International Scientific Meeting on the Impact of Participatory Health Research

Center for Interdisciplinary Research (ZiF), Bielefeld
June 1st to June 3rd 2015

Documentation

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In cooperation with

Katholische Hochschule für Sozialwesen Berlin
CIHR IRSC
Recherche partenariale du Canada
Community-Based Research Canada

ISG · Institut für Soziale Gesundheit
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Acknowledgements

We are grateful to the German Network for Participatory Health Research (PartNet), the Institute of Population and Public Health of the Canadian Institutes of Health Research (CIHR), and Community-Based Research Canada (CBRC) for their support in organizing the conference.

Our special thanks to Dr. Britta Padberg and the ZIF, the Center for Interdisciplinary Research at the University of Bielefeld, whose financial support made this event possible. Additional support was provided by the Catholic University of Applied Sciences Berlin.

And a thank you to each and every participant and presenter, who contributed to the richness of the discussions and to the respectful, critical, candid and constructive atmosphere.

Finally, we are grateful for the inspiring words of our keynote speakers Claire Donovan and Matthias Bergmann whose contribution set the groundwork for our deliberations.

Michael T. Wright

Berlin, 15th of July 2015
Summary of the Conference

Participatory approaches to research are drawing increasing attention worldwide. Participatory research means that those whose life or work is the subject of the research have a direct influence on the research process. This takes place in the context of a partnership between academic institutions, civil society, funders, decision makers and other engaged citizens. Another defining characteristic of participatory research is the explicit goal of contributing in an immediate way to positive social change, thus closing the gap between action and research. The International Collaboration for Participatory Health Research (ICPHR) provides a forum for debating the merits of participatory research in regard to health issues, including defining quality criteria for this emergent science.

There is a growing demand for academic researchers to show the impact of their work. The focus has tended to be on how studies influence other academics, as measured, for example, by various forms of bibliometrics. “High impact” denotes those journals or researchers who are most often cited. There is, however, a broader discussion regarding research impact, particularly in the applied sciences. Here the issue is the extent to which the research has resulted in a technical or social innovation. Funders are increasingly requiring that applied research demonstrate how the findings will contribute to addressing social problems. Knowledge transfer and knowledge translation have been integrated into several funding streams in the health field as a way to address the application of the knowledge generated as part of the research design. By involving the various stakeholders throughout the research process—from the generation of the research question to processes of data collection, interpretation, and dissemination—participatory health research (PHR) seeks to bridge the gap in a unique way between research, professional practice, and everyday life.

The ICPHR teamed up with the German Network for Participatory Health Research (PartNet), the Institute of Population and Public Health, Canadian Institutes of Health Research (CIHR), and Community-Based Research Canada (CBRC) to organize a conference in June on the topic of impact in PHR. Experts in PHR from eleven countries met to define what impact means in the participatory research process, how to maximize the impact of the research, and how to observe and document what impact has occurred.

Two keynote addresses from Claire Donovan (London) and Matthias Bergmann (Frankfurt am Main) provided inspiration from the larger scientific community. Donovan gave an overview of the current debate regarding scientific impact in English-speaking countries. Bergmann discussed impact from the perspective of transdisciplinary research, a participatory approach found particularly in the technical fields. The participants then engaged in various forms of dialogue using formats which are atypical for scientific meetings, including a world café and narrative sessions. The decision was taken to write a joint a position paper on the issue of impact in PHR. The paper, which will include examples from various countries and contexts, is intended to provide guidance to funders and to those involved in PHR as well as to be a contribution to the larger debate. Tina Cook (Northumbria, UK) will be serving as the editorial lead. The paper will be written and distributed with the support of the ICPHR.
Program

Chair: Michael T. Wright

Monday, June 1

09:00 – 09:45 Welcome and Warm-Up
(Short welcome from ZiF, PartNet, CBR Canada, CIHR, ICPHR)

09:45 – 10:15 Presentation: Measuring Impact in Science (Donovan)

10:15 – 10:30 Break

10:30 – 11:00 Presentation: Citizen Participation in Knowledge Production (Bergmann)

11:00 – 12:30 Open Fish Bowl on Defining Impact (Moderator: Cook)
  • Perspective of Civil Society (Gangarova/Germany)
  • Perspective of Lived Experience (Russo/Germany)
  • Perspective of Funders (Roche/Canada)
  • Perspective of Health Care Organizations (Abma/Netherlands)
  • Perspective of Training Health Practitioners (Brito/Portugal)

12:30 – 13:30 Lunch

13:30 – 15:00 World Café: Defining the Dimensions of Impact in PHR

15:00 – 15:15 Break

15:15 – 16:45 Storytelling: How PHR Impacts Research Practice
(Moderators: Wakeford, Springett) – 2 groups
  • PHR and Mixed Methods (Gibbs/Australia)
  • PHR and Qualitative Research (von Unger/Germany)
  • PHR and De-Colonizing Health Research (Martinez/Mexico)
  • PHR and “Mandatory” Participation (Guta/Canada)
  • PHR and Ethics (Banks/UK)
  • PHR and Measuring Impact (Wallerstein/USA)
  • PHR and Indigenous Epistemology (Smith/New Zealand)

16:45 – 17:00 Break

17:00 – 17:30 Round-Up

18:00 Dinner at ZiF

Tuesday, June 2

09:30 – 10:00 Introduction of Working Groups how to work on a position paper to the question “What is impact in PHR?”

10:00 – 11:00 Working Groups, Session I

11:00 – 11:15 Break

11:15 – 12:45 Working Groups, Session II

12:45 – 13:45 Lunch

13:45 – 14:15 Interim Reports from Working Groups

14:15 – 15:45 Working Groups, Session III
15:45 – 16:00  Break
16:00 – 17:00  Working Groups, Session IV

Evening program – Dinner at the restaurant “Brauhaus”

Wednesday, June 3

09:30 – 11:00  Presentation and Discussion of the Results of the Working Groups
11:00 – 11:15  Break
11:15 – 12:00  Presentation and Discussion (cont.)
12:00 – 12:30  Closing and Next Steps to work on the position paper about the impact in PHR
12:30 – 13:30  Lunch

End of the meeting
Overview of the Proceedings

Monday, June 1

The conference began with opening remarks from Michael T. Wright, as chair of the conference, Britta Padberg, Executive Secretary of the ZiF, from the German Network of Participatory Health Research (PartNet), the Canadian Institutes of Health Research (CIHR), Community-Based Research Canada (CBRC), and the International Collaboration for Participatory Health Research (ICPHR).

This was followed by keynote addresses from Claire Donovan (London) and Matthias Bergmann (Frankfurt am Main) providing inspiration from the larger scientific community on the issue of impact. Donovan gave an overview of the current debate regarding scientific impact in English-speaking countries. Bergmann discussed impact from the perspective of transdisciplinary research, a participatory approach found particularly in the technical fields.

The participants then engaged in various forms of dialogue. In the format of open fish bowl, guided by Tina Cook, the discussion was opened with five short inputs from different perspectives on defining impact. In the world café after lunch, the dimensions of impact in PHR were discussed. The question for the discussion was: What topics would you like to work on related to impact in PHR?

In the following narrative session (storytelling) the participants had the opportunity to discuss in small groups different aspects of PHR impact in research practice. Throughout the session every participant was asked to make note of how PHR impacts research practice.

Tuesday, June 2

The second day started with an introduction of the working groups. The decision was taken to write a joint a position paper on the issue of impact in PHR. The working sessions laid the groundwork for the different chapters of the position paper. The evening program was a dinner in the restaurant “Brauhaus” in the city center.

Wednesday, June 3

Each group leader presented the results of the working group discussions. The next steps for the position paper were decided. After lunch and a group picture the conference was brought to a close.
New perspectives on measuring impact in science:
Evaluating the benefits of Participatory Health Research

Dr. Claire Donovan
Brunel University London

Overview
Key points

- Setting the Scene
- Assessing research impact: healthcare research leading the way
- Potential impact of PHR on impact

Question?

Is there a word for 'impact' in German?
International social and political context

- Public accountability of science to society
- Austerity
- Increased interest in measuring research outcomes
- Ivory towers?
- UK context:
  - Research Excellence Framework (2015/16 = £1.6 billion)
    - quality 65%, environment 15%, impact 20%
  - Research Council funding (2015/16 = £2.6 billion)
    - pathways to impact
Waves of Impact Assessment (1)

- Bibliometrics
  - scientific research 'quality'

- Technometrics
  - economic returns ≠ low level impact ≠ private over public interest

- Sociometrics
  - macro social statistics ≠ no credible causal link

Waves of Impact Assessment (2)

- Altmetrics
  - social media cites of publications ≠ metrics not the same as impact ≠ but can help trace impact stories

- Narratives and case studies
  - capture wider social impact
  - include robust impact metrics
  - rely on peer and 'end-user' judgements
  - necessarily complex
Limitations of ‘measurement’

• How to capture impacts on...?
  • the research system
  • product development
  • policy and practice
  • health gain
  • improvements in service delivery
  • broader social, economic, cultural benefits

• Not measuring, but evaluating or assessing impact
The state of the art

- Quantitative and qualitative data
- Overarching narrative
- Case studies
- Impact very broadly defined

The payback framework logic model
Multi-dimensional categorisation of payback

<table>
<thead>
<tr>
<th>Category</th>
<th>Definition</th>
</tr>
</thead>
<tbody>
<tr>
<td>1. Knowledge</td>
<td>Clinical trials, conference presentations, books, book chapters, research reports</td>
</tr>
<tr>
<td>2. Benefits to future research and research databases</td>
<td>Development of research skills, preclinical and clinical research capacity</td>
</tr>
<tr>
<td>3. Benefits from informing public and policy development</td>
<td>Improved information for public and policy makers</td>
</tr>
<tr>
<td>4. Health and health sector benefits</td>
<td>Improved health, reduced incidence of certain diseases</td>
</tr>
<tr>
<td>5. Broader economic benefits</td>
<td>Economic benefits from commercial exploitation of innovations arising from R&amp;D</td>
</tr>
</tbody>
</table>

Example: NBCF (Australia)

CASE STUDY

In the late 1990s, it was becoming apparent that breast density was a significant risk factor for breast cancer. The Breast Cancer Family Registry was established to study the relationship between genetic factors and breast cancer in families. The registry was founded in 1996, with the goal of understanding the genetic and environmental factors that contribute to breast cancer risk.

The Australian Longitudinal Study on Women's Health and the National Breast Cancer Trials Group (NBCF) established an extensive database on breast cancer risk factors. This database is used to identify women at high risk of developing breast cancer and to develop strategies for prevention and early detection.

The NBCF has conducted numerous research projects aimed at improving the understanding of breast cancer risk factors. These projects include studies on the role of family history, genetic testing, and hormonal factors in breast cancer development.

The NBCF has also been involved in developing guidelines for the early detection and management of breast cancer. These guidelines are based on the latest research and are aimed at improving outcomes for women with breast cancer.

Through its research and educational initiatives, the NBCF has made significant contributions to the understanding of breast cancer risk factors and the development of strategies for prevention and early detection.
Perennial problems of impact

- Attribution vs. contribution
- Time-lags
- Positive vs. negative impacts
- Translational vs. basic research
- Different stakeholder perspectives

The potential impact of PHR on measuring impact
Co-production and best practice

- Research co-produced with research users, stakeholders and/or patient groups more likely to have impact
  - engagement throughout the research process
  - framing research ideas
  - ensuring common interests addressed
  - ready for research findings and recommendations

Current weaknesses in impact assessment

- Poor track record in defining, observing, recording, reporting and maximising benefits of co-produced research for patients, stakeholders and the public
PHR paradigm the way forward?

- Reflexive understanding of research impact
- Variety of patient and stakeholder lenses
- Non-linear and dynamic

If the challenge for impact assessment is to more meaningfully describe the benefits of co-produced research for individuals, groups and societies, then the PHR paradigm provides the way forward for redefining and reshaping the state of the art.

Thank you!

claire.donovan@brunel.ac.uk
**Publications**


Presentation II: Matthias Bergmann: “Citizen Participation in Knowledge Production”

Citizen Participation in Transdisciplinary Knowledge Production

Matthias Bergmann
ISE – Institute for Social-Ecological Research, Frankfurt/Main
Leuphana University Lueneburg

International Scientific Meeting on the Impact of Participatory Health Research
ZIR, Bielefeld, June 1st, 2015

Overview

Citizen participation and …
- ... knowledge transfer or transdisciplinarity?
- ... definitions of transdisciplinarity
- ... tasks of integration
- ... transdisciplinary knowledge generation
- Project examples for citizen participation
- A concept and a method for citizen integration
- A few words on the impact of participatory research
Why Transdisciplinarity?
From the old-fashioned knowledge transfer concept to integrated perspectives

Knowledge Generation
- Science / Research
- R&D-Process

Knowledge Implementation
- Politics/Practice/
  Societal Problem Field

Knowledge Transfer
Mutual Knowledge Communication and Learning

"[We] have to rethink the place of people in the knowledge produced by the sciences" (Nowotny 1999).
Why Transdisciplinarity?
From the old-fashioned knowledge transfer concept
to integrated perspectives

Mutual
Knowledge Communication
and Learning

Science / Research
R&D-Process

Politics/Practice/
Societal Problem Field

Not to speak of target groups
but of partners
in the R&D process

Definitions of Transdisciplinarity (1)
(GOE – Institute for Social-Ecological Research)

- Transdisciplinarity is a critical and self-reflexive research approach that relates societal with scientific problems;
- it produces new knowledge by integrating different scientific and extra-scientific insights;
- its aim is to contribute to both societal and scientific progress;
- integration is the cognitive operation of establishing a novel, hitherto non-existent connection between the distinct epistemic, social, organizational, and communicative entities that make up the given problem context.

(Jahn/Bergermann/Kel 2012)
Definitions of Transdisciplinarity (II)
(UC Irvine, School of Social Ecology)

Transdisciplinarity
- is an integrative process
- whereby scholars and practitioners representing different disciplines and epistemologies, work jointly to develop and use novel conceptual and methodological approaches, that synthesize and extend discipline-specific theories, methods, and translational strategies,
- to yield innovative solutions to particular scientific and societal problems.


Key Features/Tasks of Transdisciplinarity

Interdisciplinarity and participation of experts from the problem field
Integration
Overview

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Task of Integration in Td Research

- Cognitive-epistemic dimension
  - distinction between and linkage of expert/disciplinary knowledge bases, as well of scientific and practical real-world knowledge
- Social and organizational dimension
  - distinction between and correlation of the participating researchers’ and experts’ different interests and activities;
  - also includes the context-sensible leadership of (not only scientific) teams, mutual understanding and the willingness to learn
- Communicative dimension
  - distinction between and linking of different linguistic expressions and communicative practices, with the aim of developing something like a common discursive practice

(Bergmann et al. 2012: 45)
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The reflexive td research process
Phase 1: Constructing a common research object (1)

Real-world problems:
Contested values, lack of orientation & transformation knowledge, institutional specialization, limits to knowledge transfer...

Scientific issues:
Contested knowledge, lack of (system) knowledge and methods, disciplinary specialization, aim of generalization and transferability

Constitution and problem framing
- Building a research team: identifying expertise needed and distinguishing between specific contributions
- Common description of the societal problem
- Formulation of a common trans-disciplinary research object (epistemic object)
- Common formulation of research questions (aiming at connectivity)

Project design and integration strategy

Short digression: Continuous efforts for cognitive and social integration

Problem
Research Institution A
Research Institution B
Research Institution C
Social Expert

Transformation/Innovation

Problem
Research Institution A
Research Institution B
Social Expert

Transformation/Innovation
Continuous integration with relative results
Phase 2: Production of new knowledge (1)

Co-production of solution-oriented connectable knowledge

Phase 2: Production of new knowledge (2)

Project design and integration strategy

SUBPROJECTS
Integration interfaces
Collaboration

Coordination
Integration interfaces
Collaboration
Integration interfaces

Co-production of solution-oriented connectable knowledge
Integration methods
The reflexive research process

Phase 3: Transdisciplinary Re-Integration

- Regulatory frameworks
- Values and norms
- Changing everyday habits
- New technologies

- Embedded technologies
- Uncertainty and complexity
- Quantitative vs. qualitative knowledge

- Actor and sector specific strategies and problem solutions
- Facilities/institutions for deliberation & reflection

- Better understanding of change dynamics
- Theoretical & methodological innovations
- New research issues

Evaluation of the generated new knowledge concerning contributions to societal and scientific progress
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Transformation of the energy system – "German Energy Change"

Example 1
- Project of the Academies of the Sciences
  "Energy system of the future"
Transformation of the energy system – "German Energy Change"

**Example 1**

- Project of the Academies of the Sciences "Energy system of the future"

A set of 8 interdisciplinary working groups

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**Transformation of the energy system – "German Energy Change"**

**Example 1**

- Project of the Academies of the Sciences "Energy system of the future"

Research Forums: Formulating research agenda and guidance for societal/political action

→ Interface
Example 2

- BMBF/ Sof: „Environmentally and
  societally sound transformation of the
  energy system“

33 research consortia + project for
scientific coordination and synthesis

Transformation of the energy system – "German Energy Change"

„Environmentally and societally sound transformation of the energy system“

Three key topics:

- Options for the development of the energy system
- Citizens’ Participation in the transformation process and
  societal acceptance for the transformation
- Governance of transformation processes
How can decision making processes in decentralized energy supply systems be designed in a way that conflicts among diverse actors can be solved in a constructive spirit? How can citizens participate in approval procedures aiming to improve the acceptability of energy supply infrastructure?

"Environmentally and societally sound transformation of the energy system"

Scientific Coordination and Synthesis

Methods and quality aspects of participation and integration
Project Example: Management Strategies for Pharmaceutical Residues in Drinking Water

- **Funding:** BMBF (Social-Ecological Research Programme)
- **Duration:** 2005–2008

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**Active pharmaceutical residues (APRs) in water bodies**
**The complex negotiation and integration process**

**What's the problem?**

- Water as the most fundamental life sustaining natural resource should be free from any pollution!
- Drugs are of particular concern as they are designed to have physiological impact!
- Whether drugs in waters actually pose a risk to wildlife and humans is highly contested!
- Pharmaceutical products are associated with high individual and social benefits. Measures for keeping drugs out of waters should not compromise these benefits!

**What do the “experts” say?**

- Water that is free from contaminants does not exist; water purity is related to the level of pollution and the given measuring accuracy!
- Agreement: knowledge conflict unsolvable!
- The properties of today's drugs make their partial excretion and slow degradation in the environment unavoidable!
- Environmental engineering provides no single technology which completely eliminates all APIs from domestic sewage or drinking water sources!
- For a number of reasons, the validity of current risk assessments for APIs in waters is principally limited!
- It's wicked! Let's develop strategies that are sensitive to the conflict of values! Who do we need in the team?
Management Strategies for Pharmaceutical Residues in Drinking Water

Researchers:

Institut für sozial-ökologische Forschung (ISOE) GmbH
Forschungszentrum Karlsruhe GmbH - Institut für Technikfolgenabschätzung und Systemanalyse (ITAS)
Universitätsklinikum Freiburg - Institut für Umweltmedizin und Krankenhaushygiene,
J. W. Goethe-Universität Frankfurt am Main - Institut für Physiogeografie, Institut für Ökologie, Evolution und Diversität, Institut für Atmosphäre und Umwelt

Societal experts:
badenova AG & Co. KG, Freiburg
Arzneimittelkommission der Deutschen Ärztekammer, Eschborn
Rheingartestr. 3, 71052 Freiburg
Deutsche Vereinigung des Gas- und Wasserfachverbandes e.V. (DVGW)
Bayer HealthCare AG, Wuppertal
Bundesverband Verbraucherzentralen e.V., Berlin
Emergengenossenschaft Lippeverband, Essen
Barmer Ersatzkasse
Arzneimittelkommission der Deutschen Ärztekammer, Berlin
Deutscher Berufsverband der Umweltmediziner, Würzburg
Umweltbundesamt Dessau
Hoffmann-La Roche Ltd, Basel, Schweiz
Institut für Energie- und Umwelttechnik e.V., Duisburg
Stockholms läns Landsting, Stockholm, Schweden
The complex negotiation and integration process

Create an Epistemic Object!

Let's apply the systemic risk concept!

Yes, but we have to adapt it to intended processes!

overview

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Methods for integration in inter- and transdisciplinary research

- Integration: Methods for Phase 1: Constitution and Problem Framing
- Integration: Methods for Phase 2: Production of new Knowledge
- Integration: Methods for Phase 3: Transdisciplinary Integration
- Overview over Different Functions of Integration Methods in Transdisciplinary Research

Integrative methods
Phase 1 (a)
**Actor Analysis**
**Experts from societal Practice**
**Questions to be asked**

- In which phases of the process?
  - Developing research questions,
  - Knowledge Generation during the research work,
  - Commenting results,
  - Implementation of results

- Who / which group should be / has to be included?
  - Users, clients, managers and business representatives, etc.
  - Politicians, administration (at different governance levels)
  - Civil society organisations (environmental groups, women groups, charities, churches, trade unions etc.)
  - Other Stakeholders (neighbours and communities, suppliers, investors and creditors etc.)
  - General public and the media
Actor Analysis
Experts from societal Practice
Questions to be asked

- In which phases of the process?
- Who / which group should be / has to be included?
- Which functions do the experts have?
  - Testing practical suitability and feasibility
  - Identifying future needs
  - Increasing acceptability of results
  - Early warning system for conflicts
  - Gaining practical knowledge

Actor Analysis
Experts from societal Practice
Questions to be asked

- In which phases of the process?
- Who / which group should be / has to be included?
- Which functions are do the experts have?
- Which formats are used?
  - Information
  - Consultation
  - Cooperation
  - Collaboration
  - Empowerment
Participation – when and how?

Fig. 1 Varying degrees of involvement and selection of applied techniques in the case study on landscape development in Appenzell Ausserrhoden.

Stauffacher et al. 2008: Analytic and Dynamic Approach to Collaboration

Integrative methods throughout the td research process – Phase 1 (b)

Societal Problems

Constitution and problem framing

Building a research team; identifying expertise needed and distinguishing between specific contributions

Scientific Problems

Actor analysis

Hypothesis formulation/ group model building

Common description of the societal problem

The Impact of Participatory Research // June 1st 2015
Integration through the formulation of hypotheses

- Group Model Building for social and knowledge integration
- Example: direct and indirect causes and effects of changes in fish stocks and fish catches

![Diagram showing causal relationships between variables such as chemical inputs, poor stream quality, reproductive failure, reduced recruitment, etc.]

Literature: Bergmann et al. (2012)

Methods by analytical functions:

- Conceptual clarification and theoretical framing
- Formulation of research questions and hypotheses
- Screening, using, refining, and further developing effective integrative methods
- Integrative assessment methods
- Development and application of models
- Artifacts, services and products as boundary objects
- Procedures and techniques of integrative research organization

![Image of the book "Methods for Transdisciplinary Research" by Matthias Bergmann et al.]

The Impact of Participatory Health Research // June 1st 2015
Overview

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A few words on the impact...
- Transdisciplinary research projects often evaluated individually,
- no comparative study on the actually employed research modes or on the scholarly and societal outcomes of a larger number of research projects

But there are some research projects on their way...
- MONA – A comparison of modes of sustainability related research...
  - is comparing 100 completed third-party funded German research projects with different research modes and outputs to gain
    1. Topography of the research modes
    2. Correlation between research mode and impact
    3. Improve methodology of evaluation
A few words on the impact ...

But there are some research projects on their way ...

- TransImpact ...
  ... will analyze td projects together with a large td community concerning correlation between td research concepts and methods on one hand and a positive societal impact on the other.

Besides all similarities, is there a significant difference between transdisciplinary sustainability research and participatory health research: typology of problems, actor characteristics.
**Open Fish Bowl on Defining Impact**

The following main points were discussed during the fish bowl session:

**Minutes of Rosslynn Zulla:**

**Types of impact**

- Participation of marginalized people
- Involvement of our community at the federal level
- Benefits to community
- Small projects can be turned into a network
- Relationships (e.g. relationships between NGO and the community)

**Formats in addressing impact**

- Stories are important for policymakers
- Stories move policymakers

**Challenges relating to impact**

- Measuring impact varies
- It’s been difficult to measure impact
- Small projects are expected to have a big impact
- It’s difficult to record impact throughout the process
- Utilitarian goals are different from goals of social justice
- It’s difficult to record impact throughout the process
- Impact happens over a very long time period

**Suggestions related to impact**

- Need to give room for unexpected impact
- Try to separate research from policy
- Try to create a space for research and policy analysis instead of mixing each other
- After research, you need to have clarity on the impact
- Need to be attentive to our core values in addressing impact
- There needs to be an openness in including people in measuring impact
- We have to be responsive to the community’s needs
- Impact /Effectiveness needs to occur in different contexts
- We need to be open to new knowledge (we need to be open to advocacy)
- We, as researchers need to open up our framework for critical thinking

**Key questions**

- What is the range and value of impact from research?
- Which method works in creating an impact for the community?
- How do we as researchers use funding schemes to have a broader impact?
- Who should be in the discussion as it relates to impact?
- What purpose does impact have?
- Are stories a measure of quality?
- Does a story mean you have an impact or is it just a 'human story'?
Minutes of Tina Cook

- Contextual influence and impact
- Danger of participation being used instrumentally by funders/policy makers for certain predetermined impacts – the use of influence
- Participation is an aim and therefore an impact. Impact on personal development and opportunities.

- Importance of giving room for unexpected impacts - ripple effects
- Recognise that there are negative impacts as well as positive impacts
- Problem of being driven by 'shovel ready impacts'. Shovel ready vs meaningful.

- Social justice vs utilitarian work
- Aims can end up being driven by grants - the need to consider using grants to take forward the big picture, not as projects in themselves.
- Importance of articulating goals and our core values - first principles - what is valuable for whom

- What is valuable for whom.
- Are research projects trying to do everything - is there a need to separate out analysis for researchers and for policy analysis.
- Do we need a new truth - do the values front the global North match the values of the global South.

- Problem of only knowing in retrospect
- Importance of knowing what doesn't work - 'dark logic' model
- Importance of knowing what we know about what does not work - daring to be vulnerable

- Question whether their should be a division of concern - should scholars think about one thing and communities/NGOs consider the things from their needs and perspectives
- Importance of defining indicators of success with people - who defines impact
- The effect of the language of research impact on what is considered impact and by whom.

- Difference between changing the rules and changing the game.
- Making sure that we are not bringing home the corn but also bringing the turkeys to eat it!
World Café: Defining the Dimensions of Impact in PHR

The question for the world café was:

What topics would you like to work on related to impact of PHR? (and on what topic would you like to take the lead)

The following topics were generated:

- Ethics – negative impact
- Process to negotiate impact with various stakeholders
- Complexity of social and structural change and impact
- Defining impact – pushing the boundaries – re-defining – tensions
- Reporting impact
- Reviewing participatory papers regarding impact
- Different levels of impact
- Changing ideas of impact
- Communication of impact based on audience
- Collective impact/communities of learning
- Unexpected and challenging impacts
- Differences re: impact cross-nationally
- Impact and justice
Working Groups: Storytelling – How PHR Impacts Research Practice

During this session the participants wrote what they identified as being important when it comes to impact in PHR.

These are the cards, presented in categories:

What is impact

- Impact on local knowledge in terms of local knowledge
- Impact on capacity building in communities - how to demonstrate
- Network Effects
- Talking or writing about participation is not the same as doing participatory research, talking or writing about impact is not the same as having impact
- Complexity Theory
- More humble approach to PHR impact
- Negative impacts
- Impact to politics
- Impact <-> relationship conflicts

Capturing and show impact

- Capturing Processes
- Writing field notes will support the participatory process - decide what to share, and what NOT to share.
- Benefits of field notes
- How to share documentation

How to get impact

- Using new technologies/media as ways of increasing/extending impact
- How do we value embodies knowledge
- Collaboration on "impact" within projects
- Guidelines for identifying effective practices to produce outcomes
- Does it have to be a "battle" when seeking to make a difference?
- Sharing the information
- Exploring how partnership working relates to impact: Defining impact, Assessing impact, Measuring impact
- Developing Participatory Impact

Participation in PHR

- Research question and selection of methods should be developed participatory like all the following steps
- The participatory process needs ground rules - i.e. which information should be shared
- Limits to inclusive work when you don’t share same values of your research partner
- How work can be divided? Do peer researchers have to be involve in every single stop of research (e.g. data analysis)
• Articulation of impact of doing it in this way - The participatory element had a direct effect on the quality of the study the story was about raised it to another level as gave it appropriate focus/interpretation etc.; relationships that were built meant they (people affected by issue being researchers) made suggestions rather than agreed to doing something or not
• Scale and complexity of research can influence how participation can happen and what impacts may be.
• The complexities of PHR and difficulties of outsiders and insiders appreciating this "fake" participation
• Maybe people involved in a difficult life situation (e.g. surviving a bush fire in Australia) do not want to become peer researchers and learn about research methods -> division of labour.
• Participatory action from the research question to the presentation of results
• Is peer research utilitarian? How can you avoid this?
• Should PHR be expected all stages of implementation, or is there an issue in mixed methods about using when it is fit for purpose?
• When to participate in what activity?
• Who is missing and what can we do about it?

PHR approach and theory

• When PHR and when other approaches?
• How to construct/create guidance for a conceptual model of impact (using Nina et al’s model)

Methods

• Kitchen table focus group
• Being clear on what cannot be measured and what can
• New technology opens up participation
• Mixed Method is needed
• Storytelling is important to impact
• What about to use non-participatory elements in a participatory process?
• Gatekeepers for sampling feedback loop (validation) reflective loops (analysis)
• More discussion on the methods we use empirically and how participation can be related to the different phases Using qualitative and quantitative (and performative, creative etc.) methods in a participatory way
  o who can do what
  o who wants to do what kind of work/research task
  o how can we avoid a dogmatic/?????? approach - i.e. it should always be like this?

Ethics and Power

• Difference in power status and different interests between partners can pose ethical challenges.
• Ethics and impact - relationship with participation
• Ethical questions concerning worthy of consideration
• Researcher - researcher relations of power
• The value of getting a range of perspectives on an ethical issue by talking it through with colleagues
Important to consider

- Context
- The impact criterion for Horizon 2020 should include southern perspectives on impact on equity grounds
- Do externally imposed visions of impact have harmful effects e.g. North on South and ignoring local perspectives, neo-liberal agenda, metrics - obsessed
- How to draw more on Indigenous knowing to inform participatory research
- The learnings from indigenous research have applications for good research in general
- Indigenous Decolonising Methodology and PHR/CBPR
- How can we learn from indigenous ways of Knowing (Ma Toe Zanga)
- Words as Battle cries - Reclaiming Language from neo-liberal scientism
- There no social movement to (?) for participatory partnerships in Germany

ICPHR

- Making public different forms of impact, e.g. by publicising examples on the ICPHR site
- Build Community of Learning within ICPHR
- In the next meetings we should present our work the way we want - Posters, videos, exhibitions. We should share our stories!!! All should have the opportunity
**Working Groups: What is Impact in PHR?**

On the second day of the conference the decision was taken to work on a position paper. The following four questions were discussed in small working groups:

1. What is impact?
2. How do you get impact?
3. How do you know when you have impact?
4. What facilitates and what hinders achieving impact?

The answers to the questions were to include at least three examples. The results of the groupwork were presented on the third day. It was agreed that the group leads (Jane Springett, Tineke Abma, Tom Wakeford, Brenda Roche, Wendy Madsen) would send their summaries to Tina Cook, the editorial lead for the position paper. The following editorial group volunteered to assist Tina Cook in writing the paper: Janet Harris, Jane Springett, Irma Brito, Nina Wallerstein, Francisco Javier Mercado Martinez, Brenda Roche, Claire Donovan, Jasna Russo.
Impressions of the Conference
### List of Participants

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