Connected eHealth and the role the National Data Model

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Head of Data Standards, NHS in England

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

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Agreeing a standard

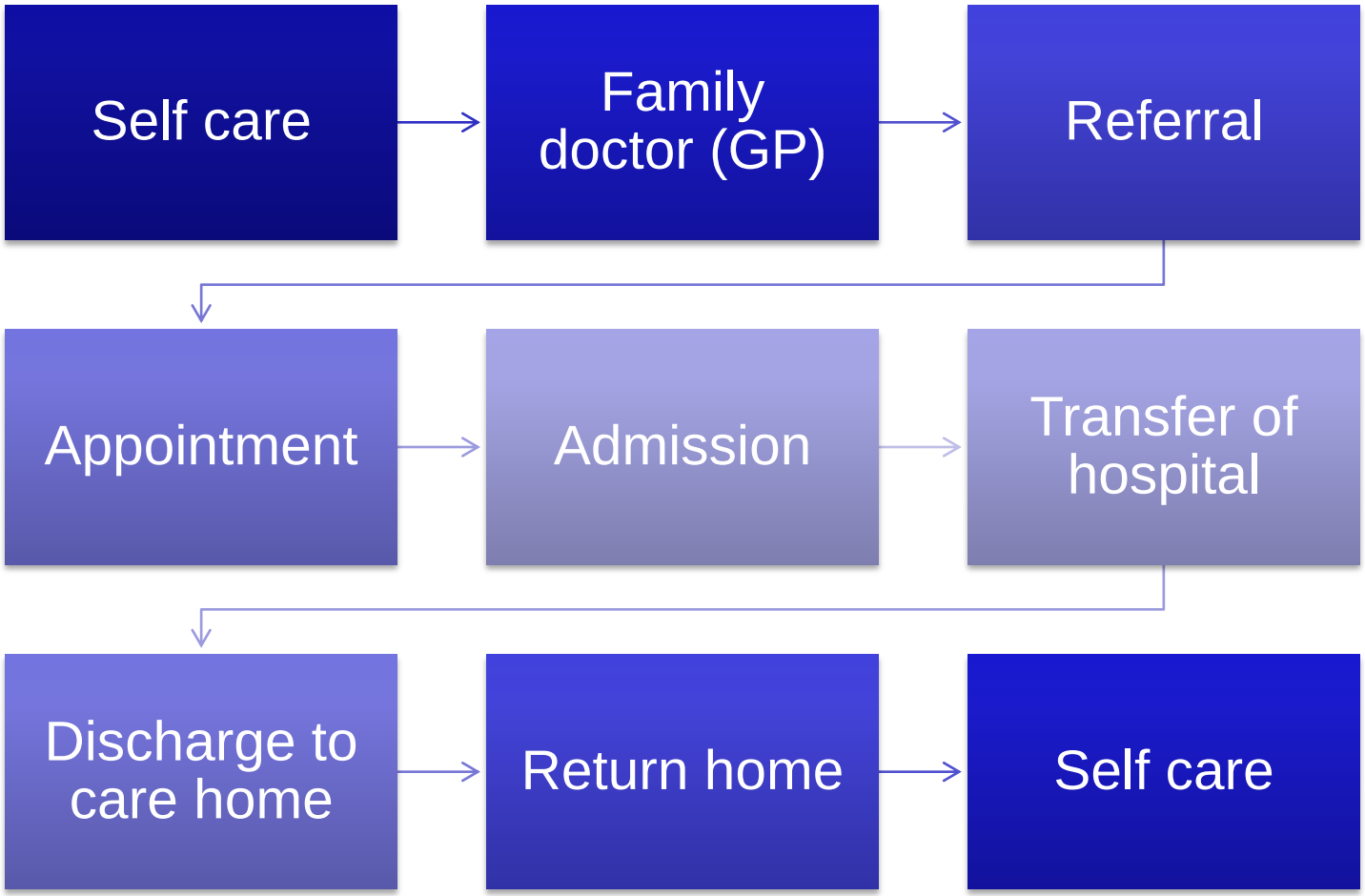
- Ireland's first railway, the Dublin and Kingstown, was built to 4 ft 8 ½ in (1,435 mm) (later known as standard gauge). The Ulster Railway (UR), taking the Irish Railway Commission's advice, used 6 ft 2 in (1,880 mm). The Dublin and Drogheda Railway began building its new line to 5 ft 2 in (1,575 mm) on the grounds of lower costs. 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.
- Source: Wikipedia

Bespoke

Standardise

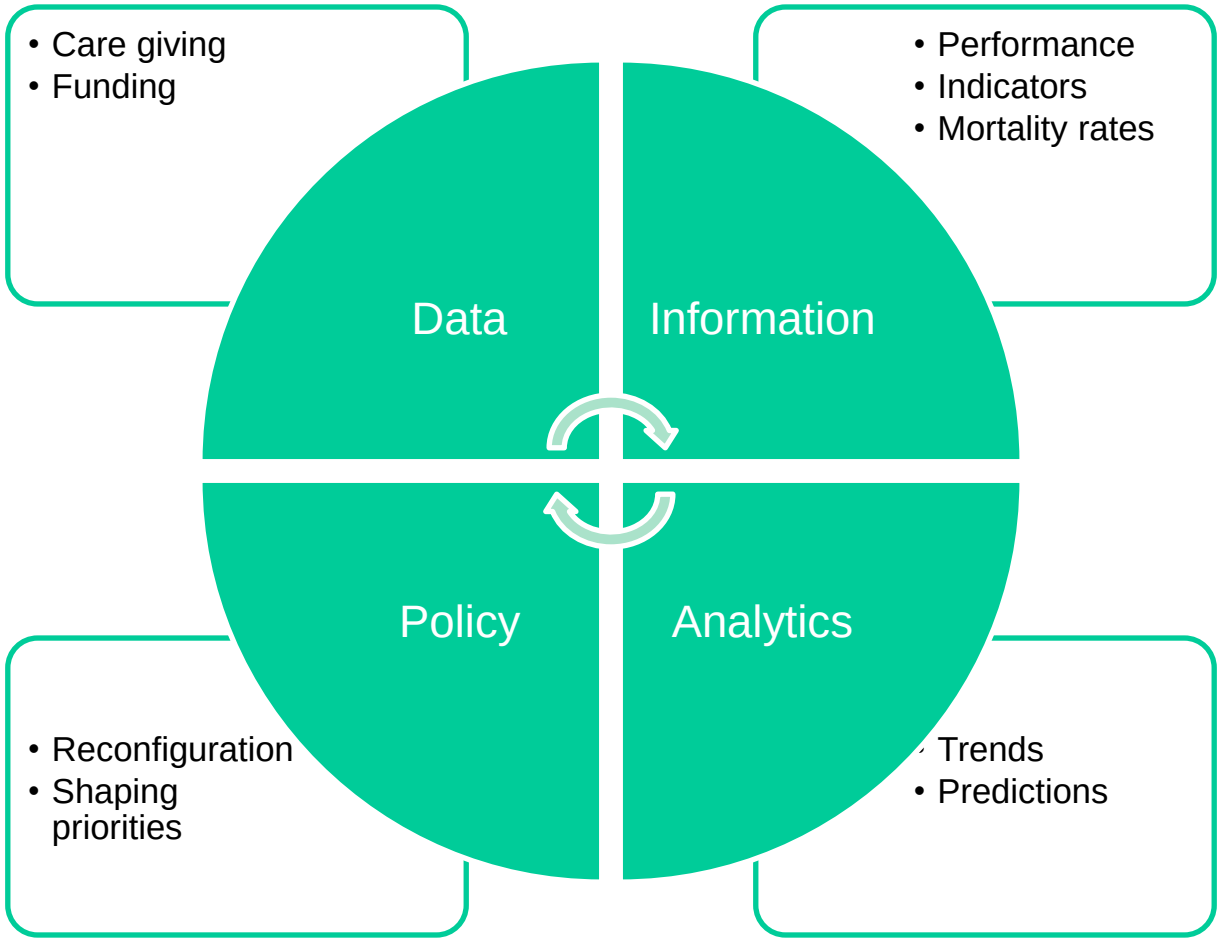
Implement

Sharing data for care



Sharing data for management

Department of Health



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.

Source: oxforddictionaries.com

Why bother with a data model and dictionary?

Department of Health

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

Department of Health

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

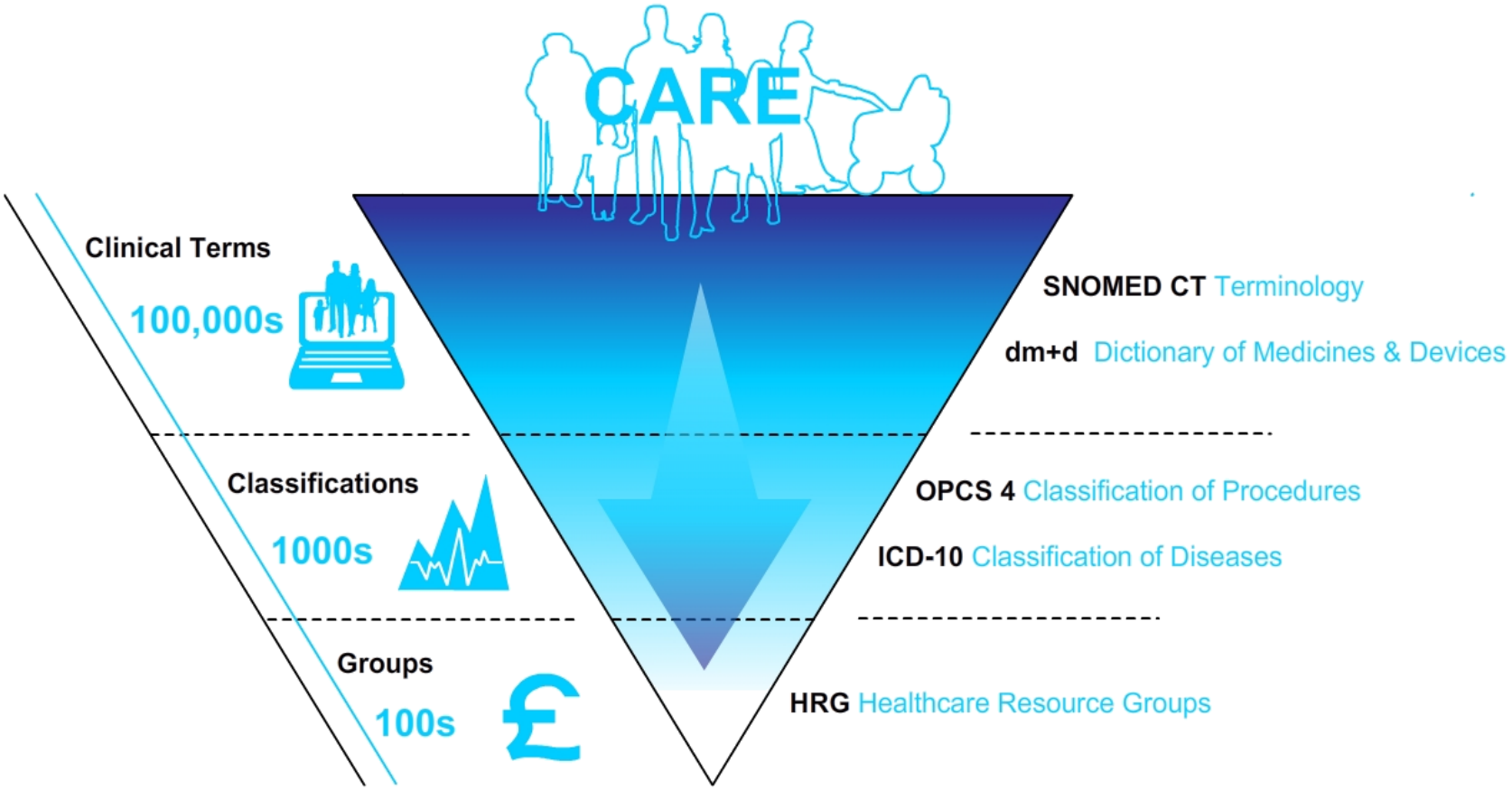
0 Never smoked

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

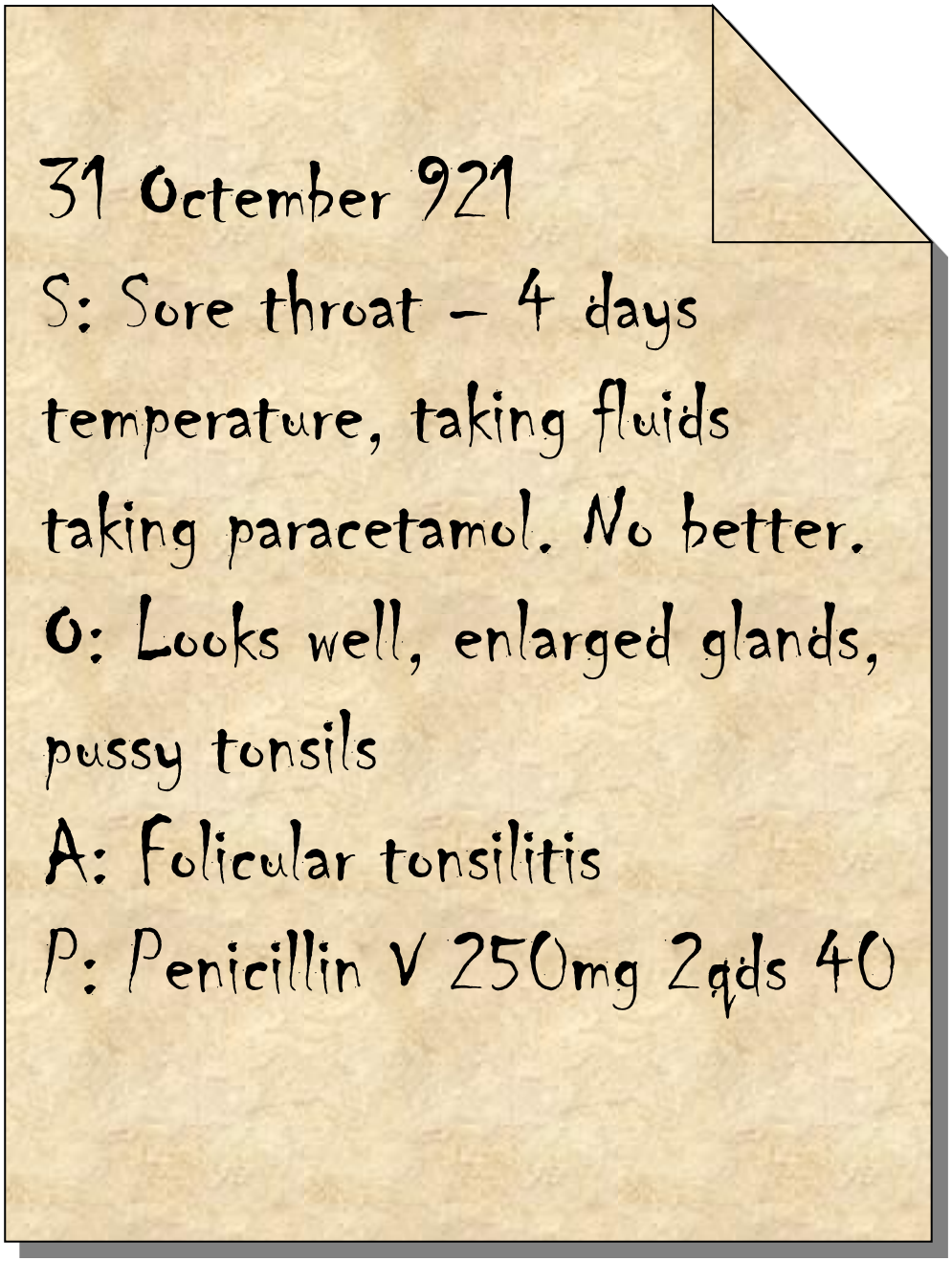
2008 documentation available from RCP and AoMRC websites

Headings/sub-headings	Definition/illustrative description of the type of clinical information to be recorded under each heading
Social history	
- 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.
Family history	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.
Systematic enquiry	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.
Patient's concerns, expectations and wishes	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.
Observations and findings	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, 02 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.
Problem list and/or differential diagnosis	Summary of problems that require investigation or treatment.
Relevant risk factors	Factors that have been shown to be associated with the development of a medical condition being considered as a diagnosis/ differential diagnosis. Thrombo-prophylaxis.
Discharge planning	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

DH Department of Health



DH Department of Health

Structure

Composition

31 October 921

S: Sore throat – 4 days

temperature, taking fluids

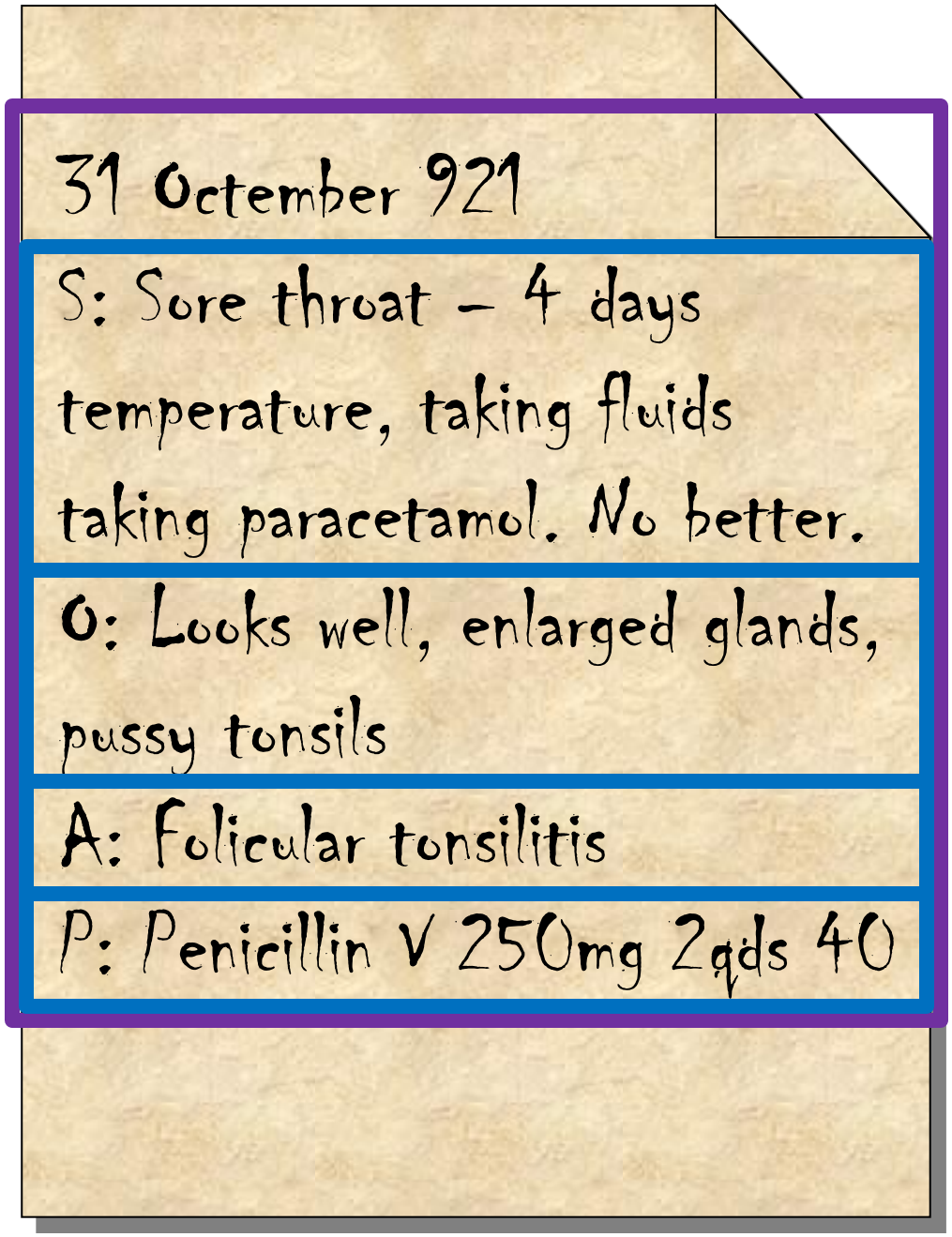
taking paracetamol. No better.

O: Looks well, enlarged glands,

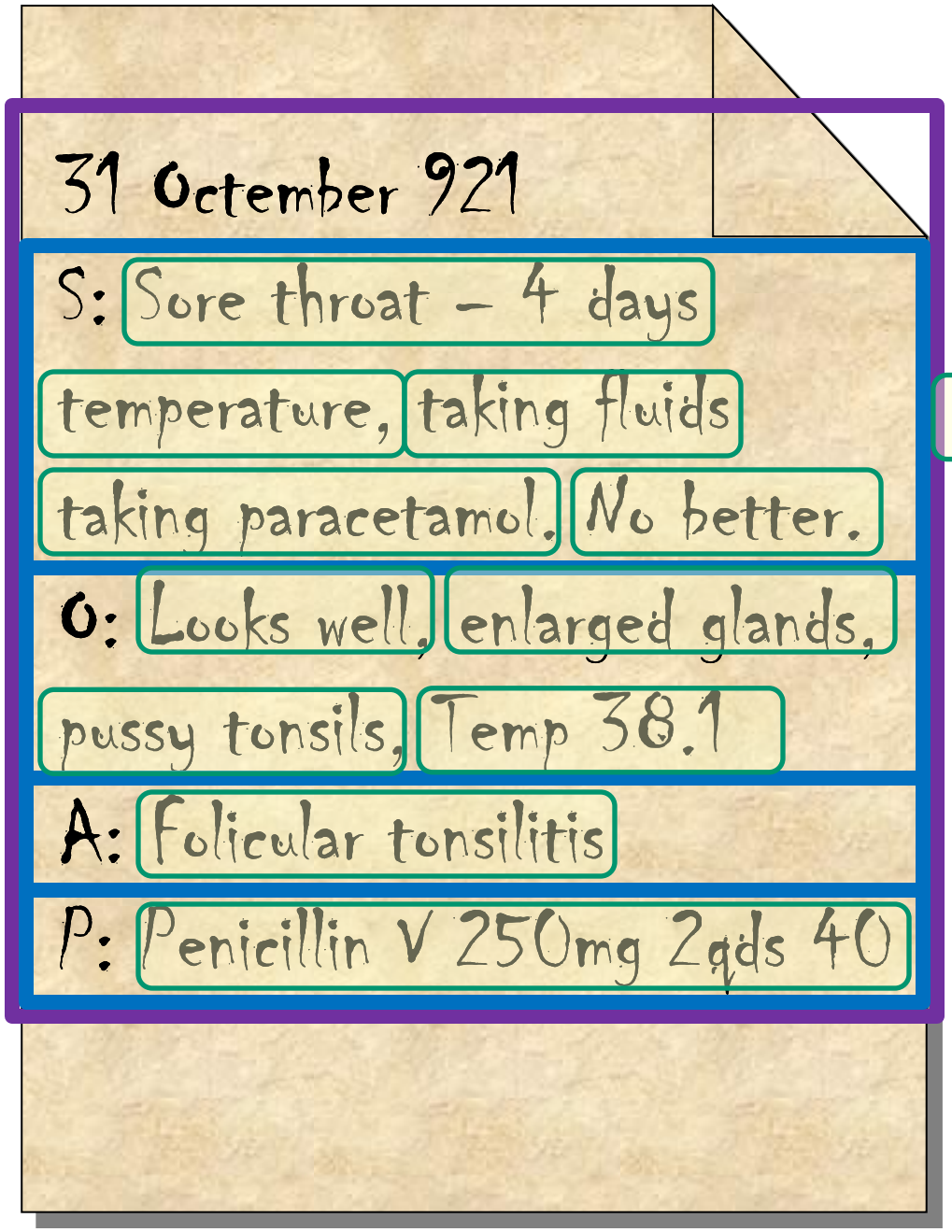
pussy tonsils

A: Folicular tonsilitis

P: Penicillin V 250mg 2qds 40



Composition Entry



DH Department of Health

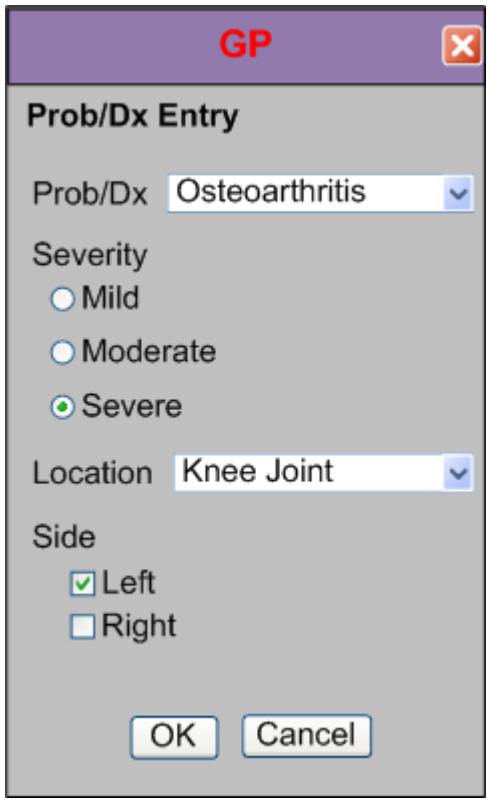
Composition

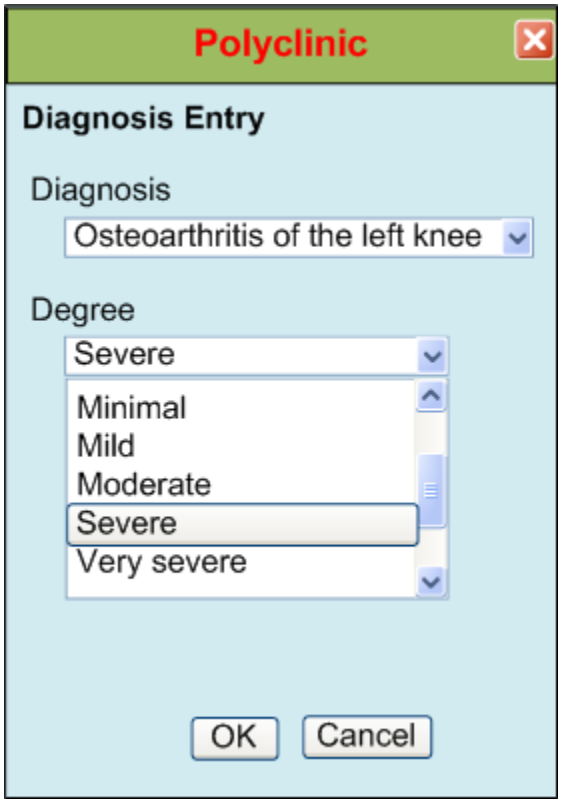
Entry

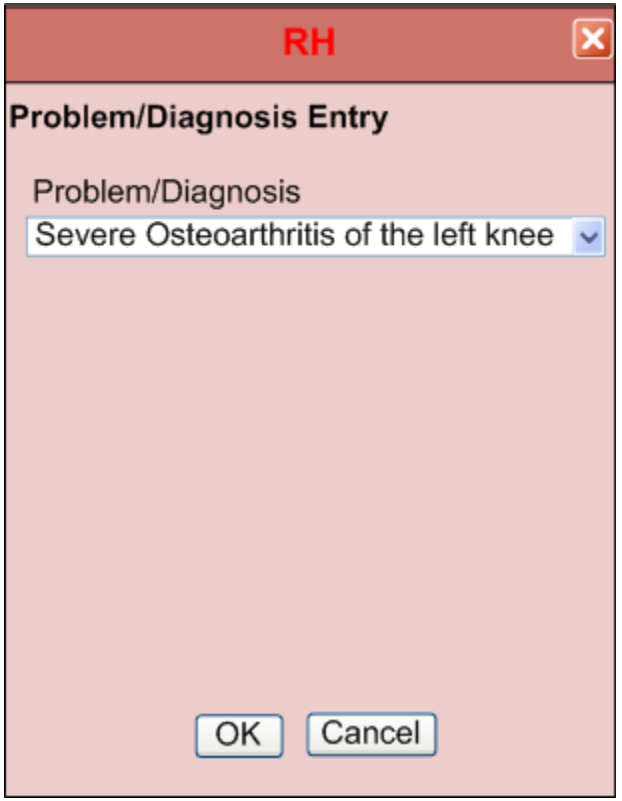
Element

Diagnoses

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



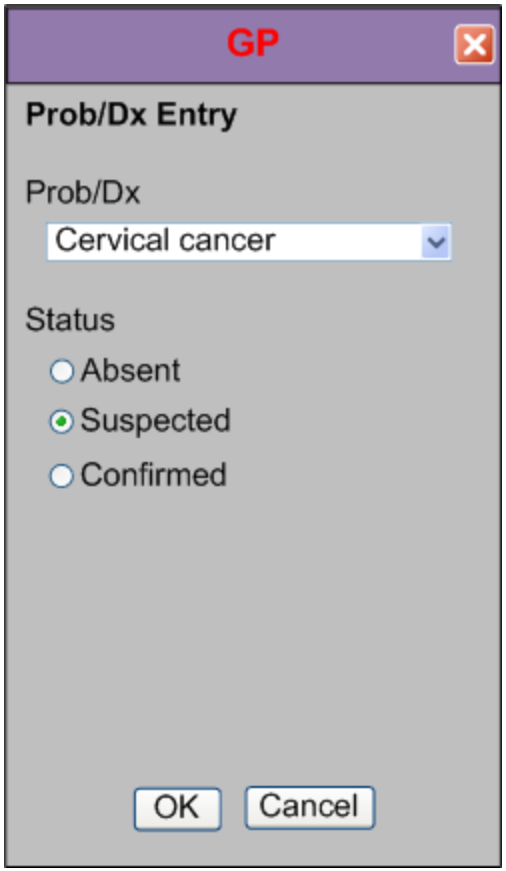


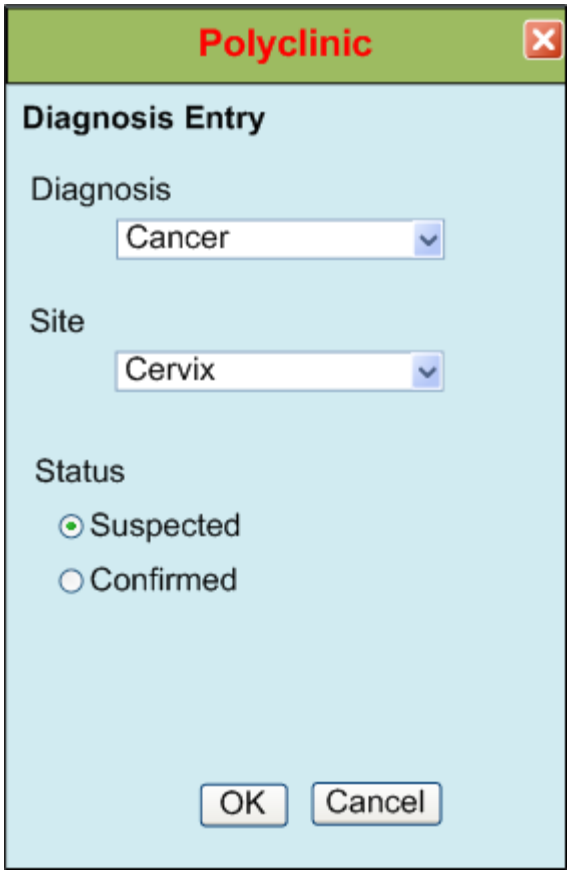


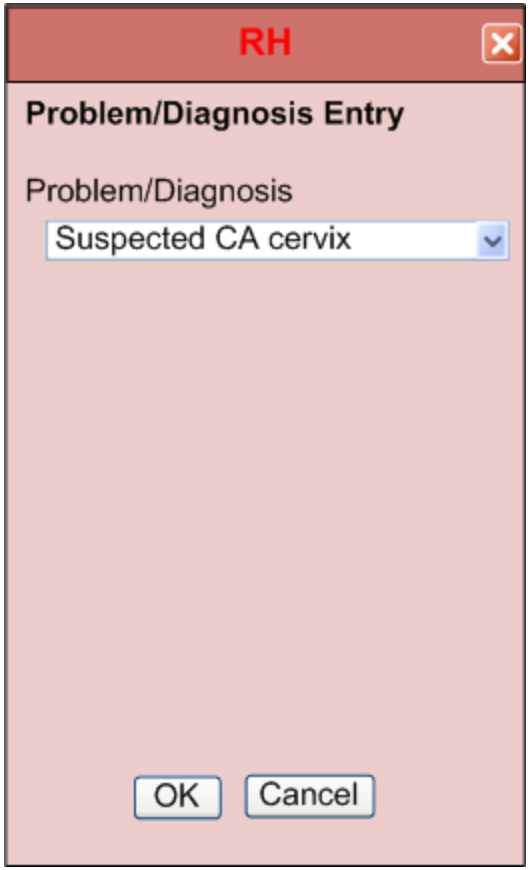
Heterogeneity in naming, syntax, representation, and structure

Diagnoses

e.g., “Suspected cervical cancer”



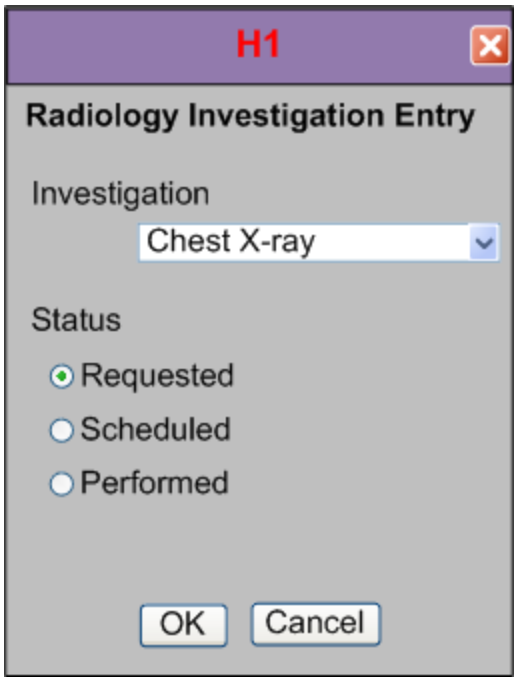


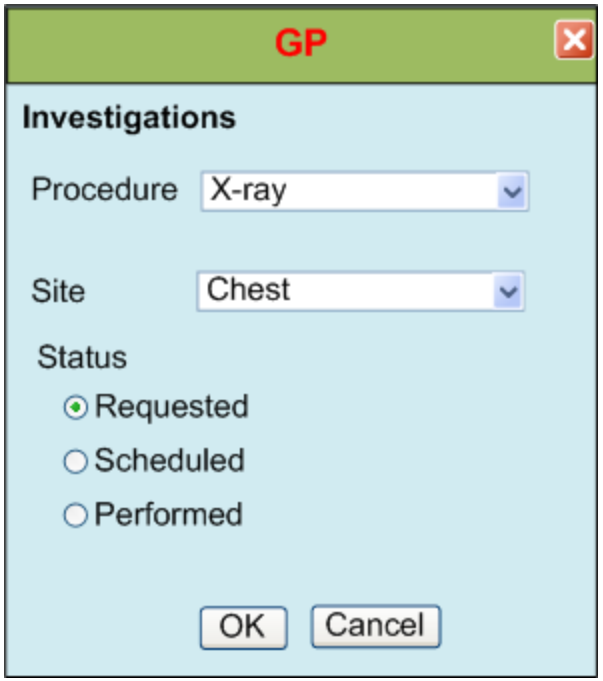


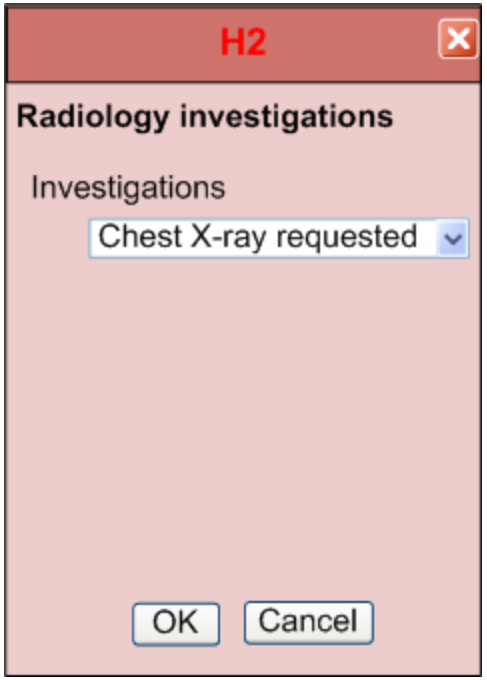
Heterogeneity in naming, syntax, representation, and structure

Procedure

e.g., “X-ray of the chest requested”



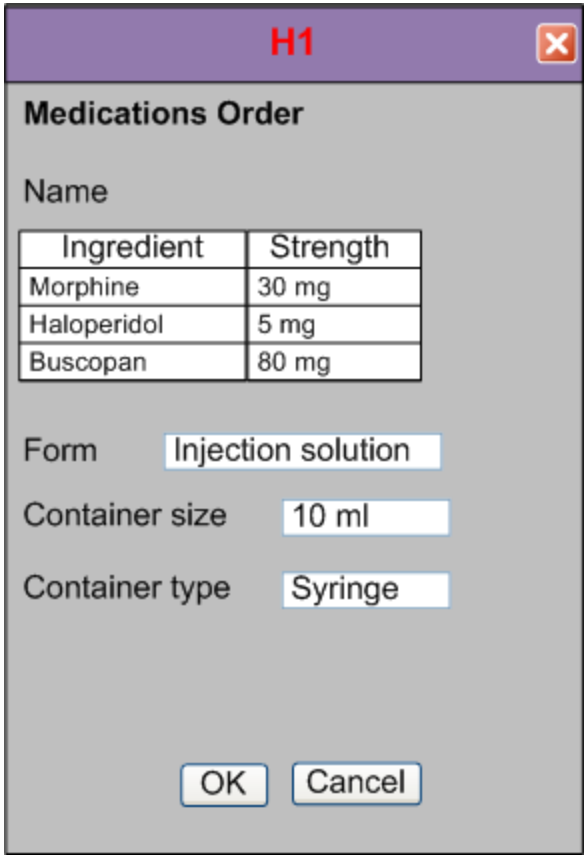


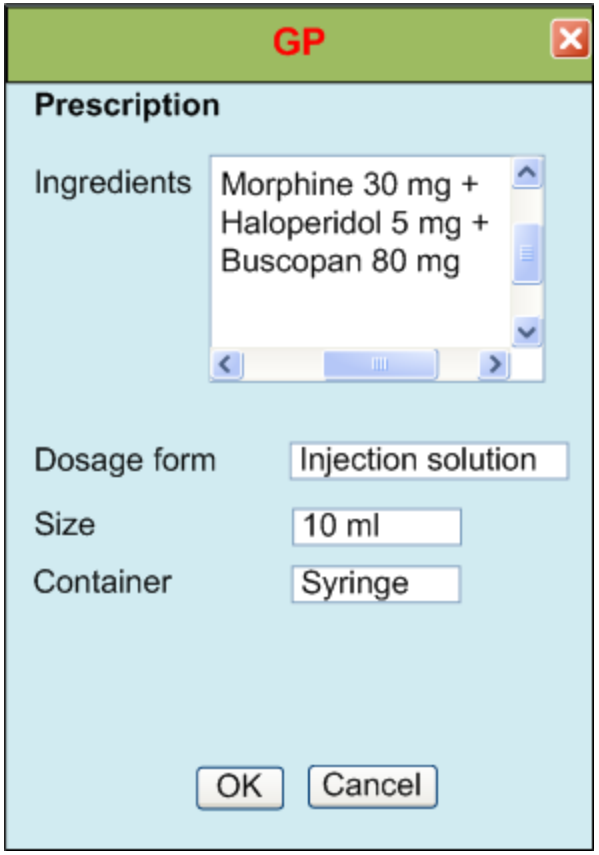


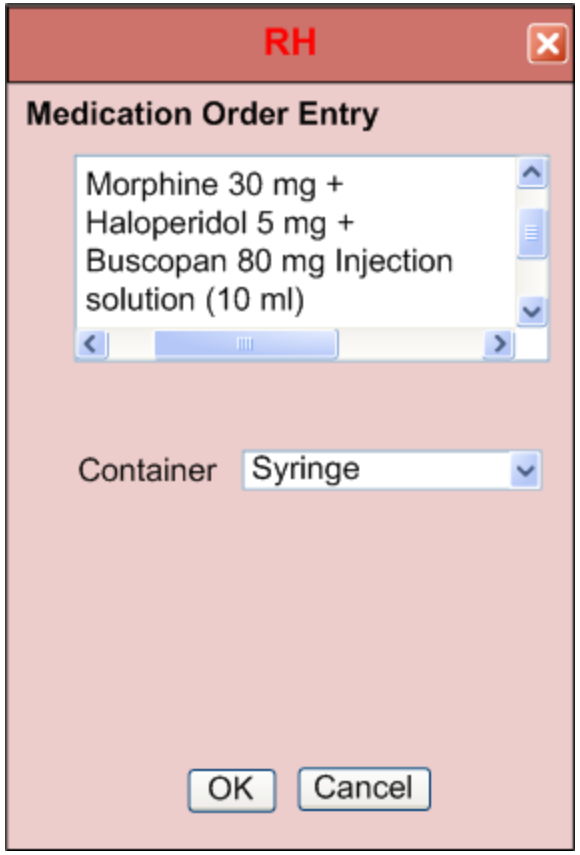
Heterogeneity in naming, syntax, representation, and structure

Medications

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

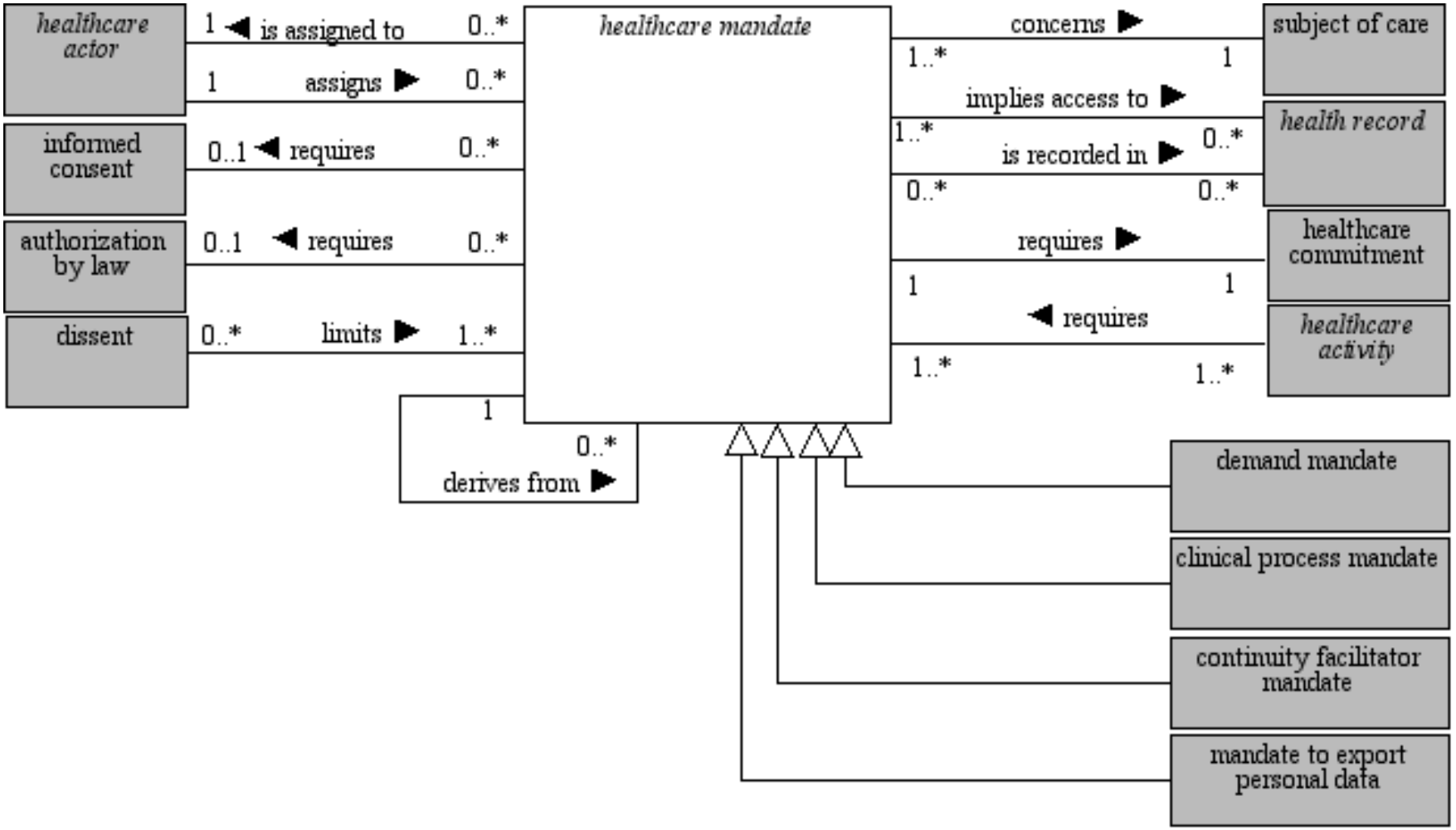




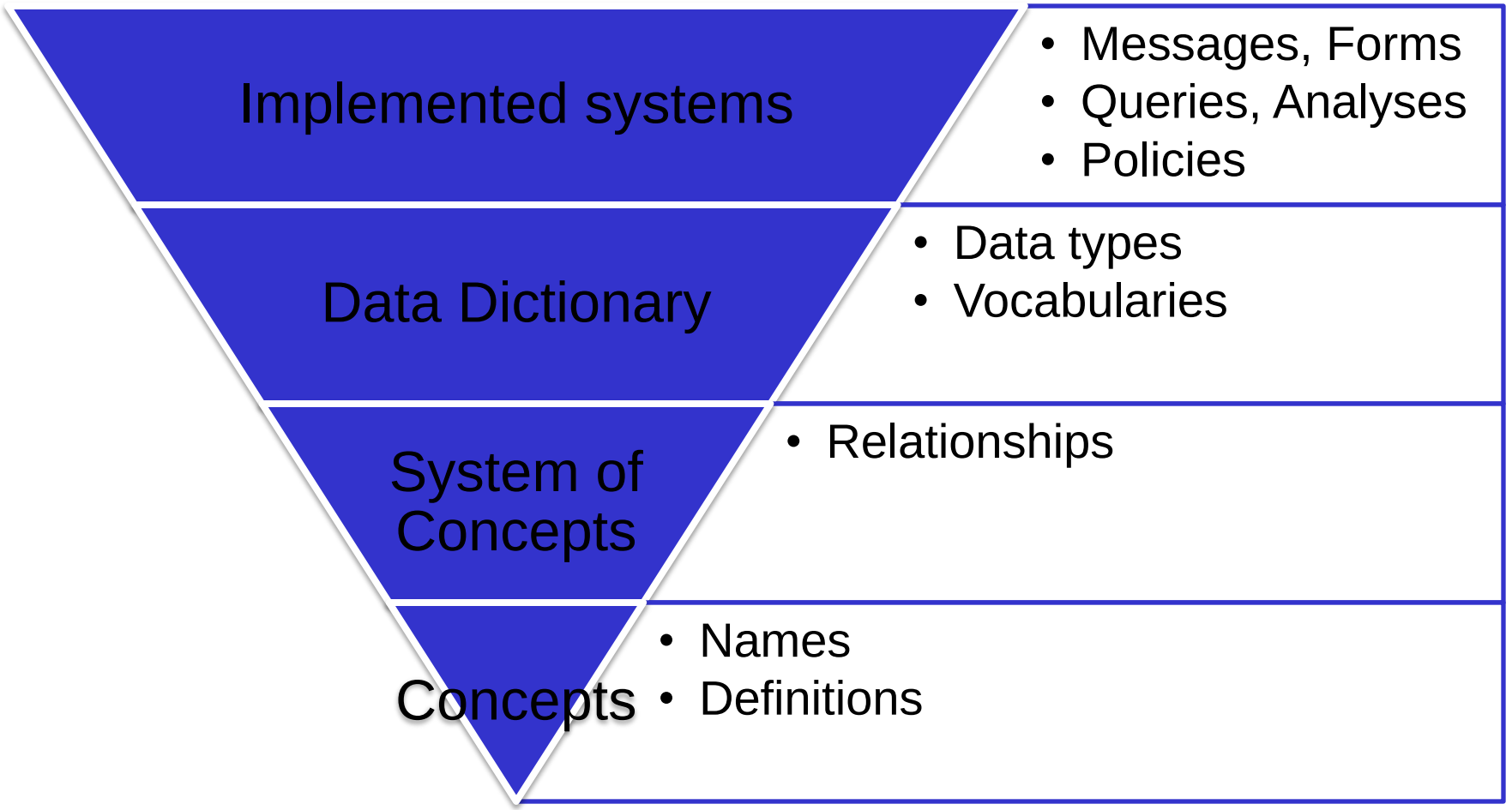


Heterogeneity in naming, syntax, representation, and structure

Relationships



DATA DICTIONARY IN AN ARCHITECTURE


Implemented systems
• Messages, Forms
• Queries, Analyses
• Policies
Data Dictionary
• Data types
• Vocabularies
System of Concepts
• Relationships
Concepts
• Names
• Definitions

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

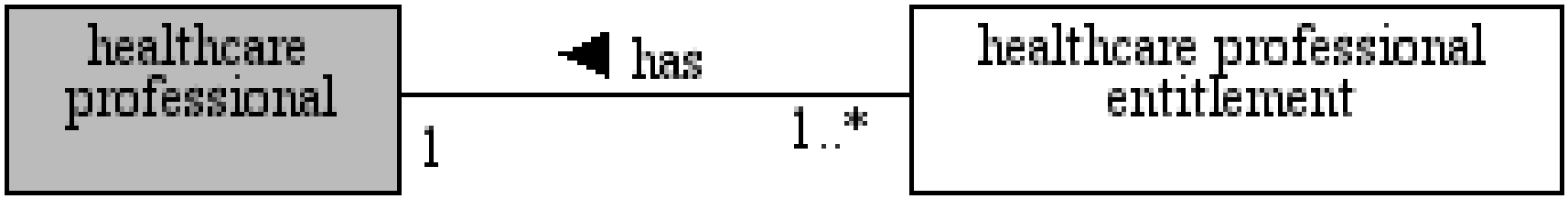
Definition: registered authorization given to a person in order to allow the person to have or perform specific roles in healthcare

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

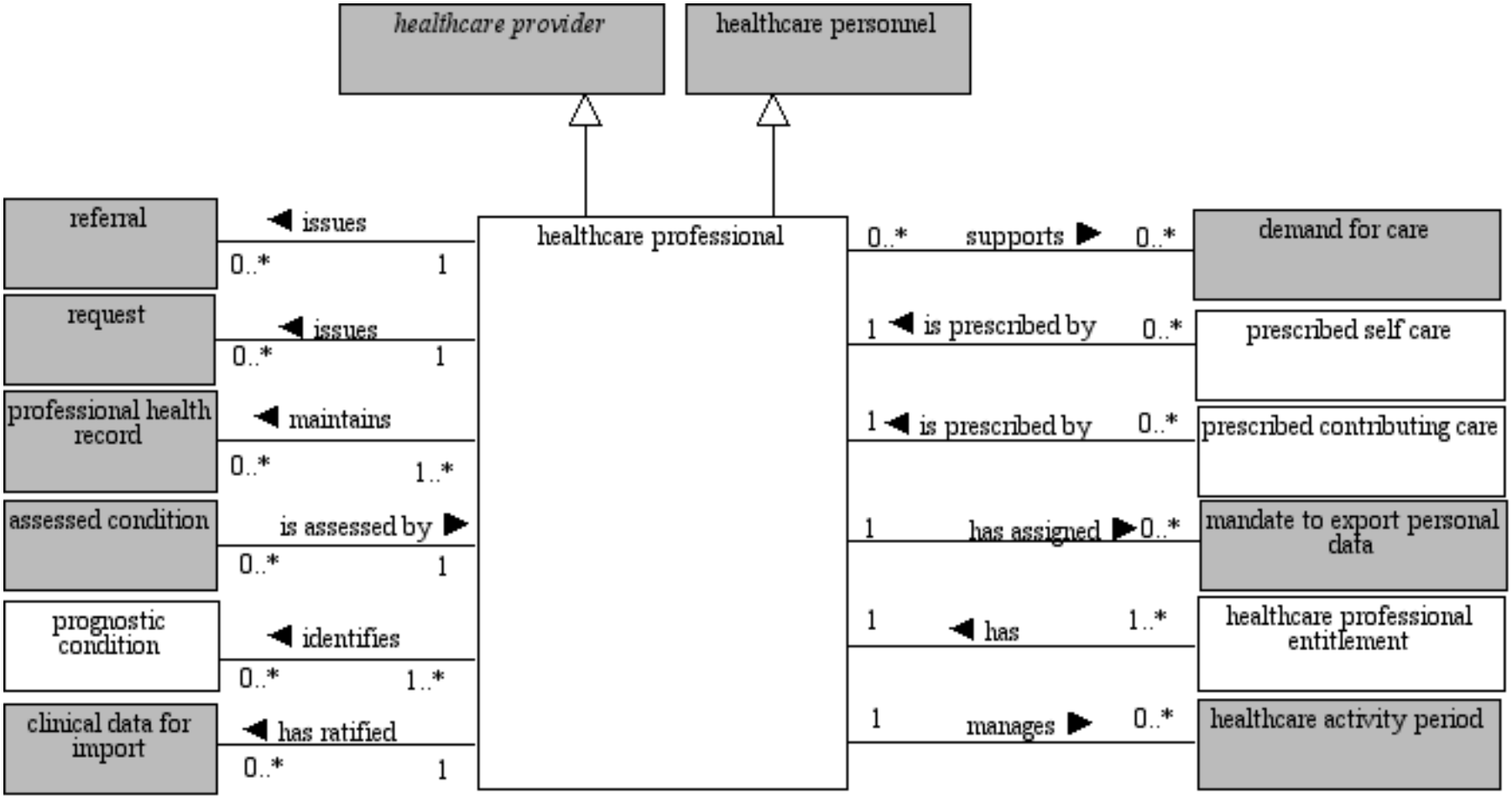
NOTE 2 The official entitlement of a healthcare professional forms the foundation for his/her official duties and rights.

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

Relationships



Relationships



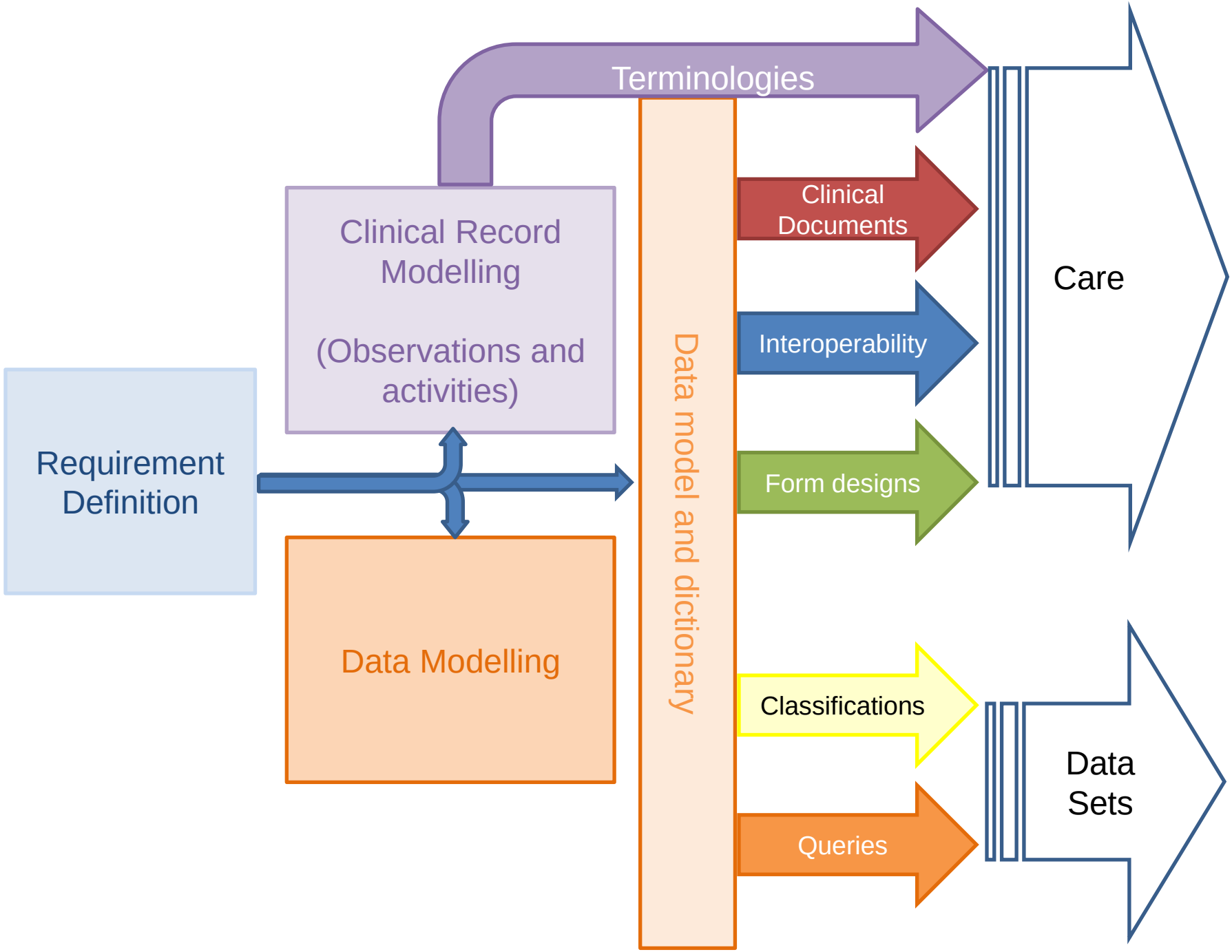
Data

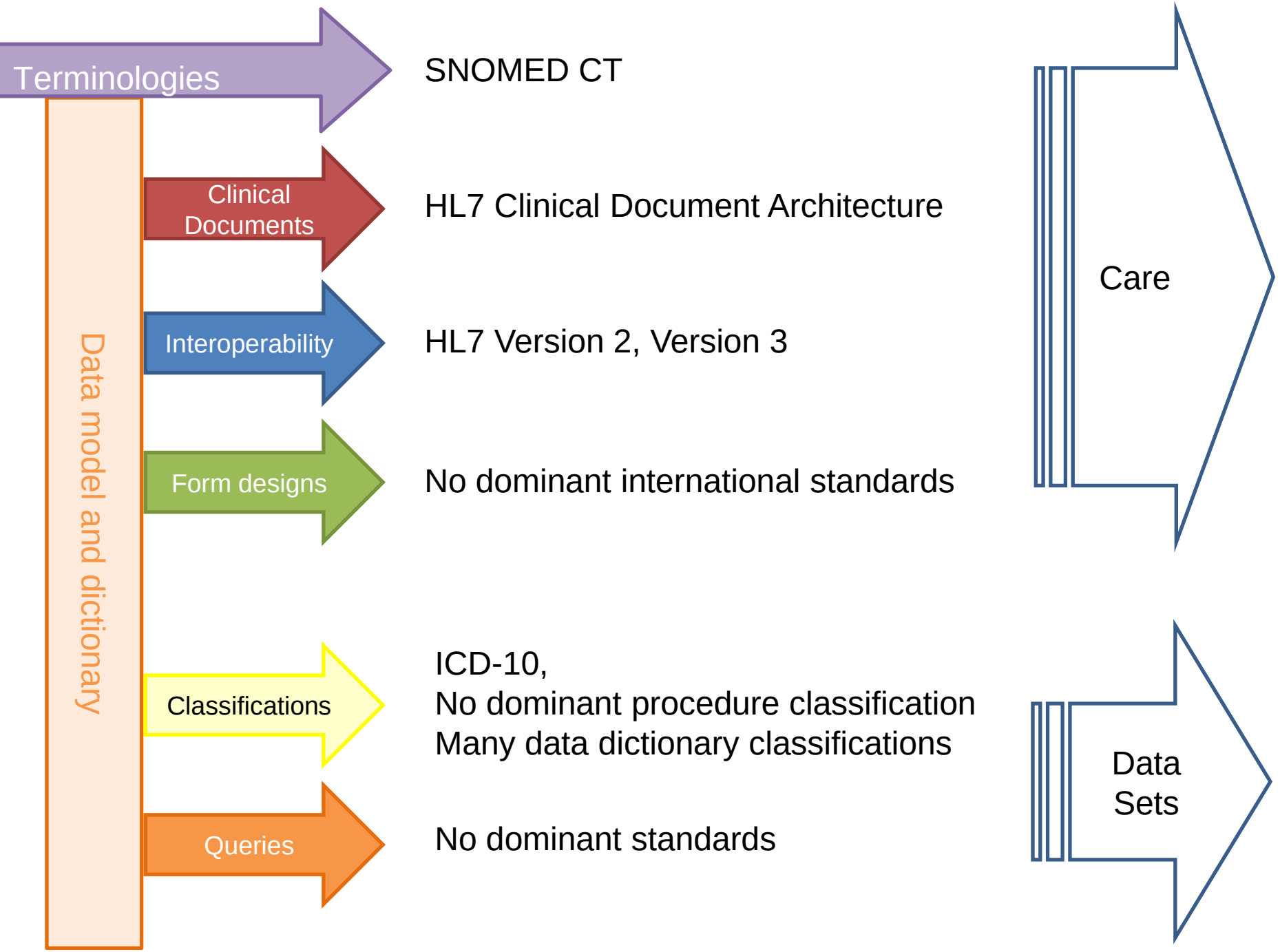
Values

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

Vocabularies

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


Terminologies
Clinical Record Modelling
(Observations and activities)
Requirement Definition
Data Modelling
Data model and dictionary
Clinical Documents
Interoperability
Form designs
Care
Classifications
Queries
Data Sets


Terminologies
SNOMED CT
Clinical Documents
HL7 Clinical Document Architecture
Interoperability
HL7 Version 2, Version 3
Form designs
No dominant international standards
Care
Data model and dictionary
Classifications
ICD-10,
No dominant procedure classification
Many data dictionary classifications
Queries
No dominant standards
Data Sets

2008 documentation available from RCP and AoMRC websites

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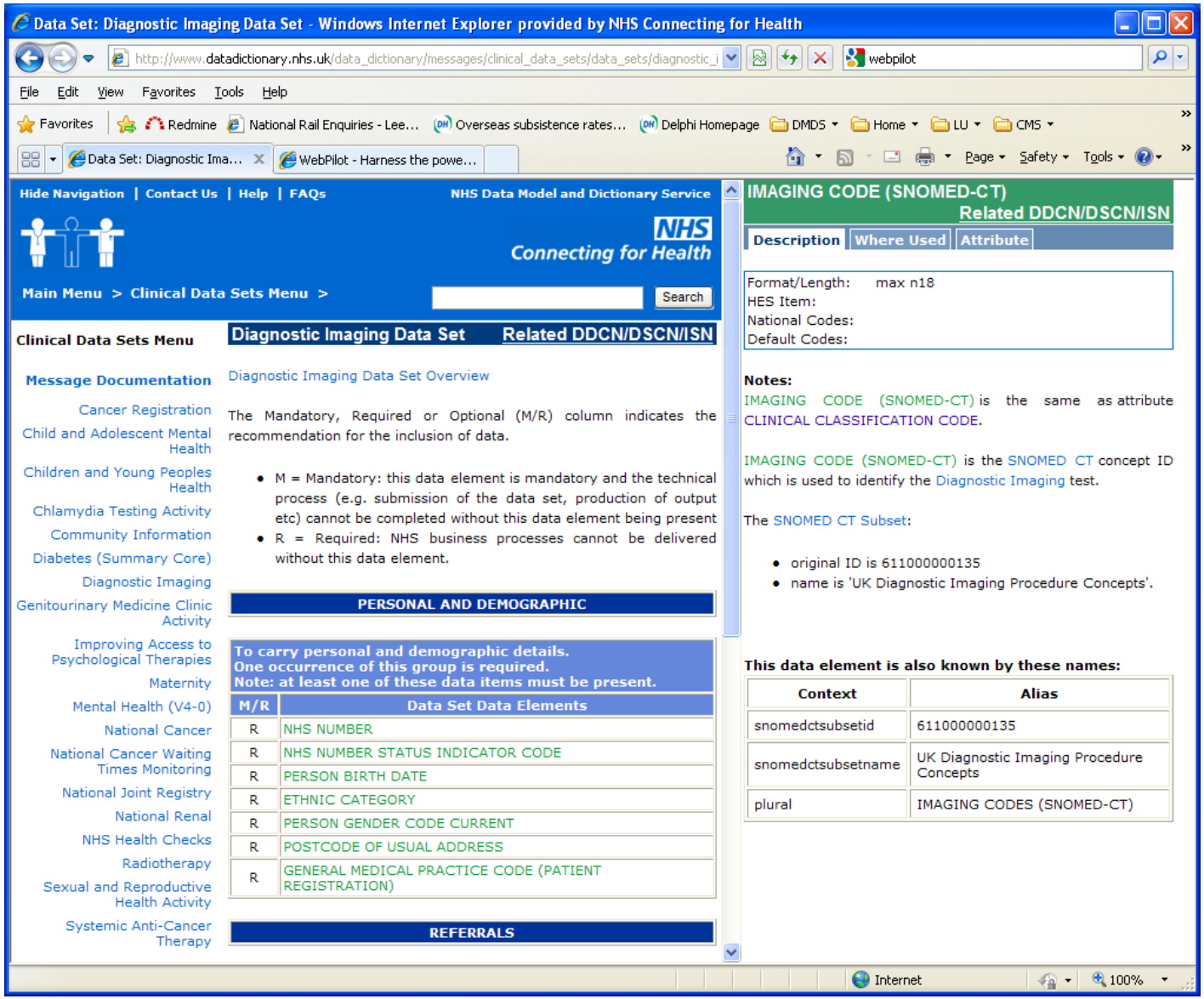
Datasets

Department of Health