

# What We Need Now

What matters to people for health and care, during COVID-19 and beyond – new National Voices I Statements 2020

What has to happen now – National Voices' recommendations to health and care leaders and professionals

There are many untold and unheard stories around health and care in this pandemic. At National Voices, we have been listening, learning and capturing people's experiences. We wanted to make sure those living with ongoing physical or mental ill-health or disability – those who have been suffering the most due to service suspensions – could tell their stories and be heard. Now we are sharing what they told us, as expressed in a set of I Statements that we believe sum up what matters to everyone using health and social care now.

The statements derive from an online platform we set up when the pandemic began, [OurCOVIDVoices](#), for people to share their stories. We analysed dozens of submissions, identifying key and recurring themes. These included details about the impact of COVID-19 and lockdown on people's physical and mental health in general, as well as their broad concerns about money, housing and accessing food. But we also homed in on their specific frustrations about information and communication relating to their health and level of risk, access to medicines, and experiences of remote care, service delays and cancellations.

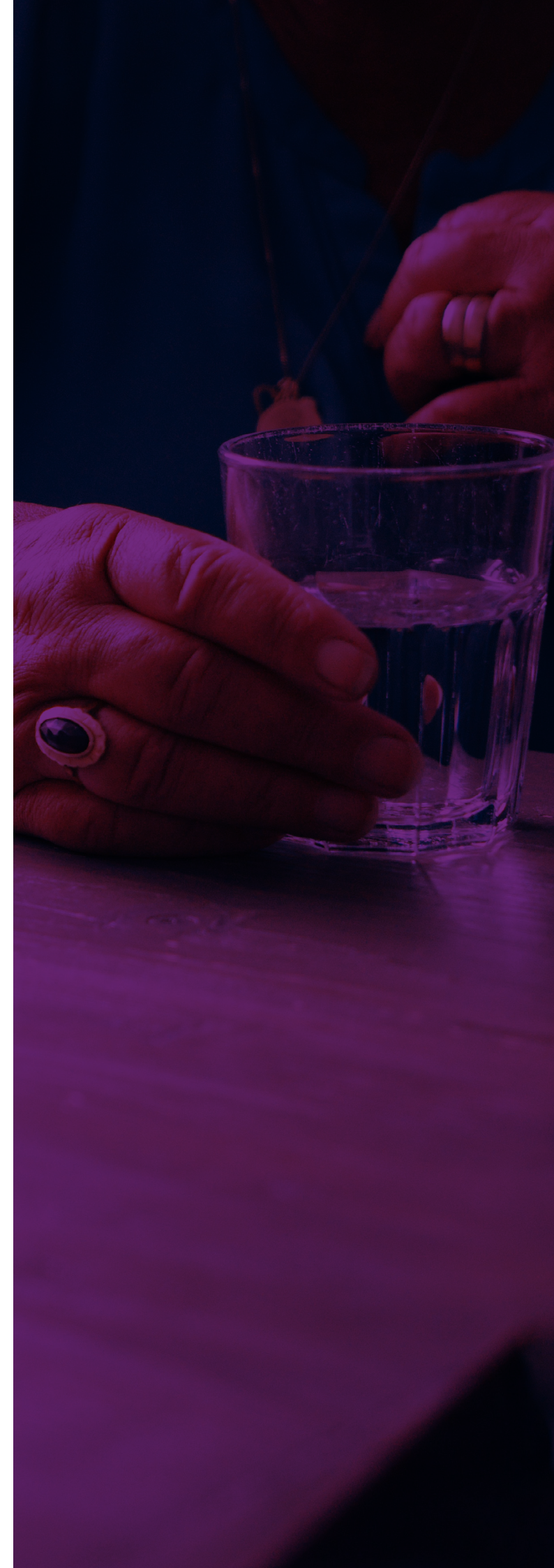
Working with the people who have had these experiences, we distilled these key themes into a number of co-produced statements – which we call I Statements – which include basic, reasonable requests like “I am listened to and what I say is acted on” and “I make decisions that are respected, and I have rights that are protected.” But we know that though reasonable, within the context of the current extraordinary pressures on the NHS, meeting these needs nevertheless mounts a considerable challenge. Restarting core services while managing COVID-19 puts the system and the people who work in it under immense strain. We have heard clearly that people understand the unenviable task before healthcare providers, and acknowledge that they may have to wait longer for care.

At the same time, we also believe that by responding to these I Statements in the ways we suggest, system leaders and healthcare providers alike could alleviate some of the negative consequences of the COVID-19 crisis. By contrast, ignoring people's needs will result in their health deteriorating and much higher costs down the road. Plus, though meeting the needs expressed in these statements may not be easy, if the NHS and other public services can address the concerns of those hardest hit, then they are much more likely to get it right for everyone in the process. Finally, responding to many of these I Statements can in fact be free and easy – it just involves tailoring basic care practices to the current context.

For example, listening to someone right now means asking them how they are in this moment, what their experience has been like, acknowledging how hard it has likely been, and how traumatised they may feel. So, it's just a different way of structuring a conversation a healthcare professional would and should be having with a patient anyway.

With that in mind, we also wanted to make these I Statements useful and practical to those leading the system, as well as those designing and delivering health and care services. We have identified some concrete actions that everyone in charge of health and care services could take to address the needs expressed in these statements – things like “Design services that keep people as safe as possible while ensuring access to the widest possible range of services” and “Ensure that respect for people's rights are at the centre of any service changes.” For service providers, we suggest “Always explicitly ask people what they think they need now” and “Be clear about what choices people have in the current context.”

We believe we can – and must – ensure that the reality of healthcare lives up to the rhetoric of a service that provides free and equal access to high quality care for all. All of us have a role to play – whether in Government, national health agencies, regional integrated care systems (ICS), local authorities, primary care networks, trusts or as individual health or care professionals, patients or their representatives. We would value opportunities to discuss with service and system leaders and providers how these outcome statements could be used to improve how health and care are delivered to people who need them during this pandemic.





1. I am listened to and what I say is acted on



In a modern democratic society, it is a basic right to be listened to and for what is heard to be acted upon. The reciprocity of relationships between citizen and government, between consumer and producer, is something we receive in many day-to-day parts of our lives. It is important in healthcare too.

Being listened to is more than just being heard. It is an expectation that the service will act on the experiences and needs expressed by the service users. It really is not unreasonable. People need to feel listened to by health and social care professionals, family and friends, the general public and the Government.

During lockdown many people reported losing skills, confidence and independence. Health and care professionals must recognise the impact lockdown has had on people, particularly (but not only) on people's mental health.

If people who have long-term experience of ill health lose their independence, they need much more from services than they did before.

People's experiences also need to be listened to, learnt from, and highlighted by all decision-makers so that decisions and communications are based on what people actually need and want. There is strong evidence from people that *"I don't think they've talked to people about how it feels"*. *"How can they know what we need if they're not hearing from us?"* Health care providers need to learn from people's experiences and *"take the initiative to join up care around each person"*.

There needs to be closer collaboration between the Government, health and social care professionals and charities who understand the groups they represent and support. *"Vulnerable people' are being lumped together in the same category, even though there is a huge variety of conditions within us and no tailored information regarding specific conditions"*. When at the start of lockdown, two million people were labelled as *"Extremely Clinically Vulnerable"* and in need of shielding, all of these people were seen within that one label. In reality, there were many very different experiences, which services need to learn from. They need to be actively inviting feedback to learn and help improve experiences for others.

What you can do:

Those designing services	Those delivering services
Always involve those using services in decisions about service changes. That means not just asking people but thinking through what they have said when designing a service. Often leaving patients out of the design of the service leads to a waste of resources.	Always explicitly ask people what they think they need now – in the current context of ongoing change. Have their needs changed? What is most important now? How does what I am being told change how I deliver these services?
Explicitly address concerns, even if you cannot always resolve them. Sometimes resources don't allow you to design what you see people need – be honest about that.	Make it clear how you are addressing their wishes, even if you cannot always meet all of them. Be honest about what you are able to deliver.





2. I make decisions that are respected, and I have rights that are protected



② I make decisions that are respected, and I have rights that are protected

People who have been ill for a long time can be made very passive by the long-term experience of their illnesses. Yet all medicine knows that the more active people are the more likely they are to regain more health. The NHS and social care need active independent people to work with in combatting ill health. That is the main reason we need to respect the decisions that people make about their lives.

*"We aren't truly respected with our decisions if they are playing choices with our life".*

The COVID-19 world is one of new trade-offs. Everyone needs to make difficult decisions that are right for them. And they are different for different people. For example, just because someone makes a considered decision to see their grandchildren, does not mean they feel safe shopping for groceries or using public transport. For vulnerable people the act of 'going out' is very different for different activities.

Shielding for millions of very different people was turned on on March 23<sup>rd</sup>, 2020 and meant no one could go out. And then turned off on August 1st, 2020 and meant everyone could go out. For many of those who are vulnerable, the end of shielding was extremely scary and daunting. Some people made the decision to continue shielding. People need something in place to protect their decision to continue to shield if they are at higher risk. For example, having legal protection in place if someone cannot go back to work due to travel, work environment or type of work.

People need clarity around what realistic 'choices' they may have, who is responsible for safety or adaptations, how they should notify people about this, and to be respected for the decisions they make. They need discussions and shared decision-making with health and social care professionals who then act on their choices.

*"Freedom to make a decision depends upon other people's behaviour, and that's not being emphasised to people in general, thus reducing our choices as shielding people".*

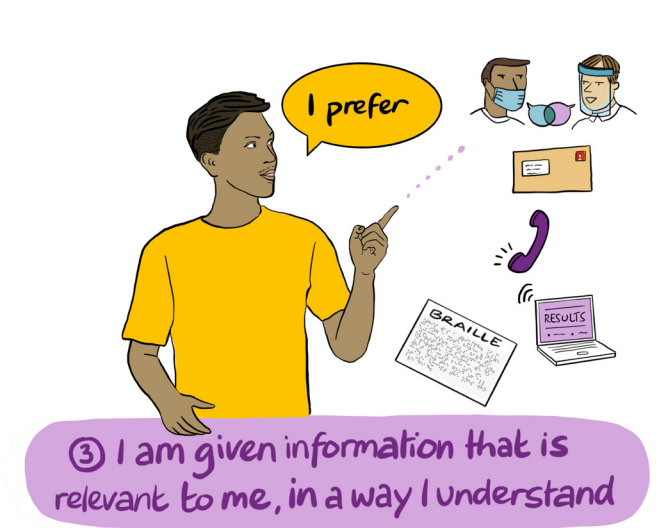
One person's freedom is another's risk. For example, not physically distancing or wearing a mask puts an even bigger risk on people in the 'shielding' category. It is important for the general public to be aware of the risks on people who are deemed as 'vulnerable', as the responsibility sits with them too. Using enforcement and clear communications can *"prevent those of us shielding having to depend on bad decisions of others"*.

What you can do:

Those designing services	Those delivering services
Carefully consider whether it is necessary for public health to limit people's choices in the current context, weighing up the potential harms to their physical and mental health. Ensure that the service you are designing can recognise and work with the very different conditions of those seen as Extremely Clinically Vulnerable.	Be clear about what choices people have in the current context, explain and justify why choices may be limited, and tell them about the potential benefits and harms of their options. This will enable people to make informed decisions about what is right for them.
Ensure that respect for people's rights – deriving from the NHS Constitution and human rights frameworks, especially to fundamental human dignity, to family life, and to equality and freedom from discrimination – is at the centre of any service changes. These rights are the ones that you would expect to be recognised for yourself and your loved ones – they are vital for everyone.	Do not assume that you know best, ask what choices people value and expect to make. Always respect people's rights. Think very hard before you override a decision that has been made by a patient. Do you have the right to do that?



3. I am given information that is relevant to me in a way I understand



Given the very high level of anxiety, many of the 15 million clinically vulnerable people decided they too should shield. To live their lives with less fear, people need accurate information about their circumstances, accompanied with honest conversations. *"Generalised information is not helpful. The information that I need for my life is very specific."*

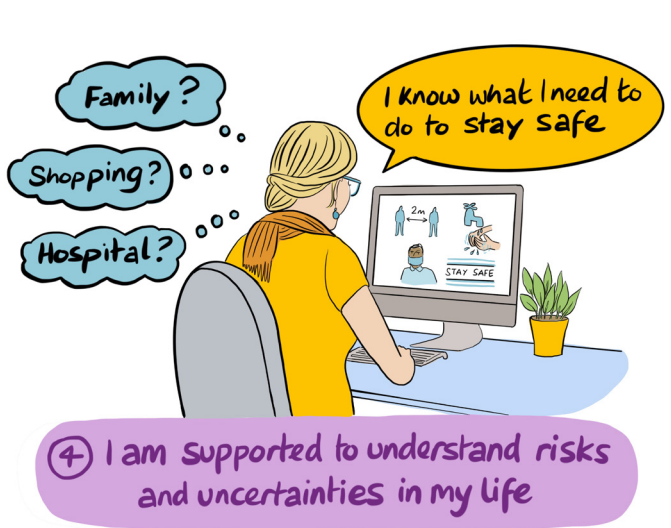
Where information is provided, it needs to be consistent and in a usable format for everyone. Online information and advice have worked well for some people, but it does not work for everyone. People understand and accept the challenges facing health and care, but there is a persistent problem with poor information, a lack of personalised advice, and 'failing admin' that layers stress and anxiety onto already difficult circumstances.

For weeks and weeks, over two million extremely clinically vulnerable people – in all of their glorious diversity – were given the same single piece of information: "Stay at home".

What you can do:

Those designing services	Those delivering services
Develop and provide clear, accurate, evidence-based, up-to-date information that allows people, patients and communities to become better informed and more involved in their health and care. The design of the service must take into account that delivery takes place with diverse individuals.	Check that people have understood the information provided, and have an opportunity to ask questions, and engage in open conversations, which take into account their personal circumstances. Expect people to be very different from each other because they are.
Ensure that information is provided in accessible formats, including easy read and community languages/BSL, in keeping with the principles of the NHS Information Standard. Remember that information that is not successfully communicated to people doesn't really matter.	Be prepared to answer any additional questions and to acknowledge the limits of your knowledge or of available evidence. Make sure you hear the question people ask as they are leaving the room.

4. I am supported to understand risks and uncertainties in my life



They need help in deciding how to make 'trade-offs', particularly once shielding is paused. Research on 'informed risk' and 'informed consent' needs to be understood and then put into practice through clear guidance and discussions with health and social care professionals. Professionals need the resources, knowledge and understanding to support people to individually assess risk – what can reduce someone's risk based on their circumstances and what kinds of risks are there? For example, should the physiotherapist come into the house? How often and long will they be coming? Will they be in protective gear? How might developments like local lockdowns affect these risks? What is the risk to me of not having the physio?

However strong the Government advice, the pandemic has shown that day to day decisions made by millions of people are what matter. People need information and support to understand the risks that apply to them.

What you can do:

Those designing services	Those delivering services
Ensure that the latest personalised risk assessment information and information about informed consent and tools are available to those delivering services.	Provide people with information about risk in a way that is personalised to their condition, age, ethnic group, employment situation, and any other relevant risk factors. Make sure people understand what you are saying.
Ensure that information about risk is communicated in terms people understand, in absolute terms, and compared to other risks they take. Acknowledge uncertainty about risk in communications.	Communicate information about risk in absolute terms, not relative terms (i.e. "the risk is 1 in a million" not "this doubles your risk"), and using comparisons that people can readily understand in relation to other risks they are used to taking. Everyone takes risks in their live all the time. Make sure the risk you are talking about is understood in terms of the everyday risks that people take. Acknowledge uncertainty about risk openly and honestly.



5. I know how to talk to the person or team in charge of my care when I need to



⑤ I know how to talk to the person or team in charge of my care when I need to

To understand someone’s specific conditions and needs, people need a professional with clinical expertise and a holistic view, along with access and time to read an individual’s notes. Getting the same letter from the Prime Minister as everyone else is helpful but having a conversation with your own primary health care team is much more important.

*“We have a right to have a conversation*

*with someone in the NHS on our particular condition – conversational support that makes a one-to-one difference”.* The professional needs to be able to provide informed advice and help to discuss risks through shared decision-making. *“Before COVID-19, personalised care was beginning to take root. That’s now reverted. People have a role to play in looking after their own health”.* Most NHS and social care is very fragmented. Over the last few years some moves towards person-centred, coordinated care has taken place, but the pandemic appears to have derailed much of that progress.

People do not want to be *“chucked from consultant to consultant”* as this will create more delays and potential anxiety for that individual. There is an understanding of the increased workload for specialists, so in addition, having a support worker or social prescriber to check in and see how people are doing could also help.

What you can do:

Those designing services	Those delivering services
Agree who is the person in charge of coordinating care for each person. Ensure that everyone involved in NHS and social care knows who that person is and works through them.	Explicitly tell the person you are caring for how they can contact the person in charge of their care, and when that coordinator is unavailable, who to contact and how.
Make sure the care coordinator knows who else is involved in that person’s care, and that they have straightforward ways of sharing information with each other.	Be mindful of the anxiety created by being passed around different care providers, especially when someone deteriorates or enters a crisis. Crisis care needs as much coordination and day by day care.
Strive towards continuity of care, in recognition of the well evidenced positive outcomes.	Strive towards continuity of care, wherever possible.
Be mindful that most of the week happens to be ‘out of hours’.	Ensure that the patient knows who to contact for their ‘out of hours’ service.

6. I know what to expect and that I am safe when I have treatment and care



⑥ I know what to expect and that I am safe when I have treatment and care

Millions of people identified as vulnerable were told to stay at home or take significant precautions. They repeatedly saw and heard health and care services, particularly hospitals, identified as the most dangerous places to be. These daily media communications left most people very afraid to go to any NHS setting even when they really needed medical help.

To unwind this fear will take patience and a lot of care from those who design and deliver services.

*“Keep me safe when I come in”.* People need reassurance that everything possible is being done to help keep them safe. *“I need to know I am safe because I need to go back home to my family”.* Health and social care professionals need to explain the process of attending a GP or hospital appointment safely in advance (including how to ‘sign in’, where to wait and what equipment will be provided).

It is important for people to be informed and prepared, through clear guidance prior to an appointment. Personal Protective Equipment (PPE) needs to be available for patients and unpaid carers, as well as professionals, and people should have a right to have a carer or a loved one attend an appointment with them.

What you can do:

Those designing services	Those delivering services
Design services that keep people as safe as possible, while ensuring access to the widest possible range of services.	Assume your patient will have concerns about their safety and ensure this is reflected in all communications with them. Recognise that you will have to spend time and effort persuading people that you have made their services as safe as possible.
Develop accessible communication that outlines the safety protocols that you have put in place.	Always explain in simple terms what measures you have put in place to keep your patient safe.
Recognise that some people will choose not to engage with the service because they do not think it is safe, or worth the risk, and decide how you will support those people so that they are not abandoned.	Be prepared to answer any additional questions.
Ensure that what you tell your patient about how you are keeping them safe and delivering services mirrors the reality of arrangements on the ground.	Where possible, make arrangements for treatments to be delivered at home or as close to home as possible.

# 7. I am supported and kept informed while I wait for treatment and care



⑦ I am supported and kept informed while I wait for treatment and care

Large sections of health and care activity may have paused, but people’s lives and their need for care haven’t.

Coming out of lockdown, people need to feel like they are no longer in a “state of limbo” through cancelled or postponed treatments and appointments, with no follow-up support for current or new diagnoses. *“I feel like I’ve been dumped”*. Given the millions of people involved, the lack of support for non-COVID-19 conditions is not good enough, and there are concerns around how and when services will resume. Clearer, open and more frequent two-way communication is needed for both the individual and the person supporting or caring for them. Service providers need to be more transparent about when services will recommence, what this will look like and how they will manage their lists and any backlog. Support and guidance available for mental wellbeing and maintaining people’s skills and confidence needs to be more prominent with a clear route of where people can get support.

## What you can do:

Those designing services	Those delivering services
Given waiting times have and will increase, use insights gained from recent research on the experience of waiting to co-design a better wait.	Keep people up to date, by acknowledging receipt of referral, and check in during the wait.
Plan how you will keep people informed about their place in the queue, when they can expect treatment, about the appointment/procedure and what to expect/how to prepare. Plan to keep everyone regularly up to date.	Tell people who is in charge of their care while they wait.
Help people understand how you will make decisions about waiting, what the wait for your service is like and what might change.	Given the anxiety caused by the length of waits, offer or signpost people to other sources of support, including to peer support and self-management.
Plan how you will put people in contact with sources of support while they wait.	Tell people how to contact you if their condition deteriorates.
Continue to monitor the experience of waiting and make improvements over time.	Provide support and signposting for carers and family members.

# 8. I am not forgotten



⑧ I am not forgotten

*“I feel totally isolated. I feel abandoned”.  
“I want to just be considered. I feel like shielders are being left behind”.*

For many vulnerable people their experience of lockdown was one of being abandoned by services. In the future, people need the appropriate access to support to be able to look after their health and wellbeing and keep safe from COVID-19.

## What you can do:

Those designing services	Those delivering services
Make sure that the services you are designing regularly engage with those people who have ongoing health and care needs as you make changes to services – codesign and coproduction should be at the centre of all service design.	Ask people how they are feeling emotionally and mentally, recognising that if you fail to contact them, they will feel forgotten and abandoned.
Provide more frequent, consistent and targeted information and communication for people who are especially vulnerable to the virus.	Signpost people to sources of psychological, emotional and practical support, including peer support.
Increase access to trauma-informed care to better support people’s mental health needs.	Integrate trauma-informed approaches into your service delivery.

People with ongoing health and care needs must not be forgotten. Their voice needs to be heard. There needs to be more frequent, consistent and targeted information and communication for people who are especially vulnerable to the virus (from the Government and health and care services), better support for their mental and physical health needs, further inclusion in the ‘shielding’ list, and provision of ongoing support and protection during the pausing of the shielding programme.

There needs to be recognition of and support for the many groups of people who have been excluded including, but not limited to: those who are shielding on behalf of someone, disabled people, blind or partially-sighted people, people affected by dementia, people with endometritis, people who cannot physically communicate, young shielders and young carers, children and siblings. *“We need to listen to families, unpaid carers, the ‘forgotten’”.*

## What system leaders can do

- Recognise that both those working in and those using health and care have been through at times **traumatic experiences**. Acknowledge this, and people's tiredness and anxiety in your communication.
- Be mindful that the heaviest burden of service cuts, and loss of support has been felt by people whose lives are already made more difficult through poverty, racism and **inequality**. Focus your efforts on those who have the worst outcomes.
- Stay **focused** on the things that people say matter to them. This is largely **not** about how national bodies divvy up their responsibilities or who heads up which programme.
- Allow the service to stay focused on what matters by **measuring what matters** and by reducing the background noise of constant change and ever more asks.
- Realise that changing one thing in health and care impacts everything else. Primary, secondary, emergency and social care – they are all part of the same **system**. Distinctions between them make no sense to people with substantial needs.
- Ask questions about the **interfaces**: How do mental and physical health need to be connected? How do health and care need to work together? How can medical and non-medical needs be met?
- Allow the service to work with communities and patients, users or families to find solutions – this will mean **solutions might look different** in different places.

## Conclusion

These statements express people's reasonable expectations of healthcare. Most would see the demand to be listened to and have one's decisions respected as basic tenets of normal healthcare. We believe the power of these statements lies in the fact that they are truly reflective of what people with significant health and care needs said they needed and wanted. We also hold that their simplicity, their self-evident realism and the pragmatism they therefore inspire demand an equally practical and grounded response from system leaders, and everyone tasked with designing and delivering health and care.

As we work with system leaders on the restarting of support for people living with ongoing ill health or disability, we hope they will use these statements to test their proposals and to develop arrangements that focus on tangible outcomes people care about: being heard, being helped to cope, being enabled to make sense of risk and options.

We at National Voices stand ready to work with system leaders, service designers and health and care professionals to realise the ambitions expressed in these statements. The profound sacrifices people have made to bring the pandemic under some degree of control and to enable acute care for patients with COVID-19 to be possible demand nothing less: we can honour their experiences by acting on them.



***“This is a timely and welcome report that should be essential reading for all leaders in the health and care system. Listening to people’s feedback and good engagement, particularly with the people delivering and receiving services, results in better outcomes. This report will help inform our next steps in terms of our Partnership principles and priorities during the pandemic.*”**

***We have recently developed a series of our own I Statements based on National Voices methods. These complement this new report and shows how much the organisation has changed the way Partnerships such as ours are working.*”**

Rob Webster, CEO Lead for West Yorkshire and Harrogate Health and Care Partnership and CEO for South West Yorkshire Partnership NHS Foundation Trust

***“As a jobbing GP in a very diverse and also deprived part of London, I am aware that the pandemic has impacted some people more than others. We need to pick people up where they are, and need to support them with tailored conversations. The work National Voices has done in convening people to talk about their needs, and in translating their expectations into things we as health professionals can actually do, is very valuable.*”**

***The I Statements and recommendations can help us as professionals in the way we work, for example by talking about physical and mental health as part of the same picture.*”**

Dr Farzana Hussain, Senior Partner,  
Project Surgery Plaistow and GP of the Year



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