Integration of Domain-Specific User Interfaces for Structured Data Entry in a Telemedicine Platform for Multi-Centric Research Networks

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Research Network Epidermolysis Bullosa

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Introduction (1)
Research Network Epidermolysis Bullosa

- Multi-centric research network [1]
  - Epidermolysis Bullosa (EB): rare hereditary skin disease
  - 7 centers within Germany involved
    - patient care (2 centers)
    - research (5 centers)
- Expectations
  - better understanding of disease mechanisms
  - development of new diagnostic services and therapies
  - more comprehensive documentation
- Challenges
  - effective data exchange between centers
  - effective collaboration and data sharing
  - suitable communication structures

Introduction (2)
Requirements RDE & SDE

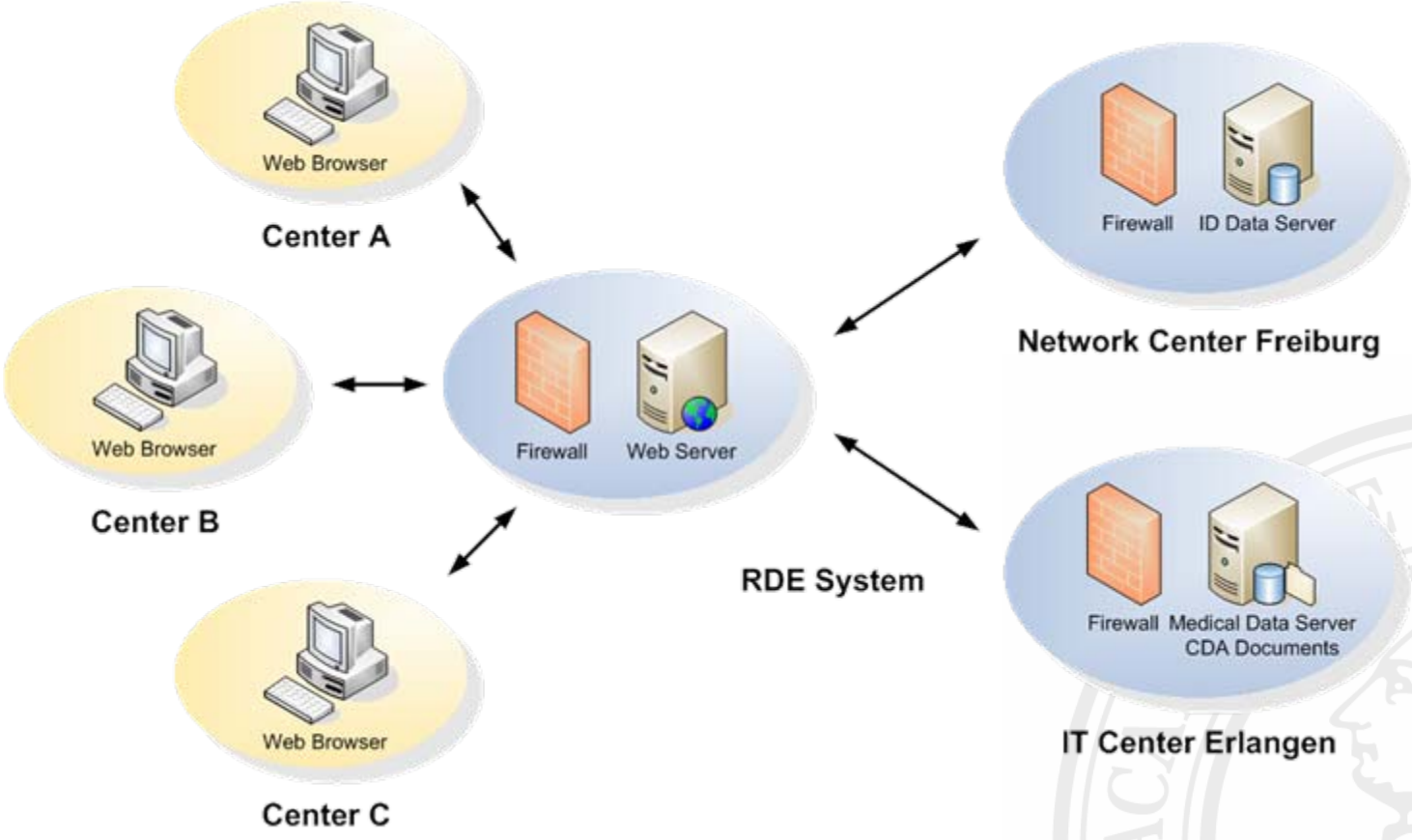
- Integrated telemedicine platform
  - remote data entry (RDE)
  - web-based
  - flexible and easily extensible platform
  - implementation of German data protection rules
  - acquisition and sharing of structured data, image data and genealogies
- Gathering requirements of structured data entry forms (SDE)
  - extraction of data items and grouping by topic and occurrence(s) within the clinical workflow
  - single-acquisition forms at patient recruitment
  - multiple-acquisition forms during course of study

Methods (1)
Components & Concepts

- Extension of existing telemedicine platform
  - addition of a web-based RDE module
  - LAMPS architecture (Linux, Apache, MySQL, Perl, SSL)
  - SDE forms
    - definition and meta information in XML file
    - parsing and rendering through XSLT
    - medical data in HL7 CDA R1
  - use of entity-attribute-value (EAV) concept for metadata storage
  - implementation of architecture requirements of the German Health Telematics Platform (TMF) [2]

Methods (2)
Data protection requirements

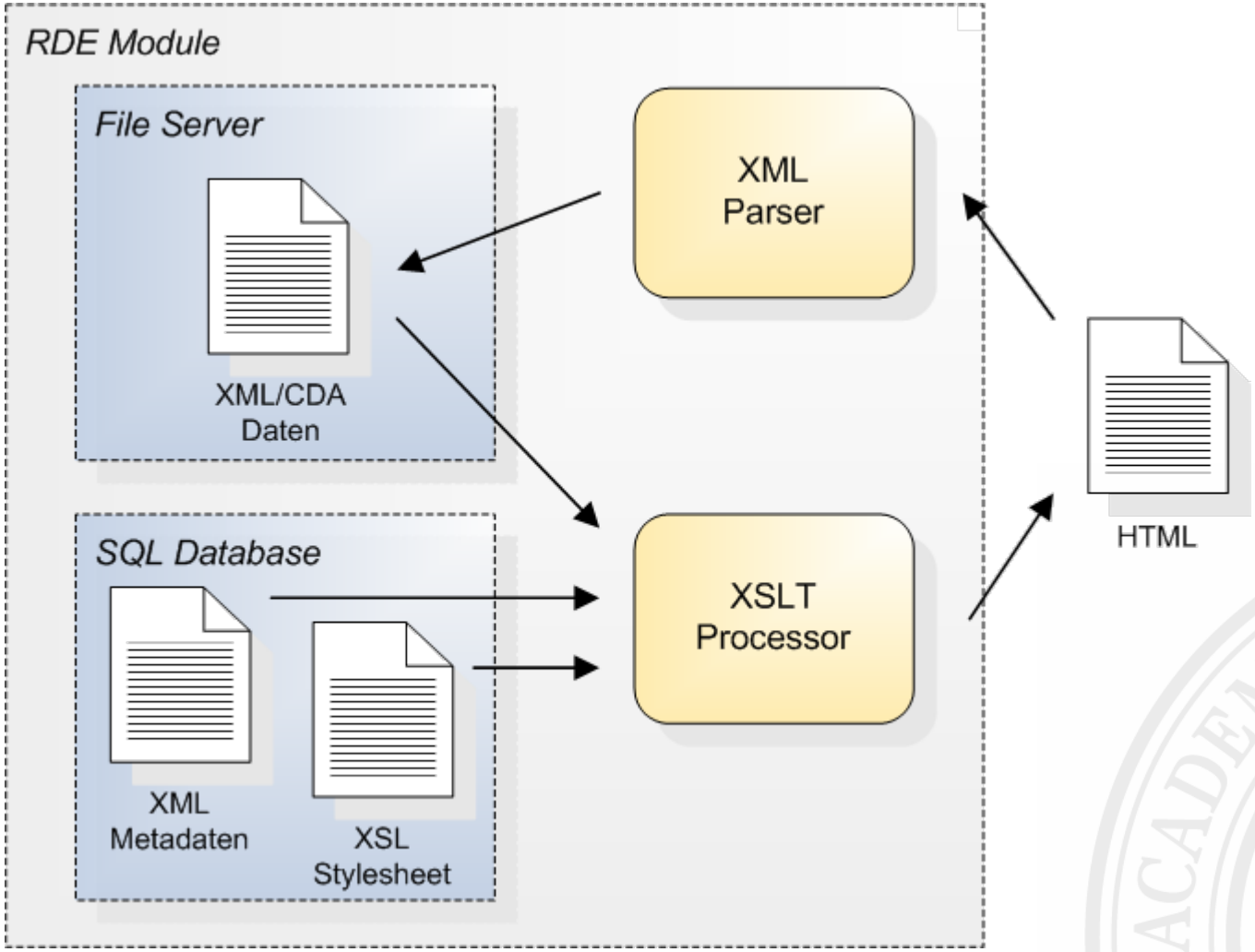
- separation of patient ID data and medical data



Methods (3)
Integration of HL7 v3 CDA R1

- CDA = Clinical Document Architecture
  - XML-based, 3 level architecture
  - header and body information (meta data/clinical data)
  - extensibility through <local-markup> segments
- proprietary namespace for local content
  - definable meta data elements for alignments, definitions and data containers
- validation of compatibility regarding all stored CDA data against the CDA schema
- suitable storage format for medical data

Methods (4)
XML-Architecture



Methods (5)
XSL-Transformation

```
- <levelone xsi:schemaLocation="urn:hl7-org/cda neb-cda.xsd">
  + <clinical_document_header></clinical_document_header>
  - <body>
    - <section>
      - <paragraph>
        - <content>
          - <local_markup ignore="all" descriptor="neb">
            - <neb:data>
              + <neb:metadata></neb:metadata>
              - <neb:chapter id="C1">
                - <neb:section id="S1.1">
                    <neb:question id="Q1.1.1">A1.1.1.15</neb:question>
                    <neb:question id="Q1.1.2">05.03.1996</neb:question>
                  </neb:section>
                - <neb:section id="S1.2">
                  - <neb:question id="Q1.2.1">
                      <neb:answer id="A1.2.1.1">off</neb:answer>
                      <neb:answer id="A1.2.1.2">on</neb:answer>
                      ...
                      <neb:answer id="A1.2.1.14">on</neb:answer>
                    </neb:question>
                    <neb:question id="Q1.2.2" idref="A1.2.1.14">Tetraparese, BWS-Skoliose</neb:question>
                  </neb:section>
                - <neb:section id="S1.3">
                  - <neb:question id="Q1.3.1">
                      <neb:answer id="A1.3.1.1">off</neb:answer>
                      <neb:answer id="A1.3.1.2">on</neb:answer>
                      <neb:answer id="A1.3.1.3">off</neb:answer>
                      <neb:answer id="A1.3.1.4">on</neb:answer>
                    </neb:question>
                    <neb:question id="Q1.3.2" idref="A1.3.1.4">assovorop</neb:question>
                  </neb:section>
                - <neb:section id="S1.4">
                  - <neb:question id="Q1.4.1">
                    - <neb:object id="O1.4.1.1">
                        <neb:answer id="A1.4.1.1.1">T88.7</neb:answer>
                        <neb:answer id="A1.4.1.1.2">Penicillinallergie</neb:answer>
                      </neb:object>
                    - <neb:object id="O1.4.1.2">
                        <neb:answer id="A1.4.1.2.1">M41.90</neb:answer>
                        <neb:answer id="A1.4.1.2.2">Skoliosis deformans</neb:answer>
                      </neb:object>
                    </neb:question>
                  </neb:section>
                </neb:chapter>
                ...
```

A.1. Dauerdiagnosen

A.1.1. Form der EB (Einfachauswahl)

- ○ EBS-?
- ○ EBS-WC
- ○ EBS-MD
- ○ EBJ-H
- ○ EBJ-PA
- ○ EBD-D
- ○ EBD-nHS
- ◉ unklassifizierbar
- ○ EBS-K
- ○ EBS-DM
- ○ EBJ-?
- ○ EBJ-nH
- ○ EBD-?
- ○ EBD-HS
- ○ noch nicht klassifiziert

definitive Diagnose am: 05.03.1996

A.1.2. EB-assoziierte Diagnosen (Mehrfachauswahl)

- ☐ Pylorusatresie
- ☐ Nageldystrophie
- ☐ Zahnschmelzdefekt
- ☐ Ösophagusstenose
- ☐ Gelenkkontrakur
- ☐ Anämie
- ☐ Eiweißmangel
- ☑ Muskeldystrophie
- ☐ Nagelverlust
- ☐ Alopezie
- ☐ Pseudosyndaktylien
- ☐ Entwicklungsverzögerung
- ☐ Eisenmangel
- ☑ sonstige: Tetraparese, BV

A.1.3. EB-assoziierte Voroperationen und Eingriffe

- ☐ Ösophagusdilatation
- ☐ Lösung von Pseudeosyndaktylien
- ☑ PEG-Anlage
- ☑ sonstige: assovorop

A.1.4. Weitere Diagnosen

Auswahl	ICD10	Beschreibung
☐	T88.7	Penicillinallergie
☐	M41.90	Skoliosis deformans

Auswahl löschen | Neuer Eintrag | ◉ am Ende ○ vor Auswahl ○ nach Auswahl

Results
Production use & features

- Production use since 09/2005
  - 150 sessions
  - 200 patients, 2 centers
  - 6 distinct acquisition forms (e.g. patient histories, physical exams, lab findings)
  - most complex document contains 111 items
  - CDA R1 structured elements primarily used for demographic data
  - adaptation for additional domain of pediatric oncology

- Features
  - integrated patient data management
  - flexible definable acquisition forms managed through revision control system
  - integration of existing graphical genealogies in Newick notation [3]
  - granular authorization management
  - plausibility checks
  - data export for further analysis

Discussion

- XML formats
  - flexible adaptation of SDE forms for various medical domains
- XSLT
  - robust and efficient method for generation of user interfaces
- HL7 CDA vs. CDISC ODM
  - data storage
  - still under development
  - semantic interoperability (HL7 CDA templates)
- Improved data quality
  - complex plausibility mechanisms

Conclusions and Outlook

- Flexibility and adaptability
  - definition of SDE forms for different medical domains
- Standards
  - XML, XSLT, HL7 CDA contribute to semantic interoperability and further interfaces to EHRs or EPRs
- Further development
  - roll out in additional medical domains
  - input validation
  - skip logic

Thanks for your attention!

- References
  - [1] www.netzwerk-eb.de/index_eng.html
  - [2] www.tmf-ev.de/site/EN/int/c_homepage.php
  - [3] www.uni-leipzig.de/~innere/tsh
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