

# Canadian Approach to Primary Care RF2 Reference Sets



## Agenda

- Overview of Canada Health Infoway and the Standards Collaborative
- Provide an overview of the EMR/HSU Terminology Project
- Infoway's approach and "journey"
  - Module ID
  - Reference Sets
- Content problems (if there is time)

# Canada Health Infoway

- Created in 2001
- \$2.1 billion in federal funding
- Independent, not-for-profit corporation
- Accountable to 14 federal/provincial/territorial governments

## **Mission:**

Fostering and accelerating the development and adoption of electronic health information systems with compatible standards and communications technologies on a pan-Canadian basis with tangible benefits to Canadians. *Infoway* will build on existing initiatives and pursue collaborative relationships in pursuit of its mission.

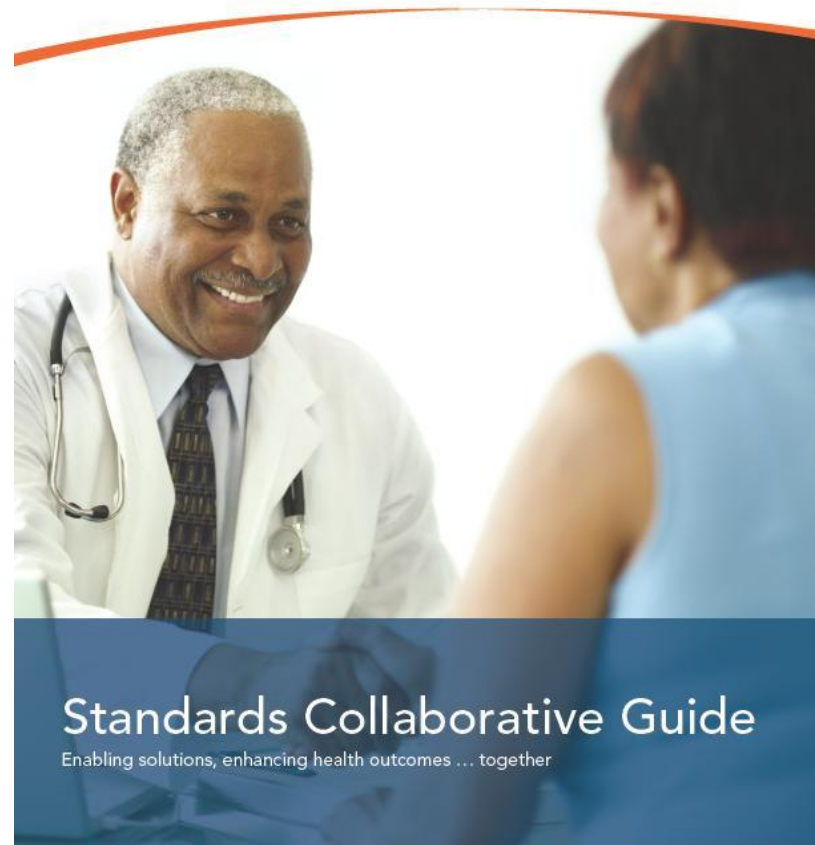
## *Infoway* business strategies

- Collaborate with health ministries and other partners
- Co-invest with public sector partners (75:25 formula)
- Leveraged investment
- Engage clinicians
- Form strategic alliances with the private sector
- Manage risk and ensure quality solutions
- Measure benefits and adjust
- Strategic investor
- Privacy safeguards



## *Infoway* Standards Collaborative (SC) – Our Role

Launched in 2006, the *Infoway* SC is a Canadian wide coordination function developed to support and sustain health information standards and foster collaboration in standards development to accelerate the implementation of pan-Canadian standards based solutions



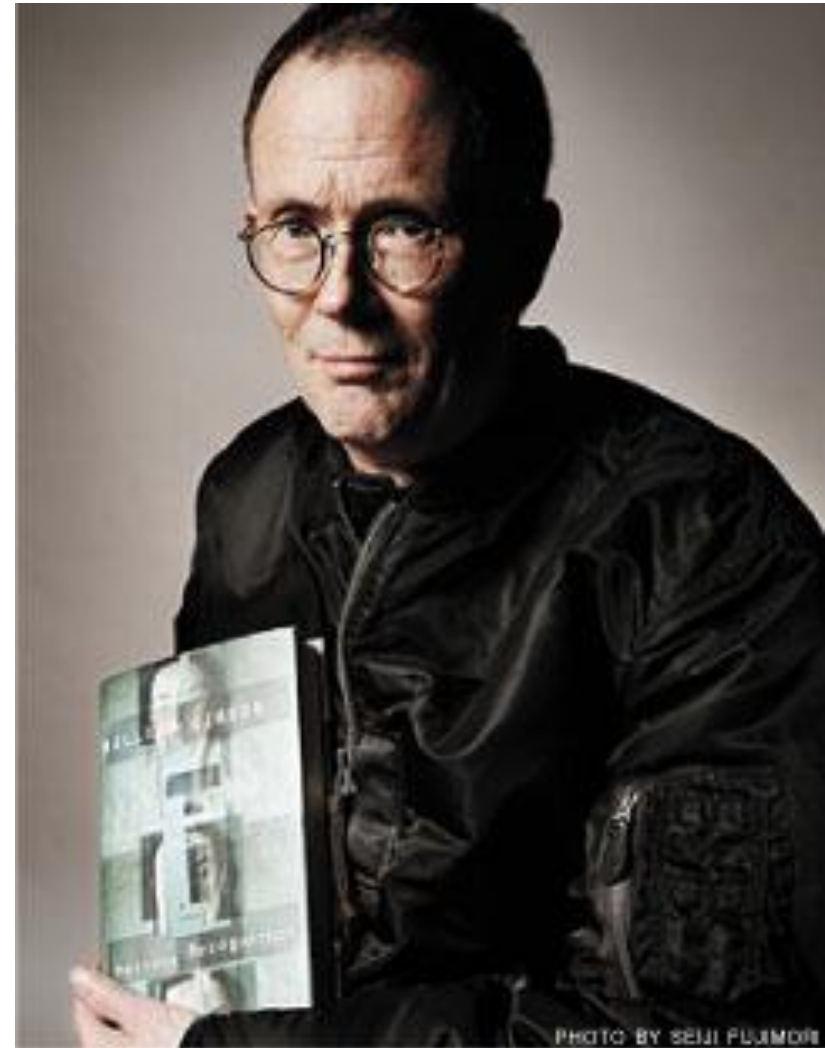
## SC Approach to pan-Canadian Terminology

- Priority health care domains were identified where pan-Canadian standards would be developed.
- Projects struck for each domain and stakeholders from different aspects of the domain were invited to participate in an advisory capacity.
- Scope and initial focus of terminology development to support pan-Canadian HL7 V3 messages
- Adopt/adapt/develop approach to Reference Terminology & value set selection
  - **Did not have license for SNOMED CT during development of value sets.**
  - AND currently reference SNOMED CT, LOINC, UCUM, ISO, & HL7 V3 code systems but also ICD-10CA



The future is  
already here – it's  
just not evenly  
distributed.

- *William Gibson, quoted in*
- [\*The Economist\*](#),
- *December 4, 2003*



# EMR/HSU Terminology Project



## Key Project Objective

Develop pan-Canadian standardized Reference Sets for approximately 53 data elements from EMR HSU Primary Health Care (PHC) data content standard

The Reference Sets targeted for completion:

- Delivery Group #1 - June 30, 2011
- Delivery Group #2 - Sept. 12, 2011
- Delivery Group #3 - Nov 24, 2011
- Delivery Group #4 - Feb 27, 2012

# Scope

- Data elements (defined in a logical information model) that support both primary and health system uses of EMR data.
  - currently and commonly required to support
    - primary health care (PHC) data at the point of service  
AND
    - health system management including; clinical program management, population surveillance, research, etc
- The content of the reference sets intended to cover a broad scope due to jurisdictional variations in implementation of EHR components and definition of how those components interoperate with EMRs.

# Overview of the list of Reference Sets being Developed

# Client Demographics

#	Name	Definition
A13	Client Administrative Ethnicity Code	Represents the Client's self-reported ethnic group to which he or she belongs, for administrative purposes. Therefore, the ethnic origin refers to a person's "roots" and should not be confused with his or her citizenship or nationality.
A2	Client Identifier Type Code	Represents the type of Client Identifier (e.g. Jurisdictional Healthcare Identifier, Passport).
A3	Client Identifier Assigning Authority Code	Represents the legal entity responsible for assigning the Client identifier.
A5	Client Administrative Gender Code	Represents a reported gender category of the Client at a given point in time used for administrative purposes.
A6	Client Highest Education Code	Represents the highest level of education completed by the Client.
A7	Client Housing Status Code	Represents the housing status of the Client.
A8	Client Primary Language Code	Represents the preferred spoken language of the Client.
A9	Client Status Code	Represents whether or not the PHC Provider considers the client to be actively seeking PHC services through them.

# Provider Demographics & Service Location

#	Name	Definition
B5	Provider Identifier Type Code	Represents the type of Provider identifier.
B6	Provider Identifier Assigning Authority Code	Represents the legal entity responsible for assigning the unique identifier to the Provider.
B7	Provider Role Type Code	Represents the role of the Provider in relation to his/her participation in a specific health care event.
B8	Provider Expertise Code	Represents the expertise or qualifications of the Provider.
C3	Service Delivery Location Type Code	Represents the type of PHC (Service Delivery Location) location where the Client received care.

# Encounter Related

#	Name	Definition
D2	Client Encounter Reason Code	Represents reason for the encounter as conveyed by the Client.
D4	Encounter Mode Code	A description of the type of contact between the Provider and the Client for a registered Encounter or visit.
D5	Encounter Payor Source Code	Represents the source of payment for the encounter.
D6	Encounter Remuneration Mode Code	Represents the type of reimbursement paid to the Provider for the Encounter.

# Observations

E1	Observation Family History Health Concern Code	Represents the relevant health concerns of a person sharing common ancestry with the Client.
E10	Observation Family History Familial Ethnicity Code	Represents the ethnicity of the family member.
E11	Observation Health Concern Code	Represents the Client's relevant clinical problems, conditions, diagnoses, symptoms, findings and complaints.
E14	Observation Social Behaviour Code	Represents a type of Client social behaviour that increases the possibility of disease or injury for the Client. This can include risk factors such as tobacco use, alcohol use, abuse of illicit or prescription drugs, and occupation.
E17	Observation Allergy/Intolerance Type Code	Represents the type of allergy or intolerance a Client has.
E18	Observation Allergy/Intolerance Agent Code	Represents the specific allergen or other agent/substance to which the Client has an allergic reaction or intolerance.
E19	Observation Allergy/Intolerance Severity Code	Represents the level of severity a Client has in relation to an allergy or intolerance.
E2	Observation Family History Social Behaviour Code	Represents the relevant social behaviours of a person sharing common ancestry with the Client. This can include risk factors, such as tobacco use, alcohol use, abuse of illicit or prescription drugs, and occupation.
E20	Observation Allergy/Intolerance Status Code	Represents whether an allergy/intolerance is "active" or "completed" (indicating no longer active).
E25	Observation Blood Pressure Measurement Anatomical Location Code	Represents the anatomical location of where the blood pressure was measured on the Client's body.
E26	Observation Blood Pressure Measurement Body Position Code	Represents the position the Client's body was in when blood pressure was measured (e.g. standing, sitting, lying).
E27	Observation Representative Blood Pressure Reading Code	Represents whether the Client's blood pressure reading is representative of the Client's current health condition.
E29	Observation Height Unit of Measure Code	Represents the Client height unit of measure captured.
E3	Observation Family History Intervention Code	Represents the relevant interventions performed on a person sharing common ancestry with the Client.
E31	Observation Weight Unit of Measure Code	Represents the Client weight unit of measure captured.
E33	Observation Waist Circumference Unit of Measure Code	Represents the Client Waist Circumference unit of measure captured.
E34	Observation Encounter Clinical Assessment Code	Represents the Provider's professional opinion of the most relevant clinical findings related to the Client's encounter. The most relevant clinical finding for the encounter can include diagnoses, symptoms and professional services.
E4	Observation Family History Familial Relationship Code	Represents the relationship between the Client and a person who shares a common ancestry.
E9	Observation Family History Death Cause Code	Represents the clinical cause of death for the family member.

# Procedure Related

F1	Intervention Code	Represents the services/activities performed by the Provider for the Client.
F3	Intervention Refusal Reason Code	Represents the reason the Client refused an intervention.
G1	Laboratory Test Name Ordered Code	Represents the lab test ordered by the Provider for the Client.
H2	Laboratory Test Result Name Code	Represents the name of the lab test performed.
H3	Laboratory Test Result Value Text (Number, Code)	Represents the result of the lab test.
H4	Laboratory Test Result Value Unit of Measure Code	Represents the unit of measure of the lab result for the lab test performed.
H6	Laboratory Test Result Reference Range Low Unit of Measure Code	Represents the unit of measure associated with the Lab Test Result Reference Range Low Number.
H8	Laboratory Test Result Reference Range High Unit of Measure Code	Represents the unit of measure associated with the Lab Test Result Reference Range High Number.
I1	Diagnostic Imaging Test Ordered Code	Represents the type of diagnostic imaging test ordered by the Provider for the Client.
K1	Referral Service Code	Represents the type of service required for the Client



# Medication Mgt

M1	Medication Prescribed Name Code	Represents the medications prescribed (or intended to be prescribed) to the Client.
M10	Medication Prescribed Frequency Text	Represents the number of occurrences within a given time period that a dose of a drug is to be administered.
M11	Medication Prescribed Route Code	Represents the part of the body on which, through which or into which a drug product is to be introduced. A drug product can have more than one route of administration.
M13	Medication Prescribed Not Given Reason Code	Represents the reason why a preferred medication was not prescribed to a Client.
M14	Medication Prescribed Adherence Code	Represents whether or not the Client has been administering the prescribed medication(s) as instructed.
M6	Medication Prescribed Strength Unit of Measure Code	Represents the units of measure for Prescribed Medication Strength.
M8	Medication Prescribed Dose Unit of Measure Code	Represents the unit of measure of a drug dose taken at any one time.
M9	Medication Prescribed Form Code	The physical configuration, presentation of state of matter of any given drug product. The dosage form in which the medication is administered (e.g. tablet, liquid, suppository, solution).
N1	Medication Dispensed Code	Represents the medication that was dispensed to the Client.
O1	Vaccine Administered Name Code	Represents the name of the vaccine that was administered to the Client.
O4	Vaccine Not Given Reason Code	Represents the reason a vaccine was not administered to a Client.

# The Process

- Performed an environmental scan
- Prioritized the data elements that needed Reference Sets
  - Assigned Reference Sets into manageable groupings
- Reference Set Approach - Adopt, adapt or develop
  - Leverage pan-Canadian Value Set
  - Leverage content identified in the environmental scan
  - Develop new content
    - If so, should the existing content drive the content or should the team select the content.
- Develop Reference Set
  - Identify issues, questions and preliminary content
  - Engage clinicians, SCWG and CIHI as required
- Clinician Review and Validation
- Address & Confirm feedback
- Publish Reference Set

# Tooling

- Developer tooling
  - Infoway project resources
    - Use the Workbench to construct reference sets drawn from SNOMED CT
    - Use DTS to construct reference sets drawn from other code systems
    - Load all reference sets into DTS to facilitate maintenance & publishing
  - Jurisdictional project resources
    - Have a requirement to constrain reference sets for their particular use. (Hope to use WB and/or DTS)
- Implementer tooling
  - Terminology mapping tool (TermWorks)
  - Have a requirement to maintain the maps

# Observations on the Process So Far

- PHC Content Data Standard Data Element definitions are being challenged
- Early Clinician Engagement is proving beneficial
- Clinician review and validation taking longer than anticipated
- Current tools produce Reference Sets in flat lists that are good for computer consumption but difficult for human review
- The process is uncovering issues that are out of scope of the Ref Set development; such as
  - the need for additional data elements,
  - Better vendor products (including better UI for large refSets)
- It is REALLY hard to create intensional reference sets in some cases due to SCT content that is not appropriate for Canadian usage.
- Some challenges when creating reference set clauses in WB for hierarchies where there are leaf concepts with multiple parents
  - For developers and for reviewers

# Module ID

# Module ID Analysis

## Our Objective

- Identify how many moduleIds will need to be assigned to the Canadian release.
- Explain how modules will be used in Canada and provide information on how the moduleIds work together.
- Identify the maintenance activities around moduleIds and the dependencies.
- Identify any considerations that may arise in the future around moduleId assignment.

## Module ID Assumptions

- Keep the two namespaces (En and Fr namespaces) currently used to create Canadian SNOMED CT instead of combining them into one extension and one namespace for the following reasons:
  - To allow de-coupled release cycles of each namespace
  - To facilitate implementation of SNOMED CT allowing implementation of only the components of the Canadian Release that are important to their system. If there is no need for the French translations in their system then implementers could exclude them since they would be in separate namespaces.
  - To avoid retirement of one namespace over the other requiring possibly creating challenges for implementers
- Currently extensions in RF1 but planning for RF2 as soon as tooling permits

## The English Canadian extension will consist of:

- Concept table
  - New concepts required to meet Canadian needs
  - **Concepts required in Refsets creation**
- Description table
  - Descriptions for new concepts (minimum of FSN and PT or preferred synonym)
  - en-CA descriptions to add to existing concepts:
    - new synonyms
    - new preferred terms to replace default preferred terms in the International Release
- Relationship table
  - Will contain almost exclusively relationships for new concepts created in the Canadian extensions
- Language Refset (en-CA)
  - Descriptions of new extension concepts
  - New synonyms for International Release concepts or changes to International release acceptability
  - Refsets will be part of the release



# French Canadian extension

- Will include:
  - Description table
    - fr-CA descriptions
      - PT or preferred synonym
  - Language Refset (fr-CA)
- New content will always be created in the en-CA extension first, even if the request was to create new French content.
- It is assumed the English extension would be released first and the French extension would be out of cycle to allow the translation to happen.

# Module ID Background

- A *moduleId* field, assigned to each component, helps identify the origin of content and dependencies in a release.
  - **Component:** Refers to any item identified by an SCTID in SNOMED CT core, or in an extension.
    - The partition identifier indicates the type of component referred to by that SCTID. E.g. ConceptId: 329064391000087**104**
- Each component within a *SNOMED CT release* references a *moduleId*. This is the module in which the component is currently maintained. A module is simply a collection of *SNOMED CT components* that are maintained as a unit by a single organization. **Each SNOMED CT component is in one, and only one module.**
- This enables release centers to compose a unified release from a number of different modules, yet still identify the origin of content within the release.
  - For example in Canada, module ids will be used to differentiate *SNOMED CT International* content, FR-CA extension content, EN-CA extension content, and **Canadian SCT reference sets**

## ModuleId Background (cont)

- Each module is in one and only one extension. Modules do not straddle extensions.
- The extension that a module resides in is defined by the SctId of the module.
- A module may not move from one extension to another over time. If the components within a module are to be moved to another extension, then a new module must be created within the destination extension to host the components that are to be transferred.
- There may be more than one module in an extension.

## Infoway Approach

- ModuleIds will be assigned at release time & not maintained in the IHTSDO WB other than the actual concept that is eventually used to populate the moduleId field in the release tables.
- Infoway does not need to have the issue of how many moduleIds will be used resolved until exporting a release from the WB is required.
- A Module Dependency RefSet will be used to define dependencies between modules.
  - This allows stating what other modules a module is dependent upon and what version of those other modules to use.

# Example for Canada for SNOMED CT Content

id	effectiveTime	active	moduleId	refSetId	referencedComponentId	sourceEffectiveTime	targetEffectiveTime
<b>UID</b>	20110131	1	[Canadian National extension module ConceptId]	[Canadian Module Depend. RefSet ConceptId]	[International Release ConceptId]	20110131	20110131
<b>UID</b>	20110131	1	[Canadian French Translation module ConceptId]	[Canadian Module Depend. RefSet ConceptId]	[International Release ConceptId]	20110131	20110131
<b>UID</b>	20110131	1	[Canadian French Translation module ConceptId]	[Canadian Module Depend. RefSet ConceptId]	[Canadian National extension module ConceptId]	20110131	20110131
<b>UID</b>	20110131	1	[Canadian RefSet Module ConceptId]	[Canadian Module Depend. RefSet ConceptId]	[International Release ConceptId]	20110131	20110131
<b>UID</b>	20110131	1	[Canadian RefSet Module ConceptId]	[Canadian Module Depend. RefSet ConceptId]	[Canadian National extension module ConceptId]	20110131	20110131
<b>UID</b>	20110131	1	[Canadian RefSet Module ConceptId]	[Canadian Module Depend. RefSet ConceptId]	[Canadian French Translation module ConceptId]	20110131	20110131

## ModuleID Maintenance

- ModuleIds can be changed over time,
  - if a Refset is created under a specific moduleId today the moduleId could be changed in the future if a need to issue it under a separate module arises.
    - **What are examples of situations when this would happen**
      - **When the definition of the ref set changes?**

## Future Considerations

- How moduleIds are used with Refsets will evolve based on several factors eg:
  - Refsets that include code systems other than SCT
    - Would we use this approach for the others. If so, increase in the number of moduleIds that are needed due to the fact that you may want different release cycles for each of these code systems or update Refsets on a different schedule.
- May be a need to have extensions released at different times which may lead to having Refsets released at different times. If this situation occurs, some Refsets may get updated more frequently than others resulting in the need for different moduleIds.
- There may be a need to develop a module for Refsets that are static and another module for Refsets that get updated more frequently.

## Discuss Who Needs to care about Module ID

- Reference Set and extension developers - yes
- Do Implementers who are mapping need to care?
  - I don't think so
- Do Implementers who implement the extensions and SCT core natively care????



# Infoway Approach to Reference Sets

## Confusion with Value Set and RefSet

- Some people think they are the same others and others think they are different.
- Suggest this get parked, discussed & socialized BROADLY for another time
  - Involve HL7 in the discussions

## Canadian General requirements for new PHC Reference Sets

### Phase 1 Scope & Requirements (limited by available tooling)

- Human readable format needed to facilitate review & mapping and be easy to use
  - (unanticipated requirement surfacing) – need to provide a format that allows reviewers to see some of the nesting and associations
- Human readable member table format should work for all code systems (not just SCT) and contain
  - Concept name, one common/preferred name-EN, a FR preferred name, and other metadata available in computable format (ie; including most of the metadata from the RF2 spec)
- Descriptor refset (human readable) – metadata table
- Module dependency refset
- Explore the machine readable format as a second step when we have the WB working
- Consider this format for existing value sets

## Phase 2 Requirements

- Produce the RF2 computable formats with the WB
  - Would need to enhance the IHTSDO spec (ie add properties). Will use the following;
    - Simple refset pattern modified
    - Query refset
    - Language refset

### BUT FIRST.....

- Need to first determine why and who would use this format
  - Assume it is targeted to those who would implement the reference sets “natively”
    - Not sure we know all the details to provide to our stakeholders at this time.

# Example Human Readable Reference Set Definition (based on Descriptor Refset)

Property	Reference Set Definition
<b>referenceSetId</b>	2.16.840.1.113883.2.20.3.192
<b>referenceSetName</b>	E4_Observation Family History Familial Relationship Code
<b>referenceSetDescription</b>	Represents the relationship between the patient and a person who shares a common ancestry.
<b>effectiveTime</b>	20110630
<b>active</b>	1/0 – suggested yes /no is more intuitive for human review.
<b>codeSystemOID</b>	2.16.840.1.113883.6.96
<b>codeSystemName</b>	SNOMED CT
<b>codeSystemVersion</b>	20110315
<b>expectedUse</b>	extract
<b>queryTable</b>	0
<b>moduleId</b>	TBD
<b>InternalID</b>	TBD
<b>sourceComment</b>	static from hierarchy = 303071001
<b>Owner</b>	Infoway

## Example of Human Readable Reference Set Member Table

CodeInSource	conceptName	enpreferredTerm	frPreferredTerm	codeSystemOID	effectiveTime	active	supersededTime	referenceSetId	moduleId	InternalID	enPreferredNameSource
67822003	Child (person)	Child	Concept not translated	2.16.840.1.113883.6.96	20110630	1		2.16.840.1.113883.2.20.3.192			SCT PT
66089001	Daughter (person)	Daughter	Concept not translated	2.16.840.1.113883.6.96	20110630	1		2.16.840.1.113883.2.20.3.192			SCT PT
65616008	Son (person)	Son	Concept not translated	2.16.840.1.113883.6.96	20110630	1		2.16.840.1.113883.2.20.3.192			SCT PT
66839005	Father (person)	Father	Concept not translated	2.16.840.1.113883.6.96	20110630	1		2.16.840.1.113883.2.20.3.192			SCT PT
72705000	Mother (person)	Mother	Concept not translated	2.16.840.1.113883.6.96	20110630	1		2.16.840.1.113883.2.20.3.192			SCT PT
40683002	Parent (person)	Parent	Concept not translated	2.16.840.1.113883.6.96	20110630	1		2.16.840.1.113883.2.20.3.192			SCT PT
50261002	Great grandfather (person)	Great grandfather	Concept not translated	2.16.840.1.113883.6.96	20110630	1		2.16.840.1.113883.2.20.3.192			SCT PT

# Proposed Query Table Format

Field	Field Type	Field Description
<b>Id</b>	OID	The identifier used to represent the query.
<b>effectiveTime</b>	Date	Specifies the date when a query or a change to a query becomes effective.
<b>refSetId</b>	OID	The identifier used to represent the reference set that the reference set member belongs to.
<b>Active</b>	Boolean	Specifies whether the query is active or inactive at the release date specified in the effectiveTime field.
<b>moduleId</b>	String	Only used for queries related to SNOMED CT concepts
<b>codeSystemOID</b>	OID	OID of the code system from which the query is derived
<b>ruleLevel</b>	Integer	Indicates the location of the filter within the overall "hierarchy" of filters. The higher the number, the deeper the nesting of the rule.
<b>Query</b>	String	The rules used to generate the reference set members for intensional reference sets.
<b>Code</b>	String	The identifier from the code system used to process the query

# Example of a Query Table

ID	effectv eTime	refsetI d	Active	CodeSy stemOI D	Module ID	RuleLe vel	Query	Code
2.16.84 0.1.113 883.5.1 06	201001 31	2.16.84 0.1.113 883.2.2 0.3.116	1	2.16.84 0.1.113 883.6.9 6	Tbd	1	Include code	3061680 03
2.16.84 0.1.113 883.5.1 06	201001 31	2.16.84 0.1.113 883.2.2 0.3.116	1	2.16.84 0.1.113 883.6.9 6	Tbd	1	Include Code	3061670 08
2.16.84 0.1.113 883.5.1 06	201001 31	2.16.84 0.1.113 883.2.2 0.3.116	1	2.16.84 0.1.113 883.6.9 6	Tbd	1	Include code & specializations of	1834440 07
2.16.84 0.1.113 883.5.1 06	201001 31	2.16.84 0.1.113 883.2.2 0.3.116	1	2.16.84 0.1.113 883.6.9 6	Tbd	1	Include specializations of code	3104340 02
2.16.84 0.1.113 883.5.1 06	201001 31	2.16.84 0.1.113 883.2.2 0.3.116	1	2.16.84 0.1.113 883.6.9 6	Tbd	2	Exclude code	1837040 01
2.16.84 0.1.113 883.5.1 06	201001 31	2.16.84 0.1.113 883.2.2 0.3.116	1	2.16.84 0.1.113 883.6.9 6	Tbd	0	Include with status=	current