Participatory Research in Behavioral Health

One-Day Training

Yale Program for Recovery and Community Health

Yale SCHOOL OF MEDICINE

Pre-Test

Welcome, Housekeeping and Self-Care

- Welcome
- Housekeeping
- Self-Care

Agenda

9:00 – 9:30	Pre-Test, Coffee and Pastry
9:30 – 9:45	Welcome, Housekeeping and Self-Care
9:45 – 10:30	Introductions - What brought you here?
10:00 – 10:30	CBPR History
10:30 – 11:30	What promotes and impedes participation?
11:30 – 12:30	Ways people have participated - Case studies and discussion
12:30 – 1:15	Lunch
1:15 – 1:45	Varieties and levels of involvement
1:45 – 2:15	Small group exercise – Idea Generation
2:15 – 3:00	Report back /Discussion
3:00 – 3:15	Break
3:15 – 4:15	Key Ingredients and Guidance for Involvement/questions
4:15	Post-test and feedback

Learning Objectives

- To learn about the history of community-based participatory research, both within the healthcare fields and outside of them.

- To have an opportunity to directly interact with one another, helping to facilitate understanding of the nature, ethos, and style of participatory research.

- To learn about facilitators and barriers to participatory research, varieties and levels of involvement, and key ingredients for meaningful participation.

Introductions

Who are you?

What brought you are?

Why is this important to you?

What is CBPR?

- Community based Participatory Research:
  - is an approach to research that involves persons of primary interest in all aspects of the process, from conceptualization through data collection, interpretation and sharing of findings
  - co-learning, a strength-based approach, and acknowledgement of privilege and power are hallmarks of CBPR. For non-academic partners to get actively engaged in research, they need to know what to expect in terms of direct benefits for them. They expect that such a project will bring about some observable changes and be directly beneficial to the target population.

What co-researchers have to say?

Recognition of Competencies:

- I just felt like, I just can't believe that doctors would want us on their team and be equal. I felt overwhelmed, felt joy to be sitting next to them equally knowing that they have all that education went to school all that time. I did go to college but I don't have what they have and still be on the same page. I felt very....I felt amazed.
- But the support that we received here from our staff is just.... You know you can go to these folks with anything and not feel judged or that you're stupid or anything like that and it wasn't like I'm your superior kind of thing. Were all on equal, we are all in this together.

What co-researchers have to say?

Building Relationships:

- For me, I didn’t know what to expect when I came over here. I didn’t know what it was about. What I was going to do. Like I said, I never knew what PRCH was. So by being involved it allowed me to recognize my own inner abilities…. That helped me, because I’m a person in recovery from addiction so I have this low self-esteem and no sense of belonging, so like the way it all happened was like wow! They helped to build my own stamina up, you know, like accomplishments, true friendships…not working those little $8.25 hour jobs where you are just another number. To me it’s like family.

Small Group Activity: Exploring Commonalities

- Where did your ancestors come from? And/or what was the earliest place in the U.S. they lived?
- What did your elders tell you about wellness and illness, e.g., what would cause you to get sick?
- When was the first time you heard anyone talking about "mental health"?

(based on the work of Anita Pernell-Arnold & Maria Restrepo-Toro)

Brief History of Patient Involvement in Research

- Rose Kushner
  - Freelance writer and survivor of breast cancer (United States)
  - Activism: Book, national committees, national organizations

- 1997: First international Conference on breast cancer advocacy

- As early as mid-90s, UK governmental officials recommend involving patients in all stages of clinical trials

- AIDS in the US/UK
  - Advocacy around patients' preferred outcomes

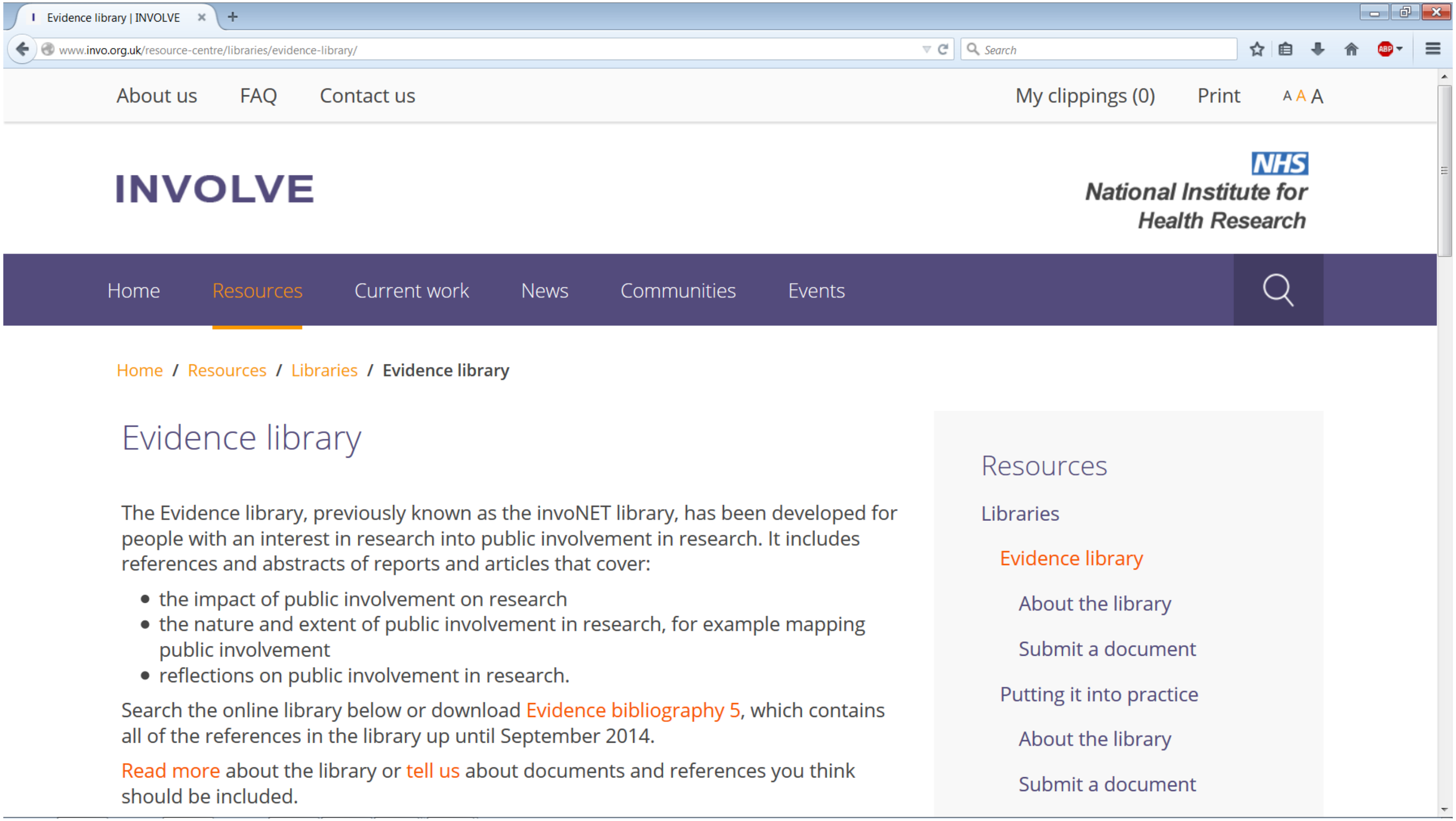
- Maternal health, 1980s

(Thornton, 2008)

International

- United Kingdom: has arguably witnessed the most rapid growth of what they call "patient and provider involvement" (PPI) (Goodare & Lockwood, 1999; Thornton, 2008)
- The National Institute for Health Research (2014): "the first research organisation in the world to establish a national advisory group, INVOLVE, to make sure the views of patients and the public are an essential part of the processes through which research is identified, prioritised, commissioned, designed, conducted and disseminated."
- Remarkable evidence database of (PPI) in research, in both bibliographical and searchable formats.

Involve



Home / Resources / Libraries / Evidence library

Evidence library

The Evidence library, previously known as the invoNET library, has been developed for people with an interest in research into public involvement in research. It includes references and abstracts of reports and articles that cover:

- the impact of public involvement on research
- the nature and extent of public involvement in research, for example mapping public involvement
- reflections on public involvement in research.

Search the online library below or download Evidence bibliography 5, which contains all of the references in the library up until September 2014.

Read more about the library or tell us about documents and references you think should be included.

http://www.invo.org.uk/resource-centre/libraries/evidence-library/

Benefits and Benefits

- Evidence shows its overall positive effect on services and its benefits for the service users themselves (Palmer et al., 2009)
- Benefits include (Beresford, 2007; Involve review):
  - facilitating empowerment,
  - enhancing relevance
  - generating novel research

Historical Challenges

- Pervasive fears and skepticism in parts of the research community
    - “Patients should not interfere in processes of which they know nothing about” (Caron-Flinterman, Broerse, & Bunders, 2005, p. 2576)
- Requires time, patience, and guidance, particularly at the outset (Palmer et al., 2009)
- Despite these challenges, the evidence from this country and around the world suggest that many benefits await such an endeavor.

The Whys of Participatory Research (via Engage Stakeholder Network)

- Rather than presume or guess, just ask “the author”
- People with lived experience are the experts of their own experiences (What does “expert” mean: expertise not just professional or technical) lived expertise
- Connection with human experience
- Can give rich story behind data; illnesses happen to people
- Bringing the findings of large studies down to the level of everyday life implications

The Whys

- Richer questions from the start/Adding questions people want to ask [and answer]

- If not drawing people in, a way to make studies more appealing

- Bridge different communities

- Address discrimination

- Replicability

- Data more reliable and valid

The Whys, continued (from Literature)

- Recovery-based practice; social justice
- Experience of behavioral health problems can inform research questions
- An alternative perspective from the ‘illness’ model
- Diversity of views on what constitutes a ‘good outcome’
- More ‘honest’ responses from participants, especially regarding satisfaction with services

The Whys

- More clinically relevant output
- Cross-fertilization of ideas
- Better recruitment
- Instruments are more ‘user friendly’ and need less piloting
- Increasingly central to funding
  - In England, “PPI” (patient and public involvement) in mental health research is now a requirement for gaining ethical permission and is becoming a requirement of funding support

Facilitators and Barriers of Participation

Facilitators and Barriers of Participation

Image from: http://blog.placespeak.com/wp-content/uploads/2013/11/overcoming-barriers.png

Small Group Activity:
What Promotes and Impedes Participation?

Question for the Group

Facilitators and Barriers of Involvement (from Engage Stakeholder Network)

- Welcoming
  - “Breaking bread”—offering food as a proper welcoming
- Community
  - “Our goal is to make life better for everyone”
  - Message for all: treat people as people
- Resources
  - Day to day realities of participants need to be addressed, e.g., transportation
- Trust
  - Participant needs trust; more transparency about the study being conducted is necessary; transparent advertising
  - People associate research with taking medication; need transparency about this as well

Facilitators and Barriers of Involvement (from Engage Stakeholder Network)

- Collaboration
  - Involving from beginning: what research questions are we going to ask (together)?
- Power dynamics and disclosure
  - Framework for how issues of oppression, poverty, etc. come up?
- Opportunity
  - How can stakeholders build on research? Research as possible, viable, and sustainable career paths for persons in recovery?

Facilitators and Barriers of Involvement (from Engage Stakeholder Network)

- Language
  - Recognize that ALL have areas that they feel uncomfortable talking about
  - Helpful to know language that is helpful or turns off stakeholders
- Commonalities
  - Getting to know each other; respect (e.g., understanding each other's schedule/time pressures); being aware of each others' needs

Striving for Dialogue/Common Ground

- Helpful to know your aspirations/know the goals of the project; understanding each other's hopes
- Keep things plain and straightforward, do not unnecessarily complicate things
- Richness to be gained by mixing science with the personal
- Communication and culture can be a barrier; speaking different languages; transparency and clarity important
- Agenda becomes clear when agreed upon by all

Case Studies from PRCH: Concrete Examples

- Participatory research in mental health: Dispatches from the field
- Program for Recovery and Community Health, and partners
- Examples include: PCORI Wellness Enhancement Project

Example of Community Based Participatory Research: What's the Story of our PCORI WE?

- People with Mental Illness are dying 25 years earlier than the rest of society*
- Can we collectively figure out a way to do something about it?

(Parks, Svendsen, Singer, & Foti, 2006)

Varieties and Levels of Involvement

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Levels of Participation (from Literature)

- Think through *level* of participation that is possible in the context of your research:
    - Consultation with stakeholders
    - Collaboration with stakeholders
    - Commissioned by: Stakeholders initiate the research (and may ask researchers to consult and collaborate with them or conduct their own research
- Be open to change of levels
- The following can be done in any of the 3 levels

Steps of the Research Process

- Identifying a research topic
  - Dialogue
  - What each person wants from the research
  - Discussing perceived possibilities and limitations of research

- Prioritizing research questions
  - Stakeholders tend to prioritize issues related to social welfare and daily living, abuse and discrimination, self-management and alternatives to mainstream treatments and services

- Funding process
  - Don’t underestimate the abilities of people who use services to review proposals and provide important input and guidance

Designing and Managing the Research

- Designing research
  - Helpful to plan this before submitting a proposal for funding
  - Sometimes asked in funding applications about how you are involving people in recovery/stakeholders/family members
  - Range of participation of stakeholders possible, from consultation to collaboration to commissioned by
- Managing the research
  - Assuring Confidentiality
  - HIPAA and Human Subjects Protection Test

Undertaking Research

- Regular meetings
- Collaboration with other organizations
- Stakeholder involvement can include: designing/ conducting instruments, interviews, focus groups, gathering/reviewing evidence, literature search (often helpful to see how research sounds to the communities it often speaks about)
- Ongoing training and support may be necessary

Analyzing Results

- Also can be done in meetings

- This process can take the form of an iterative process that provides a feedback loop to improve study

- Also, serves as type of quality and validity check

- Again, ongoing training and support may be necessary

Evaluating Research Process

- Reflection process on what went well, what did not work so well, and what all would do differently
- Non-judgmental and safe space to discuss
- Learning from each other
- Building for next time; being a role model for other researchers interested in this work

Disseminating results

- Stakeholders are more likely to want to see research change practice for the better
- Reviewing draft reports together
- Helps to collaborate on using appropriate language and avoiding excessive jargon

Participatory Levels: Case Study 1

- Study: *Is there a pathway to recovery through care coordination? Emancipatory action research with mental health service users, carers and professionals within Northumberland, Tyne and Wear*

- Level of stakeholder participation: "'an equal partnership in the true sense' in that all decisions have been made in partnership from the outset"

- Benefits:
  - Stakeholders: "feeling valued"; "being involved in something 'important'"
  - Investigator: involving service users is the best way to ensure that research speaks directly to practice concerns in the real world; service-users brought "direction, guidance, clarity, and focus to this study, at both a micro and macro level."

(Jones, 2011)

Challenges

- Challenges:
  - Stakeholders: uncomfortable with ways ethics committee viewed stakeholder involvement (while participating in the ethics committee meeting)
  - "Both the [principal investigator] and [stakeholders] identified that there appeared to be a lack of understanding/confusion within the ethics committee in relation to mental capacity, permission to consent and the consent process."
  - ethics committee very concerned about distress and "protection" of stakeholder interviewers and interviewees
  - Investigator and stakeholder both suggested that a stakeholder should be on ethics committee

Challenges, continued

Investigator:

- Translating stakeholder ideas into academic/funding language, without diluting the former
- Information-sharing and e-mail: difficult balance between email overload and partners feeling involved/included in the process

Both: difficulty sustaining motivation through long wait periods of ethical approval

- Plan to use this time in the future for training

Participatory Levels: Case Study 2

- *Cost of Stigma Inventory (COSI) study*
- Level of participation: Consultation
- Focus group "to examine a draft of the COSI questionnaire and to supply feedback, so that the questionnaire could be amended in the light of the participants' experience and knowledge of stigma and discrimination."

(Kaur, 2011)

Results of Participation?

- Questionnaire was viewed as covering an important area but had missed some items

- Resulted in, “quite substantial changes to the content, wording and layout being proposed”

- Including:

  - Item on “employed or unemployed” changed to include 9 additional items of the various ways in which service users work

  - Added a new stigma section on: “discrimination by financial institutions and in connection with housing provision”

Links to Case Studies

- NHS, National Institute for Health Research
- https://www.crn.nihr.ac.uk/mentalhealth/about-mental-health-research/information-for-researchers/
- https://www.crn.nihr.ac.uk/resources/mental-health-case-studies-service-users-in-research/

Small Group Activity: Idea generation

Image from: http://blogs.staffs.ac.uk/research/files/2013/09/Social-Innovation1.jpg

Key Ingredients and Guidance for Involvement

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Ingredients of Meaningful Involvement (via Engage Stakeholders)

- Truth/transparency, non-judgmental attitude, mutual respect
- Cultural competence/humility
- Creating spaces for open dialog regarding sensitive, typically undiscussed matters like culture and worldview
- Questions: Will co-researchers feel welcome and valued? Who is employed on the team? Who will be collecting the data? Will they be well-received and have rapport?

Ingredients of Meaningful Involvement

- Involvement from the start is important so as not to be an afterthought
- Optimal team environment enables people to contribute fully
- Find commonalities through dialogue, self-disclosure, and bringing yourself to the work
- Recognize power hierarchy and find ways to convey value for contributions and to offer opportunities for upward mobility
- Real world issues: Know how new income effects benefits; access counseling as needed; anticipate what happens when grants end

Specific Process Suggestions

- Be intentional and mindful of why you are involving stakeholders to begin with, why it's worth the additional effort
- Timeline issues: this work can be time consuming; build in flexible timelines to take that into account
- Provide sense of what to expect when, offer maps and glossary
- Preparing for the unplanned disruptions and moments of stress, how will they be handled, are they factored into the timeline?
- Anticipate/welcome disruptions as opportunities for enriching/ learning

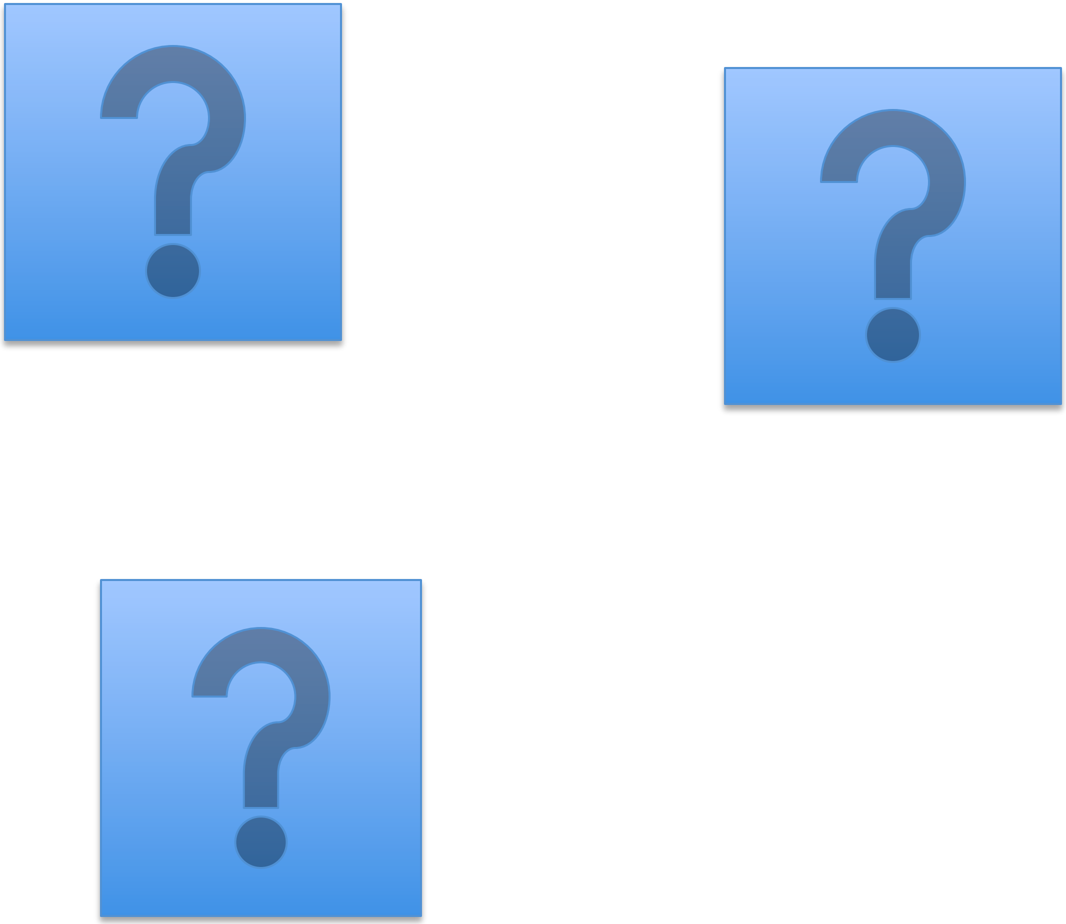
Process Suggestions (via Stakeholders)

- When teaching, use examples throughout; accessibility
- Promote mutual understanding, verified and maintained throughout process
- Individualized learning/working styles identified and supported
- Be mindful of communication strategies and be clear about expectations
- Provide ongoing support without assuming that people already know everything

Advice on Working with Researchers

- Be aware of and build on your own strengths and those of others in working toward a common goal
- Acknowledge and address areas of growth for you and for others (embrace your role as representing your perspective)
- Identify your own needs to get clarity (“break it down”) and ask questions (allow time for discussion)
- When inevitable disagreements or tensions emerge, try not to take issues or differences personally (consider context, background, life experiences)

Questions from the Group?



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Thank You!

Post-Test