

Patient experiences of NHS communications and administration



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Summary

General Communications and Administration

- There is no universal agreement about which mode of communication is preferred but people regret that email specifically and technology generally is insufficiently used and individual needs and preferences are not always recognised.
- There is a frustration that NHS text messages do not have a 'reply' option.
- Patients and their families sometimes spend a lot of time and energy chasing up the care they need as they try to resolve the problems caused by slow or inappropriate responses from healthcare providers. This can be frustrating, time-consuming and seriously impact on the physical and mental health and well-being of patients and their families and cause frustration.
- There is a great inconsistency in experiences of NHS communications and administration with some services or departments performing well and others not so well.
- Results and diagnoses are not always being delivered in a timely and appropriate manner.
- There is an incorrect, but common, assumption by service providers that everyone can access healthcare services by car or public transport.
- People want greater transparency and oversight of communications about them between service providers so they do not have to spend time 'chasing up'.
- There appears to be little public understanding about making formal complaints and, potentially, a concern that doing so might negatively impact on the quality of care they may receive.

General Practice

- People still report problems in their communications with general practice care navigators whom they sometimes consider to be less understanding than they would wish.
- Concerns remain that accessing General Practice is not working as well as patients would hope, although the telephone call-back service, recently introduced in some surgeries, is appreciated.
- Some patients, accessing out of area secondary care and needing hospital-requested blood tests cannot access their local GP practice to have their blood taken. They have to travel further afield – with consequent cost and inconvenience.
- There was little mention of the General Practice on-line consultation facility suggesting that patients are either not aware of it or are uncomfortable using it.

- Communications between GPs and hospitals are experienced as unreliable and can undermine patient safety in the transfer of care; especially with the management of prescriptions.

Urgent and Emergency Care

- There was one disturbing account of a delayed response for someone experiencing a life threatening, medical emergency which was not recognised by the call handler.
- It is difficult to locate loved ones in hospital after they have been taken by ambulance to hospital Emergency Departments and then transferred to a ward.
- Rutland patients have difficulties in determining where and when they can access minor injuries and urgent care services.

Pharmacy and medication

- There are gaps in communication between pharmacies and their customers about the progress in receiving their prescription and dispensing the drugs.
- There are delays for patients in getting the medications they need when hospital consultants have changed their prescriptions but the GP practice has not received timely notification. This compromises patients' safety and wellbeing.

Hospital services

- Hospital waiting lists are long and difficult for all. Participants reported the distressing impact of: lack of communication and information in the waiting period; clerical errors; slow or unreliable delivery of letters; delayed communication of diagnoses to patients; problems in co-ordinating or changing appointments; getting through on the telephone; call handlers who did not take ownership of patient's problems; unresponsive ward staff; and cancelled operations.
- The results of blood tests requested by hospital consultants and taken by GP practices are often not passed on to either GPs or their patients in a timely manner. This compromises GP continuing care and results in patient anxiety.

Children's Services

- Children and their families are particularly affected by slow administration and appointment processes, the impact of which spills over into their education and social development.
- Young people want to be treated holistically, involved in their own medical consultations and receive information in terms they can understand.
- Parents are naturally anxious and want the best for their children and delays or lapses in communication are distressing for all.

Patients with disabilities

- People with disabilities do not always have sufficient support with their communication needs when interacting with the NHS.

Recommendations

Recommendations are distributed among specific healthcare services; some being applicable to more than one service and, so, repeated.

a) General recommendations

1. All health and care providers should have due regard the Accessible Information Standard and give patients choices about their mode of communication, comply with their choices and recognise that 'one size does not fit all', especially regarding the needs of people with disabilities.
2. There should be a better use of technology, including:
 - More use of email
 - A technological solution so that patients can view and change their appointments if necessary
 - A response facility for text messages sent by the NHS to patients
 - A universal offer of a telephone call-back service across all healthcare services
3. All communication should include brief information for patients about the complaints process and reassurance that their care will not be adversely affected if they challenge or make a complaint.

b) General Practice

1. Care navigators and call handlers should receive mandatory, ongoing training towards continuous improvement in patient care. This should include acknowledgement that patients, as experts in their own body, know when they are in need of urgent clinical advice and respond accordingly.
2. Not everyone can drive or has ready access to transport, so all staff should offer flexibility in arranging access to care.
3. Technical help should be provided for patients with the GP online consultation facility to increase usage and people's confidence in using it.
4. Patients should have oversight of all communication about themselves between all services including between care navigator and GP and between GP and hospitals.
5. Patients needing hospital-requested blood tests, irrespective of which hospital they attend, should be able to have their blood sample taken at their GP practice rather than being sent much further away.
6. Patients should be routinely told when to expect their test results which should be delivered within that time-frame.

7. In order to ensure care and empathy, all patients should be provided with the contact details of a named person when they are given sensitive or difficult diagnoses and test results.

c) Urgent and emergency care

1. Care navigators and call handlers should receive mandatory, ongoing training towards continuous improvement in patient care. This should include acknowledgement that patients, as experts in their own body, know when they are in need of urgent clinical advice and respond accordingly.
2. Rutland residents should be provided with clearer advice on how to access urgent and emergency care.

d) Pharmacy and medication

1. Pharmacies should establish a means of informing patients when they have received a prescription from the GP and when it is dispensed and ready for collection.

e) Hospital services

1. Good and effective practices in some services and departments should be shared across to areas where communications and administration are failing.
2. Patients waiting for appointments or procedures should be given updates about their position on waiting lists and information about how to prepare for their procedure and what to expect.
3. Telephone call handlers, dealing with administration matters, should take ownership of patients' problems and not pass the caller on.
4. Patients should be given a hospital contact telephone number and reference number for every episode of communication.
5. Not everyone can drive or has ready access to transport, so all staff should offer flexibility in arranging appointments.
6. Patients should have oversight of all communication about themselves between all services including between care navigator and GP and between GP and hospitals.
7. Patients should be routinely told when to expect their test results and these should be delivered within that time-frame.
8. Results of hospital-requested blood tests should be made available to GPs and patients as soon as available rather than waiting for a hospital consultation.
9. In order to ensure care and empathy, all patients should be provided with the contact details of a named person when they are given sensitive or difficult diagnoses and test results.
10. Create and maintain standardised procedures and a specified time frame for communications from hospitals to GPs; especially when medication

changes are involved, for both inpatient and outpatients, and for those inpatients discharged on the non complex discharge (P0) pathway.

11. There should be a routine established so that the next-of-kin of patients conveyed to Emergency Departments are informed when patients are transferred to wards.

f) Children's services

1. The reported success of the Rutland Family Hub should be built upon to expand integrated support for parents, siblings and the wellbeing of all children waiting for long periods of time for diagnosis and treatment.

g) Patients with disabilities

1. All health and care providers should have due regard for the Accessible Information Standard and give patients choices about their mode of communication and recognise that 'one size does not fit all', with, especially, the needs of people with disabilities respected.

Service Provider Responses

Leicestershire Partnership Trust

"We welcome the report by Healthwatch Rutland and will use it to review what improvements we can make with regards to patient communications and administration. Although Leicestershire Partnership NHS Trust's community and mental health services were not mentioned specifically, there is some useful information here for general healthcare provider communications.

"We seek to ensure patient voice is at the heart of our services. Our Trust works very closely with our People's Council, who undertook a review of complaint and concerns related to communication in 2024. This review has resulted in a number of recommendations and actions that are now being taken forward by the Trust and the Council in partnership. This includes strengthening how we learn from and embed themes from complaints and ensuring wait times are clear in all communications.

"All of our complaint information is clearly signposted on our website and on patient information leaflets, as well as posters in our receptions. We will look to see if this can be further strengthened.

"Our Patient Experience and Involvement Team have also undertaken a programme of co-design with a group of patients, carers and staff to review and update our Customer Service Training; supporting staff who have direct contact with patients and carers to increase their skills and confidence in communicating effectively with patients, service user and carers either on the phone or face to face.

“We are committed to the Accessible Information Standard and give patients choices about their mode of communication. This is embedded onto our electronic patient records and used alongside ‘communication passports’ for people with learning disabilities. We also ensure Easy Read materials are available in our patient information and on our website; ensuring we undertake equality impact assessments in the development of any service delivery is built into our processes.

“We are increasingly focused on improving our technology to enable choice of correspondence with our patients and service users. In addition, we have created innovative websites that are aimed at children and young people and their families: www.healthforkids.co.uk, www.healthforunder5s.co.uk and www.healthforteens.co.uk. We also have a confidential chat messaging service called ChatHealth which is available in children’s services and perinatal mental health services. In addition, we have developed an online MyGuidance website that offers prescribed video self-help guides from our clinicians. We have a universal helpline for our Healthy Together 0-19 service as well as a Single Point of Access helpline for our community nursing services. Our use of Apps is growing however, ensuring all of our information is as accessible as possible online and offline remains important to ensure we do not create health inequalities of access.

“We will continue to review the recommendations in detail and make appropriate changes to our information and processes through co-production.”

Jean Knight, Managing Director, Deputy Chief Executive
Leicestershire Partnership Trust

University of Leicester Hospitals NHS Trust

“We are grateful to Healthwatch Rutland for co-ordinating this report, and to all the participants for sharing their experiences and insights. We have reviewed the report with colleagues from our patient experience, operational transformation, digital, and communications and engagement teams. We will be reflecting on the learning and recommendations as we continue to improve our services, including the ways in which we communicate with people and organise care. This includes:

“Using a wider range of communications methods, including text messages, to communicate test results and appointment details to patients. Our text platform supports patient responses, enabling two-way communication.

- Implementing our new Patient Administration System (PAS) in 2025, which will support the coordination of care, reduce duplication and error, strengthen safety, and improve patient experience.
- Expanding use of the NHS App in 2025, to give people more control over their care in line with national ambitions.
- Communicating more proactively with people on waiting lists, in partnership with others including General Practice.

- Continuing to improve our Accessible Information Standard compliance, working with the voluntary sector, community groups, and experts by experience to embed change.

“We are in the process of establishing a new digital patient forum to help us get key systems changes right, and would invite any residents of Leicester, Leicestershire and Rutland who are interested to get in touch with us here: communications@uhl-tr.nhs.uk. You do not need to be digitally confident to take part, as we need the changes to work for everyone. Similarly, we welcome the ongoing support and involvement of Healthwatch as we continue to transform our services for patients, carers and families.”

Michelle Smith, Director of Communications and Engagement
University Hospitals of Leicester NHS Trust

NHS Leicester, Leicestershire and Rutland Integrated Care Board

“We would like to thank Healthwatch Rutland for their recent survey about patients’ experiences of NHS communications and administration. We are grateful to everyone who took the time to participate in the survey and shared their stories in the qualitative research. Studies like this are so important as we work together across our health and care system to continuously improve people’s care, and being able to include these specific experiences of Rutland residents will be extremely valuable.

“The survey’s findings related to General Practice mirror what people told us in the ICB’s General Practice Experience Survey that we undertook in 2024. Practices use the survey findings to help develop their plans to improve access. We are due to repeat this survey in 2025/26 and we would like to work with Healthwatch Rutland on the development of this to maximise participation from Rutland residents. The ICB and local practices are actively working to increase awareness of some of the newer communication methods including call back functionality and online consultations. Patients can already manage their prescriptions and health record through the NHS app. Over the next year, the NHS App will be able to offer increased functionality, including the ability to cancel and re-book hospital appointments, fill in patient questionnaires and act as a secure messaging service. ”

Dr Nil Sanganee, Chief Medical Officer
NHS Leicester, Leicestershire and Rutland Integrated Care Board

Introduction

‘Communication is the process used to exchange information and it is considered effective when both parties, the sender and the receiver, give the same or similar meaning to the message being conveyed’¹

The Nursing Times (2017)² suggests that patients are more satisfied when provided with sufficient time to have their story heard, are taken seriously and are encouraged to express their own thoughts and expectations. Patients also value clear explanations and the ability to take part in the decision-making. The Nursing Times also reported that the estimated cost of poor communications then to the National Health Service (NHS) was in excess of £1 billion per year.

Healthwatch Rutland (HWR) has heard many patients’ stories about their problems with NHS communications and administration in recent years. This study was designed to understand more about the extent of the issues by exploring in depth personal experiences, both positive and negative, of communications and administration processes in everyday transactions with the NHS. People were asked to share how those processes had impacted on them and what the NHS can do to make improvements.

To be eligible for taking part, people needed to be talking about their experiences within the preceding 12 months.

1. Method

A mixed methods approach, using quantitative survey and qualitative discussion methods, was used to maximise responses.

The guidance provided by the British Sociological Statement (BSA) of Ethical Practice (2017)³ was followed to ensure the wellbeing of participants and researchers and the integrity of the work. This included ensuring participants remain anonymous and were aware of their right to withdraw at any point until the data was analysed. An information sheet was provided and consent was obtained. All face-to-face interviews were carried out by two HWR personnel.

¹ Lee, E. (2021) Accessed 26/10/2024 at: <https://cpdonline.co.uk/knowledge-base/care/effective-communication/>

² Ali, M. (2017) Communication Skills: benefits of effective communication for patients Nursing Times [online]; 113: 12,18-19. Accessed at: <https://www.nursingtimes.net/clinical-archive/assessment-skills/communication-skills-1-benefits-of-effective-communication-for-patients-20-11-2017/>

³ British Sociological Association (2017) Statement of Ethical Practice. Accessed at

https://www.britisoc.co.uk/media/24310/bsa_statement_of_ethical_practice.pdf

1.1 Quantitative study: Survey

A survey ran from July to September 2024; available online, as hard copy and in easy-read format. The survey included some questions designed to prompt free text answers as well as numerical data. Free text responses were thematically analysed. Demographic details can be found in appendix 2

30 people took part in the survey. With a small number of respondents, the results are indications only and not statistically significant. 4 people took part in the easy-read survey; all were between the ages of 25-49 including 2 men, 1 woman and 1 person who 'preferred not to say'.

1.2 Qualitative study: People's stories

Participants were recruited online via social media and the HWR website, word of mouth, at meetings and community events, through village newsletters and community and support groups for people such as carers, people with sight impairment or other disabilities.

People's experiences were collected via a mixture of face-to-face interviews, telephone interviews, emailed personal accounts and focus groups. One young people's group leader conducted a group discussion on our behalf and shared responses. Semi-structured interviews with open-ended questions were used to encourage participants to talk in detail. All transcripts were coded thematically, with a proportion being double-coded and verified by a second person. The mode of data collection is indicated in the quoted comments throughout the report.

There were 96 participants in this part of the study:

13 people took part in interviews (Interview)

4 people emailed accounts of their experiences (Email)

70 people took part in focus groups (Focus Group)

9 people took part in their leader-led focus group with responses collated and sent in as bullet points. (LFG)

2. Research Results

In total, the study heard from 130 Rutland people. The results of both the survey and qualitative discussions and interviews are presented together under thematic headings.

2.1 Means of communication: an overview

The survey questioned the most recent communication with the NHS, asking: *What format did the communication use?*

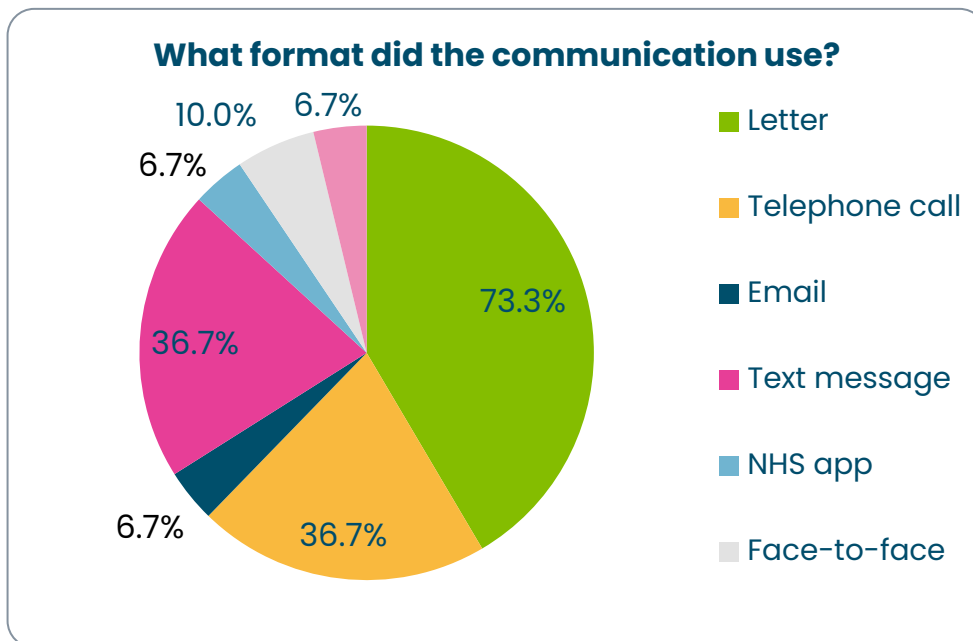


Figure 1: Survey: The format of the most recent communication with the NHS

'Communication with most respondents was carried out by letter, with telephone calls and text messaging equal in second place. Comments in 'other' were: 'on line consultation' and 'copied into hospital letter to GP regarding diagnosis but incorrectly addressed to a GP unknown to me'.

Were then asked: *How satisfied were you with the communications you received?*

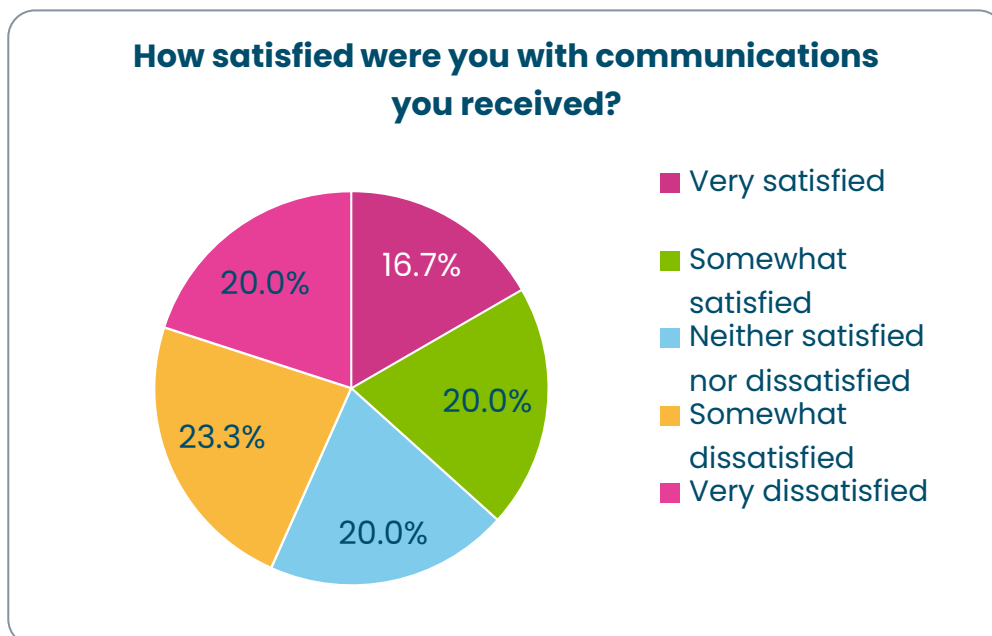


Figure 2: Survey respondents' satisfaction with communication

Slightly more people (43%) were somewhat or very dissatisfied with their communication experiences compared with 37% who were somewhat or very satisfied.

A further survey question asked: *To what extent do you agree with the following statements?*

	Strongly or somewhat disagree	Neither agree nor disagree	Somewhat or strongly agree	Don't know, not sure
The communication considered my personal needs (for example large font, required language, audio option)	27%	43%	20%	105
The reason for receiving the communication was made clear	30%	13%	56%	0%
The language used was plain and easy to understand	16%	13%	67%	3%
The communication was free of jargon and acronyms	20%	13%	66%	0%
I understood what to do next	30%	3%	63%	3%
The communication gave me enough information (for example location, date, time, contact details)	20%	3%	74%	3%
The communication gave me enough time to attend the appointment	23%	10%	63%	3%
The appointment went ahead as scheduled	23%	7%	63%	3%
I was were kept updated whilst waiting for treatment	50%	25%	25%	0%
I had to chase up communications that I/they had been told to expect but that did not arrive (such as results, medications advice, further therapy)	34%	21%	38%	7%

Table 1: Survey respondents' assessment of the communications they experienced

Survey respondents were more likely to agree or strongly agree that the communication they received contained sufficient information and gave them time to make arrangements to attend their appointments, which, mostly, went ahead as scheduled.

However, only 25% agreed that they were kept updated while awaiting treatment and only 20% somewhat or strongly agreed that their personal needs were considered in the communications they received.

Respondents were also asked: *What is your preferred method of contact for receiving information about healthcare, appointments and results?*

Answer Choices			Response Percent	Response Total
1	Letter		26.67%	8
2	Telephone call		10.00%	3
3	Email		33.33%	10
4	Text message		16.67%	5
5	NHS app		6.67%	2
6	Other (please specify):		6.67%	2

Table2: Survey respondents' preferred means of communication

Email was the most popular mode but the survey free text and comments from groups and individuals show that this is infrequently offered as an option. The two 'other' responses in Table 4 were: 'various, as suitable' and 'both letter and text'.

All 4 participants who completed the easy-read survey expressed a preference for letters. One said this was because it could be shown to their mother and the other said, 'because I can take it somewhere else'.

Thematic analysis of the free text comments offers more in-depth replies and an introduction to the potential for communication lapses:

'There's nothing like seeing a face-to-face GP. Making a call, a telephone conversation, is not the same. They can't see you and how you are looking. No doubt, if you describe yourself seriously enough, they will see you. Some things can be done over the phone but medical conditions need to be seen face to face.' (Interview)

'Using letters is slow, email would be quicker and better' (Interview)

However, some found that technology can be difficult: 'I don't use the online thing at [the] doctors'. Most people can't find what they want to find when they use it.' (Interview)

There was frustration that text messages from NHS service providers do not have a reply facility. Several participants said they wanted to be able to use email but one person spoke of their difficulties with technology:

'They asked if I could do it online but I said, "Not really as I'm not very confident." They said ok, the nurse will ask when I get to the pre-op assessment. Anyway, out of the blue, I got an online questionnaire on my phone, so I went through this thing and it took about 20 minutes. I think I might have pressed the wrong button to do something and tried to go back a few times but I couldn't'
(Interview)

The disparity of comments indicates that 'no one size fits all' for patients when communicating with healthcare providers but more use of email is wanted.

2.2 Communications with General Practice

2.2.1 Making contact

Most people's healthcare journey starts with a call or visit to their General Practice to book an appointment or make an enquiry. A recent development in some General Practices has been the introduction of a call-back option to reduce long waits for the telephone to be answered. This appears to be operating well:

'I telephoned the surgery in the morning [.....] I was number 16 in the queue and was given the choice to get a call back rather than to wait on the phone. I chose a call back option and went to lie back on the bed with my eyes closed. The call back came about 15 minutes later from a receptionist.' (Email)

GP receptionists and care navigators are trained to ensure the right patient gets to the right clinician at the right time. However, there were many reported communication problems at this first point of contact with GP practices.

Experience	Comments
Care navigators perceived as blocking access	'We couldn't get through that [reception] brick wall. They didn't seem to take it in that it mattered, you know, when it's something as serious as blood pressure fluctuating so high and so low.' (Interview)
Perception of communication breakdown between care navigators and clinicians	'There can be a problem between the surgery reception staff and the operating staff, those who do the work – the doctors and nurses. There's a [breakdown] between the front desk and the people at the back doing the work. Things get lost or misunderstood.' (Interview)
An unexpected appointment	'My [practice] recently made an appointment for me on my repeat prescription green slip. It's a mystery appointment. I'm not sure what it's for. I've called reception and they aren't sure, although they suggested it could be a medication review. But I haven't been reminded in any other way – letter, text [or] phone call.' (Interview)
Problems with the priority telephone line	'One of the issues was with Oakham Medical Practice priority line. I rang a few times and got through. But I rang once and was told it was for paramedics only. So I didn't bother them again.' (Interview)

Problems with online consultation	'I completed an online consultation form from my GP practice. The responses showed that they clearly had not read the form properly in the first instance and that they did not appreciate my circumstances'. (Survey)
Unable to get an appointment	'I've just turned 80. I was invited for an MOT (health check) via letter. I went on line – no appointments available. I called the practice – they just said, "none available, call again in a month." I'm fairly switched on but there are others who aren't and would get missed.' (Focus Group)

Table 3: Participants' experiences of their first point of contact with their GP practice

With only 2 participants mentioning the on-line consultation facility, there may be limited awareness or use of this method among the Rutland population. NHS Digital (July 2024)⁴ advise that the gathering of statistics to demonstrate the usage of this communication tool is 'still in the experimental stage.'

2.2.2 Speaking with a general practitioner

Patients' needs have increased over the years due to an ageing demography and more people living with complex comorbidities. But the number of full time equivalent GPs had, in September 2024, decreased since 2015 by 1,399 and GP patient lists have increased by over 17% in that time⁵. To deal with this, GPs are less frequently able to do house calls or provide continuity of care and patients are diverted to more appropriate practitioners such as pharmacists, physiotherapists, advanced nurse practitioners etc. However, when participants did want to speak with a doctor, they had mixed experiences.

'I did, one time, speak to a GP when I was in tears. Mum was in bed and in tears and I begged them to come out. They just kept saying, "No, give her more oramorph [a pain killer]." Mum was in bed – it was horrendous.'
(Interview)

'I had a stroke last year and the doctors haven't contacted me once. Peterborough hospital has and that's who gave me the care after the stroke. I just feel that the doctors don't care.' (Focus Group)

Others spoke more highly of communication with their GP practice:

'The news around surgeries are [sic] not always bleak. This one is a happy one. Thank you to the receptionists, the Senior Nurse Practitioner and the Doctor.' (Email)

⁴ NHS Digital (July 2024) *Submissions via Online Consultation Systems in General Practice: Supporting Information*. Accessed 19/10/2024 at: <https://digital.nhs.uk/data-and-information/publications/statistical/submissions-via-online-consultation-systems-in-general-practice/submissions-via-online-consultation-systems-in-general-practice-supporting-information>

⁵ British Medical Association (November 2024) *Pressures in general practice data analysis* Accessed 4/11/2024 at: [https://www.bma.org.uk/advice-and-support/nhs-delivery-and-workforce/pressures/pressures-in-general-practice-data-analysis#:~:text=Fewer%20doctors%20are%20looking%20after,over%2017%25\)%20since%202015.](https://www.bma.org.uk/advice-and-support/nhs-delivery-and-workforce/pressures/pressures-in-general-practice-data-analysis#:~:text=Fewer%20doctors%20are%20looking%20after,over%2017%25)%20since%202015.)

'I've been looked after by the surgery – wonderful service from the GP. I never have to chase them. They're great.' (Focus Group)

Whilst expressing satisfaction with the service received, these positive comments, nevertheless, indicate awareness that making contact with a GP practice can be fraught with communication problems.

2.2.3 GP Referrals

GPs are often seen as gatekeepers for referrals to secondary care or other health and care services. Participants spoke variously of having to 'fight' for referrals, experiencing delays or incorrect referrals:

'I was referred from my general practice for surgery and the referral was made to the wrong area so, although I was due to have 24-hour care, I was referred for a day surgery procedure at Melton Hospital.' (Interview)

'Before COVID, it all used to be handled by the surgery. It wasn't down to you to organise. But the last time I spoke to a doctor down there I had to fight for a referral. The doctor said she would do the referral and it would be passed on to the office manager but then we heard nothing.' (Interview)

'The GP referred me for rehab to get me more mobile. I was waiting with my hopes up and the Occupational Therapist confirmed that it had been declined after a couple of months. The hopes were for rehab and to be back in the wheelchair. No letters, nothing. It made me feel disappointed and let down. I had my hopes up of being independent and doing things that I love. Why did it take so long? There was also nothing on the NHS app.' (Interview)

'Hearing nothing' was a recurrent theme in patients' journeys through care pathways. To hear nothing after weeks of waiting is worrying and rejection of the referral is disheartening:

Others, however, talked about a seamless service:

'I went to the doctor with a large patch on my ear and he said it needed an urgent look by a dermatologist. He referred me to Peterborough Hospital and I saw a consultant within 2 weeks. A week after that I saw a Plastic Surgeon and 2 weeks after that I had the surgery. It was all very smooth and satisfactory.' (Interview)

These inconsistencies within the referral system, when the communication process is poor, can cause anxiety and disappointment for patients

2.3 Urgent and Emergency Care

East Midlands Ambulance Service operates the emergency ambulance service in Rutland. Derbyshire Health United (DHU) operates the NHS 111 service. Since January 2024,

people with 7 common illnesses and within certain age bands can seek help from a local pharmacist who has signed up to the Pharmacy First scheme. Part of Rutland Memorial Hospital is used by Oakham Medical Practice for their patients who have been triaged as in need of 'same day care'. The same area of the building is also used for a DHU-operated Minor Injuries Clinic (MIU) during week days (for injuries sustained within the previous 72 hours) and an Urgent Care Centre in the evenings and at weekends. When the MIU has not been busy in the recent past, clinicians have seen patients with an urgent illness need. Where to go and when therefore causes a lot of confusion for Rutland residents.

'[The paramedic at the Minor Injuries clinic] said it needs urgent attention but because it was over 72 hours since it started, he could not deal with it. He emailed [the surgery] and said my ankle needed urgent attention. I went straight over to surgery and they still could not give me an appointment.'
(Interview)

One participant spoke of the difficulties in finding family members after they had been taken by emergency ambulance to Peterborough City Hospital and subsequently admitted to a ward. Another spoke of the problems experienced with calling for urgent help when their mobile phone signal failed. There is also an assumption that everyone can drive or be driven to access urgent care:

'The receptionist asked if I could get to the surgery [...] I was in no state to drive [...] All my family that lives local was out at work and my other friend who I called was in Melton. So, I started knocking on my neighbours' doors.'
(Email)

Jane⁶ told her story about her symptoms not being fully recognised by the ambulance service call handler:

Jane's Story: Having a heart attack



Because I was talking calmly, they just didn't believe me, they said it would be 2 hours before an ambulance came [...] I just kept thinking, 'I can't wait 2 hours, I'm not going to last 2 hours' [...] My husband came home and took me to Grantham hospital [...] They could see I was having problems [...] and they prepared me to go to Lincoln hospital. The ambulance drivers were very good. They talked us through everything. They asked do I know what's happening and I said, 'I've had a heart attack'. They said no, you are having a heart attack. They explained we might have to pull over and cannot guarantee I'd get there alive.
(Interview)



⁶ Pseudonym used

Healthwatch Rutland has consistently called for clearer information for the Rutland public about how to access the most appropriate emergency or urgent care service for their needs.

2.4 Hospital care

Hospitals visited by participants included those in Leicester, Kettering, Peterborough, Nottingham, Birmingham and London.

2.4.1 Getting an appointment

53% of survey responses indicated that their most recent communication with the NHS involved communications about a hospital appointment.

23% of survey respondents said they had received communication cancelling their appointment.

Comments highlighted communication problems, the irritation at hospitals cancelling or postponing appointments and the challenges of rearranging inconvenient appointments:

'My only annoyance throughout the process of receiving a letter for the appointment and attending was that the date was changed 3 times. One of the letters providing an alternative date said, 'Due to you being unavailable for the initial date', which was incorrect. I never contacted the hospital to change the date.' (Survey)

'Trying to get through to actually alter the appointment can be very difficult. You ring one place, no answer, another, no answer you ring and ring, chasing around all the time. (Interview)

There were also the difficulties of co-ordinating multiple appointments:

'I had 2 appointments for 2 different hospitals on the same day, one in Leicester and one in Peterborough. I did manage to call through and change the first one but it's not easy to get through to change things.' (Interview)

One participant spoke positively about the app her hospital provides to give patients more control of their appointments:

'With my London appointments at UCHL they have the 'My Care' app. They will send you an email to log into the app for updates. It's pretty cool, it shows you everything. Once you log in, you can cancel, reschedule or send a message to the consultant.' (Interview)

Providing patients with a digital facility, such as an app, would seem a solution for avoiding miscommunications, lengthy waits on the telephone, lack of co-

ordination of appointments, inconvenience or people just not bothering to attend an appointment.

2.4.2 Waiting lists

According to the British Medical Association⁷, in August 2024 there were 7.64 million cases involving 6.33 million individuals waiting for planned treatment in England. Many participants spoke of their time of waiting – often for longer than expected:

‘But, with glaucoma, I’m still 2 years later, on a waiting list for Peterborough City Hospital. I got a letter saying it was a 36 week wait.’ (Interview)

‘He came home with a catheter and they said it would be 12 weeks to an operation. 12 weeks went past and he had to have a new catheter. Another 12 weeks went.’ (Interview)

Waiting is stressful – especially when the symptoms are sufficiently severe to disrupt education, work or domestic responsibilities. One participant spoke gratefully of the option she was given to attend a private hospital with all costs paid by the NHS.

2.4.3 Information before appointments or procedures

Participants’ accounts illustrate inconsistencies in patients’ experiences:

‘I find the leaflets and appointment letters helpful, that you get ahead of your operation. I felt I could prepare myself once I saw the additional information they sent.’ (Interview)

‘I received an appointment within a couple of weeks, not knowing what the MRI scan would be like. The invitation letter said, ‘Read the leaflet enclosed.’ Well there was not one. So I had to turn to Google.’ (Email)

In addition, receiving up-to-date information about their position on the waiting list might provide more reassurance for patients.

2.4.4 Outpatient experiences

This inconsistency between specialities in quality of service and communications continued into participant’s experiences of outpatients’ departments – even within the same hospital trust as shown below:

⁷ British Medical Association (October 2024) *NHS Backlog Data Analysis* Accessed 25/10/2024 at: <https://www.bma.org.uk/advice-and-support/nhs-delivery-and-workforce/pressures/nhs-backlog-data-analysis>

'Urology [Leicester General Hospital] was diabolical. I was put on the fortnight pathway as I had a raised PSA⁸. I had an appointment for 2:30 in the afternoon. We sat there, sat there, [...] sat there. A nurse came out at 5:30pm and asked, "Are you still here?" Obviously, we were still there. We were waiting. There were 2 patients waiting. We finally went in to see the Doctor [...] I got a letter for an [oncology outpatients] appointment [at Leicester General Hospital], went and was seen exactly on time. The consultant came and said, 'You can have as much time as you need and ask as many questions as you like and we can direct you on. We went through that nicely and got a letter a week later' (Interview)

2.4.5 Inpatient experience

Many participants spoke of poor-quality communication in terms of care for the patient and respect for family knowledge:

'Dad had bad pain. His catheter was full and needed emptying. I found a male nurse and asked for his help. But he just said, 'He's not my patient, go to the desk'. But there was nobody at the desk.' (Interview)

'Nobody spoke to me or my brother about what their baseline was - their likes, dislikes, pain etc. Nobody spoke to us specifically. Nobody spoke to us about mum's medication [...] I think some patients and relatives don't know what their patients should be on, but I did. Mum couldn't speak for herself but, yeah, it was a battle, a real battle.' (Interview)

One of the most inconvenient and costly experiences for many patients is when an operation is cancelled. One participant, whose husband's operation was cancelled, talked about the positive difference good communication made at the time:

'He went into the General Hospital for his operation and sat for 10 hours. A consultant came out to say that they hadn't got time for anymore operations that day. They were running late because of other appointments [...] The nurses and other medical staff at the Leicester General [...] were keeping him informed of the situation. They all took the time to chat with him and, as soon as he knew he was coming home without having his operation, the nurses fetched him some food and drink as he had not eaten or drank for over 24 hours.' (Interview)

2.5 Administration processes between hospitals and GP practices

GPs refer patients electronically to other services. After outpatient and inpatient care, a resumé of diagnostics, operations, future care and prescription needs is

⁸ PSA – prostate specific antigen – a test to gauge likelihood of prostate cancer

sent to the GP, with the patient usually receiving a copy of the letter. Many participants spoke about problems with the processes of transferring care:

Experience	Comments
Lack of 'joined up care'	'I think there is a disconnect between primary and secondary care. There must be wasted resources in terms of testing.' (Interview)
Delayed discharge	'Once I finally had my operation at the General, they couldn't discharge me because they couldn't find anyone to sign my hospital letter. So, I was definitely there 24 hours longer than I should have been.' (Interview)
Inaccurate details	'I was copied into the hospital letter to a GP regarding diagnosis but incorrectly addressed to a GP unknown to me'. (Survey)
Language unclear	'They said it was a 'lesion' but is that a cut or is it cancer? It wasn't clear.' (Interview)
Language too complex	'Wording is just not how anyone can understand, there is always too much jargon. It's bad enough getting a letter from your doctor or hospital, never mind when you can't understand it. They need to understand that we are not medically trained.' (Interview)
Communication incomplete	'Mum had a scan and the consultant reported most of the items but not the one condition which caused her death. But we needed to know and the GP surgery should have known so they could have treated her.' (Interview)
Communication problems across Integrated Care System borders	I live in Oakham. If you are a Peterborough Hospital patient and need a blood test, we have to travel all the way to Stamford to do this – I can't go to Oakham Medical Practice. I have to pay for a taxi because I don't drive. The systems don't talk to each other. It's ridiculous.' (Focus Group)

Table 4: Patients' experiences of communications between hospital and GP

2.6 Medicines management

The safe management of medications and their prescribing is crucial to patient safety. Participants spoke of various communication problems with prescriptions which meant their health, wellbeing and safety were put at risk.

One participant alerted to the fact that full details of prescribed medications are not electronically available to hospitals for patients who are admitted by emergency ambulance.

Others told of GP practices being too slow to prescribe different drugs or alter their doses in line with changes made by hospital consultants at discharge or after an outpatient consultation. In other cases, participants said that their GPs had not received instructions from the hospital doctors to change their prescriptions. In such cases, patients were left feeling helpless with nobody prepared to take ownership of the problem for them:

'I asked [at the hospital], "What about a repeat prescription?" and they said there would be a letter [to the GP]. Nothing was done, so I called the surgery. They said they had not had a letter so it wasn't their problem [and told me to ring the consultant [pause]. You can never get through to anyone [for the consultant]. I called the hospital pharmacy and they said it's the consultant's problem.' (Interview)

Another participant spoke of a medication being prescribed, to which she had previously stated she was allergic:

It has given me worry for future. If you've ever had a reaction to taking the wrong drugs you would know. I've had bad reactions. I went to the Rutland Memorial Hospital last year with a urine infection and told the specialist that I was allergic to certain medications and still got prescribed the wrong ones. I ended up in hospital. (Interview)

We also heard a complaint of the vagueness of the instructions for taking the prescribed medication:

'The consultant was vague, talked about a prescription saying I would need 1 or 2 sachets - didn't tell me which - and that the written prescription would say. But it didn't. It seemed you had to find the right dosage for yourself.' (Interview)

Delays in prescribing repeat medications were explained away as 'a glitch in the system' and there was a complaint that repeat medication is prescribed for too short a time, necessitating more repeat prescriptions requests and trips to the pharmacy.

Collection of the medications from pharmacy can also be problematic when patients are not informed of their prescriptions being ready:

'There is never any acknowledgement that they have your [prescription] request or verification that it's gone through. So you don't know when it's ready. If you turn up too soon, they are annoyed and you have to wait half an hour. But how do you know? It's not my fault. This happens 6 times a year and we never know.' (Interview)

Others were more positive:

'I think the GP practice has improved in that you will get a text message to say the prescription has been sent to the pharmacy.' (Interview)

2.7 Getting results

The journey from the initial consultation to receiving a diagnosis is often a time of anxiety and participants spoke of the distress of not knowing what is happening and what would happen as they waited for information – often, they felt, for too long.

The survey asked : *To what extent do you agree with the following statement?*

	Strongly or somewhat disagree	Neither agree nor disagree	Somewhat or strongly agree	Don't know, not sure
I had to intervene to get results of tests taken in one location made available to professionals in another other location	41%	21%	24%	14%

Table 5: Survey result: numbers of who did or did not have to intervene to get their results

Nearly a quarter (24%) of respondents had to intervene to ensure that test results taken in one location were available to professionals in another location. 41% had no problems getting the results in the right location.

The theme of delay in receiving results was highlighted:

'Nobody contacted me with the results and the consultant on the letter had left the hospital. The echocardiogram happened in October. I rang to push for the results and they came between Christmas and New Year. It showed that an artery was damaged from the heart attack.' (Interview)

Others felt that bad news was delivered in an inappropriate manner and, in one case, potentially, to a family member rather than themselves, thus breaching patient confidentiality:

'We then had a phone call from the surgery. My wife answered the phone, "We have the results, do you want me to give them to you?" My wife obviously said, "No, I will go and get him". The person on the phone said, "Mr X, hello, you've got cancer." [...] It was like somebody came and thumped you on the nose. I was prepared, but not to be spoken to like that. You don't know what circumstances that patient has at home. It was really bad.' (Interview)

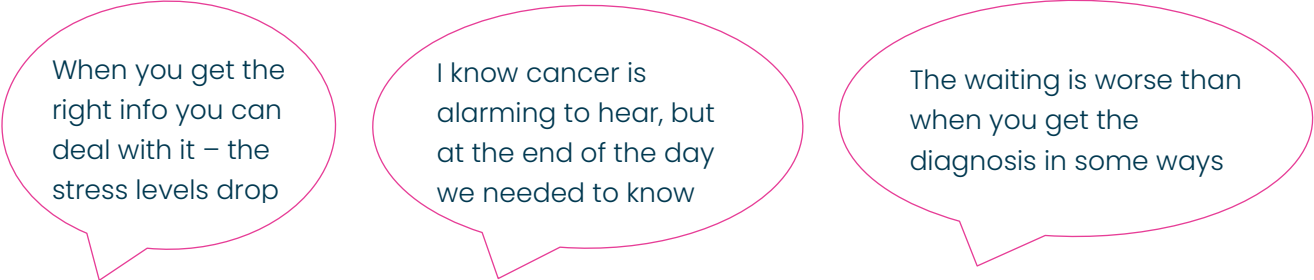
Another participant related their experience of a hospital admission having been given no diagnosis for the condition being treated:

'No results were given, I had no idea, only that I had to go back again for another appointment. It's only when I asked, 'why?' that they said, 'You still have a small shadow.' After my last scan I heard nothing. I didn't even know I'd had pneumonia until I received the discharge letter from the hospital! [...] They kept sending me for scans and thought it was linked to a kidney infection.' (Interview)

Several participants spoke of results being withheld until they had been reviewed, not as quickly as they would wish, by a senior clinician:

'There was one instance when Mum had a fall in hospital. We were told she had an Xray. But nobody gave us the result. We did ask the staff nurse but she said it had gone off to the consultant. I thought that was pretty poor.'
(Interview)

Delays in communicating results and diagnoses can have a profound result on patients and families who are feeling at their most vulnerable. Several spoke about the anxiety:



When you get the right info you can deal with it – the stress levels drop

I know cancer is alarming to hear, but at the end of the day we needed to know

The waiting is worse than when you get the diagnosis in some ways

2.8 Dealing with communication problems

Participants talked about how they and others supporting them tried to resolve the communication and administration problems they had encountered:

'My daughter has built up a good rapport with the consultant's secretary and she does all the co-ordination.' (Interview)

'When Mum comes [to hospital]. She understands me.' (Easy read survey)

Comments featured phrases such as 'begging', 'chasing up', 'being assertive' and 'complaining'.

'The General Hospital have said that they have no appointments which is why we are going to the Rutland Memorial Hospital. He has had to chase that quite a few times.' (Interview)

Two participants informed that they had changed GP practice, one spoke about their decision to change pharmacist from a local company to a national online service and two described how they had ‘gone privately’ in order to circumvent the problems they were encountering.

One participant even talked of giving up:

‘Several times, I’ve thrown the towel, oh, you can’t take it anymore. You’ve got your problems, and you can’t get help (pause) It wears you down.’ (Interview)

No participants mentioned the Patient Information (sometimes called ‘Advice’) and Liaison Service (PILS or PALS) which is available in all acute hospitals. Just one participant talked about going through a formal complaint process. Further research would be needed to determine reasons for not accessing more formal routes when things are going wrong. However, one participant described a consequent discomfort and provides some insight into feeling marked as ‘difficult’ because of their actions:

‘I think I have a little tick or flag against my name. I’m marked as difficult. It makes me feel rotten. I’m not prepared to sit back. By asking questions it limits the number of times we have to go. Some people don’t like to be asked, they don’t like having questions asked.’ (Interview)

This suggests that some people might feel too intimidated to use a formal complaint route because this will ‘mark them’ to the extent that their future care might be compromised.

2.9 Children and Young People

Although a small number of participants, parents of children with health problems provided a rich insight into their experiences of NHS communication and administration processes. Respondents on behalf of young people included:

3 survey respondents, 2 interview participants, 1 email account and several points arising from a leader-led young people’s focus group.

2.9.1 Forms of communication used by parents

Parents use all means of communication, highlighting advantages and disadvantages with all:

Form	Comments
Letters	‘Communication is by letters but it’s easy to lose them [...] Letters seem archaic, I’ve had to develop a special filing system for just NHS letters.’ (Interview)
Telephone	‘I also rang up the department and asked what was going on. It took me forever to get the right department.’ (Interview) ‘Just getting a phone call gives you no trail.’
App	‘I do have the NHS app but I find it quite confusing.’ (Interview)
Email	‘It would be much better if everything was emailed so we had it all there online.’ (Interview)

Text	'I'm happy with having a mix of texts and letters, especially because the text system is instant whereas letters obviously take a lot longer to arrive.' (Interview)
NHS Website	'I think very positively about the NHS website. The information is very sensible and useful when you look things up. It's good to have authoritative information to trust that's all really useful.' (Interview)

Table 6: Parents' opinions about means of communication

2.9.2 Appointments and waiting

One participant summed up themes from parents' experiences of appointments:

'For clinic appointments we have to see 2 separate specialists and they are not on the same day. Only the consultant can make decisions but he's only there [Melton Community Hospital] infrequently. Appointments can get changed. When one is changed it has a big impact and can cause a 2-month delay. On top of that we now have a new consultant who is reviewing the cases and making different recommendations.' (Interview)

However, there are physical, emotional and developmental impacts of lengthy delays in receiving care:

'[My child is] anxious and worries quite a lot. Wearing glasses has had quite an impact and made [them] very self-conscious. [They] used to be really, you know, rough and tumble, but now [they're] not. Having some sort of timeline setting out our options would have a positive impact on [the child]. [They] had bifocals and people made comments saying "four eyes" and things.' (Interview)

We are currently awaiting a referral for physical therapy to see if that helps, organised by the consultant, yet my son is currently off sick from school because of the pain.' (Email)

Participants in the young people's focus group drew attention to: the lack of co-ordination of appointments; no continuity of care; lengthy waiting times for appointments; and long waits in the outpatient departments.

2.9.3 The medical encounter

General practice was criticised by the young people's focus group members for unsuitable opening hours and the restriction of discussing '**only one thing**' and treating '**the symptom not the cause**' during a consultation, rather than providing a more holistic approach. There was a preference for face-to-face appointments but Zoom was not discounted. Telephone is the least preferred option. In addition, they felt they were told what medications they should take without discussions or explanations for their need or of side effects.

One interview participant described receiving support from the Health Visitor but a feeling of communication failure with the GP practice:

'I feel like the doctors don't communicate, when you try and get appointments. They have a short chat with you, they don't understand. They're a bit of a sticking point at the moment, especially because the health visitor has been so good. They don't seem to understand.' (Interview)

The young people's focus group particularly disliked the lack of information prior to hospital appointments and lengthy waits. This dislike spilled over into stress if they needed to attend an Emergency Department. Giving blood samples, especially without numbing cream or freeze spray, is stressful. They felt that information provided was often inaccessible, that they were not involved in discussions and there was a lack of information sharing between different providers of care. They also mentioned poor signage in hospitals causing problems navigating around the sites.

This issue of poor signage and problems navigating to and around hospitals was also detailed by one parent:

'On arrival at the [Leicester Royal Infirmary] hospital, the parking was a nightmare, and following this, myself and my son found the operation of the lifts ridiculous. When I finally asked a member of the physio team, who happened to need the same lift as we did, she mentioned that confusion was high and many people find it difficult to 'work them out'. (Email)

Communication failures during a hospital consultation were also described:

I felt as though the consultant was talking to me rather than discussing information with me. I was initially asked to verbalise what my son's condition is and why it happens, which I did correctly. When I requested an X-ray the consultant flat out refused [...] When I explained that he suffers a lot with his knees and so I would like to see if any bone had broken off in his knee (advice by 2-3 different physios) due to the tension on his tendons and the swelling, I was told that doesn't happen and I shouldn't be worried about it.' (email)

The consultant appears to have created a sense of an unequal partnership, with a suggestion that the parent's and physiotherapist's knowledge held no weight in the discussion.

One parent shared a positive experience of a child's overnight stay in Kettering hospital:

'We stayed overnight and afterwards they sent a letter to us at home and to the doctor at Empingham. I thought that was really good. You don't get that at Peterborough. It made me feel like I did the right thing going to hospital and I had peace of mind that the doctor was updated.' (Interview)

Natural parental anxiety and sensitivities are not being adequately recognised and addressed.

2.9.4 Community and family support

Parents talked about their need for support in dealing with their children's health problems, either formally through community services or informally from family members. Support and communication from the Rutland Family Hub was praised:

'We've also been put in touch with [the lady] through the Family Hub [...] She has been fantastic with my child. She has contacted the GP on our behalf. I was upset because they gave a repeat prescription of the same Movicol sachets and didn't even see my child. I called [the lady] and she followed it up. I've still not seen anyone but [the lady] chased them. She also spoke to the school to get a plan in place. She calls me, asks how we are getting on. She calls every couple of weeks.' (Interview)

The need for help from wider family members can also cause its own communication problems:

'We both work and if neither of us can do the appointment then the grandparents help. But messages can get lost between us – what was said to who at what appointment.' (Interview)

The experiences in this section show that parents are naturally anxious for their children's wellbeing. When children need any care, their holistic needs must be met. Furthermore, the sensitivities and wellbeing of the whole family unit should be considered by all professionals.

2.10 People with disabilities

The survey asked respondents to indicate their health status and whether or not they were carers. Some of the 30 respondents were in more than one category, as the following table demonstrates:

Answer Choices			Response Percent	Response Total
1	I am a carer		20.00%	6
2	I have a disability		30.00%	9
3	I have a long-term condition		53.33%	16
4	I am neurodivergent (Autistic, ADHD/ADD, Dyslexic, Tourette's etc.)		13.33%	4
5	None of the above		30.00%	9

Table 7: Survey respondents who are carers or have disabilities and/or longterm conditions

Free text survey comments and qualitative data were collected from people with: long term conditions; dyslexia; deafness; sight impairment; wheelchair users; and people with learning disabilities. Their comments provide an insight into how NHS communications might or might not cater for their needs:

Condition	Comments
Dyslexia	'Stop assuming that everyone is the same – they don't know what each person's experiences are – I'm dyslexic so I couldn't use the text messaging link so I was discharged. Just because you've got a mobile doesn't mean you can access information best that way. I have dyslexia & voice messages via WhatsApp are great.' (Interview)
Deafness	'Telephone calls are ok, fine. But if you are hard of hearing and it's a doctor with a foreign accent, then you can't always hear properly over the phone, especially with hearing aids. So I ask my wife to be present to interpret. I don't mind but it is a drawback personally.' (Interview)
Sight impaired	'They already know I have macular at Leicester and I said I needed telephone calls and they do that, they're good. I then get a letter afterwards.' (Focus Group) 'I prefer online letters and texts – it's very useful so that I can use text-to-speech on my phone and it does work for me.' (Focus Group) 'I prefer a telephone call every time.' (Focus Group) 'I prefer written paper but I don't always get it, then I have it for reference and don't forget.' (Focus Group)
Dependent on a wheelchair	'Last week I told the hospital that I was coming on a stretcher and they said, "Oh yeah that's fine". We got there and they said, "Nope, that can't come in here". One of the team said, "She's come from Oakham, you can't send her back". I did get seen to in the end.' (Interview)

Learning disabilities	<p><u>Primary care</u> 'Market Overton GP surgery is great in supporting our people with learning disabilities. We never have any problem in making contact and have a designated GP who we speak to when needed.' (Focus Group)</p> <p><u>Hospital care</u> 'Leicestershire hospital staff seem to have completed the Oliver McGowan training which should be given to professionals however this isn't the case everywhere. When we were admitted to a Birmingham Hospital, the staff there had not received any learning disability training and said that they couldn't cope with my son.' (Parent) (Focus Group)</p> <p>'One of our residents was admitted and when one of the carers went to visit them, their notes said that they were bed bound when actually they are one of the most physically active residents. We usually can't stop them!' (Carer) (Focus Group)</p>
Long term condition	<p>'I had an anti-epilepsy medication which was delayed. Living alone, it was so worrying. You have the lifeline but that's not there if you have a seizure. It's scary.' (Interview)</p>

Table 8: People with disabilities tell of their experiences of communications

It is clear from the variety of comments that people with disabilities only sometimes have their communication needs respected.

2.11 Impact of poor communications

Many of the experiences shared through the research illustrate the impact of poor communications and administration on participants and others around them.

Of significant impact for one participant were the problems of communication and administration involving non-emergency patient transport:

Sally's⁹ story: using non-emergency patient transport services



[Patient transport services] have a habit of not turning up. I was under pain management at Stamford last year. I'd call them and ask, "Where's the transport?" and they would say, "We have no vehicles" or they would call the day before an appointment or usually the morning of the appointment to say they have no vehicles. This resulted in me being discharged from pain management due to the amount of missed appointments because of the transport company. I have been let down over 20 times. The hospital told me I need to make more of an effort to get to appointments. I told them that I need the transport. Sometimes I give them an earlier time so that I have more chance of getting there. At times they have questioned why I call them as I am on the PIP benefit [Personal Independence Payment], they said "that (benefit) should be used for your transport". I then tell them that I need a stretcher and they book the appointment.

⁹ Pseudonym

If my pain is not managed, I miss out on things. It's a knock-on effect. I have to give the carers notice to replan their visits around transport. If the transport doesn't show then I have to let them know. It has an impact on everything.

2 years ago I was under the Glenfield Hospital due to allergies. I got to the hospital and waited 6 hours for transport back. Staff kept ringing them to say "this patient cannot wait any longer". In the end they sent me to the discharge lounge as the clinic had finished and closed. (Interview)



A participant highlighted how essential equipment failure at a weekend, with no helpline service, resulted in unnecessary stress:

'I rang and rang and heard nothing back. It took a lot to get a new machine. The impact over that weekend was awful. I was tired, had headaches, it's a different tiredness, I didn't feel well at all.' (Interview)

Other lapses in communication had a severe impact on participants' mental health; especially when receiving bad or unexpected news:

'Out of the blue, early March 2024, I received a letter from NHS Waterloo Road London telling me that I have a high risk of developing breast cancer because of radiotherapy given to me in 1983 at age 31. Apparently, I should have been receiving yearly mammograms as the radiotherapy in 1983 was different from today. The letter was full of apologies but the shock on receiving this letter was upsetting. It would have been lovely to talk to someone about my feelings but I have a great circle of friends, thank goodness, and my husband to talk to.' (Email)

Issues relating to the administration of prescriptions were also highlighted in terms of the impact on patients when things go wrong:

'It's the same with prescription change, it's such a headache. When you're not feeling well it adds to the anxiety of it all. These things should be straight forward.' (Interview)

Delays in receiving blood test results in stress and patients feeling disempowered:

'When I have a PSA¹⁰ test I have to organise through the surgery but it's usually a fortnight or 3 weeks between blood tests to getting results which I can't seem to get on the NHS app or records at the surgery, it doesn't go through. You don't get them until you see a consultant. If it's bad news you don't get

¹⁰ PSA – Prostate specific antigen – to detect prostate cancer cells.

time to be prepared before the appointment. It's a big problem that it doesn't get shared.' (Interview)

Complex medical terminology in patients' letters is difficult for people to interpret:

'I must say everything to do with eyes - the language of the letters - is not clear to us. The words are long, impenetrable and we have to look up every term.' (Interview)

There is a wish for continuity of care:

'There is no selected GP. It's like they don't care [pause] it makes you feel let down.' (Focus Group)

Stress and anxiety are the main impacts of poor communication and administration when moving between NHS services. This applies to families and carers as well as to the patients themselves. At a time when people feel most vulnerable this can exacerbate the physical impacts of illness and could involve extra costs for the NHS and other services.

2.12 Participant's suggestions for improving communications

The survey asked participants whether they had suggestions for improvement. This question was also posed during interviews.

Care navigators and call handlers One survey respondent highlighted the need for more personalised care:

'They need to be able to appreciate that not everyone fits into the algorithm box. They need to be more flexible when dealing with patients who obviously in different circumstances and have different needs. The lack of flexibility is frustrating for people who are feeling poorly and are at a low ebb. They experience this as lack of care.' (Survey)

Appointments

Participants suggest patients should have: more information about what will happen at their appointment; fewer delays in getting an appointment; sufficient notice of an appointment in order to make work, domestic and travel arrangements; an easier way to change appointment dates and times than the existing telephone system; and fewer text reminders of their appointment.

'If we had to rearrange appointments - although that was very rare as we tried to take what they offered - we had to leave a message. But then you didn't know whether they would call back.' (Interview)

Addressing errors

There was a suggestion there should be an improvement in the accuracy of the content in written communications: 'attention to detail is paramount', 'read what they send before they send it'

Cross-service communications

Participants said they wanted more transparency and better communications between different specialities and professionals within an organisation and between different service providers.

Hospitals

Hospital bureaucracy was criticised:

'It's all so departmentalised. The specialist say you need an operation but can't give you a date. Then you have to go for an Xray. Every department works separately from the others.' (Interview)

Participants also suggested: there should be better communication with relatives; a list of medications should be available in hospitals for patients admitted as an emergency; there should be a check made on patients' wellbeing some months after discharge; and better signage in hospitals.

General Practice

The results of blood tests requested by hospital consultants should be made available to GP surgeries and to patients.

There should be greater monitoring of health checks for people with long term conditions to ensure patients are not overlooked. 'I think that if the GPs could have that ability to refer people directly or have more say.' (Interview)

Accessibility

'Ask people if they need any extra support during initial contact' (Survey)

'Audio versions for people who are blind or partially sighted' (Survey)

Other

All services should seek patient and family feedback more frequently and more personalised care should be provided: 'Stop assuming that everyone is the same.'

Pharmacists should let patients know when their electronically-requested prescription is ready for collection.

3. Conclusion

Of the 130 participants in this project, many were unhappy with their experiences of NHS communication and administration processes – particularly when moving between services along care pathways. Close attention was given to the construction of questions and promotion of the research to eliminate any language biased towards receiving negative, rather than positive, replies. Despite these measures, the many responses from people who had poor experiences suggests that, generally, the Rutland population are experiencing a lot of communication difficulties within health services. Examples of the fewer positive comments have been included in order to highlight what patients do value in their encounters with NHS administration processes.

Responses across the survey, interviews, emails and focus groups show high levels of stress when people have to chase up appointments, medications, care provision, non-emergency patient transport and emergency care. In a time of almost instant global communications, people want to see better communication processes operating within the NHS. Many people felt that letters are too slow and wanted the immediacy of email. The electronic management of appointments for patients is restricted. Errors are made. All of this takes time and energy to sort when people are already experiencing the stressful impacts of illness.

Healthwatch Rutland hopes that this report, using many patients' own words, will demonstrate the difficulties being experienced – some of them with potential impacts on patient safety.

Our sincere thanks go to everyone who gave up time to talk about their experience or fill in a survey.

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Appendix 1 Acronyms and abbreviations used

Acronym/abbreviation	
BSA	British Sociological Association
DHU	Derbyshire Health United Healthcare
FG	Focus Group
GP	General Practitioner
HWR	Healthwatch Rutland
Int	Interview
MIU	Minor Injuries Unit
PALS	Patient Advice and Liaison Service
PILS	Patient Information and Liaison Service
PSA	Prostate Specific Antigen
RMH	Rutland Memorial Hospital
UEC	Urgent and Emergency Care

Appendix 2

Survey Demographics

Age category

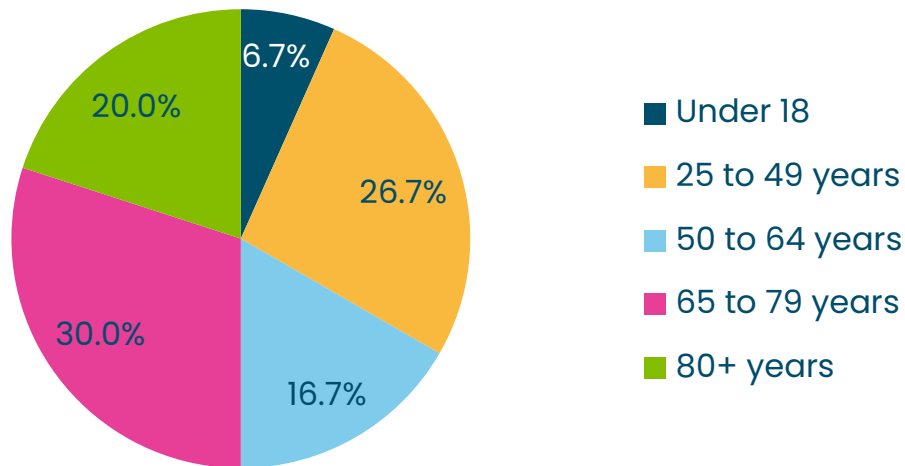


Figure 3: Ages of survey respondents

Which gender you identify with

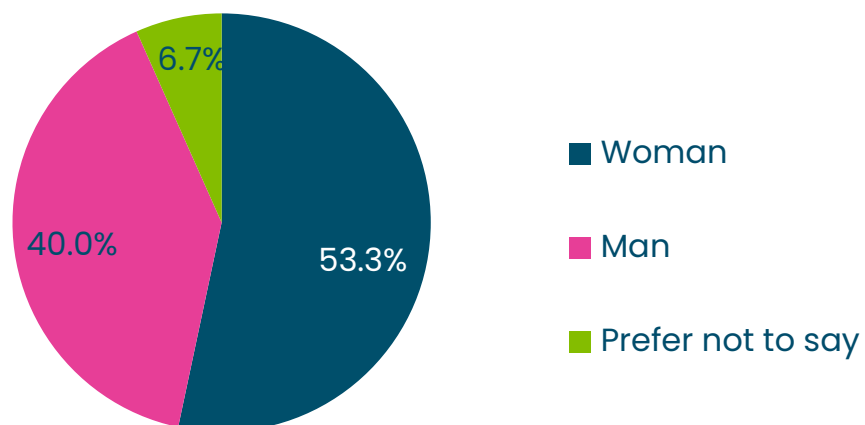


Figure 4: Gender of survey respondents

Ethnic background

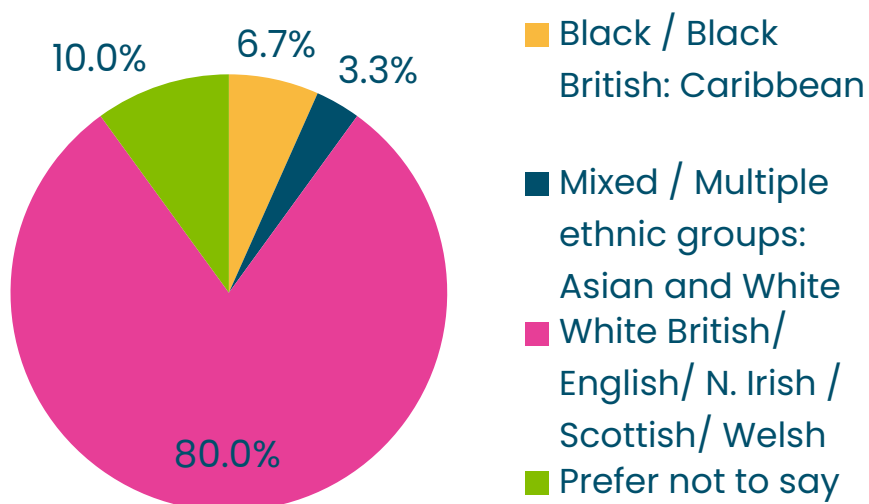


Figure 5: Ethnicity of survey respondents

Appendix 3

Question prompts for semi-structured interviews and focus groups

1. Have you had experiences of NHS administration processes or communications that have worked well?
Prompts: What was it about those experiences that you valued? How did it make you feel?
2. Could you offer examples from your own experience of NHS communication or admin processes within the last year that haven't worked as you hoped?
Prompts: Appointments, getting through on the phone/ letters, prescriptions, referrals
3. When communication or admin processes haven't worked as you expected, what has been the impact on you?
Prompts:
 - How did it make you feel?
 - What were the practical effects e.g. on your costs? or time? Your family members?
 - What are the knock-on/long term consequences for your life outside of health care eg work and family life?
4. Thinking about your experiences of NHS administration, what would you like to see change in how the NHS communicates with you?

Prompts:

- How do you feel about using computers, phones etc (why do you think we are using too much / not enough technology?)
- How would you describe the experience of being given information and what do you think could have been done better?



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