PUBLIC INVOLVEMENT IN RESEARCH, EVALUATION & SERVICE DESIGN FOR HEALTH & WELL-BEING: A PRACTICE SHARING EVENT

The School for Public Health Research (SPHR) at The University of Sheffield
The School for Public Health Research

- Funded by NIHR with nearly £20m over 5 years. Launch April 2012

- 8 members selected by open competition
SPHR research - remit

• Focus on environmental and behavioural interventions to promote healthy lives across the whole life course.

• Produce high quality, generalisable research evidence on cost-effective public health practice.

• Translate research into action.
Public Engagement, Involvement and other terms

Engagement often an umbrella term incorporating direct involvement.
BUT, lots of terms!
“PPI”
SPHR engagement remit

Diverse stakeholders locally and nationally

**Engagement with practice**
- Public Health Practice Evaluation Scheme (PHPES)
- Regional events
- Advisory boards
- **Involvement** in research projects

**Engagement with the public**
- Participants on National Advisory Board, Local Advisory Groups and School-wide Programme Advisory Groups.
- Contribute to prioritisation of applications to Public Health Practice Evaluation Scheme.
- **Involvement** in research projects
Progress to date

12 small scale projects, 7 completed so far

Three School wide programmes underway
- Alcohol and young people (6 projects)
- Ageing well (7 projects)
- Reducing inequalities (1 multi-phase project)

Public Health Practice Evaluation Scheme
- 10 projects underway
- 2-4 more in planning stage.
Examples of engagement

With practice

• 53 applications Public Health Practice Evaluation Scheme
• Evaluation workshops; many other events; today!
• Julia Burrows Director of Public Health, Barnsley
• Co-producing Doncaster domestic abuse service evaluation

With the public

• Roy Darlison and Christine Allmark advisers in Sheffield
• Research project involvement
e.g. workshops at Sheffield 50+ → inputs to Ageing Well research
e.g. residents involved in shaping products from inequalities research programme
Challenges of engagement in public health research

• Wide-ranging - aiming to provide knowledge on how to promote health and wellbeing among the whole population

• Not always focused on a service or an intervention - beneficiaries ("service users") not clearly defined and may not recognise their interest

• Often involves competing interests and balancing priorities e.g. reducing inequalities versus improving overall health

• May involve technical, statistical or economic methods
Plan for today

- Share ideas and experience
- Prompt reflection and critical debate
- Make new links
- Identify some next steps
- Timing is tight!

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<th>Time</th>
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<td>10:10-10:20</td>
<td>Exercise in pairs/threes</td>
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<td>10:20-11:00</td>
<td>3 short talks</td>
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<td>11:00-11:35</td>
<td>Small group discussions</td>
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<td>11:35-11:45</td>
<td>Feedback/comments from involvement leads</td>
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<td>11:45-12:00</td>
<td>Open discussion, next steps &amp; close</td>
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Exercise in pairs / threes

• 10 minutes

• Use your sheet to quickly jot down some ideas:
  - what you want to share today
  - what you want to gain from today

• Discuss with your partner

• Hold onto these ideas for later
Three short presentations
University and Community Researchers working together in public health research: some approaches, challenges and opportunities

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Acknowledgements to:
Punita Chowbey, Liz Such, Beverley Ferguson, Sam Amponsah
Joseph Rowntree Foundation
Background & aims

Main project
• Joseph Rowntree Foundation-funded project (2005-6)
• Links between long-term illhealth and poverty
• 12 Community Researchers
• Improved rigour and relevance

Embedded evaluation of Community Researcher model
• Ongoing reflection sessions; diary keeping
• In-depth interviews (9 CRs completed)
• Coding; discussion as a group; final messages agreed
What we did

Recruitment:
- via local orgs/networks
- two-way dialogue
- person specification

Training:
- tailored
- interactive
- phased

Retention:
- team building; fun!
- respect
- flexible work plans
- reflection; ongoing support
What worked well

• Gaining access to wide variety of participants

• Insights and nuances; working across languages

“Nobody knows a community like the people that live there... I definitely feel you’d miss a lot if you didn’t have local people involved.” (CR8)
What worked well

• Training and team working

“There’s lots of things that I’ve learnt, lots of new skills I’ve learnt, lots of new tools I’ve learnt, lots of new communication ideas I’ve learnt...” (CR4)

“I feel that, you know, the research is dependent on us. If you like, we are crucial. We are very, very important to the research itself. [I felt] 110 % ownership of it.” (CR2)
Challenges

• Being too close
  - mistrust among some local people
  - emotionally draining
  - difficulty in questioning own perspective
  - role conflicts
Challenges

• Being too close

“I remember going home and saying to my wife that, you know, I’ve met this guy with a kidney problem and da, da, da, da ... normally we wouldn’t discuss work, but I’m saying, “I think, you know what, I’m thinking of asking him to come and spend weekends, you know, just on the day, not sleeping over, but just come and sit by us and, you know, with the kids around” and, you know, and I’m thinking, you know, “Where am I going with this?” (CR2)
Challenges

• Unrealistic expectations
  - indebtedness; favours to be repaid
  - frustration at lack of tangible impact
Challenges

• Unrealistic expectations

“Some Bengali people ask, “What’s the benefit of this research project?” It was a new thing. A new question for me. But it is difficult for us to explain it. If we explain them in our way, according to our interview system, according to our aim and object, then they are not satisfied. They think no benefit. Sometimes they say, “No benefit.” (CR7)
Future directions?

Both advantages and challenges

• Clearer guidance on support to Community Researchers – avoid harm

• More time to develop common understanding on:
  → ‘ways of knowing’
  → quality in research
  → knowledge-to-action processes (often not direct)

• Longer-term relationships; ongoing funding for knowledge into action
Researching health inequalities with Community Researchers: practical, methodological and ethical challenges of an ‘inclusive’ research approach

Sarah Salway\textsuperscript{1}, Punita Chowbey\textsuperscript{2*}, Elizabeth Such\textsuperscript{1} and Beverly Ferguson\textsuperscript{3}

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Plain English summary

Public health research sometimes uses members of communities as researchers. These are called Community Researchers. The advantage of using Community Researchers is that it enables people who live in communities to participate in research by designing the research, gathering data and being involved in analysis. This ‘participatory’ approach also has the potential to reach communities that might otherwise not be included in research. There are few studies that report the experiences of Community Researchers who take part in such research. This study helps fill this gap by exploring the issues and challenges faced by Community Researchers involved in a study of health and poverty in ethnically mixed areas of east London, UK. Through the accounts of 12 researchers, the study reveals that being a community ‘insider’ had advantages: many felt they had been able to gain the trust of respondents and access people for the research that would have otherwise been missed. The role of Community Researcher was, however, difficult to manage with some researchers feeling burdened by their role and the increased knowledge they had about the lives of those in their community. In addition to the personal challenges for the Community Researchers, the findings raise various ethical and methodological issues that need consideration in participatory research.
How can the design of housing & neighbourhoods improve the wellbeing and mobility of older people?

A participatory approach to research & design

Friederike Ziegler (Urban Studies & Planning)

Martin Dudley (DWELL Dore Group)

Julia Cook (DWELL Citywide Group)
The DWELL Team

Sarah Wigglesworth, Ann Clark and Adam Park (Architecture)

Friederike Ziegler, Lee Crookes and Malcolm Tait (Urban Studies and Planning)

Sarah Barnes (ScHARR)
Participatory Design
Framework

- Inclusion
- Collaboration
- Equalities
- Empowerment
- Shared learning
- Sustainability / legacy
On the up side

- **Inclusion:**
  - Varied backgrounds / experiences
  - School and businesses, showing off

- **Collaboration:**
  - Sharing ideas, university resources

- **Equalities and empowerment:**
  - Recognition of outcome as well as process

- **Shared learning:**
  - University knowledge, local knowledge

- **Sustainability / legacy:**
  - Brochure, themes, wider context
On the down side

- **Inclusion:**
  - Not all ideas or interests, material disappearing
  - Unclear how ideas progressed

- **Collaboration:**
  - Aims? Agreements? Wider context?

- **Equalities and empowerment:**
  - Expectations not met? Focus and methods?
  - Ownership and co-production

- **Shared learning:**
  - Poor summation and review

- **Sustainability / legacy:**
  - Questions of methods and resources
Involvement

- Taking part in the DWELL Project allowed me to explore the complete process of designing accommodation for the elderly alongside other pensioners.
- The experience was mostly positive although there were some obstacles that needed to be overcome.
First the positives

- Communicating with others
- Getting an insight into retirement provision in this country and abroad
- Looking at site potential
- Thinking creatively about
  - Use of space
  - Internal and external environments
  - Communal provision
  - Potential for wider community involvement
  - What was really important
Potential to improve

- Pairs were sometimes at odds and subsequent compromises failed to please either party.

- Role play could have worked in order to improve this for example if pairs or groups had been given scenarios to aid planning.

- Many people found it difficult to dissociate their current needs in order to think about the future and the needs of others.
Group Agreement

We all agreed that the desirables for age-friendly designs were:

- Future proofing
- Flexibility
- Energy efficiency
- Having the potential for social and professional support
- The ability to buy essentials on site
- A well planned environment that capitalized on any existing features that the site provided
Reflections of the researchers

- Participatory research with older people
- Commitment and time
- Importance of dialogue with participants to design process
- Methodologies adapted for engaging different groups
- Learning process of participatory design methods for researchers
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Exploring the impacts of participatory methods

Steph Grant

&

Dave Vanderhoven
Exploring the impacts of participatory methods

Steph Grant

&

Dave Vanderhoven
Context – what we know?

- Public Health is a strategic deployment of capacities and knowledge
- Organisations defend against anxiety (Menzies-Lyth 1959)
- Keeping hold of a clear sense of what we actually do is a quality of group behaviour (Lawrence 1977)
- Bad decisions cost lives – research is vital
- Co-production: a new way of involving others in research
Background to our research

• 50% of homelessness people have a Traumatic Brain Injury (TBI)
• “Don’t believe it” : commissioner
• Limited impact : interventions focus on either drug use, homelessness, criminality
• Small research project: service users’ voices
• Design group of clinicians, survivors, NGOs and academics contributing to all phases of research
• Interview 5 homeless TBI survivors
Design and fieldwork

- Head injuries not seen
- “Dual diagnoses” difficult to support
- New ways to identify homeless survivors
- Arranging interviews with homeless people not compatible with diaries
- Interviews very emotional experiences
- Most interviewees in desperate state
- Lasting impact on interviewers
- New insights into unknown population
Strengths

• Survivor and clinician co-interviewing
• Allowing deeper stories to emerge
• Capacity to Consent judgments face-to-face
• Co-production exposes weaknesses

Opportunities to improve

• Ethics and admin processes
• Services and support provided
• Connections between Public Services
Challenges

• New insights – unsettling and need to be contained into meaningful re-actions – beyond research method and needs co-production?
• To find the right science for the job
• Practitioners, services and decision makers to absorb critiques from findings?
• Universities to adopt new roles in their cities?
Prompts for hard reflection

• Can we learn from such case studies?
• Is it easier to consider interventions when there is a cure or remedy?
• Fragmentation of services is necessary, but TBI seems to be invisible to services?
• ‘Failing individuals’ or failing public health services which is harder to confront?
• Given this, could we run services or do research without public involvement?
Painted By Joel Wilde

A piece I did about my brain tumor I had when I was 3.
I go hold of my brain scans from the hospital, copied and pasted them on to a canvas.
I sculpted a representation of my scar on the back of my neck that I was left with after the operation. Out of modrock, I inserted the needles from my growth hormone pen in resin.
Small group discussions

• About 30 minutes

• Use your sheet to quickly jot down some ideas about the:

Strengths
Weaknesses
Opportunities
Challenges

for public involvement in public health research
Thoughts on the 3 presentations

• Community researchers – access
• Teamwork important
• Expectations of all parties need to be clarified & realistic
• Embedded evaluation
• Preparation, training and support needed
• Working together
• University departments working together
Summary points from Small group discussions - 1

Strengths

• The Experiential knowledge brought by public involvement members – shared
• Teamwork / partnership working
• Valuing participants

Weaknesses

• Access
• Impact
• Support
• Representativeness – excluded groups not recognised
• Feedback to public involvement members
• Lack of clarity about what is actually meant by some terms – e.g. support
• Language – keep it simple
• Use narratives – tell the story
• Lack of time
• Researcher agendas
• Volunteering ‘type’ – what about everyone else?
### Opportunities

- Peer researchers
- Long term relationships
- Integration & Shaping
- Valuing participation (not tokenistic)
- Commitment
- Accountability
- Monitoring (ie who should monitor & audits)
- Innovative methods – e.g. social media use

### Challenges

- Training and support for public involvement members
- Personal agendas & conflicts
- Wider ‘buy in’
- Need to raise the profile of opportunities
- Plant seeds
- Communities – eroded networks
- Funding / resources to keep people involved
- Dissemination
- Defining support
- Commitment from public
- Bias
- Governance – being too risk averse
Summary points from Small group discussions - 3

Opportunities (continued)

• Practical guidance
  – Examples
  – Plain English
• What are the benefits / outcomes of the research?
• Co-production from the start
• Recognise the strengths of all aspects / views – “parity of esteem”
• Show the results of consultation
• Involve at least 2 people for peer support and confidence
• Outreach models to support people
• Creativity – make research less ‘stale’
• Preparatory workshops – local events
• Agencies for the excluded

Challenges (continued)

• Front line community worker role
• Honesty – trust / mistrust
• Danger of professionalising lay involvement
• Not just group involvement as most people are not group members
• Flexible developments as ‘one size does not fit all’
• Voices of less able communicators
• May be more than one valid outcome
• ‘Jargon-busting’
What next?

• University role to raise the profile of public involvement
  – Community researchers
  – User led research
  – Events for the public as information needs to go wider

• Integrate involvement across
  – Research, service delivery, design, commissioning

• Co-ordination needed

• Involvement network

• Local authority, Universities, NHS, Community, voluntary sector and local people to be included in more coordinated involvement work
Thank you for your participation