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Patient participation – (how) can it work?

SSPH+/ETHZ Lecture Series «This Is Public Health»
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► Competence Centre Participatory Health Care, Dr. Heidi Kaspar

Overview





What is participatory research?

Definitions | Goals | Principles

Participatory research (PR) – a definition

*The term participatory research (PR) is now widely used as a way of categorising research that has moved beyond researching "on" to **researching "with" participants**. The aim of PR is to maximize the participation of those whose life or work is the subject of the research. In PR people with experience of the focus of the research influence decision making and shape that research. This differentiates it from other forms of research where people are invited to take part in research that has already been shaped without their involvement.*

UK Participatory Research Network, <http://ukprn.weebly.com>

Goals

«[T]he purpose of any involvement activity should be to improve the health and the experience of services for patients, their relatives, carers and users of health and social care services as well as the wider public» (Ocloo & Matthews 2016: 627).

- ▶ Improve quality of research
 - ▶ Access to informants and facilitation of information
 - ▶ Relevance and impact
- ▶ Improve quality of services for better health outcomes
- ▶ Improve (marginalized) people's living conditions and reduce inequalities
- ▶ Empower (potential) service users



11 principles: Participatory health research...

1. is participatory
2. is locally situated
3. is a collective research process
4. projects are collectively owned
5. aims for transformation through human agency
6. promotes critical reflexivity
7. produces knowledge which is local, collective, co-created, dialogical and diverse
8. strives for a broad impact
9. produces local evidence based on a broad understanding of generalizability
10. follows specific validity criteria
11. is a dialectical process characterized by messiness



Approaches & applications

Prominent approaches | Driving forces

Participatory research – an umbrella term



Prominent approaches

- ▶ User Involvement, Patient and Public Involvement and Engagement (PPIE)
- ▶ Community-Based/-Partnered Participatory Research
- ▶ Co-Creation, Co-Production
- ▶ Participatory Action Research
- ▶ Citizen Science

Empowerment of users in health care: various approaches

**Health care
system**

**Train
professionals**
Human-centered
health care



**Enable users for
self-management**
Information and
education

**Users, professionals and
researchers co-create and co-produce**

History of PR in health care and beyond

Driving forces

- ▶ Beginning of participatory movements in health care: 1970's
- ▶ Grassroots, rights-based groups document harm done to marginalized people
- ▶ Critical and emancipatory thinking and activism in the Global South
- ▶ Mental health & mad studies
- ▶ Disabilities, postcolonial, feminist studies

Other areas with strong participatory movements

- ▶ Development studies
- ▶ Education research
- ▶ Social work
- ▶ Urban planning & development



Implementing participation in research

Key differentiations | Some methods

Key differentiation I: method vs. style

PR as a method

- ▶ Participation is limited to certain phases or activities
- ▶ Aim: improve quality of research
- ▶ Research(er)-driven, -owned:
 - ▶ Participation controlled by academics
 - ▶ User-informed production of knowledge

PR as a paradigm/style/approach

- ▶ Participation as a guiding principle throughout the entire project lifecycle
- ▶ Aim: Engage and empower
- ▶ Research partnership:
 - ▶ Participation controlled by team or co-researchers
 - ▶ Co-production of knowledge

Bergold & Thomas (2012); ICPHR (2013)

Key differentiation II: Who gets involved?

Professionals

- ▶ Local knowledge
- ▶ Expert knowledge
- ▶ Experts in their field

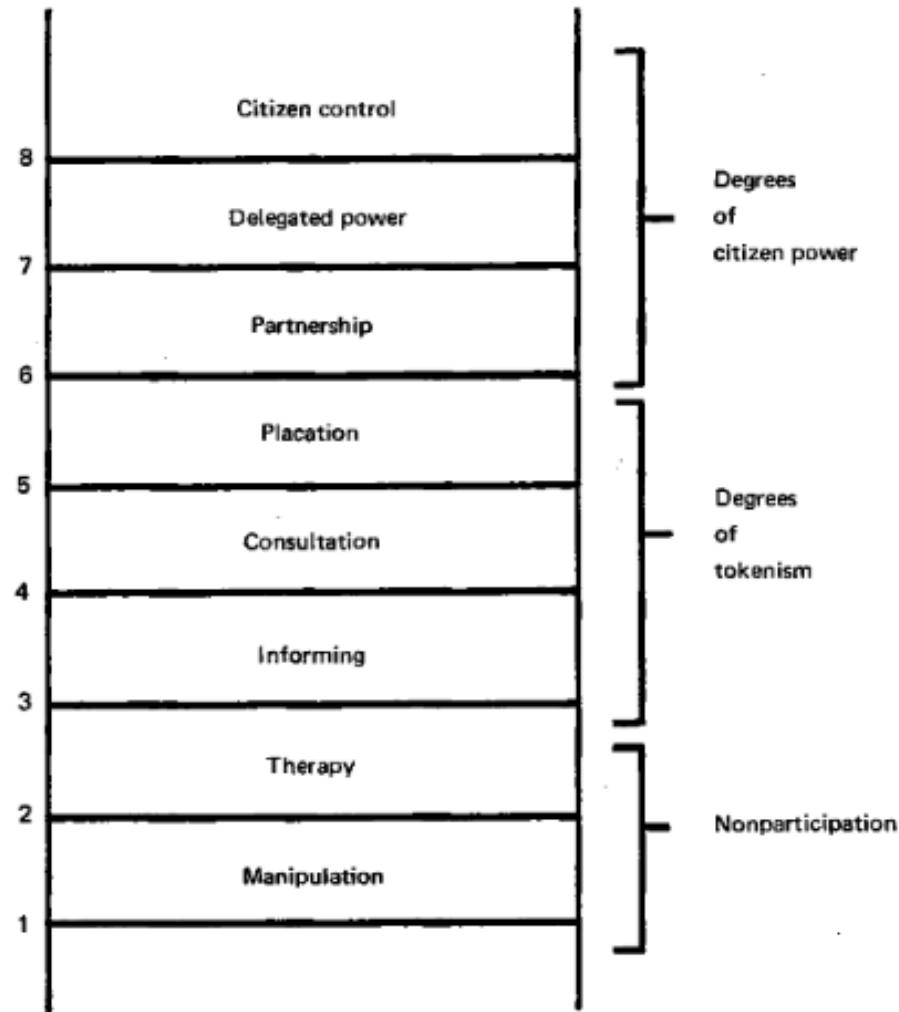
- ▶ Experts of their everyday life

Citizens, the public

- ▶ Local knowledge
- ▶ Experiential knowledge
- ▶ Experts of their everyday life

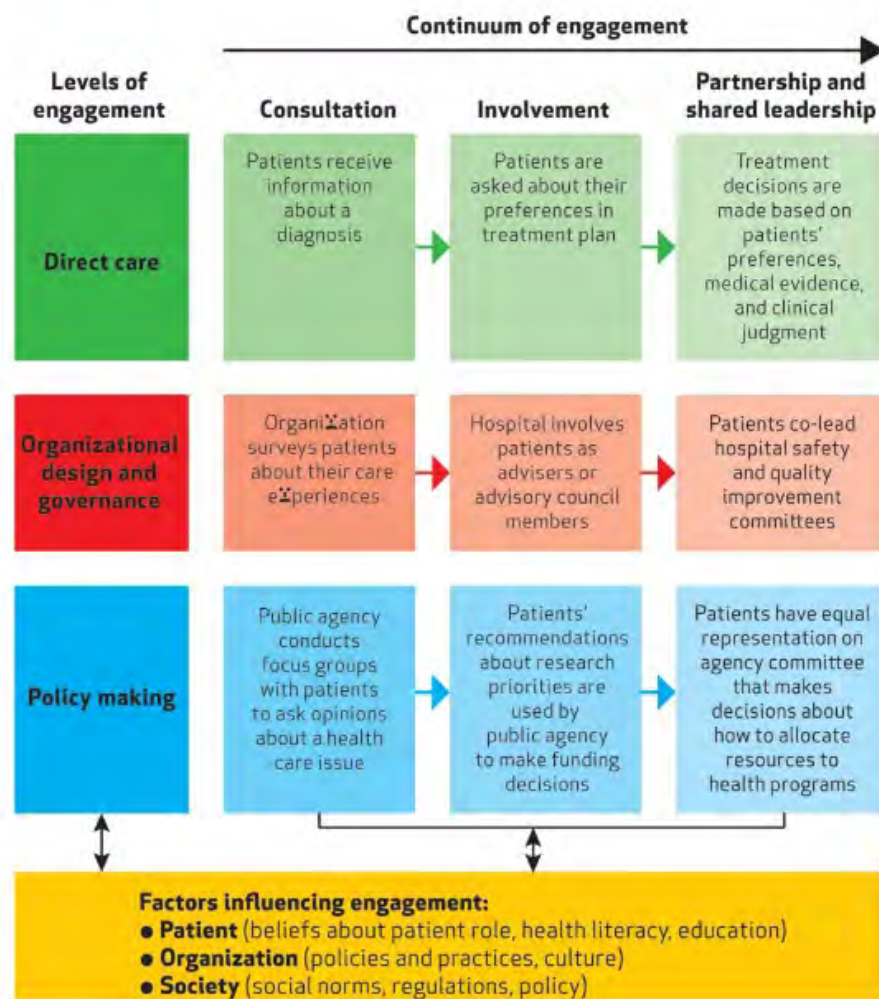
- ▶ Often vulnerable, marginalized
- ▶ Though not always and not necessarily

Key differentiation III: Level of involvement (1969)



Arnstein (1969)

Key differentiation III: Level of involvement (2013)



Carman et al. (2013)

Some popular methods in participatory research

- ▶ Visual methods (e.g. photo voice)
- ▶ Mobile methods (e.g. city walks)
- ▶ Creative methods (e.g. body mapping)
- ▶ Appreciative inquiry
- ▶ Conventional (qualitative) methods with co-researchers
- ▶ Focusgroup illustration maps



«What makes it participatory research is not the research method, but the ownership and governance framework.»

Andersson (2018: 156)



Examples and conclusions

A selected study | Dos and Don'ts | Resources

Developing caring communities for sustainable care at home

- ▶ Communit-based participatory research approach, co-production
- ▶ Research partnerships with the public, professionals (health, social work), political leaders
- ▶ Collaboratively explore needs, develop & implement initiatives and evaluate & adjust them
- ▶ Objective: Build caring structures, but what, how & for whom was collaboratively defined



Developing caring communities – What happened...



On establishing
partnerships
and ownership
On managing
expectations



On balancing
'scientific' and
'local' agendas



On transformation
and empowerment
On broad impact

How can participatory health research work?

Do's

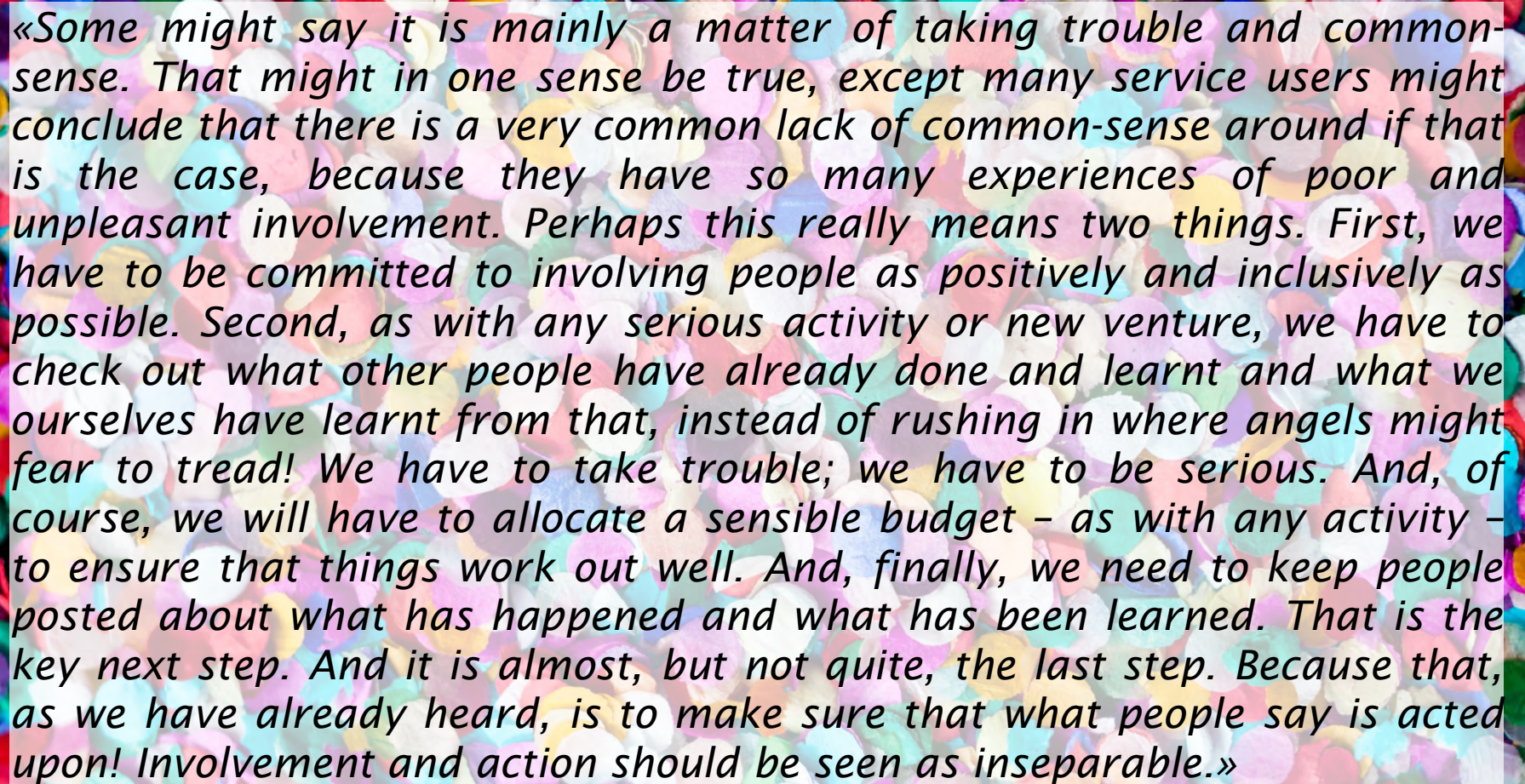
facilitators for effective participation

- ▶ **Be ambitious, but coherent**
about the level of participation you want to achieve
- ▶ **Be realistic and cautious**
about the expectations you raise
- ▶ **Be clear and open**
provide full information about the purpose and way of involvement
- ▶ **Know expectations and resources**
of people involved and your own
- ▶ **Create diverse opportunities to participate and value diverse knowledges**
- ▶ **Build confidence and competence**
- ▶ **Earn trust: «We must feel safe»**

Don'ts

barriers to effective participation

- ▶ **Tokenism**
saying involvement, without enacting it; using people for your own benefit, only; 'rent-a-patient' schemes
- ▶ **Devaluing people**
not listening, questioning expertise
- ▶ **Othering**
marking people as different
- ▶ **Safe money, or time**



«Some might say it is mainly a matter of taking trouble and common-sense. That might in one sense be true, except many service users might conclude that there is a very common lack of common-sense around if that is the case, because they have so many experiences of poor and unpleasant involvement. Perhaps this really means two things. First, we have to be committed to involving people as positively and inclusively as possible. Second, as with any serious activity or new venture, we have to check out what other people have already done and learnt and what we ourselves have learnt from that, instead of rushing in where angels might fear to tread! We have to take trouble; we have to be serious. And, of course, we will have to allocate a sensible budget – as with any activity – to ensure that things work out well. And, finally, we need to keep people posted about what has happened and what has been learned. That is the key next step. And it is almost, but not quite, the last step. Because that, as we have already heard, is to make sure that what people say is acted upon! Involvement and action should be seen as inseparable.»

Duffy & Beresford (2021: 14f.)

References

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- ▶ Carman K.L., Dardess, P., Maurer, M., Sofaer, S., Adams, K., Bechtel, C. & Sweeney, J. 2013. Patient and family engagement: A framework for understanding the elements and developing interventions and policies. In: *Health Affairs (Project Hope)*, 32:223-31.
- ▶ Duffy, J. & Beresford, P. 2021. Critical issues in the development of service user involvement. In: *The Routledge Handbook of Service User Involvement in Human Services Research and Education*, ed. by McLaughlin, H., Beresford, P., Cameron, C., Casey, H. & Duffy, J., pp. 9-16.
- ▶ International Collaboration for Participatory Health Research (ICPHR). 2013. *Position paper 1: What is participatory health research?* Version May 2013. Berlin: ICPHR, http://www.icphr.org/uploads/2/0/3/9/20399575/ichpr_position_paper_1_defintion_-_version_may_2013.pdf
- ▶ Ocloo, J., & Matthews, R. 2016. From tokenism to empowerment: Progressing patient and public involvement in healthcare improvement.” In: *BMJ Quality & Safety*, 25(8): 626-32. <https://doi.org/10.1136/bmjqs-2015-004839>.

Additional resources: some handbooks

- ▶ McLaughlin, H., Beresford, P., Cameron, C., Casey, H. & Duffy, J. (Eds.). 2021. *The Routledge handbook of service user involvement in human services research and education*. London, New York: Routledge.
- ▶ Hartung, S., Wihofszky, P., & Wright, M. T. (Eds.). 2020. *Partizipative Forschung: Ein Forschungsansatz für Gesundheit und seine Methoden*. Wiesbaden: Springer, <https://doi.org/10.1007/978-3-658-30361-7>
- ▶ von Unger, H. (2014). *Partizipative Forschung: Einführung in die Forschungspraxis*. Wiesbaden: Springer VS.
- ▶ Wallerstein, N., Duran, B., Oetzel, J. & Minkler, M. (Eds.). 2018. *Community-based participatory research for health: Advancing social and health equity*, 3rd ed. San Francisco: Jossey-Bass.



Additional resources: networks



- ▶ Participatory Science Academy
<https://www.pwa.uzh.ch/en.html>
- ▶ International Collaboration for Participatory Health Research (ICPHR)
https://oeph.at/Kompetenzgruppe_PGF
- ▶ PartNet: Netzwerk Partizipative Gesundheitsforschung
<http://partnet-gesundheit.de>
- ▶ Kompetenzgruppe Partizipation der österreichischen Gesellschaft für Public Health
https://oeph.at/Kompetenzgruppe_PGF