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Health Literacy: the missing link in effective public health and healthcare?

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Australia

Seminar to Prevention & Population Health Branch,
Vic Dept of Health, 4/11/2010
Public Health Innovation, Deakin University

Our approach

- Partnership, participatory, co-creative
- Long-term
- Innovative
  - Grounded
  - Bottom up / Top down
  - Interdisciplinary
- Whole system
- Evidence based
Deakin Public Health Innovation

Areas of endeavour

• Program Evaluation, service redesign and implementation
  • orthopaedic reform (OWL/OAHKS),
  • work place health
• Self-Management Support
  – Chronic disease self-management support
  – Program development, evaluation, implementation
    • eg heiQ: Health Education Impact Questionnaire
• The New Health literacy
  – Conceptual development and survey design
  – Wide consultation regarding processes to improve understand services and their equity
Outline

• The problem
• How I came to be in the health literacy space
• What is health literacy
• What health literacy probably isn’t
• How can it be measured
• What is the opportunity that is afforded by including health literacy in our thinking about policy and programs
Global Risks 2010
A Global Risk Network Report

A World Economic Forum Report
in collaboration with
Citi
Marsh & McLennan Companies (MMC)
Swiss Re
Wharton School Risk Center
Zurich Financial Services
<table>
<thead>
<tr>
<th>Noncommunicable diseases</th>
<th>Modifiable causative risk factors</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Tobacco use</td>
</tr>
<tr>
<td>Heart disease and stroke</td>
<td>✓</td>
</tr>
<tr>
<td>Diabetes</td>
<td>✓</td>
</tr>
<tr>
<td>Cancer</td>
<td>✓</td>
</tr>
<tr>
<td>Chronic lung disease</td>
<td>✓</td>
</tr>
</tbody>
</table>
Control of chronic disease

Health workers
Control of chronic disease

Self-management
+- carer & family
+- community
Self-management support

• Facility that health and social care services provide
• Aims to enhance consumer well-being, prevention and management of chronic conditions
• Focus on self-management ‘skills’ training
• Wide variety approaches
## Self-management education interventions

<table>
<thead>
<tr>
<th>Type of intervention</th>
<th>Examples</th>
</tr>
</thead>
<tbody>
<tr>
<td>Individual</td>
<td></td>
</tr>
<tr>
<td>Face-to-face consultation</td>
<td>Flinders University model of clinician-administered support</td>
</tr>
<tr>
<td>Telephone coaching</td>
<td>Coaching patients On Achieving Cardiovascular Health (COACH) program</td>
</tr>
<tr>
<td>Internet individual course</td>
<td>New South Wales Arthritis Foundation course</td>
</tr>
<tr>
<td>Internet group course</td>
<td>UK National Health Service’s Expert Patients Programme online</td>
</tr>
<tr>
<td>Group: ongoing cycle</td>
<td>Rehabilitation programs</td>
</tr>
<tr>
<td>Group: formal/structured</td>
<td>Stanford University program</td>
</tr>
<tr>
<td>Written information</td>
<td>Non-government organisation publications</td>
</tr>
<tr>
<td>Population</td>
<td></td>
</tr>
<tr>
<td>Television/multimedia</td>
<td>Back pain beliefs campaign; Quit anti-smoking campaign</td>
</tr>
<tr>
<td>social marketing</td>
<td></td>
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</tbody>
</table>
Self-management support is necessary

- Chronic diseases are an important health issue in all countries
- The health system cannot meet all needs so:
  - community education,
  - empowerment and
  - self-management capacity are critical
- There needs to be a shift in approach so that what happens in between a person’s contacts with the health system is as important as what happens during those contacts
  - How can this be optimised?
What is chronic disease self-management?

• Consideration of:
  • the individual with the chronic condition
  • their carers, family, community
  • health professionals and services

• Involves a holistic approach and acknowledging
  • Medical, psycho-social and cultural aspects

• Aims to empower individuals
  – Enable people to have positive and active engagement in life
Self-management Education Programs in Chronic Disease

A Systematic Review and Methodological Critique of the Literature

Asra Warsi, BA; Philip S. Wang, MD, DrPH; Michael P. LaValley, PhD; Jerry Avorn, MD; Daniel H. Solomon, MD, MPH

Background: Self-management programs have been widely reported to help patients manage symptoms and contain utilization of health care resources for several chronic conditions, but to date no systematic review across multiple chronic diseases has been reported. We evaluated the efficacy of patient self-management educational programs for chronic diseases and critically reviewed their methodology.

Methods: We searched MEDLINE and HealthSTAR for the period January 1, 1964, through January 31, 1999, then hand searched the reference section of each article for other relevant publications. We included studies if a self-management education intervention for a chronic disease was reported, a concurrent control group was included, and clinical outcomes were evaluated. Two authors reviewed each study and extracted the data on clinical outcomes.

Results: We included 71 trials of self-management education. Trial methods varied substantially and were suboptimal. Diabetic patients involved with self-management education programs demonstrated reductions in glycosylated hemoglobin levels (summary effect size, 0.45; 95% confidence interval [CI], 0.17-0.74); diabetic patients had improvement in systolic blood pressure (summary effect size, 0.20; 95% CI, 0.01-0.39); and asthmatic patients experienced fewer attacks (log rate ratio, 0.59; 95% CI, 0.35-0.83). Although we found a trend toward a small benefit, arthritis self-management education programs were not associated with statistically significant effects. Evidence of publication bias existed.

Conclusions: Self-management education programs resulted in small to moderate effects for selected chronic diseases. In light of evidence of publication bias, further trials that adhere to a standard methodology would help clarify whether self-management education is worthwhile.

Arch Intern Med. 2004;164:1641-1649
Effectiveness of self-management interventions

• Meta-analyses show improvements for selected chronic disease
  – Diabetes, Asthma, Hypertension, Heart Disease
    • clinically significant benefits
  – Arthritis
    • nil to minimal benefits
What are self-management support programs intended to achieve?
National Quality and Monitoring system for Education and Self-management programs for people with chronic diseases (2003/04)

Aim

Develop a high quality data gathering system imbedded within the service provider’s structures & is highly endorsed by all stakeholders

Funder

Commonwealth Government of Australia
Department of Health and Ageing
Scoping interviews

• Interviewing stakeholders to find out what they believe the program is and what are the important indicators of program success.
Concept mapping (group interviews) with people with chronic disease

- people who had undertaken a range of self-management programs
  - Chronic disease self-management program
  - Arthritis self-management course
  - Pain program
  - Wide range of conditions and comorbidities

- i.e., the target group
Seeding statement…

- Thinking as broadly as possible, what would you want people who had done the course to say they had got out of it?
Outcomes Hierarchy Program Logic

Self-management programs

Possible immediate effects

Improved outcomes for individuals

Possible later effects

Improved Public Health

Possible long-term effects

Possible outcomes for individuals

Health education programs

Empowerment of individuals and carers

Partnership with healthcare services and non-government organisations

Increased in knowledge

Improved disease-specific communication

Improved provider knowledge of patient needs

Change of perception of the impact of the illness

Improved patient knowledge

Improved linkages within healthcare services

Change in behaviour

Improved compliance

Self-confidence

Increased sense of coherence

Improved public health

Reduced stigma

Improved health-related quality of life

Decreased disability

Decreased morbidity

Reduced life roles

Decreased symptoms

Increased acute healthcare services

Collaborative management

Improved treatment and medication mix

Better symptom management

Decreased disease-specific mortality

Increased coherence

Increased community capacity

Increased healthcare service efficiency

Decreased disability

Decreased mortality

 Decreased use of acute healthcare services

* Boxes with italics indicate outcomes that are not easily measured because they are difficult to define and/or no standardised outcome measures are available.
Confirmatory Factor Analysis (CFA)
8 latent variables which measure their respective constructs
• no cross-loadings
• no within- and between-factor correlated errors

n=598 mainly people from low SES / low English skills
Program: LISREL: Asymptotic Covariance Matrix
Chi-sq (791), 3289, p=0.0
Root mean square error of approximation (RMSEA) = 0.05
Comparative Fit Index (CFI) = 0.95
Root Mean Square Residual (RMR) = 0.063

Components of the Health Education Impact Questionnaire (heiQ)

• What should self-management impact on?
  1. Positive and Active Engagement in Life
  2. Health-Directed Behaviour
  3. Skill and Technique Acquisition
  4. Constructive Attitudes and Approaches
  5. Self-Monitoring and Insight
  6. Health Service Navigation
  7. Social Integration and Support
  8. Emotional Well-Being
  – (Program delivery)
The Health Education Impact Questionnaire (heiQ)

Translations, users and collaborations

An emerging pattern, particularly in state run initiatives, to service the ‘worried well’.
How we came to health literacy

1. Chronic disease self-management
   - Health Education Impact Questionnaire for the evaluation of health education programs (www.heiQ.org.au)
     - Application in ~20 countries
   - People with low social status marginalised, excluded
   - Evaluation of self-management programs “screen out” many low literate people and therefore induce social inequalities

2. Linguistic framework for writing patient information
   - Prof Buchbinder et al
     - ELF: Evaluative Linguistic Framework
     - Health literacy is more than reading and writing
We need a deeper understanding of self-management support
Foundations of ‘self-care’ and ‘self-management’

- "Command" over healthcare system (e.g., treatments, care providers)
- Access to opportunities to engage in healthy activities
- Confidence to take initiative
- Supportive environments to engage in and maintain healthy behaviours

Action planning, Problem-solving

Positive and active engagement in life
Skill and technique acquisition
Self monitoring and insight
Social integration and support

Faculties to distinguish correct/useful information from incorrect/unimportant information

Access to information about health and health professionals

Capacity to understand information about health

Capacity to identify / recognise health messages

Health literacy abilities

What is health literacy?
Where did the term ‘health literacy’ come from?

*Attributed to Scot Simonds 1974:

…arguing case for school health education with the intention that pupils would not only be educated in the customary curriculum subjects but might become as ‘literate’ in health as they were, for example, in history and science.

Health literacy subsequently acquired a more limited technical meaning:

…the currency patients need to negotiate a complex health care system” e.g. ability to read and comprehend prescription bottles, appointment slips and other essential health-related materials required to successfully function as a patient

AMA Council of Scientific Affairs (Selden C, et al NIH, 1999)

Health Literacy: several definitions

• “An individual’s overall capacity to obtain, process and understand basic health information and services needed to make appropriate health decisions” (US Institute of Medicine)

• “The capacity of an individual to obtain, interpret and understand basic health information and services in ways that are health enhancing” (UK National Consumers Council)

• “Health literacy represents the cognitive and social skills which determine the motivation and ability of individuals to gain access to, understand and use information in ways which promote and maintain good health” (World Health Organization)

• “Health literacy is the ability to make sound health decisions in the context of everyday life – at home, in the community, at the workplace, the healthcare system, the market place and the political arena” (Kickbusch, 2001)
Nice definitions…

but can is it related to health and can it be measured?
Lower health literacy associated with:

- inadequate knowledge about health and healthcare system
- increased hospitalisation
- poor access and utilisation of health services

People with lower health literacy ~ 1.5 to 3 times more likely to experience poor health event

Measuring health literacy

• Health Literacy has been assessed through measuring reading ability, comprehension and word recognition skills

• 3 key tools used with patients:
  – Rapid Estimate of Adult Literacy in Medicine (REALM)
  – Test of Functional Health Literacy in Adults (TOFHLA)
  – Newest Vital Sign
Rapid Estimate of Adult Literacy in Medicine: REALM

<table>
<thead>
<tr>
<th>List 1</th>
<th>List 2</th>
<th>List 3</th>
</tr>
</thead>
<tbody>
<tr>
<td>fat</td>
<td>fatigue</td>
<td>allergic</td>
</tr>
<tr>
<td>flu</td>
<td>pelvic</td>
<td>menstrual</td>
</tr>
<tr>
<td>pill</td>
<td>jaundice</td>
<td>testicle</td>
</tr>
<tr>
<td>dose</td>
<td>infection</td>
<td>colitis</td>
</tr>
<tr>
<td>eye</td>
<td>exercise</td>
<td>emergency</td>
</tr>
<tr>
<td>stress</td>
<td>behaviour</td>
<td>medication</td>
</tr>
<tr>
<td>smear</td>
<td>prescription</td>
<td>occupation</td>
</tr>
<tr>
<td>nerves</td>
<td>notify</td>
<td>sexually</td>
</tr>
<tr>
<td>germs</td>
<td>gallbladder</td>
<td>alcoholism</td>
</tr>
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<td></td>
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</tbody>
</table>

How well does the REALM perform?

...is a person’s ability to read and pronounce common medical words and lay terms a good measure of health literacy?
Definition of 13 REALM words

Nausea  Hormones  Scoring system based upon dictionary definition
Allergic  Asthma
Calories  Colitis
Arthritis  Hepatitis
Diabetes  Antibiotics
Osteoporosis  Anaemia
Obesity

Score:
2 – correct
1 - partially correct
0 - incorrect

Barber M, Staples M, Osborne R, Clerehan R, Elder C, Buchbinder R. Up to a quarter of the general population may have suboptimal health literacy depending upon the measurement tool: results from a population-based survey. *Health Prom Inter* 2009;24:252-61.
Definition of 13 REALM words

Only 6/310 (1.9%) defined all 13 words correctly

<table>
<thead>
<tr>
<th></th>
<th>Correct</th>
<th>Partially Correct</th>
<th>Incorrect</th>
</tr>
</thead>
<tbody>
<tr>
<td>Average number of words</td>
<td>7.2</td>
<td>3.4</td>
<td>2.4</td>
</tr>
<tr>
<td>(out of 13)</td>
<td>2.7</td>
<td>1.8</td>
<td>2.0</td>
</tr>
</tbody>
</table>

Nausea
Allergic
Calories
Arthritis
Diabetes
Osteoporosis
Obesity
Hormones
Asthma
Colitis
Hepatitis
Antibiotics
Anaemia
## Pronunciation versus definition REALM words

<table>
<thead>
<tr>
<th></th>
<th>Pronunciation % Correct</th>
<th>Definition</th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td></td>
<td>% Correct</td>
<td>% Partially Correct</td>
</tr>
<tr>
<td>Hormones</td>
<td>97</td>
<td>27</td>
<td>40</td>
</tr>
<tr>
<td>Diabetes*</td>
<td>95</td>
<td>40</td>
<td>38</td>
</tr>
<tr>
<td>Obesity</td>
<td>92</td>
<td>46</td>
<td>51</td>
</tr>
<tr>
<td>Arthritis*</td>
<td>99</td>
<td>74</td>
<td>11</td>
</tr>
<tr>
<td>Osteoporosis</td>
<td>90</td>
<td>73</td>
<td>9</td>
</tr>
</tbody>
</table>

* Having the condition **not** associated with better definitions
Test of Functional Health Literacy in Adults: TOFHLA

Numeracy (17 items)

**Abbocillin VK Tablets 250mg** 50
Take ONE tablet by mouth four times a day

**Mr Ian Garfield**  nil Rpts
16/04/06 Dr Michael Lubin FF941858
$11.53

Q1. If you take your first tablet at 7.00am, when should you take the next one? __________

Q2. And the next one after that? __________

Test of Functional Health Literacy in Adults: TOFHLA

Reading comprehension (50 items)

1) Your doctor has sent you to have a _____________ X-ray.
   a. stomach
   b. diabetes
   c. stitches
   d. germs

Newest vital sign (NVS)

READ TO SUBJECT: This information is on the back of a container of a pint of ice cream.

QUESTIONS
1. If you eat the entire container, how many calories will you eat?

Newest vital sign (NVS)

READ TO SUBJECT: This information is on the back of a container of a pint of ice cream.

QUESTIONS
1. If you eat the entire container, how many calories will you eat?

Answer: 1,000


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New Health Literacy Surveys

• Health Literacy Survey – Europe (HLS-EU)
  – Europe, 10 countries

• Health Literacy Management Tool (HeLMS)
  – Australia, Thailand
Application of existing measures of health literacy

• Prevalence of low health literacy in Australia

Barber M, Staples M, Osborne RH, Clerehan R, Elder C, Buchbinder R. *Up to a quarter of the population may have suboptimal health literacy: a population-based survey.*

*Health Promotion International* 24:252-261.
Population-based survey of health literacy

• Random sample adult population from 2004 electoral roll
  • 310 participants
• Face-to-face interviews
• Trained interviewers (n=10)
# Prevalence of low health literacy

### REALM (N = 310)

<table>
<thead>
<tr>
<th>Grade 4-6</th>
<th>May need low-literacy materials; may not be able to read prescription labels</th>
<th>6 (2%)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Grade 7-8</td>
<td>May struggle with most currently available patient education materials</td>
<td>35 (11%)</td>
</tr>
<tr>
<td>High school</td>
<td>Should be able to read most patient education materials</td>
<td>269 (87%)</td>
</tr>
</tbody>
</table>

### TOFHLA (N = 309)

| Adequate | Could read and interpret most health texts                               | 288 (93%) |
| Inadequate | May be unable to read and interpret health texts                      | 8 (3%) |
| Marginal | Would have difficulty reading/interpreting health texts                | 13 (4%) |

### NVS (N = 308)

| 4-6  | Almost always indicates adequate literacy                              | 228 (74%) |
| 0-1  | Suggests highly likely (50% or more) limited literacy                 | 22 (7%) |
| 2-3  | Indicates possibility of limited literacy                             | 58 (19%) |

National survey (NAAL) suggested that ~60% of Australians have low health literacy.

*Will the real level of health literacy please stand up?*
An individual’s overall capacity to **obtain, process and understand basic health information and services** needed to make appropriate health decisions (US Institute of Medicine)

An individual’s overall capacity to obtain, process and understand basic health information and services needed to make appropriate health decisions (US Institute of Medicine)
<table>
<thead>
<tr>
<th>Measurement approach</th>
<th>Measure</th>
<th>Purpose</th>
<th>Description</th>
<th>Scoring</th>
</tr>
</thead>
<tbody>
<tr>
<td>Direct testing of patient abilities</td>
<td>Rapid Estimate of Adult Literacy in Medicine (REALM) Davis TS. Fam Med 1991</td>
<td>Identify patients with limited reading skills in primary care</td>
<td>Read aloud list of 125 words, assesses pronunciation</td>
<td>US school grade estimate: 0-78 below 3rd grade 79-103 4th to 6th grade 104-114 7th to 8th grade 115+ high school</td>
</tr>
<tr>
<td></td>
<td>Test of Functional Health Literacy in Adults (TOFHLA) Parker RM, et al. J Gen Intern Med 1995</td>
<td>Measure patients' ability to read and understand health-related materials in healthcare system</td>
<td>Reading comprehension (50 items), numeracy (17 items)</td>
<td>0-59 Inadequate 60-74 Marginal 75-100 Adequate</td>
</tr>
<tr>
<td></td>
<td>Newest Vital Sign (NVS) Weiss BS. Fam Med 2005</td>
<td>Screen for limited literacy in primary care</td>
<td>Nutrition information on ice cream label (6 items) reading comprehension and numeracy</td>
<td>0-1 marginal/inadequate literacy highly likely 2-3 possible 4-6 adequate literacy</td>
</tr>
<tr>
<td>Self-reported abilities</td>
<td>Set of Brief Screening Questions (SBSQ) Chew LD. Fam Med 2004</td>
<td>Identify people with marginal or inadequate health literacy</td>
<td>3 screening questions (e.g. How often do you have problems learning about your medical condition because of difficulty understanding written information?)</td>
<td>Degree of difficulty or frequency of problem (e.g. 0=never, 4=always)</td>
</tr>
<tr>
<td>Population-based proxy measures</td>
<td>National Assessment of Adult Literacy (NAAL): Health literacy subscale Kutner M. Nat Center for Educational Statistics 2006</td>
<td>Understand and measure health literacy in American adults</td>
<td>28 item scale (12 prose, 12 document, 4 numeracy) Three domains (clinical, prevention, navigation of the healthcare system)</td>
<td>4 scoring categories: below basic, basic, intermediate or proficient level</td>
</tr>
<tr>
<td>Health literacy matrix</td>
<td>Access/obtain</td>
<td>Understand</td>
<td>Appraise</td>
<td>Apply</td>
</tr>
<tr>
<td>------------------------</td>
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</tr>
<tr>
<td>Cure &amp; Care</td>
<td>How easily do you find information on the following medical issues?... Cancers, resp. diseases etc.</td>
<td>How easily do you understand the content of the leaflets that come with medications?</td>
<td>Do you consider advantages and disadvantages of treatment options?</td>
<td>How often do you follow your doctor's advice?</td>
</tr>
<tr>
<td>Disease prevention</td>
<td>How easily do you find information on the following risk factors?... tobacco, alcohol etc.</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Health promotion</td>
<td>How easily do you find information on the following health enhancing factors?... Nutrition and diet, exercise etc.</td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>
A gap…

With concerns about the psychometric properties and breadth of current health literacy tools we sought to develop a new scale.
Do I really have to develop a Questionnaire?
What do we measure?

How most people view / experience this part of the world around them

"Interesting theory"
Test items a, b, c...
Work with target group
Analysis (Exploratory Factor analysis)
New questionnaire (with poor content validity)

"Common" view
Test items a, b, c...
Work with target group
Analysis (Confirmatory Factor Analysis)
New questionnaire (with high construct validity)

A few individuals

How most people view / experience this part of the world around them

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Purpose of a new health literacy measure

• Assess individual ability to seek, understand and utilise health information within the health setting
  – Generic and potentially modifiable abilities and factors

• Target population
  – Adults

• Setting
  – Clinical or population
Grounded Approach
Extensive consultation with consumers

- Maximum heterogeneity
- Interview 3 distinct population groups:
  - Individuals who had taken part in a chronic disease self-management program (n=20)
  - General population (n=14)
  - Individuals who recently presented to the Emergency Department (n=14)
Concept Mapping

Workshop participants

• Individuals with chronic condition from low socioeconomic status region (n = 8)
• Individuals from general community from high socioeconomic status region (n = 7)

• Extensive grounded approaches generate items and constructs
Concept mapping workshops

Structured conceptualisation process

1. Brainstorming session

2. Sorting and rating of statements

3. Multivariate analysis

4. Interpretation of maps

Seeding statement:

Thinking about your experiences in trying to look after your health (or the health of your family), what abilities does a person need to have in order to get and to use all of the information they need?
Results: concept map (workshop #1)

- Access to health professionals (face to face, esp GP)
- Communication skills
- Emotional skills and support
- Support and support groups
- Positive attitude
- Emotional and psychological issues necessary to help yourself (require support)
- Relevant up to date information (Information needed at particular times)
- Education, Access to relevant information
- Cost and transport
Targets for measurement to capture health literacy from the patient's perspective

**Individual abilities**
1. Understanding health information
2. Accessing GP healthcare services
3. Communication with health professionals
4. Proactive about seeking further care/second opinion
5. Using health information

**Broader factors**
6. Economic barriers to care
7. Social support with utilising healthcare
8. Receptivity to improving one’s health
Construction and validation studies

Construction study

• Individuals with chronic conditions and from the general population (n=333)
  – 75% female
  – Age range: 25 – 93 years, predominantly Caucasian
  – Factor analysis
    • Refine measure and exclude problematic items based on recognised criteria
    • 37 items across 8 distinct factors

Validation study

• Individuals with chronic conditions and Emergency Department attendees (n=350)
• Item reduction / Confirmatory Factor Analyses
  – 8 new questionnaires with 3 to 4 items in each
**Questionnaire format:**

**oral or paper based**

---

### A. Are you able to:

<table>
<thead>
<tr>
<th></th>
<th>Without any difficulty</th>
<th>With little difficulty</th>
<th>With some difficulty</th>
<th>Very difficult</th>
<th>Unable to do</th>
</tr>
</thead>
<tbody>
<tr>
<td>1</td>
<td>Read health information brochures found in hospitals or at a doctor's clinic</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>2</td>
<td>Get a second opinion about your health from a health professional</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>3</td>
<td>Ask family or friends for help to understand health information</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>4</td>
<td>Carry out instructions that a doctor gives you</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>5</td>
<td>Use information from a doctor to make decisions about your health</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>6</td>
<td>Make time for things that are good for your health</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Domains</td>
<td>Are you able to:</td>
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</tbody>
</table>
| 1. Receptivity to health improvements | 1. Find the energy to manage your health  
2. Pay attention to your health needs  
3. Make time for things that are good for your health  
4. Change your lifestyle to improve your health |
| 2. Understanding health information | 1. Find health information in a language you understand  
2. Fill in medical forms e.g. Medicare  
3. Read written information e.g. leaflets given to you by a doctor  
4. Read health information brochures found in hospitals or at a doctor’s clinic |
| 3. Support with utilising healthcare | 1. Discuss your health with people other than a doctor  
2. Take a family or friend with you to a doctor’s appointment  
3. Ask someone to go with you to a medical appointment  
4. Ask family or friends for help to understand health information |
| 4. Economic barriers to care | 1. Pay to see a doctor  
2. Afford transport to medical appointments  
3. Pay for medication you need to manage your health |
| 5. Accessing GP healthcare services | 1. Know where a doctor can be contacted  
2. Know how to get a doctor’s appointment  
3. Know what to do to get a doctor’s appointment  
4. Know where you can see a doctor |
| 6. Communication with doctors | 1. Ask a doctor questions to help you understand health information  
2. Get the information you need when seeing a doctor  
3. Follow up with a doctor to understand information about your health |
| 7. Seeking a second opinion | 1. Change to a different doctor to get better care  
2. Get a second opinion about your health from a health professional  
3. Look for a second opinion about your health from a health professional |
| 8. Using health information | 1. Use information from a doctor to make decisions about your health  
2. Follow instructions that a doctor gives you  
3. Carry out instructions that a doctor gives you  
4. Use advice from a doctor to make decisions about your health |
Why the recent re-emergence of Health Literacy?

• Previous tools failed, confusing, missing key elements of common definitions
• Public Health and Health Promotion still do not meet the needs of those with low literacy
• New national / international surveys
  – Taiwan, Europe, Australia, [Thailand]
• Accepted as a priority at IUHPE (International Union for Health Promotion and Health Education)
Why the recent re-emergence of Health Literacy?

• Health education, prevention and disease management programs continue to fail to engage and improve outcomes for people who are most at risk and are disadvantaged

  – Why is this?

• Many reasons:
  – lack of tailoring of interventions to local settings
  – programs are not ongoing over time
  – lack of consideration of health literacy
  – etc
Why is health literacy important?

1. Health workers need to know a person’s capacity to process and understand health information to be able to communicate with them effectively.

2. Policy makers need to understand the community’s capacity to gain access to and understand health information to be able to set appropriate policies and then provide appropriate resources.

3. Researchers need to understand these issues to make correct judgments about research methods, findings etc.

4. Health literacy is a fundamental element of self-care, and should be considered when developing interventions.
Development of health literacy tests and health policy

Literacy & Numeracy of population → Development of scales and tests by physicians and literacy experts → Limited examination of interventions, health behaviour or compliance → Policy

Gaps:
• Only looking at selected literacy/numeracy skills
• Considers link between literacy/numeracy skills and knowledge/behaviour in isolation from environment in which the person lives
• No consultation with those people affected (consumers / patients)

Interviews with consumers / patients → Insight into what people do and why → Focus on modifiable skills/factors → Available interventions

Generating the research question with policymakers → Gaps & Opportunities (grounded policy development)
Levels of application of health literacy measurement

- National health literacy
- Different groups within communities or conditions
- Individual care planning

Increasingly refined tool

Future development

Starting point for development

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## Potential interventions to improve self-management capacity and reduce health inequalities

<table>
<thead>
<tr>
<th>Individual interventions</th>
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</thead>
<tbody>
<tr>
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# Potential interventions to improve self-management capacity and reduce health inequalities

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<th>Health Professional</th>
<th>Community Health</th>
<th>Health System</th>
<th>Policy</th>
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<td>✓</td>
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</table>
What about **implementation**?

- Academics and policymakers are typically pathetic at implementation.
- New and good ideas (with the potential to improve health care effectiveness, quality, equity, and efficiency) are frequently poorly implemented into services and systems.
- We are formally studying the implementation process of the health literacy assessment tool.
  - Prospective approach to avoid ‘pro-innovation bias’
- If you wish to use the tool, please contact us:
  - Yvonne.ginifer@deakin.edu.au
  - Formal longterm doctoral research program
Current applications

• Chronic disease self-management evaluation
  – Web-based intervention for Depression + Arthritis
  – Evaluation of the Nurse on Call telephone coaching program

• Hospital settings
  – Emergency Department
  – Cancer Hospital services (Peter MacCallum Cancer Centre)
    • Quality of care

• General Practice
  – GPVic: application in multiple settings

• Home and Community Care (HACC)

• NGOs - Diabetes management

• Chronic disease prevention and management (Thailand)
  – Cluster RCT in Rural Thailand (Health Literacy as a predictor / outcome)
  – A whole-system approach to understanding health literacy
  – National survey to inform health planning

• Others
Were to next?

- **Needs assessment**
  - What capabilities do members of our community have to effectively engage in health?

- **Assessment support**, especially for junior/inexperienced health workers
  - Need to explore whether systematic health literacy assessment of clients can improve / support care, and improve job satisfaction

- **Intervention development and application**
  - Develop in partnership with the community and government agencies

- **Monitoring**
  - Sector-wide and state-wide surveys

- **Quality of care**
  - If people exit our healthcare settings with the same health literacy as they came in, we are not doing our job!
  - Training of health workers
Control of chronic disease

Health workers
Control of chronic disease

Self management
+/- carer & family
+/- community
Control of chronic disease

Self-management
+/- carer & family
+/- community

Health promoting environments
How can we reduce the burden due to chronic diseases?

1. Set policy directions
   – whole-of-government (not just Health!)

2. Set new legislation (laws) to minimise individual’s and communities exposure to risk factor settings
   – eg smoking, limit junk food in schools, food labelling, limit advertising, ban trans fatty acids

3. Surveillance, screening
   – with reporting to key stakeholders

4. Ensure universal access to diagnosis and treatment

5. Strengthen individuals and communities
   – General education of population
   – Reduce risk factors in individuals
How can we reduce the burden due to chronic diseases? (continued)

7. Plan for and develop an appropriate workforce
   – Build communities of practice

8. Develop, import, adapt and engage in strategic implementation of a set of essential interventions
   – Through improved service delivery and reduce inequity
   – Generate intervention strategies and programs with the community
   – Though providing effective and affordable prevention and treatment through primary care

9. Support community engagement and ownership of the problem
   – Social marketing

10. Continuously evaluate, adapt, improve health programs

Understanding Health Literacy can Inform Decision Making and Planning at ALL of these levels
Health Literacy: Is it a missing link in effective public health and healthcare?
Summary – Health Literacy

• It is more than reading and writing
• It is the foundation of effective health education and empowering people to self-manage
• We don’t know the “true” number of people with low Health Literacy in Australia
• New measures of health literacy will be important research tools, and will guide policy and practice
• Implementation of health literacy tools and concepts now requires local adaptation and development of local ownership, and should improve quality of care and health outcomes
Thank you

Richard.Osborne@deakin.edu.au