



T1D
Exchange

Data Science Committee Meeting

July 2023

Co-chairs: Joyce Lee, Marina Basina

Agenda

- Welcome and introductions- Dr. Marina Basina
- EHR paper discussion- Dr. Joyce Lee
- Standardized reporting for sensors/automated insulin delivery-Dr. Joyce Lee
- Mapped sites update- Anton, T1D Exchange
- Brief T1D & T2D data spec updates- Emma,T1D Exchange

EHR Manuscript Discussion

Standardized Reporting for AID

Mapping Updates

- 30 sites fully mapped (from 28 sites in Q2)
- 4 in validation phase
- Data completeness scorecards
 - Scorecards will be sent in the following weeks with data through Q3-2023

Data Spec Updates

- No major changes
- We are starting to ask sites that are mapping to use the code 'poca1c' for POCA1c values (Point of Care HbA1c: these are done in-clinic and results are obtained in minutes instead of sending to a lab).

T2D Data Spec Overview

- Three working groups review the complete data spec

Patient/Provider/Encounter Files

Group Members:

- James Dawson (T1D Exchange), Nicole Rioles (T1D Exchange), Ann Mungmode (T1D Exchange), Lily Chao (CHLA), Kai Jones (WUSTL), Sean Delacey (Lurie), Shylaja Srinivasan (UCSF)

Variables to be discussed from current dataspec

Patient File : (variables & definitions)

- Gender: Gender- (technically, sex) of the respective patient
- Education Level: Variables include no Highschool, Highschool Graduate, College Graduate, Post Graduate Degree, Unknown
- Language: English, Spanish, Chinese, Vietnamese, French, German, Arabic, Other, Unknown

Provider File: (variable & definition)

- Provider_type: Type of provider - Physician-, Options Include: Doctor of Osteopathic Medicine, Physician Assistant, Nurse Practitioner, Registered Nurse, Registered Dietician, Exercise Physiologist, Psychologist, Social Worker, Certified Diabetes Educator, Pharmacist, Optometrist, Podiatrist, Physical therapist, Occupational therapist, Other person

Variables to be discussed from current dataspec

Encounter File:(variables & definitions)

- Class: Outpatient- An encounter during which the patient is not hospitalized overnight.
- Status/Status Reason: - The status of the encounter record. Encounters should start with a status of planned and then diverge from there to their final status. Reason for the current status; the actor scopes the reason.
 - For instance, an actor of patient and reason is illness would imply the patient was too sick while an actor of provider and reason of illness would imply the provider was sick. Likely exclusively used for canceled or rescheduled encounters.

Observation/Condition/Medication Files

Group Members:

- Holly Hardison (T1D Exchange), Emma Ospelt (T1D Exchange), Trevon Wright (T1D Exchange), Carla Demeterco Berggren (Rady Children's Hospital), Monica Bianco (Lurie Children's), Talia Hitt (Johns Hopkins) , Margaret Zupa (UPMC)

Types of Files

Observations File

- Every encounter can have many observations
- 4 main types: surveys, vital signs, lab results, social history

Conditions File

- Patients' problems list, all exhaustive conditions

Medications File

- Prescribed medications
- Status (active, re-order, on hold, etc.)

Proposed Changes

Suggestions to add:

- Waist circumference, vital signs
- ASC Suicide Screening, survey
- Insurance mediated prescription non-adherence, survey
- Substance use, survey
- Beverage and diet intake, survey
- Screen time, survey
- Secondhand Smoke/ Vaping, survey
- Medical Literacy, survey
- Date of start of medication, status
- Follow up on receiving medication, status

Medication Files

Group Members

T1D Exchange Members: Ori, Anton, Saketh

Collaborative Members:

- Dimpri Desai - Stanford
- Marina Basina - Stanford
- Mark Clements - CMH
- Sonya Haw - Grady
- Francesco Vendrame - Miami
- Alissa Roberts - Seattle

Changes to Disease

Disease

- t1d_dx_dt will change to t2_dx_dt:
- sh_events_amb_pro: Usually a telephone encounter. May not be recorded as hypo event.
- Variables to Remove:
 1. dental_exam_dt
 2. dka_serum_bicarb
 3. dka_blood_ph
 4. transportation_insecurity
 5. housing_insecurity
- Variables to Add
 1. BMI (In Observation section of Core specification)

Changes to Insulin section

insulin_regimen: Add basal-bolus mix and inhaled insulin

ins_pump_delivery:

- Remove: Low_glucose_suspend, Predictive_low_glucose_suspend, and Closed loop
- Add: manual mode

ins_pump_company: Add Mankind, CeQur

ins_pump_model: Add V-go, CeQur Simplicity

Variables to Add:

1. noninsulin_regimen which contains 5 sections to be named later
2. basal_bolus_mix_daily_inj: average daily injections
3. basal_bolus_mix_daily: average daily units