A Reference Model for

Clinical Tumour Documentation

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Topics

- Exchange of data as key feature for cancer registries

- Frameworks for development and implementation of messages not sufficient
  - => Need for domain specific knowledge

- Domain specific model for tumour documentation

- Implications for records in sending systems
  - (e.g. hospital information systems)

Cancer Registries
Importance of data exchange (I)

▍ Focus on hospital cancer registries

▍ Paper based reporting systems of decreasing acceptance

  ▍ Too much documentation tasks

  ▍ Duplicate data entry for different purposes (e.g. quality management + cancer registry)

  ▍ Data partially available in (hospital and other) information systems

Cancer Registries
Importance of data exchange (II)

- Available data (Germany)
  - HIS
    - **A**dmission, **D**ischarge, **T**ransfer (standardised, HL7)
    - including diagnosis/procedure codes
    - (laboratory, pathology, radiotherapy, ... little standardisation, individual solutions)
  - Registry office
    - Life status, address
  - Other cancer registries
    - Population based registry: death certificates

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Cancer Registries
Problems with HIS Data (I)

- Codes and procedures used for billing
  - Encounter based => repetition

```
┌──────────┐      ┌──────────────┐      ┌────────────────────┐
│ Patient  │ ───> │  Admission   │ ───> │ Diff. Types of Docs.│
└──────────┘      └──────────────┘      └────────────────────┘
```

  - Not sufficient, e.g. no date of diagnosis, morphology, staging,
  - Therapy not related to diagnosis
  - Optimisation for maximum revenue

Cancer Registries
Problems with HIS Data (II)

- Consequence
  - Integration of cancer reporting forms in HIS by manufacturers or by customisation
- But
  - Registry's model is different from HIS model
- Communication most effective if models compatible
- => Need for understanding of tumour documentation domain

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Representation of Domain Specific Data

- **HL7 Version 3**
  with Reference Information Model (RIM)
  - Framework
  - Some domains realised, but
  - No domain for cancer registration

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Reference Model for Clinical Tumour Documentation

- **Background**
  - long standing experience with the development of a hospital cancer registry system (GTDS)
    - In use in more than 40 hospital cancer registries
  - Based on a German cancer data standard
- **Realised as entity-relationship-diagram (ERD)**
- **Attribute definition not described**
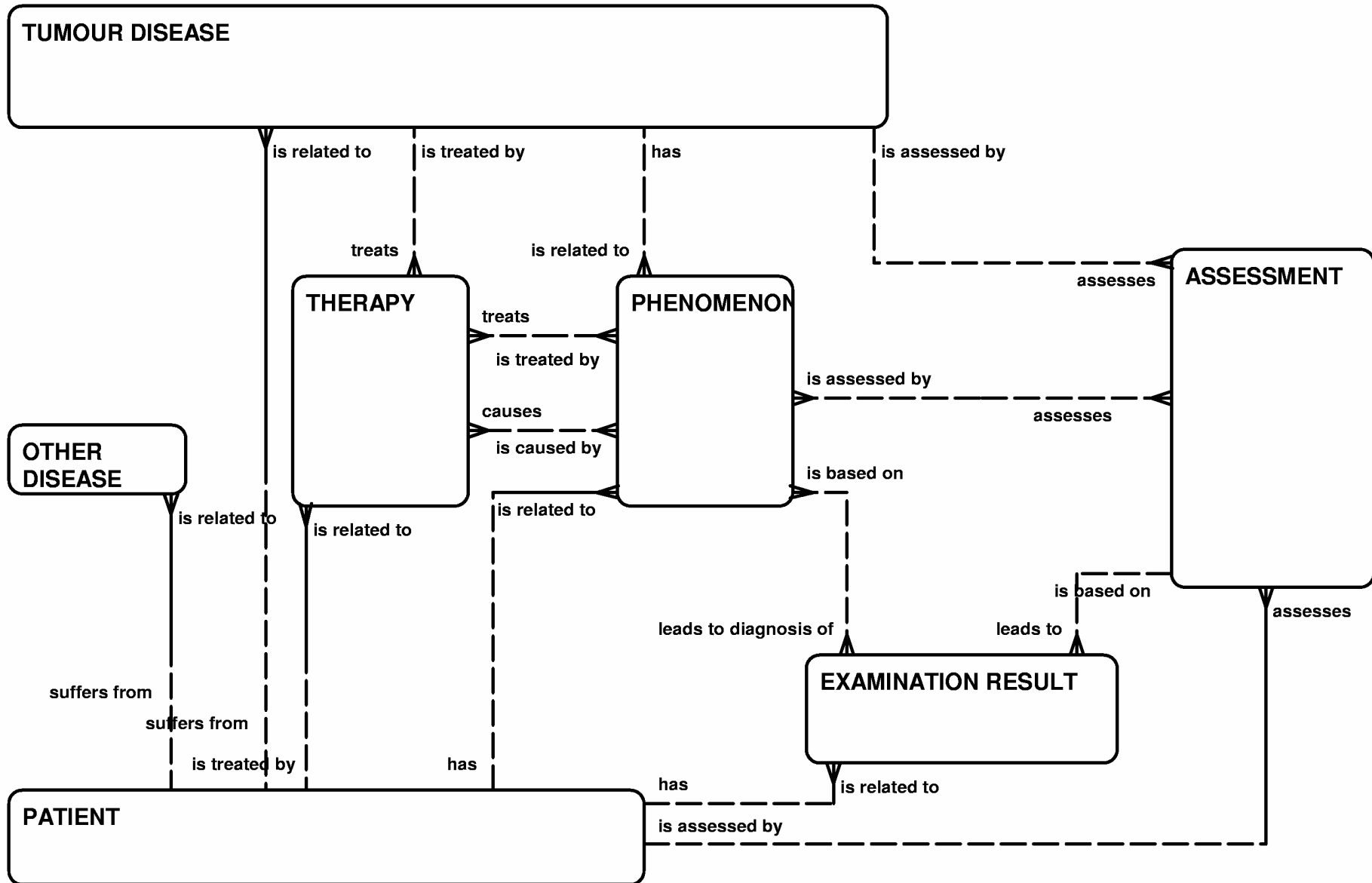 - Depend on country specific requirements
    - „Basisdokumentation für Tumorkranke"
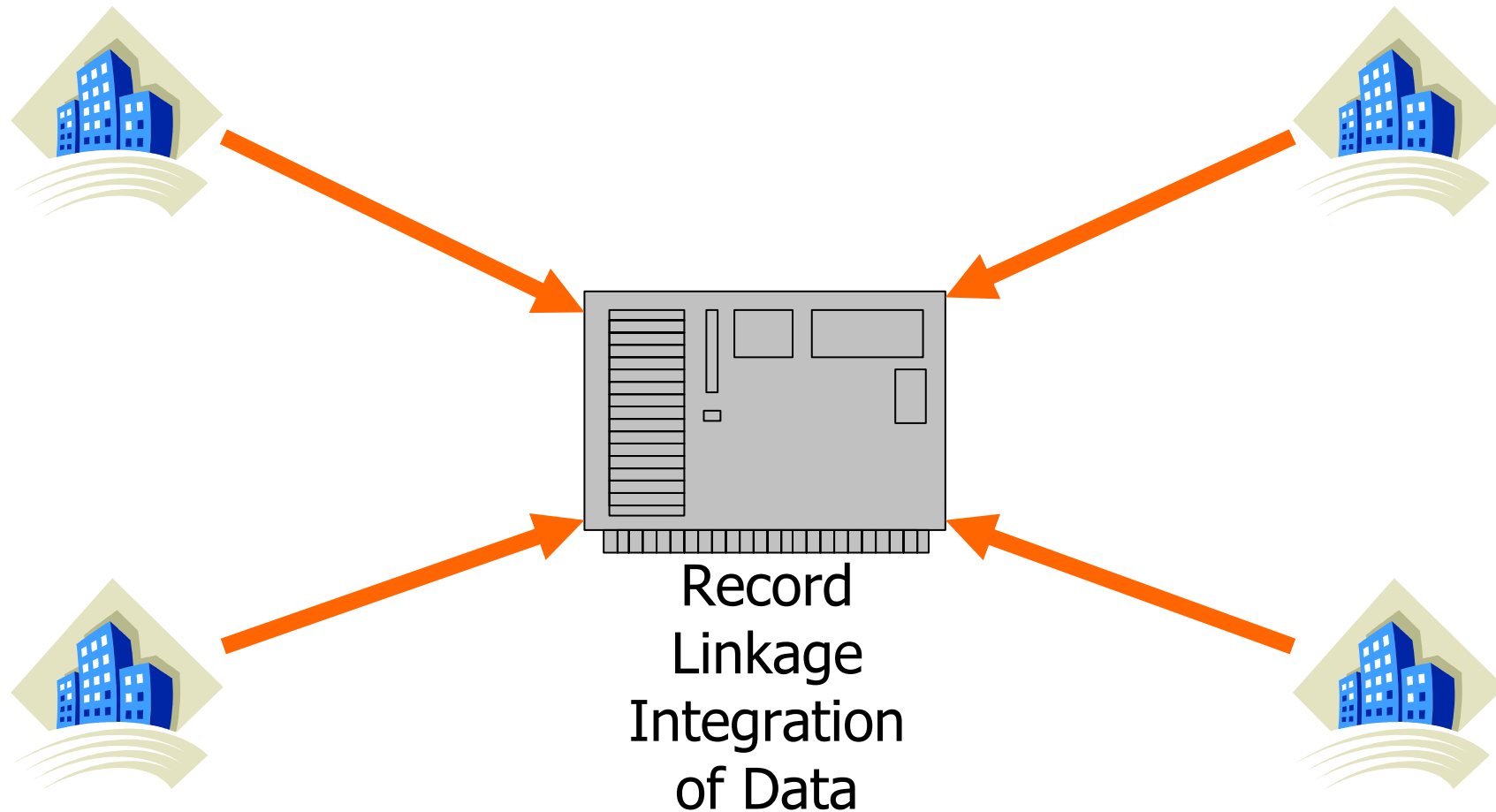   - NCI's Cancer Data Standards Repository (caDSR)
    - LOINC, SNOMED-CT, …
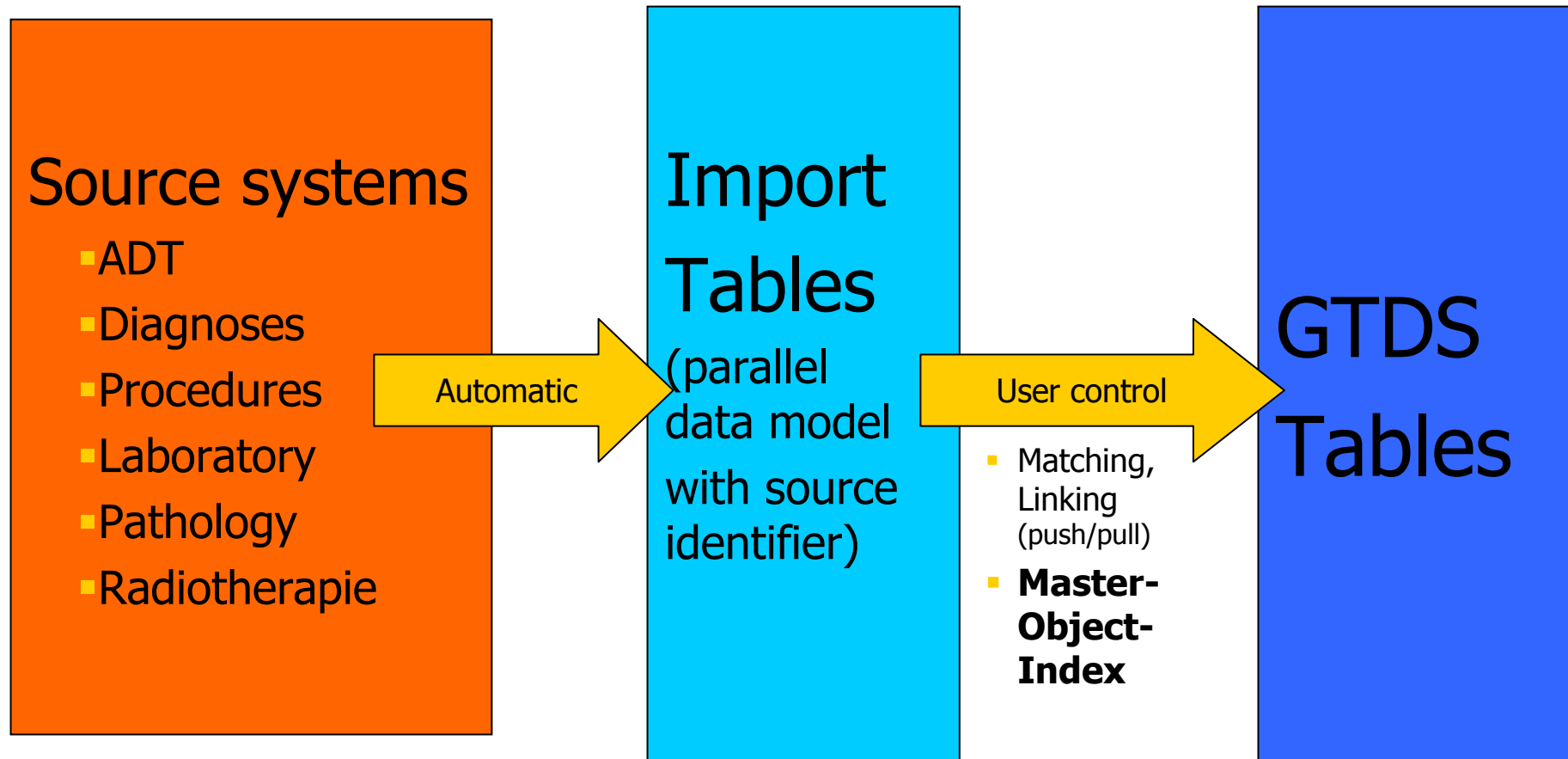
Reference Model for Clinical Tumour Documentation - ERD

TUMOUR DISEASE

is related to   is treated by   has   is assessed by

treats   is related to

ASSESSMENT

assesses

THERAPY   **PHENOMENON**

treats

is treated by

causes

is caused by

is assessed by

assesses

is based on

OTHER DISEASE

is related to

is related to

is related to

is based on

leads to diagnosis of   leads to

suffers from

suffers from

EXAMINATION RESULT

assesses

is treated by   has

has   is related to

PATIENT

is assessed by

Characteristics of Data Import into a Registry

Record
Linkage
Integration
of Data

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GTDS Design of Communication Interface (Import)

Source systems
- ADT
- Diagnoses
- Procedures
- Laboratory
- Pathology
- Radiotherapie

→ Automatic →

Import Tables
(parallel data model with source identifier)

→ User control →

- Matching, Linking (push/pull)
- **Master-Object-Index**

GTDS Tables

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Master Object Index (MOI)

- Central structure
  - to identify objects/entities
  - to transfer relationships from a source system to a target system
- Example
  - John Doe undergoes tumour surgery in hospital A
  - One year later, follow-up examination in hospital A shows complete remission
  - Both events are reported electronically from the hospital information system (HIS) to the cancer registry
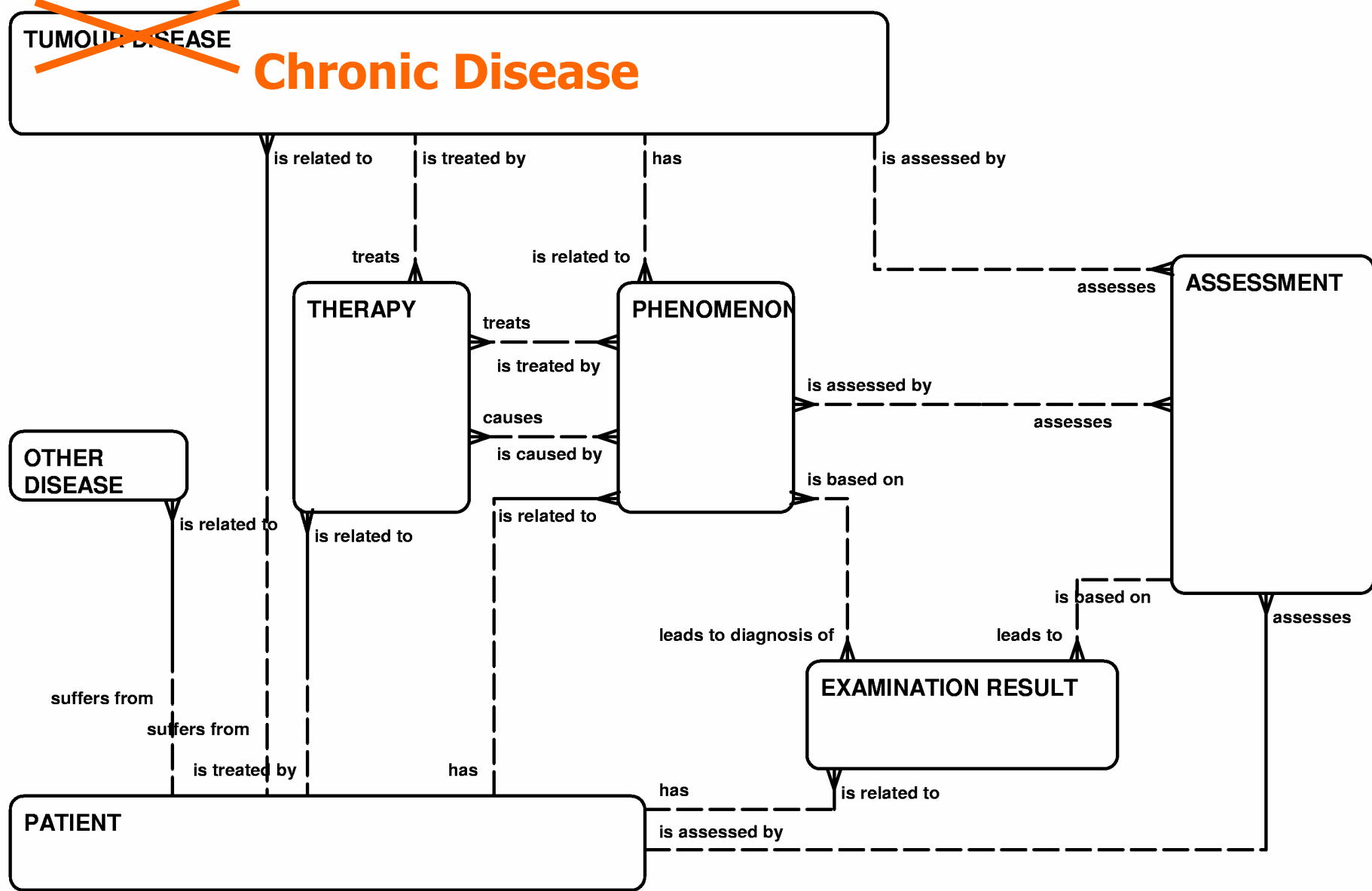
Master Object Index Example (I)

- Case 1:
- HIS A doesn't implement reference model
- stores no relationship between tumour and assessment

- Case 2:
- HIS A implements reference model
- relationships between tumours and assessments can be stored and transfered

Master Object Index Example (II)

Case 1:

On surgery reporting, only the patient identifier can be stored in the MOI

On follow up reporting, the assessment can be related to the patient, but the assessment must be related to the tumour **manually**

Case 2:

On surgery reporting, patient and tumour identifier can be stored in the MOI

On follow up reporting, the assessment can be related to the patient **and** the tumour

automatically

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A Reference Model for Chronic Diseases?

TUMOUR DISEASE

Chronic Disease

is related to | is treated by | has | is assessed by

OTHER DISEASE

THERAPY

treats | is related to

treats
is treated by
causes
is caused by

PHENOMENON

is related to

is assessed by | assesses

ASSESSMENT

assesses

is related to

is related to | is based on

is related to

leads to diagnosis of | leads to | is based on

EXAMINATION RESULT

assesses

suffers from
suffers from
is treated by | has

PATIENT

has | is related to

is assessed by

The idea is not new ...

- **...** Lawrence L Weed described the problem oriented medical record in 1969:
  - Progress notes are related to problems
  - Problems: phenomena
- SOAP
  - Subjective, objective: examination results
  - Assessment: assessment
  - Plan: important for local workflow, not implemented in the registry

Applications

- Import of data from a department system (radiotherapy documentation, in routine use)
- Import of data from another hospital cancer registry
- Import of data of a specialised breast cancer documentation system

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Conclusion

▌ Cancer registries increasingly have to import data from other systems, e.g. HIS

▌ A common domain information model is important for effective (most automatic import) implementations

▌ The implementation of the presented model requires basically the ability to implement and associate objects diseases/problems, therapies, examination results and assessments

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