Canadian Experience
Developing Primary Care Reference Sets
Agenda

• Background
• Scope of the Primary Health Care (PHC) Reference Sets
• Approach
• Overview of the challenges, lessons learned
• Introduction to user interface guidelines
• Infoway planned support for implementers
Background and Scope

• Canadian Institute for Health Information (CIHI) developed
  – 106 data elements for Electronic Medical Record (EMR) and
    Health System Use (HSU) – a PHC Content Standard (CS)
  – Extract specification

• Infoway developed 41 Reference Sets to support the coded data elements
  – Although the main focus is to support PHC CS, they would be leveraged by other point of service applications initiatives.
  – They would be used as a starting point for implementers
    – Timeline –1 year
    – Human readable format

• Infoway had previously developed >200 value sets to support HL7 V3 messages that covered most domains.
## Reference Sets Developed

<table>
<thead>
<tr>
<th>Client</th>
<th>Provider</th>
<th>Encounter</th>
<th>Laboratory</th>
<th>Allergy and Intolerance</th>
<th>Medication and Vaccine</th>
<th>Observation</th>
<th>Intervention</th>
</tr>
</thead>
<tbody>
<tr>
<td>ClientIdentifierTypeCode</td>
<td>ProviderIdentifierTypeCode</td>
<td>ClientReasonForEncounterCode</td>
<td>ObservationOrderableLabType</td>
<td>AllergyIntoleranceTypeCode</td>
<td>MedicationPrescribedDoseUnitOfMeasureCode</td>
<td>HeightUnitOfMeasureCode</td>
<td>ReasonInterventionRefusedCode</td>
</tr>
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<td>ClientIdentifierAssigningAuthorityCode</td>
<td>ProviderIdentifierAssigningAuthorityCode</td>
<td>EncounterTypeCode</td>
<td>ObservationResultableLabType</td>
<td>NonDrugAllergenCode</td>
<td>MedicationPrescribedAdherenceCode</td>
<td>WeightUnitOfMeasureCode</td>
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<td>HighestLevelEducationCode</td>
<td>ProviderRoleCode</td>
<td>EncounterPayorSourceCode</td>
<td>LaboratoryObservationUnitOfMeasureCode</td>
<td>AllergyIntoleranceSeverityCode</td>
<td>VaccineAdministeredNameCode</td>
<td>WaistCircumferenceUnitOfMeasureCode</td>
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<tr>
<td>HousingStatusCode</td>
<td>ProviderExpertiseCode</td>
<td>EncounterPaymentTypeCode</td>
<td>AllergyIntoleranceStatusCode</td>
<td>AllergyIntoleranceStatusCode</td>
<td>ReasonVaccineNotAdministeredCode</td>
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<tr>
<td>LanguageCode</td>
<td>ClientReasonForEncounterCode</td>
<td>HealthConcernCode</td>
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<tr>
<td>ClientStatusCode</td>
<td>EncounterTypeCode</td>
<td>FamilyHistorySocialBehaviourCode</td>
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<tr>
<td>EthnicityCode</td>
<td>EncounterPayorSourceCode</td>
<td>FamilyMemberRelationshipCode</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

**Client**
- ClientIdentifierTypeCode
- ClientIdentifierAssigningAuthorityCode
- HighestLevelEducationCode
- HousingStatusCode
- LanguageCode
- ClientStatusCode
- EthnicityCode

**Provider**
- ProviderIdentifierTypeCode
- ProviderIdentifierAssigningAuthorityCode
- ProviderRoleCode
- ProviderExpertiseCode
- ClientReasonForEncounterCode
- EncounterTypeCode
- EncounterPayorSourceCode
- EncounterPaymentTypeCode
- HealthConcernCode
- FamilyHistorySocialBehaviourCode
- FamilyMemberRelationshipCode
- ClientSocialBehaviourCode
- ReferralServiceCode
- ServiceDeliveryLocationCode

**Encounter**
- ClientReasonForEncounterCode
- EncounterTypeCode
- EncounterPayorSourceCode
- EncounterPaymentTypeCode
- HealthConcernCode
- FamilyHistorySocialBehaviourCode
- FamilyMemberRelationshipCode
- ClientSocialBehaviourCode
- ReferralServiceCode
- ServiceDeliveryLocationCode

**Laboratory**
- ObservationOrderableLabType
- ObservationResultableLabType
- LaboratoryObservationUnitOfMeasureCode

**Allergy and Intolerance**
- AllergyIntoleranceTypeCode
- NonDrugAllergenCode
- AllergyIntoleranceSeverityCode
- AllergyIntoleranceStatusCode

**Medication and Vaccine**
- MedicationPrescribedDoseUnitOfMeasureCode
- MedicationPrescribedAdherenceCode
- VaccineAdministeredNameCode
- ReasonVaccineNotAdministeredCode
- BloodPressureAnatomicalLocationCode
- BloodPressureBodyPositionCode
- RepresentativeBloodPressureReadingCode

**Observation**
- HeightUnitOfMeasureCode
- WeightUnitOfMeasureCode
- WaistCircumferenceUnitOfMeasureCode

**Intervention**
- ReasonInterventionRefusedCode
PHC Reference Set Development Process

**Phase 1**
- Environmental Scan
- Early Input From Clinicians
- Approach Planning

**Phase 2**
- Reference Set Development Approach
- Present Reference Set
- Approach to Stakeholder for review
- SCWG

**Phase 3**
- Present Draft Reference Set
- Stakeholder for review
- CSC
- Clinician review of Draft Reference Set
- Validate against GP/FP similar reference sets & existing VRS data.
- Development of Final Reference Set
- CIHI

**Phase 4**
- Alignment to existing pan-Canadian value sets (when applicable)
- Add new concepts to CA extension
- Post for external distribution

Canada Health Infoway
Reference Set Development Approach

**Approach**
- Adapt: 71%
- Adopt: 19%
- Develop: 10%

**Code Systems**
- UCUM: 76%
- ISO 639-3: 14%
- LOINC: 6%
- HL7: 2%
- SNOMED CT: 2%
Lessons Learned – Reference Set Development

• Scope clarification is paramount
  – Additional time required to figure out breadth and depth
  – Identifying what is out of scope is just as important
  – **Resolved by:**
    • Providing guidance in the Implementation guide
    • Use broad scope
      – Recognized that EMR providers must capture data on interactions that occur outside the PHC setting
    • Creating “child” reference sets to make it easier to consume e.g. intervention
      – InterventionCodeSubsetOperatingRoomProcedure
      – InterventionCodeSubsetPreventEducateCounseling
      – InterventionCodeSubsetAssessmentTool

• Environmental Scan provided minimal value
  – Mainly due to scope differences
Lessons Learned – Reference Set Development

• Challenges when one organization funded to develop the data elements and another the reference sets
  – Resolved by: Creating a logical model & holding frequent meetings to ensure alignment

• Team specific challenges
  – Initial development split amongst 3 resources (one person dedicated to project) – started with easier reference sets
  – 4 part time Clinicians initially
    • Their availability was a challenge
    • They did not always agree & decisions changed. Difficult to manage their review within timelines
    • Their review of “flat lists” was difficult without access to a file where they could not see relationships between concepts.
    • Line by line review of at least one clinician (44000 in health concern reference set)
Lessons Learned- Rule-Based Reference Sets

39 concepts under instrumental delivery

- Very few rule-based reference sets were developed
- SNOMED CT more granular than needed
Lessons Learned Tools

• Used an issue tracking tool (Redmine)
  – This was not an effective way of managing issues.
  – Resolved by: managing issues through weekly meetings with each individual resource and bi-weekly meetings with clinicians. Human interaction is needed.

• Authoring tools
  – Tried Workbench
  – Used excel
    • Many problems, needed an authoring tool with workflow that all participants could access
Lessons Learned Other

• Tight deadlines
  – more team input during project planning
  – Even though they were scoped as “starter reference sets”, hard to contain effort

• Getting decisions on direction can be complex and time consuming when multiple players involved
  – e.g. multiple SCWGs
User Interface Design Guidelines

• Context and Display
  – Limit the number of concepts presented to the user
  – Use plain language (E.g. “no” instead of “known absent”)

• Structured Forms
  – when there are a limited number of possible terms (20 or less)

• Search

• Elaboration

• Free-text Parsing
Infoway Implementation Support

- Jurisdictional project support
- Standards help desk support (standards@infoway-inforoute.ca)
- Education (online, education summits, jurisdictional tailored sessions)
- Terminology implementation guidance documents/Toolkit
- Standards Collaborative Work Group meetings/discussions (including Partnership)
Reference Set Maintenance and Sustainability

The maintenance and sustainability will be based on the following principles:

- Jurisdictions influence the content based on their requirements and experience
- Maintenance and evolution of reference set content will be open and transparent, but not dependent on pan-Canadian consensus
- Infoway Standards Collaborative will be nimble and pragmatic in the approach to maintenance and reference set enhancements.
- The primary focus will be to make it easy for vendors and jurisdictions to implement the reference sets.
Access to the Primary Health Care Reference Sets on the Infoway InfoCentral Website

- [https://infocentral.infoway-inforoute.ca/2_Standards/1_pan-Canadian_Standards/Terminology/3_pan-Canadian_Terminology_Artifacts](https://infocentral.infoway-inforoute.ca/2_Standards/1_pan-Canadian_Standards/Terminology/3_pan-Canadian_Terminology_Artifacts)
Thank you

standards@infoway-inforoute.ca