INTERNATIONAL COLLABORATION FOR PARTICIPATORY HEALTH RESEARCH

Promoting the science and enhancing the impact of participatory health research

Program for the Annual Working Meeting 2020

Due to the COVID-19 pandemic, our Annual Working Meeting to be hosted by our colleague Rodolfo Levin (Director, Instituto de Higiene, Facultad de Medicina-Universidad de la República) in Montevideo, Uruguay was cancelled. As an alternative, we issued a call to our members to conduct virtual workshops during the week of November 9th to the 13th. Each of the workshops will be hosted by the facilitators using their own video conferencing software. If you are interested in attending a workshop, please contact the hosts to receive the link. The hosts will be asked to write short minutes that will be collated and distributed to all who attended the workshops. We look forward to seeing you next year in person in Coimbra, Portugal! Watch our site for details!

Please Note: All times are for the Central European Time zone (the time at the ICPHR Central Office in Berlin). You will need to covert to your own time zone using one of the many online tools. Several hosts will set the day and time or are open to changing the day and time to take into account the schedules and times zones of those who wish to participate. Please inquire with the hosts.

Workshop 1

Title:	**Theory and Methods Working Group**
Host:	Sónia Dias (Portugal)
Contact:	smfdias@yahoo.com
Time and Day:	Tuesday, 10 November, 4:00 – 5:30 pm
Abstract:	

This working group meeting will be a space for discussing current and future projects on theory and methods for participatory health research. In a very informal approach, time will be given to explore emergent issues and planning for future projects in this area. Everyone interested in the topic is welcome to participate.

Workshop 2

Title:	**Participatory Health Research in UK NHS Mental Health Services: Hindrances and Helps**
Host:	Katherine Allen (UK)
Contact:	k.allen@nhs.net
Time and Day:	Please contact the host
Abstract:	

Many health research grants now call for evidence of 'public/patient involvement' on their application forms. It is also a requirement for ethical approval for health research conducted in the UK's National Health Service (NHS). This presents both opportunities and dilemmas for people committed to participatory health research. There are a number of complex questions surrounding this apparently positive move: how do these requirements relate to participatory health research? What is really meant when organisations demand public and patient involvement? How should involvement be conducted? How can it go wrong, and

how can it go right? This working group will be co-facilitated by members of a mental health NHS service user and carer research group named LEAR (Lived Experience Action Research).

Workshop 3

Title:	**Ethics in Participatory Research**
Host:	Sarah Banks (UK)
Contact:	s.j.banks@durham.ac.uk
Time and Day:	Thursday, 12 November, 1:00 – 2:30 pm
Abstract:	

In this working group we will review the work of ICPHR on ethics to date and consider priorities for the coming year. We will take stock of participants' experiences and expertise and create an agenda of issues to cover. Topics we might wish to consider include: the ethical issues arising from the impact of Covid-19 restrictions on participatory research; community-based ethics and ethical review processes; challenges to academic-led views of what is ethical; the ethics of care and relationship-based ethics in participatory research; possibilities for preparing guidelines and case studies for the web on specific ethical issues and challenges.

Workshop 4

Title:	**Strengths, Opportunities, Weaknesses and Obstacles of Doing Participatory Research with Child Co-Researchers in the Context of COVID-19**
Host:	Katitza Marinkovic (Australia)
Contact:	marinkovick@unimelb.edu.au
Time and Day:	Thursday, 12 November, 10:00 – 11:00 pm
Abstract:	

We plan to carry out a workshop where researchers will discuss the opportunities, challenges, strengths and weaknesses of doing participatory research with children in the context of COVID-19. We will use an interactive online platform (Miro or Mura) to facilitate the activity and give participants an opportunity to experience doing collaborative work with an online tool that they can use later in their work. We'll ask participants for their consent to use the outcomes of this workshop to device an online survey to gather the experiences and perspectives of a larger number of researchers interested in this approach to doing research with children. The outcomes of the workshop and the survey will be published in an open access journal. To do this, our team is currently undergoing the process of ethics approval at the University of Melbourne. This project is supported by a U21 Researcher Resilience grant.

Workshop 5

Title:	**Children and the Environment: Building Shared Knowledge and Collaborations for Participatory Research with Children**
Host:	Katitza Marinkovic (Australia)
Contact:	marinkovick@unimelb.edu.au
Time and Day:	Thursday, 12 November, 11:00 pm – midnight
Abstract:	

Children's lives and wellbeing are increasingly affected by the climate emergency and environmental degradation. At the same time, many children and youth are actively advocating for and engaging in climate action. A group of researchers in the Kids in Action network has met during the past year to organize a session during the ICPHR Annual Working Meeting of 2020 to discuss how our different lines of research intersect with the different topics related to children's experiences in relation to the environment. Our goal is to identify key knowledge, expertise, research interests and opportunities for funding that our group can use to build international research collaborations.

Workshop 6

Title:	**Social Participation in Old Age**
Host:	Petra Plunger (Austria)
	Margareta Rämgard (Sweden)
Contact:	petra.plunger@univie.ac.at
Time and Day:	Thursday, 12 November, 10:00 -12:00 am
Abstract:	

Social participation in old age is an important public health issue that has received new attention, not least in the COVID pandemic, with physical distancing measures and the definition of older people as a risk group. Based on the different experiences of the participants in the working group, we want to investigate questions about social participation in old age: e.g. how have images of old age changed with regard to social participation? What effects do we notice of the pandemic on participatory projects with older people, and how do we meet new challenges - e.g. with regard to data collection and analysis, and regarding questions of research ethics? What conclusions can be drawn from this for participatory projects with older people?

Workshop 7

Title:	**Method Reflection: Photo Voice**
Host:	Frank M. Amort (Austria)
Contact:	frank.amort@gmail.com
Time and Day:	Wednesday, 11 November 5:00-7:00 pm
Abstract:	

Photo voice as a methodological tool in PHR will be introduced and discussed. A special focus will be given to photo voice projects using social media.

Workshop 8

Title:	**Challenges for Participatory Health Research in Times of Social, Health, and Political Crises**
Host:	Sónia Acioli (Brazil)
Contact:	soacioli@gmail.com
Time and Day:	Wednesday, 11 November, 9:00 – 10:30 pm
Abstract:	

This working group intends to discuss the challenges posed in conducting participatory health research processes considering the context of local and global crises, highlighting the health crisis determined by the

COVID-19 pandemic and aggravated by the conditions of vulnerable population groups at the time of attacks on social rights, especially the right to health.

Workshop 9

Title:	**Participatory Health Research with Migrants**
Host:	Anne MacFarlane (Ireland)
	Sónia Dias (Portugal)
Contact:	Anne.MacFarlane@ul.ie
Time and Day:	Wednesday, 11 November, 5:00 – 6:30 pm
Abstract:	

The working group will be an opportunity for people interested in this area to meet others working in the field. Our proposed agenda is:

5.00-5.30	Welcome & introductions followed by update on work completed by this working group during 2020
5.30-6.00	The value of arts based research with migrants with Prof Helen Phelan, World Academy of Music and Dance, University of Limerick, Ireland
6.00-6.30	Open discussion and information on projects (current/potential) by participants at the meeting

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Workshop 10

Title:	**Kids in Action**
Host:	Lisa Gibbs (Australia)
Contact:	lgibbs@unimelb.edu.au
Time and Day:	Thursday, 19 November, 10:00 – 11.30 pm
Abstract:	

Kids in Action will be holding a workshop to update ICPHR members on the ongoing activities of the alliance of projects from all over the world who are engaging children as partners in participatory health research.

Workshop 11

Title:	**Evaluation of Participatory Health Research Working Group Meeting**
Host:	Nina Wallerstein (USA)
Contact:	NWallerstein@salud.unm.edu
Time and Day:	Monday, 9 November, 4:30-6:30 pm
Abstract:	

The Evaluation PHR Working Group has been meeting for several years to identify and share evaluation strategies of our participatory practices from around the world in order to understand the added value and benefit of participatory practices for improving health outcomes. We seek to know which practices contribute to effective academic-community (and other stakeholder) partnerships, and what are the facilitators and barriers to this effectiveness. We seek to know the range of outcomes or impacts PHR can influence, such as specific research outcomes, community capacities, or capacities of academic institutions

to engage in partnership with community and other stakeholders. Our core evaluation question therefore has been: "under what conditions, do which participatory strategies, contribute to what kind of outcomes?"

In our 2020 meeting, we will specifically discuss an investigation that we have been conducting with focus groups, particularly in the Global South, related to issues of power and empowerment within PHR partnerships. We are seeking to identify measures of power-sharing, collaborative governance, and empowerment that can be shared across multiple settings and can highlight the importance of equity within partnerships and as a major outcome for all of our work. We are also interested as a group in identifying better ways to reach out to Global South partners and to engage with other networks to expand our collaborations.

During the year, the Evaluation PHR Working Group meets monthly on the third Mondays of the month for an hour to share projects, learnings, and mutual questions. Please feel free to join us at this year's annual meeting.

Workshop 12

Title:	**Structural Racism, Colonialism, White Silence and Its Impacts on PHR**
Host:	Tanja Gangarova (Germany)
	Sharon Joneseversley (USA)
	Saskia Duijs (Holland)
	Shannon Sanchez-Youngman (USA)
Contact:	tanja.gangarova@dah.aidshilfe.de
Time and Day:	Tuesday, 10 November, 6:00-8:00 pm
Abstract:	

Recognising racism as a structural social determinant globally, with multiple impacts on health inequities in racialized communities, and therefore with significant implications for the practice and outcomes of partnerships, members of the ICPHR set the topic on the agenda at the annual meeting of the ICPHR in 2019 in Baltimore, USA. This workshop can be considered as a follow up to this meeting, and aims to build on the 2019 discussion.

Almost thirty years of evidence demonstrate the role of PHR in seeking to create equitable research environments in the pursuit of shared goals of health equity and social justice. However, not enough attention has been paid to integrating the conceptual frames developed from antiracism research, decolonial and postcolonial studies as a component of participatory partnering processes. This is crucial for confronting structural racism in conducting PHR.

While creating visibility around these often silenced issues is a shared goal, and indeed the starting point for this workshop, it became clear in 2019 that there is a lack of consensus in clearly defining the terms 'race' and 'racism' - given the varying historical and geographical contexts of practitioners as well as non-availability of data especially in the European context.

In order for PHR practitioners to be better positioned to understand the systemic organization of contemporary racism, practitioners from different contexts will be invited to make short presentations on the terms and conditions of racial theory and the lived experiences of racialized communities in their respective settings.

Through showing the ways in which hegemonic reinforcement of existing racialized social relations can be consciously or unconsciously reproduced by any person or institution, the foundations for building common definitions and working towards strategies for visibilizing and deconstructing racism in PHR will be laid.

Some of the topics to be covered by the workshop should include:

- How do white institutions and individuals benefit from a system of racialized oppression and privilege?
- How are the intersecting dimensions of racism, power, and privilege reinscribed while conducting PHR? What are the facilitators and barriers of achieving an anti-racist and decolonised agenda in current PHR work?
- How to establish a broader discussion about race and power in Europe, especially in contexts like Germany or Sweden, where the silencing of racism has resulted in cultural-based approaches for explaining difference or in an ideology of color-blindness establishing "culture" which makes racism even more invisible. What can we learn from CBPR and Participatory Action Research (PAR) partnerships in the Global South? What explicit role should communities of color and indigenous play in redefining this discussion with research institutions?
- How to establish a broader discussion about the sociopolitical and historic impacts of race, privilege and power in the United States, especially in its context of how they individually and collectively either align or conflict with the PHR principles of power, empowerment, and diversity consciousness.

Workshop 13

Title:	**Exploring Unsettling Encounters in Collaborative Research with Two Researchers without Experiential Expertise**
Host:	Gustaaf Bos (Netherlands)
	Sebastian von Peter (Germany)
Contact:	g.bos@uvh.nl
Time and Day:	Please contact the hosts
Abstract:	

Participatory health research projects often involve research collaborations between researchers with lived experiences (the people with direct experiences of the topic under study) and researchers without that experience. Maintaining collaborative research relations is challenging. A range of rather personal accounts from researchers with lived experiences attest to those challenges. Yet, there is a shortage of narratives from researchers without lived experience, rendering their specific perspectives largely unaccounted for—a gap that we would like to address in this workshop.

First, we will briefly reflect on how we—two researchers without lived experiences that work in both the fields of Mental Health (MH) and Intellectual and Developmental Disability (IDD)—perceive various personal and emotional challenges in collaborative projects under the heading of "unsettling encounters." Subsequently, we will discuss the value of unsettling encounters, and how this relates to the collaborative research projects of the workshop participants.

Workshop 14

Title:	**Methodological Challenges of Conducting Research with Children with Enduring Healthcare Needs During COVID-19 Pandemic**
Host:	Suja Somanadhan (Ireland)
	Thilo Kroll (Ireland)
Contact:	suja.somanadhan@ucd.ie
Time and Day:	Thursday, 12 November, 9:00-10:00 pm

Abstract:

The current Covid-19 pandemic is placing unprecedented pressure exerted on healthcare systems, front line health care workers and researchers. Researchers have experienced severe disruption of researching with children in the health care settings due to Covid-19. This workshop will address key methodological challenges of conducting creative arts-based modalities with children with enduring healthcare needs in the hospital settings.