ICHOM

International Consortium for Health Outcomes Measurement

Type 1 and Type 2 Diabetes in Adults

DATA COLLECTION REFERENCE GUIDE

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Diabetes In Adults

We are thrilled that you are interested in measuring outcomes for adult persons with type 1 or type 2 diabetes according to ICHOM standards. It is our hope that this Reference Guide will facilitate the process of implementing our Standard Set and ensure collection of comparable data for global benchmarking and learning.

Introducing ICHOM and the Reference Guide

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

Each Standard 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 Standard 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 Standard 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 Diabetes in Adults

The following individuals dedicated both time and expertise to develop the ICHOM Standard Set for Diabetes in Adults in partnership with ICHOM, under the leadership of Fabrizio Carinci and Massimo Massi-Benedetti, ICHOM Standard Set Chairs. The work was supported by Jana Nano and Magdalena Walbaum, ICHOM Research Fellows, Oluwakemi Okunade, ICHOM Project Leader, and Sarah Whittaker, ICHOM Research Associate.

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Supporting Organizations

The Diabetes in Adults Standard Set is made possible only through the support of the following organizations.

Thank you.

مركز إمبريال كوليدج لندن للسكري
IMPERIAL COLLEGE LONDON DIABETES CENTRE
A Mubadala Company

JDRF IMPROVING LIVES. CURING TYPE 1 DIABETES.

Scope of Diabetes in Adults Standard Set

For Diabetes in Adults, the following conditions and treatment approaches (or interventions) are covered by our Standard Set.

Conditions	Type 1 Diabetes | Type 2 Diabetes
Population	Adults Aged 18 years and Above
Treatment Approaches	Non-Pharmacological Therapy | Non-Insulin-based Pharmacological Therapy | Insulin-based Pharmacological Therapy
Excluded populations	Children and Young persons below 18 years
Excluded conditions	Diabetes mellitus types other than 1 and 2 | Secondary Diabetes | Gestational Diabetes

ICHOM Standard Set for Diabetes in Adults

Case-Mix Variables

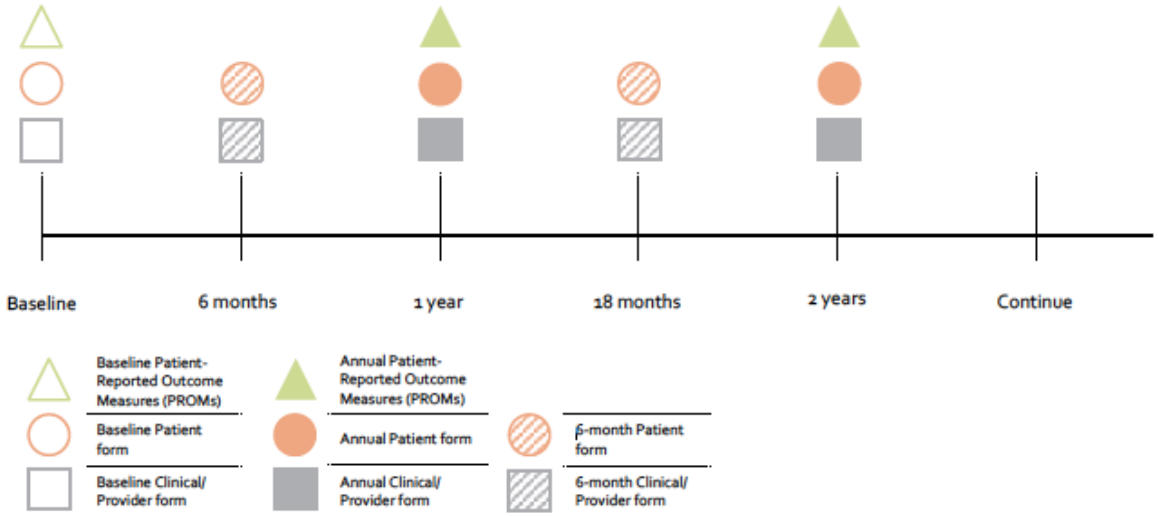
Patient Population	Measure	Timing	Data Source
Demographic Factors			
All patients	Sex	Baseline	Clinical
	Year of Birth		
	Ethnicity/Race		Patient-reported
	Education Level	Baseline and every 5 years	
Diagnosis Profile			
All patients	Diabetes Type	Baseline	Clinical
	Year of Diagnosis		
	Comorbidities	Baseline and annually	Clinical and Patient-reported
Lifestyle and Social Factors			
All patients	Smoking status	Baseline and annually	Patient-reported
	Alcohol Consumption		
	Physical Activity		
	Living Arrangements		
Treatment Factors			
All patients	Diabetes Treatment	Baseline and annually	Clinical
	Blood Pressure Lowering Therapy		
	Statin/Lipid Lowering Therapy		
	Treatment Adherence		Patient-reported
	Access to Healthcare		

Outcomes

Patient Population	Measure	Timing	Data Source
Diabetes Control			
All patients	Glycemic Control	Baseline and every 6 months	Clinical
	Intermediate Outcomes	Baseline and annually	
Acute Events			
All patients	Diabetic Ketoacidosis and Hyperosmolar Hyperglycemic Syndrome	Baseline and every 6 months	Clinical
	Hypoglycemia		
	Acute Cardiovascular Events (Stroke and Myocardial Infarction)	Baseline and annually	
	Lower Limb Amputation		
Chronic Complications			
All patients	Vision	Baseline and annually	Clinical
	Autonomic Neuropathy		
	Peripheral Neuropathy		
	Charcot's Foot		
	Lower Limb Ulcers		
	Peripheral Artery Disease		
	Ischemic Heart Disease		
	Chronic Heart Failure		
	Chronic Kidney Disease and Dialysis		
	Cerebrovascular Disease		
	Periodontal health		
Only male patients	Erectile Dysfunction		
Persons on injectable insulin or non-insulin injectable therapies	Lipodystrophy		
Health Services			
All patients	Hospitalization	Annually	Clinical
	Emergency Room Utilization		
	Financial Barriers to Care	Baseline and annually	Patient-reported
Survival			
All patients	Vital Status	Annually	Clinical
Patient-Reported Outcomes			
All patients	Psychological Wellbeing	Baseline and annually	Patient-reported
	Diabetes Distress		
	Depression		

Follow-Up Timeline and Sample Questionnaires

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



Collecting Patient-Reported Outcome Measured

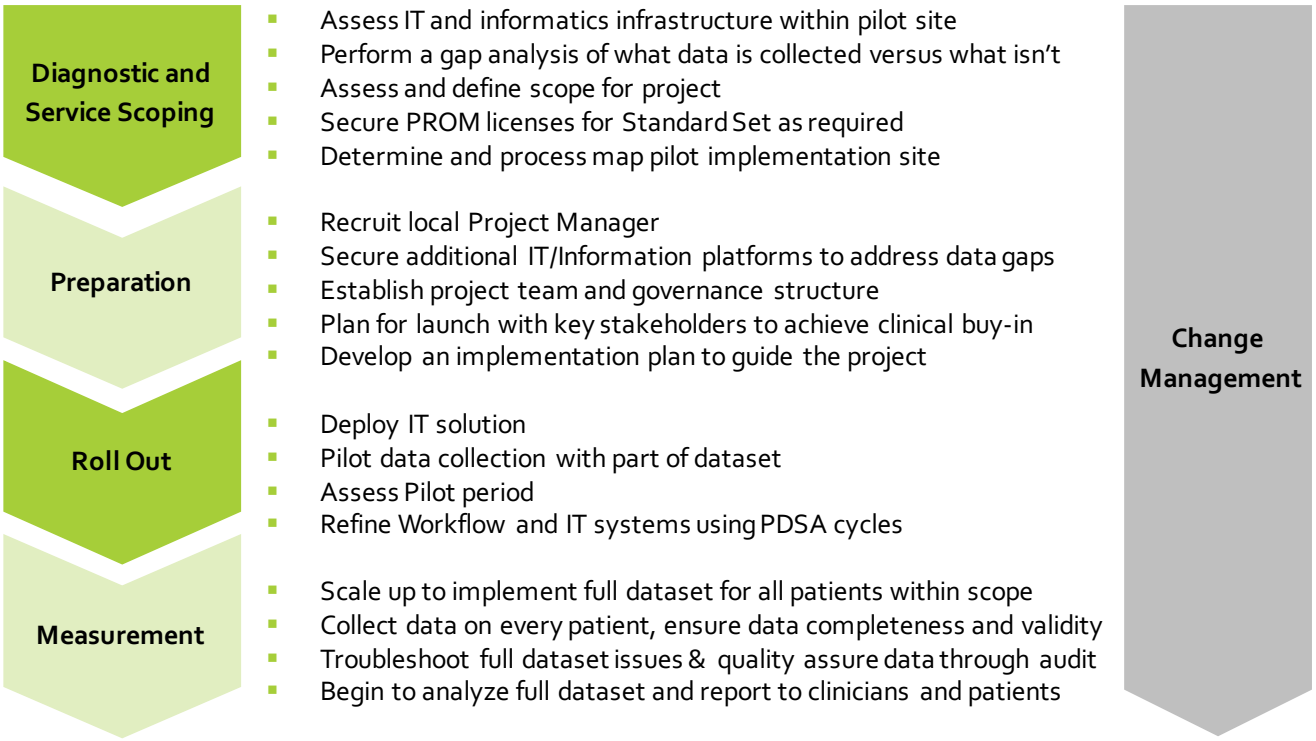
Survey(s) Used	Licensing Information	Scoring Guide
WHO (Five) Well-Being Index (WHO-5)	The WHO-5 is free for all health care organizations, and a license is not needed. There are translations available. More information may be found at www.who-5.org	The total raw score, ranging from 0 to 25, is multiplied by 4 to give the final score, with 0 representing the worst imaginable well-being and 100 representing the best imaginable well-being. The WHO-5 Scoring Guide can be located at www.who-5.org
Problem Areas in Diabetes Questionnaire (PAID)	The PAID, authored by Joslin Diabetes Center (http://www.joslin.org), is the copyright of Joslin Diabetes Center (Copyright ©2000, Joslin Diabetes Center). The PAID, provided under license from Joslin Diabetes Center may not be copied, distributed or used in any way without the prior written consent of Joslin Diabetes Center. Contact Susan D. Sjostrom at Joslin Diabetes Center at: susan.sjostrom@joslin.harvard.edu for licensing details.	Each question has five possible answers with a value from 0 to 4, with 0 representing "no problem" and 4 "a serious problem". The scores are added up and multiplied by 1.25, generating a total score between 0-100. Patients scoring 40 or higher may be at the level of "emotional burnout" and warrant special attention. PAID scores in these patients may drop 10-15 points in response to educational and medical interventions. An extremely low score (0-10) combined with poor glycemic control may be indicative for denial. The PAID Scoring Guide can be obtained by contacting Susan D. Sjostrom at Joslin Diabetes Center at: susan.sjostrom@joslin.harvard.edu
Patient Health Questionnaire (PHQ-9)	The PHQ-9 is free for all health care organizations, and a license is not needed. There are translations available. More information may be found at https://www.phqscreeners.com	Each question has four possible answers with a value from 0 to 3, with 0 representing "not at all" and 3 "nearly every day". The scores are added up, generating a total score between 0 to 27. Scores of 5, 10, 15 and 20 represent cutpoints for mild, moderate, moderately severe and severe depression, respectively. The PHQ-9 Scoring Guide can be located at https://www.phqscreeners.com
Modified Self-Administered Comorbidity Questionnaire (SCQ)	The SCQ is not copyrighted and a license is not needed. It may be found at: Sangha et al (2003) The self-administered comorbidity questionnaire: A new method to assess comorbidity for clinical and health services research. Arthritis Care & Research 49(2): 156-163	Each medical condition asks 3 questions: whether the condition is present, whether it is being treated, and whether it causes functional limitations. Each question has two possible answers of 'yes' or 'no', with 1 point attributed to every 'yes'. A maximum score of 3 is possible for each condition, generating a

The Growing ICHOM Community

There is a growing community of healthcare providers implementing the ICHOM Standard Sets. 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 Standard 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 Standard 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 ICHOM Standard Sets. Please fill in this survey: bit.ly/InitialImp or contact info@ichom.org for more information

Translating the Set Tools:

PROMs within the ICHOM Sets are available in a number of languages. To check the availability of translations, we advise contacting the Tool authors directly to obtain and translate the PROM surveys into your desired language. To independently translate PROM surveys, if permitted by its license, we recommend following the 10 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 Outcomes 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 Macular Degeneration Standard 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 Standard 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:	Administrative or clinical
Type:	Numerical
Value Domain:	None
Response Options:	According to institution

Demographic Factors

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.
Displayed 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:	YearOfBirth
Variable:	Year of Birth
Definition:	Year of birth
Supporting Definition:	None
Displayed Value:	In what year were you born?
Inclusion Criteria:	All patients
Timing:	Baseline
Data Source:	Clinical
Type:	Numerical
Value Domain:	date
Response Options:	YYYY
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.
Displayed 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:	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.
Displayed 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:	EducationLevel
Variable:	Level of education
Definition:	Highest level of education completed based on local standard definitions of education levels
Supporting Definition:	This measure may vary based on local standards for education levels so please consult the International Standard Classification to select what level most closely relates to your education experience. Please follow this link here: http://uis.unesco.org/sites/default/files/documents/international-standard-classification-of-education-isced-2011-en.pdf
Displayed Value:	Please indicate your highest level of schooling.
Inclusion Criteria:	All patients
Timing:	Baseline Every 5 years
Data Source:	Patient-reported
Type:	Single answer
Value Domain:	code
Response Options:	0= None 1= Primary 2= Secondary 3= Tertiary

Diagnosis Profile

Variable ID:	DiabetesMellitusType
Variable:	Diabetes mellitus subtype
Definition:	The type of diabetes mellitus, i.e. Type 1 or Type 2
Supporting Definition:	"Unknown" indicates whether Type 1 or Type 2 diabetes is unknown and not another type of diabetes (i.e. gestational, mody, etc.)
Displayed Value:	None
Inclusion Criteria:	All patients
Timing:	Baseline
Data Source:	Clinical
Type:	Single answer
Value Domain:	code
Response Options:	0 = No diabetes 1 = Diabetes mellitus type 1 2 = Diabetes mellitus type 2 999 = Unknown
Variable ID:	YODIAG
Variable:	Year of Diagnosis
Definition:	When were you diagnosed with diabetes?
Supporting Definition:	Record the estimated year of diagnosis based on person with diabetes' estimate or clinical records. Used to calculate diabetes duration.
Displayed Value:	None

Inclusion Criteria:	All patients
Timing:	Baseline
Data Source:	Clinical
Type:	Numerical
Value Domain:	date
Response Options:	Year of Diagnosis
Variable ID:	COMORB_DIAB
Variable:	Diabetes-Specific Comorbidities
Definition:	Indicate which comorbidities the person with diabetes is living with. Select all that apply.
Supporting Definition:	Include ALL conditions that apply at every annual follow-up.
Displayed Value:	None
Inclusion Criteria:	All patients
Timing:	Baseline Annually
Data Source:	Clinical
Type:	Multiple answer
Value Domain:	code
Response Options:	1= Malignancy 2= AIDS 3= Chronic Obstructive Pulmonary Disease 4= Peripheral Vascular Disease 5= Dementia 6= Hemiplegia 7= Active Tuberculosis 8= Active Hepatitis B 9= Active Hepatitis C 10= Presence/history of anxiety disorders 11= Presence/history of disordered eating behavior 12= Presence/ history of psychotic mental illnesses (e.g. schizophrenia) 13= Thyroid disease (hyperactive thyroid or hypoactive thyroid)
Variable ID:	ComorbiditiesSACQ
Variable:	SACQ Comorbidities
Definition:	Indicate whether the patient has a documented history of any of the following comorbidities
Supporting Definition:	Based upon the Self-administered Comorbidity Questionnaire (Sangha et al, 2003). Phrased as a patient-reported measure, but information can be abstracted by other means if patient is unable to answer.
Displayed Value:	Have you been told by a doctor that you have any of the following?
Inclusion Criteria:	All patients
Timing:	Baseline
Data Source:	Patient-reported
Type:	Multiple answer Separate multiple entries with ";"
Value Domain:	Code
Response Options:	0 = I have no other diseases 1 = Heart disease (For example, angina, heart attack, or heart failure) 2 = High blood pressure 3 =Lung disease (For example, asthma, chronic bronchitis, or emphysema) 4 = Diabetes 5 = Ulcer or stomach disease 6 = Kidney disease 7 = Liver disease 8 = Anemia or other blood disease

	9 = Cancer/Other cancer (within the last 5 years) 10 = Depression 11 = Osteoarthritis, degenerative arthritis 12 = Back pain 13= Rheumatoid arthritis 14= Other medical problems
Variable ID:	ComorbiditiesSACQ_HeartDiseaseFU1
Variable:	SACQ comorbidities: Heart Disease: Follow-Up Question 1
Definition:	Please indicate if the patient receives treatment for Heart disease (For example, angina, heart attack, or heart failure)
Supporting Definition:	Based upon the Self-administered Comorbidity Questionnaire (Sangha et al, 2003). Phrased as a patient-reported measure, but information can be abstracted by other means if patient is unable to answer.
Displayed Value:	Do you receive treatment for heart disease (For example, angina, heart failure, or heart attack)?
Inclusion Criteria:	If answered 1= Heart disease to ComorbiditiesSACQ
Timing:	Baseline
Data Source:	Patient-reported
Type:	Single answer
Value Domain:	Code
Response Options:	0= No 1= Yes
Variable ID:	ComorbiditiesSACQ_HeartDiseaseFU2
Variable:	SACQ comorbidities: Heart Disease: Follow-Up Question 2
Definition:	Please indicate if the patient's heart disease limits their function
Supporting Definition:	Based upon the Self-administered Comorbidity Questionnaire (Sangha et al, 2003). Phrased as a patient-reported measure, but information can be abstracted by other means if patient is unable to answer.
Displayed Value:	Does your heart disease limit your activities?
Inclusion Criteria:	If answered 1= Heart disease to ComorbiditiesSACQ
Timing:	Baseline
Data Source:	Patient-reported
Type:	Single answer
Value Domain:	Code
Response Options:	0= No 1= Yes
Variable ID:	ComorbiditiesSACQ_HighBloodPressureFU1
Variable:	SACQ comorbidities: High Blood Pressure: Follow-Up Question 1
Definition:	Please indicate if the patient receives treatment for high blood pressure
Supporting Definition:	Based upon the Self-administered Comorbidity Questionnaire (Sangha et al, 2003). Phrased as a patient-reported measure, but information can be abstracted by other means if patient is unable to answer.
Displayed Value:	Do you receive treatment for high blood pressure?
Inclusion Criteria:	If answered 2= High blood pressure to ComorbiditiesSACQ
Timing:	Baseline
Data Source:	Patient-reported
Type:	Single answer
Value Domain:	Code
Response Options:	0= No 1= Yes
Variable ID:	ComorbiditiesSACQ_HighBloodPressureFU2
Variable:	SACQ comorbidities: High Blood Pressure: Follow-Up Question 2
Definition:	Please indicate if the patient's high blood pressure limits their function
Supporting Definition:	Based upon the Self-administered Comorbidity Questionnaire (Sangha et al, 2003). Phrased as a patient-reported measure, but information can be abstracted by other means if patient is unable to answer.

Displayed Value:	Does your high blood pressure limit your activities?
Inclusion Criteria:	If answered 2= High blood pressure to ComorbiditiesSACQ
Timing:	Baseline
Data Source:	Patient-reported
Type:	Single answer
Value Domain:	Code
Response Options:	0= No 1= Yes
Variable ID:	ComorbiditiesSACQ_LungDiseaseFU1
Variable:	SACQ comorbidities: Lung Disease: Follow-Up Question 1
Definition:	Please indicate if the patient receives treatment for lung disease
Supporting Definition:	Based upon the Self-administered Comorbidity Questionnaire (Sangha et al, 2003). Phrased as a patient-reported measure, but information can be abstracted by other means if patient is unable to answer.
Displayed Value:	Do you receive treatment for lung disease?
Inclusion Criteria:	If answered 3= Lung disease to ComorbiditiesSACQ
Timing:	Baseline
Data Source:	Patient-reported
Type:	Single answer
Value Domain:	Code
Response Options:	0= No 1= Yes
Variable ID:	ComorbiditiesSACQ_LungDiseaseFU2
Variable:	SACQ comorbidities: Lung Disease: Follow-Up Question 2
Definition:	Please indicate if the patient's lung disease limits their function
Supporting Definition:	Based upon the Self-administered Comorbidity Questionnaire (Sangha et al, 2003). Phrased as a patient-reported measure, but information can be abstracted by other means if patient is unable to answer.
Displayed Value:	Does your lung disease limit your activities?
Inclusion Criteria:	If answered 3= Lung disease to ComorbiditiesSACQ
Timing:	Baseline
Data Source:	Patient-reported
Type:	Single answer
Value Domain:	Code
Response Options:	0= No 1= Yes
Variable ID:	ComorbiditiesSACQ_DiabetesFU1
Variable:	SACQ comorbidities: Diabetes: Follow-Up Question 1
Definition:	Please indicate if the patient receives treatment for diabetes
Supporting Definition:	Based upon the Self-administered Comorbidity Questionnaire (Sangha et al, 2003). Phrased as a patient-reported measure, but information can be abstracted by other means if patient is unable to answer.
Displayed Value:	Do you receive treatment for diabetes?
Inclusion Criteria:	If answered 4= Diabetes to ComorbiditiesSACQ
Timing:	Baseline
Data Source:	Patient-reported
Type:	Single answer
Value Domain:	Code
Response Options:	0= No 1= Yes
Variable ID:	ComorbiditiesSACQ_DiabetesFU2
Variable:	SACQ comorbidities: Diabetes: Follow-Up Question 2
Definition:	Please indicate if the patient's diabetes limits their function
Supporting Definition:	Based upon the Self-administered Comorbidity Questionnaire (Sangha et al, 2003). Phrased as a patient-reported measure, but information can be abstracted by other means if patient is unable to answer.
Displayed Value:	Does your diabetes limit your activities?

Inclusion Criteria:	If answered 4= Diabetes to ComorbiditiesSACQ
Timing:	Baseline
Data Source:	Patient-reported
Type:	Single answer
Value Domain:	Code
Response Options:	0= No 1= Yes
Variable ID:	ComorbiditiesSACQ_StomachDiseaseFU1
Variable:	SACQ comorbidities: Stomach Disease: Follow-Up Question 1
Definition:	Please indicate if the patient receives treatment for an ulcer or stomach disease
Supporting Definition:	Based upon the Self-administered Comorbidity Questionnaire (Sangha et al, 2003). Phrased as a patient-reported measure, but information can be abstracted by other means if patient is unable to answer.
Displayed Value:	Do you receive treatment for an ulcer or stomach disease?
Inclusion Criteria:	If answered 5= Ulcer or stomach disease to ComorbiditiesSACQ
Timing:	Baseline
Data Source:	Patient-reported
Type:	Single answer
Value Domain:	Code
Response Options:	0= No 1= Yes
Variable ID:	ComorbiditiesSACQ_StomachDiseaseFU2
Variable:	SACQ comorbidities: Stomach Disease: Follow-Up Question 2
Definition:	Please indicate if the patient's ulcer or stomach disease limits their function
Supporting Definition:	Based upon the Self-administered Comorbidity Questionnaire (Sangha et al, 2003). Phrased as a patient-reported measure, but information can be abstracted by other means if patient is unable to answer.
Displayed Value:	Does your ulcer or stomach disease limit your activities?
Inclusion Criteria:	If answered 5= Ulcer or stomach disease to ComorbiditiesSACQ
Timing:	Baseline
Data Source:	Patient-reported
Type:	Single answer
Value Domain:	Code
Response Options:	0= No 1= Yes
Variable ID:	ComorbiditiesSACQ_KidneyDiseaseFU1
Variable:	SACQ comorbidities: Kidney Disease: Follow-Up Question 1
Definition:	Please indicate if the patient receives treatment for kidney disease
Supporting Definition:	Based upon the Self-administered Comorbidity Questionnaire (Sangha et al, 2003). Phrased as a patient-reported measure, but information can be abstracted by other means if patient is unable to answer.
Displayed Value:	Do you receive treatment for kidney disease?
Inclusion Criteria:	If answered 6= Kidney disease to ComorbiditiesSACQ
Timing:	Baseline
Data Source:	Patient-reported
Type:	Single answer
Value Domain:	Code
Response Options:	0= No 1= Yes
Variable ID:	ComorbiditiesSACQ_KidneyDiseaseFU2
Variable:	SACQ comorbidities: Kidney Disease: Follow-Up Question 2
Definition:	Please indicate if the patient's kidney disease limits their function
Supporting Definition:	Based upon the Self-administered Comorbidity Questionnaire (Sangha et al, 2003). Phrased as a patient-reported measure, but information can be abstracted by other means if patient is unable to answer.
Displayed Value:	Does your kidney disease limit your activities?
Inclusion Criteria:	If answered 6= Kidney disease to ComorbiditiesSACQ

Timing:	Baseline
Data Source:	Patient-reported
Type:	Single answer
Value Domain:	Code
Response Options:	0= No 1= Yes
Variable ID:	ComorbiditiesSACQ_LiverDiseaseFU1
Variable:	SACQ comorbidities: Liver Disease: Follow-Up Question 1
Definition:	Please indicate if the patient receives treatment for liver disease
Supporting Definition:	Based upon the Self-administered Comorbidity Questionnaire (Sangha et al, 2003). Phrased as a patient-reported measure, but information can be abstracted by other means if patient is unable to answer.
Displayed Value:	Do you receive treatment for liver disease?
Inclusion Criteria:	If answered 7= Liver disease to ComorbiditiesSACQ
Timing:	Baseline
Data Source:	Patient-reported
Type:	Single answer
Value Domain:	Code
Response Options:	0= No 1= Yes
Variable ID:	ComorbiditiesSACQ_LiverDiseaseFU2
Variable:	SACQ comorbidities: Liver Disease: Follow-Up Question 2
Definition:	Please indicate if the patient's liver disease limits their function
Supporting Definition:	Based upon the Self-administered Comorbidity Questionnaire (Sangha et al, 2003). Phrased as a patient-reported measure, but information can be abstracted by other means if patient is unable to answer.
Displayed Value:	Does your liver disease limit your activities?
Inclusion Criteria:	If answered 7= Liver disease to ComorbiditiesSACQ
Timing:	Baseline
Data Source:	Patient-reported
Type:	Single answer
Value Domain:	Code
Response Options:	0= No 1= Yes
Variable ID:	ComorbiditiesSACQ_BloodDiseaseFU1
Variable:	SACQ comorbidities: Blood Disease: Follow-Up Question 1
Definition:	Please indicate if the patient receives treatment for anemia or other blood disease
Supporting Definition:	Based upon the Self-administered Comorbidity Questionnaire (Sangha et al, 2003). Phrased as a patient-reported measure, but information can be abstracted by other means if patient is unable to answer.
Displayed Value:	Do you receive treatment for anemia or other blood disease?
Inclusion Criteria:	If answered 8= Anemia or other blood disease to ComorbiditiesSACQ
Timing:	Baseline
Data Source:	Patient-reported
Type:	Single answer
Value Domain:	Code
Response Options:	0= No 1= Yes
Variable ID:	ComorbiditiesSACQ_BloodDiseaseFU2
Variable:	SACQ comorbidities: Blood Disease: Follow-Up Question 2
Definition:	Please indicate if the patient's anemia or other blood disease limits their function
Supporting Definition:	Based upon the Self-administered Comorbidity Questionnaire (Sangha et al, 2003). Phrased as a patient-reported measure, but information can be abstracted by other means if patient is unable to answer.
Displayed Value:	Does your anemia or other blood disease limit your activities?
Inclusion Criteria:	If answered 8= Anemia or other blood disease to ComorbiditiesSACQ
Timing:	Baseline

Data Source:	Patient-reported
Type:	Single answer
Value Domain:	Code
Response Options:	0= No 1= Yes
Variable ID:	ComorbiditiesSACQ_CancerFU1
Variable:	SACQ comorbidities: Cancer: Follow-Up Question 1
Definition:	Please indicate if the patient receives treatment for cancer/another cancer
Supporting Definition:	Based upon the Self-administered Comorbidity Questionnaire (Sangha et al, 2003). Phrased as a patient-reported measure, but information can be abstracted by other means if patient is unable to answer.
Displayed Value:	Do you receive treatment for cancer/another cancer?
Inclusion Criteria:	If answered 9= Cancer/Other cancer to ComorbiditiesSACQ
Timing:	Baseline
Data Source:	Patient-reported
Type:	Single answer
Value Domain:	Code
Response Options:	0= No 1= Yes
Variable ID:	ComorbiditiesSACQ_CancerFU2
Variable:	SACQ comorbidities: Cancer: Follow-Up Question 2
Definition:	Please indicate if the patient's cancer/other cancer limits their function
Supporting Definition:	Based upon the Self-administered Comorbidity Questionnaire (Sangha et al, 2003). Phrased as a patient-reported measure, but information can be abstracted by other means if patient is unable to answer.
Displayed Value:	Does your cancer/other cancer limit your activities?
Inclusion Criteria:	If answered 9= Cancer/Other cancer to ComorbiditiesSACQ
Timing:	Baseline
Data Source:	Patient-reported
Type:	Single answer
Value Domain:	Code
Response Options:	0= No 1= Yes
Variable ID:	ComorbiditiesSACQ_DepressionFU1
Variable:	SACQ comorbidities: Depression: Follow-Up Question 1
Definition:	Please indicate if the patient receives treatment for depression
Supporting Definition:	Based upon the Self-administered Comorbidity Questionnaire (Sangha et al, 2003). Phrased as a patient-reported measure, but information can be abstracted by other means if patient is unable to answer.
Displayed Value:	Do you receive treatment for depression?
Inclusion Criteria:	If answered 10= Depression to ComorbiditiesSACQ
Timing:	Baseline
Data Source:	Patient-reported
Type:	Single answer
Value Domain:	Code
Response Options:	0= No 1= Yes
Variable ID:	ComorbiditiesSACQ_DepressionFU2
Variable:	SACQ comorbidities: Depression: Follow-Up Question 2
Definition:	Please indicate if the patient's depression limits their function
Supporting Definition:	Based upon the Self-administered Comorbidity Questionnaire (Sangha et al, 2003). Phrased as a patient-reported measure, but information can be abstracted by other means if patient is unable to answer.
Displayed Value:	Does your depression limit your activities?
Inclusion Criteria:	If answered 10= Depression to ComorbiditiesSACQ
Timing:	Baseline
Data Source:	Patient-reported

Type:	Single answer
Value Domain:	Code
Response Options:	0= No 1= Yes
Variable ID:	ComorbiditiesSACQ_OsteoarthritisFU1
Variable:	SACQ comorbidities: Osteoarthritis: Follow-Up Question 1
Definition:	Please indicate if the patient receives treatment for osteoarthritis/degenerative arthritis
Supporting Definition:	Based upon the Self-administered Comorbidity Questionnaire (Sangha et al, 2003). Phrased as a patient-reported measure, but information can be abstracted by other means if patient is unable to answer.
Displayed Value:	Do you receive treatment for osteoarthritis/degenerative arthritis?
Inclusion Criteria:	If answered 11= Osteoarthritis, degenerative arthritis to ComorbiditiesSACQ
Timing:	Baseline
Data Source:	Patient-reported
Type:	Single answer
Value Domain:	Code
Response Options:	0= No 1= Yes
Variable ID:	ComorbiditiesSACQ_OsteoarthritisFU2
Variable:	SACQ comorbidities: Osteoarthritis: Follow-Up Question 2
Definition:	Please indicate if the patient's osteoarthritis/degenerative arthritis limits their function
Supporting Definition:	Based upon the Self-administered Comorbidity Questionnaire (Sangha et al, 2003). Phrased as a patient-reported measure, but information can be abstracted by other means if patient is unable to answer.
Displayed Value:	Does your osteoarthritis/degenerative arthritis limit your activities?
Inclusion Criteria:	If answered 11= Osteoarthritis, degenerative arthritis to ComorbiditiesSACQ
Timing:	Baseline
Data Source:	Patient-reported
Type:	Single answer
Value Domain:	Code
Response Options:	0= No 1= Yes
Variable ID:	ComorbiditiesSACQ_BackPainFU1
Variable:	SACQ comorbidities: Back Pain: Follow-Up Question 1
Definition:	Please indicate if the patient receives treatment for back pain
Supporting Definition:	Based upon the Self-administered Comorbidity Questionnaire (Sangha et al, 2003). Phrased as a patient-reported measure, but information can be abstracted by other means if patient is unable to answer.
Displayed Value:	Do you receive treatment for back pain?
Inclusion Criteria:	If answered 12= Back pain to ComorbiditiesSACQ
Timing:	Baseline
Data Source:	Patient-reported
Type:	Single answer
Value Domain:	Code
Response Options:	0= No 1= Yes
Variable ID:	ComorbiditiesSACQ_BackPainFU2
Variable:	SACQ comorbidities: Back Pain: Follow-Up Question 2
Definition:	Please indicate if the patient's back pain limits their function
Supporting Definition:	Based upon the Self-administered Comorbidity Questionnaire (Sangha et al, 2003). Phrased as a patient-reported measure, but information can be abstracted by other means if patient is unable to answer.
Displayed Value:	Does your back pain limit your activities?
Inclusion Criteria:	If answered 12= Back pain to ComorbiditiesSACQ
Timing:	Baseline

Data Source:	Patient-reported
Type:	Single answer
Value Domain:	Code
Response Options:	0= No 1= Yes
Variable ID:	ComorbiditiesSACQ_RheumatoidArthritisFU1
Variable:	SACQ comorbidities: Rheumatoid Arthritis: Follow-Up Question 1
Definition:	Please indicate if the patient receives treatment for rheumatoid arthritis
Supporting Definition:	Based upon the Self-administered Comorbidity Questionnaire (Sangha et al, 2003). Phrased as a patient-reported measure, but information can be abstracted by other means if patient is unable to answer.
Displayed Value:	Do you receive treatment for rheumatoid arthritis?
Inclusion Criteria:	If answered 13= Rheumatoid arthritis to ComorbiditiesSACQ
Timing:	Baseline
Data Source:	Patient-reported
Type:	Single answer
Value Domain:	Code
Response Options:	0= No 1= Yes
Variable ID:	ComorbiditiesSACQ_RheumatoidArthritisFU2
Variable:	SACQ comorbidities: Rheumatoid Arthritis: Follow-Up Question 2
Definition:	Please indicate if the patient's rheumatoid arthritis limits their function
Supporting Definition:	Based upon the Self-administered Comorbidity Questionnaire (Sangha et al, 2003). Phrased as a patient-reported measure, but information can be abstracted by other means if patient is unable to answer.
Displayed Value:	Does your rheumatoid arthritis limit your activities?
Inclusion Criteria:	If answered 13= Rheumatoid arthritis to ComorbiditiesSACQ
Timing:	Baseline
Data Source:	Patient-reported
Type:	Single answer
Value Domain:	Code
Response Options:	0= No 1= Yes
Variable ID:	ComorbiditiesSACQ_Other
Variable:	SACQ comorbidities: Other Medical Problems
Definition:	Please indicate what other medical problems the patient is experiencing
Supporting Definition:	Based upon the Self-administered Comorbidity Questionnaire (Sangha et al, 2003). Phrased as a patient-reported measure, but information can be abstracted by other means if patient is unable to answer.
Displayed Value:	What other medical problems are you experiencing?
Inclusion Criteria:	If answered 14= Other medical problems to ComorbiditiesSACQ
Timing:	Baseline
Data Source:	Patient-reported
Type:	Single answer
Value Domain:	String
Response Options:	None
Variable ID:	ComorbiditiesSACQ_Score
Variable:	Score of the SACQ comorbidities questionnaire
Definition:	Please indicate the summed score for all of the patient's comorbidities
Supporting Definition:	An individual can receive a max of 3 points for each medical condition: 1 point for the presence of the problem, another point if he/she receives treatment for it, and an additional point if the problem causes a limitation in function. The Max score a patient can receive is 45 points
Displayed Value:	What is the total summed score of the patient's SACQ responses?
Inclusion Criteria:	All patients
Timing:	Baseline

Data Source:	Clinical
Type:	Numerical value
Value Domain:	Quantity
Response Options:	Total summed score
Variable ID:	TSH
Variable:	Thyroid-stimulating hormone in person with type 1 diabetes
Definition:	Please provide the person with diabetes' most recent thyroid stimulating hormone levels from the past 12 months
Supporting Definition:	None
Displayed Value:	None
Inclusion Criteria:	For people with type 1 diabetes, if thyroid disease is present
Timing:	Baseline Annually
Data Source:	Clinical
Type:	Numerical
Value Domain:	quantity
Response Options:	Numerical value of TSH in mIU/L 000 if not available

Lifestyle and Social Factors

Variable ID:	SmokingStatus
Variable:	Smoking status
Definition:	A person's current and past smoking behavior
Supporting Definition:	Daily smoker: A person who smokes daily Weekly smoker: A person who smokes at least weekly but not daily Former smoker: A person who does not smoke at all now, but has smoked at least 100 cigarettes or a similar amount of other tobacco products in his/her lifetime Never-smoker: A person who does not smoke now and has smoked fewer than 100 cigarettes or similar amount of other tobacco products in his/her lifetime
Displayed Value:	Please indicate your smoking behavior. More detailed definitions are as follows: Daily smoker: A person who smokes daily Weekly smoker: A person who smokes at least weekly but not daily Former smoker: A person who does not smoke at all now, but has smoked at least 100 cigarettes or a similar amount of other tobacco products in his/her lifetime Never-smoker: A person who does not smoke now and has smoked fewer than 100 cigarettes or similar amount of other tobacco products in his/her lifetime
Inclusion Criteria:	All patients
Timing:	Baseline Annually
Data Source:	Patient-reported
Type:	Single answer
Value Domain:	code
Response Options:	0 = Current every day smoker 1 = Current weekly smoker 2 = Former smoker 3 = Never smoker 4 = Others 999 = Unknown if ever smoked
Variable ID:	ALCFREQ1
Variable:	Alcohol Frequency
Definition:	How many days per week does the patient consume alcoholic drinks or beverages?
Supporting Definition:	Please provide an estimated average frequency over the past year.

Displayed Value:	How many days per week do you consume alcoholic drinks or beverages? Please provide an estimated average frequency over the past year.
Inclusion Criteria:	All patients
Timing:	Baseline Annually
Data Source:	Patient-reported
Type:	Single answer
Value Domain:	code
Response Options:	0= Every day/7 days per week 1= 5 to 6 days per week 2= 3 to 4 days per week 3= 1 to 2 days per week 4= 1 to 3 days per month 5= Never
Variable ID:	AlcoholPerOccasion
Variable:	Alcohol Amount per drinking occasion
Definition:	On average, how many units of alcohol does the patient consume per occasion of drinking alcoholic drinks or beverages?
Supporting Definition:	Average number of drinks consumed per occasion of drinking alcohol over the last year, in whole numbers. Standard drink is defined as 10 grams of pure alcohol. This corresponds to: one can or bottle of beer (375ml or 12 oz at 3.5% alcohol by volume) - A small glass of red wine (100ml or 3.4 oz at 13% alcohol by volume) - A shot of whiskey or other spirit (30ml or 1.0 oz at 40% alcohol by volume)
Displayed Value:	On average, how many units of alcohol do you consume when you drink alcoholic drinks or beverages? Please provide an estimated average of the amount you consumed each time you consumed alcohol over the past year. A standard drink is defined as 10 grams of pure alcohol. This corresponds to: one can or bottle of beer (375ml or 12 oz at 3.5% alcohol by volume) - A small glass of red wine (100ml or 3.4 oz at 13% alcohol by volume) - A shot of whiskey or other spirit (30ml or 1.0 oz at 40% alcohol by volume)
Inclusion Criteria:	All patients
Timing:	Baseline Annually
Data Source:	Patient-reported
Type:	Numerical
Value Domain:	quantity
Response Options:	Average number of units consumed in whole numbers
Variable ID:	PHYSACT
Variable:	Physical Activity
Definition:	On average, have you been physically active over the past year? This means being active for more than 150 minutes of moderate intensity exercise **or** 75 minutes of vigorous exercise a week.
Supporting Definition:	Being active is defined in accordance with the World Health Organization (WHO) guidelines as engaging in at least 150 minutes of moderate physical activity a week or 75 minutes of vigorous activity a week
Displayed Value:	None
Inclusion Criteria:	All patients
Timing:	Baseline Annually
Data Source:	Patient-reported
Type:	Single answer
Value Domain:	code

Response Options:	0 = No 1 = Yes 999 = Unknown
Variable ID:	PHYSFUNC
Variable:	Physical Functioning Disability/functional status
Definition:	Do you have a physical disability that is preventing you from being more active?
Supporting Definition:	None
Displayed Value:	None
Inclusion Criteria:	If answered "0= No" to PHYSACT
Timing:	Baseline Annually
Data Source:	Patient-reported
Type:	Single answer
Value Domain:	code
Response Options:	0 = No 1 = Yes 999 = Unknown
Variable ID:	LivingArrangements
Variable:	Living arrangements
Definition:	The living arrangements of the person
Supporting Definition:	None
Displayed 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 supported home 3 = Homeless

Treatment Factors

Variable ID:	DIATREAT
Variable:	Diabetes Treatment
Definition:	Indicate the type of diabetes treatment [select all that applied in the past 12 months]:
Supporting Definition:	Non-pharmacological therapy includes lifestyle management addressing lifestyle factors such as diet and exercise. Alternative, complementary, and traditional medicine approaches such as homoeopathic medicines should be captured under the "other" category
Displayed Value:	None
Inclusion Criteria:	All patients
Timing:	Baseline Annually
Data Source:	Clinical
Type:	Multiple answer
Value Domain:	code
Response Options:	0= Non-pharmacological therapy 1= Oral antidiabetic drugs 2= Non-insulin injectable antidiabetic drugs

	3= Insulin 4= Other 5= No treatment *Coding systems are being developed for drug classes
Variable ID:	BPLTHERA
Variable:	Blood Pressure Lowering Therapy
Definition:	Indicate whether the person with diabetes is on blood pressure lowering medication
Supporting Definition:	Indicate if the person has been on any blood pressure lowering medication at any point in the past 12 months
Displayed Value:	None
Inclusion Criteria:	All patients
Timing:	Baseline Annually
Data Source:	Clinical
Type:	Single answer
Value Domain:	code
Response Options:	0= Yes, on ACE inhibitor 1= Yes, on Angiotensin receptor blocker 2= Yes, on other blood pressure lowering medication 3= No 999= Unknown
Variable ID:	CurrentLipidLoweringTherapy
Variable:	Lipid lowering therapy
Definition:	Person currently prescribed lipid lowering therapy
Supporting Definition:	None
Displayed Value:	None
Inclusion Criteria:	All patients
Timing:	Baseline Annually
Data Source:	Clinical
Type:	Single answer
Value Domain:	code
Response Options:	0 = No 1 = Yes 999 = Unknown
Variable ID:	ADHEDIET
Variable:	Treatment Adherence (Dietary advice)
Definition:	Please rate how well you stick to the dietary advice from your healthcare team on a scale from 1 to 10 1 = not adherent 10 = fully adherent
Supporting Definition:	This scale was developed by the Diabetes Working Group and has not yet been validated
Displayed Value:	None
Inclusion Criteria:	All patients
Timing:	Baseline Annually
Data Source:	Patient-reported
Type:	Numerical
Value Domain:	quantity

Response Options:	Integer response between 1 and 10 0 = not rated
Variable ID:	ADHEEXER
Variable:	Treatment Adherence (Exercise)
Definition:	Please rate how well you stick to advice on exercise from your healthcare team on a scale from 1 to 10 1 = not adherent 10 = fully adherent
Supporting Definition:	This scale was developed by the Diabetes Working Group and has not yet been validated
Displayed Value:	None
Inclusion Criteria:	All patients
Timing:	Baseline Annually
Data Source:	Patient-reported
Type:	Numerical
Value Domain:	quantity
Response Options:	Integer response between 1 and 10 0 = not rated
Variable ID:	ADHESUGA
Variable:	Treatment Adherence
Definition:	Please rate how well you stick to the advice on monitoring your blood sugar from your healthcare team on a scale from 1 to 10 1 = not adherent 10 = fully adherent
Supporting Definition:	This scale was developed by the Diabetes Working Group and has not yet been validated
Displayed Value:	None
Inclusion Criteria:	All patients
Timing:	Baseline Annually
Data Source:	Patient-reported
Type:	Numerical
Value Domain:	quantity
Response Options:	Integer response between 1 and 10 0 = not rated
Variable ID:	ADHEMEDI
Variable:	Treatment Adherence
Definition:	Please rate how well you stick to your prescribed medication and/or insulin regimen on a scale from 1 to 10 1 = not adherent 10 = fully adherent
Supporting Definition:	This scale was developed by the Diabetes Working Group and has not yet been validated
Displayed Value:	None
Inclusion Criteria:	All patients
Timing:	Baseline Annually
Data Source:	Patient-reported
Type:	Numerical
Value Domain:	quantity

Response Options:	Integer response between 1 and 10 0 = not rated

Outcomes

Diabetes Control

Variable ID:	HBA1C
Variable:	Glycemic Control HbA1c
Definition:	Provide the most recent HbA1c reading collected in the past 6 months
Supporting Definition:	None
Displayed Value:	None
Inclusion Criteria:	All patients
Timing:	Baseline Every 6 months
Data Source:	Clinical
Type:	Numerical
Value Domain:	quantity
Response Options:	Numerical value of HbA1c

Variable ID:	HBA1CUNIT
Variable:	Glycemic Control Units of HbA1c
Definition:	Units of HbA1c readings provided
Supporting Definition:	None
Displayed Value:	None
Inclusion Criteria:	All patients
Timing:	Baseline Every 6 months
Data Source:	Clinical
Type:	Single answer
Value Domain:	code
Response Options:	0= mmol/mol 1= %

Variable ID:	TIR
Variable:	Glycemic Control Time in range
Definition:	Provide the percentage of time in the range of 70 mg/dL – 180 mg/dL (3.9-10.0 mmol/L) over the past 6 months
Supporting Definition:	None
Displayed Value:	None
Inclusion Criteria:	Only persons with diabetes on continuous glucose monitoring
Timing:	Baseline Every 6 months
Data Source:	Clinical
Type:	Numerical
Value Domain:	quantity
Response Options:	Numerical value of time in range

Variable ID:	SystolicBloodPressure
Variable:	Systolic blood pressure
Definition:	Systolic reading of blood pressure, as measured by the indicated device type, in mmHg
Supporting Definition:	Systolic and diastolic blood pressure readings are used to determine the presence of hypertension and whether blood pressure is controlled if on blood pressure

	lowering medication. Control will be defined depending on the most relevant hypertension guidelines
Displayed Value:	None
Inclusion Criteria:	All patients
Timing:	Baseline Annually
Data Source:	Clinical
Type:	Numerical
Value Domain:	quantity
Response Options:	Numerical systolic BP in mmHG
Variable ID:	DIABP
Variable:	Diastolic blood pressure
Definition:	Diastolic reading of blood pressure, as measured by the indicated device type, in mmHg
Supporting Definition:	Systolic and diastolic blood pressure readings are used to determine the presence of hypertension and whether blood pressure is controlled if on blood pressure lowering medication. Control will be defined depending on the most relevant hypertension guidelines
Displayed Value:	None
Inclusion Criteria:	All patients
Timing:	Baseline Annually
Data Source:	Clinical
Type:	Numerical
Value Domain:	string
Response Options:	Numerical diastolic BP in mmHg
Variable ID:	LIPTCHOL
Variable:	Lipid Profile Total Cholesterol
Definition:	Most recent total cholesterol reading from the past 12 months
Supporting Definition:	None
Displayed Value:	None
Inclusion Criteria:	All patients
Timing:	Baseline Annually
Data Source:	Clinical
Type:	Numerical
Value Domain:	quantity
Response Options:	Numerical value of blood total cholesterol concentration
Variable ID:	LIPTCHOLUNI
Variable:	Units of Total Cholesterol
Definition:	None
Supporting Definition:	None
Displayed Value:	None
Inclusion Criteria:	All patients
Timing:	Baseline Annually
Data Source:	Clinical
Type:	Single answer
Value Domain:	code
Response Options:	0= mg/dL 1= mmol/L
Variable ID:	LIPLDL

Variable:	Lipid Profile LDL Cholesterol
Definition:	Most recent low density lipoprotein (LDL) cholesterol from the past 12 months
Supporting Definition:	None
Displayed Value:	None
Inclusion Criteria:	All patients
Timing:	Baseline Annually
Data Source:	Clinical
Type:	Numerical
Value Domain:	quantity
Response Options:	Numerical value of blood LDL cholesterol concentration
Variable ID:	LIPLDLUNI
Variable:	Units of LDL Cholesterol
Definition:	None
Supporting Definition:	None
Displayed Value:	None
Inclusion Criteria:	All patients
Timing:	Baseline Annually
Data Source:	Clinical
Type:	Single answer
Value Domain:	code
Response Options:	0= mg/dL 1= mmol/L
Variable ID:	LIPHDL
Variable:	Lipid Profile HDL Cholesterol
Definition:	Most recent high density lipoprotein (HDL) cholesterol from the past 12 months
Supporting Definition:	None
Displayed Value:	None
Inclusion Criteria:	All patients
Timing:	Baseline Annually
Data Source:	Clinical
Type:	Numerical
Value Domain:	quantity
Response Options:	Numerical value of blood HDL cholesterol concentration
Variable ID:	LIPHDLUNI
Variable:	Units of HDL Cholesterol
Definition:	None
Supporting Definition:	None
Displayed Value:	None
Inclusion Criteria:	All patients
Timing:	Baseline Annually
Data Source:	Clinical
Type:	Single answer
Value Domain:	code
Response Options:	0= mg/dL 1= mmol/L
Variable ID:	LIPTRY

Variable:	Lipid Profile Triglycerides
Definition:	Most recent triglycerides from the past 12 months
Supporting Definition:	None
Displayed Value:	None
Inclusion Criteria:	All patients
Timing:	Baseline Annually
Data Source:	Clinical
Type:	Numerical
Value Domain:	quantity
Response Options:	Numerical value of blood triglyceride concentration
Variable ID:	LIPTRYUNI
Variable:	Units of Triglycerides
Definition:	None
Supporting Definition:	None
Displayed Value:	None
Inclusion Criteria:	All patients
Timing:	Baseline Annually
Data Source:	Clinical
Type:	Single answer
Value Domain:	code
Response Options:	0= mg/dL 1= mmol/L
Variable ID:	WeightValue
Variable:	Body weight
Definition:	The body weight of a person, measured in the indicated units
Supporting Definition:	The collection of anthropometric measurements, particularly in those who are overweight or obese or who are concerned about their weight, should be performed with great sensitivity and without drawing attention to an individual's weight.
Displayed Value:	Please indicate your body weight.
Inclusion Criteria:	All patients
Timing:	Baseline Annually
Data Source:	Clinical
Type:	Numerical
Value Domain:	quantity
Response Options:	Numerical value of weight
Variable ID:	WeightUnit
Variable:	Body weight units
Definition:	Units of body weight
Supporting Definition:	None
Displayed Value:	Please indicate what units of measurement (kilograms or pounds) that you recorded your weight in.
Inclusion Criteria:	All patients
Timing:	Baseline Annually
Data Source:	Clinical
Type:	Single answer
Value Domain:	code

Response Options:	1 = kilograms 2 = lbs
Variable ID:	HeightValue_DIA
Variable:	Body height
Definition:	The height of a person, measured in the indicated units
Supporting Definition:	None
Displayed Value:	Please indicate your body height.
Inclusion Criteria:	All patients
Timing:	Baseline Annually
Data Source:	Clinical
Type:	Numerical
Value Domain:	quantity
Response Options:	Numerical value of height
Variable ID:	HeightUnit
Variable:	Body height units
Definition:	Units of body height
Supporting Definition:	None
Displayed Value:	Please indicate what units of measurement (centimeters or inches) that you recorded your height in.
Inclusion Criteria:	All patients
Timing:	Baseline Annually
Data Source:	Clinical
Type:	Single answer
Value Domain:	code
Response Options:	1 = centimeters 2 = inches
Variable ID:	WAISTC
Variable:	Waist Circumference
Definition:	Provide the most recent waist circumference taken in the past 12 months.
Supporting Definition:	- Waist circumference should be measured at the midpoint between the lower margin of the least palpable rib and the top of the iliac crest, using a stretch-resistant tape that provides a constant 100 g tension. [Waist Circumference and Waist–Hip Ratio: Report of a WHO Expert Consultation Geneva, 8–11 December 2008]
Displayed Value:	None
Inclusion Criteria:	All patients
Timing:	Baseline Annually
Data Source:	Clinical
Type:	Numerical
Value Domain:	quantity
Response Options:	Numerical value of waist circumference in centimeters

Acute Events

Variable ID:	DKAHHS
Variable:	Diabetic Ketoacidosis and Hyperosmolar Hyperglycemic Syndrome
Definition:	Indicate if the person with diabetes experienced Diabetic Ketoacidosis or Hyperosmolar Hyperglycemic Syndrome in the past 6 months.
Supporting Definition:	Diabetic ketoacidosis includes euglycemic and hyperglycemic ketoacidosis.
Displayed Value:	None
Inclusion Criteria:	All patients

Timing:	Baseline Every 6 months
Data Source:	Clinical
Type:	Single answer
Value Domain:	code
Response Options:	0= Yes, experienced DKA 1= Yes, experienced HHS 2= Yes, experienced both 3= No 999= Unknown
Variable ID:	HYPOL3
Variable:	Hypoglycemia - Level 3
Definition:	In the past 6 months, how many episodes of severe hypoglycemia requiring assistance from another person did the person with diabetes experience (this includes assistance from clinical and non-clinical individuals)?
Supporting Definition:	Level 3 hypoglycemia is defined as a hypoglycemic event needing assistance
Displayed Value:	None
Inclusion Criteria:	All patients
Timing:	Baseline Every 6 months
Data Source:	Clinical
Type:	Single answer
Value Domain:	code
Response Options:	0= 0 1= 1 2= 2 3= more than 2 999= Unknown
Variable ID:	HYPOL2
Variable:	Hypoglycemia - Level 2
Definition:	In the past 6 months, how many episodes of level 2 hypoglycemia (Blood glucose below 54 mg/dl (3.0 mmol/L)) did the person with diabetes experience?
Supporting Definition:	Level 2 hypoglycemia is defined as a measurable glucose concentration <54 mg/dL (3.0 mmol/L) that needs immediate action
Displayed Value:	None
Inclusion Criteria:	All patients
Timing:	Baseline Every 6 months
Data Source:	Clinical
Type:	Numerical
Value Domain:	quantity
Response Options:	Numeric Response
Variable ID:	HYPOL2AWAR
Variable:	Hypoglycemia - Level 2 Loss of awareness of hypoglycemia
Definition:	Did any of these hypoglycemic episodes occur without symptoms?
Supporting Definition:	Level 2 hypoglycemia is defined as a measurable glucose concentration <54 mg/dL (3.0 mmol/L) that needs immediate action
Displayed Value:	None
Inclusion Criteria:	If answered 1 or more to HYPOL2
Timing:	Baseline Every 6 months
Data Source:	Clinical

Type:	Single answer
Value Domain:	code
Response Options:	0 = No 1 = Yes 999 = Unknown
Variable ID:	MyocardialInfarction
Variable:	Myocardial infarction
Definition:	Indicate whether the patient has a documented history of myocardial infarction.
Supporting Definition:	Item is phrased as a patient reported measure. However, if the patient is unable to answer, this information can be abstracted from the medical records.
Displayed Value:	Have you ever been told by your doctor that you've had a heart attack or myocardial infarction?
Inclusion Criteria:	All patients
Timing:	Baseline Annually
Data Source:	Clinical
Type:	Single answer
Value Domain:	code
Response Options:	0 = No 1 = Yes 999 = Unknown
Variable ID:	CVTIA
Variable:	Cerebrovascular Disease - Acute events
Definition:	Has the person with diabetes ever experienced an acute cerebrovascular event? This includes stroke or transient ischemic attacks
Supporting Definition:	When presenting this question at annual follow-up, phrase as follows: "In the past 12 months, did the person with diabetes experience any new acute cerebrovascular events? This includes stroke or transient ischemic attacks."
Displayed Value:	None
Inclusion Criteria:	All patients
Timing:	Baseline Annually
Data Source:	Clinical
Type:	Single answer
Value Domain:	code
Response Options:	0 = No 1 = Yes 999 = Unknown
Variable ID:	LLAMP
Variable:	Lower Limb Amputation
Definition:	Has the person with diabetes had a lower limb amputation?
Supporting Definition:	When presenting this question at annual follow-up, phrase as follows: *"In the past year,* has the person with diabetes had a lower limb amputation?"
Displayed Value:	None
Inclusion Criteria:	All patients
Timing:	Baseline Annually
Data Source:	Clinical
Type:	Single answer
Value Domain:	code
Response Options:	0 = No 1 = Yes 999 = Unknown

Variable ID:	LLAMPLEV
Variable:	Lower Limb Amputation Level
Definition:	If yes to amputation, at what level is the amputation?
Supporting Definition:	If more than one procedure in the past 12 months, state the most severe level.
Displayed Value:	None
Inclusion Criteria:	If answered "1= Yes" to LLAMP
Timing:	Baseline Annually
Data Source:	Clinical
Type:	Single answer
Value Domain:	code
Response Options:	0= Distal to the ankle joint 1= Below knee 2= Above knee 999= Unknown

Chronic Complications

Variable ID:	VISIMP
Variable:	Visual Outcomes - Visual Impairment
Definition:	Does the person with diabetes experience visual impairment?
Supporting Definition:	None
Displayed Value:	None
Inclusion Criteria:	All patients
Timing:	Baseline Annually
Data Source:	Clinical
Type:	Single answer
Value Domain:	code
Response Options:	0 = No 1 = Yes 999 = Unknown

Variable ID:	VISIMPACU
Variable:	Visual Outcomes - Visual Impairment Visual Acuity
Definition:	If yes - what is the visual acuity?
Supporting Definition:	None
Displayed Value:	None
Inclusion Criteria:	If answered "1= Yes" to VISIMP
Timing:	Baseline Annually
Data Source:	Clinical
Type:	Numerical
Value Domain:	quantity
Response Options:	Numerical value of visual acuity

Variable ID:	VISIMPACUMET
Variable:	Visual Outcomes - Visual Impairment Visual Acuity Measurement Method
Definition:	Method of measurement (Snellen vs logMAR)
Supporting Definition:	None
Displayed Value:	None
Inclusion Criteria:	All patients

Timing:	Baseline Annually
Data Source:	Clinical
Type:	Single answer
Value Domain:	code
Response Options:	0= Snellen (6 meters) 1= Snellen (20 feet) 2= LogMAR
Variable ID:	VISTHREAT
Variable:	Visual Outcomes - Diabetes-related Sight Threatening Conditions
Definition:	Has the person with diabetes been diagnosed with any of the listed sight-threatening conditions? (select all that apply)
Supporting Definition:	When presenting this question at annual follow-up, phrase as follows: "*In the past year,* has the person with diabetes been diagnosed with any of the listed sight-threatening conditions?"
Displayed Value:	None
Inclusion Criteria:	All patients
Timing:	Baseline Annually
Data Source:	Clinical
Type:	Multiple answer
Value Domain:	code
Response Options:	0= Non-proliferative diabetic retinopathy 1= Proliferative diabetic retinopathy 2= Unspecified diabetic retinopathy 3= Macular edema 4= Other 5= No sight threatening conditions 999= Unknown
Variable ID:	AUTNEU
Variable:	Autonomic Neuropathy
Definition:	Is there evidence of diabetic autonomic neuropathy?
Supporting Definition:	None
Displayed Value:	None
Inclusion Criteria:	All patients
Timing:	Baseline Annually
Data Source:	Clinical
Type:	Single answer
Value Domain:	code
Response Options:	0 = No 1 = Yes 999 = Unknown
Variable ID:	PERINEUCLI
Variable:	Peripheral Neuropathy - Clinician Diagnosis
Definition:	Does the person with diabetes have evidence of peripheral neuropathy on clinical examination? This includes bedside tests such as pin prick or tuning fork tests.
Supporting Definition:	When presenting this question at annual follow-up, phrase as follows: "*In the past year,* did the person with diabetes develop evidence of peripheral neuropathy on clinical examination? This includes bedside tests such as pin prick or tuning fork tests."
Displayed Value:	None

Inclusion Criteria:	All patients
Timing:	Baseline Annually
Data Source:	Clinical
Type:	Single answer
Value Domain:	code
Response Options:	0 = No 1 = Yes 999 = Unknown
Variable ID:	PERINEUPAT
Variable:	Peripheral Neuropathy - Symptoms experienced by person with diabetes
Definition:	What symptoms are you experiencing due to your peripheral neuropathy (nerve damage to your lower or upper limbs)?
Supporting Definition:	None
Displayed Value:	None
Inclusion Criteria:	All patients
Timing:	Baseline Annually
Data Source:	Clinical
Type:	Single answer
Value Domain:	code
Response Options:	0= Numbness 1= Pain 2= Paresthesia 3= Asymptomatic/ No symptoms 999= Unknown
Variable ID:	CHARCF
Variable:	Charcot's Foot
Definition:	Is there evidence of Charcot's foot?
Supporting Definition:	At annual follow-up, do not re-present this question if responded "yes" to "Is there evidence of Charcot's foot?"
Displayed Value:	None
Inclusion Criteria:	All patients
Timing:	Baseline Annually
Data Source:	Clinical
Type:	Single answer
Value Domain:	code
Response Options:	0 = No 1 = Yes 999 = Unknown
Variable ID:	LLULC
Variable:	Lower Limb Ulcers Active lower limb ulcer present?
Definition:	Did the person with diabetes have an active lower limb ulcer in the past 12 months?
Supporting Definition:	None
Displayed Value:	None
Inclusion Criteria:	All patients
Timing:	Baseline Annually
Data Source:	Clinical
Type:	Single answer
Value Domain:	code

Response Options:	0 = No 1 = Yes 999 = Unknown
Variable ID:	LLULCSTAG
Variable:	Lower Limb Ulcers Staging
Definition:	If Yes, provide the most severe stage diagnosed using the University of Texas wound classification system
Supporting Definition:	None
Displayed Value:	None
Inclusion Criteria:	If answered "1= Yes" to LLULC
Timing:	Baseline Annually
Data Source:	Clinical
Type:	Single answer
Value Domain:	code
Response Options:	0= Stage A: No infection or ischemia 1= Stage B: Infection present 2= Stage C: Ischemia present 3= Stage D: Infection and ischemia present 999= Stage Unknown
Variable ID:	LLULCGRAD
Variable:	Lower Limb Ulcers Grading
Definition:	If Yes, provide the most severe grade diagnosed using the University of Texas Wound Classification system
Supporting Definition:	None
Displayed Value:	None
Inclusion Criteria:	If answered "1= Yes" to LLULC
Timing:	Baseline Annually
Data Source:	Clinical
Type:	Single answer
Value Domain:	code
Response Options:	0= Grade 0: Epithelialized wound 1= Grade 1: Superficial wound 2= Grade 2: Wound penetrates to tendon or capsule 3= Grade 3: Wound penetrates to bone or joint 999= Grade unknown
Variable ID:	PeripheralArteryDisease
Variable:	Peripheral artery disease
Definition:	Has the patient been diagnosed with peripheral artery disease?
Supporting Definition:	Peripheral artery disease (ICD:10 I70.2 - Atherosclerosis of arteries of extremities) diagnosed by clinician
Displayed Value:	None
Inclusion Criteria:	All patients
Timing:	Baseline Annually
Data Source:	Clinical
Type:	Single answer
Value Domain:	code

Response Options:	0 = No 1 = Yes 999 = Unknown
Variable ID:	PADPAT
Variable:	Peripheral artery disease - Symptoms experienced by person with diabetes
Definition:	Does the person with diabetes experience symptoms of peripheral artery disease?
Supporting Definition:	None
Displayed Value:	None
Inclusion Criteria:	All patients
Timing:	Baseline Annually
Data Source:	Clinical
Type:	Single answer
Value Domain:	code
Response Options:	0= No 1= Yes, intermittent claudication 2= Yes, rest pain 999= Unknown
Variable ID:	IschemicHeartDisease
Variable:	Ischemic Heart Disease
Definition:	Indicate whether the patient has ever been diagnosed with ischemic heart disease (including myocardial infarction)
Supporting Definition:	None
Displayed Value:	None
Inclusion Criteria:	All patients
Timing:	Baseline Annually
Data Source:	Clinical
Type:	Single answer
Value Domain:	code
Response Options:	0 = No 1 = Yes 999 = Unknown
Variable ID:	HeartFailure
Variable:	Heart failure
Definition:	Person has been clinically diagnosed with heart failure at any point in time
Supporting Definition:	None
Displayed Value:	None
Inclusion Criteria:	All patients
Timing:	Baseline Annually
Data Source:	Clinical
Type:	Single answer
Value Domain:	code
Response Options:	0 = No 1 = Yes 999 = Unknown
Variable ID:	CHRSTAGE
Variable:	Chronic Heart Failure Staging
Definition:	Please provide the stage of HF according to the American College of Cardiology/American Heart Association criteria (Jessup M, Abraham WT, Casey DE et al. 2009 Focused Update: ACCF/AHA Guidelines for the Diagnosis and

	Management of Heart Failure in Adults: A Report of the American College of Cardiology Foundation/American Heart Association Task Force on Practice Guidelines Developed in Collaboration With the International Society for Heart and Lung Transplantation. Journal of the American College of Cardiology 2009;53:1343-1382)
Supporting Definition:	None
Displayed Value:	None
Inclusion Criteria:	All patients
Timing:	Baseline Annually
Data Source:	Clinical
Type:	Single answer
Value Domain:	code
Response Options:	0= Stage A (At high risk of HF without structural heart disease or symptoms of HF) 1= Stage B (Structural heart disease but without signs or symptoms of HF) 2= Stage C (Structural heart disease with prior or current symptoms of HF) 3= Stage D (Refractory HF requiring specialist interventions) 4= Stage unknown 999= Not assessed
Variable ID:	eGFR
Variable:	Estimated glomerular filtration rate
Definition:	The persons estimated glomerular filtration rate (eGFR)
Supporting Definition:	eGFR as measured in milliliter per minute
Displayed Value:	None
Inclusion Criteria:	All patients
Timing:	Baseline Annually
Data Source:	Clinical
Type:	Numerical
Value Domain:	quantity
Response Options:	None
Variable ID:	RFTACR
Variable:	Renal Function Tests/Moderate to Severe Kidney Disease ACR
Definition:	What is the person with diabetes' urinary albumin/creatinine (ACR) ratio?
Supporting Definition:	Provide most recent reading from the past 12 months
Displayed Value:	None
Inclusion Criteria:	All patients
Timing:	Baseline Annually
Data Source:	Clinical
Type:	Single answer
Value Domain:	code
Response Options:	0= ACR <30mg/g or <3mg/mmol 1= ACR 30-300mg/g or 3-30mg/mmol 2= ACR > 300 mg/g or >30mg/mmol 3= ACR unknown
Variable ID:	DialysisDependent
Variable:	Dialysis dependent

Definition:	Indicate whether the person is dependent on dialysis
Supporting Definition:	None
Displayed Value:	None
Inclusion Criteria:	All patients
Timing:	Baseline Annually
Data Source:	Clinical
Type:	Single answer
Value Domain:	code
Response Options:	0 = No 1= Yes 999 = Unknown
Variable ID:	CerebrovascularDisease
Variable:	Cerebrovascular disease
Definition:	Has the patient ever been diagnosed with cerebrovascular disease?
Supporting Definition:	Cerebrovascular accident (ICD10: I60 - Subarachnoid haemorrhage, I61 – Intracerebral haemorrhage, I62 – other non-traumatic intracranial haemorrhage, I63 – cerebral infarction, I64 - Stroke, not specified as haemorrhage or infarction) or transient ischaemic attack (ICD10: G45 - Transient cerebral ischaemic attacks and related syndromes) diagnosed by a clinician. May include evidence from clinical examination or investigations.
Displayed Value:	None
Inclusion Criteria:	All patients
Timing:	Baseline Annually
Data Source:	Clinical
Type:	Single answer
Value Domain:	code
Response Options:	0 = No 1 = Yes 999 = Unknown
Variable ID:	PERIODON
Variable:	Periodontal Health
Definition:	Please provide details on the periodontal health of the person with diabetes
Supporting Definition:	None
Displayed Value:	None
Inclusion Criteria:	All patients
Timing:	Baseline Annually
Data Source:	Clinical
Type:	Single answer
Value Domain:	code
Response Options:	0= Healthy 1= Gingivitis 2= Periodontitis 999= Unknown
Variable ID:	ED
Variable:	Erectile Dysfunction
Definition:	Does the person with diabetes experience erectile dysfunction?
Supporting Definition:	When presenting this question at annual follow-up, phrase as follows: "*In the past 12 months*, did the person with diabetes experience any erectile dysfunction?
Displayed Value:	None
Inclusion Criteria:	Only male patients

Timing:	Baseline Annually
Data Source:	Clinical
Type:	Single answer
Value Domain:	code
Response Options:	0 = No 1 = Yes 999 = Unknown
Variable ID:	LIPDYS
Variable:	Lipodystrophy
Definition:	Is there evidence of lipodystrophy?
Supporting Definition:	When presenting this question at annual follow-up, phrase as follows: "*In the past 12 months*, did the person with diabetes develop new evidence of lipodystrophy?"
Displayed Value:	None
Inclusion Criteria:	Persons on injectable insulin or non-insulin injectable therapies
Timing:	Baseline Annually
Data Source:	Clinical
Type:	Single answer
Value Domain:	code
Response Options:	0 = No 1 = Yes 999 = Unknown

Health Services

Variable ID:	HOSPADMDATE
Variable:	Hospitalization Admission date
Definition:	Date of admission
Supporting Definition:	None
Displayed Value:	None
Inclusion Criteria:	All patients - for every hospitalization
Timing:	Annually
Data Source:	Clinical
Type:	Date
Value Domain:	date
Response Options:	Date of admission (DD/MM/YYYY) for every admission
Variable ID:	HOSPDISDATE
Variable:	Hospitalization Discharge date
Definition:	Date of discharge
Supporting Definition:	None
Displayed Value:	None
Inclusion Criteria:	All patients - for every hospitalization
Timing:	Annually
Data Source:	Clinical
Type:	Date
Value Domain:	date
Response Options:	Date of discharge (DD/MM/YYYY) for every admission
Variable ID:	HOSPDIAG
Variable:	Hospitalization - Discharge diagnosis
Definition:	What is the discharge diagnosis?

Supporting Definition:	- Cardiovascular - This includes myocardial infarction, acute coronary syndrome, unstable angina, stroke; decompensation of heart failure - Acute kidney injury[2] - Foot- and lower limb related- This includes foot ulcer, cellulitis, contiguous osteomyelitis, gangrene - Acute metabolic – This includes Ketoacidosis, hyperosmolar syndrome (without mentioning glucose level) dehydration, failure to thrive, acute hypoglycemia - Other (Everything that does not fall into the above clearly defined categories) - Unknown
Displayed Value:	None
Inclusion Criteria:	All patients - for every hospitalization
Timing:	Annually
Data Source:	Clinical
Type:	Multiple answer
Value Domain:	code
Response Options:	0= Cardiovascular causes 1= Acute Kidney Injury 2= Foot- and lower limb-related complications 3= Acute metabolic complications 4= Other 999= Unknown
Variable ID:	ERUTIL
Variable:	Emergency Room Utilization
Definition:	How many emergency room attendances related to diabetes has the person with diabetes had in the past year? Whether or not an emergency room attendance is related to diabetes is determined by the treating physician.
Supporting Definition:	Only include emergency room attendances with the following diagnoses: '- Cardiovascular - This includes myocardial infarction, acute coronary syndrome, unstable angina, stroke; decompensation of heart failure - Acute kidney injury[2] - Foot- and lower limb related- This includes infected foot ulcer, cellulitis, contiguous osteomyelitis, gangrene - Acute metabolic – This includes Ketoacidosis, hyperosmolar syndrome (without mentioning glucose level) dehydration, failure to thrive, acute hypoglycemia
Displayed Value:	None
Inclusion Criteria:	All patients - for every emergency room attendance
Timing:	Annually
Data Source:	Clinical
Type:	Numerical
Value Domain:	quantity
Response Options:	Numerical number of emergency room attendances (ooo if unknown)
Variable ID:	AccessToMedicines
Variable:	Access to medicines and supplies
Definition:	Does the patient experience difficulties obtaining medicine or supplies needed to manage their condition(s)?
Supporting Definition:	Access to drugs is the ability to access drugs as prescribed by healthcare provider
Displayed Value:	Do you have difficulty obtaining the medicine or supplies you need?
Inclusion Criteria:	All patients
Timing:	Baseline Annually
Data Source:	Patient-reported
Type:	Single answer
Value Domain:	code

Response Options:	0 = No 1 = Yes 999 = Unknown
Variable ID:	ACCESPROF3
Variable:	Access to healthcare (Access to healthcare professionals)
Definition:	Access to healthcare (Access to healthcare professionals)
Supporting Definition:	None
Displayed Value:	None
Inclusion Criteria:	All patients
Timing:	Baseline Annually
Data Source:	Patient-reported
Type:	Single answer
Value Domain:	code
Response Options:	0 = No 1 = Yes 999 = Unknown
Variable ID:	ACCESPROFREAS3
Variable:	Access to healthcare professionals (Reasons for lack of access)
Definition:	What are the reasons for this?
Supporting Definition:	If a person responds "difficulty paying for it" as a reason for having difficulty accessing medicines or supplies, then this will be counted as an outcome. This will only apply to the responses after the baseline response.
Displayed Value:	None
Inclusion Criteria:	All patients
Timing:	Baseline Annually
Data Source:	Patient-reported
Type:	Multiple answer
Value Domain:	code
Response Options:	0= Transportation problems 1= Difficulty paying for it 2= Not available where I live 3= Other reason 4= Unknown
Variable ID:	ACCESMEDREAS3
Variable:	Access to medicines and supplies (reasons for lack of access)
Definition:	What are the reasons for this?
Supporting Definition:	If a person responds "difficulty paying for it" as a reason for having difficulty accessing medicines or supplies, then this will be counted as an outcome. This will only apply to the responses after the baseline response.
Displayed Value:	None
Inclusion Criteria:	All patients
Timing:	Baseline Annually
Data Source:	Patient-reported
Type:	Multiple answer
Value Domain:	code

Response Options:	0= Transportation problems 1= Difficulty paying for it 2= Not available where I live 3= Other reason 999= Unknown

Survival

Variable ID:	VitalStatus
Variable:	Vital Status
Definition:	Indicate if the person has deceased, regardless of cause
Supporting Definition:	None
Displayed Value:	None
Inclusion Criteria:	All patients
Timing:	Annually
Data Source:	Clinical
Type:	Single answer
Value Domain:	code
Response Options:	0 = No 1 = Yes 999 = Unknown
Variable ID:	DEATHCAUSE_DIAB
Variable:	Cause of death
Definition:	The cause of death of the person
Supporting Definition:	None
Displayed Value:	None
Inclusion Criteria:	If answered "1= Yes" to VitalStatus
Timing:	Annually
Data Source:	Clinical
Type:	Multiple answer
Value Domain:	code
Response Options:	0= Cardiovascular 1= Acute metabolic complication of diabetes related to high or low blood glucose 2= Renal 3= Other 999= Unknown
Variable ID:	DEATHSOURCE
Variable:	Death - Source of information
Definition:	What is the source of the information on the person with diabetes' death
Supporting Definition:	None
Displayed Value:	None
Inclusion Criteria:	All patients
Timing:	Annually
Data Source:	Clinical
Type:	Single answer
Value Domain:	code
Response Options:	0= Death certificate 1= Clinical records 2= Family/ Carers 3= Other

Patient Reported Outcomes

Variable ID:	WHO-5

Variable:	WHO-5 Well-Being Index
Definition:	Psychological Wellbeing
Supporting Definition:	Measured using the 5-item WHO (Five) Well-Being Index
Displayed Value:	None
Inclusion Criteria:	All patients
Timing:	Baseline Annually
Data Source:	Patient-reported
Type:	As per tool developer
Value Domain:	N/A
Response Options:	The WHO-5 is free for all health care organizations, and a license is not needed. There are translations available. More information may be found at www.who-5.org.
Variable ID:	WHO-5_Q01
Variable:	Question 1 of WHO-5
Definition:	Please indicate for each of the 5 statements which is closest to how you have been feeling over the past 2 weeks. Over the past 2 weeks: 1. I have felt cheerful and in good spirits
Supporting Definition:	The raw score ranging from 0 to 25 is multiplied by 4 to give the final score from 0 representing the worst imaginable well-being to 100 representing the best imaginable well-being
Displayed Value:	Over the past 2 weeks: 1. I have felt cheerful and in good spirits
Inclusion Criteria:	All patients
Timing:	Baseline Annually
Data Source:	Patient-reported
Type:	Single answer
Value Domain:	code
Response Options:	5= All of the time 4= Most of the time 3= More than half the time 2= Less than half the time 1= Some of the time 0= At no time
Variable ID:	WHO-5_Q02
Variable:	Question 2 of WHO-5
Definition:	Over the past 2 weeks: 2. I have felt calm and relaxed
Supporting Definition:	The raw score ranging from 0 to 25 is multiplied by 4 to give the final score from 0 representing the worst imaginable well-being to 100 representing the best imaginable well-being
Displayed Value:	Over the past 2 weeks: 2. I have felt calm and relaxed
Inclusion Criteria:	All patients
Timing:	Baseline Annually
Data Source:	Patient-reported
Type:	Single answer
Value Domain:	code
Response Options:	5= All of the time 4= Most of the time 3= More than half the time 2= Less than half the time 1= Some of the time 0= At no time
Variable ID:	WHO-5_Q03
Variable:	Question 3 of WHO-5
Definition:	Over the past 2 weeks: 3. I have felt active and vigorous
Supporting Definition:	The raw score ranging from 0 to 25 is multiplied by 4 to give the final score from 0 representing the worst imaginable well-being to 100 representing the best imaginable well-being
Displayed Value:	Over the past 2 weeks: 3. I have felt active and vigorous
Inclusion Criteria:	All patients

Timing:	Baseline Annually
Data Source:	Patient-reported
Type:	Single answer
Value Domain:	code
Response Options:	5= All of the time 4= Most of the time 3= More than half the time 2= Less than half the time 1= Some of the time 0= At no time
Variable ID:	WHO-5_Q04
Variable:	Question 4 of WHO-5
Definition:	Over the past 2 weeks: 4. I woke up feeling fresh and rested
Supporting Definition:	The raw score ranging from 0 to 25 is multiplied by 4 to give the final score from 0 representing the worst imaginable well-being to 100 representing the best imaginable well-being
Displayed Value:	Over the past 2 weeks: 4. I woke up feeling fresh and rested
Inclusion Criteria:	All patients
Timing:	Baseline Annually
Data Source:	Patient-reported
Type:	Single answer
Value Domain:	code
Response Options:	5= All of the time 4= Most of the time 3= More than half the time 2= Less than half the time 1= Some of the time 0= At no time
Variable ID:	WHO-5_Q05
Variable:	Question 5 of WHO-5
Definition:	Over the past 2 weeks: 5. my daily life has been filled with things that interest me
Supporting Definition:	The raw score ranging from 0 to 25 is multiplied by 4 to give the final score from 0 representing the worst imaginable well-being to 100 representing the best imaginable well-being
Displayed Value:	Over the past 2 weeks: 5. my daily life has been filled with things that interest me
Inclusion Criteria:	All patients
Timing:	Baseline Annually
Data Source:	Patient-reported
Type:	Single answer
Value Domain:	code
Response Options:	5= All of the time 4= Most of the time 3= More than half the time 2= Less than half the time 1= Some of the time 0= At no time
Variable ID:	PAID
Variable:	PAID Diabetes Distress Score
Definition:	Diabetes Distress
Supporting Definition:	Measured using the 20-item Problem Areas in Diabetes questionnaire
Displayed Value:	None
Inclusion Criteria:	All patients
Timing:	Baseline Annually
Data Source:	Patient-reported
Type:	As per tool developer
Value Domain:	N/A
Response Options:	The PAID, authored by Joslin Diabetes Center (http://www.joslin.org), is the copyright of Joslin Diabetes Center (Copyright ©2000, Joslin Diabetes Center). The PAID, provided under license from Joslin Diabetes Center may not be copied, distributed or used in any way without the prior written consent of Joslin Diabetes

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Variable ID:	PHQ9
Variable:	PHQ-9 Depression Score
Definition:	Depression
Supporting Definition:	Measured using the 9-item PHQ-9 questionnaire
Displayed Value:	None
Inclusion Criteria:	All patients
Timing:	Baseline Annually
Data Source:	Patient-reported
Type:	As per tool developer
Value Domain:	N/A
Response Options:	The PHQ-9 is free for all health care organizations, and a license is not needed. There are translations available. More information may be found at https://www.phqscreeners.com.
Variable ID:	PHQ9_Q01
Variable:	Question 1 of PHQ-9
Definition:	Over the last 2 weeks, how often have you been bothered by any of the following: A. Little interest or pleasure in doing things?
Supporting Definition:	None
Displayed Value:	Over the last 2 weeks, how often have you been bothered by any of the following: A. Little interest or pleasure in doing things?
Inclusion Criteria:	All patients
Timing:	Baseline Annually
Data Source:	Patient-reported
Type:	Single answer
Value Domain:	code
Response Options:	0= Not at all 1= Several days 2= More than half the days 3= Nearly every day
Variable ID:	PHQ9_Q02
Variable:	Question 2 of PHQ-9
Definition:	Over the last 2 weeks, how often have you been bothered by any of the following: B. Feeling down, depressed, or hopeless
Supporting Definition:	None
Displayed Value:	Over the last 2 weeks, how often have you been bothered by any of the following: B. Feeling down, depressed, or hopeless
Inclusion Criteria:	All patients
Timing:	Baseline Annually
Data Source:	Patient-reported
Type:	Single answer
Value Domain:	code
Response Options:	0= Not at all 1= Several days 2= More than half the days 3= Nearly every day
Variable ID:	PHQ9_Q03
Variable:	Question 3 of PHQ-9
Definition:	Over the last 2 weeks, how often have you been bothered by any of the following: C. Trouble falling or staying asleep, or sleeping too much?
Supporting Definition:	None
Displayed Value:	Over the last 2 weeks, how often have you been bothered by any of the following: C. Trouble falling or staying asleep, or sleeping too much?
Inclusion Criteria:	All patients

Timing:	Baseline Annually
Data Source:	Patient-reported
Type:	Single answer
Value Domain:	code
Response Options:	0= Not at all 1= Several days 2= More than half the days 3= Nearly every day
Variable ID:	PHQ9_Q04
Variable:	Question 4 of PHQ-9
Definition:	Over the last 2 weeks, how often have you been bothered by any of the following: D. Feeling tired or having little energy?
Supporting Definition:	None
Displayed Value:	Over the last 2 weeks, how often have you been bothered by any of the following: D. Feeling tired or having little energy?
Inclusion Criteria:	All patients
Timing:	Baseline Annually
Data Source:	Patient-reported
Type:	Single answer
Value Domain:	code
Response Options:	0= Not at all 1= Several days 2= More than half the days 3= Nearly every day
Variable ID:	PHQ9_Q05
Variable:	Question 5 of PHQ-9
Definition:	Over the last 2 weeks, how often have you been bothered by any of the following: E. Poor appetite or overeating?
Supporting Definition:	None
Displayed Value:	Over the last 2 weeks, how often have you been bothered by any of the following: E. Poor appetite or overeating?
Inclusion Criteria:	All patients
Timing:	Baseline Annually
Data Source:	Patient-reported
Type:	Single answer
Value Domain:	code
Response Options:	0= Not at all 1= Several days 2= More than half the days 3= Nearly every day
Variable ID:	PHQ9_Q06
Variable:	Question 6 of PHQ-9
Definition:	Over the last 2 weeks, how often have you been bothered by any of the following: F. Feeling bad about yourself - or that you are a failure or have let yourself or your family down?
Supporting Definition:	None
Displayed Value:	Over the last 2 weeks, how often have you been bothered by any of the following: F. Feeling bad about yourself - or that you are a failure or have let yourself or your family down?
Inclusion Criteria:	All patients
Timing:	Baseline Annually
Data Source:	Patient-reported
Type:	Single answer
Value Domain:	code
Response Options:	0= Not at all 1= Several days 2= More than half the days 3= Nearly every day
Variable ID:	PHQ9_Q07
Variable:	Question 7 of PHQ-9

Definition:	Over the last 2 weeks, how often have you been bothered by any of the following: G. Trouble concentrating on things, such as reading the newspaper or watching television?
Supporting Definition:	None
Displayed Value:	Over the last 2 weeks, how often have you been bothered by any of the following: G. Trouble concentrating on things, such as reading the newspaper or watching television?
Inclusion Criteria:	All patients
Timing:	Baseline Annually
Data Source:	Patient-reported
Type:	Single answer
Value Domain:	code
Response Options:	0= Not at all 1= Several days 2= More than half the days 3= Nearly every day
Variable ID:	PHQ9_Q08
Variable:	Question 8 of pHQ-9
Definition:	Over the last 2 weeks, how often have you been bothered by any of the following: H. Moving or speaking so slowly that other people could have noticed? Or the opposite - being so fidgety or restless that you have been moving around a lot more than usual?
Supporting Definition:	None
Displayed Value:	Over the last 2 weeks, how often have you been bothered by any of the following: H. Moving or speaking so slowly that other people could have noticed? Or the opposite - being so fidgety or restless that you have been moving around a lot more than usual?
Inclusion Criteria:	All patients
Timing:	Baseline Annually
Data Source:	Patient-reported
Type:	Single answer
Value Domain:	code
Response Options:	0= Not at all 1= Several days 2= More than half the days 3= Nearly every day
Variable ID:	PHQ9_Q09
Variable:	Question 9 of PHQ-9
Definition:	Over the last 2 weeks, how often have you been bothered by any of the following: I. Thoughts that you would be better off dead or of hurting yourself in some way?
Supporting Definition:	None
Displayed Value:	Over the last 2 weeks, how often have you been bothered by any of the following: I. Thoughts that you would be better off dead or of hurting yourself in some way?
Inclusion Criteria:	All patients
Timing:	Baseline Annually
Data Source:	Patient-reported
Type:	Single answer
Value Domain:	code
Response Options:	0= Not at all 1= Several days 2= More than half the days 3= Nearly every day

[1] For international benchmarking work, the amount of alcohol consumed by each patient should be converted by multiplying ALCFREQ x ALCAMT x country- or region-specific number of grams per unit of alcohol

[2] Acute kidney injury is defined by using KDIGO guidelines as "An increase in serum creatinine (SCR) by >0.3mg/dL (>26.5 µmol/l) within 48 hours; or an increase in SCR to >1.5 times baseline, which is known or presumed to have occurred within the prior 7 days; or urine volume <0.5ml/kg/h for 6 hours."

[3] All responses to the Access to care questions (ACCESPROF, ACCESPROFREAS, ACCESMED, ACCESMEDREAS) should be measures at baseline and included as case-mix variables in the analysis. These questions should be repeated annually, and the presence or absence of financial barriers used as an outcome (i.e., whether or not the patient selects "Difficulty paying for it" as a response option to ACCESMEDREAS and ACCESPROFREAS).

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
Fabrizio Carinci	University of Bologna, Italy	None declared
Massimo Massi-Benedetti	Hub for International Health Research, Italy	None declared
Oluwakemi Okunade	ICHOM, United States	None declared
Jana Nano	Erasmus MC, Netherlands/ Institute of Epidemiology; Helmholtz Zentrum München, German Research Center for Environmental Health; German Center for Diabetes Research (DZD), Germany	None declared
Magdalena Walbaum	Catholic University of Chile/Ministry of Health, Chile	None declared
Sarah Whittaker	ICHOM, United States	None declared
Andreas Schmitt	Diabetes Center Mergentheim, Germany	None declared
Andrew Pumerantz	Western Diabetes Institute, Western University of Health Sciences, United States	Temple University Kornberg School of Dentistry – _Consulting Fees and Travel, Lodging, and Meals Marwar Muslim Educational & Welfare Society – _Consulting Fees Hispanic Health – _Consulting Fees McKinsey & Company – _Speaking Fees Diabetes Cross-Disciplinary Index - Creator
Anil Bhansali	Postgraduate Institute of Medical Education and Research, India	None declared
Anne Peters	The Keck School of Medicine of the University of Southern California, Los Angeles, CA, United States	Abbott Diabetes Care – _Advisory Board Becton Dickinson – _Advisory Board Bigfoot – _Advisory Board Boehringer Ingelheim – _Advisory Board Dexcom – _Research Support Eli Lilly and Co. – _Advisory Board, Speaker fees Janssen – _Advisory Board, Research Support Lexicon – _Advisory Board Livongo – _Advisory Board Medscape – _Speaker fees Merck – _Advisory Board Novo Nordisk – _Advisory Board, Speaker fees Omada Health – _Advisory Board Sanofi – _Advisory Board Science 37 – _Advisory Board
Cristina García Ulloa	Instituto Nacional de Ciencía Médicas y Nutrición, Mexico	SMID- Patent pending
Daniel Barthelmes	University Hospital Zurich, Switzerland	Novartis – _Grant

		Bayer – _Grant
Hwee-Lin Wee	Saw Swee Hock School of Public Health and Department of Pharmacy, Faculty of Science, National University of Singapore, Singapore	Pfizer Pte Ltd – _Unrestricted educational grant
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Jihan Dennaoui	National Health Insurance Company-Daman, United Arab Emirates	None declared
João Raposo	APDP/Nova Medical School Lisbon, Portugal	Astra-Zenica – _Speaker Fee Boehringer-Ingelheim – _Scientific Board Novo Nordisk – _Speaker Fee Lilly – _Speaker Fee
Katharine Barnard	Bournemouth University, United Kingdom	None declared
Maria Santana	O'Brien Institute for Public Health, Canada	None declared
Mark Peyrot	Loyola University Maryland, United States	Calibra – _Consulting, advisory board Johnson & Johnson – _Speaker fees Eli Lilly – _Consulting, advisory board Novo Nordisk – _Grant, consulting Valeritas – _Consulting, speaker fees
Mark Prabhaharan	Patient Representative, Malaysia	None declared
Naomi Levitt	University of Cape Town, South Africa	Sanofi Avntis – _Funding to attend a congress Novo Nordisk – _Funding to attend a conference Roche Diagnostics – _Financial support
Paul Buchanan	GBDOC/Blue Circle Voices*/Patient representative, United Kingdom	None declared
Rob Haig	Patient Representative, Australia	None declared
Ronit Calderon-Margalit	The Hebrew University of Jerusalem, Israel	None declared
Saf Naqvi	Imperial College London Diabetes Centre, United Arab Emirates	None declared
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Sharon Fraser	International Diabetes Federation, Belize	None declared
Søren Eik Skovlund	Aalborg University and Aalborg University Hospital, Denmark	Novo Nordisk A/S- Past Employer DrugStars Aps- Employee/Cofounder

		Patient Focused Medicines Development (PFMD)- Non-Financial Support
Tim Benson	WHO Patients for Patient Safety/ Consumers Health Forum of Australia/ Health Consumers Council of Western Australia/Patient Representative, Australia	None declared
William Polonsky	Behavioral Diabetes Institute, University of California, United States	Novo Nordisk- Consulting Fees Sanofi- Consulting Fees Eli Lilly- Consulting Fees Dexcom- Consulting Fees Intarcia- Consulting Fees Astra Zeneca- Consulting Fees Abbott- Consulting Fees Trividia- Consulting Fees Mannkind- Consulting Fees Livongo- Consulting Fees Bigfoot- Consulting Fees Roche- Consulting Fees

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Reference Guide Revisions

Reference Guide Version	Location within Reference Guide	Content Change
4.0.0	Data Dictionary, Appendix	Harmonisation updates

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