"We keep being researched"

Community views on what makes good research in Oxfordshire

"That's what I want to see… meaningful action"

November 2023

Contents

1. Summary

During summer 2023, Healthwatch Oxfordshire carried out interviews of grassroots community members, as well as those from statutory, academic and not for profit organisations in the county. We wanted to hear about views on community research, and to make sure these views were heard in the development of a community research network in the county.

For those who want to read the **long read** report, **easy read** and **shorter version** on all views that Healthwatch Oxfordshire heard on community research these are available on our website at www.healthwatchoxfordshire.co.uk/report/community-research-in-oxfordshire-november-2023/

The long read report:

- Gives the views of 22 people we interviewed from grassroots community *as well as* those from health, academic, statutory and not for profit organisations.
- Gives a full explanation of the background and thinking behind community research approaches, with references.
- Describes and maps in an appendix local examples of community research which has taken place in the county.
- Gives views on the way forward for Oxfordshire's emerging community research network.

This report should be read alongside. It brings to the fore the views and voices of the ten community members we interviewed, in their own words. Here, we have tried to include most of the voices we heard. The long read report includes the full range of topics covered.

We asked the questions '*how do community members see community research?*' in Oxfordshire and '*what does good community research look like?*'

Community members told us loud and clear that communities are tired of research 'on them' and not 'with them', and that things must change, if solutions to some of the pressing challenges are to be found. Based on the voices we heard from community members, we identified **4 key principles** that could underpin an Oxfordshire community research network. These would be:

- ➢ **Nothing about us without us.**
- ➢ **Commit to action.**
- ➢ **Value lived experience and time.**
- ➢ **Be open, transparent and accountable.**

This is what community members said:

Community members said that communities bring:

- ✓ Strong networks, ideas, skills, and strengths.
- ✓ Lived experience and local knowledge to help build solutions to challenges.
- ✓ Access to diverse voices, and culturally appropriate knowledge.

Community members said that communities told them they:

- ✓ Were tired at constantly being asked to take part in 'research' by many different organisations.
- ✓ Were sometimes asked to do 'new' research which had been done before, and had already identified issues and solutions.
- ✓ Wanted to see results, meaningful action and change from research.
- ✓ Wanted research to shift long standing health inequalities, and help build accessible, culturally appropriate services.

They said good community research would:

- ✓ See communities as equal partners in all steps of the research process – community-led from beginning to end.
- ✓ Build relationship and trust, based on a continuous, ongoing 'dialogue of equals', openness and feedback.
- ✓ Be collaborative and creative, with organisations supporting and working *with* communities rather than *'being done to'.*
- ✓ Recognise the knowledge and skills already within communities.
- ✓ Recognise and reimburse time spent by community members on research.
- ✓ Give ongoing support and infrastructure to communities to enable them to take part - including skills development, and removal of administrative burdens.
- ✓ Make a difference - with action from those in power to move towards real change in the short and long term.

Many of the views expressed here were also acknowledged by organisational representatives we interviewed and can be seen together in the **long read** report.

2. What we already know

The COVID-19 pandemic shone a light on already existing and persistent health inequalities, and in particular on the … 'greater impact faced by those from Black and Minority ethnic communities' (Public Health England 2020).

It also showed that to move forward, communities need to be at the heart of developing solutions, building on their lived experience and knowledge:

"…The pandemic recognised what communities had long known: that community-led solutions were essential to solve the deep crisis in social, economic, health and wellbeing… (giving) *greater importance… on working locally between government, community organisations and grassroots groups within places."* (Institute for Community Studies/ UK Research and Innovation, 2022:3)

One way recommended to support development of community-led solutions is through using **community research.** This is sometimes used as a catch-all to describe approaches to gathering knowledge, bringing different levels of participation, empowerment and control to community members. It can include terms like *community engagement, community insight gathering, Patient and Public involvement,* and *co-production*.

While local communities are often asked to participate in building solutions, they are rarely:

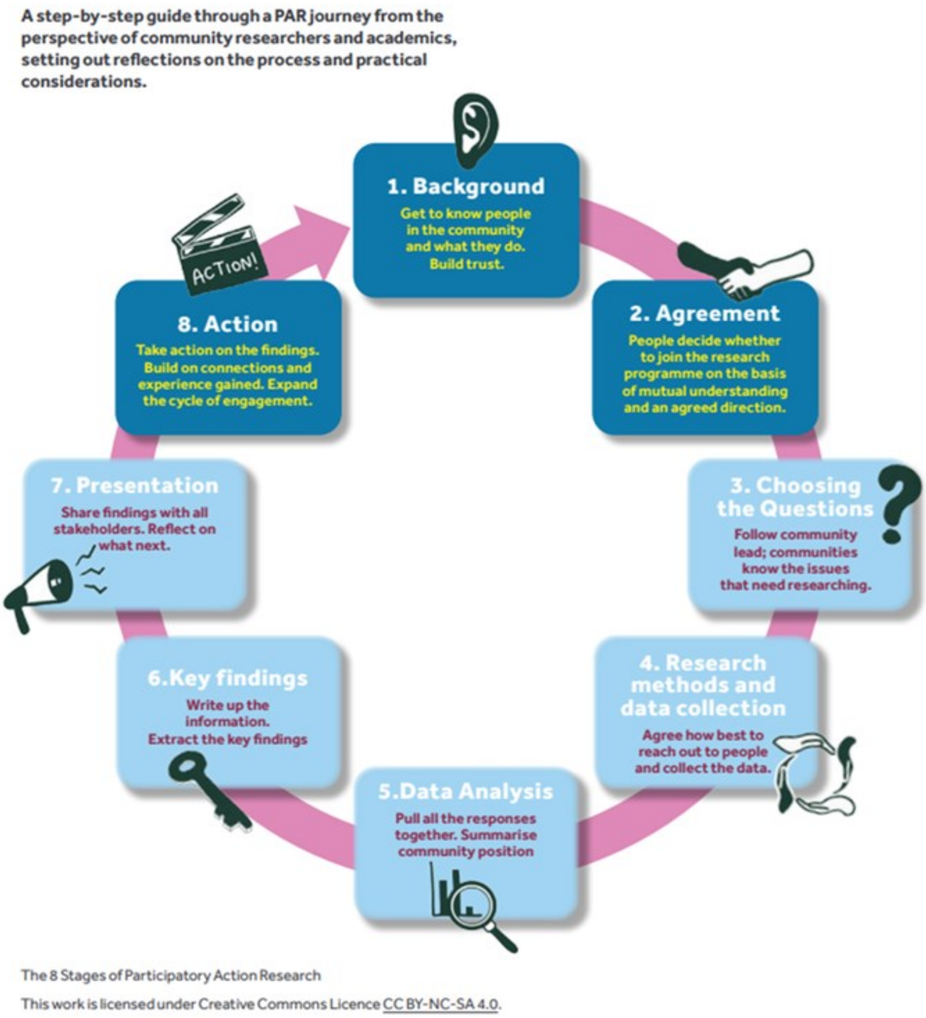
"*…given power over what and why knowledge is needed, how knowledge that affects them is created, or what knowledge is valued…*" (Institute for Community Studies/ UK Research and Innovation, 2022:3)

However, there are approaches that that can help to shift this balance of power. Community Participatory Action Research (PAR) brings communities into the centre of knowledge generation. It includes principles that:

- **Focus on justice, action and solutions.**
- **Value equality, respect, dignity, trust, and reciprocity.**
- **Works *with* and not *on* people.**
- **Uses non-controlling methods and is empowering.**
- **Fosters working together as co-researchers.**
- **Recognises participants are holders of local knowledge.**

(Based on: Ledwith, 2016 and others)

The good practice steps for the PAR journey are mapped out in the University of Reading's guide, developed with community members:



A step-by-step guide through a PAR journey from the perspective of community researchers and academics, setting out reflections on the process and practical considerations.

The 8 Stages of Participatory Action Research

University of Reading (2022) CPAR A Toolkit

3. Who we heard from

This report brings to the fore the voices of ten community members across Oxfordshire who we interviewed as part of a wider exploration of ideas behind Oxfordshire's emerging 'community research network'.

All of them had some experience of community research, some over many years. Interviews were transcribed verbatim, and with permission.

The questions we asked were:

***'How do community members see community research?'* in the Oxfordshire context and '*what does good community research look like?*'**

4. What people said

People told us about their own experience of community research, including the benefits and challenges.

What did community members say?

What's happening? We keep being researched … What's the outcome?

… you get tired, you get down, be like, "what another research?"

… Community needs to 'own' it and not just be a vessel for information

… If its community led, we will be able to explain the issues clearly…

… people don't have faith that that they will get feedback. And so people lose the interest

… no one hears the results. No one hears what's going to change

For me, to be a volunteer doesn't mean I don't love the work, but I can't afford to do it …

…it doesn't really translate into meaningful action

…that's what I want to see meaningful action

5. "Recognise the skills and knowledge in communities"

Community members said that communities:

- ✓ **Bring strong networks, ideas, skills, and strengths.**
- ✓ **Bring lived experience and local knowledge to help build solutions to challenges.**
- ✓ **Bring access to diverse voices, and culturally appropriate knowledge**.

➢ Communities bring strong networks, ideas, skills, and strengths

➢ Communities bring lived experience and local knowledge to help build solutions to challenges

Community members can often bring direct experience and insight into some of the things that drive health inequalities. Lived experience can help keep research relevant and give real insight to help to build appropriate services.

Some people we spoke to gave examples of how bringing lived experience had helped to make sure the questions being asked were relevant, and had meant that the research spoke to the community and was 'about their lives'.

> *"I think when people have owned the issue, and they're feeling 'Yes, it's us'. I think this is the power of not just the lived experience as being an experience, but as an agency of change. Yes, I believe powerfully that lived experience can be turned around to be the agent to make the change.*

> *"Because they were feeling it's a conversation, it's about them. So they were feeling can we speak about what we think, what we see. And there is an element of a lot of research and a lot of work being done by the so-called professional experts. And people had felt okay, you can have your expertise service in the hospitals or anywhere, but really it's about our lives. And how this legislation is impacting our lives - really they were the experts of that."*

One project, which explored female genital mutilation (FGM) and HIV in Oxford, showed the value of lived experience and shared understanding in doing research on sensitive topics:

> *"So at that time, we got the community and FGM was a really big thing and really they were feeling the heat of it with the lived experience… without much knowledge of the law, about some of the cultural implications of living in the UK., because these are families who some have just moved to the UK. I remember*

one of the families saying something that stuck with me, they'd left a country that was war torn… children were being recruited into child soldiers. And they were finding, because of the FGM legislation, schools would profile their children. So they were saying 'I've left one place … my children are being profiled and picked on. I've come somewhere else for that to carry on'. So if these things are not done with the community, the way it translates to them is very different."

Bringing lived experience could also support people to be part of identifying wider solutions. Community researchers themselves bring a unique insight into the issues faced by their communities:

"Well, community research, I am definitely in favour of it. Because first of all, a lot of the people that participated with this type of research, had no prior skills, and it was a really, really good approach to actually give people an opportunity to engage with, with their life structurally, and be able to look, you know, move away from a situation where they're just talking about stress and anguish, but to give them the opportunity to assess themselves from their own perspective, to say, you know, step away from this, what's going on in my life? And I could see the relief from the mothers that they had this perspective, they had this point of view, and somebody something was being, you know, acknowledged and challenged in terms of their, you know, personal circumstances.

"That's what I'm highlighting. So that's why if it's community led, their community researchers would be able to pick up some of these nuances, we'll be able to really explain the issues very clearly."

➢ Communities bring access to diverse voices, and culturally appropriate knowledge

People told us that community researchers could open doors and build trust - and often had a 'culturally specific approach' that could bring openness, which outside researchers might not be able to bring.

"So it's that cultural specificity. Because I was looking at the African heritage community, and I was somebody that's known to the community, they were quite open and willing to talk to me. So they gave of themselves, whatever information they had, they could tell me, and they will tell me.

"We did some work (2007 employed two of African heritage worked within the community) again, you see the culturally specific approach meant that you got the quality and quantity and the openness and the frankness that people would talk to you about what their experiences are, what they felt should be incorporated into the programme that was developed and delivered."

6. “We’re tired of being researched”

We heard that communities:

- ✓ **Were tired at constantly being asked to take part in ‘research’ by many different organisations.**
- ✓ **Were sometimes asked to do new research which had been done before, and had already identified issues and solutions.**
- ✓ **Wanted to see results, meaningful action and change from research.**
- ✓ **Wanted research to shift long standing health inequalities, and help build accessible, culturally appropriate services.**

➢ Communities are tired at constantly being asked to take part in ‘research’ by many different organisations

“here we go again … ”

“I don’t know if we need any more research”

“people are tired … tired”

People told us that communities were tired of being approached – often by more than one organisation at once to take part in research, without seeing results. Often small groups feel ‘bombarded’ with requests to take part in research.

> *“I think the challenges are very much like, here we go again. Here we go again, another research another group. Another thing? What’s the outcome? What’s happening? We keep being researched. There’s loads of research and documentation that’s been done.*

> *“I’ll take an example … young people being expelled, excluded from school … And we know … that there’s so many research out there, not only there’s national research, there’s local research, not only there’s local research, there are local individuals … that have researched that subject … it’s been done over and over and over again, but nothing happens. Yes, yeah, nothing happens.*

> *“One big challenge … people are tired, people are tired … call that research fatigue. They’ve been researched too much. Community research is very*

valuable, it can be very beneficial. But also … how do we avoid falling into the trap of consultation fatigue? We reproduce that, even if we're doing community research … That's the challenge. Now, even going forward, all other research now that we're trying to do or any other conversations we're trying to have with people, people are definitely more fatigued now than they were, I would say five years ago. And maybe it's that thing of, we've been in this place, it hasn't changed, or do you still need to ask that question?"

- **Communities were sometimes asked to do new research which had been done before, and had already identified issues and solutions**

We've done the research – why haven't they read the research?

'Hang on a minute … we've done this research'

"I don't know if we need any more research, we've done enough research in the community. x did it, I've always done it. So I've done it again. So enough work has been done to establish that.

"It's like they were trying to reinvent the wheel. We've done the research, why haven't they read the research? If they read the research, then they will have seen that. Well, this has been done. This has been done. But there's a shortfall here. Let's now look at how we can fill that gap in. But it's not being acted upon by all sectors … all sectors have not indicated or explained to us what they have done with the evidence that we have submitted.

"I sat there thinking 'Hang on a minute. We've done this research'. They know what needs to be done in now in the county, because we've identified it. So why are they trying to reinvent the wheel when the wheels already been invented when we we've already given them the results?"

➢ Communities wanted to see results, meaningful action and change from research

"We talk about things, but we do very little"

"no-one hears the findings, the results …"

"it doesn't translate into meaningful action"

Community members were frustrated that past research they had taken part in often had not led to any action. They were clear that they wanted to see meaningful action and change coming from research:

"And that's the thing and I think you get suspicious, you get weary, you get tired, you get down, be like, "what another research?", and still yet, there isn't no inroads making into saying, "right, we've done that research, we've concluded, and this is our action. And we're going to make sure we carry them out and bring the community along and give that confidence to say, Yeah, we're really doing that we have listened, we've researched we've heard". So, you know, it's a bit of apathy."

One person reflected on why they felt meaningful action had not happened or been seen by them:

"We talk about things, but we do very little. But I'd like to see people who have the commitment to seeing the results, and pursue those results, regardless. Also, it's pointless local authorities talking about wanting to do research, what do you do with the research after you've gathered the information? Is it just to satisfy some objective that you've got … but it doesn't really translate into meaningful action. That's what I want to see meaningful action. We've done so much research, but we've achieved very little to show to substantiate what we have said we are going to do with that. I think that's what they need more than anything else … action."

Communities who have given their views need more feedback, communication and action - "no one hears the results".

"This is the whole thing it's that policies and procedures are being made without the consultation of the people it affects. So, when they say right 'OK we're going to carry out a survey', the problem is no one hears the results. No one hears what's going to change. No one hears the findings, no one hears anything about what is going to be different based on those findings."

"So when you go to people and say, 'I want to do this questionnaire, and it's very important that I have your views'. And they turn round and say to you, 'what's the point?' Yeah, because you're not the first person that's came to me … You know, we've had other people talk about this, but we've never ever heard back about what's happening. So there then becomes a fatigue in people coming forward, because they firmly believe that whatever they say, it's falling on deaf ears, because they don't get feedback …"

There were some examples given where participatory community research had led to action. For example, one person commented on the results of a focus on Female Genital Mutilation (FGM):

"In 2016 when we did the FGM study (with Oxford University) … the voices of the women were definitely in there - their experience of FGM, their thoughts about it, their thoughts of legislation. And so one of the outcomes that came was the women said they wanted a safe space in the city, to continue having this conversation about their safety, taking care of themselves. And actually at the back of that we got funding to start a workspace the "Women of the World". And in there, we did issues about women's wellbeing."

This had led to some longer term change:

"And a lot of the work that I see is happening now would have come from that. I see the education element of it, which I see Oxford Against Cutting doing in the schools was a very big thing. These were really grassroots leaders, the women themselves … They really wanted it to be community led."

➢ Communities said they wanted research to shift long standing health inequalities, and help to build accessible, culturally appropriate services

Community members told us that one reason for research was that they wanted to see development of culturally appropriate local services which were responsive to diverse needs. They wanted 'informed decision making' that would bring lasting change that would impact on people's lives.

"And we want informed decision making. But we want it to be community led, that the community are driving it, then people would not reject it, or take it and still continue doing it in the background. And we want lasting change, because we're not just doing things for our time, put a tick and then move on. We really, really have to have that community led."

One community member gave an example of how research on different needs done with African-Caribbean heritage communities had supported the development of culturally competent services for older people. They remembered:

> *"John Kallie Court, it was basically John Kallie, a man, South African and his wife devised a place for elderly, primarily African and Caribbean people who didn't want to be in a normal* (residential) *homes. They feel isolated. And culturally, yes, there'll be the food won't be this and this won't be that. And they could have that there. And it was brilliant."*

It was frustrating however, that today there was still a lack of culturally appropriate support and services in Oxfordshire. One person reflected on former community research looking at the health and social care needs of African heritage elders:

> *"I've seen very little change in all of what 40 plus years. In terms of access to facilities, yes, they may be able to access care facility day-care facilities, in particular, the elders, but there is no ownership. It's not a space that they can identify as their own. They're very much at the mercy of whoever is there and their acceptance of them. And they can't impose their cultural mores on other people who are there who may not be as receptive to what they want, in a space of their own. I've seen later years when the West Indian day centre was set up, how different it was, they were open and welcoming to other communities, the host community, or different communities from different parts of the world. But they didn't have that similar experience."*

Other work had highlighted:

> *"Need for social services to provide special care packages for our elders, and to have employed people who knew and understood the African heritage community or the West Indian communities. They were called at the time and the peculiarities in terms of certain hygiene standards that people had in their homes."*

When it worked well, there was a positive impact of using community insight to support the recruiting and developing a diverse and culturally competent workforce, the interviewee stated:

> *"We worked with social services, to employ and train black care workers, who could go into homes and work with those people. And from that it developed to ensure that they recruited more black care workers, and trained them and the white care workers how to work with black African heritage people in particular. So those are the changes that took place at that as a result of the work that was done. So there were positive things that came out of that, in that sense. And you see more, obviously, people of African heritage working in the care facilities now."*

7. “We know what good community research looks like”

They said good community research would:

- ✓ **See communities as equal partners in all steps of the research process and be community led from beginning to end.**
- ✓ **Build relationship and trust, based on a continuous, ongoing ‘dialogue of equals’, openness and feedback.**
- ✓ **Be collaborative and creative, with organisations supporting and working *with* communities ‘*rather than being done to’.***
- ✓ **Recognise the knowledge and skills inherent in different communities.**
- ✓ **Recognise, acknowledge and reimburse time spent by community members on research.**
- ✓ **Give ongoing support and infrastructure to communities to enable them to take part, including skills development, and removal of administrative burdens.**
- ✓ **Be action focused and make a difference - bring action from those with power to move towards real change in the short and long term.**

➢ Communities want to be seen as equal partners in all steps of the research process and research should be community led from beginning to end

People told us they wanted to be involved in developing research from the start – and be able to identify the problems, questions and issues themselves. One community member who had done this said:

> *“Research that we’ve done in Oxfordshire, was community led done by community themselves for the grassroots community, in Oxford. And I think what works very well is beginning of the research, we do not just come in ideas of ourself… we have to start it in the bottom for our communities. We sit with them, have a few sessions with them, talk to them about what we really want to do together as a collective. And the communities understand that this is something, the journey, they start to get an ownership… And I think, why I believe still, that is the way for community to do research, let them come first with the planning paper, and sit down and find out what communities really want to do …(it) wasn't us leading the question, the community led the questions together.”*

This means that the questions and the way they are asked can be developed with straightforward language and easily understood:

"The community says that we want to have simple understanding, meaningful questions that we can go to our community to ask and that was all collectively agreed. And we said, wow, this is really good, because number one, it comes from the communities. Secondly, they speak in a language they understand."

One example given of collaborative research supporting community ownership was in work with Terence Higgins Trust around HIV with women from African heritage. Honesty about motivations, clear information and background to support informed choice was critical to build trust from the start.

"When this lady was with Terrence Higgins approached us and said, 'we want to do this research', actually people told her 'No Thank you. Why have you picked on us?' People are like 'you're looking at us and thinking, these Africans', I think in the 1990s, yes, people refused. They said, 'well, why has she come to us?' Then when she gave us the statistics, I went back to the community and I said, 'we cannot ignore these statistics. I think it was like the highest new cases of HIV. I think East African women. Oh, my gosh, we can't ignore that'."

Honest conversation at the start was important in getting people on board,

"We needed to have this conversation. So I said okay. And I think this is the thing about research. I'm not denying that it's useful. It's very necessary. But actually, we really need to get the community on board in whatever way. Do you think it's, if you can frame the exploration of the issue in terms of getting the community on board in a way that the community feels that they have ownership of the issue, rather than being done to. And it's in our interest to do this."

- **Communities wanted organisations to build relationship and trust, based on a continuous, ongoing 'dialogue of equals', openness and feedback**

"Don't beat about the bush, tell us its not going to happen and tell us why"

Relationships of openness and trust need to be built with local communities, not just in the short term but the long term. This involves working to understand break down and address the different barriers to communication.

"I think we've gone through that period where people are more receptive… sort of realise that they need to do more. And by they, I mean, the host community, the white establishment needs to do more, how many more times 'you're going to be told that you as an organisation, as an institution are institutionally racist? They need to open up, and I think a few are beginning to realise that the initiative has to come from them. So there is more willingness to reach out to the community, to engage with the community, and to try and work with the community."

The TORCH project with Oxford University and a Community History Project (https://torch.ox.ac.uk/), highlighted local connections to slavery and its ongoing legacy. These needed to be acknowledged for some communities to build trust in research establishments:

"Nobody really knows of Oxfordshire's connection to slavery and the slave trade, despite the fact that I say people need to know about because it's part of that history is part of what shapes and makes Oxford and Oxfordshire, it's crucial that we know that."

This included the need to break down barriers of people's view of the university as elite and 'not for them':

"For me, it was to break down those barriers within the community that sees places like Christchurch as no go areas. They weren't for them, it was for others. And they saw the benefits, it was that barrier that needed to be broken. And to let them know that this is the cathedral. It's open to anyone and everyone. This is a public space, and it is the city cathedral, therefore, anybody should be able to go in there at any time."

Organisations approaching communities to be involved in research need to change and take risks. They need to be transparent in communication and make sure they also continue to give feedback to communities. This interviewee commented:

"Also, you know, take risks, and they're also demanding transparency to things as well. So having come to us and you say, you know, 'we're going to make this happen or not, 'we're going to make this happen'. Yes, we understand this. There's a need for this. 'We're going to make a policy to it. If it's not going to happen, then don't beat about the bush, tell us it's not going to happen and tell us why. So we can react to it."

"But things get dragged on. We then get lost through other pledges or other commitments or other crises come up. And then each one seems to be important each time and you forget the one that you started out with. And so then you sort of forget to follow up on the previous issue the previous agenda. let's move on, we'll run to the next one. The next tick box exercise as I refer to it,

> *that kind of process, that way of doing things leads to disengagement from communities, lack of trust, yes, sort of apathy, cynicism, and lack of engagement because then you come and ask us again, and we won't engage with it, because nothing happened last time."*

One community member commented on the need for ongoing and more rapid, visible action and feedback on research that has already been conducted:

> *"The challenge is when you collected data for the communities and they have spoken about their feelings and what they see the system not working, and you deliver this to the right institution, right organization and are not seeing any action being taken and then our challenge is a lot of different companies and institution coming up with research, asking questions, and people are giving, but then they won't have enough feedback. They feel like what they already told, there hasn't been any action on it. And that's the challenge…"*

They also noted however, that they knew it sometimes took time to achieve some change, often years, but again that ongoing communication was key:

> *"We highlighted our report our research and it took from 2018 to 2023 to see something is happening…. You can't go back to the community again and create a new research when they already told you that what they really need to be fixed, and you haven't acted. Then that is my challenge to anyone, to say to them. Look, before you come to communities first find out how many research been done by community? What actions been taken? What result came out of it? And is that still active? Please don't do another research, find that research, and then fix it. And then the community will be gathering to you 100%. They want to support you because they see it. They value their voice being listened to… Then this network, should be more focused, with grassroots community researchers. Helping those research communities that are already doing something or those who want to develop themselves to become researchers."*

- **Communities want organisations to be collaborative and creative, with organisations supporting and working *with* communities '*rather than being done to*'**

There is no fixed approach to doing community research. It has the potential to be creative and dynamic, and to develop evolving and fast-changing methods and approaches that build on people's ideas, skills and lived experiences. It can engage with feelings, emotions, sensory perceptions, and conversations. As an arts practitioner interviewee commented:

> *"…try not to make it too formal. For example, just being able to talk to people while marching on a demo, or, or when they're sitting down listening at the end… having over a cup of tea, coffee. So nothing in that*

> *formal thing where I've put a tape recorder on or writing notes down or key points down so a more natural conversation."*

A project with Oxford Brookes, "*Finding Our Way*", exploring African Caribbean experience in Oxford gives an example of 'walking interviews':

> *"We did what we called a 'walking interview' … they chose a point on the Cowley Road that has a significance for them. And then walk us through, up or down the Cowley Road to other points of significance in their life, and that was looking at culture and cultural spaces on the road … we had one person with a voice recorder and somebody else talking to the person as they are walking and talking. So that didn't, again, have that thing of having to speak into the voice recorder to record things."*

Other examples can be found in use of films, stories and art works.

- **Communities want research that recognises the knowledge and skills inherent in different communities**

Communities bring and have within them huge skills, expertise, knowledge in the individuals who are part of them. This includes experience of networking, research, interviewing, writing reports, setting up and managing projects, and building services and community-based projects.

- **Communities want organisations to recognise, acknowledge and reimburse time spent by community members on research**

> ***"Remember, I'm a volunteer, I work - 99% of my time is volunteering"***

> ***"Let's not expect them to use their blood to prove this passion"***

> ***It's almost a luxury they cannot afford, so will you reimburse them?***

Whilst many members of grassroots community organisations give their own time to support community activities, when it comes to community research, involving a different kind of input, it is essential to recognise and value time spent.

Community members felt their close relationships ensure they value and make visible people who gave time - even if this was not recognised externally or financially:

"Our people will work on the evenings on the weekends we'll work on Sundays from church, we will work at the mosque if they're doing community. Yeah. And that's not measured that's not visible to anybody else. So when we do this community research, the beauty of us leading it, when we're leading this, we are so aware of these nuances and we value, what people are doing even if I know she did that, after she did the madrasa classes she was doing this. I will value that work without me being having to say to anybody that oh, she's just gone to the mosque it was her own time of going. But I know. Alongside that she did the community work. Which, if that had been given to any other charity, that would give outcome…"

Unequal burdens and expectations were sometimes placed by larger well-resourced organisations on under-resourced grass-roots groups and community volunteers. Community members made it clear that people should be reimbursed for their time.

"So now I've come to a hurdle. I haven't even been paid for the work that I did. Because everything I do is voluntary…"

People reflected on the impact of cost of living and volunteering. This had implications on choices about work – forced as a result of undertaking under-funded community research. Timing and adequacy of funds was key:

"Oh, no, I thought over the years, I thought it just been little pots of money …. little bits here and there. But obviously, you know, I've sort of just chosen another career path, because I can't just sit waiting for funds to come through. And I can't volunteer, as much as I would like to purely because of the cost of living. And it's obviously affected me personally at home. So I'm looking for paid work, wherever it may be, though I understand that what I've built here… will be lost if there isn't input in and I couldn't understand why the authorities, the council couldn't get together and offer about seven, eight hours role every month, to pay someone… to use their expertise for the information that they need."

The views expressed by the community researchers interviewed in this report challenge the wider system to prove - through commitment to resourcing and ongoing action - that grassroots community organisations and community researchers are being engaged as equal partners. This means that their knowledge and insights are valued – and are properly recognised and resourced.

One community member commented:

"I think the incentives for community researchers has not been good enough. Because if Oxfordshire really want to invest in community research, then they

need to empower the researcher… But if we want people to go and help you to answer problem, and don't take care of those people, then it's a joke."

There was also debate over the use of vouchers versus cash reimbursement for research time:

"Let me give you the instance in most of these involved in this research, they say they don't pay cash. One of the meetings I had last week, I said okay. 'You say you don't pay cash? Didn't I use cash for transport? Did I use food?' So if I, I take five pounds from my pocket to transport me to the meeting, it means you're supposed to return today. So don't tell me that now you will pay in food vouchers. Who does that? So, it leads me to say no. If you're serious in this thing, then you have to compensate okay, I use money. You have to return the money. Because I take money from somewhere… That time, I'm supposed to go to work but because of interest? Yeah. Because of passion? So they shouldn't just joke with you, they shouldn't joke with you."

Another person commented:

"So sometimes, we think, oh, can we just give them a five pound voucher? No, I don't agree to five pound vouchers … These researchers have equal rights … they giving their sweat and blood for this serious work. So they were reimbursed properly. So for me, actually, as we're doing this. I don't know how they move away from that five pound voucher. That's a luxury they can't afford to do it. It is not equitable enough for them."

One community member said it was important that organisations had clear plans about reimbursement for community organisations, community researchers and volunteers. Without reimbursement for time some people will just not be able to afford to participate – this perpetuates exclusion and ability for many to be involved:

"One thing, which we campaigned for very loudly, was the reimbursement of expenses …Yeah, for me, to be a volunteer doesn't mean that I don't love the work, but I can't afford to do it. And sometimes it's not something easy for people to understand - what does someone mean they can't afford to volunteer? Because most of our people will be on either no recourse to public funds (NRPF), or they've got no other way, they have to work. So if we're saying, "Well, this community research has to be community led", you might find there's a shortage of - where are these people? And I know, this is a conversation I've had even with some of my white colleagues in various places, with them saying, "Oh, aren't they passionate about the thing?" They're very passionate. Yeah. But let's not expect them to use their blood to prove this passion."

Others also said community researchers who might be already be working, looking after families, and trying to make ends meet, need to be recognised and reimbursed for their time:

"It's almost a luxury they cannot afford, so will you reimburse them in terms of what shift have they cancelled?"

Again, emphasis was placed on financial impact and time commitments on people leading already busy lives, which needs to be clearly recognised and reimbursed:

"So when we're doing this research, I say in terms of the reimbursement and everything, we argued very, very clearly that actually, if I'm telling somebody to cancel their shift, because I need them to come here, and then I have to reimburse that time. It's a conversation I'm still having with people. Some of my people - coming to prospective new research. It's almost a luxury they cannot afford, so will you reimburse them in terms of what shift have they cancelled?"

This interviewee suggested a *lived experience reimbursement* formula would support more inclusive participation and equity:

"So I know the NHS and Oxfordshire County Council have something on the lived experience reimbursement…We use that model. And that's what I'd like to see otherwise we still not have balanced it out… Otherwise, we might just end up with always repeating the same people voluntarily, because maybe only some people can afford it, then you think why isn't that diversified? So we really want to diversify. We have to really just fill up those gaps. And one of them I know is I can't afford it financially."

- **Give ongoing support and infrastructure to communities to enable them to take part, including skills development, and removal of administrative burdens**

Funded organisations need to support community organisations, community researchers and volunteers and engage with them as equal partners. This means they need to give better support for the impact of taking on research. They could give support including administration, training and for the bureaucratic demands placed on small organisations taking part in research.

One community member from a grassroots organisation described their challenges with this. The impact on them as a small volunteer group was not supported or recognised:

"… purely because for what I'm claiming they want invoices for every single person. What a nightmare! If I had known that I would not have done this."

While this interviewee had done the hard work of engaging with community members and facilitating interpretation, these efforts were felt to be unrecognised and unrewarded:

> *"All these people I've had to go back to them and say, 'Can you give me an invoice?' They looked at me like I've gone out of fashion. And out of that I hadn't even put all this time in for me. So really, I'm out of pocket already. I said do I have to do that? I don't even want to bother with (the money). I don't think it's worth it."*

Demands placed on volunteers who arenot adequately funded meant that there were real barriers to continued involvement:

> *"For a small organisation, and then they say, 'oh, you know, thing is really important'. But I've already decided I'm not doing another one ever again… I can't do all this extra work that's been added on. So really, again, back to square one, so many hours of mine has gone into this to get all this information together. That's what it's really hot to me, because today I've just sent the invoices again, because I still haven't been paid."*

This person described the 'heartache' of paperwork challenges:

> *"The research side of it is great because I've got the community… So that's not a problem. Doing the research is not a problem. Because the information, I've got it is at the tip of my hand, and I can do that. But the problem I've got is the paperwork that comes with it, and the proving of what I've done and what, how I've done it' to claim money back… it was not difficult to work with the community. It was not difficult to set up. But the heartache, and the pain that I've got now is that they're doing all these invoices. Remember, I'm a volunteer, I work, 99% of my time is volunteering."*

Despite the good intention, in actual practice community research and community researchers often remain undervalued by many larger organisations.

➢ Communities wanted research to make a difference - to bring action from those with power to move towards real change in the short and long term

We heard that there needed to be commitment from those with the levers of change to action from what was heard from communities. Bringing change involved not only community members but rested with system leaders who could influence and address the problems identified.

> *"There's no point in having that research without all the accompanying actions after this. There's no point of doing research and then nothing happens, there's no progression within the community. There has to be initiatives set up prior to even the research or even in conjunction with the research project going*

forward. That have to think on, you have to have a two-pronged attack on this, do the research, but also prep, the groundwork for all of those issues that we're seeing during the research so that we can help to counter to overcome the challenges that our participants are going through.

"So without that second element of addressing the problems, then I think this research would be quite useless. And then you get that apathy from the community of well why would I participate in more research when there's nothing coming out of it? I'm just wasting my time right now. So we won't want that to happen because once you close those doors of communication with the community, then it's very difficult to open them again."

It is important to be clear and open at the start - and not to 'over promise' change. Action needs to come through listening to insight and working with those who have the levers of change:

"We gave them a space where they feel safe. And their point of view is being listened to, but then we do not promise or over-promise. We said we will take this to the right places and right people and then we can come back to the outcomes and I think that's why the two research that we did was very meaningful to community, not only as an organisation but the community themselves. Their full word, we did not take out the voice we took what they said."

Community ownership of research is essential if it will lead to action, and visible change:

"I think you're researching with the community and the community needs to own it and establish ownership of it and not just be a vessel for the information. I think that's key. Make sure there is some tangible result that comes from it. Sometimes you don't need research to know that something needs to happen. You know, health care, maternal care, in terms of Black women … people have known about that big disparity. I'd like to see us not start from the basis of asking the communities what are the issues, but start with beginning to take some action. So can we begin to readdress this rather than what are the issues? So you just start, you start from square two rather than from zero."

Drawing on the example of a *"still live demand"* among members of Oxford's African heritage community for a cultural centre, (not met after many years), one interviewee reiterated the emerging community research network should be action orientated, stating:

"I think, even with… trying to understand the need for a cultural centre in Oxford that demand is still there. But I don't even know if you need to do research to understand why there is a need. So there's some obvious things I think people do research on, to prove the research. You need to be action based in terms of

> *how you make that demand a reality rather than we're still trying to get people to articulate why we need one, but we know we need one. So 'it's just how can we make it happen' I'm saying that, it always gets left in the policy end. And at the policy, they can say, 'we've, got this policy now. And 'we've put a little bit of money to make it happen, but it never goes beyond that. And make the community see that things are moving in the direction, of which they want, that action has been taken. I think people have become much more aware of that. Since you know, 2020, we've had enough of words, 'we've had enough of policies. What does it mean, in reality in terms of doing something?"*

Community research, though empowering in its best form, could also be emotionally taxing (even 'traumatic') especially given the challenges to bringing about real change.

It also raises the question as to where the responsibility for change should be placed. Should it be carried by the community and individuals themselves - often living with health inequalities, or within and by the 'system' itself with more power to change structural issues? Linking up the research with those who have the levers and power to influence and enact change is essential:

> *"Community research itself, has an empowering aspect, in terms of, you know, people navigating their own health. But also some of the challenges is that you've got to really be very clear that, you don't have a solution, because the people when you come to interview them around these issues, they think that you have solutions for the problems they have, which is really difficult to like, explain. So you don't want to give people false expectations. So those are the challenges that you have. And then it obviously also filled with guilt, you live filled with guilt because somebody has just, you know, really given you the struggles that they have in terms of their life and everyday life. And you can't solve their problems."*

8. What could a community research network bring? 'Nothing about us without us'

Both the long read report, the shorter one, and this report help to bring the voices of community members into view. They told us loud and clear that communities are tired of research 'on them' and not 'with them', and that things must change, if solutions to some of the pressing challenges are to be found.

Based on the voices we heard from community members, we can draw out some of the **4 key principles** to underpin an Oxfordshire community research network:

- ➢ **Nothing about us without us.**
- ➢ **Commit to action.**
- ➢ **Value lived experience and time.**
- ➢ **Be open, transparent and accountable.**

In addition to the key themes outlined above, community members shared ideas on what a community research network could bring. Again, these included:

- ✓ Clear resourcing, funding.
- ✓ Skills development, training and capacity building.
- ✓ Infrastructure, administrative and other support.
- ✓ Provision of a knowledge hub, promoting best practice for community research avoiding repeated research involving the same communities.
- ✓ Action research with clear, ongoing communication and follow through including by those with the power to influence change.
- ✓ Community-led processes built on trust.

A network could assist grassroots organisations to obtain funding and administrative support:

"Conducting community research, one of the big challenges … was the finances behind it and booking a room or buying equipment, recording equipment, for example … I can imagine if anybody wants to do some community research that this is one of the major setbacks that they'll have to face. It's always finances in the community, because community, they don't generate finances."

A research network could also support skills and training – with technical understanding, good research practice, research ethics and GDPR protocols:

"For someone who doesn't know how to protect data, collecting it online, for example, or, in any way that we conduct research … It's something that we are considering too going forward when we start to conduct our own research, that we will have to have the mechanisms in place to protect data too so that we can comply with all the GDPR laws and all the data protection laws that exist in this country … So that we know we can learn exactly how to conduct research properly."

The community research network was also envisaged as a 'knowledge hub' or a place to access knowledge and training funding for community research projects:

"Make sure we are not doing research that has already been done to death"

“Somewhere to hold the database of information really, so that if we want to do something around, which we have just recently done with the project around boys and young men's mental health, there wasn't one place where you could go and access the information. And it wasn't that we need to start from scratch. But we had to go to someone who put us in touch with somebody else to put us in touch with, say you know, there isn't like a database somewhere of where all the relevant things related to that can be stored and held.”

“I'd like to see, something to help make it easy to apply for some sort of grants or funding to follow through with the research … But also I want to see a database, someplace where we can actually access all of the information we need in order to perform the research correctly … But also’ I'd want to make sure that, there's a panel to guide us, to make sure that ’we're not doing research, which has already been done to death.”

The interviewee felt that that this type of support from a community research network would strengthen community capability:

“Then I think that that would help propel this whole idea forward, and allow more researchers to have more confidence and do research, help them love doing research. And, that way the community can benefit because we'll be developing internally, more and more people, a structure, a solid structure that can help them move forward.”

Another interviewee commented on avoiding duplication of research:

“And that’s why maybe it’s really, really useful that we finally either consolidate all this in one place, so we don’t ask people the same questions again. Even if we go back and do another research, it’s something it’s like progressive rather than hashing the same things.”

‘No point doing research and then nothing happens’

As we heard before, interviewees felt that a community research network should lead to action and solutions and speed up action on research that has already been conducted to address problems of inequality:

“So, I think we need to really accelerate this platform of learning of community research, to the point where there is an appropriate amount,

> *researching into the black and brown communities, and those people who are in need. And so that pockets of the society are not left behind. You know, with research it is really important to, to hear from those who are never heard, or seldom heard … But then also, there's no point in having that research without all the accompanying actions after this. There's no point of doing research and then nothing happens, there's no progression within the community."*

One African heritage community interviewee reiterated the view that the emerging community research network should be action orientated:

> *"I think, even with … trying to understand the need for a cultural centre in Oxford, that demand is still there. But I don't even know if you need to do research to understand why there is a need. So there's some obvious things I think people do research on, to prove the research. You need to be action-based in terms of how you make that demand a reality rather than, 'We're still trying to get people to articulate why we need one, but we know we need one.' … But it never goes beyond that … What does it mean, in reality in terms of doing something?"*

9. What happens next?

Some of the lessons learned from doing community research have already influenced change, and in a shift of understanding about how organisations need to better work with communities. This report makes sure that the voices of community members continue to influence how things develop. These reports will be shared directly with decision makers including in the community research network, Oxfordshire Place Based Partnership, Oxfordshire Health and Wellbeing Board, and Buckinghamshire, Oxfordshire and Berkshire West Integrated Care Board. It will be used to make sure that future developments take what is here into account.

For those who took part in giving their views, we will make sure that we continue to inform, engage, involve, listen and make sure you play a part. Building trust and conversation through a 'continuous, open dialogue' needs to build and continue. Action needs to be seen, and reflected in the way that decisions are made and how services are developed and planned in Oxfordshire.

10. Appendix

For reference documents, toolkits and all examples of community research in Oxfordshire we found, including research done by the community members we interviewed see the appendix on p63 of the **long read** report.

11. Acknowledgements

With thanks to all who gave their valuable time, expertise, input and insight into both reports including: Achieve Oxfordshire, Active Oxfordshire, ACKHI, AFIUK, Age UK Oxfordshire, Afrikan Heritage, Aspire, Banbury Mosque, Buckinghamshire, Oxfordshire and Berkshire West integrated Care Board (BOB ICB), Community First Oxfordshire, Dementia Oxfordshire, Flos in the Park, Good Food Oxfordshire, Health Education England SE, Mothers 4 Justice Ubuntu, Oxford Brookes University, Oxford University, Oxford Community Action, Oxford City Council Community Champions, Oxfordshire County Council, Oxford University NHS Hospital Trust (OUH), Oxford Health NHS Foundation Trust, Oxfordshire Mind, Oxford Hub, Oxford Academic Health Science Network, Oxfordshire Community and Voluntary Action (OCVA), Oxfordshire Youth, Refugee Resource, Reading University and all individual community members.

We will continue to communicate with you and make sure your voices are heard in the development of a community research network.

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