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
    - Admission, Discharge, Transfer (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
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
Representation of Domain Specific Data

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

THERAPY

OTHER DISEASE

PATIENT

PHENOMENON

ASSESSMENT

EXAMINATION RESULT

is related to

is treated by

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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

Import Tables (parallel data model with source identifier)
- Automatic

User control:
- Matching,
- Linking (push/pull)
- Master-Object-Index

GTDS Tables
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 transferred
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
A Reference Model for Chronic Diseases?

Chronic Disease

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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
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