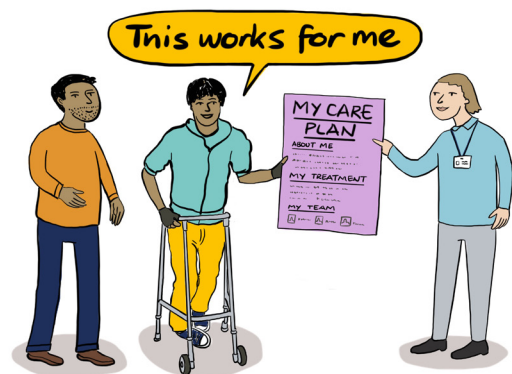


# What We Need Now

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

# The new I Statements



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

### 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.



## 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 1<sup>st</sup>, 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"*.



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

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

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”. 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.



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

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

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. 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?



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.

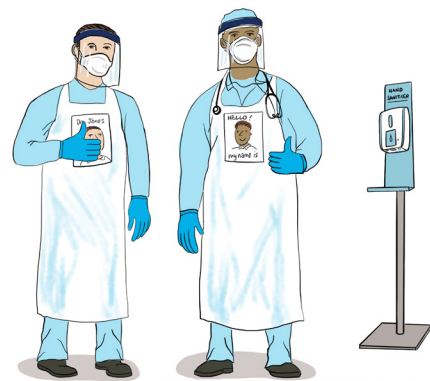
*“We have a right to have a conversation with someone in the NHS on our particular condition – conversational support that makes a one-to-one difference”.*

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.





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.



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.



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. 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 endometriosis, people who cannot physically communicate, young shielders and young carers, children and siblings.

*"We need to listen to families, unpaid carers, the 'forgotten'".*

***“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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