#### RESEARCH ARTICLE



WILEY

# Exploring the use of individualised patient-reported outcome measures in eating disorders: Validation of the Psychological Outcome Profiles

Amelia Austin<sup>1</sup> | Rachel Potterton<sup>1</sup> | Michaela Flynn<sup>1</sup> | Katie Richards<sup>1</sup> | Karina Allen<sup>1,2,3</sup> | Nina Grant<sup>2</sup> | Danielle Glennon<sup>2</sup> | Victoria A. Mountford<sup>1,2,4</sup> | Mary Franklin-Smith<sup>5</sup> | Monique Schelhase<sup>5</sup> | William R. Jones<sup>5</sup> | Lucy Serpell<sup>6,7</sup> | Kate Mahoney<sup>6</sup> | Gaby Brady<sup>8</sup> | Nicole Nunes<sup>8</sup> | Kuda Kali<sup>8</sup> | Frances Connan<sup>8</sup> | Ulrike Schmidt<sup>1,2</sup>

#### Correspondence

Prof. Ulrike Schmidt, Section of Eating Disorders, King's College London, Institute of Psychiatry, Psychology and Neuroscience, PO Box 59, 16 De Crespigny Park, London, SE5 8AF, UK. Email: ulrike.schmidt@kcl.ac.uk

#### **Funding information**

Health Foundation, Grant/Award Number: GIFTS 7294/CRM 1216

#### Abstract

**Rationale:** Psychotherapies for eating disorders (EDs) are routinely assessed using standardised patient-reported outcome measures (PROMs). PROMs have been criticised for their lack of patient centeredness and clinical utility. The Psychological Outcome Profiles (PSYCHLOPS) is an individualised PROM that allows patients to specify their own outcomes.

**Aims:** (1) To validate the use of the PSYCHLOPS in ED treatment, and (2) to identify patient concerns beyond those measured by common ED PROMs.

**Methods:** Two hundred and seventy-eight emerging adult patients, presenting with a first-episode ED (aged 16–25, illness duration <3 years) completed the PSYCHLOPS and two standardised ED PROMs (the EatingDisorder Examination Questionnaire [EDE-Q] and the Clinical Impairment Assessment Questionnaire [CIA]) at four time points across 12 months. Psychometrics of the PSYCHLOPS were assessed quantitatively against the EDE-Q and CIA. Content analysis assessed unique patient concerns identified by PSYCHLOPS.

**Results:** The PSYCHLOPS had adequate to good psychometric properties. A total of 53.3% of participants reported a concern not addressed by the EDE-Q or the CIA, the most common being depression/anxiety, academic problems, treatment concerns and disturbed sleep.

**Discussion:** PROMs can be complemented by the PSYCHLOPS to identify problems specific to an individual's context. As ED patients are typically ambivalent about change, understanding their concerns is vital in building motivation for change.

This is an open access article under the terms of the Creative Commons Attribution-NonCommercial License, which permits use, distribution and reproduction in any medium, provided the original work is properly cited and is not used for commercial purposes.

 $@\ 2020\ The\ Authors.\ European\ Eating\ Disorders\ Review\ published\ by\ Eating\ Disorders\ Association\ and\ John\ Wiley\ \&\ Sons\ Ltd.$ 

Eur Eat Disorders Rev. 2020;1–11. wileyonlinelibrary.com/journal/erv

<sup>&</sup>lt;sup>1</sup>King's College London, Institute of Psychiatry, Psychology and Neuroscience, London, UK

<sup>&</sup>lt;sup>2</sup>South London and Maudsley NHS Foundation Trust, London, UK

<sup>&</sup>lt;sup>3</sup>School of Psychological Sciences, The University of Western Australia, Western Australia, Australia

<sup>&</sup>lt;sup>4</sup>Maudsley Health, Abu Dhabi, United Arab Emirates

<sup>&</sup>lt;sup>5</sup>Leeds and York Partnership NHS Trust, Leeds, UK

<sup>&</sup>lt;sup>6</sup>North East London NHS Foundation Trust, London, UK

<sup>&</sup>lt;sup>7</sup>Division of Psychology and Language Sciences, University College London, London, UK

<sup>&</sup>lt;sup>8</sup>Central and North West London NHS Foundation Trust, London, UK

#### KEYWORDS

eating disorders, emerging adults, outcome measures, PROMS, psychometrics

#### 1 | INTRODUCTION

Eating disorders (EDs) are severe psychiatric disorders which, when left untreated, can lead to psychosocial impairment (e.g., employment difficulties, limited social relationships), physical disability and death (Treasure, Duarte, & Schmidt, 2020). In the United Kingdom, many specialist ED services collect routine outcome measures (ROMs) which serve to assess illness severity, patients' quality of life and function. The repeated collection of ROMs over the course of treatment allows for the objective evaluation of patient progress towards recovery. Recently released National Health Service (NHS) guidance on adult ED care in England suggests that all services should use ROMs, not just to track progress, but also to support the achievement of collaboratively identified, person-specific recovery goals, to empower patients and inform individualised treatment (National Collaborating Centre for Mental Health, 2019). To achieve this objective, clinicians need access to psychometrically sound ROMs which can be utilised in a collaborative and person-centred manner.

Traditionally, ROMs have been collected using patientreported outcome measures (PROMs). PROMs are standardised questionnaires, providing preset statements for the patient to rate on a numeric scale. They were initially used in research trials to determine the efficacy of new treatments and later became a tool used by clinicians to inform practice (Black, 2013). More recently, PROMs have become widespread to evaluate service performance (Dawson, Doll, Fitzpatrick, Jenkinson, & Carr, 2010). PROMs come in both universal and condition-specific formats. For example, the Clinical Outcomes in Routine Evaluation-Outcome Measure (CORE-OM; Evans et al., 2002) can be used across a variety of diagnoses, while others have been created for a specific population. In EDs, common condition-specific PROMs include the Eating Disorder Examination Questionnaire (EDE-Q; Fairburn & Beglin, 1994) and the associated Clinical Impairment Assessment Questionnaire (CIA; Bohn & Fairburn, 2008).

Despite the recent increase in the use of PROMs for mental health service evaluation in the United Kingdom (Macdonald & Fugard, 2015), many stakeholders, including patients and clinicians, express concerns about their use. One concern is that these measures have been developed with researcher or service-payer (e.g., health system) interests at the forefront rather than those of the service user (Nelson et al., 2015). This concern stems from

# **Highlights**

- The psychometric properties of the Psychological Outcome Profiles (PSYCHLOPS) are acceptable and broadly comparable to the Eating Disorder Examination Questionnaire and Clinical Impairment Assessment Ouestionnaire
- The PSYCHLOPS may effectively complement traditional patient reported outcome measures to allow for the identification of problems specific to an individual's context
- Clinical applications include collaborative treatment planning, uncovering sources of/ obstacles to patient treatment motivation and facilitation of a precision medicine approach.

the fact that implementation of PROMs is often mandated in a 'top down' fashion, meaning that commissioners, managers or policy-makers make decisions regarding when and how PROMs will be used. From this perspective, PROMs are primarily instruments that assess service efficiency rather than tools measuring patient improvement and guiding treatment. A second concern voiced by clinicians is that using PROMs may potentially have a negative impact on the therapeutic relationship (Wolpert, Curtis-Tyler, & Edbrooke-Childs, 2016). This concern is underpinned at least in part by the perception that PROMs have a depersonalising effect, reducing the unique patient experience down to scores and tick boxes (Norman, Dean, Hansford, & Ford, 2014). Other practical concerns also exist for clinicians, such as the time required for administration (Batty et al., 2013).

From a patient perspective, Robinson, Ashworth, Shepherd, and Evans (2006) suggest that standardised PROMs do not necessarily measure problems specific to their individual context. This may be because, while individuals may present with the same diagnosis, they are not necessarily in similar circumstances, facing the same barriers or working with the same resources. A second concern for patients is that the data generated by PROMs may be used for gatekeeping (Wolpert, 2014). For example, a patient may fear, and perhaps correctly predict, that only those who score above a threshold value on a specific PROM will be offered access to treatment.

-Wiley\_\_\_

Finally, there is concern that PROMs do not accurately reflect progress towards the patient's treatment goals and holistic recovery, but rather measure aspects of improvement that clinicians and services deem most valuable (Ashworth, Evans, & Clement, 2009).

To address the criticisms of PROMs, Individual PROMs (I-PROMs) have been developed. In contrast to PROMs, which present a pre-existing set of concerns for patients to rate, I-PROMs allow service users to input concerns into a free-text space before proceeding to rate the items on severity. The rationale behind I-PROMs is that they will be more acceptable to clinicians and patients while maintaining evaluative functions valued by researchers and service-level assessors. The first I-PROM created specifically for psychological therapies is the Psychological Outcome Profiles (PSYCHLOPS), a brief, one-page measure that allows patients to identify problems and concerns about functioning that are specific to them, and to rate their severity (Ashworth et al., 2004). The PSYCHLOPS was originally developed and evaluated for use in psychological therapies delivered in primary healthcare settings (Ashworth et al., 2005). Previous work by Ashworth et al. (2007) has established that the PSY-CHLOPS has acceptable psychometric properties when used in primary care, including good internal reliability (consistency across items to ensure the same construct is being measured;  $\alpha = 0.79-0.87$ ), concurrent validity (agreement between two measures that are related; in this case, the PSYCHLOPS change score and self-rated recovery,  $\rho = 0.60$ , p < 0.001 [Czachowski, Seed, Schofield, & Ashworth, 2011]), acceptability (whether the participants find the measure tolerable to complete; 91.2%–100%), sensitivity (acuteness in measuring change; d = 1.53-1.61) and convergent validity (agreement between two measures which should, theoretically, measure the same concept; in this case, agreement between change scores on the PSYCHLOPS and other validated measures,  $\rho = 0.61-0.65$ , p < 0.001).

The PSYCHLOPS has now moved beyond primary healthcare settings, with recent studies assessing its efficacy in specialist services providing psychological therapies for a range of psychiatric disorders, including psychosis (Kelly, Holttum, Evans, & Shepherd, 2012), substance abuse disorder (Alves, Sales, Ashworth, & Faísca, 2020) and post-traumatic stress disorder (BuddeAkko & AinamiMurillo-Rodriguez, 2018). Based on the empirical evidence obtained in these areas, we hypothesise that the PSYCHLOPs will be suitable for uncovering additional patient concerns in individuals receiving psychological therapy for an ED. More specifically, the purpose of this study is to explore whether, in emerging adult patients receiving outpatient psychological therapy for a first-episode ED, the PSYCHLOPS I-PROM:

- 1. Has acceptable internal reliability and concurrent validity.
- 2. Has comparable acceptability, sensitivity, and convergent validity when measured against other common condition-specific PROMs.
- 3. Reveals additional patient concerns beyond those measured by common condition-specific PROMs.

#### 2 | METHODS

# 2.1 | Participants and design

Participants were patients from the first-episode and rapid early intervention for eating disorders (FREED) service model and care pathway recruited into the FREED - Upscaled (FREED-Up) study, a longitudinal quasi-experimental evaluation (Austin et al., 2021; Flynn et al., 2020).

The demographic characteristics of the study population are summarised in Table 1. The sample included 278 emerging adults consecutively recruited from four specialist NHS ED services in England presenting with a first episode illness of short duration. All participants were between the ages of 16-25 (M = 20.19, SD = 2.39) and had been ill for <3 years. Recruitment took place across a 2-year period (between 11 January 2017 and 22 August 2018). Patients were deemed ineligible for FREED if they had immediate need for inpatient admission on referral, were unable to complete questionnaires (e.g., learning disability or non-English speaker), had planned inaccessibility for the duration of the study (e.g., travelling), were pregnant, or had a physical illness or comorbid primary mental disorder requiring priority treatment. These inclusion/exclusion criteria were used to ensure the patient had the ability to participate in the study and that there were no alternative health concerns that needed preferential treatment. In alignment with the overall goal of the FREED service to intervene early, the 3-year duration of illness criterion was used so we could identify early-stage EDs before they progressed to a more advanced stage of illness (Schmidt, Brown, McClelland, Glennon, & Mountford, 2016).

Participants were roughly equally split among three diagnostic categories (anorexia nervosa [AN] n=117, bulimia nervosa [BN] n=71, and other specified feeding or eating disorder [OSFED]/binge eating disorder [BED] n=89). Diagnosis was first assessed by a clinician and then confirmed by a researcher (A. A. or M. F.) with a semi-structured interview based on the Eating Disorder Diagnostic Scale (Stice, Telch, & Rizvi, 2000) and the EDE (Fairburn, Cooper, & O'Connor, 2008), using DSM-5 criteria (American Psychiatric Association, 2013), with

**TABLE 1** Demographic characteristics of the FREED-Up study population

Characteristic  Age $(M \pm SD)$ 20.19 $\pm$ 2.19  Sex $(F:M)$ 259:19  Diagnosis $(n, \%)$ AN 117 (42.1)
Sex (F:M) 259:19 Diagnosis (n, %)
Diagnosis $(n, \%)$
BN 71 (25.5)
OSFED/BED 89 (32.0)
Ethnicity ( <i>n</i> , %)
White 181 (65.1)
Asian 27 (9.7)
Black 11 (4.0)
Occupation (n, %)
School 18 (6.5)
University/college 156 (56.1)
Employed 72 (25.9)
Unemployed 25 (9.0)
Living arrangement (n, %)
With family 146 (52.5)
With friends 58 (20.9)
Student accommodation 28 (10.1)
With spouse/partner 13 (4.7)
On own 14 (5.0)
Other 9 (3.2)

Abbreviations: AN, anorexia nervosa; BED, binge eating disorder; BN, bulimia nervosa; OSFED, other specified feeding or eating disorder.

the researcher diagnosis being used if the clinician diagnosis differed. A total of 63% of the cohort reached the final 12-month follow-up. As reported elsewhere, no baseline characteristics (diagnosis, age of onset, gender, ethnicity or (body mass index) BMI at assessment) were predictive of completion (Austin et al., 2021).

# 2.2 | Measures

The EDE-Q is a 28-item PROM used to measure the severity of ED cognitions and frequency of ED behaviours (Fairburn & Beglin, 1994). The measure yields a score on four subscales (dietary restraint, eating concern, shape

concern and weight concern) and a global score (Fairburn & Beglin, 1994). The EDE-Q has been shown to have adequate reliability and validity (Berg, Peterson, Frazier, & Crow, 2012). Its subscales have acceptable-togood internal consistency ( $\alpha=0.70$ –0.93; Berg et al., 2012). In the current sample, there was excellent internal consistency ( $\alpha=0.93$ –0.96). The EDE-Q also measures physical characteristics, including height, weight and missed menstrual periods.

The CIA is a 16-item PROM designed to assess ED-related psychosocial impairment (Bohn & Fairburn, 2008). The scale concentrates on the last 28 days and addresses four domains of life: cognitive function, mood and self-perception, interpersonal function, and work performance. The scale produces a global score of impairment, with a score of 16 or above, indicative of a clinical ED. The CIA has been shown to have adequate reliability and validity (Bohn & Fairburn, 2008), and its subscales have good internal consistency ( $\alpha = 0.82-0.91$ ; Jenkins, 2013). In the current sample, there was excellent internal consistency ( $\alpha = 0.90-0.97$ ).

The PSYCHLOPS (Ashworth et al., 2004) is an I-PROM that allows patients to determine their own outcomes via a free-text response format. Three versions of the same measure (pre-, during- and post-therapy) are used to assess progress relative to patient determined outcomes. In the baseline pre-therapy version of the PSYCHLOPS, patients are asked to identify two problems that have been troubling them (e.g., low mood, binge eating) and one thing that is difficult to do because of this problem (e.g., hanging out with friends), and to rate the severity of these problems/ difficulties using a six-point Likert scale. A fourth question measures general well-being in the past week, again using a six-point Likert scale. The during- and post- therapy versions of the PSYCHLOPS ask patients to rate the severity of the problems/difficulty previously identified in the pre-therapy version, to again rate their general wellbeing in the past week, and to share any new problems that may have emerged. Finally, the post-therapy version includes an additional question to assess self-reported rate of recovery.

#### 2.3 | Procedure

Ethical approval by all relevant committees was obtained. The study was conducted in accordance with the Declaration of Helsinki (World Medical Association, 2013). Participants were recruited after an initial clinical assessment, with informed consent obtained before proceeding to research activities. Participants completed a baseline research assessment, including a set of online questionnaires (with the three measures

TABLE 2 Mean scores across time

	Treatment start $(n = 278)$	3 months ( $n = 216$ )	6 months ( $n = 182$ )	12 months ( $n = 175$ )
PSYCHLOPS	16.0	12.23	10.77	9.24
EDE-Q	4.08	3.17	2.85	2.38
CIA	32.70	27.24	23.68	19.90

Abbreviations: CIA, Clinical Impairment Questionnaire; EDE-Q, Eating Disorder Examinations-Questionnaire; PSYCHLOPS, Psychological Outcome Profiles.

which are the focus of the present study) before their first therapy session (more details on the FREED service/care pathway model can be found in Allen et al., [2020]), and again at 3, 6 and 12 months after initial assessment. The 12-month time point is post-therapy. At the 6- and 12-month time points, participants were invited to respond to the additional question about self-assessed rate of recovery.

# 2.4 | Analysis

# 2.4.1 | Quantitative

Internal reliability for the PSYCHLOPS was tested using Cronbach's alpha (Cronbach, 1951). This was calculated across the four questions of the pre-therapy version of the measure. A value greater than 0.7 is considered acceptable internal reliability (Nunnally & Bernstein, 1994).

Concurrent validity was tested by comparing the PSYCHLOPS overall change scores to self-reported recovery as measured by the post-therapy version of the questionnaire using correlational analysis.

To assess acceptability, completion rate was used as a proxy following the assumption that the patients who agreed to complete the measures found them at least minimally acceptable.

Sensitivity to change over time was assessed for the PSYCHLOPS, EDE-Q and CIA using Cohen's *d*, with a value of at least 0.8 indicating a large effect (Cohen, 1988). In line with the previous validations of the PSYCHLOPS (e.g., Czachowski et al., 2011), this was calculated as the change score divided by the pre-therapy standard deviation (SD).

Convergent validity was tested by exploring correlation between standardised change scores of all three measures. For this, standardised *z*-scores were calculated by subtracting the pre-therapy mean score from the overall change scores and then dividing by the pre-therapy mean (Ashworth et al., 2005). For all correlation analyses, the non-parametric Spearman's coefficient  $(\rho)$  was used as variables were not normally distributed, and

a correlation of 0.7 was considered a strong effect (Dancey & Reidy, 2007).

Missing data were substituted using multiple imputation, using fully conditional specification. To maximise the benefit, 20 imputations were used. Baseline variables (demographic and pre-treatment questionnaire scores) were used as predictors for interim scores, and interim scores were added as predictors for subsequent scores. Data were analysed using SPSS version 26.

# 2.4.2 | Qualitative

A directed approach to content analysis was used (Hsieh & Shannon, 2005). Free-text responses were coded using a subtheme classification framework developed by Ashworth et al. (2007), and adapted by Sales, Neves, Alves, and Ashworth (2018). Any response not fitting into one of the existing 65 subthemes triggered the creation of a new subtheme. This resulted in a total of 71 subthemes. Responses were coded by one author (A. A.) with a subset (25%) coded independently by a second author (R. P.). Any discrepancies were resolved through discussion. Interrater reliability was 75%. Following previous PSY-CHLOPS analysis procedure (Sales et al., 2018), if more than one subtheme was mentioned in a single free-text response, only the first was analysed.

Content matching was used to compare the 71 subthemes developed from the PSYCHLOPS responses to items in the EDE-Q and CIA (see Table S1). Two authors (R. P. and A. A.) completed this process independently, with any discrepancies resolved by discussion. Matches between a PSYCHLOPS subtheme and an EDE-Q or CIA item were classified as either 'yes/possibly yes' a match or 'no,' not a match, such that ambiguous pairs would be classified as a match to reduce coding bias. Data were analysed using NVivo 12.

#### 3 | RESULTS

Mean scores across at each time point for all measures are presented in Table 2.

TABLE 3 Completion rates of questionnaire measures across time

	Treatment start	3 months	6 months	12 months
PSYCHLOPS	98.9%	77.7%	64.0%	62.9%
Problem domain	99.6%	77.7%	64.4%	62.9%
Function domain	98.9%	77.7%	64.0%	62.9%
Well-being domain	100%	77.7%	64.7%	62.9%
EDE-Q	100%	77.7%	65.5%	62.9%
CIA	99.3%	77.0%	64.7%	62.2%

Abbreviations: CIA, Clinical Impairment Questionnaire; EDE-Q, Eating Disorder Examinations-Questionnaire; PSYCHLOPS, Psychological Outcome Profiles.

# 3.1 | Internal reliability

Cronbach's alpha across time points ranged between 0.73 and 0.84, indicating acceptable to good reliability.

# 3.2 | Concurrent validity

Change scores for the PSYCHLOPS were highly correlated to patient-rated recovery at 12 months ( $\rho = -0.69$ , p < 0.01). This coefficient (-0.69) represents a strong effect (Dancey & Reidy, 2007). From a clinical perspective, this suggests that a patient's PSYCHLOPS score is highly related to their perspective of self-recovery (i.e., high score equals less recovered, and vice versa).

# 3.3 | Acceptability

Completion rates across time points for all three measures can be found in Table 3. Completion rates were roughly similar for all measures, with approximately two-thirds of participants providing post-therapy scores at 12 months (PSYCHLOPS = 62.9%, EDE-Q = 62.9%, CIA = 62.2%).

### 3.4 | Sensitivity

The PSYCHLOPS generated an effect size of 2.14, the EDE-Q 1.40 and the CIA 1.33. These are all large effect sizes (Cohen, 1988) and therefore effective measures of change, although the PSYCHLOPS is even more sensitive due to its personalised nature.

# 3.5 | Convergent validity

Standardised change scores for the PSYCHLOPS were highly correlated with standardised change scores from

both the EDE-Q ( $\rho=0.71,\ p<0.01$ ) and the CIA ( $\rho=0.71,\ p<0.01$ ). These coefficients (0.71) represent a strong effect (Dancey & Reidy, 2007). From a clinical perspective, this suggests that improvement as measured by the PSYCHLOPS will be similarly measured by the EDE-Q and CIA (i.e., a patient with a decreasing PSYCHLOPS score across treatment will have a decreasing EDE-Q and CIA score, and vice versa).

# 3.6 | Content analysis

# 3.6.1 | Newly generated subthemes

Six new subthemes not previously included in Attia et al. (2019) content analysis framework were identified. These include (1) shape and weight concerns (preoccupation with current/future body shape or weight), (2) compensatory behaviour (i.e., engaging in behaviours in an attempt to 'make up' for eating, e.g., vomiting, taking laxatives), (3) not feeling deserving of help, (4) concerns about the treatment process, (5) concealment (of one's illness or behaviours from others) and (6) physical effects of illness (e.g., deterioration of bone density, infertility). The concerns about the treatment process category encompassed several different ideas but broadly fit into three categories (A) fear of coercion, (B) doubts about treatment effectiveness and (C) concerns about being vulnerable/open about inner self or past events.

# 3.6.2 | PSYCHLOPS subtheme frequencies

As might be expected, the most common concerns endorsed by participants on the PSYCHLOPS were eating problems (59.4%, 164/276) and shape and weight concerns (42.0%, 116/276). These were closely followed by difficulties with social interaction (24.7%, 66/276).

TABLE 4 Most common subthemes reported by the PSYCHLOPS but not by the EDE-Q or CIA

Subtheme	Example quotation		
Depression and anxiety	'Low mood'		
	'Constantly being anxious'		
	'Severe depression'		
	'Feeling low and anxious'		
Academic issues	'Go to lectures and catch up with coursework'		
	'Not getting good grades'		
	'Commit to my studies'		
	'Schoolwork. I Have dropped out of 3 classes this semester.'		
Treatment concerns			
Fear of coercion	'Scared of being admitted'		
	'Being forced to gain weight'		
Doubts about treatment effectiveness	'Will this treatment actually work for me and is it possible for me to get better?'		
	'I might be afraid if this does not work for me'		
Openness/vulnerability	'Being open about my feelings'		
	'Having to drag up the past and speak about it'		
Sleep problems	'Insomnia'		
	'Sleeping/waking up'		
	'Sleep paralysis'		
	'Getting a good night's sleep'		

Abbreviations: CIA, Clinical Impairment Questionnaire; EDE-Q, Eating Disorder Examinations-Questionnaire; PSYCHLOPS, Psychological Outcome Profiles.

#### 3.6.3 | Comparison to EDE-Q and CIA

Results of content matching can be seen in Table S1. A total of 88.9% (226/276) of participants identified a concern not measured by the EDE-Q, while 55% (153/276) identified a concern not measured by the CIA. More than half of participants (53.3%, 147/276) identified a concern not measured by either of the two PROMs. As can be seen in Table 4, the most common concerns not covered by either the EDE-Q or the CIA include depression and anxiety (17.4%, 48/276), academic issues (9.1%, 25/276), concerns about the treatment process (7.2%, 20/276) and sleep problems (4.0%, 11/276).

#### 4 | DISCUSSION

#### 4.1 | Main findings

The results obtained from psychometric testing suggest that the PSYCHLOPS is a satisfactory tool to measure change in emerging adults presenting to ED services with a first illness episode and receiving evidence-based psychological therapy for an ED. The PSYCHLOPS showed adequate-to-good internal reliability in this sample, meaning that the separate items on the PSYCHLOPS are measuring the same construct, that is global distress/impairment. Furthermore, concurrent validity testing revealed that PSYCHLOPS change scores are highly related to patient-reported recovery at the end of treatment. This suggests that the PSYCHLOPS reflects progress towards recovery as defined by the patient, which is one of the main purposes of this measure. Both internal reliability and concurrent validity were comparable to values previously found when assessing the PSYCHLOPS in primary care settings (Ashworth et al., 2005, 2009).

When comparing psychometric properties of the PSYCHLOPS to our condition-specific measures, the results revealed a general trend for similarity across the domains of acceptability and convergent validity. Moreover, using completion rates as a proxy for acceptability, emerging adults accessing treatment for a first-episode ED found the PSYCHLOPS was at least as tolerable to complete as the EDE-Q and the CIA. Convergent validity testing revealed high rates of

correlation between standardised change scores on the PSYCHLOPS when compared to the EDE-Q and CIA, meaning that improvement in patient function as measured by the PSYCHLOPS is related to the magnitude of improvement as measured by the EDE-Q or CIA. The PSYCHLOPS had higher sensitivity to change when compared to the EDE-Q or CIA, but this is to be expected when using an I-PROM, as the measurement of change is based on problems directly identified by the patients as relevant to themselves. Overall, the general comparability between psychometric properties of the PSYCHLOPS and the tried and tested PROMs (EDE-Q and CIA) build confidence that the patientspecified outcomes used in the PSYCHLOPS are as useful in measuring overall improvement as those assessed in PROMs.

Content analysis revealed the extent to which unique individual difficulties are not identified by PROMs. In our sample, roughly half of the patients experienced a difficulty not captured by the EDE-Q or CIA. This result is similar to Alves et al. (2020), which found that almost half (49%) of the participants seeking treatment for substance abuse identified a key problem or difficulty not measured by three standardised PROMs: the CORE-OM, The Patient Health Questionnaire-9 (PHQ-9; Kroenke, Spitzer, & Williams, 2001) and the substance-use-specific Treatment Outcomes Profile (TOP; Marsden et al., 2008). However, our findings were less pronounced than previous work by Sales et al. (2018), which found that, in a mixed population of general psychiatric and addiction patients, 95% identified a unique concern not measured by the PHQ-9 and 71% identified a concern not measured by the CORE-OM. However, in contrast to our study and that of Alves et al. (2020), only two PROMs were used for comparison, neither of which was disease specific. It appears that, as the number of PROMs increases, and with the inclusion of both universal PROMs (e.g., CORE-OM, PHQ-9) and disease-specific PROMs (e.g., EDE-Q, TOP), the number of unique concerns identified by the PSYCHLOPS decreases. Put simply, the PSYCHLOPS identifies a range of concerns that would otherwise only be identified by using multiple PROMs. As such, the PSYCHLOPS allows for the efficient assessment of a wide range of outcomes. In ED treatment, where it is typical for multiple PROMs to be used to assess behaviours, functional difficulties and mood comorbidity, the PSY-CHLOPS offers a convenient way to identify the key difficulties in one step.

Further analysis also revealed that the top concerns reported on the PSYCHLOPS that did not correspond to items measured by the EDE-Q or CIA included depression and anxiety, treatment concerns, sleep problems and academic issues. Comorbid depression and/or anxiety has long been known to be common amongst ED patients (Treasure et al., 2020), and sleep problems are increasingly recognised as an important issue for young people with emotional disorders or EDs (Rapee et al., 2019). Recent findings suggest that these concerns are related, with depression and anxiety mediating the relationship between sleep disturbance and EDs in college women (Goel et al., 2020). Furthermore, concerns about treatment-and in particular the potential involvement of parents-have recently been cited as a barrier to help seeking in emerging adults (Potterton, Austin, Allen, Lawrence, & Schmidt, 2020). Finally, university students with an ED reported that the illness hindered their ability to focus on academic responsibilities (Goldschen et al., 2019), and interference with life roles (e.g., ability to focus on studies) has been found to be a facilitator of help-seeking in emerging adults (Potterton et al., 2020). More specifically, Serra et al. (2020) found that binge/ purge behaviours were associated with lower academic performance and higher risk of academic failure in firstyear university students. Given that the literature has previously identified all these concerns as relevant to ED patients, and some specifically to emerging adult ED patients, it follows that these concerns should be measured during treatment if they are relevant to an individual. As these themes are not covered by the EDE-Q or CIA, the PSYCHLOPS may be a good candidate for filling this gap.

# 4.2 | Implications for practice and policy

The main clinical advantage of the PSYCHLOPS is that it provides information that would allow clinicians to tailor clinical treatment toward individualised patient formulations and treatment goals. Second, the PSYCHLOPS could be used to uncover possible sources of fear/obstacles to motivation to engage in treatment. This is particularly relevant as ED patients typically experience their symptoms as egosyntonic (Vitousek, Watson, & Wilson, 1998), especially in the early stages of illness (Potterton et al., 2020) and are ambivalent about receiving help (Leavey, Vallianatou, Johnson-Sabine, Rae, & Gunputh, 2011). Additionally, the treatment concerns revealed by the PSYCHLOPS may also provide information helpful in collaboratively choosing between which type of evidence-based therapy may be best suited to a patient. For example, a patient with AN who writes in the PSYCHLOPS that one of her most concerning problems is 'my eating disorder is my whole identity', may be guided by their clinician to consider whether the Maudsley Model of Anorexia Nervosa Treatment for

Adults, which focuses on development of a non-anorexic identity, may be the most appropriate therapeutic option. The use of the PSYCHLOPS to inform treatment choices and create more efficient intervention plans supports a precision medicine approach, that is, takes into account individual variability to provide the right treatment for the right person (Zhang, 2015).

Similar to Ashworth et al. (2005), we suggest that the PSYCHLOPS be used to complement traditional PROM use in ED services. The PROMs (e.g., EDE-Q or CIA) give a summary of distress as defined by clinicians while the PSYCHLOPS reveals those difficulties most important to the patient. Alternatively, the PSYCHLOPS could be used to capture the most pressing difficulties in one efficient measure when the use of multiple PROMS is not feasible. Therefore, the PSYCHLOPS can be used either to expand the detailed story of the individual or to quickly highlight the most distressing difficulties. In either case, the PSYCHLOPS could uncover personal motivation for recovery, assist in collaboratively planning treatment, and measure progress on items specific to an individual's holistic recovery.

# 4.3 | Strengths and limitations

The strength of the study is the use of a large well-characterised cohort of first-episode patients in the early stages of illness and who were emerging adults, that is, all at a similar stage of biopsychosocial development. The study includes the whole spectrum of ED diagnoses and a range of severities. These patients were treatment-naïve and not yet 'socialised' into what to expect from ED services and treatment. As such, their concerns are likely to reflect the full cosmos of issues affecting young people with EDs in this age group. We can only speculate, but it is likely that patients with multiple previous treatments might have a different and perhaps narrower range of concerns, for example, including their experiences with previous treatment approaches/therapists and how to make up for lost time.

This research is subject to some limitations. Convergent validity as measured by correlation between patient and clinician rating of recovery could not be tested in the current sample because the final question of the post-therapy version of the PSY-CHLOPS, intended to be completed by the therapist to capture their evaluation of patient recovery, was not used. Future work needs to evaluate the clinicians' use of the PSYCHLOPS in ED treatment and examine whether, if integrated collaboratively into treatment, I-PROMS like the PSYCHLOPS have positive impacts on treatment outcomes. Further, concurrent validity was

assessed using a single item on the PSYCHLOPS, and future research should confirm these findings with a validated recovery measure.

Similarly, the PSYCHLOPS was given at the end of the research battery, with several other psychological measures (including the EDE-Q and CIA) completed beforehand. The order in which these measures were completed may have primed participants to have preconceived ideas of problems they were 'expected' to have when completing the free-text portion of the PSY-CHLOPS. Finally, the current sample was a very specific group of ED patients, mainly female emerging adults with a short duration of illness receiving treatment in an outpatient setting. For this reason, the results may not be generalisable to patients of different age, gender, illness stage, or care setting. Despite these limitations, this study is the first to evaluate the use of an I-PROM in ED treatment, and thus provides important support for further research of these measures in ED services.

#### 5 | CONCLUSION

The PSYCHLOPS is an informative and efficient individualised outcome measure suitable for use in psychological therapies for patients with EDs. The psychometric properties of the PSYCHLOPS are acceptable and broadly comparable to the EDE-Q and CIA, two commonly used PROMS in the ED treatment. Qualitative analysis revealed that the PSYCHLOPS may effectively complement traditional PROMS to allow for the identification of problems specific to an individual's context. Alternatively, the PSY-CHLOPS could be used to assess multiple areas of difficulty and functioning when the use of several PROMs is not feasible. Clinical applications include collaborative treatment planning and uncovering sources of obstacles to patient treatment motivation. Further research will be needed to explore the use of the PSYCHLOPS across ED treatment in other age groups, illness stages, and care settings. It will also be important to evaluate clinician acceptance of the measure and the impact of I-PROM use on treatment outcomes.

#### **ACKNOWLEDGEMENTS**

The authors would like to thank Rachel Egan for her feedback on the manuscript. The authors would also like to thank all the participants from the FREED-Up Cohort. This work was supported by a Health Foundation Scaling Up Award. US receives salary support from the National Institute for Health Research (NIHR) Biomedical Research Centre for Mental Health, South London and Maudsley NHS Foundation Trust and Institute of Psychiatry, Psychology and Neuroscience, King's College

London. US is supported by an NIHR Senior Investigator Award. K. R. is funded by the Health Foundation, R. P. is funded by a PhD studentship from the NIHR Biomedical Research Centre for Mental Health, South London and Maudsley NHS Foundation Trust, and A. A. and M. F. are supported by the King's College London International Postgraduate Research Scholarship. The views expressed in this publication are those of the authors and not necessarily those of the National Health Service, the NIHR or the UK Department of Health.

#### CONFLICT OF INTERESTS

The authors declare that there is no conflict of interests.

#### ORCID

Amelia Austin https://orcid.org/0000-0002-4979-4847 Rachel Potterton https://orcid.org/0000-0002-4323-4814

#### REFERENCES

- Allen, K., Mountford, V. A., Brown, A., Richards, K., Grant, N., Austin, A., ... Schmidt, U. (2020). First episode rapid early intervention for eating disorders (FREED): From research to routine clinical practice. *Early Intervention in Psychiatry*, 14(5), 625–630. https://doi.org/10.1111/eip.12941
- Alves, P. C. G., Sales, C. M. D., Ashworth, M., & Faísca, L. (2020). "There Are Things I Want to Say But You Do Not Ask": A comparison between standardised and individualised evaluations in substance use treatment. *International Journal of Mental Health and Addiction*, 18, 861–864.
- American Psychiatric Association. (2013) Diagnostic and statistical manual of mental disorders (5th ed.) Arlington, VA.
- Ashworth, M., Evans, C., & Clement, S. (2009). Measuring psychological outcomes after cognitive behaviour therapy in primary care: A comparison between a new patient-generated measure "PSYCHLOPS" Psychological Outcome Profiles and "HADS" Hospital Anxiety and Depression Scale. *Journal of Mental Health*, 18(2), 169–177.
- Ashworth, M., Robinson, S., Evans, C., Shepherd, M., Conolly, A., & Rowlands, G. (2007). What does an idiographic measure (PSYCHLOPS) tell us about the spectrum of psychological issues and scores on a nomothetic measure (CORE-OM)? *Primary Care and Community Psychiatry*, 12(1), 7–16.
- Ashworth, M., Robinson, S., Godfrey, E., Shepherd, M., Evans, C., Parmentier, H., & Tylee, A. (2005). Measuring mental health outcomes in primary care: The psychometric properties of a new patient-generated outcome measure, "PSYCHLOPS" ('Psychological Outcome Profiles'). *Primary Care Mental Health*, 3(4), 261–270.
- Ashworth, M., Shepherd, M., Christey, J., Matthews, V., Wright, K., Parmentier, H., ... Godfrey, E. (2004). A client-generated psychometric instrument: The development of 'PSYCHLOPS'. *Counselling and Psychotherapy Research*, 4(2), 27–31.
- Attia, E., Steinglass, J. E., Walsh, B. T., Wang, Y., Wu, P., Schreyer, C., ... & Marcus, M. D. (2019). Olanzapine versus placebo in adult outpatients with anorexia nervosa: A randomized clinical trial. *American Journal of Psychiatry*, 176(6), 449–456.

- Austin, A., Flynn, M., Shearer, J., Long, M., Allen, K., Mountford, V., ... Schmidt, U. (2021). *The First Episode Rapid Early Intervention for Eating Disorders Upscaled (FREED-Up) study: Clinical outcomes.* Manuscript submitted for publication.
- Batty, M. J., Moldavsky, M., Foroushani, P. S., Pass, S., Marriott, M., Sayal, K., & Hollis, C. (2013). Implementing routine outcome measures in child and adolescent mental health services: From present to future practice. *Child and Adolescent Mental Health*, 18(2), 82–87.
- Berg, K. C., Peterson, C. B., Frazier, P., & Crow, S. J. (2012). Psychometric evaluation of the eating disorder examination and eating disorder examination-questionnaire: A systematic review of the literature. *International Journal of Eating Disorders*, 45(3), 428–438.
- Black, N. (2013). Patient reported outcome measures could help transform healthcare. *BMJ*, 346, f167.
- Bohn, K., & Fairburn, C. G. (2008). The Clinical Impairment Assessment Questionnaire (CIA 3.0). In C. G. Fairburn (Ed.), Cognitive behavior therapy and eating disorders (pp. 315–318). New York: Guilford Press.
- BuddeAkko, D. P. H. E., & AinamiMurillo-Rodriguez, E. R. W. (2018). The impact of an exercise training intervention on cortisol levels and post-traumatic stress disorder in Congolese refugees: Study protocol for a randomized control trial. *Trials*, *19*(1), 364.
- Cohen, J. (1988). Statistical power analysis for the behavioural science (2nd ed.). Academic Press.
- Cronbach, L. J. (1951). Coefficient alpha and the internal structure of tests. *Psychometrika*, 16, 297–334.
- Czachowski, S., Seed, P., Schofield, P., & Ashworth, M. (2011). Measuring psychological change during cognitive behaviour therapy in primary care: A polish study using "PSYCHLOPS" (Psychological Outcome Profiles). *PloS One*, 6(12), e27378.
- Dancey, C. P., & Reidy, J. (2007). Statistics without maths for psychology. Pearson.
- Dawson, J., Doll, H., Fitzpatrick, R., Jenkinson, C., & Carr, A. J. (2010). Routine use of patient reported outcome measures in healthcare settings. *BMJ*, 340, c186.
- Evans, C., Connell, J., Barkham, M., Margison, F., McGrath, G., Mellor-Clark, J., & Audin, K. (2002). Towards a standardised brief outcome measure: Psychometric properties and utility of the CORE-OM. *British Journal of Psychiatry*, *180*(1), 51–60.
- Fairburn, C. G., & Beglin, S. J. (1994). Assessment of eating disorders: Interview or self-report questionnaire? *International Journal of Eating Disorders*, 16(4), 363–370.
- Fairburn, C. G., Cooper, Z., & O'Connor, M. (2008). Eating Disorder Examination (EDE-Q 6.0). In C. G. Fairburn (Ed.), *Cognitive behavior therapy and eating disorders* (pp. 309–315). New York: Guilford Press.
- Flynn, M., Austin, A., Lang, K., Allen, K., Bassi, R., Brady, G., ... Schmidt, U. (2020). Assessing the impact of First Episode Rapid Early Intervention In Eating Disorders (FREED) on duration of untreated eating disorder: A multi-centre quasi-experimental study. *European Eating Disorders Review*. https://doi.org/10.1002/erv.2797 Advanced online publication
- Goldschen, L., Lundblad, W., Fertig, A. M., Auster, L. S., Schwarzbach, H. L., & Chang, J. C. (2019). Navigating the university transition among women who self-report an eating disorder: A qualitative study. *International Journal of Eating Disorders*, 52(7), 795–800.

- Goel, N. J., Sadeh-Sharvit, S., Trockel, M., Flatt, R. E., Fitzsimmons-Craft, E. E., Balantekin, K. N., Monterubio, G. E. ... Taylor, CB. (2020). Depression and anxiety mediate the relationship between insomnia and eating disorders in college women. *Journal of American College Health*. https://doi.org/10.1080/ 07448481.2019.1710152
- Hsieh, H. F., & Shannon, S. E. (2005). Three approaches to qualitative content analysis. Qualitative Health Research, 15(9), 1277–1288.
- Jenkins, P. E. (2013). Psychometric validation of the Clinical Impairment Assessment in a UK eating disorder service. *Eating Behaviors*, 14(2), 241–243.
- Kelly, V., Holttum, S., Evans, C., & Shepherd, M. (2012). A discourse analysis of power in relation to PSYCHLOPS (Psychological Outcome Profiles) in the context of CBT for psychosis. Counselling and Psychotherapy Research, 12(4), 247–256.
- Kroenke, K., Spitzer, R. L., & Williams, J. B. W. (2001). The PHQ-9: Validity of a brief depression severity measure. *Journal of General Internal Medicine*, 16(9), 606–613.
- Leavey, G., Vallianatou, C., Johnson-Sabine, E., Rae, S., & Gunputh, V. (2011). Psychosocial barriers to engagement with an eating disorder service: A qualitative analysis of failure to attend. *Eating Disorders*, 19(5), 425–440.
- Macdonald, A. J. D., & Fugard, A. J. B. (2015). Routine mental health outcome measurement in the UK. *International Review* of *Psychiatry*, 27(4), 306–319.
- Marsden, J., Farrell, M., Bradbury, C., Dale-Perera, A., Eastwood, B., Roxburgh, M., & Taylor, S. (2008). Development of the treatment outcomes profile. *Addiction*, *103*(9), 1450–1460.
- National Collaborating Centre for Mental Health. (2019). Adult eating disorders: Community, inpatient and Intensive Day patient care guidance for commissioners and providers. https://www.england.nhs.uk/wp-content/uploads/2019/08/aed-guidance.pdf
- Nelson, E. C., Eftimovska, E., Lind, C., Hager, A., Wasson, J. H., & Lindblad, S. (2015). Patient reported outcome measures in practice. *BMJ*, 350, g7878.
- Norman, S., Dean, S., Hansford, L., & Ford, T. (2014). Clinical practitioner's attitudes towards the use of routine outcome monitoring within child and adolescent mental health services: A qualitative study of two child and adolescent mental health services. Clinical Child Psychology and Psychiatry, 19(4), 576–596.
- Nunnally, J., & Bernstein, I. (1994). *Psychometric theory* (3rd ed.). New York, NY: McGraw-Hill.
- Potterton, R., Austin, A., Allen, K., Lawrence, V., & Schmidt, U. (2020). "I'm not a teenager, I'm 22. Why am I not able to snap out of it?" Seeking Help for an Eating Disorder During Emerging Adulthood. *Journal of Eating Disorders*, 8(46). https://doi.org/10.1186/s40337-020-00320-5
- Rapee, R. M., Oar, E. L., Johnco, C. J., Forbes, M. K., Fardouly, J., Magson, N. R., & Richardson, C. E. (2019). Adolescent development and risk for the onset of social-emotional disorders: A review and conceptual model. *Behaviour Research and Ther*apy, 132, 103501.
- Robinson, S. I., Ashworth, M., Shepherd, M., & Evans, C. (2006). In their own words: A narrative-based classification of clients' problems on an idiographic outcome measure for talking therapy in primary care. *Primary Care Mental Health*, 4.

- Sales, C. M. D., Neves, I. T. D., Alves, P. G., & Ashworth, M. (2018). Capturing and missing the patient's story through outcome measures: A thematic comparison of patient-generated items in PSYCHLOPS with CORE-OM and PHQ-9. *Health Expectations*, 21(3), 615–619.
- Serra, R., Kiekens, G., Vanderlinden, J., Vrieze, E., Auerbach, R. P., Benjet, C., ... Bruffaerts, R. (2020). Binge eating and purging in first-year college students: Prevalence, psychiatric comorbidity, and academic performance. *International Journal of Eating Disorders*, *53*(3), 339–348.
- Schmidt, U., Brown, A., McClelland, J., Glennon, D., & Mountford, V. A. (2016). Will a comprehensive, person-centered, teambased early intervention approach to first episode illness improve outcomes in eating disorders? *International Journal of Eating Disorders*, 49(4), 374–377. https://doi.org/10.1002/eat.22519
- Stice, E., Telch, C. F., & Rizvi, S. L. (2000). Development and validation of the Eating Disorder Diagnostic Scale: A brief self-report measure of anorexia, bulimia, and binge-eating disorder. *Psychological Assessment*, 12(2), 123.
- Treasure, J., Duarte, T. A., & Schmidt, U. (2020). Eating disorders. *The Lancet*, 395(10227), 899–911.
- Vitousek, K., Watson, S., & Wilson, G. T. (1998). Enhancing motivation for change in treatment-resistant eating disorders. *Clinical Psychology Review*, 18(4), 391–420.
- Wolpert, M. (2014). Uses and abuses of patient reported outcome measures (PROMs): Potential iatrogenic impact of PROMs implementation and how it can be mitigated. *Administration and Policy in Mental Health and Mental Health Services Research*, 41(2), 2014.
- Wolpert, M., Curtis-Tyler, K., & Edbrooke-Childs, J. (2016). A qualitative exploration of patient and clinician views on patient reported outcome measures in child mental health and diabetes services. Administration and Policy in Mental Health and Mental Health Services Research, 43, 309–315.
- World Medical Association. (2013). WMA Declaration of Helsinki— Ethical principles for medical research involving human subjects. 64th WMA General Assembly, Fortaleza, Brazil, October 2013.
- Zhang, X. D. (2015). Precision Medicine, Personalized Medicine, Omics and Big Data: Concepts and relationships. *Journal of Pharmacogenomics & Pharmacoproteomics*, 6(1), 1000e144.

#### SUPPORTING INFORMATION

Additional supporting information may be found online in the Supporting Information section at the end of this article.

**How to cite this article:** Austin A, Potterton R, Flynn M, et al. Exploring the use of individualised patient-reported outcome measures in eating disorders: Validation of the Psychological Outcome Profiles. *Eur Eat Disorders Rev.* 2020;1–11. <a href="https://doi.org/10.1002/erv.2819">https://doi.org/10.1002/erv.2819</a>