



Developing a flexible approach to Involvement.

Meeting the needs of patients, carers, patients, health providers academics and the whole research community



Chris White

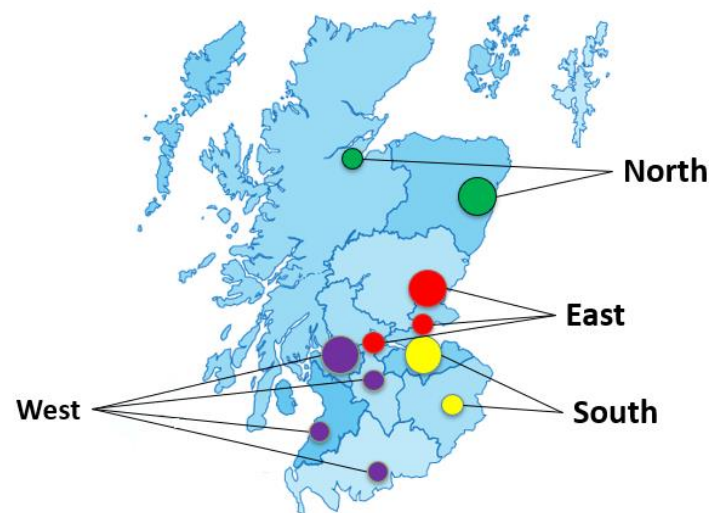
Network Peer Involvement Officer



About the Network:

The **NRS Mental Health Research Network** was established by the Chief Scientists Office in 2009 and aims to:

- Increase the amount of high-quality clinical Mental Health research in Scotland
- Support a wide range of both academic and commercial studies
- Increase the number of people participating in Mental Health research studies in Scotland.



Our PPIE Team:



Chris White, Network Peer Involvement Worker:

Building links between the research community, people with a lived experience of mental health problems and our community-based stakeholders.



•Suzy Syrett, Network Peer Researcher:

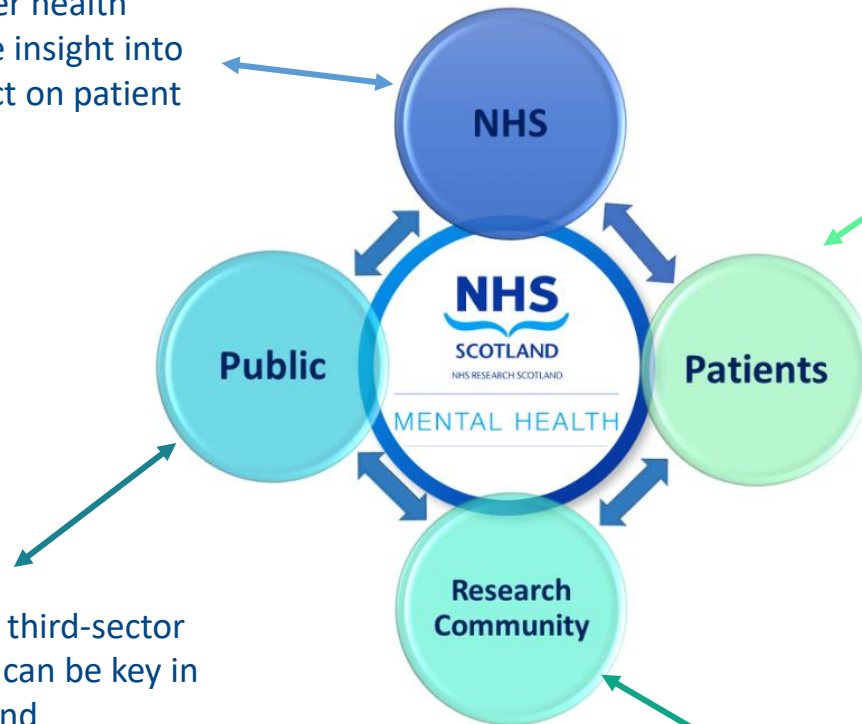
•Combining lived experience and research experience to enhancing the running and rigour of trials and optimise opportunities for involvement.



•Catherine Deith: Network Manager

Who is it we want to engage with?

Doctors, nurses, and other health professionals can provide insight into conditions and the impact on patient lives.



Patients and carers have expert insight in their conditions which can help inform research creating better designed studies.

Public interest groups, third-sector orgs, advocacy groups can be key in supporting research and disseminating

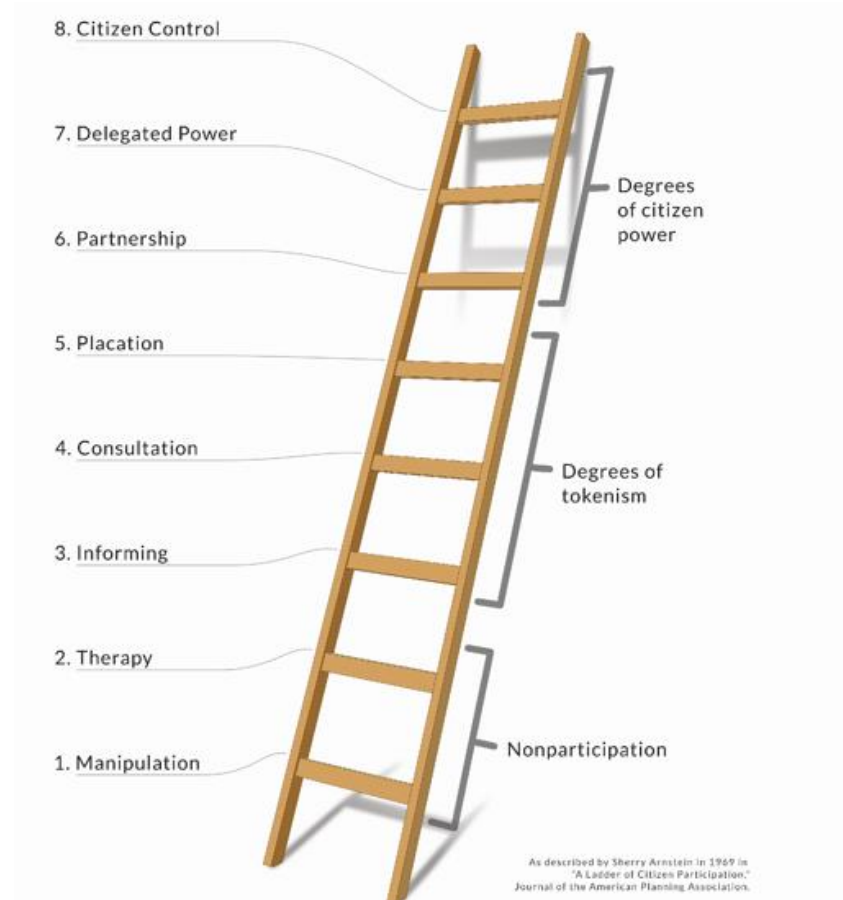
Research professionals are key in designing, conducting, and analyzing clinical studies, but can need support to develop good involvement.

Arnstien's ladder of participation

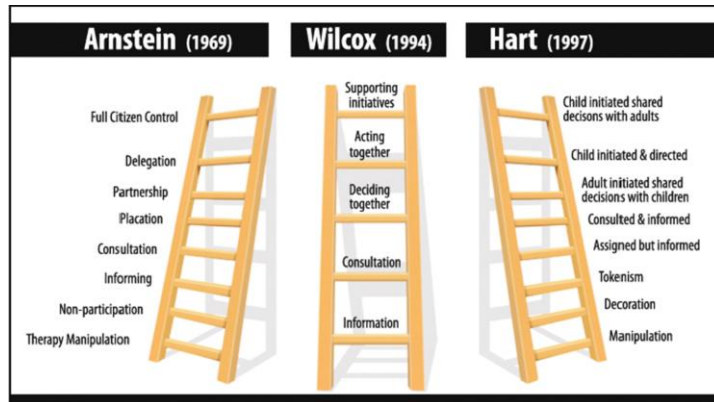
Developed in 1969, Arnstein's ladder is one model that health researches have used to think about participation

It can be useful in identify and understanding power imbalances and thinking about different types of participation.

But it has limitations: its linear hierarchy; perceptions about starting at the bottom rung and progressing upwards; problematic assumptions around language.

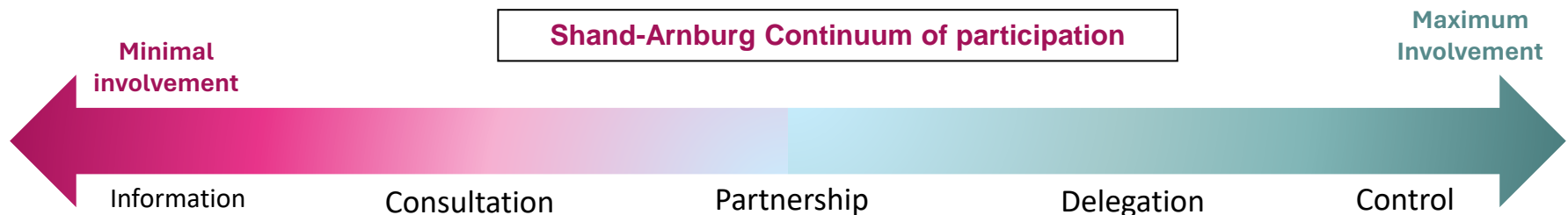


This ladder metaphor has been revised and adapted over the years. similar to Arnstein.



Rahman, A., Nawaz, S., Khan, E. *et al.*
 Nothing about us, without us: is for us.
Res Involv Engagem 8, 39 (2022).

Other models like Shand-Arnburg are more linear but are not that different.

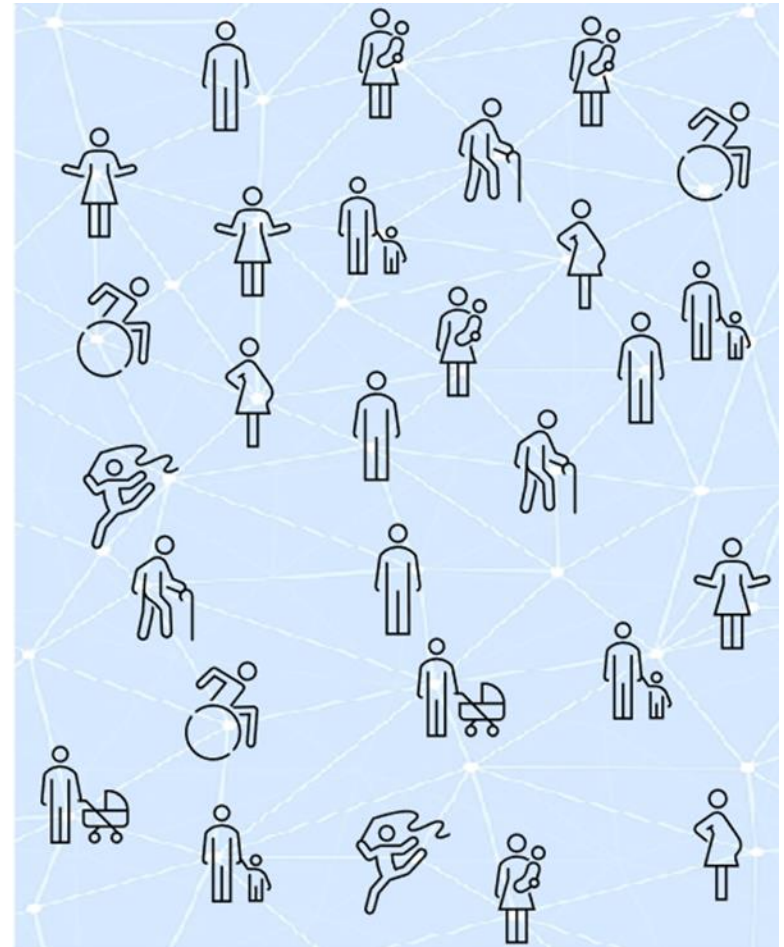


Developing a more flexible approach?

Not only do we need to think about the types of participation, but we also need to think about how involved a person wants to or is able to be.

Attrition and turnover in a PPIE members can be a problem.

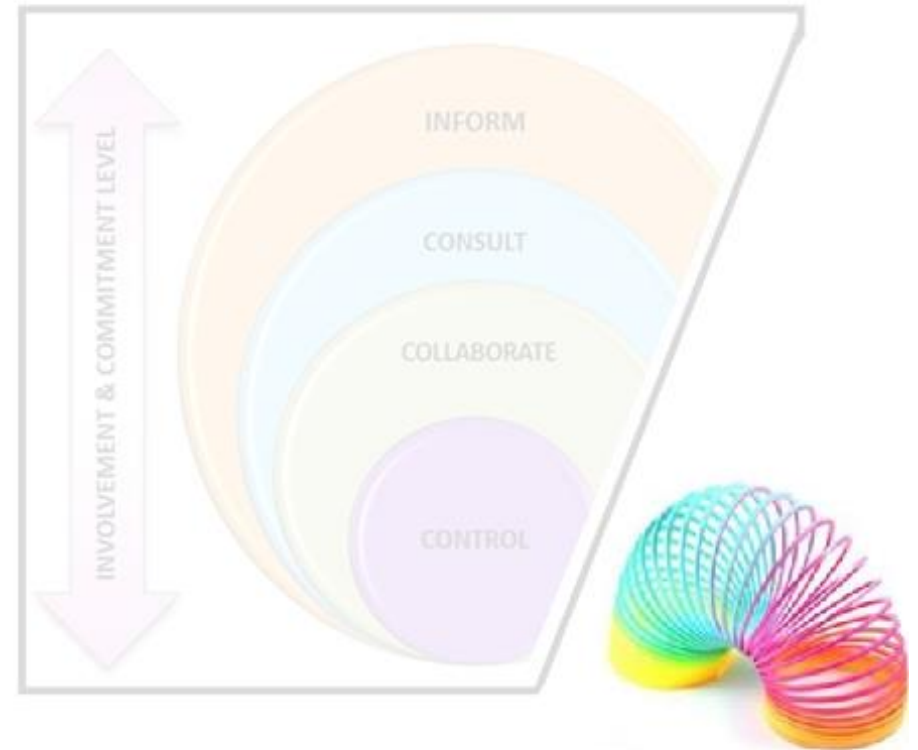
We need to understand what factors impact on people's capacity or willingness to be involved.



Taking a more flexible approach

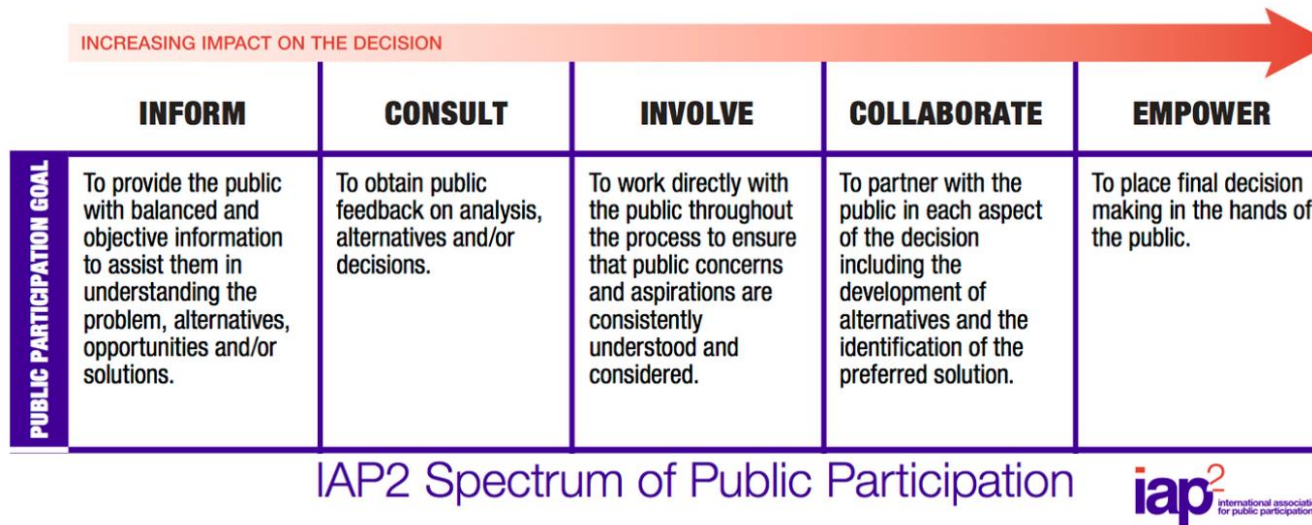


Creating a more flexible approach to participation allows individuals to give their time and skills in a way that fits around their existing commitments, schedules and lives.



Visioning a new model of participation

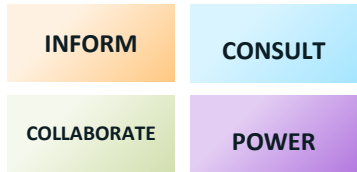
With the hierarchy of ladders not working for us we looked at alternative models. The International Association of Public Participation Spectrum of Public Participation had key ideas that met with our vision for a model to Inform, Consult, Involve and Collaborate and Empower people.



This became 4 areas of participation. We saw **involving people** happening in every area of activity.



Thinking through the mechanism



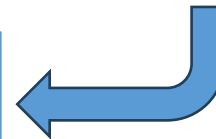
With our 4 areas of participation in place we wanted to then build in flexibility to the model.



And a continuum helps visualize movement and flexibility



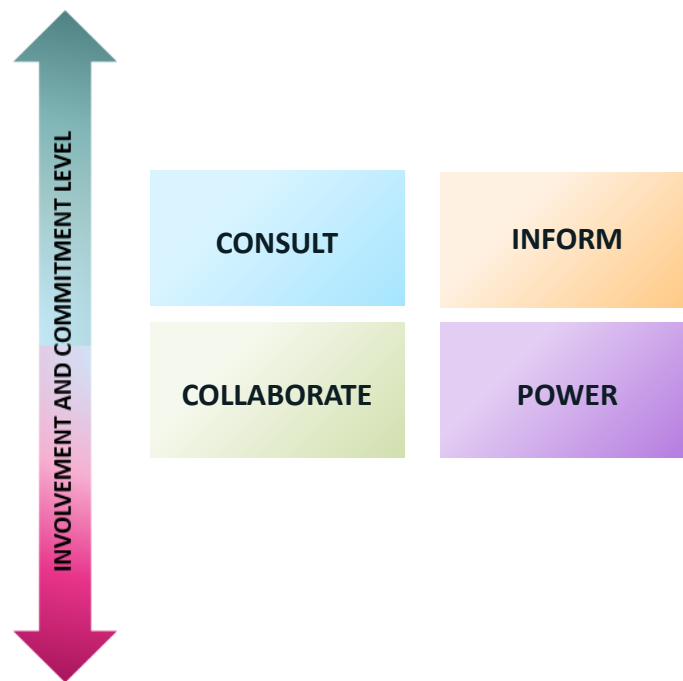
A simple switch through 90 degrees gives us a vertical slide where people can increase or decrease their level of involvement in a way that is responsive to their other commitments, schedules or lives.



Building a model of participation

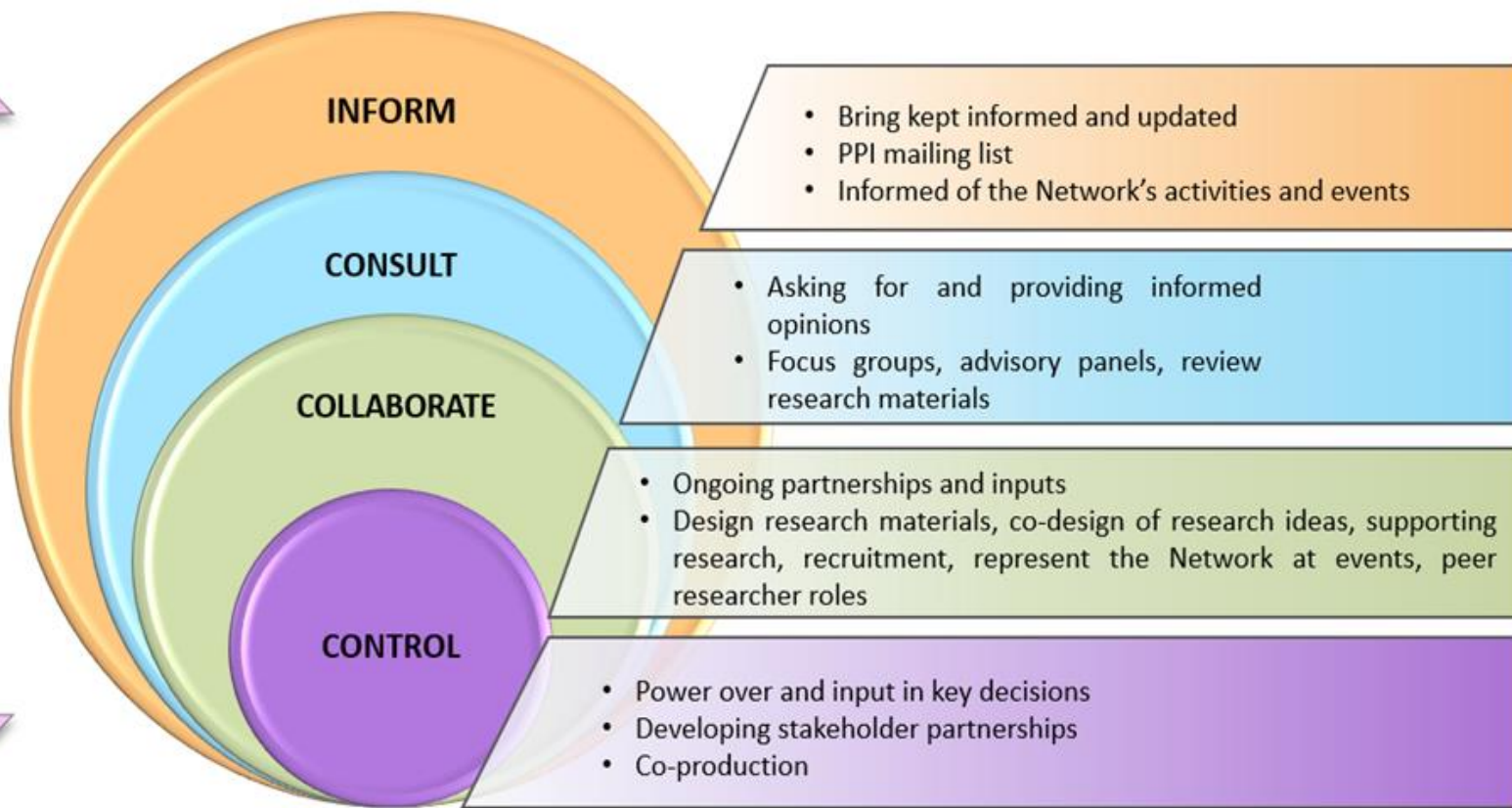


With a framework in place the final stage was to present the model in an explainable way



A new model of participation

Increase time



Decrease time



NRS Mental Health Research Network: Chris White, Suzy Syrett & Catherine Deith 2023

Adopting the model



AVATAR2 THERAPY TRIAL

As we developed the model the AVATAR2 Therapy Trial, a multisite trial with King's College London (KCL) the University of Glasgow, University of Manchester and University College London (UCL) adopted our model and tailored it to their needs

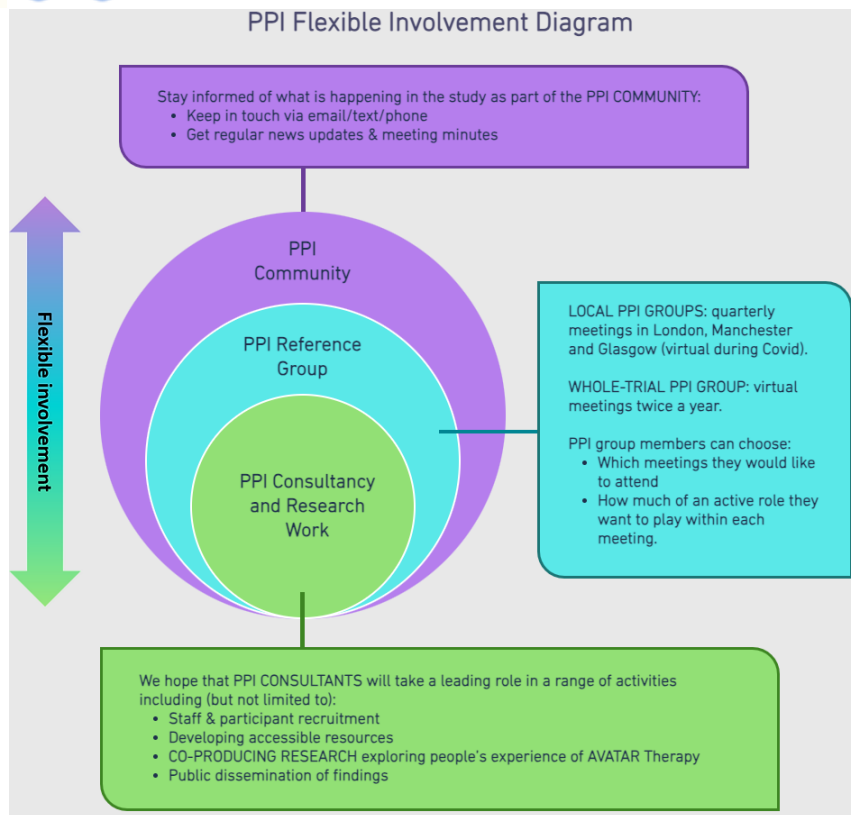
For more information on how PPI works in AVATAR2 visit their website:

<https://www.avatartherapytrial.com/patient-and-public-involvement>



PATIENT & PUBLIC INVOLVEMENT (PPI) IN AVATAR THERAPY

PPI Flexible Involvement Diagram



Our vision for a new flexible approach

A model that meets the needs of all our stakeholders and creates the conditions for having a meaningful impact on the development and delivery of high-quality research

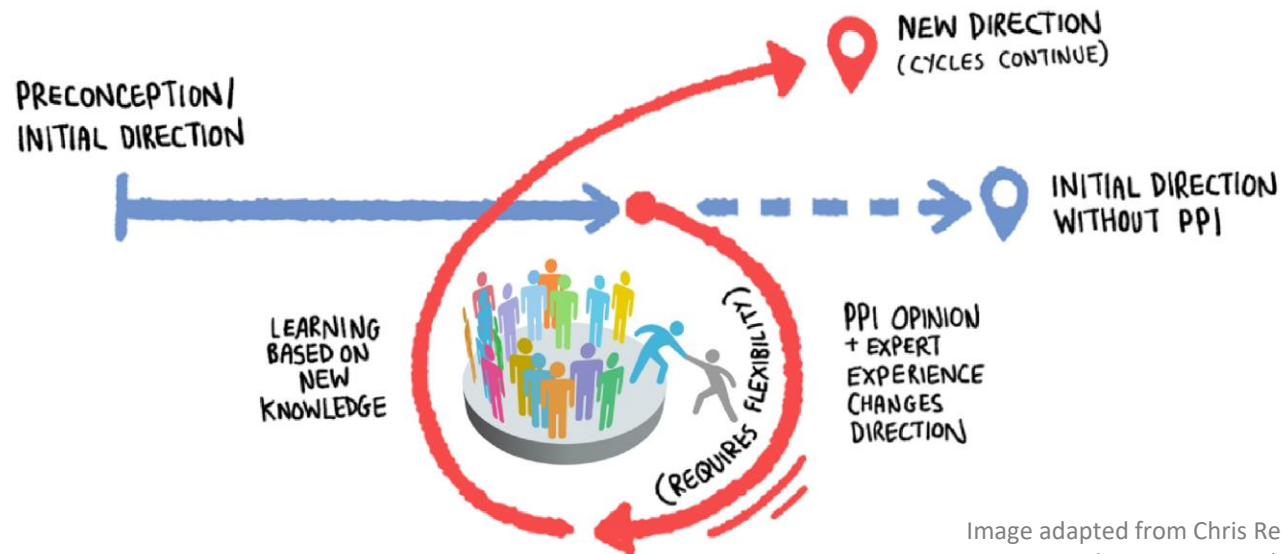
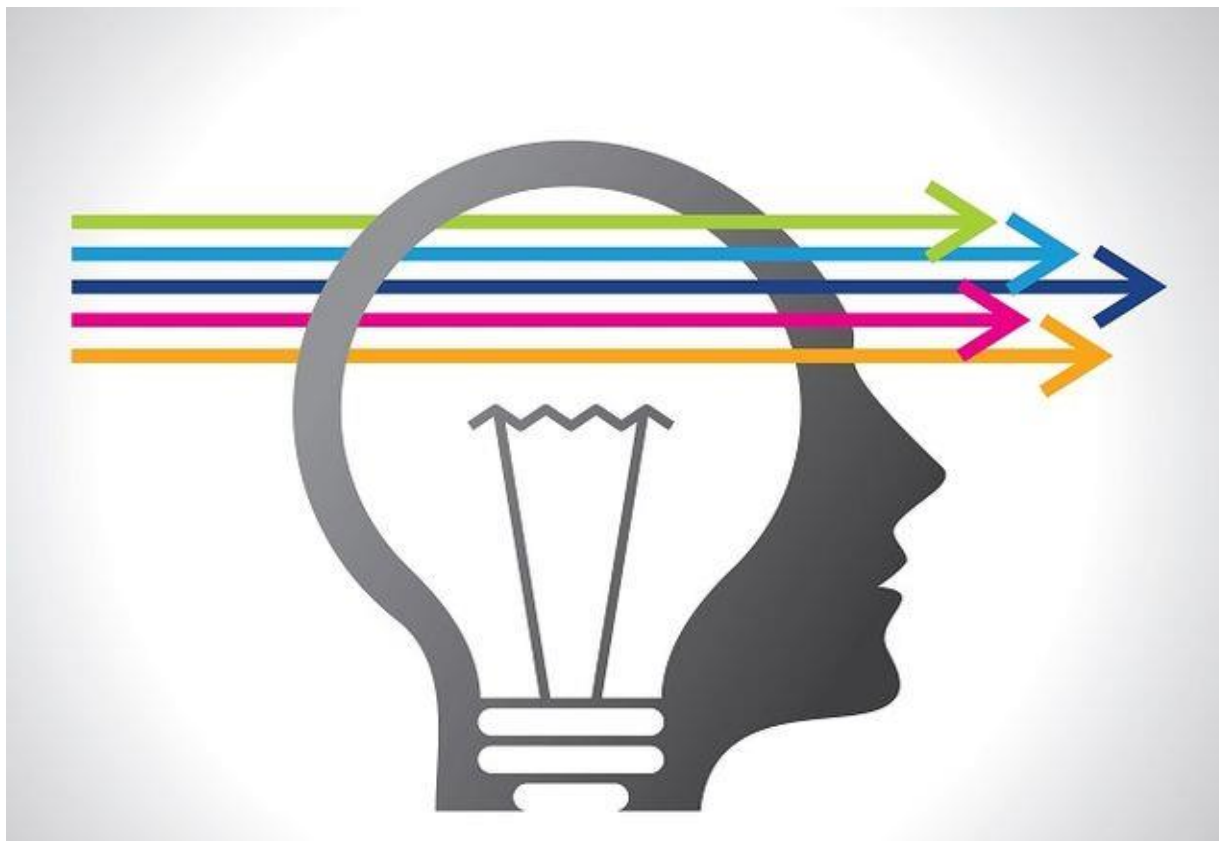


Image adapted from Chris Redford (illustrator)
Patients in the Learning Health System project

[Epistemic justice in public involvement and engagement:
Creating conditions for impact \(Kristin Liabo PhD et al, 2022\)](#)



Questions?