

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

Comensus

Janet Garner  
Angela Melling



# 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



im das Bild zu  
weiterhin das

# Value for an organisation/institution

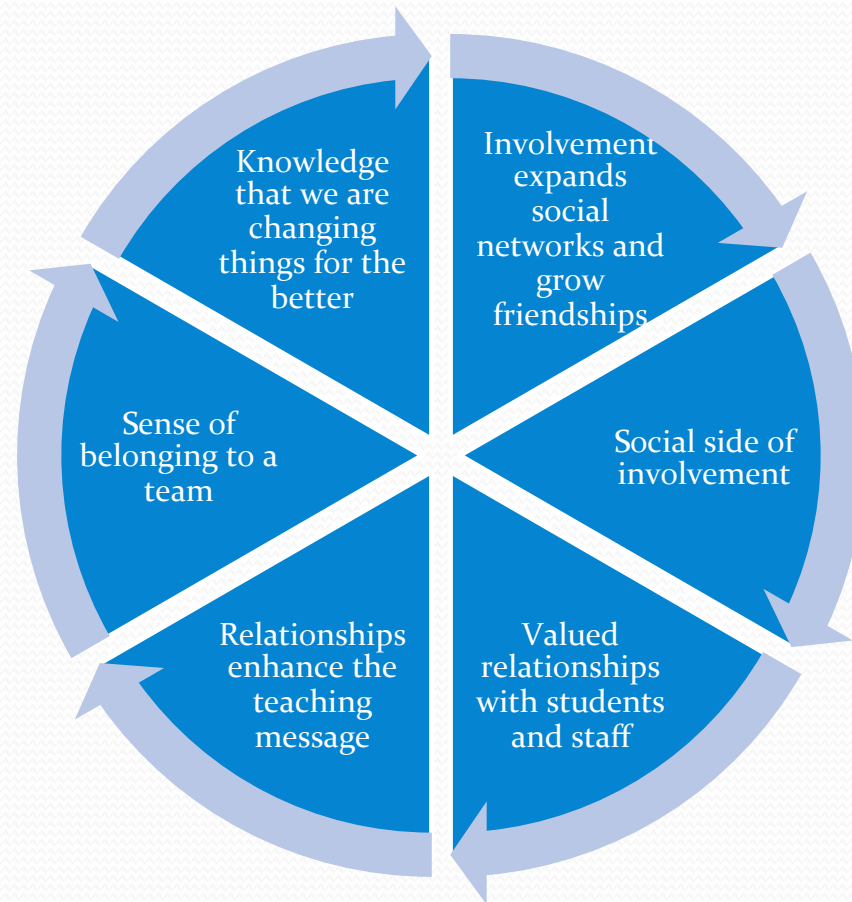
- Meaningful involvement at all levels
- Impact on student experience & learning
- Enhanced reputation-raising international profile
- Improved community image and relationships
- Scholarly outputs
- Recognised good practice
- Impact on quality reviews
- Economic impact – innovation & commissioning
-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



# 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

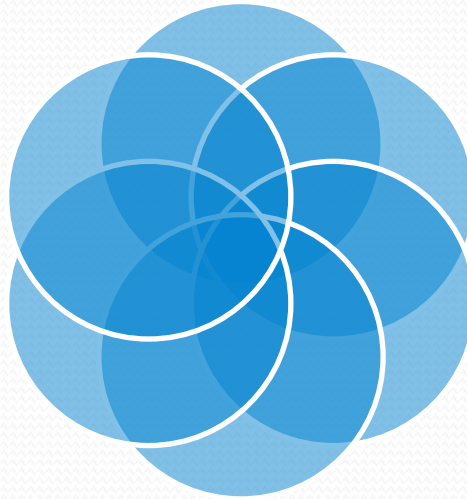
- Information technology for community groups (Sandbox)
- Bradton – elearning virtual environment
- Film Festival
- International conference
- Paid service user research post – mental health
  - Involvement practices in secure units
  - Ward based psychiatric care
  - Recovery in high secure care
- Appreciative 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)

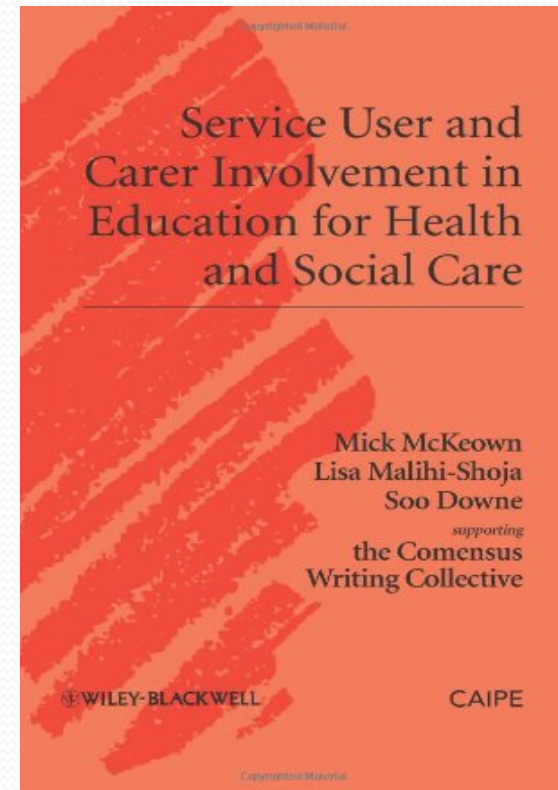
# Reflections on involvement

- Comensus Film

[https://www.youtube.com/watch?v=UrGbvPL5hxI&list=UUoP7oha9igtUTjfixf\\_Ipow](https://www.youtube.com/watch?v=UrGbvPL5hxI&list=UUoP7oha9igtUTjfixf_Ipow)

# Writing for publication

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



# References

- Downe, S., McKeown, M., Johnson, E., Comensus Community Involvement Team, Comensus Advisory Group, Koloczek, L., Grunwald, A. & Malihi-Shoja, L. (2007) The UCLan Community Engagement and Service User Support (Comensus) project: Valuing authenticity making space for emergence. *Health Expectations*, 10, 392-406.
- McKeown, M., Malihi-Shoja, L. & Downe, S. supporting The Comensus Writing Collective (2010) *Service user and carer involvement in education for health and social care*. Wiley-Blackwell.
- McKeown, M. (2009) Alliances in action: opportunities and threats to solidarity between workers and service users in health and social care disputes. *Social Theory and Health*, 7, 148-169.
- McKeown, M., Malihi-shoja, L., Hogarth, R., Jones, F., Holt, K., Sullivan, P., Lunt, J., Vella, J., Hough, G., Rawcliffe, L., Mather, M. & The CIT. (forthcoming) The value of involvement from the participants' perspective: not just a cash nexus. *Nurse Education Today: special issue on service user & carer involvement*.
- McKeown, M., Hogarth, R., Jones, F., Edwards, M., Holt, K., Traill, S., Cameron, F., Priestley, J., Watkins, G., Hellowell, M., Lunt, J. & Malihi-Shoja, L. (forthcoming) Movies, movements and moving moments: connecting film, user involvement and student learning. In T. Stickley & H. Spandler (eds) *Qualitative research in arts and mental health: contexts, meanings and evidence*. PCCS Books, Ross-on-Wye.
- Newbigging, K., Roy, A., McKeown, M., French, B. & Habte-Mariam, Z. (2012) Involving ethnically diverse service users in the research process: alliances and action. In P. Beresford & S. Carr [eds] *Social Care, Service Users and User Involvement*. Jessica Kingsley, London. pp. 120-141.
- McKeown, M., Jones, F., Wright, K., Spandler, H., Wright, J., Fletcher, H., Duxbury, J., McVittie, J., Simon, & Turton, W. (2014) It's the talk: a study of involvement practices in secure mental health services. *Health Expectations*, DOI: 10.1111/hex.12232
- McKeown, M., Dix, J., Jones, F., Malihi-Shoja, L., Carter, B., & Harrison, N. (2014) Service user involvement in mental health practitioner education: insights from movement politics. *Nurse Education Today (Special Issue) 34*, 1175–1178.
- McKeown, M. & Jones, F. (2014) *Service user involvement: policies and practice*. In I. Hulatt (ed) *Mental health policy for nurses*. Sage, London.

# Authenticity to Action conference

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

# Contact details

Comensus

Harrington 207

University of Central

Lancashire

Preston

PR1 2HE

Tel-01772 893818

[JMGarner@uclan.ac.uk](mailto:JMGarner@uclan.ac.uk)

[LMalihi-shoja@uclan.ac.uk](mailto:LMalihi-shoja@uclan.ac.uk)

[www.uclan.ac.uk/comensus](http://www.uclan.ac.uk/comensus)

[Comensus.com](http://Comensus.com)

