

# BMJ Open Health information needs, source preferences and engagement behaviours of women with metastatic breast cancer across the care continuum: protocol for a scoping review

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## ABSTRACT

**Introduction:** The health information needs, information source preferences and engagement behaviours of women with metastatic breast cancer (mBC) depend on personal characteristics such as education level, prior knowledge, clinical complications, comorbidities and where they are in the cancer journey. A thorough understanding of the information behaviours of women living with mBC is essential to the provision of optimal care. A preliminary literature review suggests that there is little research on this topic, but that there may be lessons from a slightly broader literature. This review will identify what is known and what is not known about the health information needs, acquisition and influences of women with mBC across the care continuum. Findings will help to identify research needs and specific areas where in-depth systematic reviews may be feasible, as well as inform evidence-based interventions to address the health information needs of female patients with mBC with different demographics and characteristics and across the mBC journey.

**Methods and analysis:** A scoping review will be performed using the guidelines of Arksey and O'Malley as updated by subsequent authors to systematically search scientific and grey literature for articles in English that discuss the health information needs, source preferences, engagement styles, and associated personal and medical attributes of women  $\geq 18$  years living with mBC at different stages of the disease course. A variety of databases (including Cumulative Index to Nursing and Allied Health Literature (CINAHL), PubMed, Excerpta Medica Database (EMBASE), Academic Search Premier, Cochrane Database of Systematic Reviews, PsycINFO, Health Source: Nursing/Academic Edition, and PQDT Open), oncology, patient advocacy and governmental websites will be searched from inception to present day. Research and non-research literature will be included; no study designs will be excluded. The six-stage Arksey and O'Malley scoping review methodological framework involves: (1) identifying the research question; (2) searching for relevant studies; (3) selecting studies; (4) charting the data; (5) collating,

## Strengths and limitations of this study

- Systematic summarisation of the evidence will identify information available from a wide array of relevant sources (scientific and grey literature) and publication types.
- The study will be a comprehensive review of published papers identified via major biomedical databases, not limited by time but covering a period from their inception to present day.
- No study designs or publication types will be excluded. As such, the review will integrate a wide and diverse body of literature and allow the combination of qualitative and quantitative knowledge synthesis approaches and research and non-research sources.
- The research will not be representative of the entire metastatic breast cancer (mBC) population as men with mBC and paediatric patients with mBC will be excluded from the scope of the review.
- The research will not specifically address the information needs and influences of mBC subpopulations, characterised by factors including age, race, site of metastases, hormone status, timing of advanced disease diagnosis (ie, initial vs recurrent) and stage of metastasis, which may be unique to each group.
- As a scoping review, the quality of included studies will not be evaluated.
- Included studies will be limited to those published in English due to resource constraints represented by an inability to have articles in other languages translated for inclusion. As such, the results of the review will not encompass the full international literature landscape on this topic.

summarising and reporting the results; and (6) consulting with stakeholders to inform or validate study findings (optional). Data will be extracted and analysed using a thematic chart and descriptive content analysis.

**Ethics and dissemination:** Being a secondary analysis, this research will not require ethics approval. Results will be disseminated through patient support organisations and websites and publications targeting healthcare professionals, advocates and patients.

## INTRODUCTION AND BACKGROUND

Metastatic (stage IV or stage 4) breast cancer (mBC), otherwise called advanced or secondary breast cancer, is a disease that has spread to distant sites of the body such as the liver, lungs, bone, brain, and/or other tissues or organs.<sup>1</sup> It is an incurable but treatable disease with a high risk of a shortened life span and continuous cancer-related treatment to prolong progression-free survival. Breast cancer occurs primarily in women though men can also be affected by the disease; the review will focus on women.

Women with metastatic disease have unique characteristics, needs, including information needs, and experiences that differ from those with early stage disease. Information and other resources provided to the broader breast cancer community may not be appropriate to them.

### Information needs of women with mBC

Several large patient surveys—the 2006 US-based Silent Voices Survey,<sup>2</sup> and international BRIDGE Survey (2009),<sup>3</sup> Count Us, Know Us, Join Us, and Here and Now (both 2016)<sup>4</sup>—have attested to the inadequacy and inaccessibility of mBC-specific patient information currently. Additionally, a 2013–2014 US-based mBC landscape analysis<sup>5</sup> and a March 2016 international 2005–2015 mBC Decade Report<sup>6</sup> have reported the same conclusion. Gaps identified included disease state information, prognosis, information on treatments, symptom and side effect management, and palliation. Overall, there appears to be an enduring and significant unmet need for appropriate education tailored to the informational needs of diverse mBC subgroups.<sup>7 8</sup>

Patient education or information is important to enhance patient outcomes by empowering patients and caregivers; optimising treatment outcomes; limiting treatment-related adverse events; and reducing office visits and hospitalisations.<sup>9</sup> It has been defined as: “... the process by which the patient comes to comprehend his or her physical condition and self-care by the use of various media and experiences”.<sup>10</sup>

### Preliminary literature search summary

To further probe the educational needs of women with mBC and the approaches to addressing these needs, a preliminary review of the literature was conducted using literature searches on PubMed and CINAHL. The period searched was 1950 (approximate start of oral chemotherapy) to present. This initial search was primarily concerned with gaining some insights into the character and effectiveness of teaching strategies and

methods of delivery for patient education in women with mBC, including underserved subpopulations such as African-American and Latina women. The role of digital media—computer/internet-based patient education methodologies—in optimising the education of women with mBC was also considered.

Topics searched were: internet and patient education and metastatic or advanced breast cancer; patient education/patient education methods and advanced/mBC; patient education and advanced breast cancer and African-American/black/Latina/minority women. The articles selected were full articles that described educational/health behavioural interventions in women with mBC or studies of these interventions. The selection focused on papers published in the previous 10 years. The searches returned a total of 340 results. The titles and (in many cases) abstracts of all 340 articles were reviewed.

The preliminary literature searches indicated that there are very few articles on patient education and information interventions in women with mBC in the published literature. Nine articles discuss educational or behavioural interventions in women with mBC (five from the literature search and four that were not from the search).<sup>11–19</sup> Six further articles (four from the literature search and two that were not from the search)<sup>20–25</sup> provide information on the educational and psychosocial needs of women with mBC. There are articles that address the informational needs of patients with multiple types of cancer, but these do not necessarily examine mBC on its own.

There are a few randomised controlled trials comparing educational or behavioural interventions for women with mBC. One study examined the effect of supportive-expressive psychotherapy on the survival time of women with mBC,<sup>19</sup> another looked at the effectiveness of a brief, tailored, nurse-delivered psychoeducational intervention on their quality of life or perceived needs,<sup>12</sup> and a third investigated the efficacy of cognitive therapy on reducing depression.<sup>16</sup> The preliminary literature search also failed to discover any existing scoping reviews on the subject of the proposed review. These results suggest the need for a more comprehensive and detailed examination of the literature.

### Important considerations in providing patient information

Patient information-seeking and engagement may be affected by multiple factors. Patient information engagement may be affected by psychological characteristics such as being an ‘information seeker’ or not, preferences for different information formats or learning styles, sociodemographic characteristics such as age, ethnicity and educational level, clinical factors such as the presence of comorbidities, and where a patient is on the cancer journey.<sup>26–32</sup>

### Information-seeking behaviours

Information-seeking behaviours of women with breast cancer are highly individualistic,<sup>33</sup> with some women

seeking information to cope with cancer (monitors) while others avoid information to escape the negative feelings associated with information (blunters).<sup>34</sup> Some patients also prefer to receive information via a proxy or surrogate (eg, a family member or caregiver).<sup>30 35</sup>

#### Information formats and learning styles

Women with mBC have also expressed varying information source preferences and assessments. Living Beyond Breast Cancer survey respondents cited printed patient materials, government websites and professional medical publications as the most frequently accessed sources, but scientific conferences and telephone education sessions were most valued by the majority.<sup>2</sup> Patients with cancer reactions to content, format, sources and preferences for the timing and delivery mechanisms of information will impact their information behaviours.<sup>36</sup> For example, readability, comprehensibility and cultural relevance may influence patient engagement with health information.<sup>36 37</sup>

#### Age

Generational differences affect information needs, source preferences, engagement behaviours and preferences. Older women with cancer may prefer more passive roles and express less need for information.<sup>6 32 38 39</sup> Many younger women with breast cancer may experience treatment-related sexual dysfunction that may not completely resolve<sup>40</sup> so information on sexuality may be of special interest.<sup>41</sup>

#### Education and health literacy

Inadequate health literacy (the degree to which individuals have the capacity to obtain, process and understand basic health information and services needed to make appropriate health decisions)<sup>42</sup> poses barriers to patients with cancer understanding of their disease and treatment options.<sup>43</sup> Moreover, higher educational level has been found to be associated with a more active information-seeking style.<sup>28 32 44 45</sup>

#### Ethnicity

Ethnicity, race and cultural background also influence patients with cancer information-seeking behaviours.<sup>6 46 47</sup> Thus, the use of family-based and community-based (vs purely individually directed), religious and spiritual coping strategies by African-American and Latina women with breast cancer may influence the way they access health information.<sup>6 46 48</sup>

#### Position on the care continuum

As with other cancers,<sup>32</sup> the information needs, including the type of information sought, of women with mBC vary with the stage of the patient pathway (ie, mBC diagnosis, treatment, including long-term survivorship, and the post-treatment, end-of-life phase).<sup>5</sup> An important aspect of cancer care is provision of specific information that is tailored to the specific stage of the patient along the disease continuum.<sup>29 49</sup>

Around the time of diagnosis, patients want information about the disease, side effect management, prevention of treatment-related side effects and prognosis;<sup>15 21 25</sup> at the time of treatment, treatment information (ie, monitoring treatment-related side effects and the risk-benefit profile of novel treatments) may be most relevant.<sup>50</sup> Long-term survivors' informational needs relate to their diagnosis, prognosis and treatment options, including understanding and managing treatment-related toxicities and effects such as psychosocial complications (eg, anxiety and depression and social complications).<sup>6 14</sup> In the end-of-life and palliative treatment phase, specific information needs include late-disease risks, complications of advanced disease, specific palliative care therapies and potential side effects, pain management, and skin care.<sup>51</sup>

#### Study rationale

The rationale for the proposed research is that provision of quality care to women with mBC requires information provision appropriate to different time points in the care continuum.<sup>14 15 21 25 50 51</sup> This scoping review aims to synthesise current knowledge on female patients with mBC information needs, source preferences and engagement behaviours, and influences as these evolve across their cancer journey.

#### Study objectives

The aim of this study is to explore the question: What information exists in the literature about the information needs, source preferences, engagement behaviours and associated sociodemographic and situational factors (such as disease-related or treatment-related factors) of women  $\geq 18$  years with mBC at different time points of the cancer care continuum?

#### Anticipated utility of the review

The feasibility of in-depth, systematic reviews will be determined by the scoping review.

Findings will also help to identify research needs and inform evidence-based interventions to address the health information needs of female patients with mBC with different demographics and characteristics and across the mBC journey.

#### Methods and analysis

A scoping review will be conducted of the scientific, clinical and broader literature for articles in English addressing female patients with mBC information needs, source preferences, usage and related factors across the mBC disease course. Because of a lack of resources for translation, articles published in languages other than English will be excluded.

While recognising the existence of several varying definitions of this methodology, for purposes of this review, by scoping review or study is meant: "...a form of knowledge synthesis that addresses an exploratory research question aimed at mapping key concepts, types of

evidence, and gaps in research related to a defined area or field by systematically [and iteratively] (insertion by O'Brien *et al*<sup>52</sup>) searching, selecting, and synthesizing existing knowledge".<sup>53</sup>

In their foundational article on scoping review methodology, Arksey and O'Malley<sup>54</sup> identified possible aims of scoping reviews as: to examine the extent, range and nature of research activity, determine the value of undertaking a full systematic review, summarise and disseminate research findings, or identify gaps in the existing literature. Initially, at least the first two aims will be addressed via this scoping review; potentially all four may be fulfilled.

Arksey and O'Malley<sup>54</sup> also proposed a six-stage methodological framework: (1) identifying the research question; (2) searching for relevant studies; (3) selecting studies; (4) charting the data; (5) collating, summarising and reporting the results; and (6) consulting with stakeholders to inform or validate study findings (optional).

Both Levac *et al*<sup>55</sup> and Daudt *et al*<sup>56</sup> have made significant updates to the Arksey and O'Malley scoping review framework. This study protocol is informed by and incorporates enhancements and refinements made by these two groups.

The primary objective is to provide a critical review of the state of the research apparent from the literature about the information needs and behaviours of women with mBC as they evolve across the disease course, including identifying gaps insofar as possible.

To ensure comprehensiveness of the research, information is defined broadly as comprising both cancer-related and non-cancer-related information, namely, psychological, medical and social information.

### Literature review search strategy

The scoping review will consider the international English language literature (both peer-reviewed and 'grey') that discusses patient information needs, sources and acquisition, including associated variables of women aged  $\geq 18$  with advanced or metastatic stage IV<sup>4</sup> breast cancer. Primary research studies, systematic reviews, meta-analyses, clinical guidelines, meeting abstracts and dissertations, interviews, text and opinion literature, and other publication types will be included. In order to capture a diverse body of evidence, encompassing quantitative, qualitative and mixed-methods approaches, and in keeping with the scoping review methodology focus on summarising breadth of evidence, no study designs will be excluded.

As described in the *Joanna Briggs Institute Reviewers' Manual 2015*, a three-step search strategy will be used in this research:<sup>57</sup>

1. An initial limited search of PubMed and CINAHL followed by analysis of the text words contained in the title and abstract of the retrieved articles.
2. A second search using all identified keywords and index terms across all proposed databases.

3. A search of the reference list of all identified reports and articles for additional studies.

The proposed databases to be searched (from inception to present day) include CINAHL, PubMed, EMBASE, Academic Search Premier, Cochrane Database of Systematic Reviews, PsycINFO, Health Source: Nursing/Academic Edition, Epistemonikos, the Joanna Briggs Institute Database of Systematic Reviews and Implementation Reports (JBI-SRIR), the Evidence for Policy and Practice Information and Co-ordinating Centre (EPPI-Centre) and Education Resources Information Center (ERIC).

Patient advocacy websites and publications and cancer websites will be investigated for unpublished studies. The search for unpublished studies will also include the following websites: PQDT Open (<http://pqdtopen.proquest.com/search.html>, which provides open access to dissertations and theses); Google Scholar; WHO, <http://www.who.int>; Clinical Trials.gov; Institute of Medicine (IOM), <http://www.iom.edu>; the National Cancer Institute (NCI), <http://www.cancer.gov>; National Institutes of Health (NIH), <http://www.nih.gov>; Agency for Healthcare Research and Quality (AHRQ), <http://www.ahrq.gov>; New York Academy of Medicine, <http://www.nyam.org/>; and the Virginia Henderson Global Nursing e-Repository of the Honor Society of Nursing, Sigma Theta Tau International, <http://www.nursinglibrary.org>, a repository dedicated to sharing nursing publications.

The search for grey literature will include searches of Open-Grey (<http://www.opengrey.edu>), an open access database of European grey literature and the *Grey Literature Report* (<http://www.greylit.org>), a publication of the New York Academy of Medicine.

Relevant oncology websites will be searched, including the American Society of Clinical Oncology (ASCO), <http://www.asco.org>; Oncology Nursing Society (ONS), <http://www.ons.org>; European Society for Medical Oncology (ESMO), <http://www.esmo.org>; and the American Cancer Society (ACS), <http://www.acs.org> websites.

The initial search will consist of each of the following terms linked by *OR*: information-seeking, information needs, information acquisition, information resources, information sources, information source preferences, information support, information dissemination methods, health information, patient education, health education, patient education methods, therapeutic patient education, patient knowledge, treatment education, patient concerns, patient satisfaction, patient communication, patient information, patient experience, clinical communication, physician-patient communication, patient-provider communication, communication challenges and patient-cent(e)red communication *AND* each of the following terms linked by *OR*: advanced breast cancer, metastatic breast cancer, secondary breast cancer, stage IV breast cancer and stage 4 breast cancer. A flexible and iterative approach will be employed

enabling redefining and/or fine tuning of this initial search strategy based on the results obtained.<sup>52</sup>

To assess the completeness of the above search, hand searching of reference lists and bibliographies of included studies and two or three appropriate journals for the preceding 6 months to a year will be conducted. Proposed journals are the *Journal of Cancer Education*, *Patient Education and Counseling*, and *Support Care Cancer*. Endnote will be used to manage the references retrieved.

### Study selection

The review will exclude articles that:

4. Include patients  $\leq 18$  years old. As with other paediatric patients with cancer, paediatric patients with mBC are likely to have unique information and support needs that cannot be adequately addressed within the framework of this review, but will require a separate specific review.
5. Focus mainly on men or do not differentiate between the needs of male and female patients with mBC. Although many of the findings concerning information needs, sources and engagement may be transferable from women to men, we consider that men with mBC have special needs worthy of a separate review. This protocol and scoping review will focus only on women with mBC.
6. Solely report economic research (ie, cost-effectiveness or cost-utility studies).
7. Relate to prevention and screening for breast cancer.
8. Describe genetics unless they discuss information needed by or provided to women with mBC.
9. Focus on the information needs and behaviours of women with early stage or primary breast cancer.
10. Focus exclusively on the information needs and engagement of patients' partners or family members. However, articles containing information relative to the influence of patient/caregiver interactions on the patient information engagement behaviours of women with mBC will be included.
11. Include other types of cancer in addition to mBC, but which do not discuss the information needs, sources and behaviours of women with mBC separately from those of patients with other types of cancer.
12. Focus on the informational or educational needs of healthcare professionals, unless they also address the information needs of women with mBC.
13. Concern cancer risk, mortality and epidemiology.

Articles for inclusion will be selected using a three-step process: (1) titles of articles will be scanned to determine eligibility based on the inclusion and exclusion criteria; (2) article titles and abstracts will be reviewed using the eligibility criteria; (3) full-text versions of all potentially relevant articles will be retrieved for inclusion consideration.

Author and date		Types of information sources mentioned														
Author and date		Types of information needs mentioned														
		Other	Treatment-related information	Rehabilitation	Coping information	Interpersonal/social information	Prognosis information	Cancer-specific information	Body image/sexuality information	Medical system information	Healthcare professionals	Interpersonal	Printed materials	Media	Organisational/scientific resources	Women with metastatic breast cancer

As recommended in the Levac *et al.*<sup>55</sup> methodological update, this stage of the review will be approached as an iterative process comprising searching the literature, refining the search strategy and reviewing articles for study inclusion.

Given the patient-centred focus of the proposed research, it is likely that qualitative evidence will be an important element of the output of this study. It has been expressed as both a strength and a limitation of scoping reviews that at best they encompass a wide array of literature and research study designs though the diverse and potentially complex character of the data obtained may make analysis and synthesis very demanding.<sup>52</sup> Despite the contrasting methodologies of quantitative and qualitative research, the proposed review will iteratively address these issues as the literature review evolves, data are generated, and a clearer understanding of the scope and character of the mBC information behaviour literature develops. Qualitative data will be addressed using qualitative methodology: an interpretive approach to understanding patients with mBC perceptions, values, beliefs and experiences relative to information needs, seeking, quality and knowledge assimilation may be an applicable approach to an analysis and synthesis of qualitative literature results.<sup>58 59</sup>

### Data abstraction

This step in the review process relates to 'charting the results' in review terminology. Given the iterative nature of scoping reviews, the exact path and methodology of data abstraction may change depending on the data obtained. The proposals outlined here are preliminary and subject to modification as the review evolves.

The systematic review typology chart developed by Rutten *et al.*<sup>32</sup> and modified by van Mossel *et al.*<sup>49</sup> will be adapted to create a preliminary table (table 1) to record authors and dates of included articles and types of information needs and sources mentioned using the broad categories they proposed. Relevant subcategories of information specific to breast cancer and/or mBC will be formulated using the search results; these will be used to generate two tables recording the types of information needs and sources mentioned in reviewed articles.

The methodological quality of individual included studies will not be assessed since the aim of a scoping study is to conduct a comprehensive search enabling the identification of gaps in the evidence base and indication of subject areas for future reviews.<sup>49 60</sup> While Daudt *et al.*<sup>56</sup> strongly recommend incorporation of this component into the scoping review exercise, there does not appear to be currently sufficient guidance contained within the scoping review literature to assist in conducting this process. This consideration is especially pertinent as the evaluative task involves assimilation of evidence drawn from a diverse body of qualitative, quantitative, research and non-research and other literature that is not necessarily amenable to the usual methods of quality assessment.<sup>61</sup>

As recommended by Levac *et al.*,<sup>55</sup> charting will be an iterative step; data will be continually extracted and the charting form updated accordingly. Additionally, the charting form will be piloted using the first 5–10 studies and reviewed jointly by the authors to assess whether it meets the needs of the research question and the purpose of this review, with refinements made before embarking on the full scale charting exercise.<sup>55 56</sup>

Also, as observed by O'Brien *et al.*,<sup>52</sup> since the process of charting, collating and summarising of included publications will be iterative, knowledge synthesis may involve a descriptive component (presenting frequencies of literature characteristics) as well as an analytical aspect, that is, synthesis of qualitative and quantitative data with thematic or content analysis for relevant variables.

### RESULTS

Data abstraction and synthesis will use both tabular and textual (descriptive) approaches, which will provide adequate flexibility to accommodate both quantitative and qualitative literature.

This stage of the scoping review exercise falls under the collating, summarising and reporting the results stage of the Arksey and O'Malley framework.<sup>54</sup> As suggested by Levac *et al.*,<sup>55</sup> this stage may be segmented into three discrete steps: analysing the data (including descriptive numerical summary analysis and qualitative thematic analysis); reporting the results linked to the research question; and interpreting the implications of the results for research, policy and practice.

Characteristics of the literature included in the review will be summarised in a table (table 2), and the stages of the cancer care continuum in the reviewed articles will also be tabulated (table 3). A descriptive (narrative) summary of the articles included in the review, describing the aims or purposes of included articles, concepts or approaches used in each, and the results that relate to the review question, will be presented. As suggested by Levac *et al.*,<sup>55</sup> a thematic analysis akin to a qualitative data analysis approach may be attempted intended to organise the data into overarching themes. The findings might be presented using tables and descriptions aligned with identified themes.<sup>56</sup>

Any potential implications for evidence-based patient education practice and knowledge gaps meriting primary research and/or systematic reviews will be presented.<sup>57</sup>

### Stakeholder consultation

The second part of the study will involve primary research and entails interaction with patients with mBC to solicit their contributions on their cancer-related information needs and information engagement across the disease course. Ethics approval for this phase of the study will be sought from the Education Research Ethics Sub-Committee of the Faculty of Arts FREC of Plymouth University.

The methodology will be two-pronged: (1) monitoring of online sources, including social networking sites,

**Table 2** General characteristics of included articles

Characteristic	n	Per cent
<i>Type of article</i>		
Research study		
Commentary/narrative		
Clinical practice guideline		
Literature review		
Description of a program		
Other		
<i>Data collection method</i>		
Multiple collection methods		
Original questionnaire/survey		
Existing questionnaire/survey		
Interview		
Focus groups		
Chart review/medical records		
Other		
Unknown		
<i>Research study design</i>		
Quantitative		
Qualitative		
Mixed methods		
Clinical trial		
Concurrent		
Prospective/longitudinal		
Other (mixed designs)		
Unknown		
<i>Learning theory</i>		
Discussed		
Not discussed		
<i>Geographical location of the work</i>		
USA		
UK		
Other European countries		
Australia		
Canada		
Other		
<i>Publication date</i>		

**Table 3** Stages of the cancer care continuum mentioned in the reviewed articles

Stage in cancer care continuum	n	Per cent
At diagnosis		
Treatment (including long-term survivorship)		
Post-treatment/end-of-life		

discussion boards and online support groups for relevant postings, including tweets and chats. These inputs will be synthesised using qualitative thematic analysis/discourse or conversation analysis. In-person engagement with patients with mBC support groups around the same questions will provide additional data on the research topics and context to the scoping review findings. (2) A survey of patients with mBC (using an online method as well as hard copy questionnaires) will be conducted to test the findings from the online monitoring exercise. This

corresponds to the sixth stage of the Arksey and O'Malley framework: stakeholder consultation.

### Ethics and dissemination

All data in this review will be gathered through searches of literature and other online databases, and no personal health information will be collected; thus, ethics committee approval will not be required for the scoping review portion.

Research findings will be published and presented to patients and their families and caregivers through patient support and advocacy websites and organisations.

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**Competing interests** None declared.

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**Data sharing statement** The manuscript describes a protocol for a scoping review. The results of the scoping review will be submitted for publication.

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