Balancing innovation and evidence in self-management and self-care – a consumer perspective

Leanne Wells
Chief Executive, CHF

Consumers shaping health

ASMI Conference 2016
About CHF

• National peak body for health care consumers and those with an interest in health consumer affairs
• Member based organisation
• Strategic focus:
  – Policy and advocacy
  – Capacity building
Overview

- Tomorrow’s health systems
- Health’s pain points
- The activated consumer and change
- Health literacy
- Consumers and the self management industry
Tomorrow’s health systems

- Consumer transformation
- Health care delivery transformation
- Clinical transformation
- Commercial transformation
- Pace of change
Health’s pain points

- Multi morbidity and lifestyle risk factors
- Social determinants of health
- Outmoded models of care
- Review paralysis
- A system in need of renewal
The activated consumer

- Improves patient experience
- Improves quality of care
- Improves health outcomes
- Reduces costs
- Promotes positive health behaviours
- Builds staff performance and morale
Evolving pathway

Consumers shaping health
Consumers as change agents

“Technical changes are those with well defined problems, where a clear solution can be found and the implementation path is clear... Adaptive changes are characterised by situations where the challenge is complex and to solve it requires transforming long-standing habits ....new ways of thinking and relationships....The development of new models of care and many challenges the local systems are being asked to plan for are in the domain of adaptive change....”

Nigel Edwards, , 11 March 2016
Consumers as change agents

“For decades, policymakers have focused on structural and organisational changes as the primary means of driving improvement. Other levers – competition, transparency, incentives – have also been deployed with some success. But a key lever of change has been missed: people power.... There is no more important task in the years ahead than for the NHS to stop treating patients as passive bystanders and instead enlist them as active agents of change”

Alan Milburn & Stephen Dorrell, Foreward to ‘Powerful People’, IPPR, July 2015
7 Principles of Consumer Centred Health Care

- Coordinated and Comprehensive Care
- Accessible and Affordable Care
- Informed Decision Making
- Trust and Respect
- Appropriate Care
- Whole of Person Care
- Planning and Governance
Putting people in control

- Engaging people in keeping healthy
- Shared decision making
- Supported self management
- Having a personal health or social care budget
- Involving families and carers
- Choosing a provider
- Taking part in research as part of your care and treatment
- Evaluating services through feedback
Activating consumers

- Easy
- Attractive
- Social
- Timely
Lost in translation

What we say
Digital, *paperless*, accessible, efficient, *simple*, *world class*, *personalised*, human, informed, collaborative, *sustainable*, affordable, connected, *provides better outcomes*, puts the patient in control, gives me what I want when I want it

Translation

What consumers are saying
*Make life easier and more convenient to me*
*Let me take ownership and empower me*
*Include and respect me in the relationship*
*Keep me informed*
*Enable transparent access to my information*
*Give me the best care you can*
*Reduce my costs*
Lost in translation

Consumers shaping health
Health literacy for clinicians

60% OF PEOPLE
LOW HEALTH LITERACY

Having low health literacy means your patients don’t have the knowledge they need to find, understand and use information about their health and health care. You can help change this.

How can I help my patients understand their health better?

Know your patients
- don’t assume understanding
- listen
- talk about decisions

Ensure understanding
- invite patient’s support person
- encourage questions
- ask patients to repeat information

Consider how you present information
- try different formats
- tailor information
- decision making tools

Improve your health service
- education & training
- improvement activities

Australian Commission on Safety and Quality in Health Care

www.safetyandquality.gov.au
Consumer and the Self Management Industry

- Packaging and labelling
- Complementary medicines
- Regulation of over the counter medicines
- Advertising and marketing
Packaging and labelling

• In many cases, the presentation of medicines is the first line of communication with consumers.
• More consumers are self-managing, meaning they are more reliant on the labelling of medicines.
• Labels tell consumers how to use a product, how to store it and alert them to any risks or hazards.
OTC medicine regulation

• Communication surrounding scheduling must be transparent and clear to consumers

• Direct to consumer advertising of pharmaceuticals does little more than create a market for a particular drug where one does not currently or urgently need to exist
Complementary medicines

• Phrases such as ‘scientifically proven’, ‘clinically formulated’ and ‘independently tested’ are often used on products where there has been very limited if any verifiable clinical trials establishing efficacy.

• CHF has argued for labels on these products indicating whether the product has been independently clinically tested for efficacy.
Complementary medicines

- More than half of consumers who take complementary medicines don’t know that they are medicines
- Believe that the products are independently tested
- Believe these products work as well as prescribed medicines
- Don’t realise that side effects and interactions are possible – use with care
Advertising therapeutic goods

• Information versus advertising

• Health literacy is central to medication safety and self-management:
  - Understanding of medicines
  - Understanding of directions and labels
  - Understanding of safe use
  - Understanding of questions to ask doctors/pharmacists
Conclusion

• Most health care is actually self care, family care and community care
• Tomorrow’s health system is going to be shaped by several transformational developments
• ‘People power’ and the activated consumer are overlooked agents of change
• Health literacy is not the soft underbelly – accurate, accessible, timely and relevant health and medicines information will drive a more informed consumer and better outcomes