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Principles of Involving people in research

Presented by Jack Nunn

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An expert is in the eye of the beholder

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What are we talking about?

What are we talking about?

Democracy?
Human rights?
Sharing power?

If we want to co-create **principles**, first we must define our **shared values**

Current definitions of **shared values:**

World Health Organisation - Declaration of Alma-Ata 1978:

“the people have the right and duty to participate individually and collectively in the planning and implementation of their health care”

Current definitions of **shared values:**

World Health Organisation - Ottawa Charter 1986:

"Health promotion works through concrete and effective **community action in setting priorities**, **making decisions, planning strategies** and implementing them to achieve better health. At the heart of this process is the **empowerment of communities**…This requires full and continuous access to information, learning opportunities for health, as well as **funding support**"

What do we mean by involving people?

"By public involvement we mean research being carried out **'with' or 'by'** members of the public rather than 'to', 'about' or 'for' them"

Definition from National Institute of Health Research (NIHR), adapted into 2016 'Statement on consumer and community involvement in health and medical research'

UNITED NATIONS

UNESCO Recommendation on Open Science

Adopted 2021

“**a common definition, shared values, principles and standards for open science** at the international level and proposes a set of actions conducive to a fair and equitable operationalization of open science for all at the individual, institutional, national, regional and international levels”

UNITED NATIONS

“Democracy, development and respect for all human rights and fundamental freedoms are interdependent and mutually reinforcing”

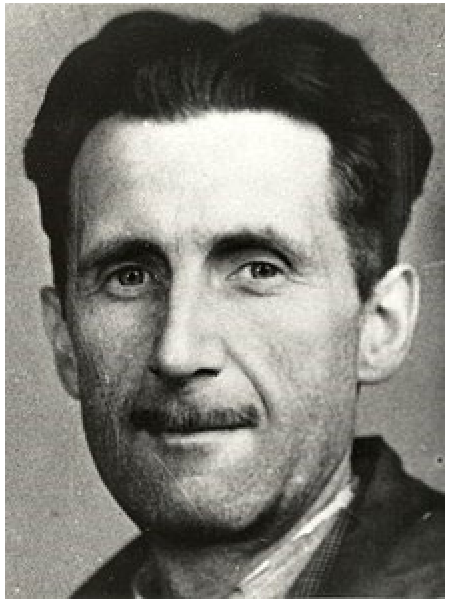
https://www.ohchr.org/en/instruments-mechanisms/instruments/vienna-declaration-and-programme-action

UNITED NATIONS

The UN has raised human rights concerns about Australian Aboriginal and Torres Strait Islander peoples’ access to health

https://documents-dds-ny.un.org/doc/UNDOC/GEN/G10/449/00/PDF/G1044900.pdf?OpenElement

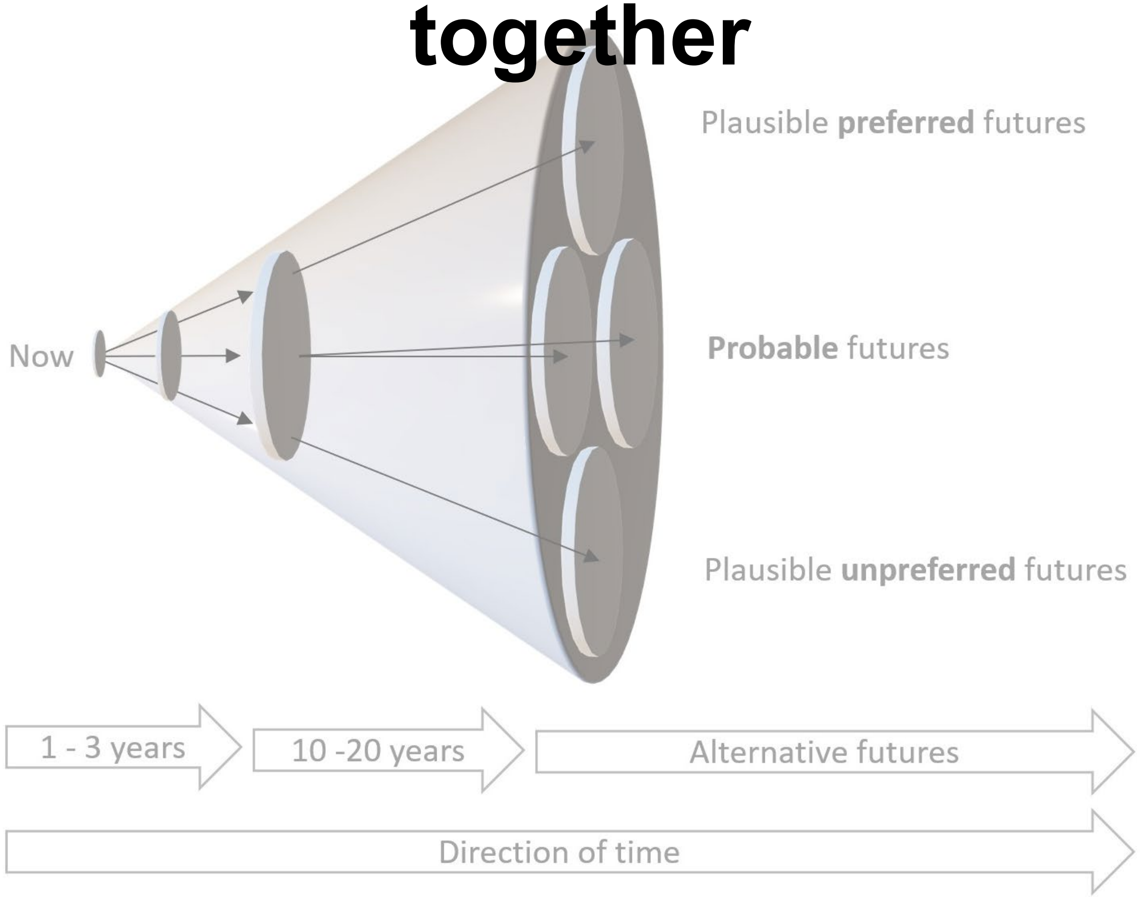
"In the case of a word like democracy, not only is there **no agreed definition**, but the attempt to make one is resisted from all sides...the defenders of every kind of régime claim that it is a democracy, and fear that they might have to stop using that word if it were tied down to any one meaning"



George Orwell

We need standardised ways of reporting involvement

We need evidence informed ways of shaping the future together



Plausible **preferred** futures

Now

Probable futures

Plausible **unpreferred** futures

1 - 3 years

10 -20 years

Alternative futures

Direction of time

Adapted from Bezold C, Hancock T. 'An Overview Of the Health Futures Field' for the WHO Health Futures Consultation. 1993. https://apps.who.int/iris/bitstream/handle/10665/61479/WHO_HST_93.4_eng.pdf

We need evidence informed ways of shaping the future together

A recent review found 65 frameworks for supporting, evaluating and reporting patient and public involvement in research:

“The plethora of frameworks combined with evidence of limited transferability suggests that a single, off-the-shelf framework may be less useful than a menu of evidence-based resources which stakeholders can use to co-design their own frameworks”

Greenhalgh T, Hinton L, Finlay T, Macfarlane A, Fahy N, Clyde B, Chant A. Frameworks for supporting patient and public involvement in research: Systematic review and co-design pilot. Health Expect. 2019 Aug;22(4):785-801. doi: 10.1111/hex.12888. Epub 2019 Apr 22. PMID: 31012259; PMCID: PMC6737756.

We need standardised ways of reporting involvement

AGREE
Advancing the science of practice guidelines

UK Standards
for Public Involvement

GRIPP2 reporting checklists:


Shared commitment to public involvement

We need standardised ways of reporting involvement

Involve Australia Guidelines coming soon…..

STARDIT

We need standardised ways of reporting involvement

STARDIT

STARDIT is an open access data-sharing system to standardise the way that information about initiatives is reported, including data about:

- **which tasks were done by different people**
- **outcomes and impacts**
- **funding – and any conflicting or competing interests**

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Learn more at:
ScienceForAll.World/STARDIT

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STARDIT

Allows people self-identify to standardised terms

Works beyond just health research

STARDIT

STARDIT is free to use, and data can be submitted by anyone.

STARDIT is currently being used by Australian Genomics, and by Cochrane to report how people are being involved in the co-creation of organisational values.

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Getting the language right

‘Who is involving who?’

- Words like ‘participation’, ‘involvement’ and ‘engagement’ can mean different things and can imply very different power relationships.
- While it is important to ask ‘who is involving who’, a more helpful question can be ‘**who is working with who, how and why**?’. ‘Who is doing which tasks?’
- Who is not involved, and why? Expectations of those involved (e.g. time)?
- How are people valued and supported? Who is being paid and why?
- Who is a ‘stakeholder’ – someone who has a stake in the research outcome – and who is not?
- How will we involve stakeholders in co-creating the language used – and do they self-identify with the terms?

Key challenges for NMHRC

- Transparency on the co-creation process of these principles
- Providing adequate funding for involvement to help avoid structural violence
- Make Australia a more attractive place to do research by aligning our terminology and reporting with international standards
- Improved transparency on ways of assessing and scoring involvement in grant process

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Questions for today

1. AMHRC ‘Ethical Guidelines: Key Principles’ I would recognise as international best practice - why isn’t this level of data required for all research in Australia?

2. How can people get involved in this process of revising the NMHRC statement? What methods should we be using to involve people?