

Mental Health Research Engagement Network

October 2025



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1. Background & Introduction

The **Mental Health Research Engagement Network (MHREN)** community research project aimed to identify research engagement strategies to increase women's participation in mental health research.

The National Institute for Health & Care Research (NIHR) and NHS England provided the funding for this project. The project was designed by the Health Research Team of Sussex Health & Care Partnership, who wrote the proposal. The Organisation responsible for delivering this part of the project was [The Trust for Developing Communities](#) (TDC).

The Trust for Developing Communities is a registered charity with a 25-year history of supporting people facing poverty and exclusion to create positive change in their lives and communities. TDC's work encompasses building communities through offering advice, health and wellbeing support, adult education, employment programmes, and youth activities for people living in high-poverty areas.

TDC's responsibilities as the lead organisation for the project were to

- Design and deliver a partnership-building, capacity-building event for community, academic, and Health & Care researchers.
- Manage the process to allocate a small grants programme for five community research projects.
- Support the delivery of the projects through development training sessions and regular check-ins with the five projects.

The project focused on providing funding to community researchers working with appropriate Voluntary Community Social Enterprises (VCSEs) to devise and deliver community research projects. The project aims to boost women's engagement in mental health research through creative participatory action projects led by community researchers.

Building Impactful Research Partnerships

An additional task for TDC as the lead on this project was to facilitate an in-person session bringing together researchers from the NHS, Research & Care teams and departments, researchers from regional academic institutions, freelance Health & Care researchers, community researchers, and representatives from Voluntary, Community, & Social Enterprise (VCSE) Organisations. The purpose of the session was to explore

the opportunities and barriers for impactful research partnerships and collaborations where community engagement and research are key factors across these different research backgrounds.

The specific objectives of this session were to

- Provide a collaborative environment where researchers can hear about other research teams and methods.
- Examine the benefits of interdisciplinary partnerships in health and care research.
- Identify potential barriers to collaboration and discuss strategies to overcome them.
- Encourage ideas for innovative research projects that address pressing health and care challenges.
- Identify pathways to the formation of new research NHS and community research partnerships.

The session was designed to be interactive and included presentations, small group discussions, and networking opportunities. Thirty-eight people attended this event.

Themes explored in this session included

A summary of the feedback on the "Building Research Partnerships" in-person session:

- **Networking opportunities:** Many attendees valued the event for networking, especially the mix of academic and community researchers.
- **Organisation and Atmosphere:** The event was generally well-organised, and the atmosphere was described as warm and conducive to sharing information.
- **Informative content:** Most attendees found the presentations and information links useful and enjoyed the research project exercise.
- **Desire for more events:** There is an apparent demand for additional events of this type 84% of respondents who completed the evaluation stated that the event influenced their thoughts and ideas for future research projects.
- Respondents felt that **future events** of this kind should go beyond mere networking and information sharing to focus on **establishing specific, actionable partnerships**. In terms of themes and topics, these events could also include requests for practical advice on ethical issues, funding opportunities, and strategies for developing and maintaining strong community-academic collaborations.

2. Mental Health Research Engagement Network, Community Research Project

For the Mental Health Research Engagement Network project, seven thousand pounds (£7,000 each) was allocated to five projects to deliver community research that aims to encourage women and individuals who use women's services from marginalised backgrounds to become more interested in participating in NHS-initiated health and care research. This was a competitive application process with funding made available to community researchers whose applications were successful.

The specifications for applicants and their projects were:

- Individuals or organisations must have experience in community research and the ability to deliver arts-based research and participatory methodologies.
- The project must work with one of the five identified groups/communities this project is targeting.
- Have a strong understanding of ethical considerations related to community-based research.
- Work collaboratively with diverse communities and groups.
- Be willing to explore partnerships and collaborations with researchers from academia, health & social care and clinical research departments.
- Be committed to supporting the dissemination of research findings in accessible and engaging formats.
- Be committed to supporting the Research Engagement Network (REN) 's aims.

The application process for the funding was divided into the following stages.

A. Expression of Interest

Applicants were asked to submit an Expression of Interest (EOI) application. Through the EOI application, applicants were required to provide the following information on their proposed projects.

- A. **Project Summary:** (600 words) A concise overview of the proposed project, including:
 - **Research Focus:** Clearly stated specific issue or topic the project would address.

- **Target Population:** The community or group the project aims to engage, along with the community researchers' background and experience working with this group.
- **Arts-Based Methods:** An outline of the specific art forms and creative approaches likely to be utilised, including the rationale for selecting the art-form approach.
- **Anticipated Outcomes:** The expected impact of the project and how the findings could be disseminated.

B. **Applicant Experience:** (200 words) A brief description of the community research/engagement experience and expertise relevant to this project

C. **Partners:** (200 words) A list of the individuals or organisations the community researchers will collaborate with, including the VCSE host, to deliver the project. Outline their roles and describe how they will support their efforts to ensure the project's success, including a statement on whether the VCSE's involvement is confirmed or anticipated.

This stage received seven expressions of interest.

B. Assessment of Applications

The applications were all assessed by an independent selection panel composed of four academics and senior NHS researchers, along with two community researchers.

The selection panel reviewed and scored the applications individually. They then met collectively to discuss their scoring and select the applications that they felt met the research brief. After assessing the EOI applications based on predetermined selection criteria, five projects were selected across each of the research group headings.

C. Successful Applications

Once the five successful EOI applications were selected, they entered the final two stages of the application process.

- **Stage One:** Each successful EOI received £1,000. With this funding, the community researcher, with support from their host VCSE, produced a further document and budget that provided a more detailed description of their project.

- **Stage Two:** Once the Community Researcher and host VCSE had produced the detailed research plan and budget to the satisfaction of the delivery panel, the remaining £6,000 was released to the VCSE organisation to support the management of the project

Once the five successful EOI applications had submitted their detailed research proposals and budgets, the TDC project team reviewed them. This assessment was carried out to ensure each application was consistent with the information provided in the EOI and that they clearly aligned with the relevant objectives of the Mental Health Research Engagement Network project. Once the details of each project were agreed, the remaining £6,000 in funding was allocated to the community researcher via their Voluntary, Community and Social Enterprise (VCSE) organisation.

The unsuccessful applicants were invited to a meeting with the project lead to discuss their project, understand why it was unsuccessful, and explore options for further development.

D. Development training

Community researchers from all successful applicants received 4 hours of development training. The training aimed to improve community researchers' knowledge and understanding of research practices relevant to the successful delivery of their projects. The subjects covered in the training were as follows.

- **Writing Impact Case Study:** After engaging with their research respondents, all projects were required to produce an Impact Case Study. This was to be a narrative-led case study highlighting the main themes, findings, and, if relevant, subsequent recommendations. This session guided community researchers on how to approach this.
- **Activity (project) Blueprint,** statistical information and monitoring
The session helped community researchers understand the importance of applying and adopting a suitable, user-led research methodology. It also aided them in grasping the principles of effective respondent recruitment and ensuring they knew how to monitor this process properly.
- **Presenting the Community Research findings:** At the conclusion of the project, community researchers were to present the findings of their research. This session sought to equip community researchers with the knowledge, skills, and support to boost their confidence in delivering clear, engaging, and impactful presentations of their community research findings.

3. Project Requirements

Each project worked with one of the following women's groups or those who identify as women.

1. Homeless
2. Neurodivergent
3. English is not their first language,
4. Older (50+), isolated, and living in East Brighton
5. Trans, Non-Binary & Intersex groups (TNBI).

The projects focused on using accessible creative methodologies to engage participants in a collaborative research process.

Where practical, researchers used a participatory action research approach, encouraging active participation from those involved. This involved defining research questions, agreeing on data collection methods, and analysing and sharing results. Projects were recommended to work with a suitable health and social care or academic researcher.

Some of the projects and community researchers had identified academic or health and social care researchers to collaborate with. Other community researchers received support to find a community researcher to partner with on their project.

4. Tasks & Responsibilities

The main tasks of the community researcher were:

- Identifying the community group to research
- Drafting the research proposal
- Deciding on and designing the research methodology for the project
- Determining the most beneficial NHS or academic support and involvement for their project
- Leading and undertaking the research, including recruiting respondents, conducting interviews, and facilitating groups
- Analysing the research data and producing an Impact Case Study based on their findings and outcomes
- Attending four hours of professional development training
- Sharing their findings at a group celebration event

Community Researchers received support from a VCSE organisation. In all cases, the VCSE and the community researcher had an existing relationship, including experience of working with the group the community researcher would be researching.

The VCSE organisations continued to provide support throughout the project delivery. In addition to supporting the community researchers with their primary tasks, VCSEs also provided the following.

- Practical and logistical support in managing and making arrangements for the interviewing and facilitation processes.
- Support and financial management, including being the budget holder for the funding.
- Advice and guidance across all delivery aspects of the project.
- Periodic supervision, progress and review meetings.
- Advocate with the MHREN Project leadership and administration.

Each VCSE organisation brought their resources, community knowledge, networks, trusted relationships, and an enthusiasm to support the MHREN project.

All VCSE organisations adopted a hands-on approach to supporting their community researchers. This involved

- Co-design and Co-production
- Regular support and supervisory sessions,
- The use of the organisation's operational, admin, and management systems
- Workspace and meeting rooms

The VCSE groups also met regularly as part of the MHREN project leadership team. They were kept updated about the overall project and were invited to attend all meetings that community researchers were expected to participate in, including the professional development sessions.

The five VCSE organisations providing oversight, support, and advice for the MHREN project were

1. **[The Clare Project](#)**: A registered charity since 2016, The Clare Project was initially established to support transgender women and trans feminine people. However, it now supports everyone whose identity falls under the transgender or non-binary umbrellas and also assists members of the intersex community.

The Clare Project offers a range of support services for the trans, non-binary, and intersex (TNBI) community in Brighton and across Sussex. They welcome TNBI individuals regardless of their gender identity, gender expression, or biological sex variation.

The organisation is led by and focused on TNBI people in both its support services and campaigning.

2. **[Diversity Resource International](#)** (DRI) is a non-profit community interest company dedicated to supporting ethnically diverse and migrant communities across the UK. Their work aims to create a safe environment for the learning and development of ethnic minority individuals, communities, and organisations.

They aim to meet the community's evolving needs and work together with others to change the processes, structures, and circumstances that sustain discrimination, abuse, and intolerance. They seek to remove obstacles to social cohesion and provide advocacy, support, networks, training, and tools to help people from ethnic minorities succeed.

3. **[Justlife](#)** is a nationwide homelessness charity that advocates for people living in temporary accommodation, with local branches in Brighton & Hove and Greater Manchester. They support individuals' diverse needs throughout their journey into and out of temporary housing. This includes enhancing their mental and physical health, helping them understand their rights, find their own home, and gain independence. On a national level, they campaign for policy changes to improve the lives of People experiencing homelessness across the country.

4. **[Sussex Interpreting Services](#)**. A registered charity has been delivering services since 1994. Sussex Interpreting Services provides high-quality, professional community interpreting, community translation, and bilingual advocacy 24 hours a day, seven days a week. Their comprehensive services also include Social Prescribing, Health Promotion, Befriending, Community Engagement, Advocacy, and Research. They work with 160 trained and accredited, freelance, locally-based linguists in 65 different languages.

5. **[East Brighton Health Forum \(Trust for Developing Communities\)](#)**. Is a partnership of local communities, services providers and anyone interested in health and well-being in East Brighton. It is community-led and facilitated by TDC with the aim of community-led coordination for health services and projects. East Brighton Health Forum is open to all community groups and frontline Health & Care services – VCSE, statutory, primary care. There are themed quarterly meetings based on area priorities. The Health Forum collates and evaluates community and service insight and learning, sets area priorities with a specific focus at each meeting and oversees pilot projects.

Because the levels of experience among community researchers varied, each VCSE organisation tailored their contribution to the project and provided adequate support to ensure high project autonomy for the community researcher. Despite the significant contributions and efforts of the community researchers, it is unlikely that the project would have been as successful as it has been without the support of the VCSE organisations.

5. The Projects & Researchers

The five MHREN projects, their community researchers and supporting VCSE organisations are in the table below.

[Mental Health Research Engagement Network - TDC](#)

Community Research Project and Researcher	VCSE organisation	Research characteristics
The Lived Experiences of Older Chinese Migrant Women in East Sussex Chi Ling Chan	Diversity Resource International	Main Black and racially minoritised with English not their first language Secondary Older (50+) isolated
Are You Talking to Me? Artie Carden	The Clare Project	Main Trans, Non-Binary & Intersex groups Secondary Neurodivergent
Homelessness & Housing Transitions: Barriers & Sources Of Support Emma C	Just Life, Brighton & Hove	Main Homeless
Cross-Cultural Cooking Exchange for Migrant Women Lai Lai Wu and Meryam Ejjia	Sussex Interpreting Services	Main Black and racially minoritised with English not their first language
East Brighton Dance 4 Health Anita Doherty	East Brighton Health Forum (Trust for Developing Communities)	Main Older (50+) isolated and living in East Brighton

6. Research Summaries & Impact

Below are extracts from the five community research projects commissioned for the Mental Health Research Engagement Network project.

Chi Ling Chan: **The Lived Experiences of Older Chinese Migrant Women in East Sussex.**

Supported by Diverse Resources International.

[Full Report](#)



Project Overview

This project was carried out with older Chinese women in East Sussex facing mental health challenges due to their intersecting vulnerabilities, such as language barriers, age, and isolation. This has often led to their exclusion from public services and research. Most of these women have never spoken about their personal experiences, and their anxieties and stressors persist to this day.

This project provided a culturally safe space for ten women to share their experiences in their native language through two storytelling workshops led by a community

researcher. Each woman brought a meaningful object to help tell her story, illustrating how limited English skills impact daily life and mental well-being. The workshops concluded with the creation of a documentary film.

These storytelling workshops offered a vital and empowering space for memory and reflection, bridging cultural and linguistic divides. The project significantly raises awareness and understanding of these hidden struggles, which stem from language barriers faced by these marginalised women. On a broader level, it aims to highlight the importance of such culturally safe spaces and encourage increased participation in mental health initiatives and research.

Outcomes and Impact

The project increased women's participation in mental health research by establishing a safe, culturally sensitive space for Chinese women to share how their lived experiences had influenced their mental health. Many participants were women who previously felt silenced or excluded from mainstream research due to language barriers, cultural stigma surrounding mental health, and a lack of trust in institutional systems.

The format of the storytelling workshop in their native language enabled women to share their experiences in their own words and at their own pace. The familiarity and trust built through the community researcher (also an interpreter and advocate) encouraged participation from these women, who might otherwise have been reluctant to engage.

Through the workshops, women were not only participants but also co-creators of knowledge. Their stories directly influenced the themes and findings of the case study, helping to highlight gender-specific experiences such as those of mothers, cultural pressure, and isolation.

This initiative marks progress in reducing stigma, raising visibility, and placing women's mental health experiences at the heart of community-based research and advocacy.

As an output of this project, the researcher produced a 20-minute video. In the recording, the respondents can be seen and heard sharing their stories of early life in the UK, the hardships they faced, and how these experiences shaped and affected their lives. The women's testimonies are powerful and moving. You can view the film here [The Women of the Chinese community in Sussex: Video link](#)

Future Engagement in Mental Health Research.

Following the storytelling session at the workshops, participants became more willing to engage in other projects related to mental health and different topics. The workshop storytelling experiences opened new opportunities and empowered them to speak up for upcoming projects.

Of the **ten** respondents to this project, **six** stated that they would, in principle, be interested in engaging with NHS-commissioned mental health research.

Artie Carden: Are You Talking to me?

Supported by The Clare Project and Sarah Polack, Researcher, Brighton and Sussex Medical School.

[Project Zine](#)

Project Overview

The project sought to understand the barriers to research engagement concerning women's mental health for trans, non-binary, and intersex people.

Its goal was to make a positive impact on communities through research by using a creative outlet. In this case, the researcher chose to adopt a collaging approach, as it represents a very accessible art form and highlights the connection between art and therapy as a practice.



The output from this research was a Zine that contained in-depth discussions, perceptions, and experiences of this respondent group regarding engaging in women's mental healthcare.

The research identified and explored recognised barriers to mental health research for this community, such as travel, the relative rurality of their location, transport-related difficulties, poor disability access, lack of incentives for participating and competing against essential commitments.

Additionally, the research also highlighted the importance of language and terminology, the prevalence of outdated and archaic policies, as well as adverse social and medical attitudes and behaviours towards trans and non-binary and intersex people. The lack of healthcare teams and academics with live experience was also recognised as a significant factor in addressing the low engagement with mental health services.

Outcome and Impact

A significant tangible outcome from this project was the online Zine. Produced by the community researcher, the Zine is an open, accessible means to understand the thoughts and experiences of this community. It is written in language and terminology that reflects their authentic voice. It also raises challenging and pertinent questions regarding why trans and non-binary people do not access mental health services and the role the institutions themselves play in inadvertently creating barriers to their involvement and engagement.

The impact of this research is that many of the respondents have expressed their experiences of perceptions in a safe and open environment. As a result, many are more inclined and confident to express these views in other settings where their experiences and contributions can make a real difference in the services provided.

Future Engagement in Mental Health Research.

Most of the respondents to the project were, in principle, prepared to engage in NHS research, provided that it reflected the points and concerns raised in this research.

Of the **four** respondents to this project, **two** stated that they would, in principle, be interested in engaging with NHS-commissioned mental health research.



Extract from the Zine

A plain-text screen-reader version of the Zine was submitted alongside the digital version. To request a copy, please get in touch with Beck Cedar beck@clareproject.org.uk

Emma C: Homelessness & Housing Transitions: Barriers & Sources of Support.

Supported by Justlife, Academic Advisors - Dr Emma Anderson and Dr Elle Whitcroft and Art Therapist - Nettie Roswell.

[Full Report](#)

Project Overview



This creative community research study explores links between women's mental health and homelessness, focusing on moving from homelessness into stable housing. Led by a community researcher with lived experience, seven women and non-binary participants (assigned female at birth, AFAB) took part in three 'River of Life' sessions, providing a safe space to reflect on experiences, share coping strategies, and highlight services that had been helpful to them.

The research found that homelessness often leads to fear, trauma, and poor mental health. Many participants struggled to trust others, including professionals, sometimes withdrawing to protect themselves. This mistrust made it harder to access help and worsened mental health challenges. Building trust takes time, and without continuous care, participants felt unsupported. Assumptions that women are “vulnerable” or “high risk” also created barriers to housing and services. Supported housing is unsafe, particularly for women living alongside men with complex needs.

Participants reported a lack of women-only housing, reliance on charities for support, limited access to mental health services, and isolation once rehoused. Financial hardship and loss of service support added further stress. Despite these challenges, participants identified positive coping strategies, including trusted relationships, creative activities, time in nature, pets, peer networks, and services that had been particularly helpful in supporting their housing and mental health needs.

Outcomes and Impact

Although this research project has concluded, the community researcher and VCSE organisations’ mission to influence policy and practice regarding women’s mental health and homelessness continues.

The Impact Case Study Report has been shared with Brighton and Hove City Council (BHCC) to feed into the Brighton and Hove Homelessness and Rough Sleeping Strategy.

They are dedicated to making research accessible and engaging, ensuring it meets the needs of communities and is both meaningful and impactful.

They will continue to advocate for this work and incorporate its methods into future initiatives at Justlife.

They shared an information sheet about current Sussex Partnership studies to encourage research participants to get involved in NHS Health and Social Care studies.

As respondents expressed interest in socialising, they are organising referrals to Justlife’s Social Connections project to help build these relationships.

Just Life has also produced an ‘Ending Well’ project summary book that highlights participants’ achievements, offers guidance on including these in a CV, provides instructions for requesting a reference from Justlife, and invites readers to join Justlife

mailing list to stay updated on future research and co-production opportunities, encouraging ongoing engagement.

Additionally, have co-produced a ‘moving-in pack’ with essential contact details for relevant support services. This Guide includes information shared by participants during the participatory ‘River of Life’ sessions and highlights good practice and supportive organisations. The guide is designed to walk people through every stage of their journey, from accessing urgent support services at the point of homelessness to finding practical, independent community and well-being support once in settled accommodation.

Lastly, the community researcher exhibited the River of Life concept at the Homeless Health Conference, organised by Arch and the Frontline Network, and at the Brighton and Hove Homelessness Research Forum, run by Justlife in partnership with Brighton and Sussex Medical School.

The Research has also been presented at the Creative Methods Symposium with Dr Emma Anderson and Dr Elle Whitcroft, the British Psychological Society (BPS) 1st South East Branch Psychology Festival with Dr Emma Anderson, and the Homeless Link Research Forum. An expression of interest has also been submitted to present the research at the Pathways from Homelessness Conference in 2026.

Future Engagement in Mental Health Research.

Some of the respondents to the research indicated they would be prepared to consider participating in future research.

Lai Lai Wu and Meryam Ejia: **Cross-Cultural Cooking Exchange for Migrant Women**

Supported by Sussex Interpreting Services.

[Full Report](#)



Project overview

The primary objective of this project was to increase women’s involvement in mental health research. We believed the most culturally suitable approach was practical and demonstrative. Engaging women in mental health research to show how simple and non-threatening it can be highlights the social and emotional benefits of participation and broadens the discussion from that initial point.

Additional aims of the project included,

- Enhance the likelihood of women’s participation in Mental Health Research.
- Examine the effects of “connecting” and “giving” on participants’ emotional well-being.
- Improve participants’ understanding of mental health and emotional well-being.
- Challenge cultural stigmas surrounding the acknowledgement and discussion of mental health.

The primary method of engagement and participation for respondents was collaborative, with group cooking activities. Four weekly sessions were delivered to promote memory sharing, emotion-driven storytelling, and cultural exchange among eight Arabic and Cantonese-speaking women living in Brighton. The relaxed and safe environment encouraged open discussions about emotional well-being and mental health, fostering positive social connections.

Working with community chefs, participants selected culturally meaningful recipes and paired up in different language groups to cook together, sharing their memories and stories. Culturally appropriate and accessible translated resources on emotional well-being and mental health, available in print and video formats, were sourced, curated, discussed, and analysed by the groups. Participants also created posters to illustrate what they had done and learnt, which have been shared and distributed within their communities.

Outcomes and Impact

Participants reported

- Desiring to engage with other Mental Health Research Projects
- enhanced emotional well-being; feeling more connected, included, informed, and open
- seeking to join more social groups and activities
- gaining more confidence to interact with people from different cultural and language backgrounds
- increasing knowledge of mental health and emotional well-being
- practically applying and using the information to monitor and improve their wellbeing
- feeling comfortable discussing mental health issues in this setting
- sharing their knowledge and experiences with the broader community

Key to achieving these impacts

- Culturally rooted, activity-based engagement methods
- Building on existing relationships and the shared identity of researchers and participants
- Designing a culturally sensitive and suitable project
- Delivering a fully accessible project with comprehensive language support

Future Engagement in Mental Health Research.

Of the **eight** respondents to this project, **six** stated that they would, in principle, be interested in engaging with NHS-commissioned mental health research.

Anita Doherty: **East Brighton Dance 4 Health**

Supported by: East Brighton Health Forum (Trust for Developing Communities) and Ali Schmidt, Research Assistant, ARC KSS.

[Full Report](#)

Project Overview

This research aimed to engage women aged 50+ in East Brighton in a mental health and loneliness project, designed to increase their involvement in mental health research.

The project's core goal was to identify the barriers to good mental health for isolated women aged 50+ and explore ways to overcome them. It sought to do so using tools and research methods that would support long-term positive impacts for women. Additionally, it aimed to create a communication bridge between community research with local participants and academia. This would offer insights into how the others in their community voice their health priorities and solutions. It is also intended to grow a 'bank' of research volunteers and tools, fostered through positive experiences and outcomes from participating in the research project.

The respondents to the research were aged 50-87 years who lacked access to local opportunities and activities to support their mental health needs. Their isolation also hindered their ability to foster community connections and boost their confidence in accessing services.

Focus groups were held in a social space where gentle exercise, music, mindfulness, and conversational social interactions helped build trusted relationships within a positive and impactful environment—utilising different research tools to discover how they could find solutions to their lived experiences and how those solutions might translate into their broader community.



Outcomes and Impact

As a result of participating in the research, all respondents have gained access to new activities and services through their involvement in this research project. These included accessing the local health services and getting ear checks, which resulted in one getting hearing aids and two accessing other support services they may not have accessed before taking part. Going to other local activity sessions using a buddy system to support each other. Example: accessing a Bingo session and 50+ activities, and joining a regional health walk for the first time.

Future Engagement in Mental Health Research

As a result of the project the group have more awareness of health research programmes and support networks, for example, the Women's Centre, Together Co befriending services and Possibility People around disability and advocacy.

The group has enhanced understanding of the advantages of engaging in local research projects and how they can benefit other women in the community, as well as potentially impacting available services. This involved exploring a broader national research project (GLAD) studying genetic links to anxiety and depression, along with an expressed interest in participating in the research.

Of the **seven** respondents to this project, **five** stated that they would, in principle, be interested in engaging with NHS-commissioned mental health research.

7. Project Summary

Overall, the collective projects have effectively introduced representatives from each targeted group to the concept and importance of participating in research.

Each project successfully created and delivered engaging and creative community research that resonated with the target groups. Relevance was felt through personal life experiences, particularly relating to well-being and mental health. It was evident that all groups had limited knowledge and experience of mental health research and the potential benefits it could provide them.

In addition to raising awareness of their value and potential contributions to health & care research, the projects also gave respondents opportunities to connect and reflect on their life circumstances and history within a trusted and safe environment. This itself delivered well-being benefits to the participants. In many cases, these respondents felt so inspired by the research process and the companionship of others sharing similar experiences that they discussed the possibility of continuing to meet informally to offer friendship and support.

Although each of the five projects was conducted independently with little collaboration among researchers, there was a high level of consistency in the nature and scope of the outcomes across all projects. This outcome highlights the common and universal benefits and principles that community research offers. By adopting a community-centred, co-creative approach, the results and impacts for targeted groups are likely to be similar.

In addition to working with marginalised groups, the projects also engaged with vulnerable populations. Many of these groups have well-recognised and justified concerns and reservations about trusting unfamiliar organisations and institutions. Such trust issues are likely to form additional barriers for potential respondents and should be taken into account by research teams when exploring participation opportunities.

The findings of this Mental Health Research Engagement Network project are clear. In many cases, the only way some members of vulnerable groups are willing to take part in NHS health & care research is with the presence and support of someone known and trusted within their support network.

Community Researcher Feedback

Each community researcher shared their insights into the design process and their research findings. They explored how the community researchers would encourage respondents to register and become aware of NIHR Health & Social Care Research.

All community researchers commented on the extent to which they enjoyed devising and delivering their research projects. For all researchers, this was the most ambitious research project to date. All left their projects feeling more confident in their abilities as researchers and possessing a greater understanding of the contributions they can make as researchers in health and social care research.

Community Researcher project highlights:

- The degree of autonomy to carry out the research alongside strong support and confidence from their VCSE organisation.
- Witnessing the difference in respondents' general well-being when given the chance to participate in an activity that, for many, has the potential to change their lives.
- The support provided by the NHS and academic researchers to their project enabled them to broaden their thinking, expand their knowledge, and add confidence and credibility to their project.
- The development training provided by TDC and the extent to which it supported understanding of the research outputs and the standards expected.

Three of the five projects involved health & care researchers. In all cases, the community researchers were highly appreciative of the contributions made by the health & care researchers. In each instance, these researchers provided their skills, knowledge, and advice on community research practices and approaches, which resulted in an improved and enriched research experience for the respondents.

The community researchers also provided feedback that they would have liked more guidance and general explanations of terminology. They had a lot to learn about the specific outputs needed, such as what the 'Impact Case Study' and 'Activity Blueprint' outputs involved, before commencing their projects. They also stated they would have liked more clarity about the need for and payment for attending the professional development sessions.

Future engagement in Health & Care Research.

Increased interest in health & care research. All six community researchers reported that following their engagement in the projects, their respondents were generally likely to consider options for involvement in health and care research.

Research interest is linked to trusted relationships. All the respondents felt that their views were based on their positive experience with their community researcher. The role, trust, and approach adopted by the community researcher played a significant part in the respondents' willingness to engage in future health & care research. The context in which this research took place, the nature of the research, and the other respondents participating (i.e., shared lived experiences, social and community associations) are all key factors in these respondents' willingness to engage in other research.

Supported group settings enable easier access to research. With the community researcher and other respondents offering a 'lived experience' connection and relevance to each other, this facilitates access. Respondents recognise that they will be entering safe and sensitive spaces.

Whilst I enjoy having learned this skill and the privilege I have of being able to pass on what I learned in plain language to others, I don't think you should HAVE TO understand complex language to be able to access new information and to be able to advocate for yourself.

I'm really pleased; ... it was a bit of a life-changing experience for the respondents, not in terms of the research element, but more that in itself is good because we can forget it's not just about what is beneficial for us and our funders, but the impact it has on those respondents.

Importance of researchers with similar lived experience. Some community researchers found that their respondents were less interested in participating if they were not directly involved. This is especially true for respondents whose first language is not English, as they would require a translator to take part. This view is not limited to those whose first

language is not English. Other respondents, especially those who could be described as 'vulnerable', have experienced social isolation or feel marginalised, also express the view that being engaged in research with a researcher who has lived experience is their preferred option.

I just really enjoyed the whole process of learning and using my lived experience, which is positive, and it's giving back to the community and helping others move forward in their journeys.

Ongoing support needed: Community researchers generally believed that getting their respondents to sign up for notifications for NIHR research projects would not be significantly problematic, provided they assured confidentiality. They also felt that some level of support was necessary for their respondents if they were to move from being on a register to actively participating in research that did not involve their community researcher.

Despite all the positives these respondents derived from participating in this series of experiments, what is unclear is the extent to which they would be equally willing to take part if the research in question did not incorporate the aspects of the research they have just been involved in. Are they likely to be as willing if the researchers were not known to them or if the location was unfamiliar?

With the first session, they didn't know I would be there and what to expect. Gradually, they felt comfortable, and then the second session, then the next session. Everyone came with a big smile on their faces because they said they're really looking forward to it.

I would say of the project that I was surprised that people are so honest about talking about something this like this which is quite hurtful and quite personal. Not understanding English... you cannot represent yourself, you cannot talk, you cannot voice your opinion, you cannot argue, and you have to be quiet.

As a final part of this project, Community Researchers will re-contact their respondents to inform them about the value and benefits of participating in NHS Health & Care by following up on specific research initiatives and registering with their details.

This work will be supported by the double-sided information flyer below. This will be disseminated to existing and potential research contacts. Community Researchers have also been asked to complete a questionnaire with their research respondents. This questionnaire will help to determine which research initiatives their respondents are interested in and identify factors that would encourage them to register and translate their interest into actual involvement and participation.

Want better Health and Care for Your Community?

You can make it happen.
Let's shape the future of health, together.

Health and social care services should work for everyone. For too long, research has overlooked the experiences of people from diverse backgrounds.

The result? Care that doesn't quite meet their needs.

How you can make a difference

Participating in research is about sharing your experiences to help create better health and care for the future.

It could be as simple as:

- **Sharing your views** in a discussion group
- **Answering a survey** about your health experiences
- **Testing a new health app** on your phone
- **Talking to a researcher** about what makes a good service
- **Trying a new drug or therapy** if you decide this is for you

Why take part?

- **Be Heard** Share what matters to you and your community
- **Improve Services** Help Health & Care teams understand your needs
- **Create Fairness** Ensure future treatments consider people like you
- **Make a Difference** Your experiences can help others get better care

We understand you might have questions or concerns.

- **It's Safe & Confidential** All our research is ethically approved
- **No Impact on Your Care** Taking part will never affect your healthcare
- **We Offer Support** Let us know how - transport, interpreters
- **You'll Be Thanked** Some studies offer a thank-you voucher
- **You are always in control** You can leave at any time

Ready to find out more?

Join our confidential community register to hear about new research opportunities. There is no pressure to take part in any research. To join the register, speak to your Community Researcher or email info@trustdevcom.org.uk

Scan the QR codes below to find out more about some current research projects you can get involved in

Be Part of Research – a free service making it easy to take part in vital health and care research. Simply say which health conditions you are interested in and you will be matched to suitable studies.



Join Dementia Research – register your interest in taking part in vital dementia research. You will be matched to studies and you can make a real difference to future dementia care, diagnosis and treatment.



Local Mental Health Research Studies with Sussex Partnership NHS Foundation Trust – research to improve care for mental health and well-being. It can be trying a new drug, taking part in a new talking therapy, attending an interview, completing a questionnaire.



Patient and Public Involvement Group – help develop research by sharing your lived experience of mental health and/or learning disabilities. To find out more call Lucy Walsh on 0300 304 0088 or email lucy.walsh20@nhs.net



Better Research. Better Health. For Everyone.

NIHR | National Institute for Health & Care Research is the Research Funding arm for the Department of Health & Social Care. NIHR have funded the community researcher grants.

  **NIHR** | National Institute for Health and Care Research

Trust for Developing Communities | A Company Limited by Guarantee Registration No. 3939332 | Registered Charity No. 1106623

Information Flyer

For more information on this project, please get in touch

Trust for Developing Communities

Community Base 113 Queens Rd Brighton BN1 3XG Company No: 3939332 Charity No: 1106623.

Email: info@trustdevcom.org.uk Web: www.trustdevcom.org.uk Tel: 01273 234 769