Involving service users and carers in health, social care and educational research

Comensus

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What is Comensus?

- University initiative
- Community involvement team
- Campus-based
- Strategic planning
- Teaching
- Events
- Research
Comensus – the context

- Participatory Action research study 2004
- Making changes-social movement
- Making sense of how change happens
- Planning, reviewing, developing
- Quality circles
- Action planning
Background- Health researchers’ attitudes to public involvement in research (INVOLVE)

- Variation on the meaning of involvement
  - as co-researchers
  - as recipients of information
  - as research participants
- Reasons for involving the public
  - moral obligation
  - Attracting public funding by citing user involvement
  - compliance with requirements of forms
Value for an organisation/institution

- Meaningful involvement at all levels
- Impact on student experience & learning
- Enhanced reputation-raising international profile
- Improved community image and relationships
- Scholarly outputs
- Recognised good practice
- Impact on quality reviews
- Economic impact – innovation & commissioning
- Research grant acquisition
Value for individual participants

- Improved sense of self-worth – co-researchers
- Contrast with previously negatively framed identity for some
- Improvements in well-being
- Colonisation of university space
- Personal development and autonomy, confidence
- Getting voice heard
- Challenging stigma
- Tolerance of difference
Social and relational benefits

Knowledge that we are changing things for the better
Involvement expands social networks and grow friendships
Social side of involvement
Valued relationships with students and staff
Sense of belonging to a team
Relationships enhance the teaching message
Researchers attitudes

- Some evidence of apprehension or even fear of service user/carer involvement
- Fear of the unknown
- Unsure how to interact with service users and carers
- Threats to professional skills and knowledge
- If more encouraging of involvement-this will result in better research
Our projects

- Information technology for community groups (Sandbox)
- Bradton – elearning virtual environment
- Film Festival
- International conference
- Paid service user research post – mental health
  - Involvement practices in secure units
  - Ward based psychiatric care
  - Recovery in high secure care
- Appreciative inquiry – university involvement
- A range of pedagogical research studies
Contribution to others’ projects

- National independent advocacy study
- Robotic shoes – physical disability
- It’s a Goal! – football & mental health
- Cancer network
- Sexual health study
- ICONs (incontinence)
Looking forward

Strategic thinking focus groups
- Changes to university infrastructure
- Involvement practices as university overhead

International connections
- Canada – mad activism and the academy
- Melbourne

Responsible Research and Innovation case study (European Funding)
Reflections on involvement

- Comensus Film

https://www.youtube.com/watch?v=UrGbvPL5hxI&list=UUoP70ha91gtUTjfixfIpow
Writing for publication

- Collective authorship
- Text book
- Plans for new book
- Numerous other publications
References


Authenticity to Action conference

- International conference
- 11-12\textsuperscript{th} March 2015
- This year’s theme – ‘Involve and Evolve’ – focus on innovations in service user involvement
- Abstracts welcome now
- Please visit comensus.com for further details or [www.uclan.ac.uk/conferences](http://www.uclan.ac.uk/conferences)
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