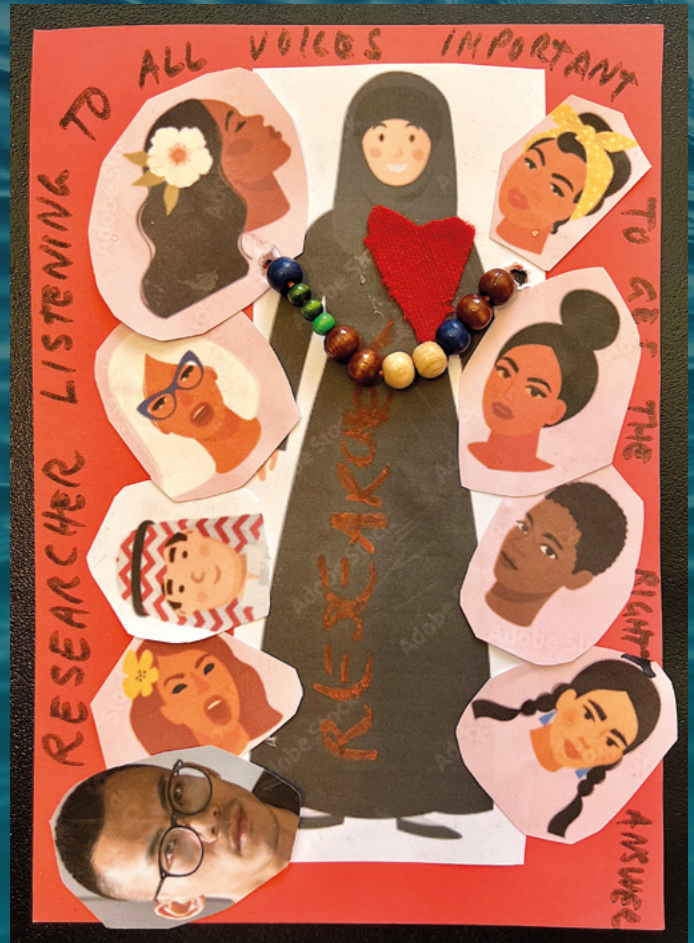


“ Talking Trials ”

Including the voices of people from minority ethnic backgrounds in health research



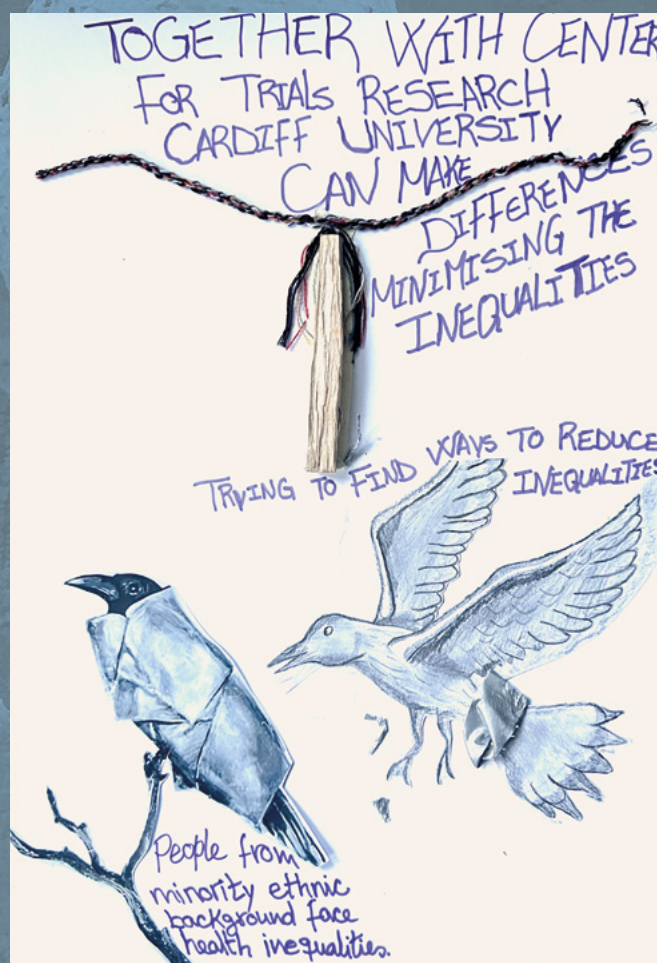
About the Talking Trials Project

People from minority ethnic communities face significant health inequalities but are under-represented in health research designed to address these inequalities.

The Talking Trials project was funded by the UK Research Innovation (UKRI) Rethinking public dialogue fund in collaboration with the Royal Society of Arts (RSA), to engage people from minority ethnic backgrounds in a rigorous and in-depth discussion about inclusive health research.

Based at the Centre for Trials Research (CTR), Cardiff University, the project brought together a group of co-researchers from diverse ethnic backgrounds to discuss health research and provide well-considered recommendations to clinical trial stakeholders to facilitate inclusive engagement and involvement in health research.

Drawing on the principles of deliberative democracy and participatory art methodology, we aimed to find out more about the views of people from minority ethnic communities on health research as well as pioneer our approach with a seldom-heard population. We used participatory art methods to deliver further learning and to provide additional communication support for participants experiencing language barriers.



Our key question:

How can people from diverse minority ethnic backgrounds influence health research in terms of both what and how this research is done?

Our project objectives:

- Provide an opportunity for people from diverse minority ethnic backgrounds to participate meaningfully in a dialogue about clinical trials research
- Develop an innovative approach addressing involvement, engagement and participation of under-represented communities in research
- Evaluate and produce shareable resources
- Generate recommendations facilitating inclusive public engagement and involvement in health research
- Provide insights into the views of people from minority ethnic backgrounds on health research and challenge barriers to their involvement in research as participants and collaborators
- Challenge structural barriers that limit opportunities for inclusion in research



Talking Trials recommendations for clinical trials practice

The Talking Trials group produced 11 well-considered recommendations for the health research community which outlined how people from minority ethnic communities can influence research development, delivery and dissemination:

Organisational cultural practices – establishing trust

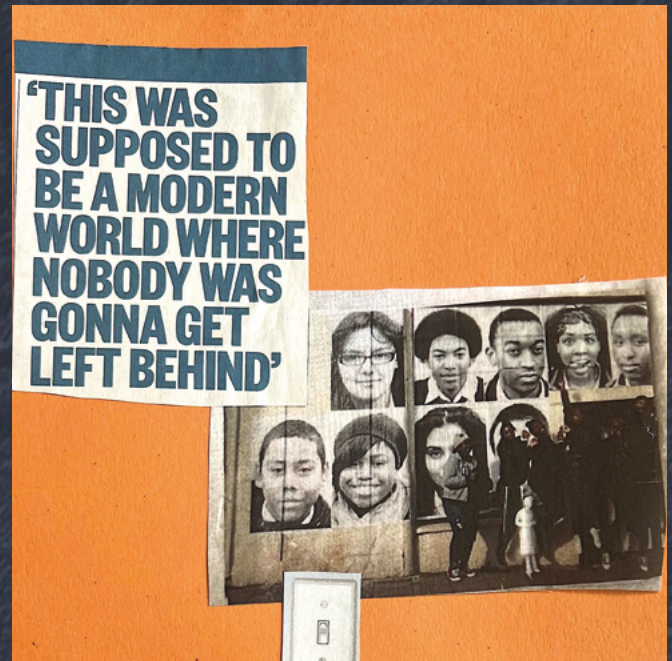
- 1** Researchers should establish a mutually beneficial relationship with community organizations that work with minority ethnic communities
- 2** Clinical Trial Units should establish a diverse community advisory panel for ongoing input into the research process

Recruitment and training – developing awareness

- 3** Cultural awareness training for researchers
- 4** Research teams should be more diverse to represent surrounding communities

Research practice

- 5** Collect data on ethnicity from trial participants
- 6** Eligibility criteria should be equally open to all and people should not be excluded because of language
- 7** Recruitment needs to be fair, flexible and inclusive
- 8** Study documents should be developed with inclusion in mind and alternative languages made available
- 9** Individualized approach to consent: people's needs, values and beliefs need to be considered during the consent process
- 10** A diverse range of communication channels should be considered and used
- 11** Celebrating diversity and developing a culture of inclusion is a continuous process of improvement, not a one-off initiative. These recommendations should be revisited every year.



Overarching methodological findings

- The participatory co-production workshops and the use of community connectors helped to redress power dynamics between researchers and people from minority ethnic backgrounds.
- The co-researchers reported increased confidence, empowerment and knowledge of health research following their involvement in the project. They felt confident and able to voice their opinion on health research both through word and imagery, reflecting on what matters to them and how this should be reported back to the research community.
- The trust developed between the group was integral to the group sharing and reflecting on their own experiences of health care and what is important to them.
- The participatory art element served to deepen enquiry and foster group cohesion.
- Projects like this can diversify the research process itself as some of our co-researchers have commenced lay research partner roles within CTR and a lay advisory group is in development.
- Close partnership with a third sector organisation was instrumental in forming a group of co-researchers from minority ethnic backgrounds.



Project planning and design

Partnership with the community organisation

Collaborating with third sector organisations is an effective way for academic researchers to make research more accessible. The South Riverside Community Development Centre (SRCDC), serving the most ethnically diverse ward in Wales, is a charitable organisation with over 40 years' experience of working within a multi-ethnic community to alleviate the effects of poverty, promote social cohesion and self-advocacy. The organisation has strong intergenerational links with communities and other third sector organisations.

SRCDC supported the project by providing the following:

- 2 Project workers to join the project delivery group, both of whom had experience of working with people from minority backgrounds and of working with and providing an approachable environment for people who don't speak English as a first language.
- Recruitment support
- Access to existing community-based classes and groups for the community connectors' sessions
- Mobile crèche facility to accommodate childcare needs of our co-researchers.
- Promotional leaflet translation into seven community languages
- Community room

Costs for the above resources were covered by the project budget and administration fee was also included to cover the costs of supporting co-researchers' recruitment, advertising the project via their community links.

Formation of project delivery group

A project delivery group was formed, consisting of two CTR project leads, an artist with a strong background in participatory arts methodologies and two SRCDC project workers.

The group meetings focused on co-researchers group recruitment strategies and planned the content and delivery of the workshop series. One of the group meetings was also used by the artist to pilot her prospective participatory arts approaches and highlight the research potential of creative collaboration.

Recruiting & establishing the co-researcher group

SRCDC's extensive expertise in engaging with ethnic minority groups was utilized as the project was advertised through their community existing links and via word of mouth. 15 residents of Riverside and surrounding areas of Cardiff were recruited as co-researchers to participate.

All co-researchers were compensated for their time spent on the projects via a honorarium of £25 per hour as per the current National Institute for Health Research guidance for public involvement and engagement.



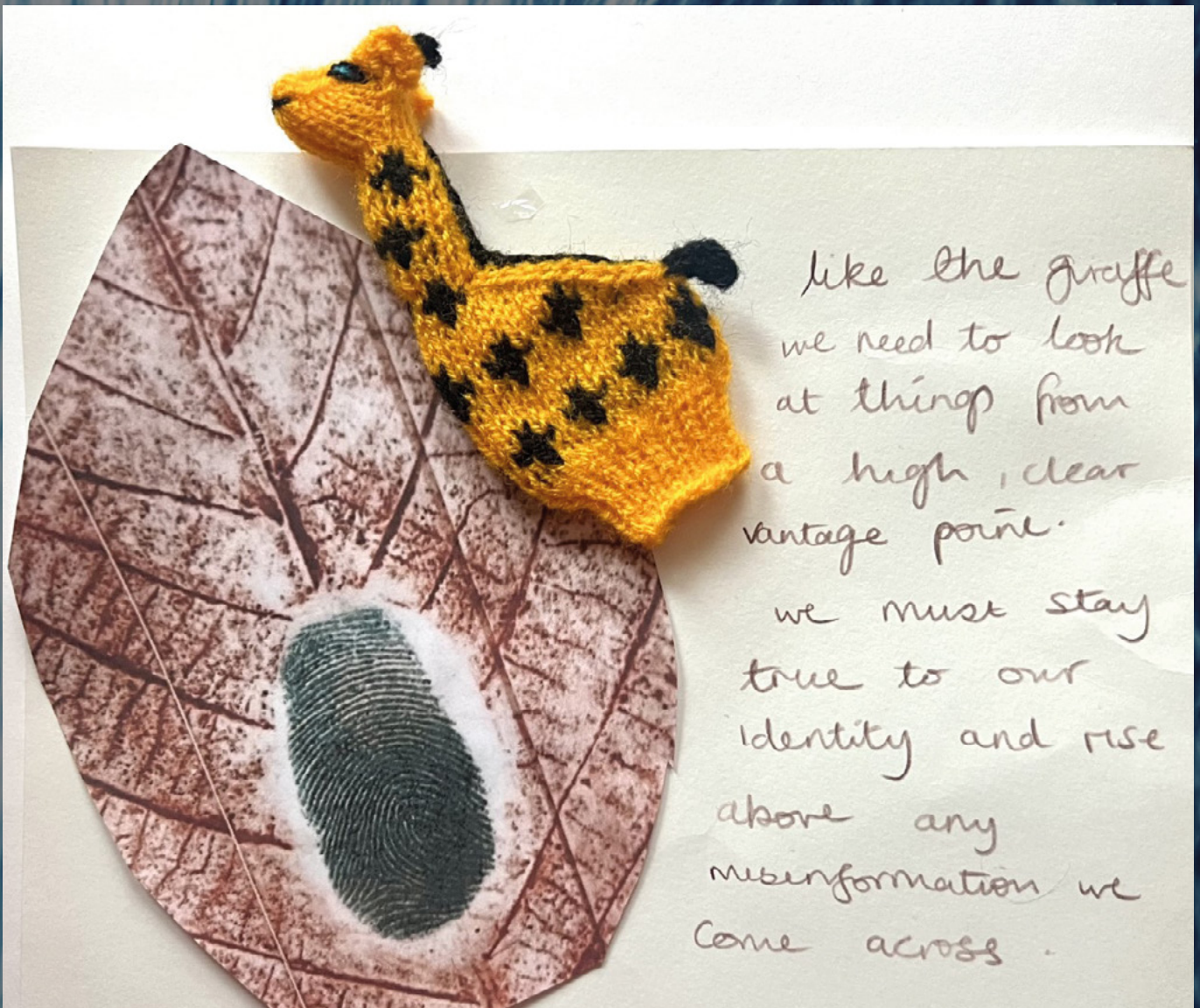
Project activities & workshops

The workshops were supported by a variety of arts materials and resources throughout the project. The co-researchers received a core package of materials designed to support a wide variety of creative enquiry including a journal, pencils, paint, textiles, contemporary collage materials, fixings and small objects/figures. As the workshops progressed, further current graphic/animation references were supplied to co-researchers to support particular interests, social/cultural context and extend the creative process.



The group met for eight co-production workshops drawing on the participatory democracy approach. Three preparatory workshops were delivered to build up the knowledge, confidence and trusting relationships as well as develop key deliberation skills of our co-researchers. Five subsequent deliberation meetings were held where good quality evidence was used to support deliberation.





like the giraffe
we need to look
at things from
a high, clear
vantage point.
we must stay
true to our
identity and rise
above any
misinformation we
come across.

Following recruitment, the project team delivered preparatory workshops which covered the following topics on the following topics:

- What is health research?
- What are clinical trials?
- Developing communication and questioning skills
- Good and bad evidence and the role of research
- The research cycle
- Public involvement in research

These preparatory workshops helped to reinforce knowledge, confidence and skills, with participatory art methodology enabling further learning and providing additional communication support for participants experiencing language barriers. Following the preparatory workshops, discussion centered on how people from minority ethnic backgrounds can influence trials research, including what is researched and how. This led on to the group proposing their own set of key recommendations on how to facilitate inclusive engagement and involvement in health research.

Workshop delivery



The Talking Trials workshops took place over both zoom and face to face sessions over 6 months. Both the project team and the co-researchers reflected that the in-person meetings proved more fruitful both in terms of promoting discussion and also a sense of group identity. An additional final deliberation workshop was arranged to allow for reflection on the project, observing and sharing themes which emerged strongly through individual and collaborative creative pieces, and a sense check of the group's final recommendations.

The workshops all followed a similar structure. Each meeting had clear stated aims, a mix of discussion, reflection through art and an opportunity for consideration for how the conversation would contribute to the final set of recommendations. Several co-researchers further developed ideas between workshops then brought along completed or new artworks to the next session and the sketchbooks proved to be a useful resource as a creative journal.

Community connectors

Utilising an ‘in-reach/out-reach’ approach, our project artist worked with four co-researchers to become ‘community connectors’. Together they each developed a session – including choices of arts methods/materials - to present their learning and journey through the project to other members of minority communities via the SRCDC’s ongoing community groups (ESOL English class, ‘Women’s Chat’ community group, young people’s group, SRCDC digital literacy class).

This proved to be a particularly important element of the process helping to further the reach of the project through gaining access to communities invisible from health research - as seen in the following quote from one of the community connectors:

“It was a great opportunity for me to reflect on what I have learnt and my journey. And all of the things I have learned I took to my group in the community. And all of the things I had to break down even more and think about how I could communicate it to their level of understanding and language. To break down the information in a very simple way so they can absorb it from the beginning. And I know their needs and what they want and what they could have. And I could help them feel more secure and a friendly environment and talk easily with each other”.



Wider Community Engagement



Art produced by the co-researchers formed the basis of a series of 10 panels curated and designed by the project artist, featuring contributions from every member of the group. We utilised this exhibition for further wider community engagement at various community events (Riverside Festival, Eid celebration event), where these panels provided a forum for further discussions about clinical trials with other members of the Riverside community. We also provided a space for children and their families to make use of similar materials to those that had been used in the Talking Trials workshops, allowing them to create their own pieces of art.

Research Ethics

Ethical approval from Cardiff University was obtained for the purpose of evaluation and inclusion of co-researcher's own words in their reflection on the process.

Acknowledgements

The two lead researchers behind this project are Martina Svobodova and Dr Nina Jacob, both researchers at the Centre for Trial Research, Cardiff University in collaboration with Dr Catherine Lamont-Robinson, an artist/researcher based at Bristol Medical School.

We would also like to thank the many people who supported the project including expert speakers (Dr Kim Smallman, Farzana Mohammed, Dr Shoba Dawson) and SRCDC staff (Allan Herbert, Mashmooma Din).

Finally, we would like to thank the UK Research Innovation (UKRI) for funding this project.

We would like to thank all the members of the Talking Trials Co-researchers for their commitment and contributions towards making this project a success:

Arafa Ali
Ayesha Mita
Aysha H Ilias
Darran Kaur
Dilwinder Kaur-landa
Hind Osman
Islah Hamad
Kense Hayan
Lamiaa Abdelhamid
Mariama Nelida Gomes Correia
Rena Zhang
Rossana Canu
Saleema Bibi
Samar Iqbal
Sarra Ibrahim
Sudi Bandyopadhyay

