The foundations and practice of Participatory Health Research & Integrated Knowledge Translation: What does stakeholder involvement mean for implementation science?

Jon Salsberg, PhD
PPI Research Unit
University of Limerick School of Medicine

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Outline of presentation

- What is Participatory Health Research?
- How does PHR integrate knowledge translation
Participatory Health Research (PHR)

Systematic enquiry, with the collaboration of those affected by the issue being studied, for the purpose of education and taking action or effecting change

Definition used by CDC and Institute of Medicine, USA, following the The Royal Society of Canada Study of Participatory Research in Health Promotion - Green, et al. 1995
...with the collaboration of those affected by the issue being studied?

Can include...

- Patients
- Carers
- Community Organisations
- Entire communities
- Charities
- Healthcare Providers
- Managers
- Policy Makers
Key areas of partner / stakeholder involvement

- Research goals and objectives
- Methods and duration of projects
- Strategy and content of evaluation
- Data collection and analysis
- Interpretation of results
- Joint dissemination of findings
  - in lay language and scientific terms to patients, communities, clinicians, administrators, scientists…

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However…

What is most important is...

Those for whom the benefit is intended are at the heart of the research decision making.
Some PHR Principles

- All partners are experts with different experiences
- Power differentials among partners are acknowledged and sensitively addressed (socio-cultural, professional, political, gender, age, formal education, etc.)
- All stakeholders discuss potential harm as well as potential benefits of research
- Process is capacity building for everyone
- Community ‘ownership’ improves uptake and sustainability, ie *impact*

Benefits of PHR

PHR involves all stakeholders – those who will use, or be affected by, the results of the research – in the research process from formulation of the research question through interpretation and dissemination of results.

And thus...

• Greatly *increases the relevance* of the research to intended users
  • by involving the context experts in the research decision making

• Greatly increases the likelihood that results and recommendations *will be acted upon* (Knowledge-to-Action)

• Reduces *end-of-grant ‘surprises’*. All stakeholders are aware of ongoing developments.
If...

Implementation Science = Knowledge Translation

then

PHR = Integrated Knowledge Translation
KT = 
Do the research then find the audience

*Integrated* KT = 
Find the audience then do the research

*Together*
Evidence-based Practice

Completely oversimplified model of KT

Refined research-derived knowledge ("evidence")

Control

Refine

Evidence-based Practice
Making research relevant: if it is an evidence-based practice, where’s the practice-based evidence?

Lawrence W Green


The usual search for explanations and solutions for the research-practice gap tends to analyze ways to communicate evidence-based practice guidelines to practitioners more efficiently and effectively from the end of a scientific pipeline. This examination of the pipeline looks upstream for ways in which the research itself is rendered increasingly irrelevant to the circumstances of practice by the process of vetting the research before it can qualify for inclusion in systematic reviews and the practice guidelines derived from them. It suggests a ‘fallacy of the pipeline’ implicit in one-way conceptualizations of translation, dissemination and delivery of research to practitioners. Secondly, it identifies a ‘fallacy of the empty vessel’ implicit in the assumptions underlying common characterizations of the practitioner as a recipient of evidence-based guidelines. Remedies are proposed that put emphasis on participatory approaches and more practice-based production of the research and more attention to external validity in the peer review, funding, publication and systematic reviews of research in producing evidence-based guidelines.

**Keywords.** External validity, evidence-based practice, dissemination, generalizability.

➤ I.e., to maximise its usability, the evidence should come from the practice context where it will ultimately be used
Evidence-based Practice

Refined research-derived knowledge ("evidence")

Completely oversimplified model of KT

A → B

Knowledge Users
Completely oversimplified model of KT

Refined research-derived knowledge ("evidence")

- Set priorities
- Define research goals and objectives

Practice-based Evidence

Those who must use the results are ‘front-loading’ the research with their contextual knowledge (↑ external validity)

Evidence-based Practice
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Look familiar?

IKT = PHR
Thank You!

More Information...

@PPI_Ignite_UL

PPI-ignite@ul.ie
Jon.Salsberg@ul.ie

Public and Patient Involvement (PPI) Research Unit