

**SYSTEMATIC REVIEW OF THE USE OF PATIENT REPORTED OUTCOME  
MEASURES IN STUDIES OF ELECTIVELY-MANAGED HAND CONDITIONS**

***Patient Reported Outcome Measures in Hand Surgery***

Hawys Lloyd-Hughes<sup>1\*</sup>, Luke Geoghegan<sup>1\*</sup>, Jeremy Rodrigues<sup>1</sup>, Michele Peters<sup>2</sup>,  
David Beard<sup>1</sup>, Andrew Price<sup>1</sup>; Abhilash Jain<sup>1</sup>

<sup>1</sup>Nuffield Department of Orthopaedics, Rheumatology and Musculoskeletal Science  
(NDORMS), University of Oxford.

<sup>2</sup>Nuffield Department of Population Health, University of Oxford.

\*These authors contributed equally

Corresponding Author:

Jeremy Rodrigues

NHIR Postdoctoral Fellow in Plastic Surgery

Nuffield Department of Orthopaedics, Rheumatology and Musculoskeletal Sciences  
(NDORMS)

University of Oxford

Windmill Road, Oxford

OX3 7HE

Email: [j.n.rodrigues@doctors.org.uk](mailto:j.n.rodrigues@doctors.org.uk)

**Declaration of competing interests:** The authors declared no potential conflicts of interest with respect to the research, authorship, and/or publication of this article.

**Funding statement:** HLH was supported by a British Society for Surgery of the Hand (BSSH) Research Fellowship, a Royal College of Surgeons of England (RCSEng) Research Fellowship, and an NIHR doctoral research fellowship (DRF-2016-09-150). JR is an NIHR Postdoctoral Fellow (PDF-2017-10-075).

**Department of Health disclaimer:** This article presents independent research funded by the NIHR. The views expressed are those of the authors and not necessarily those of the NHS, the NIHR or the Department of Health.

## **ABSTRACT**

### **Background**

Electively-managed conditions account for over 100 000 inpatient surgeries a year in the English National Health Service alone, with further procedures in other regions of the UK, or performed on an outpatient basis. To quality assure this care and to conduct research, effective outcome measurement is critical. Traditional surgeon-centric outcome measures correlate poorly with hand function and are seldom important to patients. There has been an advent in the use of patient reported outcome measures (PROMs) in hand surgery although consensus of PROM choice appears to be lacking. This systematic review aimed to describe the use of relevant PROMs in clinical research of electively-managed hand conditions.

### **Methods**

A PRISMA-compliant methodology was used. A bespoke search strategy was developed in conjunction with a search strategist, and applied to Medline, EMBASE, CINAHL and PSYCHINFO from 1992 to June 2017. Pre-specified stepwise inclusion criteria were used to identify studies describing adult patients undergoing treatment for electively-managed hand conditions distal to the distal radius, with clinical outcomes measured using one or more PROMs.

### **Results**

Of 4554 results, 834 met inclusion criteria. PROMs identified included 9 disease-specific, 8 site-specific and 4 generic quality of life measures. Across all, the

Disabilities of the Arm, Shoulder and Hand (DASH) was the most commonly used (overall frequency 41.0%). The most commonly reported disease-specific measure was the Boston Carpal Tunnel Questionnaire (overall frequency 23.0%). The most commonly reported generic quality of life of measure was the SF-36 (overall frequency 4%). Time-analysis demonstrated predominance of site-specific PROMs since the year 2000.

## **Conclusions**

Various PROMs have been used to study electively-managed hand conditions, with site-specific PROMs most popular. However, there appears to be limited consensus on choices. A future systematic evaluation of the published psychometric properties of identified PROMs may inform standardisation of measurement.

**Key words:** Hand; Outcome Assessment (Health Care); Outcome measures; Patient-reported outcome measures; PROMs;

## INTRODUCTION

Measuring patient-centred outcomes may help to optimise care, support effective clinical decision-making, and improve the quality and results of clinical research.<sup>1)</sup>

Traditionally in hand conditions, functional outcome has been assessed using surgeon-reported observation and testing, such the assessment of grip strength and joint angles.<sup>2)</sup> Previously, such surgeon-centred outcomes were described as “objective”, yet they do not necessarily capture what is important to patients and their lives.<sup>3)</sup> Thus, they may potentially misdirect clinical care and research.<sup>4)</sup>

Patient-reported outcome measures (PROMs) are reports directly from the patient, without interpretation of the patient’s response by a clinician or other intermediates.<sup>5)</sup> If designed appropriately, they allow conceptualisation of the quality of care through consideration of the patient’s real-world physical status and functional ability.<sup>6,7)</sup>

A variety of PROMs have been developed for patients with hand conditions. Broadly, these can be categorised as generic instruments, site-specific and disease-specific instruments.<sup>4)</sup> The generic measures focus on widely applicable constructs such as health status or emotional well-being and are applicable to whole populations regardless of health status; site-specific PROMs are constrained to specific organ systems such as the hand or the upper limb; disease-specific instruments are designed to apply to a population with a specified disease pathology.

Given an abundance of PROMs for electively managed hand conditions, consensus regarding specific PROM usage would be desirable, as this would allow extrapolation and comparison of findings between studies. Although clinical implementation of PROMs remains largely based on individual preference, international consensus processes have attempted to describe core outcome sets for hand conditions,<sup>8,9)</sup> and

97 others are ongoing. Such endeavours have been successfully completed in other  
98 clinical areas.<sup>10)</sup>

99 The aim of this systematic review was to appraise of the use of hand-relevant PROMs  
100 in published research, and provide an overview of the currently used disease specific,  
101 site specific and generic PROMs. Cataloguing the currently used PROMs supports the  
102 future assessment of the psychometric properties of all relevant instruments, and  
103 provides information about the anticipated volume of existing data that might be  
104 expected for each PROM. This review aims to do so independently from a consensus-  
105 forming group, and thus is not influenced by the need to generate consensus at the  
106 end of the project. However, it will provide information that will contribute to the  
107 pragmatic selection of outcome measures in hand surgery.

## METHODS

Appropriate components of the PRISMA statement were used to design this study.<sup>11)</sup>

### **Search strategy**

Bespoke sensitive search strategies were developed in conjunction with a search strategist. They combined index and free text terms, to identify studies describing adult patients (P), undergoing treatment for electively-managed hand conditions distal to the distal radius (I and C), with clinical outcomes measured using one or more PROMs (O). Randomised controlled trials (RCTs), non-randomised controlled trials, cohort studies, case-control studies, cross-sectional surveys and case series were included, irrespective of sample size. Systematic reviews, case reports, expert opinion, studies related to PROM development or validation (rather than clinical outcome of treatment), and studies of trauma were not included. No date or language limits were applied.

Full search strategies are given in appendix 1. Specific hand conditions included within the search strategy included Dupuytren's disease, carpal tunnel syndrome, stenosing tenosynovitis, thumb base arthritis, arthridites of the hand and wrist, cubital tunnel syndrome, ulnar and median nerve compression syndromes. They were applied to Medline & In Process (1946-June 2017), EMBASE (1974- June 2017), CINAHL (1981-June 2017) and PsycINFO (1806- June 2017) separately on 16<sup>th</sup> January 2016 and rerun on 12<sup>th</sup> June 2017.

The reference lists of included articles were also hand searched for further relevant publications.

## **Study selection**

After pooling and electronic de-duplication, two authors independently screened all abstracts to identify potential studies for review, using pre-specified stepwise inclusion criteria (see Figure 1, PRISMA flow chart). All clinical study types irrespective of sample size were included. Adult populations from all ethnic origins with non-traumatic pathologies of the hand treated with any intervention (surgical, active non-surgical, placebo and observatory interventions) were included if the use of PROMs was specified. Studies that involved mixed cohorts of more than one condition were excluded if PROM use in specific constituent conditions was not reported. The journal title, author names and supporting institutions were not masked. Any disagreement was resolved by a third author.

## **Data extraction and analysis**

Standardised data extraction was performed in duplicate. These included study source, design, clinical condition, intervention and the PROM(s) used.

Once the PROMs used were counted and described, the specifics of the PROMs were extracted from cited publications or web resources. PROMs were analysed by condition and use over time. To account for variation in the number of articles published over time, the number of PROMs published relative to the total number of articles indexed on PubMed (multiplied by 1 million for convenience) was calculated.



157 No risk of bias assessment was appropriate in this study, given that it focussed on  
158 frequency of use of PROMs.

## RESULTS

### Search results

Database searching yielded 4,554 studies for screening. A further 2,418 studies were not included as they were either not clinical studies, did not involve an adult population, or did not study electively-managed conditions of the hand and wrist. In 1,114 studies no PROM was involved, and therefore they were excluded. A final 188 studies were excluded as they reported the evaluation of measurement properties of PROMs only. This left 834 studies that met the inclusion criteria and were therefore analysed (see PRISMA flow diagram, Figure 1).

### PROMs identified

PROMs identified included 9 disease-specific measures; 8 site-specific measures and 4 generic measures (see Table 1). Tables 2-4 provide conceptual overviews of the identified PROMs and include summaries of individual scoring systems.<sup>12-27)</sup> The generic health status/quality of life measures used were the Short Form 36 health survey questionnaire (SF-36) and the Short Form 12 health survey questionnaire (SF-12); <sup>27)</sup> EuroQol 5d 3-level (EQ5D-3L)<sup>28)</sup> and 5-level (EQ5D-5L); <sup>29)</sup> and the Patient Specific Functional Scale (PSFS).<sup>30)</sup>

### Descriptive analysis

Across all conditions, the Disabilities of the Arm, Shoulder and Hand (DASH) was the most commonly used PROM, followed by the Boston Carpal Tunnel Questionnaire, also termed the Levine Katz questionnaire (BCTQ/LK) and the QuickDASH. Figure 2 demonstrates the frequency of reported PROM use across all studies; measures with a greater than one percent reporting frequency are displayed.

184

185 In studies of carpal tunnel syndrome (CTS), the BCTQ/LK was the most commonly  
186 used PROM, followed by the DASH and QuickDASH. Figure 3 shows the frequency  
187 of the commonest PROMs used in studies of specific conditions.

188

189 For all other conditions including conditions where disease-specific PROMs were  
190 available, the DASH was the most frequently used PROM. Combinations of PROMs  
191 within a single study were commonly encountered; the use of DASH in conjunction  
192 with the BCTQ/LK was the most commonly reported combination.

193

194 Figure 4 demonstrates the change in PROM use over time number of articles using  
195 PROMs relative to the number of PubMed indexed articles in total that year (multiplied  
196 by 1 million for convenience). The relative frequency of PROM use has increased  
197 steadily since the early 1990s. The use of site-specific PROMs has predominated  
198 since the year 2000, but has risen faster than other groups. The use of disease-  
199 specific PROMs has overtaken combinations more recently. Despite the only  
200 recommendation of relevance by The Core Outcome Measures in Effectiveness Trials  
201 (COMET) advocating the use of combinations of PROMs for Dupuytren's disease  
202 studies in 2013 <sup>31)</sup> the frequency of use of PROM combinations since then has fallen  
203 across all hand conditions.

204

## DISCUSSION

This systematic review has identified variation in PROM use in published studies of electively-managed hand conditions. Twenty-four different PROMs were identified from 834 studies: 9 disease-specific measures; 8 site-specific measures and 4 generic measures. Furthermore, the choice of types of PROMs has fluctuated over time, even after the only core outcome set recognised by COMET was published for Dupuytren's disease in 2013.<sup>31)</sup>

Furthermore, the use of combinations of PROMs was encountered, with the most popular reported combination including a site-specific PROM and a disease-specific one. The COMET set was based on one review of Dupuytren's disease outcome measurement,<sup>32)</sup> which recommended using a combination of generic and disease-specific PROMs to ensure adequate assessment of a patient's status. This suggests that the relative strengths of generic and disease specific PROMs are leveraged and thus used in combination to account for their individual limitations. However, using more than one instrument may increase the administrative burden placed on patients unduly, only if the combined number of items were markedly higher. This could affect PROM completion and further and increase analytical burden.<sup>33)</sup> The feasibility of a using a single PROM to address all relevant domains may not be supported by the conceptual framework underpinning outcome measurement in hand surgery.<sup>34)</sup>

The three most common site-specific instruments encountered (DASH, QuickDASH and the Michigan Hand Questionnaire), were all developed in North America. Their popularity may reflect the volume of research using PROMs that has been designed and conducted there. Further, the DASH has been translated into more than 50

languages following original publication, with the QuickDASH translated into 2 further languages at the time of this publication. In contrast, the MHQ has also been translated and validated in 5 languages, with such disparity likely to influence the popularity of the DASH.<sup>35)</sup> The results of the present study, specifically the popularity of the DASH are in keeping with similar reviews of outcome measurement following trapeziometacarpal osteoarthritis,<sup>36)</sup> wrist osteoarthritis<sup>37)</sup> and Dupuytren's disease.<sup>32)</sup>

Carpal tunnel syndrome was the most researched condition. In articles related to CTS, the Boston Carpal Tunnel Questionnaire was the most frequently used instrument. Although despite disease-specific measures being available for other common conditions (Dupuytren's disease, rheumatoid arthritis and osteoarthritis), site-specific PROMs were more commonly used. Like the DASH, the BCTQ/LK was developed in North America and subsequently translated into 2 other languages. <sup>38,39)</sup>

Generic measures may be less sensitive to change than more specific tools, and therefore may not be able to detect important changes in patient's status.<sup>40)</sup> A measure unable to detect or reflect changes as the patient improves or deteriorates is of little clinical or research value, which may explain the infrequent use of generic measures. However, such measures hold merit in the comparison of intervention effect across populations with different health conditions, as may be performed in cost utility analysis.

Our results must be considered in view of the limitations of this study. Although a sensitive methodology was used to perform the literature search and screen articles it is possible that some relevant publications may not have identified or included. Some

relevant papers may have been inadvertently excluded as development or validation papers. However, given the large number of included studies, we believe that this review is likely to provide a fair representation of PROM use. Furthermore, there is no clear reason for any such error to be biased against a specific PROM compared to others. This study has considered the use of PROMs in research, but this may not reflect PROM use in clinical practice.

In conclusion, a wide variety of outcome measures have been used to study electively-managed conditions of the hand and wrist. The current systematic review provides a overview of which PROMs have been used in the hand surgery literature and with what frequency. It demonstrates a predominance of site-specific PROMS. In order to further rationalise the choice of PROMs, to guide the development of core outcome sets, or to verify a new outcome set, an independent systematic evaluation of the psychometric properties of the identified instruments is required.

**Acknowledgements:** Neal Thurley, outreach librarian at Bodleian Healthcare Libraries, provided expert assistance in the design and conduct of the literature search.

**Disclosures:** JR is funded by the NIHR. This work represents independent research funded by the NIHR. The views expressed are the authors' own, and are not necessarily those of the NIHR, NHS or Department of Health.

## REFERENCES

1. 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(8): 886-905.
2. Ball C, Izadi D, Verjee LS, Chan J, Nanchahal J. Systematic review of non-surgical treatments for early dupuytren's disease. *BMC Musculoskelet Disord.* 2016;17(1): 345.
3. Rodrigues J, Zhang W, Scammell B et al. Validity of the disabilities of the arm, shoulder and hand patient-reported outcome measure (dash) and the quickdash when used in dupuytren's disease. *J Hand Surg Eur Vol.* 2016;41(6): 589-99.
4. Szabo RM. Outcomes assessment in hand surgery: When are they meaningful? *J Hand Surg Am.* 2001;26(6): 993-1002.
5. Nelson EC, Eftimovska E, Lind C, Hager A, Wasson JH, Lindblad S. Patient reported outcome measures in practice. *BMJ.* 2015; 350: 7818.
6. Dawson J, Fitzpatrick R, Carr A, Murray D. Questionnaire on the perceptions of patients about total hip replacement. *J Bone Joint Surg Br.* 1996;78(2): 185-90.
7. Dawson J, Fitzpatrick R, Murray D, Carr A. Questionnaire on the perceptions of patients about total knee replacement. *J Bone Joint Surg Br.* 1998;80(1): 63-9.
8. Rudolf KD, Kus S, Chung KC, Johnston M, LeBlanc M, Cieza A. Development of the international classification of functioning, disability and health core sets for hand conditions--results of the world health organization international consensus process. *Disabil Rehabil.* 2012;34(8): 681-93.

9. Goldhahn J, Beaton D, Ladd A, Macdermid J, Hoang-Kim A. Recommendation for measuring clinical outcome in distal radius fractures: A core set of domains for standardized reporting in clinical practice and research. *Arch Orthop Trauma Surg.* 2014;134(2): 197-205.
10. International Consortium on Health Outcome Measurement. Completed Conditions, 2018. <http://www.ichom.org/medical-conditions/> (Accessed 08/10/2018)
11. Moher D, Liberati A, Tetzlaff J, Altman DG. Preferred reporting items for systematic reviews and meta-analyses: The prisma statement. *Ann Intern Med.* 2009;151(4): 264-9.
12. Allen KD, Jordan JM, Renner JB, Kraus VB. Validity, factor structure, and clinical relevance of the auscan osteoarthritis hand index. *Arthritis Rheum.* 2006;54(2): 551-6.
13. Levine DW, Simmons BP, Koris MJ et al. A self-administered questionnaire for the assessment of severity of symptoms and functional status in carpal tunnel syndrome. *J Bone Joint Surg Am.* 1993;75(11): 1585-92.
14. Mohan A, Vadher J, Ismail H, Warwick D. The southampton dupuytren's scoring scheme. *J Plast Surg Hand Surg.* 2014;48(1): 28-33.
15. Leeb BF, Sautner J, Andel I, Rintelen B. Sacrah: A score for assessment and quantification of chronic rheumatic affections of the hands. *Rheumatology (Oxford).* 2003;42(10): 1173-8.
16. Beaudreuil J, Allard A, Zerkak D et al. Unite rhumatologique des affections de la main (uram) scale: Development and validation of a tool to assess dupuytren's disease-specific disability. *Arthritis Care Res.* 2011;63(10): 1448-55.



17. Meenan RF, Mason JH, Anderson JJ, Guccione AA, Kazis LE. AIMS2. The content and properties of a revised and expanded Arthritis Impact Measurement Scales Health Status Questionnaire. *Arthritis Rheum.* 1992;35(1): 1-10.
18. Citron N, Hulme CE, Wardle N. A self-administered questionnaire for basal osteoarthritis of the thumb. *J Hand Surg Eur.* 2007;32(5):524-8.
19. Hudak PL, Amadio PC, Bombardier C. Development of an upper extremity outcome measure: the DASH (disabilities of the arm, shoulder and hand) [corrected]. The Upper Extremity Collaborative Group (UECG). *Am J Ind Med.* 1996;29(6): 602-8.
20. Beaton DE, Wright JG, Katz JN. Development of the quickdash: Comparison of three item-reduction approaches. *J Bone Joint Surg Am.* 2005; 87: 1038-46.
21. Chung KC, Pillsbury MS, Walters MR, Hayward RA. Reliability and validity testing of the Michigan hand outcomes questionnaire. *J Hand Surg Am.* 1998; 23(4): 575-87.
22. Dias JJ, Bhowal B, Wildin CJ, Thompson JR. Assessing the outcome of disorders of the hand. Is the patient evaluation measure reliable, valid, responsive and without bias? *J Bone Joint Surg Br.* 2001;83(2): 235-40.
23. MacDermid JC, Turgeon T, Richards RS, Beadle M, Roth JH. Patient rating of wrist pain and disability: a reliable and valid measurement tool. *J Orthop Trauma.* 1998;12(8):577-86.
24. Cooney WP, Bussey R, Dobyns JH, Linscheid RL. Difficult Wrist Fractures Perilunate Fracture-Dislocations of the Wrist. *Clin Orthop Relat Res.* 1987; 214: 136-47.

25. Stratford PW. Development and initial validation of the Upper Ectremity Functional Index. *Physiother Can.* 2001; 52: 259-67.
26. Duruöz MT, Poiraudau S, Fermanian J, Menkes CJ, Amor B, Dougados M, Revel M. Development and validation of a rheumatoid hand functional disability scale that assesses functional handicap. *J Rheumatol.* 1996;23(7):1167-72.
27. Ware JE, Jr., Sherbourne CD. The mos 36-item short-form health survey (sf-36). I. Conceptual framework and item selection. *Med Care.* 1992; 30: 473-83.
28. Brooks R. Euroqol: The current state of play. *Health Policy.* 1996;37(1): 53-72.
29. Herdman M, Gudex C, Lloyd A et al. Development and preliminary testing of the new five-level version of eq-5d (eq-5d-5l). *Qual Life Res.* 2011;20(10): 1727-36.
30. Stratford P. Assessing disability and change on individual patients: A report of a patient specific measure. *Physiother Can.* 1995;47(4): 258-63.
31. COMET (Core Outcome Measures in Effectiveness Trials) Initiative. Optimal outcome measures for accessing treatment for Dupuytren's disease: a systematic review and recommendations for future practice, 2013. <http://www.comet-initiative.org/studies/details/643?result=true> (Accessed 04/02/18).
32. Ball C, Pratt AL, Nanchahal J. Optimal functional outcome measures for assessing treatment for dupuytren's disease: A systematic review and recommendations for future practice. *BMC Musculoskelet Disord.* 2013;14(1): 131.

33. Chenok K, Teleki S, SooHoo NF, Huddleston J, Bozic KJ. Collecting patient-reported outcomes: Lessons from the california joint replacement registry. *EGEMS (Wash DC)*. 2015;3(1): 1196.
34. Forget NJ, Jerosch-Herold C, Shepstone L, Higgins J. Psychometric evaluation of the disabilities of the arm, shoulder and hand (dash) with dupuytren's contracture: Validity evidence using rasch modeling. *BMC Musculoskeletal Disord*. 2014;15(1): 361.
35. Dubert T, Voche P, Dumontier C, Dinh A. [the dash questionnaire. French translation of a trans-cultural adaptation]. *Chir Main*. 2001;20(4): 294-302.
36. Marks M, Schoones JW, Kolling C, Herren DB, Goldhahn J, Vliet Vlieland TPM. Outcome measures and their measurement properties for trapeziometacarpal osteoarthritis: A systematic literature review. *J Hand Surg Eur Vol*. 2013;38(8): 822-38.
37. McPhail SM, Bagraith KS, Schippers M, Wells PJ, Hatton A. Use of condition-specific patient-reported outcome measures in clinical trials among patients with wrist osteoarthritis: A systematic review. *Adv Orthop*. 2012; 273421.
38. Cheng HM, Sampaio RF, Mancini MC, Fonseca ST, Cotta RM. Disabilities of the arm, shoulder and hand (dash): Factor analysis of the version adapted to portuguese/brazil. *Disabil and Rehabil*. 2008;30(25): 1901-9.
39. Oteo-Alvaro A, Marin MT, Matas JA, Vaquero J. [spanish validation of the boston carpal tunnel questionnaire]. *Med Clin (Barc)*. 2016;146(6): 247-53.
40. Revicki DA, Cella D, Hays RD, Sloan JA, Lenderking WR, Aaronson NK. Responsiveness and minimal important differences for patient reported outcomes. *Health Qual Life Outcomes*. 2006; 4(1):70.

# Tables

**Table 1:** Overview of All Identified Patient Reported Outcome Measures.

Disease specific PROM	Site specific PROM	Generic quality of life measurement
AUSCAN	DASH	SF-36
BCTQ/LK	Quick DASH	SF-12
SDSS	MHQ	EQ-5D
SACRAH	PEM	PSFS
URAM	PRWE	
AIMS2	MWS	
Modified Nelson score	UEFI	
Hi-Ob*	Duruöz hand index/CHFS	
CTS-6*		

**AIMS2-** Arthritis Impact Measurement Scales 2; **AUSCAN-** Australian Canadian Osteoarthritis Hand Index; **BCTQ/LK-** Boston Carpal Tunnel Questionnaire/ Levine Katz Questionnaire; **CHFS:** Cochin Hand Function Scale; **CTS-6-** Carpal Tunnel Syndrome 6; **DASH-** Disabilities of the Arm, Shoulder and Hand questionnaire; **Hi-Ob-** Historical Observation scale; **MHQ-** Michigan Hand outcomes Questionnaire; **MWS-** Mayo Wrist Score; **PEM-** Patient Evaluation Measure; **PRWE-** Patient rated wrist evaluation; **PSFS-** Patient Specific Functional Scale; **SACRAH-** Score for Assessment and quantification of Chronic Rheumatic Affections of the Hands; **SDSS-** Southampton Dupuytren's Scoring Scheme; **SF-12-** Short Form 12; **SF-36-** Short Form 36; **UEFI-** Upper Extremity Functional Index; **URAM-** Unité Rhumatologique des Affections de la Main Scale.

\* Included as meets the operational definition of a PROM, but use may be considered as a diagnostic adjunct

405 **Table 2:** Conceptual Overview of Identified Disease Specific Patient Reported Outcome Measures.

PROM	Author	Disease applicability	Scoring	Modular subscales (if applicable)	Minimum-maximum score	Response scale
<b>Australian/Canadian Osteoarthritis Hand index (AUSCAN)</b>	Allen et al. <sup>12)</sup>	Osteoarthritis of the hand	Total score is calculated from the summed weights for each subscale. The lower the score the lesser the disability.	1) Pain: 20 points 2) Stiffness: 4 points 3) Physical function: 36 points	0-60	15 items scored on a 5 point Likert scale and 100mm VAS
<b>Boston Carpal Tunnel Questionnaire (BCTQ/LK)</b>  <b>AKA Levine-Katz / Brigham and Women's Carpal Tunnel Questionnaire/ The Carpal Tunnel Instrument</b>	Levine et al. <sup>13)</sup>	Carpal Tunnel Syndrome	Total score is calculated from the summed weights of functional and symptom severity sub scales.  The lower the score the lesser the better the outcome.	1) Functional status: 40 points 2) Symptom severity <ul style="list-style-type: none"> <li>▪ Pain: 25 points</li> <li>▪ Numbness: 20 points</li> <li>▪ Weakness: 10 points</li> </ul>	1-5	19 items scored on a 5 point Likert scale. Summed scores are divided by the number of questions answered.
<b>The Southampton Dupuytren's Scoring Scheme (SDSS)</b>	Mohan et al. <sup>14)</sup>	Dupuytren's disease	Total score is calculated from the summed weights of the 5 items investigating disease associated disability.  The lower the score, the lesser the disability.		0-20	5 items scored on a 5 point Likert scale
<b>Score for Assessment and Quantification of Chronic Rheumatic Affections of the Hands (SACRAH)</b>	Leeb et al. <sup>15)</sup>	Rheumatoid arthritis of the hand	The score for each subscale is calculated; the overall score is the average of the three subscale scores.  The lower the score, the better the outcome.	1) Function: 17 items 2) Stiffness: 2 items 3) Pain: 4 items	0-100	23 items scored on a 100mm VAS The average score for each subscale is calculated, an overall average measure for the three categories is then obtained.
<b>Unité Rhumatologique des Affections de la Main Scale (URAM)</b>	Beaudreuil et al. <sup>16)</sup>	Dupuytren's disease	Total score is calculated from the summed weights of the 9 items investigating disease associated disability.  The lower the score, the lesser the disability.		0-45	9 items scored on a 6 point Likert scale.
<b>Arthritis Impact Measurement Scales 2 (AIMS2)</b>	Meenan et al. <sup>17)</sup>	Arthritis	Total score is calculated from the summed weight and scalar conversion of the 12 domains. Scores are normalised in the range 0-10. A further 21 items assess satisfaction, health perception, arthritis impact and demographic data.	1) Mobility: 5 items 2) Walking and bending: 5 items 3) Hand and finger function: 5 items 4) Arm function: 5 items	12 health scores ranging from 0-10 are obtained.	57 items scored on a 5 point Likert scale.

			The lower the score, the lesser the disability.	5) Self-care tasks: 4 items 6) Household tasks: 4 items 7) Social activities: 5 items 8) Support from family and friends: 4 items 9) Arthritis pain: 5 items 10) Work: 5 items 11) Level of tension: 5 items 12) Mood: 5 items		
<b>Modified Nelson Score</b>	Citron et al. <sup>18)</sup>	Thumb osteoarthritis	The raw scores of 10 individual items are added to provide a total score. Each Likert scale has a corresponding scoring system and individual weight.		0-100	2 items scored on a 7 point Likert (scale: 0-12 points) 6 items scored on a 6 point Likert (scale: 0-10 points) 1 item scored on a 5 point Likert: (scale: 0-8 points) 1 item scored on a 3 point Likert (scale: 0-8 points)
<b>VAS = Visual analogue scale</b>						

406

407

408 **Table 3:** Conceptual Overview of Site-Specific Patient Reported Outcome Measures.

PROM name	Author	Scoring	Number of modules	Modular subscales	Optional modules	Minimum-maximum score	Response scale
<b>Disabilities of the Arm, Shoulder and Hand Questionnaire (DASH)</b>	Hudak et al. <sup>19)</sup>	Each module is scored independently.  The lower the score, the better the function.	1 Required  2 Optional	1) Activities of daily living: 105 points 2) Social activities: 5 points 3) Work activities: 5 points 4) Symptoms: 25 points 5) Sleeping: 5 points 6) Confidence: 5 points	1) Sports/hobbies: 20 points 2) Work: 20 points	0-100	30 items scored on 5 point Likert scale
<b>QuickDASH</b>	Beaton et al. <sup>20)</sup>	Shortened version of the DASH. Each module is scored independently.  The lower the score, the better the function.	1 Required  2 Optional	1) Activities of daily living: 25 points 2) Social & work activities: 10 points 3) Recreation: 5 points 4) Symptom severity: 10 points 5) Sleeping: 5 points	1) Sports/hobbies: 20 points 2) Work: 20 points	0-100	11 items scored on a 5 point Likert scale
<b>Michigan Hand Outcomes Questionnaire (MHQ)</b>	Chung et al. <sup>21)</sup>	Each sub-scale is scored independently and normalised to 100. The total MHQ score is an average of all subscale scores.  A higher score indicates more pain on the pain scale but better hand performance in the other scales.  Each hand can be assessed separately.	1 Required	1) Function: 25 points 2) Activities of daily living A. One handed activities of daily living: 25 points B. Two handed activities of daily living: 35 points 3) Work: 25 points 4) Pain: 25 points 5) Aesthetics: 20 points 6) Satisfaction: 30 points		0-100	37 items scored on a 5 point Likert scale.  Multiple responses required for select items leading to 57 questions in total.
<b>Patient Evaluation Measure (PEM)</b>	Dias et al. <sup>22)</sup>	18 items are scored as a percentage of the maximum possible score.  The lower the score, the better the function.	1 Required	1) Treatment: 5 items 2) Subjective hand function: 10 items, 11 <sup>th</sup> item added by Dias et al. 3) Overall assessment: 3 items		0-77 (for 11-item PEM part 2)	11 items scored on a 7 point Likert scale
<b>Patient Rated Wrist Evaluation (PRWE)</b>	MacDermid et al. <sup>23)</sup>	Pain score= sum of the 5 pain items. Function score = sum of the 10 pain items divided by 2. Scores from each subscale are combined	1 Required	1) Pain: 5 items 2) Function: 10 items a. Specific activities (6 items) b. Usual activities (4 items)		Total: 0-100 Pain: 0-50	15 items scored on a 10 point Likert scale

		to provide an overall total score.				Function: 0-50	
		The lower the score, the better the function.					
<b>Mayo Wrist Score (MWS)</b>	Cooney et al. <sup>24)</sup>	Scores from each subscale are combined to provide an overall total score.  The higher the score, the better the function.	4 required	1) Pain: 25 points 2) Grip strength: 25 points 3) Range of motion: 25 points 4) Return to employment: 25 points		0-100	3 items scored on a 5 point Likert scale; 1 item scored on a 7 point Likert scale
<b>Upper Extremity Functional Index (UEFI)</b>	Stratford et al. <sup>25)</sup>	The raw scores of the questions are added to provide a total score.  The higher the score, the better the function.	1 required	20 individual items (no sub-scales)		0-80	20 items scored on a 5 point Likert scale
<b>Duruöz Hand Index/ Cochin Hand Function Scale (CHFS)</b>	Duruöz et al. <sup>26)</sup>	The raw scores of the questions are added to provide a total score.  The lower the score, the better the function.	5 required	1) Kitchen work: 8 items 2) Dressing: 2 items 3) Hygienic practices: 2 items 4) Office work: 2 items 5) Other: 4 items		0-90	18 items scored on a 6 point Likert scale

409

410



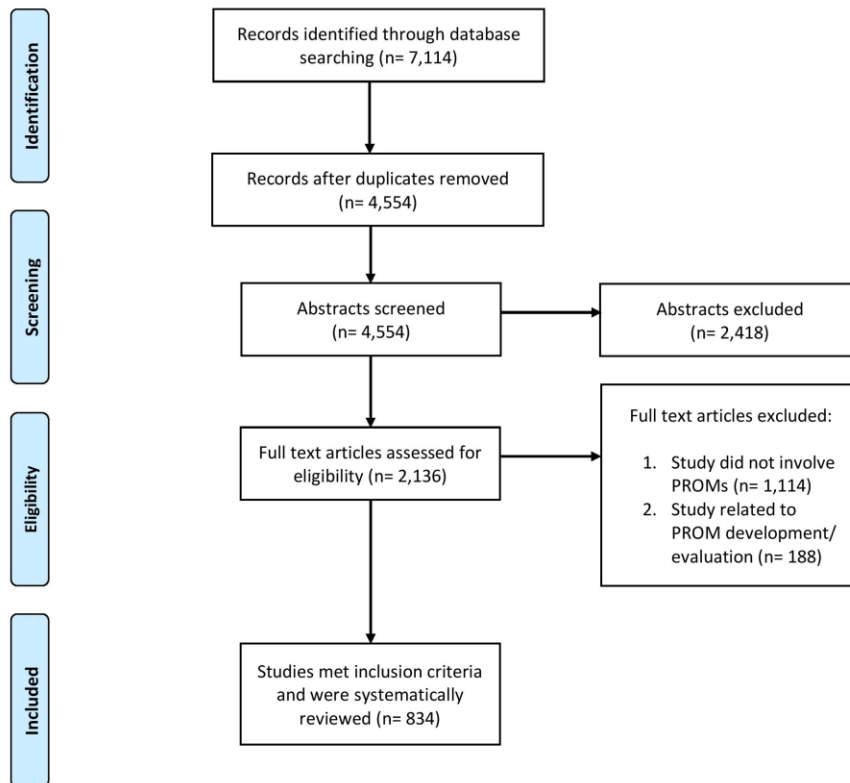
411 **Table 4: Conceptual Overview of Generic Quality of Life Measures.**

412

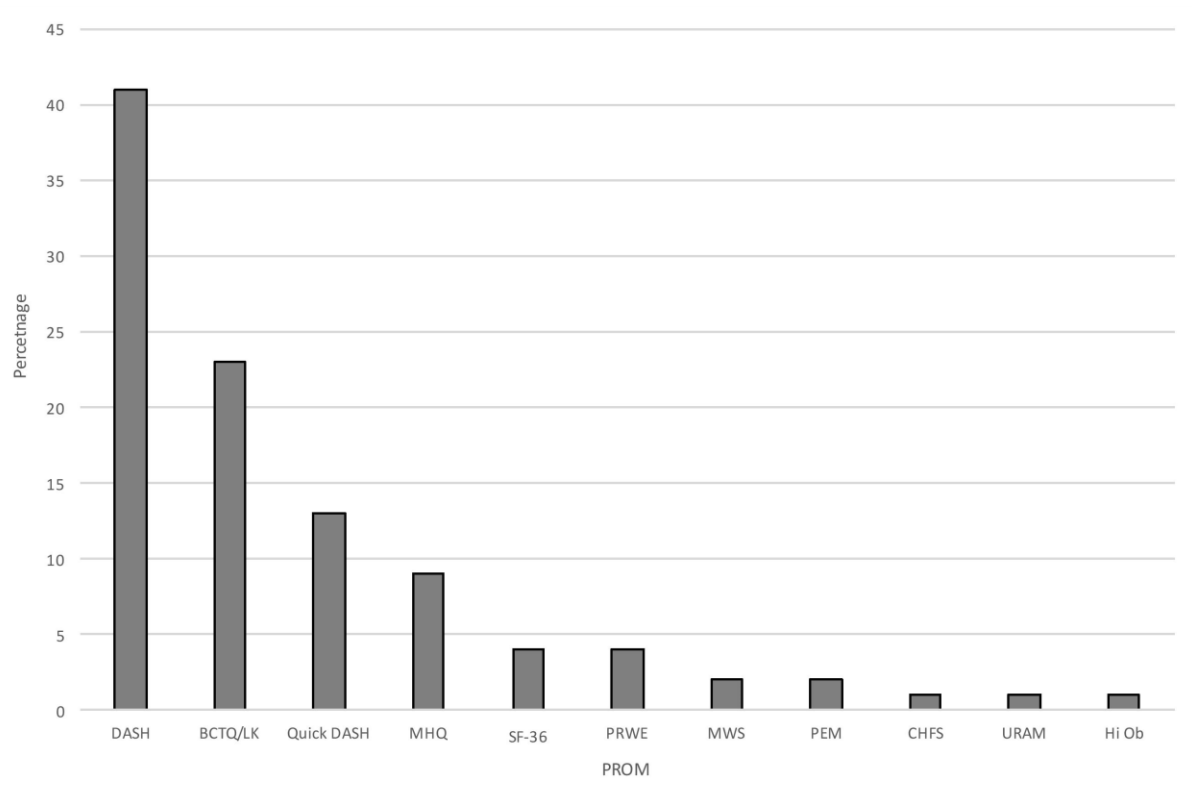
PROM	Author	Scoring	Modular subscales (if applicable)	Minimum- maximum score	Response scale
<b>SF-36</b>	Ware et al. <sup>27)</sup>	Aggregate scores are compiled as a percentage of the total available points using RAND scoring table. Scores from questions addressing a specific area of health status are averaged together for a final score within each of the 8 dimensions measured.  The lower the score the greater the disability.	1) Eight individual sections <ul style="list-style-type: none"> <li>▪ Vitality</li> <li>▪ Physical functioning</li> <li>▪ Bodily pain</li> <li>▪ General health perceptions</li> <li>▪ Physical role functioning</li> <li>▪ Emotional role functioning</li> <li>▪ Social role functioning</li> <li>▪ Mental health</li> </ul>	Each scale is transformed onto a 0-100 scale assuming each question carries equal weight. Range: 0-100	28 items scored on a 3 point Likert scale; 7 items scored in binary format and 1 item investigates health changes over the past year and is not used for health-related quality of life evaluation
<b>SF-12</b>	Ware et al. <sup>27)</sup>	Aggregate scores are compiled as a percentage of the total available points using RAND scoring table. Scores from questions addressing a specific area of health status are averaged together for a final score within each of the 8 dimensions measured.  The lower the score the greater the disability.	1) Eight individual sections <ul style="list-style-type: none"> <li>▪ Vitality</li> <li>▪ Physical functioning</li> <li>▪ Bodily pain</li> <li>▪ General health perceptions</li> <li>▪ Physical role functioning</li> <li>▪ Emotional role functioning</li> <li>▪ Social role functioning</li> <li>▪ Mental health</li> </ul>	Each scale is transformed onto a 0-100 scale assuming each question carries equal weight. Range: 0-100	3 items scored on a 6 point Likert scale; 3 items scored on a 5 point Likert scale; 2 items scored on a 3 point Likert scale and 4 items scored in binary format
<b>EQ5D-3L</b>	Brooks et al. <sup>28)</sup>	Total score is calculated from the summed weights for each subscale.  The lower the score the lesser the disability.	3) EQ-5D descriptive system <ul style="list-style-type: none"> <li>▪ Mobility</li> <li>▪ Self-care</li> <li>▪ Usual activities</li> <li>▪ Pain/discomfort</li> <li>▪ Anxiety/depression</li> </ul> 4) EQ-5D visual analogue scale	Health status is presented as a 5-digit number corresponding to user response: <ul style="list-style-type: none"> <li>▪ 1 = No problems</li> <li>▪ 2 = Some problems</li> <li>▪ 3 = Extreme problems</li> </ul> Range: 11111- 33333	5 items scored on a 3 point Likert scale and 200mm VAS
<b>EQ5D-5L</b>	Herdman et al. <sup>29)</sup>	Total score is calculated from the summed weights for each subscale.  The lower the score the lesser the disability.	1) EQ-5D descriptive system <ul style="list-style-type: none"> <li>▪ Mobility</li> <li>▪ Self-care</li> <li>▪ Usual activities</li> <li>▪ Pain/discomfort</li> <li>▪ Anxiety/depression</li> </ul> 2) EQ-5D visual analogue scale	Health status is presented as a 5-digit number corresponding to user response: <ul style="list-style-type: none"> <li>▪ 1 = No problems</li> <li>▪ 2 = Slight problems</li> <li>▪ 3 = Moderate problems</li> <li>▪ 4 = Severe problems</li> <li>▪ 5 = Extreme problems</li> </ul> Range: 11111- 55555	5 items scored on a 5 point Likert scale and 200mm VAS
<b>PSFS</b>	Stratford et al. <sup>30)</sup>	Patients identify activities they are having difficulty performing. The lower the score the greater the disability.	5 patient specified activities	The total score represents the aggregate scores for all activities divided by the number of activities.	5 items scored on 11 point Likert scale

# Figures

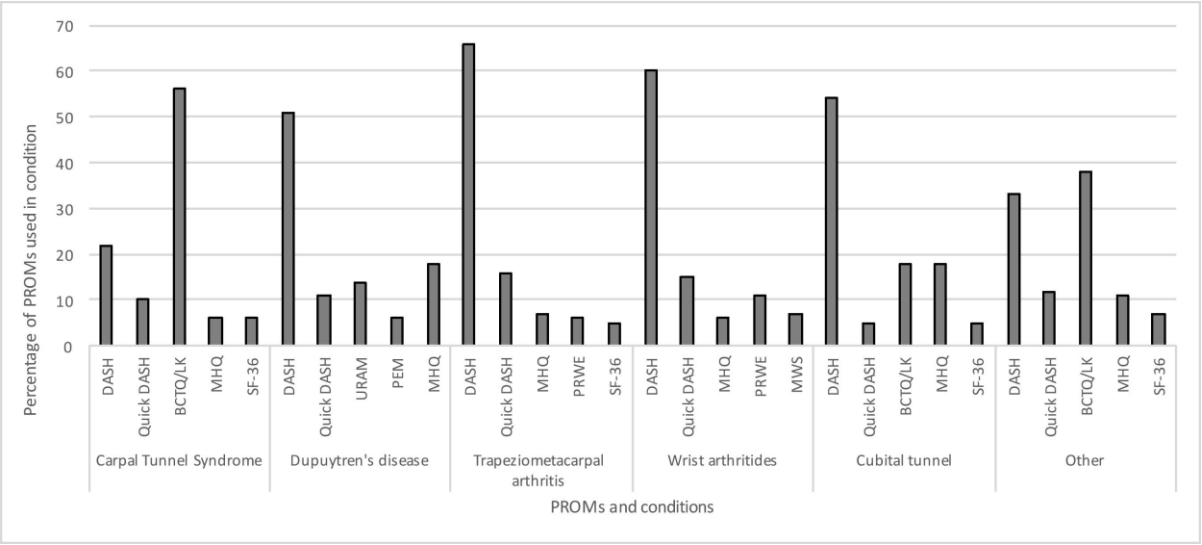
**Figure 1: PRISMA flow diagram**



**Figure 2:** The frequency of use of PROMs across all studies. (PROMs used in >1% of studies displayed. MWS: Mayo Wrist Score; CHFS: Cochin Hand Function Scale; HiOb: Historic and Objective Scale).



423 **Figure 3:** Bar charts of the top five reported PROMs by specific clinical pathology.



424

425

**Figure 4:** Relative frequency of reported PROM use across all studies, stratified by year.

