



ICHOM

International Consortium for
Health Outcomes Measurement

Psychotic Disorders
**DATA COLLECTION
REFERENCE GUIDE**

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Measuring

results

Psychotic

Disorders

that matter



We are thrilled that you are interested in measuring outcomes for your patients with psychotic disorders. It is our hope that this Reference Guide will facilitate the process of implementing this Set of Patient-Centered Outcome Measures and ensure collection of comparable data for global benchmarking and learning.

© 2022 ICHOM. All rights reserved. When using this set of outcomes, or quoting therefrom, in any way, we solely require that you always make a reference to ICHOM as the source so that this organization can continue its work to define more Sets of Patient-Centered Outcome Measures.

Please cite as follows: ICHOM Psychotic Disorders, May 2020, available at: <https://www.ichom.org/portfolio/psychotic-disorders/>

Introducing ICHOM and the Reference Guide

ICHOM brings together patient representatives, clinician leaders, and registry leaders from all over the world to develop Sets of Patient-Centered Outcome Measures, which are comprehensive yet parsimonious Sets of outcomes and case-mix variables we recommend all providers to track.

Each Set focuses on patient-centered results and provides an internationally-agreed upon method for measuring each of these outcomes. We do this because we believe that standardized outcomes measurement will open up new possibilities to compare performance globally, allow clinicians to learn from each other, and rapidly improve the care we provide our patients.

Our Sets include initial conditions and risk factors to enable meaningful case-mix adjustment globally, ensuring that comparisons of outcomes will take into account the differences in patient populations across not just providers, but also countries and regions. A comprehensive data dictionary, as well as scoring guides for patient-reported outcomes, is included in the appendix.

Our aim is to make these Sets freely accessible to healthcare institutions worldwide to begin measuring, and ultimately benchmark the outcomes they achieve. In order to have a guide from which we can benchmark outcomes, we require feedback from initial implementation efforts. As such, this Reference Guide may undergo revisions on a regular basis. If you have any suggestions or would like to provide feedback, please contact info@ichom.org.

Working Group Members for Psychotic Disorders

The following individuals dedicated both time and expertise to develop the ICHOM Set for Psychotic Disorders in partnership with ICHOM, under the leadership of Professor Donald Addington, ICHOM Set Chair. The work was supported by Emily McKenzie, ICHOM Research Fellow, Lucy Matkin and Luz Sousa Fialho, ICHOM Project Managers, and Beth Jagger, Christiana Ilesanmi, Ifeoma Nneka Emelurumonye, Shannon Quinney and Timea Gintner, ICHOM Research Associates.

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Supporting Organizations

The Psychotic Disorders Set is made possible only through the support of the following organizations.

Thank You.



Scope of the Psychotic Disorders Set of Patient-Centered Outcome Measures

For Psychotic Disorders, the following conditions and treatment approaches (or interventions) are covered by our Set.

Conditions	Schizophrenia and other psychotic disorders based on ICD-11 and DSM-5 criteria Bipolar Type I Disorder based on ICD-11
Populations	Adults aged 18 years and above and adolescents aged 12-17 years
Treatment approaches	All treatment settings and modalities
Excluded population	Children below 12 years

ICHOM Set of Patient-Centered Outcome Measures for Psychotic Disorders

Case-Mix Variables

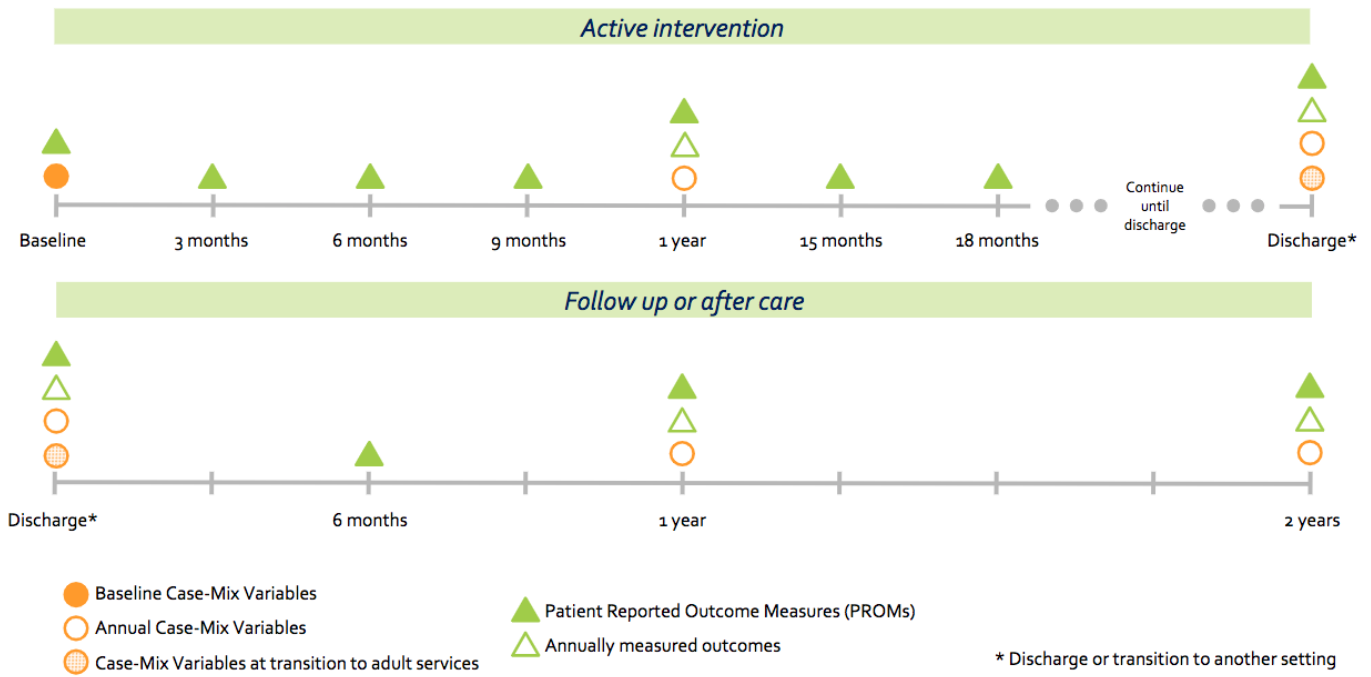
Patient Population	Measure	Timing	Data Source
Demographic factors			
All patients	Year of birth	Baseline	Clinical
	Sex		
	Gender identity		
	Sexual orientation		
	Level of Education	Baseline; Transition to adult services; Annually if still in education	Patient-reported
	Work / Education status		
	Housing status	Baseline; Annually	
	Living arrangements		
Ethnicity	Baseline		
Adult patients; Adolescent patients (where appropriate)	Contact with law enforcement	Baseline; Annually	
Clinical factors			
All patients	Comorbidities	Baseline; Annually	Patient-reported
	Hospitalisations	Baseline	Clinical
Adult patients; Adolescent patients (where appropriate)	Adverse life experiences	Baseline; Transition to adult services	Patient-reported
Intervention factors			
All patients	Intervention setting	Baseline; Annually	Clinical
	Intervention type		

Outcomes

Patient Population	Outcome	Timing	Data Source
Symptoms			
All patients	Symptoms of depression Suicidal Ideation and Behaviour Positive and Negative Symptoms	Baseline; Ongoing; Six months after discharge; Annually after discharge for two years	Patient-reported
Patients with Bipolar Type I disorder	Mania/Hypomania		
All patients	Sleep Quality Relapse Rate	Annually	Clinical
Recovery			
All patients	Personal Recovery Quality of Life	Baseline; Ongoing; Six months after discharge; Annually after discharge for two years	Patient-reported
Functioning			
All patients	Global Functioning Social Functioning Role Functioning Physical Health	Baseline; Ongoing; Six months after discharge; Annually after discharge for two years	Patient-reported
Treatment			
Patients receiving antipsychotic medication	Side Effects	Baseline; Ongoing; Six months after discharge; Annually after discharge for two years	Patient-reported

Follow-Up Algorithm

The following algorithm illustrates when the Set variables should be collected from patients and clinicians.



Collecting Patient-Reported Outcomes

Psychotic Disorders Surveys Used	Licensing Information	Scoring Information
Patient Health Questionnaire 9-item (PHQ9)	Free to use. The measure and translations are downloadable from this website and no permission is required to reproduce, translate, display or distribute them.	The scoring guide may be found at the same link.
Modified Colorado Symptom Index (MCSI)	Free to use. Measure available here .	The scoring guide may be found at the same link.
Recovering Quality of Life – 20-item version (ReQoL20)	A free license can be requested for publicly funded healthcare, individual medical practices, and users who are not funded or are funded by non-commercial entities. Licensing fees apply for commercial users. Licences are available from the Oxford University Innovation Ltd	The scoring guide may be found here .
Altman Self-Rating Mania Scale (ASRM)	Free to use. Measure available here .	The scoring guide may be found at the same link.
PROMIS Short Form v1.0 – Sleep Disturbance 4a (PROMIS-Sleep)	Respondent-ready PDFs for the instrument are available at https://www.healthmeasures.net/index.php?option=com_instruments&view=measure&id=181&Itemid=992 . These measures may be used in paper or electronic form for single use (i.e., solely for the user’s own individual clinical trial, academic research study, healthcare or clinical application, community-based or educational program, or other discrete application with a defined timeline, area of focused health measurement, and deliverables or research products) without permission or fees as long as the text is not changed.	The scoring guide may be found at the same link.
WHO Disability Assessment Schedule 2.0 – 12-item version (WHODAS12)	The WHODAS 12 can be used for non-commercial purposes following the completion of a free user agreement found at: https://www.who.int/standards/classifications/international-classification-of-functioning-disability-and-health/who-disability-assessment-schedule . The inclusion of the WHODAS 12 in an electronic records or data capture system requires a license, available at: https://www.who.int/about/policies/publishing/permissions	The scoring guide may be found here .
KIDSCREEN-10 Index (KIDSCREEN10)	For funded and non-funded academic research and non-commercial organisation research and evaluation studies (public and	The scoring guide may be found here .

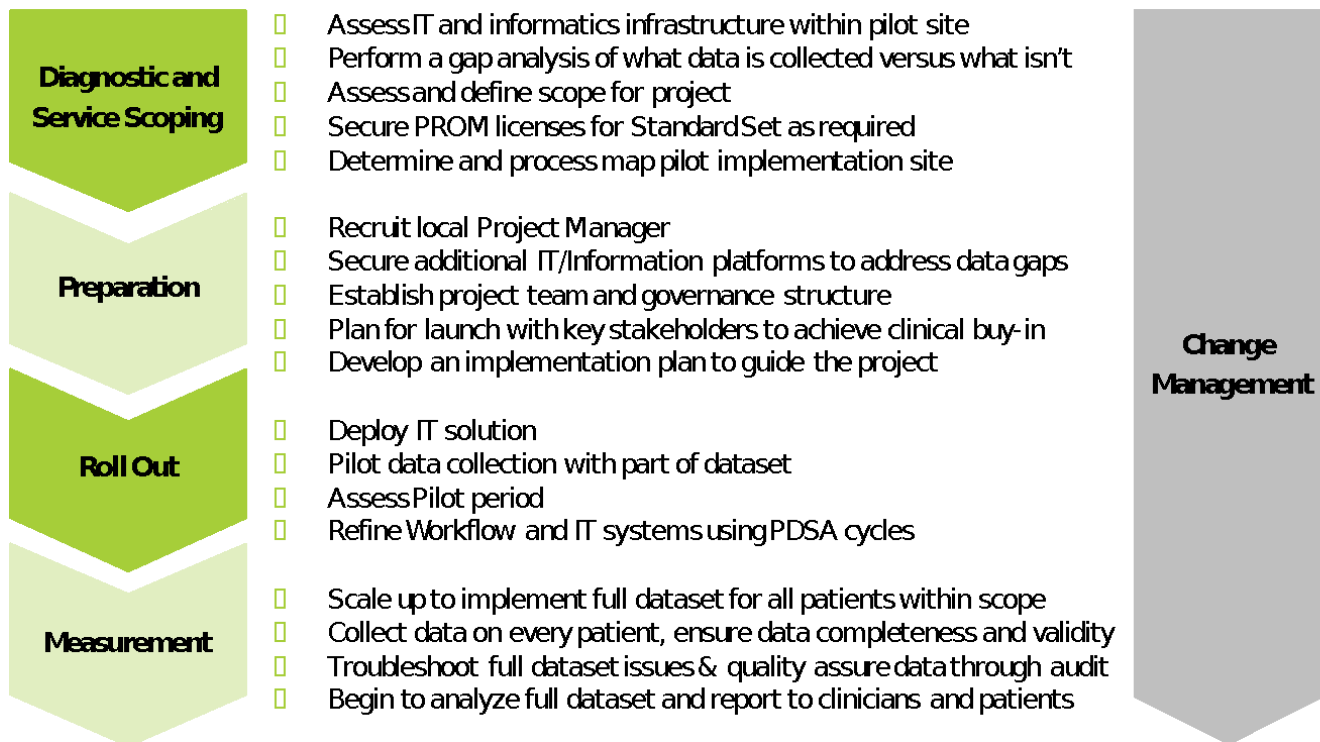
	national organisations, hospitals, healthcare centres etc.), no additional fees for usage. To use and/or translate complete this Collaboration Form .	
Patient Health Questionnaire 15-item (PHQ15)	Free to use. The measure and translations are downloadable from this website and no permission is required to reproduce, translate, display or distribute them.	The scoring guide may be found at the same link.
Glasgow Antipsychotic Side-Effect Scale (GASS)	Free to use. Measure available at: https://doi.org/10.1177%2F0269881107087976 .	The scoring guide may be found at the same link.
Modified Self-Administered Comorbidity Questionnaire (SCQ)	The SCQ is not copyrighted and a license is not needed. It may be found at: Sangha et al (2003) The self-administered comorbidity questionnaire: A new method to assess comorbidity for clinical and health services research. <i>Arthritis Care & Research</i> 49(2): 156-163	Each medical condition asks 3 questions: whether the condition is present, whether it is being treated, and whether it causes functional limitations. Each question has two possible answers of 'yes' or 'no', with 1 point attributed to every 'yes'. A maximum score of 3 is possible for each condition, generating a maximum total score of 45 points.

The Growing ICHOM Community

There is a growing community of healthcare providers implementing the Set. To support your organization in implementing the set and the measurement of outcomes data, we have outlined a framework to guide the implementation and reporting of patient-centered outcomes. All materials can be downloaded for free from ICHOM Connect, for further information or to enquire about implementation support offered by ICHOM Partners, please contact us: info@ichom.org.

Implementation framework:

The framework below, outlines the structured process to guide the implementation of an ICHOM Set at your organization. Typically, an implementation project takes 9 months to complete.



Implementation Study:

We are keen to find out if you have implemented or are implementing our Sets. Please fill in this survey: bit.ly/InitialImp or contact info@ichom.org for more information.

Translating the Set Tools:

PROMs within the ICHOM Sets are available in a number of languages. To check the availability of translations, we advise contacting the Tool authors directly to obtain and translate the PROM surveys into your desired language. To independently translate PROM surveys, we recommend following the ten steps outlined below:^{*1}

Step 1	Preparation	Initial work carried out before the translation work begins
Step 2	Forward Translation	Translation of the original language, also called source, version of the instrument into another language, often called the target language
Step 3	Reconciliation	Comparing and merging more than one forward translation into a single forward translation
Step 4	Back Translation	Translation of the new language version back into the original language
Step 5	Back Translation Review	Comparison of the back-translated versions of the instrument with the original to highlight and investigate discrepancies between the original and the reconciled translation, which is then revised in the process of resolving the issues
Step 6	Harmonization	Comparison of back translations of multiple language versions with each other and the original instrument to highlight discrepancies between the original and its derivative translations, as well as to achieve a consistent approach to translation problems
Step 7	Cognitive Debriefing	Testing the instrument on a small group of relevant patients or lay people in order to test alternative wording and to check understandability, interpretation, and cultural relevance of the translation
Step 8	Review of Cognitive Debriefing Results and Finalization	Comparison of the patients' or lay persons' interpretation of the translation with the original version to highlight and amend discrepancies
Step 9	Proofreading	Final review of the translation to highlight and correct any typographic, grammatical or other errors
Step 10	Final Report	Report written at the end of the process documenting the development of each translation

*These ten steps follow the ISPOR Principles of Good Practice: The Cross-Cultural Adaptation Process for Patient-Reported Outcome Measures¹ Wild, D., Grove, A., Martin, M., Eremenco, S., McElroy, S., Verjee-Lorenz, A., et al. (2005).

Principles of good practice for the translation and cultural adaptation process for patient-reported outcomes (PRO) measures: Report of the ISPOR task force for translation and cultural adaptation. *Value in Health*, 8(2), 94–104. doi:10.1111/j.1524-4733.2005.04054.x.

Appendix

Introduction to the Data Dictionary

This data dictionary is designed to help you measure the ICHOM Psychotic Disorders Set as consistently as possible to the Working Group recommendation. ICHOM is actively preparing for benchmarking efforts based on this data, and all data submitted for comparisons will need to be transformed into the following data structure if not already structured as such. **For technical use an Excel version of this data dictionary is also available for download on ICHOM Connect. Excel data dictionary is the most up-to-date version and it is the recommended document to plan data collection.**

Please timestamp all variables. Some Set variables are collected at multiple timepoints, and we will ask you to submit these variables in a concatenated VARIABLEID_TIMESTAMP form for future analyses. For example, VARIABLEID_BASE (baseline); VARIABLEID_6MO (6-month follow-up); VARIABLEID_1YR (1-year follow-up), etc.

Case-Mix Variables

Variable ID: N/A

Variable: Patient ID

Definition: Indicate the patient's medical record number

Supporting Definition: This number will not be shared with ICHOM. In the case patient-level data is submitted to ICHOM for benchmarking or research purposes, a separate ICHOM Patient Identifier will be created and cross-linking between the ICHOM Patient Identifier and the medical record number will only be known at the treating institution

Displayed Value: None

Inclusion Criteria: All patients

Timing: On all forms

Data Source: Clinical

Type: Numerical

Value Domain: N/A

Response Options: According to institution

Demographic Factors

Variable ID: YearOfBirth

Variable: Year of birth

Definition: Year of birth

Supporting Definition: None

Display Value: In what year were you born?

Inclusion Criteria: All patients

Timing: Baseline

Data Source: Clinical

Type: Date by DD/MM/YYYY

Value Domain: Date

Response Options: YYYY

Variable ID: Sex

Variable: Sex

Definition: The patient's sex at birth.

Supporting Definition: For statistical purposes, the following category codes, labels and definitions are preferred:

CODE 1 Male: Persons who have male or predominantly masculine biological characteristics, or male sex assigned at birth.

CODE 2 Female: Persons who have female or predominantly feminine biological characteristics, or female sex assigned at birth.

CODE 3 Other: Persons who have mixed or non-binary biological characteristics (if known), or a non-binary sex assigned at birth.

The value meaning of 'Other' has been assigned to Code 3 for this value domain, which replaces 'Intersex or indeterminate' for the superseded value domain Sex code N. Terms such as 'indeterminate,' 'intersex,' 'non-binary,' and 'unspecified' are variously used to describe the 'Other' category of sex. The label 'Other' is used because a more descriptive term has not been widely agreed within the general community.

Sex refers to the chromosomal, gonadal and anatomical characteristics associated with biological sex. Where there is an inconsistency between anatomical and chromosomal characteristics, sex is based on anatomical characteristics.

Display Value: Please indicate your sex at birth.

Inclusion Criteria: All patients

Timing: Baseline

Data Source: Clinical

Type: Single answer

Value Domain: Code

Response Options: 1 = Male
2 = Female
3 = Other
999 = Undisclosed

Variable ID: Gender

Variable: Gender identity

Definition: The patient's gender identity.

Supporting Definition: None

Display Value: Do you think of yourself as...?

Inclusion Criteria: All patients

Timing: Baseline

Data Source: Patient-reported

Type: Single answer

Value Domain: Code

Response Options: 1 = Boy/Man
2 = Girl/Woman
3 = Non-binary
4 = Trans man/Transgender man/FTM//Trans woman/Transgender woman/MTF
5 = None of these describe me, and I'd like to specify
999 = Prefer not to answer

Variable ID: SexualOrientation

Variable: Sexual orientation

Definition: The patient's sexual orientation.

Supporting Definition: None

Display Value: Do you think of yourself as...?

Inclusion Criteria: All patients

Timing: Baseline

Data Source: Patient-reported

Type: Single answer

Value Domain: Code

Response Options: 1 = Straight or heterosexual
2 = Gay or lesbian or homosexual
3 = Bisexual

4 = None of these describe me, and I'd like to specify

5 = I don't know right now

999 = Prefer not to answer

Variable ID: EducationLevel

Variable: Level of Education

Definition: Highest level of education completed based on local standard definitions of education levels

Supporting Definition: Mapping of the ICHOM definition of level of education to the level of schooling as defined by ISCED (International Standard Classification).

ICHOM mapping 'None':

Level 0: Early Childhood Education; designed with a holistic approach to support children's early cognitive, physical, social and emotional development and introduce young children to organized instruction outside of the family context to develop some of the skills needed for academic readiness and to prepare them for entry into primary education. Designed for children 0-2 years.

Level 1: Primary Education; designed to provide students with fundamental skills in reading, writing, and mathematics (i.e. literacy and numeracy) and establish a solid foundation for learning and understanding core areas of knowledge, personal and social development, in preparation for lower secondary education. Typically lasts until ages 10-12.

ICHOM mapping 'Primary':

Level 2: Lower secondary education; lays the foundation for lifelong learning and human development upon which education systems may then expand further educational opportunities. Students enter between ages 10-13 and usually finish between 14-16 years.

Level 3: Upper secondary education, designed to complete secondary education in preparation for tertiary education or provide skills relevant to employment, or both. Students usually enter between 14-16 and finish by ages 17-18.

ICHOM mapping 'Secondary':

Level 4: Post-secondary non-tertiary education; provides learning experiences building on secondary education, preparing for labour market entry as well as tertiary education. The content of level 4 programmes is not sufficiently complex to be regarded as tertiary education, although it is clearly post-secondary.

Level 5: short-cycle tertiary education; designed to provide participants with professional knowledge, skills, and competencies. Typically, they are practically-based, occupationally-specific, and prepare students to enter the labour market.

ICHOM mapping 'Tertiary':

Level 6: Bachelor's or equivalent level; often designed to provide participants with intermediate academic and/or professional knowledge, skills and competencies, leading to a first degree or equivalent qualification.

Level 7: Master's or equivalent level; designed to provide participants with advanced academic and/or professional knowledge, skills and competencies, leading to a second degree or equivalent qualification.

Level 8: Doctoral or equivalent level; designed primarily to lead to an advanced research qualification.

Display Value: Please indicate your highest level of schooling.

Inclusion Criteria: Adolescent patients – Parents

Timing: Baseline

Data Source: Patient-reported

Type: Single answer

Value Domain: Code

Response Options: 0 = None

1 = Primary

2 = Secondary

3 = Tertiary

Variable ID: EducationLevel

Variable: Level of Education

Definition: Highest level of education completed based on local standard definitions of education levels

Supporting Definition: Mapping of the ICHOM definition of level of education to the level of schooling as defined by ISCED (International Standard Classification).

ICHOM mapping 'None':

Level 0: Early Childhood Education; designed with a holistic approach to support children's early cognitive, physical, social and emotional development and introduce young children to organized instruction outside of the family context to develop some of the skills needed for academic readiness and to prepare them for entry into primary education. Designed for children 0-2 years.

Level 1: Primary Education; designed to provide students with fundamental skills in reading, writing, and mathematics (i.e. literacy and numeracy) and establish a solid foundation for learning and understanding core areas of knowledge, personal and social development, in preparation for lower secondary education. Typically lasts until ages 10-12.

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Level 7: Master's or equivalent level; designed to provide participants with advanced academic and/or professional knowledge, skills and competencies, leading to a second degree or equivalent qualification.

Level 8: Doctoral or equivalent level; designed primarily to lead to an advanced research qualification.

Display Value: Please indicate your highest level of schooling completed.

Inclusion Criteria: Adult patients

Timing: Baseline

Transition to adult services

Annually if still in education

Data Source: Patient-reported

Type: Single answer

Value Domain: Code

Response Options: 0 = None

1 = Primary

2 = Secondary

3 = Tertiary

Variable ID: WORK
Variable: Work Status
Definition: What is your work status?
Supporting Definition: None
Display Value: None
Inclusion Criteria: Adult patients
Timing: Baseline
Annually
Data Source: Patient-reported
Type: Single answer
Value Domain: Code
Response Options: 0 = Unemployed
1 = Part-time employment
2 = Full-time employment
3 = Retired

Variable ID: Work_FollowUp
Variable: Work status/ Educational status
Definition: The patient's work/educational status.
Supporting Definition: None
Display Value: What is your work/educational status?
Inclusion Criteria: All patients
Timing: Baseline
Annually
Data Source: Patient-reported
Type: Single answer
Value Domain: Code
Response Options: 0 = Unable to work due to a physical condition
1 = Unable to work due to mental health condition
2 = Not working by choice (retired, homemaker, other)
3 = Seeking employment or applying for studies (I consider myself able to work)
4 = Part-time work, volunteering, school, or vocational training
5 = Full-time work, volunteering, school, or vocational training

Variable ID: Housing_Q01
Variable: Housing status Question 1
Definition: Indicate whether the patient had stable and suitable housing status in the past month.
Supporting Definition: None
Display Value: This past month, have you had stable and suitable housing?
Inclusion Criteria: All patients
Timing: Baseline
Annually
Data Source: Patient-reported
Type: Single answer
Value Domain: Code
Response Options: 0 = No
1 = Yes

Variable ID: Housing_Q02
Variable: Housing status Question 2
Definition: Indicate whether the patient is at risk of eviction.
Supporting Definition: None
Display Value: Are you at risk of eviction?
Inclusion Criteria: All patients
Timing: Baseline

Data Source: Annually
Patient-reported
Type: Single answer
Value Domain: Code
Response Options: 0 = No
1 = Yes

Variable ID: LivingArrangements
Variable: Living arrangements
Definition: The living arrangements of the person
Supporting Definition: None
Display Value: None
Inclusion Criteria: All patients
Timing: Baseline
Annually
Data Source: Patient-reported
Type: Single answer
Value Domain: Code
Response Options: 0 = Lives alone.
1 = Lives with others.
2 = Lives in a supported home (i.e. assisted living, congregate care, skilled nursing home, etc.)
3 = Homeless

Variable ID: Race
Variable: Race
Definition: The biological race of the person
Supporting Definition: This measure should be recorded based on local standards in the particular geographic region and should be self-reported by the patient. This is an optional question but ICHOM encourages that this information is collected and is as racially and ethnically inclusive as possible. This data will help to support combating health disparities based on race but all patient data regarding race and ethnicity will be kept confidential. The patient's response will then be coded based on LOINC's standards. All patients may choose not to answer as well.
Display Value: Please indicate the biological race that you identify with
Inclusion Criteria: All patients
Timing: Baseline
Data Source: Patient-reported
Type: Single answer
Value Domain: Code
Response Options: Please report your race based on your geographic region's local standards

Variable ID: Ethnicity
Variable: Ethnicity
Definition: The cultural ethnicity of the person that they most closely identify with
Supporting Definition: This measure should be recorded based on local standards in the particular geographic region and should be self-reported by the patient. This is an optional question but ICHOM encourages that this information is collected and is as racially and ethnically inclusive as possible. This data will help to support combating health disparities based on ethnicity but all patient data regarding race and ethnicity will be kept confidential. The patient's response will then be coded based on LOINC's standards. All patients may choose not to answer as well.
Display Value: Please indicate the ethnicity that you identify with
Inclusion Criteria: All patients
Timing: Baseline

Data Source: Patient-reported
Type: Single answer
Value Domain: Code
Response Options: Please report your ethnicity based on your geographic region's local standards

Variable ID: EthnicMinority_Q1
Variable: Ethnic minority / marginalisation Question 1
Definition: Indicate whether the patient belongs to an ethnic minority.
Supporting Definition: None
Display Value: Do you consider yourself to be in an ethnic minority where you live?
Inclusion Criteria: All patients
Timing: Baseline
Data Source: Patient-reported
Type: Single answer
Value Domain: Code
Response Options: 0 = No
1 = Yes
999 = Prefer not to say

Variable ID: EthnicMinority_Q2
Variable: Ethnic minority / marginalisation Question 2
Definition: Indicate whether the patient is a member of a marginalised group.
Supporting Definition: None
Display Value: Do you consider yourself to be a member of a marginalised group where you live?
Inclusion Criteria: All patients
Timing: Baseline
Data Source: Patient-reported
Type: Single answer
Value Domain: Code
Response Options: 0 = No
1 = Yes
999 = Prefer not to say

Variable ID: CONVICTION
Variable: Contact with law enforcement
Definition: Indicate whether the patient has been convicted for an offence.
Supporting Definition: To be administered to adolescents only if and when it is deemed appropriate to do so, and for whom this measure would not cause unnecessary distress.
Baseline – ever been convicted (lifetime).
Annually – ever been convicted (in the last 12 months).
Display Value: Have you ever been convicted for an offence?
Inclusion Criteria: Adult patients
Adolescent patients (where appropriate – see supporting definition)
Timing: Baseline
Data Source: Patient-reported
Type: Single answer
Value Domain: Code
Response Options: 0 = No
1 = Yes
999 = Prefer not to say

Variable ID: CONVICTION
Variable: Contact with law enforcement
Definition: Indicate whether the patient has been convicted for an offence.
Supporting Definition: To be administered to adolescents only if and when it is deemed appropriate to do so, and for whom this measure would not cause unnecessary distress.
Baseline – ever been convicted (lifetime).
Annually – ever been convicted (in the last 12 months).

Display Value: Have you been convicted for an offence in the past 12 months?
Inclusion Criteria: Adult patients
Adolescent patients (where appropriate – see supporting definition)
Timing: Annually
Data Source: Patient-reported
Type: Single answer
Value Domain: Code
Response Options: 0 = No
1 = Yes
999 = Prefer not to say

Clinical Factors

Variable ID: ComorbiditiesSACQ
Variable: SACQ Comorbidities
Definition: Indicate whether the patient has a documented history of any of the following comorbidities
Supporting Definition: Based upon the Self-administered Comorbidity Questionnaire (Sangha et al, 2003). Phrased as a patient-reported measure, but information can be abstracted by other means if patient is unable to answer.
Displayed Value: Have you been told by a doctor that you have any of the following?
Inclusion Criteria: All patients
Timing: Baseline
Data Source: Patient-reported
Type: Multiple answer Separate multiple entries with ";"
Value Domain: Code
Response Options: 0 = I have no other diseases
1 = Heart disease (For example, angina, heart attack, or heart failure)
2 = High blood pressure
3 = Lung disease (For example, asthma, chronic bronchitis, or emphysema)
4 = Diabetes
5 = Ulcer or stomach disease
6 = Kidney disease
7 = Liver disease
8 = Anemia or other blood disease
9 = Cancer/Other cancer (within the last 5 years)
10 = Depression
11 = Osteoarthritis, degenerative arthritis
12 = Back pain
13 = Rheumatoid arthritis
14 = Other medical problems

Variable ID: ComorbiditiesSACQ_HeartDiseaseFU1
Variable: SACQ comorbidities: Heart Disease: Follow-Up Question 1
Definition: Please indicate if the patient receives treatment for Heart disease (For example, angina, heart attack, or heart failure)
Supporting Definition: Based upon the Self-administered Comorbidity Questionnaire (Sangha et al, 2003). Phrased as a patient-reported measure, but information can be abstracted by other means if patient is unable to answer.
Displayed Value: Do you receive treatment for heart disease (For example, angina, heart failure, or heart attack)?
Inclusion Criteria: If answered 1= Heart disease to ComorbiditiesSACQ
Timing: Baseline
Data Source: Patient-reported
Type: Single answer
Value Domain: Code

Response Options: 0= No
1= Yes

Variable ID: ComorbiditiesSACQ_HeartDiseaseFU2

Variable: SACQ comorbidities: Heart Disease: Follow-Up Question 2

Definition: Please indicate if the patient's heart disease limits their function

Supporting Definition: Based upon the Self-administered Comorbidity Questionnaire (Sangha et al, 2003). Phrased as a patient-reported measure, but information can be abstracted by other means if patient is unable to answer.

Displayed Value: Does your heart disease limit your activities?

Inclusion Criteria: If answered 1= Heart disease to ComorbiditiesSACQ

Timing: Baseline

Data Source: Patient-reported

Type: Single answer

Value Domain: Code

Response Options: 0= No
1= Yes

Variable ID: ComorbiditiesSACQ_HighBloodPressureFU1

Variable: SACQ comorbidities: High Blood Pressure: Follow-Up Question 1

Definition: Please indicate if the patient receives treatment for high blood pressure

Supporting Definition: Based upon the Self-administered Comorbidity Questionnaire (Sangha et al, 2003). Phrased as a patient-reported measure, but information can be abstracted by other means if patient is unable to answer.

Displayed Value: Do you receive treatment for high blood pressure?

Inclusion Criteria: If answered 2= High blood pressure to ComorbiditiesSACQ

Timing: Baseline

Data Source: Patient-reported

Type: Single answer

Value Domain: Code

Response Options: 0= No
1= Yes

Variable ID: ComorbiditiesSACQ_HighBloodPressureFU2

Variable: SACQ comorbidities: High Blood Pressure: Follow-Up Question 2

Definition: Please indicate if the patient's high blood pressure limits their function

Supporting Definition: Based upon the Self-administered Comorbidity Questionnaire (Sangha et al, 2003). Phrased as a patient-reported measure, but information can be abstracted by other means if patient is unable to answer.

Displayed Value: Does your high blood pressure limit your activities?

Inclusion Criteria: If answered 2= High blood pressure to ComorbiditiesSACQ

Timing: Baseline

Data Source: Patient-reported

Type: Single answer

Value Domain: Code

Response Options: 0= No
1= Yes

Variable ID: ComorbiditiesSACQ_LungDiseaseFU1

Variable: SACQ comorbidities: Lung Disease: Follow-Up Question 1

Definition: Please indicate if the patient receives treatment for lung disease

Supporting Definition: Based upon the Self-administered Comorbidity Questionnaire (Sangha et al, 2003). Phrased as a patient-reported measure, but information can be abstracted by other means if patient is unable to answer.

Displayed Value: Do you receive treatment for lung disease?

Inclusion Criteria: If answered 3= Lung disease to ComorbiditiesSACQ

Timing: Baseline

Data Source: Patient-reported

Type: Single answer
Value Domain: Code
Response Options: 0= No
1= Yes

Variable ID: ComorbiditiesSACQ_LungDiseaseFU2
Variable: SACQ comorbidities: Lung Disease: Follow-Up Question 2
Definition: Please indicate if the patient's lung disease limits their function
Supporting Definition: Based upon the Self-administered Comorbidity Questionnaire (Sangha et al, 2003). Phrased as a patient-reported measure, but information can be abstracted by other means if patient is unable to answer.
Displayed Value: Does your lung disease limit your activities?
Inclusion Criteria: If answered 3= Lung disease to ComorbiditiesSACQ
Timing: Baseline
Data Source: Patient-reported
Type: Single answer
Value Domain: Code
Response Options: 0= No
1= Yes

Variable ID: ComorbiditiesSACQ_DiabetesFU1
Variable: SACQ comorbidities: Diabetes: Follow-Up Question 1
Definition: Please indicate if the patient receives treatment for diabetes
Supporting Definition: Based upon the Self-administered Comorbidity Questionnaire (Sangha et al, 2003). Phrased as a patient-reported measure, but information can be abstracted by other means if patient is unable to answer.
Displayed Value: Do you receive treatment for diabetes?
Inclusion Criteria: If answered 4= Diabetes to ComorbiditiesSACQ
Timing: Baseline
Data Source: Patient-reported
Type: Single answer
Value Domain: Code
Response Options: 0= No
1= Yes

Variable ID: ComorbiditiesSACQ_DiabetesFU2
Variable: SACQ comorbidities: Diabetes: Follow-Up Question 2
Definition: Please indicate if the patient's diabetes limits their function
Supporting Definition: Based upon the Self-administered Comorbidity Questionnaire (Sangha et al, 2003). Phrased as a patient-reported measure, but information can be abstracted by other means if patient is unable to answer.
Displayed Value: Does your diabetes limit your activities?
Inclusion Criteria: If answered 4= Diabetes to ComorbiditiesSACQ
Timing: Baseline
Data Source: Patient-reported
Type: Single answer
Value Domain: Code
Response Options: 0= No
1= Yes

Variable ID: ComorbiditiesSACQ_StomachDiseaseFU1
Variable: SACQ comorbidities: Stomach Disease: Follow-Up Question 1
Definition: Please indicate if the patient receives treatment for an ulcer or stomach disease
Supporting Definition: Based upon the Self-administered Comorbidity Questionnaire (Sangha et al, 2003). Phrased as a patient-reported measure, but information can be abstracted by other means if patient is unable to answer.
Displayed Value: Do you receive treatment for an ulcer or stomach disease?
Inclusion Criteria: If answered 5= Ulcer or stomach disease to ComorbiditiesSACQ

Timing: Baseline
Data Source: Patient-reported
Type: Single answer
Value Domain: Code
Response Options: 0= No
1= Yes

Variable ID: ComorbiditiesSACQ_StomachDiseaseFU2
Variable: SACQ comorbidities: Stomach Disease: Follow-Up Question 2
Definition: Please indicate if the patient's ulcer or stomach disease limits their function
Supporting Definition: Based upon the Self-administered Comorbidity Questionnaire (Sangha et al, 2003). Phrased as a patient-reported measure, but information can be abstracted by other means if patient is unable to answer.
Displayed Value: Does your ulcer or stomach disease limit your activities?
Inclusion Criteria: If answered 5= Ulcer or stomach disease to ComorbiditiesSACQ
Timing: Baseline
Data Source: Patient-reported
Type: Single answer
Value Domain: Code
Response Options: 0= No
1= Yes

Variable ID: ComorbiditiesSACQ_KidneyDiseaseFU1
Variable: SACQ comorbidities: Kidney Disease: Follow-Up Question 1
Definition: Please indicate if the patient receives treatment for kidney disease
Supporting Definition: Based upon the Self-administered Comorbidity Questionnaire (Sangha et al, 2003). Phrased as a patient-reported measure, but information can be abstracted by other means if patient is unable to answer.
Displayed Value: Do you receive treatment for kidney disease?
Inclusion Criteria: If answered 6= Kidney disease to ComorbiditiesSACQ
Timing: Baseline
Data Source: Patient-reported
Type: Single answer
Value Domain: Code
Response Options: 0= No
1= Yes

Variable ID: ComorbiditiesSACQ_KidneyDiseaseFU2
Variable: SACQ comorbidities: Kidney Disease: Follow-Up Question 2
Definition: Please indicate if the patient's kidney disease limits their function
Supporting Definition: Based upon the Self-administered Comorbidity Questionnaire (Sangha et al, 2003). Phrased as a patient-reported measure, but information can be abstracted by other means if patient is unable to answer.
Displayed Value: Does your kidney disease limit your activities?
Inclusion Criteria: If answered 6= Kidney disease to ComorbiditiesSACQ
Timing: Baseline
Data Source: Patient-reported
Type: Single answer
Value Domain: Code
Response Options: 0= No
1= Yes

Variable ID: ComorbiditiesSACQ_LiverDiseaseFU1
Variable: SACQ comorbidities: Liver Disease: Follow-Up Question 1
Definition: Please indicate if the patient receives treatment for liver disease
Supporting Definition: Based upon the Self-administered Comorbidity Questionnaire (Sangha et al, 2003). Phrased as a patient-reported measure, but information can be abstracted by other means if patient is unable to answer.

Displayed Value: Do you receive treatment for liver disease?
Inclusion Criteria: If answered 7= Liver disease to ComorbiditiesSACQ
Timing: Baseline
Data Source: Patient-reported
Type: Single answer
Value Domain: Code
Response Options: 0= No
1= Yes

Variable ID: ComorbiditiesSACQ_LiverDiseaseFU2
Variable: SACQ comorbidities: Liver Disease: Follow-Up Question 2
Definition: Please indicate if the patient's liver disease limits their function
Supporting Definition: Based upon the Self-administered Comorbidity Questionnaire (Sangha et al, 2003). Phrased as a patient-reported measure, but information can be abstracted by other means if patient is unable to answer.
Displayed Value: Does your liver disease limit your activities?
Inclusion Criteria: If answered 7= Liver disease to ComorbiditiesSACQ
Timing: Baseline
Data Source: Patient-reported
Type: Single answer
Value Domain: Code
Response Options: 0= No
1= Yes

Variable ID: ComorbiditiesSACQ_BloodDiseaseFU1
Variable: SACQ comorbidities: Blood Disease: Follow-Up Question 1
Definition: Please indicate if the patient receives treatment for anemia or other blood disease
Supporting Definition: Based upon the Self-administered Comorbidity Questionnaire (Sangha et al, 2003). Phrased as a patient-reported measure, but information can be abstracted by other means if patient is unable to answer.
Displayed Value: Do you receive treatment for anemia or other blood disease?
Inclusion Criteria: If answered 8= Anemia or other blood disease to ComorbiditiesSACQ
Timing: Baseline
Data Source: Patient-reported
Type: Single answer
Value Domain: Code
Response Options: 0= No
1= Yes

Variable ID: ComorbiditiesSACQ_BloodDiseaseFU2
Variable: SACQ comorbidities: Blood Disease: Follow-Up Question 2
Definition: Please indicate if the patient's anemia or other blood disease limits their function
Supporting Definition: Based upon the Self-administered Comorbidity Questionnaire (Sangha et al, 2003). Phrased as a patient-reported measure, but information can be abstracted by other means if patient is unable to answer.
Displayed Value: Does your anemia or other blood disease limit your activities?
Inclusion Criteria: If answered 8= Anemia or other blood disease to ComorbiditiesSACQ
Timing: Baseline
Data Source: Patient-reported
Type: Single answer
Value Domain: Code
Response Options: 0= No
1= Yes

Variable ID: ComorbiditiesSACQ_CancerFU1
Variable: SACQ comorbidities: Cancer: Follow-Up Question 1
Definition: Please indicate if the patient receives treatment for cancer/another cancer

Supporting Definition: Based upon the Self-administered Comorbidity Questionnaire (Sangha et al, 2003). Phrased as a patient-reported measure, but information can be abstracted by other means if patient is unable to answer.

Displayed Value: Do you receive treatment for cancer/another cancer?

Inclusion Criteria: If answered 9= Cancer/Other cancer to ComorbiditiesSACQ

Timing: Baseline

Data Source: Patient-reported

Type: Single answer

Value Domain: Code

Response Options: 0= No
1= Yes

Variable ID: ComorbiditiesSACQ_CancerFU2

Variable: SACQ comorbidities: Cancer: Follow-Up Question 2

Definition: Please indicate if the patient's cancer/other cancer limits their function

Supporting Definition: Based upon the Self-administered Comorbidity Questionnaire (Sangha et al, 2003). Phrased as a patient-reported measure, but information can be abstracted by other means if patient is unable to answer.

Displayed Value: Does your cancer/other cancer limit your activities?

Inclusion Criteria: If answered 9= Cancer/Other cancer to ComorbiditiesSACQ

Timing: Baseline

Data Source: Patient-reported

Type: Single answer

Value Domain: Code

Response Options: 0= No
1= Yes

Variable ID: ComorbiditiesSACQ_DepressionFU1

Variable: SACQ comorbidities: Depression: Follow-Up Question 1

Definition: Please indicate if the patient receives treatment for depression

Supporting Definition: Based upon the Self-administered Comorbidity Questionnaire (Sangha et al, 2003). Phrased as a patient-reported measure, but information can be abstracted by other means if patient is unable to answer.

Displayed Value: Do you receive treatment for depression?

Inclusion Criteria: If answered 10= Depression to ComorbiditiesSACQ

Timing: Baseline

Data Source: Patient-reported

Type: Single answer

Value Domain: Code

Response Options: 0= No
1= Yes

Variable ID: ComorbiditiesSACQ_DepressionFU2

Variable: SACQ comorbidities: Depression: Follow-Up Question 2

Definition: Please indicate if the patient's depression limits their function

Supporting Definition: Based upon the Self-administered Comorbidity Questionnaire (Sangha et al, 2003). Phrased as a patient-reported measure, but information can be abstracted by other means if patient is unable to answer.

Displayed Value: Does your depression limit your activities?

Inclusion Criteria: If answered 10= Depression to ComorbiditiesSACQ

Timing: Baseline

Data Source: Patient-reported

Type: Single answer

Value Domain: Code

Response Options: 0= No
1= Yes

Variable ID: ComorbiditiesSACQ_OsteoarthritisFU1

Variable: SACQ comorbidities: Osteoarthritis: Follow-Up Question 1

Definition: Please indicate if the patient receives treatment for osteoarthritis/degenerative arthritis

Supporting Definition: Based upon the Self-administered Comorbidity Questionnaire (Sangha et al, 2003). Phrased as a patient-reported measure, but information can be abstracted by other means if patient is unable to answer.

Displayed Value: Do you receive treatment for osteoarthritis/degenerative arthritis?

Inclusion Criteria: If answered 11= Osteoarthritis, degenerative arthritis to ComorbiditiesSACQ

Timing: Baseline

Data Source: Patient-reported

Type: Single answer

Value Domain: Code

Response Options:
0= No
1= Yes

Variable ID: ComorbiditiesSACQ_OsteoarthritisFU2

Variable: SACQ comorbidities: Osteoarthritis: Follow-Up Question 2

Definition: Please indicate if the patient's osteoarthritis/degenerative arthritis limits their function

Supporting Definition: Based upon the Self-administered Comorbidity Questionnaire (Sangha et al, 2003). Phrased as a patient-reported measure, but information can be abstracted by other means if patient is unable to answer.

Displayed Value: Does your osteoarthritis/degenerative arthritis limit your activities?

Inclusion Criteria: If answered 11= Osteoarthritis, degenerative arthritis to ComorbiditiesSACQ

Timing: Baseline

Data Source: Patient-reported

Type: Single answer

Value Domain: Code

Response Options:
0= No
1= Yes

Variable ID: ComorbiditiesSACQ_BackPainFU1

Variable: SACQ comorbidities: Back Pain: Follow-Up Question 1

Definition: Please indicate if the patient receives treatment for back pain

Supporting Definition: Based upon the Self-administered Comorbidity Questionnaire (Sangha et al, 2003). Phrased as a patient-reported measure, but information can be abstracted by other means if patient is unable to answer.

Displayed Value: Do you receive treatment for back pain?

Inclusion Criteria: If answered 12= Back pain to ComorbiditiesSACQ

Timing: Baseline

Data Source: Patient-reported

Type: Single answer

Value Domain: Code

Response Options:
0= No
1= Yes

Variable ID: ComorbiditiesSACQ_BackPainFU2

Variable: SACQ comorbidities: Back Pain: Follow-Up Question 2

Definition: Please indicate if the patient's back pain limits their function

Supporting Definition: Based upon the Self-administered Comorbidity Questionnaire (Sangha et al, 2003). Phrased as a patient-reported measure, but information can be abstracted by other means if patient is unable to answer.

Displayed Value: Does your back pain limit your activities?

Inclusion Criteria: If answered 12= Back pain to ComorbiditiesSACQ

Timing: Baseline

Data Source: Patient-reported

Type: Single answer

Value Domain: Code
Response Options: 0= No
1= Yes

Variable ID: ComorbiditiesSACQ_RheumatoidArthritisFU1
Variable: SACQ comorbidities: Rheumatoid Arthritis: Follow-Up Question 1
Definition: Please indicate if the patient receives treatment for rheumatoid arthritis
Supporting Definition: Based upon the Self-administered Comorbidity Questionnaire (Sangha et al, 2003). Phrased as a patient-reported measure, but information can be abstracted by other means if patient is unable to answer.
Displayed Value: Do you receive treatment for rheumatoid arthritis?
Inclusion Criteria: If answered 13= Rheumatoid arthritis to ComorbiditiesSACQ
Timing: Baseline
Data Source: Patient-reported
Type: Single answer
Value Domain: Code
Response Options: 0= No
1= Yes

Variable ID: ComorbiditiesSACQ_RheumatoidArthritisFU2
Variable: SACQ comorbidities: Rheumatoid Arthritis: Follow-Up Question 2
Definition: Please indicate if the patient's rheumatoid arthritis limits their function
Supporting Definition: Based upon the Self-administered Comorbidity Questionnaire (Sangha et al, 2003). Phrased as a patient-reported measure, but information can be abstracted by other means if patient is unable to answer.
Displayed Value: Does your rheumatoid arthritis limit your activities?
Inclusion Criteria: If answered 13= Rheumatoid arthritis to ComorbiditiesSACQ
Timing: Baseline
Data Source: Patient-reported
Type: Single answer
Value Domain: Code
Response Options: 0= No
1= Yes

Variable ID: ComorbiditiesSACQ_Other
Variable: SACQ comorbidities: Other Medical Problems
Definition: Please indicate what other medical problems the patient is experiencing
Supporting Definition: Based upon the Self-administered Comorbidity Questionnaire (Sangha et al, 2003). Phrased as a patient-reported measure, but information can be abstracted by other means if patient is unable to answer.
Displayed Value: What other medical problems are you experiencing?
Inclusion Criteria: If answered 14= Other medical problems to ComorbiditiesSACQ
Timing: Baseline
Data Source: Patient-reported
Type: Single answer
Value Domain: String
Response Options: None

Variable ID: ComorbiditiesSACQ_Score
Variable: Score of the SACQ comorbidities questionnaire
Definition: Please indicate the summed score for all of the patient's comorbidities
Supporting Definition: An individual can receive a max of 3 points for each medical condition: 1 point for the presence of the problem, another point if he/she receives treatment for it, and an additional point if the problem causes a limitation in function. The Max score a patient can receive is 45 points
Displayed Value: What is the total summed score of the patient's SACQ responses?
Inclusion Criteria: All patients
Timing: Baseline

Data Source: Clinical
Type: Numerical value
Value Domain: Quantity
Response Options: Total summed score

Variable ID: Hosp_Lifetime
Variable: Hospitalisations – Lifetime
Definition: Number of lifetime hospitalisations related to the target condition.
Supporting Definition: None
Display Value: How many times have you been hospitalised due to your [target condition] previously in your life?
Inclusion Criteria: All patients
Timing: Baseline
Data Source: Clinical
Type: Numerical value
Value Domain: Quantity
Response Options: None

Variable ID: ACES_Q01
Variable: Question 1 of the Adverse Childhood Experiences Score
Definition: Prior to your 18th birthday, Did a parent or other adult in the household often or very often... Swear at you, insult you, put you down, or humiliate you? or Act in a way that made you afraid that you might be physically hurt?
Supporting Definition: To be administered to adolescents only if and when it is deemed appropriate to do so, and for whom this measure would not cause unnecessary distress.
Display Value: Prior to your 18th birthday, Did a parent or other adult in the household often or very often... Swear at you, insult you, put you down, or humiliate you? or Act in a way that made you afraid that you might be physically hurt?
Inclusion Criteria: Adult patients
Adolescent patients (where appropriate – see supporting definition)
Timing: Baseline
Transition to adult services
Data Source: Patient-reported
Type: Single answer
Value Domain: Code
Response Options: 0 = No
1 = Yes

Variable ID: ACES_Q02
Variable: Question 2 of the Adverse Childhood Experiences Score
Definition: Did a parent or other adult in the household often or very often... Push, grab, slap, or throw something at you? or Ever hit you so hard that you had marks or were injured?
Supporting Definition: To be administered to adolescents only if and when it is deemed appropriate to do so, and for whom this measure would not cause unnecessary distress.
Display Value: Did a parent or other adult in the household often or very often... Push, grab, slap, or throw something at you? or Ever hit you so hard that you had marks or were injured?
Inclusion Criteria: Adult patients
Adolescent patients (where appropriate – see supporting definition)
Timing: Baseline
Transition to adult services
Data Source: Patient-reported
Type: Single answer
Value Domain: Code
Response Options: 0 = No
1 = Yes

Variable ID: ACES_Qo3
Variable: Question 3 of the Adverse Childhood Experiences Score
Definition: Did an adult or person at least 5 years older than you ever... Touch or fondle you or have you touch their body in a sexual way? or Attempt or actually have oral, anal, or vaginal intercourse with you?
Supporting Definition: To be administered to adolescents only if and when it is deemed appropriate to do so, and for whom this measure would not cause unnecessary distress.
Display Value: Did an adult or person at least 5 years older than you ever... Touch or fondle you or have you touch their body in a sexual way? or Attempt or actually have oral, anal, or vaginal intercourse with you?
Inclusion Criteria: Adult patients
Adolescent patients (where appropriate – see supporting definition)
Timing: Baseline
Transition to adult services
Data Source: Patient-reported
Type: Single answer
Value Domain: Code
Response Options: 0 = No
1 = Yes

Variable ID: ACES_Qo4
Variable: Question 4 of the Adverse Childhood Experiences Score
Definition: Did you often or very often feel that ... No one in your family loved you or thought you were important or special? or Your family didn't look out for each other, feel close to each other, or support each other?
Supporting Definition: To be administered to adolescents only if and when it is deemed appropriate to do so, and for whom this measure would not cause unnecessary distress.
Display Value: Did you often or very often feel that ... No one in your family loved you or thought you were important or special? or Your family didn't look out for each other, feel close to each other, or support each other?
Inclusion Criteria: Adult patients
Adolescent patients (where appropriate – see supporting definition)
Timing: Baseline
Transition to adult services
Data Source: Patient-reported
Type: Single answer
Value Domain: Code
Response Options: 0 = No
1 = Yes

Variable ID: ACES_Qo5
Variable: Question 5 of the Adverse Childhood Experiences Score
Definition: Did you often or very often feel that ... You didn't have enough to eat, had to wear dirty clothes, and had no one to protect you? or Your parents were too drunk or high to take care of you or take you to the doctor if you needed it?
Supporting Definition: To be administered to adolescents only if and when it is deemed appropriate to do so, and for whom this measure would not cause unnecessary distress.
Display Value: Did you often or very often feel that ... You didn't have enough to eat, had to wear dirty clothes, and had no one to protect you? or Your parents were too drunk or high to take care of you or take you to the doctor if you needed it?
Inclusion Criteria: Adult patients
Adolescent patients (where appropriate – see supporting definition)
Timing: Baseline
Transition to adult services
Data Source: Patient-reported
Type: Single answer

Value Domain: Code
Response Options: 0 = No
1 = Yes

Variable ID: ACES_Qo6
Variable: Question 6 of the Adverse Childhood Experiences Score
Definition: Were your parents ever separated or divorced?
Supporting Definition: To be administered to adolescents only if and when it is deemed appropriate to do so, and for whom this measure would not cause unnecessary distress.
Display Value: Were your parents ever separated or divorced?
Inclusion Criteria: Adult patients
Adolescent patients (where appropriate – see supporting definition)
Timing: Baseline
Transition to adult services
Data Source: Patient-reported
Type: Single answer
Value Domain: Code
Response Options: 0 = No
1 = Yes

Variable ID: ACES_Qo7
Variable: Question 7 of the Adverse Childhood Experiences Score
Definition: Was your mother or stepmother:
Often or very often pushed, grabbed, slapped, or had something thrown at her? or
Sometimes, often, or very often kicked, bitten, hit with a fist, or hit with something
hard? or Ever repeatedly hit over at least a few minutes or threatened with a gun or
knife?
Supporting Definition: To be administered to adolescents only if and when it is deemed appropriate to do so, and for whom this measure would not cause unnecessary distress.
Display Value: Was your mother or stepmother:
Often or very often pushed, grabbed, slapped, or had something thrown at her? or
Sometimes, often, or very often kicked, bitten, hit with a fist, or hit with something
hard? or Ever repeatedly hit over at least a few minutes or threatened with a gun or
knife?
Inclusion Criteria: Adult patients
Adolescent patients (where appropriate – see supporting definition)
Timing: Baseline
Transition to adult services
Data Source: Patient-reported
Type: Single answer
Value Domain: Code
Response Options: 0 = No
1 = Yes

Variable ID: ACES_Qo8
Variable: Question 8 of the Adverse Childhood Experiences Score
Definition: Did you live with anyone who was a problem drinker or alcoholic, or who used
street drugs?
Supporting Definition: To be administered to adolescents only if and when it is deemed appropriate to do so, and for whom this measure would not cause unnecessary distress.
Display Value: Did you live with anyone who was a problem drinker or alcoholic, or who used
street drugs?
Inclusion Criteria: Adult patients
Adolescent patients (where appropriate – see supporting definition)
Timing: Baseline
Transition to adult services
Data Source: Patient-reported

Type: Single answer
Value Domain: Code
Response Options: 0 = No
1 = Yes

Variable ID: ACES_Q09

Variable: Question 9 of the Adverse Childhood Experiences Score

Definition: Was a household member depressed or mentally ill, or did a household member attempt suicide?

Supporting Definition: To be administered to adolescents only if and when it is deemed appropriate to do so, and for whom this measure would not cause unnecessary distress.

Display Value: Was a household member depressed or mentally ill, or did a household member attempt suicide?

Inclusion Criteria: Adult patients
Adolescent patients (where appropriate – see supporting definition)

Timing: Baseline
Transition to adult services

Data Source: Patient-reported

Type: Single answer

Value Domain: Code

Response Options: 0 = No
1 = Yes

Variable ID: ACES_Q10

Variable: Question 10 of the Adverse Childhood Experiences Score

Definition: Did a household member go to prison?

Supporting Definition: To be administered to adolescents only if and when it is deemed appropriate to do so, and for whom this measure would not cause unnecessary distress.

Display Value: Did a household member go to prison?

Inclusion Criteria: Adult patients
Adolescent patients (where appropriate – see supporting definition)

Timing: Baseline
Transition to adult services

Data Source: Patient-reported

Type: Single answer

Value Domain: Code

Response Options: 0 = No
1 = Yes

Intervention Factors

Variable ID: InterventionSetting_Q01

Variable: Question 1 of Intervention setting

Definition: Indicate the patient's intervention setting.

Supporting Definition: None

Display Value: Does this intervention involve an overnight stay at an institution providing mental health support?

Inclusion Criteria: All patients

Timing: Baseline
Annually

Data Source: Clinical

Type: Single answer

Value Domain: Code

Response Options: 0 = No
1 = Yes

Variable ID: InterventionSetting_Q02

Variable: Question 2 of Intervention setting

Definition: Indicate the patient's intervention setting.
Supporting Definition: None
Display Value: Does this intervention involve the use of a digital platform?
Inclusion Criteria: All patients
Timing: Baseline
Annually
Data Source: Clinical
Type: Single answer
Value Domain: Code
Response Options: 0 = No
1 = Yes

Variable ID: InterventionType_Q01
Variable: Question 1 of Intervention type
Definition: Indicate the patient's intervention type.
Supporting Definition: If answer is 0 = No intervention / treatment in place, skip question 2 and 3 of Intervention type.
Display Value: Is the intervention delivered to an individual, or to a group?
Inclusion Criteria: All patients
Timing: Baseline
Annually
Data Source: Clinical
Type: Single answer
Value Domain: Code
Response Options: 0 = No intervention / treatment in place
1 = Individual
2 = Group
3 = A mix of both

Variable ID: InterventionType_Q02
Variable: Question 2 of Intervention type
Definition: Indicate the patient's treatment approaches.
Supporting Definition: None
Display Value: What is the treatment approach? (all that apply)
Inclusion Criteria: All patients
Timing: Baseline
Annually
Data Source: Clinical
Type: Multiple answer
Separate multiple entries with ";"
Value Domain: Code
Response Options: 1 = Crisis intervention
2 = Counselling
3 = Psychotherapy (including CBT, IPT, DBT, or other psychotherapies)
4 = Physical treatment (e.g. light therapy, electroconvulsive therapy, rTMS, or others)
5 = Pharmacotherapy (if so, proceed to next question)
6 = Lifestyle interventions, guided self-help or psychoeducation
888 = Other

Variable ID: INTERVENTION_TYPE_Q03
Variable: Question 3 of Intervention type
Definition: Indicate the patient's prescribed medications.
Supporting Definition: None
Display Value: What type of medication is prescribed? (all that apply)
Inclusion Criteria: All patients receiving medication for mental health disorders
Timing: Baseline

Data Source: Annually
Clinical
Type: Multiple answer
Separate multiple entries with ";"
Value Domain: Code
Response Options: 1 = Selective serotonin reuptake inhibitors (SSRIs)
2 = Tricyclic and related antidepressants
3 = Other atypical antidepressants
4 = Atypical antipsychotic medication
5 = Herbal medication
6 = Mood stabilisers
7 = Anti-convulsants
8 = Beta-blockers
9 = Complementary medications
10 = Uncertain
888 = Other

Outcomes

Symptoms

Variable ID: PHQ9_Q01
Variable: Question 1 of PHQ9
Definition: Over the last 2 weeks, how often have you been bothered by any of the following:
A. Little interest or pleasure in doing things?

Supporting Definition: None
Display Value: Over the last 2 weeks, how often have you been bothered by any of the following:
A. Little interest or pleasure in doing things?

Inclusion Criteria: All patients
Timing: All time points
Data Source: Patient-reported

Type: Single answer
Value Domain: Code
Response Options: 0 = Not at all
1 = Several days
2 = More than half the days
3 = Nearly every day

Variable ID: PHQ9_Q02
Variable: Question 2 of PHQ9
Definition: Over the last 2 weeks, how often have you been bothered by any of the following:
B. Feeling down, depressed, or hopeless

Supporting Definition: None
Display Value: Over the last 2 weeks, how often have you been bothered by any of the following:
B. Feeling down, depressed, or hopeless

Inclusion Criteria: All patients
Timing: All time points
Data Source: Patient-reported
Type: Single answer

Value Domain: Code
Response Options: 0 = Not at all
1 = Several days
2 = More than half the days
3 = Nearly every day

Variable ID: PHQ9_Q03
Variable: Question 3 of PHQ9

Definition: Over the last 2 weeks, how often have you been bothered by any of the following:
C. Trouble falling or staying asleep, or sleeping too much?

Supporting Definition: None

Display Value: Over the last 2 weeks, how often have you been bothered by any of the following:
C. Trouble falling or staying asleep, or sleeping too much?

Inclusion Criteria: All patients

Timing: All time points

Data Source: Patient-reported

Type: Single answer

Value Domain: Code

Response Options: 0 = Not at all
1 = Several days
2 = More than half the days
3 = Nearly every day

Variable ID: PHQ9_Qo4

Variable: Question 4 of PHQ9

Definition: Over the last 2 weeks, how often have you been bothered by any of the following:
D. Feeling tired or having little energy?

Supporting Definition: None

Display Value: Over the last 2 weeks, how often have you been bothered by any of the following:
D. Feeling tired or having little energy?

Inclusion Criteria: All patients

Timing: All time points

Data Source: Patient-reported

Type: Single answer

Value Domain: Code

Response Options: 0 = Not at all
1 = Several days
2 = More than half the days
3 = Nearly every day

Variable ID: PHQ9_Qo5

Variable: Question 5 of PHQ9

Definition: Over the last 2 weeks, how often have you been bothered by any of the following:
E. Poor appetite or overeating?

Supporting Definition: None

Display Value: Over the last 2 weeks, how often have you been bothered by any of the following:
E. Poor appetite or overeating?

Inclusion Criteria: All patients

Timing: All time points

Data Source: Patient-reported

Type: Single answer

Value Domain: Code

Response Options: 0 = Not at all
1 = Several days
2 = More than half the days
3 = Nearly every day

Variable ID: PHQ9_Qo6

Variable: Question 6 of PHQ9

Definition: Over the last 2 weeks, how often have you been bothered by any of the following:
F. Feeling bad about yourself - or that you are a failure or have let yourself or your family down?

Supporting Definition: None

Display Value: Over the last 2 weeks, how often have you been bothered by any of the following:
F. Feeling bad about yourself - or that you are a failure or have let yourself or your family down?

Inclusion Criteria: All patients

Timing: All time points

Data Source: Patient-reported

Type: Single answer

Value Domain: Code

Response Options: 0 = Not at all
1 = Several days
2 = More than half the days
3 = Nearly every day

Variable ID: PHQ9_Q07

Variable: Question 7 of PHQ9

Definition: Over the last 2 weeks, how often have you been bothered by any of the following:
G. Trouble concentrating on things, such as reading the newspaper or watching television?

Supporting Definition: None

Display Value: Over the last 2 weeks, how often have you been bothered by any of the following:
G. Trouble concentrating on things, such as reading the newspaper or watching television?

Inclusion Criteria: All patients

Timing: All time points

Data Source: Patient-reported

Type: Single answer

Value Domain: Code

Response Options: 0 = Not at all
1 = Several days
2 = More than half the days
3 = Nearly every day

Variable ID: PHQ9_Q08

Variable: Question 8 of PHQ9

Definition: Over the last 2 weeks, how often have you been bothered by any of the following:
H. Moving or speaking so slowly that other people could have noticed? Or the opposite - being so fidgety or restless that you have been moving around a lot more than usual?

Supporting Definition: None

Display Value: Over the last 2 weeks, how often have you been bothered by any of the following:
H. Moving or speaking so slowly that other people could have noticed? Or the opposite - being so fidgety or restless that you have been moving around a lot more than usual?

Inclusion Criteria: All patients

Timing: All time points

Data Source: Patient-reported

Type: Single answer

Value Domain: Code

Response Options: 0 = Not at all
1 = Several days
2 = More than half the days
3 = Nearly every day

Variable ID: PHQ9_Q09

Variable: Question 9 of PHQ9

Definition: Over the last 2 weeks, how often have you been bothered by any of the following:
I. Thoughts that you would be better off dead or of hurting yourself in some way?

Supporting Definition: None
Display Value: Over the last 2 weeks, how often have you been bothered by any of the following:
I. Thoughts that you would be better off dead or of hurting yourself in some way?
Inclusion Criteria: All patients
Timing: All time points
Data Source: Patient-reported
Type: Single answer
Value Domain: Code
Response Options: 0 = Not at all
1 = Several days
2 = More than half the days
3 = Nearly every day

Variable ID: PHQ9_Q10
Variable: Question 10 of PHQ9
Definition: If you checked off any problems, how difficult have these problems made it for you to do your work, take care of things at home, or get along with other people?

Supporting Definition: None
Display Value: None
Inclusion Criteria: All patients
Timing: All time points
Data Source: Patient-reported
Type: Single answer
Value Domain: Code
Response Options: 0 = Not difficult at all
1 = Somewhat difficult
2 = Very difficult
3 = Extremely difficult

Variable ID: MCSI_Q01
Variable: Question 1 of the Modified Colorado Symptom Index
Definition: Please think about how often you experienced certain problems and how much they bothered or distressed you during the past month. For each problem, please pick one answer choice that best describes how often you have had the problem in the past month (30 days): How often have you felt nervous, tense, worried, frustrated, or afraid?

Supporting Definition: None
Display Value: How often have you felt nervous, tense, worried, frustrated, or afraid?
Inclusion Criteria: All patients
Timing: All time points
Data Source: Patient-reported
Type: Single answer
Value Domain: Code
Response Options: 0 = Not at all
1 = Once during the month
2 = Several times during the month
3 = Several times a week
4 = At least every day
7 = RF
8 = NA
9 = Don't know

Variable ID: MCSI_Q02
Variable: Question 2 of the Modified Colorado Symptom Index
Definition: How often have you felt depressed?

Supporting Definition: None
Display Value: How often have you felt depressed?

Inclusion Criteria: All patients
Timing: All time points
Data Source: Patient-reported
Type: Single answer
Value Domain: Code
Response Options: 0 = Not at all
1 = Once during the month
2 = Several times during the month
3 = Several times a week
4 = At least every day
7 = RF
8 = NA
9 = Don't know

Variable ID: MCSI_Q03
Variable: Question 3 of the Modified Colorado Symptom Index
Definition: How often have you felt lonely?
Supporting Definition: None
Display Value: How often have you felt lonely?
Inclusion Criteria: All patients
Timing: All time points
Data Source: Patient-reported
Type: Single answer
Value Domain: Code
Response Options: 0 = Not at all
1 = Once during the month
2 = Several times during the month
3 = Several times a week
4 = At least every day
7 = RF
8 = NA
9 = Don't know

Variable ID: MCSI_Q04
Variable: Question 4 of the Modified Colorado Symptom Index
Definition: How often have others told you that you acted "paranoid" or "suspicious"?
Supporting Definition: None
Display Value: How often have others told you that you acted "paranoid" or "suspicious"?
Inclusion Criteria: All patients
Timing: All time points
Data Source: Patient-reported
Type: Single answer
Value Domain: Code
Response Options: 0 = Not at all
1 = Once during the month
2 = Several times during the month
3 = Several times a week
4 = At least every day
7 = RF
8 = NA
9 = Don't know

Variable ID: MCSI_Q05
Variable: Question 5 of the Modified Colorado Symptom Index
Definition: How often did you hear voices, or hear and see things that other people didn't think were there?
Supporting Definition: None

Display Value: How often did you hear voices, or hear and see things that other people didn't think were there?

Inclusion Criteria: All patients

Timing: All time points

Data Source: Patient-reported

Type: Single answer

Value Domain: Code

Response Options: 0 = Not at all
1 = Once during the month
2 = Several times during the month
3 = Several times a week
4 = At least every day
7 = RF
8 = NA
9 = Don't know

Variable ID: MCSI_Qo6

Variable: Question 6 of the Modified Colorado Symptom Index

Definition: How often did you have trouble making up your mind about something, like deciding where you wanted to go or what you were going to do, or how to solve a problem?

Supporting Definition: None

Display Value: How often did you have trouble making up your mind about something, like deciding where you wanted to go or what you were going to do, or how to solve a problem?

Inclusion Criteria: All patients

Timing: All time points

Data Source: Patient-reported

Type: Single answer

Value Domain: Code

Response Options: 0 = Not at all
1 = Once during the month
2 = Several times during the month
3 = Several times a week
4 = At least every day
7 = RF
8 = NA
9 = Don't know

Variable ID: MCSI_Qo7

Variable: Question 7 of the Modified Colorado Symptom Index

Definition: How often did you have trouble thinking straight or concentrating on something you needed to do (like worrying so much or thinking about problems so much that you can't remember or focus on other things)?

Supporting Definition: None

Display Value: How often did you have trouble thinking straight or concentrating on something you needed to do (like worrying so much or thinking about problems so much that you can't remember or focus on other things)?

Inclusion Criteria: All patients

Timing: All time points

Data Source: Patient-reported

Type: Single answer

Value Domain: Code

Response Options: 0 = Not at all
1 = Once during the month
2 = Several times during the month

3 = Several times a week
4 = At least every day
7 = RF
8 = NA
9 = Don't know

Variable ID: MCSI_Qo8

Variable: Question 8 of the Modified Colorado Symptom Index

Definition: How often did you feel that your behaviour or actions were strange or different from that of other people?

Supporting Definition: None

Display Value: How often did you feel that your behaviour or actions were strange or different from that of other people?

Inclusion Criteria: All patients

Timing: All time points

Data Source: Patient-reported

Type: Single answer

Value Domain: Code

Response Options: 0 = Not at all
1 = Once during the month
2 = Several times during the month
3 = Several times a week
4 = At least every day
7 = RF
8 = NA
9 = Don't know

Variable ID: MCSI_Qo9

Variable: Question 9 of the Modified Colorado Symptom Index

Definition: How often did you feel out of place or like you did not fit in?

Supporting Definition: None

Display Value: How often did you feel out of place or like you did not fit in?

Inclusion Criteria: All patients

Timing: All time points

Data Source: Patient-reported

Type: Single answer

Value Domain: Code

Response Options: 0 = Not at all
1 = Once during the month
2 = Several times during the month
3 = Several times a week
4 = At least every day
7 = RF
8 = NA
9 = Don't know

Variable ID: MCSI_Q10

Variable: Question 10 of the Modified Colorado Symptom Index

Definition: How often did you forget important things?

Supporting Definition: None

Display Value: How often did you forget important things?

Inclusion Criteria: All patients

Timing: All time points

Data Source: Patient-reported

Type: Single answer

Value Domain: Code

Response Options: 0 = Not at all

1 = Once during the month
2 = Several times during the month
3 = Several times a week
4 = At least every day
7 = RF
8 = NA
9 = Don't know

Variable ID: MCSI_Q11
Variable: Question 11 of the Modified Colorado Symptom Index
Definition: How often did you have problems with thinking too fast (thoughts racing)?
Supporting Definition: None
Display Value: How often did you have problems with thinking too fast (thoughts racing)?
Inclusion Criteria: All patients
Timing: All time points
Data Source: Patient-reported
Type: Single answer
Value Domain: Code
Response Options: 0 = Not at all
1 = Once during the month
2 = Several times during the month
3 = Several times a week
4 = At least every day
7 = RF
8 = NA
9 = Don't know

Variable ID: MCSI_Q12
Variable: Question 12 of the Modified Colorado Symptom Index
Definition: How often did you feel suspicious or paranoid?
Supporting Definition: None
Display Value: How often did you feel suspicious or paranoid?
Inclusion Criteria: All patients
Timing: All time points
Data Source: Patient-reported
Type: Single answer
Value Domain: Code
Response Options: 0 = Not at all
1 = Once during the month
2 = Several times during the month
3 = Several times a week
4 = At least every day
7 = RF
8 = NA
9 = Don't know

Variable ID: MCSI_Q13
Variable: Question 13 of the Modified Colorado Symptom Index
Definition: How often did you feel like hurting or killing yourself?
Supporting Definition: None
Display Value: How often did you feel like hurting or killing yourself?
Inclusion Criteria: All patients
Timing: All time points
Data Source: Patient-reported
Type: Single answer
Value Domain: Code
Response Options: 0 = Not at all

- 1 = Once during the month
- 2 = Several times during the month
- 3 = Several times a week
- 4 = At least every day
- 7 = RF
- 8 = NA
- 9 = Don't know

Variable ID: MCSI_Q14

Variable: Question 14 of the Modified Colorado Symptom Index

Definition: How often have you felt like seriously hurting someone else?

Supporting Definition: None

Display Value: How often have you felt like seriously hurting someone else?

Inclusion Criteria: All patients

Timing: All time points

Data Source: Patient-reported

Type: Single answer

Value Domain: Code

Response Options: 0 = Not at all
 1 = Once during the month
 2 = Several times during the month
 3 = Several times a week
 4 = At least every day
 7 = RF
 8 = NA
 9 = Don't know

Variable ID: ASRM_Qo1

Variable: Question 1 of the Altman Self-Rating Mania Scale

Definition: There are 5 groups of statements in this questionnaire, read each group of statements carefully. You should choose the statement in each group that best describes the way you have been feeling for the past week: Positive mood

Supporting Definition: Please note: The word "occasionally" when used here means once or twice; "often" means several times or more and "frequently" means most of the time.

Display Value: Positive mood

Inclusion Criteria: Patients with Bipolar Type I disorder

Timing: All time points

Data Source: Patient-reported

Type: Single answer

Value Domain: Code

Response Options: 1 = I do not feel happier or more cheerful than usual.
 2 = I occasionally feel happier or more cheerful than usual.
 3 = I often feel happier or more cheerful than usual.
 4 = I feel happier or more cheerful than usual most of the time.
 5 = I feel happier of more cheerful than usual all of the time.

Variable ID: ASRM_Qo2

Variable: Question 2 of the Altman Self-Rating Mania Scale

Definition: Self-confidence

Supporting Definition: None

Display Value: Self-confidence

Inclusion Criteria: Patients with Bipolar Type I disorder

Timing: All time points

Data Source: Patient-reported

Type: Single answer

Value Domain: Code

Response Options: 1 = I do not feel more self-confident than usual.

2 = I occasionally feel more self-confident than usual.
3 = I often feel more self-confident than usual.
4 = I frequently feel more self-confident than usual.
5 = I feel extremely self-confident all of the time.

Variable ID: ASRM_Qo3
Variable: Question 3 of the Altman Self-Rating Mania Scale
Definition: Sleep Patterns
Supporting Definition: None
Display Value: Sleep Patterns
Inclusion Criteria: Patients with Bipolar Type I disorder
Timing: All time points
Data Source: Patient-reported
Type: Single answer
Value Domain: Code
Response Options: 1 = I do not need less sleep than usual.
2 = I occasionally need less sleep than usual.
3 = I often need less sleep than usual.
4 = I frequently need less sleep than usual.
5 = I can go all day and all night without any sleep and still not feel tired.

Variable ID: ASRM_Qo4
Variable: Question 4 of the Altman Self-Rating Mania Scale
Definition: Speech
Supporting Definition: None
Display Value: Speech
Inclusion Criteria: Patients with Bipolar Type I disorder
Timing: All time points
Data Source: Patient-reported
Type: Single answer
Value Domain: Code
Response Options: 1 = I do not talk more than usual.
2 = I occasionally talk more than usual.
3 = I often talk more than usual.
4 = I frequently talk more than usual.
5 = I talk constantly and cannot be interrupted.

Variable ID: ASRM_Qo5
Variable: Question 5 of the Altman Self-Rating Mania Scale
Definition: Activity Level
Supporting Definition: None
Display Value: Activity Level
Inclusion Criteria: Patients with Bipolar Type I disorder
Timing: All time points
Data Source: Patient-reported
Type: Single answer
Value Domain: Code
Response Options: 1 = I have not been more active (either socially, sexually, at work, home, or school) than usual.
2 = I have occasionally been more active than usual.
3 = I have often been more active than usual.
4 = I have frequently been more active than usual.
5 = I am constantly more active or on the go all the time.

Variable ID: PROMIS-Sleep_4a_Q1
Variable: PROMIS-29 - Sleep109
Definition: Please respond to each question or statement by marking one box per row. In the past 7 days...

Supporting Definition: My sleep quality was...
Display Value: None
In the past 7 days...
My sleep quality was...
Inclusion Criteria: All patients
Timing: All time points
Data Source: Patient-reported
Type: Single answer
Value Domain: Code
Response Options: 1 = Very good
2 = Good
3 = Fair
4 = Poor
5 = Very poor

Variable ID: PROMIS-Sleep_4a_Q2
Variable: PROMIS-29 - Sleep116
Definition: In the past 7 days...
My sleep was refreshing...

Supporting Definition: None
Display Value: In the past 7 days...
My sleep was refreshing...
Inclusion Criteria: All patients
Timing: All time points
Data Source: Patient-reported
Type: Single answer
Value Domain: Code
Response Options: 1 = Very much
2 = Quite a bit
3 = Somewhat
4 = A little bit
5 = Not at all

Variable ID: PROMIS-Sleep_4a_Q3
Variable: PROMIS-29 - Sleep20
Definition: In the past 7 days...
I had a problem with my sleep...

Supporting Definition: None
Display Value: In the past 7 days...
I had a problem with my sleep...
Inclusion Criteria: All patients
Timing: All time points
Data Source: Patient-reported
Type: Single answer
Value Domain: Code
Response Options: 1 = Not at all
2 = A little bit
3 = Somewhat
4 = Quite a bit
5 = Very much

Variable ID: PROMIS-Sleep_4a_Q4
Variable: PROMIS-29 - Sleep44
Definition: In the past 7 days...
I had difficulty falling asleep

Supporting Definition: None
Display Value: In the past 7 days...

Inclusion Criteria: I had difficulty falling asleep
All patients
Timing: All time points
Data Source: Patient-reported
Type: Single answer
Value Domain: Code
Response Options: 1 = Not at all
2 = A little bit
3 = Somewhat
4 = Quite a bit
5 = Very much

Variable ID: Hosp12mo
Variable: Hospitalisations – 12 months
Definition: Number of hospitalisations related to the target condition in the past 12 months.
Supporting Definition: None
Display Value: How many times has the patient been hospitalised due to your [target condition] in the past 12 months?
Inclusion Criteria: All patients
Timing: Annually
Data Source: Clinical
Type: Numerical value
Value Domain: Quantity
Response Options: None

Recovery

Variable ID: REQOL20_Q01
Variable: Question 1 of the Recovering Quality of Life – 20-item version
Definition: I found it difficult to get started with everyday tasks.
Supporting Definition: None
Display Value: I found it difficult to get started with everyday tasks.
Inclusion Criteria: All patients
Timing: All time points
Data Source: Patient-reported
Type: Single answer
Value Domain: Code
Response Options: 0 = Most or all of the time
1 = Often
2 = Sometimes
3 = Only occasionally
4 = None of the time

Variable ID: REQOL20_Q02
Variable: Question 2 of the Recovering Quality of Life – 20-item version
Definition: I felt able to trust others.
Supporting Definition: None
Display Value: I felt able to trust others.
Inclusion Criteria: All patients
Timing: All time points
Data Source: Patient-reported
Type: Single answer
Value Domain: Code
Response Options: 0 = None of the time
1 = Only occasionally
2 = Sometimes
3 = Often

4 = Most or all of the time

Variable ID: REQOL20_Q03

Variable: Question 3 of the Recovering Quality of Life – 20-item version

Definition: I felt unable to cope.

Supporting Definition: None

Display Value: I felt unable to cope.

Inclusion Criteria: All patients

Timing: All time points

Data Source: Patient-reported

Type: Single answer

Value Domain: Code

Response Options: 0 = Most or all of the time

1 = Often

2 = Sometimes

3 = Only occasionally

4 = None of the time

Variable ID: REQOL20_Q04

Variable: Question 4 of the Recovering Quality of Life – 20-item version

Definition: I could do the things I wanted to do.

Supporting Definition: None

Display Value: I could do the things I wanted to do.

Inclusion Criteria: All patients

Timing: All time points

Data Source: Patient-reported

Type: Single answer

Value Domain: None

Response Options: 0 = None of the time

1 = Only occasionally

2 = Sometimes

3 = Often

4 = Most or all of the time

Variable ID: REQOL20_Q05

Variable: Question 5 of the Recovering Quality of Life – 20-item version

Definition: I felt happy.

Supporting Definition: None

Display Value: I felt happy.

Inclusion Criteria: All patients

Timing: All time points

Data Source: Patient-reported

Type: Single answer

Value Domain: Code

Response Options: 0 = None of the time

1 = Only occasionally

2 = Sometimes

3 = Often

4 = Most or all of the time

Variable ID: REQOL20_Q06

Variable: Question 6 of the Recovering Quality of Life – 20-item version

Definition: I thought my life was not worth living.

Supporting Definition: None

Display Value: I thought my life was not worth living.

Inclusion Criteria: All patients

Timing: All time points

Data Source: Patient-reported

Type: Single answer
Value Domain: Code
Response Options: 0 = Most or all of the time
1 = Often
2 = Sometimes
3 = Only occasionally
4 = None of the time

Variable ID: REQOL20_Qo7
Variable: Question 7 of the Recovering Quality of Life – 20-item version
Definition: I enjoyed what I did.
Supporting Definition: None
Display Value: I enjoyed what I did.
Inclusion Criteria: All patients
Timing: All time points
Data Source: Patient-reported
Type: Single answer
Value Domain: Code
Response Options: 0 = None of the time
1 = Only occasionally
2 = Sometimes
3 = Often
4 = Most or all of the time

Variable ID: REQOL20_Qo8
Variable: Question 8 of the Recovering Quality of Life – 20-item version
Definition: I felt hopeful about my future.
Supporting Definition: None
Display Value: I felt hopeful about my future.
Inclusion Criteria: All patients
Timing: All time points
Data Source: Patient-reported
Type: Single answer
Value Domain: Code
Response Options: 0 = None of the time
1 = Only occasionally
2 = Sometimes
3 = Often
4 = Most or all of the time

Variable ID: REQOL20_Qo9
Variable: Question 9 of the Recovering Quality of Life – 20-item version
Definition: I felt lonely.
Supporting Definition: None
Display Value: I felt lonely.
Inclusion Criteria: All patients
Timing: All time points
Data Source: Patient-reported
Type: Single answer
Value Domain: Code
Response Options: 0 = Most or all of the time
1 = Often
2 = Sometimes
3 = Only occasionally
4 = None of the time

Variable ID: REQOL20_Q10
Variable: Question 10 of the Recovering Quality of Life – 20-item version

Definition: I felt confident in myself.
Supporting Definition: None
Display Value: I felt confident in myself.
Inclusion Criteria: All patients
Timing: All time points
Data Source: Patient-reported
Type: Single answer
Value Domain: Code
Response Options: 0 = None of the time
1 = Only occasionally
2 = Sometimes
3 = Often
4 = Most or all of the time

Variable ID: REQOL20_Q11
Variable: Question 11 of the Recovering Quality of Life – 20-item version
Definition: I did the things I found rewarding.
Supporting Definition: None
Display Value: I did things I found rewarding.
Inclusion Criteria: All patients
Timing: All time points
Data Source: Patient-reported
Type: Single answer
Value Domain: Code
Response Options: 0 = None of the time
1 = Only occasionally
2 = Sometimes
3 = Often
4 = Most or all of the time

Variable ID: REQOL20_Q12
Variable: Question 12 of the Recovering Quality of Life – 20-item version
Definition: I avoided things I needed to do.
Supporting Definition: None
Display Value: I avoided things I needed to do.
Inclusion Criteria: All patients
Timing: All time points
Data Source: Patient-reported
Type: Single answer
Value Domain: Code
Response Options: 0 = Most or all of the time
1 = Often
2 = Sometimes
3 = Only occasionally
4 = None of the time

Variable ID: REQOL20_Q13
Variable: Question 13 of the Recovering Quality of Life – 20-item version
Definition: I felt irritated.
Supporting Definition: None
Display Value: I felt irritated.
Inclusion Criteria: All patients
Timing: All time points
Data Source: Patient-reported
Type: Single answer
Value Domain: Code
Response Options: 0 = Most or all of the time

1 = Often
2 = Sometimes
3 = Only occasionally
4 = None of the time

Variable ID: REQOL20_Q14
Variable: Question 14 of the Recovering Quality of Life – 20-item version
Definition: I felt like a failure.
Supporting Definition: None
Display Value: I felt like a failure.
Inclusion Criteria: All patients
Timing: All time points
Data Source: Patient-reported
Type: Single answer
Value Domain: Code
Response Options: 0 = Most or all of the time
1 = Often
2 = Sometimes
3 = Only occasionally
4 = None of the time

Variable ID: REQOL20_Q15
Variable: Question 15 of the Recovering Quality of Life – 20-item version
Definition: I felt in control of my life.
Supporting Definition: None
Display Value: I felt in control of my life.
Inclusion Criteria: All patients
Timing: All time points
Data Source: Patient-reported
Type: Single answer
Value Domain: Code
Response Options: 0 = None of the time
1 = Only occasionally
2 = Sometimes
3 = Often
4 = Most or all of the time

Variable ID: REQOL20_Q16
Variable: Question 16 of the Recovering Quality of Life – 20-item version
Definition: I felt terrified.
Supporting Definition: None
Display Value: I felt terrified.
Inclusion Criteria: All patients
Timing: All time points
Data Source: Patient-reported
Type: Single answer
Value Domain: Code
Response Options: 0 = Most or all of the time
1 = Often
2 = Sometimes
3 = Only occasionally
4 = None of the time

Variable ID: REQOL20_Q17
Variable: Question 17 of the Recovering Quality of Life – 20-item version
Definition: I felt anxious.
Supporting Definition: None
Display Value: I felt anxious.

Inclusion Criteria: All patients
Timing: All time points
Data Source: Patient-reported
Type: Single answer
Value Domain: Code
Response Options: 0 = Most or all of the time
1 = Often
2 = Sometimes
3 = Only occasionally
4 = None of the time

Variable ID: REQOL20_Q18
Variable: Question 18 of the Recovering Quality of Life – 20-item version
Definition: I had problems with my sleep.
Supporting Definition: None
Display Value: I had problems with my sleep.
Inclusion Criteria: All patients
Timing: All time points
Data Source: Patient-reported
Type: Single answer
Value Domain: Code
Response Options: 0 = Most or all of the time
1 = Often
2 = Sometimes
3 = Only occasionally
4 = None of the time

Variable ID: REQOL20_Q19
Variable: Question 19 of the Recovering Quality of Life – 20-item version
Definition: I felt calm.
Supporting Definition: None
Display Value: I felt calm.
Inclusion Criteria: All patients
Timing: All time points
Data Source: Patient-reported
Type: Single answer
Value Domain: Code
Response Options: 0 = None of the time
1 = Only occasionally
2 = Sometimes
3 = Often
4 = Most or all of the time

Variable ID: REQOL20_Q20
Variable: Question 20 of the Recovering Quality of Life – 20-item version
Definition: I found it hard to concentrate.
Supporting Definition: None
Display Value: I found it hard to concentrate.
Inclusion Criteria: All patients
Timing: All time points
Data Source: Patient-reported
Type: Single answer
Value Domain: Code
Response Options: 0 = Most or all of the time
1 = Often
2 = Sometimes
3 = Only occasionally

4 = None of the time

Variable ID: REQOL20_Q21

Variable: Question 21 of the Recovering Quality of Life – 20-item version

Definition: Please describe your physical health (problems with pain, mobility, difficulties caring for yourself or feeling physically unwell) over the last week.

Supporting Definition: None

Display Value: Please describe your physical health (problems with pain, mobility, difficulties caring for yourself or feeling physically unwell) over the last week.

Inclusion Criteria: All patients

Timing: All time points

Data Source: Patient-reported

Type: Single answer

Value Domain: Code

Response Options: 0 = Very severe problems

1 = Severe problems

2 = Moderate problems

3 = Slight problems

4 = No problems

Functioning

Variable ID: WHODAS_Q01

Variable: Question 1 of WHODAS 2.0

Definition: This questionnaire asks about difficulties due to health conditions. Health conditions include diseases or illnesses, other health problems that may be short or long lasting, injuries, mental or emotional problems, and problems with alcohol or drugs.

Think back over the past 30 days and answer these questions, thinking about how much difficulty you had doing the following activities. For each question, please select only one response. In the past 30 days, how much difficulty did you have in:

S1: Standing for long periods such as 30 minutes?

Supporting Definition: None

Display Value: This questionnaire asks about difficulties due to health conditions. Health conditions include diseases or illnesses, other health problems that may be short or long lasting, injuries, mental or emotional problems, and problems with alcohol or drugs.

Think back over the past 30 days and answer these questions, thinking about how much difficulty you had doing the following activities. For each question, please select only one response. In the past 30 days, how much difficulty did you have in:

S1: Standing for long periods such as 30 minutes?

Inclusion Criteria: All patients in adult services or services that follow transition to adulthood

Timing: All time points

Data Source: Patient-reported

Type: Single answer

Value Domain: Code

Response Options: 0 = None

1 = Mild

2 = Moderate

3 = Severe

4 = Extreme or cannot do

Variable ID: WHODAS_Q02

Variable: Question 2 of WHODAS 2.0
Definition: S2: Taking care of your household responsibilities?
Supporting Definition: None
Display Value: S2: Taking care of your household responsibilities?
Inclusion Criteria: All patients in adult services or services that follow transition to adulthood
Timing: All time points
Data Source: Patient-reported
Type: Single answer
Value Domain: Code
Response Options: 0 = None
1 = Mild
2 = Moderate
3 = Severe
4 = Extreme or cannot do

Variable ID: WHODAS_Qo3
Variable: Question 3 of WHODAS 2.0
Definition: S3: Learning a new task, for example, learning how to get to a new place?
Supporting Definition: None
Display Value: S3: Learning a new task, for example, learning how to get to a new place?
Inclusion Criteria: All patients in adult services or services that follow transition to adulthood
Timing: All time points
Data Source: Patient-reported
Type: Single answer
Value Domain: Code
Response Options: 0 = None
1 = Mild
2 = Moderate
3 = Severe
4 = Extreme or cannot do

Variable ID: WHODAS_Qo4
Variable: Question 4 of WHODAS 2.0
Definition: S4: How much of a problem did you have joining in community activities (for example, festivities, religious or other activities) in the same way as anyone else can?
Supporting Definition: None
Display Value: S4: How much of a problem did you have joining in community activities (for example, festivities, religious or other activities) in the same way as anyone else can?
Inclusion Criteria: All patients in adult services or services that follow transition to adulthood
Timing: All time points
Data Source: Patient-reported
Type: Single answer
Value Domain: Code
Response Options: 0 = None
1 = Mild
2 = Moderate
3 = Severe
4 = Extreme or cannot do

Variable ID: WHODAS_Qo5
Variable: Question 5 of WHODAS 2.0
Definition: S5: How much have you been emotionally affected by your health problems?
Supporting Definition: Covering Global, Social and Interpersonal Functioning outcomes.
Display Value: S5: How much have you been emotionally affected by your health problems?
Inclusion Criteria: All patients in adult services or services that follow transition to adulthood

Timing: All time points
Data Source: Patient-reported
Type: Single answer
Value Domain: Code
Response Options: 0 = None
1 = Mild
2 = Moderate
3 = Severe
4 = Extreme or cannot do

Variable ID: WHODAS_Qo6
Variable: Question 6 of WHODAS 2.0
Definition: S6: Concentrating on doing something for ten minutes?
Supporting Definition: None
Display Value: S6: Concentrating on doing something for ten minutes?
Inclusion Criteria: All patients in adult services or services that follow transition to adulthood
Timing: All time points
Data Source: Patient-reported
Type: Single answer
Value Domain: Code
Response Options: 0 = None
1 = Mild
2 = Moderate
3 = Severe
4 = Extreme or cannot do

Variable ID: WHODAS_Qo7
Variable: Question 7 of WHODAS 2.0
Definition: S7: Walking a long distance such as a kilometer [or equivalent]?
Supporting Definition: None
Display Value: S7: Walking a long distance such as a kilometer [or equivalent]?
Inclusion Criteria: All patients in adult services or services that follow transition to adulthood
Timing: All time points
Data Source: Patient-reported
Type: Single answer
Value Domain: Code
Response Options: 0 = None
1 = Mild
2 = Moderate
3 = Severe
4 = Extreme or cannot do

Variable ID: WHODAS_Qo8
Variable: Question 8 of WHODAS 2.0
Definition: S8: Washing your whole body?
Supporting Definition: None
Display Value: S8: Washing your whole body?
Inclusion Criteria: All patients in adult services or services that follow transition to adulthood
Timing: All time points
Data Source: Patient-reported
Type: Single answer
Value Domain: Code
Response Options: 0 = None
1 = Mild
2 = Moderate
3 = Severe
4 = Extreme or cannot do

Variable ID: WHODAS_Q09
Variable: Question 9 of WHODAS 2.0
Definition: S9: Getting dressed?
Supporting Definition: None
Display Value: S9: Getting dressed?
Inclusion Criteria: All patients in adult services or services that follow transition to adulthood
Timing: All time points
Data Source: Patient-reported
Type: Single answer
Value Domain: Code
Response Options: 0 = None
1 = Mild
2 = Moderate
3 = Severe
4 = Extreme or cannot do

Variable ID: WHODAS_Q10
Variable: Question 10 of WHODAS 2.0
Definition: S10: Dealing with people you do not know?
Supporting Definition: None
Display Value: S10: Dealing with people you do not know?
Inclusion Criteria: All patients in adult services or services that follow transition to adulthood
Timing: All time points
Data Source: Patient-reported
Type: Single answer
Value Domain: Code
Response Options: 0 = None
1 = Mild
2 = Moderate
3 = Severe
4 = Extreme or cannot do

Variable ID: WHODAS_Q11
Variable: Question 11 of WHODAS 2.0
Definition: S11: Maintaining a friendship
Supporting Definition: None
Display Value: S11: Maintaining a friendship
Inclusion Criteria: All patients in adult services or services that follow transition to adulthood
Timing: All time points
Data Source: Patient-reported
Type: Single answer
Value Domain: Code
Response Options: 0 = None
1 = Mild
2 = Moderate
3 = Severe
4 = Extreme or cannot do

Variable ID: WHODAS_Q12
Variable: Question 12 of WHODAS 2.0
Definition: S12: Your day-to-day work?
Supporting Definition: None
Display Value: S12: Your day-to-day work?
Inclusion Criteria: All patients in adult services or services that follow transition to adulthood
Timing: All time points
Data Source: Patient-reported
Type: Single answer

Value Domain: Code
Response Options: 0 = None
1 = Mild
2 = Moderate
3 = Severe
4 = Extreme or cannot do

Variable ID: WHODAS12_Q13
Variable: Question 13 of WHODAS 2.1
Definition: S13: Overall, in the past 30 days, how many days were these difficulties present?
Supporting Definition: None
Display Value: S13: Overall, in the past 30 days, how many days were these difficulties present?
Inclusion Criteria: All patients in adult services or services that follow transition to adulthood
Timing: All time points
Data Source: Patient-reported
Type: Numerical value
Value Domain: Quantity
Response Options: Number of days

Variable ID: WHODAS12_Q14
Variable: Question 14 of WHODAS 2.2
Definition: S14: In the past 30 days, for how many days were you totally unable to carry out your usual activities or work because of any health condition?
Supporting Definition: None
Display Value: S14: In the past 30 days, for how many days were you totally unable to carry out your usual activities or work because of any health condition?
Inclusion Criteria: All patients in adult services or services that follow transition to adulthood
Timing: All time points
Data Source: Patient-reported
Type: Numerical value
Value Domain: Quantity
Response Options: Number of days

Variable ID: WHODAS12_Q15
Variable: Question 15 of WHODAS 2.2
Definition: S15: In the past 30 days, not counting the days that you were totally unable, for how many days did you cut back or reduce your usual activities or work because of any health condition?
Supporting Definition: None
Display Value: S15: In the past 30 days, not counting the days that you were totally unable, for how many days did you cut back or reduce your usual activities or work because of any health condition?
Inclusion Criteria: All patients in adult services or services that follow transition to adulthood
Timing: All time points
Data Source: Patient-reported
Type: Numerical value
Value Domain: Quantity
Response Options: Number of days

Variable ID: KIDSCREEN10_Q01
Variable: Question 1 of the KIDSCREEN-10 Index
Definition: Have you felt fit and well?
Supporting Definition: None
Display Value: Have you felt fit and well?
Inclusion Criteria: Adolescents in services working exclusively with children and young people
Timing: All time points
Data Source: Patient-reported
Type: Single answer

Value Domain: Code
Response Options: 0 = Not at all
1 = Slightly
2 = Moderately
3 = Very
4 = Extremely

Variable ID: KIDSCREEN10_Q02
Variable: Question 2 of the KIDSCREEN-10 Index
Definition: Have you felt full of energy?
Supporting Definition: None
Display Value: Have you felt full of energy?
Inclusion Criteria: Adolescents in services working exclusively with children and young people
Timing: All time points
Data Source: Patient-reported
Type: Single answer
Value Domain: Code
Response Options: 0 = Never
1 = Seldom
2 = Quite often
3 = Very often
4 = Always

Variable ID: KIDSCREEN10_Q03
Variable: Question 3 of the KIDSCREEN-10 Index
Definition: Have you felt sad?
Supporting Definition: None
Display Value: Have you felt sad?
Inclusion Criteria: Adolescents in services working exclusively with children and young people
Timing: All time points
Data Source: Patient-reported
Type: Single answer
Value Domain: Code
Response Options: 0 = Never
1 = Seldom
2 = Quite often
3 = Very often
4 = Always

Variable ID: KIDSCREEN10_Q04
Variable: Question 4 of the KIDSCREEN-10 Index
Definition: Have you felt lonely?
Supporting Definition: None
Display Value: Have you felt lonely?
Inclusion Criteria: Adolescents in services working exclusively with children and young people
Timing: All time points
Data Source: Patient-reported
Type: Single answer
Value Domain: Code
Response Options: 0 = Never
1 = Seldom
2 = Quite often
3 = Very often
4 = Always

Variable ID: KIDSCREEN10_Q05
Variable: Question 5 of the KIDSCREEN-10 Index
Definition: Have you had enough time for yourself?

Supporting Definition: None
Display Value: Have you had enough time for yourself?
Inclusion Criteria: Adolescents in services working exclusively with children and young people
Timing: All time points
Data Source: Patient-reported
Type: Single answer
Value Domain: Code
Response Options: 0 = Never
1 = Seldom
2 = Quite often
3 = Very often
4 = Always

Variable ID: KIDSCREEN10_Q06
Variable: Question 6 of the KIDSCREEN-10 Index
Definition: Have you been able to do the things that you want to do in your free time?
Supporting Definition: None
Display Value: Have you been able to do the things that you want to do in your free time?
Inclusion Criteria: Adolescents in services working exclusively with children and young people
Timing: All time points
Data Source: Patient-reported
Type: Single answer
Value Domain: Code
Response Options: 0 = Never
1 = Seldom
2 = Quite often
3 = Very often
4 = Always

Variable ID: KIDSCREEN10_Q07
Variable: Question 7 of the KIDSCREEN-10 Index
Definition: Have your parent(s) treated you fairly?
Supporting Definition: None
Display Value: Have your parent(s) treated you fairly?
Inclusion Criteria: Adolescents in services working exclusively with children and young people
Timing: All time points
Data Source: Patient-reported
Type: Single answer
Value Domain: Code
Response Options: 0 = Never
1 = Seldom
2 = Quite often
3 = Very often
4 = Always

Variable ID: KIDSCREEN10_Q08
Variable: Question 8 of the KIDSCREEN-10 Index
Definition: Have you had fun with your friends?
Supporting Definition: None
Display Value: Have you had fun with your friends?
Inclusion Criteria: Adolescents in services working exclusively with children and young people
Timing: All time points
Data Source: Patient-reported
Type: Single answer
Value Domain: Code
Response Options: 0 = Never
1 = Seldom

2 = Quite often
3 = Very often
4 = Always

Variable ID: KIDSCREEN10_Q09
Variable: Question 9 of the KIDSCREEN-10 Index
Definition: Have you got on well at school?
Supporting Definition: None
Display Value: Have you got on well at school?
Inclusion Criteria: Adolescents in services working exclusively with children and young people
Timing: All time points
Data Source: Patient-reported
Type: Single answer
Value Domain: Code
Response Options: 0 = Not at all
1 = Slightly
2 = Moderately
3 = Very
4 = Extremely

Variable ID: KIDSCREEN10_Q10
Variable: Question 10 of the KIDSCREEN-10 Index
Definition: Have you been able to pay attention?
Supporting Definition: None
Display Value: Have you been able to pay attention?
Inclusion Criteria: Adolescents in services working exclusively with children and young people
Timing: All time points
Data Source: Patient-reported
Type: Single answer
Value Domain: Code
Response Options: 0 = Never
1 = Seldom
2 = Quite often
3 = Very often
4 = Always

Variable ID: KIDSCREEN10_Q11
Variable: Question 11 of the KIDSCREEN-10 Index
Definition: In general, how would you say your health is?
Supporting Definition: None
Display Value: In general, how would you say your health is?
Inclusion Criteria: Adolescents in services working exclusively with children and young people
Timing: All time points
Data Source: Patient-reported
Type: Single answer
Value Domain: Code
Response Options: 0 = Poor
1 = Fair
2 = Good
3 = Very good
4 = Excellent

Variable ID: PHQ15_Q01
Variable: Question 1 of the Patient Health Questionnaire 15-item
Definition: During the past 7 days, how much have you been bothered by any of the following problems?
Stomach pain.
Supporting Definition: None

Display Value: During the past 4 weeks, how much have you been bothered by any of the following problems?
Stomach pain.

Inclusion Criteria: All patients

Timing: All time points

Data Source: Patient-reported

Type: Single answer

Value Domain: Code

Response Options: 0 = Not bothered at all
1 = Bothered a little
2 = Bothered a lot

Variable ID: PHQ15_Q02

Variable: Question 2 of the Patient Health Questionnaire 15-item

Definition: Back pain.

Supporting Definition: None

Display Value: Back pain.

Inclusion Criteria: All patients

Timing: All time points

Data Source: Patient-reported

Type: Single answer

Value Domain: Code

Response Options: 0 = Not bothered at all
1 = Bothered a little
2 = Bothered a lot

Variable ID: PHQ15_Q03

Variable: Question 3 of the Patient Health Questionnaire 15-item

Definition: Pain in your arms, legs, or joints (knees, hips, etc.).

Supporting Definition: None

Display Value: Pain in your arms, legs, or joints (knees, hips, etc.).

Inclusion Criteria: All patients

Timing: All time points

Data Source: Patient-reported

Type: Single answer

Value Domain: Code

Response Options: 0 = Not bothered at all
1 = Bothered a little
2 = Bothered a lot

Variable ID: PHQ15_Q04

Variable: Question 4 of the Patient Health Questionnaire 15-item

Definition: Menstrual cramps or other problems with your periods.

Supporting Definition: None

Display Value: Menstrual cramps or other problems with your periods.

Inclusion Criteria: Female patients

Timing: All time points

Data Source: Patient-reported

Type: Single answer

Value Domain: Code

Response Options: 0 = Not bothered at all
1 = Bothered a little
2 = Bothered a lot

Variable ID: PHQ15_Q05

Variable: Question 5 of the Patient Health Questionnaire 15-item

Definition: Headaches.

Supporting Definition: None

Display Value: Headaches.
Inclusion Criteria: All patients
Timing: All time points
Data Source: Patient-reported
Type: Single answer
Value Domain: Code
Response Options: 0 = Not bothered at all
1 = Bothered a little
2 = Bothered a lot

Variable ID: PHQ15_Qo6
Variable: Question 6 of the Patient Health Questionnaire 15-item
Definition: Chest pain.
Supporting Definition: None
Display Value: Chest pain.
Inclusion Criteria: All patients
Timing: All time points
Data Source: Patient-reported
Type: Single answer
Value Domain: Code
Response Options: 0 = Not bothered at all
1 = Bothered a little
2 = Bothered a lot

Variable ID: PHQ15_Qo7
Variable: Question 7 of the Patient Health Questionnaire 15-item
Definition: Dizziness.
Supporting Definition: None
Display Value: Dizziness.
Inclusion Criteria: All patients
Timing: All time points
Data Source: Patient-reported
Type: Single answer
Value Domain: Code
Response Options: 0 = Not bothered at all
1 = Bothered a little
2 = Bothered a lot

Variable ID: PHQ15_Qo8
Variable: Question 8 of the Patient Health Questionnaire 15-item
Definition: Fainting spells.
Supporting Definition: None
Display Value: Fainting spells.
Inclusion Criteria: All patients
Timing: All time points
Data Source: Patient-reported
Type: Single answer
Value Domain: Code
Response Options: 0 = Not bothered at all
1 = Bothered a little
2 = Bothered a lot

Variable ID: PHQ15_Qo9
Variable: Question 9 of the Patient Health Questionnaire 15-item
Definition: Feeling your heart pound or race.
Supporting Definition: None
Display Value: Feeling your heart pound or race.
Inclusion Criteria: All patients

Timing: All time points
Data Source: Patient-reported
Type: Single answer
Value Domain: Code
Response Options: 0 = Not bothered at all
1 = Bothered a little
2 = Bothered a lot

Variable ID: PHQ15_Q10
Variable: Question 10 of the Patient Health Questionnaire 15-item
Definition: Shortness of breath.
Supporting Definition: None
Display Value: Shortness of breath.
Inclusion Criteria: All patients
Timing: All time points
Data Source: Patient-reported
Type: Single answer
Value Domain: Code
Response Options: 0 = Not bothered at all
1 = Bothered a little
2 = Bothered a lot

Variable ID: PHQ15_Q11
Variable: Question 11 of the Patient Health Questionnaire 15-item
Definition: Pain or problems during sexual intercourse.
Supporting Definition: None
Display Value: Pain or problems during sexual intercourse.
Inclusion Criteria: All patients
Timing: All time points
Data Source: Patient-reported
Type: Single answer
Value Domain: Code
Response Options: 0 = Not bothered at all
1 = Bothered a little
2 = Bothered a lot

Variable ID: PHQ15_Q12
Variable: Question 12 of the Patient Health Questionnaire 15-item
Definition: Constipation, loose bowels, or diarrhoea.
Supporting Definition: None
Display Value: Constipation, loose bowels, or diarrhoea.
Inclusion Criteria: All patients
Timing: All time points
Data Source: Patient-reported
Type: Single answer
Value Domain: Code
Response Options: 0 = Not bothered at all
1 = Bothered a little
2 = Bothered a lot

Variable ID: PHQ15_Q13
Variable: Question 13 of the Patient Health Questionnaire 15-item
Definition: Nausea, gas, or indigestion.
Supporting Definition: None
Display Value: Nausea, gas, or indigestion.
Inclusion Criteria: All patients
Timing: All time points
Data Source: Patient-reported

Type: Single answer
Value Domain: Code
Response Options: 0 = Not bothered at all
1 = Bothered a little
2 = Bothered a lot

Variable ID: PHQ15_Q14
Variable: Question 14 of the Patient Health Questionnaire 15-item
Definition: Feeling tired or having low energy.
Supporting Definition: None
Display Value: Feeling tired or having low energy.
Inclusion Criteria: All patients
Timing: All time points
Data Source: Patient-reported
Type: Single answer
Value Domain: Code
Response Options: 0 = Not bothered at all
1 = Bothered a little
2 = Bothered a lot

Variable ID: PHQ15_Q15
Variable: Question 15 of the Patient Health Questionnaire 15-item
Definition: Trouble sleeping.
Supporting Definition: None
Display Value: Trouble sleeping.
Inclusion Criteria: All patients
Timing: All time points
Data Source: Patient-reported
Type: Single answer
Value Domain: Code
Response Options: 0 = Not bothered at all
1 = Bothered a little
2 = Bothered a lot

Treatment

Variable ID: GASS_Q01
Variable: Question 1 of the Glasgow Antipsychotic Side-Effect Scale
Definition: Over the past week:
I felt sleepy during the day.
Supporting Definition: None
Display Value: Over the past week:
I felt sleepy during the day.
Inclusion Criteria: Patients receiving antipsychotic medication
Timing: All time points
Data Source: Patient-reported
Type: Single answer
Tick list
Value Domain: Code
Response Options: 0 = Never
1 = Once
2 = A few times
3 = Everyday
(Tick last box if distressing)

Variable ID: GASS_Q02
Variable: Question 2 of the Glasgow Antipsychotic Side-Effect Scale
Definition: I felt drugged or like a zombie.

Supporting Definition: None
Display Value: I felt drugged or like a zombie.
Inclusion Criteria: Patients receiving antipsychotic medication
Timing: All time points
Data Source: Patient-reported
Type: Single answer
Tick list
Value Domain: Code
Response Options: 0 = Never
1 = Once
2 = A few times
3 = Everyday
(Tick last box if distressing)

Variable ID: GASS_Q03
Variable: Question 3 of the Glasgow Antipsychotic Side-Effect Scale
Definition: I felt dizzy when I stood up and/or have fainted.
Supporting Definition: None
Display Value: I felt dizzy when I stood up and/or have fainted.
Inclusion Criteria: Patients receiving antipsychotic medication
Timing: All time points
Data Source: Patient-reported
Type: Single answer
Tick list
Value Domain: Code
Response Options: 0 = Never
1 = Once
2 = A few times
3 = Everyday
(Tick last box if distressing)

Variable ID: GASS_Q04
Variable: Question 4 of the Glasgow Antipsychotic Side-Effect Scale
Definition: I have felt my heart beating irregularly or unusually fast.
Supporting Definition: None
Display Value: I have felt my heart beating irregularly or unusually fast.
Inclusion Criteria: Patients receiving antipsychotic medication
Timing: All time points
Data Source: Patient-reported
Type: Single answer
Tick list
Value Domain: Code
Response Options: 0 = Never
1 = Once
2 = A few times
3 = Everyday
(Tick last box if distressing)

Variable ID: GASS_Q05
Variable: Question 5 of the Glasgow Antipsychotic Side-Effect Scale
Definition: My muscles have been tense or jerky.
Supporting Definition: None
Display Value: My muscles have been tense or jerky.
Inclusion Criteria: Patients receiving antipsychotic medication
Timing: All time points
Data Source: Patient-reported
Type: Single answer

Value Domain: Tick list
Code
Response Options: 0 = Never
1 = Once
2 = A few times
3 = Everyday
(Tick last box if distressing)

Variable ID: GASS_Qo6
Variable: Question 6 of the Glasgow Antipsychotic Side-Effect Scale
Definition: My hands or arms have been shaky.
Supporting Definition: None
Display Value: My hands or arms have been shaky.
Inclusion Criteria: Patients receiving antipsychotic medication
Timing: All time points
Data Source: Patient-reported
Type: Single answer
Tick list
Value Domain: Code
Response Options: 0 = Never
1 = Once
2 = A few times
3 = Everyday
(Tick last box if distressing)

Variable ID: GASS_Qo7
Variable: Question 7 of the Glasgow Antipsychotic Side-Effect Scale
Definition: My legs have felt restless and/or I couldn't sit still.
Supporting Definition: Code
Display Value: My legs have felt restless and/or I couldn't sit still.
Inclusion Criteria: Patients receiving antipsychotic medication
Timing: All time points
Data Source: Patient-reported
Type: Single answer
Tick list
Value Domain: Code
Response Options: 0 = Never
1 = Once
2 = A few times
3 = Everyday
(Tick last box if distressing)

Variable ID: GASS_Qo8
Variable: Question 8 of the Glasgow Antipsychotic Side-Effect Scale
Definition: I have been drooling.
Supporting Definition: Code
Display Value: I have been drooling.
Inclusion Criteria: Patients receiving antipsychotic medication
Timing: All time points
Data Source: Patient-reported
Type: Single answer
Tick list
Value Domain: Code
Response Options: 0 = Never
1 = Once
2 = A few times
3 = Everyday

(Tick last box if distressing)

Variable ID: GASS_Q09
Variable: Question 9 of the Glasgow Antipsychotic Side-Effect Scale
Definition: My movements or walking have been slower than usual.
Supporting Definition: None
Display Value: My movements or walking have been slower than usual.
Inclusion Criteria: Patients receiving antipsychotic medication
Timing: All time points
Data Source: Patient-reported
Type: Single answer
Tick list
Value Domain: Code
Response Options: 0 = Never
1 = Once
2 = A few times
3 = Everyday
(Tick last box if distressing)

Variable ID: GASS_Q10
Variable: Question 10 of the Glasgow Antipsychotic Side-Effect Scale
Definition: I have had uncontrollable movements of my face or body.
Supporting Definition: None
Display Value: I have had uncontrollable movements of my face or body.
Inclusion Criteria: Patients receiving antipsychotic medication
Timing: All time points
Data Source: Patient-reported
Type: Single answer
Tick list
Value Domain: Code
Response Options: 0 = Never
1 = Once
2 = A few times
3 = Everyday
(Tick last box if distressing)

Variable ID: GASS_Q11
Variable: Question 11 of the Glasgow Antipsychotic Side-Effect Scale
Definition: My vision has been blurry.
Supporting Definition: None
Display Value: My vision has been blurry.
Inclusion Criteria: Patients receiving antipsychotic medication
Timing: All time points
Data Source: Patient-reported
Type: Single answer
Tick list
Value Domain: Code
Response Options: 0 = Never
1 = Once
2 = A few times
3 = Everyday
(Tick last box if distressing)

Variable ID: GASS_Q12
Variable: Question 12 of the Glasgow Antipsychotic Side-Effect Scale
Definition: My mouth has been dry.
Supporting Definition: None
Display Value: My mouth has been dry.

Inclusion Criteria: Patients receiving antipsychotic medication

Timing: All time points

Data Source: Patient-reported

Type: Single answer

Tick list

Value Domain: None

Response Options: 0 = Never

1 = Once

2 = A few times

3 = Everyday

(Tick last box if distressing)

Variable ID: GASS_Q13

Variable: Question 13 of the Glasgow Antipsychotic Side-Effect Scale

Definition: I have had difficulty passing urine.

Supporting Definition: None

Display Value: I have had difficulty passing urine.

Inclusion Criteria: Patients receiving antipsychotic medication

Timing: All time points

Data Source: Patient-reported

Type: Single answer

Tick list

Value Domain: Code

Response Options: 0 = Never

1 = Once

2 = A few times

3 = Everyday

(Tick last box if distressing)

Variable ID: GASS_Q14a

Variable: Question 14 (a) of the Glasgow Antipsychotic Side-Effect Scale

Definition: I have felt like I am going to be sick or have vomited.

Supporting Definition: None

Display Value: I have felt like I am going to be sick or have vomited.

Inclusion Criteria: Patients receiving antipsychotic medication

Timing: All time points

Data Source: Patient-reported

Type: Single answer

Tick list

Value Domain: Code

Response Options: 0 = Never

1 = Once

2 = A few times

3 = Everyday

(Tick last box if distressing)

Variable ID: GASS_Q14b

Variable: Question 14 (b) of the Glasgow Antipsychotic Side-Effect Scale

Definition: I have had problems opening my bowels (constipation).

Supporting Definition: None

Display Value: I have had problems opening my bowels (constipation).

Inclusion Criteria: Patients receiving antipsychotic medication

Timing: All time points

Data Source: Patient-reported

Type: Single answer

Tick list

Value Domain: Code

Response Options: 0 = Never
1 = Once
2 = A few times
3 = Everyday
(Tick last box if distressing)

Variable ID: GASS_Q15

Variable: Question 15 of the Glasgow Antipsychotic Side-Effect Scale

Definition: I have wet the bed.

Supporting Definition: None

Display Value: I have wet the bed.

Inclusion Criteria: Patients receiving antipsychotic medication

Timing: All time points

Data Source: Patient-reported

Type: Single answer

Tick list

Value Domain: Code

Response Options: 0 = Never

1 = Once

2 = A few times

3 = Everyday

(Tick last box if distressing)

Variable ID: GASS_Q16

Variable: Question 16 of the Glasgow Antipsychotic Side-Effect Scale

Definition: I have been very thirsty and/or passing urine frequently.

Supporting Definition: None

Display Value: I have been very thirsty and/or passing urine frequently.

Inclusion Criteria: Patients receiving antipsychotic medication

Timing: All time points

Data Source: Patient-reported

Type: Single answer

Tick list

Value Domain: Code

Response Options: 0 = Never

1 = Once

2 = A few times

3 = Everyday

(Tick last box if distressing)

Variable ID: GASS_Q17

Variable: Question 17 of the Glasgow Antipsychotic Side-Effect Scale

Definition: The areas around my nipples have been sore and swollen.

Supporting Definition: None

Display Value: The areas around my nipples have been sore and swollen.

Inclusion Criteria: Patients receiving antipsychotic medication

Timing: All time points

Data Source: Patient-reported

Type: Single answer

Tick list

Value Domain: Code

Response Options: 0 = Never

1 = Once

2 = A few times

3 = Everyday

(Tick last box if distressing)

Variable ID: GASS_Q18

Variable: Question 18 of the Glasgow Antipsychotic Side-Effect Scale
Definition: I have noticed fluid coming from my nipples.
Supporting Definition: None
Display Value: I have noticed fluid coming from my nipples.
Inclusion Criteria: Patients receiving antipsychotic medication
Timing: All time points
Data Source: Patient-reported
Type: Single answer
Tick list
Value Domain: Code
Response Options: 0 = Never
1 = Once
2 = A few times
3 = Everyday
(Tick last box if distressing)

Variable ID: GASS_Q19
Variable: Question 19 of the Glasgow Antipsychotic Side-Effect Scale
Definition: I have had problems enjoying sex.
Supporting Definition: None
Display Value: I have had problems enjoying sex.
Inclusion Criteria: Patients receiving antipsychotic medication
Timing: All time points
Data Source: Patient-reported
Type: Single answer
Tick list
Value Domain: Code
Response Options: 0 = Never
1 = Once
2 = A few times
3 = Everyday
(Tick last box if distressing)

Variable ID: GASS_Q20
Variable: Question 20 of the Glasgow Antipsychotic Side-Effect Scale
Definition: I have had problems getting an erection.
Supporting Definition: None
Display Value: I have had problems getting an erection.
Inclusion Criteria: Male patients receiving antipsychotic medication
Timing: All time points
Data Source: Patient-reported
Type: Single answer
Tick list
Value Domain: Code
Response Options: 0 = Never
1 = Once
2 = A few times
3 = Everyday
(Tick last box if distressing)

Variable ID: GASS_Q21
Variable: Question 21 of the Glasgow Antipsychotic Side-Effect Scale
Definition: Tick yes or no for the last three months:
I have noticed a change in my periods.
Supporting Definition: None
Display Value: Tick yes or no for the last three months:
I have noticed a change in my periods.

Inclusion Criteria: Female patients receiving antipsychotic medication

Timing: All time points

Data Source: Patient-reported

Type: Single answer

Tick list

Value Domain: Code

Response Options: 0 = No

3 = Yes

(Tick last box if distressing)

Variable ID: GASS_Q22

Variable: Question 22 of the Glasgow Antipsychotic Side-Effect Scale

Definition: I have been gaining weight.

Supporting Definition: None

Display Value: I have been gaining weight.

Inclusion Criteria: Patients receiving antipsychotic medication

Timing: All time points

Data Source: Patient-reported

Type: Single answer

Tick list

Value Domain: Code

Response Options: 0 = No

3 = Yes

(Tick last box if distressing)

Working Group Member Conflicts of Interests

At the beginning of the Working Group process, we ask all Working Group members to declare any conflicts of interests they have. We then circulate these within the Group to ensure transparency.

Name	Affiliation	Declarations
Addington, Donald	University of Calgary, Canada	None declared.
Anderson, Elizabeth	Patient representative, Canada	None declared.
Baandrup, Lone	Mental Health Centre Copenhagen, Denmark	None declared.
Bakhshy, Amrit	Patient representative, Schizophrenia Awareness Association, Pune, India	Caregiver and mental health activist.
Brabban, Alison	Tees, Esk & Wear Valleys NHS Foundation Trust; NHS England, United Kingdom	None declared.
Coombs, Tim	Illawarra Institute for Mental Health, University of Wollongong, Australia	None declared.
Correll, Christoph U.	Hofstra Northwell School of Medicine; Feinstein Institute for Medical Research; The Zucker Hillside Hospital, Department of Psychiatry, United States	Honorarium: Acadia, Alkermes, Allergan, Angelini, Axsome, Gedeon Richter, Gerson Lehrman Group, IntraCellular Therapies, Janssen/J&J, LB Pharma, Lundbeck, MedAvante-ProPhase, Medscape, Neurocrine, Noven, Otsuka, Pfizer, Recordati, Rovi, Sumitomo Dainippon, Sunovion, Supernus, Takeda, and Teva. Grant: Berlin Institute of health (BIH), Janssen, the National Institute of Mental Health (NIMH), Patient Centered Outcomes Research Institute (PCORI), Takeda, and the Thrasher Foundation. Has provided expert testimony for Janssen and Otsuka. Served on a Data Safety Monitoring Board for Lundbeck, Rovi, Supernus, and Teva. Received royalties from UpToDate and is also a stock option holder of LB Pharma.
Cupitt, Caroline	South London and Maudsley NHS Foundation Trust, United Kingdom	None declared.
Dimitriadis, Fokion	Patient representative, Greece	None declared.

Name	Affiliation	Declarations
Keetharuth, Anju D.	School of Health and Related Research, University of Sheffield, United Kingdom	Developed the measure Recovering Quality of Life, which has been included in this Set of Patient-Centered Outcome Measures.
Lima Sanchez, Dania Nimbe	Medicine School, Universidad Nacional Autónoma de México, Mexico	None declared.
McCrone, Paul	Institute for Lifecourse Development, Faculty of Education, Health and Human Sciences, University of Greenwich, United Kingdom	None declared.
McKenzie, Emily	University of Calgary, Canada	None declared.
Moller, Mary D.	Pacific Lutheran University, Tacoma, WA, United States	Honorarium: Alkermes Pharmaceutical and Otsuka Pharmaceutical.
Mulder, Niels C. L.	Erasmus MC, Rotterdam, Netherlands	Have been involved in the Dutch translation and validation of the ReQoL10 but have no financial interests in it.
Roe, David	University of Haifa, Israel	None declared.
Sara, Grant	NSW Ministry of Health; University of Sydney, Australia	None declared.
Shokraneh, Farhad	University of Nottingham, United Kingdom	None declared.
Sin, Jacqueline	University of Reading, United Kingdom	None declared.
Woodberry, Kristen	Maine Medical Center Research Institute, United States	None declared.

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Reference Guide Revisions

Reference Guide Version	Location within Reference Guide	Content Change
4.0.0	Data Dictionary, Appendix	Harmonization updates
4.0.0	Whole Document	Wording change. Replacing 'Standard Sets' to 'Sets of Patient-Centered Outcome Measures'

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