

# Research Engagement Network Development Programme

# **Greater Manchester Integrated Care Partnership – Full Report**



## Working in collaboration with:





# **GREATER MANCHESTER VCSE LEADERSHIP GROUP the sector's voice in Devolution**



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### **Additional information:**

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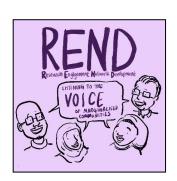
## **Contents**

Contents	3
1. About this report	4
1.1 The Greater Manchester Journey	4
1.2 Our Regional Engagement Network Aims	5
1.3 Our Approach	5
2. What we learned in phase one	7
2.1 The GM landscape is complex	7
2.2 Multiple barriers to sustainable partnerships need to be addressed	7
2.3 We need to work with community assets to improve the approaches we use .	9
2.4 There is no network-wide system for monitoring participation in research	10
3. What we are planning in phase two	12
Appendix 1:	14
Appendix 2:	16

### 1. About this report

The NHS England funded Research Engagement Network Development (REND) programme was launched in October 2022 to develop local partnerships between Integrated Care Systems (ICS), NIHR research infrastructure and Voluntary, Community, Faith and Social Enterprise (VCFSE) organisations to better enable diverse communities to get involved in research, and to embed this within ICS governance structures. The programme aims to increase the diversity of those who take part in research to be more representative of the local population; support engagement with communities who are typically underrepresented in research and support ICSs to develop and grow local Research Engagement Network activity.

In Greater Manchester, we were awarded funding to deliver phase one of the work (1st December 2022 to 31st March 2023) and further funding for phase two (1st September 2023 to 31st March 2024). This report details the findings of phase one and how these have led to the plans for phase two.



#### 1.1 The Greater Manchester Journey

Greater Manchester (GM) has extensive research infrastructure and a thriving Voluntary, Community, Faith and Social Enterprise (VCFSE) sector supported by NHS GM (Greater Manchester's Integrated Care System). These organisations have been working to strengthen their regional infrastructure for Public and Community Involvement, Engagement and Participation (PCIEP) including joint meetings, forums, events and scoping together how to improve collaboration between organisations. Additionally, NHS GM has been engaging with communities in partnership with Healthwatch and the VCFSE sector to develop an engagement framework for working with people and communities.

GM is in a unique place of having a triparty VCFSE Accord (signed in 2021) between GM Combined Authority, NHS GM and the GM VCSE Leadership Group committing to cross-sector collaboration and a 'One Greater Manchester' NIHR infrastructure. The VCSE Leadership Group plays a key role in coordinating the participation of VCFSE sector organisations.

Whilst in a strong position to work together with multiple exemplars of joint community engagement there remain key issues to address in the region, including:

- Our most marginalised communities have little awareness of and do not see the value of research for them. We need to strengthen reciprocal relationships that build trust
- There is a need for investment in, and learning from, the work of VCFSE organisations to build trust with communities and partnerships based on approaches that have previously worked well.
- There is a need for improved coordination between GM's many research assets and methods for monitoring and evaluating diverse and inclusive involvement and participation in research.

#### 1.2 Our Regional Engagement Network Aims

In phase one of this work, we aimed to:

- Co-produce improved approaches for creative engagement and communication in partnership with VCFSE organisations to build trust and trustworthiness in the research system, with those communities currently more excluded from research.
- 2. Develop an improved network-wide system for monitoring and evaluating diverse and inclusive involvement and participation in research within specific areas and communities in our region where inequalities are most evident.

#### 1.3 Our Approach

- Through the programme, we have created a shared purpose to scope organisational barriers and map the assets we have in GM to support diverse communities to become more involved in research.
- We surveyed and held workshops with eleven of GMs research infrastructure organisations. We asked which VCFSE partners they had worked with, who they wanted to connect with more, how they connected with partners and what barriers they encountered to creating sustainable partnerships. We requested case studies of good practice that demonstrated impact for the community, VCFSE organisations, and the research organisations. We also

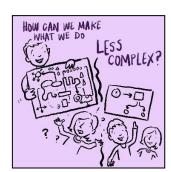
- collected evidence of shared learning and sustainability. Twenty case studies were submitted (see appendix for selection).
- In parallel, VCFSE leads for the programme, the Caribbean African Health Network (CAHN), surveyed VCFSE organisations to ask similar questions about barriers and enablers of sustainable research partnerships. CAHN held online and face-to-face discussions and were invaluable in creating the relationships needed to have these conversations with diverse communities. Existing networks were used and information was shared through voluntary sector infrastructure organisations such as 10GM, Greater Manchester Centre for Voluntary Organisations (GMCVO), Manchester's Local voluntary and community sector support organisation (Macc), Voluntary Sector North West, the Greater Manchester VCSE Leadership Group. Twenty-six VCFSE organisations responded to our survey and a total of ninety-nine individuals connected with us to share their views and experiences. We built on this intelligence through face-to-face events and workshops, attending activities organised and led by VCFSE organisations. Events were hosted by organisations in Bolton and Manchester. (See Appendix link for report)
- We engaged community connectors from Bolton, the Roma community, The <u>Black Health Agency for Equality</u>, The Men's Room and the Big Life team to scope existing links between research infrastructure and VCFSE organisations. We also worked with <u>Awakening Minds</u> in Rochdale to create an audio of the communities' views on taking part in research about mental ill health.
- We conducted a visually minuted consultation on all survey findings with the Greater Manchester VCSE Leadership Group where we developed our next steps for how to implement our short, mid, and long-term actions. The following section summarises our learning along with the visual minutes from this consultation.

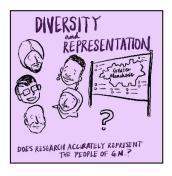
## 2. What we learned in phase one

#### 2.1 The GM landscape is complex

The research landscape in GM is complex and not easily understood by those outside of it. Our <u>mapping</u> of links between VCFSE organisations and research teams showed a lot of interactions in some areas of Greater Manchester (particularly

Central Manchester) and very few in other areas (e.g., Wigan and Bolton). Knowing how to find and connect to researchers was a barrier for some groups, whereas a sense of saturation and 'research fatigue' were experienced by others. Some respondents had worked with many different research organisations but highlighted that they had not always received feedback, recognition or updates.





Although this mapping was not extensive due to the timeframes for delivery it did highlight that there is a need for greater coordination between research organisations as to their community partnerships. The findings also indicate that opportunities for involvement are not distributed equally across the different regions (see appendix).

# 2.2 Multiple barriers to sustainable partnerships need to be addressed

Multiple organisational and institutional barriers get in the way of developing trusted relationships. We need to make research systems and processes more accessible including better integration of community partners into research teams, and research governance and processes. Where research funding models are project or programme based this creates a challenge for the sustainability of continuous engagement and relationship building.







Continuous engagement with smaller organisations is important for the development of trusted relationships with communities. Smaller organisations are disadvantaged and lack the resources to make the connections with research teams. Support with knowing how to engage for mutual benefit is crucial. Joined-up approaches that are not scattergun or 'extractive', will support building long-term relationships.





Some VCFSE organisations experience issues around capacity, resource and time to get involved in research as well as feeling they lack the skills to take part in research (grant application writing, data collection, analysis and writing up research). Crucially, not being recognised as equals in a partnership was experienced by VCFSE organisations when working with research teams.

'We can collect evidence, we can write cases we can publish; we just need skills to do this better and not be a step or ladder for others. We need the research knowledge so we improve what we already do anyway".

The VCFSE organisation's role in research is often not recognised or funded and there are no reciprocal arrangements in place where research teams can use their knowledge and skills to support VCFSE activity and evidence of their impact. This includes recognition of the need for improved mechanisms to capture the impact of inclusive engagement.

Trust issues based on historical negative research experiences for some communities was a common theme.





Many highlighted a mismatch of health priorities for communities versus those of research agendas and described how a lack of cultural awareness and understanding from researchers leads to dis-engagement. Communication barriers, both in terms of languages spoken and other communication needs, also create challenges for partnership working if needs are not met.







# 2.3 We need to work with community assets to improve the approaches we use

Community champions are seen as an important and crucial role to support engagement with diverse communities about research. Those that work within VCFSE organisations or groups in the heart of communities. These champions are often not recognised, adequately funded and lack the connections to network and access to support and training.

There was a need identified to create a *Respectful Research Charter* framework for more equitable working relationship between research organisations and the VCFSE sector to include the following guiding principles:

- Community ownership: community-led priorities, with meaningful research driven by community need and an understanding that community need doesn't always match researcher priorities. Start the work to understand the community before any research begins.
- Respect for community values: communities know their neighbourhoods, take time to listen and learn and use cultural sensitivity and competence.
- Embed research in communities: research organisations should endeavour to form long-term relationships that are mutually beneficial partnerships, fostering trust and ongoing dialogue.
- Accessible approaches: that account for communication and accessibility needs.
   Using creative approaches to help break down barriers
- Mutual benefit for all: reciprocal approaches, reimbursement for time, knowledge and skills exchange; appreciation and feedback mechanisms

Access to funding was the most cited support needed by VCFSE organisations (85.2%) with other institutional barriers such as timely payments and reimbursing VCFSEs appropriately to reflect skills, knowledge and contribution were cited as important factors.













# 2.4 There is no network-wide system for monitoring participation in research

In the first phase of the REN programme, we scoped the literature and reached out to local colleagues to identify current ways of assessing 'diverse and inclusive involvement and participation' in research. These are summarised in the Appendix. There are no optimal solutions for assessing these across the research pathway and multiple organsiations, and several metrics will likely need to be gathered (enriched by qualitative insights) to provide a picture of the baseline position and future progress in terms of diverse and inclusive involvement and participation.

The following were recognised as GM assets for monitoring inclusive involvement and participation:

- Audit of local studies
- NIHR Clinical Research Network data (number of participants and location only)

- o Research for the Future and other research registers
- Unique data sets, such as the GM Integrated Care Record, which brings health care records together
- Monitoring of the diversity of people actively involved in research<sup>1</sup>
- Process measures, e.g., the number of research-ready communities, organisations having diverse inclusion strategies in place

Building on this, we aim to develop a blueprint for an improved Greater Manchester-wide system for monitoring diverse and inclusive involvement and participation in research. This blueprint would consider the key stakeholders for such a system, where data should be held, and what systems would feed into the system. We'll also consider how to maximise accessibility for stakeholders and communities and the measures and indicators that would be most acceptable and useful for, local stakeholders.

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<sup>&</sup>lt;sup>1</sup> https://researchinvolvement.biomedcentral.com/articles/10.1186/s40900-023-00434-5

### 3. What we are planning in phase two

Conversations with VCFSE groups have helped create new links, networks and partnerships and a greater understanding of methods for future improvements for enabling inclusive involvement, engagement and participation for research addressing health inequalities.

Moving forward, we recognise the key aim of our collaborative work needs to make research systems and processes more joined up, accessible and equitable.

- We want to see organisational barriers removed particularly payment policies and more integration of community researchers into research teams with access to systems and resources, and improved alignment of inclusion strategies across the GM research infrastructure.
- We want to develop an empowered community of champions and shared learning/networking events to showcase successful collaboration models, providing support and developing mechanisms for feedback. We also want to explore the value of VCFSE-led community research engagement hubs to coordinate the activity between research and VCFSE organisations with continued investment, decentralising research and ways of working to ensure relationships can be sustained over time.
- We will further co-develop a 'Respectful Research Charter' between VCFSE and research organisations to foster sustainable partnership working. This will provide guidance for engaging with diverse communities and address barriers in working together.
- Co-production approaches will be enhanced by facilitating skills exchange and knowledge sharing across organisations and enabling mutual benefit from partnerships. Individuals or members of community organisations may benefit from training in research skills and knowledge, such as research design, data analysis, and ethical considerations. Research teams will benefit from increased training to ensure they are 'Community Ready' by learning about VCFSE led approaches that work and support greater cultural sensitivity. This 'skills exchange' concept will be further developed to explore what is of mutual benefit to support conversations about taking part in research.
- We'll work collectively to build on mechanisms for capturing data about participation that are not reliant on one funding source. We aim to show demonstrable progress over time with cross-infrastructure agreement on key variables to include a sustainable route to collate the data.

"There is so much to do to educate the community that healthcare research is not about them and us that we need to be innovative about engagement and listen more. When the community is engaged from the start, and they understand what is being done, they feel valued."

#### Gertrude Wafala, Research Lead at CAHN

"The project outputs lay the foundation for future engagements with various communities and create a pathway to forging mutually beneficial relationships between researchers and communities, which I am very excited about. Taking part in a successful project such as this is a testament to the power of collaboration and the strength of shared vision."

**Percy Akudo,**Business Support Manager at CAHN

"ICS REN team has enabled a strategic and extended approach to co-creating priorities for how we – VCFSE and research communities - work together in health research, to address inequalities, in a fair, respectful and inclusive way. We look forward to continuing to work with this community of practice to embed the benefits of research with our GM population."

#### Prof Bella Starling,

Director at Vocal

"An outreach approach using creative approaches has provided a foundation for greater diversity and inclusion for research and addressing health inequalities by facilitating new dialogue with some of our most underserved and marginalised communities."

#### **Prof Caroline Sanders.**

Lead for Public and Community Involvement and Engagement at the NIHR Applied Research Collaboration GM and NIHR GM Patient Safety Research Collaboration

# **Appendix 1:**

Table 1 below shows a list of the organisations that engaged with this project and gave insights into the barriers and potential solutions for sustainable partnerships.

Research Infrastructure Organisations	VCFSE organisations
GM ICB (Integrated Care Board)	Action Together
NIHR ARC-GM (Applied Research Collaboration Greater Manchester)	GMCVO
GM REVAL (Rapid Service Evaluation team)	10 GM Population Health
Manchester Metropolitan University	Age UK Bury
University of Bolton	Ephrata Church Community
University of Manchester	Future Directions CIC
The Ideas Fund	Reproductive Advisory Services
Research for the Future	Carers Manchester South
NIHR School for Social Care Research	City in the Community
NIHR School for Primary Care Research	BHS for Equality in Health and Social Care
NIHR Policy Research Unit for Older People and Frailty	Caribbean African Health Network (CAHN)
NIHR Greater Manchester Clinical Research Network	African and Caribbean Community Association (ACCA)
NIHR Research Design Service North West	The Men's Room
NIHR Greater Manchester Patient Safety Research Collaboration	Josephine Idoko
Health Innovation Manchester	Black Beetle Health CIO
NIHR Manchester Biomedical Research Centre	Manchester's Got Talent Communities
NIHR Manchester Clinical Research	Lobular Breast Cancer UK

Facility		
NHS Wrightington, Wigan and Leigh	Ryder Brow Community Allotment	
Clinical Research Hub	Society	
	Jesuscina Foundation	
	George House Trust	
	Women Arise CIC	
	KaskoSan Ltd Roma	
	Can Survive UK	
	Christ United Ministries	
	We Matter	
	Reinventing Success	
	Awakening Minds	
	Made By Mortals	
	MACC (Manchester Community Central)	

# **Appendix 2:**

Output title	Link to document
1/ Visual minutes	
Visual minutes from workshops of the barriers and facilitators to inclusive involvement	Link
2/ VCFSE mapping	Link 1
A visual geographical map of the VCSE organisations who have worked with /are working with GM research infrastructure	Link 2
3/ Report from VCFSE sector	
A report of a survey / 1:1 discussions and engagement events by CAHN with VCSE sector groups	Link
4/ PowerPoint slides of scoping exercises	
Scoping work was undertaken to review the barriers and facilitators to involving communities currently under-represented	Link
5/ Framework to create a Respectful Research Charter between VCFSE and research organisations	Link
6/ Scoping report towards a system wide approach to monitoring and evaluating diverse and inclusive involvement and engagement	Link
7/ Audio output from community groups addressing the issue of trust	Audio-1 Audio 2 Audio 3
8/ Report on improving under-representation of GMs	Link 1
minoritized and racialised communities in research	Link 2
9/ Case Studies – exemplars of inclusive researcher and VCFSE engagement	Link
10/ Roadmap to creating sustainable networks success	Link

#### For more information, please contact:

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Produced by the NIHR Applied Research Collaboration Greater Manchester

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The information in this report is correct at the time of printing.

