

# Portal of Medical Data Models

Information Infrastructure for  
Medical Research and Healthcare

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# Agenda

- Background
- Portal of Medical Data Models
- Hands-on-training
- Discussion

# BACKGROUND

# The Current Information System Landscape in Healthcare

- Electronic Health Records (EHRs)
  - **25% - 40%** of physicians daily workload
  - Proprietary data models for each hospital
  - **> 1000 documentation forms** per hospital with uncontrolled redundancy
- Research documentation (EDC)
  - Large and increasing amount of CRFs per study:  
55 pages (1999-2002) => **180 pages** (2003-2006)
  - Large overlap with routine documentation, especially to exclude adverse events

# Medical Data Models: A LARGE-Scale Problem

- Disease-specific: ICD-10: ~13.300 diagnoses
- Complex vocabulary: ~300.000 terms (SNOMED)
- Language specific: EHR in the local language
- EHR-specific: >800 EHR-products in Europe
- Trial-specific: ~ 210.000 trials  
with >1000 data items per trial

Medical Data Models  
are complex and heterogeneous ...



**and >99% are secret !!!**

>99% of Medical data models are secret

Differentialblutbild			Datum: <input type="text"/> <input type="text"/> <input type="text"/> . <input type="text"/> <input type="text"/> <input type="text"/> . <input type="text"/> <input type="text"/> <input type="text"/> <input type="text"/>		
Haemoglobin		<input type="text"/>	<input type="radio"/> mmol/l <input type="radio"/> g/dl		
Leukozyten		<input type="text"/>	<input type="radio"/> GPt/l <input type="radio"/> / $\mu$ l <input type="radio"/> $10^3$ / $\mu$ l <input type="radio"/> /nl		
Neutrophile		<input type="text"/>	<input type="text"/>		%
oder	Stabkernige	<input type="text"/>	<input type="text"/>		%
	Segmentkernige	<input type="text"/>	<input type="text"/>		%
Lymphozyten		<input type="text"/>	<input type="text"/>		%
Monozyten		<input type="text"/>	<input type="text"/>		%
Eosinophile		<input type="text"/>	<input type="text"/>		%
Basophile		<input type="text"/>	<input type="text"/>		%
Blasten		<input type="text"/>	<input type="text"/>		%
Immunkomplexozyten		<input type="text"/>	<input type="text"/>		%
Myelozyten		<input type="text"/>	<input type="text"/>		%
Metamyelozyten		<input type="text"/>	<input type="text"/>		%
Sonstige Zellen		<input type="text"/>	<input type="text"/>		%
Thrombozyten		<input type="text"/>	<input type="radio"/> GPt/l <input type="radio"/> / $\mu$ l <input type="radio"/> $10^3$ / $\mu$ l <input type="radio"/> /nl		

Top Secret

# Semantic Annotation for Data Integration: Concepts

Attribute name NOT sufficient for data integration:

Example “size”:

Body height, Tumor diameter or Foot size ?

=> Semantic code provides clarity,  
e.g. Body height C0005890



# Semantic annotation for data integration:

## Permissible values

Data type is NOT sufficient for data integration:

Example “size”, data type FLOAT:

Unit m, cm or mm?

⇒ Unit must be provided,  
e.g. UCUM: m

Code list is NOT sufficient for data integration:

Example “gender”, code list “m=male, f=female”

⇒ Semantic codes provide clarity,  
e.g. male C0024554, female C0015780

Abstract ▾

Send to: ▾

Methods Inf Med. 2014;53(6):516-7. doi: 10.3414/ME14-04-0002. Epub 2014 Nov 7.

## Missing semantic annotation in databases. The root cause for data integration and migration problems in information systems.

Dugas M<sup>1</sup>.

 Author information

### Abstract

Data integration is a well-known grand challenge in information systems. It is highly relevant in medicine because of the multitude of patient data sources. Semantic annotations of data items regarding concept and value domain, based on comprehensive terminologies can facilitate data integration and migration. Therefore it should be implemented in databases from the very beginning.

PMID: 25377893 [PubMed - in process]





# Medical information management is a challenge



⇒ Astronomic number of medical forms !

⇒ Independently developed forms are incompatible

⇒ Compatible data only with form sharing

# **PORTAL OF MEDICAL DATA MODELS (MDM)**

<http://medical-data-models.org>

[MDM-Trailer](#)

# Open Medical Data Models: Goals

- **Improved design** of data models (Best Practice)
- **Accelerated development** of documentation forms
- **Standardized** forms
- Better **EHR-EDC-Integration** (semantic annotation)
- More **efficient clinical trials**

# Collaboration partners





## Welcome to the MDM-Portal!

You are on the website of the world's largest open-access registry for medical forms.



(c) Q.pictures / pixelio.de

watch our video

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**DFG**

In cooperation with



### Medical Data Models offers:

#### Current forms:

6319

#### Form versions:

13504

#### Items:

477198

#### Languages:

over 40

### Current publications:

Portal of medical data models: information infrastructure for medical research and healthcare [Dugas M, et al.]

Open Metadata/Open Access to Documentation Forms [Dugas M, et al.]

### Contact:

Institute of Medical Informatics  
Director: Prof. Dr. Martin Dugas  
Albert-Schweitzer-Campus 1, Building A11  
48149 Münster, Germany  
E-mail: imi@uni-muenster.de

## Table of contents:

1. Clinical Trials
  1. Eligibility Determination
  2. Medical History and physical examination
  3. Laboratory
  4. Apparative diagnostics
  5. Treatment
  6. Outcome and Follow-up
  7. Adverse Events
2. Electronic Health Records
3. Registries
4. Quality Assurance
5. Disease-Related Forms
  1. Cardiovascular Diseases
  2. Neurology
  3. Oncology
  4. Diabetes Mellitus
  5. Traumatic Injuries
6. Other

### Medical Data Models offers:

<b>Current forms:</b>	6319
<b>Form versions:</b>	13504
<b>Items:</b>	477198
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48149 Münster, Germany  
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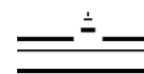
Funded by



In cooperation with



Institut für  
Medizinische Informatik



contact

Advanced search

You can type your search terms into the following fields. If you search for multiple terms in the title field you will get all the forms that meet at least one of those terms. You can specify your search by using the operators AND, OR and NOT.

WHO

You can filter your results by limiting them to forms tagged with the following keywords:

- ☐ Clinical Trial (378)
- ☐ Breast Neoplasms (135)
- ☐ Colorectal Neoplasms (87)
- ☐ Hepatitis C (67)
- ☐ Treatment Form (56)
- ☐ Follow-Up Studies (44)
- ☐ Quality of Life (39)
- ☐ Eligibility Determination (31)
- ☐ On-Study Form (27)
- ☐ Registration (27)

Load additional filters

You need to be logged in in order to compare forms with one another.

Displaying Form **1 - 30** of **409** in total

[! ← Previous](#) [1](#) [2](#) [3](#) [4](#) [5](#) [! ...!](#) [12](#) [13](#) [14](#) [Next →](#)

Rating	Forms	Actions
★★★★★	Breast Cancer Adverse Event NCT00382070 version 6, 2015-04-01	
★★★★★	Colorectal Cancer Non-Protocol Therapy NCT00303628 version 5, 2015-03-25	
★★★★★	WHO-5 version 16, 2016-05-02	
★★★★★	Integrated Fitness - Child Protocol PhenX Toolkit version 1, 2016-05-01	
★★★★★	Eligibility Breast Cancer NCT02448576 version 1, 2016-04-30	
★★★★★	Eligibility Advanced Breast Cancer NCT00754325 version 1, 2016-04-28	
★★★★★	Characteristics of Current Residence Protocol PhenX Toolkit version 2, 2016-04-26	
★★★★★	Cancer Treatments Protocol PhenX Toolkit version 2, 2016-04-26	
★★★★★	Sibship/Birth Order Protocol PhenX Toolkit version 2, 2016-04-26	
★★★★★	Eligibility Schizophrenia NCT00056498 version 1, 2016-04-24	
★★★★★	Eligibility Adult Acute Myeloid Leukemia With 11q23 (MLL) Abnormalities NCT01083706	

Funded by



contact

Form data

Detailed view

CC BY-NC 3.0

## WHO-5



WHO (Five) Well-Being Index (1998 version)  
<http://www.who-5.org>

**Created:** 2016-05-02 by Martin Dugas  
**Author / Copyright:** Psykiatric Center North Zealand, Hillerød, Denmark  
**License:** CC BY-NC 3.0



Quality of Life



Patient Reported Outcome (PRO)

You need to be logged in to download this form.

## Comments (0)

You need to be logged in to create comments.

Languages (29) ▾

Versions (15) ▾

### WHO (Five) Well-Being Index

## Over the last two weeks (0)

### I have felt cheerful and in good spirits

- ☐ All of the time(5)
- ☐ Most of the time(4)
- ☐ More than half of the time(3)
- ☐ Less than half of the time(2)
- ☐ Some of the time(1)
- ☐ At no time(0)

### I have felt calm and relaxed

- ☐ All of the time(5)
- ☐ Most of the time(4)
- ☐ More than half of the time(3)
- ☐ Less than half of the time(2)
- ☐ Some of the time(1)
- ☐ At no time(0)

### I woke up feeling fresh and rested

- ☐ All of the time(5)
- ☐ Most of the time(4)
- ☐ More than half of the time(3)
- ☐ Less than half of the time(2)
- ☐ Some of the time(1)
- ☐ At no time(0)

### My daily life has been filled with things that interest me

- ☐ All of the time(5)
- ☐ Most of the time(4)
- ☐ More than half of the time(3)
- ☐ Less than half of the time(2)
- ☐ Some of the time(1)
- ☐ At no time(0)

Form data

Detailed view

CC BY-NC 3.0

## WHO-5



WHO (Five) Well-Being Index (1998 version)  
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Quality of Life



Patient Reported Outcome (PRO)

Actions ▾

Download ▾

Downloads (1):

PDF downloads: 1

**Comments (0)**

Languages (29) ▾

Versions (15) ▾

S.0000

## WHO (Five) Well-Being Index

### Over the last two weeks

Name:Over the last two weeks

Description:Over the last two weeks

#### Item

I have felt cheerful and in good spirits

#### Description

I have felt cheerful and in good spirits

#### Datatype

integer

#### Aliases:

#### UMLS CUI [1]

C3261637

#### Measurement Units

#### Range checks

#### Codelistitems

All of the time(5)

Most of the time(4)

More than half of the time(3)

Less than half of the time(2)

Some of the time(1)

At no time(0)

<http://Medical-Data-Models.org>

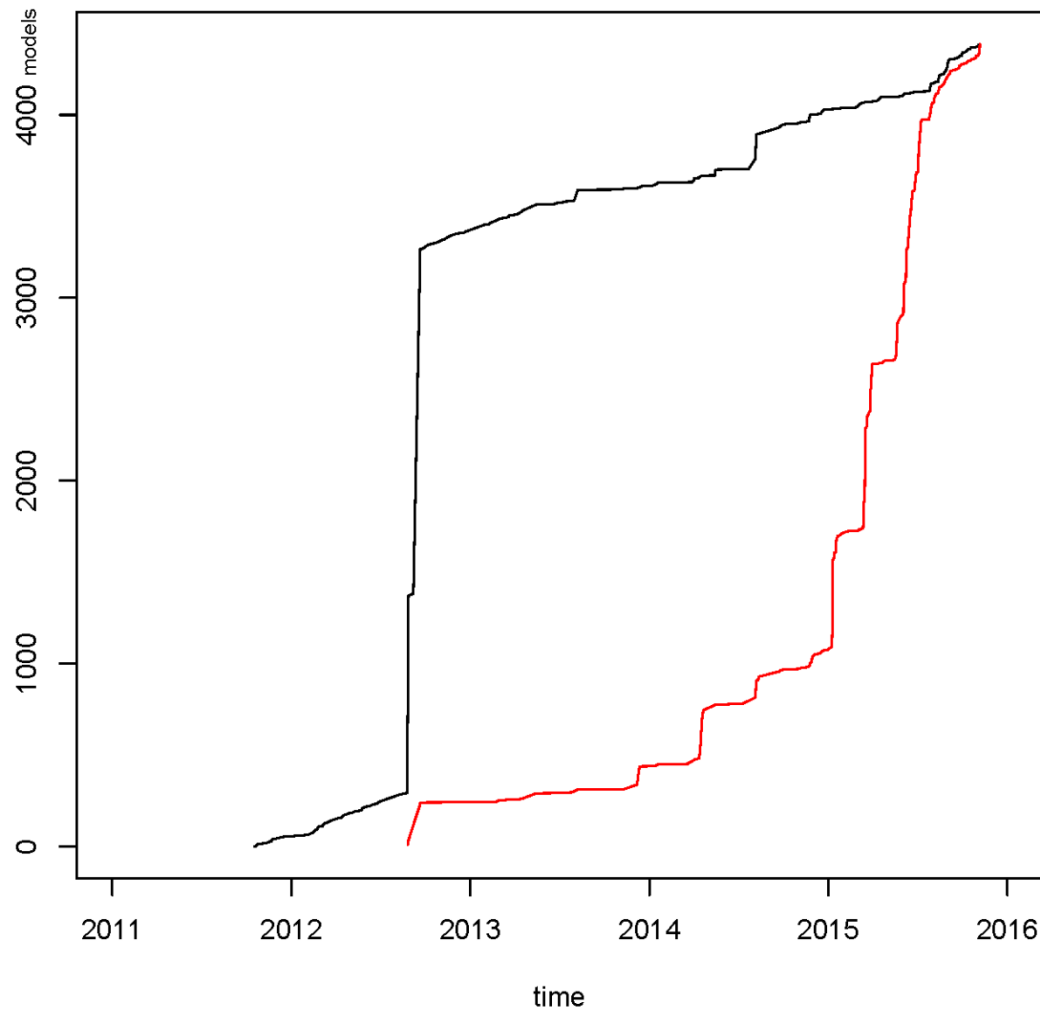
Largest public portal for medical forms worldwide

- Contents: Focus on oncology forms
  - ~6.300 Forms / 180.000 data elements
  - Pediatric oncology (GPOH): Ewing, EWOG MDS 2006, EWOG SAA 2010, CWS 2007-HR, SIOP CNS GCT II
  - Leukemia: CML TIGER, AML-AZA
- Semantic annotations:  
UMLS, SNOMED, MedDRA, LOINC codes
- CDISC ODM-Editor

# <http://Medical-Data-Models.org>

- Keyword search (MeSH, multilingual)
- Download formats:
  - **PDF**
  - **Excel, CSV**
  - **ODM**
  - **REDCap**
  - **CDA**
  - **FHIR**
  - **SQL**
  - **SPSS, R**
- Upload of new forms by users

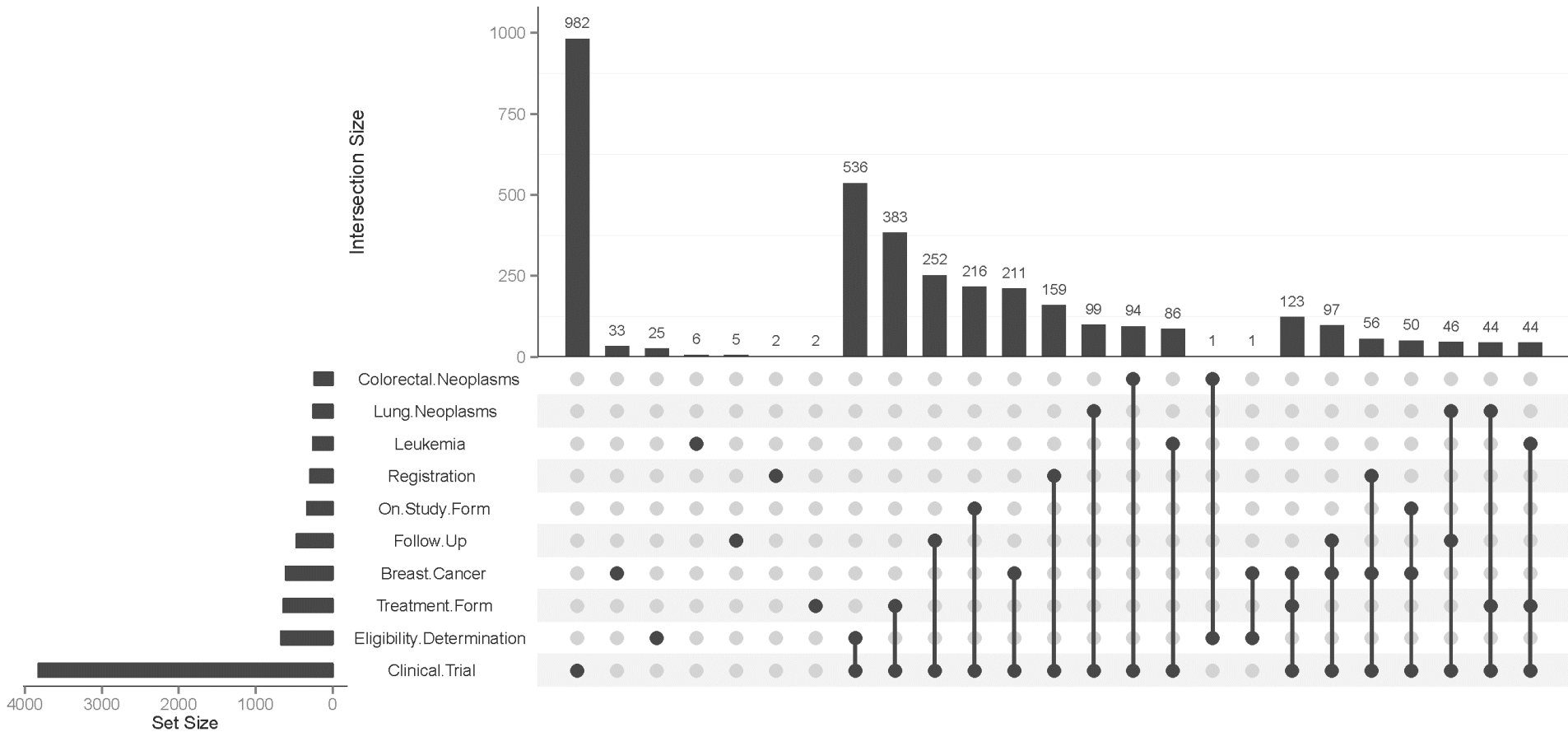
# Contents: Time course



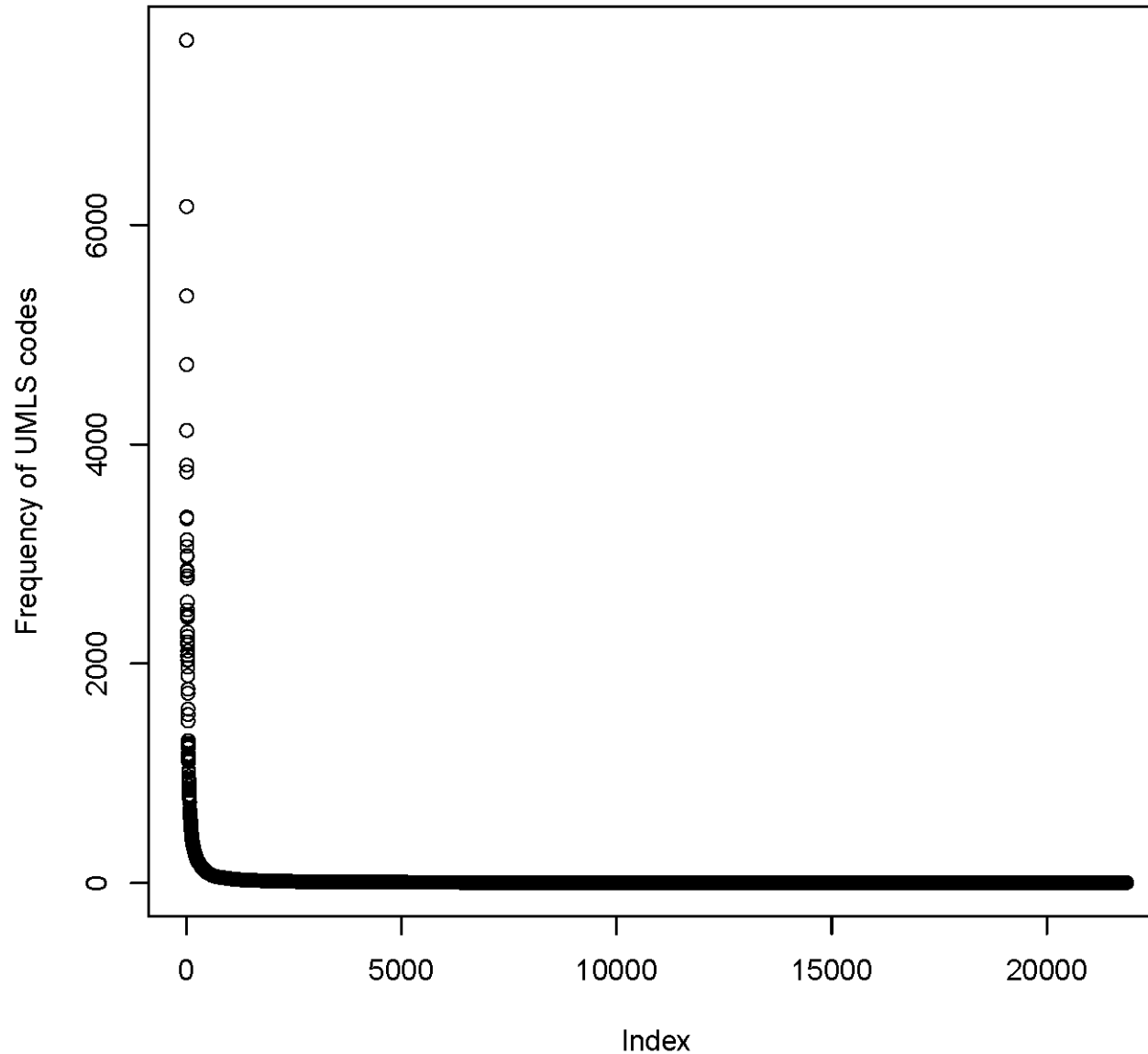
[Dugas et al., Database 2016, PMID 26868052]



# Frequent keywords



# Frequency distribution of UMLS codes: „long tail“



<http://Medical-Data-Models.org>

- Online-Discussion of forms:  
Comments at item-, item group- or form level
- Version management
- Multilingual forms: overall > 40 languages

# ODM-Editor

WHO (Five) Well-Being Index (WHO-5)			en ▾	Form manager
Over the last two weeks	Over the last two weeks			
Lately cheerful	I have felt cheerful and in good spirits	C3261637	integer	5=All of the time 4=Most of the time 3=More than half of the time 2=Less than half of the time 1=Some of the time 0=At no time
Lately relaxed	I have felt calm and relaxed	C3261651	integer	5=All of the time 4=Most of the time 3=More than half of the time 2=Less than half of the time 1=Some of the time 0=At no time
Lately active and vigorous	I have felt active and vigorous		integer	5=All of the time 4=Most of the time 3=More than half of the time 2=Less than half of the time 1=Some of the time 0=At no time
Lately slept well	I woke up feeling fresh and rested		integer	5=All of the time 4=Most of the time 3=More than half of the time 2=Less than half of the time 1=Some of the time 0=At no time
Lately daily life interesting	My daily life has been filled with things that interest me		integer	5=All of the time 4=Most of the time 3=More than half of the time 2=Less than half of the time 1=Some of the time 0=At no time
New item				
New itemgroup		Download ODM		Upload to Portal

« [Back to the list](#)

#### Scientific Domain

- ✦ [Biological and Medical Sciences](#)
- ✦ [Information Science and Technology](#)

#### RI Category

- ✦ [Telemedicine laboratories and E-Health technologies](#)
- ✦ [Repositories](#)
- ✦ [Databases](#)
- ✦ [Data Archives, Data Repositories and Collections](#)
- ✦ [Research Data Service Facilities](#)
- ✦ [Conceptual Models](#)
- ✦ [Clinical Research Centres](#)

[Home Page](#) » [List of Research Infrastructures](#) » [Portal of Medical Data Models](#)

## MDM - Portal of Medical Data Models

<https://medical-data-models.org>

#### Contact:

Prof. Dr. Martin Dugas

#### Details:

Average number of national users per year: 300

Average number of European users per year: 150

Average number of international users per year: 50

Main status: Operational from 2011

RI Type: Single-sited

#### Description:

The Portal of Medical Data Models (MDM) is a multi-lingual repository of medical data models for the scientific community. It contains data models from medical research (clinical studies) and routine patient care (electronic health records). MDM is an officially registered research infrastructure funded by the German Research Foundation (DFG). It was established in 2011 as an open access repository. To date there are >4.000 data models with >300.000 data elements available for download. Tumor medicine is a key topic in MDM and there are close links with the European Leukemia Network (ELN). MDM is the largest system of its kind world-wide. It is developed and maintained in close collaboration with the University Library of Münster.

#### Keywords:

Medical data model, clinical studies, electronic health records (EHR), CDISC ODM, HL7 CDA

#### Research Service(s):

##### Metadata for Information Systems in biomedical research

The MDM portal provides metadata for information systems in clinical research and routine healthcare.

#### Equipment:

##### Internet Portal for Medical Data Models

MDM content is available to the scientific community via <https://medical-data-models.org>



**MDM-PORTAL: LIVE DEMO**  
**[HTTP://MEDICAL-DATA-MODELS.ORG](http://MEDICAL-DATA-MODELS.ORG)**

# **HANDS-ON-TRAINING**

# DISCUSSION



- Test of MDM portal:  
download, upload, form rating & discussion,  
what contents should be added?  
what technical formats should be supported?
- Contribute ODM forms
- Test of EDC systems regarding ODM compatibility

# Portal of Medical Data Models

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Medical Research and Healthcare

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