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

Approaches & applications
Prominent approaches | Driving forces

Implementing participation in research
Key differentiations | Some methods

Examples and conclusions
A selected study | Dos and Don’ts | Resources
What is participatory research?

Definitions | Goals | Principles
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.

The 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

ICPHR (2013)
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

<table>
<thead>
<tr>
<th>PR as a method</th>
<th>PR as a paradigm/style/approach</th>
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<tbody>
<tr>
<td>Participation is limited to certain phases or activities</td>
<td>Participation as a guiding principle throughout the entire project lifecycle</td>
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<tr>
<td>Aim: improve quality of research</td>
<td>Aim: Engage and empower</td>
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<tr>
<td>Research(er)-driven, -owned:</td>
<td>Research partnership:</td>
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<tr>
<td>▶ Participation controlled by academics</td>
<td>▶ Participation controlled by team or co-researchers</td>
</tr>
<tr>
<td>▶ User-informed production of knowledge</td>
<td>▶ Co-production of knowledge</td>
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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)

Factors influencing engagement:
- **Patient** (beliefs about patient role, health literacy, education)
- **Organization** (policies and practices, culture)
- **Society** (social norms, regulations, policy)
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)
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 balancing ‘scientific’ and ‘local’ agendas
- On establishing partnerships and ownership
- On managing expectations
- On transformation and empowerment
- On broad impact
## How can participatory health research work?

<table>
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<tr>
<th>Do’s</th>
<th>Facilitators for effective participation</th>
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<tr>
<td>▶ Be ambitious, but coherent</td>
<td>about the level of participation you want to achieve</td>
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<tr>
<td>▶ Be realistic and cautious</td>
<td>about the expectations you raise</td>
</tr>
<tr>
<td>▶ Be clear and open</td>
<td>provide full information about the purpose and way of involvement</td>
</tr>
<tr>
<td>▶ Know expectations and resources</td>
<td>of people involved and your own</td>
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<tr>
<td>▶ Create diverse opportunities to</td>
<td>participate and value diverse knowledges</td>
</tr>
<tr>
<td>▶ Build confidence and competence</td>
<td></td>
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<tr>
<td>▶ Earn trust: «We must feel safe»</td>
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<table>
<thead>
<tr>
<th>Don’ts</th>
<th>Barriers to effective participation</th>
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<tr>
<td>▶ Tokenism</td>
<td>saying involvement, without enacting it; using people for your own benefit, only; ‘rent-a-patient’ schemes</td>
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<tr>
<td>▶ Devaluing people</td>
<td>not listening, questioning expertise</td>
</tr>
<tr>
<td>▶ Othering</td>
<td>marking people as different</td>
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<tr>
<td>▶ Safe money, or time</td>
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Andersson (2018); Duffy & Beresford 2021; Ocloo & Matthews (2016)
«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

Additional resources: some handbooks


Additional resources: networks

- Participatory Science Academy

- International Collaboration for Participatory Health Research (ICPHR)
  [https://oeph.at/Kompetenzgruppe_PGF](https://oeph.at/Kompetenzgruppe_PGF)

- PartNet: Netzwerk Partizipative Gesundheitsforschung
  [http://partnet-gesundheit.de](http://partnet-gesundheit.de)

- Kompetenzgruppe Partizipation der österreichischen Gesellschaft für Public Health
  [https://oeph.at/Kompetenzgruppe_PGF](https://oeph.at/Kompetenzgruppe_PGF)