

Community Perspective on CHIM studies: Experiences with community engagement in the UK with COVID-19 trials



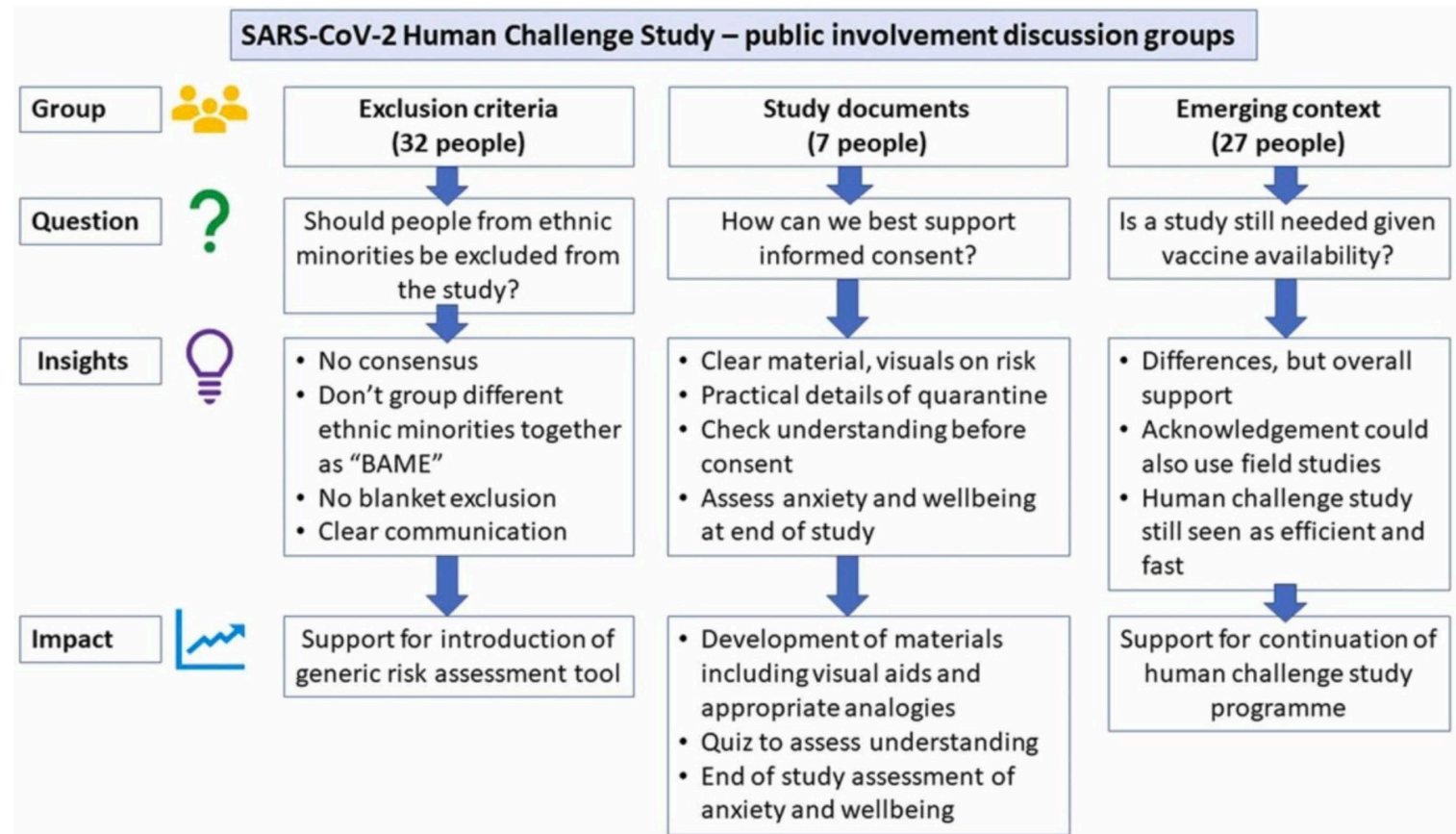
E D C T P

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The role of public involvement in the design of the first SARS-CoV-2 human challenge study during an evolving pandemic

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[Home](#) › [...](#) › [Patient and public involvement in research](#) ›

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involvement toolkit**

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Resource

Involvement engagement ladder

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Article

A Ladder Of Citizen Participation

Sherry R. Arnstein

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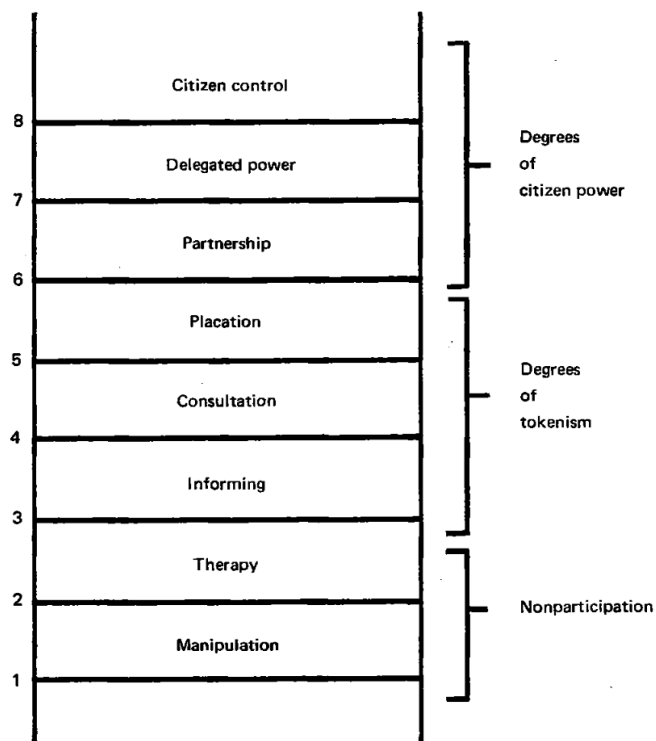
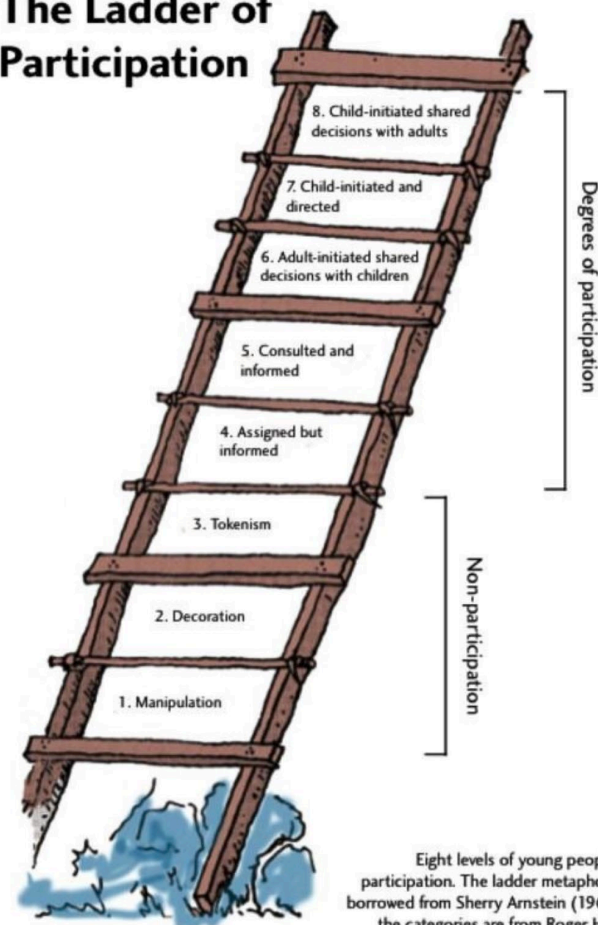


FIGURE 2 *Eight Rungs on a Ladder of Citizen Participation*

The Ladder of Participation



Eight levels of young people's participation. The ladder metaphor is borrowed from Sherry Arnstein (1969); the categories are from Roger Hart.

Type of participation	What happens at each level	Implications and views	Power
User owned	People with lived experience: - Define the problem or need - Design and provide the solution, delivery and evaluation. Researchers support this with funding. Work is within user-run organisations.	People doing it themselves. Enabling, empowering. Researchers trust that people are best placed	People have power over the research they need and will affect them.
User-led	People with lived experience lead the process, with others, to: - Design and provide the solution, delivery and evaluation. - Define the problem or need Researchers support this with a range of resources. Work is within existing services and systems.	to lead and own the development and delivery of what they need - if resources are provided.	People have expertise that researchers don't – and this expertise matters most.
Co-Production	Researchers work in partnership with people with lived experience to: - Co-plan and define the problem or need and - Co-design the solution, co-deliver the research and co-evaluate it People with lived experience form a majority of committee and project group memberships. Researchers ensure they privilege, hear, value, debate and act upon consumer views. Decisions are not made unless the majority of users agree. Power imbalances are proactively redressed. People with lived experience are part of delivering and evaluating the research	Doing with people. Collaborative partnering. Researchers share power and potential equally with the people who will be affected by the research.	Researchers share the power with the people who the research is for and about The expertise of people with lived experience is just as critical as other expertise.
Co-Design	Researchers work in partnership with people with lived experience to plan, design, deliver or evaluate the research. For whichever part of the process that is co-developed, patients and the public form a majority of committee or project group memberships. Their views are privileged, heard, valued, discussed and acted upon. Power imbalances are proactively redressed. People with lived experience may or may not be part of delivering the end result.	Recognition that each party has something valuable to bring to the process. Decision making is shared, as is design and delivery to some degree – or even completely.	
Engage	Researchers involve people with lived experience in thinking through some, many or all aspects of decisions. This is most commonly seen by having a minority of team members as people with lived experience (good practice should be a minimum of 2). People with lived experience are a minority, often with less power and resources than others, and just one of many stakeholders.	Doing for people People with lived experience without power Researchers take account of peoples' lived experience perspectives and opinions in some way	Researchers hold the power and value their own expertise most of all.
Consult	Researchers ask people with lived experience what they think, and this becomes one of many considerations. This is most commonly done by holding dedicated consultation sessions or surveys with people.	They create limited opportunities for people to 'have their say' or get involved - but researchers make the final decisions	
Inform	Researchers tell patients and members of the public about their decisions. They may provide an opportunity for feedback. What is done with feedback varies.	Doing to people. Passive recipients. People with lived experience	
Educate	Researchers teach patients and the public about what they've decided so people know why it is good for them.	are not part of research design or delivery.	
Coerce	Researchers expect patients and the public to accept the decisions made on their behalf.	Researchers make the decisions based on their own expertise.	
Exclude	Patients and members of the public are unable to access services or systems or decision making.	Excluding people. No involvement in any way.	



1 Participant consultation

Proof reading participant information/posters

Commenting on the design of recruitment process

Commenting on the design of participant activities

Helping to share/publicise results

Informal  Formal

2 Helping to set research priorities:

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Priority Setting Partnerships

3 As co-researchers/ co-creators / community researcher etc. (members of the research team)

1. Participant Consultation

What does an ethics committee look for?

- That it has been done
- That an attempt as been made for it to be representative
- That the feedback has been recorded
- If the feedback hasn't been incorporated why?
- That the study has been improved/changed
- A process of receiving and acting on participant feedback is in place
- How results will be fed back to participants/communities

For phase 1 units & increasingly other types of research formal, ongoing participant panels are used

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Qualitative research methodology



Service Evaluation / Needs Assessment / Priority Setting Panel

Ethical issues might be covered explicitly under professional responsibilities/ existing governance responsibilities



If not, a formal research ethics review might be helpful

3

As co-researchers/ co-creators / community researcher etc.
(members of the research team)

Experience?

Dynamics of engagement?

Any special arrangements?

Nature of ongoing involvement?

Fair payment

Indemnity/contract

Results dissemination

Future involvement?



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We've developed 4 best practice principles for public involvement, which you should follow when planning research. They are:

1. Involve the right people
2. Involve enough people
3. Involve those people enough
4. Describe how it helps



<https://www.hra.nhs.uk/planning-and-improving-research/best-practice/public-involvement/guidance-for-researchers/>



<https://sites.google.com/nihr.ac.uk/pi-standards/home>