Examining service-user perspectives for the development of a good outcome checklist for individuals at clinical high risk for psychosis

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Abstract

Aims: Around 15% of patients at clinical high risk for psychosis (CHR-P) experience symptomatic remission and functional recovery at follow-up, yet the definition of a good outcome (GO) in this population requires further development. Outcomes are typically designed and rated by clinicians rather than patients, to measure adverse as opposed to GOs. Here we investigate how CHR-P subjects define a GO, with the aim of developing a checklist that could be used to measure GO in this clinical group.

Methods: A set of GO-focused questions were designed in collaboration with a service-user. CHR-P patients (n = 48) were asked to rate the importance of items that could indicate short-term (1 year) and long-term (5 years) GO. These items were then ranked using the relative importance index (RII).

Results: Patients rated improvement in subjective wellbeing (RII = 0.829) and non-specific presenting symptoms (RII = 0.817) amongst the factors most important for indicating GO in the short-term, and improved resilience (RII = 0.879) and negative symptoms (RII = 0.858) as key items for indicating long-term GO. Patients regarded building resilience (RII = 0.842) and having support from mental health services (RII = 0.833) as being protective for their mental health. These measures were included in a preliminary 12-item GO checklist (GO-12) for assessing GO in CHR-P subjects.

Conclusions: Patient-defined measures of GO included items that are not incorporated into conventional measures of outcomes in CHR-P subjects, such as subjective wellbeing and resilience. Integrating patient-defined metrics of GO may improve the assessment of outcomes in the CHR-P population.

KEYWORDS
good outcome, relative importance index, resilience, service-user-defined outcomes, subjective wellbeing
1 | INTRODUCTION

Traditionally, clinical outcomes in individuals at clinical high risk for psychosis (CHR-P) (Fusar-Poli, 2017) have been defined with respect to transition to psychosis, however, recently, outcomes have also been described in terms of symptom remission and functional recovery (Yung & Nelson, 2013). The onset of psychosis is a clinically meaningful outcome, as it usually necessitates a change in clinical management and treatment. Similarly, if presenting symptoms improve and an individual no longer meets criteria for the CHR-P state, they may require less clinical support. Assessing functional outcome is also useful as some CHR-P subjects who do not develop psychosis continue to function poorly in comparison to the general population (Addington et al., 2011). Conversely, some CHR-P patients who become psychotic retain relatively good functioning. Therefore, level of functioning may provide a measure of disability independent of symptom-severity or transition status (Carrión et al., 2013).

Around 15% of the CHR-P population exhibit symptomatic remission at follow-up, they are not psychotic, and are functioning well (Rutigliano et al., 2016). The CHR-P group exhibit several longitudinal clinical and functional trajectories (Allswede et al., 2020; Polari et al., 2018), including outcomes such as remission and recovery. However, a standardized and well-established definition of a favourable outcome in this cohort is still in development, particularly one that incorporates multiple domains (eg, symptoms, functioning, comorbidities and personal wellbeing). We conducted a Delphi study with a panel of CHR-P expert researchers and clinicians (n = 46) to establish consensus on factors that could be used to define a ‘good outcome’ (GO), and to develop a framework for assessing GO in CHR-P patients (Petros et al., 2019). The experts defined GO in terms of a combination of clinical, functional and wellbeing metrics, consistent with the multi-faceted nature of the CHR-P state (Fusar-Poli et al., 2016). Ninety-eight items were endorsed by ≥80% of the sample, and 30 were considered significant for defining short- and long-term GO. These fell into four major domains: Functioning; Symptoms; Distress and Suicidality; and Subjective Wellbeing. A good level of daily functioning was regarded as fundamental for indicating GO, and was rated above role and social functioning, and symptom amelioration. The largest domain, containing the greatest number of GO indicators, was Subjective Wellbeing, representing personally meaningful, service-user-defined outcomes (eg, personal goal-achievement), typically regarded as features of ‘recovery’ (Jacob, 2015). This suggests that, ideally, a combination of patient and clinician-rated items should be used to evaluate GO in CHR-P patients.

Whilst conventional measures of outcome in the CHR-P population are useful, they were originally developed to determine adverse outcomes, rated by clinicians not patients. Identifying the views of patients with lived experience in outcome-focused research supports the ongoing movement towards mental health care centred on client values and preferences (Byrne, Davies, & Morrison, 2010). To our knowledge, this is the first study to explore which GOs are meaningful to the CHR-P population. The results complement data from our previous study (Petros et al., 2019) and will inform the development of a CHR-P-specific GO checklist.

2 | METHOD

CHR-P patients (n = 104) drawn from two early detection services [Outreach and Support in South London (OASIS) (South London and the Maudsley NHS Foundation Trust) (Fusar-Poli, Byrne, Badger, Valmaggia, & McGuire, 2013) and Tower Hamlets Early Detection Service (THEDS) (East London NHS Foundation Trust)] participated in the study.

2.1 | Study procedures

Ethical approval was obtained from the London—Queen Square NHS Research Ethics Committee. Potential participants received an email containing the study information sheet and a link to the online consent form and survey (implemented using Qualtrics software; Qualtrics, Provo, Utah). The survey comprised four sections: (a) demographic characteristics; (b) patients’ subjective opinions on their mental health; (c) psychometric measures to assess symptoms and functioning (see Supporting Information Material 1; Slide 2, for list of measures) and (d) GO-focused questions (see Supporting Information Material 1). Items identified as potentially relevant to GO and protective factors were drawn from our previous work (Petros et al., 2019) and presented to a service-user who assisted in the design of the GO questions and associated statements. A final open-ended question asked how protective factors could be improved to enhance mental health in young people experiencing psychological problems. Electronic medical records were reviewed to determine diagnoses, prescribed medication and psychological intervention.

2.2 | Data analysis

Data were analysed using SPSS (Version 25 IBM Corporation 2017). Demographic characteristics were described using frequencies, percentages, means and SDs. Responses for each GO indicator were analysed using the relative importance index [RII (Holt, 2014)] method, with the formula: $\text{RII} = \frac{\Sigma W}{N}$, where $W$ was the number of participants selecting each response on the Likert scale multiplied by the response point integer (ranging from 1 to 5), $A$ was the highest weight (ie, 5) and $N$ was the total number of participants. The GO indicators were ranked for importance using RII, the higher the RII value, the more important the indicator was for GO. The ranked data were then examined using percentiles. To complement the RII analysis, the cumulative percentage of endorsement for the GO indicators was calculated, a method comparable to the analysis used in Petros et al. (2019). Items were considered important indicators of GO if ≥80% of the sample ‘agreed’ or ‘strongly agreed’ with the GO statement.

The GO items were separated into domains (Table 1) that overlapped with those that emerged from our previous work (Petros et al., 2019). Domain categories were determined following independent rating (by NP, AEC and SV) with disagreements resolved by discussion. This process led to the inclusion of three additional domains
(5, 6, and 7) resulting in seven GO domains. Mean scores were calculated for each GO domain (sum of Likert responses/number of items). Domain scores and total psychometric scores were assessed for normality using histograms. Spearman’s correlation analyses were performed to examine associations between the GO and protective factor domains and between the psychometric and domain scores. Due to the exploratory nature of these analyses, statistical threshold of $P \leq .01$ was employed.

### 3 | RESULTS

#### 3.1 | Demographic and clinical characteristics

Of the 104 CHR-P patients approached, 48 (46%) participated in the study (Table 2). There were no significant differences in gender ($X^2[1] = 1.71, P = .193$); age ($U = 1221.500, P = .423$); or time receiving clinical care ($U = 1253, P = .551$) between the study participants and those who did not take part ($n = 56$).

The majority (75%) of patients reported an improvement in their mental health and wellbeing subsequent to presentation, and 83% stated that they felt better at the time of assessment. However, over half of the sample exhibited mild-to-moderate depressive symptoms, anxiety and moderate-to-severe impairment in role and social functioning, and half reported moderate-to-severe psychological distress (Table 2). The sample demonstrated low wellbeing and recovery scores, with a mean recovery score comparable to that seen in patients with chronic psychosis (Slade et al., 2015). The mean number of different psychotic-like experiences (PLEs) reported was 6.46 ($\pm 3.96$); 93.8% of patients reported at least one PLE, with 10% reporting more than 12 in the 3 months preceding assessment.

The GO indicators and protective factors were grouped into domains. Spearman’s correlations revealed inconsistencies in the relationship between the GO domains (Supporting Information Material 2); this was less true for the protective factor domains, suggesting minimal floor or ceiling effects.

#### 3.2 | Relative importance index

Items ranked in the top 25% of GO indicators and protective factors are presented (Tables 2 and 3); see Supporting Information Material 3 for RII and ranking of all GO items. Items from the Subjective Wellbeing domain were considered most important for short-term and long-term GO (Table 3); self-reported improvement in wellbeing (RII = 0.829) and resilience (RII = 0.879) ranked highest both within this domain and overall. Regarding symptomatology, improvement of non-specific presenting symptoms (RII = 0.817) was considered an important indicator of GO in the short-term, but in the long-term improvement of negative symptoms (RII = 0.858) ranked higher. In contrast, none of the items related to Functioning ranked in the top 25% of GO indicators. Items associated with Diagnoses and Medication ranked low (25th percentile) and absence of substance abuse/dependence ranked as the least important indicator of short-term GO (see Supporting Information Material 3: Table 1).

Patients indicated that items within the Subjective Wellbeing domain were most protective of their mental health; they also considered support from mental health services as having a vital influence on their improvement (Table 4). Some patients expressed how they thought protective factors could be improved to enhance mental health and wellbeing (see Supporting Information Material 4).

Items that appeared in the top 25% of GO indicators and protective factors using the RII method overlapped with those rated as important by $\geq 80\%$ of the sample, when using the same analysis strategy employed in Petros et al. (2019) (see Supporting Information Material 5). This indicates consistency across the two different analytical strategies.

| Table 1 | Good outcome and protective factor domains |
|---------|------------------------------------------|
| 1       | Functioning                               |
| 2       | Symptoms                                 |
| 3       | Distress and suicidality                 |
| 4       | Subjective wellbeing                     |
| 5       | Other clinically relevant factors         |
| 6       | Insight                                  |
| 7       | Diagnoses and medication                 |
| 1       | Community support                         |
| 2       | Mental health services support            |
| 3       | Cognitive factors                        |
| 4       | Subjective wellbeing                     |
| 5       | Social network and support               |
| 6       | Daily living factors                     |
| 7       | Premorbid factors                        |

#### 3.3 | GO domain scores

Patients were given a score for each GO domain (mean response on indicators of short-term and long-term GO) and each protective factor domain. Correlational analyses (see Supporting Information Material 6) indicated a negative relationship between scores on the Functioning domain and depressive symptoms ($r_s = -0.37, P = .010$) and psychological distress ($r_s = -0.37, P = .009$). However, wellbeing ($r_s = 0.46, P = .001$) was positively associated with scores on the Functioning domain and with scores on the protective factor domain Subjective Wellbeing ($r_s = -0.39, P = .006$), whilst scores on this latter domain were negatively associated with symptoms of anxiety ($r_s = -0.38, P = .007$).
| Item                                    | Measure                                                                 | Figure                                      |
|-----------------------------------------|-------------------------------------------------------------------------|---------------------------------------------|
| Gender                                  | Female                                                                  | n = 25                                      |
|                                         | Male                                                                    | n = 23                                      |
| Age                                     | Years                                                                   | 23.1 (±4.8)                                 |
| Ethnicity                               | Caucasian                                                               | n = 24                                      |
|                                         | Black                                                                   | n = 13                                      |
|                                         | Asian                                                                   | n = 7                                       |
|                                         | Mixed-race                                                              | n = 3                                       |
|                                         | Latino                                                                  | n = 1                                       |
| Employment status                       | Currently working                                                       | n = 29 (45% full-time)                      |
| Education status                        | Currently studying                                                      | n = 21 (71% full-time)                      |
| Current education level                 | College                                                                 | n = 8                                       |
|                                         | Undergraduate degree level                                              | n = 10                                      |
|                                         | Masters’ degree level                                                  | n = 1                                       |
|                                         | Other not specified                                                     | n = 2                                       |
| Highest level of education achieved     | Secondary school                                                       | n = 3                                       |
|                                         | College level                                                           | n = 11                                      |
|                                         | Undergraduate degree level                                              | n = 9                                       |
|                                         | Masters’ degree level                                                  | n = 1                                       |
|                                         | Missing                                                                 | n = 23                                      |
| Time receiving CARE from CHR-P service  | Months                                                                  | 11.1 (±8.6)                                 |
| CHR-P subgroup                          | Attenuated psychotic symptom (APS) group                                | n = 44                                      |
|                                         | Genetic risk and deterioration (GRD) group                              | n = 7                                       |
|                                         | Brief and limited intermittent psychotic symptom (BLIPS) group           | n = 2                                       |
| Diagnostic categories                   | None                                                                    | n = 8                                       |
|                                         | Mental disorder, not otherwise specified                                | n = 30                                      |
|                                         | Neurotic, stress-related and somatoform disorders                       | n = 13                                      |
|                                         | Schizophrenia, schizotypal and delusional disorders                     | n = 7                                       |
|                                         | Mood (affective) disorders                                              | n = 4                                       |
|                                         | Person with feared complaint in whom no diagnosis is made               | n = 4                                       |
|                                         | Mental and behavioural disorders due to psychoactive substance use       | n = 2                                       |
|                                         | Disorders of psychological development                                  | n = 1                                       |
|                                         | Behavioural and emotional disorders with onset in childhood and adolescence | n = 1                                      |
| Psychological intervention received from current care team | Yes                                                                    | n = 35                                      |
|                                         | No                                                                      | n = 11                                      |
|                                         | Missing                                                                 | n = 2                                       |
| Medication prescribed                   | None                                                                    | n = 27                                      |
|                                         | Anti-depressants                                                        | n = 17                                      |
|                                         | Tranquillizers                                                          | n = 5                                       |
|                                         | Anti-psychotics                                                        | n = 2                                       |
| Frequency of psychotic-like experiences (PLEs) | Community Assessment of Psychotic Experiences-Positive Scale-15: CAPE-15 (Capra, Kavanagh, Hides, & Scott, 2013) | 9.10 (±7.03)                                 |
| Distress associated with PLEs           |                                                                         | 9.78 (±7.61)                                 |
| Depressive symptoms                     | Quick Inventory of Depressive Symptomology: QIDS (Rush et al., 2003)     | 10.73 (±5.80)                               |

(Continues)
In line with initiatives to involve individuals with lived experience in outcome-focused clinical research (Byrne et al., 2010; Neil et al., 2009), we examined which GOs are meaningful to CHR-P patients. For our sample, improvements in wellbeing and resilience were particularly important for indicating short-term and long-term GO, beyond indices of clinical and functional status. The findings complement our previous work showing that CHR-P experts value the integration of patient perspectives, when assessing outcome (Petros et al., 2019). However, improved functioning and symptomatic remission, two outcomes typically assessed in clinical and research settings and considered important for...
by experts (Petros et al., 2019), were not ranked highly by patients. Improvement of non-specific and negative symptoms were deemed important. We have used data from our two investigations to develop a CHR-P-specific GO checklist.

Both CHR-P patients and professionals (Petros et al., 2019) regarded factors relating to Subjective Wellbeing as important for indicating GO. Such items have been linked to recovery (Jacob, 2015) in patients with established psychosis (Slade & Hayward, 2007). In the present study, patients indicated that learning from the experience of mental health problems was crucial to indicating short-term GO. This notion of growth post-adversity is an inherent feature of resilience (Fletcher & Sarkar, 2013), a construct rated by our sample as being critical for long-term GO. Resilience can be seen as a process of adaptation in the face of adversity (Bonanno, 2004), and likely plays a role in enabling people to maintain wellbeing despite susceptibility to mental illness. There are few CHR-P studies on resilience, however, findings suggest that low baseline resilience is associated with poor psycho-social functioning and transition to psychosis (Kim et al., 2013).

To enhance mental wellbeing and functioning in the CHR-P population, psychological interventions could be developed to promote resilience, in addition to reducing symptoms, our patients supported this notion by rating protective factors highly if they centred on self-reliance and personal strength (eg, self-efficacy/agency). A good working alliance with psychiatric services was also considered important for fostering GO. This finding supports research indicating a link between established therapeutic relationships and service engagement in early-psychosis patients (Browne, Nagendra, Kurtz, Berry, & Penn, 2019; Lecomte et al., 2008), which may set the foundation for successful clinical intervention (Svensson & Hansson, 1999). Surprisingly, support from friends/family was not considered essential for GO by the sample, despite being a known protective factor for common mental disorders (Smyth, Siriwardhana, Hotopf, & Hatch, 2015), and being associated with better functioning in psychosis patients (Prueßner, Iyer, Faridi, Joober, & Malla, 2011).

A reduction in distress and fear associated with symptoms was considered important for indicating short-term GO by the sample and was rated higher than symptom reduction and remission, consistent with evidence that distress, not attenuated psychotic symptoms (APS), motivates CHR-P patients to seek professional help (Falkenberg et al., 2015). Improvement of ‘non-specific’ presenting symptoms was rated highly for short-term GO: however, responses were dependent on what patients believed their presenting symptoms were (ie, psychotic or features of comorbid axis I disorders). Comorbidities are common in CHR-P patients (Addington et al., 2017), therefore, we asked about APS explicitly. We could not exclude the possibility that patients did not believe their symptoms were psychotic, thus, the item on presenting symptoms was included to capture opinion on what prompted their help-seeking, without being too prescriptive. These ‘non-specific’ symptoms could have been viewed as psychotic by some patients, whilst for others they may have been viewed as mood- or anxiety-related.

Negative symptom amelioration was deemed important for long-term GO by the sample, as we previously found in professionals (Petros et al., 2019). This suggests that negative symptoms should be given greater priority in the assessment and monitoring of CHR-P patients, particularly as they are associated with psycho-social dysfunction (Kim et al., 2013) and poor outcome (Salokangas et al., 2014). Furthermore, negative symptoms are associated with poor resilience in CHR-P patients (Marulanda & Addington, 2016), and could impact the development of secure interpersonal relationships, a key ingredient for building and maintaining resilience (Bretherton, 1996).

The sample did not consider good functioning (daily, social or role) as being highly important for indicating GO, unlike the professionals (Petros et al., 2019), moreover, good functioning was considered less

| Protective factor | Relative importance index | Overall ranking | Domain ranking (no. of rankings within domain) |
|-------------------|---------------------------|-----------------|-----------------------------------------------|
| Resilienceα       | 0.842                     | 1               | 4 (9)                                         |
| Access to psychotherapy/confidential support where one can disclose and process traumaα | 0.833 | 2 | 2 (5) |
| Ability to seek professional psychiatric support when neededα | 0.825 | 3 | 4 (9) |
| Self-compassionα  | 0.821                     | 4               | 4 (9)                                         |
| Self-efficacy     | 0.813                     | 5               | 4 (9)                                         |
| Sense of agency and control | 0.796 | 6 | 4 (9) |
| Hope/positive future thinking | 0.792 | 7 | 4 (9) |
| Strong relationship with care team | 0.792 | 7 | 2 (5) |
| Lack of self-stigma | 0.779 | 8 | 4 (9) |
| Cognitive reserve | 0.767                     | 9               | 3 (4)                                         |

αTop 10%.
important in the more symptomatic patients (e.g., more depressed). Our findings are inconsistent with reports that functioning may be a better indicator of CHR-P outcome than symptomatic status (Brandizzi et al., 2015; Carrion et al., 2013). It is important to note that the overall result could be a reflection of symptom-severity within the group. Depressed mood in CHR-P patients has been linked to motivational deficits, particularly in relation to anticipatory pleasure (Schlosser et al., 2014), which could lead to social isolation and avoidance of vocational goals. Therefore, the low ratings for 'good functioning' as a GO indicator could signify difficulties in symptom-related motivation in our sample, which also exhibited poor functioning.

4.1 | CHR-P GO checklist: Design, rating and utilization

At present the method for assessing GO in CHR-P patients requires further development; we extended our initial framework (Petros et al., 2019) based on professional-expert views to create a preliminary GO checklist that also includes patient-selected items (see Supporting Information Material 7). These items correspond to the four original GO-framework domains: (a) Functioning; (b) Symptoms; (c) Distress and Suicidality; (d) Subjective Wellbeing, with key changes appearing in the last two domains. For the new checklist, we retained these domains, keeping only three items from each (see Figure 1). The GO checklist contains 12 items (GO-12) and is presented as a chart, as inspired by the International Consortium for Health Outcomes Measurement [(ICHOM), https://www.ichom.org]

The GO-12 incorporates items identified in our previous (Petros et al., 2019) and current work as being important to CHR-P professionals and patients. We have included items related to functioning based upon the high ratings given by CHR-P experts and in light of evidence suggesting the importance of functioning as an outcome indicator (Brandizzi et al., 2015; Carrion et al., 2013). Some symptom-related items were split between short-term (<1 year) and long-term (>1 year) GO, negative and positive symptoms were included, with focus on amelioration in the short-term and remission in the long-term. Improvement of presenting symptoms would be difficult to measure reliably, as these symptoms are 'non-specific' and different for each patient, therefore could be assessed qualitatively. A reduction in distress associated with symptoms was important to both groups and a reduction in fear of symptoms was deemed essential to patients. Resilience was one of the most important indicators of GO to patients and is linked to tolerance to stress; an item rated highly by professionals (Petros et al., 2019).

The scoring system of the GO-12 checklist was inspired by the Historical-Clinical-Risk Management-20, Version 3 (HCR-20V3) (Douglas, 2014), a comprehensive risk assessment used in adult forensic settings. The aim is for each GO-12 item to be scored based upon presence, with a higher total score indicating better outcome. The checklist employs a simple, yet comprehensive design, allowing for integration into routine assessment using data from clinician-rated tools and patient-reported outcome measures. For the checklist to be universal and accessible, data collection methods are not restricted to specific instruments or parameters. Several widely used instruments that have demonstrated validity and reliability in the CHR-P

FIGURE 1  The good outcome 12-item (GO-12) checklist for patients at clinical high risk for psychosis
population could be used to determine GO for each item. For example, the Comprehensive Assessment of At-Risk Mental State (Yung, Phillips, Yuen, & McGorry, 2006; Social and Occupational Functioning Assessment Scale (Goldman, Skodol, & Lave, 1992) and Resilience Scale for Adults (Friborg, Hjemdal, Rosenvinge, & Martinussen, 2003) could be used to assess symptoms, functioning and resilience, respectively. The next phase of our work will involve assessing the validity and reliability of the GO-12 using pre-existing datasets and assessing the feasibility of scoring the GO-12 using data collected by different instruments.

A major limitation of this study was the modest sample size; however, the number of patients involved matched the number of professionals that participated in our previous study. Participants were self-selected, this was a potential source of bias, however, those who participated were demographically similar to those who did not. A further bias relates to treatment experience, most of the participants had received psychological intervention from their care team (Table 2), therefore, it is possible that specific items, for example, ‘access to psychotherapy’ may not have ranked as highly in a medication-only or no-treatment sample. The cross-sectional design of the study precluded a longitudinal assessment of the stability of the patients’ views, which may have differed pre- and post-clinical intervention.

This is the first study to examine GO in the CHR-P group from the perspective of the patients and to develop a checklist that can be used to assess GO. Our findings indicated that CHR-P patients have differing views on what constitutes a GO compared to professionals, suggesting that a collaborative effort is key to the development of measures that assess outcomes in this population.

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AUTHOR CONTRIBUTIONS

Natalia Petros, Georgina King and Wing See Leung recruited patients onto the study. Natalia Petros conducted the quantitative analysis and wrote the draft manuscript. Natalia Petros, Alexis E. Cullen and Sandra Vieira determined the domain categories and the items included. All authors were involved in the design of the study and revised and approved the final version of the manuscript. A CHR-P service-user was involved in designing the GO questionnaire that was implemented to elicit patient views, we would like to take this opportunity to thank this individual for their time and valuable contribution to the study.

DATA AVAILABILITY STATEMENT

Data sharing is not applicable to this article as no new data were created or analyzed in this study.

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