Research
Engagement
Network

Engaging Marginalised Communities: A Community Research Project

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July 2024

Switchboard
Connecting you to LGBTQ support

DIVERSITY
RESOURCE
INTERNATIONAL

sussexinterpretingservices

Crawley
Community
Action

the clare project

Trust for
Developing
Communities

Voluntary Action
Arun & Chichester

3VA Wealden Eastbourne Lewes District

brighton and sussex
health research partnership

NIHR | Clinical Research Network
Kent, Surrey and Sussex

NHS
Sussex

NHS
Sussex Partnership
NHS Foundation Trust

Abstract

A 6-month Sussex-based project was funded by NHS England (£100,000) under their Research Engagement Network (REN) development programme in October 2023.

This project had 3 key aims:

1. To create a **regional network of diverse community researchers** who could support Sussex-based health and care research.
2. To **build the capacity of community researchers** through development training and qualitative interviewing experience.
3. To **engage minoritised groups from areas of deprivation in Sussex** and investigate how to **improve their participation in health and care services and research**.

VCSE partners recruited fifteen community researchers with lived experience of the communities and marginalised groups that were the focus of the research i.e., Lesbian, Gay, Bisexual, Transgender, Queer, Questioning, and other identities (LGBTQ+), Trans, Non-binary and intersex (TNBI) or Racially Minoritised/Global Majority. Forty-two people were interviewed between 27th February 2024 and 22nd March 2024.

Key recommendations

1. Research teams should consider how negative experiences and perceptions of marginalisation by mainstream society might impact engagement in health and care research.

2. Further research with TNBI communities is needed to identify and address the challenges they face when engaging with the NHS.

3. Ensure translation and interpretation support is included in all health and care research activities.

4. Health and care research teams should adopt a co-creative approach, exploring partnerships with relevant Voluntary, Community and Social Enterprise (VCSE) organisations at the early stages of planning a research study.

5. Integrate community engagement and co-creation approaches into the planning of health and care research to support healthcare topics important to local communities.

6. Maximise the accessibility of online information through local NHS websites.

7. Ensure marketing and communication materials for research reflect a broad demographic profile, enabling potential respondents to see themselves represented.

8. Researchers should be mindful of unintentional barriers to participation that may arise due to language or learning differences.

Contents

Executive Summary

Since the COVID-19 pandemic, there has been increased awareness that people from minoritised groups are less likely to be included in, and participate in, health and care research. The national Research Engagement Network (REN) Development Programme, launched in 2022 and funded by NHS England and the Department of Health and Social Care, has funded Integrated Care Systems to grow their local research engagement networks by working with local voluntary, community and social enterprise (VCSE) sector organisations to engage these “underserved” communities.

The Brighton and Sussex Health Research Partnership (HRP) worked in partnership with NHS Sussex, NIHR Clinical Research Network Kent, Surrey and Sussex (CRN KSS) and Sussex Partnership NHS Foundation Trust, to successfully bid for £100,000, to:

- Create a regional network of diverse community researchers to support Sussex based health and care research.
- Build the capacity and capability of community researchers through development training and qualitative interviewing experience.
- Engage minoritised groups from areas of deprivation in Sussex and investigate how to improve their participation in health and care services and research.

Support was sourced from the University of Chichester to ensure robust academic evaluation.

With a local focus on Racially Minoritised/Global Majority communities and Lesbian, Gay, Bisexual, Transgender and non-binary people, local VCSE partners recruited fifteen community researchers who are members of these communities. The community researchers received training and support to interview community members from targeted areas of deprivation across Sussex, with interviewees recruited by wider place-based VCSE partners, thus broadening the partnership working integral to the REN. Researchers interviewed forty-two people over February and March 2024.

The research elicited views on:

- Experiences and perceptions of the NHS
- Accessing health and care information
- Awareness and understanding of health and care research.
- Participating in health and care research

Live examples of health and care research were used to provide context and to gather views on these particular studies.

Key recommendations from the project:

1. Research teams should consider how negative experiences and perceptions of marginalisation by mainstream society might impact engagement in health and care research.
2. Conduct further research with Transgender, Non-binary, and Intersex (TNBI) communities to identify challenges they face when engaging with the NHS.
3. Ensure translation and interpretation support is included in all health and care research activities.
4. Health and care research teams should adopt a co-creative approach, exploring partnerships with relevant VCSEs at the early stages of planning a research study.
5. Integrate community engagement and co-creation approaches into the planning of health and care research to support healthcare topics important to local communities.
6. Maximise the accessibility of online information through local NHS websites.
7. Ensure that marketing and communication of research materials reflect a broad demographic profile, allowing potential respondents to see themselves represented.
8. Researchers should be mindful of unintentional barriers to participation that may arise due to language or learning differences.

Next steps

Further REN funding has been secured for a three-month period beyond the original end of project (end March 2024), which will facilitate the production of summary and learning resources and maintain VCSE partner engagement.

Recommendations from the project will be reviewed and addressed. Community researchers will be invited to undertake further insight capture for NHS Sussex based on the views elicited through their research. This approach will ensure the continuation of their skills whilst fostering further opportunities that build on existing work and include underserved communities in local health and care research.

The Sussex Diversity in Research Engagement Network, which has successfully brought together key project partners and attracted wider interest and input, will be maintained. Learning from other regional and national REN work will inform the ongoing direction of the Sussex Network. In addition, further funding opportunities are available for RENs, including a focus on expanding and diversifying activity to increase applied mental health research taking place in underserved communities. The Sussex REN partnership submitted an Expression of Interest for this opportunity on July 1st 2024.

Background and Introduction

Since the COVID-19 global pandemic, there has been an improved awareness that people from minoritised groups are less likely to be included in, and therefore participate in, health and care research. Inclusion or participation could mean working with research teams to decide what should be studied, designing studies, or taking part in a research study (i.e., answering questions). The term 'Underserved Groups' is now commonly used to refer to those excluded from research and highlights that the onus of this lack of inclusion lies with the health and care research community.

There is a range of factors that contribute to the lack of inclusion of underserved groups, operating at different levels and for various reasons. These include individual researchers' recruitment of participants, the structures of health and care services, language barriers, research exclusion criteria, historical discrimination, lack of trust, and stigma associated with certain health conditions.

Sussex's 1.7 million population is diverse and distributed over large coastal, rural and economically disadvantaged areas. The obstacles to research inclusion, participation and engagement are further compounded for people who live in these areas and also identify as Lesbian, Gay, Bisexual, Transgender, Queer, Questioning, and other identities (LGBTQ+; 5% of the population) and those who are Racially Minoritised/the Global Majority (9% of the population).

When the health and care research community fails to embrace Sussex's diversity in its studies, this impacts the extent to which health inequalities can be addressed. Many local health and care researchers actively want to improve diversity in research, and contribute to reductions in health inequalities, but have reported being unsure where to start.

The quality and reach of health and care research has greater impact for marginalised groups when conducted in collaboration with the communities it aims to serve. Engaging community researchers and people with lived experiences, such as those from marginalised communities or with diverse health conditions, serves as a means to amplify seldom heard voices within research, and builds on existing good practice of community engagement across the NHS and local authorities. Furthermore, employing co-creative approaches facilitates the design of more meaningful health and care research, ultimately leading to better outcomes, success rates and impact on inequalities.

Project Partners

This community researcher project was delivered in partnership by the following organisations:

- The Brighton and Sussex Health Research Partnership (HRP),
- NHS Sussex

- NIHR Clinical Research Network Kent Surrey Sussex (CRN KSS)
- Sussex Partnership NHS Foundation Trust (SPFT)

and the following Voluntary, Community & Social Enterprise (VCSE) organisations:

- Brighton & Hove Switchboard who provide support services run for and by LGBTQ+ people
- Crawley Community Action for the people of Crawley
- Diversity Resource International (DRI) who support ethnically diverse and migrant communities across Sussex to improve lives and achieve potential
- Sussex Interpreting Services (SIS) who deliver a range of language support services and community engagement initiatives
- The Clare Project who support Trans, Non-Binary and Intersex adults in Sussex
- Trust for Developing Communities (TDC) who work with communities facing poverty and exclusion to take action and deliver community-led solutions
- Voluntary Action Arun & Chichester (VAAC) who promote and support charities and community groups in Arun and Chichester
- Voluntary Action for Eastbourne, Lewes District, and Wealden (3VA) who support communities in East Sussex.

The key aims of this project were to:

1) to create a regional network of diverse community researchers who could support Sussex-based health and care research;
2) build the capacity of community researchers through development training and qualitative interviewing experience;
3) engage minoritised groups from areas of deprivation in Sussex and investigate how to improve their participation in Health and care services and research.

Findings would be used to make recommendations to health and care research teams on best practice and approaches for including marginalised communities in local Sussex-based research. Community insights and learning from this project will also support ongoing change and improvement in local health and care services and key work programmes, including primary care and prevention. Learning will also support work to engage with and involve diverse groups from Core20PLUS5 neighbourhoods and communities in coproduction and service design, development and improvement activities in line with the Sussex Health and Care Working with People and Communities Strategy.

Funding

This 6-month project was funded by NHS England (£100,000) under their Research Engagement Network (REN) development programme in October 2023.

Research Methods

This project was developed on the principles of community research.

> “Community-based research is conducted with and by, not on or to, community members.”

Community research has at its core an accessible, inclusive methodological approach in which a co-creative, community-focused approach is foremost.

Project Aims

This project had 3 key aims:

1. To create a regional network of diverse community researchers who could support Sussex-based health and care research.
2. To build the capacity of community researchers through development training and qualitative interviewing experience.
3. To engage minoritised groups from areas of deprivation in Sussex and investigate how to improve their participation in health and care services and research.

Project Objectives

- To interview community members about their views and opinions on health and care research and how it can be conducted to increase the involvement and participation of people from LGBTQ+, TNBI, and racially minoritised/global majority backgrounds.

- To explore what matters to community members and which health topics would attract them to participate in health and care research.

- To discuss what health and care research means to communities and their experiences of participating in research, identify barriers and enablers, and identify the best channels for communicating about participation in research.

- To discuss live examples of health and care studies to understand specific barriers and facilitators.

- To make recommendations on tangible steps that researchers across partner organisations, and research delivery teams can take to engage diverse communities better.

Community researcher recruitment and development training

Community researchers were required to have experience or an interest in community engagement, be open-minded, non-judgmental, and curious, recognise the value of research, and be able to commit time to the project's training and research.

Each VCSE partner recruited 1 or 2 community researchers (15 in total) with lived experience of the communities and marginalised groups that were the focus of the research i.e., LGBTQ+, TNBI or Racially Minoritised/Global Majority. VCSEs partners connected with known communities which they already had strong links with and extensive experience supporting.

All community researchers underwent bespoke training to ensure they possess appropriate research skills and knowledge of qualitative and community research. This training was designed to equip them with the necessary tools and understanding to contribute to the research process effectively. The learning objectives of the training were to understand:

- Background and objectives of the REN project
- Principles of qualitative research
- Principles of community research
- Community research in practice
- The core principle for good qualitative interviewing.
- How to use the discussion/interview guide during the interview
- Analysing qualitative interviews
- Coding and preparing qualitative analysis for report writing.
- Summary report writing
- Opportunities for community researchers

The Trust for Developing Communities devised and delivered the training with support from VCSE partner organisations and REN partners from the NHS and National Institute for Health and Care Research.

Community research respondent recruitment

Respondents were recruited based on the following criteria:
1. Lived in one of the following locations in an area of socioeconomic disadvantage:
    - Arun and Chichester
    - Crawley
    - Weldon, Eastbourne and Lewes District
2. Identified as LGBTQ+, TNBI or Racially Minoritised/Global Majority.

Project partners based in the key areas of focus facilitated the recruitment. Respondents could also be known to the community researchers.

All respondents were given a £25 gift voucher as a 'thank you' to remunerate their time.

Qualitative data collection and analysis

Community researchers interviewed between 2–4 respondents each. They asked respondents questions using a semi-structured interview guide which covered: experiences of participating in health and care research, how inclusion could be improved, perceived barriers and enablers to participation, health topic areas of interest, and best channels for communicating research opportunities. The study adverts for two live research studies were also presented and participants were asked their opinion about the attractiveness of the recruitment materials and the study. The two live studies were:

1. Outdoor swimming as a nature-based intervention for stress, depression and anxiety (OUTSIDE II).

2. A survey to learn about thoughts and perceptions of medical device technology used to diagnose, monitor, or treat a health condition (MINDER).

The interviews were recorded and later transcribed, and the transcribed interviews were analysed using Thematic Analysis methods.

Each community researcher produced a summary report of the interviews they conducted. Their report summaries were then analysed and consolidated to make this report.

Summary Findings

In total, forty-two people were interviewed between 27th February 2024 and 22nd March 2024.

Most respondents were new to the concept of community research. However, if asked to guess what it meant, most responded with a broadly accurate description of community research.

Overall, respondents' responses did not suggest a substantive relationship between their attitudes and experiences towards the NHS and where the respondents lived. The exceptions to this were Trans, Non-Binary, and Intersex respondents. Some commented that compared to Brighton, their location was not as well-resourced regarding support services, groups and knowledgeable healthcare professionals.

Experiences and Perceptions of the NHS

Most respondents said in principle that the NHS was a highly appreciated, valued, well-respected, and world-leading institution. Specific mention was made to the service's free-for-all nature at the point of delivery; NHS staff (nurses, doctors) were described as professional and, in most cases, kind, caring, and considerate.

Respondents from TNBI backgrounds seemed proportionally less positive about experiences in the NHS. Many respondents reported difficult, negative, and challenging experiences when engaging with the NHS. Many of these respondents spoke specifically of difficulties arising from gender-critical behaviour, attitudes, and views.

Most respondents, while acknowledging the value and benefits of the NHS, also perceived that the NHS is not working as effectively as it could. Most felt this was due to inadequate or restrictive funding, staff shortages, challenging work conditions, and high, unplanned demand.

Several issues were common across all respondents. These included:
- Waiting times to see their GP
- Inability to secure a face-to-face appointment with their GP
- Waiting times for hospital referrals, appointments, diagnosis, and surgery
- Unhelpful or rude reception staff, typically in GP practices.

Accessing health and care Information

Respondents typically access information on the NHS in various ways. Many initially mentioned their GPs (e.g., when they were in a GP surgery). However, when prompted, only a minority could be more specific about when and what type of information they were accessing through this means.

Many respondents said they typically sought specific information directly from their GP. Overall, these respondents expressed satisfaction with this approach to accessing NHS information.

The internet was also commonly mentioned. Most respondents said they would ‘Google’ their health symptoms or concerns. However, many respondents were uncertain about the sites they accessed through Google. Nevertheless, some respondents stated they were accessing the NHS website, which was universally acknowledged as helpful and trustworthy.

An exception among research respondents regarding accessing health information online, were those with English as a second language. They felt using the internet was less accessible than speaking with GPs directly or accessing flyers, posters, or booklets. These respondents preferred speaking directly to their GP, and although they would access flyers, printed materials and information, they would want to follow this up with a consultation with their GP.

Some respondents from TNBI backgrounds were cautious regarding information sources. For TNBI respondents, it was important that the information they accessed was objective, acknowledged the importance of gender-affirming care, and was a genuine and trustworthy source.

LGBTQ+ respondents were equally responsive and vocal compared to other respondents. Their comments, perspectives, and experiences were reflective and aligned with the research findings. Moreover, they were unequivocal in their belief in the value and benefits of community research and its ability to engage with marginalised groups, including LGBTQ+ people, effectively.

Awareness and understanding of health and care research

Overall, there was a mixed response about the extent to which respondents were aware of health and care research, especially in the NHS.

A few respondents recalled taking part in clinical research conducted by their GP practice or a hospital department where they were receiving treatment. Some said they had taken part either because they felt they should (soft pressure from health professionals) or due to a sense of ‘giving back’ to help others.

Participating in health and care research

Regardless of their knowledge or awareness of this subject, most respondents recognised the societal benefit of participating in health and care research. However, a minority expressed caution when discussing the possibility of participating in such research.

There were mixed views on the extent to which respondents preferred to have researchers with the same backgrounds and characteristics as them. Participant from LGBTQ+ groups, TNBI groups and those with English as a second language generally felt they would be more comfortable being interviewed by researchers from their backgrounds with shared lived experiences.

Feedback on live research examples

Live research 1: Outdoor swimming as a nature-based intervention for stress, depression and anxiety (OUTSIDE II).

Most respondents who had time to assess this study advert materials expressed a degree of interest. However, only a minority of respondents felt they were likely to spontaneously pick up the information if they saw it in a public setting.

A minority of respondents said they were unlikely to click on the QR code unless they were sure they would receive new information, not information already contained in the leaflet. A few respondents said the QR code would put them off as they felt it required a level of technical knowledge they did not possess.

Live research 2: MINDER: Technology Integrated Health Management Technology Perceptions; a survey to learn about thoughts and perceptions of medical device technology used to diagnose, monitor, or treat a health condition.

Most respondents seemed less interested in the MINDER research and responded less positively to the information. Many respondents acknowledged that it was likely to represent an exciting study for those who have a specific interest in the condition being addressed and the technology being researched. However, most said it did not relate or was irrelevant to them.

Recommendations

1. **What experiences have individuals had in participating in health and care research?**
   Why don't people from different marginalised groups take part in local studies?

A minority of respondents to this study had experience in participating in health and care research.

Respondents' general perception regarding why they had not taken part in health and care research is that they had not been asked or approached to participate. Some believe this is because health and care research teams do not consider them appropriate for their research studies.

It is **recommended** that when planning or considering health and care research, research teams are aware of, and consider, how negative experiences and perceptions of being perceived as 'other' (i.e., marginalised) by mainstream society might influence and impact the willingness to take part in health and care research.

Trans, Non-Binary and Intersex (TNBI)

Many TNBI respondents faced direct gender-based discrimination. This discrimination prevented them from accessing the full range of health and care services necessary to meet their specific and unique needs. Attitudes they experienced from some healthcare professionals caused discomfort and distress, forcing many to seek alternatives or circumvent areas of the NHS to meet their health and care needs.

The negativity experienced by some of these respondents resulted in many adopting a cautious approach when engaging with all aspects of the NHS. Their caution heightened their scrutiny and questioning of the NHS, primarily to feel safe and ensure the authenticity of the NHS's intentions.

Although most TNBI respondents would, in principle, participate in health and care research, they would only do so with assurances that the difficulties they have experienced in areas of the NHS would not be replicated in the research study. Many of the problems and challenges experienced by TNBI respondents are long-standing. In principle, most would participate in health and care research that they believe will benefit them or others like them.

It is **recommended** that further research be conducted specifically with TNBI communities. The aim would be to identify the extent and breadth of the challenges, barriers, and struggles faced when engaging with the NHS. Therefore, the NHS could use what is learned from a broader study to identify enablers and encourage people from TNBI backgrounds to participate in health and care research, especially in the NHS.

English as a second language

Despite expressing praise and speaking positively, many respondents with English as a second language also spoke of the challenges and frustrations they experience when interacting with the NHS. Examples of positive engagement included the availability of GPs and NHS staff who dedicated sufficient time to ensure complete understanding of the information or advice given. Similarly, the patient was able to ensure the healthcare professional understood them. The perceived lack of translated materials and the limited access to interpreters limit the impact and effectiveness of these respondents' engagements with the NHS.

It is **recommended** that translation and interpretation support and resources are factored into and accompany all health and care research activity. This will likely involve ensuring resources are available for interpretation and that information on the research requirements is available in other languages. In addition, awareness of cultural and faith-based sensitivities should also be an inherent consideration when conducting research.

2. What practical steps can we take locally to improve inclusion in research? Any perceived barriers/enablers.

Among some, there’s a strong perception that health and care research teams are less interested in people from different (i.e., theirs) backgrounds for health and care research.

Most respondents know, or have experience working with, VCSEs and support groups. These bodies typically have good relationships and reputations among respondents. Involving community and support groups in health and care research will likely provide added authenticity, confidence, and incentive for these respondents to participate in NHS health and care research.

It is **recommended** that health and care research teams explore partnerships with relevant and appropriate VCSEs or support organisations at the early stages planning and designing a research study. Attention should be given to ensuring the groups and organisations align with the communities the research seeks to engage with. Adopting a co-creative approach to community research will likely result in better engagement and participation from marginalised community groups.

3. What health topics would attract participation in health and care research? What matters to people in our local communities?

Most respondents prioritise health conditions and challenges commonly observed in their communities such as diabetes, cancer, gender-affirming care, high blood pressure, and dementia. Although the concept of community research was new to most respondents, it was a method of engagement they could relate to which would encourage their participation in health and care research which covered these topics and more generally.

It is **recommended** that community engagement principles and a co-creation community research approach be factored into planning relevant health and care research. This integration will help support the identification of healthcare topics important to local communities and establish areas of study that could address them.

4. What are the best channels for communicating research participation opportunities?

Overall, (but not exclusively) GPs are typically the preferred health and care information source. Notwithstanding discontent with appointments and waiting times to see GPs, many GPs remain trusted and are preferred information sources. However, this does not necessarily extend to health and care research.

While the practical limitation of GPs' time and capacity is recognised, consideration should be given to exploring what role, if any, GPs might have in advocating involvement in actual or the principle of health and care research.

For most respondents, the internet provides an important (and sometimes vital) point of reference and source of information on health matters. The NHS website was mentioned and applauded. However, many believe the NHS website is not as accessible as it should be. Neurodivergent and people with English as a second language are seen as disadvantaged by the current NHS website.

It is **recommended** that consideration be given to maximising the accessibility of online information through local NHS websites. Its accessibility features should be prominent, clear, and practical. Users should be required to navigate only a few pages to access the information they acquire.

Many respondents find traditional information sources such as flyers, posters, and booklets valuable. However, the research found that respondents are less likely to engage with these sources if they contain dense text or if used images do not reflect the diversity of their population. In addition, it was felt that all information needs to be clear and concise, and photos need to be impactful.

It is **recommended** that the marketing and communication of research materials used to encourage involvement and participation, should reflect a broad demographic profile. In addition, potential respondents should be able to see themselves reflected in marketing information and imagery.

For many respondents, perceptions of accessibility are vital in deciding whether they will participate in health and care research. Language and neurodivergence are significant barriers to participation in this regard.

It is **recommended** that whatever channels are used to communicate research participation opportunities, researchers should be aware of unintentional barriers to participation that may arise due to language or learning differences.

Main Findings

In total, forty-two people were interviewed between 27th February 2024 and 22nd March 2024. 20 people identified as LGBTQ+ or TNBI and 22 identified as being from Racially Minoritised/Global Majority communities.

Most respondents were new to the concept of community research. However, if asked to guess what it meant, most responded with a broadly accurate description of the community research. It was widely acknowledged as a research concept likely to provide findings reflective of people from their backgrounds and life experiences. Most respondents welcomed the opportunity to participate in a community-researched-themed project. They held high hopes that research of this nature would be more relevant to them and ultimately have a more direct and tangible impact on them and those from their communities.

Overall, respondents' responses did not suggest a substantive relationship between their attitudes and experiences towards the NHS and where the respondents lived. When responding to questions on the NHS, most respondents' perceptions and experiences did not refer to where they live. However, it should be noted the research questions did not specifically ask respondents to consider or compare their NHS experiences or perceptions based on where they lived.

The exceptions to this were TNBI respondents. Some commented that compared to Brighton, their location was not as well-resourced regarding support services, groups and knowledgeable healthcare professionals. In addition, some respondents felt that general attitudes to gender identity were less advanced in their locations compared to Brighton.

Experiences and perceptions of the NHS.

Interviews began with community researchers asking respondents about general perceptions and experiences of the NHS. Across most respondents, there was consistency in their responses to this question. Most respondents said in principle, the NHS was a highly appreciated, valued, well-respected and world-leading institution. Specific mention was made to the nature of the service being free for all at the point of delivery; NHS staff (nurses and doctors) were described as professional and, in most cases, kind, caring and considerate. Also mentioned was the perception that NHS staff are committed, dedicated and hard-working.

Most respondents could provide examples and real-life experiences when the NHS provided them with care and support for themselves or their families that they greatly appreciated. Interestingly, many of these positive reflections on the NHS experiences referenced by respondents tended to relate to hospital or specialist healthcare instead of primary GP practice interactions.

Many respondents with experience of healthcare services in different countries were more likely than others to praise the virtues of the NHS more broadly. These respondents typically compared the NHS far more favourably to the healthcare systems in the countries they had once lived. Most respondents in this category highlighted that the NHS is a free service. They had experienced a health service they were expected to pay for, which was in stark contrast to the health service they now had available.

> *’They supported me a lot as I suffered from mental health issues as I fled from a horrible war in my country, and I am feeling mentally unstable. The treatment is completely right, and they referred me to the right people, and I am feeling on the mend.”*

The exception to this was respondents who had recently arrived in the UK due to conflict in their country of origin. These respondents perceived fewer disparities between the health system they were familiar with and that of the NHS. In some respects, they believed that the health system they were accustomed to offered benefits in terms of care delivery that were superior to those in the UK. Nevertheless, they acknowledged the admirable principles, intentions and efforts of the NHS.

However, TNBI respondents expressed less positivity towards the NHS, with many recounting difficult, negative, and challenging experiences. Specifically, they highlighted issues related to gender-critical behaviour, attitudes, and views. Typical were instances where respondents' gender identities were disregarded, deemed irrelevant, or met with scepticism. Moreover, in both primary and secondary care settings, many respondents felt they encountered comparable challenges, struggles, and negative attitudes from NHS healthcare professionals

The difficulties and negativities experienced by TNBI respondents were profound and fundamental. This has caused many to develop strong adverse reactions to elements of the NHS, which resulted in some expressing a lack of trust and confidence in the NHS's ability to meet their health needs.

On this latter point, some respondents spoke of their distress or disappointment over their doctor's limited knowledge or experience regarding gender-affirming care. It was also considered that the NHS, in general, needs to do significantly better to support TNBI individuals in navigating NHS services to obtain the same degree of benefits as the wider population. Many respondents emphasised that gender identity often coexists with a neuro-divergent diagnosis. In these circumstances, the difficulties experienced with the NHS were usually compounded, and sometimes, their conditions were inadequately treated.

These experiences have caused many TNBI people to conclude that engaging with the NHS to obtain the healthcare they seek would be challenging.

> *“I know people who have tried for as long as they could to keep a health issue at bay themselves because they didn’t want to face going into the care of the NHS.”*
>
> *“The boundaries of really having to prove you are trans… unless you really fit into that expectation of what a lot of people expect trans people to be, especially if it is a cis doctor or cis healthcare professional.”*
>
> *“Issues that don’t relate to their gender at all, their gender always comes into it, and it always influences and becomes the main target. So other issues are just left alone.”*
>
> *“They were uninterested in providing bridging services and said they didn't have the information even though there are easy-to-access documents available from the NHS.”*

Many respondents, while acknowledging the value and benefits of the NHS, accompanied that belief with a perception that the NHS is not working as effectively as it could. Most felt this was due to inadequate or restrictive funding, staff shortages, challenging work conditions, and high, unplanned demand. The solution to these issues was widely considered to be more **government funding** for the NHS. Many respondents believed that the government was not doing enough to support the NHS, and as a result, the service was not as effective as it could be despite the efforts of NHS frontline staff.

> *"There are people within the NHS with the best intentions, but there are not enough resources, and it’s underfunded.”*

Despite many respondents speaking highly and favourably about the NHS with minimal prompting, most also acknowledged that several aspects of the NHS needed improvement and that their experiences with it had not always been positive. Further, many respondents whose immediate or spontaneous perception of the NHS was highly positive shortly after gave examples of experiences with the NHS that they found to be highly negative, disappointing and, in some cases, distressing.

Several issues were common across all respondents. These included:

- Waiting times to see their GP
- Inability to secure a face-to-face appointment with their GP
- Waiting times for hospital referrals, appointments, diagnosis, and surgery
- Unhelpful or rude reception staff.

A common criticism of the NHS was based on experiences booking or accessing a GP. Many respondents gave examples of difficulties making GP appointments or attempting to speak to them. Some heavily criticised systems for booking appointments as not being accessible and practical. Accessibility was commented on by many respondents with English as a second language. They gave examples of difficulties communicating with NHS staff or with the booking systems that required them to provide information, symptoms, and why they needed to see a doctor. Neurodivergent respondents spoke of having similar problems. In addition, speaking with a receptionist only sometimes resolved these issues, as recalled experiences of not being understood, or not understanding when talking to NHS hospital or GP reception staff.

> *"You can't get past the receptionist, dogmatic kind of thing. And it's like you have to have a body armour before you try to make an appointment."*

Other specific experiences included:

- Dismissive attitudes and responses from senior health professionals.
- The NHS of the past felt more effective, was better managed, had adequate resources and was not operating beyond capacity.
- Not having enough information following medical procedures, which could result in worsening health. Respondents have experienced situations where their doctor’s post-procedure or surgery advice, recommendations, or consultations were not fully understood. In some cases, failure to understand resulted in their condition worsening, not improving, or they experienced additional complications.
- Unwillingness to make reasonable adjustments to accommodate respondents’ neurodivergence or language barriers.
- Difficulty getting assurances that an interpreter would be present for those who needed one. For some respondents, despite asking for an interpreter, or hoping one could be provided, the NHS could not guarantee one would be provided.
- Short-notice cancellation of hospital appointments or procedures.
- Misdiagnosis due to a failure to understand and acknowledge the patients' perceptions or concerns.
- Frustration of not being able to see the same doctor consistently, prompting the perception that patients have to repeatedly explain their problems to different doctors. Some felt this system promoted inconsistent and confusing care.

> *"The surgeon who did the operation was the first one who explained to me what he was about to do. So, until that point, I didn't really understand what was happening."*

Nevertheless, despite these experiences, respondents still broadly held positive perceptions of the NHS. Indeed, amongst some of the Racially Minoritised/Global Majority respondents, there was a degree of reluctance to be seen as too critical of the NHS. This hesitancy appeared to be borne out of a concern that being too critical could impact the extent to which they have access to the NHS. For that reason, many who were critical of the NHS spoke of specific instances and circumstances but would typically qualify those negative experiences by concluding that the NHS is essentially a good or excellent service.

Accessing health and care Information.

Respondents were asked how they typically found information on the areas of health and care that were important to them.

Not surprisingly, across all respondents, there is a mixture of ways by which they typically access information on the NHS. Many respondents initially mentioned their **GPs** (e.g., when they were in a GP's surgery). However, when prompted, only a minority could be more specific about when and what type of information they were accessing through this means. Usually, in these examples, respondents were referring to posters and leaflets. It was unclear if accessing this information was intentional and sought a specific health concern or if it was something they did randomly.

Many respondents mentioned flyers and information booklets in GP surgeries and hospital waiting rooms. Overall, there was not a strong sense that respondents paid much attention to these means of information unless they were directly presented to them. Many felt aware that information on various health conditions was routinely available. However, unless they had a question related to a specific health condition, or they were given the information directly, they would be unlikely to spontaneously access the information themselves. Nevertheless, respondents did not feel it was of no value, only that its relevance to them had to be precise. Lastly, some respondents said they had been given flyers and booklets that they had found to be highly informative and beneficial, and they could be designed to be both impactful and informative.

> *''Text, flyers, reaching communities…[having this information] in their home … I want to know more about…services and [to] access service clearly."*

Many respondents said they typically sought specific NHS information directly from their GP and expressed overall satisfaction with this approach. The benefits of accessing information through their GP was described as

- Reassuring
- Direct
- Building trust, rapport, and mutual understanding.

However, it was also recognised that getting new information from GPs could not always be taken for granted.

> *"They don't really tell you there are services. So finding services is hard when you don't know those are things. So, for me, all I've really done is have my local GP, and I go. That's pretty much it."*

The **internet** was also commonly mentioned. Most respondents said they would **'Google'** their health symptoms or concerns. However, many respondents were uncertain about the sites they accessed through Google. Nevertheless, some respondents specifically stated that they were accessing the **NHS website**.

The NHS website was universally acknowledged as helpful and trustworthy. For some respondents, it was their first action when faced with a health concern before booking a GP appointment. A few respondents said they had become so adept at using the NHS website that they could support friends and family in understanding health conditions. Some respondents mentioned that diagnosing children's ailments was something they routinely accessed online. A few respondents said they typically found booking GP appointments for their children more challenging. Therefore, they would seek information online to determine or confirm the seriousness of their child's condition.

Overall, the benefits of the internet in accessing health and care information were:

- Convenient
- Prompt
- Comprehensive information
- A reasonable alternative to a conversation with a health profession
- Respondents could be more confident when making a GP appointment or speaking with a GP.

The downsides of accessing health information on the internet were:

- It could cause or increase concern
- The language was not always accessible to neurodivergent people or those with English as a second language. There is also a need for some to use Google Translate with the NHS Website.

In most cases, it appeared that respondents would use an online source because of its convenience, especially when they felt the chances of a prompt response or intervention from the doctor were unlikely. Some respondents said they used several different online platforms, including chat rooms. TNBI respondents said they commonly accessed a range of health information websites.

> *"I turn to the internet. There are many really good web pages, UK-specific pages where if you have a question, you can post it, and you'll get someone who's been there, and you'll get an insight into how the system should work and what should be available."*

> *"There is some helpful stuff on the website if you know where to look. It's not the easiest thing to figure out so it does take some trial and error but it's there somewhere."*

An exception among respondents regarding accessing health information online were those with English as a second language. Some of these respondents expressed frustration because they needed help understanding the information given.

> *"I feel the system is confusing, and the system is getting so complicated now, not for people with basic English…"*

Some respondents from **TNBI** backgrounds were cautious regarding the sources of information they used. It was important for TNBI people that the information they accessed was objective, acknowledged the importance of gender-affirming care, and was a genuine and trustworthy source. Many spoke of the need to work hard to find sources of information they fully trusted and consider suitably knowledgeable. For this reason, they felt they could spend much of their time finding out health and care information. However, addressing their own perceptions of mistrust and poor experiences has taught them a lot about their health needs. Their knowledge has made them feel more confident about how the NHS should meet their health needs.

Many TNBI respondents spoke of the benefits of support groups to compensate for the lack of relevant and trustworthy information on subjects such as gender critical care or the intersection between TNBI and neurodivergence. Perceptions amongst TNBI respondents were that more groups were emerging, both in person and online. They were seen as addressing a vital and unmet need. In addition, some felt that NHS and other mainstream information sources could learn a lot from these TNBI-focused sites.

> *"You can, you know, go for instance, to support groups. They're great for finding things out. … Yeah, it's nice to see someone else's medical journey, and what direction to go in. For me, because it took a long time to go in the right direction."*

> *"Thanks to The Clare Project setting up transcendence services, there is at least a little bit of a hub there where you can say does anyone have any experience with this, but predominantly it would be going on to the internet."*

In general, when preferred options failed to provide sought after health information, many said they would commonly turn to friends and family. Most who did so were comfortable with this approach and generally satisfied with the information or advice received. However, this tended to relate to instances when family or friends had experienced similar health-related issues. A few respondents mentioned word-of-mouth as distinct from family and friends. This was information they had come across that had not yet been given to them directly or by someone with specific knowledge. However, most respondents appeared to accept that information from these sources should only be accepted or acted upon after verifying its accuracy through established and trusted sources.

Lastly, TV programmes such as Embarrassing Bodies were mentioned as a source of health information.

> *"I think everyone who has watched that maybe learns, oh, well, if you've got this issue, then you can be referred to this, and then you think, oh, well, I can tell my doctor that, and I think that conversation goes well".*

Not surprisingly, when asked about respondents' preferred health information sources, most said that they preferred information that was presented, clear, and concise regardless of its subject. For many respondents, the Internet provided that combination. For others, engaging directly with their GP or other relevant health care professionals (e.g. pharmacist, specialist nurse) offered them the security they needed when accessing health information. Overall, the responses suggest that most respondents will use the Internet for convenience. However, most respondents welcome having timely, direct access to relevant and knowledgeable health professionals for their information needs.

Awareness and understanding of health and care research

Overall, there is a **mixed response** about the extent to which respondents were **aware of health and care research.** Most said they had heard of the term but only a minority of these had previously participated in health and care research. Overall, many respondents needed clarification on whether the questions they were asked in a survey on wellbeing or a medical condition could be defined as health and care research. Interestingly, the description given by the respondents implies that they have taken part in health and care research. In several cases, respondents who had answered questions on a health-related topic were unsure who had commissioned the study or what it was specifically about.

A few respondents recalled taking part in clinical research led by their GP practice or a hospital department where they were receiving treatment. Some said they had taken part because they felt they should (soft pressure from health professionals) or through a sense of 'giving back' to help others. Completing surveys on satisfaction levels of their GP practice was also mentioned as an experience of health and care research.

Most respondents who had not taken part in health and care research said this was because they had never been approached to participate in a study, rather than being asked but declining. A few respondents were unsurprised that they had never been contacted to join in health and care research because they had no experience of anyone from their background (ethnicity, gender identity, or sexual orientation) ever participating in research.

A few, typically TNBI respondents, perceived that some areas of medical research had historically and globally involved experimental research on minoritised groups, with unclear medical or patient benefit. This perception caused them to be apprehensive about the concept of health (medical) research. However, these views were not directly related to knowledge of health and care research. Instead, these views were made to reinforce the need to state the purpose and benefits of research clearly.

Despite levels of awareness and experience, there was a common interpretation (i.e., definition) of health care research, namely, that it was typically an activity undertaken by the NHS involving the public to identify how the NHS can improve its services and the health outcomes for the public. Health and care research was often interpreted as primarily clinically focused. By this, respondents meant that it involved addressing specific conditions and was typically led by medical, clinical, and academic researchers.

Participating in health and care research.

Despite varying levels of knowledge or awareness regarding health and care research, most respondents recognised the societal benefits of participation. However, a minority, particularly TNBI individuals, remained cautious about taking part. This group expressed concerns based on personal experiences, observations of others, and troubling information they had encountered regarding inadequate attempts at gender-affirming care. Influencing factors included:

- Respondents like them were rarely involved in health and care research
- Researchers responsible for research studies seldom reached out to *their* communities for participants
- There was a scarcity of positive health and care research focusing on gender identity.

Nevertheless, most respondents said they would participate in health and care research if asked because it:

- contributes to advancing medical treatments that would benefit people like them and ultimately their communities
- gives back to the NHS
- improves the knowledge and experience of health professionals of the healthcare needs of marginalised groups
- contributes to a better understanding of specific conditions.

> *“If it were for specific topics surrounding transgender healthcare, then yes, I’d seek out research opportunities, but for things like mental health, I wouldn't really be looking for that. I would be more keen to get involved in trans-related research.”*

> *‘’Yes of course if it helps to resolve our issues, I will not hesitate to take part in health and social research.’’*

Although not specific, many respondents acknowledged the need to ensure that people they saw as themselves were included in research activities and initiatives designed to provide them with benefits. However, many felt that their involvement or participation in research should be taken seriously, and that several factors and conditions needed to be implemented for them to participate. The most commonly mentioned **factors and conditions** were:

- **Clarity on the research's purpose and intended outcome/result** must be provided in an accessible, clear, and concise manner. Potential participants should also have an opportunity to investigate the rationale behind the approach to the research. This ensures that factors they believe are essential have been considered in research planning process.

- **Research teams are trustworthy and relevant.** Those leading the research should give potential participants confidence that they are reliable, have good intentions, and are sufficiently knowledgeable about working with people from their backgrounds. Some respondents were suspicious that sometimes the purpose of research, as described, may also have hidden or undisclosed objectives. Many respondents said that voluntary and community groups they know and trust could play a key role in assuring communities of the authenticity and safety of research and research teams. This would also significantly reduce respondents' reservations about participating in research. The Clare Project and Diversity Resource International were two trusted organisations specifically mentioned in this respect.

  > *"Anything clearly flagged as coming from the community organisations, anything that's been endorsed by a community group. I think that's really important if you have that trust of a group behind it that says ''Yes of course if it helps to resolve our issues, I will not hesitate to take part in health and social [research]'' all, this is welcome."*

- **Participants' time and effort is appropriately remunerated.**
  Most respondents appreciated receiving a gift voucher as recognition for their time contributed to the research. They emphasised the importance of appropriate recognition, as failure to provide it might lead to perceptions of exploitation and undervaluing of participants' contributions by researchers. Moreover, not reimbursing expenses could exclude individuals unable to afford participation. Respondents also believed that research participants should not incur financial losses, thus suggesting provision for transport, refreshments as needed, and coverage of lost earnings to ensure equitable participation regardless of financial circumstances.

- **There is a process to feedback on the research results**. Many respondents expressed a desire for a method or system to understand how their contributions to research were interpreted in the findings and recommendations. Some recounted participating in research for statutory bodies but remained unaware of how their input was used or its role in enhancing services or aiding decision-making. The absence of feedback left some feeling fatigued and disappointed, leading them to consider declining future requests for involvement in research.

- **Reasonable accessibility adjustments can be made.** Some respondents felt that accessibility and inclusion practices for health and care research appear to be limited or non-existent. Many strongly believed that accessibility adjustments would be necessary to ensure that all, regardless of background or circumstances, can participate in research. For example, respondents with English as a second language typically had limited knowledge of health and care research. They felt that improving their awareness relied on having research information available in their language. Similarly, neurodivergent respondents commented that research information was often overly academic and verbose, and assumed neurotypical reading styles. They advocated for the use of Plain English text and emphasised the importance of clear, concise, and easily readable formats and language. Most respondents felt that to be genuinely inclusive and accessible, sufficient time and resources should be allocated.

- **Clarity on the nature and extent of involvement should be provided**. All respondents willing to participate in health and care research believed it was essential to clarify the extent of their participation. This included time, location, the main activity in the study, and what exactly would be required of the respondent. Again, this had to be provided simply, clearly, and concisely.

> *"They should provide a form or something for people who don’t have phones… it would be more inclusive if there were a non-online option. The information might not be the most accessible ADHD-wise."*

Preferences for matching participant and researcher characteristics

There were mixed views on the extent to which respondents preferred researchers to have backgrounds and characteristics similar to theirs. Generally, respondents who were LGBTQ+, TNBI, or had English as a second language felt more comfortable with researchers from their backgrounds and lived experiences. This perception stemmed from the belief that researchers with shared lived experience would inherently understand respondents' general life barriers and challenges. A community researcher was seen as more likely to know how to ask sensitive questions effectively. Additionally, a community researcher with lived experience was considered more intuitive and likely to understand the participants' experiences and related concerns.

Respondents who preferred researchers from their background were typically those who had experienced difficulties and challenges when engaging with the NHS and other service providers. Based on their experiences, they believed that researchers who understood the broader context and factors of the lived experience would be more sensitive and aware of issues relevant to the respondent’s circumstances and life experiences.

> *‘’Yes it will be great to do it and you’re honest; I feel comfortable more because of the language; we came from the same cultural background, you understand me more because you [are] like me, and your experience like me, and I feel you’re not judging me."*

> *‘’Feeling we understand each other, the language, safe and secure, confidence to talk, trust. I know you have been through the same experience, and you understand my problems more and understand my feelings, and you have the cultural awareness."*

A minority of respondents felt that having a researcher from their community was not preferable. A few respondents felt that being interviewed by someone from their background might prompt overfamiliarity, which could make interviewers judgmental. Some felt that anonymity and confidentiality would be lost, and private information would be shared or leaked to others in their community. None of the respondents gave evidence of this happening in a research context. However, they were aware that confidential information about people in their community was being shared with others. One or two said the nature of relationships and customs in their community raised concerns that their privacy and confidentiality would not be secure. Nevertheless, respondents did not express any strong objections to being interviewed by somebody from their community; instead, they stated that the issue of privacy and confidentiality is one that assurances should be given.

Live Research Examples

Overall, there were mixed views and reactions to the two live research examples.

Live research 1: Outdoor swimming as a nature-based intervention for stress, depression, and anxiety (OUTSIDE II).

Study registration details can be found at https://doi.org/10.1186/ISRCTN24759023

Take part in our study

First name

Surname

Are you aged 18 or older?

Phone number

Email

What is your closest location?

I confirm I can travel to this location and attend the course at the time advertised

Note: The study website can be found https://outside2.co.uk (accessed 03.07.2024). Images updated since the fieldwork of this study.

Most respondents who had time to assess this study advert materials expressed a degree of interest. However, only a minority of respondents felt they were likely to spontaneously pick up the information if they saw it in a public setting.

Some respondents felt that they found the information interesting once they read it. However, they added that overall, they did not think it was presented in an interesting, concise, or visually stimulating way.

Some said the objective of addressing wellbeing issues through swimming and physical activity was an exciting approach. Some respondents were unaware of the different types of NHS non-medicine interventions (e.g., social prescribing) to treat mental wellbeing. Roughly half of the respondents who assessed the information said they would click on the QR code to explore more details. Some said they expected to see direct information on how to participate in the project.

A minority of respondents said they were unlikely to click on the QR code unless they were sure they would receive new information, not information already contained in the leaflet.

A few respondents said the QR code would put them off as they felt it required a level of technical knowledge they did not possess. Some respondents said they were unlikely to be interested in this initiative because it was unlikely to be sufficiently culturally or gender sensitive. One commented that outdoor swimming suggested a level of proficiency they did not have.

A few respondents commented on the individuals in the images. Some felt the images did not represent an inclusive reflection of today's society. This reinforced their perceptions of who was considered preferred research respondents.

Live research 2: A survey to learn about thoughts and perceptions of medical device technology used to diagnose, monitor, or treat a health condition (MINDER).

Study registration details can be found at https://doi.org/10.1186/ISRCTN71000991

The study is being run by Surrey & Boarders NHS Foundation Trust and recruitment details can be found here https://www.sussexpartnership.nhs.uk/our-research/mental-health-dementia-research/research-studies/current-research-studies?open=19716#single-accordion-19716

Most respondents seemed less interested in the 'MINDER: Technology Perceptions' research than the invitation to participate in OUTSIDE II.

Overall, responses to the MINDER research were comparatively less positive. Many respondents acknowledged that the MINDER research was likely to represent an interesting study for those with a specific interest in the condition being addressed and the technology being researched. However, most said it did not relate or was irrelevant to them. Therefore, they would likely wait to follow up or read the information in detail. A few respondents said the information could have been presented in a way that, for them, prompted interest. Some added that the language used in this document was academic in tone and, therefore, not inclusive.

It was also commented that this had minimal visual impact and was likely to be overlooked by most people if placed alongside other health information with a stronger visual style.

Appendix

Community Research: Its Context and Purpose

Introduction

The goal of research, as defined in the UK policy framework, is to derive generalisable or transferable new knowledge to answer questions using scientifically sound methods [1].

Health and Social Care Research aims to improve the evidence base, reduce uncertainties, and lead to improvements in care. Organisations that participate in research tend to provide higher-quality care. In the UK, the policy framework [1] applies to a broad scope of health and social care research, including research on public health, research undertaken by government health departments and the NHS, and any clinical or non-clinical research using NHS/social care resources or undertaken within the health and social care systems that could impact service quality. The research is conducted according to this policy framework to ensure it is done ethically and protects participants.

Community research, also referred to as community engagement and involvement (CEI), is an approach that involves members of the public and communities in the research process [2]. It aims to ensure that the voices and perspectives of those most likely affected by the research outcomes are heard and included. In this context, " community " typically refers to a group with shared interests, concerns, or identities rather than solely a geographic or place-based community. Community research promotes inclusion and collaboration between researchers and the communities they work with.

Community research is important because it ensures that the research is undertaken in collaboration with the communities most affected by the research outcomes [2]. This improves the relevance, quality and impact of the research. A commitment to community engagement and involvement from the start leads to greater understanding and uptake of research findings in policy and practice, ultimately improving the health and well-being of communities. The following section focuses on the inception and adoption of community research.

Inception and Adoption

The inception and adoption of community research can be traced back to two main strands in the mid-20th century: a pragmatic, practical approach in Europe and the USA and an emancipatory approach influenced by Paulo Freire in Latin America in the 1970s [3].

The pragmatic approach has its roots in the work of German social psychologist Kurt Lewin in the 1940s. Lewin developed action research, a participatory approach that aimed to understand social issues and implement and test solutions in real-world settings. His work emphasised the importance of involving community members in research and sought to bridge the gap between theory and practice. This laid the foundation for the emergence of community-based participatory research (CBPR) in the following decades [3].

Following World War II, the world saw significant social and political changes, including movements for civil rights, decolonisation, and social justice. These movements highlighted the limitations of traditional research approaches and the need for more inclusive and participatory methods. Building upon the principles laid out by Lewin and critiques of earlier models, CBPR emerged as a methodology that emphasised collaboration with communities. It aimed to address social inequities and improve community health and well-being through research that was co-created with those it intended to serve [3].

The emancipatory approach to participatory action research was distinct, growing out of socio-political processes like popular education movements in Latin America, Asia, and Africa in the 1960s and 1970s. This period was marked by a proliferation of social movements, including the civil rights movement, feminist movements, and environmental activism. These movements demanded research approaches that were both participatory and emancipatory, aligning with the ethos of CBPR. The era saw a surge in community engagement in research, with scholars and activists working together to tackle inequality, environmental degradation, and public health issues. This approach explicitly recognised the interrelationship of knowledge and power in who controls knowledge production and interpretation, solidifying the role of community research in driving social change and highlighting the importance of community agency in the research process [3].

Using Community Research

The National Institute for Health Research (NIHR), the UK's largest health and care research funder, has significantly emphasised community research as part of the UK Government's commitment to the Leave No One Behind Agenda [2]. Leave No One Behind is the central, transformative promise of the 2030 Agenda for Sustainable Development and its Sustainable Development Goals (SDGs) [4]. It represents the unequivocal commitment of all UN Member States to eradicate poverty in all its forms, end discrimination and exclusion, and reduce the inequalities and vulnerabilities that leave people behind and undermine the potential of individuals and humanity. Accordingly, the UK Government has committed to prioritising the interests of the world's most vulnerable and disadvantaged people, the poorest of the poor and those most excluded and at risk of violence and discrimination, to eradicate extreme poverty and ensure no one is left behind [5]. As part of this commitment, the NIHR has firmly focused on community engagement and involvement in its research funding and processes. The NIHR guidance [6] suggests several methods and tools to engage communities and gather data in co-produced research. These include:

1. Developing open, honest, trusting, and reciprocal relationships between research organisations and communities. Organisations and researchers must proactively facilitate public involvement and develop relationships beyond the research community.
2. Establishing research reference groups attached to the research organisation, with members undergoing training and working on individual projects. This allows the community to help shape the research strategy over time.

3. Providing induction [and ongoing] training on co-producing research to research staff and public members to raise awareness and address challenges.
4. Creating safe spaces for people to step outside their official roles, develop trusting relationships, and share personal information unrelated to the project.

These methods focus on building solid and equitable relationships and creating environments that support meaningful community engagement and collaboration throughout the research process. The following are examples of successful community research projects in the UK.

Accessibility and Suitability of Residential Alcohol Treatment for Older Adults

This study [7], a partnership between the University of Bedfordshire and Alcohol Research UK, explored the experiences of older adults in residential alcohol treatment services. The research questions were developed by a person with lived experience of alcohol dependence who had volunteered in rehab services. The project team included academic researchers and expert-by-experience researchers (PEERs). PEERs were treated as equal team members, with meaningful responsibilities such as conducting interviews, and were named on publications. The lived experience was valued as a form of expertise.

The collaborative approach ensured the research was relevant to those using alcohol treatment services. PEERs gained research skills, while academics benefited from fresh perspectives and motivation. A key challenge was negotiating if and when to disclose PEERs' lived experiences, as it risked stigma but could also encourage others' involvement.

Findings revealed that a quarter of residential rehabs in England excluded older adults through arbitrary age limits, contrary to the Equality Act 2010—the involvement of PEERs aimed to challenge negative stereotypes about involving people with addiction experience in research.

Developing an intervention to support participation in leisure of children and young people with neuro disability

This project [7], based at Newcastle University, aimed to develop evidence-based techniques for allied health professionals to support the leisure participation of children and young people with neuro disability. The three-year research program involved reviewing evidence, consulting stakeholders, and creating a practical manual for NHS use.

Eight young people aged 16-21 with neuro disability experience formed a co-production group called AniMates. They were involved in data analysis, interpretation, and dissemination through creating an animated film. The researcher and a participatory artist worked to build relationships, ensure accessibility, and enable the young people's leadership.

Reciprocal benefits included the researcher learning to open the data to fresh perspectives, the artist facilitating creative and accessible engagement, and the young people gaining skills and friendships. The co-production challenged assumptions about how policy translates into young people's real lives. Funding for paid roles enabled ongoing youth involvement. The AniMates film highlighted tensions around "hanging out with friends" as an aspect of leisure participation, which the researcher had not previously focused on. This youth-identified priority became central to the findings, showing how co-production shaped the research.

3. Co-produced service Evaluation of Ethnic Minority Community Service User Experiences in a Specialist Mental Health Service During the COVID-19 Pandemic.

This research [8] was a collaborative evaluation conducted During the COVID-19 pandemic to assess the experiences of ethnic minority community members using a specialised mental health service. The study aimed to understand their unique challenges, access barriers, and overall satisfaction with the service. By involving service users and providers, the research aimed to improve the quality and inclusivity of mental health care during these challenging times.

The study's co-production model, involving service users and professionals, underscores the importance of **inclusive and participatory research**. By actively involving ethnic minority community members, the evaluation process became more holistic and culturally sensitive. The research sheds light on the experiences of ethnic minority individuals accessing mental health services during the pandemic. Their narratives provided valuable context for understanding their unique challenges, including language barriers, cultural stigma, and access disparities. The study identified barriers to effective mental health service utilisation, such as lack of culturally competent care, communication gaps, and limited awareness of available resources.

Conversely, it highlights facilitators, such as peer support networks and community engagement. Recommendations included improvements in cultural competency training, language access, community-based interventions, and anti-stigma campaigns**.** It highlights the need for policymakers to prioritise funding for culturally sensitive mental health services, the inclusion of ethnic minority voices in policy discussions and offering telehealth and digital solutions to enhance access during crises like the pandemic. While this study focuses on a specific context, its findings resonate globally as ethnic minority communities worldwide face similar challenges, and co-produced evaluations can inform better mental health services. This research underscores the need for inclusive, culturally competent, and community-driven mental health services.

Implications and Benefits

Community research meaningfully engages communities throughout the research process and offers significant benefits for enhancing health and social care research's quality, relevance, and impact. By centring the priorities and perspectives of those most affected by the studied issues, this approach ensures that projects address communities' real-world needs and experiences. Participatory methods empower communities by recognising their lived experience as valuable expertise, providing opportunities for skill-building, leadership development, and enhanced social connections. Community research contributes to the larger goals of social justice and health equity by surfacing the complex realities of how policies and programs are experienced on the ground and informing the development of more effective, culturally appropriate, and equitable practices.

However, realising the transformative potential of community research requires overcoming significant challenges. Prevailing academic norms and institutional structures often undervalue forms of knowledge that fall outside traditional scientific frameworks, and pursuing genuinely inclusive and collaborative research demands substantial investments of time, resources, and effort. Funders and institutions can support the growth and impact of community research by providing dedicated resources, training, and infrastructure and embracing more flexible approaches to research design, timelines, and deliverables. Conducting effective and equitable community research also requires a deep commitment to reflexivity, humility, and power-sharing on the part of researchers and institutions, consistently prioritising the needs and aspirations of communities even when they diverge from academic incentives or expectations.

As the examples in this report illustrate, community research holds immense potential to drive meaningful change in health and social care policy and practice. By honouring communities' knowledge and agency, this approach can generate research that is not only rigorous but also relevant, responsive, and actionable. Continued investment in and commitment to community engagement will be essential for building a more equitable and effective health and social care system that leaves no one behind.

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