



Identifying priorities and developing strategies for building capacity in amputation research in Canada

Sander L. Hitzig, Amanda L. Mayo, Ahmed Kayssi, Ricardo Viana, Crystal MacKay, Michael Devlin, Steven Dilkas, Aristotle Domingo, Jacqueline S. Hebert, William C. Miller, Jan Andrysek, Fae Azhari, Heather L. Baltzer, Charles de Mestral, Douglas K. Dittmer, Nancy L. Dudek, Sharon Grad, Sara J. T. Guilcher, Natalie Habra, Susan W. Hunter, W. Shane Journeay, Joel Katz, Sheena King, Michael W. Payne, Heather A. Underwood, José Zariffa, Andrea Aternali, Samantha L. Atkinson, Stephanie G. Brooks, Stephanie R. Cimino & Jorge Rios

To cite this article: Sander L. Hitzig, Amanda L. Mayo, Ahmed Kayssi, Ricardo Viana, Crystal MacKay, Michael Devlin, Steven Dilkas, Aristotle Domingo, Jacqueline S. Hebert, William C. Miller, Jan Andrysek, Fae Azhari, Heather L. Baltzer, Charles de Mestral, Douglas K. Dittmer, Nancy L. Dudek, Sharon Grad, Sara J. T. Guilcher, Natalie Habra, Susan W. Hunter, W. Shane Journeay, Joel Katz, Sheena King, Michael W. Payne, Heather A. Underwood, José Zariffa, Andrea Aternali, Samantha L. Atkinson, Stephanie G. Brooks, Stephanie R. Cimino & Jorge Rios (2021) Identifying priorities and developing strategies for building capacity in amputation research in Canada, *Disability and Rehabilitation*, 43:19, 2779-2789, DOI: [10.1080/09638288.2020.1720831](https://doi.org/10.1080/09638288.2020.1720831)

To link to this article: <https://doi.org/10.1080/09638288.2020.1720831>



Published online: 08 Feb 2020.



Submit your article to this journal [↗](#)



Article views: 522



View related articles [↗](#)












View Crossmark data [↗](#)

RESEARCH PAPER



Identifying priorities and developing strategies for building capacity in amputation research in Canada

Sander L. Hitzig^a , Amanda L. Mayo^b , Ahmed Kayssi^c, Ricardo Viana^d, Crystal MacKay^e, Michael Devlin^e, Steven Dilkas^e , Aristotle Domingo^f, Jacqueline S. Hebert^g , William C. Miller^h, Jan Andrysekⁱ, Fae Azhari^j, Heather L. Baltzer^k, Charles de Mestral^l, Douglas K. Dittmer^m, Nancy L. Dudekⁿ, Sharon Grad^o, Sara J. T. Guilcher^p , Natalie Habra^q, Susan W. Hunter^r , W. Shane Journeay^s , Joel Katz^t , Sheena King^u, Michael W. Payne^d, Heather A. Underwood^v, José Zariffa^w , Andrea Aternali^t, Samantha L. Atkinson^a, Stephanie G. Brooks^a, Stephanie R. Cimino^a and Jorge Rios^a

^aSt. John's Rehab Research Program, Sunnybrook Research Institute, Sunnybrook Health Sciences Centre, Toronto, Canada; ^bPhysical Medicine and Rehabilitation, St. John's Rehab Hospital, Sunnybrook Health Sciences Centre, Toronto, Canada; ^cDivision of Vascular Surgery, Sunnybrook Health Sciences Centre, Toronto, Canada; ^dDepartment of Physical Medicine & Rehabilitation, Schulich School of Medicine & Dentistry, Western University, London, Canada; ^eWest Park Healthcare Centre, Toronto, Canada; ^fAmputee Coalition of Toronto, Toronto, Canada; ^gDepartment of Medicine, Faculty of Medicine and Dentistry, Division of Physical Medicine and Rehabilitation, University of Alberta, Edmonton, Canada; ^hDepartment of Occupational Science and Occupational Therapy, Faculty of Medicine, University of British Columbia, Vancouver, Canada; ⁱHolland Bloorview Kids Rehabilitation Hospital, Bloorview Research Institute, Toronto, Canada; ^jDepartment of Mechanical and Industrial Engineering, University of Toronto, Toronto, Canada; ^kDivision of Plastic and Reconstructive Surgery, Faculty of Medicine, University of Toronto, Toronto, Canada; ^lSt. Michael's Hospital, Li Ka Shing Knowledge Institute, Toronto, Canada; ^mPhysical Medicine & Rehabilitation, Grand River Hospital, Kitchener, Canada; ⁿDivision of Physical Medicine and Rehabilitation, University of Ottawa, Ottawa, Canada; ^oDepartment of Physical Medicine and Rehabilitation, Hamilton Health Sciences, McMaster University, Hamilton, Canada; ^pLeslie Dan Faculty of Pharmacy, University of Toronto, Toronto, Canada; ^qDivision of Physical Medicine and Rehabilitation, Gingras-Lindsay Montreal Rehabilitation Institute, University of Montreal, Montreal, Canada; ^rSchool of Physical Therapy, Western University, London, Canada; ^sProvidence Healthcare, Unity Health Toronto, Toronto, Canada; ^tDepartment of Psychology, Faculty of Health, York University, Toronto, Canada; ^uG.F. Strong Rehabilitation Centre, Vancouver, Canada; ^vDivision of Physical Medicine and Rehabilitation, University of British Columbia, Vancouver, Canada; ^wKITE, Toronto Rehabilitation Institute, University Health Network, Toronto, Canada

ABSTRACT

Background: Compared to other patient population groups, the field of amputation research in Canada lacks cohesion largely due to limited funding sources, lack of connection among research scientists, and loose ties among geographically dispersed healthcare centres, research institutes and advocacy groups. As a result, advances in clinical care are hampered and ultimately negatively influence outcomes of persons living with limb loss.

Objective: To stimulate a national strategy on advancing amputation research in Canada, a consensus-workshop was organized with an expert panel of stakeholders to identify key research priorities and potential strategies to build researcher and funding capacity in the field.

Methods: A modified Delphi approach was used to gain consensus on identifying and selecting an initial set of priorities for building research capacity in the field of amputation. This included an anonymous pre-meeting survey ($N=31$ respondents) followed by an in-person consensus-workshop meeting that hosted 38 stakeholders (researchers, physiatrists, surgeons, prosthetists, occupational and physical therapists, community advocates, and people with limb loss).

Results: The top three identified research priorities were: (1) developing a national dataset; (2) obtaining health economic data to illustrate the burden of amputation to the healthcare system and to patients; and (3) improving strategies related to outcome measurement in patients with limb loss (e.g. identifying, validating, and/or developing outcome measures). Strategies for moving these priorities into action were also developed.

Conclusions: The consensus-workshop provided an initial roadmap for limb loss research in Canada, and the event served as an important catalyst for stakeholders to initiate collaborations for moving identified priorities into action. Given the increasing number of people undergoing an amputation, there needs to be a stronger Canadian collaborative approach to generate the necessary research to enhance evidence-based clinical care and policy decision-making.

► IMPLICATIONS FOR REHABILITATION

- Limb loss is a growing concern across North America, with lower-extremity amputations occurring due to complications arising from diabetes being a major cause.
- To advance knowledge about limb loss and to improve clinical care for this population, stronger connections are needed across the continuum of care (acute, rehabilitation, community) and across sectors (clinical, advocacy, industry and research).

ARTICLE HISTORY

Received 7 August 2019
Revised 20 January 2020
Accepted 21 January 2020

KEYWORDS

Amputation; Canada; capacity building; consensus workshop; interdisciplinary research; patient engagement

- There are new surgical techniques, technologies, and rehabilitation approaches being explored to improve the health, mobility and community participation of people with limb loss, but further research evidence is needed to demonstrate efficacy and to better integrate them into standard clinical care.

Introduction

Individuals who experience lower or upper limb loss face multiple challenges to their mobility, function, physical and mental health [1–4], and ability to participate in their community [5–7]; which can negatively influence quality of life (QoL) [8–10]. For instance, people with limb loss struggle with activities of daily living [11], and are at high risk for developing secondary complications, such as osteoarthritis (in the contralateral limb), osteopenia/osteoporosis in the residual limb (increasing the risk for fracture), low back pain, phantom limb pain, and psychosocial issues stemming from poor body image [12–15]. Causes for amputation include trauma (e.g. workplace accident, motor vehicle accident), dysvascular disease (due to complications from diabetes and/or peripheral vascular disease), infection, cancer, frostbite and congenital limb deficiencies.

Worldwide, limb loss is a growing concern, with diabetes-related lower extremity amputation (LEA) now a leading cause of the global burden of disability [16]. The most comprehensive review of the global epidemiology of limb loss and congenital limb deficiency was done in 2003 [17], which found great variation across countries in terms of LEA, with the lowest rates (all causes) observed in Okayama, Japan (2.0/10,000 persons) and the highest rates (major and minor) found in Native American Men in the Navajo Region of the United States (5.9/10,000, 9.9/10,000, respectively) [18]. Irrespective of age, race, ethnic origin, or nationality, the incidence of diabetes-related LEA was 2 to 3 times greater in men than women [17]. In the United States, there were 1.6 million persons with limb loss in the year 2005, with 38% of the amputations occurring due to complications associated with dysvascular disease with a comorbid diagnosis of diabetes mellitus [19]. Further, the rates of amputation in the United States are anticipated to double by the year 2050 [19].

Less is known about the epidemiology of upper-limb extremity limb loss. In terms of upper-limb congenital deficiencies, there is data showing the range to be between 3.5 per 10,000 births (including pregnancy terminations) [20] to 7.1 per 10,000 births [21], with major congenital deficiencies being significantly higher (12.9 per 10,000 births) [22]. With regard to traumatic etiologies, one study in Sweden found trauma-related upper-extremity amputations (UEA) to be 0.1 per 10,000 between 1976 and 1980 [23], and another Brazilian study from 2017 showing that major UEA (hands and fist; upper limbs) were approximately 5% or less of all limb loss cases between 2008 and 2015 (361,585 in total) [24]. Similarly, rates of UEA in the United States are lower than LEA, with major UEA estimated to be only 8% ($n = 41,000$) of all limb loss incidents in 2005 [19].

In Canada, data regarding the incidence and prevalence of all limb loss populations are incomplete. There has been an increased focus on obtaining epidemiological data regarding major LEA due to the increase in the prevalence of diabetes in the country [25], but this has overshadowed efforts on obtaining incidence and prevalence data on UEA. Recent Canadian national incidence data show that 44,430 LEA were performed between 2006 and 2012 (mean age 65.7 ± 16.6 years; 68.8% male), and that the majority (65%) were due to diabetes [26]. There were

differences in incidence rates across provinces, with Newfoundland and Labrador showing the highest LEA rates (37.9 per 100,000 individuals) compared to other provinces; while British Columbia and Québec had the lowest rates (19.6, and 20.1 per 100,000, respectively) [26], which might be due to their lower diabetes and obesity rates. In Ontario alone, there were an estimated 1,500 persons with diabetes who had a limb amputated in 2008; with 51% of those with a contralateral lower limb amputated within 5 years [27].

The mortality rates associated with dysvascular LEA are known to be extremely high, estimated at approximately 15% at 30 days post-amputation and nearly 30% by one year [28]. In Canada, there is some Ontario data also showing a high risk for death, with the incidence of death being 18.9 and 11.4 (adjusted hazard ratio 1.22, 95%, confidence interval 1.13–1.31) following major and minor ipsilateral LEA, respectively [29]. Furthermore, the LEA population has a high number of comorbidities and secondary health conditions, which can include cardiovascular disease, hypertension, renal disease, phantom limb pain, osteoarthritis, heterotopic ossification, anxiety and depression [15,30–33]. These conditions impact treatment outcomes and negatively affect health and wellbeing [15,30–33]. The high rates of comorbidities and mortality in the dysvascular LEA population are alarming, and there is a clear need to develop evidence-based approaches to minimize these adverse outcomes.

A preliminary scan of the rehabilitation literature produced by Canadian research centers shows there are numerous publications related to gait, mobility and prosthetics [34–40], with some data providing a national scope of available rehabilitation services and outcomes [41–43]. Less is known about post-amputation QoL and community participation outcomes, rehabilitation approaches, and impact on the healthcare system, with fewer Canadian studies encompassing these topics (e.g. [5–7,44]). Although not a uniquely Canadian issue, there is a need for valid amputation-related outcome measures across functional, psychological and social domains [45]. There are a few population-specific patient-reported outcome measures that assess QoL, but these are focused on narrow domains of wellbeing, such as prosthetic satisfaction (e.g. Trinity Amputation and Prosthesis Experience Scales [46]; Prosthetic Profile of the Amputee [47]) and body image (e.g. Amputee Body Image Scale [48]). Further, outcome measures are not used consistently across centers; hampering the ability for robust comparisons across Canadian limb loss care sites.

Despite the pockets of innovative and promising lines of research aimed at improving the physical, mental and social health of people with limb loss, the full potential of the Canadian field is not being realized partly because of a lack of dedicated funding agencies and national coordinating research organizations for limb loss. Other patient populations with chronic disabilities, such as spinal cord injury (SCI) and stroke, have several provincial, national and international research funding agencies, which can support preliminary pilot data; thereby contributing to higher success for obtaining highly competitive national sources of funding (e.g. Canadian Institutes of Health Research) available to fund long-term programs of research. For instance, SCI researchers can apply for funding from Canadian agencies such as

the Ontario Neurotrauma Foundation, Rick Hansen Institute, as well as international funders including the Paralyzed Veterans of America, Craig H. Nielsen Foundation, and the Wings for Life Spinal Cord Research Foundation, among others. In particular, funding from the Rick Hansen Institute supported researchers in Canada to obtain important data highlighting the economic burden of the lifetime costs associated with SCI (\$1.5 million CAD for people with paraplegia; \$3 million CAD for tetraplegia), and newly injured individuals cost the healthcare system approximately \$2.7 billion CAD per year [49]. These economic data in turn provides a convincing argument to fund studies and influence policies that can help with the recovery process and/or better manage the condition once people are discharged into the community. Similar to limb loss, SCI is a relatively infrequent event, with an incidence of approximately 3,500 new cases per year and a prevalence of approximately 86,000 people with traumatic and non-traumatic SCI living in Canada [50]. Hence, obtaining important insights on a population that hold healthcare and social system implications can help strengthen arguments for research funding.

Moreover, greater access to available funding specific to a patient population can promote excellence in research. A recent bibliometric examination of global SCI rehabilitation publications by Liu and colleagues [51] found that Canada ranked among the top three countries in the world for the highest SCI citations rates. Clearly, access to population-specific funding can serve as an important catalyst for attracting researchers to work in an area, and can have a substantial impact on the productivity and quality of research output; all of which can lead to more innovation and uptake by clinicians and decision-makers to advance care for a population [52].

The lack of funding sources for amputation-related research can be a disincentive to scientists to work in the field. Along with the geographic difficulties of supporting collaborations in a country as vast as Canada, there is a need to strengthen professional, academic and social ties among healthcare centres, research institutes, and community advocacy groups to build an organized coalition for research. Provincial and regional groups, such as the Ontario Association for Amputee Care (OAAC) and the Amputee Coalition of Toronto (ACT), and national organizations such as the Amputee Coalition of Canada, the International Society for Prosthetics and Orthotics (ISPO) Canada, and the War Amps have formed to help people with limb loss, but they primarily play an advocacy and educational role to enhance clinical standards and social care. Across these groups and among clinical centres across Canada, there lies great opportunity to build stronger ties and develop innovative lines of inquiry in this under-researched Canadian patient population. Realizing this opportunity requires a stronger level of infrastructure to raise awareness about amputation research across Canada and to help create opportunities for collaboration; and thereby improve research funding outcomes.

Recognizing the challenges of the amputation research landscape in Canada, our team aimed to identify an initial common set of priorities to build capacity in the field of amputation research, and to develop accompanying strategies to move these priorities into action *via* a consensus-building initiative. The outcomes of this initiative serve as a useful 'roadmap' to all Canadian limb loss stakeholders by providing a list of priority areas as an initial starting point to stimulate a national dialogue to advance amputation-related research. Further, the processes described in this article can be applied to other domains as it provides a useful model on how to organize and gain consensus on an emerging topic from a diverse group of expert stakeholders.

Methods

The processes that guided the initiative were informed by the Delphi Method, which is a "structured group communication method for soliciting expert opinion about complex problems or novel ideas, through a series of questionnaires and controlled feedback" [53]. Traditional Delphi studies do not have participants directly interact with one another and use anonymous sequential questionnaires to obtain consensus on the issue at hand [54,55]. However, we modified the approach to include an anonymous and non-anonymous component to obtain consensus from an expert panel on which priorities should be addressed to build capacity in research in limb loss and to strengthen relationships among stakeholders across Canada.

Figure 1 provides an overview of the Delphi process to identify and obtain consensus on research priorities, which included one anonymous round followed by two sequential non-anonymized rounds employed at an in-person consensus meeting workshop. At the consensus-workshop meeting, the first round was more divergent in nature where a broad list of potential research topics generated from the anonymous round were presented to the attendees to critically reflect upon, and provided them with an opportunity to add topics they felt were missing. The second round adopted a two-step convergent process to support the selection of the top priorities. To achieve consensus, our team preset an agreement rate of 80% from the meeting attendees on the top priorities. Overall, the design and steps described above have been previously applied by members of our team to successfully develop research agendas in other content areas [56,57].

Expert panel identification

A critical step in the Delphi process is the selection of an expert panel since the input provided by participating members will have a direct impact on the quality of the produced results [54,58]. A suggested approach for identifying participants is to make contacts with those who have firsthand knowledge with the issue at hand [58]. Given the breadth of research topics that could fall under the heading 'limb loss', our team sought to invite a heterogeneous group of stakeholders within the field. This included individuals with expertise in amputation at the clinical, research, policy and/or personal level (i.e. with lived experience).

Similar to previous approaches used by members of our team [56,57], an initial list of expert panel attendees were identified by relying on the core team's existing network [58], which was comprised of individuals who were conducting research, providing care and/or providing advocacy in amputation across the continuum of care (i.e. acute, rehabilitation, community), and included persons living with limb loss. As well, a preliminary scan of the Canadian literature in amputation was also undertaken to help identify potential participants [59]. Through a group discussion and subsequent follow-ups, a list of potential attendees was generated.

Pre-meeting survey and expert speakers

An important step towards achieving consensus is to provide the expert panel with sufficient context and information to move through the rounds in the Delphi approach [60]. To ensure that the expert panel would be sufficiently oriented to the goals of the initiative and to identify potential research priorities, an anonymous pre-meeting survey was first sent out to all attendees *via* an online-survey platform and were asked about their awareness of current research in limb loss across Canada, whether they

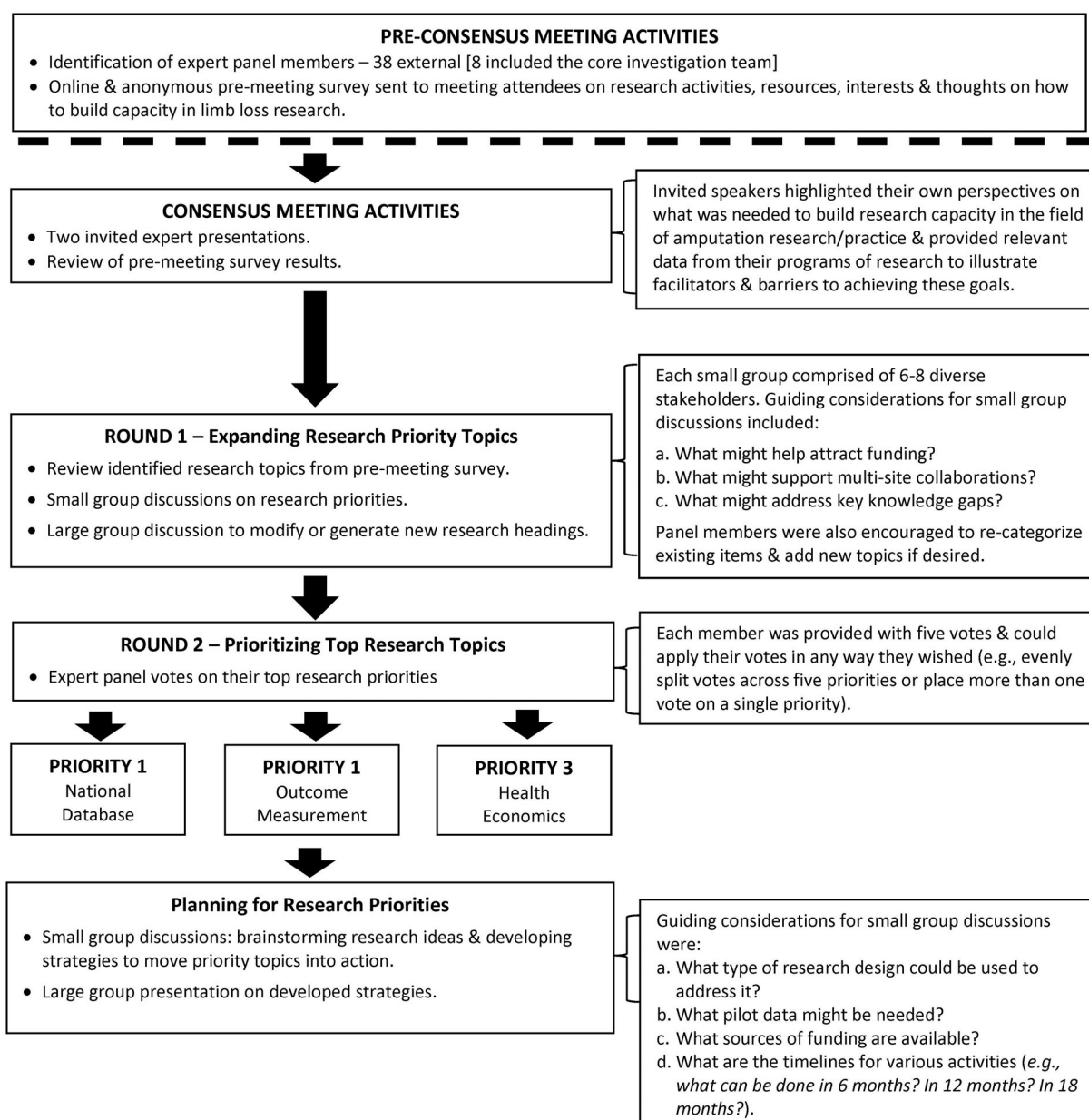


Figure 1. Modified Delphi approach and Consensus-workshop structure and processes for generating the top three amputation research priorities.

were participating in funded/unfunded lines of research, type of research being pursued (including level of institutional support), areas of interest, willingness to collaborate, and their thoughts on what was needed to build capacity in the field. Prior to the in-person meeting consensus-workshop, attendees were provided a report summarizing the intended objectives of the consensus-workshop, the pre-meeting survey results, and meeting attendee biosketches. Further, at the consensus-workshop, two expert key-note speakers were invited to present to help focus discussions at the subsequent Delphi rounds.

Results

Pre-meeting survey results

A total of 31 persons completed the pre-meeting survey, which included a relatively diverse group of stakeholders from the invited expert panel (see Table 1). In terms of their awareness of current amputation research across Canada, the sample reported a

moderate level of awareness (median score of 6.0; 0 = not at all aware; 10 = fully aware). Eight of the respondents (26%) had a score less than five, indicating low levels of awareness. However, almost all of the respondents were undertaking research in amputation in some capacity (81%; see Table 2). The majority was interested in collaborating on research (87%), and many were already collaborating at the local (52%), regional/provincial (32%), national (16%), and international levels (6%). In terms of institutional support, only 26% reported receiving a high level of support to undertake research while 45% stated they had little to no support at all.

Tables 3 and 4 describe the respondent's populations of interest and their areas of research interests, respectively. With regard to areas of interest, the top three areas were outcome measurement (i.e. development and validation of measures; $n = 23$), rehabilitation (i.e. physical therapy, occupational therapy, etc.; $n = 22$) and mobility and gait ($n = 20$).

When asked about what was needed to build capacity in amputation research, common suggestions put forth included the

Table 1. Anonymous pre-meeting survey respondents primary role in amputation ($N=31$).

Role	Total
Physiatrist	11
University professor	6
Other (i.e., government organization, research staff)	5
Scientist at a Research Institute	4
Surgeon	2
Physical therapist	2
Person with limb loss	1

Some respondents had more than one identified role (i.e. clinician and researcher, etc.) not shown here.

Table 2. Pre-meeting survey list of current areas of amputation research ($N=31$).

Research area	Frequency
Health outcomes	14
Qualitative research	11
Gait and mobility	8
Prosthetics development and/or evaluation	8
Health services utilization	6
Pain	4
Patient education	4
Medical aspects of amputation	4
Mental health	3
Rehabilitation trials	3
Healthcare provider education	2
Surgical techniques	1

Participants were asked to choose all areas of research that applied.

LEA: Lower extremity amputation; UEA: Upper extremity amputation.

Table 3. Pre-meeting survey list of research interests related by limb loss patient population ($N=31$).

Population	Frequency
LEA	25
Adult populations	20
Trauma-related	16
Dysvascular-related	16
UEA	12
Other etiology (e.g. cancer)	12
Paediatrics	6

Participants were asked to choose all areas of research that applied.

LEA: Lower extremity amputation; UEA: Upper extremity amputation.

need for more collaborations, the need for funding opportunities and protected time for front-line staff to engage in research. Respondents felt these supports might foster greater awareness of research initiatives undertaken across centres and facilitate collaborations. The creation of a national database was also highlighted as a means to gain a better understanding of the number of people with amputation and its impacts on the individual and society. It might also create opportunities for shared datasets and facilitate better access to potential research participants. Other comments included a lack of awareness of amputation rehabilitation since it is a relatively small patient population group, and there is a lack of dedicated scientists working in amputation; thereby hampering the ability to build research capacity.

Consensus-workshop results

A total of 50 persons were invited to the consensus-workshop in Toronto, Ontario, and 38 attended (20 women; 18 men) the

Table 4. Pre-meeting survey list of research interests by topic ($N=31$).

Research area	Frequency
Outcome measurement	23
Rehabilitation	22
Gait and mobility	20
Patient education	16
Prosthetics	15
Other psycho-social issues	15
Evidence-based guideline development	15
Community participation	14
Health system utilization	14
Phantom limb pain/syndrome	13
Post-traumatic stress disorder, depression, anxiety, etc.	10
Healthcare professional education	10
Secondary health conditions/comorbidities	10
Acute care management	7
Surgical techniques	6
Employment	5
Wound care	5

Participants were asked to choose all areas of research that applied.

Table 5. Meeting attendees ($N=38$; 18 women; 20 men).

Role(s)	Total
Physiatrists ¹	12
University professor/scientists ²	9
Trainees/highly qualified personnel ³	5
People with limb loss/community advocate ⁴	3
Vascular surgeons ⁵	3
Physical therapists ⁶	3
Prosthetists ⁷	2
Wound care specialist (chiropody) ⁸	1

Meeting attendees had diverse professional experiences (e.g. trained as an occupational therapist but now working as a physiatrist, etc.) and/or perspectives that extended across multiple roles (e.g. lived experience with limb loss and community advocate). See details below.

¹Occupational therapists ($n=1$; associate professor; $n=1$ assistant professor); Engineer ($n=1$; assistant professor); Full professor ($n=1$); Associate professors ($n=2$); Assistant professors ($n=4$).

²Clinical psychologist (full professor; $n=1$); Physical therapists ($n=3$ assistant professors); Occupational therapist (full professor; $n=1$); psycho-social researcher (assistant professor; $n=1$); Engineers; $n=3$; 1 assistant professor with traumatic LEA; 2 associate professors).

³PhD student ($n=1$; rehabilitation sciences); Master's student ($n=1$; clinical psychology); Medical student ($n=1$); Research staff ($n=2$).

⁴Dysvascular bilateral LEA ($n=1$; community advocate); Congenital upper limb ($n=1$; community advocate); Community advocate ($n=1$).

⁵Assistant professors ($n=3$).

⁶Rehabilitation inpatient manager ($n=1$); Non-governmental organization representative ($n=1$).

⁷Non-governmental representative ($n=1$).

⁸Non-governmental representative ($n=1$).

meeting on May 2019 (including the 8 core investigation team members; see Table 5). Of those who declined the invitation, two were from Ottawa, one from Winnipeg, one from Québec, and the rest from Toronto. Of those who attended, the majority were from across Ontario, including London, Hamilton, Ottawa, Toronto and Waterloo ($n=33$), and the rest were from British Columbia ($n=3$), Alberta ($n=1$) and Québec ($n=1$). The meeting was led by a professional and neutral facilitator, whose role was to direct and mediate the group discussions, synthesize group feedback, and to ensure consensus was achieved. Further, the neutral facilitator played a critical mobilizing role and promoted empowerment among meeting attendees [61] while ensuring that all viewpoints were given equitable opportunity to be shared with, and valued by, the larger group. To help further minimize in-group bias, the 38 members from the expert panel were pre-assigned to one of six table groups, each comprised of five to

Table 6. Research priorities generated at consensus meeting (Round 1; N=38).

Research area
1. Create a database to track the epidemiology of the population as well as to serve as a mechanism to help link research groups;
2. Develop clinical guidelines for both LEA & UEA;
3. Improve outcome measurement;
4. Identify multi-morbidity & long-term outcomes;
5. Obtain epidemiological data;
6. Focus efforts on technology;
7. Obtain health economics data to illustrate the burden of amputation to the healthcare system & to the individual with limb loss;
8. Identify ways to prevent amputation;
9. Create a national association;
10. Identify funding to support research;
11. Develop self-management approaches.
Priorities listed in no particular order.
LEA: Lower extremity amputation; UEA: Upper extremity amputation.

seven persons from different backgrounds and perspectives (e.g. surgical, rehabilitation, advocacy, etc.).

Round one – identifying research priority areas

Following a presentation about the pre-meeting survey results (see Table 4), the members of the expert panel were asked to first review the findings and consider which three-to-five topics should be prioritized to help build capacity in the field of amputation (see Figure 1). At the large group report-back session of the meeting, 11 topics were generated (see Table 6). A brief explanation was provided by the small groups on why these items were selected for consideration. This step completed the expansion of potential research priority areas and the divergent phase of the consensus-workshop.

Round two – prioritizing research areas

Once the group agreed on the generated priorities, the members of the expert panel were asked to vote independently for the research headings they deemed to be of highest priority (see Figure 1). The top three priorities selected by the group were: (1) Develop a national database to obtain robust epidemiological and outcomes data about the population; (2) Obtain health economics data to illustrate the burden of amputation to the healthcare system and to the individual with limb loss; and (3) Identify a strategy to improve outcome measurement across various domains (e.g. technology, QoL, functional, etc.). It should be noted that the development of best practice guidelines was the only other priority that received a comparable number of votes to the top three (25 votes or more). However, not one expert panel member objected to focusing on the three top domains for further development, indicating consensus had been achieved.

Strategies for advancing identified research priority areas

After the three identified priorities were established, participants separated into self-selected groups to generate strategies for moving them forward, with two separate groups being assigned each to the national database and outcomes measurement priorities, and one group working on the health economics priority (See Figure 1).

National database

To support evidence-based decision making in healthcare from surgical amputation in acute care, to rehabilitation, and then to the community, access to consistent, reliable and valid sources of clinical data are required [62]. A prospective clinical database or registry can support these efforts by collecting data on the etiology of the amputation, “patient-, and system-related factors to provide measurements on patient-centered outcomes, cost, safety, and efficacy that are needed for clinical and cost-effectiveness research and quality improvement effort” [62].

Common themes generated from both database working groups were related to identifying key stakeholders to engage and essential data elements to include within the first 6–12 months to support the planning of the database. One action item was to identify partners across the spectrum, such as clinicians across the continuum of care, policy-makers, and other public and private organizations, which should include advocacy groups with persons with lived experience across Canada. Having a broad representation of stakeholders was deemed critical to ensure there would be sufficient buy-in for this type of system as well as to determine which variables would be crucial for minimally answering key questions about the epidemiology and clinical outcomes of this population. Between 12 and 18 months of database development, there would be a need to further refine the proposed data elements and to begin investigating information technology solutions and related issues (i.e. How would data be collected and by whom? How would privacy be maintained?). To support these planning activities, it was suggested to examine how other groups worked to develop similar types of databases [63–66] and to explore funding sources that could help facilitate discussions across stakeholder groups.

Health economics

Within the finite funding envelope of the Canadian healthcare system, health economics can play a vital role in helping decision-makers decide on setting priorities and the allocation of scarce resources (physical, human and financial) to meet the health needs of all Canadians [67]. Hence, having strong health economic data related to amputation could serve to help better illustrate to decision-makers the cost to the system and value of supporting this patient population, which could lead to more efficient clinical interventions and cost-saving policies (e.g. change in allocation of resources). In terms of strategies for moving this priority item forward, the group felt that the first steps in determining the parameters to investigate could be informed by undertaking systematic reviews of the literature on the direct (i.e. to the system) and indirect (i.e. to the individual, such as lost productivity, employment) costs of amputation within the first 6 months. This would also help to identify knowledge gaps and opportunity areas for investigation. Within the 12 to 18 month timeframe, outreach to a network of groups interested in supporting health economic analyses could be achieved and a series of studies could be planned (i.e. examining differences in post-amputation outcomes across etiological groups and the cost of prevention strategies such as limb preservation surgical techniques).

Outcome measurement

Outcome measures are critical for understanding how a patient group is performing prior to any intervention, which can then support the direction of, and evaluation of, treatments [68]. The

use of reliable and valid outcome measures is a critical component of evidence-based decision making in the healthcare system. Similar rationales that emerged from the two break-out groups working on outcome measurement identified the need to establish a taxonomy of the types of outcomes currently being collected and to identify what was being commonly used across centres, both clinically and in research. The outcome of this exercise would be to foster a greater awareness of available measures and to start gaining consensus on key measures that could facilitate the comparison of outcomes across different sites. Strategies could include conducting a systematic review (or identifying existing reviews) on available outcome measures and by also undertaking an environmental scan of existing amputation care and research sites on the types of measures being utilized. Protocols for these types of activities could be established by the end of the initial 6-month period, and then implemented (or piloted) by the 12-month period, and likely could be finalized at 18 months. At the end of these activities, a common set of outcome measures to be used across centres could be proposed and gaps in outcome measurement in amputation could be identified; which could spur projects to develop outcome measures to address these gaps.

Discussion

This paper describes the processes and outcomes of a consensus-building workshop for developing an initial agenda to build research capacity in the amputation population in Canada. The outcomes of the workshop identified three research priorities from an expert panel comprised of representative stakeholders across the continuum of care (acute, rehabilitation, and community). The priorities were to: (1) develop a national database to obtain robust limb loss epidemiological and outcomes data; (2) obtain health economics data to illustrate the burden of amputation to the healthcare system; and (3) identify a strategy to improve outcome measurement across various domains (e.g. technology, QoL, functional, etc.). All attendees at the meeting endorsed the three selected priorities; thereby achieving consensus.

Although the planning of accompanying strategies for the three top priorities was the focus of the latter part of the consensus-workshop, the other identified research topics could easily be woven across priorities. For instance, pursuing research on multimorbidity and long-term outcomes following amputation could be framed within a health economics paradigm or be included as data elements in the development of a national database. However, the more critical issue to move any priority into action is to identify sources of funding, continue to raise awareness of amputation research in Canada and to build strong networks in order to facilitate multi-site collaborations. As noted, there are no dedicated Canadian limb loss funders; requiring researchers to pursue national, provincial and/or funders that are much broader in scope.

Relatively weak cohesion among stakeholders in the field was highlighted by pre-meeting survey results and reinforced by discussions at the meeting. One of the generated topics that provides a possible solution to strengthening ties across the country is the creation of a national limb loss association. A first step from our working group towards facilitating the groundwork for a future national association will be to have the Ontario Association for Amputee Care (www.oaac.ca) host on their website an index of researchers working across the country that can be accessed by persons seeking collaborators. Partnerships with other regional

and national organizations will also be explored to see if there are communication mechanisms that can be leveraged to support efforts to stay connected. With regard to the issue of funding, the lack of dedicated amputation funding sources means that planning for grants will need to recognize the current Canadian funding landscape in order to effectively compete with other researchers working in other fields. Given that the connections made at our consensus-workshop had professionals from acute care (e.g. surgeons), rehabilitation, and people with limb loss from across the country, designing multi-site projects with a continuum of care and/or patient-engagement in research framework aligns nicely with current national funding opportunities. However, pilot data will likely need to be obtained to elevate success with national funders, and other existing funding sources will need to be explored.

Limitations

In terms of our methodological approach, the use of a Delphi approach was appropriate since it is useful for scenarios where there is a lack of empirical evidence or when there are strong differences of opinion. This was potentially a substantial challenge for our group since our expert panel spanned the continuum of care as well as different professions that were informed by individual agendas (e.g. research vs. clinical care vs. advocacy). Moreover, the in-person components (e.g. invited speakers) might have influenced the decision-making of the group, which tend to be minimized in more traditional forms of Delphi studies [55]. To manage group dynamics and potential power imbalances in priority identification, the use of an initial anonymous round and neutral facilitator at the meeting were used. Fortunately, the collective recognition that research is a necessary and useful tool to support evidence-based clinical decision making and promote advocacy efforts facilitated our ability to achieve consensus.

Using a Delphi process for achieving consensus, however, does not imply that the “right” answer has been found [69] nor that a correct answer exists. The achieved consensus on amputation research priorities simply reflects an expert group’s opinion and should be interpreted as such [70]. Therefore, the resulting priorities are reflective of, but may not be generalizable to the larger limb loss field. We recognize that we did not include all possible different stakeholders (e.g. social work, nursing, etc.). As well, a greater national representation, along with a higher number of people with limb loss, might have further strengthened our end result. However, the generated priorities are meant to help facilitate an initial national dialogue on how to advance limb loss research, and our team made strong efforts to engage people with lived experience at all phases of this initiative (project inception, implementation, and dissemination) to ensure that our processes were transparent and accountable to them while working to identify priorities that were reflective of their needs [71–74]. The adoption of a patient engagement in research approach [75] is an explicit understanding that patients are the ultimate recipients of research findings, and consequently should be seen as the most important stakeholders [76]. Regardless, our initiative successfully engaged the participation of persons with research, clinical and policy expertise in amputation, as well as from persons with lived experience. Thus, we feel that we had an expert panel with relevant perspectives for generating and advancing the targeted priorities, which yielded a strong degree of consensus. Further, the described methodological approach can be adopted by other groups across the world interested in developing their own

specific research, care and/or policy agendas (including the full list of priorities in Table 6) in the field of amputation.

Next steps

Presently, our working group is aiming to continue to build momentum on early successes in research and to identify emerging opportunities that can help the research field to expand. Although there is weak cohesion nationally, there are strong pockets of research developing across the country. In Ontario, there has been growth in the number of dedicated research scientists working from major amputation care sites who have been collaborating with clinician scientists (acute care and rehabilitation) on a number of funded projects, which include several of the following studies that are: obtaining health-related QoL, community participation and health service utilization outcomes data in dysvascular LEA [77,78] and other populations [79], exploring the use of internet cognitive behavioural therapy to meet the mental health needs of patients recovering from amputation [80], assessing the effectiveness of targeted muscle reinnervation surgical treatments to address neuromas, exploring new technologies, such as 3D printing [81] and wearable sensors and systems [82], to improve prosthetic functioning [83], developing a computer-based app to measure post-amputation pain and other related sequelae [84], and developing a patient-reported outcome on quality of life in people with LEA [85]. In addition to on-going work on mobility, gait and prostheses post-amputation [86–88], an emerging Ontario network is starting to coalesce.

In Québec, osseointegration [89], which consists of a surgically inserted titanium rod into the residual limb to connect to an individual's prosthesis, is now listed as a covered procedure under its public health insurance plan, and offers a unique opportunity to embed a variety of evaluations (lived experience, economic, functional, etc.) to help gather much needed data to facilitate this procedures inclusion in other provincial health care insurance plans. In Alberta, there is recently approved funding for a case series of lower limb osseointegration. These approvals emphasize the need for a standard approach across Canada to provide equal treatment opportunities for all Canadians with limb amputation. Targeted reinnervation surgery has also been clinically available for over a decade in Alberta, and has led to international collaborations exploring novel UEA prostheses and the development of outcome measures to assess their effectiveness [35,90]. Finally, British Columbia has had success in accessing national data sets related to amputation [26] and experience in conducting nationwide surveys to evaluate clinical capacity for rehabilitation care [26,41]. This expertise and experiences can be useful for outreach to limb loss rehabilitation programs across Canada.

Conclusion

In summary, the outcomes of a consensus-workshop informed by a modified Delphi approach has led to the identification of three top priorities that people across the country can work together on to build capacity in amputation research in Canada. Despite current challenges with the availability of research funds for this population, there is a growing appetite for national collaborations and opportunities to undertake innovative, interprofessional and multi-sector research to inform evidence-based clinical practice and to support advocacy efforts to ensure that people aging with limb loss in Canada can have the necessary supports and resources to optimize their health and wellbeing.

Acknowledgements

The authors would also like to acknowledge the support Dan Blocka from Boundless Biomechanical Bracing, Mariam Botros from Wounds Canada, Betty Cheung and Adam Saporta from St. John's Rehab Hospital at Sunnybrook Health Sciences Centre, and Shane Glasford from Sunnybrook Centre for Independent Living (SCIL) at Sunnybrook Health Sciences Centre. As well, we would like to thank Ethan J. Mings from the Desk Consulting Group Inc. for his support in planning and facilitating the consensus-workshop. Finally, we would like to dedicate this article to Ms. Jean Kim, our patient partner, who sadly passed away prior to our consensus workshop.









Disclosure statement

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

Funding

Funding for this initiative was provided by the Canadian Institutes of Health Research (CIHR) Planning & Dissemination Grant Program [Grant# 158363].

ORCID

Sander L. Hitzig  <http://orcid.org/0000-0002-9139-9250>
 Amanda L. Mayo  <http://orcid.org/0000-0001-7061-2529>
 Steven Dilkas  <http://orcid.org/0000-0003-0840-7326>
 Jacqueline S. Hebert  <http://orcid.org/0000-0003-0788-0568>
 Sara J. T. Guilcher  <http://orcid.org/0000-0002-9552-9139>
 Susan W. Hunter  <http://orcid.org/0000-0002-7571-3895>
 W. Shane Journeay  <http://orcid.org/0000-0001-6075-3176>
 Joel Katz  <http://orcid.org/0000-0002-8686-447X>
 José Zariffa  <http://orcid.org/0000-0002-8842-745X>

References

- [1] Pezzin LE, Dillingham TR, MacKenzie EJ. Rehabilitation and the long-term outcomes of persons with trauma-related amputations. *Arch Phys Med Rehabil*. 2000;81(3):292–300.
- [2] Fortington LV, Dijkstra PU, Bosmans JC, et al. Change in health-related quality of life in the first 18 months after lower limb amputation: a prospective, longitudinal study. *J Rehabil Med*. 2013;45(6):587–594.
- [3] Turner AP, Meites TM, Williams RM, et al. Suicidal ideation among individuals with dysvascular lower extremity amputation. *Arch Phys Med Rehabil*. 2015;96(8):1404–1410.
- [4] Armstrong TW, Williamson MLC, Elliott TR, et al. Psychological distress among persons with upper extremity limb loss. *Br J Health Psychol*. 2019;24(4):746–763.
- [5] Journeay WS, Pauley T, Kowgier M, et al. Return to work after occupational and non-occupational lower extremity amputation. *Occup Med (Lond)*. 2018;68(7):438–443.
- [6] Boulias C, Meikle B, Pauley T, et al. Return to driving after lower-extremity amputation. *Arch Phys Med Rehabil*. 2006; 87(9):1183–1188.
- [7] Hebert JS, Ashworth NL. Predictors of return to work following traumatic work-related lower extremity amputation. *Disabil Rehabil*. 2006;28(10):613–618.

- [8] Amtmann D, Morgan SJ, Kim J, et al. Health-related profiles of people with lower limb loss. *Arch Phys Med Rehabil*. 2015;96(8):1474–1483.
- [9] Sinha R, Van Den Heuvel WJ. A systematic literature review of quality of life in lower limb amputees. *Disabil Rehabil*. 2011;33(11):883–899.
- [10] de Putter CE, Selles RW, Haagsma JA, et al. Health-related quality of life after upper extremity injuries and predictors for suboptimal outcome. *Injury*. 2014;45(11):1752–1758.
- [11] Zucker-Levin A. Functional outcome following amputation. *Top Geriatr Rehabil*. 2004;20(4):253–261.
- [12] Gailey R, Allen K, Castles J, et al. Review of secondary physical conditions associated with lower-limb amputation and long-term prosthesis use. *JRRD*. 2008;45(1):15–29.
- [13] Bhutani S, Bhutani J, Chhabra A, et al. Living with amputation: anxiety and depression correlates. *J Clin Diagn Res*. 2016;10(9):RC09–RC12.
- [14] McDonald S, Sharpe L, Blaszczyński A. The psychosocial impact associated with diabetes-related amputation. *Diabet Med*. 2014;31(11):1424–1430.
- [15] Padovani MT, Martins MR, Venancio A, et al. Anxiety, depression and quality of life in individuals with phantom limb pain. *Acta Ortop Bras*. 2015;23(2):107–110.
- [16] Lazzarini PA, Pacella RE, Armstrong DG, et al. Diabetes-related lower-extremity complications are a leading cause of the global burden of disability. *Diabet Med*. 2018. Available from: <https://www.ncbi.nlm.nih.gov/pubmed/29791033>
- [17] Ephraim PL, Dillingham TR, Sector M, et al. Epidemiology of limb loss and congenital limb deficiency: a review of the literature. *Arch Phys Med Rehabil*. 2003;84(5):747–761.
- [18] Unwin N. Epidemiology of lower extremity amputation in centres in Europe, North America and East Asia. *Br J Surg*. 2000;87(3):328–337.
- [19] Ziegler-Graham K, MacKenzie EJ, Ephraim PL, et al. Estimating the prevalence of limb loss in the United States: 2005 to 2050. *Arch Phys Med Rehabil*. 2008;89(3):422–429.
- [20] Stoll C, Calzolari E, Cornel M, et al. A study on limb reduction defects in six European regions. *Ann Genet*. 1996;39(2):99–104.
- [21] Castilla EE, Cavalcanti DP, Dutra MG, et al. Limb reduction defects in South America. *BJOG*. 1995;102(5):393–400.
- [22] Rosano A, Botto LD, Olney RS, et al. Limb defects associated with major congenital anomalies: clinical and epidemiological study from the International Clearinghouse for Birth Defects Monitoring Systems. *Am J Med Genet*. 2000;93(2):110–116.
- [23] Nylander G, Vilkkii S, Ostrup L. The need for replantation surgery after traumatic amputations of the upper extremity—an estimate based upon the epidemiology of Sweden. *J Hand Surg Br*. 1984;9(3):257–260.
- [24] Monteiro Peixoto A, Zimpel SA, Alves de Oliveira AC, et al. Prevalence of upper and lower limb amputations of SUS patients in the state of Alagoas between 2008 and 2015. *Fisioter Pesqui*. 2017;24(4):378–384.
- [25] Bilandzic A, Rosella L. The cost of diabetes in Canada over 10 years: applying attributable health care costs to a diabetes incidence prediction model. *Health Promot Chronic Dis Prev Can*. 2017;37(2):49–53.
- [26] Imam B, Miller WC, Finlayson HC, et al. Incidence of lower limb amputation in Canada. *Can J Public Health*. 2017;108(4):e374–e380.
- [27] Canadian Association of Wound Care. 2016. Available from: <http://cawc.net/index.php/public/facts-stats-and-tools/statistics/>.
- [28] Fortington LV, Geertzen JH, van Netten JJ, et al. Short and long term mortality rates after a lower limb amputation. *Eur J Vasc Endovasc Surg*. 2013;46(1):124–131.
- [29] Huseynova K, Sutradhar R, Booth GL, et al. Risk of contralateral lower limb amputation and death after initial lower limb amputation - a population-based study. *Heliyon*. 2018;4(10):e00836.
- [30] Butowicz CM, Dearth CL, Hendershot BD. Impact of traumatic lower extremity injuries beyond acute care: movement-based considerations for resultant longer term secondary health conditions. *Adv Wound Care (New Rochelle)*. 2017;6(8):269–278.
- [31] Matsumoto ME, Khan M, Jayabalan P, et al. Heterotopic ossification in civilians with lower limb amputations. *Arch Phys Med Rehabil*. 2014;95(9):1710–1713.
- [32] Kuffler DP. Origins of phantom limb pain. *Mol Neurobiol*. 2018;55(1):60–69.
- [33] Pedras S, Carvalho R, Pereira MG. A predictive model of anxiety and depression symptoms after a lower limb amputation. *Disabil Health J*. 2018;11(1):79–85.
- [34] Sinitski EH, Lemaire ED, Baddour N, et al. Fixed and self-paced treadmill walking for able-bodied and transtibial amputees in a multi-terrain virtual environment. *Gait Posture*. 2015;41(2):568–573.
- [35] Hebert JS, Lewicke J, Williams TR, et al. Normative data for modified Box and Blocks test measuring upper-limb function via motion capture. *J Rehabil Res Dev*. 2014;51(6):918–932.
- [36] Dudek NL, Marks MB, Marshall SC, et al. Dermatologic conditions associated with use of a lower-extremity prosthesis. *Arch Phys Med Rehabil*. 2005;86(4):659–663.
- [37] Kendell C, Lemaire ED, Kofman J, et al. Gait adaptations of transfemoral prosthesis users across multiple walking tasks. *Prosthet Orthot Int*. 2016;40(1):89–95.
- [38] Hunter SW, Higa J, Frengopoulos C, et al. Evaluating knowledge of falls risk factors and falls prevention strategies among lower extremity amputees after inpatient prosthetic rehabilitation: a prospective study. *Disabil Rehabil*. 2019. Available from: <https://www.ncbi.nlm.nih.gov/pubmed/30686062>
- [39] Frengopoulos C, Burley J, Viana R, et al. Association between montreal cognitive assessment scores and measures of functional mobility in lower extremity amputees after inpatient rehabilitation. *Arch Phys Med Rehabil*. 2017;98(3):450–455.
- [40] Devlin M, Pauley T, Head K, et al. Houghton Scale of prosthetic use in people with lower-extremity amputations: reliability, validity, and responsiveness to change. *Arch Phys Med Rehabil*. 2004;85(8):1339–1344.
- [41] Imam B, Miller WC, Finlayson HC, et al. Lower limb prosthetic rehabilitation in Canada: a survey study. *Physiother Can*. 2019;71(1):11–21.
- [42] Kayssi A, Dilkas S, Dance DL, et al. Rehabilitation trends after lower extremity amputations in Canada. *PM R*. 2017;9(5):494–501.
- [43] Kayssi A, de Mestral C, Forbes TL, et al. Predictors of hospital readmissions after lower extremity amputations in Canada. *J Vasc Surg*. 2016;63(3):688–695.

- [44] Asano M, Rushton P, Miller WC, et al. Predictors of quality of life among individuals who have a lower limb amputation. *Prosthet Orthot Int*. 2008;32(2):231–243.
- [45] Hebert JS, Wolfe DL, Miller WC, et al. Outcome measures in amputation rehabilitation: ICF body functions. *Disabil Rehabil*. 2009;31(19):1541–1554.
- [46] Gallagher P, Maclachlan M. The Trinity Amputation and Prosthesis Experience Scales and quality of life in people with lower-limb amputation. *Arch Phys Med Rehabil*. 2004; 85(5):730–736.
- [47] Gauthier-Gagnon C, Grise MC. Prosthetic profile of the amputee questionnaire: validity and reliability. *Arch Phys Med Rehabil*. 1994;75(12):1309–1314.
- [48] Breakey JW. Body image: the lower-limb amputee. *J Prosthet Orthot*. 1997;9:58–66.
- [49] Krueger H, Noonan VK, Trenaman LM, et al. The economic burden of traumatic spinal cord injury in Canada. *Chronic Dis Inj Can*. 2013;33(3):113–122.
- [50] Noonan VK, Fingas M, Farry A, et al. Incidence and prevalence of spinal cord injury in Canada: a national perspective. *Neuroepidemiology*. 2012;38(4):219–226.
- [51] Liu X, Liu N, Zhou M, et al. Bibliometric analysis of global research on the rehabilitation of spinal cord injury in the past two decades. *TCRM*. 2018;15:1–14.
- [52] Cohen G, Schroeder J, Newson R, et al. Does health intervention research have real world policy and practice impacts: testing a new impact assessment tool. *Health Res Policy Sys*. 2015;13(1):3.
- [53] Day J, Boveva M. A generic toolkit for the successful management of Delphi Studies. *Elec J Bus Res Methods*. 2005;3: 103–117.
- [54] Linstone HA, Turoff M. The Delphi survey: method techniques and applications. Reading: Addison-Wesley; 1975.
- [55] Sinha IP, Smyth RL, Williamson PR. Using the Delphi technique to determine which outcomes to measure in clinical trials: recommendations for the future based on a systematic review of existing studies. *PLoS Med*. 2011;8(1): e1000393.
- [56] Hitzig SL, Hunter JP, Ballantyne EC, et al. Outcomes and reflections on a consensus-building workshop for developing a spinal cord injury-related chronic pain research agenda. *J Spinal Cord Med*. 2017;40(3):258–267.
- [57] McDonald L, Hitzig SL, Pillemer KA, et al. Developing a research agenda on resident-to-resident aggression: recommendations from a consensus conference. *J Elder Abuse Negl*. 2015;27(2):146–167.
- [58] Anderson DH, Schneider IE. Using the Delphi process to identify significant recreation research-based innovations. *J Park Rec Admin*. 1993;11(1):25–36.
- [59] Miller G. The development of indicators for sustainable tourism: results of a Delphi survey of tourism researchers. *Tourism Manag*. 2001;22(4):351–362.
- [60] Hus CC, Sandford BA. The Delphi technique: making sense of consensus. *Pract Assess Res Eval*. 2007;12:1–8. <https://pareonline.net/pdf/v12n10.pdf>.
- [61] Yetim F, Turoff M. Structuring communication processes and enhancing public discourse: the Delphi method revisited. Proceedings of language-action perspective on communication modeling; Proceedings of the 9th International Working Conference on the Language-Action Perspective on Communication Modelling (LAP 2004); 2004 Jun 2–3. New Brunswick (NJ): Rutgers University, The State University of New Jersey; 2004. Available from: <http://cite-seerx.ist.psu.edu/viewdoc/summary?doi=10.1.1.86.7579>
- [62] Dvorak MF, Cheng CL, Fallah N, et al. Spinal cord injury clinical registries: improving care across the SCI care continuum by identifying knowledge gaps. *J Neurotrauma*. 2017;34(20):2924–2933.
- [63] Noonan VK, RHSCIR Network, Kwon BK, et al. The Rick Hansen Spinal Cord Injury Registry (RHSCIR): a national patient-registry. *Spinal Cord*. 2012;50(1):22–27.
- [64] Wei Y, McCormick A, MacKenzie A, et al. The Canadian neuromuscular disease registry: connecting patients to national and international research opportunities. *Paediatr Child Health*. 2018;23(1):20–26.
- [65] Fang J, Kapral MK, Richards J, et al. The Registry of Canadian Stroke Network : an evolving methodology. *Acta Neurol Taiwan*. 2011;20(2):77–84.
- [66] Davie-Smith F, Paul L, Nicholls N, et al. The impact of gender, level of amputation and diabetes on prosthetic fit rates following major lower extremity amputation. *Prosthet Orthot Int*. 2017;41(1):19–25.
- [67] Madore E. The health care system in Canada: effectiveness and efficiency 1993; BP-350E. Available from: <http://publications.gc.ca/Collection-R/LoPBdP/BP/bp350-e.htm>.
- [68] Feters L, Tilson J. Evidence based physical therapy. Philadelphia (PA): F.A. Davis Company; 2012.
- [69] Keeney S, Hasson F, McKenna HP. A critical review of the Delphi technique as a research methodology for nursing. *Int J Nurs Stud*. 2001;38(2):195–200.
- [70] Powell C. The Delphi technique: myths and realities. *J Adv Nurs*. 2003;41(4):376–382.
- [71] Esmail L, Moore E, Rein A. Evaluating patient and stakeholder engagement in research: moving from theory to practice. *J Comp Eff Res*. 2015;4(2):133–145.
- [72] Hogg WE. Crowdsourcing and patient engagement in research. *Can Fam Physician*. 2015;61(3):283–284.
- [73] Johansson V. From subjects to experts—on the current transition of patient participation in research. *Am J Bioeth*. 2014;14(6):29–31.
- [74] Lough S. Need to define patient engagement in research. *CMAJ*. 2015;187(12):E385–E386. 6.
- [75] Canadian Institutes of Health Research. Strategy for patient-oriented research - patient engagement framework 2019. Available from: <http://www.cihr-irsc.gc.ca/e/48413.html>.
- [76] Natale CV, Gross D. The ROI of engaged patients. *Healthc Financ Manage*. 2013;67(8):90–97.
- [77] Mayo AL, Hitzig SL, Devlin M, et al. Health and quality of life outcomes post-amputation in Ontario. Ontario (Canada): Physician Services Incorporated Foundation; 2017.
- [78] Hitzig SL, Mayo AL, Devlin M, et al. Health and quality of life outcomes post-amputation in Ontario – pilot study. Toronto (Canada): Ontario Association for Amputee Care; 2017.
- [79] Sayed Ahmed B, Lamy M, Cameron D, et al. Factors impacting participation in sports for children with limb absence: a qualitative study. *Disabil Rehabil*. 2018;40(12):1393–1400.
- [80] Kayssi A, Mayo A. Online cognitive behavioural therapy intervention to improve post-operative outcomes following major amputation. Toronto (Canada): Blair Foundation Vascular Surgery Innovation Fund; 2019.
- [81] Ribeiro D, Cimino SR, Mayo AL, et al. 3D Printing and amputation: a scoping review. *Disabil Rehabil Assist*

- Technol. 2019. Available from: <https://www.ncbi.nlm.nih.gov/pubmed/31418306>
- [82] Andrysek J, Ramdial S, Wright VF. Biomechanical biofeedback targeting the high-level rehabilitation of mobility in youth with lower limb amputations. Toronto (Canada). Canadian Institutes of Health Research, Collaborative Health Research Projects (NSERC partnered); 2019.
 - [83] Andrysek J, Wright FV, Rotter K, et al. Long-term clinical evaluation of the automatic stance-phase lock-controlled prosthetic knee joint in young adults with unilateral above-knee amputation. *Disabil Rehabil Assist Technol*. 2017;12(4): 378–384.
 - [84] Aternali A, Katz J. Computer-based application exploring the role of phantom limb ‘telescoping’ in post-amputation pain. *Clinical Innovation Poster Abstracts. Canadian Journal of Pain*. 2019;3(1): A50–A51.
 - [85] Hitzig SL, Devlin M, Dilkas S, et al. Developing a Patient Reported Outcome for Amputation (PRO-AMP). Toronto (Canada): Canadian Institutes of Health Research; 2019.
 - [86] Sturk JA, Lemaire ED, Sinitski EH, et al. Maintaining stable transfemoral amputee gait on level, sloped and simulated uneven conditions in a virtual environment. *Disabil Rehabil Assist Technol*. 2019;14(3):226–235.
 - [87] Hunter SW, Frengopoulos C, Holmes J, et al. Dual-task related gait changes in individuals with trans-tibial lower extremity amputation. *Gait Posture*. 2018;61:403–407.
 - [88] Eshraghi A, Safaeepour Z, Geil MD, et al. Walking and balance in children and adolescents with lower-limb amputation: a review of literature. *Clin Biomech (Bristol, Avon)*. 2018;59:181–198.
 - [89] Hebert JS, Rehani M, Stiegelmar R. Osseointegration for lower-limb amputation: a systematic review of clinical outcomes. *JBS Rev*. 2017;5(10):e10.
 - [90] Hebert JS, Olson JL, Morhart MJ, et al. Novel targeted sensory reinnervation technique to restore functional hand sensation after transhumeral amputation. *IEEE Trans Neural Syst Rehabil Eng*. 2014;22(4):765–773.