

Setting the top 10 eating disorder research and translation priorities for Australia




Australian & New Zealand Journal of Psychiatry
1–11

DOI: 10.1177/00048674221128754

© The Royal Australian and
New Zealand College of Psychiatrists 2022

Article reuse guidelines:
sagepub.com/journals-permissions
journals.sagepub.com/home/anp



Phillip Aouad^{1*} , Ashlea Hambleton^{1*}, Peta Marks^{1*},
Danielle Maloney^{1,2}, Shannon Calvert³, Belinda Caldwell⁴,
Siân A McLean⁵ , Beth Shelton⁶, Katherine Cowan⁷,
John Feneley⁸, Genevieve Pepin⁹, Susan Paxton¹⁰,
Michelle Williams¹¹, Thy Meddick¹², Sarah Squire¹³, Ian Hickie¹⁴ ,
Frances Kay Lambkin¹⁵, Stephen Touyz¹ and Sarah Maguire¹

Abstract

Objectives: People with eating disorders, as well as their caregivers, experience high symptom burden, reduced quality of life and increased risk of early mortality. A lack of resources, disjointed vision and limited uptake of the evidence have limited the translation and implementation of research into practice. Little is known about what stakeholders (people with a lived experience, caregivers, health care professionals, researchers and policymakers) see as the most important research priorities. This study aimed to identify Australia's top 10 consensus-derived research and translation priorities for eating disorders.

Methods: Participants ($n = 606$) included people with a lived experience, carers, health care professionals (clinicians) and researchers working in eating disorders. The methodology aligned with the James Lind Alliance priority setting process, which involved oversight by a co-design advisory committee and utilised a national online interim priority setting survey and co-design workshops to identify the top 10 research and translation priorities.

Results: The initial national consultations elicited 1210 issues from 480 individuals. From this, 606 participants short-listed 59 plain language questions in order of personal priority. In total, 16 questions were consistently ranked as important. As a final step, 24 individuals (with equal representation from all 4 stakeholder groups) attended the final

¹InsideOut Institute for Eating Disorders, Central Clinical School, Faculty of Medicine and Health, The University of Sydney, Sydney, NSW, Australia

²Sydney Local Health District, NSW Health, Sydney, NSW, Australia

³Private Lived Experience Consultant, Perth, WA, Australia

⁴Eating Disorders Victoria, Melbourne, VIC, Australia

⁵School of Psychology and Public Health, La Trobe University, Melbourne, VIC, Australia

⁶National Eating Disorders Collaboration, Sydney, NSW, Australia

⁷James Lind Alliance, Southampton, UK

⁸NSW Health, Sydney, NSW, Australia

⁹School of Health & Social Development, Faculty of Health, Deakin University, Geelong, VIC, Australia

¹⁰Department of Psychology and Counselling, La Trobe University, Melbourne, VIC, Australia

¹¹Royal Hobart Hospital, Tasmanian Health Service, Hobart, TAS, Australia

¹²Mental Health Alcohol and Other Drugs Branch, Clinical Excellence Queensland, Brisbane, QLD, Australia

¹³Butterfly Foundation, Sydney, NSW, Australia

¹⁴Brain and Mind Centre, The University of Sydney, Sydney, NSW, Australia

¹⁵School of Medicine and Public Health, University of Newcastle, Newcastle, NSW, Australia

*P.A., A.H. and P.M. are equal first authors.

Stephen Touyz and Sarah Maguire are also affiliated to Sydney Local Health District, NSW Health, Sydney, NSW, Australia

Corresponding author:

Phillip Aouad, InsideOut Institute for Eating Disorders and Central Clinical School, Faculty of Medicine and Health, The University of Sydney, Sydney, NSW 2006, Australia.

Email: phillip.aouad@sydney.edu.au

prioritisation workshop to co-establish the top 10 research and translation priorities.

Conclusion: The findings highlight the need for people with a lived experience, carers, health professionals and researchers to work collaboratively to develop co-designed research and translation activities that address the key areas of early intervention, prevention, understanding the aetiology of eating disorders and effective treatment of people experiencing eating disorders.

Keywords

Anorexia nervosa, bulimia nervosa, eating disorders, Australia, research, priorities, policy

Background

Eating disorders (EDs) are complex illnesses that impact biological, emotional, social and vocational domains. Combined with disordered eating, eating disorders affect 16.3% (>4 million) of the Australian population (Hay et al., 2015). Globally, the lifetime prevalence rates for eating disorders are estimated to be 8.4% (3.3–18.6%) for women and 2.2% (0.8–6.5%) for men, with prevalence rates continuing to rise (Galmiche et al., 2019). Eating disorders result in serious medical, mental health and quality-of-life consequences (De La Rie et al., 2005) to the individual experiencing the eating disorder and their carers. Perhaps most striking is the elevated mortality rates of eating disorders, specifically anorexia nervosa (AN), which yields the highest mortality rate of any psychiatric illness (5.8 standardised mortality rate) (Arcelus et al., 2011).

Research and the translation and implementation of research into practice can positively affect lives, and more importantly, save lives. To date, research innovation in the field of eating disorders, particularly in Australia, has been hampered by insufficient resourcing and investment compared to other psychiatric conditions, which receive considerably more funding (Murray et al., 2017). Specifically, eating disorders receive AUD\$1.10 per affected individual, compared with autism (AUD\$32.62), schizophrenia (AUD\$67.36) and depression (>AUD\$100) (Murray et al., 2017). There appears to be a reliance on pockets of excellence, and a lack of coherent vision and plan, resulting in intermittent discoveries and limited uptake of the evidence. In recognition of this issue, the Australian Government Department of Health commissioned InsideOut Institute to develop the country's first-ever national Eating Disorders Research and Translation Strategy (herein referred to as the 'Strategy'). The Strategy's primary purpose is to support increased output and impact of eating disorder research, research translation, and implementation in Australia. The final phase of developing the Strategy was an independent process to identify Australia's current top 10 research and translation priorities. Similar processes have taken place in the Netherlands (Van Furth et al., 2016), Canada (Obeid et al., 2020) and a previous Australian prioritisation study used a Delphi study design (Hart and Wade, 2020).

The current paper is exploratory in nature and reports on the process of identifying top 10 consensus-derived research and translation priorities – specifically in the field of eating disorders in Australia. Furthermore, the study examines whether differences in research priorities exist between eating disorder stakeholders. This process may act as a blueprint for setting national research translation priorities elsewhere and serves as an example of a broader strategy in action using co-design principles.

Method

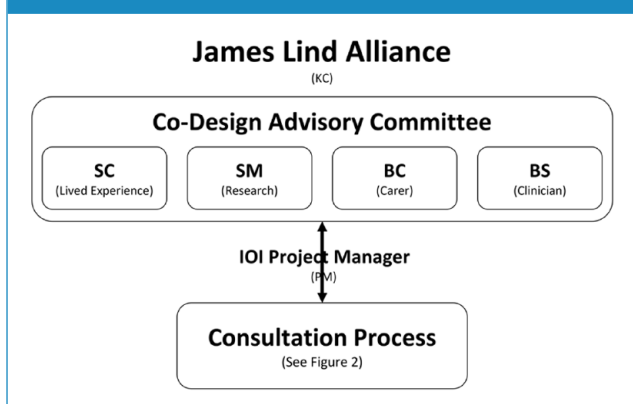
Study design and priority setting process

The project drew on aspects of the James Lind Alliance (JLA) priority setting method and was carried out in association with the JLA. The JLA was established in 2004 and developed the evidence-based co-design priority setting process to identify evidence uncertainties and prioritise research topics (Cowan and Oliver, 2021). Central to the JLA priority setting process is that people with lived experience, carers and clinicians should agree on priority areas (Cowan and Oliver, 2021). The current study added to the JLA priority setting process by including the perspectives of researchers, adhering to JLA principles, which assert that priority setting processes must be guided by (1) equal voices; (2) inclusivity; (3) transparency of the process, methods and interests; and (4) a commitment to using and contributing to the evidence base.

A clear governance structure was established and included a JLA consultant, a co-design advisory committee and a project manager (Figure 1). A JLA adviser had full oversight of the prioritisation process, facilitated the priority setting workshops and conducted independent data analyses of the interim survey and collaborative analysis of workshop outcomes.

Co-design advisory committee. The co-design advisory committee was a sub-group of the Strategy Advisory Committee consisting of a person with a lived experience, a carer, a clinician and a researcher. The role of the co-design advisory committee was to oversee the entire priority setting process. This work included coding the long list of research questions, conducting a plain language review of the

Figure 1. Project governance structure.



interim list (see procedure) and observing the final priority setting workshops.

Project manager. The project manager, provided by Inside-Out Institute, coordinated coding and merging of the long list with oversight and approval by the committee and guidance from the JLA consultant. The project manager also provided reports between the consultations and the committee and assisted with the organisation of the final prioritisation workshops.

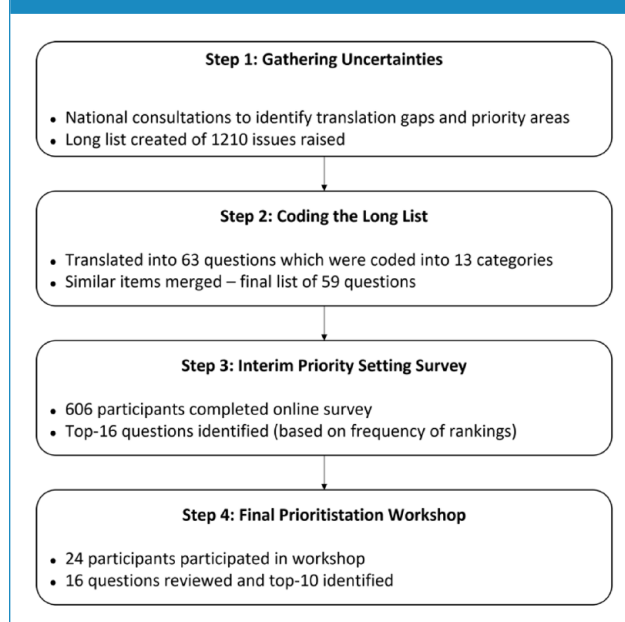
Procedure

We followed four primary steps during the consultation process (Figure 2). These steps were informed by JLA processes and included the following:

Step 1: Gathering uncertainties. During a series of national consultations, contributors (individuals, organisations, peak bodies) discussed the research and translation gaps and priorities they felt needed further research to highlight and address perceived evidence uncertainties in eating disorders.

Step 2: Coding the long list. The long list was coded into 13 categories, identified by an expert consensus process through a previously conducted study using Delphi methodology (Hart and Wade, 2020). After coding, similar questions were merged and checked against existing research evidence in collaboration with the advisory committee. Additional categories were thematically determined for questions that did not fall into one of the pre-existing Delphi-derived categories, specifically categories relating to data, recovery, translation, workforce and communication (Hart and Wade, 2020). Final categories included prevention, the origin of EDs, social and emotional determinants, early identification, treatment, diagnosis, data, epidemiology, recovery, research, translation, workforce and communication (see Table 1). After coding, similar questions were merged and checked

Figure 2. Consultation process.



against existing research evidence in collaboration with the advisory committee.

Exclusion criteria for not coding certain questions were applied to items that were too broad (e.g. ‘How do we cure eating disorders?’); too specific; or which focused on policy or strategy imperatives rather than questions that researchers could feasibly answer (e.g. ‘How do we increase funding in eating disorders research?’). Consensus to exclude questions was based on a review, discussion and agreement between the co-design committee.

Step 3: Interim Priority Setting: A National Survey. People with a lived experience of an eating disorder, families and carers, clinicians and researchers across Australia were invited to complete the 10-minute interim priority setting survey, which consisted of a series of single-item questions. Upon entering the online survey, participants were presented with the participant information statement and consent forms. Once completed, they self-selected the participant type they felt most relevant to their situation (individual with a lived experience, carer, clinician or researcher). Participants were presented with 59 plain language research and translation questions, such as ‘How can public health messaging around healthy eating and weight be delivered without impacting on the development of eating disorders and inducing weight stigma?’. Participants were then asked to shortlist all questions they thought were most important for research to address, *based on their situation and experience*. Participants were then asked to select their top 10 questions from the previously shortlisted items.

Table 1. Definitions of research priority area categories.

Research priority area (category)	Description
Prevention	Developing prevention strategies for eating disorders, body image and related issues
The origin of eating disorders	Understanding the aetiology of eating disorders
Social and emotional determinants	Understanding the social and emotional factors that influence eating disorder development
Early identification	Identifying early warning signs and indicators for the development of eating disorders
Treatment	Developing effective and accessible interventions and models of care
Diagnoses	Developing effective, reliable, accurate and useful diagnostic practices and tools
Data	Using data to capture, describe and inform health care outcomes and approaches
Epidemiology	Understanding the distribution, sociodemographic risk factors, patterns and health outcomes of eating disorders across the population
Recovery	Understanding the recovery process, preventing relapse, increasing quality of life and increasing remission rates
Research	Understanding how to use research to improve knowledge and approach to eating disorder care and to inform policy and decision-making
Translation	Understanding how to effectively translate research from knowledge to practice
Workforce	Developing the eating disorder workforce
Communication	Developing better public health messages and awareness of eating disorders and using communication to bring research into the public domain

Step 4: Final Prioritisation Workshops. The final prioritisation workshops were held online due to the national distribution of participants, with the most frequently ranked priorities for each stakeholder group from Step 3 presented at the workshop. During the workshop, 4 groups (with an equal mix of role types) independently reviewed the 16 most frequently ranked priorities and discussed them among the larger group to settle on a consensus-derived top 10.

Recruitment

Interim priority setting survey. Eligible participants were recruited using a snowball sampling technique. Specifically, an email was sent to 480 individuals and 80 organisations who participated in the initial consultation stages of the Strategy process and had agreed to participate in ongoing consultation – these organisations and individuals were encouraged to disseminate the survey link through their networks. The survey was also promoted through Facebook advertising and Twitter. Advertising directed potential participants to a purpose-built website, which detailed the project, the purpose of the interim priority setting survey and further information regarding how to participate.

Final prioritisation workshops. Workshop participants were recruited from a list of those who completed the Expression of Interest (EOI) form at the end of the Interim Priority Setting

Survey. The co-design advisory committee reviewed the EOI list to ensure equal representation of stakeholders and (as far as possible) diversity of lived experience, age, gender, geography, and clinical and research expertise. The final top 10 priorities list is published on the JLA website according to best practice and procedures (JLA.nihr.ac.uk) (Cowan and Oliver, 2021).

Ethics

The study was approved by the Sydney Local Health District (Sydney, New South Wales, Australia) Human Ethics Review Committee.

Data analysis

SPSS v26 (IBM Corp.) was used to analyse all data. Descriptive statistics were used to determine survey participant characteristics. A power analysis was considered; however, given the nature of the analysis and sampling procedure, the sample size obtained was sufficient to meet all aims of the current study (Murphy et al., 2014). JLA methodology was used in the final prioritisation workshop to determine the top 10 priorities.

Mitigation of data dredging was ensured by following the JLA process, having the co-design committee oversee all elements of the priority setting process and using descriptive statistics to determine sample characteristics.

Results

National consultations

Over 480 individuals, representing 80 organisations, participated in the National consultations. Participants included individuals with lived experience and carers, clinicians, service providers, academics and researchers, and representatives from State and National mental health commissions. Department of Health representatives from Australian Federal, State and Territory Governments participated in each consultation. The contributors raised 1210 separate issues. These issues were converted into a long list of plain language questions.

Interim priority setting survey

Of the 643 people who entered the survey, 606 participants responded either fully or partially to the survey, meaning they chose which areas of research they believed should be examined and ranked them. Thirty-four people commenced but did not consent or complete the survey, and three people did not specify their role, rendering their responses ineligible for inclusion in final analyses. The completion rate was >92.4%, with a final sample of 606 responses recorded.

The majority of participants identified as lived experience (41.4%, $n=251$), followed by health professionals (29.7%, $n=180$), carers (20.3%, $n=123$) and researchers (8.6%, $n=52$). The average age of respondents was 39.52 years ($SD=13.42$). Of the 606 participants, 391 identified as women (64.5%) (includes transgender, $n=2$) and 32 as men (5.3%). Of note, 183 participants did not respond to the gender question or preferred not to say (30.2%). Of those that disclosed both gender and role ($n=426$), 160 women and 4 men identified with having a lived experience of an eating disorder; 81 women and 4 men indicated to caring for someone with an eating disorder; 118 women and 18 men indicated to be health professionals; and 32 women and 6 men indicated to be researchers. Table 2 further outlines the sample's sociodemographic characteristics.

The long list of research issues was coded into 59 plain language questions. After ranking by frequency, questions that met the following conditions were included in the initial 'interim priority list':

- The top three questions from across the four stakeholder groups (totalling eight questions);
- Questions that were ranked in the top 10 for at least two stakeholder groups (six questions);
- Questions ranked in the top 10 for at least one stakeholder group *and* aligned with eating disorder experience/expertise (three questions).

Table 2. Demographic characteristics of participants who completed interim priority setting survey.

	Interim priority setting survey (N = 606); n (%)
Stakeholder group	
Lived experience	251 (41.4)
Carer	123 (20.3)
Health professional	180 (29.7)
Researcher	52 (8.6)
Gender	
Men	32 (5.3)
Women	391 (64.5)
Preferred not to say or undisclosed	183 (30.2)
State/territory	
Queensland	45 (7.4)
New South Wales	165 (27.2)
Victoria	131 (21.6)
Australian Capital Territory	6 (1.0)
South Australia	11 (1.8)
Western Australia	37 (6.1)
Northern Territory	5 (.8)
Tasmania	10 (1.7)
Missing	195 (32.1)
Location	
Metropolitan	331 (54.6)
Regional and rural	74 (12.2)
Missing	195 (32.1)
Education	
Did not complete secondary education	3 (0.5)
Year 10 ^a	3 (0.5)
Year 12 ^a	26 (4.3)
TAFE/apprenticeship ^a	18 (3.0)
Tertiary education (graduate certificate, bachelor's degree)	164 (27.1)
Post-graduate education (Master's, PhD)	204 (33.7)
Other	8 (1.3)
Unknown	179 (29.5)

TAFE: Technical and Further Education (similar to technical college); GCE/O: General Certificate of Education/ Ordinary-Level; GCSE/A: General Certificate of Secondary Education/ A-Level.

^aYear 10 (similar to middle school; or GCE/O Level schooling); Year 12 (similar to senior high school; or GCSE/A Level schooling).

Table 3. Top 16 research questions from the interim priority setting survey.

Rank	Research and translation question
1	How can eating disorder treatments and treatment pathways be more individualised to consider diverse needs, stage of life, illness duration, type and diagnosis?
2	How can GPs and other health professionals better identify disordered eating and the symptoms of all stages of all types of eating disorders, and intervene appropriately as part of routine practice?
3	How can public health messaging around healthy eating and weight be delivered without impacting on the development of eating disorders and inducing weight stigma?
4	How do we help someone to maintain recovery and avoid relapse?
5	What are the barriers to early intervention in eating disorders and how can these be addressed?
6	What is the role of social media in the development of eating disorders and how can we harness its influence to prevent them?
7	How do we ensure all Australians have equitable access to effective eating disorder treatments no matter where they live or what they can afford?
8	What impact does trauma have on the development and treatment of an eating disorder?
9	What are the key risk and protective factors and how do they impact on the development of (or the risk of developing) an eating disorder?
10	What genetic or biochemical factors contribute to risk/protection or onset of an eating disorder?
11	What existing eating disorder services, treatments or treatment factors have the best long-term outcomes?
12	Are there particular strategies parents/families can use that help prevent the development of an eating disorder?
13	What services do people with eating issues first present to and how can we embed early intervention into those settings?
14	What are the positive and negative impacts of current treatment – how can we reduce the negative impact and increase the positive?
15	What support and skills do families need to help their loved one at all ages and stages of treatment across the recovery journey?
16	How do we increase public knowledge about eating disorders and address stigma, discrimination and stereotyping?

GPs: general practitioners.

The co-design advisory committee merged two questions, given their similar theme. This process resulted in a total of 16 questions (see Table 3). Table 4 (represented visually in Figure 3) indicates the ranked research priorities in the online survey of each stakeholder group.

Final prioritisation workshops

The top 16 questions from the interim priority setting survey were presented at the final prioritisation workshop to 24 participants, with equal representation of the 4 stakeholder groups: individuals with lived experience, carers, clinicians and researchers. Deliberation and discussion regarding which questions should be included in the top 10 occurred between stakeholders over two rounds, with groups re-configured for the second round to enable discussion and exposure to people presenting a range of different

perspectives. This process culminated in a consensus-derived final top 10 research and translation priorities. Participants agreed that the questions should not be ranked in priority and that all questions were equally important. Hence, the questions were transformed into 10 non-ranked priority areas for eating disorder research and translation and represented in an infinity symbol (Figure 4): risk and protective factors, prevention, early identification, equity of access, treatment outcomes, individualised medicine, support families, early intervention, do no harm and stigma and health promotion.

Discussion

This study was the first research priority setting exercise using a JLA-aligned process including individuals with a lived experience, caregivers, health professionals and

Table 4. Top 10 ranked research priorities in the online survey of each stakeholder group.

Rank	Lived experience (N=251)	Rank	Carers (N=123)	Rank	Clinicians (N=180)	Rank	Researchers (N=52)
1	What impact does trauma have on the development and treatment of an eating disorder?	1	Treatment: What support and skills do families need to help their loved one at all ages and stages of treatment across the recovery journey?	1	How can public health messaging around healthy eating and weight be delivered without impacting on the development of eating disorders and inducing weight stigma?	1	What are the key risk and protective factors and how do they impact on the development of (or the risk of developing) an eating disorder?
2	How can public health messaging around healthy eating and weight be delivered without impacting on the development of eating disorders and inducing weight stigma?	2	What genetic or biochemical factors contribute to risk/protection or onset of an eating disorder?	2	How can eating disorder treatments and treatment pathways be more individualised to consider diverse needs, stage of life, illness duration, type and diagnosis?	2	How can public health messaging around healthy eating and weight be delivered without impacting on the development of eating disorders and inducing weight stigma?
3	How do we ensure all Australians have equitable access to effective eating disorder treatments no matter where they live or what they can afford?	3	Treatment: How can eating disorder treatments and treatment pathways be more individualised to consider diverse needs, stage of life, illness duration, type and diagnosis?	2	What impact does trauma have on the development and treatment of an eating disorder?	2	What are the barriers to early intervention in eating disorders and how can these be addressed?
4	How can GPs and other health professionals better identify the signs and symptoms of early stages of all types of eating disorder and intervene appropriately?	4	Treatment: What are the positive and negative impacts of current treatment – how can we reduce the negative impact and increase the positive?	4	How do we ensure all Australians have equitable access to effective eating disorder treatments no matter where they live or what they can afford?	4	How can GPs and other health professionals better identify the signs and symptoms of early stages of all types of eating disorder and intervene appropriately?
5	How can eating disorder treatments and treatment pathways be more individualised to consider diverse needs, stage of life, illness duration, type and diagnosis?	5	How do we ensure all Australians have equitable access to effective eating disorder treatments no matter where they live or what they can afford?	4	What are the risks/benefits of implementing eating disorder prevention strategies at a young age?	4	What is the role of social media in the development of eating disorders and how can we harness its influence to prevent them?
5	How do we ensure that GPs and other health professionals have the knowledge, skills and confidence to engage in eating disorder health promotion, early intervention and treatment as part of their routine practice?	6	How can GPs and other health professionals better identify the signs and symptoms of early stages of all types of eating disorder and intervene appropriately?	6	How can GPs and other health professionals better identify the signs and symptoms of early stages of all types of eating disorder and intervene appropriately?	4	Are there particular strategies parents/families can use that help prevent the development of an eating disorder?

(Continued)

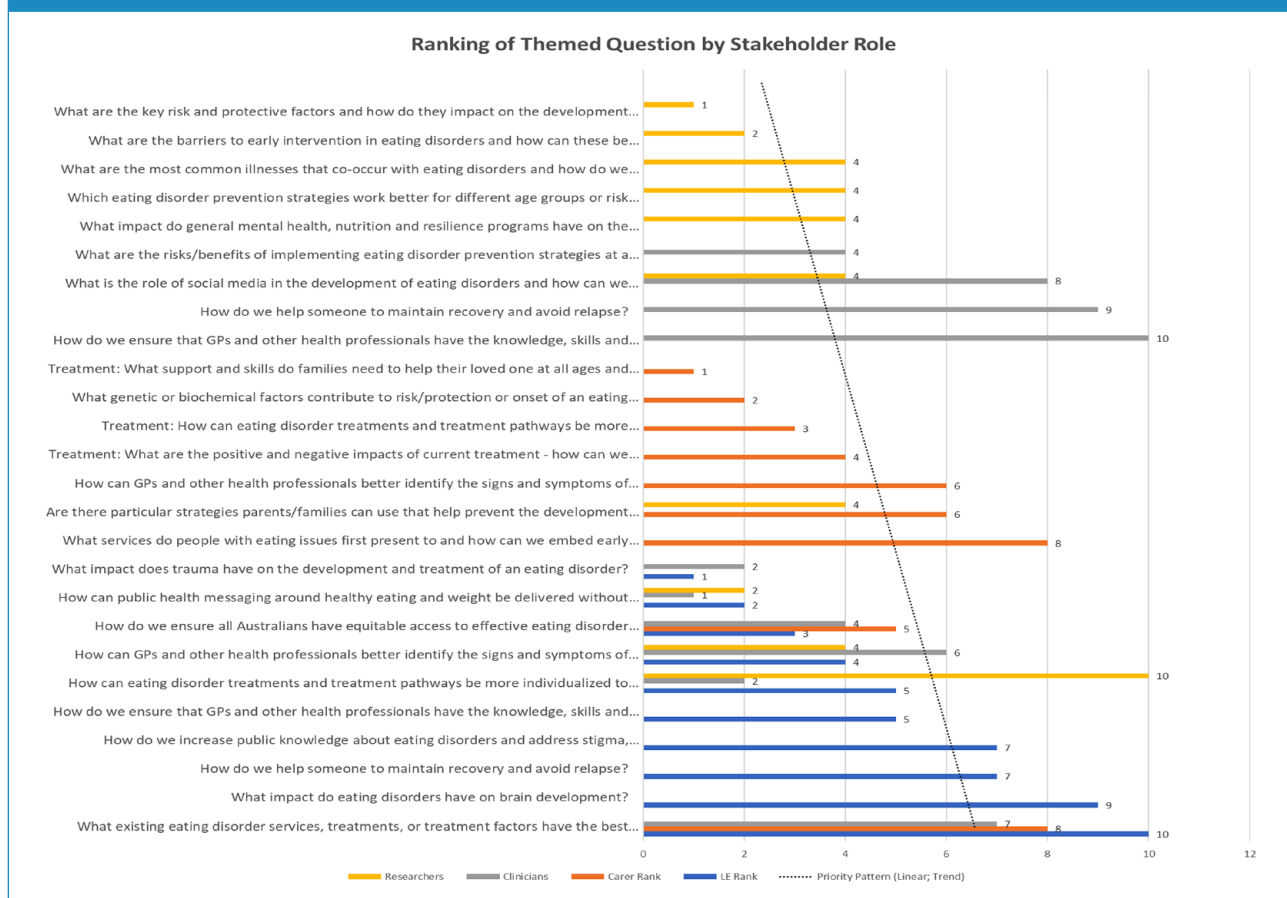
Table 4. (Continued)

Rank	Lived experience (N = 251)	Rank	Carers (N = 123)	Rank	Clinicians (N = 180)	Rank	Researchers (N = 52)
7	How do we increase public knowledge about eating disorders and address stigma, discrimination and stereotyping?	6	Are there particular strategies parents/families can use that help prevent the development of an eating disorder?	7	What existing eating disorder services, treatments or treatment factors have the best long-term outcomes?	4	What are the most common illnesses that co-occur with eating disorders and how do we make sure we treat them as well as the eating disorder?
7	How do we help someone to maintain recovery and avoid relapse?	8	How do we help someone to maintain recovery and avoid relapse?	8	What is the role of social media in the development of eating disorders and how can we harness its influence to prevent them?	4	Which eating disorder prevention strategies work better for different age groups or risk groups, to reduce harm or prevent them altogether?
9	What impact do eating disorders have on brain development?	8	What existing eating disorder services, treatments or treatment factors have the best long-term outcomes?	9	How do we help someone to maintain recovery and avoid relapse?	4	What impact do general mental health, nutrition and resilience programmes have on the development of eating disorders?
10	What existing eating disorder services, treatments or treatment factors have the best long-term outcomes?	8	What services do people with eating issues first present to and how can we embed early intervention into those settings	10	How do we ensure that GPs and other health professionals have the knowledge, skills and confidence to engage in eating disorder health promotion, early intervention and treatment as part of their routine practice?	10	How can eating disorder treatments and treatment pathways be more individualised to consider diverse needs, stage of life, illness duration, type and diagnosis?

GPs: general practitioners.

N indicates joint positions in ranking.

Figure 3. Visual representation of top 10 ranked research priorities in the online survey of each stakeholder group.



researchers undertaken for eating disorders in Australia. The project identified the top 10 list of research and translation priorities for eating disorders determined by stakeholders as a collective. This paper aimed to describe the process and present the top 10 research and translation priorities for stakeholders in the field of eating disorders.

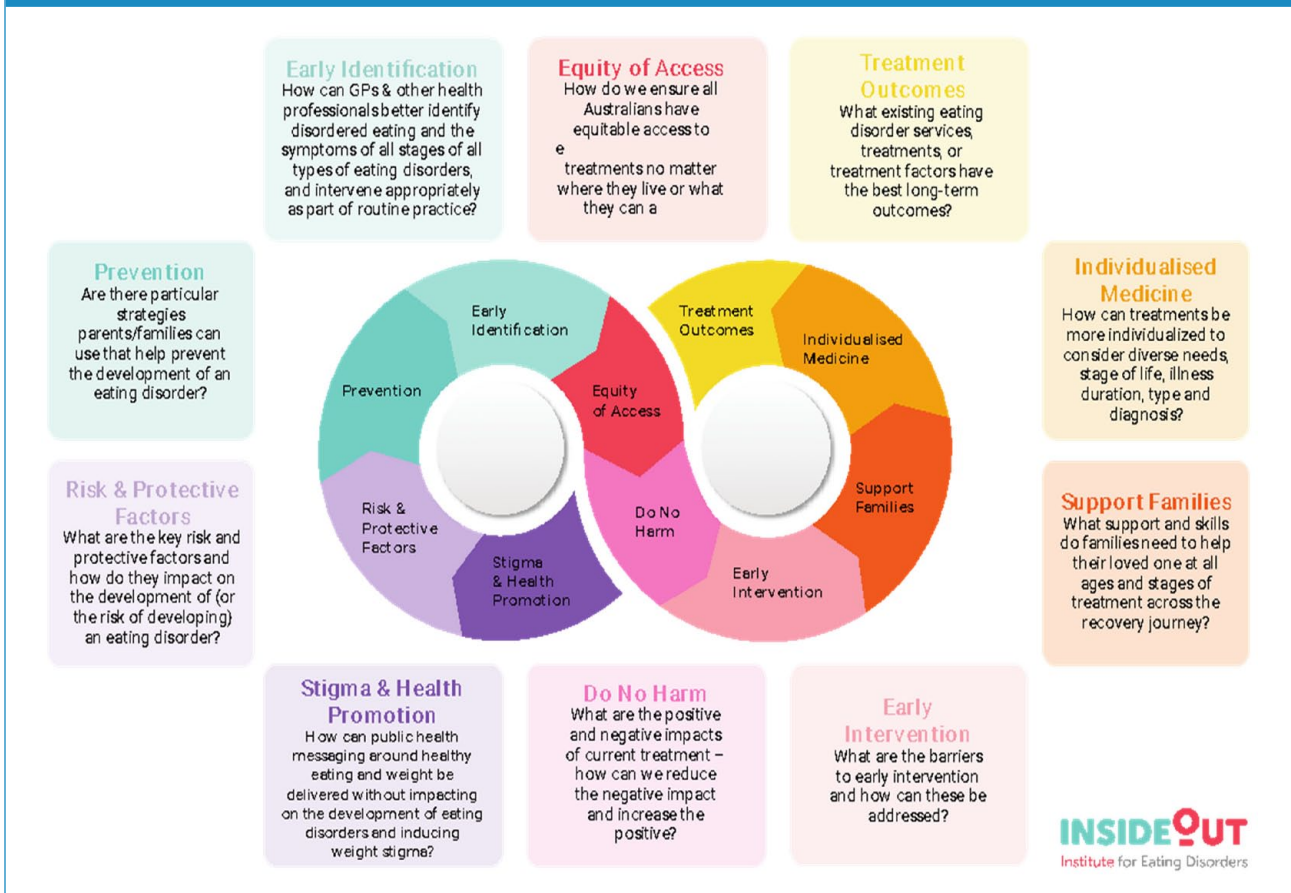
Overall, the interim survey found good consensus across stakeholders regarding what domains should be considered primary research priorities. The treatment of eating disorders and early intervention were endorsed across all groups as research and translation priority areas. Individuals with a lived experience of eating disorders primarily endorsed research questions concerning treatment, followed by early intervention and the origin of eating disorders. Given that eating disorders are often difficult to treat, and the treatment experience can be distressing, it is not surprising that further research into these areas was seen as most important by this cohort. Similarly, carers primarily focused on early intervention and treatment research questions. Perhaps unsurprisingly, given their role, clinicians endorsed treatment research questions, followed by early intervention, communication and workforce. Researchers also endorsed risk and treatment questions, followed by prevention, early intervention, and the social and emotional determinants of eating disorders.

Representatives from all stakeholder groups reviewed the shortlisted priorities from the survey and agreed on the final top 10 research questions during the online consensus workshops. The top 10 questions were translated into priority areas and related to the entire ED spectrum, from early prevention and identification to support of families and individualised treatment approaches and outcomes. Similar results have been observed in other JLA priority setting processes (Obeid et al., 2020; Van Furth et al., 2016), suggesting a potential international consensus on ED research priorities.

Future studies

Future studies may wish to consider how the outlined priorities may be rigorously examined – some priorities may be more appropriate for trial methodologies (early intervention, individualised medicine, treatment outcomes); other priorities suited for observational studies (early identification, prevention, risk and protective factors), qualitative studies (support families, do no harm) or mixed-methods studies (equity of access, stigma and health promotion). The JLA method recommends that once the top 10 evidence uncertainties are determined, stakeholders reconvene to

Figure 4. Top 10 priorities.



translate those areas into actionable research questions, which would be a natural next step for the field in Australia.

Specifically, the research community plays an important role in responding collaboratively to the outlined priorities, beginning with first working in co-design teams to translate priorities into actionable research questions. Beyond the realm of research, it is crucial that government and health agencies seriously consider adopting the priorities established as part of large priority setting processes, to ensure that work is done in a manner that is meaningful to individuals who utilise this arm of the health system. Similarly, targeted calls for funding in line with established priority areas may help address issues of replicability within the field by making transparent the most important gaps in research, care and service delivery at a national scale.

Strengths and limitations

This large national prioritisation study included the combination of diverse stakeholders, including individuals with a lived experience, carers, health professionals and researchers, and key organisations and bodies in the field of eating disorders. The total number of people who participated across all stakeholder groupings was relatively high considering the

field of EDs in Australia is reasonably small. The credibility of the study findings benefits from the number and diversity of people who participated. Furthermore, the priority setting workshop enabled the exchange of perspectives and shared decision-making at a deeper level of consultation and joint decision-making, which the survey alone could not achieve.

The interim priority setting survey results are limited by the unequal distribution of participant groups based on self-identified role (individuals with a lived experience, carers, clinicians and researchers) and potential differences within roles (e.g. current vs historic lived experience) may potentially influence participant's choices. However, given Australia's relatively small number of eating disorder researchers, a sample of 52 researchers represents a significant proportion of this population. Furthermore, a disproportionate number of people identified as female to those identified as male or transgender across all participant groups. Given that people were invited to participate in the interim priority setting survey, there is the potential for selection bias, which may have impacted which priorities were focused on – e.g., emotional determinants vs aetiology (i.e. genetic or biochemical) of eating disorders. Due to such limitations, the generalisability of conclusions should be considered. However, the co-design advisory committee

prioritised diversity when selecting the final prioritisation workshop participants. Additionally, using a JLA-aligned approach ensured rigour and objectivity during the establishment of priorities. Disciplines wishing to follow the outlined process would benefit from engaging with diverse stakeholders as early as possible in the consultation process. Engagement with community organisations that have a focus on diversity and underrepresented groups may provide valuable partnerships and contributions to the priority setting process.

Conclusion

The top 10 research and translation priorities were identified using a rigorous co-design process involving individuals with lived experience, carers, clinicians and researchers. Moreover, the findings highlight that consensus between stakeholders is achievable; critical to the development of policy, practice, and research planning; and that a co-designed approach to research priority setting brings together individuals with a lived experience, carers, health professionals and researchers with a shared goal of addressing these complex and deadly illnesses that impact every life domain.

Acknowledgements

The authors would like to thank the James Lind Alliance (JLA), Australian Government and all lived experience individuals, carers, clinicians/health professionals, researchers and all those involved with the advisory committee for their support, input with the project and the meaningful work that they do.

Author Contributions

P.A. and A.H. prepared the first draft of the manuscript and analysed data relating to the research priorities. P.M., D.M. and S.M. contributed extensively to the direction and editing of the first draft and were responsible for the conception, management and coordination of the larger study project.

Declaration of Conflicting Interests

The author(s) declared no potential conflicts of interest with respect to the research, authorship and/or publication of this article.

Funding

The author(s) disclosed receipt of the following financial support for the research, authorship and/or publication of this article: The current study was supported by the Australian Government Department of Health as part of the development of the National Eating Disorder Research and Translation Strategy 2020–2030.

Ethics Approval and Consent to Participate

This study was approved by the Sydney Local Health District Ethics Review Committee (Approval Number: X20-0339 and 2020/ETH02053). All participants have provided informed consent as part of the data collection process.

Consent for Publication

Participants were aware that data from the current study may be analysed, reported and published and that no identifiable information will be published.

ORCID iDs

Phillip Aouad  <https://orcid.org/0000-0003-0999-7495>

Siân A McLean  <https://orcid.org/0000-0002-4273-2037>

Ian Hickie  <https://orcid.org/0000-0001-8832-9895>

Availability of Data and Materials

The datasets generated and/or analysed during the current study are not publicly available due to the ongoing nature of the study. Data requests are at the discretion of the data owner and/or participating institutions. Initial requests may be sought by contacting the listed corresponding author.

References

- Arceus J, Mitchell AJ, Wales J, et al. (2011) Mortality rates in patients with anorexia nervosa and other eating disorders: A meta-analysis of 36 studies. *Archives of General Psychiatry* 68: 724–731.
- Cowan K and Oliver S (2021) *The James Lind Alliance Guidebook: Version 10*. Southampton: National Institute for Health Research.
- De La Rie SM, Noordenbos G and Van Furth EF (2005) Quality of life and eating disorders. *Quality of Life Research* 14: 1511–1522.
- Galmiche M, Déchelotte P, Lambert G, et al. (2019) Prevalence of eating disorders over the 2000–2018 period: A systematic literature review. *The American Journal of Clinical Nutrition* 109: 1402–1413.
- Hart LM and Wade T (2020) Identifying research priorities in eating disorders: A Delphi study building consensus across clinicians, researchers, consumers, and carers in Australia. *International Journal of Eating Disorders* 53: 31–40.
- Hay P, Girosi F and Mond J (2015) Prevalence and sociodemographic correlates of DSM-5 eating disorders in the Australian population. *Journal of Eating Disorders* 3: 19.
- Murphy KR, Myers B and Wolach A (2014) *Statistical Power Analysis: A Simple and General Model for Traditional and Modern Hypothesis Tests*, 4th Edition. New York: Routledge.
- Murray SB, Pila E, Griffiths S, et al. (2017) When illness severity and research dollars do not align: Are we overlooking eating disorders? *World Psychiatry* 16: 321.
- Obeid N, Mcvey G, Seale E, et al. (2020) Cocreating research priorities for anorexia nervosa: The Canadian Eating Disorder Priority Setting Partnership. *International Journal of Eating Disorders* 53: 662–672.
- Van Furth EF, Van Der Meer A and Cowan K (2016) Top 10 research priorities for eating disorders. *The Lancet Psychiatry* 3: 706–707.