



**Hertfordshire & West Essex  
Research and Engagement  
Network Programme:  
Engaging Diverse  
Communities in Research**

## Background

The NHS Long Term Plan has an ambition to increase the number of people participating in research. In particular, NHS England 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 demographic groups and that research trials will not be designed to meet the needs of the population.

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

The Hertfordshire and West Essex ICS was awarded initial funding from NHS England for Phase One of this project. Phase One 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 research.

Given the success of Phase One, Hertfordshire and West Essex ICS was awarded further funding to complete Phase Two. Phase Two looked to build on this by continuing to focus on increasing opportunities and access to take part in research for communities, whilst also ensuring the sustainability of these approaches.

## Methodology

In Phase One, Healthwatch Hertfordshire held a series of one-to-one interviews with Hertfordshire residents to understand their attitudes towards research, factors preventing them from participating in research, and how research can be made more inclusive. Although our engagement in Phase One highlighted important themes and findings, we received limited uptake by typically seldom heard groups who are less likely to participate in research.

To address this gap, our engagement in Phase Two looked to engage specifically with groups who are less likely to participate in research. The cohorts we engaged with included:

- **Adults with a lived experience of mental health and/or addiction:** Working in partnership with Viewpoint we ran two focus groups<sup>1</sup>. A graphic illustrator captured both focus groups, the drawings of which are shared in this report.
- **Adults with a learning disability:** Working in partnership with Herts People First we ran one focus group and a series of one-to-one interviews<sup>2</sup>.

---

<sup>1</sup> Viewpoint is a charity that supports people who have a background in mental health as well as addiction challenges: [Viewpoint \(hertsviewpoint.co.uk\)](https://www.viewpoint.org.uk/)

<sup>2</sup> Herts People First is a user-led, rights based self-advocacy organisation run by and for adults with a learning disability.

- **Children and young people:** Working in partnership with the University of Hertfordshire's Young People's Advisory Group we ran one focus group<sup>3</sup>.

The following aims were explored with all cohorts:

- Understanding people's views and perceptions of research
- Exploring factors which may prevent and/or encourage research participation
- Identifying how research opportunities can be more effectively promoted
- Exploring interest in schemes including: Be Part of Research, Research Champions and community-led research

## Summary of Engagement

Across the cohorts we engaged with **61** participants who had varying perspectives. For adults with a lived experience of mental health and/or addiction, the recurring theme was **mistrust**. This mistrust was underpinned by concerns around confidentiality and privacy, previous experiences of discrimination and segregation, and challenges around feeling represented and included.

In contrast, for adults with learning disabilities, the underlying theme was **accessibility**. They shared that researchers need to offer more accessible information, choice, flexibility and reasonable adjustments to enable people with learning disabilities and other communities to participate in research.

Children and young people emphasised that researchers need to make information about research opportunities, and research itself, more **creative and engaging** should they want to increase research participation amongst children and young people.

Given that each cohort has their own views and perspectives, this report has been divided into three sections to ensure the themes are discussed in-depth.

---

<sup>3</sup> Herts YPAG is a group of children and young people aged 10-17 who meet to learn about research and work with researchers to plan and do research about children and young people: [Hertfordshire YPAG | Generation R](#)

# Engagement with People with a Lived Experience of Mental Health and/or Addiction

*In partnership with Viewpoint we engaged with 38 adults with a lived experience of mental health and/or addiction through two focus groups. This cohort was particularly vocal about their mistrust in research which was often underpinned by concerns about confidentiality, challenges with representation and inclusion, and fears about discrimination and segregation.*

*For this cohort, improving inclusivity and diversity in research participation requires researchers to actively build trust and rapport with communities and improve their cultural competency.*

## Understanding of Research

Across both focus groups, participants had a very good understanding of research, and an in-depth knowledge of the research process. Definitions of research centred around expanding knowledge, obtaining answers and impact, conducting systematic investigations, and collecting and analysing data. They were also aware that a range of organisations undertake research, with common examples including government agencies, the NHS, universities and charities.

*“Research is the creation of new knowledge and using existing knowledge...this involves meeting people and doing a lot of systematic investigation.”*

*“Research is a process of exploration and discovery undertaken to answer questions, solve problems or advance understanding within a specific area of interest.”*

*“Research is a systematic and rigorous process of gathering, analysing and interpreting information in order to increase our understanding of a particular issue or topic.”*

For most participants, a core purpose of research is to make recommendations and improve outcomes.

*“Trying to find solutions to certain problems that could help people.”*

*“I think in any kind of research there has to be an outcome from it, you know.”*

Most participants would be interested in taking part in research, particularly if it is an area of interest or something they feel they could add value to.

*"It's got to be something quite powerful that's going to pull me in to do something – it's got to be for a great cause, then yeah I'd definitely do it."*

*"I think any kind of research has to be something that you have a genuine interest in."*

*"If it's something that I know will impact people living in certain societies, people of different ethnicities or sexual orientation that I may belong, yeah, I would love to participate."*

A large number of participants said they had taken part in research before. Topics were often of personal interest or related to their lived experience. Most participants had a positive experience when they participated in research, and emphasised that they felt they were adding value and making a difference.

*"I did enjoy taking part in the studies. I feel like it's something positive to be involved in. I have a high sense of pride for contributing to my society and I enjoy learning from other people's experiences."*

*"In research for the NHS, I was the one who initiated the conversation. They talked about research when I took my wife for antenatal treatment and I saw a signpost about it and I said I had the experience they wanted in their research, the topic was about managing childbirth for people from ethnic minority groups."*

*"I've participated in research within the NHS and engaged in Patient and Public Involvement and Engagement (PPIE) activities beyond the NHS. My focus has been on mental health, disability and helped in understanding how ethnic minorities perceive and access services."*

## **Promoting Research Opportunities**

Most participants were very keen to take part in research, but often did not know what opportunities were available - highlighting the need for improved promotion, advertisement and awareness of research opportunities.

*"I think for me, I would like to take part but I've never really been told about it or seen any advertisement. I've just never really known about what's out there."*

*"I would like to see opportunities for research publicised more widely, it is hard to find out about what is available."*

## **Range of Communication Methods**

The most common suggestion was the importance of using a range of communication methods to advertise research opportunities. By using forms of printed media and social

media platforms, participants emphasised that information about research opportunities would reach a wider and more diverse audience.

*"Many valuable research opportunities go unnoticed due to inadequate promotion. Enhancing the visibility of research opportunities through various channels can help reach a broader audience."*

*"research opportunities could be better advertised through targeted outreach strategies, utilising diverse communication channels."*

*"Advertisements should be done on social media and printed media as well, that will go a long way."*

In terms of social media, a few participants suggested that organisations could use advertisements on social media platforms to increase awareness of research opportunities. In contrast, participants said printed media such as leaflets and pamphlets need to be circulated in a range of community settings to reach a range of people and different communities.

*"I don't know about the budget for the NHS but you know, it'd be good if they could circulate ads on social media platforms, raising awareness in a campaign over several months."*

*"Pamphlets or leaflets could be circulated in different hospitals as well as other organisations. It needs to reach people of different communities and people that live in rural communities so they have an opportunity to share their experiences."*

*"Printing more flyers and posting them to schools, companies and churches etc."*

### **Community Outreach**

Participants suggested that undertaking community outreach, particularly with communities who are less likely to engage in research, is important for increasing participation and awareness. By researchers speaking directly with communities and adopting a more personalised approach, some participants felt this may build trust and encourage people to consider taking part in research.

*"Better recruitment strategy is essential. Being more personalised, having a more centred approach, advertising in channels where you might struggle to reach people like community centres or faith centres."*

*"Researchers coming to communities – that could work."*

*"People doing research should invite people along to find out more and how to take part."*

## **Collaboration**

A number of participants suggested that researchers should work in collaboration with other partners and organisations across the system and work collectively to encourage greater research participation, particularly from groups and communities who are less likely to take part.

*“Collaborative efforts between institutions, utilising centralised platforms for posting opportunities and ensuring clear, concise information about eligibility and benefits can enhance the visibility and accessibility of research opportunities.”*

*“Engage with local communities and stakeholders to raise awareness about research opportunities and encourage participation.”*

## **Use of Mailing Lists and Patient Lists**

In relation to NHS research, participants said that the NHS could be more proactive in using its mailing lists and patient lists to share research opportunities. This method would be particularly if wanting to target particular cohorts.

*“There could be a mailing list where you go to your local NHS and periodic emails are sent out with information about upcoming or ongoing research opportunities.”*

*“My GP practice recently sent me a text about training they’re holding, maybe they could send messages letting us know about research going on.”*

*“Maybe like twice in a month do like an ad campaign to try and target local NHS users around here.”*

## **Barriers to Research Participation**

When asked about three barriers that may prevent themselves, and others, from taking part in research, participants discussed a range of factors at length. It is important to highlight that **mistrust** is a sentiment that runs in the majority of the themes listed below.

### **Privacy and Confidentiality**

One of the main barriers preventing participants from taking part in research was concerns about privacy and confidentiality. Participants were apprehensive about how their data would be safely stored and used and how their identity would remain anonymous and their privacy protected.

*“I’m really concerned about the safety of the information I’m going to provide any researcher with.”*

*"Another big thing is consent. Some of their information may likely be leaked and people can likely use it without their proper approval so they feel discouraged about joining in."*

*"We want to be in control of the information and where it's going because it's so personal."*

Some participants felt the collecting of personal information and data in some research studies was intrusive and they questioned whether it was necessary.

*"I feel a whole lot of criteria for participants is quite personal, and I don't feel like sharing a whole lot of personal information with someone."*

*"The whole requirement to participate can become so personal. I'm beginning to ask myself 'Is it really going to be de-identified research? Are people's opinions anonymous?'"*

In particular, a few participants commented that due to their lived experience of mental health, reassurance about data protection and confidentiality is even more crucial to them.

*"I need to know if it's a trusted source or not, especially coming from a mental health and vulnerable position. Who am I sharing my details with? Where is it going?"*

*"The people that have suffered from mental health, it's always the fear that you take part in something and your information is going to be taken away and used against you. That's the history we have."*

Unsurprisingly then, many participants said it is important that researchers do more to address concerns around privacy and confidentiality and clearly explain how their information will be used and protected.

*"I think privacy and protection could help people participate in research. If I wanted to participate in research, I want to know what measures are being taken to protect my data and make sure my information is stored safely."*

*"Proactively address ethical concerns. Clearly explain data privacy procedures, informed consent protocols, and participant rights in all communication materials."*

### **Communication Barriers**

Communication barriers were another significant concern for most, with participants sharing that information about research opportunities, and when research is conducted, tends to only be delivered in English which fundamentally excludes other groups from being able to participate.



Some participants also shared that researchers can use complex terminology and jargon which may deter people from participating, or not have the literacy or communication skills to be able to effectively to take part.

*"You need to consider the language being used. You know, we do have language barriers, some people may not be good at English, some people cannot really understand what you may be writing. Language barriers are one of the biggest problems we face, and it could prevent people that you really need in research."*

*"Language barriers are still being overlooked. Improving this could help cut across different languages and still go a long way."*

*"Another barrier could be language, communication, literacy and your understanding of some complex medical things."*

### **Challenges with Representation and Inclusion**

Many participants had concerns relating to ethnicity and culture and shared that researchers do not have an adequate understanding of ethnic, cultural and religious beliefs and felt that research opportunities are often not welcoming to ethnically diverse communities – all of which creates a reluctance and hesitancy to take part in research.

*"I think the hindrances could be cultural, because different cultures have different beliefs and going into a culture and imposing your beliefs is definitely one of the biggest hindrances. "*

*"Some individuals feel stigmatised based on their identity, fear of discrimination, fear of negative repercussion. I think that might also prevent people's participation."*

*"At some point people don't feel very included in research and the problem with that is how can you include marginalised groups or people from ethnic minorities?"*

A number of participants said that ethnically diverse groups may feel reluctant to take part in research in case due to researchers lacking cultural competency, concerns about unconscious bias and not being treated equally.

*"Black people, Asians, Latinos in the UK sometimes feel that joining research is not really a thing because of their ethnicity and being looked at differently. Clinical trials for diabetes or hypertension as an example. It prevents people from participating in this research or clinical trial because they feel when they come out they will be segregated or looked at in a certain way."*

*"We are involved in research but the discrimination and lack of representation is still high."*

A few participants shared their experiences of receiving negative judgement from their community and peers for participating in research, again highlighting the sentiment that ethnically diverse communities may not be trusting of research.

*I think some people think 'Why are you doing that? Why are you speaking out?' especially the older generation when it comes to mental health."*

*"Coming from an Indian background I'm actually taking a risk by sharing some intimate and personal details."*

One participant discussed how religious factors can also be a barrier to research participation.

*"I've got a few Muslim friends and they know people that have tried to end their lives and they can't tell anyone because it says in the Quran it's a sin to attempt to end your life. So even working with some Muslim ladies and you ask 'Have you had any thoughts of suicide' and they're like 'no, no, no' and you can see that they can't share it – they want to, but they can't."*

### **Previous Poor Experiences**

As mentioned, many participants felt discouraged and sceptical about taking part because of their cultural and/or ethnic background. However, participants were also often reluctant to take part in research due to having previous experiences of discrimination in professional environments, and were fearful that they would encounter similar experiences when participating in research.

*"I think if they had negative feedback or negative experiences and fear of being or feeling exploited, disrespected, harmed or treated or neglected in some way, I think that's also going to harm and cause them to see research as a bad thing and also spread bad news about research to others."*

*"When you've been traumatised by professional people, it does have a cause and effect I'm afraid."*

*"From what I've heard from others, professional people put fear in people, making threats. So when you've got people who've had that kind of experience, that can be a massive barrier to take part in research."*

Linked to this, some participants were hesitant about taking part in research since outcomes and improvements have not seemed to improve, especially for seldom heard communities, despite many studies undertaken. Participants questioned the value of

research and whether their participation would really make a tangible or positive difference.

*"What is the outcome or breakthrough? What are the achievements of research? We've heard for many years that the NHS is conducting research but what does that mean? They need to solve problems of concern for minority groups, why has it not improved?"*

*"What is the overall gain of taking part for the participants?"*

*"Uncertainty about the research outcomes may discourage me."*

## **Practical Barriers to Research Participation**

Participants listed a range of practical barriers which may prevent them and/or others from taking part in research.

### **Time Constraints**

Due to factors such as work and caring responsibilities, a number of participants said they do not have enough time to take part in research. Studies can also require years of participation which some participants are not willing or able to commit to.

*"For the majority of people, time constraints is a big problem because the majority of people work full-time and then for them to join research is really a very big problem because of their work schedule and daily activities."*

*"Participation requires a significant time commitment, you know it might actually conflict with people's individual obligations and their priorities."*

*"Time constraints – research could be more concise and the timeframe could be reduced...if the time constraint could be reduced, I think it could interest more people to participate."*

*"Research takes a lot of time...so I think the time constraint is something people look out for in the research because they don't want to spend time that they don't have."*

### **Financial Constraints**

Some participants were concerned about the costs involved in research participation, such as the need to travel and taking time off work.

*"Funding is one of the key things that stops a lot of people."*

*"I would like to be part of research but funding and resources could draw me back."*

*"Affordability and getting to places is a concern for many."*

## **Encouraging Research Participation**

When asked how researchers could encourage more people to be part of research, participants gave a range of important suggestions.

### **Clear Communication**

Given the concerns about privacy and confidentiality, participants said it is important that researchers provide clear information detailing the purpose of the study, its benefits, any potential risks, and how their personal information will be handled. Participants also suggested that researchers should be available and proactive in answering any queries or concerns in a personal manner, rather than signposting elsewhere.

*"I would like to see clear communication about the purpose and benefits of the study, transparent information about the risks involved, easy access to support and assistance throughout the process."*

*"The NHS can offer support to individuals who are interested in participating in research by providing assistance and answering any questions they may have. This can help alleviate concerns and barriers that may prevent individuals from taking part."*

*"NHS should ensure transparent communication about the research process, potential risks and benefits. Using plain language in informed consent forms to enhance understanding amongst participants would also help."*

### **Building Trust and Improving Cultural Competency**

Participants emphasised that researchers do not seem to account for different cultures, ethnicities and religions and suggested the need for researchers to educate themselves on cultural competency and be more proactive in engaging with communities. Participants felt that by researchers having a better understanding of culture, communities may feel more inclined to take part in research.

*"Educating the research team and people who conduct research on culture."*

*"In order to have better representation, it needs to be better included in the community on all levels. Some people in the community may have mixed viewpoints, so then it's the job of the researcher to involve as many members as possible from communities."*

Linked to this, a number of participants emphasised the importance of researchers building trust, rapport and genuine relationships with communities.

*"I think with me it's about constant assurance, that time and patience, and building that genuine, compassionate, trusting relationship."*

*"I think building trust comes from establishing a relationship through active engagement and transparency."*

*"I have taken part in research things with the NHS purely because I trust the people that I'm talking to and I know the information isn't going to be used against me."*

Some participants also suggested that researchers should collaborate with trusted organisations and/or individuals to promote research opportunities, with participants sharing that they need to know the research is from a reliable source and someone they can trust.

*"I think the key to it is having people you can trust and go to. Once you've won the trust of somebody, they're going to be more inclined to open up. It's about having trusted people telling you about research."*

*"To take part in a research project, you know it's gotta be kosher, you know. I wouldn't trust any stranger coming to me and asking me if I would take part in a research project. It's gotta come from a reputable source."*

### **Increasing Choice and Flexibility**

A number of participants said that research studies need to be made more flexible. Common examples included:

- Conducting research online, by phone or in-person
- Conducting research outside of typical working hours (such as evenings and weekends)
- Allowing participants to choose the research location.

By providing greater choice in how to take part, participants argued that this would make research more accessible and inclusive, and account for people's individual needs, preferences as well as their reasonable adjustments.

*"I think we should talk about the flexibility aspect of interviewing physically and also virtually."*

*"Flexibility in participation is going to increase uptake, some sessions should be remote, some sessions should be physical, that person could have that accessibility and preference and choose. It makes it flexible and so people can have options."*

*"Research studies may be conducted on a specific site, you may want to go to a particular location to take part."*

## **Providing Incentives**

Some participants felt that researchers should provide financial incentives to encourage people to participate in research, but also to show their apprehension to participants for taking the time to contribute.

*"It's nice to get the money but it's also that appreciation and sincere acknowledgment that someone is sharing their personal stuff for that research to happen."*

*"Giving a £10 incentive to patients or to individuals that are interested in taking part so that your time was actually appreciated and your efforts. So I think that incentive is always a nice thing."*

*"If people could see an incentive for participating that would stimulate them to get engaged."*

## **Adding Value and Obtaining Feedback**

Linked to this, a number of participants said it would be beneficial if researchers should outline how taking part in research will have a positive outcome. Likewise, if research has taken place, researchers should share the feedback so people know how their information was used. One participant also suggested that researchers should showcase success stories to encourage people to take part.

*"I like to know what I'm saying has value and what I'm doing is valuable."*

*"I remember doing it once and I got no feedback about it and obviously I shared something quite deep and personal. I'm like where is this information going? They gaslight you to get you to take part because they need you and then you don't hear back from them. That's put me off to be honest."*

*"Share research findings with participants, communicate the outcomes of studies in understandable language."*

*"Showcase success stories. Feature testimonials from previous participants to highlight the positive impact of research and inspire others to get involved."*

## **Research Opportunities**

### **Be Part of Research**

When asked whether participants would be interested in signing up to the NHS Be Part of Research<sup>4</sup> scheme, a large number said they would like to and asked for more information.

*"I would like to sign up for it."*

*"I would be absolutely interested in that."*

### **Research Champions**

Organisations such as the National Institute for Health and Care Research (NIHR) have Research Champion roles<sup>5</sup> in which members of the public volunteer to spread the word about research opportunities. Participants were asked whether they would be interested in becoming a Research Champion, with the majority stating they would be.

*"I would like to be a Research Champion, it's a really nice thing to do – spreading the word and making sure more people know about research. And I think when people see familiar faces as Research Champions, it stirs them up to participate and it's going to give them that trust – because people don't participate because of lack of trust."*

*"Yes, I would love to be a Research Champion."*

*"Yes, I was even looking for a way to do this, I'm highly interested."*

### **Community-led Research**

Participants were also asked if they would be interested in being involved with community-led research<sup>6</sup> in which the community would play an active role in the shaping and conducting of research. Again, a large number of participants were interested in finding out more.

*"I think community-led research would definitely be more engaging and it would lead to environmental changes...I think it would be beneficial to have research to be done starting from the community like grassroot led leading to speedy interventions and improvement."*

*"Collaborating with community organisations and local stakeholders can help ensure research efforts are aligned with community needs and priorities. By involving community leaders and representatives, the NHS can gain insights into the specific"*

---

<sup>4</sup> Be Part of Research is a website to help people find out about health and social care research taking place: [Be Part of Research \(nihr.ac.uk\)](https://www.nihr.ac.uk)

<sup>5</sup> Research Champions are volunteers who spread the word about research: [Research Champions | NIHR](https://www.nihr.ac.uk)

<sup>6</sup> Community-led research puts communities at the forefront – allowing them to develop their own research questions and decide what the focus will be. This approach ensures communities' local needs and priorities are being addressed.

*challenges faced by different population groups and co-create research projects and interventions that directly address those challenges.”*

*“We need to be in there, we need to be involved in this – we shouldn’t be on the outside looking in.”*

Although some participants raised that some communities are disengaged with institutions and trust needs to be built to encourage communities to get involved with community-led research.

*“It sounds good but how can you better include all communities as disengagement may be difficult with a few.”*

*“Discrimination can be a barrier to community-led research.”*

*“How do you include communities in the first place when they are facing barriers?  
Community empowerment is great but how do we do this?”*

In addition, a few participants said they would like to be involved in community-led research in a capacity which does not involve facilitating or leading the work. One participant said their apprehension would be fear of “failure” or “rejection.”

*“My setback may be fear of failure, rejection or uncertainty about research outcomes may discourage me from taking risks or pursuing ambitious research projects.”*

*“I would like to take part but not facilitate.”*

Engage Visually<sup>7</sup> attended both focus groups and illustrated the discussion in real-time, producing the graphics below.

---

<sup>7</sup> [Engage Visually | Graphic Facilitation & Graphic Recording. Bringing thoughts together and ideas to life](#)



# Making Research for All

viewpoint  
Together we can influence change



healthwatch  
Hertfordshire



Research:  
Solving, finding solutions to a specific question  
→ Systematic  
→ Methods  
→ Analysing  
→ Data

Expanding Knowledge

Meaning of Research

There is feedback of Results and Findings but does it create **Change?**

For example:  
Access for Black and Minority Ethnic (BME)?  
Continues to share Research findings...

But people of BME Communities continue to have poor access

Finding solutions to problems that could help people

Awareness of Research

Advertise Opportunities

Remember... if people aren't accessing the NHS they may be unlikely to participate or hear about research

Diversity Aiming for a broad Audience

Screens at GP

- Stiers
- Newsletters
- Social media

Keeping Communities informed through different community networks

Could it Bias?

If there is a financial gain would this change

Is it a Role? Is it paid? Expenses?

The purpose of any role could help clarify this

Research Champions and Community

Inclusive

Safe and Effective



Your friendly Local/Neighbourhood Researcher



Researchers go to the people/community and offer Incentives

Could be Empowering but HOW? "Build Foundation"



Your Ideas and Solutions



Provide Training, Mentoring, Confidentiality and Continued Information

Provides a trusted person to a given group or community

Accessible

GP

Ensure a Diverse Workforce

Cultures and different Beliefs understand... Curiosity

Build Trust with Transparency, and with Safety and Support

Sometimes very personal questions

Security of My Data



funding

Language and Languages

Jargon Acronyms English Not 1st Language

Communication

Personal Invite

Access to information

Time

Geography and Travel

Awareness

Sign up to Research

<https://bepartofresearch.nhr.ac.uk>



Diverse



Barriers to Research Participation

Use of Social Media  
Are the right people using the adverts

www.engagevisually.co.uk

# Making Research for All

viewpoint  
Together we can Influence Change

HWE  
Hertfordshire and West Essex Integrated Care System

healthwatch  
Hertfordshire

Any activity to Uncovering **NEW** Knowledge

Means aiming at an Outcome Impact

Having a Purpose the What and Why?

How it is going to help?

Science Bodies  
Clinical Medical  
Charitable Groups  
Social Research  
Journalism

Meaning of Research

Stigmatising

Stop Labelling Me

Sharing Lived Experience is very Valuable

Shared to improve for All!

Meaningful to the Person Involved

Different Forms of Research

from Personal to Huge Clinical Trials

Market Research

Will you take part in this research?



Awareness of Research

Increase Awareness through Social Media but

Concern about Scams!

GP's  
Schools  
Colleges  
Faith Venues

Research is the starting point

I have been put off because of Lack of information about the research and a Lack of Feedback



**Accessible**



**Safe and Effective**



**Trust**

word of mouth

Needs to come from a Trusted Source

GP  
Peers

All Questions Answered before committing

**Inclusive**

Interesting/balance

Do I trust you to answer openly

Me as Participant

How Valid is the data I gather if you cannot be open

Participant

Researcher

Research Champions and Community

Support to become a research champion

Training

Confidence

Member of Community

Researcher

Learning both ways

Dynamic Participation Options

different ways to be Involved

Choices about how to be involved

flexibility

Not creating barriers through

Long Long Long Forms

Language

Clear Plain English

Written

1:1 Online

Face to face

Time

Day of Week

Time of Day

Communication Needs

Different Ways needed for different people

Same-Sex

disability

Old and Young

different

**Diverse**

feeling Safe

Fear of

- Failure
- Rejection
- Feeling Vulnerable
- Sharing

Concerns about the Safety of my information

How it could be used against me

Provide

- Constant Assurance
- After Care
- Support with the impact from being involved

Improve ways of and ease of Finding research that interests and that is Valuable, Needed and will make a difference

Not like the

Needs Hoagstock

Your Ideas and Solutions

Co-production and Involvement

Engage Local Communities

Uncertainty of Outcome? ... Have a

Clear Purpose

What is the end goal?

Genuinely Value my time and information



www.engagevisually.co.uk

Capturing the views of people with a lived experience of mental health and/or addiction on how researchers can make research more accessible, diverse and inclusive.

## Engagement with Adults with Learning Disabilities

*In partnership with Herts People First we engaged with **11** adults with learning disabilities and **one** support worker. The engagement included one focus group (consisting of six adults with learning disabilities) and five one-to-one interviews.*

*For this cohort, the biggest challenge to research participation was accessibility. People with learning disabilities shared that they need more flexibility, choice and reasonable adjustments put in place to help them be able to take part in research. It was also important that researchers were more proactive in welcoming and encouraging people with learning disabilities to participate.*

### Understanding of Research

The majority of people with learning disabilities had a good understanding of research, with most agreeing that the core purpose of undertaking research is to find out new information.

*“Research means getting information for something you want to know about.”*

*“Research is about finding out people’s point of view on a particular issue.”*

Participants could list various examples of different types of research activity, including testing new medications or devices, trialling new care pathways, and finding out more information through surveys and consultations. They were also aware that a wide range of organisations conduct research, including charities, pharmaceutical companies, county councils and the NHS.

*“New medications are tested to see how they work on people.”*

*“Like the consultation we did on buses, some time ago. That’s a good example and consultation is a type of research.”*

*“It’s getting to know something and it can also be by getting to know other people, like asking for their stories and memories.”*

People with learning disabilities emphasised the value and importance of research, sharing that without research being undertaken, improvements to society would not be achieved.

*“Without research, we wouldn’t find out what works and what doesn’t work and find out new things.”*

*"It's about how you get new ideas about how to do stuff because if you don't tell people things that aren't working well, they don't know it and they can't make it better for you, so without research, they can't make things better for people."*

## **Barriers to Research Participation**

### **Accessibility: Travel and Location**

Practical barriers were mentioned by the majority of people with learning disabilities. The need to travel and the location of research was problematic for most participants, with many commenting that if the research cannot take place in their home or local area, they would find it challenging to participate. Having to travel to a place they do not know or have not been to was also daunting to a few participants and would make them reluctant to take part.

*"Things like where the venue actually is, we would need support to get there."*

*"Where it takes place and transport, because that's quite difficult."*

*"In a research setting we would be going somewhere where we didn't know which I'm not sure I'd like to do."*

### **Accessibility: Time**

Time was another barrier mentioned by people with learning disabilities. Some participants said they are not given enough time to take part in the research study, particularly if the subject matter is complex for them to understand. One participant is in employment and said it can be difficult for them to participate in research, given that studies tend to take place during typical working hours.

*"When people ask me to take part in something, the first thing I have to say is when. I work and that finishes usually around 5:00, 6:30."*

*"Sometimes they say we need this in three weeks, we need a reasonable length of time to do it so it's not rushed."*

*"It may take more time for us to understand it depending on how complicated it is, because some things need a bit more explaining."*

### **Accessible Information**

All participants emphasised the importance of accessible information. Some said they have received information about research opportunities or been invited to take part in a research study but could not understand it because it was not in an Easy Read format. Not

receiving information in Easy Read and other accessible formats (such as video, audios, and languages) was a significant barrier for people with learning disabilities and often prevents them from participating in research.

*"It's really important that people have something that works for them, whether that is Easy Read, written down, or whether it's a film of somebody talking really clearly."*

*"It's not in Easy Read and we try to say can you put it in Easy Read."*

*"You're not taking into consideration that we live in a multicultural society, with lots of different communities. When you give research, the information needs to be accessible so that person can translate from English to whatever language."*

Participants also commented that information about research opportunities often includes complex terminology and jargon which can be difficult to understand. They emphasised the importance of researchers using simple language and communicating with people with learning disabilities in a way they can understand so they have an equal opportunity to take part.

*"With research, it's a big jargony word that needs explaining to begin with. I'm always having to de-jargonise whoever is actually explaining things to begin with."*

*"They have to learn how to actually communicate with people with learning disabilities."*

However, one participant commented that when producing communication materials in Easy Read, the information should be the same but explained using plain English. Often this participant finds that information is "left out" or diluted which excludes people with learning disabilities and gives the impression that their knowledge is "worth less."

*"What we call the jargon version is left out, that means that when a person with a learning disability reads the accessible information version, they come away with a different version, and they get information that a person with a learning disability doesn't. Researchers value accessible information so little that they will project it in a way that implies to me as a person with a learning disability that my knowledge is worth less than actually our knowledge."*

### **Trust and Reliability**

A number of people with learning disabilities said they would only consider taking part in research if they heard about the study through a reliable, trustworthy source. Building a rapport and trust with the researcher(s) was also important to participants, who commented that they would feel more inclined to take part if they knew the researcher conducting the study.

*"I won't have a stranger, if I know who it is, I would do it."*

*"Trust is so important to me because if I can't trust the person, I don't want to do it."*

*"We have to kind of know the person that we will be receiving the actual information from. Or we actually have to kind of know someone who would know that person and would be able to say you can do this, this is a reliable source."*

### **Lack of Impact**

Although not a practical barrier, a few people with learning disabilities said they are reluctant to take part in research because they have not been any tangible, positive outcomes from previous studies undertaken. Information about how their involvement will result in positive change was therefore very important to the participants, and would encourage them to consider participating.

*"I often kind of think well, we've been telling you this for the last 20 years but you haven't actually improved things. We don't see the actual improvements after the research."*

*"What change will actually happen, how will that change and how will that actually impact the individual."*

### **Encouraging Research Participation**

#### **Accessibility**

Improving accessibility was the most common suggestion made by people with learning disabilities, who generally felt that research opportunities are difficult to take part in because they have not been made accessible and inclusive of their needs.

*"It's annoying that so many research things are done without thinking of how to make things come across ok for everyone, not just one set of people."*

Most people with learning disabilities said they would feel more inclined to participate in research if they could choose how they could take – whether this be online or in-person. A few participants would prefer to take part in research using an online platform or in their own home and often this was to retain their anonymity and privacy. One participant said it would be helpful if research could take part in their home due to their physical disability. In contrast, another participant would prefer to participate in-person and liked the idea of meeting new people.

*"Zoom. Because I know where to go and how to get it set up and I can do it on my own, you know what I mean? I do like my privacy, I do like to keep private."*

*"I'll do it in my flat or on Zoom. I don't want too many people to hear it and gossip."*

*"It would be helpful for someone to come to me...it's a lot easier if they come to my house...it's easier for my body because I get a lot of stress doing it."*

*"I wouldn't mind travelling. I like travelling and meeting new people."*

Similarly, people with learning disabilities had their own preferences for how they would like to participate in research. For some, they would feel more comfortable taking part on a one-to-one basis, while others would prefer to participate in a group setting. Regardless of preferences, having this option to choose how they would like to take part was important to all participants.

*"I think having both options open, because some people work better on a one-to-one basis and some people are happy to answer questions in a wider group."*

*"One-to-one, I don't like groups, I'm not comfortable with that."*

The majority of people with learning disabilities also said they would feel more inclined to participate in research if they could bring a carer or support worker with them to help them.

*"The second big thing is support to take part. Support is a really big thing to enable you to take part."*

*"It's a very good idea to have someone that could help you."*

### **Including People with Learning Disabilities**

Some participants suggested that researchers need to include and involve people with learning disabilities in their research by being proactive in building trust and confidence in people with learning disabilities, and ensuring they feel welcomed to participate. One participant felt that people with learning disabilities are *"left out"* and that researchers need to do more to address this inequality.

*"Making us aware that we are welcomed to take part, and that the type of disability we are, that we are welcomed."*

*"The majority of time we are left out. That's what needs changing."*

*"It's about building trust and confidence."*

Linked to this, some participants said it can be daunting to take part in research with people they either do not know or may not have an understanding of learning disabilities. They suggested that being able to take part in research with other people with learning

disabilities could help them feel more comfortable, and enable them to have greater confidence in sharing their views.

*"It may be that if you're going somewhere, you're sitting with strangers who don't know a thing about you or don't know how difficult things can be for you. They don't understand what your learning disability is."*

*"Maybe a group specifically for people with learning disabilities because often in the group, if it's a mixed group of people with learning disabilities and people without, then the voices of people with learning disabilities always kind of gets left out."*

### **Case Study: Power Dynamics**

Edward emphasised that at times, there can be a power imbalance between recipients and researchers which needs to be addressed should we want to encourage more people with learning disabilities to take part in research.

*"A lot of the research that is being done is done to people. So you've this passive recipient of being asked loads of questions by these people who think they're more important kind of thing. Those to me are like power issues and usually because the people that are asking the questions don't have a learning disability."*

Edward suggested that to overcome these power dynamics, research studies should be co-produced, and should be co-produced with people with learning disabilities if the study is looking to specifically engage with this community.

*"Involve people with the learning disability at the very beginning even in terms of putting questions together and how you're going to do it. It would be a lot better because people with learning disabilities would have helped with those questions and how to get what is needed, you know, for the aims of the research. The foundations have been built wrong."*

### **Providing Feedback**

Some participants said they previously taken part in research and did not receive any feedback on the outcomes of the study. For some people, this has made them reluctant to consider taking part in future research opportunities.

*"Loads of people have been doing research, when I took part, I didn't hear what they found. I'd love for them to come back and tell us what has been found."*

*"It would be helpful if when we did research, we heard back from various people on how it's helped other people...sometimes we don't get that. We've done consultations in the past and no one's fed back the results of how that's helped people."*



*"They get all of that information, all of that knowledge and then it's like so what are you doing to do next? And then we heard nothing."*

### **Promoting Research Opportunities**

Positively, all participants said they would like to know about research opportunities they could get involved with. However, none of participants knew how they could take part in research and often only received information from Herts People First about studies they could participate in.

*"I have so little knowledge of what research is going on in Hertfordshire."*

*"Some people may not have the support and may not be told about research they can get involved with. The only information that we get is through Herts People First."*

People with learning disabilities emphasised that research needs to be more widely promoted. Common suggestions included:

- Using a variety of formats such as videos, posters and leaflets, to promote research opportunities.
- Providing a phone number on all communication materials, in addition to weblinks and email addresses.
- Communication materials should explain what research is, why it is important, and the value it has in society.
- Research opportunities should be shared within the community – including the use of roadshows.

*"You could advertise it using video and banners and escalate it and talk to strangers and tell them about the video."*

*"Putting a phone number on posters. Don't expect everyone to be able to email because that's difficult for some of us."*

*"Get it out there and let people know about it in the community, roadshows and stuff like that."*

*"I think it would be good if we could know about when it's taking part and information about what it's about and why it's important."*

### **Research Champions and Community-led Research**

The majority of people with learning disabilities would be interested in becoming a Research Champion, so they could share information about research opportunities with their friends, family and community.

*"I like to come out and do this work and speak to people in the community."*

*"I like to take part and talk to a lot of people out there and get information across."*

Linked to this, some people with learning disabilities would consider taking part in community-led research and had some ideas about what topics could be explored.

*"It could be a system that would bring people with learning disabilities together, as a team."*

*"Could we look at where people with learning disabilities are supporting other people with learning disabilities...I have epilepsy as well so often there is a role reversal. I think that's something that needs looking at."*

# Children & Young People Workshop

*In partnership with the University of Hertfordshire's Young People Advisory Group (Herts YPAG) we engaged with 11 children and young people aged between 10 and 18 years old to explore their views towards research.*

*To encourage children and young people to take part in research, it is important that information about research opportunities, and the research itself, is creative and engaging.*

## **Barriers to Research Participation**

Practical barriers were most commonly cited as reasons preventing participation in research. Time was the most significant challenge, with most children and young people sharing that they often do not have enough time to take part in research, or are not able to participate due to the research taking place during school hours.

Travel and location was another key barrier, with children and young people stating that if research takes place outside of their local area, it would be difficult for them to travel there.

*"The research might also happen at times where young people aren't available, such as during school or college."*

*"Not knowing how much time you will have to commit and what you are getting into."*

*"I think it harder for some people to travel further away. But it could help if you pay for travel costs."*

Language was also recognised as a potential barrier by a number of children and young people, who said that the use of complex terminology and jargon in the advertisement of research opportunities can be difficult to understand, and can deter them from wanting to participate.

Some children and young people also said that some people have misconceptions about research, and assume that most research studies take place in laboratories and involve clinical trials, which may prevent them from participating.

*"Sometimes the more complex words are harder to understand."*

*"Research can seem scientific and quite difficult, which can put some young people off."*

*"People think of clinical trials and labs when they hear research."*

Lastly, one young person commented that children and young people may not want to take part in research in case they appear to be the “odd one out” of their friendship group.

*“Peer pressure, feeling like the odd one out.”*

## **Encouraging Research Participation**

To encourage children and young people to take part in research, most of the group said it is important to emphasise how their participation in research will add value and be making a difference. One young person also suggested that children and young people may feel more inclined to take part in research if they could reference their participation in applications, such as University placements and job applications.

*“I’d like to know the impact of the research and how it could change things and make a difference.”*

*“It might help if they understand how taking part in research could help them in the future with their job or uni application.”*

Reassurance that their identity will remain anonymous and that any information provided will be confidential was also important, and the group suggested that researchers need to do more to assure children and young people that their data will not be shared with anyone else.

*“Telling people that their answers are confidential.”*

*“Tell kids that their answers are confidential since they may worry that their answers might come back to their families, school.”*

Some children and young people said that research opportunities need to be made more accessible, and suggested that providing more choice and a range of ways to participate – including online, in-person, in group settings and on a one-to-one basis, would encourage more children and young people to take part.

*“More one-to-one or anonymous surveys.”*

*“Offer online and in-person.”*

Receiving a financial incentive was also mentioned as a way of encouraging children and young people to take part, and would show appreciation for them taking their time to contribute and share their views.

*"What may stop children from taking part is like, they might think they're doing all of this work but they're actually not getting anything back from it. So I think it would make it more appealing if you could have a gift card or something."*

Lastly, most of the group said that using creative methods, such as painting, plasticine and Play-Doh, as a form of methodology when undertaking research, would encourage more children and young people to participate.

*"I think creative methods could make [children and young people] feel less nervous."*

*"You could advertise how the research will have a creative side to it."*

## **Promoting Research Opportunities**

Children and young people were asked how the NHS could better promote research opportunities, and the majority suggested that information about research studies needs to be made visible in a range of community settings – such as in parks, shops and leisure centres.

They also said that opportunities to take part in research should be promoted more widely on social media channels – including Facebook, X, Instagram and TikTok to reach a range of audiences.

One young person said the NHS could work in partnership with public figures and organisations that work with children and young people to promote research opportunities.

*"Posters around shops and school."*

*"Advertising in schools and in certain lessons."*

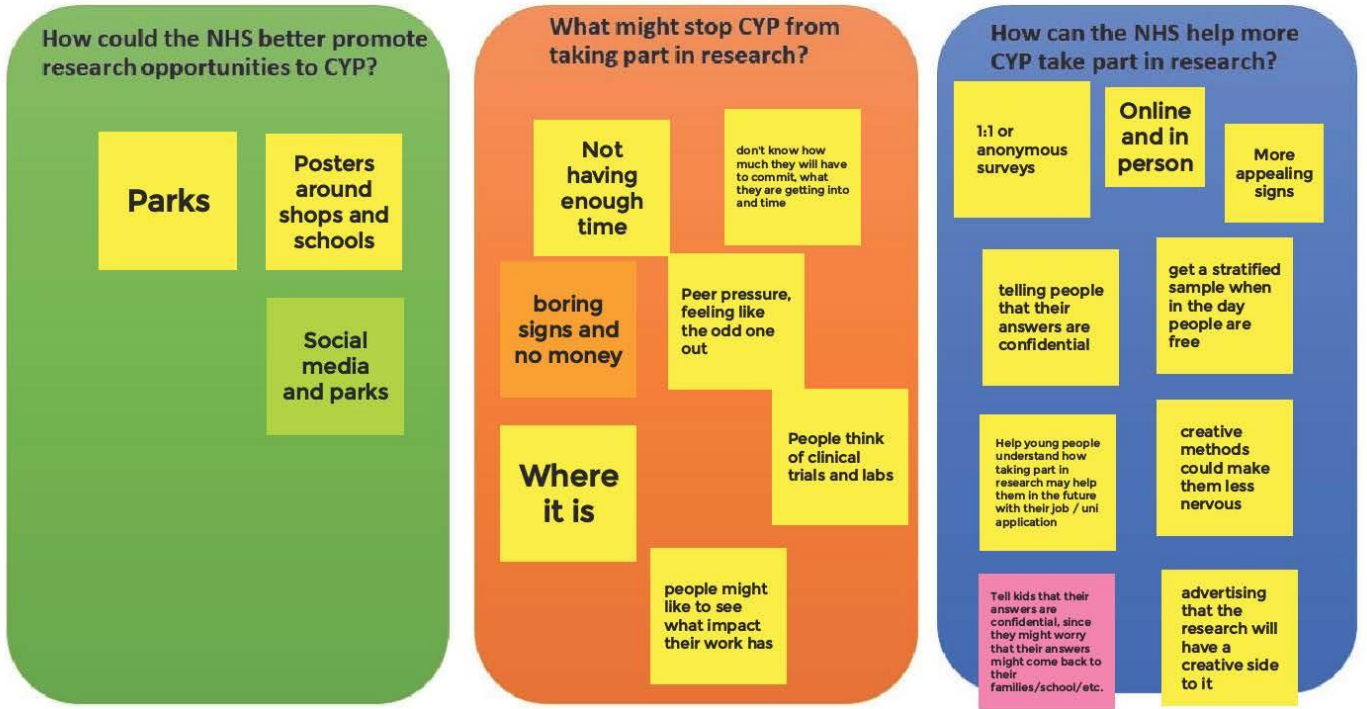
*"The NHS could partner up with companies that children and young people are involved with or teaming up with certain celebrities or people to promote research and people who can relate to young people more."*

Children and young people emphasised that it is important that any posters advertising research opportunities need to be made more creative, colourful and fun to engage and attract children and young people to find out more or take part.

*"Add more colour and fun to the posters."*

*"Make more appealing signs and posters about research."*

The image below shows what some members of the group captured on Google Jamboard.



Thank you to Viewpoint, Herts People First and the University of Hertfordshire's Young Person's Advisory Group (YPAG) for supporting with this engagement, and thank you to our participants for sharing their views.