Standardized Quality Assurance Forms for Organ Transplantations

with Multilingual Support, Open Access and UMLS Coding

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Organ Transplantations

• Live-saving treatment for end-stage diseases [1][2]

- HEART: 10%
- LIVER: 27%
- KIDNEYS: 47%
- LUNGS: 11%

Numbers by Deutsche Stiftung Organtransplantation

• Huge demand: „21 people die each day waiting for transplants that can't take place because of the shortage of donated organs”

[US Department of Health & Human Services]
Role of QA

• Necessary to measure, maintain and further develop medical quality of procedures, e.g. organ transplantations

• 72 transplantation centers coordinated by Eurotransplant (Austria, Belgium, Croatia, Germany, Hungary, Luxembourg, the Netherlands and Slovenia) for organ allocation [4]

➢ Beyond Eurotransplant: Quality assurance and its documentation is carried out by different institutes in different countries

➢ Standardization of documentation enforces
  ▪ harmonious
  ▪ transparent
  ▪ complete
  data acquisition for all hospitals
QA in Germany

• Since 2000: All German health service providers are obliged by law to apply Quality Assurance for Organ transplantations [5].

• Documentation forms established by the Institute for Applied Quality Improvement and Research in Health Care (AQUA)
  ➢ Long term expert consensus-driven process
  ➢ >4 million documentation cases, outstanding efforts at international level [6]
QA in Germany

• Existent and well-established documentation forms could be reused to standardize and discuss QA documentation
  ➢ Not only in Germany but all over the world!

• What we need:
  ➢ International Form Repository
  ➢ Sharing of semantically interoperable forms
  ➢ User-driven community to further discuss/re-edit existing forms
Research Methods

Overview: Form conversion and Form sharing

<table>
<thead>
<tr>
<th>AQUA Forms MS ACCESS</th>
<th>ODM Forms 1.3.2</th>
</tr>
</thead>
<tbody>
<tr>
<td>+ Structured Items</td>
<td>+ Structured Items</td>
</tr>
<tr>
<td>- Standardized model</td>
<td>+ Standardized model</td>
</tr>
<tr>
<td>- Semantic codes</td>
<td>+ Semantic Codes</td>
</tr>
<tr>
<td>- Multilingual</td>
<td>+ Multilingual</td>
</tr>
</tbody>
</table>

Manual review of every form by three medical experts including one physician (IELTS 7.5), consensus-based after automatic syntactic form conversion:

- Item translation
- Item coding using Unified Medical Language System (UMLS) based on coding principles [18]
- Frequency Analysis of Medical Concepts based on UMLS codes

International Form Repository: https://medical-data-models.org

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Results: Form conversion and coding

- 16 QA forms -> 16 ODM forms
- 433 data items, 374 concepts occurrences, 132 unique concepts
- 92% concepts could be coded via UMLS

Table 1 Examples of Missing UMLS codes

<table>
<thead>
<tr>
<th>Concept Name</th>
<th>Frequency</th>
</tr>
</thead>
<tbody>
<tr>
<td>Recipient/donor ID as ET-Number</td>
<td>15</td>
</tr>
<tr>
<td>Exceptional MELD score</td>
<td>2</td>
</tr>
<tr>
<td>Medical Urgency Code ET-Status</td>
<td>1</td>
</tr>
<tr>
<td>Domino liver transplantation</td>
<td>1</td>
</tr>
<tr>
<td>Weight of resected liver</td>
<td>1</td>
</tr>
</tbody>
</table>

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Results: Public sharing

- All ODM forms are provided on our forms repository: medical-data-models.org
- Download as ODM or other structured formats (SPSS, SQL, CSV, CDA)
Results: Public sharing

Quality assurance Follow-up Liver Transplant (AQUA)

Survival status of recipient (0)*
Deceased patient*
- no (0)
- yes (1)
- unknown or follow-up not possible (9)

Date of death (dd.mm.yyyy)

Languages (2)
English
German

Overlebensstatus des Empfängers (0)*
Patient verstorben*
- nein (0)
- ja (1)
- unbekannt oder Follow-up nicht möglich (9)

Todesdatum (TT.MM.JJJJ)

Languages (2)
English
German

Cause of death
- Intraoperative death (death on table) (A1)
- Infection-Bacterial infection (B1)
- Infection-Viral infection (B2)
- Infection-HIV (B3)
- Infection-Fungal infection (B4)
- ...

Todesursache
- Intraoperative death (death on table) (A1)
- Infection-Bacterial infection (B1)
- Infection-Viral infection (B2)
- Infection-HIV (B3)
- Infection-Fungal infection (B4)
- ...

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Results: Public sharing

Quality assurance Follow-up Liver Transplant (AQUA)

- State: Current
- Version: 4
- License:
- Created at: 2015-06-16
- Uploaded by: Julian Varqhe
- Your rating: ★★★★★
- Average rating: ★★★★★
- Keywords: Liver Transplantation, Follow-Up, Quality Assurance

Survival status of recipient (0)

- Name: Überlebensstatus des Empfängers
- Description: Survival status of recipient
- Item: Deceased patient*
- Datatype: integer
- Aliases:
  - UMLS CUI-1: C1306577
- Codelistitems:
  - no(0)
  - yes(1)
  - unknown or follow-up not possible(9)
Results: Common Data Elements

• Which item concepts are most common?
Results: Common Data Elements

Table 2. Top five extract of the most frequent administrative or demographic concepts, CUI: Concept unique identifier.

<table>
<thead>
<tr>
<th>Concept Name</th>
<th>CUI</th>
<th>Frequency</th>
</tr>
</thead>
<tbody>
<tr>
<td>Organ recipient/donor ID (ET Number)</td>
<td>-not available-</td>
<td>15</td>
</tr>
<tr>
<td>Date of birth</td>
<td>C0421451</td>
<td>15</td>
</tr>
<tr>
<td>Gender</td>
<td>C0079399</td>
<td>14</td>
</tr>
<tr>
<td>Facility's Section Identifier of service provider</td>
<td>C1547540</td>
<td>12</td>
</tr>
<tr>
<td>Medical specialty of service provider</td>
<td>C0037778</td>
<td>12</td>
</tr>
</tbody>
</table>

Table 3. Top five extract of the most frequent clinical concepts.

<table>
<thead>
<tr>
<th>Concept Name</th>
<th>CUI</th>
<th>Frequency</th>
</tr>
</thead>
<tbody>
<tr>
<td>Cause of death</td>
<td>C0007465</td>
<td>11</td>
</tr>
<tr>
<td>Diagnosis/Diagnoses</td>
<td>C0011900</td>
<td>8</td>
</tr>
<tr>
<td>Steroids (Pharmacotherapy)</td>
<td>C0038317</td>
<td>6</td>
</tr>
<tr>
<td>Azathioprine (Pharmacotherapy)</td>
<td>C0004482</td>
<td>6</td>
</tr>
<tr>
<td>Blood group (AB-classification)</td>
<td>C0427624</td>
<td>6</td>
</tr>
</tbody>
</table>

➢ Full list available in paper supplement [16]

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Results: Cumulative concept coverage

Figure 1. Cumulative frequencies, starting left with most frequent concept ‘Organ recipient/donor ID (ET Number)’

- by only using 40% of all unique concepts, 80% of all concepts occurrences in the QA-forms can be covered
Summary

- First repository for E-forms for QA + multilingual + semantic codes
- Repository provides open access for worldwide reuse, discussion and versioning
- UMLS-coverage analysis indicates concept coverage of 92% with few but critically important concept definition gaps

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Limitations

• Adoption into local information systems might require further implementation details (medical relevance, value domain, conditional items, further item description)
• UMLS coding can be ambiguous (no classification)
• Translation not validated (e.g. by backtranslation)
References

[16] https://drive.google.com/folderview?id=0BxfnhHTIk8tqelUwMII2UXInU1E&usp=sharing


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