# Tools for patients to describe their chronic pain – A Scoping Review

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# Abstract

## Background

Effective communication of chronic pain is essential for accurate diagnosis and treatment. However, chronic pain can be complex and challenging for patients to describe. Tools that support patient self-reporting of pain (referred to as pain communication tools or pain tools) may help address this challenge. However, the availability and characteristics of such tools have not been comprehensively synthesized.

## Objectives

1. To identify and describe pain communication tools that individuals living with chronic pain can use to support describing their pain.
2. To examine the pain-related information that the tools convey.
3. To summarize how pain tools have been evaluated.

## Methods

A scoping review was conducted following the Joanna Briggs Institute methodology and reported in accordance with PRISMA-ScR guidelines. Peer-reviewed literature (2000–2024) was searched in MEDLINE, PsycINFO, CINAHL, CDSR, CENTRAL, and Web of Science. Grey literature was identified through a structured Google search. Eligible sources described tools intended for patient use during clinical or telehealth encounters. Data were charted on pain tool characteristics, pain dimensions addressed, and evaluation methods.

## Results

From 7,204 database records and 288 websites, 103 distinct pain communication tools were identified (77 from peer-reviewed sources; 26 from grey literature). Most pain tools (77%) addressed multiple pain dimensions, with pain intensity (73%), impact on daily life (56%), and pain location (32%) most frequently represented. Formats included written questionnaires, verbal descriptors, visual scales, and digital applications; 16 pain tools were exclusively digital. Evaluation data were reported for 63% of pain tools, primarily focusing on psychometric properties (statistical characteristics describing a measurement tool's reliability and validity), such as test–

retest reliability and construct validity. Only 24% of pain tools were assessed for user-friendliness.

## Conclusions

Numerous pain communication tools exist, but most emphasize only a limited set of pain dimensions and lack evaluation of patient usability and experience. Future research should prioritize patient-centred assessments and health literacy considerations to ensure these tools effectively support communication in clinical practice.

**Keywords:** Chronic pain; pain communication tool; scoping review

# Plain Language Summary

Living with chronic pain can shape daily life in significant ways, and explaining pain to a healthcare provider can be challenging. People may struggle to find the right words to describe how pain impacts them. This struggle can lead to misunderstandings, delayed diagnoses, and frustration for patients. One way to improve communication is to use pain communication tools, such as questionnaires, scales, diagrams, or apps, to help patients share details about their pain. These tools can include questions about pain intensity, location, and its impact on daily activities.

We reviewed research and online resources to find out what pain communication tools are available for people with chronic pain. We looked at the information these pain tools collect and whether they have been tested for quality and ease of use (by practitioners or patients).

## What we found

We identified 103 different pain tools designed to help patients describe their pain. Most pain tools cover more than one aspect of pain, such as severity, location, and impact on daily life. Pain tools come in different formats: written questionnaires, visual scales, and digital apps. Sixteen pain tools were only available online or as mobile apps. Seventy three percent (73%) of the pain tools considered pain intensity and 77% considered more than one pain characteristic or dimension. Sixty three percent of the pain tools had been tested for reliability (how consistent they are) and validity (whether they measure what they claim to measure). However, only 24% were tested for user-friendliness (for practitioner or patient).

## Why this matters

Although many pain tools exist, most focus on a few pain details, mainly pain intensity, and rarely consider how easy they are for patients to use. Future research should ensure these pain tools are clear, accessible, and helpful for real-life conversations between patients and healthcare practitioners.

# Introduction

Pain is personal and complex. Communicating effectively in a healthcare setting can be challenging for many reasons, including unfamiliar medical terminology used by healthcare practitioners (HCPs), unequal power dynamics between patients and HCPs, language barriers, diverse cultural understandings of pain, and the complexity of chronic pain itself. These communication barriers can negatively impact diagnosis and treatment, leading to invalidating experiences for patients. Over time, these challenges can strain the patient-HCP relationship.

This project was conceived and initiated by an independent patient partner, KN, and it was through their personal experience with these communication barriers that they conceived and initiated a project to identify self-reported *pain communication tools*, also known as *pain tools*. A *pain tool* is defined as a resource that helps an individual self-report the dimensions or nature of their physical pain to HCPs. These pain tools can include questionnaires, scales, surveys, inventories, assessments, and patient-reported outcome measures that patients engage with through written, verbal, or non-verbal communication (1), as well as interactive 3D objects that patients can manipulate to convey their pain experience (2, 3). Whether the content of the pain tool was accessible, written in plain patient-oriented language, or followed best practices in health literacy and design was outside the purview of this scoping review.

KN submitted a proposal to the Strategy for Patient-Oriented Research Evidence Alliance's (SPOR EA's) *Patient and Public Health Research Topic Priority-Setting Exercise* (4). A feasibility assessment, including a scoping literature search, identified no existing reviews and concluded that there was scope for further synthesis of the literature in this area. The project was selected as one of the 20 highest-priority topics for funding based on its impact, uniqueness, potential to address an unmet need and an evidence gap, and timeliness and importance (4).

This patient-initiated project aimed to identify pain tools that support people with chronic pain in communicating with HCPs about the nature of their pain. Specifically, the review addressed the following questions:

1. What pain communication tools were available to help people with chronic pain communicate with HCPs about the nature of their pain?

2. What pain-related information (dimensions) was being communicated in these pain tools?
3. How were the pain tools evaluated?

# Methods

This scoping review of peer-reviewed and grey literature was conducted using the Joanna Briggs Institute methodology (JBI) (5, 6). A scoping review approach was chosen to identify existing pain communication tools, examine the types of information conveyed through these pain tools, and identify gaps in pain tools available to patients for communicating chronic pain. Reporting follows the PRISMA Extension for Scoping Reviews (PRISMA-ScR) guidelines (7). The review was registered a priori with the Open Science Framework (https://doi.org/10.17605/OSF.IO/NR8CB). Although the registered protocol included an additional research question, "Who participated in studies evaluating these pain tools?" This question was not addressed because most included articles and online materials were reviews of pain tools and did not report participant characteristics.

## Patient partner involvement

This project was conceived and initiated by a patient partner (patient research co-lead and first author, KN). She submitted the initial proposal to the SPOR EA, who matched her with an academic research ally (LCL) and her team. KN co-led the scoping review with LL and was supported by a patient partner (CFA), a postdoctoral fellow (CAP), and a graduate student (MAG). As patient research partners, KN and CFA provided input on the work plan, participated in developing the eligibility criteria, and contributed to all aspects of the scoping review, including data extraction and charting. KN drafted the manuscript, and CFA provided feedback.

As co-lead, KN also made budgetary decisions, developed and led the knowledge mobilization activities, and is the lead author of this paper. The patient partners collaborated with the research team at every stage of the study via online meetings, email, text, and phone. Patient partners were compensated at CA$40 per hour for their work, in accordance with SPOR patient partner compensation guidelines (8).

## Eligibility criteria

Eligible articles described pain communication tools intended for people living with chronic pain to use during medical or rehabilitation visits in clinical settings, at home, or through telehealth appointments to support describing their pain with HCPs. Studies were excluded if they:

- used a pain tool solely as an outcome measure to assess the effectiveness of an intervention
- focused on the development or validation of a pain tool within a research setting
- relied exclusively on HCP's clinical assessment

Conference abstracts and non-English publications were excluded. In addition, the grey literature review excluded open-access research articles.

## Search strategy

### Peer-review literature

An experienced librarian developed a comprehensive set of search strategies reflecting the *population* (people living with chronic pain), the *concept* (resources, including written material, guides and pain tools, that support individuals in communicating the nature of their pain, such as intensity and type), and the *context* (medical or rehabilitation visits in clinics or hospitals, at home, or via telehealth). The search strategy was developed and evaluated using the 2015 Peer Review of Electronic Search Strategies (PRESS) Guideline (9) (see **Supplemental Material A**). Searches were conducted in MEDLINE, PsycINFO, CINAHL, the Cochrance Database of Systematic Reviews (CDSR), CENTRAL, and Web of Science, covering the period from January 1, 2000, to May 24, 2024.

An initial pilot screening was conducted with 50 articles. All authors independently screened titles and abstracts against the eligibility criteria, yielding a 26% agreement rate. The low agreement was attributable to the broad scope of the review and the small number of articles included in the pilot. Following clarification and refinement of the eligibility criteria, a second pilot screening was conducted using 251 articles, with discrepancies resolved by a third reviewer. This process achieved an agreement rate of 80%, which was deemed sufficient to proceed with full title and abstract screening.

Consistent with the JBI methodology for scoping review, a two-level screening process involving at least two reviewers was employed. Duplicate records were automatically removed using Covidence software. During level 1 screening, titles and abstracts were assessed against the eligibility criteria. Articles that met the criteria advanced to level 2 full-text screening, during which reasons for exclusion were recorded. Conflicts between reviewers were resolved through discussion, with a third reviewer adjudicating when consensus could not be reached.

**Grey literature**

A search for grey literature in the form of a website review was conducted via Google Canada and was based on the JBI methodology (5). The search terms, based on the peer-review literature search strategy, were selected by KN, CFA, CAP, and MAG. The website review included searches for the following countries and pain associations and organizations within these countries:

- Australia
- Canada
- New Zealand
- United Kingdom
- United States of America

The search terms include:

- Chronic pain
- Communication
- Communication barriers
- Express, describe, report, self-report, characterize, explain, chronic pain
- Health communication
- Health literacy, plain language
- Infographic, visual, picture communication aids
- Knowledge translation, KT, knowledge dissemination, KD, knowledge mobilization, KM, integrated knowledge translation, IKT materials or products

- Pain + education, guide, handout, pamphlet, booklet, book, resource, toolkit, tool, aid, evaluation, self-reflection, self-analysis, (self-)survey, (self-)inventory, (self-)inquiry, (self-)assessment, (self-)questionnaire, guidance
- Pain language
- Patient material, patient education material

Using the inclusion criteria, four authors (KN, CFA, CAP, and MAG) screened websites for the grey literature review between April 2 and June 16, 2024, and completed the review between January 4 and February 28, 2025. For each search term and each search term combination, the first 10 Google results (websites) were screened for eligibility. This approach is consistent with grey literature methods, as relevant material often appears within early search results, and users seeking health information commonly limit their viewing to the first page. One of the four authors extracted data from each eligible website onto an Excel data extraction form (**Supplemental Material D**). Large language model (LLM) platforms (artificial intelligence), such as ChatGPT, Gemini, and Claude, were not used to search for or synthesize information.

### Data charting

Data were extracted from the eligible peer-reviewed articles using a standardized data extraction form (**Supplemental Materials B & C**) within Covidence. For articles identified through the database search, the data extraction process was piloted iteratively in accordance with JBI guidance (6) and was completed by three authors (KN, MAG, CFA). The extracted data was then reviewed by two additional co-authors (CAP, LCL) to ensure accuracy and completeness. For the grey literature, data extraction was performed by KN, CFA, CAP, and MAG. KN and MAG then collated the data, and MAG performed the final data checking. All extracted data were exported to Excel and mapped (organized) by the type of pain-related information communicated (pain dimensions), the pain tool used, and the evaluation method.

## Results

The database search identified 7,204 articles as potentially relevant, of which 92 journal articles were assessed for eligibility, and 43 were included for data extraction

(2, 3, 10-50). The grey literature search screened 288 websites/webpages; of those 39 were assessed for eligibility and provided information (51-90). **Figure 1** presents the PRISMA flow diagram.

A total of 103 distinct pain communication tools were identified, including 77 from peer-reviewed literature and 26 additional pain tools from the grey literature[1] (**Table 1**). Pain tools that had the same description and similar name were classified as one pain with variations. The information in **Table 1**, is based on the available information in the references. Of those, 26 pain tools (25%) focused on a single pain dimension, whereas 77 (75%) addressed multiple pain dimensions. Across all pain tools, the most frequently represented dimensions were *pain intensity* (n = 75; 73%), *impacts on daily life* (n = 58; 56%) and *pain location* (n = 33; 32%). Among the unidimensional pain tools, 12 captured *pain intensity*, and 7 captured *impacts on daily life*. A summary of the dimensions and information that these pain tools help individuals to communicate is presented in **Table 1** and **Figure 2**.

Among the 77 identified multidimensional pain tools, the most frequently reported evaluation methods were *test-retest reliability, user friendliness*, and *construct validity*, each reported in 17 (22%), 15 (19%), and 14 (18%) pain tools, respectively. Similarly, among the 26 unidimensional pain tools, the most frequently reported evaluation methods were *test-retest reliability*, *user-friendliness*, and *construct validity*, reported in 11 (42%), 10 (38%), and 10 (38%) tools, respectively. The reported methods to assess validity, measurement properties, and user friendliness are presented in **Figures 3 and 4**. Overall, 38 of the 103 pain tools (37%) lacked evaluation information in the included articles. Additional details on the parameters of evaluation are available in **Supplementary Materials C and D**.

While 16 of the 103 pain tools (16%) are available only in digital form. One pain tool used cards, another relied on tangible items as metaphors for pain, while the remaining tools were designed to be completed through writing or online. Details on the methods of administration of the included pain communication tools are available in **Supplementary Materials C and D**.

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[1] Pain communication tools identified in both peer-reviewed and grey literature were counted under peer-reviewed literature.

## Discussion

This scoping review identified 103 distinct self-report pain communication tools designed to help patients convey the nature of their physical pain, with 75% supporting the reporting of multiple pain dimensions. The finding was unexpected, given the lead author's prior experience suggesting a limited availability of multidimensional pain communication tools for patients. While many pain tools do exist, most focus on a narrow set of pain dimensions, such as pain intensity and the impact of pain on daily functioning. In contrast, relatively few pain tools help individuals describe pain triggers, experiences with medications, or the use of self-care and coping strategies. A variety of formats have been used to facilitate the description of pain, including verbal responses, written text, facial icons, sliding scales, numeric rating scales, and tactile objects. Sixteen pain tools were identified as being designed exclusively for digital use. Given the widespread use of online resources and mobile applications, the number of digitally delivered pain communication tools is likely to continue growing.

The majority of identified pain tools were originally developed for research or as outcome measures. This development method likely explains why evaluations focus on psychometric properties rather than communication effectiveness, even though these pain tools are fundamentally designed to help patients communicate their pain experience. From a patient perspective, usability is a critical feature of an effective tool; however, this review found that only 24% of tools had been assessed for user-friendliness, and the intended user (patient or HCP) for the evaluation was generally missing.

This scoping review has limitations. The database search was restricted to publications from 2000 to 2024. As many pain communication tools were developed before 2000 and were already well established in both research and clinical practice by then, detailed reporting on their development, validation, and evaluation processes may have been less common in later literature. As well, the information in describing the pain tools in **Table 1** are based on the available information in the references. These references may not have included an image of the tool or may not have fully described the pain tool, which may have impacted the completeness of the table. In addition, the grey literature search did not incorporate large language models (LLMs).

Given the ongoing evolution of online search methodologies and the increasing use of LLMs for information retrieval and synthesis, the findings of the grey literature review may have differed if LLM platforms had been incorporated.

In conclusion, chronic pain is a multidimensional phenomenon, and high-quality communication is important (91). As pain communication tools rely on patient self-reporting, further research is needed to evaluate and validate them using patient-oriented parameters, such as patient experience, usability, and readability. Therefore, the meaningful involvement of patient partners and experts in health literacy is essential, as the pain tools that patients are asked to use must adequately reflect the complexity of their lived experiences.

## Supplemental material

Supplemental material A: Search strategy

Supplemental material B: Data extraction form

Supplemental material C: Data extraction table – Peer-reviewed literature

Supplemental material D: Data extraction table – Grey literature

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## Author contributions

KN conceptualized the research, obtained funding along with LCL, and drafted this review. The remaining authors (MG, CFA, CAP, LCL) contributed to the development of the protocol, participated in the scoping review, and reviewed and edited early drafts of the manuscript prepared by KN. All authors read and approved the final manuscript.

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## Data availability statement

Data are available in the Supplementary Material files.

## Declarations

Not applicable.

## Ethics approval

Not required.

## Competing interests

None declared.

## Patient partner consent for publication

Consent was obtained directly from patient partners.

## Definitions

**Patient:** an individual awaiting or under medical care and treatment.

**Patient partner:** In this paper, a patient partner is someone with lived experience with chronic pain. Their experience increases the diversity of perspectives in a research project, and they are considered an expert in their own right.

**Pain communication tool (pain tool):** as a tool that helps a patient communicate (self-report) the dimensions or the nature of their physical pain to a healthcare practitioner. This definition includes documents, e.g., questionnaires, scales, surveys, inventories, assessments, and patient-report outcome measures that the patient engages with through written, verbal, or non-verbal communication. This definition also includes interactive 3D objects that patients can manipulate. Whether the content of the pain tool was accessible, i.e. was the pain tool written in plain patient-oriented language, following best practices in health literacy and design principles, was outside the purview of this scoping review.

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