

More than just ‘participation’: A rights-based approach to research

Few, if any, would argue that ageing-related policy and practice should reflect the basic human rights principles of participation, accountability, non-discrimination, equality and empowerment.

Across countries and service settings, there is an increased commitment to providing systems of aged care that support older adults to live active, meaningful lives, and promote each person’s choice and control, dignity and autonomy.

Yet despite growing (entirely reasonable) expectations of a rights-based approach to ageing, rights-based research in the field is yet to catch up.

A rights-based approach to research supports each person’s right to dignity, inclusion, agency and equity through meaningful research. For this research to be meaningful, it should be valued by researchers *and* participants, feel worthwhile and have a positive impact. It should also be relevant, measurable and translatable in real world settings.

So, given the well-known philosophy of person-centred care, why is this sector lagging when it comes to rights-based research? Or are we calling it ‘participation’? And if so, does that participation extend beyond inviting participants to provide data, and later sending them a summary of the findings?

In practice, the elements of rights-based research include:

- ▶ Respecting participants’ individuality and diversity, and integrating their insights as experts-by-experience
- ▶ Inviting older adults, their families, staff and other stakeholders to identify research topics, co-develop solutions and contribute to data collection, analysis and reporting

- ▶ Involving a range of internal stakeholders and participants in the transfer of knowledge into practice
- ▶ Producing disaggregated (‘broken down’) data to improve understanding and comparison of population groups and situations
- ▶ Sharing and disseminating findings through a range of channels, to maximise its potential to inform policy and practice, and to support advocacy.

You may recognise strong parallels with the language of ‘participatory research’, ‘co-design’ or implementation science. Referring to ‘rights-based research’ in no way neglects these frameworks, but shows the importance of consistent terminology and shared understanding. These are important in any research context, but are arguably most critical when the aim is to bridge the gap between evidence and practice.

It also raises the issue of implementation. Take service providers, for example, who access evidence, but find no guidance on the most effective and sustainable approach to its implementation or evaluation. Without describing and evaluating the different components of implementation in non-research setting, the potential benefits of an intervention are limited.

Once the research and implementation processes are done, attention shifts to the dissemination of findings. In rights-based research, the aim is to increase public awareness, improve practice and inform advocacy. Academic journals may not be the best vehicle to achieve these aims. To support, educate and advocate, we should also be sharing our work on community and industry platforms. Think about where people might come across community newspapers and industry magazines, and provide opportunities for your work to be read by those who are most affected by the findings: older adults and those who care for them.