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## International consensus on patient-centred outcomes in eating disorders

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**Title:** International consensus on patient-centered outcomes in eating disorders.

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## **Key Words**

Eating disorders, anorexia nervosa, bulimia nervosa, binge eating disorder, ARFID, OSFED, patient reported outcomes, outcome measurement, quality improvement

## **Abstract**

The effectiveness of mental health care can be improved through coordinated and wide-scale outcome measurement. The International Consortium for Health Outcomes Measurement (ICHOM) has produced collaborative sets of outcome measures for various mental health conditions, but no universal guideline exists for eating disorders (EDs). This position paper presents a set of outcomes and measures for EDs as determined by 24 international experts from professional and lived experience backgrounds. An adapted Delphi technique was used, and results were validated through an open review survey. Final recommendations suggest tracking outcomes across four domains: ED behaviours/cognitions, physical health, co-occurring mental health conditions and quality of life/social functioning. Outcomes are captured across three to five patient reported measures. For children aged 6 to 12, the measures include the Children's Eating Attitude Test (or for those with ARFID, the Eating Disorder in Youth Questionnaire), the KIDSCREEN-10, and the Revised Children's Anxiety and Depression Screener-25. For adolescents aged 13-17, the measures include the Eating Disorder Examination Questionnaire (EDE-Q), or for ARFID, the Nine-item ARFID Screener (NIAS), the Patient Health Questionnaire-2/9 (PHQ-2/9), the Generalised Anxiety Disorder-2/7 (GAD-2/7), and the KIDSCREEN-10. For adults age 18+, measures include the EDE-Q (or for ARFID, the NIAS), the PHQ-2/9, the GAD-2/7, the Clinical Impairment Assessment, and the World Health Organization Disability Assessment Schedule 2.0-12. These questionnaires should be supplemented by information on patient characteristics and circumstances (i.e., demographic, historical, and clinical factors). International adoption of these guidelines will allow comparison of research and clinical intervention to better determine which settings and interventions work best and for whom.

## Introduction

Eating disorders (EDs) are disabling and potentially deadly disorders that impact both physical and mental health.<sup>1</sup> They affect an estimated 55.5 million individuals worldwide each year.<sup>2</sup> Individuals diagnosed with an ED have a mortality rate two to five times higher than age-matched controls without an ED.<sup>3</sup> In addition to personal cost, the yearly economic cost associated with EDs is estimated at \$64.7 billion in the US,<sup>4</sup> £9.4 billion in the UK,<sup>5</sup> and \$52.6 billion in Australia.<sup>6</sup> EDs are also present in low- and middle-income countries, although reliable costing data are not available.

Remission rates from EDs are still relatively modest, with illness persisting in at least one third of patients after treatment,<sup>7,8</sup> signalling the need for continued improvement in available care. While increasing timely access to evidence-based treatment is a key issue,<sup>9</sup> another major barrier to care improvement is the lack of longitudinal wide-scale monitoring of patient progress. The collection of comparable outcome data across countries, health care systems, and treatment approaches is necessary in order to evaluate care effectiveness and determine best practices in the treatment of patients with EDs.<sup>10</sup>

Some effort has been made toward the collection of routine outcome data in patients with EDs, although this has been hampered by two key hurdles. First, despite much enthusiasm and discussion, there is a lack of consensus on what constitutes a “good outcome” in EDs, with multiple proposed definitions of recovery existing.<sup>11</sup> Second, there currently exists no universal guidance on the methodology (e.g., validated instruments, objective physical markers, time between data collection points, etc.) of tracking improvement in clinical care. These inconsistencies in outcome conceptualisation, measurement tools and data timepoints limit comparability, further reducing the potential to evaluate the effectiveness of different approaches.

To address the lack of global guidance an international working group was convened to create recommendations on outcome measurement in EDs, 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 previously produced consensus-based Sets in depression, anxiety, obsessive compulsive disorder (OCD), post-traumatic stress disorder (PTSD), personality disorders, and psychosis,<sup>12-15</sup> as well as numerous non-mental health related conditions.

The goal of the current Set is to address outcomes that are important to the clinicians providing care for EDs, but with a distinct focus on outcomes relevant to those receiving the care. The ICHOM Set for EDs does not attempt to define recovery or the diverse ways in which recovery is experienced/understood. The Set does not suggest binary cut-off 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 ED and associated symptoms. The Set is suitable for use with individuals aged 6+ and covers the following diagnoses: anorexia nervosa (AN), avoidant/restrictive food intake disorder (ARFID), binge-eating disorder (BED), bulimia nervosa (BN) and other specified feeding and eating disorders (OSFED).

(Panel 1 approx. here)

(Figure 1 approx. here)

### **Recommended outcomes and measures**

The working group reached consensus ( $\geq 70\%$  approval) on the following outcomes and measures via iterative rounds of voting (see appendix for details). The working group recommends tracking treatment response across four outcome domains including ED behaviours/cognitions, physical health, co-occurring mental health conditions, and quality of life/social functioning. These outcomes should be tracked using 3-5 measurement instruments depending on age and presentation. The measurement instruments were selected by the working group based on appraisal criteria (see appendix pp 29-30) and accessibility. During the subsequent open review, 92% of individuals with lived experience endorsed the chosen outcomes as encompassing all important outcomes in clinical practice and 87% of professionals endorsed the chosen measurement tools. Selection of appropriate measures should be made based on two criteria: 1) presentation, and 2) age. The working group would like to remind clinicians that these measures are suggested for the purpose of tracking change and not to make an official diagnosis.

**ED behaviours/cognitions.** The Set recommends measuring ED behaviours and cognitions based on presentation type. For those with AN, BED, BN, or OSFED we recommend measuring *dietary restriction, binge eating, compensatory behaviours, body image, and symptom severity*. To measure these outcomes in adolescents (age 13-17) and adults (age 18+), the working group suggests using the Eating Disorder Examination Questionnaire (EDE-Q), a 28-item self-report measure with extensive psychometric evidence and multiple language translations.<sup>16</sup> Shorter versions of the EDE-Q were also discussed by the working group, but these tools either did not cover all of the included outcomes selected (e.g., the EDE-Q7)<sup>17</sup> or are still building psychometric evidence (e.g., the EDE-QS<sup>18</sup>). To measure the relevant outcomes for children (age 6-12), the working group recommends using The Children's Eating Attitude Test (ChEAT), a 26-item self-report questionnaire<sup>19</sup>. The ChEAT demonstrated good reliability and validity across international settings.<sup>20,21</sup> Other possible measures for children were also considered, including the Eating Disorder Examination Questionnaire for Children (ChEDE-Q)<sup>22</sup> and the Eating Disorder -15 (ED-15) parent and youth versions,<sup>23,24</sup> but these measures were passed over based on a lack of available language translations and/or peer-reviewed psychometric evidence.

For individuals with ARFID the working group recommends measuring *dietary restriction, lack of interest in food and fear of aversive consequences of eating, and symptom severity*. In adolescents and adults, the Nine-item ARFID Screener (NIAS)<sup>25</sup> can be used to measure these outcomes. The NIAS has good reliability and validity across multiple language translations.<sup>26,27</sup> For children, the 14-item Eating Disorder in Youth Questionnaire (EDY-Q)<sup>28</sup> was selected by the working group.

**Physical health.** *Vital status* (i.e., survival) should be tracked for all individuals as this is a harmonised outcome across all ICHOM Sets. For those patients who would have expected menstruation (i.e., those with female reproductive anatomy and of typical post-pubertal age who are not pregnant, using hormonal contraception, post-menopausal, or have other medical conditions that result in the absence of periods) but who are currently amenorrhoeic, *resumption of menses* should be tracked. The outcome of *weight/BMI* was voted into the set given the crucial role that underweight plays in physical health problems and increased mortality<sup>29</sup> but was later removed due to a lack of group consensus on measurement and use of this data (see 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. The working group would like to remind clinicians that 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), which measures both anxiety (15 items) and depression (10 items) via self-report, should be used.<sup>30</sup> The RCAD-25 is widely used, available in multiple languages, and has shown strong psychometric properties in various populations,<sup>31,32</sup> however, it has not to our knowledge been validated yet in children with EDs. The RCADS-25 was chosen in large part due to its use in the child and youth Set for depression, anxiety, OCD and PTSD.<sup>12</sup> Depression in adolescents and adults can be measured via The Patient Health Questionnaire 2-item (PHQ-2), a screener for depressive symptoms.<sup>33</sup> Where time and settings allow, the full PHQ-9 can be used to further assess depressive symptoms and suicidal ideation.<sup>34</sup> The PHQ-9 and PHQ-2 have good psychometric properties including sensitivity to change,<sup>35-37</sup> and the PHQ-9 has been validated in EDs.<sup>38</sup> The working group would like to remind those using the PHQ-9 that 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.<sup>39</sup> Where time and settings allow, the full GAD-7 can be used.<sup>40</sup> Both of these versions of the GAD have demonstrated good psychometric properties, including sensitivity to change.<sup>37,40,41</sup>

**Quality of life & social functioning.** It is recommended to measure *general quality of life*, *ED-specific quality of life* and *social functioning* (which includes *interpersonal relationships* and the ability to engage in *work/school*) for all patients. The working group recommends measuring quality of life and social functioning in children and adolescents via the KIDSCREEN-10.<sup>42</sup> The KIDSCREEN-10 was previously selected for the child and youth Set for depression, anxiety, OCD and PTSD, and the working group chose to keep this measure harmonised across conditions. For adults, the 16-item Clinical Impairment Assessment (CIA), which contains multiple items related to social functioning, including the ability to engage with work and manage interpersonal relationships, should be used.<sup>43</sup> The CIA has good psychometric properties, including sensitivity to change.<sup>43</sup> 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.<sup>44</sup> The 5-dimension, 5-level Euroquol (EQ-5D-5L) measure was also strongly considered as a measure of general quality of life,<sup>45</sup> but the WHODAS 2.0-12 was eventually selected in large part to allow for comparison with the Set for adults with depression and anxiety.

(Table 1 approx. here)

### **Recommended case-mix factors.**

The goal of the current Set is to enable comparison between settings in order to benchmark outcomes. To facilitate this, additional consideration and adjustment needs to be made for factors that impact outcomes. Potential case-mix factors were identified via literature review, the full details of which can be found in the appendix, and previous ICHOM sets. The following demographic, historical, clinical, and intervention factors were selected after reaching consensus ( $\geq 70\%$  approval) within the working group. Subsequently they were endorsed by 91% of professionals during the open review.

**Demographic factors.** Age and sex at birth should be reported by a clinician at baseline. Gender, race, ethnicity, marginalisation, sexual orientation, level of education, living arrangement/situation and financial stress should be reported by patient or carer at baseline and updated annually if applicable. For adults only, work/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 skipped.

**Historical factors.** Patients and/or carers can report the age of ED onset and any history of previous ED-specific treatment. Clinicians should report any previous ED diagnoses if applicable. For adults only, adverse childhood experiences can be measured using the Adverse Childhood Experiences (ACES) Questionnaire.<sup>46</sup> These historical factors only need to be assessed at initial baseline.

**Clinical factors.** Current ED diagnosis (including subtype if applicable) and body mass index (BMI) should be reported by clinician. For children, mental health comorbidities should be reported by the clinician via the provisional problems list of the Current View Tool.<sup>47</sup> The Current View Tool was chosen based on its previous use in the child and youth Set for depression, anxiety, OCD and PTSD.<sup>12</sup> Adults can self-report mental health comorbidities using an adapted version of this list. Physical comorbidities (including metabolic, gastro-intestinal and endocrine disorders) are self/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 includes the intervention setting (e.g., inpatient, outpatient), intervention approach (e.g., group, individual), treatment type (e.g., psychotherapy type/dose, medication type/dose, dietetic intervention, etc.) and the use of any technology to deliver services.

### **Recommended measurement timepoints.**

A visual guideline for timepoint collection can be seen in Figure 2. All aspects reached consensus ( $\geq 70\%$  approval) within the working group and the full timeline was endorsed by 78% of professionals during the open review. As per working group consensus, individuals entering higher intensity settings (e.g., inpatient or residential care) should have outcomes assessed at baseline, every two weeks, and at discharge/transition to lower intensity care. For individuals in lower intensity care (e.g., outpatient treatment) or those with no treatment in place, outcomes should be measured at baseline, 3, 6, 12, 18, and 24 months. When a transition of care occurs, a new baseline should be created, with timepoint recommendation now being measured from this re-established starting point. This is applicable to transitions between levels of care, such as from inpatient to outpatient treatment, or transition between services, such as paediatric to adult setting. We highlight the importance of capturing outcomes across transitions especially for young adults who often find themselves 'caught' between child and adult services.<sup>48</sup>



(Figure 2 approx. here)

### **Strengths and limitations**

This project represents a notable success in collaboration across multiple stakeholder groups in not only the ED 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 ED 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/OCD/PTSD (KIDSCREEN-10, RCADS-25) and adult anxiety and depression (PHQ-9, GAD-7, WHODAS 2.0-12).<sup>12-15</sup> Therefore, comparisons will be possible not only between healthcare systems and countries but also across diagnoses. An additional strength of the Set is that every attempt was made to select questionnaires that are open domain and available at no cost to minimise the burden of implementation.

It is also important to recognise the limitations of this work. Specifically, there are groups of individuals who were not well represented within the group and/or process, including gender diverse individuals and young people. While 53% of the professional members of the working group had expertise working with children and adolescents, the lived experience representation of young people including adolescents and emerging adults would have been ideal. There was also limited representation from experts in ARFID. These absences were often reflected in the existing literature, with the psychometric properties of tools sometimes unavailable for underrepresented genders, ethnicities, and diagnoses. Moreover, some of the measures are not yet validated in specific languages or countries. Finally, the professional open review which was held to obtain feedback on the Set recruited only 50 participants, of whom 34 identified themselves primarily as clinicians (see appendix pp. 27). The small size of this professional review may not fully represent the views of frontline clinicians.

Further, the project team experienced difficulties identifying child appropriate measures for ED symptoms with AN, BED, BN or OSFED presentation. More specifically, it was difficult to find measures that were free, available in English, and easily accessible (i.e., would be feasible for a clinician to obtain relatively easily). Working group members were familiar with several potential questionnaires but these measures had a general lack of published peer-reviewed evidence, translations, or licensing details.

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 (e.g., body mass index [BMI] less than 18.5 kg/m<sup>2</sup> in adults), but also individuals who are weight suppressed according to their individual biological disposition. All working group members recognised the vital importance of weight restoration in certain ED diagnoses, but there was also a strong concern from some members around traditional weight measurement practices. These included the use of hard minimum cut-off weights, which are often insufficient for restoring psychological health, and the use of weight measurement in non-restrictive EDs.<sup>49</sup> These concerns should be considered within the historic context of the iatrogenic consequences of weight-centric ED treatment and the stigmatisation of larger bodies needing more weight for psychological recovery.<sup>50</sup> The outcome of weight/BMI was voted into the Set but was eventually removed by the project team in the final phase of the project due to lack of group consensus on how this information should be collected and used. While the Set will continue to collect BMI information as a case-mix variable (at baseline and annually), the removal of this outcome will likely impact the use of the Set during the frequent measurement (every two weeks) of inpatient and residential treatment in restrictive EDs. In these settings, movement toward outcomes

may be underestimated as this is generally a time highly focused on weight restoration. The absence of a weight outcome also limits the potential exploration of the relationship between weight restoration and outcomes in the other domains, that is, ED behaviours and cognitions, co-occurring mental health conditions, and quality of life and social functioning. The outcome of weight/BMI should be revisited when the field can gain 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 ED.

### **Implementation and future directions**

Information and resources related to the Set can be accessed from ICHOM (see Panel 2). Further details on the availability of individual questionnaires can also be found in the appendix. The Set is appropriate for use not only in specialised services but also 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, specifically around the practicality of multiple case-mix variables. Finally, the Set has the potential to be used as a tool across treatment to deliver progress feedback to individual patients and guide care decisions, and future data on implementation in this manner would be invaluable.

The ED Set should be considered a working document with the ability to adapt to upcoming innovations and shifting opinions in ED research and practice, especially the publication of new psychometric evidence for shorter, more concise measurement tools. Future consideration should be given to reviewing the balance of harmonisation between mental health measurement sets for other diagnoses (e.g., anxiety and depression) and specific priorities exclusive to EDs. Widespread uptake of this Set has the potential to create extensive treatment-based-evidence and help determine which treatment approaches work best for whom.

### **Data Sharing**

The ED 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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## **Contributors**

LF: conceptualisation, funding acquisition, methodology, supervision, writing - reviewing and editing. CP & TKR: conceptualisation, methodology, supervision, writing - review & editing. UD, CI, TL, IM: project administration, investigation, data curation, visualisation, writing - reviewing and editing. AA: conceptualisation, investigation, methodology, writing - original draft. SBA, BC, ECCS, CSN, SDH, JD, CH, BHD, JL, YL, PPPM, SM, MM, CMM, EM, IRP, JR, LS, HS, ET, ETCV, MCMT, EVF, & JW: investigation, methodology, writing - reviewing & editing.

## **Declarations of interest**

TKR is on the Clinical Advisory Board of Arise. CP is a member of the Clinical Advisory Board for Equip Health. UD, CI, TL, IM, and LZ were employed by 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 CEO of the Academy for Eating Disorders and has unpaid positions on the Board of the European Chapter of the AED 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 (NEDA), who supported the ICHOM project with funding. PPPM, SBA, and BHD report the funding below. BC, CSN, SDH, JD, CH, JL, YL, SM, MM, CMM, EM, IRP, JR, HS, ET, ETCV, MCMT, EVF, and JW report nothing to disclose.

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## Panel 1: Methods

A full, detailed description of the methodology used to produce the Set can be found in the Supplementary Material. In brief, the working group included 24 lived experience and/or professional experts from 13 countries (see appendix pp. 2). All working group members held equal voting power during the consensus building process. A core project team (CP, TKR, LF, AA, TL, UD, IM, CI) provided guidance and research support but did not vote.

**Process overview:** Over nine video calls across one year (April '21 to May '22) the working group engaged in a modified Delphi approach to develop consensus on recommendations (see Figure 1). Video calls included presentation of external input, including summaries of current research literature by the project team. After each call votes were cast anonymously via online survey. Voting was held for all aspects of the Set, including outcomes, measurement tools, case-mix factors/treatment details and timepoints.

**Outcome selection.** Following the Core Outcome Measures in Effectiveness Trials (COMET),<sup>51</sup> 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.

**Measurement tools.** After 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, responsiveness/sensitivity to change). Tools with the best evidence were shortlisted and presented to the working group. While information on psychometric properties informed voting decisions, working group members were asked to also consider burden on users and feasibility within low resource contexts.

**Case-mix factors/treatment details.** Variables that impact outcomes (i.e., confounders) were identified via the systematic scoping review, previous ICHOM Sets and a rapid review of systematic reviews and meta-analyses on treatment predictors, mediators, and moderators in EDs (see 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 EDs, 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 from professionals ( $n=50$ ) and individuals with lived experience ( $n=157$ ) across 12 countries. Suggestions with multiple instances were reconsidered by the working group with another round of discussion and voting.

**Table 1. Broad level overview of the ED Set**

	Timepoints	Variable	Reporter	Tool (child) Ages 6-12	Tool (adolescent) Ages 13-17	Tool (adult) Age 18+
Outcomes	Baseline, 3/6/12/24 months  OR  Every 2 weeks in intensive settings	ED cognitions/ behaviours	Patient/carer	EDY-Q (ARFID) ChEAT (all other diagnoses)	NIAS (ARFID) EDE-Q (all other diagnoses)	NIAS (ARFID) EDE-Q (all other diagnoses)
		Physical health	Clinician	-	-	-
		Other psychological symptoms	Patient/carer	RCADS-25	GAD-2/7 PHQ-2/9	GAD-2/7 PHQ-2/9
		QoL & social functioning	Patient/carer	KIDSCREEN-10	KIDSCREEN-10	CIA WHODAS 2.0-12
Case-mix	Baseline, annually	Demographic factors	Clinician & patient/carer	-	-	-
		Clinical factors	Clinician & patient/carer	Current view tool (provisional problems)	Current view tool (provisional problems)	Current view tool (provisional problems) - adapted SACQ - adapted
	Baseline	Historical factors	Clinician & patient/carer	-	-	ACE-Q
Treatment related factors	Baseline, annually	Treatment-related factors	Clinician	-	-	-

ACE-Q = Adverse childhood experiences questionnaire, ChEAT = Children's Eating Attitude Test, CIA = Clinical Impairment Assessment, EDE-Q = Eating Disorder Examinations Questionnaire, EDY-Q = Eating Disorder in Youth Questionnaire, GAD = Generalised Anxiety Disorder, NIAS = Nine Item ARIFD Screener, PHQ = Patient Health Questionnaire, RCADS = Revised Children's Anxiety and Depression Screener, SACQ = Self-administered comorbidities questionnaire, WHODAS = World Health Organization Disability Assessment Scale.



**Figure 1. Process overview of the ICHOM ED project.**

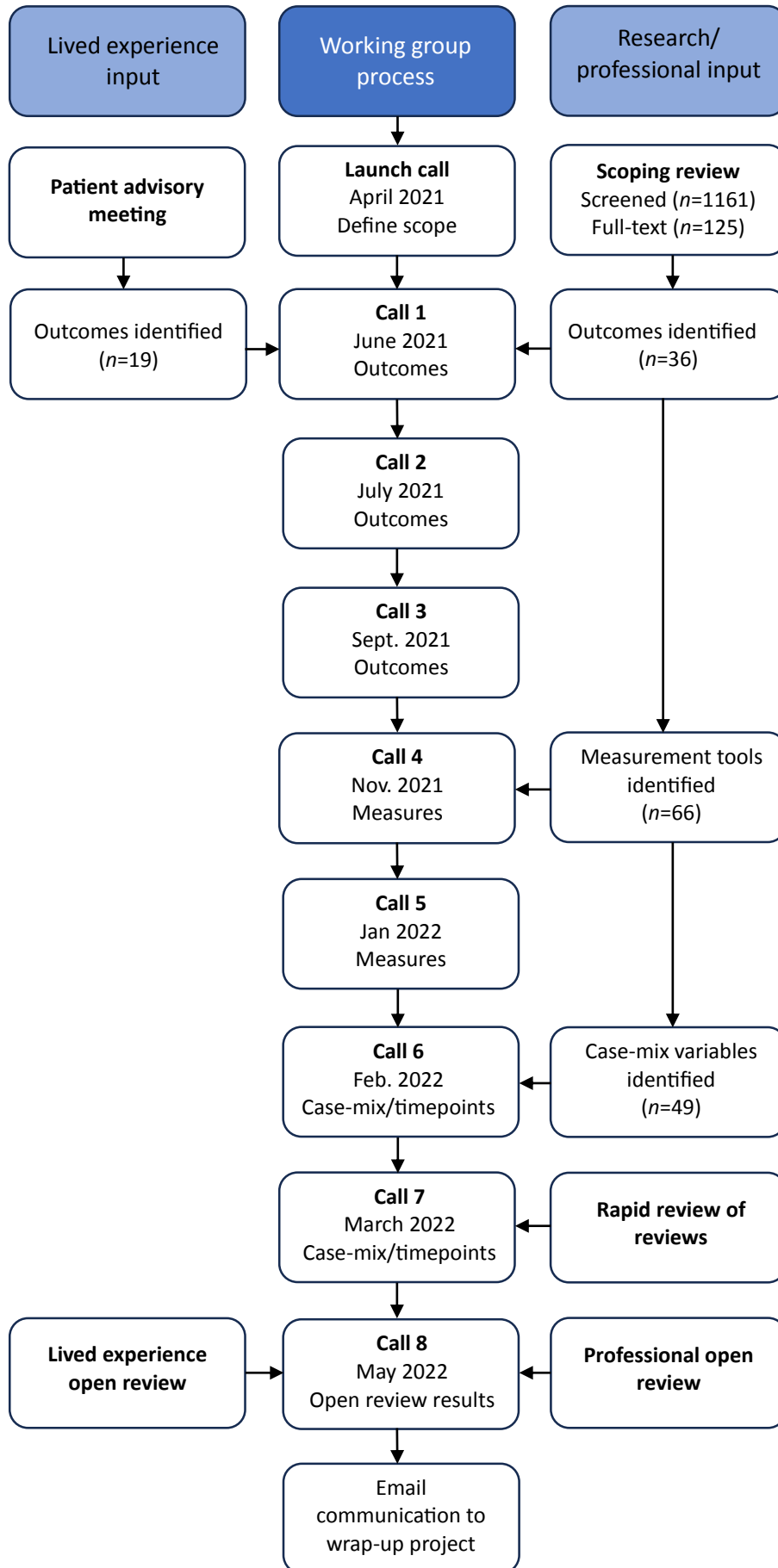
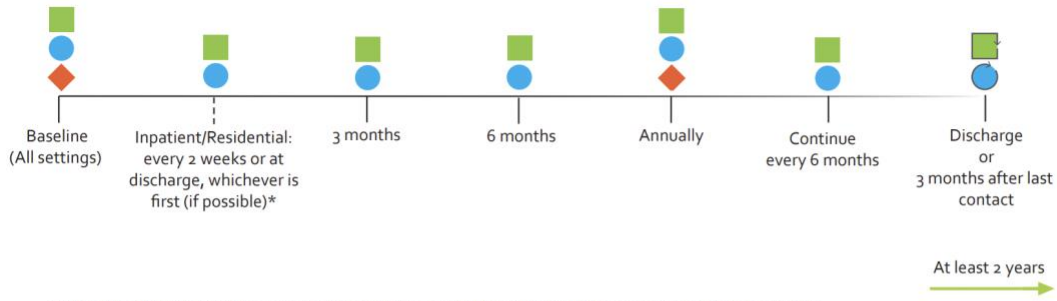


Figure 2. Timeline for data collection



\*Only clinical and patient-reported outcomes in the Eating Disorder Behaviours and Cognitions and Other Psychological Symptoms domains.

The outcome measures should be administered at the indicated time points:

- Patient-Reported Outcome Measures
- Clinical-Reported Outcome Measures
- ◆ Case-Mix Variables

Tracked Ongoing for at least 2 years