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Co-designing inclusive community involvement in research: reflections on the *I Am More Than*... project with people experiencing homelessness

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Abstract

Background There is a pressing need for more inclusive research practices, as recognised by researchers, funding bodies and community organisations. It is increasingly acknowledged that research should actively involve a more diverse range of voices, such as individuals experiencing homelessness or vulnerable housing. Despite their valuable insights, they are often excluded due to systemic barriers, such as lack of opportunity or confidence to participate, limited access to resources and inflexible research structures. As a result, their perspectives are frequently missing from studies that shape policies and services. In response, the *I Am More Than...* project sought to co-design inclusive approaches with people with lived and living experiences of being homeless and vulnerably housed, to increase opportunities for their involvement in shaping and designing health and social care research. This was achieved through a partnership between Bournemouth University, an integrated care system, and two community organisations: Lantern Trust and HealthBus Trust.

Focus This paper shares our reflections on the co-design of inclusive community involvement in research, sharing the perspectives of Jim, a community researcher with experience of homelessness, and Lantern Trust – a partner on the project, and the community organisation that supported Jim. We present the challenges, opportunities, and lessons learned, from the perspectives of the community partners, offering recommendations that may be transferable to other researchers and community organisations aiming to work inclusively in research.

Conclusion The *IAm More Than...* project highlighted the need for a reciprocal approach for research to be inclusive, the value of collaborating with community organisations with existing relationships with the communities they serve, and the need for a shift in power for research to be inclusive. Creativity, flexibility and a willingness to try new approaches can facilitate inclusive research practice.

Keywords Homelessness, Vulnerably housed, Inclusive research, Collaboration, Partnership, Public involvement, Community involvement



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Introduction

The need for more inclusive research is key to achieving high-quality research which tackles health and social inequalities. Along with a new Equality, Diversity and Inclusion (EDI) strategy, United Kingdom Research and Innovation (UKRI) published action plans in March 2023 intended to create a more inclusive research and innovation system. The National Institute for Health and Care Research (NIHR) [1] introduced a new requirement in January 2025 for research funding applicants to demonstrate how their work will address existing health and social care inequalities. Increasing the diversity of who is involved in shaping, conducting and participating in research, is one way to address this need [2, 3]. It can however be challenging to work in inclusive ways. Researchers must think creatively and work flexibly to truly engage with marginalised communities who are under-served by research, such as those experiencing homelessness, and give much greater thought to how to address the inherent power imbalances within existing societal and system structures (4). Creating flexible opportunities so individuals can contribute according to their needs and preferences is essential to achieving genuine inclusivity.

The I Am More Than... project is a United Kingdom (UK) based collaboration between Bournemouth University, Dorset Integrated Care System (ICS) and two Dorset community organisations, Lantern Trust and Health-Bus Trust. I Am More Than... is part of the Research Engagement Network (REN) Programme, an initiative by National Health Service (NHS) England which funds regional ICSs across the country to work inclusively and bring the voices of a range of people and communities into health and care research. In Dorset, a rural and coastal community in the south of England, with disproportionality high levels of homelessness and housing instability, we chose to work collaboratively with people with lived and living experience of homelessness and being vulnerably housed, to co-design inclusive approaches to increase opportunities for their involvement in shaping and designing health and social care research, in order to broaden participation.

The methodological approach of the *I Am More Than...* project is reported separately [5]; and involved university researchers and a project coordinator providing mentoring and support to project workers and community researchers (those with lived experience) within two community organisations (HealthBus Trust and Lantern Trust) to engage a wide and diverse range of people experiencing homelessness in identifying the challenges, enablers and solutions for involving homeless people in research. The purpose was for a diverse community under-served by research, to take the lead in designing inclusive approaches to involvement whilst building

research capacity in voluntary and community sector organisations (VCSOs) to drive this change. In the *I Am More Than...* project, the community organisations were able to co-design how they and the community researchers they supported wanted to be involved and it became the responsibility of the ICS and university partners to commit to making system changes to enable this happen. National Institute for Health and Care Research (NIHR) [6] emphasise that collaborative working and co-production are key to ensuring that projects are meaningful and inclusive, and we were keen to genuinely focus on supporting equity and tackling inequality by increasing the diversity of who is involved in research throughout the research cycle.

This paper focuses on a specific aspect of the collaboration: insights from one community researcher with lived experience of homelessness who worked on the project, and of the community organisation that supported him, to amplify the experience of community involvement in research from the perspective of community partners. Their unique perspectives offer valuable insights into their motivations, the process, the impact of their contributions, the challenges faced, and the innovative practices implemented to challenge traditional research power structures. When creating a range of outputs from this project for different audiences (journal papers, event reports, films, art installations, and blog posts), all partners were encouraged to identify outputs they wanted to lead on and what support they would need. For this paper, Robertson, Bailey and Graham from Lantern Trust suggested a reflective paper on their role in the project, in part to provide an alternate view to the largely academic lens through which journal papers are usually written. Although the whole paper has been co-authored with contributions from academic, community and lived experience partners, distinct voices have been maintained in the reflective sections, to highlight Robertson's, Bailey's and Graham's perspectives.

Through this reflective paper, we aim to build on existing knowledge about inclusive research practices and share ways of working that can inform future health and social care research, from a community organisation's perspective.

Background

Homelessness

Homelessness is a growing issue in England. According to government statistics for 2023–2024, homelessness applications for assistance in England reached 40,685, a 4% increase from the previous year and the highest level since 2011–2012. In total, 33,619 households were assessed as either homeless or at risk of losing their home during this period [7]. Shelter highlights that accurately measuring homelessness is challenging, but their

research estimates that in England, 354,016 people were experiencing rough sleeping, temporary accommodation, or insecure housing on any given night in 2024 [8]. Homeless Link [9] emphasises the persistent health inequalities and poorer health outcomes facing people who are homeless. Within this project, we adopted the term homeless and vulnerably housed to ensure that it was inclusive of all people without their own home including people living in tents, and on the street as well as people in temporary accommodation, sofa surfing, staying with family/friends or in inappropriate accommodation such as poorly run Houses in Multiple Occupation (HMOs).

In response to these needs Lantern Trust delivers a wide range of services including advocacy, crisis response, welfare benefits, housing and accommodation support to people in the Weymouth and Portland area of South Dorset: Lantern Trust - Giving you hope when you need it most. In contrast, the second community partner, HealthBus Trust in Bournemouth in the east of the county, offers an outreach GP-led service providing accessible healthcare: Home - The HealthBus Trust. Developing a partnership between the university and the two community organisations in the I Am More Than. project was crucial because of their trusted relationships with those experiencing homelessness and vulnerable housing and a deep understanding of individuals' needs. This approach aligns with others [10, 11, 12] who highlight the value of researchers reaching out to relevant communities rather than expecting them to approach researchers and the role of community researchers (those with lived experience of the topic being explored) in making these connections [4].

Inclusive research

In their review of engaging people living in vulnerable circumstances in research, Goedhart et al. [13] highlight that inclusivity is crucial to reducing health inequalities. Although public involvement in research is increasing, people from inclusive health groups (a term used to refer to describe people who are socially excluded, who typically experience multiple risk factors for poor health, such as those who are homeless and vulnerably housed), are often excluded [2, 3, 6, 14] and equality and diversity have been neglected aspects of research involvement [10]. Goedhart el al. [13] emphasise that inclusivity is mutually beneficial to communities and researchers but describe challenges including personal and systemic barriers, such as lack of opportunity or confidence to participate, limited access to resources, and inflexible research structures. They suggest strategies to overcome these: building trust, ensuring cultural sensitivity and aligning with the needs and preferences of communities and individuals to ensure authentic involvement. In addition to building capacity and confidence within communities, the *I Am More Than.* project sought to surface the power imbalances present when seeking to facilitate collaborations between communities and research institutions. To facilitate more inclusive and flexible involvement opportunities, we identified the need for system change and senior leadership buy-in. In collaboration with community researchers, the partner community organisations and over 50 stakeholders, we identified that embedding an inclusive research approach required:

- 1. Listening and insight gathering.
- 2. Leadership engagement and commitment.
- 3. Collaboration and community engagement.
- 4. Empathy and understanding.
- 5. Building trust through relationships.
- 6. Flexibility and person-centred approaches.
- 7. Awareness and education activities.
- 8. Cultural and perceptual shifts.

[15].

To address inclusivity for people with lived experience of homelessness, the I Am More Than... project deliberately began with an undefined approach so that everyone involved could co-design the direction and priorities of the project. We aimed to find ways for people experiencing homelessness or being vulnerably housed to have a voice in research, without imposing a set agenda or set way of being involved. The university partners intentionally avoided being prescriptive, so the community organisations and community researchers could shape the project on their terms; examples of which are shared later in this paper along with the challenges encountered of this unscripted approach. This iterative and co-designed approach aligns with other researchers working with groups who face barriers to engaging in research (16-17)and goals to address imbalances of power.

Methods

Ethical approval

Ethical approval to undertake the project was obtained from Bournemouth University's Research Ethics Committee to undertake and publish findings from the project and was conducted under the University's Research Ethics Code of Practice.

Getting started

Starting the project with a focus on building relationships and trust was crucial to the collaborative power-sharing process [18]. Following initial exploratory conversations, the university partners were invited to one of Lantern Trust's *Your Voice* groups. *Your Voice* is a monthly customer-led group which aims to direct the services Lantern Trust develops. Each meeting is held with a clear

topic in mind as raised by our customers (the term used by Lantern Trust for people accessing its services and support). Volunteers with lived experience of the topic are invited to attend and the sessions are facilitated by a member of Lantern Trust staff.

Sharing pizzas in the drop-in centre, Lantern Trust staff, customers and university partners explored what being involved in co-designing an inclusive approach to involvement in research might and could look like. Exploring the principle of "Nothing about us, without us, is for us" [19], which emphasises that for research to be inclusive, meaningful and accountable; those individuals and communities affected by it must be properly involved, with opportunities to share power throughout the process [20]. The relaxed, familiar, informal environment helped to create a space where people experiencing homelessness or being vulnerably housed felt able to engage in informal conversations about how they might like to be involved. It was during these conversations that someone shared "If I am going to be involved in research you need to understand who I am first, - that I am more than just homeless" leading to the re-naming of the project as 'I Am More Than...' Along with HealthBus, Lantern Trust staff continued these conversations within established group structures over many weeks with background support from university partners and the wider project team through weekly operational group meetings. Working at the pace of trust and led by those with lived and living experience who were to become community researchers, the *I Am More Than*. project became a reality with community researchers and partners engaging in conversations, group activities, obtaining written accounts, and art projects, to seek a deeper understanding of the barriers, enablers and solutions to involving more people who are homeless in research.

Reflections from the community perspective

In keeping with our inclusive approach to research, this next section is presented through the voices of a community researcher with lived experience of homelessness, and two members of staff at Lantern Trust. Recognising that this paper is primarily grounded in their perspectives, we have intentionally kept their voices distinct to avoid diluting them.

Jim robertson, community researcher, Lantern Trust *A personal perspective*

Before experiencing homelessness, I had a relatively well-paid job. However, I was a functioning addict, and a succession of unfortunate life events including redundancy and bereavement contributed to me losing my job, wife, family and home. I used my savings to maintain my drug habit and pay for deposits, getting sicker with undiagnosed cancer. I was missing work, so jobs dried up as I

wasn't reliable. I lost my home and sought help from the council, who housed me in emergency accommodation. I stayed in a bed and breakfast (B&B) with no kitchen facilities for seven months, it was stressful. During this time, my cancer was diagnosed and treated but recovering at the B&B was far from ideal. The council eventually housed me, and my situation has improved since then.

The I am more Than... project

During the time that I experienced homelessness, I attended Lantern Trust where I met Tanya (Education, Training & Employment Coordinator). She invited me to contribute to the I Am More Than... project as a community researcher. A team of us worked together at Lantern Trust: four community researchers, supported by Tanya and Mike. At the start, we knew that we were doing a research project, but we were not sure what it involved. Initially, the project was disconcertingly undefined and confusing. I kept asking questions, though the answers were unclear because we were figuring it out as we went along. It was hard to explain what we were doing or why, and I doubted we would finish in the timeframe. I felt like I needed to know what we were doing, but at the same time, the project needed to be on our terms. However, we quickly found our feet, and, in the end, we pulled it together, which was great.

My role as a community researcher was to recruit people and interview them about their experiences of homelessness or vulnerable housing. It was good to hear everyone's stories - I like to hang out with people and it's amazing how much you can find out from them. I found that people feel flattered being asked to talk about themselves and like the opportunity to have a person enquire into their experiences.

The value of sharing experiences in research

I found that for many people I interviewed, it was cathartic to share their experiences. Initially, some wanted to take part because we provided a voucher, but they expressed that it was a release to talk about what they had been through. No one left the process unhappy – they all seemed to get something positive out of it. At first, individuals would recall difficult and painful memories, but by the end of the conversation, they would be a lot lighter in mood. They were appreciative that someone was genuinely interested in their perspectives and experiences. I noticed that the more socially isolated individuals were, the more they valued this interest, which highlights that people do want to have a say and contribute to research.

Personal benefits from the project

Having felt lukewarm about the *I Am More Than...* project at the beginning, I am now really keen on it. I have a new job as carer with someone with an acquired brain

injury and I believe *I Am More Than...* played a significant role in helping me to move forward in my career because I was reminded of my skills and abilities. Although I have guilt about my past mistakes, I was raised to care for others and to use my strengths to make a positive difference.

I worked in publishing before I experienced homelessness, but my new role is more rewarding. It gives me direct satisfaction and a sense of purpose. I wanted to do something that made me happier - something outdoors or working in care or supporting people - and this has validated me. Not even a year ago, I lacked a sense of identity, and I was in a bad place. Being part of the project allowed me to contribute meaningfully, and it seemed that my contributions were genuinely useful.

Although the project was not the only factor in helping me to move forward, it made a real difference and granted a sense of purpose I'd previously lacked. Looking ahead, I would like to work in drug and alcohol services as a lived experience worker. I know I have transferrable skills, and I plan to move into this in the future.

Challenges

Working as a community researcher was challenging at times because I had to learn what to do and understand the project. Sometimes it was difficult to find the best place to do the interviews with people because of their situation, and it was not always possible to follow people up because of the complexity of their lives.

At times, I felt a bit uncomfortable because the project was undefined. As much as I wanted to think outside of the box, I still found myself thinking what is it the commissioners want? Although I was out of my comfort zone because it was initially unstructured, we were supported and encouraged to take the lead in defining it ourselves. There were two stakeholder events which also helped to make it clearer. These events included people from all different community, health and social care and academic organisations, as well as people with lived experience of homelessness. We all got together to share learning and ideas from the project.

Community partner perspective: Lantern trust, Tanya Bailey and Mike Graham

More than a project: A way of working

Before the *I Am More Than...* project, there was Lantern Trust and the journey we had been on. The emphasis on how Lantern grows and creates new services is based on always listening to the voices of the people who use our services. Rather than being a one-off event, it is an ongoing, fluid process where we shape services based on the voices of those who rely on them. This is our approach. So, our approach within the *I Am More Than...* project was actually our approach to working with people anyway.

For Lantern Trust, being part of this project gave us a voice at the same table as research academics. It enabled us to challenge the status quo alongside others and say that this has to lead to sustainable change. This can't be a one-off event. It has been incredible to be part of a project where we have had an equal voice – we have never experienced that before.

Challenges faced

On one hand, we wanted this approach to be different, for us to have control and be supported by the university partners. On the other hand, we were not used to the power being flipped in this way, nor to the project being unstructured and flexible rather than rigid. There was some discomfort with this, both for staff at Lantern, who might have preferred clear guidelines and a defined way of working, and for the community researchers. For example, Jim, who was used to structured project management in his previous role, felt concerned about what was wanted and expected by the project funders.

This is about a power shift, which is where the challenge lies for academic institutions. We need to empower community organisations to become expert researchers by embedding researchers permanently within the organisation so that researchers become part of the heartbeat of that community.

Traditional research projects might have value, but in our experience, they often do not lead to meaningful change. This is not to devalue the research itself, but when working with groups negatively impacted by systems, a lack of outcomes can cause harm. If the research doesn't lead to change, how do you sustain a role like that?

Innovative practices

The *I Am More Than...* project is very different from traditional research, which tends to involve a kind of helicopter approach — researchers come in, oversee the research, look in from the outside and do not leave anything in return [21]. Control and power over the project are with the researchers, and research is 'done' to people without them having agency in it.

From the community organisation's perspective, it was challenging for some of us to adapt to this new way of working in research. We were already used to listening to and acting on the voices of our customers – that approach is fundamental to Lantern Trust's way of working. What was different about the *I Am More Than...* project was that we were saying: this is not a predefined project with clear objectives and outcomes. It was about flipping the power so that, rather than the university having control over how this project was undertaken, we were all collaborating.

All along, the key objective was to explore ways of making research more inclusive and to find out what having a voice in research would mean to people experiencing homelessness or those who were vulnerably housed. To some extent, this required trusting the process and believing that there would be positive outcomes even if the project was not clearly defined. We had to do it this way because it needed to be flexible to meet the needs of everyone involved. That was the whole point.

As much as it's okay to give the power to the community and say, "What do you want this to look like?" the whole process has been guided and supported, ensuring it's fair and effective. Support is a crucial element of working collaboratively with community partners [5, 14, 21, 22, 23], facilitating true inclusivity and involvement.

Lessons learned and recommendations

The *I Am More Than...* project is now in its third phase, focusing on co-designed and co-facilitated webinars and workshops to share our learning with other community partners. The goal is to help them explore ways to engage in research as part of the inclusive research agenda and to build capacity and infrastructure to enable them to drive this change leading to the involvement of other underserved communities, beyond those who are homeless and vulnerably housed. This phase also responds to the NIHR's requirements for research inclusivity in funding applications [1]. As researchers increasingly approach VCSOs for collaboration, developing a supportive network ensures that these partnerships are formed in ways that are both acceptable and beneficial to VCSOs and the communities they serve.

Throughout the project, we found that it was important to acknowledge that not everyone wanted to be involved in research. We concluded that the priority for VCSOs was to have the opportunity and choice to participate by removing barriers, such as fixed meeting times and locations, expectations of ongoing commitment, lack of trust and discomfort with traditional research language or settings [13]. Boxall et al. [22] highlight that there is no one-size-fits-all approach to inclusive research. We appreciated that not everyone wanted to be a community researcher but ensured that anyone who gave their input was a researcher of sorts - we ensured that their contribution still fed into the design of the broader *I Am More* Than... approach. We learnt to ensure that everyone had the freedom to say what they wanted, and we provided guidance and support to shape their contributions into something actionable [23]. This approach aligns with the Health Research Authority [24] who advocate for increasing the diversity of people taking part in research. For diversity to be achievable, researchers must be responsive to the needs of individuals and communities and take active steps to breaking down these barriers.

The co-authors reflect on how the project has felt fair and inclusive from the start. By building relationships and taking time to get to know one another at workshops and meetings, we recognised each other as equals, bringing different types of expertise. The project is not led by the university or one community partner, it is *us*-led. As the UK Collaborative on Development Research (UKCDR) and ESSENCE [25] emphasise, good-practice research involves collaborative efforts where all the partners contribute and mutually benefit, rather than researchers extracting data and knowledge from participants.

Underpinning inclusive research approaches are trust and the need to build relationships [26]. We recognised that if the agenda was to conduct research or recruit public contributors to projects in isolation of these relationships, the project was not going to work as it leads to helicopter research, where researchers come in, collect data, and leave [21]. We have observed varying reactions from community organisations in response to requests to be involved in research, with some accepting the nature of this unequal involvement, which perhaps reflects wider societal imbalances of power, and others declining opportunities due to this extractive approach. The I Am More Than... approach is different as we have worked together to create an equal partnership in the research process which has now laid the foundations for ongoing opportunities to involve people who are homeless and vulnerably housed as participants, public contributors and community researchers, on a whole range of research projects.

Ultimately, the voice of lived experience should shape future commissioning and system changes. In the *I Am More Than...* project, we have found this aligns with the desires of both community organisations and the people we serve. However, achieving this vision requires trust in communities and individuals as the true experts.

Based on our collective learning and insights from the *I Am More Than...* project, our message to researchers and academics is to trust community partners and community researchers to lead on how best to engage communities. We can work together to set the parameters, and all work within them. As community partners, we are best placed to identify how best to achieve the outcomes in the way we know works best within our own communities.

Our key points for inclusive research involvement with communities

 Don't be frightened to do research with marginalised groups and communities under-served by research.
 As Jim, one community researcher, said, 'I found that people feel flattered being asked to talk about

- themselves and like the opportunity to have a person enquire into their experiences.'
- Collaborate with community partner organisations to recruit and support community researchers on the ground during their everyday activities.
- Establish regular partner support throughout the duration of the project. We met every week.
- Ensure people have time and space to give context to who they are "If I am going to be involved in research, you need to understand who I am first that I am more than just homeless."
- Try not to have a fixed idea as to how you are going to involve people – co-design this together.
- Allow as much time as possible for working together
 you will need much more time than you think.
- Get everyone involved to capture their reflections on the process on an ongoing basis to enable ongoing growth and learning.
- Create opportunities for people with lived experience and community partners to be published in their own words.

Conclusion

The success of the I Am More Than... project highlights the value of collaboration, partnership and a shift in power for research to be inclusive. Key to this has been the relationships between the community organisations and Bournemouth University, without which the project could not have worked. It was essential to have the involvement and support of HealthBus Trust and Lantern Trust for people with lived experience of homelessness to contribute as community researchers. Lantern Trust's existing relationship with Jim and their continued support enabled his meaningful involvement as a community researcher. Through his role, Jim, and other community researchers, gained skills and confidence, leading to new opportunities. This way of working demonstrates the reciprocal nature of inclusive research – it is not just about 'doing' research, it is about working in mutually beneficial ways to enable people to be involved on their terms in a way that works for them. The *I Am More* Than... project illustrates that creativity, flexibility and a willingness to try new approaches can facilitate inclusive research practice.

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Data availability

No datasets were generated or analysed during the current study.

Declarations

Ethics approval and consent to participate

Ethical approval was obtained from the university's Research Ethics Committee to undertake and publish findings from the project and was conducted in accordance with the university's Research Ethics Code of Practice.

Consent for publication

All authors have consented to the publication of this manuscript.

Competing interests

The authors declare no competing interests.

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