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Standardized Quality Assurance Forms for Organ Transplantations

with Multilingual Support, Open Access and UMLS Coding

By Julian Varghese

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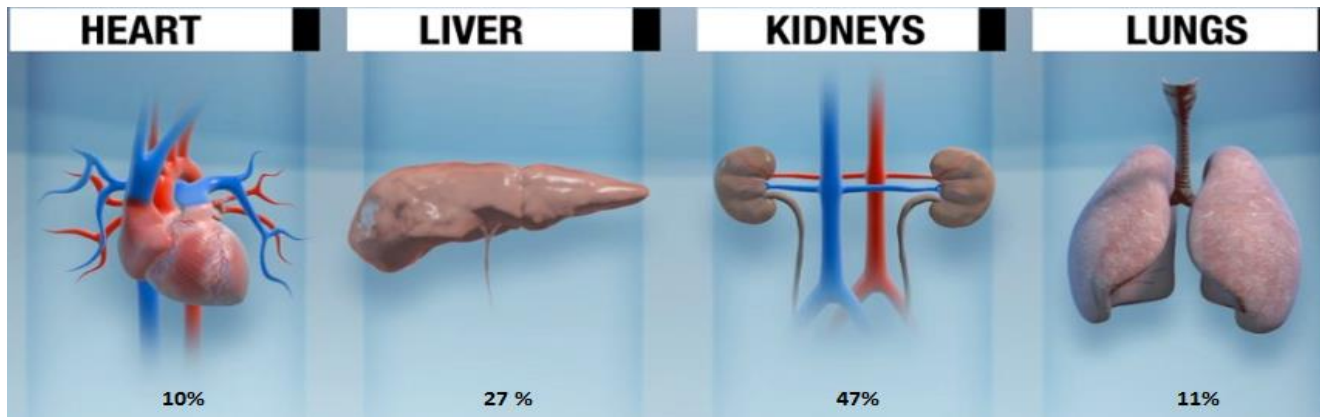
Institute of Medical Informatics

University of Muenster, Germany



Organ Transplantations

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



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

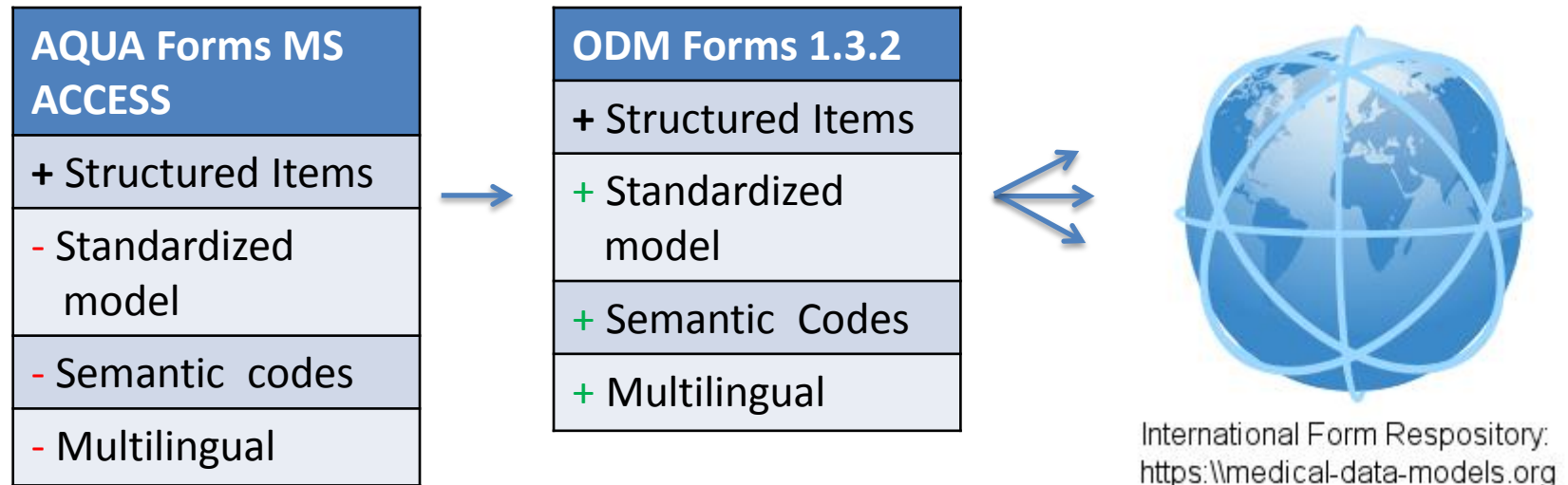
- Since 2000: All German health service providers are obliged by law to apply Quality Assurance for Organ transplantations [5].
- Documentation forms established by the Institute for Applied Quality Improvement and Research in Health Care (AQUA)
 - Long term expert consensus-driven process
 - >4 million 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



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

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

Concept Name	Frequency
Recipient/donor ID as ET-Number	15
Exceptional MELD score	2
Medical Urgency Code ET-Status	1
Domino liver transplantation	1
Weight of resected liver	1


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)


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Medical Data Models



Portal




My forms



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A-Z

Keywords



Administration

Portal	
Best rated forms:	Medical Data Models offers:
CDASH LAB Result Assessment (Scenario ...	★★★★★
EHR4CR data inventory	★★★★★
WHO (Five) Well-Being Index	★★★★★
register Finish Cancer Registry cancer	★★★★★
NCI Standard Adverse Event/Serious Adve...	★★★★★
CDA discharge letter VHitG 1.50 CDA_disc...	★★★★★
CDASH	★★★★★
CDASH ECG – Scenario 2 (local processing)	★★★★★
Follow Up	★★★★★
Unfallhergang SHT-Register	★★★★★
	Current forms: 4123 Form versions: 10237 Itemgroups: 54148 Items: 346273 Tags: 18190 Ratings: 112 Comments: 35
	Most frequent keywords: Clinical Trial Treatment Form Breast Cancer Eligibility Determination Follow-Up Colorectal Neoplasms Leukemia On-Study Form Cancer Registration

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Results: Public sharing

Quality assurance Follow-up Liver Transplant (AQUA)

Documentation form for quality assurance in German Health Care by the institute for applied quality Improvement and Research in Health Care (Aqua), <https://www.aqua-institut.de/en/home>. Internal Aqua form version: LTXFU Specification 2015 V02

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



Download

Languages (2)

English

German

Languages (2)

English

German

Survival status of recipient (0)*

Deceased patient*

- no (0)
- yes (1)
- unknown or follow-up not possible (9)

Date of death (dd.mm.yyyy)

Überlebensstatus des Empfängers (0)*

Patient verstorben*

- nein (0)
- ja (1)
- unbekannt oder Follow-up nicht möglich (9)

Todesdatum (TT.MM.JJJJ)

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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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.

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

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

Concept Name	CUI	Frequency
Cause of death	C0007465	11
Diagnosis/Diagnoses	C0011900	8
Steroids (Pharmacotherapy)	C0038317	6
Azathioprine (Pharmacotherapy)	C0004482	6
Blood group (AB-classification)	C0427624	6

➤ Full list available in paper supplement [16]

Results: Cumulative concept coverage

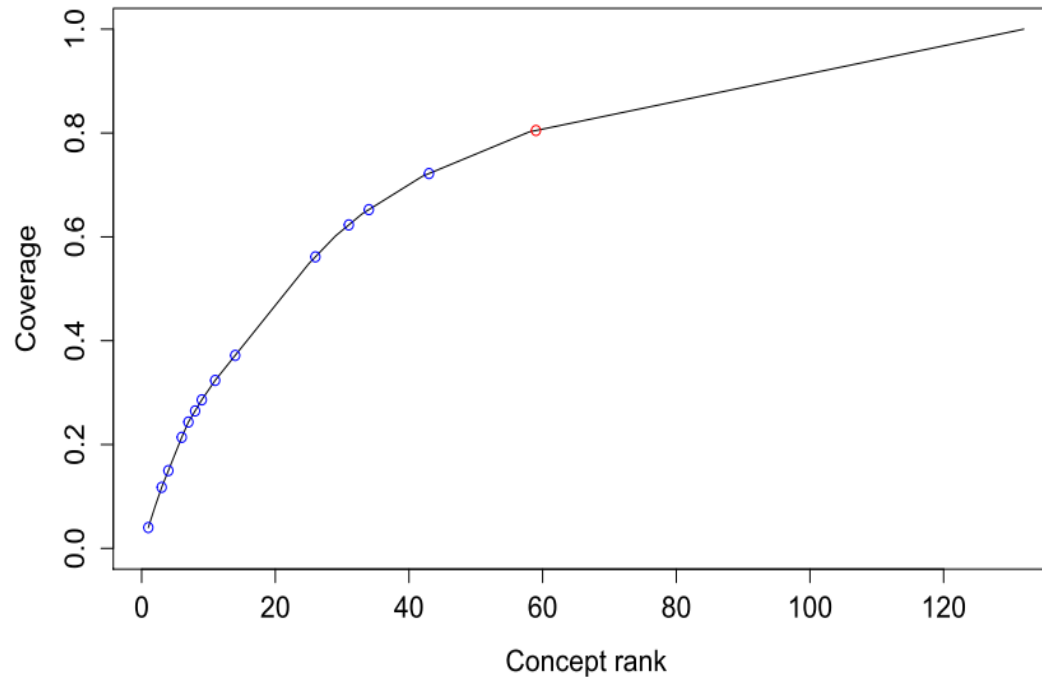


Figure 1. Cumulative frequencies, starting left with most frequent concept 'Organ recipient/donor ID (ET Number)'

- 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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CDASH ECG – Scenario 2 (local processing)		On-Study Form
Follow Up		Cancer
Unfallhergang SHT-Register		Registration

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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

- [1] J.L. Platt, New directions for organ transplantation, *Nature*, 1998, 392(6679 Suppl), 11-17.
- [2] P. Burra, M. De Bona, Quality of life following organ transplantation, *Transplant International*, 2007, 20(5), 397-409.
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- [5] A. Bramesfeld, G. Willms, Cross-Sectoral Quality Assurance, § 137a Social Code Book V, *Public Health Forum*, 2014: 22(2), 14.e1-14.e3.
- [6] G. Heller, J. Szecsenyi, G. Willms, B. Broge, Quality measurement using administrative data in mandatory quality assurance, *Zeitschrift für Evidenz, Fortbildung und Qualität im Gesundheitswesen*, 2014, 108(8-9), 465-469.
- [16] <https://drive.google.com/folderview?id=0BxfnhHTIk8tqelUwMII2UXInU1E&usp=sharing>
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- [I1] http://ichef.bbci.co.uk/news/660/media/images/68575000/jpg/_68575776_heart_donation_spl.jpg
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