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# Experiences of Urgent Primary Care services

# Contents

Acknowledgements	3
Introduction	4
Part 1: Key access challenges	5
Part 2: Challenges in keeping patients safe	13
How can we improve safety?	19

## Acknowledgements

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# Introduction

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On 8 July 2024, National Voices held a workshop for its members to consider the experiences of diverse patient groups when they access Urgent Primary Care when their GP surgery is closed. The workshop was designed to inform a study being led by the Nuffield Department of Primary Care Health Services, at the University of Oxford, entitled *Optimising Patient Risk Management in Urgent Primary Care Services*.

The study is exploring people's experiences of seeking urgent care when their GP surgery is closed from services including NHS 111, out-of-hours GPs, Urgent Treatment Centres, Minor Injuries Units, etc. It has a particular focus on people who may be more at risk of poor health outcomes including:

- Children and young people.
- People experiencing mental health crisis.
- Frail and older people with multiple long-term conditions.
- People at the end of life.
- People with special access requirements or facing health inequalities.

The aim of the study is to identify how to optimise the quality and safety of the care received from these services. To inform the study, National Voices brought together representatives of member and non-member organisations including:

- Age UK.
- Behind the Smile.
- British Geriatrics Society.
- Caribbean and African Health Network.
- Compassion in Dying.
- Derbyshire Mind.
- Hertfordshire Mind.
- Marie Curie.
- Mind.
- National Association of Deafened People.
- Thomas Pocklington Trust.

During a two-hour workshop, the group shared their evidence and insight around people's experiences of these services and the extent to which these services were effective in keeping people safe. This short report outlines the key insights they shared.

## Part 1: Key access challenges

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Participants shared insights around the experiences of the communities and cohorts with which they worked in accessing Urgent Primary Care services. A number of key themes emerged.

### Lack of awareness and understanding

Participants told us that it was hard for people to understand the complex range of primary care services available to support people out of hours and as a result people did not know the right service to access or were put off from accessing services at all.

We heard that this could be a particular challenge for people who had recently arrived into the UK and effectively had to “learn” two separate systems, one for accessing health care inside working hours and the second for outside working hours.

“For many of the communities that we work with, a lot of that is around the fact that the services are not easily understood or accessible. So, it's not necessarily as straightforward as language, but it's just that the system itself is complicated [...] Many mainstream sort of NHS messaging fails to reach into these communities.”

Several participants told us that the complexity of accessing Urgent Primary Care services was off-putting and that it often felt like they were designed to encourage people *not* to use them.

“I think overall it feels sometimes it's set up to make people come back on a Monday.”

### Communication and accessibility issues

For people with additional communication needs and/or those who are digitally excluded, we heard that Urgent Primary Care services were often *more* inaccessible than regular daytime services.

People with additional communication needs often struggle to access appropriate support with health services, but we heard that these problems could be even more pronounced in Urgent Primary Care services. For

example, access to interpretation and translation services are often even more limited in these services. Furthermore, people with long-standing “flags” on their records around specific communication needs were often contacted through inappropriate means as out-of-hours staff did not have access to their records. Participants highlighted that the Accessible Information Standard, which covers all NHS services, is regularly breached in out-of-hours and urgent care situations.

In addition, we heard that many of the “front doors” of services were inaccessible to people with additional communication needs and those who are digitally excluded.

For example:

- Blind and partially sighted people may struggle to access telephone menus which require people to press buttons.
- Many people perceived that services and/or information about services was only or primarily available online.
- The wide variation in digital tools used to access different services meant that services could be hard for those with limited digital skills to access.

“I think some of the promise was that if you make those services more accessible for people that are digitally connected, that frees up space for those that are less connected to get in through the traditional routes. But I don't think that's really panned out at all. So, people really, really struggle to get through.”

We heard particular concerns around the increasing requirement to send in photos to out-of-hours professionals, which could create barriers for people with limited resources or who lack confidence in using digital tools.

“They're trying to rely too much on technology a lot these days with...things like having to send in photos and when some people in our group have got just the basic £10 phones and don't even have smartphones, they don't have a computer and so unless you've got access to the technology, sometimes you can't access certain services,”

“We have had feedback where for example, you may be asked to send in a photo of something to be looked at. I think there's a lot of people who are very wary of those methods of sending things through. They can be worried about things like privacy and again, if you're not someone who uses a phone camera every day for your social life and everything else, the idea of sending these things across these and it's supposedly secure portals is a difficult one.”

We also heard about challenges in physical access to services. In particular, we heard that patients were often referred to services that were long distances from their homes, without any consideration of whether the patient had access to transport to get there.

## Inconsistent services across the country

A key challenge, identified by participants working with a range of communities, was the lack of consistency in the support available in different geographical areas of the country, in relation to both generalist Urgent Primary Care services, and more specialist out of hours support into which people with more specific needs may be referred.

For example:

- The Community Urgent Eye Care services, which were first established during the COVID-19 pandemic, are not available in all communities in England. NHS 111 services may not be aware of where services are or are not available and may end up making referrals to services that don't exist or fail to refer to those that are available.
- NHS 111 and other urgent services are often unaware of out-of-hours support provided by the voluntary, community and social enterprise (VCSE) sector for people experiencing mental health crises, even where these are commissioned by the NHS.
- There is a wide variation in the services available to people at the end of life out-of-hours, and so NHS 111 may not be aware of how to refer people.

This wide geographical variation made clear communication about accessing Urgent Primary Care services very difficult and meant that it was hard to establish clear pathways through to specialist support out-of-hours.

*"You phone 111 and you might get sent to a service and actually they've not been given the latest up-to-date information on where those services are available. So, there's danger of being bounced around [...] I don't know whether that's true for other services, but particularly with eyecare services, [...] until we've got uniform coverage there's scope for misadventure in the system."*

## Lack of shared records across regular daytime and out-of-hours services

This was identified as a significant challenge for participants working with a range of communities which had a wide range of implications including:

- People being forced to repeat traumatic personal histories to multiple staff.
- Failure to meet communication needs due to a lack of access to communication needs “flags” on patient records.
- Inappropriate prescribing or signposting due to reliance on the patient to report any additional needs (e.g. inability to swallow medicines).
- Failure to take account of patients’ previously stated wishes, for example advanced directives for end of life care.

“When you are ringing up 111 and they don't really have access to things like your frailty status or the kind of medications you're on or the other consultations that you may have had in the recent weeks, we know the older people are more likely to have had recent contact with services as well either through the emergency route or outpatient route or just with their GP not being able to have that history of contact with the NHS really throws it out.”

“Anticipatory conversations are had, and advanced care planning and conversations are had, and that information is recorded and documented, but then when it's not available electronically to the people who need to see it, quite often the family members just don't feel confident enough to advocate for that person and what they wanted. So, actions happen that are contrary to what the family felt that they had planned together just simply because the record sharing isn't there when it needs to be.”

The issues were not limited to the lack of access to shared health records – the inability of out-of-hours services to access social care records was also a challenge.

“Many [older people] are users of social care and there's very relevant things that come from their social care records that aren't shareable or don't get around. And likewise, even setting things up that might be resolved through a social care intervention isn't really possible through the routes that made available to people.”

The issues around continuity of care caused by the lack of access to patient records were seen as having a significant impact on people’s trust and confidence in the care received in Urgent Primary Care services. This could



lead people to avoid using these services in future and/or to access additional services due to an ongoing need for reassurance.

## Lack of integration within the wider health system

Participants told us that the gulf between Urgent Primary Care services and other parts of the health system including regular primary care services, secondary care services and services provided by the VCSE sector had significant impacts on people's experiences.

The fact that Urgent Primary Care services are commissioned and run separately from regular services led to a sense of disconnection – with Urgent Primary Care providers often unaware of the full health and landscape in their communities – including social care and services commissioned from the VCSE sector. This meant there were missed opportunities to refer people to specialist services such as non-clinical mental health support, culturally appropriate health services etc.

## Rigid systems that do not respond to complexity

Another key challenge reported by participants was the reliance on scripts and rigid protocols within Urgent Primary Care services, and particularly NHS 111. Participants told us that staff following scripts were ill-equipped to pick up the nuances of need among those with complex or multiple conditions; to identify the severity of mental health issues; and to ask the right questions of people living with frailty and those at the end of life.

“A lot of users have got other complicated health problems, either very, very old living with frailty or have some other disability actually, which makes it harder for those people to be persistent enough to get those services.”

“I think that there's a whole thing around using forms or formatted things to take information from patients which doesn't allow them to tell their story.”

Participants also shared insights around some of the specific issues faced by some of the key groups of interest to the study:

## a) Gaps in support for people at end of life

We heard that people at the end of life who have been discharged to die in the community often lack clarity about how to access appropriate support out-of-hours. This could be a particular issue for older adults living with frailty at the end of life as they were less likely to be in touch with specialist end of life services. Colleagues from Marie Curie highlighted their in-depth report<sup>1</sup> on the challenges faced by people in accessing support out-of-hours.

We heard that people at the end of life and their families were often not given clear information about what to expect and often needed reassurance but were not able to access this when calling services such as NHS 111.

“When things go wrong, and when I talk about things going wrong, I mean when things happen that the family are not expecting, then that's often the point at which they'll need to use this sort of urgent care services.”

“The family members panic, they don't understand what's happening and they might call 111 for example. The experience is often really poor and really unhelpful for the family. And when I say it's poor it's because it's not set up for that detail in that nuance.”

“A really typical experience might be like a daughter phones 111 and they go through all of that process, somebody calls them back, they have a conversation and the outcome of that conversation is 'Right, we're going to prescribe you something and you can go pick that up from the chemist'. So, the daughter goes to pick that up from the chemist or from wherever, but that person's already lost the ability to swallow, but that hasn't been medically communicated in the right way. So that person can't take the medication, so it needs subcutaneous medication, but then getting that medication is delayed by a really long time and it's really traumatic for the family members and for the person.”

We also heard that there can be significant issues in accessing key services out-of-hours, for example, a lack of community pharmacies that are open overnight and no stock of key medications. The challenges differ from one geographical area to the next – in the best cases there is seamless specialist 24-hour-a-day provision, but in other areas there are significant gaps in capacity.

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<sup>1</sup> Marie Curie (2022), *Better End of Life 2022*, Available at: [better-end-of-life-report-2022.pdf](#)

Participants explained that providing effective end of life care involves a complex chain of services and professionals and that out-of-hours services such as NHS 111 are not able to effectively slot into and engage with these chains of services.

“That's a very big supply chain to get wrong. And that's one of the critical elements around pain control in particular in the final days of life that is problematic for families and carers, and it lives on certainly in the lives of carers after the person has died.”

The lack of access to people's digital records can also be a significant issue, in some cases leading to people being unable to access the right support. This can leave family members traumatised after their loved ones have died.

## b) Challenges for people experiencing mental health issues

We heard that people with mental health issues were often confused about the best ways to access support out-of-hours and in urgent situations.

“For somebody who's not experiencing a mental health crisis, it's hard enough to get your head around what may or may not be the routes.”

When people did access services, we heard that the script-based and protocol-based approaches to interactions in some Urgent Primary Care services and a lack of training and expertise in supporting people with mental health issues meant that people's experiences were often poor.

Participants also told us that there were often missed opportunities to signpost people to available support. We heard that too often people in crisis are advised to wait for daytime GP appointments when they could have accessed alternative non-clinical support or de-escalation, including from the VCSE sector.

## c) Barriers for people from minoritised ethnic communities

We heard that people from minoritised ethnic communities often lacked clear information about how to access Urgent Primary Care services.

“Many mainstream NHS messaging fails to reach into these communities and that affects a lot of different ways, but one of them is that people just don’t understand what options are there.”

We heard that some services lacked appropriate expertise to support people – for example we heard that refugees and asylum seekers may face barriers when accessing 24-hour pharmacy services, due to staff lacking understanding of their entitlements.

## d) Barriers for older adults

Several participants noted that older adults were far more likely to have multiple conditions and to have multiple recent contacts with health services and therefore to be negatively affected by the lack of join up between regular and Urgent Primary Care services, and social care etc.

## Part 2: Challenges in keeping patients safe

Having identified a range of challenges, we went on to discuss the extent to which Urgent Primary Care services were able to keep patients safe. We recognised that in some cases people's experiences may be clinically safe, but that they may not feel safe as a result of their interactions.

We heard that poor experiences of Urgent Primary Care services, even when safe at the time, could contribute to people being less safe in future – as they may delay or avoid accessing appropriate services when issues arise.

*“The risk is, because it's so difficult, [people] think... shall I just leave it until my own practice is open? And anecdotally in my job, I've seen lots and lots of patients who've turned up after Christmas who clearly had a stroke or had chest pain the whole time. So quite serious illnesses, life-threatening things, but actually in their head they've gone, 'It's such a hassle that I would rather just wait until I come along and see my own GP.’”*

*“Eventually you'd find lots more people may not be willing or ready to access any of these services because they keep running into these challenges or these barriers. And over time you find that accessing them starts to get limited and more limited over time.”*

At the same time, others who do not feel safe may end up repeatedly re-accessing services or accessing more acute services including Accident and Emergency.

We recognised that most people accessing Urgent Primary Care services are already experiencing stress and worry. Participants told us that too often services were not responsive to these realities.

### Feeling heard and building trust

One of the biggest challenges for patient safety that was identified by our participants was a sense of not feeling heard. Participants told us that when people did not feel that their issues had been heard by services, they were less likely to trust the advice given.

This could lead them ignoring the advice, choosing to avoid services in future, or accessing or re-accessing additional services – leading to unnecessary waste in the system.

“When you look at some of the evidence that's come out around older people's care, some of the key themes that's been highlighted is the perception people have about how the consultation's gone. So actually, was the clinician interested in me? How did they speak to me? Because actually if they felt they were a bit harsh and a bit abrupt then I'm far likely to re-access that service again.”

“If you said to me ‘Oh if it gets red and sore, come back to me’, but it was said in a slightly unhelpful way, then actually I'm more likely to say, ‘Actually I'll leave it until my own doctor's around after the weekend or when the holiday's over’.”

The “script-based” nature of some services was seen as running counter to their ability to help people feel heard. In turn this impacted people’s sense of trust.

“I think that telling the story is what allows them to build trust in that consultation. So, I think unfortunately because we use junior clinicians to take that initial call, that takes away that ability to have conversations that are a bit more meaningful.”

## Lack of clear information

Participants told us that people were often left without any clarity about their next steps following interactions with Urgent Primary Care services. The formal practice of “safety netting” – in which health professionals give advice around what to look out for and when to return for further support – was not working effectively for many people.

Participants recognised that understanding appropriate levels of risk could be very difficult – particularly where people have specialist needs – for example mental health issues or palliative care needs. However, we heard that often people were given inappropriate advice or insufficient advice to allay their concerns. Participants told us that it often felt like NHS 111’s only role was to assess if you needed an ambulance or to go to A&E rather than to offer active support.

Participants pointed out that often people accessed Urgent Primary Care services because they needed reassurance about something that had changed or was worrying them. In many cases this happened after an episode of secondary care – in which patients were left without clear information about what to expect. For example, we heard that people newly fitted with catheters often found themselves having to call NHS 111 because of unexpected changes in their condition. Better information provision at the point of discharge from secondary care could avoid people having to access these services in the first place.

We also heard that too often the advice people are given can feel too generic – more like an insurance company “boilerplate” than personalised advice. In addition, the failure to provide written advice, or advice in other formats that can be checked again later, can mean that information is forgotten. These issues can be exacerbated where people have additional communication needs.

“When you are under such an anxiety level, such a pressure level, you sometimes think you understood, you’ve got the message... But when it comes to hearing loss, just writing down a simple small note and saying, ‘make sure you continue taking the tablets’ is not enough you need more.”

## Treatment of frequent callers

Participants noted that following negative experiences of care, while some people stop accessing services that do not reassure them, others continue to access and re-access services to seek further assurances. This can lead to people being labelled as “frequent callers / frequent attenders.” Participants told us that sometimes this means their concerns are taken less seriously.

Participants argued that some conditions are so distressing that even with good advice people will need reassurance – for example when people are feeling breathless, even if they understand their condition, they may need reassurance. Participants told us that is reasonable for them to seek support repeatedly and this should not lead to less support being offered.

“It almost becomes the boy that cried wolf scenario, but actually that’s a risk for patients or for users really.”

“We also see that mental health, people with learning disabilities or dementias where they forget that they’ve got a condition, and they

keep calling up and these people also appear out of ours and we don't know how to handle that. So, we label them [frequent flyers].”

## Inappropriate referrals and missed opportunities to refer

Participants told us that that failures to make referrals were a significant challenge across Urgent Primary Care services, leading to patients often receiving sub-optimal care.

Participants told us that a key challenge was that no one in the system seemed to be responsible for joining up support across Urgent Primary Care and regular services. We heard from VCSE organisations providing support that they struggled to establish clear referral routes from Urgent Primary Care services into their support offers.

“It's down to individual organisations to market their services [...] I spent quite a lot of time trying to engage with harder hitting organisations that might be able to send us more appropriate people.”

Participants shared insights around some of the specific issues faced by some of the key groups of interest to the study:

### a) Safety issues for older adults

We heard that there could be particular challenges for older adults in accessing Urgent Primary Care services as they may be particularly easily “put off” accessing services and may be likely to understate the severity of their needs.

“The other thing which we can't ignore, and it is something particularly in my clinical work anecdotally and certainly some of the research is how stoic older people tend to be and the belief that certainly for the older old, the over 85s is the generation where the NHS was seen as something that we shouldn't overburden. I think because we've made out-of-hours a special time, a lot of people don't feel they can contact people out-of-hours, which creates a risk in itself.”



Participants pointed out that people from some cultural backgrounds were also more likely to avoid accessing health services due to a sense of duty not to “burden” doctors.

## b) Managing risk in mental health

Participants working with people experiencing mental health issues recognised that managing risk among people in mental distress could be particularly challenging. However, we heard that too often advice given was inappropriate – either unnecessarily pushing people towards A&E or making suggestions which minimised people’s distress or were not practical – such as advising someone to go for a walk in the middle of the night.

“It's very different ball game in mental health considering safety and risk because a lot of [the assessment] will be to do with the intention of the person that's in contact with us and not necessarily how their body reacts in a physiological way.”

“People sometimes panic and push people into ED [the emergency department] when they don't need to be there. I think when people mention things like suicide and things, they automatically assume that that has to go into a clinical ED setting, which it doesn't.”

We also heard that Urgent Primary Care services were often unaware of prior agreements around information sharing with family members and carers and this could lead to failure to share vital information and missed opportunities to bring support to people.

## c) Key risks for people at end of life

Participants working with people at the end of life highlighted some of the ways in which people accessing Urgent Primary Care services may be put at risk. Participants reported that patient safety issues were far more common out-of-hours.

Challenges included:

- A lack of access to previous records leading to inappropriate referrals, advice or prescribing
- Issues with accuracy in prescribing
- Lack of continuity of care leading to loss of trust and confidence

“I think listening is a critical part of training and I know when staff are under pressure, this is one of the most difficult things to keep going. But listening and feeling listened to is a critical part to patient safety and that perception of patient safety.”

## d) Fear and mistrust among people from minoritised ethnic communities

We heard that people from minoritised ethnic communities were particularly impacted by the “script-based” approaches taken in Urgent Primary Care services, and the failure to make people feel listened to.

A lack of cultural sensitivity often exacerbated the lack of trust, leaving people feeling unsafe in Urgent Primary Care Services.

“Especially when it comes to people from our community, it's just having that feeling of the person listening to you, that's what it is. You need to establish that connection, that relationship with a person on the other end of the line. And a lot has to do with listening. And so I think in addition to what everyone else has said, you need to have that cultural sensitivity training.”

## How can we improve safety?

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Participants discussed ways in which Urgent Primary Care Services could be improved to ensure more patients had positive experiences and received care that was both safe and experienced as safe.

### Improving existing services

There were a range of suggestions for improving existing services, including:

- Implementing the Accessible Information Standard and the Reasonable Adjustment flag across all services.
- Ensuring that patients' access to public and private transport is taken into account when making referrals.
- Training staff in:
  - a) active listening and person-centred support.
  - b) supporting people who may be more vulnerable such as those with mental health issues, those living with frailty, people at end of life.

*"It is all about having that extra time for that person. Otherwise the person can feel like you're just checking boxes and as you said, at the end of the day, you signpost me somewhere else, I may be able to access it or I may not feel safe accessing it, but because I don't, I've not established that relationship with you and it doesn't feel like you actually really care about what I'm going through, you're just doing your job. Then at the end of the day, it is less likely that I would re-access that service again. So, for me, that's what I think it is, a lot has to do with remodelling the service but then also incorporating more of a listening thing to it."*

- Improving communication by:
  - a) Creating communications materials in a range of formats to convey when and how services can be accessed and encouraging people to use out-of-hours services if needed.
  - b) Ensuring that the advice given at the end of patient interactions is communicated appropriately in a way that reflect their specific communication needs and understanding is checked.
  - c) Using a range of tools – e.g. leaflets, texts, voice notes – to give people "take away" information, so that patients can

review advice they have been given during consultations – with as much information being personalised to the patient as possible.

## Reconfiguring services

We also heard suggestions for reconfiguring services, including:

- Offering patients more direct routes back into services should issues escalate – e.g. a fast-track to a GP appointment, a different number to call for follow-up.
- Creating more effective pathways through support available out-of-hours in each local area by joining up the offer across the NHS, social care and VCSE support through better signposting and understanding of what is available, to who and when.
- Sharing records across Urgent Primary Care Services and regular GP and other primary care services so that patients receive seamless care without having to repeat their stories or needs.
- Moving away from script or protocol-based interactions to more flexible consideration of what is driving the patient to access services and how the interactions can be made of the most value.

“I think having a real look at how the NHS thinks about these issues and focuses back on what is going to be helpful for the person, what is the real value-add for this interaction? Not just, let's make sure they're not dying, they've not got chest pains, they've not got an acute injury that needs something, but here's an opportunity to have a conversation about what they're doing with their meds, have a conversation about any long running issues they've been experiencing, have a think about what might be a useful follow up from this call and then you come back to it later”

- Move towards seven-day services to remove the dividing line between out-of-hours and regular primary care services.

“Every illness, the mental or physical health doesn't happen in a nine-to-five. You can't put it in that you're going to go and be ill in between those hours Monday to Friday. And so having access to the services outside Monday to Friday, nine to five is really the change that could be needed.”

“Should we have a primary care network model that the groups of practices within that primary care network provide that care? And that way they would have access to all the clinical records that are needed to react appropriately to people.”

# National Voices

National Voices is the leading coalition of health and social care charities in England. We have more than 200 members covering a diverse range of health conditions and communities, connecting us with the experiences of millions of people. We work together to strengthen the voice of patients, service users, carers, their families and the voluntary organisations that work for them.

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