Many thanks to Susanne and the team for inviting me to be discussant at this important session which has given us some excellent presentations taking forward both conceptual and methodological thinking in this area. It is a privilege to be able to comment on and if I may critique the presentations and in doing so, raise some questions. In the limited time we have rather than commenting on each paper in turn I’m going to review the papers addressing 5 questions to frame the discussion:

1. What does user participation actually achieve particularly in the health and social care arena?
2. What impact does it have on older people? Is it a valued role for older people or a cheap way of doing research using older volunteers? Can it be used therapeutically? (Combatting isolation and loneliness for example)
3. Can it lead to innovation in our conceptual and methodological repertoire?
4. Does it add meaning and legitimise research findings? Does it make for better science, policy and practice?
5. How transferable is user participation in an international context?

Some introductory remarks if I may:

There are a number of imperatives as to why user involvement is becoming central to research as illustrated in our first paper:

- Demographic- increasing numbers of older people and increasing research interest into the lives and situations of older people across the globe;
- Resource imperative as we have to deliver good value research from shrinking public funding for research; Greater expectations from the public
- Policy and practice imperative to demonstrate research with impact.

It is vital that any research of a participatory nature involves older people at the start of the process if it is to have success. User involvement is gaining traction. If stakeholders and users such as older people are involved in any
research question then there is an expectation now from research funders (certainly in the UK) that they will be involved in the process through co design, consultation, dissemination, implementation and developing impact. Involving older people in a tokenistic way is increasingly exposed.

There has to be a clear conceptual and methodological framework as part of the application. Paper 1 was useful in this respect taking us through the different forms of user participation and their characteristics and examples of method to ensure that researchers understand the level of engagement required with users.

To genuinely involve older people in the process there is a need to develop frameworks, principles for understanding user participation and engagement with the need for sound methods that are evaluated and tested and alongside a consideration of ethics.

The papers in this symposium set out a framework and roadmap to do this and answer the 5 questions.

Returning to our 5 questions then:

1. & 2. What does user participation actually achieve and what impact does it have on older people?

Some sub questions here:

A.

We need to be clear about who are the users and stakeholders? We need to be clear about who is benefitting and who is contributing to what as it can lead to exploitation- Is equal weight given to the voices of all participants? are policy-makers participants in the same way as older people? Consideration of different roles within a team engaging older people – trainers, support workers.

Is it a valued role for older people or a cheap way of doing research using older volunteers? Can it be used therapeutically particularly in the health and social care arena? (Combatting isolation and loneliness for example)

Paper 3: Applying a world café method
Jargon – what does the title mean? How do we know the world café method is a positive experience for older people? Important to report on when things don’t go as well as planned also- are there areas of health research for example that are sensitive for certain people?

Is it more beneficial to the researcher?

Users perhaps should have a voice in such symposia– should perhaps have an older person speaking of their experience, something the Lund team have considerable experience in taking forward.

B.

1st paper Conceptual and theoretical underpinnings talks about ‘empowerment’

Take issue with the word ‘empowerment’ – I give you power – is it really a shift in power that this is all about? What are the limitations of this? Are we really empowering older people?

Perhaps we need to think about rights, responsibilities and risks as a guiding framework with the emphasis on responsibilities and risks as much as empowerment? What rights do users have in the relationship- IP, payment, follow on support? What responsibilities and what risks? Safeguards needs to be developed for both the researcher and the older person (particularly in health research). What if the users don’t deliver? User participation is not a one off event but needs careful relationship management - sustainability of the relationship between all parties.

Useful schemata in paper 1 on patient and public involvement– yet to what extent do we counsel people as a method? Peer to peer support?

3. Can it lead to innovation in our conceptual and methodological repertoire?

All the papers address this and nudge the field forward. 2nd paper Methodological considerations mentions people with complex and multiple needs – dementia, sensory deprivation, and vulnerable adults but could go further.

Evaluation of the method is important- what works, with whom and in what context are key areas to explore.
How do we scale up best practice be creative and innovate in the area of method? What impact does the method we use have on older people?

For me it also raises a wider question of research funding – difficult to get for this type of research and user participation is often embedded within an empirical study and seen as a work package or marginal element in terms of taking the concept and method forward. Often studies that really are innovative are locally funded so doesn’t have the ability to evaluate any scalability. Great to see UserAge get funding to really explore these areas. Where will innovation come from in this area?

4. Does it add meaning and legitimise research findings? Does it make for better science, policy and practice?

A.

To what extent do we employ user involvement to legitimise a course of action; what if the research results are different to those expected when older people are involved through the process? In paper 3 Important statement re risk in the penultimate slide – is it meant to validate and deepen the analysis but what if it contradicts it? What are the consequences?

We also need a realistic acknowledgement of the diverse needs and often conflicting needs of different users- ok if you all share an issue or a problem.

B.

Choosing the ‘right’ users- common thread through all the papers – who are the right users and who does benefit most? Can result in the usual voices particularly if going through User organisations where there are gatekeepers.

C.

The jury is out on whether we produce better science. Costs to research of training users in doing analysis translation, IP, payment issues raises issues of sustainability. Do you use the same groups given the investment in time and resource with them- sustainability issue versus usual suspects? Important to build a long term relationship with different users to understand their worlds-good examples of working with older people through all the papers. How do we do this given piecemeal and short term funding for research? How can we ensure collaborations are sustained on non-funded bids?
5. How transferable is user participation in an international context?

The papers 2 from Sweden and 1 from the UK - Western European perspective. How transferable to other cultural contexts - we need to expand our understanding and my challenge to all the speakers is to reflect on how this might translate across (both methodologically and theoretically to an Asian, Arabic culture)

Given the globalisation of research and ageing and its increasing interdisciplinary nature how do we understand user participation in this global world; make it applicable as a method in different cultural context and thoroughly evaluate what impact it has on the individual and societies - may need a different methodology eg need testimonials and life stories

Conclusion

Usage gives us potentially the opportunity to explore these areas further. The future is set on developing co design with users at the heart of the research process. It’s easy to pledge, difficult to do, but the collection of papers presented in this symposium have shown us a clear strategic direction of travel for user participation and we are very grateful.

Thank You.

Judith Phillips