

Cocreating Research Priorities for Anorexia Nervosa: The Canadian Eating Disorder Priority Setting Partnership

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For which topic were research priorities identified?

anorexia nervosa

In which location was the research priority setting conducted?

North America - Canada

Why was it conducted at all?

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 leading 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. It is additionally argued that publicly funded research related to health care systems and conditions should prioritize those 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.

What was the objective?

to identify and prioritize the top 10 research priorities for females, 15 years or older, with anorexia nervosa

What was the outcome?

a ranking list of 10 research questions

How long did the research prioritization take?

April 2017 - September 2018

Which methods were used to identify research priorities?

JLA method

How were the priorities for research identified exactly?

Step 1: setting up PSP: establishing steering group, defining scope. Step 2: gathering and identifying questions: survey to collect opinions on the most important research priorities for AN in females aged 15 years and older, 897 responses. Step 3: data processing: collating responses, removing out-of-scope responses or unanswerable submissions, similar or duplicate questions grouped together, formulating 71 indicative questions in line with PICO format, check against evidence, resulting in 61 indicative questions. Step 4: interim ranking: survey asking participants to identify top 10 most important questions, indicative questions that received at least 20% of votes moved forward, in total 21 indicative questions selected as important. Step 5: final prioritization: workshop: prior to the workshop participants were asked to establish own preliminary ranking of the uncertainties, during workshop series of small group discussions and small group rankings, followed by plenary discussions and rankings

Which stakeholders took part?

Those with lived experience, families, and healthcare professionals. Survey: 147 participants: 24% with lived experience, 24% carers, 18% healthcare professionals. Interim ranking: 48 participants. Workshop: 28 participants: 32% with lived experience, 32% carers, 29% providers, 7% who identified as both someone with lived experience and a provider.

How were stakeholders recruited?

Survey was disseminated widely to the ED community via distribution lists of partnering organizations and communication strategies using a range of social media platforms. Survey 2 was disseminated, in the same order, to various ED community members. As to the workshop, individuals were invited to participate in the workshop consisting 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.

Were stakeholders actively involved or did they just participate?

Stakeholders not only participated but were also actively involved in the research prioritization process. They were part of a steering group. The steering group consisted of 9 members: 3 members from each stakeholder group (individuals with lived experience, carers, healthcare professionals). The members supported the investigative team and participated in the workshop.

