What should an effective whole of system approach to patient education and self-management look like? Insights from Australia?

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Chair of Public Health
Deakin University
Australia

Les Journees de la Prevention
Paris April 2009
Australia

- Commonwealth of Australia
- Capital: Canberra
- Type: Democratic, federal state system, the British monarch is sovereign
- Smallest continent, sixth largest country
- 6 states, 2 territories
Population distribution
Australia

- Population: 21.7 million
- Life Expectancy: 78.5 male/83.3 female
- Population >65: 12.4%
- Health Expenditures (government and the private sector) 9.8% of GDP
- 3.32 medical practitioners 1000 residents (major cities)
  - rural disparities: 0.86 / 1000 outer regional areas
- 10.5 nurses/1000 population
- First prescriber: Nil
- Main contributor to education?: Varied
- Importance...
Is patient education the solution to increasing health care costs?

• The promise of patient education…
  – More informed patients (people)
    • Increased primary prevention
      – Reduction of unhealthy behaviours
    • Earlier treatment
    • Better choice of providers
    • Better choice of services
    • Decisive secondary prevention behaviour
  – Reduced healthcare costs
  – Increased workplace productivity
Current Australian Government initiatives

- Sharing Healthcare Initiative
- Australian Better Health Initiative
- Council of Australian Governments
- Other
  - Medicare Extended Primary Care items for GPs / Allied health
  - National Health Priority Areas
    - National Service Improvement Frameworks
  - National Reform Agenda / Intergenerational Report
Policy initiatives
2007 / 08 Federal budget

• Sharing Healthcare Initiative
  – *A particular focus of this activity will be on addressing the information needs of Indigenous people and those from culturally and linguistically diverse backgrounds*
  – $22.4 million over 4 years

• Chronic and complex conditions – supporting patient care
  – *The Government will fund new Medicare items that better reflect the additional time and complexity involved in treating patients with chronic and multiple illnesses. … The Medicare rebate will be available for specialist doctors who deal with patients with complex needs*
  – $291.3 million over 4 years
Australian Better Health Initiative (ABHI)

- 4 key programs ($500 million over 4 years)
  - prevention across the continuum
  - strengthening early detection and early treatment
  - integration and continuity of prevention and care
  - self-management

- Commonwealth
  - Audit of self-management support services
  - Steps towards introducing self-management support training into national medical, nursing and allied health curricula

- State government
  - Community based programs
Many policy initiatives

• Some key questions about these policies:
  • What is the main objective?
  • What is the best mix of services?
  • What are the priority areas for systems reform?
  • How will we know when we have achieved a good outcome?
    • What would a good outcome look like?
    • How can we measure such an outcome?
An outline of what self management might be...
What is self-management?

- Consideration of:
  - The individual with the chronic condition
  - Their family and carers
  - Health professionals

- Involves a holistic approach and acknowledging
  - Medical
  - Psycho-social
  - Cultural aspects

- Aims to empower individuals

- Tension
  - Empowerment
  - Sick roles
  - “Medicalising” people
Self-management support

• The facility that health and social care services provide

• Aim to enhance patient well-being and management of chronic conditions
## 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, social marketing</td>
<td>Back pain beliefs campaign; Quit anti-smoking campaign</td>
</tr>
</tbody>
</table>

Effectiveness of self-management interventions

• Meta-analyses show small to moderate improvements for selected chronic disease
  – Diabetes, Asthma, Hypertension clinically significant benefits
  – Arthritis
    • nil to minimal benefits

• “Self-efficacy” has been shown to improve in many studies
Outcomes of self-management

- Clinical outcomes
  - Lower blood pressure, asthma, diabetes
- Symptoms
  - Pain, asthma severity
- Self-reported outcomes
  - Difficulty in performing daily activities
  - Quality of Life
- Behaviour
  - Physical activity, diet, smoking
  - Use of care plans
- What about ‘self-efficacy’ as an outcome?
Limitations of meta-analyses

• Reviews are limited:
  – heterogeneity of self-management interventions
  – types of outcomes measured
    • Some clinical outcomes
    • Some patient reported outcomes
      – Pain
      – Disability

• Why weak outcomes for some diseases and inconsistent results?
  – Poor quality interventions?
  – Wrong patients entering programs?
  – Wrong outcomes being measured?

• Are the ‘right’ outcomes being measured?
  – Is a new questionnaire needed?
Not another questionnaire!
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 Department of Health and Ageing, Australia
Program logic

• Development of a clear understanding of what it is you need to measure

• **Outcomes hierarchy** is a particular type of Program Logic useful for questionnaire development
  - It scopes the causal chain (i.e. proximal, intermediate and distal impacts on individuals)
  - It greatly assists in defining what might be necessary and feasible to measure.
Outcomes Hierarchy Program Logic

Self-management programs

Possible immediate effects

Improved outcomes for individuals

Possible later effects

Improved Public Health

Possible long term effects

Perspective

• Consultation
  – People who have undertaken a chronic disease education program
  – Doctors, Nurses, Trainers, Educators
  – Policy makers

  – What do they believe are valuable outcomes?
Seeding statement for Concept Mapping workshops…

• Thinking as broadly as possible, what would you want people who had done the course to say they had got out of it?

• Two prompts were also used:
  – What did they get out of it while they were doing the course?
  – What difference did it make to them once it was over?

• Nominal group approach
### Concepts derived

<table>
<thead>
<tr>
<th># Statement</th>
<th>Clus</th>
<th>Bridge</th>
<th># Statement</th>
<th>Clus</th>
<th>Bridge</th>
</tr>
</thead>
<tbody>
<tr>
<td>1 I have a better understanding of my condition</td>
<td>1</td>
<td>0.50</td>
<td>26 Have a better understanding of your illness and ways to feel better...</td>
<td>4</td>
<td>0.08</td>
</tr>
<tr>
<td>2 Feel better from talking to others with same condition</td>
<td>5</td>
<td>0.46</td>
<td>27 Knowing how to speak to your doctor</td>
<td>7</td>
<td>0.28</td>
</tr>
<tr>
<td>3 Felt confident to be more active and exercise</td>
<td>2</td>
<td>0.27</td>
<td>28 Builds confidence and a positive outlook (you CAN...</td>
<td>9</td>
<td>0.27</td>
</tr>
<tr>
<td>4 Goals are motivating</td>
<td>1</td>
<td>0.15</td>
<td>29 Learn how to say NO to people</td>
<td>11</td>
<td>0.26</td>
</tr>
<tr>
<td>5 Feel less despondent</td>
<td>2</td>
<td>0.34</td>
<td>30 Feel more positive / optimistic about the future</td>
<td>6</td>
<td>0.38</td>
</tr>
<tr>
<td>6 Feel you're not the only one coping with this</td>
<td>3</td>
<td>0.88</td>
<td>31 Have learnt new ways of dealing with illness</td>
<td>2</td>
<td>0.05</td>
</tr>
<tr>
<td>7 Have learnt new ways of dealing with illness</td>
<td>4</td>
<td>0.46</td>
<td>32 Have learnt new ways of dealing with illness</td>
<td>5</td>
<td>0.46</td>
</tr>
<tr>
<td>8 Know specific techniques for coping with symptoms/pain</td>
<td>5</td>
<td>0.26</td>
<td>33 Learn how to say NO to people</td>
<td>4</td>
<td>0.08</td>
</tr>
<tr>
<td>9 Go out and do exercise regularly</td>
<td>6</td>
<td>0.14</td>
<td>34 Know your own limitations</td>
<td>2</td>
<td>0.14</td>
</tr>
<tr>
<td>10 Motivation to be active</td>
<td>7</td>
<td>0.28</td>
<td>35 Know about aids and devices that can make life easier</td>
<td>10</td>
<td>0.57</td>
</tr>
<tr>
<td>11 Seeing that other people can cope with the same or different</td>
<td>9</td>
<td>0.26</td>
<td>36 Techniques to relax and cope with pain better</td>
<td>3</td>
<td>0.03</td>
</tr>
<tr>
<td>12 Motivation and encouragement to do a little more each</td>
<td>11</td>
<td>0.28</td>
<td>37 People remain motivated and keep doing things</td>
<td>11</td>
<td>0.19</td>
</tr>
<tr>
<td>13 Get to the point where you WANT to be more active</td>
<td>11</td>
<td>0.28</td>
<td>38 Have opportunities to renew your motivation after the program</td>
<td>11</td>
<td>0.18</td>
</tr>
<tr>
<td>14 Set goals that are reasonable and within reach</td>
<td>11</td>
<td>0.28</td>
<td>39 Do your best to do more things with their life</td>
<td>11</td>
<td>0.56</td>
</tr>
<tr>
<td>15 Continue setting goals for yourself once the course over</td>
<td>9</td>
<td>0.22</td>
<td>40 Understand the need to keep moving</td>
<td>9</td>
<td>0.28</td>
</tr>
<tr>
<td>16 Find alternative ways to control pain</td>
<td>2</td>
<td>0.03</td>
<td>41 Dispel myths about avoiding activity</td>
<td>10</td>
<td>0.20</td>
</tr>
<tr>
<td>17 Understand more about medication and how to use it</td>
<td>2</td>
<td>0.15</td>
<td>42 Learn that pain doesn't need to stop you doing things</td>
<td>4</td>
<td>0.08</td>
</tr>
<tr>
<td>18 Learn you don't have to put up with pain - should do</td>
<td>5</td>
<td>0.39</td>
<td>43 Leaders are there for you and are supportive</td>
<td>6</td>
<td>1.00</td>
</tr>
<tr>
<td>19 Talk to people who understand and don't think you are</td>
<td>5</td>
<td>0.46</td>
<td>44 Better able to handle stress</td>
<td>1</td>
<td>0.49</td>
</tr>
<tr>
<td>20 Learn that your symptoms are real and there are real</td>
<td>2</td>
<td>0.14</td>
<td>45 Control the extent to which you get into stressful</td>
<td>4</td>
<td>0.15</td>
</tr>
<tr>
<td>21 Able to talk to family and explain things better</td>
<td>6</td>
<td>0.66</td>
<td>46 Understand things that can exacerbate your illness or</td>
<td>2</td>
<td>0.14</td>
</tr>
<tr>
<td>22 Being more aware of techniques, tips and tricks to help</td>
<td>3</td>
<td>0.00</td>
<td>47 Know your own limitations</td>
<td>10</td>
<td>0.23</td>
</tr>
<tr>
<td>23 Have time to discuss your illness in detail</td>
<td>7</td>
<td>0.60</td>
<td>48 Improved relationship with Doctors and health</td>
<td>7</td>
<td>0.28</td>
</tr>
<tr>
<td>24 Learn to keep a balance with work, exercise and rest</td>
<td>5</td>
<td>0.54</td>
<td>49 Course participants help educate doctors and others</td>
<td>8</td>
<td>0.57</td>
</tr>
<tr>
<td>25 Learn to respond better to the needs of your body</td>
<td>4</td>
<td>0.11</td>
<td>50 Greater confidence in getting what you want from</td>
<td>8</td>
<td>0.57</td>
</tr>
</tbody>
</table>

Using any system you like, group the statements...
Motivation (ongoing)
Getting moving (fitness)
Understanding and control
Managing illness: techniques & skills (3)
- knowledge (2)
With cluster 4 but more general
Self management of illness
Positive approach to life and activity
Getting moving (fitness)
Understanding and control
Social support
Health professionals
Being supportive
Relationships with Drs/health profs
Assertiveness with Drs/health profs
Support in illness
Realistic limits
Motivation (ongoing)
Clusters provide ‘data driven’ specification of theoretical constructs of the ‘impact of health education’
Construct definitions

• Constructs were derived from
  – Project derived sources
    • Concept mapping
    • Stakeholder interviews & surveys
    • Program logic
    • Literature

• Items were derived from the patients’ words and the meaning embodied in their words
Resulting constructs

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 wellbeing

Dimensions (and items) 

- thoroughly inform
- Course leaders, Trainers
- Healthcare professionals
- Researchers, Policy makers
- Funders

- (Program delivery)
**Confirmatory Factor Analysis (CFA)**

8 latent variables which measure their respective constructs well
- no cross loading of items on other latent variables
- no loading of latent variables or items on item errors

N=592

LISREL: Asymptotic Covariance Matrix
Chi-sq (791), 3289, p=0.00

Root mean square error of approximation (RMSEA) = 0.05
Comparative Fit Index (CFI) = 0.95
Root Mean Square Residual (RMR) = 0.063

Quality monitoring
Collating data:
From individual participant to Federal funders
Further evidence is needed to:

• Inform decisions on what type of programs to implement
• Help health care professionals to understand the value of self-management to support their active participation
• Generate evidence-informed policy and programs
• Inform funders to so they can get the best value for money
• Understand which patients have the greatest capacity benefit and engage
Making quality and monitoring easy

Welcome to the heiQ™ evaluation system.

The heiQ™ is an Australian-developed health education impact evaluation system. It consists of a set of eight scales. Each scale is an independent questionnaire and together they provide a comprehensive profile of the intended outcomes of health education self-management programs.

The scales include:
- Health directed behaviour
- Positive and active engagement in life
- Emotional well-being
- Self-monitoring and insight
- Constructive attitudes and approaches
- Skill and technique acquisition
- Social integration and support
- Health service navigation

The heiQ™ is designed to measure effectiveness of health education programs and to inform health professionals, researchers, funders and policymakers on the outcomes of health education programs delivered to people with chronic diseases. The heiQ™ system provides course leaders and their affiliated institutions with valuable information about consumer satisfaction, service delivery quality, and effects of quality improvement activities. The above 8 scales can be 'mixed and matched' depending on what you need to measure, the intended outcomes of your program, and how brief your assessment needs to be.

The heiQ is being used in Australia, Japan, USA, Canada, United Kingdom, The Netherlands, Germany and others.

Further information can be found here and please contact us if you’d like to be put in contact with people in your region who are using the heiQ™.
Course Delivery Report

Organisation:
Course ID:
Start Date: 2007-11-12
Course Leader 1: 193 Course Leader 2: 193
Course Type: Cancer Lifestyle Education Support
Number of participants: 23
Number of valid heiQs: 23 Baseline, 22 Follow up
Non-completers: 0

How did your participants judge the quality of your course?

<table>
<thead>
<tr>
<th>Course Delivery Quality</th>
<th>1 strongly disagree</th>
<th>2 disagree</th>
<th>3 disagree slightly</th>
<th>4 disagree slightly</th>
<th>5 agree</th>
<th>6 strongly agree</th>
<th>Your group's average</th>
<th>National Average</th>
<th>Your group vs national average</th>
</tr>
</thead>
<tbody>
<tr>
<td>1. I intend to tell other people that the program is very worthwhile.</td>
<td>0</td>
<td>0</td>
<td>0</td>
<td>0</td>
<td>1</td>
<td>21</td>
<td>5.55</td>
<td>5.47</td>
<td>0.48</td>
</tr>
<tr>
<td>2. The program has helped me set goals that are reasonable and within reach.</td>
<td>0</td>
<td>0</td>
<td>0</td>
<td>0</td>
<td>3</td>
<td>18</td>
<td>5.88</td>
<td>5.32</td>
<td>0.54</td>
</tr>
<tr>
<td>3. I trust the information and advice I was given in the program.</td>
<td>0</td>
<td>0</td>
<td>0</td>
<td>0</td>
<td>4</td>
<td>18</td>
<td>5.82</td>
<td>5.45</td>
<td>0.37</td>
</tr>
<tr>
<td>4. Course leaders were very well organised.</td>
<td>0</td>
<td>0</td>
<td>0</td>
<td>0</td>
<td>4</td>
<td>18</td>
<td>5.82</td>
<td>5.66</td>
<td>0.27</td>
</tr>
<tr>
<td>5. I feel it was worth my time and effort to take part in the program.</td>
<td>0</td>
<td>0</td>
<td>0</td>
<td>0</td>
<td>3</td>
<td>18</td>
<td>5.88</td>
<td>5.66</td>
<td>0.30</td>
</tr>
<tr>
<td>6. Difficult topics and discussions were handled well by my program leaders.</td>
<td>0</td>
<td>0</td>
<td>0</td>
<td>0</td>
<td>3</td>
<td>18</td>
<td>5.88</td>
<td>5.48</td>
<td>0.30</td>
</tr>
<tr>
<td>7. I thought the program content was very relevant to my situation.</td>
<td>0</td>
<td>0</td>
<td>0</td>
<td>1</td>
<td>4</td>
<td>17</td>
<td>5.73</td>
<td>5.43</td>
<td>0.30</td>
</tr>
<tr>
<td>8. I feel that everyone in the program had the chance to speak if they wanted.</td>
<td>0</td>
<td>0</td>
<td>0</td>
<td>5</td>
<td>17</td>
<td>18</td>
<td>5.77</td>
<td>5.93</td>
<td>0.24</td>
</tr>
<tr>
<td>9. The people in the group worked very well together.</td>
<td>0</td>
<td>0</td>
<td>0</td>
<td>4</td>
<td>17</td>
<td>18</td>
<td>5.81</td>
<td>5.61</td>
<td>0.20</td>
</tr>
</tbody>
</table>
### Health Education Impact Report

**Organisation:**
**Course ID:**
**Start Date:** 2002-11-12
**Course Leader 1:** 192  **Course Leader 2:** 193
**Course Type:** Cancer Lifestyle Education and Support
**Number of participants:** 23
**Number of valid NFOs:** 23  **Baseline:** 22  **Follow up:**
**Non-completers:** 0

How does your group compare with the other groups in Australia at the start of the course?

<table>
<thead>
<tr>
<th>Baseline scores</th>
<th>Your group’s average (Baseline)</th>
<th>National average</th>
<th>Your group vs the national average</th>
<th>Compared to the national average your group scored...</th>
</tr>
</thead>
<tbody>
<tr>
<td>1. Health and directed behaviour</td>
<td>2.93</td>
<td>2.88</td>
<td>0.05</td>
<td></td>
</tr>
<tr>
<td>2. Positive and active engagement in life</td>
<td>3.06</td>
<td>2.97</td>
<td>0.11</td>
<td></td>
</tr>
<tr>
<td>3. Emotional wellbeing</td>
<td>2.90</td>
<td>2.79</td>
<td>0.20</td>
<td></td>
</tr>
<tr>
<td>4. Self-monitoring and Insight</td>
<td>2.91</td>
<td>3.03</td>
<td>-0.12</td>
<td></td>
</tr>
<tr>
<td>5. Constructive attitude shift</td>
<td>3.35</td>
<td>3.09</td>
<td>0.26</td>
<td>higher</td>
</tr>
<tr>
<td>6. Skill and technique acquisition</td>
<td>2.72</td>
<td>2.87</td>
<td>-0.15</td>
<td></td>
</tr>
<tr>
<td>7. Social integration and support</td>
<td>3.23</td>
<td>2.91</td>
<td>0.32</td>
<td></td>
</tr>
<tr>
<td>8. Health service navigation</td>
<td>3.11</td>
<td>3.12</td>
<td>-0.01</td>
<td></td>
</tr>
</tbody>
</table>

How much did your group and each individual participant improve?

<table>
<thead>
<tr>
<th>Improvements</th>
<th>Your group’s average (Follow Up)</th>
<th>Number of participants who had a substantial change</th>
</tr>
</thead>
<tbody>
<tr>
<td>1. Health and directed behaviour</td>
<td>3.51</td>
<td>12 of 22 = 55%</td>
</tr>
<tr>
<td>2. Positive and active engagement in life</td>
<td>3.50</td>
<td>13 of 22 = 59%</td>
</tr>
<tr>
<td>3. Emotional wellbeing</td>
<td>3.10</td>
<td>2 of 22 = 9%</td>
</tr>
<tr>
<td>4. Self-monitoring and Insight</td>
<td>3.35</td>
<td>14 of 22 = 64%</td>
</tr>
<tr>
<td>5. Constructive attitude shift</td>
<td>3.56</td>
<td>8 of 22 = 36%</td>
</tr>
<tr>
<td>6. Skill and technique acquisition</td>
<td>3.29</td>
<td>13 of 22 = 59%</td>
</tr>
<tr>
<td>7. Social integration and support</td>
<td>3.50</td>
<td>9 of 22 = 41%</td>
</tr>
<tr>
<td>8. Health service navigation</td>
<td>3.26</td>
<td>8 of 22 = 36%</td>
</tr>
</tbody>
</table>
Application of the heiQ

Current licensed users
n = 103 national
n = 6 international

Pending licenses
n = 23 national
n = 34 international
Some outcomes of chronic disease self-management programs can be measured, but...

Programs are generally poorly integrated
- Unknown coverage of those who might benefit most
Can chronic disease self-management education programs be integrated into the care continuum?
Foundations of ‘self-care’ and ‘self-management’

Level 6
Command

- "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

Level 5
Self-management

Action planning, Problem-solving

Level 4
Health education and empowerment (heiQ)

- Positive and active engagement in life
- Health directed behaviour
- Skill and technique acquisition
- Constructive attitudes and approaches
- Self monitoring and insight
- Health service navigation
- Social integration and support
- Emotional wellbeing

Level 3
Knowledge

- Faculties to distinguish correct/useful information from false/unimportant information

Level 2
Access

- Access to information about health and health professionals

Level 1
Cognitive capacity

- Capacity to understand information about health
- Capacity to identify/recognise health messages
Health literacy

What is it and why is it important?
Health Literacy

Definition:

“An individual’s capacity to seek, understand and utilise health information to make informed decisions about their own health”

US Department of Health & Human Services “Health People 2010”
Current patient-centred care approach

- Emphasis on self-management
- Partnerships between patients and health professionals

Assumption

- This approach assumes a minimum level of *health* literacy (to navigate the healthcare system and participate in decisions about care)
Health literacy at the individual level

• Critical factor in individual’s engaging in their own health

• Require specific skills and knowledge to be able to:
  – seek information
  – understand rights and responsibilities
  – negotiate the healthcare system
  – make health decisions for themselves

• All these impact on the probability of an individual achieving and maintaining good health
How is health literacy currently measured?

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

- 3 key tools:
  - Rapid Estimate of Adult Literacy in Medicine (REALM)
  - Test of Functional Health Literacy in Adults (TOFHLA)
  - Newest Vital Sign
# REALM

- **66 items**

<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>
</tbody>
</table>

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TOFHLA

• Focus on functional health literacy (reading, comprehension, numeracy)

• 2 components:
  (i) Reading ability (50 items)

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

2) You must have an _____________ stomach when you come for ______ .
   a. asthma
   b. empty
   c. incest
   d. anaemia
   a. is
   b. am
   c. if
   d. it

Relationship between Health Literacy and Health Outcomes
Relationship between health literacy and outcomes

- Lower health literacy associated with:
  - inadequate knowledge about health and healthcare system
  - increased hospitalisation
  - poor access and utilisation of health services
    - Lower health literacy ~ 1.5 to 3 times more likely to experience poor health event

Health literacy in Victoria: A population survey

Prof Rachelle Buchbinder
Prof Richard Osborne
A/Prof Rosemary Clerehan
Prof Catherine Elder
Population-based study of health literacy

- Random sample adult population from 2004 electoral roll - 310 participants
- Face-to-face interviews
- Trained interviewers (n=10)

### REALM

<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>

### TOHFLA

<table>
<thead>
<tr>
<th>Inadequate</th>
<th>May be unable to read and interpret health texts</th>
<th>8 (3%)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Marginal</td>
<td>Would have difficulty reading/interpreting health texts</td>
<td>13 (4%)</td>
</tr>
<tr>
<td>Adequate</td>
<td>Could read and interpret most health texts</td>
<td>288 (93%)</td>
</tr>
</tbody>
</table>

### NVS

<table>
<thead>
<tr>
<th>0-1</th>
<th>Suggests highly likely (50% or more) limited literacy</th>
<th>22 (7%)</th>
</tr>
</thead>
<tbody>
<tr>
<td>2-3</td>
<td>Indicates possibility of limited literacy</td>
<td>58 (19%)</td>
</tr>
<tr>
<td>4-6</td>
<td>Almost always indicates adequate literacy</td>
<td>228 (74%)</td>
</tr>
</tbody>
</table>
Key findings

• Health literacy (as measured by reading, understanding written information and numbers) is an important determinant of health

• A substantial proportion of the population (13% to 26%) may have suboptimal skills to function ‘effectively’ within the healthcare setting

• BUT
  – Current measures of health literacy are inadequate.
  – What might be all the relevant ‘health literacy’ skills?
  – How can we inform health policy in this area?
Reading/numeracy ability vs uptake and impact of ‘education’
Multimedia education and medication uptake and concordance

- Educational package designed (first)
  - Can we evaluate its effectiveness?
  - Not really!
- What education “should” be delivered to a person who “needs” to take an important medication appropriately?
  ... detailed consultation
  ... questionnaire development
Medication Health Impact Questionnaire (meiQ)

1. Information quality
   - I feel I have been fully informed about this medication

2. Active communication
   - I am confident in my ability to communicate with my doctors

3. Informed decision making
   - I have "had a say" in choosing this medication

4. Accept diagnosis and treatment
   - I understand what might happen if I don’t take this medication

5. Self-management role
   - It is my job to make sure I take my medication safely

6. Self-management ability
   - I know what to do if I get side effects from my medication

7. Self-management support
   - I know I have the back up I need if I have problems with my medication
Foundations of ‘self-care’ and ‘self-management’

Level 6
Command
- "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

Level 5
Self-management
Action planning, Problem-solving
- Faculties to distinguish correct/useful information from fallacious/unimportant information

Level 4
Health education and empowerment (heiQ)
- Positive and active engagement in life Health directed behaviour
- Skill and technique acquisition Constructive attitudes and approaches
- Self monitoring and insight Health service navigation
- Social integration and support Emotional wellbeing

Level 3
Knowledge
Access to information about health and health professionals

Level 2
Access
Capacity to understand information about health

Level 1
Cognitive capacity
Capacity to identify / recognise health messages
We need to understand health literacy better!
Development of health literacy tests and policy

Literacy & Numeracy skills of population

Development of scales and assessment measures

Limited examination of interventions, health behaviour or compliance

Policy

Gaps:

Interviews with patients

• Only looking at select literacy skills

• Derived from physicians and literacy experts

• Look at relationship between literacy skills and patient knowledge/behaviour in isolation from broader healthcare system

• No consultation with patients

Results: What people do and why

Focus on modifiable skills/factors

Available interventions

Gaps & Opportunities
Objective:

• Document patient experiences in “real life” situations

• Focus on:
  – Factors affecting patients in seeking, understanding and utilising health information
  – Identify generic health literacy skills critical to “patient functioning”
Qualitative study

Interview and workshops:
- 3 distinct population groups:

(1) Individuals who had taken part in a chronic disease self-management program
(2) General population
(3) Individuals who recently presented to the Emergency Department
Interview focus

• Key areas – patient experience:
  1. Seeking medical help
  2. Navigating the healthcare system
  3. Seeking and understanding health information
  4. Skills to function in the healthcare system
Key findings

1. Triggers for seeking medical help
2. Enablers and barriers to seeking and understanding health information
3. Skills required to function in the healthcare environment
   - Grounded approach:
     • Interviews, workshops, literature review
Reconceptualisation of Health Literacy: 7 skills for effective engagement in healthcare

- Knowing when to seek health information
- Knowing where to seek health information
- Verbal communication skills
- Assertiveness
- Literacy skills
- Capacity to process and retain information
- Application skills (incorporating information into lifestyle)
Health Literacy Assessment – potential interventions

7 skills for effective engagement in healthcare

- Knowing when to seek health information
- Knowing where to seek health information,
- Verbal communication skills
- Assertiveness
- Literacy skills
- Capacity to process and retain information
- Application skills (incorporating information into lifestyle)

Interventions for patients:
- Education programs
- Counselling

Healthcare setting:
- Professional training
- Screening tools

Broader community:
- Linguistic framework
- Literacy programs
Are these skills modifiable or manageable through available interventions?

<table>
<thead>
<tr>
<th>Knowing when to seek health information</th>
<th>Patients</th>
<th>Social support</th>
<th>Health Professional</th>
<th>Community</th>
<th>Healthcare System</th>
<th>Government Policy</th>
</tr>
</thead>
<tbody>
<tr>
<td>Knowing where to seek health information</td>
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<tr>
<td>Verbal communication skills</td>
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<td>Assertiveness</td>
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<td>Literacy skills</td>
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<td>Capacity to process and retain information</td>
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<tr>
<td>Application skills (incorporating information into lifestyle)</td>
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</table>
Health Literacy Assessment

• We need to be able to measure the 7 key skills individuals require to effectively engage in healthcare

  – We need to measure health literacy skills in
    • The general population
    • Those most at risk of poor health due to limited access to ‘healthcare opportunities’

  – We need to document the effectiveness (inclusion / impact / needs met) of self management interventions for people with low health literacy
Development of a measure of health literacy...
Draft health literacy dimensions

1.
2.
3.
4.
5.
6.
7.
8.
Discussion
Barriers to effective patient education

– Access
  • Health literacy
  • Absence of opportunities to engage in self-management activities
– Motivation / absence of triggers
– Complexity of programs for patients
  • Patients are sick people!
– Absence of perceived or real rewards
– Critical mass of programs, trained educators, referral systems
– Evidence that it works!
What might an effective whole of system approach to self management look like?
• A systems approach needs to consider the whole system!
Whole of system

1. Consistent policy
   – An overarching policy
   – Linked local policies and programs
2. Consider the disease continuum
   – Prevention through to late stage disease
3. Make interventions appropriate
   – Tailor, especially for lower socioeconomic groups
4. Build expectations around self-care
5. Build the workforce and programs in pace with building the referral base
6. Undertake demonstration projects
7. Generate local ownership
8. Evaluate and provide feedback
   – To patients, educators, clinicians, program managers, policymakers
9. Use continuous quality improvement / tailoring
10. Mainstream
Barriers to introduction of innovations

1. Relative advantage
   – sine qua non for adoption.

2. Compatibility
   – with values, norms and perceived needs

3. Complexity
   – those perceived as simple to use are more easily adopted and implemented.

4. Trialability
   – innovations that can be experimented with by intended users on a limited basis will be more easily adopted and implemented

5. Observability
   – see others using it

6. Re-invention
   – if individual can adapt, refine or modify to own needs

Greenhalgh et al
Burden of disease attributed to selected risk factors

Figure 25 Disease burden attributed to selected risk factors by sex, Victoria, 2001
Care of people with chronic disease

Health care
Care of people with chronic disease

Self management
+/- carer
+/- community
The way forward…Research and policy priorities

• Understand health literacy and skills needed to access and use healthcare effectively
  – To what extent are such skills modifiable?
  – What is the ‘prevalence’ of inadequate skills?

• Interventions
  – What is available?
  – What is the evidence of efficiency & effectiveness?
  – What is the sustainability / appropriateness?
  – Who has the ‘capacity to benefit’
    • Individuals, Families, Communities

• Where are the biggest “opportunities”?
  – Short term
  – Long term
  – Demographic groups (Indigenous people, immigrants, the poor and less educated, old/young etc)
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