

An introduction to patient-reported outcome measures (PROMs) in physiotherapy

Kyte, Derek; Calvert, M.; Van Der Wees, P.j.; Ten Hove, R.; Tolan, S.; Hill, J.c.

DOI:

[10.1016/j.physio.2014.11.003](https://doi.org/10.1016/j.physio.2014.11.003)

License:

Creative Commons: Attribution-NonCommercial-NoDerivs (CC BY-NC-ND)

Document Version

Publisher's PDF, also known as Version of record

Citation for published version (Harvard):

Kyte, D, Calvert, M, Van Der Wees, PJ, Ten Hove, R, Tolan, S & Hill, JC 2014, 'An introduction to patient-reported outcome measures (PROMs) in physiotherapy', *Physiotherapy*.
<https://doi.org/10.1016/j.physio.2014.11.003>

[Link to publication on Research at Birmingham portal](#)

Publisher Rights Statement:

Article published under Creative Commons Non-Commercial-No Derivatives license - <http://creativecommons.org/licenses/by-nc-nd/4.0/>.

Eligibility for repository checked March 2015

General rights

Unless a licence is specified above, all rights (including copyright and moral rights) in this document are retained by the authors and/or the copyright holders. The express permission of the copyright holder must be obtained for any use of this material other than for purposes permitted by law.

- Users may freely distribute the URL that is used to identify this publication.
- Users may download and/or print one copy of the publication from the University of Birmingham research portal for the purpose of private study or non-commercial research.
- User may use extracts from the document in line with the concept of 'fair dealing' under the Copyright, Designs and Patents Act 1988 (?)
- Users may not further distribute the material nor use it for the purposes of commercial gain.

Where a licence is displayed above, please note the terms and conditions of the licence govern your use of this document.

When citing, please reference the published version.

Take down policy

While the University of Birmingham exercises care and attention in making items available there are rare occasions when an item has been uploaded in error or has been deemed to be commercially or otherwise sensitive.

If you believe that this is the case for this document, please contact UBIRA@lists.bham.ac.uk providing details and we will remove access to the work immediately and investigate.



Debate Article

An introduction to patient-reported outcome measures (PROMs) in physiotherapy

D.G. Kyte^{a,b}, M. Calvert^b, P.J. van der Wees^c, R. ten Hove^d,
S. Tolan^d, J.C. Hill^{e,*}

^a School of Sport, Exercise & Rehabilitation, University of Birmingham, Birmingham, UK

^b Primary Care and Clinical Sciences, University of Birmingham, Birmingham, UK

^c Radboud University Medical Centre, Scientific Institute for Quality of Healthcare, Nijmegen, The Netherlands

^d Chartered Society of Physiotherapy, UK

^e Arthritis Research UK Primary Care Centre, Primary Care Sciences, Keele University, Stoke-on-Trent, UK

Abstract

The use of patient-reported outcome measures (PROMs) is set to rise in physiotherapy. PROMs provide additional ‘patient-centred’ data which is unique in capturing the patient’s own opinion on the impact of their disease or disorder, and its treatment, on their life. Thus, PROMs are increasingly used by clinicians to guide routine patient care, or for the purposes of audit, and are already firmly embedded in clinical research. This article seeks to summarise the key aspects of PROM use for physiotherapists, both in routine clinical practice and in the research setting, and highlights recent developments in the field. Generic and condition-specific PROMs are defined and examples of commonly used measures are provided. The selection of appropriate PROMs, and their effective use in the clinical and research settings is discussed. Finally, existing barriers to PROM use in practice are identified and recent physiotherapy PROM initiatives, led by the Royal Dutch Society for Physical Therapy are explored.

© 2014 Chartered Society of Physiotherapy. Published by Elsevier Ltd. All rights reserved.

Keywords: Physiotherapy; Patient-reported outcomes; Patient-reported outcome measures; PROMs; Clinical practice; Physiotherapy research

Introduction

Patient-reported outcome measures (PROMs) have been collected in the NHS since 2009 and look set to profoundly change the face of modern healthcare delivery [1]. PROMs are increasingly used by clinicians to guide and audit routine care, and are already firmly embedded in clinical research. These important patient-centred measures are likely to have a growing impact on physiotherapists, in the UK and internationally. Patient-reported outcome research findings will increasingly guide policy makers and clinicians in providing evidence-based treatment.

In addition, the routine clinical use of PROMs may allow physiotherapists to more effectively track treatment impact, thus aiding the development of optimal management strategies. Indeed, the Chartered Society of Physiotherapy (CSP) actively encourages such an approach, stating: ‘Physiotherapists must be able to demonstrate measurable improvements in the clinical outcomes of their patients as part of daily practice.’ [2]. The use of PROMs to measure health status in routine practice has some distinct advantages over traditional research-based outcome measures, as they may directly facilitate change behaviour for patients, clinicians, managers and policymakers. Widespread adoption of PROMs across physiotherapy is therefore something for the profession to embrace as it has the potential to empower patients, support clinical decision-making and drive forward quality improvement.

* Corresponding author. Tel.: +44 01782 733900; fax: +44 01782 733911.
E-mail address: j.hill@keele.ac.uk (J.C. Hill).

<http://dx.doi.org/10.1016/j.physio.2014.11.003>

0031-9406/© 2014 Chartered Society of Physiotherapy. Published by Elsevier Ltd. All rights reserved.

This article seeks to summarise the key aspects of PROM use for physiotherapists, both in routine clinical practice and in the research setting, and highlights recent developments in the field.

What are PROMs?

Patient-reported outcomes measures (PROMs) are defined as: ‘... any report of the status of a patient’s health condition that comes directly from the patient, without interpretation of the patient’s response by a clinician or anyone else.’ [3]. PROM information can be gathered using paper-based or electronic questionnaires. Their use in clinical practice helps to ensure the patient ‘voice’ is present in all aspects of care, which is essential to ensure therapeutic management remains patient-centred [4]. PROMs capture patient’s own opinions on the impact of their condition, and its treatment, on their life. Questionnaires are therefore usually designed to focus on one or more specific elements of a patient’s well-being. Some PROMs specifically measure a combination of physical, mental and social aspects, collectively known as health-related quality of life (HRQL), while others evaluate single dimensions of health, for example, physical activity [5]. The specific questions within a PROM (known as ‘items’) are usually grouped together to form appropriate sub-categories, or ‘domains’. For example, several questions regarding ambulation may be grouped within the domain ‘mobility’. Patient’s answers in these sub-categories provide individual domain scores, which are often combined to generate an overall PROM score. Scoring methods vary between PROMs, however, so it is important to carefully check each instrument’s instructions.

PROMs can be broadly categorised as either generic or condition-specific instruments [6]: this distinction is important. Generic PROMs measure the wellbeing of all types of patients, regardless of their illness or disorder. Thus, they are particularly useful for comparing outcomes at *the group, or aggregate level*. For example, the EQ-5D [7] is a common generic PROM recommended by the CSP as a standard measure for out-patient MSK physiotherapy practice [2]. Its consistent use across therapy services will allow local and national comparisons with other providers and with the general population.

Generic PROMs may not always provide a sufficient level of detail or responsiveness for measuring change in a single patient over time, however. In this instance, physiotherapists should also consider utilising a condition-specific PROM. These measures focus on a particular disease or disorder and address the most relevant concerns for a target population; an example is the Neck Disability Index [8]. Condition-specific PROMs tend to be more responsive to subtle changes in the patient’s condition, and are therefore better suited to measuring outcomes at *the individual level*.

A third category of PROMs which has gained attention in research and practice, are individualised instruments such

as the Patient Generated Index [9], Patient Specific Function Scale [10] or the MYMOP [11]. Individualised measures examine patients’ own definition of health related quality of life and challenge the prevailing approach of pre-definition of the outcomes being measured by researchers and clinicians. Their particular value is for goal setting and monitoring progress at a highly individual level, which tends to make them more sensitive to change than conventional measures. However, policy makers tend not to favour the use of individualised instruments in isolation, they are therefore typically used in combination with other types of PROMs.

Common PROMs in physiotherapy research and routine practice

PROMs are increasingly collected in physiotherapy research, usually as secondary outcomes in clinical trials, often accompanying a more objective ‘clinical’ primary outcome. Recent examples include the ‘mirror therapy for patients with severe arm paresis after stroke’ trial [12], which used a generic PROM to measure independence in activities of daily living (the Barthel Index), alongside a condition-specific measure of quality of life in stroke patients (the Stroke Impact Scale). These secondary outcomes were collected alongside a primary outcome, measured using an objective physical test (the Fugl–Meyer Assessment), which evaluated functional upper limb recovery. This use of both objective and patient-reported trial outcomes is now common and ensures that trials better capture information regarding aspects of recovery that are important to patients. Further examples are presented in Table 1.

The use of PROMs in routine UK physiotherapy practice is less well established, but is increasing as part of the wider quality improvement agenda driven by the commissioners of services [13]. Physiotherapy providers are therefore being asked to use PROMs to evidence the quality of their care, alongside other metrics such as safety and patient experience data. Significantly the CSP included PROMs in their 2012 ‘Any Qualified Provider’ (AQP) national specification for musculoskeletal physiotherapy [14]. Since then the use of PROMs has been extended for wider monitoring by commissioners and also as a contract requirement for many private sector health insurers. The CSP has thus promoted the use of the EuroQol EQ-5D PROM [7] as a routine generic patient reported outcome measure with extensive take up by the UK profession. More recently, the society has started to encourage a combined approach: advocating routine collection of a generic PROM alongside both a condition-specific PROM and a patient-reported experience measure. The CSP has also been working with its professional networks to make recommendations for routine PROM collection relating to particular conditions or pathways of care. To help facilitate consistency and best practice in PROM data collection, the CSP has recently set up a health informatics team to provide

Table 1
PROMs in selected recent physiotherapy trials.

Study	Subject	PROMs
Brovold T, Skelton DA, Bergland A. Older adults recently discharged from the hospital: effect of aerobic interval exercise on health-related quality of life, physical fitness, and physical activity. <i>J Am Geriatr Soc</i> 2013;61:1580–5	The effect of aerobic interval exercise on health-related quality of life, physical fitness, and physical activity in older adults recently discharged from the hospital	Medical outcomes study 36-item short form survey (SF-36) ^{a,c} Physical activity scale for the elderly (PASE) ^{b,d}
Cross JL, Elender F, Barton G, Clark A, Shepstone L, Blyth A, et al. Evaluation of the effectiveness of manual chest physiotherapy techniques on quality of life at six months post exacerbation of COPD (MATREX): a randomised controlled equivalence trial. <i>BMC Pulm Med</i> 2012;12:33	Effectiveness of manual chest physiotherapy techniques on quality of life at six months post exacerbation of COPD	Saint Georges respiratory questionnaire ^{a,d}
Cuesta-Vargas AI, Gonzalez-Sanchez M, Casuso-Holgado MJ. Effect on health-related quality of life of a multimodal physiotherapy program in patients with chronic musculoskeletal disorders. <i>Health Qual Life Outcomes</i> 2013;11:19	Effect on health-related quality of life of a multimodal physiotherapy programme in patients with chronic musculoskeletal disorders	Short form-12 health survey (SF-12) ^{a,c} EuroQoL-5D ^{b,c} Visual analogue scale (VAS) ^{b,c}
Kjeken I, Bo I, Ronningen A, Spada C, Mowinckel P, Hagen KB, et al. A three-week multidisciplinary in-patient rehabilitation programme had positive long-term effects in patients with ankylosing spondylitis: randomized controlled trial. <i>J Rehabil Med: Off J UEMS Eur Board Phys Rehabil Med</i> 2013;45:260–7	Long-term effects of a three-week multidisciplinary in-patient rehabilitation programme for patients with ankylosing spondylitis	Bath Ankylosing Spondylitis Disease Activity Scale (BASDAI) ^{a,d} Bath Ankylosing Spondylitis Functional Index (BASFI) ^{a,d} Medical outcomes study 36-item short form survey (SF-36) ^{b,c}
Kromer TO, de Bie RA, Bastiaenen CH. Physiotherapy in patients with clinical signs of shoulder impingement syndrome: a randomized controlled trial. <i>J Rehabil Med: Off J UEMS Eur Board Phys Rehabil Med</i> 2013;45:488–97	Physiotherapy in patients with clinical signs of shoulder impingement syndrome	Shoulder pain and disability index ^{a,d} Patient's global impression of change ^{a,c} Weekly pain score ^{b,c} Generic patient-specific scale ^{b,c} Patients' satisfaction with treatment ^{b,c}
Ruta D, Garratt AM, Leng M, Russell IT, MacDonald LM. A new approach to the measurement of quality of life: the patient generated index. <i>Med Care</i> 32;1109–26	Mirror therapy for patients with severe arm paresis after stroke	Barthel index ^{b,c} Stoke impact scale ^{b,d}
van Nimwegen M, Speelman AD, Overeem S, van de Warrenburg BP, Smulders K, Dontje ML, et al. Promotion of physical activity and fitness in sedentary patients with Parkinson's disease: randomised controlled trial. <i>BMJ</i> 2013;346:f576	Promotion of physical activity and fitness in sedentary patients with Parkinson's disease	LASA physical activity questionnaire (LAPAQ) ^{a,c} Activity diary ^{b,c} Parkinson's disease questionnaire (PDQ-39) ^{b,d}

Abbreviations: PROMs, patient-reported outcome measures.

^a Primary outcome.

^b Secondary outcome.

^c Generic measure.

^d Condition-specific measure.

leadership in this rapidly changing environment and further information is available at www.csp.org.uk/proms.

Selecting an 'appropriate' PROM

When searching for an appropriate PROM, it is first important to ask the following questions: (a) 'what do I want to measure?'; (b) 'what is the rationale for assessment?'; and (c) 'at what level will the measurement take place (group or individual)?' For clinicians wanting to benchmark the performance of their service it is also increasingly important to

ask (d) 'what PROMs are recommended and being used by others?' The first question will help determine which health domain(s) should be utilised, e.g., pain, mobility, social functioning, etc. Consideration should also be given to capturing the most relevant health domains for the target population. The second, third and fourth questions will aid selection of the appropriate tool. For instance, to measure differences in pain between patient groups in a trial, in a way that would be easily generalisable to the population, a generic PROM may be most appropriate [6]. If, on the other hand, one wished to measure the same changes in a single patient with knee pain, in order to inform decisions about ongoing treatment, a

sensitive condition-specific measure may be the best option [15]. Of course, it may be appropriate and optimal to use a generic, and condition-specific PROM and/or a patient generated scale in combination [16]. Whatever the final selection, it should be underpinned with a clear understanding of the ultimate purpose of outcome measurement in the given context, to ensure the right tool is selected for the job.

PROMs should also be selected based on the strength of their measurement properties (i.e., reliability, validity and responsiveness), which should be established in the population of interest, and also on other key aspects including acceptability and interpretability. Reliability encompasses: test-retest reliability, or the degree to which results are replicated over time in stable patients; internal consistency, how well items that are grouped in a particular domain correlate; and, in interviewer administered PROMs, inter-rater reliability, i.e., agreement between two independent interviewers [17]. Validity encompasses: content validity, or the degree to which the PROM evaluates all important aspects of the disease/disorder; construct validity, whether behaviour of the measure is consistent with hypotheses regarding: (a) probable relationships with other instruments and/or (b) performance of the tool in different subgroups; and criterion validity, i.e., correlation with a 'gold standard' [17]. Some measures are better than others in their ability to discriminate between individuals with different levels of severity at a single point in time, and some are better than others in their responsiveness, which is their ability to detect change within individuals over time [17]. PROMs should also be acceptable to their target population, both in terms of the questions asked (e.g., are they appropriately worded?) and their overall patient burden (e.g., is the completion time for the PROM agreeable?) [15]. Measures must also be easily interpretable, i.e., the meaning of differences in PROM score should be clearly understood [18].

There are a number of resources available to aid both location and selection of validated PROMs. The Patient-Reported Outcome and Quality of Life Instruments Database (PROQOLID; www.proqolid.org) [19] can be searched for specific instruments (e.g., 'Neck Disability Index') or by disease/disorder (e.g., 'osteoarthritis'), or domain (e.g., 'pain'). The International Society for Quality of Life Research (ISOQOL) has published recommendations on the agreed minimum measurement property standards for PROMs [20]. Finally, the COnsensus-based Standards for the selection of health Measurement INstruments (COSMIN) group have produced a critical appraisal checklist (available at www.cosmin.nl) for the evaluation of PROM measurement properties [17,18,21].

Using PROMs in research

Before commencing a research study, one should ensure that each PROM is validated in the population under study, typically in a longitudinal or cross-sectional study or as part

of a clinical trial [5,22]. If not, a validation process will need to be factored in to the design of the project (see Coyne et al. [22] for details). As mentioned above, the instrument should possess adequate measurement properties, responsiveness, acceptability and interpretability. In addition, it is vital to include comprehensive details surrounding the collection of PROM data in the study protocol, this will help maximise the quality of the data, and is especially important where PROM assessment might take place across multiple research sites [23]. In particular, plans for the prevention of missing PROM data (either individual items or whole questionnaires) should be routinely included as this can be a common problem [24]. Local guidelines regarding the inclusion of PROM information in protocols are available [25] and international consensus guidelines are in development [26]. Finally, a CONSORT (Consolidated Standards of Reporting Trials) PRO checklist has been developed to assist researchers in reporting patient-reported outcome trial results [27].

Using PROMs in clinical practice

PROMs can assist physiotherapists in their clinical reasoning process for diagnosis and treatment, with a specific focus on the patient's perspective. Involving the patient in this way can also help stimulate self-management [28]. PROMs can also be used by the physiotherapist, in concert with the patient, to identify the main problems in functioning and activities in daily living. Thus, PROMs can assist in establishing treatment objectives and monitor treatment results. When using PROMs for monitoring purposes, however, physiotherapists should be aware questionnaire data will likely incorporate a degree of measurement error at the individual patient level. Therefore it is important to be aware of the PROMs Minimal Clinically Important Change Score (MCID), defined as the smallest difference in PROM domain score which patients may perceive to be beneficial and which is 'significant enough to change patient management' [29]. Those PROMs that have been developed for use at the group level in research settings (especially generic tools) may be less reliable at the individual patient level [30], therefore, PROM measurement should always be used as an adjunct to clinical judgement.

Barriers to PROM use

Clinicians widely recognise the potential use of PROMs for improving the process of care by enhancing communication, patient education, shared-decision making and monitoring response to treatment. However, several barriers to the use of PROMs have been identified, which could lessen their usefulness in informing important health care decisions. Boyce and colleague's [31] review of qualitative studies investigating the experiences of healthcare professionals using PROMs identified practical barriers including:

the absence of a PROM collection infrastructure and the additional staff burden from PROM measurement that was 'disruptive to normal work duties' [32]. Similarly, a systematic review undertaken by allied health professionals, outlined a number of potential obstacles to routine outcome measurement, including: the absence of effective PROM-specific organisational and peer-support; and a lack of knowledge and confidence about using outcome measures [33]. These findings highlight the importance of having efficient PROM collection systems, as well as training staff involved in implementing the process.

Several studies have identified the added value of PROMs in improving the communication between clinicians and patients and for detecting health problems that would otherwise have gone unnoticed [34]. However, systematic reviews that assess the effectiveness of PROMs feedback on patient-outcomes show that the impact of such interventions is variable [34,35]. Effectiveness appears to be related to the function of the PROM, with the highest impact associated with the use of PROMs as management tools in outpatient settings for a specialised patient population; while the evidence for use of generic PROMs was less conclusive [35]. This research highlights the importance of having a target population in mind, with clear goals in place, to ensure routine PROM collection delivers the maximum benefit for patient care.

The use of PROMs for benchmarking

PROMs data have been introduced for service evaluation and commissioning of care in several countries. The National Health Service (NHS) in England introduced the routine collection of PROMs data in 2009, using the EQ-5D as generic questionnaire alongside other condition-specific questionnaires to collect data before and after elective surgical procedures including total hip and knee replacements [36]. In the Netherlands, PROMs data are being collected by purchasers of care for accountability purposes in combination with patient experience measures [37]. While international case studies illustrate the use of PROM data in clinical practice settings and implementation at health system level for performance measurement, these efforts have not yet demonstrated the feasibility of integrating the use of PROMs on a wide scale [38].

The use of PROMs at group level for quality improvement or performance measurement has received little attention in the literature. A recent systematic review found only one study that assessed peer-comparison feedback for improving patient functional status, and found no statistical differences between intervention and control groups [35]. The effectiveness of public reporting of PROMs data has also not yet been studied. However, indirect evidence for the effectiveness of public reporting of performance measures suggests that quality improvement activities of healthcare practitioners increase based on public report cards [39,40].

The use of PROMs data for performance measurement provides unique methodological challenges. First, the PROM itself should be valid and reliable for measuring treatment results at patient level. Second, the performance measure as derived from the PROM data should be valid and reliable to identify practice variation and quality of healthcare providers. Third, data should be reported and presented in an unambiguous manner to support commissioners and patients in making informed choices [41–43]. Advanced methodology is needed to enhance interpretation of data in comparing the quality of providers to inform patients and purchasers. Based on emerging evidence, guidance and research efforts to improve the interpretability of patient-reported outcomes is likely to enhance decision-making and the impact from using PROMs in practice.

PROMs: recent directions

The Royal Dutch Society for Physical Therapy (KNGF) has established a national four-year programme to stimulate the use of PROMs in clinical practice and provide performance measurement. In a series of pilot projects PROMs are being tested for their added value in supporting physiotherapists and patients in decision-making. A national database has been established for aggregating data at the group level to measure the results and quality of physiotherapy services. Data will be fed back to physiotherapists for quality improvement purposes, and the validity and reliability of data for developing performance measures will be tested. The current focus of the programme is the use of PROMs in primary care practice for five main patient groups (low back pain, neck pain, hip and knee problems, and shoulder complaints). PROMs will also be tested for several chronic conditions such as peripheral artery disease.

In the UK, ideas for a similar programme are still in their infancy but are being discussed within the CSP. Underpinning research is required to develop methods to enable future benchmarking of physiotherapy services using PROM data and the provision of national normative PROM change scores. At present, data describing the variability of clinical outcomes and costs among physiotherapy services is lacking. To enable future fair comparisons, methods are required to enable the standardisation of PROMs information using appropriate adjustment for local case-mix (e.g., deprivation, age and ethnicity) and to ensure PROMs data is able to identify variability in performance.

Conclusion

Within UK physiotherapy, PROMs are making a rapid transition from their traditional home within research to real-life busy clinical practice. The main driver for this change appears to be the political context and the demands of commissioners for evidence of the quality of care services

provide. There are several key messages for physiotherapists wishing to utilise PROMs. For clinicians, it is important that PROMs are selected carefully, to ensure they realise their potential in playing a direct role in assisting clinical reasoning, management and shared decision-making. It is crucial that the tool captures the aspects of health that matter the most to the patient population for which they are intended. For managers there are key messages to ensure the successful integration of PROMs into practice, including the importance of addressing barriers such as knowledge deficits and a lack of confidence in using PROMs; and also overcoming the complexity of establishing a culture of routine data collection. Finally, for leaders of the profession we highlight the urgent need to ensure that appropriate organisational and peer-support on this topic is available, which includes case examples of best practice, alongside clear guidance on the choice of PROMs for different conditions relevant to physiotherapy practice. We also call for greater funding of the underpinning research required to enable future benchmarking and performance comparisons.

Ethical approval: Not applicable.

Funding: D.K. is supported by a National Institute for Health Research (NIHR) School for Primary Care Research (SPCR) funded Ph.D. studentship. J.H. has been supported to develop and validate a new musculoskeletal PROM by the National Institute for Health Research UK Research for Patient Benefit Programme (PB-PG-0909-20283). No other funding sources reported. The funders had no role in the decision to publish, or preparation of the manuscript.

Conflict of interest: None to declare.

References

- [1] Black N. Patient reported outcome measures could help transform healthcare. *BMJ* 2013;346:f167.
- [2] Chartered Society of Physiotherapy. Patient reported outcome measures – how do you use patient-reported outcome measurement in routine musculoskeletal outpatient physiotherapy practice?; 2014. Available from: <http://www.csp.org.uk/professional-union/practice/evidence-base/patient-reported-outcome-measures> [accessed March 2014].
- [3] FDA. Guidance for industry: patient-reported outcome measures: use in medical product development to support labeling claims; 2009 <http://www.fda.gov/downloads/Drugs/GuidanceComplianceRegulatoryInformation/Guidances/UCM193282.pdf>
- [4] Sloan JA, Berk L, Roscoe J, Fisch MJ, Shaw EG, Wyatt G, et al. Integrating patient-reported outcomes into cancer symptom management clinical trials supported by the National Cancer Institute-sponsored clinical trials networks. *J Clin Oncol: Off J Am Soc Clin Oncol* 2007;25:5070–7.
- [5] Fayers P, Machin D. *Quality of life – the assessment analysis and interpretation of patient-reported outcomes*. 2nd ed. John Wiley & Sons Ltd; 2007.
- [6] Calvert MJ, Freemantle N. Use of health-related quality of life in prescribing research. Part 1: Why evaluate health-related quality of life? *J Clin Pharm Ther* 2003;28:513–21.
- [7] Rabin R, de Charro F. EQ-5D: a measure of health status from the EuroQol Group. *Ann Med* 2001;33:337–43.
- [8] Vernon H, Mior S. The neck disability index: a study of reliability and validity. *J Manip Physiol Ther* 1991;14:409–15.
- [9] Ruta D, Garratt AM, Leng M, Russell IT, MacDonald LM. A new approach to the measurement of quality of life: the patient generated index. *Med Care* 1994;32:1109–26.
- [10] Stratford P, Gill C, Westaway M, Binkley J. Assessing disability and change on individual patients: a report of a patient specific measure. *Physiother Can* 1995;47:258–63.
- [11] Paterson C. Measuring outcome in primary care: a patient-generated measure, MYMOP, compared to the SF-36 health survey. *Br Med J* 1996;312:1016–20.
- [12] Thieme H, Bayn M, Wurg M, Zange C, Pohl M, Behrens J. Mirror therapy for patients with severe arm paresis after stroke – a randomized controlled trial. *Clin Rehabil* 2013;27:314–24.
- [13] DoH. *Equity and excellence. Liberating the NHS*. United Kingdom: Department of Health; 2011.
- [14] CSP. Any qualified provider – CSP member briefing (No. 3); 2012. Available from: <http://www.csp.org.uk/publications/any-qualified-provider-aqp-briefing-3> [accessed April 2014].
- [15] Bent NP, Wright CC, Rushton AB, Batt ME. Selecting outcome measures in sports medicine: a guide for practitioners using the example of anterior cruciate ligament rehabilitation. *Br J Sports Med* 2009;43:1006–12.
- [16] Calvert M, Freemantle N. Use of health-related quality of life in prescribing research. Part 2: Methodological considerations for the assessment of health-related quality of life in clinical trials. *J Clin Pharm Ther* 2004;29:85–94.
- [17] Mokkink LB, Terwee CB, Knol DL, Stratford PW, Alonso J, Patrick DL, et al. The COSMIN checklist for evaluating the methodological quality of studies on measurement properties: a clarification of its content. *BMC Med Res Methodol* 2010;10:22.
- [18] Mokkink L, Terwee C, Patrick D, Alonso J, Stratford P, Knol D, et al. The COSMIN study reached international consensus on taxonomy, terminology, and definitions of measurement properties for health-related patient-reported outcomes. *J Clin Epidemiol* 2010;63:737–45.
- [19] Patient-Reported Outcome and Quality of Life Instruments Database (PROQOLID); 2014. Available from: <http://www.proqolid.org> [accessed March 2014].
- [20] Reeve BB, Wyrwich KW, Wu AW, Velikova G, Terwee CB, Snyder CF, et al. ISOQOL recommends minimum standards for patient-reported outcome measures used in patient-centered outcomes and comparative effectiveness research. *Qual Life Res* 2013;22(8):1889–905. <http://dx.doi.org/10.1007/s11136-012-0344-y>.
- [21] Terwee C, Mokkink L, Knol D, Ostelo R, Bouter L, de Vet H. Rating the methodological quality in systematic reviews of studies on measurement properties: a scoring system for the COSMIN checklist. *Qual Life Res* 2012;21:651–7.
- [22] Coyne KS, Tubaro A, Brubaker L, Bavendam T. Development and validation of patient-reported outcomes measures for overactive bladder: a review of concepts. *Urology* 2006;68:9–16.
- [23] Kyte D, Draper H, Ives J, Keely T, Calvert M. Inconsistencies in Health-Related Quality of Life (HRQL) data-collection in clinical trials – a potential source of bias? Interviews with research nurses and trialists. *Qual Life Res* 2013;20(Suppl.).
- [24] Fairclough D, Peterson HF, Chang V. Why are missing quality of life data a problem in clinical trials of cancer therapy. *Stat Med* 1998;17:667–77.
- [25] TRoG. *Psycho-Oncology Co-operative Research Group (University of Sydney) Resources*; 2013. Available from: <http://www.pocog.org.au> [accessed November 2013].
- [26] International Society for Quality of Life Research (ISOQOL). *Best practices for pros in randomized clinical trials taskforce*; 2014. Available from: <http://www.isoqol.org/about-isoqol/committees/best-practices-for-pros-in-randomized-clinical-trials> [accessed March 2014].

- [27] Calvert M, Blazeby J, Altman DG, Revicki D, Moher D, Brundage M. Reporting of patient reported outcomes in randomised trials: the CONSORT PRO extension. *JAMA* 2013;309:814–22.
- [28] Greenhalgh J. The applications of PROs in clinical practice: what are they, do they work, and why. *Qual Life Res* 2009;18:115–23.
- [29] Juniper EF, Guyatt GH, Willan A, Griffith LE. Determining a minimal important change in a disease-specific quality of life questionnaire. *J Clin Epidemiol* 1994;47:81–7.
- [30] de Vet HCW, Terwee CB, Mokkink LB, Knol DL. Measurement in medicine: a practical guide. Cambridge: Cambridge University Press; 2011.
- [31] Boyce MB, Browne JP. Does providing feedback on patient-reported outcomes to healthcare professionals result in better outcomes for patients? A systematic review. *Qual Life Res* 2013;22:2265–78.
- [32] Boyce MB, Browne JP, Greenhalgh J. The experiences of professionals with using information from patient-reported outcome measures to improve the quality of healthcare: a systematic review of qualitative research. *BMJ Qual Saf* 2014;23(6):508–18, <http://dx.doi.org/10.1136/bmjqs-2013-002524>.
- [33] Duncan EA, Murray J. The barriers and facilitators to routine outcome measurement by allied health professionals in practice: a systematic review. *BMC Health Serv Res* 2012;12:96.
- [34] Valderas JM, Kotzeva A, Espallargues M, Guyatt G, Ferrans CE, Halyard MY, et al. The impact of measuring patient-reported outcomes in clinical practice: a systematic review of the literature. *Qual Life Res* 2008;17:179–93.
- [35] Boyce MB, Browne JP. Does providing feedback on patient-reported outcomes to healthcare professionals result in better outcomes for patients: a systematic review. *Qual Life Res* 2013;22:2265–78.
- [36] Devlin NJ, Appleby J. Getting the most out of PROMS: putting health outcomes at the heart of NHS decision-making. London: The King's Fund; 2010.
- [37] Miletus. Stichting miletus. Zeist; 2013.
- [38] Van der Wees PJ, Nijhuis-van der Sanden MWG, Ayanian JZ, Black N, Westert GP, Schneider EC. Integrating the use of patient-reported outcomes for both clinical practice and performance measurement: views of experts from three countries. *Milbank Q* 2014 [in press].
- [39] Fung CH, Lim YW, Mattke S, Damberg C, Shekelle PG. Systematic review: the evidence that publishing patient care performance data improves quality of care. *Ann Intern Med* 2008;148:111–23.
- [40] Smith MA, Wright A, Queram C, Lamb GC. Public reporting helped drive quality improvement in outpatient diabetes care among Wisconsin physician groups. *Health Aff (Millwood)* 2012;31:570–7.
- [41] Devlin NJ, Parkin D, Browne J. Patient-reported outcome measures in the NHS: new methods for analysing and reporting EQ-5D data. *Health Econ* 2010;19:886–905.
- [42] Deutsch A, Gage B, Smith L, Kelleher C. Patient-reported outcomes in performance measurement. Washington, DC: National Quality Forum (NQF); 2012.
- [43] Cella D, Hahn EA, Jensen SE, Butt Z, Nowinski J, Rothrock N. Methodological issues in the selection, administration and use of patient-reported outcomes in performance measurement in health care settings. Washington, DC: National Quality Forum (NQF); 2012.

Available online at www.sciencedirect.com

ScienceDirect