

Outcomes of Interest to the Cochrane Consumers & Communication Group

Notes on using the outcomes taxonomy

The taxonomy was developed by the Consumers and Communication Group to help authors identify outcomes of importance to communication interventions.¹ In the past, triallists had evaluated consumer interventions against a fairly narrow range of outcomes. The taxonomy expands the range of outcomes which are potentially relevant to many different review questions.

In identifying outcomes of importance for your review, please use relevant literature and the taxonomy as sources of ideas. However, in line with Cochrane Collaboration advice (see below), your final choice of primary and secondary outcomes is a deliberate process for identifying outcomes tailored to your particular research question.Cochrane reviews should include all outcomes that are likely to be meaningful to clinicians, patients (consumers), the general public, administrators and policy makers, but should not include outcomes reported in included studies if they are meaningless to decision makers (Cochrane Handbook 2012, 5.4.1).

- Authors should keep the total number of outcomes selected for inclusion in the review as small as possible, avoiding trivial outcomes and interim and process outcomes. Large numbers of outcomes, while sometimes necessary, can make reviews unfocussed, unmanageable for the user, and prone to selective outcome reporting bias (Methodological standards for the conduct of Cochrane Intervention Reviews, version 2 (15 Nov 2011) (hereafter 'MECIR'), item 15).
- During the peer review process for their protocol and review, authors may receive suggestions as to additional outcomes; these suggestions need to be considered in the context of the overall advice to focus on a relatively small number of carefully-selected outcomes.
- Using broader outcomes (or outcome categories) that could include a number of different individual outcome measures is one way to limit the total number of outcomes. However, authors should define in advance how outcome measures will be selected where there are several possible measures (eg. Multiple definitions, assessors or scales), and give a rationale (MECIR, item 17) (see Brennan 2009 protocol on continuous quality improvement for an example of how to select one outcome measure from each trial per outcome category, or contact the Consumers & Communication Review Group for advice on different options).
- Authors should define in advance details of what are acceptable outcome measures (eg. Diagnostic criteria, scales, composite outcomes) (MECIR, item 16).
- If authors are including a 'Summary of findings' table, they should choose up to seven main outcomes at the protocol stage. Main outcomes are those that are essential for decision-

¹ Hill S, Lowe D, McKenzie J (2011) Identifying outcomes of importance to communication and participation. In: Hill S (ed), *The Knowledgeable Patient: Communication And Participation in Health*, Wiley Blackwell, UK, pp. 40-53.

making, and should usually have an emphasis on patient-important outcomes (Cochrane Handbook 2012, 5.4a).

- Primary outcomes are the two or three outcomes from among the main outcomes that the review would be likely to be able to address if sufficient studies are identified, in order to reach a conclusion about the effects (beneficial and adverse) of the intervention(s). (Cochrane Handbook 2012, 5.4a).
- Secondary outcomes include the remaining main outcomes (other than primary outcomes) plus additional outcomes useful for explaining effects. (Cochrane Handbook 2012, 5.4a).
- Review authors are encouraged to direct any queries about the use of the taxonomy, and selection of outcomes for their review, to the Group' s Managing Editor in the first instance (<u>m.prictor@latrobe.edu.au</u>)

Consumer Oriented Outcomes:

Knowledge and Understanding

- Information access and use
- Knowledge acquisition (level of knowledge or increase in knowledge about a disease, condition, procedure or treatment)
 - o Knowledge about expected and undesired effects of treatment
 - Knowledge of risk, accurate risk perception
 - o Family members level of knowledge
 - Changes to beliefs about disease, condition, etc
- Retention of information, ability to recall information
 - o Sustaining change to knowledge, beliefs
- Patient satisfaction with the information provided (see Satisfaction)
- Psychological stress due to receiving information (see Psychological health)

Communication

- Communication aides
 - Use of recordings or summaries; internet; voice bulletin boards; computer assisted instruction (CAI)
 - o Perceptions of usefulness
- Communication enhancement
 - o Improved communication with provider
- Communication skills / techniques (see Skills Acquisition)

Patient Involvement in Care Process

- Decision-making
 - Decision-making process
 - Decision-support provided
 - Decisional conflict
 - The decision/s made (eg. types of care plans agreed)
 - Participants' perceptions of who made the decision/s
 - o Satisfaction with the decisions made (see Satisfaction)
 - o Clarity of values

- o Agreement between personal values for outcomes and choice
- o Implementation of preferred choice
- o Adherence to chosen option
- Patient and carer preferences
- o Informed consent
- Advance directives
- Patient-held information
 - o Availability of patient-held records or notes when required

Evaluation of Care

- Consumer-professional interactions experience
 - Perceptions and ratings of care or interventions
 - o Training program assessment
- Satisfaction
 - o Patient satisfaction with the information provided
 - Satisfaction with the decision/s made
 - o Satisfaction with care
 - Carer satisfaction
 - Sense of control

Support

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- Practical support
 - o Provision of or use of technical aids
- Psychosocial support
 - Partner or family support
 - o Peer support
 - o Self-help groups

Skills Acquisition

- Activities of daily living skills
 - Infant care abilities
- Communication skills / techniques
- Self-care skills
- Social skills
- Symptom control skills
 - o Relaxation techniques

Health Status and Wellbeing

- Physical health of patient or carer
 - o Level of activities of daily living
 - o Level of dependency
 - o Self-care abilities, self efficacy
- Psychological health of patient or carer
 - o Level of anxiety, depression, mood, wellbeing
 - o Self-esteem, levels of confidence
 - Perceptions of coping

- Psychological stress due to receiving information
- Psychosocial outcomes
 - Quality of life, life satisfaction
 - Family functioning
 - Social activity
 - Cost of illness (economic, social or psychological cost or personal loss to self, family or immediate community, ie. personal cost)

Health Behavior

- Attitudes
 - Attitude towards the disease, condition, treatment or health care, lay beliefs
- Compliance
 - o Acceptance of health care
 - o Patient compliance (with treatment, medication)
 - o Self care compliance
 - Factors affecting compliance
 - o Intent to change health behavior
- Health enhancing life-style or behaviour outcomes
 - o Diet
 - o Exercise
 - Weight control
 - o Breastfeeding
 - o Self examination
 - Self monitoring eg. blood glucose level
- Risk-taking behaviour
 - o Smoking
 - o Sexual practices
 - o Drug taking
 - o Alcohol consumption
 - Use of interventions or services
 - Use of services (eg. screening or vaccination programs)

Treatment Outcomes

- Adverse outcomes
 - Complications, complication rate
 - Need for medical intervention (eg. Caesarian sections)
 - o Morbidity, mortality
 - o Relapse
 - o Side effects of drugs
- Clinical assessments (eg. Wound healing, symptom resolution)
- Pain assessment or control
 - o Use of medications or other means to reduce pain
- Physiological measures (eg. Blood pressure, cell counts, blood glucose level)

Health Care Provider Oriented Outcomes

Knowledge and Understanding

- Attitudes, behavior of health professionals
 - Towards treatments or interventions (e.g. regarding smoking cessation in pregnancy)
 - o Clinician anxiety
- Level of knowledge or skills
 - Performance of procedures measures (number of attempts, completion, time taken)

Consultation processes

- Practice style
 - o Level of patient-centred care
- Provision of interventions
 - Choices offered
 - Rate of prescribing medications

Health Service Delivery Oriented Outcomes

Service Delivery Level

- Adverse events
 - o Complaints and litigation
 - Reporting of adverse events
- Health economic outcomes
 - o Costs of specific interventions (eg. educational, medical)
 - Costs of care (eg. costs of in-patient care, costs of home-care)
 - Cost of discharge planning (eg. to hospital and community)
- Service utilization
 - o Admission to hospital
 - Usage of specific services (eg. Use of outpatient treatment)
 - o Length of stay in hospital
 - o Readmission rate to hospital

Related to Research

- Involvement in research
- Recruitment and retention to trials
- Feedback from participation in trials

Societal or Governmental

- Health care monitoring
 - o Audit
 - o Accreditation
 - o Quality of care
 - Health care planning

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- Priority setting
- Health care policy or legislation.