NHS at 75 Insights report

National **Voices**

Project Scope

On Wednesday 25 May 2023 National Voices brought together around 50 members and people with lived experience in response to an invitation from the NHS Assembly to offer insights and recommendations on future directions for the NHS as it reaches its 75th anniversary.

Insights were sought around five key themes, and discussions were informed by an overview from existing evidence prepared by Healthwatch England. The themes were:

- **Prevention**: enabling people to live healthier lives, with an emphasis on the potential role of technology

- **Personalisation**: giving people power to control their own care and have shared responsibility for achieving better health

- **Participation**: Involving patients and their families at every level of decision making and service design

- **Primary and community care:** focusing on strengthening these local services which are the foundation for most care and treatment

- **Partnerships:** the NHS working better with other organisations to improve health and care for all

This report summarises key insights under each theme and offers a set of recommendations for future action to ensure the NHS can continue to deliver in line with its core values into the future.

Context

"Overall the under-resourcing of the NHS is preventing the delivery or the design of care that we all want, need and have a right to."

Members and people with lived experience were aware of the current pressures and challenges faced by the NHS, not just as a result of the COVID-19 pandemic, but also as a result of longstanding underinvestment and significant workforce pressures. They recognised the need for significant recovery work across all areas of NHS activity, as set out in current recovery plans.

Inevitably this context informed and shaped the scale and nature of people's ambitions for the future NHS. Participants agreed that the evidence presented by Healthwatch was a good summary of the key issues, but as expected from more condition or community specific groups also raised some very specific additional concerns and ideas for improvement.

Participants were clear that the priority for now is to set out a practical plan for reforming the system starting from the things they experience today, rather than a purely aspirational statement of future intent which would feel disconnected from their current reality.

Insights

Overarching themes

"Every one of us has been touched by the NHS and that produces so much goodwill. People want to give back, they want to help the service improve, they actually want to do that."

Across our discussions it was clear that the focus for the NHS in its next phase must be on **getting the basics right** from the perspective of people who use health and care services.

Across all of the themes we discussed we saw a need for the NHS to:

- Improve how it **communicates** with people about their access options, treatment and ongoing care – we heard that too often communication with the NHS is one-way, and that people do not feel listened to. We also heard of significant failures to meet additional communication needs.

- Work to **build relationships** with people and communities – we heard that too often the NHS asks people to engage on its terms, rather than meeting people where they are and working to establish trust. Good work happened during the pandemic to establish more trusting relationships with communities, often through trusted intermediaries, but progress since has faltered here.

- Focus on **what matters to people** - we heard that people wanted the NHS to listen to their priorities rather than pursuing targets set by the system, or imposing its own ideas or systems on people's lives. People understand that the NHS is under pressure, and they know that there will sometimes be limits to what can be done, but too often they feel they have to fight to get the care they want, and are left to pick up the pieces of a fragmented system.

Below we explore in more detail the key insights identified under each theme.

Prevention

Participants agreed with the aim to rebalance NHS activity towards supporting people to live healthier lives for longer. They wanted to see the NHS working with people, and meeting them in their communities , to deliver practical changes that enabled people to live well. However, they identified a number of significant challenges that need to be addressed:

Awareness:

- People's access to preventative interventions and support to stay well continues to be hampered by low awareness of what is available. These problems are particularly pronounced among groups more likely to experience health inequalities – for example people from minoritised ethnic groups, people who do not speak English as a first language, people who experience homelessness, and people living in poverty.

- Failure to meet standards around accessible and inclusive communication was a significant issue in relation to preventative interventions, with generic communications often failing to reach people with additional needs.

Access:

"If we are going to change the way the NHS works, the services need to be coming out to the community. That's where people know about them. They can't wait for people to come to them."

- For most participants, their GP practice remained the main gateway to preventative support, so pressures on GP services were a significant barrier to accessing screening, vaccination and other priorities. People saw opportunities to widen access by working with community organisations, as seen in the COVID-19 vaccination campaign.

- Access to preventative interventions is patchy, and these services are often under-funded and unavailable. For example, access to PrEP via sexual health clinics; or support with diet and nutrition – sometimes the support offered is "one-size-fits-all" and stigmatising.

- There are missed opportunities to work with community organisations, including Voluntary Community and Social Enterprise (VCSE) organisations and faith groups, as trusted intermediaries, to improve awareness of, and access to, preventative support.

Challenges in secondary prevention

"We've experienced further health issues just because there was no kind of joined up thinking or listening to the people that know."

- We heard from individuals living with a range of conditions about how gaps in GPs' knowledge had led to missed opportunities to offer preventative support to avoid condition escalation. This included:
    - Failure to offer appropriate medication to avoid or reduce side-effects
    - Lack of access to preventative support around the common conditions which often go alongside people's "primary" diagnosis.
    - Failure to provide information about key symptoms and/or the implications of a diagnosis. This was compounded by a lack of signposting to VCSE partners who could provide additional help.
    - Lack of rehabilitation support to enable people to recover from surgery/adapt to new medication or equipment (e.g. hearing aids).

- There are missed opportunities to enable people to act as experts in their own care in determining what kinds of interventions would most help them stay well. There is specific opportunity to develop this more among people with chronic or recurring conditions who would benefit more from self-referral, more direct access to prescriptions and faster routes in to hospital specialists through things like Patient Initiated Follow Up.

- Inconsistent access to screening was an issue across a range of conditions. Participants told us that this was sometimes because GPs were not sufficiently aware of the risk factors, or warning signs of certain conditions, particularly when prevalence of conditions varies in some communities. Participants recognised that GPs could not be expert in every condition, but wanted to see improved training and greater use made of expert organisations in the VCSE sector which often provide simple toolkits and guides which GPs and other practice staff can access.

Data challenges

"There isn't any category in the NHS data dictionary for Gypsy, Roma and Traveller groups, so we're completely invisible."

- Gaps in data – for example the lack of data around Gypsy, Roma and Traveller populations –lead to missed opportunities to identify and intervene early to reduce health inequalities.

- There are missed opportunities to use data to inform early intervention – for example data on parental mental ill-health could be used to support earlier intervention among children (who are more likely to face mental health issues in future).

Insufficient action to reach minoritised and marginalised communities

"No communities are hard to reach. It's because we're not communicating in the right way."

- There is still too little action to address barriers of stigma – for example there is still a lot of stigma around HIV, and in some religious communities these barriers are even higher with patients trapped between conflicting advice from health professionals and religious leaders. People also told us that they experienced clinicians who did not believe in their conditions or take their severity seriously - examples of this included ME/CFS and hyperemesis gravidarum

- Working with trusted organisations and intermediaries can help to build up trust and reduce stigma, but blanket approaches may leave some groups behind – for example working to reach black people only via faith communities may leave, for example, LGBTQ+ black people unserved.

Lack of ongoing precautions on COVID-19

- The failure to learn lessons from the pandemic and to retain protections including mask wearing, distancing, and enhanced ventilation, means that we continue to leave people vulnerable to COVID-19 and Long Covid, and potentially other respiratory conditions.

- The lack of wider access to anti-virals for COVID-19 also represents a missed opportunity to prevent long-term ill-health.

Gaps in support for mental health

- Gaps in community-based support for mental health are significant and represent a major area of need – many VCSE organisations and peer support groups are having to fill this gap to support communities, but without the necessary resource to do so.

- The failure to address the potential mental health impact of living with physical health conditions represents a missed opportunity.

Personalisation

"My recovery started when my clinician asked me what I really wanted. I was very lucky not many clinicians know that they need to ask this question."

Participants welcomed the NHS's aspiration – as set out in the NHS Long-term Plan – to provide everyone with personalised care and support, but for many this felt some way off, as many faced significant challenges accessing basic care of any sort. Those who were more positive about having received personalised care, often described this in terms of having had a good relationship with a particular clinician, or other professional, who had worked with them in responding to their health and care needs.

Failure to listen

"I hear people tell me they can't be bothered to go to the NHS 'cos it's too much effort, or to their doctor 'cos they never listen to them."

- Participants were clear that being listened to is the critical first step in personalised care, but for many the NHS still fell at this first hurdle. Many felt "done to" by health and care services – for example many women and birthing people were not enabled to use their right to make an informed choice about their care.

- We heard that people with long-term conditions, and carers, were not always treated with respect. People described experiences of being dismissed and patronised, rather than treated as experts in their own experiences and circumstances.

- Many people need support to exercise their right to personalised care, but the NHS is often reluctant to resource organisations providing advocacy and supporting self-advocacy. Similarly, clinical staff do not have the time to provide this support.

Gaps in support

"It's wonderful that some people are able to access services but this is a postcode lottery."

- We heard about a range of gaps in support which meant that people were not able to receive care around the issues that mattered to them. This included experiences of being denied treatments which were recommended in National Institute for Health and Care Excellence (NICE) guidance, or which people had prior experience of using to good effect.

- Too many people faced a "postcode lottery" to access services – with the service they received dependent less on their own choices and preferences and more on decisions made by local health leaders.

- Participants recognised the work being done to introduce new roles in primary care to support personalised care, however we heard that access was not always consistent – for example young carers were not always able to access social prescribing support.

- Consistency of the offer was felt to be important as it ensures everyone gets the help they need, but also makes it easier for people to understand the support on offer.

Clearer information and standards

- Participants with expertise in a range of conditions expressed frustration around the failure to consistently implement NICE guidelines.

- In the context of the creation of Integrated Care Systems (ICSs), there was increasing concern over variation in the implementation of NICE standards across the country and there was a lack of clarity around how patient organisations would be able to advocate for better access across 42 separate authorities.

- Greater clarity is needed around the status of guidelines and what people should expect in relation to NICE recommended treatments and approaches, including what should happen when they self-advocate for treatment recommended by the regulator. If not addressed, it can feel to users as though NICE guidance is false advertising.

Gaps between support

> *"Just trying to get through to somebody, say, to change your outpatients appointment, people find it excruciatingly difficult."*

- The gaps *between* services also remained a major issue for many groups – with people describing having experienced "buck passing" between services, and finding themselves carrying a significant burden of bureaucracy and administration to manage their care.

- We heard that too often people fell down the gaps between services with referrals which were lost or never made, and a lack of follow up on tests and screening.

- The significant gulf between health and social care was a significant issue for people with a range of conditions including Parkinson's, Alzheimer's, MS etc.

> *"When things cut across healthcare or health authority boundaries, there is no national health service. That's quite a big problem."*

Under-investment in VCSE services

"There's a lot of heavy lifting being done by a lot of small organisations but we aren't seeing any of the finance and that needs to change."

- Participants recognised that offering holistic care and support centred around the person was a skill – and that often these skill-sets were more deeply rooted outside the health system in VCSE organisations.

- The VCSE sector is well-placed to offer people practical, social and emotional support, but they are not always invited or resourced to bring these services into the NHS offer.

- Initiatives like social prescribing and peer support which are part of the NHS's vision of personalised care and support rely on the presence of a thriving VCSE sector, but the sector is often under-funded and particularly weak in the most deprived communities.

Peer support

"I've got a thousand members in my peer education group and every single one of them has found health relief through talking to me that they couldn't find with their GP."

- Participants with lived experience of long-term conditions spoke about the power of peer support groups both in enabling people to live well and also in empowering people to self-advocate for better care, however investment in peer support is patchy particularly outside the field of mental health and access to groups is often reliant on using social media.

A lack of meaningful choice

"In many cases care doesn't feel personalised. In the current climate, we are made to feel lucky that we are seeing someone at all!"

- A lack of capacity in services meant that people's right to choose was not always meaningful

- For many people the key challenge is the sheer number and complexity of the appointments they need to manage, and the multiple systems and processes used for booking them. In our discussions we heard that people wanted to see this burden reduced, and wanted to be able to make informed decisions about how to prioritise different appointments. Notably none of our participants expressed strong views on choosing which hospital to attend.

- We heard that what would make the most difference to people would be the option to see multiple professionals at the same time – so that care decisions could be balanced and coordinated in real time.

"People are in a really difficult situation, in that they don't have the choices that they should have and they don't know the options that they could have. And it's very different depending on geography."

Poor record keeping and gaps in data

- We heard that failure to gather basic information about people, and to include this in people's records was a major barrier to quality care – for example people were not always asked about their sexuality or gender status, even when it may be relevant.

- Failure to record people's caring status, or when they were supported by a carer was another key gap which meant that too often people did not receive the support they needed around key decisions in their care.

- Failure to record and make available information about people's communication needs was another significant and ongoing challenge.

- While some participants had seen improvements in relation to enabling them to access their own patient records, these were not always complete. For example some apps allowed access to GP notes but not information from consultants or hospital appointments – this made the process of coordinating their own care more challenging.

Poor communication

- We heard that poor communication was still a major barrier to personalised care – this included the failure to provide inclusive communication support including British Sign Language (BSL) and other spoken language interpretation, the refusal to communicate with people's carers (especially when they were caring at a distance), and the failure to provide timely updates on changes to people's treatment and appointments.

Stigma, prejudice and discrimination

"When you have a stigmatised condition or you are from minority group, there is a whole system that tells you that you are less valuable."

- We heard that too many people faced stigma, prejudice and discrimination in accessing health services - with services offered or not offered on the basis of stereotypical assumptions, and people's lack of trust in health systems creating a barrier to access.

- We heard that too often blanket policies were enacted in relation to particular groups, and this meant that for marginalised people personalised care was not available.

"If the NHS is really going to be able to provide services for the diverse populations that it serves, then it needs to be really good training and resources on how to recognise conditions in different parts of the population."

A "binary" service

"A clear theme we hear from patients is wanting the NHS to treat them as a whole person, not body parts, or a condition."

- The NHS continues to struggle to appropriately support people across multiple conditions and identities – for example we heard about failure to adapt support to people's different cultural requirements, or to meet the needs of trans people.

A multi-disciplinary approach

- Similarly, we heard that the NHS is poor at treating people living with multiple conditions, yet as more people live for longer with multiple conditions, more people will end up being supported by a team of clinicians and other professionals, rather than an individual medical professional.

- We heard that the system currently transfers all of the emotional and practical work of coordinating these professionals to the individual and their carers. We heard that what worked for people were approaches that brought multiple professionals together.

- We heard positive reports about multidisciplinary team-working in some areas, but access to this way of working was not consistently available in different areas of the country and across conditions.

Continuity of care

"Patients should be able to choose what their continuity looks like."

- Continuity of care was considered central to the provision of personalised care, as it is only when people are able to build up relationships of trust with a professional that they can ensure that care is tailored to their needs.

- Participants recognised that continuity meant different things to different people and could be delivered in different ways – while some wanted to see the same professional, for others continuity could be dealt with by having access to a single plan and record of care and a consistent point of contact.

Colocation

"My local GP practice is a polyclinic and it's incredible… being able to do so much in the same place is really convenient."

- Participants reported positive experiences of accessing collocated services – including services where health, care and VCSE sector services were available in the same place.

Participation

Many of our participants had experiences of being part of work by the NHS to involve people and communities in the design and delivery of services. However, the imbalance of power in the relationship between people and communities and the health systems in which they are invited to participate means that it is not clear whether this participation makes a meaningful difference.

Limited opportunities

"In many cases, the NHS are not experts and they've actually gotta reach out and listen to the people that are."

- Most people want to feel like active participants in their treatment and care, but too often they are faced with professionals who appear not to want to be questioned, and conversations can feel very one way.

- A number of participants talked about the power dynamics in appointments, about how it still feels like clinicians hold all the power.

For patients who want to practise shared decision making… it's affected by the culture within that hospital about whether that's something the hospital is pressing.

Lack of responsiveness

"We saw the burden of evidence being quite low during the pandemic and how we reacted to things quite quickly based on feedback. And I think that's something that we should try and hold onto."

- We heard that the NHS tends to rely on formal participation processes rather than making itself open to ongoing feedback. Participants told us that they had, in some cases, found the NHS more responsive during the pandemic, but that previous modes were now returning

Targets

- Targets in the NHS are rarely jointly agreed with the people who use services and sometimes feel to be at odds with what people really want.

Failure to involve the VCSE

- The VCSE sector can play a crucial role in connecting people with lived experience to the health system and in advocating with and for people who use health and care services, but the sector is not always given opportunities to participate.

- Where the sector is involved it is more often in service delivery, rather than to support the NHS in connecting with communities.

A lack of feedback

"Too often people with lived experience are asked to participate but not actually listened to meaningfully."

- We heard from people who had taken up opportunities to get involved in developing services and guidelines, but their advice had been ignored, or they weren't informed of the outcome of the projects they were involved in.

- There is a need for greater honesty with people who participate in these exercises – around any pre-existing parameters for discussion, and around why decisions are taken in the face of their advice.

A lack of diverse voices

"We need to build up trust of health institutions within more marginalised communities."

- Even where efforts have been made to ensure that people and communities can influence the health system, not enough is being done to ensure that diverse voices are heard.

- People from marginalised and minoritised communities can find themselves excluded from opportunities to participate.

- Community-based organisations can play a role in bridging the gap between marginalised and minoritised groups and the NHS, but they need resources to do this.

Lack of commitment

"In maternity, the coproduction groups, Maternity Voices Partnerships are often just mouthpieces for the policies of the Trust, not genuine vehicles for bringing about change."

- We heard that too often coproduction efforts are tokenistic, and in some cases coproduction initiatives become "hijacked" by group-think or dominated by professional voices.

Partnerships

The NHS Long-term Plan and the creation of ICSs herald a new era of partnership for the NHS. Participants recognised the intention for people, communities and VCSE organisations to be partners in newly developing systems but saw that there was a long way to go before this could be a reality.

Partnership in practice

"I had peer-to-peer one-to-one and basically it was life changing but unfortunately their funding has just been cut so they're no longer able to offer support."

- Where partnerships work they can make an enormous difference – for example Positively UK provides peer support in collaboration with NHS HIV Clinics. Peer supporters with lived experience are an integral part of the multidisciplinary team.

- Effective partnerships are built on relationships of mutual respect and rely on ensuring that VCSE partners can fully contribute by adequately resourcing them to do so.

Unequal partnerships

- The power sharing and mutual respect, on which true partnerships are built, are not always evident when the NHS seeks partnerships with people, or with the VCSE sector.

- The lack of funding for VCSE organisations is one reason for the imbalance in power in its partnership with the NHS. VCSE organisations are being asked to provide services at significantly lower rates than the same support would cost within the NHS, or being invited to partner with the NHS without being resourced to do so. This is a significant issue because partnership requires significant work and yet few charities can legitimately invest resources in partnership for its own sake (as they are legally required to pursue work in line with their charitable objects first).

- We heard that often partnerships are forged with apparent representatives of patients, such as specialist charities, and not the people with lived experience.

Partnership with community organisations

"We are the trusted voices. There needs to be a better collaborative approach locally, nationally, regionally as well."

- Partnership working will be crucial to providing better health and care services to people from marginalised and minoritised communities, but the organisations working with and for these communities are often very small and lack the resources and scale to engage with NHS structures.

- Some participants reported that their local NHS bodies preferred to partner with large national charities, neglecting local community organisations.

- The lessons learned from the COVID-19 pandemic, that grass-roots charities can often provide more immediate, practical support than larger organisations, does not appear to have been embedded in future engagement with the VCSE sector.

Practical barriers to meaningful partnership

"Understanding how the NHS works is absolutely mind boggling. There's a real lack of transparency as to where decisions are made and who holds responsibility and accountability, both at a national and local level."

- It is difficult for VCSE sector organisations to know where to start in partnering with the NHS – whether to forge relationships with Primary Care Networks (PCNs), with individual NHS providers, with place-based partnerships, or with ICSs – this is a particular challenge as the scale and "footprint" of most charities is not aligned to NHS structures.

- The demands from the NHS on VCSE sector organisations to engage in partnership building activities are currently unsustainable.

- There are concerns among smaller charities operating at national level around how to partner with the NHS – they do not have the capacity to build relationships with 42 ICSs but are increasingly being advised to do so and that seeking progress at national level won't work.

- Current arrangements for partnerships with ICSs are not always adequate - for example many ICSs have one 'VCSE rep' to represent the whole VCSE sector perspective, and these roles can be dominated by those service delivery organisations rather than those focused community engagement.

- We heard that carers and their organisations were often left out of partnership.

Lack of partnership in practice

"We are a free service, and the NHS aren't using us when actually we bridge the gap between the NHS and patients."

- While there is commitment to partnership at strategic level we heard that too often the NHS fails to recognise the potential of partnership to improve their service delivery.

- Some VCSE organisations described being unable to forge partnerships with NHS providers even when they were offering free services which would benefit patients.

- We heard that many NHS services failed to signpost people to relevant help and support available from the VCSE sector, and that it was hard to establish referral routes and pathways across organisational boundaries.

- The failure to partner with VCSE organisations often creates a gulf between NHS and VCSE services.

Lack of commitment to partnership

- We heard that staff and services within the NHS are so stretched that there is little time for many to think about and embrace partnership properly.

Primary and Community Care

"I do think people need to be given the option of whether they would like to have the old style family GP who they see from birth upwards or if they wish to move around freely and are happy to see different people if it suits them."

Primary care services are the doorway to the NHS for the majority of people, yet access to these services is a pressing challenge. Improving access and ensuring more people can be supported outside of hospital will be vital if we are to realise the vision set out in the NHS Long-term plan. However, we heard that for many people this vital gateway to the NHS is inaccessible, or leads them into a system that is labyrinthine and fragmented, rather than joined up and responsive.

"Our GP practice has been incredible and they've treated us as a family with empathy, with respect and we felt listened to and valued."

Access challenges

"When I try to make appointments, I feel like a number or an annoyance - not a real person."

- Access remained the biggest challenge faced in primary care and many reported this had got worse as workforce pressures had increased and new processes had been introduced during the pandemic.

- Lack of access to services for people who worked, cared or otherwise lacked flexibility to attend appointments at short notice was a significant challenge. The commitment to ending the 8am scramble for appointments was therefore welcome, but participants were not clear how this would be realised in practice.

- Some groups continued to face challenges in registering for primary care services, including migrants, refugees and asylum seekers, people who lived nomadically, and homeless people

- The digital divide was a significant issue in primary care with an increasing emphasis on digital tools to access treatment. We heard concerns about digital exclusion caused by lack of skills, equipment or access to WiFi - all of which were exacerbated for people in poverty.

- Phone based access and triage systems were also unhelpful for people who did not speak English fluently and for people who were D/deaf or who had hearing loss.

- The withdrawal of COVID-19 mitigations had left access to primary care more difficult for those who were clinically extremely vulnerable, or at risk of, or had Long Covid.

Failure to use technology appropriately

"We're listened to, while they're [GPs] typing away what they're gonna do for us and what they're gonna prescribe, but they don't actually hear how things are."

- Participants recognised technology could in theory play a role in freeing up primary care professionals' time and spoke of some positive experiences of telephone and video consultations.

- However, in practice technology often acted as a barrier for many – for example creating additional complex triage phases to get appointments, or meaning GPs were too busy looking at screens to focus on their patients.

- We heard that too often technology was offered as a default rather than an alternative or optional benefit – this flew in the face of the offer to personalise care.

Lack of flexibility

"Accessing a GP is still excruciating. You can only see the doctor for 10 mins for one diagnosis and there is no time to talk about the medication prescribed."

- Participants told us that primary care services continued to be inflexible and not tailored to the realities of people's conditions – a key issue was restricted appointment times which meant that GPs often refused to discuss more than one condition, which meant that important interactions between conditions, or clusters of symptoms could be missed.

Poor administration and front of house

"It's the fact that if it's not urgent, it's not important. [We need to think about how people] are treated along the whole journey. If you get these little things wrong, people are going to be upset from the get go."

- We heard significant frustration with the attitude and behaviour of public facing administration staff in primary care, including receptionists and telephone operators who were perceived as acting as gatekeepers, for example demanding personal information without explanation or sensitivity.

- We also heard about failure to recognise and respond to people's communication needs – with people repeatedly sent information in the wrong format or via media they could not use.

Lack of support for people with additional needs

- We heard that primary care services were not always responsive to people who had additional needs around their access. This included:
  - Support for people with neurodiversity
  - People who are D/deaf or who have hearing loss; or people who are blind or have sight-loss
  - People who do not speak English as a first language
  - People with low literacy skills
  - People who are digitally excluded

Continuity of care

"As a carer, our GP has always been our trusted anchor point and that means so much."

- Where people had built up positive relationships with GPs or other primary care professionals, these relationships were described as having a significant positive impact.

- However conversely a lack of continuity of care in primary care was seen as a barrier to receiving personalised and appropriate care.

- Continuity – in the sense of an ongoing relationships with a lead healthcare professional – was seen as a particular priority for people with long-term and ongoing conditions and for groups who have experienced trauma and may take time to build trust.

- However, participants recognised that continuity of care was not critical for every patient and meant different things to different people. The ability to choose engagement methods was seen as most important.

Gaps in understanding of conditions

- People reported significant gaps in GPs' knowledge and understanding of a range of conditions, especially where their conditions were complex, rare or one of many diagnoses. These knowledge gaps resulted in a lack of timely diagnosis and treatment.

- Further training on key conditions would be one solution, but there may also be opportunities to enable more people to access specialists directly, and to partner with VCSE organisations which can offer specialist support. People also spoke about being experts in their own condition but medical professionals not trusting or listening to their knowledge.

- People with some rare or poorly understood conditions reported facing stigma and stereotyping in primary care. People said that they often felt they were not taken seriously as experts in their own condition.

Poor data

- A lack of data and gaps in data collection in primary care mean there are missed opportunities to identify and to intervene proactively to address health inequities.

- We heard that healthcare professionals do not always use SNOMED/read codes to record patient needs and identities.

Problems with referrals

"The sickest person in the room are the ones having to double check that they're [the GP] doing the things that they say they're doing. It's so inefficient."

- Long, and increasing, waits for specialist or diagnosis services were a significant challenge, with people reporting inadequate support and a lack of communication from primary care services while waiting.

- People were often not referred to sources of support outside the NHS – for example charity helplines and peer support group - which could offer support to people waiting or ineligible for NHS support. This meant that people were either left waiting for a diagnosis, or diagnosed and left without support until things worsened – we heard this could be a particular issue for people with dementia, for example.

- We heard multiple reports of referrals not being made or being lost, leading to additional suffering, and damaging breakdowns of trust.

- Individuals and organisations with expertise across a range of conditions argued that there needed to be clearer pathways established between primary and secondary care, and more effective systems for people with multiple conditions – for example routes from one secondary care specialist to the next without requiring people to go back to primary care.

- We heard that people often had to push for referrals from primary care, and this drove inequity of access, with some groups – for example older people and people from marginalised communities such as Gypsy, Roma and Traveller communities – feeling less able to challenge.

"Having clear pathways GPs to follow and then for patients to understand how they access the support that they need when it goes beyond primary care would be really, really powerful."

Lack of join up

- People reported experiencing fragmented services in primary care.

- There were frustrations at the lack of partnership working between primary and community care services – for example across the dividing line between mental and physical health services, as well as across ICS boundaries – and around the lack of links between VCSE organisations and primary and community care services.

Recommendations

Our overarching recommendation to the NHS Assembly as it marks the 75th anniversary of the NHS is that the focus for this next phase must be on **getting the basics right.**

An NHS that is fit for its the future will:

- **Communicate clearly, openly and inclusively**

    o   Clearly communicate its offer to people in ways that work for them, including via trusted intermediaries where appropriate

    o   Ensure people with communication needs have access to the adaptations and support they need whenever and wherever they engage with the NHS

    o   Clearly state people's rights and entitlements, and be honest if these are not being met

- **Build positive relationships with people, by listening openly, and responding honestly**

    o   Listen to people, recognising that they are the experts in their own experiences

    o   Take time to build or win back trust

    o   Give people clear information about what to expect

    o   Be honest about what it doesn't know and can't do, and explain why

- **Work to achieve things that matter to people**

    o   Work towards outcomes defined by people, and measure these outcomes against people's experiences

    o   Focus on innovations that will improve people's experience, rather than innovating for its own sake

- **Share power with the people and organisations that can help it to achieve its goals**

    o   Partner well, and inclusively, from a position of humility about the limitations of its influence on people's wider wellbeing

- **Actively include, taking steps to identify and address inequity**

    o   Collect and share data on what is happening to who and where

    o   Identify inequity

    o   Act to meet the needs of the most excluded first

We make the following recommendations under the 5 "Ps" set out for this consultation:

Recommendations on prevention

- **The NHS cannot deliver effective prevention alone** – partnership with people and communities, and with the VCSE sector and faith organisations will be critical: the NHS should be funding work to build community capacity including groups and activities, peer support and outreach, across a range of communities.

- **Better data is needed to appropriately target preventative activity** – closing gaps in data around marginalised and minoritised communities, such as LGBTQ+ people and Gypsy, Roma and Traveller Communities; and ensuring consistent recording of carer status and access needs will be critical.

- **Technology can play a role in prevention if codesigned** – there must be a commitment to codesigning technology with people who use it and ensuring those who are digitally excluded are not given second-rate treatment or access. Given the growing reliance on technology to access basic services, the NHS should consider whether providing support to access digital technology may be a preventative intervention in itself.

Recommendations on personalisation

- **Personalised care starts with listening** – the NHS workforce needs the right training and skills to recognise people as experts in their own experience, and to involve them in identifying how to respond to their needs. People are more interested in choosing what happens to them and how it happens, than on where it happens and who delivers the service.

- **We must measure outcomes for people** – in its next phase the NHS should be measured against the outcomes it achieves for people, not units of activity or length of time waiting.

- **Personalised care must not stop at organisational boundaries** – the care people need should wrap around them regardless of who provides it. People want to access one health and care system - that might be achieved by giving people a named point of contact across their care, by colocating services, or using digital tools to help people coordinate with a range of professionals through a single interface.

Recommendations on participation

- **The NHS must reframe its understanding of participation** – rather than inviting people to participate in its services, the NHS must recognise that it is seeking to participate in people's lives to support their health and wellbeing.

It can demonstrate this shift by joining the conversations people and communities are already having, including with local authorities and VCSE organisations, rather than always expecting people to come to its tables.

- **Participation must be a core tenet of the NHS** – strengthening the mechanisms for participation is critical. Participation must be a core requirement at every stage and should be reported on regularly. People who get involved in the design and delivery of NHS strategies and services should not only be invited to inform solutions, but also to identify the questions that matter to them. Respect for people's time must be foremost and people must receive honest feedback on what happens as a result of their involvement.

- **The NHS must support marginalised and minoritised communities to participate in the health system** – the NHS must actively invite and practically enable the participation of people from communities whose voices may not otherwise be heard such as through payment for time/travel and considering the timing and location of engagement events. Partnering with community organisations may be an effective way of achieving this.

Recommendations on partnerships

- **Partnership should be the default mode for the future NHS** – it should seek meaningful and deep partnerships with others working to achieve similar goals, and should approach partnership in a spirit of humility recognising the long history of, and deep expertise in partnership working that is held outside the NHS: in local authorities, VCSE organisations and beyond.

- **The mechanisms for partnership need to be simple and transparent** – VCSE organisations need clear information about how they can partner with the NHS at different levels to achieve their goals – recognising that partnership is not an end in itself. They need to be resourced to engage in partnership activity and meaningful efforts should be made to engage smaller charities.

Recommendations on Primary and Community Care

- **Primary care must offer an open door for all** – People need to know how to access primary care services, and need to be able to find support when they need it. Building the workforce must be a priority so that more people can get an appointment when they need it.

- **Digital tools can improve primary care, but there must be alternatives** – Systems must be rigorously evaluated across diverse communities and conditions to ensure that they are improving rather than reducing access, and there must always be alternative, easily accessible provision for those for whom technology does not work.

- **Primary care must be a gateway not a gatekeeper** – Where people need referrals to secondary care, pathways need to be clear and seamless, with the potential for direct referral into multiple services and clarity around how these will be coordinated. People should not have to fight for each referral. Technology could play a role in supporting new systems for improved referral, but so too could VCSE sector organisations and peer support groups. Clear communication around the point of referral and while people wait is critical.

- **Primary care services must adapt to be person-centred** – People need support that is tailored to their needs – ten-minute appointments with a different professional each time may work for some people, but are unlikely to be appropriate for people with multiple conditions or long-term or ongoing health needs. We need to build greater flexibility and responsiveness into the system.

- **Primary care needs to tap into wider expertise** – including people with lived experience and specialist organisations in the VCSE sector.

Appendix: Attendee list

Name	Organisation
Adrian Grant	Norfolk Autism Partnership Board
Alexandra Paterson	
Alice Hilborn	Cancer Research UK
Amy Deptford	Crohn's & Colitis UK
Andy McGowan	Our Time
Ben Jupp	NHS England
Chris Lewis	Your Simpal
Chris Hopson	NHS England
Christiana Ashare	Viewpoint
Fateha Majid	Lived Experience Representative
Felicity Crump	Macular Society
Joanne Taylor	Children's Liver Disease Foundation
Joe Skelton	NHS England
June Green	Caribbean African Health Network
Keval Sachdev	Aikyam UK
Kirit Mistry	South Asian Health Action
Laura Bennett	Carers UK
Leah Boylan	Arthritis Action
Leigh Walmsley	Arthritis Action
Lorraine Stanley	SWAD Dorset
Louise Sellar	The Thyroid Trust
Louise Woodward	Lived Experience Partner, National Voices
Lubna Latif Curtis	Prostate Cancer UK
Lyn Mynott	Thyroid UK
Maya Anaokar	The Patients Association
Michael Natt	Lived Experience Representative
Non Hill	Harry's Hat
Oliver Kianchehr	Our Time
Phil Drinkwater	Cancer Research UK
Kirsty Wright	Pregnancy Sickness Support
Rachel Brown	Viewpoint
Rich Bamos	Lived Experience Representative
Rob Webster	West Yorkshire ICB
Rosie Hollinshead	Friends Families & Travellers
Ruairi OConnor	NHS England
Sally Callow	Stripy Lightbulb CIC
Sam Freeman Carney	Parkinson's UK
Sandra Jayacodi	Lived Experience Partner, National Voices
Shanthi Gunesekera	Birthrights
Silvia Petretti	Positively UK
Simon Pearse	National Association of Deafened People
Tara Riddle	Improve Thyroid Treatment Group
Tracey Maitland	Myaware
Urte Macikene	Healthwatch England
Victoria Wareham	Dystonia UK

National Voices

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

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