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Strategies for Engaging Senior Citizens and Their Informal Caregivers in Health Policy Development: A Scoping Review Protocol

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Title: Strategies for Engaging Senior Citizens and their Informal Caregivers in Health Policy Development: A Scoping Review Protocol

Abstract

Introduction

Care for senior citizens is a global policy issue. There has been limited focus on senior citizen and informal caregiver engagement in policy development. Encouraging senior citizen participation through active engagement in the policy-making process enhances the provision of better services and the creation of responsive policies and is critical to better healthcare. Accordingly, this review aims to map the available evidence to provide an overview of strategies for engaging senior citizens and informal caregivers in health policy development.

Methods and Analysis

A scoping review will be conducted. This study will use the updated methodological guidance for conducting a scoping review developed by the Joanna Briggs Institute (JBI). This review aims to answer the question: “What is known in the literature about strategies for engaging senior citizens and informal caregivers in health policy development?” Titles and abstracts will be screened to determine eligibility for full-text review based on already established eligibility criteria. Data will be extracted from relevant articles. A summary of extracted data will be presented. The results will be interpreted within the Multidimensional Framework for Patient and Family Engagement in Health and Healthcare.

Ethics and Dissemination

Ethical review is not required as scoping reviews are a form of secondary data analysis that synthesizes data from publicly available sources. Findings from this proposed review will be disseminated in conferences and to the global scientific community through published academic papers in reputable health policy-related journals.

Keywords: senior citizens, informal caregivers, engagement, health policy development

Article Summary

Strengths and limitations of this study

- This is the first known review that seeks to address knowledge and evidence gaps on strategies for engaging senior citizens and informal caregivers in health policy development from existing literature.
- The review will build on the Multidimensional Framework for Patient and Family Engagement in Health and Healthcare, thus a theoretical contribution to the literature
- Publications will be searched from multiple electronic databases with peer-reviewed literature and a broad range of grey literature sources, using a comprehensive search strategy, thus an opportunity to retrieve all potentially relevant publications.
- All languages will be included, thereby reducing publication bias based on the language of publication.
- According to scoping review methods, the optional quality assessment of articles will not be performed

Data statement

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Introduction

Around 16 percent of the world's population is predicted to be 65 or older in 2050 (1). Care needs increase with age, and senior citizens have unmet care needs related to their physical and psychological health, social life, and the environment in which they live and interact (2). Senior citizens are extensive users of health and social care services and are greatly affected by health policy decisions across all care settings. Similarly, informal caregivers assume many different roles in providing care support for senior citizens, thus constituting a heavy burden on them (3). Their input or that of their informal caregivers in health policy development is under-represented (4). Little is known about strategies used to engage them in designing or implementing policies that matter to them (5). Yet senior citizens and their informal caregivers should have a voice in any decisions made since involving their perspectives in all stages of policy-making can improve the success and ownership of policies and sustainability of the outputs (6). As most previous research on engagement at the policy level focuses on the general population, this does not often reflect senior citizens' unique and complex social and healthcare needs.

Citizen engagement and deliberative methods can change knowledge and attitudes (7), promote active citizenship, and improve relationships between the government and citizens (8, 9). Effective citizen engagement and public deliberation can also lead to improved outcomes for citizens, policymakers, and policymaking. When citizens are engaged, policy makers are better aware of what outcomes need to be addressed. Citizen engagement can improve multiple types of outcomes such as instrumental, developmental, and democratic outcomes. *Instrumental outcomes* mean generating awareness of lived experience and improving the quality of policymaking by ensuring that policies, programs, and services align with the values and needs of citizens, provision of better services, healthcare and improved quality of care (10, 11), and the creation of responsive policies (12-14). *Developmental outcomes* mean providing education and raising awareness about pressing health issues and developing citizens' capacity to take part in public policy matters (15), and *democratic outcomes* mean supporting transparency, accountability, trust, and empowerment (9, 16-18). Citizen engagement benefits individuals, organizations, and society by increasing knowledge, power, and problem-solving ability (19). Finally, involving citizens in policy decisions can increase the legitimacy and transparency of decision-making processes and help inform health policy decisions (20). Senior citizen and informal caregiver engagement in policy is pivotal as health policy decisions are not only relevant to them but also impact the healthcare system.

Previous research has tried to understand mechanisms needed to engage senior citizens in healthcare decision-making, research, and planning (21, 22). However, there is limited published literature specifically focused on senior citizen and informal caregiver engagement in health policy development. Most existing research focuses on *all* citizens' engagement in research and at point

of care. Similarly, there is a dearth of literature on caregiver engagement in health policy development. Few examples for caregiver engagement in health policy development exists. For example, Keogh et al. (23), described the use of an innovative approach, being Carers assembly to increase the involvement of caregivers of people with dementia in the policymaking process in Ireland.

Thus, this current scoping review aims to provide an overview of available research evidence on strategies for senior citizens’ and informal caregivers’ engagement in health policy decision-making. This research synthesis aims to map the literature on strategies for senior citizens and informal caregiver engagement in health policy and to provide an opportunity to understand key concepts and identify knowledge gaps on engagement strategies. The review will provide an evidence-based foundation to guide senior citizen engagement in health policy development and demonstrate how engagement strategies have been used in health policy development in different contexts.

This scoping review will be the first to synthesize the existing evidence on strategies for senior citizen and informal caregiver engagement in health policy development as described in peer-reviewed and grey literature. It is thus a novel scoping review to identify and describe engagement strategies for senior citizens and informal caregivers as used in different contexts.

Methods:

Scoping review design

This scoping review will follow the approach recommended by the Joanna Briggs Institute (24). The scoping review methodology was chosen for its suitability for addressing our proposed topic as it will provide opportunity to assess the extent of the available evidence on engagement strategies for senior citizens and informal caregivers in health policy development, as well as identify and analyze knowledge gaps.

Senior citizens will refer to persons aged 65 and above for this review. The term *citizen* will be used more comprehensively without discrimination to refer to every person in a society or country (25). *Informal caregiver* is an unpaid individual (for example, a spouse, partner, family member, friend, or neighbor) involved in assisting others with activities of daily living and medical tasks (26). *Citizen engagement* is defined as the meaningful involvement of individual citizens in policy or program development, from agenda-setting and planning to decision-making, implementation, and review(27).

Conceptual model

This scoping review will use the Multidimensional Framework for Patient and Family Engagement in Health and Healthcare proposed by Carman et al. (28) (Figure 1), which was influenced by Arnstein’s ladder of participation (29). This framework presents engagement in three elements: continuum, levels, and factors influencing engagement. These three elements will guide in mapping evidence from the literature. It outlines a continuum of engagement activities (consultation, partnership, and shared decision-making) across three levels of the healthcare system (individual care, organizational governance, and government policy) and describes factors influencing engagement. The framework presents engagement at the personal level of care as

considering patients' preferences and values in treatment decisions. At the organizational care and governance level, patients' and families' perspectives are considered in the design and governance of healthcare organizations and projects. Engagement at the policy-making level is centered on developing, implementing, and evaluating health care programs and policies through collaborations between citizens and policymakers (28). Engagement occurs at the lower end of the continuum but with a limited effect on decision-making. In contrast, there is active partnership, signified by a bi-directional flow of information at the higher end, and shared decision-making responsibility. Furthermore, this study will expand on the Multidimensional Framework for Patient and Family Engagement in Health and Healthcare (28) by including components in the extraction table specific to senior citizen and informal caregiver engagement in health policy development. The scoping review will identify and describe different strategies/methods for senior citizen and informal caregiver engagement in health policymaking. More specifically, this review will extract and synthesize data on items relevant to the framework: continuum of engagement, phase of policy development in which engagement occurs, factors influencing engagement, and engagement outcomes. Additionally, outcomes of engagement, comparisons of engagement strategies, and efforts to involve minority groups will also be extracted and synthesized.

Search strategy

In line with the Joanna Briggs Institute (JBI) recommendations (24), a three-step search strategy will be utilized. An initial limited search of two online databases (MEDLINE (through PubMed) and Embase) will be conducted. This search will use the search strategy in Table 1. This will be followed by an analysis of the keywords in the title and abstract of retrieved papers and the index terms used to describe the articles. A second search will use all identified keywords and index terms across other databases: Health Systems Evidence, Health Evidence, and CINAHL. Thirdly, the reference lists of identified reports and articles will be searched for additional sources. We will work with a librarian for the refinement of the search strategy and conducting the search on all relevant databases. Authors of primary sources or reviews will also be contacted when necessary for further information. With consultation from stakeholder groups and major international organizations, sources that would hold grey literature on practices for engaging senior citizens and their informal caregivers in health policy development will be identified. A search will be conducted, and all available information will be retrieved.

Search results will be imported into Endnote 20 where duplicates will be removed, then into an online systematic review software, Covidence (www.covidence.org). Titles and abstracts will be screened to determine eligibility for full-text review based on the eligibility criteria described in the following section. All research team members will first screen a sample together using the eligibility criteria, then two researchers will independently screen all titles and abstracts. Disagreements will be discussed and resolved through discussion or involving a third team member, and consensus will be reached. A PRISMA flow diagram of the literature search and selection process will be presented.

Table 1: Search strategy

DATABASE	CONCEPT	SEARCH TERMS
PUBMED	SENIOR CITIZEN	("Aged"[Mesh] OR "aged patient"[tiab] OR "aged people"[tiab] OR "aged person"[tiab] OR "aged adult"[tiab] OR "aged citizen"[tiab] OR elder*[tiab] OR "oldest old"[tiab] OR "older adult"[tiab] OR "older patient"[tiab] OR "older subject"[tiab] OR "older citizen"[tiab] OR "older person"[tiab] OR "older people"[tiab] OR senior*[tiab] OR "old age"[tiab] OR "advanced age"[tiab] OR aging[tiab] OR ageing[tiab] OR "Geriatrics"[Mesh] OR geriatr*[tiab] OR gerontolog*[tiab] OR Centenarian*[tiab] OR Nonagenarian*[tiab] OR Octogenarian*[tiab] OR septuagenarian*[tiab])
	ENGAGEMENT	"Patient Participation"[Mesh] OR participat*[tiab] OR Empower*[tiab] OR Activat*[tiab] OR Deliberat*[tiab] OR engag*[tiab] OR involv*[tiab] OR "Stakeholder Participation"[Mesh] OR "stakeholder role"[tiab]
	HEALTH POLICY DEVELOPMENT	"Health Policy"[Mesh] OR "health polic"[tiab] OR "healthcare polic"[tiab] OR "health care polic"[tiab] OR "Policy Making"[Mesh] OR "policy making"[tiab] OR "policymaking"[tiab] OR "policy development"[tiab] OR "policy analys"[tiab] OR "advisory committ"[tiab] OR "task force"[tiab] OR "review commit"[tiab] OR "policy formulation"[tiab] OR "policy evaluation"[tiab] OR "health care reform"[tiab] OR "healthcare reform"[tiab]
EMBASE	SENIOR CITIZEN	'aged'/exp OR 'the aged':ti,ab,kw OR 'aged patient':ti,ab,kw OR 'aged people':ti,ab,kw OR 'aged person':ti,ab,kw OR 'aged adult':ti,ab,kw OR 'aged citizen':ti,ab,kw OR 'elder':ti,ab,kw OR 'oldest old':ti,ab,kw OR 'older adult':ti,ab,kw OR 'older patient':ti,ab,kw OR 'older subject':ti,ab,kw OR 'older citizen':ti,ab,kw OR 'older person':ti,ab,kw OR 'older people':ti,ab,kw OR 'senior':ti,ab,kw OR 'old age':ti,ab,kw OR 'advanced age':ti,ab,kw OR 'aging':ti,ab,kw OR 'ageing':ti,ab,kw OR 'geriatrics'/exp OR 'geriatr':ti,ab,kw OR 'gerontology'/exp OR 'gerontolog':ti,ab,kw OR 'Centenarian':ti,ab,kw OR 'Nonagenarian':ti,ab,kw OR 'Octogenarian':ti,ab,kw OR 'septuagenarian':ti,ab,kw
	ENGAGEMENT	'patient participation'/exp OR 'patient engagement'/exp OR 'patient empowerment'/exp OR 'stakeholder engagement'/exp OR 'patient activation'/exp OR 'participat':ti,ab,kw OR 'Empower':ti,ab,kw OR 'Activat':ti,ab,kw OR 'engag':ti,ab,kw OR 'involv':ti,ab,kw OR 'deliberation'/exp OR 'deliberat':ti,ab,kw OR 'stakeholder role':ti,ab,kw
	HEALTH POLICY DEVELOPMENT	'health care policy'/exp OR 'health care polic':ti,ab,kw OR 'health polic':ti,ab,kw OR 'healthcare polic':ti,ab,kw OR 'policy making':ti,ab,kw OR 'policymaking':ti,ab,kw OR 'policy development'/exp OR 'policy development':ti,ab,kw OR 'policy analys':ti,ab,kw OR 'advisory committ':ti,ab,kw OR 'task force':ti,ab,kw OR 'development of polic':ti,ab,kw OR 'review commit':ti,ab,kw OR 'policy formulation':ti,ab,kw OR 'policy evaluation':ti,ab,kw OR 'health care reform':ti,ab,kw OR 'healthcare reform':ti,ab,kw
CINAHL	SENIOR CITIZEN	(MH "Aged") OR (MH "Geriatrics") OR (MH "Caregivers") OR TI (Elderl* OR "Older Persons" OR the aged OR "aged patient" OR "aged people" OR "aged person" OR "aged adult" OR "aged citizen" OR "oldest old" OR "older adult" OR "older patient" OR "older subject" OR "older citizen" OR "older person" OR "older people" OR "senior" OR "old age" OR "advanced age" OR aging OR ageing OR geriatr* OR

		gerontolog* OR Centenarian* OR Nonagenarian* OR Octogenarian* OR septuagenarian*) OR AB (Elderl* OR "Older Persons" OR "the aged" OR "aged patient*" OR "aged people" OR "aged person*" OR "aged adult*" OR "aged citizen*" OR "oldest old" OR "older adult" OR "older patient*" OR "older subject*" OR "older citizen*" OR "older person*" OR older people" OR senior* OR "old age" OR "advanced age" OR aging OR ageing OR geriatr* OR gerontology OR Centenarian* OR Nonagenarian* OR Octogenarian* OR septuagenarian*)
	ENGAGEMENT	(MH "Consumer Participation") OR (MH "Political Participation") OR (MH "Stakeholder participation") OR TI (participat* OR Empower* OR Activat* OR Deliberat* OR Engag* OR involv* OR "stakeholder role") OR AB (participat* OR Empower* OR Activat* OR Deliberat* OR Engag* OR involv* OR "stakeholder role")
	HEALTH POLICY DEVELOPMENT	(MH "Policy Making") OR (MH "Health Policy+") OR TI ("Health polic*" OR "healthcare polic*" OR "health care polic*" OR policymaking OR "policy making" OR "policy development*" OR "policy analys*" OR "advisory committ*" OR "task force*" OR "development of polic*" OR "review commit*" OR "policy formulation*" OR "policy evaluation*" OR health care reform* OR healthcare reform*) OR AB ("Health polic*" OR "healthcare polic*" OR "health care polic*" OR policymaking OR policy making" OR "policy development*" OR "policy analys*" OR "advisory committ*" OR "task force*" OR "development of polic*" OR "review commit*" OR "policy formulation*" OR "policy evaluation*" OR health care reform* OR healthcare reform*)
HEALTH SYSTEMS EVIDENCE		Older adult* OR caregiver* AND participat* OR Empower* OR Activat* OR Deliberat* OR engag* OR involv* AND "Health Policy" OR "health polic*" OR "healthcare polic*" OR "health care polic*" OR "Policy Making" OR "policy making" OR "policymaking" OR "policy development*" OR "policy analys*" OR "advisory committ*" OR "task force*" OR "development of polic*" OR "review commit*" OR "policy formulation*" OR "policy evaluation*" OR health care reform* OR healthcare reform*
HEALTH EVIDENCE	SENIOR CITIZEN	("Aged" OR "the aged" OR "aged patient*" OR "aged people" OR "aged person*" OR "aged adult*" OR "aged citizen*" OR elder* OR "oldest old" OR "older adult*" OR "older patient*" OR "older subject*" OR "older citizen*" OR "older person*" OR "older people" OR senior* OR "old age" OR "advanced age" OR aging OR ageing OR "Geriatrics" OR geriatr* OR gerontolog* OR Centenarian* OR Nonagenarian* OR Octogenarian* OR septuagenarian*) AND ("Patient Participation" OR participat* OR Empower* OR Activat* OR Deliberat* OR engag* OR involv* OR "stakeholder role") AND ("Health Policy" OR "health polic*" OR "healthcare polic*" OR "health care polic*" OR "Policy Making" OR "policy making" OR "policymaking" OR "policy development*" OR "policy analys*" OR "advisory committ*" OR "task force*" OR "development of polic*" OR "review commit*" OR "policy formulation*" OR "policy evaluation*" OR health care reform* OR healthcare reform*)

Inclusion/exclusion criteria

Empirical studies, e.g., qualitative, quantitative, and mixed methods research, systematic and scoping reviews, and grey literature reports will be included if they report on policy development in the areas of health and well-being, address the use or evaluation of a method/practice for engaging senior citizens and informal caregivers in health policy development, focus on senior citizens defined as persons with a minimum age of 65 (or a majority of participants are aged 65 and above), and/or their informal caregivers or addressed with proxy words such as chronically ill, dementia, and frail elderly, and address policy development at regional, national, or international level.

Due to a dearth of literature on senior citizen engagement in health policy development, there will be no limit to publication year. There will also be no exclusion of studies based on language, meaning all studies reported in all languages will be included. Abstracts of studies in languages other than English will first be translated using the help of a colleague who is proficient in the language. If considered relevant, the full texts will then be translated using the help of a translation firm. Studies discussing senior citizen and informal caregiver engagement in research or at the point of care will be excluded. Studies addressing *all* citizen engagement with no particular attention to senior citizens will be excluded.

Data charting, summarizing, and reporting the results

A preliminary data charting table (see Table 2) has been developed and will be piloted to familiarize with results, based on the elements presented in the engagement framework by Carman et al (28). This Multidimensional Framework for Patient and Family Engagement in Health and Healthcare will be used to guide analysis and data will be categorize based on the elements. We will first capture information on engagement approaches used in the included relevant articles, their characteristics and how they were used to engage senior citizens and/or informal caregivers in health policy development. Then, we will interpret these findings based on the elements in the framework. We will extract data on continuum of engagement, phase of policy development, factors influencing policy makers to create opportunities for engagement, outcomes of engagement, comparisons of engagement strategies, efforts/initiatives to ensure engagement of senior citizens of minority groups, if stated Two researchers will pilot the data extraction table. The table will be further refined and updated as required in accordance with the review’s objectives. A descriptive summary of the findings will be presented. Data on authors, sources of evidence, year of publication, country/origin/setting of study, engagement frameworks will be extracted and presented.

Patient and public involvement

There was no patient nor public involvement.

Table 2: Data charting table

Scoping Review Details	
Article title	
Review objectives	
Review questions	
Study type (case, empirical, review)	
Study design (quantitative, qualitative)	
Evidence source details and characteristics	
Citation details	
Country/geographical setting	
Context	
Participants/population studied (age, sex, number)	
Inclusion/Exclusion Criteria	
Population	
Includes senior citizens aged 65 and above and/or their caregivers	
Concept	
Describes strategies for senior citizen and informal caregiver engagement	
Context	
Describes strategies for senior citizen and informal caregiver engagement in policies around health and well-being	
Details/results extracted from publications	
Name of engagement strategies discussed	
Description of strategy	
Stated continuum of engagement (consultation, involvement, partnership, and shared leadership)	
Stated phase of policy development (e.g. policy formulation, implementation, or evaluation)	
Stated factors influencing policy makers to create opportunities for engagement in health policy development	
Stated outcome(s) of engagement strategies	
Change in knowledge and attitude of engaged senior citizens and informal caregivers	

Promotion of active citizenship (e.g., do senior citizens and informal caregivers feel a sense of citizenship and participation in decision making)	
Impact on relationship between the government and the citizens	
Senior citizens' and informal caregivers' awareness of one-another's lived experiences	
Increased knowledge about care transitions and engagement	
Developed capacity to take part in public policy matter	
Any other reported outcomes	
Data on comparisons of different engagement approaches	
Data on efforts/initiatives to ensure engagement of senior citizens of minority groups, if stated	
How strategy was used for engagement in health policy development	
Topics discussed using engagement approaches	
Stated engagement frameworks discussed	

Ethics and dissemination: This study does not require ethical approval as it will use publicly available data and does not involve human subjects' research. This study will constitute the first step in a research plan aimed at identifying engagement strategies and comparing them for variation, content, and breadth and depth of insights. The findings of this review will guide researchers, stakeholders, government, and non-governmental organization as well as policy makers in conversations around engagement in this context.

Author Contributions

ORK drafted the scoping review protocol. JPD, TvA, and ME revised and reviewed the protocol.

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Competing statement

The authors have no conflict of interest to report.

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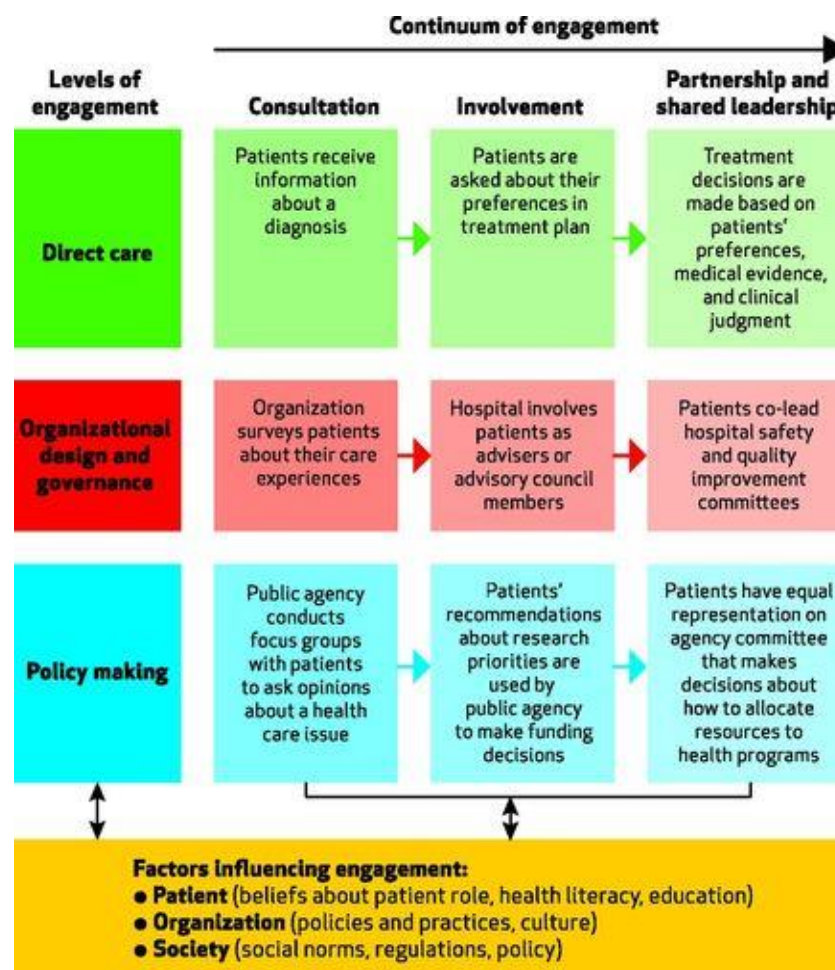
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Figure 1: A multidimensional framework for patient and family engagement in health and healthcare by Carman et al (28)



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Title: Strategies for Engaging Senior Citizens and their Informal Caregivers in Health Policy Development: A Scoping Review Protocol

Abstract

Introduction

Care for senior citizens is a global policy issue. There has been limited focus on senior citizen and informal caregiver engagement in policy development. Encouraging senior citizen participation through active engagement in the policy-making process enhances the provision of better services and the creation of responsive policies and is critical to better healthcare. Accordingly, this review aims to map the available evidence to provide an overview of strategies for engaging senior citizens and informal caregivers in health policy development.

Methods and Analysis

A scoping review will be conducted. This study will use the updated methodological guidance for conducting a scoping review developed by the Joanna Briggs Institute (JBI). This review aims to answer the question: “What is known in the literature about strategies for engaging senior citizens and informal caregivers in health policy development?” Titles and abstracts will be screened to determine eligibility for full-text review based on already established eligibility criteria. Data will be extracted from relevant articles. A summary of extracted data will be presented. The results will be interpreted within the Multidimensional Framework for Patient and Family Engagement in Health and Healthcare.

Ethics and Dissemination

Ethical review is not required as scoping reviews are a form of secondary data analysis that synthesizes data from publicly available sources. Findings from this proposed review will be disseminated in conferences and to the global scientific community through published academic papers in reputable health policy-related journals.

Keywords: senior citizens, informal caregivers, engagement, health policy development

Article Summary

Strengths and limitations of this study

- This is the first known review that seeks to address knowledge and evidence gaps on strategies for engaging senior citizens and informal caregivers in health policy development from existing literature.
- The review will build on the Multidimensional Framework for Patient and Family Engagement in Health and Healthcare, thus a theoretical contribution to the literature
- Publications will be searched from multiple electronic databases with peer-reviewed literature and a broad range of grey literature sources, using a comprehensive search strategy, thus an opportunity to retrieve all potentially relevant publications.
- All languages will be included, thereby reducing publication bias based on the language of publication.
- According to scoping review methods, the optional quality assessment of articles will not be performed

Data statement

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Introduction

Around 16 percent of the world's population is predicted to be 65 or older in 2050 (1). Care needs increase with age, and senior citizens have unmet care needs related to their physical and psychological health, social life, and the environment in which they live and interact (2). Senior citizens are extensive users of health and social care services and are greatly affected by health policy decisions across all care settings. Similarly, informal caregivers assume many different roles in providing care support for senior citizens, thus constituting a heavy burden on them (3). Their input or that of their informal caregivers in health policy development is under-represented (4). Little is known about strategies used to engage them in designing or implementing policies that matter to them (5). Yet senior citizens and their informal caregivers should have a voice in any decisions made since involving their perspectives in all stages of policy-making can improve the success and ownership of policies and sustainability of the outputs (6). As most previous research on engagement at the policy level focuses on the general population, this does not often reflect senior citizens' unique and complex social and healthcare needs.

Citizen engagement and deliberative methods can change knowledge and attitudes (7), promote active citizenship, and improve relationships between the government and citizens (8, 9). Effective citizen engagement and public deliberation can also lead to improved outcomes for citizens, policymakers, and policymaking. When citizens are engaged, policy makers are better aware of what outcomes need to be addressed. Citizen engagement can improve multiple types of outcomes such as instrumental, developmental, and democratic outcomes. *Instrumental outcomes* mean generating awareness of lived experience and improving the quality of policymaking by ensuring that policies, programs, and services align with the values and needs of citizens, provision of better services, healthcare and improved quality of care (10, 11), and the creation of responsive policies (12-14). *Developmental outcomes* mean providing education and raising awareness about pressing health issues and developing citizens' capacity to take part in public policy matters (15), and *democratic outcomes* mean supporting transparency, accountability, trust, and empowerment (9, 16-18). Citizen engagement benefits individuals, organizations, and society by increasing knowledge, power, and problem-solving ability (19). Finally, involving citizens in policy decisions can increase the legitimacy and transparency of decision-making processes and help inform health policy decisions (20). Senior citizen and informal caregiver engagement in policy is pivotal as health policy decisions are not only relevant to them but also impact the healthcare system.

Previous research has tried to understand mechanisms needed to engage senior citizens in healthcare decision-making, research, and planning (21, 22). However, there is limited published literature specifically focused on senior citizen and informal caregiver engagement in health policy development. Most existing research focuses on *all* citizens' engagement in research and at point

of care. Similarly, there is a dearth of literature on caregiver engagement in health policy development. Few examples for caregiver engagement in health policy development exists. For example, Keogh et al. (23), described the use of an innovative approach, being Carers assembly to increase the involvement of caregivers of people with dementia in the policymaking process in Ireland.

Thus, this current scoping review aims to provide an overview of available research evidence on strategies for senior citizens’ and informal caregivers’ engagement in health policy decision-making. This research synthesis aims to map the literature on strategies for senior citizens and informal caregiver engagement in health policy and to provide an opportunity to understand key concepts and identify knowledge gaps on engagement strategies. The review will provide an evidence-based foundation to guide senior citizen engagement in health policy development and demonstrate how engagement strategies have been used in health policy development in different contexts.

This scoping review will be the first to synthesize the existing evidence on strategies for senior citizen and informal caregiver engagement in health policy development as described in peer-reviewed and grey literature. It is thus a novel scoping review to identify and describe engagement strategies for senior citizens and informal caregivers as used in different contexts.

Methods:

Scoping review design

This scoping review will follow the approach recommended by the Joanna Briggs Institute (24). The scoping review methodology was chosen for its suitability for addressing our proposed topic as it will provide opportunity to assess the extent of the available evidence on engagement strategies for senior citizens and informal caregivers in health policy development, as well as identify and analyze knowledge gaps.

Senior citizens will refer to persons aged 65 and above for this review. The term *citizen* will be used more comprehensively without discrimination to refer to every person in a society or country (25). *Informal caregiver* is an unpaid individual (for example, a spouse, partner, family member, friend, or neighbor) involved in assisting others with activities of daily living and medical tasks (26). *Citizen engagement* is defined as the meaningful involvement of individual citizens in policy or program development, from agenda-setting and planning to decision-making, implementation, and review(27).

Conceptual model

This scoping review will use the Multidimensional Framework for Patient and Family Engagement in Health and Healthcare proposed by Carman et al. (28) (Figure 1), which was influenced by Arnstein’s ladder of participation (29). This framework presents engagement in three elements: continuum, levels, and factors influencing engagement. These three elements will guide in mapping evidence from the literature. It outlines a continuum of engagement activities (consultation, partnership, and shared decision-making) across three levels of the healthcare system (individual care, organizational governance, and government policy) and describes factors influencing engagement. The framework presents engagement at the personal level of care as

considering patients' preferences and values in treatment decisions. At the organizational care and governance level, patients' and families' perspectives are considered in the design and governance of healthcare organizations and projects. Engagement at the policy-making level is centered on developing, implementing, and evaluating health care programs and policies through collaborations between citizens and policymakers (28). Engagement occurs at the lower end of the continuum but with a limited effect on decision-making. In contrast, there is active partnership, signified by a bi-directional flow of information at the higher end, and shared decision-making responsibility. Furthermore, this study will expand on the Multidimensional Framework for Patient and Family Engagement in Health and Healthcare (28) by including components in the extraction table specific to senior citizen and informal caregiver engagement in health policy development. The scoping review will identify and describe different strategies/methods for senior citizen and informal caregiver engagement in health policymaking. More specifically, this review will extract and synthesize data on items relevant to the framework: continuum of engagement, phase of policy development in which engagement occurs, factors influencing engagement, and engagement outcomes. Additionally, outcomes of engagement, comparisons of engagement strategies, and efforts to involve minority groups will also be extracted and synthesized.

Search strategy

In line with the Joanna Briggs Institute (JBI) recommendations (24), a three-step search strategy will be utilized. An initial limited search of two online databases (MEDLINE (through PubMed) and Embase) will be conducted. This search will use the search strategy in Table 1. This will be followed by an analysis of the keywords in the title and abstract of retrieved papers and the index terms used to describe the articles. A second search will use all identified keywords and index terms across other databases: Health Systems Evidence, Health Evidence, and CINAHL. Thirdly, the reference lists of identified reports and articles will be searched for additional sources. We will work with a librarian for the refinement of the search strategy and conducting the search on all relevant databases. Authors of primary sources or reviews will also be contacted when necessary for further information. With consultation from stakeholder groups and major international organizations, sources that would hold grey literature on practices for engaging senior citizens and their informal caregivers in health policy development will be identified. A search will be conducted, and all available information will be retrieved.

Search results will be imported into Endnote 20 where duplicates will be removed, then into an online systematic review software, Covidence (www.covidence.org). Titles and abstracts will be screened to determine eligibility for full-text review based on the eligibility criteria described in the following section. All research team members will first screen a sample together using the eligibility criteria, then two researchers will independently screen all titles and abstracts. Disagreements will be discussed and resolved through discussion or involving a third team member, and consensus will be reached. A PRISMA flow diagram of the literature search and selection process will be presented. The study is being conducted between April and November 2022.

Table 1: Search strategy

DATABASE	CONCEPT	SEARCH TERMS
PUBMED	SENIOR CITIZEN	("Aged"[Mesh] OR "aged patient"[tiab] OR "aged people"[tiab] OR "aged person"[tiab] OR "aged adult"[tiab] OR "aged citizen"[tiab] OR elder*[tiab] OR "oldest old"[tiab] OR "older adult"[tiab] OR "older patient"[tiab] OR "older subject"[tiab] OR "older citizen"[tiab] OR "older person"[tiab] OR "older people"[tiab] OR senior*[tiab] OR "old age"[tiab] OR "advanced age"[tiab] OR aging[tiab] OR ageing[tiab] OR "Geriatrics"[Mesh] OR geriatr*[tiab] OR gerontolog*[tiab] OR Centenarian*[tiab] OR Nonagenarian*[tiab] OR Octogenarian*[tiab] OR septuagenarian*[tiab])
	ENGAGEMENT	"Patient Participation"[Mesh] OR participat*[tiab] OR Empower*[tiab] OR Activat*[tiab] OR Deliberat*[tiab] OR engag*[tiab] OR involv*[tiab] OR "Stakeholder Participation"[Mesh] OR "stakeholder role"[tiab]
	HEALTH POLICY DEVELOPMENT	"Health Policy"[Mesh] OR "health polic"[tiab] OR "healthcare polic"[tiab] OR "health care polic"[tiab] OR "Policy Making"[Mesh] OR "policy making"[tiab] OR "policymaking"[tiab] OR "policy development"[tiab] OR "policy analys"[tiab] OR "advisory committ"[tiab] OR "task force"[tiab] OR "review commit"[tiab] OR "policy formulation"[tiab] OR "policy evaluation"[tiab] OR "health care reform"[tiab] OR "healthcare reform"[tiab]
EMBASE	SENIOR CITIZEN	'aged'/exp OR 'the aged':ti,ab,kw OR 'aged patient':ti,ab,kw OR 'aged people':ti,ab,kw OR 'aged person':ti,ab,kw OR 'aged adult':ti,ab,kw OR 'aged citizen':ti,ab,kw OR 'elder':ti,ab,kw OR 'oldest old':ti,ab,kw OR 'older adult':ti,ab,kw OR 'older patient':ti,ab,kw OR 'older subject':ti,ab,kw OR 'older citizen':ti,ab,kw OR 'older person':ti,ab,kw OR 'older people':ti,ab,kw OR 'senior':ti,ab,kw OR 'old age':ti,ab,kw OR 'advanced age':ti,ab,kw OR 'aging':ti,ab,kw OR 'ageing':ti,ab,kw OR 'geriatrics'/exp OR 'geriatr':ti,ab,kw OR 'gerontology'/exp OR 'gerontolog':ti,ab,kw OR 'Centenarian':ti,ab,kw OR 'Nonagenarian':ti,ab,kw OR 'Octogenarian':ti,ab,kw OR 'septuagenarian':ti,ab,kw
	ENGAGEMENT	'patient participation'/exp OR 'patient engagement'/exp OR 'patient empowerment'/exp OR 'stakeholder engagement'/exp OR 'patient activation'/exp OR 'participat':ti,ab,kw OR 'Empower':ti,ab,kw OR 'Activat':ti,ab,kw OR 'engag':ti,ab,kw OR 'involv':ti,ab,kw OR 'deliberation'/exp OR 'deliberat':ti,ab,kw OR 'stakeholder role':ti,ab,kw
	HEALTH POLICY DEVELOPMENT	'health care policy'/exp OR 'health care polic':ti,ab,kw OR 'healthcare polic':ti,ab,kw OR 'healthcare polic':ti,ab,kw OR 'policy making':ti,ab,kw OR 'policymaking':ti,ab,kw OR 'policy development'/exp OR 'policy development':ti,ab,kw OR 'policy analys':ti,ab,kw OR 'advisory committ':ti,ab,kw OR 'task force':ti,ab,kw OR 'development of polic':ti,ab,kw OR 'review commit':ti,ab,kw OR 'policy formulation':ti,ab,kw OR 'policy evaluation':ti,ab,kw OR 'health care reform':ti,ab,kw OR 'healthcare reform':ti,ab,kw
CINAHL	SENIOR CITIZEN	(MH "Aged") OR (MH "Geriatrics") OR (MH "Caregivers") OR TI (Elder! OR "Older Persons" OR the aged OR "aged patient" OR "aged people" OR "aged person" OR "aged adult" OR "aged citizen" OR "oldest old" OR "older adult" OR "older patient" OR "older subject" OR "older citizen" OR "older person" OR "older people" OR "senior" OR "old age" OR "advanced age" OR aging OR ageing OR geriatr* OR

		gerontolog* OR Centenarian* OR Nonagenarian* OR Octogenarian* OR septuagenarian*) OR AB (Elderl* OR "Older Persons" OR "the aged" OR "aged patient*" OR "aged people" OR "aged person*" OR "aged adult*" OR "aged citizen*" OR "oldest old" OR "older adult" OR "older patient*" OR "older subject*" OR "older citizen*" OR "older person*" OR older people" OR senior* OR "old age" OR "advanced age" OR aging OR ageing OR geriatr* OR gerontology OR Centenarian* OR Nonagenarian* OR Octogenarian* OR septuagenarian*)
	ENGAGEMENT	(MH "Consumer Participation") OR (MH "Political Participation") OR (MH "Stakeholder participation") OR TI (participat* OR Empower* OR Activat* OR Deliberat* OR Engag* OR involv* OR "stakeholder role") OR AB (participat* OR Empower* OR Activat* OR Deliberat* OR Engag* OR involv* OR "stakeholder role")
	HEALTH POLICY DEVELOPMENT	(MH "Policy Making") OR (MH "Health Policy+") OR TI ("Health polic*" OR "healthcare polic*" OR "health care polic*" OR policymaking OR "policy making" OR "policy development*" OR "policy analys*" OR "advisory committ*" OR "task force*" OR "development of polic*" OR "review commit*" OR "policy formulation*" OR "policy evaluation*" OR health care reform* OR healthcare reform*) OR AB ("Health polic*" OR "healthcare polic*" OR "health care polic*" OR policymaking OR policy making" OR "policy development*" OR "policy analys*" OR "advisory committ*" OR "task force*" OR "development of polic*" OR "review commit*" OR "policy formulation*" OR "policy evaluation*" OR health care reform* OR healthcare reform*)
HEALTH SYSTEMS EVIDENCE		Older adult* OR caregiver* AND participat* OR Empower* OR Activat* OR Deliberat* OR engag* OR involv* AND "Health Policy" OR "health polic*" OR "healthcare polic*" OR "health care polic*" OR "Policy Making" OR "policy making" OR "policymaking" OR "policy development*" OR "policy analys*" OR "advisory committ*" OR "task force*" OR "development of polic*" OR "review commit*" OR "policy formulation*" OR "policy evaluation*" OR health care reform* OR healthcare reform*
HEALTH EVIDENCE	SENIOR CITIZEN	("Aged" OR "the aged" OR "aged patient*" OR "aged people" OR "aged person*" OR "aged adult*" OR "aged citizen*" OR elder* OR "oldest old" OR "older adult*" OR "older patient*" OR "older subject*" OR "older citizen*" OR "older person*" OR "older people" OR senior* OR "old age" OR "advanced age" OR aging OR ageing OR "Geriatrics" OR geriatr* OR gerontolog* OR Centenarian* OR Nonagenarian* OR Octogenarian* OR septuagenarian*) AND ("Patient Participation" OR participat* OR Empower* OR Activat* OR Deliberat* OR engag* OR involv* OR "stakeholder role") AND ("Health Policy" OR "health polic*" OR "healthcare polic*" OR "health care polic*" OR "Policy Making" OR "policy making" OR "policymaking" OR "policy development*" OR "policy analys*" OR "advisory committ*" OR "task force*" OR "development of polic*" OR "review commit*" OR "policy formulation*" OR "policy evaluation*" OR health care reform* OR healthcare reform*)

Inclusion/exclusion criteria

Empirical studies, e.g., qualitative, quantitative, and mixed methods research, systematic and scoping reviews, and grey literature reports will be included if they report on policy development in the areas of health and well-being, address the use or evaluation of a method/practice for engaging senior citizens and informal caregivers in health policy development, focus on senior citizens defined as persons with a minimum age of 65 (or a majority of participants are aged 65 and above), and/or their informal caregivers or addressed with proxy words such as chronically ill, dementia, and frail elderly, and address policy development at regional, national, or international level.

Due to a dearth of literature on senior citizen engagement in health policy development, there will be no limit to publication year. There will be no language restrictions included in the eligibility criteria and in the search strategy. This means that search results in every language (of the world/where an article on the subject has been written) generated from our search strategy will be included for review, if they meet all other eligibility criteria. Abstracts of studies in languages other than English will first be translated using the help of a colleague who is proficient in the language. If considered relevant, the full texts will then be translated using the help of a translation firm. Studies discussing senior citizen and informal caregiver engagement in research or at the point of care will be excluded. Studies addressing *all* citizen engagement with no particular attention to senior citizens will be excluded.

Data charting, summarizing, and reporting the results

A preliminary data charting table (see Table 2) has been developed and will be piloted to familiarize with results, based on the elements presented in the engagement framework by Carman et al (28). This Multidimensional Framework for Patient and Family Engagement in Health and Healthcare will be used to guide analysis and data will be categorize based on the elements. We will first capture information on engagement approaches used in the included relevant articles, their characteristics and how they were used to engage senior citizens and/or informal caregivers in health policy development. Then, we will interpret these findings based on the elements in the framework. We will extract data on continuum of engagement, phase of policy development, factors influencing policy makers to create opportunities for engagement, outcomes of engagement, comparisons of engagement strategies, efforts/initiatives to ensure engagement of senior citizens of minority groups, if stated Two researchers will pilot the data extraction table. The table will be further refined and updated as required in accordance with the review’s objectives. A descriptive summary of the findings will be presented. Data on authors, sources of evidence, year of publication, country/origin/setting of study, engagement frameworks will be extracted and presented. Regardless of the study designs of the included studies, the descriptions of the engagement strategies reported in the included studies will be the focus of the analysis and this will be guided by the Multidimensional Framework for Patient and Family Engagement in Health and Healthcare.

Patient and public involvement

There was no patient nor public involvement.

Table 2: Data charting table

Scoping Review Details	
Article title	
Review objectives	
Review questions	
Study type (case, empirical, review)	
Study design (quantitative, qualitative)	
Evidence source details and characteristics	
Citation details	
Country/geographical setting	
Context	
Participants/population studied (age, sex, number)	
Inclusion/Exclusion Criteria	
Population	
Includes senior citizens aged 65 and above and/or their caregivers	
Concept	
Describes strategies for senior citizen and informal caregiver engagement	
Context	
Describes strategies for senior citizen and informal caregiver engagement in policies around health and well-being	
Details/results extracted from publications	
Name of engagement strategies discussed	
Description of strategy	
Stated continuum of engagement (consultation, involvement, partnership, and shared leadership)	
Stated phase of policy development (e.g. policy formulation, implementation, or evaluation)	
Stated factors influencing policy makers to create opportunities for engagement in health policy development	
Stated outcome(s) of engagement strategies	
Change in knowledge and attitude of engaged senior citizens and informal caregivers	

Promotion of active citizenship (e.g., do senior citizens and informal caregivers feel a sense of citizenship and participation in decision making)	
Impact on relationship between the government and the citizens	
Senior citizens' and informal caregivers' awareness of one-another's lived experiences	
Increased knowledge about care transitions and engagement	
Developed capacity to take part in public policy matter	
Any other reported outcomes	
Data on comparisons of different engagement approaches	
Data on efforts/initiatives to ensure engagement of senior citizens of minority groups, if stated	
How strategy was used for engagement in health policy development	
Topics discussed using engagement approaches	
Stated engagement frameworks discussed	

Ethics and dissemination: This study does not require ethical approval as it will use publicly available data and does not involve human subjects' research. This study will constitute the first step in a research plan aimed at identifying engagement strategies and comparing them for variation, content, and breadth and depth of insights. The findings of this review will guide researchers, stakeholders, government, and non-governmental organization as well as policy makers in conversations around engagement in this context.

Author Contributions

ORK drafted the scoping review protocol. JPD, TvA, and ME revised and reviewed the protocol.

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Competing statement

The authors have no conflict of interest to report.

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Figure caption

Figure 1: A Multidimensional Framework For Patient And Family Engagement In Health And Health Care

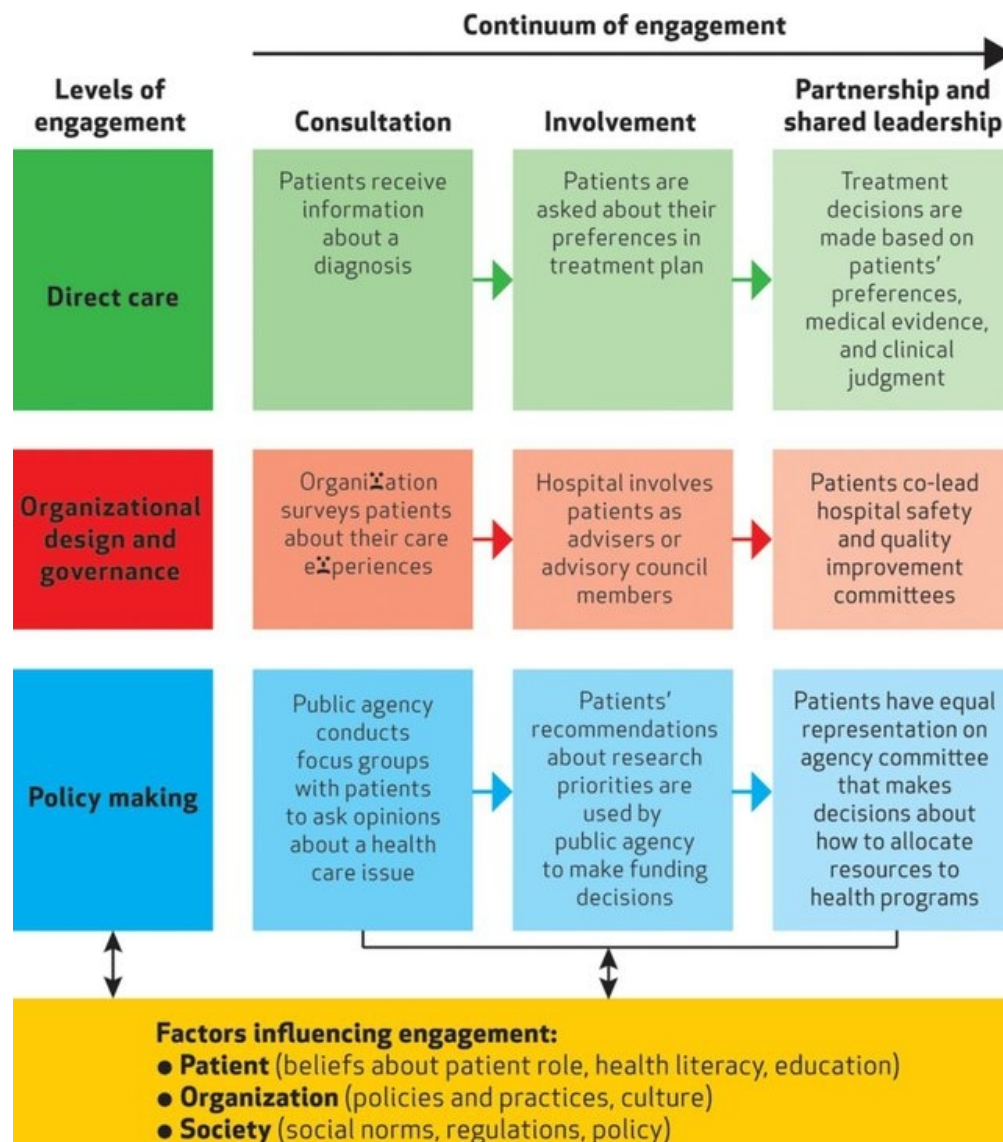


Figure 1: A Multidimensional Framework For Patient And Family Engagement In Health And Health Care

54x61mm (300 x 300 DPI)

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.	Page 0
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.	Page 0
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.	Page 1,2
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.	Page 2
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.	N/A
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.	Page 7
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.	N/A
Search	8	Present the full electronic search strategy for at least 1 database, including any limits used, such that it could be repeated.	Page 4-6
Selection of sources of evidence†	9	State the process for selecting sources of evidence (i.e., screening and eligibility) included in the scoping review.	Page 3
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.	Page 7
Data items	11	List and define all variables for which data were sought and any assumptions and simplifications made.	Page 8, 9
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

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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.	Page 7
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
Characteristics of sources of evidence	15	For each source of evidence, present characteristics for which data were charted and provide the citations.	N/A
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
N/A Synthesis of results	18	Summarize and/or present the charting results as they relate to the review questions and objectives.	N/A
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
Limitations	20	Discuss the limitations of the scoping review process.	N/A
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
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.	Page 11

JB1 = 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*. 2018;169:467–473. doi: 10.7326/M18-0850.