Supplementary Table 1 Details of papers included in the scoping review

Authors	Publication year	Summary of Guidance/Recommendations outlined in publication
General papers on PROM development and adaptation		
U.S. Department of Health and Human Services, Food and Drug Administration, Center for Drug Evaluation and Research (CDER), Center for Biologics Evaluation and Research (CBER), Center for Devices and Radiological Health (CDRH). Guidance for Industry Patient-Reported Outcome Measures: Use in Medical Product Development to Support Labeling Claims.[2]	2009	Guidance describes how the FDA reviews and evaluates existing, modified, or newly created patient-reported outcome (PRO) instruments used to support claims in approved medical product labeling. *Extensive guidance on PROMs use from development to implementation in trials. Many aspects relevant to adaptation of existing PROMs.*
Bausewein C, Daveson BA, Currow DC, et al. EAPC White paper on outcome measurement in palliative care: Improving practice, attaining outcomes and delivering quality services-Recommendations from the European Association for Palliative Care (EAPC) Task Force on Outcome Measurement.[20]	2016	This White paper aims to provide expert recommendations on outcome measurement in palliative care in clinical practice and research. *Twelve recommendations are proposed covering the key parameters of measures focusing on palliative care. These recommendations are relevant to other clinical areas.*
Downing J, Namisango E, Harding R. Outcome measurement in paediatric palliative care: lessons from the past and future developments.[3]	2018	This paper provides recommendations for the development of locally relevant, validated tools to measure outcomes for children. *Specific PROMs considerations when utilising PROMs in palliative care paediatric populations that are relevant to PROMs use generally.*
Jensen RE, Snyder CF, Basch E, et al. All together now: findings from a PCORI workshop to align patient-reported outcomes in the electronic health record. [87]	2016	This paper reports on the findings for a workshop and provide actionable guidance across research and practice settings to promote and sustain widespread adoption of patient-reported outcomes across patient populations, healthcare settings and electronic health record systems. *Recommendations regarding the routine integration of PROMs within electronic health record. Many recommendations*

		relevant to PROMs use generally.
Matza LS, Patrick DL, Riley AW, et al. Pediatric patient-reported outcome instruments for research to support medical product labeling: Report of the ISPOR PRO good research practices for the assessment of children and adolescents task force.[87]	2013	The purpose of this task force report is to recommend good practice for pediatric PRO research that is conducted to inform regulatory decision making and support claims made in medical product labeling. *The report focuses on PROMs for adolescents and children, but the principles of good practice are more broadly applicable.*
Ovretveit J, Zubkoff L, Nelson EC, et al. Using patient-reported outcome measurement to improve patient care.[76]	2017	The purpose of this paper is to provide an introduction to the use and value of patient-reported outcome measures in quality improvement and to give practical guidance and resources for using PROMs for quality improvement. *The paper provides information on some PROMs resources that can be accessed for quality improvement and discusses some considerations when selecting and using a PROM.*
Acaster S, Cimms T, Lloyd A. The design and selection of patient-reported outcome measures (PROMs) for use in patient centred outcomes research. [79]	2012	This report outlines a set of draft minimum standards for the development, selection and use of PROMs data. *Provides a summary of guidance documents used to develop the report and includes considerations for adapting existing PROMs.*
Black N. Patient reported outcome measures could help transform healthcare. [9]	2013	This paper provides a clinical perspective regarding the application of PROMs to drive health care organisation and delivery. *General introduction to PROMs, including key considerations and guidance about how they can be applied to organise and delivery of healthcare. Some principles relevant to PROMs adaptation.*
Brundage M, Blazeby J, Revicki D, et al. Patient-reported outcomes in randomozed clinical trials: development of ISOQOL reporting standards. [90]	2013	This paper reports in the development of expert guidance on a suite of reporting standards for PROM outcomes of randomised controlled trials. *The final guidance also includes recommended standards for reporting PROMs generally.*
Calvert M. Maximising the impact of patient reported outcomes assessments for patients and society. [78]	2019	This paper focuses on recent developments in the use of PROMs and considers strategies for efficient PROM data

		collection. *This paper provides an overview of PROMs considerations which are relevant to adaptations of PROMs.*
Chan EKH, Edwards TC, Haywood K, et al. Implementing patient-reported outcome measures in clinical practice: A companion guide to the ISOQOL User's guide. [91]	2018	This user guide provides an evidence synthesis that outlines core considerations for implementing PROM assessment in clinics and hospitals. *The guide provides an overview of issues to be considered when implementing PROMs that are relevant to PROMs adapations.*
Dawson J. The routine use of patient reported outcome measures in heathcare settings. [92]	2010	This paper provides guidance regarding the implementation of PROMs at a local level and highlights considerations and common pitfalls . *This paper provides an general overview of PROMs and how they can be implemented sucessfully. Some issues are relevant to PROMs adaptation.*
European Medicines Agency. Reflection paper on the regulatory guidance for the use of health-related quality of life (HRQL) measures in the evaluation of medicinal products. [5]	2005	The scope of this reflection paper is to discuss the place that a health-related quality of life (HRQL) may have in the drug evaluation process and to give some broad recommendations on its use in the context of existing guidance. *Some issues raises are relevant to PROM adaptation.*
Luckett T, King MT. Choosing patient-reported outcome measures for cancer clinical research- Practical principles and an algorithm to assist non-specialist researchers. [19]	2010	The purpose of this article is to give practical advice to researchers wishing to choose measures of quality of life and other patient-reported outcomes (PROs) for cancer clinical research. *Outlines 6 guiding considerations when selecting cancer PROMs- but these can be broadly applied when selecting PROMs in other clinical areas.*
Rothrock NE, Kaiser KA, Cella D. Developing a valid patient-reported outcome measure. [93]	2011	This article describes the processes for constructing valid PROMs, from conceptutal model development through to instrument validation. *This article includes a generic introduction to PROMs and their development, some issues of which are relevant to adaptation of PROMs.*
Smith DJ, Huntington J. Choosing the "correct" instrument. [94]	2006	This paper provides an overview of some of the key questions that should be considered

		when selecting a PROM. *It provides some relevant real-world examples of why adaptation might be needed.*
Snyder CF, Watson ME, Jackson JD, et al. Patient-reported outcome instrument selection: Designing a measurement strategy.[25]	2007	This paper discusses issues in the design of a measurement strategy related to the use of PROMs. *Offers some useful guidance on key considerations when adapting PROMs, types of adaptations and additional validations.*
Anfray C, Arnold B, Martin M, et al. Reflection paper on copyright, patient-reported outcome instruments and their translations. [26]	2018	This paper provides guidance to help 1) authors of PROMs understand the basic rules of intellectual property and copyright that protect the integrity of their instruments and derivatives; and 2) provide recommendations to authors and users of PROMs to prevent misuse or abuse. *Provides guidance that is relevant to any adaptation of an existing PROM.*
Specific guidance relating to assessment of existing PROMs		
Mokkink LB, de Vet HCW, Prinsen CAC, et al. COSMIN risk of bias checklist for systematic reviews of patient-reported outcome measures.[13]	2018	The purpose of this updated paper is to provide and updated version of the COSMIN checklist into a version exclusively for use in systematic reviews of PROMs, aiming to assess risk of bias studies on measurement properties. *This paper provides updated guidance regarding the checklist and scoring system used to assess the rsk of bias of studies included in systematic reviews of PROMs.*
Prinsen CAC, Mokkink LB, Bouter LM, et al. COSMIN guideline for systematic reviews of patient-reported outcome measures. [14]	2018	This paper provides guidance on the conduct of systematic reviews of PROMs and includes methodology for combining the methodological quality of studies on measurement properties with the quality of the PROM itself. *This methodological guideline aims to support authors conducting PROMs systematic reviews in a clear and consistent way. This will facilitate an evidence based selection of PROMs.*
Van der Wees PJ, Verkerk EW, Verbiest MEA, et al. Development of a framework with tools to support the selection	2019	This paper reports on the development of a framework to support the selection and implementation of PROMs. Each step provides guidance and tools to support the

and implementation of patient-reported outcome measures. [17]		pricess. *The authors present a 'PROM-cycle' and provide guidance and discussion under each phase. The first three phases are most relevant to PROM selection and adaptation.*
Valderas JM, Ferre M, Mendivil J, et al. Development of EMPRO: ATool for the Standardized Assessment of Patient-Reported Outcome Measures.[83] Website: http://medicine.exeter.ac.uk/research/healthresearch/healthservicesandpolicy/projects/proms/theemprotool/	2008	This paper details the development of the EMPRO tool- a new tool for the standardized assessment of PROMs. *The EMPRO provides a useful tool to aid investigators who need to choose between alternative measures.*
Francis DO, McPheeters ML, Noud M, et al. Checklist to operationalise measurement characteristics of patient-reported outcome measures. [21]	2016	This paper presents a simplified checklist to evaluate the strengths and weaknesses of candidate PROMs developmental properties. *Many aspects of the checklist are relevant to PROMs adaptation.*
Greenhalgh J, Long AF, Brettle AJ, et al. Reviewing and selecting outcome measures for use in routine practice. [22]	1998	This paper provides a checklist to aid the critical review of candidate PROMs. *Many aspects of the checklist are relevant to PROMs adaptation.*
Pesudovs K, Burr JM, Harley C, et al. The Development, Assessment, and Selection of Questionnaires. [95]	2007	This article summarises how previously developed instruments are best assessed using a systematic process and presents a quality assessment tool for researchers to determine whether an appropriately developed PROM current exists. *Quality assessment tool which is useful for assessing existing PROM quality and as a guide for new instrument development as well as adaptation.*
Scientific Advisory Committee of the Medical Outcomes Trust. Assessing health status and quality-of-life instruments: Attributes and review criteria. [24]	2002	This paper offers eight key attributes of health status and quality of life instruments and the criteria by which instruments would be reviewed on each of these attributes. *These attributes are relevant to adaptations of PROMs.*
Patient involvement in PROM development and adaptation		
Addario B, Geissler J, Horn MK, et al. Including the patient voice in the development and implementation of patient-reported outcomes in cancer clinical trials.[50]	2019	This guidance aims to optimise PRO development and implementation in clinical trials, resulting in robust, relevant data that reflects the patient experience and that supports decisions made by all stakeholders

		involved in research and health care. *General principles around the assessment of PROMS in drug development, which are applicable to other clinical areas.*
Carlton J, Peasgood T, Khan s, et al. An emerging framework for fully incorporating public involvement (PI) into patient-reported outcome measures (PROMs).[53]	2020	This paper provides a timely review and sets out an emerging framework for fully incorporating PI into PROM development. *Generic guidance that serves as a prompt and reference point of stages to consider including PI when developing a PROM.*
Absolom K, Holch P, Woroncow E, et al. Beyong lip service and box ticking: how effective patient engagement is integral to the development and delivery of patient-reported outcomes. [52]	2015	This paper describes why patient involvement is integral to PROM development. *This paper reflects on patient involvement in PROM development case studies and the benefits of it. Some aspects relevant to PROM adaptation.*
Butt Z, Reeve B. Enhancing the patient's voice: Standards in the design and selection of patient-reported outcomes measures (PROMs) for use in patient-centred outcomes research.[51]	2012	This paper reports on the minimum standards for the design and selection of a PROM and outlines the critical characteristics on which a PROM is deemed to be appropriate. *This paper is relevant to determining the appropriateness or otherwise of existing PROMs in the clinical field.*
Issues relating to PROMs content validity		
Magasi S, Ryan G, Revicki D et al. Content validity of patient-reported outcome measures: perspectives from a PROMIS meeting.[47]	2012	This paper makes recommendations regarding the advancement of the science of content validity. *General recommendations on content validity made relevant to all clinical areas.*
Terwee CB, Prinsen CAC, Chiarotto A, et al. COSMIN methodology for evaluating the content validity of patient-reported outcomes measures: a Delphi study. [16]	2018	This paper reports on updated consensus guidance and methodology for content validity. *This updated methodology can contribute to the selection and use of high-quality PROMs in research and clinical practice.*
Brod M, Tesler LE, Christensen TL. Qualitative research and content validity: developing best practices based on science and experience. [48]	2009	This paper provides an overview of the current state of knowledge regarding qualitative research to establish content validity of PROMs. *This paper includes methods for ensuring content validity of both new and existing PROMs.*
Patrick DL, Burke LB, Gwaltney CJ, et al. Content validity-Establishing and reporting the evidence in	2011	These two papers are intended to be read together. They offer suggestions for good

newly developed patient reported outcomes (PRO) instruments for medical product evaluation: ISPOR PRO good research practices task force report: Part 1: Eliciting concepts for a new PRO instrument Part 2- Assessing respondent understanding. [45,46]		practice in planning, executing and documenting qualitative studies that are used to support the content validity of PROMs. *Many of the aspects discussed in these papers are relevant to PROM adaptation.*
Rothman M, Burke L, Erickson P, et al. Use of existing patient-reported outcome (PRO) instruments and their modifications: The ISPOR good research practices for evaluating and documenting content validity for the use of existing instruments and their modification PRO rask force report.[18]	2009	This article provides and overview of key issues involved in assessing and documenting content validity as it relates to using existing instruments. *The focus of this article is on content validity specifically in relation to existing and adapted PROMs. It provides a summary of the steps for identifying and evaluating existing PROMs, examples of threats to validity and ensuring content validity through the application of appropraite research methods.*
Guidance on cross-cultural adaptation		
Beaton DE, Bombardier C, Guillemin F, et al. Guidelines for the process of cross-cultural adpatation of self-report measures. [32]	2000	The guidelines presented in this paper are based on a review of cross-cultural adaptation in the medical, sociological and psychological literature. *Relevance to cross-cultural adaptation of existing PROMs.*
Epstein J, Santo RM, Guillemin F. A review of guidelines for cross-cultural adaptation of questionnaires could not bring out a consensus. [28]	2015	This paper reviews the start of the art in cross-cultural adaptation methods. *Provides a review of the various methods of cross-cultural adaptation available.*
Herdman M, Fox-Rushby J, Badia X. 'Equivalence' and the translation and adaptation of health-related quality of life questionnaires. [34]	1997	This paper reviews definitions of the various types of equivalence and discusses the ways in which different types of equivalence relate to the orientation of cross-cultural work. *Useful guide to issues specifically in relation to translation and cross-cultural adapation.*
Wild D, Grove A, [34]M, et al. Principles of good practice for the translation and cultural adaptation process for patient-reported outcomes (PRO) measures: Report of the ISPOR task force for translation and cultural adaptation. [27]	2005	After identifying a lack of consistency in current methods and published guidelines for translation, this paper reports on the synthesis of available methods to produce this guidance document. *Relevant to adaptations that intend to translate existing PROMs.*

Wild D, Eremenco S, Mear I, et al. Multinational trials-recommendations on the translations required, approaches to using the same language in different countries, and the approaches to support pooling the data: The ISPOR patient-reported outcomes translation and linguistic validation good research practices task force report. [29]	2009	This report provides a decision tool to assist which requirements for different translations. *This paper helps to define the specific translation requirements for different scenarios. It includes the requirements required for each country and the approach to use when the same language is spoken in more than one country.*
Kuliś D, Bottomley A, Velikova G, et al, EORTC Quality of Life Group Translation Procedure. [31]	2017	This report outlines the EORTC process of translation of Cancer quality of life tools. *Relevant to the adaptation of existing PROMs*

Papers are categorised according to the main theme[1] of the publication. [1]For simplicity, publications are categorised according to their main themes and may also include guidance on some of the other themes.

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