

Recommendations

October 2020

What We Need Now

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

We know that though reasonable, within the context of the current extraordinary pressures on the NHS, meeting the needs expressed in National Voices' new I Statements nevertheless mounts a considerable challenge. Restarting core services while managing Covid 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 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 always 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.

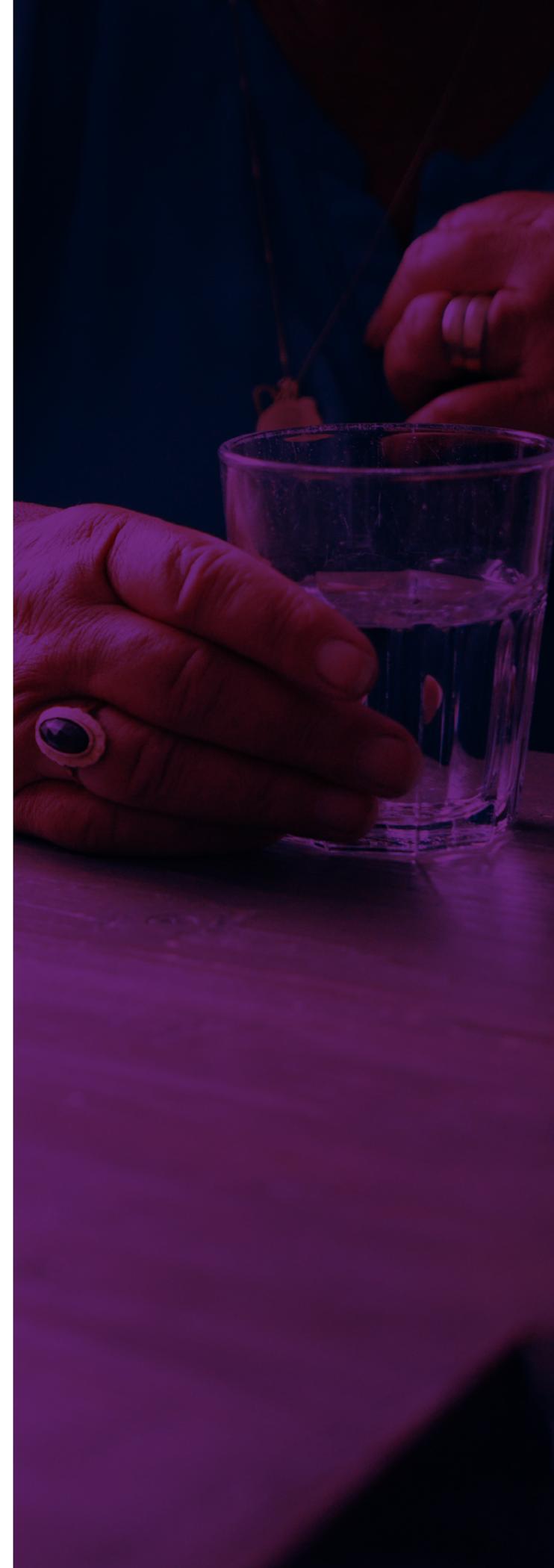
For example, listening to someone right now means asking them how they are in this moment, what their experience has been like, acknowledging how hard it has likely been, and how traumatised they may feel. So, it's just a different way of structuring a conversation a healthcare professional would and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

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.



What those designing and delivering services can do

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

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

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

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

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 lives 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

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

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

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

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.

“ 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