



International Collaboration for Participatory Health Research

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Funding Participatory Health Research

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Disclaimer

The opinions expressed in this position paper are those of the editorial group and the ICPHR Baltimore working group on funding. They do not necessarily represent the opinions of their institutions.

How To ...

Support Meaningful Participatory Health Research as a Funding Organization ...

... and Why!

Are YOU getting adequate return on your investments when funding health research?

No? Not as much as you would like? Not sure?

Funding more Participatory Health Research could be the answer!

Participatory Health Research (PHR) is different. Involving patients, the public or other relevant stakeholders throughout the research cycle requires different rules and different ways of thinking by all, but it comes with true merit. PHR makes health research more meaningful. Especially for those who are at the focus of the research. For patients and the public, PHR is a means for empowerment, reduction of inequalities, and ownership in research aiming for the improvement of their health and well-being (ICPHR May 2013). PHR can facilitate broader impact through greater acceptance of its results. It increases trust and generates benefits for all direct participants as well as society as a whole. For funding organizations, this integrative approach to research offers not only scientific and economic, but also social returns on investments. The value generated here can be more comprehensive and enduring, because it matters to all involved.

Since 2009, ICPHR has been paving the way for PHR, providing a definition, demonstrating its uniqueness and benefits, and also underlining the challenges and prerequisites that need to be addressed for PHR to actually function and have an impact (ICPHR May 2013). For funding organizations, these challenges and prerequisites translate into principles for funding that may differ widely from more traditional, non-participatory approaches in health-related research. Currently, funding organizations worldwide show a continuously rising interest in PHR. Thus, it is important to translate what is known about PHR and its challenges into principles that can be utilized by funders. Meaningful PHR can only happen with the understanding and support of those organizations worldwide that are active in funding research.

At the ICPHR Annual Working meeting 2019 in Baltimore, USA, a working group came together in order to provide some guidance especially, but not exclusively, for the audience of funding organizations. The focus was how to adequately support PHR and thus maximize its impact.

The first result of this endeavor is this short paper. It has two main aims. Firstly, it outlines benefits funders may harvest from investing in PHR. And secondly, it highlights some of the most effective ways for funders to support PHR.

This paper is more political than academic. It does not attempt to be exhaustive or to cover the vast body of knowledge already in existence concerning the background and mechanisms of PHR. It rather provides an exemplary spotlight of merits and prerequisites of successful involvement and collaboration in PHR, as compiled in a brainstorming process of the Baltimore working group. This input was fueled by the knowledge and experiences of the working group members with their various personal and occupational backgrounds as patients, members of the public, and participatory health researchers. The contributors intend the paper to be an entry point, providing initial insights and selected references for further, more in-depth information.

We do not understand this paper as a final version, but rather as a working paper which can be edited and expanded over time. Any reader is welcome to forward comments and suggestions to the authors, as well as references to additional policies and statements on ways to support PHR as a funding organization.

The first important result of the working group meeting in Baltimore is the following:

Funding Organizations can support Participatory Health Research by...

Asking how!

If you represent a funding body, we hope that this paper's contents are of use to you for promoting PHR within your organization! If you have any further questions, please do not hesitate to contact the ICPHR Central Office for further guidance.

Part 1: Benefits of PHR for Funding Organizations

PHR is rewarding in ways that differ from classical health-related research. Offering new perspectives, there is much to gain from this type of research. Not only for the people involved, but also for the bodies providing the means for it to happen, namely funders and policy makers! In our view, there is something to gain from PHR for every funding body. But different funding bodies may benefit differently, depending on their background, strategy, and aims. The following shortlist is not intended to be comprehensive or exhaustive. Instead, it reflects individual inputs from participatory health researchers organized in ICPHR, and provides references to existing literature on the impact of PHR.

- **PHR facilitates social return on investments in health research.** (Abma et al. 2019; Wright et al. 2018)
 - PHR provides direct links to strategic priorities on social care and public engagement that may already be in place at your organization.
 - Should your organization intend to place more emphasis on the social impact of health research in the future, PHR provides an ideal entry point.
 - Through initiating interdisciplinary and impactful research projects involving all relevant stakeholder groups, PHR has the potential to create visible, enduring impact, meaningful change, and true value for the money.
 - PHR can help prove that health-related research can actually have social impact.

- **PHR makes your funding organization an investor in social change and social impact.** (Abma et al. 2019; Roura et al. 2021)
 - PHR provides answers to inequality challenges. It can support the transformation of social and health inequity as well as exclusionary structures and policies.
 - It empowers those involved, serves as a means for their increased ownership in research, and produces results focused on improvement of their health and well-being.
 - PHR fosters and improves democratic processes. It can enable societies to address structural, overarching aspects or social determinants affecting health equity.
 - Over time, it has the potential to change social norms.

- **PHR is a means to increase the sustainability and impact of health research and its results.** (Cacari-Stone et al. 2014; Dias et al. 2018)
 - In the medium and long term, active involvement of communities and other stakeholders in PHR can lead to sustained partnerships, increased trust and higher levels of individual or agency capacity.

- These outcomes positively influence health research productivity as well as the acceptance and translation of results.
- **PHR can increase the visibility and credibility of your funding agency in communities.**
 - PHR promotes trust, partnership and capacity not only among the groups involved in the actual research, but also between the groups and the funding organizations.
- **Investing in PHR now makes you a pioneer.**
 - PHR is still a relatively new form of research. Investing in it now will make you part of a steadily growing worldwide group of funders pioneering the field (Sheridan et al. 2017; CIHR 2014; Califf et al. 2016). Already, increased interest and activity in PHR among funders and policy makers leads to an increased number of funded PHR projects. These projects continuously add to a knowledge base of dos and don'ts, criteria for impact, and methodology in PHR which is invaluable for ensuring quality and future success. Joining now as a funder will help to further promote this process.

Part 2: The Best Ways for Funders to Support Meaningful PHR

PHR is unique¹. The participatory process makes it more organic, more time-consuming, and less predictable than the usual health research. Also, PHR requires different types of expertise, and its impact or success often cannot be gauged by traditional criteria. For funding institutions, this means that special funding mechanisms must be applied, and different perspectives must be adopted to enable PHR to unfold its full potential (PartNet et al. 2020; Bethmann et al. 2021).

The following short list states some basic points to consider from the perspective of a funding organization intending to support PHR. As in Part 1, this list is not intended to be comprehensive or exhaustive. It reflects the experiences of participatory health researchers in ICPHR, while providing references to more extensive papers on the nature of, and the prerequisites for, meaningful PHR.

- **Fund more research on participatory health research itself.**
 - PHR is an emerging form of research. Although an impressive knowledge base already exists, it is still not entirely clear which methods of involvement are most effective in which settings, how to build good partnerships between all groups involved in a PHR project (Merzel & D’Afflitti 2003)² or how to adequately measure success and impact in PHR. Systematic overviews of existing literature are scarce.
 - Specific calls for research-on-research—or meta-research—projects in the field of PHR help lay a more solid foundation of information, methodology and tools (Fleurence et al. 2015).
- **Support training of all groups involved.**
 - The first step towards funding or conducting meaningful PHR is asking how! All parties involved in PHR—be it academic researchers, patients, community members or other relevant stakeholders—should receive quality-controlled information on the background, philosophy, and methodology of this type of research via suitable training measures.
 - Training in health literacy is a means to achieve empowerment and equality for patients and others involved in PHR.
 - As a funding organization interested in PHR, you should also invest in training your own personnel.

¹ Because of its unique characteristics, such as: democratic participation, collective process, collectively owned research, aim for broad impact and transformation. For further information see ICPHR quality criteria as described in Position Papers 1 and 2 (ICPHR May and October 2013).

² Compare this description of grant criteria from the National Institutes of Health (USA): <https://www.ccphealth.org/resources/promising-practices-community-engagement-in-research-funding-announcements-peer-review-criteria/>

- As a funding organization well-versed in PHR, you can either pass on your own expertise and expectations by offering training courses yourself or offer platforms for external experts to train interested groups.
 - You can also make training and capacity-building a mandatory part of the PHR projects you fund: Be sure to offer additional funds for such activities.
 - Funding PHR-oriented student summer schools, or pre/post doctorate fellowships can also be effective tools for PHR training.
- **Allow for sufficient timelines and financial support to foster meaningful PHR.**
 - The true merits of PHR often only unfold after investments have been made for some time. One of the keys to successful PHR projects is the establishment of sustainable, high-quality commitments, relationships and partnerships between academia and community partners. Provided these are indeed well-established and maintained for a sufficient amount of time, they can lead to medium- and longer-term outcomes such as policy change or increased individual or agency capacity (Zimmerman et al. 2019). Thus, they can lay the foundation for actual social impact and increased social or health equity (Oetzel et al. 2018).
 - For funding institutions, the need for longer-term commitment translates into funding periods which can be much longer than for other, non-participatory research projects. In PHR, research projects should ideally be preceded by a preparatory phase for the development of partnerships, establishment of infrastructure and smaller pilot projects. This allows for a natural progression through need identification, partnering, and planning of the actual research project. Staging multi-phase calls with separate funding-phases for partnering, the research phase, and the dissemination of results has already proven successful³.
 - In order to pave the way for success, funding organizations should provide sufficient funding for all phases of PHR projects. Also, funding should be made available not only to academic institutions but also to community partners, and it should cover all aspects and means which may be important for enabling communities and individual persons to participate (also see “training” above).
 - **Allow for sufficient flexibility to foster meaningful PHR.**
 - In comparison to non-participatory research, the organic nature of PHR necessitates a much higher degree of flexibility in funding organizations. When prospective partners of a PHR-project come together for the first time, it is often simply not possible to foresee the course the project will take or the exact budgetary necessities. Budgets, milestones, methodologies or the required external input and expertise may change

³ The National Institute on Minority Health and Health Disparities (USA) has awarded grants for up to eleven years: <https://www.nimhd.nih.gov/about/overview/>

over time. It is important to keep this in mind and allow for adequate freedom when defining the formal standards and requirements for PHR calls and projects.

- **When assessing impact and success of PHR, make sure to apply appropriate viewpoints and criteria.** (ICPHR 2020)
 - Some of the questions most frequently asked about PHR by academic researchers and funding organizations alike are: “Is it really worth it?”, “What is the impact?” or “How do I measure success?” PHR is less straightforward and more time-consuming than traditional health-related research. Furthermore, traditional criteria for evidence (as in clinical research) can often not be applied. When gauging the impact of PHR, “softer” medium or longer-term outcomes such as policy change, increased individual or agency capacity, increased meaningfulness (relevance) of the research, incremental social change, or increased health equity need to be considered. These require new, different, and often unusual sets of criteria and tools for measurement. Ideally, these should be defined together with the communities involved at the outset of the projects.
 - When planning to support PHR, funding organizations should open themselves up to new forms of evidence and methods for gathering it. They should allow alternative deliverables and accept other types of expertise than they would do when funding health-research without stakeholder involvement.

- **Recommendations for specific stages in the funding cycle**

To increase the chances for supporting truly meaningful PHR, funding organizations are encouraged to consider the following recommendations for action at specific stages of the funding cycle, ranging from the conception of calls and formal criteria for funding to guidelines for applications and project review.

- **Funding Program and Call**

Patients and the public should already be involved in the conception of funding programs or calls. Including their voices and opinions at the level of agenda and priority setting helps prevent misguided efforts, thereby increasing the chances for acceptance and impact of the funded research.

- **Call Text**

Make PHR an explicit focus in your calls! If you intend to fund and support meaningful PHR, make sure to clearly state this in your calls⁴.

Also, be clear about what you actually mean by “participation” or “involvement,” and specify the stakeholders who, in your view are required. This will help to avoid tokenism.

Clearly formulate your prerequisites for meaningful and ethical PHR in the projects you fund (ICPHR October 2013; PCORI 2016).

Make partnerships with the specific communities addressed in projects a prerequisite for funding. Also, make sure communities or their representatives are involved throughout the entire cycle of research. You may also want to consider declaring only projects with a project lead or a co-applicant from the community as eligible⁵

Accept the expertise of research partners outside of academia.

Explicitly allow PHR specific methodology (e.g., photo voice, group-level assessment, etc.) in projects.

Provide resources and categories of funding that are relevant to community members, and which enable them to participate. In some cases, this may be as simple and basic as providing an allowance to pay for food.

Be sure to distribute benefits and (administrative) responsibilities in projects among all project participants. For instance, allow community-based organizations or community members to be principal investigators, allow non-academics to be on salary or contractors in projects, or provide separate awards to academic and community partners.

Utilize your call or funding initiative to foster the exchange and interaction between health-related academia and practice (Bialek 2000)^{6,7} e.g., by

⁴ See this example from Americorps (formally the Corporation for National and Community Service) in the United States: <https://www.nationalservice.gov/build-your-capacity/grants/funding-opportunities/2018/community-conversations-research-competition>

⁵ Compare these criteria for peer review from Community-Campus Partnerships for Health (USA): <https://community-wealth.org/content/promising-practices-community-engagement-research-funding-announcements-peer-review-criteria>

⁶ Compare these statements from the Association of Schools of Public Health (USA): <https://www.aspph.org/teach-research/models/demonstrating-excellence-in-the-scholarship-of-practice-based-service-for-public-health/>; <https://www.aspph.org/teach-research/models/demonstrating-excellence-in-academic-public-health-practice/>

⁷ For multiple perspectives on collaboration between schools of public health and public health agencies see Kegler et al. (2006).

allowing, enabling and promoting both that practitioners be hired for positions in academia and that academic staff engage in practice placements.

- **Application**

Require clear information regarding strategies for involvement in all stages of the project cycle in proposals for PHR projects.
Ask for or allow recommendation letters not only from academics, but also from communities.

Where deemed necessary, accept formats of applications other than written (e.g., video or audio).

- **Review**

Apply community-oriented review criteria such as the quality, level of establishment and sustainability of a partnership (Cargo & Mercer 2008)⁸.

Make sure review panels/reviewers have appropriate PHR expertise. You may want to consider placing non-academics or academics with proven expertise/track record on PHR on review panels.

⁸ See the description of the review process of the Navajo Nation in Minkler & Wallerstein (2008), p. 443ff.

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