



**INTERNATIONAL COLLABORATION FOR PARTICIPATORY HEALTH RESEARCH**

*Promoting the science and enhancing the impact of participatory health research*

<http://www.icphr.org/>

## **International Collaboration for Participatory Health Research (ICPHR)**

### **Terms of Reference**

**November 2020**

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## 1. Who We Are

ICPHR is a scientific and nongovernmental network, open to stakeholders from all countries interested in the promotion, dissemination, and further development of participatory health research (PHR) embedded in common values and principles. The ICPHR is a community of practice

- composed of those people who initiate, advocate for, and facilitate PHR projects (inside and outside of academia), thereby offering a unique collective expertise. These are people who are not just interested in one project, but who lead or want to lead such projects as a central part of what they do;
- focused on synthesizing knowledge from world experience on what PHR is and what it does, thus being a “think tank” for PHR;
- whose members are from diverse backgrounds (cultural, racial, geographical, professional, etc.), have diverse perspectives in research, and work in diverse contexts (e.g. academia, CBOs, non-profits/voluntary sector, governmental organizations, funders, etc.); and
- whose structure is decentralized and acts as an international network.

## 2. Our Mission

The mission of the ICPHR is to bring together systematically the knowledge, practice, and experience of PHR in different countries for the purpose of strengthening PHR regarding issues of quality, credibility, and impact on policy, health and well-being.

### 2a. Goals and Objectives

The goal of the ICPHR is to establish PHR as an integrated part of local, regional, national and international strategies to address issues of health equity. PHR addresses these issues using the collective wisdom of community voice and scientific practice producing real time solutions. We seek to strengthen the position of PHR in research institutions (within and outside universities), nongovernmental organizations, and policy-making structures. To reach this goal, the following objectives have been set:

- Objective 1: To Define PHR. An evolving conceptual clarity regarding PHR will be reached through international consensus on:
  - a common definition describing the distinguishing features of PHR;
  - an explanation of the scientific (theoretical and methodological) basis for PHR; and
  - ways to build theory on the social, economic, and political determinants of health based on PHR findings.

- Objective 2: To Enhance the Quality of PHR. The quality of PHR will be enhanced by defining guidelines for best practice in
  - PHR education, co-learning, and skills development;
  - engagement/participation of communities;
  - research methods and design; and
  - translating findings into action, policies, and innovation.
  
- Objective 3: To Reinforce the impact of PHR. The impact of PHR will be strengthened by:
  - defining a broader concept of impact;
  - capturing the short and long term effects unique to PHR;
  - synthesizing the empirical findings and theoretical models which have been generated by PHR; and
  - establishing a knowledge base of PHR projects where users will be able to both contribute their own work and also search for the work of others on key dimensions (e.g. community characteristics, methods, health issue, type of impact).

## 2b. Activities of ICPHR

The ICPHR mission is accomplished through stakeholders supporting each other's efforts to:

- foster local/national/international networks;
- produce evidence of the quality, value and impact of PHR;
- provide scientific evidence to support optimal health and social change;
- gather like-minded stakeholders to serve as a think tank and support system for conducting PHR;
- develop guidelines for capacity building in PHR;
- develop guidelines for conducting and evaluating PHR;
- create a database of resources on the theory, practice, and outcomes of PHR;
- describe theory, evidence, and the unique impact of PHR as compared to other research approaches;
- find a means for conducting systematic reviews of the PHR literature in order to contribute to the body of international knowledge on improving community health; and
- establish a resource and repository for evidence-based PHR literature.

### 3. Our Values

- Ways of working together/work atmosphere
  - Showing respect toward each other
  - Actively seeking to identify and resolve barriers to participation
  - Providing mutual support
  - Recognising privilege and utilising strategies to promote agency
  - Ensuring equal opportunities for input from all members, regardless of title or status
  - Being able to participate with one's own unique perspective, experience, and knowledge
  - Adopting an inquiring stance
  - Learning from one another (co-learning)
  - Giving constructive feedback
  - Providing an independent perspective without the dominance of any specific institution or interest group
  - Conducting work in a diversity of languages
  
- Common goals
  - Exploring emergent science/knowledge
  - Promoting more impact of PHR
  - Advocating for PHR
  - Being visible as a network
  - Providing evidence, knowledge, and tools to support increased health/social justice
  
- Common principles described in the first Position Paper and including
  - Diversity from an intersectional perspective
  - Collaboration/co-laboring
  - Openly mindful/open-minded
  - Being value-based and communicating that to others

### 4. Our History

The ICPHR was founded in 2009 by the WZB Berlin Social Science Center, Germany (Michael Wright), the Wellesley Institute in Toronto, Canada (Brenda Roche and Bob Gardner), and the Liverpool John Moores University, UK (Jane Springett), with the Central Office located at the WZB. Over time, the Executive Committee (ExCom) was expanded to include members from other countries. In 2011, the Central Office moved to the Catholic University of Applied Sciences in Berlin, Germany. In 2014 the ExCom was reorganized as a consortium of researchers, each member responsible for coordinating a specific area of expertise. The purpose of this reorganization was to expand the capacity of the ICPHR for joint projects. An Annual Working Meeting for all

ICPHR members has been conducted since 2010, taking place in a different country and being hosted by a different ICPHR member each year. A steady increase in joint projects, a growing membership, the need to relocate the Central Office, and the desire to increase further the capacity of the ICPHR resulted in the formation of a Strategic Planning Group in 2019. This group initiated a process for reflecting on the purpose, values, and achievements of the ICPHR, setting the groundwork for further growth. This included writing Terms of Reference and making changes in the structure and governance of the ICPHR.

## 5. Governing Structure

The ICPHR is a network of people who initiate and facilitate PHR projects. The structures of the ICPHR, following the core principle of distributive leadership, should reflect the previously stated value placed on diversity. Structural elements of the ICPHR are described below.

### 5a. Steering Group

The Steering Group governs the ICPHR. This body makes decisions on all matters beyond day-to-day operations. The Steering Group has the following characteristics:

- The group is formed by ICPHR members who volunteer to serve.
- It is desirable that Associated Networks and standing Working Groups be represented on the Steering Group.
- New members are approved by the existing Steering Group members.
- Steering Group members serve 3-year terms, on a voluntary, non-remunerated basis. It is recommended that a departing member seek out a replacement.
- The minimum number of members should be nine (including the five members of the Coordinating Committee and four at-large members). There should be a sufficient number of members to achieve a diverse representation of the ICPHR.
- The Steering Group designates a member as the facilitator who convenes and facilitates the meetings. Ideally, the facilitator should serve a term of at least one year.
- The Steering Group meets at least quarterly (see Section 6).
- The Steering Group chooses the host organization for the Central Office and reviews the work of the host organization, issuing a new call every five years.
- Expectations of Steering Group members:
  - Regular attendance of Group meetings (i.e. attends a majority of meetings) and takes an active role in accomplishing tasks of the Group
  - Provide timely and judicious input on key committee/workgroup/project deliverables
  - Contribute to the planning of key meetings and assist with the dissemination of results/reports
  - Promote communication between ICPHR and stakeholder groups

- Open and close ICPHR special functions and activities (e.g., workshops, annual working meetings, etc.)
- Facilitate ICPHR succession planning
- Additional Steering Group criteria, roles and responsibilities may be developed over time as identified by the Steering Group.

## 5b. Coordinating Committee

The Coordinating Committee is a subgroup of the Steering Group that carries out the decisions of the Steering Group and provides oversight and support to the Central Office of the ICPHR.

- The Coordinating Group is composed of five members, who volunteer to serve at least one 3-year term, non-remunerated. In some cases, the Lead Coordinator Elect will constitute a sixth member (see below).
- New members are approved by the Steering Group.
- The Coordinating Group meets at least bimonthly (see Section 6).
- Members are designated to fill the following standing roles: Lead Coordinator, Membership Coordinator, Finance Coordinator, Communications Coordinator, and Strategic Coordinator.
  - The Lead Coordinator organizes and documents the meetings, acts as liaison to the Steering Group and the Central Office, and supports communication and coordination between the other members of the Coordinating Committee.
  - The Membership Coordinator develops and implements a membership growth and retention plan every three years and plans the annual membership drive.
  - The Finance Coordinator monitors the annual budget of the ICPHR and develops an annual fundraising plan.
  - The Communications Coordinator develops and oversees the internal and external communication of the ICPHR.
  - The Strategic Coordinator develops and oversees activities for maintaining and expanding on strategic partnerships with other organizations.
- A Lead Coordinator Elect is selected by the Steering Group, serving on the Coordinating Committee and assuming the role of Lead Coordinator after the three-year term of the existing Lead Coordinator expires. The Lead Coordinator Elect can also exercise one of the other Coordinator roles.

- The Coordinating Committee also performs the following functions:
  - Prepares the annual work plan and budget
  - Oversees hiring and supervision of contracted personnel
  - Guides the Steering Group in addressing issues and concerns as they arise
  - Reviews all expenses, monitors budgets and provides regular reports to the Steering Group
  - Establishes and maintains charitable status for the ICPHR

### 5c. Central Office

The Central Office manages the daily operations of the ICPHR with the support and oversight of the Coordinating Committee. The Central Office has the following characteristics:

- Is hosted by an organization with international experience and ties for a period of five years.
- Dedicates one part-time, paid staff person (at least 0.5 FTE)
- Manages communication: web site (including repository), social media, newsletter
- Links members to each other, based on interest, region, or language
- Links associated networks with the ICPHR
- Seeks funding and international partnerships for the ICPHR
- Maintains the membership list using an online membership database
- Monitors and responds (or delegates as appropriate) emails sent to ICPHR's general email address
- Provides support to the Coordinating Committee in sending communications to all members
- Provides support to the Coordinating Committee in performing its duties

### 5d. Working Groups

The Working Groups are constellations of members who are working on joint projects. There are two forms:

- Standing groups: Groups of members working on an ongoing project/topic (e.g. Kids in Action, evaluation, training). Standing groups are encouraged to designate a representative to be a member of the Steering Group.
- Ad hoc groups: Groups of members working together on a time-limited project (e.g. position/discussion papers)



## 5e. Associated Networks

Associated Networks are the local and regional networks of participatory researchers that have been recognized by the Steering Group as being associated with the ICPHR. Associated Networks will evidence their commitment to PHR and to the active development of links between the work of the ICPHR and their own. They will display the ICPHR logo on their own websites, and they will be linked to the ICPHR website. The Associated Networks are encouraged to designate a representative to be a member of the Steering Group.

## 5f. Membership

ICPHR is open to people from all countries interested in initiating, advocating for, and facilitating PHR projects and further developing PHR embedded in common values and principles.

## 6. Operations

### 6a. Annual Working Meeting

The Annual Working Meeting (AWM) provides all ICPHR members with the opportunity to discuss issues of common concern and to initiate and work on joint projects. The AWM is:

- open to anybody interested in PHR;
- free to all attendees;
- hosted each year by a different member (ideally alternating between world regions);
- characterized by a style of working in which anyone may propose and/or initiate a topic for joint work;
- conducted using participatory processes;
- a place to work together in small groups on specific topics/projects;
- a place to discuss overarching issues in plenary;
- conducted according to an agenda that is set collaboratively for the upcoming year; and
- a meeting with both in-person and online opportunities to participate

### 6b. Meetings

Meetings of the Steering Group are convened at least quarterly via teleconference and/or at the call of the Lead Coordinator. Efforts are to be made to hold an in-person meeting at least once annually. A simple majority for a Steering Group meeting is necessary to achieve a quorum; a minimum of 50% plus 1 (one may be the Lead Coordinator or their alternate) must participate in the meeting. A member participating shall be deemed to be present at the meeting and shall be entitled to vote and be

counted in the quorum accordingly. Decisions are made based on consensus. In reaching consensus, it is important:

- to solicit all members for possible solutions (the person expressing the concern and the rest of the group both have a responsibility to find solutions); and
- to encourage members to suggest improvements or alternatives that meet the objectives of the entire Steering Group.

Meetings of the Coordinating Committee are convened at least bimonthly via teleconference, and/or at the call of the Lead Coordinator. Efforts are to be made to hold an in-person meeting at least once annually.

Working Groups and Associated Networks will be invited to provide regular updates to the Steering Group.

The Lead Coordinator and/or another member of the Coordinating Group will meet with the Affiliated Networks and Working Groups as needed.

#### 6c. Website

Up-to-date information is maintained on the ICPHR website, <http://www.icphr.org/>.

#### 6d. Grant Management

The Coordinating Committee will work with the Central Office to develop proposals and hire contracted personnel. Contracted project managers and/or consultants will be responsible for deliverables outlined in their contract/terms of agreement with direction, guidance and support from Central Office.

#### 6e. Confidentiality

It is the duty of the Steering Group, the Coordinating Committee, and the Central Office to keep confidential any information. This entails any information made known to, or learned by, members through various sources including, but not limited to, electronic media, hard copy files, written and verbal communications. Members shall not reveal, make known, disclose, or provide access to confidential information to anyone who does not have designated rights to obtain the information. Confidential information is to be discussed only among members of the Steering Group, the Coordinating Committee, and the Central Office.

## 6f. Ethical Guidelines for Funding, Sponsorship and Research

The ICPHR shall adhere to the following guidelines:

- Ethical principles will be followed as outlined in Position Paper 2, *Participatory Health Research: A Guide to Ethical Principles and Practice*.
- Consensus must be reached by the Steering Group before seeking and/or accepting any funds and/or support from sponsorship.
- Funding and/or sponsorship support should only be accepted from the following sources that meet ethical considerations determined by the Steering Group:
  - Governmental/non-governmental agencies
  - Professional associations/groups
  - Foundations/Philanthropics
  - Corporations
  - Individuals

## 6g. Intellectual Property

Issues of intellectual property need to be determined and clarified when ICPHR is considering accepting external funding and support.

## 6h. Conflict of Interest

A conflict of interest arises when a member's private interests, the interests of their organization, or the interests of someone with whom the member has a close personal or external professional relationship supersede or compete with the member's dedication to the interests and purpose of ICPHR. All members are expected to perform duties conscientiously and have an obligation to declare a conflict of interest prior to discussion of an issue. Upon declaration of a conflict, the member must absent themselves from the proceedings.

## 6i. Review of Terms of Reference

The Terms of Reference will be reviewed annually by the Steering Group or at the call of the Lead Coordinator. The review will also be a topic on the agenda of the Annual Working Meeting.

## 6j. Contact Lists

The Central Office will keep an updated contact list of the Steering Group and the Coordinating Committee. Members may contact the Central Office at any time to receive an updated contact list.