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Quality of patient, family, caregiver, and public engagement in decision-making in healthcare systems: a scoping review protocol

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1 **Title:** Quality of patient, family, caregiver, and public engagement in decision-making in health-
2 care systems: a scoping review protocol

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52 health care

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32 **Abstract**

33 **Introduction**

34 To advance person- and family-centred health care, government initiatives have supported the
35 engagement of patients and family caregivers in decision-making in healthcare systems. There is,
36 however, no consensus on how to define success for such initiatives. This scoping review aims to
37 identify the key elements for defining the quality of patient and family caregiver engagement in
38 decision-making across the engagement levels (individual, community/organization, system) in
39 healthcare systems. We will use those elements to develop a conceptual evaluation framework.

41 **Methods and analysis**

42 This scoping review follows Arskey and O'Malley's methodology. 1) The research question was
43 identified through team discussions. 2) Articles for data source will be identified using a
44 librarian-informed search strategy for seven bibliographic databases as well as grey literature
45 sources. 3) Selected articles will be relevant to the evaluation of patient and family caregiver
46 engagement in healthcare systems. 4) Two researchers will independently extract data into
47 predefined and emerging categories. 5) The researchers will reconcile and organize the identified
48 elements. The research team's collective perspective will then refine the elements, and select,
49 interpret, and summarise the results. 6) Persons from key stakeholder groups will be consulted to
50 refine the emergent conceptual framework.

52 **Ethics and dissemination**

53 We will seek ethics approval for the stakeholder consultation. This study follows an integrated
54 knowledge translation approach. The results will inform evaluation of the Patients as Partners
55 Initiative of the British Columbia Ministry of Health, and will be disseminated as a scientific
56 article, a research brief, and presentations at conferences and stakeholder meetings.

63 **Strengths and limitations of this study**

64 1. A conceptual evaluation framework will be developed that covers all three levels of patient
65 and family caregiver engagement in decision-making within healthcare systems.

66 2. A comprehensive search strategy of electronic bibliographic sources published, and grey
67 literature is being used to capture available evidence.

68 3. This study employs an integrated knowledge translation approach involving a multi-
69 stakeholder research team.

70 4. The consultation of stakeholders from British Columbia will refine, contextualize, and validate
71 the content of the emergent conceptual evaluation framework, but may limit its direct
72 applicability to international settings.

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94 Introduction

95 Healthcare systems are starting to embrace a person- and family-centred health care approach to
96 better meet the priorities of patients and the public.¹⁻³ This approach positions patients, families,
97 and informal caregivers as partners engaged in the healthcare decision-making and care process.⁴
98 ⁵

99 In British Columbia, the Patients as Partners Initiative was created in 2008 by the Ministry of
100 Health to build capacity for, and strengthen the engagement of, patients, families, informal
101 caregivers (not hired caregivers), and the public in decision-making in the healthcare system.
102 With the goal as an enabler for advancing person- and family-centred health care in the
103 province,⁶⁻⁸ this initiative supports activities to include a patient voice, choice, and representation
104 in decision-making. The Ministry of Health's 2018 Patient, Family, Caregiver and Public
105 Engagement Framework⁸ depicts decision-making as occurring at three levels of engagement in
106 the healthcare system: (1) the individual level which comprises a person's or their family
107 caregiver's direct involvement in a person's own care; (2) the community level which denotes a
108 person taking part in activities related to healthcare programs and services; and (3) the system
109 level which covers taking part in policy and strategic planning targeted at the healthcare system.⁸
110 The ultimate goal of the Patients as Partners Initiative is to support achieving the quadruple aims
111 of optimal patient and provider experience, better health outcomes, and better cost-
112 effectiveness.^{9 10} For simplicity, patient and family caregiver will be used to cover the many
113 categories of individuals and groups served by the healthcare system, and who would be engaged
114 as health care partners. We broadly define 'patients' as individuals served within a given context
115 by a healthcare system from public health services of preventative care through to palliative care.
116 Family is a biological or legal relative or an individual otherwise considered by a person to be
117 family. A family caregiver refers to a 'family' member who provides informal care and support
118 to a patient.

119 Tasked with evaluating the Patients as Partners Initiative, our research team has recognized the
120 lack of a comprehensive framework for evaluating this type of policy-driven initiative. A good
121 foundation for an evaluation framework is the Donabedian conceptual framework – a
122 foundational tool that is widely accepted as a standard for guiding systematic evaluation of the
123 quality of health care.^{11 12} Its three-dimension approach of structure-process-outcome could be

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3 124 adopted and applied to conceptualize the quality of patient and family caregiver engagement in
4 125 decision-making in healthcare systems. For the current study, structure comprises the settings in
5 126 which engagement activities occurs, such as organizational structure, materials, and human
6 127 resources; process denotes the methods by which engagement occurs, such as the activities of
7 128 patient and other stakeholders; and outcome is the effect of engagement activities, for example,
8 129 improvements in patients' knowledge, skills, behaviours, and health status.¹¹ The Donabedian
9 130 framework thus provides overarching dimensions of a healthcare system within which to map the
10 131 key elements on this topic of patient and family caregiver engagement in decision-making.

11 132 A recent systematic review by Dukhanin et al. (2018) proposed a taxonomy of metrics for the
12 133 evaluation of "patient, public, consumer and community" engagement in decision-making at the
13 134 organization (i.e. community) and system levels of engagement in healthcare systems.¹³ Their
14 135 inductive qualitative analysis of 199 sources produced a taxonomy covering process and
15 136 outcome metrics.¹³ A few commentaries on this taxonomy viewed it as useful for evaluation, and
16 137 highlighted issues for improving its applicability.¹⁴⁻¹⁶ Notably, the taxonomy does not address
17 138 engagement of individuals in their own care, although it is crucial for shared decision-making.¹⁵
18 139 ¹⁶ Second, it did not explicitly address structure metrics, such as institution and organization
19 140 characteristics, thus missing an important dimension of the Donabedian framework.^{11 14-16} One
20 141 commentary explicitly noted that distinguishing structure metrics could have strengthened the
21 142 taxonomy.¹⁴ Third, Dukhanin and colleagues reviewed only continuous systematic processes of
22 143 engagement, to the exclusion of episodic and one-time engagement activities.¹³

23 144 The quality of patient and family caregiver engagement is a value-laden concept that challenges
24 145 finding consensus on elements of importance, reliable measures, and methods for evaluation.¹⁷
25 146 Only limited evaluation tools, such as the Public and Patient Engagement Evaluation Tool,¹⁹ are
26 147 available with sparse evidence on their validity. Available frameworks define the levels and
27 148 spectrum of patient and family caregiver engagement in healthcare decision-making.^{4 8} Other
28 149 progress made in shaping the understanding of the quality of patient and family caregiver
29 150 engagement in decision-making in healthcare systems include the Patient Health Engagement
30 151 model⁵ and the Patient Health Engagement Scale¹⁸ which are both directed at the individual level
31 152 of engagement, and a systematic review of 11 evaluation tools focused on health system
32 153 decision-making.^{18 19} The tools reported in that review seem to lack comprehensiveness and

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3 154 adequate validation.^{14 19} Further, we do not know the extent to which those tool cover the
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5 155 important elements of patient and family caregiver engagement since those elements have not
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7 156 been fully mapped out. Recently, Abelson and colleagues (2018) have reiterated the need for an
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9 157 evaluation framework for engagement at the organization and system level.²⁰ Given the existing
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11 158 gap, there is need for a conceptual evaluation framework for patient and family caregiver
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13 159 engagement in decision-making across all levels of engagement (individual,
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15 160 community/organization, system) in healthcare systems.
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18 162 **Study Rationale**

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20 163 While patient and family caregiver engagement is touted as key for optimal and sustainable
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22 164 health care,^{21 22} there is little evidence on whether patient and family caregiver engagement
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24 165 initiatives improve healthcare systems. A major barrier to developing this evidence base is a lack
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26 166 of consensus on how success in patient and family caregiver engagement should be defined (e.g.,
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28 167 what are the key elements and ideal outcomes of such engagement?). Therefore, a
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30 168 comprehensive framework, informed by the literature and perspectives of key stakeholders, is
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32 169 needed to provide a way for thinking about how patient and family caregiver engagement
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34 170 initiatives can be, and should be, evaluated. This framework would also be important for
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36 171 determining indicators to monitor and evaluate such initiatives. Furthermore, an evaluation
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38 172 framework would be helpful for establishing an agenda for research and policy on the quality of
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40 173 patient and family caregiver engagement in decision-making in healthcare systems.
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43 175 **Study objective**

44 176 We aim to identify the key elements for defining the quality of patient and family caregiver
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46 177 engagement in decision-making across the three levels of engagement (individual,
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48 178 community/organization, and system) within healthcare systems, and use those elements to
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50 179 develop a conceptual evaluation framework.
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53 181 **Methods and analysis**

54 182 **Protocol design**

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3 183 This study will be guided by Arksey and O'Malley (2005) scoping review methodology
4 184 enhanced by Levac et al (2010), and follow the standards of Preferred Reporting Items for
5 185 Systematic Reviews and Meta-Analyse Extension for Scoping Reviews (PRISMA-ScR)
6 186 checklist.²³⁻²⁵ The methodology consists of six stages. They include (1) identifying the research
7 187 question, (2) identifying relevant studies, (3) selecting studies, (4) charting the data, (5) collating,
8 188 summarizing, and reporting results, and (6) consulting with stakeholders.^{23 24} The final protocol
9 189 will be prospectively registered with the Open Science Framework.²⁵
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181 **Stage 1: Identify the research question**

182 The research question, proposed by the lead author CBH, was refined through discussion with
183 the research team, and fits the types of questions answered through scoping reviews.²⁶ The
184 primary question is “What key elements define the quality of patient, family, caregiver, and
185 public engagement in decision-making in healthcare systems for use in the evaluation of a
186 provincial engagement initiative?”
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198 **Stage 2: Identify relevant studies**

199 Search terms have been collaboratively determined by our research team. Our search strategy
200 was informed by a university-based health science librarian with expertise in systematic
201 literature reviews, a MEDLINE search filter for identifying patient and public engagement in
202 health research, and the search strategy by Duhkanin et al. (2018).^{13 27} We will search seven
203 electronic bibliographic databases: CINAHL (EBSCO), Cochrane Library (Ovid), EMBASE
204 (Ovid), MEDLINE (Ovid), PsycINFO (EBSCO), Social Work Abstracts (EBSCO) and Web of
205 Science from their inception to the search date. The proposed electronic search strategy for
206 electronic databases is provided as supplementary Appendix 1. The search strategy for
207 MEDLINE was peer reviewed by the librarian using the PRESS (Peer Review of Electronic
208 Search Strategies) checklist.²⁸
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212 Our search will be broad because of the variety of terms used in this area, and the semi-organized
213 and evolving nature of this body of literature. Search of the bibliographic databases will use a
214 combination of four blocks of terms: 1) patient and family caregiver engagement, 2) decision-

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3 212 making, 3) evaluation, and 4) healthcare system. For example, the first block pairs the terms for
4 213 health care partners (e.g., caregiver, community, consumer, family, patient, public, senior,
5 stakeholder, user) and engagement (e.g., advocate, activation, collaboration, consult, involve,
6 214 participate, represent), and use indexing terms. Search terms will typically be used as both
7 215 keywords in the title and/or abstract and subject headings as appropriate. No language or date
8 216 limits will be set during the searches to capture articles translated to English from other
9 217 languages and any foundational articles.
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16 219 To capture all relevant articles, we will search reference lists of key articles and used Google
17 220 Scholar to locate articles citing them. A targeted search of the grey literature will be conducted
18 221 for relevant local, provincial, national and international organisations' websites and related
19 222 health or scientific organisations for studies, reports, and conference abstracts. Some grey
20 223 literature sources will be selected from the list by Dukhanin et al.,¹³ the Canadian Agency for
21 224 Drugs and Technologies in Health (CADTH) Grey Matters (a checklist of health-related grey
22 225 literature sources from across the world),²⁹ and the Canadian Evaluation Society's grey literature
23 226 database. Finally, other literature will be identified by searching Google.ca, with a focus on the
24 227 first 100 search hits for each set of search terms.
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34 229 **Stage 3: Select studies**

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36 230 Retrieved articles will be transferred directly from a bibliographic database or Endnote (version
37 231 x7.8) reference management software to the Covidence software for screening,³⁰ and duplicates
38 232 of articles will be removed automatically. The screening process will consist of two steps: (1) a
39 233 title and abstract/summary, and (2) full-text screening. For the first step, two researchers will
40 234 independently screen the titles and abstracts of each retrieved article for inclusion against a set of
41 235 minimum eligibility criteria using three rating options: no, yes, and maybe. The selection process
42 236 will be refined through periodic discussing between the researchers doing the screening. This is
43 237 to ensure the eligibility criteria are robust enough to capture the articles that may relate to the
44 238 evaluation of patient and family caregiver engagement in decision-making in healthcare systems.
45 239 Articles deemed relevant by either or both reviewers (i.e., combined yes or maybe ratings) will
46 240 be included in the full-text review. In the second step, the full-text of each article will be
47 241 independently reviewed by two researchers to determine whether it meets the eligibility criteria
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242 using two rating options: no and yes. Inter-rater agreement will be determined with the first 100
243 articles using simple agreement (the number of agreements divided by the number of
244 comparisons) for step two screening, and then Cohen's κ statistic calculated.^{31 32} Disagreement
245 about including any full-text article will be settled by reviewing the article again and reconciling
246 its eligibility through further discussions between the two researchers. When an agreement is not
247 reached, a third researcher will be involved to obtain consensus.

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249 **Eligibility criteria**

250 An article will be included when it: (1) is available in the English Language, (2) describes patient
251 and family caregiver engagement within healthcare systems, and (3) provides useful information
252 on aspects of patient and family caregiver engagement in decision-making to evaluate. 'Useful
253 information' includes descriptions or definitions, information on relevance, and information on
254 relationships among aspects of patient and family caregiver engagement in decision-making.
255 There will be no restrictions on the type of study design for research articles. An article will be
256 excluded if the setting is: (1) outside of the healthcare sector (e.g., urban planning, forestry,
257 transport), (2) specific to the research sector not directly related to health care, or (3) specific to
258 the education sector not directly related to health care. The eligibility criteria will undergo
259 iterative refinement throughout the study as is common for scoping review.²⁴

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261 **Stage 4: Data collection**

262 Full-text of each selected article will be uploaded into NVivo qualitative data management and
263 analysis software (QSR International Pty Ltd, Burlington, MA). Two researchers will
264 independently collect and tabulate the characteristics of each article, including its publication
265 year, authors, article type (e.g., original research, policy, and guidelines), country of origin,
266 healthcare setting, and any other characteristics agreed on by the research team. Two researchers
267 will use a directed content analysis,³³ a qualitative data analysis technique, to independently
268 extract relevant information from the articles by coding them within six major categories:
269 "structure", "process", and "outcome" from the Donabedian framework,¹¹ and "individual (direct
270 care)", "community/organization", and "system" level from the British Columbia Ministry of
271 Health's engagement framework.⁸ Intercoder reliability between the two researchers for each of

272 these six codes will be calculated as simple agreement using a subset of the articles at the start of
273 the coding process.^{31 34} The minimum threshold for reliability will be 80%. When this threshold
274 is not reached for a code, the researchers will discuss the discrepancies, make any necessary
275 refinements, and independently apply the code to a new subset of articles. Even when the 80%
276 agreement threshold is reached, negotiated agreement will be calculated where there are
277 inconsistencies of coding between researchers.³⁴ During negotiated agreement, the researchers
278 will discuss the discrepancies to achieve a common understanding of the definition and use of
279 each code.³⁴ Once all of the articles are coded and any differences between researchers
280 reconciled, these coded segments of each article will be open coded independently by the
281 researchers to identify relevant elements for defining the quality of patient and family
282 engagement in healthcare systems. A critical appraisal of the articles is not applicable given the
283 nature of the data and aim of this study.

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285 **Stage 5: Data summary and synthesis of results**

286 Using a single file with all the data, the researchers who coded the articles will discuss the codes
287 by comparing them towards combining comparable themes/concepts and naming and defining
288 them as unique elements. These elements will be presented to, and discussed by, the research
289 team to get a collective perspective on their names, definitions, appropriateness, and
290 acceptability. The elements will be suitably arranged to create an emergent conceptual evaluation
291 framework. The research team will review and refine the emergent conceptual evaluation
292 framework, noting any gaps.

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294 **Stage 6: Stakeholder consultation**

295 While stakeholder consultation is not mandatory in the Arksey and O'Malley methodology, it
296 will be conducted as recommended by Levac et al. to increase the robustness, applicability,
297 feasibility, and acceptability of the conceptual framework.^{23 24} Adding credibility to the study,
298 our study team consists of the Patients as Partners Initiative lead, a program evaluation specialist,
299 a patient partner, a family caregiver partner, and health services researchers. However, because
300 this is an emerging and evolving area of practice and research, we will consult other persons
301 from the key stakeholder groups (health system leaders and decisions makers, managers and

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3 302 staff, health care providers, and health care users) in British Columbia for their insights to
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5 303 supplement, confirm or refute, and extend the emergent conceptual evaluation framework. The
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7 304 stakeholder consultation will be valuable to refine, contextualize, and validate the framework for
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9 305 implementation in British Columbia.

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11 12 307 **Ethics and dissemination**

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15 308 A literature synthesis does not require research ethics board approval. Ethics approval will be
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17 309 sought, however, for the stakeholder consultation stage of this study. We will wait for the
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19 310 preliminary results from the literature synthesis before applying for research ethics board
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21 311 approval. This study follows an integrated knowledge translation approach,³⁵ given the research
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23 312 team is a partnership between leadership of the Patients as Partners Initiative and other
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25 313 stakeholders. In addition to the patient perspectives to be captured from the literature and
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27 314 through stakeholder consultation, our patient partner will contribute their perspective throughout
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29 315 the entire research process and help to share findings with appropriate knowledge users.
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31 316 Furthermore, the family caregiver on our team represents a non-profit organization dedicated to
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33 317 advancing the priorities of family caregivers in the healthcare system. Each research team
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35 318 member will contribute to disseminating the results through conference presentations, a scientific
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37 319 article, a research brief, and presentations at stakeholder meetings.

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39 320 The conceptual evaluation framework on the quality of patient and family caregiver engagement
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41 321 in decision-making in healthcare systems will be a key step in the evaluation of the Patients as
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43 322 Partners Initiative. The results will inform evaluation of the Patients as Partners Initiative of the
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45 323 British Columbia Ministry of Health for quality improvement. We hope the framework will be
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47 324 applicable to other jurisdictions and provide guidance to determine the important domains and
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49 325 indicators for patient and family caregiver engagement initiatives in healthcare systems to
50
51 326 advance person- and family-centred health care. A key reason the resulting framework could be
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53 327 applicable to other jurisdictions is the systematic approach being taken to gather evidence from
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55 328 the literature irrespective of jurisdictions.

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57 58 330 **Patient and public involvement**

331 A patient and a family caregiver have been a member of our research throughout the
332 development of this scoping review protocol, and plan to be an actively involved in each stage of
333 this study. The research team's process of working together is guided by the Patient Engagement
334 In Research (PEIRS) Framework that lays out eight themes for ensuring meaningful patient
335 engaged research.³⁶

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446 Partners Initiation, for contributions to the initial conceptualization of this study.

447

448 Contributions

1
2
3 449 CBH obtained funding, conceptualised the research, and drafted this protocol. Each author
4
5 450 (CBH, MES, NC, SG, MD, ML, AK, JM, LCL) has made intellectual contribution to the
6
7 451 development of this protocol and the acquisition of project funding. All authors (CBH, MES,
8
9 452 NC, SG, MD, ML, AK, JM, LCL) review and edited the protocol and provided input through
10
11 453 team discussions and by email.
12
13 454

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28
29 462

30 31 463 **Competing interests:**

32
33 464 SG is the manager of the Patients as Partners Initiative within the British Columbia Ministry of
34
35 465 Health. JM is employee by Family Caregivers of British Columbia, a paid partner of the Patients
36
37 466 as Partners Initiative, which is a non-profit organization that provides support and advocates for
38
39 467 family caregivers within British Columbia, Canada.
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Appendix A - Electronic Database Search Strategy

MEDLINE (Ovid) and Cochrane Library (Ovid)

Block 1: patient and caregiver engagement

1. Community Integration.mp. or Community Integration/
2. Consumer participation/ or Patient participation/
3. (Consumer participation or patient participation or public participation or patient Engagement or “patient and public engagement” or “patient and public involvement”).kf.
4. ((caregiv* or coproducer or child or children or citizen or client or communit* or customer* or consumer* or family* or lay or layperson or marginalize* or patient* or parent* or public or senior* or stakeholder* or youth* or user*) adj3 (advoca* or activation or collaborat* or consult* or empower* or engage* or involve* or participat* or representat* or perspective* or activism or coproduc* or partner*)).tw,kf.
5. **1 or 2 or 3 or 4**

Block 2: decision making

6. (Decision Making or decision-making).mp. or Decision Making/
7. Organizational Decision Making.kf. or Decision Making, Organizational/
8. policy making/ or advisory committees/
9. (policy making or advisory committee* or governance or advisory board*).mp.
10. Patient Care Planning/
11. Governing Board/
12. **6 or 7 or 8 or 9 or 10 or 11**

Block 3: evaluation

13. Health Impact Assessment.mp. or Health Impact Assessment/
14. "quality of health care"/ or "outcome and process assessment (health care)"/ or program evaluation/ or quality assurance, health care/ or quality improvement/ or quality indicators, health care/
15. (quality adj2 (care or healthcare)).mp
16. (assess* or effective* or evaluat* or impact* or indicator* or meaningful* or measure* or metric* or outcome* or process* or structure* or quality or tool* or instrument*).tw.
17. **13 or 14 or 15 or 16**

Block 4: healthcare system

18. health policy/ or health care reform/
19. health polic*.mp.
20. "delivery of health care"/ or exp "delivery of health care, integrated"/ or exp health services accessibility/ or healthcare disparities/ or exp managed care programs/
21. delivery of health care.mp.
22. (Health system* or health care system* or healthcare system* or healthcare organization* or health care organization* healthcare organisation* or health care organisation*).mp.
23. Health priorit*.mp. or health priorities/
24. **18 or 19 or 20 or 21 or 22 or 23**
25. **Block 1, Block 2, Block 3, and Block 4 were combined using the ‘AND’ operator.**

EMBASE (Ovid)**Block 1: patient and caregiver engagement**

1. Community Integration.mp. or Community Integration/
2. *Patient participation/
3. ((caregiv* or coproducer or child or children or citizen or client or communit* or customer* or consumer* or family* or lay or layperson or marginalize* or patient* or parent* or public or senior* or stakeholder* or youth* or user*) adj3 (advoca* or activation or collaborat* or consult* or empower* or engage* or involve* or participat* or representat* or perspective* or activism or coproduc* or partner*)).tw.
4. **1 or 2 or 3**

Block 2: decision making

5. (Decision Making or decision-making).mp. or Decision Making/
6. management/ or *advisory committee/
7. (policy making or advisory committee* or governance or advisory board*).mp.
8. *Patient Care Planning/
9. *board of trustees/
10. **5 or 6 or 7 or 8 or 9**

Block 3: evaluation

11. Health Impact Assessment.mp. or *Health Impact Assessment/
12. “*health care quality”/ or “outcome assessment”/ or *quality control/ or “*total quality management”/
13. (quality adj2 (care or healthcare)).mp.
14. (assess* or effective* or evaluat* or impact* or indicator* or meaningful* or measure* or metric* or outcome* or process* or structure* or quality or tool* or instrument*).tw.
15. **11 or 12 or 13 or 14**

Block 4: healthcare system

16. *health care policy/
17. health polic*.mp.
18. "delivery of health care"/ or “*integrated health care system”/ or health care disparities/
19. delivery of health care.mp.
20. (Health system* or health care system* or healthcare system* or healthcare organization* or health care organization* healthcare organisation* or health care organisation*).mp.
21. Health priorit*.mp.
22. *health care/
23. **16 or 17 or 18 or 19 or 20 or 21 or 22**

24. **Block 1, Block 2, Block 3, and Block 4 were combined using the ‘AND’ operator**

**Social Work Abstracts (EBSCO), PsycINFO (EBSCO), and CINAHL Complete (EBSCO),
Web of Science (ran with default setting - all fields searched)**

Block 1: patient and caregiver engagement

1. "Community integration"
2. "Patient participation"
3. "Patient engagement"
4. "Patient involvement"
5. "Public involvement"
6. "Patient and public engagement"
7. "Patient and public involvement"
8. "Citizen engagement" OR "marginalized engagement" OR "aboriginal engagement" OR "refugee engagement"
9. "Caregiver engagement"
10. "Family engagement"
11. "Youth engagement"
12. "Senior engagement"
13. "Aboriginal engagement"
14. **1-13 combined using OR**

Block 2: decision making

14. "Decision Making"
15. Decision-making
16. "Advisory committee"
17. "Advisory board"
18. Governance
19. **14-19 combined using OR**

Block 3: evaluation

20. "Health Impact Assessment"
21. "health care quality"
22. "outcome assessment"
23. "quality indicator*"
24. indicator*
25. assess*
26. evaluat*
27. effective*
28. impact*
29. meaningful*
30. measure*
31. metric*
32. outcome*
33. process*

34. structure*
35. quality
36. tool*
37. instrument*
38. **20-37 combined using OR**

Block 4: healthcare system

39. "health care polic*"
40. "Health polic*"
41. "delivery of health care"
42. "delivery of healthcare"
43. "integrated health care system"
44. "integrated healthcare system"
45. "quality improvement"
46. "health care disparities"
47. "Health system*"
48. "health care system*"
49. "healthcare system"
50. "healthcare organization*"
51. "health care organization*"
52. "healthcare organisation*"
53. "health care organisation*"
54. "Health priorit*"
55. "health care"
56. **29-55 combined using OR**
57. **Block 1, Block 2, Block 3, and Block 4 were combined using the 'AND' operator.**

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.	1
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.	2
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.	6
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.	6
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.	7
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.	9
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.	7-8
Search	8	Present the full electronic search strategy for at least 1 database, including any limits used, such that it could be repeated.	Appendix
Selection of sources of evidence†	9	State the process for selecting sources of evidence (i.e., screening and eligibility) included in the scoping review.	8-9
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.	9-10
Data items	11	List and define all variables for which data were sought and any assumptions and simplifications made.	4-5, 9-10
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).	N/A



SECTION	ITEM	PRISMA-ScR CHECKLIST ITEM	REPORTED ON PAGE #
Synthesis of results	13	Describe the methods of handling and summarizing the data that were charted.	10
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.	N/A, in progress
Characteristics of sources of evidence	15	For each source of evidence, present characteristics for which data were charted and provide the citations.	N/A, in progress
Critical appraisal within sources of evidence	16	If done, present data on critical appraisal of included sources of evidence (see item 12).	N/A
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.	N/A, in progress
Synthesis of results	18	Summarize and/or present the charting results as they relate to the review questions and objectives.	N/A, in progress
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.	N/A, in progress
Limitations	20	Discuss the limitations of the scoping review process.	3
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.	N/A, in progress
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.	16

JBI = Joanna Briggs Institute; PRISMA-ScR = Preferred Reporting Items for Systematic reviews and Meta-Analyses extension for Scoping Reviews.

* Where *sources of evidence* (see second footnote) are compiled from, such as bibliographic databases, social media platforms, and Web sites.

† A more inclusive/heterogeneous term used to account for the different types of evidence or data sources (e.g., quantitative and/or qualitative research, expert opinion, and policy documents) that may be eligible in a scoping review as opposed to only studies. This is not to be confused with *information sources* (see first footnote).

‡ The frameworks by Arksey and O'Malley (6) and Levac and colleagues (7) and the JBI guidance (4, 5) refer to the process of data extraction in a scoping review as data charting.

§ The process of systematically examining research evidence to assess its validity, results, and relevance before using it to inform a decision. This term is used for items 12 and 19 instead of "risk of bias" (which is more applicable to systematic reviews of interventions) to include and acknowledge the various sources of evidence that may be used in a scoping review (e.g., quantitative and/or qualitative research, expert opinion, and policy document).

From: Tricco AC, Lillie E, Zarin W, O'Brien KK, Colquhoun H, Levac D, et al. PRISMA Extension for Scoping Reviews (PRISMA-ScR): Checklist and Explanation. *Ann Intern Med.* ;169:467–473. doi: 10.7326/M18-0850



BMJ Open

Quality of patient, family, caregiver, and public engagement in decision-making in healthcare systems: a scoping review protocol

Journal:	<i>BMJ Open</i>
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Primary Subject Heading:	Health policy
Secondary Subject Heading:	Patient-centred medicine, Health policy, Health services research
Keywords:	Patient participation, patient and public engagement, decision making, quality of health care

SCHOLARONE™
Manuscripts

1 **Title:** Quality of patient, family, caregiver, and public engagement in decision-making in health-
2 care systems: a scoping review protocol

3
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29 **Keywords:** Patient participation, patient and public engagement, decision making, quality of
30 health care

31 Word count: 3135/4,000 (main text only)

32 **Abstract**

33 **Introduction**

34 To advance person- and family-centred health care, government initiatives have supported the
35 engagement of patients and family caregivers in decision-making in healthcare systems. There is,
36 however, no consensus on how to define success for such initiatives. This scoping review aims to
37 identify the key elements for defining the quality of patient and family caregiver engagement in
38 decision-making across the engagement domains (individual, community/organization, system)
39 of British Columbia's healthcare system. We will use those elements to develop a conceptual
40 evaluation framework.

41

42 **Methods and analysis**

43 This scoping review follows Arskey and O'Malley's methodology. 1) The research question was
44 identified through team discussions. 2) Articles for data source will be identified using a
45 librarian-informed search strategy for seven bibliographic databases as well as grey literature
46 sources. 3) Selected articles will be relevant to the evaluation of patient and family caregiver
47 engagement in healthcare systems. 4) Two researchers will independently extract data into
48 predefined and emerging categories. 5) The researchers will reconcile and organize the identified
49 elements. The research team's collective perspective will then refine the elements, and select,
50 interpret, and summarise the results. 6) Persons from key stakeholder groups will be consulted to
51 refine the emergent conceptual framework.

52

53 **Ethics and dissemination**

54 We will seek ethics approval for the stakeholder consultation. This study follows an integrated
55 knowledge translation approach. The results will inform evaluation of the Patients as Partners
56 Initiative of the British Columbia Ministry of Health, and will be disseminated as a scientific
57 article, a research brief, and presentations at conferences and stakeholder meetings.

58

59

60

61

62

63 **Strengths and limitations of this study**

- 64 1. A conceptual evaluation framework will be developed that covers all three domains of patient
65 and family caregiver engagement in decision-making within healthcare systems.
- 66 2. A comprehensive search strategy of electronic bibliographic sources published, and grey
67 literature is being used to capture available evidence.
- 68 3. This study employs an integrated knowledge translation approach involving a multi-
69 stakeholder research team.
- 70 4. The consultation of stakeholders from British Columbia will refine, contextualize, and validate
71 the content of the emergent conceptual evaluation framework, but may limit its direct
72 applicability to international settings.

94 Introduction

95 Healthcare systems are starting to embrace a person- and family-centred health care approach to
96 better meet the priorities of patients and the public.¹⁻³ This approach positions patients, families,
97 and unpaid caregivers as partners engaged in the healthcare decision-making and care process.^{4 5}

98 In British Columbia, the Patients as Partners Initiative was created in 2008 by the Ministry of
99 Health to build capacity for, and strengthen the engagement of, patients, families, unpaid
100 caregivers, and the public in decision-making in the healthcare system. With the goal as an
101 enabler for advancing person- and family-centred health care in the province,⁶⁻⁸ this initiative
102 supports activities to include a patient and family caregiver voice, choice, and representation in
103 decision-making. The Ministry of Health's 2018 Patient, Family, Caregiver and Public
104 Engagement Framework⁸ depicts decision-making as occurring in three domains of engagement
105 in the healthcare system: (1) the individual domain which comprises a person's and/or their
106 family caregiver's direct involvement in a person's own care; (2) the community domain which
107 denotes a person and their family caregiver taking part in activities related to healthcare
108 programs and services; and (3) the system domain which covers taking part in policy and
109 strategic planning targeted at the healthcare system.⁸ The ultimate goal of the Patients as Partners
110 Initiative is to support achieving the quadruple aims of optimal patient and provider experience,
111 better health outcomes, and better cost-effectiveness.^{9 10} For simplicity, patient and family
112 caregiver will be used to cover the many categories of individuals and groups served by the
113 healthcare system, and who would be engaged as health care partners. We broadly define
114 'patients' as individuals served within a given context by a healthcare system from public health
115 services of preventative care through to palliative care. Family is a biological or legal relative or
116 an individual otherwise considered by a person to be family. A family caregiver refers to a
117 'family' member who provides unpaid care and support to a patient.

118 Tasked with evaluating the Patients as Partners Initiative, our research team has recognized the
119 lack of a comprehensive framework for evaluating this type of policy-driven initiative. A good
120 foundation for an evaluation framework is the Donabedian conceptual framework – a
121 foundational tool that is widely accepted as a standard for guiding systematic evaluation of the
122 quality of health care.^{11 12} Its three-dimension approach of structure-process-outcome could be
123 adopted and applied to conceptualize the quality of patient and family caregiver engagement in

1
2
3 124 decision-making in healthcare systems. For the current study, structure comprises the settings in
4
5 125 which engagement activities occurs, such as organizational structure, materials, and human
6
7 126 resources; process denotes the methods by which engagement occurs, such as the activities of
8
9 127 patient and other stakeholders; and outcome is the effect of engagement activities, for example,
10
11 128 improvements in patients' and family caregivers' knowledge, skills, behaviours, and health
12
13 129 status.¹¹ The Donabedian framework thus provides overarching dimensions of a healthcare
14
15 130 system within which to map the key elements on this topic of patient and family caregiver
16
17 131 engagement in decision-making.

18 132 A recent systematic review by Dukhanin et al. (2018) proposed a taxonomy of metrics for the
19
20 133 evaluation of "patient, public, consumer and community" engagement in decision-making at the
21
22 134 organization (i.e. community) and system domains of engagement in healthcare systems.¹³
23
24 135 Their inductive qualitative analysis of 199 sources produced a taxonomy covering process and
25
26 136 outcome metrics.¹³ A few commentaries on this taxonomy viewed it as useful for evaluation, and
27
28 137 highlighted issues for improving its applicability.¹⁴⁻¹⁶ Notably, the taxonomy does not address
29
30 138 engagement of individuals in their own care, although it is crucial for shared decision-making.¹⁵
31
32 139 ¹⁶ Second, it did not explicitly address structure metrics, such as institution and organization
33
34 140 characteristics, thus missing an important dimension of the Donabedian framework.^{11 14-16} One
35
36 141 commentary explicitly noted that distinguishing structure metrics could have strengthened the
37
38 142 taxonomy.¹⁴ Third, Dukhanin and colleagues reviewed only continuous systematic processes of
39
40 143 engagement, to the exclusion of episodic and one-time engagement activities.¹³

41 144 The quality of patient and family caregiver engagement is a value-laden concept that challenges
42
43 145 finding consensus on elements of importance, reliable measures, and methods for evaluation.¹⁷
44
45 146 Only limited evaluation tools, such as the Public and Patient Engagement Evaluation Tool,¹⁸ are
46
47 147 available with sparse evidence on their validity. Available frameworks define the levels and
48
49 148 spectrum of patient and family caregiver engagement in healthcare decision-making.^{4 8} Other
50
51 149 progress made in shaping the understanding of the quality of patient and family caregiver
52
53 150 engagement in decision-making in healthcare systems include the Patient Health Engagement
54
55 151 model⁵ and the Patient Health Engagement Scale⁵ which are both directed at the individual
56
57 152 domain of engagement, and a systematic review of 11 evaluation tools focused on health system
58
59 153 decision-making.¹⁹ The tools reported in that review seem to lack comprehensiveness and

1
2
3 154 adequate validation.^{14 19} Further, we do not know the extent to which those tool cover the
4
5 155 important elements of patient and family caregiver engagement since those elements have not
6
7 156 been fully mapped out. Recently, Abelson and colleagues (2018) have reiterated the need for an
8
9 157 evaluation framework for engagement at the organization and system domains.²⁰ Given the
10
11 158 existing gap, there is need for a conceptual evaluation framework for patient and family
12
13 159 caregiver engagement in decision-making across all domains of engagement (individual,
14
15 160 community/organization, system) in healthcare systems.
16
17 161

18 162 **Study Rationale**

19
20 163 While patient and family caregiver engagement is touted as key for optimal and sustainable
21
22 164 health care,^{21 22} there is little evidence on whether patient and family caregiver engagement
23
24 165 initiatives improve healthcare systems. A major barrier to developing this evidence base is a lack
25
26 166 of consensus on how success in patient and family caregiver engagement should be defined (e.g.,
27
28 167 what are the key elements and ideal outcomes of such engagement?). Therefore, a
29
30 168 comprehensive framework, informed by the literature and perspectives of key stakeholders, is
31
32 169 needed to provide a way for thinking about how patient and family caregiver engagement
33
34 170 initiatives can be, and should be, evaluated. This framework would also be important for
35
36 171 determining indicators to monitor and evaluate such initiatives. Furthermore, an evaluation
37
38 172 framework would be helpful for establishing an agenda for research and policy on the quality of
39
40 173 patient and family caregiver engagement in decision-making in healthcare systems.
41
42 174

43 175 **Study objective**

44 176 We aim to identify the key elements for defining the quality of patient and family caregiver
45
46 177 engagement in decision-making across the three domains of engagement (individual,
47
48 178 community/organization, and system) within the province of British Columbia healthcare system
49
50 179 and use those elements to develop a conceptual evaluation framework.
51
52 180

53 181 **Methods and analysis**

54 182 **Protocol design**

183 This study will be guided by Arksey and O'Malley (2005) scoping review methodology
184 enhanced by Levac et al (2010), and follow the standards of Preferred Reporting Items for
185 Systematic Reviews and Meta-Analyse Extension for Scoping Reviews (PRISMA-ScR)
186 checklist.²³⁻²⁵ The methodology consists of six stages. They include (1) identifying the research
187 question, (2) identifying relevant studies, (3) selecting studies, (4) charting the data, (5) collating,
188 summarizing, and reporting results, and (6) consulting with stakeholders.^{23 24} The final protocol
189 will be prospectively registered with the Open Science Framework.²⁵

190

191 **Stage 1: Identify the research question**

192 The research question, proposed by the lead author CBH, was refined through discussions within
193 the research team, and fits the types of questions answered through scoping reviews.²⁶ The
194 primary question is “What key elements define the quality of patient, family, caregiver, and
195 public engagement in decision-making in healthcare systems for use in the evaluation of a
196 provincial engagement initiative?”

197

198 **Stage 2: Identify relevant studies**

199 Search terms were collaboratively determined by our research team. Our search strategy was
200 informed by a university-based health science librarian with expertise in systematic literature
201 reviews, a MEDLINE search filter for identifying patient and public engagement in health
202 research, and the search strategy by Duhkanin et al. (2018).^{13 27} We will search seven electronic
203 bibliographic databases: CINAHL (EBSCO), Cochrane Library (Ovid), EMBASE (Ovid),
204 MEDLINE (Ovid), PsycINFO (EBSCO), Social Work Abstracts (EBSCO) and Web of Science
205 from their inception to the search date of April 23, 2019 and update it on June 14, 2019. The
206 proposed electronic search strategy for electronic databases is provided as supplementary
207 Appendix A. The search strategy for MEDLINE was peer reviewed by the librarian using the
208 PRESS (Peer Review of Electronic Search Strategies) checklist.²⁸

209 Our search will be broad because of the variety of terms used in this area, and the semi-organized
210 and evolving nature of this body of literature. Search of the bibliographic databases will use a
211 combination of four blocks of terms: 1) patient and family caregiver engagement, 2) decision-

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3 212 making, 3) evaluation, and 4) healthcare system. For example, the first block pairs the terms for
4 213 health care partners (e.g., caregiver, community, consumer, family, patient, public, senior,
5 stakeholder, user) and engagement (e.g., advocate, activation, collaboration, consult, involve,
6 214 participate, represent), and use indexing terms. Search terms will typically be used as both
7 215 keywords in the title and/or abstract and subject headings as appropriate. No language or date
8 216 limits will be set during the searches to capture articles translated to English from other
9 217 languages and any foundational articles.
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16 219 To capture all relevant articles, we will search reference lists of key articles and used Google
17 220 Scholar to locate articles citing them. A targeted search of the grey literature will be conducted
18 221 of relevant local, provincial, national and international organisations' websites and related health
19 222 or scientific organisations for studies, reports, and conference abstracts. Some grey literature
20 223 sources will be selected from the list by Dukhanin et al.,¹³ the Canadian Agency for Drugs and
21 224 Technologies in Health (CADTH) Grey Matters (a checklist of health-related grey literature
22 225 sources from across the world),²⁹ and the Canadian Evaluation Society's grey literature database.
23 226 Finally, other literature will be identified by searching Google.ca, with a focus on the first 100
24 227 search hits for each set of search terms.
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34 229 **Stage 3: Select studies**

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36 230 Retrieved articles will be transferred directly from a bibliographic database or Endnote (version
37 231 x7.8) reference management software to the Covidence software for screening,³⁰ and duplicates
38 232 of articles removed. The screening process will consist of two steps: (1) a title and
39 233 abstract/summary, and (2) full-text screening. For the first step, two researchers will
40 234 independently screen the titles and abstracts of each retrieved article for inclusion against a set of
41 235 minimum eligibility criteria using three rating options: no, yes, and maybe. The selection process
42 236 will be refined through periodic discussing between the researchers doing the screening. This is
43 237 to ensure the eligibility criteria are robust enough to capture the articles that may relate to the
44 238 evaluation of patient and family caregiver engagement in decision-making in healthcare systems.
45 239 Articles deemed relevant by either or both reviewers (i.e., combined yes or maybe ratings) will
46 240 be included in the full-text review. In the second step, the full-text of each article will be
47 241 independently reviewed by two researchers to determine whether it meets the eligibility criteria
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3 242 using two rating options: no and yes. Inter-rater agreement will be determined with the first 100
4 243 articles using simple agreement (the number of agreements divided by the number of
5 244 comparisons) for step two screening, and then Cohen's κ statistic calculated.^{31 32} Disagreement
6 245 about including any full-text article will be settled by reviewing the article again and reconciling
7 246 its eligibility through further discussions between the two researchers. When an agreement is not
8 247 reached, a third researcher will be involved to obtain consensus.
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15 16 249 **Eligibility criteria**

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18 250 An article will be included when it: (1) is available in the English Language, (2) describes patient
19 251 and family caregiver engagement within healthcare systems, and (3) provides useful information
20 252 on aspects of patient and family caregiver engagement in decision-making to evaluate. 'Useful
21 253 information' includes descriptions or definitions, information on relevance, and information on
22 254 relationships among aspects of patient and family caregiver engagement in decision-making.
23 255 There will be no restrictions on the type of study design for research articles. An article will be
24 256 excluded if the setting is (1) outside of the healthcare sector (e.g., urban planning, forestry,
25 257 transport), (2) specific to the research sector not directly related to health care, (3) specific to the
26 258 education sector not directly related to health care, and if (4) descriptions of engagement fall
27 259 below the level of consult on the IAP2 spectrum of public participation.³³ Engagement must be,
28 260 therefore, at the level of consult, involve, collaborate or empower to be considered authentic
29 261 engagement with patients and family caregivers.³³ The IAP2 spectrum is consistent with the
30 262 "ladder of citizen participation" in the seminal work by Sherry Arnstein.^{33 34} Arnstein's ladder
31 263 considers consultation and involvement to be tokenism because the citizen does not have power
32 264 in decision-making, while the IAP2 considers them active levels of engagement because the
33 265 public has influence but not power over decision-making.^{33 34} The eligibility criteria will undergo
34 266 iterative refinement throughout the study as is common for scoping review.²⁴
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50 268 **Stage 4: Data collection**

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52 269 Full-text of each selected article will be uploaded into NVivo qualitative data management and
53 270 analysis software (QSR International Pty Ltd, Burlington, MA). Two researchers will
54 271 independently collect and tabulate the characteristics of each article, including its publication
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3 272 year, authors, article type (e.g., original research, policy, and guidelines), country of origin,
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5 273 healthcare setting, and any other characteristics agreed on by the research team. Two researchers
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7 274 will use directed content analysis,³⁵ a qualitative data analysis technique, to independently
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9 275 extract relevant information from the articles by coding them within six major categories:
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11 276 “structure”, “process”, and “outcome” from the Donabedian framework,¹¹ and “individual (direct
12
13 277 care)”, “community/organization”, and “system” domains from the British Columbia Ministry of
14
15 278 Health’s engagement framework.⁸ Intercoder reliability between the two researchers for each of
16
17 279 these six codes will be calculated as simple agreement using a subset of the articles at the start of
18
19 280 the coding process.^{31 36} The minimum threshold for reliability will be 80%. When this threshold
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21 281 is not reached for a code, the researchers will discuss the discrepancies, make any necessary
22
23 282 refinements, and independently apply the code to a new subset of articles. Even when the 80%
24
25 283 agreement threshold is reached, negotiated agreement will be calculated where there are
26
27 284 inconsistencies of coding between researchers.³⁶ During negotiated agreement, the researchers
28
29 285 will discuss the discrepancies to achieve a common understanding of the definition and use of
30
31 286 each code.³⁶ Once all of the articles are coded and any differences between researchers
32
33 287 reconciled, these coded segments of each article will be open coded independently by the
34
35 288 researchers to identify relevant elements for defining the quality of patient and family
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37 289 engagement in healthcare systems. A critical appraisal of the articles is not applicable given the
38
39 290 nature of the data and aim of this study.
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292 **Stage 5: Data summary and synthesis of results**

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43 293 Using a single file with all the data, the researchers who coded the articles will discuss the codes
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45 294 by comparing them towards combining comparable themes/concepts and naming and defining
46
47 295 them as unique elements. These elements will be presented to, and discussed by, the research
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49 296 team to get a collective perspective on their names, definitions, appropriateness, and
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51 297 acceptability. The elements will be suitably arranged to create an emergent conceptual evaluation
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53 298 framework. The research team will review and refine the emergent conceptual evaluation
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55 299 framework, noting any gaps.
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301 **Stage 6: Stakeholder consultation**

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3 302 While stakeholder consultation is not mandatory in the Arksey and O'Malley's methodology, it
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5 303 will be conducted as recommended by Levac et al. to increase the robustness, applicability,
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7 304 feasibility, and acceptability of the conceptual framework.^{23 24} Adding credibility to the study,
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9 305 our team consists of the Patients as Partners Initiative lead, a program evaluation specialist, a
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11 306 patient partner, a family caregiver partner, and health services researchers. However, because
12
13 307 this is an emerging and evolving area of practice and research, we will consult other persons
14
15 308 from the key stakeholder groups (health system leaders and decisions makers, managers and
16
17 309 staff, health care providers, and health care users) in British Columbia for their insights to
18
19 310 supplement, confirm or refute, and extend the emergent conceptual evaluation framework. The
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21 311 stakeholder consultation will be valuable to refine, contextualize, and validate the framework for
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23 312 implementation in British Columbia. This study is embedded within the British Columbia
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25 313 Ministry of Health, and given its scope, time and fiscal constraints, we will not consult
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27 314 international stakeholders.
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316 **Patient and public involvement**

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31 317 A patient and a family caregiver have been members of our research team throughout the
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33 318 development of this scoping review protocol and will be actively involved in each stage of this
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35 319 study. The research team's process of working together is guided by the Patient Engagement In
36
37 320 Research (PEIRS) Framework, which outlines eight themes for ensuring meaningful patient
38
39 321 engaged research.³⁷ Starting at the initial conversation with the patient/family caregiver partners,
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41 322 the study lead (CBH) sought to gather information that addressed each of the eight themes. He
42
43 323 also worked with the patient/family caregiver partners to co-develop an understanding of the
44
45 324 proposed project, the expected roles, and time commitment. For example, discussions on the
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47 325 theme of "convenience" helped the research team to decide on the best team meeting times,
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49 326 given each member's other activities and personal situations.³⁷ The patient and family caregiver
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51 327 have contributed to shaping this protocol through team discussions. For example, they
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53 328 emphasized the unique role of family caregivers and that 'consult' can be authentic engagement
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55 329 for healthcare system decision-making. The specific contributions of the patient and family
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57 330 caregiver will be decided through team discussions as the study progresses through its stages.
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332 **Ethics and dissemination**

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3 333 A literature synthesis does not require research ethics board approval. Ethics approval will be
4 334 sought, however, for the stakeholder consultation stage of this study. We will wait for the
5 335 preliminary results from the literature synthesis before applying for research ethics board
6 336 approval. This study follows an integrated knowledge translation approach,³⁸ given the research
7 337 team is a partnership between leadership of the Patients as Partners Initiative and other
8 338 stakeholders. In addition to the patient perspectives to be captured from the literature and
9 339 through stakeholder consultation, our patient/family caregiver partners will contribute their
10 340 perspectives throughout the entire research process and help to share findings with appropriate
11 341 knowledge users. Furthermore, the family caregiver on our team represents a non-profit
12 342 organization dedicated to advancing the priorities of family caregivers in the healthcare system.
13 343 Each research team member will contribute to disseminating the results through conference
14 344 presentations, a scientific article, a research brief, and presentations at stakeholder meetings.

15 345 The conceptual evaluation framework on the quality of patient and family caregiver engagement
16 346 in decision-making in healthcare systems will be a key step in the evaluation of the Patients as
17 347 Partners Initiative. The results will inform evaluation of the Patients as Partners Initiative of the
18 348 British Columbia Ministry of Health for quality improvement. We hope the framework will be
19 349 applicable to other jurisdictions and provide guidance to determine the important domains and
20 350 indicators for patient and family caregiver engagement initiatives in healthcare systems to
21 351 advance person- and family-centred health care. A key reason the resulting framework could be
22 352 applicable to other jurisdictions is the systematic approach being taken to gather evidence from
23 353 the literature irrespective of jurisdictions. We plan to submit our findings for publication by
24 354 April 2020.

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474 **Contributions**

43 475 CBH obtained funding, conceptualised the research, and drafted this protocol. Each author
44 476 (CBH, MES, NC, SG, MD, ML, AK, JM, LCL) has made intellectual contribution to the
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47 479 team discussions and by email.
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14
15 488

16
17 489 **Competing interests:**

18
19 490 SG is the manager of the Patients as Partners Initiative within the British Columbia Ministry of
20
21 491 Health. JM is employee by Family Caregivers of British Columbia, a paid partner of the Patients
22
23 492 as Partners Initiative, which is a non-profit organization that provides support and advocates for
24
25 493 family caregivers within British Columbia, Canada.
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Appendix A - Electronic Database Search Strategy

MEDLINE (Ovid) and Cochrane Library (Ovid)

Block 1: patient and caregiver engagement

1. Community Integration.mp. or Community Integration/
2. Consumer participation/ or Patient participation/
3. (Consumer participation or patient participation or public participation or patient Engagement or “patient and public engagement” or “patient and public involvement”).kf.
4. ((caregiv* or coproducer or child or children or citizen or client or communit* or customer* or consumer* or family* or lay or layperson or marginalize* or patient* or parent* or public or senior* or stakeholder* or youth* or user*) adj3 (advoca* or activation or collaborat* or consult* or empower* or engage* or involve* or participat* or representat* or perspective* or activism or coproduc* or partner*)).tw,kf.
5. **1 or 2 or 3 or 4**

Block 2: decision making

6. (Decision Making or decision-making).mp. or Decision Making/
7. Organizational Decision Making.kf. or Decision Making, Organizational/
8. policy making/ or advisory committees/
9. (policy making or advisory committee* or governance or advisory board*).mp.
10. Patient Care Planning/
11. Governing Board/
12. **6 or 7 or 8 or 9 or 10 or 11**

Block 3: evaluation

13. Health Impact Assessment.mp. or Health Impact Assessment/
14. "quality of health care"/ or "outcome and process assessment (health care)"/ or program evaluation/ or quality assurance, health care/ or quality improvement/ or quality indicators, health care/
15. (quality adj2 (care or healthcare)).mp
16. (assess* or effective* or evaluat* or impact* or indicator* or meaningful* or measure* or metric* or outcome* or process* or structure* or quality or tool* or instrument*).tw.
17. **13 or 14 or 15 or 16**

Block 4: healthcare system

18. health policy/ or health care reform/
19. health polic*.mp.
20. "delivery of health care"/ or exp "delivery of health care, integrated"/ or exp health services accessibility/ or healthcare disparities/ or exp managed care programs/
21. delivery of health care.mp.
22. (Health system* or health care system* or healthcare system* or healthcare organization* or health care organization* healthcare organisation* or health care organisation*).mp.
23. Health priorit*.mp. or health priorities/
24. **18 or 19 or 20 or 21 or 22 or 23**
25. **Block 1, Block 2, Block 3, and Block 4 were combined using the ‘AND’ operator.**

EMBASE (Ovid)**Block 1: patient and caregiver engagement**

1. Community Integration.mp. or Community Integration/
2. *Patient participation/
3. ((caregiv* or coproducer or child or children or citizen or client or communit* or customer* or consumer* or family* or lay or layperson or marginalize* or patient* or parent* or public or senior* or stakeholder* or youth* or user*) adj3 (advoca* or activation or collaborat* or consult* or empower* or engage* or involve* or participat* or representat* or perspective* or activism or coproduc* or partner*).tw.
4. **1 or 2 or 3**

Block 2: decision making

5. (Decision Making or decision-making).mp. or Decision Making/
6. management/ or *advisory committee/
7. (policy making or advisory committee* or governance or advisory board*).mp.
8. *Patient Care Planning/
9. *board of trustees/
10. **5 or 6 or 7 or 8 or 9**

Block 3: evaluation

11. Health Impact Assessment.mp. or *Health Impact Assessment/
12. “*health care quality”/ or “outcome assessment”/ or *quality control/ or “*total quality management”/
13. (quality adj2 (care or healthcare)).mp.
14. (assess* or effective* or evaluat* or impact* or indicator* or meaningful* or measure* or metric* or outcome* or process* or structure* or quality or tool* or instrument*).tw.
15. **11 or 12 or 13 or 14**

Block 4: healthcare system

16. *health care policy/
17. health polic*.mp.
18. "delivery of health care"/ or “*integrated health care system”/ or health care disparities/
19. delivery of health care.mp.
20. (Health system* or health care system* or healthcare system* or healthcare organization* or health care organization* healthcare organisation* or health care organisation*).mp.
21. Health priorit*.mp.
22. *health care/
23. **16 or 17 or 18 or 19 or 20 or 21 or 22**

24. **Block 1, Block 2, Block 3, and Block 4 were combined using the ‘AND’ operator**

**Social Work Abstracts (EBSCO), PsycINFO (EBSCO), and CINAHL Complete (EBSCO),
Web of Science (ran with default setting - all fields searched)**

Block 1: patient and caregiver engagement

1. "Community integration"
2. "Patient participation"
3. "Patient engagement"
4. "Patient involvement"
5. "Public involvement"
6. "Patient and public engagement"
7. "Patient and public involvement"
8. "Citizen engagement" OR "marginalized engagement" OR "aboriginal engagement" OR "refugee engagement"
9. "Caregiver engagement"
10. "Family engagement"
11. "Youth engagement"
12. "Senior engagement"
13. "Aboriginal engagement"
14. **1-13 combined using OR**

Block 2: decision making

14. "Decision Making"
15. Decision-making
16. "Advisory committee"
17. "Advisory board"
18. Governance
19. **14-19 combined using OR**

Block 3: evaluation

20. "Health Impact Assessment"
21. "health care quality"
22. "outcome assessment"
23. "quality indicator*"
24. indicator*
25. assess*
26. evaluat*
27. effective*
28. impact*
29. meaningful*
30. measure*
31. metric*
32. outcome*
33. process*

34. structure*
35. quality
36. tool*
37. instrument*
38. **20-37 combined using OR**

Block 4: healthcare system

39. "health care polic*"
40. "Health polic*"
41. "delivery of health care"
42. "delivery of healthcare"
43. "integrated health care system"
44. "integrated healthcare system"
45. "quality improvement"
46. "health care disparities"
47. "Health system*"
48. "health care system*"
49. "healthcare system"
50. "healthcare organization*"
51. "health care organization*"
52. "healthcare organisation*"
53. "health care organisation*"
54. "Health priorit*"
55. "health care"
56. **29-55 combined using OR**

57. **Block 1, Block 2, Block 3, and Block 4 were combined using the 'AND' operator.**

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.	1
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.	2
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.	6
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.	6
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.	7
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.	9
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.	7-8
Search	8	Present the full electronic search strategy for at least 1 database, including any limits used, such that it could be repeated.	Appendix
Selection of sources of evidence†	9	State the process for selecting sources of evidence (i.e., screening and eligibility) included in the scoping review.	8-9
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.	9-10
Data items	11	List and define all variables for which data were sought and any assumptions and simplifications made.	4-5, 9-10
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).	N/A



SECTION	ITEM	PRISMA-ScR CHECKLIST ITEM	REPORTED ON PAGE #
Synthesis of results	13	Describe the methods of handling and summarizing the data that were charted.	10
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.	N/A, in progress
Characteristics of sources of evidence	15	For each source of evidence, present characteristics for which data were charted and provide the citations.	N/A, in progress
Critical appraisal within sources of evidence	16	If done, present data on critical appraisal of included sources of evidence (see item 12).	N/A
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.	N/A, in progress
Synthesis of results	18	Summarize and/or present the charting results as they relate to the review questions and objectives.	N/A, in progress
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.	N/A, in progress
Limitations	20	Discuss the limitations of the scoping review process.	3,11
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.	N/A, in progress
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.	16,17

JBI = Joanna Briggs Institute; PRISMA-ScR = Preferred Reporting Items for Systematic reviews and Meta-Analyses extension for Scoping Reviews.

* Where *sources of evidence* (see second footnote) are compiled from, such as bibliographic databases, social media platforms, and Web sites.

† A more inclusive/heterogeneous term used to account for the different types of evidence or data sources (e.g., quantitative and/or qualitative research, expert opinion, and policy documents) that may be eligible in a scoping review as opposed to only studies. This is not to be confused with *information sources* (see first footnote).

‡ The frameworks by Arksey and O'Malley (6) and Levac and colleagues (7) and the JBI guidance (4, 5) refer to the process of data extraction in a scoping review as data charting.

§ The process of systematically examining research evidence to assess its validity, results, and relevance before using it to inform a decision. This term is used for items 12 and 19 instead of "risk of bias" (which is more applicable to systematic reviews of interventions) to include and acknowledge the various sources of evidence that may be used in a scoping review (e.g., quantitative and/or qualitative research, expert opinion, and policy document).

From: Tricco AC, Lillie E, Zarin W, O'Brien KK, Colquhoun H, Levac D, et al. PRISMA Extension for Scoping Reviews (PRISMA-ScR): Checklist and Explanation. *Ann Intern Med.* ;169:467–473. doi: 10.7326/M18-0850

