**Appendix 1**: PRISMA-ScR reporting guidelines

*This checklist is uploaded as separate file.*

|  |  |
| --- | --- |
| PICOS | Scoping review - Partnership principles and strategies |
| Framework domains\* | Principles and strategies |
| Research question(s) | - 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). |
| Population\* | Researchers and research users, including trainees, policy and decision makers, funders, people with lived experience, clinicians working with or in the area of research about spinal cord injury and other related disabilities or health conditions. |
| Intervention | Any type of research partnership approach in the area of health research about spinal cord injury or related physical disabilities or health conditions |
| Comparators | n/a |
| Primary outcomes | Principles and strategies |
| Secondary outcomes\* | General descriptive study characteristics and partnership characteristics |
| Other criteria | See ***Table 1*** – Main text |

**Appendix 2:** Primary research questions and PICOS elements

*PICOS:* population, intervention, comparators, outcomes, study design. \* The partnership domains of the consensus-based guiding framework published in Hoekstra & Mrklas et al. (1).

**Appendix 3:** Deviations from the protocol

**Deviation from primary research question**

As outlined in the supplementary file of our protocol paper (1), our original primary research questions was *“What principles and strategies are used to guide the different types of health research partnerships?”.*

In contrast to what we outlined in our protocol paper, our current scoping review addressed the following research questions:

* What partnership principles are reported in the literature that could be used to guide spinal cord injury (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).

Based on our experiences with conducting the previous review of reviews (2), we decided to change our research questions because of the following two main reasons.

1. Feasibility of search strategy and timeline of the project

As outlined in the methods section of this review and described in our protocol paper*,* the findings of our scoping review informed the development of the SCI Integrated Knowledge Translation (IKT) Guiding Principles. For that reason, our screening process was on a specific timeline. After conducting the review of reviews (2), we realized that we needed to narrow our research questions because of the large number of potentially relevant studies. We decided to narrow our research questions by focusing on specific populations. When we started title/abstract screening, we focused on general groups of people with physical disabilities. However, after the first phase of abstract screening we decided to further narrow the research questions by focusing on specific populations (i.e., spinal cord injury (SCI) and related disabilities and health conditions). This narrow focus was needed as screening a large number of full text articles was not considered to be feasible in the context of this project due to the significant amount of time it would take to screen these articles. In consultation with members of the SCI Guiding Principles Consensus Panel, we therefore decided that we only included articles in this review that describes, reflects and/or evaluates a type of research partnership approach in the area of health research about SCI or related physical disabilities or health conditions. The decision to focus this review on specific disabilities/conditions was made during a conference call meeting with the SCI Guiding Principles Consensus Panel (see **Appendix 5**).

1. Lack of reporting on details regarding principles and strategies

Due to the generally lack of reporting on specific details regarding what principles (and strategies) were used to guide the research partnerships, we decided to revise our research questions and focus on what principles and strategies were reported in the literature that could be used to guide SCI research partnerships. In addition, we decided to focus this scoping review on providing systematic overviews of partnerships principles and strategies. By doing so, we were able to validate our findings from the previous review of reviews, use the findings of this scoping review to inform the development of the SCI IKT Guiding Principles. Furthermore, the findings may also be a first step towards creating a classification system to provide reporting guidance (see **discussion section**).

**Secondary research questions**

In our protocol paper we outlined seven secondary research questions regarding the use of partnership principles and strategies (e.g., “*How can the identified strategies be linked to the identified principles?”)*. Because we focused our primary research questions on what principles and strategies *could be used* instead of *were used* due to the lack of details reported in the included articles, we have not addressed any of our originally intended secondary research questions in this scoping review. As described in the discussion section our scoping review, more research on linking partnership strategies and principles as well as a better reporting on partnership principles and strategies is needed to address our originally intended secondary research questions.

**Appendix 4:** Panel members’ names, organizations and roles.

*Removed to allow blinded peer review process*

**Appendix 5:** The Integrated knowledge translation approach.

The research question related to developing guiding principles for Integrated Knowledge Translation (IKT) derived from members of the Spinal Cord Injury (SCI) Guiding Principles Consensus Panel (3). The table below provides an overview of research activities, associated dates, topics discussed, panel members’ concerns and suggestions, and our responses.

| **Research phase** | **Date** | **Strategies and topics discussed** | **Concerns and suggestions from panel** | **Our responses** |
| --- | --- | --- | --- | --- |
| *Conceptual design* | 13 Sept 2017 | One-day meeting to establish the consensus panel. During this meeting, the need for a literature review focusing on principles and strategies of research partnership was discussed and outlined as a priority for the panel. | - | - |
| 4 December 2017 | A conference call to discuss the establishment of a Coordinated Multicenter Team Approach to conduct the proposed reviews (a review of reviews (2) and scoping review). | Panel mentioned that they were concerned about the timeline, as they did not ask for two reviews. The panel approved the approach as long as it would not result in a heavy delay of the development of the IKT SCI guiding principles. | We discussed the expected timelines and highlighted that two reviews would increase the rigor of development of the IKT SCI guiding principles. |
| *Before starting data extraction* | March 4, 2019 | A conference call to discuss inclusion criteria for full text screening (see manuscript) and discuss the data extraction plan.  During this call, the panel also discussed the findings from the review of reviews. Some of the feedback/comments related to the review of reviews, also applied to the scoping review. | The panel agreed with the proposed inclusion and exclusion criteria for full text. In particular, the panel discussed and agreed with the decision to exclude arthritis research partnerships and focus on specific disabilities/conditions related to spinal cord injury. In response to data extraction form of the review of reviews, the panel mentioned that they would be interested in specific partnership characteristics, including motivation for the partnership.  In the discussion about the findings from the review of reviews, the panel mentioned that it would be helpful to include a list of example strategies, rather than ‘overarching strategies’. They suggested to report findings related to the strategies with more level of detail in the scoping review. | Tables 4 and 5 provide further details about partnership strategies, including a list of example strategies. We also added Table 6 for further guidance on using partnership principles and strategies.  In response to panel members’ suggestion to report/ extract information on partnership characteristics, additional information about partnership characteristics is available on OSF. We also included in the discussion a call to improve reporting on partnership characteristics. |
| *Data analysis, interpretation, and dissemination of results.* | July 2021 | Panel members and co-authors approved final version of the manuscript. | The panel did not provide any additional comments or feedback. |  |

IKT = Integrated Knowledge Translation; SCI = Spinal Cord Injury. Please note that in the context of the development of the IKT Guiding Principles, the panel had various discussions related to partnership principles and strategies. While these discussions were specifically focused on SCI Guiding Principles and not specifically on the findings of the scoping review, the discussions may have facilitated/ influenced the data interpretation and presentation of the current scoping review. Please see Gainforth *et al.* (2020) (3) for further details about the partnership and their engagement strategies.

**Appendix 6:** List of included articles.

1. Bird, M.L., et al., *Building a Bridge to the Community: An Integrated Knowledge Translation Approach to Improving Participation in Community-Based Exercise for People After Stroke.* Phys Ther, 2019. **99**(3): p. 286-296.
2. Boote, J.D., et al., *'But is it a question worth asking?' A reflective case study describing how public involvement can lead to researchers' ideas being abandoned.* Health expectations : an international journal of public participation in health care and health policy, 2014. **17**(3): p. 440-451.
3. Fairbrother, P., et al., *Involving patients in clinical research: the Telescot Patient Panel.* Health Expect, 2016. **19**(3): p. 691-701.
4. Gesell, S.B., et al., *Methods guiding stakeholder engagement in planning a pragmatic study on changing stroke systems of care.* J Clin Transl Sci, 2017. **1**(2): p. 121-128.
5. Goldfinger, J.Z., et al., *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.* Contemp Clin Trials, 2012. **33**(5): p. 1065-73.
6. Harrison, M. and R. Palmer, *Exploring patient and public involvement in stroke research: a qualitative study.* Disabil Rehabil, 2015. **37**(23): p. 2174-83.
7. Heaton, J., J. Day, and N. Britten, *Collaborative research and the co-production of knowledge for practice: an illustrative case study.* Implementation Science, 2015. **11**(1).
8. Hebblethwaite, S. and L. Curley, *Exploring the Role of Community Recreation in Stroke Recovery Using Participatory Action Research and Photovoice.* 2015, 2015. **49**(1).
9. Hubbard, I.J., G. Vyslysel, and M.W. Parsons, *Interprofessional, practice-driven research: reflections of one "community of inquiry" based in acute stroke.* J Allied Health, 2009. **38**(2): p. e69-74.
10. Morgan, L.J., et al., *Consumers leading public consultation: the general public's knowledge of stroke.* Fam Pract, 2005. **22**(1): p. 8-14.
11. Nanninga, C.S., et al., *Combined Clinical and Home Rehabilitation: Case Report of an Integrated Knowledge-to-Action Study in a Dutch Rehabilitation Stroke Unit.* Physical Therapy, 2015. **95**(4): p. 558-567.
12. Sadler, E., et al., *Shaping innovations in long-term care for stroke survivors with multimorbidity through stakeholder engagement.* PLoS One, 2017. **12**(5): p. e0177102.
13. Sims, S., et al., *How to develop a patient and carer advisory group in stroke care research.* Nurse Res, 2013. **20**(3): p. 6-11.
14. Skolarus, L.E., et al., *Individual and community determinants of calling 911 for stroke among African Americans in an urban community.* Circ Cardiovasc Qual Outcomes, 2013. **6**(3): p. 278-83.
15. Skolarus, L.E., et al., *Community-based participatory research: a new approach to engaging community members to rapidly call 911 for stroke.* Stroke, 2011. **42**(7): p. 1862-6.
16. Abma, T.A., *Patient participation in health research: research with and for people with spinal cord injuries.* Qual Health Res, 2005. **15**(10): p. 1310-28.
17. Allin, S., et al., *Participatory Design of an Online Self-Management Tool for Users With Spinal Cord Injury: Qualitative Study.* JMIR Rehabil Assist Technol, 2018. **5**(1): p. e6.
18. Duda, M.A., R.J. Riopelle, and J. Brown, *From theory to practice: an illustrative case for selecting evidence-based practices and building implementation capacity in three Canadian health jurisdictions.* Evidence & Policy: A Journal of Research, Debate and Practice, 2014. **10**(4): p. 565-577.
19. Gainforth, H.L., et al., *Using Network Analysis to Understand Knowledge Mobilization in a Community-based Organization.* Int J Behav Med, 2015. **22**(3): p. 292-300.
20. Gainforth, H.L., et al., *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.* Health Promot Pract, 2015. **16**(1): p. 55-62.
21. Ginis, K.A.M., et al., *A case study of a community-university multidisciplinary partnership approach to increasing physical activity participation among people with spinal cord injury.* Translational behavioral medicine, 2012. **2**(4): p. 516-522.
22. Martin Ginis, K.A., *Takin' it to the Streets: A Community-University Partnership Approach to Physical Activity Research and Knowledge Translation.* 2012. **1**(4): p. 190.
23. Lala, D., et al., *Developing a Model of Care for Healing Pressure Ulcers With Electrical Stimulation Therapy for Persons With Spinal Cord Injury.* Top Spinal Cord Inj Rehabil, 2016. **22**(4): p. 277-287.
24. Newman, S.D., *Evidence-based advocacy: using Photovoice to identify barriers and facilitators to community participation after spinal cord injury.* Rehabil Nurs, 2010. **35**(2): p. 47-59.
25. Newman, S.D., et al., *A community-based participatory research approach to the development of a Peer Navigator health promotion intervention for people with spinal cord injury.* Disabil Health J, 2014. **7**(4): p. 478-84.
26. Newman, S.D., S.L. Toatley, and M.D. Rodgers, *Translating a spinal cord injury self-management intervention for online and telehealth delivery: A community-engaged research approach.* J Spinal Cord Med, 2019. **42**(5): p. 595-605.
27. Sweet, S.N., et al., *Operationalizing the RE-AIM framework to evaluate the impact of multi-sector partnerships.* Implementation Science, 2014. **9**(1): p. 74.
28. Wolfe, D.L., et al., *An inclusive, online Delphi process for setting targets for best practice implementation for spinal cord injury.* J Eval Clin Pract, 2019. **25**(2): p. 290-299.
29. Goodwin, E., et al., *Involving Members of the Public in Health Economics Research: Insights from Selecting Health States for Valuation to Estimate Quality-Adjusted Life-Year (QALY) Weights.* Appl Health Econ Health Policy, 2018. **16**(2): p. 187-194.
30. Mulligan, H., A. Wilkinson, and J. Snowdon, *A fatigue management programme for persons with multiple sclerosis: development, theory and practical considerations.* Physical Therapy Reviews, 2017. **22**(1-2): p. 3-6.
31. Puhan, M.A., et al., *A digitally facilitated citizen-science driven approach accelerates participant recruitment and increases study population diversity.* Swiss Med Wkly, 2018. **148**: p. w14623.
32. Synnot, A.J., et al., *Consumer engagement critical to success in an Australian research project: reflections from those involved.* Aust J Prim Health, 2018. **24**(3): p. 197-203.
33. Synnot, A.J., et al., *Producing an evidence-based treatment information website in partnership with people affected by multiple sclerosis.* Health Science Reports, 2018. **1**(3): p. e24.
34. Ehde, D.M., et al., *Developing, testing, and sustaining rehabilitation interventions via participatory action research.* Arch Phys Med Rehabil, 2013. **94**(1 Suppl): p. S30-42.
35. van Twillert, S., et al., *Incorporating self-management in prosthetic rehabilitation: case report of an integrated knowledge-to-action process.* Phys Ther, 2015. **95**(4): p. 640-7.
36. Bartlett, D., et al., *Moving from parent "consultant" to parent "collaborator": one pediatric research team's experience.* Disabil Rehabil, 2017. **39**(21): p. 2228-2235.
37. Wintels, S.C., et al., *How do adolescents with cerebral palsy participate? Learning from their personal experiences.* Health Expect, 2018. **21**(6): p. 1024-1034.
38. Staley, K., I. Abbey-Vital, and C. Nolan, *The impact of involvement on researchers: a learning experience.* Research Involvement and Engagement, 2017. **3**(1): p. 20.
39. Aldersey, H.M., et al., *Barriers and Facilitators for Wheelchair Users in Bangladesh: A Participatory Action Research Project.* 2018, 2018. **29**(2): p. 21.

**Appendix 7:** The timing and nature of the research user engagement in the research process.

Fourteen of the 39 studies (36%) included examples of research user engagement strategies across the three main research phases. The majority of the articles described a collaborative engagement process (n=36), of which 15 included examples of a consultation-based engagement process. Eight studies described examples of a patient/public-led engagement process. The majority of the patient/public-led engagement process used a CBPR (n=4) or PAR (n=2) approach. In 31 out of 39 articles (79%), one or more research users were identified as co-author on the article.

**Table 6.1:** The timing and nature of the research user engagement in the research process.

| **Article** | **Research phase** | | | **Engagement approach** | | | **Co-authorship** |
| --- | --- | --- | --- | --- | --- | --- | --- |
| *Planning phase* | *Conducting phase* | *Dissemination phase* | *Consultation* | *Collaboration* | *Patient- and*  *public-directed* |  |
| ***Stroke*** | | | | | | | |
| Bird | ✓ | ✓ |  |  | ✓ |  | Yes |
| Boote | ✓ |  | ✓ | ✓ | ✓\* |  | Yes |
| Fairbrother | ✓ | ✓ | ✓ | ✓ | ✓\* |  | Yes |
| Gesell | ✓ | ✓ | ✓ | ✓ | ✓ |  | Yes |
| Goldfinger | ✓ | ✓ |  |  | ✓ | ✓ | Yes |
| Harrison |  |  |  | ✓ | ✓ |  | Yes |
| Heaton | ✓ | ✓ | ✓ | ✓ | ✓ | ✓ | Not clear |
| Hebblethwaite | ✓ | ✓ | ✓ |  | ✓ | ✓ | Yes |
| Hubbard |  | ✓ |  |  | ✓ |  | Yes |
| Morgan | ✓ |  | ✓ |  | ✓ |  | Yes |
| Nanninga | ✓ | ✓ | ✓ |  | ✓ |  | Not clear |
| Sadler | ✓ |  | ✓ | ✓ |  |  | Not clear |
| Sims | ✓ | ✓ |  |  | ✓ |  | Not clear |
| Skolarus | ✓ | ✓ |  |  | ✓ | ✓ | Yes |
| Skolarus | ✓ | ✓ |  |  | ✓ | ✓ | Yes |
| ***SCI*** |  |  |  |  |  |  |  |
| Abma | ✓ | ✓ |  | ✓ | ✓ |  | No |
| Allin | ✓ |  |  | ✓ | ✓ |  | Yes |
| Duda |  |  |  |  | ✓ |  | Yes |
| Gainforth | ✓ |  | ✓ |  | ✓ |  | Yes |
| Gainforth | ✓ |  | ✓ |  | ✓ |  | Yes |
| Martin Ginis |  |  | ✓ |  | ✓ |  | Yes |
| Martin Ginis | ✓ |  | ✓ |  | ✓ |  | No |
| Lala |  |  | ✓ | ✓ | ✓ |  | Yes |
| Newman | ✓ |  | ✓ |  | ✓ | ✓ | Yes |
| Newman | ✓ | ✓ | ✓ |  | ✓ |  | Yes |
| Newman | ✓ | ✓ | ✓ |  | ✓ |  | Yes |
| Sweet |  | ✓ |  |  | ✓ |  | Not clear |
| Wolfe | ✓ | ✓ | ✓ |  | ✓ |  | Yes |
| ***MS*** | | | | | | | |
| Goodwin |  | ✓ |  | ✓ | ✓ |  | Not clear |
| Mulligan | ✓ |  |  |  | ✓ |  | Yes |
| Puhan Milo | ✓ |  | ✓ |  |  | ✓ | Yes |
| Synnot | ✓ | ✓ | ✓ | ✓ | ✓ |  | Yes |
| Synnot |  |  | ✓ |  | ✓ |  | Yes |
| ***Other*** |  |  |  |  |  |  |  |
| Bartlett | ✓ | ✓ | ✓ | ✓ | ✓ |  | Yes |
| Wintels | ✓ | ✓ |  | ✓ | ✓ |  | Yes |
| Ehde | ✓ | ✓ | ✓ | ✓ | ✓ |  | Yes |
| van Twillert | ✓ | ✓ | ✓ |  | ✓ |  | Yes |
| Staley | ✓ | ✓ | ✓ | ✓ | ✓ |  | Yes |
| Aldersey | ✓ | ✓ | ✓ |  |  | ✓ | Yes |

*Notes:* Research phase: A check mark indicates that the paper described a research partnership strategy linked to the specific research phase (planning, conduct, dissemination). Level of engagement is defined using three levels outlined by Centre for Healthcare Innovation (4). The level of engagement is determined based on the description of research users’ roles in the research process. Consultation happens when research users provide feedback or input and can occur via focus groups, working groups, expert panels, priority-setting activities. Collaboration happens when research users are actively engaged in the research process as co-researchers, co-investigator, and/or as members of research steering committees with some type of shared decision making power. Patient- and public directed happens when research users have actively decision making power over the research process and can occur when research users are co-investigators and/or member of a steering committee. \* These articles were included because the authors reflected on their research user engagement processes and discussed a collaborative research activity. In their reflection process, the authors described that their research user engagement activities so far were ‘consultation-based’, but that they intended a collaborative approach in the continuation of the project.

**Appendix 8:** Comparing partnership principles from current scoping review with other literature

Comparing partnership principles with findings from Hoekstra et al.’s review of review

We identified three key differences in identified partnership principles. First, in contrast to the review of reviews, we did not identify principles related to the ethical issues of conducting and/or disseminating research in partnership with research users. As the ethics of conducting research in partnership with research users can be challenging (e.g., ethical boards have no experiences with partnered approaches or participants are also partners), future research should focus on tools and resources to support researchers, research users and research ethics board on how to address these ethical challenges/issues related to the partnered approach (5-7). Second, in the current scoping review we did not identify principles specifically on social justice. This might be explained by the narrow focus of this scoping review (i.e., health research partnerships related to specific disabilities) in comparison with the review of reviews (i.e., research partnership across all areas and all populations). It is possible that principles related to social justice would be more common in research related to broader groups of populations (e.g., people with disabilities) or other research domains (e.g., social sciences). Third, while the meaning of the overarching principles from the current scoping review overlaps with almost all overarching principles of the review of reviews, the wording of these overarching principles differs. These differences reflect the subjective nature of the extraction and synthesizing process of the partnership principles (i.e., the results reflect our perspective of the literature). As different teams may have different preferences for specific wording, we encourage researchers and research users who want to adopt certain principles to operationalize them with their team before using them as principles to guide their partnerships.

Comparing partnership principles with generally accepted Principles of Community Engagement by Clinical and Translational Science Awards Consortium

The principles of community engagement developed by Clinical and Translational Science Awards Consortium (8) are for many researchers in the United States a guide to support research partnerships. The document outlines nine principles that could be applied in a variety of partnerships and contexts and are considered to be essential to the success of community-engaged health promotion and research. We identified three key differences in the partnership principles between the principles outlined in our scoping review and the principles of the community engagement (8). First, the principles of community engagement do not explicitly refer to the research process. This is in contrast to some of the overarching principles described in our scoping review (e.g. Research users should be involved in any phases of the research process; Undertake research relevant to research users with lived experience). This difference may be explained by the fact that the principles of community engagement are not limited to research partnerships and could be applied in other partnerships and settings and contexts. Second, the principles of community engagement have a strong focus on improving health and creating change, in contrast to the principles outlined in our scoping review. This difference may be explained by the difference in scope of the principles outlined in our review and the scope of the principles of community engagement (scope of our review: is research partnerships in health research about SCI and other related conditions vs scope of community engagement partnerships more broadly to improve health and creating change). Third, the principles of community engagement are organized into three sections: 1) items to consider prior to beginning engagement, 2) what is necessary for engagement to occur, and 3) what to consider for engagement to be successful. This organization structure differs from the processes outlined in Table 3 of our scoping review (e.g. relationships, co-production of knowledge). Despite the differences in focus of the principles (community engagement in various populations/settings) and differences in how the principles are worded and organized, the general meaning of the nine principles of community engagement overlap with the meaning of the overarching principles described in the current scoping review. We did not identify principles that were unique for research partnership related to SCI or other disabilities. The uniqueness of the findings from our current scoping review compared to the principles of community engagement is the clear distinction in our findings between partnership principles (norms and values) and strategies (observable actions).

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