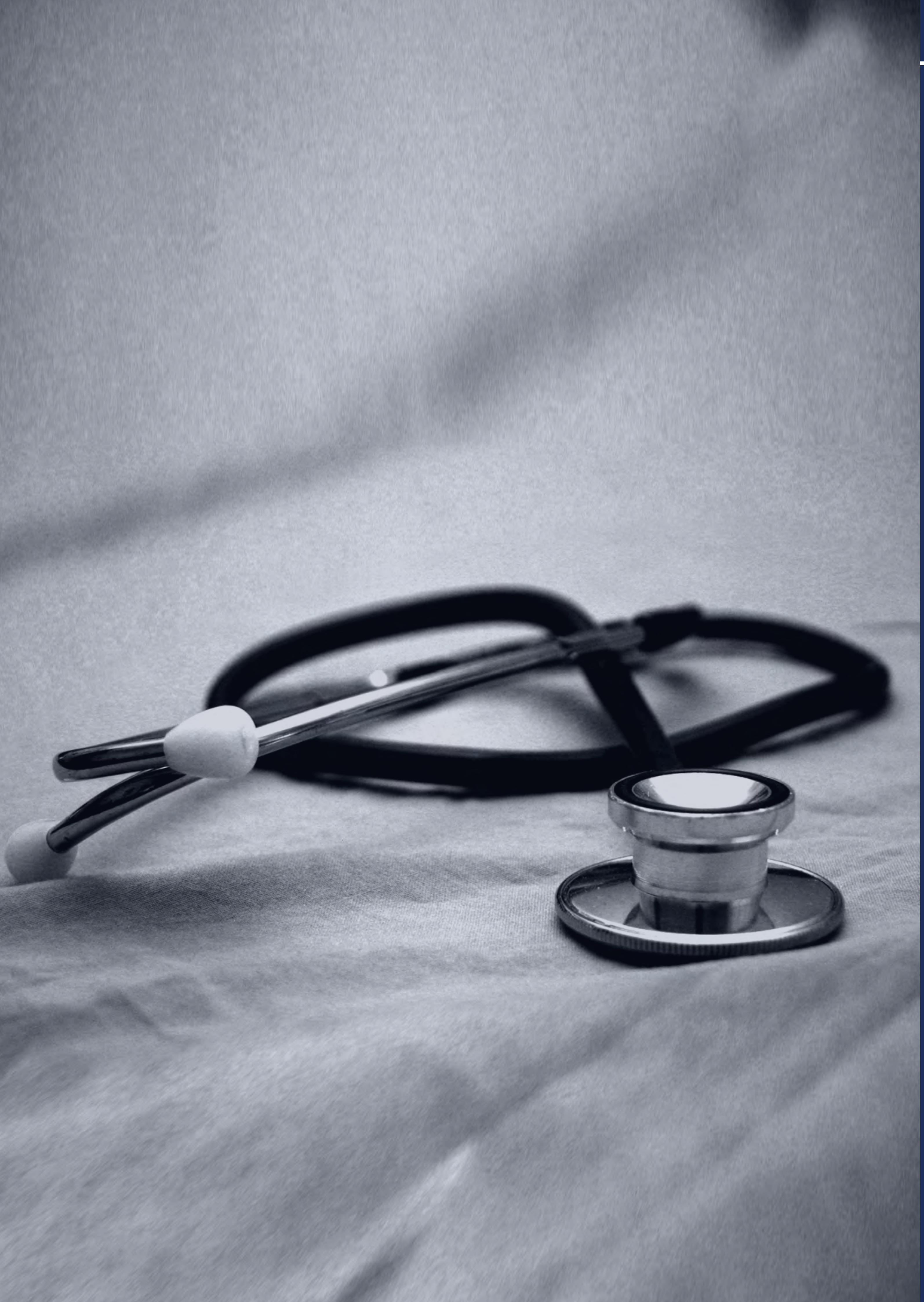
What We
Need Now

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

National Voices



This report was researched and written by Chloe Reeves, a brilliant health and care policy consultant we would thoroughly recommend to others who need input from a down to earth, hard-working freelancer who writes beautifully.

Paul Corrigan inspired the idea of refreshing our original I Statements, for which a heartfelt thanks.

The report is based on the work we did throughout the first phase of the pandemic to capture the experiences of people with ongoing health and care needs, through **OurCOVIDVoices**. This platform was developed by **AYUP**, a tech-for-good digital agency in Leeds, at very little cost, and breakneck speed. We couldn't have done this development without the generous input from Mark Brown from **Social Spider**, building on work the Hearing Voices Network had already done around story telling.

The I Statements were brought to life by illustrations done by Sandra Howgate.

The whole National Voices team (including our short-term communications consultant Dan Watson) supported the development and running of OurCOVIDVoices. We also had support from a volunteer filmmaker, Adam Perry, and a volunteer marketer, Maya Anayokar – thank you. Tash Howard volunteered to help run the focus groups and to make sense of what we heard. Sam Thomas volunteered some time to help us understand what we had started. Most amazingly, Laura Porro was enabled by her employer, the social enterprise **PPL**, to give two days a week to this project pro bono. We could not have done this work without her steady, calm and brilliantly organised leadership. We are so grateful to all of you.

Thank you to the Health Foundation, without whose financial support this project would not have been possible.

Finally, we want to thank all the people who told their stories on OurCOVIDVoices and who contributed to our focus groups. Your generosity of spirit has shaped the way we see the world already, and will do so for months and years to come. We will never forget what you told us.

Thank you.

Professor Donal O'Donoghue
Registrar, Royal College of Physicians

The NHS constitution puts people at the centre of all that we do. The patient is the most important person in the room. They are the expert in how they perceive their condition, how it affects and limits what they can do. The clinical encounter should therefore be a meeting of experts, a meeting of equals. But this is not always the case.

The I Statements distilled by National Voices provide powerful insights for health and care services. They constitute a framework that can be easily adapted to help us meet patients as equals and deliver what they need.

The I Statements will help us become better attuned to the voices of all our patients. As a result, we will have a greater understanding of their concerns, of how their conditions are affecting them and what their personal health and care needs are.

But being heard is more than being listened to. The statements bring the individual into focus, many of whom have multiple conditions that overlap and often compete in the way we as clinicians and health services currently care and treat. From this perspective, how the service user feels, how they experience their conditions and how they impact their lives, should shape the way care and holistic pathways are developed.

These statements are reasonable requests. They support efficient and effective delivery of equitable, high-quality care. So they should be acted on now, not put to one side until after the pandemic has passed.

National Voices has developed concrete recommendations for those designing and delivering healthcare services – so that's all of us! Patients and carers, managers and health system leaders, health and care practitioners. Acting on them will be a COVID-19 innovation that will help both now, and as we rebuild our health and care system.

Cherelle Augustine, Sickle Cell advocate and Co-Founder of Broken Silence Charitable Organisation

'It's your job but this is my life'

Right now, as the pandemic continues, I manage the best that I can. Living with Sickle Cell means I'm used to managing myself and my condition. I've noticed that the way my body is and the signs and symptoms I have are changing. Even though Sickle Cell is unpredictable, it still catches me off guard when I have an unexpected change to my normality.

I'm living with more pain whilst working out how to keep myself safe and still see family and friends and continue to work. It makes me anxious to think about the future. As somebody living with a long term condition, I am often caught between systems that either ask me to prove how unwell I am to get support or tell me I am not well enough to participate in society in a way that will enable me to maintain my quality of life. It's exhausting to frequently be in limbo.

I fully endorse this report. 'What we need now' is what we have always needed. Governments and policies change but the need to be respected and listened to does not change. I live with my condition every day and want to share my perspective in the care and treatment I get so that I feel mentally and physically well and can get on with making the best of life.

I'd encourage healthcare workers, patients, and their carers to use the 'I' statements as a shared place to start from. If we get stuck or are not sure what to do, these statements will ground us in what really matters. Make this the constant. Even after the virus becomes a distant memory, these statements will remain relevant and will help all of us move forward in creating quality of life for all.

Contents

Introduction

This report summarises how National Voices engaged with people who have ongoing health and care needs during the first phase of the pandemic and how this engagement led to a set of statements that describe what people who use health and care services now expect these services to look and feel like.

What we have found is that some needs and expectations are a constant, and do not change very much – whereas others need to be brought into the context of the ongoing health crisis caused by COVID-19.

Some years ago, National Voices set out to describe what good health and care look like from the service user perspective in a set of I Statements. These statements were widely used in training and service redesign efforts because they cut through much of the jargon and system blinkers that limited the effectiveness of ambitions to make health and care work better for people. We hope this new set of statements we have developed in light of the COVID-19 pandemic will help inform the restarting of health and care services in the same way. With severely restricted resources, and access to timely care remaining a problem for the foreseeable future, focussing on the things that really matter to people is more important now than ever.

What is OurCOVIDVoices?

The arrival of COVID-19 made everyday life feel very different. Health and care services were being delivered differently, if at all – many services stopped altogether. People's ability to take part in their communities and to see friends and family was severely limited. Everything from food shopping, to home care, to doctors' appointments changed. National Voices is convinced that we needed to capture the experiences of people with ongoing health and care needs throughout the first phase of the pandemic. With the relentless focus on people needing COVID-19 care, we had a sense that the lives of people who still lived with dementia, depression or diabetes were at risk of being forgotten. We also had a sense that people who didn't live with ill health or disability in their everyday lives didn't and maybe couldn't fully appreciate how difficult some people's lives had become and how vulnerable some people felt. This included those people charged with making decisions for all of us. We felt that the experiences of people whose health, care and lives had been most disrupted, needed to be taken to decision making rooms. And so we did.

That is why we launched OurCOVIDVoices – a project to collect first-person accounts of living through the 2020 COVID-19 pandemic.[1] We wanted to share with the world how people with long-term conditions, disabilities and other health and care needs are living during the pandemic. We wanted to use the insight people gave us to influence decision-makers to do better. It is in the blind spots where the harm occurs. We want to reduce the size of our collective blind spots.

What are the I Statements?

A few years ago, National Voices did a lot of work to explain – in easy to understand terms – what good, coordinated and person-centred health and care actually means. They worked with people who use services and their carers to develop what became known as I Statements – an explanation of what this all means from an individual perspective [see Appendix A].

These I Statements were published by the Department of Health (as it was at the time) in their Integrated Care: Our Shared Commitment,[2] which set out how local areas could use existing structures (like Health and Wellbeing Boards) to bring together local authorities, the NHS, care and support providers, education, housing services, public health and others to make steps towards integration.

As well as providing a coherent[3] explainer to people working within 'the system' of health and care, the I Statements helped people accessing health and care services know what they should expect. The aim was to empower people to challenge the system if it fell short of what good looks like.

While the I Statements describe what good health and care look like for all, the way 'the system' realises this will inevitably look different for different people. There is a gradient of inequality that needs to be understood and addressed if people from all backgrounds are to be able to say, "The I Statements describe my experience".

There are also parts of 'the system' where the gap between what good looks like – as described by the I Statements – and people's experiences of health and care is particularly pronounced. Since the original I Statements were launched, National Voices has developed some short supplementary I Statements that aim to help people working in and making decisions about health and care understand and close these gaps. These include end-of-life care, older people's care (particularly as people transition across the clunky divide between services for people under-65 and 65+) and care in acute mental health settings.

Some progress has been made towards realising the I Statements, but we have a long way to go.

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1. https://ourcovidvoices.co.uk/
2. www.gov.uk/government/publications/integrated-care
www.nationalvoices.org.uk/sites/default/files/public/publications/narrative-for-person-centred-coordinated-care.pdf
3. Signed up to by 14 organisations, including the Department of Health, NHS England, NICE, CQC, ADASS, PHE and TLAP – the first time there was agreement about what good looked like.

AIMS AND OBJECTIVES: What did we want to do? What questions did we want to answer?

We decided to look together at the experiences people told on our platform, and at the I Statements, since these were developed some years ago. We wanted to understand whether a collection of experiences told on OurCOVIDVoices could be translated into a set of expectations that describe what people say they now need, and whether the I Statements we already had needed to be changed, updated or complemented.

Ultimately, National Voices exists to make what matters to people matter across health and care. This work tries to do this during the extraordinary context of a worldwide pandemic.

METHODOLOGY: How did we answer our questions?

Our report summarises findings from the first 50 personal accounts that people have shared through the OurCOVIDVoices website, with the analysis taking place during the week commencing 8th June 2020.

We used a combination of QDA Miner Lite (qualitative data analysis software)[4] and manual thematic analysis. Using a software package allowed us to handle large amounts of data, to code that data and to then efficiently search and retrieve relevant chunks of data. However, we did not want our analysis to be led by software, we did not have the resources to ascribe extremely detailed coding, and we did not believe that doing so would be worth the investment.[5] We therefore depended as much (if not more) on manual analysis as on analysis using software.

The personal accounts were analysed verbatim, except for one story, which pointed readers to an interview they had already given to a national newspaper. The first-person quotes were extracted from the original article and included in our analysis.

Our thematic analysis used a combination of deductive (pre-determined) and inductive approaches.

Variables

- **Date.** *Date created.* Where personal accounts were cross posted from other sources, their original posting date was recorded rather than the date that they were added to the OurCOVIDVoices website, thereby allowing us to understand any chronological patterns.
- **Location.** *East Midlands; East of England; Greater London; North East; Northern Ireland; North West; Not stated; Scotland; South East; South West; Wales; West Midlands; Yorkshire and the Humber.*
- **Setting.** The primary setting of the personal account. *Not stated; At home; Care home (residential or nursing); Hospital; Other community setting; Supported or extra-care housing.*[6]
- **Age.** As people have provided information in different formats with regard to age, we have used age bandings that represent the key transition points with health and care services. *Adult 18-64; Adult 65+; Child <18; Not stated.*
- **Gender.** *Female; Male; Not stated; Other.*

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[4] https://provalisresearch.com/products/qualitative-data-analysis-software/freeware/

[5] See for example, Taylor B, Henshall C, Kenyon S, et al. Can rapid approaches to qualitative analysis deliver timely, valid findings to clinical leaders? A mixed methods study comparing rapid and thematic analysis. BMJ Open 2018;8:e019993

[6] We recognise that care homes, support housing and extra-care housing are people's homes, but for the purposes of understanding the impact of COVID-19 and responses to the pandemic on people's lives and experiences, we have separated these out.

- **About Child.** Enabling us to separate personal accounts of caring for children with health and care needs, from personal accounts written by children. *No; Unclear; Yes.*
- **Carer.** A carer is someone who provides support to family or friends who could not manage without this help. This could be caring for a relative, partner or friend who is ill, frail, disabled or has mental health or substance misuse problems. All the care they give is unpaid. *Author is a carer; Author may be a carer; Author has a carer; Author may have a carer; Not stated/Unclear.*
- **Shielding.** Identifying personal accounts that are written by people who are shielding. This enables National Voices to distinguish these from wider experiences of and reflections about shielding (e.g. that are shared by carers, neighbours and people reflecting on COVID-19 responses in general). *No; Not stated/unclear; Yes.*

Deductive framework

In the first instance, we used the headline themes and associated code definitions developed by the North West London Health and Care Partnership in their Community Voices project to capture the impact of COVID-19 on Black, Asian and Minority Ethnic (BAME) communities and frontline staff in North West London.

Within the National Voices team, we have considerable knowledge and experience of advocating with and providing services to people and their carers, and of working with others, including our Members, to do the same – including during the COVID-19 pandemic. These themes and associated code definitions, which have already been successfully used in a similar project, resonated with us and provided a useful foundation for our analysis. In alphabetical order:

- **Childcare.** Other aspects not covered within relationships. Including: views and experiences of home-schooling and returning to school; views on having children at home, e.g. techniques to manage this and impact on household.
- **Dealing with and managing death.** How are [non-frontline] people dealing with and managing death and the related processes during COVID-19? Including: dealing with COVID-19 related deaths; dealing with non-COVID-19 related deaths; and experiences of funerals.
- **Domestic violence.** Anything related to the impact of COVID-19 and related measures on domestic violence. Including: impact on domestic violence; and support/help received.
- **Employment.** The impact of COVID-19 and related measures on people's employment. Including: gain or loss of employment; experiences of furlough; treatment by employers; impact on employment, e.g. going to work. We added experiences of volunteering to this definition.

- **Financial issues.** The impact of COVID-19 and related measures on people's financial health. Including: considerations of debt; benefits; rent and mortgage payments; loss of wages; impact on life and family; and approaches that people are taking to increase their finances.
- **Housing.** Anything to do with housing, housing payments and conditions during the pandemic and related measures. Including: overcrowding; outdoor space; multiple occupancy; and tenancy issues.
- **Mental health.** The impact of COVID-19 and the lockdown on people's mental health. Including: finding and getting support; managing existing mental health issues; and coping strategies.
- **Relationships.** Anything to do with relationships with friends, family, partners [cohabiting or not], including challenges, but also ways to cope and new approaches to relationships. Including: impact on family relationships; impact on children and relationships with children (e.g. visitations); impact on romantic relationships; impact on life with extended family; and impact on friendships.
- **Sources of information and understanding.** Where people are finding information about COVID-19 and related measures and what they understand. Including: understanding about COVID-19; understanding about lockdown measures, including shielding; getting information from different sources; and understanding Government decisions.

We did not adopt the North West London Health and Care Partnership codes relating to the experiences of frontline staff, as this is not a perspective captured through OurCOVIDVoices. We also developed an inductive framework, as we felt the deductive framework could limit in-depth exploration of the data and theme development.[7]

Inductive framework

The National Voices Associate leading the review of the I Statements spent time reading the personal accounts and familiarising herself with the data. She generated a first version of the coding scheme and then grouped the codes into relevant themes. The generated themes were then checked against the data to ensure they were consistent with all the data set. A provisional thematic map was generated, and these initial themes and their definitions were presented to and discussed with the rest of the team. Following this, a final version of the themes and definitions was created:

- **Experiences of shielding.** Anything related to people dealing with shielding or the impact of shielding, including: explicit mention of shielding; extremely vulnerable; receiving a shielding letter; references to being "on the [shielding] list"; and people who are clinically vulnerable, or likely to be so, who have chosen to self-isolate for safety.
- **Experience of 'system' responses.** Anything related to health and social care services, and/or professionals. Sub-codes were used:
- **Access to medicines.** Anything related to accessing medicines, including pharmacies; pharmacists; prescriptions; and delivery services.
- **Administrative practices.** Anything related to administration, including: the process and activity of running health and care services; anything about receiving letters, emails, telephone calls, text messages, and so on, about appointments, treatments and so on.
- **New models of care.** Anything related to new ways of doing things, other than those included within non-face-to-face contact.
- **Non-face-to-face contact.** Anything related to people with health and care needs and/or their carers accessing services via non-face-to-face means. Including: telephone conversations; video [Zoom etc] conversations; and app-based conversations.
- **Ongoing non-COVID-19 care.** Anything related to ongoing non-COVID-19 health and care, that has not been affected by waits, delays or cancellations.
- **Physical health.** Anything related to physical health, including: reported improvement; reported deterioration; changes with regard to smoking; changes with regard to diet; changes with regard to alcohol use; changes with regard to drug use; and changes with regard to exercise.
- **Waits, delays and cancellations.** Anything related to waits, delays and cancellations of non-COVID-19 related health and care. Including: mental health (recognising overlap with the mental health theme); cancer; new presentations of symptoms, conditions and disease; longstanding conditions and disease; and people who turn down, rearrange or miss appointments because they do not feel safe accessing care.
- **Loneliness and isolation.** Anything explicitly related to feelings of loneliness and isolation, recognising there may be overlap with the mental health theme.
- **Practicalities.** Anything related to day-to-day activities, including shopping; getting out and about; maintaining the home; and maintaining a garden.
- **Risk-based decisions.** Anything related to weighing risk and trade-offs, especially in light of COVID-19.
- **Self-management and coping strategies.** Anything related to utilising and building on people's strengths to manage their symptoms, conditions or disease, including some expected overlap with the mental health code. Including: health coaching; peer support; self-management education; references to activities described as helping people cope; and less structured resilience-building activities.

Additionally, health conditions (e.g. dementia, diabetes, rheumatoid arthritis) and healthcare professionals (e.g. psychiatrist, nurse, physiotherapist, GP) were used as codes and individually tagged within the personal accounts in order to assist with future analysis, as well as text retrieval for future National Voices projects.

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[7] North West London Health and Care Partnership used a similar mixed approach

Health and wellbeing

Physical health. Experiences of physical health during the pandemic are varied. Some people report their physical health to have improved, while others report it to have deteriorated. There is a distinction between the general need to keep active and exercise, and those people who depend upon doing so to prevent serious harm. People have had to be creative in order to keep active. A significant number of people reported challenges in accessing food (see the Practicalities section, below), but a smaller number of people reported these challenges as impacting their physical health. However, such impacts were substantial, including for people on restricted diets. Examples included managing conditions such as colitis or diabetes, and managing issues such as oesophageal strictures. Some people also reported losing skills, including mobility, speech and language.

- *"As a person with a physical disability, not commuting into London has been good for me. My physical health has improved as a result and I'm enjoying being able to do more things with less pain".*
- *"Once lockdown came into play, everything got worse. Firstly, getting food supplies was impossible in the early days… This impacted further on my ability to eat the correct foods to control my blood glucose levels".*
- *"Keeping active and exercising is a massive part of my life, as it is critical to preventing my spine fusing together and causing irreversible damage. This could result in me becoming permanently wheelchair-bound and increase the pain. I also need to keep my weight under control, as this can put more stress on my joints. I have to be creative in finding ways of exercise. I have tried to order some exercise equipment online, but most are either sold out or out of my price range. I am making do with my Yoga mat and a 9kg dumbbell as my temporary gym".*
- *"I'm just worried – will I be able to cope with people when all this is over, will I be able to go on stage and talk and do the things I usually do? I'm finding my speech is getting difficult because I'm not speaking much to other people".*

Mental health. This was also a mixed theme. Some people reported coping well with the pandemic and lockdown, including a few who were surprised by and/or proud of their personal resilience. Some people reported successfully drawing upon pre-pandemic talking therapies and coping strategies to manage their mental health in lockdown [see Self-management and coping strategies, below]. However, a larger number of people reported the pandemic, particularly lockdown, to have had an adverse impact on their mental health. For a number of people, the sudden loss of normal routine had proven especially difficult. A number of people expressed concerns the pandemic would have a long-term impact on their mental health.

- *"Things had been deteriorating before lockdown, but I feel the isolation has definitely not helped… The mundane routines of meetings and appointments that meant I had to keep functioning on some level are no longer there and it feels even harder to see life as worth living. I'm worried that when this isolation is over, I will have sunk to a place that I can't get back from".*
- *"The nights are bad I don't sleep too well and am having anxiety dreams. The emotional toll of this is high. I am a reasonably strong person having coped for a long time with two serious illnesses and pain everyday but I would say this is one of the hardest things I have ever dealt with particularly not knowing just how long this will go on for..."*
- *"My anxiety has been so high and has felt overwhelming and unbearable most of the time. I have tried to do things to help stay calm… but concentrating on anything has been near impossible. I have either been unable to sleep at all or wanted to sleep a lot and this has often left me feeling unwell".*

Self-management and coping strategies. Many people emphasised the importance of consistent routine. Contributors reported both doing everything they could to maintain their normal routines, and working hard to establish and adjust to new ones. Demarcating sections of the day was reported to be beneficial, for example tuning into PopMaster on Radio 2, making an event of a favourite TV soap opera or scheduling Zoom chats with loved ones. A number of people reported drawing on techniques learned through cognitive behavioural therapy, other talking therapies and mindfulness to maintain their mental health. Consciously learning new skills and trying to turn the lockdown situation into a constructive, positive experience also featured prominently in people's accounts. A number of people noted that reducing their exposure to news and analysis of the pandemic situation became important as lockdown progressed.

- *"Routine is important, and I've found I have more self-discipline than I realised. I'm getting used to my new regime. This has been vitally important and is helping me through my days in this new world".*
- *"I am relentlessly focusing on, in these days of isolation, doing things for myself… walking the dog, learning new skills, growing stuff…"*
- *"Giving myself five things to do every day makes me feel productive and positive. I continue to study Chinese and am experimenting with recipes".*

- *"I have developed strategies and a new routine. If I'm feeling low I don't give myself a hard time. I do something easy and fun to distract myself: watch a TV drama, do a simple crossword or read. Then, however difficult it feels I get off that sofa, give myself a simple, quick task such as cleaning a kitchen drawer or tidying a bookshelf and I give myself a pat on the back. Generally a small activity creates positive energy and I do more".*
- *"I limited listening to the news and daily briefings (something I still do) and limited looking at social media. I downloaded the 'Calm' app and increased my anti-anxiety medication. I did yoga, walked around the garden, reached out to friends. I had to find positive ways of coping, a new normal".*
- *"I'm spending a lot of mental energy trying to reframe these things for myself right now. I watch the announcements to piece together my armour, to chip away at the uncertainty. But I'm careful. I focus and re-orientate myself on what I can know, I move away from what I can't. I measure out how much COVID-19 news I consume".*
- *"I am thankful to have a big garden where I live and use my trampoline to process the things going on because it is a very important part of maintaining good levels of mental health. If I don't process, my mental health deteriorates and I get busy brained, and have to take extra medication".*
- *[Pre-COVID-19, my doctor] suggested talking therapy and when I said "Yes, I'll have a go at that" I was told the waiting list was nearly nine months… Despite the fact I would be funding this I decided to find myself some local counselling help. I have been doing this for 13 months. It helped me clear my head and concentrate on the things I could do rather than those I could not do. It assisted me to create a 'tool box' of ideas that I could draw upon when the pain flared. Then came the LOCKDOWN … I needed every tool in my box to do without the help of my counsellor, although she was available at the end of the telephone. This is how I am managing today and for the foreseeable future".*

Practicalities. Access to food and essentials was a pronounced problem for many people at the beginning of lockdown, which has continued to be an issue for some. Accessing online delivery slots was problematic, even for people who received their official letter advising them to shield. One person reported having everything set up with their usual supermarket – who had proactively identified them as extremely clinically vulnerable – only to be told the supermarket's list had been scrapped and replaced with the Government's list, which they did not (yet) appear on. Neighbours, local communities and charities are all reported to have met critical food needs. As the food situation stabilised, people reported utilising online shopping for the purpose of recreation, including buying craft materials and exercise equipment. As lockdown eased, people who were shielding or taking additional precautions reported strong concerns about their ability to stay safe while buying food and other essentials. A number of visually impaired people reported finding shopping, accessing local amenities and using public transport to have been extremely difficult since lockdown began. One person with dementia reported an especially positive experience of a utility company going out of their way to make sure she had heating; identifying the seriousness and nuance of her situation and providing recognition and reassurance each time they phoned her or she phoned them with updates.

- *"I've got emergency cover by Scottish Gas for my boiler and my central heating, so dutifully phoned them. Bit of a nightmare listening to all of this about the virus and responses and all of that… Because I was agitated and frightened and wondering how I was going to survive without heating. But, eventually, I got to speak to a human being and what a difference that made! The lady on the line responded and I could hear her voice changed, once she realised that I had dementia and respiratory challenges and that this was emergency and I was concerned. She reassured me and set up for someone to come and see me sometime this morning".*
- *"We both struggle getting access to food and essentials. Once again, the local voluntary services and charities have been incredible in supporting us both with food… and it's really comforting to know that there are people out there who can help and again are only a phone call away".*
- *"I tried online deliveries from supermarkets but they were all booked up no matter what time of the day I tried. In the end I found an 'Elderly and vulnerable' hour offered at one supermarket from 8.00am to 9.00am each day which was well organised and quiet but I felt on edge going round the store…"*
- *"The irony is that I have food for my cats for the next three months, it's just my food which is difficult to get! The pet websites are easier to order from online and they are still taking orders, even if it takes a bit longer. It is straightforward to get food for cats and dogs; it just isn't as easy to get human food!"*
- *"For many visually impaired people they may have felt confident that they knew the layout of their local food shop and could easily arrange their weekly shop. But like everything else, this is now a thing of the past. Shop opening times have changed, people now queue outside, markings on the floor dictate where to stand… For me, knowing if I am being beckoned into the shop for my turn is a frustrating experience and not knowing if I am too near other people or even where the queue is proves to be yet another frustrating barrier".*
- *"As a visually impaired key worker I have had to get to work throughout the lockdown and travelling on public transport has been a challenge. Routes that I am familiar with change over night, with one-way systems in place in stations, signage I cannot see to read, cones on floors and barriers outside stations all obstructing routes I have been using for years".*

Financial issues. With the exception of fears about workers' rights as lockdown eases, none of the first 50 personal accounts explicitly referred to financial issues or concerns. Where money was mentioned, it was in the context of feeling "lucky", for example to "have very good pensions" or to be able to do banking online. Some people described situations that indicated that their financial means were limited and that they couldn't simply fix a problem by spending more money, but they didn't explicitly say so.

People clearly are experiencing financial issues during the pandemic. There may be a bias to OurCOVIDVoices' self-selecting sample. There is also emerging evidence from elsewhere of a divergence between households' expectations about their personal finances compared to expectations for the economy as a whole. Resolution Foundation analysis found that 55 per cent of respondents to ONS' recent Opinions and Lifestyle survey expect the general economic situation to get a lot worse in the next 12 months compared to just 8 per cent who expect the financial position of their household to get a lot worse.[8]

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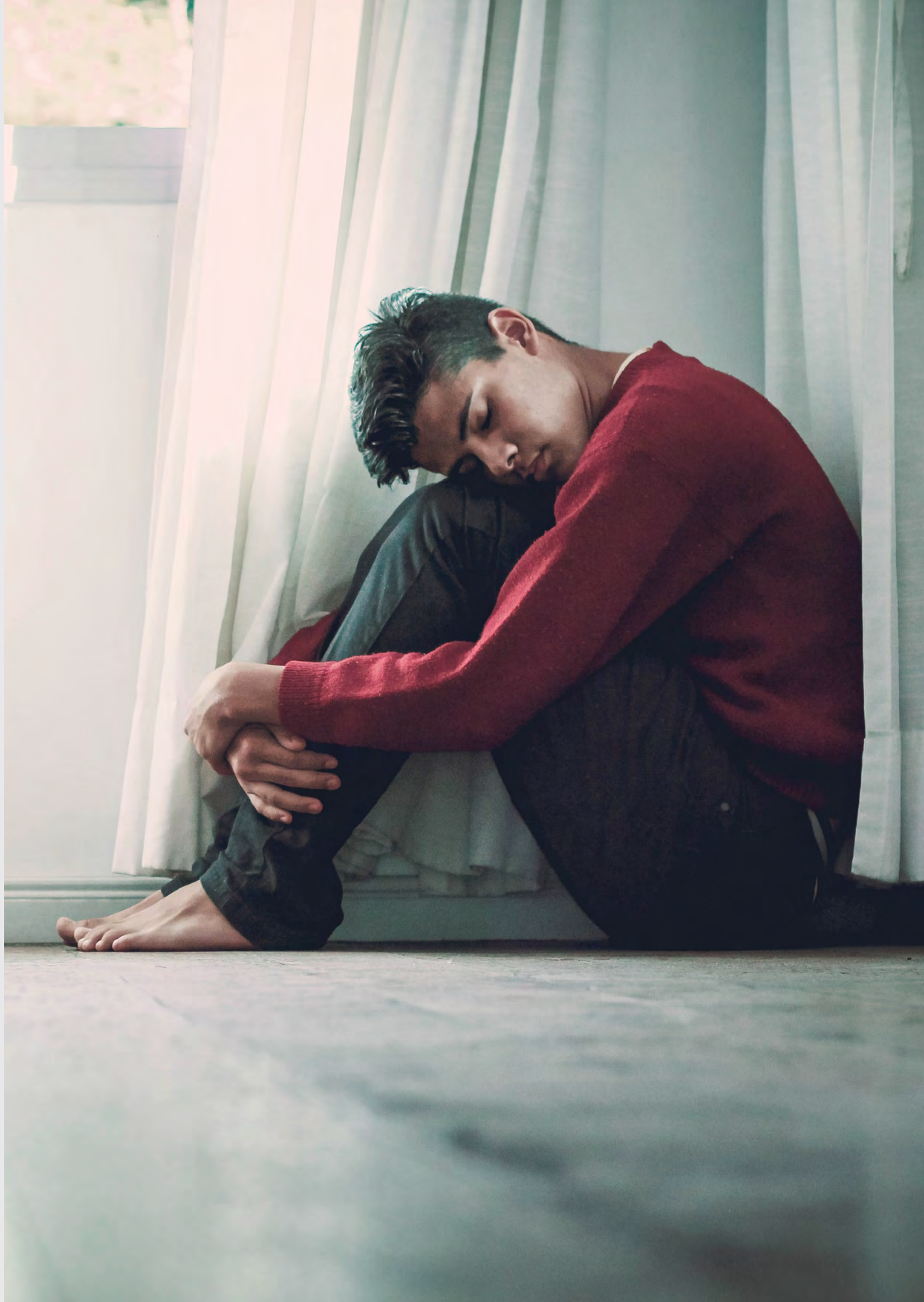
[8] www.resolutionfoundation.org/publications/the-economic-effects-of-coronavirus-in-the-uk

Employment. Employment is a relatively common theme within the personal accounts. Contributors generally report supportive employers who have enabled them to work from home and have understood the needs of people who are shielding. However, some people report high levels of anxiety about what the future holds as lockdown eases, and a number report having friends who have not been supported by their employers. Experiences of working from home are mixed, with some people enjoying it and some eager to return to their pre-pandemic ways of working.

- *"The virus could not have come at a worse time for me. I had only recently regained the ability to walk after eight months on crutches following a bad flare up. This resulted in losing my job. I was hoping to start on a new career, but this has obviously been put on hold due to the uncertainty over how and when I can enter the job market again".*
- *"We hope (probably against hope) that the government will protect workers' rights… and that whether we are in the highest risk group or just have "underlying health conditions" we are allowed to work remaining isolated if we choose to… We may need retraining if our previous work role can't be performed virtually. We would love it if working from home was not implied to be shirking. We would love everyone to remember how difficult "splendid isolation" is to live in".*
- *"I am seven weeks in and counting. I am working from home and loving every minute of it. It has been liberating and stress free. I want to always work from home now".*
- *"I am a person with mild learning disabilities and epilepsy… I have been working from home which is much harder than you think. There are lots of distractions at home. I like meeting and networking with people usually, which I must do without now. I have been using Zoom and Microsoft Teams to keep in contact with my work colleagues".*
- *"I'm grateful to work; for the purpose and meaningful activity it gives me. For the feeling of being there to support others".*

Housing. None of the first 50 personal accounts referred to housing (as defined in the Methodology section). However, there was a strong recurring theme – especially among people who have been shielding – about the great value people place on having a garden. Being able to sit in, exercise in, plan and tend to a garden was talked about in terms of positive wellbeing and as an important coping strategy. Those without a garden keenly felt its absence. In a later account someone describes not having a kitchen, which made food deliveries even more essential, and anxieties about their availability.

- *"I have only been outside twice in the past 10 weeks (both times for essential medical appointments). I have no garden so I have only felt the sun on my face for those fleeting escapes. I can get some breeze from opening my windows, but it's not the same. I heard this week that it looks like it will have been the sunniest spring since records began – feels like a cruel irony as I have missed it all".*



Relationships, loneliness and dealing with death

Relationships. There was a general theme of gratitude and appreciation for existing relationships, whether they continue to be in-person within the household, or are now being conducted by phone, video call or instant messaging. Technology had generally been embraced and utilised in order to maintain contact, though it was noted to be a poor substitute for key events like birthday celebrations. Many commented on missing physical contact, including hugs. This was especially pronounced for grandparents missing physical contact with their grandchildren. Some people reported relationships to have been strengthened by the unusual shared experience of the pandemic and lockdown.

- *"I'm so glad I do have my husband at home. I don't know how I would cope if I was alone".*
- *"I really do have a lot to be grateful for. I'm grateful for a partner who I can talk to, who shares the crushing weight of this time with me and for whom I can do the same".*
- *"I wondered if we would argue a lot but actually we have laughed and apart from having to bite my tongue because of his illness or my being unwell and feeling so poorly, I'd say we are dealing with it OK".*
- *"As a family we have discovered depths of resilience we didn't know we had. I have seen my children grow in the context of immense challenge and a need to care for each other".*
- *"I am using my telephone as much as I can and have several WhatsApp groups going with family in other countries, and one with the neighbours where I live… My husband has started writing a blog for the family every evening which our eldest daughter in France is keeping them for the future".*
- *"I am lucky to be chatting to friends online through Facebook, Zoom and I Skype with my counsellor once a week which has been beneficial".*
- *"Adjusting to having no physical human contact has been tough. Luckily, I have access to the internet and use FaceTime to keep in contact with loved ones".*
- *"I'm missing people, or more specifically being in the presence of people. I've had plenty of virtual interactions via Zoom, however without physical touch it's not the same".*
- *"Strands of communication are still open but nothing really beats being together at a time like this. Nothing is more precious or more missed than those hugs of reassurance".*
- *"I can now go and see my daughter and family in their garden. And we did it at the weekend, us sitting on the chairs we took, in a circle of stones that 31-month-old Lyra cannot enter. Saying goodbye hearing her ask "Can I cuddle Nana?" was so hard. That was not what I would call a proper visit".*

Childcare. While only a couple of the personal accounts referred to childcare, those that did focused on the challenges of trying to shield with a young child. Contributors reported feeling guilty about having to restrict their child/ren's movements and relationships.

Domestic violence. Few of the personal accounts referred to domestic violence. Some alluded to parent abuse, but more information would be needed to draw findings. One personal account reflected on lockdown giving a parent and adult child the space to talk through the daughter's recently ended "toxic relationship", but it should be noted that no further details were provided and no explicit findings can be drawn with regard to domestic violence.

- *"The telephone, one of the oldest forms of technology available to us because she had no internet, was a lifesaver those first three weeks. We spoke every day. We had to talk. But you know, talking is such an under used tool to beat depression. We hear so often how it's good to talk and when you're under extreme circumstances like lockdown it truly is. For months beforehand, so many things were unsaid. Now we are talking and putting the world to rights and helping lift our mood".*

Loneliness and isolation. The isolation of lockdown has exacerbated feelings of loneliness for some people, and led to new feelings of loneliness for others. A number of people express a sense of being overwhelmed by the enormity of it all, with feelings of loneliness heightened – especially for people who are shielding – by the lack of known endpoint.

However, there were a couple of people who noted their relief and/or enjoyment at the new norm of online meetings and fewer in-person get-togethers and meetings.

- *"I just keep thinking, "When will I be able to have a hug again?" – no-one can answer".*
- *"As a single parent, working, in lockdown, while caring for two children alone, the exhaustion and loneliness of this can feel overwhelming".*
- *"The starkness of this isolation is highlighted most in the pretence of getting ready for work. I shower and shave just like I would for a normal workday, except business is conducted in the realm once restricted for slumber and love".*
- *"I am one of the shielding. I feel alone and invisible. I have two invisible autoimmune diseases so I am used to people not understanding my illness because I look OK people think I'm OK but now no one who isn't shielding can understand the loneliness".*
- *"Sometimes living alone in 'normal' times is lonely, but this is different – we have been forced into isolation by a hidden enemy".*
- *"In mid-March I met my family with the knowledge that we would not meet again for some time… I sometimes feel sad, alone and scared. These feelings are normal in such times I know but some days I feel I'm living on another planet".*
- *"I don't mind my own company, that's why I think I like working from home so much, I realised I am a little bit more antisocial than I thought I was, but I do make the effort with family and my only friend, COVID-19 has given me permission not to visit people, or go to meetings or events I would rather not be at, and I find myself loving the Zoom world".*

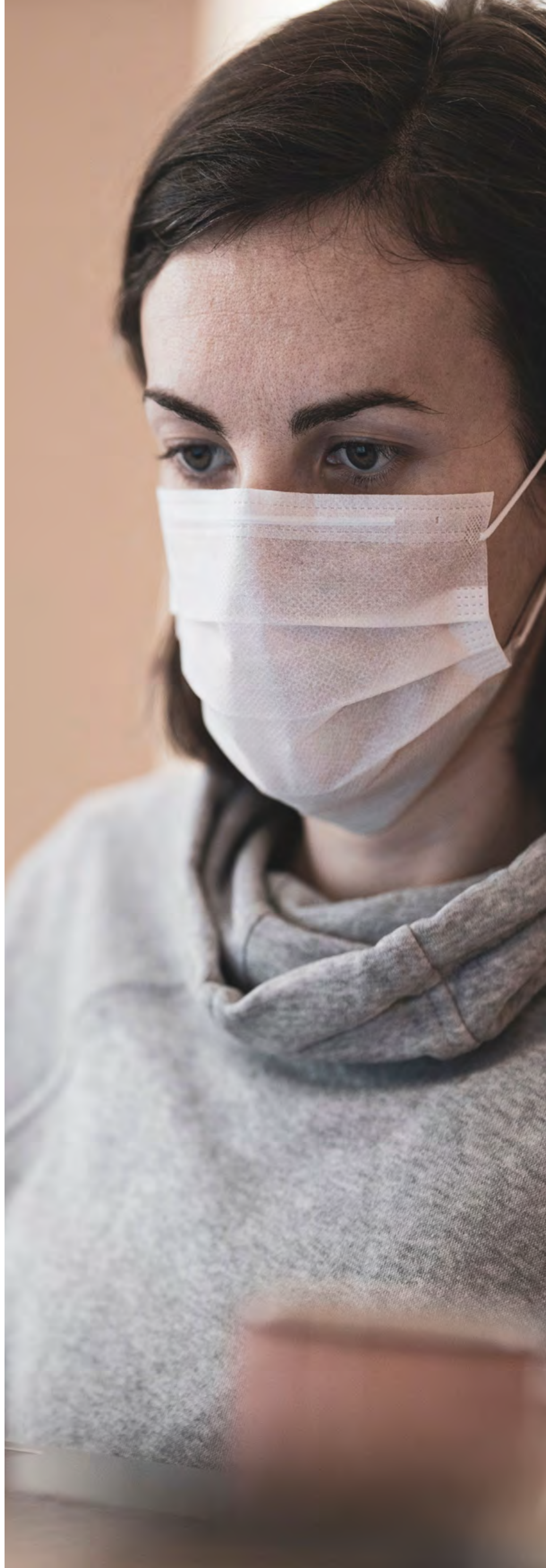
Dealing with and managing death. Although there were only a few references to death, the experiences were diverse and they had profoundly affected their contributors. Some people identified lockdown as exacerbating the loneliness of a bereavement experienced prior to the pandemic. Some people reflected on how the loneliness and isolation of lockdown had forced them to deal with feelings about bereavement that they had previously tried to avoid by keeping busy and socialising. Some people shared experiences of being bereaved during the pandemic. There was also an emerging sense that the presence of death – in care homes, hospital and communities – is something that weighs heavy on people's minds, even when they are not directly affected by it.

- *"For the first time in my life I am living alone. My husband died last year and although things have been made easier thanks to some bereavement counselling through the local hospice, the loneliness has certainly been reinforced by the pandemic".*
- *"My mother-in-law was diagnosed with cancer and was dead within three weeks. We attended her memorial via Skype. And here I am, still breathing, still hurting, surviving. Somehow".*
- *"[One month after the care home went into lockdown], my Grandma gave up. Following a pattern that is sadly familiar in care settings, she decided to stop eating, and then drinking; to refuse to get out of bed; and to allow herself to die… Her death was peaceful and quiet... But instead of the end we'd all envisaged, with family by her bedside, she died holding the hand of a wonderful care worker, while her closest family raced to be with her for their designated end-of-life visit and didn't quite make it. Don't get me wrong, I'm not angry. Her quality of life was poor, the end was near for her anyway… But it's hard not to wonder what went through her mind… my Grandma died because of COVID-19, and I'd like that to be known".*
- *"We've become really accustomed as a nation to logging into the BBC to see the government's latest public announcements; measuring the success of this time by a changing death count, infection rate and weighing the implications for the extension of lockdown… Did we even think about how heavy the constant mention of death and duty would weigh on us all? The toll it would take?"*

People who are shielding

Experiences of shielding. While around two million people were told to shield, there is of course an enormous diversity within this group, which is borne out in the contributions to OurCOVIDVoices. Some people who are shielding led very active lives before lockdown and acutely feel their loss of independence. Some people, accustomed to being predominantly housebound, have found an unexpected freedom in knowing that others were now in the same boat. Some people reported barely noticing a difference to their lives. Similarly, while some people reported feelings of fear and isolation, others reported a new enthusiasm for arts, socialising, exercise and new hobbies that were suddenly available online – and a hope that these opportunities to participate from home persist beyond the pandemic. As lockdown has eased and the shielding programme 'paused', there is a strong common theme of concern for the future and a feeling of having been forgotten by wider, non-shielding society. A number of people stated their intention to shield until a vaccine becomes available.

- *"Life is easier now than it was back then. Everyone has learnt to video chat, theatre has moved online, I take art and exercise classes over Zoom, home working has finally been fully embraced now everyone has been forced to do it. When lockdown lifts, I hope those who are 'healthy' remember how important these things were for their own sanity and sense of community so that everyone, disabled or not, can continue to live a fuller life if they are stuck at home".*
- *"People, including my close friends, don't seem to realise how strict shielding is until I tell them, and I can't help feeling so resentful of them complaining about their lack of access to pubs and stuff, when we have so many freedoms already – we can go for a walk, we can go to the shops, we can see friends at a distance. My mum can't do any of that".*
- *"I am very lucky and have been able to move out of London to my friend's farm that has private land on which my husband, dog and I can safely exercise. My other friends, who also have cystic fibrosis and are post-transplant, are stuck – either living on their own or in childhood bedrooms that are full of trauma as it is where they spent their final months almost dying before they received their call for new lungs".*
- *"Some people say that we are used to a life of isolation. That chronic illness has prepared us to handle this situation. It is true that we spend months at home when our disease is flaring, that we have had to depend on others to help with shopping and getting our medication. We have learnt to manage dwindling finances and seek support. We have learnt that time is a great healer. We are resilient and resourceful but that doesn't mean that I am mentally prepared for months of shielding".*
- *"When the UK was put into Lockdown, I watched my social media feed fall into absolute chaos. Everyone saying "This is terrifying", "We literally cannot leave the house unless it's essential!" and "Are we just expected to stay indoors now?". I barely even notice a difference in lockdown because this is what life is always like for me".*
- *"The easing of lockdown scared me and made me feel very down, then the announcement for those shielding just made me cross. My Consultant says to just stay in and continue as we are, which is what we had planned to do anyway, I think there will have to be a vaccine available for me to go out again".*
- *"I'm afraid I'm only in my fifties and I feel like I've so many years to lose if I get this virus and die so it feels like so much is at stake… I am frightened of how long I might need to be isolated maybe a year until there is vaccine maybe a bit longer. I am fortunate to have a small garden but when your whole world is a small house and garden it's so hard but I won't break isolation no matter how hard I have to stay isolated".*



Information and decision-making

Sources of information and understanding. This was a frequent theme and one framed by a lot of frustration. People reported being confused by official information, advice and guidance, and sometimes finding it to be in conflict. The message to "stay at home" during lockdown was felt to be clear and easy to understand, but a number of people noted the information to have been one-way, with no mechanism for asking questions. There was a theme around how much easier people's lockdown experiences would have been if someone with understanding of their circumstances and needs had contacted them with tailored information and advice. Some people felt overwhelmed by the amount of information that is available, the frequency with which it changes and the challenge of identifying what is evidence-based and credible. Some people reported stress and anxiety caused by information gaps and the speculation that filled them, for example whether chemotherapy services would be halted during lockdown. A number of people reported contacting charity helplines for up-to-date advice and guidance, and charities were generally seen to be a source of useful and credible information. Local networks, including community Facebook groups, were reported to be helpful sources of local information. "Trust" was mentioned a number of times in the context of information. People reported finding it difficult to know who to trust, and struggling with the enormity of trusting politicians, scientific advisors and others to make decisions that to individuals are the difference between life and death.

- *"I want to know why do I keep getting different rules and regulations all the time it's all very confusing".*
- *"I feel the process around the shielding letters was slow and disorganized…. I have had three copies of the letter but still Tesco don't have me on their list".*
- *"Facebook, although it has its faults, has been a real asset to us. Residents groups have been able to keep in touch with their members even if it is just to see how long the queue at Asda is on a specific day".*
- *"[M]y director asked me to contact my friends at Asthma UK for advice. The nurse on the helpline suggested working from home sooner rather than later".*
- *"And when I came out [of hospital] the GP had advised Heather that I needed to shield for 14 days and so did she, not using the same toilet, not sitting on the same sofa, not using the same towels etc. So I asked the [hospital] doctors before I got discharged what I was meant to do. And they said yes, because I'd been an inpatient, it was wise for me to shield myself for 14 days but not for Heather to shield… unless I showed any symptoms. So, it's just strange that you get conflicting advice".*
- *"Their message during lockdown was clear, but now with the easing on the lockdown their messaging has been farcical and I don't even bother listening to them anymore".*

- *"I would say the Government have caused me more tears than when my Dad died and I feel really frightened about how it is being handled, frustrated at not getting replies to my questions all that has made me ill physically so I have to stop sometimes and take time out".*
- *"I'm hearing conflicting things and I feel powerless… What do I know? I'm no medic, no scientist. Then I look at the UK Government strategy for the next few months and it's vague at best".*
- *"It has been a real test in trust; trusting politicians (Ha!), trusting the scientific advisers to be frank and logical, to tell the truth in a way which cuts through political machinations. Trusting their professionalism, trusting the data and their models. Ultimately, trusting the decision-making of strangers who are more informed than me, to make the right call".*

Risk-based decisions. Weighing-up information and advice in order to make risk-based decisions was a common theme, especially among those people who are shielding. People reported a substantial mental burden associated with this, and significant challenges around understanding trade-offs. People also raised concerns that their decisions would not be understood or respected by others, as well as concern that allowing some risk (such as seeing grandchildren) would mean they would be pushed to take other risks (such as grocery shopping or collecting medication).

- *"The currency I'm using now to make a deal and a decision with myself is risk. On the left hand side of the scales is the risk of me catching the virus, passing it on, and the guilt of not doing as the government suggests(?!) on the right hand side is my yearning to cuddle my granddaughter, my worries about my daughter and her husband struggling to work full time from home whilst looking after a toddler, and my suspicion that the government don't really know what they're doing, so why feel guilty? The scales are tipping to the right".*
- *"First please understand the risks – you are given a bowl with 100 sweets in it. You are invited to pick one to eat. But, you are warned two of those sweets will kill you, 18 of them will make you so ill you will be hospitalised, but most people find their sweets OK. Have a sweet. No? These are the risks the average person runs with COVID-19. Now, let's make you over 70, or with an "underlying health condition" so your bowl of sweets has up to 15 that will kill you and most of the rest will hospitalise you. I hope you'll agree no sane person would voluntarily eat those sweets".*
- *"I miss not having to think about the sacrifices I will have to make and how weighty my decision-making can be in the name of the collective good; as minor as "Should I go to the shops now"? "Should I buy this?" to the big ones, like staying away from the people I love the most to help shield them".*

‘System’ responses

Access to medicines. People report depending upon the delivery services established/extended by pharmacies. A couple of people reported difficulties accessing their medication due to particular challenges, such as moving home just prior to lockdown. People who experienced challenges accessing medication before lockdown, reported these persisting or being exacerbated during lockdown.

- *“My pharmacy have been really helpful in delivering prescriptions and both local people and delivery drivers have been brilliant”.*
- *“GPs are dismissing their pain more than usual. This is a common occurrence with endometriosis anyway, but we have a number of people who have had surgeries cancelled, and still their GP’s refuse to prescribe temporary pain relief on the basis that their pain isn’t real or isn’t as severe as our members are reporting”.*
- *“I have been prescribed an Eternacept injection that needs to be kept refrigerated at all times. Moving to a new address caused problems – the first delivery driver could not find my flat and I was unable to go outside to give directions. There were two further attempts over the next two weeks to deliver the medicine, during which I began to get increasingly worried that I might run out. Luckily, the next driver was able to find me on the fourth attempt, but I am still concerned that I will have further problems in the future and run out of injections”.*

Non-face-to-face contact. Responses were mixed. Some people reported the shift from face-to-face to online/telephone contact to have made accessing health and care services easier. Some people wondered why services had previously reported things like video assessments to be too difficult or insufficient for decision-making. There was an emerging theme that people missed the routine of face-to-face contact in mental health services, and some people reported struggling with the shift from regular appointments to “contact me if you need to” support – some people felt isolated or burdened by the onus being shifted onto them to ask for help. Some people reported being excluded by the rapid shift to online consultations.

- *“Her GP receptionist said Mum needed an online consultation to assess her Diabetes Type 2. Mum is 83, lives alone and is digital free. She said they have a few call slots a day and would call Mum the next afternoon. They didn’t”.*
- *“The NHS, GP & Council have been amazing, all have rung at intervals to check that all was OK and reinforce their presence should we need it”.*
- *“I find myself thinking… “Why has it always been a nightmare until now?” Why has doing assessments via the phone being impossible before? Why has any process to get support been so “challenging” (to use an oft-worn phrase). Why have I been told up to now that video assessment, phone calls, or just reading my notes isn’t sufficient?”*

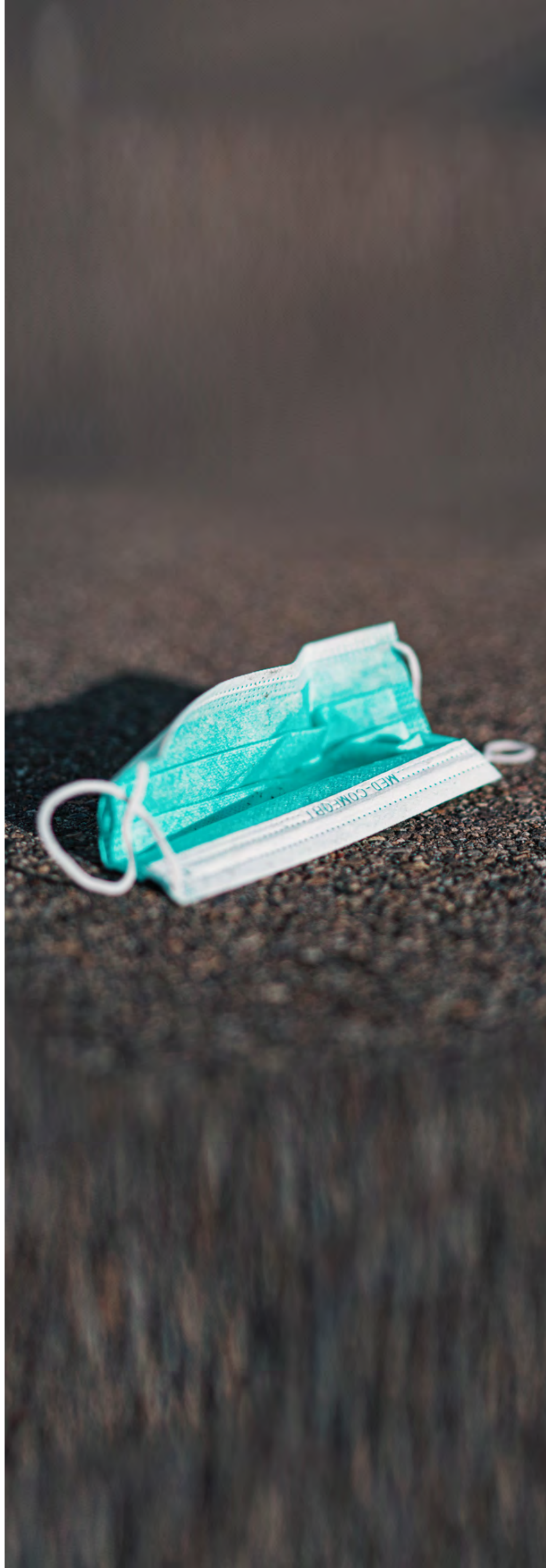
Waits, delays and cancellations. This was a strong recurrent theme. People report having had a range of appointments, treatments, services and surgeries delayed or cancelled. People were understanding about the pressures facing health and care services, but were anxious – sometimes to the point of reported distress – about the future and the impact of waiting on their long-term health. People did not have information about when health and care services would resume, and reported having no information or advice about what they should do in the interim, including if their needs increased or they reached a point of crisis. This also impacted upon carers.

- *“I had a six-monthly review of my diabetes scheduled at the start of lockdown. I knew that my doctor’s surgery was closed except for urgent appointments but I hadn’t been told that my appointment had been cancelled. I assumed that given the poor control of my diabetes that they still wanted to see me – I even got a text reminder to attend the morning of my appointment. As the door was locked, I rang the reception to ask to be let in, only to be told that my appointment has been cancelled”.*
- *“He [a child with a long-term condition] has been unable to see his physiotherapist to try out a new walking frame that we had been discussing and also cannot receive some new parts that need to be fitted to his wheelchair which will help with keeping his spine straight. Two other appointments cancelled are his six monthly heart scans and endocrinology at Great Ormond Street. These are a critical part of his care”.*
- *“I’ve spent a lot of time in tears this week – the pain in my spine, stretching down into my hips and legs isn’t easing up. It just gets worse. I keep trying to get up and stretch and ease it, but I know the only thing that would actually help is hydrotherapy... and I can’t get to it… I won’t go to hydrotherapy ever again, I expect”.*
- *“I was put forward to take part in a trial of some new drugs called Platform. The doctor who was looking after me for the trial told me that the Platform trial could be ending for everybody because of COVID-19…”*
- *“[W]hat 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”.*
- *“Health care 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 over night. Our need for care did not”.*
- *“I have recently been diagnosed with cirrhosis and am awaiting further investigation. However, waiting has meant a prolonged period of major swelling in my abdomen, legs and feet from fluid retention. This has meant that mobilising is impossible, as I get so out of breath, especially when the swelling is at its worse… I am so scared what the outcome of all of my health issues will be and worry about how long I can continue as I am”.*

- *"All hospital appointments have been cancelled, meaning I have had just two telephone consultations with my psychiatrist and no contacts for my diabetes or liver disease. The stress and worry around this has been harrowing and crippling for much of the time… I am left with massive anxiety and am unsure that I will cope for much longer without treatment".*
- *"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".*
- *"I do know of carers who have reached crisis point and under normal circumstances would be arranging respite care or even permanent care for their loved one in a residential home. This is just not possible at the moment…"*

Ongoing non-COVID-19 care [apart from waits, delays and cancellations]. For many people who are shielding, attending medical appointments was reported to be the only time they left their homes. People reported feeling apprehensive and fearful about accessing non-COVID-19 care. One person reported having been placed on ward with patients suspected to have COVID-19. People reported how "strange" services were, with A&Es quiet, staff wearing PPE and loved ones no longer allowed to accompany people or visit them. A number of people noted how kind and reassuring staff had been. Some people reported they were now unable to access services because of the way they had been hastily reconfigured.

- *"I have been having to go into the hospital very occasionally. I am very lucky that my brother is a newly graduated doctor who has not started in his role yet, so he has been taking the weekly blood tests that I need to be having and couriering it in to the hospital for me by bicycle as we don't live that far".*
- *"Unfortunately she ended up in A&E after a suicide attempt and reports that she was left in a room for hours by herself and that she wasn't even allowed to go to the toilet. She was then discharged from the hospital and was told "we would normally admit you to the mental health unit, but because of COVID-19 we aren't going to do that". It then took almost 48 hours for the mental health response team to make contact".*
- *"…with the COVID-19 situation, nobody is allowed to go in with you, so I went in and sat and waited in a fairly empty A&E and got seen relatively quickly. They did a CT scan and they said there was some parts on that scan that were unclear and that they thought I might have had a stroke or a TIA so I was admitted to hospital. And it's very strange seeing all the nurses in masks, because you can't really see their faces, you can't see their smile… No visitors at all allowed, so that was quite strange and I spent three days in hospital".*
- *"…what was very unnerving for me was the fact I was [after a planned surgery] put on a ward with suspected coronavirus patients… Scary stuff".*
- *"We have done injections in a car boot. Delayed essential blood tests, pushed things that could wait – like checks for eye damage and x-rays for bone damage – out to the future".*
- *"I worry about going to the doctors for my three monthly blood test it feels so risky".*
- *"Going to a hospital is a particular concern – I may be risking infection by going there and my body may not be able to fight the infection due to my weakened immune system. This has also impacted my ability to attend my scheduled appointments and take blood tests".*
- *"I have to attend retinal screening every six months as I have retinopathy. I had to cancel my latest appointment. Due to COVID-19, these were only being offered at a couple of sites – one at the other side of the city in which I live and the other being in another city. You cannot drive for a few hours after testing due to drops they use to dilate your eyes. People with diabetes are particularly susceptible to COVID-19 and more vulnerable to developing severe symptoms. Because of this I didn't want to risk using public transport (two buses to get to the hospital), had I even been able to get on a bus with limits on passenger numbers due to social distancing. A taxi would have cost around £30 for both trips (unaffordable) and no patient transport was offered".*



Analysis

What do these findings mean?

We wanted to gain insight into the experiences of people living through the COVID-19 pandemic in the UK, particularly people using health and care services and the people caring for them. OurCOVIDVoices – and the generosity of the people who shared a diversity of stories – has given us this insight.

We set out to consider the implication of people's experiences, with a particular focus on adults using health and care services in England.

- **How have people's lives changed?** Every story is different. However, the majority of people report substantial changes to their day-to-day routines and activities, to their relationships and connectedness to others, and to their interactions with health and care services. Some people report changes – both positive and negative – to their health and wellbeing. A larger group report concerns about the long-term impacts of the pandemic on their health and wellbeing, particularly their mental health.
- **Are there recurring themes within people's experiences?** Lacking the information required to take informed decisions – particularly decisions about risk – is a strong theme. Concern about non-COVID-19 care also features prominently within the personal accounts. Some interactions with health and care services had been positive, with a recurrent theme of staff being reassuring and kind, particularly in acute care. However, waits, delays and cancellations have caused frustrations, particularly when people have not been given any information about what will happen next, or what they should do if their circumstances change. The personal accounts are full of understanding about the challenges facing the system, and sympathy for the pressures facing health and care staff. However, people report worry, stress and anxiety about the impact waiting will have on their health and wellbeing, with a smaller number of people reporting immediate harms.
- **Are there groups of people who are experiencing the pandemic differently to the wider population?** Recognising the enormous diversity within the group, people who are shielding report experiencing the pandemic differently to the wider population. While the personal accounts were mixed at the beginning of lockdown, with people reporting both positive and negative impacts of shielding, this changed over time. As politicians and other decision-makers began to talk about lockdown easing, people who were shielding reported increasing concerns about the future, and a feeling of having been forgotten by wider, non-shielding society. A number of people stated their intention to shield until a vaccine becomes available.

We set out to then consider what this means for the original I Statements [see Appendix A] National Voices developed some years ago.

- **Do they continue to explain what coordinated and person-centred health and care should look like from an individual's perspective?** Yes. People shared a lot of detail about their experiences of health and care through OurCOVIDVoices. The things that had worked well aligned with the I Statements, and the things that had worked less well would be addressed if the I Statements were realised. Despite the unique and challenging context of the pandemic, and despite mixed ideas within policy-making about how health and care should be structured, led and funded, people's ideas about what coordinated and person-centred health and care should look like remain unchanged.
- **Do we need supplementary I Statements to describe what good looks like with regard to the immediate COVID-19 pandemic?** There are pronounced gaps, because of COVID-19 and because of responses to COVID-19, between what health and care services should look like (as described by the I Statements) and what people are currently experiencing. These include pronounced gaps that have opened up or widened because of COVID-19 and responses to COVID-19. A short, supplementary set of new I Statements would help both the people working in health and care and the people making decisions about health and care understand what these gaps are so they can work now to close them.
- **Do the I Statements capture everything people say about their lives and expectations?** No, reading the experiences people shared with us, it is clear (if anyone needed reminding) that people's lives largely take place outside of health and care services. And that many of the things people say they need cannot be delivered by NHS or social care: access to outside space, connection with friends and family, job security, a feeling of being heard, and of being important enough to matter when decision makers address the future. It is important to bear in mind that the old, and new I Statements, address what people with ongoing health conditions, impairments or disabilities say they need from health and care, but that there is much more they actually said they need.

Collaboratively developing a new set of I Statements

Focus Groups

Our findings were shared with and explored by two focus groups. The focus groups included people who had shared their stories through the OurCOVIDVoices platform, as well as people with other vulnerabilities, not just clinical, in addition to representatives from organisations who are supporting people through the pandemic and its challenges.

In the first virtual session, we discussed the concerns people had from their experiences of shielding and the pandemic generally; ideas for ongoing or transitional support to be put in place to help people to feel safer; and what decision makers and policy makers should be prioritising before and beyond the pausing of the shielding programme on 1st August 2020.

The second session explored whether there were pronounced gaps between what health and care services should look like and what they have actually been like for people during the pandemic. Possible new I Statements were discussed, with five breakout rooms discussing and feeding back on options.

The themes highlighted through these discussions aligned with and extended the findings from analysis of the written contributions to OurCOVIDVoices. A draft set of new I Statements emerged from these discussions.

A further research meeting was held with National Voices staff and associates to consider the draft new I Statements in light of the work, learning and advocacy of Members, and the current policy context.

Survey

The draft set of new I Statements was shared with contributors to the OurCOVIDVoices platform, seeking comment on language, as well as an assessment of the importance that contributors place on each of the proposed statements.

A final set of new I Statements

Amendments were made to the new draft I Statements at each of these stages, with significant consideration given to wording, emphasis and ordering. We hope we have done justice to the experiences people shared with us. We now have a set of eight powerful new I Statements.

Our aim is to help both the people working in health and care, and the people making decisions about health and care, understand the pronounced gaps – because of COVID-19 and responses to COVID-19 – between what coordinated person-centred health and care should look like and what people are currently experiencing. We need to take action now to close the gaps. The new I Statements can also act as powerful outcomes measures, driving improvement.

We envisage these statements being used by everyone designing or delivering health and care services. We also hope that they help people who use health and care to ask for what they need. Finally, we think they can serve as a reminder that when you ask people what they think needs to change in health and care, they do not comment on commissioning structures, regulatory frameworks or organisational boundaries.

This does not mean that these issues don't matter. But it means that it is unlikely that changes to structures, NHS bodies, regulations and incentives in and of themselves will deliver the changes people need. We need to work backwards from what people say matters to them. Much of this can be achieved within existing arrangements of roles and responsibilities. Much of it is about communication, about making it clear that you listen, both to the individual in front of you, and the community you are trying to serve. Having worked with this insightful, realistic group of people who shared their experiences and expectations with us, we are more sceptical now than ever that restructures are the answer to much that matters to people.

The new I Statements

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

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.

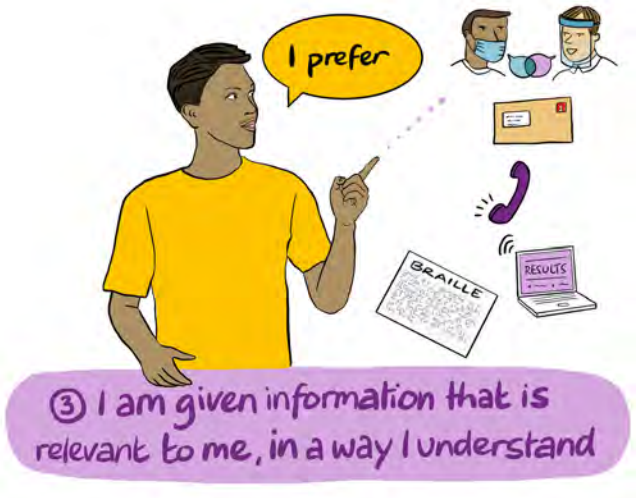
"We aren't truly respected with our decisions if they are playing choices with our life".

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 23rd, 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.

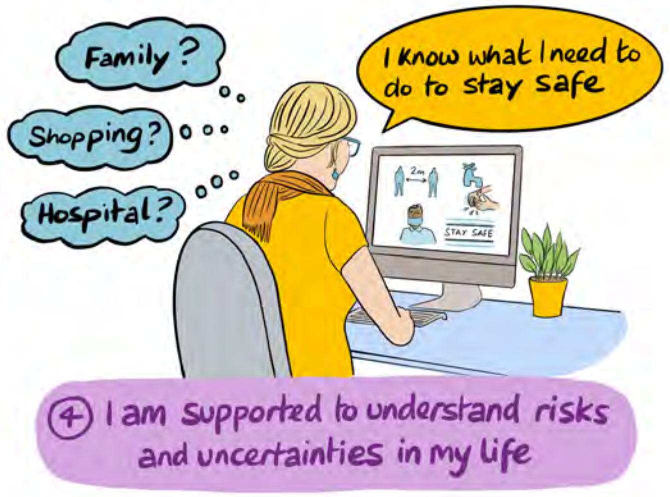
"Freedom to make a decision depends upon other people's behaviour, and that's not being emphasised to people in general, thus reducing our choices as shielding people". One person's freedom is another's risk. For example, not physically distancing or wearing a mask puts an even bigger risk on people 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"*.



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.

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.

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.

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.

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.

"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 endometritis, people who cannot physically communicate, young shielders and young carers, children and siblings. *"We need to listen to families, unpaid carers, the 'forgotten'"*.

Operationalising the new I Statements

We know that though reasonable, within the context of the current extraordinary pressures on the NHS, meeting the needs expressed in these new I Statements 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.

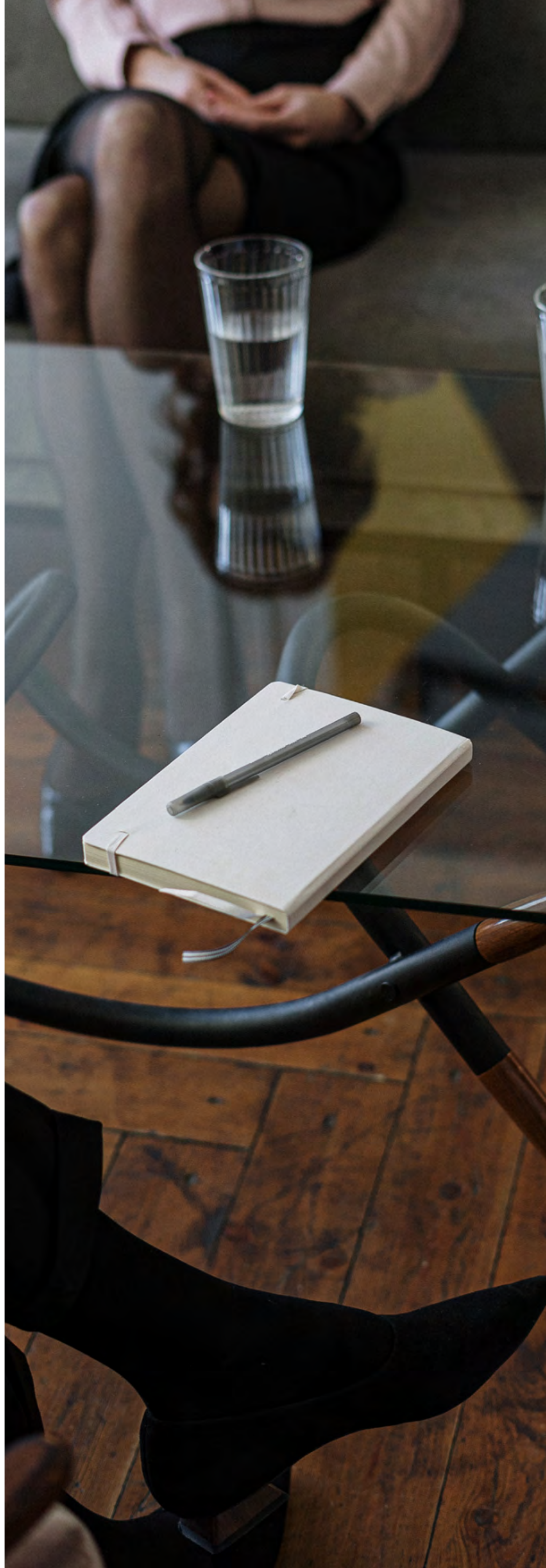
At the same time, we also believe that by responding to these I Statements in the ways we suggest, system leaders and healthcare providers alike could alleviate some of the negative consequences of the COVID-19 crisis. By contrast, ignoring people's needs will result in their health deteriorating and much higher costs down the road. Plus, though meeting the needs expressed in these statements may not 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 is 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.



Operationalising the new I Statements

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 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

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. Be mindful that most of the week happens to be 'out of hours'	Strive towards continuity of care, wherever possible. 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

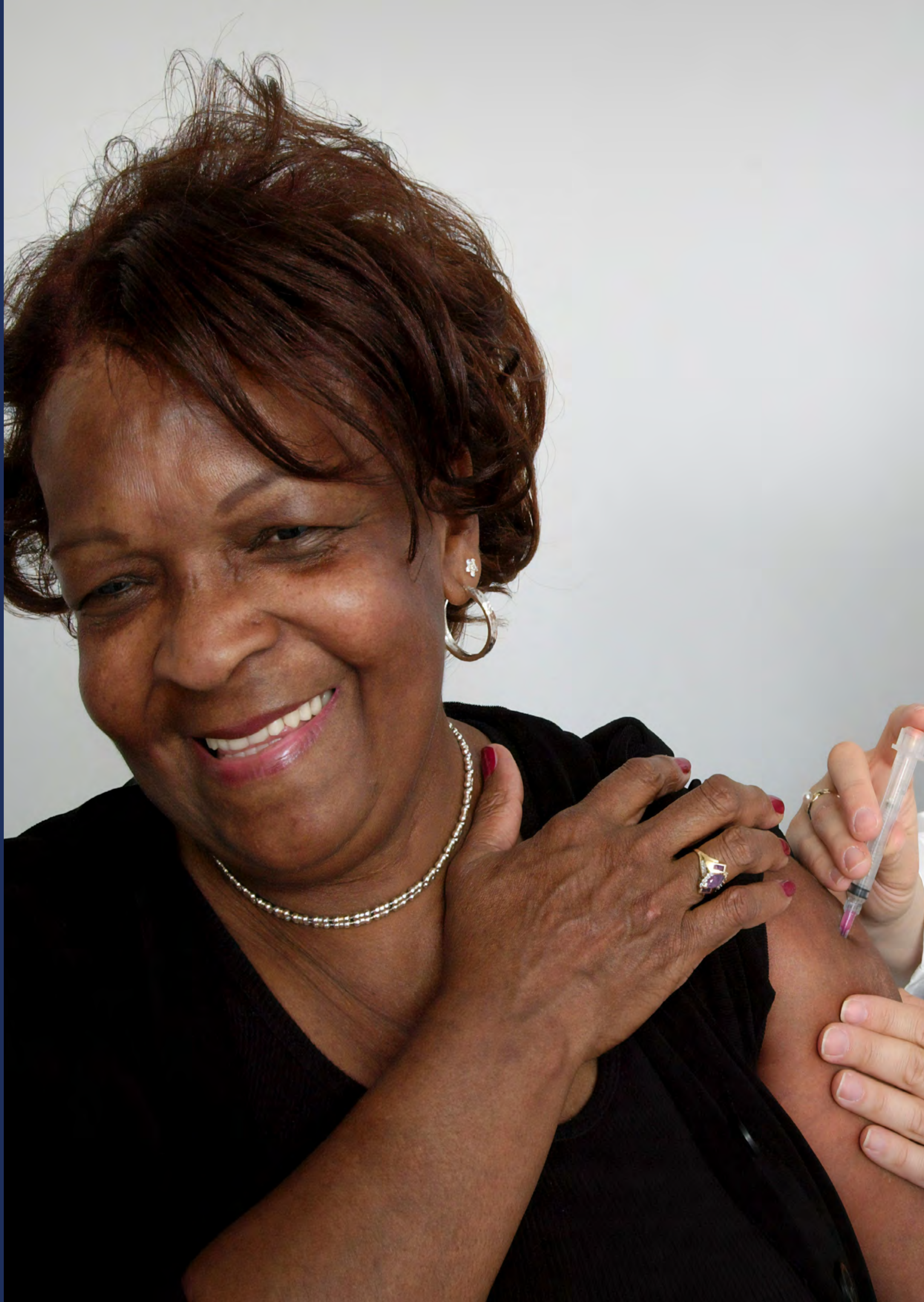
Those designing services	Those delivering services
Make sure that the services you are designing regularly engage with those people who have ongoing health and care needs as you make changes to services – codesign and coproduction should be at the centre of all service design.	Ask people how they are 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.

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.



Appendix A: Original I Statements[9]

Coordinated, person-centred health and care

Summary:

"I can plan my care with people who work together to understand me and my carer(s), allow me control, and bring together services to achieve the outcomes important to me."

My goals/outcomes

- All my needs as a person are assessed.
- My carer/family have their needs recognised and are given support to care for me.
- I am supported to understand my choices and to set and achieve my goals.
- Taken together, my care and support help me live the life I want to the best of my ability.

Care planning

- I work with my team to agree a care and support plan.
- I know what is in my care and support plan. I know what to do if things change or go wrong.
- I have as much control of planning my care and support as I want.
- I can decide the kind of support I need and how to receive it.
- My care plan is clearly entered on my record.
- I have regular reviews of my care and treatment, and of my care and support plan.
- I have regular, comprehensive reviews of my medicines.
- When something is planned, it happens.
- I can plan ahead and stay in control in emergencies.
- I have systems in place to get help at an early stage to avoid a crisis.

Communication

- I tell my story once.
- I am listened to about what works for me, in my life.
- I am always kept informed about what the next steps will be.
- The professionals involved with my care talk to each other. We all work as a team.
- I always know who is coordinating my care.
- I have one first point of contact. They understand both me and my condition(s). I can go to them with questions at any time.

Information

- I have the information, and support to use it, that I need to make decisions and choices about my care and support.
- I have information, and support to use it, that helps me manage my condition(s).
- I can see my health and care records at any time. I can decide who to share them with. I can correct any mistakes in the information.
- Information is given to me at the right times. It is appropriate to my condition and circumstances. It is provided in a way that I can understand.
- I am told about the other services that are available to someone in my circumstances, including support organisations.
- I am not left alone to make sense of information. I can meet/phone/email a professional when I need to ask more questions or discuss the options.

Decision-making including budgets

- I am as involved in discussions and decisions about my care, support and treatment as I want to be.
- My family or carer is also involved in these decisions as much as I want them to be.
- I have help to make informed choices if I need and want it.
- I know the amount of money available to me for care and support needs, and I can determine how this is used (whether it's my own money, direct payment, or a 'personal budget' from the council or NHS).
- I am able to get skilled advice to understand costs and make the best use of my budget.
- I can get access to the money quickly without over-complicated procedures.

Transitions

- When I use a new service, my care plan is known in advance and respected.
- When I move between services or settings, there is a plan in place for what happens next.
- I know in advance where I am going, what I will be provided with, and who will be my main point of professional contact.
- I am given information about any medicines I take with me – their purpose, how to take them, potential side effects.
- If I still need contact with previous services/professionals, this is made possible.
- If I move across geographical boundaries I do not lose my entitlements to care and support.

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[9] Original document: https://www.nationalvoices.org.uk/sites/default/files/public/publications/narrative-for-person-centred-coordinated-care.pdf

> ***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

National Voices

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