Using SNOMED CT-enabled data collections in a national clinical research program: primary care data can be used in secondary studies

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Publication Details
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Abstract
Background: National Institute of Clinical Studies (NICS) research Objectives: review pain management, care guidelines Participants: Australian EDs, opt-in Duration: 3 years Sampling: 60 patients each 3 months, over-sampling Cohort: abdominal pain and traumatic injuries Method: medical record review by clinicians

Keywords
research, clinical, national, collections, data, enabled, ct, snomed, primary, studies, care, used, program, secondary, can, be

Publication Details

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This conference paper is available at Research Online: http://ro.uow.edu.au/ahsri/327
Using SNOMED CT® - enabled data collections in a national clinical research program

Donna Truran, Patricia Saad, Ming Zhang, Kerry Innes, Madonna Kemp
Sue Huckson, Scott Bennetts
Background

National Institute of Clinical Studies (NICS) research

**Objectives:** review pain management, care guidelines

**Participants:** Australian EDs, opt-in

**Duration:** 3 years

**Sampling:** 60 patients each 3 months, over-sampling

**Cohort:** abdominal pain and traumatic injuries

**Method:** medical record review by clinicians
The problem, the context

ICD used as a proxy terminology

Original study design & sampling strategy was based on ICD

Some hospitals using SNOMED CT

Changed circumstances needed new approach
Encoded data use

Codes used only as a ‘hook’

ICD codes specified by HIM - best match to the study protocol

Pragmatic: use what we’ve got, code selections based on skilled advice which **aligned research protocol with ICD**

**NOT** a review of a data collection, **NOT** a coding audit

But a **review by clinicians of the original medical record**
Mapping?

- NICS tried to map and found it wasn’t useful
  - High cost, low value
  - Degraded meaning, many gaps
  - Needed a different approach

**Instead**

- Use SNOMED CT concepts identifiers to retrieve relevant cases
Design

Don’t triangulate, but directly align, de-couple

Switching option
Collaborative approach

Terminologists
- Analysis and alignment SNOMED CT content which best suits study purposes
- QA and prepare contents for clinical review
- Prepare retrieval query and test final endorsed SNOMED CT concept lists

Clinicians
- Provide study protocols
- Review all Candidate SNOMED CT concepts

Data Managers
- Execute data extraction on live data according to the NICS specification
- Produce extracted and formatted data and send to NICS

NICS research team performs clinical review of care delivery in ED
Methods and results

Terminologists and analysts

Identify candidate SNOMED CT concepts

\[ n = 227 \text{ concepts relevant to abdominal pain} \]
\[ n = 10,006 \text{ concepts relevant to traumatic injuries} \]
\[ N = 10,233 \]

Some detailed review by clinicians and researchers

foreign bodies? obstetric pain?
Clinicians, Researchers

Clinical review:
- Selected concepts which are clinically relevant
- Mindful of existing patient cohort
- Mindful to prevent any sort of systematic bias

From 10 233 candidate SNOMED CT concepts

Removed 107 (not required)

Excluded candidate concepts relevant to obstetrics
Methods and results

Testing (data custodians and managers)

Retrieval query written and tested against trial data

Review for any systematic bias

- Concept Utilisation $n = 867$ (or $\sim 9\%$ of endorsed concepts)
- Case Identification $n = 5324$ (or $\sim 20\%$ of patient cases)

Query performance: worked properly and quickly

Workflow: understandable, reproducible, useful
Outcomes

- Generic retrieval query
- SNOMED CT RefSet table(s)
  - concepts and descriptions, versions
- Retrieval Workflow

NICS Research program continues
SNOMED CT users are participating

Approach is enabling and non-disruptive
Retrieval workflow (simplified)

1. SNOMED CT Version
2. Dates To Extract
3. Data Sources
4. Data Items

- ED Diagnosis Field Using SNOMED CT Concept ID?
  - Yes: Run Query based on Date and Endorsed List
  - No: Transfer Endorsed List to ED Diagnosis Format

- Transfer ED Diagnosis to SNOMED CT ID

- Receive Data From Query
- Produce Result table
- Send back to NICS

- Run Query based on Date and Endorsed List
  - Yes: Transfer ED Diagnosis to SNOMED CT ID
  - No: Send back to NICS
Issues

**Inputs will influence outputs**
NICS-ACCTI had no control over inputs (out of scope)

**Maximum approach – large Retrieval RefSet because:**

Clinical domain was broad scope

Non-standard implementations of SNOMED CT variously
- all of SNOMED CT
- constrained SNOMED CT
- local hand-crafted subsets
- concepts displayed in interface
- descriptions for interface & concepts in the database
- different versions of SNOMED CT
Implications

SNOMED CT input RefSets must serve the clinical users

If we know what SNOMED CT content is available to enter, then Retrieval RefSets can mimic that content

**But:**

There will be a persistent requirement for Retrieval RefSets for:
- Local use and ad hoc interests
- Research, clinical care reviews
- Care delivery and service monitoring
- Aggregation and reporting
Early adopters encountered first hurdles

Preference for mapping because ‘everyone understands ICD’

SNOMED CT merely unfamiliar at this time

Non-standard SNOMED CT implementations will have predictable knock on effects
Recommendations

Clinical use case

use a clinical terminology – SNOMED CT

Statistical reporting use case

use a statistical classification – ICD

Occam’s Razor:
“...don’t invent entities beyond necessity...”
Recommendations

Necessarily collaborative development work
- terminologists, clinicians and data users.

Education, training and support for users and implementers

Further alignment between specifications will be required for:
  • particular and various input RefSets
  • particular and various retrieval RefSets

Ongoing maintenance and support mechanisms needed
Thank you

Questions?

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