International consensus on patient-centred outcomes in eating disorders

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The effectiveness of mental health care can be improved through coordinated and wide-scale outcome measurement. The International Consortium for Health Outcomes Measurement has produced collaborative sets of outcome measures for various mental health conditions, but no universal guideline exists for eating disorders. This Position Paper presents a set of outcomes and measures for eating disorders as determined by 24 international experts from professional and lived experience backgrounds. An adapted Delphi technique was used, and results were assessed through an open review survey. Final recommendations suggest outcomes should be tracked across four domains: eating disorder behaviours and cognitions, physical health, co-occurring mental health conditions, and quality of life and social functioning. Outcomes are collected using three to five patient-reported measures. For children aged between 6 years and 12 years, the measures include the Children's Eating Attitude Test (or, for those with avoidant restrictive food intake disorder, the Eating Disorder in Youth Questionnaire), the KIDSCREEN-10, and the Revised Children's Anxiety and Depression Screener-25. For adolescents aged between 13 years and 17 years, the measures include the Eating Disorder Examination Questionnaire (EDE-Q; or, for avoidant restrictive food intake disorder, the Nine-Item Avoidant Restrictive Food Intake Disorder Screener [NIAS]), the two-item Patient Health Questionnaire (PHQ-2), the nine-item Patient Health Questionnaire (PHQ-9), the two-item Generalised Anxiety Disorder (GAD-2), the seven-item Generalised Anxiety Disorder (GAD-7), and the KIDSCREEN-10. For adults older than 18 years, measures include the EDE-Q (or, for avoidant restrictive food intake disorder, the NIAS), the PHQ-2, the PHQ-9, the GAD-2, the GAD-7, the Clinical Impairment Assessment, and the 12-item WHO Disability Assessment Schedule 2.0. These questionnaires should be supplemented by information on patient characteristics and circumstances (ie, demographic, historical, and clinical factors). International adoption of these guidelines will allow comparison of research and clinical interventions to determine which settings and interventions work best, and for whom.

Introduction

Eating disorders are disabling and potentially deadly disorders that affect both physical and mental health,[1] and that affect an estimated 55·5 million individuals worldwide each year.[2] Individuals diagnosed with an eating disorder have a mortality rate 2–5 times higher than age-matched controls without an eating disorder.[3] In addition to personal cost, the yearly economic cost associated with eating disorders is estimated at US$64·7 billion in the USA,[4] £9·4 billion in the UK,[5] and AU$52·6 billion in Australia.[6] Reliable costing data for eating disorders in low-income and middle-income countries are not available.

Remission rates from eating disorders are still modest, with illness persisting in at least a third of patients after treatment,[7,8] signalling the need for continued improvement in available care. Increasing timely access to evidence-based treatment is a key issue,[9] and a major barrier to care improvement is the scarcity of longitudinal wide-scale monitoring of patient progress. The collection of comparable outcome data across countries, health-care systems, and treatment approaches is necessary to evaluate care effectiveness and determine best practices in the treatment of patients with eating disorders.[10]

Some effort has been made towards the collection of routine outcome data in patients with eating disorders, although this has been hampered by two key hurdles. First, despite much enthusiasm and discussion, there is no consensus on what constitutes a good outcome in eating disorders, with multiple proposed definitions of recovery existing.[11] Second, no universal guidance on the methodology (eg, validated instruments, objective physical markers, or time between data collection points) of tracking improvement in clinical care exists. These inconsistencies in outcome conceptualisation, measurement tools, and data timepoints limit comparability, reducing the ability to evaluate the effectiveness of different approaches.

An international working group was convened (figure 1; panel) to create recommendations on outcome measurement in eating disorders, including what to measure (outcomes), how to measure (tools), and when to measure (timepoints). This guideline, or Set, was coordinated by the International Consortium for Health Outcomes Measurement (ICHOM), which has produced consensus-based Sets in depression, anxiety, obsessive compulsive disorder, post-traumatic stress disorder, personality disorders, and psychosis,[12–15] as well as numerous non-mental health-related conditions.

The goal of the Eating Disorder Set is to address outcomes that are important to the clinicians providing

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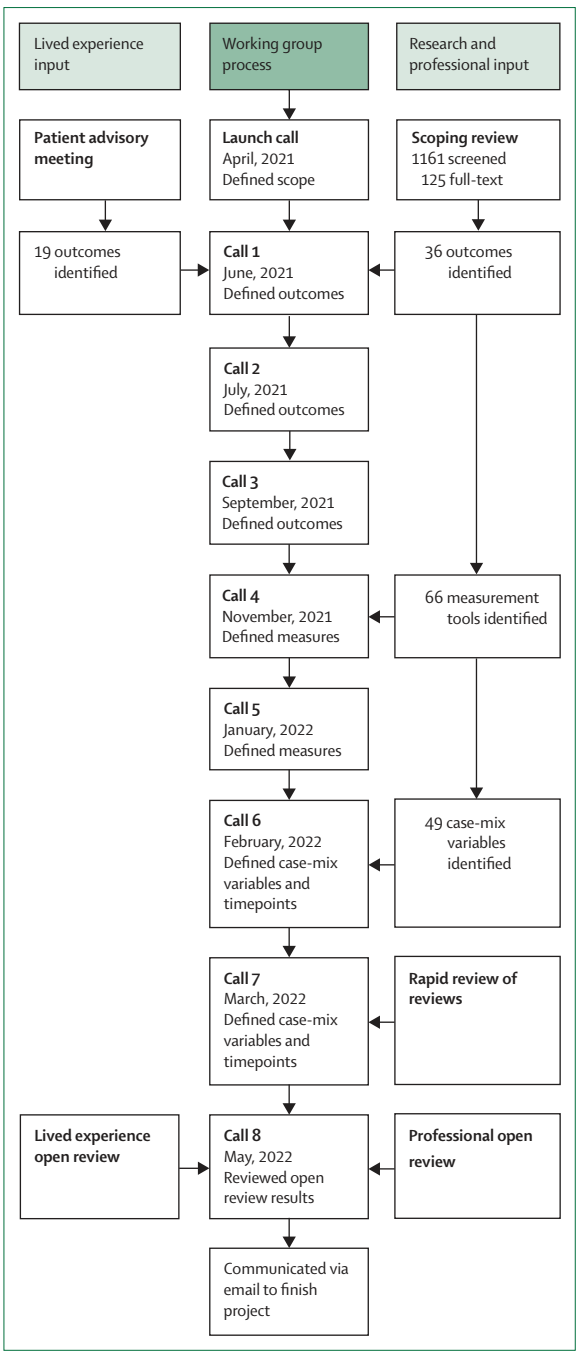

Figure 1: **Process overview of the ICHOM Eating Disorder project**
ICHOM=International Consortium for Health Outcomes Measurement.

care for patients with eating disorders, but with a distinct focus on outcomes relevant to those receiving the care. The ICHOM Set for eating disorders does not attempt to define recovery or the diverse ways in which recovery is experienced or understood. The Set does not suggest binary cutoff points, or thresholds, to diagnose illness or health, but rather supports the collection of continuous data on outcomes deemed core to the improvement or resolution of an eating disorder and its associated symptoms. The Set is suitable for use with individuals older than 6 years, and covers anorexia nervosa, avoidant restrictive food intake disorder, binge eating disorder, bulimia nervosa, and other specified feeding and eating disorders.

Recommended outcomes and measures

The working group reached a consensus (defined as ≥70% approval throughout the working group's process) on the following outcomes and measures via iterative rounds of voting (appendix pp 6–16). The working group recommends tracking treatment response across four outcome domains: eating disorder behaviours and cognitions, physical health, co-occurring mental health conditions, and quality of life and social functioning. These outcomes should be tracked using three to five measurement instruments, depending on the age and presentation of the patient (table). The measurement instruments were selected by the working group on the basis of appraisal criteria (appendix pp 29–30) and accessibility. During the subsequent open review (panel), 144 of 157 (92%) of the individuals with lived experience of having an eating disorder endorsed the chosen outcomes as encompassing all important outcomes to track in relation to the chosen diagnoses in clinical practice, and 43 of 49 (87%) of the professionals endorsed the chosen measurement tools. Selection of appropriate measures should be made on the basis of two criteria: presentation and age of the patient. These measures are suggested for the purpose of tracking change and not for making an official diagnosis.

Information and resources related to the Set can be accessed from ICHOM. Details on the availability of individual questionnaires can be found in the appendix (p 31).

Eating disorder behaviours and cognitions

The Set recommends measuring eating disorder behaviours and cognitions on the basis of presentation type. For people with anorexia nervosa, binge eating disorder, bulimia nervosa, or other specified feeding and eating disorders, we recommend measuring dietary restriction, binge eating, compensatory behaviours, body image, and symptom severity. To measure these outcomes in adolescents (aged 13–17 years) and adults (aged ≥18 years), the working group suggests using the Eating Disorder Examination Questionnaire (EDE-Q),[16] a 28-item self-report measure with extensive psychometric evidence and multiple language translations. Shorter versions of the EDE-Q were also discussed by the working group, but these tools either did not cover all of the outcomes selected (eg, the seven-item EDE-Q),[17] or are still building psychometric evidence (eg, the EDE-Q Short).[18] To measure the relevant outcomes for children (aged 6–12 years), the working group recommends using the Children's

Panel: Methods

A detailed description of the methods used to produce the Set can be found in the appendix (pp 1–33). The working group comprised 24 individuals from 13 countries (appendix p 2). Of these individuals, five were recruited as experts who had lived experience of an eating disorder (three individuals with personal lived experience and two carers), and 19 were recruited as experts by profession (ie, clinicians and researchers). Professional members represented a range of disciplines, including psychiatry, psychology, paediatrics, social work, and public health. Several individuals had both professional and personal experience. 10 of 19 (53%) professional members of the working group had expertise working with children and adolescents. All working group members held equal voting power during the consensus-building process. A core project team provided guidance and research support but did not vote.

Process overview
Over nine video calls between April, 2021, and May, 2022, the working group engaged in a modified Delphi approach to develop a consensus on recommendations for the Set (figure 1). The video calls included a presentation of external input, including summaries of current research literature by the project team. After each call, votes were cast anonymously via an online survey. Voting was held for all aspects of the Set, including outcomes, measurement tools, case-mix factors and treatment details, and timepoints.

Outcome selection
Following the Core Outcome Measures in Effectiveness Trials,[19] outcomes (n=81) were identified from multiple sources, including a systematic scoping review (clinical trials and qualitative research) and a patient advisory meeting exclusive to working group members with lived experience of having an eating disorder or caring for someone with an eating disorder.

Measurement tools
After a consensus was reached on outcomes, relevant measures (n=85) were identified from the systematic scoping review and working group expertise. Measures were screened for feasibility (availability, cost, and language translations) and evaluated for psychometric performance (reliability, validity, and responsiveness and sensitivity to change). Tools with the best evidence were shortlisted and presented to the working group. Although information on psychometric properties informed voting decisions, working group members were asked also to consider the burden on users and feasibility of use within low-resource contexts.

Case-mix factors and treatment details
Variables that affect outcomes (ie, confounders) were identified via the systematic scoping review, previous International Consortium for Health Outcomes Management (ICHOM) sets, and a rapid review of systematic reviews and meta-analyses on treatment predictors, mediators, and moderators in eating disorders (appendix pp 18–23).

Timepoint selection
A proposed timeline for data collection was created based on previous ICHOM mental health sets. This proposal was adjusted by the project team to be more suitable for eating disorders, presented to the working group, adjusted based on feedback, and put to vote.

Open review
A draft version of the Set was subject to open review by health-care professionals, researchers, and eating disorder advocates (n=50) and individuals with lived experience of an eating disorder, including carers (n=157) across 12 countries. Suggestions with multiple instances were reconsidered by the working group with another round of discussion and voting.

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See Online for appendix

Eating Attitude Test, a 26-item self-report questionnaire[20] that showed good reliability and validity across international settings.[21,22] Other possible measures for children were considered, including the Eating Disorder Examination Questionnaire for Children[23] and the Eating Disorder-15 parent and youth versions,[24,25] but these measures were decided against because of a shortage of available language translations, or peer-reviewed psychometric evidence, or both.

For individuals with avoidant restrictive food intake disorder, the working group recommends measuring dietary restriction, lack of interest in food, fear of aversive consequences of eating, and symptom severity. In adolescents and adults, the Nine-item Avoidant Restrictive Food Intake Disorder Screener (NIAS)[26] can be used to measure these outcomes. The NIAS has good reliability and validity across multiple language translations.[27,28] For children, the 14-item Eating Disorder in Youth Questionnaire[29] was selected by the working group.

Physical health

Vital status (ie, survival) should be tracked for all individuals, as it is a harmonised outcome across all ICHOM Sets. For those patients who would have expected menstruation (ie, those of typical post-pubertal age with female reproductive anatomy, who are not pregnant, using hormonal contraception, or post-menopausal, and who do not have other medical conditions that result in the absence of periods), but who currently have amenorrhoea, resumption of menses should be tracked. The outcome of weight or BMI was voted into the Set, given the crucial role that being underweight plays in physical health problems and increased mortality,[30] but was later removed due to the group not reaching a consensus on the measurement

	Reporter	Tool (child, age 6–12 years)	Tool (adolescent, age 13–17 years)	Tool (adult, age ≥18 years)
Outcomes (measured at baseline and 3, 6, 12, and 24 months, or every 2 weeks in intensive settings)				
Eating disorder cognitions and behaviours	Patient or carer	EDY-Q (ARFID) or ChEAT (all other diagnoses)	NIAS (ARFID) or EDE-Q (all other diagnoses)	NIAS (ARFID) or EDE-Q (all other diagnoses)
Physical health	Clinician	NA	NA	NA
Other psychological symptoms	Patient or carer	RCADS-25	GAD-2 or GAD-7, and PHQ-2, or PHQ-9	GAD-2 or GAD-7, and PHQ-2, or PHQ-9
Quality of life and social functioning	Patient or carer	KIDSCREEN-10	KIDSCREEN-10	CIA and WHODAS 2·0-12
Case-mix variable				
Demographic factors (measured at baseline and annually)	Clinician and patient or carer	NA	NA	NA
Clinical factors (measured at baseline and annually)	Clinician and patient or carer	Current View Tool (provisional problems)	Current View Tool (provisional problems)	Current View Tool (provisional problems)—adapted and SACQ—adapted
Historical factors (measured at baseline)	Clinician and patient or carer	NA	NA	ACE-Q
Treatment-related factors				
Treatment-related factors (measured at baseline and annually)	Clinician	NA	NA	NA

ACE-Q=Adverse Childhood Experiences Questionnaire. ARFID=avoidant restrictive food intake disorder. ChEAT=Children's Eating Attitude Test. CIA=Clinical Impairment Assessment. EDE-Q=Eating Disorder Examinations Questionnaire. EDY-Q=Eating Disorder in Youth Questionnaire. GAD-2=two-item Generalised Anxiety Disorder questionnaire. GAD-7=seven-item Generalised Anxiety Disorder questionnaire. NA=not applicable. NIAS=Nine-Item Avoidant Restrictive Food Intake Disorder Screener. PHQ-2=two-item Patient Health Questionnaire. PHQ-9=nine-item Patient Health Questionnaire. RCADS-25=25-item Revised Children's Anxiety and Depression Screener. SACQ=Self-Administered Comorbidities Questionnaire. WHODAS 2·0-12=12-item WHO Disability Assessment Scale 2·0.

Table: **Broad-level overview of the eating disorder Set per variable**

and use of these data (see strengths and limitations section for further discussion).

Co-occurring mental health conditions

Anxiety and depression should be measured in all patients. For adolescents and adults, suicidality should be measured where appropriate. Should suicidality be measured, responses will need to be reviewed in real time, to administer any risk protocols if necessary. For children, the Revised Children's Anxiety and Depression Scale 25 (RCADS-25) should be used, which measures both anxiety (15 items) and depression (ten items) via self-report.[31] The RCADS-25 is widely used, available in multiple languages, and has shown strong psychometric properties in various populations;[32,33] however, the scale has not to our knowledge been validated yet in children with eating disorders. The RCADS-25 was chosen in large part due to its use in the child and youth Set for depression, anxiety, obsessive compulsive disorder, and post-traumatic stress disorder.[12] Depression in adolescents and adults can be measured using the Patient Health Questionnaire 2-item (PHQ-2), a screening tool for depressive symptoms.[34] Where time and settings allow, the full PHQ-9 can be used to assess depressive symptoms and suicidal ideation.[35] The PHQ-9 and PHQ-2 have good psychometric properties, including sensitivity to change,[35–38] and the PHQ-9 has been validated in eating disorders.[39] When using the PHQ-9, the item on suicidal ideation should be reviewed in real time to support safeguarding responsibilities. The outcome of anxiety in adolescents and adults can be measured using the Generalised Anxiety Disorder 2-item (GAD-2), a screener for anxiety symptoms.[40] Where time and settings allow, the full GAD-7 can be used.[41] Both of these screening tools have shown good psychometric properties, including sensitivity to change.[38,41,42]

Quality of life and social functioning

Measuring general quality of life, eating disorder-specific quality of life, and social functioning (which includes interpersonal relationships and the ability to engage in work or school) for all patients with eating disorders is recommended. The working group recommends measuring quality of life and social functioning in children and adolescents using the KIDSCREEN-10.[43] The KIDSCREEN-10 was previously selected for the child and youth Set for depression, anxiety, obsessive compulsive disorder, and post-traumatic stress disorder, and the working group chose to keep this measure for harmonisation across conditions. For adults, the 16-item Clinical Impairment Assessment (CIA) should be used, which contains multiple items related to social functioning, including the ability to engage with work and manage interpersonal relationships.[44] The CIA has good psychometric properties, including sensitivity to change.[44] Adults should also complete the World Health Organisation Impairment Assessment 2.0 (WHODAS 2.0-12), a 12-item measure of general quality of life.[45] The

five-dimension, five-level Euroquol measure was considered as a measure of general quality of life,[46] but the WHODAS 2.0-12 was selected, in large part to allow for comparison with the Set for adults with depression and anxiety.

Recommended case-mix factors

The goal of the current Set is to enable comparison between settings to benchmark outcomes. To facilitate this comparison, factors that affect outcomes should be considered and adjustments made when necessary. Potential case-mix factors were identified by literature review, the full details of which can be found in the appendix (pp 3–5) and previous ICHOM sets. The following demographic, historical, clinical, and intervention factors were selected after reaching a consensus within the working group. In the open review, the factors were endorsed by 45 of 50 (90%) professionals. Case-mix factors were not evaluated by the lived-experience review group.

Demographic factors

Age and assigned sex at birth should be reported by a clinician at baseline. Gender, race, ethnicity, sexual orientation, level of education, living arrangement or situation, financial stress, and any form of self-identified marginalisation should be reported by the patient or carer at baseline, and updated annually if applicable. For adults only, work status, post-secondary education status, housing security, and relationship status can be reported by the patient at baseline and updated annually. In countries where sexual orientation is not culturally appropriate or safe to ask about, this question can be omitted.

Historical factors

Patients or carers, or both, can report the age of eating disorder onset and any history of previous eating disorder-specific treatment. Clinicians should report any previous eating disorder diagnoses if the patient has been diagnosed with any eating disorders previously. For adults only, adverse childhood experiences can be measured using the Adverse Childhood Experiences Questionnaire.[47] These historical factors need to be assessed only at initial baseline.

Clinical factors

Current eating disorder diagnosis (including subtype, if applicable) and BMI should be reported by the clinician. For children, mental health comorbidities should be reported by the clinician via the provisional problems list of the Current View Tool.[48] The Current View Tool was chosen based on its previous use in the child and youth Set for depression, anxiety, obsessive compulsive disorder, and post-traumatic stress disorder.[12] Adults can self-report mental health comorbidities using an adapted version of this list. Physical comorbidities (including metabolic, gastrointestinal, and endocrine disorders) are self-reported or carer-reported. For adults only, frequency of alcohol and tobacco consumption, weight suppression (in context of historically higher weight), and current motivation to change can be self-reported. All clinical factors should be reported at baseline, with modifiable variables updated annually.

Intervention factors

All information relating to treatment can be reported by the clinical team. This information includes the intervention setting (eg, inpatient or outpatient), intervention approach (eg, group or individual), treatment type (eg, psychotherapy type and dose, medication type and dose, or dietetic intervention), and the use of any technology to deliver services.

Recommended measurement timepoints

The working group reached a consensus on all aspects of the timing of data collection, and the full timeline was endorsed by 39 of 50 (78%) professionals who responded to the open review (figure 2). The timeline was not reviewed by the lived experience group. As per the working group consensus, individuals entering high-intensity settings (eg, inpatient or residential care) should have outcomes assessed at baseline, every 2 weeks, and at discharge or transition to lower-intensity care. For individuals in lower-intensity care (eg, outpatient treatment), or those with no treatment in place, outcomes should be measured at baseline, 3 months, 6 months, 12 months, 18 months, and 24 months. When a transition of care occurs, a new baseline should be created, with the timepoint recommendation being measured from this re-established starting point. This recommendation is

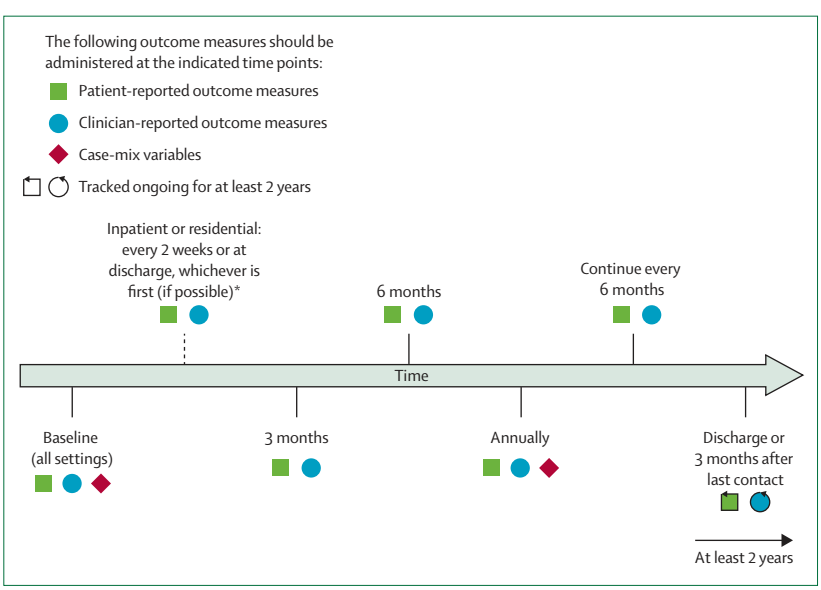

Figure 2: **Timeline for data collection**
*Only clinician and patient-reported outcomes in the eating disorder behaviours and cognitions and other psychological symptoms domains. Dashed line indicates intensive settings only.

applicable to transitions between levels of care or transition between services, such as a transition from a paediatric to an adult setting. Capturing outcomes across transitions is important, especially for young adults who often find themselves caught between child and adult services.[49]

Strengths and limitations

This project represents a notable success in collaboration among multiple stakeholder groups in not only the eating disorder field, but also across other psychiatric diagnoses. ICHOM aims to harmonise Sets across diagnoses where possible, to allow for simplified data collection in transdiagnostic services and for comparison of data between diagnoses. The eating disorder Set has overlapping timepoints and measures with the Sets created for personality disorders (WHODAS 2.0-12), substance use disorder (WHODAS 2.0-12 and KIDSCREEN-10), children's anxiety, depression, obsessive compulsive disorder, and post-traumatic stress disorder (KIDSCREEN-10, RCADS-25), and adult anxiety and depression (PHQ-9, GAD-7, WHODAS 2.0-12).[12–15] Therefore, comparisons will be possible not only between health-care systems and countries, but also across diagnoses. Every attempt was made to select questionnaires that are open domain and available at no cost.

Recognising the limitations of this work is important. Specifically, there are groups of individuals who were not well represented within the group, or process, or both, including gender-diverse individuals and young people (defined as adolescents and adults aged younger than 25 years). There was little representation from experts in avoidant restrictive food intake disorder. These absences were often reflected in the existing literature, with the psychometric properties of tools sometimes unavailable for under-represented genders, ethnicities, and diagnoses. The professional open review which was held to obtain feedback on the Set recruited only 50 participants, of whom 34 identified primarily as clinicians (appendix p 27).

The project team encountered difficulties identifying child-appropriate measures for eating disorder symptoms of anorexia nervosa, binge eating disorder, bulimia nervosa, or other specified feeding and eating disorder presentation. Some of the measures are not yet validated in specific languages or countries. It was difficult to find measures that were free, available in English, and easily accessible by clinicians.

Another limitation of the Set is the absence of an outcome for tracking weight in those individuals who need weight restoration for recovery. A weight-related outcome is important not only for individuals who are underweight according to standard guidelines, but also individuals who are weight suppressed according to their individual biological disposition. All working group members recognised the importance of weight restoration in certain eating disorder diagnoses, but there was strong concern from some members around traditional weight measurement practices. These included the use of strict minimum weight limits, which are often insufficient for restoring psychological health, and the use of weight measurement in non-restrictive eating disorders.[50] These concerns should be considered within the historical context of the iatrogenic consequences of weight-centric eating disorder treatment and the stigmatisation of larger bodies needing more weight for psychological recovery.[51] The outcome of weight or BMI was voted into the Set but was eventually removed by the project team in the final phase of the project due to the group not reaching a consensus on how this information should be collected and used. Although the Set recommends to continue collecting BMI information as a case-mix variable (at baseline and annually), the removal of this outcome will probably affect the use of the Set during the frequent measurement (every 2 weeks) of inpatient treatment and residential treatment in restrictive eating disorders. In these settings, movement towards outcomes might be underestimated, as inpatient and residential treatment are highly focused on weight restoration. The absence of a weight outcome also limits the exploration of the relationship between weight restoration and outcomes in the other domains (ie, eating disorder behaviours and cognitions, co-occurring mental health conditions, and quality of life and social functioning). The outcome of weight and BMI should be revisited when the field can reach a consensus on a way to use this information to support treatment decisions, track progress, and view weight restoration as necessary but not sufficient for a good outcome in treatment for a low-weight eating disorder.

Implementation and future directions

The eating disorder Set is appropriate for use in specialised services and in primary care settings. It should be piloted by interested parties with feedback informing future revisions. Emerging data on the feasibility of the Set will be particularly important, particularly concerning the practicality of multiple case-mix variables. The Set has the potential to be used as a tool across treatment to deliver progress feedback to individual patients and to guide care decisions: data on implementation in this manner would be valuable.

The eating disorder Set should be considered a working document with the ability to be adapted to future innovations and shifting opinions in eating disorder research and practice, especially the publication of new psychometric evidence for shorter, more concise measurement tools. Consideration should be given to reviewing the balance of harmonisation between mental health measurement sets for other diagnoses (eg, anxiety and depression) and specific priorities exclusive to eating disorders. Widespread uptake of this eating disorder Set has the potential to create extensive treatment-based

evidence and help determine which treatment approaches work best for whom.

Contributors

MdLSF contributed to the conceptualisation, funding acquisition, methods, supervision, writing, reviewing, and editing of this Position Paper. CP and TKR contributed to the conceptualisation, methods, supervision, writing, reviewing, and editing. UDS, CI, TL, and IM contributed to the project administration, investigation, data curation, visualisation, writing, reviewing, and editing. AA contributed to the conceptualisation, investigation, and methods, and wrote the original draft. SBA, BC, CSEC, SNC, SD-H, JD, CEKH, BH-D, JL, YL, PPPM, SM, MM, CMM, EM, IRP, JR, LS, HS, ET, ET-CV, M-CMT, EFvF, and JEW contributed to the investigation, methods, writing, reviewing, and editing.

Declaration of interests

TKR is on the Clinical Advisory Board of Arise. CP is a member of the Clinical Advisory Board for Equip Health. UDS, CI, TL, IM, and MdLSF were employed by the International Consortium for Health Outcomes Measurement (ICHOM) at the time this work was conducted. AA received personal fees from ICHOM during the study. EM is the former chief executive officer of the Academy for Eating Disorders and has unpaid positions on the Board of the European Chapter of the Academy for Eating Disorders and on the Canadian National Initiative for Eating Disorders Board of Directors. LS is the vice president of Mission and Education at the National Eating Disorders Association, who supported the ICHOM project with funding. All other authors declare no competing interests.

Data sharing

The Eating Disorder Set reference guide and flyer are available from ICHOM at no cost. The set can be accessed at https://connect.ichom.org/patient-centered-outcome-measures/eating-disorders/. The reference guide contains detailed information on the recommended measurement tools, case-mix factors, and timepoints for data collection.

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