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Gaining consensus on clinical quality outcomes for eating disorders: Framework for the development of an Australian national minimum dataset

Emma Bryant ,[1] Catherine Broomfield,[1] Jennifer Burrows,[1] Sian McLean,[2,3] Peta Marks,[1] Danielle Maloney,[1] Stephen Touyz,[1] Sarah Maguire[1]

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[1]InsideOut Institute for Eating Disorders, Faculty of Medicine and Health, University of Sydney and Sydney Local Health District, Camperdown, Sydney, Australia
[2]Department of Psychology, Counselling and Therapy, La Trobe University, Melbourne, Victoria, Australia
[3]Australia and New Zealand Academy for Eating Disorders, Castlecrag, New South Wales, Australia

Correspondence to
Emma Bryant;
emma.bryant@sydney.edu.au

ABSTRACT

Objectives Eating disorders (EDs) are complex psychiatric illnesses requiring multidisciplinary care across both mental and medical healthcare settings. Currently, no nationally comprehensive, consistent, agreed on or mandated data set or data collection strategy exists for EDs in Australia: thus, little is known about the outcomes of care nor treatment pathways taken by individuals with EDs. InsideOut Institute was contracted by the Australian Government Department of Health to develop a minimum dataset (MDS) for the illness group with consideration given to data capture mechanisms and the scoping of a national registry.

Design A four-step modified Delphi methodology was used, including national consultations followed by three rounds of quantitative feedback by an expert panel.

Setting Due to social distancing protocols throughout the global SARS-CoV-2 pandemic, the study was conducted online using video conferencing (Zoom and Microsoft Teams) (Step 1), email communication and the REDCap secure web-based survey platform (Steps 2–4).

Participants 14 data management organisations, 5 state and territory government departments of health, 2 Aboriginal and Torres Strait Islander advising organisations and 28 stakeholders representing public and private health sectors across Australia participated in consultations. 123 ED experts (including lived experience) participated in the first quantitative round of the Delphi survey. Retention was high, with 80% of experts continuing to the second round and 73% to the third.

Main outcome measures Items and categories endorsed by the expert panel (defined a priori as >85% rating an item or category 'very important' or 'imperative').

Results High consensus across dataset items and categories led to the stratification of an identified MDS. Medical status and quality of life were rated the most important outcomes to collect in an MDS. Other items meeting high levels of consensus included anxiety disorders, depression and suicidality; type of treatment being received; body mass index and recent weight change.

Conclusions Understanding presentation to and outcomes from ED treatment is vital to drive improvements in healthcare delivery. A nationally agreed MDS has been defined to facilitate this understanding and support improvements.

STRENGTHS AND LIMITATIONS OF THIS STUDY

⇒ There was broad participation in the Delphi study from the national eating disorder community: including expert clinicians from all relevant healthcare disciplines, consumers, researchers, policy-makers and advocates representing every state and territory in Australia.
⇒ Retention was high, maximising validity.
⇒ There were high levels of agreement across the panel, leading to the stratification of a tiered dataset based on what the panel deemed 'imperative' to collect.
⇒ Lack of standardised patient-reported experience measures and quality of life instruments means further scoping is needed.

INTRODUCTION

Eating disorders (EDs) are complex mental illnesses with considerable negative physical and psychosocial ramifications[1–5] associated with significant disability.[6–9] Conservative estimates place 4–5% of the Australian population with an ED at any one time,[10 11] with poor overall treatment outcomes, high mortality rates, and a national fiscal cost of $69.7 billion per year.[11] However, inaccurate epidemiological and cost data generated from incomplete healthcare statistics means the true burden of EDs is not known.[6 12–14]

Despite substantial recent commitment to the delivery of evidence-based treatment for Australians living with EDs, including the creation of a dedicated Medicare programme (Eating Disorder Treatment and Management Plan or EDP) tripling the number of government-rebated psychological sessions available to individuals with EDs, as well as large scale investment in a number of states,[15] little attention has been paid to understanding the outcome of that investment. Currently, ED treatment providers (including those accessing the EDP) are under no obligation to collect data relating to their

services given the lack of a nationally centralised system or mandatory collection process.[16 17] This means most prevalence and clinical outcome data are estimated or derived from small population or cohort studies, resulting in large uncertainty intervals and underpowered burden estimates.[6 18] Data from public community and hospital care are limited. Additionally, widespread structural exclusion of EDs from national mental health plans and national surveys of mental well-being contributes to the lack of population-level data and further limits our understanding of the impact of these conditions on the healthcare system, the individual and their family and carers.[6 16 17 19 20] What little data exists suggest EDs have one of the highest average public hospital acute care costs per separation (discharge) of all medical conditions[21] and can be as disabling as severe forms of schizophrenia.[7 8 22]

ED care is inherently complex, with both psychological and medical intervention frequently required across a spectrum of severity. Over the course of treatment, an individual may access a combination of public and private inpatient and day programme stays; acute ambulatory or emergency presentations; community mental healthcare and regular consultation with general practitioners and private practice clinicians (including dietitians, psychiatrists, psychologists and social workers) via outpatient care. Research shows many individuals make a full recovery if the right treatment is received at the right time[23]; however, in Australia, lack of integrated pathways means care is frequently inconsistent and difficult to navigate resulting in treatment delay, interruption and/or protraction.[15] Thus, not only is there limited information on who is presenting to healthcare services with an ED, what treatment they are receiving, who is delivering that treatment and how effective that treatment is; there is also little information on how treatment services interact with each other at either a local or system level. Consequences of treatment delay and lack of integrative, harmonious care pathways are well researched and clear: they significantly increase an individual's risk of illness chronicity and mortality.[24–26]

Nationally standardised data collection is increasingly understood as best practice in any illness group for the understanding of potential healthcare gaps, driving improvements in illness detection, national policy and service planning, treatment outcomes and support.[27–32] Example mechanisms for the collection of data include minimum datasets, such as the Primary Mental Healthcare Minimum Dataset and the National Bowel Cancer Screening Programme National Best Endeavours Dataset,[33] and population or disease-based registries. Population and disease-based registries exist for many major illness groups, including dementia,[34] prostate cancer,[35] HIV[36] and palliative care.[37] In 2016, the Australian Commission on Safety and Quality in Healthcare identified mental disorders in their prioritised list of clinical domains for Clinical Quality Registry development. Despite this, no registries currently exist for any mental disorder.

The Australian Government's first National Eating Disorders Research and Translation Strategy,[38] released in 2021, identified data collection as a priority recommendation for quality improvement and care. Consistent national reporting of pathology, healthcare utilisation and outcomes in EDs will be crucial to understanding the impact of illness on Australians and improving current high morbidity and mortality rates. As such, InsideOut Institute for Eating Disorders was contracted by the Australian Government Department of Health as part of the 2019–2022 National Leadership in Mental Health Programme and the Psych Services for Hard-to-Reach Groups Programme to deliver three interlinked data activities for the purposes of improving data collection in EDs: scope and develop a consensus MDS for EDs, identify standard mechanisms to capture the MDS at the point of care and scope feasibility for a national registry for people with an ED. The data activities aimed to inform future implementation of a system optimal for assessing and evaluating ED healthcare practices provided across the country.

METHODS

Study design

An extensive national consultation process was conducted alongside benchmarking activities, literature reviews and consensus building research methods. The current paper reports empirical data on the National Delphi study, the results of which were considered in tandem with all other activities conducted as part of the data projects to arrive at a consensus MDS for EDs.

The Delphi methodology, originally conceived by Dalkey and Helmer in the 1950s, is a multistage survey method designed to generate consensus-based data among a group of individuals deemed experts within a field using a process of controlled feedback and anonymity.[39–41] The method has a wide range of applications, including policy-making, theorising, forecasting and issue identification and concept/framework development.[42 43] It has been increasingly used to gain consensus on MDS required for diseases related to physical health.[44–46] Still in its infancy in terms of its application to develop MDS for psychiatric disorders, the method has recently been applied to determining core outcome sets when researching mental illness, including addiction,[47–49] depression,[50–52] schizophrenia[53 54] and trauma-related disorders,[55–57] among others.

In line with these other illness groups, a modified four-step Delphi approach comprising of a broad national consultation and three survey rounds (see figure 1) was used to establish consensus on clinically relevant data items, as well as the settings, age and diagnostic scope of the data collection.

Contextual challenges and imperatives of data capture and the feasibility of a national registry for EDs were explored qualitatively to inform decisions relating to implementation of the data items. A series of questions were posed at each consultation, in the email surveys, and in key expert interviews to help identify data gaps, data item collection priorities and obstacles to and opportunities for standardised data collection. The study was approved by the University of Sydney's Human Research Ethics Committee (protocol no. 2021/849).

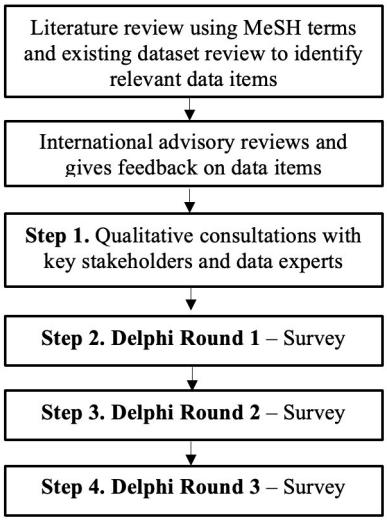

Figure 1 Modified Delphi process.

Step 1. Qualitative consultations—key stakeholders

Nationwide consultations involving key stakeholders were conducted using video conferencing software (due to social distancing restrictions throughout the global SARS-CoV-2 pandemic) between June and December 2021. This included individuals representing public and private healthcare services (inpatient, outpatient and community), Primary Health Networks (independent organisations government-funded to coordinate primary healthcare in their region), primary care and private practice specialist services, non-government organisations, research and advocacy institutes, and people with a lived experience (LE) (both consumers and carers). These meetings provided an opportunity for stakeholders to understand the scope of the data projects; discuss what data are already captured and identify existing point of care data collection processes; challenges and opportunities within and across their respective services; review and provide input to a clinically relevant MDS; and explore the feasibility of a national registry. Feedback was used to inform the subsequent steps of the Delphi study to arrive at consensus on a National MDS (see Delphi Rounds 1–3) and to understand how these items might be implemented.

Qualitative consultations—data managers and jurisdictions

As part of scoping data capture at the point of care and the feasibility of a national registry, the project team also consulted with state and territory data managers and specialists expert in national data classification and governance, point of care data collection challenges and opportunities, data platforms and the establishment, operation and maintenance of national registries. These consultations continued to August 2022 and included the Australian Institute of Health and Welfare; Mental Health Data and Analysis Section, Mental Health Services and Evidence Branch, Department of Health; Australian Mental Health Outcomes Classification Network; Medicare (Department of Health); Australian Dementia Network Registry; National Prostate Cancer Registry; ANZ Congenital Heart Alliance; Palliative Care Outcomes Collaboration; National HIV Register (Kirby Institute); OCEAn study (School of Public Health, University of Sydney); Logicly Data Management group and State government data managers.

Steps 2–4. Delphi rounds: anonymous email questionnaires

Participants and recruitment

In March 2022 on completion of the first round of qualitative consultations, all stakeholders were invited to take part in the Delphi study, as was a larger group of experts. Members of the Australia and New Zealand Academy for Eating Disorders (ANZAED)—the primary professional body for EDs in Australia—were notified of the Delphi study and invited to participate via email. Additionally, healthcare professionals registered with InsideOut Institute's treatment services database who had indicated an interest in participating in research were also notified via email of the Delphi study and invited to participate.

With only one recent example of the utilisation of the Delphi methodology for developing an MDS for mental illness,[58] guidelines from the use of the technique in broader contexts were adopted. A review of the Delphi method suggests that when using a sample size of 20 or more participants, the research is likely to produce stable findings.[59] The application of the Delphi methodology to determine an MDS for physical health conditions has used sample sizes of between 20 and 100.[44 45 60–67] Given our aim to include broad representation from diverse expertise across the country, we endeavoured to recruit a final sample size of at least 50 individuals to form the expert panel.

Individuals were deemed 'experts' according to the following criteria

- Individuals with LE of any ED (either personal or as carer/loved one).
- Professionals working with government and non-government ED organisations, including the National Eating Disorders Collaboration, Eating Disorders Victoria, Eating Disorders Queensland, Butterfly Foundation, EndED and Eating Disorders Families Australia.
- Individuals working in ED policy and advocacy.
- Specialist ED clinicians in private practice, ED services or community mental health teams.
- Professional registered members of ANZAED.
- Academic researchers from ED research institutes and university departments across Australia.

Measures

Three rounds of questionnaires designed to cover the most salient data elements and categories for the assessment of clinical quality outcomes in EDs were delivered in a synchronous format via the secure web-based survey platform REDCap between March 2022 and May 2022. Participants (hereafter 'panellists') were provided 2 weeks to complete each questionnaire. Reminder emails were distributed 1 week prior to closing date with the aim of reducing attrition. In

circumstances where an extension for completing the questionnaire was requested by panellists, this was permitted.

Dataset development

Initial data items were generated based on Leginski *et al*'s decision standards for data content development consistent with previous research.[68] This framework recommends data elements considered for inclusion in a proposed dataset reflect concepts of need (items critical to the subsequent processing and categorising of data); tradition (minimum items when considering idiosyncrasies of setting or illness); professional judgement (items which key stakeholders deem important to address a question or explain a data pattern, based on their experience and knowledge) and empiricism (where the extent to which an item contributes to the explanation of variance in the database is testable).[68] As such, the items were informed through comprehensive review of the literature—including existing ED MDS' in countries outside of Australia, qualitative consultations with stakeholders and advice from an international panel of ED treatment and research experts.

Round 1

The following demographic information was collected in Round 1: gender, location (State), type and years of ED expertise, type of clinician (if relevant) and type of LE (if relevant). Panellists were then asked to rate the importance of inclusion of each data category, diagnosis, setting and item on a five-point Likert scale ('not essential' to 'imperative'). Four to seven response categories are considered optimal for a Delphi study (less than four may compromise reliability and discriminating power, while too many response options can lead to inconsistency in category interpretation and arbitrary division between responses).[69 70] There were 12 subsections: 9 categories (core features of illness, co-occurring psychiatric conditions, treatment characteristics—healthcare utilisation, treatment characteristics—treatment delivered, medical status, functional assessment, quality of life (QoL), patient-reported outcome measures (PROMs) and patient-reported experience measures (PREMs)) and 3 scoping questions (settings, diagnoses and age). Round 1 also included scoping questions relating to existing standardised PROMs used to assess core features of ED and comorbid psychopathology.

Rounds 2 and 3

Questionnaires administered for Rounds 2 and 3 comprised of categories, diagnoses, settings and data items which had not met consensus (defined below) in the previous round. Those items not meeting consensus were retained in the following round and presented as ordinal data demonstrating overall per cent agreement for each of the five previously rated categories of relative importance. This allowed panellists to reconsider their position in the context of the overall response. Minor adjustments were made to the Likert scale in these rounds based on feedback from Round 1.

Following Round 1 feedback, a statement regarding co-occurring conditions was generated for rating in Round 2: 'Depression and anxiety are the most important comorbidities to capture features of when an individual presents with an eating disorder. Do you agree with this statement?'. Panellists were then given the opportunity to provide qualitative feedback to justify their answer. Questions regarding the use of PROMS in EDs were also adapted based on the overall panel response in Round 1. This included querying the efficacy of the Eating Disorder Examination Questionnaire (EDE-Q), and other standardised instruments in assessing for specific ED diagnosis, for example, 'As the EDE-Q or an adapted version of the EDE-Q (adolescent or short) was deemed most preferred by a significant majority of panel members for Anorexia Nervosa (AN), Bulimia Nervosa (BN), Other Specified Feeding or Eating Disorder (OSFED) and Unspecified Feeding or Eating Disorder (UFED), we are now going to ask you about this questionnaire specifically. Please move to the next question if you do not have expertise in this area. How well does the EDE-Q (including adapted versions) assess for core features of eating disorders?'.

Data analysis

As data was non-normally distributed, the most appropriate measures of central tendency to report for those items meeting consensus were mode, median and per cent panellist agreement. These were provided to panellists as they met consensus between rounds. Consensus was defined a priori as >85% agreement, or >85% of the panel rating an item as 'very important' or 'imperative'. The process of item inclusion/re-rating was as follows.

Endorse (include in MDS): ≥85% 'very important' or 'imperative'.

Re-rate: 'near' consensus (≥75%–85%); no consensus reached (round 2 only); no consensus reached with >10% variability between two rounds (rounds 1 and 2; instability of responses).

Reject (remove from MDS): ≥85% 'somewhat unimportant' or 'not essential'; no consensus reached with <10% variability between two rounds (Rounds 1 and 2; stability of responses).

Consensus levels were calculated using SPSS statistical software (V.28).

Patient and public involvement

This study was led by an LE researcher and is inherently based on patient (LE) and ED community involvement (see previous sections), including in all aspects of design, methodology, recruitment and measure development. All participants, stakeholders and contributors were informed of the results of the Delphi study as it progressed.

RESULTS

Step 1—consultations

A number of key themes were generated from the consultations. Widely raised was the need to improve ED data consistency, quality and availability. This

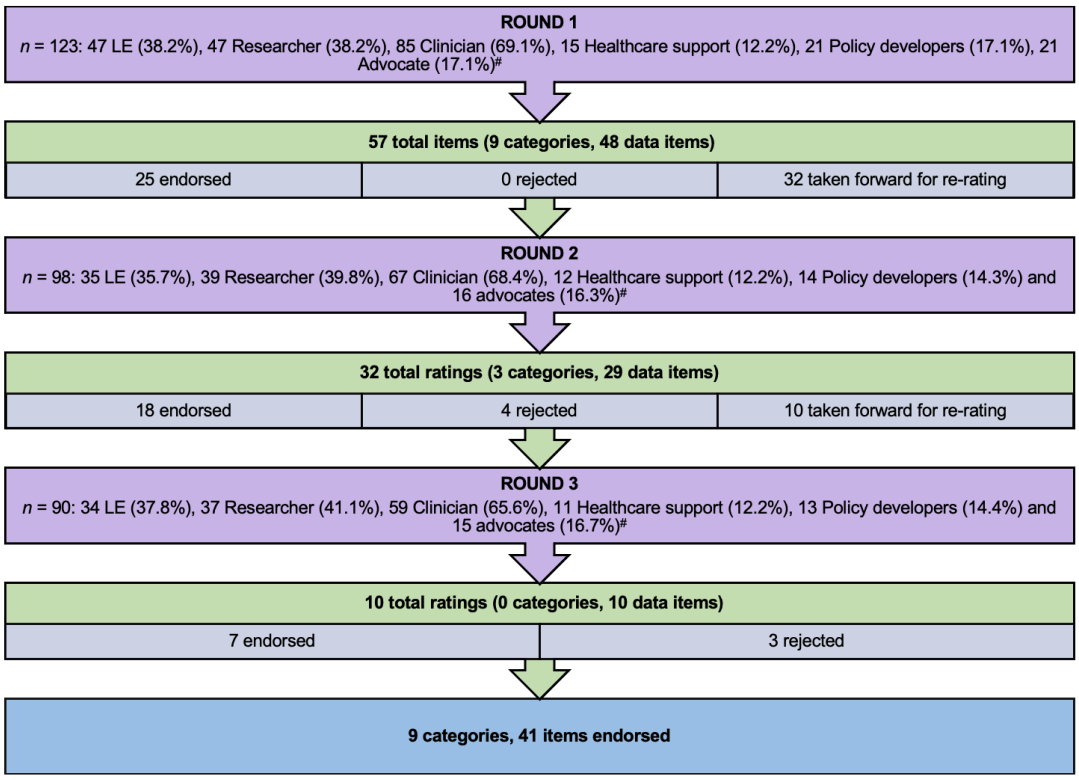

Figure 2 Flow diagram of response rate and endorsement/rejection process for each round of the Delphi study. #Panellists could select 'all that apply'—% does not total 100.

applied both to population data for disease surveillance and service evaluation and to clinical outcome data for individual patient care. Stakeholders agreed this was necessary for the monitoring and evaluation of ED service delivery, including assessing patterns of care and outcomes of care; measuring the cost-effectiveness of current and alternative service models and treatment pathways; and exploring the value of novel therapies, services or technologies. Standardised and centralised data collection practices were also considered necessary to monitor QoL, daily function and consumer views on service needs, access and satisfaction with service provision. Many clinicians expressed the need for support to capture and extract data, that is, a dedicated person responsible for this in each setting and external resourcing/management. There was an emphasis on minimising duplication—that datasets and systems should be automated with capacity to link into existing datasets and systems. A staged approach to MDS or registry rollout was considered to be ideal, given the complexity and breadth of ED care across the country. This would involve the piloting of one or two diagnosis/es in one or two settings, which could be further rolled out following investment into evaluation and research capacity in existing clinical service funding matrices.

Dataset items generated from literature review, benchmarking and the authors' own clinical and LE were preliminarily canvassed with participants, with feedback sought on missing or redundant items. These items were then taken to an international advisory of ED experts, who edited and reviewed the initial dataset for surveying in the Delphi study.

Steps 2–4 Delphi rounds: anonymous email questionnaires

Panel response rate and characteristics

A maximum total of 4899 individuals were contacted to participate in the Delphi study, including 3933 ANZAED mailing list members, 469 InsideOut Institute mailing list members and 28 individuals who participated in original consultations. As these categories are not mutually exclusive, the exact number of people contacted is unable to be ascertained.

A total of 1879 ANZAED members opened the email and 113 clicked on the survey link. Two hundred and twenty seven IOI research mailing list members opened the email and 98 clicked on the survey link. Stakeholders from the original consultations were emailed separately, thus no data were captured on unique clicks or accesses from them.

A total of 123 individuals provided complete responses in the first round of the survey. The majority (54.5%) of these individuals had 10 years or more years of ED experience. They represented every state and territory in Australia, and every professional group treating EDs. Ninety-eight individuals (80%) engaged in the second round of the survey and 90 individuals engaged in the third and final round of the survey (73% of those who

Table 1 Consensus results, categories to include in minimum dataset

Category (N)	% panellists' showing agreement ('very important' or 'imperative')							% panellists' rating category 'imperative'
	Total panellists	LE: personal/carer	Clinician	Researcher	Advocacy	Healthcare support	Policy development	Total panellists
Medical status	97	100/92	97	95	100	92	93	66
QoL	97	95/100	100	92	94	100	94	40
TC—treatment delivered	90	78/88	94	89	95	93	86	55
PROMs	88	94/88	85	89	95	87	95	39
TC—healthcare utilisation	87	94/81	87	81	90	93	91	43
Functional assessment	87	82/83	86	85	94	92	73	28
Comorbidities	86	91/88	85	87	90	87	100	41
Core features of illness	86	75/94	86	89	86	87	71	37
PREMs	85	94/75	86	81	81	80	82	39

LE, lived experience; PREMs, patient-reported experience measures; PROMs, patient-reported outcome measures; TC, treatment characteristics.

participated in Round 1). Almost 40% of participants across all three rounds had LE of an ED (either personal or as a carer). Full demographic information can be found in online supplemental table 1.

Ratings by round

A flow diagram of response rate and endorsement/rejection process for each round of the Delphi study can be found in figure 2. Scoping questions are not included.

Diagnostic scope

A large majority of panellists agreed that data on diagnosis of AN (99%), Atypical-AN (98%), BN (96%), Binge Eating Disorder (93%) and Avoidant Restrictive Food Intake Disorder (ARFID) (93%) were very important or imperative to consider for inclusion in a MDS for EDs. Fewer agreed UFED (87%) or OSFED (85%) were very important or imperative to capture. Pica (–42%) and Rumination Disorder (–37%) did not meet consensus by the third round; however, a large percentage of panellists rated them 'somewhat unimportant' or 'not essential.' See online supplemental table 2 for levels of endorsement.

Settings scope

All ED care settings proposed for the collection of MDS ED data met consensus. A large majority of panellists rated general practice (96%), specialist public tertiary inpatient units (95%), private practice (92%) and public hospital non-specialist inpatient units (91%) as very important or imperative data collection sites. Slightly fewer agreed on emergency (89%), specialist private hospital (89%), headspace (87%) and ambulatory care (86%) (online supplemental table 3).

Age scope

A large majority of panellists agreed that all ages (97%) should be included in the MDS (no lower or upper age limit).

Data categories

All data categories proposed for inclusion in the MDS met consensus. A large majority of panellists rated medical status (97%), QoL (97%) and treatment characteristics—treatment delivered (90%) as very important or imperative for inclusion in the MDS. Slightly fewer agreed on PROMs (88%), treatment characteristics—healthcare utilisation (87%), functional assessment (87%), comorbidities (86%), core features of illness (86%) and PREMs (85%). More than equal to 50% of the panel rated medical status (66%) and treatment characteristics—treatment delivered (55%) as 'imperative' (table 1).

Dataset items

All but seven data items (PICA, Rumination Disorder, attention-deficit/hyperactivity disorder, sleep disturbances, menstrual status, muscular disorders and hormone levels) met consensus. Substance-use disorders (96%), anxiety disorders (95%) and suicidality (94%) met high levels of consensus for inclusion in an MDS (see

table 2). Interestingly, 'affective/mood disorders' was not among the highest ranked. This item met consensus early in the study (in Round 1). In subsequent rounds, the confidence level of panellists appeared to increase, thus a higher level of consensus was achieved in later stages. In consideration of this and given their frequent comorbidity with EDs,[71] depressive and anxiety disorders were further queried in Round 2 of the survey (see 'other scoping questions').

Type of service being delivered (ie, inpatient, outpatient, public community care, public private practice, etc) was considered the most important characteristic of treatment to capture (96%) in an MDS and the only item in that category reaching >50% endorsement as 'imperative' (66%). There were high levels of agreement (≥50%) that the type of psychotherapeutic, nutritional, psychopharmacological and family/carer intervention delivered to an individual with ED was imperative to record in an MDS.

Medical indicators meeting high levels of consensus included bone health disorders (eg, osteoporosis) (95%), formal diagnosis of malnutrition (94%), cardiac abnormalities (93%), cognitive function (93%) and weight change in recent months (91%). Those indicators deemed 'imperative' to collect by >50% of the panel included formal diagnosis of malnutrition, weight change in recent months and body mass index (BMI).

Other scoping questions

Questions were posed to panellists regarding standardised questionnaires frequently used to assess core features of ED psychopathology. This included selecting the instrument they thought best assessed core symptoms of a specific diagnosis (adults and children) and in the following round, rating the efficacy of the highest ranked questionnaires from the previous round. If the panellist felt they were not sufficiently expert in any area to rate, they were given the opportunity to report this. These questions were not delivered for the purposes of refining dataset items, they were scoping questions for further exploration given the potential use of diagnostic instruments and PROMS in an MDS and were considered by the research team in tandem with all other activities undertaken as part of the data projects.

Regarding assessment in adults, over 75% of respondents rated the EDE-Q (either the full form or an abbreviated version) as the most appropriate instrument to assess for features of AN, BN and OSFED. 42.5% of respondents rated the Binge Eating Disorder Screener 7 (BEDS-7) as the most appropriate instrument to assess for features of BED in adults (vs 42.0% for the EDE-Q). The Pica Rumination Disorder Interview Questionnaire (PARDI-AR-Q) was rated the most appropriate instrument to assess for features of ARFID, Pica and Rumination Disorder in Adults (54.5%) followed by the Nine Item ARFID Screen (NIAS) (24.0%).

Regarding assessment in children, between 56% and 76% of respondents rated the EDE-A as the most appropriate instrument to assess for features of AN, BN, BED and OSFED. 42.5% of respondents rated the BEDS-7 as the most appropriate instrument to assess for features of BED in adults (vs 42.0% for the EDE-Q). The PARDI-AR-Q was rated the most appropriate instrument to assess for features of ARFID, Pica and Rumination Disorder in Adults (54.5%) followed by the NIAS (24.0%). The EDE-Q was rated the most appropriate instrument to assess for features of ARFID, Pica and Rumination Disorder in children (30%).

In Round 2, 66% of respondents reported that they believed the EDE-Q assessed for features of AN/BN/OSFED and UFED 'very well', while only 25.7% believed it assessed for features of BED 'very well'.

A total of 87% of panellists agreed or strongly agreed that depression and anxiety are the most important co-occurring conditions to capture core features of in an MDS for EDs. There was occasional disagreement in qualitative feedback regarding this question, with some panellists regarding Obsessive Compulsive Disorder (OCD), personality disorders, autism spectrum disorder and/or substance use disorders to be more important to capture.

Final MDS

A total of 41 items comprising nine clinical categories met final consensus for inclusion in the MDS (table 3). 'core features of illness', 'QoL', 'functional assessment' and 'PROMS/PREMS' were considered 'categories' due to the need for standardised measures or single indicators to be scoped and implemented for their measurement. High levels of consensus for all items were considered in conjunction with benchmarking activities and consultation feedback concerning feasibility, resulting in the decision to tier the dataset using a National 'Best Endeavours' framework. A National Best Endeavours Data Set specification is a data set that is not mandated for collection but there is a commitment to provide data nationally on a 'best endeavours' basis.[72] This involved the stratification of Delphi responses into those items rated 'very important' and those rated 'imperative'. Any item meeting >95% consensus or rated 'imperative' by 50% or more of panellists was identified as a Tier 1 item (or an item which may be considered 'required' in a Best Endeavours dataset specification). The remaining items were identified as Tier 2 items (or items which may be considered 'optional' in a Best Endeavours— dataset specification).

DISCUSSION

Psychiatry is the only healthcare specialty lacking basic biological metrics for the measurement of pathology and treatment response in its most common disease states and as such relies heavily on reliable, feasible and harmonious psychometric and clinical outcome measures for the understanding of illness status and treatment efficacy.[73] The importance of collecting uniform measures in a timely, consistent manner and linking data across healthcare services cannot be understated. Current global efforts to harmonise clinical and research outcome measures in mental health are occurring in acknowledgement of the serious impact lack of consistent

Table 2 Overall consensus results and consensus results by expertise: individual data items to include in minimum dataset

Item	% panellists' showing agreement ('very important' or 'imperative')							% panellists' rating item 'imperative'
	Total panellists ('very important' or 'imperative')	LE: personal/ carer	Clinician	Researcher	Advocacy	Healthcare support	Policy development	Total panellists
Substance-use disorders	96	91/100	97	97	100	100	93	26
Anxiety disorders	95	94/100	94	91	100	100	95	50
Suicidality	94	84/100	93	94	100	100	91	54
Personality disorders	92	91/83	97	87	88	92	87	37
Autism spectrum disorders	92	91/83	97	87	94	92	93	49
Post-traumatic stress disorder and c-PTSD	91	94/87	92	89	100	93	91	44
Affective/mood disorders	90	91/81	90	91	90	80	91	45
Non-suicidal self-harm	85	81/94	84	85	100	87	82	37
ADHD	79	90/75	83	78	87	82	86	14
Sleep disturbances	43	59/50	37	44	56	42	40	0
Type of service being delivered (ie, inpatient, outpatient, public community care, public private practice, etc)	96	94/94	98	98	100	100	100	66
Referral (services the patient is referred to during episode of care)	93	95/92	93	92	100	91	100	17
Public or private patient	92	91/100	94	92	94	100	87	49
Involuntary or voluntary status of patient	92	86/92	94	95	94	92	83	42
Admission and discharge date	89	91/94	93	87	100	100	95	46
Telehealth or F2F	89	95/100	92	89	87	91	79	11
Psychotherapeutic intervention (eg, CBT, FBT, SSCM, DBT, etc) delivered during episode of care	93	81/100	93	91	95	87	91	67
Family/carer intervention delivered during episode of care	92	73/100	98	90	94	92	80	56
Nutritional intervention (eg, enteral feeding and dietetic schedule/meal plan) delivered during episode of care	91	84/94	92	87	95	93	86	62
Other pharmacological intervention delivered during episode of care	89	90/92	90	86	100	91	79	34
Psychopharmacological intervention (eg, antidepressants and mood stabilisers) delivered during episode of care	88	78/88	89	89	90	86	86	55
Neurological intervention delivered during episode of care	85	81/100	86	86	93	100	79	32
Peer support intervention delivered during episode of care	85	81/100	86	86	93	91	86	12

Continued

Table 2 Continued

Item	% panellists' showing agreement ('very important' or 'imperative')							% panellists' rating item 'imperative'
	Total panellists ('very important' or 'imperative')	LE: personal/ carer	Clinician	Researcher	Advocacy	Healthcare support	Policy development	Total panellists
Is illness duration essential to collect in a minimum dataset for EDs?	89	91/94	89	87	95	100	91	44
Is time from first symptoms to treatment (in months) essential to collect in a minimum dataset for EDs?	85	94/94	83	85	95	93	91	44
Bone health disorders	95	95/92	97	90	94	92	80	39
Formal diagnosis of malnutrition	94	86/92	98	90	94	92	87	70
Cardiac abnormalities	93	95/92	95	90	94	92	80	36
Cognitive function	93	95/92	92	90	100	92	87	45
Weight change in recent months	91	78/81	94	91	86	80	77	58
Endocrine disorders	90	91/92	91	90	94	92	87	27
Kidney/liver disorders	90	95/92	90	89	87	82	71	22
BMI	88	77/83	94	87	56	75	73	57
Electrolyte levels	88	95/92	89	82	94	83	67	42
Gastrointestinal disorders	87	91/92	89	79	94	83	87	28
Menstrual status	84	86/83	91	76	73	73	71	28
Muscular disorders or conditions	84	81/83	88	78	73	82	71	11
Hormone levels	46	68/75	60	51	81	75	40	16

ADHD, attention-deficit/hyperactivity disorder; BMI, body mass index; CBT, cognitive behavioural therapy; c-PTSD, Complex Post-Traumatic Stress Disorder; DBT, dialectical behaviour therapy; EDs, eating disorders; FBT, family-based treatment; F2F, face-to-face; LE, lived experience; SSCM, specialist supportive clinical management.

Table 3 Final agreed minimum dataset

Tier 1—best endeavours, required*	
Demographics†	Weight change in recent months
Clinical ED diagnosis	Formal diagnosis of malnutrition
► Anorexia Nervosa	**Treatment characteristics**
► Atypical Anorexia Nervosa	Type of service being delivered (ie, inpatient, outpatient, public community care, public private practice etc)
► Bulimia Nervosa	
► Binge Eating Disorder	
► Avoidant Restrictive Food Intake Disorder	**Treatment delivered**
► Other Specified Feeding or Eating Disorder	Psychotherapeutic intervention delivered (eg, CBT, FBT, SSCM, DBT etc)
► Unspecified Feeding or Eating Disorder	Nutritional intervention delivered (eg, enteral feeding, dietetic schedule/meal plan)
Co-morbid diagnosis/es or concerns	Psychopharmacological intervention delivered
Anxiety disorders	Family/carer intervention
Affective/mood disorders	**Other**
Suicidality	QoL‡
Medical indicators	
BMI	
Tier 2—best endeavours, optional	
Comorbid diagnosis/es or concerns	**Illness profile**
PTSD and c-PTSD	Illness duration
SUD	Time from first symptoms to treatment (in months)
Personality disorders	**Treatment characteristics**
ASD	Admission and discharge date
Non-suicidal self-harm	Telehealth or F2F delivery
Medical indicators	Public or private patient
Electrolytes	Voluntary or involuntary
Gastrointestinal	Referrals out during episode of care
Kidney/liver	**Treatment delivered**
Bone health	Peer support intervention
Cardiac	Neurological intervention
Cognitive function	Other pharmacological intervention
Endocrine	**Other**
Kidney/Liver	Functional assessment‡
Core features of illness	PROMS/PREMS
EDE-Q or adapted version§ ‡	

*>50% of panellists rated 'imperative'.
†Demographic details were not queried as part of the Delphi study.
‡Standardised instrument or single indicator to be scoped.
§EDE-Q is included as the most preferred standardised questionnaire
ASD, autism spectrum disorder; BMI, body mass index; CBT, cognitive behavioural therapy; c-PTSD, complex post-traumatic stress disorder; DBT, dialectical behaviour therapy; EDE-Q, Eating Disorder Examination Questionnaire; FBT, family-based treatment; F2F, face to face; PREMs, patient-reported experience measures; PROMs, patient-reported outcome measures; PTSD, post-traumatic stress disorder; QoL, quality of life; SSCM, specialist supportive clinical management; SUD, substance use disorder.

and comparable data poses to the development and implementation of effective interventions in mental health. Given high relapse rates and poor overall outcomes, this is of particular importance in EDs.

The development of a framework to capture nationally consistent data in EDs aims to address significant challenges in the understanding of the true outcomes of care being delivered as well as cross-validity and replicability of research.[73–76] The national consultation and Delphi study described in this paper provides collaborative direction for the implementation of national healthcare data collection initiatives, which may improve the availability, consistency and quality of information relating to the care delivered to all Australians with EDs.

Presented is the collective framework for an MDS that the expert panel endorsed as necessary when considering clinical outcome in EDs. With most criteria agreed on by the panel, the endorsed data were further specified to identify items deemed imperative to include in the national best endeavours dataset ('required') and those that were considered relevant ('optional'). Essential criteria endorsed by panellists spanned across multiple domains, including diagnostic categories, comorbidities, medical indicators, healthcare utilisation and previous treatment interventions.

In consideration of the diagnostic scope of a nationally centralised dataset collection, the panel largely agreed that five ED diagnoses are imperative to include—AN, BN, BED, OSFED and ARFID, with AN (including Atypical AN) of immediate priority. For diagnoses with limited population prevalence data such as Pica and Rumination disorder, the panel were collectively undecided as to their inclusion within the MDS. This finding was supported by qualitative feedback that a focus on more prevalent EDs should take precedence at the current time.

There was a high level of agreement that all ages should be included in the MDS. There were also high levels of agreement that individuals presenting to general practice, specialist tertiary inpatient units and private practice should be captured in the MDS. However, it appears that panellists believe it is hospital-based or medical care that is imperative to record, while settings in which longer-term therapeutic work takes place (such as private practice and ambulatory care) are important but not imperative. This is interesting given one key and visible avenue of ED care delivery, via the Medicare Eating Disorder Treatment Plan, takes place in private practice.

High levels of agreement across the panel were observed for healthcare utilisation and treatment characteristics, especially in relation to the type of service and psychotherapeutic intervention delivered. Along with providing patterns of service utilisation and allowing for the assessment of resource demand, the collection of this information will provide insight into outcomes stemming from different types and modes of treatment being offered to consumers. This is particularly important given current poor outcomes and a limited evidence base for existing AN treatments.[77 78]

There was initial uncertainty among panellists regarding the importance of recording medical status in an MDS for EDs. While it was the only category that did not meet consensus in Round 1, it ultimately ended up achieving the highest level of consensus along with 'quality of life'. BMI, perhaps unsurprisingly, was the most contentious medical item with the greatest variance in percentage agreement—only 56% of advocates rated it 'very important' or 'imperative', compared with 77% of individuals with personal LE and 94% of clinicians. However, 'BMI' and 'weight change over recent months' had the highest 'imperative' rating behind 'formal diagnosis of malnutrition', so there remains clear support for body weight as a vital measure in understanding clinical presentation and outcome in EDs.

There were slight observed differences in patterns of responding between all groups. Most interesting was the

observation that individuals with personal LE were more aligned with clinicians and policy developers in many of their ratings pertaining to dataset items than they were to advocates (the latter aligned better with carers). Items meeting much lower levels of consensus among personal LE than in other groups included: family/carer intervention, peer support intervention, neurological intervention, psychopharmacological intervention and suicidality. Menstrual status (eg, dysregulation and amenorrhoea), which ultimately was rejected, was endorsed by both LE (personal) and clinicians, but not by any other group. LE (personal) and LE (carer) met quite different levels of consensus on many items, suggesting the two types of LE bring different perspectives as regards clinical outcome and what is important to measure.

Some dataset specifications will require further scoping regarding the use of single indicators versus standardised instruments (and if the latter, an instrument identified), should an MDS be implemented. These include core features of illness (though the EDE-Q has been suggested as the 'most preferred' by the Delphi panellists), quality of life, functional assessment, PROMs and PREMs.

It is important to determine the manner in which an MDS for EDs will most effectively and feasibly be implemented. It is well understood that healthcare professionals at all levels and in all settings are constrained by time during patient encounters. It will be vital to align data elements with standard practice data collection procedures (eg, existing electronic healthcare records), ensuring minimal additional data entry by the workforce. Workforce skills are critical to the successful establishment and efficient use of an MDS or registry. Adequate investment in training will maximise data quality and ensure data entry processes are not onerous.[68] Furthermore, the MDS must be flexible so that it is not only easily integrated into routine operations of diverse healthcare settings but also able to be expanded or tailored to provide additional data in specific sectors. As stated by Leginski *et al*, 'minimum datasets should not be regarded as isomorphic with the full content of a decision support system or management information system. Every such system requires tailoring to accommodate local policy information that affects decisions; to address procedures and account for who has responsibility for and access to data; and to satisfy the culture of the organisation, its clientele and staff'. Importantly, the development of culturally appropriate data collection practices and assessment tools will require specific consideration in many settings.

The current study included broad representation from ED experts of all types (including up to 40% with LE), from every state and territory in the country, allowing for a range of voices in the decision about what clinical outcomes are important in EDs. Additionally, the Delphi methodology allowed for multifactorial analysis of agreeance. This included thematic analysis of qualitative feedback, total percentage agreement, agreement by round and strength of agreement. Contextualising these results within the framework of activities conducted for the data projects meant the final agreed dataset reflects both existing data collection practices as well as future data collection priorities, with consideration given to feasibility. Nevertheless, there are some limitations. There were inherent biases in response (where the nature of a panellist's ED expertise informed what they deemed most important—eg, clinicians prioritised type of therapeutic intervention delivered whist policy-makers were more interested in healthcare utilisation). Further, while the sample size was large for a Delphi study, only a small percentage of those individuals contacted to participate took part. This is likely due to the less personalised, large-scale method of recruitment of ED professionals and experts (via the national body and national research centre's respective mailing lists) than is typical of Delphi studies. This was deemed necessary given the national implications of the findings; however, consideration should be given in future to methods that enhance the participation of voices underrepresented in research.

An extensive national consultation process conducted alongside benchmarking activities, literature reviews and a modified four-step Delphi study successfully generated a consensus-based framework for a MDS for EDs, which can be implemented independently of or in tandem with a clinical quality registry. This would ideally be rolled out in a staged implementation process, with initial piloting of one diagnostic group (likely AN) in one or two settings (likely specialist tertiary ED units and/or private practice).

Any ED data activity at the individual, jurisdictional or organisational level should be progressed within a broader national framework, thus reducing duplication, improving consistency and fostering collaboration to drive innovation and system change. It is anticipated that, where possible and relevant, such efforts will need to be agreed, shared and coordinated nationally, with the opportunity for leadership on these nationally coordinated activities to be generated from any part of the sector. Data activities (including implementation of the MDS and/or the establishment of a clinical quality registry) should be supported by the building of evaluation and research capacity into existing clinical service funding matrices and will require ongoing evaluation. This has the potential to improve the availability, consistency and quality of information relating to the care delivered to all Australians with EDs, providing an enhanced understanding of outcomes to ensure the healthcare we invest in is evidence-based and optimally delivered.

Twitter Emma Bryant @emmajbryant_

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ORCID iD

Emma Bryant http://orcid.org/0000-0003-1918-6020

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