

# Connected eHealth and the role the National Data Model

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# Data

- There are three kinds of lies: lies, damned lies, and statistics.
  - Attributed to Benjamin Disraeli by Mark Twain
- A well-known lawyer, now a judge, once grouped witnesses into three classes: simple liars, damned liars, and experts. He did not mean that the expert ...
  - Nature, page 74 Nov 26, 1885
- People use statistics the way a drunk uses a lamp post — for support, not illumination
  - Vin Scully

# Topics

- What is a data model and dictionary / why have one?
- Data Dictionary in an architecture
- International Concept model
- The English Data Dictionary – strengths and weaknesses

# Operational Information Standards matter



... but for the fire  
brigade three blows  
of a whistle means  
get out of here now!

For the police three  
blows of a whistle  
means come here  
quickly ...







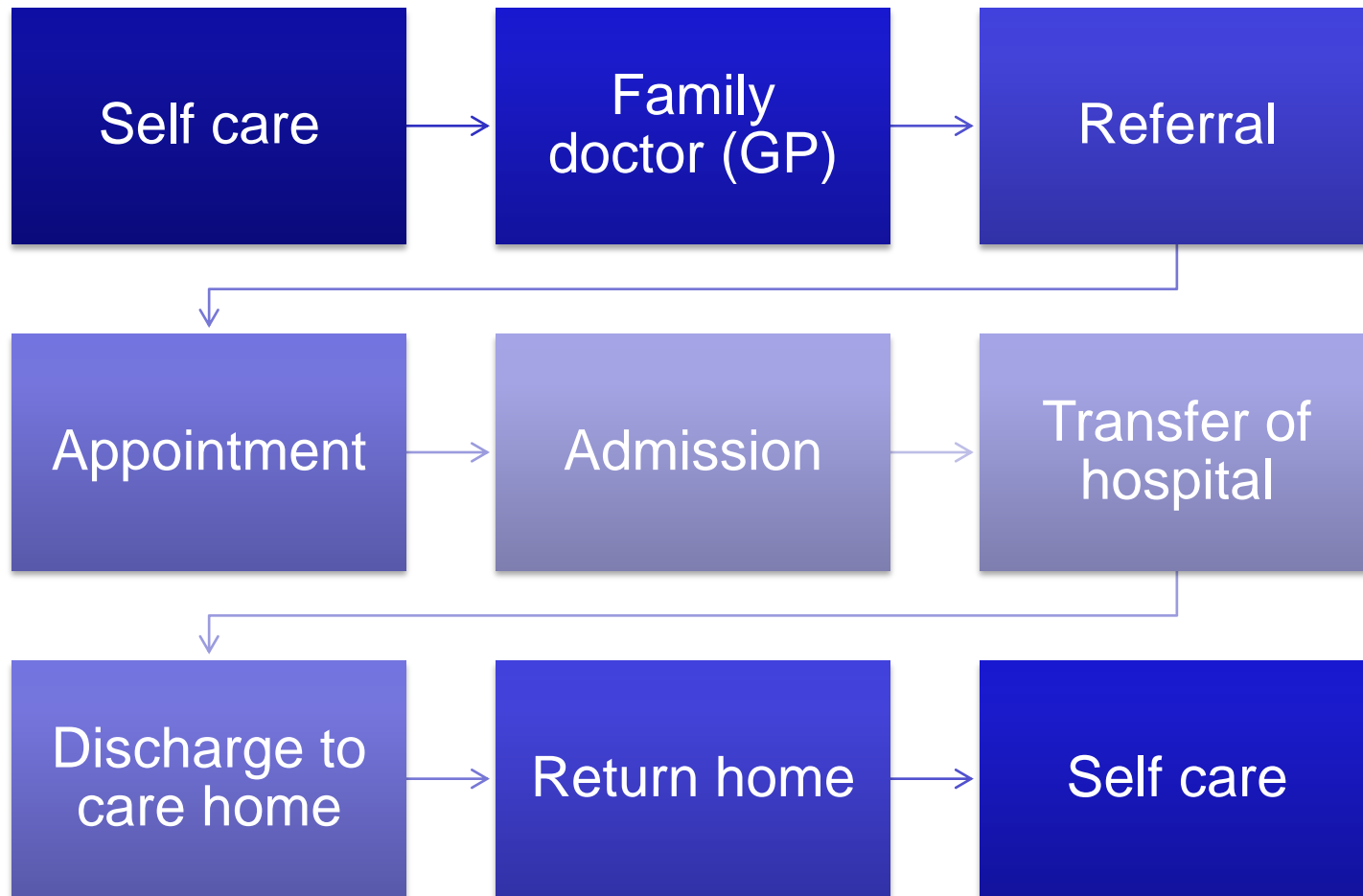
Bogies exchange operation in [Ussuriisk](#) (near [Vladivostok](#)) at the [Chinese](#)—[Russian](#) border. <http://commons.wikimedia.org/wiki/User:Schutz>

# Agreeing a standard

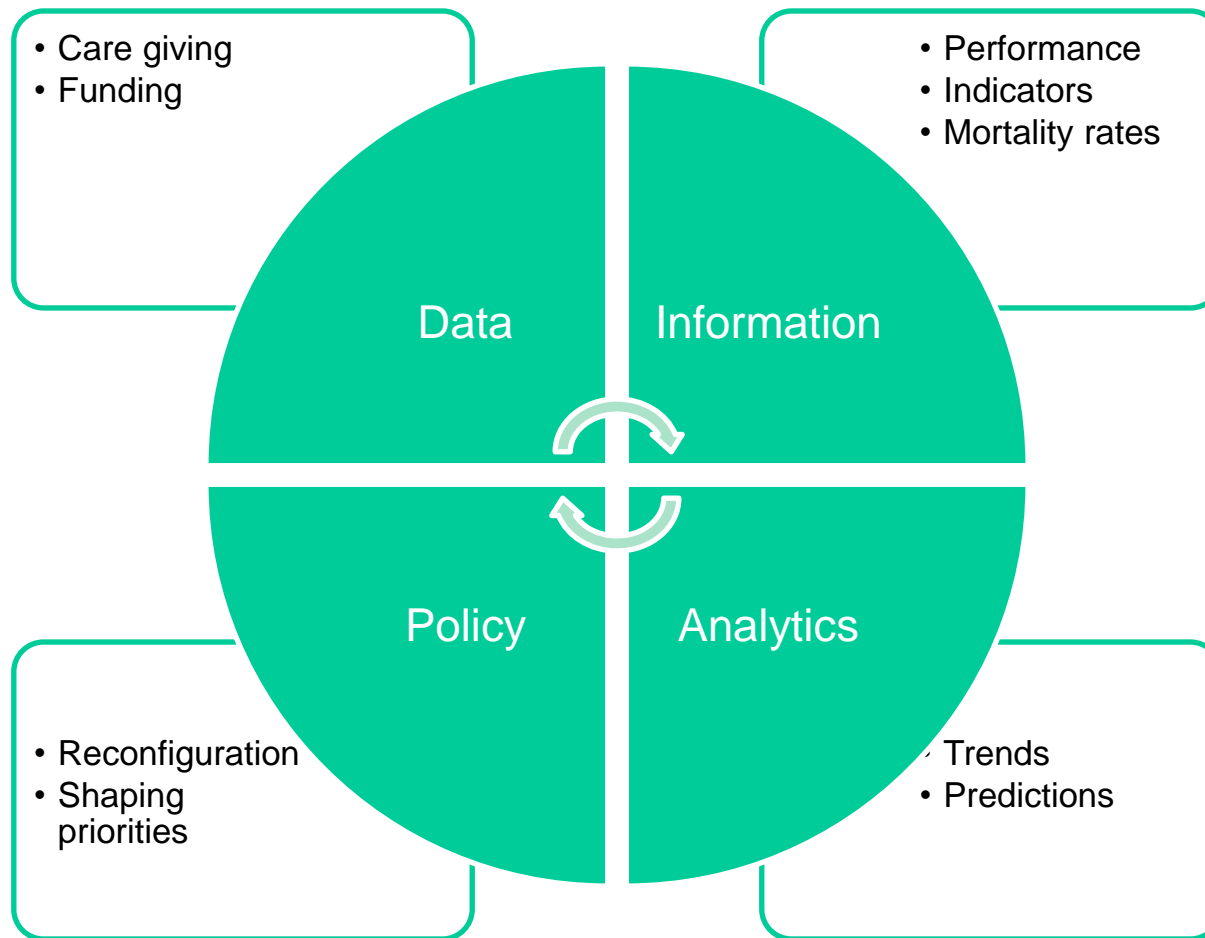
- Ireland's first railway, the Dublin and Kingstown, was built to 4 ft 8 ½ in (1,435 mm) (later known as standard gauge). The Ulster Railway (UR), taking the Irish Railway Commission's advice, used 6 ft 2 in (1,880 mm). The Dublin and Drogheda Railway began building its new line to 5 ft 2 in (1,575 mm) on the grounds of lower costs. **Bespoke** Following complaints from the UR the Board of Trade investigated the matter, and in 1843 recommended the use of 5 ft 3 in (1,600 mm) and that compensation be paid to the UR for the costs incurred in changing to the new gauge. **Implement**

- Source: Wikipedia

# Sharing data for care



# Sharing data for management





# What is a Data Model and Dictionary

## Dictionary

- a book that lists the words of a language in alphabetical order and gives their meaning, or that gives the equivalent words in a different language.

## Data dictionary

- a set of information describing the
- **contents**,
- **format**, and
- **structure** of a database
- and the **relationship** between its elements,
- used to control access to and manipulation of the database.

# Why bother with a data model and dictionary?

We can agree data  
when we  
implement systems

It must cost an awful  
lot to maintain a  
central publication

We can use  
vendors  
configurations –  
they have the  
experience

Our system may  
not be the  
same as [the]  
data dictionary

# Data Dictionary

## Content

Vocabularies

Terminologies

Classifications

## Format

Data types

## Structure

XML

Class models

Hierarchies

Headings

## Relationships

Context

Meaning

# Content

The SMOKING STATUS  
of the PERSON at the  
time the TOBACCO  
USAGE is recorded.

National Codes:

- 1 Current smoker
- 2 Ex-smoker
- 3 Non-smoker - history  
unknown
- 4 Never smoked
- Z Not Stated

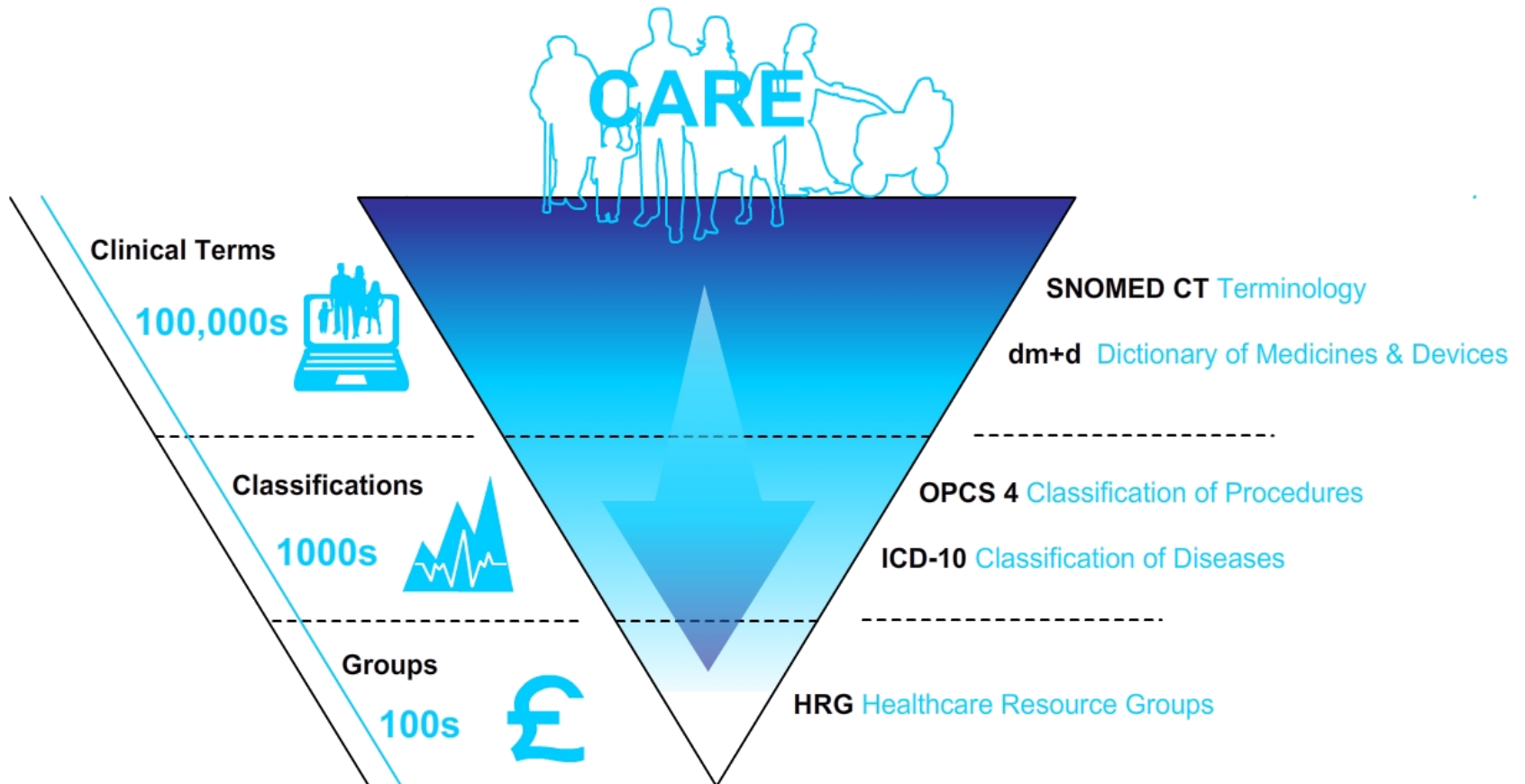


History of smoking

- 0 Never smoked
- 1 Current smoker
- 2 Former smoker
- 9 Not known



# Clinical Information Architecture





# SNOMED CT



- Around 400,000 clinical concepts, with around 2,000,000 phrases
- Two licencing models
  - 19 member nations, priced on Gross National Product of the country
  - Affiliate, allowing use outside member nations
- Includes the Read codes used in many GP systems
- Allows new ideas to be represented by creating expressions

# Format for computers

- Simple data types
  - Integer
  - Binary
  - Date / time
  - String
- Physical form
  - <XML>
  - |HL^7|V2
- Complex data types
  - Measurement with unit
  - Human time (each Wednesday except half terms, Winter)
  - Code + value + unit
- Character sets
  - ASCII
  - UTF-8

# Format for people

## DATE OF BIRTH (PATIENT IDENTIFICATION)

Related DDCN/DSCN/ISN

Description	Where Used
Format/Length:	an11 (DD-Mmm-CCYY)
HES Item:	
National Codes:	
Default Codes:	

### Notes:

**DATE OF BIRTH (PATIENT IDENTIFICATION)** is the date of birth of the **PATIENT** as displayed in human readable forms, for example **PATIENT** identity bands. The date format is displayed in accordance with the [NHS Common User Interface Standard - Date Display \(ISB 1503\)](#).

For neonates and newborn babies, the data element **TIME OF BIRTH (PATIENT IDENTIFICATION)** must be recorded.

# English Data Dictionary



## Strengths

- Widely used
  - 23,000 people per month
- Modelled as one resource
- Freely available
- Heart of hospital funding rules
- Core of performance management

## Weaknesses

- Poor links to clinical care
- Value sets not machine readable
- No queries
- Not available off-line
- Not linked to other data dictionaries internationally

# English Data Dictionary



## Opportunities

- Successor to the current version
- Focused on recording care, not collecting statistics
- Based on International System of Concepts
- Alignment with other nations

## Threats

- Without an overhaul it will slowly become discredited



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**A Clinician's Guide to Record Standards – Part 1:**  
Why standardise the structure  
and content of medical records?

Information Governance

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**A Clinician's Guide to Record Standards – Part 2:**  
Standards for the structure and content  
of medical records and communications  
when patients are admitted to hospital

Information Governance

Headings/sub-headings	Definition/illustrative description of the type of clinical information to be recorded under each heading
<b>Social history</b>	
- Lifestyle	The record of lifestyle choices made by the patient which are pertinent to his or her health or social care. Example the record of the patient's current and previous use of tobacco products, alcohol, recreational drugs, pets, hobbies and sexual habits, menstrual and coital history.
- Social and personal circumstances	The record of a patient's social background, network and personal circumstances, eg occupational history, housing and religious, ethnic and spiritual needs.
- Services and carers	The description of services and carers provided for the patient to support their health and social wellbeing.
<b>Family history</b>	The record of significant illness in family relations deemed to be significant to the care or health of the patient, including mental illness and suicide.
<b>Systematic enquiry</b>	The record of clinical information gathered in response to questions to the patient about general symptoms from various physiological systems, including food intake (increasing/decreasing), weight change, swallowing difficulties. Mood/anxiety etc.
<b>Patient's concerns, expectations and wishes</b>	The record of the patient's comments related to their perceptions of their symptoms, their wishes and goals related to their health and their perceptions of their anticipated treatment (which may influence treatment). This could be the carer giving information if the patient is not competent. Also the extent to which the patient wants clinical information to be shared with relatives and others.
<b>Observations and findings</b>	Any clinical observation or finding made by the clerking doctor, with or without specific clinical examination.

- General appearance	The record of a doctor's 'end of the bed' assessment including general clinical examination findings, eg clubbing, anaemia, jaundice, obese/malnourished/cachectic, height, weight etc.
- Structured scales	eg Glasgow Coma Scale, ADL scales such as Barthel, nutrition screening scale etc.
- Vital signs	The record of essential physiological measurements, eg respiration rate, O <sub>2</sub> saturation, heart rate, blood pressure, temperature and weight, Early Warning Score (EWS), including the time and date they were obtained.
- Mental state	eg Depression, anxiety, confusion, delirium.
- Cardiovascular system	The record of findings from the cardiovascular system examination.
- Respiratory system	The record of findings from the respiratory system examination.
- Abdomen	The record of findings from the abdominal examination.
- Genito-urinary	The record of findings from the genito-urinary examination.
- Nervous system	The record of findings from the nervous system examination.
- Musculoskeletal system	The record of findings from the musculoskeletal system examination.
- Skin	The record of findings from examination of the skin.
<b>Problem list and/or differential diagnosis</b>	Summary of problems that require investigation or treatment.
<b>Relevant risk factors</b>	Factors that have been shown to be associated with the development of a medical condition being considered as a diagnosis/ differential diagnosis. Thrombo-prophylaxis.
<b>Discharge planning</b>	Information in relation to discharge planning should be entered here, starting at the time of admission.

# Summary

- Standards are critical to a joined up healthcare system
- A data dictionary holds **contents, format, structure and relationships**
- A data dictionary enables letters, referrals, clinical records, queries, classifications, datasets and policy / management decisions to be compatible with the healthcare system
- SNOMED CT is the only suitable terminology and an essential ingredient





31 October 921

S: Sore throat – 4 days  
temperature, taking fluids  
taking paracetamol. No better.

O: Looks well, enlarged glands,  
pusy tonsils

A: Follicular tonsilitis

P: Penicillin V 250mg 2qds 40

# Structure



# Composition

31 October 921

S: Sore throat – 4 days  
temperature, taking fluids  
taking paracetamol. No better.

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# Composition Entry

31 October 921

S: Sore throat – 4 days

temperature, taking fluids

taking paracetamol. No better.

O: Looks well, enlarged glands,

pussy tonsils, Temp 38.1

A: Follicular tonsilitis

P: Penicillin V 250mg 2qds 40

# Composition Entry

Element

# Diagnoses

e.g., “Severe osteoarthritis of the left knee ”

**GP**

**Prob/Dx Entry**

Prob/Dx: Osteoarthritis

Severity:

- ☐ Mild
- ☐ Moderate
- ☒ Severe

Location: Knee Joint

Side:

- ☒ Left
- ☐ Right

OK Cancel

**Polyclinic**

**Diagnosis Entry**

Diagnosis: Osteoarthritis of the left knee

Degree:

- Severe
- Minimal
- Mild
- Moderate
- Severe
- Very severe

OK Cancel

**RH**

**Problem/Diagnosis Entry**

Problem/Diagnosis: Severe Osteoarthritis of the left knee

OK Cancel

Heterogeneity in naming, syntax, representation, and structure

# Diagnoses

e.g., “Suspected cervical cancer”

**GP**

**Prob/Dx Entry**

Prob/Dx

Cervical cancer

Status

☐ Absent

☒ Suspected

☐ Confirmed

OK

Cancel

**Polyclinic**

**Diagnosis Entry**

Diagnosis

Cancer

Site

Cervix

Status

☒ Suspected

☐ Confirmed

OK

Cancel

**RH**

**Problem/Diagnosis Entry**

Problem/Diagnosis

Suspected CA cervix

OK

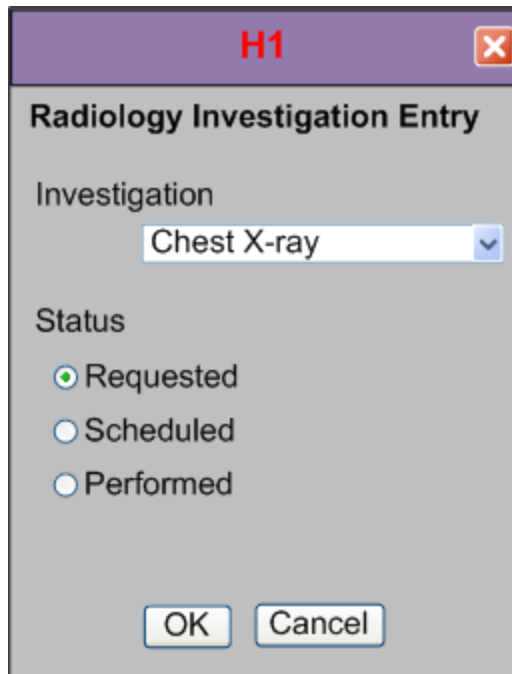
Cancel

Heterogeneity in naming, syntax, representation, and structure



# Procedure

e.g., “X-ray of the chest requested”



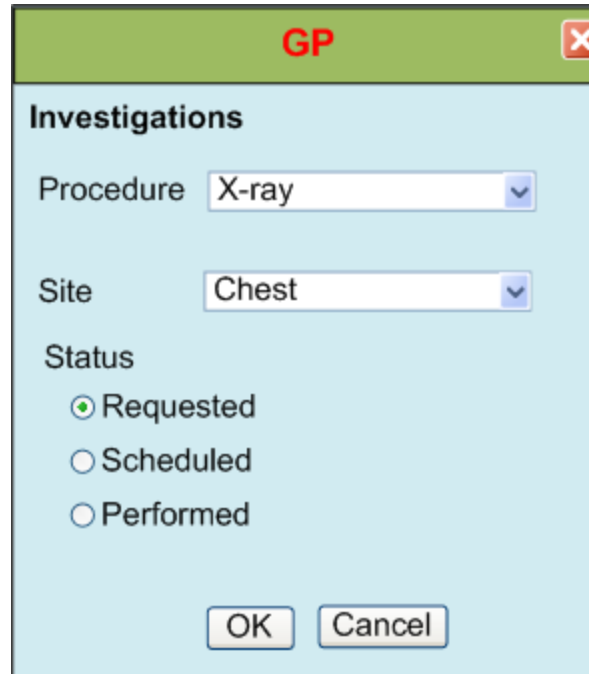
**H1** [X]

**Radiology Investigation Entry**

Investigation  
Chest X-ray [v]

Status  
☒ Requested  
☐ Scheduled  
☐ Performed

OK Cancel



**GP** [X]

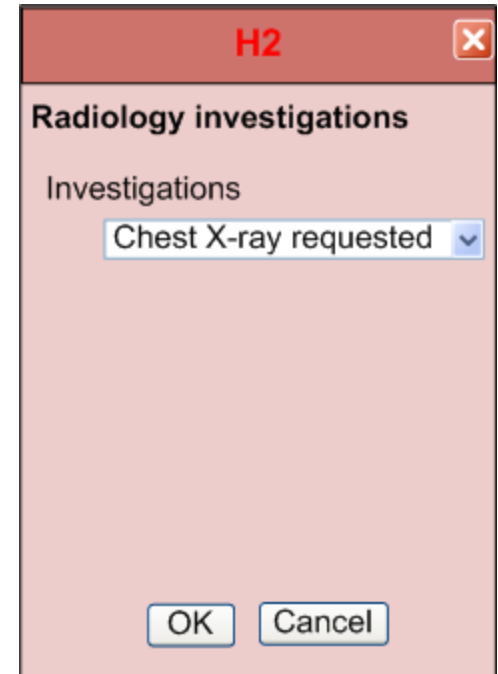
**Investigations**

Procedure X-ray [v]

Site Chest [v]

Status  
☒ Requested  
☐ Scheduled  
☐ Performed

OK Cancel



**H2** [X]

**Radiology investigations**

Investigations  
Chest X-ray requested [v]

OK Cancel

Heterogeneity in naming, syntax, representation, and structure

# Medications

e.g., “**Morphine 30 mg + Haloperidol 5 mg + Buscopan 80 mg Injection Solution (10 ml syringe)**”

**H1**

Medications Order

Name

Ingredient	Strength
Morphine	30 mg
Haloperidol	5 mg
Buscopan	80 mg

Form

Container size

Container type

**GP**

Prescription

Ingredients

Dosage form

Size

Container

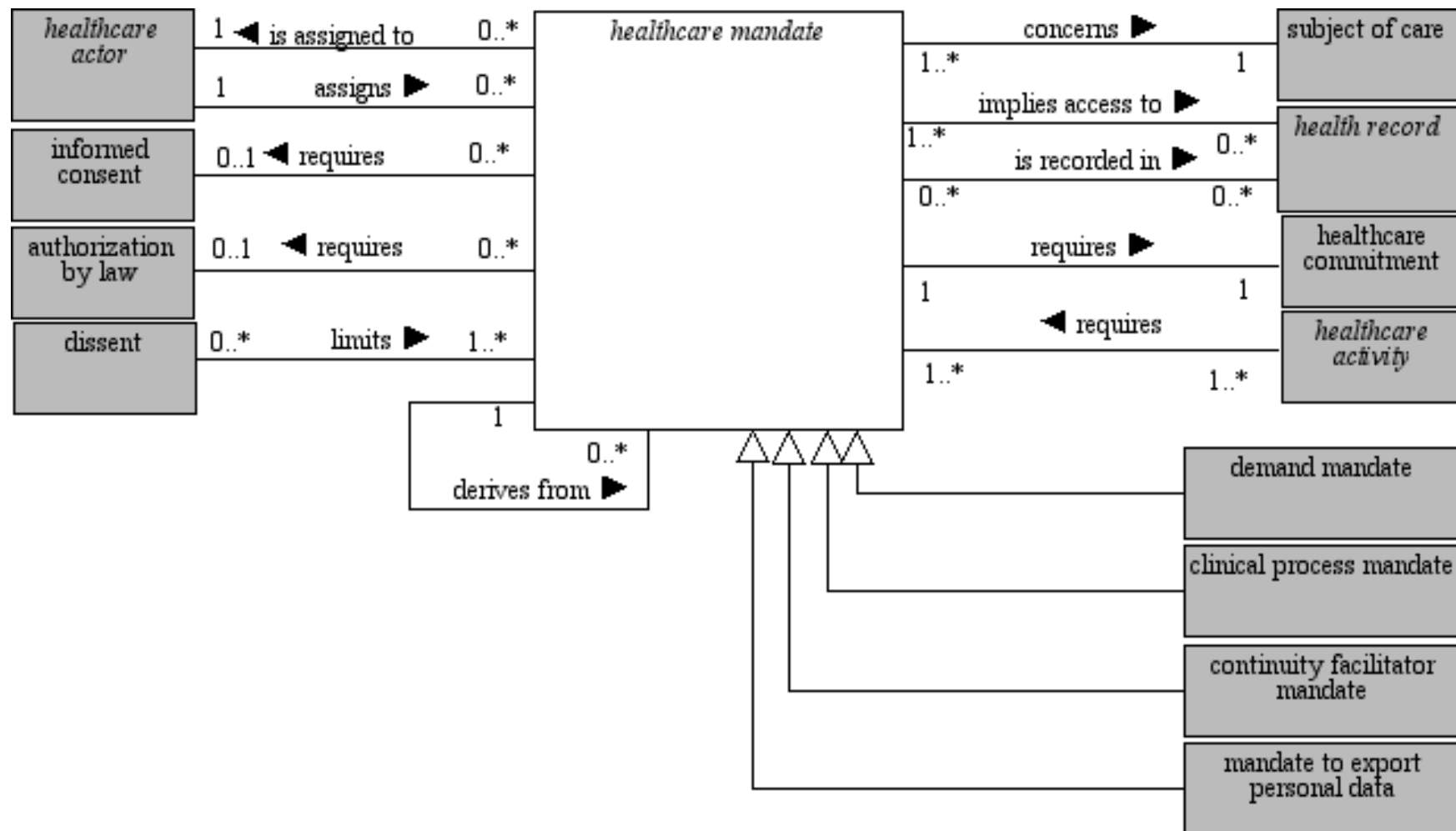
**RH**

Medication Order Entry

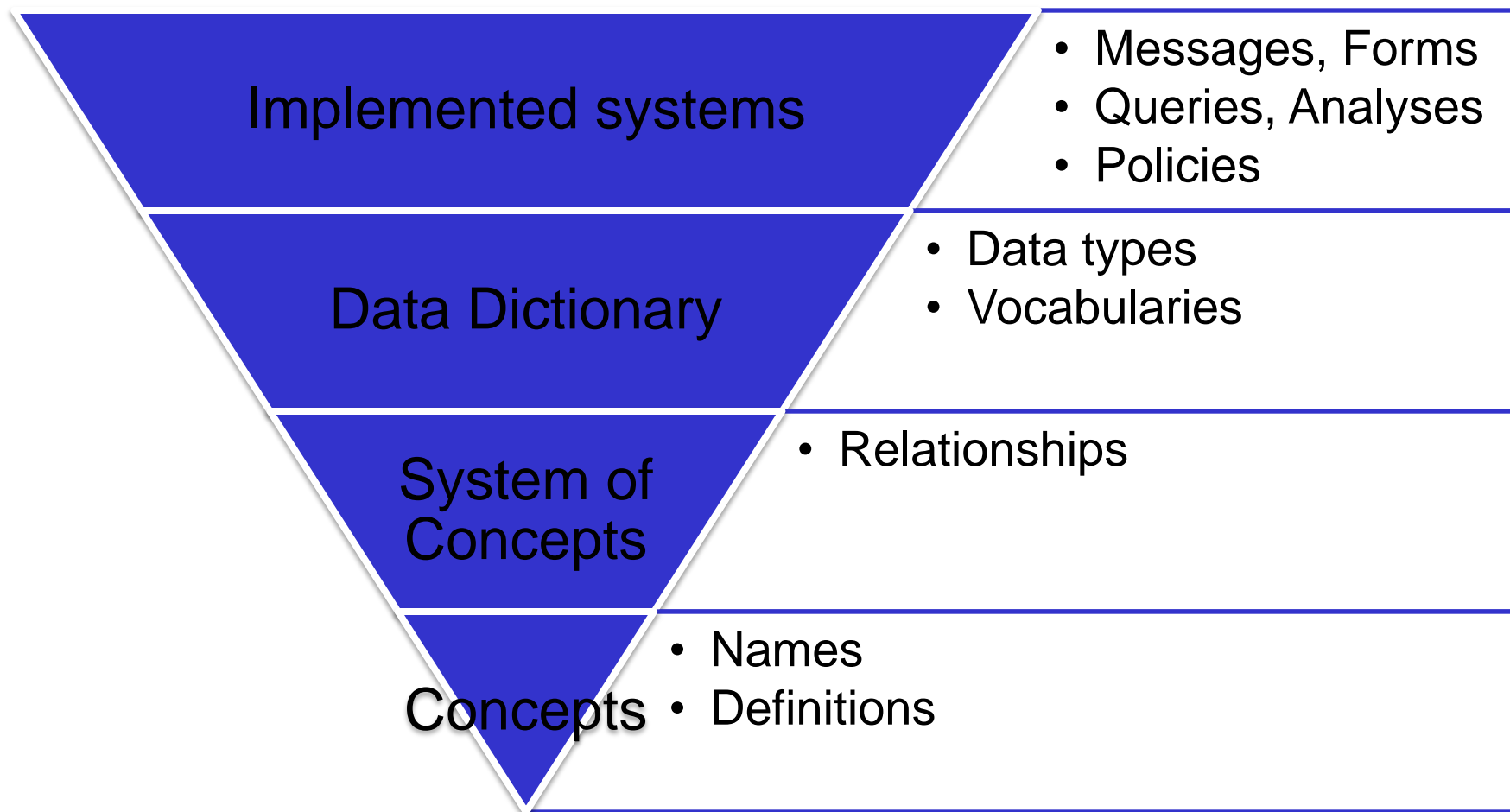
Container

Heterogeneity in naming, syntax, representation, and structure

# Relationships



# DATA DICTIONARY IN AN ARCHITECTURE



# Concepts

## healthcare professional

Synonym: care professional

Definition: healthcare personnel having a healthcare professional entitlement recognized in a given jurisdiction

EXAMPLES GP, medical consultant, therapist, dentist, nurse, radiographer etc.

## Healthcare professional entitlement

Synonym: care professional entitlement

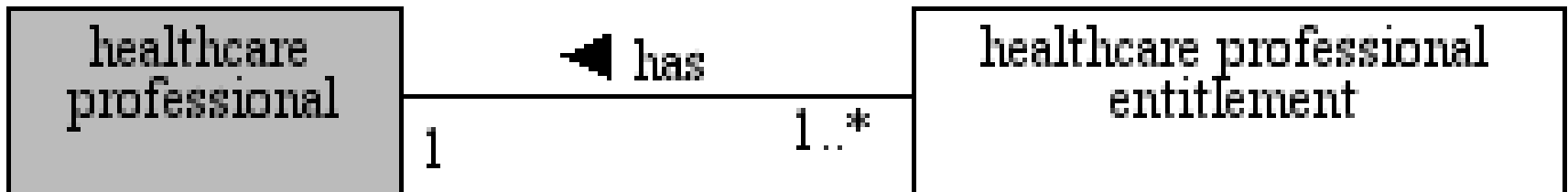
Definition: registered authorization given to a person in order to allow the person to have or perform specific roles in healthcare

NOTE 1 Entitlement is usually backed by evidence of having received, or continuously receiving, the necessary qualification, the relevant education and training.

NOTE 2 The official entitlement of a healthcare professional forms the foundation for his/her official duties and rights.

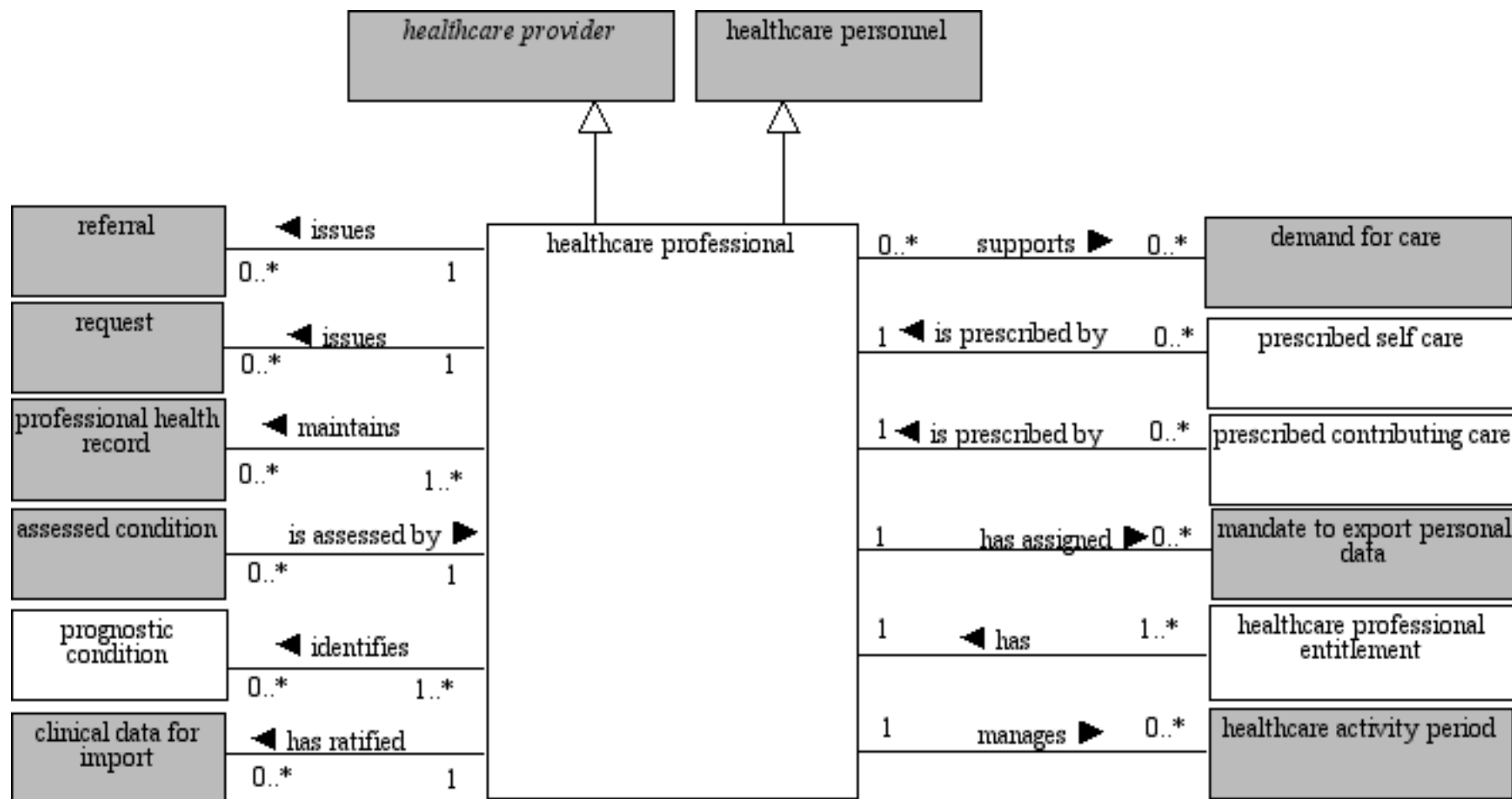
EXAMPLES Diploma, professional registration (e.g. registered nurse).

# Relationships





# Relationships



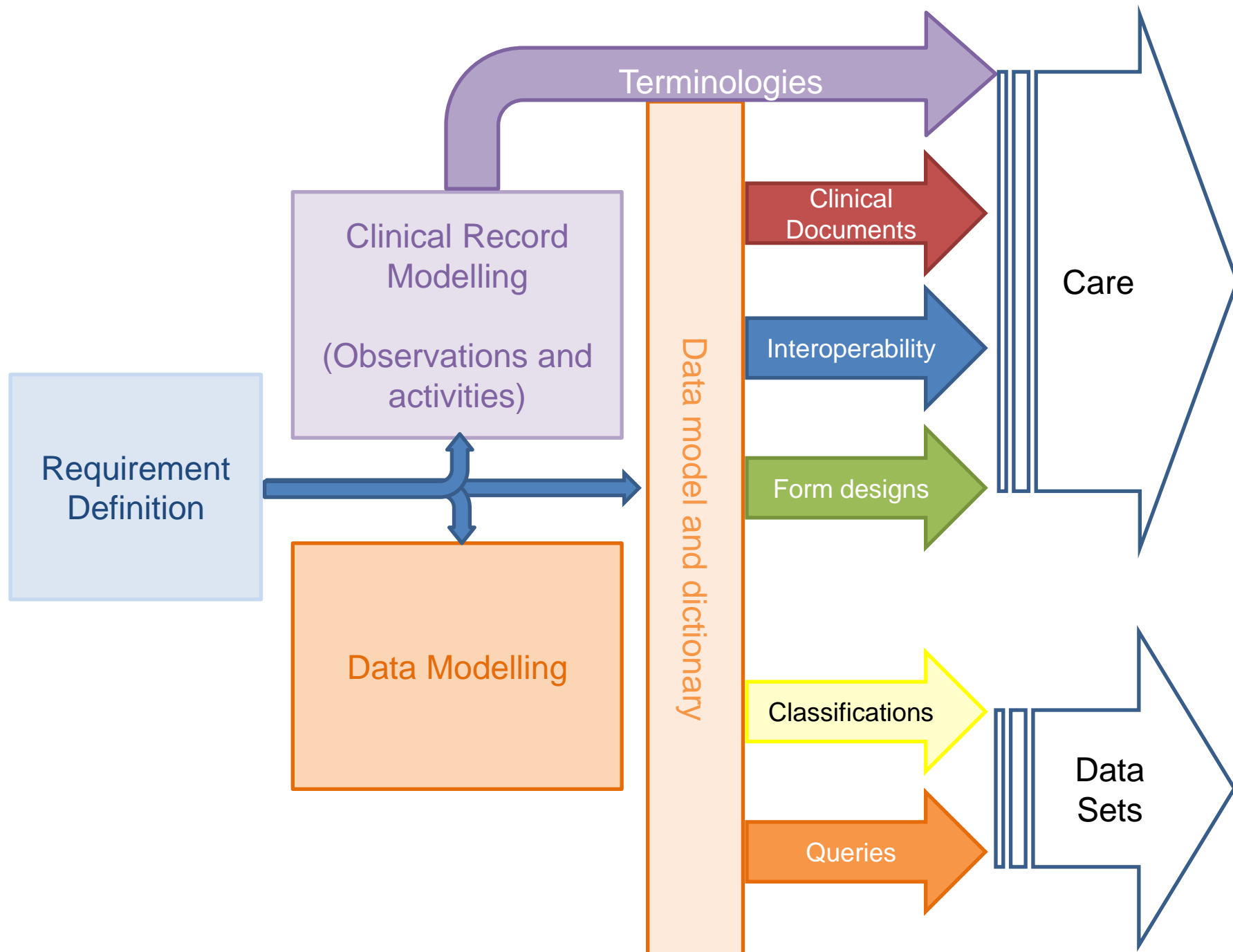
# Data

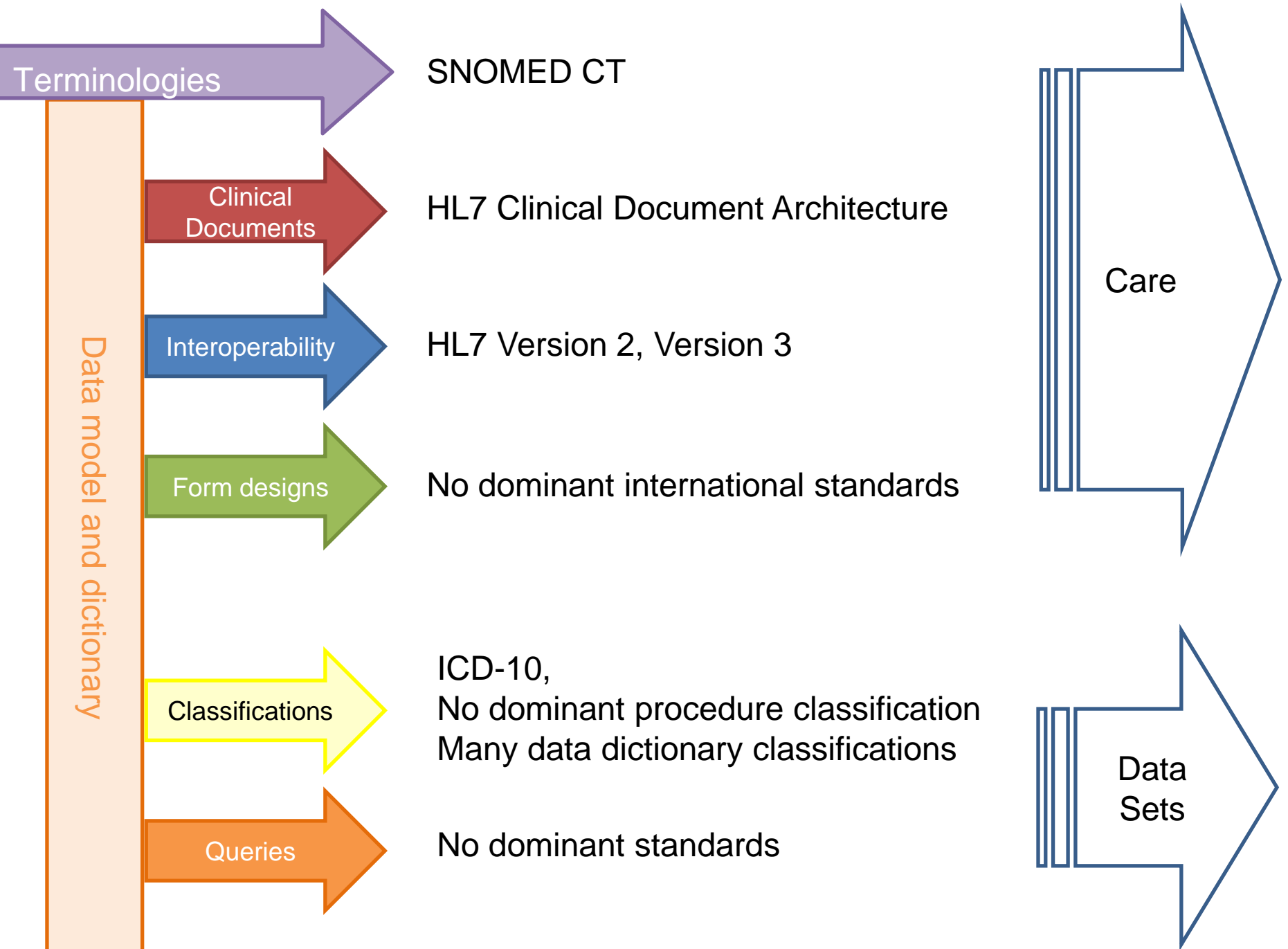
## Values

- Numbers
- Text
  - Names, narrative
- Dates
- Identifiers

## Vocabularies

- Units
  - E.g. UCUM
- Terms / phrases
  - E.g. SNOMED CT
- Context





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# Datasets

Data Set: Diagnostic Imaging Data Set - Windows Internet Explorer provided by NHS Connecting for Health


http://www.datadictionary.nhs.uk/data\_dictionary/messages/clinical\_data\_sets/data\_sets/diagnostic\_i... webpilot

File Edit View Favorites Tools Help

★ Favorites ★ Redmine National Rail Enquiries - Lee... (DH) Overseas subsistence rates... (DH) Delphi Homepage DMDS Home LU CMS

Data Set: Diagnostic Ima... WebPilot - Harness the power...

Hide Navigation | Contact Us | Help | FAQs NHS Data Model and Dictionary Service

 **NHS**  
Connecting for Health

Main Menu > Clinical Data Sets Menu >  Search

**Clinical Data Sets Menu** **Diagnostic Imaging Data Set** **Related DDCN/DSCN/ISN**

**Message Documentation** Diagnostic Imaging Data Set Overview

Cancer Registration  
Child and Adolescent Mental Health  
Children and Young Peoples Health  
Chlamydia Testing Activity  
Community Information  
Diabetes (Summary Core)  
Diagnostic Imaging  
Genitourinary Medicine Clinic Activity  
Improving Access to Psychological Therapies  
Maternity  
Mental Health (V4-0)  
National Cancer  
National Cancer Waiting Times Monitoring  
National Joint Registry  
National Renal  
NHS Health Checks  
Radiotherapy  
Sexual and Reproductive Health Activity  
Systemic Anti-Cancer Therapy

The Mandatory, Required or Optional (M/R) column indicates the recommendation for the inclusion of data.

- M = Mandatory: this data element is mandatory and the technical process (e.g. submission of the data set, production of output etc) cannot be completed without this data element being present
- R = Required: NHS business processes cannot be delivered without this data element.

**PERSONAL AND DEMOGRAPHIC**

To carry personal and demographic details. One occurrence of this group is required. Note: at least one of these data items must be present.

M/R	Data Set Data Elements
R	NHS NUMBER
R	NHS NUMBER STATUS INDICATOR CODE
R	PERSON BIRTH DATE
R	ETHNIC CATEGORY
R	PERSON GENDER CODE CURRENT
R	POSTCODE OF USUAL ADDRESS
R	GENERAL MEDICAL PRACTICE CODE (PATIENT REGISTRATION)

**REFERRALS**

**IMAGING CODE (SNOMED-CT)**  
Related DDCN/DSCN/ISN

Description	Where Used	Attribute
Format/Length: max n18 HES Item: National Codes: Default Codes:		

**Notes:**  
IMAGING CODE (SNOMED-CT) is the same as attribute CLINICAL CLASSIFICATION CODE.  
IMAGING CODE (SNOMED-CT) is the SNOMED CT concept ID which is used to identify the Diagnostic Imaging test.  
The SNOMED CT Subset:

- original ID is 611000000135
- name is 'UK Diagnostic Imaging Procedure Concepts'.

**This data element is also known by these names:**

Context	Alias
snomedctsubsetid	611000000135
snomedctsubsetname	UK Diagnostic Imaging Procedure Concepts
plural	IMAGING CODES (SNOMED-CT)

Internet 100%