Effective Health Consumer

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We’d like to ask your help in establishing [and getting OMERACT approval] for a new scale for use in assessing and improving the ‘effectiveness of a Consumer/Patient’

What sort of things are we thinking of?

Examples from our literature review:

- Find and understand options
  - Search and access information, ask questions, tailor information to self
- Clarify personal values
  - Set priorities, anticipate consequences, communicate
- Negotiate chosen roles
  - Active versus passive, assertiveness, empathy
- Negotiate and achieve preferred options
  - Persistence, lifestyle changes

Why do we need an Outcome Scale for the ‘Effective Consumer’

At long last:

- Patients are being encouraged to participate in the health care system and in their own health care
- There is more emphasis on care that is patient-centred where the patient’s needs and wants are addressed and considered

Creating the New Consumer

- There are programmes and initiatives to empower, educate and provide information to consumers so that they can manage their disease and use health care resources effectively
- The programmes assume that an empowered, educated or ‘effective’ consumer exists

So we need an OMERACT outcome measure to assess these interventions!
BUT.....

- What IS an effective health consumer?
- How would we know if someone was an effective health consumer?
- What skills or characteristics would an effective health consumer have?
- How would we measure whether someone had these skills or characteristics?

Six Phases of the Project

1. Search the literature for definitions of a consumer and discuss with experts
2. Conduct in-depth interviews of stakeholders for their views of an effective consumer
3. Create a list of characteristics of effective consumers and survey stakeholders' views
4. Combine data and analyse measures of an effective consumer for validity, truth and feasibility (OMERACT filter)
5. Develop agreement about characteristics and create research agenda at Consensus Conference
6. Disseminate results

Progress to Date

- Literature search of definitions performed and analysed
- Preliminary definition of effective consumer developed
- In-depth semi-structured interviews conducted and quick analysis done
- Preliminary list of 55 characteristics of an effective consumer created from all of the above analyses

Preliminary List of Characteristics of an Effective Health Consumer

- Combined data from the interviews, literature search and definition to create list
- Over 90 characteristics found but much overlap
- 55 unique characteristics identified
- 12 factors that affect how people cope and manage their disease were identified
- Input from stakeholders now necessary

Themes from interviews

- Information Seeking
- Decision Making Considerations
- Implementing Decisions
- Role Negotiation
- System Negotiation
- Interaction With Social Environment
- Individual Differences

Now we want your help in checking out whether you agree with these items

- Then we want to survey a wide selection of patients, professionals, politicians from all over the world to get their opinions.
- In 2005 June in Ottawa there will be a consensus meeting to see if we can develop a preliminary scale
- Will review status at OMERACT 8 in 2006.
So....
After questions re clarification, it is time to move into small groups.

Tasks for the Small Groups

- **1100-1200** - Breakout into small discussion groups

  A] What characteristics do you think that people with musculoskeletal diseases should have, to handle their disease.

  B] What do you think of the Draft Survey in your package?

Agenda for today

- **1100-1200** - Breakout into small discussion groups

  What characteristics do you think that people with musculoskeletal diseases should have, to handle their disease?

  What do you think of the Draft Survey in your package?

- **1200-1230** - Recongregate and report back highlights from group discussions