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Eating Disorder Research Priorities

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TITLE:

**Identifying research priorities in eating disorders: a Delphi study building consensus
across clinicians, researchers, consumers and carers in Australia**

Running Title: Eating Disorder Research Priorities

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Conflict of Interest

The authors will not benefit financially or otherwise from the publication of this research and have no conflicts of interest to declare.

Data Availability Statement

The data from this study is available upon request to the authors.

Abstract

Introduction: Eating disorders are under-represented among successful applications for medical research funding. Developing agreement on the top research priorities may assist in fostering collaborations, innovation and meaningful consumer and carer involvement. This study aimed to develop consensus among Australian clinicians, researchers, consumers, carers and interested members of affiliated industries, on the priorities for eating disorders research. **Methods:** The Delphi expert consensus method was used. Participants were 291 members of the Australia New Zealand Academy for Eating Disorders (ANZAED) or the National Eating Disorders Collaboration (NEDC). Three panels were formed based on participant expertise: 'ED Specialists', Consumers/Carers, and Affiliates. A total of 32 potential research areas (29 in Survey 1, 3 in Survey 2) were rated on a 5-point scale of importance, with 80% agreement across all three panels required for endorsement as a priority. Participants also ranked 7 broad research domains in order of priority. **Results:** Research areas describing early intervention and evidence-based treatments were the most highly rated, with more than 90% endorsement from each of the three panels. The research domains of accessible evidence-based treatments, early intervention and detection, and origins of eating disorders, were the most highly ranked. The ED Specialists and consumer/carers panels had very similar patterns of responding, while the affiliate panel showed small differences. **Discussion:** Using the Delphi expert consensus method resulted in a collaborative consensus driven eating disorders research agenda for the Australian context and forms a model upon which other countries may also develop their funding priorities.

[245 words]

Key words: Delphi, collaboration, eating disorders, medical research, funding priorities

Identifying research priorities in eating disorders: a Delphi study building consensus across clinicians, researchers, consumers and carers in Australia

Eating disorders are often neglected by important data collection and research funding initiatives that are used to inform policy and service development (Hart, Mitchison, & Hay, 2018; Murray, Pila, Griffiths, & Le Grange, 2017). For example, in Australia eating disorders were excluded from the 2013–2014 replication of the national Child and Adolescent Survey of Mental Health and Wellbeing and have never been included in the adult Australian national mental health surveys. In the United States (US), a report by the National Institute of Mental Health (Insel, 2015; Murray et al., 2017) suggested that across all psychiatric conditions and the burden of illness they represent, funding for eating disorder research was the most discrepant, receiving the lowest sum for the highest burden of disease. In Europe, the Horizon 2020 program (Elfeddali et al., 2014) – the biggest ever in European research and innovation – did not specifically allocate funding for eating disorder research (Schmidt et al., 2016).

Neglect of eating disorders in large mental health research initiatives highlights an important gap between the level of research funding and the economic and epidemiologic burden of these disorders. Eating disorders have numerous claims to receiving better representation. For example, anorexia nervosa has the highest mortality risk ratio of all non-

substance use mental disorders (Chesney, Goodwin, & Fazel, 2014). Annual Mission Australia reports demonstrate body image (an important risk factor for eating disorders) to be one of the top three concerns for youth (V. Bailey et al., 2016; Bullo, Cave, Fildes, Hall, & Plummer, 2017). Individuals with eating disorders have higher health care utilisation than individuals with all other forms of mental illness (Striegel-Moore et al., 2008), including treatment related to metabolic syndrome independent of high body weight (Hudson et al., 2010). While we have evidence-based, manualized treatments for eating disorders (A. G. Bailey et al., 2014), various barriers to treatment exist (Hart, Granillo, Jorm, & Paxton, 2011), with as few as 8% of individuals receiving treatment (Cachelin, Rebeck, Veisel, & Striegel-Moore, 2001; Striegel Weissman & Rosselli, 2017). In addition, the burden of eating disorders on health systems is extremely high. In Australia, in the year 2012 alone, eating disorders were estimated to cost the health system \$A99.9 million (Deloitte Access Economics, 2012). In the European Union the cost estimate is €1 trillion per year (Schmidt et al., 2016), and in the US, a systematic review places the direct and indirect costs of an eating disorder at between \$US 1,288 to \$US 8,042 per person (Stuhldreher et al., 2012) with 30 million Americans estimated to experience an eating disorder (Hudson, Hiripi, Pope, & Kessler, 2007; Le Grange, Swanson, Crow, & Merikangas, 2012).

In an environment of extremely competitive funding for research in eating disorders, there have been attempts to define priorities and encourage efficient use of scarce resources. In the US these attempts have focused on specific diagnostic groups, including binge eating disorder (Tanofsky-Kraff et al., 2013), anorexia nervosa (Agras et al., 2004) and avoidant-restrictive food intake disorder (Eddy et al., 2019). Of note is that these efforts have largely

involved researchers and clinicians only. In Europe, the James Lind Alliance set the priorities for eating disorder research (van Furth, van der Meer, & Cowan, 2016), using a four step process culminating in patients, carers, researchers and clinicians deciding on the top 10 at a final facilitated prioritization workshop. More recently, the European Psychiatric Association has partnered with the European Brain Council to create the Value of Treatment project. This is designed to estimate the economic costs of psychiatric and neurological disorders and provide evidence-based cost-effective policy recommendations, with eating disorders a current focus of this work (European Psychiatric Association, 2019). In Canada, a Priority Setting Partnership, similar to the European Lind Alliance, has been funded by the Canadian Institutes of Health Research (CHEO Research Institute, 2019) to determine research priorities for female patients with anorexia nervosa aged over 15 years. Results are due in late 2019.

The eating disorders field has yet to develop national consensus on the priorities for research funding in Australia. Doing so could help efficient use of resources, even in the context of minimally available research funding, if research teams focus their efforts on areas of agreed priority, or the consensus building process leads to more multidisciplinary and innovative collaborations (Fleurence & Torgerson, 2004; Frist, 2002). This is especially timely, given the establishment of the Medical Research Future Fund in 2015 and the opportunity for funding eating disorders research under the Million Minds Mental Health Mission (Department of Health, 2018a). For example, an exercise in consensus building (Jorm, 2015) could in itself help promote the importance of conducting eating disorders research in Australia by providing an opportunity to appropriately collaborate with those with

lived experience and those who have or are playing significant roles in supporting those with lived experience (i.e., consumers and carers).

The aim of the current study was therefore to develop consensus among researchers, clinicians, consumers and carers in the field of eating disorders on the priorities for funding eating disorders research in Australia. This study used the Delphi method to develop agreement on which research domains are key priorities in the lead up to the first ever release of dedicated eating disorders research funding, as part of the Australian Government's Million Minds Mental Health Research Initiative announced in 2018.

Method

Study Design

The Delphi method is a group facilitation technique that uses an iterative multistage process to transform opinion into group consensus (Hasson, Keeney, & McKenna, 2000). It is commonly used within health sciences to enhance decision making and clinical practice where these cannot easily nor ethically be subject to randomized controlled trials. Delphi studies are considered to produce high-quality outcomes from consensus, where the participants and methods include: (1) diversity of expertise, (2) independence of ratings, (3) decentralization, where there are not power imbalances across participants, and (4) valid aggregation methods for coordinating the group's response (Jorm, 2015). The Delphi method has previously been successfully used in eating disorders research (Hart, Damiano, Chittleborough, Paxton, & Jorm, 2014; Hart, Jorm, Paxton, Kelly, & Kitchener, 2009).

Participants

Australian members of the two pre-eminent eating disorder professional and advocacy organisations; the Australia and New Zealand Academy for Eating Disorders (ANZAED) and the National Collaboration for Eating Disorders (NEDC) were invited to participate.

ANZAED is the sister chapter of the international Academy for Eating Disorders and is the peak professional body for eating disorder clinicians and researchers in Australia. The NEDC is made up of both a steering committee appointed by the Australian Government Department of Health in 2009, and a membership of several hundred people and organisations with an expertise and/or interest in eating disorders. Members were invited to participate via an emailed link to the online survey hosted by Qualtrics.com. In August 2018, the invitation was emailed to the Australian members of the ANZAED (n=336; New Zealand members were excluded) and NEDC (n=2,112) listservs. According to the ANZAED electronic mailing system, of the 336 members sent the survey invitation, 54.8% opened the email and 7.4% clicked on the survey link. When a reminder email was sent one week later, 59.4% opened the email and 17.3% clicked on the link. According to the NEDC mailing system, 38.59% of all recipients opened the email and 18.16% clicked on the survey link (148 people), though 7.37% couldn't be delivered, indicating the listserv may have been populated with a high number of out of date email addresses.

Of the 2448 total combined NEDC and ANZAED members emailed, 291 individuals responded to the survey (12%); 201 provided complete responses with a further 90 providing partial responses. Demographic data for the 265 individuals who provided responses to relevant questions are provided in Table 1. In the context of previous Delphi studies in the mental health field, this study engaged a very large sample (Jorm, 2015). Participants were

aged between 18-68 years ($M = 41.78$, $SD = 12.10$) and were from every state and territory within Australia (38% Victoria, 29% New South Wales, 12% Queensland, 9% Western Australia, 7% South Australia, 3% Tasmania and 1% Australian Capital Territory) with the exception of the Northern Territory, which had no representatives. Of the respondents who completed the survey, 92% were female. When asked to select one of five options describing area of expertise, most respondents reported having a consumer or carer background ($n=109$, 41%), followed by primarily clinician specialising in eating disorders ($n=77$, 29%). The next largest group were those who selected clinician and/or researcher not specialising in eating disorders ($n=38$, 14%) and then those reporting as primarily researchers specialising in eating disorders ($n=26$, 10%). There were 15 individuals (6%) who reported a background in affiliated industries (e.g., education, sport, fitness, fashion, media etc). This spread reflects the diverse membership base of the organisations used to recruit participants.

The five areas of expertise were used to collapse participants into three panels, according to similarity of expertise and ability to form a large enough sub-sample to allow valid responding across rounds while allowing for attrition (Jorm, 2015). The first panel – Eating Disorder Specialists (‘ED Specialists’, $n=103$, 35%) – was made up of clinicians and researchers specialising in the field. The second panel – Consumers and Carers ($n=109$, 37%) - remained as an independent group. The final panel - Affiliates ($n=53$, 18%) - comprised the clinicians and researchers not specialising in eating disorders, along with those from industry.

Measures

An electronic survey hosted by Qualtrics.com was developed to have participants rate the importance of specific research areas, and to rank broad research domains in order of

priority, to establish consensus. To develop the survey, first the NEDC steering committee was asked to provide areas of research they considered priorities for the eating disorder field and for meeting the Million Minds Mission of “*helping people who might otherwise not be part of mental health research and clinical trials to access new ways of diagnosis, treatment and recovery.*” This process uncovered 13 potential research priorities. Next, programs and abstracts from leading scientific meetings in the field (Australian New Zealand Academy for Eating Disorders, Academy for Eating Disorders, Eating Disorders Research Society and the Harvard Catalyst/STRIPED Symposium on the Prevention of Eating Disorders 2018) were reviewed by the first author for emerging research areas that could become priorities in the Australian context. This led to the inclusion of a further 16 items. A list of the 29 items presented in the survey is provided in Table 2.

To explain the research areas presented to participants in the survey, each began with a short synopsis of the topic, followed by a list of three to four specific examples of what studies in this area might examine. For example, the research area *Early intervention at all critical risk periods* was presented with the synopsis: *Evidence supports the idea that if treated early with effective treatments, individuals experiencing eating disorders can avoid developmental crisis and be returned to a healthy developmental trajectory*). This was then followed by examples: *Research in this area could:* - *Investigate early intervention in children, especially for Avoidant Restrictive Food Intake Disorder (ARFID) and anorexia nervosa (AN);* - *Investigate new avenues for early intervention across the lifespan and whether different initiatives are required for different groups at different stages (e.g., menopausal women, young boys);* - *Understand how other mental illnesses might precede*

eating disorders or contribute to eating disorder onset). In accordance with previous Delphi consensus research (Hart et al., 2014; Hart et al., 2009; Jorm, 2015) participants were asked to rate how important each of the 29 research areas were as a priority for funding, using a 5-point scale including the options 'Essential', 'Important', 'Don't Know/Depends', 'Unimportant' and 'Should not be included'.

The 29 research areas were grouped into seven domains according to thematic analysis (1. Accessible Evidence Based Treatment, 2. Origins of Eating Disorders, 3. Early Detection and Early Intervention, 4. Prevention, 5. Social and Emotional Determinants in Eating Disorders, 6. Comorbidity and Suicidality, 7. Under-served and Under-researched Groups). In addition to rating each of the 29 research areas on a scale of importance, participants were also asked in the first-round survey to rank the seven broad research domains in order of priority (Rank 1 = highest priority, Rank 7=lowest). This allowed participants to develop consensus on the top funding priorities based on large programs of research, without needing to consider specific research designs.

In the first survey, at the end of each of the seven research domains, participants could propose new research areas or domains that had not already been covered by the survey. This open-ended responding allowed the Delphi method undertaken to be exhaustive of potential priority research areas (Jorm, 2015). Copies of the two surveys will be made available upon request to the authors.

Procedure

Human Research Ethics approval was granted by the Social and Behavioral Research Ethics Committee of Flinders University (project no: 8124). An in-person presentation was

made at the ANZAED annual conference in early August 2018 (n~450), two weeks prior to the release of the survey, to inform members of the aim of the study, eligibility criteria and upcoming opportunity to participate. A generic link to the online survey was then created and sent in the body of an email inviting members to complete the survey. ANZAED and NEDC sent separate emails to their members, using the same email invitation template supplied by the authors. Initial invitations were sent in mid-August 2018, with a reminder email and the same survey link sent one week later. The survey collector remained opened for a period of 15 days, after which time the survey was closed and data were analysed. The following criteria for consensus was used:

(a) Endorsed. If between 80% and 100% of all three panels rated a research area as either Essential or Important, the area was endorsed as a research priority;

(b) Re-rate. The two scenarios that categorized a research area for re-rating in a second-round survey were if (i) between 70% and 79% of two or three panels rated a research area as either Essential or Important, or (ii) between 80% and 100% of any one panel rated a research area as either Essential or Important;

(c) Rejected. If none of the above conditions were met.

At the end of first-round, participants were sent a report outlining results. The research areas to be re-rated were displayed with the frequency of each panel's use of the five response options, so that participants could compare their response to that of their panel and other panels' ratings. The function of the report was to allow participants to decide whether to maintain or modify their ratings in the next questionnaire round. Novel research ideas provided by participants in the open-ended fields of the first-round were drafted into new

items and entered into the second-round survey for rating. The same criteria for endorsing, excluding and re-rating statements were applied in the second round, with one exception. If a statement was re-rated and again failed to achieve a consensus of between 80 and 100% across all three panels, it was then excluded. The outcome of this process was a very high level of consensus on which areas and domains of eating disorders research are of top priority for awarding funding. The Delphi procedures employed in this study have been used widely in previous studies, including in eating disorders research (Hart et al., 2014; Hart et al., 2009; Jorm, 2015).

Results

Rating of research areas

At the end of Round 1, 20 of the 29 research areas were endorsed as priorities (see Table 3). Items describing early intervention and evidence-based treatments were the most highly rated, with more than 90% endorsement from each of the three panels, and across the whole sample. Although the remaining nine items failed to reach the required level for endorsement (80% or more of each of the three panels selecting an area as ‘Essential’ or ‘Important’), they did meet criteria for re-rating in the second-round survey.

The participant feedback fields gave rise to three new items, which were entered into the second-round survey. Participant comments also led to alternative wordings for five existing items that were being re-rated in Round 2. Both the original item and its proposed alternative wording were presented in the second survey, to allow participants to choose between versions. Participants were instructed to rate the version they preferred more highly.

At the end of Round 2, all three new items were endorsed, along with two items that were re-rated. The remaining seven items being re-rated were rejected after again failing to reach the required level for endorsement (see Table 4). All the alternate wording items fell in the re-rate category at the end of the second survey. However, because the pattern of rating was very similar to the original items, which had failed to achieve endorsement upon re-rating, the alternate wording items were considered unlikely to be endorsed if given the opportunity to be rated again in a subsequent round. Hence, the alternate wording items were rejected, and no further rounds were completed.

Ranking of research domains

Rankings of research domains mirrored the findings of research area ratings, where evidence-based treatment and early intervention and detection, were considered priorities (see Table 5). When the percentage of participants using Ranks 1, 2 or 3 was summed for each domain, the top ranked priorities overall were Accessible and Evidence-based treatments (69%), Origins of Eating Disorders (62%), and Early Intervention and Detection (48%). More than two-thirds of the whole sample placed Accessible Evidence-based Treatments in one of the top three priority ranks, and more than half placed better understanding the Origins of Eating Disorders and creating more effective means of Early Intervention and Detection in one of the top three positions.

Figure 1 presents the proportion of each of the three panels placing the seven research domains in Ranks 1, 2 or 3. The majority of both the ED Specialist and Consumers/Carers panels placed the domain of Accessible Evidence-based Treatments in Rank 1, giving it the highest priority for research funding. The next most popular research domain placed in Rank

1, by these two panels, was Origins of Eating Disorders, followed very closely by Early Intervention and Detection. The Affiliates panel showed a slightly different pattern of responding, with the majority placing Early Intervention and Detection in Rank 1, followed by a slightly smaller proportion placing Accessible Evidence-based Treatments in Rank 1.

[Insert Figure 1 about here]

Second place rankings showed more variability across the panels. For ED Specialists, Under-served and Under-researched groups was most often placed in Rank 2. However, the Consumer/Carer panel positioned the domain of Prevention most frequently in Rank 2, followed very closely by Social and Emotional Determinants, Suicidality and Comorbidity, as well as Under-served and Under-researched groups. The Affiliates panel placed Social and Emotional Determinants most often in Rank 2.

The ED Specialists used Rank 3 most often for the Origins of Eating Disorders domain, whereas the Consumer/Carers panel most often placed Accessible Evidence-based Treatments in Rank 3, followed closely by the Origins domain. Affiliates also commonly placed the Origins domain in Rank 3.

Discussion

This study engaged the Delphi method to develop consensus on the Australian priorities for funding eating disorders research. Specialists in eating disorder treatment and research, consumers and carers, as well as those affiliated with the eating disorders sector through their industry, clinical or research work, reached strong agreement on which research domains are key priorities for funding and which specific research areas should be considered by funding bodies for development and investment.

Across the whole sample, the domains of Accessible Evidence-based Treatments, Origins of Eating Disorders, and Early Detection and Intervention were ranked as the top three priorities for research funding. Within these domains, the research areas of ‘Early intervention at all critical risk periods’, ‘What to do when first line treatments don’t work’, ‘Enhancing existing eating disorder treatments’, ‘Accessible services’ and ‘Early detection’ were all very highly rated with more than 90% of each of the three panels endorsing these as ‘Essential’ or ‘Important’ research priorities.

These findings are largely consistent with the top-10 research priorities established by the Lind Alliance in Europe (van Furth et al., 2016). Those top-10 priorities reflected a focus on studying how evidence-based treatments can be personalised into clinical formulations suited to an individual’s particular symptoms, underlying psychosocial issues and co-morbidities (van Furth et al., 2016). The Australian priorities, whilst also prioritising treatment research, did however reflect a greater focus on early detection and intervention. This may be due to the differing methodologies, given the Lind Alliance focused on unanswered research questions whereas the current study focused on ranking and rating research domains. But it may also reflect a particular strength of the Australian mental health research community, who are known as world leaders in early intervention (McGorry, Killackey, & Yung, 2007; Wade, 2018) or the focus of public mental health literacy campaigns which are widely broadcast in Australia and stress the importance of early detection and intervention (Harman & Heath, 2017; Kelly, Jorm, & Wright, 2007).

Better understanding the origins of eating disorders was a highly ranked priority in the current study, especially conducting a national, population-based epidemiological survey.

This echoes the call of the 2012 Deloitte Access Economics report produced in Australia, which outlined the need for better data and greater focus on the full range of eating disorders rather than just anorexia nervosa and bulimia nervosa (Deloitte Access Economics, 2012). Better understanding the origins of eating disorders has not been listed as a high priority in Europe or the US, perhaps reflecting the paucity of high-quality epidemiological research on eating disorders in Australia, where a national survey has never evaluated the prevalence, incidence or burden of these illnesses (Hart et al., 2018).

The major strength of the current study was the large sample and diversity of the experts who responded, including consumers and carers forming one of the three panels and being given equal weight to those who specialize as professionals or have experience in affiliated industries. The ED Specialist and Consumer/Carers panels showed mostly similar patterns of responding both across domain rankings, and the research area ratings of importance. Inclusion of consumers and carers in this study fulfils the Australian Medical Research and Innovation Priorities 2018-2020 (Department of Health, 2018b) of consumer-driven research being used to purposefully connect researchers to consumers with the intent of enhancing the direction of research as well as evidence translation into every day clinical practice. This study is especially novel in its inclusion of affiliates to the eating disorder sector. The Affiliate panel showed slightly different patterns of responding, but were not out of step with the other panels, distinguishing the results of this study from other eating disorder research using the Delphi method where larger discrepancies across panels have arisen (Hart et al., 2014; Hart et al., 2009). The Affiliate panel tended to rate research areas that were more likely to involve their industries (i.e. Macro-level/public health interventions

and understanding the role of social media) more highly than the traditional treatment research areas highly endorsed by the Consumers/Carers and ED Specialist panels.

Collaborating with experts outside of the eating disorder sector may assist in raising the profile of eating disorders research and attracting more equitable funding at a level better matched to the associated burden of disease.

Whilst the development of the European research priorities included those with lived experience, involvement of experts by experience in developing research priorities has not yet occurred in the US. A replication of the current method in the US would be of benefit to the eating disorder field broadly, by both ensuring that research priorities in the US truly represent the diverse spectrum of relevant stakeholders, but also by providing a point of comparison against which the current findings may be compared. Replication of the Delphi method across other countries could inform a global perspective on eating disorder priorities by identifying where new studies produce priorities that map onto those from previous research versus those which emerge as particular to national interests.

Despite its strengths, there are a number of important limitations to this research. The first is that the review for the survey development was not systematic, but the methodology was appropriate for the study purpose. The second is that, although the sample size was much larger than many Delphi studies (Hasson et al., 2000; Jorm, 2015), we note that only 12% of people emailed participated in this research, and methods to further include the voices not represented in this study need to be considered. A further limitation is that the presentation order of research domains in the survey were not randomized. It is possible that the order of presentation influenced the domain rankings, given that the top-ranked domains were also

those that were presented earlier in the survey. However, when broken down across panels – as in Figure 1 – it is clear the domains shown later in the survey (e.g., Under-served and Under-researched Groups, Suicidality and Comorbidity) were given genuine and strong consideration, being often placed in Rank 2. Future research could overcome this limitation by randomising the presentation of research domains to participants, to ensure that attentional biases or recency effects do not confound results. Finally, participant attrition across survey rounds was 40%. Previous Delphi studies have suggested that participant retention at the level of 70% is required to ensure that attrition does not bias results (Jorm, 2015). Attrition may have been higher in the current study than previous Delphi studies because the researchers did not have access to individual email addresses. The invitation to participate was forwarded through membership listservs. Participants clicked into the online survey and were asked to provide an email address for follow-up. A large proportion of individuals did not provide an address and due to typographical errors, those who did may still not have provided an accurate one. This issue is overcome by the research team emailing potential participants directly, but this would have required a breach of privacy on behalf of the membership organisations and was thus not deemed appropriate for this study.

To ensure that the priorities set in this research do indeed catalyse efficient use of scarce resources, the findings of our study need to be clearly and effectively communicated. The next steps for translation of these priorities into action are therefore very important and will include: dissemination of findings across Australia especially to funding bodies (i.e., national and state governments, philanthropic and not-for-profit organizations); lobbying to ensure these priorities are reflected in national initiatives, especially national mental health

surveys and medical research strategies; and comparison of these priorities against new research setting priorities in other countries as they emerge, to inform a global consensus.

Conclusions

A large, national and diverse sample of the eating disorders field agrees, with a very high level of consensus, that creating accessible evidence-based treatments, better understanding the origins of eating disorders, and developing early intervention and detection initiatives, are the top-priorities for funding eating disorders research in Australia. The Delphi method is a useful strategy for developing national consensus across broad and diverse stakeholders on priorities for medical research.

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TABLES

Table 1. Participant characteristics by panel

Demographics	ED Specialists		Panel Consumers/Carers		Affiliates	
	n	%	n	%	n	%
n (%)	103	35.2	109	37.2	53	18.10
Age Mean (SD)	39.6	(10.8)	45.0	(13.1)	39.4	(10.7)
<i>Sex</i>						
Female	94	91.3	101	92.7	48	90.6
Male	9	8.7	7	6.4	4	7.5
Other	0	0.0	1	0.9	0	0.0
I do not wish to say	0	0.0	0	0.0	1	1.9
<i>Education</i>						
High School or less	0	0.0	11	10.1	1	1.9
Some University	2	1.9	27	24.8	3	5.7
Bachelor Degree	21	20.4	43	39.4	21	39.6
Masters	38	36.9	21	19.3	19	35.8
Doctoral or Professional degree (JD, MD)	42	40.8	7	6.4	9	17.0
<i>Sexual orientation</i>						
Heterosexual (straight)	94	91.3	98	89.9	44	83.0
Homosexual (gay)	2	1.9	2	1.8	1	1.9
Bisexual	4	3.9	4	3.7	3	5.7
Other	0	0.0	1	0.9	2	3.8
Prefer not to say	3	2.9	4	3.7	3	5.7
<i>Cultural background</i>						
First Australian	0	0	0	0.0	2	3.8
African	1	1.0	1	0.9	0	0.0
American	1	1.0	4	3.7	0	0.0
Asian	3	2.9	2	1.8	4	7.5
British/UK	8	7.8	7	6.4	0	0.0
Jewish/Middle	2	1.9	2	1.8	2	3.8
European	5	4.9	5	4.6	4	7.5
New Zealander	0	0	4	3.7	2	3.8
Other	8	7.8	6	5.5	0	0.0
<i>Participation</i>						
Round 1 complete	89	86.4	77	70.6	35	66.0

Round 2 complete	41	39.8	33	30.3	8	15.1
Attrition	48	46.6	44	40.4	27	50.9

Table 2. Potential research priorities for panel rating and ranking by seven domains

Domain 1: Accessible Evidence Based Treatment
1.1 Integrated Care
1.2 Accessible services
1.3 Families as therapists
1.4 What to do when first line treatments don't work
1.5 Matching treatments to profiles
1.6 Enhancing existing ED treatments
1.7 Exploring family involvement in treatment (new in Round 2)
1.8 Evaluating multi-disciplinary treatment (new in Round 2)
Domain 2: Origins of Eating Disorders
2.1 National dataset
2.2 Physical pathways, impact, role in diagnosis
2.3 Understanding new diagnostic categories
2.4 Utilising emerging genetic analyses
Domain 3: Early Detection and Early Intervention
3.1 Early intervention at all critical risk periods
3.2 Early detection
3.3 Enhancing existing early intervention programs
Domain 4: Prevention
4.1 Enhancing existing prevention interventions
4.2 Macro-level public health interventions
4.3 Exploring combined mental health prevention programs
4.4 Exploring the role of anti-obesity interventions and combined prevention programs
4.5 Innovating eating disorders prevention
Domain 5: Social and Emotional Determinants in Eating Disorders
5.1 Social determinants of health and impacts on disordered eating
5.2 Defining recovery
5.3 The role of social media
Domain 6: Comorbidity and Suicidality
6.1 Using ED interventions to treat other disorders
6.2 Encouraging health providers to assess eating and exercise behaviors in individuals with existing mental health conditions
6.3 Impact of weight stigma on provision of quality of health services for individuals with mental health problems
6.4 Using suicide prevention interventions with ED consumers
6.5 Understanding the relationship between self-harm and EDs
6.6 Understanding reasons for suicidality (new in Round 2)
Domain 7: Under-served and Under-researched Groups
7.1 Social factors in eating disorders
7.2 Aboriginal and Torres Strait Islander health service eating disorder capacity
7.3 Understanding EDs across the lifespan

Table 3. Endorsed items rated as ‘Essential’ or ‘Important’ by at least 80% of each of the three panels

	ED Specialists	Consumers / Carer	Affiliates	Total Sample
3.1 Early intervention at all critical risk periods	96%	99%	95%	97%
1.4 What to do when first line treatments don’t work	95%	99%	93%	96%
1.6 Enhancing existing ED treatments	95%	95%	98%	96%
1.2 Accessible services	92%	98%	93%	95%
3.2 Early detection	95%	94%	91%	94%
3.3 Enhancing existing early intervention programs	89%	95%	98%	93%
2.1 National dataset	93%	93%	88%	92%
1.1 Integrated Care	91%	94%	88%	92%
7.3 Understanding EDs across the lifespan	97%	85%	95%	92%
6.4 Using suicide prevention interventions with ED consumers	87%	98%	90%	92%
6.2 Encouraging health providers to assess eating and exercise behaviors in individuals with existing mental health conditions	88%	95%	90%	91%
6.5 Understanding the relationship between self-harm and EDs	90%	92%	90%	91%
4.1 Enhancing existing prevention interventions	88%	90%	98%	91%
4.4 Exploring the role of anti-obesity interventions and combined prevention programs	88%	93%	90%	90%
1.3 Families as therapists	84%	91%	98%	89%
1.5 Matching treatments to profiles	87%	90%	91%	89%
2.2 Physical pathways, impact, role in diagnosis	82%	93%	90%	88%
5.2 Defining recovery	82%	96%	82%	88%
4.3 Exploring combined mental health prevention programs	83%	88%	95%	87%
6.3 Impact of weight stigma on provision of quality of health services for individuals with mental health problems	83%	87%	93%	86%
4.2 Macro-level/public health	83%	85%	100%	89%*

interventions				
5.3 The role of social media	80%	82%	100%	87%*

* Items re-rated in Round 2 after failing to reach endorsement in Round 1

Table 4: Rejected items rated as ‘Essential’ or ‘Important’ by less than 80% of all three panels

	ED Specialists	Consumer Carer	Affiliates
2.3 Understanding new diagnostic categories	80%	85%	63%
2.4 Utilizing emerging genetic analyses	54%	85%	63%
4.5 Innovating eating disorders prevention	73%	76%	86%
6.1 Using eating disorder interventions to treat other disorders	51%	75%	83%
5.1 Social determinants of health and impacts on disordered eating	66%	73%	100%
7.2 Aboriginal and Torres Strait Islander health service eating disorder capacity	66%	70%	83%
7.1 Social factors in eating disorders	56%	63%	83%

Table 5: Ranking of research domains across whole sample

	Domain Ranking							Sum Ranks 1,2,3
	1	2	3	4	5	6	7	
Accessible Evidence Based Treatment	41%*	5%	23%	18%	6%	4%	2%	69%
Origins of Eating Disorders	19%	6%	36%*	16%	5%	9%	7%	62%
Early Intervention and Detection	20%	6%	21%	23%*	12%	11%	6%	48%
Prevention	9%	18%	8%	15%	18%	21%	10%	35%
Social and Emotional Determinants in Eating Disorders	3%	20%	6%	12%	24%	21%	12%	30%
Suicidality & Comorbidity	4%	16%	4%	10%	25%*	23%*	17%	25%
Under-researched & under-served groups	3%	27%*	1%	5%	8%	9%	46%*	31%

Boldface indicates modal response for Domain

** indicates modal response for Rank*

FIGURES**Figure 1**

Percentage of participants placing each domain in Rank 1, Rank 2, and Rank3, by panel membership (ED Specialists, Consumers/Carers, Affiliates). Rank 1 was most often used for the domains of Accessible Evidence-based Treatments, Origins of Eating Disorders and Early Intervention and Detection. More Affiliates ranked Early Intervention and Detection in first place than ED Specialists or Consumers/Carers. Rank 2 was most often used for the domains of Under-served and Under-researched Groups, Prevention and Social and Emotional Determinants of Eating Disorders, though the Affiliates more commonly placed Suicidality and Comorbidity in Rank 2 than they did Prevention. Rank 3 was most often used for the domains of Origins of Eating Disorders, Accessible Evidence-based Treatments as well as Early Intervention and Detection.

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