



Delivered by Sandwell Consortium on
behalf of Sandwell & West
Birmingham NHS Trust

2025

Improving Understanding of Research Engagement

Community Research Project:
Findings from Community Focus Groups in Sandwell


Sandwell and West Birmingham
NHS Trust



1. Introduction

This report presents the findings of the *Improving Understanding of Research Engagement* (IURE) community research project, delivered by Sandwell Consortium and its community partners on behalf of Sandwell & West Birmingham (S&WB) NHS Trust.

Healthcare research is essential to improving treatments, services, and patient outcomes. The NHS recognises the need to increase participation in research and to ensure that research opportunities are accessible to all communities. However, evidence shows that participation in healthcare research is not representative of the populations served, particularly within diverse areas such as Sandwell.

As part of its commitment to enabling wider and more inclusive research engagement, Sandwell & West Birmingham NHS Trust commissioned Sandwell Consortium to undertake a qualitative project to better understand local communities' awareness, perceptions, and experiences of healthcare research. The research also sought to identify the barriers and enablers that in particular influence participation by residents of south Asian origin (27% of the population served by the S&WB NHS Trust) and other minoritised ethnic communities.

The findings from the IURE research project will help shape key plans and actions to support the Trust to improve inclusive engagement in healthcare research, and ensure that future research reflects the needs of the local population.

2. Research approach and methodology

This project employed a qualitative, community-based research approach to explore local understanding, perceptions, and experiences of healthcare research, in particular among minoritised ethnic communities in Sandwell.

A series of focus groups and facilitated discussions were delivered across a range of community settings in Sandwell, working with established community organisations and trusted local partners. This approach was chosen to ensure engagement with individuals who may not typically access or participate in healthcare research activities.

Sandwell Consortium and S&WB NHS Research team co-designed a standardised topic guide, with external feedback from the Community Engagement Lead for the Sandwell Health Determinants Research Collaboration (HDRC) (based in Sandwell MBC Public Health).

The topic guide provided the framework for guided discussion of **five key themes**:

- awareness and understanding of healthcare research
- perceived benefits and risks
- previous experience of research participation
- barriers and enablers to engagement, and

- preferences for communication and involvement.

Twelve focus groups took place across eleven community organisations (listed at *Appendix 1*) during December 2025.

A total of 107 participants took part in the focus groups. Participants were made up of residents with 14 ethnicities and with 12 different first languages. 63% of participants were of south Asian origin, and 37% from other minoritised ethnic communities, with African (12%) and Arabic (10.5%) being the next largest cohorts. (See *Appendix 2* for a detailed demographic profile of the participants).

Participants were recruited from among service users/general public attending the centres for services including ESOL, health and wellbeing groups, welfare benefits advice and employment support.

Discussions were in community languages and English, with bilingual groups facilitators as well as local community interpreters to assist if needed.

Discussions were therefore in local neighbourhood settings and delivered in an informal semi-structured way. This supported an inclusive approach that allowed participants to share views openly in familiar and trusted environments. Notes were taken during sessions, and all responses were anonymised, with no personal identifiers recorded. Background demographic information (such as ethnicity, gender, age, first language, and community organisation) was collected in an anonymised and aggregated form to support the findings.

Responses from all groups were collated and analysed thematically to identify recurring views, shared concerns, and any differences across communities. These themes form the basis of the findings presented below.



The Ileys Community Association Focus Group

3. Questions & Key Findings

This section provides a summary of responses extracted from the notes of the discussion groups and are set out under the broad themes and questions from the topic guide. The discussion groups are available as a separate stand-alone Appendix to this report.

3.1. Awareness and understanding of Healthcare Research

Question 1) When you hear the term healthcare research what comes to mind?

Overall, awareness and understanding of healthcare research varied significantly across participants.

Participants associated healthcare research primarily with hospitals, doctors, scientists, and clinical trials; and in relation to cancer, COVID-19, diabetes, and testing new medicines. Research was frequently described in terms of “medical testing,” “drug trials,” or “experiments,” with some participants expressing concern about being “tested on.”

All focus groups highlighted a limited awareness among participants that surveys, questionnaires, feedback forms, and service evaluations are also forms of healthcare research. Several participants reported completing NHS questionnaires in the past without realising that these contributed to research activities.

Understanding was particularly limited among participants for whom English was not their first language, with many stating that the term “research” itself was unclear or unsettling. Some participants required examples before they could engage meaningfully in discussion.

Despite these gaps, once ‘research’ was explained, participants recognised its potential value and relevance to improving healthcare services.

“I thought research means blood test or medicine test. I didn’t know a questionnaire is also research.” BIC participant

“I get worried if it will affect my healthcare or doctors/GP or change something that is working now to something that doesn’t work” CCF participant.

3.2. Perceived purpose of healthcare research

Question 2) What do you think is the purpose of research in health (NHS)?

The majority of participants believed that the purpose of healthcare research is to:

- improve treatments and medications
- help doctors better understand illnesses, and
- improve NHS services and patient care.

“It is to improve healthcare so people can live healthier. It also ensures that decisions based on scientific not on assumptions” Brushstrokes participant.

However, alongside mostly positive views, in four of the twelve focus groups people expressed scepticism about or mistrust of healthcare research. Some participants questioned whether research genuinely leads to improvements, describing it as a “tick-box exercise,” “paper-filling,” or a way of generating funding rather than delivering meaningful change.

“Money making & tick box exercise, just a formality.” SWEDA participant

“Research has not been useful, quality of service is getting worse, especially staff attitude and hospitality.” CCF Participant

Concerns were also raised about research being driven by financial, data gathering or organisational priorities, rather than the needs of patients and communities. This tension between perceived benefit and mistrust was a recurring theme throughout discussions, often mentioned by older male members of the groups.

3.3. Perceived benefits of healthcare research

Question 3) Do you think there are any positive things about research in health?

In all the groups, participants identified clear positive outcomes of healthcare research when it is conducted and used effectively. These included:

- development of safer and more effective medicines,
- earlier diagnosis of illness,
- improved treatment options and health outcomes,
- greater confidence in medications and vaccinations,
- improvements to healthcare services based on patient feedback.

“Research can be good and bad, they can get better from listening to people’s needs, but sometimes it gets ignored.” CCF Participant

Some participants, and in particular several in the Bangladeshi Islamic Centre female focus group, valued the idea that research could benefit future generations, children, or wider communities, even if there was no immediate personal benefit.

However, several groups noted that these positives are not always visible to the public, and that a lack of communication about outcomes reduces confidence in research overall.

“No, as no publicity and public is not made aware of what survey/research has been done. They are not approached in their own language, directly with them” SWEDA Participant

3.4. Perceived risks and negative perceptions of research

Question 4) Do you think there are any negative things about research in health?

Responses to this question were mixed within and across groups.

Participants in the SYCC focus group stated they did not see significant negatives, provided that research is well-regulated and carried out safely, but in every other group a range of concerns were raised, including:

- fear of side effects or harm from new treatments (participants in 90% of the groups).

- anxiety about data protection and misuse of personal information
- lack of transparency about how research findings are used
- concerns linked to COVID-19 vaccination research, which had negatively influenced trust in research for some individuals.

“COVID injections, the research was rushed and not tested properly in fact public was scared/forced into having the vaccinations” SWEDA participant

Language barriers and complex information were repeatedly cited as contributing to fear and reluctance, particularly where participants felt unable to fully understand what they were being asked to consent to.

“I get scared when I don’t understand the English. I don’t want to say yes to something I don’t understand.” BIC participant

“Testing on people – no one wants to be the first person tested on.” SC Residents Panel participant

“People have to volunteer their time, we don’t have time.” IFA participant

“I am not very comfortable sharing personal information and not fully understanding what they are doing with my information.” BWA participant

3.5. Previous experience of participation in research

Question 5) Have you ever been approached to take part in any research relating to your health?

The vast majority (94%) of participants (100/107) reported that they had never knowingly been approached to take part in healthcare research.

- 2 x participants recalled involvement in COVID-related research,
- 3 x participants had been offered clinical trials, or condition-specific clinics,
- 2 x participants were involved in research conducted by Warwick University which focused on cardiac arrest awareness and response. This was done in partnership with the Ileys Community Centre.

Many participants only realised during the focus group discussions that they had previously completed surveys or feedback forms linked to NHS services which would count as research.

This highlights a key finding: research participation is often not recognised as research by the participants.

Several participants expressed frustration that they had provided feedback in the past but had not seen any resulting improvements, leading to disengagement and loss of trust.

3.6. Barriers to participation

Question 6) What would prevent you from taking part in any form of healthcare research?

Participants identified a wide range of barriers to engaging in healthcare research. The most frequently cited included:

- language barriers, particularly where information is only available in English
- fear of not understanding consent forms or research processes
- lack of trust that feedback will lead to meaningful change
- time constraints due to work, caring responsibilities, or health issues
- travel and accessibility challenges
- digital exclusion, including lack of devices, skills, or confidence
- concerns about data security and privacy.

All participants of the Ileys group shared negative experiences when accessing NHS and GP services, including difficulties accessing services; feeling unheard or misunderstood; experiences of discrimination within healthcare settings; and language and cultural barriers that affect communication and trust. These challenges have contributed to a lack of confidence from this group in healthcare services.

Some members of the BIC group stated that a fear of signing something they don't understand is a barrier to taking part.

“Selling of personal information, scared of details being sold on as they get fake calls and messages” BWA Participant.

“If we take part, will they take our opinions seriously?” SWEDA Participant

The CCF group shared that negative past experiences with healthcare services and staff attitudes further reduced willingness to engage in research activities.

“Nothing would encourage me anymore. I have given lots of feedback before for years and there was no change, I feel completely unheard. Sometimes staff seem untrained for talking to public, terrible and cold attitude with no care for the patients or the job. For example, new Sandwell Birmingham hospital has terrible layout and very confusing for everyone, lots of people complain and give feedback on how to make it better but they didn't change anything.” CCF Participant

3.7. Enablers and motivators for participation

Question 7) What would interest you or encourage you to take part in research with the NHS?

Participants gave clear examples about what would make them more likely to engage in healthcare research.

Key enablers included:

- clear, simple explanations in accessible language
- face-to-face discussions in familiar, safe community settings

- information delivered through trusted sources such as GPs, pharmacists, or community workers
- seeing clear evidence that research leads to real improvements
- relevance to personal or family health conditions
- financial incentives or reimbursement for time and travel.

Participants consistently emphasised that trust, transparency, and relevance are essential for meaningful engagement.

“If you have been personally affected by an illness, you are more likely to take part and be interested in that research.” SC Residents’ Panel participant

“If I feel comfortable and the questions are easy and quick and the language was simple to understand”. Brushstrokes participant

The majority of the SYCC group said they would be more willing to participate if taking part meant they could access earlier appointment dates or quicker assessments for their health concerns, as long waiting times are a major frustration for them.

3.8. Communication preferences

Question 8) Would you like information about the research that you could participate in, in health or the NHS?

Participants expressed diverse preferences for communication, highlighting the need for multiple, inclusive approaches.

Digital methods such as text messages, WhatsApp, emails, and the NHS App were valued for convenience, particularly for reminders. However, digital communication alone was widely viewed as insufficient due to:

- language barriers
- digital literacy issues
- fear of scams or misinformation.

Written communication (letters and leaflets) was valued for being “official” and providing a physical record; but was also seen as intimidating when overly long or complex.

Strong support was expressed for:

- visual and verbal communication
- short summaries rather than lengthy documents
- information delivered in community languages
- engagement through community centres and trusted local organisations.

3.9 Awareness of research opportunities

Question 9) Would you like to be made aware of different research, relating to health or the NHS, that you could take part in?

Responses to this question were mixed but also highlighted several consistent themes.

Many participants expressed an interest in being informed about research opportunities, particularly where these related directly to their own health conditions, their families, or their wider community.

Participants emphasised that information would need to be presented in an accessible format and in clear simple language, with an understanding of what participation would involve and what benefit it might offer.

“Face to face discussions. They need to go into the community and speak directly to the people” SWEDA group

However, across three of the groups, participants stated that they were less willing to engage in research opportunities due to previous negative experiences. These included perceptions that feedback is often not acted upon, concerns about risk, particularly in relation to clinical trials, and a lack of trust that participation would lead to meaningful change.

As a result, willingness to be made aware of research opportunities was closely linked to relevance, trust, and perceived value.

“No, the forms and questionnaires are time consuming, and I don’t understand why they want the information when they don’t use any feedback” CCF participant.

3.10 Preferred channels for research opportunities

Question 10) How would you like to find out about opportunities for you to participate in research in the NHS?

Participants identified a range of preferred ways to find out about opportunities to participate in healthcare research.

Trusted sources such as GPs, hospitals, pharmacies, and community organisations were consistently viewed as the most reliable channels for receiving information. Face-to-face communication within community settings was particularly valued, as it allowed participants to ask questions, build trust, and better understand research opportunities.

Digital communication methods including text messages, WhatsApp, emails, and the NHS App were widely supported, particularly for sharing brief information and reminders. WhatsApp was frequently highlighted in some groups as a familiar and accessible platform, especially when combined with simple language or visual content.

Written communication, such as letters, leaflets, and posters, was also seen as important, particularly when provided in community languages and displayed in familiar settings such as GP surgeries, community centres, and libraries. Participants consistently emphasised that no single communication method would be suitable for all, reinforcing the need for a multi-channel, inclusive approach.

3.11 Preferred channels for research opportunities

Question 11) How would you like to find out about opportunities for you to participate in research in the NHS?

Participants expressed a strong desire to be informed about the outcomes of healthcare research, particularly where findings result in improvements to services or patient care. Trusted sources such as GPs, hospitals, pharmacies, and community organisations were consistently identified as preferred channels for receiving this information. Participants in eight of the groups mentioned GP's Surgery as a good and trustworthy way to get information, with participants in three of the groups saying that posters/leaflets in GP's surgeries are always a good way for them to receive information.

"Posters in waiting rooms will be read because they can be interesting while waiting" CCF participant.

Preferences varied depending on confidence with technology and language. Digitally confident participants favoured emails, text messages, WhatsApp, and the NHS App, while others, particularly older participants and those with limited English, preferred letters, visual materials, or verbal explanations in community languages. Across groups, participants emphasised the importance of transparency, including sharing both positive and negative findings of research, and clearly explaining how the NHS is acting on research outcomes.

3.12. Seeking further information about NHS Research

Question 12) What ways (if any) would you use to find out more for yourself about research in the NHS (past or future)?

Every group had participants who said that they would look for information using Google or similar search engine, the NHS website, or social media. But each group also had participants said that they would not seek information independently unless prompted or supported.

Many participants preferred to rely on trusted health professionals, such as asking GPs, nurses, or pharmacists, particularly where language barriers or lack of confidence were present. Community advisors and face-to-face discussions were also highlighted as important, especially within community settings where participants felt more comfortable asking questions.

"When I go to community centre, advertising there, or any leaflets or booklets they give are useful for information" CCF Participant.

Some participants were apprehensive about asking GPs in case they would understand them. Others said that asking questions might make them seem *"stupid for not understanding"*.

3.13. Views on digital communication platforms

Participants identified several advantages of digital communication platforms, including speed, convenience, and ease of access. Platforms such as WhatsApp were viewed positively due

to familiarity, with short videos, voice notes, and visual content helping to improve understanding. Email wasn't seen as favourable with residents who use email, stating they don't use or check their inbox on a regular basis.

However, significant disadvantages were also raised. These included digital exclusion, lack of access to suitable devices or internet, low digital confidence (particularly among older participants), language barriers, and concerns around data security, scams, and misinformation. Many participants stated that long or complex English messages were difficult to understand and often ignored.

Overall, participants felt that digital communication is useful but should not be relied upon as the sole method of engagement. WhatsApp was the most used digital platform across all groups, but some participants mentioned concerns about misinformation or scams on the platform.

"The digital communication platforms are useful because you can access them anytime and anywhere, but they are not fully trusted" Brushstrokes participant.

"WhatsApp voice notes are helpful" BIC participant

Many in the female group said they communicate using voice notes, as *"long English messages are hard to read" BIC participant*

3.14. Views on written communication

Written communication, including letters and forms, was viewed as both valuable and challenging.

Participants appreciated written materials as they are official, trustworthy, and provide a physical record that can be kept, shared, or referred back to.

At the same time, many participants described written communication as daunting, particularly where documents were lengthy, written in complex English, or required detailed form completion. Language barriers were a significant issue, with some participants relying on family members or community support to understand correspondence. Others noted that letters can be delayed, misplaced, or become outdated.

Participants emphasised that written communication is most effective when it uses clear language, appropriate font size, visual support, and community languages, and when combined with verbal explanation, where possible.

"When I see a long letter, I get scared. I don't understand most of it." BIC participant

"Written is important because I need paper documents for a lot of things, and I like to keep my own record of appointments, so I don't forget." CCF Participant

4. Recommendations for a Quality Improvement Initiative

Based on the findings from the community focus groups, the following recommendations are proposed to support increased, inclusive engagement in healthcare research across Sandwell. These recommendations focus on improving awareness, trust, accessibility, and participation, particularly among communities that are currently under-represented in healthcare research.

4.1. Improve awareness and understanding of healthcare research

Recommendation:

Develop clear, simple explanations of what healthcare research is, using plain language and real-life examples.

Rationale:

Findings show that many participants associate research only with clinical trials or testing medicines and are unaware that surveys, questionnaires, and feedback activities are also forms of research. This lack of understanding creates fear, mistrust, and disengagement.

Suggested actions:

- Use simple explanations and avoid technical or academic terminology
- Clearly explain that research includes surveys, feedback, and service evaluation
- Provide short summaries rather than lengthy documents
- Use visual aids, examples, and verbal explanations where possible.

4.2. Deliver research engagement in trusted community settings

Recommendation:

Embed research engagement activity within community centres and trusted local organisations, using face-to-face approaches wherever possible.

Rationale:

Participants consistently reported higher levels of trust and confidence when discussions take place in familiar, safe environments and are facilitated by trusted community partners.

Suggested actions:

- deliver engagement sessions in community centres, libraries, GP surgeries, and faith/community venues
- work with community organisations and health ambassadors to share information
- use community-led approaches rather than relying solely on hospital-based engagement.

4.3. Address language and accessibility barriers

Recommendation:

Ensure research information and opportunities are accessible in **community languages** and appropriate formats.

Rationale:

Language barriers were one of the most significant obstacles to participation. Participants expressed fear of signing up to research they do not fully understand and a lack of confidence in engaging with English-only materials.

Suggested actions:

- translate key information into common community languages (including use of videos)
- offer verbal explanations and interpreting support
- use large fonts, clear layouts, and short sentences
- avoid overly long forms and complex consent documentation.

4.4. Build trust through transparency and feedback***Recommendation:***

Improve transparency by clearly communicating how research findings are used and what changes result from community participation.

Rationale:

A source of disengagement was frustration that feedback is given but no visible improvement follows. This has led to loss of trust and reluctance to engage in future research.

Suggested actions:

- share outcomes of research in accessible formats
- clearly communicate “you said, we did” messages
- be honest where change is not possible and explain why
- share both positive and negative findings openly.

4.5. Reduce practical barriers to participation***Recommendation:***

Remove or minimise practical barriers such as time, travel, childcare, and digital exclusion.

Rationale:

Many participants cited lack of time, transport, caring responsibilities, and digital skills as reasons for non-participation.

Suggested actions:

- offer flexible participation options (short sessions, drop-ins, remote where appropriate)
- provide reimbursement or vouchers for time and travel
- avoid digital-only research approaches
- offer support with completing forms or surveys.

4.6. Use inclusive and multi-channel communication approaches***Recommendation:***

Adopt a mixed communication model that combines digital, written, video and face-to-face methods.

Rationale:

No single communication method was suitable for all participants. While digital methods are convenient, they do not on their own provide an inclusive approach.

Suggested actions:

- use text messages, WhatsApp, and emails for short updates and reminders
- continue using letters and leaflets for official communication and record-keeping
- use posters, videos, and verbal communication in community settings
- ensure communications are short, clear, and translated where needed.

4.7. Demonstrate relevance and personal benefit***Recommendation:***

Clearly communicate how participation in research is relevant to individuals, families, and communities.

Rationale:

Participants were more willing to engage when research related to conditions affecting them or their families, or when they believed it would benefit future generations.

Suggested actions:

- clearly explain who the research is for and why it matters
- highlight community and family-level benefits
- be clear about what participants will gain (knowledge, reassurance, contribution, incentives).

4.8. Strengthen community involvement in research design***Recommendation:***

Involve residents, service users and community organisations earlier in the design and delivery of research engagement activity.

Rationale:

Participants expressed a desire to be more meaningfully involved rather than only asked to respond to surveys.

Suggested actions:

- involve community representatives in shaping engagement approaches
- pilot research materials with community groups before wider rollout
- use community feedback to refine language, format, and delivery methods.

5. Conclusion

This community research project has provided valuable insight into awareness, perceptions, and experiences of healthcare research among Black Asian and minoritised ethnic, faith and linguistic communities in Sandwell. These communities that are currently under-represented in healthcare research within the Trust and within the NHS more broadly *[citation needed]*.

While many participants recognise the potential benefits of healthcare research, their understanding of what research involves remains limited. Their participation in research is also hindered by significant barriers and challenges.

Key challenges identified include:

- low awareness of non-clinical research
- language and accessibility barriers
- lack of trust resulting from previous experiences, and
- practical constraints such as time, travel, and digital exclusion.

At the same time, the findings highlight clear opportunities to improve engagement. Participants consistently expressed willingness to engage when research is clearly explained, delivered through trusted community settings, made accessible in appropriate languages and formats, and when there is transparency about how feedback and findings are used.

The recommendations outlined in this report provide a practical framework to inform a Quality Improvement Initiative aimed at strengthening inclusive research engagement. By addressing the identified barriers and building on existing community strengths, Sandwell & West Birmingham NHS Trust can improve access to healthcare research and ensure that future research better includes and reflects the needs of the diverse populations it serves.

Sandwell Consortium CIC
January 2026

Appendix 1

Participating organisations in focus groups for the IURE Research project

- **Bangladeshi Islamic Centre:** A voluntary charity organisation which aims to promote the well-being of the local community, and work towards lifelong learning for excellence. www.bicentre.org.uk
- **Bangladeshi Women's Association:** BWA provides an advice and advocacy service to the local community with workers who speak local languages. They also provide training for people to enhance skills and job opportunities, organise activities and outings for families. www.bwa-org.co.uk
- **Brushstrokes (part of Father Hudson's Caritas):** Working to help the most vulnerable members of our community as well as newly arrived families and individuals in Sandwell. Delivering a range of services including community learning, health and wellbeing, welfare and immigration advice services and employment support. www.brushstrokessandwell.org.uk
- **Community Connect Foundation:** CCF provides quality services to local residents of North Smethwick. Many have gained qualifications and moved on to find employment in the UK. CCF also provides welfare benefits advice, community learning, employment support, and health and wellbeing services. www.communityconnectfoundation.org.uk
- **Confederation of Bangladeshi Organisations/Greets Green Resource Centre:** CBO's overall vision is to improve quality of life for all local residents but primarily Bangladeshi and other BME groups living and working in the Sandwell Borough. www.cbo786.co.uk
- **Ideal for All:** Ideal for All is a user-led charity and social enterprise working to make life better for disabled, elderly and vulnerable people and their carers. www.idealforall.co.uk
- **Ileys Community Association:** Ileys provides a range of services for residents and particularly target support at communities from Somalia and other African countries. www.ileyscommunity.org
- **Smethwick Pakistani Muslim Association (SPMA):** A community-based organisation that seeks to represent and meet the needs of the Pakistani and the general ever-changing community in Smethwick and the surrounding areas. www.spmaltd.org.uk

- **Smethwick Youth & Community Centre (SYCC):** Engages with and supports the local community through a range of activities and services, including welfare advice, community learning and health and wellbeing. www.sycc.biz
- **SWEDA (Skills Work Enterprise Development Agency):** provides business advice, training and support for residents in disadvantaged neighbourhoods in Sandwell. www.sweda.org.uk
- **Sandwell Consortium CIC** (Lead for the IURE Research project): co-ordinates local services delivered by community-led organisations for Sandwell residents. Sandwell Consortium hosts a Residents Panel made up of residents from our community partners who come together to share experiences on health and wellbeing services in Sandwell.

Appendix 2

Demographics of participants in focus groups

12 focus groups took place across venues in Sandwell with 107 participants from Black and minoritised ethnic communities. The ethnicity, gender, first language and age of the research participants are set out in the tables below.



