

**Submission to the Health and
Social Care Select Committee
Inquiry on ‘Delivering core NHS
and care services during the
pandemic and beyond’**

“Healthcare for us has changed beyond all recognition. In the month before lockdown we had a collective total of 12 face to face appointments for mental health support. All of this stopped overnight. Our need for care did not.”

- Ephra, recently bereaved mother and carer for a child with a chronic condition

1. Introduction

National Voices is the leading coalition of health and social care charities in England. We work together to strengthen the voice of patients, service users, carers, their families and the voluntary organisations that work for them. We have 150 members covering a diverse range of health conditions and communities, connecting us with the experiences of millions of people.

We have been working with our members since the start of this crisis to identify and respond to the challenges people living with ongoing health and care needs are facing. We are regularly briefing system leaders (NHSE&I, CQC, RCGP, NHSX, DHSC) about what our members tell us needs to be sorted out for those with ill health or disabilities.

We have also developed and launched a mechanism that enables us to hear directly from people living through the Covid-19 crisis ‘OurCovidVoices’. Our hope is that this will become a substantial citizen-generated qualitative dataset of people’s experiences that will be both a first draft of history and a resource for policymakers to better understand the impact of their policies. The quotes included in this submission were lifted from the emerging insight gathered on this site.

Below, we set out what we see as the primary ongoing health and care needs during the acute and next phases of the crisis, focusing on some major conditions as well as mental health and health inequalities. For us, **the key is active citizen engagement with patients, their families and carers, so that policymakers understand the impact of recent and future system-wide changes and ensure that people’s rights are respected.** In order to know which changes are welcome and should be retained, and what is not working for people and needs to be set aside, it is essential that health policymakers and providers at all levels engage patients in a meaningful coproduction process.

We will only know what positive changes have taken place if we work with people who have health and care needs – they are the only ones who can tell what works.

2. Ongoing health and care needs during the acute phase of the crisis

The delivery of core NHS and care services is vital to those we support. During this acute phase of the pandemic, our member charities have reported a number of concerns to us, ranging from the impact of the suspension of services to access to food and medicine to the uptick in mental health. Many of our members are submitting detailed evidence of impacts on specific condition groups. We will focus here on overarching themes.

2.1 Access to diagnosis, treatment and rehabilitation

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“What alarmed me most was when the doctor told me that his hospital could possibly stop treating cancer patients needing chemotherapy because of the immune system breakdown it causes and covid 19. As a cancer patient who is still alive because of chemotherapy, that is a truly frightening thought. I only hope this doesn’t happen!!”

- Cancer patient

Our members report widespread difficulties in accessing necessary care. Many kidney patients have had reduced and delayed dialysis, and the suspension of the transplant programme will have pushed some onto dialysis. People living with cancer have had their treatment disrupted and would like to see a plan for the restoration of cancer services as soon as possible. Screening has been paused, with unknown consequences for rates of early diagnosis and survival. In neurology, specialist services have been reduced. Mental health services have been disrupted.

2.2. Reduction of community care, including continuing healthcare and rehabilitation

The picture varies locally, and we do not have national data, but there are widespread concerns about the reduction of community healthcare provision. Home visits and continuing healthcare have been cut or stopped. Some people have been told to rely on family carers. As more people leave hospital very soon after they come out of critical care, often with very substantial rehabilitation needs, it is not clear how those needs can be met with community care cut back severely in many places.

“My mental health suffered. Anxiety took hold and I was experiencing panic attacks. I felt overwhelmed, unable to cope. I limited listening to the news and daily briefings (something I still do) and limited looking at social media.”

- Diabetes nurse, living with Behcet’s disease, shielding

2.3 Social care and special needs provision

“Before lockdown he was visited by a mentor from social services. To help him with his anxiety. To help him with his emotions. Not now. No warning. No explanation. The mentor has just disappeared.”

- Eva, mother of a child with special educational needs

Our members report that social care packages have been cut or reduced, home visits stopped, carers’ support discontinued. Where respite care is no longer provided, carers are now shouldering more. When families cannot even leave the house, these pressures can lead to exhaustion, stress, and ultimately very unsafe situations for both the carer and the person they care for.

2.4 Care homes

It seems that as plans and decisions were made about resources, workforce and testing, people living in care homes and their ongoing needs were an afterthought. Many homes closed to visitors before the official lockdown. We have heard of instances where care

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homes were told GPs or nurses would not visit, or that residents would not be admitted to hospital if they fell ill – without discussion or consultation. People living in care homes seem to be affected by a double burden of no visits, which clearly impacts people’s quality of life, and at times lack of access to timely, responsive NHS care. This is unacceptable.

2.5 Medicines

Many members reported that their beneficiaries had difficulties accessing essential medicines because of shortages, changed opening times, shielding and so on. There are currently no medicines reviews taking place – which can impact people living with multiple long-term conditions. Pharmacists are working hard to provide everyone with what they need, but much anxiety has been caused.

2.6 Access to critical care

In the context of pressures on critical care, at times ill-conceived and badly executed conversations about end of life care and DNR decisions were started with people who live with long-term conditions, are older, or have learning disabilities. This caused much anger and distress. National Voices pulled together this statement, signed by over 80 organisations, reiterating the need to remain true to our values of human rights and equality. Blanket bans on who can access what care can never be right, whether they are based on age or any other characteristic. Everyone deserves to have their care based on individual decisions, wherever possible based on the person’s expressed wishes.

“It can be lonely sometimes even though I have a neighbour downstairs, I live up 5 flights of stairs. She helps me with letters, cooks on Sunday, irons my clothes and occasionally gets some shopping in. This really helps me.”

- Gary, living with learning disability and epilepsy

2.7 End of life care

We have heard concerns from members that hard won progress around good quality end of life care for all was lost on occasion: people not being allowed a family member to visit in the last hours of their lives (this has now been corrected), people not getting access to oxygen or pain relief if they die outside of hospital, family carers not always supported with their needs.

But we have also heard that there has been a big rise in demand for support to plan ahead, confirming that when given the opportunity and right support, people want to talk about the end of life and put plans in place, to give them greater control over their future and to help their family when the time comes. We need to hang onto improvements that have been made, for example by adopting more personalised care plans and community level access to end-of-life care drugs.

2.8 Inequalities

Emerging data shows clearly that people in poorer neighborhoods are disproportionately affected by Covid-19. It also seems that people with BAME backgrounds carry a

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disproportionate burden of morbidity and mortality. We believe that this requires urgent attention, and also think it is reasonable to assume that at least some of this inequality derives from people's non-Covid health needs not being met. The link between poverty and multimorbidity, and deprivation and years lived in ill health is clear. We cannot accept a trade-off between addressing these inequalities or addressing the Covid-19 crisis. We will not get to grips with Covid-19, if we do not reduce these shocking inequalities.

2.9 Summary

"I have had important medical appointments put off because of the virus and two serious appointments failed to happen because, it seems, Covid-19 issues were considered more important than my own life-threatening condition. A friend of mine has had a triple by-pass operation postponed."

Martin, living with 12 long term conditions

Whilst we have never spent more money on health and care before, never talked more about health services and health policy, it is no doubt true that those who needed health and care services before Covid-19, and will continue to do so after this acute crisis is over, have experienced service cuts and a reduction in the support they need. Many will also have experienced a deterioration of their health and wellbeing.

It is also undoubtedly true that most of the decisions described above were made without the meaningful involvement of the people most directly affected, their carers and families. 'Many decisions about us, without us', is unfortunately true. We understand that many of these decisions needed to be made quickly and could not wait for good evidence, but their negative impact on people and communities is now clear and was often also largely predictable.

It is of critical importance that as we approach a new period of the Covid-19 crisis, we involve all those who are affected by decisions, and arrive at models that support people with their lives. This is not just a matter of good practice, but of human rights, particularly where people's freedoms and access rights continue to be curtailed.

"I hope others who are not as vulnerable to Covid as we are speak up with us and say we deserve more than to just be told to lock ourselves away behind closed doors for 18 months."

Sharon, living with cystic fibrosis

3. The next phase of our Covid-19 response

These last weeks have been very difficult for almost everyone, but particularly for those living with ongoing health and care needs. We realise that the next period could be characterised by even more need, an even more depleted service, even more overstretched workforce, even longer waits, even less personalisation and a return to transactional care models that focus on the most urgent clinical need. This would harm the people our members work with and for.

To prevent this worst case scenario from happening, we need to get some important things right: We need to understand how people feel about using health and care services now, encourage and enable use by people with ongoing health issues, and support those who are waiting. We also need to learn what worked, and what did not, by listening to people who rely on services.

3.1 Understanding what makes people vulnerable

“I feel the process around the shielding letters was slow and disorganized, as well as missing people off the list. Not me, I got my letter but know of others who didn't, but should have. I have had three copies of the letter but still Tesco don't have me on their list.

Person living with two ‘invisible’ immune conditions

The NHS/ Government created categories of people: ‘extremely vulnerable’ and ‘vulnerable’. We will not go into the details of the problems with the data used or the confusion and anxiety generated. The point now is that whether someone is vulnerable does not just depend on narrow clinical indicators. Vulnerability can stem from housing, violence, trauma or carers’ responsibilities – it can also derive from discrimination and stigma. A more holistic understanding of vulnerability that reflects the layers of vulnerability (clinical, social, financial) must inform a service response as we move out of the acute phase of the crisis.

3.2 Understanding how people feel about using services

People with ongoing or new health needs are not using services as much as they need to. Recent research by Traverse has revealed that this partly stems from concerns about taking time away from other patients, not wanting to distract doctors from other work, and anxiety about attending healthcare settings.

Clearly, it is important to meet urgent and emergency healthcare needs, and it is good that the Government and NHS are addressing this through messaging now. But the entrance point to urgent care is clear – go to A&E. For people with ongoing needs, it is not at all clear how to access care. Broad messages about the NHS being open are not helpful when access to cancer or mental health care will vary locally. Communication needs to be grounded in local arrangements.

3.3 Understanding what works for whom and what does not

The Traverse research also explored how people felt about the new service models they used – waiting in a car, rather than a waiting area, and speaking to a clinician over the phone or through video consultation. Much has been said about how fast the NHS managed to innovate these models during the crisis. We welcome more options to accessing healthcare beyond face-to-face visits. But we need to ensure that these new care models are properly tested with those whose perspective matters the most: the people with ongoing health and care needs.

It is now urgent for those in charge of service design and delivery to reach out to patient groups to review and evaluate the services that have sprung up. Much should be retained,

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but online models will need to be complemented by face-to-face consultations where people live with complexity or struggle to use smart phones or online forms.

3.4 Understanding waiting

4.4 million people were waiting for elective care before the Covid-19 crisis. This number is bound to grow significantly as a result of recent cancellations. Health and care leaders need to think through the information and support needs of the rapidly growing number of people waiting for NHS assessment, diagnosis or treatment.

National Voices is investigating the experiences of people who are waiting. We started this work before Covid-19, but it now has new urgency. Through a literature review and an analysis of Care Opinion data, we have identified some common themes, including pain, psychological distress, fears around deterioration in health, threats to employment and loss of income, and increasing lack of trust in care providers. At its worst, this experience is described as a life 'on hold,' characterised by uncertainty and precarity in relation to family, work and social lives. This sense of a lack of control arising from the uncertainties of waiting will likely be compounded by the psychological effect of lockdown.

It is essential now to properly value and acknowledge the experience of waiting. Supporting people who are waiting needs to be thought of as a necessary part of health care. As one interviewee has said: 'It's the not knowing that kills you'.

4. The VCSE support offer

"Grateful that we have each other and that there are lifelines of support in our community still helping us day by day. It's not easy. It's a challenge but as long as we remember that there are incredible charities and support networks out there, reach out and you will find that we are never truly alone."

- Carol, living with lung conditions

Our member charities – and many others – have stepped up to meet people's significantly increased information and advice needs, as well as emotional and peer support. Hardly any of this is funded by the NHS or local authorities, and charities cannot do their usual community fundraising. This makes the work health and care charities do unsustainable, which will cause a major problem for the NHS, but more importantly for the people we support. Where are people going to go with their information and advice needs if charities need to reduce their service offer? GPs and clinical teams are a more expensive, and less holistic way, of supporting people who do not just struggle with clinical needs but are often also lonely and worried about their incomes or carers responsibilities. Charities are experts at seeing the person, not the illness.

We need charities to be able to continue doing this work in partnership with the health and care system.

5. Conclusion

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The health and care system's (necessary) response to the Covid-19 crisis has caused many problems for people living with ongoing health and care needs. As the acute phase passes, the next period needs to place those people at the centre: listen to their experience and ensure that those with the biggest needs (who are often also those at the receiving end of inequality and disadvantage) are prioritised.

Supporting people through the new normal will require us to intelligently blend non-medical support (advice, information, and carers, emotional and peer support) with clear access routes to high quality clinical care – for ongoing as well as urgent health needs. These models must be built with the users' experience front and centre.

“Life has changed but is still being lived!!! I haven't been worsted or cowed by this invisible foe. I am working full time and living but just in a different way.”

- Aaron, shielding with severe asthma

For questions about this submission, please contact Dr Rebecca Steinfeld, Head of Policy, National Voices: rebecca.steinfeld@nationavoices.org.uk