Diabetes Data Strategy (Diabe-DS) Use Case

Final Draft – August 2011

Overview

The collection of data elements selected by the Diabetes Data Strategy (Diabe-DS) prototype project team are not comprehensive and do not cover all aspects of type 1 diabetes (T1D) care. The data elements included in the Diabe-DS data set are those that are needed for both patient care and secondary uses. Therefore the Diabe-DS data elements represent an important, but not complete, set of data elements for T1D. The Diabe-DS Use Case presented here includes key activities (represented as a collection of 'mini' use cases) in research, public health, and quality measurement that leverage data collected in a clinical setting. The Diabe-DS Use Case highlights the expected common data elements required for both primary clinical data collection and secondary uses (i.e., research, public health, and quality measurement).

- The Diabe-DS Use Case is made up of several 'mini' use cases which describe key components of care.
- The model is centered on the diagnosis and care of an adolescent with T1D.
- The project does not consider transitions between primary care provider and hospital events.
- The setting addresses only care in an outpatient clinic.
- The use case describes the preferred future state with regard to the collection, access, and exchange.

The 'mini' use cases include:
- Initial Presentation to Primary Care Provider (Pediatrician) with Symptomatic Hyperglycemia
- Endocrinologist Referral
- Ordering of Laboratory Tests (to support initial diagnosis of T1D)
- Initial Visit (Diagnostic) with Diabetes Specialist (Pediatric Endocrinologist)
- Ordering, i.e., prescribing, and Dispensing of Pharmaceuticals to treat T1D
- Patient Education: Diet, Exercise, Medication Administration, and Teaching
- Medication Dispensing for out-patient administration of insulin
- Results Monitoring
- Follow up visit-Diabetes Nurse Educator
- Follow up Specialist Visit (Monitoring)
- Public Health Use Case-Diabetes Care and Surveillance
- Clinical Research Use Case – Patient Screening
- Quality Measurement and Reporting Use Case

As the use cases are developed and data requirements are modeled, it is predictable that the use case content may evolve and expand over time.

Initial Presentation to Primary Care Provider (Pediatrician) with Symptomatic Hyperglycemia

Mother takes her 16 year old daughter, Sweet Sally Teenager, to the family pediatrician after the daughter has experienced recurrent vaginal yeast infections for which she has used over the counter Vagisil. She has also had an unintentional 15 lb weight loss. The mother has also noticed that her daughter seems to tire easily and is more irritable than usual.

At the pediatrician's office, the pediatrician conducts an assessment which includes a limited history and physical exam. Vital signs are documented which include temperature, blood pressure, pulse rate, and respiratory rate. The pediatrician documents the presence of symptoms of polydipsia and polyuria. The pediatrician documents the results of a capillary non-fasting glucose (finger stick blood glucose), which although not diagnostic, is 200 milligrams per deciliter (mg/dl.) He also documents the results of a urine test strip which shows large glucose as well as trace to small ketones. The pediatrician, who has

experience diagnosing diabetes in children, contacts a pediatric endocrinologist at a large, highly integrated health system to refer Sweet Sally to an outpatient pediatric endocrinology clinic. The pediatrician documents Sally's family history, history of childhood illnesses/viruses, problem list, physical exam findings, diagnosis list, medication and allergy lists, narrative records and today's lab results, all of which are forwarded to the outpatient pediatric endocrinology office after discussing the patient with the receiving pediatric endocrinology team.

Actors, Actions and Data Elements [Primary Care Visit]

Actor	Action	Data Elements
Teenager	Experience	Yeast infection indicator *[Yeast infections indicator (186.1)]* Weight loss indicator *[Unexplained weight loss indicator (186)]* Fatigue *[Fatigue (512)]* Date of birth *[Age at diagnosis of T1D (139);Date of birth (486)]*
Pediatrician	Conduct	Patient history *[Patient history (540)]* Physical exam *[Physical exam (539)]* Screening visit *[Type 1 diabetes presumptive diagnosis reason (4); Encounter type (203.1)]*
Pediatrician	Document	Polydipsia indicator *[polydipsia indicator (#184); Type 1 diabetes symptoms present indicator (700)]* Polyuria indicator *[polyuria indicator (#183)] [Type 1 diabetes symptoms present indicator (700)]* Capillary blood glucose *[blood glucose without fasting (1510); random blood glucose test result in mg/dl (#178);Capillary blood glucose (541)]* Urinalysis test strip results *[urine ketone test results (#181); Biochemical indicators for Type 1 diabetes (6); ketoacidosis lab test type (110)]* Family history *[Number of relatives with type 1 diabetes (29); Number of first degree relatives with type 1 diabetes (29.1); Family history first degree (620)]* Medication *[Concomitant medication indicator (1); (1740);Medications affecting glucose homeostasis indicator (41)]* Temperature *[Body temperature (557)]* Systolic Blood pressure *[Systolic blood pressure (561)]* Diastolic Blood pressure *[Diastolic blood pressure (562)]* Pulse rate *[Pulse (558)]* Respiratory rate *[Respiratory rate (559)]* Oxygen saturation *[Oxygen saturation (560)]*

The patient is referred to a pediatric endocrinologist and the primary care physician's office staff schedules an appointment time, in agreement with Sally's mother, at the time of the visit.

Endocrinologist Referral
Prior to the visit, the office manager of the Endocrinologist verifies Sally's eligibility with her health insurance company and confirms that the office is 'in-network' for Sally's benefit plans. She also validates participation in the medical and pharmacy benefits available for Sally's care.

Sally's mother is directed to the referral office website to download and complete requisite paperwork prior to the visit. [Note: The data collected with this set of forms requested by the specialist are **out of scope** of the current Diabe-DS demonstration project. The forms would likely include detailed data on the following: birth history, neonatal complications, length of initial hospitalization (proxy for neonatal complications), breast feeding history, dates at attainment of developmental milestones, detailed past medical history, and psychosocial assessment. Sample forms can be looked at in a later phase of the Diabe-DS project to understand these specific data elements.]

Because Sweet Sally appears metabolically stable with trace ketones, the labs will be drawn after a 12 hour fast. Sally is instructed to drink only water for 12 hours prior to the having the blood drawn the next morning.

Ordering of Laboratory Tests for Endocrinologist Visit (to support initial diagnosis of T1D)
The following laboratory tests are requested by the endocrinologist and are to be completed prior to the initial outpatient endocrinology office visit. The order for laboratory tests is sent electronically to the outpatient clinic laboratory. She is sent to lab for blood work.

- Electrolytes
- Complete Blood Count (CBC)
- Insulin Auto Antibodies Tyrosine Phosphatase (IA2) Insulin Auto Antibody (IAA)
- Glutamic Acid Decarboxylase Autoantibody (GADA)
- Oral Glucose Tolerance Test (OGTT) (including fasting glucose and insulin levels)
- HbA1c
- Urinalysis
- Venous blood pH
- Thyroid Auto Antibodies

Actors, Actions and Data Elements [Laboratory visit]

Actor	Actions	Data Elements
Endocrinologist	Order	Electrolytes *[Electrolytes test order indicator (533)]* Complete blood count (CBC) *[CBC test order indicator (542)]* Insulin Auto Antibodies Tyrosine Phosphatase (IA2) *[Insulin Auto Antibodies tyrosine phosphatase (IA2) test order indicator (543); Biochemical autoantibodies order indicator (131); Diabetes-related autoantibody type (137); Type 1 Diabetes diagnosis method (206); Type 1 Diabetes presumptive diagnosis reason (4)]* Insulin Auto Antibody (IAA) *[Insulin Auto Antibody test order (534): Biochemical autoantibodies order indicator (131); Diabetes-related*

		autoantibody type (137); Type 1 Diabetes diagnosis method (206)] Glutamic Acid Decarboxylase Autoantibody (GADA) *[Glutamic Acid Decarboxylase Antibodies order indicator (535); Biochemical autoantibodies order indicator (131);Type 1 diabetes diagnosis method (206)]* Oral Glucose Tolerance Test (OGTT) (includes fasting glucose and insulin) *[Oral glucose tolerance test order indicator (536);Type 1 diabetes diagnosis method (206)]* HbA1c *[HbA1c test order indicator (538); Type 1 diabetes diagnosis method (206)]* Repeat urinalysis *[Urinalysis test order indicator (544)]* Venous blood pH *[Venous blood pH test order indicator (545)]* Thyroid Auto Antibodies *[Thyroid auto antibodies test order indicator (546)]*

Initial Visit (Diagnostic) with Diabetes Specialist (Pediatric Endocrinologist)

Sally arrives for her scheduled appointment with the specialist three days after the blood work is drawn. Sally Teenager's registration information, which was completed at home by her mother and includes the administrative information, is reviewed for accuracy. The office takes a picture of Sally and confirms the registration information. Sally provides a first morning urine which is evaluated for urine ketones, protein and white blood cells. The results are captured in her (specialist) electronic clinic health record.

The office nurse documents the following baseline measurements and assessments:
- Height (in inches and converted to centimeters) –64 in/160 cm (include z-score and percentile)
- Weight (in pounds and converted to kilograms) – 105 lb/47.7 kg (include z-score and percentile)
- Body Surface Area (BSA) – 1.47 m^2
- Calculated Body Mass Index (BMI) – 18.0 kg/m2 (include z-score and percentile)
- Vital signs, including temperature, blood pressure, pulse rate, respiratory rate
- Reviewed medications currently used, including prescription and non prescription drugs. For each medication, the current dose, frequency and most recent usage is verified. The duration of taking the medication, as well as the reasons for the medication is also verified.
- There is no use of steroids or other immunosuppressive agents.
- Family history is reviewed and documented. Sally has a paternal uncle with Type 1 diabetes.

Lab Results Values (have returned and populated into the electronic health record)
- Electrolytes: Sodium 137mEq/L; Potassium 4.8 mEq/L; Chloride 103 mEq/L
- Complete Blood Count (CBC): Hct 41.0 percent; Hgb 12.0g/dl; White Blood Count 4.5mm3
- Insulin Auto Antibodies Tyrosine Phosphatase (IA2): positive
- Insulin Auto Antibody (IAA): positive
- Glutamic Acid Decarboxylase Autoantibody (GADA): positive
- Oral Glucose Tolerance Test (OGTT) (includes fasting glucose and insulin level): 131 fasting and 265 mg/dl at 120 minutes
- HbA1c: 8.8%
- Repeat urinalysis: moderate Ketones; no white cells

- Venous blood pH: 7.30
- Thyroid Auto Antibodies: Negative

Initial Interview:
During the first appointment interview, Sally and her mother are asked to describe her symptoms. She says she eats all the time. 'I can eat all the candy bars I want and I never gain weight.' She says she is 'always drinking water, juice, anything-- I am always thirsty.' She also relates she has to go to the bathroom frequently--- 'like every hour'. Upon questioning, she also reveals that she frequently wakes in the night to urinate. And further she feels that she needs to have a nap every afternoon. She says her clothes are loose and while she is not certain of how much weight she has lost, she thinks that she needs new clothes that will fit her better. She denies nausea and vomiting, self induced or otherwise until feeling "a little nauseous this morning." She also denies having had diarrhea. She reports that she has had multiple vaginal yeast infections over the past year.

The endocrinologist documents other components of the exam in including, but not limited to:
- Age at menarche or date (month and year)
- Tanner staging
- Post-pubertal status (indicator)
- Psychosocial screening, including behavioral concerns, grade in school, name of the school, presence of school nurse, school performance, special education/leaning needs, after school sports activities, marital status of the parents, and members of the household
- Dental/oral exam
- Eye exam
- Foot exam
- Vaccine History

Actors, Actions and Data Elements [Endocrinologist initial visit]

Actor	Actions	Data Elements
Office manager	Verify	Eligibility
Office nurse	Documents	Height *[Height (518)]* Weight *[Weight (519)]* Body Surface Area (BSA) (Derived) *[Body Surface Area (#45)]* Body Mass Index (BMI) *[Overweight indicator (937); Body weight assessment performed indicator (971)]* Temperature *[Body temperature (557)]* Blood pressure *[Systolic blood pressure (561); Diastolic blood pressure (562)]* Pulse rate [Pulse (558)] Respiratory rate *[Respiratory rate (559)]* Oxygen Saturation *[Oxygen saturation (560)]* Medications *[Concomitant Medication Indicator (1); Medications affecting glucose homeostasis indicator (41); Insulin secretagogue indicator (907)]]* Use of steroids or other immunosuppressive agents *[Chronic Immunosuppressant Use Indicator (36); also (41)]* Family history *[Number of relatives*

			with type 1 diabetes (29); Number of first degree relatives with type 1 diabetes (29.1); Family history first degree (620); Family autoimmune disease diagnosis indicator (30);Total number first degree relatives in family (81.1); Total number of first degree relatives in family that have been screened for T1D with a pancreatic antibody testing panel (81.2); Number of first degree relatives screened for type 1 diabetes (81.3); Maternal Diabetes indicator (113); Biological mother reported type of diabetes (114); Type 1 diabetes family relationship (111)]
Endocrinologist	Documents		Age at menarche *[Age at menarche (523)]* Tanner staging *[Tanner staging (524)]* Post-pubertal status (indicator) *[Post-pubertal status indicator (552)]* Grade in school *[Grade in school (550)]* Name of the school *[Name of school (552)]* After school sports activities *[Average number hours of physical activity per day (504)]* Parents' marital status *[Parent(s)' marital status (553)]* Members of the household *[Household members (554)]* Dental exam *[Dental examination date (149)]* Eye exam *[Comprehensive Eye Exam Date (167); Eye Exam Date (143); Eye exams (905)]* Foot exam *[Foot exam performed (151)]* Electrolytes test result *[Electrolytes test result (522)]* Complete blood count (CBC) results *[CBC test result (521)]* Insulin Auto Antibodies Tyrosine Phosphatase (IA2) results *[Insulin auto antibodies tyrosine phosphatase (IA2) results (549); T1D presumptive diagnosis reason (4); Also (206,137)]* Insulin Auto Antibody (IAA) result *[Insulin auto antibody test result (555); Also (4, 206,137)]* Glutamic Acid Decarboxylase Autoantibody (GADA) result *[Glutamic acid decarboxylase antibodies*

		indicator (33);Also (206,137)] Oral Glucose Tolerance Test (includes fasting glucose) result *[Oral glucose tolerance test result in mg/dl (153); Oral glucose tolerance test result in mmol/l (154); Plasma glucose test result (187); Impaired glucose tolerance indicator (195); Fasting plasma glucose test result (106); Also (206, 137)]* HbA1c result *[HbA1c test result (10.1); HbA1c test result (10.2); HbA1c test performed (11); HbA1c value (9); Ketoacidosis lab test type (110); Also (206)]* Urinalysis result *[Urinalysis test result (556)]* Venous blood pH result *[Ketoacidosis lab test type (110);Venous blood pH test result (547)]* Thyroid Autoantibodies result *[Thyroid autoantibodies test result (548)]* Immunization status *[Influenza vaccination status indicator (500); Pneumococcal vaccination status indicator (501)]*
Teenager	Experience	Vaginal yeast infections *[Yeast infections indicator (186.1)]* Hunger *[Polyphagia indicator (185)]* Thirst *[Polydipsia indicator (184)]* Fatigue *[Fatigue (532)]* Weight loss *[Unexplained weight loss indicator (186)]]*

Ordering and Dispensing of Pharmaceuticals

The endocrinologist determines that a combination of insulins will provide the best regimen for Sweet Sally's diabetes management, giving her a flexible insulin schedule to match her school and extra-curricular activities' schedules. Insulins will be dosed as 0.8 units per kg body weight.

The endocrinologist orders the following pharmaceuticals and supplies using e-prescribing:
- Lantus (insulin glargine): 0.8 units per kg body weight subcutaneously (SQ) at 5:00 to 6:00 p.m. daily
- NovoLog (insulin aspart) (rapid acting): 1 unit per 12 grams carbohydrate SQ 15 minutes before eating plus 1 unit to lower glucose 50 mg/dl to pre-meal target=120 mg/dl. At bedtime, 1 unit to lower glucose 100 mg/dl to a bedtime and overnight target equal to150 mg/dl.
- Blood Glucose Test strips (one month supply)
- One Touch (brand) Glucose Monitor
- Alcohol swabs
- Insulin syringes/needles
- Sharps disposal bin
- Glucagon emergency kit
- Urine or serum ketone strips

The orders are written as *Dispense As Written* (DAW) and sent to the pharmacy that is part of the approved network and local to where Sally and her mother live.

Actors, Actions and Data Elements

Actor	Actions	Data Elements
Endocrinologist	Determine	Diabetes Management Method *[Diabetes management method (140)]*
Endocrinologist	Order	Insulin glargine *[Insulin medication ordered (223); Insulin type (906); Basal insulins (918) Medication name (529); Medication code (530)]* Units *[Insulin dose amount ordered (531)]* Insulin aspart *[Insulin medication ordered (223); Insulin type (906); Prandial (bolus) insulins (917)]* SQ (subcutaneously) *[Insulin Administration method (65)]* Insulin dose amount *[Insulin dose amount ordered (531)]*

Patient Education: Diet, Exercise, Medication Administration and Teaching
Having been diagnosed as a new onset diabetic, a care team assigned to work with her will include a physician, diabetes nurse educator, nutritionist, and medical social worker. Each team member has responsibilities in Sally's care and will collaborate to construct the most effective plan of care for her.

Sally and her parents are scheduled with the office nurse diabetes educator the following day and enrolled in a 4 day New Onset Diabetes Education program. Sally's father works two jobs so Sally's mother will be the primary care giver and will attend all program sessions with Sally. In addition, as a requirement for Sally's completion of the New Onset Diabetes Education program, the diabetes team will meet with Sally's father to review Sally's diabetes management plan and teach him how to dose and administer insulin.

During the day-long educational session, the diabetes nurse educator focuses on:
- Assessment of usual dietary intake, patterns of activity or exercise, insulin prescription to fit her lifestyle, eating habits at home and at school or work
- Insulin administration, diet, exercise and developmentally appropriate management tasks for an adolescent girl to assume, and skin care, including foot care.

The education program discussions and results are documented in the health record. [Note: specific data elements to identify family members taught to administer insulin and other aspects of the New Onset Diabetes Education program are out of scope for the first phase of the Diabe-DS demonstration.]

Medication Administration
The diabetes nurse educator explains the correction factor concept, the importance of checking blood glucose before meals and the importance of giving insulin, as required, before meals and at bedtime.

Sally and her parents are taught that correction factor doses of NovoLog are given only every 4 hours. If Sally decides to eat a snack two hours after eating a meal when she had been given a correction factor, she will only cover her carbohydrate intake using the insulin to carbohydrate ratio.

The diabetes nurse educator demonstrates the technique for checking blood sugar. Sally does a return demonstration showing the process of setting up the monitor in preparation for the test, cleansing the skin

with water, using sterile technique to lance her fingertip, applying a drop of blood on the glucose monitoring stick, placing it into the monitoring device and reading the blood glucose result.

The diabetes nurse educator then demonstrates the technique for drawing up insulin, how to get bubbles out of the syringe, and the injection. For safety, the educator stresses the importance of having two people verify the accuracy of the insulin dosage. Sally conducts a return demonstration of all the steps to verify understanding and dosage accuracy. Her mother validates that the dosage is correct. Sally does the return demonstration of the injection on herself.

The importance of pre-meal and pre-snack glucose monitoring, and regular intervals of blood glucose monitoring are stressed. Sally and her parents agree that they understand this importance. They are instructed on site rotation.

The components of blood glucose monitoring and tracking glucose trends that were discussed include:
- Date/time of monitoring
- Blood sugar level; if finger stick glucose greater than 250 mg/dl, were urine or serum ketones were checked and what they were; discuss how to correct using the correction factor
- Types of Insulin administered (if insulin was required)
- The number of units for each type of insulin she administered
- Site of the insulin injection
- How she is feeling physically and emotionally
- Any illness e.g. a cold, flu,

Sally is instructed to follow the same process, recording the insulin administration at the following times:
- 0700 (before breakfast)
- 1200 (before lunch)
- 1700 (before dinner)
- 2100 (at bedtime)

Sally is also instructed to check her blood sugar prior to any sports activity or physical exertion which is not part of her normal pattern of exercise. In addition, she is asked to check her sugars whenever she feels shaky, confused, hungry, lightheaded, diaphoretic, experiences frequent urination, has an unquenchable desire to drink fluids or does not feel well in general. Whenever she checks her blood sugar, she is to record the facts associated with checking the sugar. This will become a log in her Personal Health Record (PHR) that will be shared with her nurse educator throughout the outpatient education program. It will also be shared with the nutritionist and endocrinologist when she returns for a visit in 1 to 2 weeks and 4 to 6 weeks, respectively.

Nutrition and Physical Activity
The diabetes nurse educator also discusses nutrition with Sally and her mother and schedules time for additional nutritional education. In the interim, the diabetes nurse educator provides pamphlets on nutrition, the food plate (replacement for food pyramid), and an outline for a 2000 calorie ADA diet.

Sally is asked to describe her general activity level. Her mother estimates that she walks 2 miles a day. She currently is in Physical Education—a required high school class—and they are doing cross county running. Physical education is scheduled 5 days a week and the time per period is 30 minutes of running with stretching before and after. Sally hates the class because she has been so tired recently.

Sally is referred to group education classes for nutrition and cooking instruction.

Skin and Foot Assessment
In this scenario, a skin and foot assessment is done visually, focusing on the presence of calluses, reddened areas, fissures and dryness. The diabetes nurse educator notes only dryness around the heels

of both feet. Sally is wearing flip-flops. She is instructed in wearing protective footwear including socks to which Sally responds, "That's a drag."

Actors, Actions and Data Elements [Diabetes nurse educator visit]

Actor	Actions	Data Elements
Diabetes nurse educator	Refers	Nutrition Classes *[Nutritional therapy consult order (515); Diabetes management method (140)]*
Diabetes nurse educator	Documents	Physical activity *[Average number hours of physical activity per day (504)]* Foot exam *[Foot exam performed (151); Foot care education indicator (904); Foot problems indicator (150)]*
Diabetes nurse educator	Discusses	Testing and tracking blood glucose and insulin administration components *[Diabetes education status indicator (502); Glycemic control method (160); Diabetes management method (140); Self-monitoring of blood glucose (947)]* *Blood glucose testing [Capillary random blood glucose (541)]* *Blood glucose testing date [Home blood glucose monitoring test date (59)]* Blood glucose testing time *[Home blood glucose monitoring test time (60)]* Blood sugar level *[Self-monitored blood glucose test result (155); Home blood glucose monitoring result (61)]*
Diabetes nurse educator	Demonstrates	Insulin administration technique *[Insulin administration method (65)]*
Diabetes nurse educator	Schedules	Nutrition therapy *[Nutritional therapy consult order (515)]*

Medication Dispensing
The following medications have been order by the endocrinologist electronically:

Trade Name	RxNorm Code	Strength	Firm Name
LANTUS INSULIN GLARGINE	220378	100UNT/ML	SANOFI AVENTIS
INSULIN NOVOLOG FOR INJECTION	575679	100UNT/ML	PHYSICIANS TOTAL CARE INC
GLUCAGON EMERGENCY KIT	310497	1 MG/ML	ELI LILLY AND COMPANY

Sally and her mother go to the pharmacy to pick up the medications and supplies. The pharmacist explains the correction factor concept, the importance of checking blood glucose before meals and the importance of giving insulin, as required, before meals and at bedtime.

Actors, Actions and Data Elements [Medication dispensing]

Actor	Actions	Data Elements
Pharmacist	Dispenses	Insulin glargine *[Insulin medication*

		dispensed (213); Insulin type (906); Medication name (529); Medication code (530); Basal insulins (918)] Insulin aspart [Insulin medication dispensed (213); Prandial (bolus) insulins (917); Insulin type (906); Medication name (529); Medication code (530)]
Sally Teenager	Picks up	Insulin glargine for Injection [Basal insulins (918)] Insulin aspart for Injection [Prandial (bolus) insulins (917)]

Results Monitoring

Sally is asked to regularly record the following information in her Personal Health Record (PHR) diabetic log in order to learn more about diabetes and how it affects her.   This will also be shared with her nurse educator as well as the nutritionist and endocrinologist during future visits:

Date	3/14/2011	3/14/2011	3/14/2011	3/14/2011
Time	0700	1200	1700	2100
Blood Sugar Level				
Insulin Aspart Units				
Insulin Glargine Units				
Injection Site				
Physical Activity				
What You Ate				
G Carbs				
How were you feeling?				

Actors, Actions and Data Elements

Actor	Actions	Data Elements
Sally Teenager	Records	Blood sugar level [Capillary random blood glucose (541); Self monitoring glucose result (992); Home blood glucose monitoring result (61); Self-monitored blood glucose test result (155)] Insulin aspart Units [Prandial (bolus) insulins (917)] Insulin glargine Units [Basal insulins (918)] Injection site [Insulin administration body site (527)] Physical Activity [Physical activity average daily hours (504)] Food eaten [Number fruits/vegetables consumed daily (505)] Gram carbs Mood

			Date *[Home blood glucose monitoring date (59)]* Time *[Home blood glucose monitoring time (60)]*

Follow up Visit – Diabetes Nurse Educator

Sweet Sally and her mother complete a 4 day intensive education program and return to the Nurse educators' office 7 days later to evaluate Sally's progress and adherence to the new lifestyle and insulin administration plan.

Sally authorizes the nurse access rights to the diabetes log in her PHR. The nurse downloads the log prior to the visit. Below is one day of Sally's recording using the diabetes log provided during her Teenagers and Diabetes classes:

Date	3/14/2011	3/14/2011	3/14/2011	3/14/2011
Time	0700	1200	1700	2100
Blood Sugar Level	130	175	94	225
NovoLog (insulin aspart) Units	0.5	0.5 units	0	7.
Lantus (insulin glargine) Units	19		19	
Injection Site	Left Lower	Right Lower		Left Upper
Physical Activity			Ran extra hurdles	
What You Ate	2 eggs/4 slices bacon	Not hungry	OK	Holy Cow Ice Cream- 3 scoops
G Carbs	5.2	Not hungry	Maybe 100	90
How were you feeling?	Good	Grouchy	30 minutes before this I felt faint, dizzy— ate some candy bars and drank a bunch of juice and took my glargine but no NovoLog because my BG was 94 mg/dl	Tired

Together they review and agree that drawing up insulin and rotating sites is working well. Sally says she gets 'really shaky' when she gives herself a shot and has stuck herself with a needle once. The most difficult part is 'recording everything and eating the right stuff'. The educator again reviews measuring carbs. She provides online resources for looking up carbohydrate content and reviews the target carbohydrate to insulin ratio. Sally comments, 'I just don't get that.' Her mother indicates that it is a daily struggle for the entire family since 'we usually eat on the run.' The nurse educator suggests that they enroll in a class focused on healthy cooking. They agree to continue meeting weekly and between appointments, the diabetic nurse educator will periodically access and review Sally's log. She also asks Sally to call her every other day and give a verbal update.

Knowing that Sally's appointment with the endocrinologist is scheduled soon, she prepares a report summarizing progress and indicates that continued and additional education is needed as this has been particularly difficult for Sally and her family. Since Sally is having difficulty adapting to the new lifestyle requirements, she also recommends referral to a social worker specializing in diabetes counseling for adolescents.

Actors, Actions and Data Elements

Actor	Actions	Data Elements
Diabetes nurse educator	Reviews	Diabetes management log [*Glycemic control method (160); Diabetes management method (140)]* Blood sugar level *[Capillary random blood glucose (541); Self monitoring glucose result (992); Home blood glucose monitoring result (61); Self-monitored blood glucose test result (155)]* NovoLog (insulin aspart) Units [*Prandial (bolus) insulins (917)]* Lantis (insulin glargine) Units [*Basal insulins (918)]* Injection site *[Insulin administration body site (527)]* Physical Activity *[Physical activity average daily hours (504)]* Food eaten *[Number fruits/vegetables consumed daily (505)]* Gram carbs Mood Date *[Home blood glucose monitoring date (59)]* Time *[Home blood glucose monitoring time (60)]*

Follow up Visit - Specialist (Monitoring)
Sally is scheduled to see the endocrinologist 4 weeks from her first appointment. In preparation for the appointment, the office requests that Sally have labs drawn on the day before the visit to monitor her progress.

The following laboratory tests are ordered and are to be drawn in a fasting state:
- Thyroid function
- Celiac screening with an IgA level and tissue transglutaminase antibody titre
- Fasting lipids
- HbA1C

Sally authorizes the endocrinologist's office access rights to her PHR. Her diabetes log is downloaded to the office for review during her visit. Her glucometer readings are also downloaded to the office the day before the appointment.

On arrival to the office for the second visit, the following information is gathered by the office nurse:
- Weight (kilograms); height (centimeters) and calculated BMI (with percentiles and z-scores)
- Vital signs, including temperature, blood pressure, pulse rate, respiratory rate and oxygen saturation.

The lab results are reviewed by the endocrinologist and the following is noted:

- Sally has gained 5 pounds and she is very unhappy about that.
- Her HbA1c is 8.6%
- Other than at 0700, she has been erratic in checking her blood glucose. The range has been between 75 and 225 milligrams per deciliter and predominantly in the high 140-150 range.
- She describes herself as being very tired.
- Her mother says she is very crabby and emotionally 'all over the board'.
- They have continued to visit the diabetic nurse educator weekly and have had some interim calls.

The endocrinologist also refers Sally to a social worker specializing in diabetes counseling for help with her diabetes management issues.

Actors, Actions and Data Elements

Actor	Actions	Data Elements
Endocrinologist	Orders	Thyroid function *[Autoimmune disease diagnosis indicator (12)]* Thyroid antibodies *[Autoimmune disease diagnosis indicator (12); Thyroid autoantibodies order indicator (546)]* Celiac screening *[Autoimmune disease diagnosis indicator (12)]* Random lipids *[Triglycerides (927); High-density lipoprotein cholesterol (HDL-C) (928)]* HbA1C *[HbA1c test order indicator (538); Type 1 diabetes diagnosis method (206)]*
Office Nurse	Documents	Weight *[Weight (519)]* Temperature *[Body temperature (557)]* Blood pressure *[Systolic blood pressure (561); Diastolic blood pressure (562)]* Pulse rate *[Pulse (558)]* Respiratory rate *[Respiratory rate (559)]* Oxygen Saturation *[Oxygen saturation*
Endocrinologist	Reviews	Weight *[Weight (519); Overweight indicator (937)]* *HbA1C result [HbA1c value (9); HbA1c test result (10.1); HbA1c test result (10.2)]* Thyroid function result *[Autoimmune disease diagnosis indicator (12)]* Thyroid autoantibodies result*[Thyroid autoantibodies test result (548)]* Celiac screening result *[Autoimmune disease diagnosis indicator (12)]* Random lipids result *[Triglycerides (927); High-density lipoprotein cholesterol (HDL-C) (928)]*

Public Health Use Case-Diabetes Care and Surveillance

The goals of public health for diabetes care management include:
1. Monitor prevalence of diabetes in the community and HbA1c testing trends (including frequency and levels);
2. Inform clinical decisions for diabetes care management by providing providers with community health information and community resources;
3. Improve communication between patients and providers and provide patients with educational materials and information on community resources.

The endocrinologist's office regularly receives public health report criteria through an interface between the public health agency's information system and his EHR. Since Sweet Sally's HbA1c is 8.8%, this triggers an alert based on the report criteria. The alert tells the provider he needs to send data about Sally to the public health agency.

The following data will be electronically extracted from the EHR into the reporting form:
- Demographic data including county of residence, race, ethnicity, household income, Sally's age and education level.
- Influenza immunization status
- Pneumococcal immunization status
- Number of diabetes-related hospitalizations
- Physical activity and diet information from Sally's Personal Health Record
- Diabetes education status

The endocrinologist or office staff member will validate the data in the reporting form prior to transmitting to the public health agency. The data may be transmitted through a Health Information Exchange or transmitted through another secure system. It will be anonymized through either of these for use by public health.

The public health agency retrieves the data and aggregates it with data from other providers. The data is used to generate surveillance reports which are transmitted back to the providers for use in diabetes care management. The aggregated data is also used for diabetes surveillance and to manage resources for diabetes patients.

Since Sally has a PHR, her provider will give her mother information about the public health programs for Type 1 diabetes. If her mother chooses to enroll her, the public health agency will be able to send preventive care reminders to her. They can also provide her with additional diabetic education and let her know of additional resources in her community for management of her diabetes.

Actors, Actions and Data Elements

Actor	Actions	Data Elements
Endocrinologist	Validates	County of residence *[Address county/parish name (506)]* Race *[Race(511)]* Ethnicity *[Ethnicity (512)]* Household income *[Household income (509)]* Sally's age *[Date of birth (516)]* Education level *[Education level (510]* Influenza immunization status *[Influenza vaccination status indicator (500)]* Pneumococcal immunization status

		[Pneumococcal vaccination status indicator (501) Number of diabetes related hospitalizations *[Diabetes related hospitalizations (512)]* Physical activity *[Average number hours of physical activity per day (504)]* Diet information *[Number fruits/vegetables consumed per day (505)]* Diabetes education status *[Diabetes education status indicator (502)]*

[Note: Points for future consideration - How many states produce triggers based on report criteria to trigger submission of data to public health? Currently aware that NYC flags personal A1c data. The info is extracted by insurance companies. It would be interesting to know if more communities will do this. Unsure of the level of success in NYC. Consider for future research and enhancement in phase II of the Diabe-DS project.]

Clinical Research Use Case – Patient Screening
Objective: To utilize EHR data to identify possible patients for a given trial.

A researcher affiliated with the outpatient specialty clinic has been recruited by colleagues at a national conference to participate (as a site investigator) in a research study by identifying and enrolling patients. To do so, this researcher needs to give an estimate of the number of patients he might recruit for the trial, and wants to use EHR data to provide a listing of patients that are potentially eligible for the study. This same estimate of the approximate number of patients that might be screened and enrolled in the study will be important to include in the local IRB application for the study. This particular study uses the following eligibility criteria:

Inclusion Criteria:
Potential participants must meet the following inclusion criteria:
- Be within 3-months of diagnosis of type 1 diabetes based on American Diabetes Association (ADA) criteria.
- Be between the ages of 8 and 45 years old.
- Must have stimulated C-peptide levels > 0.2 pmol/ml (measured during an MMTT administered no more than one month prior to the date of randomization).
- Must have either detectable anti-GAD, anti-ICA512/IA-2, insulin autoantibodies (unless received insulin therapy for 7 days or more), or islet cell autoantibodies.

Note: For screening purposes, it is not necessary to match on every criterion. The screening function is to identify the most potentially eligible patients and prevent the researcher from meeting with every potentially eligible T1D study subject.

The researcher has a query interface to the clinic EHR and can query for patients with the four inclusion criteria. From this list the researcher can review records in more detail or contact the treating physician regarding the eligibility and recruitment of that patient for the trial.

Actors, Actions and Data Elements

Actor	Actions	Data Elements
Researcher	Queries	Date of birth *[Date of birth(516)]* Age at diagnosis *[Age at diagnosis of T1D (139)]*

		C-peptide level *[Stimulated C-peptide levels > 0.2 pmol/ml indicator* Anit-GAD *[Glutamic Acid Decarboxylase antibodies indicator (33)]*

Quality Measurement and Reporting Use Case

Objective: To utilize EHR data to compute institutional quality measures and report to regulatory and accrediting bodies.

Quality measure information is collected at the point of care using an electronic health record system, assembled, and transmitted via secure data exchange for internal quality improvement, pay-for-reporting, pay-for-performance, or public reporting purposes.

Providers may use an EHR that assembles and submits patient level or aggregate level quality measurement data or rely upon a third party to aggregate the data on behalf of the organization, such as a health information exchange (HIE) or a quality report processing entity. Regardless, after the patient care encounter, the provider uses an EHR to assemble data in accordance with electronic measure (eMeasure) specifications.

Existing NQF-endorsed ambulatory clinical quality measures that have undergone eMeasure retooling can be found at http://www.qualityforum.org/Projects/e-g/eMeasures/Electronic_Quality_Measures.aspx#t=2&s=&p=1%7C, and are developed for a number of specific patient populations. At the time of this writing, two measures were targeted to diabetes patient populations and are presented in the table immediately below. We are aware that the measures as written apply to patients 18-75 years of age and not the pediatric age group. However, for illustrative purposes we include them, and expect that relevant diabetes control measures for pediatric population will be available in time. In the same vein, we have adopted the adult quality measure based on foot exam recommendation for adult patients, since the current guideline for pediatric patients is more vague. [See ADA clinical practice recommendations at ADA.org under Pediatric Care section.] We predict that in the future, more relevant and robust quality measures for pediatric diabetes management will be more readily available. Following the table of QMs below is a list of CDEs identified by the Diabe-DS project and the specific Quality Measure (QM) for which they correspond.

Measure Title	Numerator	Denominator	Exclusions
QM #1: Diabetes Care HbA1c control (<8.0%) (NQF0575) The percentage of patients 18 - 75 years of age with diabetes (type 1 and type 2) who had HbA1c control (<8.0%) (meaningful use measure)	Number of patients whose most recent automated HbA1c level is <8.0%. The member is not numerator compliant if the automated result for the most recent HbA1c test is = 8.0% or is missing a result, or if an HbA1c test was not done during the measurement year.	Number of patients 18 - 75 years of age identified as having diabetes during the measurement year or the year prior to the measurement year. Includes patients with an active diagnosis of diabetes and/or indication that a diabetic medication is active, ordered or dispensed.	Exclusions: - Patients with a diagnosis of polycystic ovaries who did not have any face-to-face encounters with a diagnosis of diabetes, in any setting, during the measurement year or the year prior to the measurement year. Diagnosis can occur at any time in the member's history, but must have occurred by December 31 of the measurement year. - Patients with gestational or steroid-induced diabetes who did not have any face-to-face encounters with a diagnosis of

			diabetes, in any setting, during the measurement year or the year prior to the measurement year. Diagnosis can occur during the measurement year or the year prior to the measurement year, but must have occurred by December 31 of the measurement year.
QM #2: Diabetic Foot Exam (NQF056) The percentage of patients 18 - 75 years of age with diabetes (type 1 and type 2) who had a foot exam (visual inspection, sensory exam with monofilament, or pulse exam). (meaningful use measure)	Number of patients with a foot exam procedure performed.	Number of patients 18-75 years of age identified as having diabetes during the measurement year or the year prior to the measurement year. Includes patients with an active diagnosis of diabetes and/or indication that a diabetic medication is active, ordered or dispensed.	Exclusions: - Patients with a diagnosis of polycystic ovaries who did not have any face-to-face encounters with a diagnosis of diabetes, in any setting, during the measurement year or the year prior to the measurement year. Diagnosis can occur at any time in the member's history, but must have occurred by December 31 of the measurement year. - Patients with gestational or steroid-induced diabetes who did not have any face-to-face encounters with a diagnosis of diabetes, in any setting, during the measurement year or the year prior to the measurement year. Diagnosis can occur during the measurement year or the year prior to the measurement year, but must have occurred by December 31 of the measurement year.
***Additional management criteria set by the ADA (available at diabetes.org) that have specific age and duration criteria.** We list them below as data elements of particular relevance to future quality measures. These are included here because they are of interest, but they are not explored in depth in this Diabe-DS Use Case version,*			

The following patient level data elements are assembled to support quality analysis and reporting activities.

Actors, Actions and Data Elements

Actor	Actions	Data Elements
Provider	Assembles	Birth date (QM #1, 2) *[Date of birth(516)]* Encounter date (QM #1, 2) *[Encounter datetime (203)* Encounter type (QM #1, 2) *[Encounter type (203.1)]* Active diagnosis diabetes (QM #1, 2) *[Active diagnosis diabetes (172.1,*

		172.2)] Active diagnosis gestational diabetes (QM #1, 2 exclusion) *[Active diagnosis gestational diabetes (175.2, 175.3)]* Active diagnosis steroid induced diabetes(QM #1, 2 exclusion) *[Active diagnosis steroid induced diabetes (180.1, 180.2)]* Active diagnosis polycystic ovaries (QM #1, 2 exclusion) *[Active diagnosis polycystic ovaries (179.1, 179.2, 179.3)]* Active alpha-glucosidase inhibitor medication (QM #1, 2) *[Alpha-glucosidase medication active (230)]* Active amylin analog medication (QM #1, 2) *[Amylin analog medication active (231)]* Active antidiabetic medication (QM #1, 2) *[Antidiabetic medication active (232)]* Active insulin medication (QM #1, 2) *[Insulini medication active (233)]* Active antidiabetic-combination medication (QM #1, 2) *[Antidiabetic combination medication active (234)]* Active biguanide medication (QM #1, 2) *[Biguanide medication active (235)]* Active meglitinide medication *[Meglinitide medication active (236)]* Active sulfonylurea medication (QM #1, 2) *[Sulfonylurea medication active (237)]* Active thiazolidinedione medication (QM #1, 2) *[Thiazolidinedione medication active (238)]* Other active medication indicative of diabetes (QM #1, 2) *[Other medication indicative of diabetes active (239)]* Dispensed alph-glucosidase inhibitor medication (QM #1, 2) *[Alpha-glucosidase medication dispensed (210)]* Dispensed amylin analog medication (QM #1, 2) *[Amylin analog medication dispensed (211)]* Dispensed antidiabetic medication (QM #1, 2) *[Antidiabetic medication dispensed (212)]* Dispensed insulin medication (QM #1, 2) *[Insulin medication dispensed (213)]* Dispensed antidiabetic-combination medication (QM #1, 2) *[Antidiabetic-*

		combination medication dispensed (214)] Dispensed biguanide medication (QM #1, 2) *[Biguanide medication dispensed (215)]* Dispensed meglinitide medication (QM #1, 2) *[Meglinitide medication dispensed (216)]* Dispensed sulfonylurea medication (QM #1, 2) *[Sulfonylurea medication dispensed (217)]* Dispensed thiazolidinedione medication (QM #1, 2) *[Thiazolidinedione medication dispensed (218)]* Other dispensed active medication indicative of diabetes (QM #1, 2) *[Other medication indicative of diabetes dispensed (219)]* Ordered alph-glucosidase inhibitor (QM #1, 2) medication *[Alpha-glucosidase medication ordered (220)]* Ordered amylin analog medication (QM #1, 2) *[Amylin analog medication ordered (221)]* Ordered antidiabetic medication (QM #1, 2) *[Antidiabetic medication ordered (222)]* Ordered insulin medication (QM #1, 2) *[Insulin medication ordered (223)]* Ordered antidiabetic-combination (QM #1, 2) medication *[Antidiabetic-combination medication ordered (224)]* Ordered biguanide medication (QM #1, 2) *[Biguanide medication ordered (225)]* Ordered meglinitide medication (QM #1, 2) *[Meglinitide medication ordered (226)]* Ordered sulfonylurea medication (QM #1, 2) *[Sulfonylurea medication ordered (227)]* Ordered thiazolidinedione medication (QM #1, 2) *[Thiazolidinedione medication ordered (228)]* Other ordered active medication indicative of diabetes (QM #1, 2) *[Other medication indicative of diabetes ordered (229)]* HbA1c test performed (QM #1) *[HbA1c test performed (11)]* HbA1c test result (QM #1) *[HbA1c test result (10.1, 10.2)]* Foot exam performed (QM #2) *[Foot*

		exam performed (151)]