Fourth ICPHR Annual Working Meeting Minutes
Executive Summary
June 5 – 7, 2013
Newcastle-upon-Tyne, United Kingdom
Hosted by: Northumbria University

The goals of the meeting were to:
- To be informed on the progress regarding projects and position papers since the last annual working meeting in Coimbra
- To raise and discuss new ideas and issues, including posters on members' work
- To work together on current projects, position papers, new ideas and issues
- To discuss and finalize the specific location and timing of the 2014 ICPHR annual working meeting in Brazil

Attendance
The meeting was attended by twenty-seven new and returning International Collaboration on Participatory Health Research (ICPHR) members. Attendees were from the following countries:

Canada	Portugal	Germany
Ireland	England	Netherlands
Brazil	United States	Scotland
Mexico	Sweden	Australia

Meeting Overview
The majority of the meeting was spent in small group discussions about the current status of those position papers and projects that are in progress, and suggestions for their further development and refinement. Some time was also given to exploring issues arising, and strategic planning for the ICPHR. Over the three days, specific topics discussed included:

Current Projects and Position Papers

- **Definitions Position Paper 1**

  This paper focuses on defining the core features of Participatory Health Research (PHR) as compared to other forms of public health research. Discussion focused on revisions to the paper which included (1) better articulation of the spectrum of PHR upfront in the paper, (2) the need to provide example scenarios of how PHR has been used and the impact it has, (3) the need for scenarios to cover a wide variety of expertise, (4) changing terminology (e.g., from 'paradigm' to 'approach' when discussing PHR, and different wording than 'maximizing participation').

- **Ethics in Practice Position Paper 2**

  This paper is a revised version of a guide that was developed in 2012 focusing on ethical principles and practice in community-based participatory research. The discussion was around final revision to the paper and preparing materials for the web that are internationally relevant, for example: practical tools (e.g., how to do informed consent) and case examples of ethically challenging situations.

- **Facilitation Position Paper 4 (NEW)**

  This position paper attempts to bring together some critical reflections on the wide-ranging set of experiences among facilitators of participatory processes, particularly in the context of research. The lead for this paper introduced the ICPHR's perspective on 'facilitation' highlighting the fact that it has become one of the many analytic 'black boxes' in the study of participatory research. The group agreed that there was a need to establish an editorial group for the paper and invite all ICPHR members to write a contribution of 500 words with the theme: "My critical reflections on facilitation"

- **Interactive Knowledgebase**

  This project began with the piloting of a database to bring together published studies and other material on Participatory Health Research. The concept has now evolved and in March of 2013 the project leads applied for a grant to fund the Interactive Knowledgebase (IK). The IK is intended to be (1) an online central repository for the collection of PHR work (academic and non-academic), (2) a platform to stimulate reflection in project leads about the ways they were participatory and how their work created impact, and (3) an interactive space for novice and expert practitioners to discuss, network and learn from each other's experiences. As funding was not awarded, discussion centred on suggestions for improvement to the concept: to use the platform as (1) a training space for students, (2) a place to house a glossary of terms, and (3) an important space for community groups to share their PHR work, including ongoing work.

- **International PHR Short Course**

  This is a continuing education course introducing the participants to the concepts and methods of Participatory Health Research. So far it has been run in Germany and the England. At the meeting the question of awarding credits (and evaluation) was raised, and how to run this course online across different time zones, languages and institutions. Suggestions were also made to keep in a repository documentation of how the course was carried out and materials used, and add modules on facilitation, cultural competency/intelligence/ sensibility, advocacy and lobbying.

- **PHR Literature Reviews (NEW)**
  There are several literature reviews of PHR that have either recently been completed (e.g., in Canada and Portugal) or are in progress across the ICPHR but we do not have an inventory to keep track of them all. Few attendees joined this discussion so it was decided that an effort would be made to track down all of the literature reviews happening and add them to the prototype for the interactive knowledgebase.

- **Publication Strategies (NEW)**

  This project addresses issues related to the publication of PHR and the publication of the work of the ICPHR. The discussion revolved around where the ICPHR should publish (journals were suggested) and the importance of developing a set of reporting guidelines to ensure consistency in the reporting of PHR and increase the impact. One of the project leads also introduced the prospect of publishing a special issue of the journal Educational Action Research dedicated to the work of the ICPHR.

- **ICPHR website re-launch (NEW)**

  The ICPHR is launching a new website using weebly. All meeting attendees responded (in groups) to a set of questions for ideas and improvements to the current website that were fed back to the person re-developing the website. To summarize the feedback, attendees wanted to see an online space that is more interactive, resourceful, and dynamic. More visuals (photos, power point presentations) were also encouraged, as well as pages of the site being in different languages supported by local translators.

Issues arising

- **Educational Action Research (EAR) Journal Special Issue**
  Publishing a special issue in EAR was recognized as a way to raise the profile of the ICPHR: A special issue could include bringing together the different participatory traditions providing examples, an orientation to what the ICPHR is, and comparison of PHR practice by language group or region. Some attendees offered to jointly write an article on the different traditions of PHR and how they come together in the ICPHR, and all ICPHR members were encouraged to draft articles.

- **Interactive Knowledgebase**

  There was an interest to discuss next steps for the IK; the discussion covered suggestions for inclusion of grey literature (e.g., non-academic and evaluations),

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expansion of the dimensions by which the data is categorized, and a registration process. The most time was spent on the last item; there was a strong interest to develop a set of registration questions that would not only result in capturing data but also provide a first opportunity for those adding their work to reflect in novel ways on the participatory process they used and the impacts created by the work.

- **Funding for the ICPHR**

    The discussion included suggestions for how to establish the ICPHR to better receive income (e.g., register as a non-profit to accept donations, use accounts separate from the university institutions, and connect to NGOs) and ways to generate income, in light of the upcoming AWM in Brazil. Actions were stipulated including the ICPHR Executive Committee exploring the possibility of becoming an NGO, applying to CIHR for a Meeting Grant, setting the ICPHR as a non-profit, and determining if SPOR (Strategy for Patient Oriented Research, a division of Canada's largest funding agency) can be used to our advantage.

- **Raising the Profile of the ICPHR**

    In this lively discussion, working group members suggested creating an ICPHR working group with the focus of raising the profile of the ICPHR (to advocate, lobby, and market the ICPHR). Using the website (the more visits to the website, the higher it shows up on Google searches), the EAR special issue and citation strategies (e.g., adding "participatory health research" as a key word/subject heading/MeSH term, adding the ICPHR website to your signature in emails) were other ways of raising the profile.

- **Widening/Increasing ICPHR's Inclusivity**

    Discussion focused mainly on the suggestion to restructure the ICPHR into three levels to ensure cultural diversity and increase the connection to NGOs and other groups:

    A. an international level that has representation across different language groups;
    B. an official language level (one for each language represented in the ICPHR); and
    C. a local PHR level within each language group

    There was also some general discussion about the interest to allow non-academics to publish directly in journals, and the importance of paying attention to being ethical and inclusive within the ICPHR (Sarah's ethical guidelines were cited for guidance here).

- **Brazil ICPHR AWM 2014**

  More than one proposal was put forward for the next ICPHR AWM in Brazil. The rest of the meeting was spent discussing the pros and cons of holding the AWM in May versus August. While a decision was not reached at the meeting, other ICPHR members provided their input and those who submitted proposals opted to collaborate after the meeting to plan a final proposal together and submit to the ICPHR Executive Committee.

Strategic Planning
  1. *Who are the strategic partners who can help us advance our work?*
  2. *Who do we know whom we can personally engage?*

Other questions that arose and were discussed as well in this session included:
  1. What are the goals of these partnerships?
  2. Where can we find funders for activities at a national and international level?

AWM Action Items
Discussions were concluded with the development of a list of action items. All action items have been compiled by ICPHR member and begin on page 3.

Poster Session
Three posters were displayed during the AWM and discussed informally:

- *Communication support in primary care practices for patients requiring multi-lingual consultations*
  -Joe LeMaster, U of Kansas, USA

- *Participatory Action Research to develop empowerment and partnership between clients and professionals in the context of care*
  -Vivianne Baur and Saskia Duijs, VU University Medical Centre, Netherlands

- *Showing and growing community resilience*
  -Wendy Madsen, Central Queensland University, Australia

2014 ICPHR Annual Working Meeting
The next AWM will be held in Rio De Janiero, Brazil in August, 2014.

*Please email emma.wilkins@ualberta.ca if you have questions or concerns about these minutes.