Working together to improve health and social care

September 2021

National Voices' Submission to the Health and Social Care Select Committee's inquiry into *Clearing the backlog caused by the pandemic*

National Voices

Introduction

National Voices

National Voices is the leading coalition of health and social care charities in England. We have more than 180 members covering a diverse range of health conditions and communities, connecting us with the experiences of millions of people. We work together to strengthen the voices of patients, service users, carers, their families, and the voluntary organisations that work for them. Our mission is to democratise and humanise health and care.

We have been asked by the Committee to respond to the inquiry on _Clearing the backlog caused by the pandemic_, which aims to quantify the level of pent-up demand for key healthcare services, and to consider whether fundamental changes to the organisation and delivery of NHS services will be required to manage the backlog of cases caused by the pandemic.

Specifically, we have been asked:

1. What is the **anticipated size of the backlog and pent-up demand from patients** for different healthcare services including, for example, elective surgery; mental health services; cancer services; GP services; and more widely across the healthcare system?

2. What **capacity is available within the NHS** to deal with the current backlog? To what extent are the required resources in place, including the right number of staff with the right skills mix, to address the backlog?

3. How much **financial investment will be needed** to tackle the backlog over the short, medium, and long-term; and how should such investment be distributed? To what extent is the financial investment received to date adequate to manage the backlog?

4. How might the organisation and work of the NHS and care **services be reformed** in order to effectively deal with the backlog, in the short-term, medium-term, and long-term?

5. What positive **lessons** can be learnt from how healthcare services have been redesigned during the pandemic? How could this support the future work of the NHS and care services?

6. How **effectively has the 111 call-first system** for A&E Departments been? What can be done to improve this?

7. What can the Department of Health & Social Care, national bodies and local systems do to **facilitate innovation** as services evolve to meet emerging challenges?

8. To what extent is **long-covid contributing** to the backlog of healthcare services? How can individuals suffering from long-covid be better supported?

Answering some of these questions – around the size of the backlog, capacity of the NHS to deal with it, and the amount of financial investment needed, for example – is beyond our organisational remit and expertise.

However, we do have a range of insights – drawn from our research projects and member charities – that mean we are in a strong position to comment on how the effects of the backlog are being *experienced* by people using services, their families and carers. In addition, we have a number of *recommendations* about what needs to be done to improve people's experiences of waiting for care while the NHS works to clear the backlog, to ensure equitable and inclusive access to the range of healthcare services that are currently available, whether online or face-to-face, and to support people living with Long Covid, especially those confronting health inequalities. We outline these three key recommendations in more detail below.

1. Communicate with people while they wait

Unprecedented numbers of people are waiting for healthcare. People understand the challenge, to the system and to healthcare workers, of the backlog created by the pandemic. But our members and fellow patient charities believe there needs to be urgent clarity for those waiting for new or ongoing treatment about how long they can expect to wait, what services and resources are available while they wait, and what to do if they deteriorate.

Signposting to voluntary sector-provided services is one option, but it must be recognised that such requests for support have already increased significantly throughout the pandemic while, at the same time, charities' incomes have dropped. So, charities cannot simply pick up the pieces left by the absence of statutory services without additional Government financial support.

Our insight work tells us that good communication and non-clinical support are essential to alleviating the negative physical and mental health effects of waiting for care. Our report [Patient Noun Adjective: understanding the experience of waiting for care](#) explored the experiences of people waiting. It found that poorly managed waits are having an impact on the physical health, mental health, employment, housing, and relationships of those interviewed; that the way information is communicated impacted on their sense of control and ability to manage uncertainty; and that people want to be more involved in decisions and planning their own care and treatment.

"Frustration doesn't cover it. It affects me in a physical way, I am overwhelmed, really upset, tied up in knots."

"I just wish someone would tell me what's happening."

"I always have to ring and check. They change things without telling me."

We recommended that alongside the effective management of waiting times and pathways, policy leads, commissioners, and providers:

1. **Understand the importance of improving the experience of waiting.**

2. **Invest in developing patient-centred information and communication.**

3. **Support people while they wait:**

- Provide and support **self-management and shared decision making.**
- **Monitor routinely** and provide clear pathways to specialist advice.
- Explore potential for a carefully delivered **virtual healthcare offer.**
- Partner with, and signpost to, **voluntary, community and peer support.**

Building on this report, we co-produced, together with a number of other patient charities and NHSEI, guidance on [Good Communication with Patients Waiting for Care](#), laying out the core principles to support the standardisation of clear, person-centred communication with patients across the heath service.

Key theme		Key action
	Patient-centred	All clinical communications to patients should centre around their specific care, not internal NHS processes or systems.
	Shared decision-making	All clinical communications to patients should enable clear, shared decision-making and mechanisms for the patient to provide a response.
	Safety reassurance	All clinical communications to patients should reinforce that the NHS is safe and is here to care for all patients who need it.
	Deliberate language	Language should be clear, honest and easy to understand, and tone should be active. Avoid turns of phrase which patients themselves may not identify with – eg 'clinically extremely vulnerable' or having 'minor symptoms'. If required, handle compassionately.
	The whole patient journey	Provide a clear message, with compassionate tone about upcoming appointments or cancellations. Provide clarity on what happens next and when, even if it's uncertain, and give commitment to follow up again.
	Contact point for patients	Ensure it is easy for patients to get information about their upcoming care and to raise any questions, ideally by telephone and email.
	Interim information and services	If care has been cancelled, offer alternative and credible channels for information – eg health charities and/or other local support – as well as alternative services, as long as their waiting lists aren't also long.
	Cancellation policy	Provide clear instructions, using established behaviour change methodology, to set out how a patient can cancel their care if required, while reducing the risk of a 'did not attend'.
	Communications method	Ensure an inclusive communications method for each patient, taking into account their personal circumstances. Ensure there is a mechanism for the patient to get back in touch if required.

This is a great blueprint of how to communicate well with people waiting for care, and it is a faithful reflection of the views of the patient charities involved in co-producing it. However, our concern is that this clinical communication standard is still not widely known about throughout the health system – and that it needs to be.

Our ask, therefore, is that policymakers on this committee ask NHSEI leaders to ensure that this standard is disseminated and implemented so the ambitions set out can be realised widely across the healthcare system – especially within Elective Care – to ensure that all those managing the waiting lists can provide the same high level of communication and support to people while they wait for care.

2. Ensure inclusive access to healthcare services, whether online or face-to-face

COVID-19 necessitated a rapid shift toward digital healthcare. For many, the changes were positive, increasing convenience, avoiding travel time, and minimising infection risk. But not for everyone. Some people remain excluded from digital healthcare as well as online services more broadly – lacking the resources, skills, confidence, or trust to access online appointments. These people tend to be at the sharpest ends of health inequalities, meaning that there is a risk that the leap to digital healthcare will further widen existing health inequalities.

With the support of NHSEI, we set out to investigate what drives digital exclusion, what are people's experiences of digital healthcare, and what are the VCSE-led innovations that are successfully overcoming digital exclusion.

Our report Unlocking the digital front door: Keys to inclusive healthcare was published in May 2021, and includes personal narratives, a catalogue of VCSE innovations, and principles for those designing and delivering services. The people we spoke to told us –

"It's very important that no matter how far we move forward with modern technology we don't leave anyone behind"

"English is not my first language so if you make just one mistake with an online appointment then everything is not going to work for me"

"Digital healthcare puts me off accessing services because I want somebody to talk to face-to-face, a doctor that can treat me like a human being"

We found that people may be digitally excluded for a wide range of reasons and there isn't a 'simple fix' of giving people equipment or training. Often a combination of access, health and social elements need to be addressed for people to engage successfully in remote models of healthcare or find a suitable alternative. We identified many examples of innovative partnerships between healthcare organisations and VCSE organisations coming together to think creatively to tackle the challenges of remote healthcare. Themes of peer-to-peer support and offering more tailored, personalised responses featured strongly in inclusive approaches to delivering new models of care.

Based on these finding we recommended that system leaders:

- Make **inclusion** the core principle driving your work on recovery and restart.

- Ensure that **choice and personalisation** are the formative design principles for all care, and for primary care in-particular.

- Check your technology optimism bias: do not incentivize the use of certain tech or processes – only **incentivize inclusion and quality care.**

- **Evaluate** and publish how your transformation programmes impact people at risk of exclusion. Set out what you are doing to mitigate these risks.

- Publish your results of **user testing** and set out plans on how you will improve people's experience.

- **Invest** in technology that clearly demonstrates how it aids inclusion.

- Understand, support and **challenge primary care** as the most important gate keeper and enabler of inclusive care throughout the whole system.

- Understand that health care is just one of the needs people have who are affected by poverty, racism or discrimination, **build care models** that allow for other needs to be identified and addressed appropriately.

- Secure funding that enables remote care to be delivered **free at the point of use**: free Wi-Fi, free data, free calls, free kit for those in need. It is not the job of the poorest citizens to subsidise the roll out of new care models.

- Refresh and strengthen your commitment to the **Accessible Information Standard** and Guidance on Communicating With Patients Who Are Waiting For Care. Provide funding for providers to **ensure good communications**.

We stand ready to work with our system and sector partners to put our collective insight and ambition towards a more joined-up, person-centred, safer, experience of care, where virtual and face to face services adapt to meet the full range of clinical, emotional, and practical needs of people at risk of exclusion and address the barriers to access and use confronting some groups.

3. Support people living with Long Covid

National Voices has started an NHSE&I-funded project exploring the support services available to people experiencing Long Covid, with a particular focus on those facing health inequalities. Based on our preliminary conversations and learnings, some key insights have emerged, which we summarise here.

To what extent is Long Covid contributing to the backlog of healthcare services?

Although the current backlog on mainstream healthcare services due to Covid is estimated at more than 18 months, it remains unknown how much Long Covid itself has contributed to this. However, given the complexity and severity of Long Covid, together with the large number of people it effects, it seems likely that Long Covid will indeed have contributed to the additional strain on services, and in turn to the backlog.

Long Covid comprises a complex range of health conditions, currently effecting over one million people in the UK. Of those, 400,000 people have suffered with Long Covid for over a year. Sufferers require a range of services, in particular holistic needs assessments, peer community support, and multi-agency clinical and psychological care. As research and insights emerge, many estimate that the strain of the Long Covid condition on healthcare services will contribute to backlogs within the system for many years to come.

The National Institute for Health Research (NIHR) has committed £19.6 million to expand Long Covid pathways and reduce waiting times through ensuring that GPs have access to multi-disciplinary, rehabilitation and psychological therapies to signpost patients. The hope is that redirecting patients through multi-agency care will reduce the stress on NHSEI to address all needs, especially in Primary Care.

Others hope to alleviate some of the stresses on healthcare services stemming from Long Covid by supporting people at home. A recently commissioned study by Dr Manoj Sivan at the University of Leeds entitled "Optimising standards of care for Long Covid in hospitals, doctors' surgeries and at home"[1] should go some way in forming a basis for the response to Long Covid and waiting times, with funding support to the tune of £3.4m from NIHR.

NHSEI themselves are looking to further develop the 'Your Covid App' to align the functionality with that of the 'Living with Covid' app, to help keep Long Covid sufferers with self-directed treatment away from mainstream healthcare services and to further reduce waitlist backlogs.

Clearly, then, there are efforts underway to both better support people living with Long Covid and reduce the impact of their health needs on services and on the backlog. But emerging insight seems to suggest that inequalities are shaping diagnosis and service uptake, and that still far too many people experience delays, or even dismissal when they approach services for help.

How can individuals suffering from Long Covid be better supported?

Early learnings are beginning to emerge suggesting that individuals from marginalised communities who are suffering from Long Covid do not have adequate tools, access to services or understanding of their condition to seek – and get – the support they need. Sufferers often also have pre-existing, often undiagnosed, health conditions, which exacerbate the ongoing indications and implications of their Long Covid.

Community leaders have identified the need for on-the-ground support of those least likely to be able to access Long Covid hubs as part of outreach programmes within the community. A strengths-based approach to care, as opposed to a needs-based approach, which builds upon the assets that an individual already has in order to address their own

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[1] https://www.leeds.ac.uk/news-health/news/article/4871/creating-a-gold-standard-of-care-for-long-covid

care vulnerabilities has also been identified as a support mechanism, though this is not a substitute for medical and clinical diagnosis.

In order to prevent people – especially vulnerable people from marginalised communities – remaining on waiting lists for many months before receiving tailored support for their Long Covid symptoms, we ask healthcare leaders to prioritise the following:

- Create accessible and inclusive information about Long Covid, as well as the local support available

- Liaise directly with communities and their organisations, to build effective support, in particular based around peer support models

- Extend Long Covid hub support to more marginalised members of communities

- Co-design personalised self-management tools and peer-support and advocacy groups

- Ensure that all research and programme building is co-produced with those with lived experience of Long Covid, and that the learnings from engaging with communities are formally considered throughout the process of building solutions .

And, in building new models of care for long covid we know that successful models for supporting people with LTCs have in common:

- An **Inclusion offer**, instead of rigid assessment thresholds

- **Seamless referral**, no wrong or right way in

- **Choice**, personalisation, autonomy, outreach

- **Community** placed both within and outside the statutory service

- Bearing the discomfort of advocacy and voice- politics and power are acknowledged – **coproduction**

Conclusion

It is not yet clear how long it will take to clear the current backlog in healthcare services. Nor indeed what exactly that will require, beyond, clearly, significant investment in health services and in the exhausted, burnt out and likely traumatised workforce essential to providing them.

But that should not stop health system leaders or those designing and delivering services from better supporting people while they wait for care as the backlog is cleared. Lots can and should be done to alleviate the worst impacts on people waiting. Good, clear, accessible communication is key. **There is already an excellent Clinical Communication Standard available that does exactly that – it just needs to be properly disseminated and widely implemented, especially across Elective Care.**

Where services are now running differently, in hybrid models combining face to face and online services, it is crucial that people understand how to access services and have choices that enable them to remain or become included. For example, it's important to make sure eConsults to see a GP are as simple and straightforward as possible, and that accessing a GP the 'old fashioned' way, by calling or turning up at the surgery, remain available – otherwise Primary Care providers run the risk of excluding significant swathes of people from accessing their frontline services. Again, **there is a wealth of insight about digital exclusion that we at National Voices, and our partners, have developed, alongside tried and tested methods for overcoming it – system leaders and those designing and delivering services need to know about these insights and then apply the solutions to their context**.

In a similar vein, we are learning more and more about Long Covid every day. Not just clinically, but also what support people need and what services are helping. Clearly, we need to know more. But the key here is to work with people to co-design services and co-produce solutions. So **we ask system leaders and those designing and delivering services to ensure that all research and programme building is co-produced with those with lived experience of Long Covid, and builds on what we know works in long term conditions care: multi agency support models, straddling clinical and non-clinical needs.**

Finally, it is important to remember that the actual scale of the backlog is much bigger than the numbers of people captured on formal waiting lists for Elective Care. **There are vast numbers of people with 'unmet need'** – whose routine services and/or support were suspended during the acute phases of the pandemic, and whose health has likely deteriorated both physically and mentally. That pain and suffering is not captured in official lists of people waiting for joint replacements – yet it is no less real, pressing and in need of a response.

Most of our advice and asks are directed at system leaders and those designing and delivering health services. But we know that they cannot act alone – that they need the moral support of political leaders like yourselves, and the financial support of Government in order to achieve these goals. So overriding all our other asks is **our ask to you, in the Health and Social Care Select Committee, to give that moral support and amplify our calls for crucial financial investment in health and care services at this critical juncture**.

Without significant and sustained investment, both in the short and long term, we will not achieve any of the ambitions outlined in this paper, or any others we all share. Inequalities will increase, outcomes won't improve and there is a real risk that the NHS will increasingly be seen as an 'emergency only' service that does little to support people to live well ill health or disability.

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