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Waiting for Treatment and Self-Management: Summary of the Desk Research

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



'A Different Perspective' on the NHS and Social Care by Shani Shamah, Citizen Reader

You just have to care – to make a difference in someone's life, you don't have to be brilliant, rich, beautiful or perfect.

Giving peace of mind is a priority – help people to make deliberate life choices to protect mental, emotional and spiritual state.

Help fight the demons – waking-up every morning to continue fighting the demons is so tiring and demands continual bravery

Holding the hand-wonderful people who can guide and support are needed to help find oneself again. It is the minimum – I achieved because I had my husband to hold my hand to guide, encourage and push me to take control and self-manage to move forward.

Maintain a sense of normality – even in times of trauma trying to maintain a sense of normality is called surviving.

Everyone deserves a life that is worth living

THE IMPACT of WAITING

increased waiting time

burden



I'm worried I'll be FORGOTTEN

The harder people's life circumstances, the harder it is to cope with waiting

↑ ANXIETY
DEPRESSION

IMPACTED

↓ QUALITY OF LIFE

This has implications for recovery

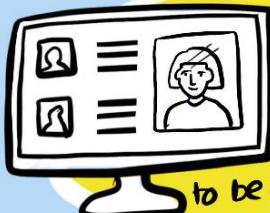


WHAT PEOPLE NEED

- 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

ACTIVE LIST MANAGEMENT
call to assess + inform



REVIEW PATIENTS REGULARLY to see who doesn't need to be on the list



SELF MANAGEMENT SUPPORT
codesigned with patients



COORDINATED ACROSS PRIMARY + SECONDARY CARE

WAITING LIST PRIORITISATION MUST BE ADJUSTED FOR FAIRNESS

WAITING

This desk research has been commissioned by the [Joint Programme for Patient, Carer 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 GSTT Charity and supported by KCH Charity to ensure the involvement of patients, carers and the public in ongoing changes and the development of services necessitated by the COVID pandemic.

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

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

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

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

London South Bank University's Health Systems Innovation Lab and People's Academy will support the delivery of the three projects outlined above.

This desk research summary provides background information and context to help shape and inform the project.

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1. Scope of the desk research

This is a summary of the desk research conducted by the academic team. We also consulted a citizen reader who provides her thoughts and commentary throughout.

The term ‘waiting’ is used in this paper to describe waiting for any of the following: (specialist or therapist) consultation, investigations, diagnosis and intervention (treatment or surgery). This includes new or follow up appointments. The term ‘self-management’ is used in this paper to describe when health professionals, teams and services (both within and beyond the NHS) work in ways that ensure that people have the knowledge, skills, confidence and support they need to manage their condition(s) effectively in the context of their everyday life (The Health Foundation, 2015).

The terms ‘person/people’ are used rather than ‘patients’ with the exception of quoting other sources.

The desk research questions were:

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 search question was therefore:

“For patients on long waiting lists, what is the evidence for supportive interventions and self-management that promote safety?”

2. Key messages from the desk research

1. People are fearful that they will be forgotten, particularly when communication is lacking whilst people wait.
2. As people wait over the ‘norm’, anxiety as well as illness and disability may increase.
3. 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.
4. 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):
 - Burden on quality of life: physical health, mental health and wellbeing
 - Burden on their financial stability (impact on their job)
 - 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 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, 2020).

5. Information and guidance should also be provided (including for ‘red flags’, safe waiting, peer support and preparing for intervention/surgery).

3. Contextual information

3.1 Background from our Citizen Reader

"The effects of Covid -19 are going to continue for some time. Although it is clear that there will be no return to 'normal', at least in the near future, the experience of covid-19 has demonstrated the need to reconsider the way that the NHS has traditionally delivered services. The overall picture is one of major delay, disruption, increased demands on services. For instance, previous national targets, such as for expanding access to mental health services, will now need to be revised to account for the greater need. Additionally, Covid-19 has exposed the widened existing inequalities in health and care throughout the country.

I am concerned for the impact the pandemic has had on people's attitude to accessing care and the impact on their choices and behaviours. How people are experiencing care delivery, how to secure ongoing involvement to continue to innovate in service delivery building on progress made in the pandemic. The relationship between the NHS and the public is complex. For patients on waiting lists, a lack of control arising from the uncertainties involved in waiting and from fear of further deterioration and of loss of income/employment severely curtails the ability to 'get on with one's life' in a meaningful way and to plan effectively for the future. Waiting impacts on family, work, and social lives. Waiting often leads to an increasing lack of trust in care providers (National Voices, 2020). Personalised self-management support interventions can be highly effective in improving outcomes for people living with complex long-term conditions.

What is needed:

- *Taking an asset-based approach, recognising people as owners, consumers and coproducers of the NHS, any approach to waiting lists must be transparent about the issues causing waits and the decisions about wait.*
- *People should be informed of and involved in prioritization of services and the impact of the pandemic on waiting.*
- *The wait should be as safe as possible, in terms of missed serious illness and worry for the person waiting, which will require collaboration between people and professionals to ensure the most at need find their way to the top of the*

queue. Waiting can be harmful, and people need to be able to flag accelerating deterioration.

- *People should be collaborators in the design of any solutions (self-management, or NHS provided to support people whilst waiting (on the premise that the wait is safe))*

3.2 Context – the extent of waiting

Figures provided by the Trusts show the number of patients who were waiting to start treatment at the end of January 2021 across their sites (see supplementary info, section 5A). In a 2007 research study, England had achieved the most sustained improvement in waiting times out of five countries due to ‘major funding boosts, ambitious waiting-time targets, and a rigorous performance management system’ (Willcox et al, 2007). However, in recent times demand has been exceeding supply; before the pandemic there were already 4.43 million people on a waiting list for care and as of November 2021 this had risen to 6 million people (BMA, 2022). Long waiting lists have a negative impact on client satisfaction, staff moral, referrer’s opinion of the service and staff moral, stress, burnout, job satisfaction and reduced effectiveness (Lynch and Hedderman, 2006; McGill et al, 2020). Waiting can also increase the burden on physical health, finances, time, emotional wellbeing, and relationships and reduce continuity of care, whilst increasing intervention needs (McGill et al, 2020). A review of 51 studies with various waiting list types assessed the psychological burden of waiting in the COVID-19 context (Gagliardi et al, 2021). Most people and caregivers reported anxiety, depression, and poor quality of life, which further deteriorated with increasing wait time and for women, new immigrants, younger age and lower socio-economic stability (Gagliardi et al, 2021).

3.3 Local context

The Ipsos MORI (2021) and GSTT (2020) survey results were focused on the experience of virtual appointments and services during the pandemic, but some results from these surveys provided feedback in relation to waiting, as follows:

- When asked ‘what would make you more comfortable using that health service? And what else would make you more comfortable?’ some people said shorter waiting times, or a faster service would be helpful.

- The third most common reason for feeling uncomfortable using a hospital service face to face was concern about waiting times, mentioned by one in ten people (10%).
- Issues such as scheduling appointments and waiting times remain important to patients attending virtual appointments. Waiting times were lower than those experienced during face to face appointments but being left in a virtual waiting room caused distress and being called early (day before) meant patients were unable to prepare.
- One survey respondent quoted: *“I was called out of the blue while looking after my toddler who was screaming for much of the call. I explained that I was not able to talk and was okay with waiting for a face-to-face appointment. I then received a letter claiming that several things had been discussed that had not been mentioned. All in all, I found the experience extremely unsatisfactory and had the impression that the person on the phone was simply trying to fill her quota of completed appointments.”*

4. Useful resources

This section sets out resources to aid communication, care and supported self-management for people on waiting lists:

- NHSE ‘Good communication for patients waiting for care guidance’ (2021): This guidance outlines core principles for providers to help deliver personalised, patient centred communications to patients who are waiting for care. It has been produced by NHS England and NHS Improvement with support from Healthwatch, National Voices, the Patient’s Association, The Richmond Group of Charities and Versus Arthritis. It is primarily aimed at acute Trusts but may also be of interest to the wider system. There is a small section of information on self-management and mental health self-care. Sources of information for patients and professionals are also signposted.
- NHSE ‘Clinical validation of surgical waiting lists framework and support tools’ (2020) is a resource to help manage surgical waiting lists. It includes a question-and-answer list for patients, supporting distressed patients and advice for Trusts to ensure that staff also understand the process.
- National Voices ‘Improving our understanding of the experience of waiting for care’ (2020). National Voices is a coalition of health and social care charities who advocate for people and their carers/families. The group have investigated the experience of waiting for care and have provided context on the experience of waiting for care, as well as how to develop patient-centred approaches to help those who are waiting.
- Scottish Government ‘Coronavirus (COVID-19): supporting elective care - clinical prioritisation framework’ (2020): Includes active waiting list management guidance and questions and prompts for patients.
- Ede and Phillips ‘A wait on your mind?’ (2021). Includes ‘what waiters want’ advice for NHS Trusts, for developing patient-centered information and communication materials. The paper also provides examples and suggestions including waiting letters.
- The Health Foundation ‘A practical guide to self-management support’ (2015): This includes what self-management is, examples and how to use it with specific patient group resources. Various forms of self-management are also described

and signposted.

- Advisory Board 'The 3-step framework for managing your waiting list' (2020): This framework covers how to prioritise waiting lists alongside post-covid healthcare management.
- World Health Organization (WHO) 'Maintaining Essential Health Services: Operational Guidance for the COVID-19 Context: interim guidance' (2020). Guidelines for maintaining essential health services in the COVID-19 context.

5. Supplementary information

Number of patients waiting to start treatment at the end of January 2021 across the founder partners. Figures provided by GSTT.

Treatment Function	GSTT	KCH	RBHT	Total
Other	25,271	18,057	785	44,113
Oral Surgery	4,314	5,982	0	10,296
Ophthalmology	4,677	5,079	0	9,756
Ear, Nose & Throat (ENT)	5,218	2,725	0	7,943
Gynaecology	3,552	4,344	0	7,896
Cardiology	3,391	1,735	2,233	7,359
Trauma & Orthopaedics	2,995	4,265	0	7,260
Urology	2,532	2,289	0	4,821
General Surgery	708	3,810	0	4,518
Thoracic Medicine	501	1,350	2,384	4,235
Dermatology	2,098	1,381	0	3,479
Gastroenterology	1,867	1,171	0	3,038
Neurology	782	1,239	0	2,021
Plastic Surgery	1,802	20	0	1,822
Neurosurgery	0	1,794	0	1,794
General Medicine	175	1,406	0	1,581
Rheumatology	446	671	0	1,117
Cardiothoracic Surgery	0	179	833	1,012
Geriatric Medicine	506	334	0	840
TOTALS	60,835	57,831	6,235	124,901

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