Consumer Involvement in Developing Supportive Care Research: An evolution in approach

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What roles do consumers play in research?

- Patient & public involvement (PPI) embedded into research governance expectations in many countries:
  - Setting the agenda
  - Design & delivery
Roles cont.

• Prioritising research ideas
• Review of research protocols
• Funding decisions
• Research proposal design
• Designing patient information
• Outcome tool development
• Advocating for research funding

Thompson et al, Qual Health Res, 2014
PHCRIS.org.au
Limited impact

- **Focused priorities** (Saunders & Crossing, BMC Res Notes, 2012)
- **Grant & Funding support** (Arain et al, Health Expectations, 2013)
- **Improved recruitment** (Arain et al, Health Expectations, 2013)
- **Positive attitudes** (Andejeski et al, J Women's Health &GB Res, 2002)
- Little evidence of changes in the process or nature of the research endeavour or outcomes for patients
The Department of Cancer Experiences Research

- Multidisciplinary research group

AIMS TO

- Understand patient experiences of cancer and its treatment
- Develop novel interventions aimed at improving patient experiences
- Focus on patient voice in the design and delivery of interventions
- Focus on empowerment and self-management
MRC Framework for development & evaluation of complex interventions: 2008

**Development**
1. Identifying the evidence base
2. Identifying/developing theory
3. Modelling process and outcomes

**Feasibility/piloting**
1. Testing procedures
2. Estimating recruitment/retention
3. Determining sample size

**Evaluating**
1. Assessing effectiveness
2. Understanding change process
3. Assessing cost-effectiveness

**Implementation**
1. Dissemination
2. Surveillance and monitoring
3. Long term follow-up

**Non-linear Interacting Flexible process**
Preparing Patients for Chemotherapy

- Patients involved in developing intervention

- Patient voices to deliver evidence based messages
  - Credibility of message
  - Engaging style
  - Avoidance of talking heads
Patients as interventions agents: The Pentagon Trial

- Nurse & Peer support intervention
- Patients enjoy the combination of professional & peer support
- Peers love the experience of being an extension of the multidisciplinary team
  - Embedded in team vs Cancer Connect role
Putting it together

**ASTROID**

- Program of work to address the needs of men under Active Surveillance for low risk prostate cancer

- Understand needs of men and partners
- Develop decision aid
- Test its impact for men and partners
Features of Patient Involvement

- Member of program steering committee
- Conceptualizing the study design
- Developing intervention content
- Leading consumer consultation & feedback - DVD input coordination
- Publications & presentations
- Media promotion of the findings
- Sourcing funding for the program
- Advocating to others re patient involvement
Researcher Impressions

- Better interventions
  - Credible, relevant, appropriate, strongly endorsed by participants
  - Focused on what matters to patients
- Peer to peer enhancement of involvement
- Link to translational opportunities through patient organisations
- Happy funders
- Professionally rewarding
## Success Factors

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<tr>
<th>Success Factor</th>
<th>Additional Information</th>
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<td>Be clear about the needs of the program &amp; the possibilities for involvement</td>
<td>• Commit time to the patients involved</td>
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<td>Embed patient involvement into the process</td>
<td>• This is not an optional extra but built in</td>
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<td>Pick the right patient(s) for the right reasons</td>
<td>• Not about advocacy but focus on patient needs</td>
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<td>• Availability &amp; readiness for the work</td>
<td>• E.g. media training, research ethics &amp; governance, the research process &amp; scientific endeavour</td>
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<td>Provide training to lift confidence</td>
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MRC Framework - a work in progress

Development
1. Identifying the evidence base
2. Identifying/developing theory
3. Modelling process and outcomes

Patient experiences:
What is the problem to be addressed?
How should this occur?
Build into intervention elements

Feasibility/piloting
1. Testing procedures
2. Estimating recruitment/retention
3. Determining sample size

Patient experiences of the intervention to guide refinement.
Patient to patient discussion of what works and what doesn’t?
Patient refinement of outcome measures.

Non-linear Interacting Flexible process

Evaluating
1. Assessing effectiveness
2. Understanding change process
3. Assessing cost-effectiveness

Patient interviews about impact alongside quantitative measures.

Implementation
1. Dissemination
2. Surveillance and monitoring
3. Long term follow-up

Patient advocacy
Patient-led publication and presentation
Thank you.

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