

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?

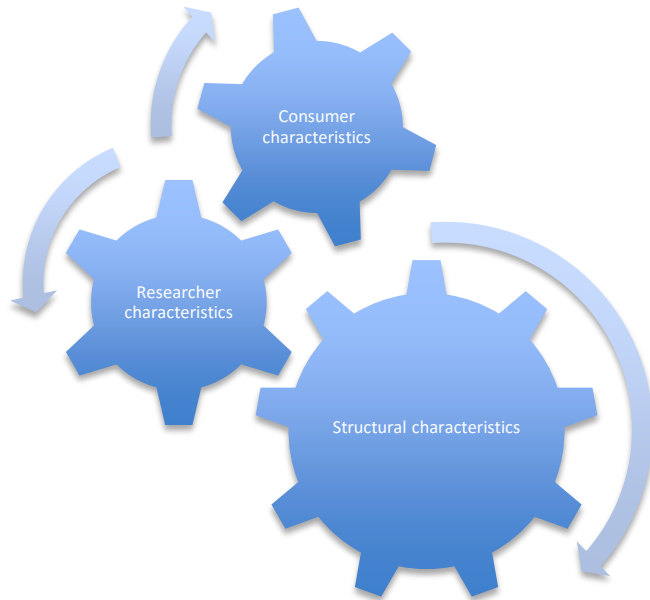


- Identifying research topics and prioritising research
- Commissioning and funding
- Project design and management
- ‘Doing’ research
- Disseminating and implementing findings
- Evaluating impact

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?



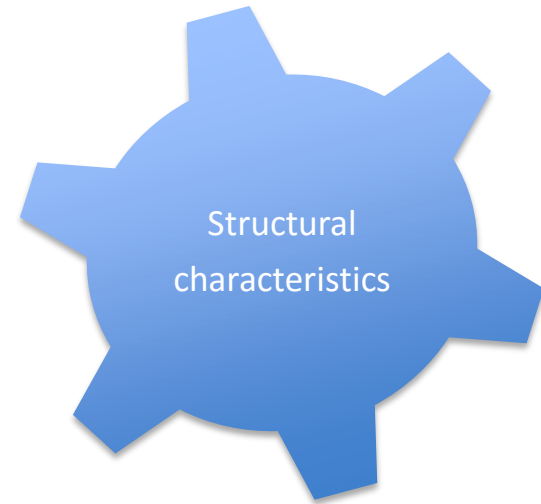
Characteristics of researchers

- 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

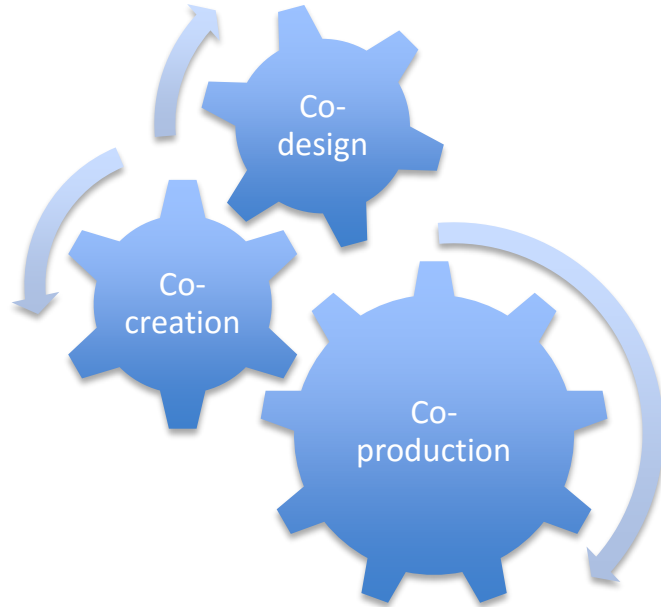


Not a smooth or well-oiled process

- 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

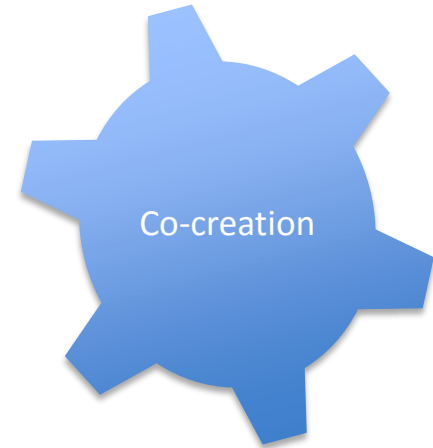
Co-production

- 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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