Hands-on experience developing a reference set for optometrists

Annemieke Coops (OVN)
Pim Volkert (Nictiz - NRC)
What will be covered?

- Problem statement
- Development process of reference set
- Implementation of reference set
- Management of reference set
- What we have learned
Annemieke Coops

• Policy advisor Dutch Optometric Association
• Background in clinical practice, research and education
Goals of Project

- Improve quality of medical documentation & exchange information with others professionals
- Extract data from patient records for policy and quality analysis
- Enable possibility to use the same data for multiple purposes

→ Need for standardisation
Target Group

- Optometrists in the Netherlands (± 1000)
- 75% primary care – 25% hospital care
Which Standard?

ICD

ICPC

Snomed
Which Standard?

Looking again at our goals...

Improve quality of medical documentation & exchange information with others professionals

Extract data from patient records for policy and quality analysis

Enable possibility to use the same data for multiple purposes
Which Standard?

Looking again at our goals...

- Improve quality of medical documentation & exchange information with others professionals
- Extract data from patient records for policy and quality analysis
- Enable possibility to use the same data for multiple purposes
Where to Start? – Part I

- Step by step approach in development
- Identify different elements of patient record and their priority for standardization
  - Case history: visit reason
  - Optometric tests
  - Findings
  - Diagnosis
Where to Start? – Part II

• Development process of a reference set – reference set committee
  
  Phase 1: Overview of terminology used in practice
  Phase 2: Select terms from international Snomed release
  Phase 3: Translate terminology to Dutch
  Phase 4: Validate reference set
  Phase 5: Work out final version in ART-DECOR
Considerations and Difficulties with the Development of a Reference Set

– General terms and/or specific terms
  • E.g. cataract and/or posterior subcapsular cataract
  • Balance between as complete as possible and practical use
  • Take into account healthcare setting → optometry first line healthcare

– Committee members and optometrists in validation process tend to think in terms of coding rather than describing findings
Where are we now?

- Reference set with diagnosis
  - development completed and → December 2013
  - implemented → February 2014
- Reference set with optometric tests
  - development completed → September 2014
- Reference set with visit reason
  - phase 2 development process
How do Practitioners Start Using the Reference Set?

• Implementation in software packages of patient records – part I
  – Approach all software companies
  – Additionally to reference set, implementation of standard for patient records
  – Pilot with 3 software companies (80% of market)
Optometric software

Problem statement

Development

Implementation

Management
Optometric software
Optometric software
• Updating reference set
  – Service Level Agreement
    • Questions and change requests → Service desk → OVN
    • Assessment of request → OVN committee (every 6 months)
    • Implementation of changes → Nictiz-NRC
    • Distribution of updated reference set → OVN committee (every 12 months if relevant)

• Updating software packages
  – Agreement with software companies: implementation within 2 months after release
  – Notice from OVN, downloadable from Nictiz website
  – SNOMED CT License Agreement software company – Nictiz
• Not always easy to define how detailed/specific terminology has to be
  → Take into account health care setting where reference set is used
• Committee members found it hard to keep the purpose of reference sets in mind: recording findings rather than coding
• Committee members were not keen on jointly working on reference set in ArtDecor
Let's change...
Pim Volkert

- Coordinator Terminology & NRC
- 2 years Product Manager Semantic Interoperability
- 3 years ALERT Life Sciences Computing
- 11 years Rivierenland Hospital
## Roles Identified

<table>
<thead>
<tr>
<th>Role</th>
<th>Entity</th>
</tr>
</thead>
<tbody>
<tr>
<td>User</td>
<td>Optometrists</td>
</tr>
<tr>
<td>Keeper</td>
<td>OVN</td>
</tr>
<tr>
<td>Sponsor</td>
<td>OVN</td>
</tr>
<tr>
<td>Autorisator</td>
<td>Committee of OVN</td>
</tr>
<tr>
<td>Expert</td>
<td>Committee of OVN</td>
</tr>
<tr>
<td>Functional Manager</td>
<td>Service Desk of OVN</td>
</tr>
<tr>
<td>Technical Manager</td>
<td>Nictiz</td>
</tr>
<tr>
<td>Distributor</td>
<td>OVN/Nictiz</td>
</tr>
</tbody>
</table>
In the Beginning

<table>
<thead>
<tr>
<th>originalText</th>
<th>Vertaling</th>
<th>vertalingen (A)</th>
</tr>
</thead>
<tbody>
<tr>
<td>A-pattern vergence</td>
<td>A-patroonvergentie</td>
<td>Is dit nu juist?</td>
</tr>
<tr>
<td>Anterior synechiae</td>
<td>anterieure synechiae</td>
<td>Is dit nu juist?</td>
</tr>
<tr>
<td>Bull's eye macular dystrophy</td>
<td>Bull's eye maculopathie</td>
<td>Moet het zijn:</td>
</tr>
<tr>
<td>Capsular Fibrosis</td>
<td>nastaar</td>
<td>Ik weet niet hoe het heet, echter nastaar. Waar wordt deze term, of de mislukte vertalingen?</td>
</tr>
<tr>
<td>Central retinal artery occlusion</td>
<td>centraal retinale arterieocclusie</td>
<td></td>
</tr>
</tbody>
</table>
ADHD - attention deficit hyperactivity disorder (disorder)

Snomed CT context

HIërarchie

- Attention deficit hyperactivity disorder
  - Adult attention deficit hyperactivity disorder
  - Attention deficit hyperactivity disorder, combined type
  - Attention deficit hyperactivity disorder, inattentive presentation (restrictive)
  - Attention deficit hyperactivity disorder, predominantly hyperactive impulsive type
  - Attention deficit hyperactivity disorder, predominantly inattentive type
  - Child attention deficit disorder
  - Deficit in attention motor control and perception
  - Hyperkinesis with developmental delay
  - Hyperkinetic conduct disorder
  - Undifferentiated attention deficit disorder

406506008 - Attention deficit hyperactivity disorder (disorder)

General name
- Attention deficit hyperactivity disorder (disorder)

Synonyms
- ADHD - attention deficit disorder with hyperactivity
- Nederlands - Voorkeurterm

Definitie (Primitive)

Is a
- Disorders of attention and motor control
- Mental disorder usually first evident in infancy, childhood

Referentieset
- Dutch Optometrist simple reference set

GTG simple map
- XUaas

SNOMED RT ID simple map
- D9-00084

ICD-10 complex map reference set
- F90.0

ICD-9-CM equivalence complex map reference set
- 314.01
SNOMED CT - Output
Feedback of Software Engineers

- Documentation used
- Offered assistance used
- Looked at the Nictiz browser

They ‘simply’ implemented it.
1st Results

Diagnoses

- Cataract beginnend
- Cataract stervend
- choroidale bloeding
- Pseudoaak
- Bloeding
- Geen bijzonderheden
- Glaucoomsuspect
- Microaneurysma
- Cataract beginnend
- Glaucom
- nuclear cataract
- Vlamvormige bloeding
- Mouches volantes (floaters)
- Posterior subcapsulair cataract
- Pterygium
- myope
- Drusen
- Pucker
- Glaucoomsuspect
- matuur cataract
- Retina drusen
- Exsudaten
- Microaneurysma
- Esoforie
- Maculadegeneratie
- Hypertroop
- refractie-afwijking
- diabetische retinopathie
- angiopathy
- maculagat
- Subcapsular cataract
- Naevus
Data in Realtional View

- [Conjunctivitis(9826008)]
  - [bacteriële conjunctivitis(128350005)]
  - [allergische conjunctivitis(473460002)]
  - [seizoensgebonden allergische conjunctivitis(231855007)]
  - [keratoconjunctivitis sicca(302896008)]
  - [contactlensgerelateerde conjunctivitis(416454006)]
  - [virale conjunctivitis(45261009)]

- [Keratoconus(65636009)]

- [oculaire hypertensie(4210003)]

- [strabismus(22066006)]
  - [Exoforie(46343005)]
  - [Hyperforie(421452007)]
  - [Esoforie(62176008)]
  - [Hypertropie(40608009)]
  - [Hypoforie(8016009)]
  - [Esotropie(16596007)]
  - [Exotropie(399054005)]
Experiences from Different Viewpoints

- End user
- Developer
- Refset manager
- Refset owner
- NRC
End User View

• Rich choice is appreciated
• Feel more involved
• Upgrade of quality
Developers View

• Standard Content = Less discussions with Client
• Feel recognized as a more serious player
Refset Management View

- Stakeholders maintain their own refset
- Assumed and felt ownership
Refset Owner’s View

• SNOMED CT
  • Finding all relevant terms in SNOMED CT not always easy due to different paths – finding terms via different ‘mother’-terms

• National Release Center support
  • Committee members were afraid ‘to do something wrong’ when jointly working on the reference set in ART-DECOR
  • Not so easy to see which sets need to be taken to finalize the reference set
  • Good en quick support from the release centre team
NRC View

- Greenfield is excellent way to learn to work with Snomed
- Few vendors make communication easy
- Small simple refset was a good learning experience
- Tools in place: refset editor, browser, QC procedures
- Last but not least lucky to start with such a partners
Lessons Learned NRC

• Do not underestimate the power of Excel
• Guide developers on their level – and sit with them
• Check final output data asap