**What is an Effective Health Consumer?**

*Defining and measuring the characteristics of effective health consumers among persons with musculoskeletal conditions.*

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**Investigators**

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- **Canada:** Peter Tugwell, Annette Connor, Nancy Santesso, George Wells, Michelle Driedger  
- **Consumers:** Janet Wales (Aus), Annie Qualman (Canada), + Panels  
- **Funding:** Canadian Institutes for Health Research

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**B1. Health Consumer**

- In Australia participation of consumers in health care decision-making is increasingly accepted as a social, legal and political norm.  
- Spectrum of involvement:  
  - Active involvement of patients in clinical decision affecting their care through to consumer councils’ involvement in health service policy and planning.

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**B2. Who are Health Consumers?**

- **Individual**  
  - Individual receiving/received health care services (patients)  
  - Carers/family members who support patients  
  - Groups of consumers sharing a common experience or chronic illness  
  - Consumer organisations including advocacy, self-help and consumer network organisations  
  - Potential consumers such as those with unmet needs or from population groups with particular needs or access issues  
  - Community members (future users and the wider community that benefits from health care services)  
  - Community Taxpayers and citizens who ultimately pay for services

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**B3. Health Consumers**

The focus on a consumer-centred model assumes:  
- that health consumers are more or less able to make appropriate decisions about the types of care, including self-care, they should receive or participate in, and  
- that they are willing to accept responsibility for their own health management.

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**B4. Health Consumers**

Consumers who make informed choices will be:  
- less dissatisfied with care.  
- Achieve better health outcomes for the individual and for the community.  
- Skilling and education of health consumers should result in:  
  - better informed decision making on the part of the individual;  
  - increased compliance with health care decisions;  
  - better resource utilisation;  
  - improved quality of care; safer practice; and  
  - improved community support for evidence based practice.
B5. Health Consumers
- Reflected in
  - NHMRC consumer guides to CPGs
  - Cochrane Collaboration consumer networks
  - Proliferation of terminology of effective health consumers
  - Similar concepts from other researchers:
    - The Expert Patient (NHS)
    - The Informed Patient (Berwick)
    - The Activated Patient (Hibbard)
- Overlap with decision making aids

B6. Attributes of Health Consumers
Literature describes range of attributes include:
- personal assertiveness,
- communication skills,
- the ability to access and critically appraise relevant information from pamphlets, newspapers and the Web;
- ability to identify and ask relevant questions of health professionals;
- ability to make and implement decisions about lifestyle changes;
- ability to participate in shared decision-making about tests and treatment;
- ability to follow medication regimes;
- ability to navigate a complex health care system to obtain the care they need.

B7. Health Consumers and Effectiveness
- What attributes make an individual more or less effective in engaging with the health system for their own and others benefits?
- What factors might be modifiable?

B8. Why musculoskeletal disease?
- High dependency on patient reported health status as measures of health outcomes.
- Well developed collaboration for developing patient based outcome measures (OMERACT).
- Treatment options increasing in complexity and include pharmaceutical, surgical and non-medical therapies.
- Significant scope for self-care

B7: Why musculoskeletal disease?
- 2nd most common cause of presentations to GP.
- 3rd leading cause of health system expenditure
  - (2001-2 estimated total cost > $4.7 billion (9.6% of total allocated health expenditure) cf $5.4 billion for CVD.
- 1993-1994 nearly 300,000 hospital admissions, 15 M medical services and > 13 M prescriptions
- MSD present in >50% of people aged over 65 years
- Osteoarthritis > 5% of years lost due to disability in Australia.
- Most common co-morbidity.
Hypotheses
Consumers, patients and clinicians will identify a consistent set of skills, behaviours, attitudes, and beliefs characteristic of effective health consumers.
These can be measured reliably with an appropriate set of indicators.

Aims
➢ To develop an operational definition of an effective health consumer in terms of skills, behaviours, attitudes and beliefs as perceived by health consumers and clinicians;
➢ To identify and define indicators which can be used to measure those skills, behaviours, attitudes and beliefs;
➢ To promote consensus on those indicators using the OMERACT process.

Methodology
➢ Step 1. Thematic Analysis of Literature
➢ Step 2. Expert Interpretation
➢ Step 3. Indepth Interviews with consumers and clinicians.
➢ Step 4. OMERACT Round 1.
➢ Step 5. Survey of Importance of Attributes
➢ Step 6. Identification or Development of Scales for Final Questionnaire
➢ Step 7. OMERACT Round 2.

Step 1. Thematic Analysis
➢ 1. Personal attributes of the patients/individual differences
➢ 2. Agency/self-management/person-centred idealism
➢ 3. Decision making
➢ 4. Communication Acts by the Patient
➢ 5. Access to Information and Resources
➢ 6. Rights and responsibilities
➢ 7. Relationship between patient and professionals, others, institution and culture
➢ 8. Market metaphor

Step 2: Working Model
Four Domains
D1. Confidence and competence in ability to find and understand options
D2. Ability to clarify personal values
D3. Ability to negotiate chosen roles
D4. Ability to negotiate and achieve preferred option

Step 3. Indepth Interviews
➢ Semi-structured interviews with patients, family members, and clinicians in both Canada and Australia (40 in each).
➢ Initial content analysis resulted in a list of 94 characteristics of an effective health consumer.
➢ Further refined at a meeting of investigators and associated researchers resulting in a working list of 55 characteristics.
Step 4. The OMERACT Process

➢ Consensus-based approach reflecting lack of gold standards against which most patient relevant outcome indicators of MSD can be validated.
➢ Potential indicators are assessed using the OMERACT Filter. To be considered must address:
  • 1. Truth: is the measure truthful, does it measure what it intends to measure? Is the result unbiased and relevant? (Issues of face, content, construct and criterion validity.)
  • 2. Discrimination: does the measure discriminate between situations that are of interest? (Issues of reliability, discriminant validity and sensitivity to change.)
  • 3. Feasibility: Can the measure be applied easily, given constraints of time, money, and interpretability? (Issues of practicality.)

(Boers et al., 1998)

Step 4. OMERACT 1

➢ Pre-meeting email survey of clinicians asking them to rank the characteristics
➢ In meeting discussion by panel of 40 health consumers (multi-country)
➢ In meeting Delphi process of attributes from interviews and from any additions from health consumer panel

Post OMERACT 6 Domains

D1. Seeks, finds and understands health information and adapts to oneself
D2. Clarifies and weighs values, roles, priorities and consequences to make decisions related to health and disease
D3. Communicates needs, concerns, values, decisions and goals related to health and disease

Post OMERACT 6 Domains

D4. Makes and implements decisions and goals related to health and disease
D5. Individual Traits that may affect coping and managing disease
D6. Factors that may affect coping and managing disease

D1a. Seeks, finds and understands health information and adapts to oneself

➢ Wants information
➢ Seeks information (about causes, treatments, side effects of treatments, etc.)
➢ Finds information (knows the sources of information [such as the Internet, health care providers, friends, support groups, etc.] and how to access those sources)
➢ Able to evaluate the quality of the information
➢ Aware of who can evaluate the quality of the information

D1b. Seeks, finds and understands health information and adapts to oneself

➢ Understands the information
➢ Understands that general health information needs to be adapted to own situation
➢ Knows how the disease affects own body
➢ Knows how the disease affects emotions
➢ Knows how the disease affects lifestyle (for example, limitations)
<table>
<thead>
<tr>
<th>D2a. Clarifies and weighs values, roles, priorities and consequences to make decisions related to health and disease</th>
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</thead>
<tbody>
<tr>
<td>➢ Has a sense of personal identity – not just someone with a disease</td>
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<td>➢ Aware that what is ‘normal’ or a ‘normal life’ changes with the effects of the disease</td>
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<tr>
<td>➢ Able to connect with family and friends</td>
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<tr>
<td>➢ Deals with the deformities caused by the disease</td>
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<td>➢ Deals appropriately with the challenges of the invisibility of the disease</td>
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<tr>
<td>➢ Clarifies what is important</td>
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<td>➢ Prioritises what is important</td>
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<table>
<thead>
<tr>
<th>D2b. Clarifies and weighs values, roles, priorities and consequences to make decisions related to health and disease</th>
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<tbody>
<tr>
<td>➢ Able to recognize views of others</td>
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<tr>
<td>➢ Understands the role family and friends can play when making decisions</td>
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<tr>
<td>➢ Understands the role health care providers can play when making decisions</td>
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<tr>
<td>➢ Able to play the role one wants in making a decision</td>
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<tr>
<td>➢ Able to play the role one wants in the health care team</td>
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<tr>
<td>➢ Able to play the role one wants in society</td>
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<tr>
<td>➢ Able to weigh the pros and cons of a decision</td>
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<tr>
<td>➢ Has realistic expectations of the consequences of a decision</td>
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<tr>
<th>D3a. Communicates needs, concerns, values, decisions and goals related to health and disease</th>
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<tr>
<td>➢ Communicates concerns with family and friends</td>
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<tr>
<td>➢ Communicates concerns with health care providers</td>
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<tr>
<td>➢ Listens to family and friends</td>
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<tr>
<td>➢ Listens to health care providers</td>
</tr>
<tr>
<td>➢ Creates an open and trusting relationship based on mutual respect with health care providers</td>
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<tr>
<td>➢ Knows what and how much information one should provide to friends and family about the disease</td>
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<th>D3b. Communicates needs, concerns, values, decisions and goals related to health and disease</th>
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<tr>
<td>➢ Knows what and how much information one should provide to health care providers</td>
</tr>
<tr>
<td>➢ Manages time with health care providers for a productive appointment (for example, preparing before, making a list of questions, prioritizing concerns, etc.)</td>
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<tr>
<td>➢ Able to be assertive to get what is needed to meet health needs (for example, information and treatments)</td>
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<tr>
<td>➢ Able to know who to work with to meet health needs</td>
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<th>D4a. Makes and implements decisions and goals related to health and disease</th>
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<tr>
<td>➢ Aware that one can participate in decision making with health care providers</td>
</tr>
<tr>
<td>➢ Wants to participate in decision making with health care providers</td>
</tr>
<tr>
<td>➢ Feels confident in making decisions about health</td>
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<tr>
<td>➢ Makes decisions about health (for example, about choosing a health care provider or treatments, when to find information, about changing lifestyle, etc.)</td>
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<tr>
<td>➢ Feels a sense of control over the disease</td>
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<tr>
<td>➢ Can take charge of day to day aspects of living with the disease, health decisions, etc.</td>
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<tr>
<td>➢ Aware of what someone is fully entitled to in the health care system (for example, right to information, treatment, time with health care providers, safety, healthy environment, etc.)</td>
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<th>D4b. Makes and implements decisions and goals related to health and disease</th>
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<tbody>
<tr>
<td>➢ Able to set realistic goals about disease management</td>
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<tr>
<td>➢ Able to negotiate with others to implement decisions about disease management</td>
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<tr>
<td>➢ Able to negotiate with health care system to implement decisions about disease management</td>
</tr>
<tr>
<td>➢ Able to organize self to implement decisions</td>
</tr>
<tr>
<td>➢ Able to change lifestyle based on decisions (for example, changing diet, exercise, daily routines, chores, etc.)</td>
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<tr>
<td>➢ Able to recognize and deal with outside influences after making a decision (for example, conflicting advice about treatments, peer pressure to go beyond physical limitations, etc.)</td>
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D5a. Individual Traits that may affect coping and managing disease

- Feels independent
- Tries to achieve well-being with the disease
- Able to use support to help manage the disease
- Able to handle emotions
- Stays positive despite negative aspects of the disease
- Copes with depression that can occur when dealing with the disease
- Has patience
- Is flexible/Adaptable (for example, when making lifestyle changes, when changing treatments, when dealing with physical limitations caused by the disease)

- Has strength and courage
- Is self motivated
- Is determined
- Has self esteem
- Has developed a realistic outlook
- Able to face fears
- Able to mourn losses caused by the disease
- Has a healthy skepticism
- Is resilient or able to bounce back from a setback

D6. Factors that may affect coping and managing disease

- Depression
- Amount of Pain
- Stage of illness
- Age, Gender, Sex (male or female)
- Cultural situation/society beliefs
- Personal beliefs in health
- Physical environment
- Access to health care resources
- Access to support – family, groups, friends, etc.
- Place of residence – urban vs. rural
- Motivation for treatment
- Perception of illness
- Education level
- Financial resources
- Physical ability
- Access to information resources

Next Steps

- Survey of consumers and clinicians ranking attributes
- Review of literature for validated scales for defined attributes
- Development of new scales where no attribute measure is available
- Finalisation of Instrument through OMERACT consumer and clinician groups

Future Research

- To validate the questionnaire for measuring health consumer effectiveness in terms of its repeatability and predictive capacity.
- To identify those attributes or characteristics of an effective health consumer that are most closely associated with better health outcomes and better health care utilisation through a prospective study.
- To identify those attributes and characteristics of an effective health consumer that are most likely to be amenable to modification through educational or other interventions.