NIHR | Applied Research Collaboration

Reflections of the Inclusive Involvement in Research Advisory Group (2021-2026)



National Institute of Health and Care Research, Applied Research Collaboration, East of England.



Who is this Summary for?

Those who work in public involvement will find our experiences a valuable learning resource.

- We are a group of people interested in inclusive involvement in research.
- Our ideas helped direct the NIHR ARC Inclusive Involvement in Research theme
- We met 19 times over 5 years
- We heard from researchers, students and community members who came to tell us about their work.
- We provided comments and feedback based on our own lived experience.
- Researchers changed their work as a direct result of what we said.
- The Advisory Group was an important part of the National Institute of Health and Care Research (NIHR) Applied Research Collboration (ARC) East of England research theme.





Public Members:

Inclusive Involvement in Research Advisory Group members:

Teresa (left), Amander (right) - back row.

Mary (left), Sunny (right) - front row.

With many thanks to all those who gave their time.

Contents

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Who is this Summary for? 1

Contents 2

Aims of the Advisory Group: 3

Who was in the Advisory Group? 3

More about Our Public Members: 4

Customers? Service Users? Something else? 6

What did we talk about? 7

What did we learn? 8

Positives and Challenges 9

Researcher Comments 10

Some of the research discussed: 11

The use of Artificial Intelligence 12

AI Rap - The Advisory Group Tried Using "AI" 13

🎤 Inclusive Involvement Advisory Group Rap 🎤 14

Event Planning: 15

Appendix: The Detail 16

Terms of reference (agreed in 2023) 16

Advisory Group Meetings Dates (2021-2026) 17

Note 18

Thank you! 18

Aims of the Advisory Group:

- ✓ Encouraging collaboration between academics within theme and the communities they are working with;
- ✓ Understanding issues Advisory Group members are experiencing and hearing in their local communities;
- ✓ Developing the capacity, research knowledge and skills of public contributors. Enabling further involvement in research;
- ✓ Providing critical feedback to researchers within the Inclusive Involvement in Research theme and increase involvement and engagement of the public and communities within four distinct populations: Peterborough and the Fens, Stevenage, Thurrock, and Great Yarmouth and Waveney

Who was in the Advisory Group?

Four members of the public and four researchers.

Chair: Peter Beresford

*Public Contributors: Amander Wellings, Teresa O'Keeffe, Mary Ledgard, Sunny Saini (with support from Neil Woodbridge), Graham Rhodes**

Researchers from Universities of Essex, East Anglia and Hertfordshire: Sally Burrows, Elspeth Mathie, Ewen Speed, Fiona Poland, Linda Birt, Laura Watts, Reena Masrani.

*In Sept 2024 we learned that Graham Rhodes has sadly passed away. Graham was a highly valued member of the Inclusive Involvement Advisory Group who worked with the team in the previous version of the ARC (the CLAHRC) where he co-chaired the PPI Coordinating Group. Members of the group shared their appreciation of Graham.

More about Our Public Members:

Click on web links for more information (**in blue**)

Amander Wellings lives in Norwich and is one of three public members on the **"Make it Public" campaign, Health Research Authority**.



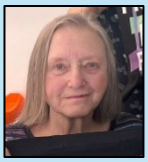
Amander writes poetry and one of these "March in March" is available online: **We March in March - a poem by Amander Wellings - Health Research Authority (hra.nhs.uk)**.Amander was successful in becoming a Co-lead for the first time on an NIHR study on **Creative Learning Abilities Partnerships** in 2023 with her poetry published in the 2025 NIHR final report.

"It would be my dream to not need the term "underserved communities" anymore. All should be included in designing and carrying out research that informs the services they receive. So services better fit their needs. We need to make the world more inclusive"

"Creative methods help break down the barriers between researchers and public"

"I am autistic and ADHD I always think outside the box and bring many different erspectives. I also have diabetes, fibromyalgia and hearing impairment"

Mary Ledgard: As a lay representative on the Inclusive Involvement in Research theme in ARC East of England Mary has been involved in a range of activities.



"In addition to the theme meetings I have attended the Inclusive Involvement Advisory Group which has exposed me to different ways in which under-represented groups can take part in research. I have also taken part in hybrid discussion groups on the relationship between researchers and their subjects on themes such as trust.

I have particularly enjoyed working with PhD students throughout. I now represent ARC East of England on the Health Research Authority's Shared Commitment to Public Involvement in Health and Social Care Research where I am helping to edit an article on the burden involvement imposes on public contributors.

My overall experience in working on the theme has broadened my appreciation of the opportunities for and implications of public involvement in research. As someone who works extensively in the voluntary sector, I am making good use of what I have learnt."

Click on web links for more information

Sunny Saini lives in Grays, part of Essex and is a dedicated Director for **Thurrock Lifestyle Solutions**, known for his creativity, leadership, and commitment to supporting people in his community.



Sunny brings enthusiasm, kindness, and a positive spirit to everything he does. Sunny's vision is "a *world where disabled people live with no barriers and have a positive community experience, their individual aspirations are met and they have total choice and control*".

Sunny presented in the ARC East of England Community of Practice on **Coproduction: An empty ritual**.

For Sunny, being part of the Advisory Group has meant having a valued and respectful space where his voice, ideas, and lived experience truly matter. This involvement has had a meaningful impact on him — helping him grow in confidence, deepen his understanding of research, and contribute to discussions that shape real, positive change. Sunny's participation has allowed him to bring practical insight, encouragement, and a thoughtful perspective to the group — something he values deeply and is proud to contribute.

Outside of his professional work, Sunny Saini is better known as DJ Sunrise, providing live entertainment music for friends and customers — always creating an atmosphere where everyone gets up to dance. Fun fact: Sunny Saini, also known as DJ Sunrise, has a special talent for turning any gathering into a dance floor with his uplifting mixes and feel-good energy.

Memorable event: One unforgettable moment was when DJ Sunrise transformed a small community get together into a full-on celebration — the kind of night people still talk about because no one wanted the music to end.

Teresa O'Keeffe: Following a Senior Management career in Recruitment across Logistics and Construction, I wanted to find a more impactful direction. In 2011, I moved to Essex and into the Thurrock community.



"As a Community Project Manager and volunteer, I seek to support and represent those whose voices cannot be present. My experience of working with community groups and businesses, gives me a broad view across the thoughts of local people. Ensuring that health and other services are considering the spectrum of needs of the entire community is something that I feel passionate about"

"My involvement with the advisory group has helped me to ensure that the voices of the groups that I support are heard. It was particularly helpful to talk with the PhD students and provided a useful insight into their current and upcoming projects which will impact on Health and Care going forward. I feel privileged to be part of this informative and caring group. "

Peter Beresford was the Advisory Group Chair. He has a background as a long term recipient of mental health services as well as living on welfare benefits.



Peter co-chairs the national disabled people's organisation **Shaping Our Lives** and works part-time at the University of East Anglia. He has worked in grassroots community organisations a lot in the past which has been good and now does more writing and research in ways which are accessible to lots of other people and which involve people and their lived experience. He recently has another book **The Antidote** published.

He likes making things and loves old motorcycles, and having a garden he loves watching the flowers come.

Customers? Service Users? Something else?

The group did not agree on a single term to describe public members; some really disliked service users, whilst others identified as service users. One member wanted to use the term customer. We agreed that it was important to acknowledge and respect our differences and that was good. It is positive for everyone to be able to self-define. People also had different roles and jobs, sometimes this is called "wearing different hats".

What did we talk about?



Members of the Advisory Group shared their knowledge, views and experiences with one another and with visiting researchers. This was enhanced by their involvement in different areas of research:

- Two of our members sit on the **National Shared Commitment** to Public Involvement in Health and Social Care Research.
- Members have also shared information; for example Learning from Lives and Deaths – people with Learning disability and autistic people: click here: **LeDeR**.
- Some members have participated in the Applied Research Collaboration, East of England Inclusive Research **Community of Practice** with wider academic and statutory partners.
- Some have been involved with the **Make it Public Campaign** – transparency and openness in health and social care research (Health Research Authority)

What did we learn?

How to engage different people



- ✓ Respect all voices, all skills and different perspectives
- ✓ The importance of <u>having a voice</u>
- ✓ 'Voices' can be heard in different ways (in meetings, through 'chat' function, or after meetings)



- ✓ Cameras on or off in meetings (having a choice) but acknowledging that if cameras are on it helps with access e.g. lip reading, hearing impaired or knowing when to comment, neurodiversity can make this difficult if you can't see the speaker.



- ✓ Recognising the <u>impact and power of language</u>. Terms such as Service User and Consumer may be used by some interchangeably but should be carefully thought about.
- ✓ Language can make people feel uncomfortable. We need to <u>respect</u> each other's decision to describe themselves how they want to.



- ✓ Recognition of <u>power</u> dynamics and creating a space so people can comment and question and conversation are <u>equal</u>.



- ✓ Discussed "usual suspects" and aiming for <u>diversity</u>, include both experienced and new advisory group members.
- ✓ Building a bridge between researcher and research.



- ✓ Importance of <u>trust</u>.

How to Ensure Inclusive Involvement



- ✓ The importance of keeping in touch with public members in between meetings and using appropriate communication methods (i.e. Whatsapp).



- ✓ Thinking about potential benefits to both the research and to all those involved in the research when codesigning activities.
- ✓ Offer opportunities to enhance skills



- ✓ Avoid using abbreviations - suggestion to write all acronyms in full, so no need for a glossary.

Meetings



Sometimes it has been hard to have regular quarterly meetings and for all public contributors to be able to attend. Some Advisory Group meetings had poor attendance.

Having accurate, accessible meeting notes provides an important record for those not attending.



Enough time must be factored in for pre-meeting with public contributors, a pre-meeting can assist being able to effectively contribute.

Positives and Challenges



- Our Public Contributors have shared that they are very happy to be members of the Advisory Group.
- They felt they got a lot of support to help them feel comfortable to share their experiences and ideas within the group and have learnt from each other.
- With support public contributors felt able to do more.
- Sharing ideas that may not otherwise be thought about.



- However, one member was frustrated with lots of discussion and wanted more action.
- Another wanted to be involved at the start of projects (which was not always possible with PhD students or the projects that already had their own Public Involvement).

"That is the joy of bringing people together with very, very different backgrounds"

Researcher Comments

Researchers from the Inclusive Involvement in Research Theme arranged to come to Advisory Group meetings to share their work and get feedback and advice from public members. They were very pleased with the help that they got to make their research more inclusive.

"All attendees are experts in their own lived experience and their engagement and ability to consider opportunities to be more inclusive in both the research and importantly the dissemination of results is inspiring. To me as a researcher extremely helpful. Personally I always enjoy the wide ranging and thought-provoking discussions this group stimulates" ***(Linda Birt – Researcher 2025)***

"I have used the advice from our meeting. Guidance from the IIRP advisory members - I ensured my wording was 'non-medical', reapproached the charity using my initial contact, devised a basic form on my analysis (whilst ensuring it provided valuable PPI feedback on my findings), and was clear on why the PPI views were so value to this research. It was a really helpful meeting (and) provided me with the reassurance that I have fulfilled that duty of care to my participants who have given me their time by ensuring it is from a patient perspective**" Amanda Farwell (PhD Student)**

"When people from a community open ourselves up to you, that's when you know that your research is working because we're comfortable saying what we want to say and how we feel to you... it's all about breaking down the barriers. And being equal with the people" (Public member)

Some of the research discussed:

Click on the title for a link to more information on each project (hover over and control click)

Gypsy, Roma, Traveller (GRT) Health Access Project

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Gypsies, Roma, Traveller communities face barriers to access healthcare services. The project developed a community of practice to co-design solutions. The group discussed the trusted relationships, community links, gatekeepers, stigma, literacy and communication.

Creative Learning Abilities Partnership (CLAPS) *Co-led by Amander Wellings*.

The project is working with people with learning disabilities and autism who have not been involved in research before. Using creative methods and workshops to shift the narrative from "learning disabilities" to "learning abilities", and co-producing research. Coproduction is about partnership building and needs to be 'messy' and flexible.

The Discovery Project

The group discussed dementia, including personal experiences, the challenges of living with and caring for someone with dementia, and the importance of social connectedness. The importance of accessibility and inclusivity was highlighted, including considering social anxiety, technical barriers, and the need for clear communication.

Universal Research in Design

University of East Anglia is aiming to be an accessible University. Disability is diverse (mobility, vision, hearing, cognition, mental, wellbeing, fatigue, pain) with 20% of population being disabled. We considered what made research more inclusive and friendly for those with disabilities.

Digital Access for People with Visual Impairments

The study included anyone over 60 and initially involved talking to organisations specifically working with people with visual impairments.

PhD Students linked to the Inclusive Involvement in Research Theme

Amanda Farwell: palliative care and heart failure patients and care givers (Jan 2022)

Alice Wreford: social connections and what we look for in our social relations (May 2022)

Lara Williamson: volunteer-run activity impact on health inequalities in a coastal town.

Ellice Parkinson: drinking and dehydration for older adults long term care settings.

Shanice Thomas: older people using digital devices and going online (Sept 2024)

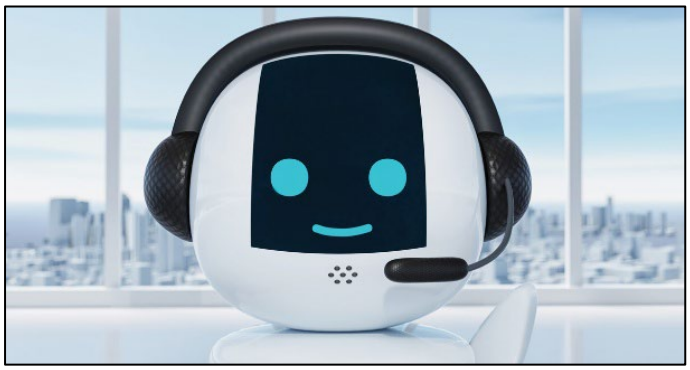
The use of Artificial Intelligence

A common topic was the growing use of "technology", Artificial Intelligence (AI), AI Bots

- We talked about **smart phones** and people who did not have access (**digital exclusion).**
- Phones **apps** need to be downloaded for parking, managing bills, grocery shopping.
- The use of supermarket apps or loyalty cards means those who are not members are **excluded** and cannot access 'bargains', cheaper prices, or promotions that are only available online.
- Difficult to make doctors' appointments and use **health care**.
- It is not just 'older people' who struggle with technology use - **all people can feel intimidated**. The speed at which technology is changing was highlighted, the skills needed as well as the anxieties and fears it could generate.
- It is sometimes felt as if every part of life now involves the **use of technology** or going online (e.g. banks, going out)
- People felt as though technology was being **forced upon them** without having a **choice** and yet not all people have smartphones or computers or are (or want to be) digitally able.

AI Chat Bot

Artificial intelligence was discussed and having to interact with AI bots and how skilled we are to use AI and various tools. At one Advisory Group meeting **an AI bot joined** our meeting which prompted a group debate around the ethics around this. The group discussed how it felt as if there was a loss of control over digital tools and what they were doing. There were concerns over AI bots replacing human contact and ethical concerns over what this meant. While AI may be useful there were fears that there would be mistakes, creativity would be lost, as well as issues of privacy and confidentiality being potentially compromised.





Here's a fun rap inspired by the Inclusive Involvement Advisory Group meeting and chat contributions on digital inclusion, AI bots, and community research and coproduced with Microsoft Copilot!

AI Rap - The Advisory Group Tried Using "AI"

We made comments on some of the AI strange choice of words, phrases and things it got wrong!

🎤 "Digital Real Talk" – Advisory Group Rap 🎤 Author: Co-Pilot. (Verse 1) 9.9.2025.

Yo, we logged on, said hello, no bots in sight,
Peter kicked it off, got the vibe just right.
Sally on the mic, with a plan so bold,
"Let's blog this meeting," yeah, this story's gold.

Amanda said CLAPS got some funding to grow,
Barnet met Lowestoft, still keeping the flow.
Partnerships alive, even when projects pause,
Community's strong, and that deserves applause.

(Chorus)
Digital divide, we're breaking it down,
From Yarmouth to Barnet, all over town.
AI bots creeping, but we're staying wise,
Keep the human touch, no tech disguise.

(Verse 2)
Shanice hit the stage with the Anchorage beat,
Older folks online, not always a treat.
Familiarisation, that's how trust is made,
Not just research, it's a people parade.
Focus groups sound like a test, that's real,
Let's call it a workshop, change how we feel.
Some scared of tech, ethics need to care,
Support is key, just being there.

(Bridge)
Speed of change, like Windows 11,
Updates dropping faster than ageing's rhythm.
Right to choose? Gotta go online,
But what if tech's not part of your design?
Designed by men, middle-class and white,
We need diverse minds to get it right.
Solution Focus, strength not stress,
Let's train with patience, not make a mess.

(Verse 3)
Gill spoke up for those losing sight,
Digital access should be a right.
Wordy sheets? Nah, let's simplify,
Use photos, diagrams, let understanding fly.
Carers Voice, Norfolk and Waveney crew,
Reach the sheltered, bring them through.
After COVID, some don't go out,
Let's meet them where they are, no doubt.

(Final Chorus)
Digital divide, we're breaking it down,
From Yarmouth to Barnet, all over town.
AI bots creeping, but we're staying wise,
Keep the human touch, no tech disguise.

Sunny also created a rap using AI shown below.

🎤 Inclusive Involvement Advisory Group Rap 🎤

(Verse 1)

Yo, we're the voices that rise, no disguise,

Breaking down walls, reaching for the skies.

From every background, every single lane,

We bring the unity, not just the name.

We advise, we uplift, we include,

No room for silence, no time for feud.

Equity's the rhythm, inclusion's the beat,

Together we stand, no one's obsolete.

(Chorus)

Inclusive minds, we're changin' the game,

Advisory crew, you remember the name.

Diverse by design, strong in our groove,

We make the world better with every move.

(Verse 2)

Ideas flowin' from every side,

We listen, we learn, we never divide.

Policy, progress, people first,

We quench injustice, we cure the thirst.

From boardrooms to classrooms, we ignite,

A future that's fair, bold, and bright.

We're not just talkin', we walk the walk,

Empowerin' voices, let the people talk.

(Chorus)

Inclusive minds, we're changin' the game,

Advisory crew, you remember the name.

Diverse by design, strong in our groove,

We make the world better with every move.

(Outro)

So here's to the group that's breakin' the mold,

Advising with heart, fearless and bold.

Inclusive Involvement, we rise above,

Powered by purpose, driven by love. 💥

"*This was a group activity and discussion of work led by public members that could only have happened in the constructive varied way it did because of all the trustful respectful relationship-building that happened over quite a long time. We were able to show this in the creative writing and activities produced on the day and in the times leading up to it. It was good to be able to thank each other properly - and with cake and rhythms!*"
Quote from Fiona Poland (talking about the face to face meeting and AI blog).

We also talked about Event Planning:

When inviting Public Contributors to an event think of what information would be helpful without overloading. It is suggested that short 'vital' information be given in the main text of the email with further detail attached. We made lots of suggestions:

- ✓ Contact name and phone number of someone able to support with event registration, digital access or anything else, and a person who can support on the day.
- ✓ Frequency of breaks (refreshments, diabetes, toilet breaks).
- ✓ Use of microphones, hearing loops/BSL interpreter, live captions.
- ✓ Any opportunities to feed into the event in another way? (before or afterwards)
- ✓ Is the event being recorded and available for those who cannot join?
- ✓ Can others attend the meeting? Are young children able to be present? Are those driving an invited person welcome to attend?
- ✓ Availability of a quiet room?
- ✓ What/where are the parking facilities? Spaces, charges, reservations, disabled access etc.
- ✓ If there are any opportunities for people to test technology before an online meeting?

- ✓ For live events consider if slides be shared beforehand? Might need to prepare 2 sets for this to remove anything that is only for the live delivery ('gags', answers etc).
- ✓ Consider if carers and the cared for are placed in same groups as they might not feel able to express themselves fully.

When public contributors are asked to attend any ARC events or other activities make sure information about support, payment and expenses is included

Appendix: **The Detail**

Terms of reference (agreed in 2023)

Advisory Group for the Inclusive Involvement in Research

Purpose of the group

- To provide constructive comments on the work of researchers within the Inclusive Involvement in Research theme. This could include thoughts around the types of research planned, the community groups we are working with and how, and progress towards meeting planned targets.
- To support the researchers in the theme to connect with local community partners.

Group Members

The Patient and Public Involvement and Engagement advisory group for the theme Inclusive Involvement in Research is made up of at least four public partners from East of England and four academic staff within the Inclusive Involvement in Research theme representing the four universities

Members are free to leave the group at any time, without giving reason. The group will look to extend the expertise on the group as funding becomes available.

How we will work

Members of the advisory group will be able to freely share their experiential knowledge to help researchers within the Inclusive Involvement Theme, to develop improved practices of inclusion and improved engagement with communities.

Members will also be able to develop knowledge or skills which are helpful for them in their work or life.

Meetings

The group will meet at least four times a year. Meetings will take place virtually. This will be reviewed every 6 months.

A draft agenda and any documents will be sent (via email or post depending upon the member's preference) to the group at least a week before the meeting date. Members will be invited to add items to the agenda either before or during the meeting.

Materials will be produced in an accessible format and the offer of pre-meeting will be made should members require this in order to participate fully.

Each meeting will have a Chair and the role of Chair will be reviewed every 12 months to provide others with the opportunity to develop these skills if they wish.

The group will run until September 2024 when the funding for the Applied research Collaboration comes to an end. It is hoped partnerships can continue in other forms after this date. (This was then extended for 18 months in ARC extension until March 2026).

The aims of the Inclusive Involvement in Research Theme

One of the six research themes in ARC EoE is Inclusive Involvement in Research in ARC.

"The core value for our inclusive involvement is to reach out to local communities, build relationships, identify research and research partners"

Groups that our theme strive to work with are people with long-term health conditions, disabled people, people with mental distress, young people, those who experience health inequalities and who may be discriminated against in our society.

We aim to:

- Find best ways to meet with others so that we always include people in communities that do not usually have opportunities to be involved in research
- Work together (co-design) with people in communities to plan, carry out, share and use research
- To especially focus our activities and support on the four communities who we know experience severe disadvantages in relation to health and social care needs: Great Yarmouth and Waveney, Peterborough and the Fenlands, Stevenage and Thurrock
- Identify research topics and use methods which are accessible to and inclusive of all people in the East of England.

Advisory Group Meetings Dates (2021-2026)

Online - a total of 17.

2021	13th July, 29th September
2022	17th January, 9th May, 6th September, 6th December
2023	28th March, 13th June, 19th September, 21st November
2024	13th February, 5th May, 10th September
2025	4th March, 3rd June, 9th September, 2nd December

Face to Face meeting to come together, celebrate and reflect (with option to join online)

2026	3rd March

Note

In creating this summary, we had lots of discussions about how to make the report more accessible, and who it is was aimed at. We hope that other groups will be interested to read and can learn from our experiences.

One of the suggested ways of illustrating our learning was to use a jigsaw puzzle image. This was discouraged, for more reading please see here: https://theconversation.com/why-the-autism-jigsaw-puzzle-piece-is-such-a-problematic-symbol-253807

Thank you!

We want to thank all the public members, services users, customers and public involvement contributors for all their input, guidance, feedback to our IIR theme over the past six years. Many thanks to our Chair Peter Beresford. It has been invaluable working with you. There will be opportunities to work together again in ARC2, but we wanted to recognise the work we have done together.



Elspeth Mathie and Sunny.



Peter Beresford (Chair)

A description of the NIHR ARC East of England Workstream is available here: Research Inclusion Workstream