Learning from experiments in public and participant involvement

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Structure

• Background
• Motivations
• The involvement spectrum
• Challenges
• The EPAD experience
• Suggestions and proposals
Background

- Expanding scale, scope and depth of health data
- Challenges include consent, distribution of benefits, trust
- Governance
  - ‘Adaptive’, ‘responsive’,
  - Engaged – public/patient/participant
  - New models (data trusts, co-operatives, collaboratives etc. for diverse data)
  - Biobank experience
Participant involvement/engagement in governance (PEG)

- Alignment with societal expectations and collective goals of health research
- Legitimacy
- Build trust
- ‘Data subjects’ as stakeholders in both inputs and outputs
- Reciprocity
- Contribution to ethical considerations (cf Dresser)
- Role of participants in successful research (cf Morris and Balmer, Pols)
Publics, participants and ‘subjects’ in governance

Wave I
- From consultation to deliberation
- Upstream engagement

Wave II
- From community engagement to participant engagement and involvement in governance
Challenges

- Representation
- Authority/effectiveness
- Focus of issues
- Accountability (internal, external)
- Inclusion
- Implementation and adoption
- Practicalities
- Space for ‘amateurs and dilettantes’ (cf Weber, Hennion)

“The most important weakness is one common to all representational approaches: how well the views of the representatives reflect those of the people they represent.” (Cohen and Mello 2019, JAMA, emphasis added)
The EPAD consortium 2015-2020

- Public/private consortium, funded €60m by the Innovative Medicines Initiative (IMI) for development of secondary prevention of Alzheimer disease.
- 11 European countries, 39 partners
- Longitudinal cohort, adaptive clinical trial platform, bioresource
Participant Panel

- Recommended by ELSI group
- **Locally** (Scotland, Spain, France, NL, England)
- Common ToR on recruitment, meeting rules
- **Centrally** (through feedback to PI, General Assembly)
- EPAD participant panel in study governance
  - Study experience, research design and documentation, logistics and retention, dissemination
  - Access for re-contact
  - Planning
Challenges

**Representation**
Challenges from both researchers and participants
Participants as ‘delegates’ or ‘trustees’

**Authority**
Based on equal involvement with research community
Direct communication with project leadership
Importance of interpersonal relationships

**Focus**
Work directed by participants

**Implementation and buy-in**
Facilitated by *active involvement* of PI and study teams, but unevenly distributed (5 of 11 countries)
Inclusion
All participants eligible, 2 year term
But how to develop

Accountability
Discursive accountability to participants, to group
But – limited accountability to a) cohort and b) external publics

Practicalities
Language
Expectations
Ethics and regulatory considerations (esp. France)
Core funded but still requires time and commitment
Space for adaptation
Participant-led involvement
Adaptation and openness in governance
Commitment to discussion and refinement
Finding the ‘right’ PEG: experimentation and learning

• Core questions:
  • What do we want from PEG?
  • What do participants want?
  • How do the approaches we adopt reflect these?
  • How can they be incorporated in conventional research structures?
• Experimentation requires
  • Experimental Space
  • Documentation and sharing experience
Thanks to...

EPAD Research Participants Panel

EPAD ELSI group
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