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[Intervention Protocol]

Routine provision of information on patient-reported outcome measures to healthcare providers and patients in clinical practice

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ABSTRACT

This is the protocol for a review and there is no abstract. The objectives are as follows:

To assess the impact of the routine use of patient-reported outcomes (PROs) in clinical practice on the process of care (including patient-physician communication, professionals' awareness of patients' quality of life, diagnosis and recognition rates, treatment rates, health services and resource use, as well as patient behaviour); patients' and professionals' experiences of care; and health outcomes (both generic and disease-specific, using both routinely-used clinical measures and PROs).

Description of the condition

Definition of patient-reported outcome measures

BACKGROUND

Routine provision of information on patient-reported outcome measures to healthcare providers and patients in clinical practice (Protocol)

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Patient-reported outcomes (PROs) measure the patient's subjective appraisal of outcomes from their own perspective (Valderas 2008b). PRO measures offer complementary information to the objective measurements usually collected in clinical practice to support decision making (e.g. blood tests, imaging, functional tests). PROs allow for systematised collection of subjective information on health status and offer an opportunity for improving processes and outcomes of health care. The potential benefits of their use in clinical practice range from screening, diagnosing, and monitoring to promoting patient-centred care (Greenhalgh 2009). Historically, the use of PRO measures has been far less common in clinical practice than in research, where PROs are often selected as outcome measures in clinical trials (Fitzpatrick 1998; FDA 2009). At an individual level and within the clinician-patient interface, PRO measures have been used for screening and monitoring a condition, such as depression symptoms; for monitoring the progress of the patient during the course of treatment or throughout time; and for promoting patient-centred care, by explicitly assessing the patient's perspective (Greenhalgh 2009).

Description of the intervention

PROs have been defined as assessments of any aspect of a patient's health status which are provided directly by the patient (Valderas 2008b; FDA 2009), usually through a questionnaire scale. PRO is an umbrella term: it can be applied to an array of different outcomes, including symptoms, functioning, perceived health status and health-related quality of life (McKenna 2011).

PROs can measure generic aspects of health. One such example is the Short Form 36, which assesses physical functioning and psychological wellbeing, as well as evaluating overall health (Garratt 1993). In theory, such generic measures can be used within and between populations, regardless of their age, gender, and disease or condition. Greater effort, however, has been devoted to the development of PRO measures for specific diseases or conditions (Garratt 2002), from common conditions such as diabetes (Bradley 1999), to less frequent ones, including amyotrophic lateral sclerosis (Gibbons 2011), and haemophilia (Arranz 2004).

The use of PRO measures in clinical practice at a patient level can be defined as a complex intervention, including different components (Craig 2008). In its most basic form, in a typical PRO intervention the patient is given one or more questionnaires to complete, usually about their health status or health-related quality of life, and results are then fed back to the healthcare professional. The International Society for Quality of Life Research recently operationalised all the aspects that should be taken into account when trying to implement PROs in clinical practice, suggesting a set of eight methodological steps to be followed (Snyder 2012). These steps are establishing goals; identifying patients and settings; selecting questionnaires; defining the administration and scoring procedures; reporting results; facilitating score interpretation; establishing protocols to address issues raised by the questionnaires;

and assessing the eventual impact of the questionnaire in clinical practice.

While these standardised steps can be found in almost all interventions using PRO measures, considerable variation exists between trials. For instance, instruments can be self-completed (Rand 1988) or interviewer-administered (German 1987); completed in the clinical setting (Christensen 2005) or posted to the patient's home (Lewis 1996); and supported by an electronic format such as online or tablet administration (Velikova 2004) or rely on pencil and paper (Trowbridge 1997). As for the feedback, discrepancies might exist between trials as to when the information is given to healthcare professionals, e.g. immediately before the visit (Berry 2011); how it is given, e.g. printed form (Saitz 2003); and by whom, e.g. available in the notes (Linn 1980). More importantly, considerable differences occur regarding the amount of feedback provided. For example, in some studies the only information fed back to healthcare professionals were the scores each patient obtained in the PRO measure (Bergus 2005), whereas in other studies professionals were given information on how to apply interpretation guidelines for the scores (Rosenbloom 2007), or treatment guidelines for the conditions detected by the PRO measure (Saitz 2003). The number of times the patient completes the measure and the information is then fed back to the professional can also vary considerably, from single responses (Hoepfer 1984) to multiple feedbacks (Klinkhammer-Schalke 2012). Reflecting this, there is also variation in whether the clinician receives the scores at a single point in time or the patient scores over a period of time. Finally, the endpoints used to assess the impact of PROs in clinical practice have also been a source of considerable discrepancy, with trials inconsistently reporting on processes of healthcare (e.g. patient-clinician communication), outcomes of healthcare (e.g. changes in the number or rate of symptoms or complaints), and patient experience (e.g. overall satisfaction with care).

How the intervention might work

The Feedback Intervention Theory (FIT) relies on the assumption that behaviour is regulated through comparison with standards or goals, and that feedback can draw attention to existing gaps (Kluger 1996). If a patient scores above the established cut-off point in a depression screening scale, then the healthcare professional will be made aware of this discrepancy between the desired state of psychological wellbeing and the current distress experienced by the patient. FIT further postulates that once the gap has been identified, different methods can be followed in order to decrease it and attain the standard, including increasing the effort currently done (Kluger 1996). This could be substantiated by the professional using several strategies, including providing advice, referring to other services, or altering the medication plan. All of these are proximal outcomes that would, potentially, trigger more distal outcomes, such as improved functioning and increased

health-related quality of life. However, whether these outcomes do materialise depends on a range of other contextual factors such as the patient's acceptance of, and adherence to, any treatment changes and the effectiveness of that treatment.

Why it is important to do this review

In the UK, PROs are one of the cornerstones of the current reform of the National Health Service for the transition towards an outcomes-oriented performance model. In the US, initiatives such as the Patient Reported Outcomes Measurement Information System (PROMIS 2007), funded by the National Institutes of Health, or the inclusion of PROs in electronic health record software, such as EpicCare (EpicCare 2015) held by Group Health Cooperative, highlight the progressive relevance these outcome measures play in healthcare contexts. The US Department of Health and Human Services also plans to incorporate PRO into meaningful use standards, which is likely to prompt more widespread use (Hostetter 2011).

The level of evidence for the impact of using PROs in clinical practice has been mixed (Espallargues 2000; Gilbody 2001; Greenhalgh 1999; Marshall 2006; Valderas 2008a). Valderas 2008a found that there was more evidence for impact upon the processes rather than the outcomes of care). Specifically, there was an increase for the rate of diagnoses and chart notations for the conditions targeted by the interventions (e.g. diagnosis of depression in primary care). Similarly, there was also a positive effect on the advice and education provided by the healthcare professionals. Furthermore, Valderas 2008a identified a total of 36 endpoints for the 28 randomised controlled trials (RCTs) included in their systematic review, which seems to reiterate the lack of consensus amongst researchers of how the intervention should work and thus what constitutes a relevant indicator when using PROs in clinical practice.

Notwithstanding the potential benefits for clinical practice, several objections have been raised in relation to their routine use. Healthcare professionals have expressed doubts about the clinical utility of PRO measures, as they consider that little value is added to their clinical judgement (Leydon 2011; Taylor 1996). Healthcare professionals have also described how burdensome the use of PROs can be, as it requires time to administer the measures and time to learn how to analyse and interpret the results (Brown 2006), and also to integrate them into clinical practice in an efficient and non-disruptive manner (Nelson 1990). Clinicians have voiced concerns that the PRO measures might represent a threat to the holistic nature of the patient-doctor relationship (Leydon 2011). It has also been suggested that PRO measures increase the healthcare professional's responsibility and burden of care, as they might detect problems that could otherwise go unnoticed (Tavabie 2009).

Taking both the potential benefits and risks and the current health policy initiatives into account, it becomes essential to ascertain

to what extent the use of PRO measures in clinical practice does actually improve processes and outcomes of care. Previous reviews have provided mixed evidence and a number of relevant studies have been subsequently published (Valderas 2010).

OBJECTIVES

To assess the impact of the routine use of patient-reported outcomes (PROs) in clinical practice on the process of care (including patient-physician communication, professionals' awareness of patients' quality of life, diagnosis and recognition rates, treatment rates, health services and resource use, as well as patient behaviour); patients' and professionals' experiences of care; and health outcomes (both generic and disease-specific, using both routinely-used clinical measures and PROs).

METHODS

Criteria for considering studies for this review

Types of studies

Randomised controlled trials (RCTs) and cluster RCTs, where individuals (healthcare professionals or patients) or groups of individuals (including whole hospitals or practices) were randomly allocated to either a control or an intervention group. We will not include studies that follow a non-randomised controlled design, such as interrupted before-and-after studies and interrupted time series.

Types of participants

We will only include studies where participants have been recruited in primary (e.g. health practitioner's office) or secondary/tertiary (e.g. hospital) care settings in order to ensure that interventions are delivered as part of clinical care. We will exclude studies conducted outside primary and secondary/tertiary healthcare settings (e.g. assisted living facilities) in order to ensure that PRO information is used for clinical purposes only. There will be no age restriction or gender restriction, nor restrictions based on the presence or absence of any specific disease.

Types of interventions

We will include studies if they report a replicable intervention, where standardised or individualised PRO measures are administered to patients and the resulting information on each individual patient is subsequently fed back to healthcare providers or patients, or both. Patient-reported outcome (PRO) measures will be

defined as the assessment of any aspect of a patient's health status which is provided directly by the patient (FDA 2009), usually through a questionnaire or scale. PROs may be used for a number of different outcomes, including measurements of health status, quality of life, symptoms and functioning (McKenna 2011). We will include studies regardless of whether information was provided to patients only or to healthcare providers only or to both. Studies will be included irrespective of whether the results were fed back along with guidelines regarding their optimal use, or other educational strategies. Studies will be included if they have been conducted either during a specific procedure, for instance a surgical procedure; or during routine care, for example a primary-care appointment. The comparison (control) condition will consist of routine clinical practice without the feedback of any information to the healthcare professionals.

Types of outcome measures

Primary outcomes

Our primary outcomes will include generic or disease-specific patient-reported outcomes such as health-related quality of life and functioning.

Secondary outcome measures will be considered for the process of care.

For the processes of health care, the following endpoints will be considered:

- Patient-physician communication (e.g. patients' ratings of the quality of the communication);
- Diagnosis and recognition (e.g. number of target diagnoses made);
- Treatment (e.g. changes to treatment);
- Health services and resource use (e.g. referral to specialist or social care);
- Patient behaviour (e.g. compliance with treatment);
- Patient empowerment (e.g. measured using available self-reported instruments); and
- Healthcare professionals' awareness of patients' quality of life.

Other outcomes: patients' experiences (e.g. overall satisfaction with care) and healthcare professionals' perceptions (e.g. attitude and overall satisfaction with intervention); consultation length; healthcare costs.

Adverse effects: distress following or related to PRO completion.

Search methods for identification of studies

Electronic searches

We will search the following databases: MEDLINE (In-Process & Other Non-Indexed Citations and Ovid MEDLINE(R), 1948 to Present, accessed through OvidSP); EMBASE (1974 to present, accessed through OvidSP); PsycINFO (1967 to present, accessed through OvidSP); and CINAHL (from 1981 to present, accessed through EBSCO). The search strategy will be adapted to the specific requirements of each database, namely through the use of different thesaurus terms where applicable and truncation and wildcard characters. Appendix 1 displays the search strategy for MEDLINE. We will also search the Cochrane Effective Practice and Organisation of Care Group specialised register, and the Cochrane Central Register of Controlled Trials (CENTRAL), the *Cochrane Database of Systematic Reviews* (CDSR), and the Database of Abstracts of Reviews of Effects (DARE). We will not apply language restrictions, but searches will always be conducted in English. Studies in languages other than English will be included.

Searching other resources

Additionally, we will identify on-going trials using the online trials registry of the National Institutes of Health (US) (interventional studies with interventions: "patient reported outcomes" OR "patient reported outcome" OR "quality of life" OR "functional status", and all default settings); and the World Health Organization International Clinical Trials Registry Platform, using the same search criteria. All the documents deemed as relevant, i.e. those that are chosen to be included in the review after full text evaluation, will be subjected to a forward citation search using Web of Science. Previously published reviews will also be screened for potentially-relevant references. We will contact authors of the included studies to request information about on-going studies.

Data collection and analysis

Selection of studies

Two reviewers will independently assess each reference in title and abstract form to ascertain whether they meet the eligibility criteria. We will pilot the eligibility criteria against a random sample of approximately 1% of all the documents received, after which two reviewers will independently screen all of the references. Because we will be aiming for maximum sensitivity at this stage, we will include all references assessed as relevant by at least one team member, and will only exclude references unanimously assessed as irrelevant.

We will follow the same strategy for the full text documents selected for inclusion in the review. Again, we will conduct a sensitivity strategy with a random sample of approximately 1% of the records. As at this stage it is desirable for maximum specificity to be achieved, we will discuss disagreements between the team

members until consensus is reached, and we will only include references rated as relevant by all the reviewers. We will contact a third reviewer if consensus is not achievable. Whenever pertinent and possible, we will contact authors for the documents that received a discrepant rating, in order to clarify any queries. We will document the selection process through a PRISMA flow diagram. We will describe all the studies that fulfil the inclusion criteria in the 'Characteristics of included studies' table.

Data extraction and management

We will independently save all the retrieved results to a bibliographic database using reference management software (Reuters 2011). We will save all the results and remove any duplicates. Two reviewers will independently extract data from the studies assessed as relevant during the stage of study, and we will resolve any disagreements through discussion. We will design the data extraction form according to aspects considered to be relevant for the present systematic review, including those suggested by the Cochrane Effective Practice and Organisation of Care Group (EPOC 2014), and will cover the following domains:

- a) Study features: clinical setting (type of setting, academic status, and country); method of randomisation (including allocation concealment and blinding); unit of randomisation and analysis (patient/healthcare professional or practice/hospital); number of arms;
- b) Participants' features: inclusion and exclusion criteria; patients' characteristics (sociodemographic information using the PROGRESS framework; health condition; and whether new or known to the healthcare professional); healthcare professionals' characteristics (profession; level of training; and previous experiences with PRO measures); number of participants;
- c) Intervention features: design, which may be: Single simple feedback (one PRO at a single time); Multiple simple feedback (one PRO at multiple times); Single complex feedback (multiple PROs at a single time); Multiple complex feedback (multiple PROs at multiple times); and how PROs were used (which may be for the intervention or for assessing outcomes, or both);
- d) Administration features: method for data collection (self-reported; interviewer; other); support used (pencil and paper; computer-assisted; other); setting of data collection (home; clinical; other); facilitator (no facilitator; clinical facilitator; research facilitator; other); other relevant administration-related characteristics;
- e) Feedback: timing (associated with visits or not; scores given before appointments, during or other); amount of information provided (last score; previous scores; application of interpretation guidelines; application of treatment guidelines; other); support used (printed form; computer-assisted; other); method for feeding back the information (handed by patients; handed by research staff; available in notes; other);
- f) Description of the intervention: narrative description as provided by authors;

g) Results: results as provided by authors, both for processes and outcomes of care;

h) Other features: study identifier; source of funding; ethical approval; sample size calculation; prospectively-identified barriers to change; methodological quality.

Complex health interventions might pose specific challenges to assessment (Craig 2008); and data synthesis (Shepperd 2009). Specific recommendations on how to overcome these limitations have now been suggested, including identifying key components of the interventions and categorising them according to those components (Shepperd 2009). When extracting data, we will thus also categorise the identified interventions according to their main components.

Given the likely heterogeneity of outcomes in this review we propose to handle the outcome results in a two-stage approach. In the first stage, we will:

- 1) Collate data according to the headings outlined in the 'Types of outcome measures' section;
- 2) Extract the appropriate data for each arm according to the principle of intention to treat (i.e. according to the original random allocation). For dichotomous data: number of patients experiencing outcome/total patient number. For continuous data: total patient number, outcome mean and standard deviation (SD). We will seek continuous data reported as mean and SD for change in outcome from baseline (adjusted for baseline score); and, where not available, mean absolute outcome and SD at follow up will be recorded. For other outcome types (e.g. event rate, time to event) we will extract data appropriately;
- 3) Extract outcome data for all follow-up points;
- 4) Extract outcome data by subgroups according to the characteristics of the intervention (straight feedback of the results to the healthcare professional; or feedback along with guidelines regarding how to interpret results or other educational strategies); and patient characteristics (educational level). When required and feasible, data will be transformed in order to standardise outcomes, for instance for differences in the direction of the scales.

We will pilot the data extraction form with a small sample of articles finally selected. The sample will be purposively selected to ensure heterogeneity in terms of type of studies and interventions. All researchers will participate in this pilot. It is anticipated that information obtained at the pilot level might inform potential changes to the data extraction form. Extracted data will be stored in an electronic database, which will be created using RevMan 5 (RevMan 2012).

Assessment of risk of bias in included studies

We will assess risk of bias based on the parameters suggested by the Cochrane Collaboration (Higgins 2011), which comprises six domains: sequence generation; allocation concealment; participants' blinding (either patients or healthcare providers); incomplete outcome data; selective reporting; and other sources of bias,

including whether the used PROs have been previously validated for the specific setting and population. Furthermore, we will take into account the complementary risk of bias parameters for RCTs proposed by the Cochrane Effective Practice and Organisation of Care Group, namely the similarity of baseline measurement, both for outcome measures and participants' characteristics, and the protection against contamination (EPOC 2014a). We will classify each parameter as high risk of bias, low risk of bias, or unclear, and obtained information will be summarised in tabulated form, using RevMan 5. We will express level of confidence in the evidence for each outcome using the GRADE criteria, by assessing the type of evidence, limitations in study design, indirectness of evidence, unexplained heterogeneity of findings, imprecision of results, and probability of publication bias in accordance with the guidance of Higgins 2011. We will use the EPOC Worksheets for preparing summary of findings using GRADE (EPOC Worksheets 2013). As a guide, we will judge a study as at high risk of bias if more than three of the nine individual items are considered to be high risk.

Measures of treatment effect

We will calculate risk ratios with 95% confidence intervals (CIs) for dichotomous data. Where studies use continuous scales of measurement to assess the effects of the intervention, mean differences (MD) with 95% CIs will be used; or, when studies use different scales or measurements, we will use the standardised mean difference (SMD). Where studies use other outcome metrics, e.g. rates of events or time to event, we will seek the appropriate overall measure of effect, e.g. rate risk ratio, hazard ratio.

Unit of analysis issues

If any cluster randomised clinical trials are included, we will contact the trial authors to obtain an estimate of the intra-cluster correlation (ICC) where appropriate adjustments for the correlation between participants within clusters have not been made, or impute it using estimates from the other included trials, or from similar external trials. We will inflate the trial standard errors. We will try to either reduce the size of trials to its 'effective sample size' or recalculate the effects using an approximately correct analysis and using design effect calculated from the ICC (Higgins 2011). Whenever studies include more than one intervention arm, we will seek to combine arms to create a single pair-wise comparison or we will conduct pair-wise comparisons by comparing each intervention arm to the control arm (splitting the control arm sample size).

Dealing with missing data

We will attempt to obtain missing data by contacting the authors of the trials. If data remain unavailable (allowing for a maximum

waiting period of one month for a reply), the impact of the missing data will be discussed (see 'Sensitivity analysis' below).

For dichotomous outcomes, we will make analyses according to the intention-to-treat method (Higgins 2011), which includes all participants irrespective of compliance or follow-up. For the primary analyses, we will assume that participants lost to follow up are alive, and have no serious adverse events. For continuous outcomes we will perform available patient analysis and include data only on those for whom results are known (Higgins 2011). If it is not possible to obtain SDs either from authors or by calculation, the missing data will be imputed by using SDs from other included trials, specifically trials with a low risk of bias (Furukawa 2006).

Assessment of heterogeneity

First, we will explore clinical heterogeneity across studies by comparing the population, intervention and control arms. We will then explore statistical heterogeneity observed in the trials both by visual inspection of a forest plot, and by using a standard Chi^2 value with a significance level of $P = 0.10$. We will assess heterogeneity using the I^2 statistic. An I^2 estimate greater than or equal to 50% with a statistically significant value for Chi^2 , will be interpreted as evidence of a substantial problem with heterogeneity (Higgins 2011). If this is the case, we will explore reasons for heterogeneity. If there is high inconsistency, and clear reasons for this are found, we will present data separately.

Data synthesis

We will perform data synthesis according to recommendations in the *Cochrane Handbook for Systematic Reviews of Interventions* (Higgins 2011), using RevMan 5 (RevMan 2012) and STATA v13 (StataCorp 2013). Given the likely heterogeneity of data in this review we propose to handle the outcome results in a two-stage approach. In the first stage, we will: (1) collate data according to the headings outlined in the 'Types of outcome measures' section; (2) according to outcome, extract the appropriate data for each arm according to the principle of intention to treat (i.e. according to the original random allocation). For dichotomous data: number of patients experiencing outcome/total patient number. For continuous data: total patient number, outcome mean and standard deviation (SD). We will seek continuous data reported as mean and SD for change in outcome from baseline (adjusted for baseline score) and where not available, mean absolute outcome and SD at follow up will be recorded. For other outcome types (e.g. event rate, time to event) we will extract data appropriately; (3) we will extract outcome data at all follow-up points; (4) where reported, we will also extract this outcome data by subgroups according to the characteristics of the intervention (straight feedback of the results to the healthcare professional; feedback along with guidelines regarding how to interpret results or other educational strategies) and patient characteristics (educational level).

In the second stage, based on the quality and consistency of outcome reporting, we will decide to synthesise results across studies using either a formal quantitative meta-analytic approach or a more descriptive approach that focuses on summarising the size and direction of treatment effect separately for each individual study. If enough information is provided by the studies included in the review, the potential impact of moderator variables will be considered through meta-regression analysis. When required and feasible, data will be transformed in order to homogenise outcomes, for instance for differences in the direction of the scales. We will employ the I^2 statistic to assess heterogeneity (Higgins 2003). Due to the expected heterogeneity of the data, we will employ random-effects methods (Deeks 2008). We will also perform the meta-analysis using a fixed-effect model and if there are discrepancies between results from the two models, both sets of results will be presented, otherwise we will report the results from the random-effects model only. Further specification of the methods for analysis (e.g. MD versus WMD) will be tailored to the type of outcome data. If the heterogeneity of studies is found to be substantial, i.e. I^2 above 50%, we will not perform a meta-analysis, although we will still quantify the results by calculating effect sizes and will apply a structured synthesis approach (EPOC 2014b).

Subgroup analysis and investigation of heterogeneity

No interactions or effect modifiers are being hypothesised in this review, and therefore we do not pre-specify stratified meta-analysis or meta-regression analyses (with exception of risk of bias - see

'Sensitivity analysis' below). However, where conducted, we will seek to data extract and report trial level subgroup analyses to inform hypothetical models of subgroup analysis for future meta-analyses.

Sensitivity analysis

We will conduct a sensitivity analysis by verifying the impact that the exclusion of certain studies (e.g. those with high overall risk of bias (see definition above), and those with large samples) has on the overall results. Whenever relevant and possible we will contact study authors in order to obtain missing information, allowing for a maximum waiting period of one month for a reply. Where authors fail to provide missing information, existing data will be analysed and the hypothetical impact of the missing data examined as sensitivity analysis. Finally a sensitivity analysis will be undertaken to examine the impact varying the ICC for reanalysis of cluster randomised trials.

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REFERENCES

Additional references

Arranz 2004

Arranz P, Remor E, Quintana M, Villar A, Díaz JL, Moreno M, et al. Hemofilia-QoL Group. Development of a new disease-specific quality-of-life questionnaire to adults living with haemophilia. *Haemophilia* 2004;**10**(4):376–82.

Bergus 2005

Bergus GR, Hartz AJ, Noyes R Jr, Ward MM, James PA, Vaughn T, et al. The limited effect of screening for depressive symptoms with the PHQ-9 in rural family practices. *Journal of Rural Health* 2005;**21**(4):303–9.

Berry 2011

Berry DL, Blumenstein BA, Halpenny B, Wolpin S, Fann JR, Austin-Seymour M, et al. Enhancing patient-provider communication with the electronic self-report assessment for cancer: A randomized trial. *Journal of Clinical Oncology* 2011;**29**(8):1029–35.

Bradley 1999

Bradley C, Todd C, Gorton T, Symonds E, Martin A, Plowright R. The development of an individualized questionnaire measure of perceived impact of diabetes on

quality of life: The ADDQoL. *Quality of Life Research* 1999;**8**(1-2):79–91.

Brown 2006

Brown H, Bacigalupo R. Health visitors and postnatal depression: identification and practice. *Community Practitioner: the Journal of the Community Practitioners' & Health Visitors Association* 2006;**79**(2):49–52.

Christensen 2005

Christensen KS, Toft T, Frostholt L, Ornbøl E, Fink P, Olesen F. Screening for common mental disorders: who will benefit? Results from a randomised clinical trial. *Family Practice* 2005;**22**(4):428–34.

Craig 2008

Craig P, Dieppe P, Macintyre S, Michie S, Nazareth I, Petticrew M. Developing and evaluating complex interventions: the new Medical Research Council guidance. *BMJ* 2008;**337**:a1655.

Deeks 2008

Deeks JJ, Higgins JPT, Altman DG (editors). Chapter 9: Analysing data and undertaking meta-analyses. In: Higgins JPT, Green S (editors). *Cochrane Handbook for Systematic*

- Reviews of Interventions Version 5.1.0 (updated March 2011). The Cochrane Collaboration, 2011. Available from www.cochrane-handbook.org.
- EpicCare 2015 [Computer program]**
Epic. EpicCare EMR. Verona: Epic, 2015.
- EPOC 2014**
Effective Practice, Organisation of Care (EPOC). Good practice data extraction form. EPOC Resources for review authors. Oslo: Norwegian Knowledge Centre for the Health Services; Vol. 2014. Available at: <http://epoc.cochrane.org/epoc-resources> (accessed 14 March 2014).
- EPOC 2014a**
Effective Practice, Organisation of Care (EPOC). Suggested risk of bias criteria for EPOC reviews. EPOC Resources for review authors. Oslo: Norwegian Knowledge Centre for the Health Service; Vol. 2014. Available at: <http://epoc.cochrane.org/epoc-resources> (accessed 14 March 2014).
- EPOC 2014b**
Effective Practice, Organisation of Care (EPOC). Analysis in EPOC reviews. EPOC Resources for review authors. Oslo: Norwegian Knowledge Centre for the Health Services; Vol. 2014. Available at: <http://epocoslo.cochrane.org/epoc-specific-resources-review-authors> (accessed 27 October 2014).
- EPOC Worksheets 2013**
Norwegian Knowledge Centre for the Health Services. Worksheets for preparing Summary of Findings tables using GRADE [Worksheets for preparing Summary of Findings tables using GRADE]. Effective Practice and Organisation of Care (EPOC). EPOC Resources for review authors. 2013.
- Espallargues 2000**
Espallargues M, Valderas JM, Alonso J. Provision of feedback on perceived health status to health care professionals: A systematic review of its impact. *Medical Care* 2000;**38**(2):175–86.
- FDA 2009**
US Department of Health and Human Services Food and Drug Administration. *Guidance for Industry Patient-Reported Outcome Measures: Use in Medical Product Development to Support Labeling Claims*. <http://www.fda.gov/downloads/Drugs/Guidances/UCM193282.pdf>.
- Fitzpatrick 1998**
Fitzpatrick R, Davey C, Buxton MJ, Jones DR. Evaluating patient-based outcome measures for use in clinical trials. *Health Technology Assessment* 1998;**2**(14):i–86.
- Furukawa 2006**
Furukawa TA, Barbui C, Cipriani A, Brambilla P, Watanabe N. Imputing missing standard deviations in meta-analyses can provide accurate results.. *Journal of Clinical Epidemiology* 2006;**51**(1):7–10.
- Garratt 1993**
Garratt AM, Ruta DA, Abdalla MI, Buckingham JK, Russell IT. The SF-36 Health Survey Questionnaire: an outcome measure suitable for routine use within the NHS?. *BMJ* 1993;**306**(6890):1440–4.
- Garratt 2002**
Garratt A, Schmidt L, Mackintosh A, Fitzpatrick R. Quality of life measurement: Bibliographic study of patient assessed health outcome measures. *BMJ* 2002;**324**(7351):1417–19.
- German 1987**
German PS, Shapiro S, Skinner EA, Von Korff M, Klein LE, Turner RW, et al. Detection and management of mental health problems of older patients by primary care providers. *JAMA* 1987;**257**(4):489–93.
- Gibbons 2011**
Gibbons CJ, Mills RJ, Thornton EW, Ealing J, Mitchell JD, Shaw PJ, et al. Development of a patient-reported outcome measure for fatigue in motor neurone disease: the Neurological Fatigue Index (NFI-MND). *Health and Quality of Life Outcomes* 2011;**9**:101.
- Gilbody 2001**
Gilbody SM, House AO, Sheldon TA. Routinely administered questionnaires for depression and anxiety: Systematic review. *BMJ* 2001;**322**(7283):406–9.
- Greenhalgh 1999**
Greenhalgh J, Meadows K. The effectiveness of the use of patient-based measures of health in routine practice in improving the process and outcomes of patient care: A literature review. *Journal of Evaluation in Clinical Practice* 1999;**5**(4):401–16.
- Greenhalgh 2009**
Greenhalgh J. The applications of PROs in clinical practice: What are they, do they work, and why?. *Quality of Life Research* 2009;**18**(1):115–23.
- Higgins 2003**
Higgins JP, Thompson SG, Deeks JJ, Altman DG. Measuring inconsistency in meta-analyses. *BMJ* 2003;**327**(7414):557–60.
- Higgins 2011**
Higgins JPT, Altman DFG, Sterne JAC (editors). Chapter 8: Assessing risk of bias in included studies. In: Higgins JPT, Green S (editors). *Cochrane Handbook for Systematic Reviews of Interventions* Version 5.1.0 (updated March 2011). The Cochrane Collaboration, 2011. Available from www.cochrane-handbook.org.
- Hoepfer 1984**
Hoepfer EW, Nycz GR, Kessler LG, Burke JD Jr, Pierce WE. The usefulness of screening for mental illness. *Lancet* 1984;**1**(8367):33–5.
- Hostetter 2011**
Hostetter M, Klein S. Using Patient-Reported Outcomes to Improve Health Care Quality. The Commonwealth Fund. <http://www.commonwealthfund.org/Newsletters/Quality-Matters/2011/December-January-2012/In-Focus.aspx>.
- Klinkhammer-Schalke 2012**
Klinkhammer-Schalke M, Koller M, Steinger B, Ehret C, Ernst B, Wyatt JC, et al. Regensburg QoL Study Group. Direct improvement of quality of life using a tailored quality

- of life diagnosis and therapy pathway: Randomised trial in 200 women with breast cancer. *British Journal of Cancer* 2012;**106**(5):826–38.
- Kluger 1996**
Kluger AN, DeNisi A. The effects of feedback interventions on performance: A historical review, a meta-analysis, and a preliminary feedback intervention theory. *Psychological Bulletin* 1996;**119**(2):254–84.
- Lewis 1996**
Lewis G, Sharp D, Bartholomew J, Pelosi AJ. Computerized assessment of common mental disorders in primary care: effect on clinical outcome. *Family Practice* 1996;**13**(2): 120–6.
- Leydon 2011**
Leydon GM, Dowrick CF, McBride AS, Burgess HJ, Howe AC, Clarke PD, et al. QOF Depression Study Team. Questionnaire severity measures for depression: a threat to the doctor-patient relationship?. *BJGP* 2011;**61**(583): 117–23.
- Linn 1980**
Linn LS, Yager J. The effect of screening, sensitization, and feedback on notation of depression. *Journal of Medical Education* 1980;**55**(11):942–9.
- Marshall 2006**
Marshall S, Haywood K, Fitzpatrick R. Impact of patient-reported outcome measures on routine practice: a structured review. *Journal of Evaluation in Clinical Practice* 2006;**12**(5):559–68.
- McKenna 2011**
McKenna SP. Measuring patient-reported outcomes: Moving beyond misplaced common sense to hard science. *BMC Medicine* 2011;**9**(86):1–12.
- Nelson 1990**
Nelson EC, Landgraf JM, Hays RD, Wasson JH, Kirk JW. The functional status of patients. How can it be measured in physicians' offices?. *Medical Care* 1990;**28**(12):1111–26.
- PROMIS 2007**
Cella D, Yount S, Rothrock N, Gershon R, Cook K, Reeve B, et al. The Patient-Reported Outcomes Measurement Information System (PROMIS): progress of an NIH Roadmap cooperative group during its first two years. *Medical care* 2007;**45**(5 supply 1):S3.
- Rand 1988**
Rand EH, Badger LW, Coggins DR. Toward a resolution of contradictions. Utility of feedback from the GHQ. *General Hospital Psychiatry* 1988;**10**(3):189–96.
- Reuters 2011 [Computer program]**
Reuters T. Endnote X5. New York, NY: Thompson Reuters, 2011.
- RevMan 2012 [Computer program]**
The Nordic Cochrane Centre, The Cochrane Collaboration. Review Manager (RevMan). Version 5.3. Copenhagen: The Nordic Cochrane Centre, The Cochrane Collaboration, 2014.
- Rosenbloom 2007**
Rosenbloom SK, Victorson DE, Hahn EA, Peterman AH, Cella D. Assessment is not enough: A randomized controlled trial of the effects of HRQL assessment on quality of life and satisfaction in oncology clinical practice. *Psycho-Oncology* 2007;**16**(12):1069–79.
- Saitz 2003**
Saitz R, Horton NJ, Sullivan LM, Moskowitz MA, Samet JH. Addressing alcohol problems in primary care: a cluster randomized, controlled trial of a systems intervention. The screening and intervention in primary care (SIP) study. *Annals of Internal Medicine* 2003;**138**(5):372–82.
- Shepperd 2009**
Shepperd S, Lewin S, Straus S, Clarke M, Eccles MP, Fitzpatrick R, Wong G, Sheikh A. Can we systematically review studies that evaluate complex interventions?. *PLoS Medicine* 2009;**6**(8):e1000086.
- Snyder 2012**
Snyder CF, Aaronson NK, Choucair AK, Elliott TE, Greenhalgh J, Halyard MY, et al. Implementing patient-reported outcomes assessment in clinical practice: A review of the options and considerations. *Quality of Life Research* 2012;**21**(8):1305–14.
- StataCorp 2013 [Computer program]**
StataCorp. Stata Statistical Software. Version Release 13. College Station, TX: StataCorp LP, 2013.
- Tavabie 2009**
Tavabie JA, Tavabie OD. Improving care in depression: qualitative study investigating the effects of using a mental health questionnaire. *Quality in Primary Care* 2009;**17**(4): 251–61.
- Taylor 1996**
Taylor KM, Macdonald KG, Bezjak A, Ng P, DePetrillo AD. Physicians' perspective on quality of life: An exploratory study of oncologists. *Quality of Life Research* 1996;**5**(1): 5–14.
- Trowbridge 1997**
Trowbridge R, Dugan W, Jay SJ, Littrell D, Casebeer LL, Edgerton S, et al. Determining the effectiveness of a clinical-practice intervention in improving the control of pain in outpatients with cancer. *Academic Medicine* 1997;**72**(9):798–800.
- Valderas 2008a**
Valderas JM, Kotzeva A, Espallargues M, Guyatt G, Ferrans CE, Halyard MY, Revicki DA, Symonds T, Parada A, Alonso J. The impact of measuring patient-reported outcomes in clinical practice: A systematic review of the literature. *Quality of Life Research* 2008;**17**(2):179–93.
- Valderas 2008b**
Valderas JM, Alonso J. Patient reported outcome measures: a model-based classification system for research and clinical practice.. *Quality of Life Research* 2008;**17**(9):1125–35.
- Valderas 2010**
Valderas JM, Espallargues M, Kotzeva A, Alonso J. Assessing the impact of routinely measuring patient-

reported outcomes in clinical practice: critical appraisal of 34 randomized clinical trials.. *Quality of Life Research*. London, 2010; Vol. 17(Suppl 1).

Velikova 2004

Velikova G, Booth L, Smith AB, Brown PM, Lynch P, Brown JM, et al. Measuring quality of life in routine oncology practice improves communication and patient well-being: A randomized controlled trial. *Journal of Clinical Oncology* 2004;**22**(4):714–24.

* Indicates the major publication for the study

APPENDICES

Appendix I. MEDLINE search strategy

#1 exp “outcome assessment” (Health Care)/
#2 Outcome? adj2 assessment.tw
#3 patient reported outcome?.tw
#4 outcome? measure?.tw
#5 exp health status/
#6 health status.tw
#7 exp “quality of life”/
#8 quality of life.tw
#9 (QL or QoL or HRQL or HRQoL).tw
#10 (function* adj2 (status or psychological or mental or physical or social)).tw
#11 disabilit*.tw
#12 exp “Activities of Daily Living”/
#13 activities of daily living.tw
#14 (wellbeing or well being).tw
#15 exp happiness/

(Continued)

#16 (happi* or happy).tw

#17 1 or 2 or 3 or 4 or 5 or 6 or 7 or 8 or 9 or 10 or 11 or 12 or 13 or 14 or 15 or 16

#18 (“value in health” or “value health” or “quality of life research” or “qual lif res” or “health & quality of life outcomes” or “health qual lif out”).jn

#19 17 or 18

#20 assessment.tw

#21 index.tw

#22 indices.tw

#23 instrument?.tw

#24 measure?.tw

#25 profile?.tw

#26 rating?.tw

#27 report*.tw

#28 scale?.tw

#29 schedul*.tw

#30 scor*.tw

#31 exp health surveys/

#32 survey?.tw

#33 20 or 21 or 22 or 23 or 24 or 25 or 26 or 27 or 28 or 29 or 30 or 31 or 32

#34 (symptom? adj2 (assessment or index or indices or instrument? or measure? or profile? or rating? or report* or scale? or schedule? or scor* or survey?)).tw

#35 19 or 34

#36 exp Self-Assessment/

#37 self-assess*.tw

#38 exp Questionnaires/

#39 questionnaire?.tw

(Continued)

#40 self report*.tw

#41 36 or 37 or 38 or 39 or 40

#42 (Validation Studies or Comparative Study).pt. or exp psychometrics/ or psychometr*.tw. or clinimetr*.tw. or clinometr*.tw. or exp observer variation/ or observer variation.tw. or exp Health Status Indicators/ or exp reproducibility of results/ or reproducib*.tw. or exp discriminant analysis/ or reliab*.tw. or unreliab*.tw. or valid*.tw. or coefficient.tw. or homogeneity.tw. or homogeneous.tw. or internal consistency.tw. or (cronbach* and (alpha or alphas)).tw. or (item and (correlation* or selection* or reduction*)).tw. or agreement.tw. or precision.tw. or imprecision.tw. or precise values.tw. or test-retest.tw. or (test and retest).tw. or (reliab* and (test or retest)).tw. or stability.tw. or interrater.tw. or inter-rater.tw. or intrarater.tw. or intra-rater.tw. or intertester.tw. or inter-tester.tw. or intratester.tw. or intra-tester.tw. or interobserver.tw. or inter-observer.tw. or intraobserver.tw. or intraobserver.tw. or intertechnician.tw. or inter-technician.tw. or intratechnician.tw. or intra-technician.tw. or interexaminer.tw. or inter-examiner.tw. or intraexaminer.tw. or intra-examiner.tw. or interassay.tw. or inter-assay.tw. or intraassay.tw. or intra-assay.tw. or interindividual.tw. or inter-individual.tw. or intraindividual.tw. or intra-individual.tw. or interparticipant.tw. or inter-participant.tw. or intraparticipant.tw. or intra-participant.tw. or kappa.tw. or kappa's.tw. or kappas.tw. or repeatab*.tw. or ((replicab* or repeated) and (measure or measures or findings or result or results or test or tests)).tw. or concordance.tw. or (intraclass and correlation*).tw. or discriminative.tw. or known group.tw. or factor analysis.tw. or factor analyses.tw. or dimension*.tw. or subscale*.tw. or (multitrait and scaling and (analysis or analyses)).tw. or item discriminant.tw. or interscale correlation*.tw. or error.tw. or errors.tw. or individual variability.tw. or (variability and (analysis or values)).tw. or (uncertainty and (measurement or measuring)).tw. or standard error of measurement.tw. or sensitiv*.tw. or responsive*.tw. or ((minimal or minimally or clinical or clinically) and (important or significant or detectable) and (change or difference)).tw. or (small* and (real or detectable) and (change or difference)).tw. or meaningful change.tw. or ceiling effect.tw. or floor effect.tw. or Item response model.tw. or IRT.tw. or Rasch.tw. or Differential item functioning.tw. or DIF.tw. or computer adaptive testing.tw. or item bank.tw. or cross-cultural equivalence.tw

#43 33 or 41 or 42

#44 35 and 43

#45 (15-dimensional health-related quality of life measure or Affect Balance Scale or APMG-15 or Attitudes Professionnelles des Medecins Generalistes or APPO-09 or Attitudes Professionnelles des Pharmaciens d'Officine or AQoL or Assessment of Quality of Life or ATD-PA or Assistive Technology Device Predisposition Assessment or AUQUEI or Brief Hospice Inventory or CDC HRQOL-14 or (Centers for Disease Control and Prevention Health-Related Quality of Life Measure) or (Child Health and Illness Profile) or Child Health Questionnaire or COOP-C or WONCA or Client Satisfaction Questionnaire or Duke Health Profile or DUSOCS or (Duke Social Support and Stress Scale) or DUSOI or Duke Severity of Illness Checklist or EQ-5D or Euroqol EQ-5D or Family System Test or FKB 20 or BIQ-20 or Fragebogen zum Korperbild or Body Image Questionnaire or Functional Limitations Profile or Functional Status Questionnaire or gars or Groningen Activity Restriction Scale or ghsq or Glasgow Health Status Questionnaires or gqol or Global Quality of Life Scale or Grogono Health Index or halex or (Health and Activity Limitation Index) or Health Assessment Questionnaire or hdlf or (Health and Daily Living Form) or Health Utilities Index or iadl or Instrumental Activities of Daily Living or Illness Behavior Questionnaire or Indice de Resistencia a la Enfermedad or iwls or Impact of Weight Loss Scale or KIDSCREEN or kindl or Revidierter KINDer Lebensqualitatsfragebogen or London Handicap Scale or Modified Barthel Index or mcsi or Multidimensional Caregiver Strain Index or Mental Health Inventory or mhiq or McMaster Health Index Questionnaire or mhlc or Multidimensional Health Locus of Control Scales or Moss Kitchen Assessment Revised or MOS-SSS or MOS Social Support Survey or mtap or Multidimensional Task Ability Profile or Nottingham Health Profile or oars or (Older Americans Resources and Services Multidimensional Functional Assessment Questionnaire) or pedsql or Pediatric Quality of Life Inventory or PGC Morale Scale or Philadelphia Geriatric Center Morale Scale or Patient Generated Index or pgwbi or Psychological General Well-Being Index or piads or Psychosocial Impact of Assistive Device Scale or Quality of Life Profile for the Chronically Ill or Palliative Care Outcome Scale or pqol or Perceived Quality of Life scale or psms or Physical Self-Maintenance Scale or qalys or Quality Adjusted Life Years or ql-index or Spitzer's Quality of Life Index or (Ferrans and Powers Quality of Life Index) or qlq-e or (Quality of Life Questionnaire and evans) or qlsi or Quality of Life Systemic Inventory or qodd or (Quality of Dying and Death) or qoli or Quality of Life Inventory

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or qols or Flanagan's Quality of Life Scale or (Quality of End-of-life care and Satisfaction with Treatment scale) or Quebec User Evaluation of Satisfaction with assistive Technology or Quality of Well Being scale or QWB-SA or Quality of Well-Being scale Self-Administered or sas-sr or Social Adjustment Scale - Self Report or sat-p or Satisfaction profile or Screen for Caregiver Burden or SCSORF or Santa Clara Strength of Religious Faith Questionnaire or seiqol or Schedule for the Evaluation of Individual Quality of Life or sf-12 or sf-12v2 or sf-12 health survey or sf-12v2 health survey or sf-36 or sf-36 health survey or sf-36v2 or sf-36v2 health survey or Sickness Impact Profile or sisc or (Structured Interview for Symptoms and Concerns) or Silver Lining Questionnaire or slqp or Subjective Quality of Life Profile or (sss-30 or sss-15) or Service Satisfaction Scale or stas or Support Team Assessment Schedule or SWED-QUAL or Swedish Health-Related Quality of Life Survey or TAAQOL or TNO-AZL Questionnaire for Adult's Health-related Quality of Life or TACQOL or TNO AZL Children's Quality of Life or TAPQOL or TNO-AZL Preschool children Quality of Life questionnaire or TEAQR or Tableau d'Evaluation Assistee de la Qualite de Vie or TedQL or Quality of Life measure for children aged 3-8 years or TSQM or Treatment Satisfaction Questionnaire for Medication or wanq or Wyke's Assessment of Need Questionnaire or Ways of Coping Questionnaire or WCHMP or (Warwick Child Health and Morbidity Profile) or who-5 or WHO Five Well-Being Index or WHOQOL-100 or WHOQOL-BREF or World Health Organization Quality of Life assessment instrument or Work Limitations Questionnaire or WPAI or (Work Productivity and Activity Impairment Questionnaire) or YQOL or Youth Quality of Life Instrument or ZungSAS or Zung Self-rating Anxiety Scale or (PEDI-MCAT or Pediatric Evaluation of Disability Inventory Multidimensional Computer-Adaptive Testing or Salience of Lifestyle Index or (SLDS or Satisfaction with Life Domains Scale) or (GFRS or Geriatric Functional Rating Scale) or (GQLQ or Geriatric Quality of Life Questionnaire) or (QOLPSV or Quality of Life Profile Seniors- Version) or (MVQOLI or Missoula VITAS Quality of Life index) or (MYMOP or Measure Yourself Medical Outcome Profile) or (PSQL or Profile of the Subjective Quality of Life) or (MPOC or Measure of Processes of Care) or Fatigue Impact Scale or (HCIQ or Health Consequences of Injury Questionnaire) or (MAHSC or Multi-Attribute Health Status Classification) or (RDRS-2 or Rapid Disability Rating Scale 2) or (AM-PAC CAT or Boston University Activity Measure for Post Acute Care) or Aging Males Symptoms Scale or Barthel Index or (Brief IPQ or Brief Illness Perception Questionnaire) or (ComQOL or Comprehensive Quality of Life scale) or Environmental Status Scale or (FEFA or Frail Elderly Functional Assessment questionnaire) or Functional Impairment Scale or Functional Status Index or (GAIS or Global Adjustment to Illness Scale) or (GHRI or General Health Rating Index) or (GQLI or Goteborg Quality of Life Instruments) or (G-QOL or Global Quality Of Life Score) or How Are You? Scale or Health Behavior Scale or (HOOP or Housing Options for Older People) or howRu or Health Practice Index or (HPLP or Health-Promoting Lifestyle Profile) or Health Perceptions Questionnaire or Illness Perception Questionnaire or (IPQ-R or Revised Illness Perception Questionnaire) or Illness Severity score or (LASA-HD or (Linear Analogue Self-Assessment - Holmes and Dickerson)) or (LASA-PB or (Linear Analogue Self-Assessment - Priestman and Baum)) or Linear Analogue Self-Assessment or (MQLQ or Multilingual Quality of Life Questionnaire) or (MQOL or McGill Quality of Life questionnaire) or (PEDI or Pediatric Evaluation of Disability Inventory) or (PEPS or Patient Evaluated Problem Score) or (PSDI or Physical Symptoms Distress Index) or (QLPI or Quality of Life Profile Inventory) or (QLRS or Quality of Life Rating Scale) or (QOL-Q or Qualite de la Vie Questionnaire) or (R36IHS or Rand 36-Item Health Survey) or Rehabilitation Activities Profile or Reintegration to Normal Living or (SBQOL or Smithkline Beecham Quality of Life scale) or (SF-20 or MOS Short Form) or (SIP-HMS or Sickness Impact Profile - Home Management Scale) or (SIQR or Symptom Impact Questionnaire) or (SQLI or Sendera Quality of Life Index) or (Selby's QL Uniscale or Selby's quality of life uniscale) or Treatment Response Scale or Visual Analogue Scale or Visual Analogue Thermometer or (VSQOL or Vital Signs Quality of Life Questionnaire) or World Health Organization Symptom Checklist or (WI HSS QOL or Wisconsin HSS Quality of Life Inventory) or (MRFA or Medical Rehabilitation Follow Along) or Satisfaction with Illness scale) or (ONYCHO or Onychomycosis Quality of Life questionnaire or Cardiac Depression Scale or Cardiac Health Profile or dasi or Duke Activity Status Index or milq or Multidimensional Index of Life Quality or PACT-Q or Perception of Anticoagulant Treatment Questionnaire or APQLQ or Angina Pectoris Quality of Life Questionnaire or MacNew or MacNew Heart Disease Health-related Quality of Life Questionnaire or Seattle Angina Questionnaire or Chronic Heart Failure Questionnaire or kccq or Kansas City Cardiomyopathy Questionnaire or mlhf or Minnesota Living with Heart Failure Questionnaire or Quality of Life at the End of Life Measure or qual-e or Cambridge Pulmonary Hypertension Outcome Review or chal or Quality of Life Questionnaire for Arterial hypertension or hyper 31 or Hypertension Health Status Inventory or minichal or Short form of Quality of Life Questionnaire for Arterial hypertension or MacNew Heart Disease Health-related Quality of Life Questionnaire or Myocardial Infarction Dimensional Assessment Scale or ql-sp or Quality of Life Questionnaire for Cardiac Spouses or Assessment of Quality of Life in lower limb arteriopathy or clau-s or Claudication Scale or Edinburgh Claudication Questionnaire or Peripheral Artery Questionnaire or Walking Impairment Questionnaire or pact-q or Perception of Anticoagulant Treatment Questionnaire or Canadian Neurological Scale or mrs-si or Structured Interview for

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the Modified Rankin Scale or NEWSQOL or Newcastle Stroke-specific Quality of Life measure or nihss or National Institutes of Health Stroke Scale or SAQOL-39 or (Stroke and Aphasia Quality of Life Scale) or Stroke Impact Scale & Stroke Toolbox or ss-qol or Stroke-Specific Quality Of Life measure or Stroke-Specific Quality Of Life or avvq or Aberdeen Varicose Veins Questionnaire or VEINES QOL Sym or (VENous INSufficiency Epidemiological and Economic Study) or PACT-Q or (Health Complaints Scale or (HHAQ or Heart Health Assessment Questionnaire) or (HPPQ or Heart Patients Psychological Questionnaire) or (HRQOL-Hy or Health-related Quality of Life questionnaire for hypertensive patients) or (HTSC or Heart Transplant Symptom Checklist) or (JQLIS or Jachuck's Quality of Life Impairment Scale) or (MCLQ or Milwaukee Cardiovascular Life Quality questionnaire) or (MPFH or Medical-Psychological Questionnaire for Heart Patients) or (NYHA-FCS or New York Heart Association Functional Classification Scale) or (PHTQ or Perception of Heart Transplantation Questionnaire) or (PSOCS or (Processes, Structures, and Outcomes of Cardiac Surgery)) or (QLIHD or Quality of Life Ischemic Heart Disease) or (QLIS-H or Quality of Life Impairment Scale Hypertension) or Quality of Life Impairment Scale - Hypertension or Rose Cardiovascular Questionnaire or (SSAP or Subjective Symptoms Assessment Profile) or (UBQ-H or Utility Based Quality of life - Heart questionnaire) or Frenchay Activities Index or (R-ADL or Rivermead ADL Scale) or (SA-SIP30 or Stroke Adapted 30-item SIP version))) or (MPQOL or Miami Pediatric Quality of Life Questionnaire Parent Scale or Oxford Hip Score or Cystic Fibrosis Questionnaire or PIQoL-AD or Parents' Index of Quality of Life in Atopic Dermatitis or QoLIAD or Quality of Life Index for Atopic Dermatitis or Isia or Life Satisfaction Index for Adolescents or A36 Hemophilia-QoL or Hemophilia-specific health-related quality of life questionnaire or QUAL HEMO or Haemophilia age group-specific Quality of life questionnaire) or (dhsi or Digestive Health Status Instrument or GIQLI or Gastrointestinal Quality of Life index or Celiac Disease Questionnaire or Cystic Fibrosis Questionnaire or GSRS or Gastrointestinal Symptom Rating Scale or QLI-CP or Quality of Life Index for Colostomy Patients or FIQL or Fecal Incontinence Quality of Life scale or fisi or Fecal Incontinence Severity Index or ndb score or Neurogenic Bowel Dysfunction score or dsiq or (Digestive Symptoms and Impact Questionnaire) or GERD-HRQL or Gastroesophageal Reflux Disease Health Related Quality of Life scale or GSAS or Gastroesophageal Reflux Disease Symptom Assessment Scale or gsfq or GERD Symptom Frequency Questionnaire or GSRS-self or Gastrointestinal Symptom Rating Scale self-administered version or HBQOL or Heartburn-Specific Quality of Life Instrument or ndi ndi-sf or Nepean Dyspepsia Index or PAGI-QOL or Patient Assessment of Upper Gastrointestinal Disorders-Quality of Life or PAGI-SYM or Patient Assessment of Gastrointestinal Disorders Symptom Severity Index or QOLRAD or (Quality Of Life in Reflux and Dyspepsia) or Reflux-Qual or Quality of Life Questionnaire in Gastroesophageal Reflux or GCSI or Gastroparesis Cardinal Symptom Index or PAGI-QOL or Patient Assessment of Upper Gastrointestinal Disorders-Quality of Life or PAGI-SYM or Patient Assessment of Gastrointestinal Disorders Symptom Severity Index or GSRS-self or Gastrointestinal Symptom Rating Scale self-administered version or IBDQ or Inflammatory Bowel Disease Questionnaire or IBDQOL or Inflammatory Bowel Disease Quality of Life Questionnaire or IMPACT III or RFIPC or Rating Form of IBD Patient Concerns or FDDQL or Quality of Life Questionnaire for Functional Digestive Disorders or GSRS or IBS-36 or IBS-QOL or Irritable Bowel Syndrome - Quality Of Life or CLDQ or Chronic Liver Disease Questionnaire or (GRDS or Gastroesophageal Reflux Data Sheet or Harvey-Bradshaw Index or (HRQOL-GERD or Health-related Quality of Life questionnaire for individuals with gastroesophageal reflux disease) or (IBDSI or Inflammatory Bowel Disease Stress Index) or (McMaster IBDQ or McMaster Inflammatory bowel disease questionnaire) or (WISP or Well-being Index for Surgical Patients) or (QLDUP or Quality of Life in Duodenal Ulcer Patients))) or (MCAS or Modified Caregiver Appraisal Scale or BCTSQ or (Brigham and Women's Hospital Carpal Tunnel Syndrome Questionnaire) or Boston Carpal Tunnel Syndrome Questionnaire or OFDQ or Osteoporosis Functional Disability Questionnaire or PRWE or Patient-Rated Wrist Evaluation or NBD score or Neurogenic Bowel Dysfunction score or Qual-OT or Quality of Life in Occupational Therapy or QUALIVEEN or AWQV2 or Amphetamine Withdrawal Questionnaire Version 2 or CMDQ or Common Mental Disorder Questionnaire or Smoker Anchored Withdrawal Grid or Smoker Complaint Scale or STAR-SMOQ55 or Situation X Trait Adaptive Response Smoking Motivation questionnaire or TLFB or Timeline Followback Method) or (ICD-QOL or Implantable Cardioverter Defibrillator Quality of Life Questionnaire or AcroQoL or Acromegaly Quality of Life questionnaire or ADDQoL or Audit of Diabetes Dependent QoL or D-FISQ or (Diabetes Fear of Injecting and Self-testing Questionnaire) or das-3 or Diabetes Attitude Scale or Diabetes Care Profile or dcsq or Diabetes Clinic Satisfaction Questionnaire or Diabetes Empowerment Scale or dfbs or Diabetes Family Behavior Scale or Diabetic Foot Ulcer Scale or DHP-1 or DHP-18 or Diabetes Health Profile or DiabMedSat or Diabetes Medication Satisfaction or DIMS or Diabetes Impact Measurement Scales or Diabetes Knowledge Questionnaire or Diabetes Knowledge Test or Diabetes Mellitus History or Diabetes Productivity Measure or DQLCTQ or Diabetes Quality of Life Clinical Trial Questionnaire or dqol or Diabetes Quality of Life measure or dqoly or Diabetes Quality of Life for Youth scale or dsc-r or Diabetes Symptom Checklist-Revised or Diabetes Symptom Measure or (DSMP or DSMP-F) or Diabetes Self-Management Profile or DSQOLS or Diabetes specific quality of life scale or DTSQ-for-FIT20 Status or DTSQ-

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for-FIT20 Change or Functional Insulin Treatment Satisfaction Questionnaire or dtsq or dtsqs or dtsqc or Diabetes Treatment Satisfaction Questionnaire or Hypoglycemia Fear Survey or Impact of Child Illness scale or itsq or Insulin Treatment Satisfaction Questionnaire or Multidimensional Diabetes Questionnaire or mnsi or Michigan Neuropathy Screening Instrument or Norfolk QOL-DN or Norfolk Quality of Life Questionnaire - Diabetic Neuropathy or Problem Areas in Diabetes scale or PedsQL Diabetes Module or Pediatric Quality of Life Inventory Diabetes Module or psit or Patient Satisfaction with Insulin Therapy questionnaire or Studying the Hurdles of Insulin Prescription or w-bq or Well-Being Questionnaire or we-care or (Well-being and Satisfaction of CAREgivers of Children with Diabetes Questionnaire) or go-qol or Graves' Ophthalmopathy Quality of Life Questionnaire or EORTC QLQ-OV28 or (European Organization for Research and Treatment of Cancer Quality of Life Questionnaire - Ovarian Cancer Module) or QLQ-OV28 or (PMDI or Personal Models of Diabetes Interview or (QoL-AGHDA or Quality-of-life measure in growth hormone-deficient adults)) or (avft or Arabic Visual Function Test or covd or College of Optometrists in Vision Development Quality of Life Outcomes Assessment or Impact of Vision Impairment or LVQOL or Low Vision Quality-of-Life Questionnaire or NEI-VFQ25 or National Eye Institute Visual Function Questionnaire-25 or Objectif Douleur En Ophtalmologie et Neuro-ophtalmologie or osdi or Ocular Surface Disease Index or Ocular Surface Disease Questionnaire or QOLVFQ or (Quality of Life and Vision Function Questionnaire) or vf-14 or Visual Function Index or ideel or Impact of Dry Eye on Everyday Life or comtol or Comparison of Ophthalmic Medications for Tolerability Questionnaire or glauqol or Glaucoma Quality of Life Questionnaire or go-qol or Graves' Ophthalmopathy Quality of Life Questionnaire or NEI-RQL-42 or National Eye Institute - Refractive Error Quality of Life Instrument - 42 or Refractive Error Quality of Life Instrument or (Refractive Status and Vision Profile) or (Glaucoma Symptom Scale or Measure of outcome in ocular disease or (VCM1 or Vision Core Measurement))) or (Cardiff Breast Scales or NEMOQC or New Mother Quality of Care questionnaire or ORTHO BC-SAT or ORTHO Birth Control Satisfaction Assessment Tool or EHP-30 or Endometriosis Health Profile-30 or BISF-W or Brief Index of Sexual Functioning for Women or CSFQ or Changes in Sexual Functioning Questionnaire or DISF or Derogatis Interview for Sexual Functioning or DSFI or Derogatis Sexual Functioning Inventory or FSAQ or Fallowfield's Sexual Activity Questionnaire or FSFI or Female Sexual Function Index or Index of Sexual Life or MFSQ or McCoy Female Sexuality Questionnaire or Personal Experiences Questionnaire or SPFS or Self-Perception of Female Sexuality or WSFQ or Watts Sexual Function Questionnaire or UFS-QOL or (Uterine Fibroid Symptom and Quality of Life questionnaire) or HOIQ or Herpes Outbreak Impact Questionnaire or Herpes Symptom Checklist or RGHQoL or Recurrent Genital Herpes Quality of Life Questionnaire or UFS-QOL or (Uterine Fibroid Symptom and Quality of Life questionnaire) or MENQOL or Menopause-specific Quality of Life Questionnaire or Menopause Representations Questionnaire or Menopause Rating Scale or UQOL or Utian Quality of Life scale or Women's Health Questionnaire or Menorrhagia Outcomes Questionnaire or Menstrual Distress Questionnaire or EORTC QLQ-OV28 or QLQ-OV28 or (European Organization for Research and Treatment of Cancer Quality of Life Questionnaire - Ovarian Cancer Module) or EORTC QLQ-CX24 or QLQ-CX24 or (European Organization for Research and Treatment of Cancer Quality of Life Questionnaire - Cervical Cancer Module) or (QOL-SPE or Quality-Of-Life instrument for Symptomatic Patients with Endometriosis or (HRQOL-E or Health-related Quality of Life instrument for symptomatic patients with endometriosis) or Index of Sexual Function or (U-IIQ or Urge-Incontinence Impact Questionnaire) or (UIWQ or Urinary Incontinent Women Questionnaire) or (U-UDI or Urge-Urinary Distress Inventory) or Urogenital Distress Inventory or Genital Herpes Measure)) or (MPQOL or Miami Pediatric Quality of Life Questionnaire Parent Scale or A36 Hemophilia-QoL or Hemophilia-specific health-related quality of life questionnaire or QUAL HEMO or Haemophilia age group-specific Quality of life questionnaire or qol-e) or (AIMS2 or Arthritis Impact Measurement Scales or ASQoL or Ankylosing Spondylitis Quality of Life Questionnaire or BASDAI or Bath Ankylosing Spondylitis Disease Activity Index or BASFI or Bath Ankylosing Spondylitis Functional Index or CHAQ or Childhood Health Assessment Questionnaire or Foot Function Index or JAQQ or Juvenile Arthritis Quality of Life Questionnaire or MACTAR or McMaster Toronto Arthritis Patient Preference Disability Questionnaire or Oxford Elbow Score or Oxford Hip Score or Oxford Shoulder Score or PSAQoL or Psoriatic Arthritis Quality of Life Instrument or QOL-RA or Quality of Life-Rheumatoid Arthritis Scale or RAQoL or Rheumatoid Arthritis Quality of Life Questionnaire or Attitudes to Asthma Questionnaire or Adolescent Asthma Quality of Life Questionnaire or AAQOL or Asthma Bother Profile or Asthma Control Diary or Asthma Control Questionnaire or acss or Asthma Control Scoring System or Asthma Control Test or About My Asthma or aq30 or aq20 or Airways Questionnaire or aqlq or Asthma Quality of Life Questionnaire or AQLQ-M or (Asthma Quality of Life Questionnaire and Marks) or AQLQ-NAA or Asthma Quality of Life Questionnaire for Native American Adults or Asthma Symptom Checklist or Asthma Self-Efficacy Scale or asui or Asthma Symptom Utility Index or Bronchial Hyperresponsiveness Questionnaire or caqs or Childhood Asthma Questionnaires or Childhood Asthma Questionnaire or Inhaled Corticosteroid Questionnaire or KASE-AQ or (Knowledge, Attitude and Self-efficacy Asthma Questionnaire) or LWAQ or Living with Asthma Questionnaire or MiniAQLQ or Mini Asthma Quality

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of Life Questionnaire or PACQLQ or Paediatric Asthma Caregiver's Quality of Life Questionnaire or PAQLQ or Paediatric Asthma Quality of Life Questionnaire or QLQ-Asthma or Questionnaire for the Assessment of Quality of Life in Asthma Patients or SGRQ or St George's Respiratory Questionnaire or PIQoL-AD or Parents' Index of Quality of Life in Atopic Dermatitis or QoLIAD or Quality of Life Index for Atopic Dermatitis or GO-QOL or Graves' Ophthalmopathy Quality of Life Questionnaire or AIDS-HAQ or AIDS Health Assessment Questionnaire or HAT-QoL or HIV Symptom Index or HIV-SQUAD or Symptom Quality of Life Adherence or HIV Overview of Problems - Evaluation System or MOS-HIV or Medical Outcome Study-HIV Health Survey or MPQOL or Miami Pediatric Quality of Life Questionnaire Parent Scale or MQOL-HIV or Multidimensional Quality of Life questionnaire for HIV AIDS or Multidimensional Quality of Life questionnaire for HIV or SLEQoL or Systemic Lupus Erythematosus Quality of Life Questionnaire or EDSS or Expanded Disability Status Scale or HAQUAMS or Hamburg Quality of Life Questionnaire Multiple Sclerosis or MSIS-29 or Multiple Sclerosis Impact Scale or MSQLI or Multiple Sclerosis Quality of Life Inventory or MSQOL-54 or Multiple Sclerosis Quality of Life-54 or MSWS-12 or Multiple Sclerosis Walking Scale or PS-MS or Performance Scales for Multiple Sclerosis or Qual-OT or Quality of Life in Occupational Therapy or SI-MS or Symptom Inventory for Multiple Sclerosis or Myasthenia Gravis Questionnaire or (SLDI or Systemic Lupus International Coordinating Committee or (SLDI and American College of Rheumatology) or (SLICC ACR or damage Index) or (SLEDAI or Systemic Lupus Erythematosus Disease Activity Index) or Rheumatology Attitudes Index or (MHAQ or Modified Health Assessment Questionnaire) or (MSOK or Patient-based Measure of the Severity of Osteoarthritis of the Knee) or (SAJC or Self-Administered Joint Count) or (THAOEQ or Total Hip Arthroplasty Outcome Evaluation Questionnaire) or (PPDQ or Patient Preference Disability Questionnaire) or (ACAAI-LQ or American College of Allergy, Asthma & Immunology - Life Quality) or (Acute AQLQ or Acute Asthma Quality of Life Questionnaire) or Life Activity questionnaire for Childhood Asthma or (LAQ-AA or Life Activities Questionnaire for Adult Asthma) or (LAQ-CA or Life Activities Questionnaire for Childhood Asthma) or LIFE-Aor Life Activities Questionnaire for Adult Asthma or LIFE-Cor Life Activities Questionnaire for Childhood Asthma or (PCAQ or Perceived Control of Asthma Questionnaire) or Tasmanian Asthma survey or HIV Assessment Tool or (HIV-QL31 or HIV-Quality of Life - 31 items) or (Symptom Distress Module or HIV Symptom Index) or Keitel Functional Assessment or Simple Shoulder Test)) or (BPHII or Benign Prostatic Hyperplasia Impact Index or DAN-PSS-1 or Danish Prostatic Symptom Score or I-PSS or International Prostate Symptom Score or ICSmale or ICSQoL or International Continence Society-Benign Prostatic Hyperplasia or Symptom Problem Index or UROLIFE or BPHQoL9 or Benign Prostatic Hypertrophy Health-Related Quality of Life Questionnaire or NIH-CPSI or National Institute of Health Chronic Prostatitis Symptom Index or BSFQ or Brief Sexual Function Questionnaire or CSMH-SFQ or (Center for Marital and Sexual Health Sexual Functioning Questionnaire) or Erectile Dysfunction Inventory of Treatment Satisfaction or FSHQ or Florida Sexual History Questionnaire or iief or iief-5 or International Index of Erectile Function or Index of Sexual Life or mshq or Male Sexual Health Questionnaire or (Self-Esteem and Relationship Questionnaire) or Sexual Function Index or slqq or Sexual Life Quality Questionnaire or Expanded Prostate Cancer Index Composite or PC-QoL or Prostate Cancer Quality of Life scale or PROSQOLI or Prostate Cancer Specific Quality of Life Instrument or QOLM-P14 or Quality of Life Module Prostate 14 or UCLA-PCI or UCLA Prostate Cancer Index or UCLA-PCI-SF or UCLA Prostate Cancer Index Short Form or HOIQ or Herpes Outbreak Impact Questionnaire or Herpes Symptom Checklist or RGHQoL or Recurrent Genital Herpes Quality of Life Questionnaire or CSFQ or Changes in Sexual Functioning Questionnaire or DISF or Derogatis Interview for Sexual Functioning or DSFI or Derogatis Sexual Functioning Inventory or FSHQ or Florida Sexual History Questionnaire or WSFQ or Watts Sexual Function Questionnaire or (Index of Sexual Function or (RSSF or Radiumhemmetts Scale of Sexual Functioning) or Urogenital Distress Inventory or Prostate Outcomes Questionnaire or (PORPUS or Patient-oriented prostate utility scale) or Genital Herpes Measure or (MMAP or Maine Medical Assessment Program symptom index))) or (FIM instrument or pasi or Patient-Specific Index or SAT-16 or WeeFIM or WeeFIM instrument or worc or Western Ontario Rotator Cuff index or wosi or Western Ontario Shoulder Instability Index or 10-item Implantable Cardioverter Defibrillator Quality of Life Questionnaire or AcroQoL or Acromegaly Quality of Life questionnaire or Oxford Hip Score or AIMS2 or Arthritis Impact Measurement Scales or ASQoL or Ankylosing Spondylitis Quality of Life Questionnaire or BASDAI or Bath Ankylosing Spondylitis Disease Activity Index or BASFI or Bath Ankylosing Spondylitis Functional Index or CHAQ or Childhood Health Assessment Questionnaire or Foot Function Index or JAQQ or Juvenile Arthritis Quality of Life Questionnaire or MACTAR or McMaster Toronto Arthritis Patient Preference Disability Questionnaire or Oxford Elbow Score or Oxford Hip Score or Oxford Shoulder Score or PSAQoL or Psoriatic Arthritis Quality of Life Instrument or QOL-RA or Quality of Life-Rheumatoid Arthritis Scale or RAQoL or Rheumatoid Arthritis Quality of Life Questionnaire or lsa or Life Satisfaction Index for Adolescents or Fibromyalgia Impact Questionnaire or fiqr or Revised Fibromyalgia Impact Questionnaire or Fibromyalgia Rapid Screening Tool or mapt or (Hip and Knee Questionnaire) or INQoL or Individualized Neuromuscular Quality of Life Questionnaire or Foot Function Index or Patient-

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Specific Index or SAT-16 or OsteoARthritis Treatment Satisfaction Questionnaire or auscan or Australian Canadian Osteoarthritis Hand Index or koos or (Knee Injury and Osteoarthritis Outcome Score) or womac or (Western Ontario and McMaster Universities Arthritis Index) or woos or Western Ontario Osteoarthritis of the Shoulder index or ecos-16 or Short Osteoporosis Quality of Life Questionnaire or ofdq or Osteoporosis Functional Disability Questionnaire or opaQ or Osteoporosis Assessment Questionnaire or OPTQoL or Osteoporosis Targeted Quality of Life Questionnaire or Qualeffo-41 or (International Osteoporosis Foundation and Quality of Life questionnaire) or qualios or QUALity of Life questionnaire In OSTeoporosis or Brace Questionnaire or (Keitel Functional Assessment or Simple Shoulder Test or Rheumatology Attitudes Index or (SPADI or (Shoulder Pain and Disability Index)) or Osteoarthritis Pain Assessment or (MHAQ or Modified Health Assessment Questionnaire) or (MSOK or Patient-based Measure of the Severity of Osteoarthritis of the Knee) or (SAJC or Self-Administered Joint Count) or (THAOEQ or Total Hip Arthroplasty Outcome Evaluation Questionnaire) or (MRFA or Medical Rehabilitation Follow Along) or (PPDQ or Patient Preference Disability Questionnaire) or (Disabilities of the Arm, Shoulder, and Hand questionnaire) or Musculoskeletal Function Assessment instrument or (OQLQ or Osteoporosis Quality of Life questionnaire) or Harris Hip Score)) or (aqel or Assessment of Quality of life at the End of Life or artq or Attitudes to Randomised Clinical Trials Questionnaire or Brief Fatigue Inventory or Body Image Scale or Brief Pain Diary for ambulatory patients with advanced cancer or Care Notebook or Cancer Rehabilitation Evaluation System or casc or Comprehensive Assessment of Satisfaction with Care or cpns or Cancer Patient Need Survey or CQOLC or Caregiver Quality of Life Index-Cancer or crfds or Cancer-Related Fatigue Distress Scale or ctsq or Cancer Therapy Satisfaction Questionnaire or Eastern Cooperative Oncology Group performance status scale or ECOG Performance Status or EORTC QLQ-C30 or QLQ-C30 or (European Organization for Research and Treatment of Cancer Quality of Life Questionnaire - Core Questionnaire) or ESAS-r or Edmonton Symptom Assessment System Revised or FACIT or Functional Assessment of Chronic Illness Therapy Measurement System or FLIC or Functional Living Index Cancer or flie or Functional Living Index - Emesis or givio or Interdisciplinary Group for Cancer Care Evaluation questionnaire or glq-8 or hqli or Hospice Quality of Life Index or Illness Distress Scale or Karnofsky Performance Status or lasa-s or Linear Analogue Self-Assessment-Selby or Mental Adjustment to Cancer Scale or mane or (Morrow Assessment of Nausea and Emesis) or mdasi or MD Anderson Symptom Inventory or mmql or Minneapolis-Manchester Quality of Life instrument or mpac or Memorial Pain Assessment Card or MPQOL or Miami Pediatric Quality of Life Questionnaire Parent Scale or msas or Memorial Symptom Assessment Scale or NA-ACP or Needs Assessment for Advanced Cancer Patients or Needs Evaluation Questionnaire or Needs at the End-of-Life Screening Tool or (Osoba Nausea and Vomiting Module) or Palliative Care Assessment or pacis or Perceived Adjustment to Chronic Illness Scale or Psychological Distress Inventory or PedsQL Cancer Module or Pediatric Quality of Life Inventory Cancer Module or pnat or Patient Needs Assessment Tool or QOL-CA or Quality of Life Cancer Scale or QOL-RTI or Quality of Life Radiation Therapy Instrument or qq-q or Quality-Quantity questionnaire or qual-e or Quality of Life at the End of Life Measure or rscl or Rotterdam Symptom Checklist or SCFS-6 or Schwartz Cancer Fatigue Scale or Subjective Chemotherapy Impact scale or scns or Structural-Functional Social Support Scale or Therapy Impact Questionnaire or Breast Cancer Chemotherapy Questionnaire or IBCSG-QLC or International Breast Cancer Study Group - Quality of Life Core Form or REPERES-60 or Subjective Health Estimations or gsrS or Gastrointestinal Symptom Rating Scale or QLI-CP or Quality of Life Index for Colostomy Patients or UFS-QOL or (Uterine Fibroid Symptom and Quality of Life questionnaire) or Expanded Prostate Cancer Index Composite or PC-QoL or Prostate Cancer Quality of Life scale or PROSQOLI or Prostate Cancer Specific Quality of Life Instrument or QOLM-P14 or Quality of Life Module - Prostate 14 or UCLA-PCI or UCLA Prostate Cancer Index or UCLA-PCI-SF or UCLA Prostate Cancer Index Short Form or EORTC QLQ-H&N35 or QLQ-H&N35 or (European Organization for Research and Treatment of Cancer Quality of life - Head and Neck Cancer Module) or HNQOL or (Head and Neck Quality of Life instrument) or LORQv3 or Liverpool Oral Rehabilitation Questionnaire or LPSQ or Liverpool-PEG-Specific Questionnaire or ndii or Neck Dissection Impairment Index or UW-QOL or University of Washington Quality of Life Instruments or Xerostomia-specific Questionnaire or EORTC QLQ-LC13 or QLQ-LC13 or (European Organization for Research and Treatment of Cancer Quality of Life Questionnaire - Lung Cancer Module) or lcss or Lung Cancer Symptom Scale or Norfolk QOL-NET or Norfolk Quality of Life - Neuroendocrine Tumor Questionnaire or Neuroendocrine Tumor Questionnaire or EORTC QLQ-OV28 or QLQ-OV28 or (European Organization for Research and Treatment of Cancer Quality of Life Questionnaire - Ovarian Cancer Module) or EORTC QLQ-CX24 or QLQ-CX24 or (European Organization for Research and Treatment of Cancer Quality of Life Questionnaire - Cervical Cancer Module) or (Edmonton Staging System or (PMH PSQ-MD or Princess Margaret Hospital Patient Satisfaction with Doctor Questionnaire) or (PPSC or Play-Performance Scale for Children) or Comprehensive questionnaire for assessing cancer patients' Perception of the Quality of Care or (RDCQ or Reaction to the Diagnosis of Cancer Questionnaire) or Family Pain Questionnaire or (S-PEC or St Gallen Pain Evolution Chart) or (RSSF or Radiumhemmet's Scale of Sexual Functioning) or (EFAT or

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Edmonton Functional Assessment Tool) or ((EORTC QLQ-BR23 or European Organization for Research and Treatment of Cancer Quality of Life Questionnaire - Breast Cancer Module) or QLQ-BR23 or (HNRQ or (Head and Neck Radiotherapy Questionnaire)) or (HRCA-QL or Hebrew Rehabilitation Centre for the Aged Quality of Life) or Life Ingredient Profile or (OTTAT or Oncology Treatment Toxicity Assessment Tool) or Psychological Distress Inventory or (PEDQOL or Self-rating QoL questionnaire for children or Self-rating quality of life questionnaire for children) or (PSHN or (Performance Status scale for Head and Neck cancer patients)) or Psychosocial Summary Scale or (PSS-HN or (Performance Status Scale for Head and Neck)) or (QDDC or Qualitator Daily Diary Card) or (QLILC or Quality of Life Inoperable Lung Cancer questionnaire) or (QLI-P or Quality of Life Index Padilla) or (Quality of Life Index and Padilla) or (QLI-RT or Quality of Life Index-Radiation Therapy) or (QLQ-C30 or Quality of Life Questionnaire Core 30 Items) or (QOL-ACD or Quality of Life questionnaire for cancer patients treated with Anticancer Drugs) or (QOL-CS or Quality of Life-Cancer Survivors) or (RMH-PO or Royal Marsden Hospital Paediatric Oncology quality of life questionnaire) or (SBI-15R or Systems of Belief Inventory) or Surviving Cancer Profile or (SELT or Skalen zur Erfassung von Lebensqualität bei Tumorkranken) or (SICPA or Stanford Inventory of Cancer Patient Adjustment) or (SOGQLQ or Southwest Oncology Group Quality of Life Questionnaire) or University of Liverpool Questionnaire or (WICQP or (Wright Impact of Cancer Questionnaire and Parents)) or Food Frequency Questionnaire or (MCPQ or Mayo Clinic Postlaryngectomy Questionnaire))) or (Brunnstrom Recovery Scale for Hemiplegic Voluntary Control or bupp or Burke Perceptual Profile or ccse or Cognitive Capacity Screening Examination or mmse or Mini Mental State Examination or QUALIVEEN-30 or QUALIVEEN or sat-16 or SF-QUALIVEEN or QUALIVEEN Short Form or ICD-QOL or Implantable Cardioverter Defibrillator Quality of Life Questionnaire or AcroQoL or Acromegaly Quality of Life questionnaire or AAIQOL or (Activity and Affect Indicators of QOL) or ACQLI or Alzheimer's Carer's Quality of Life Instrument or ADCPQ or Alzheimer's Disease Caregiver Preference Questionnaire or ADRQL or Alzheimer's Disease-Related Quality of Life or Apathy Inventory or Clinical Dementia Rating or cerad or Consortium to Establish a Registry for Alzheimer's Disease Neuropsychological Assessment Battery or Disability Assessment for Dementia or DMS48 or MM-CGI or Marwit Meuser Caregiver Grief Inventory or Neuropsychological Test Battery or QOL-AD or Quality of Life in Alzheimer's Disease or QUALID or Quality of Life in Late-Stage Dementia Scale or ALSAQ or Amyotrophic Lateral Sclerosis Assessment Scales or Oxford Knee Score or SAQOL-39 or (Stroke and Aphasia Quality of Life Scale) or Aberdeen Back Pain Scale or abps or ofdq or Oswestry Disability Index or Osteoporosis Functional Disability Questionnaire or Psychosocial Functioning Questionnaire for Patients with Low Back Pain or rmdq or Roland-Morris Disability Questionnaire or mcas or Modified Caregiver Appraisal Scale or BCTSQ or (Brigham and Women's Hospital Carpal Tunnel Syndrome Questionnaire) or adas-cog or Alzheimer's Disease Assessment Scale, Cognitive part or Cornell-Brown Scale for Quality of Life in Dementia or d-qol or Dementia Quality of Life Instrument or DEMQOL or Measurement of health-related quality of life for people with dementia or Memory Impairment Screen or Neuropsychiatric Inventory or QOLAS or Quality of Life Assessment Schedule or Zarit Burden Interview or Isia or Life Satisfaction Index for Adolescents or CDIP-58 or Cervical Dystonia Impact Profile or esi-55 or Epilepsy Surgery Inventory or Glasgow Epilepsy Outcome Scale or Impact of Child Illness scale or (Katz Adjustment Scale and Epilepsy) or lsss or Liverpool Seizure Severity Scale or newqol or Quality of Life in Newly Diagnosed Epilepsy measure or Quality of Life in Newly Diagnosed Epilepsy or qolas or Quality of Life Assessment Schedule or QOLCE or Quality of Life in Childhood Epilepsy Questionnaire or QOLIE-10 or Quality of Life in Epilepsy Inventory-10 or QOLIE-31 or Quality of Life in Epilepsy Inventory-31 or QOLIE-89 or Quality of Life in Epilepsy Inventory-89 or QOLIE-AD-48 or Quality of Life in Epilepsy Inventory-Adolescents-48 or Fibromyalgia Impact Questionnaire or fiqr or Revised Fibromyalgia Impact Questionnaire or Fibromyalgia Rapid Screening Tool or Frontal Assessment Battery or GHABP or Glasgow Hearing Aid Benefit Profile or hana or Headache Needs Assessment questionnaire or Migraine Disability Assessment or MSQ Version 2 1 or Migraine-Specific Quality-of-Life Questionnaire or MSQoL or Migraine-Specific Quality-of-Life Questionnaire or ulfi or Upper Limb Functional Index or edss or Expanded Disability Status Scale or HAQUAMS or Hamburg Quality of Life Questionnaire Multiple Sclerosis or MSIS-29 or Multiple Sclerosis Impact Scale or MSQLI or Multiple Sclerosis Quality of Life Inventory or MSQOL-54 or Multiple Sclerosis Quality of Life-54 or MSWS-12 or Multiple Sclerosis Walking Scale or PS-MS or Performance Scales for Multiple Sclerosis or Qual-OT or Quality of Life in Occupational Therapy or SI-MS or Symptom Inventory for Multiple Sclerosis or INQoL or Individualized Neuromuscular Quality of Life Questionnaire or Myasthenia Gravis Questionnaire or Neck Disability Index or Norfolk QOL-NET or Norfolk Quality of Life - Neuroendocrine Tumor Questionnaire or abps or Aberdeen Back Pain Scale or Brief Pain Inventory or Neuropathic Pain 4 Questions or Integrated Pain Score or lanns or (Leeds Assessment of Neuropathic Symptoms and Signs Pain Scale) or mpac or Memorial Pain Assessment Card or McGill Pain Questionnaire or Neuropathic Pain Scale or npsi or Neuropathic Pain Symptom Inventory or ofdq or Osteoporosis Functional Disability Questionnaire or pqas or Pain Quality Assessment Scale or pqas-r or Revised Pain Quality Assessment Scale or seq pain or Standard Evaluation Questionnaire on

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Pain or SF-MPQ-2 or Short-form McGill Pain Questionnaire or sopa or Survey of Pain Attitudes or Treatment Outcomes in Pain Survey or WHYMPI or West Haven - Yale Multidimensional Pain Inventory or Wong-Baker FACES or Wong-Baker FACES Pain Rating Scale or PDQ-39 or Parkinson's Disease Questionnaire or PDQL or Parkinson's Disease Quality of Life Questionnaire or PDQUALIF or Parkinson's Disease Quality of Life Scale or PDSS-2 or Parkinson's Disease Sleep Scale 2 or Parkinson's Impact Scale or (pims and parkinson) or SCOPA-COG or SCOPA-SLEEP or Scales for Outcomes in Parkinson's Disease or (Schwab and England Activities of Daily Living scale) or asrs or Augmentation Severity Rating Scale or irls or International Restless Legs Syndrome Study Group Rating Scale or P-RLS-SS or Pediatric Restless Legs Syndrome Severity Scale or RLS-QoL or Restless Legs Quality of Life Scale or Hopkins RLS QoL or Hopkins RLS Quality of Life Scale or Epworth Sleepiness Scale or fosq or Functional Outcomes of Sleep Questionnaire or jseq or Jenkins Sleep Evaluation Questionnaire or lseq or Leeds Sleep Evaluation Questionnaire or psqi or Pittsburgh Sleep Quality Index or saqli or Sleep Apnea Quality of Life Index or Neurogenic Bowel Dysfunction score or Qual-OT or Quality of Life in Occupational Therapy or QUALIVEEN or Canadian Neurological Scale or mrs-si or Structured Interview for the Modified Rankin Scale or NEWSQOL or Newcastle Stroke-specific Quality of Life measure or nihss or National Institutes of Health Stroke Scale or SAQOL-39 or (Stroke and Aphasia Quality of Life Scale) or Stroke Impact Scale & Stroke Toolbox or ss-qol or Stroke-Specific Quality Of Life measure or Dizziness Handicap Inventory or UCLA-DQ or UCLA Dizziness Questionnaire or Vertigo Handicap Questionnaire or Vertigo Symptom Scale or Voice Handicap Index or (Frenchay Activities Index or (R-ADL or Rivermead ADL Scale) or (SA-SIP30 or Stroke Adapted 30-item SIP version) or (OSAPOS or Obstructive Sleep Apnea Patient-Oriented Severity Index) or Glasgow Outcome Scale or Glasgow-Pittsburgh Scale or Minor Symptom Evaluation or Dallas Pain Questionnaire or Heat Beam Dolorimeter or (HHPPAI or Home Hospice Patient Pain Assessment Instrument) or (IPAT or Initial Pain Assessment Tool) or (ISCRG or Illness Self Concept Repertory Grid) or (LBPRS or Low Back Pain Rating Scale) or (MMPAP or Multiperspective Multidimensional Pain Assessment Protocol) or Pain Assessment questionnaire or Pain Assessment Index or (PATC or Pain Assessment Tool for Children) or Pain Catastrophizing Scale or Pain Disability index or (PDS-2 or Pain Distress Scales) or (PD-SLBP or Pain Drawing in Subacute Low Back Pain) or Pain-O-Meter or (PPAT or Pediatric Pain Assessment Tool) or (QBPS or Quebec Back Pain Scale) or Rivermead Post-traumatic Amnesia Protocol or Rivermead Post-concussion symptoms Questionnaire or (SPE-PC or Subjective Pain Evaluation - Pre-school Children) or SPE-PC or Global Deterioration or Progressive Deterioration Scale or Disability Rating scale or (FGSCI or Frankel Grade for Spinal Cord Injury) or Glasgow Coma Scale or Hunt-Hess Classification of SAH or Headache Impact Test or ((HRQOL-CE or Health-related Quality of Life) and specifically for children with epilepsy) or (HRQOL-MS or Health-related Quality of Life questionnaire for patients with multiple sclerosis) or Minimal Record of Disability or MS Self-Efficacy Scale or Perceived Handicap Questionnaire or (QLPSD or Quality of Life Profile for Spine Deformities) or Rankin Scale or (Side Effects and Life Satisfaction) or (SI-PS-MS or Symptom Inventory & Performance Scale measures for Multiple Sclerosis) or (UPDRS or Unified Parkinson's Disease Rating Scale Awakenings) or (WPSI or Washington Psychosocial Seizure Inventory) or (RDSQ or Rivermead Disability Status Questionnaire) or (SPADI or (Shoulder Pain and Disability Index)) or Osteoarthritis Pain Assessment or Family Pain Questionnaire or (S-PEC or St Gallen Pain Evolution Chart) or Modified Post-Sleep Inventory or Sleep Dysfunction scale or Numerical Rating Scale or (QLH-Y or Quality of Life Headache in Youth) or (MBPC or (Memory and Behavior Problems Checklist)) or Mental Status Questionnaire or (PMSQ or Short Portable Mental Status Questionnaire) or (SCAG or Sandoz Clinical Assessment Geriatric) or Subjective Stress scale or Rheumatology Attitudes Index)) or (Oxford Hip Score or Celiac Disease Questionnaire or ADDQoL or Audit of Diabetes Dependent QoL or Appraisal of Diabetes Scale or D-FISQ or (Diabetes Fear of Injecting and Self-testing Questionnaire) or das-3 or Diabetes Attitude Scale or Diabetes Care Profile or Diabetes Clinic Satisfaction Questionnaire or Diabetes Empowerment Scale or dfbs or Diabetes Family Behavior Scale or Diabetic Foot Ulcer Scale or DHP-1 or DHP-18 or Diabetes Health Profile or DiabMedSat or Diabetes Medication Satisfaction or dims or Diabetes Impact Measurement Scales or Diabetes Knowledge Questionnaire or Diabetes Knowledge Test or Diabetes Mellitus History or Diabetes Productivity Measure or DQLCTQ or Diabetes Quality of Life Clinical Trial Questionnaire or dqol or Diabetes Quality of Life measure or dqoly or Diabetes Quality of Life for Youth scale or dsc-r or Diabetes Symptom Measure or (DSMP or DSMP-F) or Diabetes Self-Management Profile or DSQOLS or Diabetes specific quality of life scale or DTSQ-for-FIT20 Change or DTSQ-for-FIT20 Status or dtsq or Functional Insulin Treatment Satisfaction Questionnaire or dtsqs or dtsqc or Diabetes Treatment Satisfaction Questionnaire or Hypoglycemia Fear Survey or Impact of Child Illness scale or itsq or Insulin Treatment Satisfaction Questionnaire or Multidimensional Diabetes Questionnaire or mnsi or Michigan Neuropathy Screening Instrument or Norfolk QOL-DN or Norfolk Quality of Life Questionnaire - Diabetic Neuropathy or Problem Areas in Diabetes scale or PedsQL Diabetes Module or Pediatric Quality of Life Inventory Diabetes Module or psit or Patient Satisfaction with Insulin Therapy questionnaire or Studying the Hurdles of Insulin Prescription or w-bq or Well-Being Questionnaire or we-care or (Well-being and Satisfaction

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of CAREgivers of Children with Diabetes Questionnaire) or debq or Dutch Eating Behavior Questionnaire or IWQOL-Kids or Impact of Weight on Quality of Life - Kids or IWQOL-Lite or Impact of Weight on Quality of Life - Lite or OWLQOL or (Obesity and Weight-Loss Quality of Life measure) or WRSM or Weight-Related Symptom Measure or (ORWELL 97 or Obesity Related Well-Being or (QLDUP or Quality of Life in Duodenal Ulcer Patients))) or (AdolRQLQ or Adolescent Rhinoconjunctivitis Quality of Life Questionnaire or MiniRQLQ or Mini Rhinoconjunctivitis Quality of Life Questionnaire or NRQLQ or Nocturnal Rhinoconjunctivitis Quality of Life Questionnaire or PRQLQ or Paediatric Rhinoconjunctivitis Quality of Life Questionnaire or RQLQ or Rhinoconjunctivitis Quality of Life Questionnaire or GHABP or Glasgow Hearing Aid Benefit Profile or PAR-ENT-QoL or (effects of Rhinopharyngitis and otitis of the child upon family life) or RhinQLQ or Rhinitis Quality of Life Questionnaire or rsdi or Rhinosinusitis Disability Index or rsui or Rhinitis Symptom Utility Index or Dizziness Handicap Inventory or UCLA-DQ or UCLA Dizziness Questionnaire or Vertigo Handicap Questionnaire or Vertigo Symptom Scale or Voice Handicap Index or (MCPQ or Mayo Clinic Postlaryngectomy Questionnaire or (PQLQ or Paediatric Quality of Life Questionnaire) or (MD POSI or Meniere's Disease Patient-Oriented Severity Index) or (OM-CSI or Otitis Media Clinical Severity Index) or Otitis Media Diary or (OM-FSQ or Otitis Media Functional Status Questionnaire) or (UPSIT or University of Pennsylvania Smell Identification Test) or (Vertigo, Dizziness and Imbalance questionnaire) or Hearing Coping Assessment)) or (Kingsley Alopecia Profile or SAQOL-39 or (Stroke and Aphasia Quality of Life Scale) or 8-item ICD-QOL or 8-item Implantable Cardioverter Defibrillator-specific Quality of Life Questionnaire or PACT-Q or Perception of Anticoagulant Treatment Questionnaire or abps or Aberdeen Back Pain Scale or Oswestry Disability Index or ofdq or Osteoporosis Functional Disability Questionnaire or Psychosocial Functioning Questionnaire for Patients with Low Back Pain or rmdq or Roland-Morris Disability Questionnaire or FACIT or Functional Assessment of Chronic Illness Therapy Measurement System or heiq or Health Education Impact Questionnaire or Constipation Assessment Scale or Neurogenic Bowel Dysfunction score or pac-qol or Patient Assessment of Constipation Quality of Life questionnaire or pac-sym or Patient Assessment of Constipation Symptoms or cqlq or Cough Quality of Life Questionnaire or CDIP-58 or Cervical Dystonia Impact Profile or Aberdeen Dyspepsia Questionnaire or dsiq or (Digestive Symptoms and Impact Questionnaire) or FDDQL or Quality of Life Questionnaire for Functional Digestive Disorders or GRSR-self or Gastrointestinal Symptom Rating Scale self-administered version or Leeds Dyspepsia Questionnaire or ndi-sf or Nepean Dyspepsia Index or PAGI-QOL or Patient Assessment of Upper Gastrointestinal Disorders-Quality of Life or PAGI-SYM or Patient Assessment of Gastrointestinal Disorders Symptom Severity Index or QOLRAD or (Quality Of Life in Reflux and Dyspepsia) or qpd-32 or Questionnaire for Peptic Disease-32 items or Severity of Dyspepsia Assessment or Brief Fatigue Inventory or crfds or Cancer-Related Fatigue Distress Scale or D-FISQ or Daily Fatigue Impact Scale or defis or Dutch Exertion Fatigue Scale or dufs or Dutch Fatigue Scale or Fatigue Impact Scale or Fatigue Symptom Inventory or Fatigue Severity Scale or Iowa Fatigue Scale or vas-f or Lee Fatigue Scale or Multidimensional Assessment of Fatigue or Multidimensional Fatigue Inventory or mfsi or Modified Fatigue Impact Scale or mfsi or Multidimensional Fatigue Symptom Inventory or SCFS-6 or Schwartz Cancer Fatigue Scale or gcsi or Gastroparesis Cardinal Symptom Index or PAGI-QOL or Patient Assessment of Upper Gastrointestinal Disorders-Quality of Life or PAGI-SYM or Patient Assessment of Gastrointestinal Disorders Symptom Severity Index or GHABP or Glasgow Hearing Aid Benefit Profile or Menorrhagia Outcomes Questionnaire or Menorrhagia Questionnaire or Menstrual Distress Questionnaire or (inv-2 or invr) or (Rhodes Index of Nausea and Vomiting-FORM 2) or (Index of Nausea, Vomiting, and Retching) or mane or (Morrow Assessment of Nausea and Emesis) or Nausea Questionnaire or Neck Disability Index or debq or Dutch Eating Behavior Questionnaire or IWQOL-Kids or Impact of Weight on Quality of Life - Kids or IWQOL-Lite or Impact of Weight on Quality of Life - Lite or OWLQOL or (Obesity and Weight-Loss Quality of Life measure) or wrsm or Weight-Related Symptom Measure or abps or Aberdeen Back Pain Scale or Brief Pain Inventory or Neuropathic Pain 4 Questions or hana or Headache Needs Assessment questionnaire or Integrated Pain Score or lanss or (Leeds Assessment of Neuropathic Symptoms and Signs Pain Scale) or mpac or Memorial Pain Assessment Card or McGill Pain Questionnaire or npsi or Neuropathic Pain Scale or Neuropathic Pain Symptom Inventory or OFDQ or Osteoporosis Functional Disability Questionnaire or pqas or Pain Quality Assessment Scale or pqas-r or Revised Pain Quality Assessment Scale or seq pain or Standard Evaluation Questionnaire on Pain or SF-MPQ-2 or Short-form McGill Pain Questionnaire or sopa or Survey of Pain Attitudes or Treatment Outcomes in Pain Survey or WHYMPI or West Haven - Yale Multidimensional Pain Inventory or Wong-Baker FACES or Wong-Baker FACES Pain Rating Scale or Epworth Sleepiness Scale or fosq or Functional Outcomes of Sleep Questionnaire or jseq or Jenkins Sleep Evaluation Questionnaire or lseq or Leeds Sleep Evaluation Questionnaire or psqi or Pittsburgh Sleep Quality Index or saqli or Sleep Apnea Quality of Life Index or OAB-q or (Overactive Bladder symptom and health-related quality of life questionnaire) or contilife or Quality of Life Assessment Questionnaire Concerning Urinary Incontinence or Detrusor Instability Score or I-QOL or Urinary Incontinence-Specific Quality of Life Instrument or ICIQ-FLUTS or International Consultation on Incontinence Questionnaire-

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Female Lower Urinary Tract Symptoms or ICIQ-UI Short Form or International Consultation on Incontinence Questionnaire - Urinary Incontinence Short Form or Incontinence Stress Index or King's Health Questionnaire or mudi or Male Urogenital Distress Inventory or musiq or Male Urinary Symptom Impact Questionnaire or n-qol or Nocturia Quality of Life Questionnaire or pmses or Broome Pelvic Muscle Exercise Self-Efficacy Scale or (Symptom Severity Index for stress incontinence in women or Symptom Impact Index for stress incontinence in women) or uihl or Urinary Incontinence Handicap Inventory or Urinary Symptom Profile or yips or York Incontinence Perceptions Scale or Dizziness Handicap Inventory or UCLA-DQ or UCLA Dizziness Questionnaire or Vertigo Handicap Questionnaire or Vertigo Symptom Scale or Voice Handicap Index or (MPSI or Modified Post-Sleep Inventory or Sleep Dysfunction scale or Numerical Rating Scale or (QLH-Y or Quality of Life Headache in Youth) or Hearing Coping Assessment or Qualite de Vie et Migraine or Rivermead Head Injury follow-up questionnaire or (SRFS or Self-Rating Fatigue Scale) or (V-RQOL or Voice-related quality of life) or (WHeadQ or Waters Headache Questionnaire) or (ORWELL 97 or Obesity Related Well-Being) or Fatigue Impact Scale or (HCIQ or Health Consequences of Injury Questionnaire) or (OSAPOS or Obstructive Sleep Apnea Patient-Oriented Severity Index) or Dallas Pain Questionnaire or Heat Beam Dolorimeter or (HHPPAI or Home Hospice Patient Pain Assessment Instrument) or (IPAT or Initial Pain Assessment Tool) or (ISCRG or Illness Self Concept Repertory Grid) or (LBPRS or Low Back Pain Rating Scale) or (MMPAP or Multiperspective Multidimensional Pain Assessment Protocol) or Pain Assessment questionnaire or Pain Assessment Index or (PATC or Pain Assessment Tool for Children) or Pain Catastrophizing Scale or Pain Disability index or (PDS-2 or Pain Distress Scales) or (PD-SLBP or Pain Drawing in Subacute Low Back Pain) or Pain-O-Meter or (PPAT or Pediatric Pain Assessment Tool) or (QBPS or Quebec Back Pain Scale) or Rivermead Post-traumatic Amnesia Protocol or (SPE-PC or Subjective Pain Evaluation - Pre-school Children) or (Oral Functioning Scale and Kiyak) or (SPADI or (Shoulder Pain and Disability Index)) or Osteoarthritis Pain Assessment or Frenchay Activities Index or (R-ADL or Rivermead ADL Scale) or (SA-SIP30 or Stroke Adapted 30-item SIP version) or Family Pain Questionnaire or (S-PEC or St Gallen Pain Evolution Chart)) or (4DSQ or Four-Dimensional Symptom Questionnaire or basis-24 or (Revised Behavior and Symptom Identification Scale) or BASIS-32 or (Behavior and Symptom Identification Scale) or BPRS or Brief Psychiatric Rating Scale or Brief Symptom Inventory or (Camberwell Assessment of Need for adults with Developmental and Intellectual Disabilities) or (Comprehensive Assessment and Referral Evaluation) or CES-D or Center for Epidemiologic Studies Depression Scale or EWPS or Endicott Work Productivity Scale or Global Assessment Scale or General Health Questionnaire or GSDS-II or Groningen Social Disabilities Schedule or General Satisfaction Questionnaire or MAACL-R or Multiple Affect Adjective Checklist-Revised or Mayers' LSQ 1 or Mayers' LSQ 2 or (Mayers' Lifestyle Questionnaire 1 or Mayers' Lifestyle Questionnaire 2) or mmse or Mini Mental State Examination or PAIS-SR or Psychosocial Adjustment to Illness Scale or Piers-Harris 2 or Piers-Harris Children's Self-Concept Scale Second Edition or Piers-Harris Children's Self-Concept Scale or Profile of Mood States or POMS or POMS-bi or Profile of Mood States Bipolar Scale or PRIME-MD PHQ or Primary Care Evaluation of Mental Disorders Patient Health Questionnaire or PSYCHLOPS or Psychological Outcome Profiles or PTQL or Pictorial Thai Quality of Life or Q-LES-Q or (Quality of Life Enjoyment and Satisfaction Questionnaire) or (QLQ-IR or QLQ-SR) or Oregon Quality of Life Questionnaire Interviewer Rating version or Oregon Quality of Life Questionnaire Interviewer Respondent Self-Report version or Oregon Quality of Life Questionnaire or QPD Panel or Quick PsychoDiagnostics Panel or RBMT or Rivermead Behavioral Memory Test or Social Behaviour Schedule or SCL-90-R or Symptom Checklist-90-Revised or Social Functioning Schedule or SOS-10 or Schwartz Outcome Scale-10 or VABS or Vineland Adaptive Behaviour Scales or W-QLI or Wisconsin Quality of Life Index or AAIQOL or (Activity and Affect Indicators of QOL) or ACQLI or Alzheimer's Carer's Quality of Life Instrument or ADCPQ or Alzheimer's Disease-Related Quality of Life or Apathy Inventory or Clinical Dementia Rating or cerad or Consortium to Establish a Registry for Alzheimer's Disease - Neuropsychological Assessment Battery or Consortium to Establish a Registry for Alzheimer's Disease - Clinical Assessment Battery or Disability Assessment for Dementia or DMS48 or MM-CGI or Marwit Meuser Caregiver Grief Inventory or Neuropsychological Test Battery or QOL-AD or Quality of Life in Alzheimer's Disease or QUALID or Quality of Life in Late-Stage Dementia Scale or CMDQ or Common Mental Disorder Questionnaire or DUKE-AD or Duke Anxiety - Depression Scale or HADS or (Hospital Anxiety and Depression scale) or HAM-A or Hamilton Anxiety Scale or LSAS or Liebowitz Social Anxiety Scale or (Panic and Agoraphobia Scale) or STAI or State-Trait Anxiety Inventory or SWAM scale or Satisfaction With Antipsychotic Medication scale or Body Image Scale or DAS24 or Derriford Appearance Scale - Short form or DAS59 or Derriford Appearance Scale or YQOL-FD or Youth Quality of Life Instrument - Facial differences Module or ADAS-COG or Alzheimer's Disease Assessment Scale, Cognitive part or Cornell-Brown Scale for Quality of Life in Dementia or d-qol or Dementia Quality of Life Instrument or DEMQOL or Measurement of health-related quality of life for people with dementia or Memory Impairment Screen or Neuropsychiatric Inventory or QOLAS or Quality of Life Assessment Schedule or Zarit Burden Interview or Beck Depression Inventory or Carroll Rating Scale for Depression or Geriatric Depression Scale or Hamilton Depression

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Rating Scale or Harvard Department of Psychiatry-NDSD scale or (IDS-SR or IDS-C) or Inventory of Depressive Symptomatology or MADRS or Montgomery-Asberg Depression Rating Scale or Major Depression Inventory or (QIDS-SR or QIDS-C) or Quick Inventory of Depressive Symptomatology or QLDS or Quality of Life in Depression Scale or Rand 8-item Depression Screener or Short Depression Interview or SDSS or Signs of Depression Screening Scale or debq or Dutch Eating Behavior Questionnaire or EDI-3 or Eating Disorder Inventory or BSFQ or Brief Sexual Function Questionnaire or CSMH-SFQ or (Center for Marital and Sexual Health Sexual Functioning Questionnaire) or Erectile Dysfunction Inventory of Treatment Satisfaction or FSHQ or Florida Sexual History Questionnaire or iief-5 or International Index of Erectile Function or Index of Sexual Life or MSHQ or Male Sexual Health Questionnaire or (Self-Esteem and Relationship Questionnaire) or Sexual Function Index or SLQQ or Sexual Life Quality Questionnaire or Profile of Female Sexual Function or Camberwell Assessment of Need or Camberwell Assessment of Need for the Elderly or DIS-IV or Diagnostic Interview Schedule - IV or ILSS or Independent Living Skills Survey or LQOLP or Lancashire Quality of Life Profile or (Personal and Social Performance Scale) or (Quality of Life Questionnaire or Client Experiences Questionnaire) or QLS-BC or Quality of Life Schedule or Research Diagnostic Criteria or Social Dysfunction Index or Social Role Performance schedule or Threshold Assessment Grid or Treatment Attitudes in Psychiatry Scales or ASRS or Augmentation Severity Rating Scale or irls or International Restless Legs Syndrome Study Group Rating Scale or P-RLS-SS or Pediatric Restless Legs Syndrome Severity Scale or RLS-QoL or Hopkins RLS QoL or Restless Legs Quality of Life Scale or Hopkins RLS Quality of Life Scale or ASFQ or (Antipsychotics and Sexual Functioning Questionnaire) or (DAI-30 or DAI-10) or Drug Attitude Inventory or NSA-16 or Negative Symptom Assessment or Quality of Life Scale or Social Dysfunction Index or SFS2 or Social Functioning Scale or Subjects' Response to Antipsychotics or Satisfaction With Antipsychotic Medication scale or Subjective Well-being under Neuroleptic treatment or ASEX or Arizona Sexual Experience Scale or FSDS or Female Sexual Distress Scale or AWQV2 or Amphetamine Withdrawal Questionnaire Version 2 or AWQV or Smoker Anchored Withdrawal Grid or Smoker Complaint Scale or STAR-SMOQ55 or Situation X Trait Adaptive Response Smoking Motivation questionnaire or TLFB or Timeline Followback Method or CMDQ or Common Mental Disorder Questionnaire or (TRIG or Texas Revised Inventory of Grief or (TSCS or Tennessee Self-Concept Scale) or Inventory of Current Concerns or Impaired Control Scale or Motivational Structure Questionnaire or (NABSQ or Newcastle Adolescent Behaviour Screening Questionnaire) or (PALS or (Perceived stress, Affect, Loneliness and Satisfaction)) or Geriatric Hopelessness Scale or (MUNSH or Memorial University of Newfoundland Scale of Happiness) or (OAHMQ or (Older Adult Health and Mood Questionnaire)) or (RPGM or Revised Philadelphia Geriatric Morale scales) or (MBPC or (Memory and Behavior Problems Checklist)) or Mental Status Questionnaire or (PMSQ or Short Portable Mental Status Questionnaire) or (SCAG or Sandoz Clinical Assessment Geriatric) or Subjective Stress scale or Present State Examination or Schedules for Clinical Assessment in Neuropsychiatry or Life Closure scale or Profile of Adaptation to Life or (SDRS or Social Dysfunction Rating Scale) or (SAHD or Schedule of Attitudes toward Hastened Death) or (PADQ or Psychosocial Aspects of Donation Questionnaire) or (NCSE or Neurobehavioral Cognitive Status Examination) or (RPAB or Rivermead Perceptual Assessment Battery) or Trail-Making Test or (WAIS or Wechsler Adult Intelligence Scale) or Sense of Coherence Scale or Jalowiec Coping Scale or Multidimensional Coping Inventory or (MEPSI or Modified Erikson Psychosocial Stage Inventory) or Parenting Stress Index or Impact of Event Scale or (RLCQ or Recent Life Changes Questionnaire) or Schedule of Recent Experience or (Levels of Attribution and Change) or Meaning of Illness Questionnaire or Multiple Locus of Control or (PHLOC or Parent Health Locus of Control scales) or (RIES or Revised Internal-External Scale) or Occupational Stress Inventory or Life Orientation Test or Eysenck Personality Inventory or Karolinska Scales of Personality or (MMPI or Minnesota Multiphasic Personality Inventory) or Maudsley Personality Inventory or Multidimensional Personality Questionnaire or PRF-Eor Personality Research Form E or Treatment Services Review or Retirement Descriptive index or (RSES or Rosenberg's Self-Esteem Scale) or Self-Esteem Inventory or (SLSCL or Self-Liking Self-Competence Scale) or (ISSI or Interview Schedule for Social Interaction) or Social Experiences Checklist or Social Problem Questionnaire or (AAIS or Adolescent Alcohol Involvement Scale) or Addiction Admission Scale or (AASE or Alcohol Abstinence Self-Efficacy Scale) or Adolescent Diagnostic Interview or Alcohol Dependence Scale or Alcohol Expectancy Questionnaire or (AEQ-A or Alcohol Expectancy Questionnaire-Adolescent Form) or Addiction Potential Scale or Addiction Severity Index or (ASRPT or Alcohol-Specific Role Play Test) or (AUDADIS or "Alcohol Use Disorders and Associated Disabilities Interview Schedule") or "Alcohol Use Disorders Identification Test" or (BL-VAS or Bond-Lader VAS) or (BPRPI or Brown-Peterson Recovery Progress Inventory) or CAGE Questionnaire or (CDDR or "Customary Drinking and Drug Use Record") or Comprehensive Drinker Profile or (CIDI core or Composite International Diagnostic Interview) or (CIWA-AD or Clinical Institute Withdrawal Assessment) or (CLDH or Cognitive Lifetime Drinking History) or (CSDD or Cornell Scale for Depression in Dementia) or Drinking Expectancy Questionnaire or Drinking Problems Index or (DRIE or Drinking-Related Internal-External Locus of Control Scale) or (DrInC or Drinker Inventory of Consequences) or (DRSEQ or Drinking Refusal Self-

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Efficacy Questionnaire) or (DSML or Drinking Self-Monitoring Log) or (DUSI-R or “Drug Use Screening Inventory”) or (EPDS or Edinburgh Postnatal Depression Scale) or Follow-up Drinker Profile or (F-SMAST or Adapted Short Michigan Alcoholism Screening Test for Fathers) or Family Tree Questionnaire for Assessing Family History of Alcohol Problems or (GAFS or Global Assessment of Functioning Scale) or Geriatric Mental State or (HSCL or Hopkins Symptom Checklist) or (IDTS or Inventory of Drug-Taking Situations) or (IPAT-A or IPAT Anxiety scale) or (IPAT-D or IPAT Depression scale) or (IQCODE or Informant Questionnaire on Cognitive Decline in the Elderly) or MacAndrew Alcoholism Scale or (MACL or Mood Adjective Check-List) or Munich Alcoholism Test or Michigan Alcoholism Screening Test or (McSad or Utility measure for major, unipolar depression) or (MHRSD or Modified Hamilton Rating Scale for Depression) or (Mental, Physical, and Spiritual well-being scale) or (NAEQ or Negative Alcohol Expectancy Questionnaire) or Obsessive Compulsive Drinking Scale or (PANSS or (Positive and Negative Syndrome Scale for Schizophrenia)) or (PBDS or Perceived Benefit of Drinking Scale) or (PCL-C or Post Traumatic Stress Disorders Checklist-Civilian) or Personal Experience Inventory or Psychiatric Epidemiology Research Interview or (PESQ or Personal Experience Screening Questionnaire) or Personal Health Survey or (PI-ED or Paediatric Index of Emotional Distress) or Purpose in Life Scale or (PIPD or Predictive Index for Postpartum Depression) or Problem Oriented Screening Instrument for Teenagers or (PPAAUS or (Primary Prevention Awareness, Attitude and Usage Scales)) or (Psychiatric Research Interview for Substance and Mental Disorders) or (PSAS or Psychiatric Symptom Assessment Scale) or Pediatric Symptom Checklist or Problem Situation Inventory or Index Rand Quantity Frequency or Quantity-Frequency Methods or QLI-L or (Quality of Life Interview and Lehman) or (QMHAU or “Questionnaire Measure of Habitual Alcohol Use”) or (RAATE or (Recovery Attitude and Treatment Evaluator)) or (RAPI or Rutgers Alcohol Problem Index) or Renard Diagnostic Interview or Restrained Drinking Scale or (RTCQ-TV or Readiness to Change Questionnaire Treatment Version) or (SAAST or Self-Administered Alcoholism Screening Test) or (SADD or Short Alcohol Dependence Data) or (SADQ or Severity of Alcohol Dependence Questionnaire) or (SADS or (Schedule for Affective Disorders and Schizophrenia)) or (Survey of Activities and fear of Falling in the Elderly) or (SAS-II or Social Adjustment Scale - II) or (SASSI or Substance Abuse Subtle Screening Inventory) or Self-report for Childhood Anxiety Related Disorder or Situational Confidence Questionnaire or (SCQOL or Smoking Cessation Quality of Life questionnaire) or (Stages of Change Readiness and Treatment Eagerness Scale) or Symptom Questionnaire or (SQLS or Schizophrenia Quality of Life Scale) or (SQOLB or Sertraline Quality of Life Battery) or (SRQ-D or Self Rating Questionnaire for Depression) or Symptom Rating Test or (SSAGA-II or Semi-Structured Assessment for the Genetics of Alcoholism) or Scale for Suicide Ideation or (SUDDS-IV or “Substance Use Disorders Diagnostic Schedule”) or T-ACE or Toronto Alexithymia Scale or (T-ASI or Teen-Addiction Severity Index) or (TBAQ or Toddler Behavior Assessment Questionnaire) or (Temptation and Restraint Inventory) or (URICA or University of Rhode Island Change Assessment Scale) or Veterans Alcoholism Screening Test or Vietnamese Depression Scale or (WSWS or Wisconsin Smoking Withdrawal Scale) or (YAAPST or Young Adult Alcohol Problems Screening Test) or (Y-BOCS or Yale-Brown Obsessive Compulsive Scale) or Zung Depression Scale or Wechsler Memory Scale or (WMS-C or Wechsler Memory Scale - Children) or (HPPQ or Heart Patients Psychological Questionnaire) or Salience of Lifestyle Index or (SLDS or Satisfaction with Life Domains Scale) or (MAHSC or Multi-Attribute Health Status Classification) or (RDRS-2 or Rapid Disability Rating Scale-2) or Global Deterioration or Progressive Deterioration Scale or Index of Sexual Function or (MPSI or Modified Post-Sleep Inventory) or Sleep Dysfunction scale or (TRIG or Texas Revised Inventory of Grief) or (TSCS or Tennessee Self-Concept Scale)) or (Chronic Respiratory Disease Questionnaire or CRQ-SAS or Chronic Respiratory Disease Questionnaire Self-Administered Standardized or PICQoL or Paediatric Intensive Care Quality of Life questionnaire or (Attitudes to Asthma Questionnaire or Adolescent Asthma Quality of Life Questionnaire or AAQOL or Asthma Bother Profile or Asthma Control Diary or Asthma Control Questionnaire or acss or Asthma Control Scoring System or Asthma Control Test or About My Asthma or aq30 or aq20 or Airways Questionnaire or aqlq or Asthma Quality of Life Questionnaire or AQLQ-M or (Asthma Quality of Life Questionnaire and Marks) or AQLQ-NAA or Asthma Quality of Life Questionnaire for Native American Adults or Asthma Symptom Checklist or Asthma Self-Efficacy Scale or asui or Asthma Symptom Utility Index or Bronchial Hyperresponsiveness Questionnaire or caqs or Childhood Asthma Questionnaires or Childhood Asthma Questionnaire or Inhaled Corticosteroid Questionnaire or KASE-AQ or (Knowledge, Attitude and Self-efficacy Asthma Questionnaire) or LWAQ or Living with Asthma Questionnaire or MiniAQLQ or Mini Asthma Quality of Life Questionnaire or PACQLQ or Paediatric Asthma Caregiver’s Quality of Life Questionnaire or PAQLQ or Paediatric Asthma Quality of Life Questionnaire or QLQ-Asthma or Questionnaire for the Assessment of Quality of Life in Asthma Patients or SGRQ or St George’s Respiratory Questionnaire) or WURSS or Wisconsin Upper Respiratory Symptom Survey or cqlq or Cough Quality of Life Questionnaire or Cystic Fibrosis Questionnaire or IIWS or Influenza Impact Wellbeing Scale or Influenza Symptom Severity scale or EORTC QLQ-LC13 or QLQ-LC13 or (European Organization for Research and Treatment of Cancer Quality of Life Questionnaire - Lung Cancer Module) or LCSS or Lung Cancer Symptom Scale or CAP-Sym or Community-Acquired Pneumonia

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Symptom questionnaire or (AQ30 or AQ20) or Airways Questionnaire or BDI-TDI or (Baseline and Transition Dyspnea Indexes) or baseline dyspnea index or Transition Dyspnea Index or Bronchial Hyperresponsiveness Questionnaire or Breathing Problems Questionnaire or Clinical COPD Questionnaire or Chronic Respiratory Disease Questionnaire or CRQ-SAS or Chronic Respiratory Disease Questionnaire Self-Administered Standardized or Inhaled Corticosteroid Questionnaire or PFSDQ or Pulmonary Functional Status & Dyspnea Questionnaire or PFSDQ-M or Pulmonary Functional Status & Dyspnea Questionnaire-modified or qual-e or Quality of Life at the End of Life Measure or SGRQ or St George's Respiratory Questionnaire or SOLQ or Seattle Obstructive Lung Disease Questionnaire or PACT-Q or Perception of Anticoagulant Treatment Questionnaire or MRF26 or Mageri Foundation Respiratory Failure Questionnaire or AdolRQLQ or Adolescent Rhinoconjunctivitis Quality of Life Questionnaire or MiniRQLQ or Mini Rhinoconjunctivitis Quality of Life Questionnaire or NRQLQ or Nocturnal Rhinoconjunctivitis Quality of Life Questionnaire or PAR-ENT-QoL or (effects of Rhinopharyngitis and otitis of the child upon family life) or PRQLQ or Paediatric Rhinoconjunctivitis Quality of Life Questionnaire or RhinQLQ or Rhinitis Quality of Life Questionnaire or RQLQ or Rhinoconjunctivitis Quality of Life Questionnaire or rsdi or Rhinosinusitis Disability Index or rsui or Rhinitis Symptom Utility Index or rsdi or Rhinosinusitis Disability Index or Voice Handicap Index or (Satisfaction with Illness scale or (ACAAI-LQ or American College of Allergy, Asthma & Immunology - Life Quality) or (ISAAC or (International Study of Asthma and Allergies in Childhood)) or Life Activity questionnaire for Childhood Asthma or (LAQ-AA or Life Activities Questionnaire for Adult Asthma) or (LAQ-CA or Life Activities Questionnaire for Childhood Asthma) or LIFE-Aor Life Activities Questionnaire for Adult Asthma or LIFE-Cor Life Activities Questionnaire for Childhood Asthma or (PCAQ or Perceived Control of Asthma Questionnaire) or Tasmanian Asthma survey or Feinstein's Index of Dyspnoea or Fletcher's Scale or Human Activity Profile Test or (MRC-D or Medical Research Council scale - Dyspnoea) or Oxygen Cost Diagram or Pulmonary Function Status Scale or pfss or (RIQLQ or Respiratory Illness Quality of Life Questionnaire) or (RQLQ or Respiratory Quality of Life Questionnaire) or (VAS-D or Visual Analogue Scale - Dyspnoea) or (OSAPOS or Obstructive Sleep Apnea Patient-Oriented Severity Index))) or (CDLQI or Children's Dermatology Life Quality Index or DLQI or Dermatology Life Quality Index or DQOLS or Dermatology Quality of Life Scales or DSQL-CD or Dermatology-Specific Quality of Life instrument for Contact Dermatitis or Dermatology-Specific Quality of Life instrument for Contact Dermatitis or FDLQI or Family Dermatology Life Quality Index or (skindex or skindex-29 or skindex-16) or Acne Disability Index or DSQL-Acne or Dermatology-Specific Quality of Life Instrument for Acne or Kingsley Alopecia Profile or (AIMS2 or Arthritis Impact Measurement Scales or ASQoL or Ankylosing Spondylitis Quality of Life Questionnaire or BASDAI or Bath Ankylosing Spondylitis Disease Activity Index or BASFI or Bath Ankylosing Spondylitis Functional Index or CHAQ or Childhood Health Assessment Questionnaire or Foot Function Index or JAQQ or Juvenile Arthritis Quality of Life Questionnaire or MACTAR or McMaster Toronto Arthritis Patient Preference Disability Questionnaire or Oxford Elbow Score or Oxford Hip Score or Oxford Shoulder Score or PSAQoL or Psoriatic Arthritis Quality of Life Instrument or QOL-RA or Quality of Life-Rheumatoid Arthritis Scale or RAQoL or Rheumatoid Arthritis Quality of Life Questionnaire) or Breast Cancer Chemotherapy Questionnaire or IBCSG-QLC or International Breast Cancer Study Group - Quality of Life Core Form or REPERES-60 or Subjective Health Estimations or PIQoL-AD or Parents' Index of Quality of Life in Atopic Dermatitis or QoLIAD or Quality of Life Index for Atopic Dermatitis or Dermatitis Family Impact questionnaire or IDQOL or Infants' Dermatitis QOL Index or Patient-Oriented Eczema Measure or CCVUQ or Charing Cross Venous Ulcer Questionnaire or Diabetic Foot Ulcer Scale or LFUQ or (Leg and Foot Ulcer Questionnaire) or SLEQoL or Systemic Lupus Erythematosus Quality of Life Questionnaire or Onychomycosis Quality of Life questionnaire or Psoriasis Disability Index or PQOL-12 or 12-Item Psoriasis Quality of Life Questionnaire or PSAQoL or Psoriatic Arthritis Quality of Life Instrument or Cuestionario Especifico en Condilomas Acuminados or (HRQOL-O or Health-related Quality of Life onychomycosis) or (QLDUP or Quality of Life in Duodenal Ulcer Patients) or (QLPO or Quality of Life of Persons with Onychomycosis) or (SLDI or Systemic Lupus International Coordinating Committee) or (SLICC ACR or damage Index) or (SLEDAI or Systemic Lupus Erythematosus Disease Activity Index) or Keitel Functional Assessment or Simple Shoulder Test or (MHAQ or Modified Health Assessment Questionnaire) or (MSOK or Patient-based Measure of the Severity of Osteoarthritis of the Knee) or (SAJC or Self-Administered Joint Count))) or (CHILD-ROIDP or Child-Oral Impact on Daily Performance Index or COHQoL or Child Oral Health Quality of Life Questionnaire or LORQv3 or Liverpool Oral Rehabilitation Questionnaire or (OHIP or OHIP-14) or Oral Health Impact Profile or OIDP or Oral Impact on Daily Performance Index or Oral Impact on Daily Performance Index - modified version or PAR-ENT-QoL or (effects of Rhinopharyngitis and otitis of the child upon family life) or (effects of Rhinopharyngitis or otitis of the child upon family life) or ((Oral Functioning Scale and Kiyak) or (PoSSe or Postoperative symptom severity))) or (WISP or Well-being Index for Surgical Patients or Ostomy Adjustment Scale or Transplant Disease Questionnaire or (PQLQ or Paediatric Quality of Life Questionnaire) or (PoSSe or Postoperative symptom severity) or (THAOEQ or Total Hip Arthroplasty Outcome Evaluation Questionnaire) or (MCPQ

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or Mayo Clinic Postlaryngectomy Questionnaire) or (Patient-Specific Index or BREAST-Q or CROQ or Coronary Revascularisation Outcome Questionnaire or SQLI or Stoma Quality of Life Index or Stoma-QOL or Stoma-QOL or (pasi and patient))) or (ESRD-SCL-TM or End-Stage Renal Disease Symptom Checklist- Transplantation Module or KDQOL or Kidney Disease Quality of Life instrument or qual-e or Quality of Life at the End of Life Measure or DAN-PSS-1 or Danish Prostatic Symptom Score or ICIQ-FLUTS or International Consultation on Incontinence Questionnaire-Female Lower Urinary Tract Symptoms or ICSmale or ICSQoL or International Continence Society-Benign Prostatic Hyperplasia study quality-of-life or MSHQ or Male Sexual Health Questionnaire or (UROLIFE or TM-BPHQoL9) or Benign Prostatic Hypertrophy Health-Related Quality of Life Questionnaire or OAB-q or (Overactive Bladder symptom and health-related quality of life questionnaire) or contilife or Quality of Life Assessment Questionnaire Concerning Urinary Incontinence or Detrusor Instability Score or I-QOL or Urinary Incontinence-Specific Quality of Life Instrument or ICIQ-FLUTS or International Consultation on Incontinence Questionnaire-Female Lower Urinary Tract Symptoms or ICIQ-UI Short Form or International Consultation on Incontinence Questionnaire - Urinary Incontinence Short Form or Incontinence Stress Index or King's Health Questionnaire or MUDI or Male Urogenital Distress Inventory or musiq or Male Urinary Symptom Impact Questionnaire or n-qol or Nocturia Quality of Life Questionnaire or pmses or Broome Pelvic Muscle Exercise Self-Efficacy Scale or (Symptom Severity Index for stress incontinence in women or Symptom Impact Index for stress incontinence in women) or uihi or Urinary Incontinence Handicap Inventory or Urinary Symptom Profile or yips or York Incontinence Perceptions Scale or QUALIVEEN or QUALIVEEN-30 or SF-QUALIVEEN or QUALIVEEN Short Form or USS PROM or Urethral stricture surgery patient-reported outcome measure or (Urogenital Distress Inventory or (U-IIQ or Urge-Incontinence Impact Questionnaire) or (UIWQ or Urinary Incontinent Women Questionnaire) or (U-UDI or Urge-Urinary Distress Inventory) or (MMAP or Maine Medical Assessment Program symptom index) or Prostate Outcomes Questionnaire or (PORPUS or Patient-oriented prostate utility scale) or (HQLQ or Haemodialysis Quality of Life Questionnaire))) or (WURSS or Wisconsin Upper Respiratory Symptom Survey or CMV-EYE or Quality of Life with Eye Disease or AIDS-HAQ or AIDS Health Assessment Questionnaire or HAT-QoL or HIV-AIDS-Targeted Quality of Life or HIV-SI or HIV Symptom Index or HIV-SQUAD or Symptom Quality of Life Adherence or HIV Overview of Problems - Evaluation System or MOS-HIV or Medical Outcome Study-HIV Health Survey or MPQOL or Miami Pediatric Quality of Life Questionnaire Parent Scale or MQOL-HIV or Multidimensional Quality of Life questionnaire for HIV-AIDS or HOIQ or Herpes Outbreak Impact Questionnaire or Herpes Symptom Checklist or RGHQoL or Recurrent Genital Herpes Quality of Life Questionnaire or IIWS or Influenza Impact Wellbeing Scale or Influenza Symptom Severity scale or Cuestionario Especifico en Condilomas Acuminados or (Genital Herpes Measure or HIV Assessment Tool or (HIV-QL31 or HIV-Quality of Life - 31 items) or (Symptom Distress Module or HIV Symptom Index))) or (((Physical Performance Test or (Rosow and Breslau Scale) or Rivermead Motor Assessment or Rivermead Mobility Index or Self Care Assessment Schedule or Situational Control of Daily Activities or Timed Manual Performance Test or Nuclear Attitudes Questionnaire or Nurses' Observational Scale for Inpatient Evaluation or Relatives Stress Scale or Food Benefits Assessment or Nutritional Assessment Index or Nutrition Screening Initiative self-assessment tool or Life Support Preferences Questionnaire or Family History Screen for Epidemiologic Studies or (Family Adaptability and Cohesion Evaluation Scales) or Family Environment Scale or (HAPA or (Home Life and Personal Adaptation)) or Marital Adjustment Test or (REFAMOS or Relationship with Family of Origin Scale) or Wisconsin Gait Scale or Hospital Admission Risk Profile or (TOFHLA or Test of Functional Health Literacy in Adults) or (PRQ-2000 or Personal Resources Questionnaire-2000) or (PRQ-85 or Personal Resource Questionnaire-85) or (NPQ-E or Nursing Practice Questionnaire-Education) or Physical Activity Index or Physical Activity Scale or Specific Activity Scale or Weekly Activity Checklist or Resident Assessment Instrument or (SCES or Sheltered Care Environment Scale) or (WOFS or Ward Organisational Features Scales) or Supervision Rating Scale or (MRC-NCA or Medical Research Council - Needs for Care Assessment) or (Needs and Resources Assessment) or (PLNS or Patient Learning Needs Scale) or (PRQC or Patient Rated Quality of Care) or (SATMED-Q or Treatment Satisfaction with Medicines Questionnaire) or Trust in Physician Scale or Rosser Index of Disability or (MCSDS or (Marlowe and Crowne Social Desirability Scale) or (SSIn or Stereopsis Screening Inventory) or Work Performance Scale or Life Closure scale or Profile of Adaptation to Life or (SDRS or Social Dysfunction Rating Scale) or (SAHD or Schedule of Attitudes toward Hastened Death) or (PADQ or Psychosocial Aspects of Donation Questionnaire) or (NCSE or Neurobehavioral Cognitive Status Examination) or (RPAB or Rivermead Perceptual Assessment Battery) or Trail-Making Test or (WAIS or Wechsler Adult Intelligence Scale) or Wechsler Memory Scale or (WMS-C or Wechsler Memory Scale - Children) or Sense of Coherence Scale or Jalowiec Coping Scale or Multidimensional Coping Inventory or (MEPSI or Modified Erikson Psychosocial Stage Inventory) or Food Frequency Questionnaire or Parenting Stress Index or (TRIG or Texas Revised Inventory of Grief) or Impact of Event Scale or (RLCQ or Recent Life Changes Questionnaire) or Schedule of Recent Experience or (Levels of Attribution and Change) or Meaning of Illness Questionnaire or Multiple Locus of Control or

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(PHLOC or Parent Health Locus of Control scales) or (RIES or Revised Internal-External Scale) or Occupational Stress Inventory or Life Orientation Test or Eysenck Personality Inventory or Karolinska Scales of Personality or (MMPI or Minnesota Multiphasic Personality Inventory) or Maudsley Personality Inventory or Multidimensional Personality Questionnaire or PRF-Eor Personality Research Form E or (MPOC or Measure of Processes of Care) or Treatment Services Review or Retirement Descriptive index or (TSCS or Tennessee Self-Concept Scale) or (RSES or Rosenberg's Self-Esteem Scale) or Self-Esteem Inventory or (SLSCL or Self-Liking Self-Competence Scale) or (ISSI or Interview Schedule for Social Interaction) or Social Experiences Checklist or Social Problem Questionnaire or Salience of Lifestyle Index or (SLDS or Satisfaction with Life Domains Scale) or (EASY-Care and sheffield) or Fisher Grading Scale on Relation of CT SAH to Vasospasm or (ISAAC or (International Study of Asthma and Allergies in Childhood)) or Injury Severity Score or Minimum Data Set or (MEES or Mainz Emergency Evaluation Score) or Muscle Strength Grading or Ontario Health Survey or (Papille Grading System for Subependymal and Germinal Matrix and Hemorrhage) or (PRAC-Test or (PRAGmatic Content and face validity Test)) or (QLIV or Quality of Life Instrument Veterinary) or (RAPS or Rapid Acute Physiology Score) or Revised Trauma Score or Spetzler AVM Grading System or Trauma Score or Time Trade Off or (Health and work Questionnaire) or Health-related quality of life questionnaire for women with polycystic ovary syndrome or Alzheimer's disease related quality of life or satisfaction with life scale or A-RHDQoL or Age-Related Hormone Deficiency-Dependent Quality of Life Questionnaire or AQLQ or Asthma Quality of Life Questionnaire or Chronic Respiratory Disease Questionnaire or QUOLIS or Quality of Life Interview Schedule or Paediatric Asthma Quality of Life Questionnaire or SQLP or Subjective Quality of Life Profile or ADDQOL or Audit of Diabetes Dependent Quality of Life or DSQOLS or Diabetes Specific Quality of Life Scale or RetDQoL or Retinopathy Dependent QoL or GQLQ or Geriatric Quality of Life Questionnaire or Patient-Specific Index or HDQoL or Hormone Deficiency-dependent Quality of Life or ThyDQoL or Thyroid-Dependent Quality of Life or JAQQ or Juvenile Arthritis Quality of life Questionnaire or KPSI or Knee Patient-Specific Index or MacDQoL or Macular Disease-Dependent Quality of Life or QLI-MH or Quality of Life Index for Mental Health or PGPQ or Patient-Specific Functional Scale or OA GO AWAY or RDQOL or Renal-Dependent Quality of Life or MACTAR or McMaster-Toronto Arthritis Patient Preference Disability Questionnaire or Problem Elicitation Technique or SCI-SET or Spinal cord injury spasticity evaluation tool or Meaning in Life Depth or LLATBI or Living Life After Traumatic Brain Injury or EyeDQoL or Eye-Dependent Quality of Life or (Experienced Meaningfulness and Meaninglessness Questionnaire) or Interview on Meaning in Life or SBQOL or SmithKline-Beecham Quality of Life Index or SmithKline-Beecham Quality of Life Index Scale or Helpful Aspects of Therapy or (Duggan and Dijkers) or (Gottschalk and Lolas) or Fulfilment of Meaning Scale or Meaning Essay Document or Personal Meaning Systems or Questionnaire of Life Meaning Sources or (Personal questionnaire and shapiro) or (Impact on Roles and Functioning Scale) or Perceived Control of Daily Activities Scale or Family Quality of Life Survey or Longer term Unmet Needs after Stroke or Impact of dry eye on everyday life or Psychosocial Rehabilitation Outcomes Toolkit or Patient-Generated Subjective Global Assessment or Toronto outcome measure for craniofacial prosthetics or Quality of Life for Respiratory Illness Questionnaire or Scale for the Assessment of Positive Symptoms or Scale for the Assessment of Negative Symptoms or mini Asthma Quality of Life Questionnaire or Separation Anxiety Daily Diary or Patient-Generated Subjective Global Assessment or Social Support Network Inventory or Norbeck social support questionnaire or Quality of Life Self-Assessment Inventory or Inter-goal Relations Questionnaire or Personal Projects Analysis or CFS Sense of Control scale or Carolina Index of Self-Regulation or COPD Self Efficacy Scale or UCSD Shortness of Breath Questionnaire or Recurrent Genital Herpes Quality of Life Questionnaire or Baseline dyspnea index or FertiQoL or ABILHAND-Kids or Schizotypal Personality Questionnaire or Personal Wellbeing Index or Cystic Fibrosis Coping Scale or Cystic Fibrosis Quality of Life Questionnaire or Taylor Manifest Anxiety Scale or Functional Assessment of Cancer Therapy General or Anderson Symptom Inventory or Functional Assessment of Chronic Illness Therapy or Cancer Therapy Satisfaction Questionnaire or (Child and Adolescent Functional Assessment Scale) or Temporomandibular joint questionnaire or Eating Disorders Quality of Life or Marks Asthma Quality of Life Questionnaire or Health Status Questionnaire or Quality of Life in Epilepsy Inventory for Adolescents or BOMET-QoL or Global Initiative for Asthma or Asthma Control Test or Fear of Cancer Recurrence or Mental Adjustment to Cancer or CHOICE Health Experience Questionnaire or System of Belief Inventory or Multidimensional Scale of Perceived Social Support or Quebec back pain disability scale or Bath Spondylitis Functional Index or Patient Needs Scale or Revised Children Manifest Anxiety Scale or Separation Anxiety Inventory for Children or Inventory for the Assessment of Quality of Life in Children) and Adolescents) or Kansas City Cardiomyopathy Questionnaire or Headache-Specific Locus of Control Scale or Oral Health Impact Profile or international index of erectile function or Sexual Life Quality Questionnaire or Questionnaire of quality of life in patients with primary hyperhidrosis or Tinnitus Handicap Inventory or Hearing Handicap Inventory or Satisfaction with Life Scale or Good death Inventory or Impact of Weight on Quality of Life inventory or Fibromyalgia Impact Questionnaire or McGill Quality of Life questionnaire or Reciprocal Social Support Scale or questionnaire for

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satisfaction of hospitalized patients or Living With Asthma Questionnaire or Rhinasthma questionnaire or Zerssen list of complaints or COPM or Canadian Occupational Performance Measure or CoMQoL or Comprehensive Quality-of-Life scale or (Quality of Life Index and ferrans) or qols or (Quality of Life Scale and flanagan) or IQOLI or Individual Quality of Life Interview or MYCaW or (Measure Yourself Concerns and Wellbeing) or MYMOP or Measure Yourself Medical Outcome Profile or Patient Generated Index or QOLAS or Quality of Life Assessment Schedule or QLSI or Quality of Life Systemic Inventory or FLZM or Questions on Life Satisfaction or SEIQoL or Schedule for the Evaluation of Individual Quality of Life or SEIQol-DW or SEIQoL-Direct Weighting or Schedule for Meaning in Life Evaluation or SDQLM or Subjective Domains of quality of life measure or Goal attainment scale or PSYCHLOPS or Psychological Outcome Profiles or QoL-GAP or QOLI or Quality of Life Inventory or SQLP or Subjective Quality of Life Profile or W-QLI or Wisconsin Quality of Life Index or Zung Self Rating Depression Scal* or Zung Self-Rating Depression Scal* or Center for Epidemiologic Studies Depression)).tw

#46 44 or 45

#47 (visit or visits or appointment* or consultation*).tw.

#48 (monitor* or screen* or management or follow-up* or followup* or follow up*).tw

#49 ((clinical or medical or dental or general or family or surgical) adj practice).tw

#50 47 or 48 or 49

#51 exp feedback/ or (feedback or fed back).tw.

#52 exp decision making/ or decision making.tw. or exp communication/ or communication.tw. or exp physician-patient relations/

#53 51 or 52

#54 (randomised controlled trial or controlled clinical trial).pt. or random*.ab. or trial.ti. or placebo.ab. or clinical trials as topic.sh

#55 46 and 50 and 53 and 54

#56 exp animals/ not humans.sh.

#57 55 not 56

CONTRIBUTIONS OF AUTHORS

Daniela C Gonçalves prepared the first draft and subsequent drafts of the protocol based on feedback from the co-authors. All authors have contributed to the development of the protocol. Nia Roberts provided specific feedback on search strategies.

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