Engaging consumers in health care and health services research

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The issue being addressed

- Shift towards greater engagement with consumers in health care, health services planning and health research

- Jargon
  - Consumer engagement
  - Consumer involvement
  - Public participation
  - Consumer advocacy
  - Customer satisfaction
Assumptions

- Engaging consumers is a natural progression in health care, health services, and health related research
- More engagement equates to better quality, cost effective and highly valued health care

However...

Consumer engagement is an experience, it is not something that is ‘done’
Three philosophical traditions

- Civil rights, moral obligation – ‘nothing about me without me’
- Personal responsibility – shared decision making, self-management, empowerment
- Cost and quality of health care – safe and cost-effective health care
Three areas of focus

- Health care – the actual care delivered, received and experienced
- Health services – tangible and less tangible elements of service
- Health research – across all areas of health care and health services
Who and what?

- Identifying research topics and prioritising research
- Commissioning and funding
- Project design and management
- ‘Doing’ research
- Disseminating and implementing findings
- Evaluating impact
How?

- Establish a legitimate involvement process
  - Consultation
  - Collaboration
    - Consumer-controlled / consumer-led research
- Invite diverse participation
- Manage power dynamics
- Align goals, purpose, involvement, method, techniques, steps and resources
Consumer engagement in research

- Engaging consumers is part of best possible care
- Consumers not always engaged early in projects
- Often different priorities between researchers and consumers
Characteristics of consumers

- Focus – what is important to consumers?
- Expertise – tension between being an expert and losing ‘native’ consumer perspective
- Representativeness – who or what can consumer be expected to represent?
- Convenience – who is available to provide or advocate for the consumer perspective?
Characteristics of researchers

- Research tradition
- Disciplinary focus
- Individual preferences and idiosyncrasies
- Lens
- Motivation
Influential Structures

- Funding models
- Organisational culture / heritage
- Purpose for engaging consumers
- Job descriptions
- Research support
Not a smooth or well-oiled process

- No linearity – continual progression and retracement
- Multiple interacting factors
- Time / rewards / motivation
- Requires a clear vision
- Takes time
- Expectation creation and management
- Mutual understanding
- Need to value consumers and authentically engage
Dealing with complex interactions

- Co-production usually associated with the activity surrounding the delivery of health care
- Co-design usually relates to the design of service delivery processes and includes technology
- Co-creation is aligned with value and an overall concept of health and wellbeing
Co-production

- Facilitates empowerment
- Underpinned by self-determination
- Acknowledges and combines the worth and experience of each individual
- Co-production blurs the boundaries between scientists, service providers and end users
- When used effectively, puts ‘termites in the ivory towers’ by adding diversity to traditional ways of thinking
Co-creation

- Engaging in values guided action
- Purpose is to change service environment and the way that consumers are perceived
- Requires commitment, effective communication practices and values the humanity and perspective of each contributor in a collaborative process
Co-design

- Aims to improve the health of people in a community by involving them in the creation of tangible outputs
- A social process that can fortify individuals’ knowledge and skills through participation
- Often focuses on the design of care spaces – buildings, care pathways, technological interventions
Take home message: Perspective...
Thank you

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