

Connecting Communities: Valuing our Differences and Learning Together

The Greater Manchester Public and
Community Involvement and
Engagement Forum
October 2021



Working in Collaboration with:

The Member Organisations of the Greater Manchester Public and Community Involvement and Engagement Forum

Full list available here: <https://arc-gm.nihr.ac.uk/greater-manchester-forum>

Authors:

Sue Wood (Head of NIHR ARC-GM)

Caroline Sanders (University of Manchester; NIHR ARC-GM)

Aneela McAvoy (PCIE Manager NIHR ARC-GM)

Nicky Timmis (PPIE Manager Health Innovation Manchester)

Forward

Why Connecting Communities is Crucial for our Research and Action to Address Health Inequalities, and to Improve Health and Care for All



Greater Manchester is famous for many things including its industrial and innovative past, its music, creativity and culture. The historic symbol of the worker bee was adopted in the midst of the industrial revolution to signify Manchester as a hive of activity made up of hard-working communities. You don't have to look too hard to find plenty of references to 'a strong sense of community' across the localities and neighbourhoods of Greater Manchester. However, experiences of community vary, and valuing differences is crucial to involve and engage with all communities (especially marginalised communities and those who are seldom heard) to identify and address inequalities.

The [Greater Manchester Public and Community Involvement and Engagement Forum](#) came together at a time when the world was changing at the start of the COVID-19 pandemic. Before the national lockdown, we had met a couple of times face-to-face, before lockdown started and we quickly moved online and had many energetic discussions about shared and different experiences, and what had changed for communities in Greater Manchester during the pandemic. Members of the forum have been directly involved in community action to tackle COVID-19 and inequalities experienced across many local communities. This provided a strong basis for shared learning and members have highlighted the importance of grass roots organisations and existing networks for co-producing appropriate responses to COVID-19. Our discussions highlighted experiences of racism during the pandemic that amplified inequalities; the positive and negative experiences of healthcare; as well as experiences highlighting digital inequalities that could further disadvantage those with the greatest need.

The 'Connecting Communities' event was an opportunity to show how communities and networks linked to the forum have come together and worked creatively to ensure that communities are supported and listened to. The sessions brought together many examples of work to improve access to public involvement and engagement opportunities supporting both researchers and health and care organisations to understand public need during a very challenging time. They also highlighted creative and collaborative ways to maximise diversity and inclusion for public involvement and engagement enabling communities to become involved in their preferred way.

Professor Caroline Sanders (University of Manchester)

Contents

Forward	2
1. Introduction	4
2. Listening to Young People’s Voices.....	6
3. Supporting Diversity and Inclusion	8
4. Creative Styles for Inclusive Vibes	11
5. The Human Experience Perspective	13



1. Introduction

The Greater Manchester Public and Community Involvement and Engagement Forum was set up with the ambition to support public involvement leaders from diverse backgrounds and different organisations including voluntary and community groups to: undertake inclusive involvement and engagement activity; share resources and learning and work on creative outputs together. Our first event: ***Connecting Communities: Valuing our Differences and Learning Together*** took place between the 18th October and the 21st October 2021. Although the event was held on-line the communities of Greater Manchester were supported to showcase their work through various routes with the opportunity to pre-record sessions. The resources for this event including all the presentations are available [here](#):

The themes for the week included:

- **Listening to Young People's Voices:** taking action to make a positive difference for young people
- **Supporting Diversity and Inclusion:** understanding the values and needs of Greater Manchester communities through inclusive involvement
- **Creative Styles for Inclusive Vibes:** involving people through creative means such as drama, poetry, song and animations
- **The Human Experience Perspective:** exploring the value that the experience service users and carers bring to education and research

The week's events were opened by Caroline Sanders talking about how the connections that have been created across the region brings strength to our networks and where there is a willingness to support each other we are stronger together. We were introduced to the Greater Manchester Public and Community Involvement and Engagement Forum members who represent multiple organisations including voluntary groups and charities. The forum has been working together throughout the COVID-19 pandemic to share involvement opportunities and create new opportunities for connections to be made for mutual benefit.

“The Forum is very informative with varied agendas and a space where seldom heard voices don’t have to shout as loud.” (Nasrine Akhtar - Awakening Minds)

“A unique space and there are very few spaces in which the complexities of identity in relation to design of processes, and ‘real’ consultation and involvement actually take place in a meaningful way.” (Tess Gregson - 42nd Street)

The Health Innovation Manchester Public and Community Involvement and Engagement Panel (members of the public) joined us to tell us about their personal experiences of getting involved in research and health and care innovation. They told us about their motivations for becoming involved including: improving their own understanding of a medical condition; helping researchers to understand lived experiences; the ability to influence professional understanding of cultural differences; ensuring different voices can be heard and knowing that their own personal views can make a difference.

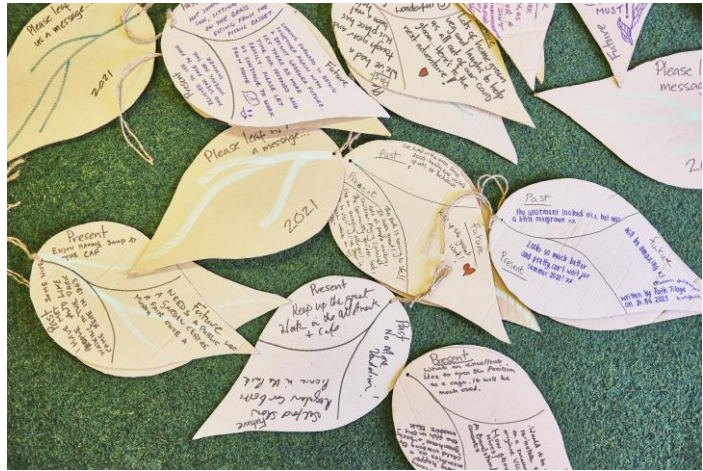
The panel had some key messages for research teams and health care professionals wanting to involve members of the public:

- Involve the public as early as possible in the process.
- Build mutual trust and respect.
- Learn together through the process, you don’t have to have all the answers up front.
- Avoid jargon and abbreviations that make it difficult for public members to understand what is being discussed.
- Make what you are a doing accessible to as many people as possible.
- Make public participants feel valued and tell them the difference their input is making.
- Provide rapid and adequate re-imburement for their time and expenses.

2. Listening to Young People's Voices

Our session listening to young people's voices highlighted the creative and imaginative ways in which young people have been involved in research.

Kainat Nafees a 22yr old student talked passionately about the value of young people voicing their opinion to improve services



for their own and future generations and being able to act as an advocate for her own community. She talked about the barriers that prevent young people from accessing the support they need so by young people being advocates raising awareness and understanding, it can help influence service provision. Kainat also reflected on the fact that it is uncommon for young people to get this kind of attention and there may be assumptions that young people do not have enough to say or insights to bring, but by everyone collectively working together, young people can bring about positive change. Lived experience are different between people from the same communities and experiences may differ based on individuals' age.

Annie Keane and Voice Up from [Vocal](#) demonstrated how creative approaches such as the arts and the use of images like the digital comic created through the [Planet DIVOC-91](#) project, can be good ways of engaging young people and are approaches which can be universally applied. There is a need to make opportunities more attractive to young people. Using these types of approaches enables young people to talk about issues that are important to them. In the Planet DIVOC-19 project the important issues were equity, stigma, mental health and misinformation.

We also heard during this session from Salford Foundation (Alex Kershaw); Child and Adolescents Mental Health Services Digital (Jessica Kenworthy); Nurturing Foundations (Celeste Makeba); and researchers at the University of Manchester

(Rebecca Pedley and Gail Davidge) with public co-researchers Rebecca Gosling and Ezra Rose.

Key learning from the sessions:

- Inclusion of young people may help them to develop new skills and gain confidence which will aid their personal development and be of value to them in developing their CVs.
- Including young people in research can be a game changer but there is a lack of awareness that involvement and engagement opportunities exist and what benefit it brings for all involved. Improving awareness of the opportunities in schools and colleges is a key action.
- Young people are passionate and knowledgeable about mental health in particular.
- Research methods training is usually created by adults for adults. If we are to involve more young people, we need to tailor our approaches to their needs.
- Young people often experience periods of great change and the longevity of young people's involvement is often seen as a measure of adopting the right approach. Flexibility needs to be factored into the approach and hybrid methods available to enable young people to continue to engage, particularly when they are away from home or limited by school/college hours.
- Educate researchers about how to explain their research to young people. Researchers need to prepare properly and ensure materials are accessible.
- Involvement can be fun. Using creative styles can help attract different audiences.

3. Supporting Diversity and Inclusion

The communities of Greater Manchester are diverse, if we are to create equal involvement opportunities for all, we need to understand the values and needs of these communities and create better ways of enabling their voices to be heard. In our sessions on diversity and inclusion we heard some inspiring talks from our community leaders and community groups from diverse backgrounds who are working with research teams to improve access and inclusion.

Isabel Adeymi from the NIHR Greater Manchester Patient Safety Translational Research Centre and Faye Bruce Chair of the Caribbean and African Health Network, with Nasrine Akhtar of Awakening Minds, talked about their work together to explore the experiences of black and ethnic minority women using maternity services during COVID-19 pandemic. Dr Sudeh Cheraghi-Sohi also from the Centre shared experiences of involving marginalised groups during the pandemic for work focusing on experiences of people living with dementia, people with sensory impairments, and work focusing on mental health.

Yen Siang Tan, Chief Executive Officer of the Wai Yin Society and Chares Kwaku-Odoi, Chief Officer at Caribbean and African Health Network, reflected on being part of the GM Public and Community Involvement and Engagement Forum and the importance of communities knowing they have a right to a seat at the table.

Professor Bella Starling, Director of [Vocal](#), talked about the co-creation of inclusive online training package for researchers and public contributors developed with Vocal's Black Asian and Minority Ethnic Research Advisory Group. Jane McDermott from Policy Research Unit University of Manchester and members of the Greater Manchester Older People's Network, introduced the work they have done to help older people without digital access stay well during the pandemic, as part of the Keeping Well at Home Campaign. Nicky Timmis from Health Innovation Manchester and Nasrine Akhtar from Awakening Minds, talked about a project they worked on together to explore public access to online GP services during the pandemic,

highlighting the value of partnership working and inclusivity to ensure the voices and issues faced by marginalised communities were represented.

Julie Marshall from Manchester Metropolitan University's Communication and Disability Group gave a thought-provoking session on how to support those living with communication disability and their immediate family and caregivers.

Key learning from the sessions:

- Building relationships and trust is more important than ever.
- Respecting the value of community champions and their trusted links to communities will pay dividends. The cultural insights and knowledge that community champions bring enables more in-depth understanding and honesty from participants. The subtlety in the meanings of what participants shared and couldn't share is also better understood. These trusted links are built up over many years and should be valued for the impact they can bring to successful inclusion.
- There are vast numbers of voluntary organisations in Greater Manchester to link in with, but many are small teams with no communication support to tell people who they are and what they do. There is mutual value to be gained in linking voluntary groups together, along with linkages to larger organisations.
- Some communities feel voiceless and don't see themselves as having a seat at the table. We need to change this and tell people they have a voice and will be listened to.
- Intersectionality is a key concept, nobody is one thing, we need to understand the many layers of our communities and the people within in them.
- Communities are not hard to reach, research teams and health and care services have poorly designed approaches when it comes to asking more marginalised groups to be involved. Explaining the purpose and process for involvement in a way that resonates with the culture and values of different communities is essential.

- A hybrid approach to future involvement activities is needed to be truly inclusive. In one way, moving things on-line during the pandemic opened up opportunities for some, but closed them for others.
- Creating a safe environment to raise concerns and being prepared to listen and address these concerns is key to improving things in the future.
- One in five people will have communication difficulties at some point in their life and improving access means being open to all methods of communication. Give it time, ask how to make things better for that person, be prepared to listen and keep trying if the approach chosen isn't work.



4. Creative Styles for Inclusive Vibes

Creative co-production involving people through creative means such as drama, poetry, song and animations was strong theme across the event. Whilst the COVID-19 pandemic could have easily dampened creativity the communities of Greater Manchester looked for new inventive ways to unleash their creative flare.

We heard from Paul Hines at Made by Mortals and Stephanie Gillibrand NIHR Applied Research Collaboration Greater Manchester about an inspiring project using creative immersive techniques to enable young people to talk about their feelings towards the COVID-19 vaccine programme. The approaches used aimed at helping the young people make more sense of the topic and answer in a none threatening way. Paul Hines also talked with Dr Paul Clarkson, Deputy Director Social Care and Society, University of Manchester, about how they have used participatory methods in a project about using data in social care to make research involvement more engaging and more interesting to the participants.

String of Hearts, a community arts organisation, explained how they have been bringing older adults together through music making. The Music Hotline is a free phone call service for people who don't use the internet, to support connections, self-expression and creativity whilst COVID-19 restrictions continue. They introduced us to one of the songs that had been created as part of the work.

The poems at the end of this report are examples of some of the creative ways being used to discuss key messages.

Key learning from the sessions:

- Participatory methods can be undervalued but can help to make things more engaging, it brings issues being discussed to life not only for participants but for policy makers/ health and care service delivery planners.
- Creating involvement approaches with communities can really make a difference.

- Experiential approaches enable individuals to immerse themselves and moves them in to a place where they can connect with something on a more human level.
- Where topics are sensitive, and/or within groups that may find it difficult to express their own view point, using characters and drama enables them to talk about topics in the 3rd person.
- Using the power of photography, the diversity of the Greater Manchester communities can be visualised and helps illustrate '*what community means to me*'. A photograph competition launched at the event will be displayed at the Whitworth Art Gallery in Manchester 2nd December 2021 - 17th December 2021.
- The Forum members were left asking how we can do more of this, we are all learning.



5. The Human Experience Perspective

In exploring the value that experiences of service users and carers bring to education and research, we heard from teams across research and education settings who are working with valued public contributors to improve the work that they do.

Researchers from the NIHR Applied Research Collaboration Greater Manchester talked about how their partnerships with the public and communities of Greater Manchester have helped to shape the research that they do ensuring that it meets the needs of the populations it is intended to help. Abi Brown discussed her work with service users to define and measure 'parity of esteem'; ensuring mental health is seen as equal to physical health in service provision. Rachel Meacock described working with public members on a research grant and how early engagement with public partners helped shape the



research questions to strengthen the bid. Ruth Watkinson and Steph Gillibrand described how they have worked with young people and those from black and ethnic minority groups to better understand why people in these groups do or do not take up the offer of the COVID-19 vaccine. Pauline Whelan, Charlotte Stockton-Powdrell and Simon Foster introduced a project to co-develop a Public Involvement and Engagement App that can be used to help young people become more involved in mental health research.

Bimpe Kuti from the University of Bolton and Abi Idowu, a service user, talked about 'The Service User and Carer Initiative', which is part of a teaching and learning strategy in Higher Education where service users discuss their lived experiences with students helping them to better understand the reality of living with long term health conditions.



Teams from the NIHR Centre of Primary Care and Health Services Research talked about work of the Primary Care Research in Manchester Engagement Resource and how its members work with researchers in shaping the programmes of work. They were joined by Rebecca Morris (researcher) and Kay Gallacher (public contributor) talking about co-developing a patient safety guide. In a session called Personal Shielding Stories: The voice of people living with arthritis and musculoskeletal disease - Charlotte Sharp; Joyce Fox and Lynn Laidlaw and the COVID-19 Shielding Voices shared their experiences of working together. Whilst Stephanie Snow; Sam Franklin; Kay Gallacher and Hawys

Williams described the importance of celebrating and rewarding community involvement in different ways.

Katherine Grady and Philip Hammond joined us from the NIHR Clinical Research Network Greater Manchester initiative [Research for the Future](#), an NHS-supported campaign that helps people find out about and take part in health and care research.

Key learning from the sessions:

- It is important to ensure the lived experience of real patients and carers is used to educate and shape the future health and care work force. It encourages future health and care professionals to see patients as human beings not just diseases. Involvement improves the quality-of-care of services and drives quality and service improvements. It can inject reality into students learning and enhance the experience.
- Public contributors that live with a, or multiple, long term conditions, can often feel useless; like they have nothing to bring. Involvement creates opportunities for this experience to be an asset.
- From a public contributor perspective, it can build confidence and empower them to become an active participant in their own care and treatment.
- The support offered to public contributors is key to creating a positive experience. Peer support, where public contributors learn from each other informally, can often be more valuable than formal training and resources.
- Co-production can be challenging and takes time. One size does not fit all so different approaches are needed for different people; it is important to be adaptable and responsive to change as different populations will have different needs. It can be useful to work iteratively (a process of continually refining what has been created) so it is fit for purpose for all involved.
- A multi-disciplinary approach to co-production helps to foster true partnerships between researchers, academics, health care professionals and the public - “the sum of the whole is greater than the sum of its parts”.
- It is important to think about the role(s) people may need to take on and how public contributors can be supported in this, for example co-chairing/co-facilitating meetings or discussion groups.
- Need to consider the inclusion of people of working age; employment can exclude people who work.
- Measuring the impact of public involvement is important and considering what ‘making a difference’ means to the team is imperative.
- Feedback to participants about how their involvement has made a difference.

- Most importantly celebrate and reward contributions that public members have made.



A Seat at the Table

*If you want me to have a seat at the table just ask
I may not be knocking on your door but come and knock on mine*

*Send me an invite, put me on the guest list, send a VIP golden edged envelop make
me feel wanted, I will come and take a seat at the table*

*Tell me where to come, how to get there, make it local to me and provide me a chair
Not an emergency chair, the one you only get out at Christmas, when Great Aunt
Pru turns up unannounced. A proper chair, a comfy chair, a seat at the table
Don't seat me at the end where conversations are hard to hear. Give me pride of
place, a central point, a chair with a purpose*

*Don't start eating without me I don't want to arrive late, half way through the meal,
conversations already started before I take my seat at the table*

*Pass me the menu, but don't make it fancy, with words in an unfamiliar language,
fancy names, abbreviations. Turn up the lighting, make the text less small, pass me
my readers from the table in the hall. How will I know what to choose from my seat at
the table?*

*When the bill arrives don't forget you invited me, don't expect me to pay I've given up
my time to be here at your table*

*I may not even make it today, my seat may be empty, but don't give up on me yet,
life got in the way. I have plenty to say, I will be back
so please save me a seat at the table*

By Sue Wood (NIHR Applied Research Collaboration Greater Manchester)

The Meeting

One by one
The panel log in
Warms words are exchanged
Then we begin

We've learnt how to Zoom
How to mute
Raise our hands
Pay tributes

We have an agenda
A running order
There is Joanna
The minutes recorder

Guest speakers attend
At times from above
They brave the panel
And fall in love.

It's easy to do
I've done it myself
All so unique
Their input top shelf

Passionate about health care
Their own views to give
Vocal experience
Of lives long lived.

Opinions opined
insight aired
Valuable knowledge
All to be shared.

by Russ Cowper (Public Contributor) and Aneela McAvoy (NIHR ARC- GM)

For more information, please contact Joanna.Ferguson@manchester.ac.uk

Produced by NIHR Applied Research Collaboration Greater Manchester [date]
The information in this report/brochure is correct at the time of printing.