healthwatch Oxfordshire

Your voice on health and care services

Community Research in Oxfordshire – an overview

October 2023

"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."

1. Contents

Acknowledgements: With thanks to all who gave their valuable time, expertise, input and insight into this report 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 them and make sure that their voices are heard in the development of a community research network.

Research and report:

- Veronica Barry (Healthwatch Oxfordshire)
- Nigel Carter

(Some funding was received from UKRI to support aspects of this work.)

2. Overview

Over the past decade **Healthwatch Oxfordshire** (HWO) have developed practical knowledge, insight and understanding from using community participative action research (CPAR) approaches working with and alongside seldom heard communities. (See: Our work with community researchers - Healthwatch Oxfordshire)

We have also participated in Health Education England's *Community Participatory Action Research* Programme (CPAR) Cohorts 1 (2021-2) and 2 (2023-4), as a host organisation to support training, mentoring and facilitation of grassroots community researchers.

Oxfordshire County Council (Public Health), academics, statutory and local community organisations have been meeting throughout 2022-3 to explore foundations for the establishment of a **community research network** (CRN) for the county. (See terms of reference in box 1 below)

As part of these discussions, Healthwatch Oxfordshire emphasised that **central to development of an Oxfordshire community research network, it is important to understand and recognise the views of community members who have led on some of this work and to learn from the legacy of research and work that has taken place in Oxfordshire already to date.**

Numerous research and insight gathering projects have been undertaken over the years by different communities, groups and organisations in Oxfordshire.

Those with lived experience and strong community relationships have contributed in various ways using community research approach, or allied approaches – and have skills, knowledge, expertise, learning and insights that can support the network development. It is important that their voice is brought to the fore. We will continue to communicate with them and make sure that their views are heard in the development of a community research network.

During July and August 2023, Healthwatch Oxfordshire reached local networks to gain an insight into views about community research, and to attempt to map some of the work that had already been carried out. We wanted to hear local community voices and views about community research.

We undertook in-depth interviews with community members (10), and organisational representatives drawn from statutory health and care, local authority, academic as well as voluntary sector organisations (11). This report brings together their views and insights to contribute to shaping and development of a community research approach for the county.

To help set up a community research network as a collaborative group, a community steering group was established in 2022 with the following purpose:

- To support the strengthening of community, resident, patient, and wider public agency in research and development relating to community services, assets, and needs.
- To strengthen the quality and applicability of research to support community health and wellbeing and to tackle inequalities.

The group aims:

- To take an inclusive approach to identifying and engaging residents and communities across Oxfordshire to interact with and be part of Oxfordshire's community research network (CRN).
- To co-design the overarching governance structure for developing a community-led Public Health and Inequalities Research Strategy in Oxfordshire.
- To be a key partner in the development of a community-led Oxfordshire Public Health and Inequalities Research Strategy tackling the wider determinants of health and inequalities including:
    - Organising and delivering community research and engagement workshops across the county.
    - Developing and implementing a network of community research champions.
- To identify appropriate individuals, communities, and organisations to form public, patient, and community involvement (PPCI) panels for research projects and programmes, and to identify PPCI project co-applicants.
- To facilitate recruitment to research studies where applicable and the dissemination of findings
- To support the development of community-led approaches to research and engagement, including Community Participatory Action Research (CPAR).
- To support and co-design research funding applications focusing on public health and inequalities.

(Source: TOR for Community Research steering Group).

UK Research and Innovation (UKRI) funding contributed to support of a series of meetings, dialogue and workshops during 2022-3 to learn more about what a community research network might look like for the county.

Box 1 Terms of reference for a community research steering group.

3. Summary of key points

From our conversations with grassroots community members and representatives from a range of organisations, key themes emerged which highlighted both common and contrasting views and perspectives on community research, and what a network might bring to Oxfordshire.

What community members said:

- Wanted recognition for the existing strengths and assets in communities, including building on the strong networks among those with lived experience as agents of change and on the skills, knowledge and expertise within communities.
- Voiced a sense of 'research fatigue' at constantly being invited to participate in new rounds of community research which didn't recognise or build on legacy of previous work – don't 'reinvent the wheel'.

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

- Wanted to move from research 'on' to research 'with' or 'by' - away from extractive research to be equal partners in community led research, with active involvement from beginning to end, in an open and transparent process and with continuous dialogue and feedback - '*a dialogue of equals*.'

  "Here we go again, another research another group. Another thing? What's the outcome? What's happening? We keep being researched."

- Called for research linked to meaningful action and change, especially in addressing underlying issues which drive inequalities, and supporting creation of culturally appropriate services. This would include commitment to action by those with resource and power to bring about change.

  "I want to see meaningful action. We talk about things, but we do very little."

- Wanted reimbursement, recognition, and valuing of time that community members put into community led research to foster inclusive participation - especially when working with funded organisations.
- Also identified need for support, skills and capacity development for existing and emerging community researchers, and removal of onerous administrative burdens.

  "They're very passionate. Yeah. But let's not expect them to use their blood to prove this passion."

What organisational representatives said:

Whilst organisations represented a range of views, understanding and levels of experience, some common themes arose:

- Recognised dangers of overwhelming communities and were aware of pressure of demands – wanted to avoid duplication with mapping, better coordination and support to understand what was already happening, where, by and who with.

  "We need a proper way of coordinating understanding of communities … We don't want everybody talking to everybody all the time because they just get fed up."

- Wanted clearer understanding of principles of 'good' community research, including what, how and when to use, and how to resource and support building skills with communities.

  "I would like to do it properly but mindful it takes time, energy and resources, also aware we might not have the training."

- Understood the need to involve communities in design and development of research, and need to build dialogue, trust and cultural literacy.

  "Because it's around giving back to the communities, trusting the communities, sometimes us as commissioners and service providers, we have our own priorities, but the communities have their own priorities as well, so any sort of research, yes we can have our priorities, but let's see how they can marry with the priorities of the communities as well."

- Commitment and accountability of those with levers to bring about and change was important. Recognised the need for action and change, but were wary of time to deliver and need for resourcing (e.g. financial or service change) both short term impact as well as longer term.

What could a community research network bring for Oxfordshire?

- ✓ Commitment to principles of equity, trust, respect, openness, collaboration and willingness to change 'extractive' approaches to research, with communities as equal partners.
- ✓ Shared understanding of what makes 'good' community research.
- ✓ Coordination and mapping of what is going on in the county to avoid duplication.
- ✓ Creation of a knowledge hub, resource repository and sharing good practice and learning.
- ✓ Identifying support needs - resourcing, reimbursement, admin and organisational support, infrastructure needed to build community research capacity both in organisations and in communities.

- ✓ Skills development for both organisations and communities – peer networks and training.
- ✓ Supporting organisations with cultural competency and community engagement skills, as well as understanding organisational changes needed.
- ✓ Supporting 'what matters' to communities in identifying research priorities.
- ✓ Link and voice to those with power to support meaningful action and change, feedback and accountability.

4. What we did

During July and August 2023, Healthwatch Oxfordshire reached local networks to gain an insight into views about community research, and to attempt to map some of the work that had already been carried out. We wanted to hear local community voices and views about community research.

We undertook in-depth interviews with community members (10), and organisational representatives drawn from statutory health and care, local authority, academic as well as voluntary sector organisations (11).

Interviewees were drawn from a cross section of grassroots community members, community researchers, representatives of established voluntary sector organisations, academic institutions, and health and care system leaders. Community grassroots interviews brought to the fore voices from Oxfordshire's diverse and multi-ethnic communities, as well as other seldom heard groups. All interviewees gave their permission at the start of the interview and with agreement that selected anonymised quotes could be used within the report.

This report presents what we have heard from both community members and 'system' representatives, including those in health and care sectors, academic, and local authorities, as well as community and voluntary sector, and grassroots groups.

Whilst it will in no way have uncovered all the groups involved community research, it does give insight into some of the challenges and opportunities for the county in taking a more coordinated approach to community research as a way of tackling inequalities in health.

5. Emerging policy context

The COVID-19 pandemic shone a light on and amplified already existing and persistent intersecting inequalities.

An inquiry into differential impact of COVID-19 and report *'Beyond the Data: Understanding the Impact of COVID-19 on BAME groups'*, brought to the fore the impact of these inequalities on Black and Minority Ethnic Communities in particular (Public Health England, 2020). With the advocacy of community voices, it strongly recommended the need to:

"Support community participatory research, in which researchers and community stakeholders engage as equal partners in all steps of the research process, to understand the social, cultural, structural, economic, religious, and commercial determinants of COVID-19 in BAME communities, and to develop readily implementable and scalable programmes to reduce risk and improve health outcomes."

The calls from those with lived experience of health inequalities for change, along with this report have been a strong driver behind emerging interest and recent shift towards more participative research approaches both in academia and statutory sectors.

Health Education England South-East for example, launched Community Participatory Action Researcher Programme (CPAR) Cohorts 1 (2021-2) and 2 (2023-4) Public Health Wider Workforce - Working across Thames Valley (hee.nhs.uk). This launched a comprehensive training and mentoring programme to support community researchers to explore the health inequalities faced by marginalised communities and galvanise action and change by those developing and delivering services. In the outline of the programme, they define to the key features of Community Participatory Action Research (CPAR):

*"**Community** indicates that the research is based on the issues that affect community members. **Participatory** means engaging communities in the research process. **Action** indicates that the outcome of the research will lead to change for that community. Researchers commonly come from the communities affected and will play a key role in developing the local research agenda, the research question, and the tools to collect, analyse and disseminate their findings. The research should lead to an action or actions."* (Health Education England- CPAR programme guidance)

COVID-19 has necessitated closer relationships between communities and service providers and brought increased collaboration and listening.

Oxfordshire County Council Public Health, and Buckinghamshire, Oxfordshire and Berkshire West Integrated Care Board (BOB ICB) and others in the county are all exploring ways in which community voices can come to the fore through community research and wider engagement.

The Community Paradigm – towards a 'community-centred' research culture

The authors of *'The Community Paradigm'* (New Local 2021), also give insight into political and socio-economic drivers influencing the current public- communities interface. This sets the wider context within which local Community-Based Research Models now sit:

"The long term challenges are formidable: rising health inequalities … higher demand on the NHS, councils and other services; unemployment and economic disruption, new pressures on public finances." (New Local 2021)

There is a need for changed and closer relationships with communities. Local services face an imperative to address the wider determinants of health of local populations (Health Foundation and Institute of Health Equity, 2020)

"Community research often takes place among minority and disadvantaged communities due to the importance of addressing disparities … there is actually an ethical requirement for the research to be responsive to the health needs and concerns of the community in which the research is being conducted. For this reason, there is greater use in working with community members as research workers, often in order to improve participant recruitment and follow-up. Thus, health research should have 'local social value' by virtue of asking scientific questions that address important problems for communities participating in the research." (Centric and Impact on Urban Health, 2021)

The current shift to '*community-centred*' and '*community led*' research brings community voices to the fore, underpinned by principles of agency, self-determination, and collaboration.

"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 … greater importance was put on working locally between government, community organisations and grassroots groups within places." (Institute for Community Studies/ UK Research and Innovation, 2022)

Authors of '*The Community Paradigm*', reiterate this community action:

"The response to the pandemic revealed the latent power of communities springing rapidly into action … those parts of the country where the public sector enabled and supported the sudden upsurge of mutual aid and volunteering were also those parts that responded most effectively." (New Local, 2021)

And, in their call for a new model of public service delivery they suggest key principles and policy for practice:

- *Empowering communities – Resourcing Communities – Creating a culture of community collaboration*.
- *Participatory and deliberative decision-making – Collaborative delivery – Community commissioning.*

Here 'Participatory and deliberative decision-making' means:

"Communities must have influence over the big strategic decisions which affect their services as well as matters of implementation and delivery. This will require the adoption of more participatory and deliberative approaches to decision-making…" (New Local 2021)

6. What is community research?

A spectrum of approaches

Community Research is a broad term used in a variety of ways, with different meanings to different actors. It encompasses a *spectrum of approaches* to research and insight gathering, involving communities.

It is important to be clear and honest about what terms and approaches are being used, what for, by whom and how.

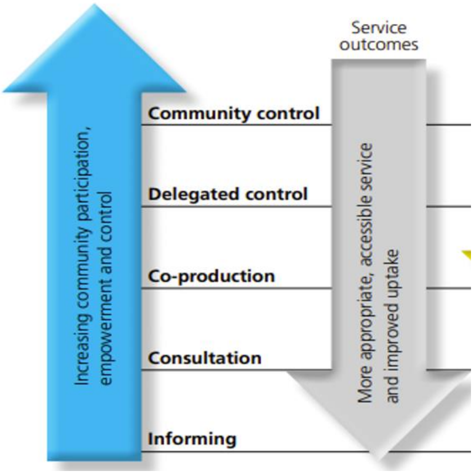


Figure 1. A spectrum of approaches. (Popay, 2006)

Community research is sometimes used as a catch all to describe a spectrum of approaches, offering differing levels of participation, empowerment and control (see example in figure 1 above). This may include terms like – community engagement or involvement, community insight gathering, Patient and Public

Involvement (PPI) and co-production. In all, community views may be sought by researchers or organisations to support insight, understanding and development of services.

However, there may be underlying tensions in that the different aims, expectations and demands of those involved, highlight power differentials and can leave the needs and priorities of communities being sidelined:

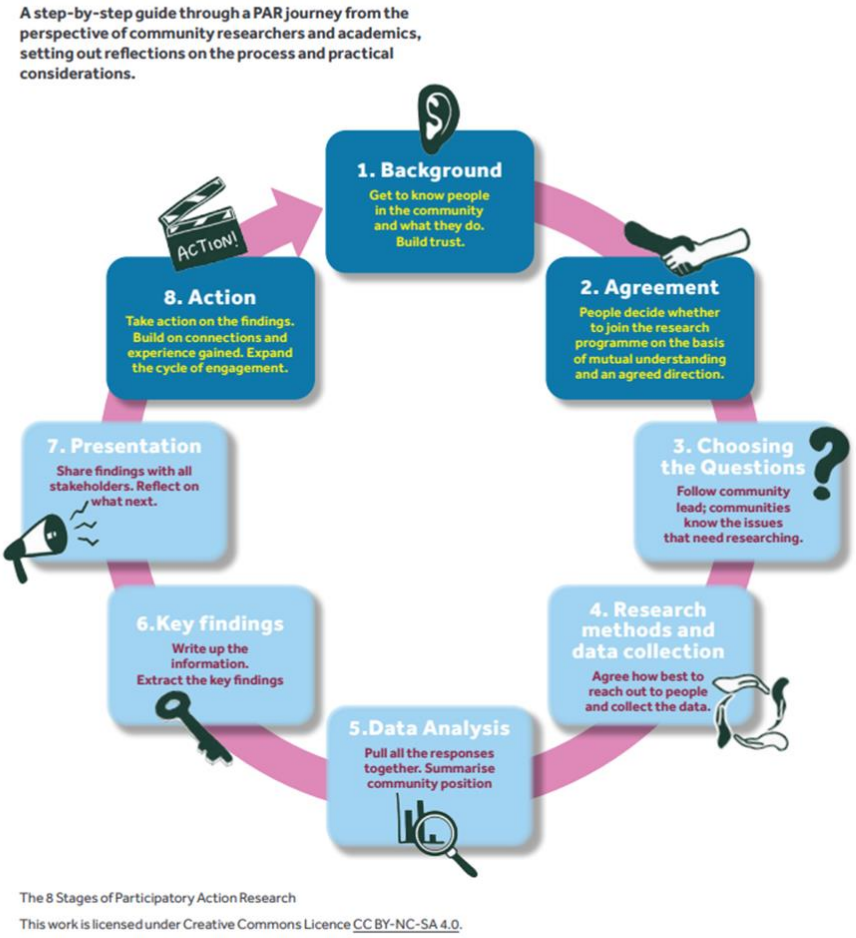
"Community research (CR) is unlike Community Based Participatory Research (CBPR), in that it can demonstrate a disparity of power between professional and community researchers, as professional researchers have an aim to produce an efficient project." (Centric and Impact on Urban Health, 2021)

Shifting the balance of power

The other end of the spectrum represents a shift in power towards greater community control. *Community Based Research*, *Participatory Action Research (PAR), and Community Participatory Action Research (CPAR) approaches* can help to counter some of the power imbalances embedded in traditional 'extractive' research. It helps to shift research away from being 'on' communities towards being 'with' or 'by' communities.

"PAR tackles inequalities by conducting research with the people who experience them so that those who are usually the objects of study become partners in research and policy decision making." (Synergi, 2019)

At its most authentic, community research brings more control to communities through use of participative and action-based research. Here, communities are at the heart of the research process from beginning to end.



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.

1. Background
Get to know people in the community and what they do. Build trust.

2. Agreement
People decide whether to join the research programme on the basis of mutual understanding and an agreed direction.

3. Choosing the Questions
Follow community lead; communities know the issues that need researching.

4. Research methods and data collection
Agree how best to reach out to people and collect the data.

5.Data Analysis
Pull all the responses together. Summarise community position

6.Key findings
Write up the information. Extract the key findings

7. Presentation
Share findings with all stakeholders. Reflect on what next.

8. Action
Take action on the findings. Build on connections and experience gained. Expand the cycle of engagement.

The 8 Stages of Participatory Action Research

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Figure 2. University of Reading (2022) CPAR A Toolkit.

"…. PAR reflects a commitment to building capacity and doing research that is useful to the community, especially in light of communities of colour who have traditionally not benefitted from the results of research conducted or interventions planned. In this way, PAR is a response to exploitative research practices wherein communities are used as mere 'laboratories' for external policy makers, planners and researchers." (Centric and Impact on Urban Health, 2021)

Key principles and values underpin Community Participatory Action Research (PAR) approaches including:

- 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)

Christina Silver describes three key elements of Participatory Action Research as embracing *people, power and praxis*:

- **People** reflects a people-centred approach with lay people actively directing research to support meaningful change for their local communities.
- **Power** aims to address the power imbalances and hierarchies associated with traditional forms of research. This can bring lay people as equal partners in the research process.
- **Praxis** recognises interconnection of theory and practice in research. This echoes values of equity, democracy and social justice.

This brings a dynamic, cyclical and action and solution-based focus into this research approach:

"Rather than gathering information from research subjects and generating findings which may, or may not, be implemented subsequently, the focus is on changing practice as part of the research process. It is a cyclical process, moving between stages of enquiry, intervention and evaluation … Action Research is achieved through collaboration between researchers and participants and by following a cyclical process of planning, acting, observing and reflecting." (Silver, 2008)

PAR actively engages with questions of power, and a critical reflection on roles and relationships between 'researcher' and 'researched'.

"While we cannot entirely eliminate power differentials … between academic and co-researcher … (and) those that exist within any group (e.g. age, gender, class, sexuality, race, religion) PAR urges us to be up front about them and encourage review, debate, disagreement and open dialogue." (Synergi, 2019)

What is community?

"The meaning of community remains contentious … Defining 'community' has been a longstanding challenge. It can be readily agreed that a community involves a group of people with something in common, but it is less easy to find agreement about what that thing is." (Crow, 2018:1)

Instead of attempting the impossible task of a definition of 'community' that will satisfy everyone, Crow suggests it may be more helpful to – *"explore the many different ways in which people understand 'community'… and the related variety of … approaches … to be used in studying community…"* (Crow, 2018:1)

Community Development specialist, Alison Gilchrist, refers to the *'idea of community'*, and identifies other ways people connect as:

- Communities of identity (sharing cultural activities and experiences).
- Communities of interest or passion.

- Communities of purpose (to achieve a common goal).
- Communities of practice (to exchange experience and learning).
- Communities of inquiry (to collectively investigate an issue).
- Communities of support (to provide mutual and encouragement).
- Communities of circumstance (to deal with temporary, unplanned, situations).

(Gilchrist, 2019)

Community research as 'knowledge construction'.

Alison Gilchrist notes community-led research is a form of *'knowledge construction'* with collaborations between agencies, community members, groups, and community-university partnerships. She comments:

"Ideally a defining feature should be that communities themselves suggest the enquiry topics … community members may be trained up as researchers to gather data and be involved in interpreting the evidence to identify implications and potential solutions. Thus, the investigation should itself involve community members at every stage and … benefit those who identified that issue in the first place, in terms of problems resolved and increased appetite for further research and development." (Gilchrist, 2019: 52)

And, in relation to the co-production of knowledge, Alison Gilchrist highlights important caveats:

"There may well not be an equal distribution of power, time and resources between community members and researchers, especially if these come from an academic institution. Training, payments and incentives for community researchers may be needed and there are issues to be discussed around the ownership and presentation of the research findings, as these amount to intellectual property that has been co-produced. There are some important ethical principles that need to be observed, including respect for tacit knowledge and local insights." (Gilchrist, 2019: 53)

Considering the caveats noted by Alison Gilchrist, the report –*'An equitable future for research and innovation: Building sustained community involvement in knowledge production'*, (Institute for Community Studies and UKRI, 2022) gives insights that:

"Community representatives must have a greater role in decision-making and research funding agendas. Creating equitable involvement necessitates shifting power to communities in research and innovation priority setting, commissioning and funding design. Currently community participation is frequently limited to what has been called 'problem solving' participation, based on agendas and research quotas."

It includes assertion that those involved in research should build:

*"… **ownership in communities**: this means ceding power to communities to own, share and use the knowledge and information they create and need – as equal representatives … This means going beyond the usual approach where knowledge typically remains in the control and … benefits a university research partner or research funder. Additionally, it means providing support and breaking down barriers so communities can freely and openly access and use different kinds of data. Ultimately it means understanding knowledge as a common resource we all have a stake in."* (Institute for Community Studies and UKRI, 2022)

7. Local examples

The **appendix** highlights some of the local approaches found in Oxfordshire to insight gathering and research - with and by communities - using a variety of approaches.

For example, some have developed learning and approaches in conjunction with communities, using participative research approaches:

Healthwatch Oxfordshire

Building on local learning and input with communities Healthwatch Oxfordshire has developed simple models of community and participative research here: https://healthwatchoxfordshire.co.uk/news/healthwatch-oxfordshire-creates-new-model-of-engagement-showcasing-the-benefits-of-community-research/

A 'theory of change' model for community research, mapping potential short and long term outcomes and impact can be seen here: https://healthwatchoxfordshire.co.uk/wp-content/uploads/2022/11/Healthwatch-Oxfordshire-community-research-theory-of-change.png

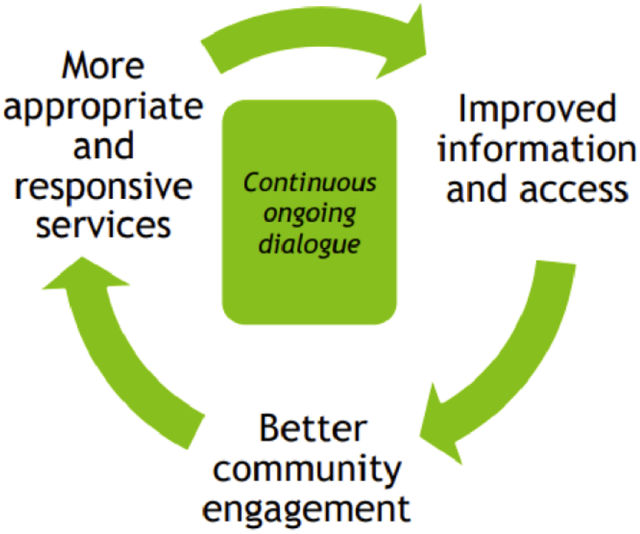
A film gives views on community research from the researcher's point of view https://www.youtube.com/watch?v=CGpQUn0CL7M

Examples of reports and films using this approach can be found here: https://healthwatchoxfordshire.co.uk/reports

One example of a report by Healthwatch Oxfordshire working together and collaboratively with Oxford Community Action – *'Oxford's New and Emerging Communities Views on Wellbeing'* (2021) illustrates shared learning built on participatory action research (https://healthwatchoxfordshire.co.uk/report/oxfords-new-and-emerging-communities-views-on-wellbeing-january-2021/)

This community-based research was developed collaboratively from the start, listened to Black and Minoritorised community volunteers' insights on stigma and barriers to directly discussing mental health. The approach was developed and designed together in a participative process.

Voices from the community emphasized a need for relationship of **continuous, open dialogue** with communities to support the development of more appropriate and responsive services and to tackle persistent health inequalities:



"The message is loud and clear – that to build access, trust and culturally appropriate services – communities want to see support designed and delivered with their input, within community settings, and building on community networks. Services need to actively engage and reach out to enable this to happen in a continuous and ongoing dialogue and build relationships over time."

Healthwatch Oxfordshire has also acted to host community researchers under the Health Education England CPAR Cohorts 1 and 2 (2023-4) supporting community researchers to focus on topics of their choice including women's views on maternity, healthy living within the Sudanese community, and exploring impact of cost of living in relation to food (see appendix). Researchers are reimbursed for their time.

(See also: Appendix for other examples of reports and films using this approach with Healthwatch Oxfordshire).

Box 2 Healthwatch Oxfordshire community research

Health Education England (HEE) South East and Office of Health Improvement and Disparities South East (OHID SE)

Community Participatory Action Research Programmes (CPAR). Two cohorts (Phase 1 2021-2 and Phase 2 2023-4). A programme of training and mentoring for up to 30 Community Researchers from across the South East, from voluntary, community, faith and social enterprise (VCFSE) organisations, the NHS and local authorities. The programme supports organisations working with communities adversely affected by health inequalities to recruit, train and mentor their workforce in **Community Participatory Action Researcher (CPAR)**. Five groups in Oxfordshire, including Healthwatch Oxfordshire (hosting researchers) have taken part in this programme, along with others across Buckinghamshire, Oxfordshire and Berkshire West Integrated Care Board (BOB ICB). (See appendix: Banbury Mosque, African Mother's Ubuntu, Banbury Lifehouse, and Healthwatch Oxfordshire with community researchers including from Oxford Community Action) https://thamesvalley.hee.nhs.uk/wp-content/uploads/sites/5/2023/03/CPAR-Cohort-2-Guide-to-Application_published_2.pdf

Box 3 the CPAR programme

University of Reading

During 2023-4 University of Reading is supporting Health Education England for Cohort 2 of the Community Participatory Action Research, providing training and mentoring to up to 40 community researchers across the South East. (See appendix)

Building on decades of work, the university has co-developed a practical *Community* Participatory Action Research (CPAR) Toolkit https://research.reading.ac.uk/community-based-research/wp-content/uploads/sites/114/2023/06/PAR-Toolkit-v10.pdf This advocates a *'community-centred'* focus to address power imbalances, recommending a transformational turn away from research processes that extract knowledge and information from communities:

"The whole research culture needs to shift from extractive to inclusive, allowing durable collaborative partnerships with the community to be established. Continuity and the progression of research into action is integral to PAR, and yet it can be difficult to maintain adequate funding and partner engagement. The PAR approach and its outputs need to be better understood, valued and invested in." (Participatory Action Research: A Toolkit', University of Reading, June 2023).

Box 4 University of Reading

Mothers 4 Justice Ubuntu

Oxford based collective of family members and activists directly supporting people who have come into contact with the criminal justice system. Taking part in Health Education England Phase 1 Community Participatory Action Research (CPAR), (2021-2) with **community researchers** project on family experience of criminal justice system https://mothers4justiceubuntu.wordpress.com/research/ *'Pandemic within a pandemic: The Impact of COVID-19 on prisoners and their families'* (April 2022)

Box 5 Mothers 4 Justice Ubuntu

Oxford City Council – Community Champions Programme

– Working with local communities to bring community-led insight into health inequalities and identify action. Partnership with local anchor organisations. **https://www.oxford.gov.uk/info/20351/tackling_inequality/1516/oxford_community_champions_programme**

'Community champions have the flexibility and autonomy to design their approach to best suit their community – whether that's through running a workshops with health colleagues, picnics in local parks, or having conversations on social media. These Champions will be a long-term voice for their communities who will be fully involved not just in collecting insights to the barriers, but also being part of creating practical solutions to address these challenges'.

Box 6 Community Champions Oxford

8. Voices of Oxfordshire - community members

The following section brings the views of community members from grassroots groups who gave their time to speak to us. They brought insights from their own experience community research including the benefits and inherent challenges, and views on what a network might look like.

What did they 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

Community seeking action, change and impact?

There was a strong consensus across all the community members interviewed for this report that there is *already* an extensive and rich body of community-based research which has been undertaken over the years across Oxfordshire – but was often not recognised, and had seen little visible outcome, change or action.

As a result, they highlighted community research should:

- Gather insight leading to **action to create meaningful change** to address social and health inequalities.
- Contribute to the **removal of barriers** preventing seldom heard communities across Oxfordshire from receiving equal access and equal outcomes from local services.

Community members - based on their lived experience - voiced a **sense of frustration** around being invited to participate in new rounds of collaborative community research whilst not seeing any tangible action, change or impact. They questioned the outcomes of community research which had already taken place.

Research fatigue: "here we go again"…

"I don't know if we need any more research"

The dangers of community research fatigue was expressed … some interviewees questioned whether further community research was necessary.

One community member commented on their experience of community research over recent and past years in Oxford:

"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."

"people are tired, people are tired"

Referring directly to *research fatigue*, one community interviewee noted the impact of COVID-19, observing:

"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?"

There is a view that often the same, often small groups are 'bombarded' with requests to take part in research.

Seeing meaningful action "We talk about things, but we do very little"

Community members were clear that they wanted to see meaningful action and change coming from research - and this had not happened:

"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."

They also noted that often *we know* what the challenges and problems are …

"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."

And reflecting on why community-based research developed in partnership with local authorities was perceived not to have delivered *'meaningful action'* or change, this interviewee stated:

"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."

Feedback, communication and action - "no one hears the results"

Another voluntary group representative referred to current Oxfordshire wide community-based research processes as *'reinventing the wheel'* and linked this to a fundamental problem around *gaps in implementation of policy*, *follow through* and *accountability* to those whom polices are directly affecting:

"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 …"

A 'dialogue of equals' accessible, appropriate and inclusive approaches

This interviewee noted that community research needs to be accompanied by inclusive and accessible community engagement processes appropriate for seldom heard communities - via a dialogue of equals, adding:

"So we need to clearly identify to the people what research is and we need to clearly identify… what we would do after that research, how we are going to feed that back? In what format would that be fed back? We have to make sure that we understand, not everybody has computers, so it's no good sending them out in email. Not everybody, has easy access to travel. So wherever we're going to feed it back it needs to be in a centralised location. And the primary thing is we need to make sure that people are fed back, even if it's in drops. So we can say, 'right. this first day we'll feed back on this bit, and we will let you know exactly what we're going to be doing for the next stages'. And this is, so that people think, 'right, okay. At least I know that you're going to feed back to me'."

This lack of feedback was seen to drive loss of faith, and impact on willingness to engage, including for example with a community research network:

"At the moment, people don't have that faith that that they will get feedback. And so people lose the interest.

"And so, when it comes to the community research network, it becomes harder to get that input. Because you may have done everything right. But experiences that they've had from other people are saying, 'well, sorry, mate, but I've had too many bad experiences with this type of thing? So I'm not interested'."

Communities want to be included in ideas development and implementation plans with real time response. One community member stated:

"If a researcher brings ideas, then they should make sure they implement … So when it comes to implementation. Is that they give it to someone who does not even know much about it? Or they don't carry it out? Or giving excuses or whatever … if they involve participants in implementation, hopefully, it will work well, because for instance … if people that started with the research if those people are involved and other organisations are involved, definitely it will be executed … And even those people doubt, and rubbished the implementation they will still monitor the effectiveness … So that everything changes quick, so quick than we expect … this city council, for instance … they should also respond to the issues and implement it as quick as possible."

Don't reinvent the wheel - "*Hang on a minute. We've done this research!*"

Experience of previous research not bringing any change, impacted on a sense of suspicion and some confusion about the role and value of a community research network:

"Because when we sat in at the CRN right. 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. So 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?"

Addressing power imbalances – "*Remember, I'm a volunteer, I work - 99% of my time is volunteering*"

Another emerging theme and consensus point across the interviewees was the need for funded organisations to address power imbalances. This means moving beyond extractive processes to engage with community organisations, researchers and volunteers as equal partners. Research projects could be collaborative and co-produced. We heard clearly there was need for support of administrative, and logistical burdens placed on small organisations taking part in research.

Some of the tensions were articulated in practical terms highlighting the unequal burdens being placed by larger well-resourced organisations on under-resourced grass-roots groups and community volunteers.

One community member from a grassroots organisation commented on the experience of managing bureaucratic administrative burdens and project delivery expectations. The impact on a volunteer group was not supported or recognised:

"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 and 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."

Where 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."

The isolation of grass-roots community researchers who are already under-resourced but are then left even more vulnerable by lack of adequate resourcing was clear. Administrative support, absence of a supportive peer researcher network, and lack of consideration of the need to factor in more lead-in time and provide proper financial payment/reimbursement is clearly exposed in this interviewee's testimony:

"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 interviewee continued:

"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."

This researcher also spoke of the impact on cost of living, and implications on choices about work, from undertaking under supported 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."

As relayed in the testimony above, part of the problem might be that despite the rhetoric, community research and community researchers remain in actual practice undervalued by larger organisations.

Prioritise resource and support to community researchers – *"Let's not expect them to use their blood to prove this passion"*

The views expressed by the community researchers interviewed in this report challenge the wider system to prove - through committed resourcing and ongoing action - that grassroots community organisations and community researchers are being engaged as equal partners. This means that rather than being co-opted, instrumentalised and extracted for their knowledge and insights - they are properly recognised and resourced.

One community member observed:

"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."

And referring to issues around community researchers and volunteers being reimbursed for their work and time by vouchers or cash payments, this interviewee queried the fairness of being reimbursed by vouchers rather than their preference - cash payment:

"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."

One community member emphasised a more equitable *balanced approach* between the large organisations and grassroots community organisations, which advanced equality, diversity and inclusion. This necessitates clarity about reimbursement for community organisations, community researchers and volunteers. Without reimbursement for time some people will be excluded from participation – thus perpetuating exclusion and diversity gaps:

"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."

Value - visibility of community input

Further comments reiterated these themes that community researchers needed 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?"

Community members commented that with their relationships 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…"

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?

"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."

This interviewee therefore advocated adopting a *lived experience reimbursement* formula to foster 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."

Community-led research developing responsive services - bringing lived experience as an agency of change-

"*So you can see if these things are not done with the community. The way it translates to them is very different."*

The practical application of benefits of research which is community led, based on lived experience and mindful of cultural nuances, was shared by another interviewee. Reflecting on recent health research projects looking at female genital mutilation (FGM) and HIV in Oxford.

They commented on the results of a focus on 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 well being.

"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."

Lived experience was seen as critical to informing appropriate interventions and approaches,

"I think, 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.

"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 U.K., 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.

"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. 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."

Community ownership as "agency of change" – *"getting the community on board in a way that the community feels that they have ownership of the issue, rather than being done to"*

One example given of collaborative research supporting community ownership and engagement 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 and was critical to build trust.

"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'.

"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."

"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."

Identifying the questions with the community - what's important? "Community is … not just a vessel for information" and "Start from square two rather than from zero"

Interviewees emphasised the need to be involved in developing the research from the start – and that it was critical to be able to identify the questions and issues themselves.

One community researcher described working with their own community together to develop research ideas and questions reflecting:

"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, different times, talk to them about what we really, 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 approach also means that the questions and the way they are asked are accessible and relevant to the communities:

"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."

It is also seen as important to be clear and open at the start about what might happen with the insight and how change might take a while - and not to 'over promise' 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."

Reiterating the need for community ownership of research linked to action, another interviewee, stated:

"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."

Community Research Dilemmas – "you can't solve their problems"

Being realistic, open and honest about action and potential solutions (long and short term) and managing expectations was also seen as crucial by those from the community who had been part of community research.

One interviewee's reflection highlighted the support needs of community researchers themselves as they take on an intermediary role. Emotional dilemmas and impacts experienced by community researchers when confronting lived experiences of structural challenges faced by community members were clear.

"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".

Community research 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 the need for adequate support to community researchers, and also on where the onus on 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 focusing on changing 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."

Using creative approaches.

There is no fixed approach to community research - it has the potential to use creative, dynamic and develop fast changing and constantly evolving methods and approaches building on lived experiences. It can engage with feelings, emotions, sensory perceptions, conversations - embracing change and dynamic environments. One interviewee – an arts practitioner, commented on this potential:

"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 to other things happening. Done it through 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."

An example is found in 'walking interviews' for a project with Oxford Brookes, "*Finding Our Way*", exploring the African Caribbean experience in Oxford.

"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 … it took in food as well as music, spaces or community spaces, community hall spaces. And that was done with a voice recorder. But what we did was that we, 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."

One person commented on the process of research and role of the arts and creative form in research, linked to wellbeing…

"Because of the health benefit that comes from engaging in the arts, in terms of one own sense of belonging or, or sense of well-being … I'd love to see some cultural element as part of the network".

Other examples are found in use of films, stories, art works (see appendix).

Cultural literacy – building culturally appropriate services

One of the ultimate aims of community research must be to influence service design and development. Oxfordshire has an ethnically and culturally diverse population - the 2021 census highlighted 23.2% of Oxfordshire's residents come from non-white British backgrounds. This compares to 19% in England (Oxfordshire Insight JSNA 2023). 29% of residents in Oxford City were from a black or minority ethnic group in 2021. (Oxford City Council, 2023)

The report *Beyond the Data: Understanding the Impact of Covid-19 on BAME Communities* (OHID 2021) recommended:

"*For culturally appropriate approaches to be incorporated within a wider determinants focus on reducing health inequalities for "long term sustainable change.*"

Community members interviewed echoed this, wanting to see development of culturally appropriate local services responsive to diverse needs.

One community member gave an example of how past needs assessments with African-Caribbean heritage communities had led to development of culturally competent services for older people. One interviewee 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."*

Similarly, recalling former community research looking at the health and social care needs of African heritage elders, one interviewee expressed frustration that there was still a lack of culturally appropriate support and services:

"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 of this kind 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."

Noting the positive impact of 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."

(These sentiments were highlighted in the report and film made by Healthwatch Oxfordshire and Oxford Community Action in 2021 on community wellbeing in Oxford's new and emerging communities – see appendix).

Building relationship and trust

Connections of grass-roots community researchers to particular social networks can enhance the quality of community-based research. This can bring deeper levels of trust and relationship:

"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."

One interviewee alluded to the barriers of trust between academic institutions and local communities. They highlighted the importance of community participation to break down barriers associated with Oxford University's historic ‘town and gown’ as well as exclusion and perceptions of accessibility of public places:

“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.

“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.”

Recognising the historical legacy of local research institutions

Some community members acknowledged a recent shift in community - university dialogue towards wanting better collaboration, which they linked to institutions needing to be responsive to community demands for racial justice, equality, diversity and inclusion (for example, following the killing of George Floyd and focus by Black Lives Matter). One interviewee commented:

“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.”

Relationships of openness and trust needed to be built with local communities, working to break down barriers to dialogue. The TORCH project with Oxford University and a Community History Project (https://torch.ox.ac.uk/) as well as research into local roots, highlighted connections to slavery and its ongoing legacy:

“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.”

Community researchers' views – what could an Oxfordshire community research network bring?

In addition to the key features outlined in narratives above, interviewees shared ideas around how an evolving community research network could play a positive enabling role. This included:

- ✓ Clear resourcing, funding.
- ✓ Skills development 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.

For example, one community researcher noted a community research network could assist grassroots community organisations through providing funding and administrative support:

"Conducting community research, one of the big challenges which, fortunately, we didn't really suffer from it, because we had other organisations helping us, was the finances behind it and booking a room or buying equipment, recording equipment, for example. Or, you know, giving people some sort of expenses, in order to help carry out this research. Luckily, we didn't have that as an organisation because we partnered with Healthwatch Oxfordshire. So, because of that, it was a lot easier. But 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."

And referring to grassroots community organisations support needs in relation to the technical aspects of understanding and following good research practice, research ethics, and GDPR protocols, this interviewee added:

"But then there are other challenges as well. So for example, collecting data, you know, for someone, who doesn't know how to protect data, you know, collecting it online, for example, or, in any way that we conduct research, this is something that that is quite a technical point. But it's something that should definitely be considered. 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 is another barrier that we know we'll face when we start conducting our research. But again, we are partnering with Healthwatch Oxfordshire to help walk us through these things. So that we know we can learn exactly how to conduct research properly."

Knowledge hub - "Making sure we're not doing research that's already been done to death"

The community research network functioning as a central data base[1] or knowledge portal and training hub that can assist community organisations to acquire funding for community research projects was also envisaged by this interviewee:

"Community research network' 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.

"I'd like there to be some sort of panel to maybe assist. Not to necessarily direct but to help assist with how to conduct research, a training programme, perhaps. 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. So if that was available freely, and we could access that, and then we know that we are doing research properly. That's good.

"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. But also something to help people, which gives them the confidence that they're doing something right. You know, that people have never done much research, they might be quite indecisive about things, because they think, Oh, I don't know how to really do this. But if there's like a support group or support network that you can consult and say that, okay. Is this a good idea? Or is that not a good idea?

"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:

"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."

The community research network role in providing a "solid structure" of peer support networks[2] to assist community researchers to develop good practice would be a positive step, according to this interviewee, because it would help:

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[1] Note for example, Oxfordshire JSNA now has 'Local Research' chapter where local research is highlighted

[2] Note e.g., the HEE CPAR 2 has embedded peer support throughout its programme 2023-4

"To not redo work but also help them to, to propel them forward a lot more quickly. Because 'it's always indecisiveness. And even now, when I'm thinking about the research' I'm doing, you know, we're always thinking like, is it good? Is it bad, but we need someone to throw ideas at. And when we have that someone, someone who's very experienced in this kind of research, who will know what sort of research methods work or what sort of research types work or topics, then then we can progress a lot more quickly."

"No point doing research and then nothing happens"

Whilst calling for the community research network to accelerate development of a local platform for supporting community research, this interviewee reiterated the points raised in previous sections. The dangers of communities *"closing the door to communication"* were real, if action and solutions were not being brought forward to address problems of inequality highlighted by research:

"So, I think we need to really accelerate this platform of learning of community research, to the point where there is an appropriate amount, you know, 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 I think a solid structure where we are developing researchers from the community, helping them, supporting them to grow, and to develop. And then, you know, someone going to the community, or, coming from the community, to explain what sort of research needs to be done, or what proofs we need, for example, maybe in you know, to help put forward a project. 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. 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. So we won't ever want to be in that position. So whatever research we do, it has to be linked with something, some sort of solution to help the problems that we've uncovered in the research."

For one interviewee, the community research network would be seen as playing a beneficial role if it helped to speed up action on research that has already been conducted, commenting:

"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 highlighted the time taken to achieve some change, often years:

"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."

"We've had enough of policies–" - what does it mean … in terms of doing something?"

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 view that 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?"

Issuing a challenge around an emerging community research network being willing to take risks and also be transparent in its communication with communities and the wider public, this interviewee, said:

"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."

The community research network's potential for enabling transparent and open access processes of knowledge exchange between research institutions and communities was alluded to by this interviewee, in the following manner:

"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 … Also as well, the link between things because nothing is ever single or singular, there's always intersectionality."

Collaboration alongside resourcing that respects the autonomy of community organisations engaged in community research was presented as something one researcher would like to see from an Oxfordshire community research network:

"To actually see some form of collaborations with services in a way that doesn't compromise our ethos. We need the resources whereby when people come to us, they know that if they have an issue, if they have any issue, we can actually signpost them to different places. But also, you know, the collaboration, not only

just our organisation, I need intervention from major institutions in terms of say the universities creating a space whereby if people have struggled, and they do have the qualifications, or they have access, give them spaces to advance so that others can see that this can change. So we need resources to be able to do that. You need Oxford University to come in. We need also Brookes. But more than anything we need resources, we need funding. And then we need volunteers."

9. Voices of Oxfordshire Health and Care system leaders, and voluntary sector organisations on Community Research

Having heard from community representatives, this section brings to the fore the views of health and care system leaders, and other organisational representatives. Whilst there are common sentiments and cross cutting themes with the community voices in previous sections, they are separated so as to highlight their difference from organisational perspectives and viewpoints.

Whilst the themes have common elements, this section reveals the insight and expressed needs of these funded and supported organisations.

We interviewed eleven representatives from organisations within the county, and one with wider regional perspective. This included those from academic and research institutions, health and care system commissioners and providers, local authorities, as well as from the more established resourced, funded and staffed voluntary sector organisations.

We asked about their understanding of community research and insight into its use as a means to promote a wider determinants approach to tackling health inequalities. These system leaders also shared their ideas, ambitions and queries around the role of an emerging Oxfordshire community research network.

What did they say?

> ***It needs coordination to make sure that things aren't overwhelming for communities.***
>
> ***We don't want everybody talking to everybody all the time because they just get fed up***

> ***Avoid that duplication … you know, sometimes it's not possible to join everything into one project … but being respectful of what other people are doing in the area***

Research priorities to be informed by what's important to people.

I would like to see they are brought in at the beginning, and work through the process together to the end …

Extractive research is wrong and it's got to stop

Understanding community research - what it is and what it's for

Initial conversations focused on a general discussion of what community research could be for. Views expressed indicated a range of perspectives, organisational understanding and experience of, and motivations for gaining community views. These ranged from system wide engagement and strategy development to public and patient involvement in service design and delivery.

Being clear about the different ways in which the terms are used, is key, as is building a shared understanding of what community research can bring as distinct from wider ongoing engagement and insight processes:

One public health representative reflected on the difference between research and consultation:

"Because the County Council have probably got at any one time about 20 consultations open … I guess what's the difference? Is this kind of defining the difference between a consultation on a service and community research?"

One organisational research representative commented on different rationale behind their use of terminology, setting research apart from insight gathering:

"So we have worked with the community organisations … we've labelled it as 'engagement' because I rarely use the term 'research'. And because if you're doing a piece of patient of public engagement you don't need ethics. If you're doing research, it's debatable sometimes whether or not this needs to have ethics approval. And also there's the idea of research that it is generalizable. And very often this stuff isn't generalisable. So I tend not to use the term research unless I really do think this is a piece of research."

Some, including the voluntary sector, valued involvement of community views as **supporting service, strategy and organisational development**, through understanding what was working and what changes could be made:

Reflecting on how an organisation listens to lived experience voices to guide communication and strategy development, this voluntary sector representative, noted:

"We try and get the (ambassadors) to bring views into that, so we don't make decisions on basis of us not having that lived experience, we trust their judgement on what we are seeing and hearing from them. It's handy having … the wording for that for example that we would come up with in the back office, would be different, so for example we went and met with a group of parents, who said 'this is what we would look for, these are the words we would use' … so it's really useful."

Whilst insights informed service development, they could also provide an important organisational function in understanding impact and **supporting funding bids and development of future work** by voluntary organisations,

"We are on the same page as to what makes good community research - do regular insight gathering from people we work with and happy with the diversity of responses, so we do that to see what difference the programme is making, that is the main reason, and then we can go back to funders and say we want to do more of this, less of that, the positive knock on is you get gems about what people do want or not, what their experiences are, and it probably starts to blend into research, even if we are doing it for evaluation in a way, it informs what we do next …"

One interviewee made reference to **varied understandings about who, what and where the 'community' is**. Often, as an organisation, they were approached by universities reaching out to the third sector as if they were '*the community*':

"In our partnership the university see us as 'community researcher' and there is an understanding gap there - as the community see us as an intermediary…."

This in turn could impact on the **way research priorities were set** within academic research organisations. For a senior leader from an umbrella research group, consideration needs to be given to how different groups and constituencies have different priorities, agendas and different understanding around what research is and who it is for, commenting:

"There's a disparity between what's important to people in the broader sense of people, communities, patients', and what's important to people, and what gets researched. There's a huge mismatch in what is important to people."

There was hope that an emerging community research network could help address this mismatch:

"So you would hope that it would help to allow researchers to understand what's important and for research priorities to be informed by what's important to people. Particularly for those groups where we don't tend to have as good connections, understandings and that is both, that are sort of generally what's important to people … And those aren't necessarily the same thing".

Others identified important nuances about **representation and voice**, including the need for community research to be more inclusive and diverse, as one research organisation representative noted:

"There's something to say, more generally when we do patient and public involvement in research, we tend to have older retired professionals who on the whole tend to be white. That is absolutely fine, those people have a role to play, but actually they often don't have the right connections to other communities in order to represent their views. You know the answer is to have embedded long term relationships with communities such that whenever, that relationship can be asked to say, look we're doing X, can you get some people to have a conversation with them. So you're more able to include and represent the views of diverse communities."

One public health interviewee also suggested that a community research network could play an enabling role to improve communication, language and dialogue with communities:

"It will also help reducing the language that is not helpful, not using terms and names that don't value, anything in deficit terms 'deprived', 'BAME', or 'hard to reach' … people are more likely to tell the truth of the situation to people they see as part of their community, and the language used is kind … so a lot could be improved and beneficial in working with community representatives in the dialogue with communities."

Many conversations focused on **reflections on what makes 'good' community research?**

The University of Reading has built wide experience to address this issue, clearly defining 'good community research' in a toolkit, with a 'PAR Wheel' guiding key aspects of good community research:

"The University of Reading has developed, a 'PAR wheel and 8 stages of PAR, which says all stakeholders need to build relationships and participate from beginning to end, and need to work on action together."

The Participatory Action Research (PAR) Wheel

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Figure 3 PAR Wheel: Source University of Reading, 2023.

See: (See PAR Wheel. Source: University of Reading CPAR Toolkit. https://research.reading.ac.uk/community-based-research/wp-content/uploads/sites/114/2023/06/PAR-Toolkit-v10.pdf)

https://research.reading.ac.uk/research-blog/participatory-action-research-a-toolkit/

Pooling expertise and resources via the Community research network

Discussing how organisations might benefit sharing insight and being linked into other partners in a community research network, this voluntary sector interviewee, commented:

"Some of the early stages of relationship building saying we are interested in mental health (for example), others are interested in other related aspects about populations, so can we as professionals have that early conversation and bring resources together as a group … we run services specifically badged mental health, and it would be interesting for us to see what wellbeing needs different populations have and understand in a more granular way…."

Providing training to support participatory action research

A number of interviewees saw that a community research network could act as a **good practice knowledge and training hub** which organisations, who acknowledge their lack of expertise around PAR methods, could consult.

This voluntary sector interviewee identified a 'training gap':

"Also having a project well defined enough a really clear research question, and then recruiting the researchers, or asking them to help design the question, but having a real clear idea about what the researchers will do, giving them the freedom to do it and the support they need is a real training gap, giving them the technical skills they need, and the emotional support – personal side to support with resources to do it we have that in house but to, go out and do in a participatory way - we don't have that, so making sure it was a really clearly defined piece of work with a clear start and end and a follow up for them is important."

A representative from another county wide organisation shared their ideas around how applying Participatory Action Research methods and being part of an emerging community research network could support a current initiative aimed at developing lived experience champions:

"Historically always felt that research has a therapeutic value for those who participate, so have encouraged … barrier is so much going on and so confusing it's hard to pass messages onto clients. We've built strong relationship with a university wanting to build an evidence base, using our networks to reach carers and patients and staff, looking at systems. got another piece of seed funding to build based on PAR put on a two day workshop which was a great success, as commissioners came and we illustrated a good model of co-production. Researchers now coming under huge pressure to get out of ivory tower and start engaging with people … and we could contribute to that."

Addressing the skills deficit

Highlighting the training, skills and capacity building support that the community research network could provide for voluntary sector organisations linking to community researchers, one interviewee, commented:

"If we wanted to use a community research approach … project plan … focus groups, we would love to have them led by community researchers, but we don't know how to train them to do that …. and that is something this network could add, helping us to train community researchers, so there is some value, accreditation etc … Also useful to show what actually is involved in this, it doesn't follow a normal project planning process, so what would a funding application look like for this for example? What differences would you need to see in funding mechanisms?… Some kind of peer network needed."

Building confidence and skills in reaching communities

Some organisations expressed a lack of confidence in using participatory methods, reaching communities, and hesitancy in starting to engage wider community in insight gathering or research.

One representative from a county wide voluntary sector organisation discussed how their organisation's desire to do community research was hampered by organisational doubts around having sufficient knowledge and capability to conduct community research. They noted:

"Community research and user led research has been on our top 'to do list', for some time, but I think there is a hesitancy about doing it, I don't want to be tokenistic, I want to do it properly, I don't want it to be a tick box exercise, and consultation exercise where we say you can give us your views about something and we will go off and do it … I would like to do it properly but mindful it takes time, energy and resources, also aware we might not have the training."

One comment about 'research' revealed a concern that formal academic research skills might be needed to do it properly:

"I am aware someone might not have the research academic background to do that kind of work …. and that going out and doing action research in your own community is very different, than being in this privileged position as outside researcher role, whose job is to be objective, and neutral."

Community research and user led research - are they the same thing?

Some voiced further a tension between use of internal service user audits and limited experience of external community engagement. Complex choices were identified including selection of community members, and reaching seldom heard. This was expressed by one voluntary sector organisational interviewee, who queried:

"How do we select those people … and also our research question as the biggest question lately has been about who doesn't use our services, as we have a direct line to people who do use our services … good at working with our experts by experience. All our services want to improve by getting service user feedback, but it is the people we don't get through the door that we really want to hear from about why didn't they come, what was it that put them off, what was it they needed from us that we didn't offer?

"By definition we don't have access to those people, as they are not using our service, so using existing service users and networks is one thing and finding people who don't use our services, and the gaps is another thing … internally we are reasonably comfortable in seeking service user views, but we would like to hear from people more regularly, we have some experience of setting up service user groups, feedback groups, and people with ongoing relationship involved, and some is more embedded, in local hubs, service user conversations also go to improving and developing services."

Understanding whether to work with and how to support and protect more vulnerable service users was also seen as important, if community research was to involve them as one commentator noted:

"There is a risk as well if we are saying put yourselves out there, and learn this complex and important new skill, feels like a big ask …. and we also have such a diverse user group, and to say they are representative is hard, so to say any service user is representative of the community is also not the case."

Recognising the challenges and benefits of community research with organisations

Further conversations moved on to discuss the potential benefits, challenges and pitfalls of organisations undertaking community research. These echoed some of the same concerns expressed by community members – emphasising need for building relationships, taking time, involving and resourcing community from the start in the research process - as well as ways to avoid the challenges of research fatigue, and extractive process.

"Extractive research is wrong and it needs to stop"

Reflecting on the learning from the HEE CPAR 1 cohort of community researchers, one interviewee demanded a shift away from extractive processes:

"CPAR 1 community researchers were engaged in, at the end the researchers became visible, and there was so much interest in the work and the system wanted to hear from the community researchers … but we said it was very unfair for people to keep asking the community researchers to share their experiences, output and findings, where are they getting this time? If you really want to engage the community researchers, you need to connect at organisational level, organisation to organisation, so then at least you can understand how to reward the community researchers, otherwise they are sharing their experiences but need to be paid, for example, one researcher got paid for sharing knowledge with a hospital. We keep saying this is the community researchers' time and they need to be paid, we keep reminding organisations this … that it's extractive and wrong and it needs to stop."

A representative from one umbrella group in the voluntary sector related their organisation's turn to a more participatory form of engagement. This had been prompted by grassroots community organisations demands for an end to 'extractive engagement' processes:

"This is something we are hearing increasingly - initially it was OX4 work around community wealth building and we wanted to talk to the groups about this and what had worked … we got a strong view from them that there has been a lot of extractive work done, by groups including ourselves … feel extracted and not their

voices, even though we funded time etc. So we are now looking at how we can do this in a more participatory way - and not sure about how to go about it."

A representative from one local health promotion organisation discussing their approach to engaging with grass-roots community organisations as "moving in the direction of community research" expressed that a more coordinated approach could help alleviate research fatigue. They commented:

"It's about research involving actual members of the community, so we have done a lot of work with (service users) and that helps alleviate research fatigue, which is people from external organisations dropping in, whereas if it's people dropping in and having a much less formal conversation, then that alleviates the research fatigue."

Involving community at the start brings greater insight

Interviewees recognised the benefits of involving community in developing research focus and guiding insight from the start. One public health representative reflected on seeing this in action in a past university, health and community project.

They emphasised the value of genuinely involving communities:

"So for me good research is involving communities from the design stage, have time for it to persevere and know it won't be a quick one, not to just have tick boxes and get it done."

"They recruited community members, to go into the communities that they were part of and to talk about some of the issues of female genital mutilation (FGM). And they also kind of had a focus of talking to men and community leaders … And it just absolutely made sense … Obviously there are some reasons why it doesn't always work, but it makes sense to take that approach to go in at a very micro-level … that really in-depth conversation was really quite fascinating to get that."

Discussing the Community Participatory Action Research (CPAR) model developed by the University of Reading in collaboration with local community researchers and community organisations as documented in the *'Participatory Action Research: A Toolkit'* (2023), a researcher from the University of Reading highlighted the essential need and good practice for communities to be included in research processes from the very beginning through to the end:

"What is important - the active engagement of all the stakeholders as what normally happens, especially the community, they are not involved at the beginning and they are not involved at the end, they are kind of brought into the middle, and find it so difficult to understand what is actually happening, so I would like to see, they are brought in at the beginning, and work through the process together, to the end, so they can walk through the process together. That

way collaboration and partnership is real rather than having this extractive method where you involve members of the community in one way, or in a small way, and participative processes are not involved- so I want to see an inclusive process where everyone is involved from beginning to the end."

Community Champions Programme – Taking a Bottom up approach

Oxford City Council has led on establishment of a Community Champions Programme via government funds, adopting a bottom–up approach and applying co-production principles in engaging local community groups. Shared good practice and learning from this approach is relevant to the community research network:

"From a city point of view engagement has been around community champions and involved insight gathering to try and understand barriers people are facing in accessing health and care services … What we have done is initially done a consultation with communities the unique selling point (USP) of this programme it is a bottom up approach where we went out to communities to really understand what their objectives are rather then imposing what central government wants to achieve … jointly co-producing an memorandum of understanding (MOA) that works for the communities, where they stated what their priorities are rather than trying to marry them to the central government priorities and I think that is what is a really powerful way of engagement as communities feel their voices are really captured and they are respected."

The need to ensure flexibility within programmes, co-designed or co-produced with community representatives, as well as mutually agreeing a **memorandum of understanding** clearly defining roles, responsibilities and outcomes, is highlighted:

"There was a lot of flexibility brought in for communities to let us know what their priorities are and to give funding for those priorities, but also the flexibility to move around the programme to make it work for them and to use the funding in a flexible way. They know their communities and they know what the priorities are, what the communities need. It was good for us to work in a bottom up way and provide the resources needed and empower them to achieve that. That was the USP - that initial engagement and really capturing the voices and developing the MOU to make sure it works for both the community and for the council in general."

Oxford Community Champions Programme | Oxford Community Champions Programme | Oxford City Council

Box 7 Community Champions programme

More engagement with participatory process also builds deeper and more genuine conversations and dialogue between organisations and communities as a step to change.

Discussing the overlap between community research methods and the current programme of Oxfordshire Public Health commissioned Community Insight Profiles[3] (see appendix), one interviewee from public health speculated on whether the new Oxfordshire community research network could encourage the deeper conversations and trust being delivered by community research and community profile approaches beyond 'tick box' exercises:

"There's rich information coming out about what it's like to live in that area, and I think what's really fascinating is when researchers are able to kind of have a conversation rather than being a tick sheet … that would be really useful to encourage within the Community research network … Build really new relationships to kind of build that trust."

Highlighting the balancing of tensions, constraints and complications of a voluntary sector organisation working with university researchers whilst seeking to engage community members around a shared research agenda, one voluntary sector representative stated:

"We are looking at the potential of community research for community wealth building, and finding solutions co designing solutions, owned by the community … we are facing problems with that as to do it we need ethics approval, and to have ethics approval you have to pre determine what you are going to do and be quite specific, but then if you are working with a community and going to co-design that is something that develops and you can't say what you are going to do … It's an impossible situation, so we are putting some things into ethics saying maybe that is what it might look like and then they say we can go back and get changes, but that makes the time much longer."

Achieving win-win by addressing the priorities of communities.

Understanding the priorities and aims of communities was seen as important for ensuring community 'buy in'. Taking time to understand motivations, was seen as a part of finding a 'win-win' where both organisational and community agendas could be addressed with honesty and openness. Advising that the community research network should seek to accommodate and be respectful of the priorities of communities in relation to the setting mutually agreed research agendas, one local authority representative noted:

"Because it's around giving back to the communities, trusting the communities, sometimes us as commissioners and service providers, we have our own

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[3] [Community Insight Profiles | Oxfordshire Insight]()

priorities, but the communities have their own priorities as well, so any sort of research, yes we can have our priorities, but let's see how they can marry with the priorities of the communities as well, because I know for example the whole programme was around vaccine and vaccine uptake, but when you go to communities they were not their priorities, but they had issues you could embed this in, for example they had issues around maternal health for black women, immigration concerns, mental health and housing concerns, so how can we turn this so we are looking at the wider determinants of health? The research priority can be achieved but the priorities of the communities can also be achieved, with this engagement, otherwise the research would not be meaningful, people will not have, the energy will not be there, there is nothing in it for the community, it's just for the academic or the researcher, that's often how it is seen."

And, reflecting on the need for the community research network to fully involve communities at the beginning and be clear about motivations:

"When we went to a refugee support group they said 'tell us about your agenda, there must be an agenda around why you are gathering these insights' as in these communities there is already a stigma around, not stigma, there are perceptions about the ultimate reason or agenda for the research. And unless communities … can see themselves reflected in the research, often it is not meaningful, because the energy is not there, so if we can break that barrier that first step to really discuss from the design stage what that research should look like, then it's not a set thing, you have an agenda to research a fixed topic, bring it to the community and discuss with them about how the research will work discuss with them, how it will work with the specific communities, otherwise they won't go with the agenda, and you won't get the best out of them."

Discussing the key stages of community research that the community research network will need to apply to achieve real and meaningful change, this interviewee explained:

"First is trying to hear - to be able to capture the voices of communities is where you start from and hopefully involving communities in any design of research and what you want to do … communities need to be involved from the design stage, involved in whatever research we are hoping to do. Important to capture this because what I see is research that has already been designed and then reach out to communities to capture views, for me that is not inclusive research, it needs to be moving towards that inclusive engagement, and we cannot be inclusive if we already have an agenda planned and then go out to communities."

Taking time to build relationships

Others noted that much **more time** needed **to be allocated to community research** programmes to facilitate the **building of relationships and trust**.

One local authority representative noted:

"We also need to give it a lot of time, even if you have established relationships with certain communities, if you are an academic, or council worker, they view you in a different way, as part of the system, so if this network is a group of professionals, really giving it time and building relationship and trust is important, and also what is important those going out to do the research, it depends on the work being done and the topic you are covering, but sometimes it depends on the people who you send out to do the research, if communities can relate to the person, they will engage … "

It was also important to understand there were nuances in who was the best intermediary for some aspects of research - taking into account issues like cultural bias, or class:

"… It depends on the topic of research, what is being researched on … certain communities won't talk to someone they relate to for example domestic abuse, but if talking about other topics they will talk to you rather than a white middle class British, so it varies, it's not one size fits all … it's about doing the background work and understanding the barriers for the community."

Others noted the change needed in and challenges to organisational ways of working demanded by this approach:

"Some of the things that are difficult around this are the timescales we would typically work on and the way we would plan a project, are plan, do this, do that, and write a report by a certain time, and I am aware with community research that won't work as its about how life works not how you want it to work for you … so that would be something we really have to think about and ultimately it would make the research more expensive, time wise, costing etc."

Don't overwhelm communities with demands

Realism and sustainability in the context of the volume and frequency of demands for community research, survey and consultation activity taking place across the county, and the range of themes, was seen as important.

The Community Insight Profile format has involved public health commissioning a delivery organisation and working in partnership with a steering group, as well as local community researchers. In this context a public health representative cautioned against uncoordinated engagement processes which could lead to overwhelming communities:

"Need to be quite mindful about what's realistic and sustainable in terms of every time a health profile is produced. You know it's kind of managing all that work as well … So it's kind of different in different areas depending on who's been part of the steering group, how engaged we've managed to get the community because we've found this really different … different engagement from councillors

in different areas … So that's interesting in terms of community research, because I think councillors have got a really interesting role in terms of, knowing the groups, knowing people to contact."

There is potential for beneficial connections and coordination between community voices, community research initiatives at 'place' as the wider Buckinghamshire, Oxfordshire and Berkshire West Integrated Care Board (BOB ICB) develops. *(Note also, a coordinated BOB ICB wide bid to develop a research engagement network was recently successful (autumn 2023), with remit to drive change through sharing community insights within ICB and mapping existing research and engagement, and staff training and development needs).*

One academic interviewee, posed a challenge:

"BOB ICB is a positive thing, but the question is how practical will they be? How can they translate hearing to practical, they will be useful if they can come down and look at the issues that are being raised, and make them real, not theoretical , those policies and strategies need to be more practical where the marginalised and voiceless are heard and rewarded about what they want to change, it's all about co-design, co-production, and working with communities to find solutions, rather than just doing and saying this is what we are doing for you … the communities are the experts, they are the experts with their problems and with their solutions, and they need to be engaged, those voices need to be heard."

A positive practical example of action-based funding via the BOB ICB to tackle health inequalities at place, can be seen in the establishment of the '*Well Together'* programme in 2023. (This will be focused on listening to community priorities and developing action to tackle health inequalities in Oxfordshire working with identified 'anchor' communities around prevention - see appendix OCVA). One voluntary sector interviewee, reflected:

"It needs coordination to make sure that thing aren't overwhelming for communities.

"I think that's really important … the upfront conversations about that … it's brilliant that lots of organisations now are wanting to talk to people, particularly in priority areas (areas of deprivation or health inequality*) … it's kind of overwhelming isn't it? And it's a pressure on those communities to respond to that. And how do you, get the balance right between involving communities and getting that feedback to help inform services without completely overloading them and kind of fatiguing it all? And then they don't want to engage. I wonder whether the network can explore something around that balance."*

Need for coordination and not duplication

Numerous interviewees commented on the need for better coordination and less duplication of research and reaching out to communities. One academic interviewee for example, stressed the importance that Oxfordshire's emerging community research network learn the lessons from previous work (for example Health Education England CPAR approach) making sure grassroots communities are integral to collaborative knowledge exchange processes:

"Yes they are starting, my only advice is to learn from the work that has happened before, so you will learn from the lessons and mistakes people have made before, learn from these lessons and take them on, and then you will be on a better footing, the other thing is to involve the grassroots communities, and invite everyone round the table rather than just policy makers - this knowledge is all about sharing the knowledge and be open to partnership and collaboration - Oxford is open minded trying to bring everyone to the table and say what can we do … let the communities sit on the driving seat and let them lead, those without voice can sit and say this is the way we want to run… it is good to see community researchers doing the presentations … let's work together and reach out so people can share their knowledge, share what we have learnt with others… bringing it all together is important."

And, hoping that the community research network could be a central coordinating point, another interviewee, suggested:

"A network's ability to add into the conversation, as there is overlap between all of us in the questions we are asking, so rather than doing it in isolation, there could be a central place 'we would like to know about x,y,z' and that would bring coordination, aligning what you are asking across communities, as I have no doubt we are all targeting the same communities, reducing the frequency of doing that would be good, if we could streamline and not have different organisations repeatedly going to the same place, that would reduce the fatigue people feel."

The need to avoid *'duplication'* was noted. This was linked to the high number of community-based research, consultations and surveys taking place at the same time in any given geographical locality within Oxfordshire. This interviewee wondered if a community research network might play a coordinating role *tracking activity*:

"Avoid that duplication … you know, sometimes it's not possible to join everything into one project … but being respectful of what other people are doing in the area. And I think also within the community research network, I don't know if there's ever a way to solve it, is this issue of crossover and duplication and never really knowing who exactly is doing what … We were kind of relying on other partners to tell us. And if the partners grounded in some way to the area they're working in, like through the health and wellbeing partnerships, or linked in with the district, local authority or something like that and they're kind of parachuting in doing something and going away again, it's really difficult to know. So I wonder

whether there's a way to see if it's possible to kind of you know track some of that."

Given the wide variety of engagement processes on health and wellbeing across the county, one interviewee, commented that the emerging community research network could play a mapping role:

"And I don't think it could or should be a gatekeeping function, no. Perhaps it could be a kind of a mapping or repository or some way of capturing at any given point of time what is happening and where are the opportunities to join it … And it might be that people are doing things in a geographical basis so there might be a way to kind of you know measure and record some of that, see what's going on even if it is thematic."

Signalling, in relation to the emerging community research network, the risks of uncoordinated activity and stating preference for framing things as engagement rather than as research, they cautioned:

"But there is a real risk with a lot of uncoordinated stuff going on because people need to show they've done some community involvement type of thing. And if that is not properly coordinated, this proper way of coordinating understanding of communities … We don't want everybody talking to everybody all the time because they just get fed up … It's really important that the community research network does make sure that key players who are doing community involvement … needs to be properly coordinated with the action of others …"

A number of points around the potential coordinating role of the community research network were shared with reference to the PAMOJA Report (2021) stated:

"Another one that is important is Pamoja, set up in the pandemic which recognises ethnically diverse groups are experiencing fatigue, and that in a sense brings a bit of coordination of that, and I think the CR network will bring a sense of coordination with things, rather than everyone going to the same communities all the time, and asking similar questions, a network could bring a sense of coordination, so you have a better chance of knowing what is going on."

Need for action and change

Organisations echoed community voices with emphasis on the need for action, outcomes and tangible change. There was a recognition that this had not always been realised.

Highlighting that the CPAR 2 programme will be placing greater emphasis on action and delivering change, one interviewee providing context for this stated:

"When you are talking about this approach, the whole process is action, so you need to make the action more visible even in the funding process … sometimes communities feel they are being used as guinea pigs as they don't see the

action … It's not easy, but we need to raise the questions, action is the main thing communities want to see … the solutions to the problems they have researched, and the communities will feel valued if the actions are taken on board … People are recognising in the past it was research focusing on extraction and not action, people are asking 'what is it benefitting me?' in this research, because so many people come and ask us things, do the research, get their funding but leave us without any feedback, even without appreciating the work they do … so the question is, whose narratives are you listening to and whose voices are you taking on board? Seriously value the voices in the communities, and go back and show them this is where the change can happen, otherwise people don't see where the data goes, and communities are now starting to question 'where is the action?' and they are actually getting tired, bored and fatigued with the research and saying we don't want to take part in this anymore."

Commenting that good community research should be focussed on addressing issues that are important to communities and lead to change, the interviewee said:

"In terms of 'good research' working with communities, it comes down to good questions, what are you asking people and why, as if you are asking something that will go back into improving something or delivering something new, then you are going to get good engagement, because there is a real reason for asking the question. For example, surveys with our participants we get good results and good insights into what we can do differently. So keeping people engaged with community research, it's about being open telling people the reason you are asking that question, so research is as useful as the purpose behind it…so what are you going to do with that information, is it going to lead to change?"

One public health representative echoed this need for action:

"I guess the important thing always for me is … what comes out? … And so from that an action plan was produced … I think it was the FGM Safeguarding that brought together all the county wide partners. So it felt like there was a clear journey between what people said. It went into an action plan and then people were taking that forward to make a change. Of what people had said, and so that kind of sparked my interest."

They noted it was important to reassure community members that there was a mutual plan to take work forward, stating:

"So I think good community research … needs to be clearer and assurance given to communities that we're going to be engaged … And there's a plan about how things will be taken forward … I was really pleased that we got challenged at the beginning of the process to be able to allay some of the fears and to give reassurance to community partners or residents that might be part of the steering group that you know this funding is there, ready for the ground … And

see the piece of work as part of a bigger picture … it wasn't just a standalone piece of research and then the report gets put on the shelf, you know celebrated at a meeting somewhere and then kind of doesn't go forward."

One researcher concluded a focus on achieving real change should be linked to effective monitoring, tracking, feedback and evaluation of change alongside transparent accountability processes:

"We hear from communities, they are angry, 'how much research has already been done, and what has been done about that?' and can we feed back to communities, which is why it's so important to have community champions, doing the research, in the first phase and then going back to do something about what was said, it should be like 'You said, We did' and focused on change. Outcome is very important."

The importance of properly resourcing community researchers

Interviewees recognised the need for organisations and management to provide sufficient reward and accord proper value to community researchers' time, knowledge and input. One academic interviewee stated:

"You find when it comes to payment this kind of approach is not really valued, properly funded and many of the community partners' end up using their time, and are not properly rewarded. The PAR Wheel has the principles A-Z … T for time to be rewarded and recognised…this work takes time and the evidence is people are not often recognised and rewarded, so we are when applying for funding for example… bring that element in saying everyone needs to be rewarded and valued.

"It's pointless to bring in community and not reward them, these communities are people, they need to put food on the table for their families, and asking people to do work for which they are not rewarded is extractive, so we are making this visible, on the model and principles - time needs to be valued, people need to be flexible, everyone needs to be listened to and hear their voice, so we are asking the management to take this on."

A community research network was seen to have potential to provide guidance and support around developing and navigating protocols such as financial reimbursement for community members' time. This voluntary sector interviewee stated:

"We have thought about it, mostly we speak directly with participants and get good feedback, we have a network of ambassadors now, who have lived experience, we haven't worked out funding for them, we won't have them on a platform when one person is being paid and others are not … there is an argument if they are giving up time, they should be paid for their time, but we haven't done that … a network would be useful for looking at that."

Learning from the Community Champions programme can help provide some examples of flexible resourcing mechanisms used to support community members participating in the programme. One local authority interviewee noted that many of the community champions had to contend with intersecting inequalities as well as a cost of living crisis. They emphasised the need to abandon extractive and exploitative research and public engagement processes, recalling:

"When we designed the programme, often people in communities ask us 'what is in it for us?' often people come in and extract without giving back, that has come out quite strongly in our engagement, before this, so when designing we bore this in mind 'what is in it for us, what will you give us back? Because it's not just you coming in to take the insights, we have to also be able to gain something so in the design we made sure there is something for the researchers, and the communities … so that came in the form of training we offered, the Make Every Contact Count (MECC) training, the upskilling, personal development budget the champion would have to upskill themselves in any area of their choice not necessarily linked to what they are doing, some did a course to learn to swim. Some used their funding for driving, some did an accounting course. They had up to £200 per person for this. Some did Mental Health First Aid. So there was a variety, and not prescribed it was their choice and they saw a value in that. When we did the induction training we gave them a £50 voucher for the training and MECC training because as volunteers we couldn't pay them but we wanted to appreciate their time and its coming strongly in the second phase, people don't want to engage, unless their time is recognised."

Understanding legislation around employment and benefits is also essential:

"And we are looking at ways to do this without employing them so in that stage to develop it together with them, so it works for both community and the council. But they are saying we are being asked about inequality, cost of living but if people are being asked to volunteer from low income backgrounds who are from you know who have caring responsibilities or can't afford to volunteer because of financial reasons, are we not adding to that inequality? So it's really providing those resources and empowering them - we funded the anchor organisations for them to be able to recruit and support champions for us, and also have the resources to use flexibly to upskill to support the champions along the way."

This interviewee made the observation that clarity and openness from the start is key so as to avoid miscommunication about reimbursement:

"Communication needs to be very clear and transparent … if you want people to volunteer that is a different thing and you need to make it clear that people are not going to be paid for their time, but if you are asking people to give their time and you are going to pay them, we are saying pay them for the time it takes to

do the research - because one thing is that this research takes a lot of time, it is labour and resource intensive, so for people to be involved beginning to end it needs to be paid properly, not just a few hours here and there, people need to look at the time, how long will this project take so people are paid for the input of time for this work, rather than saying we are going to pay you three hours, or a day … and yet it is taking longer than that, so they need to understand how long this work will take. And what is not recognised is the time in actually building relationships, and building relationships takes some time, and that is normally neglected or given minimal focus, as in the beginning people want to just talk about research, or research questions, but we need to take a step backwards, take time, to build relationships, as there is no meaningful research without meaningful relationships. Relationships are important and people need to value how long this takes, and this needs to be supported and paid."

Organisational challenges and questions raised around doing community research

Other challenges and questions related to doing community research for larger organisations were raised in these discussions. These revealed varying levels of confidence in both understanding and application of a community research approach, and indicate some of the organisational, skills and cultural competency challenges faced in orienting towards communities – which need to be recognised.

These are listed in the table below, and provide insight into issues and challenges a community research network might explore:

Building trust with communities

- Communities are research tired … we're being extractive, what is the value to them? haven't been involved in the design stage ….
- Who can speak for communities? Where do you draw the line on who is speaking for?
- Definition of what constitutes 'community' research helpful …. universities see third sector as 'community' - communities don't.
- Using people with lived experience to sit on steering groups and advisory groups - can feel tokenistic - people advising on development of plans, it's difficult
- Overwhelming demands on communities
- Access to communities - hard, they don't respond often …
- Number of organisations approaching these groups - could there be more coordination around this? - we don't want to do all the work, but want to know what is happening so we can share.
- Insight into what people want?

- Skills in the organisation? Cultural competency?

Understanding what ‘good’ means

- Key is to understand what is ‘good approach’ to community research?
- Could be a single point of contact for that organisation, with multiple organisational questions added?
- Better understanding of how we define outputs / outcomes and what these are - how do people use learning and what happens?
- Timeline of change … influencing and tracking immediate change seen by communities and longer term change …
- Making decisions about cost, prioritisation - hard decisions.
- Siloed organisational structures.
- Holding stakeholder events to hear what is wanted and asking big questions about what we should be doing.
- Community research network as **a learning and knowledge hub?**
- Network could enable sharing insight into how to frame questions, use of language, and development of surveys with community input.
- Issues around GDPR, funding, money how to manage, support and pay, logistics.
- Different resource levels of voluntary sector and statutory – how can reimbursement be realized by all?
- When to reimburse and when not?

Identifying organisational change

- Organisational culture change/ confidence/ skills and cultural literacy
- Reluctant to do lots of community engagement without commitment to action – don’t have a community engagement approach. How to develop a proper community engagement approach for the organisation?
- If you set a priority writing a funding proposal - goals and fluid nature of organisations - might change ….
- Funding and reporting structures not flexible enough.
- Fitting community research into tight time frames.
- NHS staff don’t have capacity to think about this stuff – financial pressures.
- Skills and confidence - can’t do as ‘don’t know where to start’.
- Hand holding - ways for institutions to learn.
- Can you teach us how to do?
- More focus on change in organisations and approach
- Holding hands of people in senior roles to help them deliver organisational change – senior buy in at top.
- Sharing expertise.

- How can we work together?
- Embracing risk.
- 'Crowded space' … who has relationships?
- Defining ethics, knowledge ownership.
- Skills development.
- Organisational gaps.
- Trust and competition- reluctance to share information,
- Same groups always being asked.
- Protecting information.
- Constraints - time frames too short.
- Pay? Be clear up front - pay via organisations not individuals.

10. Appendix - Mapping what is out there

Below is an indicative list of some examples of community-based research found in Oxfordshire.

Note: this is not exhaustive but represents examples of what we were able to find via call outs to community and statutory sector – there will be more out there. It represents a spectrum of research approaches not all strictly 'community research' including participatory action research, community led and more traditional research, insight gathering, PPI and engagement. Other useful resources are included.

Academic sector

Oxford Brookes University

Research Networks https://www.brookes.ac.uk/research/networks range of approaches including ethnographic, mixed, qualitative methods around themes of health, urban environments, with some participative approaches.

e.g. Healthy Urban Mobility – working with communities in Barton and Rose Hill to understand impact of immobility on health, and explore how to support improved mobility, tackling health inequalities- developed Barton underpass mural with participative approach with local communities.

e.g. Healthy Ageing and Care research network
https://www.brookes.ac.uk/research/networks/healthy-ageing-and-care/

bspencer@brookes.ac.uk Ben Spencer. Network Lead, Research Fellow in Built Environment and Healthy Ageing, School of the Built Environment.

Oxford University

- **Engagement and Partnership** https://www.ox.ac.uk/about/organisation/strategic-plan-2018-24/engagement-and-partnership and strategic plan 2018-24 (Professor Alex Betts)

- **Oxford Health Biomedical Research Centre NIHR** in partnership with Oxford Health NHS Foundation Trust https://oxfordhealthbrc.nihr.ac.uk/
- **Diversity in Research Group:** exploring factors preventing under-served communities from getting involved in research, and is developing an approach to outreach work with them. Working under Oxford Health Biomedical Research Centre. Public and patient involvement https://oxfordbrc.nihr.ac.uk/ppi/diversity-in-research-group/?highlight=diversity%20in%20research

- https://oxfordbrc.nihr.ac.uk/ **NIHR Oxford Biomedical Research Centre** is a collaboration between the University of Oxford and Oxford University Hospitals NHS Foundation Trust (OUH). Public and patient involvement.

- **Science Together** https://www.mpls.ox.ac.uk/public-engagement/science-together-oxford-researchers-and-communities/community-group-partners-2022-23-1 connecting Oxford's community groups with researchers from the University of Oxford and Oxford Brookes University to respond to major issues and questions impacting the lives of local people. These research projects are defined by the community groups, and have practical outcomes that address particular challenges or opportunities they have identified for people who live and work in Oxfordshire. Currently have worked with: Cutteslowe Primary School, EMBS Community College, Muzo Akademy II, Oxford Community Action, AFIUK, Oxford United, Oxford Mutual Aid. Contact: rachel.ashwanden@mpls.ox.ac.uk
- **Nuffield Department of Primary Care Health Sciences** https://www.phc.ox.ac.uk/ppi Patient and Public Involvement (PPI) in research
- **Community-University** Knowledge Exchange/ Community History Projects **2022-2023**: (with Euton Daley & The Unlock the Chains Collective): TORCH https://www.torch.ox.ac.uk/finding-our-way-0
- **GLAM Oxfordshire (Gardens, Libraries and Museums)** https://www.glam.ox.ac.uk/home

Statutory Sector – District and local government

Oxfordshire County Council (OCC)

- **Co-Production approach** https://www.oxfordshire.gov.uk/residents/community-and-living/our-work-communities/co-production-oxfordshire experts by experience,

communities of practice, and champions network across social care and council services https://www.oxfordshire.gov.uk/sites/default/files/file/our-work-communities/WorkingTogether.pdf
Email: coproduction@oxfordshire.gov.uk

Public Health Oxfordshire County Council

- 2022-3 convened establishment and collaborative approach towards development of Oxfordshire's emerging community research network with initial support of funds from UKRI. Contact: Adam.Briggs@Oxfordshire.gov.uk
- **Community Insight profiles** for ten most deprived wards and others in county **–** providing an in-depth understanding of local health needs and community assets. Insight work in partnership with local community organisations (e.g. OCF, Oxford Hub, Oxford City Council) and including community researchers. https://insight.oxfordshire.gov.uk/cms/community-insight-profiles
- **Joint Strategic Needs Assessments and Oxfordshire insight** Jsna@oxfordshire.gov.uk and https://insight.oxfordshire.gov.uk/cms/joint-strategic-needs-assessment which has a chapter on *Local Research* as repository of community based and local research from a range of partners.

Other examples within Public Health work include:

- Healthy Place shaping approach and Active Neighbourhood travel routes – e.g. insight gathering in Blackbird Leys with local community members around active travel and cycling.
- Greenspace and Us – community insight to understand barriers and enablers to accessing greenspace for teenage girls in East Oxford Rosie.Rowe@oxfordshire.gov.uk
- Whole systems obesity in depth community conversations led by Press Red to inform strategy.
- Community health development workers with research built into their remit.
- Prevention and Inequalities Network meetings coordinating joined up approach to prevention (jointly convened with BOB ICB Place)

Oxford City Council

- **Oxford Community Champions Programme** – working with local communities to bring community-led insight into health inequalities and identify action. Partnership with local anchor organisations. https://www.oxford.gov.uk/info/20351/tackling_inequality/1516/oxford_community_champions_programme **Fatou Ceesay. Programme Coordinator** FBADJIECEESAY@oxford.gov.uk
- **Thriving Communities Teams** and community health development officers, and youth officers working on the ground with communities around prevention, physical activity, mental wellbeing. E.g. Undertook community insight work for Public Health for Barton Community Insight Profile.

District Councils:

- **South Oxfordshire District Council** undertaking local community health insight profiles with public health.
- **West Oxfordshire District Council** Youth Needs Assessment 2023 Youth Needs Assessment - summary report for informal Cabinet Aug 2022.pdf (westoxon.gov.uk)

Health and care sector

Health Education England (HEE) South East and Office of Health Improvement and Disparities South East (OHID SE)

- **Community Participatory Action Research Programmes (CPAR).** Two cohorts (Phase 1 2021-2 and Phase 2 2023-4) A programme of training and mentoring for up to 30 Community Researchers from across the South East, from voluntary, community, faith and social enterprise (VCFSE) organisations, the NHS and local authorities. The programme supports organisations working with communities adversely affected by health inequalities to recruit, train and mentor their workforce in **Community Participatory Action Researcher (CPAR)**. Five groups in Oxfordshire, including Healthwatch Oxfordshire (hosting) have taken part in this programme, along with others across BOB ICB. https://thamesvalley.hee.nhs.uk/wp-content/uploads/sites/5/2023/03/CPAR-Cohort-2-Guide-to-Application_published_2.pdf Contact: Joanne McEwan Joanne.McEwan@hee.nhs.uk https://thamesvalley.hee.nhs.uk/school-of-public-health/public-health-wider-workforce/ for Evaluation of Phase 1 CPAR (2021-2) and Toolkit https://thamesvalley.hee.nhs.uk/wp-content/uploads/sites/5/2022/10/HEETV-CPAR-Toolkit.pdf

https://wessex.hee.nhs.uk/community-participatory-action-research-programme/ showcase of Phase 1 CPAR.

Oxford University Hospitals NHS Trust (OUH)

- Patient involvement and patient experience team https://www.oxfordhealth.nhs.uk/get-involved/patient/
- Patient involvement in research https://www.oxfordhealth.nhs.uk/get-involved/patient/get-involved-in-research/ https://www.ouh.nhs.uk/research/patients/

- Recent engagement activities include reaching out to community as an 'anchor organisation' to tackle health inequalities, and maternity inclusion workshops.

Oxford Health NHS Foundation Trust

- Experience and Involvement Team - Patient involvement and experience https://www.oxfordhealth.nhs.uk/get-involved/patient/

  https://www.oxfordhealth.nhs.uk/get-involved/patient/get-involved-in-research/

Buckinghamshire, Oxfordshire and Berkshire West Integrated Care Board (BOB ICB)

- https://www.bucksoxonberksw.icb.nhs.uk/about-us/get-involved/
- https://www.england.nhs.uk/long-read/working-in-partnership-with-people-and-communities-statutory-guidance/ Working in partnership with people and communities: statutory guidance for ICBs.
- Possible resourcing and endorsement of community research approach at ICB level, and Research Fund to explore way forward at ICB level.
- Oxfordshire Place Based Partnership – supporting collaboration in ten areas in Oxfordshire to tackle health inequalities and support prevention – through the '*Well Together*' programme and working with community asset building approach and evaluation (see OCF and OCVA).

Other sector:

Healthwatch Oxfordshire https://healthwatchoxfordshire.co.uk/

Healthwatch Oxfordshire (HWO) as **independent watchdog** has long developed participative and collaborative research approaches including work with community researchers on insights of, barriers to and experience of health and social care https://healthwatchoxfordshire.co.uk/our-work/community-research/. Gives support to enable communities to identify issues of importance and to gather insight together and enables dialogue with providers and commissioners to bring about change. All reports are shared with Health and Wellbeing Board and others as well as relevant health and care providers.

Healthwatch Oxfordshire models of community research: https://network.healthwatch.co.uk/guidance/2022-09-05/working-community-researchers-to-achieve-change-people model and learning resource for Healthwatch England:

What community research is not:

- A quick fix.
- Easy.
- Tokenistic.
- A clear-cut ‘toolkit’ approach.
- A guaranteed product, outcome or ‘success’.
- Without risk.
- Appropriate in all circumstances.

What are the challenges?

- Doesn’t stick to ‘office hours’ – challenges boundaries.
- Researchers vary in skills and confidence and may need different levels of support.
- Researchers and community members have busy lives, often juggling jobs and family, so they have little time.
- Needs ongoing problem solving, e.g. challenges with boundaries, GDPR and confidentiality.
- May not be free of community ‘politics’.
- Needs understanding how to support beyond the research to protect/ navigate researcher and community in dialogue with health and care system and subsequent demands.

- Organisational and service change is slow and takes time, leaving communities frustrated. Make sure to focus on real changes that people can see.
- Clear pathway on reimbursement process for community researchers' time, including transparency around responsibility for tax and benefits declarations if direct payment.

- **Reports and films:** https://healthwatchoxfordshire.co.uk/our-work/the-project-fund-reports/
- https://healthwatchoxfordshire.co.uk/our-work/research-reports/
- 2021-4 Hosting and support 4 **community researchers** (2 in 2023-4 with Oxford Community Action) using Community Participatory Action Research (CPAR) under **HEE SE CPAR Phase 1 and 2** programmes (2021-4)
- Contributing to showcasing, learning and development of CPAR approaches across the South East.

Examples of community led research with Healthwatch Oxfordshire:

- *Men's Health* joint work with East Oxford United Football Club (2018) film and report https://www.youtube.com/watch?v=GcDG7wKMZ40 (**What happened?** Influenced recommissioning of community-based NHS checks by public health in 2023).
- *Oxford's New and Emerging Communities Views on Wellbeing* jointly with Oxford Community Action (2021) report and film. https://healthwatchoxfordshire.co.uk/our-work/our-videos/ (**What happened?** Over 20 community members trained in MHFA, and led to establishment of regular community listening sessions with mental health provider).
- https://www.youtube.com/watch?v=dWrLPS2Ublg *Women's views on maternity care* conversations and film with community researcher Omotunde Coker and women in Oxford (2022) (CPAR HEE 2021-2) (**What happened?** Oxford Brookes used film for midwifery training and women to deliver face to face workshops for midwifery students in 2023. Ongoing dialogue with OUH around maternity inequalities, and action to build community links). Influenced Flo's Early Lives, Equal Start project (see below).
- Community researcher Nagla Ahmed on *Wellbeing in Oxford's Sudanese Community* (2022) https://healthwatchoxfordshire.co.uk/report/food-and-healthy-lifestyles-what-we-heard-from-the-sudanese-community-in-

oxfordshire-march-2022/ (**What happened?** Highlighted need for women only culturally appropriate swimming sessions at leisure centres – added to voice for change since addressed by others and wider system).

- *Hearing from the Albanian Community* (2022) https://healthwatchoxfordshire.co.uk/report/hearing-from-albanian-and-arabic-speaking-communities-february-2022/ (**What happened?** CQC used insight to improve engagement and communication strategy for encouraging people to speak up about services).
- Overview of HWO work with community researchers, model, theory of change and short films from community researchers themselves: https://healthwatchoxfordshire.co.uk/our-work/community-research/
- Range of work and historic reports in partnership with communities including: maternity care, FGM, refugee and migrants, Boaters, Men's health, and via project fund to support communities to carry out research on topics of importance. https://healthwatchoxfordshire.co.uk/reports

Oxford Academic Health Science Network (OAHSN) (now called: Health and Innovation Oxford and Thames Valley)

(hosted by OUH NHS Foundations Trust) https://www.oxfordahsn.org/

- https://www.oxfordahsn.org/our-work/our-programmes/community-involvement-and-workforce-innovation/about-the-team/our-policies/ **See also:** Payment policy for patients and public.

Voluntary and community sector

Abingdon Bridge Social Media Anxiety Resilience Team (SMART) carried out insight gathering with young people on mental health and social media. https://www.theabingdonbridge.org.uk/

Achieve Oxfordshire gather insight from people involved in services to drive improvement and service development for weight loss services. https://www.achieveoxfordshire.org.uk/

Active Oxfordshire insight gathering from people involved in Active Oxfordshire programmes to drive improvement, learning and development of tailored support. https://www.activeoxfordshire.org/

AFIUK African families in the UK serve the interests of African and other ethnic minority families where the parents were born and educated overseas, while their children have been born in the UK. Range of insight and community-based insight work including understanding barriers to cancer screening and care workshops, and HIV sexual health project. https://www.afiuk.org/

Afrikan and Afrikan Caribbean Kultural Heritage Initiative (ACKHI) **https://www.facebook.com/ackhi03/** past use of community research approaches. *Out of Africa* https://antislavery.ac.uk/items/show/585 and https://www.history.ox.ac.uk/article/exploring-oxfords-connections-to-slavery-through-portraiture

Afrikan Heritage Community Association https://www.facebook.com/people/Afrikan-Heritage-Community-Association supported Leys community insight profiles, and have done insight work into needs of older residents with support of Healthwatch Oxfordshire.

Aspire Oxfordshire empower people facing homelessness, poverty and disadvantage to find employment and housing. Took part in community research insight workshops for emerging community research network (2023). https://www.aspireoxfordshire.org/

Asylum Welcome Stories of Change and Health Access Project. https://www.asylum-welcome.org/

Banbury Madni Masjid - Green Dome Trust worked with **community researchers** under **HEE SE CPAR Phase 1** (2021-2) to explore "*How has the Covid-19 pandemic affected the BAME community?*". For copies email Banbury Mosque at: **banburymosque@yahoo.com.** Other insight work has included work with: Oxfordshire Public Health, insight on community research network development and work on cancer care with Katharine House Hospice.

Banbury Lifehouse Community Church worked with **community researchers** under **HEE SE CPAR Phase 1** (2021-2) to explore attitudes to COVID-19 vaccine with black and minority ethnic community in Banbury. Report available from HEE. https://www.lifehousecommunitychurch.co.uk/banbury

Community First Oxfordshire (CFO) https://www.communityfirstoxon.org/ – community based insight gathering, and neighbourhood planning. Undertook Community Health Profiles for Public Health in Berinsfield, Abingdon Caldecott, and Banbury.

Citizens Advice North Oxfordshire and South Northants (CANOSN) research into Cost of Living Crisis (2023) and Covid-19 Effects on Mental Wellbeing among service users. **Contact: Andrew Carter** andrew.carter@cano.org.uk

Dementia Oxfordshire https://www.dementiaoxfordshire.org.uk/about-us/ peterjohnson@dementiaoxfordshire.org.uk working with University of Warwick on 'knowledge mobilisation' in dementia support systems and potential community participatory research approaches. (see also Age UK Oxfordshire https://www.ageuk.org.uk/oxfordshire/)

Flo's Oxford: Early Lives Equal Start –https://www.flosoxford.org.uk/eles/ '*responds to ..issues identified by mothers from across OX4's African, Caribbean, South Asian, East Timorese, Arab and other ethnic minority communities'* community based project '*co-produced together with mothers and midwives in our community…along with representatives from our partners in the Oxfordshire Maternity Voices Partnership'* and working to support '*women to become maternity advocates, through providing training and mentoring for 'meaningful systemic changes'* *earlylives@flosoxford.org.uk*

Good Food Oxfordshire Cost of living stories from people with lived experience of food poverty https://goodfoodoxford.org/food-support/cost-of-living-stories/ and reports on aspects of the food system https://goodfoodoxford.org/reports/ https://goodfoodoxford.org/blog/food-experiences-of-black-asian-and-minority-ethni/

LEAF (Lived Experience Advisory Forum) an independent group run by and for people with lived experience of homelessness in Oxfordshire. (with support of Oxfordshire Homeless Movement) carried out insight gathering into housing and homelessness inequalities.

See for example (2021) https://oxfordgatehouse.org/wp-content/uploads/2023/03/LEAF-Aspire-Storytelling-report-LONG-final.pdf

Makespace Oxford https://makespaceoxford.org/ research on impact of COVID and lived experience of living and working in Oxford, using Community Action Research approach.

Mothers 4 Justice Ubuntu. Collective of family members and activists directly supporting people who have come into contact with the criminal justice system. Took part in **HEE SE CPAR Phase 1 (2021-2)** with **community researchers** project on family experience of criminal justice system. https://mothers4justiceubuntu.wordpress.com/research/ '*Pandemic within a pandemic: The Impact of COVID-19 on prisoners and their families*' (April 2022)

My Life, My Choice https://mylifemychoice.org.uk/research/ **user led organisation which co produces research into the lives of people with learning disabilities.**

Old Fire Station Storytelling project https://oldfirestation.org.uk/our-work/storytelling-evaluation-methodology/oxfordshire-storytelling-report/ Oxfordshire Comms Group (Achieve Oxfordshire, Home-Start Oxford, Healthwatch Oxfordshire, West Oxfordshire District Council, Rethink Mental Illness, and Oxfordshire County Council) in collaboration with the Old Fire Station. https://insight.oxfordshire.gov.uk/cms/mental-health-and-wellbeing

Owned by Oxford Community Wealth Building report (2023) https://ownedbyoxford.org.uk/2023/05/16/owned-by-oxford-report/ *used action research and asset-based community development approach.*

Oxfordshire Bangladeshi Association - Needs Assessment on Substance Misuse and Barriers to accessing drugs services **(2004)** working with volunteer community researchers. https://mycouncil.oxford.gov.uk/Data/Oxford%20Health%20Overview%20and%20Scrutiny%20Sub%20Committee/200503311430/Agenda/26067item6.pdf

Oxford Community Action (OCA) support new and emerging Black, Asian and Minority Ethnic Communities (BAME) alongside more established **BAME communities** to **tackle** and overcome **barriers** created by structural inequalities. Undertaken community led research including a number of projects with Healthwatch Oxfordshire (see details HWO above), Public Health, and others on range of issues including sexual health, men's health, mental wellbeing, food insecurity. In 2023 two researchers training with Healthwatch Oxfordshire under HEE CPAR Phase 2 (2023-4) exploring food insecurity and cost of living in East Oxford https://oxfordcommunityaction.org/who-we-are/

Oxford Hub volunteering and community projects to tackle inequality, including focus on Leys, Rose Hill, Cowley and Littlemore. https://www.oxfordhub.org/ Worked with community researchers to support Leys and Rose Hill Community Insight Profiles for public health.

Oxfordshire Community and Voluntary Action (OCVA) support and partnership building for Oxfordshire's voluntary sector https://ocva.org.uk/ Hosting *Well Together* inequalities in health programme with OCF, and Communities of Practice. Provided infrastructure support to Oxford Community Champions.

OX4 Food Crew Nine grassroots organisations in OX4 working to tackle food insecurity. Carrying out evaluation and insight into programmes to date and in Oct 2023 with OCA and Healthwatch Oxfordshire. https://www.ox4foodcrew.co.uk/

Oxfordshire Mind Insight from service users and experts by experience to drive service development https://www.oxfordshiremind.org.uk/

https://www.oxfordshiremind.org.uk/support-us/involvement/ including Lived Experience interviewers, Experts by Experience and Involvement Champions.

Oxfordshire Palliative Care Network – Public Engagement exploring how to better hear from voices of underserved communities in Oxfordshire in end of life care. Interest in developing work with community researchers. Alison Waller: Helen and Douglas House awaller@helenanddouglas.org.uk

Oxfordshire Parent Carers Forum independent group enabling the voices of parent carers of children and young people with SEND across Oxfordshire to be heard survey based and insight into experience of parents and carers e.g. reports on CAMHS, and SEND support https://www.oxpcf.org.uk/

Pamoja (2021). Insight gathering with community researchers to hear from BAME led groups in Oxfordshire and support scoping establishment of a network and steering group of Black, brown and minoritized ethnic groups with support of OCVA and OCF. Report available via AFIUK or OCVA.

Refugee Resource psychological and social support to refugees, asylum seekers and vulnerable migrants https://www.refugeeresource.org.uk/ Held workshops in 2023 gaining insight into community research for emerging community research network.

Terence Higgins Trust (Oxfordshire) - Breaking Barriers programme – insight, learning and creation of videos with community members (women from African and Caribbean heritage and with AFIUK), on subjects linked to HIV stigma, sexual health and care.
https://www.youtube.com/playlist?list=PLwspbA2qeKI58qEA6eFUigZqOWvQfP6i5

https://www.sexualhealthoxfordshire.nhs.uk/services/tht/

Turning Point working with Oxford City Council Community Champions Programme to explore vaccine hesitancy with those with lived experience of drug and alcohol addiction (2022).
https://www.oxford.gov.uk/downloads/file/8093/turning_point_vaccine_hesitancy_report_-_august_2022

Well Together Programme Community First Oxfordshire (CFO) and Oxfordshire Community and Voluntary Action (OCVA) will coordinate prevention funding directly to support existing and new social infrastructure organisations and groups in the 10 priority areas in Oxford, Banbury and Abingdon. Investing directly in work with 'anchor' organisations and grass roots groups will lead to tangible, high level impacts in prevention, tackling health inequalities at a local level.

Funding is via the Buckinghamshire, Oxfordshire and Berkshire West integrated Care Board for two years from 2023.

Other historical:

Oxford City Primary Care Trust (2009) Community Engagement Research Project as part of DOH Delivering Race Equality in Mental Health- Black and Minority Ethnic Access to Local Mental Health Services. Identifying barriers to mental health services for black and minority ethnic communities with recommendations to support change.

African Caribbean Community Association (ACCAN) (2000) Oxford: participation in Department of Health's Black and Minority Ethnic Drug Misuse Needs Assessment Project (University of Central Lancashire) https://clok.uclan.ac.uk/2591/1/Buffin_rep2comeng2.pdf

11. Other useful resources and references

Reading and key references for all stakeholders and groups participating in the emerging Oxfordshire Community research network might include:

Black Thrive https://lambeth.blackthrive.org/our-research/ Black-led research in Lambeth around mental health and wider determinants

Co-Production – see Elinor Ostrom (1970s) https://www.thinklocalactpersonal.org.uk/co-production-in-commissioning-tool/co-production/In-more-detail/where-did-co-production-come-from/

Centric Community Research build a bridge between institutions and communities by making research more accessible for the excluded https://centric.org.uk/a-disruptive-approach-to-research/what-is-community-research/

Centric. https://urbanhealth.org.uk/wp-content/uploads/2022/04/Community-Research-Literature-Review.pdf Community Research - A literature review.

Department of Health (2007) A Dialogue of Equals. The Pacesetters Community Engagement Guide. (See also podcast with activist Stafford Smith

https://www.kingsfund.org.uk/audio-video/podcast/dialogue-equals-stafford-scott-community-activism).

Gilchrist, A. (2019) *The Well-Connected Community: A networking approach to community development*

Health Foundation and Institute of Health Equity (2020) Build back fairer: The COVID-19 Marmot Review https://www.instituteofhealthequity.org/resources-reports/build-back-fairer-the-covid-19-marmot-review/build-back-fairer-the-covid-19-marmot-review-full-report.pdf

Healthwatch Cambridgeshire and Peterborough: give training, infrastructure support and resource to community researchers – for community listening project supporting the engagement for local ICB, and health and care teams into primary care https://www.healthwatchpeterborough.co.uk/news/2023-06-20/healthwatch-recruiting-community-researcher-volunteers-digital-inclusion-project

https://www.healthwatchcambridgeshire.co.uk/news/2023-02-14/volunteer-healthwatch-community-researcher-help-improve-how-services-work-local

Institute for Community Studies and UKRI, (2022) –*'An equitable future for research and innovation: Building sustained community involvement in knowledge production'*, https://eprints.icstudies.org.uk/id/eprint/399/1/An%20equitable%20future%20for%20research%20and%20innovation.pdf

Ledwith Margaret (2016) *'Community Development in Action: Putting Freire into Practice*

Morrison, E. (2022) An equitable future for research and innovation: Building sustained community involvement in knowledge production. Working Paper. Institute for Community Studies.

New Local (2021) The Community Paradigm. Why public services need radical change and how it can be achieved.

NHS England and NHS Improvement: Public Narrative approach https://www.england.nhs.uk/wp-content/uploads/2021/03/qsir-public-narrative.pdf

Office for Health Improvement and Disparities (Public Health England) (2021) *Beyond the data 2021: Understanding the impact of COVID-19 on BAME groups* - with recommendation for greater use of community participatory research *'in which researchers and community stakeholders engage as equal partners in all* *steps of the research process'* towards tackling health inequalities (10). Including recommendations 5. *Fund, develop and implement culturally competent COVID-19 education and prevention campaigns in partnership with local BAME and faith communities* 6. *Accelerate efforts to target culturally competent health promotion and disease prevention programmes for non-communicable diseases.*

https://assets.publishing.service.gov.uk/government/uploads/system/uploads/attachment_data/file/892376/COVID_stakeholder_engagement_synthesis_beyond_the_data.pdfhttps://www.ed.ac.uk/sites/default/files/atoms/files/emma2020.8.25_inequalities_covid_bame_beyond_the_data_summary_ep_002.pdf

Popay, J. (2006) Community Engagement and community development and health improvement- a background paper for NICE.

Public Health England (2020) Beyond the Data: understanding the impact of Covid-19 on BAME groups.

Runnymede Trust and ICM (2020) *Overexposed and Under-protected: The Disproportionate Impact of Covid-19 on Black and minority ethnic communities'* https://www.runnymedetrust.org/publications/over-exposed-and-under-protected intersecting with the Black Lives Matter protests for racial justice following the killing of George Floyd in the US. The pandemic shone a light on and amplified already existing and persistent intersecting inequalities including ethnic health inequalities (e.g. Black Women's Maternal Health, see: https://www.nhsrho.org/wp-content/uploads/2022/02/RHO-Rapid-Review-Final-Report_v.7.pdf; and – https://healthwatchoxfordshire.co.uk/news/we-want-to-hear-about-black-maternity-experiences-in-oxfordshire/).

Scottish Community Development Centre SCDC providing training and mentoring for community researchers under **HEE SE CPAR** Phase 1 and 2 https://www.scdc.org.uk/

https://www.scdc.org.uk/community-led-action-research

Silver, C., (2008). Participatory approaches to social research. In Researching social life (No. 6, pp. 101-124). SAGE Publications Ltd.

Synergi (2019) https://legacy.synergicollaborativecentre.co.uk/filling-the-policy-gap-with-participatory-action-research/ *'Ethnic Inequalities in Severe Mental Illness Study'*,2019). *"Adopting a Participatory Action Research approach this study – the first of its kind – is co-produced with ethnic minority people with lived experience of severe mental illness.* ('Filling the policy gap with Participatory

Action Research'). https://legacy.synergicollaborativecentre.co.uk/filling-the-policy-gap-with-participatory-action-research/

UK Standards for Public Involvement in Research
https://sites.google.com/nihr.ac.uk/pi-standards/home

NIHR National Institute for Health and Care Research
https://www.nihr.ac.uk/documents/payment-guidance-for-researchers-and-professionals/27392

University of Central Lancashire (UCLAN). Community Based Research approach: Community Research and Mental Health Course aims are described as seeking to: *"develop and extend students' knowledge and understanding of the issues involved in conducting community based research in the field of mental health."* https://www.uclan.ac.uk/cpd/courses/community-research-mental-health-cert

Recommended Toolkits:

To help explore further some of the key issues as highlighted in this background context, Alison Gilchrist recommends looking at toolkits on community-led action research including:

Scottish Community Development Centre and the Association for Research in the Voluntary and Community Sector.

University of Oxford. Community History Toolkit (https://www.history.ox.ac.uk/community-history-toolkit)

University of Reading *'Participatory Action Research Toolkit'* (2023) refers to **'Co-production'** as a key element within CPAR, see also Thomas-Hughes, H (2018), *'Critical Conversations with Community Researchers: Making Co=Production Happen?'* https://research-information.bris.ac.uk/ws/portalfiles/portal/350615050/Thomas_Hughes_2018_Critical_Conversations_with_Community_Researchers_Making_Co_Production_Happen.pdf

Oxfordshire County Council *'Working Together. getting started with co-production'* guide offers this succinct definition of co-production:

"Co-production is the process where providers and stakeholding citizens equally share a whole-life responsibility for the creation and delivery of products, services or knowledge. Co-production is underpinned by the principles of equality, diversity, access and reciprocity." ('Working Together: getting started with co-production', Oxfordshire County Council, 2022).

Owned by Oxford Community Wealth Building Initiative. An example of a *'bottom-up'* approach to developing *'community power'* . *'Building Community Wealth From The Ground-Up: The Owned By Oxford Report,'* 2023 – https://ownedbyoxford.org.uk/2023/05/16/owned-by-oxford-report/)

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haruka email mai ami iha hello@healthwatchoxfordshire.co.uk

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