Cocreating research priorities for anorexia nervosa: The Canadian Eating Disorder Priority Setting Partnership

Nicole Obeid PhD | Gail McVey PhD | Emily Seale MPH | Wendy Preskow | Mark L. Norris MD

Abstract

Objective: The Canadian Eating Disorder Priority Setting Partnership was established to identify and prioritize the top 10 research priorities for females, 15 years or older, with anorexia nervosa, by incorporating equal input from those with lived experience, families, and healthcare professionals.

Method: This project, which closely followed the James Lind Alliance guidelines, solicited research priorities from the Canadian eating disorder community by means of a five-step process including use of a survey, response collation, literature checking, interim ranking survey, and in-person prioritization workshop.

Results: The initial survey elicited 897 priorities from 147 individuals, with almost equal representation from all three stakeholder groups. From this, 603 responses aligned with the project objectives and were collapsed into 71 broader indicative questions. Based on available systematic reviews, 18 indicative questions were removed as they were considered answered by existing literature while 8 indicative questions were added from the recommendations of the reviews. In total, 61 indicative questions were ranked in an interim ranking survey, where 21 questions were prioritized as important by at least 20% of respondents. As a final step, 28 individuals from across Canada attended the prioritization workshop to coestablish the top 10 research priorities.

Discussion: Top priorities were related to treatment gaps and the need for more surveillance data. This systematic methodology allowed for a transparent and collaborative approach to identifying current priorities from both the service user and provider perspective. Wide dissemination is anticipated to promote work that is of high relevance to patients, families, and clinicians.

KEYWORDS
anorexia nervosa, James Lind Alliance, patient partners, Priority Setting Partnership, research priorities

INTRODUCTION

It is estimated that 15% of females and 5.5% of males from high-income countries will be affected by an eating disorder (ED) or their subthreshold variants (Limbers, Cohen, & Gray, 2018; Schmidt et al., 2016), which in Canada translates to close to 5.5 million females and 2 million males suffering from a significant eating-related struggle at any given time. Elevated mortality rates are associated with all EDs (Hoang, Goldacre, & James, 2014), although anorexia nervosa (AN) in particular carries the highest risk with a standardized mortality ratio of...
5.35 in inpatient samples (Fichter & Quadflieg, 2016), with males at even greater risk (Quadflieg, Strobel, Naab, Voderholzer, & Fichter, 2019). Substantial rates of psychosocial impairment (Udo & Grilo, 2018), somatic conditions (Udo & Grilo, 2019), and comorbidity are also associated with all EDs (Dooley-Hash, Adams, Walton, Blow, & Cunningham, 2019; Kambanis et al., 2019; Mohammadi et al., 2019).

Despite these morbid realities, the field of EDs in Canada continues to be vastly underfunded, understudied, and poorly understood (Standing Committee on the Status of Women, 2014) with limited research dollars available to further the evidence. Research questions usually tackled with the scarce funding available typically follows the priorities set by academia and industry, potentially limiting the breadth of research carried out. Individuals with lived experience, families, and clinicians are seldom afforded opportunities to contribute to the identification and setting of research priorities in the field, potentially lending to research questions being studied that are not of relevance to those most closely affected by the disorder; findings that do not have real-world benefit; and/or research being conducted that can be seen as wasteful of the limited funding available (Chalmers & Glasziou, 2009). It is additionally argued that publicly funded research related to health care systems and conditions should prioritize those

### TABLE 1
List of the Canadian Eating Disorder Priority Setting Partnership partnering organizations

- National Initiative of Eating Disorders (NIED)
- Eating Disorder Association of Canada (EDAC)
- Eating Disorder Foundation of Canada (EDFC)
- National Eating Disorder Information Center (NEDIC)
- Hopewell Support Center
- Sheena’s Place
- Looking Glass Foundation

### Stage 1: Initiation of the Priority Setting Partnership
(April, 2017 to December, 2017)
- 84 individuals interested in participating
- 9 individuals selected for steering committee

### Stage 2: Gathering and identifying questions (first survey)
(January, 2018 to February, 2018)
- 147 participants completed first survey
- 897 total raw suggestions identified

### Stage 3: Processing and collating the questions
(March, 2018 to June, 2018)
- Existing evidence checked in databases
- 603 questions reworded into 71 indicative questions
- 294 out-of-scope questions removed
- 8 questions added from literature search
- 18 questions answered by systematic reviews (22 partially answered)
- 61 total questions forwarded to interim prioritization stage

### Stage 4: Interim prioritization (second survey)
(March, 2018 to August, 2018)
- 45 participants completed online survey
- Aggregated weighted and unweighted analysis based on frequency of rankings
- Top 21 questions identified

### Stage 5: Final priority setting workshop
(September 14, 2018)
- 28 participants participated in the workshop
- Final top 10 questions identified

### FIGURE 1
Flow chart describing the number of participants and responses at each step of the five-stage process

### TABLE 2
Demographics of Canadian Eating Disorder Priority Setting Partnership participants

<table>
<thead>
<tr>
<th></th>
<th>Steering Committee (n = 9)</th>
<th>First survey (n = 147)</th>
<th>Workshop (n = 28)</th>
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<tbody>
<tr>
<td>Gender</td>
<td></td>
<td></td>
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<tr>
<td>Male</td>
<td>8 (5.4)</td>
<td>2 (7.1)</td>
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<tr>
<td>Female</td>
<td>9 (100.0)</td>
<td>113 (76.9)</td>
<td>25 (89.3)</td>
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<tr>
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<td>1 (3.6)</td>
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<tr>
<td>Unknown</td>
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<tr>
<td>Age</td>
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<tr>
<td>15–25</td>
<td>1 (11.1)</td>
<td>33 (22.4)</td>
<td>3 (10.7)</td>
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<td>26–35</td>
<td>1 (11.1)</td>
<td>19 (12.9)</td>
<td>6 (21.4)</td>
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<td>36–45</td>
<td>3 (33.3)</td>
<td>22 (15.0)</td>
<td>2 (7.1)</td>
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<td>46–55</td>
<td>4 (44.4)</td>
<td>29 (19.7)</td>
<td>8 (28.6)</td>
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<tr>
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<td>Province</td>
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<tr>
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<td>73 (49.7)</td>
<td>6 (21.4)</td>
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<td>2 (7.1)</td>
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<tr>
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<td>Stakeholder group</td>
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<tr>
<td>Lived experience</td>
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<td>35 (23.8)</td>
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<tr>
<td>Carer</td>
<td>3 (33.3)</td>
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<td>26 (17.7)</td>
<td>8 (28.6)</td>
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<tr>
<td>Lived experience and carer</td>
<td>10 (6.8)</td>
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<tr>
<td>Lived experience and healthcare professional</td>
<td>1 (11.1)</td>
<td>12 (8.2)</td>
<td>2 (7.1)</td>
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<tr>
<td>Carer and healthcare professional</td>
<td>6 (4.1)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Unknown</td>
<td>23 (15.6)</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

Note: N.B. West: British Columbia, Alberta, Saskatchewan, Manitoba; Central: Ontario, Quebec; Atlantic: New Brunswick, Nova Scotia, Prince Edward Island, Newfoundland, and Labrador.
questions most relevant to those closest to the system (Kelly et al., 2015). A greater body of high-quality research that builds on the priorities of the service users and providers themselves could increase the impact, dissemination, and use of new knowledge in the field.

As a result, the Canadian Eating Disorder Priority Setting Partnership (CEDPSP) was launched to identify and disseminate the current research needs in this field according to those most closely touched by the illness, namely, those with lived experience, families, and carers, and healthcare providers who treat individuals with EDs. The CEDPSP provided a first step to encourage dialog among a range of stakeholders about research priorities needed to help advance the field. The objective of this work was to coestablish the top 10 research priorities for AN in females 15 years or older, by engaging those with lived experience, carers, and clinicians from the Canadian ED community to gain their perspective of the most relevant research questions that need answering.

2 | METHOD

An investigative team comprised of two researchers, a clinician and a carer, oversaw a 17-month patient-oriented research initiative that was reviewed by two research ethics board. The team collaborated with the James Lind Alliance (JLA; http://www.jla.nihr.ac.uk/) for methodology, including enlisting the help of a certified JLA consultant to help oversee the process. The JLA provides a rigorous and transparent five-step procedure for developing a Priority Setting Partnership (PSP). To date, over 100 PSPs have been conducted around the world, including recent Canadian PSPs on fibromyalgia, kidney cancer, and dementia (Bethell et al., 2018; Fitzcharles et al., 2017; Jones et al., 2017).

Alongside the investigative team, a host of pan-Canadian and local ED-related organizations collaborated with the CEDPSP (Table 1). They promoted the work, widely shared the project surveys or requests for participation, provided support (cash or in-kind contributions), and disseminated the study findings.

2.1 | Stage 1: Initiation of the PSP

A nine-person Steering Committee was established to support the investigative team. Self-nomination procedures for participation were enabled to reduce any bias or selection preference. Next steps included establishing a focus for the project given the short timeline, limited resources, vastness of the field of EDs, and guidance from the JLA Advisor. The decided focus was on AN in females aged 15 years and older given the high morbidity and mortality associated with that diagnosis (Espie & Eisler, 2015), the high levels of healthcare utilization that exists with this patient population, and as AN has the largest evidence base across diagnostic categories of EDs which would benefit Step 4 of this process. Prioritization questions were further narrowed to (a) treatment issues, (b) cooccurring or concurrent struggles (social, psychological, academic/vocational), and (c) access to service issues.

2.2 | Stage 2: Gathering and identifying questions

An online survey hosted by RedCap (Harris et al., 2009) was used to collect opinions on the most important research priorities for AN in females aged 15 years and older. The survey was available for 3 weeks and was disseminated widely to the ED community via

![FIGURE 2](chart showing the breakdown of responses from the initial survey by stakeholder groups)
distribution lists of partnering organizations and communication strategies using a range of social media platforms.

2.3 | Stage 3: Processing and collating the questions

As a first step to collating the survey responses, they were organized and refined by removing those that were out of scope (e.g., about bulimia nervosa, or males) or unanswerable (e.g., "I'm worried my daughter won't get better"). Next, similar or duplicate questions were grouped together in an attempt to create one broader question. Once grouped accordingly, the refined responses were made into indicative questions in line with the PICO (Patient; Intervention; Comparison; Outcome) concept (Guyatt et al., 2011). These indicative questions were then checked against existing up-to-date systematic reviews to learn which, if any, already had adequate evidence (1 systematic review for narrow topics; 3 systematic reviews for broader questions) available to answer the specific questions.

2.4 | Stage 4: Interim prioritization

The interim prioritization stage was a second opportunity for the community to lend their voice to the project. In this stage, an electronic survey containing the grouped indicative questions derived in Stage 3 was disseminated, in the same order, to various ED community members to gain their opinion as to the most important indicative questions from the list. Respondents were asked to state which 10 questions they found most important, but were not asked to rank order them. The indicative questions that received at least 20% of
<table>
<thead>
<tr>
<th>Type of question</th>
<th>List of questions</th>
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</table>
| Questions prioritized during the interim prioritization process (n = 21) | What are the best ways to educate healthcare professionals (e.g., medical students, primary care, mental health, specialty, etc.) and educators about anorexia nervosa, and how does this impact early identification rates, access to services, and recovery?  
How could the system better support individuals with anorexia nervosa through transition periods (e.g., adolescent to adult program, inpatient to outpatient, community to hospital, etc.) so that care is streamlined and easier to navigate?  
What is the short- and long-term efficacy of treatment methods for anorexia nervosa at different ages, and which ones are the best?  
What are the most helpful and least helpful treatment elements as identified by recovered individuals (e.g., specific dietitian, use of meal plans, forced social outings, etc.), and what long-term outcomes do they perceive them to help with (e.g., coping/relaxation abilities, connectedness to oneself, etc.)?  
Does access to care across Canada fulfill the needs (e.g., emotional, physical, psychological, spiritual) of individuals with anorexia nervosa, and if not, what is the best way to improve access to treatment?  
Once recovered/discharged from services, what is the most effective way of preventing relapse from anorexia nervosa?  
What are the effects of repeated inpatient admissions for individuals with anorexia nervosa, and should treatment be different after repeated admissions?  
How does anorexia nervosa affect social and family relationships (e.g., spouse, parents, siblings, friends, work, school, etc.), and what social supports have been helpful during treatment?  
Of those diagnosed with anorexia nervosa, what are the rates of recovery, relapse, dropouts, and length of treatment across Canada?  
What is the most effective way of treating co-occurring/comorbid disorders for individuals with anorexia nervosa, and should treatments occur separately or at the same time? Why?  
What is the most effective way of educating families and caregivers on anorexia nervosa (e.g., signs and symptoms, best practices at home, etc.) and on ways to support individuals going through recovery?  
Does access to different types of services (e.g., inpatient, outpatient, day program, etc.) impact the identification, outcomes, trajectories, and recovery of anorexia nervosa?  
What are the wait times across Canada for adolescent girls and women suffering from anorexia nervosa? Are they equitable? How can we decrease wait times for services?  
Are programs for anorexia nervosa equitable across Canada (e.g., access to specialized care, wait times, resources, etc.)?  
How does treating adolescents with anorexia nervosa as adults (e.g., right to refuse treatment) impact treatment outcomes?  
What are the effects of the public focus on the obesity crisis on those with anorexia nervosa?  
Why are there so few community-based healthcare professionals trained to deal with anorexia nervosa?  
What are the potential co-occurring conditions associated with anorexia nervosa, and how do they affect one another?  
How does weight impact the identification and treatment of anorexia nervosa?  
What is the most effective way of emotionally, financially, and practically supporting carers of individuals with anorexia nervosa?  
What is the stigma associated with anorexia nervosa and how can we effectively destigmatize the disorder? |
| Questions added based on recommendations from the literature (n = 8) | Are individuals from ethnic minorities affected by anorexia nervosa differently?  
Do patients with higher IQ have better prognosis?  
Does peer-to-peer mentorship help with recovery from anorexia nervosa?  
How does body-checking and body image avoidance affect those with anorexia nervosa?  
What is the effect of rumination on those with anorexia nervosa?  
What is the most effective role for occupational therapists in anorexia nervosa?  
What is the relationship between smoking and anorexia nervosa?  
What, if any, are the causal relationships between gut microbiota and anorexia nervosa behaviors? |
| Questions removed as considered answered with substantial evidence (n = 18) | How are treatment outcomes influenced by the different stages of behavior change throughout treatment (e.g., level of motivation)?  
How do family practices and beliefs (e.g., dieting, body image behaviors, etc.) affect the development, maintenance, trajectory, outcomes, and recovery of anorexia nervosa? |

(Continues)
votes from those surveyed were moved on to the final prioritization workshop.

2.5 | Stage 5: Final priority setting workshop

A final face-to-face workshop was the culminating step in the priority setting process. The intent was to discuss and rank the top 10 research priorities based on the results from Stage 4. Individuals invited to participate in the workshop consisted of the Steering Committee, several members of the investigative team, and individuals who had self-nominated for the project and were selected for a role of workshop attendee. Prior to the workshop, invitees were each asked to establish their own preliminary ranking of the uncertainties from Stage 4 and to bring with them a copy of the ranking for discussion. As recommended by the JLA, the day consisted of a mix of large group discussions and small breakout groups structured to promote feedback and opinions from the different perspectives and to accomplish the goals in specified periods of time.

3 | RESULTS

The CEDPSP was a collaborative process that took place between April 2017 and September 2018. Figure 1 depicts the outcome and timelines of the five-step methodology used for the CEDPSP.

<table>
<thead>
<tr>
<th>Type of question</th>
<th>List of questions</th>
</tr>
</thead>
<tbody>
<tr>
<td>How does anorexia nervosa affect short-, mid-, and long-term emotional/identity development, maturation, and processing, and do current treatment services address these?</td>
<td></td>
</tr>
<tr>
<td>How does social interaction impact anorexia nervosa patients’ physical, mental, and emotional regulation?</td>
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<tr>
<td>How does social media and other social triggers affect the development, maintenance, trajectory, outcomes, and recovery of anorexia nervosa?</td>
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<tr>
<td>How does weight restoration and recovery from anorexia nervosa affect patients’ brain health (e.g., brain chemistry, neurotransmitters, brain tissue, etc.)?</td>
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<tr>
<td>Is there a relationship between anorexia nervosa and the perception of self? Does treatment focus on these and increase the chances of recovery?</td>
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<tr>
<td>Is there a relationship between trauma and anorexia nervosa, and is trauma-informed care effective at improving treatment outcomes?</td>
<td></td>
</tr>
<tr>
<td>What are current barriers to recovery from anorexia nervosa, and how do we overcome them?</td>
<td></td>
</tr>
<tr>
<td>What are the Canadian evidence-based guidelines for the identification and short-, mid- and long-term treatment of anorexia nervosa that can be used by publicly- or privately funded collaborative care teams? If none exist, what signs, symptoms, diagnostic criteria, and treatment specifications</td>
<td></td>
</tr>
<tr>
<td>What are the risk factors of anorexia nervosa? What are the protective factors?</td>
<td></td>
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<tr>
<td>What is the association between chronic diseases and anorexia nervosa?</td>
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<tr>
<td>Is there a relationship between anorexia nervosa and sexuality (e.g., sexual intimacy, sexual preference, etc.)?</td>
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<tr>
<td>Is there a relationship between anorexia nervosa and spirituality?</td>
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<tr>
<td>The effectiveness of online programs in the treatment of anorexia nervosa: What’s available and what are the gaps?</td>
<td></td>
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<tr>
<td>What are the effects of different pharmacotherapies on patients’ objective and subjective outcomes (e.g., weight, connection to body, etc.)?</td>
<td></td>
</tr>
<tr>
<td>What is the effectiveness and feasibility of treatment methods currently provided to anorexia nervosa patients?</td>
<td></td>
</tr>
<tr>
<td>What is the role of genetic/biological heredity in the development, maintenance, and outcomes of anorexia nervosa?</td>
<td></td>
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</tbody>
</table>

3.1 | Stage 1: Initiation of the PSP

Through the self-nomination process, 84 individuals with lived experience, carers and/or healthcare professionals expressed interest in joining the CEDPSP. Based on anonymized criteria, including age, gender, geographic location, and experience within stakeholder group, nine individuals, with three members from each stakeholder group, were selected to join the Steering Committee (Table 2). The first Steering Committee meeting took place in November 2017 and members worked collaboratively through teleconference calls and email correspondence over the next 10 months.

3.2 | Stage 2: Gathering and identifying questions

The online questionnaire created to gather the uncertainties remained open for 3 weeks, between January and February 2018. This questionnaire yielded 897 responses from 147 individuals, with the distribution of respondents’ stakeholder groups depicted in Figure 2. Almost equal numbers of those with lived experience (24%), carers (24%), and healthcare professionals (18%) responded to the survey. Furthermore, 17% of respondents provided experiences and perspectives from a combination of stakeholder groups.
### TABLE 4  List of the final top 10 research priorities

<table>
<thead>
<tr>
<th>Rank</th>
<th>Final top 10 priorities</th>
<th>Number of affiliated raw priorities</th>
<th>Examples of raw questions</th>
</tr>
</thead>
</table>
| 1    | What is the short- and long-term efficacy of treatment methods for anorexia nervosa at different ages and which ones are the best? | 35 | *"I understand there is very likely a biological component to anorexia nervosa. What type of treatment is most advantageous for this?"*  
*"What is the efficacy of outpatient support groups? What makes them successful or not successful?"* |
| 2    | What are the most helpful and least helpful treatment elements as identified by recovered individuals, and what long-term outcomes do they perceive them to help with? | 8 | *"Given the challenges of treating anorexia nervosa successfully, have we identified what were the most successful treatment ingredients identified by recovered individuals 10 years post episode?"*  
*"What are the target anorexia nervosa sufferer's views on the current state of care and support, or the lack thereof? Detailed questions about access, waiting times, ignorance and discrimination against them, whether intended or not."* |
| 3    | Of those diagnosed with anorexia nervosa, what are the rates of recovery, relapse, dropouts, and length of treatment across Canada? | 19 | *"[What are the] correlations of length of time to recovery outcomes and time spent in treatment?"*  
*"[What are the] actual 'recovery' rates in quantitative and qualitative terms compared across treatment modalities."* |
| 4    | Once recovered/discharged from services, what is the most effective way of preventing relapse for anorexia nervosa patients? | 20 | *"What types of supports work best at preventing relapses and chronicity?"*  
*"Is there a specific type of treatment that is more beneficial to reduce the risk of relapse?"* |
| 5    | What are the best ways to educate healthcare professionals (e.g., medical students, primary care, mental health specialists, etc.) and educators about anorexia nervosa, and how does this impact early identification rates, access to services, and recovery? | 21 | *"How can doctors be better trained to recognize the symptom and to believe concerns of parents?"*  
*"What information do health professionals need to better identify and treat anorexia in the early, mid and late stages of the illness?"* |
| 6    | How could the system better support individuals with anorexia nervosa through transition periods so that care is streamlined and easier to navigate? | 18 | *"Best strategies to transition patients back to home community after admission to inpatient/residential care away from their community."*  
*"What can be done to manage the transition periods between being diagnosed, accepted, and starting treatment, and then leaving treatment?"* |
| 7    | What is the most effective way of treating co-occurring/comorbid disorders for individuals with anorexia nervosa, and should treatments occur separately or at the same time? Why? | 25 | *"What is the most effective treatment (and order of treatments) for patients with an ED with other co-occurring disorders like trauma, depression, anxiety?"*  
*"Are there any best practices for combined treatment?"* |
| 8    | What are the effects of repeated inpatient admissions for anorexia nervosa patients, and should treatment be different after repeated admissions? | 4 | *"Does repeated inpatient anorexia treatment program admissions result in a lower ability to function in the 'real world' outside of hospital, with patients getting too used to socializing in that clinical hospital environment, and how can treatment providers combat this?"*  
*"Do repeated admissions to inpatient anorexia treatment program lessen the effectiveness of the program? (Becoming a cycle of going in and out of treatment, the same people going in and out of treatment.)"* |
| 9    | What is the most effective way of educating families and caregivers on anorexia nervosa and on ways to support patients through recovery? | 14 | *"How can parents and families know better the signs of an eating disorder?"*  
*"As a parent, how can I love and support my daughter without walking on eggshells or caving in to the eating disorder?"* |
| 10   | What are the wait times across Canada for adolescent girls and women suffering from anorexia nervosa? Are they equitable? How can we decrease wait times for services? | 5 | *"What are the approximate wait times for treatment across Canada for eating disorders?"*  
*"What needs to be done to shorten wait times to get into programs for persons afflicted with an eating disorder?"* |
3.3 | Stage 3: Processing and collating the questions

From March to June, 2018, questions were sorted and refined to retain a list of unique questions that pertained to treatment, access to service, and cooccurring issues related to AN in females (15 years and older). Out of the 897 questions that were collected, 294 questions were eliminated because they were beyond the scope of the research project (Figure 3). The remaining 603 questions were identified as being within the project scope and were collapsed into 71 indicative questions to eliminate redundancy and collate similar questions. A methodological search of published peer-reviewed literature was conducted to determine how many of the indicative questions had already been answered by up-to-date systematic reviews and whether there were other indicative questions emanating from the systematic reviews that remained an area of uncertainty. Within the systematic reviews that were examined, eight indicative questions were determined to be unanswered and within the scope of the project (e.g., What, if any, are the causal relationships between gut microbiota and AN behaviors?) and were therefore added to the list of indicative questions (see Table 3). In total, 18 questions were removed from the remaining list based on this process (see Table 3). This yielded a total of 61 indicative questions at the end of this stage.

3.4 | Stage 4: Interim prioritization

The 61 uncertainties were then placed through an interim prioritization process. The survey asked participants (n = 48) to select 10 of the 61 indicative questions that were the most important research priorities to them. In total, 21 indicative questions were selected as important by at least 20% of respondents (see Table 3, also available at http://www.cheori.org/en/CEDPSP). The Steering Committee unanimously agreed to carry these questions forward to the final stage.

3.5 | Stage 5: Final priority setting workshop

The CEDPSP invited 38 individuals to attend the workshop from the self-nominated list who consisted of a balanced mix of those with lived experience, carers, and service providers from across Canada who had varied experiences with EDs. Twenty-eight individuals (74%) of those invited were able to attend. The workshop was held in Toronto, Canada in September, 2018. The participants represented individuals from six provinces, and consisted of 32% with lived experience, 32% carers, 29% providers, and 7% who identified as both someone with lived experience and a provider. The majority of the attendees were female (89%). The workshop resulted not only in the establishment by rank of the top 10 priorities but also a meaningful knowledge exchange between stakeholders not normally sitting at the same table (see Table 4).

4 | DISCUSSION

This patient-oriented research project saw various stakeholders from the Canadian ED community come together to coestablish the top 10 research priorities for AN in females (15 years and over), and provided a first attempt of this type of methodology in the field at a national level. The success of the meaningful engagement enabled the voices from different perspectives to come together to agree upon where our research efforts should be targeted, overcoming previous limitations of having only certain stakeholder groups contribute to what research questions get answered and allowing for those who are most affected by the illness to have a voice. This project also provided a platform for the introduction of patient-oriented research in EDs in Canada and set the stage for the use of various patient engagement strategies in research and the establishment of a patient partner forum.

The priorities that were derived from this process included a range of broad questions that have the potential for multiple implications. Interestingly, the top three priorities were related to treatment-related questions, looking for answers relating to effective treatment options and efficacy studies, how we can leverage learned experience to help inform effective treatment strategies, and collaborating to gather surveillance or epidemiological data to better position the field to advocate for more treatment options. These priorities would not be unlike those mentioned in multiple research reports across the field (e.g., Garfinkel, 2002; Murray, Quintana, Loeb, Griffiths, & Le Grange, 2019), including those formulated for policy purposes (e.g., Standing Committee on the Status of Women, 2014). In general, the top 10 questions could be more generally categorized into clusters of questions related to those pertaining to treatment (#1, 2, 4, 7, 8), education/training (#5, 9), epidemiology (#3), and services (#6, 10) speaking to the overlap or relatedness of some of the priorities. Additionally, some priorities seem more appropriate for studies using a trial methodology RCT (#1, 4, 5, 9), while others seem better suited for surveillance studies (#3, 10), pragmatic trials (#7), qualitative/narrative studies (#2), or mixed methods studies (#6, 8) providing further support that much research is still needed to better inform the field.

A first of its kind in Canada, this large national prioritization exercise included the combination of diverse perspectives from 147 individuals affected by EDs who identified research questions that are of relevance to Canada. Additional diverse input for this project was provided by a combination of stakeholders who made up the Steering Committee—those with lived experience, carers, and healthcare professionals—who alongside the investigative team provided oversight for this project, and provided a first glimpse of how to successfully work together to achieve the project goals. The breadth and distribution of different key stakeholders throughout the entire process allowed for credibility and relevance of the identified priorities, and permitted this process to truly reflect the shared perspectives of the community. This not only helped with partnership building at a national level by engaging with all collaborators and ED national organizations to aid with this project, but also allowed for the establishment of a patient partner forum, where participants in this project were introduced to the principles of patient-
oriented research, some of the considerations when doing this kind of work, and together learned how best to work together to achieve shared goals. Feedback gained from the project showed that the mixture of the perspectives from various stakeholders was powerful, and individuals felt they had an opportunity to express themselves, which for some was identified as a first. Additionally, the use of the JLA methodology to guide this work provided a rigorous method for the coestablishment of the priorities, and aided to ensure the process was objective and had well outlined steps to guide the process.

Benefits of the use of this methodology, wherein those most affected by EDs have contributed to the top 10 research priorities, allowed for a mechanism to minimize avoidable sources of waste and inefficiency in research. It also provides a guide for researchers and research funders in the field of EDs to ensure future research is relevant to those with lived experience, carers, and healthcare professionals in the field. Attaining the input from the users and providers of the service presents clear directions for future research that has great relevance and provides guidance as to where to focus research efforts that will likely have the most gain for those affected by EDs.

While the first in Canada, a similar priority-setting exercise has taken place in the Netherlands (van Furth, van der Meer, & Cowan, 2016), and in Australia using a Delphi study design (Hart & Wade, 2019). Although both of these priority projects included a larger scope involving all types of EDs and topic areas (e.g., prevention), several similarities of the priorities across the different projects emerged, suggesting some congruence at an international level. Namely, priorities related to factors involved in recovery, treatment for comorbid disorders that often present with EDs, and the need for effective treatments at all stages of illness were echoed across the three projects. Questions regarding how best to involve families in the recovery process were also mentioned by all. While other similarities materialized when comparing results of any two of the priority exercises, there were also notable differences across projects. This may be in part due to differing methodologies used, the nonequivalent health systems across countries, and the needs of any given population. For example, research priorities related to prevention and enhancing early intervention were highly ranked by both the Dutch and Australian projects, which may be reflective of the differing project methodologies used, the differing foci of the projects, or because advanced early intervention mental health service programs are already in place in some countries making enhancement of these systems a more pertinent issue (headspace; McGorry et al., 2007). Encouragement for ongoing priority-setting exercises across the globe in the field of EDs would continue to grow our understanding of the research priorities of those most affected by an ED and allow for opportunities to continue to solicit answers to the most pressing research questions that are affecting those at an international scale.

## Limitations and Future Directions

Although the use of patient-oriented research provides a new and enriching method in which to conduct research, there were some limitations worth noting. Namely, this process, which was mainly based on self-nomination procedures, was unlikely to be representative of all Canadians as certain groups, provinces, and territories, and genders were not represented throughout the project (e.g., Francophones, Indigenous populations, individuals from the Territories). Similarly, as the survey was web-based individuals without internet access would not be represented in the opinions expressed. Limiting the scope to AN in females 15 years and older may have excluded those with other types of EDs who felt the survey may not have been relevant to them, as well as restricted the priority setting to other EDs diagnoses, males, children with EDs, and other aspects of research that require addressing. The hope is that future work will be stimulated in this same realm that can address these different areas now that the stage has been set for this kind of work. Additionally, collating responses into broader categories for purposes of data management likely diluted the specific research questions that emanated from the survey process and made the priorities themselves broad questions with multiple parts requiring several research studies necessary to answer a specific priority. It may have also included the top 10 priorities less accessible to researchers and funders as they do not appear as specific research questions that on their own could be advanced as research proposals. Specific work to make the questions more research specific might go a long way to furthering work on these priorities.

A further limitation of this prioritization process may have been the lower response rate that was derived from the community survey as it was only available for a short 3-week period due to time restraints related to the project. Also, as approximately two out of three of those who answered the survey were service users, this may have lent to greater emphasis on priorities about clinical care and available treatment options versus other types of research questions that are potentially less accessible to nonclinicians or nonscientists (e.g., studies examining the biological/genetic basis for AN). Furthermore, we did not directly solicit opinions from researchers and instead relied on the unanswered priorities derived from the literature to partially provide this perspective. We also acknowledge that there was no systematic method for soliciting opinions on all research areas in the field (social, genetic, etc.), therefore areas of study may have been missed. We also are unable to ignore that prioritization in this manner is highly subjective, and that it is possible to get different results if a different set of individuals participated in various aspects of the process.

Final and ongoing stages of this project consist of disseminating widely the priorities and getting them into researchers, policy, and research funders hands in order to promote this much needed work in the field. Recognition of the need to spend time deriving specific and direct research question(s) from the priorities is noted, given the large scope of the majority of the research uncertainties in their current format. Future aims are to continue to encourage the uptake of the priorities, looking for innovative ways to study some of the priorities, promoting the current methodology for any future priority setting exercises, and continuing to build on the partnerships developed during this project to further this work and the use of patient-oriented research methodologies in the field of EDs.
CONCLUSIONS

The top 10 research priorities that were derived from this structured process achieved the goals of meaningful partnership development and knowledge exchange among a diverse number of stakeholders. The “patient” voice was embedded in all stages and discussions within the project, and the top priorities agreed upon reflect well the community’s view of what is most important to study next in AN-affecting females.

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CONFLICT OF INTEREST

The authors declare no potential conflict of interest.

DATA AVAILABILITY STATEMENT

The data that support the findings of this study are available from the corresponding author upon reasonable request.

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