Consumer involvement in clinical trials: How do we measure impact on quality and cost?

‘The consumer perspective now and in 5 years’

Anne McKenzie
Melbourne November 2016
What is consumer involvement in research?

Consumer involvement is about researchers, consumers and community members working in partnership to make decisions about research priorities, policy and practice.

Research being conducted that is with consumers rather than to or for them.

It's about getting the whole picture – one that is inclusive of the consumer ‘voice’.

Source: INVOLVE UK 2008
and what it’s not about

- Participants (subjects) in research / recruitment to trials
- An opportunity to ‘tick the box’
- Public relations and fundraising

Source: INVOLVE UK 2008
Hands-up Research

- Hands up if you conduct clinical trials
- Keep you hand up if you have consumer involvement in the management of that trial
- Keep your hand up if you have consumers involved at all levels and stages of the trial:
  - Design phase
  - Steering committee
  - Community reference group
- Keep your hand up if you have evaluated the impact of the involvement activities on the trial
Consumer value for research

From a consumer perspective research has three key phases:

- Development of hypothesis, methodology and funding
- Conduct of research and reports
- Communicate and implement results

Maximum value for consumers is where each phase is managed efficiently and the results ultimately lead to improved health outcomes

It's all about the impact of the investment of time and money and the translation of research results into policy and practice
National support for consumer involvement

• National and state consumer organisations

• NHRMC:
  – Community and Consumer Advisory Committee
  – Clinical Trials Section
  – Revised Statement

• MRFF commitment

• Involvement programs:
  – Cancer Australia
  – WA Health Translation Network

Source: INVOLVE UK 2008
Consumer and Community Health Research Network

Provides:

- Advocacy and support
- An evidence base
- Community links & networks
- Methods for involvement
- Resources
- Teaching and training

www.involvingpeopleinresearch.org.au
Good practice initiatives

• Cancer clinical trial groups:
  – Consumers on Safety and Data Monitoring Committees
  – Consumer Chair and Consumer Advisory Panels
  – Consumer involved in developing protocols

• Telethon Kids Institute collaborating with Menzies:
  – Oral Rotavirus Vaccine Trial with community involvement in all stages from concept → funding → implementation

• Miracle Babies Foundation

• CanTeen
Internationally: consumer involvement making a difference

- The National Institute for Health Research UK:
  - INVOLVE
  - Research Design Services

- Medical Research Council:
  - Patient Involvement group

Source: Simon Denegri
NIHR National Director for Patients and the Public in Research and Chair, INVOLVE
Improving access to research

Source: Simon Denegri
NIHR National Director for Patients and the Public in Research and Chair, INVOLVE
And yet in Australia ......

Consumers still see inefficiencies because:

• Their priorities for research aren’t always considered so it’s hard to define the value or cost

• They haven’t been consulted or informed about outcome measures

• Funding efforts focused on NHMRC limits opportunities for innovative models / partnerships

• Trials have less than optimal recruitment numbers

• Results communicated mainly through peer review journals / conference presentations which can be influenced by publication bias e.g. important negative findings not reported
Its time to make the shift

Of course they can participate as soon as our planning is over!
Adding value

Consumers can meaningfully contribute by:

• Being involved in developing the research hypothesis
• Having input into protocols to suit needs of consumer group/s
• Developing patient documents
• Using their networks to increase trial participation
• Providing a consumer perspective on results and findings
• Assisting with communication and implementation of results
• Supporting and advocating for translation into policy and practice and new research
What’s needed to support increased consumer involvement?

National Centre for consumer and community involvement that provides:

– Training for researchers and consumers
– Resources and toolkits
– Support for researchers to implement involvement initiatives
– Rewards and recognition for good practice
– Links to the community

ACTA (and other associations) calling for consumer involvement to be standard practice in all research

Researchers and consumers working together to add value to health research
5 years down the track

We have the public posted at all levels

Source: INVOLVE UK 2008
THANK YOU

Contact details:

Anne.McKenzie@uwa.edu.au

www.involvingpeopleinresearch.org.au

Source: INVOLVE UK 2008