May 2026

NHS England messaging user engagement

Findings from group interviews with VCSE practitioners and lived experience partners

NHS England

National Voices

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1. Introduction

NHS England increasingly relies on digital channels to communicate with people about appointments, tests, and next steps in care. These messages can support timely action and reduce avoidable delays, but they can also widen inequalities where systems assume stable access to devices, consistent connectivity, and confidence navigating multi-step digital journeys. This project was commissioned to strengthen the evidence base on how NHS messages can be designed and delivered in ways that prompt action while remaining inclusive for groups most at risk of exclusion.

The work focused on four target groups: older people, parents and carers, digitally excluded people, and people facing language barriers. It aimed to identify the barriers that prevent people from receiving, understanding, trusting, and acting on messages, alongside the conditions and practices that enable messaging to work well in real-world circumstances. The findings are intended to inform NHS England's digital communications strategy, with a particular emphasis on designing "digital-by-default" approaches that do not become "digital-only".

The project combined a light-touch, purposive scoping review of relevant policy, research, and practice evidence with four facilitated online group interviews involving National Voices member organisations and Lived Experience Partners. Evidence and insights were synthesised using five cross-cutting themes adapted from NHS England's Inclusive Digital Healthcare framework: Access, Accessibility, Skills and capability, Beliefs and trust, and Patient-centredness.

This report presents key findings by theme, detailed findings by target group, and practical implications for inclusive messaging design and delivery.

2. Methodology

This project examined how to design and deliver NHS messages that prompt timely action among four target groups: older people, parents and carers, digitally excluded people, and people facing language barriers. The approach combined a light-touch scoping review with targeted qualitative engagement, so that findings were grounded in lived experience as well as existing evidence and were relevant to NHS England's digital communications strategy.

The work was delivered in three phases: (1) scoping and project set-up, (2) group interviews, and (3) framework-led analysis and reporting.

Phase 1: Scoping and project management

A light-touch, purposive scoping review was undertaken to map what is already known about digital messaging, inclusion, and "what works", and to identify gaps relevant to the four target groups. Searches were conducted using Google Scholar and general search engines, supplemented by targeted review of relevant NHS England guidance and National Voices resources, alongside materials supplied by NHS England.

The scoping review was designed to be practical and decision-focused rather than exhaustive. Sources were selected purposively to capture high-relevance policy, research, evaluations, and credible grey literature. Findings were extracted into an evidence log and used to inform both the interview topic guide and a short briefing pack for participants.

Development of the five themes

The scoping review used NHS England's Inclusive Digital Healthcare framework as an organising lens and adapted it for messaging. This produced five cross-cutting domains that structured both evidence extraction and interview analysis: Access, Accessibility, Skills and capability, Beliefs and trust, and Patient-centredness. These domains were treated as an analytic framework rather than a fixed theory of change, and were refined iteratively as the scoping review progressed and as interview insights were integrated.

Phase 2: Group interviews and engagement

Qualitative engagement was designed to complement the desk-based review by testing and deepening understanding of barriers, enablers, and practical implications for messaging. Eight National Voices member organisations with relevant expertise were invited to participate. Selection focused on organisations with direct experience working with one of the four target groups and insight into how digital messaging affects access, inclusion, and action.

Four online group interviews were conducted, each lasting approximately 90 minutes, with one interview per target group. For each group, two organisations took part in a facilitated discussion alongside up to two Lived Experience Partners, ensuring that professional and lived perspectives informed the findings. Discussions followed a semi-structured topic guide to support comparability across groups while allowing participants to surface group-specific issues, examples of good practice, and suggestions for improvement.

Participation payments were offered in line with National Voices' remuneration policy to support inclusive engagement. With informed consent, sessions were recorded and anonymised transcripts produced. Data were stored securely and handled in accordance with GDPR requirements and National Voices' data protection policy.

Phase 3: Framework-led synthesis, analysis, and reporting

Analysis combined scoping review findings with interview data using a framework-led synthesis approach. Interview transcripts and notes were reviewed and coded within the five theme domains developed through the scoping review (Access, Accessibility, Skills and capability, Beliefs and trust, and Patient-centredness). Within each domain, the analysis identified: (1) group-specific experiences and mechanisms, (2) cross-cutting patterns across the four groups, and (3) practical implications for messaging design and delivery.

Findings were triangulated between the scoping review and engagement insights, with explicit attention to distinguishing between (a) direct participant testimony and (b) design implications derived through synthesis. The reporting therefore separates evidence by target group, cross-cutting findings, and implications for practice.

3. Key findings by theme

3.1 Access

Across all four groups, access to NHS messages is shaped less by whether messages are technically sent, and more by whether they are received in time, noticed, and acted upon. Participants consistently described access failures where messages arrived too late, were missed entirely, or were routed through channels that people could not reliably use, leading directly to missed or delayed care.

For people who are digitally excluded, access is fundamentally unstable. Phones may be unavailable or unreliable due to loss, damage, or theft, meaning that digital contact cannot be assumed as a baseline. This instability was repeatedly highlighted in the evidence, including references to phones being "broken, stolen or lost", which interrupts receipt of time-critical messages and undermines continuity of care.

Older people similarly experience access barriers, though through a different mechanism. Many lack smartphones altogether, while others struggle to navigate multiple, fragmented systems. Participants described confusion between the NHS App and separate hospital portals, resulting in uncertainty about where information would appear and whether anything had been received at all. This reinforces the risk that messages are effectively inaccessible even when technically delivered.

People facing language barriers reported access problems that are tightly coupled with comprehension. Messages delivered only in English were often misinterpreted and/or deprioritised because recipients could not immediately understand their purpose or urgency. In these cases, access failure is not simply about delivery, but about whether a message can be engaged with at all.

Parents and carers face distinctive access challenges linked to their role as proxies. Messages are often sent to the "wrong" person (for example, the patient rather than the carer who manages appointments), requiring carers to monitor multiple inboxes and systems. A recurring concern was the absence of a consistent approach to recognising proxy responsibility, with carers describing fragmented and unreliable access to information they need in order to coordinate care.

3.2 Accessibility

Accessibility barriers arise when messages cannot be understood, interpreted, or acted upon, even when they are successfully delivered. Across groups, participants described messages that lacked sufficient context – such as the reason for an appointment, preparation instructions, or next steps – making them difficult to use in practice.

For people facing language barriers, accessibility challenges were both immediate and severe. English-only written messages can create immediate barriers to understanding and acting, particularly for high-stakes communications such as procedures or test results.

Participants also highlighted that machine or AI translation can be unreliable for medical language, leading to confusion, anxiety, and failed preparation.

Older people reported accessibility issues linked to format and presentation. App-based ecosystems were described as confusing and poorly integrated, with information spread across multiple platforms. This made it harder to locate, interpret, and trust messages, even when they were technically accessible.

Digitally excluded participants similarly described difficulty interpreting messages that assumed a level of digital confidence or familiarity they did not have. Complex layouts, dense text, and unclear instructions compounded existing access issues and discouraged engagement.

Parents and carers emphasised accessibility problems linked to role complexity. Messages often failed to reflect caring responsibilities or provide sufficient information to plan around appointments, increasing cognitive load and stress.

3.3 Skills and capability

Across all groups, participants described digital messaging systems that assume a level of confidence, memory, and procedural skill that cannot be taken for granted. Even relatively small points of friction – such as log-ins, passwords, or multi-step processes – were enough to prevent people from completing tasks.

For digitally excluded people, limited digital skills interact with unstable access, making it difficult to recover from errors or interruptions. Older people similarly

described dropping out when processes became complicated or unfamiliar, particularly where help was not immediately available.

Parents and carers face a distinct capability challenge driven by real-world caring load. Managing appointments, medications, and logistics for others leaves little capacity to navigate complex digital processes, even where carers themselves are digitally confident.

3.4 Beliefs and trust

Trust emerged as a foundational issue across all four groups. Participants consistently expressed concern about scams and fraud, particularly when messages arrived unexpectedly or included links. Older people, in particular, described strong caution, with participants noting widespread fear of being misled or exploited.

These concerns were not limited to older people. Across groups, uncertainty about message legitimacy reduced engagement, delayed action, or led people to ignore messages entirely. Trust issues are consistent across all four groups, rather than isolated to one population.

For parents and carers, trust was also affected by repeated failures to recognise recorded authority (such as power of attorney), undermining confidence in systems and increasing frustration.

3.5 Patient-centredness

Participants across all groups emphasised the importance of messaging systems that feel reassuring, flexible, and responsive to individual circumstances. Hybrid pathways – such as combining letters, SMS, and digital messages – were widely valued, with letters often seen as "official" and SMS valued for speed.

For older people, patient-centredness was closely tied to reassurance, continuity, and anxiety reduction. Clear communication, predictable reminders, and the ability to speak to someone when needed were all described as central to feeling supported.

Parents and carers similarly emphasised the need for systems that recognise caring roles and reduce administrative burden, rather than adding to it.

4. Findings by target group

4.1 Older people

Older people's experiences are shaped by structural access barriers, fragmented systems, procedural thresholds at the point of entry, heightened sensitivity to legitimacy and scams, and a strong preference for communication that is flexible, sequenced, and responsive to individual needs. Exclusion is not framed primarily as a matter of "digital skills", but as the interaction between device availability, connectivity, message reliability, and the emotional impact of unclear or inaccurate information.

4.1.1 Access

A central access issue is the over-assumption of smartphone ownership. Some older people do not have smartphones at all, while others rely on limited devices that do not support app-based communication. Access can also be uneven within households, where one partner manages digital communication and the other cannot, meaning digitisation can exclude individuals who previously relied on shared arrangements.

"I think we probably overestimate the number of older people who have smartphones … I can tell you that 4.3 million older people [in the UK] don't have a smartphone."

Connectivity further undermines reliable access. Poor mobile reception – particularly in rural or coastal areas – and delayed or unreliable post reduce the likelihood that time-sensitive messages are noticed or acted upon. Even where messages arrive, older people may struggle to identify which messages matter and where to find them, particularly across non-integrated app and portal ecosystems.

"Phones are often the thing that [older] people prefer to use. But … where we work, there's lots of issues with digital signals and stuff, so you try and phone somebody who goes straight to answerphone because there's no reception or phone signal."

4.1.2 Accessibility

Accessibility issues for older people arise less from literacy and more from format, fragmentation, and information quality. Participants describe confusion and anxiety caused by incomplete or out-of-date records, with emotional distress linked directly to uncertainty about whether information is accurate.

> *"Health records are more often than not out of date. I mean, my health record shows absolutely no mention that I have Crohn's disease. […] It doesn't bother me because I know what I'm doing, but for a lot of people much older than me it's unfair, it's cruel, because they worry all the time."*

Sensory and format constraints also shape usability. Phone-based communication can be inaccessible where audio clarity or accents impede comprehension, highlighting that accessibility barriers relate to delivery and channel design as much as content.

> *"Foreign accents are killers for me because quite often they speak too quickly. […] I can hear the volume, but I can't decipher different syllables."*

4.1.3 Skills and capability

Challenges are concentrated at procedural thresholds, particularly log-in and verification. These entry-point barriers deter engagement even among otherwise confident users and can lead people to abandon digital routes entirely.

> *"I hadn't logged into my NHS app for quite some time and then tried to log back in and it was suspicious that I was a hacker, so I had to go through loads of new checks just to prove that I was the same person. […] I can't imagine what it's like for older people being in that situation. I think many of them would just quit or not bother."*

Supported onboarding is a critical enabler. Hands-on assistance – such as Digital Champion support or Age UK sessions – can transform first use from a source of stress into a point of relief, enabling access that would not otherwise occur.

4.1.4 Beliefs and trust

Trust is highly sensitive to expectation and familiarity. Unexpected messages are often interpreted as potential scams, leading to non-engagement as a protective behaviour. Fear and worry may outweigh direct experience of harm, with perceived risk driving disengagement even in the absence of personal fraud incidents.

"If they're not expecting that information, they can be suspicious of whether they should be responding to it or not, because it's really easy for something like that to look like a scam."

4.1.5 Patient-centredness

Older people strongly prefer hybrid, sequenced communication that offers choice, redundancy, and opt-out. Simple, timely reminders – particularly SMS reminders – are described as effective in supporting follow-through. Patient-centred messaging is experienced where services respect recorded needs and preferences and where communications reduce, rather than amplify, anxiety.

"I think you can't really answer that question [of which channel should be used as first choice] for everybody … different people with different needs will give you a different answer. […] Why does it have to be either/or? Why can't it be both?"

4.2 People facing language barriers

People facing language barriers experience NHS messaging as a high-stakes, time-sensitive process that often fails where English-only systems intersect with complex digital journeys and clinical content. Language needs shape whether messages can be found, understood, trusted, and acted upon, particularly where misunderstanding has immediate consequences.

4.2.1 Access

Access is multi-channel, with appointment information arriving through letters, texts, emails, and app messages, but the NHS App is frequently difficult to use

in practice. Messages can be hard to locate and are easily lost among other content, increasing the risk of missed or forgotten appointments when details cannot be found in time. This leads some people to seek alternative channels, not out of preference for "offline" routes, but because app-based messaging is not usable given language and navigation constraints.

"For me, the NHS App is very hard and confusing, with lots of other messages. It's very confusing. I honestly forget about my appointment."

Access risks become acute where messages contain high-stakes instructions that must be followed precisely and within a short timeframe. Failure to understand preparation instructions for procedures such as colonoscopy or endoscopy can result in wasted appointments and delayed care, even where messages technically arrive.

"About three months ago I was going for a diagnostic test, colonoscopy and endoscopy. It's very important that you don't eat for six hours before you go, but I didn't know about that. When I got there, I had eaten food – they said, 'the doctor can't see you, you need to go home again and make another appointment."

4.2.2 Accessibility

Accessibility barriers are primarily linguistic but extend beyond translation alone. English-only messages and processes often require people to rely on ad hoc translation tools or family members to interpret content, which can delay action and reduce independence. Machine translation is not consistently reliable for medical language, creating fear of error and reinforcing reliance on others.

"My children download translation apps in my phone. Now they've downloaded ChatGPT – when I get message from the NHS, I just copy and paste. But sometimes the medical word translation is very wrong – it makes me scared, so often I wait for my children to read it and explain it to me."

Design and navigation problems compound these barriers. Dense layouts, large volumes of information, and weak signposting make it harder to identify what matters, such as appointment time and location, even when translation support is available.

"I don't think [the NHS app] is very well designed. […] There are some issues in relation to the user interface … I find it a little bit more difficult to navigate."

4.2.3 Skills and capability

Capability is shaped by practical "how-to" knowledge rather than general digital literacy. Knowing where a message is, what it means, and what to do next is often constrained by English proficiency and navigation difficulty. Where these barriers prevent independent action, people commonly rely on children or family members to complete tasks, even when this is undesirable.

"If I need to know something suddenly and quickly, I run to my daughter and say, 'please show me'."

There is a clear demand for structured support, including community-based help and simple demonstrations of how to use digital tools, to reduce reliance on informal assistance.

4.2.4 Beliefs and trust

Trust is closely tied to uncertainty about meaning, sender, and purpose. Messages that arrive in English-only formats, contain unclear links, or come from unfamiliar sources are less likely to be acted on until they can be verified through a trusted person or organisation. Reliance on informal translators can further undermine trust, as uncertainty about meaning increases hesitation and fear of making mistakes.

"I worry about [asking someone to translate a message] because the message is private, it's just for you – you can't trust other people not to show other people."

Trust is also affected by perceived inflexibility when appointments are missed due to language barriers. Where there is no follow-up or allowance for misunderstanding, service responses can feel punitive and discourage future engagement.

"I have a friend who was two times late for her dentist appointment. After three times, the dentist said 'you can't come to this dentist, because you missed your appointment three times'. She said she doesn't know English, but the dentist rejected her from the service."

4.2.5 Patient-centredness

Patient-centred messaging for this group is defined by access to information in a person's own language, particularly for high-stakes communications, alongside clear choice and fallback routes across channels. Messaging that is accessible reduces stress, supports inclusion, and improves follow-through by making expectations and next steps clear.

"For important information, if the message can be in my own language I'll be very happy – it will be very easy for the NHS and for me."

Patient-centred approaches also protect dignity and privacy by reducing the need to involve family members in confidential health communication. Recording language needs once and using them consistently across services is a central expectation, enabling digital communication to work rather than be rejected.

"English is the default, obviously, because it's an English country. But I think if the NHS could acknowledge the fact that the UK is becoming a lot more diverse, that would definitely make a lot of people feel more included in their healthcare journey."

4.3 Digitally excluded people

Digitally excluded people experience NHS messaging within conditions of material insecurity and unstable access rather than personal preference. Digital exclusion arises from unreliable access to devices, power, data, and contact points, combined with systems that assume smartphone ownership, consistent connectivity, and confidence with multi-step processes.

4.3.1 Access

Access is constrained by the instability of basic resources. Phones may be broken, stolen, or intermittently available, and charging, SIM access, and stable contact details cannot be assumed. Housing insecurity further undermines communication, meaning that fallback letters can fail where people lack a permanent or reliable address.

"The actual client base that we work with, that I've worked with personally, if they're sleeping in tents they haven't got access to be able to charge their phone. And they obviously have no address, so they're not getting letters."

As a result, digital messages may not reach people consistently across any channel. An access strategy that assumes receipt, persistence, or retrievability of messages does not hold in these conditions.

4.3.2 Accessibility

Even where messages arrive, they may be unusable because they lack context. Messages that do not clearly state what an appointment relates to, where it is, or what action is required are difficult to interpret, particularly for people managing multiple conditions or services. This leads directly to confusion and missed appointments.

"People have got multiple conditions and they might be going to multiple clinics. In Newcastle, if you have an appointment, it doesn't tell you what the appointment is about – it just gives you a time and date. It doesn't even tell you where the appointment is. They don't know which consultant, which department, which service it's for."

"They sometime can't interpret messages because they don't know what it's relating to … and then they miss their appointments. We hear that all the time."

Usability problems also arise from design and process complexity. Forms and websites that are multi-step, not designed for mobile use, or require switching between screens or logins are often abandoned before completion.

4.3.3 Skills and capability

Skills and capability barriers are most acute at procedural thresholds. Passwords, verification steps, and account recovery processes function as "last-hurdle" barriers, particularly where people lack email access or stable internet. Once access is lost, re-entry can be impossible.

"It's really hard for them to remember their passwords, so they are literally falling at the first hurdle."

"They don't have access to the internet, they don't have email addresses, or they don't have access to their email, and so therefore they can't access their NHS app."

Capability is task-specific rather than absent. Many digitally excluded people can use familiar tools such as WhatsApp but struggle with NHS systems that require logins, identity checks, or unfamiliar navigation.

"We tend to speak with our communities on WhatsApp, and we actually find that's a really good way of doing it. […] People will send voice clips … they will send a photograph of a letter, so I can look at it and say, 'you've got a hospital appointment at Saint Bart's on the third of November at 12.30, is that OK? Do you want me to send the post code?' That's really, really effective."

4.3.4 Beliefs and trust

Trust is shaped by fear of scams and unsafe links. Messages containing shortened links, QR codes, or unclear sender information are often ignored, even when NHS-branded, because risk-avoidance norms override institutional trust.

"We can teach people how to use QR codes … but for a very long time we told people, 'don't click on links that you don't know'. Now we're telling people to use QR codes to go to websites they don't know. There's an irony there, and it puts people at risk."

Trust also depends on the ability to verify messages through known routes. Letters, phone calls, or face-to-face contact may be trusted more than digital messaging, even when slower, because they allow confirmation through a familiar service or person.

4.3.5 Patient-centredness

Patient-centred messaging is framed in terms of choice, flexibility, and human support rather than improved wording alone. Digitally excluded people strongly reject one-size-fits-all or digital-only approaches and prefer hybrid models that allow escalation to phone or face-to-face contact.Offering multiple pathways respects individual preferences and promotes confidence, rather than forcing users to confirm to a single mode of communication.

Patient-centred design also emphasises co-design as a form of respect and inclusion. Involving users in the creation of messaging and interfaces ensures that systems reflect real needs and preferences. Familiar tools and multimodal formats, which combines text, voice and images, can empower users by reducing friction and supporting comprehension. Integrating trusted support alongside digital communication, rather than replacing it, reinforces a sense of agency and choice.

4.4 Parents and carers

Parents and carers experience NHS messaging in a context of high administrative burden and fragmented communication routes. Exclusion for carers arises less from device access or digital skill and more from the interaction between caring responsibilities and systems that assume a single user, a single set of contact details, and straightforward one-person workflows.

4.4.1 Access

Access is undermined by inconsistent and duplicated messaging across channels. The same information may arrive via app notifications, texts, and letters, often staggered over time, which increases checking and comparison rather than providing reassurance. For time-poor carers, duplication creates avoidable administrative work and reinforces a sense of fragmentation.

"There doesn't seem to be a consistent approach. We get letters, digital notifications through the NHS app, text messages – and sometimes they're duplicated, so you'll get a message in the app, you'll also get a text, and then a week or two later you'll get a letter through the door. So you do spend a lot of time going over the same information again and again, which is not helpful when you're time poor."

Access is further complicated by the need to manage multiple accounts for dependants alongside limited or ineffective proxy access. Carers are often required to log in and out of accounts to identify who a message relates to, increasing effort and the risk of error.

Responding to messages also requires coordination rather than simple action. Appointments must be aligned with transport, care cover, and medication

schedules, which makes early or inflexible appointments particularly difficult to attend or reschedule. As one carer put it, "that's taken a huge amount of liaison and coordination… to get that one appointment and all the care provision… lined up."

"I've had to cancel an appointment because it's so early in the day that we can't get there. But when another appointment comes, it'll be the same time on another day. And when it comes, I know I've got to go and reorganise all the care."

4.4.2 Accessibility

Accessibility is shaped by whether messages can be acted on quickly and accurately. Fragmented or poorly structured communications increase confusion and generate additional follow-up, as carers must re-read messages, cross-check information, and contact services to clarify next steps.

Design issues compound this burden. Dense text, ambiguous wording, non-clickable phone numbers, and links that are not mobile-optimised make messages harder to act on and can force carers to switch devices mid-task. Messages that do not clearly identify who they relate to further increase workload where carers manage care for more than one person.

4.4.3 Skills and capability

Skills and capability barriers arise from system complexity and volume rather than lack of digital competence. Carers routinely manage medication timing, appointments, transport, and interactions with multiple services, where small errors have immediate consequences and require rapid correction.

"I have to sit down and work out if we're going to wake her at this time [for an appointment]. And what time do we need to do the medication? Because we normally do it this time. […] It just doesn't take into account any of that."

Administrative workload is high and sustained. Carers describe spending many hours each week on health-related administration, far exceeding nominal estimates and adding to ongoing pressure.

"I would say that probably 10 hours a month is not enough. It's different hours per week on different things. It might be dealing with community nurses … doctor's appointments, managing prescriptions. Any sort of error anywhere,

like an error on a chart, and suddenly care workers can't use it. You've got to jump on that straight away."

4.4.4 Beliefs and trust

Trust is closely linked to recognition of carers' legitimacy and authority. Repeated failure to recognise recorded powers of attorney or caring roles creates frustration, lengthens interactions, and undermines confidence in systems.

"I frequently find myself explaining to people that ring up and want to speak to my wife – 'we need to speak to the patient' – well, I've got power of attorney. You've got a copy of it, it should be on your system. […] Can you talk to me?"

Where systems do not reliably recognise carers or provide clear, dependable information, carers increase service contact to double-check and resolve issues. This raises workload for both carers and services rather than reducing demand.

"If I had a pound for every time I've told someone that I actually have a power of attorney for her, then I'd be a rich man. A simple phone call can often turn into something more elaborate because you just have to get past all of that before you can actually deal with what it is you're trying to deal with."

4.4.5 Patient-centredness

Patient-centred messaging for carers reflects the realities of caring, including variable schedules, travel distance, special needs, and the need to coordinate multiple elements of care. Approaches that treat appointments as fixed and non-negotiable increase disruption when flexibility is not available.

"With the appointment on Friday … I asked the doctor to make it clear on the referral that there were special needs. […] But they couldn't accommodate the time I needed. So we're having to pull carers in hours before they normally come, which disrupts medication administration for her in the morning, and affects everything basically."

Carers value messaging that reduces duplication and supports a more joined-up approach. Clear identification of who a message is for, acknowledgement of known needs and constraints, access to a human contact for complex situations, and choice of channel depending on task complexity are central to reducing burden and stress.

5. Cross-cutting findings

This section draws together the mechanisms that cut across the four target groups. It highlights how barriers and enablers cluster by theme, and where common system assumptions create predictable points of failure.

5.1 Barriers and challenges

Across the four target groups, barriers arise less from digitisation itself and more from a mismatch between system assumptions and real-world conditions. Systems often assume stable device access, reliable connectivity, single-user accounts, and confidence with multi-step processes. When these assumptions fail, people miss messages, delay action, and carry higher administrative and emotional burdens.

5.1.1 Access

Access breaks down where devices, charging, data, and stable contact details cannot be assumed. This is most pronounced where housing or contact arrangements are unstable, and where letter fallback is not reliable. Access is also undermined where people cannot monitor multiple channels consistently, or where app messages are hard to locate among other content.

Time sensitivity amplifies these failures. When messages relate to appointments, preparation, or required actions, even short delays can lead to missed attendance or wasted journeys. Access becomes further compromised where account design assumes a single user and does not reliably support proxy or shared access, which is common in caring and household contexts.

Connectivity also affects access. Patchy signal and unreliable infrastructure reduce the reliability of digital contact and make it harder to reach services when clarification is needed.

5.1.2 Accessibility

Messages often fail to support safe action because they lack sufficient context. Where messages do not clearly state what they relate to, why they matter, or what to do next, recipients may receive the message but remain unable to

act. This is particularly risky for people managing multiple conditions or navigating several services.

English-only messaging and interface steps create immediate accessibility barriers for people facing language barriers. Reliance on machine translation can introduce clinical risk, and reliance on others can delay action and reduce independence. Accessibility barriers also arise from format and presentation, including readability, sensory needs, and channel suitability, which can make both app and phone routes difficult to use.

For carers, interaction design problems increase cognitive and administrative load. Non-clickable elements, static formats, and poor mobile optimisation make messages harder to act on quickly, which compounds existing time pressure.

5.1.3 Skills and capability

Having a device does not equate to being able to use digital systems for health tasks. Capability barriers emerge where systems rely on passwords, email access, and recovery processes that function as hard stops. Navigating these multi-step systems requires technical knowledge and familiarity with digital functions. Tasks that appear straightforward to experienced users, such as retrieving a verification code, may involve switching between platforms, remembering different log-in details and comprehending online instructions. Meaningful use therefore depends on a set of digital capabilities that many people may not have, particularly when tasks require multiple steps across different platforms. For example, forgotten passwords, inaccessible email accounts or multi-factor authentication requirements can impede access where people have limited confidence or support to navigate recovery steps. Although these may be treated as routine security steps by system designers, they can become exclusionary checkpoints for people with lower technical literacy. For people facing language barriers, capability is also shaped by navigation difficulty and English prompts, which can lead to unsafe guessing or task abandonment.

Procedural friction deters engagement across groups. Log-in steps, verification, and identity checks reduce completion, particularly where documentation is limited or trust in uploading information is low. Fear of making mistakes further inhibits engagement and pushes people towards human contact routes.

For carers, capability barriers are driven by cognitive load and fatigue rather than lack of digital competence. Complex coordination reduces the capacity to troubleshoot errors, even among those who are otherwise confident users. Reliance on support is widespread, but support is not always available at the point of need, which increases the likelihood of missed or delayed action.

5.1.4 Beliefs and trust

People often assess legitimacy before acting on messages, and uncertainty can lead to delay or non-engagement. Scam awareness makes people cautious about links, unknown senders, and unexpected messages, even when the message is genuine. For people facing language barriers, uncertainty about meaning further compounds legitimacy concerns and increases privacy risks where messages must be shared for translation.

For carers, trust depends on recognition of legitimacy and authority. Where recorded roles or authority are not recognised consistently, frustration increases and service contact becomes longer and more frequent. Trust is also harmed where systems respond inflexibly to missed appointments linked to known barriers, which can discourage future engagement.

5.1.5 Patient-centredness

Person-centred care is undermined where communication forces a single digital route without meaningful alternatives. Fragmentation and duplication create repeated checking and chasing, which increases workload and stress, particularly for carers. Poor information quality can also undermine reassurance and increase anxiety.

Privacy and dignity are compromised where people must rely on family or others to access private health information. Person-centredness also breaks down where systems do not accommodate shared responsibility, proxy action, and variable availability, which are normal features of caring and household contexts.

5.2 Enablers and successes

Successful messaging depends on reducing points of friction and providing safe fallbacks when uncertainty arises. Systems work best when they minimise unnecessary steps and offer clear alternatives if digital routes fail. What enables engagement is an ecosystem of clear messages, practical support, and genuine choice.

5.2.1 Access

Timely and predictable reminders support follow-through where they reduce reliance on complex navigation or log-in. Hybrid routes increase reliability where access conditions are unstable, provided duplication is purposeful and coordinated. Community organisations, libraries, and support hubs can function as practical access points where devices, data, or confidence are limited.

Phone and face-to-face contact act as enabling backstops. Human routes enable clarification and completion when digital journeys are unclear, and they reduce the risk of delay and escalation.

5.2.2 Accessibility

Messages work best when they are concise, structured, and explicit about next steps. Accessible language provision is critical for high-stakes content, particularly where misunderstanding instructions or relying on informal translation from family, friends or online tools risks delaying timely action and compromising privacy. This is especially relevant for messaging about test results, appointments or follow-ups, where unclear wording may deter individuals from engaging or responding appropriately. Navigation improves where message environments reduce clutter and support simple retrieval of key information. For example, general notifications within the NHS App can make it difficult to locate specific appointment details.

Familiar, multimodal tools can support understanding where dense text is a barrier. Voice and images can reduce reliance on complex forms and improve practical interpretation in real-world conditions.

5.2.3 Skills and capability

Supported onboarding enables engagement at first use and reduces distress. Assistance from trusted community organisations or peers can make the digital systems feel more approachable, providing practical and relevant guidance. For example, peer mentors and community workers can provide tailored tutorials on processes in an accessible way to overcome initial barriers such as account setup and password management. Confidence builds through repeated, guided practice rather than one-off instructions, particularly where tasks are unfamiliar or high-stakes. Digital Champion-style models provide a useful example of how this can work in practice, combining guided skills support with peer encouragement and, where available, access to loaned devices or data support. Human routes enable real-time troubleshooting and reduce fear of making mistakes.

Early support prevents failure. Support offered before missed appointments or drop-off is more effective than recovery after harm has occurred. In practice, participants described this as proactive, relationship-based follow-up when a digital step is not completed (for example, a phone call from a known person when an electronic questionnaire is not returned), and structured "warm" support that helps people get set up and learn how to use the NHS App in a trusted setting (for example, GP-linked invitations and in-person support through local Digital Champion models).

5.2.4 Beliefs and trust

Trust improves when sender identity is clear and communications match recognisable routes. Verification routes enable safe engagement where scam concern would otherwise suppress action. Participants described a practical dilemma: long-standing "don't click unknown links" advice sits uneasily alongside messaging that includes links or prompts to scan QR codes. They indicated that when messages are unexpected or when the sender is not immediately recognisable, people may ignore them as a protective response. "Safe verification" therefore needs to mean routes that do not require clicking a link in the original message – for example, confirming authenticity through a known contact point or a familiar service relationship (such as a follow-up call from a recognised staff member or using an established, trusted pathway to check what a message relates to). Trusted intermediaries can enable

legitimacy checking and comprehension, particularly for people facing language barriers.

Recognition of carers' legitimacy and authority also supports trust. Recording proxy status/authority (for example, an advocate or power-of-attorney role) in a visible, standardised way; and ensuring that this information is reliably surfaced and acted on across services and contact routes, so carers are not repeatedly asked to re-explain or re-prove their legitimacy, reduces repeated gatekeeping and makes proxy action safer and less burdensome.

5.2.5 Patient-centredness

Choice and control over channels support autonomy and reduce anxiety. Access to a person for explanation and reassurance enables completion where uncertainty would otherwise block action. Participants described reassurance as operationally grounded in timely human contact – either as an alternative route (telephone or face-to-face) when digital steps are difficult, or as follow-up when a digital interaction has not been completed. For older people, in-person support was repeatedly framed as the most comfortable and trustworthy option, with telephone as a second-best route where travel or access makes face-to-face difficult. Co-design supports respectful inclusion and improves fit with real-world conditions, particularly for people at highest risk of exclusion.

System coherence reduces burden for carers. Joined-up communication across channels supports coordination and reduces stress.

6. Implications for practice

This section translates the findings into practical implications for inclusive messaging. It sets out participant priorities and a set of design proposals to support digital-by-default approaches that remain workable in real-world conditions.

6.1 Participant priorities

Participants prioritise messaging that is usable in real-world conditions. They emphasise channel choice with reliable fallback routes, timely support where processes are complex, and recognition of roles such as proxy authority. These priorities reflect the need for messaging that enables action rather than assuming capacity.

Across the four groups, "usable" was consistently framed as (1) being able to identify that a message is genuine and relevant, (2) being able to locate it again when needed, and (3) being able to complete the required action without hitting avoidable procedural barriers. Participants also emphasised that messaging should reflect the reality that health-related tasks are often shared – within households, families, and caring relationships – and that systems should support legitimate "acting on behalf of" arrangements where appropriate.

Examples raised by participants included formal authority (e.g., power of attorney/advocacy roles) and informal responsibility (e.g., family members routinely managing appointments or interpreting messages).

6.1.1 Access

Access is understood as the ability to notice and act on messages using channels that work in practice. Where app-based routes are confusing or unreliable, people want alternatives such as text messaging and backup routes so a single point of failure does not block action.

Participants described practical access barriers including delayed letters arriving after appointment dates, phones being broken or stolen, lack of data or charging access, and difficulty retrieving app messages among other notifications. In this context, redundancy is not perceived as wasteful

duplication but as risk management: receiving a text as well as an app notification, or a follow-up call when a digital step is not completed, reduces the likelihood of missed appointments caused by unstable access conditions. Redundancy is valued as protection against missed messages rather than as duplication for its own sake.

6.1.2 Accessibility

Language provision is treated as essential for safe use, particularly for high-stakes or time-critical content.

Participants facing language barriers described difficulty locating and interpreting appointment information within the NHS App when content was presented only in English. In high-stakes contexts – such as procedure preparation – misunderstanding written instructions led to cancelled or repeated appointments. Where machine translation tools were used, participants reported that medical terminology was sometimes translated inaccurately, increasing confusion and anxiety. As a result, some relied on family members to interpret messages, raising privacy concerns.

Participants consistently emphasised that messages must be understandable enough to support safe action. Where wording is unclear, where the purpose/next step is not obvious, or where content assumes high literacy or English proficiency, recipients may be unable to act even if they receive the message. Participants described this leading to delay, reliance on others, and increased risk in time-critical or preparatory contexts.

While language barriers were the most explicit example raised, similar mechanisms were discussed in relation to literacy and readability more broadly (for example, when short digital messages are difficult to interpret or when formats make it hard to identify what is required).

6.1.3 Skills and capability

Support is most valuable when it is available before failure occurs. Participants described multi-step processes involving passwords, identity verification and log-in recovery as points at which people "give up" or disengage.

Older people, in particular, described being locked out of accounts or required to repeat security checks, and suggested that many would abandon the process entirely. Early support therefore includes practical onboarding (for example, guided first use of the NHS App), accessible explanations of verification steps, and proactive follow-up when digital forms are not completed.

People emphasise the need for early help to prevent missed appointments and breakdowns, alongside structured onboarding that enables first use of digital routes. One-off instructions are insufficient where confidence is low or tasks are complex.

6.1.4 Beliefs and trust

Across the group interviews, participants described trust as something that is "proved" operationally: through predictable and recognisable communication routes, clear sender identity, and consistent handling of recorded information about a person's situation (including communication needs and any legitimate "acting on behalf of" arrangements).

Trust depends on systems recognising recorded authority and allowing legitimate proxy action without repeated verification. Parents and carers described having power of attorney or formal advocacy roles recorded, yet still being required to re-establish legitimacy at each interaction. They emphasised that trust is strengthened when recorded proxy status is visible and acted upon consistently across services, so carers are not repeatedly challenged or required to switch between accounts to access essential information. When carers' roles are not recognised in practice, friction increases and confidence erodes.

Participants across groups also linked trust to message legitimacy. Unexpected digital messages or links were sometimes ignored because they resembled scam communications. Trust therefore depends not only on respectful tone, but on predictable delivery patterns, recognisable sender identity, and safe ways to verify authenticity without clicking unknown links. Trust is therefore tied to record use and workflow, not messaging tone alone.

6.1.5 Patient-centredness

Meaningful choice is central to person-centred messaging. Participants described person-centred messaging as messaging that preserves choice and dignity while still enabling timely action. This includes the ability to opt out where digital routes do not work in practice, and to access a viable alternative that is timely and functional (not merely theoretical).

Participants linked "viable alternatives" to two practical needs: (1) a non-digital route that remains reliable when devices/connectivity/literacy are limiting, and (2) access to a human route for clarification and reassurance when uncertainty would otherwise block action. Co-design was valued as a way of ensuring that messaging systems account for real-world constraints (shared responsibility, variable capacity, time pressure, and the emotional impact of uncertainty), rather than assuming an ideal user and a single channel.

6.2 National Voices proposals

Inclusive, digital-by-default messaging depends on reducing points of failure and providing safe fallbacks when uncertainty arises. Effective systems combine clear, timely messages with practical support and genuine choice, rather than relying on a single ideal channel. The proposals below translate participants' lived experiences into system-level design requirements. Each is directly linked to a recurrent failure mode identified in the research (missed appointments, disengagement due to friction, mistrust of digital routes, proxy exclusion, or unsafe reliance on informal translation), and therefore represents a practical lever within NHS messaging design and implementation.

6.2.1 Access

Access should be designed as timely actionability rather than simple delivery. Time-critical messages should be clearly signalled and delivered through low-friction channels, with redundancy where delay would cause harm. Systems should assume unstable access conditions, including broken devices, limited connectivity, and lack of fixed addresses, and should provide alternatives that remain workable in these contexts.

Message design (format, signalling, channel selection and timing) is within NHS control. For example, clearly labelling time-critical communications, coordinating reminder intervals, and enabling secondary contact routes where a digital step is not completed directly reduce the risk of missed attendance caused by delayed letters, unstable devices or overlooked notifications.

Services should use consistent, recognisable delivery patterns so people know where messages will appear and how to retrieve them. Services should consolidate routes where possible and coordinate messaging across channels to avoid avoidable duplication. Proxy and shared-access pathways should be supported as standard, reflecting the realities of caring roles and shared devices.

Consistency is valuable because participants described uncertainty about where to look for messages (app, text, portal, letter), and confusion over which account a notification related to. Standardised delivery patterns and clearer signalling of "who this is for" reduce cognitive load and administrative burden. Supporting proxy and shared-access pathways reduces repeated re-verification and unnecessary contact, thereby lowering workload for both patients and services.

6.2.2 Accessibility

Messages should meet a minimum standard of actionability. They should state what the message relates to, why it matters, and what to do next in clear terms. Messages should be written so recipients do not have to infer purpose, urgency, or required action.

This is actionable at the template and content-design level. Introducing a structured message format (e.g., "What this is about / Why it matters / What you need to do / By when") directly addresses participant accounts of receiving messages that were difficult to interpret or that required additional clarification before action could be taken.

Translation for clinical and preparatory content should be treated as a safety requirement. Services should provide language support routes that do not rely on ad hoc machine translation or family members for confidential or high-stakes information. Accessibility should also include readability, sensory needs,

and channel suitability, including clear phone routes where needed and careful handling of record-linked information to avoid unnecessary distress.

Participants described inaccurate medical translation and reliance on informal interpreters as creating confusion, privacy risks and, in some cases, repeated appointments. Embedding language support into messaging pathways (rather than treating it as optional) reduces clinical risk and improves preparation compliance. Similarly, improving readability and reducing dense or static formats addresses literacy-related barriers identified across groups, not only among those facing language barriers.

6.2.3 Skills and capability

Messaging systems should minimise procedural barriers such as log-in, password recovery, and repeated verification. Assisted routes should be available by default, alongside streamlined authentication where possible. First use should be supported through onboarding and repeatable, practical help rather than one-off guidance.

Participants repeatedly identified log-in recovery, security checks and multi-step verification as points at which people disengage. Streamlining authentication and providing assisted routes is actionable through configuration decisions (e.g., session persistence policies, recovery design, assisted authentication workflows). Doing so reduces abandonment and prevents avoidable failure at early stages of the digital journey.

Messaging journeys should be designed on the assumption that capability is task-specific and varies with stress, time pressure, and caring responsibilities. Processes should reduce cognitive load through step-by-step scaffolding and task-appropriate simplification. Where safe and appropriate, services should support multimodal formats that enable understanding and action without relying on dense text alone.

Participants described digital confidence as fluctuating, particularly under stress or when managing multiple responsibilities. Designing journeys that reduce steps, clarify progress, and avoid unnecessary switching between platforms reduces cognitive load and improves completion rates. Multimodal options (e.g., structured summaries, clearer navigation, supportive visuals where appropriate) address comprehension barriers without requiring high literacy or technical fluency.

6.2.4 Beliefs and trust

Messages should include clear sender identity and legitimacy cues, and services should provide verification routes that do not rely on clicking links. Verification should be available through trusted contact points, such as known phone numbers or in-service confirmation mechanisms, so people can act safely when unsure.

Sender labelling, domain consistency, and inclusion of clear verification instructions are controllable aspects of message design. Participants described ignoring unexpected digital messages due to scam concerns; therefore, predictable formats and safe verification routes directly increase engagement and reduce unnecessary contact triggered by doubt.

Recorded authority, preferences, and language needs should be stored and surfaced consistently across services. Systems should use this information to reduce repeated verification and to support legitimate proxy action. Language support should be provided in ways that protect privacy and dignity, reducing the need to share confidential messages with family members.

Operationally, this means ensuring that recorded proxy status, communication preferences and language needs are visible and respected across platforms and teams. Participants described repeated explanations of authority and repeated gatekeeping as eroding confidence and increasing workload. Consistent record use therefore improves efficiency as well as trust.

6.2.5 Patient-centredness

Choice of channel should be guaranteed, including opt-out and viable alternatives where digital routes do not work. Messaging pathways should not penalise non-digital routes or treat them as secondary. Proxy and shared-responsibility workflows should be supported explicitly, reflecting caring roles, shared devices, and multiple dependants.

Participants described digital routes as workable only when alternatives remain genuinely functional. Treating non-digital routes as secondary increases delay

and anxiety; maintaining viable alternatives preserves access and reduces escalation.

Co-design with groups at highest risk of exclusion should be embedded as a delivery requirement. Services should coordinate communication across channels and services to reduce duplication, lower burden, and improve dignity, particularly for carers.

Embedding co-design ensures that messaging systems are tested against real-world conditions before scale-up. Participants' accounts show that fragmentation across services increases administrative burden and stress; coordination reduces repeated checking, repeated explanations, and unnecessary duplication, improving both experience and efficiency.

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National Voices

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