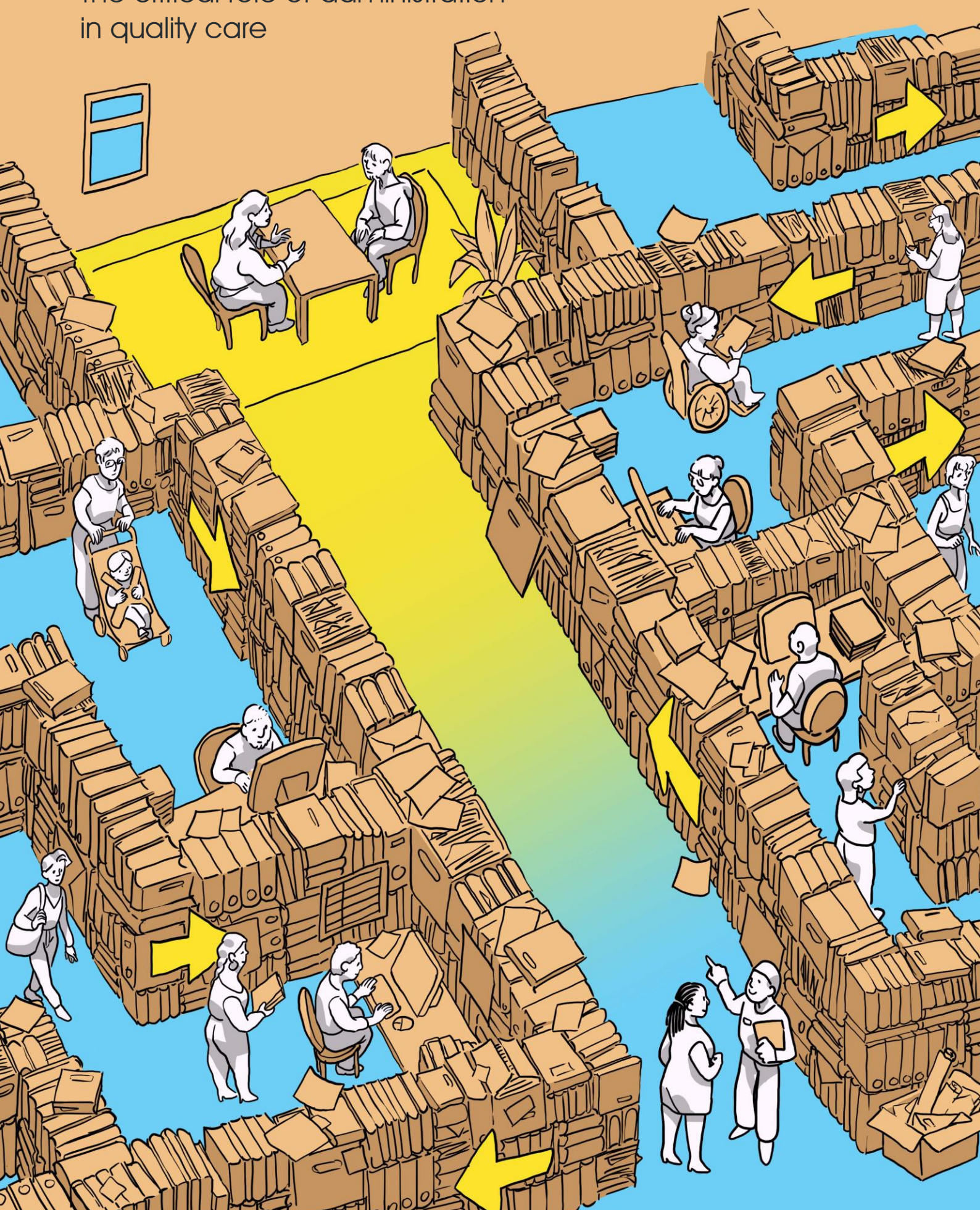


# Paper Works:

The critical role of administration  
in quality care



# Foreword



*Everyone should feel valued as they interact with the healthcare system. But many people encounter issues with administrative processes that create barriers to a good experience of care.*

*Administrative errors, poor communication, use of acronyms, inaccessible language and formats often frame the experience of care, as they set the scene at the start, conclude the tone at the end of an interaction with the care system, but also often run all the way through periods of ongoing healthcare. Therefore, it is really important to ensure that we get this communication and the processes right as we know it will affect a person's perception of the overall care and may in fact detract from a really excellent experience at the point of care.*

*National Voices have worked with The King's Fund and Healthwatch England to create interesting and thought-provoking insights into this underexplored and consequently less understood area of a person's experience. This report provides a good basis for further co-production work to take forward the recommendations outlined in the report. Completing that work will require energy, resources, and dedication from all areas of healthcare and staff will need to be supported, especially given the last year with the impact of COVID.*

*This report gives the NHS a sound starting point to explore improvements that we can make together co-producing with patients, carers, staff, and voluntary sector organisations.*

*I look forward with the Heads of Patient Experience (HOPE) Network to working with National Voices as part of our person-centred communication workstream to take this work forward from a secondary care provider perspective.*

**Lesley Goodburn**, Experience of Care Lead for Provider Improvement and Lead for the Heads of Patient Experience (HOPE) Network, NHS England - NHS Improvement

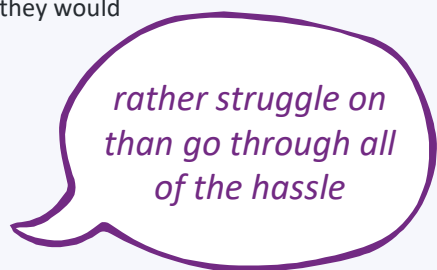


# Executive Summary

National Voices is a coalition of health and care organisations from the voluntary and community sector working together to democratise and humanise health and care. Through gathering in-depth insight from people who frequently access a variety of health services, we explored what NHS administration looks like from a patient perspective, and the impact it can have on people's lives.

This report is not singling out a select group of 'administrators', but exploring NHS administration in a broader sense, which refers to all processes surrounding the direct delivery of care: the before, the after, and in-between. We recognise that back or front office staff are too often disregarded, blamed or side-lined, but these findings highlight that administrative processes and staff are pivotal to a healthcare service fit for purpose and, as such, improving administration needs increased attention and energy.

Administration is a gatekeeper and enabler to quality care; when these processes go wrong, the impacts go far beyond mere inconvenience. For people with substantial needs who rely on the functionality of health and care services for quality of life, administration not only cuts to the heart of their healthcare experience, but to their wellbeing and life more broadly. When administrative processes are not accessible, patients can be thrust into stressful, even unsafe situations, experience low value care, or find themselves excluded from accessing care altogether. One research participant reported that instead of getting the care they need, they would



of administrative processes.

We found that the administrative problems within the NHS can be divided into:

- Bureaucratic barriers
- Disconnect between NHS services
- Human and system error
- Rigid rather than compassionate and responsive process
- A lack of inclusive and effective communication.

Research participants reported that such administrative problems in the NHS can affect people in direct and indirect ways, including:

- Causing distress
- Straining relationships
- Financial cost for patients and services
- Reducing trust in health services
- Undermining people's dignity and privacy
- Exacerbating physical health problems
- Consuming people's time.

## Poor administration may:



**Waste resource and time** of patients and carers as well as highly pressurised healthcare staff and systems.



**Exacerbate ill health,** cause distress and increase pressure on relationships.



**Undermine dignity and privacy** of patients, especially those who have specific communication requirements or who are struggling with stigma.



**Erode trust** in the health system resulting in people delaying seeking support.



**Embed inequity** as people with more time, or higher literacy, knowledge or income will be more able to overcome obstacles.



Moreover, we expect that these impacts will be unequal. Though everyone can experience poor NHS administration as frustrating and as a barrier to accessing care, people with confidence, good literacy, or without specific accessibility requirements are more likely to be able to overcome barriers, develop coping strategies, know their rights, understand their options, and chase communications. By contrast, people who do not have those advantages are more likely to be detrimentally affected by administrative failures, further exacerbating existing health inequity. One interviewee said, *“It isn’t the way it should be, but if you phone you’re seen quicker. It’s the classic thing of ‘those who shout the loudest get what they need’.”*

We recommend that the NHS urgently looks to improve administration, tying in with its current priorities of tackling health inequity and helping a pressurised and at times exhausted workforce become more efficient in the face of rising unmet need. Improving administrative processes will allow healthcare staff to focus their time on ways of working that create value for people, instead of wasting energy on inefficient, bureaucratic or complex processes – more important than ever after the past year and a half of unprecedented pressure. Key goals which need to be achieved to improve patient experience and thus, health outcomes, include:

- Improved care coordination.
- Personalised patient communications.
- Central involvement of experts by experience in the design and delivery of health services – including the relevant administrative processes to facilitate them.
- Improved workforce understanding of the importance of good administration and compassionate communication.

Our insight – albeit based on a small sample of interviews – suggests that as it stands, these goals are not being reached – and asking ‘why not?’ is central to the sector’s agenda of inclusion and equity. Smooth administrative processes are essential for an integrated healthcare service, so system designers need to focus on simplifying admin and supporting staff – and in the meantime, teams and organisations may have to work across boundaries with a focus on communication and enabling equitable access – sometimes by finding bespoke solutions.

Personal narratives in National Voices’ recent publication, [Unlocking the Digital Front Door: Keys to Inclusive Healthcare](#) illustrate how the seismic shift towards virtual and remote care necessitated by the COVID-19 pandemic exacerbated access and administrative barriers in many cases. The issues caused by unreliable or inadequate process predate digital service models – and it is clear to see that new digital platforms and changes are not simple solutions to the complex administrative issues that need to be resolved.

We recommend that reform programmes in the NHS, for example around primary care or elective waits, pay detailed and sustained attention to the kind of administrative processes that are needed to facilitate good care. This report illustrates that conducting and sharing further insight work and progressing strategic coproduction is vital, both in terms of understanding staff experience and deepening understanding of patient experience. Engaging administrative staff – through initial training and ongoing support – will be paramount, as their work directly facilitates good care. Together, those providing, designing and using services can work to improve systems, and in turn, build trust, address inequalities, and improve people’s health and wellbeing.



# Acknowledgments

---

Thank you to our colleagues at The King's Fund and Healthwatch England for sharing our learning and thinking. Thank you to SignHealth for their contribution and consistent support. Thank you to National Voices' member charities for their insight and to National Voices' core team who work hard to amplify patient experiences and make positive change – especially to Ella Wright, Policy and Insight Officer. Thank you to Savannah Fishel, Policy and Engagement Officer, who led this project. Thank you to our designer Jen Sangwin ([Sangers & Mash](#)) and illustrator [Lucie Arnoux](#). Most of all, thank you to all the people who gave us their time and were generous and thoughtful with sharing their experiences, which were at times distressing. We are so grateful.



# Contents

---

7	<b>1. Introduction: What is NHS administration and how we understand people's experience of it</b>
8	<b>2. What we found: problems in NHS administration</b>
8	<b>2a.</b> Bureaucratic barriers to accessing care
10	<b>2b.</b> Disconnect between services
12	<b>2c.</b> Human and system errors
13	<b>2d.</b> Rigid rather than compassionate and responsive process
14	<b>2e.</b> Lack of inclusive and effective communication
17	<b>3. What we found: The impacts of poor administration on people</b>
17	<b>3a.</b> Causing distress
18	<b>3b.</b> Straining relationships
18	<b>3c.</b> Financial cost for people and services
18	<b>3d.</b> Undermining confidence in health services
19	<b>3e.</b> Undermining people's dignity and privacy
19	<b>3f.</b> Exacerbating people's physical health problems
20	<b>3g.</b> Consuming people's time
21	<b>4. What better NHS administration looks like</b>
23	<b>5. Conclusion</b>
24	<b>6. Appendix</b>

# 1. Introduction: What Is Administration and How We Researched It

National Voices undertook insight work in partnership with Healthwatch England, the independent champion for people using health and care services, and The King's Fund, a charity and research organisation working to improve health and care in England. Read about Healthwatch England's insight into the role of NHS administration in improving people's experiences of care [here](#). The King's Fund have produced a long read entitled [Admin matters: the impact of NHS administration on patient care](#) which similarly argues that high-quality NHS admin processes can improve patient experience, help to address inequalities and promote better care. Their long read suggests a framework for improving the quality of administration based on insight from patients, carers and NHS staff.

## What is administration?

We took the lead from our interviewees, who defined NHS administration as:

*"Appointments, dealing with gatekeepers, receptionists, switchboards, and people coordinating or not coordinating care".*

*"Everything other than the face-to-face meeting with the doctors and transport providers. Medical care and the transport providers are excellent. The service is excellent. Arrangements leading up to that is giving all the problems."*

*"Letters, phone calls, emails, texts: not doctors and nurses but all the people in between."*

*"Admin includes: the process of making appointments; appointments running smoothly; ensuring people are at the right place at the right time and the right information is shared to make an appointment worthwhile; write ups and follow ups; getting the supplies that we depend on: prescriptions, supplies etc; and regular reviews to check supplies, for instance equipment such as wheelchairs."*

The above definitions illuminate that patient-facing administration is broad, and that people encounter different aspects of administration through the lenses of their individual experiences. According to The King's Fund definition, administration can be roughly divided into: (1) back-office work related to general functioning, such as human resources, procurement, payroll; as well as patient related administration, such as bed allocation, room bookings, equipment booking, and (2) front-office work, including referrals, appointment booking, discharge, with systems such as electronic health records straddling both.

This project focuses on front office administration which involves direct contact with patients. It also includes straddling processes, such as patient records, as they are explicitly used in patient-facing communications such as appointments.

## How we approached understanding administration:

The King's Fund interviewed a small number of staff working in NHS services, reviewed existing literature, analysed relevant publicly available datasets and incorporated the findings of Healthwatch England and National Voices into their work. Each organisation contributed to a shared understanding of what is going on for people, but is also taking forward their own conclusions. National Voices conducted insight work in the form of interviews and an interactive workshop. Our research provides insight into the impact of poor NHS administration on patients, service users and carers.

We consulted with National Voices' member charities on what they have heard about administration from their beneficiaries and conducted in-depth interviews with nine people who have experience of using more than one NHS service. Our interviewees included people who are living with, or care for someone who is living with, long-term conditions including dementia, cardiac problems and arthritis, among others listed in the appendix. The conversations were led by the interviewee, with participants encouraged to share stories, and open-ended questions asked such as:

- What does NHS administration mean to you?
- What have your experiences been with NHS administration?
- What are the consequences of this for you?
- What would good administration look like to you?

We also hosted a workshop for 10 British Sign Language users in collaboration with the charity SignHealth. The workshop surfaced many pitfalls of NHS administration which will be relevant for people from other cohorts with specific access needs, such as individuals living with physical or learning disabilities, for whom English is not their first language, who cannot read or write, or who do not have a proven address, telephone or access to the internet.

Most of our research was conducted before the outbreak of the COVID-19 pandemic, and as such it is important to acknowledge that we adapted our methodology after the project commenced. Our plans originally included engaging people from NHS England and the Care Quality Commission, and codesigning priority solutions through in-person workshops, which then was no longer possible. We recognise that many of the conversations may have been different during the height of the pandemic, but it is likely that the findings are not only relevant, but possibly exacerbated, as the NHS has been put under extreme pressure and unmet need has risen exponentially.

## 2. What we Found: Problems in NHS Administration

This report identifies key themes falling out of administrative problems raised by interviewees. Two overarching issues that cut across various themes are counterproductive rigidity of process and communication that fails to meet access requirements. One research participant said,

*It is set up almost like a triage system, so a staff member can do the appointments but they can't go beyond what they're allowed, it's almost like they follow a strict rule and it's not their fault and often they feel quite frustrated for you as well.*

A lack of options or flexibility to meet diverse needs, as well as communication failures with the patient and internally amongst staff teams, were commonly reported. The [Accessible Information Standard](#) legally requires healthcare services to follow a specific and consistent approach to meeting communication needs but many experiences of our interviewees suggest that too often the standard is not met.

The administrative problems identified in this report can be broadly separated into:

- Bureaucratic barriers
  - For example, regulations which make accessing appointments complicated, requiring people to get re-referred each time instead of allowing routine follow-ups or easy routes back into a service.
- A lack of integration between services
  - For example, updated patient records not being shared with appropriate clinicians after referrals.
- System and human error
  - For example, misplaced or incorrect forms, patient records and invite letters.
- Rigid rather than compassionate and responsive process
  - For example, a lack of privacy in communications such as letters and hospital announcements, or staff interactions that at times are perceived as unfriendly and uncaring.
- Lack of effective and inclusive communication
  - For example, the use of inaccessible jargon, or access requirements such as British Sign Language interpreters not being met.





## 2a: Bureaucratic Barriers to Accessing Care

“Very often not a single person but the system is to blame.”

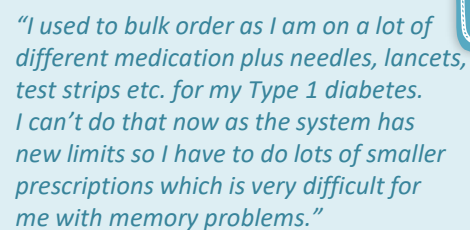
A recurring theme amongst interviewees was too many complicated levels and unnecessary hoops to jump through before receiving care, wasting valuable patient and staff time. Research participants reported:

### Inflexible and complex processes compromising healthcare staff’s ability to help:

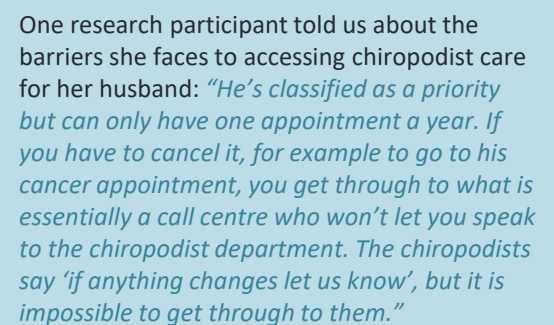
- Participants reported cases of receptionists refusing to let patients speak with a doctor and various interviewees mentioned that not allowing routine follow ups, particularly for community care, exacerbates excessive rigidity of processes as *“a physio, GP or paediatrician has to do a referral and treat it as a whole new case even though the person is well known to them”*. One participant who is a carer for her daughter said: *“It’s vital to get through to wheelchair services to make adjustments to make sure my daughter isn’t in pain or doesn’t become deformed so these long waits are a real problem. Referrals bring so much more bureaucracy: forms to fill in etc, instead of just allowing a 20-minute follow up.”* Some GPs are requiring patients to go to pharmacies before booking appointments, which one participant described as *“a waste of time and effort for me, the GP and the pharmacy. There’s no flexibility.”*
- Interviewees raised concerns around the process required to get supplies or medicine – even if it is repeat prescriptions and to treat long term conditions. *“We can’t run out of medicine, nappies, syringes, feeding formula – and there’s four or five different routes I have to go through, not counting GPs.”* A research participant who has various long-term conditions caused by a head injury said, *“each time I think, ‘how many times am I going to have to ring the pharmacy?’ Last time it was a dozen. I didn’t used to have this hassle now I have nothing but hassle.”*
- Telephone numbers are frequently not direct, but the beginning of a long process of complicated and repetitive phone interactions. One participant said, *“You’re poised at the phone from 7.30 and you just can’t get through, our practice is so oversubscribed. It is hard enough trying to get through to a GP, never mind when you’re feeling ill.”* One participant told us of her experience jumping through hoops to speak to a clinician in an urgent situation, *“You can wait forever for 111 to answer. I asked for a doctor but she put me through to a community nurse, who said you need to speak to a doctor. I lost a quarter of an hour in a stressful situation.”*

### It is necessary to develop workarounds to combat the system’s bureaucracies:

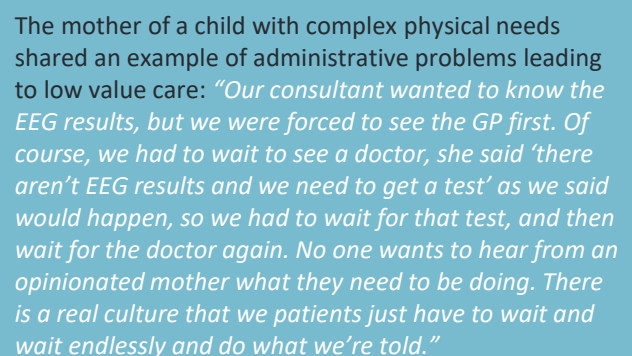
- Interviewees raised the point that those who lack the knowledge or ability to mitigate the effects of poor administration will likely be affected disproportionately. One participant said, *“My husband had cellulitis on his leg and woke up with a big blister. I was trying to speak to a doctor, but the surgery said I had to wait or ring 999. As soon as I said I’d phone the practice manager, they suddenly let me speak to a doctor. But a lot of people wouldn’t have been aware they can use their practice manager and carry on through the receptionist.”*
- *“You figure out what to say so you can get what you need. If I have to phone the GP I won’t phone up and say hello I need to sort a prescription, I’ll phone up and say hello can I talk to Dr X because they’ve told me to phone in that situation. It makes you feel like you’re manipulating people.”*



*“I used to bulk order as I am on a lot of different medication plus needles, lancets, test strips etc. for my Type 1 diabetes. I can’t do that now as the system has new limits so I have to do lots of smaller prescriptions which is very difficult for me with memory problems.”*



One research participant told us about the barriers she faces to accessing chiropodist care for her husband: *“He’s classified as a priority but can only have one appointment a year. If you have to cancel it, for example to go to his cancer appointment, you get through to what is essentially a call centre who won’t let you speak to the chiropodist department. The chiropodists say ‘if anything changes let us know’, but it is impossible to get through to them.”*



The mother of a child with complex physical needs shared an example of administrative problems leading to low value care: *“Our consultant wanted to know the EEG results, but we were forced to see the GP first. Of course, we had to wait to see a doctor, she said ‘there aren’t EEG results and we need to get a test’ as we said would happen, so we had to wait for that test, and then wait for the doctor again. No one wants to hear from an opinionated mother what they need to be doing. There is a real culture that we patients just have to wait and wait endlessly and do what we’re told.”*

## 2b: Disconnect Between Services

“No one takes responsibility in admin... there is endless finger pointing and feedback is ignored.”

Patients fail to receive a joined-up care experience when services and clinical staff (such as consultants, psychiatrists, GPs, operational staff etc...) do not communicate – for instance on patient requirements, care updates and task assignment. Staff members and services can end up blaming one another when patients or clinicians are not aware of important information, and such communication failures can expose patients to unnecessary risks. Interviewees told us that they experienced the system working in silos, with staff only allowed to do certain things in their remit, and clinicians failing to manage expectations of patients as they are referred to a different service. Research participants reported:

*The disconnect between services means that when things go wrong it isn't picked up until far down the line.*

### **A failure of intelligence sharing, and contradictory information given out from different services, resulting in low value care and unnecessary risks:**

- *“None of the different departments contact each other”:* there is a lack of communication between: the GP, who is aware of specialist needs, and hospitals providing services; between hospitals when patients are moved; between different services for patients with complex needs; as well as administrative staff who repeat the same questions which have already been asked according to interviewees.
- A participant with early onset dementia reported receiving contradictory advice from clinicians in different services, for instance, *“Talking to neurologists meant I realised how much damage my epileptic fits had done to my endocrine system. The endocrinologists just said no to this, they said to ignore it. There's such a difference between the two.”*
- Local services do not have access to notes from other boroughs, which is especially problematic if a person in crisis finds themselves away from home. An interviewee who attends a specialist community mental health team told us: *“Sometimes when I'm in a crisis I'll bolt, I end up in a different borough. I've been detained by police in a different place that doesn't have access to my notes. There needs to be a way for the burden not to be on me to have that information.”*
- Participants reported transport services falling through or last minute changes not being communicated to the patient.
- One interviewee felt that *“many of our appointments aren't worthwhile as the correct information just isn't there”.*

## Confusion over which service is appropriate, even from within the system:

- Different services point patients away from themselves, back to places they have already tried. For instance, when condition-specific or emergency numbers are unresponsive, patients go to A&E and are met with frustration and told that they should have contacted their specialist. Respondents reported having to go to different services because their original attempts to access care were unsuccessful, for instance, *“My friend fell and texted 111 like you’re supposed to, but nobody came, so they rang an ambulance”*.
- Automated forms from the GP telling patients to see condition-specific nurses when they are already registered with consultants elsewhere, or patients being referred to the wrong places, for example which do not offer their treatment.
- Patients being sent back to where they have already been is a common experience.

## Accountability and responsibility either not explicit amongst staff themselves, or not communicated to patients:

- Interviewees shared examples of a clinician saying that a person is on a waiting list, or that changes to medication have been recorded, but the paperwork had not been processed. *“Although you may have multiple providers, no one is really overseeing it, no one is checking that this has worked, except the patient really, and you’re not in a position to do very much about that.”*
- *“There is very little interaction between NHS and social care in my city... Services don’t interact when people are ill. Nasty, blaming letters are flying about – this is the last thing that’s needed in a difficult situation.”*



One interviewee who cares for her daughter who has a variety of complex conditions including dystonia, epilepsy and curvature of the spine told us, *“My daughter was due to go under general anaesthetic twice at roughly the same time. The absolutely obvious thing would be to do both tests under the same general anaesthetics – they were tests, not operations. I remember asking them: could these be done together? Everyone agreed it was possible, but the admin wouldn’t allow it. If cardiology wanted to make it work, they could. It just wasn’t a priority for them, not really on their radar.”*

An interviewee with Meniere’s disease told us, *“I’ve been under three departments over the last five years. I have a rare problem that they don’t fully understand. I had an ENT appointment sometime last year. I was referred over elsewhere to see an audiology consultant who did some tests. He said he would write up the notes and send them back to an ENT consultant. It took a few months to get appointment with the ENT consultant, who hadn’t received notes despite that being the whole point of the appointment – to discuss the audiology consultant’s report. I emailed the hospital who said they did send it to the GP and ENT consultant. For some reason somewhere along the system they didn’t have the notes despite them being sent over. It was a waste of my time to turn up without anything to say.”*

*“I was in hospital at night, and the staff were suddenly panicking and giving me injections. They didn’t explain anything to me and said that there was not time to source an interpreter. My GP was already aware that I was at high risk of blood clots, yet there was a failure of communication as the information was not passed on.”*

## 2c: Human and System Errors

“There’s always some error. Every time. I can’t correct every letter, but I try to remind them when I go back so it is better the next time.”

The people we spoke to frequently described receiving incorrect information causing unnecessary risks, struggling with glitching systems, and failing to have their expectations managed appropriately. Participants reported:

### Inaccuracies in patient communication:

- Insufficient and incorrectly recorded notes containing important information such as dosage. One interviewee who has engaged with many NHS services throughout her daughter’s life said, *“The clinic letters are incomplete. They might leave off a heart condition, or epilepsy. Yet, they might include a squint my daughter was treated for as a toddler. It’s totally random.”*
- One interviewee described an experience in an ENT clinic where *“the wrong child was called in and photos taken of their ears.”*
- Physical letters inviting people to arrange appointments continuing even when the suggested appointment has been rejected via a digital form, or a reschedule/cancellation letter sent before original appointment letters. One interviewee reported that this particularly confused other people in her dementia care group.
- One interviewee *“had to apply to the GP twice as they lost my first application form. My parents also signed up, but I had to chase the surgery as their accounts had been set up incorrectly and they didn’t have access to see their test results or their medical records.”*
- Names being called in one waiting room and not another when the patient has been sent to the other, resulting in missed appointments.

### Digital prescription services failing:

- Apps decide whether patients are taking their medication properly and can incorrectly stop prescriptions, forcing people to seek out a prescription again through their doctor.
- A participant reported ordering medication via an app three times with no option to cancel without cancelling everything.
- One carer reported incorrect supplies arriving; *“For his catheter bag – they send three different lots. When wrong medication or supplies are sent, nobody – including the chemist – will have it back. It’s a total waste.”*

*“Over the three years I was seeing a psychiatrist I received three letters, the last one about what was happening one year before. My medication changed five times in that time. My GP had no letters through. Mental health admin doesn’t seem to exist”.*

*“I did a bit of digging and found that my Type 1 diabetes, coeliac disease and Asperger’s had all been tagged as ‘inactive’ because of a system fault, meaning I’d apparently been cured. The GP said they’d got a new system in but had got in contract staff to migrate data from the old system who had no medical experience. She said that she’d checked all her other patients’ records as she was worried that their details had also been entered incorrectly. The information about the system specifics hadn’t been passed to medical personnel when the new system was rolled out.”*



## 2d: Rigid rather than compassionate and responsive process

*“You have to make allowances, be flexible, you can't make hard and fast rules because people don't fit in boxes.”*

Participants felt that staff were overworked and stressed themselves, and as a result patients can feel that respectful and personalised patient communication is no longer a priority. National Voices' recent [publication on the emotional support needs of people living with long term conditions](#) (and #AskMeHowIAm campaign) emphasises the importance of compassionate interactions between staff and patients – and argues that, because mental and physical health are intertwined, people should be treated holistically instead of creating arbitrary barriers. The impact of negative interactions with administrative staff shows us that administrative staff and processes are absolutely central to the delivery of a positive care experience. Automated and digital systems – and therefore the switch to virtual care necessitated by COVID-19 – have in many cases exacerbated these issues, and the use of such communications may be inappropriate or problematic when sharing triggering or complex information. (See National Voices' research [The Dr Will Zoom You Now](#) and [Unlocking the Digital Front Door: Keys to Inclusive Healthcare](#) for more on digital and remote care.) Transport presents problems for anyone trying to access in-person care, but such barriers are particularly difficult to overcome for people living with conditions that make travelling difficult. Interviewees reported failures in patient transport services, long journeys at inconvenient hours and relying on carers and family to attend appointments, often when the booking logistics have failed to take into account specific access requirements. Research participants reported:

### Insensitively written communications:

- Letters highlight the cost of consultations as a warning not to miss them, which participants reported to be stressful and degrading. *“People don't book appointments just for the laughs. People who read these letters are not the people who need to hear the costs.”*
- Interviewees spoke about letters failing to treat confidential information as such and sometimes using alarmist messaging.

### Inflexible interactions with administrative staff:

- One interviewee said that when she rings the pharmacy about her prescription *“They say they've ordered it then I ring weeks later and they say they were too busy to order it. It's so much hassle and they won't be honest to me.”*

*It absolutely matters what receptionists are like. All those things make a difference.*

- Staff members are pressurised for time and some interviewees perceived experiences of communication as robotic or even rude, resulting in low value care. One interviewee said, *“There is a lack of understanding. We're constantly using the services and relying on them and there is no sense that they might think about what that might be like. Some staff have the attitude that people are trying to get things they don't need or aren't entitled to and that is simply not a way to deal with parents of disabled children. They're trying to ensure clinicians' time is taken up by people who need it most, but they aren't always qualified to make that decision.”*
- One interviewee described her experience trying to maintain stock of necessary medical supplies to manage long term conditions, *“I am very conscious of NHS resources and I make them last a very long time.. I always feel a little bit on the backfoot because they seem to think we're trying to get what we don't absolutely need.”*

*“I went to A&E I told them I have dementia – I told the nurse, ‘I want to bring my husband because I will forget what you're saying’. The nurse practitioner muttered, complained, and said that having dementia doesn't matter – they can't have too many people in at once.”*

*“We needed an appointment urgently due to a broken wheelchair. There's barely been a week where we haven't been at a hospital. I had to give up my job to manage all this – and the receptionist said that there was one single opportunity to come and get the chair fixed, and that was that. I remember crying because it was all so difficult – I am more hardened now – and I remember she said, ‘Are you crying?!’ I remember her tone in my head still. It was the final straw. If I didn't turn up to work the next day I would lose my job. This was less to do with systems and more to do with the kind of people you employ”.*

A participant with Type 1 diabetes told us, *“After telling the nurse and receptionist that I couldn't make appointments before 12.00, as I don't drive and have to take 3 buses, I got an appointment rescheduled for 10.30. I could only get through to voicemail to the number on the letter and eventually gave up. Instead of being seen every four weeks, it will be three months.”*

*“When my Meniere's is particularly bad, I babble, I'm incoherent and paralytic, almost like an epileptic attack. When I went to see the GP I said ‘I can't go on like this’, and the GP said the cost of calling an ambulance is X amount of pounds, so he told me to dial a taxi instead which I am physically unable to do during a Meniere's attack.”*

## 2e: Lack of Inclusive and Effective Communication

“The key is flexibility: people with invisible conditions might look quite normal, but they are struggling to process and interact with the services.”

Interviewees made it clear that offering informed choice is vital. Failing to communicate in ways that patients can engage with risks making it impossible for them to engage at all; meeting accessibility needs (and abiding by the [Accessible Information Standard](#)) is not a luxury, but a necessity. People reported a sense of injustice in that certain people will be able to mitigate the impacts of poor communication and access essential information more successfully than others, thus exacerbating and embedding inequalities in health outcomes. A lack of communication causes risks to patient health and is a major barrier to accessing care.

We focused a portion of our research on people with hearing impairments, but their experiences of administration speak volumes about barriers for people with specific accessibility requirements. Research participants reported:

### Overcomplicated or insufficient information:

- Research participants reported feeling overwhelmed by pre-appointment information and inaccessible jargon: *“usually there’s a great wad of paper coming with your appointment information. It’s too much – a whole bundle of letters. At every appointment they ask your ethnicity and they don’t even want the form when you get there. It’s ridiculous – it doesn’t change. It’s a useless piece of paper.”* Another said, *“I am always bemused at how much the NHS must spend on postage... We went through an outpatient phase where every appointment was confirmed by two letters and a text.”*
- *“You don’t get any news when you’re on the waiting list. People have complained so bitterly about it at our community wheelchair service. You have to keep following up.”* (See National Voices’ project on people’s experiences of waiting for care, [Patient. Noun. Adjective](#), which explores how delays and cancellations affect people’s lives and includes practical steps for mitigating the impacts of waiting.)

*I am up at 5am to look after my husband, so when do I have time to read a 25-page booklet? As well, we need verbal explanations. However bad the news is, we can cope with it. Explain why you’re doing tests, explain to the patient what to expect.*



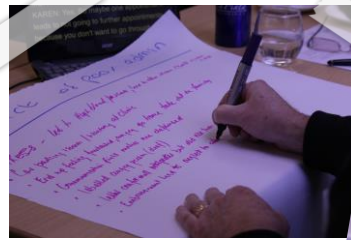
## Respondents highlighted the importance of different communication options:

- Many participants mentioned drawbacks of phones, relying on family members to make calls and translate symptoms. One interviewee with severe mental illness reported that they are *“phone call phobic, especially out of the blue. Too many hospital appointment confirmations are by phone and come through as private numbers with robotic appointment tools which are impossible to follow. If they have my number, why not text?”*
- Written communications (necessary for people with hearing impairments) require high English literacy and language skills.
- Many people do not have access to digital resources, and participants reported that appropriate training is not provided for various digital systems: *“I am computer literate but it took me a long time to even get into the Patient Knows Best platform. I didn’t even understand what it was at first.”* (See National Voices’ two research projects on [remote care](#) and [digital inclusion](#) for more information and advice on inclusive service design and delivery.)
- Sometimes it is important for healthcare professionals to communicate to the patient themselves, and at other times it is appropriate to communicate with their carer. One full-time carer said, *“They will ask him a question – but his answer is just random because he doesn’t understand. I want them to explain to me first, as a carer. I know that their time is short. But I can explain it to him.”*
- One attendee of our British Sign Language workshop said, *“There are no reasonable adjustments to meet Deaf people’s needs”*. Participants pointed out that:
  - Not all Deaf people sign, yet the system often fails to recognise this.
  - A lot of people in the NHS are not native English speakers, so lip reading is difficult as their lip pattern is different.
  - Participants reported booking of foreign language translators instead of British Sign Language interpreters and being charged via text for missed appointments when the patient attends but the interpreter does not.

## One size does not fit all

We collaborated with SignHealth to host a workshop with British Sign Language users where people discussed experiences of administration and what better administration would look like. Many of the experiences and ideas shared in this workshop feature in this report, but communication that does not recognise or meet the requirements of Deaf people was by far the most common concern of participants.

- When interpreters are booked on people’s behalf, as was frequently reported, preferences are not considered, for example *“a female patient may want a female interpreter”*, especially if they are discussing a gender-specific condition.
- *“When errors are made, for instance two interpreters are booked, we are victimised and told that we’re expensive.”* One participant said that this emerges because Deaf people are rarely involved in high level decision making: they felt that *“Deaf people... are not valued.”*



## Concerns over one-way communication:

- One-way text services or postal letters do not give the receiver agency. One participant who receives appointment bookings via post said, *"You're told out of the blue, 'your child has an appointment on this day at this time' and you might have another appointment, or you might be away, then you have to figure out how to follow it up. Why can't it be done by email or text? Wouldn't it save money?"*
- Respondents reported missing a call and being removed from a list in the system and having to return to the referral stage.
- If a name call is missed in the hospital, that patient may lose their place in the queue. An interviewee with a hearing impairment told us, *"I went to A&E reception to ask to be told when my daughter's name was called. I'd missed it two hours earlier."*



A patient with a long-term mental health condition reported, *"I had an endocrinology appointment but I was in a crisis so I couldn't call them to cancel. The hospital have an online form I could fill in but it didn't go through so they just discharged me."*

Letters arriving both via Patient Knows Best and the post *"confuse a lot of members in the dementia group. Often people with dementia don't even have computers, or they're wary about it and don't want to use it"*. Another participant told us that her husband, who has vascular dementia *"is unable to use the telephone. As soon as he has answered he has forgotten what they have said. So, he hears it is ringing and calls me. By the time I get there we've missed it."*

After one round of radiology, a participant had *"heard nothing since. No follow up and it was months ago. Whilst we were in hospital, communication was great. Then we never heard anything after."*

*"We called an ambulance for pneumonia but there was no interpreter. How do you get an interpreter in an emergency situation? It is common to call on a family member. Where is the personal dignity?"* Another Deaf participant said, *"I cannot communicate as there is no interpreter, so I don't know what the injections they give me are. I have cancer and have almost died many times. I'm not improving, I'm getting worse."*



## 3. The impacts of poor administration

“There are people who are in constant pain or can’t go out because they are just waiting to be seen. It really can be the difference between being able to live a good life and not.”

Frequent experiences of poor administration can have a cumulative impact over time on people’s lives, but individual incidences can also have severe consequences. People with specific communication needs or additional requirements are likely to be less able to mitigate the consequences of weak administration and as a result, can be impacted disproportionately.

### 3a: Causing distress

Interviewees identified feelings of shame, frustration, embarrassment, worthlessness and a decline in self-esteem. Some people described traumatic experiences and remain aggrieved by the administrative processes they encountered at difficult times, for example:

- *“Five years ago my mum died and I didn’t know all the information as to why. I was the last person to know because nobody was using Sign. My mental health deteriorated.”*

*I shouldn’t have to psych myself up to call the wheelchair service and then recover afterwards. It can be adversarial, and there’s a sense that you’re constantly making demands you’re not entitled to make.*

- *“Poor admin has made it more difficult to cope with all of my conditions. It causes you a lot of distress that may not be seen. My GP not getting my letter about medication should just annoy me, but it’s more than this, it makes me very stressed.”*

*You feel like you’re not that bad, like you don’t deserve to get help. Even having a formal letter acknowledging you were about to be seen would make a difference.*

- *“This whole experience has made me very anxious. The system – meaning the widest possible system, including social care and education as well – could either make anxiety worse or help, and often it is the former. When I hear from the GP surgery ‘the GP hasn’t authorised this’ about a prescription I’m thinking ‘why? What if we run out? When will they authorise it?’ I’m constantly anxious.”*
- *“Waiting for a diagnostic assessment is anxiety inducing because I don’t know where I stand, I don’t know what to expect. With the autism service I’m just in limbo. I don’t know how to explain myself to people. You start to internalise it in a way and think the system is the way it is and I can’t change it so you sort of just start to feel almost like it’s your fault that you can’t get your needs met. If you need to keep pushing for things over and over again you start to blame yourself for it.”*
- *“If my prescriptions get screwed up it makes my anxiety worse. The experience I had was triggering. I feel powerless.”*



### 3b: Straining relationships

Interviewees reported that feelings of frustration and resentment transferred onto other areas of their lives. Respondents also remarked that administrative failures increase pressures on carers, family members and friends, especially when they are needed to carry out tasks, accurately mediate communications or accompany people to appointments. When awaiting information, interviewees reported being unable to make plans with people and cancelling at last minute due to a lack of agency over appointments. People also described the impact on relationship dynamics when clinicians engage with young people instead of their carers, or carers instead of patients, because accessible communication requirements are not met.

- *“I have a friend who takes me to appointments. She gets very frustrated at the lack of help for Meniere’s disease. Notes aren’t available so she writes her own. By the time we’ve waited for an appointment, she is far more annoyed than me. It almost makes me think I should ask for someone else to help me. On a couple of occasions she has written to the healthcare trust, but all she gets back is a generic letter”.*
- An interviewee who described constantly chasing up communication said, *“All this has made me grumpier! Everyone I interact with, such as my family, is affected by that a bit. You become impatient, despondent about the world, less convinced you can get what you need without it being a massive battle. It is hard to for it not to impact your life. It’s made me a grumpier parent.”*

### 3c: Financial cost for patients and services

Taking time off work for appointments (which are sometimes cancelled anyway), not receiving necessary letters to prove appointments or diagnoses to employers, and the costs associated with accessing care all have negative impacts. For instance, travel, parking, interpreters and phone calls – especially when numerous follow ups are required – all cost money. Not only do administrative inefficiencies cost patients money, but unnecessary appointments, misplaced records and misunderstandings cost the NHS, especially when patients are pushed to try to access services which are less appropriate for their condition.

*If I had been treated it would have saved money but it got worse and worse, ending up more expensive*

- One interviewee shared the experience of their grandson who made an appointment, phoned in the morning to confirm, and only at that point was told it was cancelled. *“He was given no reason and had already taken annual leave.”*
- A research participant with dementia said that *“Parking is so expensive I now rely on my husband to pick me up and drop me off – it is too difficult to battle with parking.”*

- An interviewee in her 30s with Ehlers-Danlos syndrome told us that, *“After having a seizure, I wrote to my neurologist to fill in a form for the DVLA, which sat on their desk for over 6 months without being filled out. In meantime I can’t drive. Access to Work partially paid for taxis, as I can’t use public transport. It cost both me and the government.”*
- Interviewees report being expected to cancel their appointment via phone if they are unable to make the appointment – which interviewees with hearing or memory impairments reported as an inaccessible method of communication – or being fined £60 for missing it.

### 3d: Undermining Confidence in Health Services

Interviewees reported that bad administrative experiences can amass resentment of the system, and dissolve trust in healthcare services altogether. Interviewees reported fatigue from being repeatedly asked for feedback but witnessing no visible changes.

- *“From now on I’ll only go to A&E. I won’t bother with anything else because the surgery doesn’t respond. I don’t feel supported.”*
- *“It confirmed my worst fears about the system. I used to work in health and social care policy, so I had a strong impression of how it all worked and I had a reasonably good sense it was difficult for people to get what they need. My experience has reinforced that. Sometimes when you know how it is supposed to work and it still doesn’t, it makes you feel even worse... We are very lucky to have service free at the point of delivery, and it is good in an emergency, but the less high-profile community services struggle – what about some obscure rehab centre in some unglamorous town? It is still the NHS even though it isn’t in a shiny hospital. The system works much better for some than others.”*
- *“I won’t trust that NHS services will have done anything useful. The damage has been done, I don’t believe that anything is going to be different.”*

*Referrals were getting lost, so I stopped going to the dentist when I was 14. Because I’ve had episodic eating issues, I’ve not been able to get myself to go back. A care coordinator referred me to a specialist dentist, she said she would chase it up and I still haven’t heard anything. I have just decided to live with it. It’s going to get worse. I’m just quite cynical about it all. I’m tired. You have to spend so much time justifying why you need what you need. The admin difficulties, and the way you have to fight through gatekeeping, and everything set up to be as unfriendly as possible, it works in conjunction with the fact you know the services are overstretched. The thresholds for accessing services are really high. You feel like you have to justify yourself. It’s a constant reminder that you’re getting something precious that you shouldn’t feel like you have a right to. I know intellectually everyone has a right. It’s hard to transfer that to yourself when there are all these barriers.*

### 3e: Undermining People’s Dignity and Privacy

Interviewees reported that attempts to communicate with patients who have access requirements can spark privacy concerns, as well as feelings of disempowerment caused by being disregarded or sidestepped.

- *“There was no interpreter at the hospital so the staff were talking directly to my young hearing child, but I wanted to explain to them that she is coeliac so she requires gluten-free food.”*
- Various participants raised concerns about healthcare staff disconnected from patients yet making decisions on their behalf in meetings. *“Talking about me without me: they just said if I’m not happy, make a complaint. There’s something wrong here.”*
- *“A new audio and visual appointment announcement screen has been installed at the GP surgery, which I’m happy about because I worry that I’ll miss being called if I’m in a fugue state, which I’m prone to especially in stressful situations like waiting rooms. However, the system announces and displays full names and titles. I spoke to my GP about privacy concerns and she’s raised this with surgery management but nothing has been done two months later.”*
- An interviewee described her experience of using the Patient Knows Best digital platform: *“You get a faceless email saying someone has looked at your records online which is frightening. I had one come in, I had no idea who it was from. It didn’t say it was from my neurologist who I saw months ago, which I finally found out that it was. It is not fit for purpose.”*



### 3f: Exacerbating People’s Physical Ill Health

Participants have avoided getting help because of traumatic administrative experiences, access barriers and safety concerns, resulting in poorer health. Miscommunications, for instance caused by inaccessible jargon or error, also create unnecessary risks for the patients, especially when important information is being communicated such as dosage or self-medication advice. The stress caused by poor administration in itself can lead to health problems, for instance high blood pressure, as well as the physical exertion of attending many appointments when coping with a chronic condition.

- One interviewee reported that her husband’s patient passport was not read, so he was inappropriately injected with warfarin, a blood thinner, despite previous haemorrhages. His health was impacted permanently and drastically resulting in ten hours of fits, brain surgery and life support for a month: he is *“no longer my husband. I lost him.”*

*My life has been on hold for 16 years, frankly, due to someone not reading a record.*

*I told my hospital. Now there’s a big notice on his file to read all records – my doctor told me. Well, they should do that on everyone’s files! He lost his emotional side, logic and short-term memory. He went out like a light. He slowly got worse, and three years later was diagnosed with cancer and diabetes.”*

A participant who uses British Sign Language said *“barriers create more stress, and our health gets worse.”* Another told us that administrative complications have directly worsened their condition, as *“stress is known to contribute directly to Meniere’s disease.”*

- A respondent shared her experience of waiting to access care: *“For ten minutes I was held at number twelve in the phone queue trying to get patient transport whilst I was in the ENT, which was closing, and they couldn’t give an approximate time. I cannot sit here for hours on end and get chronic headaches from stress. My choice was getting vertigo on a bus or sitting indefinitely on the phone with a chronic headache.”*

### 3g: Consuming people's time

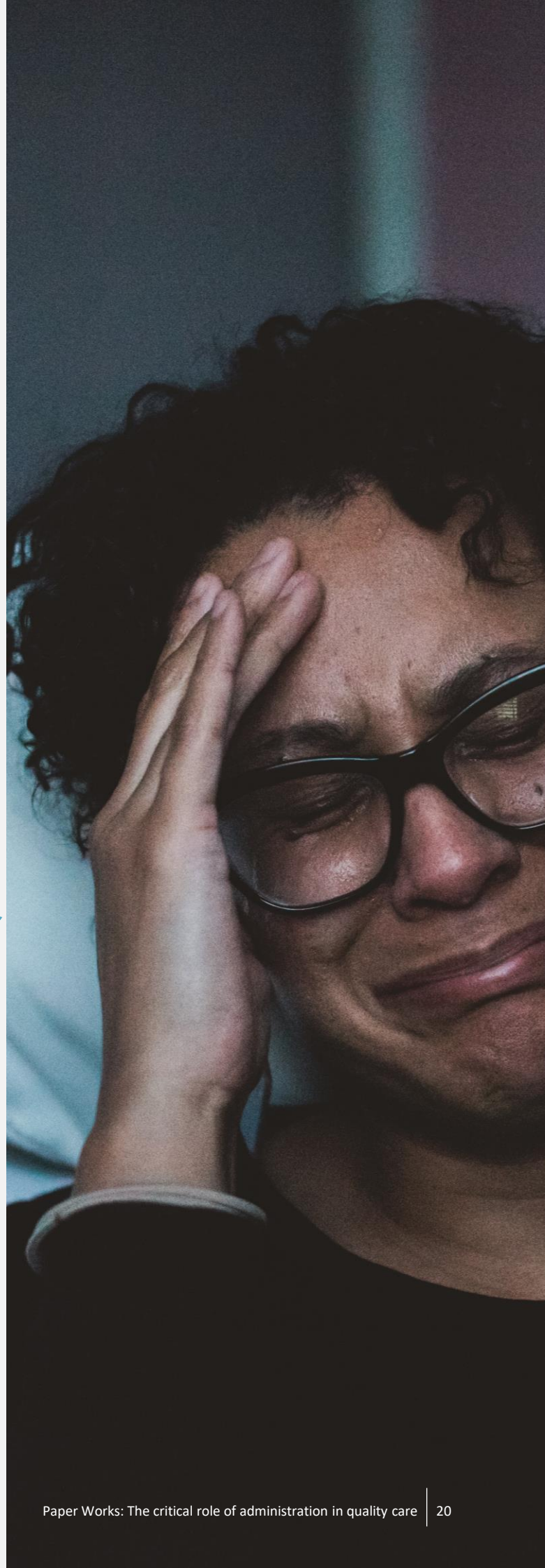
Interviewees made it clear that engaging with services takes up time, as does surrounding inefficient administration, for instance, waiting for calls back – resulting in intense stress about these being missed – filling in lengthy forms, explaining situations numerous times to various people, inappropriate travel, correcting mistakes, attending cancelled appointments, learning to operate complicated changing systems and recruiting helpers who may already be overstretched.

- *“I have to go into a GP because I can't book an appointment over the phone. I queue up at 8am and no slot is guaranteed.”*
- *“I try to book the first appointment of the day to avoid sitting two hours in the waiting room. I try to make the system work for us instead of us constantly being at the mercy of it. My time is not valued. That applies across the board. Waiting for half the day, having to weigh up one appointment over another, having to turn up to the hospital three times in a fortnight thinking we could have gone just once, having to make repeated calls to chase people”.*
- *“I just think I cannot fit in hanging around for a whole day today where I've got to be at an appointment for my daughter or my brother.*

*And I think I just can't do this, I've got a life. So you just don't bother. You just think I'll just carry on, I'll just self-medicate.*

*Which isn't healthy. You know so there are times when I know I should have gone, but the effort has just made it so impossible”.*

- *“Outpatients talk to each other, and we know we're given the same times. It's something patients have always complained about, and the NHS says it doesn't do it, but it does do it! And it needs to not do it! We always get some confusing explanation about why things have to be that way and you sort of lose the will to live as you listen to it. It would be nice if patient time was valued more than it is. That's the politest way I can put it – I've spent years of my life just waiting. This tends to be at hospitals not community care services.”*



## 4. What Better Administration Looks Like

“Stress less, live longer, save on costs, that is our dream.”

The aim of this report is to share people’s experience of administration and raise awareness about how important smooth and accessible administrative processes are. However, many of our participants did share examples of good administration and ideas for improvement. We propose an analysis into the causes of poor administration before formal recommendations for improvement can be offered. We have grouped improvement suggestions into four themes. These themes are unsurprising, and many patient and advocacy groups have made them before. The fact they surface again here indicates that we need to address administrative processes if we want to make progress on these long-standing goals.

### 1: Coordinated care

“I want joined-up thinking between clinicians. Coordination and togetherness.”

This research focused on people with long term conditions who are accessing various NHS services at the same time. The insight shows that if services fail to communicate with one another, patients can have a fragmented care experience in which different areas clash and contradict. One participant said, *“One thing that has always been clear is that there is zero coordination in the system. Each clinical area works on its own. They don’t talk to each other, no one overviews it – is that too much to ask? For someone to say ‘we are making this family come in three times this week’ and take into account all the relevant clinical areas.”*

Central to a joined-up care experience is naming those who are responsible for what and ensuring this is communicated across departments. One research participant said, *“Generally, the NHS admin side works very well. With a little bit of forethought and integration between departments it would be so much better. Why do we need strict guidelines where admin staff only work for one department? Why is it not integrated? People should be retrained to do things correctly in a joined-up way.”* Various interviewees emphasised the importance of having a coordinator responsible for overseeing a person’s care, who ensures notes are shared between the right people, appointments do not clash, and who can arrange for separate appointments to be merged where possible.

### 2: Personalised and consistent patient communications

“Deaf people are not all the same – different people have different needs and require different communication strategies.”

If information has not been communicated accessibly, it has not been communicated at all. Various workshop attendees agreed that NHS services need to *“properly monitor and implement Accessible Information Standards”* and consistently offer different communication options to patients. *“If they know they have disabled patients, for instance, they should tell us clearly where we can park, how close it is, if we have to pay etc.”*

One research participant who engages with both endocrinologists and dementia care said that healthcare staff *“band together and make decisions in meetings. They won’t listen to what I know is wrong with me.”* Listening to the patient is vital in order to meet their needs and make it possible for a variety of people to access and benefit from care, so it should always be the case that all relevant records are read and understood by staff, such as health history, medication, dietary needs and communication preferences. Information about patients must be considered and consulted on, for instance offering transport options or adjustments if required.

Participants emphasised that communication should come down to choice, for example, if someone is living with a hearing impairment, options should be offered such as Makaton, British Sign Language, lip reading, notes, Deafblind hand-on signing and phonetic speech-to-text technology, though participants recognised that the latter is expensive. Other specific suggestions included professionally translating consent forms into British Sign Language as participants said that relying on a family member is not appropriate. Some participants suggested in-house interpreters, while others emphasised the right to choose an interpreter: *“No department takes ownership of booking interpreters. We should be booking them ourselves”*.

Designing administrative systems which are simple is important to improve administrative processes for both staff and patients. Participants said that they want uncomplicated and consistent systems to contact GPs and hospitals such as two-way text.

Communicating directly with patients – or their carers if this is their preference – is especially important when patients are waiting for care and the recently published [Clinical Communications Standard](#), which mentions [National Voices’ research into people’s experiences of waiting for care](#), must be abided by. Services should also be required to offer specific explanations whenever administrative errors have occurred so that patients understand the situation and to allow positive changes to be implemented. As one participant said, *“Every time they make an error they don’t really investigate...They need to let me know why this problem happens and explain what they will do to avoid it in future. Instead, we get generic emails. There’s no real sincerity in apologies. It would save time in long run.”* National Voices’ recent publication, [What We Need Now](#), highlights that above all people feel that they are in a relationship with the system: people want to be listened to, communicated with and to know that they have not been forgotten.

### 3: Codesigning administrative systems

“It is vital to acknowledge that patients are a part of the NHS. You can’t have one without the other. The patient knows themselves the best.”

NHS system designers and policymakers must recognise that in healthcare the experts are those who have the experience; many participants agreed that that people know best what care and communication they need. People living with long term conditions should be represented in staffing, management, system planning and policymaking decisions. Interviewees reported that a lack of diversity and representation means staff do not have the required cultural understanding. *“At the end of the day they never ever bring Deaf employees into the system to help with awareness and to improve services. It’s really an important point, power and voice making.”* Codesign is not only important for new systems, but it is an ongoing process. Any changes that are made, particularly to patient communication systems, should be tested with a variety of patients and staff to ensure people are not excluded from accessing care.

In National Voices’ recent [Unlocking the Digital Front Door: Call to Action](#) we emphasise the importance of listening to people and offer five key principles for inclusive innovation and system design:

1. Make inclusion the core principle: inclusion first, not digital first.
2. Always co-design with people most at risk of exclusion.
3. Offer supported choice and personalisation: adapt communications.
4. Support staff and provide appropriate training.
5. Know that health is wider than healthcare and take into account patients’ broader circumstances.

National Voices and the Q Community are collaborating through the [Voices for Improvement](#) project to connect and support service users and patients involved in improvement – find out more about our work on codesign here.

*“There needs to be coordination between patient, doctor and admin systems. All should work together. It is not easy, but it is attainable.”*

### 4: Training and supporting all NHS staff on: cultural competency, sensitivity, the experience of living with long term conditions and the impacts of poor administration

“I can remember a time when the receptionists were more friendly. Now they’re often behind glass, they just seem like automatons, they don’t smile. All those things make a difference.”

Whilst staff perceived as uncaring can add to anxiety and deter people from engaging with their healthcare, friendly staff can help ease this anxiety and give people a sense of reassurance and control especially when administrative mistakes are made. Various research participants raised concerns that it is not always clear to staff how severe and far-reaching the impact of poor administration can be. *“There could definitely be training for administrative staff about what it is like to live with long term conditions, disability and medical complexity – and the fact that we have to talk to so many people about lots of different things, so that they understand.”* Many participants told us that if administrative staff understood the wider picture – for instance that patients or carers are trying to coordinate with other services simultaneously – they will be less likely to partake in a culture of suspicion: *“The system needs to be predicated on the idea that patients aren’t trying to game everything. It should be approached from the perspective that people act for a reason not out of malice or laziness. There should be a less blaming approach.”*

Participants also felt that staff need more training on social skills, cultural sensitivity and mental health needs, especially as they are frequently engaging with people in traumatic or stressful situations. British Sign Language users told us that *“we need good quality Deaf awareness and perspective training delivered by Deaf people.”* One interviewee shared his appreciation that at his mental health centre, he is acknowledged and given a cup of tea while he waits: *“When receptionists acknowledge the system’s barriers and are more empathetic and understanding it makes all the difference.”*

## 5. Conclusion and call to action

The experiences shared in this report illustrate that administration should not be considered an issue of convenience, or simply lumped in as ‘red tape’, but acknowledged as a critical feature of a healthcare system that is truly fit for purpose. NHS administration is a gatekeeper and enabler to healthcare, and when it falls short patients receive low value care, valuable resources are wasted and trust is eroded in the system. Too often it falls on the patient or carer to remind the NHS how they are entitled to be treated. This risks exacerbating health inequity as people are not equally able to overcome administrative obstacles and mitigate the effects of these. One participant remarked,

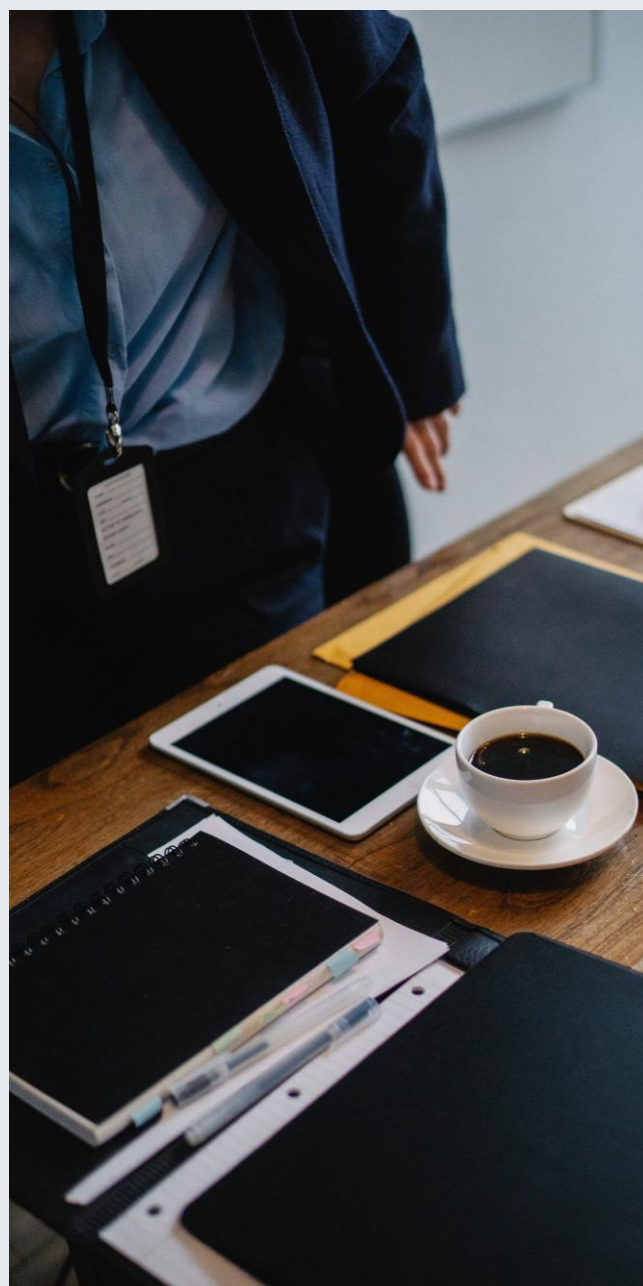
*Sometimes I'll accept it, sometimes I have to get snobby. But less outspoken carers, people who don't highlight the barriers, how do they cope? I'm worried about them. I've had to find strength to speak out.*

Failures in NHS administration can prevent people from accessing healthcare, so we cannot have inclusion without quality administrative processes. NHS administration is deserving of more focus and research than it is currently granted in healthcare policy in order to provide high quality care and ensure good use of time and resources. We suggest further work is conducted on this topic, focusing on five areas:

1. The causes of poor NHS administration, nationally and locally, which will involve understanding staff experience of administration.
2. The impact of COVID-19 on NHS administration.
3. Digital healthcare and exclusion – it is vital to acknowledge that administrative issues are not solved simply by making services digital, or outsourcing administrative tasks, which often shifts the burden from staff back toward patients. For more detail on digital exclusion, and the impact of COVID-19 on accessing healthcare, see [The Dr. Will Zoom You Now](#) and [Unlocking the Digital Front Door: Keys to Inclusive Healthcare](#).
4. Administration in other related services, such as social care or children's services.
5. Coproduction of good processes between clinical and clerical staff and people using services – what can be done centrally and what needs to be done locally?

We report here on only a small piece of insight work. Much more work is needed to ensure better ways of working shape better experiences and outcomes of care.

We have suggested some ideas for improvements, inspired by patient insight. However, all changes or potential solutions should be tested with patients and staff. Although often side-lined when considering patient experience, administrative staff and processes are integral to patient interactions with the healthcare system.



## 6. Appendix

The SignHealth workshop was held in-person on 13th March 11am – 3pm with SignHealth’s beneficiaries.

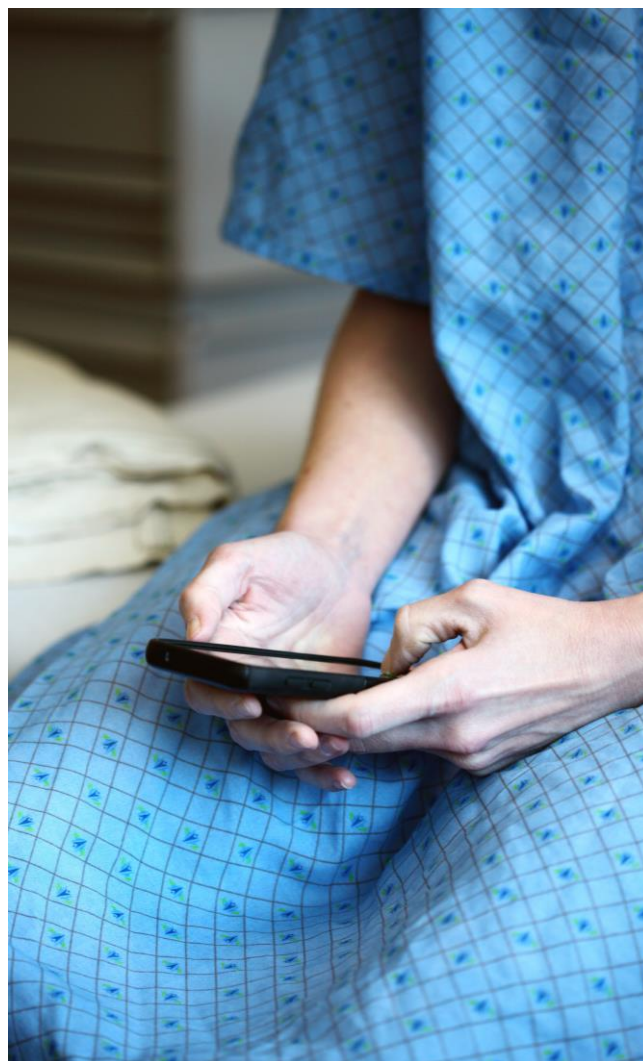
People volunteering to participate will be those most likely to have something to say and as a result this work will be biased by nature. The report is not intended to quantify the scale of occurrence of poor administration in the NHS, but rather to better understand what poor administration can look like for those who might be most affected by it and how it can impact them. It is safe to assume that those who have less flexible jobs or who are less financially stable will be affected to an even greater detriment. To find participants, a survey was sent out via National Voices’ member charities ensuring a variety of interviewees and diverse experiences.

The questions were:

1. Contact details
2. What is your gender?
3. How old are you?
4. Are you from a minority ethnic background?
5. Please confirm that you have more than one health problem or use more than one service?
6. What condition/s do you have?
7. Would you like to be considered for an in-depth phone interview (approx.. 60 mins)?
8. Would you like to be considered to attend a workshop on the 23<sup>rd</sup> March 11AM-3PM at The King’s Fund, London?
9. Do you think you could help us understand how people’s life circumstances impact their experience of NHS administration?
10. What does poor administration mean to you?
11. What type of poor administration do you feel you’ve had experience with? (Checkboxes)
12. What have your personal experiences of administration in the NHS been? Please be specific about an occasion or occasions where you’ve experienced poor administration.
13. When you’ve experienced poor administration, what impact has this had on your life? (Checkboxes)
14. Feel free to explain your choices above.
15. What do you think could have made your experience of administration better? Or reduced its impact on you?
16. Is there anything else you would like to share about this?

Two interviews were conducted in 2020, since the outbreak of the COVID-19 pandemic, whilst the other participants shared their experiences in 2019.

The full range of conditions which interviewees shared with us included the following: endocrine issues; sarcoidosis; osteoarthritis; rheumatoid arthritis; dystonia; gastrostomy issues; scoliosis; a blood clotting condition; depression; anxiety disorder; autism; schizophrenia; diabetes; injuries to (and replacements for) joints and bones; learning disabilities; foot fungi; Ehlers-Dhanlos syndrome; chronic migraines; dysthymia; vertigo; eating disorders; swollen adenoids; malfunctioning thyroids; Meniere’s disease; bladder conditions; keloid scarring; conditions caused by premature birth; asthma; cancer; diabetes; hearing impairments; coeliac disease; vascular dementia; seizures; epilepsy; brain injury; and cellulitis.





June 2021

---

National Voices is a registered charity, no. 1057711,  
and a company limited by guarantee, no. 3236543.  
The Foundry, 17 Oval Way, Vauxhall, London SE11 5RR

