

Democratising consumer, patient and carer involvement:

Are we being effective?

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Janet (North Metropolitan Alliance for Future Health) receives some funding from the Australian Department of Health and Ageing for Cochrane activities in Australia

Health care is changing



- Increasing responsibility put on health consumers, patients and carers - to develop skills for a pro-active role in our health care
- 'Health literacy' and 'self management' as a vital part of health care
- 'Shared decision making' and 'patient-centred' health care!

A Story



About a weight problem

Health literacy

- Before: the public should be 'science literate'
 - now we are being asked to be 'health literate'
 - how much of this is about 'thinking like healthcare providers'?
- Not every adult (in Australia) can read and write (in English) or do basic arithmetic.



Many people have mental conditions and older people, in particular, develop problems with their thought processes, their 'cognitive function'.

- It is important to retain 'who we are' - and to recognise that we may need counselling and support
 - rather than talking about our 'emotions' as part of the disease process.

Health literacy: what do patients and the public want?

The delivery of high quality, and appropriately targeted consumer health information

In order to:

- understand [what is wrong](#)
- gain a realistic idea of [prognosis](#)
- make the most of [consultations](#)
- understand the processes and likely outcomes of possible [tests and treatments](#)
- assist in [self-care](#)
- learn about [available services](#) and sources of help
- provide [reassurance](#) and help to cope
- help [others understand](#)
- [legitimise](#) seeking help and concerns
- learn how to [prevent](#) further illness
- identify further [information and self-help groups](#)
- identify the [‘best’ healthcare providers](#).

Self help



I remember the days when groceries were carried to your car and technical support a do-it-yourself experience

The important issues for patients

– by consumers

- ***Navigating the health system*** – the services available.
- ***Accessing healthcare providers***
 - *Attributes of the health care provider* – clinically skilled, good communication skills; listens, respect for the knowledge, needs and views of the person with health problem(s).
 - *The relationship*: trusting the health care provider(s); respect for each other.
- ***Information and its communication*** – clear, free of medical ‘jargon’, sufficient detail, relevant, tailored to individual, timely, honest (both parties); can be communicated to family and others; relevant and applicable treatment recommendations.
- ***A role in managing own health care***: particularly with chronic health conditions .
 - *Decision making*: discussion with healthcare providers and significant others, seeking information from a variety of sources prior to making the decision.
 - *Decision taking*: implementation of the decision, motivation, environmental enablers including costs.

A role in managing own health care

... diabetes is something you have to manage yourself. You have to be in control of that and seek the assistance and support from more knowledgeable people when and if it's required but ultimately it's your responsibility to manage that....

Susan Goodall (2003) (Australia)

From what 'school' do we gain awareness about health care?

- Media (including publications).
- Industry (brochures, posters and 'advertisements').
- Government.
- Patient and consumer support organisations.
- Personal experience, asking friends and family.
- The internet – also accessing the views and experiences of other people; articles or more frequently through interactive bulletin boards and chat sites.
- ❖ Pseudo science is used to produce the wanted results
- ❖ Public issues tend to arise from 'science in the making'
- ❖ As a culture we are coming to realise that experts too have disagreements and have their own agendas - objectivity and impartiality are very hard to find.

“To be able to adhere to discharge instructions after a visit to the emergency department (ED), patients should understand:

Both the care that they received and their discharge instructions.”



- A study in which 140 adult patients, or their caregivers, were interviewed after discharge from ED (2 US hospitals).
- The people’s understanding was compared with the information in their medical notes.

The end result was that:

- “Many patients do not understand their ED care or their discharge instructions.
- Most patients appear to be unaware of their lack of understanding [particularly of post-ED care] and report inappropriate confidence in their comprehension and recall.”

Engel KG et al. Patient Comprehension of Emergency Department Care and Instructions: Are Patients Aware of When They Do Not Understand? *Annals of Emergency Medicine* 2008 published online 11 July 2008.

This study was taken up by the New York Times (and Health Behavior News Service, HBNS)



We are given the clear message:

- “A vast majority of emergency room patients are discharged without understanding the treatment they received or how to care for themselves once they get home.....And that can lead to medication errors and serious complications that can send them right back to the hospital.
- The greatest confusion surrounded home care — instructions about things like medications, rest, wound care and when to have a follow-up visit with a doctor.
- People were not aware of what they did not understand, suggesting that simply asking a patient if he (or she) understands is not enough.”

In the New York Times: Other doctors were interviewed

- “We’re finding that people are just not prepared for self-care, and that’s what is bringing them back,
- In the past, patients who did not follow discharge instructions were often labeled noncompliant. “Now, it’s being called health illiteracy,”
- as many as half of all patients are considered to lack the ability to process and understand basic health information that they need to make decisions.
- But the patient is only part of the equation; doctors are notoriously inept at communicating to patients.”

The New York Times: and the Joint Commissioner



- "...hospitals are now being forced to face their communication inadequacies. "We've raised the bar of what's expected of hospitals,"
- 'AND the Medicare Payment Advisory Commission has recommended a policy change that would reduce Medicare payments to hospitals with excessive readmission rates.'
- That is, a policy change that could have effect - as it affects funding.....

Patient responsibility in health care

- To lose weight, exercise, and overall improve lifestyle
- Make and keep to appointments and checkups, manage medications
- Share in decision making about treatments – and then to adhere to treatments and care plans
- Arrange often complex integrated care plans and coordinated care (maybe involving specialists, allied health (nutritionist, physiotherapist, occupational therapist, podiatrist, exercise sessions) etc
- Yet people often cannot readily access their general practitioner (the gatekeeper for other providers) for the care and support they need.
- This, again, is an area that a policy may be effective – through paying general practitioners less for jobs nurses can do (as being proposed in Australia (and elsewhere)).



Safety and Quality of Health Care

- As the public, we are being asked to take part in the safe and effective (quality) delivery of health care.



Visit a hospital and you are likely to see posters and signs all around about 'Washing Hands'.



The 'Patient Journey' is being followed to assess healthcare services.

(in Australia)

Formal consumer participation



- Engagement at the 'member of the public', or 'citizen' level refers to involving consumers - not just the public as represented by associations, health professionals, lobbyists and interest groups - in policy formulation, priority setting and program delivery.
- This level of engagement is a key component of 'governance' .
- Is how a society steers itself and how citizens are accorded a voice on issues of public concern, and how decisions are made on these issues.
- **In Australia**
 - Public (and other) hospitals in Australia have Community Advisory Committees (through policy and legislation)
 - In Melbourne Central, consumers have been successfully introduced onto Root Cause Analysis review panels
 - General Practice Divisions have Consumer Liaison Groups
 - Success is mixed, for example dependent on the level of commitment by Management , funds made available.
 - Department of Health and Ageing and other health committees.

Policy



- Consumers are involved in health care improvement as consumer advocates, consumer representatives, through patient support groups, non-government disease-based organisations and consumer organisations (often which take on 'policy')
- These are often very poorly funded and are limited by governance issues, staffing limitations and insurance requirements
- Consumer representatives in Australia are nominated as members of many healthcare committees, we have a seat at the table. Sometimes we still have to defend our position in providing the consumer perspective (as we cannot be representative of all; much the same as our politicians in the lower house of government, the House of Representatives cannot represent all populations in Australia)
- Many patient support groups continue to authentically represent consumers, patients and carers.
- Others have changed. They have become corporatised:
 - Chief Executive Officers and staff;
 - Boards (there may be a 'consumer')
 - Professional roles including educators (who do not have direct experience of the health condition)
 - Provide services
 - Fund research; prioritise research
 - Provide participants for clinical trials
 - Educate patients and provide self-management courses
 - Inform government policy
 - Patients and carers may have become 'a resource' (from which they gain funding).

Patient Charters and Principles for Health Care: for example

The Australian Commission on Safety and Quality of Health Care

Sees the experiences, knowledge, wisdom and perceptions of patients and consumers as essential to its work to improve safety and quality.

Principles to shape Australia's health system

- People and family centred
- Equity
- Shared responsibility
- Strengthening prevention and wellness
- Comprehensive
- Value for money
- Providing for future generations
- Recognise broader environmental influences which shape our health
- Taking the long term view
- Safety and quality
- Transparency and accountability
- Public voice
- A respectful and ethical system
- Responsible spending on health, and
- A culture of reflective improvement and innovation

More on patient-centred health care

- How do patients and carers have our voices heard and taken note of – you wonder when an article is published in a healthcare journal about a topic that is dear to our hearts and is what the public have been talking about for years –
 - and has been addressed by Community Advisory Committees
- Access to food in hospitals – food out of reach; utensils of packaging causing difficulties; not in a comfortable position for eating (London)
 - The publishing and financial power is more 'in the hands of other than patients and consumers'; creating evidence?
 - Patients are the 'subject of research' rather than patient-centred health care being 'a work in progress'?

Naithani S et al. Hospital inpatients' experiences of access to food: a qualitative interview and observational study. *Health Expectations* 2008;11:294-303.]



Considering patient non-participation

In Sweden, local acute care hospital, 362 patients – inpatients and outpatient clinics – because:

- Lacking information: 'not getting my results from laboratory tests and examinations and no communication about my health situation'.
- Lacking recognition: 'Having this for over a year, yet not being believed or not listened to. Telling that I'm allergic to a drug, but getting that drug anyway'.
- Organisation-centred care: 'not being able to influence the time and date for visits to my physician'.
- Feeling insecure in healthcare interactions: 'Not knowing if the health professionals have the knowledge that they claim and thus the basis for their decision'; 'Not feeling secure enough to tell my whole story or ask questions to the health professionals'.



Empowerment of consumers



- Mothers of children with allergies, anaphylactic reactions in Australia (life threatening but 'low risk' in terms of numbers per population).
- Doctors concentrating on measurable (laboratory or skin test) physical evidence rather than precaution in response to uncertainty and histories (includes the real life environment and family situation) as given by parents.
- Prescribing an autoinject could empower the parent.
- Parents preferred relationships with doctors that recognised their concerns, addressed their information needs and confirmed they were managing their child's allergy appropriately.



Hu W et al. When doctors disagree: a qualitative study of doctors' and parents' views on the risks of childhood food allergy. *Health Expectations* 2008;11:208-19



Cochrane Consumer Network

- Our members are 'informed consumers' within The Cochrane Collaboration
 - we read and comment on Cochrane systematic reviews and their plain language summaries.



The Collaboration sets out to minimise (real or perceived) bias or confounders in its work - Sponsorship policy states that sponsorship of a Cochrane review by any commercial source or sources (as defined above) is prohibited to provide a clear barrier between the production of Cochrane reviews and any funding from commercial sources with financial interests in the conclusions of Cochrane reviews.



We are not just looking for the breakthrough or cure – that every new treatment is going to be (so we have to have it now) whatever the possible harms.

- **We ask, what is the evidence?**
- **AND form partnerships in health care**



Consumers become involved – from the website www.cochrane.org, word of mouth etc.

Cochrane Consumer Network



- Consumers, patients and carers have formally been involved in the Collaboration since Registration of the Cochrane Consumer Network (CCNet) as part of The Cochrane Collaboration in 1996.
- CCNet has members from over 55 countries
 - an international Geographical Centres Advisory Group
 - encourages consumers to give input into the development of Cochrane systematic reviews - that could extend across the 51 review groups based on areas of health care
 - is not a legal entity in its own right
- involves civil society as a part of social inclusion
- promotes evidence-based health care.
- Dedicated consumers live with the health condition and do not 'leave' it when they change jobs.

We define evidence-based health care as:

- a combination of current best research evidence, the expertise of the healthcare provider, and patient values and preferences within a social and geographical environment.
- *Evidence-based health care is about making decisions on health care for and with individuals, families and communities.*





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- “One of the strongest arguments for the distance between common sense and science is that the whole of science is totally irrelevant to people’s day-to-day lives” (science explains the familiar in terms of the unfamiliar).



Trust on a social level makes knowledge and understanding redundant

THE WIZARD OF ID by Brant Parker and Johnny Hart



BELIEVE ME, AN OPERATION
IS NECESSARY



PROVE IT