AROUND the VIRTUAL CONSULTATION

PREPARATION for VIRTUAL ACCESS

PATIENT + FAMILY

Patients need time to prepare, to think of questions and send any key information in advance.

TECHNOLOGY

Technology needs to be set up to support a good consultation and shared decision making.

CLINICIAN

Allow time to plan, read notes and check they have everything they need in advance; and afterwards to arrange follow ups.

ADJUSTMENTS + ACCESS

Visual / hearing impairments, or different language or levels of understanding need prior notice. Remember body language aids understanding. Adjust for access.

INFORMATION

Ensure there is access to health records and a health passport for issues that matter to the patient but might not be in a traditional record.

DURING the VIRTUAL CONSULTATION

AFTER the VIRTUAL CONSULTATION

VIRTUAL ACCESS CHARTER

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Ensuring virtual consultations do everything a good consultation should do

1. Be prepared - *A preparatory call to the patient to check they are prepared for the consultation; Clinicians read the notes before you meet the patient*

2. Consistency of relationship - *see the same person where the patient has complex needs*

3. Introduce yourself

4. Build the relationship - *start with listening to the patient / carers needs are concerned about. Make eye contact and stay present. Repeat what you've heard to check your understanding and so the patient feels heard. Check how the patient feels about the issue.*

5. Bring in other expertise if needed - *be able to call on other members of the multi-disciplinary team if needed in the consultation.*

6. When making agreements double check the patient understands - *ask them to repeat back what they think has been agreed. Use good shared decision-making practice.*

7. Make space for the patient to ask questions. *Recognise that some people may need more reassurance about the next steps.*

8. Ask for feedback *at the end and clarify what next.*

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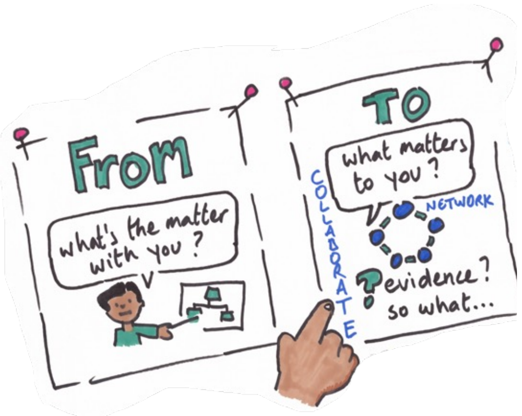
Patient Experience Measures



- Fast access to reliable healthcare advice
- Effective treatment delivered by trusted professionals
- Continuity of care and smooth transitions
- Involvement of, and support for, family and carers
- Clear information, communication, and support for self-care
- Involvement in decisions and respect for patient's preferences
- Emotional support, empathy and respect
- Attention to physical and environmental needs

Picker Institute. About us: [Principles of Person Centred care.]

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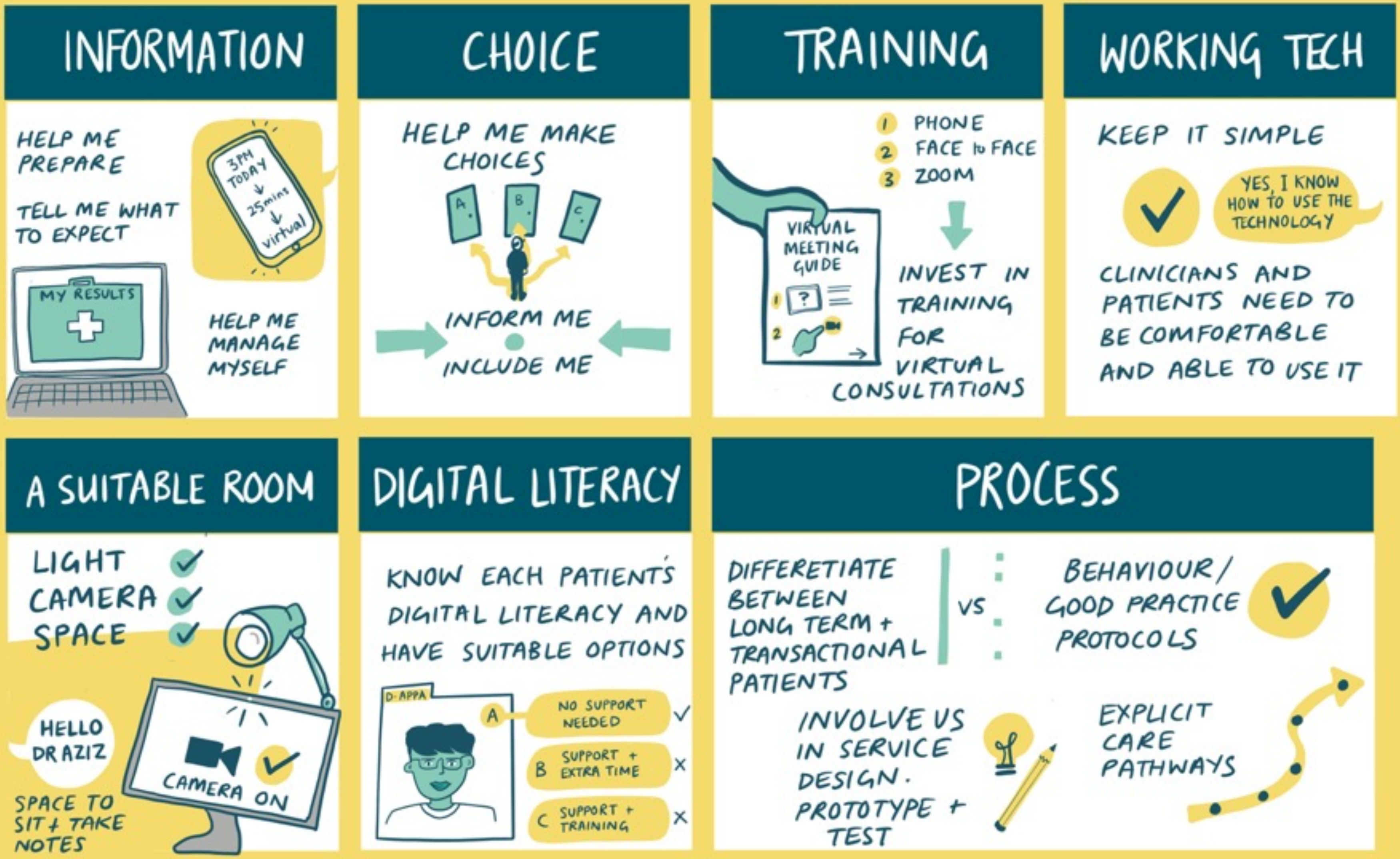
Additional recommendations

1. The overall recommendation is for the Trusts to engage with the evidence provided by the desk research and use this to design virtual access.
2. This requires a strategy for disseminating the evidence provided, and we recommend that the Trusts generate a Self-assessment Tool using the desk research and the charter, against which to assess all aspects of Virtual Access performance.
3. The patient feedback metrics provided in this report should be used to generate evidence for this self-assessment process.
4. Reviewing how and where staff can access training and support in clinical areas when clinics are moving online – staff commented that shadowing senior colleagues during clinics was an important training tool, but this is not built in to scheduling virtual clinics.



INFORMATION

HELP ME PREPARE

TELL ME WHAT TO EXPECT

HELP ME MANAGE MYSELF

CHOICE

HELP ME MAKE CHOICES

INFORM ME

INCLUDE ME

TRAINING

1. PHONE
2. FACE to FACE
3. ZOOM

INVEST IN TRAINING FOR VIRTUAL CONSULTATIONS

WORKING TECH

KEEP IT SIMPLE

CLINICIANS AND PATIENTS NEED TO BE COMFORTABLE AND ABLE TO USE IT

A SUITABLE ROOM

- LIGHT ✓
- CAMERA ✓
- SPACE ✓

SPACE TO SIT + TAKE NOTES

DIGITAL LITERACY

KNOW EACH PATIENT'S DIGITAL LITERACY AND HAVE SUITABLE OPTIONS

- A NO SUPPORT NEEDED ✓
- B SUPPORT + EXTRA TIME ✗
- C SUPPORT + TRAINING ✗

PROCESS

DIFFERETIATE BETWEEN LONG TERM + TRANSACTIONAL PATIENTS VS BEHAVIOUR/ GOOD PRACTICE PROTOCOLS

INVOLVE US IN SERVICE DESIGN. PROTOTYPE + TEST

EXPLICIT CARE PATHWAYS

TOP THINGS THE TRUSTS MUST SORT OUT

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How the outputs add value

- You get better at virtual consultations and become an exemplar
- Increased quality and safety of virtual consultations
- Increased staff and service user confidence
- Increased skills in working collaboratively with professionals, people and communities
- People who can do, choose virtual appointments
- More effective ways of working both online and face to face; improved use of resources
- A network of ‘access’ champions & mapped assets for future work

Waiting and Self Management

https://www.lsbu.ac.uk/business/research-enterprise-and-innovation/health-systems-innovation-lab/what-we-do/patient-carer-and-public-involvement-in-covid-recovery/waiting-for-treatment-and-self-management

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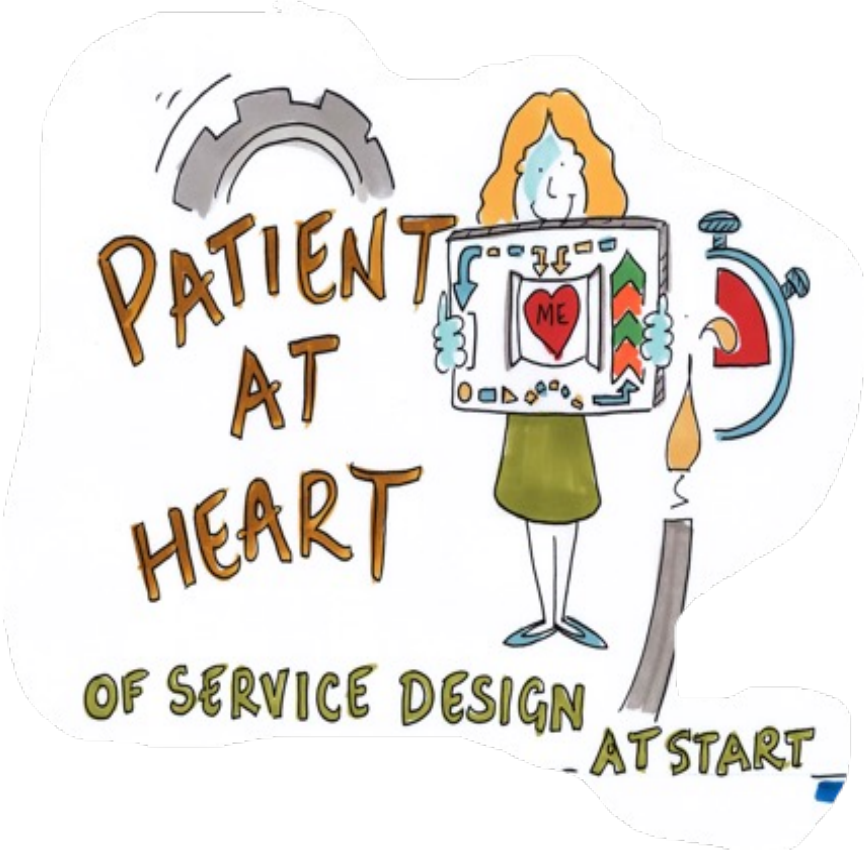
Co-Design Process



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

Clinical groups chosen by the Design Team

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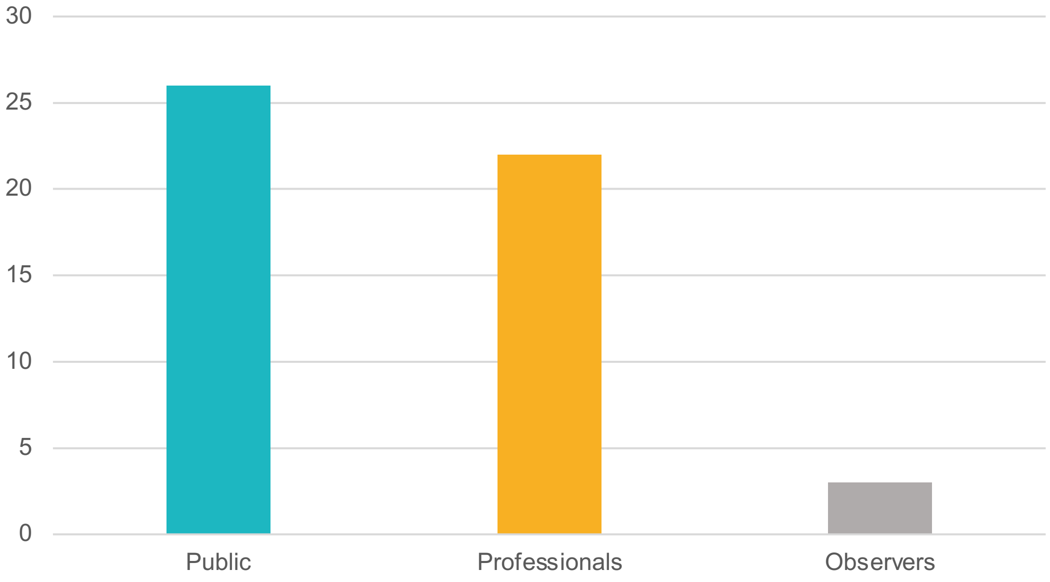
Waiting Who Came?

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



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

I need to be able to take my records with me between services

The Care Plan needs to include:
1. What Next?

2. What to look out for and who to contact when things change

3. Red Flags – so everyone knows (hosp/GP/ Patient/ Carer)

Write to me not to the GP

Letters are an important resource, especially when you have lots of different appointments

Apps are great but I am not sure how good they are when you are involved with multiple care providers

Patients need clear info about plan of care, how long they are likely to wait, what they can do while waiting, what to do if things change, where to find alternative sources of support

Specific example of not keeping community opticians in the loop. We do all the outpatient referrals in our community but don't receive copies of the outpatient letter so don't know action plans, re-referral

Patient held care plan for how to wait safely

IT solutions are great but the answer to a safe waiting care plan is not just another App

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

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Patient Experience Measures

Satisfaction

Communication – getting information

Deterioration

Call handling

Impact on people – mental, emotional, functional, harm

Measures that support people to be more active in their care

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Waiting Recommendations

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.
2. Make sure that support to people on the Waiting List is provided equitably and universally.
3. Provide regular updates to people waiting in terms of what next and timescales, and what to do if you deteriorate. Living with uncertainty makes waiting harder.
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, where to go for help.
5. Help people navigate the whole system of waiting. Provide Care Navigators.
6. People need support to help themselves. Provide dedicated Health and Wellbeing Coaches.
7. Enable Peer Support.
8. Provide family counselling for people who are traumatised by the COVID experience and struggling to cope on the waiting list as a result.
9. In relation to measuring what matters to people who are waiting please see section on Measuring People's Experience in this report.

How the outputs add value

- Improved collaboration with stakeholders to support those who are waiting
- Safe management of people waiting & preventing problems (and complaints) whilst people are waiting
- Treatment for those that need it most
- Improved communication with service users
- People able to support themselves and each other as they wait
- Effective use of other services/resources as identified during mapping process
- You have people locally who can do this work

So what?

- Valuable link forged with some patients, carers and health professionals who were involved in both the LSBU project and delivery of GSTT’s surgical strategy. This helped the co-design of a new area on GSTT’s website and its content – all about having surgery at GSTT.

- Also has supported the development and testing in some specialties with particularly long waiting lists. Sending text messages to patients to confirm that they are on the waiting list, have not been forgotten and who to contact if needed.

Long COVID

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

https://www.lsbu.ac.uk/business/research-enterprise-and-innovation/health-systems-innovation-lab/what-we-do/patient-carer-and-public-involvement-in-covid-recovery/long-covid

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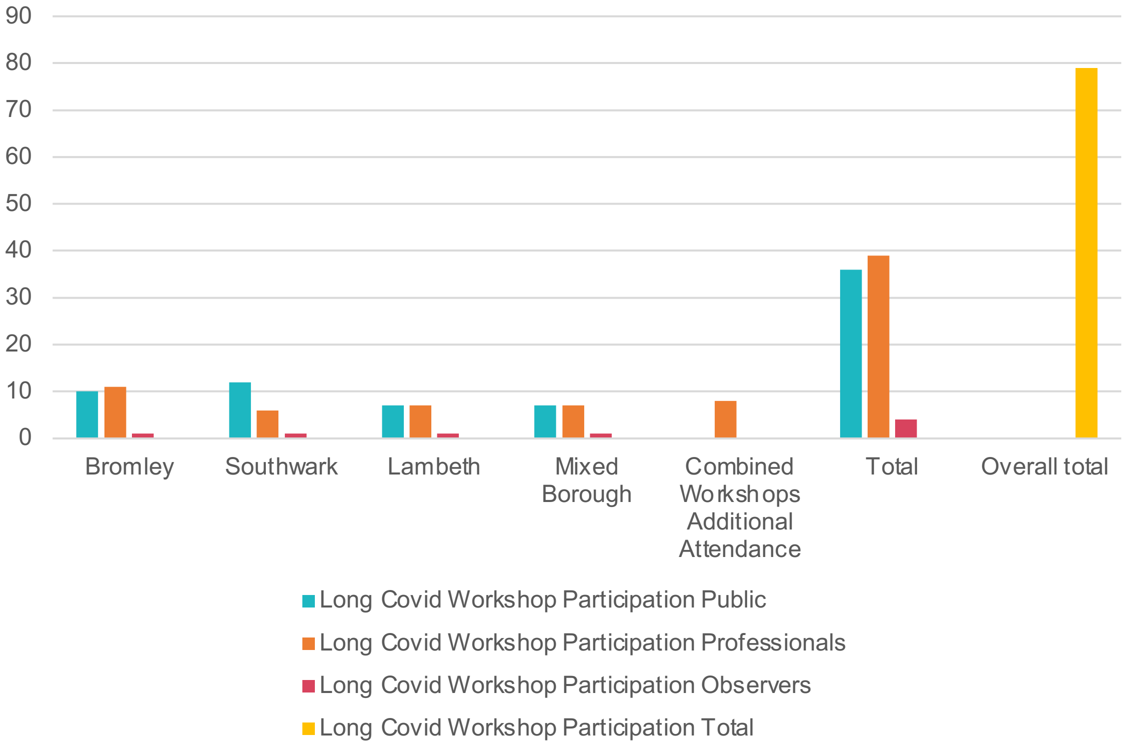
Long COVID Who Came?

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



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Living with Long COVID

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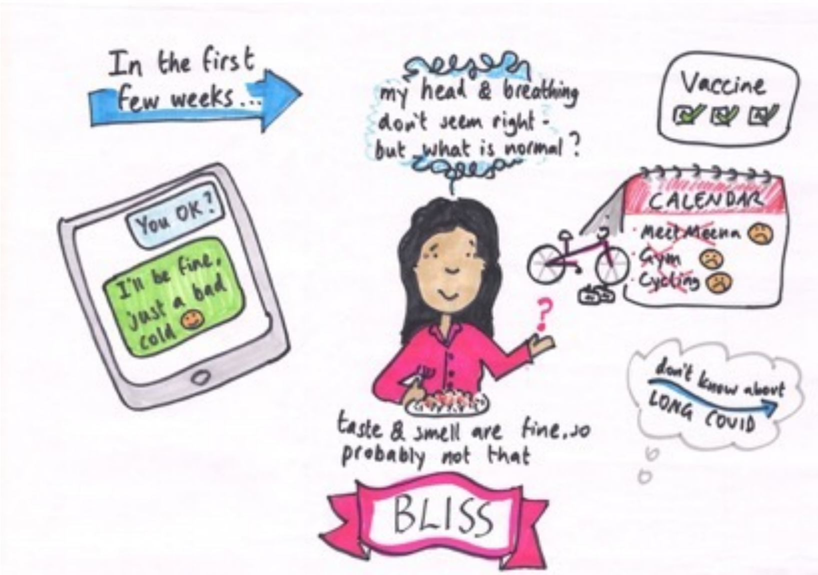

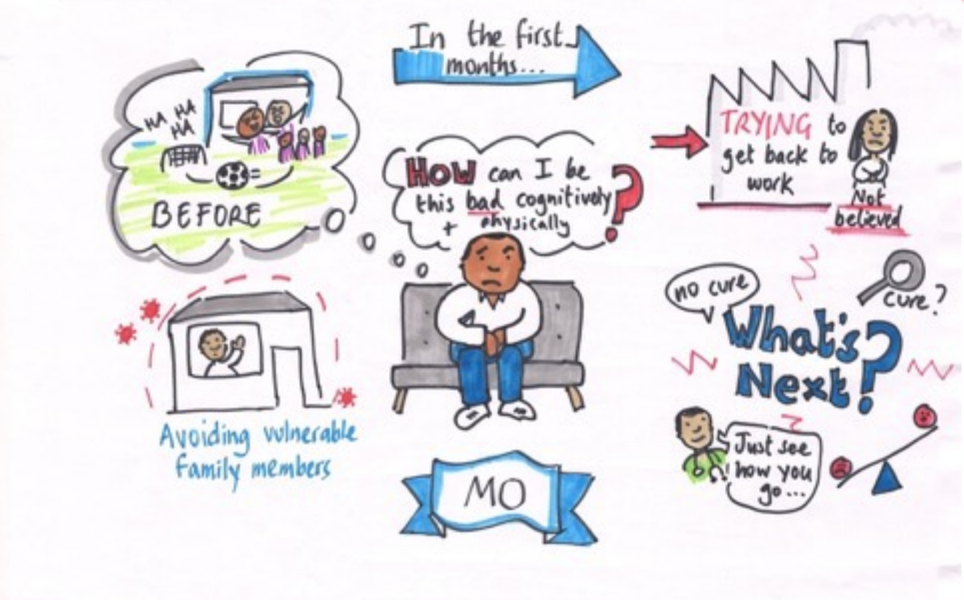

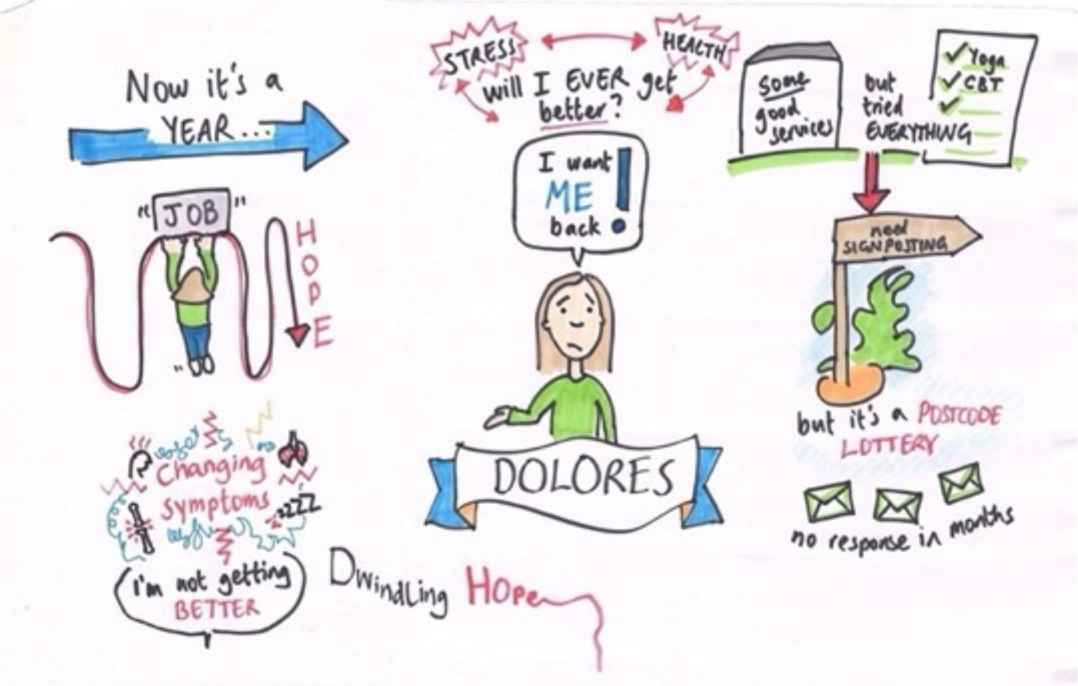

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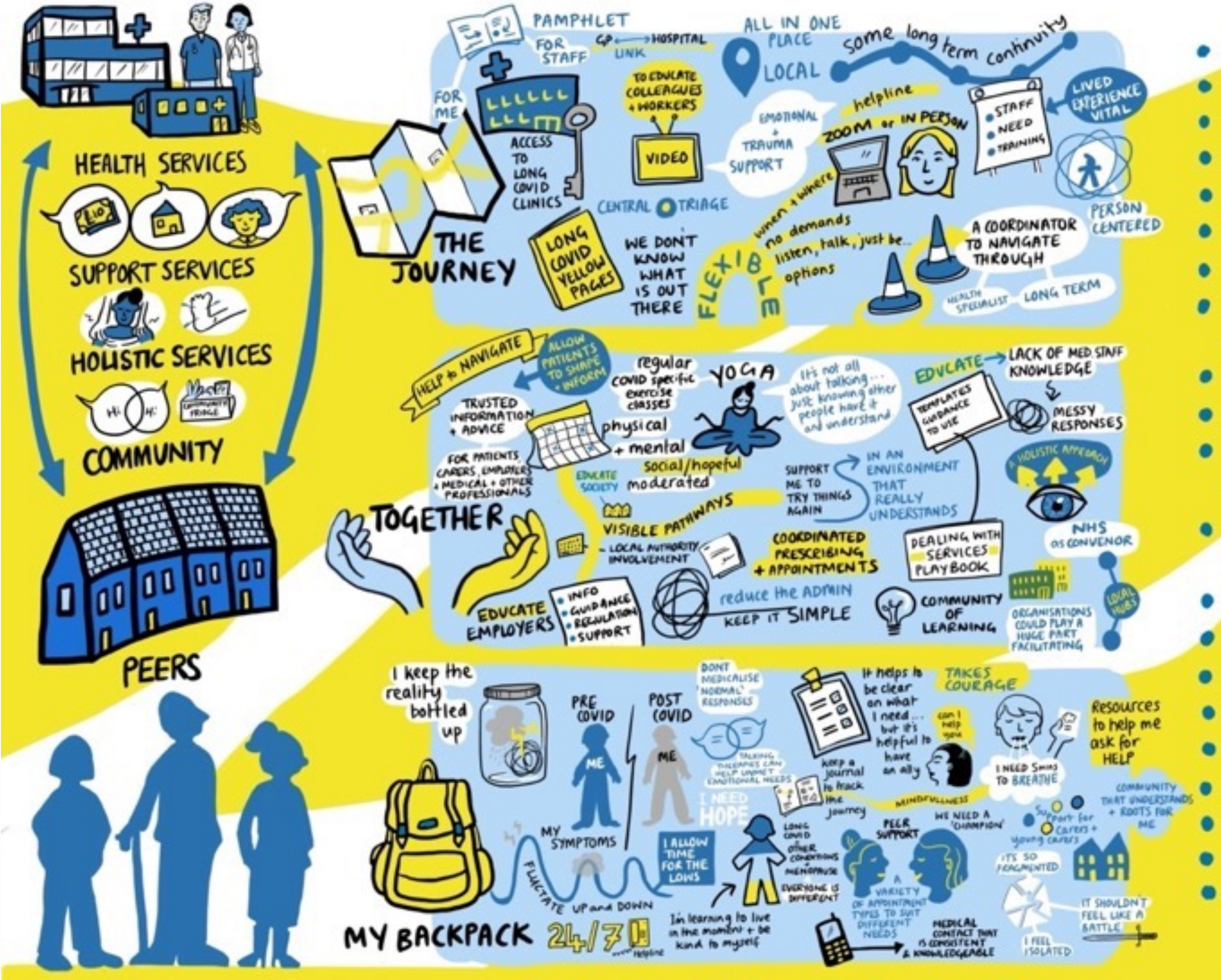

- A safe place to try things
- Talking therapies
- Long COVID clinic
- A care navigator
- Peer support activities
- Curated resources
- Reduce admin
- COVID champions connect to Social Prescribers
- All agencies understand
- GP sick-note as catalyst
- Work with employers and unions to develop pathways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

A New Model of Care for Long COVID

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&...

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Hope

Peer Support

Why me? Why is affecting me more/longer?

Need of an understanding GP

We need someone to tell us who to contact at the start.

we need a pathfinder - so we know what we can try at each stage of our Long Covid

Someone to talk to about the psychological burdens of debilitation, and adjusting to a change of self-image and expectations.

Family responsibilities need to be accounted for

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My Backpack

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Short-term goals

Unaware of existence of social prescribers. Not sure if my GP has one.

Two Key things a patient needs to understand: 1) What's wrong with me (and is it expected)? 2) What help can I get (tailored to the symptoms/history I have)?

A guide for relatives

Are there medical research projects for patients to get involved in that are involved in improving diagnosis and treatment?

Need a multi-disciplinary assessment, but that just doesn't happen... GPs doing their best, but simply don't have sufficient in-depth knowledge.

Mixture of resources needed: some self-serve to be read as suits; some speaking to a real person who can advise. Also maybe pairing someone early stage with someone who has recovered.

who can you talk to when - often it is the employer you speak to first and they really need to signpost someone to help asap

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From the NHS & Services

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What we Need to do Together

Curated Resources

Access to getting to any medical advice and treatment at the time when you need it

Importance of remembering everyone needs different support at different times. Symptoms change and journeys are all different. Service have to be tailored to the individual.

Employment:

Employers and Occ Health need good information to guide them in dealing with employees experiencing long covid - both generic and personalised, e.g. what could be produced that could accompany fitnotes - e.g. ideas for how to create sustainable return to work plans and other options like sabbaticals where needed.

Leaders set the tone - need top level endorsement- HR is not always enlightened - need to target all managers, giving them the skills to support workers with long term conditions- focusing on a culture of belief of the individual's experience, and tailored support

Encouragement of innovative / experimental / creative solutions

Focus on what value your employees bring - avoid losing valuable people and their skills by finding a way to keep them connected, even if they need a long period off work / reduced work

- A safe place to try things
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Long COVID Recommendations

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

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What this means right now for PC

- There are people who are not diagnosed as Long Covid but need help.
- There are people who have slipped between services.
- There are people who are experiencing fragmented appointments for ‘parts’.
- There are people turning up frequently needing help.
- They need services but they also need support to manage themselves
- They feel forgotten.

To help people live as well as they can with Long Covid.

1. To be recognised and heard (diagnosis helps but its not the most crucial).
2. Dedicated Social Prescribing Support for people living with Long Covid for regular check-ins
3. Care Navigator as they get referred for multiple interventions.
4. Support in groups – peer support.
5. Sicknotes for employers

Long COVID Recommendations

Primary Care should:

1. Provide a working diagnosis for people who present with the symptoms of Long COVID; and identify the cohort of people with Long COVID on the GP list.
2. Provide Long COVID specific Social Prescribing – we suggest this is a cohort for the coming SP funding.
3. Provide Long COVID specific Care Navigators
4. Support the development of local peer support networks (people living with Long COVID can’t do the heavy lifting of setting this up)
5. Refer for talking therapies and life coaches.

Long COVID Recommendations

The NHS should:

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

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How the outputs add value

1. People experiencing Long Covid are involved and engaged in their present and their future
2. Learning from those that know it best
3. Establishing a peer community bringing a wider set of resources to work together – that convenes, advocates, supports

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What Can I Do?

Share, talk and share some more! The more we talk about Long COVID the more it is recognised! If you are living with Long COVID and at work you could use the picture from our work on your signature like this:

Name, address etc

Be patient. Some of us need more time than others

Spread

Collaborating with local people

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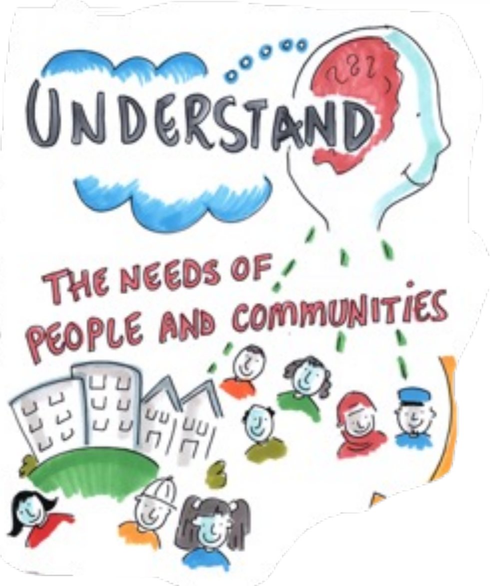

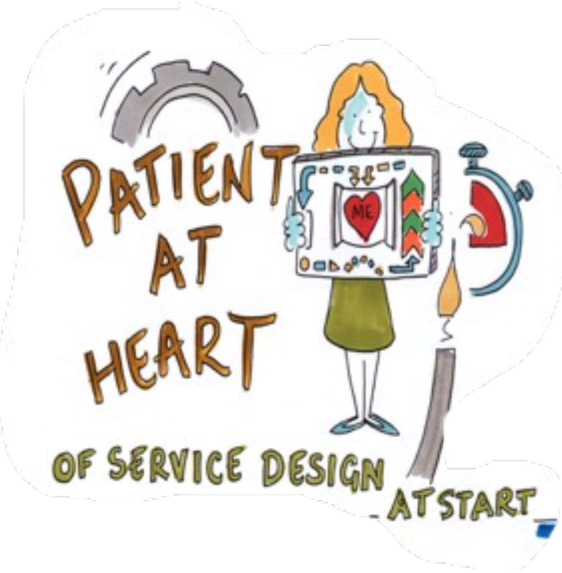

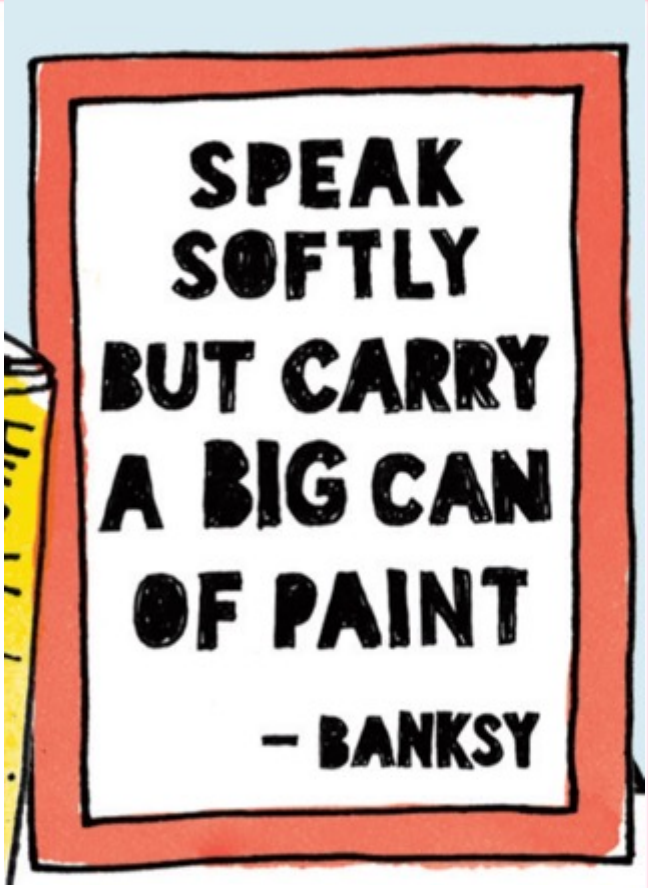
SPEAK SOFTLY BUT CARRY A BIG CAN OF PAINT

– BANKSY

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Three big ideas

1. Service users are a wasted asset.
2. Professionals also need help from their clients, their clients' families and their neighbours.
3. We all depend on the 'core economy'.

Co-production


TimeBanks USA

“Somewhere in the process something has gone wrong. If you're constantly defining people by what they lack or need, it's not difficult for people to lose sense of what they have to give. And it's not a humane way to live.” **Edgar Cahn**

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It’s the Core Economy

“No society has the money to buy, at market prices, what it takes to raise children, make a neighborhood safe, care for the elderly, make democracy work or address systemic injustices.”

“The only way the…world is going to address…social problems…is by enlisting the very people who are now classified as clients and consumers and converting them into co-workers, partners and rebuilders of the core economy”.

Edgar Cahn (2011)

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Six definitions of co-production

1. Designed to build on people's existing capabilities.
2. Providing services which depend on reciprocal relationships between professionals and clients, or services and communities.
3. Encouraging mutual support networks among users.
4. Blurring the distinctions between professionals and users.
5. Organising services as catalysts for broader services.
6. Recognising users as assets to the service.

How to do it

1
- Identify & understand problems -
- Co-discover

2
- Come up with ideas for change
- Co-design

3
- Do the change together
- Co-deliver

4
- Did it work?
- Co-evaluate

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