

## WORKSHOP ABSTRACT

# Including people with lived experience in research design and the publication process: why, how, and when do we do it?

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  - 10: Radboud UMC, Netherlands
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**Background:** Even as co-designed projects and citizen science are on the rise, there is still very little inclusion of people with lived experience in the scientific development, implementation and writing process. This workshop creates a safe space and an opportunity for researchers to learn from people with lived experience why, when and how to use their skills, and what support is needed, as well as for researchers to define what they need to learn in order to co-produce research going forward.

**Audience:** Everyone who is interested in integrated care research, no prior knowledge necessary

**Approach:** Including people with lived experience in research can lead to better research quality and focus the research on questions that are more relevant to people. This in turn can reduce research waste, increase impact and ensure that the needs of all stakeholders are met. Integrated care research should include people with lived experience in all roles (researcher, author, reviewer, editor), but often there is a lack of confidence and knowledge about how to ensure meaningful participation, and regular updates and feedback on the impact this participation had. This workshop will bring together people with lived experience and researchers with and without experience in co-design and co-production to openly discuss fears and concerns, what approaches exist and what support is needed for people with lived experience and researchers alike to increase the active involvement of people with lived experience in research design, implementation and the scientific publication process.

When entering the room, people will be asked to mark their experience with research on a flipchart and in what role they have been involved so far, if at all.

10' Introduction to workshop and reflection on experience in the room

15' Round table discussion: based on 4 - 6 real life case examples from different settings and including different lived experiences, people will discuss good examples, barriers, necessary competencies and potential for improvements.

15' Presentation of outcomes in plenary and summary according to the following topics:

- Barriers for people with lived experience / researchers
- Necessary competences / education and training needs
- Examples (good or bad), lessons learned

10' Plenary discussion on priorities and next steps, including what can IFIC and IJIC do

5' Summary and commitment (every participant will be asked to write down one action they will take forward on Monday)

Outcomes: Creating a space to meet and openly discuss challenges is in itself a positive outcome to ensure meaningful inclusion of people with lived experience in the future. More specifically, the outcomes will be used to develop educational materials and training sessions for (IJIC) authors, IJIC lived experience reviewers, IJIC editorial board members, and integrated care researchers. The workshop will also inform further actions needed to strengthen the competences of people with lived experience and researchers to co-produce research.