ICHOM

International Consortium for Health Outcomes Measurement

Personality Disorders
DATA COLLECTION REFERENCE GUIDE

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ICHOM

PERSONALITY DISORDERS

We are thrilled that you are interested in measuring outcomes for your patients with personality 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 Personality Disorders, June 2020, available at: https://www.ichom.org/portfolio/personality-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 Personality Disorders

The following individuals dedicated both time and expertise to develop the ICHOM Set for Personality Disorders in partnership with ICHOM, under the leadership of Professor Mike Crawford, ICHOM Set Chair. The work was supported by Valentina Prevolnik Rupel, ICHOM Research Fellow, Beth Jagger and Luz Sousa Fialho, ICHOM Project Managers, and Lisa-Marie Chadderton and Timea Gintner, ICHOM Research Associates.

Australia
Andrew Chanen

Belgium
Charlotte Delvaux
Fieke van Gorp

Canada
Lucie Langford

Mexico
Karla Patricia Pacheco Alvarado

Netherlands
Anroud Arntz
Jan van Busschbach

New Zealand
Brian McKenna

Norway
Åse-Line Baltzersen
Wei Wang

United Kingdom
Julia Blazdell
Karen M. Wright
Marika Cencelli
Paul Moran

United States
Carla Sharp

Supporting Organizations

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

Thank You.

Scope of Personality Disorders Set of Patient-Centered Outcome Measures

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

Conditions	All Personality Disorders based on ICD-11 and DSM-5 criteria
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
Excluded conditions	Substance use induced Personality Disorder | Organical causes, including head injury | Personality change/disorder secondary to other mental condition | Subthreshold personality dysfunction, personality difficulty
Excluded treatment approaches	Use of drugs for comorbid conditions | Sedative medication for Personality Disorder in a crisis

ICHOM Set of Patient-Centered Outcome Measures for Personality Disorders

Case-Mix Variables

Patient Population	Measure	Timing	Data Source
Demographic factors			
All patients	Year of birth	Baseline	Clinical
	Sex		
	Gender identity		Patient-reported
	Sexual orientation		
	Level of Education	Baseline; Transition to adult services; Annually if still in education	Patient-reported
	Work Status	Baseline; Annually	
	Housing status		
	Living arrangements		
	Ethnicity	Baseline	
	Race		
Adult patients; Adolescent patients (where appropriate – see supporting information)	Contact with law enforcement	Baseline; Annually	
Clinical factors			
All patients	Comorbidities	Baseline	Patient-reported
	Hospitalisations	Baseline; Annually	Clinical
Adult patients; Adolescent patients (where appropriate – see supporting information)	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
Mental Health			
All patients	Identity Disturbance	All time points	Patient-reported
	Emotional Distress		
	*Emotional Dysregulation**		
	Suicidal Ideation and Behaviour		
Behaviour			
All patients	Impulsivity	All time points	Patient-reported
	*Aggression**		Clinical
	*Self-harm**		
Functioning			
All patients	Global Functioning	All time points	Patient-reported
	Social Functioning		

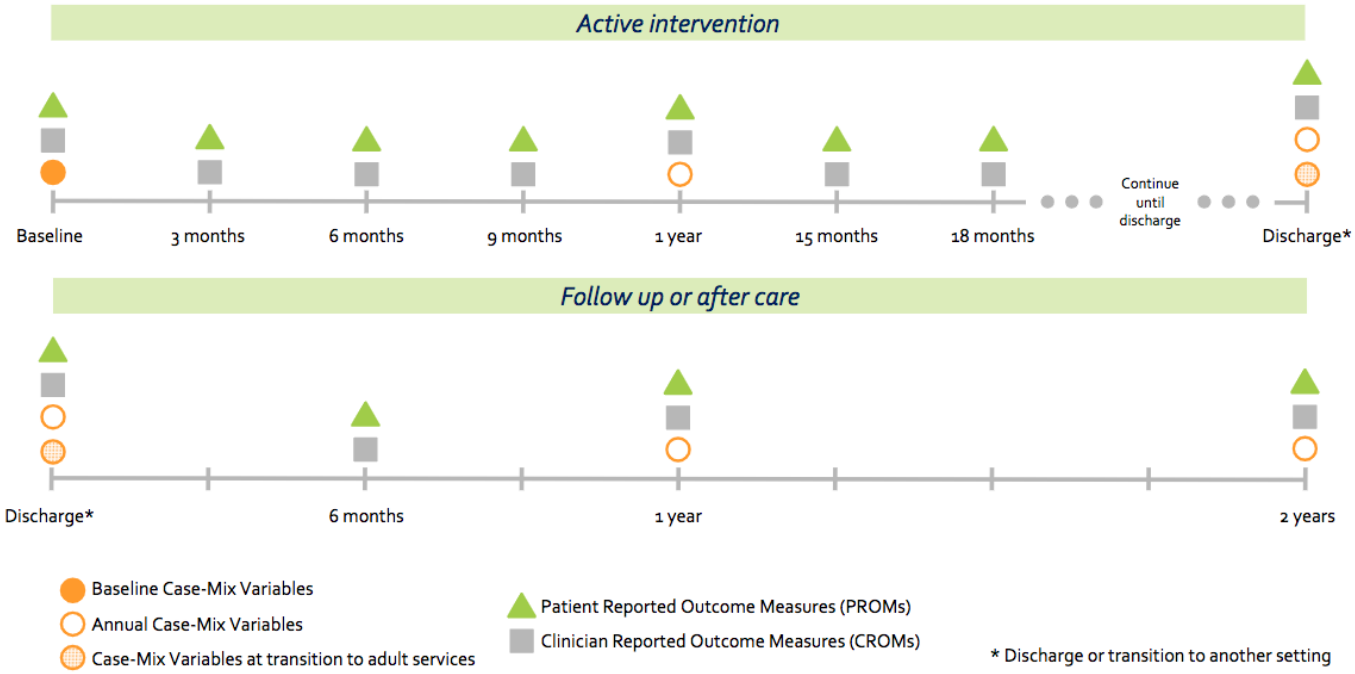
** Optional outcomes.*

Patient Population	Outcome	Timing	Data Source
All patients	Interpersonal Functioning	All time points	Patient-reported
	Self-care		
Recovery			
All patients	Sense of Belonging	All time points	Patient-reported
	Health-Related Quality of Life		
	Severity of Personality Disorder		
Social Environment			
	*Coping with Past Experiences of Trauma***		

*** After a thorough research, the Working Group was not able to identify an adequate outcome measure to capture this outcome. Therefore, the outcome being important to service users, the Sets of Patient-Centered Outcome Measures can identify this as a gap in current available outcome measures and make a research recommendation for the future.*

Follow-Up Algorithm

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



Collecting Patient-Reported Outcomes

Personality Disorders Surveys Used	Licensing Information	Scoring Information
Level of Personality Functioning Scale – Brief Form 2.0 (LPFS-BF 2.0)	Free to use for non-profit organizations. Please contact LPFSBP@deviersprong.nl for permission to distribute electronic versions of this measure. The measure and its translations can be found here.	The scoring guide may be found at the same link.
Recovering Quality of Life – 10-item version (ReQoL10)	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.
*Difficulties in Emotion Regulation Scale - 16-item version (DERS-16)**	Free to use. Measure available at: https://link.springer.com/article/10.1007%2Fs10862-015-9514-x.	The scoring guide may be found at the same link.
Columbia Suicide Severity Rating Scale - Screener/Recent - Self-report (C-SSRS)	Free to use in a multitude of community and healthcare settings (full list of settings), no special permission required. Measure available from here. A licensing agreement is required to use the C-SSRS in clinical trials.	The scoring guide may be found here.
*Modified Overt Aggression Scale (MOAS)**	Free to use. Measure available here.	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 national organisations, hospitals, healthcare centres etc.), no additional fees for usage. To use and/or translate complete this Collaboration Form.	The scoring guide may be found here.
PROMIS Short Form v2.0 - Social Isolation 4a	Free to use. All English and Spanish PROMIS measures are publicly available here for use in one's individual research, clinical practice, educational assessment, or other application without licensing or royalty fees. Commercial users must seek permission to use, reproduce, or distribute measures. Integration into proprietary technology requires written permission.	The scoring guide may be found at the same link.
	The SCQ is not copyrighted and a license is not needed. It may be found at:	Each medical condition asks 3 questions: whether

Modified Self-Administered Comorbidity Questionnaire (SCQ)	Sangha et al (2003) The self-administered comorbidity questionnaire: A new method to assess comorbidity for clinical and health services research. Arthritis Care & Research 49(2): 156-163	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.

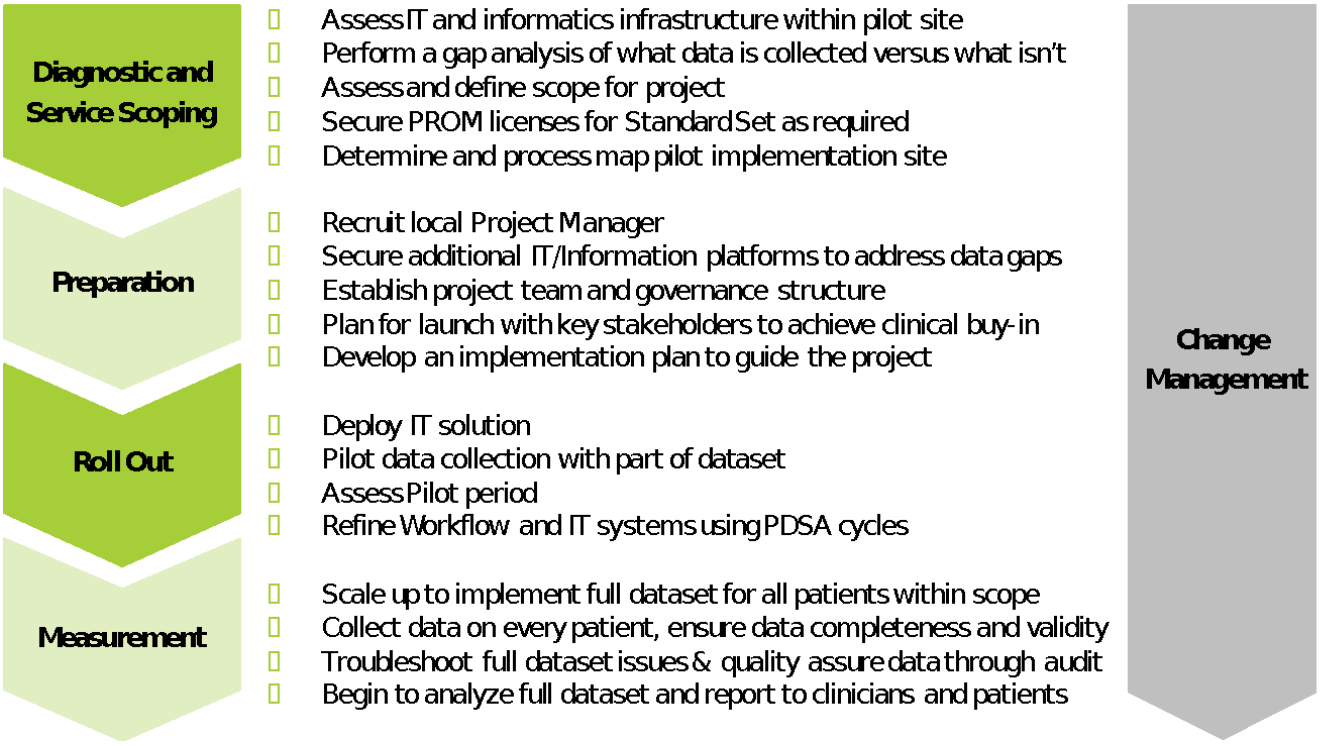
* *Optional outcome measures.*

ICHOM International Consortium for Health Outcomes Measurement

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 Set 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 Set. Please fill in this survey: bit.ly/InitialImp or contact info@ichom.org for more information.

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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 Measures [1] 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 Personality 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. 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 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 Annually
Data Source:	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:	COMORB
Variable:	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). Please do not select target condition.
Display Value:	Have you been told by a doctor that you have any of the following?
Inclusion Criteria:	All patients
Timing:	Baseline Annually
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 = Leg pain when walking due to poor circulation 4 = Lung disease (For example asthma, chronic bronchitis, or emphysema) 5 = Diabetes 6 = Kidney disease 7 = Liver disease 8 = Problems caused by stroke 9 = Disease of the nervous system (For example Parkinson's disease or Multiple Sclerosis) 10 = Cancer (within the last 5 years) 11 = Depression 12 = Anxiety 13 = Arthritis 14 = Sexually transmitted disease 15 = Substance abuse (For example alcohol or drugs) 16 = Somatoform disorder (unexplained medical symptoms) 17 = Personality disorder 18 = Chronic pain disorder 19 = Schizophrenic disorder 888 = Other 999 = Prefer not to say
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 Annually
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 Annually
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 Annually

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 Annually
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 Annually
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 Annually
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 Annually
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 Annually
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 Annually
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 Annually
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 Annually
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 Annually
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 Annually
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 Annually
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 Annually
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 Annually
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 Annually
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 Annually
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 Annually
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 Annually
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

	Annually
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 Annually
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 Annually
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 Annually
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 Annually
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 Annually
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 Annually
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 Annually

Data Source:	Patient-reported
Type:	Free text
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 Annually
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:	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
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_Q03
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_Q04
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_Q05
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_Q06
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_Q07
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_Q08
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-Related 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 Annually
Data Source:	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

Mental Health

Variable ID:	LPFS-BF_Q01
Variable:	Question 1 of the Level of Personality Functioning Scale - Brief Form 2.0
Definition:	I often do not know who I really am.
Supporting Definition:	None

Display Value:	I often do not know who I really am.
Inclusion Criteria:	All patients
Timing:	All time points
Data Source:	Patient-reported
Type:	Single answer
Value Domain:	Code
Response Options:	1 = Very false or often false 2 = Sometimes or somewhat false 3 = Sometimes or somewhat true 4 = Very true or often true
Variable ID:	LPFS-BF_Q02
Variable:	Question 2 of the Level of Personality Functioning Scale - Brief Form 2.0
Definition:	I often think very negatively about myself.
Supporting Definition:	None
Display Value:	I often think very negatively about myself.
Inclusion Criteria:	All patients
Timing:	All time points
Data Source:	Patient-reported
Type:	Single answer
Value Domain:	Code
Response Options:	1 = Very false or often false 2 = Sometimes or somewhat false 3 = Sometimes or somewhat true 4 = Very true or often true
Variable ID:	LPFS-BF_Q03
Variable:	Question 3 of the Level of Personality Functioning Scale - Brief Form 2.0
Definition:	My emotions change without me having a grip on them.
Supporting Definition:	None
Display Value:	My emotions change without me having a grip on them.
Inclusion Criteria:	All patients
Timing:	All time points
Data Source:	Patient-reported
Type:	Single answer
Value Domain:	Code
Response Options:	1 = Very false or often false 2 = Sometimes or somewhat false 3 = Sometimes or somewhat true 4 = Very true or often true
Variable ID:	LPFS-BF_Q04
Variable:	Question 4 of the Level of Personality Functioning Scale - Brief Form 2.0
Definition:	I have no sense of where I want to go in my life.
Supporting Definition:	None
Display Value:	I have no sense of where I want to go in my life.
Inclusion Criteria:	All patients
Timing:	All time points
Data Source:	Patient-reported
Type:	Single answer
Value Domain:	Code
Response Options:	1 = Very false or often false 2 = Sometimes or somewhat false 3 = Sometimes or somewhat true 4 = Very true or often true
Variable ID:	LPFS-BF_Q05
Variable:	Question 5 of the Level of Personality Functioning Scale - Brief Form 2.0

Definition:	I often do not understand my own thoughts and feelings.
Supporting Definition:	None
Display Value:	I often do not understand my own thoughts and feelings.
Inclusion Criteria:	All patients
Timing:	All time points
Data Source:	Patient-reported
Type:	Single answer
Value Domain:	Code
Response Options:	1 = Very false or often false 2 = Sometimes or somewhat false 3 = Sometimes or somewhat true 4 = Very true or often true
Variable ID:	LPFS-BF_Q06
Variable:	Question 6 of the Level of Personality Functioning Scale - Brief Form 2.0
Definition:	I often make unrealistic demands on myself.
Supporting Definition:	None
Display Value:	I often make unrealistic demands on myself.
Inclusion Criteria:	All patients
Timing:	All time points
Data Source:	Patient-reported
Type:	Single answer
Value Domain:	Code
Response Options:	1 = Very false or often false 2 = Sometimes or somewhat false 3 = Sometimes or somewhat true 4 = Very true or often true
Variable ID:	LPFS-BF_Q07
Variable:	Question 7 of the Level of Personality Functioning Scale - Brief Form 2.0
Definition:	I often have difficulty understanding the thoughts and feelings of others.
Supporting Definition:	None
Display Value:	I often have difficulty understanding the thoughts and feelings of others.
Inclusion Criteria:	All patients
Timing:	All time points
Data Source:	Patient-reported
Type:	Single answer
Value Domain:	Code
Response Options:	1 = Very false or often false 2 = Sometimes or somewhat false 3 = Sometimes or somewhat true 4 = Very true or often true
Variable ID:	LPFS-BF_Q08
Variable:	Question 8 of the Level of Personality Functioning Scale - Brief Form 2.0
Definition:	I often find it hard to stand it when others have a different opinion.
Supporting Definition:	None
Display Value:	I often find it hard to stand it when others have a different opinion.
Inclusion Criteria:	All patients
Timing:	All time points
Data Source:	Patient-reported
Type:	Single answer
Value Domain:	Code
Response Options:	1 = Very false or often false 2 = Sometimes or somewhat false 3 = Sometimes or somewhat true 4 = Very true or often true

Variable ID:	LPFS-BF_Q09
Variable:	Question 9 of the Level of Personality Functioning Scale - Brief Form 2.0
Definition:	I often do not fully understand why my behaviour has a certain effect on others.
Supporting Definition:	None
Display Value:	I often do not fully understand why my behaviour has a certain effect on others.
Inclusion Criteria:	All patients
Timing:	All time points
Data Source:	Patient-reported
Type:	Single answer
Value Domain:	Code
Response Options:	1 = Very false or often false 2 = Sometimes or somewhat false 3 = Sometimes or somewhat true 4 = Very true or often true
Variable ID:	LPFS-BF_Q10
Variable:	Question 10 of the Level of Personality Functioning Scale - Brief Form 2.0
Definition:	My relationships and friendships never last long.
Supporting Definition:	None
Display Value:	My relationships and friendships never last long.
Inclusion Criteria:	All patients
Timing:	All time points
Data Source:	Patient-reported
Type:	Single answer
Value Domain:	Code
Response Options:	1 = Very false or often false 2 = Sometimes or somewhat false 3 = Sometimes or somewhat true 4 = Very true or often true
Variable ID:	LPFS-BF_Q11
Variable:	Question 11 of the Level of Personality Functioning Scale - Brief Form 2.0
Definition:	I often feel very vulnerable when relations become more personal.
Supporting Definition:	None
Display Value:	I often feel very vulnerable when relations become more personal.
Inclusion Criteria:	All patients
Timing:	All time points
Data Source:	Patient-reported
Type:	Single answer
Value Domain:	Code
Response Options:	1 = Very false or often false 2 = Sometimes or somewhat false 3 = Sometimes or somewhat true 4 = Very true or often true
Variable ID:	LPFS-BF_Q12
Variable:	Question 12 of the Level of Personality Functioning Scale - Brief Form 2.0
Definition:	I often do not succeed in cooperating with others in a mutually satisfactory way.
Supporting Definition:	None
Display Value:	I often do not succeed in cooperating with others in a mutually satisfactory way.
Inclusion Criteria:	All patients
Timing:	All time points
Data Source:	Patient-reported
Type:	Single answer
Value Domain:	Code
Response Options:	1 = Very false or often false 2 = Sometimes or somewhat false

	3 = Sometimes or somewhat true 4 = Very true or often true
Variable ID:	DERS-16_Q01
Variable:	Question 1 of the Difficulties in Emotion Regulation Scale - 16-item version
Definition:	I have difficulty making sense out of my feelings.
Supporting Definition:	*Optional outcome measure.*
Display Value:	I have difficulty making sense out of my feelings.
Inclusion Criteria:	All patients
Timing:	All time points
Data Source:	Patient-reported
Type:	Single answer
Value Domain:	Code
Response Options:	1 = Almost never 2 = Sometimes 3 = About half the time 4 = Most of the time 5 = Almost always
Variable ID:	DERS-16_Q02
Variable:	Question 2 of the Difficulties in Emotion Regulation Scale - 16-item version
Definition:	I am confused about how I feel.
Supporting Definition:	*Optional outcome measure.*
Display Value:	I am confused about how I feel.
Inclusion Criteria:	All patients
Timing:	All time points
Data Source:	Patient-reported
Type:	Single answer
Value Domain:	Code
Response Options:	1 = Almost never 2 = Sometimes 3 = About half the time 4 = Most of the time 5 = Almost always
Variable ID:	DERS-16_Q03
Variable:	Question 3 of the Difficulties in Emotion Regulation Scale - 16-item version
Definition:	When I'm upset, I have difficulty getting work done.
Supporting Definition:	*Optional outcome measure.*
Display Value:	When I'm upset, I have difficulty getting work done.
Inclusion Criteria:	All patients
Timing:	All time points
Data Source:	Patient-reported
Type:	Single answer
Value Domain:	Code
Response Options:	1 = Almost never 2 = Sometimes 3 = About half the time 4 = Most of the time 5 = Almost always
Variable ID:	DERS-16_Q04
Variable:	Question 4 of the Difficulties in Emotion Regulation Scale - 16-item version
Definition:	When I'm upset, I become out of control.
Supporting Definition:	*Optional outcome measure.*
Display Value:	When I'm upset, I become out of control.
Inclusion Criteria:	All patients
Timing:	All time points

Data Source:	Patient-reported
Type:	Single answer
Value Domain:	Code
Response Options:	1 = Almost never 2 = Sometimes 3 = About half the time 4 = Most of the time 5 = Almost always
Variable ID:	DERS-16_Q05
Variable:	Question 5 of the Difficulties in Emotion Regulation Scale - 16-item version
Definition:	When I'm upset, I believe that I will remain that way for a long time.
Supporting Definition:	*Optional outcome measure.*
Display Value:	When I'm upset, I believe that I will remain that way for a long time.
Inclusion Criteria:	All patients
Timing:	All time points
Data Source:	Patient-reported
Type:	Single answer
Value Domain:	Code
Response Options:	1 = Almost never 2 = Sometimes 3 = About half the time 4 = Most of the time 5 = Almost always
Variable ID:	DERS-16_Q06
Variable:	Question 6 of the Difficulties in Emotion Regulation Scale - 16-item version
Definition:	When I'm upset, I believe that I'll end up feeling very depressed.
Supporting Definition:	*Optional outcome measure.*
Display Value:	When I'm upset, I believe that I'll end up feeling very depressed.
Inclusion Criteria:	All patients
Timing:	All time points
Data Source:	Patient-reported
Type:	Single answer
Value Domain:	Code
Response Options:	1 = Almost never 2 = Sometimes 3 = About half the time 4 = Most of the time 5 = Almost always
Variable ID:	DERS-16_Q07
Variable:	Question 7 of the Difficulties in Emotion Regulation Scale - 16-item version
Definition:	When I'm upset, I have difficulty focusing on other things.
Supporting Definition:	*Optional outcome measure.*
Display Value:	When I'm upset, I have difficulty focusing on other things.
Inclusion Criteria:	All patients
Timing:	All time points
Data Source:	Patient-reported
Type:	Single answer
Value Domain:	Code
Response Options:	1 = Almost never 2 = Sometimes 3 = About half the time 4 = Most of the time 5 = Almost always
Variable ID:	DERS-16_Q08

Variable:	Question 8 of the Difficulties in Emotion Regulation Scale - 16-item version
Definition:	When I'm upset, I feel out of control.
Supporting Definition:	*Optional outcome measure.*
Display Value:	When I'm upset, I feel out of control.
Inclusion Criteria:	All patients
Timing:	All time points
Data Source:	Patient-reported
Type:	Single answer
Value Domain:	Code
Response Options:	1 = Almost never 2 = Sometimes 3 = About half the time 4 = Most of the time 5 = Almost always
Variable ID:	DERS-16_Q09
Variable:	Question 9 of the Difficulties in Emotion Regulation Scale - 16-item version
Definition:	When I'm upset, I feel ashamed with myself for feeling that way.
Supporting Definition:	*Optional outcome measure.*
Display Value:	When I'm upset, I feel ashamed with myself for feeling that way.
Inclusion Criteria:	All patients
Timing:	All time points
Data Source:	Patient-reported
Type:	Single answer
Value Domain:	Code
Response Options:	1 = Almost never 2 = Sometimes 3 = About half the time 4 = Most of the time 5 = Almost always
Variable ID:	DERS-16_Q10
Variable:	Question 10 of the Difficulties in Emotion Regulation Scale - 16-item version
Definition:	When I'm upset, I feel like I am weak.
Supporting Definition:	*Optional outcome measure.*
Display Value:	When I'm upset, I feel like I am weak.
Inclusion Criteria:	All patients
Timing:	All time points
Data Source:	Patient-reported
Type:	Single answer
Value Domain:	Code
Response Options:	1 = Almost never 2 = Sometimes 3 = About half the time 4 = Most of the time 5 = Almost always
Variable ID:	DERS-16_Q11
Variable:	Question 11 of the Difficulties in Emotion Regulation Scale - 16-item version
Definition:	When I'm upset, I have difficulty controlling my behaviours.
Supporting Definition:	*Optional outcome measure.*
Display Value:	When I'm upset, I have difficulty controlling my behaviours.
Inclusion Criteria:	All patients
Timing:	All time points
Data Source:	Patient-reported
Type:	Single answer
Value Domain:	Code

Response Options:	1 = Almost never 2 = Sometimes 3 = About half the time 4 = Most of the time 5 = Almost always
Variable ID:	DERS-16_Q12
Variable:	Question 12 of the Difficulties in Emotion Regulation Scale - 16-item version
Definition:	When I'm upset, I believe that there is nothing I can do to make myself feel better.
Supporting Definition:	*Optional outcome measure.*
Display Value:	When I'm upset, I believe that there is nothing I can do to make myself feel better.
Inclusion Criteria:	All patients
Timing:	All time points
Data Source:	Patient-reported
Type:	Single answer
Value Domain:	Code
Response Options:	1 = Almost never 2 = Sometimes 3 = About half the time 4 = Most of the time 5 = Almost always
Variable ID:	DERS-16_Q13
Variable:	Question 13 of the Difficulties in Emotion Regulation Scale - 16-item version
Definition:	When I'm upset, I become irritated with myself for feeling that way.
Supporting Definition:	*Optional outcome measure.*
Display Value:	When I'm upset, I become irritated with myself for feeling that way.
Inclusion Criteria:	All patients
Timing:	All time points
Data Source:	Patient-reported
Type:	Single answer
Value Domain:	Code
Response Options:	1 = Almost never 2 = Sometimes 3 = About half the time 4 = Most of the time 5 = Almost always
Variable ID:	DERS-16_Q14
Variable:	Question 14 of the Difficulties in Emotion Regulation Scale - 16-item version
Definition:	When I'm upset, I start to feel very bad about myself.
Supporting Definition:	*Optional outcome measure.*
Display Value:	When I'm upset, I start to feel very bad about myself.
Inclusion Criteria:	All patients
Timing:	All time points
Data Source:	Patient-reported
Type:	Single answer
Value Domain:	Code
Response Options:	1 = Almost never 2 = Sometimes 3 = About half the time 4 = Most of the time 5 = Almost always
Variable ID:	DERS-16_Q15
Variable:	Question 15 of the Difficulties in Emotion Regulation Scale - 16-item version
Definition:	When I'm upset, I have difficulty thinking about anything else.
Supporting Definition:	*Optional outcome measure.*

Display Value:	When I'm upset, I have difficulty thinking about anything else.
Inclusion Criteria:	All patients
Timing:	All time points
Data Source:	Patient-reported
Type:	Single answer
Value Domain:	Code
Response Options:	1 = Almost never 2 = Sometimes 3 = About half the time 4 = Most of the time 5 = Almost always
Variable ID:	DERS-16_Q16
Variable:	Question 16 of the Difficulties in Emotion Regulation Scale - 16-item version
Definition:	When I'm upset, my emotions feel overwhelming.
Supporting Definition:	*Optional outcome measure.*
Display Value:	When I'm upset, my emotions feel overwhelming.
Inclusion Criteria:	All patients
Timing:	All time points
Data Source:	Patient-reported
Type:	Single answer
Value Domain:	Code
Response Options:	1 = Almost never 2 = Sometimes 3 = About half the time 4 = Most of the time 5 = Almost always

Behaviour

Variable ID:	C-SSRS-SR_Q01
Variable:	Question 1 of the Columbia Suicide Severity Rating Scale – Screener/Recent – Self-Report
Definition:	Have you wished you were dead or wished you could go to sleep and not wake up?
Supporting Definition:	None
Display Value:	Have you wished you were dead or wished you could go to sleep and not wake up?
Inclusion Criteria:	All patients
Timing:	All time points
Data Source:	Patient-reported
Type:	Single answer
Value Domain:	Code
Response Options:	0 = No 1 = Yes
Variable ID:	C-SSRS-SR_Q02
Variable:	Question 2 of the Columbia Suicide Severity Rating Scale - Screener/Recent - Self-Report
Definition:	Have you actually had any thoughts about killing yourself?
Supporting Definition:	If answer is "Yes" to question 2, answer questions 3, 4, 5, and 6. If answer is "No" to question 2, go directly to question 6.
Display Value:	Have you actually had any thoughts about killing yourself?
Inclusion Criteria:	All patients
Timing:	All time points
Data Source:	Patient-reported
Type:	Single answer
Value Domain:	Code
Response Options:	0 = No

	1 = Yes
Variable ID:	C-SSRS-SR_Q03
Variable:	Question 3 of the Columbia Suicide Severity Rating Scale - Screener/Recent - Self-Report
Definition:	Have you thought about how you might do this?
Supporting Definition:	None
Display Value:	Have you thought about how you might do this?
Inclusion Criteria:	All patients
Timing:	All time points
Data Source:	Patient-reported
Type:	Single answer
Value Domain:	Code
Response Options:	0 = No 1 = Yes
Variable ID:	C-SSRS-SR_Q04
Variable:	Question 4 of the Columbia Suicide Severity Rating Scale - Screener/Recent - Self-Report
Definition:	Have you had any intention of acting on these thoughts of killing yourself? (As opposed to you have the thoughts but you definitely would not act on them.)
Supporting Definition:	None
Display Value:	Have you had any intention of acting on these thoughts of killing yourself? (As opposed to you have the thoughts but you definitely would not act on them.)
Inclusion Criteria:	All patients
Timing:	All time points
Data Source:	Patient-reported
Type:	Single answer
Value Domain:	Code
Response Options:	0 = No 1 = Yes
Variable ID:	C-SSRS-SR_Q05
Variable:	Question 5 of the Columbia Suicide Severity Rating Scale - Screener/Recent - Self-Report
Definition:	Have you started to work out, or worked out, the specific details of how to kill yourself and did you intend to carry out your plan?
Supporting Definition:	None
Display Value:	Have you started to work out, or worked out, the specific details of how to kill yourself and did you intend to carry out your plan?
Inclusion Criteria:	All patients
Timing:	All time points
Data Source:	Patient-reported
Type:	Single answer
Value Domain:	Code
Response Options:	0 = No 1 = Yes
Variable ID:	C-SSRS-SR_Q06a
Variable:	Question 6 (a) of the Columbia Suicide Severity Rating Scale - Screener/Recent - Self-Report
Definition:	Have you ever done anything, started to do anything, or prepared to do anything to end your life? Examples: Collected pills, obtained a gun, gave away valuables, wrote a will or suicide note, took out pills but didn't swallow any, held a gun but changed your mind or it was grabbed from your hand, went to the roof but didn't jump; or actually took pills, tried to shoot yourself, cut yourself, tried to hang yourself, etc.
Supporting Definition:	None

Display Value:	Have you ever done anything, started to do anything, or prepared to do anything to end your life? Examples: Collected pills, obtained a gun, gave away valuables, wrote a will or suicide note, took out pills but didn't swallow any, held a gun but changed your mind or it was grabbed from your hand, went to the roof but didn't jump; or actually took pills, tried to shoot yourself, cut yourself, tried to hang yourself, etc.
Inclusion Criteria:	All patients
Timing:	All time points
Data Source:	Patient-reported
Type:	Single answer
Value Domain:	Code
Response Options:	0 = No 1 = Yes
Variable ID:	C-SSRS-SR_Q06b
Variable:	Question 6 (b) of the Columbia Suicide Severity Rating Scale - Screener/Recent - Self-Report
Definition:	Did you do any of these things in the past 3 months?
Supporting Definition:	None
Display Value:	Did you do any of these things in the past 3 months?
Inclusion Criteria:	All patients
Timing:	All time points
Data Source:	Patient-reported
Type:	Single answer
Value Domain:	Code
Response Options:	0 = No 1 = Yes
Variable ID:	C-SSRS-SR_Q06c
Variable:	Question 6 (c) of the Columbia Suicide Severity Rating Scale - Screener/Recent - Self-Report
Definition:	If yes, what did you do?
Supporting Definition:	None
Display Value:	If yes, what did you do?
Inclusion Criteria:	All patients
Timing:	All time points
Data Source:	Patient-reported
Type:	Free text entry
Value Domain:	String
Response Options:	None
Variable ID:	MOAS_Q01
Variable:	Question 1 of the Modified Overt Aggression Scale
Definition:	Rate the patient's aggressive behavior over the past week. Select as many items as are appropriate. Refer to the pocket guide for the full measure.
Supporting Definition:	*Optional outcome measure.*
Display Value:	Verbal aggression
Inclusion Criteria:	All patients
Timing:	All time points
Data Source:	Clinical
Type:	Multiple answer Separate multiple entries with ";"
Value Domain:	Code
Response Options:	0 = No verbal aggression 1 = Shouts angrily, curses mildly, or makes personal insults 2 = Curses viciously, is severely insulting, has temper outbursts 3 = Impulsively threatens violence towards others or self

	4 = Threatens violence towards others or self repeatedly or deliberately
Variable ID:	MOAS_Q02
Variable:	Question 2 of the Modified Overt Aggression Scale
Definition:	Rate the patient's aggressive behavior over the past week. Select as many items as are appropriate. Refer to the pocket guide for the full measure.
Supporting Definition:	*Optional outcome measure*.
Display Value:	Aggression against property
Inclusion Criteria:	All patients
Timing:	All time points
Data Source:	Clinical
Type:	Multiple answer Separate multiple entries with ";"
Value Domain:	Code
Response Options:	0= No aggression against property 1 = Slams door, rips clothing, urinates on floor 2 = Throws objects down, kicks furniture, defaces walls 3 = Breaks objects, smashes windows 4 = Sets fires, throws objects dangerously
Variable ID:	MOAS_Q03
Variable:	Question 3 of the Modified Overt Aggression Scale
Definition:	Rate the patient's aggressive behavior over the past week. Select as many items as are appropriate. Refer to the pocket guide for the full measure.
Supporting Definition:	*Optional outcome measure.*
Display Value:	Autoaggression
Inclusion Criteria:	All patients
Timing:	All time points
Data Source:	Clinical
Type:	Multiple answer Separate multiple entries with ";"
Value Domain:	Code
Response Options:	0 = No autoaggression 1 = Picks or scratches skin, pulls hair out, hits self (without injury) 2 = Bangs head, hits fists into walls, throws self onto floor 3 = Inflicts minor cuts, bruises, burns, or welts on self 4 = Inflicts major injury on self or makes a suicide attempt
Variable ID:	MOAS_Q04
Variable:	Question 4 of the Modified Overt Aggression Scale
Definition:	Rate the patient's aggressive behavior over the past week. Select as many items as are appropriate. Refer to the pocket guide for the full measure.
Supporting Definition:	*Optional outcome measure.*
Display Value:	Physical aggression
Inclusion Criteria:	All patients
Timing:	All time points
Data Source:	Clinical
Type:	Multiple answer Separate multiple entries with ";"
Value Domain:	Code
Response Options:	0 = No physical aggression 1 = Makes menacing gestures, swings at people, grabs at clothing 2 = Strikes, pushes, scratches, pulls hair of others (without injury) 3 = Attacks others, causing mild injury (bruises, sprain, welts, etc.) 4 = Attacks others, causing serious injury

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_Q03
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_Q04
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_Q05
Variable:	Question 5 of WHODAS 2.0
Definition:	S5: How much have you been emotionally affected by your health problems?
Supporting Definition:	None
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_Q06
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_Q07
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_Q08
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

Recovery

Variable ID:	REQOL10_Q01
Variable:	Question 1 of the Recovering Quality of Life – 10-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:	REQOL10_Q02
Variable:	Question 2 of the Recovering Quality of Life – 10-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:	REQOL10_Q03
Variable:	Question 3 of the Recovering Quality of Life – 10-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:	REQOL10_Q04
Variable:	Question 4 of the Recovering Quality of Life – 10-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:	REQOL10_Q05
Variable:	Question 5 of the Recovering Quality of Life – 10-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:	REQOL10_Q06
Variable:	Question 6 of the Recovering Quality of Life – 10-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:	REQOL10_Q07
Variable:	Question 7 of the Recovering Quality of Life – 10-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:	REQOL10_Q08
Variable:	Question 8 of the Recovering Quality of Life – 10-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:	REQOL10_Q09
Variable:	Question 9 of the Recovering Quality of Life – 10-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:	REQOL10_Q10
Variable:	Question 10 of the Recovering Quality of Life – 10-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:	REQOL10_Q11
Variable:	Question 11 of the Recovering Quality of Life – 10-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
Variable ID:	PROMIS-ISOLATION_Q01
Variable:	Question 1 of PROMIS Short Form v2.0 - Social Isolation 4a
Definition:	Please respond to each item by marking one box per row: I feel left out…
Supporting Definition:	None
Display Value:	I feel left out.
Inclusion Criteria:	All patients
Timing:	All time points
Data Source:	Patient-reported
Type:	Single answer
Value Domain:	Code
Response Options:	1 = Never 2 = Rarely 3 = Sometimes 4 = Usually 5 = Always
Variable ID:	PROMIS-ISOLATION_Q02
Variable:	Question 2 of PROMIS Short Form v2.0 - Social Isolation 4a
Definition:	I feel that people barely know me.

Supporting Definition:	None
Display Value:	I feel that people barely know me.
Inclusion Criteria:	All patients
Timing:	All time points
Data Source:	Patient-reported
Type:	Single answer
Value Domain:	Code
Response Options:	1 = Never 2 = Rarely 3 = Sometimes 4 = Usually 5 = Always
Variable ID:	PROMIS-ISOLATION_Q03
Variable:	Question 3 of PROMIS Short Form v2.0 - Social Isolation 4a
Definition:	I feel isolated from others.
Supporting Definition:	None
Display Value:	I feel isolated from others.
Inclusion Criteria:	All patients
Timing:	All time points
Data Source:	Patient-reported
Type:	Single answer
Value Domain:	Code
Response Options:	1 = Never 2 = Rarely 3 = Sometimes 4 = Usually 5 = Always
Variable ID:	PROMIS-ISOLATION_Q04
Variable:	Question 4 of PROMIS Short Form v2.0 - Social Isolation 4a
Definition:	I feel that people are around me but not with me.
Supporting Definition:	None
Display Value:	I feel that people are around me but not with me.
Inclusion Criteria:	All patients
Timing:	All time points
Data Source:	Patient-reported
Type:	Single answer
Value Domain:	Code
Response Options:	1 = Never 2 = Rarely 3 = Sometimes 4 = Usually 5 = Always

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
Arntz, Anroud	Department of Clinical Psychology, University of Amsterdam, Netherlands	None declared.
Baltzersen, Åse-Line	Patient representative, The Norwegian National Advisory Unit on Personality Psychiatry, Norway	Communication advisor for The Norwegian National Advisory Unit on Personality Psychiatry.
Blazdell, Julia	Patient representative, West London Health Trust, United Kingdom	None declared.
Cencelli, Marika	Patient representative, United Kingdom	Working for Mental Health Policy and Strategy, NHS England and NHS Improvement.
Chanen, Andrew	Orygen; The University of Melbourne, Australia	Grant: National Health and Medical Research Council and Australian Research Council. Director of Clinical Programs and Services, Orygen, Melbourne, Australia. Professorial Fellow, Centre for Youth Mental Health, The University of Melbourne.
Crawford, Mike	Imperial College London, United Kingdom	Professional fees: Central & North West London HHS Foundation Trust. Grant: National Institute for Health Research and the Department of Health on behalf of Imperial College London. Professor of Mental Health Research, Imperial College London, Director of the College Centre for Quality Improvement at the Royal College of Psychiatrists, Trustee of the Maytree (a charity providing support for people in a suicidal crisis).
Delvaux, Charlotte	Patient representative, Te gek!?, Belgium	None declared.
Langford, Lucie	Patient representative, University of Toronto, Canada	None declared.
McKenna, Brian	Auckland University of Technology, New Zealand	None declared.

Name	Affiliation	Declarations
Moran, Paul	Centre for Academic Mental Health, Department of Population Health Sciences, Bristol Medical School, University of Bristol, United Kingdom	Recipient of competitively-awarded grants for the purposes of undertaking research in the field of personality disorder.
Pacheco Alvarado, Karla Patricia	Tecnologico de Monterrey, Escuela de Medicina y Ciencias de la Salud, Mexico	None declared.
Prevolnik Rupel, Valentina	Institute for Economic Research, Slovenia	None declared.
Sharp, Carla	University of Houston, United States	None declared.
van Busschbach, Jan	Erasmus MC, Netherlands	A member of the EuroQol Group.
van Gorp, Fieke	Patient representative, Belgium	None declared.
Wang, Wei	Norwegian University of Science and Technology, Norway	Grant: Zhejiang University and Natural Science Foundation of China.
Wright, Karen M.	University of Central Lancashire, United Kingdom	None declared.

ICHOM Contact Information

Website	http://www.ichom.org

Business Address	**United States Office** 399 Boylston St. 6th floor Boston MA, 02116 **United Kingdom Office** One Alfred Place, 1 Alfred Place, 2nd floor London WC1E 7EB

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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