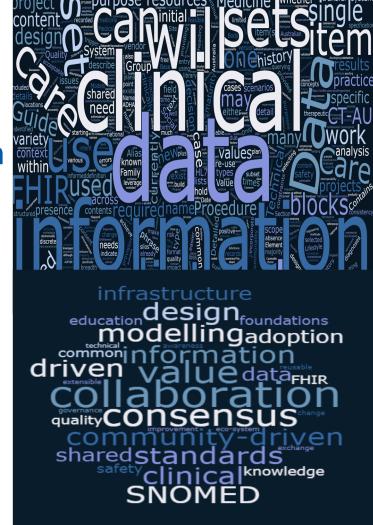


A community approach to data quality: FHIR IG and SNOMED CT ValueSets for Primary Care

SNOMED International Expo 31 October 2019 Kate Ebrill, CSIRO





From little data...

big data grows





Commonwealth Department of Health's role

- Commonwealth DoH committed to funding projects to support improved data quality in the primary health sector
- Wanted to encourage main users of primary health clinical systems (GPs) to have greater influence in designing the software they use
- Funded CSIRO in 2018 to run several projects that put clinicians at the centre of the process, with vendors and all Commonwealth Health agencies supporting their ideas
- Encouraging other software development projects beginning to adopt similar approach, given success of this community driven, co-design process

21 October, 2019 3

Why quality matters?

- High-quality health records support good patient care
- High-quality health records facilitate:
 - safe clinical decision making
 - effective communication between health professionals
 - trusting partnerships with patients
 - coordination and continuity of care
 - Population Health
 - Research





Why this Collaboration?

There are no agreed common data definitions for primary care within Australia

- RACGP Standards for General Practice, OPTIMUS project
- Australian Digital Health Agency My Health Record (Event Summary and Shared Health Summary)
- Federal and State Health Departments, PHNs
 - data requirements to support NKPIs
 - Local integrated care programs
- Software vendors
 - different labels for fields
 - · Different terminologies
- Multiple data extract providers- different approaches
- Overlapping data requirements
- An opportunity for harmonisation and alignment



Data... what do we know?

- Somewhere between 60-80% of clinical data is:
 - Free text entries
 - Narrative, progress notes, aide memoirs, practice management
 - Proxy terms
 - MBS item numbers, drugs
 - Not the data we expect
 - Diagnosis as procedures, Procedures in Diagnosis,
 Prescriptions as medical history
 - Missingness
 - Outdated and not curated



Misspelled, mis-typed, ambiguous

| Patient identifier | Problem managed (Diagnosis, Finding) | |
|--------------------|--|-------------------------------|
| 10000 | DNA | [did not attend, or DNA test] |
| 10001 | +/- swelling | [swelling present or absent?] |
| 10002 | Sistitus [cystitis] | |
| 10003 | Anxiote | [anxiety; n=651 variants] |
| 10004 | Hypecholesterolaemia [without the 1st 'r' but otherwariants] | vise all different ; n=758 |



According to the General Practice Insights Report 2016/2017:

- REASON FOR ENCOUNTER: 84.5% had at least one reason recorded and 15.5% had no data entered in the RFE field
- DIAGNOSIS: 29.4% of patient records had at least one diagnosis recorded but 70.6% had no data entered in the diagnosis field
- REASON FOR PRESCRIPTION: 11.9% had at least one reason for prescription but 88.1% had no data entered in RFP field

Single Provision, Multiple Use

- 1. Reduce effort for practices, clinicians and software Industry.
- Support exchange between clinical systems;
- Enable interrogation of data sets using standardised queries, resulting in consistent data results;
- Support safe and accurate data extracts, aggregation and analyse of primary care data (assuming appropriate privacy, consent and authorisation);
- 5. Enable standardised knowledge related activities such as common decision support tools across systems, rather than unique per project or implementation;
- Deliver a ready-made library of information models that can fasttrack the development of new clinical systems, applications or projects.



Core Design Principles

The core design principles

- Single provision, single development- multiple use and reuse
- Driven by a clinical safety use case
- Reduce duplication of effort
- Not data for data's sake
- Driven by primary use not secondary use needs
- What systems can support now or with minimal effort
- Standards based



Staged approach

Existing Specifications

Harmonised Content

Primary Care Data Dictionary

FHIR Implementation Guide



Primary Care, Standards Data Specifications, Data Sets, KPIs, Assessments, FHIR, OpenEHR Medicine tentil...

Harmonised clinical data items and identification of core common items

The state of the s

Primary care clinical information model



FHIR IG- Primary Care Au Practice to Practice Record Exchange

Identification of all the existing specifications in Primary Care that would inform the development of the core data requirements.

Candidate core data elements which are common to multiple existing specifications, that enable structured data recording and data reuse

Release 1 of the Data Dictionary defines the core common data elements to enable quality use of information as well as enable the safe and meaningful exchange of information to other care providers.

The Dictionary includes: meta data, definitions and recommended terminology bindings

Enter once, multiple use and interoperable exchange and reuse

Community, consensus based development process with multidisciplinary clinical content and technical working groups. An industry agreed specification, informed by the Primary Care Data Dictionary Core Common Model for the exchange of an individuals record when they request a transfer of their records from their current practice to a new practice.

FHIR reso thro

FHIR IG profiles based on the HL7au Base resources, progressively developed and tested through a Community process.

Endorsement proposed to be progressed through HL7au

Initial meeting of stakeholders to identify all potential data inputs, use cases and priorities for the projects.

Community established with clinical and technical working groups.

Use case agreed- reusable core data set, associated SNOMED CT Value Sets and a FHIR IG to exchange.

Clinical Content and Technical Working Groups consensus on the core data items to be defined and included in a data dictionary and identification of the first use cases to exchange these core data items.

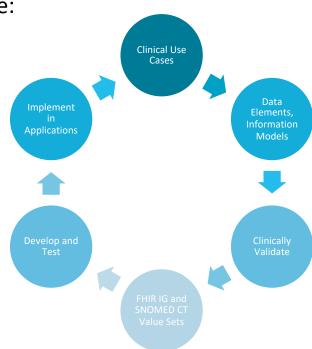
Outputs progressively developed and iterated through a series of face to face workshops (4) and webconferences (5)

Endorsement proposed to be progressed through clinical colleges and professional groups.



The **core principles** for the approach to **delivery** include:

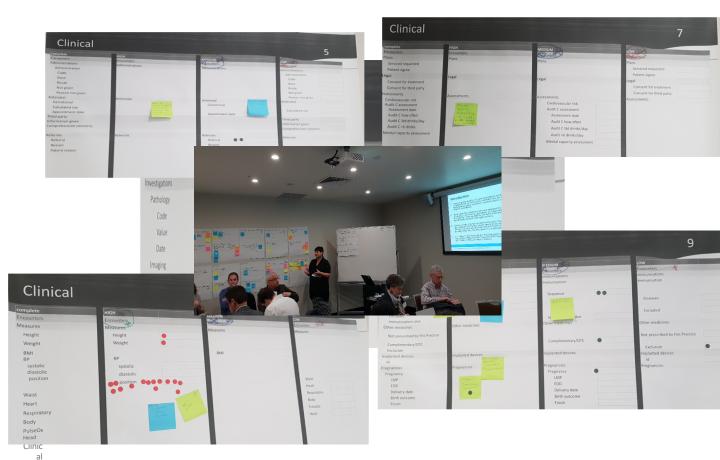
- 1. Community approach
- 2. Open and transparent
- 3. Consensus driven
- 4. Agile and iterative





Conto

Identification, Harmonisation and Prioritisation



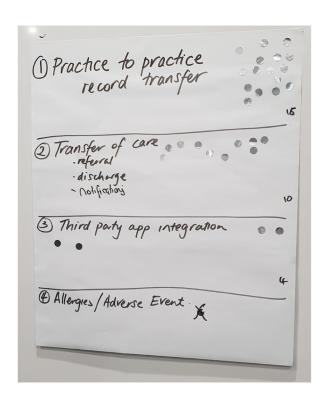


Agreed Project Scope

- Practice to Practice Record Transfer
- Continuity of Care (Primary to Acute to Primary)
- Third party app integration

Project delivery

- Agreed process to develop and validate the Information Model and FHIR Implementation Guide
- Connectathons test the IM and FHIR IG



- Starting point- Common Data Set to support practice to practice record transfer, and transfer of care
- At its core is the RACGP Local Clinical Record, KPIs, referral and the MyHR Shared Health Record Specifications
- Data Dictionary document defines each item, includes the valid value sets which support each item. Documents the various names that are used within existing GP software.
- SNOMED CT Primary Care Value sets developed to support the data dictionary.



Who is part of the Community?



Over 70 members in the CWG

5 teleconferences and 4 face to face meetings

Over 70 members in the TWG

4 teleconferences and 4 face to face meetings





The Data Model

Where we landed for Release 1

Core principle- enter once, maintain and re-use often

- Clinically useful to receiving clinician
- Supports safe transfer of care
- Systems can or with minimum effort provide functionality

57 data elements

- 40 codeable with SNOMED CT and other Value Sets
- Comments allowed
- Free text can be supported
- Support most use cases

Some pragmatic decisions for now given system capability Some issues reserved for Release 2

Outstanding content considerations: Sex, Gender, Birth Country and Ethnicity

Additional implementation considerations: Medico-legal, digital consent and workflow.

csiro.clinfhir.com Demographics Person-Name Date-of-Birth Gender-Identity □ Birth-Sex Address - □ ATSI-status Language Birth-Country — C Ethnicity ← Contacts ♠- □ Follow-up-List → Vaccination-List ← Clinical-Notes ♠ □ Social-History-Summary ← Family-History-Summary Care Plans Advanced Care Directives

🗅 🗀 Clinical

Key Diagnostics

Entitlement 🗀 Legal



Value Sets and Bindings

Structured coded data; free text discouraged





SNOMED and FHIR





ValueSets developed for:

- Diagnoses
- Procedures
- Reason for Encounter
- Medications
- · Adverse Reactions... etc

Required bindings ensure that data is valid

- Dx are entered in Dx
- Px are entered in Px
- Rx are entered in Rx
- Hx is entered in Hx

Non valid entries are prevented
Data structures are predictable, uniform
Is machine processable
Can send and receive with minimal curation
Preserves semantics



Single definition multiple use and reuse

| | | | | / | / | | | // | // | // | // | / | / | | | / | /. | / | / | // | / | // | / | / | / | // | // | /// | / | | | / | / | // | | / | / | // | // | |
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| Common Core Data Model - potential for re-use | | 8 | 1 | 5/ | | ste / | // | 1 / S | | | te, | | J. Hall | / , | / / | / / | | // | | | | 100 | / . | / / | / / | and / | | | 100 | OF . | 000 | 8/ | 8/ | | - Carlo | 130 | / / | | | |
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| Absence or Family history | | | - | | - | - | | - 4 | | _ | | - | _ | _ | _ | _ | | | | | _ | _ | 4 | - | | | | _ | | - | 4 | | | - 4 | | _ | | | | |
| Health risk assessment/factors | 14 | | - 1 | | | | | - 1 | | - 1 | - 1 | 1 | 1 | 1 | | | | | | | - | | | 1 | | | | 1 | | 1 | 1 | - 1 | - 1 | - 1 | | | | | | |
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| Contraindications | 16 | | 1 | 1 | 1 | | | - 1 | | | 1 | 1 | 1 | 1 | | | | 1 | | | | | | 1 | | | | 1 | | 1 | 1 | 1 | 1 | 1 | | | | | | |
| Adverse event | 6 | | | | 1 | | 1 | 1 | | | | | | | 1 | | | | 1 | | | | | | | | - 1 | | | | | | | | | | | | | |
| ere planning | | | | | | | | | | | | | | | | | | | | | | | | | | | | | | | | | | | | | | | | |
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| Laboratory test order Laboratory test results | | | - 1 | - 1 | 1 | - 1 | - | 1 | | - 1 | 1 | 1 | - | 4 | 4 | 1 | + | - 1 | 1 | - | + | + | + | + | + | + | - | - 1 | | 1 | 1 | | \vdash | - 1 | | 1 | 1 | - 1 | - 1 | |
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| Pulmonary function tests. | | | _ | 1 | _ | | | | | 1 | | 1 | - | \top | | | | | | - | - | \top | \top | \top | \top | | | 1 | | | | | | | | \top | | \Box | | |
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| Alcohol consumption summary | 13 | | - 1 | 1 | 1 | 1 | | 1 | | | | - 1 | - 1 | \neg | \neg | \neg | | | | | | | | | 4 | | | - 1 | | | 1 | | | - 1 | | 1 | 1 | | | |



In parallel -Education and Change

- 1. Aboriginal and/or Torres Strait Islander status
- 2. Allergies and adverse reactions
- 3. Medications & Reason for Medication
- 4. Reason for Encounter and Diagnosis
- 5. Immunisations



Training packages available

Training Package:

Train the Trainer/Peak Bodies Presentation Slides

Webinar Presentation Slides (1 hour)

Face to Face Presentation Slides (1 hour)

Teamwork Practice Questionnaire Draft Quality Improvement Activity (PDSA) eg raise awareness of clinical coding

1-page Summary Guides

- Best Practice
- MedicalDirector
- Communicare

Training Workbooks

- Best Practice
- MedicalDirector
- Communicare

Videos

- Best Practice
- MedicalDirector
- Communicare

Multi-modal options

designed with you, designed for you!





112 Training Resources



BP PREMIER

Module 1 - Extra page of learning links - Adding Aboriginal and Torres Strait Islander status - BP PREMIER - Train IT Medical .pdf

Module 1 - Key reasons to code Aboriginal and Torres Strait Islander status - BP PREMIER - Train IT Medical .JPG

Module 1 - Summary Sheet - Adding Aboriginal and Torres Strait Islander status - BP PREMIER - Train IT Medical .docx

Module 1 - Video - Adding Aboriginal and Torres Strait Islander status - BP PREMIER - Train IT Medical .mp4

Module 1 - Video Script - Adding Aboriginal and Torres Strait Islander Status - BP PREMIER - Train IT Medical .docx

Module 2 - Key reasons to code Allergies and Adverse Reactions - BP PREMIER - Train IT Medical .JPG

Module 2 - Summary Sheet - Allergies and Adverse Reactions - BP PREMIER - Train IT Medical .docx

Module 2 - Video - Allergies and Adverse Reactions - BP PREMIER - Train IT Medical .mp4

Module 2 - Video Script - Allergies and Adverse Reactions - BP PREMIER - Train IT Medical .docx

Module 3 - Key reasons to code diagnoses - BP PREMIER - Train IT Medical .JPG

Module 3 - Summary Sheet - Diagnosis Coding - BP PREMIER - Train IT Medical .docx

Module 3 - Video - Diagnosis coding - BP PREMIER - Train IT Medical .mp4

Module 3 - Video Script - Diagnosis coding - BP PREMIER - Train IT Medical .docx

Module 4 - Key reasons to code a Medication and Reason for Medication - BP PREMIER - Train IT Medical .JPG

Module 4 - Summary Sheet - Medication and Reason for Medication - BP PREMIER - Train IT Medical .docx

Module 4 - Video - Medication and Reason for Medication - BP PREMIER - Train IT Medical .mp4

Module 4 - Video Script - Medication and Reason for Medication - BP PREMIER - Train IT Medical .docx

Module 5 - Key reasons why adding an immunisation is important - BP PREMIER - Train IT Medical .JPG

Module 5 - Summary Sheet - Adding an Immunisation - BP PREMIER - Train IT Medical .docx

Module 5 - Video - Adding an Immunisation - BP PREMIER - Train IT Medical .mp4

Module 5 - Video script - Adding an Immunisation - BP PREMIER - Train IT Medical .docx

Summary Sheet - Configuration Options - BP PREMIER - Train IT Medical .docx

Summary Sheet - Reason for visit - BP PREMIER - Train IT Medical .docx

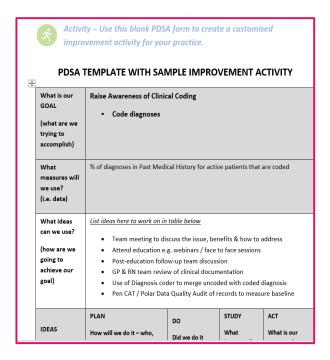
Bp Premier Learning Workbook - Standardised data coding - unbranded - Train IT Medical v2.docx

Stored for you on 'Confluence' https://confluence.csiro.au

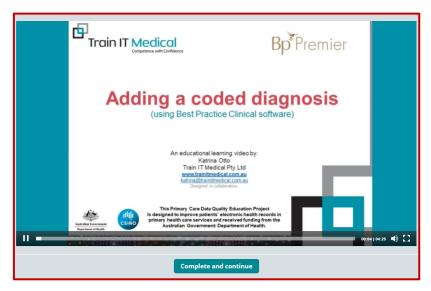


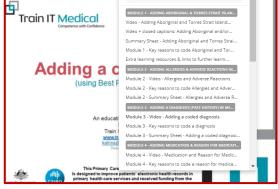
Quality Improvement (PDSA) samples





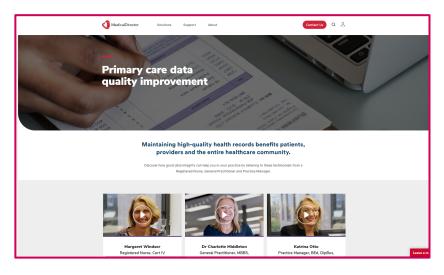








MedicalDirector



"Guidelines for maintaining high quality data for your active patients."

Access via: https://www.medicaldirector.com/PCDQIP



12 Months on – Community Achievements

The Data Model

Common Core - enter once, use often

Practice to Practice use case

Reusable components for additional use cases.

Data Dictionary

Summary cheat sheet Terminology Value Sets, Bindings

FHIR Implementation Guide

AU Base - progress Worked examples Connectathons

Reusable components for Phase 2

Education materials

Slide decks

Videos

How-to guides

Supporting materials

Search strategies

Mapping and migration

Dealing with terminology conten

Data inputs

Analytics

Using SNOMED encoded data Other reporting requirements Starter sets, inferring Dx Data outputs





Where to next

The community is expanding more clinicians, organisations and Vendors joining!

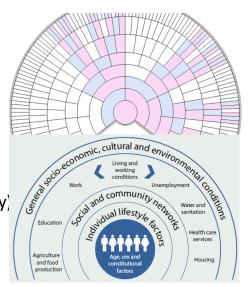
Data Dictionary and Value Sets

- Demographics
- Clinical
 - Family history
 - Social determinants (HL7 -International Gravity)
 - Risk factors

Important for

- Identification of risk factors, risk prediction
- Social determinants of health
- Pro-active intervention and care delivery
- Preventive health programs
- Healthcare Assessments

FHIR IG – use cases being discussed with the Community next month





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Thank you