DEMOS

the patients association

"I LOVE THE NHS, BUT…"
PREVENTING NEEDLESS HARMS CAUSED BY POOR COMMUNICATIONS IN THE NHS

TONI BRUNTON-DOUGLAS
ALASDAIR DE COSTA
PATTI GARCIA GOMEZ
ANDREW BRIGHTWELL
MIRIAM LEVIN

PMA

the patients association

NOVEMBER 2023

CONTENTS

ACKNOWLEDGEMENTS

Patients Association

At the Patients Association we believe patients should be actively involved in decisions made about their care and in the design of the health and care system. As an independent charity campaigning for improvements in health and social care, we believe improvements can only be achieved if the system works in partnership with patients.

We work in partnership with patients, health and care providers and organisations that regulate services for patients to improve both the experience and outcome of care. By using our set of patient partnership principles and working in partnership, we ensure the voice of patients is heard and acted upon.

We seek out the views, opinions and concerns of patients and enable them to tell us what they think by working directly with them, or via our free helpline, and from regular surveys of people who use health and care services. We deliver our work equitably, for the benefit of all.

PMA

The PMA is the leading professional membership body for non-clinical healthcare professionals, with a network of over 50,000 across the healthcare sector.

The PMA is a recognised institution and provider of professional services, which provides professional recognition, progressive professional development and career pathway support for non-clinicians across all healthcare environments. The PMA delivers learning opportunities and formal education programmes, together with a comprehensive portfolio of workshops.

The PMA is always appreciative of the support and engagement across our vibrant community of 50,000 professionals – which is key to the work we do and the impact we can have.

OUR CALL TO ACTION

In this report we make a powerful case for the urgent need to improve communication within the NHS. We demonstrate how fundamental good communication is to the quality of care and treatment that people receive and the levels of trust and satisfaction they feel. Communication and supporting administration should not be seen as a 'nice to have', but as fundamental to the functioning of the NHS.

We are calling on the government to recognise the critical importance of communication within our health system and to support the NHS to deliver improvements in this space.

Our work with the public, patients and staff on solutions suggests that relatively simple changes would make a big difference if they were consistently implemented across the country. In short, we are calling for:

1. **An expansion of the system of care coordinators** and improving access to clinicians with oversight of all the care received by people with complex conditions.

2. **An expansion of the system of care navigators** in GP surgeries across the country, helping people to navigate complex systems and linking people up with the right services.

3. **Improvements to the uptake and use of the NHS App** through improved functionality and greater publicity.

In these ways, we want to see good communication practice built into the architecture of the NHS, rather than handled as an afterthought. Alongside this, we also call for a cultural shift that places a new and vital focus on good and effective communication and patient partnership, and on the (non-clinical) staff and systems that enable this. One way to focus minds on this is for the NHS to ensure services measure and value their impact on patient experience.

We welcome the fact that some of these changes are outlined in the Primary Care Recovery Plan.[1] Our deliberative work offers further detail that would allow some of the recommended changes to be delivered in a way that puts the patient experience first.

By making communication between our health system and patients a priority and supporting the NHS to deliver the changes it needs to, we believe the government can bring about significant improvements to people's experience of care and their perceptions of it as an institution.

Polly Curtis
Chief Executive, Demos

Rachel Power
Chief Executive, the Patients Association

Ian Jones and Austin Ambrose
Directors, PMA

---

1   NHS England » Delivery plan for recovering access to primary care, https://www.england.nhs.uk/long-read/delivery-plan-for-recovering-access-to-primary-care-2/

EXECUTIVE SUMMARY

"It's a bit of a toxic relationship. I love our NHS – I will stand up for it all day long. But at the same time, I understand that it's quite damaged"

- Community Conversations participant

This project is the result of two years of engaging with just under 2000 members of the public, patients and staff about their experiences of the NHS, using deliberation, co-design, polling and discussion groups. This work exposed the fact that poor NHS communication is one the public's biggest issues with the NHS and a cause of their growing dissatisfaction with the service.

Poor NHS communication manifests in three main ways:

1. Difficulty accessing or navigating the health system because it is unclear what communication to expect or who to communicate with at different points.

2. Administrative errors creating inaccurate or erroneous communication leading to problems with care, treatment or experience.

3. Staff not being able to communicate internally or advise on next steps to patients because they don't know or understand enough about their medical history.

Staff and patients are needlessly harmed by poor communication in the NHS. Both staff and patients have shared that poor communication is undermining the patient experience, leading to poor outcomes, endangering patient safety and negatively impacting people's mental health. Poor communication is increasing the burden on already overworked staff.

This problem is widespread. 2023 polling found that over half (55%) of the public experienced a poor communications issue in the last five years. Over 1 in 10 people (11%) said their care or treatment had been affected by an admin or IT error. 17% have not known whether a referral made for them had been lost, and 18% did not know who to contact about care or treatment once a referral had been made. More than one in four (26%) have had to chase a referral themselves to ensure they got seen. 9% had a mistake in a communication they've received relating to their treatment.

Poor communication disproportionately affects some patients more than others. Disabled people, people with long-term health conditions and women are all more likely to report being affected by poor communication. For example, 22% men had to chase up a referral to be seen, compared to 29% women.

Poor communication is a priority for the public in deliberation. When they take the time to deliberate on the most important issues in health and care, improving NHS communication is the public's biggest priority after addressing the workforce crisis. It does not, however, come up as a priority if you measure public opinion

using measures of more instinctive views like polling or focus groups.

Poor communication is not prioritised sufficiently by politicians and NHS leaders. There is inadequate focus on addressing poor communication in the NHS at the moment, in part because of a misplaced sense that it is not a public priority compared to other issues like waiting times. This is despite the fact that polling shows that members of the public who reported having experienced poor communication in the last five years had poor views of the NHS as a result:

- 30% said it had damaged their trust in the NHS.

- 45% said it made them worry about the quality of care the NHS provides.

- 31% said it made them worry that NHS money is being wasted.

- 26% said it made them worry that NHS staff time is being wasted.

In co-design work run in partnership with the Patients Association and PMA, staff and patients drew up three possible ways to alleviate the worst impacts of poor communication:

1. **Expanding the system of care coordinators** and improving access to clinicians with oversight of all of the care received by people with complex conditions.

2. **Expanding the system of care navigators** in GP surgeries across the country, helping people to navigate complex systems and linking people up with the right services.

3. **Improving the uptake and use of the NHS App** through improved functionality and greater publicity.

But there is a broader, more structural problem that needs addressing. That lots of the solutions being implemented focus on supporting people to navigate ever more complex systems suggests there is something more fundamentally wrong with how the NHS does administration, and the complexity of the systems people have to contend with. The way the NHS does administration and bureaucracy is currently not meeting the needs of patients and ultimately the whole system will need reform. Non-clinical staff need employing in sufficient numbers and IT systems need to be made enablers of, not barriers to, good communication.

NHS, politicians and governments need a serious plan for how NHS communication will improve to improve patient experience and public confidence in the NHS. Public confidence in the NHS has deteriorated rapidly recently. To enable it to recover, politicians need to prioritise addressing the vector through which most people interact with the NHS most regularly - communication. Other solutions to problems in the NHS, relating to workforce, waiting lists and ambulance response times require longer-term solutions.

INTRODUCTION

> " *It's very difficult to be negative about something that's so precious and that we're so supportive of. It's a wonderful thing having free health care. Sometimes you feel really guilty for having to point out its weaknesses as well."*
>
> **- Community Conversations participant**

"I love the NHS, but…" was a common refrain amongst our research participants; the patients, NHS staff and members of the public who we asked to share their experiences of the healthcare system. There is a deep reluctance amongst people in the UK to criticise the NHS without first going to great pains to establish how proud they are of it as a national institution and how committed they are to the ethos of providing healthcare free at the point of use. Once their gratitude towards the NHS has been firmly set out, what follows the 'but' will be familiar to many of the millions of people who regularly use or work in the NHS:

"…I can't get through to book an appointment."

"…I wasn't told everything about my condition."

"… I can't access the information I need in order to treat patients in a timely manner."

In this report, we examine these and other examples of poor communication within the NHS that affect patients and staff. These communication issues were surfaced through our deliberative work with the British public that aimed to understand their health and care priorities, and develop those priorities into policies.

Poor communication is a problem across the NHS: in primary care, at the join between primary and secondary care, and across secondary care too. There are specific pain points, and often these examples of communication are between one part of the system and another, between members of staff or between the system and patients. Some participants raised issues with interpersonal communication between staff and patients inside clinical settings during our work, but these are a different cache of issues and so we have not directly addressed this in this report.

Sometimes, these experiences can be fleeting or quite minor: a name misspelt in an email, an errant text message or a letter arriving slightly later than expected. The cumulative effect of these, however, is damaging, and erodes public confidence that the system is organised and working effectively.

But often poor communication is more serious. Over and over again we heard stories from patients and staff of critical appointments missed, diagnoses not shared or shared too late, and referrals for treatment that simply went missing.

This can lead to harmful delays in care or treatment, it can detrimentally affect patients' mental health, and can cause unnecessary disruption to the health system.

And in some cases, poor communication endangers patient safety with tragic consequences. Recently, following the avoidable death of 13-year-old Martha Mills in NHS care, there has been an important discussion about rebalancing the power between staff and patients. At the heart of issues with Martha's care at King's

College Hospital, lay problems with communication between the doctors responsible for her. Merope Mills, Martha's mother, has been campaigning for the implementation of 'Martha's Rule' ever since; a rule that would give parents the right to ask for a second opinion from another medical team. Demos has worked with Martha's family to design the policy that underpins Martha's Rule. In her moving foreword to Demos' report calling for Martha's Rule, Merope describes some of the communication issues that so tragically hampered her daughter's care:

> *"On paper, Martha was allocated a named consultant at King's, but in practice this meant nothing. There was no name by her bedside, and a different consultant every day took up the reins of her care, starting from scratch, relying on incomplete notes written by junior doctors on the patient record."*[2]

But as it stands, improving communication – between the NHS and its patients as well as between members of staff within the NHS – is nowhere on the political agenda. And unsurprisingly, as a result, it's not an NHS priority either.

This is partly because, traditionally, communication issues are not seen as being a priority to the public. It's not something that comes out strongly in polling or focus groups. And whilst communication problems may be understood as something people do experience, they're often seen as less important than the 'real issues' in the NHS such as reducing waiting times or solving the workforce crisis.

We have used a mixture of approaches including co-design and deliberation, complemented with discussion groups and polling, to better understand what people want to see change. And when you take this approach and bring these groups together, starting with how people are experiencing health and care, they prioritise issues relating to patient experience, particularly improving communication in the NHS.

In this report, we share what we've learned along the way. We explore how poor communication is experienced by patients and staff, how it manifests as a public priority, and where the political space for action might be. We then point towards some potential solutions.

Ultimately, we hope this will trigger a much-needed debate about the importance of improving communication across the NHS, an aspect of the health system that has been neglected for too long and urgently needs addressing.

---

2   Merope Mills in Polly Curtis and Claudia Wood, "Martha's Rule: a new policy to amplify patient voice and improve safety in hospitals", Demos, September 2023, demos.co.uk/wp-content/uploads/2023/08/Marthas-Rule_finalversion.pdf

FIGURE 1
METHODS DIAGRAM

POLLING
Nationally representative polling, 2018, 2019, 2020

UK wide

COMMUNITY CONVERSATIONS
Distributed dialogues with capacity building
January - May 2021

101 conversations | 715+ people | England Scotland Wales

PEOPLE'S PANEL
Citizen's assembly
Autumn 2021

50 hours | 100 members | 12 sessions

IDEAS FOR CHANGE
Co-design with patients and staff
Summer 2022

9 hours | 36 participants | 4 sessions

RECONVENED PEOPLE'S PANEL
Citizen's assembly
Autumn 2022

9 hours | 69 members | 12 sessions

TESTING
Focus groups, national representative polling, and export engagement
November - December 2022

6 discussion groups | UK wide | Expert engagement

POLLING
Nationally representative polling, 2023

UK wide

METHODOLOGY

Through polling conducted in 2018, 2019 and 2020 we identified that improving health and care provision was consistently viewed by the British public as the greatest challenge facing the country. We then developed a two-year long process of deliberation with the public, co-design with staff and patients, and expert consultation. We aimed to capture people's experiences and views of health and care, establish the public's priorities for health and care and develop solutions to complex problems. The mixture of insights developed by using a range of different methodologies provided a unique insight into the attitudes of members of the public, patients, and those on the frontline.

COMMUNITY CONVERSATIONS

Our process started with a set of Community Conversations, bringing together over 700 patients and staff in 100-plus distributed dialogues, designed to include people from across the geography and demographics of the UK. Participants included members of the public, frontline NHS staff, care-workers, people who draw on social care and patients with complex or long-term conditions.

They discussed their experiences of health and care, what's working well now and what could be better. The experiences shared were often extremely powerful and moving. They shared times where they had been dismissed or not taken seriously, found themselves lost in the health system, not been told how long they'd have to wait for care or of being bounced from pillar to post.

Working with the conversation hosts, we drew out key themes through participatory sense-making. We then used polling to measure how widespread these experiences were among the public at large. The results of the polling and conversations were used to provide material for the next stage of discussion, at the People's Panel.

PEOPLE'S PANEL

We worked with Involve and Democratic Society to convene the People's Panel, a citizen's assembly of 100 members of the public, representative of people living in England, Scotland and Wales. Participants listened to the stories and viewpoints shared in the Community Conversations and engaged with sector experts. They were tasked with deciding – over the course of four weekends – which health and care issues should be prioritised and tackled first. Over the course of their deliberations, it was clear that they were leaning towards issues that could be broadly categorised as "patient experience".

By the final weekend, their top two priorities were dealing with recruitment, retention and training of health and social care staff, and tackling poor communication between the NHS and people. Specifically, they set out the poor communications challenge as being: **"Poor communication between different services, departments and patients leads to delays and gaps in receiving important care. This causes confusion, distress and disappointment for patients, especially for those with complex conditions and care needs".** They discussed waiting times too but overall were much more concerned about "poor information flow" between the system and patients and within the system, as well as what they saw as a "disconnected and inefficient" referral process. Concern about the lack of integration between health and social care was raised, but primarily described in terms of a lack of "signposting in a timely manner". The common underpinning they identified at the root of all of these problems: poor communication.

FIGURE 2
WHAT THE PEOPLE'S PANEL TOLD US ABOUT THE IMPACT OF POOR COMMUNICATIONS FROM THE NHS ON THEM AND THEIR LOVED ONES

Finding your way onto the system

- Wastes service users' money and time if signposted to incorrect providers, ie: wasted journeys, holiday, time off taken
- First point of contact system doesn't seem to work. Are the communications / IT systems fit for purpose?
- People slip through the net. Some people never get to see the specialist or get an appointment
- Current signposting and access to provision differs depending on your GP
- People feel lost and powerless
- People's conditions have worsened by the time they access services
- Length of time to get appointment
- Sometimes my issues are related but do not get treated that way

Referral to consultants/specialists

- Have had to chase services myself to ensure I would receive them
- No way of finding out where you are in the process
- People have a lot of chasing to do and it's exhausting
- Some but not all patient information is shared, and patients don't have access
- Staff negatively impacted as they do not have time to appropriately support people who may have been referred to the wrong service
- Short notice of cancellations / operations
- Poor communications causes stress and wastes resources
- Communication all comes in paper form
- Referred to wrong service delaying treatment
- Health and care haven't kept up to date with the latest medical, organisational and technological trends
- Delays in surgery causing conditions to become worse and causing bigger issues for patients

Navigating the system

- People don't know where they are in the process. This causes frustration
- Collaboration between services is especially important for people with multiple conditions
- Communication needs to be timely and relevant
- Having tests in one location and the data can't be accessed in other locations
- Specially affects any individual with multiple chronic conditions and multiple care issues
- Lack of coordination between services leading to people being sent to wrong or inappropriate services
- Patients need to keep repeating their story
- Poor communication creates cumulative effect of delays and negative experiences for patients
- When you are unwell, you have to coordinate your own care and it affects you mentally and emotionally
- Everyone can tell at least one story on their experience of this

Discharge/ leaving care

- Family members' experience of navigating system from hospital to care home
- Lack of care packages when discharged from hospital

IDEAS FOR CHANGE

Our next step was to take the People's Panel's framing and work with sector experts to engage staff and patients in devising solutions. We worked with Imperial College Health Partners to identify examples of best practice across the NHS (see Appendix 1), and then with the Patients Association and PMA to engage people with long-term health conditions and GP practice managers respectively to develop those examples into potential national-level solutions via co-design workshops. In doing so, we found again and again that this was an issue people had deep-seated feelings about and wanted to see tackled, both inside and outside the NHS.

We reached out to the public by contacting existing audiences and running advertisements on Facebook and Instagram, encouraging people to share their experiences of poor communication and how those experiences made them feel. Over 1,000 people responded in two weeks. We synthesised these stories to provide material for the co-design workshops, and much of it is shared throughout this report.

The ideas of those participating in the co-design workshops were fed into a reconvened People's Panel, who helped refine them and then voted on which they wanted to see taken forward.

TESTING

Finally, we tested the solutions co-designed by staff, patients and members of the public for salience in polling, and through discussion group message testing. We also tested their viability and relevance through interviews and roundtables with sector experts. Polling questions were repeated in 2023 to bring the data up to date.

CHAPTER 1
EXPERIENCES OF POOR COMMUNICATION

AN OVERVIEW OF THE PROBLEM

Poor communication, in one form or another, impacts the majority of people who use the NHS across primary care, secondary care and the joins in-between. Our most recent polling, conducted in September 2023, asked the public about a range of specific poor communication issues and found that over half (55%) reported an issue in the last five years.

We found that issues relating to, or caused by, poor communication are concerningly widespread. When asked about their experiences of health and care within the last twelve months, among the UK population:

- 8% had not been notified about something important relating to their treatment.

- 16% had not been kept properly updated whilst waiting for treatment.

- 9% had a mistake in a communication they'd received relating to their treatment.

- 14% had a problem with a referral.

This adds to the existing evidence base. The Patients Association's 2020 survey into patient experiences highlighted a gap between what patients want from NHS communications, and what they experienced. Of the patients surveyed, 66% said that communication was an important aspect of their care, yet 41% were not happy with the communication they'd received from clinicians and staff. 'Being listened to, believed, or taken seriously' was important for 68%, but only 38% felt they had been treated in this way. Finally, 'coordination between different parts of the system involved in my care' was important for 61%, but only 46% felt they experienced this.[3]

There is also evidence to show that communication errors can affect people in huge numbers. In September 2023 the BBC revealed that a single hospital trust had failed to send some 24,000 letters from senior doctors to GPs and patients over the previous five years because of an administrative error. They reported that "most of the letters explain what should happen when patients are discharged from hospital, but a significant number of the unsent letters are written by specialised clinics spelling out care that is needed… crucial tests and results may have been missed by patients". A similar story in *Pulse* in March 2023 found that another trust had failed to send 53,000 letters to local GPs due to an IT fault. Just two faults or mis-aligned processes in two hospital trusts led to 77,000 letters remaining unsent.

3   "Being a Patient", The Patients Association, July 2020, www.patients-association.org.uk/blog/new-report-being-a-patient

> *"My GP practice seems particularly bad at referring people properly. There have been numerous instances where I've personally had to chase radiology referrals that never reached the radiology dept, despite being assured by the GP that they would "personally do the referral". Many times I've been assured the referral would be "urgent", only to find it has gone through as "routine" and there's nothing anyone can do."*
>
> **- Participant via social media**

The results of poor communication between both patients and staff and between staff members themselves, range from inconvenience and irritation, to significant negative outcomes for people's health. It can prevent patients from being able to access the care they need, lead to errors in treatment and prompt situations where they have to explain their condition repeatedly. Ultimately, it makes them less satisfied with the care that they are given. When communication is found wanting, it often falls on patients to fill the gaps.

> *"You know in the good old days, you saw one GP and they knew your history the minute they looked at you. Whereas now, they're having to look back at the screen for records. They're having to look back to see what you've done and what you've had, or what have you. So there's no continuity there, is there?"*
>
> **- Community Conversations participant**

Which patients are most affected?

Unsurprisingly, those engaging regularly with the NHS feel the effects of poor communication most often and are most likely to raise it as a problem. This broadly includes people whose ill health or physical impairment makes them more reliant on the NHS, as well as bringing them into contact with those services more frequently and/or for longer periods of time than the average citizen.

For instance, the Patients Association looked into experiences over the pandemic and found that poor communication or a lack of communication were the most commonly raised issues by patients who were shielding or clinically extremely vulnerable. A typical complaint from this group was that people didn't feel their needs or health conditions were appropriately recognised or catered for when the NHS was communicating with them. Others highlighted the impression that those with chronic conditions or who are disabled but not in the 'shielding' group, had been forgotten.[4] They said they wanted healthcare professionals to 'check in' and communicate with them much more proactively, to ensure they had what they needed, knew where to go and generally make them feel seen and cared for. A lack of communication, exacerbated by the pandemic, left them feeling isolated and abandoned.

A key theme that emerged from our Community Conversations was that those with long-term and complex health conditions were particularly likely to bear the brunt of poor communication. The complexity of their conditions and the siloing of treatment into specialisms meant that people in this group were more likely to report having to disentangle communication errors between departments. And the regularity with which these patients have to engage with the system mean repeated errors in communication compound to become much

---

4   "Pandemic Patient Experience", The Patients Association, September 2020, www.patients-association.org.uk/blog/pandemic-patient-experience

more damaging and frustrating. It can even present a major barrier to getting treatment at all. For example, one person told us via social media that: "incorrect or inaccurate information has been passed on between medical professionals regarding my son's needs which meant that for three years he was being rejected from services he required… after three years he was finally accepted for a referral to occupational therapy as he needs a high level of support due to his complex needs." Being a patient can be particularly daunting when it is not clear that clinicians understand the details of what care or treatment you are receiving. For those with complex health conditions, this happens all too often.

> *"I've got loads of patients where they're dealing with one thing and the next thing is falling apart. And nobody is paying attention to that because nobody joins it all together."*
>
> **- Community Conversations participant and NHS staff member**

It is noteworthy that people with long-term conditions are also more likely to experience interpersonal communication problems too. Our 2021 survey showed half of people with long-term mental health conditions (47%) and two in five with long-term physical health conditions (38%) have recently been dismissed or not taken seriously by a doctor.[5]

> *"I have a chronic illness and so have frequent contact with both the NHS and contracted out services. Poor communication has the most impact when I am worried already and need help. The worst experience was with a contracted out GP's service for out of hours. They asked me to come to them and then forgot I was there for what seemed like ages. It was awful… they told me I should have reminded them I was there."*
>
> **- Participant via social media**

Disabled people and others who have specific accessibility needs are another group more likely to feel the adverse impacts of poor communication. We conducted polling on the experience of Disabled people when seeking NHS care in 2021. We found that 45% of Disabled people have been dismissed or not taken seriously by a healthcare professional in the last five years (compared to 27% of the general population).[6]

In our Community Conversations, lots of Disabled people shared their experiences of not having their specific communication needs catered for by the NHS, or at worst even anticipated or recognised in the first place. One participant, Wendy, told us that: "I am taken to hospital and I ask for an interpreter. They say, 'Oh, you can't because it's the weekend.' But we need interpreters 24 hours. Why don't they have a list of interpreters that can be contacted out of hours?" "I am profoundly deaf", one social media participant told us, "I sent an email to the local NHS Ear Nose and Throat department saying why I couldn't attend an appointment and that I couldn't make or receive phone calls because of my deafness. It was rearranged and then it was cancelled and the text said: 'please call this number to re-book'".

We also heard from people with learning disabilities that it can be particularly hard for them to navigate the system without support. One participant, Ben, shared that: "A lot of people who tend to care for people with disabilities like myself are not very good at doing things like form filling… you get told to get your friend to help you or [to] go do it yourself. Now, how can you do a form for yourself if you've got a learning disability?"

5   https://engagebritain.org/health-care-living-with-a-long-term-condition/
6   https://engagebritain.org/health-care-experiences-with-disability-summary/

> *"I'm being treated palliatively for cancer, there has been a number of occasions where I've not had bookings for scans that are due or overdue, so I'm now in the mindset that if I don't hear within a week of when they are due then I ring up the oncology or colorectal departments to chase them."*
>
> **- Participant via social media**

Our polling from both 2022 and 2023 evidences that the gender gap in health also manifests when it comes to NHS communication. Strikingly, in both surveys, for almost every example of poor communication we asked about, a higher proportion of women reported having experienced the issue than men. 61% of women reported having experienced at least one of the examples of poor communication we asked about in our 2023 poll, compared to 49% of men.

CHART 1
HAVE YOU EXPERIENCED ANY OF THE FOLLOWING WHEN SEEKING NHS SUPPORT?
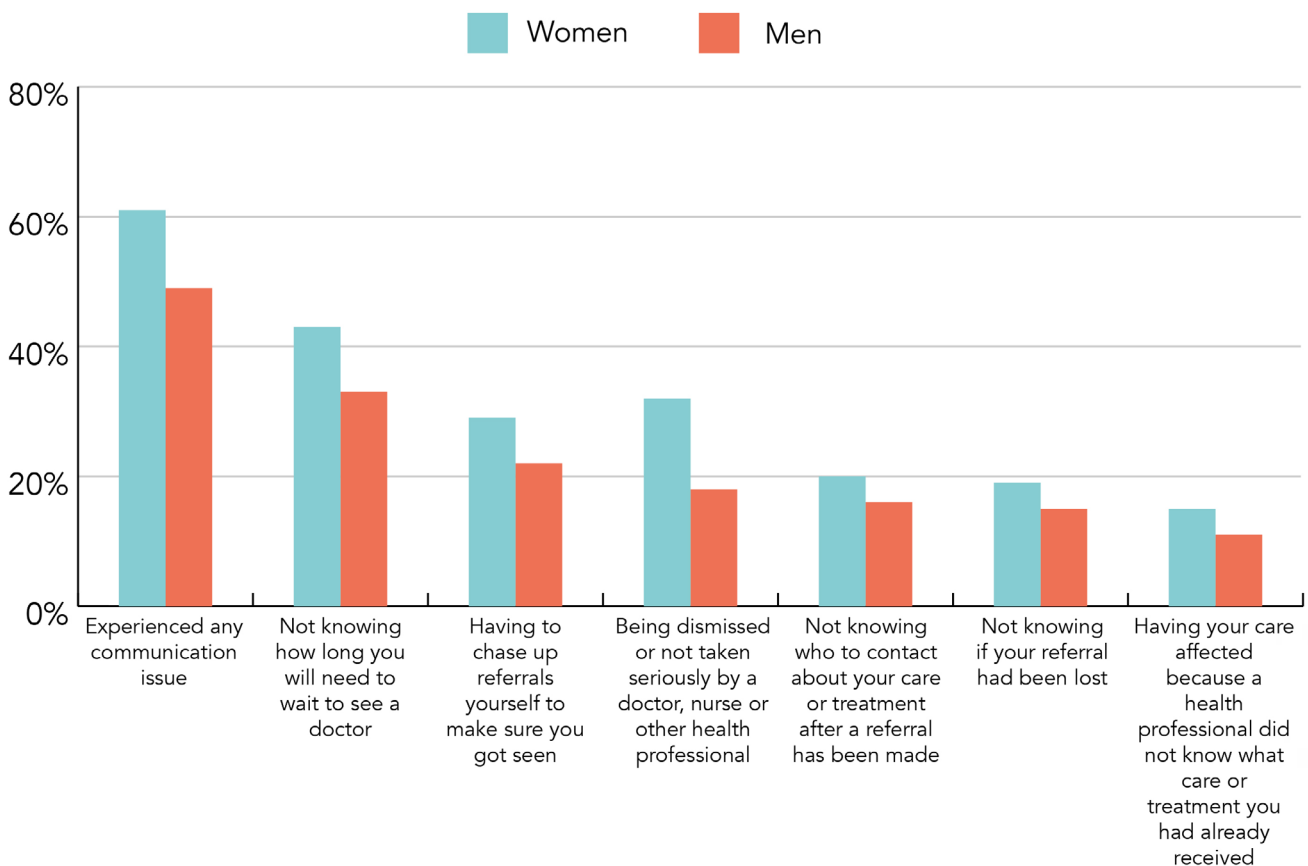
HOW POOR COMMUNICATION IS EXPERIENCED

Broadly speaking, the communication issues that patients described to us over the course of the deliberative engagement can be categorised into one of three types:

1. **Difficulty accessing or navigating the health system** because it was unclear what communication to expect or who to communicate with at different points.

2. A**dministrative errors creating inaccurate or erroneous communication** leading to problems with care, treatment or experience.

3. **Staff not being able to communicate internally or advise on next steps to patients** because they don't know or understand enough about their medical history.

Poor communication in the NHS manifests in complex and often overlapping ways. It is experienced by both staff and patients, and each will use different labels to describe similar events, in part because of their different perspectives on the same issue. And often a poor experience of care for a patient is a product of multiple failures in communication by the system.

Difficulty accessing or navigating the system

The NHS's failure to communicate with people how to get the help they needed or what they could expect in terms of their treatment pathway was a recurring theme in the Community Conversations and People's Panel. Through the course of these conversations with patients and the public, it became clear that almost everyone had a story of feeling lost when trying to navigate the NHS. People told us that they didn't get the information they needed about their treatment or what was happening next, causing, at best, confusion and at worst, delay and stress.

In polling conducted in 2023, we found that 24% of the UK public have reported struggling to know where to turn for help when seeking NHS support in the last five years. This issue impacts certain groups more severely than others; in a separate survey from 2021, 46% of people with a disability said they had struggled to know where to get the help they needed.[7]

The participants in the People's Panel were concerned about patients' experience when waiting for treatment and a lack of communication at that point. They were particularly concerned that people were having to wait for long periods of time to see a GP or hospital doctor, with no sense of how long they were likely to have to wait for. Indeed, our polling in 2023 found two in five people (38%) report having not known how long they will need to wait to see a doctor in the last five years.

The difficulty navigating the system of referrals between primary and secondary care was another issue that was raised in the Community Conversations and prioritised by the People's Panel. They were concerned that people were not being proactively updated enough about their referrals and that it was difficult to know who to contact to find out what was going on. Our 2023 nationally representative polling backed up the qualitative insight and found that a significant proportion of the UK public struggled with communication specifically around referrals. In the last five years:

- 17% have not known whether a referral made for them had been lost.

- 18% did not know who to contact about care or treatment once a referral had been made.

- 26% have had to chase up referrals themselves to ensure they got seen.

People simply do not always know where they need to go to seek support. Sometimes, when the relevant information is not communicated directly by a health worker, knowing where to get reliable information can be extremely difficult. As Allan told his Community Conversation: "the big thing that everyone says is that they wish they knew what was on offer and what paths they should go down."

---

7 "Experiences of the NHS", Health and Care Survey, Engage Britain, September 2021, www.engagebritain.org/health-care-survey-experiences-nhs

> *"And if you're not tapped into the system, and you're not in the right place at the right time talking to the right person, you don't get the information that you need. That would be my biggest downside with the interactions through my parents that I've had with the NHS. If you're not in the right place, you've had it really. There isn't enough broad-based information about what you can get."*
>
> **- Community Conversations participant**

Staff are also alive to how difficult navigating the system is for patients. In the co-design workshops we ran in partnership with the PMA as part of our Ideas for Change exercise, they were really clear about this. Staff were concerned that there was not enough resource put into informing patients on how to navigate the system and managing their expectations.

For staff, patients not feeling able to trust the recommendations of non-clinical staff was a particular worry. Staff said patients often preferred to see GPs when, in their view, non-clinical staff like GP receptionists were actually better placed to help patients navigate to a helpful solution. They wanted the NHS to better communicate to the public the training non-clinical staff receive and the role they play in making care more efficient. These concerns were reflected in the Government's May 2023 Delivery Plan for Primary Care, which looked to expand the role of receptionists to act as navigators.[8]

> *"I have spent most of my career in the NHS. And most of my free time trying to help everyone in my social and family circle gain an understanding and make the most of service provision...I know that some of the problem is about managing expectations, but we are an ill-informed public and don't know about what we may be entitled to."*
>
> **- Participant via social media**
>
> *"I have concerns about being triaged by non medical staff at my GP surgery. These admin staff decide if I can have an urgent appointment or have to wait three weeks for a routine appointment."*
>
> **- Participant via social media**

Administrative errors are creating inaccuracies in communications

The Community Conversations surfaced dozens of examples of errors being made in NHS communications. This included incorrect health or treatment information being given in letters or over the phone, receiving letters for appointments after the date they had been scheduled for, delays in results being given to patients, and failures to pass on information to the patient.

These experiences are alarmingly widespread. Our 2023 polling shows that with over 1 in 10 people (11%) saying their care or treatment had been affected by an admin or IT error within the past 5 years.

---

8   https://www.england.nhs.uk/wp-content/uploads/2023/05/PRN00283-delivery-plan-for-recovering-access-to-primary-care-may-2023.pdf

Further:

- 18% had their care, or the care of an immediate family member, delayed or affected because they were referred to the wrong service.

- 26% reported either themselves or a close family member having been inconvenienced because they were given the date and time of an appointment without enough notice.

It is plausible that the number of people having their care impacted by administrative errors is being underreported here, as patients are not necessarily aware of every error made in the course of their treatment.

> *"It's miscommunication. I could paper my house with hospital letters that say utter jibberish. And…I see letters that have been sent to my GP about things I'm supposed to have said or been diagnosed with, or conversations that we had…honestly, it's quite scary because then the next time you go to see anybody, they're only going on what is written about you. And that can be downright dangerous. Sometimes it's about the patient before you, or the patient after you. Sometimes it's about what the doctor was thinking when he spoke to you, it's nothing to do with what you said to him or he said to you."*
>
> **- Community Conversations participant**

Time and time again, people have experienced breakdowns in the NHS' administrative and communication processes that left them distressed. Failures in communication added to uncertainty and confusion for patients, who did not know whether to believe one communication they had received or another, and were unsure how to clarify. In some cases, errors had serious knock-on impacts on their treatment that worsened their health in a way that was avoidable, leading to increased anxiety and frustration. And sometimes people were simply made anxious because they felt they were reliant on a system that was not working as it should be. One such example that we heard via social media was: "I was given a prescription for anxiety medication. I gave the form to a member of staff who told me they would pass it onto the right person. I came back four days in a row before I finally had a doctor re-write the prescription and get me my medication because it went missing. And the other people I spoke to simply referred me back and forth between the doctors surgery receptionist and the pharmacy. This increased the anxiety for which I was getting the medication to help."

Another example of this type of communication problem came from a person who described their local GP surgery as being "in administrative cardiac arrest", after experiencing "four e-consults where no one called me. A letter to the practice manager meant an apology and a successful e-consult… immediately followed by one referral letter not sent and one not written, or at least not found when I went to pick it up."

> *"I had a CT scan of my lung. Was told the results would reach my GP in seven days. Ten days later, four telephone calls with another two by my GP surgery, five different people within the radiology department giving five different [pieces of] information, only to be informed that my CT scan hadn't even been looked at. Despite me and my family fearing the worst, not one NHS person communicated any urgency, concerns or empathy! But above all, none of them knew anything!"*
>
> **- Participant via social media**

These types of communication failure can have dire consequences for people's health. Through our Community Conversations, social media engagement and People's Panel, we heard dozens of stories of how failing to share information in a timely way led to delayed decision making for clinicians and patients, or rendered it impossible to make a decision at all. One such example, shared by a participant via social media, helps bring this type of issue to life. This person said they had "discovered a blood test that was abnormal had not been passed on to me… I've been very ill for over two years, appointments have taken months, I've had no treatment and I'm steadily getting worse with no help, no treatment and no diagnosis. I ended up being rushed to A&E. They had the answer the entire time! If only they'd informed me of the blood test result I could have researched it myself!"

Another shared a story of a very serious issue almost being missed due to poor communication. They told us via social media: "I went for an urgent appointment for an ultrasound on my abdomen, to be told there was no record of me on the system for that day. When I explained the booking team had called me two days earlier and asked me to come down I was told there was no record of this and the clinic was full. As it happened the sonographer did scan me [and told me] I had a mass in my gall bladder and needed to contact my GP ASAP as it needed further investigation."

In the workshops run with the PMA, staff recognised the same issues. They said that staff across the board, but particularly non-clinical staff and receptionists, are not being given sufficient protected time to complete the training they need in administration and communication. Doing so would have a marked positive improvement on communication with patients, and help to reduce the number of administrative or communication errors.

"I think by the very nature of the things that we do, we can become a little too robotic. And I think if we were all treated as human beings, that includes the staff as well, you would be treated a little bit more individually. And there would be a little bit more understanding about your needs, whether that be communication with parents, or anything really…"

- Community Conversations Participant and NHS staff member

Communications issues can be easily compounded, with miscommunications between patients and staff leading to further miscommunication between staff members, and bad experiences for both. As one person who responded on social media put it: "Doctors have either misheard or misinterpreted what I have said. They have written the wrong information to one another, sometimes saying the opposite of what is actually going on. This has led to wrong advice and wrong medications. It causes delays in treatment, and doctors believe what each other says over what I say. It's very frustrating and frightening at times."

"I think sometimes some of this lack of communication, or good communication, can come out of people who have been working shift after shift back-to-back. And not every patient is a nice patient."

- Community Conversations Participant

Patients Association research has uncovered similar issues. One person called for a "nominated health professional who they could get to know and would get to know the patient" and lamented the lack of "consistent follow-up."[9]

9   "Pandemic Patient Experience", The Patients Association, September 2020, www.patients-association.org.uk/blog/pandemic-patient-experience

Staff not being able to communicate internally or advise on next steps to patients

People are also extremely concerned about a perceived lack of information sharing within the NHS and the knock-on impact that had on patients. In our Community Conversations we heard many stories of patients encountering staff who did not know anything about their medical history. People were frustrated that they had to explain themselves or their condition again and again, when they felt staff should have the information to hand already or had failed to share vital information with each other. This was particularly frustrating for those with complex or long-term conditions, who often have to regularly engage with multiple different doctors across a range of medical specialities when seeking support.

Someone who shared their experience on social media explained that "having to explain my conditions repeatedly to each different member of staff I see, especially as I have several rare conditions, is exhausting. Having to teach the doctors and nurses about my conditions before they treat me is dangerous and makes me feel extremely unsafe visiting the hospital or GP surgery. Staff should at least look at my medical file prior to the appointment so they know what my issues are and my current treatment plans."

This experience is all too common. 13% of adults report that in the last five years they have had their care affected because a health professional did not know what care or treatment they had already received. In the Patient Association's 2023 Winter Experience Survey, only one in three patients surveyed reported that their care had been well-coordinated over the previous winter.[10] Poor coordination of care and exchange of information regarding a patient's treatment or wishes make shared decision making – where patients are treated as equal partners in decisions about their care – impossible on a consistent basis.

> *"[My] child is under four different hospitals and so many consultants, and they never talk to each other even if they are in the same hospital. I spend hours and hours of time being the messenger between doctors to the extent I cannot work. I cannot plan ahead as they give me such short notice of appointments. Her treatment has been late due to shitty communication... When we were sent to a hospital in a different part of the country the local hospital were unable to access her notes when we were transferred. It causes me a huge amount of anxiety and stress."*
>
> **- Participant via social media**

Their research into being a patient uncovered the same issue. Those they spoke with emphasised that improving information sharing would make their experience of being a patient better. They suggested that having "a flow of information so I stop telling my story 1,000 times", improving "information-sharing between healthcare providers", and "professionals taking responsibility for closing the communications loop" would all significantly help.[11]

The Patient's Association's research has also identified specific pain points within the system. As one participant told them: "There is a total failure of inputting between primary and secondary care and it must be addressed. Patients shouldn't have to run around and make sense of or obtain sketchy forms from hard pressed consultants to pass on to GPs who don't have enough context to make sense of the data."[12] This was a common theme in our Community Conversations too. Jess, a participant, said: "often what gets communicated within GP land never filters through or vice versa. I am between departments as well. You seem to waste a lot of your appointment, having been referred to somebody else, explaining why you're there."

10   "Patient Experience Winter Survey", The Patients Association, March 2023, www.patients-association.org.uk/blog/survey-of-patients-paints-a-mixed-picture-of-experiences
11   "Being a Patient", The Patients Association, July 2020.
12   "Being a Patient", The Patients Association, July 2020.

"Some years ago I collapsed while at work and was taken to hospital in an ambulance. I was admitted when they diagnosed that I had suffered a stroke. After two to three weeks I was discharged and had expected some support in the form of physio and perhaps someone from the community nursing team. I eventually gave up waiting. Some months later a lovely lady knocked on my door and introduced herself as the stroke nurse. She was apologising profusely that I had waited several months. Apparently my work address and home address had different health board areas. No one in the hospital discharge team had passed on the information to my health board or community so I had been missed from lots of support that should have been made available. The stroke nurse found out about me completely by accident whilst talking to a colleague about someone different."

- Participant via social media

Recent Patients Association research into the Summary Care Records found that they were not being implemented consistently in practice and that patients were having to take on responsibility. "If the SCR has been about for a while", one said, "why is it that carers are still having the burden of frequently explaining details of their loved one to every health and care professional they come across?"[13] Another patient, in conversation with the Patients Association, called for "a personal folder of medical contact and actions being taken so that the patient has the information on-hand each visit, like a care pack. [I'm] fed up of seeing different doctors and explaining over again and again."[14]

Staff are also affected by this problem. In our workshops, organised alongside the PMA, they pointed to issues caused by a lack of a universal, accessible and fast means for staff to access and share information with patients. They described inconsistency across primary care in the tools that staff can use to execute the basics, for example scheduling appointments, cancelling pre-existing appointments, checking the progress of a referral or accessing test results.

Staff in our workshops said that they are rarely appropriately informed about changes made to the services that were available to patients. They said it was rare for them to receive this information in a way they as people inside the system found easy to interpret, and that they worried about how these changes could be communicated to patients. For example, staff noted that the government announced a new round of Covid vaccinations to the country before GP practices were informed, so reception staff received phone calls from patients trying to book vaccination appointments before they had had a chance to put processes in place. They called for messages or service updates to be communicated centrally and to explicitly lay out how they would provide benefit to patients and staff. Central communications support would save each individual GP practice from having to create their own messaging campaigns to inform people.

13   "Developing a Data Pact: the relationship between the public, their data and the health and care system", The Patients Association, September 2023, www.patients-association.org.uk/Handlers/Download.ashx?IDMF=c348045e-4ffc-43e5-a2ce-8a21ca1c6c5e
14   "Being a Patient", The Patients Association, July 2020.

The impact of poor communication on patients

Issues with NHS communication both with patients and within the system itself causes major unnecessary distress to patients. Rectifying this issue has the potential to improve both patient's ability to access appropriate care, and their satisfaction with the care they're given.

Our 2023 polling evidences the profound impact poor communication has on patient wellbeing and mental health. Lots of people report having felt the impact of poor communication on their mental health. We asked the 55% of people who reported having experienced poor communication when seeking NHS support how that experience made them feel. They reported a range of impacts.

CHART 2
% RESPONDENTS WHO EXPERIENCED AT LEAST ONE EXAMPLE OF POOR COMMUNICATIONS

Stressed	Anxious	Angry	Confused	Low	Did not notice an impact
51%	48%	38%	17%	17%	8%
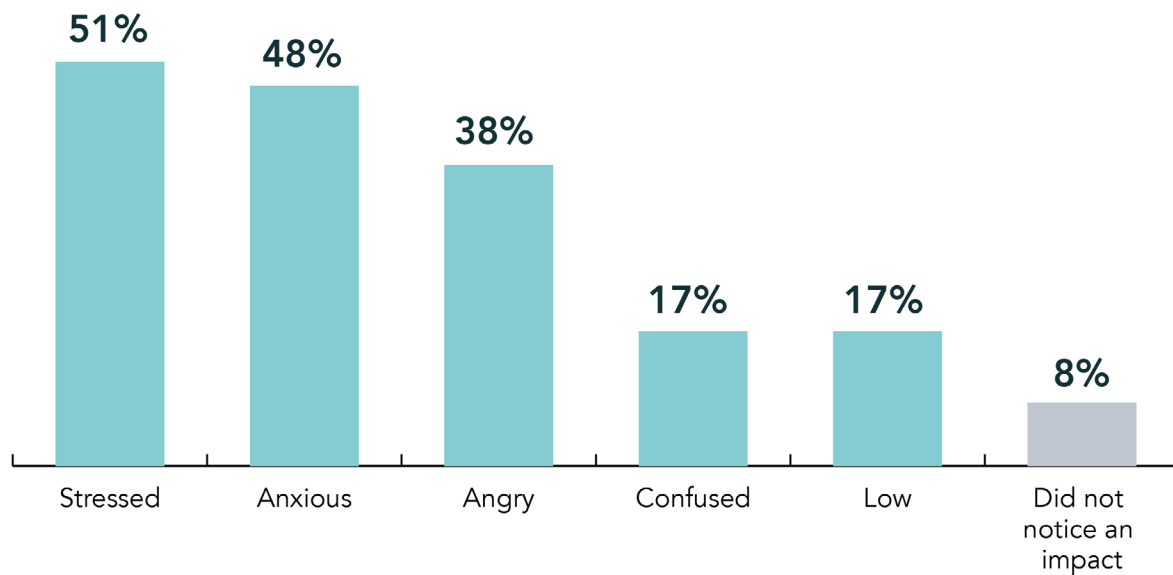
Patients Association research has found one in two patients report that their health and care needs negatively affect their mental health.[15] This is only compounded by poor communication. One person in their study was quoted as saying:

> *"Communication breakdown has meant I am now traumatised by health professionals, particularly doctors. It has eroded all trust in the NHS. I have not had healthcare for over five years. I am caught in an endless cycle of [going] to see [a] GP for a referral to psychiatrists only to be ignored… once a referral is sent it takes about a year only to be told to go back to the GP to send a referral".*
>
> **- Patient Association research participant**

Another research participant shared that "it has made me feel anxious and stressed to fight to get answers as to whether a referral has been sent and then accepted", concluding that "it's a minefield sometimes".

In our Community Conversations and social media engagement exercises, we heard repeatedly from people just how mentally taxing it was to try to get support both for themselves and their loved ones from the NHS.

---

15 "Patient Experience Winter Survey", The Patients Association, March 2023, www.patients-association.org.uk/blog/survey-of-patients-paints-a-mixed-picture-of-experiences

People reported that it made them feel anxious, depressed, lonely and led to lost sleep. "I have constant issues with poor NHS services in dealing with my disabled son's care", one person told us, "it is causing me daily mental health issues and anxiety problems and there doesn't seem to be an end to it as none of the services listen or act on what I am asking for."

This issue becomes dangerously self-perpetuating when communication failures happen whilst people are seeking support with their mental health. As one person told us: "I was told on two occasions [that] I would get a phone call at a certain time from the mental health team, [it] never happened. I made a complaint, never heard anything from them. Where am I supposed to go now? [I have] no faith or trust in that mental health team."

The impact of poor communication on staff

Though the most obvious impacts of poor communication are on patients, staff are also negatively affected in myriad ways. This is particularly damaging in an environment where, as we have heard directly from staff, they are already under extreme pressure, overworked and exhausted. Indeed, a YouGov survey in July 2023 found that 72% of NHS staff already have less than enough time to spend with patients.

> *"You've only got a certain amount of time and something has to give, and you don't want to compromise your care of patients. But how do you fit everything into that time, when each year you're being asked to do more and more within that short amount of time?"*
>
> **- Community Conversations participant and NHS staff member**

Staff report the knock-on impacts of poor communication as having a significant impact on an already unsustainable workload, intensifying their administrative burden and further limiting the time they can devote to speaking with patients or performing clinical tasks.

The most obvious direct impact on staff was poor communication from other staff within the system making their job harder to do.

> *"I work for [an] NHS hospital and every day lack of communication affects patients and staff. I think it is the biggest problem. Not being told where to go or staff not being told what is happening. We have had a problem with incorrect letters for more than 4 years and nothing is done."*
>
> **- Participant via social media**

The lack of a functioning and well-integrated IT system was a particular concern of staff. They are often seen as unhelpful and introducing new barriers to communication, rather than helping to streamline.

One clinician told the Patients Association that they wanted "a faster working EMIS [medical information system] so I have to stare less at the blue circle of death and have more time to discuss". Another called for "digital systems that are interoperable so I can be confident that information about patients' preferences can be shared."[16]

16   "Shared decision making from the perspective of clinicians", Patients Association, https://www.patients-association.org.uk/blog/health-professionals-perceptions-of-shared-decision-making-report

But the impact of poor communications also manifests when trying to reach patients. Difficulty communicating straightforwardly with patients leads to staff spending more time on administrative tasks than is necessary, particularly those tasks which could have been simplified or automated. And time spent rectifying the problems resulting from poor communication with patients, such as patient complaints or confusion, creates an additional work burden. And when patients don't attend appointments because of administrative errors, that wastes staff time.

> *"I was treated as an NHS patient at a private hospital [and] received a very stern letter telling me I had missed my appointment. I rang and explained I hadn't received my appointment letter and I didn't know I was supposed to be there. I made a new appointment over the phone. The original letter arrived two days later."*
>
> **- Participant via social media**

One patient even told us via social media about a time that a member of staff had to come back to the hospital to see them out of hours because of a communications error. Clearly this was frustrating for the patient but must have been incredibly inconvenient for the member of staff as well. As the patient described: "I went to the hospital for an appointment. I logged in on the touch screen system [but] my notes didn't get put in the clinic tray. I was the last appointment of the day. All the doctors went home without seeing me. [The] nurse had to ring the consultant who came back to see me."

Poor communication in the NHS has serious consequences for staff, making their jobs harder to undertake at a time when they are already under severe pressure. Unless the situation is rectified, the NHS will be facing an uphill battle to meet the expectations of patients, staff and society at large. Why, then, are politicians not taking urgent action?
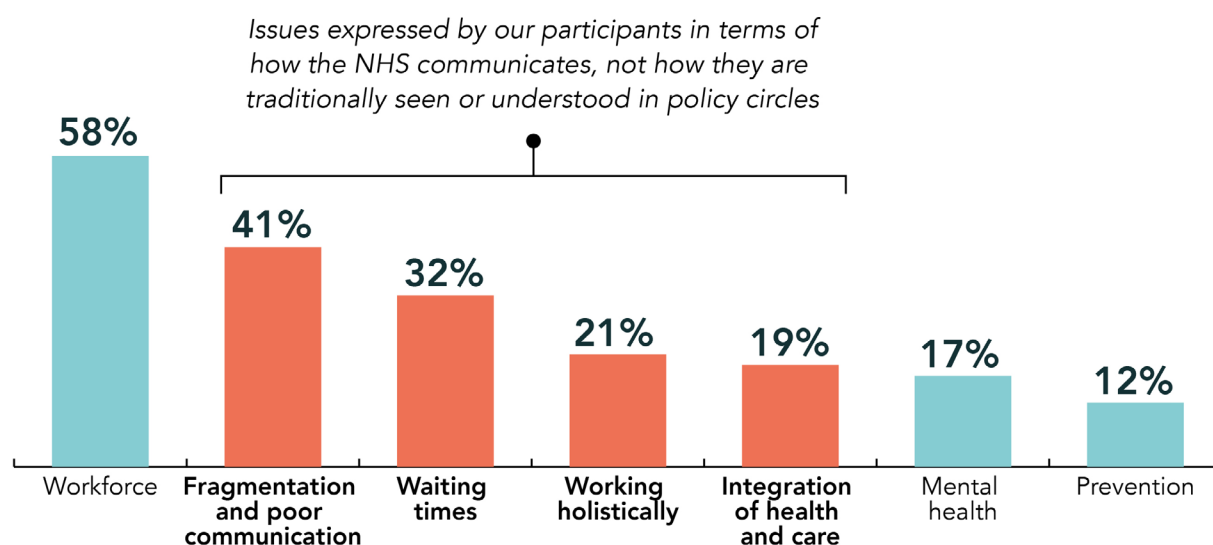
CHAPTER 2
AN OPPORTUNITY FOR CHANGE

A PRIORITY IN DELIBERATION

In Autumn 2021, we brought together the People's Panel to consider the first-hand experiences of those who had participated in over 100 Community Conversations, listen to experts in health and care, and reflect on their own experiences of the system.

After four weekends of deliberation, what they prioritised was fascinating. Their priorities looked very different from the conventional issues that emerge as priorities from more traditional attitudinal research into health and care. Rather than focus on changes to service delivery or funding, they zeroed in on elements that they felt would improve the experience of staff and patients. As such, their biggest priority was the recruitment, retention and training of the health and care workforce. Improving communication between the system and patients, and between practitioners within the health system, came out as the second most important priority for improvement.

CHART 3
% OF PEOPLE INCLUDING PRIORITIES IN THEIR TOP TWO ISSUES ON THE FOURTH WEEKEND OF THE PEOPLE'S PANEL

Issues expressed by our participants in terms of how the NHS communicates, not how they are traditionally seen or understood in policy circles

Workforce	Fragmentation and poor communication	Waiting times	Working holistically	Integration of health and care	Mental health	Prevention
58%	41%	32%	21%	19%	17%	12%

Source: BritianThinks polling for Engage Britain, September 2020

Partly, this focus on poor communication was seen as underpinning many other issues faced by the NHS. They believed that the amount of time people were having to wait for care was a problem, but it was a far greater issue that people were having to wait an unexpectedly long time for care *and* not receiving updates of how long they'd have to wait or why they were waiting. Participants felt that where issues like long waiting times couldn't be addressed directly due to financial constraints, improving communication would help ease the worst of the impacts they had on people.

FIGURE 3
POOR COMMUNICATION ISSUES PRIORITISED ON THE FOURTH WEEKEND OF THE PEOPLE'S PANEL

After staffing, the next four priorities identified by the People's Panel are set out below. The challenge statements were written by the members of the People's Panel. Although their priority challenges were notionally about different issues, the Panel actually focused each on communication and the problems that are caused by poor communication.

PRIORITY 2:	PRIORITY 3:	PRIORITY 4:	PRIORITY 5:
POOR COMMUNICATIONS	**LENGTHY PROCESS AND WAITING TIMES**	**HOLISTIC HEALTH AND CARE**	**INTEGRATED HEALTH AND SOCIAL CARE**
Poor communication between different services, departments and patients leads to delays and gaps in receiving important care, which causes confusion, distress and disappointment for patients, especially for those with complex conditions and care needs.	The referral process is disconnected and inefficient because it is outdated and has not evolved with the needs of people and advances in technology. There is poor information flow between primary and specialist care, and poor communication between health and care services and people using them.	The system doesn't require professionals to look at the bigger picture, which results in treating individual conditions and not the whole person.	Service users are not always signposted in a timely manner to the appropriate health and social care services that best meet their needs. Delays in intervention can adversely impact patient outcomes.

A PUBLIC PRIORITY?

Why then, is improving communication within the NHS so far down the political agenda?

The answer partly lies in the simplified way in which we engage the public on their priorities for change.
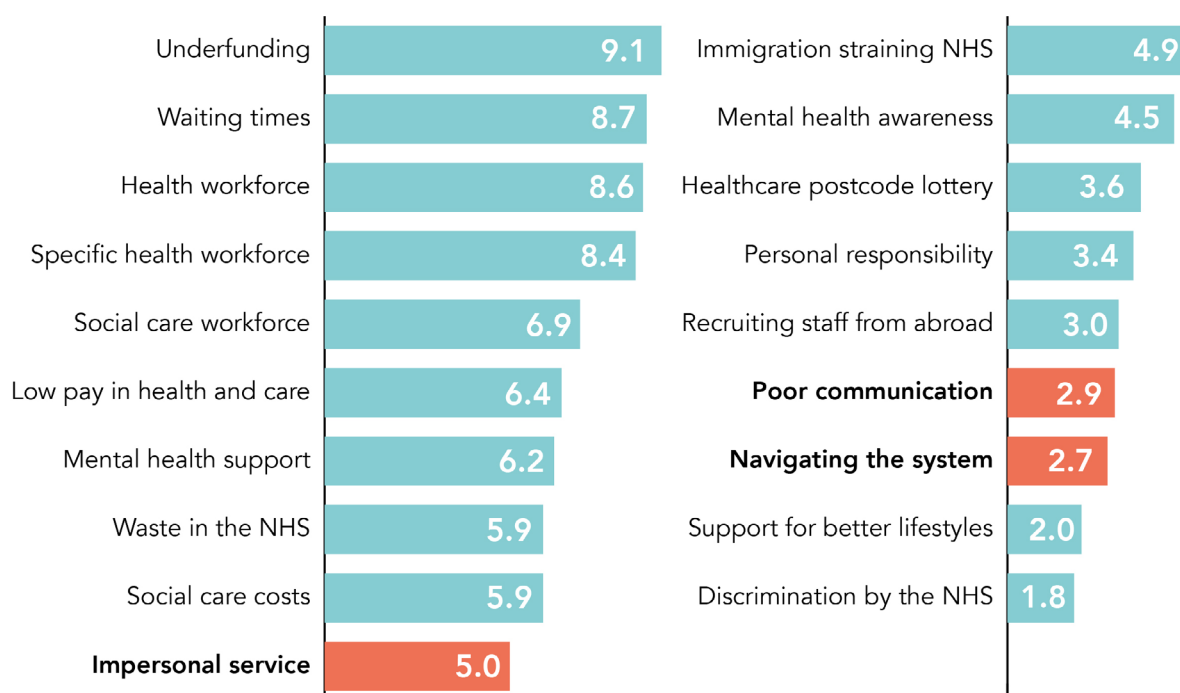
Deliberative exercises are designed to get the public to think in detail about trade-offs and priorities. Participants have to challenge their own preconceptions about issues and listen carefully to the views of others. They often end up changing their mind over the course of a deliberative process as a result.

But the focus of political commentary around public priorities for the NHS isn't on deliberation. It relies on more traditional measures of public opinion – such as polling and focus groups – which act as temperature checks. These ask people to give often instinctive, knee-jerk reactions to prompts in shorter timeframes. The results are very different to those of deliberation. When we ran an issue prioritisation exercise in polling in 2022, issues relating to poor NHS communications emerged as low ranking considerations for the public.

What emerges is a complicated picture. When people are asked to discuss and engage with the topic in detail, improving how the NHS communicates is a top priority. But for those that haven't engaged in such a deliberation – that is to say, most of the public – it's very far down the list.

CHART 4

KEY HEALTH AND CARE CHALLENGES FACING THE UK ORDERED AS PRIORITISED BY THE BRITISH PUBLIC VIA MAXDIFF*

Challenge	Score
Underfunding	9.1
Waiting times	8.7
Health workforce	8.6
Specific health workforce	8.4
Social care workforce	6.9
Low pay in health and care	6.4
Mental health support	6.2
Waste in the NHS	5.9
Social care costs	5.9
Impersonal service	5.0
Immigration straining NHS	4.9
Mental health awareness	4.5
Healthcare postcode lottery	3.6
Personal responsibility	3.4
Recruiting staff from abroad	3.0
Poor communication	2.9
Navigating the system	2.7
Support for better lifestyles	2.0
Discrimination by the NHS	1.8

Source: BritianThinks polling for Engage Britain, January 2022
*MaxDiff is a statistical technique which allows us to score public priorities relative to each other

A DIFFICULT ISSUE TO RAISE UP THE AGENDA

It is important to acknowledge that public perception of the issue is not the only thing inhibiting reform efforts.

In politics and policymaking, what counts is what's measured. It is unsurprising that what drives headlines and political focus and therefore public perception of what most needs improvement is what can be straightforwardly quantified, with targets that hold people or services accountable.

How the NHS communicates with patients is often intangible in a way that waiting times, ambulance response times or delayed discharges are not.

There's very little information or measurement on the scale of this problem. As Director of Annapurna Strategy and former Director of Strategy at the Department of Health, John Hall, wrote in his reflections on the People's Panel:

"The NHS primarily uses data for performance management and comparing institutions. So there is a risk that if it is not counted, it does not count. Existing data on individual "patient episodes" tells us little about the overall experiences of people with repeated interactions and multiple chronic conditions. Panel members spoke of their exhaustion at having to coordinate their own care, especially at times when they felt particularly unwell. Yet almost all of the large data-sets collected by the NHS focus on interactions with individual organisations. With rare exceptions, such as the Cancer Patient survey, there is remarkably little data available across patient pathways or whether people are falling through gaps (lost records, referrals etc)."[17]

When planning for system reforms, it's far easier for a technocrat in Whitehall to fiddle with the wiring diagrams of the NHS than it is for them to actually tackle problems with people's experience of care. This is particularly true in a fiscally constrained environment, where a cost or efficiency saving might not be so obvious and the argument for more funding from the Treasury is that much harder to make.

17   John Hall, "Involving people in policymaking", engagebritain.org/peoples-panel-digest.

Indeed, this is reflected in the NHS's actual priorities. There are plenty of NHS documents and strategies for putting working with patients at the heart of the system, and the importance of working with patients is clearly well-understood. But communication is nowhere near as prominent as it should be.[18] None of the NHS's thirty-one national objectives for 2023/24 relate directly to improving communication with patients.[19]

AN ISSUE OF BURNING IMPORTANCE

That is not to say there are no measures suggesting the importance of this as an issue.

Much of how the public experiences the NHS is through how it communicates. And we know that public confidence in the NHS has deteriorated rapidly in the last five years.

CHART 5
% OF PEOPLE IN THE UK THAT ARE SATISFIED OR DISSATISFIED WITH THE NHS, 1984-2021
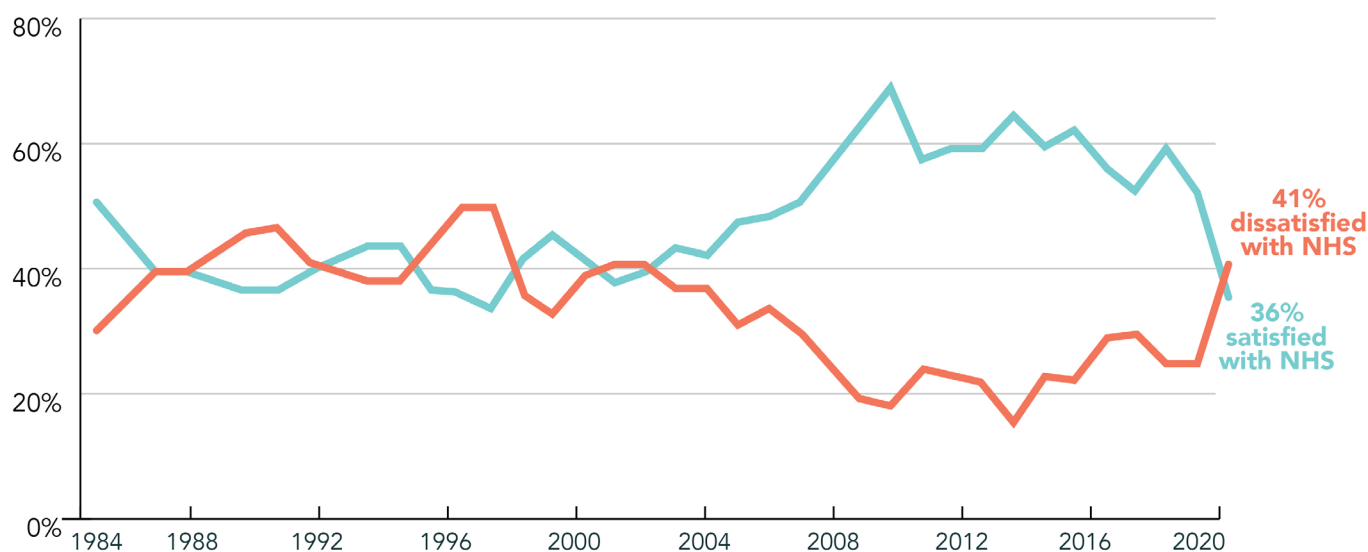
Source: The King's Fund analysis of the King's Fund and British Social Attitudes data

Improving communication could be a vital piece of the puzzle if the NHS wants to improve public satisfaction. We polled members of the public who reported having experienced poor communication in the last five years on how their experience affected their view of the NHS. Given the reluctance to criticise the NHS, a surprising number reported their view having changed.

- 30% said it had damaged their trust in the NHS.

- 45% said it made them worry about the quality of care the NHS provides.

- 31% said it made them worry that NHS money is being wasted.

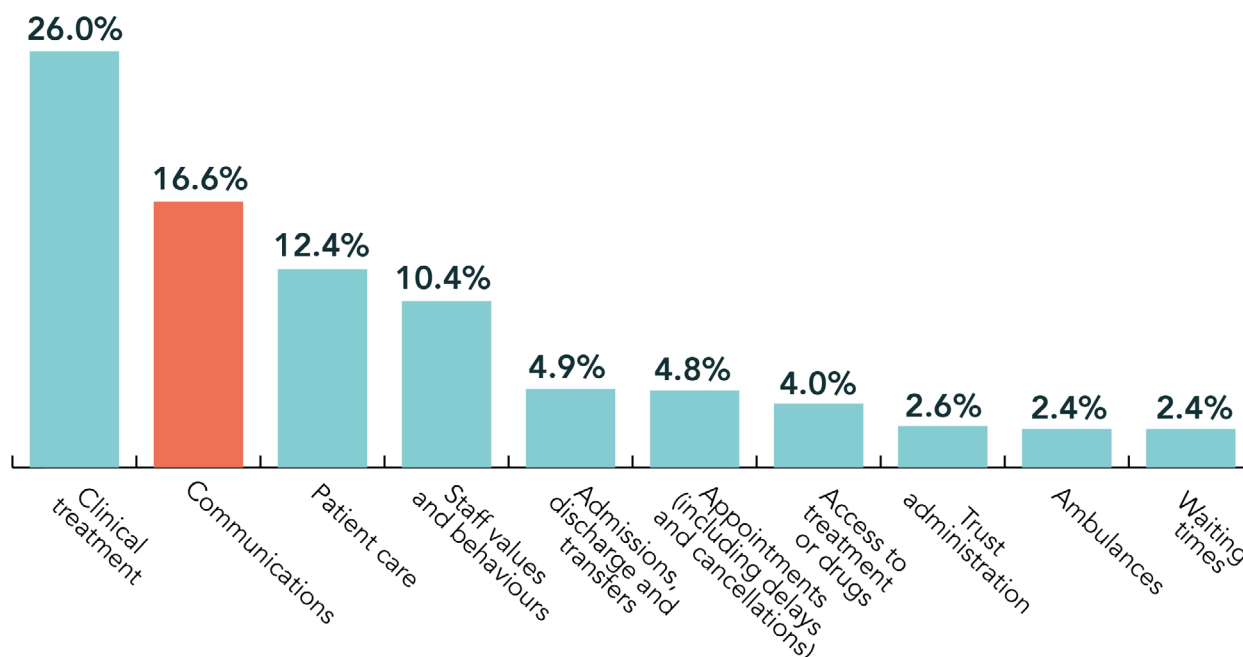- 26% said it made them worry that NHS staff time is being wasted.

There are other signs that this has been an issue burning under the surface for some time. For example, the latest data for England on written patient complaints in the NHS has communications as the single biggest source of complaints outside of clinical treatment across both primary and secondary care. This has been true every year since the data was first published in 2015-16. Indeed, last year communications was the cause of 17% of written complaints to NHS England about secondary care, compared to 26% of complaints being about clinical treatment.

18   See: NHS Constitution, 2012; NHS England Five Year Forward Plan, 2014; Long Term Plan, 2018; Comprehensive Model for Personalised Care, 2018; NHS Assembly on the NHS at 75, 2023.
19   https://www.england.nhs.uk/wp-content/uploads/2022/12/PRN00021-23-24-priorities-and-operational-planning-guidance-v1.1.pdf

CHART 6
TEN LARGEST DRIVERS OF COMPLAINTS IN SECONDARY CARE 2022-23

A bar chart titled "Ten largest drivers of complaints in secondary care 2022-23" showing percentages for ten categories:
- Clinical treatment: 26.0%
- Communications: 16.6%
- Patient care: 12.4%
- Staff values and behaviours: 10.4%
- Admissions, discharge and transfers: 4.9%
- Appointments (including delays and cancellations): 4.8%
- Access to treatment or drugs: 4.0%
- Trust administration: 2.6%
- Ambulances: 2.4%
- Waiting times: 2.4%

A MUCH-NEEDED CONVERSATION

That poor communication emerges as such a strong priority in deliberation suggests that there could be strong public support for improving how the NHS communicates. However, it does not have the same immediate resonance as other more prominent issues. There is currently very little electoral gain in addressing poor communication as an issue, because it lacks the resonance, visibility and headline grabbing quality of issues like ambulance response times or A&E waiting times. That is despite the fact that poor communication links to – and in some case underwrites – all of these in ways that are increasingly well understood.

One popular criticism of the NHS is that it wastes public money through bureaucratic mismanagement. Some politicians – and voters – see this as a reason for resisting calls for greater investment in the service. It is possible that examples of poor communication, which are often byproducts of poor practice or culture, might help to confirm these views or, in some cases, fuel them. As we have noted elsewhere, without any way to measure these instances or their impact, they are likely to go unrecognised by the system. And, in turn, it will be hard – if not impossible – to track how they affect public views of the service. Nonetheless, it is not unreasonable to think that prioritising improving communication with staff and patients would go some way to demonstrating that the NHS is alive to the issues its bureaucracies cause for patients, staff and public. And, in so doing, help to build greater belief that investment in the service can be money well spent.

Demonstrating that inefficiency and waste in the system are being tackled by improving how the system interacts with patients in a way that is tangible would go a long way to reassuring people that their money is being spent well. And this is particularly important if a government is raising money through general taxation to fix other problems in the NHS. System changes to alleviate issues like longer waiting times or chronic understaffing will all take years to filter through. It is very plausible that the public won't feel the effects of a cash injection into the NHS until after the next election. If a government wants people to feel like they are getting a return on what they're paying for inside a single election cycle, system changes that take years to take effect will need to be complemented by improvements in the patient experience where the payoff is more immediate.

Improving how the NHS communicates will be critical to stopping the deterioration of public satisfaction with how the NHS is run. This presents politicians with a clear opportunity. Its resonance as an issue suggests that real improvements that address the way the NHS communicates with people would be a relatively easy win for politicians and well-received by people on the sharp end of the issues. It would certainly improve people's lives.

And what is more, some of the solutions are already being put in place in parts of the NHS. But political leadership will be needed to drive comprehensive, system-wide change.

CHAPTER 3
HOW TO IMPROVE COMMUNICATION

What might these solutions look like? In an attempt to kick off a conversation about ways of improving NHS communications, we worked with patients and practitioners to identify and prioritise examples of best practice across the system.

As a starting point, we worked with Imperial College Health Partners to identify ten examples of good practice in local areas or particular services, where communication between the system and patients, or between elements of the system is particularly strong (see Appendix 1). This allowed us to capture practical ideas that are already working successfully and could be used more widely. Then, in July 2022, we took these examples back to our People's Panel, to patients with complex health needs (in partnership with The Patients Association), and to GP practice managers (with the PMA). Each group assessed the examples to see whether they would in fact crack the issues identified, as well as thinking about what else could be done to improve NHS communications. We listened to their feedback, and then through further workshops in November 2022, tested and refined these further into three potential solutions.

CARE COORDINATORS

"Having one clinician who has oversight of all their medical needs could be a huge help for some patients and remove a lot of stress from their care."

- Participant

Our workshop of practitioners, patients, and members of the public created a vision for care coordinators that they would like to see rolled out across the UK. For them, a care coordinator would be a clinician within the system who has oversight of all the care received by people with complex conditions. They would ensure that appointments, treatment plans and medications are coordinated, without the patient or their carer having to play this role. They would also need to have appropriate specialist training, experience and expertise to manage complex needs – meaning that it may not be the GP who plays this role. Regular joint meetings would be held so that professionals can discuss complex cases collaboratively, and patients can be treated holistically.

When we ran another set of workshops to strength-test the proposal, they identified that it will be vital for patients to trust and have confidence in their care coordinator, with the approach being patient centred and patient led. It's vital that the person taking on this role is a clinician with knowledge of the patients' case and care. They need strong organisational skills, and the ability to communicate and coordinate with other staff, as well as having the authority and accountability to make sure the system properly serves the patient. This coordinated care approach would also need to be consistent across the UK. As well as ensuring that care runs more smoothly for patients, this model would also encourage a deeply collaborative way of working, with joint responsibility for care.

They were inspired by Connecting Care for Children (CC4C), a child health GP hub in North London. These hubs involve a multi-disciplinary team (MDT) meeting, which always includes GPs from local surgeries, and at least one paediatrician from the local hospital. They can also include other relevant members of children's health care teams as appropriate, such as school nurses, social workers, physiotherapists. Our participants saw the value of this approach for children, and called for a similar approach for adults with complex health needs.

The MDT meeting has two functions: first, a specialist will upskill GPs on a frequently encountered children's health issue. The GPs can then ask questions, both about that week's topic, and about specific cases. This is most useful for cases that are just under the threshold for specialist referral, where the GP may want some extra guidance, or in situations where families need extra reassurance rather than a full referral. The intention of this scheme is to improve patient outcomes and save money, as it reduces the number of 'wasted' hospital referrals.

An impact study of the CC4C model by Montgomery-Taylor, Watson, and Klaber found the scheme was highly successful. Most clinic attendees felt really listened to (99%), involved in decisions (88%), very confident in the care they were receiving (99%) and satisfied that their concerns were addressed and that they had received clear explanations (96%). 88% of respondents answered that, as a result of the appointment, they felt more comfortable taking their child to see their GP, and every respondent said they would recommend the service to friends and family. In terms of costs, Patel et al found that CC4C led to a 39% reduction in outpatient referrals, a 22% reduction in presentations to the emergency department (ED), and a 17% reduction in acute hospital admissions.[20]

CARE NAVIGATORS

Our participants also expressed lots of support for care navigators and called for the existing system of care navigators to be expanded in response to increased demand.

Care navigators are trained NHS staff (often non-clinical frontline staff, such as receptionists and patient liaison officers, or volunteers) who actively listen to patients' needs and can help direct them to the most appropriate local service or person. While they exist currently in many GP practices, they are by no means universal, and our participants wanted to see this provision available to everyone, regardless of where they live.

Practitioners and patients alike wanted to see care navigators in GP surgeries across the country, improving communication by freeing up GPs' time, minimising avoidable appointments and reducing pressure on other frontline staff to provide information on or chase up referrals. They will take the pressure off knowing where to turn from the public. They can also link people with services outside the health system, which is particularly important with those who have complex needs that need addressing which might have a knock-on impact on their health. Care navigators will need to be empathetic, excellent at administration, and clear communicators.

Currently, reception staff are the frontline in GP practices and bear the brunt of patient frustrations. They could take on the care navigator role but need support and training to be able to do this. Realigning the whole role with appropriate training would be a relatively quick win, as would re-naming 'receptionists', as this alone puts people off from explaining their medical issues to the person on the front desk.

Regardless of whether this role is a new one, or is taken on by existing non-clinical staff, it will be vital to build patients' trust in this system. The idea of employing care navigators can fall down if they are not trusted or are seen to be 'just the receptionist' acting as a blocker. The investment here is in people and training; making sure that the care navigator fulfils their role to the community, and that the community understands the importance of the navigator. They will need accredited, nationally recognised training and to be monitored by

20   Montgomery-Taylor, Watson, and Klaber 'Child Health General Practice Hubs: a service evaluation', Archives of Disease in Childhood, April 2016, 101(4), www.pubmed.ncbi.nlm.nih.gov/26699536, pp.333-7

the CQC. To facilitate this, Integrated Care Board contracts should allow practices to close for staff training, which happens in some places but not consistently across the country.

THE NHS APP

> *"I think it would be extremely useful for a patient to have a single app to use for all their NHS needs."*
>
> **- Participant**

Many of the examples of best practice identified by Imperial College Health Partners were apps (see appendix 1). Whilst there was lots of enthusiasm for a number of different apps used across the health system, both patients and staff wanted the multitude of already-available NHS apps to be rationalised, operate more effectively together, and share information.

Ideally, they wanted a single, nationally consistent app that would allow them to manage their referrals, schedule, and track appointments, and see their whole health record in one place, while also holding information relating to hospital discharge and tracking symptoms. Patients want to be able to query incorrect information and ensure the record is updated, and said the app should have contact details for clinics so patients can speak to admin staff directly about appointments if needed. They also wanted clinicians to be able to access the records in their app when necessary.

They recognised that digital solutions won't work for everyone, but wanted to make sure the app was as accessible as possible. They wanted computer terminals in GP practices, libraries, and other community settings – along with staff trained in supporting patients to respond digitally – so that everyone could use it.

There is an existing NHS App that currently allows patients to access their Covid vaccination pass, view their health record and test results, book and manage GP appointments, order repeat prescriptions, and attend online consultations.

Matthew Gould, the CEO of NHSX who led on the development of the app, has publicly said that he doesn't want to make the NHS App too bulky. Instead, he wants to work on making an NHS App library, where outside healthcare apps that are already working well can be linked to the NHS App.[21] So, for example, someone who has diabetes could link an NHS-accredited diabetes management App to their NHS App, and someone who doesn't won't have their home screen clogged with lots of confusing features that they don't need to use.

The NHS App has already been widely adopted, with about 29 million users. But our workshop participants worried that most of the group, despite being highly engaged, didn't seem to know much about the App or the features it offers. As well as improved functions, they called for greater publicity for the App and what it does.

LONG TERM SOLUTIONS

These are all extremely practical solutions to the problem. None of them are new or novel, and NHS leaders already know they're important: the three solutions prioritised by our workshops are already being rolled out in different parts of the system. These changes need to be implemented consistently across the system and across the country, and with enough urgency to make a difference to people's lives. They need proper funding and resourcing with sufficient staff to deliver the change, rather than becoming another addition to an already difficult to sustain workload. There are signs, such as the government's recent 'Delivery plan for recovering

---

21   Gould, 'The NHS App: a platform for innovation', Technology in the NHS, 31 May 2019 https://healthtech.blog.gov.uk/2019/05/31/the-nhs-app-a-platform-for-innovation/

access to primary care', that these changes might be starting to happen, even if much more could be done in terms of a clear training offer and driving parity of esteem for non-clinical staff.[22]

But the fact that our participants, be they patients, staff or members of the public, all called for additional support to help them navigate around or administer within an extremely complex system, suggests something more fundamental needs addressing.

The way the NHS is currently undertaking administration and bureaucracy is clearly failing to meet the needs of patients. This is a key driver of poor communication and a large part of the reason people need additional support to navigate the system. Poor communication also acts as a major barrier to patients being meaningfully involved in decisions about their care and treatment. All of the insights included in this report from the Patients Association's wider work seek to further that objective: making more patients partners in their own care and in the design and delivery of the services they use.

Shared decision making is where patients and staff work together to make these choices. This idea is well established in multiple streams of health policy and guidance. Whilst much of the focus on shared decision making is about what takes place in interactions between clinicians and patients, wider communication and effective administration plays a vital role in facilitating that. Working in partnership with patients is impossible when poor communication means clinicians do not confer or know what the other is doing, when patients are given mixed or conflicting messages, or receive uncoordinated care. Taken together, these factors can cause a paralysis of decision making and take patients further out of the loop.

'Being asked questions and having actual conversations is sometimes inconsistent. There is a postcode lottery on being given the opportunity to make choices about the care patients receive and their options for care'.

'Paternalism needs to stop. Patients want more control over their bodies and care and nobody knows better than them. Listen to patients and give them more choice'.

'Continue to communicate with patients, including the family and community surrounding them. Help us to carry on. Communication should be constant throughout, including when things go wrong'.

(Patients Association focus group participants on the NHS' 75 anniversary)

The King's Fund has studied NHS administrative practice in detail, and made a clear case for the need for high-quality administration across the system to "improve patient experience, reduce inequalities, promote better care – and contribute to a better working environment for staff". As they note, "it has seldom been a major focus for policy-makers and leaders."[23] It can be argued that a system that needs its own system to enable people to navigate it might be too complex. In that case, just providing more navigation tools isn't a long term answer.

---

22   "Delivery plan for recovering access to primary care", www.england.nhs.uk/wp-content/uploads/2023/05/PRN00283-delivery-plan-for-recovering-access-to-primary-care-may-2023.pdf
23   Leo Ewbank, Laura Lamming, Julia Cream and Lillie Wenzel, "Admin Matters: the impact of NHS administration on patient care", The King's Fund, https://www.kingsfund.org.uk/publications/admin-matters-nhs-patient-care, 24 June 2021.

> *"We [the ambulance service] take less than 50% of our patients anywhere. A lot of the time we're dealing with patients in their own homes, and it's about navigating the system for them and putting them in touch with the right person to help them. Whether that's referring them back to their GP or getting a district nurse out, or patching them up at home and discharging them. But a lot of the time we are there signposting and navigating the system for them, rather than taking them anywhere to be treated. I guess that demonstrates there is a problem in the system. It's far too complicated."*
>
> **- Sandra, Community Conversations participant**

And as we have explored in this report, the impact of poor administration and the poor communication it drives has serious impacts on patients' lives. It isn't the narrow or esoteric area of reform it might appear.

There are tentative signs that politicians are starting to acknowledge at least the problem. In an interview with *The Times*, the Chancellor Jeremy Hunt said: "It is absolutely outrageous that doctors and nurses spend around a third of their time doing admin when they could be looking after patients". But they fail to acknowledge the scale of the challenge they are grappling with. Hunt has tasked government departments with quantifying how many hours are spent on "unnecessary admin", apparently presaging an attempt to reduce the administrative burden.[24] Similarly, in Labour's plan for the NHS ahead of the next election, the only substantial acknowledgement of administration is to say that the "revolution in technology" will help to "reduce the administrative burdens on staff".[25]

In our co-design workshops with the Patient's Association, one participant told us that their neurologist had lost three admin staff over the previous six months and was now having to spend time they should be using on clinical tasks doing all the admin themselves.

This needs a more serious focus. As research by the Institute for Government and Public First have pointed out, "in 2014 (the latest data available) the NHS was spending less than half the OECD average on administration and management combined".[26] They go on to point out that "since 2009 the percentage of managers in the NHS has reduced from 2.6% of all staff to 1.9%".

It's not simply a case of more money or more administrative staff being a solution to the issue. But they are necessary preludes to tackling the more systemic problems with NHS admin that lead to so many communication failures. Without sufficient focus on administration that treats it not as a burden but an essential part of care, improving patients' experience of the NHS will be extremely difficult. A combined effort to ensure non-clinical staff are well trained in administration and communication, that the NHS employs non-clinical staff in sufficient numbers to undertake high-quality administration, and that IT systems are enablers of not barriers to good communication will all ensure efforts to improve communication aren't just a sticking plaster.

In addition, if the maxim 'what's measured is what counts' is true, then holding the NHS to account on improving the way it communicates with patients through a measurable target may help to focus minds. For example, a target that it must report on which measures patient satisfaction, not their experience of their clinical treatment or relationship with clinicians, but with their experience of accessing NHS services.

Doing so will require politicians to be honest with the public about the costs involved in enacting those solutions across the system. It is all too tempting to promise improvements on the clinical side and to neglect the less immediately salient non-clinical elements. Any serious reform of the NHS will need to do both.

24   Steven Swinford and Oliver Wright, "Jeremy Hunt: 'Britain doesn't need to be famous for pessimism'", The Times, https://www.thetimes.co.uk/article/jeremy-hunt-interview-chancellor-uk-economy-tax-cuts-benefits-hs2-s0vk3gpf7/
25   The Labour Party, "Build an NHS Fit for the Future", 5 Missions for a Better Britain, https://labour.org.uk/wp-content/uploads/2023/05/Mission-Public-Services.pdf, p.9.
26   Sam Freedman and Rachel Wolf, "The NHS productivity puzzle: why has hospital activity not increased in line with funding and staffing?", Public First and The Institute for Government, June 2023, https://www.instituteforgovernment.org.uk/sites/default/files/2023-06/nhs-productivity-puzzle_0.pdf, pp.41-2.

CONCLUSION

Loved by almost all, the NHS nonetheless finds itself, more than 75 years after its birth, facing profound challenges.

When polled, the British public can name many of the issues facing the NHS: funding, workforce, and the impact of social care. But you will not find 'poor communications' named once in these polls – nor in policy briefings given to politicians, or headlines in the media. Yet, as we identify in this report, poor communication dogs countless engagements with the NHS and causes enormous harm to patients.

It arose first when we asked hundreds of people across Britain to share their experiences of health and care. Later, participants in our citizens' assembly made it one of their top-two priorities for improving health and care in Britain.

In its most well publicised forms, such as the case of Martha Mills, communication failure has been part of a catalogue of errors leading to a tragic death. At the very least, it still eats away bit-by-bit at people's trust in our most loved institution. While Martha's name will be remembered for the rule enshrining patients' and loved ones' right to trigger a clinical review, action, too, should be taken to address the countless examples of harm that, thankfully, did not end so tragically.

These communication failures, while absent from polling, are prioritised when the public deliberates their experiences of the NHS. Indeed, they may help to fuel public concern about waste, mismanagement and poor decision-making by the service.

Their impact however, is felt most acutely by patients with long-term conditions and staff. In our workshops of patients and practice managers – with our partners in this work, PMA and the Patient's Association – we heard countless times the impacts this could have.

Our work on solutions suggests that relatively simple changes could make a big difference to people's everyday experiences of interacting with the NHS. Fixes like the training for frontline staff in GP practices as care navigators and clinical coordinators for people with complex conditions have already been shown to work.

Nor are they the only attempts to improve communications in the NHS. Examples include, 'Hello, my name is', a campaign to encourage NHS staff to share their names started by a terminal cancer patient, and NHS doctor, Helen Grainger. It was widely adopted by staff across the service. NHS England's Accessible Information Standard followed work with the charity Sense, part of efforts to improve the health service's inclusivity. And throughout our work with the public, patients and staff, it was clear that many staff work hard to improve communications.

But the individual efforts of staff are too often undermined by administrative failures, oversights or, simply, sloppy practice. And, while campaigns can improve the way patients are addressed, and signposting will help patients navigate complex systems, they fall short of solving the deep rooted issues. To do that the NHS must unpick choices that are hard-coded into its remit, its institutional values, and the legacy systems upon which it relies.

Looking ahead to 2024, NHS funding and reform are likely to be high on voters', and politicians' agendas for the next election. But reforming the NHS will present obvious trade-offs for politicians, as they consider how to pay for greater and greater NHS demand.

To secure ongoing public buy-in for NHS reform and investment, politicians would be wise to consider the

public's priorities for the NHS in a more nuanced way. As we have identified, improving communication may be one fruitful way of doing this – helping to prove the NHS is tackling the harm and waste it causes for staff and patients.

NHS commissioners meanwhile will focus on redesigning services to save money and improve clinical outcomes. In some cases, these changes may include significant impacts for patients and the public, as services are relocated, removed, or substantially changed.

In the context of a wealth of examples of poor communication, such reforms may put more stress on the NHS's ability to communicate effectively. And if constant experiences of poor communication are helping to undermine trust in the NHS now, they are also likely to undermine confidence in reform.

There are many reasons for the NHS to confront poor communications more forcefully than it currently is – most pressingly because of the amount of needless harm it causes patients. But there is also a political and wider service improvement gain from doing so.

By making the improvement of NHS communication a priority, a future government may be able to help assuage some of the many valid concerns reforms present for taxpayers and patients alike, and in time be part of how the service rebuilds trust and helps to build a more resilient, responsive and clinically effective NHS in the future.

APPENDICES

APPENDIX 1: GOOD PRACTICE CASE STUDIES FROM ACROSS THE NHS

We worked alongside Imperial College Health Partners to gather examples of best practice. We then worked alongside the PMA to recruit a group of GP practice managers and other non-clinical staff to review the examples of good practice used across the NHS shared below. The participants shared how these existing solutions would improve communication between the NHS and people. The participants also shared what else could be done.

Care Navigators:

Care Navigators are trained staff who can help direct patients to the most appropriate service or person depending on their needs. The role is often carried out by non-clinical front-line staff, such as receptionists and patient liaison officers, or volunteers.

As part of their role, Care Navigators have access to up-to-date information about the services offered across local NHS providers and the wider care and support sector. They can play a key signposting role, helping to link patients with services they might not otherwise have known about or considered. The aim is to remove the onus from the patient and to support them to access the most appropriate service first-time.

- **Solution type:** Workforce model

- **Problem addressed:** navigating a complex system

- **Care setting:** multiple, including GP practices, A&E, and hospitals

- **Patient pathway:** often used to support patients entering the system or on complex care pathways e.g. cancer, post-stroke

- **Scale:** the concept is used widely across the UK; approaches cary by local areas.

- **Patient benefits:** Supports patients to be seen by the right person, at the right place and at the right time; Creates an opportunity for a conversation where patients are asked about their wider needs and actively listened to by trained staff; and Raises awareness of the different services available, enabling patients to make more informed choices around how to manage their health and wellbeing.

- **System benefits:** Can reduce the burden on stretched services (such as GPs and A&E) where another service is actually more appropriate for the patient's need; Facilitates improved links between health, social care and the voluntary sector; and Development opportunity for non-clinical staff, with the potential to improve engagement and retention.

- **Challenges:** Resource intensive – requires organisational support and investment to train staff for these roles and ensure their knowledge of local services remains up-to-date; Whilst the concept is widely used there is not one consistent approach. This makes it hard to accurately evaluate; and Do patients feel comfortable discussing their issues with non-clinical staff?

No Wrong Door:

No Wrong Door is an approach to delivering mental health services that aims to ensure that individuals are supported to access the help they need, when they need it, regardless of where they first turn for help.

The model involves GPs, local authorities, community services and the voluntary sector working together to meet the physical, mental and social needs of service users in a coordinated way.

The network of partners is coordinated centrally, with an emphasis on local, community-based care. Where people are waiting to access specific services, support and signposting is offered in the interim.

- **Solution type:** Workforce model

- **Problem addressed:** navigating a complex system

- **Care setting:** multiple; with a focus on taking a joined-up approach

- **Patient pathway:** community mental health

- **Scale:** introduced on the Isle of Wight in 2021, but builds on a similar approach used elsewhere for children in care.

- **Patient benefits:** Patients no longer need to be experts in navigating the system in order to get the support they need; Reduces the likelihood of patients 'falling between the gaps' or being bounced around the system; and Services work together to treat the whole-person, pathing the way for better outcomes.

- **System benefits:** Facilitates improved links between health, social care and the voluntary sector; and Patients are more effectively triaged to the most appropriate service(s).

- **Challenges:** Requires central coordination across multiple services. How well would it work in large cities with particularly complex systems?; How might the absence of a shared care record infrastructure in a local area limit success?; and How are patient expectations managed when waiting for more specialist services (which are often the most oversubscribed)?

Manage Your Referral:

The NHS e-Referral Service (e-RS) supports referrals to secondary care (hospitals or specialist clinics) from GPs.

The patient-facing part of the service – Manage Your Referral – is available on the NHS website and via the NHS App. There is also a low-cost telephone service for patients who would prefer not to book online.

The service allows patients to track the status of referrals and schedule appointments. When making these bookings, patients are given the option to select a time, date or place of their choice. All of the appointment details, including contact details for the referrer and the referral number, are available for the patient to refer back to. Patients can also use the service to cancel or reschedule appointments if needed.

- **Solution type:** website where patients can view and manage referrals.

- **Problem addressed:** expectation raising

- **Care setting:** primary care (GP practices), remote support

- **Patient pathway:** referrals to specialist care

- **Scale:** used throughout the NHS in England. There have been at least 17 million referrals using this system in the last year.

- **Patient benefits:** Provides a single source of information and improved transparency around the referral process; Allows patients to choose appointment dates/times/locations that work for them; and Patients can refer back to referral and appointment details saved in their patient profile.

- **System benefits:** More consistent processes and a clear audit trail; Fewer missed appointments - if patients can choose their own appointment, they are more likely to turn up; and Improved efficiency – less

time spent scheduling appointments and processing paperwork.

- **Challenges:** Not all referrals are made on this system, e.g. Manage Your Referral is not yet in use for all referrals between specialist services; and Positive patient experiences when using the Manage Your Referral still rely on good communication from the GP to the patient, e.g. setting expectations around wait-times, and signposting to information in the interim.

Patients Know Best:

Patients Know Best is an online service that gives patients secure access to their health record. It links to the NHS App and is designed to improve how patients experience and access NHS services and information.

The platform enables patients to see their appointments, test results, medication lists and care plans together in one place. Patients can also use the platform to upload journal entries and track symptoms, which can support clinicians to monitor their health remotely. Patients can choose to share information with carers and clinicians so that everyone looking after them understands the type of care and support they need and want. Some services also enable patients to use the platform to message their healthcare teams.

- **Solution type:** personal health record

- **Problem addressed:** expectation setting, joined-up care

- **Care setting:** remote support

- **Patient pathway:** not pathway specific, often used by patients with long-term conditions

- **Scale:** used across the NHS in England and Wales since 2008 with over a million patients now using the platform.

- **Patient benefits:** Patients have a complete record of their care that they can refer back to and use to prepare for upcoming appointments; Information can be shared with carers and other professionals – reducing the need for patients to have to repeat their story; and Enables patients to share and receive information (e.g. test results) without needing to wait to book an appointment.

- **System benefits:** Care plans can be created and shared across relevant teams, making it easier to coordinate care; Supports staff to monitor patients remotely – reducing unnecessary appointments and creating capacity; and A complete, real-time record of current and past data for patients.

- **Challenges:** Not used consistently across the UK. Different areas / services use different platforms, and patients could end up having to use several; Digital exclusion and potential inequalities in care; and Services still need to set clear expectations around which staff can be messaged, likely response times, and how sensitive test results will be shared.

Connecting Care for Children:

Connecting Care for Children is a workforce model which brings together paediatric specialists - such as consultants, school nurses, early years teams and health visitors – together with GPs to care for children in their area.

The model involves regular joint meetings between these professionals, where complex cases can be discussed in a collaborative way. GPs also have a telephone hotline they can call for paediatric advice in between.

This partnership approach aims to support GPs to continue caring holistically for children in community settings, reducing the need for onward referrals. Families receive one management plan, agreed on by the multi-disciplinary team, and should therefore receive more consistent messaging – even when interacting with multiple services.

- **Solution type:** workforce model

- **Problem addressed:** joined-up care

- **Care setting:** Primary care (GP practices)

- **Patient pathway:** Paediatrics (children and young people)

- **Scale:** started in 2012; used by around 40 GP practices across North West London

- **Patient benefits:** Children can receive specialist care in a local setting, which is often more relaxing and familiar for them; Fewer points of contact, enabling better relationship-building (particularly with the child's GP); and Joined-up care - parents get one management plan, agreed on by a multi-disciplinary team of professionals; especially beneficial for children with complex needs

- **System benefits:** Stronger working relationships are built by frequent communication and sharing expertise across services; and Better care in the community and outside of hospital settings helps reduce unnecessary admissions and referrals (and for the children, reduces time away from education)

- **Challenges:** The model has been driven by strong buy-in from local clinicians, without additional funding – likely to be hard to scale without wider support and funding; Has only been trialed in one locality, would it work as well in other areas?; and Has only been trialled in one locality; would it work as well in other areas?

Rix Wiki:

RIX Wiki is an online portal that enables young adults with learning disabilities to share their needs, goals, and preferences.

Wikis are simple, secure and easy to build personal webpages where users can upload photos, videos and documents to help tell their story. Wikis help capture the personal needs and wishes of individuals, alongside information from their families and carers, that can help to improve understanding of what matters most to the person and what works best.

Once a Wiki is made, it can be securely shared with other people who regularly interact with that person including education, health and care professionals. The aim is to support person-centred care where professionals get to know individuals on their own terms rather than through a service lens.

- **Solution type:** patient resource/communication tool

- **Problem addressed:** joined-up care, supporting those with complex needs

- **Care setting:** multiple, can be used to support communication in hospital, school, and other care settings.

- **Patient pathway:** young adults with learning disabilities and special educational needs (SEN)

- **Scale:** was being piloted at the time of the workshops by the local NHS in Leicester and Leicestershire and Rutland councils.

- **Patient benefits:** supports independence and improves self-advocacy by enabling users to tell their own stories and communicate their needs; improved communication and information sharing between patients, their families, and providers; and less repeating of stories or information being lost.

- **System benefits:** patient information in one place to better understand patient and family needs; greater understanding of the patient as a whole-person to provide care; and enables alternative communication with patients who may not be able to communicate.

- **Challenges:** places a lot of responsibility on the service user and their carer to fill in the information and keep it up to date, which could be time consuming; not every user/patient/carer might find the site easy to use; and to realise the tool's full value, all health and care professionals, school staff, etc., need to commit to using the Wiki.

Patient Check.in:

Patient check.in is a check-in process which allows patients in A&E to see real-time updates of their position in the queue and their likely wait time. On arrival, patients complete a brief questionnaire, which enables them to tell clinicians why they are in the emergency department in their own words.

The questionnaire can be completed on a smartphone whilst the patient waits, or reception can register patients without a smartphone. Once registered, patients can monitor their position in the queue either on their phone or on TV screens in the waiting room. Having this waiting time information readily available aims to help manage patient expectations and reduce anxiety around being forgotten, passed over or missed.

- **Solution type:** check-in process

- **Problem addressed:** expectation setting

- **Care setting:** emergency departments (A&E)

- **Patient pathway:** on arrival and whilst waiting in A&E

- **Scale:** developed by, and in use in, one London Emergency Department since 2021 at the time of the workshops.

- **Patient benefits:** improved transparency in relation to waiting times; reduces anxiety around unclear queue position; reassuring patients they have not been missed or bypassed; and supports patient-centred care by empowering patients to tell their story in their own words.

- **System benefits:** all relevant staff can see patients' questionnaires – reducing the need for patients to have to repeat their story; clinicians can review the patients' questionnaire in advance allowing for more informed consultations; and reception staff receive a lower volume of questions and can focus on patients in greatest need.

- **Challenges:** is seeing a position in the queue and an estimated wait time enough to reduce patient anxiety, especially if the times indicate a long wait?; and would it feel like a two-tier system for those with smartphones and those without?

Hospital Discharge Checklist:

A short checklist designed to support people aged 65+ to prepare for leaving hospital. This checklist aims to guide patients and carers in their conversations with hospital staff, ensuring they know the important information to ask for and are able to record it before being discharged. It has been developed to reflect the most common questions posed by patients when leaving hospital including symptoms to look out for, changes to medication, and plans for getting home.

- **Solution type:** patient information leaflet (printed paper version)

- **Problem addressed:** expectation setting and joined-up care

- **Care setting:** hospital

- **Patient pathway:** when leaving hospital and returning home or transitioning to community care

- **Scale:** piloted and evaluated across three hospitals in Surrey at the time of the workshops.

- **Patient benefits:** supports patients and carers to identify key questions to ask, and prompts them to then ask those questions before being discharged; key information is recorded in one place; and patients and carers more likely to feel empowered and safe when leaving hospital, knowing what is happening next.

- **System benefits:** helps to identify potential gaps or concerns around the patient's next steps; enables knowledge sharing between different care providers and smoother transitions; and more consistency in discharge conversations.

- **Challenges:** not all of the questions are relevant in all instances; successful use relies on hospitals to figure out a way to build it into their existing processes, and to carve out time from staff who are already under time pressure to help complete it; and paper document which can only be seen/edited by those with the patient, potential to be lost in transition.

Licence to publish

Demos – Licence to Publish

The work (as defined below) is provided under the terms of this licence ('licence'). The work is protected by copyright and/or other applicable law. Any use of the work other than as authorized under this licence is prohibited. By exercising any rights to the work provided here, you accept and agree to be bound by the terms of this licence. Demos grants you the rights contained here in consideration of your acceptance of such terms and conditions.

1 Definitions

a 'Collective Work' means a work, such as a periodical issue, anthology or encyclopedia, in which the Work in its entirety in unmodified form, along with a number of other contributions, constituting separate and independent works in themselves, are assembled into a collective whole. A work that constitutes a Collective Work will not be considered a Derivative Work (as defined below) for the purposes of this Licence.

b 'Derivative Work' means a work based upon the Work or upon the Work and other pre-existing works, such as a musical arrangement, dramatization, fictionalization, motion picture version, sound recording, art reproduction, abridgment, condensation, or any other form in which the Work may be recast, transformed, or adapted, except that a work that constitutes a Collective Work or a translation from English into another language will not be considered a Derivative Work for the purpose of this Licence.

c 'Licensor' means the individual or entity that offers the Work under the terms of this Licence.

d 'Original Author' means the individual or entity who created the Work.

e 'Work' means the copyrightable work of authorship offered under the terms of this Licence.

f 'You' means an individual or entity exercising rights under this Licence who has not previously violated the terms of this Licence with respect to the Work, or who has received express permission from Demos to exercise rights under this Licence despite a previous violation.

2 Fair Use Rights

Nothing in this licence is intended to reduce, limit, or restrict any rights arising from fair use, first sale or other limitations on the exclusive rights of the copyright owner under copyright law or other applicable laws.

3 Licence Grant

Subject to the terms and conditions of this Licence, Licensor hereby grants You a worldwide, royalty-free, non-exclusive, perpetual (for the duration of the applicable copyright) licence to exercise the rights in the Work as stated below:

a to reproduce the Work, to incorporate the Work into one or more Collective Works, and to reproduce the Work as incorporated in the Collective Works;

b to distribute copies or phono-records of, display publicly, perform publicly, and perform publicly by means of a digital audio transmission the Work including as incorporated in Collective Works; The above rights may be exercised in all media and formats whether now known or hereafter devised. The above rights include the right to make such modifications as are technically necessary to exercise the rights in other media and formats. All rights not expressly granted by Licensor are hereby reserved.

4 Restrictions

The licence granted in Section 3 above is expressly made subject to and limited by the following restrictions:

a You may distribute, publicly display, publicly perform, or publicly digitally perform the Work only under the terms of this Licence, and You must include a copy of, or the Uniform Resource Identifier for, this Licence with every copy or phono-record of the Work You distribute, publicly display, publicly perform, or publicly digitally perform. You may not offer or impose any terms on the Work that alter or restrict the terms of this Licence or the recipients' exercise of the rights granted hereunder. You may not sublicence the Work. You must keep intact all notices that refer to this Licence and to the disclaimer of warranties. You may not distribute, publicly display, publicly perform, or publicly digitally perform the Work with any technological measures that control access or use of the Work in a manner inconsistent with the terms of this Licence Agreement. The above applies to the Work as incorporated in a Collective Work, but this does not require the Collective Work apart from the Work itself to be made subject to the terms of this Licence. If You create a Collective Work, upon notice from any Licensor You must, to the extent practicable, remove from the Collective Work any reference to such Licensor or the Original Author, as requested.

b You may not exercise any of the rights granted to You in Section 3 above in any manner that is primarily intended

for or directed toward commercial advantage or private monetary compensation. The exchange of the Work for other copyrighted works by means of digital file sharing or otherwise shall not be considered to be intended for or directed toward commercial advantage or private monetary compensation, provided there is no payment of any monetary compensation in connection with the exchange of copyrighted works.

c If you distribute, publicly display, publicly perform, or publicly digitally perform the Work or any Collective Works, you must keep intact all copyright notices for the Work and give the Original Author credit reasonable to the medium or means You are utilizing by conveying the name (or pseudonym if applicable) of the Original Author if supplied; the title of the Work if supplied. Such credit may be implemented in any reasonable manner; provided, however, that in the case of a Collective Work, at a minimum such credit will appear where any other comparable authorship credit appears and in a manner at least as prominent as such other comparable authorship credit.

5 Representations, Warranties and Disclaimer

a By offering the Work for public release under this Licence, Licensor represents and warrants that, to the best of Licensor's knowledge after reasonable inquiry:

i Licensor has secured all rights in the Work necessary to grant the licence rights hereunder and to permit the lawful exercise of the rights granted hereunder without You having any obligation to pay any royalties, compulsory licence fees, residuals or any other payments;

ii The Work does not infringe the copyright, trademark, publicity rights, common law rights or any other right of any third party or constitute defamation, invasion of privacy or other tortious injury to any third party.

b Except as expressly stated in this licence or otherwise agreed in writing or required by applicable law, the work is licenced on an 'as is' basis, without warranties of any kind, either express or implied including, without limitation, any warranties regarding the contents or accuracy of the work.

6 Limitation on Liability

Except to the extent required by applicable law, and except for damages arising from liability to a third party resulting from breach of the warranties in section 5, in no event will licensor be liable to you on any legal theory for any special, incidental, consequential, punitive or exemplary damages arising out of this licence or the use of the work, even if licensor has been advised of the possibility of such damages.

7 Termination

a This Licence and the rights granted hereunder will terminate automatically upon any breach by You of the terms of this Licence. Individuals or entities who have received Collective Works from You under this Licence, however, will not have their licences terminated provided such individuals or entities remain in full compliance with those licences. Sections 1, 2, 5, 6, 7, and 8 will survive any termination of this Licence.

b Subject to the above terms and conditions, the licence granted here is perpetual (for the duration of the applicable copyright in the Work). Notwithstanding the above, Licensor reserves the right to release the Work under different licence terms or to stop distributing the Work at any time; provided, however that any such election will not serve to withdraw this Licence (or any other licence that has been, or is required to be, granted under the terms of this Licence), and this Licence will continue in full force and effect unless terminated as stated above.

8 Miscellaneous

a Each time You distribute or publicly digitally perform the Work or a Collective Work, Demos offers to the recipient a licence to the Work on the same terms and conditions as the licence granted to You under this Licence.

b If any provision of this Licence is invalid or unenforceable under applicable law, it shall not affect the validity or enforceability of the remainder of the terms of this Licence, and without further action by the parties to this agreement, such provision shall be reformed to the minimum extent necessary to make such provision valid and enforceable.

c No term or provision of this Licence shall be deemed waived and no breach consented to unless such waiver or consent shall be in writing and signed by the party to be charged with such waiver or consent.

d This Licence constitutes the entire agreement between the parties with respect to the Work licenced here. There are no understandings, agreements or representations with respect to the Work not specified here. Licensor shall not be bound by any additional provisions that may appear in any communication from You. This Licence may not be modified without the mutual written agreement of Demos and You.

DEMOS

Demos is a champion of people, ideas and democracy. We bring people together. We bridge divides. We listen and we understand. We are practical about the problems we face, but endlessly optimistic and ambitious about our capacity, together, to overcome them.

At a crossroads in Britain's history, we need ideas for renewal, reconnection and the restoration of hope. Challenges from populism to climate change remain unsolved, and a technological revolution dawns, but the centre of politics has been intellectually paralysed. Demos will change that. We can counter the impossible promises of the political extremes, and challenge despair – by bringing to life an aspirational narrative about the future of Britain that is rooted in the hopes and ambitions of people from across our country.

Demos is an independent, educational charity, registered in England and Wales. (Charity Registration no. 1042046)

Find out more at **www.demos.co.uk**

DEMOS