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SC I Guiding Principles Consensu; Hoekstra, Femke; Trigo, Francisca; Sibley, Kathryn M.; Graham, Ian D.; Kennefick, Michael; Mrklas, Kelly J.; Tram Nguyen; Vis-Dunbar, Mathew; Gainforth, Heather L.

Published in:

Journal of spinal cord medicine

DOI:

[10.1080/10790268.2022.2033578](https://doi.org/10.1080/10790268.2022.2033578)

IMPORTANT NOTE: You are advised to consult the publisher's version (publisher's PDF) if you wish to cite from it. Please check the document version below.

Document Version

Publisher's PDF, also known as Version of record

Publication date:

2023

[Link to publication in University of Groningen/UMCG research database](#)

Citation for published version (APA):

SC I Guiding Principles Consensu, Hoekstra, F., Trigo, F., Sibley, K. M., Graham, I. D., Kennefick, M., Mrklas, K. J., Tram Nguyen, Vis-Dunbar, M., & Gainforth, H. L. (2023). Systematic overviews of partnership principles and strategies identified from health research about spinal cord injury and related health conditions: A scoping review. *Journal of spinal cord medicine*, 46(4), 614-631. <https://doi.org/10.1080/10790268.2022.2033578>

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To cite this article: Femke Hoekstra, Francisca Trigo, Kathryn M. Sibley, Ian D. Graham, Michael Kennefick, Kelly J. Mrklas, Tram Nguyen, Mathew Vis-Dunbar, SC. I. Guiding Principles Consensus Panel & Heather L. Gainforth (2023) Systematic overviews of partnership principles and strategies identified from health research about spinal cord injury and related health conditions: A scoping review, *The Journal of Spinal Cord Medicine*, 46:4, 614-631, DOI: [10.1080/10790268.2022.2033578](https://doi.org/10.1080/10790268.2022.2033578)

To link to this article: <https://doi.org/10.1080/10790268.2022.2033578>



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Review

Systematic overviews of partnership principles and strategies identified from health research about spinal cord injury and related health conditions: A scoping review

Femke Hoekstra ^{1,2,3}, Francisca Trigo³, Kathryn M. Sibley^{4,5}, Ian D. Graham ^{6,7}, Michael Kennefick¹, Kelly J. Mrklas^{8,9}, Tram Nguyen^{10,11,12}, Mathew Vis-Dunbar ¹³, SC. I. Guiding Principles Consensus Panel, Heather L. Gainforth ^{1,2}

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Study design: Scoping review.

Objective: To identify and provide systematic overviews of partnership principles and strategies identified from health research about spinal cord injury (SCI) and related health conditions.

Methods: Four health electronic databases (Medline, Embase, CINAHL, PsycINFO) were searched from inception to March 2019. We included articles that described, reflected, and/or evaluated one or more collaborative research activities in health research about SCI, stroke, multiple sclerosis, Parkinson's disease, amputation, cerebral palsy, spina bifida, amyotrophic lateral sclerosis, acquired brain injury, or wheelchair-users. Partnership principles (i.e. norms or values) and strategies (i.e. observable actions) were extracted and analyzed using directed qualitative content analysis.

Results: We included 39 articles about SCI (n = 13), stroke (n = 15), multiple sclerosis (n = 5), amputation (n = 2), cerebral palsy (n = 2), Parkinson's disease (n = 1), and wheelchair users (n = 1). We extracted 110 principles and synthesized them into 13 overarching principles. Principles related to building and maintaining relationships between researchers and research users were most frequently reported. We identified 32 strategies that could be applied at various phases of the research process and 26 strategies that were specific to a research phase (planning, conduct, or dissemination).

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Supplemental data for this article can be accessed at <https://doi.org/10.1080/10790268.2022.2033578>.

Color versions of one or more of the figures in the article can be found online at www.tandfonline.com/yscm.

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DOI 10.1080/10790268.2022.2033578

Conclusion: We provided systematic overviews of principles and strategies for research partnerships. These could be used by researchers and research users who want to work in partnership to plan, conduct and/or disseminate their SCI research. The findings informed the development of the new SCI Integrated Knowledge Translation Guiding Principles (www.iktpinciples.com) and will support the implementation of these Principles within the SCI research system.

Keywords: Integrated knowledge translation, Spinal cord injury, Research partnership, Collaborative research, Stakeholder engagement, Principles and strategies, Knowledge syntheses

Introduction

While health research has the potential to improve the lives of many people with spinal cord injury (SCI), research findings are not always used or translated to clinical, community, and/or policy settings.^{1–6} Engaging research users (e.g. people with SCI, clinicians, representatives of community organizations) as partners (i.e. co-researchers or collaborators) in the research process has been identified as a promising approach to enhance the translation of research findings to clinical, community and/or policy settings.^{7–10} Such research partnership approaches also support previous calls from people with disabilities indicating that there should be “nothing about us, without us”¹¹. Research partnerships have been defined as “individuals, groups, or organizations that are engaged in collaborative research activities involving at least one researcher and any stakeholder”¹² and have been increasingly promoted, requested,^{13,14} and applied in various research areas,^{15–20} including SCI research.^{21–23}

Despite the growing popularity of research partnerships and the potential positive outcomes and impacts on the research process, partnership and community/society,^{16,17,24} SCI research partnership approaches are still a relatively understudied topic.^{25,26} This disconnect is concerning, as SCI researchers have been accused of taking a tokenistic approach in their partnerships (i.e. research users are asked to endorse a research project over which they have little control).^{11,21,23,27,28} Furthermore, researchers and research users have reported many challenges or concerns when working in partnership (e.g. additional time/resources, lack of partnership skills, unclear roles and responsibilities).^{15,29–32} Together, this illustrates the potential need and value in developing guidance on how to meaningfully work together in research partnerships.^{25,26,33}

While some partnership guidance exists in terms of facilitating factors,^{15,20,25,34} mechanisms,³⁵ and principles or guidelines,^{17,36–39} limited evidence-based tools and resources exist that are tailored to SCI research partnerships. This need for tailored partnership guidance has been expressed by SCI researchers and research users. More specifically, there have been calls to develop guidance on SCI research partnership

processes, in terms of partnership *principles* and *strategies*, to help SCI researchers and research users to overcome partnership challenges and improve meaningful research partnerships.²²

A first step to creating guidance for SCI research partnerships is understanding what principles and strategies could be used to guide these partnerships by reviewing the relevant literature. Partnership *principles* are defined here as “fundamental norms, rules, or values that represent what is desirable and positive for a person, group, organization, or community, and help it in determining the rightfulness or wrongfulness of its actions”⁴⁰, and *strategies* are defined as “observable actions designed to achieve an outcome”⁴¹. Acquiring systematic overviews of partnership principles and strategies identified from the literature could inform the development of evidence-based resources and tools to guide SCI research partnerships. Furthermore, an overview of principles and strategies as potential underlying and explanatory partnership processes,²⁵ may also provide reporting and evaluation guidance, and subsequently may contribute to enhancing our inquiry and understanding of partnership outcomes and impacts.^{17,18,42}

While a previous review of reviews provided an extensive list of potential principles and strategies based on general partnership literature,¹⁷ further research is needed to identify partnership principles and strategies that are specific to and/or relevant for the SCI research context. To date, various reviews have been conducted on research partnerships and/or research user engagement in the rehabilitation and disability research area.^{9,10,43–46} However, these reviews did not provide systematic overviews of partnership principles and strategies relevant for SCI research partnerships with a broad group of potential research users (e.g. people with lived experiences of a disability or health condition, clinicians, representatives of community organizations, policy- and decision-makers). We conducted a scoping review to understand what partnership principles and strategies could be used to guide SCI research partnerships. More specifically, we identified and provided systematic overviews of partnership principles and strategies identified from health research about

SCI and other related health conditions (e.g. multiple sclerosis (MS), stroke). Pragmatically, this broader scope allowed us to identify a variety of principles and strategies that could be used to inform the development of partnership resources relevant to SCI research partnerships with a diverse group of research users. The research questions were:

- What partnership principles are reported in the literature that could be used to guide SCI research partnerships? (RQ1).
- What partnership strategies are reported in the literature that could be used to plan, conduct and/or disseminate SCI research in partnership with research users? (RQ2).

Methods

Project overview and perspective

This scoping review is part of two larger projects. The first project relates to a pan-Canadian collaborative review project¹² aimed to synthesize the research partnership literature by conducting a review of reviews,¹⁷ scoping reviews, and an umbrella review. These reviews are guided by a consensus-based framework including the following four research partnership domains: principles, strategies, outcomes and impacts.¹² The current scoping review focuses on two of these key research partnerships domains, namely principles and strategies specifically related SCI research.

The second project relates to the development of the Integrated Knowledge Translation (IKT) guiding principles for SCI research partnerships.²² In the context of this project, a multidisciplinary team of SCI researchers, research users, and funders has been working together to co-develop guiding principles and related resources to support meaningful SCI research partnerships. This North American initiative was a response to the need to offer and improve research partnership guidance. The findings from this scoping review were used to inform the development of the guiding principles and will be used to inform the development of resources and tools to guide SCI research partnerships (www.iktprinciples.com).

The study protocol is published in Systematic Reviews and registered on Open Science Framework (OSF).^{12,47} The planning, conduct and reporting of the findings of this scoping review was guided by steps described by Arksey, O'Malley *et al.*⁴⁸ and Levac *et al.*⁴⁹ as well as the Preferred Reporting Items for Scoping reviews PRISMA-ScR for Scoping Reviews.⁵⁰ Appendix 1 includes the PRISMA-ScR reporting guidelines. Appendix 2 outlines the primary

research questions and the PICOS elements for this scoping review. Appendix 3 describes deviations from the protocol.

We approached this review from a pragmatic perspective, which means that the primary objective of the research is to apply research to find solutions for practical problems in “real-world” settings.⁵¹ Pragmatism focuses on the practical outcomes of the knowledge within a particular context instead of focusing on seeking a single truth.

Research user engagement in the scoping review

Aligning with our pragmatic approach,⁵² a multidisciplinary panel (i.e. “SCI Guiding Principles Consensus Panel”) consisting of SCI researchers, research users and funders meaningfully engaged at various points in the review process. This panel was established to develop IKT Guiding Principles for conducting and disseminating SCI research in partnership with research users.²² At the start of the project, the panel held a one-day meeting to establish consensus about the vision of the project, key terms and definitions, research design, and panel members’ roles and responsibilities. They established their own definition of IKT: “*meaningful engagement of the right research user at the right time throughout the research process*”.²² Because no guiding principles for SCI research partnerships were available at the start of this project, the panel did not discuss or operationalize specific principles used to guide their partnership. Instead, the panel agreed that they would adopt the IKT Guiding Principles for SCI research partnerships as soon as they are available. In the context of this scoping review, panel members were engaged in the decision to conduct a review, the formulation of the research question (i.e. decision to focus the findings on specific population groups), the preparation of the data extraction forms, and the data interpretation. Appendix 4 outlines panel members’ names, organizations and roles. Appendix 5 outlines key partnership strategies used to engage panel members in the design and conduct of this scoping review. Further details about the SCI Guiding Principles Consensus Panel and the IKT Guiding Principles project is described elsewhere.²²

Search strategy

Four health databases (Medline, Embase, CINAHL, PsycINFO) were searched by the academic librarian (MVD) from inception to March 2019. The search strategy included two parts: (1) search terms focusing on capturing the research partnership approach (e.g.

participatory research, community-engaged research, patient and public involvement, knowledge translation, engaged scholarship); (2) search terms focusing on capturing research about people with SCI and related disabilities or health conditions (e.g. rehabilitation, SCI, stroke, MS). The first part of the search strategy was developed using the findings from our previous review of reviews on research partnership approaches and aimed to capture the variety of terms used to describe research partnership approaches (see OSF). Both parts of the search strategy were independently reviewed and assessed by another academic librarian (CN) using the Peer Review of Electronic Search Strategies (PRESS) checklist.⁵³ The search strategy was finalized using the results from the PRESS checklist. The final search strategies of all databases and the PRESS checklist are available on OSF (<https://osf.io/mzuwp/>).

Eligibility criteria

We included articles that described, reflected, and/or evaluated a type of research partnership approach in health research about SCI and other related disabilities and/or health conditions. To be included the article needed to provide at least one example of a research partnership principle or strategy. In consultation with the SCI Guiding Principles Consensus Panel, we decided to include articles about SCI and related disabilities or health conditions, including: stroke, MS, cerebral palsy (CP), Parkinson's disease, amputation, Amyotrophic Lateral Sclerosis (ALS), acquired brain injuries, and wheelchair users. Broadening our scope from SCI to related disabilities and health conditions allowed us to identify more extensive overviews of principles and strategies that may be relevant for SCI research partnerships. We excluded articles that focused on general groups of people with physical disabilities for feasibility reasons (i.e. screening a large number of full text articles was considered as not being feasible and relevant in the context of this project due to the significant amount of time it would take to screen these articles). **Table 1** outlines the inclusion and exclusion criteria. The criteria used to screen titles and abstracts are available on OSF (<https://osf.io/mzuwp/>).

Screening process

Results from the search strategies were exported to and managed using Endnote X.7.5.3 and Microsoft Excel. The de-duplication process was completed using the steps outlined by Bramer *et al.*⁵⁴ Two team members [FH and FT, FH and HG] independently used an

Excel screening tool and the abstract-level eligibility criteria to screen titles and abstracts. Cohen's kappa statistics were used to calculate reliability between each screening pair during title/abstract screening as well as full text screening. Screening processes were started once a kappa ≥ 0.6 was reached. Cohen's kappa was calculated after each screening block. The mean kappa scores were reported for each screening pair and screening phase (title/abstract and full-text). Consensus discussions were held to resolve any disagreements between screeners. The full text screening process was conducted independently by same screening pairs. Disagreements between screeners were resolved through discussion. If disagreements could not be resolved throughout discussion, a third team member (HLG, MK, or HG) was consulted to resolve the disagreement.

Data extraction and analyses

Data extraction of study and partnership characteristics was done by one team member (FH, FT, MK) using an online data extraction form (Qualtrics) and Excel. The following study characteristics were extracted and exported to Excel: first author, year of publication, country of first author, title, disability/health condition, study design, study aims, and general conclusion. The following partnership characteristics were extracted: partnership terms, partnership members, definition or description of the partnership, and level of engagement. Afterwards, the first author (FH) reviewed the extracted information and discussed any uncertainties in extracted information (e.g. partnership definitions or description, study design) with one of the study members (HG, FT, MK). Data extraction and analysis of the principles and strategies were guided by directed qualitative content analysis⁵⁵ including the following key steps:

- *Development of the coding manual.* Using the previous established definition of research partnership principles¹² and a list of extraction rules, two coders (FH, HG) independently extracted principles from a selection of included studies ($n = 6$; 15%). The coders reviewed and discussed the extracted information, resolved disagreements and developed the coding manual for research partnership principles iteratively. Similarly, two coders (FH and FT, FH and MK) independently extracted strategies from a selection of included studies ($n = 6$, 15%) using the previous established definition of strategy, a list of extraction rules, and the coding manual developed during the previous review of reviews (see OSF). This version of the coding manual was then adapted and refined based on the extracted information on research partnership

Table 1 Inclusion and exclusion criteria.

	Inclusion criteria	Exclusion criteria
General	<ul style="list-style-type: none"> – The article describes, reflects and/or evaluates a type of research partnership approach in the area of health research about SCI or other related physical disabilities or health conditions, in which research users were engaged in the research process. 	
Population	<ul style="list-style-type: none"> – The article relates to one of the following disabilities or populations: <i>Spinal Cord Injury, Stroke, Multiple Sclerosis, Parkinson disease, Amputation, Cerebral Palsy, Spina Bifida, Amyotrophic Lateral Sclerosis, Acquired Brain Injury, wheelchair-users</i>. This includes articles that focus on occupational therapists, nurses, physiotherapists or other healthcare providers working with one (or more) of the abovementioned groups. 	<ul style="list-style-type: none"> – The article focuses on general group of people with a (physical) disability or health condition. – The article focuses on any of the excluded populations combined with one of the included population (e.g. wheelchair users with chronic pain).
Partnership	<ul style="list-style-type: none"> – The article meets our definition of <u>health research partnership</u>: <ul style="list-style-type: none"> • <u>Research partnership</u> is defined as “<i>individuals, groups or organizations engaged in collaborative research activity involving at least one health researcher (e.g. individual affiliated with an academic institution), and any stakeholder (e.g. decision or policy maker, health care administrator or leader, community agency, charities, network, patients etc.)</i>.”¹⁷ • <u>Collaborative research activity</u> refers to an activity or moment in the process of planning, conducting or disseminating research in which there is an indication of shared decision making between at least one researcher and at least one stakeholder. – The research relates to one of the four pillars of health research as defined by CIHR: biomedical, clinical research, health services research or population health research. – The article describes, reflects and/or evaluates a <u>research partnership</u> OR describes, reflects and/or evaluates at least one <u>collaborative research activity</u>. 	<ul style="list-style-type: none"> – The article does not meet our definition of <u>health research partnership</u> (e.g. physician – patient partnership; student-teacher partnership) or does not provide enough information about the collaborative research activity to determine eligibility. – The article relates to patient engagement in health care decisions instead of research. – Research users are <i>only</i> included as participants and not as research partners (e.g. Delphi studies). – If the article <u>describes</u> a research partnership approach or collaborative research activity without <u>reflecting</u> or <u>evaluating</u> it, the article is excluded if: <ul style="list-style-type: none"> • <i>all</i> research users are also <i>all</i> participants in the research (100% overlap between participants and research users) OR • the research users are only engaged in the design of the study and not in the conduct or disseminating phase. – The article describes a public-private partnership (PPP) or university-industry partnership. – The article does not relate to one of the CIHR’s health domains.
Outcomes	<ul style="list-style-type: none"> – The article describes at least one clear example of a <u>principle</u> that was used or could be used to guide a research partnership team OR at least one clear example of a <u>strategy</u> used to engage research users in the collaborative research activity. – <u>Principles</u> are defined as “<i>fundamental norms, rules, or values that represent what is desirable and positive for a person, group, organization, or community, and help it in determining the rightfulness or wrongfulness of its actions. Principles are more basic than policy and objectives, and are meant to govern both</i>”.¹² – <u>Strategies</u> are defined as “<i>observable actions designed to achieve an outcome</i>”.¹² 	<ul style="list-style-type: none"> – The article does not describe a clear example of a partnership principle or strategy.
Other	<ul style="list-style-type: none"> – The article uses quantitative, qualitative, or mixed-method research methods. – The article is published in English language. – The article is published in a peer-reviewed journal. 	<ul style="list-style-type: none"> – The article describes a literature review or describes a study protocol. – The article is not published in English language. – Books, theses, editorials, and conference abstracts are excluded.

Note: A detailed description of the eligibility criteria including additional definitions and illustrating examples is published on Open Science Framework. CIHR = Canadian Institutes of Health Research.

strategies. The reason why we used the existing coding manual for strategies but not for the principles is that we experienced that the extraction process of strategies

(i.e. observable actions) was more straightforward than the extraction process of principles (i.e. norms or values). After establishing or adapting the coding

manuals, data extraction of the remaining studies was conducted by one team member (FH, FT, MK).

- **First round of analysis.** After data extraction of principles and strategies was completed, the first author (FH) grouped together the codes that had similar meaning and removed codes that did not meet our definitions. The first and last author (FH and HLG) discussed content of the coding manuals, re-organized the codes, and removed codes that did not meet our pre-established definitions. This step resulted in two organized Excel sheets listing the principles and strategies extracted from the included studies.
- **Final round of analysis – principles (RQ1).** The project leads (FH, HLG) synthesized the principles into overarching principles and grouped them into related processes. Other team members (KMS, IG, KM, TN, MVD) and panel members reviewed these overarching principles and provided feedback. Based on the feedback, the first and last author (FH, HLG) refined and finalized the overarching principles. To enhance transparency in our decision processes, different versions are available on OSF.
- **Final round of analysis – strategies (RQ2).** The first author (FH) removed and re-organized the findings of the strategies and discussed and refined the findings after a meeting with the last author (HLG). Afterwards, two team members (TF, MK) who were involved in the data extraction, reviewed the findings and provided feedback. The results were then finalized

by the first author (FH) based on the feedback from other team members and panel members.

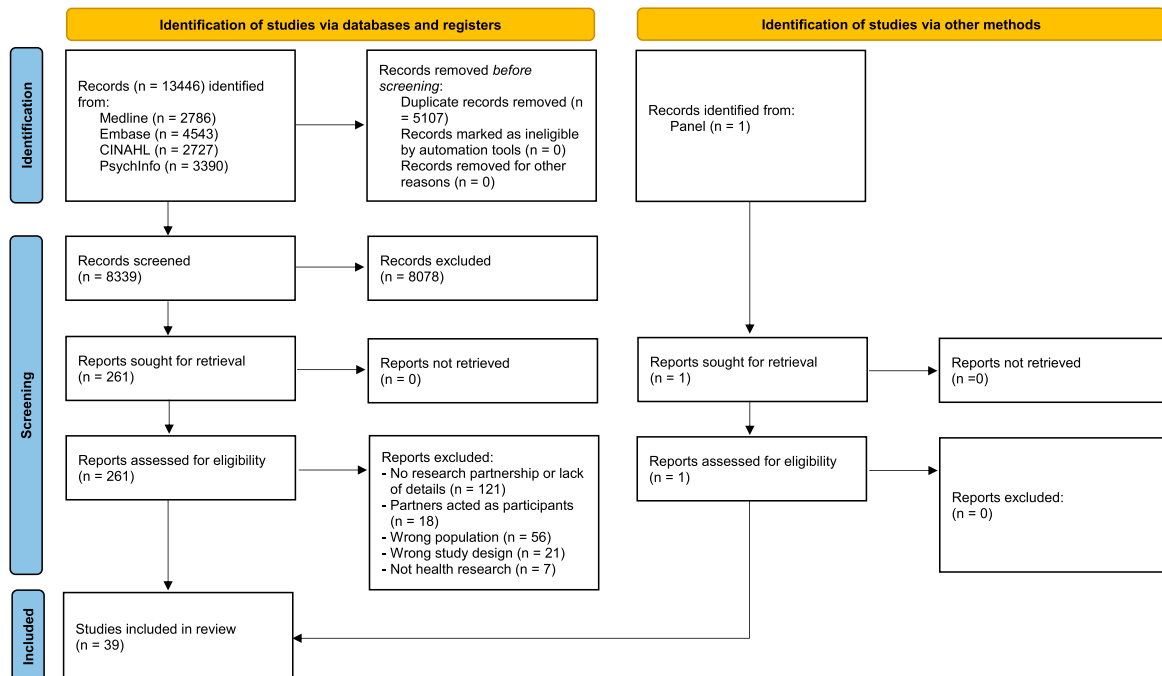
Results

Literature search

The search strategy resulted in a total of 8339 unique citations (Figure 1), of which 8078 were excluded after title and abstract screening. Full texts of 262 articles were reviewed, of which 39 were included in this scoping review. The mean Cohen’s Kappa for each of the screening pairs was considered as “substantial” for title/abstract level (mean Kappa: 0.63 and 0.61) and full-text screening level (mean Kappa: 0.64 and 0.65).⁵⁶ A list of included articles is presented in Appendix 6, a list of excluded articles is available via OSF.

Study and partnerships characteristics

An overview of study characteristics of the included studies is presented in Table 2. The majority of the articles were published between the years 2015–2019 (n = 22, 56%). The remaining articles were published between the years 2011–2014 (n = 13, 33%) or 2004–2010 (n = 4, 10%). Articles were published by first authors from Canada (n = 11), UK (n = 10), USA (n = 9), The Netherlands (n = 4), Australia (n = 3), New Zealand (n = 1), and Switzerland (n = 1).



From: Page MJ, McKenzie JE, Bossuyt PM, Boutron I, Hoffmann TC, Mulrow CD, et al. The PRISMA 2020 statement: an updated guideline for reporting systematic reviews. *BMJ* 2021;372:n71. doi: 10.1136/bmj.n71. For more information, visit: <http://www.prisma-statement.org/>

Figure 1 The PRISMA flowchart.

Table 2 Study and partnership characteristics.

First author	Year	Country	Title	Partnership information type*			Partnership terms		Co-authorship**
				Descr	Refl	Eval	Key term	Other terms	
<i>SCI (n = 13)</i> Abma ⁵⁷	2005	The Netherlands	Patient Participation in Health Research: Research With and for People With Spinal Cord Injuries	✓	✓		Patient participation in health research		No
Allin ⁷⁵	2018	Canada	Participatory Design of an Online Self-Management Tool for Users With Spinal Cord Injury: Qualitative Study	✓			Participatory design Process		Yes
Duda ⁷⁶	2014	USA	From theory to practice: an illustrative case for selecting evidence-based practices and building implementation capacity in three Canadian health jurisdictions	✓			PAR	Participatory Action framework of engaged scholarship	Yes
Gainforth ⁷⁷	2015	Canada	Using Network Analysis to Understand Knowledge Mobilization in a Community-based Organization	✓			Partnership team	Knowledge mobilization initiative	Yes
Gainforth ⁷⁸	2015	Canada	Examining the feasibility and effectiveness of a community-based organization implementing an event-based knowledge mobilization initiative to promote physical activity guidelines for people with spinal cord injury among support personnel	✓			Partnership approach	Knowledge mobilization initiative	Yes
Martin Ginis ⁷⁹	2012	Canada	A case study of a community-university multidisciplinary partnership approach to increasing physical activity participation among people with spinal cord injury	✓	✓		Community-university multidisciplinary partnership	CBPR; IKT	Yes
Martin Ginis ⁸⁰	2012	Canada	Takin' it to the Streets: A Community-University Partnership Approach to Physical Activity Research and Knowledge Translation	✓	✓		Community-university partnership		No
Lala ⁸¹	2016	Canada	Developing a Model of Care for Healing Pressure Ulcers With Electrical Stimulation Therapy for Persons With Spinal Cord Injury	✓			CBPR	PAR	Yes
Newman ⁸²	2010	USA	Evidence-based advocacy: Using Photovoice to identify barriers and facilitators to community participation after spinal cord injury	✓			CBPR	Research partnership	Yes
Newman ⁶¹	2015	USA	A community-based participatory research approach to the development of a Peer Navigator health promotion intervention for people with spinal cord injury	✓			CBPR	Community-engaged research	Yes
Newman ⁸³	2018	USA	Translating a spinal cord injury self-management intervention for online and telehealth delivery: A community-engaged research approach	✓			Community-engaged research	CBPR	Yes
Sweet ⁸⁴	2014	Canada	Operationalizing the RE-AIM framework to evaluate the impact of multi-sector partnerships			✓	Community-university partnership		Not clear

Continued

Table 2 Continued

First author	Year	Country	Title	Partnership information type*			Partnership terms		Co-authorship**
				Descr	Refl	Eval	Key term	Other terms	
Wolfe ⁸⁵	2018	Canada	An inclusive, online Delphi process for setting targets for best practice implementation for spinal cord injury	✓			Stakeholder engagement	Participatory research	Yes
<i>Stroke (n = 15)</i> Bird ⁸⁶	2019	Canada	Building a Bridge to the Community: An Integrated Knowledge Translation Approach to Improving Participation in Community-Based Exercise for People After Stroke	✓			IKT		Yes
Boote ⁸⁷	2014	UK	"But is it a question worth asking? A reflective case study describing how public involvement can lead to researchers ideas being abandoned	✓	✓		Public involvement		Yes
Fairbrother ⁵⁹	2013	UK	Involving patients in clinical research: the Telescot Patient Panel	✓	✓		PPI	Joint collaborative approach	Yes
Gesell ⁶⁰	2017	USA	Methods guiding stakeholder engagement in planning a pragmatic study on changing stroke systems of care	✓	✓		Stakeholder engagement	CBPR	Yes
Goldfinger ⁸⁸	2012	USA	Peer education for secondary stroke prevention in inner-city minorities: Design and methods of the prevent recurrence of all inner-city strokes through education randomized controlled trial	✓	✓		CBPR		Yes
Harrison ⁸⁹	2015	UK	Exploring patient and public involvement in stroke research: a qualitative study		✓	✓	PPI		Yes
Heaton ³⁵	2016	UK	Collaborative research and the co-production of knowledge for practice: an illustrative case study		✓	✓	Co-production of knowledge		Not clear
Hebblethwaite ⁹⁰	2015	UK	Exploring the Role of Community Recreation in Stroke Recovery Using Participatory Action Research and Photovoice	✓			PAR		Yes
Hubbard ⁹¹	2009	Australia	Interprofessional, practice-driven research: reflections of one 'community of inquiry' based in acute stroke		✓		Practice-driven Research (collaborative)		Yes
Morgan ⁹²	2005	UK	Consumers leading public consultation: The general public's knowledge of stroke	✓			User involvement	Consumer involvement	Yes
Nanninga ⁹³	2014	The Netherlands	Knowledge Translation and Implementation Special Series. Combined Clinical and Home Rehabilitation: Case Report of an Integrated Knowledge-to-Action Study in a Dutch Rehabilitation Stroke Unit	✓			PAR	Integrated Knowledge-to-Action process	Not clear
Sadler ⁹⁴	2017	UK	Shaping innovations in long-term care for stroke survivors with multimorbidity through stakeholder engagement	✓			Stakeholder engagement;	Co-production	Not clear
Sims ⁹⁵	2011	UK	How to develop a patient and carer advisory group in stroke care research		✓		Patient and carer advisory group in public involvement		Not clear
Skolarus ⁹⁶	2013	USA	Individual and community determinants of calling 911 for stroke among African Americans in an urban community	✓			CBPR		Yes

Continued

Table 2 Continued

First author	Year	Country	Title	Partnership information type*			Partnership terms		Co-authorship**
				Descr	Refl	Eval	Key term	Other terms	
Skolarus ⁹⁷	2011	USA	Community-based participatory research: a new approach to engaging community members to rapidly call 911 for stroke	✓			CBPR		Yes
<i>MS (n = 5)</i> Goodwin ⁹⁸	2018	UK	Involving Members of the Public in Health Economics Research: Insights from Selecting Health States for Valuation to Estimate Quality-Adjusted Life-Year (QALY) Weights	✓	✓		Public involvement		Not clear
Mulligan ⁹⁹	2017	New Zealand	A fatigue management programme for persons with multiple sclerosis: development, theory and practical considerations	✓			PAR		Yes
Puhan ¹⁰⁰	2018	Switzerland	A digitally facilitated citizen-science driven approach accelerates participant recruitment and increases study population diversity	✓		✓	Citizen-science driven approach	Citizen or patient engagement	Yes
Synnot ⁶²	2018	Australia	Consumer engagement critical to success in an Australian research project: reflections from those involved	✓	✓		Consumer engagement		Yes
Synnot ¹⁰¹	2018	Australia	Producing an evidence-based treatment information website in partnership with people affected by multiple sclerosis	✓			Consumer participation in research		Yes
<i>Amputation (n = 2)</i> Ehde ¹⁰	2013	USA	Developing, Testing, and Sustaining Rehabilitation Interventions Via Participatory Action Research	✓			PAR		Yes
Van Twillert ¹⁰²	2014	The Netherlands	Knowledge Translation and Implementation Special Series. Incorporating Self-Management in Prosthetic Rehabilitation: Case Report of an Integrated Knowledge-to-Action Process	✓			PAR	Engaged scholarship; co-creation	Yes
<i>Cerebral Palsy (n = 2)</i> Bartlett ⁵⁸	2017	Canada	Moving from parent "consultant" to parent "collaborator": one pediatric research team's experience	✓	✓		Collaborative partnerships	PAR; family-centered research	Yes
Wintels ¹⁰³	2018	The Netherlands	How do adolescents with cerebral palsy participate? Learning from their personal experiences	✓			Participatory Research;	Co-creation	Yes
<i>Parkinson's disease (n = 1)</i> Staley ¹⁰⁴	2017	UK	The impact of involvement on researchers: a learning experience	✓	✓	✓	Patient/public involvement		Yes
<i>Wheelchair users (n = 1)</i> Aldersey ¹⁰⁵	2018	Canada	Barriers and Facilitators for Wheelchair Users in Bangladesh: A Participatory Action Research Project	✓			PAR		Yes

Notes: *Partnership information type: description (Descr), reflection (Refl), and/or evaluation (Eval) of a research partnership approach. **Co-authorships: yes indicates that one or more research users were listed as co-author. Not clear indicates that there was not a clear indication that a research user was listed as co-author based on the information in the article and/or co-authors' affiliations. No indicates that there was no indication of a co-authorship as the article was published by a single author who was identified as a researcher and affiliated to an academic organization. CBPR = Community-based participatory research; PAR = Participatory Action Research; IKT = Integrated Knowledge Translation.

Included articles were related to: SCI (n = 13), stroke (n = 15), MS (n = 5), Amputation (n = 2), CP (n = 2), Parkinson (n = 1), and wheelchair users (n = 1). The included articles were qualitative studies (n = 15), case studies/reports (n = 12), non-experimental cross-sectional studies (n = 5), mixed methods studies (n = 3), intervention trial design (n = 1), implementation study (n = 1), and prospective observational study (n = 1). Twenty-two articles (56%) described a research partnership approach without reflecting or evaluating the research partnership approach or collaborative research activities. Thirteen articles (33%) included a reflection on collaborative research activities, and 7 articles (18%) included an evaluation.

The extracted information on the timing and nature of research user engagement in main phases of the research process (i.e. planning, conduct, dissemination) is presented in Appendix 7. Research users were most frequently engaged in the planning phase of the research process (31 out of 39, 79%) followed by the dissemination phase (25 out of 39, 64%), and conduct phase (24 out of 39, 61%). A detailed overview of the

extracted study and partnership characteristics is available on OSF – Table I.

Principles

Although we extracted 110 principles from 31 articles (OSF-Table II), most of the articles did not provide details on how and what principles were used to plan, conduct and/or disseminate their research in partnership. The 8 articles that did not include any extractable principles were those that described a research partnership approach without reflecting or evaluating on it. The principles were synthesized into 13 overarching principles related to 5 different processes (Table 3). The 5 processes are:

- Relationship between researchers and research users
- Co-production of knowledge
- Meaningful research user engagement
- Capacity building
- Communication between researchers and research users

The coding manuals and principle-codes identified within each of the included studies are available on

Table 3 A systematic overview of partnership principles.

Processes	Overarching principles	Context			
		SCI (n = 13)	Stroke (n = 15)	MS (n = 5)	Other (n = 6)
Relationships between researchers and research users	Trust, mutual respect, and/or credibility as foundations for building and maintaining partnership relationships.	6/13 (46%)	4/15 (27%)	3/5 (60%)	2/6 (33%)
	Value and/or respect for everyone's expertise and input.	1/13 (8%)	5/15 (33%)	2/5 (40%)	1/6 (17%)
	Acknowledge diversity, strive for representation and/or inclusivity.	2/13 (15%)	5/15 (33%)	1/5 (20%)	1/6 (17%)
	Empower community members.	2/13 (15%)	3/15 (20%)	0	1/6 (17%)
Co-production of knowledge	Research users should be involved in any phases of the research process.	3/13 (23%)	9/15 (60%)	2/5 (40%)	1/6 (17%)
	Findings should be shared to encourage their awareness and use.	4/13 (31%)	3/15 (20%)	1/5 (20%)	0
	Co-ownership of the research process and products, and sharing decision making and power related to research activities.	6/13 (46%)	3/15 (20%)	3/5 (60%)	3/6 (50%)
Meaningful research user engagement	Pragmatism and/or flexibility in the collaborative research activities and/or open for research users' ideas.	2/13 (15%)	3/15 (20%)	0	1/6 (17%)
	Undertake research relevant to research users with lived experience.	3/13 (23%)	2/15 (14%)	0	1/6 (17%)
	Partnerships are mutually beneficial.	1/13 (8%)	3/15 (20%)	1/5 (20%)	0
Capacity building	Capacity building among research users.	3/13 (23%)	1/15 (7%)	0	1/6 (17%)
	Researchers and research users learn from each other and share expertise and knowledge.	3/13 (23%)	5/15 (33%)	0	1/6 (17%)
Communication between researchers and research users	Open and/or ongoing communication and mutual understanding.	1/13 (8%)	1/15 (7%)	0	1/6 (17%)

Notes: SCI = Spinal cord injury; MS = Multiple Sclerosis.

OSF-Table II. The most frequently identified principles related to the following overarching principles:

- Trust, mutual respect, and/or creditability as foundations for building and maintaining partnership relationships (15 of 39 articles, 38%)
- Research users should be involved in any phases of the research process (15 of 39 articles, 38%)
- Co-ownership of the research process and products and sharing decision making and power related to research activities (15 of 39 articles, 38%).

From 6 articles (SCI, stroke, MS, CP),^{35,57–61} we identified 10 or more partnership principles per article. The article with the highest number of identified research partnership principles was published by Bartell *et al.* (2017)⁵⁸, in which the authors described their collaborative research experiences with parents of young people with CP.

Strategies

We extracted 58 partnership strategies from the 39 included articles (OSF-Table III). After combining strategy-codes with similar meaning, we identified 32 strategies that could be applied throughout the research process (Table 4) and 26 strategies related to specific phases of the research process (Table 5). While all included articles provided at least one example of a research partnership strategy, the extent to which authors provided example strategies varied largely. In 31% of the articles (12 out of 39), we identified 10 or more different research partnership strategies. The articles with the highest number of identified research partnership strategies (i.e. >20 different strategies) were derived from articles about stroke ($n = 2$),^{59,60} MS ($n = 1$)⁶² and CP ($n = 1$).⁵⁸ The strategies that could be applied throughout the research process related to the following 8 categories:

- Partnership representation
- Ongoing monitoring and evaluation of collaborative research activities
- Development of norms, rules and expectations
- Fostering the collaboration and communication processes
- Communication methods (verbal, written, visual)
- Education and training
- Time and resources
- Practical support

Of the strategies that could be applied throughout the research process, the most frequently reported strategy was having structured meetings (face-to-face, phone, or conferences calls) between researchers and research users (25 out of 39 articles, across all research areas/groups). The strategies related to specific phases of

the research process, were grouped into strategies related to the planning of the research, conduct of the research or dissemination and application of the research (Table 5).

Discussion

This scoping review is the first that provides systematic overviews of research partnership principles (i.e. norms or values) and strategies (i.e. observable actions) from 39 included articles that described, reflected and/or evaluated a research partnership about SCI or related health conditions. In general, the majority of the included articles provided limited details on which partnership principles and strategies were used to plan, conduct and/or disseminate the research. From the included articles in this scoping review, the vast majority of the research partnership approaches were SCI-related research in North America and stroke-related research in UK.

Partnership principles

We extracted >100 principles, which we synthesized into 13 overarching principles. In terms of the synthesized overarching principles, the findings from this scoping review confirmed the findings from our previous related review of reviews.¹⁷ We were able to organize the principles in the same way (i.e. using similar processes or categories) as we did in our previous review, suggesting that these processes may be used as a first step to building a classification system for research partnership principles. Furthermore, the most frequently reported principles identified in the current scoping review aligned with the findings from the previous review of reviews and interview study with SCI research partnership champions and related to “*building and maintaining relationships*”, “*research user engagement in the research process*”, and “*co-ownership and sharing decision-making*”. These confirming results may suggest that these principles are relevant for general research partnership approaches and not specific for a research area, population or type of partnership.

While we identified some differences in principles reported in the current scoping review compared to the results of the review of reviews¹⁷ and other commonly accepted principles for community engagement⁶³, we did not identify specific partnership principles that are clearly unique for SCI research partnerships (see Appendix 8). While this was in contrast with our expectations, the findings align with recently published IKT Guiding Principles for Conducting and Disseminating SCI research in partnership.²² These 8 Guiding Principles, informed by this review and other

Table 4 A systematic overview of strategies that could be applied throughout the research process.

Categories	Examples strategies	Context			
		SCI	Str	MS	Oth
Partnership representation	- Use of targeted strategy to identify/recruit research users (e.g. researcher send out an email about the research idea)	✓	✓	✓	
	- Recruit research user(s) via professionals network or community network	✓	✓	✓	✓
	- Researcher gets out into relevant communities and gets involved	✓	✓		
	- Research users or funding agencies initiate the partnership	✓			
Ongoing monitoring and evaluation of collaborative research activities	- Selection of research users from different disciplines, sectors and backgrounds (diverse team)	✓	✓	✓	✓
	- Monitor and/or evaluate collaborative research activities	✓	✓	✓	✓
Development of norms, rules and expectations	- Use a framework to guide the collaborative research activities	✓	✓		
	- Development and agreement of norms, rules and/or expectations	✓	✓	✓	
Fostering the collaboration and communication processes	- Define level of research users' commitment/ engagement (e.g. consultation, collaboration, patient- or public-directed)		✓	✓	
	- Develop shared goals common mission	✓			
	- Include a knowledge broker or other facilitator to support the collaborative process (e.g. facilitate conversations)	✓	✓	✓	
	- Use different tools to ensure that research users understand and/or participate in everything (e.g. flipcharts, communication tools)		✓		
	- Researchers read collection of autobiographical life stories	✓			
	- Provide opportunities for people to ask questions before meetings and/or provide pre-meeting information materials	✓	✓	✓	
	- Have continuous dialogue/ maintain communication		✓		✓
	- Have meetings at times and location convenient for research users	✓	✓	✓	✓
	- Have informal meetings (to get to know each other)			✓	✓
	- Adopt a common taxonomy / language	✓			✓
Communication methods (verbal, written, visual)	- Have structured meetings (face-to-face, phone, conference calls)	✓	✓	✓	✓
	- Gather information via focus groups or workshops or brainstorm sessions with research users	✓	✓	✓	✓
	- Gather information via interviews or consultations	✓	✓		
	- Gather information via surveys or email	✓	✓	✓	✓
	- Provide online platforms for interaction / web portal	✓	✓		
	- Gather information via visual and/or active methods (e.g. photo voice)	✓	✓		
	- Use consensus methods (e.g. nominal group techniques/ Delphi approaches)	✓	✓		
	- Educate and/or train research users (e.g. training in research ethics, interview techniques)	✓	✓		✓
Education and training	- Educate and/or train researchers		✓		✓
	- Provide education and/or training opportunities on collaborative research for all partners (e.g. training in CBPR principles and processes)	✓			
	- Funding for the collaborative research activities	✓	✓		✓
Time and resources	- Offer financial support to research users	✓	✓	✓	✓
	- Allow flexible handling of time schedules	✓			
Practical support	- Offer practical support	✓	✓	✓	✓

Notes: SCI = Spinal Cord Injury; Str = Stroke; MS = Multiple Sclerosis; Oth = Other population. A ✓ indicates that the strategy has been identified in at least one article related to the specific population (SCI, Stroke, MS, or Other). The order of the categories and example strategies does not represent importance or relates to the frequencies.

data sources,^{17,64} are also formulated in a broad way without specifically highlighting potential unique characteristics of SCI research partnership. Together, this suggest that many of the identified principles from this scoping review may be used to guide a variety of partnerships with different types of research users, in different contexts, and in different research areas. However, given the limited details reported on partnership principles, these findings need to be interpreted with caution and more research is needed.

Partnership strategies

We identified 58 research partnership strategies from the included articles. Our findings from the current scoping review align with the findings from our previous related review of reviews,¹⁷ previous literature reviews focusing on partnership strategies within and outside disability and rehabilitation context,^{9,20,65} and an existing framework to advance reporting of patient engagement in rheumatology research.⁶⁶ This scoping review adds to the existing partnership literature by providing a

Table 5 A systematic overview of strategies that are specific for a phase in the research process.

Research phase	Examples strategies	Population			
		SCI	Str	MS	Oth
Planning the research	Engagement of research users in:				
	Engagement of research users in the planning of research:*	✓	✓	✓	✓
	- grant writing / grant preparation	✓	✓		✓
	- identifying and/or prioritizing relevant topics for the research agenda	✓	✓	✓	✓
	- selecting the research topic or identifying or refining the research question	✓	✓		✓
	- developing the study proposal or protocol	✓	✓		✓
	- assessing, developing or refining research instruments (e.g. questionnaires, interview guides)	✓	✓	✓	✓
Conduct the research	- developing the informed consent and other participant information		✓		✓
	Engagement of research users in conducting the research:*	✓	✓	✓	✓
	- recruiting participants	✓	✓	✓	✓
	- collecting data phase	✓	✓		✓
	- conducting interviews or supervising focus groups/workshops		✓		✓
	- reviewing the literature	✓	✓	✓	✓
	- analyzing the data	✓	✓	✓	✓
Dissemination and application of the research	- interpreting the findings	✓	✓	✓	✓
	Engagement of research users in disseminating the research:*	✓	✓	✓	✓
	- writing reports or scientific papers	✓			✓
	- knowledge translation (KT) activities (e.g. providing feedback on draft reports / KT summaries)	✓	✓	✓	✓
	- co-authoring outputs (e.g. a scientific paper)		✓	✓	
	- approving of publications or reports		✓	✓	
	- advising, formulating and implementing action plans (dissemination plans)	✓	✓		✓
	- developing key messages		✓		
	- developing practice and policy recommendations	✓			
	- translating scientific data into comprehensible research findings	✓	✓	✓	✓
- communicating the findings / conference presentations		✓	✓	✓	
- developing of tools and resources (e.g. websites)			✓		
- establishing the future research agenda and/or identifying future research gaps			✓	✓	

Notes: SCI = Spinal Cord Injury; Str = Stroke; MS = Multiple Sclerosis; Oth = Other population. A ✓ indicates that the strategy has been identified in at least one article related to the specific context (SCI, Stroke, MS, or Other). *These rows illustrate the engagement of research users in the specific research phase. A ✓ indicates that at least one strategy was identified to engage research users in the specific phases of the research (planning, conduct, and dissemination).

method to extract and organize research partnership strategies, which could be evolved towards a classification system. We used our consensus-based guiding framework¹² including a common definition to identify research partnership strategies from existing literature and organized them into strategies applied at specific phases of the research phase and those that can be applied throughout the research. While we do not know which strategies would work the best under which circumstances, our findings may help researchers, trainees, and research users to think through, select, report on strategies that they will use or have used to work together in partnership, within and beyond SCI research.

Scientific and practical implications

The findings from this scoping review have important scientific and practical implications. To the research partnership literature, we add insight into potential underlying and explanatory partnership processes, in terms of principles and strategies. By presenting

systematic overviews of principles and strategies, our findings may be used to develop a classification system that can provide reporting and evaluation guidance. By doing so, we hope that this scoping review will create awareness among researchers, trainees, and research users to think about how to plan, conduct, and disseminate research in partnership, how to report on it, and how to evaluate quality partnerships. Subsequently, improving the reporting and evaluation of partnership processes will help to understand and explain partnership outcomes and impacts.

For SCI researchers, trainees, and research users who engage in research partnerships, the findings from this scoping review can be used to plan, conduct, and evaluate their collaborative research activities (e.g. how and which principles and strategies to adopt when). More specifically, the overviews of principles and strategies provided in this review have informed and can inform the development of resources relevant for (SCI) research partnerships. While additional research efforts (e.g. consensus

Table 6 Initial guidance for using research partnership principles and strategies when planning, conducting and/or disseminating SCI research in partnership with research users.

Guiding steps	Description	Additional resources
1 Determine the type of research partnership approach that aligns with your partnership orientation, historical roots and engagement processes.	There are differences in partnership orientation, historical roots and engagement processes between different types of research partnership approaches (e.g. CBPR, PAR, IKT)	67,68,70
2 Select and/or develop guiding principles for your partnership project	Guiding principles can be selected or developed on a partnership- either at a project-level (e.g. for a specific project) or for a specific context (e.g. the North American SCI IKT Guiding Principles). It is important that all involved agree upon and adopt the guiding principles.	22,36,39,69, www.iktprinciples.com
3 Operationalize the principles and select partnership strategies that align with the selected principles and ensure that these principles are guiding the partnerships.	The partnership team can use the findings from this scoping review and related data sources to operationalize the principles and select strategies that align with these principles. An example of a strategy that may facilitate a principle on "co-ownership of research products" is that research users are listed as a co-author on the scientific publication (i.e. strategy).	17,22,64
4 Differentiate between strategies that could be applied throughout the research process and those specific for a research phase.	Table 4 provides an overview of identified strategies that could be applied throughout the research process and Table 5 provides an overview of strategies specific for a research phase.	9,17,20,65,66
5 Communicate, monitor, reflect and evaluate your adopted partnership principles and strategies.		17,22

Notes: CBPR = Community-based participatory research; PAR = Participatory Action Research; IKT = Integrated Knowledge Translation.

discussion/surveys/interviews) are needed to develop such resources to understand what principles and strategies should be used under which circumstances, Table 6 provides summarizing guiding steps and links to additional resources.^{9,20,22,42,64,66–71}

Limitations

Some limitations of our scoping review need to be addressed. First, there was a large variation in the extent to which authors report on whether and how they have worked together in partnership. As such, our findings are limited by what was reported in the included articles. We also did not verify our findings with authors of the included articles. Second, we may have missed relevant articles due to a lack of reporting on partnership information or because they were not captured by our search strategy. In line with our pragmatic approach and the primary aims of this scoping review (i.e. providing an overview of principles and strategies), we acknowledge that we may have missed articles. We did not do an in-depth hand-search to capture any potentially missed articles. Despite these limitations, we were still able to identify a large number of partnership principles and strategies from a variety of articles relevant for SCI research partnerships. Third, the overviews of the principles and

strategies are our reflection of the literature. Other groups may have synthesized the findings differently. We also did not report on *guiding principles* for research partnerships. Instead, we identified principles that could be used to guide SCI research partnerships. To develop guiding principles for research partnerships, additional community-engaged efforts are needed to ensure the guiding principles would be relevant and useful for specific groups of end-users. Lastly, the lead authors (FH, HLG) as well as our panel (SCI Guiding Principles Consensus Panel) have a specific interest in SCI research. As we were aware of many research partnership projects conducted in North America, it is possible that we were more likely to identify and include studies related to SCI research partnerships compared to research partnerships related to other populations. To limit our biases, we used a systematic process to identify related articles (e.g. extensive search strategy, clear eligibility criteria, screening in duplicate). To enhance transparency, we published details of our processes on OSF.

Future directions and gaps in the literature

Based on the findings from this scoping review, we summarized future directions for SCI research partnership approaches.

- More consistency and coherency in partnership terms.** Our findings confirmed findings from previous reviews^{9,15–17,72} that there is a large variation in use of research partnership terms. There is a need for a more consistent way of describing and reporting on the research partnership approaches and processes.^{25,42} SCI researchers and research users should be aware of the different underlying motivations and social locations of different types of research partnership approaches.^{67,68} Nguyen *et al.*⁶⁷ published an overview of different research partnership terms and definitions, as well as key differences and similarities between different types of research partnership approaches. Using this and other overview articles,^{67,68,73} may help partnership teams to describe, reflect, and evaluate on their research partnership approach in more a consistent and coherent way.
- Better reporting on partnership principles and strategies.** In line with previous reviews on research partnerships approaches within and beyond SCI research,^{9,17} we found a large variation in the extent to which authors report on how they have worked together in partnership. Hamilton *et al.*⁶⁶ provides reporting guidance for patient engagement projects in the area of rheumatology by summarizing key components of patient engagement (how, when and why). Similar reporting guidance is needed for SCI research partnerships to better and more systematically report on partnership processes (i.e. principles and strategies) and partnership characteristics (e.g. expertise, roles, gender identity and expression, sex assigned at birth, ethnicity, age),⁷⁴ which will be essential to advance our understanding of partnership outcomes and impacts (i.e. how, when and why partnerships result in positive outcomes and impact).
- Linking research partnership strategies to principles.** No studies were identified that explicitly provided information on which strategies could or should be used to adopt certain principles (i.e. linking principles and strategies). Linking strategies to principles may support partnership teams to enact to certain principles (e.g. IKT Guiding Principles). Future research should focus on identifying which strategies should or could be used to help teams enact to certain principles by conducting primary research studies (e.g. interviews, surveys, consensus methods) rather than literature reviews. Similarly, limited information is available on how and what principles and strategies should or should not co-occur. Future research should focus on studying how and what combinations of principles and/or strategies could contribute to positive partnership outcomes and impacts. Subsequently, these new insights can then be used to develop evidence-based tools and resources to support the implementation of the new SCI IKT Guiding Principles (www.iktprinciples.com) and/or improve the guidance to SCI research partnerships.

Conclusion

We provided systematic overviews of partnership principles and strategies that could be used by researchers and research users who want to work in partnership to plan, conduct and/or disseminate their SCI research. The findings informed the development of the new SCI Integrated Knowledge Translation Guiding Principles (www.iktprinciples.com) and will support the implementation of these Principles within the SCI research system.

Acknowledgements

The authors would like to thank Harrison Grogan (HG) for assisting in data screening and extraction and Christine J. Neilson (CN) for her contribution to the conceptual design and conduct of the search strategy. The members of the SCI Guiding Principles Consensus Panel include: Heather L. Gainforth, Chris McBride, Kim Anderson, Hugh Anton, John Chernesky, Susan Forwell, Jocelyn Maffin, Kathleen Martin Ginis, W. Ben Mortenson, Peter Athanasopoulos, Rhonda Willms.

Conflict of interest

No potential conflict of interest was reported by the author(s).

Declaration of Interest

The authors do not have competing financial interests in relation to the work. Of note, author (HLG) and the SCI Guiding Principles Consensus Panel play a leadership role within the SCI Research System.

Funding

This research is supported in part by the IKTR Network Canadian Institutes of Health Research Foundation Grant (FDN #143237), a Canadian Institutes of Health Research Project Grant (FRN: 156372), a Michael Smith Foundation for Health Research Scholar Award for HG (Scholar Award #16910), and by the International Collaboration on Repair Discoveries (F17–01540). KMS is supported by a Canada Research Chair in Integrated Knowledge Translation in Rehabilitation Sciences. None of the funding bodies had a role in writing this manuscript, or in data collection, analysis or interpretation of the data.

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