

EXECUTIVE SUMMARY

Aims of the report

The aims of the set of reviews included in this report are to identify self-reported health instruments (both generic and disease-specific) for use in asthma, Chronic Obstructive Pulmonary Disease (COPD), diabetes, epilepsy, heart failure and stroke; to assess evidence relating to the development and evaluation of these instruments and make recommendations wherever possible about the most appropriate instruments for use in the NHS in relation to groups rather than individuals (for example, for the purposes of audit, quality assurance, evaluation and research). An additional aim is to carry out two reviews with accompanying recommendations in relation to instruments (i) to assess patients' perceptions of quality of care and (ii) carer impact, both reviews focusing exclusively on long-term conditions.

Introduction (Chapter 1)

The context for the reviews is briefly explained. A range of policy initiatives have resulted in patients and the public being more central to the ways in which services are developed and delivered. One important means of increasing patient and public involvement is through patient-reported health instruments. The proliferation of such instruments requires that complex considerations are involved in the choice of instrument. In particular the evidence for measurement properties and feasibility of use of instruments need to be considered. A set of criteria for assessing evidence regarding instruments is described. It should be pointed out that no advice exists in the literature as to how weigh conflicting and contrasting evidence for different properties of instruments, so some considerable judgment is required in overall assessment of the evidence to determine overall comparative performance of instruments. 'Appropriateness' is one of the key criteria. This criterion has to rely on users' judgements of the degree of fit of the content of an instrument to a specific intended application; something that, a priori, cannot be determined solely by reviewing evidence of formal measurement properties. Users have to judge the degree of fit of the content of an instrument to any specific given application and context. The evidence of this review is intended to support and complement such judgements of appropriateness.

Methods (Chapter 2)

A search strategy was designed to retrieve references relating to the eight reviews included in this report. Where appropriate the strategy was based on searches of a bibliography of over 12,000 records relating to published instrument evaluations developed by the National Centre for Health Outcomes Development (NCHOD) at the University of Oxford and publicly available as the Patient-reported Health Instruments (PHI) website (<http://phi.uhce.ox.ac.uk/>). Additional searching was carried out by hand searching of relevant journals and searches from reference lists of included articles. Included articles were abstracted and assessed according to a standard protocol. A total of 398 studies were included in the review.

Generic instruments (Chapter 3)

To avoid duplication of material across chapters, chapter 3 provides a description of the generic instruments considered in any of the reviews.

Asthma (Chapter 4)

Fifty articles were found that provided useful information on measurement properties for the generic and asthma-specific instruments included in the review. Five generic instruments were identified which were evaluated with patients with asthma: SF-36, SF-12, EuroQol -EQ-5D, Sickness Impact Profile and the Health Utilities Index. Nine asthma-specific instruments were included in the review: The Juniper collection of Asthma Quality of Life Questionnaires: AQLQ, MiniAQLQ, AQLQ(S), Acute AQLQ, ACQ, and the ACD; The Marks Asthma Quality of Life Questionnaire (MAQLQ), Living With Asthma Questionnaire and the St. George's Respiratory Questionnaire.

Recommendations

The SF-36 is recommended as a generic instrument for the broad evaluation of health-related quality of life for people with asthma.

Among asthma-specific instruments, particularly the AQLQ Juniper collection and the MAQLQ are recommended, with different versions of the AQLQ instruments selected for particular purposes.

Chronic obstructive pulmonary disease (Chapter 5)

Forty-six articles provided useful evidence of measurement properties of the instruments included in the review for people with COPD. Seven generic instruments were identified that had been evaluated with people with COPD: SF-36; SF-20; SF-12; EuroQol -EQ-5D; Sickness Impact Profile; Dartmouth COOP and Nottingham Health Profile. Five COPD patient-reported health instruments were included in the review: Breathing Problems Questionnaire, Chronic Respiratory Questionnaire, Functional Performance Inventory, Seattle Obstructive Lung Disease Questionnaire and the St. George's Respiratory Questionnaire.

Recommendations

The SF-36 is recommended as a generic instrument for the broad evaluation of health-related quality of life for people with COPD.

Among COPD-specific instruments, particularly the CRQ and SGRQ are recommended.

Diabetes (Chapter 6)

Ninety-one articles provided useful evidence of the measurement properties of the instruments included in the review. Six generic instruments were identified which were evaluated with patients with diabetes: SF-36; SF-12; Sickness Impact Profile;

Health Utilities Index; Quality of Well-Being Scale and the EuroQol -EQ-5D. Six diabetes-specific instruments were assessed: Appraisal of Diabetes Scale/ADS; Audit of Diabetes-Dependent Quality of Life/ADDQoL; Diabetes 39/D-39; Diabetes Health Profile/DHP; Diabetes Quality of Life Measure/DQOL and the Diabetes Quality of Life Clinical Trial Questionnaire/DQLCTQ.

Recommendations

Of generic instruments, the SF-36 is recommended.

There is insufficient positive evidence strongly to single out any particular disease-specific instrument in diabetes. Of the large number of such instruments, ADQOL, DHP and DQOL may warrant more attention to establish the case for a disease-specific instrument.

Epilepsy (Chapter 7)

Seventy-one articles provided useful evidence of measurement properties of the instruments included in the review. Seven generic instruments were identified which were have been assessed for use with epilepsy: SF-36; SF-12; EuroQol -EQ-5D; Health Utilities Index; Q Twist; Nottingham Health Profile and the Sickness Impact Profile. Eight epilepsy-specific instruments were identified which were evaluated with patients with epilepsy: Epilepsy Surgery Inventory-55; Katz Adjustment Scale; Liverpool Quality of Life (LQOL) Battery and Seizure Severity Scale; Quality of Life in Epilepsy-89 (QOLIE-89); Quality of Life in Epilepsy-31; Quality of Life in Epilepsy-10; Side Effects and Life Satisfaction (SEALS) Inventory; and the Washington Psychosocial Seizure Inventory.

Recommendations

The SF-36 is recommended as a generic instrument for use with patients with epilepsy.

Of epilepsy-specific instruments, the ESI-55 and the QOLIE-89 are recommended although the ESI-55 needs testing to be used outside of the specific surgical context.

Heart failure (Chapter 8)

Eighty-nine articles provided evidence of measurement properties of the instruments included in the review. Four generic instruments were identified which were evaluated with patients with Heart Failure: SF-36; SF-12; Sickness Impact Profile; EuroQol -EQ-5D. Four heart failure-specific instruments were identified which were evaluated with patients with various cardiovascular conditions resulting in heart failure: Chronic Heart Failure Questionnaire; Kansas City Cardiomyopathy Questionnaire; MacNew (ex QLMI – Quality of Life after Myocardial Infarction Questionnaire); and the Minnesota Living with Heart Failure Questionnaire.

Recommendations

This review supports the use of the SF-36 and the SF-12 as generic instruments.

The MLHFQ is recommended as a heart-failure specific instrument. However, some possible remaining problems may exist with wording and content validity due to the narrow focus of the instrument.

Stroke (Chapter 9)

A total of 48 articles provided useful evidence regarding the instruments included in the review. Six generic instruments were identified in the review which had been evaluated with people who have experienced a stroke: SF-36, SF-12, SF-6D, EuroQol- EQ-5D, Health Utilities Index, and the Nottingham Health Profile. Seven stroke-specific instrument were identified which had been evaluated with patients with stroke: Stroke Impact Scale (SIS); Stroke Specific Quality of Life Scale (SS-QOL); Subjective Index of Physical and social Outcomes (SIPSO); Barthel Index; Frenchay Activities Index; Nottingham Extended ADL scale; and the London Handicap Scale.

Recommendations

Overall, the SF-36 is recommended. There is evidence to support the EuroQol EQ-5D as a brief, reasonably well acceptable measure of general health in stroke, although the evidence is more limited.

At the present stage of development no single multi-dimensional health instrument has sufficient information available to justify recommendation. Both the SIS and the SIPSO seem highly promising but further evidence is required for both measures. It seems that, at least for the time being, interview and self completion versions of the Barthel Index, Frenchay Activities Index and Nottingham Extended ADL Scale would appear the most appropriate condition-specific instruments

Carer impact (Chapter 10)

A total of seventy-five articles were included which reported instruments to assess experiences of those who care for individuals with long-term conditions.

Six generic health instruments were included which had been evaluated with carers: SF-36, SF-12, GHQ, Health Utilities Index Mark 2 (HUI2), Reintegration to Normal Living Index and the Ferrans and Power Quality of Life Index. Such measures provide indirect evidence of the experiences of carers by assessing broad aspects of health that may be related to caring.

Seven general carer instruments (providing direct evidence through their focus on questions about the caring experience) have evidence of measurement properties from multiple evaluations with carers: Appraisal of Caregiving Scale (ACS) (2 evaluations), Bakas Caregiver Outcomes Scale (BCOS) (3), Caregiver Burden Inventory (CBI) (3), Caregiving Appraisal Scale (CAS) (2), Caregiving Impact Scale (CIS) (2), CSI (9), Caregiver Well-Being Scale (3) and Zarit Burden Interview (ZBI) (12).

Recommendations

Two generic health status instruments, SF-36 and GHQ, can be used to provide indirect evidence of carer impact. The CSI and ZBI provide more direct evidence of carer impact, with the CSI being somewhat more supported for use in the format of self complete questionnaire.

It is not possible currently to make definite recommendations for instruments to be used to investigate carer impact. Nevertheless the combined use of generic and general carer instruments may be a sensible strategy.

Patient perceptions of quality of healthcare (Chapter 11)

A total of 13 patient-reported measures of health care quality, of relevance to chronic disease were included for more detailed assessment in the review.

Recommendations

No single measure was considered appropriate to recommend. However the following had some desirable features that are described:

- Patient Assessment of Chronic Illness Care (PACIC)
- The Picker Institute questionnaires
- The OutPatient Experience Questionnaire (OPEQ)
- The QUOTE measures
- The Health care System Hassles Questionnaire (HSHQ)
- EORTC IN-PATSAT32. Although specific to the evaluation of health care for in-patients (receiving medical and/or surgical care) with cancer, it is commended for the extensive involvement of patients and health professionals, across a wide range of cultural settings, in item development and subsequent evaluation.

More generally, although no single measure is unambiguously to be recommended, it is clear that there is a growing consensus of topics, domains and methods that should be included in any assessment of the views regarding quality of care of individuals with long-term conditions.