



BMJ Open What are the respiratory health research priorities in Alberta, Canada? A stakeholder consultation

Heather Sharpe ¹, Lisa Cerato,² Darlene Derech,² Lisa Guirguis,³ Kathleen Hayward,² Tara Lohmann,⁴ Joanna E MacLean,⁵ Elizabeth Manafo,⁶ Janice Paskey,² Jananee Rasiah ⁷, Mark Rimkus,² Syeda Kinza Rizvi,² Gerry Robinson,² Brent Seefried,² Zeeyaan Somani,² Mindy Tindall,² Harissios Vliagoftis,¹ Sachin R Pendharkar,⁴ Michael K Stickland,^{1,2} On behalf of the Steering Committee

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For numbered affiliations see end of article.

Correspondence to
Dr Heather Sharpe;
hsharpe@ualberta.ca

ABSTRACT

Objective The Respiratory Health Strategic Clinical Network (RHSCN) was launched to facilitate respiratory and sleep health through implementation of innovative, patient-centred, evidence-informed coordinated services in Alberta. In collaboration with project partners, the RHSCN aimed to determine the respiratory research priorities for Alberta.

Design The four phases of this research prioritisation project were (1) identifying research questions from stakeholders, (2) determining which research questions had been answered in existing literature, (3) prioritising unanswered questions and (4) finalising the priorities through an inperson workshop.

Setting The study occurred in Alberta, Canada over a 2-year period beginning in March 2017.

Participants A total of 448 patients, clinicians and other stakeholders consented to participate in the survey.

Results A total of 595 possible questions were submitted, with 343 unique questions identified. Of the questions, 94 were out of scope, 155 answered by existing literature and 10 were combined with others, while 83 were determined to be unanswered in the literature. Stakeholders were surveyed again to prioritise the remaining 83 questions and they were reviewed by the project's Steering Committee (clinicians and patients). At the inperson workshop, the Steering Committee identified 17 research topics as priority areas for respiratory and sleep research in Alberta.

Conclusion A stakeholder-led research prioritisation process identified optimal clinical management/follow-up, equitable access to services, and management of social, psychological and mental health issues related to respiratory/sleep health as priority research areas.

INTRODUCTION

In Alberta, respiratory disease is a prevalent, costly burden on the healthcare system. It is estimated that chronic obstructive pulmonary disease (COPD) costs the province over \$250 million per year,¹ while asthma leads to missed days at school, frequent healthcare

STRENGTHS AND LIMITATIONS OF THIS STUDY

- ⇒ Patients, caregivers, clinicians and researchers identified respiratory and sleep health research priorities to assist in determining how research funding/support would be allocated and to subsequently inform stakeholders of the chosen priorities.
- ⇒ A four-phase approach was used: (1) identifying research questions from stakeholders, (2) determining which research questions had been answered in existing literature, (3) prioritising unanswered questions and (4) finalising the priorities through an inperson workshop.
- ⇒ Methodological limitations of the study include challenges associated with an online survey, such as readability, using convenience sampling, possibility of selection and motivation bias, and inability to measure sampling error, all of which may have impacted the generalisability of study results.
- ⇒ Additionally, we anticipate that respiratory research priorities may have shifted since the COVID-19 pandemic.

utilisation and negative impacts on quality of life.²⁻⁴ Obstructive sleep apnoea (OSA) is likely underdiagnosed in Canada⁵ and may lead to reduced quality of life, workplace and vehicular accidents, and decreased work productivity.⁶⁻¹⁰ In early 2014, the Respiratory Health Strategic Clinical Network (RHSCN) was launched by Alberta Health Services (the provincial health authority) to address the many challenges associated with respiratory and sleep disorders with the aim to facilitate optimal respiratory health through implementation of innovative, patient-centred, evidence-informed and coordinated services in the province of Alberta.¹¹ The RHSCN supports all respiratory-related conditions, with priority areas being asthma, COPD and sleep-disordered breathing. The RHSCN

consists of a core committee which guides the overall direction of the Network, as well as several working groups that undertake specific projects to support the provision of evidence-based respiratory healthcare within Alberta Health Services through quality improvement initiatives, development of clinical practice guidelines and implementation of innovative interventions. The scientific office within the RHSCN facilitates clinical research through funding and research support to promote clinical respiratory research, uptake of best evidence, building research capacity in the province and directing the Network's research priorities.

Historically, research agendas were dictated by the scientific community; however, there is a growing recognition that patients, caregivers and clinicians should be engaged in identifying research priorities.¹² Increasingly in Canada there have been several research prioritisation activities that used a patient-oriented approach.^{13–15} The James Lind Alliance (JLA) suggests that patients, caregivers and clinicians work together to identify treatment uncertainties related to specific conditions and prioritise those they collectively agree to be most important.¹⁶ Using a modified JLA approach, the purpose of this project was to engage patient, caregiver, clinician and researcher stakeholders to identify the respiratory research priorities that would assist the RHSCN scientific office in determining how research funding/support would be allocated and to subsequently inform stakeholders of the chosen priorities.

METHODS

Steering Committee development

The project was conducted from March 2017 to February 2019. Project oversight was performed by a Steering Committee. Patient engagement professionals from Alberta Health Services and Alberta Strategy for Patient-Oriented Research Support for People and Patient-Oriented Research and Trials Unit helped to identify patients/caregivers who might be interested in Steering Committee membership. Patients and caregivers met with the project lead (HS) by phone to discuss the scope of the project and the required commitment. Steering Committee members were not compensated beyond travel expenses. The Steering Committee comprised four individuals with personal experience, two caregivers, four respiratory physicians (broadly representing clinicians from paediatrics, sleep medicine, asthma/allergy and COPD), two respiratory therapists, two pharmacists, one nurse and the Scientific Director of the RHSCN; within the group there was representation from academic and community-based clinicians. We did not request Steering Committee members to disclose personal information related to dimensions of diversity; however, the group acknowledged the importance of broad representation and felt the group was generally representative, while respecting the privacy of the team members.

Priority setting process

The initial inperson meeting of the Steering Committee provided an opportunity to introduce the project, discuss examples of similar work from other groups¹⁴ and review the process of priority setting. As the RHSCN addresses both respiratory and sleep health concerns, both topics were included in the priority setting and deemed equally important.

The Steering Committee chose to follow a modified JLA priority setting partnership method, as described by the Alberta Depression Research Priority Setting Project.¹⁴ This approach was selected as it had demonstrated feasibility, rigour and significant patient/caregiver engagement.¹⁷ The adopted process was similar to the JLA method; however, the voices of individuals with personal experience participated throughout (without the funnel approach, whereby the number of participants is reduced at each phase) with an egalitarian, consensus-building strategy within the Steering Committee.¹³ The four-phase process included (1) identifying potential research questions by stakeholders, (2) determining research questions that had been answered, (3) prioritising unanswered questions and (4) finalising the priority list at an inperson workshop.

Participant recruitment

Study participants included individuals who participated in the online surveys designed to elicit their research priorities. We distributed the survey using posters, cards with QR (quick response) codes and survey links (respiratory and sleep clinics in the province (both adult and paediatric), healthcare professional respiratory special interest groups, social media platforms, and patient advocacy and support groups). Participants were asked to share the survey link widely. The RHSCN further shared the survey links through provincial respiratory/sleep newsletters and email communications to members. The survey aimed to include three groups: (1) individuals with personal experience of respiratory disease or sleep disorders, (2) caregivers of individuals with respiratory disease or sleep disorders, and (3) healthcare providers to individuals with respiratory disease or sleep disorders. Participants self-identified to which group(s) they belonged via the survey. Participants were not directly reimbursed but were offered to enter a draw for a gift card prize for participation.

Patient and public involvement

This project was co-led by patient/caregiver team members of the Steering Committee. Every phase of the methodology included patient/caregiver involvement as they were equal members and active decision makers. Patients and caregivers were involved in the study design, implementation, data analysis and manuscript preparation (including authorship). Additionally, knowledge translation activities will include working with patient/family groups to disseminate the research prioritisation questions.

Data analysis

Phase 1: identify potential research questions by stakeholders

To obtain broad input of potential research questions, the Steering Committee designed an initial survey asking two open-ended questions:

- ▶ What questions do you have about breathing problems?
- ▶ What questions do you have about sleep problems?

Participants were provided with the rationale and context for the survey, information about how the data would be used and contact information for seeking further information, and were asked to provide their consent (by clicking a consent box on the online survey) to participate and use their responses for the study. They were invited to answer one or both questions. They were also asked optional questions including gender and age group. The survey was designed to take less than 10 min to complete and was first reviewed/tested by members of the Steering Committee with personal experience with respiratory health or sleep concerns. The survey was completed online over a 2-month period (Winter 2017) using the Research Electronic Data Capture (REDCap) online platform, hosted by the University of Calgary. REDCap is a secure, web-based software platform designed to support data capture for research studies.^{18 19} Incomplete surveys (those without submitted questions) were excluded from the analysis.

Phase 2: determine research questions that had been answered

Online supplemental material 1 provides a detailed summary of the process used to identify whether the submitted questions had already been answered in the literature. In brief, research questions that were submitted by the participants via the survey in phase 1 were reviewed by two members of the team. Duplicate questions were removed and similar questions were collated. Questions were reframed where necessary to ensure they identified the patient population, intervention, control and outcome where possible. For each question topic, the following databases were searched for relevant, up-to-date systematic reviews, clinical practice guidelines and/or study protocols (ie, studies in process) that addressed the specific research question:

- ▶ Cochrane Database of Systematic Reviews (Evidence Based Medicine (EBM) Reviews).
- ▶ American College of Physicians Journal Club via Medline (Ovid).
- ▶ Database of Abstracts of Reviews of Effects via Medline (Ovid).
- ▶ Medline databases (Ovid).
- ▶ Canadian Respiratory Guidelines (Canadian Thoracic Society).
- ▶ Global Initiative for Asthma.
- ▶ American Academy of Family Physicians (AAFP) (USA).
- ▶ National Institute for Health and Care Excellence (NICE) guidelines (UK).

Research questions were defined as answered if we were able to provide a summary conclusion addressing the question and citation for the reference. Questions that were determined not to be adequately answered in the literature (ie, the topic was not addressed by the above sources) were included in the list of unanswered questions to move forward to phase 3, while questions confirmed to have been already answered did not move forward to phase 3. Although policy and knowledge translation questions were initially considered out of scope, they were provided to the Steering Committee in a separate list for their consideration in phase 3. This was done at the request of the Steering Committee as the group felt that knowledge translation and policy questions may have significant relevance to the work of the RHSCN.

Phase 3: prioritisation of unanswered questions

The final list of unanswered questions was divided into two categories: (1) questions relating to breathing problems and (2) questions relating to sleep problems. Participants in phase 1 were contacted again and asked to select their top 10 priorities from one or both categories via a new REDCap survey (Spring 2018). Data from this survey were used to inform the Steering Committee's discussion during the final workshop.

Phase 4: final inperson priority setting workshop

The Steering Committee participated in an inperson workshop, with additional participation by health professional groups and patient/caregivers that were under-represented, such as pharmacy and parents/guardians, with a total of 11 participants. The workshop was led by a trained facilitator with experience working with the Strategic Clinical Network and an understanding of Alberta's healthcare system. The workshop included an overview of the results of the two surveys and the RHSCN scope and work. Following a discussion of the results, the Steering Committee participants split into two groups to prioritise the existing sleep research questions and respiratory research questions. The two groups then worked collectively to compare priority rankings and remove questions that were deemed as low priority by both groups. The Steering Committee mutually discussed the remaining questions and subsequently conducted a second round of prioritisation as one group, again removing low priority questions. The final list of questions was determined through group consensus and included combining some questions when appropriate and refining wording.

During the workshop, participants made the following key decisions to guide the work:

- ▶ The list should not be guided by an arbitrary number (eg, top 10); rather, the most important questions should be included in the list.
- ▶ Several 'out of scope' questions were important and should not be dismissed without consideration, despite this approach being atypical from research prioritisation methods.

Table 1 Survey participants' demographic characteristics

Characteristics	Total respondents, n (%) (N=448)
Do you prefer to answer questions related to breathing problems, sleep problems or both? (n=409)	
Breathing problems	81 (19.8)
Sleep problems	123 (30.1)
Both (breathing and sleep problems)	205 (50.1)
Category, may choose more than one (n=446)	
Person with breathing problems	132 (29.6)
Person with sleep problems	185 (41.5)
Family/caregiver of person with breathing problems	90 (20.2)
Family/caregiver of person with sleep problems	117 (26.2)
Healthcare professional: breathing problems	148 (33.2)
Healthcare professional: sleep problems	128 (28.7)
Other (dentist, scientist, patient with comorbidities)	11 (2.5)
Gender (n=446)	
Female	347 (77.8)
Male	86 (19.3)
Non-binary	5 (1.1)
Prefer not to respond/did not respond	8 (1.8)
Age (years)	
≤17	1 (0.2)
18–29	44 (9.9)
30–49	116 (26.0)
50–79	197 (44.2)
≥80	4 (0.9)
Did not respond	4 (0.9)

- The significant overlap between respiratory and sleep health created redundancies in two lists, and a hybrid approach was developed.

RESULTS

We received 461 responses to the first survey (table 1). Responses from 13 participants were removed as they did not clearly provide consent, leaving a total of 448 survey responses. The survey methods were successful at gaining broad representation from the three core groups: 317 participants stated they were an individual with personal experience with respiratory disease/patient (71.1%), 207 stated they were a caregiver of an individual with respiratory disease (46.4%), and 276 stated they were a healthcare professional who provided care for individuals with respiratory disease (61.9%). Of note, many respondents selected more than one category with which they identified. See table 1 for participants' characteristics.

A total of 595 research questions were submitted. Two data scientists reviewed the questions for redundancy, leaving 343 unique questions. Of the remaining questions, 66 were determined to be answered in the existing literature, while 94 were judged to be out of scope (policy and cost-related questions). Of the 183 research questions

remaining, 2 questions were deemed not to be research questions, 89 were mapped to evidence and identified as answered, while 92 were identified as unanswered and remained in the list of unanswered questions for consideration. The Steering Committee determined that of the 92 questions, 3 were answered in the literature, 1 was determined to be out of scope and 5 were combined with other questions or deemed not to be research questions, leaving 83 possible research questions. Table 2 provides an overview of the mapping of the final research questions and answered questions by category.

In the second survey, 140 stakeholders participated to rank the remaining questions. The inperson workshop allowed the Steering Committee to review the remaining questions collectively and identify 17 final priority areas for respiratory and sleep research in Alberta. The final list included six questions for sleep health, three questions for respiratory health and eight questions that were applicable to both sleep and respiratory health (see box 1).

DISCUSSION

The RHSCN research prioritisation process identified 17 priorities for respiratory and sleep health, integrating

Table 2 Submitted research questions by topic reviewed and finalised by the Steering Committee

Total	Total questions	Answered in the literature	Remaining research questions
Asthma	33	20	13
Combustibles*	4	1	3
COPD	3	2	1
Devices	13	4	9
Diagnostic	7	4	3
General medicine	14	11	3
ILD‡	9	4	5
Nasal	4	3	1
OSA	25	19	6
Sleep	35	17	18
Other	25	4	21
Cost and policy†	0	0	0
Total	172	89	83

*Combustibles included cigarette smoking, vaping and cannabis, as well as secondary effects from these products.

†Cost and policy questions were deemed out of scope and represented in the out-of-scope data.

‡ILD refers to interstitial lung disease

COPD, chronic obstructive pulmonary disease; OSA, obstructive sleep apnoea.

the perspectives of patients/caregivers and clinicians/researchers. These priorities included equitable access to health services, the economic impact of respiratory and sleep conditions, community-based management (such as referrals, self-management, when to seek medical care), and disease diagnosis, control and management (box 1). This research is novel as it was co-owned and codeveloped by patient/caregivers and clinicians/researchers, and is the first Canadian research prioritisation project that aimed to address both respiratory and sleep health. This prioritisation will assist with decision making for the RHSCN related to allocation of resources and Network priorities.

Including individuals with personal experience as co-owners in research increases legitimacy and opportunity for innovation.²⁰ Additionally, researchers have moral and ethical responsibilities to ensure that the voice of patients and families is represented in research priorities.²¹ A strength of this research is the high participation of patients and caregivers in the process, which is reflected in the nature of the research questions prioritised. As suggested by Breault and colleagues,¹⁴ the higher the level of participation from individuals with lived experiences (and their caregivers), the more closely a research prioritisation list will reflect the true priorities of the community. The questions identified in this study had a strong focus on policy, equitable access to services, and management of social, psychological and mental health

Box 1 List of final research questions

Questions for respiratory and sleep

- ⇒ What is the relationship between social, psychological and mental health issues and respiratory disease/sleep disorders for the individual/family?
- ⇒ What is the economic impact of respiratory disease/sleep disorders for community and inpatient/urgent care in Alberta?
- ⇒ For individuals with suspected respiratory disease/sleep disorders, when is it appropriate for a primary care provider to refer to a specialist, compared with continuing care, to ensure the best treatment/health outcomes? What are the educational needs of primary care providers to facilitate this?
- ⇒ What model of care is most effective at transitioning patients and their families from paediatric to adult respiratory/sleep care?
- ⇒ For individuals living with respiratory disease/sleep disorders, what are the most effective self-management interventions and/or community support/resources?
- ⇒ What strategies will improve equitable access to respiratory/sleep care for Albertans?
- ⇒ What are the patient and families' priorities related to the treatment of their breathing/sleep problems?
- ⇒ For individuals with respiratory/sleep problems, which interventions, resources and programmes in the community will result in fewer specialty care, emergency department or hospital visits?

Questions for respiratory

- ⇒ How can we improve access to pulmonary rehabilitation for individuals with respiratory disease?
- ⇒ For individuals with respiratory disease, how do environmental factors (humidity, air pollution, etc) impact disease control/management in Alberta?
- ⇒ How does an individual with respiratory disease determine if different therapies will be worth the additional cost (money, risk of side effects, exacerbations)?

Questions for sleep

- ⇒ For individuals with suspected sleep-related breathing disorders (eg, obstructive sleep apnoea), what is the recommended ongoing clinical management/follow-up care to improve and sustain health outcomes?
- ⇒ Do treatments besides continuous positive airway pressure (CPAP) improve outcomes for individuals with sleep-related breathing disorders (eg, obstructive sleep apnoea and/or hypoventilation)?
- ⇒ What is the current quality of provision and interpretation of investigations for sleep-related breathing disorders in Alberta?
- ⇒ What strategies can be used to promote sleep as an important contributor to health?
- ⇒ For individuals experiencing poor quality sleep, at what point should they seek medical advice to improve health outcomes?
- ⇒ What are the policy factors that inform insurable coverage for testing and treatment of sleep-related breathing disorders in Alberta?

issues related to respiratory/sleep health. Over two-thirds of survey respondents indicated they were patients, and almost half stated they were caregivers of someone with a respiratory or sleep problem (note: individuals could select more than one role).

Respiratory-specific research prioritisation has also increased in prominence. In the Netherlands, patient focus groups and questionnaires were used to identify research priorities for asthma and COPD.²² Two significant priorities



that arose were knowledge about the causes of the diseases and development of more effective medications, with little emphasis on sociopolitical factors that impact healthcare. In contrast, our priorities for respiratory/sleep health research had a strong emphasis on social, economic and healthcare access issues. This variance may be the result of the autonomy of the Steering Committee, who made modifications to the proposed structure and inclusion criteria of the priorities by including out-of-scope policy and economic questions in the final review, or a reflection of shifting priorities over time, and the nature of the RHSCN being focused on health service delivery, rather than translational/clinical research.

Other targeted respiratory research prioritisation activities identified some priorities with similar themes to this research. A formal JLA on asthma was previously conducted in the UK.²³ Our recent work is consistent with their JLA which identified the importance of managing adolescent and young adult care as an important priority, as well as identifying effective self-management interventions. Additional research has identified nursing-related respiratory research priorities through modified Delphi approaches.²⁴ This work determined patient understanding of asthma control and the clinical and cost-effectiveness of respiratory nurse interventions as the most prominent research priorities.²⁴ While these priorities were nursing-specific, consistent with the current work, cost/economic impact was highlighted as an important priority. A separate modified Delphi was conducted in critical care, adult pulmonary and sleep conditions across 45 countries to identify nursing research priorities to inform research and advise funding agencies.²⁵ This extensive project resulted in research priorities focused on four broad areas: communication, education, risk reduction and psychological support.²⁵ Similar to this previous work, our project identified psychological factors that impact respiratory disease/sleep disorders and self-management support (such as education) as important priorities.

In 2015, the American Thoracic Society released a statement on the importance of sleep health and included research priorities.²⁶ This document highlighted the importance of conducting research linking sleep quality and health outcomes.²⁶ This priority, developed by international sleep medicine leaders, is consistent with the research priority identified by our process (What strategies can be used to promote sleep as an important contributor to health?). A JLA initiative was recently completed in Saskatchewan, Canada to assess the research priorities for sleep apnoea.²⁷ Alignment with our work shows common priorities related to equitable access, follow-up care/re-evaluation and additional therapies (beyond continuous positive airway pressure (CPAP)) for OSA treatment.²⁷ Recent work in Quebec, Canada surveyed 148 patients with COPD to develop a health and healthcare research agenda for COPD. This work identified that relief of breathlessness was a research and healthcare priority for patients.²⁰ While management of breathlessness was not specifically identified within the current prioritisation process, we did identify self-management

and community support/resources as a research priority (For individuals living with respiratory disease/sleep disorders, what are the most effective self-management interventions and/or community support/resources?). Research prioritisation activities have increased in recent years and similarities with our work are demonstrated; however, this research is important as it was developed by stakeholders from across the healthcare system with a focus on driving the local respiratory and sleep research agenda.

Limitations

There are limitations to consider related to this research. First, an online survey platform was convenient, cost-effective and timely; however, it may have prevented some individuals from participating in the research. Second, as participants self-selected their participation, our results may be influenced by motivation bias, selection bias and participant sampling error. We did not undertake specific approaches to target Indigenous populations and caregivers, those with a primary language other than English, nor those with limited internet access. It is important to note that the study sample was predominantly women. These limitations of sampling methodology may limit the generalisability of study findings. In future research, we would advocate for requesting ethnicity/race information from participants and using this information to guide purposeful recruitment of participants. As well, we would suggest developing a targeted strategy for ensuring representation from those without internet access and ensuring key populations are included.

Third, the time commitment for participating as a Steering Committee member was substantial. Members attended two full-day inperson meetings and approximately 6 hours of telephone meetings, plus numerous emails/material reviews over the course of 18 months. The participation level of the patient/caregiver steering committee demonstrated strong commitment; however, future groups may consider additional strategies, such as role-sharing, to decrease volunteer fatigue. Also, these members were identified specifically for participation in this work, which may have resulted in additional selection bias. Fourth, this research focused on the province of Alberta, and while the results may be broadly translatable, generalisability may be limited. However, prioritisation activities driven by local stakeholders are important to providing research priorities of value to the local community. Finally, given the data for this study were collected over 2017–2019, there may be changes in respiratory research priorities following the COVID-19 pandemic.

CONCLUSION

By involving individuals with personal experience with respiratory disease, caregivers and healthcare professionals, a research priority list comprising six questions

for sleep health, three questions for respiratory health and eight questions that were applicable to both sleep and respiratory health was developed. Broadly, this research was novel as the research priorities demonstrated an increased focus on issues such as equitable access, economic impact and community disease management (including resource allocation and self-management support). This research exercise will lead to a more focused distribution of research funds and other resources locally and will inform other groups as they look to support research that is more relevant to patients.

Author affiliations

- ¹Medicine, University of Alberta, Edmonton, Alberta, Canada
²Alberta Health Services, Edmonton, Alberta, Canada
³Faculty of Pharmacy, University of Alberta, Edmonton, Alberta, Canada
⁴Medicine, University of Calgary, Calgary, Alberta, Canada
⁵Pediatrics, University of Alberta, Edmonton, Alberta, Canada
⁶Independent Consultant, Toronto, Ontario, Canada
⁷Faculty of Nursing and College of Health Sciences, University of Alberta, Edmonton, Alberta, Canada

Twitter Jananee Rasiah @JananeeRasiah

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Contributors As this work was co-owned and developed in collaboration with patient/caregiver advisors, all members of the Steering Committee were responsible for study design and interpretation of results. All authors have given permission for the submission of the manuscript and have agreed to be listed as coauthors. HS led the Steering Committee (SC) through the study design process, data collection and analysis, was responsible for drafting the manuscript and editing, is the corresponding author, and the guarantor for this study. LC facilitated the final workshop to the creation of the final prioritisation list and provided feedback on the manuscript. DD, JP, SKR, GR, ZS and MT are patient/caregiver advisors who are members of the SC, were involved in study design, data collection and analysis, and final research prioritisation, and were responsible for providing feedback on the manuscript. LG, KH, TL, JEM, SRP, JR, MR, BS and HV are health professionals/academic representatives of the SC, were involved in study design, data collection and analysis, and final research prioritisation, and were responsible for providing feedback on the manuscript. EM determined if the submitted research questions were answered in the existing literature, was responsible for methodology and reporting, and provided feedback on the manuscript. MKS is the Scientific Director of the RHSCN, was involved in study design, data collection and analysis, and final research prioritisation, and was responsible for providing feedback on the manuscript.

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ORCID iDs

Heather Sharpe <http://orcid.org/0000-0002-5223-5085>
 Jananee Rasiah <http://orcid.org/0000-0002-2987-1200>

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