Evaluation and quality monitoring of patient education programs: What is effective and from whose perspective?

Professor Richard Osborne, BSc, PhD
Chair of Public Health
Deakin University
Topics

• development of a system to understand the benefits of CDSM
• implementation of the Health Education Impact Questionnaire (heiQ) across sectors and disease groups
• what is important to patients, healthcare professions, educators and policymakers
Research that informs this presentation

• National Health and Medical Research Council
  – Advancing arthritis public health research and evidence-informed policy in Australia
National Chronic Disease Strategy

• Australian Better Health Initiative (ABHI) ($500 million over 4 years)
  • prevention across the continuum
  • strengthening early detection and early treatment
  • integration and continuity of prevention and care
  • self-management

– Australian government activities under ABHI
  • Numerous activities

– State government activities under ABHI
  • Numerous activities
Care of people with chronic disease

Health care
Care of people with chronic disease

Self management
 +/- carer
 +/- community
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

• Facility that health and social care services provide

• Enhance patient well-being and management of chronic conditions

• Focus on self-management ‘skills’ training

• Wide variety of diverse approaches
  • Focus on formal education programs
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 some studies
Outcomes of CDSM

• Symptoms
  – Pain
  – Ability of perform daily activities
  – Quality of Life

• Behaviour
  – Physical activity
  – Use of plans

• What about ‘self-efficacy’ as an outcome?
Self-Efficacy for Managing Chronic Disease scale

1. **How confident are you that you can keep the fatigue caused by your disease from interfering with the things you want to do?**

2. **How confident are you that you can keep the physical discomfort or pain of your disease from interfering with the things you want to do?**

3. **How confident are you that you can keep the emotional distress caused by your disease from interfering with the things you want to do?**

4. **How confident are you that you can keep any other symptoms or health problems you have from interfering with the things you want to do?**

5. **How confident are you that you can do the different tasks and activities needed to manage your health condition so as to reduce you need to see a doctor?**

6. **How confident are you that you can do things other than just taking medication to reduce how much you illness affects your everyday life?**
How confident are you that you can keep the fatigue caused by your disease from interfering with the things you want to do?

How confident are you that you can keep the physical discomfort or pain of your disease from interfering with the things you want to do?

How confident are you that you can keep the emotional distress caused by your disease from interfering with the things you want to do?

How confident are you that you can keep any other symptoms or health problems you have from interfering with the things you want to do?

How confident are you that you can do the different tasks and activities needed to manage your health condition so as to reduce your need to see a doctor?

How confident are you that you can do things other than just taking medication to reduce how much you illness affects your everyday life?
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 poor 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
The questionnaire development team

- Experienced ‘developers’
- Content specialists and field workers
  - Clinicians, practitioners, people on the ground
- Stakeholders
  - Expected users of the questionnaire
- Consumers
Scoping interviews

• Interviews with stakeholders to find out:
  – what they believe the program is
  – what would be important indicators of program success

• 29 in depth interviews
  – NGOs (Arthritis, Heart, Asthma, Diabetes Foundations)
    • CEOs, managers
    • Trainers, Master trainers
  – Government
    • Commonwealth, State, Veteran’s Affairs
  – Clinicians
    • Physicians, physiotherapists, specialists etc
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.
Overarching principles

Health education programs should;

1. Be appropriate for a wide range of chronic conditions
2. Include diverse delivery models
3. Be accessible
4. Meet identified needs
5. Be timely and appropriate
6. Impact on quality of life
7. Be evidenced based
8. Involve skilled delivery
Outcomes Hierarchy Program Logic

Self-management programs → Improved outcomes for individuals → Improved Public Health

Possible immediate effects
Possible later effects
Possible long term effects
The patient perspective

• People who have undertaken a chronic disease program
  – What do they believe are valuable outcomes?
• Concept Mapping…
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?*

• 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>#</th>
<th>Statement</th>
<th>Clus</th>
<th>Bridge</th>
<th>#</th>
<th>Statement</th>
<th>Clus</th>
<th>Bridge</th>
</tr>
</thead>
<tbody>
<tr>
<td>1</td>
<td>I have a better understanding of my condition</td>
<td>1</td>
<td>0.50</td>
<td>26</td>
<td>Have a better understanding of your illness and ways to</td>
<td>4</td>
<td>0.08</td>
</tr>
<tr>
<td>2</td>
<td>Feel better from talking to others with same condition</td>
<td>5</td>
<td>0.46</td>
<td>27</td>
<td>Knowing how to speak to your doctor</td>
<td>7</td>
<td>0.28</td>
</tr>
<tr>
<td>3</td>
<td>Felt confident to be more active and exercise</td>
<td>2</td>
<td>0.05</td>
<td>28</td>
<td>Knowing how to speak to your doctor</td>
<td>9</td>
<td>0.27</td>
</tr>
<tr>
<td>4</td>
<td>Goals are motivating</td>
<td>9</td>
<td>0.14</td>
<td>29</td>
<td>Learn how to say NO to people</td>
<td>4</td>
<td>0.13</td>
</tr>
<tr>
<td>5</td>
<td>Feel less despondent</td>
<td>6</td>
<td>0.34</td>
<td>30</td>
<td>Feel more positive / optimistic about the future</td>
<td>9</td>
<td>0.27</td>
</tr>
<tr>
<td>6</td>
<td>Feel you're not the only one coping with this</td>
<td>5</td>
<td>0.38</td>
<td>31</td>
<td>Have learnt new ways of dealing with illness</td>
<td>2</td>
<td>0.02</td>
</tr>
<tr>
<td>7</td>
<td>Have learnt new ways of dealing with illness</td>
<td>11</td>
<td>0.11</td>
<td>32</td>
<td>Have ongoing social support from course</td>
<td>5</td>
<td>0.30</td>
</tr>
<tr>
<td>8</td>
<td>Know specific techniques for coping with symptoms/pain</td>
<td>9</td>
<td>0.26</td>
<td>33</td>
<td>Learn about nutrition (myths and things that really help)</td>
<td>2</td>
<td>0.09</td>
</tr>
<tr>
<td>9</td>
<td>Go out and do exercise regularly</td>
<td>9</td>
<td>0.14</td>
<td>34</td>
<td>Have a knowledge of non-traditional treatment options</td>
<td>2</td>
<td>0.08</td>
</tr>
<tr>
<td>10</td>
<td>Motivation to be active</td>
<td>11</td>
<td>0.11</td>
<td>35</td>
<td>Know about aids and devices that can make life easier</td>
<td>3</td>
<td>0.00</td>
</tr>
<tr>
<td>11</td>
<td>Seeing that other people can cope with the same or</td>
<td>11</td>
<td>0.26</td>
<td>36</td>
<td>Techniques to relax and cope with pain better</td>
<td>3</td>
<td>0.03</td>
</tr>
<tr>
<td>12</td>
<td>Motivation and encouragement to do a little more each</td>
<td>11</td>
<td>0.28</td>
<td>37</td>
<td>People remain motivated and keep doing things</td>
<td>11</td>
<td>0.19</td>
</tr>
<tr>
<td>13</td>
<td>Get to the point where you WANT to be more active</td>
<td>11</td>
<td>0.28</td>
<td>38</td>
<td>Have opportunities to renew your motivation after the</td>
<td>11</td>
<td>0.18</td>
</tr>
<tr>
<td>14</td>
<td>Set goals that are reasonable and within reach</td>
<td>9</td>
<td>0.22</td>
<td>39</td>
<td>Doing more things with their life</td>
<td>11</td>
<td>0.56</td>
</tr>
<tr>
<td>15</td>
<td>Continue setting goals for yourself once the course over</td>
<td>11</td>
<td>0.03</td>
<td>40</td>
<td>Understand the need to keep moving</td>
<td>9</td>
<td>0.28</td>
</tr>
<tr>
<td>16</td>
<td>Find alternative ways to control pain</td>
<td>2</td>
<td>0.03</td>
<td>41</td>
<td>Dispel myths about avoiding activity</td>
<td>10</td>
<td>0.20</td>
</tr>
<tr>
<td>17</td>
<td>Understand more about medication and how to use it</td>
<td>2</td>
<td>0.15</td>
<td>42</td>
<td>Learn that pain doesn't need to stop you doing things</td>
<td>4</td>
<td>0.08</td>
</tr>
<tr>
<td>18</td>
<td>Learn you don't have to put up with pain - should do</td>
<td>5</td>
<td>0.39</td>
<td>43</td>
<td>Leaders are there for you and are supportive</td>
<td>6</td>
<td>1.00</td>
</tr>
<tr>
<td>19</td>
<td>Talk to people who understand and don't think you are</td>
<td>5</td>
<td>0.46</td>
<td>44</td>
<td>Better able to handle stress</td>
<td>1</td>
<td>0.49</td>
</tr>
<tr>
<td>20</td>
<td>Learn that your symptoms are real and there are real</td>
<td>2</td>
<td>0.14</td>
<td>45</td>
<td>Control the extent to which you get into stressful</td>
<td>4</td>
<td>0.15</td>
</tr>
<tr>
<td>21</td>
<td>Able to talk to family and explain things better</td>
<td>6</td>
<td>0.66</td>
<td>46</td>
<td>Understand things that can exacerbate your illness or</td>
<td>2</td>
<td>0.14</td>
</tr>
<tr>
<td>22</td>
<td>Being more aware of techniques, tips and tricks to help</td>
<td>3</td>
<td>0.00</td>
<td>47</td>
<td>Know your own limitations</td>
<td>10</td>
<td>0.23</td>
</tr>
<tr>
<td>23</td>
<td>Have time to discuss your illness in detail</td>
<td>7</td>
<td>0.60</td>
<td>48</td>
<td>Improved relationship with Doctors and health</td>
<td>7</td>
<td>0.28</td>
</tr>
<tr>
<td>24</td>
<td>Learn to keep a balance with work, exercise and rest</td>
<td>5</td>
<td>0.54</td>
<td>49</td>
<td>Course participants help educate doctors and others</td>
<td>8</td>
<td>0.57</td>
</tr>
<tr>
<td>25</td>
<td>Learn to respond better to the needs of your body</td>
<td>4</td>
<td>0.11</td>
<td>50</td>
<td>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
Cluster analysis + multi-dimensional scaling

<table>
<thead>
<tr>
<th>No</th>
<th>Statement</th>
<th>Clus</th>
<th>Bridge</th>
</tr>
</thead>
<tbody>
<tr>
<td>Cluster 1: (As for 4 but general)</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>44</td>
<td>Better able to handle stress</td>
<td>1</td>
<td>0.49</td>
</tr>
<tr>
<td>1</td>
<td>I have a better understanding of my condition</td>
<td>1</td>
<td>0.50</td>
</tr>
<tr>
<td>Cluster 2: Managing illness - knowledge</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>16</td>
<td>Find alternative ways to control pain</td>
<td>2</td>
<td>0.03</td>
</tr>
<tr>
<td>7</td>
<td>Have learnt new ways of dealing with illness</td>
<td>2</td>
<td>0.05</td>
</tr>
<tr>
<td>34</td>
<td>Have a knowledge of non-traditional treatment options</td>
<td>2</td>
<td>0.08</td>
</tr>
<tr>
<td>33</td>
<td>Learn about nutrition (myths and things that really help)</td>
<td>2</td>
<td>0.09</td>
</tr>
<tr>
<td>46</td>
<td>Understand things that can exacerbate your illness or symptoms</td>
<td>2</td>
<td>0.14</td>
</tr>
<tr>
<td>20</td>
<td>Learn that your symptoms are real and there are real reasons for them</td>
<td>2</td>
<td>0.14</td>
</tr>
<tr>
<td>17</td>
<td>Understand more about medication and how to use it</td>
<td>2</td>
<td>0.15</td>
</tr>
<tr>
<td>Cluster 3: Managing illness – techniques and skills</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>22</td>
<td>Being more aware of techniques, tips and tricks to help manage your</td>
<td>3</td>
<td>0.00</td>
</tr>
<tr>
<td>35</td>
<td>Know about aids and devices that can make life easier</td>
<td>3</td>
<td>0.00</td>
</tr>
<tr>
<td>8</td>
<td>Know specific techniques for coping with symptoms/pain (eg.</td>
<td>3</td>
<td>0.02</td>
</tr>
<tr>
<td>36</td>
<td>Techniques to relax and cope with pain better</td>
<td>3</td>
<td>0.03</td>
</tr>
<tr>
<td>Cluster 4: Understanding and control</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>26</td>
<td>Have a better understanding of your illness and ways to manage</td>
<td>4</td>
<td>0.08</td>
</tr>
<tr>
<td>29</td>
<td>Learn how to say NO to people</td>
<td>4</td>
<td>0.08</td>
</tr>
<tr>
<td>42</td>
<td>Learn that pain doesn't need to stop you doing things</td>
<td>4</td>
<td>0.08</td>
</tr>
<tr>
<td>25</td>
<td>Learn to respond better to the needs of your body</td>
<td>4</td>
<td>0.11</td>
</tr>
<tr>
<td>30</td>
<td>Feel more positive / optimistic about the future</td>
<td>4</td>
<td>0.13</td>
</tr>
<tr>
<td>45</td>
<td>Control the extent to which you get into stressful situation</td>
<td>4</td>
<td>0.15</td>
</tr>
<tr>
<td>31</td>
<td>Have options to deal with things other than just feeling desperate</td>
<td>4</td>
<td>0.23</td>
</tr>
<tr>
<td>Cluster 5: Social support in illness</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>32</td>
<td>Have ongoing social support from course</td>
<td>5</td>
<td>0.30</td>
</tr>
<tr>
<td>6</td>
<td>Feel you're not the only one coping with this</td>
<td>5</td>
<td>0.38</td>
</tr>
<tr>
<td>18</td>
<td>Learn you don't have to put up with pain - should do something about</td>
<td>5</td>
<td>0.39</td>
</tr>
<tr>
<td>2</td>
<td>Feel better from talking to others with same condition</td>
<td>5</td>
<td>0.46</td>
</tr>
<tr>
<td>19</td>
<td>Talk to people who understand and don't think you are complaining</td>
<td>5</td>
<td>0.46</td>
</tr>
<tr>
<td>24</td>
<td>Learn to keep a balance with work, exercise and rest</td>
<td>5</td>
<td>0.54</td>
</tr>
</tbody>
</table>
Cluster analysis + multi-dimensional scaling
Clusters provide ‘data driven’ specification of theoretical constructs of the ‘impact of health education’.
Stakeholder perspectives

- What are the relevant program outcomes from the *end user / key stakeholder* perspective?
  - Practitioners, trainers, researchers, funders and policy makers

- Concept Mapping …
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 intent
Results: 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
   – (Program delivery)

Dimensions (and items) **thoroughly inform**
Course leaders, Trainers
Healthcare professionals
Researchers, Policy makers
Funders
1. Positive & active engagement in life

Keywords:
getting engaged in life, intent for actions, indicators of now being engaged and involved in life.

• This construct covers motivation to be active and embodies the notion of participants in self-management/ health education programs engaging or re-engaging in life-fulfilling activities as a result of program involvement.

• Items in this construct aim to measure the individuals’ activities to convert intention into positive outcomes, and implies a change of lifestyle and life activities.
2. Health Directed Behaviour

Keywords:
healthy behaviours including prevention, diet, exercise, relaxation; tangible change

• This construct is similar to the first in that relates to a change in lifestyle, however this change is **tangible** and specifically related to healthful behaviours.
• Activities may include changes in diet, exercise and relaxation routines.
• These activities may be aimed at either disease prevention and/or health promotion.
3. Skill and technique acquisition

Keywords:
symptom relief skills, skills and techniques to manage own health

• This construct aims to capture the knowledge-based skills and techniques (including the use of aids) that participant’s acquire or re-learn to help them manage and cope with disease-related symptoms and health problems
3. Constructive attitudes and approaches

Keywords:
Minimising the illness –
“"I am not going to let this disease control my life””

• This construct is embodied by the statement “I am not going to let this disease control my life” and includes a shift in how the individual views the impact of their condition(s) on their life
5. Self monitoring and insight

Keywords:
Self monitoring of (sub) clinical indicators, self management, setting reasonable limits or targets, and insight into living with a health problem

• This construct captures the individuals’ ability to monitor their condition, and their physical and/or emotional responses that lead to insight and appropriate actions to self manage.
• An important component of this construct is the individuals’ acknowledgment of realistic disease-related limitations, and the ability and confidence to adhere to these limits.
• This may also relate to the monitoring of specific sub-clinical indicators of disease status
6. Health services navigation

Keywords: Communication, Decision processes, Relationships, Understanding. Interaction with and negotiation of the healthcare system, including the confidence to talk with healthcare professionals. The understanding of ways to access healthcare to get needs met

- This construct is concerned with an individual's understanding of and ability to confidently interact with a range of health organizations and health professionals.
- Further, it measures the confidence and ability to communicate and negotiate with healthcare providers to get needs met
7. Social integration and support

Keywords:
social interaction, feelings of social isolation as a result of the illness, “kinship” in group leading to sense of support, seeking support from others.

• This construct aims to capture the positive impact of social engagement and support that evolves through interaction with others.
• This impact may arise from interaction with others sharing similar health-related life experiences.
• This ‘shift’ also involves the confidence to seek support from interpersonal relationships as well as from community-based organizations.
8. Emotional wellbeing

Keywords:
Overall health-related negative affect. Attitude to life; anxiety, stress, anger and depression

- This construct measures overall negative affective responses to illness, including anxiety, anger and depression (which are attributed to the illness).
- These indicators give a sense of individuals’ general emotional wellbeing and satisfaction with life
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

Good constructs + Good items = Good Scales

- Well defined concept
- Excess items
- Very high reliability

- Medium defined concept
- Enough good items
- Good reliability

- Poorly defined concept
- Insufficient items
- Low reliability

- OK concept
- Insufficient items
- Bad items
- Very Low reliability
Reliability and Validity

Reliable & valid

Neither valid nor reliable

Valid Not reliable

Reliable Not valid
### Examples of items

Please answer the following questions:

Check a box by crossing it:

|   |   |   |   | X |   |   |

On most days of the week, I do at least one activity to improve my health (e.g., walking, relaxation, exercise)

|   |   |   |   |   |   |   |

I am very good at using aids and devices to make my life easier

|   |   |   |   |   |   |   |

Most days I am doing some of the things I really enjoy

|   |   |   |   |   |   |   |

As well as seeing my doctor, I regularly monitor changes in my health

|   |   |   |   |   |   |   |

I often worry about my health

|   |   |   |   |   |   |   |
Course Impact – Active Engagement in Life

**Mean** = 0.3447  
**Std. Dev.** = 0.75951  
**N** = 738

“0.00” no change  
Substantial change  
>0.5 Effect Size

36%
## heiQ scale scores

### Courses from around Australia

<table>
<thead>
<tr>
<th></th>
<th>Baseline mean</th>
<th>Baseline sd</th>
<th>Change score mean</th>
<th>% ES&gt;0.5</th>
</tr>
</thead>
<tbody>
<tr>
<td>1. Positive &amp; active engagement in life</td>
<td>4.49</td>
<td>0.98</td>
<td>0.34</td>
<td>36.0</td>
</tr>
<tr>
<td>2. Health directed behaviour</td>
<td>4.31</td>
<td>1.22</td>
<td>0.41</td>
<td>48.0</td>
</tr>
<tr>
<td>3. Skill and technique acquisition</td>
<td>4.15</td>
<td>0.92</td>
<td>0.55</td>
<td>34.3</td>
</tr>
<tr>
<td>4. Constructive attitudes &amp; approaches</td>
<td>4.57</td>
<td>0.95</td>
<td>0.27</td>
<td>31.4</td>
</tr>
<tr>
<td>5. Self monitoring and insight</td>
<td>4.73</td>
<td>0.65</td>
<td>0.28</td>
<td>41.2</td>
</tr>
<tr>
<td>6. Health service navigation</td>
<td>4.69</td>
<td>0.88</td>
<td>0.17</td>
<td>27.6</td>
</tr>
<tr>
<td>7. Social integration &amp; support</td>
<td>4.13</td>
<td>1.19</td>
<td>0.25</td>
<td>32.0</td>
</tr>
<tr>
<td>8. Emotional wellbeing</td>
<td>3.37</td>
<td>1.21</td>
<td>0.26</td>
<td>32.4</td>
</tr>
</tbody>
</table>

About one third of the participants have a substantial change.
Quality monitoring
Collating data:
From individual participant to Federal funders

National benchmarks

State specific reports

Organisation specific reports

Course specific reports

Participants

Commonwealth Department of Health

Victoria

NSW

etc

Brokerage
Quality Improvement
Feed back system

Data collected as part of routine procedures (prompt & useful feedback)
Further evidence is needed to:

• Inform decisions on what type of programs to implement
• Help health care professionals to understand the value, participate and refer
• Generate evidence-informed policy and programs
• Inform funders to invest
• Understand which patients have the greatest capacity benefit and engage
Making quality and monitoring possible

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 would 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: 192 Course Leader 2: 193
Course Type: Cancer Lifestyle-Education and 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 agree 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>23</td>
<td>5.95</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>19</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>5.46</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>5.55</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>5.86</td>
<td>6.06</td>
<td>0.20</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>5.86</td>
<td>5.48</td>
<td>0.38</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>0</td>
<td>4</td>
<td>17</td>
<td>5.73</td>
<td>6.43</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>0</td>
<td>5</td>
<td>17</td>
<td>5.77</td>
<td>5.63</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>0</td>
<td>4</td>
<td>17</td>
<td>5.81</td>
<td>5.61</td>
<td>0.30</td>
</tr>
</tbody>
</table>
### Health Education Impact Report

**Organisation:**

**Course ID:**

**Start Date:** 2007-11-12

**Course Leader 1:** 192  **Course Leader 2:** 193

**Course Type:** Cancer Lifestyle-Education and Support

**Number of participants:** 23

**Number of valid hEIos:** 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>2.83</td>
<td>2.88</td>
<td>0.05</td>
<td></td>
</tr>
<tr>
<td>2. Positive and active engagement in life</td>
<td>3.09</td>
<td>2.97</td>
<td>0.12</td>
<td></td>
</tr>
<tr>
<td>3. Emotional wellbeing</td>
<td>2.88</td>
<td>2.78</td>
<td>0.10</td>
<td></td>
</tr>
<tr>
<td>4. Selfmonitoring 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>2.67</td>
<td>-0.15</td>
<td></td>
</tr>
<tr>
<td>7. Social integration and support</td>
<td>3.23</td>
<td>2.98</td>
<td>0.25</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 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>3.61</td>
<td>12 of 22 = 55%</td>
</tr>
<tr>
<td>2. Positive and active engagement in life</td>
<td>3.60</td>
<td>13 of 22 = 59%</td>
</tr>
<tr>
<td>3. Emotional wellbeing</td>
<td>3.18</td>
<td>2 of 23 = 9%</td>
</tr>
<tr>
<td>4. Selfmonitoring and insight</td>
<td>3.26</td>
<td>14 of 22 = 64%</td>
</tr>
<tr>
<td>5. Constructive attitude shift</td>
<td>3.55</td>
<td>8 of 22 = 38%</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>3.60</td>
<td>9 of 22 = 41%</td>
</tr>
<tr>
<td>8. Health service navigation</td>
<td>3.26</td>
<td>8 of 22 = 38%</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
Integration of chronic disease self-management education programs into the care continuum
International policy review

• Sources:
  • Websites, grey and peer reviewed articles, interviews with international government bureaucrats
  • Structured interviews

• UK, Denmark, Canada, USA, Japan, Germany

• ‘Operationalisation’ issues
UK – Expert Patients Programme

- Multi-million pound ‘centrepiece’ of National Health System reform
- Based on ‘Anglicised’ version of the Stanford University self-management program
- Implemented across Primary Care Trusts across the UK
- Evaluation of EPP (in original form) indicated limited reach to patients and uptake by health professionals
- Conversion of the program into a Community Interest company
Denmark

• Aiming to implement Stanford program across 60 of 98 health districts

• Public campaign to increase profile of programs across health sector

• Funding until 2008

• Concern of limited reach

• Does the program / implementation strategy induce health inequalities?
  – Those people with the lowest health literacy are excluded
Care of people with chronic disease

Self management
+/- carer
+/- community
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
A closer look at where CDSM might fit in to the system
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

Level 4
Health education and empowerment (heiQ)
- Positive and active engagement in life
- Skill and technique acquisition
- Self monitoring and insight
- Social integration and support

Level 3
Knowledge
- Health directed behaviour
- Constructive attitudes and approaches
- Health service navigation
- Emotional wellbeing

Level 2
Access
- Faculties to distinguish correct/useful information from fallacious/unimportant information

Level 1
Cognitive capacity
- Access to information about health and health professionals
- 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 assessed?
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>

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       a. is
   b. empty        b. am
   c. incest       c. if
   d. anaemia      d. it

TOFHLA

• Weighting of numeracy items combined with reading items provides score of 0 to 100:

  < 60: inadequate literacy
  60 – 74: marginal literacy
  ≥ 75: adequate literacy
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)

Representativeness of sample

Sociodemographic comparisons between study and population

* Means significantly different from Victorian general population

- Income >$40000
- Post-school qualifications
- Age 50+
- Metropolitan
- Australian born
- Female
<table>
<thead>
<tr>
<th>REALM</th>
<th>(N = 310)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Grade 4-6</td>
<td>May need low-literacy materials; may not be able to read prescription labels</td>
</tr>
<tr>
<td>Grade 7-8</td>
<td>May struggle with most currently available patient education materials</td>
</tr>
<tr>
<td>High school</td>
<td>Should be able to read most patient education materials</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>TOHFLA</th>
<th>(N = 309)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Inadequate</td>
<td>May be unable to read and interpret health texts</td>
</tr>
<tr>
<td>Marginal</td>
<td>Would have difficulty reading/interpreting health texts</td>
</tr>
<tr>
<td>Adequate</td>
<td>Could read and interpret most health texts</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>NVS</th>
<th>(N = 308)</th>
</tr>
</thead>
<tbody>
<tr>
<td>0-1</td>
<td>Suggests highly likely (50% or more) limited literacy</td>
</tr>
<tr>
<td>2-3</td>
<td>Indicates possibility of limited literacy</td>
</tr>
<tr>
<td>4-6</td>
<td>Almost always indicates adequate literacy</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?
Development of health literacy tests and policy

Gaps:
- 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
A new framework for health literacy
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

- Maximum heterogeneity sampling (purposeful) across disease stage, age and gender.
  - common factors to be identified across large variation

Interview 3 distinct population groups:

1. Individuals who had taken part in a chronic disease self-management program (n=20)
2. General population (n=14)
3. Individuals who recently presented to the Emergency Department (n=13)
Interview focus

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

Synthesis of

1. 47 in-depth interviews with consumers
2. Four concept mapping workshops
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)
Do the current assessments measure the skills patients need?

<table>
<thead>
<tr>
<th>Skill Description</th>
<th>REALM</th>
<th>TOFHLA</th>
<th>NVS</th>
</tr>
</thead>
<tbody>
<tr>
<td>Knowing when to seek health information</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Knowing where to seek health information</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Verbal communication skills</td>
<td>?</td>
<td>?</td>
<td>?</td>
</tr>
<tr>
<td>Assertiveness</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Literacy skills</td>
<td>✓</td>
<td>✓</td>
<td>✓</td>
</tr>
<tr>
<td>Capacity to process and retain information</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Application skills (incorporating information into lifestyle)</td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>
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
## Types of 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>
Are these skills modifiable through available interventions?

<table>
<thead>
<tr>
<th></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 when to seek health information</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Knowing where to seek health information</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Verbal communication skills</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Assertiveness</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Literacy skills</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Capacity to process and retain information</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Application skills (incorporating information into lifestyle)</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</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
    • General population
    • Those most at risk
    • Those with the capacity to benefit
The way forward…Research and policy priorities

• The 7 health literacy skills
  – To what extent are they 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)
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
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
Acknowledgments

• Funders:
  – National Health and Medical Research Council
  – Commonwealth Department of Health and Ageing
  – Victorian Department of Human Services

• Team
  – Joanne Jordan
  – Rachelle Buchbinder
  – Sandra Nolte
  – Ilana Ackerman
  – Gerald Elsworth
  – Amanda Springer
  – Sabina Cicirello
  – Jenni Livingston
  – Nicola Reavley
  – And many more…
Thank you

Professor Richard Osborne
Deakin University
Australia

richard.osborne@deakin.edu.au
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
Thank you

Professor Richard Osborne
Deakin University
Australia

richard.osborne@deakin.edu.au