

# SEQUenCE: a service user-centred quality of care instrument for mental health services

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## **Abstract**

**Objective:** To develop a quality of care instrument that is grounded in the service user perspective and validate it in a mental health service.

**Design:** The instrument (SEQUenCE (SErvice user QUality of CarE)) was developed through analysis of focus group data and clinical practice guidelines, and refined through field-testing and psychometric analyses.

**Setting:** All participants were attending an independent mental health service in Ireland.

**Participants:** Participants had a diagnosis of bipolar affective disorder (BPAD) or a psychotic disorder.

**Intervention(s):** Twenty-nine service users participated in 6 focus group interviews.

Seventy-one service users participated in field-testing: 10 judged the face validity of an initial 61-item instrument; 28 completed a revised 52-item instrument from which 12 items were removed following test-retest and convergent validity analyses; 33 completed the resulting 40-item instrument.

**Main Outcome Measures:** Test-retest reliability, internal consistency and convergent validity of the instrument.

**Results:** The final instrument showed acceptable test-retest reliability at 5-7 days ( $r=.65$ ;  $p<.001$ ), good convergent validity with the Verona Service Satisfaction Scale ( $r=.84$ ,  $p<.001$ ), and good internal consistency (Cronbach's  $\alpha=.87$ ).

**Conclusions:** SEQUenCE is a valid, reliable scale that is grounded in the service user perspective and suitable for routine use. It may serve as a useful tool in individual care planning, service evaluation and research. The instrument was developed and validated with

service users with a diagnosis of either BPAD or a psychotic disorder; it does not yet have established external validity for other diagnostic groups.

**Keywords:** Patient-Centred Care, Patient Satisfaction, Healthcare Quality Improvement, Mental Health, Health Services Research

## INTRODUCTION

The Recovery Model of mental health care emphasises that service development should incorporate the expert knowledge of service users. Qualitative research into the lived experience of mental illness and recovery is one important means of exploring this knowledge. Mental health services research can better align itself with the Recovery Model through the development and utilisation of assessment tools that are grounded in the service user experience and operationalise good quality care from the perspective of the service user. These measures can be used to inform changes to care practices and service provision by evaluating the aspects of mental health care that service users believe help or hinder their recovery. They can also be used to monitor a service's progress in improving care in line with service users' preferences.

Many quality of care assessments neglect the service user perspective.(1) The quality of mental health services has commonly been assessed by examining how well their practices correspond to a set of clinical practice guidelines (CPGs).(2, 3) CPGs provide a consensus clinical perspective on what constitutes good care based on the best available evidence but have been criticised for not according adequate importance to service user preferences.(4) The UK National Institute for Health and Clinical Excellence has broadened the definition of "quality" in its guidelines(5, 6) to take account of the service user experience. However, many guidelines, and thus the quality of care studies utilising them, do not adequately explore preference-related evidence.(1, 7, 8)

Unlike conventional quality of care studies, patient satisfaction studies generally collect data directly from healthcare users in order to evaluate services. While there is an abundance of patient satisfaction surveys, some specific to mental health care settings, few have strong or

well-described psychometric properties.(9) Furthermore, satisfaction surveys often consist of questions that reflect managerial concerns; marginalising service users' perspectives on what matters in care means that many satisfaction surveys are not primarily user-centred.(10) Therefore patient satisfaction is not interchangeable with quality of care from the user's perspective.(11) Measuring reported satisfaction with aspects of a service is quite different to exploring which aspects service users believe are important for recovery and the extent to which they believe a service is delivering on these aspects.(12) In short, a patient can be reasonably satisfied with a service without believing it to be of a very high quality..

Instruments that attempt to incorporate the service user perspective often provide inadequate methodological detail on the steps involved in their development.(13) This study identified this shortcoming in the literature and sought to improve on existing quality of care scales for mental health services by providing a thorough overview of the item generation and field-testing processes. This methodological transparency is intended to bolster the credibility of the resulting instrument as a service user-centred tool and inform other researchers seeking to similarly incorporate the perspectives of service users in novel instruments. Our approach involved qualitative analysis of focus group data and CPGs, followed by psychometric assessment and refinement of the resulting quality of care instrument. We focused on two diagnostic categories during this process: bipolar affective disorder (BPAD) and psychotic disorder.(14) Service users with these diagnoses tend to have extensive and repeated contact with mental health services. These conditions were selected on the grounds that both tend to be viewed as 'chronic' in nature and are associated with extensive stigma.

A gap in the literature exists for a service user-centred instrument suitable for use in mental health services. Existing tools fall short, being too lengthy or difficult to administer,(15) only

partially service user-centred,(13, 16), not adequately tested psychometrically,(17) developed with a focus on satisfaction rather than quality,(18) or examining only one aspect of inpatient care.(19) By addressing these issues, the SEQUenCE will be the first instrument to bridge this gap . Thus, the aim of this study was to develop and validate a brief, service user-centred, English-language instrument (SEQUenCE (SErvice user QUality of CarE)) that can be routinely used to assess quality of care in mental health services.

## **METHODS**

All participants were inpatients or outpatients of an independent mental health service in Dublin, Ireland, with a nationwide catchment area. Potential participants were identified through a review of medical charts or referral from a member of a treating team. Eligible service users were aged 18 or older, had a diagnosis of bipolar affective disorder (BPAD) (International Classification of Diseases (ICD)-10: F31) or a psychotic disorder (ICD-10: F20, 22, 25, 28, 29)(14) from a consultant psychiatrist of at least six months standing, and gave informed consent. Inpatients were required to have been admitted to hospital at least two weeks prior to their participation date to ensure sufficient exposure to the service and the hospital environment. Study exclusion criteria were: current involuntary status; diagnosis of a personality disorder; diagnosis of a primary substance abuse disorder; or diagnosis of moderate to severe cognitive impairment.

There were two key phases in the development of the SEQUenCE (Figure 1).

**[Insert Figure 1]**

### **Phase 1: Item generation: Focus group data**

Six group interviews were held, involving 29 participants. Two researchers facilitated the groups. This included one researcher with self-experience of mental health services, thus helping to ensure that all aspects of care covered by the SEQUenCE, and all information yielded by focus groups had value for service users. The format of the focus groups was largely unstructured in order to increase the validity of the data and limit the distortion of participants' lived experiences. To avoid imposing the researcher's preconceived ideas on the topic, participants were asked to give their opinions on what constitutes good quality mental health care as well as on the aspects of care that hinder recovery through a series of non-

directive probes (e.g., “Was there anything any of you found particularly helpful or unhelpful in your care?”).

The analysis process was based on Braun and Clarke’s framework for thematic analysis.(20) The final coding framework was iteratively refined to ensure groundedness and comprehensiveness. This involved deleting any codes which: i) were covered in a similar or more general code, ii) did not pertain to quality of care, iii) were poorly grounded across the groups, or iv) were grounded in data too ambiguous to allow for the construction of a questionnaire item. For each code, a corresponding questionnaire item was created. A detailed description of the conduct, analysis and findings of the focus groups are described elsewhere.(21)

### **Phase 1: Item generation: Clinical practice guidelines**

*The National Institute for Health and Care Excellence (NICE)* and the American Psychiatric Association (APA) clinical practice guidelines for schizophrenia and BPAD were selected due to their widespread use in a number of different health care systems.(5, 6, 22, 23) The key recommendations and executive summaries of each set of CPGs were analysed inductively by two of the researchers using an iterative process to exclude codes which were: i) covered in a similar or more general code, ii) too general or ambiguous to form the basis of a meaningful item, iii) too specific to be applicable to the majority of service users, or iv) not related to mental health care. For each code, a corresponding questionnaire item was created.

### **Phase 1: Item generation: Amalgamation of focus group and CPG derived items**

Questionnaire items derived from analysis of focus group data and CPGs were compared. To refine the instrument before field-testing, ostensibly similar items were either modified or



merged and any unique CPG-derived items grounded in two or fewer guidelines or adequately covered in a more general item were removed. One of these items, related to individual care planning, was retained despite being grounded in two or fewer guidelines because neither set of CPGs was specific to Ireland, and Irish regulatory authorities define individual care planning as a core component of good quality care.(24)

## **Phase 2: Field-testing: Face validity and acceptability assessment**

In order to assess the acceptability and face validity of the SEQUenCE, participants rated the importance of each item as a component of good quality mental health care on a 5-point likert scale (ranging from *unimportant* to *very important*). Items that did not meet the mean threshold of 4 (*important*) were removed. Participants were also asked standardised questions about the layout, ease of understanding and comprehensiveness of the instrument.

## **Phase 2: Field-testing: Test-retest reliability, convergent validity, and internal consistency assessment**

Further field-testing of the resultant instrument involved an iterative process of validity and reliability assessment, and removal or adjustment of problematic/redundant items. For the purpose of measuring test-retest reliability and internal consistency, participants completed the SEQUenCE on two occasions, 5-7 days apart. They indicated whether they agreed or disagreed (on a 5-point likert scale) with each quality of care item with reference to their experiences of the mental health service during the preceding 12-month period. To assess convergent validity, participants also completed the Verona Service Satisfaction Scale – European Version for Patients (VSSS-EU). The rationale for using this tool was that as most previous satisfaction instruments have demonstrated weak reliability and validity, (9) the VSSS-EU was the first validated, multi-dimensional tool which assessed patient satisfaction in mental health services.(25) Although service user satisfaction is not interchangeable with quality of care, this 63-item scale is a reliable, well-established measure of service satisfaction for use in mental health settings and so is the most suitable of the available measures.(25) Internal consistency was measured using Cronbach's alpha. Items were removed during this process because they: a) overlapped in meaning with another item; b) were ambiguous or vague; c) were difficult for service users to understand; or d) showed poor

test-retest reliability. The order of items was also changed to better disperse longer, negatively phrased and conceptually related items.

### **Statistical analyses**

Convergent validity was assessed by examining the correlation (Spearman's rank correlation coefficient or Pearson's  $r$ ) between participants' scores on the quality of care instrument and the VSSS-EU. Pearson's  $r$  was also used to assess test-retest reliability by comparing the quality of care instrument scores at both time points. To calculate internal consistency, missing data were imputed using an Expectation-Maximisation single algorithm and Cronbach's alpha was measured. To determine differences between subgroups we used independent t-tests.

## **RESULTS**

The characteristics of participants who took part in each stage of the development of the SEQUenCE are presented in Table 1.

**[Insert Table 1 here].**

### **Item generation**

Forty-one items were generated from analysis of focus group data. Forty-one items were generated from analysis of CPGs. Amalgamation reduced the total number of items to 70. Nine items unique to CPGs were deleted, resulting in a 61-item instrument for field-testing.

### **Acceptability and face validity testing**

The preliminary 61-item SEQUenCE was tested for acceptability and face validity. Participants (n=10) found the vast majority of items easy to understand and all items were perceived as at least ‘moderately important’ components of good quality mental health care (i.e. received a mean score of  $\geq 3$  on the 5-point likert scale). Nine items that did not reach the mean threshold of 4 were removed, resulting in a 52-item version of the instrument.

### **Test-retest reliability, convergent validity, and internal consistency assessment**

The 52-item SEQUenCE was further refined following subsequent reliability and validity field-testing, resulting in the final 40-item SEQUenCE. Convergent validity was good for the both the 52-item SEQUenCE (n=27,  $r_s=.83$ ,  $p<.001$ ) and for the final 40-item SEQUenCE (n=33,  $r=.84$ ,  $p<.001$ ). Test-retest reliability was good for the 52-item instrument (n=14,  $r=.80$ ,  $p<.001$ ) and fair for the 40-item instrument (n=29,  $r=.65$ ,  $p<.001$ ).

The percentage of missing data was low for the 52-item SEQUenCE (1.5%) and very low for the 40-item SEQUenCE (0.3%). After imputation of missing data, using the Expectation–

maximization algorithm, the 52-item SEQUenCE had very high internal consistency (n=28, Cronbach's alpha = 0.96), possibly indicative of redundancy,(26) with 24 inter-item correlations of greater than .8 identified. Cronbach's alpha was good (n=33,  $\alpha$ = 0.87) for the final 40-item SEQUenCE; furthermore, no two items had a correlation score of greater than 0.8 (with one exception,  $r=.81$ ; *Staff treat me with respect* and *The physical environment of this service has a positive impact on my well-being*), indicating that items elicited unique information.(26)

### **Perceptions of quality of care**

No differences in satisfaction or quality of care scores by diagnosis, age or sex were observed between subgroups (Table 2). Overall, mean scores on both instruments were relatively high and showed limited variability.

**[Insert Table 2].**

Of the 40 SEQUenCE items, those with the highest and lowest median scores are illustrated in Table 3. The lowest median scores were found for items relating to discharge planning and medication and for an item assessing overall treatment adequacy. The highest median score was found in response to an item gauging service users' feeling of security during their hospital stay. The final 40-item SEQUenCE had an administration time of 10-15 minutes.

**[Insert Table 3]**

## **DISCUSSION**

This paper describes the development of a self-completed questionnaire (the SEQUenCE) that measures service users' perceptions of the quality of care provided to them in a secondary mental health service setting. Items were developed using a well-described, non-directive methodology which allowed service users to define the components of care important to them that impact upon perceived quality. Field-testing results suggested that the instrument fulfils the requirements of an acceptable tool for routine assessment of care quality in a mental health setting.

We aimed to be as transparent as possible in our description of the development of our quality of care instrument, both in order to demonstrate that the process was primarily service-user centred and to provide a guide for other researchers. Field-testing confirmed that the SEQUenCE has good convergent validity (significantly correlated with mean scores on the VSSS-EU), acceptable test-retest reliability over 5-7 days, and good internal consistency. Inter-item correlations were generally low and positive, indicating minimal redundancy among the 40 items. Acceptability testing and missing data analysis indicated that the SEQUenCE was easy to understand and complete. Finally, the brevity of the instrument (10-15mins administration time) in comparison to, for example, the VSSS-EU (20-30mins)(25) is an advantage in time-pressured clinical or research settings.

The main advantage of the SEQUenCE over other quality of care tools relates to the involvement of service users at each stage of its development. In line with previous instruments, focus group data emphasized the importance of staff-patient relationship, the hospital environment, and collaborative nature of care as central to patients' conceptualizations of good quality of care. Service users acting as a major source of support

for each other within hospital and that the implementation of best practice guidelines does not necessarily improve the service users experience were novel findings from the focus groups. These findings are described in full in a previous paper.(21) The focus on patient satisfaction ratings comes at the expense of credible attempts to understand which aspects of care matter to service users.(11, 12) Knowledge of what service users consider important and unimportant to their care is crucial, as this gives satisfaction ratings a context, as well as highlighting aspects of a service that should be improved. The SEQUenCE is more clearly grounded in the service user perspective, given its primary rooting in focus group data. Moreover, it asks service users about the extent to which a service is delivering on an aspect of care, rather than about satisfaction, thus avoiding the conceptual ambiguity of satisfaction ratings.

There are a number of limitations of this study. Recruiting from an independent mental health service limited the involvement of some socio-economic groups and therefore the generalisability of findings to users of the public health system. However, the recruitment centre setting shares many of the characteristics of secondary mental health services internationally and offered the unique advantage of a nationwide-catchment area. Moreover, almost half of Irish adults have health insurance and can access independent services.(27) The instrument was developed and tested with two specific service user groups - those diagnosed with a psychotic disorder or bipolar affective disorder – known to have extensive contact with mental health services. Service users are not a homogeneous group. Both the Recovery Model and the tenets of patient-centred care emphasise personal values. Although we anticipate that many of the same components of quality of care would be important to service users in other diagnostic categories, the localisation of quality of care studies to specific diagnostic groups may be important if we wish to capture the key issues important to

these populations. Furthermore it should be acknowledged that the acceptability and face validity testing of the present instrument drew on a relatively small group of participants (n=10).

There are inherent challenges involved in moving from qualitative data to a quantitative instrument with good psychometric properties. However, in general, the SEQUenCE performed well in tests of reliability and validity. Test-retest reliability was somewhat lower for the final 40-item SEQUenCE compared to its 52-item predecessor. One possible explanation lies with the different composition of the samples used; the 52-item SEQUenCE was field-tested with a mixture of inpatients and outpatients, while the 40-item version was administered to inpatients only. One would expect to see more variability in scores of inpatients across time since they regularly encounter new and distinct phases of their treatment and care plan right throughout their hospital stay (e.g. initial assessment, medication review, group/programme attendance, discharge planning), while outpatients tend to be at a more stable phase in their interaction with services. Ideally, the SEQUenCE should be administered as close to discharge as possible, in order to ensure the service user has experience of all stages of their individual care plan.

Average quality of care scores from field-testing were quite high. We acknowledge that positively skewed service user satisfaction or quality of care scores are common in the literature and can be cause for concern with regard to instrument sensitivity.(28) However, VSSS-EU scores were similarly high, and this measure has been demonstrated to have good sensitivity as a satisfaction measure.(29) It is possible that the tendency for positive responding might be representative of the study setting itself rather than the design of the SEQUenCE. The independent service we recruited from has been recognised by the national



regulatory authority as providing a high standard of care, excellent admission and discharge processes and individual care plans, and a wide range of therapeutic services and programmes.(30)

The present findings support the reliability and validity of the SEQUenCE administered in a secondary mental health service context. Future research will explore validation of the instrument in other psychiatric settings and populations. Healthcare policy increasingly highlights user experience of care as a key variable to capture and ultimately respond to. The SEQUenCE allows services to assess how well they are meeting the needs of their service users with regard to the components of care that matter most to them. Measuring quality of care from the service user's perspective, not just satisfaction, should be a core component of future quality assessment and improvement initiatives in mental health services.

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## **COMPETING INTERESTS**

None.

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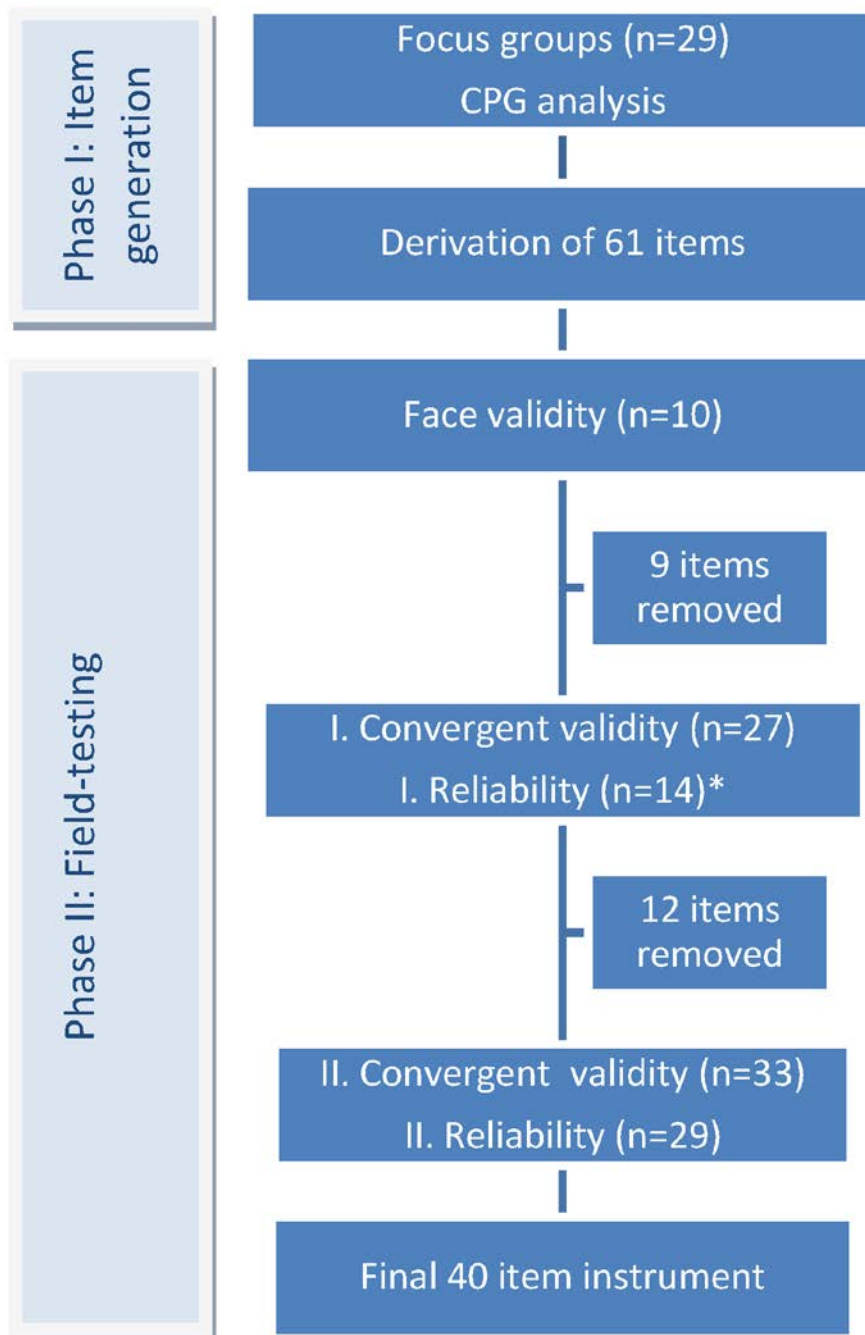
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## Figures

Figure 1: Study design and participant flow



## Tables

Table 1 Participant characteristics

Characteristic	Focus groups (n=29)*	Acceptability and face validity testing (n=10)	Construct validity and reliability field-testing (n=61)*	All (n=99)
Age range in years	22-74	26-76	18-77	18-77
Mean age in years (SD)	46.2 (14.3)	45.6 (17.5)	44.9 (15.3)	45.2 (15)
Male (n, %)	15 (51.7%)	4 (40%)	28 (45.9%)	47 (47.5%)
Diagnosis				
Psychosis (n, %)	10 (34.5%)	5 (50%)	16 (26.2%)	31 (31.3%)
BPAD (n, %)	19 (65.5%)	5 (50%)	45 (73.8%)	68 (68.7%)
Inpatient at time of participation (n, %)	21 (72.4%)	10 (100%)	51 (83.6%)	81 (81.8%)

\*one individual participated in the focus group and field-testing stages

Table 2 Service user satisfaction and perceived quality of care by diagnosis, age and sex

		VSSS-EU score Mean (SD)	Diff	Sig	SEQUenCE* score Mean (SD)	Diff	Sig
Range		1-5			1-5		
		n=60			n=33		
Diagnosis	BPAD	4.04 (0.46)	0.16	.27	3.73 (0.42)	0.04	.82
	Psychosis	3.87 (0.58)			3.69 (0.43)		



Age	<45	3.90 (0.48)	-0.21	.10	3.78 (0.42)	0.15	.34
	>45	4.10 (0.50)			3.63 (0.41)		
Sex	Male	3.94 (0.55)	-0.10	.45	3.64 (0.50)	-0.12	.46
	Female	4.04 (0.45)			3.76 (0.38)		
All		3.99 (0.50)			3.72 (0.42)		

\*only participants who completed the final 40-item instrument were included

Table 3: Highest and lowest median SEQUenCE item scores

SEQUenCE Item	Median Score
<b>Highest median score</b>	
I feel safe and protected in this service	5
<b>Lowest median score</b>	
I have discussed with staff how to access services if I become unwell in the future	3
Staff take practical steps to facilitate my transition from inpatient to outpatient care	3
Staff clearly explain to me the potential benefits and risks of medications	3
Staff closely monitor me for side effects of my medication	3
I need more treatment and care than I am currently receiving	3

**INSTRUCTIONS**

We are interested in your experiences of xxxxxx Hospital/Service during **this admission**.

Below is a list of statements about mental health care. Please mark the answer that best describes your experiences of xxxxxx Hospital/Service during this admission.

1 = Strongly Disagree, 2 = Disagree, 3 = Neither agree nor disagree, 4 = Agree, 5 = Strongly Agree

Please feel free to express your opinion, whatever it is.

**All your answers will be treated confidentially.**

		Strongly Disagree	Disagree	Neither Agree nor Disagree	Agree	Strongly Agree
1	Staff make an effort to approach and speak with me	1	2	3	4	5
2	I feel safe and protected in this service	1	2	3	4	5
3	Psychotherapy (i.e., any form of talking therapy) is available to me	1	2	3	4	5
4	I am afraid to share information with my psychiatrist	1	2	3	4	5
5	The physical environment of this service has a positive impact on my wellbeing	1	2	3	4	5
6	Staff make mistakes when dispensing my medication	1	2	3	4	5
7	My family/carers have been offered information about the nature and management of my illness	1	2	3	4	5
8	I have discussed with staff how to access services if I become unwell in the future	1	2	3	4	5
9	The atmosphere in this service is supportive and positive	1	2	3	4	5
10	It is easy to meet and interact with other service users	1	2	3	4	5
11	I have been prescribed medications that have had an excessive negative impact on my physical health	1	2	3	4	5
12	Daily life in this service is predictable and structured	1	2	3	4	5
13	Staff take the time to listen to me	1	2	3	4	5
14	I have been given information on how to recognise triggers and early warning signs of my illness	1	2	3	4	5
15	I feel I can question my psychiatrist	1	2	3	4	5
16	Staff are honest with me	1	2	3	4	5
17	I have been over-medicated to the extent that I have been unable to function	1	2	3	4	5

		Strongly Disagree	Disagree	Neither Agree nor Disagree	Agree	Strongly Agree
18	Staff treat me with respect	1	2	3	4	5
19	With the help of staff, I have developed strategies for coping with my illness	1	2	3	4	5
20	I have a keyworker (i.e., staff member allocated to me) who has a positive impact on my care	1	2	3	4	5
21	Staff share information and communicate well	1	2	3	4	5
22	Staff clearly explain to me the potential benefits and risks of medications	1	2	3	4	5
23	I am involved in decisions about my treatments and care	1	2	3	4	5
24	Staff have discussed with me how lifestyle factors (e.g., routine, sleep, exercise, activities) can influence my mental health	1	2	3	4	5
25	Staff are sincere and make an effort to understand me	1	2	3	4	5
26	My psychiatrist tries to minimise the side effects I experience from my medication	1	2	3	4	5
27	Staff closely monitor me for side effects of my medication	1	2	3	4	5
28	Unnecessary restrictions are placed on my freedom	1	2	3	4	5
29	Recreational activities in this service are varied and well-organised	1	2	3	4	5
30	Staff take practical steps to facilitate my transition from inpatient to outpatient care	1	2	3	4	5
31	I meet with my psychiatrist often enough and for long enough	1	2	3	4	5
32	I believe I am on more medications than I need	1	2	3	4	5
33	Nurses in this service spend enough time talking to patients	1	2	3	4	5
34	Staff explore, and take into account, my life circumstances	1	2	3	4	5
35	Staff evaluate any risk I might pose to myself or others	1	2	3	4	5
36	Staff support me emotionally in preparing for weekend leave and/or discharge	1	2	3	4	5
37	I need more treatment and care than I am currently receiving	1	2	3	4	5
38	I have a care plan and was involved in its creation	1	2	3	4	5

		Strongly Disagree	Disagree	Neither Agree nor Disagree	Agree	Strongly Agree
39	I have not required outpatient care from this service in the past 12 months					<input type="checkbox"/>
	OR					
	Outpatient care is easy to access (e.g., location, cost, opening hours)	1	2	3	4	5
40	I do not wish to return to work and/or education					<input type="checkbox"/>
	OR					
	I have been offered support in returning to work and/or education by this service	1	2	3	4	5