



Hertfordshire and
West Essex Integrated
Care System

healthwatch
Hertfordshire

Research Network Development Programme: Towards a more Inclusive Participation in Research across the Hertfordshire and West Essex Integrated Care System

Engaging with Hertfordshire Residents and Hearing their Stories

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About the Research Network Development Programme

The NHS Long Term Plan has an ambition to increase the number of people participating in NHS research to 1 million people registering their interest by 2023/24. In particular, NHS England has recognised a specific need to increase the diversity of people who get involved in research, as without diverse participants, there is a risk that research outcomes will not be as effective across diverse population groups and that research trials will not be designed to meet the needs of a diverse population.

To help achieve this, NHS England set up the Research Network Development Programme (REND) which aims to support Integrated Care Systems (ICS) across the country to work with partner organisations to develop and grow their local research engagement networks and activity.

Hertfordshire and West Essex Integrated Care System

The Hertfordshire and West Essex ICS has been awarded initial funding from NHS England under the REND programme to begin Phase One of this project.

Phase One has involved working towards the shared goal of creating more inclusive participation in research, with the long-term aim of enabling all individuals and communities in Hertfordshire to be offered the opportunity, and to be supported, to be involved in NHS research.

Partners involved in the programme include the Hertfordshire and West Essex Integrated Care Board (ICB), all local NHS Trusts¹, Healthwatch Hertfordshire, Healthwatch Essex, Hertfordshire County Council, Essex County Council, National Institute of Health and Care Research (NIHR), University of Hertfordshire, Community Pharmacy Hertfordshire and the Eastern Academic Health Science Network.

Methodology

To complement the various workstreams encompassing this project, Healthwatch Hertfordshire held one-to-one interviews with Hertfordshire residents, with a particular focus on understanding:

- Attitudes towards NHS research, and the NHS more generally
- Factors preventing, and encouraging, participation in NHS research
- Accessibility and inclusivity within NHS research, and the NHS as a system

The engagement opportunity was promoted through our communication channels and shared with the NHS and other statutory services and the Voluntary, Community, Faith and Social Enterprise (VCFSE) sector across Hertfordshire to share and distribute through their networks, contacts and social media channels.

¹ East and North Hertfordshire Hospitals NHS Trust, Hertfordshire Community NHS Trust, Hertfordshire Partnership University NHS Foundation Trust, Central London Community Healthcare NHS Trust and West Hertfordshire Teaching Hospitals NHS Trust

Learning and Limitations

Although efforts were made to target groups which are typically seldom heard and/or known to be less likely to participate, or to be offered the opportunity to participate in NHS research, uptake by these groups was limited.

Moving into Phase Two of this programme, it is important that significant time is spent to build genuine relationships and trust with these groups, with a particular focus on reaching and hearing from the communities we know are under-represented in local NHS research.

Despite this limitation, the engagement has highlighted a number of factors to consider, particularly in regards to understanding what would encourage someone to take part in NHS research, and what barriers might prevent an individual's ability to participate. The engagement also includes valuable perspectives on the NHS as a system, and how some groups could be excluded from accessing healthcare services and therefore, are inherently omitted from participating in NHS research.

Key Findings



Demographics

In total 20 Hertfordshire residents shared their views on NHS research. Of the 20 respondents, 11 have participated in NHS research and 9 have never taken part, or been offered the opportunity.

The table below provides an overview of the demography of the respondents.

Demography	Category	Number of Respondents
Age	35-44 years old	1
	45-54 years old	1
	55-64 years old	5
	65-74 years old	9
	Over 75 years old	4
Gender	Male	11
	Female	9
Ethnicity	White British	17
	White Other: Eastern European	2
	Asian/Asian British: Pakistani	1
Long-term Condition	I have a long-term condition	12
	I don't have a long-term condition	8
Disability	I have a disability	9
	I don't have a disability	11
Carer	I am a carer for someone	5
	I am not a carer for someone	15
Religion	Church of England	6
	Jewish	3
	Catholic	2
	Muslim	1
	No religion	8
Sexuality	Heterosexual	19
	Homosexual	1
District	Broxbourne	
	Dacorum	1
	East Hertfordshire	5
	Hertsmere	1
	St. Albans	3
	Stevenage	3
	Three Rivers	1
	Watford	3
Welwyn Hatfield	1	

Awareness of NHS Research

Most respondents who have not taken part in NHS research were aware that it takes place and had a good understanding of the types of research the NHS carries out. Interestingly, a few of the respondents who had participated in clinical research, such as testing a new medication, could not be certain as to whether this research was conducted by the NHS alone, in partnership with the NHS, or by an external organisation, indicating the need for greater clarity.

“I’ve done a drugs trial but I don’t know if it was for a private company or the NHS though.”

“I think it was NHS research but I wasn’t explicitly told.”

“There’s always a sort of strange boundary between NHS research, which purely derives within the NHS, and those which have some commercial interest, either through a drug company or through a slightly different research organisation. It’s not clear where the boundaries are.”

Almost all of the respondents who have participated in NHS research were offered the opportunity to take part through their consultant or GP practice. Only a couple found out about the study they took part in through an alternative method. As such, respondents – whether or not they have taken part in NHS research – both questioned how someone would find out about the research opportunities available, and how NHS research is advertised to the general public.

“I’m aware of the research but I’m not so sure about how to take part. I’ve heard occasionally of the odd study where they’ve been asking people in the newspaper but often that’s too late. So I haven’t ever really heard of anything through my GP practice or in my hospital or anything.”

“I don’t think I’ve really noticed research being advertised widely. It’s only when I get a personal contact that I dig into it and find out more about it, but more often than not, it’s through that contact, as opposed to general information. I mean there may well be information leaflets out there but we all lead a busy life, so unless someone points to it, you kind of walk past it.”

Respondents also queried how someone who does not tend to access NHS services, whether this be due to choice or lack of need, would find out and/or be approached about participating in NHS research.

"I'm fascinated by how people get linked into research because I'm not a regular visitor to the GP fortunately, but no one has ever said to me, at any time, "do you fancy doing a bit of research". Or I've never seen a poster in the GP surgery. I don't know how people get into it, I wouldn't know how to access it."

Respondents suggested that at a local and national level, the NHS could do more to help people become aware of and/or access research opportunities, and look to develop ways of hearing from people who do not regularly use NHS services, or groups they do not tend to engage with in particular.

"Do more people need to be involved in research? If so why isn't our NHS doing more to promote it? I'm sure people would take part but don't hear about it, don't know about it, or don't know how to access it!"

"I'd imagine most people involved in research are like me. Someone with a condition who uses the NHS pretty often, so we can be picked up, we get asked to take part. What about everyone else though? Arguably their involvement is needed even more."

One respondent felt it was particularly important that people from ethnically diverse communities were offered the opportunity to participate in NHS research, not only to add value, but to ensure the research is more diverse and captures a range of backgrounds and perspectives.

"I think it's very important we all take part in NHS research. One, from the perspective of a general user of a service, and secondarily, to make sure people of a disadvantaged background, like ethnic minorities, are not left behind."

Similarly, one respondent said it is important that trust is built with ethnically diverse groups, as often, ethnically diverse communities can be very sceptical of research, due to historic misconduct and mistreatment.

"It is really hard to get ethnic minorities involved. I know because I have two daughters-in-law who are Black and I know their initial response would be "oh they are trying it out on us again" and of course a lot of experiments have been done on Black people and a lot of minorities and poor people. They need to be reassured and that the research is here to help, not to use them as guinea pigs."

While another respondent felt the NHS should do more to make younger people aware of NHS research, particularly since they are less likely to regularly access NHS and tend to be under-represented in research.

“Trying to get the perspective of the average 20 or 30 year old who doesn’t have any health problems is difficult, they don’t even think about it, and they probably wouldn’t know about NHS research.”

Encouraging Participation in NHS Research: Key Factors

Information

Regardless of the type of research, all respondents who have not taken part in NHS research emphasised the importance of receiving thorough, detailed information about the study. In particular, respondents felt it would be important to know about the context of the study, previous research undertaken in relation to the study, and how their involvement would be adding value.

“I would hope that before actually doing anything, somebody would talk me through a bit more about that particular project.”

“It would need to be explained to be correctly and clearly. You’d want to know all the ins and outs.”

“I would certainly want to know what was currently happening and why it was felt that needed to change and whoever was carrying out the research, what they expected to get out of it”

Information about the intended outcomes of the study and how it could lead to improvements was also very important to most of the respondents. They emphasised that if the intended benefits of the research are not clearly outlined, then they would feel far less inclined to participate, particularly if there is a significant time commitment expected of them.

“There’s not much point getting involved if there is no information about how it will benefit, or if it is a new medicine or something, how they hope it might benefit. I don’t expect everything to be promised, and I don’t expect miracles, but some indication is needed.”

“I’d want an idea of what difference it will make, especially if I’m being expected to give up my time.”

With the exception of a couple of respondents, the majority who have taken part in NHS research – whether this was clinical or a different type of research – said they were provided with enough

information about the study and their involvement to make an informed decision. They also felt reassured by healthcare professionals and able to raise any concerns or questions before agreeing to participate.

“They were very professional and I felt I was given a lot of information about the project so I could make up my mind whether it was for me or not.”

“I was told all about the study and I still asked a lot of questions which they were happy to answer, but I’m glad I had all that information as then I knew all the ins and outs.”

Personal Story

Katie* took part in NHS research several years ago and although her experience was generally positive, Katie felt that she was not given enough information about the study she was involved in, particularly in regards to the intended value of the research, and its potential outcomes.

“You didn’t get too much information, it would have been nice to know what the benefits were of what I was doing, something a bit more formal than what I was given, and information about outcomes, how they were moving forward.”

Even after the study had ended, Katie did not receive any information about the impact the research has had. Not receiving this information has made Katie feel far less inclined to take part in other research opportunities.

“You know, I gave up some of my time, and I didn’t hear anything else about it. It was an abrupt end. I would have really liked to have receive some follow-up information about the research. I’d think twice about taking part in research again now I’d had that experience.”

The type of research was also a determining factor for most of the respondents. The majority did not have many concerns about sharing information on their care and/or experience, however most did have reservations about participating in research that is more clinical – whether that be testing a new treatment, device or medication.

“It depends on what the nature of the study was. What you would need to know to take part in a clinical trial would be very different from what would stop me from sharing information about my care. So the information I would want would vary according to what the study was about.”

Respondents suggested that if they were asked to take part in this form of research, then they would need even more information about the study, its history, and its intended impact, as well as reassurance from healthcare professionals about how their health, safety and data will be

protected. Respondents said they would also need detailed information about the potential risks and side effects, to help them make an informed decision.

“I wouldn’t feel very confident or comfortable in taking part in anything clinical so I’d need a lot of reassurance. Information about why it’s important, how I’ll be kept safe, any risks and side effects.”

“I would have reservations if I was to take a placebo control for something, I may not take part, because I may be given the placebo.”

“There are some forms of research which I think would be quite straightforward and others I’d be a bit nervous about. Obviously talking about experiences with a health service is all fine, but some of the other stuff I’d want to really know about possible side effects.”

Data Protection

Respondents who have, and those who have not taken part in NHS research, both emphasised the importance of receiving information about data protection, consent and confidentiality, and the need to have this information shared clearly and thoroughly, so they could feel confident and reassured about their participation.

Specifically, respondents wanted it to be clear how their data will be used, who their data will be shared with, how long their data will be stored, and what the NHS intends to do with their personal information.

“Knowing what they’re going to do with the information when they’ve got it, I think that’s the most important thing.”

“How they’re going to protect my data is really important and I’d want to receive thorough information about this so I know exactly what’s going on.”

Respondents who have a clinical background, or have friends or family who have worked in the NHS or a similar field, tended to feel more comfortable about sharing their data and personal information, and felt more assured that their personal information would be handled sensitively.

“I’m not worried about data protection because I know how it works and I’m not worried about clinical input because I understand that as well.”

However, one respondent questioned whether regulations around data protection are always followed, given the data breaches that have occurred within large companies. Although the respondent felt that the NHS is better at protecting people's data, it could do more to improve its processes and procedures.

"Is it always followed to the letter of the law? I would question that. We have these laws in place but if you look at various companies that have been fined hundreds of millions of pounds because they've allowed their data to be abused or misused, as individuals, we have no control over that. I think the NHS goes a long way to protect your records, your data, but are there holes? Clearly – we've seen them. Can it be improved? I'm sure. It's good that it's in place, at least there is some kind of accountability, but that's not to say there aren't holes."

Personal Story

Niall* shared that he would not have any concerns about sharing his data with the NHS, but would feel reluctant to share his personal information if an external organisation was involved in the research study.

"I would have concerns about sharing my data with an outside external organisation. Sometimes the NHS actually subcontracts things out to an independent organisation. I would be wary of giving information completely to an organisation like that because I'm not sure what they'd use it for."

Related to these reservations, Niall has lost some trust in the NHS after feeling forced to share his personal data with an external organisation when accessing a local NHS service. Despite raising his concerns, Niall did not receive a response, which only reinforced his feelings of mistrust.

"I was a patient under a local service which was provided by a separate organisation. To access the program of exercise that I was given I had to tick a box to agree that I would give them all of my personal data. This organisation actually has a parent in America, it's not a British company. I wrote to the Clinical Commissioning Group at the time to indicate I wasn't happy to provide that data. I asked how they monitor this and if they had a commissioning agreement that this data wasn't shared with the parent company but they never came back to me and that's affected my faith in the NHS, especially NHS commissioning."

Positively, all of the respondents who have taken part in NHS research said they were provided with information on data protection, consent and confidentiality, and that this information was

not only given in hard-copy, but explained to them very clearly and thoroughly, with plenty of opportunities to raise any questions or concerns.

“I felt really reassured about how my data was going to be used because they went into so much detail and really made sure we understood.”

“There were no problems with data protection, they were so on top of them and gave so much information but explained it to us all too.”

Adding Value

For all of the respondents who have not taken part in NHS research, a key factor determining whether they would participate, is whether their involvement and contribution would add value and make a tangible difference. Regardless of the type of research, most of the respondents would feel reluctant to take part if they felt their contribution would have no meaningful impact.

“I’d take part if I thought any of my input could help, particularly with my age or any of my health conditions. If I could be of any use, I’d be happy to do that.”

“I would if it was about my own health and would help others. I wouldn’t just do something just to do it, if you know what I mean.”

“I’d take part if I think they’ll be able to use the research and if I thought there would be some tangible results to the NHS, to health.”

“I would take part to try and make things better for everyone. It’s like the COVID jobs, somebody had to try them!”

Similarly, the majority of the respondents who have taken part in NHS research said the primary reason they decided to participate was to add value. For respondents who took part in clinical forms of research, they wanted to support the NHS in better understanding medical conditions, particularly terminal or long-term conditions such as cancer, dementia and diabetes.

For respondents who participated in other types of research, such as sharing their experience, they wanted to help the NHS to improve services and how services can operate better for patients.

More generally, all of the respondents, whether they have participated in NHS research or not, wanted to give back to the NHS and to help others in the community.

"I believe everyone should do research if they have time because even if it doesn't help you, it would help someone else."

"It's positive, at least I feel like I am giving something back. I've taken quite a bit out of the NHS at various times."

"I felt good taking part in the research, it's important we all help to find out about terminal diseases and long-term conditions."

Personal Story

Morgan* is an identical twin and has been participating in NHS research with his twin for around 20 years. Morgan was very positive about the experiences he has had, sharing that the staff have always been professional, kind, and light-hearted, which Morgan recognised is probably not the "norm" within medical research.

"I've really enjoyed doing it. The staff have always been very kind and professional and I've always had a great time going up there. We enjoy it because we just have a bit of a laugh when we go up there and I know medical research is not always like that. The banter was great and the staff were brilliant."

Morgan also said that one of the main reasons he continues to participate is because of the value he and his twin are adding, and the impact the work is having. Morgan has appreciated being kept informed about this, and it has motivated him to continue taking part in future opportunities.

"The work they've done has resulted in significant improvements in some areas. There's something about adding value, not to be too pretentious about it, but there's something about if they can find things out from research and help people around the world or locally, even if it saves a few lives or improves a few lives, it seems to be worth going. It's been really good to be kept informed on this, it's really motivating."

One respondent shared that they were shocked to have been asked to take part in NHS research whilst in premature labour and felt this could have been handled more sensitively, given the severity of the situation. However, because the study focused on learning more about premature labour, the respondent was happy to take part.

"I mean it was a bit of a shock because I went into premature labour but from what I remember it was research into premature labour so I was happy to take part."

In contrast, one respondent wanted to add value by sharing their experience as a carer, but felt their involvement was treated as a tick-box exercise, rather than a genuine interest in understanding their views and experiences.

“I think they included me as a part of an afterthought. I mentioned that to them and they said we’ve got to get carers on board, as if it was a requirement, not something they wanted to do or because I could help.”

Respondents who have taken part in NHS research also emphasised that it is important that healthcare professionals and researchers tell people about the value the research study will have, and how their involvement will be making a meaningful difference, as this is a key factor someone will consider when determining whether they will take part.

“The critical point is that people understand what impact they are having. So if people do research they are reasonably going to say what’s going to happen with the research and what is the evidence that it is going to make a difference. I think that’ll be really important for people.”

Interestingly, one respondent who has worked in the NHS said they found that some staff did not always want to support NHS research. Although staff understood the value and the importance of the research, they did not have the capacity or enough time in their own working hours to be involved.

“We participated an audit and the feeling in the team was that it’s all very well expecting us to do this, but we don’t have time. It always took some time out of their normal working day when they were already busy. So if staff are asked to do research they should be given the time to do it. The staff were very grumpy about it, saying we don’t have time to do this, we are already busy.”

Outcomes and Impact

Linked to the importance of research adding value, respondents who have participated in NHS research also noted that the primary reason they decided to take part was so they could contribute to health research and make a positive impact.

However, almost all of the respondents who have taken part said that they were not informed about the results and/or outcomes of the research they had been involved with. For some of these respondents, not receiving this information has made them question whether they would give up their time to participate in NHS research again.

Given that adding value and having a positive impact was a significant factor for both groups of respondents, it is important that researchers and healthcare professionals ensure there is a robust feedback loop and that participants are kept updated on any outcomes.

“I would have liked to have known any outcomes of the research.”

“I don’t actually get to see the final reports or outcomes. So to me, once I’ve provided that information, it’s gone into a black hole. It would be nice, for me, to actually see how that information is being used and received.”

“I never saw the outcome. They seem to put a lot of effort into gathering information but now I can’t be sure if it was used. You get involved in things but you never see the outcome. I’ve never been told what the outcome was of all that effort.”

“I would like to have known at the end, what it was all about and what the outcome was.”

Personal Story

Gosia* has taken part in NHS research on several occasions, and not once have the results or the outcomes of the research been shared with her.

“My biggest gripe is that I don’t know what happens after my input. I’d love to know how much of what I said was taken on board, what changes have been made. I’m sure they do make changes and improve things, but I don’t know about it and it would be nice to have some kind of report and feedback to say that’s happened.”

Gosia emphasised that it is important for her to find out about the results of the research she has participated in, so she could share the improvements with people in her community, and use this as a way of encouraging them to consider participating in future research opportunities.

“If I knew about the results then I could go round and say well, actually, I did this and it made a difference. More often than not, people are going to say “why am I going to waste my time if you’re not going to do anything with what I say?” People are already a little way so they need to know what impact and change has or will happen.”

Preventing participation in NHS research: Key factors

Employment

Respondents who have not taken part in NHS research identified a number of barriers which could prevent them, and others, from participating in research opportunities. Respondents in employment noted that they would be reluctant to use their annual leave to participate in a research study, and recognised that their company might not be supportive of them taking time off work.

“Work is likely to play a part in preventing me from participating.”

“I wouldn’t use my annual leave to take part in research, no matter how important it was.”

“I work full-time so I don’t know how feasible it would be for me to take part. I wouldn’t want to use my annual leave and I’m not sure whether my company would support me with time off work.”

One respondent said that their son has cystic fibrosis and is often invited to take part in NHS research. However, their son has not, and cannot, participate because they cannot afford to take the time out of work.

“My son has cystic fibrosis and he is invited to lots of trials, but that would mean him having to take time off work and he can’t afford to take this time off work.”

Some respondents who have taken part in NHS research acknowledged that if they had been in employment, they would have wanted compensation if their participation required them to take time off work. Others said they would not have been able to participate, because it would have been too difficult to request the time out of work..

“If I had been working and I’d lost time at work, I’d want to be recompensated for that and I’m sure other people would.”

“Luckily I was retired but had it been while I was working I don’t think I could have committed to it.”

Finance

Some of the respondents who have not taken part in NHS research said that they would feel more inclined to participate if they were to receive compensation – whether this was a voucher incentive, an hourly rate, or a one-off payment. They emphasised that the payment did not need to be significant, but would be a welcome gesture to recognise their contribution.

“The NHS doesn’t want to spending loads of money on funding participation but it is important to recognise the time people have given.”

“I understand they probably can’t give you loads of money like private drug companies but even a thank you voucher is a nice touch.”

Respondents also acknowledged that although expenses tend to be covered, waiting for this payment to be made could exclude some groups from being able to participate. Respondents felt that this could be an “easy fix” when considering ways in which research opportunities could be made more inclusive and accessible.

Personal Story

Stuart* has participated in several research studies, and although he has not faced barriers in participating, he noted that other people might be excluded if they are expected to travel, due to the initial cost of fuel and/or public transport.

“It’s all voluntary, they do pay expenses. We got rail fares and it comes through a month later. If I go to London now on the train during the peak times its 30 quid or something and it takes about a month for the money to come through which is not a problem for me, but for some people, 30 or 40 quid then waiting a month for the money to come through might be an issue for them if their money is tight, it’s not ideal. If someone’s got to fork out money and wait awhile to get it back then that’s an inclusivity issue.”

Stuart also noted that some people might not be able to get the time off work to take part, and felt this could exclude a fairly large proportion of people.

“I guess now with zero hour contracts and less security in some jobs and other things, it does become quite difficult for people in certain jobs to get time off to do something, which is a shame really. We ought to be encouraging as widespread people as possible to get involved, otherwise the only people that come forward are the ones in jobs like I had.”

Some respondents felt that although compensating people for their participation in NHS research would be ideal, this could be problematic for people receiving benefits.

Receiving financial payments would likely impact their benefits, which people cannot afford to lose or have reduced. This automatically excludes groups of people from participating in NHS research, and was recognised by respondents as another area in which healthcare professionals and researchers need to address.

"I suppose paying someone for their time could be difficult for someone on benefits which is a huge shame."

Personal Story

Tara* has cerebral palsy and has volunteered for many different organisations and in various projects over the past few years. Tara feels it is important that people are compensated and recognised for giving up their time to take part in a research study, but shared that financial incentives are often problematic for people receiving benefits.

"Payment is a very difficult thing for people on benefits. It affects people's benefits. They will sometimes recognise someone taking part through vouchers but even that impacts people's disability benefits."

Tara feels this automatically excludes certain groups from participating in NHS research, as they do not want their benefits impacted, but also do not have the time or capacity to take part without some form of compensation.

"It excludes people. There are people that can't afford to take part because they can't afford to lose their benefits. But people shouldn't be expected to give up all this time for nothing, that's not fair either."

Travel and Location

Some respondents noted that for people who do not, or cannot drive, they are reliant on public transport and/or their friends and family for travel arrangements. Dependent on the location of the research study, respondents felt that this could prevent either them, or others, from being able to take part.

"I wouldn't want to travel too far. It would have to be within reason. I have a blue badge and my knee gives me a lot of bother."

"I can't drive because both my leg and balance are affected and I can't rely on my partner because they've got health issues. It means I'd have to travel, I wouldn't be able to do that unless it was on a bus route."

One respondent who took part in NHS research shared that they had to travel from Luton to Mount Vernon every day for 4 weeks. The respondent said that that the location was not ideal for them and that it became expensive for them to participate. Although they were reimbursed

for their travel expenses, the respondent said it left them out of pocket for longer than they would have liked and recognised that this could have been a barrier for others.

“I lived in Luton and had to go to Mount Vernon so it was a bit of a journey. I wasn’t reimbursed for my time but they paid towards my petrol because I had to go five days a week for four weeks, so it was getting really expensive.”

Another respondent who has participated in NHS research said that when they started to look for new opportunities, the majority of studies were not located in or near Hertfordshire, and would be too difficult for them to travel to.

“I tried to do some studies after that but I didn’t get in, and all of the research got further away and far more difficult for me to get to so I stopped looking after that.”

Personal Story

Adam* does not drive so he is reliant on using public transport. Due to this, Adam recognised that this could be a barrier preventing him from participating in NHS research. Adam emphasised that the study would have to be remote, or local to his home, as travelling across the county, or out of the county, is often too difficult and/or too expensive.

“I’ve got no problem going by bus or train or anything like that but I don’t like driving and I won’t drive. So that might be a barrier stopping me, if I had to drive or public transport was difficult, like getting to the other side of the county. I know they’d probably pay my transport costs but it can be a lot of money upfront to then wait for. I’d rather do something local but are there many opportunities local to me?”

More generally, Adam felt that NHS services can be difficult to access, particularly for those who do not or can not drive. Adam emphasised that NHS services in Hertfordshire are spread widely across the county, meaning that those reliant on public transport are often at a disadvantage, and excluded from accessing the local NHS.

“I can’t get blood tests done at my GP practice so I have to go to Barnet and it takes me three buses to get there and three buses to get back. Services in Hertfordshire are scattered all over the place and it makes it so difficult for anyone who can’t drive. And there are a lot of people who can’t drive and it’s often people who already experience more inequality than others. It’s important that the NHS thinks about this and staff leading on NHS research, especially if they want to be more inclusive.”

Time Commitment

Some respondents noted that the time commitment required for some research studies could prevent them from taking part, with a few respondents stating that they would be hesitant to participate in a study which looked to run for over a year, simply because they would not have the time or capacity.

“I’d need to consider how long the study was and how much of my time was needed in a given period.”

“My involvement would depend on how much investment I might need to make in terms of being involved and what my own circumstance was.”

“People probably can’t even give you two hours because they’re busy. It’s about prioritising what is important.”

One respondent shared that the research study they participated in was very time-consuming, with the respondent having to attend monthly check-ups during the first year of the study, followed by check-ups every 6 months, and then annually for the next 10 years. Fortunately the respondent was retired and could attend, but they questioned whether this level of commitment would have been feasible if they were working.

“I had to go initially for monthly check-ups for the first year, then it was six monthly check-ups and then after that it was once a year. It only stopped last year and started in 2012 so that’s 10 years. Fortunately I am retired and back then I was retired so I could do all of this but if I was to be working I don’t think I could have, given all the time commitments.”

Another respondent took part in a research study investigating ovarian cancer screenings, in which their participation was expected to last for 10 years. After 3 years, the respondent decided to stop their involvement due to this commitment becoming too onerous for them, particularly as they were in employment.

“The study was 10 years but you had to go every 6 months for scans and things. I did it for about 3 years and then it was too cumbersome. Suddenly I thought I can’t take another half a day off to go up there. It was hard to tip off half a day here and half a day there.”

Linked to this, most respondents who identified as a carer shared that their caring responsibilities could prevent them from having the time to participate in NHS research, especially if the research required a significant amount of their time.

“My life as a carer is not linear, not one day is the same, so it would be hard for me to commit to some studies, as my partner might need me.”

“My other half is not terribly well and we care for his mother, so there would be consideration as to what effect that would have on the rest of the household.”

Language and Communication

With the exception of two respondents, the majority said they would not have any language or communication needs which could potentially prevent them from participating in NHS research. However, most respondents did recognise that this could be a significant barrier, and would need the support of the NHS to accommodate and address.

“English is my first language so I would be fine but I would expect the NHS could provide interpreters and things like that so someone could take part?”

“I can read, write, all of that. If the NHS wants research to be inclusive though it would need to adapt to meet any needs.”

One respondent has been assessed as becoming deaf, and recognised that this could be a barrier to any future participation in NHS research, but hoped that this would be addressed to enable inclusivity and accessibility.

“I’ve been assessed as becoming deaf, I’m not profoundly deaf, but I suppose this could limit what I could participate in. I would hope that some adaptations or adjustments could be considered though.”

Another respondent said that when they had a stroke, they were then diagnosed with aphasia, meaning they sometimes struggle to understand words. Again, although they recognised this could be a barrier to participation, they hoped reasonable adjustments could be made.

“When I had a stroke I was left with aphasia where I can’t sometimes understand the words. I would hope staff would adapt the study or whatever it is for me so I could take part but maybe it’s not that easy.”

Personal Story

*Lucy has taken part in NHS research investigating dementia, some of which has involved MRI scans, and completing online questionnaires. Overall, Lucy has had a positive experience when participating in the research studies, but felt that people with language and/or communication needs would be excluded from taking part in the online studies, due to the type of questions asked.

“For example, the online questionnaires, English would have to be your base language, because some of the questions are subtle, and some of the cognitive tests are also subtle, using double negatives etc within a question, in order to check that you’re understanding.”

Lucy also felt that those who do not have access to, or do not feel confident using online technology would be, or feel, excluded from taking part.

“I did the studies at home, so if you don’t have a computer or you don’t know how to use a computer you wouldn’t be able to take part would you? It would be impossible and that means some people can’t take part even if they’d want to.”

Medical History

Respondents who have a long-term condition and/or disability tended to have more reservations about taking part in NHS research, particularly if this would involve testing a new device, treatment or medication, in case it affected their existing medical condition(s). Respondents noted that they would need information about potential side effects and the implications participating could have on their health, so they could make an informed decision as to whether the intended benefits of the research outweigh any potential risks.

“I have a few health problems so I’d really need to consider if I feel up to it.”

“I’ve had six surgeries, I’ve got allergy asthma, I’ve got arthritis in my jaw, and that’s just naming a few things. All of those conditions could stop me from being able to take part and it would depend on how I’m feeling too.”

“I take a lot of medication and have quite a lot of autoimmune diseases so maybe I’ve a good candidate for research! But it could have side effects or impact the medicine I’ve already on so I’d have to really think about it, and whether any risks are worth taking.”

Personal Story

Felicity* shared that she would have no reservations about participating in NHS research which involved sharing information, but would have concerns about taking part in clinical forms of research. Due to her previous and existing medical history, Felicity would be not actively seek to participate in this type of research, and if offered the opportunity, she would need a lot of reassurance about the potential risks, side effects and implications on their own health.

“Questionnaires are not a problem, I’m quite willing to complete a questionnaire, but if it was something clinical I’d need a lot more information first. I’ve had a minor stroke, I’ve had vasculitis, I’ve had septicaemia. I’d want to know about any sort of side effects or will it harm any medication that I’m on, all of those type of things. I wouldn’t seek out that type of research but if I was approached then maybe I’d consider it.”

On a practical level, Felicity also questioned whether she would have the physical and mental capability to participate in clinical forms of research, and would be concerned that participating could prove too demanding on her health.

“I’m quite healthy for my age but I don’t want to tip myself over the brink! Even if there was the slightest risk I’d be very cautious... I’ve been through enough I think.”

Attitudes towards the NHS

As part of this engagement, respondents were asked about their general feelings towards the NHS as a system, and whether their views on the NHS also affected their attitudes towards NHS research.

Systemic Barriers

It is important to note that the majority of respondents were very positive about the NHS, emphasising that it is a “wonderful” and “excellent” organisation which they were very grateful for.

“It’s first class, it has helped me and my family for so many years.”

“It’s wonderful, aren’t we lucky to have the NHS?”

However, some respondents felt that the NHS has become less accessible to the public, largely because the service is too overstretched and underfunded, and as such, is unable to always

meet the demands of its patients in a timely, efficient manner, is not able to prioritise inclusivity and accessibility, even though this should be paramount.

“It is only a shell of what was the aim of the service. People didn’t look at you and think of you as a burden, it was more if you need help, we’re here to help you. That’s not the case anymore. It’s become more a business.”

“The whole concept of the NHS is wonderful but whether that’s quite where it is now, I’m not sure. There are comments that the brand name is still there but the cradle to grave and free at the point of need, those aspirations, I’m not sure are still around.”

“I think because of the stretch the NHS is under at the moment it is less accessible and less inclusive because that can’t be the highest priority.”

“It has become more and more overstretched and I feel it’s lost direction along the way.”

Similarly, some respondents said that the NHS has become too fragmented, and in turn has become too complicated for people to navigate, which has impacted the quality of care and the level of access for patients.

“It’s become very large as it provides all sorts of services, it often feels fragmented and people in the system find the structures quite complicated sometimes. So for the general public, it is often very difficult to get an understanding of primary care, acute care, what hospitals do.”

“I find using the NHS very difficult in terms of accessing the treatment they provide, it just seems to be a challenge.”

Respondents noted that due to either their background and/or interest in healthcare, navigating the NHS is often not a problem for them, but recognised that for the average person, it is often very difficult to understand and access.

“Because of the roles and positions that I hold, I actually find it quite easy to open doors. That is not the case with everybody. A lot of people will not have the same access that I do. One, they may not even know who to access, and two, even if they did, they may not get the access. More often than not, they may be fobbed off.”

"I can navigate my way round the NHS quite well but I know from other people, family members and friends, that they find it very frustrating and inaccessible!"

"People like me know a bit about how things work and have experience using the NHS and navigating around it, so for us it's more accessible. I think for people that can't get access or don't have that broader understanding of how it fits together, it's harder."

Linked to this, respondents felt that if the NHS was easier to access and navigate, it would encourage more people to use the service, and would increase the public's trust and confidence in the NHS – seeing it as somewhere they can get help, rather somewhere they will burden.

"There's going to be hesitation to seek help, but that could be better if access was a bit easier."

"It's much harder to access services so people don't, and people lose trust."

Negative Experiences

Some respondents shared that their own negative experience of using the NHS has impacted their level of trust in the NHS and has made them question whether they would feel comfortable using the service.

"I've noticed a few mistakes by my GP practice and when I've raised it, I've had quite a lot of resistance and aggression from them. Definitely affects your trust a bit."

"I want to use the NHS but I myself have experienced problems, so I decided to go private. I now have some reservations about using the NHS too."

"Even in my own case, I was called into hospital, I had to have an operation to remove a small lump. I was told it was benign and then within 7 days I was called back in to say sorry, we got that wrong, it wasn't benign, it was stage 3 cancer. There's too many mistakes made. The NHS isn't consistently good."

One respondent shared how one person's negative experience with the NHS can influence the views and perceptions of others, and make them feel reluctant to access the service, in case they receive the same, or worse care.

"Someone's personal experience of something is very quickly distributed, dissipated among the community when it's negative. So more often than not, you don't hear anything when it's positive because that's the service you expect to receive. But when it's negative, it goes viral very quickly."

Personal Story

Mike* shared that he has had several poor experiences when using the NHS and on multiple occasions, he has been misdiagnosed and/or had his health concerns dismissed by healthcare professionals.

"I fell over and got taken to hospital and it was misdiagnosed and I've been suffering ever since. Everyone denied that I'd injured myself and I had to go to the Parliamentary Ombudsman and since then I've been suffering with my mobility. On top of that I came down with a nasty cough, it took a year before they diagnosed me and I still have trouble breathing. I've been having terrible headaches since 2020 but they won't do any tests."

As a result of these negative experiences, Mike has lost trust in the NHS and would only access the service if his concerns were life-threatening.

"I've got no faith in the NHS whatsoever. You only go to your GP if you're desperate. I have no faith in my GP surgery. I've had so many bad experiences using the NHS in the past few years."

In light of these systemic barriers, one respondent felt that the NHS should focus less on research, and more on how it can improve the service more generally.

"There's research being done into cancer treatment, dementia, all of these and I applaud all that, but there does come a point where we need to look at generally how the NHS can be put together better, it feels disjointed and that's sad."

Inclusivity and Accessibility

The majority of respondents felt that the NHS is inclusive and accessible to the public, but did recognise that their experience might not be reflective of other people, particularly those that are typically under-represented.

"If you're say, a white male, you'll be ok. But we need to think about those groups that might find it more difficult, say to communicate or access the NHS."

Some respondents felt that the onus to share information about communication needs, access requirements and cultural preferences seems to be on the patient, when in fact they felt it should be the responsibility of clinicians to find out whether someone needs to be supported in a particular way.

"Healthcare professionals need to ask, prompt patients, otherwise they won't find this out and that's not the patients fault, care needs to be personalised."

Digital Exclusion

Some respondents said that although they do not have problems accessing technology, there are a large number of people who do not have access to technology, or do not feel competent using it. Respondents acknowledged that in recent years, particularly since the COVID-19 pandemic, the NHS has become more reliant on digitalisation, which is excluding certain groups from being able to access the NHS.

"I get that technology is moving forward but there isn't that level of understanding and this is about people's health, we need to make sure as a duty of care that there is inclusion for everybody."

"Not everybody is computer literate, not everybody can use it. That side of things needs to improve I think."

"Using technology is no issue for me, but if you were to ask that of someone else, they may not be included or would not feel that they are included. An example is that GP practices have changed completely. If you are not digitally enabled, you can't do anything."

One respondent shared that their GP practice recently conducted a survey with its patients and found that over a quarter of its patients do not have a mobile or computer.

"Our GP practice did a survey and about 30% of patients haven't got a mobile phone or computer so they can't do the things they are expected to do. It's very sad but a good example of how some people are not being treated as fairly as others."

Another respondent said that their step-son has autism and struggles to use technology, and emphasised the importance of the NHS recognising that it is not only the older generation who can be digitally excluded.

Physical Access

Some respondents felt that because the NHS has become more fragmented, services can be difficult to physically access. Respondents noted that in some cases, people will have to travel across the county for an appointment which can be challenging, particularly for those who are reliant on public transport and/or their friends and family for travel arrangements. Respondents also felt this could be problematic for people with work and/or caring responsibilities, and that the NHS needs to do more to address and recognise these factors.

“Some people don’t even drive and it becomes much more difficult for them, and they are reliant on family or community members to help them.”

“I have an autistic step-son and his memory is incredible but if you ask him to add up to 20, he can’t and he can’t use any technology. It’s not just old age, some people are just not of that world.”

“There are a lot of people, especially those in later life, who don’t have access to transport. They are very isolated and they are pushed aside and forgotten about. But we have a duty of care to include all people.”

“You used to get the service you needed, it was close to where you needed it, you didn’t have to travel miles and miles.”

Language and Communication

Although the majority of respondents did not have any language or communication needs, they felt that the NHS could do more to accommodate for this, rather than expecting people to rely on friends and family members, when this might be inappropriate and/or jeopardise their privacy.

“One time they said “the doctor will speak to you on the phone” but if I didn’t have the language skills, and the doctor wasn’t able to examine me, how do I explain what I’m suffering?”

“People with language needs are very dependent if they’ve got an advisor or a member of the family. It’s not fair for them to rely on that.”

Aadi's* story below addresses a number of these raised in this engagement and is a clear indication of how the NHS needs to be more inclusive and accessible.

Personal Story

Aadi* feels the NHS has become less accessible and less inclusive, with decision-makers within the NHS often adopting a homogenised approach, rather than addressing individual needs, preferences and cultures.

"It's become more of a business and the people making the decisions may not always be aware of the needs of the people they serve. They're basing it on the majority and that's where the disadvantage and discrimination starts to creep in. From a patient's perspective, people of say, South Asian heritage, will have different needs to people of Eastern European heritage, yet they're all lumped together with the BAME label. To say the BAME community needs this, that's completely wrong because the needs of people are completely different."

Aadi went on to give an example of how the NHS often fails to accommodate and religious and/or cultural dietary requirements, noting that this is a clear example of lack of inclusion.

"There would be a lot of people from a Muslim background who would want to use Halal, kosher, right? I have experienced it and more often than not family members will take their own food in, now that should not be necessary. Let's make sure that people are given the food they need, that their dietary requirements are met."

Aadi also shared how language and communication needs are not always respected or accommodated for by the NHS, and how this is a significant barrier preventing people from accessing services, as well as another example of unequal treatment.

"I don't have a problem with language, but there is an older generation who may not be at the same level, they have deficiencies in language, maybe even in education generally because of the background they come from. I went with my partner recently for a hospital appointment and when I got there they said we've got an interpreter here for your partner, and I wasn't expecting that. More often than not, someone who does have language deficiencies will take along a family member anyway because they're not expecting to have that kind of service. That should be provided by the NHS but you don't always get it."

"My parents are quite elderly, my father's English is a lot better than my mother's, but would we allow them to go by themselves? No. Because more often than not there is more confusion and misunderstanding. By one of my siblings going with them, we make sure they are receiving the services they need, they're able to explain the problem."

Although Aadi felt some improvements have been made, he questioned whether this was genuine or tokenistic.

"I think it has improved but sometimes they think it is being forced from the top, so it becomes more a tick box than actually empathetic."

Conclusion

Our engagement has found that the majority of respondents are aware NHS research takes place and have a good understanding of the types of research this can involve. Most respondents would take part in NHS research, as long as they were given clear and thorough information about the study, information about any potential risks, and information about data protection, consent and confidentiality. This was particularly important to respondents if the research opportunity was clinical, rather than simply sharing their experience.

Adding value was also significant to respondents, as well as receiving information about the impact and/or outcomes of the research – which did not happen for most respondents who had previously participated in NHS research.

Although most respondents would not, or did not, face any barriers to participation, they recognised that there are various factors which could prevent someone from taking part in NHS research. Key factors included: employment, financial implications, language and communication, physical access and time commitments.

The engagement also asked respondents about their general feelings towards the NHS, in which many respondents were very positive. However, they also felt that there are significant systemic challenges which are affecting people's access to the NHS, and their trust and confidence in the NHS.

Questions about the inclusivity and accessibility of the NHS were also asked. Again, most respondents acknowledged that the NHS is accessible and inclusive for them, but might not be for other groups and communities. In particular, respondents felt the NHS needs to do more to address digital exclusion, physical access barriers, language and communication needs, and cultural preferences, to ensure that everyone receives fair and equal treatment.

Healthwatch Hertfordshire hopes this initial engagement provides the Hertfordshire and West Essex ICS with an outline of the factors which might encourage participation in NHS research, and the factors which could prevent it, as well as important reflections on access to healthcare and the accessibility and inclusivity of the NHS.

Moving into Phase Two, we would suggest building on this engagement by working directly with local groups and communities to understand more about their specific attitudes towards the NHS, and NHS research, to continue this work on ensuring more inclusive research participation.