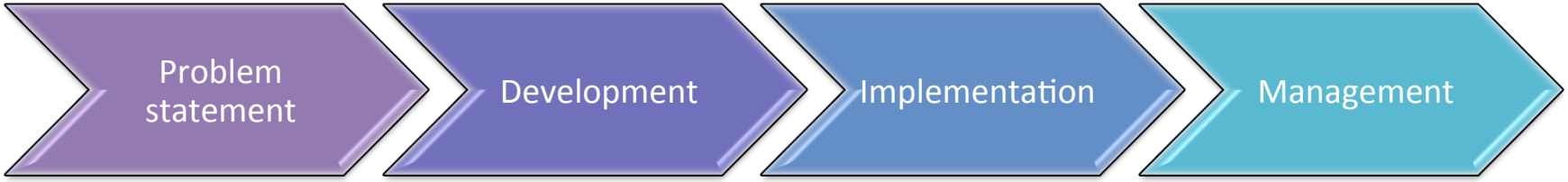
Hands-on experience developing a reference set for optometrists

Annemieke Coops (OVN)
Pim Volkert (Nictiz - NRC)

What will be covered?

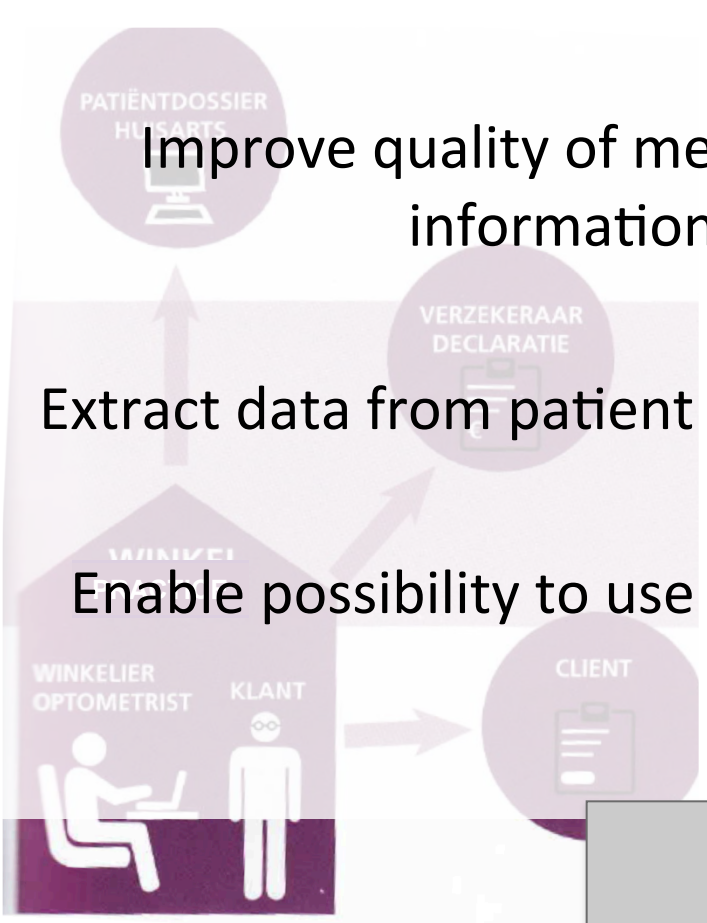
- Problem statement
- Development process of reference set
- Implementation of reference set
- Management of reference set
- What we have learned



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

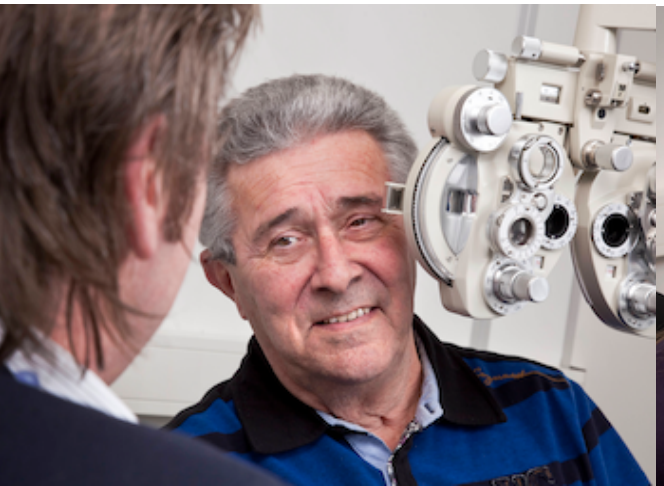
Extract data from patient records for policy and quality analysis

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

Snomed

ICPC

Which Standard?

Looking again at our goals…

Snomed

ICD

Improve quality of medical documentation & exchange information with others professionals

ICPC

Extract data from patient records for policy and quality analysis

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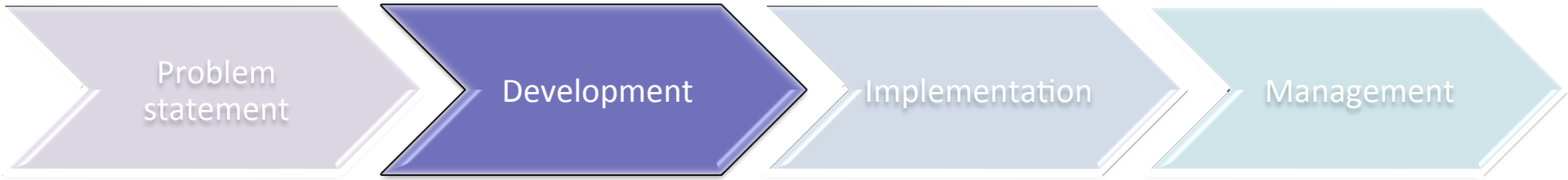
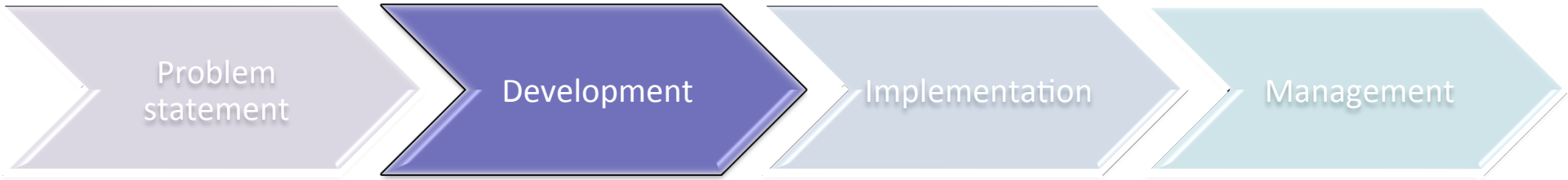
Where to Start? – Part I

- 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



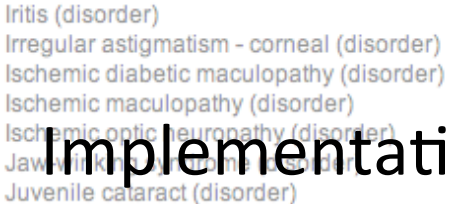
Considerations and Difficulties with the Development of a Reference Set

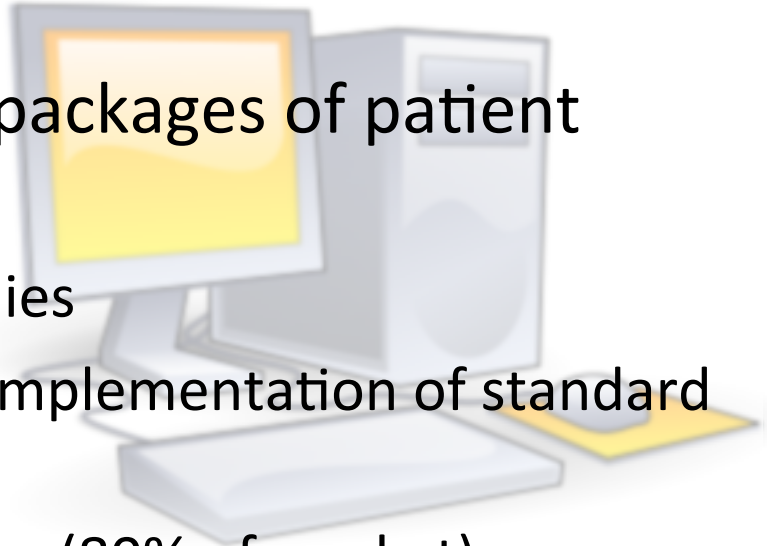
- General terms and/or specific terms
  - E.g. cataract and/or posterior subcapsular cataract
  - Balance between as complete as possible and practical use
  - Take into account healthcare setting → optometry first line health care
- Committee members and optometrists in validation process tend to think 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

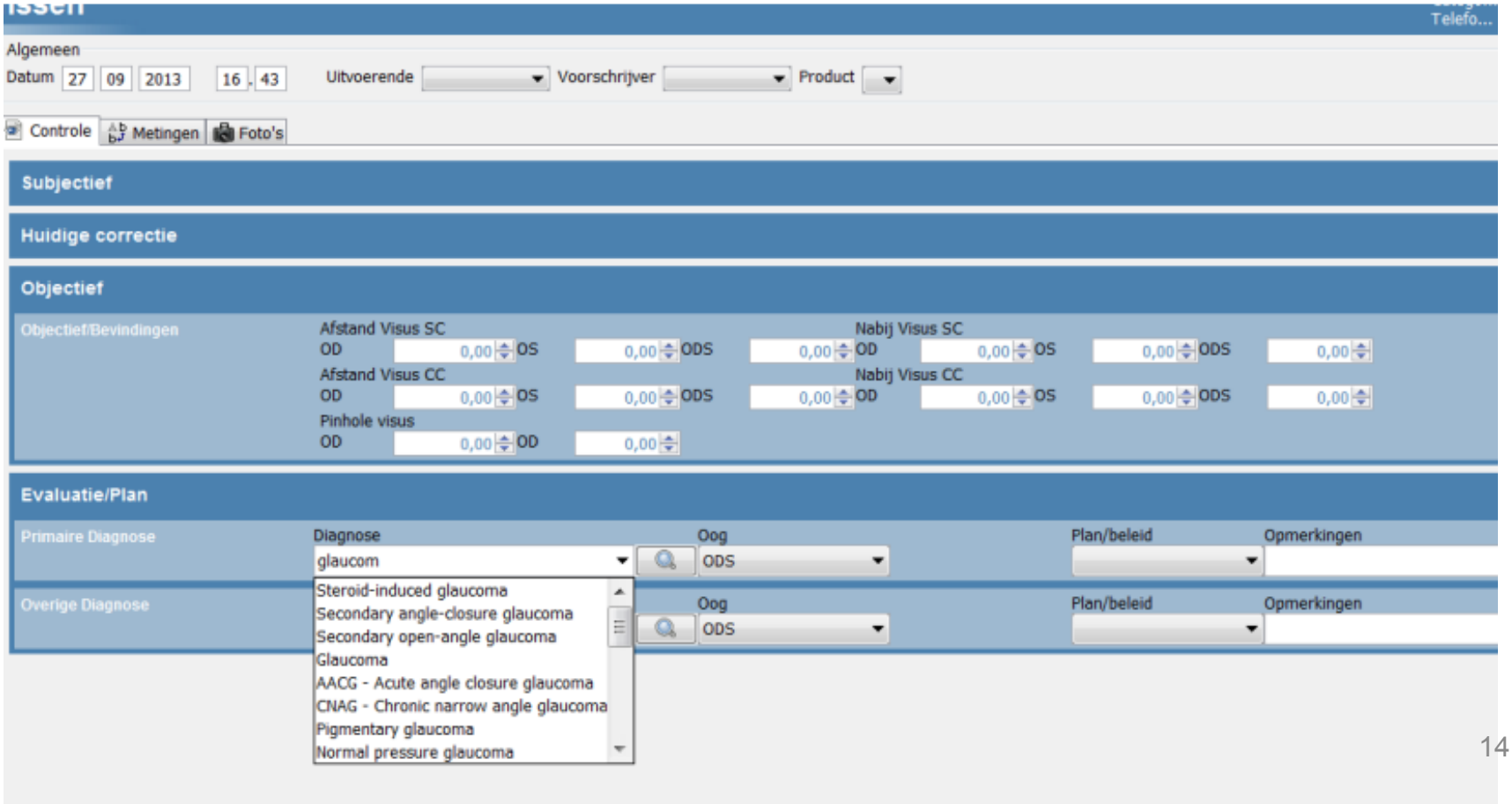
How do Practitioners Start Using the Reference Set?





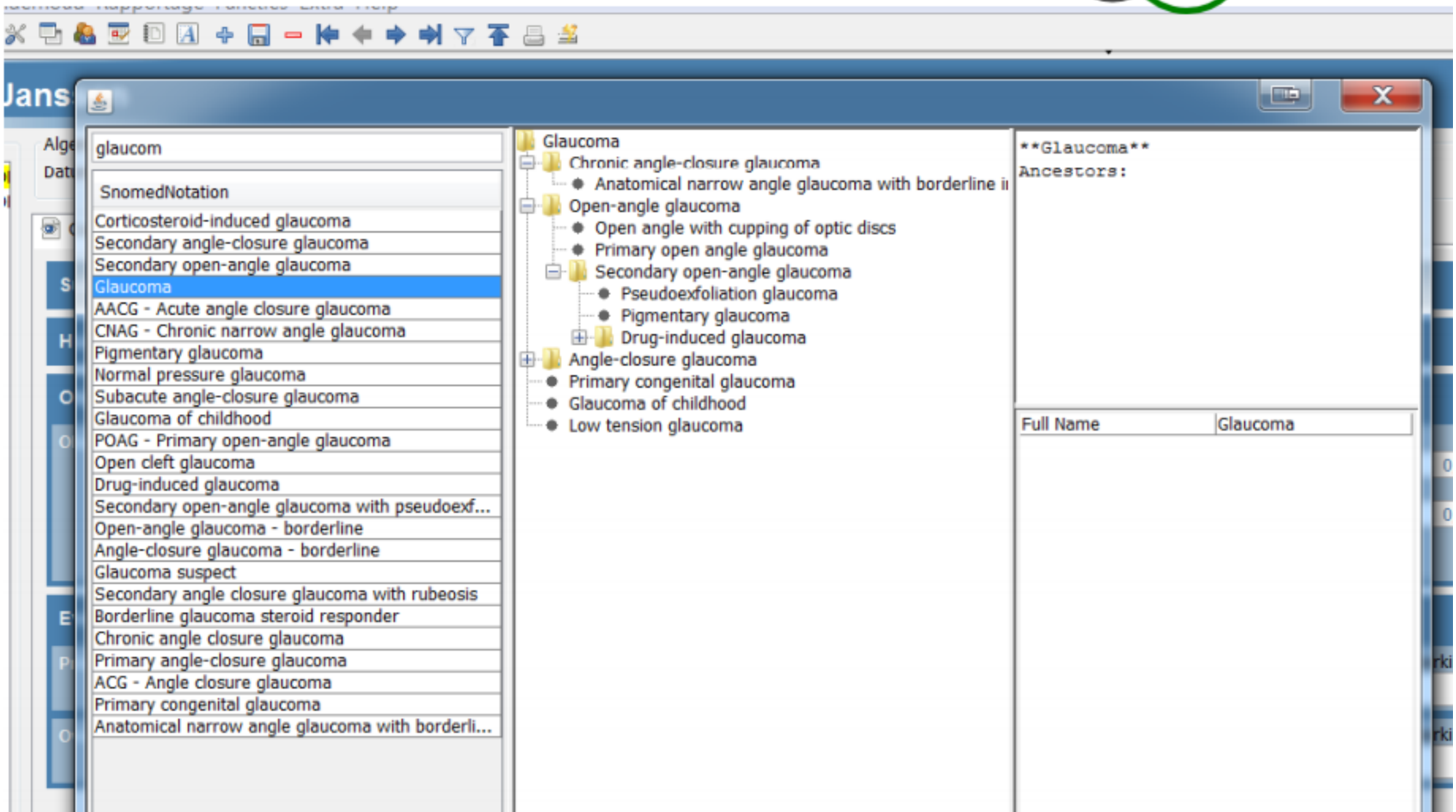
- Implementation in software packages of patient records – part I
  - Approach all software companies
  - Additionally to reference set, implementation of standard for patient records
  - Pilot with 3 software companies (80% of market)

Optometric software

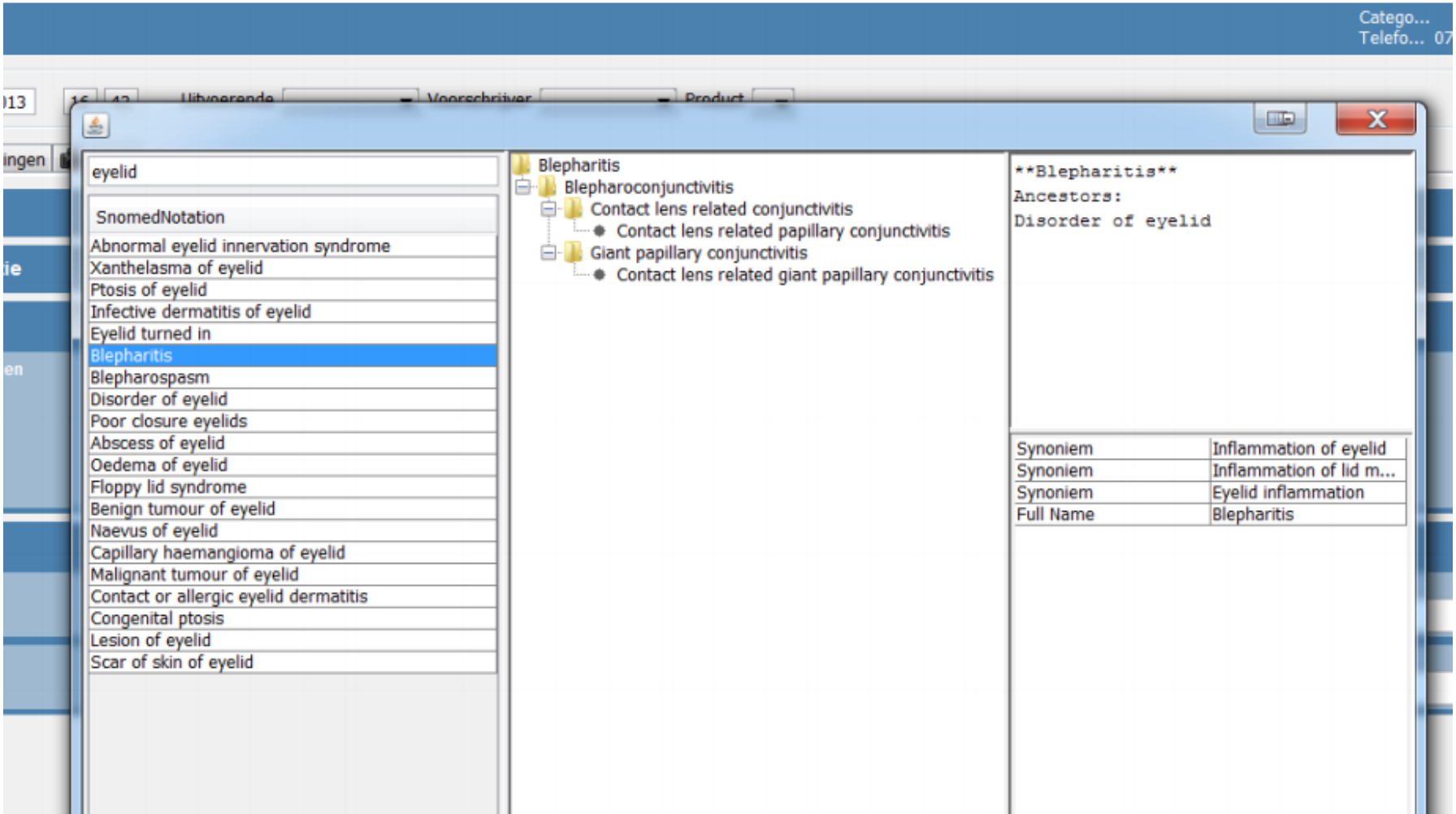


Problem statement | Development | Implementation | Management

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

What we have learned…

- 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

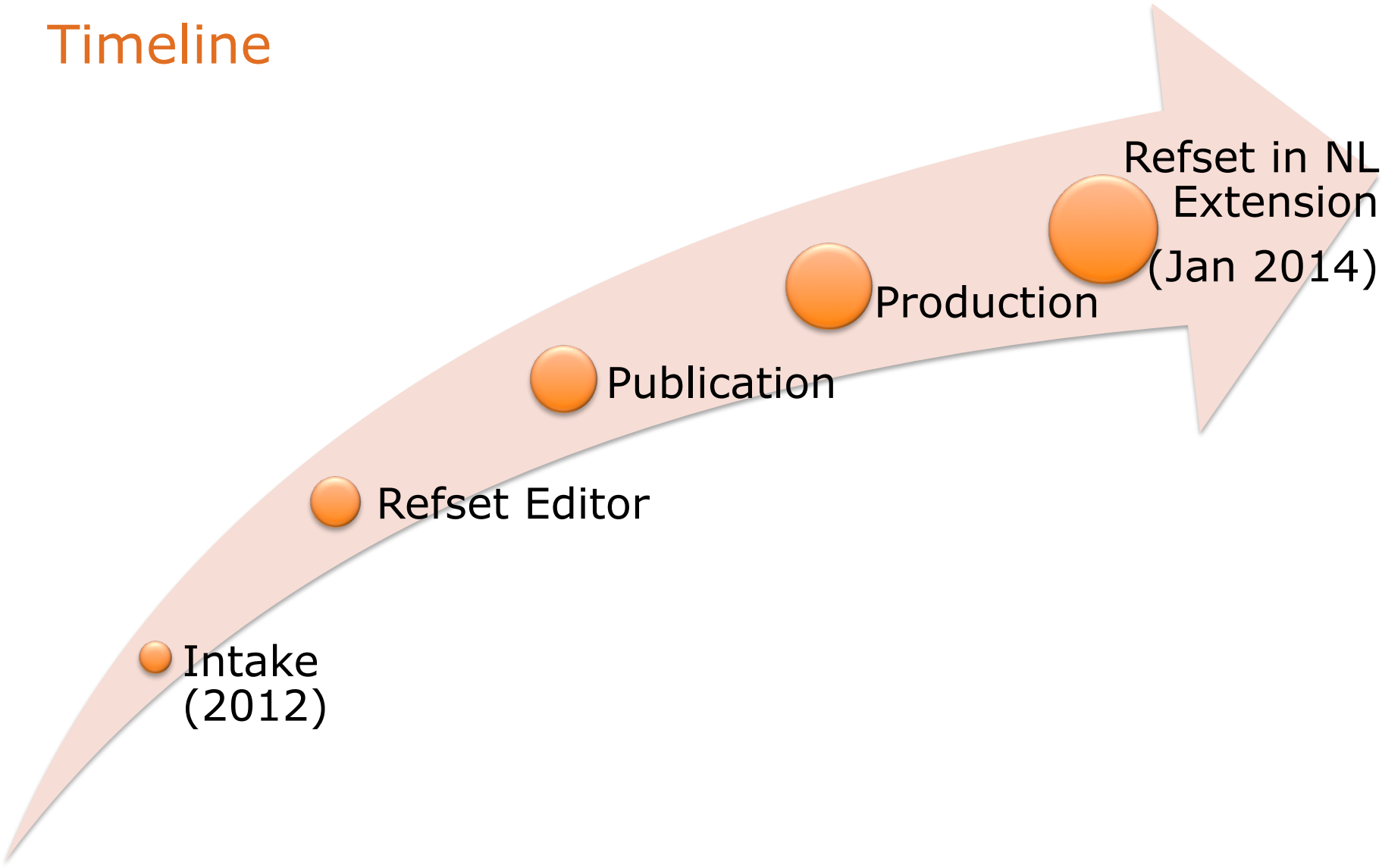
Pim Volkert

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

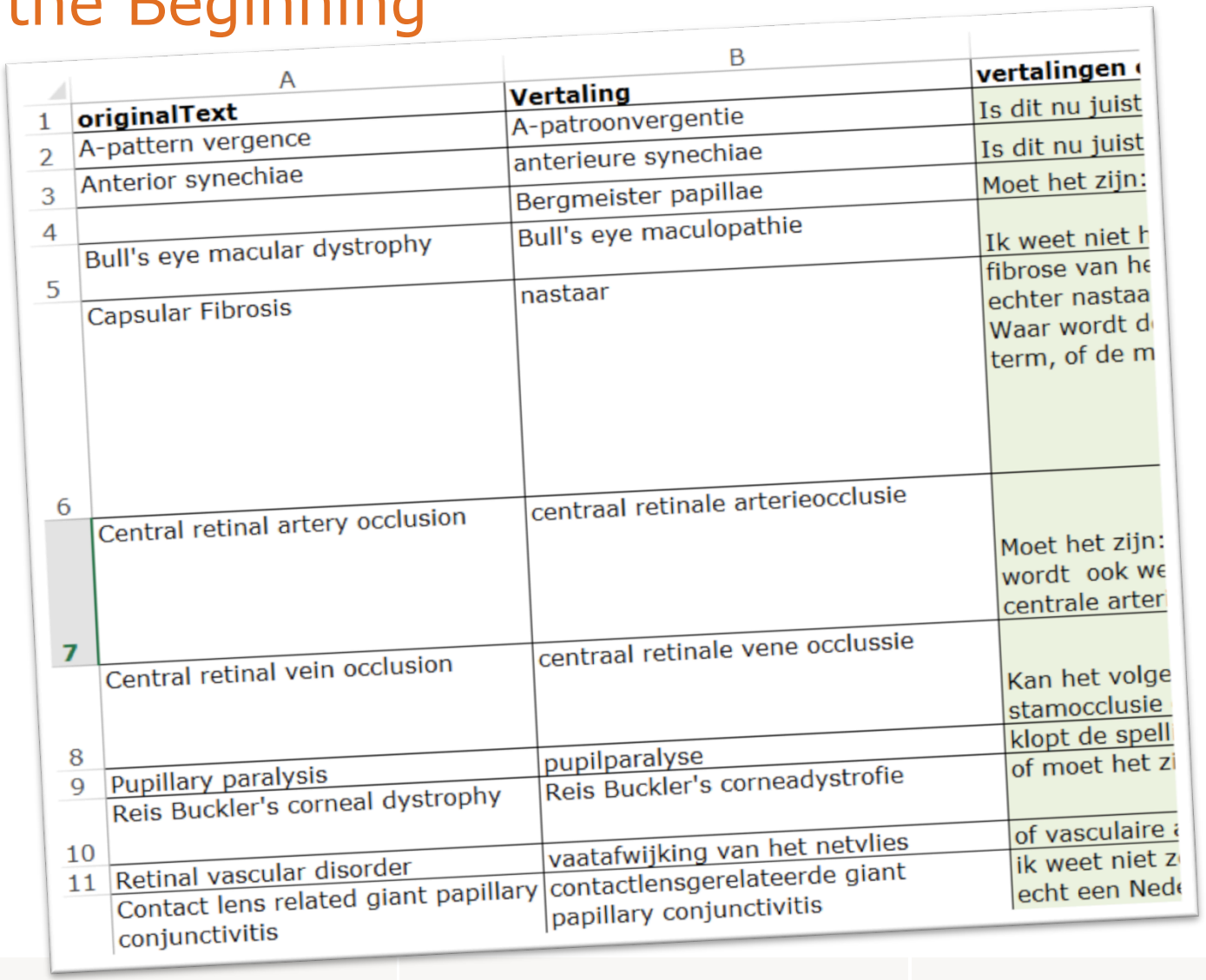
Roles Identified

User	Optometrists
Keeper	OVN
Sponsor	OVN
Autorisator	Committee of OVN
Expert	Committee of OVN
Functional Manager	Service Desk of OVN
Technical Manager	Nictiz
Distributor	OVN/Nictiz

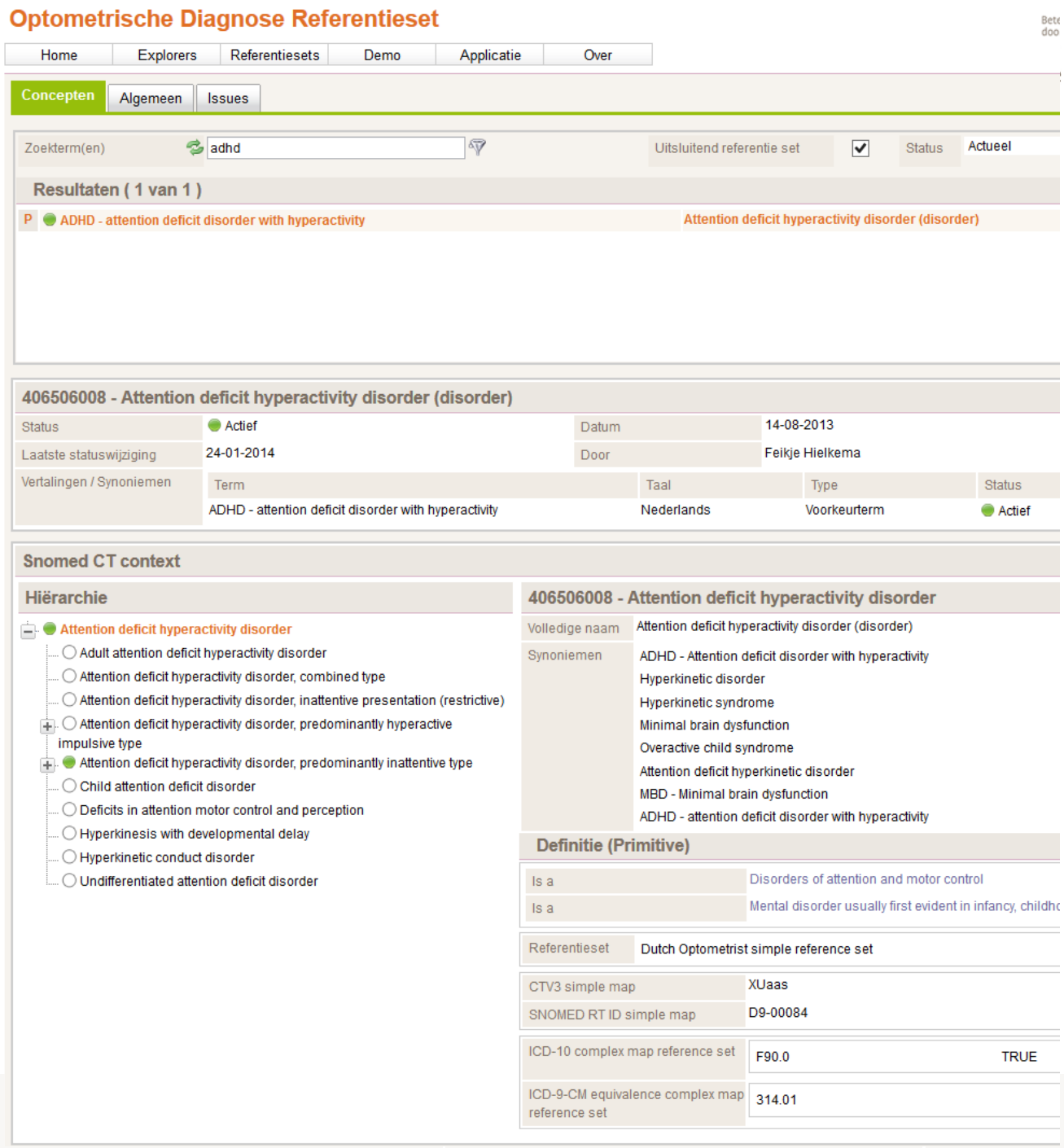
Timeline


Intake
(2012)
Refset Editor
Publication
Production
Refset in NL
Extension
(Jan 2014)

In the Beginning



	A	B	
1	**originalText**	**Vertaling**	**vertalingen**
2	A-pattern vergence	A-patroonvergentie	Is dit nu juist
3	Anterior synechiae	anterieure synechiae	Is dit nu juist
4		Bergmeister papillae	Moet het zijn:
5	Bull's eye macular dystrophy	Bull's eye maculopathie	Ik weet niet h
6	Capsular Fibrosis	nastaar	fibrose van he echter nastaa Waar wordt d term, of de m
7	Central retinal artery occlusion	centraal retinale arterieocclusie	Moet het zijn: wordt ook we centrale arter
8	Central retinal vein occlusion	centraal retinale vene occlussie	Kan het volge stamocclusie
9	Pupillary paralysis	pupilparalyse	klopt de spell
10	Reis Buckler's corneal dystrophy	Reis Buckler's corneadystrofie	of moet het zi
11	Retinal vascular disorder	vaatafwijking van het netvlies	of vasculaire a
	Contact lens related giant papillary conjunctivitis	contactlensgerelateerde giant papillary conjunctivitis	ik weet niet z echt een Ned


Optometrische Diagnose Referentieset
Home
Explorers
Referentiesets
Demo
Applicatie
Over
Concepten
Algemeen
Issues
Zoekterm(en)
adhd
Uitsluitend referentie set
Status
Actueel
Resultaten (1 van 1)
P
ADHD - attention deficit disorder with hyperactivity
Attention deficit hyperactivity disorder (disorder)
406506008 - Attention deficit hyperactivity disorder (disorder)
Status
Actief
Datum
14-08-2013
Laatste statuswijziging
24-01-2014
Door
Feikje Hielkema
Vertalingen / Synoniemen
Term
Taal
Type
Status
ADHD - attention deficit disorder with hyperactivity
Nederlands
Voorkeurterm
Actief
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
Deficits in attention motor control and perception
Hyperkinesis with developmental delay
Hyperkinetic conduct disorder
Undifferentiated attention deficit disorder
406506008 - Attention deficit hyperactivity disorder
Volledige naam
Attention deficit hyperactivity disorder (disorder)
Synoniemen
ADHD - Attention deficit disorder with hyperactivity
Hyperkinetic disorder
Hyperkinetic syndrome
Minimal brain dysfunction
Overactive child syndrome
Attention deficit hyperkinetic disorder
MBD - Minimal brain dysfunction
ADHD - attention deficit disorder with hyperactivity
Definitie (Primitive)
Is a
Disorders of attention and motor control
Is a
Mental disorder usually first evident in infancy, childh
Referentieset
Dutch Optometrist simple reference set
CTV3 simple map
XUaas
SNOMED RT ID simple map
D9-00084
ICD-10 complex map reference set
F90.0
TRUE
ICD-9-CM equivalence complex map reference set
314.01

SNOMED CT - Output

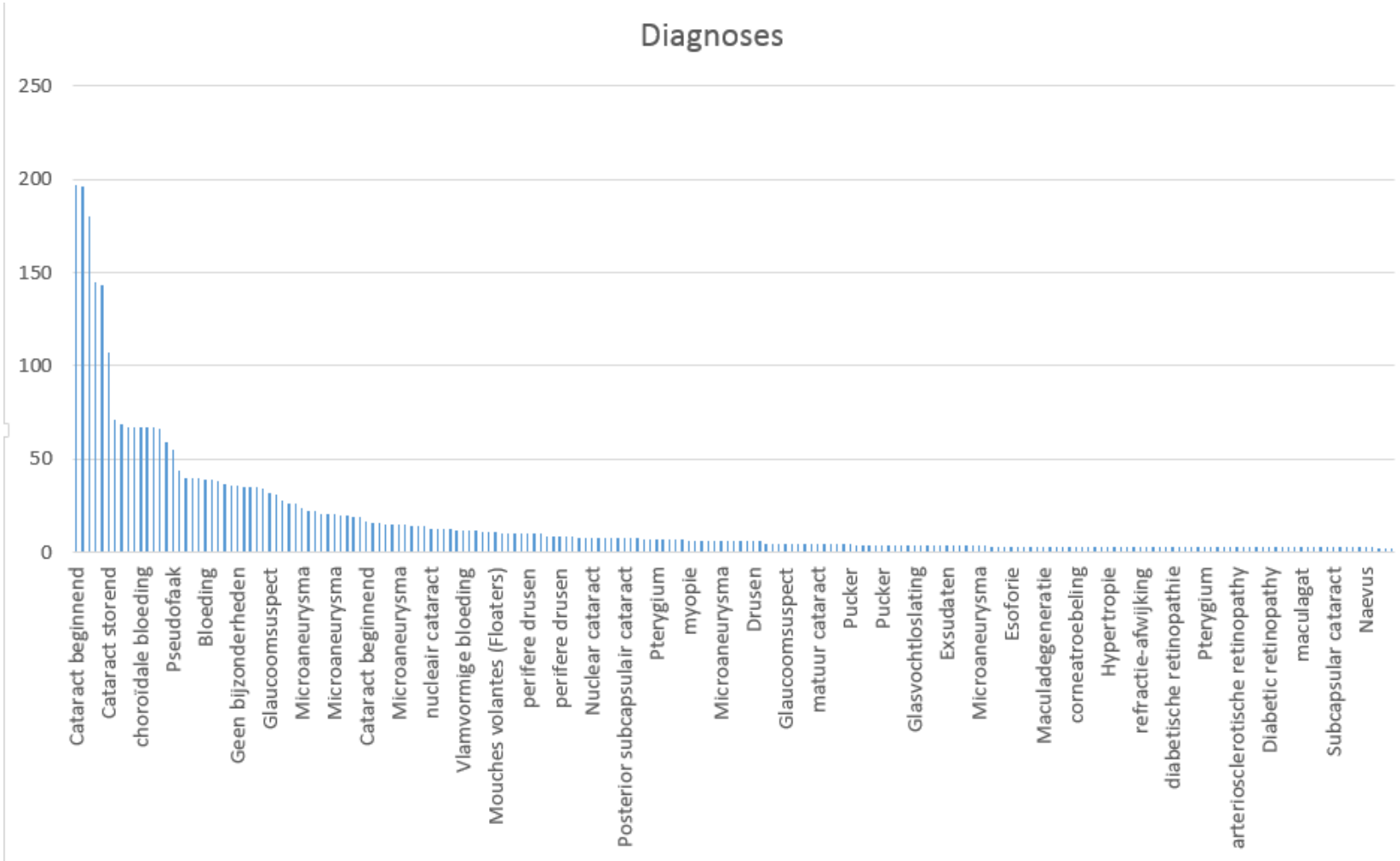
```
        @moduleId                Module waar deze concept versie onder valt
        @definitionStatusId      Id van de definitie status
        @definitionStatus        GB voorkeursterm van de definitie status
      -->
      <concept conceptId="392291006" effectiveTime="20070131" moduleId="900000000000207008"
definitionStatusId="900000000000073002" definitionStatus="Defined">
        <!--
           desc element bevat de Snomed description(s) die bij het concept horen
           @type                 soort term. fsn= fully specified name, pref=preferred for language,
           @id                   id van de description zelf.
           @count                aantal 'woorden' in de term
           @length               string lengte van de term
           @effectiveTime        Moment van opname description in release
           @moduleId             Module waar deze description versie onder valt
           @languageCode         tweeletterige taalcode, specificeert alleen taal niet 'dialect'.
           @typeId               type id als conceptId
           @caseSignificanceId   aanduiding of description hoofdlettergevoelig is

           @count en @length worden door de terminology explorer gebruikt voor het soorteren van zoekres
        -->
        <desc type="fsn" id="1466471017" count="3" length="33" effectiveTime="20030131" moduleId="900000
languageCode="en" typeId="900000000000003001" caseSignificanceId="900000000000020002">Angle-closure glaucoma
(disorder)</desc>
        <desc type="pref" id="1486271011" count="2" length="22" effectiveTime="20030131" moduleId="90000
languageCode="en" typeId="900000000000013009" caseSignificanceId="900000000000020002">Angle-closure glaucoma
        <desc type="syn" id="2621430019" count="5" length="28" effectiveTime="20060731" moduleId="900000
languageCode="en" typeId="900000000000013009" caseSignificanceId="900000000000017005">ACG - Angle closure g
        <desc type="syn" id="2647496011" count="3" length="21" effectiveTime="20070131" moduleId="900000
languageCode="en" typeId="900000000000013009" caseSignificanceId="900000000000020002">Narrow angle glaucoma
        <desc type="syn" id="2647495010" count="2" length="21" effectiveTime="20070131" moduleId="900000
languageCode="en" typeId="900000000000013009" caseSignificanceId="900000000000020002">Narrow-angle glaucoma
        <!--
           ancestors element bevat een lijst van alle ancestors van het concept.
           Is aanwezig voor supersnel subsumption testing: Is A een subtype van B?
        -->
        <ancestors>
           <!--
              id element bevat de id van de ancestor
              @distance   geeft de minimale 'afstand' tot de ancestor weer
           -->
           <id distance="1">73013002</id>
```

Feedback of Software Engineers

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

They ‘simply’ implemented it.

1st Results


Diagnoses
250
200
150
100
50
0
Cataract beginnend
Cataract storend
choroïdale bloeding
Pseudofaak
Bloeding
Geen bijzonderheden
Glaucoomsuspect
Microaneurysma
Microaneurysma
Cataract beginnend
Microaneurysma
nucleair cataract
Vlamvormige bloeding
Mouches volantes (Floaters)
perifere drusen
perifere drusen
Nuclear cataract
Posterior subcapsulair cataract
Pterygium
myopie
Microaneurysma
Drusen
Glaucoomsuspect
matuur cataract
Pucker
Pucker
Glasvochtloslating
Exsudaten
Microaneurysma
Esoforie
Maculadegeneratie
corneatroebeling
Hypertropie
refractie-afwijking
diabetische retinopathie
Pterygium
arteriosclerotische retinopathy
Diabetic retinopathy
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)]

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

Betere zorg
door betere informatie

Nictiz

Pim Volkert
Coordinator
Terminology

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