Research Heroes

Community Engagement Event

Making Research Everybody's Business

Date: 21 January 2025

Hosted by: North London RRDN (Sandra O'Sullivan, Arti Sharma, Stuart Blackburn, Antoinette McNulty), Paddington Life Sciences (Suki Balendra)

Chaired by: Patricia Wharton

Presenters: Suki Balendra & Austen El-Osta

Getting together on research matters

The ‘Making Research Everybody’s Business’ event in January 2025 brought together 32 delegates – primarily from the community – to explore a crucial question:

How do we ensure research is accessible and inclusive for underrepresented groups?

This gathering with community members allowed us to consider some of the common barriers to participation in research, and how these barriers could be overcome.

The first session focused on understanding research and barriers to participation. This started with a general introduction to different types of research, particularly interventional studies, and an overview and initial findings of the Research Heroes study - the largest study in the UK aimed at promoting engagement among groups often underrepresented in research.

The second session focused on co-producing solutions to increase engagement on research matters and reduce barriers to participation, with a particular emphasis on underserved communities.

Participants engaged in six roundtable discussions, each facilitated by a rapporteur, to explore key themes and practical solutions. Key insights from the event are presented in the next following sections.

The Research Heroes Study

In the UK, policy efforts led by organisations such as the National Institute for Health and Care Research (NIHR) have sought to improve the diversity of research participants. These include the development of toolkits, targeted recruitment strategies and inclusive research design principles. However, evidence on the population-level barriers and enablers to participation remains fragmented and often limited by small sample sizes or narrow geographic focus.

There remains a critical need for large-scale, population-based insights that can inform more inclusive recruitment practices, outreach strategies and public engagement campaigns.

The *Research Heroes Study* led by the Self-Care Academic Research Unit (SCARU) at Imperial College London is a national initiative designed to address this gap by investigating why many communities remain underrepresented in health and care research, despite having the most to gain from it. The study was co-designed by Research Champions and community groups including input from the Nourish Hub and the Al-Manaar Muslim Culture Heritage Centre. The study was commissioned by Sandra O'Sullivan (North London RDN) and adopted on the NIHR portfolio. To our knowledge, it is one of the largest surveys of public engagement with health and care research ever conducted in the UK. The study focused on who participates in research, who is left out, and why.

The primary aim of the *Research Heroes Study* was to identify the demographic, experiential and structural predictors of participation in health and social care research. In doing so, we sought to better understand the underlying drivers of underrepresentation and to inform strategies to reduce inequities in research participation.

Specifically, we investigated the factors that influenced engagement, such as age, gender identity, ethnicity, education, disability status, English language proficiency, prior experience working in healthcare or research, and whether a participant had been explicitly invited to take part.

The study also addressed several secondary aims. These included assessing public understanding of research and its perceived relevance, identifying common barriers to participation, exploring preferred modes of engagement and communication and in examining participant satisfaction among those with previous research experience.

Finally, we sought to understand patterns in refusal to participate in research, including the sociodemographic characteristics associated with declining participation.

Insights from the Research Heroes Study

- Public understanding of research was strikingly low: only 6.4% fully understood what research is, yet nearly 80% believed it could benefit themselves or their communities.

- Participation was higher among those who had been explicitly invited to take part; lack of invitation was the single strongest predictor of non-participation.

- Just under 40% of respondents had ever taken part in research, but 77% had never been informed or invited by a healthcare provider.

- When people do participate, experiences are overwhelmingly positive: over 85% felt well informed, and more than 70% were satisfied with their involvement.

- The main motivations were altruism and curiosity, while the most common barriers were structural (time constraints, lack of awareness, irrelevant study topics and overly complex research processes).

- Participation patterns highlighted stark inequities: older adults, those with higher education, English fluency, and prior healthcare experience were significantly more likely to engage.

- Ethnic minority groups, non-English speakers, and gender-diverse participants reported lower satisfaction, highlighting gaps in cultural inclusion and communication quality.

- In underserved cohorts, disability emerged as the strongest predictor of research engagement, challenging assumptions about who is “reachable” and highlighting the importance of accessible design.

- Younger adults showed interest but were less likely to have participated, indicating a mismatch between traditional engagement methods and younger people’s preferred modes of involvement.

- Practical enablers, such as better care, clearer communication, shorter surveys, translated materials, financial reimbursement and culturally aligned research champions, were widely endorsed across groups.

- Digital participation was preferred by most respondents, but exclusive reliance on digital routes risks excluding those with limited digital access or literacy.

- Completing the survey itself increased research awareness for more than half of participants, demonstrating that engagement tools can also serve as public education interventions.

Sandra O’Sullivan, Research Delivery Manager,
North London RRDN, Primary Care and Out of Hospital Settings, said

“Diversity in clinical trials is not a matter of political correctness; it is a fundamental requirement for scientific validity and health equity”.

Dr Suki Balendra, Director of Strategic Partnerships,
Paddington Life Sciences. said:

“For many groups, the persistent lack of diversity in contemporary clinical trials … only exacerbates those perceptions that research institutions do exclude and are not worthy of our trust. It’s hugely important to recruit patients that are diverse into your clinical trials to ensure that they are fair and that you build trust with your communities”.

Dr Austen El-Osta, Principal Investigator
of the Research Heroes Study, Imperial College London, said:

“Research becomes transformational only when the people most often left out are placed at the centre. The Research Heroes Study shows that communities are not peripheral to the evidence base but are in fact the evidence base and when we create the conditions for trust, access and reciprocity, participation flourishes and the science itself becomes more equitable”.

Key Insights from Discussions

Underserved communities are often willing to engage in research but face systemic barriers. The discussions revealed three major themes:

1. Awareness and trust in research,
2. The changing nature of research priorities,
3. The need for effective strategies to engage with underserved groups. There was also a strong call to reframe what we mean by ‘hard-to-reach’ groups.

> *“We need to stop calling them ‘hard-to-reach’*
> *& start calling them ‘need-to-reach”*

1. Awareness and Trust in Research

Many participants had limited awareness of different types of research, particularly clinical trials. Trust emerged as a central factor in willingness to participate.

Most trusted sources of research information:

- Healthcare providers (GPs, hospitals, social prescribers)
- Community engagement events
- Word of mouth and family history of participation

Less trustworthy, but also common sources:

- Social media
- TV documentaries
- Newspaper advertisements

Who Do People Trust?

Long-standing GPs & healthcare professionals
They are seen as reliable sources

Community leaders & faith groups
These are key promoters of culturally relevant engagement

Friends & family members
As they are those with firsthand research experience

In-person or telephone explanations
These are preferred over impersonal leaflets

2. Research Priorities That Matter to Communities

Participants noted that while that the current research opportunities available are important, they do not particularly resonate with some members of the community.

Participants identified key areas they believe should be prioritised in research:
- Health conditions/disease: chronic diseases (diabetes, hypertension, cardiovascular disease), black maternal mortality, sickle cell disease.
- Mental health & wellbeing: depression, childhood trauma, etc.
- Access to Healthcare Services (incl. NHS App etc.)
- Social Isolation & Loneliness
- Crime & safety
- Environmental pollution & sustainability
- Women's health
- Access to housing: Impact of housing conditions, cultural diet, substance abuse, and intergenerational trauma.
- Family wellbeing & childcare
- Disabilities & accessibility issues

3. Effective Strategies for Engaging with Underserved Communities

Preferred Communication Channels:
- Community-based outreach (roadshows, local events, places of worship).
- SMS reminders from GP surgeries.
- Social media platforms (Instagram, WhatsApp).
- Printed & digital flyers in libraries, community centres.

Language & Messaging:
- Research must be framed as a civic duty, similar to jury service.
- Hopeful & engaging language – avoid clinical jargon & judgmental tones.
- Emphasising direct benefits (e.g., vouchers, improved local services, policy impact).
- Speaking to lived experiences, particularly in conditions like sickle cell disease.

Structural & Logistical Considerations
- Trusted messengers – GPs, community champions, faith leaders.
- Peer-led & culturally matched engagement – long-term relationship-building rather than one-off outreach.
- Ongoing updates & feedback loops – ensuring participants see the impact of their involvement.

From insight to impact: a call to action

This roundtable wasn't just a listening exercise, but a mandate for change. The voices in the room were clear: research must become more inclusive, responsive, and relevant to those it claims to serve. The following calls to action distil what we heard into a practical agenda for researchers, funders, and system leaders. It's time to move from intention to implementation.

Stop calling them 'hard-to-reach'

Reframe the narrative. These are *need-to-reach* communities. Language shapes attitudes & action

Build authentic trust, not token touchpoints

Partner with long-standing GPs, community champions, and faith leaders. Relationships, not outreach campaigns, drive engagement

Design research that matters

Prioritise mental health, chronic illness, black maternal health, sickle cell disease, domestic abuse & social determinants
because that's what communities care about

Simplify the message. Humanise the method

Replace jargon with stories. Swap flyers for face time. Treat research like civic duty: accessible, inclusive & essential

Meet people where they are. Literally

Local events, places of worship, schools, WhatsApp groups. This is the real-world research infrastructure

Close the loop, visibly

Participants must *see* the impact of their involvement. Without feedback, trust withers

Create continuity, not one-offs

Embed research into everyday institutions (e.g., schools, libraries, community centres so it becomes familiar, not foreign)

Fund community-led models

Resource peer-led, culturally matched programmes with long-term funding and structural backing

Mandate transparency in research outcomes

Share what worked, what didn't, and what's next. Let communities shape the future agenda

What's Next?
Moving from Insights to Action

From the discussions, four critical next steps emerged:

1. **Building Trust:** Collaborate with trusted local figures & maintain transparency in research objectives and outcomes.
2. **Simplifying Communication:** Use accessible, non-technical language & multiple engagement channels.
3. **Demonstrating Tangible Benefits:** Provide incentives & ensure research findings lead to meaningful change.
4. **Creating Long-Term Engagement Models:** Embed research discussions in schools, faith groups, and cultural networks.

By embedding these principles into future research initiatives, we can break down barriers and ensure research is truly representative of the communities it aims to serve.

Thank you to all participants who contributed their time, insights and lived experiences to this important conversation

For more information, please contact Suki Balendra (suki.mistry1@nhs.net)

Our partners

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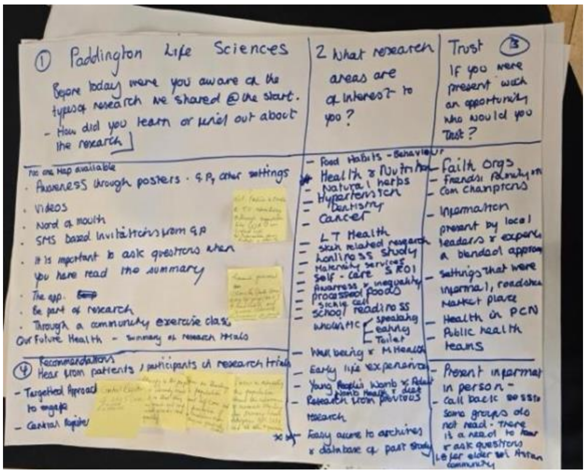

① Paddington Life Sciences

Before today were you aware of the types of research we shared @ the start.

- How did you learn or find out about the research

- No one map available
- Awareness through posters · G.P., other settings
- Videos
- Word of mouth
- SMS based invitations from G.P
- It is important to ask questions when you have read the summary
- The app.
- Be part of research
- Through a community exercise class

Our Future Health - summary of research trials

④ Recommendations

Hear from patients / participants in research trials

- Targeted Approach to engage
- Central Register

2 What research areas are of interest to you?

- Food Habits - Behaviour
- Health & Nutrition
- Natural herbs
- Hypertension
- Dentistry
- Cancer
- LT Health
- Skin related research
- loneliness study
- Maternity services
- Self - care
- Awareness & inequality
- processed foods
- Sickle cell
- School readiness
- wholistic – speaking, eating, Toilet
- Well being & M Health
- Early life experiences
- Young People's womb & Adult womb health & diet
- Research from previous research
- Easy access to archives & database of past study

Trust ③

If you were present with an opportunity who would you Trust?

- Faith orgs
- Friends, family
- Com champions
- Information present by local leaders & experts, a blended approach
- Settings that were informal, roadshow, Market place
- Health in PCN
- Public health teams

- Present information in person –
- Call back sessions

Some groups do not read - there is a need to hear & ask questions

Letter elder in Asian community

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NIHR | Applied Research Collaboration Northwest London

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