

# 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



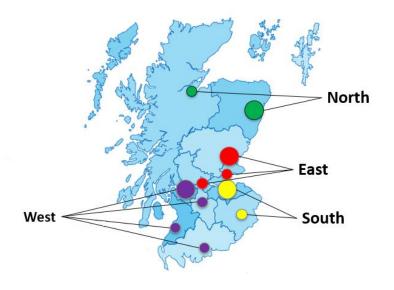


#### **About the Network:**



# 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.



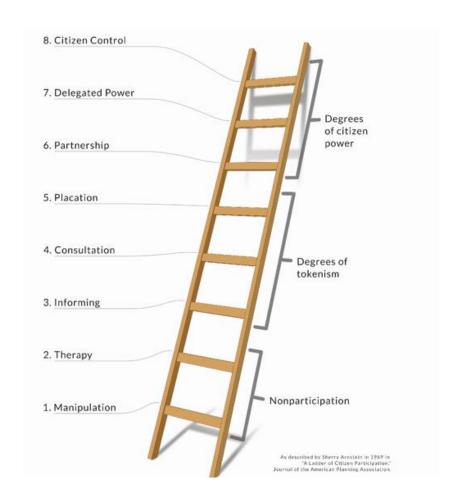
# Arnstien's ladder of participation



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.

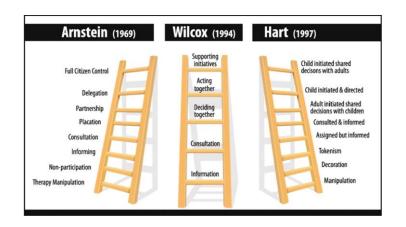
But it has limitations: its linear hierarchy; perceptions about starting at the bottom rung and progressing upwards; problematic assumptions around language.







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.











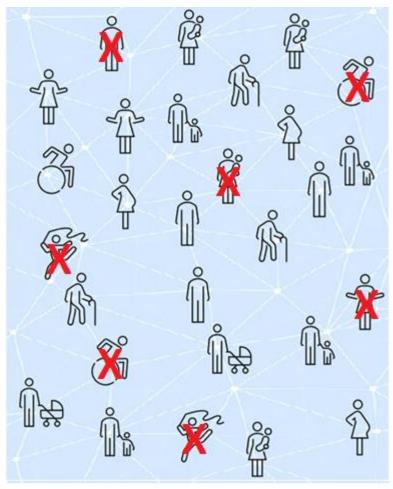
## **Barriers to participation**

SCOTLAND

The people we want to engage often have diverse and complex lives with a multitude of Socioeconomic factors potentially creating barriers to participation. Ethnicity, Age, Gender, Social-

economic class can all impact on participation.

- Limitations on time
- Illness and/or disability
- Fluctuating symptoms
- Financial situation
- Location (rurality, access to transport)
- Caring responsibilities
- Childcare
- **Employment**
- Personal changes
- Burnout
- Lack of opportunities
- Dissatisfaction,
- Lack of recognition
- Mismatched expectations





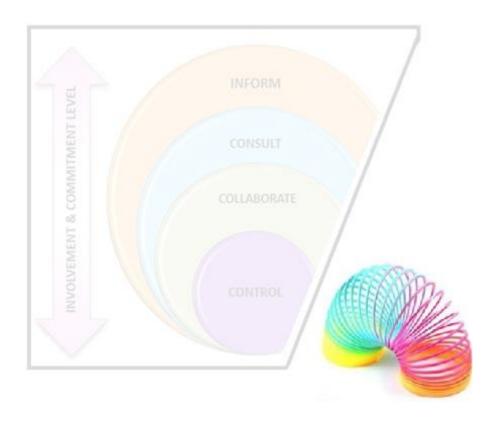


# Taking amore flexible approach





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

NHS SCOTLAND NIS RESEARCH SCOTLAND MENTAL HEALTH

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.

INCREASING IMPACT ON THE DECISION				
INFORM	CONSULT	INVOLVE	COLLABORATE	EMPOWER
To provide the publi with balanced and objective information to assist them in understanding the problem, alternative opportunities and/o solutions.	feedback on analysis, alternatives and/or decisions.	To work directly with the public throughout the process to ensure that public concerns and aspirations are consistently understood and considered.	To partner with the public in each aspect of the decision including the development of alternatives and the identification of the preferred solution.	To place final decision making in the hands of the public.

IAP2 Spectrum of Public Participation



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









# Thinking through the mechanism



INFORM

CONSULT

COLLABORATE POWER

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

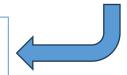
INVOLVEMENT AND COMMITMENT LEVEL

And a continuum helps visualize movement and flexibility

Minimal involvement

Maximum Involvement

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.



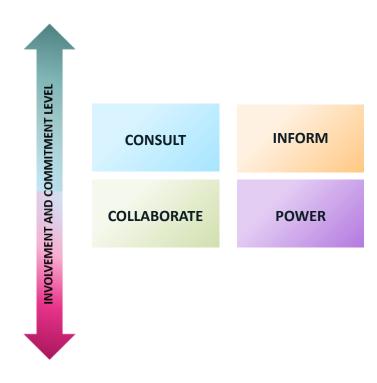




# **Building a model of participation**



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



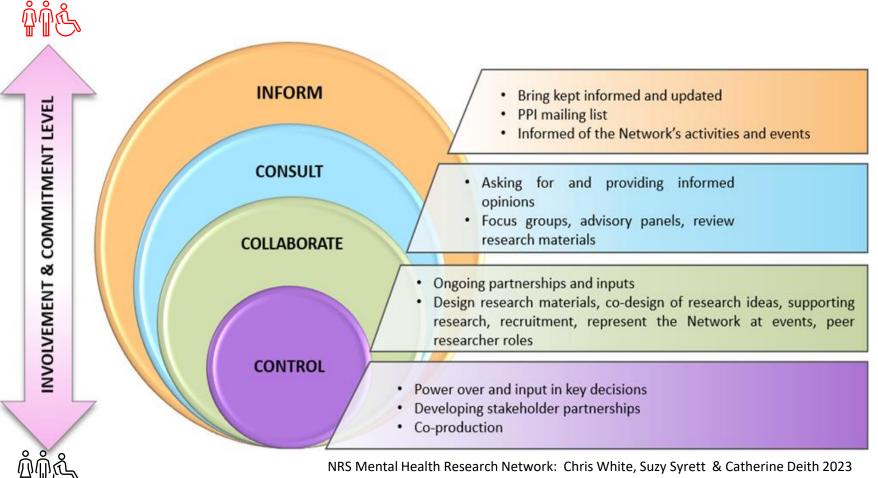




## A new model of participation



Increase time







Decrease time

## Adopting the model





# AVATAR2 THERAPY TRIAL

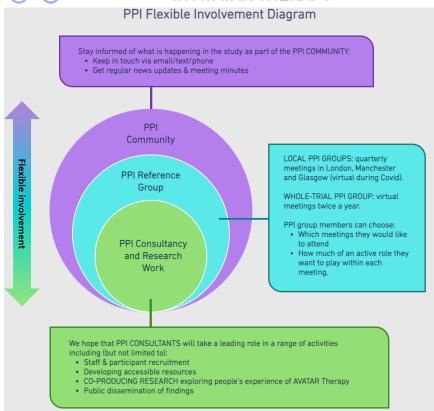
As we developed the model the AVATAR2 Therapy Trial, a multisite trial with King's College London (KCL) the University of Glasgow, University of Manchester and University College London (UCL) adopted our model and tailored it to their needs

For more information on how PPI works in AVATAR2visit their website:

https://www.avatartherapytrial.com/patientand-public-involvement



#### PATIENT & PUBLIC INVOLVEMENT (PPI) IN AVATAR THERAPY

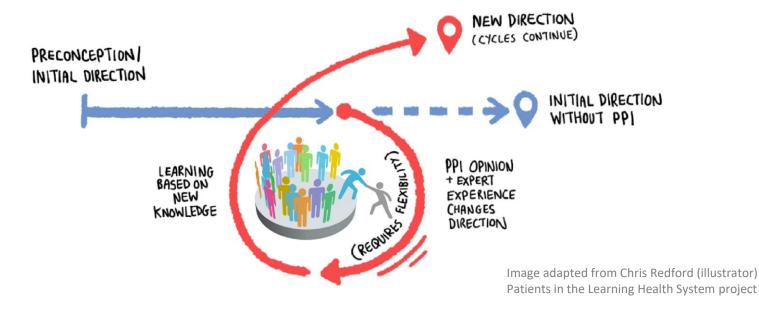




## Our vision for a new flexible approach



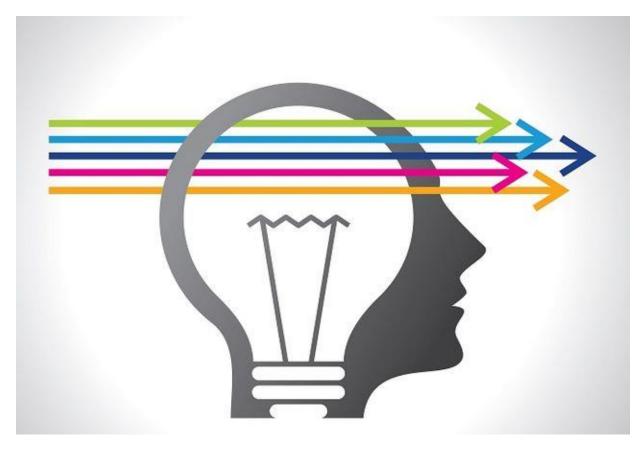
A model that meets the needs of all our stakeholders and creates the conditions for having a meaningful impact on the development and delivery of high-quality research



<u>Epistemic justice in public involvement and engagement:</u>
Creating conditions for impact (Kristin Liabo PhD et al, 2022)







**Questions?** 



