

Diversity and inclusivity in public involvement: Considerations for designing authentic involvement across your study lifecycle

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Research

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- ⌘ The standards & principles for public involvement
- ⌘ Public involvement support
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What is public involvement?

NHS Health Research Authority (2020) defines public involvement in research as research being carried out ‘with’ or ‘by’ members of the public rather than ‘to’, ‘about’ or ‘for’ them.

Involvement	Participation
Where members of the public are actively involved in research projects and in research organisations. Advising during several stages of the research cycle	Where people take part in a research study. E.g. People being recruited to a clinical trial or other research study to take part in the research.
Engagement	
Public engagement is telling people about your research, why it is important, what it found out and the impact and implications of the results.	
<p>Public involvement & qualitative research</p> <p>Difference between the two – you will require ethical approval for qualitative research. Public involvement you do not.</p>	

Four principles for meaningful public involvement

Principle 1: Involve the right people – people with relevant lived experience (patients, services users, or carers)

Principle 2: Involve enough people – to provide a reasonable breadth and depth of views (depends on the scope of the study, but always more than 1 person)

Principle 3: Involve those people enough – feasible, productive, and appropriate to the research, and at the right times.

Principle 4: Describe how it helps – the impact of public contributors, why their experience is relevant and how their involvement will help



How we work

WALES
vector | eps.10



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opportunities**

Support you can access for public involvement



PUBLIC
INVOLVEMENT
OPPORTUNITIES



ENABLING
INVOLVEMENT FUND

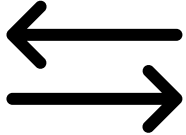
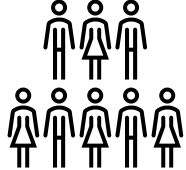




TRAINING AND
GUIDANCE



PUBLIC
INVOLVEMENT
FORUM

Strategies to involving under-served community groups

<p>Push not pull Go to where groups congregate</p> 	<p>User experience design Make it easy for groups to participate – what needs to change?</p> 
<p>Influencer engagement Link with community leaders</p> 	<p>Trusted intermediary engagement Partner with other organisations</p> 

Identifying under-served communities

It is important to know and map who you need to reach. Be clear about who you want to talk to and get to know your different audiences. Some key considerations to be aware of:

Build Trust

Find a form of involvement that works for different groups

Strive for representation

Go beyond digital engagement

Learn about the groups Make it beneficial to community groups

Feedback



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Talking Trials: participatory approaches to creating community dialogue

Martina Svobodova & Nina Jacob



Talking Trials Phase 1

- 8 3 co-production workshops during the spring and summer 2021 using participatory arts methodologies
- 8 We introduced clinical trials, what they are and why they are important. We explored perceptions and views on clinical trials amongst the group.
- 8 In August 2021 we took the exhibition at the Riverside Festival where we had the opportunity to engage with the wider Riverside community (close to 200 people visited our tent)



Talking Trials Phase 1

What we learnt in phase 1:

- ⌘ Partnership with the South Riverside Community Development Centre (SRCDC) to establish a project delivery group essential for co-researcher recruitment
- ⌘ Participatory art methodologies proved useful in overcoming any language barriers and helped cement the group as a cohesive unit from the outset
- ⌘ The focus on co-production helped foster a group of individuals new to research to become involved as co-researchers (rather than research participants) and democratise research
- ⌘ Projects like Talking Trials can help diversify the research process itself as two of our co-researchers have commenced lay research partner roles within the Centre for Trials Research.



“Talking Trials” CONVERSATIONS ACROSS COMMUNITIES 



LIFE IS LIFE CAN ZOOM BY
MEDICINE SAVES LIVES

For research to improve the health of our communities, that research needs to represent the interests of everyone in them. To achieve this, we need to start talking to communities traditionally excluded from research and more importantly, start listening to what they say.


In the summer of 2021 we held a series of workshops with a group of Riverside residents from minority ethnic backgrounds. We discussed clinical trials – what they are and why they are important. We explored perceptions and views on clinical trials amongst the group, and each of us produced several items of artwork alongside these conversations. These pieces of artwork have been incorporated into an exhibition from artist-facilitator Catherine Lamont-Robinson. Quotes and pieces from the group have been included to reflect the themes identified.

Sarah Bridges and Martina Svobodova
Talking Trials Lead Researchers
Centre for Trials Research



Keeping the patient at the heart of the research

“Talking Trials” WHAT IS COMMUNITY? 



I see my family sharing and gathering a support network


Love and genuine care and concern for others



JOURNEY
METHINK - THINKERS - M - TO - CHANGE BODIES


As a community we have our own shells around us...


... our own mental blocks



THE STRONGER OF EVERY THING IS ONLY AS STRONG AS THE WEAKEST LINKS IN THE CHAIN

PROBABILITY OF THE PATIENT TO BE HEARD


“Talking Trials” A STEP INTO CLINICAL TRIALS 



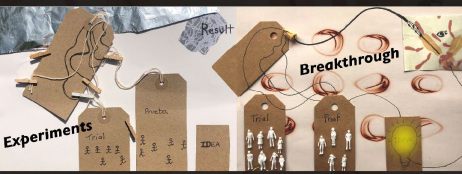
Your body is a unique laboratory

Yet all bodies are connected

All will not flow, until the hearts and souls of all are engaged on the journey of the clinical trial



Brave to enter the unknown



Experiments **Breakthrough**

Talking Trials

FEARS AND HOPES



Knowing what the trial helps makes everything more meaningful

She has a different eye colour
She has a really rare condition

She has excellent eye colour
She has really rare condition

We need lots of detail, the ins and outs - pros and cons - we have to understand EVERYTHING

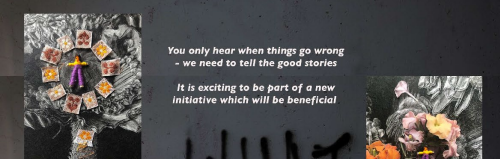
Side-effects... everyBODY is different

STAY connected

No one really knowing the risks and benefits

You 100% need to know you will be taken care of

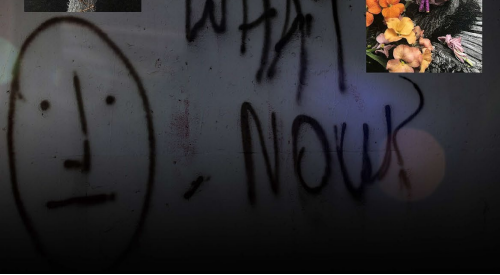
You need to know people to contact during and after the trial is complete



You only hear when things go wrong - we need to tell the good stories


It is exciting to be part of a new initiative which will be beneficial

WHAT NOW



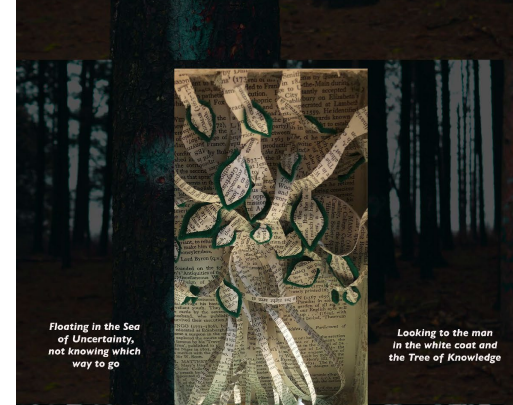
Talking Trials

THE HEAD AND THE HEART



A man in two worlds "Do's and Don'ts"

Thinking so hard, on an island



Floating in the Sea of Uncertainty, not knowing which way to go

Looking to the man in the white coat and the Tree of Knowledge




This represents my anxiousness about a Clinical Trial, I'm having a sleepless night

I feel like my mind and body are disconnected, remembering the birdsong in the morning and the sunrise helps me to do this

Talking Trials

WE NEED TO TALK




Although we are all different, our fears, phobias and basic emotions are all the same

We need to feel safe and confident that our needs are being met

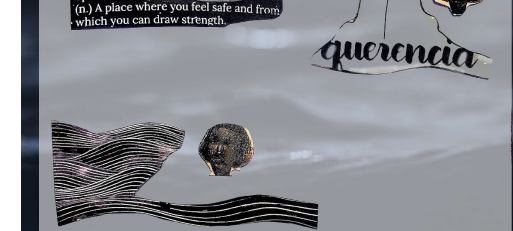
We can miss the small details

We need to talk!



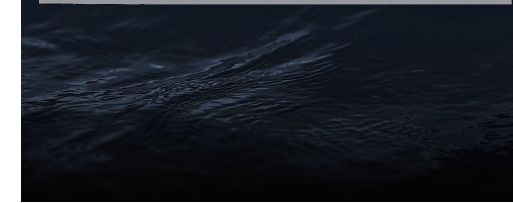
Building trust Respecting individuality

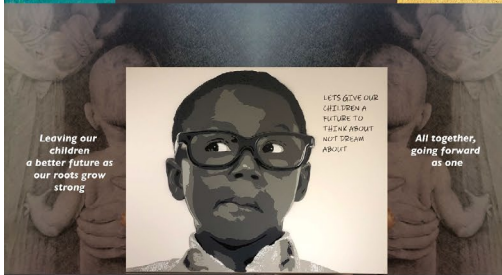
Relying on the doctor to explain and share trial information



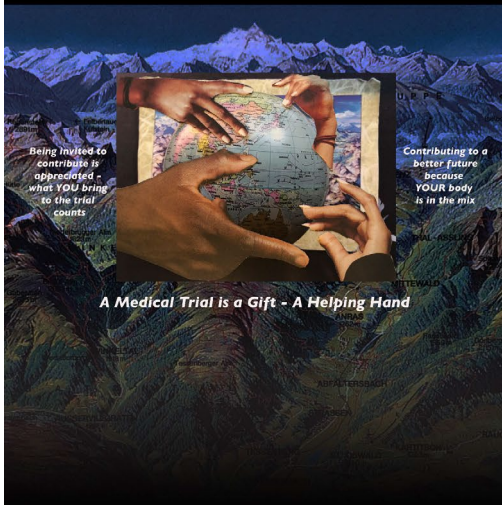
Spanish (n.) A place where you feel safe and from which you can draw strength.

querencia





The different branches represent the different people and cultures



Special thanks and appreciation to all the Talking Trials co-researchers

- | | |
|---|---|
| <p>Arafa Ali
Aysha Mita
Saleema Bibi
Nasra Ahmed
Mamadu Saliu Djalo
Sudipta Bandyopadhyay</p> | <p>Filomeno Fernandes Games Cuino
Santa Daba
Mariama Neïda Games Correia
Fatima Mussa Abdelmoula Mahmoud
Rossana Canu
Alka Horne
Kenise Hayan</p> |
|---|---|

We would also like to thank those who helped the project to happen

- | | |
|---|---|
| <p>Allan Herbert
Mashmooma Din
Sarra Ibrahim
Jim Fitzgibbon
Nick Lewis
Carl Smith</p> | <p>Julia Townson
Carl Phillips
South Riverside Community
Development Centre
The River Music Project</p> |
|---|---|

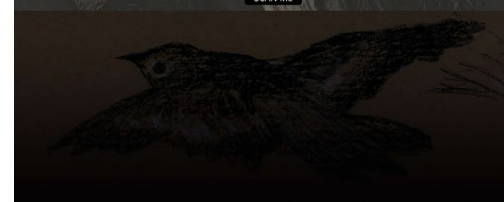
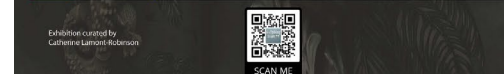
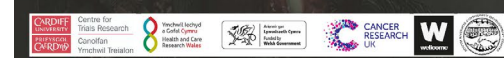
Sarah Bridges
Martina Svobodova



Talking Trials Lead Researchers
Centre for Trials Research

Artists whose works have inspired co-researchers

- | | | |
|---|--|--|
| <p>Kwami Dabene - <i>Fifa and Quercia</i>
https://www.kwamidabene.com/portfolio/wotr-wonderful-words</p> | <p>Jan D'oh Bristol Street Artist
<i>Future To Think About</i>
http://www.jan-doh.co.uk</p> | <p>Oshi Weorasinghe - <i>Experience, Impression, Knowledge, Growth</i>
https://outofourheads.net</p> |
| <p>Carolyn Eaton - <i>Dorset Moon</i>
https://www.instagram.com/carolyn.eaton (Luna Jarous Project)</p> | <p>Chiðona Nnoli - <i>Family</i>
http://www.nnle.co</p> | <p>X-Fiving - <i>Dujiangyan Zhongshuge Library Project</i> @xifivingart
Photographer: Shao Feng</p> |
| | <p>Esti Igwelesob - <i>A Portrait in Time</i>
https://outofourheads.net</p> | <p>Jan Connors - <i>Heartfelt Exhibition Bristol Community Arts Project</i></p> |
- (selected photographic backgrounds from <https://outofourheads.net>)





“I have been involved with the Talking Trials project during the pandemic of COVID-19. It was first time in my entire life to be involved actively talking about medical trials. It has given me a depth insight about what is involved and how community members can have their say and be part of a bigger picture. I find the research project very useful, interesting and rewarding in terms of how the whole process worked. I have been asked if I would like to become a research partner for another study in the Centre for Trials Research. I am delighted to have this opportunity and be able to give my opinion and ideas which may represent the BME communities in Cardiff.”

Mashmooma Din

Project worker, South Riverside Community Development Centre

Research Partner, Talking Trials and Panoramic-PEP studies



“In 2012, my daughter was born and diagnosed with Tetralogy of Fallots (ToF), a congenital heart condition. I am very keen to improve the outcome of families going through a similar phase, by sharing my observations and experiences. So as part of Talking Trials, I was delighted to contribute to discussions on how more people from minority ethnic communities could be encouraged to join clinical trials. I found the discussions very interesting and rewarding. It was exciting to learn how people perceive trials, the hinderances and issues like trust and impact of the community that influence decision making in an individual. I especially enjoyed the concept of people expressing themselves through the medium of art.

I have been recently invited to join the Panoramic PEP trial as a Research Partner, which is another exciting initiative. It will be a steep learning curve, but I am delighted to be able to get involved in this way.”

Sudipta Bandyopadhyay

Research Partner, Talking Trials and Panoramic-PEP studies



Our next steps

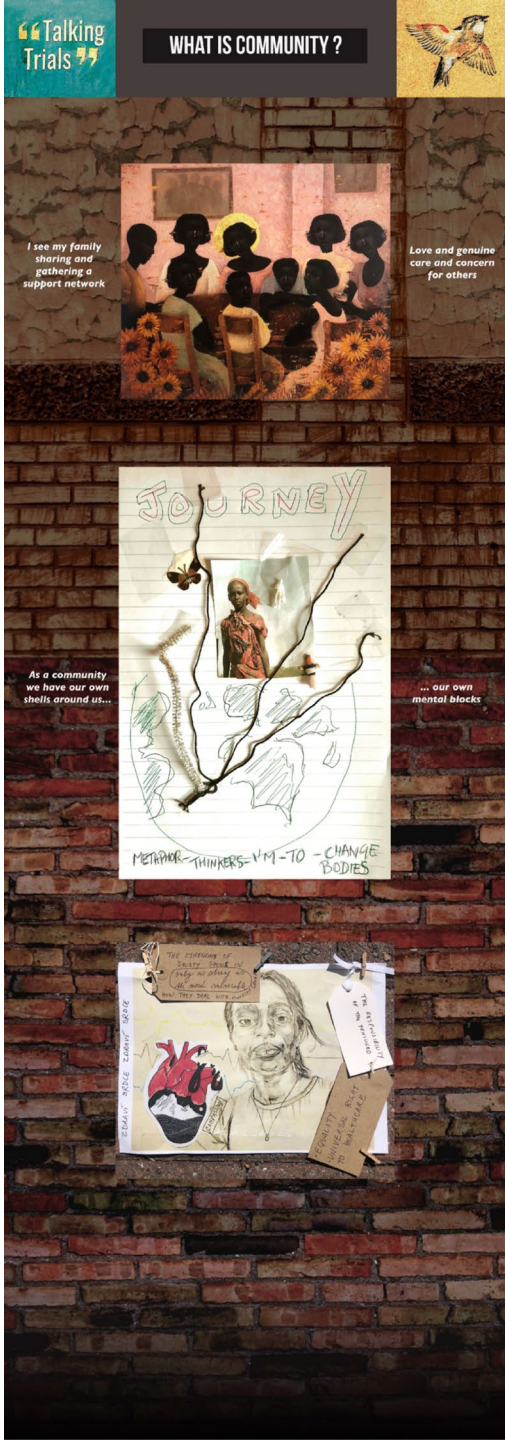
- ⌘ Paper to be submitted to Health Expectations Wiley journal
- ⌘ Further funding from the 'Rethinking public Dialogue UKRI experimentation fund' run in partnership with RSA (Royal Society for Arts, manufactures and commerce)
- ⌘ The 9 months pilot project started October 2022



Talking Trials pilot design

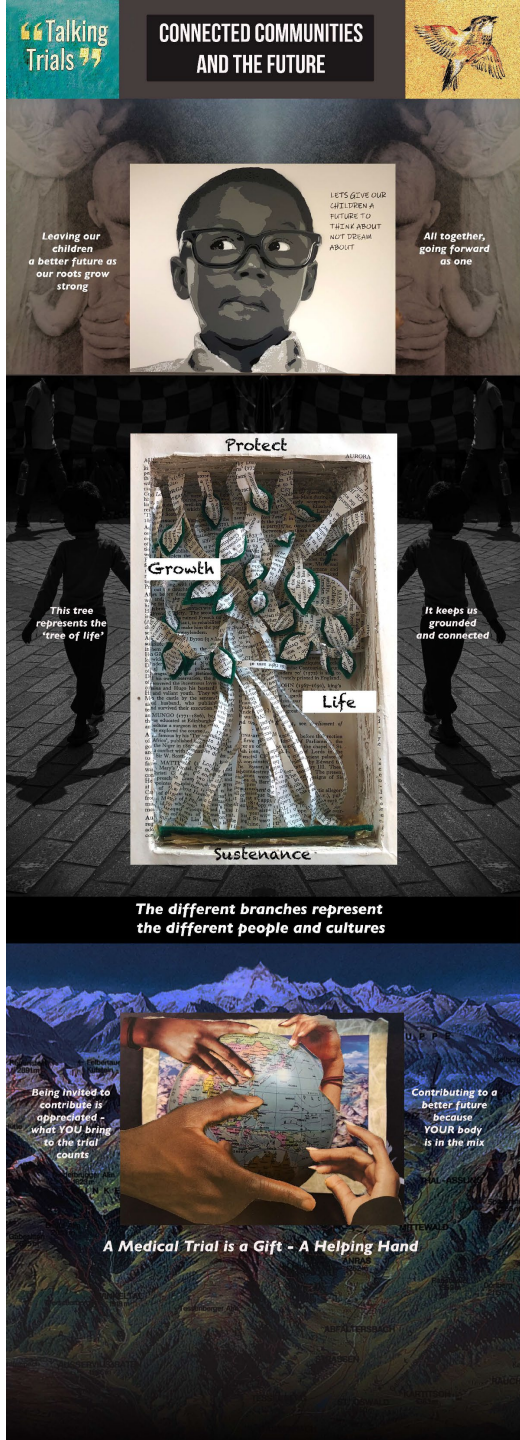
Hypothesis:

A deliberative democratic approach to public dialogue combined with participatory art methodologies can provide clinical trials units with practical recommendations to address underrepresentation of people from minority ethnic communities in clinical trials and change practices within the clinical trials unit.



Talking Trials pilot design

- Further developing our **partnership with SRCDC** to form a **co-researcher group**
- **8 co-production workshops** (Learning Stage - 3 meetings, Deliberation Stage – 5 meetings) with the use of participatory arts
- **Community Connectors** (our artist will work with some of the co-researchers to develop a session content to allow them to present their learning and journey through the project to other community groups via the SRCDC ongoing community groups)
- **Co-researchers will present recommendations** on how to make research more inclusive for people from minority ethnic communities' perspective to the CTR PPI&E Hub, the wider CTR community and stakeholders within Health and Care Research Wales



Talking Trials 2 evaluation

The study will adopt a mixed methods approach using data from various sources. The following evaluation methods will be used:

- **Ethnographic data** will be produced to gain a deeper understanding on the purpose, relevance and benefits of the project as seen by different stakeholders. This will be achieved through **qualitative interviews with the co-researchers & observations of all meetings**
- Co-researchers group **evaluation meeting**
- Talking Trials project delivery group members reflections

Include Roadmap

4 key points:

- ⌘ Ensure eligibility criteria and recruitment pathway do not limit participation in ways you do not intend.
- ⌘ Make sure your trial materials are developed with inclusion in mind.
- ⌘ Ensure staff are culturally competent.
- ⌘ Build trusting partnerships with community organisations that work with ethnic minority groups.

THANK
YOU!

For more information and support – please email us on
research-involvement@wales.nhs.uk