

Improving health literacy: what should - or could - be on an Australian policy agenda?

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- Create space to think about health literacy
 - Explore ideas for improving it
 - Should it be on a national agenda and how?
 - Presentation is an initiative of Cochrane Policy Liaison Network, which is supported by the Australasian Cochrane Centre and the Department of Health and Ageing

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What is happening out in the community?

- Informants and Acknowledgements
 - Arthritis Victoria
 - Young Women's Arthritis Support Group
 - DHS Victoria, Participation Advisory Committee
 - Mary Draper, Royal Women's Hospital
 - Adrian Edwards and Michelle Edwards, Cardiff University
 - Sally Green, Australasian Cochrane Centre
 - Tere Dawson and Tony McBride, Health Issues Centre
 - Vivian Lin, La Trobe University
 - Michael Summers, MS Society
- Research
- Submissions to National Health and Hospitals Commission (NHHRC)

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Health market literacy

- In Australia, women do not have babies on 29 Feb or 1 April
- Unless these dates fall on the weekend
- In which case, doctors win in $\frac{3}{4}$ of the cases
- Women win in $\frac{1}{4}$ of the cases
- Conclusion:
 - “This suggests that while doctors have more power than patients, patients are sometimes able to influence medical decisions for non-medical reasons.”
 - Source: Gans and Leigh, Bargaining Over Labor: Do Patients Have Any Power? Social Science Research Network, 2006, <http://ssrn.com/abstract=907406>

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Consumer-led health literacy

- People looking for information
- People sharing information
 - What are their sources?
- Health professionals asking consumers for information.
 - View Kidney Health Australia: YOUR KIDNEY BLOG, www.kidney.org.au

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Definition of health literacy: involves:-

- Functional: outcome of health education:
 - Involves skills to read and understand health information
- Interactive literacy:
 - Social and personal skills to apply information
- Critical health literacy:
 - Cognitive and social skills to analyse critically and to support action
 - Source: Nutbeam: 2000. Health Promotion International, 15(3), 259

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Policy frame #1

- **Negative frame**
 - Deficit in patients, eg less adherence

- **Positive frame**
 - About empowerment
 - Navigating through life, keeping health in mind
 - Knowing about the body's functions and signs of dysfunction
 - Seeking, finding, interpreting and understanding information
 - Knowing what constitutes good advice
 - Knowing how to translate this into action

- Sources:
 - Hill S. Editorial. A Positive Frame for Health Literacy. *Health Issues*, Issue 92, 2007.
 - Commentary: Gravier S. Health Literacy Alliance, University of Adelaide, 2007
 - Edwards M, Hill S, Edwards A. Forthcoming, May 2009. Health Literacy – achieving consumer 'empowerment' in health care decisions. In A. Edwards and G. Elwyn, eds, *Shared decision making in health care: achieving evidence based patient choice*, 2e, Oxford University Press.

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Evidence base for a focus on health literacy

- Lower health literacy: leads to reduced abilities around
 - Screening
 - Child health management (diagnosis and medicine management)
 - Following discharge instructions
- Lower health literacy
 - Poorer health outcomes
 - » Source: AHRQ, *Literacy and Health Outcomes*, Evidence Report/Technology Assessment: Number 87. 2004.

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Broaden the frame

- Arguments for focus on literacy
 - Living longer with more than one condition
 - More emphasis on self-care, short periods of health service
 - Need intelligent users of services
 - Need people able to self-care or care for others
 - Need people to be skilled users of information and skilled in relationships, able to find support

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Policy opportunities

- Underlying interest
 - Much discussion (seminars) in the community
 - Inheritor of consumer participation agenda
 - Sharper focus with information-divide?
 - Some research

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Policy opportunity: National Health and Hospitals Reform Commission

- Principles (with direct link to health literacy)
 - **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

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Policy opportunity: Global interest

- WHO WPRO People at the Centre of Care Initiative
 - Policy Framework
 - Actions at four levels
 - Individuals, families and communities
 - Health practitioners
 - Health care organizations
 - Health systems
 - www.wpro.who.int/sites/pci

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Australian data: is there a problem?

- HL measured across 5 Skill Levels:
 - 40% men and 41% women achieved HL Skill Level 3 or above.
 - Nearly 60% (aged 15-74) were below Skill Level 3.
 - **Lowest area of achievement was for ‘problem solving’ skills.**

– Source; ABS. *Health Literacy, Australia*. 2006

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Making it concrete: Eggs of areas where problem solving skills are needed:

- Preventing and managing chronic illnesses
- Caring for children or for parents
- Immunizations
- End of life decisions
- Pain control
- Medication management
- Safety (in hospital, in community)
- Treatment options for cancer

• Source; Kathy Kendall, Queensland consumer, Australian Health Care Reform Alliance

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Making it concrete: areas where problem solving skills are needed:

- Seeking information and using it
- Finding and using quality information from Internet
- Sharing information about treatments and side effects on the Internet with others
- Reading about research and new treatments in the media
- Being an effective and accountable board member

- Source: Discussion with NGOs

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Evidence-informed strategies

- Evidence:
 - Growing evidence base for interventions to improve interactions with consumers and carers;
 - interventions around communication, information, skills, behaviour, quality, reducing harms, participation.
 - » See www.thecochranelibrary.com and <http://www.latrobe.edu.au/cochrane/reviews.html>
 - Growing capacity to use evidence for policy making:
 - E.G. overviews of systematic reviews
 - See Ryan R, Santesso N, Hill S, Kaufman C, Grimshaw J. Consumer-oriented interventions for evidence-based prescribing and medicine use: an overview of Cochrane reviews (Protocol). *Cochrane Database of Systematic Reviews* 2008, Issue 4.
- Context for evidence:
 - Some consumers want more information: others don't
 - This is a policy dead-end
 - There is a role for all: refer functional, interactive and critical literacy

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Health literacy and use of health services

- Health care affordability has become important again
 - (NATSEM, *Distribution of Expenditure on Health Goods and Services by Australian Households*, Report for the NHHRC, 2008)
- Whose issue is this?
- Positive frame:
 - Importance of dialogue between doctors and consumers
 - Importance of strengthening capacity of system

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- | | |
|---|-------|
| • In past two years, doctor recommended treatment you thought had no benefit. | • 17% |
| • Skipped treatment due to cost. | • 17% |
| • Did not fill Rx or skipped doses due to cost | • 13% |

– Schoen et al. Toward Higher-performance health systems ... 2007, Health Affairs exclusive. [The Commonwealth Fund]

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Policy frame #2

- Health literacy is a cross-cutting policy issue
- Links aspects of consumers' experiences across policy domains and programs
- Needs an approach that:
 - Builds capacity in individuals;
 - Builds capacity for people to work better with each other;
 - Build capacity for health systems and organisations to integrate health literacy concepts and strategies;
 - Is evidence-informed.

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Policy implications: why it should be on the agenda

- Has universal aspects.
 - Eg, knowledge of health care entitlements
- Has social inclusion agenda.
 - Eg, relation of literacy to educational level to health status
- Has capacity to weaken or strengthen health system.
- Has life-course relevance.
- Has implications for workforce.

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What should be on the agenda?

- Policy model:
 - Integration?
 - Single issue? Return to this
- How could health literacy capacity be built?



Policy frame #3


- How could health literacy be built?
 - What is being proposed?
- Conceptual frame for building health system capacity for health literacy
 - Source: Draper & Hill (adapted 2008 with Dell Horey, from *The Role of Patient Satisfaction Surveys in a National Approach to Hospital Quality Management*, 1995, after Pfeffer & Coote 1991)

SCIENTIFIC APPROACHES	MARKET SOLUTIONS	LEGAL APPROACHES	DEMOCRATIC PARTICIPATION
<p><i>Rely on:</i> Objective measurement and statistics</p> <p><i>Consumers are:</i> subjects of research</p> <p><i>Strategies:</i></p> <ul style="list-style-type: none"> • Evidence based medicine, • Outcomes, • Clinical Practice Guidelines, • Patient surveys, • Research into the patient experience 	<p><i>Rely on:</i> Market information or more responsive services</p> <p><i>Consumers are:</i> informed choosers</p> <p><i>Strategies:</i></p> <ul style="list-style-type: none"> • Information on providers, • Marketing, • Statement of expectations, • Consumer surveys 	<p><i>Rely on:</i> defined rights, access to judicial and semi-judicial institutions</p> <p><i>Consumers are:</i> citizens with rights</p> <p><i>Strategies:</i></p> <ul style="list-style-type: none"> • Right to complain, • Legal redress, • Legislation, • Transparent decision making, • Advocacy 	<p><i>Rely on:</i> ways to participate individually and collectively in health decisions</p> <p><i>Consumers are:</i> equal partners and citizens</p> <p><i>Strategies:</i></p> <ul style="list-style-type: none"> • Consultation, • Involvement in decisions, • Hand held records, • Representation, • Consumer membership of collective decision making structures, • Consumer advisory structures, • Accountability to consumers
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NHHRC submissions

- Recommended on topic of health literacy

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RACP submission to NHHRC, #315

SCIENTIFIC APPROACHES & DEMOCRATIC PARTICIPATION

- Health literacy part of public voice principle
- Help people diagnose and treat minor illness
- Support patients in active management
 - 40% of doctors always ask people about treatment options and ask their views

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National Breast and Ovarian Cancer submission to NHHRC, #122

SCIENTIFIC APPROACHES & DEMOCRATIC PARTICIPATION

- Health literacy ideas in People and family-centred principle
 - Evidence-based information available in accessible and timely way
 - Communication skills be recognised as a compulsory competency for all professions
 - Consumers at all levels of decision making
 - Supported through education and training
 - ‘Living document’ – repository of patient information
 - Use new technologies to improve collaboration

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Microsoft submission to NHHRC, #111

MARKET SOLUTIONS

- Health Vault
- Platform for data storage and transferability
- Collect, store and share personal health information
- Can upload patient-controlled diagnostic tests, eg BP
- Plus new search function customised to quality health information

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'Choice' submission to NHHRC, #63

EDUCATION FOR DEMOCRATIC PARTICIPATION

- Australia has promoted financial literacy through budget initiative
- Recommends similar program, utilising school education
- Using nurses for chronic illness/health promotion education

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Policy implications

- Has universal aspects.
- Has social inclusion agenda.
- Has capacity to weaken or strengthen health system.
- Has life-course relevance.
- Has implications for workforce.
- **Complex mix of proposed strategies**

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- What is a multi-jurisdictional national framework for advancing literacy?
 - What would enable cross portfolio linkages?
 - What are some of the levers?

 - Site for national policy?
 - See Hill S and Draper M. Submission to the NHHRC, No 403. Public Voice Principle (Role of AHMAC), 2008

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Levers: having a policy

- DHS Victoria 'Doing it with us not for us', 2006-09
 - Individual, health service, program and department levels
 - <http://www.health.vic.gov.au/consumer/>
- Policy acts as a driver, provided a framework for actions
 - Enabled linkages between consumers, departmental initiatives, building of evidence base
 - Provided opportunities through training and conference
 - Stimulated departmental actions
 - Links to indicators and Quality of Care reports

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Levers: How could we build literacy around health information?

- Experience with Knowledge Transfer (KT) push strategies:
 - getting evidence to out to community
- Less experience with KT pull strategies:
 - enabling people to pull evidence into lives, services, systems
- Need a KT strategy to consumers for evidence-based health care
 - Building capacity to use *The Cochrane Library*
 - *Cochrane Library* Summit in December
 - National conversation on increasing the use of and usability of the CL
- NICS-NHMRC role?
- Linkages to Health Insite?

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Health literacy challenges: Equity, complexity and health literacy

- No. of people with more than one health problem (multi-morbidity) increasing;
- Consumers need to manage, coordinate, prioritise, communicate effectively, select, decide;
- Our outlook is single disease;
 - Chronic, special combinations notwithstanding
- Guidelines, information resources all organised along single diseases;
- Building literacy around multi-morbidity:
 - What issues for consumers are the most difficult to manage? Starting with 'arthritis plus'.

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Building technical leadership to address complex literacy challenges

- Data that captures experiences of 'literacy in action'
- National surveys of consumers' experiences
- Objectives of measurement, improvement and policy impact
 - Source: Draper M and Hill S. Submission to the NHHRC, A national approach to measuring patient experience, 2008

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Policy makers want actionable messages. Why wouldn't consumers?

- Create space to think about health literacy
- Explore ideas for improving it
- Should it be on a national agenda and how?
- What would I propose?

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SCIENTIFIC APPROACHES

MARKET SOLUTIONS

LEGAL APPROACHES

DEMOCRATIC PARTICIPATION

Strategies:

- Assembling evidence of effective interventions
- Knowledge transfer strategy to consumers for *The Cochrane Library*
- Policy infrastructure: National patient experience surveys
- Researching experiences of multi-morbidity and health literacy

Strategies:

Strategies:

Strategies:

- National policy focus
- Push strategies for reaching consumers and community organizations around evidence-informed health care
- Pull strategies ie to empower them to become more health literate

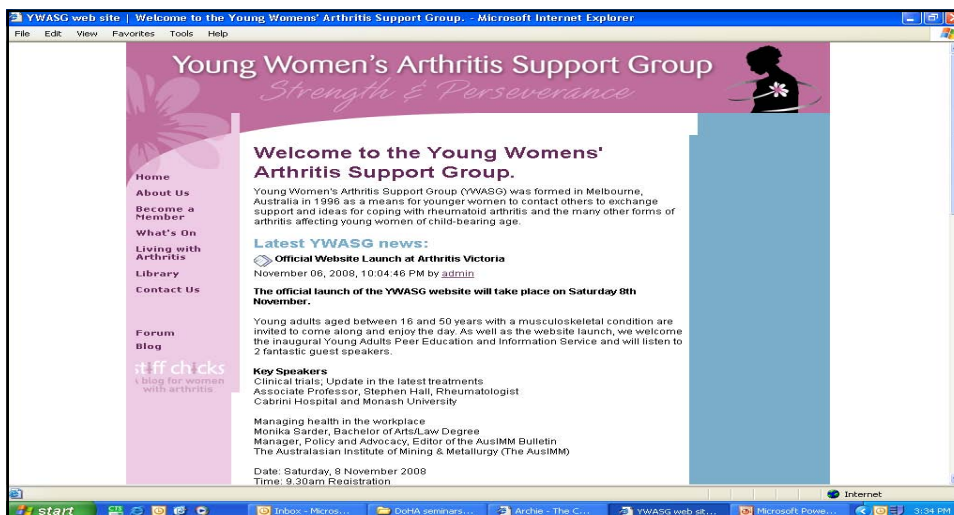
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Health literacy of the future: Advocates for MS in Parliament House, October 2008



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Health literacy in action

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Centre to be launched early in 2009.

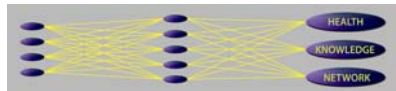
A site for research and knowledge transfer for improving health communication and participation across all levels of the health sphere. The Centre's mission is to improve communication with and participation by consumers and carers through evidence-informed policy and decision making.



Cochrane Consumers & Communication Review Group coordinates the preparation and publication of Cochrane systematic reviews of the effects of interventions to improve interactions with consumers and carers - including interventions around communication, information, skills, behaviour, quality, reducing harms, participation.

Effectiveness
Research

Through the Effectiveness Research arm, we produce systematic reviews in Victorian priority areas. We develop tools and resources to aid with researching and implementing interventions for communication and participation. We are a place for innovation in research.



Health Knowledge Network is a knowledge transfer service, producing accessible summaries of and sharing information about research - our work and others', in the communication and participation sphere. The Network gives us the capacity to listen to and respond to priorities of the Victorian health sector.

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