Improving Healthcare Data Interoperability

Core CDE Recommendations

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Grant support provided by The Pew Charitable Trusts
Webinar Objectives

• Project Progress Report
• Review core common data elements (CDEs)
  – Review metadata concepts for CDEs
  – Review of CDEs and assigned metadata values
• Explain feedback process
• Q & A
Improving Healthcare Data Interoperability

Project Overview

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“Interoperability” Problem Statement

• Interoperability of what?
• What will it take to make interoperability a reality?
• What can the registry community do to accelerate interoperability?
Project Goals

- Evaluate current state of registries
  - Identify common concepts shared across registries
  - Assess use of data standards for those concepts
- Identify predicate work in CDE interoperability
  - National common data models
  - Environmental scan
- Create an implementation guide
  - All-in-one package of recommendations for database developers

Improving Healthcare Data Interoperability
# Participating Registries

<table>
<thead>
<tr>
<th>American Academy of Ophthalmology</th>
<th>Creaky Joints Patient Powered Research Network</th>
</tr>
</thead>
<tbody>
<tr>
<td>American College of Cardiology NCDR</td>
<td>Cystic Fibrosis Foundation</td>
</tr>
<tr>
<td>American College of Gastroenterology</td>
<td>Michigan Surgical Quality Collaborative</td>
</tr>
<tr>
<td>American College of Obstetricians and Gynecologists</td>
<td>National Osteoporosis Foundation</td>
</tr>
<tr>
<td>American College of Radiology</td>
<td>Neuropoint</td>
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<tr>
<td>American Optometric Association</td>
<td>North American Association of Central Cancer Registries</td>
</tr>
<tr>
<td>American Orthopedic Association</td>
<td>Outpatient Endovascular and Interventional Society</td>
</tr>
<tr>
<td>American Physical Therapy Association</td>
<td>Plastic Surgery Registries Network (GRAFTS, TOPS)</td>
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<tr>
<td>American Podiatric Medical Association</td>
<td>Renal Physicians Association</td>
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<tr>
<td>American Society for Clinical Pathology</td>
<td>Society for Vascular Surgery</td>
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<tr>
<td>American Society for Radiation Oncology</td>
<td>Society of Interventional Radiology</td>
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<tr>
<td>American Society for Anesthesiologists</td>
<td>Society of Thoracic Surgeons</td>
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<tr>
<td>American Society of Echocardiography</td>
<td>University of Massachusetts Medical School: Function &amp; Outcomes Research for Comparative Effectiveness in Total Joint Replacement</td>
</tr>
<tr>
<td>American Society of Nuclear Cardiology</td>
<td>United Network for Organ Sharing</td>
</tr>
<tr>
<td>American Urogynecologic Society</td>
<td>VANGUARD</td>
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<tr>
<td>American Urological Association</td>
<td>Vermont Oxford Network</td>
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<tr>
<td>Americas Hernia Society</td>
<td>Women's Health Initiative</td>
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<tr>
<td>Arthritis Research Center Foundation</td>
<td></td>
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</tbody>
</table>

*Improving Healthcare Data Interoperability*
Progress Report (by Aims)

• **Aim 1:** Case Report Form review
  – Completed (38 registries)
  – Concordance analyses completed \( \rightarrow \) CDEs

• **Aim 2:** National Data Standards, Data Models review
  – Completed (6 CDMs)
  – Concordance analyses completed \( \rightarrow \) CDEs

• **Aim 3:** Best Practice recommendations
  – Purpose of today’s discussion
  – Implementation Guide \( \sim \) December 1

*Inputs to a roadmap* that catalyzes the *governance structural, operational, and technical transformations* needed to implement a common clinical data element set *across EHI and registry systems, and national data models.*

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Core Concepts of Interest

- Patient ID
- Sex (birth sex)
- Date of birth
- Race
- Ethnicity
- Diagnosis
- Smoking status – also:
  - EtOH
  - Illicit substances
- Risk Factors/Medical History
- Laboratory results
- Vital signs
- Medications
- Care team members –
  - attending physician
  - physician operator (procedure)
- Procedures
- Unique Device Identifiers
- Mortality/Death

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Key CDE Metadata (set of data that describes and gives information about other data)

1. Clinical concept label (human prompt – CRF, data entry screen)
2. Clinical definition
3. Clinical allowed values (human prompt – CRF, data entry screen)
4. Database field label
5. Database field data type / format (e.g., char, date, float, integer, list)
6. Database field business rules (edit checks, range checks, etc.)
7. Database allowed values (as stored in db)
8. Allowed values clinical definitions
9. Reference ontology concept binding
10. Reference ontology allowed values bindings
11. FHIR references (profiles, resources)
12. Other sources, references, notes
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Candidate Core CDEs

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Duke Health
### Draft USCDI Version 1 Data Classes

<table>
<thead>
<tr>
<th>1. Patient name</th>
<th>2. Sex (birth sex)</th>
</tr>
</thead>
<tbody>
<tr>
<td>3. Date of Birth</td>
<td>4. Preferred Language</td>
</tr>
<tr>
<td>5. Race</td>
<td>6. Ethnicity</td>
</tr>
<tr>
<td>7. Smoking Status</td>
<td>8. Laboratory tests</td>
</tr>
<tr>
<td>9. Laboratory values/results</td>
<td>10. Vital signs</td>
</tr>
<tr>
<td>11. Problems</td>
<td>12. Medications</td>
</tr>
<tr>
<td>15. Care Team members</td>
<td>16. Assessment and plan of treatment</td>
</tr>
<tr>
<td>17. Immunizations</td>
<td>18. Procedures</td>
</tr>
<tr>
<td>19. Unique device identifier(s) for a patient’s implantable device(s)</td>
<td>20. Goals</td>
</tr>
</tbody>
</table>
USCDI – Relevant to Registries?

- Patient name
- Date of birth
- Race
- Smoking status
- Lab values / results
- Problems
- Medication allergies
- Care team members
- Immunizations
- UDI
- Provenance
- Sex
- Preferred language
- Ethnicity
- Laboratory tests
- Vital signs
- Medications
- Health concerns
- Assessment / plan of rx
- Procedures
- Goals
- Clinical notes
Query: Candidate Common CDEs

8 As Is (more or less)
- Patient name
- Date of birth
- Sex
- Race
- Ethnicity
- Smoking status
- Procedures
- UDI

7 Adjusted (select modifications)
- Vital signs: height, weight, BP, pulse
- Lab results (via model)
- Medications (via model)
- Care team: only doctor
- *EtOH use
- *Substance abuse
- *Vital status (death)
  *not in USCDI
1. Clinical concept label: Given Name [First Name]
2. Clinical definition: The given or first name of the patient.
3. Clinical allowed values:
4. Database field label: GIVEN_NAME, Patient.name.given
5. Database field data type / format: Char(140)
6. Database field business rules: Allow any number of given names per patient.
7. Database allowed values:
8. Allowed values definitions:
9. Reference ontology concept: LOINC 45392-8 (First Name)
10. Reference ontology allowed values:
12. Sources / references / notes:
Recommendation: Family Name

1. Clinical concept label: Family Name [Last Name]
2. Clinical definition: The family or last name of the patient.
3. Clinical allowed values:
4. Database field label: FAMILY_NAME, Patient.name.family
5. Database field data type / format: Char(70)
6. Database field business rules: Allow only one family name per patient.
7. Database allowed values:
8. Allowed values definitions:
9. Reference ontology concept: LOINC 45394-4 (Last Name)
10. Reference ontology allowed values:
12. Sources / references / notes:
Recommendation: Suffix

1. Clinical concept label: Suffix
2. Clinical definition: The suffix of a patient name, if any, differentiating between parents and children with the same first name.
3. Clinical allowed values:
4. Database field label: SUFFIX_NAME, Patient.name.suffix
5. Database field data type / format: Char(10)
6. Database field business rules:
7. Database allowed values:
8. Allowed values definitions:
9. Reference ontology concept: LOINC 45395-1 (Name Suffix)
10. Reference ontology allowed values:
12. Sources / references / notes:
1. Clinical concept label: Sex [Birth Sex, Sex (Birth Sex)]
2. Clinical definition: The biological sex of a patient, assigned at birth, not to be confused with the social construct of gender.
3. Clinical allowed values: F, M, UNK [Female, Male, Unknown]
4. Database field label: SEX, birthsex
5. Database field data type / format: Value Set – Char(3)
6. Database field business rules:
7. Database allowed values: F | M | UNK
8. Allowed values definitions: Female, Male, Unknown - a proper value is applicable, but not known. Includes ambiguous, variations of unknown, and variations of null.
9. Reference ontology concept: LOINC: LL3324-2, Sex assigned at birth
10. Reference ontology allowed values: LOINC: LA3-6, LOINC: LA2-8, LOINC: LA4489-6
12. Sources / references / notes: USCDI
Recommendation: Race

1. Clinical concept label: Race
2. Clinical definition: Grouping of people based on shared physical or social qualities into categories generally viewed as distinct by society.
3. Clinical allowed values: American Indian or Alaska Native, Asian, Black or African American, Native Hawaiian or other Pacific Islander, White, Other race [Other], Unknown, Asked but no answer
4. Database field label: RACE, race
5. Database field data type / format: Value Set - Char(50)
6. Database field business rules:
7. Database allowed values: American Indian or Alaska Native | Asian | Black or African American | Native Hawaiian or Other Pacific Islander | White | Other | UNK | ASKU
8. Allowed values definitions: American Indian or Alaska Native | Asian | Black or African American | Native Hawaiian or Other Pacific Islander | White | Other Race | Unknown - a proper value is applicable, but not known. Includes variations of unknown, and variations of null. | Asked but no answer - Information was sought but not found (e.g., patient was asked but did not know)
9. Reference ontology concept: CDC PHIN VADS: 1000-9 Race
Recommendation: Ethnicity

1. Clinical concept label: Ethnicity, [Hispanic or Latino Ethnicity]
2. Clinical definition: Grouping of people who identify with each other based on similarities in ancestry, language, history, society, culture, or nation.
3. Clinical allowed values: Hispanic or Latino | Not Hispanic or Latino
4. Database field label: ETHNICITY, ethnicity
5. Database field data type / format: Value Set - Char(50)
6. Database field business rules:
7. Database allowed values:
8. Allowed values definitions:
9. Reference ontology concept: CDCREC: 2133-7 Ethnicity
10. Reference ontology allowed values:
Recommendation: Date of Birth

1. Clinical concept label: Date of Birth [Birth Date] [DOB]
2. Clinical definition: The date of birth of the patient.
3. Clinical allowed values:
4. Database field label: BIRTH_DATE, Patient.birthDate
5. Database field data type / format: Date
6. Database field business rules:
7. Database allowed values:
8. Allowed values definitions:
9. Reference ontology concept: LOINC: 21112-8
10. Reference ontology allowed value bindings: LOINC: 21112-8
12. Sources / references / notes: 2015 CCDS and USCDI, Office of the National Coordinator for Health IT.
1. Clinical concept label: Smoking Status [Tobacco Use]
2. Clinical definition: The current smoking status of an individual.
3. Clinical allowed values: Current heavy tobacco smoker, current light tobacco smoker, current some day smoker, former smoker, never smoker, smoker current status unknown, current every day smoker, unknown if ever smoked
4. Database field label: SMOKING_STATUS
5. Database field data type / format: Value Set – Char(50)
6. Database field business rules:
7. Database allowed values: [same as clinical allowed values]
8. Allowed values definitions: [CDC definitions]
9. Reference ontology concept: LOINC 72166-2
10. Reference ontology allowed values: CDC PHIN VADS 428071000124103, ...
11. FHIR references: https://www.hl7.org/fhir/us/core/StructureDefinition-us-core-smokingstatus.html;
13. Sources / references / notes: USCDI
Recommendation: Device Identifier

1. Clinical concept label: UDI Device Identifier [UDI DI]
2. Clinical definition: The device identifier (DI) is a mandatory, fixed portion of a Unique Device Identifier (UDI) that identifies the labeler and the specific version or model of a device.
3. Clinical allowed values:
4. Database field label: UDI_DI, Device.udi.deviceIdentifier
5. Database field data type / format: Char(140)
6. Database field business rules:
7. Database allowed values:
8. Allowed values definitions:
9. Reference ontology concept:
10. Reference ontology allowed values:
11. FHIR references: https://www.hl7.org/fhir/us/core/StructureDefinition-us-core-device-definitions.html
12. Value set:
13. Sources / references / notes:
Recommendation: Height

1. Clinical concept label: Height
2. Clinical definition: Distance from the bottom of the feet to the top of the head.
3. Clinical allowed values:
4. Database field label: HEIGHT, BodyHeight
5. Database field data type / format: Float
6. Database field business rules:
7. Database allowed values:
8. Allowed values definitions:
9. Reference ontology concept: LOINC 8302-2
10. Reference ontology allowed value bindings:
12. Sources / references / notes: USCDI; also CDE for unit of measure
Recommendation: Height Unit

1. Clinical concept label: **Height Unit of Measure**
2. Clinical definition: **Unit of measure of height.**
3. Clinical allowed values:
4. Database field label: **BODYHEIGHT_UOM, Observation.valueQuantity**
5. Database field data type / format: **Char(5)**
6. Database field business rules:
7. Database allowed values: **cm | in | [in_i]**
8. Allowed values definitions: **Centimeter | Inches**
9. Reference ontology concept: **LOINC 8302-2**
10. Reference ontology allowed values:
Recommendation: Weight

1. Clinical concept label: Weight
2. Clinical definition: The mass of an individual.
3. Clinical allowed values:
4. Database field label: BODYWEIGHT, BodyWeight
5. Database field data type / format: Float
6. Database field business rules:
7. Database allowed values:
8. Allowed values definitions:
9. Reference ontology concept: LOINC: 29463-7
10. Reference ontology allowed values:
12. Sources / references / notes:
1. Clinical concept label: **Weight Unit of Measure**
2. Clinical definition: **Unit of measure of weight.**
3. Clinical allowed values:
4. Database field label: **BODYWEIGHT_UOM, Observation.valueQuantity**
5. Database field data type / format: **Char(5)**
6. Database field business rules:
7. Database allowed values: **kg | g | lb | [lb_av]**
8. Allowed values definitions: **kilogram, gram, pound**
9. Reference ontology concept:
10. Reference ontology allowed values
Recommendation: Heart Rate

1. Clinical concept label: Heart Rate [Pulse]
2. Clinical definition: The number of heartbeats per minute.
3. Clinical allowed values:
4. Database field label: HEARTRATE, HeartRate
5. Database field data type / format: Integer
6. Database field business rules:
7. Database allowed values:
8. Allowed values definitions:
9. Reference ontology concept: LOINC: 8867-4
10. Reference ontology allowed value:
12. Sources / references / notes:
Recommendation: Diastolic Blood Pressure

1. Clinical concept label: Diastolic Blood Pressure [Diastolic BP]
2. Clinical definition: The minimum pressure of circulating blood on the walls of arteries in between heartbeats, measured in mm Hg.
3. Clinical allowed values:
4. Database field label: BP_DIASTOLIC
5. Database field data type / format: Integer
6. Database field business rules:
7. Database allowed values:
8. Allowed values definitions:
9. Reference ontology concept: LOINC: 8462-4
10. Reference ontology allowed values:
12. Sources / references / notes:
Recommendation: Systolic Blood Pressure

1. Clinical concept label: Systolic Blood Pressure [Systolic BP]
2. Clinical definition: The maximum pressure of circulating blood on the walls of arteries during a heartbeat, measured in mm Hg.
3. Clinical allowed values:
4. Database field label: BP_SYSTOLIC
5. Database field data type / format: Integer
6. Database field business rules:
7. Database allowed values:
8. Allowed values definitions:
9. Reference ontology concept: LOINC: 8480-6
10. Reference ontology allowed values:
12. Sources / references / notes:
1. Clinical concept label: **Date of Death** [Death Date]
2. Clinical definition: **The death date of a patient.**
3. Clinical allowed values:
4. Database field label: **DEATH_DATE**, **Patient.deceased**[x]
5. Database field data type / format: **Date**
6. Database field business rules:
7. Database allowed values:
8. Allowed values definitions:
9. Reference ontology concept:
10. Reference ontology allowed values:
11. FHIR references: [https://www.hl7.org/fhir/patient-definitions.html#Patient.deceased_x](https://www.hl7.org/fhir/patient-definitions.html#Patient.deceased_x)
12. Sources / references / notes: PCORnet, OHDSI
Recommendation: Proceduralist NPI

1. Clinical concept label: Proceduralist National Provider Identifier [Proceduralist NPI]
2. Clinical definition: The National Provider Identifier of the proceduralist who is the primary operator of a procedure.
3. Clinical allowed values:
4. Database field label: PROCEDURALIST_NPI
5. Database field data type / format: Char(10)
6. Database field business rules:
7. Database allowed values:
8. Allowed values definitions:
9. Reference ontology concept:
10. Reference ontology allowed values:
11. FHIR references: https://www.hl7.org/fhir/us/core/StructureDefinition-us-core-careteam.html
12. Sources / references / notes: https://npiregistry.cms.hhs.gov/
1. Clinical concept label: Clinician National Provider Identifier [Clinician NPI]
2. Clinical definition: The National Provider Identifier of the clinician to whom management of a patient is attributed.
3. Clinical allowed values:
4. Database field label: CLINICIAN_NPI
5. Database field data type / format: Char(10)
6. Database field business rules:
7. Database allowed values:
8. Allowed values definitions:
9. Reference ontology concept:
10. Reference ontology allowed values:
12. Sources / references / notes: [https://npiregistry.cms.hhs.gov/](https://npiregistry.cms.hhs.gov/)
1. Clinical concept label: Procedure Code
2. Clinical definition: The billing code for a specific procedure that is performed.
3. Clinical allowed values:
4. Database field label: PROCEDURE_CODE, Procedure.code
5. Database field data type / format: Char(11)
6. Database field business rules:
7. Database allowed values:
8. Allowed values definitions:
9. Reference ontology concept:
10. Reference ontology allowed values:
Recommendation: Procedure Date

1. Clinical concept label: Procedure Date
2. Clinical definition: The date the procedure was performed.
3. Clinical allowed values:
4. Database field label: PROCEDURE_DATE, Procedure.performed[x]
5. Database field data type / format: Date
6. Database field business rules:
7. Database allowed values:
8. Allowed values definitions:
9. Reference ontology concept:
10. Reference ontology allowed values:
11. FHIR references: https://www.hl7.org/fhir/us/core/StructureDefinition-us-core-procedure.html
12. Sources / references / notes:
Recommendation: Illicit Drug Use

1. Clinical concept label: Illicit Drug Use
2. Clinical definition: Illicit drugs are pharmacologically active agents that are illegal to make, sell or use, and / or are used for non-medical reasons.
3. Clinical allowed values: Recent | Remote | None | Unknown
4. Database field label: ILLICIT_DRUG_USE
5. Database field data type / format: Char(7)
6. Database field business rules:
7. Database allowed values: Recent | Remote | None | Unknown
8. Allowed values definitions: Recent: Illicit drug use within one year of the survey including the day of the survey | Remote: Illicit drug use more than one year prior to the survey | None: No illicit drug use | Unknown: Illicit drug use status is not known
9. Reference ontology concept:
10. Reference ontology allowed value bindings:
11. FHIR Profile:
12. FHIR Resource:
13. Sources / references / notes: Louise Richards and Ira Cisin, OPERATIONAL DEFINITIONS IN SOCIO-BEHAVIORAL DRUG USE RESEARCH 1975, MEASURES OF CURRENCY OR RECENCY OF DRUG ABUSE (pg 25-26); www.drugabuse.gov
1. Clinical concept label: Alcohol Use
2. Clinical definition: Alcohol use is the consumption of any beverages containing ethyl alcohol (EtOH).
3. Clinical allowed values: <=1 drink/week | 2-7 drinks/week | >=8 drinks/week | None | Unknown
4. Database field label: ALCOHOL_USE
5. Database field data type / format: Char(15)
6. Database field business rules:
7. Database allowed values: <=1 drink/week | 2-7 drinks/week | >=8 drinks/week | None | Unknown
8. Allowed values definitions:
9. Reference ontology concept:
10. Reference ontology allowed values:
11. FHIR references:
12. Sources / references / notes:
Four Types of Medication Questions

• Provide a list of medications (n=12)
  – *List all medications patient is currently taking.*

• Specific, domain-pertinent medications (n=12)
  – *Does the patient have a TOBI Podhaler?*

• Medications in a class of drugs (n=18)
  – *Is the patient on Anticoagulation drugs?*

• Medications administered related to a procedure (n=8)
  – *Indicate if patient was prescribed for Ciprofloxacin (Cipro) antibiotic after biopsy.*
1. Medication Name
2. Medication Dose
3. Medication Dose Units
4. Medication Code Source
5. Medication Code
6. Medication Class
Recommendation: Medication Name

1. Clinical concept label: Medication Name
2. Clinical definition: Identifies the medication being administered. This is a link to a resource that represents the medication which may be the details of the medication.
3. Clinical allowed values:
4. Database field label: MEDICATION_NAME, Medication.code.text
5. Database field data type / format: STR(128)
6. Database field business rules:
7. Database allowed values:
8. Allowed values definitions:
9. Reference ontology concept:
10. Reference ontology allowed value bindings:
11. FHIR references: https://www.hl7.org/FHIR/2015May/medicationprescription-definitions.html#MedicationPrescription.medication
Recommendation: Medication Code

1. Clinical concept label: Medication Code
2. Clinical definition: A code that specifies a medication
3. Clinical allowed values:
4. Database field label: MEDICATION_CODE, Medication.code
5. Database field data type / format: Char(12)
6. Database field business rules:
7. Database allowed values:
8. Allowed values definitions:
9. Reference ontology concept:
10. Reference ontology allowed values: per RxNorm
11. FHIR references: https://www.hl7.org/fhir/medication-definitions.html#Medication.code
<table>
<thead>
<tr>
<th>Medication Classes</th>
<th>Medication Class Source</th>
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<tbody>
<tr>
<td>Anticoagulation; Anti-platelet Therapy</td>
<td></td>
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<tr>
<td>Anticoagulation; Anti-platelet Therapy; Immunosuppressants; Oral antibiotic; Chlorhexidine; IV Antibiotic</td>
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<tr>
<td>Anti-platelet: Anti-coagulation; Immunosuppressants</td>
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<tr>
<td>Adjuvant Hormonal Therapy; Antibiotic</td>
<td>SNOMED</td>
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<tr>
<td>Chronic antibiotics-inhaled and/or oral; CFTR Modulators; Bronchodilators; Corticosteroids</td>
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<tr>
<td>Statins</td>
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<tr>
<td>Steroids; Probiotics</td>
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<tr>
<td>Anti-platelet; Anticoagulants; Thrombin Inhibitors; LMWH; Steroids; Immunosuppressants; Thrombolytic Agents; Vasopressor; Opioids</td>
<td>CPT</td>
</tr>
<tr>
<td>Beta Blockers; ACE Inhibitor; Angiotensin Receptor Blocker; Aldosterone Blocing Agent; Statin; Non-Statin Lipid-Lowering Agent; Anticoagulant; GP Inhibitor</td>
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<tr>
<td>Antiarrhythmic Agent; Beta Blocker; Calcium Channel Blocker; Long Acting Nitrates; Non-Statin; Statin</td>
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<tr>
<td>Rapid; Basil; Pre-Mixed Insulin; Sulfonylureas; Glindes; Thiazolidine Diones; DPP-4 Inhibitor; Alpha-Glusbidae; Bile Acid Sequestrants; Dopamine Agonists; Amylinometrics; GLP-1 Agonists; SGLT-2 Inhibitors; Combinations</td>
<td>GPI; MMSL; NDC; RxNorm; SNOMED-CT; Other</td>
</tr>
<tr>
<td>ACE-Inhibitor; Antiarrhythmic Agents; ARB; Beta Blocker; Aldosterone Antagonist; Lipid Lowering Statin; Antiplatelet Agents</td>
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<tr>
<td>SEER*RX</td>
<td>NCI</td>
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<tr>
<td>Anticoagulation; Anti-Platlet Therapy, Pain</td>
<td></td>
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<tr>
<td>Beta-Blockers; Anticoagulation; Anti-Platelet Therapy, Pain</td>
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<tr>
<td>Insulin; Antibiotic</td>
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<tr>
<td>Immunosuppressive Medications; Steroids</td>
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<tr>
<td>Overactive Bladder</td>
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Feedback Process

Grant support provided by The Pew Charitable Trusts
Next Steps

• Stakeholder Feedback
  – Email with link/spreadsheet to go out this week
  – Due by 15OCT2018

• Final Project Report (posted to website)
  – Overview, Background, Methods, Results
  – CDE recommendations
  – Environmental Scan

• Manuscript (publication journal & date TBD)
Questions?

Email:
Rebecca.Wilgus@duke.edu
James.Tcheng@duke.edu

Visit the project website:
https://dcri.org/registry-data-standards/