



INTRODUCTION and SCOPE

THE COCHRANE COLLABORATION Consumers and Communication Review Group

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This introductory document comprises:

- (1) a summary of the scope of the Group on Consumers and Communication
- (2) a listing of topics and interventions of interest to the Group
- (3) an outline of outcomes of interest to the Group
- (4) a brief description of the Group's specialised register, and information about the type of study design which are included on the register
- (5) a note about the relationships between the Group on Consumers and Communication and other review groups
- (6) a list of personnel and editors, with contact details.

We welcome comments on the scope document, and invite expressions of interest in working with the Group in any way. We can be contacted at our Group editorial base (see last page for details)

(1) Summary

This review group undertakes systematic reviews of the effects of interventions (particularly those which focus on information and communication) which affect consumers' interactions with healthcare professionals, services and researchers.

The interventions may relate to individual use of healthcare services, for example communication between consumers and health professionals during consultations and throughout episodes of care, or to consumer participation in health care planning, policy, and research. Techniques and media for communicating information to consumers are also within the scope of the group. Outcomes of interest include effects on people's knowledge and decision making, healthcare use, experience of health care, and health and wellbeing. We are also interested in healthcare system outcomes.

Reviews that focus on health promotion or therapeutic counselling are not within the scope of this Group.

The term "consumer" is used here to include actual and potential recipients of health care, their families, non-professional carers, and advocates. Various other terms may be used to describe these groups of people. We recognise that no one term is universally preferred.

(2) List of Topics

There are many possible ways of classifying the interventions of interest to this Group. We have organised our list into six sections, according to communication processes: 1) directed to the consumer, 2) from the consumer, 3) between healthcare providers and consumers, 4) between consumers, 5) to healthcare providers from another source, and 6) service delivery interventions.

Within each section, we have listed particular topics. This list is not exhaustive, but is intended to provide a more detailed outline of the Group's scope. It is also used as a

framework for classifying studies on the Group's register. We recognise that some interventions may be used for a variety of purposes, and the outline should not be taken to mean that other purposes or outcomes are not of interest to the Group. Expressions of interest in topics relevant to the Group's scope are welcome, whether or not they are specifically listed below.

The scope of the Consumers and Communication Group includes health promotion in terms of strategies, measures of compliance, and uptake rates for screening programmes.

Topic list

Interventions directed to the consumer (Group 1)

- Counseling
 - Medication or genetic or diet counseling
 - Cognitive behavioural counseling for coping
- Cross-cultural communication
- Health promotion
 - Participation in screening programs
 - [P] [Influence of comprehensive versus partial information on consumers' screening choices](#)
 - Smoking cessation
 - Vaccination programs
 - Heart programs
 - Healthy behaviour change
 - [R] [Interventions implemented through sporting organisations for increasing participation in sport](#)
 - [R] [Policy interventions implemented through sporting organisations for promoting healthy behaviour change](#)
- Information provision
 - About trial participation
 - [R] [Audio-visual presentation of information for informed consent for participation in clinical trials](#)
 - About choices
 - [R] [Information for pregnant women about caesarean birth](#)
 - [R] [Interventions to support the decision-making process for older people facing the possibility of long-term residential care](#)
 - Patient-specific details
 - [R] [Personalised risk communication for informed decision making about taking screening tests](#)
 - About available health services
 - [R] [Provision of a surgeon's performance data for people considering elective surgery](#)
- Genetic risk assessment
 - [R] [Disclosing to parents newborn carrier status identified by routine blood spot screening](#)
- Instruction
 - About treatment
 - About medication
 - [R] [Written information about individual medicines for consumers](#)
 - On discharge
 - [R] [Written and verbal information versus verbal information only for patients being discharged from acute hospital settings to home](#)
 - Prescriptions for screening or exercise
- Marketing/advertising
 - To participate in research
 - Mass media campaigns
- Consumer education
 - About disease/condition
 - [P] [Interventions \(non-pharmacological\) for preparing children and adolescents for hospital care](#)
 - [P] [Interventions for improving understanding and minimising the psychological impact of screening](#)
 - About risk reduction
 - Sex education
- Reminder systems directed to the consumer
 - To attend screening
 - To have vaccination
 - To keep appointments
 - To take medication
 - [R] [Interventions for enhancing medication adherence](#)
 - [R] [Reminder packaging for improving adherence to self-administered long-term medications](#)
- Skills training
 - Information use
 - Relaxation techniques
 - Self-examination methods
 - Communication skills
 - [R] [Interventions before consultations for helping patients address their information needs](#)
 - Self-care skills
- Social support
 - Emotional/psychosocial support
 - Patient advocacy
- Other
 - [P] [Negative versus positive framing of health information](#)
 - [P] [Physical rehabilitation involving goal setting for older people living in the community](#)

- [P] [Using different statistical formats for presenting health information](#)

Interventions from the consumer (Group 2)

- Consumer participation in reviews, committees, policy formulation
 - [P] [Involving service users as researchers for the evaluation of adult statutory mental health services](#)
 - [R] [Methods of consumer involvement in developing healthcare policy and research, clinical practice guidelines and patient information material](#)
- Feedback
 - Consumer reporting of self-monitoring
 - Reporting of consumer preferences
 - Satisfaction with usual care
 - Patient diaries
- History taking or patient profiling
 - Medical history
 - Socio-economic factors
 - Measurement of patient expectations
- Information-seeking initiated by the consumer, or information given by the consumer to the provider
 - During consultations
 - [R] [Interventions for improving older patients' involvement in primary care episodes](#)
 - Surveys of consumers
 - Development or assessment of questionnaires
- Provider education
 - [P] [Involving service users as trainers for professionals working in adult statutory mental health services](#)
- Other
 - Participation in trials

Interventions for communication exchange between providers and consumers (Group 3)

- Discussion (individual, group)
 - [R] [Interventions for improving communication with children and adolescents about a family member's cancer](#)
 - [R] [Interventions for improving communication with children and adolescents about their cancer](#)
- Interview
 - Motivational interview/therapy
 - Consultation process
 - [P] [Educational interventions for improving the communication skills of general practice trainees in the clinical consultation](#)
- Negotiation or decision making
 - Care plans

- Goal setting
- Compliance contracts
 - [R] [Contracts between patients and healthcare practitioners for improving patients' adherence to treatment, prevention and health promotion activities](#)
- Informed consent
- Shared decision making
 - [R] [Decision aids for people facing health treatment or screening decisions](#)
- Patient-held medical record
 - Health card or booklet
 - Information sheet specific to particular patient
 - Recording of consultation
 - [R] [Recordings or summaries of consultations for people with cancer](#)
 - Patient summaries
 - Medication record
- Other
 - [R] [Interventions for improving patients' trust in doctors and groups of doctors](#)

Interventions for communication between consumers (Group 4)

- Focus groups
- Peer support
 - Self-help groups
 - Learning together
 - Sharing experiences
 - [P] [Peer support strategies for improving the health and well-being of individuals with chronic diseases](#)
 - [P] [Peer support telephone call interventions for improving health](#)
 - Group education
 - Group visits
 - Buddy systems
- Individual self-help
 - Individual self-help
 - Lay help
 - [R] [Self-management education programmes by lay leaders for people with chronic conditions](#)
 - Self-management learning by oneself
- Skills training
- Support
 - Family teamwork
 - Presence of family member, carer or other person during education session, or consultation, or treatment, in support of patient
- Other

Interventions for communication to the healthcare provider from another source (Group 5)

- Education programs
 - Skills training in communication or patient-centred care skills
 - [R] [Interventions for providers to promote a patient-centred approach in clinical consultations](#)
- Reminder systems for the clinician
- Other

Service delivery interventions (Group 6)

- Structure and delivery of care
 - Family access to healthcare provider or to hospitalised patient
 - Visiting hours
 - Rooming-in
 - Parent rooms
 - Healthcare provision
 - Specialist nurses or pharmacists providing the intervention
 - Health plan choices
 - Convenience of location of care
 - Appointment choices
 - [P] [Group visits as part of ongoing care for improving health](#)
 - Consumer as healthcare provider
 - [P] [Involving service users as service providers for adult statutory mental health services](#)
 - Treatment or care changes/choices
 - Administration or packaging of medication
 - Extent of physical examination
 - Coordination of care
 - Discharge planning coordination
 - Case management
 - Team care
 - Technology-based interventions
 - Remote consultation by telephone or internet
 - Interactive Health Communication Applications
 - [R] [Interactive Health Communication Applications for people with chronic disease](#)
 - [R] [Interactive computer-based interventions for sexual health promotion](#)
 - Other
 - [R] [Telephone follow-up, initiated by a hospital-based health professional, for postdischarge problems in patients discharged from hospital to home](#)
- Supportive environment
 - Change in context of care
 - Hospital versus home care

- Home visits
- Family care versus professional care
 - [R] [Family-centred care for children in hospital](#)
- Environmental effects
 - Colours
 - Background music
- Imagery
 - Visual or psychological imagery as relaxation technique
 - Guided imagery
- Music
- Virtual reality
- Placebo effect
 - Physical or psychological
 - [R] [Placebo interventions for all clinical conditions](#)
- Other
 - Touch

(3) Outcomes of interest to the Group

A wide range of outcomes will normally be considered in reviews, although some reviews may focus on one specific outcome. Examples of the kinds of outcomes of interest include:

A. CONSUMER ORIENTED OUTCOMES:

i. Knowledge and Understanding

Information access and use

Knowledge acquisition (level of knowledge or increase in knowledge about a disease, condition, procedure or treatment)
Knowledge about expected and undesired effects of treatment
Knowledge of risk, accurate risk perception
Family members level of knowledge
Changes to beliefs about disease, condition, etc

Retention of information, ability to recall information
Sustaining change to knowledge, beliefs

Patient satisfaction with the information provided (see Satisfaction)
Psychological stress due to receiving information (see Psychological health)

ii. Communication

Communication aides

Use of recordings or summaries; internet; voice bulletin boards;
computer assisted instruction (CAI)
Perceptions of usefulness

Communication enhancement

Improved communication with provider

Communication skills / techniques (see Skills Acquisition)

iii. 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
Satisfaction with the decisions made (see Satisfaction)

Clarity of values

Agreement between personal values for outcomes and choice

Implementation of preferred choice

Adherence to chosen option

Patient and carer preferences

Informed consent

Advance directives

Patient-held information

Availability of patient-held records or notes when required

iv. Evaluation of Care

Consumer-professional interactions experience

Perceptions and ratings of care or interventions

Training program assessment

Satisfaction

Patient satisfaction with the information provided

Satisfaction with the decision/s made

Satisfaction with care

Carer satisfaction

Sense of control

v. Support

Practical support

Provision of or use of technical aids

Psychosocial support

Partner or family support

Peer support

Self-help groups

vi. Skills Acquisition

Activities of daily living skills

Infant care abilities

Communication skills / techniques

Self-care skills

Social skills

Symptom control skills

Relaxation techniques

vii. Health Status and Wellbeing

Physical health of patient or carer

Level of activities of daily living
Level of dependency
Self-care abilities, self efficacy

Psychological health of patient or carer

Level of anxiety, depression, mood, wellbeing
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)

viii. Health Behavior

Attitudes

Attitude towards the disease, condition, treatment or health care, lay beliefs

Compliance

Acceptance of health care
Attitudes towards the disease, condition or treatment
Patient compliance (with treatment, medication)
Self care compliance
Factors affecting compliance
Intent to change health behavior
Medical error

Health enhancing life-style or behavior outcomes

Diet
Exercise
Weight control

Breastfeeding
Self examination
Self monitoring eg. blood glucose level

Risk-taking behavior

Smoking
Sexual practices
Drug taking
Alcohol consumption

Use of interventions or services

Use of services (eg. screening or vaccination programs)

ix. Treatment Outcomes

Adverse outcomes

Complications, complication rate
Need for medical intervention (eg. Caesarian sections)
Morbidity, mortality
Relapse
Side effects of drugs

Clinical assessments (eg. Wound healing, symptom resolution)

Pain assessment or control

Use of medications or other means to reduce pain

Physiological measures (eg. Blood pressure, cell counts, blood glucose level)

B. HEALTH CARE PROVIDER ORIENTED OUTCOMES:

i. Knowledge and Understanding

Attitudes, behavior of health professionals

Towards treatments or interventions (eg. regarding smoking cessation in pregnancy)
Clinician anxiety

Level of knowledge or skills

Performance of procedures measures (number of attempts, completion, time taken)

ii. Consultation processes

Practice style

Level of patient-centred care

Provision of interventions

Choices offered
Rate of prescribing medications

C. HEALTH SERVICE DELIVERY ORIENTED OUTCOMES:

i. Service Delivery Level

Adverse events

Complaints and litigation
Reporting of adverse events

Health economic outcomes

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

Admission to hospital
Usage of specific services (eg. Use of outpatient treatment)
Length of stay in hospital
Readmission rate to hospital

ii. Related to Research

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

iii. Societal or Governmental

Health care monitoring

Audit
Accreditation
Quality of care

Health care planning

Priority setting

Health care policy or legislation

(4) Study designs and the Group's specialised Trials Register

The Group's register of studies includes randomised and non-randomised controlled trials. Controlled trials are the study designs that can most reliably evaluate the effects of interventions. The Group therefore encourages reviews in the many areas of our scope for which trial data exist.

Where trial data are either unavailable or of inadequate quality, however, or where other study designs are more appropriate for a particular question, the Group will consider reviews which include other study designs, if a satisfactory search strategy can be undertaken.

In November 2007, our specialised Trials Register had 6566 coded reports of randomised controlled trials (RCTs) and controlled clinical trials (CCTs). All reports are coded to tailor the Register to the needs of our reviewers. The coding provides a more pertinent database as it allows reviewers to retrieve studies that cannot be obtained by using MeSH (Medical Subject Heading) terms alone.

Reports are coded:

- By the Group's scope
- For intervention (eg. consumer education)
- For health condition (eg. person has joint disease) and
- By outcome (eg. knowledge acquisition, compliance, health service utilization)

(5) Overlap with other review groups

Reviews of interventions related to consumers' interactions with health care services may also be undertaken by relevant condition-specific review groups. For example, the Airways Group is undertaking reviews of educational interventions with adults and children with asthma. The Consumers and Communication Group will liaise with the condition-specific review groups and reviewers to ensure that there is no unnecessary duplication of effort and to help ensure that reviewers can benefit from access to a range of relevant

perspectives and skills. The Group will also liaise with other groups and reviewers wherever relevant combination of reviews is considered.

The Consumers and Communication Group shares some common interests with the collaborative review group on Effective Practice and Organisation of Care (EPOC). EPOC focuses on interventions intended to change professional behaviour and improve the delivery of health care. Most, but not all, of these interventions are aimed at health professionals. The two groups have agreed that in the case of interventions which are of interest to both groups, the editors will discuss options such as joint conduct and management of reviews, basing decisions on judgements about how best to ensure that the interests covered by both groups are reflected, and that the resulting reviews are of as high a quality as possible.

The scope of the Consumers and Communication Group does not generally include health promotion interventions which specifically aim to change aspects of people's lifestyle. It is expected that such reviews will generally fall within the scope of specific groups, such as Tobacco Addiction, or groups considering diseases such as cancer and heart disease.

(6) Editorial Team and Contact Details for the Group

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