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Driving better intervention outcomes in eating disorders: A systematic synthesis of research priority setting and the involvement of consumer input

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Driving better intervention outcomes: A systematic synthesis of research priority setting studies and the involvement of consumer input

Objective: Setting specific research priorities and involving consumers in this process is one pathway to driving better intervention outcomes in eating disorders. We reviewed research priority setting in the field and the involvement of consumers in this priority setting.

Method: A systematic review following the PRSIMA Statement was conducted and eight studies were identified for inclusion; four included substantial input from consumers, and four were researcher-led. Similarities and differences across the types of studies were examined.

Results: Research priorities informed by consumers were primarily concerned with producing better interventions and outcomes. A large degree of overlap with researcher-led priorities was present. The former studies had a greater focus on early intervention, bridging the research-practice gap, and recovery, while the latter were more likely to address diagnosis, genetic factors, brain circuitry, and pharmacotherapy. Priorities endorsed across more than one consumer-informed study included: the role of self-harm, working with health care professionals to increase early detection, supporting transition between services, and six issues about improved treatments.

Conclusions: The eating disorder field needs to engage in more meaningful involvement of co-design across consumers, clinicians and researchers along the entire research journey, not just research priority setting. An integrated research strategy incorporating a co-design perspective has the potential to drive better outcomes.

Highlights:

- Very few examples of research priorities co-designed across consumers, clinicians and researchers exist.
- A large degree of overlap between consumer-informed and researcher-led research priorities was present.
- Research priorities informed by consumers were primarily concerned with producing better interventions and outcomes.

Keywords: consumers; carers; clinicians; research priorities; researcher-led; eating disorders

Improving outcomes in eating disorder interventions is both pertinent and urgent. On one hand, there have been many important advances in ED research over the last 20 years, including: better understanding that EDs are a result of the complex interplay of genetic (accounting for an average of 52% of the variance) and environmental influences (Culbert, Racine, & Klump, 2015); expansion of diagnoses and introduction of more meaningful diagnostic criteria that better map what is observed in the community (Fairburn & Cooper, 2011); a number of evidence-based guidelines for interventions that produce significant improvements (Hilbert, Hoek, & Schmidt, 2017; Hay et al., 2014); and identification of universal and selected prevention approaches that can protect against the development of an ED (Watson et al., 2016). On the other hand, only 25% of people with an ED seek treatment (Hart, Granillo, Jorm, & Paxton, 2011; Micali et al., 2017) with considerable barriers to receiving timely and appropriate diagnosis and treatment (Ali et al., 2017). Between 22% and 42% of children with anorexia nervosa receiving Family Based Treatment have poor outcome at 12-month follow-up (Lock et al., 2010; Eisler et al., 2016), and only 33% of people with bulimia nervosa and binge eating disorder are remitted at end of outpatient cognitive behaviour therapy (Linardon & Wade, 2018). It is evident that optimising our treatments still has a long way to go, and this will require a large body of research.

Limited resources, however, set constraints on the conduct of research in psychological disorders and impose the need to develop research priorities strategically (Cristea & Naudet, 2019). The field of eating disorders (EDs) is particularly vulnerable to limited resources, even when compared to other mental illnesses. For example, in the United Kingdom, disorders related to anxiety, psychosis, autism, and depression receive four to nine times more research funding than EDs (Woelbert, Kirtley, Balmer, & Dix, 2019). This disparity is even more marked in Australia and the United States, where (respectively) government funding for ED research equates to approximately

\$1.10 (\$0.73) per affected individual, compared to \$32.62 (\$58.65) for autism and \$67.36 (\$89.67) for schizophrenia (Murray, Pila, Griffiths, & Le Grange, 2017).

In this environment of finite resources, it is imperative to conduct research that has a high likelihood of improving outcomes in real-world settings. Among the strategies required for optimising our outcomes will be the involvement of partnerships with consumers, including seeking service users' feedback at the end of an intervention, and assessing their preference at the beginning of an intervention. Evidence also suggests the setting of research priorities can achieve better general health outcomes, especially when conducted in partnership with consumers (Tomlinson, Chopra, Hoosain, & Rudan, 2011). Furthermore, in health research, involvement of stakeholders in research priority setting achieves a variety of other outcomes than can increase the usefulness of research (Tong et al., 2019). It helps to ensure that funding decisions and research meet critical evidence gaps to inform decision making (Chalmers et al., 2014). It facilitates shared responsibility and accountability in implementing the research agenda. It informs preferred interventions for evaluation and acceptability of research design (Cristea & Naudet, 2019). It improves the relevance and legitimacy of research, and thus can aid in improved and quicker translation of findings.

To this end, setting research priorities is a helpful exercise, but one where usefulness is likely to be maximised if *both* conductors and users of research are involved. Since 2004, the James Lind Alliance, a United Kingdom National Institute for Health Research supported scheme, has advocated for consumers, carers and health care professionals (but not researchers) to work together to agree which gaps in knowledge matter most and deserve priority attention. The inclusion of both consumers and researchers in research development has been particularly embraced by the National Health and Medical Research Council (NHMRC; <https://www.nhmrc.gov.au/about-us/consumer-and-community-engagement>), the major source of research funding in Australia. Neither research priority setting nor

inclusion of consumers in setting such priorities has been previously reviewed in the eating disorder field.

The aim of the current synthesis is to examine occasions of research priority setting in EDs. We seek to identify the extent to which consumers (defined here as those with lived experience of an eating disorder and their carers or support network) have been involved in setting these priorities, and the overlap between specific research areas highlighted across the different studies. In so doing, we hope to highlight co-designed themes across consumers, healthcare providers, and researchers, to inform an integrated research strategy that will drive better outcomes in EDs over the next 20 years.

Method

Search Strategy

The review process was conducted according to the PRISMA statement (Moher, Liberati, Tetzlaff, & Altman, 2009). A literature search was conducted on 6th April 2020 using PsycINFO and Scopus databases to locate studies on research priorities in eating disorders. The following keywords and Boolean search terms were combined and searched in the database: (*research prior**) in the title or abstract or keywords AND (*eating disord** OR *anorexia** OR *bulimia** OR *binge**) in the title or abstract or keywords. No other limiters were set.

Inclusion criteria

Studies were included if their primary data (surveys or group consensus) related to identifying research priorities in EDs. Studies were excluded if they were reviews or book chapters or opinions (i.e., not presenting primary data) or were not primarily focused on eating disorders (e.g., references to EDs were either mentioned tangentially or the word “anorexia” related to the underweight observed

in physical illness). As there was no pre-determined quality appraisal, this can best be presented as a scoping review.

Data Synthesis

The research priority process informed by consumers tended to list specific questions or issues that needed to be answered by the field. In contrast, researcher-led priorities tended to highlight themes, associated with specific research questions. In order to examine overlap we used the themes identified in the latter and grouped the questions from the former together accordingly. Where no theme existed to represent the questions, we generated new themes for this purpose.

Results

Studies identified

The process identifying ten studies for full text screening is shown in **Figure 1**. Two full text studies were not included in the synthesis; one was a secondary report on the NIH priority-setting exercise (Rudorfer & Goldstein, 1997), and the other did not include content on EDs in the research priority setting (Sharan et al., 2009). The eight studies included for synthesis (signified in the reference list) were summarised; four involved input from consumers, and four did not.

Research priorities involving consumers

The 35 priority research questions and issues identified as the top concerns in research priorities informed by consumer input are specified in **Table 1**. Across all these studies there was a heavy emphasis on prioritising research that develops, evaluates or innovates *interventions* for EDs - be they preventive, early or treatment interventions - as opposed to basic science or epidemiology.

The earliest example (Witton, Leichner, Sandhu-Sahota, & Filippelli, 2007) surveyed patients and their families ($n=72$) registered in the Eating Disorders Program at British Columbia Children's

Hospital. In response to an open-ended question (*“From your experience, what issues do you think are important for us researchers to pursue?”*) answered by 58 people, the two most endorsed areas included treatment issues and family dynamics. Examples of treatment issues included: establishing the effectiveness of existing treatments for adolescents with eating disorders, inpatient versus outpatient treatment, and establishing new and innovative treatment options. Examples of family dynamics included: overprotective parenting, the impact of divorce, and the role of siblings.

The second occasion emerged from the Netherlands, a collaboration with the James Lind Alliance (van Furth, van der Meer, & Cowan, 2016). Individuals with or recovered from an ED, their families and clinicians were asked to submit unanswered questions to be addressed in research. There was no identification of whether the clinicians also conducted research. The 956 submissions from 412 respondents (340 patients with an eating disorder) were grouped into 77 indicative research questions, ranked by 375 respondents. Responses from patients, carers and clinicians were weighted such that equal representation of each was achieved. Eight of the top ten research priorities related to treatment of EDs, with one focused on prevention (identifying specific risk factors and the effect of targeting these), and one focused on aetiology (causes of destructive behaviours).

The third research priority setting exercise was conducted in Australia, using Delphi study methodology (Hart & Wade, 2020), and is the only example of co-design where researchers were explicitly involved, along with consumers, carers and clinicians, in setting priorities. This work was conducted with 291 members of the Australia and New Zealand Academy for EDs and the National EDs Collaboration. Broad research domains developed by the authors (i.e., Accessible and Evidence based treatments) each containing specific research areas (i.e., What to do when first line treatments do not work, Matching treatments to profiles) were rated by three different panels: Consumers and Carers (n=109, 37%), ED Specialists (n=103, 35%, clinicians and researchers), and Affiliates (n=53, 18%, non-ED specialists with an interest in eating disorders). Endorsed research areas had to be rated

as an ‘Essential’ or ‘Important’ priority by at least 80% of each of the three panels. Participants also ranked the seven broad research domains in order of priority. The top-ranked domains were Accessible and Evidence-based treatments (69%), Origins of Eating Disorders (62%), and Early Intervention and Detection (48%). Of the 32 specific research areas (29 in Survey 1, 3 in Survey 2), the most highly rated were those describing research on early intervention and evidence-based treatments.

Finally, and most recently, the James Lind Alliance methodology was also used in Canada, with a relatively narrow focus on anorexia nervosa in females aged 15 years and above (Obeid, McVey, Seale, Preskow, & Norris, 2020). Once again those with lived experience, families, and carers, and healthcare providers treating individuals with EDs, were included in the voting, without information provided as to whether any of the clinicians were also researchers. The initial survey elicited 897 priorities from 147 individuals, with almost equal representation from all three stakeholder groups. Eight of the ten final priorities focused on questions related to treatment, one focused on early identification and educating professionals about EDs, and one focused on educating parents and caregivers to aid the recovery process.

Researcher-led priorities

The four researcher-led priority setting studies with no consumer input included the National Institute for Health (NIH) study looking at all EDs (Grilo et al., 1997) and disorder-specific priority setting studies on binge eating disorder (Tanofsky-Kraff et al., 2013), anorexia nervosa (Agras et al., 2004), and avoidant and restrictive feeding and intake disorder (Eddy et al., 2019). Themes were identified in each publication, with various areas for further research summarised throughout in narrative form, but none provided a summary of top questions, such as those found in the consumer informed studies. The themes from the researcher-led priorities are listed in the first column of **Table**

1, in non-italicised bold font. The priorities identified by the NIH study included: (1) Definitions and diagnostic classifications and associated functional impairment, (2) Risk factors, including how genes, brain, metabolism, environment and temperament work, (3) Prevention, (4) Treatment and the implications for treatment where comorbidity with other mental illness and obesity were present. The disorder specific research priorities tended to follow these themes, except for prevention, which was not mentioned across these three studies.

In contrast to the consumer-informed priorities, the NIH priorities did not mention of early intervention, bridging the research-practice gap, or navigating currently available interventions, so these were added as themes to our framework. Among the disorder-specific researcher-led studies, defining recovery was mentioned once (Eddy et al., 2019), as was using outcomes that incorporate quality of life (Agras et al., 2004), but these were subsumed under different themes (diagnosis and treatment), whereas the consumer-informed priorities mentioned recovery much more frequently, and it was thus included as an additional standalone theme.

Discussion

The aim of the current synthesis was to summarise studies on research priority setting in EDs. With the exception of the Australian study (Hart & Wade, 2020), it appears that co-designed research priorities (i.e., involving consumers, clinicians *and* researchers) are rare. The four studies that have included consumer input are methodologically disparate, using three different methodologies with slightly different groups of participants, and with only one explicitly including researchers. Nevertheless, in the research priorities highlighted we see a common emergent concern; namely improving interventions and outcomes for people with EDs and their families and loved ones. The themes that were generated to address this concern cover the full spectrum of research from critical

pre-intervention research steps (e.g., elucidating ED burden, distribution and risk factors), to intervention design, and access to care.

Consistent with the Delphi study (Hart & Wade, 2020) that indicated widespread agreement between ED experts and consumers across many research priorities, we note in the current study that the researcher-led priorities were all consistent with the themes arising from the consumer-informed research priorities. Compared to the research priorities informed by consumers and carers, researcher generated issues were more likely to address diagnosis, genetic factors, brain circuitry, and pharmacological treatments. Consumer-informed studies had a greater focus on the themes of early intervention, bridging the research-practice gap, and recovery. Even though specific questions generated by consumers were less likely to address genetic factors than researcher-led priorities, we note that consumers have an interest in “understanding emerging genetic analyses”, rated as essential or important by 85% of consumers, but only 54% of ED specialists in the Delphi study (Hart & Wade, 2020). This does suggest that priority setting, when generated by consumers, will naturally focus more on treatment which is most germane to their immediate experience, but that provision of wider themes (such as the Delphi procedure) may result in firm endorsement from consumers. Hence choice of methodology when setting co-designed research priorities needs to be carefully considered. Another implication for managing differences in research priorities is ensuring that biological and diagnostic issues are clearly explained and communicated. Use of the Medical Research Council documentation (www.mrc.ac.uk/complexinterventionsguidance) linking risk factors and model testing to development of complex interventions may also be helpful.

The inclusion of consumer-informed priorities provides the ED research community with a “corrective nudge” toward the central question: “Will this lead to better outcomes?”, as indicated by nine specific research priorities that were endorsed across more than one consumer-informed study. The first of these was the role of self-harm and self-destructive behaviours, with the latter terminology

emerging from the Netherlands priority setting exercise. In addition to the harm caused by disordered and restrictive eating, and the self-harming function of purging (Kostro, Lerman, & Attia, 2014), people with EDs are at a 5- to 6-fold increased risk of suicide attempts (Udo, Bitley, & Grilo, 2019), ranging from 16% to 44% across EDs. Reviews suggest that self-injury and suicide attempts are more frequent in any ED with binge/purge behaviours (Mandelli, Arminio, Atti, & De Ronchi, 2019; Kostro et al., 2014) than those without. A better understanding of the function of such behaviours will have implications for improving treatment, for example treatment adjuncts for emotion regulation work in those who self-harm, such as have appeared in Enhanced Cognitive Behaviour Therapy (CBT-E; Fairburn, 2008) and the Maudsley Model of Anorexia Nervosa Treatment for Adults (MANTRA; Schmidt, Wade, & Treasure, 2014). Emerging evidence suggests that the addition of dialectical behaviour skills training for EDs accompanied by binge and purge behaviours leads to greater reductions in these behaviours than wait list control and active therapy conditions (Safer, Robinson, & Jo, 2010); we also need to ascertain whether this extends to all accompanying self-harm behaviours.

The second and third research priorities related to health system issues, namely working with health care professionals to increase early detection and intervention and supporting individuals to navigate transition between services. The lack of recognition of EDs in primary health-care settings (Keski-Rahkonen et al., 2009) is an issue that requires innovative research to examine a systems approaches to improving detection and the resulting impact on patients and their families (Cadwallader, Godart, Chastang, Falissard, & Huas, 2016). Improved consideration of mental health issues in weight and diet related presentations to primary care physicians may be a start (Hay et al 2020). Probably the most pressing transition concern is that between adolescent and adult services, given that the peak age of onset for eating disorders is 15–25 years and the average duration of illness is 6 years (Schmidt et al., 2016), which will result in a significant number of patients being transferred

from child and adolescent mental health services to adult services (Winston, Paul, & Juanola-Borrat, 2012). Failure to manage and integrate transitional care effectively can lead to young people losing contact with health and social care systems, resulting in adverse effects on health and well-being (Dimitropoulos, Herschman, Toulany, & Steinegger, 2016). Innovative research is required that investigates new systems such as a youth model that spans this entire age range and whether it is better suited to enhancing outcomes in EDs (Raballo, Poletti, & McGorry, 2017).

Finally, six issues related to improved treatments were endorsed across more than one study. Broadly speaking these can be summarised as enhancing treatments and developing personalised medicine approaches, also called a staging approach, which examines the best treatment formats for an individual including intensity of treatment, inclusion of families in treatment, and impact of age on treatment. Development of more effective treatments is particularly needed for anorexia nervosa, where network meta-analysis suggests no difference between the outcomes of any of our current outpatient therapies for adults (Zeeck et al., 2018). Preference for less restrictive treatment settings is strong but there is insufficient evidence to support this (Hay, et al., 2019). Future research needs to evaluate use of augmentation therapies in the face of non-response to interventions, and such research will require a greater focus on the testing of mediators and moderators of our interventions (Kraemer et al., 2016). Translation of all these priorities to international settings will, of course, need to recognise specific priorities based on cultural and societal differences. For example, the mental health of Indigenous peoples is an urgent piece of research required in Australia but may find overlap with other countries working with First Nation peoples. Another example is the impact of COVID-19, where different countries have experienced vastly different rates of infection and death and lockdown.

The Australian NHMRC notes that inclusion of consumers in deciding research priorities is only a first step in conducting true co-design research. They advocate seven further steps that the ED community should consider when further developing research projects aligned with the emergent

priorities. Following the collective setting of research priorities, next comes a consideration of ethics and consent procedures with consumers. Third, training in data collection if relevant. Fourth and fifth, analysis and reporting of data to ensure clear and understandable outcomes that answer the central questions initially posed. Sixth, presentation of findings to consumer communities and organisations before external dissemination, to ensure development of local translation of research findings. Finally, joint reflection to ensure that the research contributed to the implementation of better practices moving forward. While this all takes some forward planning and extra time, it does achieve a more focused use of resources and is more likely to achieve research outcomes that make a discernible difference to future outcomes for the ED community (Chalmers et al., 2014; Cristea & Naudet, 2019). With so much at stake, we hope that an integrated research strategy based on the priorities identified in this co-design synthesis will drive better outcomes in ED research in the future.

References

* research priority setting not involving consumers; ** research priority setting involving consumers

- *Agras, W. S., Brandt, H. A., Bulik, C. M., Dolan-Sewell, R., Fairburn, C. G., Halmi, K. A., . . . Wilfley, D. E. (2004). Report of the National Institutes of Health workshop on overcoming barriers to treatment research in anorexia nervosa. *International Journal of Eating Disorders*, 35, 509-521. doi: 10.1002/eat.10261
- Ali, K., Farrer, L., Fassnacht, D. B., Gulliver, A., Bauer, S., & Griffiths, K. M. (2017). Perceived barriers and facilitators towards help-seeking for eating disorders: A systematic review. *International Journal of Eating Disorders*, 50, 9-21. doi: 10.1002/eat.22598
- Byrne, S., Wade, T. D., Hay, P., Touyz, S., Fairburn, C. G., Treasure, J., ... Crosby, R. D. (2017). A randomised controlled trial of three psychological treatments for anorexia nervosa. *Psychological Medicine*, 47, 2823-2833. doi: 10.1017/S0033291717001349
- Cadwallader, J. S., Godart, N., Chastang, J., Falissard, B., & Huas, C. (2016). Detecting eating disorder patients in a general practice setting: A systematic review of heterogeneous data on clinical outcomes and care trajectories. *Eating and Weight Disorders*, 21, 365-381.
- Chalmers, I., Bracken, M. B., Djulbegovic, B., Garattini, S., Grant, J., Gülmezoglu, A. M., et al. (2014). How to increase value and reduce waste when research priorities are set. *The Lancet*, 383, 156-165. doi: 10.1016/S0140-6736(13)62229-1
- Cristea, Ioana A; Naudet, Florian. (2019). Increase value and reduce waste in research on psychological therapies. *Behaviour Research and Therapy*. Advance Online Publication, doi: 10.1016/j.brat.2019.103479
- Culbert, K.M., Racine, S.E., & Klump, K.L. (2015). Research Review: What we have learned about the causes of eating disorders - a synthesis of sociocultural, psychological, and biological research. *Journal of Child Psychology and Psychiatry*, 56, 1141-1164. doi: 10.1111/jcpp.12441
- Dimitropoulos, G., Herschman, J., Toulany, A., Steinegger, C. (2016). A qualitative study on the challenges associated with accepting familial support from the perspective of transition-age youth with eating disorders. *Eating Disorders: the Journal of Treatment and Prevention*, 24, 255-270. doi: 10.1080/10640266.2015.1064276
- *Eddy, K. T., Harshman, S. G., Becker, K. R., Bern, E., Bryant-Waugh, R., Hilbert, A., . . . Thomas, J. J. (2019). Radcliffe ARFID Workgroup: Toward operationalization of research diagnostic criteria and directions for the field. *International Journal of Eating Disorders*, 52, 361-366. doi:10.1002/eat.23042
- Eisler, I., Simic, M., Hodsoll, J., Asen, E., Berelowitz, M., Connan, F., ... Landau, S. (2016). A pragmatic randomised multi-centre trial of multifamily and single-family therapy for adolescent anorexia nervosa. *BMC Psychiatry*, 16, 422. doi: 10.1186/s12888-016-1129-6
- Fairburn, C. G. (2008). *Cognitive Behavior Therapy and Eating Disorders*. Guilford Press: London.

- Fairburn, C.G. & Cooper, Z. (2011). Eating disorders, DSM5 and clinical reality. *British Journal of Psychiatry*, 198, 8-10. doi:10.1192/bjp.bp.110.083881
- *Grilo, C. M., Devlin, M. J., Cachelin, F. M., & Yanovski, S. Z. (1997). Report of the National Institutes of Health (NIH) Workshop on the Development of Research Priorities in Eating Disorders. *Psychopharmacology Bulletin*, 33, 321-333.
- Hart, L., Granillo, M., Jorm, A., & Paxton, S. (2011). Unmet need for treatment in the eating disorders: A systematic review of eating disorder specific treatment seeking among community cases. *Clinical Psychology Review*, 31, 727-735. doi: 10.1016/j.cpr.2011.03.004
- **Hart, L. M., & Wade, T. D. (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. doi: 10.1002/eat.23172
- Hay, P., Chinn, D., Forbes, D., Madden, S., Newton, R., Sugenor, L., ... & Ward, W. (2014). Royal Australian and New Zealand College of Psychiatrists clinical practice guidelines for the treatment of eating disorders. *Australian and New Zealand Journal of Psychiatry*, 48, 977-1008. doi: 10.1177/0004867414555814.
- Hay, P., Ghabrial, B., Mannan, H., Conti, J., Gonzalez-Chica, D., Stocks, N., ... & Touyz, S. (2020). General practitioner and mental healthcare use in a community sample of people with diagnostic threshold symptoms of bulimia nervosa, binge-eating disorder, and other eating disorders. *International Journal of Eating Disorders*, 53(1), 61-68. doi: 10.1002/eat.23174
- Hay, P. J., Touyz, S., Claudino, A. M., Lujic, S., Smith, C. A., & Madden, S. (2019). Inpatient versus outpatient care, partial hospitalisation and waiting list for people with eating disorders. *Cochrane Database of Systematic Reviews*, (1). doi: 10.1002/14651858.CD010827.pub2
- Hilbert, A., Hoek, H. W., & Schmidt, R. (2017). Evidence-based clinical guidelines for eating disorders: international comparison. *Current Opinion in Psychiatry*, 30, 423-437. doi: 10.1097/YCO.0000000000000360
- Keski-Rahkonen, A., Hoek, H. W., Linna, M. S., Raevuori, A., Sihvola, E., Bulik, C. M., ... Kaprio, J. (2009). Incidence and outcomes of bulimia nervosa: a nationwide population-based study. *Psychological Medicine*, 39, 823-831. doi: 10.1017/S0033291708003942
- Kostro, K., Lerman, J.B. & Attia, E. (2014). The current status of suicide and self-injury in eating disorders: a narrative review. *Journal of Eating Disorders*, 2, 19. doi: 10.1186/s40337-014-0019-x
- Kraemer, H. C. (2016). Messages for clinicians: Moderators and mediators of treatment outcome in randomized clinical trials. *American Journal of Psychiatry*, 173, 672-679. doi: 10.1176/appi.ajp.2016.15101333
- Linardon, J., & Wade, T. D. (2018). How many individuals achieve symptom abstinence following psychological treatments for bulimia nervosa? A meta-analytic review. *International Journal of Eating Disorders*, 51, 287-294. doi: 10.1002/eat.22838

- Lock, J., Le Grange, D., Agras, W. S., Moye, A., Bryson, S. W., & Jo, B. (2010). Randomized clinical trial comparing Family-Based Treatment with Adolescent-Focused individual therapy for adolescents with anorexia nervosa. *Archives of General Psychiatry*, 67, 1025-1032. doi: 10.1001/archgenpsychiatry.2010.128
- Mandelli, L., Arminio, A., Atti, A.-R., & De Ronchi, D. (2019). Suicide attempts in eating disorder subtypes: a meta-analysis of the literature employing DSM-IV, DSM-5, or ICD-10 diagnostic criteria. *Psychological Medicine*, 49, 1237-1249. doi: 10.1017/S0033291718003549
- Micali, N., Martini, M. G., Thomas, J. J., Eddy, K. T., Kothari, R., Russell, E., ... Treasure, J. (2017). Lifetime and 12-month prevalence of eating disorders amongst women in mid-life: A population-based study of diagnoses and risk factors. *BMC Medicine*, 15, 12. doi: 10.1186/s12916-016-0766-4
- Moher, D., Liberati, A., Tetzlaff, J., & Altman, D. G. (2009). Preferred reporting items for systematic reviews and meta-analyses: The PRISMA statement. *Annals of Internal Medicine*, 151(4), 264-269. doi: 10.1037/0022-0167.52.4.629
- Murray, S. B., Pila, E., Griffiths, S., & Le Grange, D. (2017). When illness severity and research dollars do not align: are we overlooking eating disorders? *World Psychiatry*, 16, 321. doi: 10.1002/wps.20465
- **Obeid, N., McVey, G., Seale, E., Preskow, W., & Norris, M. L. (2020). Cocreating research priorities for anorexia nervosa: The Canadian Eating Disorder Priority Setting Partnership. *International Journal of Eating Disorders*. Advance Online Publication, doi: 10.1002/eat.23234
- Raballo, A., Poletti, M., & McGorry, P. (2017). Architecture of change: Rethinking child and adolescent mental health. *Lancet*, 4, 656-658. doi: 10.1016/S2215-0366(17)30315-2
- Rudorfer, M. V., & Goldstein, H. (1997). Research priorities in eating disorders. *Psychopharmacology Bulletin*, 33, 317-319.
- Safer, D. L., Robinson, A. H., & Jo, B. (2010). Outcome from a randomized controlled trial of group therapy for binge eating disorder: comparing dialectical behavior therapy adapted for binge eating to an active comparison group therapy. *Behavior Therapy*, 41, 106-120.
- Schmidt, U., Dingemans, A., Favaro, A., Himmerich, H., Herpertz-Dahlmann, B., ... Zipfel, S. (2016). Eating disorders: The big issue. *Lancet Psychiatry*, 3, 313-315. doi: 10.1016/S2215-0366(16)00081-X
- Schmidt, U., Wade, T. D., & Treasure, J. (2014). The Maudsley Model of Anorexia Nervosa Treatment for Adults (MANTRA): development, key features, and preliminary evidence. *Journal of Cognitive Psychotherapy*, 28, 48-71. doi: 10.1891/0889-8391.28.1.48
- Sharan, P., Gallo, C., Gureje, O., Lamberte, E., Mari, J. J., Mazzotti, G., Patel, V., Swartz, L., Olifson, S., Levav, I., De Francisco, A., & Saxena S. (2009). Mental health research priorities in low- and middle-income countries of Africa, Asia, Latin America and the Caribbean. *British Journal of Psychiatry*, 195, 354-363. doi: 10.1192/bjp.bp.108.050187

- *Tanofsky-Kraff, M., Bulik, C. M., Marcus, M. D., Striegel, R. H., Wilfley, D. E., Wonderlich, S. A., & Hudson, J. I. (2013). Binge eating disorder: The next generation of research. *International Journal of Eating Disorders*, 46, 193-207. doi:10.1002/eat.22089
- Tomlinson, M., Chopra, M., Hoosain, N., & Rudan, I. (2011). A review of selected research priority setting processes at national level in low and middle income countries: towards fair and legitimate priority setting. *Health Research and Policy Systems*, 9:19. doi: 10.1186/1478-4505-9-19
- Tong, A., Synnot, A., Crowe, S., Hill, S., Matus, A., ... Craig, J. C. (2019). Reporting guideline for priority setting of health research (REPRISE). *BMC Medical Research Methodology*. Advance Online Publication, doi: 10.1186/s12874-019-0889-3
- Udo, T., Bitley, S., & Grilo, C. (2019). Suicide attempts in US adults with lifetime DSM-5 eating disorders. *BMC Medicine*, 17, 120. doi: 10.1186/s12916-019-1352-3
- **van Furth, E. F., van der Meer, A., & Cowan, K. (2016). Top 10 research priorities for eating disorders. *The Lancet Psychiatry*, 3, 706-707. doi:10.1016/S2215-0366(16)30147-X
- Watson, H. J., Joyce, T., French, E., Willan, V., Kane, R. T., Tanner-Smith, E. E., ... Egan, S. J. (2016). Prevention of eating disorders: A systematic review of randomized, controlled trials. *International Journal of Eating Disorders*, 49, 833-62. doi: 10.1002/eat.22577
- Winston, A.P., Paul, M., & Juanola-Borrat, Y. (2012). The same but different? Treatment of anorexia nervosa in adolescents and adults. *European Eating Disorder Review*, 20, 89-93. doi: 10.1002/erv.1137
- **Witton, N. S., Leichner, P., Sandhu-Sahota, P., & Filippelli, D. (2007). The research directions survey: Patient and parent perspectives of eating disorder research. *Eating Disorders*, 15, 205-216. doi: 10.1080/10640260701323466
- Woelbert, E., Kirtley, A., Balmer, N., & Dix, S. (2019). How much is spent on mental health research: developing a system for categorising grant funding in the UK. *The Lancet Psychiatry*, 6, 445-452. doi: 10.1016/S2215-0366(19)30033-1
- Zeeck, A., Herpertz-Dahlmann, B., Friederich, H. C., Brockmeyer, T., Resmark, G., Hagenah, U., ... Hartmann, A. (2018). Psychotherapeutic Treatment for Anorexia Nervosa: A Systematic Review and Network Meta-Analysis. *Frontiers of Psychiatry*, 9, 158. doi: 10.3389/fpsy.2018.00158

Table 1: Top research priorities for eating disorders (EDs)

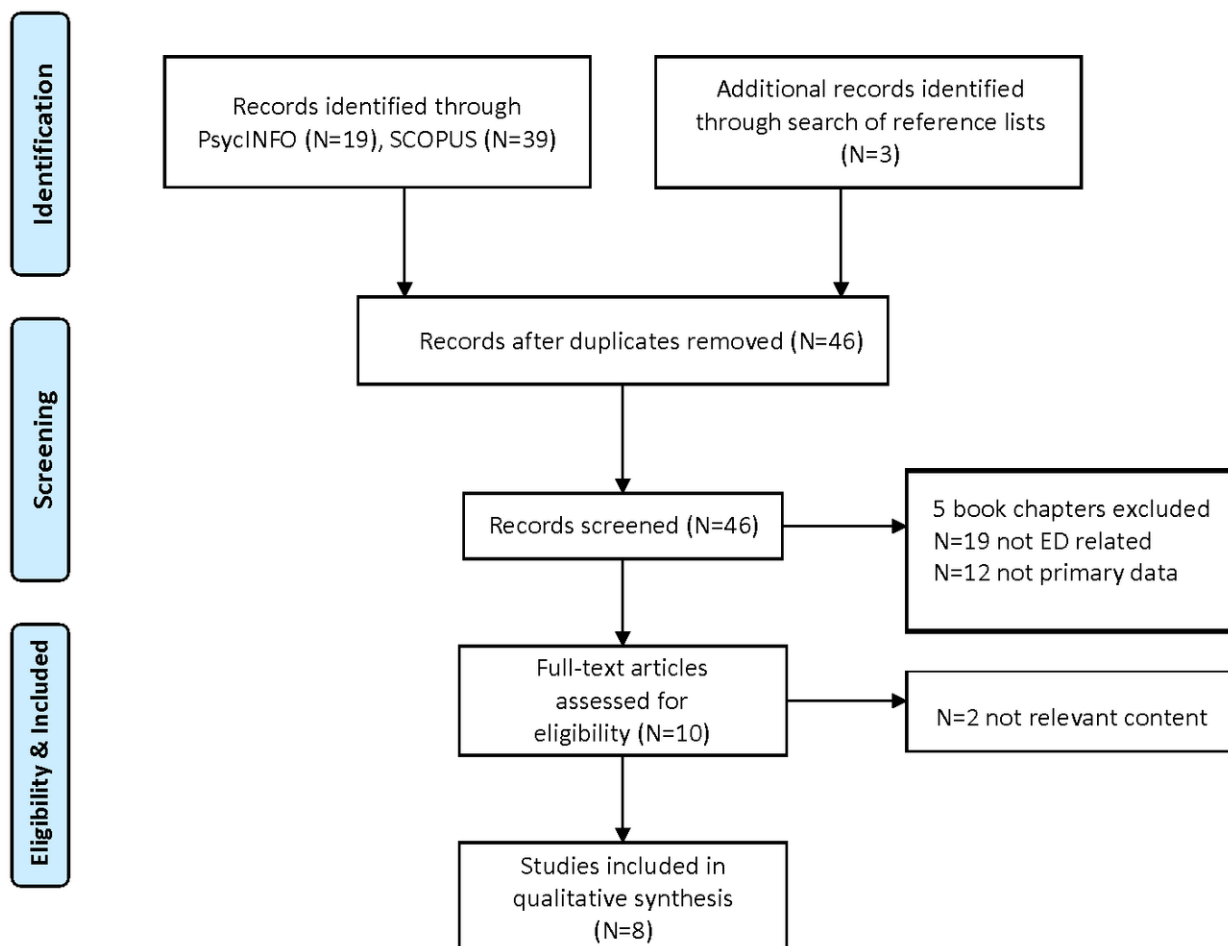
Themes ^a	Specific research priorities informed by consumers
Risk factors, models	1. Are there specific risk factors for the development of an ED? 2. How can prevention target these risk factors? 3. <i>*What causes the need for self-destructive behaviour in patients with an ED? Understanding the relationship between self-harm and EDs.</i> 4. <i>Physical pathways, impact, role in diagnosis.</i> 5. <i>The role of social media.</i>
Prevention	6. <i>Enhancing existing prevention approaches. Exploring combined mental health prevention programs.</i> 7. <i>Exploring the role of anti-obesity and combined prevention programs.</i> 8. <i>Macro-level/public health interventions.</i>
Early intervention	9. *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? <i>Encouraging health providers to assess eating and exercise behaviours in individuals with existing mental health conditions. Impact of weight stigma on provision of quality of health services for individuals with mental health problems.</i> 10. <i>Early detection.</i> 11. <i>Early intervention at all critical risk periods.</i> 12. <i>Enhancing existing early intervention programs.</i>
Bridging the research-practice gap	13. Of those diagnosed with anorexia nervosa, what are the rates of recovery, relapse, dropouts, and length of treatment? 14. *How could the system better support individuals with anorexia nervosa through transition periods so that care is streamlined and easier to navigate? <i>Integrated care.</i> 15. What are the effects of repeated inpatient admissions for anorexia nervosa patients, and should treatment be different after repeated admissions? 16. What are the wait times for adolescent girls and women suffering from anorexia nervosa? Are they equitable? How can we decrease wait times for services? 17. <i>What to do when first line treatments don't work?</i> 18. <i>Using suicide prevention interventions with ED consumers.</i>

	19. <i>Accessible services.</i>
Diagnosis and functional impairment	20. <i>National data set (What is the profile of the full spectrum of eating disorders across the community?)</i> 21. <i>Understanding EDs across the lifespan.</i>
Treatment approaches, accounting for comorbidity with other mental illness and obesity	22. Which patient and disorder-related features can be used to provide more personalised treatment? 23. Is it more effective to address the eating disorder symptoms first or the underlying problems? 24. *What is the most effective treatment (and order of treatment) for patients with an eating disorder and a co-morbid disorder? 25. *Which treatment setting (outpatient, at home, day treatment, inpatient or residential, with or without parents) provides the best treatment outcome? Inpatient versus outpatient treatment. 26. *Is it better to use a protocol based on a guideline or to tailor treatment to the individual? <i>Matching treatments to profiles.</i> 27. *How can loved ones contribute to the recovery process of the eating disorder? <i>Families as therapists.</i> Overprotective parenting, the impact of divorce, and the role of siblings. 28. What is the influence of the quality of the working relationship between the treatment team and the patient on treatment outcome? 29. * What is the short- and long-term efficacy of treatment methods for anorexia nervosa at different ages and which ones are the best? 30. 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? 31. * <i>Enhancing existing treatments. Establishing new and innovative treatment options.</i>
Recovery	32. Which factors influence the duration of recovery and the possibility of complete recovery? 33. Once recovered/discharged from services, what is the most effective way of preventing relapse for anorexia nervosa patients? 34. What is the most effective way of educating families and caregivers on anorexia nervosa and on ways to support patients through recovery? 35. <i>Defining recovery.</i>

Note: Netherlands, **Canada (2007 & 2020)**, *Australia*

^aThemes in italics (as seen in Column 1) are unique to research priorities involving consumers, while non-italicised themes are common to research priorities informed by consumers and researchers.

*indicates questions that were endorsed across more than one consumer-informed study.



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Driving better intervention outcomes in eating disorders: A systematic synthesis of research priority setting and the involvement of consumer input

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