

<p>Name of your approach to assess societal impact</p>	<p>Participatory health research</p> <p>Janet Harris (Sheffield University, UK): Participatory Health Research</p>
<p>Approach description</p> <p>Please summarize your approach and its application context/options in a few sentences or bullet points.</p>	<p>Participatory health research (PHR) is an approach that involves people with different knowledge and experiences in developing and conducting studies of health interventions. It is based on the principle of knowledge democracy e.g. that people with different knowledge bases in different knowledge systems need to be equally valued in order to produce relevant and credible research. PHR may use an existing theory as its starting point (an a priori approach), inductively develop theory for how and why something works, or combine priori and inductive approaches to produce a theoretical framework. PHR can be used to test existing hypotheses, and/or to generate hypotheses about how and why health interventions work (or don't work). Analysis focuses on identifying how a project contributed to change in the specific local context, taking into account how context has either facilitated or constrained the effectiveness of the project.</p>

Concepts used in the approach

Please insert definitions for key concepts and components.

Activities: In PHR, a research team is assembled that includes local people who are affected by the situation, academic researchers, and other stakeholders who are in a position to influence and support both the research process and use of the findings. Ideally, tasks are agreed based on their particular experiences, knowledge and expertise. Despite the principle of knowledge democracy, however, the extent of involvement in PHR varies from one-off consultation, to active and equal collaboration across all stages. For example, outcomes are usually specified by the funders of PHR, but people may be engaged in defining the outcomes that are valued by local people and communities. Methods for measuring outcomes and collecting data may be defined by academic researchers, or critiqued by local people and revised, or co-produced. Both qualitative and quantitative approaches can be used to collect data, including interviews, case studies, storytelling, visual tools, survey, meeting notes, and mapping. Data analysis may be done by academic researchers and presented to local people for comment, or done collaboratively with community researchers.

Outputs can include: co-production of culturally-centred interventions; processes for integrating community and academic knowledge; development of plans for implementing a health intervention or initiative; local strategies for health promotion or health protection; tailoring of health information for specific groups and contexts; developing new or revised training programmes based on needs of participants; local strategies for disseminating information via social media; visual or other forms of artistic representation (storytelling, music, dance) to describe health challenges and promote individual reflection and public debate; community forums; development of local health and wellbeing networks; public hearings or stakeholder to share learning and promote deliberative dialogue.

Outcomes: A change in knowledge, attitudes, skills, and/or relationships, manifested as a change in behavior, that result in whole or in part from the research and its outputs. Answers the question: who is doing what differently as a result of the research?

Intermediate Outcomes:

Over the course of the project, PHR participants experience changes in knowledge, attitudes, skills, relationships and/or behaviour (KASRB) in relation to

- Increased ability to work effectively with people from different knowledge systems, with different forms of expertise.
- Increased understanding of how lived experience and local context contribute to health and health inequalities

- Strengthening of existing relationships across sectors, enabling increased understanding of local situations and conditions
- Development of networks and partnerships to co-produce research

End-of-project Outcome: At the conclusion of a PHR project/program, changes have been observed in relation to

- Increased individual/agency capacity to participate in PHR
- Development of trans-disciplinary research teams that continue to work together
- Tailored dissemination strategies that lead to use of findings to change health service delivery
- Changes in health or social policy

High-level Outcome: Over the longer term, PHR projects have demonstrated 'ripple effects', for example

- Ability of partnerships to successfully apply for funding to continue existing research over the longer term
- Demonstrated success in applying for funding to conduct other health research projects
- Partnership synergy: development of equitable and sustainable partnerships that go on to address a wide range of health conditions and health inequalities over the longer term

Impacts/ Realized benefits: PHR defines impact as occurring throughout the course of a project and beyond, on individual, group, organisational, and system levels, in communities of practice, institutions and organisations that are involved. The process of doing research together and the interactions that occur have an effect both on the actual research project and on the people involved.

A PHR approach can transform communities, in terms of leading to greater local and collective ownership over local conditions and ability to collaborate on creating healthy environments in the broadest sense of the term. The approach promotes the development and expansion of social networks as a by-product of collaborative research, thereby increasing sense of belonging and wellbeing over the longer term.

PHR can also support achievement of health equity and promote social justice by ensuring that local knowledge is reflected in both the conduct and findings of health research. A change in state or flow; a change in economic, social, or environmental conditions resulting in whole or in part from a chain of events to which research has contributed.

<p>Key challenges</p> <p>Please write down what you are struggling with concerning the application of your approach.</p>	<ul style="list-style-type: none"> • Promoting interactions where different types of knowledge are seen to have equal legitimacy • Creating safe environments where people who were previously acknowledged to be the 'experts' can learn from others • Raising awareness regarding unequal power relations between funders, academics and community people wanting to participate in the research • Recognising the jargon used by different knowledge systems and working to develop a shared terminology. • Demonstrating the importance of capturing interactions and relationships as important outputs alongside those that are commonly defined in health research • Illustrating how qualitative and relational processes impact on the ability of research projects to achieve quantitate outcomes • Negotiating the pre-determined requirements of funders and commissioners, who may be requiring outcomes that are not achievable in certain local contexts
<p>Visualization and narratives</p> <p>Please add short information on whether and how you use visualization, narratives or other boundary objects in your approach.</p>	<p>Visualisation and narratives are used at different stages of PHR to (a) help co-researchers frame the problems to be addressed by the project; (b) describe the challenges to implementing the project and recruiting participants; (c) present the data; (d) disseminate descriptions of the research process to engage stakeholders; present the findings. The methods include storytelling, case studies, vignettes, photovoice, other forms of visual representation such as diagrams, images and pictures, drama, music, poetry.</p>

Strengths and weaknesses

From your own perspective:
What would you consider as strengths and weakness of your approach?

Strengths:

- Co-produced logic models clearly illustrating potential pathways from problem to outcomes
- Intersubjective validity: Research is viewed as credible and meaningful by a variety of stakeholders with different perspectives
- Contextual validity: The research is grounded in the local situation
- Catalytic validity: The research is useful in terms of presenting possibilities for social action
- Empathic validity” The research process increases empathy among participants
- Focus on strengths and capabilities (as opposed to a needs-based, deficit approach to health) which can identify new forms of knowledge and collective action to make positive local improvements and inform local and national strategies and policies

Weaknesses

- Academic researchers are required to reserve time for interactive processes with new stakeholders, which is rarely protected for those managing a number of research projects
- Acknowledgement of other forms of knowledge challenges stakeholders who are accustomed to being seen as experts
- Local people (‘community researchers’) feel initially unempowered and underskilled to participate
- Relationships between people from different knowledge systems need to be facilitated
- Dependent upon funder and commissioner support for the research process, particularly in the initial stages of co-producing the research brief and design

Learn more

If possible, please insert a link to a website, paper etc. where details of your approach and its application can be found.

International Collaboration for Participatory Health Research (ICPHR) (2020) Position Paper 3: Impact in Participatory Health Research. Version: March 2020. Berlin: International Collaboration for Participatory Health Research.
http://www.icphr.org/uploads/2/0/3/9/20399575/icphr_position_paper_3_impact_-_march_2020_1.pdf

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Harris, J., Cook, T., Gibbs, L., Oetzel, J., Salsberg, J., Shinn, C., Springett, J., Wallerstein, N., Wright, M., Searching for the impact of participation in health and health research: Challenges and methods," Biomedical Research International, 2018, Article ID 9427452, 12 pages, 2018.
<https://doi.org/10.1155/2018/9427452/>.

Oetzel, J. Wallerstein, N., Duran, B., Sanchez-Youngman, S., Nguyen, T., Woo, K., Wang, J., Schulz, A.M., Kaholokula, J.K, Israel, B.A., Alegria, M., (2018). Impact of Participatory Health Research: A Test of the CBPR Conceptual Model: (Pathways to Outcomes within Community-Academic Partnerships), Biomedical Research International, Article ID 7281405, doi:10.1155/2018/7281405.