

METHODOLOGICAL CONSIDERATIONS RELATED TO EQUITY, DIVERSITY, AND INCLUSION IN CLINICAL EPIDEMIOLOGY

Using PROGRESS-plus to identify current approaches to the collection and reporting of equity-relevant data: a scoping review

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Abstract

Objectives: Our objectives were to identify *what* and *how* data relating to the social determinants of health are collected and reported in equity-relevant studies and map these data to the PROGRESS-Plus framework.

Study Design and Setting: We performed a scoping review. We ran two systematic searches of MEDLINE and Embase for equity-relevant studies published during 2021. We included studies in any language without limitations to participant characteristics. Included studies were required to have collected and reported at least two participant variables relevant to evaluating individual-level social determinants of health. We applied the PROGRESS-Plus framework to identify and organize these data.

Results: We extracted data from 200 equity-relevant studies, providing 962 items defined by PROGRESS-Plus. A median of 4 (interquartile range = 2) PROGRESS-Plus items were reported in the included studies. 92% of studies reported age; 78% reported sex/gender; 65% reported educational attainment; 49% reported socioeconomic status; 45% reported race; 44% reported social capital; 33% reported occupation; 14% reported place and 9% reported religion.

Conclusion: Our synthesis demonstrated that researchers currently collect a limited range of equity-relevant data, but usefully provides a range of examples spanning PROGRESS-Plus to inform the development of improved, standardized practices. © 2023 The Authors. Published by Elsevier Inc. This is an open access article under the CC BY license (<http://creativecommons.org/licenses/by/4.0/>).

Keywords: Equity; Social determinants of health; Guideline; Methods; PROGRESS-Plus; Scoping review

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What is new?**Key findings**

- This review of 200 equity-relevant studies identified 962 PROGRESS-Plus items

What this adds to what was known?

- Researchers most often collect and report a limited range of equity-relevant data

What is the implication and what should change now?

- Data that spans PROGRESS-Plus needs to be more comprehensively collected and reported to understand and address health inequities
- The examples identified will inform guidelines to improve routine practices

1. Introduction

Increasing recognition of the imperative to conduct health research through a “health equity lens” has begun to change research practices, reporting, and policy [1–6]. For example—leading medical journals have updated their guidance for authors on the reporting of data detailing the race and ethnicity of participants [5] and the representativeness of study populations [1]; and the World Health Organization has identified the need to prioritize investigation into relationships between social determinants of health (SDoH) and the effectiveness of health interventions [2]. Aligned with these approaches has been a widespread suggestion that researchers must do better at collecting, reporting and interpreting “equity-relevant” data to facilitate understanding of health inequalities and prompt action to address avoidable disparities in health.

Routinely collecting equity-relevant data has the potential to provide information about the generalizability of study findings; and allow analysis of whether an intervention has differential effects across strata of society. It also has the potential to prompt researchers to further consider equity issues in the planning, conduct and interpretation of health research and can be used to guide population targeting for clinical studies [7–10]. The collection of equity-relevant data can be challenging for authors due to the complexity of considerations (including cultural or personal sensitivities; inconsistent or changing terminology), gaps in understanding and a lack of clear guidance.

Attention has been given to improving the reporting of equity-relevant data through the publication of extensions to reporting guidelines for equity considerations for systematic reviews [11], clinical trials [12], and observational studies [13]. However, despite this available guidance evaluations of current practices indicate that adequate reporting

standards are yet to be met [14]. Both the collection and reporting of equity-relevant information is likely to be improved through the development and implementation of clear, consensus-based guidance on what equity-relevant information should be routinely collected and how to collect it.

The PROGRESS (Place; Race/ethnicity/culture/language; Occupation; Out of Work, Gender and sex; Religion, Education, Socioeconomic status, Social capital) framework can be usefully applied to assist with the identification and classification of equity-relevant data. It can prompt researchers to consider equity when planning studies and collecting data. The PROGRESS acronym was initially proposed in 2003 [15] and subsequently expanded to PROGRESS-Plus [16,17] to incorporate additional context-specific characteristics (e.g., age, disability) that can contribute to inequities in health. We applied the PROGRESS-Plus framework in this scoping review to prompt the identification of participant characteristic data relevant to evaluating individual-level SDoH.

This scoping review is an important first step in a broader project [18] that aims to develop and recommend a minimum dataset of equity-relevant items for broad application in the pain field (www.isshoos.org). This review intends to draw from health research (broadly) to inform this work, through identifying current approaches to the collection and reporting of data relating to PROGRESS-Plus. Our primary objective is to identify *what* data relating to the SDoH are collected in equity-relevant studies (in any field of health) and describe *how* these data are collected. Our secondary objective is to map the items to the PROGRESS-Plus framework.

2. Methods

The protocol for this review was developed in accordance with best-practice guidance for the development of scoping reviews [19] and registered on Open Science Framework (<https://osf.io/dqan2/>). The registered protocol describes a two-stage scoping review that aims to develop a comprehensive set of items (extracted from published studies) used to identify SDoH in clinical and research settings. Stage 1 of this review has been completed [18]; this manuscript reports Stage 2. Our reporting is consistent with PRISMA extension for scoping reviews [20].

2.1. Search strategy

We systematically searched MEDLINE and Embase for equity-relevant studies that were published during the most recent full calendar year (2021), by developing a search strategy that incorporated a validated search filter devised to identify equity-relevant trials [21]. Since equity-relevant trials focus on analyses across PROGRESS-Plus, we expected that these studies would identify more diverse

populations and include a broader range of items used to identify SDoH than a general search without this filter. We conducted two separate search processes using English search terms. Firstly, we searched for randomized trials (individually randomized or cluster randomized) and longitudinal cohort studies (see [Appendix 1a](#) for the full search strategy). Secondly, we re-ran the search strategy to identify studies with a cross-sectional design ([Appendix 1b](#)).

2.2. Selection criteria

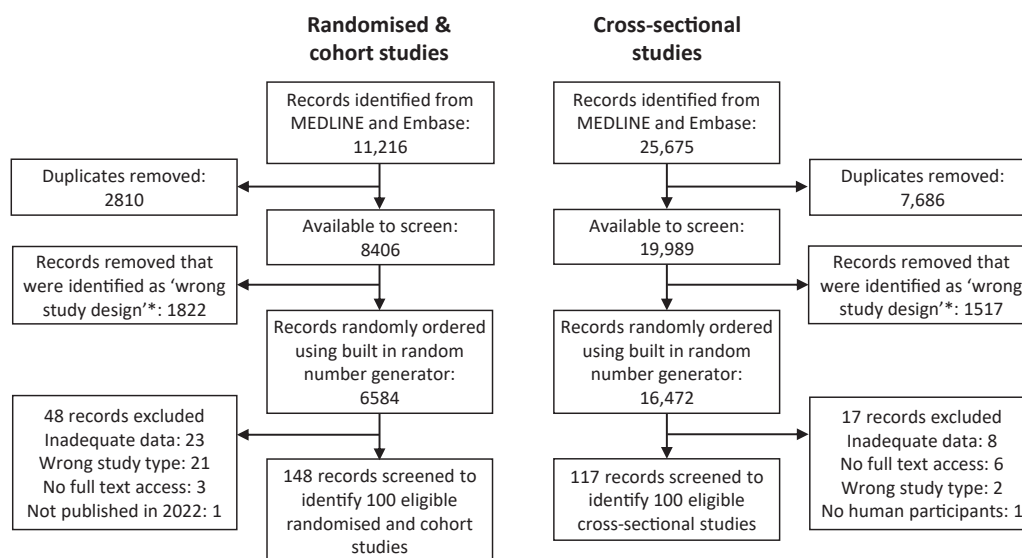
We included studies published in any language that involved human participants in health research, without limitation to participant age, language or other sociodemographic characteristics. All studies identified by our database searches were considered “equity-relevant” due to our use of a search filter designed to identify equity-relevant studies. To be included in this review—studies were also required to have collected and reported two or more participant characteristics relevant to PROGRESS-Plus [16]. The PROGRESS-Plus characteristic and how it was measured must have been reported explicitly in the published documents. We referred to published definitions of the PROGRESS-Plus framework to determine the relevance and appropriate classification of data in this study. For example—Oliver et al. (2008) defined ‘Socioeconomic Status’ as an: “Income-related measure for example, means-tested benefits/welfare, affluence measures etc.”; and Social Capital as: “Neighborhood/community/family support” (p. 26). O’Neill et al. (2014) provided further examples and contextualization’s which informed appropriate selection and categorization of data. We included all studies that reported the variable names and/or the questions asked

of participants and provided details of all response categories. We excluded study protocols, reviews, commentaries, conference abstracts; and studies that did not include the response categories for the PROGRESS-Plus characteristic of interest.

2.3. Screening and data extraction

We managed the citations of the two searches for longitudinal and cross-sectional studies separately to ensure that each study design was adequately represented in our results. We exported the search results into Excel where we listed the studies in random order using a built-in random number generator. Two independent reviewers screened the studies for eligibility (ELK, AC, SS, ST), beginning at the top of the (randomly ordered) list. Pairs of reviewers screened the records until they reached agreement on 100 studies that met the eligibility criteria. This process resulted in 100 randomly selected studies for each study design (200 in total) being included in this review. Any discrepancies or disagreements between the two reviewers were discussed and a third reviewer was consulted to resolve any conflicts (if required). Previous research has demonstrated that a sample of 200 equity-relevant studies is sufficient to provide broad coverage across the PROGRESS-Plus characteristics [14].

Five reviewers (ELK, AGC, AC, SS, ST) extracted the relevant data from the included studies using a standardized and pilot-tested excel spreadsheet. Ten percent of the included studies were extracted in duplicate and cross-checked for accuracy. Any inconsistencies were resolved and corrected; a third reviewer was consulted in the case of persisting disagreement. We extracted data relevant to



*Includes protocols, conference abstracts, editorials, reviews etc.

Fig. 1. PRISMA flow diagram.

Table 1. Summary characteristics of included studies

Study characteristics	No of studies (%)
Publication year	
2021	200 (100%)
Income Level of Country	
High or upper–middle-income countries	162 (81%)
Lower or lower–middle-income country	38 (19%)
Study design	
RCT	32 (16%)
Cluster RCT	5 (3%)
Longitudinal Cohort	57 (29%)
Cross-sectional	106 (53%)
Study population	
Adults	139 (70%)
Children and Adolescents	19 (10%)
Other	17 (9%)
Older Adults	13 (7%)
Household/Families	12 (6%)
Study participants recruited from	
Community	79 (40%)
Healthcare	59 (30%)
National Survey	36 (18%)
School	24 (12%)
Work	2 (1%)

the following fields: study authors, country of study, publication language (if not English), study design, description of the study population and setting. We extracted the following additional items: the type of SDoH measured, (i.e., *what* was measured)—classified according to PROGRESS-Plus, and *how* the variable was measured

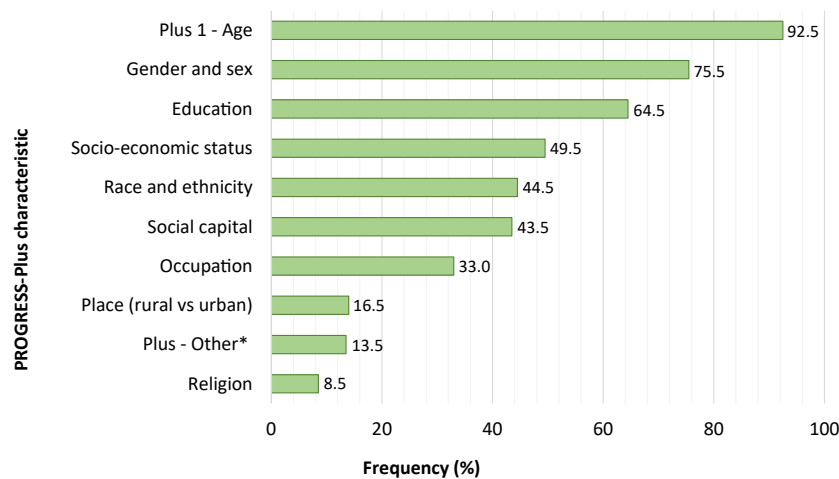
(i.e., the variable name and/or the question asked; and the response options), including categories or cut-offs used. In cases where all response options were reported but the questions were not provided in detail, the variable name (as reported) and response options were extracted, and study authors were contacted with a request for further question details. The authors were emailed with our specific request on three occasions over a 4-week period. Studies were not excluded from this review if the authors did not reply. In the case of no response from the corresponding authors the variable name (rather than the question asked) was inserted into the data extraction form.

2.4. Data synthesis

We summarized the characteristics of included studies descriptively and calculated the median and interquartile range for the number of PROGRESS-Plus characteristics reported in each study. We calculated the number of studies that collected data relevant to each of the PROGRESS-Plus characteristics and identified subcategories of questions evaluating each characteristic. These results were tabulated alongside examples of the questions addressing each subcategory from the included studies.

3. Results

Our searches identified 11,216 randomized and cohort study records and 25,675 cross-sectional study records (see Figure 1). We removed duplicates—resulting in 8,396 unique randomized and cohort study records and 17,989 unique cross-sectional study records that we exported into Excel. We sorted the spreadsheets by “Publication Type” to enable rapid exclusion of record types that did not meet



*sexual orientation (7), disability (1), HIV status (2), insurance status (11), immigration/citizenship status (4), caring responsibilities (1), jail detention (1)

Fig. 2. The frequency of reporting of PROGRESS-Plus characteristics in included studies. (For interpretation of the references to color in this figure legend, the reader is referred to the Web version of this article.)

Table 2. An overview of *how* researchers collect and report data relevant to PROGRESS-Plus (with examples)

PROGRESS-Plus characteristic	Subcategory	Question example
Place	Region of residence (urban/rural)	How would you describe the region in which you live?
	Type of housing	How would you describe the place where you live?
Race, ethnicity, culture, language	Ethnicity/ethnic background	How would you describe your ethnic heritage? What ethnic group do you belong to?
	Race/racial background	What is your racial background? Which race group do you consider yourself to belong to?
	Race/ethnicity	What is your ethnic/racial group? (Check all that apply)
	Country of birth	What is your country of birth?
	Skin color	What is your skin color?
	Other/not classified	E.g., are you of Aboriginal or Torres Strait Islander origin?
	Occupation	Employment status
Occupation type		What is your occupation? How would you best describe your work type? (e.g., white collar, blue collar etc.)
Other/not classified		E.g., what factors contribute to job-related stress?
Gender and sex	Gender or gender identity	What is your gender? What term best describes your gender identity?
	Gender/sex (not specified)	Are you male/female?
	Sex	What is your sex?
	Sex assigned at birth	What sex were you assigned at birth?
Religion	Religion/religious belief	To what religion or church do you belong? What religion do you identify with?
	Spirituality/religiosity	Self-reported religiosity and spirituality measure
Education	Education attainment	What is your highest level of education??
	Years of education	How many years of education have you completed?
	Literacy	Are you literate?
	Other/not classified	E.g., what is your school type? (public/private)
Socioeconomic status	Individual or household income	What is your annual individual income? What is your households total net monthly income?
	Ability to manage on current income	How well are you able to meet your basic living expenses?
	Receipt of public assistance	Do you receive public income assistance? Do you receive free or reduced-price lunch at school?
	Postcode classification/deprivation index	What is your postcode where you live?
	Other/not classified	E.g., poverty classification, wealth index
Social capital	Marital status	What is your marital/relationship status?
	Family size/structure	Who are you currently living with?
	Cohabitants	How many people live in your household (including yourself)?
	Church/society/club memberships	Do you engage in any of the following social activities at least once a month?
	Significant others/social connectedness	How often do you have phone calls or visits from your children/relatives/friends? During the past 12 mo, how often have you felt lonely?
	Other/not classified	E.g., who is your primary caregiver?

(Continued)

Table 2. Continued

PROGRESS-Plus characteristic	Subcategory	Question example
+Plus	Age	What is your age?
		What is your date of birth?
	Sexual orientation	How do you describe your sexuality?
	Insurance status	What type of health insurance do you currently have?
	Immigrant/citizenship status	Describe your citizenship status
	Chronic disease/disability	Are you living with a chronic disease?
	Other/not classified	What is your HIV status? E.g., are you the main caregiver of a family member with chronic disease? Are you currently on home detention?

our inclusion criteria, before randomly ordering the citation list.

The characteristics of the 200 included studies are provided Appendix 4; a summary of the study characteristics is provided in Table 1. One-quarter of all studies (50 studies) were conducted in the United States of America. Twenty studies were conducted in China, 11 in Brazil, 10 in Australia, eight in India, and six each in Ethiopia and Iran. Details of the countries represented in five or less studies, for each of the searches, are provided in Appendix 5. The largest proportion (60%) of randomized and longitudinal studies were conducted in high-income countries, 21% were conducted in lower–middle-income countries, 13% in upper–middle-income countries, and the smallest proportion (6%) were conducted in low-income countries. The income level of the included studies (as classified by the World Bank) are summarized in a figure in Appendix 6.

Twenty-seven percent of included studies provided detailed descriptions of both the questions asked to describe participant characteristics and the relevant response categories for the items defined by PROGRESS-Plus. The remaining 73% of studies adequately detailed the response options but did not provide full details of the questions asked of participants. Upon contacting the authors, 43% of the contacted authors replied and provided further relevant information.

We extracted a total of 962 items from the included studies. A median of four items (interquartile range = 2) defined by PROGRESS-Plus were reported in the included studies (Figure 2). The most frequently reported characteristic was age (92% of studies). Also commonly collected and reported were data relating to sex and/or gender (78%) and educational attainment (65%). Half of all included studies reported data on socioeconomic status (49%), race/ethnicity/culture/language (45%), social capital (44%) (most frequently marital status). Less frequently, data were reported on occupation (33%), and place of residence (rural vs. urban living) (14%). Few studies (9%) reported data on religion. An overview of *how* researchers collect and report PROGRESS-Plus data, with identified

subgroups and examples is provided in Table 2. The frequency with which items relevant to each subgroup is reported in the included studies is provided in Table 3. When studies reported more than one item related to a PROGRESS-Plus characteristic, they received a single count for reporting this characteristic.

4. Discussion

In summary, we extracted data from 200 equity-relevant studies to provide a set of 962 items used to evaluate individual-level SDoH. We mapped the items to the PROGRESS-Plus framework and subgrouped the item types within each category. Our synthesis demonstrated that researchers most often report a limited range of equity-relevant data; and provides a comprehensive set of items spanning PROGRESS-Plus to indicate *what* equity-relevant data researchers currently collect, and *how* they collect it.

This study revealed that age, gender/sex, and education status were reported in the majority of studies (i.e., >65%); there was common reporting of socioeconomic status, race/ethnicity/culture/language and social capital; and infrequent reporting of data related to occupation, place of residence, and religion. These findings are largely consistent with a 2020 study investigating the frequency of reporting of PROGRESS-Plus characteristics in individual and cluster randomized trials [14]. Our data indicate that sex and gender reporting are mostly inadequate and that the data relating to socioeconomic status and education status are highly disparate and likely to impede the potential to for data pooling. Evaluation of social capital mainly focuses on marital status and possibly overlooks aspects of social and community connectedness that may also be relevant to health outcomes. Furthermore, while race/ethnicity/culture/language data are collected in almost half of the included studies, the predominance of included studies conducted in the United States must be considered—these data may be collected less frequently in broader global contexts.

Table 3. PROGRESS-Plus subcategories and their frequency of reporting

PROGRESS-Plus characteristic	Subcategory	Frequency of reporting
Place	Urban/rural	27
	Housing type	7
Race, ethnicity, culture, and language	Ethnicity	12
	Racial background	25
	Race/ethnicity	24
	Country of birth	9
	Skin color	4
	Other	11
Occupation	Employment status	43
	Occupation type	25
	Other	4
Gender/sex	Gender	72
	Gender/sex (not specified)	18
	Sex	66
	Sex assigned at birth	3
Religion	Religion	16
	Spirituality	1
Education	Education attainment	99
	Years of education	27
	Literacy	2
	Other	10
SES	Income	64
	Ability to manage	13
	Public assistance	3
	Postcode	10
	Other	19
Social capital	Marital status	63
	Family size/structure	12
	Cohabitants	23
	Church/society/club	3
	Social connectedness	10
	Other	3
Plus	Age	185
	Sexual orientation	7
	Chronic disease/disability	2
	HIV	2
	Citizenship status	4
	Caregiver	2
	Jail detention	1
	Insurance status	12

Abbreviations: SES, socioeconomic status; RCT, randomised controlled trial.

It is important to recognize that while the items extracted from included studies were able to be mapped to PROGRESS-plus, it does not necessarily follow that these

items have informed understanding about the drivers of health inequities. The degree to which variables can provide information about disadvantage is also dependent on the context and setting of the study, characteristics of the study sample, the analyses undertaken and the interpretation of the results. The PROGRESS-Plus data reported in the included studies at times fall short of informing readers about the diversity of study participants or how well the study sample represents the population impacted by the health condition being studied. e.g.—the data collected relating to sex and gender appeared inadequate in the majority of the included studies. This is consistent with the results of a study examining the reporting of sex and gender in Campbell and Cochrane systematic reviews conducted in 2016 and 2017 [22]. In the current study, 89% of the items evaluating this PROGRESS-Plus characteristic reported binary (i.e., “male” and “female”) response options to sex and gender questions only. While in many cases this reflected inadequate response options being provided by study authors, factors such as a lack of diversity of study participants, or participants’ unwillingness to disclose gender diversity may also have contributed to these findings. Only three studies distinguished between what sex participants were assigned at birth and gender identity (as a nonbinary construct)—an approach that has been recommended as respectful and inclusive and warrants consideration in future studies [23].

This scoping review has several methodological strengths. It was conducted and reported in accordance with best-practice recommendations for scoping reviews [19,20]; and the protocol was preregistered Open Science Framework. Minor deviations from the protocol have been transparently reported in Appendix 3. The results of the searches were screened in duplicate to confirm study eligibility. Data extraction was subsequently shared between reviewers with 10% of the data extraction undertaken in duplicate confirming accuracy and consistency. We acknowledge that not extracting all data in duplicate may increase the risk of error; however, we consider that this is not likely to have impacted the findings of this review.

Some limitations of this study should be acknowledged. Our random selection of 200 studies has resulted in a comprehensive but incomplete evaluation of data items that have been used to evaluate SDoH in recent research. This number was guided by a study demonstrating that 200 articles is sufficient to provide a broad spread of data items across the PROGRESS-Plus characteristics [14]. Our results were consistent with these findings. In addition, our study provides an up-to-date evaluation of current practices; contributes important evidence that suboptimal data reporting across PROGRESS-Plus is not confined to randomized trials; and supports the imperative for ongoing efforts to improve data collection and reporting [24,25]. It was also not important that we find *all* items used to evaluate SDoH, but to scope recent literature to extract examples of current approaches. There are some limitations

related to the characteristics of the included studies. The studies included in this review were predominantly conducted in high-income and upper–middle-income countries, with a high proportion conducted in the United States of America. This will have impacted the type of data collected, perhaps suggesting acceptability of question types that may not be relevant to all contexts. We consider however, that applying an equity filter to our search strategy likely resulted in a larger proportion of low-income and middle-income countries being identified than would otherwise have been the case; and contributed to the geographical diversity of included studies, and the variety of items extracted. Finally, we recognize that our review may have under-reported the practice of collecting equity-relevant data—our results are derived from the published manuscripts, and we recognize that some studies may have collected equity-relevant but not reported it.

This study highlights limitations in the collection and reporting of equity-relevant data in health research and suggests a need to improve the comprehensiveness and consistency with which researchers collect and report equity-relevant data. This review also provides a highly useful collection of items spanning PROGRESS-Plus describing *what* equity-relevant data researchers currently collect, and *how* it is collected. These findings are a highly important basis informing our broader initiative (www.isshoos.org) to develop a minimum dataset for the routine, standardized collection of equity-relevant data in human pain research. This dataset will be recommended for broad implementation as a fundamentally important step toward further understanding and addressing health inequities.

CRedit authorship contribution statement

Emma L. Karran: Conceptualization, Methodology, Investigation, Formal analysis, Writing – original draft, Project administration. **Aidan G. Cashin:** Conceptualization, Methodology, Investigation, Formal analysis, Writing – review & editing. **Trevor Barker:** Conceptualization, Methodology, Formal analysis, Writing – review & editing. **Mark A. Boyd:** Conceptualization, Methodology, Formal analysis, Writing – review & editing. **Alessandro Chiarotto:** Conceptualization, Methodology, Investigation, Formal analysis, Writing – review & editing. **Omar Dewidar:** Conceptualization, Methodology, Formal analysis, Writing – review & editing. **Vina Mohabir:** Conceptualization, Methodology, Formal analysis, Writing – review & editing. **Jennifer Petkovic:** Conceptualization, Methodology, Writing – review & editing. **Saurab Sharma:** Conceptualization, Methodology, Investigation, Formal analysis, Writing – review & editing. **Sinan Tejani:** Investigation, Formal analysis, Writing – review & editing. **Peter Tugwell:** Conceptualization, Methodology, Investigation, Formal analysis, Writing – review & editing. **G. Lorimer Moseley:** Conceptualization, Methodology,

Writing – review & editing, Funding acquisition, Supervision.

Data availability

All data files are available upon reasonable request.

Declaration of competing interest

E.L.K. has received speaker fees for lectures on pain and rehabilitation from professional and scientific bodies and reimbursement of travel costs related to presentations at scientific conferences/symposia. G.L.M. has received support from Reality Health, ConnectHealth UK, Institutes of Health California, AIA Australia, Workers' Compensation Boards and professional sporting organisations in Australia, Europe, South America, and North America. Professional and scientific bodies have reimbursed him for travel costs related to presentation of research on pain and pain education at scientific conferences/symposia. He has received speaker fees for lectures on pain, pain education, and rehabilitation and conference travel support from Sequirus. He receives royalties for books on pain and pain education. P.T. has received consulting fees to provide independent medical consultation and professional services. He is an independent Committee Member for clinical trial Data Safety Monitoring Boards for FDA-approved trials being conducted by UCB Biopharma GmbH & SPRL, Parexel International, and Prahealth Sciences. P.T. is an [unpaid] Chair of the Management Subcommittee of the Executive Committee of a registered non-profit independent medical research organization, OMERACT. OMERACT receives unrestricted educational grants from the American College of Rheumatology, European League of Rheumatology, and several pharmaceutical companies listed in this section, which is used to support fellows and international patient groups and support a major international bi-annual conference which results in many peer-reviewed publications. There are no competing interests for any other author.

Supplementary data

Supplementary data to this article can be found online at <https://doi.org/10.1016/j.jclinepi.2023.09.017>.

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