Community Researchers Project

Evaluation Report

Introduction

Tackling persistent health inequalities demands more than policy shifts. It requires the voices, insights, and leadership of those with lived experience.

In recognition of the challenges around health inequalities, Healthwatch Bucks (with funding from the Buckinghamshire, Oxfordshire and Berkshire West Integrated Care Board) delivered a community-led research initiative designed to develop and support an infrastructure for people with lived experience and from communities facing health inequalities, to gain and deliver research embedded within their communities.

At the heart of this initiative are the community researchers themselves which included people with lived experience embedded within local networks. Those community researchers brought deep personal insight, local knowledge, and an unwavering commitment to improving outcomes for their communities. Through training, mentoring, and hands-on research, they explored the barriers individuals and families face in accessing support, voiced some hidden experiences, and began to shape locally rooted solutions.

This evaluation report presents some of their reflections, views as well as the influence of their work. It highlights how community-led research can build trust, increase confidence, and catalyse action, particularly when it is relational, flexible, and grounded in the everyday realities of those most affected by health and care inequalities.

Participants

This evaluation draws on the insights of some community researchers who were directly involved in a pilot project focused on addressing local health and care challenges. Participants brought a unique perspective shaped by deep connections within their communities and lived experience of navigating the health and social care system, both personally and alongside others. The researchers come from diverse backgrounds, including lived experience of multiple layers of deprivation including caring for children with SEND, a member of the Romany Gypsy community and an Urdu speaker supporting female members of the Buckinghamshire Pakistani community.

Through in-depth interviews, participants reflected on their journey as community researchers, what they learned, the impact of their work, and the opportunities and barriers they encountered along the way. Their stories form the foundation of this report.

Evaluation

This report outlines an evaluation commissioned by Buckinghamshire Health and Social Care Academy (BHSCA) and undertaken by the University of Bedfordshire (UoB). This evaluation captures the experience of community researchers who took part in a pilot project aimed at understanding and addressing local health and care challenges. It serves three key purposes:

- To reflect on the role of community-led research in identifying the issues that matter most to underserved communities, and how this approach supported more honest, open conversations about health inequalities.

- To understand the impact on those involved, not only in terms of skills gained and confidence built, but also how researchers felt about their ability to influence change and advocate for others.

- To gather learning that can shape future work, including what helped participants feel heard, what made a difference in their communities, and how support structures, e.g. mentoring, enabled or limited their contribution.

By centring the voices of those who are involved with this work, this report offers an insight into what it takes to make community research meaningful, impactful, and inclusive.

For this evaluation, a thematic analysis approach was adopted focusing on one-to-one interviews conducted with participants. Interviews explored participants' experiences and perspectives in depth.

The one-to-one interviews were completed by three participants which enabled a more in-depth exploration of participant experiences, offering rich, qualitative data. All data collection was conducted anonymously. In the reporting of results, participants are referred to using the label "P" followed by their assigned number (e.g., P1, P2) to maintain confidentiality while allowing for clear attribution of quotes and viewpoints. Thematic analysis was used to analysis the data and to identify key themes for the results.

A call for joining community researcher was made with a role outline communicated to potential participants. A community researcher toolkit was developed as part of the programme in partnership with Buckinghamshire New University with input from people

and communities facing health inequalities. This toolkit is designed to take individuals through the essential steps of community research.

A call out for potential community researchers was made to a wide range of organisations and communities within Buckinghamshire with a clear role description outlining expectations.

Results

The one-to-one interviews reveal that participating in this community research project had a profound impact on individuals who were often excluded from formal decision-making processes. The community researchers, gained confidence, developed research skills, and created a space to enable them to start to influence how health and care services understand and respond to local needs**.**

1. Identifying & Understanding Key Health and Care Issues

Participants surfaced pressing but overlooked challenges, especially around SEND support, mental health, and systemic inflexibility.

"You're told you're a liar, or you're covering for your child." P3

"Nobody wanted to know until things got really bad." P1

This research allowed participants to voice experiences that had long been minimised or ignored, providing a platform for visibility and validation.

Through hands-on involvement, participants gained insight into research practices and developed new capabilities in interviewing, presenting, and advocacy.

"It gave me back some confidence – like I wasn't just a problem parent anymore." P2

Even those with no prior research experience began to see their lived knowledge as legitimate and valuable.

2- Confidence in Research and Support to voice concerns

Participants reported significant increases in self-confidence (self-assessed), especially in sharing their views and understanding the value of their perspectives.

"I've got a lot of experience in this, in this, in this." P3

"It built my confidence up because before that meeting I was very, very sceptical on what I was doing" P2

Participants also reported feeling that they had a rare opportunity to be heard as they were supported by the project's design and facilitation.

"Someone finally asked what I thought." P1

"Marcela (project lead) has been fantastic… willing to work with me." P3

Participants also reflected on the environment created through this project and how safe they found the environment:

3- Involvement in Change

While some were still early in the process, all participants had been actively involved in identifying change ideas, from parent support groups to system-level feedback loops.

"We're at the very start… but I'm hoping we can bring a lot more families together." P3

"It made me realise I could actually make a difference." P2

There was cautious optimism that decision-makers could be influenced, especially when research is paired with strong relationships and clear stories.

"…move forward with this project, we'll take it,… move forward, learn with them and progress with them and help our communities to have their voices heard… being able to make those small changes even if it's small. If it takes time. But at least work towards it" P1

Discussion

Some key points raised throughout the interviews is the lack of cultural understanding among mainstream professionals, particularly in healthcare and education. This gap creates significant barriers to effective communication, access, and trust for Gypsy, Roma, and Traveller (GRT) communities for example. The complexity of GRT culture often goes unrecognised, leading to frustration and missed opportunities for meaningful engagement.

Participants stressed the importance of authentic, community-rooted representation. They expressed dissatisfaction with superficial or tokenistic involvement, highlighting that true progress depends on empowering people from within the community to take leadership roles. When community members shape practice and policy, the solutions become more relevant and respectful of lived realities. Participants' experience with this project boosted their confidence not only in themselves and their abilities but in the system itself and in the possibility of future change.

Systems themselves were often described as rigid and ill-equipped to meet the needs of marginalised communities. Bureaucratic processes often result in confusion, missed appointments, or unintended consequences. The standard ways institutions operate simply do not accommodate the distinct ways these communities live and engage with services, reinforcing exclusion rather than inclusion (e.g. through written communications).

Underlying these challenges is a fragile but essential issue: trust. Distrust of services, particularly police, social care, and health providers, is deeply rooted in history and lived experience. This mistrust cannot be overlooked or dismissed as mere perception. Building trust requires consistent respect and genuine cultural engagement, which takes time and effort to achieve. The community research programme is seen as a way to start to building that trust.

Collaboration between different community members and public institutions is seen as vital. However, those acting as bridges, like the community researchers, need appropriate training, respect, and clear support structures and forums to be effective. There is a shared desire for partnership, but this must be built ethically and with community leadership firmly at the centre.

Education and co-training emerged as a promising path forward. Participants described the potential of co-designed training programmes, where community members and professionals learn from each other. This approach holds promise to dismantle barriers and challenge institutional biases through mutual understanding.

Finally, while the scale of change needed is significant and often slow, there is optimism about what grassroots work can achieve. The community researchers acknowledge the difficulty of shifting entrenched systems, but their commitment to sustained effort and mutual respect offers hope that meaningful progress is possible.

Recommendations

1- Embed Ongoing Cultural Competency Training

Develop regular, co-designed training sessions where community researchers and professionals learn from each other, fostering deeper cultural understanding and reducing barriers. Participants enjoyed their roles and expressed their willingness to develop deeper connections and engagement with their communities

2- Strengthen Support Structures for Community Researchers
Strengthen mentoring, resources, and flexible working arrangements to continue to empower researchers, especially those facing health or personal challenges, ensuring their sustained involvement.

3- Promote Genuine Community Leadership in Decision-Making
Ensure community researchers have meaningful roles in shaping policies and services, moving beyond tokenism to authentic influence and shared ownership of change by identifying suitable mechanisms through which to do this.

4- Facilitate Flexible Engagement Methods
Introduce virtual platforms like webinars and online forums to include isolated or vulnerable community members, increasing accessibility and widening participation.