DEFINING AND MEASURING NEED FOR CHILDREN'S PALLIATIVE CARE:

A PROTOCOL FOR A RAPID SCOPING REVIEW

ECHPI

Evidence for Children's Palliative Care in Ireland

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3 Abstract

Background: Children's palliative care (CPC) can improve symptom control and quality of life for children and their parents, potentially reduce the need for hospitalisations, and increase the likelihood that the preferred place of death is achieved. However, internationally, availability and access to CPC services falls far behind that of adult services. A key reason for this is the difficulty in identifying those who are most in need of palliative care with referrals based on a range of factors including, and not limited to, the child's prognosis, complex care requirements, and/or family needs. Children who need palliative care include those with life-threatening conditions, where curative treatment may be feasible but could fail, or life-limiting conditions, where premature death is inevitable. Similarly, other children may present with complex needs that make them eligible for palliative care. However, in a resource-poor environment where the demand for CPC may exceed supply, it is imperative that palliative care is targeted at those who are most in need of it. Aim: To identify and explore how the need for palliative care is defined and measured. Design: A rapid scoping review of peer-reviewed articles and grey literature. Method: This review will adopt the Joanne Briggs Institute (JBI) methodological approach for conducting scoping reviews. Included

studies will be published in English from 2008 to present. Study screening and data extraction will be conducted by at least two reviewers. Results: The scoping review will examine the definition and measurement of need for palliative care in the literature.

Keywords

Palliative care, children, need, eligibility criteria, life-limiting conditions, life-threatening conditions

4 Introduction

The benefits of children's palliative care are widely reported ranging from reducing symptom burden and the need for hospitalisations to improving quality of life for children and their families. However, the availability, accessibility, and delivery of children's palliative care services across different parts of the world remains inconsistent. Children who need palliative care include, but are not limited to, those with life-limiting or life-threatening conditions. Available literature on how the need for palliative care among children is defined and measured is limited and requires further exploration. In this scoping review we will address some of those knowledge gaps, making a valuable contribution to the field of children's palliative care.

5 Background and rationale

5.1 Children's palliative care

Children's palliative care (CPC) is defined as *"an active and total approach to care, from the point of diagnosis or recognition throughout the child's life, death and beyond. It embraces physical, emotional, social and spiritual elements and focuses on enhancement of quality of life for the child or young person, and support for the family. It includes the management of distressing symptoms, provision of short breaks and care through death and bereavement"* (Together for Short Lives (TfSL) 2018, p.9). There is growing evidence in favour of early integration of palliative care into the care of children, improving their quality of life and extending supports to families (Bergstraesser, 2013; Connor *et al.*, 2017; World Health Organization, 2018 ; Benini *et al.*, 2022).

The number of children requiring palliative care continues to increase with advancements in medicine and technology, longer survival rates for some illnesses, and more recently, the expansion of eligibility criteria for palliative care (Bogetz *et al.*, 2014; Connor *et al.*, 2017; Fraser *et al.*, 2021; Benini *et al.*, 2022). However, there exists a myriad of challenges to delivering timely, quality and equitable CPC services (Twamley *et al.*, 2014; Chong *et al.*, 2020; Fraser *et al.*, 2020; Roland, 2022). For example, a referral to CPC may be delayed due to uncertainty around prognosis or associated care needs (Twamley *et al.*, 2014).

Understanding the need and demand for palliative care is essential to planning services and improving access to CPC. However, efforts to identify which children will benefit most from palliative care intervention is challenging due to the heterogeneous population, uncertain illness trajectories and evolving needs (Benini *et al.*, 2021; Fraser *et al.*, 2021). This may be compounded with the inconsistent application of definitions and terminologies for CPC or life-limiting conditions leading to a mis- or missed diagnosis of patients with a need for palliative care (Bergstraesser, 2013). The following section highlights some of the difficulties in defining and measuring the need for children's palliative care.

5.2 Complexities in defining the need for children's palliative care

As part of a European-wide initiative to update the 2006 IMPaCCT (International Meeting for Palliative Care in Children, Trento) standards and procedures for CPC, the definition and eligibility criteria for CPC were re-examined by an expert panel within the context of changing settings, resources, and challenges (GO-PPaCS, Global Overview – Paediatric Palliative Care Standards, Benini *et al.*, 2022). Some of the recognised challenges included the heterogeneous nature of conditions requiring CPC, the complexity of needs, and the role of the family (Benini *et al.*, 2008).

The panel agreed on several key points, most notably that all children diagnosed with life-limiting, life-threatening or terminal conditions should be eligible for CPC. Table 1 outlines these key terms as they are commonly defined although it is noted that alternative interpretations have been discussed in the literature. For example, the term 'life-limiting' can encompass both limited quality and limited duration of life (Macauley, 2019).

TABLE 1 Definitions for life-threatening, life-limiting and terminal illness

Condition description	Details	Example
Life-threatening condition (or serious illness)	A condition with a high probability of premature death due to severe illness, but also a chance of long-term survival to adulthood	Children receiving cancer treatment, children with severe neurological impairment, children in intensive care due to acute injury, children with technology dependency
Life-limiting condition	A condition where there is no reasonable hope of cure: premature death is expected	Duchenne muscular dystrophy, Tay Sachs Disease, Trisomy 13, Trisomy 18
Terminal illness	A condition in which death becomes inevitable in children with life-limiting or life-threatening illnesses.	

Source: Together for Short Lives, 2018
Notes: The term 'complex chronic condition' is also used to describe children with a life-limiting or life-threatening condition (Fraser et al. 2021).

Life-limiting conditions that affect children and young people may be categorised into five individual groups based on prognosis and duration (Table 2) (Together for Short Lives, 2018; American College of Obstetricians and Gynecologists (ACOG) Committee, 2019). For example, congenital conditions diagnosed at birth often require immediate and intense palliative intervention compared to neurological conditions requiring longer or intermittent periods of care (Benini *et al.*, 2008).

TABLE 2 Five categories of life-threatening and life-limiting conditions

Group	Description
1	Life-threatening conditions for which curative treatment is possible but may fail. Access to palliative care services may be necessary due to the complexity of the patients' needs (e.g., cancer, complex congenital cardiopathies, severe injuries resulting from trauma). There is no longer need for palliative care services upon achievement of long-term remission or following successful curative treatment.
2	Conditions in which premature death is inevitable; however, long periods of intensive treatment aimed at prolonging life and allowing for a good QoL (e.g., cystic fibrosis).
3	Progressive conditions without curative treatment options for which treatment is exclusively palliative and may commonly extend over many years (e.g., Batten disease, muscular dystrophy, chromosomopathies).
4	Irreversible but non-progressive conditions with complex healthcare needs leading to complications and, likely, premature death (e.g., severe cerebral palsy and disabilities following brain or spinal cord injury). Palliative care may be required at any stage and there may be unpredictable and periodic episodes of care.
5	Unborn children with major health problems who may not live through birth, infants who may survive for only a few hours/days, infants with birth anomalies that may threaten vital functions, and infants for whom intensive care has been appropriately applied but developed an incurable disease.

Source: Together for Short Lives, 2018; American College of Obstetricians and Gynecologists (ACOG) Committee, 2019

However, the GO-PPaCS panel also acknowledged that alternative conceptions of the need for CPC exist and called for standardisation of eligibility criteria (Benini *et al.*, 2022). For example, children may be identified as palliative care patients based on the complexity of their needs and the intensity of care required rather than on prognosis only (Wood *et al.*, 2010; Jankovic *et al.*, 2019; Roland, 2022).

Some clinicians determine the need for palliative care using the "surprise question" (i.e., "would you be surprised if the person died in the next 12 months?") in addition to implementing specific palliative care assessment tools (Twamley *et al.*, 2014; Burke, 2018; Alizadeh *et al.*, 2022). This question is particularly relevant to identifying those children in the last year of life who will require specialist palliative care (Burke, 2018).

Considering alternative approaches, the GO-PPaCS panel outlined a series of CPC eligibility criteria that encompass, but expand on, the presence/absence of a life-limiting, life-threatening, or terminal illness to include factors such as frequency of hospitalisations, symptom burden and bereavement (Table 3).

TABLE 3 Eligibility criteria for children's palliative care

Eligibility criteria
Diagnosis of a life-limiting/ life-threatening condition
Serious episodes of hospitalisations ○ At least three hospitalisations for serious clinical crises over a period of 6 months ○ Hospitalisation of over 3 weeks without clinical improvement according to the medical team ○ Admission to ICU of over 1 week without clinical improvement
Use of invasive medical devices for life support
Life-threatening condition that causes difficulties in the management of pain or other symptoms
Life-threatening conditions and complex psychosocial and spiritual needs of the child and family, including but not limited to: ○ Limited social support ○ The simultaneous need for more than three specialised services ○ A child with difficult and complex management of care handover between the hospital setting and the home
Difficulties in making significant decisions for children and/or the family ○ Difficulties in achieving consensus between the child, family and medical team on treatment and goals of care (e.g., resuscitation, use of parenteral nutrition/IV hydration or continuation of chemotherapy in the terminal stages).
The anticipation of special support during the mourning period.

Source: Benini *et al.*, 2022
Notes: Modified from Jankovic *et al.*, 2019

Furthermore, a palliative care approach should be introduced at the time of diagnosis and the level of care provided should be commensurate with the specific needs of the child and their family (Benini *et al.*, 2022). This is in line with recommendations in the UK that the diagnosis and severity of a life-limiting condition is considered alongside child and family needs (Together for Short Lives, 2018).

5.3 Complexities in measuring need for children's palliative care

The lack of standardised and precise CPC eligibility criteria across countries and healthcare settings causes challenges for assessing and quantifying the need for palliative care among children (Fraser *et al.*, 2020; Benini *et al.*, 2022). Further challenges include lack of consistency between databases, diverse methods of data collection (e.g., prevalence vs incidence), a lack of robust data, and limited information on the complexity, severity and needs of the children and their conditions (Connor *et al.*, 2017; Fraser *et al.*, 2020; Benini *et al.*, 2022).

Available literature on measuring or quantifying need for CPC is limited but three broad approaches are identified, from counting premature deaths from natural causes to more inclusive approaches based on prevalence of complex chronic conditions or specified life-limiting diagnoses drawing variously on hospital in-patient data, mortality data, cancer registry data, intensive care patient data (Feudtner *et al.*, 2000; Chavoshi *et al.*, 2015; Connor *et al.*, 2017; Fraser *et al.*, 2021). A fourth approach, using a 'Phase of Illness' measure, whereby need for palliative care is based on the stage of illness rather than on prognosis, has also been proposed (Burke, 2018; Mather *et al.*, 2018). Patients may be classified into one of four distinct clinical stages of illness (stable, unstable, deteriorating and dying) and can move between these stages depending on their needs.

5.4 Scoping review rationale

The aim of this rapid scoping review is to identify how the need for CPC is defined and measured in the literature. The decision to adopt a rapid scoping review method is based on the premise that CPC is still a growing specialist area in terms of population, methods, context, and discipline. Scoping reviews provide a broad overview of a specific topic and can map underlying definitions and concepts (Arksey and O'Malley, 2005; Munn *et al.*, 2018), which fits with the focus of this review.

We are aware of a recent scoping review protocol published in the Open Science Framework (OSF) which aims to examine classification models used to identify children who would benefit from paediatric palliative care and apply these methods to a Latin American context (Ramos-Guerrero *et al.*, 2023). While our review also incorporates measurement issues such as classification models, our overall focus is broader in scope (i.e., definition as well as measurement of need for CPC).

This review forms part of a larger research project designed to improve CPC policy, planning and delivery in Ireland (ECHPI: Evidence for Children's Palliative Care in Ireland).[1] The project seeks to (i) define and document the life-limiting conditions experienced by children in Ireland, (ii) quantify the number and geographic profile of children with these conditions with specific focus on those in unstable, deteriorating, and dying stages, and examine complexity of need, (iii) examine hospital use, (iv) assess equality and equity of geographic access to CPC, and (v) detail systematically the evidence and outline the priorities and actions for CPC policymakers, planners and providers, supporting the national goal of universal CPC in Ireland.

6 Scoping review objectives

6.1 Research Question

Within this scoping review, we aim to address the following research question:

- How has the need for children's palliative care been defined in the literature (e.g., presence of life-limiting conditions, serious episodes of hospitalisations) and what methods have been used to quantify that population?

6.2 Objectives

Specifically, we will examine:

1. How is need for children's palliative care defined in the literature (e.g., eligibility criteria, conceptual discussions, etc.)
2. How do the above definitions vary?
3. What approaches are used to measure need for children's palliative care (e.g., estimated prevalence of specified life-limiting diagnoses using hospital admissions data, analysis of mortality data, etc.)?
4. What are the main differences/similarities between the different measurement approaches?

[1] https://professionalpalliativehub.com/research/palliative-care-research-studies/childrens-palliative-care/ [last accessed 08/06/2023]

7 Scoping review methods/ design

7.1 Design

This review will be conducted in line with the methodology for scoping reviews described by the Joanne Briggs Institute (JBI) (Peters, 2020). Findings will be presented using the Preferred Reporting Items for Systematic Reviews and Meta-Analyses Extension for Scoping Reviews (PRISMA-ScR) (Tricco *et al.*, 2018) [Appendix 1].

7.1.1 Identifying relevant studies

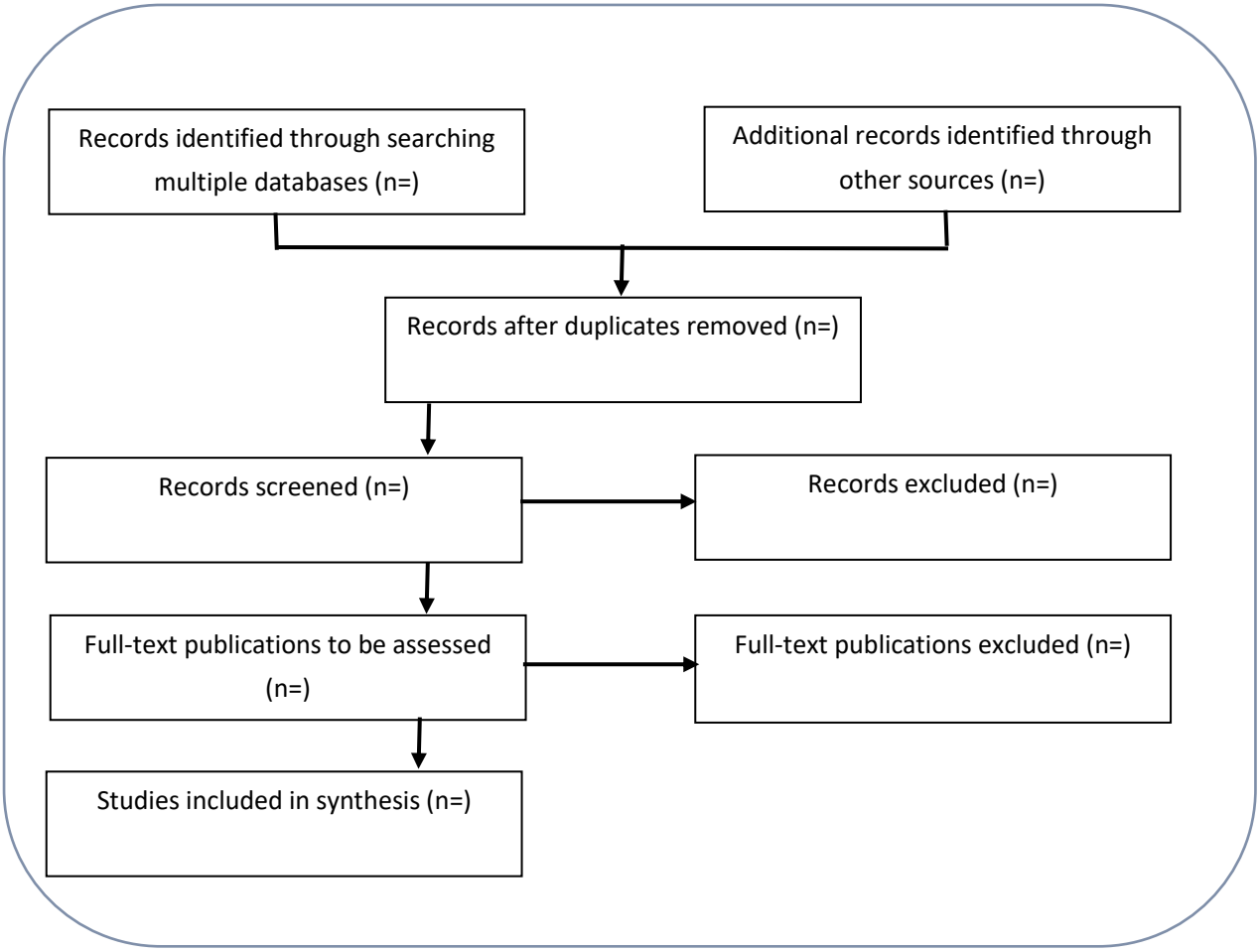
Selection of the search terms and eligibility criteria are guided by the PCC (Population, Concept and Context) framework (Peters, 2020). A list of potential key words and index terms has been drawn up by the research team to include standard search terms used in other scoping reviews (Table 4). It is anticipated that this list will be refined and added to as the search process proceeds. A subject librarian with expertise in systematic and scoping reviews will support the development of search strategies. An initial search of Web of Science will be followed by an analysis of the search terms contained in the titles and abstracts in the retrieved literature. The subject headings relevant to the review topic will also be examined. Academic and grey literature will be retrieved from additional bibliographic and review databases including CINAHL, Cochrane Library, EMBASE, Medline, and PsycINFO. The search may be supplemented through various approaches, for example, by scanning the publication lists of targeted organisations for relevant material. The final search results will be exported into Covidence© and duplicates removed.

TABLE 4 Search terms

	Search Terms
Population	(adolescen* OR baby OR babies OR boy* OR child* OR "early birth*" OR girl* OR infant* OR juvenile* OR learner* OR "low birth weight*" OR minor* OR neonat* OR newborn* OR "new born*" OR pediatric* OR paediatric* OR perinatal OR premature OR preterm OR "pre term" OR pupil* OR schoolboy* OR schoolgirl* OR student* OR teen* OR young* OR youth)
AND Context NEAR/15 Concept	(("dying" OR (complex NEAR/2 need*) OR ((hospice OR palliative OR terminal*) NEAR/2 (care OR disease* OR ill*)) OR ((life) NEAR/2 (limiting OR "end of" OR shorten* OR incompatible OR threaten*))) NEAR/15 (categor* OR classif* OR concept* OR eligibil* OR epidemiol* OR estimat* OR incidence* OR prevalen* OR quantif* OR quantity OR terminol* OR ((defin*) NEAR/2 need*)))

All search activities (including date of search, platform, etc.) will be recorded in an Excel spreadsheet. The search strategy results will be presented in a Preferred Reporting Items for Systematic Reviews and Meta-Analyses (PRISMA) flowchart (Figure 1) which will outline how and why studies were eliminated as well as the final number forming the basis of the synthesis. This will inform the narrative summary of the screening decision process.

Fig. 1 Flow chart for the current review



7.1.2 Selecting eligible studies

All studies that meet the criteria identified in Table 5 will be included. Where a systematic review is included, we will count the number of studies included in the review that will potentially meet the inclusion criteria of the current study. Two independent reviewers will screen the titles and abstracts in Covidence© for relevance against the eligibility criteria. Selected publications will undergo full text review for relevance and data will be extracted into a data extraction tool saved in Microsoft Forms. A third reviewer will be consulted where discrepancies occur.

TABLE 5 Eligibility criteria

	Inclusion criteria	Exclusion criteria
Population	Children & young adults (0-19 years)	Adults
Concept	Definition and measurement of need for palliative care	
Context	Children's Palliative Care (including key terms used in the CPC context, e.g., life-limiting conditions, life-threatening conditions, complex needs, dying, etc.).	
Years	2008 to present	
Language	English	Other languages
Study design (where relevant)	Quantitative, qualitative, and mixed methods studies, study protocols, discussion/conceptual papers; policy documents.	
Study meets one of the following:	- Discussion/conceptual papers that include discussion of eligibility criteria/need for CPC or methods for measuring/quantifying need for CPC. - Primary research estimating/quantifying need for CPC.	

7.2 Data extraction and charting process

A multistep process will be adopted for data extraction. A data extraction tool will be customised based on JBI's 'template source of evidence details, characteristics and results extraction instrument' (Peters, 2020). Two reviewers will pilot the extraction tool on a sample of papers with revisions and/or additions to the tool made where appropriate. All data relevant to the research questions and objectives will then be extracted from the final selection of studies under key headings (Table 6).

TABLE 6 Data extraction form

Key headings	
1	Title
2	Year
3	Author(s)
4	Country
5	Context
6	Population/participants (age, diagnosis)
7	Study design (where relevant)
8	Definition of need for CPC
9	Measurement approach of need for CPC

7.3 Analysis of results

Findings will be presented in tabular form in terms of the range of approaches to defining and measuring need for CPC. Any strengths and/or weaknesses highlighted by the authors will also be reported. Thematic synthesis (and descriptive where relevant e.g., number of participants in a study) will be implemented at the analysis stage to allow for the identification of key definitions and methods of measurement. This will inform the next phase of our ECHPI project.

8 Discussion

8.1 Summary

Available literature on how we define and measure the need for palliative care among children is varied and requires further exploration. It is anticipated that the current scoping review will present a summary overview of the range of these definitions and measurement methods making a valuable contribution to the field of children's palliative care.

8.2 Public and patient involvement (PPI)

This scoping review forms part of a larger project that aims to address important gaps in evidence in CPC in Ireland in collaboration with key stakeholders including PPI representatives. Involving PPI in this project is imperative as it has made it clear that the intention to open a discussion about how we define life-limiting conditions and need for palliative care in Ireland is important. Our PPI co-applicant is a member of the project advice team and will be involved in interpreting the findings from the scoping review alongside our co-researchers, clinical experts, and international collaborator.

8.3 Dissemination and ethics

The scoping review will synthesise definitions of need for CPC for children aged 0-19 years and how they are measured as described in the literature. The findings will be used to inform a stakeholder consensus process exploring the definition of life-limiting conditions among children for application in Ireland. The findings will be disseminated in collaboration with PPI representatives on the research team through for example, an open-access peer reviewed publication, infographic, oral and poster presentations, and via social media platforms including The Palliative Hub of the All-Ireland Institute for Hospice and Palliative Care (https://professionalpalliativehub.com/research/).

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10 Appendix 1

Preferred Reporting Items for Systematic Reviews and Meta-Analyses Extension for Scoping Reviews (PRISMA-ScR) Checklist

SECTION	ITEM	PRISMA-ScR CHECKLIST ITEM	REPORTED ON PAGE #
TITLE			
Title	1	Identify the report as a scoping review.	Click here to enter text.
ABSTRACT			
Structured summary	2	Provide a structured summary that includes (as applicable): background, objectives, eligibility criteria, sources of evidence, charting methods, results, and conclusions that relate to the review questions and objectives.	Click here to enter text.
INTRODUCTION			
Rationale	3	Describe the rationale for the review in the context of what is already known. Explain why the review questions/objectives lend themselves to a scoping review approach.	Click here to enter text.
Objectives	4	Provide an explicit statement of the questions and objectives being addressed with reference to their key elements (e.g., population or participants, concepts, and context) or other relevant key elements used to conceptualize the review questions and/or objectives.	Click here to enter text.
METHODS			
Protocol and registration	5	Indicate whether a review protocol exists; state if and where it can be accessed (e.g., a Web address); and if available, provide registration information, including the registration number.	Click here to enter text.
Eligibility criteria	6	Specify characteristics of the sources of evidence used as eligibility criteria (e.g., years considered, language, and publication status), and provide a rationale.	Click here to enter text.
Information sources	7	Describe all information sources in the search (e.g., databases with dates of coverage and contact with authors to identify additional sources), as well as the date the most recent search was executed.	Click here to enter text.
Search	8	Present the full electronic search strategy for at least 1 database, including any limits used, such that it could be repeated.	Click here to enter text.
Selection of sources of evidence	9	State the process for selecting sources of evidence (i.e., screening and eligibility) included in the scoping review.	Click here to enter text.
Data charting process	10	Describe the methods of charting data from the included sources of evidence (e.g., calibrated forms or forms that have been tested by the team before their use, and whether data charting was done independently or in duplicate) and any processes for obtaining and confirming data from investigators.	Click here to enter text.
Data items	11	List and define all variables for which data were sought and any assumptions and simplifications made.	Click here to enter text.
Critical appraisal of individual sources of evidence	12	If done, provide a rationale for conducting a critical appraisal of included sources of evidence; describe the methods used and how this information was used in any data synthesis (if appropriate).	Click here to enter text.
Synthesis of results	13	Describe the methods of handling and summarizing the data that were charted.	Click here to enter text.
RESULTS			
Selection of sources of evidence	14	Give numbers of sources of evidence screened, assessed for eligibility, and included in the review, with reasons for exclusions at each stage, ideally using a flow diagram.	Click here to enter text.
Characteristics of sources of evidence	15	For each source of evidence, present characteristics for which data were charted and provide the citations.	Click here to enter text.
Critical appraisal within sources of evidence	16	If done, present data on critical appraisal of included sources of evidence (see item 12).	Click here to enter text.
Results of individual sources of evidence	17	For each included source of evidence, present the relevant data that were charted that relate to the review questions and objectives.	Click here to enter text.
Synthesis of results	18	Summarize and/or present the charting results as they relate to the review questions and objectives.	Click here to enter text.
DISCUSSION			
Summary of evidence	19	Summarize the main results (including an overview of concepts, themes, and types of evidence available), link to the review questions and objectives, and consider the relevance to key groups.	Click here to enter text.
Limitations	20	Discuss the limitations of the scoping review process.	Click here to enter text.

SECTION	ITEM	PRISMA-ScR CHECKLIST ITEM	REPORTED ON PAGE #
Conclusions	21	Provide a general interpretation of the results with respect to the review questions and objectives, as well as potential implications and/or next steps.	Click here to enter text.
FUNDING			
Funding	22	Describe sources of funding for the included sources of evidence, as well as sources of funding for the scoping review. Describe the role of the funders of the scoping review.	Click here to enter text.

Source: Tricco *et al.*, 2018