

## **Systematic review on the provision of information to patients**

### **Review protocol**

#### **Project Team**

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#### **Background**

The provision of information to, and communication with, patients by healthcare professionals is essential to help them understand and actively manage their disease conditions. In May 2007, the Picker Institute carried out a survey in England to identify which aspects of care hospital patients regarded as most important (Boyd, 2007). The results suggested that a truly 'patient-centered' NHS would place a high priority on communication, patient-professional interactions, and treating patients as individuals. Patients and carers need to have a greater involvement in healthcare. A number of approaches have been tried to promote improvements in provision of information to and communication with patients and their carers. The provision of comprehensive information using clear and understandable language is increasingly necessary.

The Health Services Research & Effectiveness Unit has been commissioned by SIGN to systematically examine this topic and produce a concise and comprehensive overview of the research evidence. The purpose of the review will be to determine the current state of evidence on effective approaches for healthcare professionals to provide information to and communicate with patients and where appropriate with their carers. The review will consider the provision of information to and communication about the condition itself, its treatment, management and prognosis. The research synthesis will focus upon five specific long term conditions (Asthma, Cancer, Cardiovascular disease, Chronic Obstructive Pulmonary Disease (COPD) and Diabetes). Such long term conditions have a significant effect on the population in terms of mortality and reduced quality of life. The disease conditions chosen correspond to the key priorities of NHSScotland and NHSQIS. Uncovering social and cultural differences in the manner in which patients wish to receive information will be of particular interest. The report produced will provide a core of evidence which will be useful in the development of all SIGN guidelines and also informative to other parts of NHSQIS that are concerned with the provision of information by healthcare professionals to patients.

For the purpose of this review the following definitions will be used:

- Information: a message which creates awareness, adds and improves knowledge and understanding
- Communication: exchange of information between patients/carers and healthcare professionals by different methods

- Healthcare professionals: any qualified person involved in the delivery of care for people affected by any disease conditions

### **Objective**

The systematic review will address the following research question:

- To determine the most effective methods for patients and carers to receive information on the nature, management, treatment and prognosis of their long term condition from healthcare providers.

This will include consideration of the following areas:

- The most appropriate healthcare professional to provide the information
- Optimal timing for the provision of the information
- Format in which information should be given (written, verbal, face to face communication, video, audio, computer-based etc)
- Level, language and detail of the information provided (quantity and depth but not quality of content will be studied, however consideration will be given to the appropriateness and evidence based nature of the information)

### **Methods**

The aim is to use standard systematic review methodology; however it is possible that this method might not be appropriate to evaluate complex multifaceted interventions. Therefore as part of this work the use of alternative review methodologies may be explored.

### ***Criteria for selecting studies for this review:***

Where appropriate, a hierarchical approach for the selection of literature will be followed as detailed:

- Systematic reviews or meta-analyses of controlled studies
- Randomised or quasi randomised controlled trials (RCTs)
- Controlled trials without randomisation (CTs)
- Experimental studies - controlled before and after studies (CBAs)
- Non experimental studies, such as comparative studies, case series and observational studies
- Expert committee reports or reviews and opinions

However for some aspects of this work, for example the consideration of why interventions work or do not work, qualitative studies are likely to provide the most useful evidence, and the foregoing hierarchy therefore does not apply.

### ***Inclusion criteria***

#### ***Population***

- Patients with a confirmed diagnosis of the following long term conditions: Asthma, Cancer, Cardiovascular Disease, Chronic Pulmonary Obstructive Disease (COPD), Diabetes
- Setting: Hospital, home or community settings
- Patients of 18 years and over, both sexes and all races or ethnic groups
- The carers of patients meeting the foregoing criteria

#### ***Intervention***

- Methods by which health professionals provide information to and communicate with patients and/or their carers

### **Outcomes**

As the scope of the review is broad and the interventions considered will be complex and multifaceted involving a combination of elements, it is expected that the studies identified and included under each specific condition will report a wide range of outcome measures. Both objective and subjective/self-reported outcome measures will be considered. However, preference will be given to the former, and to appropriately validated measures. Selected outcomes will be grouped and reported as clinical, patient/carer related outcomes for each specific condition.

*Examples:*

- *Clinical - disease specific measures, decrease in mortality & morbidity*
- *Patient - satisfaction, understanding, knowledge, experience, behaviour change, compliance, self management of disease, quality of life*
- *Carer - satisfaction, understanding, knowledge, experience*
- *Changes in use of health services - number of unscheduled admissions, contacts with health professionals*

### **Exclusion criteria**

Studies which focus on providing information and communication within the following situations will be excluded:

- Screening
- Complimentary therapies
- Bereavement care
- Spiritual services
- Social support services
- Counselling services
- Psychological support services

Studies where the focus is on highlighting the existence of these services as part of general information provided on the management of the patient's condition will however be considered.

The following study types will also be excluded:

- Studies focussing on content and quality of information
- Studies focussing on structured/tailored/interactive education programmes
- Where there are multiple publications of the same study, publications other than the most recent/informative
- Studies with insufficient information in the text
- Studies published in languages other than English
- Narrative reviews of quantitative data, abstracts, editorials, letters to editors, opinion papers and conference proceedings
- Paediatric studies

Cultural, societal and health system differences will be taken into account, with studies from the UK being selected in preference to those from elsewhere, and studies undertaken in countries very dissimilar to the UK will be excluded.

### **Search strategy for identification of studies**

The search strategy will involve systematically searching electronic databases and relevant patient information websites to identify published literature. The searches will be built based upon the inclusion and exclusion criteria listed earlier. In addition, bibliographies of identified literature will be scanned to identify any additional material. Electronic databases to be searched are included in Table 1.

**Table 1 Electronic databases to be searched**

|   |
|---|
| Medline   |
| Embase  |
| Cochrane Database of Systematic Reviews (CDSR)        |
| Cochrane Central Register of Controlled Trials (CCTR) |
| Web of Science  |
| Database of Abstracts of Reviews of Effects (DARE)    |
| NCCHTA  |
| National Institute of Clinical Excellence (NICE)      |
| HTA Database  |
| TRIP database   |
| UpToDate  |
| Cancerlit   |

***Data collection and analysis***

***Data Extraction***

Data extraction will be carried out on studies which meet the inclusion criteria. The following details will be recorded: author, publication year, country, setting, type of study, objectives, population characteristics, methodology, intervention details, outcome measures and key findings. If available, quantitative data such as meta-analysis will be extracted from systematic reviews. Studies will be appraised and discussed separately by condition.

***Quality assessment and grading of evidence***

Studies will be appraised by one reviewer with ten percent of studies being subject to a quality check by a second reviewer. Any disagreement on an element of a study will be resolved through discussion or through consultation with a third reviewer. Reviewers will not be blinded to any of the publication details. Quality assessment will be undertaken using appropriate critical appraisal tools such as the SIGN methodology checklists.

***Data Synthesis & Statistical analysis***

Synthesising evidence about interventions with multiple elements will pose a methodological challenge in this review. A high degree of heterogeneity between studies, populations, interventions and outcome measures is expected, and as such it is likely to be impossible to conduct any quantitative synthesis for the different conditions. The possibility of conducting any statistical analysis in specific conditions where outcome measures in common are reported, will however be explored. The use of novel approaches to synthesising evidence from complex and multifaceted interventions may also be explored although if it is found that the use of these methods is complex and not possible within the proposed review period, data will be synthesised in a descriptive/narrative way and the novel methods studied as part of a further research project.

## Review Timetable

The key milestones for the project are given in the table below:

|                            |                                |
|----------------------------|--------------------------------|
| Protocol development       | 5 <sup>th</sup> May 2008       |
| Data collection            | 6 <sup>th</sup> June 2008      |
| Draft report publication   | 1 <sup>st</sup> November 2008  |
| Final report publication   | 31 <sup>st</sup> December 2008 |
| Dissemination/ publication | 1 <sup>st</sup> March 2009     |

## Dissemination

The results of the review will be disseminated to the following groups:

Project Team

All NHS QIS

Scottish Government Health Directorate

NHS Boards in Scotland

Directors of planning

UK based patient information groups

Publication in a peer reviewed journal

## References

Boyd J (2007). The 2006 Inpatients Importance Study. Picker Institute.

## Existing Evidence

### References

1. Gysels M; Higginson I.J et al. Guidance on Cancer Services. Improving Supportive and Palliative Care for Adults with Cancer. Research Evidence Manual. National Institute of Clinical Excellence (NICE).

2. Coulter A., Ellins J. Patient-focussed Interventions. A review of the evidence. Quest for Quality and Improved Performance (QUIP). Picker Institute Europe August 2006.

3. L.J Trevena et al. A systematic review on communicating with patients about evidence. Journal of Evaluation in Clinical Practice 2006 12: 13-23.

4. W Anderson. A rapid review of the evidence relating to patient information and communication (DH August 2004) P5.

5. McPherson et al. Effective Methods of Giving Information in Cancer: a Systematic Literature of Randomised Controlled Trials. Journal of Public Health Medicine 2001; 23: 227-34.

6. Scott JT, Entwistle VA, Sowden AJ, Watt I. Recordings or summaries of consultations for people with Cancer (Cochrane Review). The Cochrane Library, Oxford: update software 2001.

7. Stewart MA. Effective physician-patient communication and health outcomes: a review. Canadian Medical Association Journal 1996; 152:1423-33.