



# Lessons Learned from the 2023 UK Studyathon

**OHDSI Community Call**  
**Jan. 23, 2024 • 11 am ET**



# Upcoming Community Calls

Date	Topic
Jan. 23	2023 UK Study-A-Thon Lessons Learned
Jan. 30	Phenotype Phebruary Introduction
Feb. 6	Workgroup OKRs / Phenotype Phebruary Update 1
Feb. 13	Workgroup OKRs / Phenotype Phebruary Update 2
Feb. 20	Workgroup OKRs / Phenotype Phebruary Update 3
Feb. 27	Workgroup OKRs / Phenotype Phebruary Update 4



# WG Leads: Please Sign Up For OKR Announcements

## Currently Signed Up:

- FHIR + OMOP
- Generative AI and Analytics in Healthcare (GAIA)
- HADES
- Methods Research
- NLP
- Perinatal and Reproductive Health
- Registry
- Steering Group
- Health Equity
- Oncology
- CDM
- Medical Devices

## 2024 Workgroup OKR Announcements

In order to highlight different initiatives and opportunities throughout the environment, workgroups will share their 2024 Objectives and Key Results (OKRs) during February community calls. These will be 2-3 minute presentations that will be posted to the OHDSI workgroup page. If you choose to include slides, please send them to Craig Sachson by 5 pm ET the day before your selected community call.

1. Workgroup Name \*

Enter your answer

2. Presenter Name \*

Enter your answer

3. Date to Present? \*

- Feb 6
- Feb 13
- Feb 20
- Feb 27



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Feb. 27	Workgroup OKRs / Phenotype Phebruary Update 4



# Three Stages of The Journey

**Where Have We Been?**

**Where Are We Now?**

**Where Are We Going?**





# OHDSI Shoutouts!



Congratulations to the team of **Xu Zuo**, **Yujia Zhou**, **Jon Duke**, **George Hripcsak**, **Nigam Shah**, **Juan Banda**, **Ruth Reeves**, **Timothy Miller**, **Lemuel Waitman**, **Karthik Natarajan**, and **Hua Xu** on the publication of **Standardizing Multi-site Clinical Note Titles to LOINC Document Ontology: A Transformer-based Approach** in the *2023 AMIA Annual Symposium Proceedings*.

AMIA Annual Symposium  
Proceedings Archive



[AMIA Annu Symp Proc.](#) 2023; 2023: 834–843.  
Published online 2024 Jan 11.

PMCID: PMC10785935  
PMID: [38222429](#)

## Standardizing Multi-site Clinical Note Titles to LOINC Document Ontology: A Transformer-based Approach

[Xu Zuo](#), M.S.,<sup>1</sup> [Yujia Zhou](#), M.D., M.S.,<sup>1</sup> [Jon Duke](#), M.D.,<sup>2, 10</sup> [George Hripcsak](#), M.D.,<sup>3, 10</sup> [Nigam Shah](#), Ph.D.,<sup>4, 10</sup> [Juan M. Banda](#), Ph.D.,<sup>5, 10</sup> [Ruth Reeves](#), Ph.D.,<sup>6, 10</sup> [Timothy Miller](#), Ph.D.,<sup>7, 10</sup> [Lemuel R Waitman](#), Ph.D.,<sup>8</sup> [Karthik Natarajan](#), Ph.D.,<sup>3, 10</sup> and [Hua Xu](#), Ph.D.<sup>9, 10</sup>

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### Abstract

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The types of clinical notes in electronic health records (EHRs) are diverse and it would be great to standardize them to ensure unified data retrieval, exchange, and integration. The LOINC Document Ontology (DO) is a subset of LOINC that is created specifically for naming and describing clinical documents. Despite the efforts of promoting and improving this ontology, how to efficiently deploy it in real-world clinical settings has yet to be explored. In this study we evaluated the utility of LOINC DO by mapping clinical note titles collected from five institutions to the LOINC DO and classifying the mapping into three classes based on semantic similarity between note *titles* and LOINC DO codes. Additionally, we developed a standardization pipeline that automatically maps clinical note titles from multiple sites to suitable LOINC DO codes, without accessing the content of clinical notes. The pipeline can be initialized with different large language models, and we compared the performances between them. The results showed that our automated pipeline achieved an accuracy of 0.90. By comparing the manual and automated mapping results, we analyzed the coverage of LOINC DO in describing multi-site clinical note titles and summarized the potential scope for extension.

Journal Article

Journal Article



# OHDSI Shoutouts!



Congratulations to the team of **Huzaifa Khan, Abu Saleh Mohammad Mosa, Vyshnavi Paka, Md Kamruz Zaman Rana, Vasanthi Mandhadi, Soliman Islam, Hua Xu, James C McClay, Sraboni Sarker, Praveen Rao, and Lemuel Waitman** on the publication of **Mapping Clinical Documents to the Logical Observation Identifiers, Names and Codes (LOINC) Document Ontology using Electronic Health Record Systems Structured Metadata in the 2023 AMIA Annual Symposium Proceedings.**

AMIA Annual Symposium  
Proceedings Archive



[AMIA Annu Symp Proc.](#) 2023; 2023: 1017-1026.  
Published online 2024 Jan 11.

PMCID: PMC1078591  
PMID: [3822232](#)

Mapping Clinical Documents to the *Logical Observation Identifiers, Names and Codes* (LOINC) Document Ontology using Electronic Health Record Systems Structured Metadata.

[Huzaifa Khan](#), B.S.,<sup>1,2</sup> [Abu Saleh Mohammad Mosa](#), Ph.D.,<sup>2</sup> [Vyshnavi Paka](#), M.S.,<sup>2</sup> [Md Kamruz Zaman Rana](#), M.S.,<sup>2</sup> [Vasanthi Mandhadi](#), M.S.,<sup>2</sup> [Soliman Islam](#), M.Sc.,<sup>2</sup> [Hua Xu](#), PhD,<sup>3,4</sup> [James C. McClay](#), M.D.,<sup>2</sup> [Sraboni Sarker](#), M.S.,<sup>5</sup> [Praveen Rao](#), Ph.D.,<sup>5</sup> and [Lemuel R. Waitman](#), Ph.D.<sup>2</sup>

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## Abstract

[Go to:](#)

As Electronic Health Record (EHR) systems increase in usage, organizations struggle to maintain and categorize clinical documentation so it can be used for clinical care and research. While prior research has often employed natural language processing techniques to categorize free text documents, there are shortcomings relative to computational scalability and the lack of key metadata within notes' text. This study presents a framework that can allow institutions to map their notes to the LOINC document ontology using a Bag of Words approach. After preliminary manual value- set mapping, an automated pipeline that leverages key dimensions of metadata from structured EHR fields aligns the notes with the dimensions of the document ontology. This framework resulted in 73.4% coverage of EHR documents, while also mapping 132 million notes in less than 2 hours; an order of magnitude more efficient than NLP based methods.



# OHDSI Shoutouts!



Congratulations to the team of **Joel Swerdel and Mitchell Conover** on the publication of **Comparing broad and narrow phenotype algorithms: differences in performance characteristics and immortal time incurred** in the *Journal of Pharmacy & Pharmaceutical Sciences*.



TYPE Original Research  
PUBLISHED 03 January 2024  
DOI 10.3389/jpps.2023.12095



## OPEN ACCESS

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RECEIVED 22 September 2023  
ACCEPTED 15 December 2023  
PUBLISHED 03 January 2024

CITATION  
Swerdel JN and Conover MM (2024),  
Comparing broad and narrow  
phenotype algorithms: differences in  
performance characteristics and  
immortal time incurred.  
*J. Pharm. Pharm. Sci.* 26:12095.  
doi: 10.3389/jpps.2023.12095

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## Comparing broad and narrow phenotype algorithms: differences in performance characteristics and immortal time incurred

Joel N. Swerdel <sup>1,2\*</sup> and Mitchell M. Conover <sup>1,2</sup>

<sup>1</sup>Observational Health Data Analytics, Global Epidemiology, Janssen Research and Development, Titusville, NJ, United States, <sup>2</sup>Observational Health Data Sciences and Informatics, New York, NY, United States

**Introduction:** When developing phenotype algorithms for observational research, there is usually a trade-off between definitions that are sensitive or specific. The objective of this study was to estimate the performance characteristics of phenotype algorithms designed for increasing specificity and to estimate the immortal time associated with each algorithm.

**Materials and methods:** We examined algorithms for 11 chronic health conditions. The analyses were from data from five databases. For each health condition, we created five algorithms to examine performance (sensitivity and positive predictive value (PPV)) differences: one broad algorithm using a single code for the health condition and four narrow algorithms where a second diagnosis code was required 1–30 days, 1–90 days, 1–365 days, or 1- all days in a subject's continuous observation period after the first code. We also examined the proportion of immortal time relative to time-at-risk (TAR) for four outcomes. The TAR's were: 0–30 days after the first condition occurrence (the index date), 0–90 days post-index, 0–365 days post-index, and 0–1,095 days post-index. Performance of algorithms for chronic health conditions was estimated using PheValuator (V2.1.4) from the OHDSI toolstack. Immortal time was calculated as the time from the index date until the first of the following: 1) the outcome; 2) the end of the outcome TAR; 3) the occurrence of the second code for the chronic health condition.





# Three Stages of The Journey

**Where Have We Been?**

**Where Are We Now?**

**Where Are We Going?**





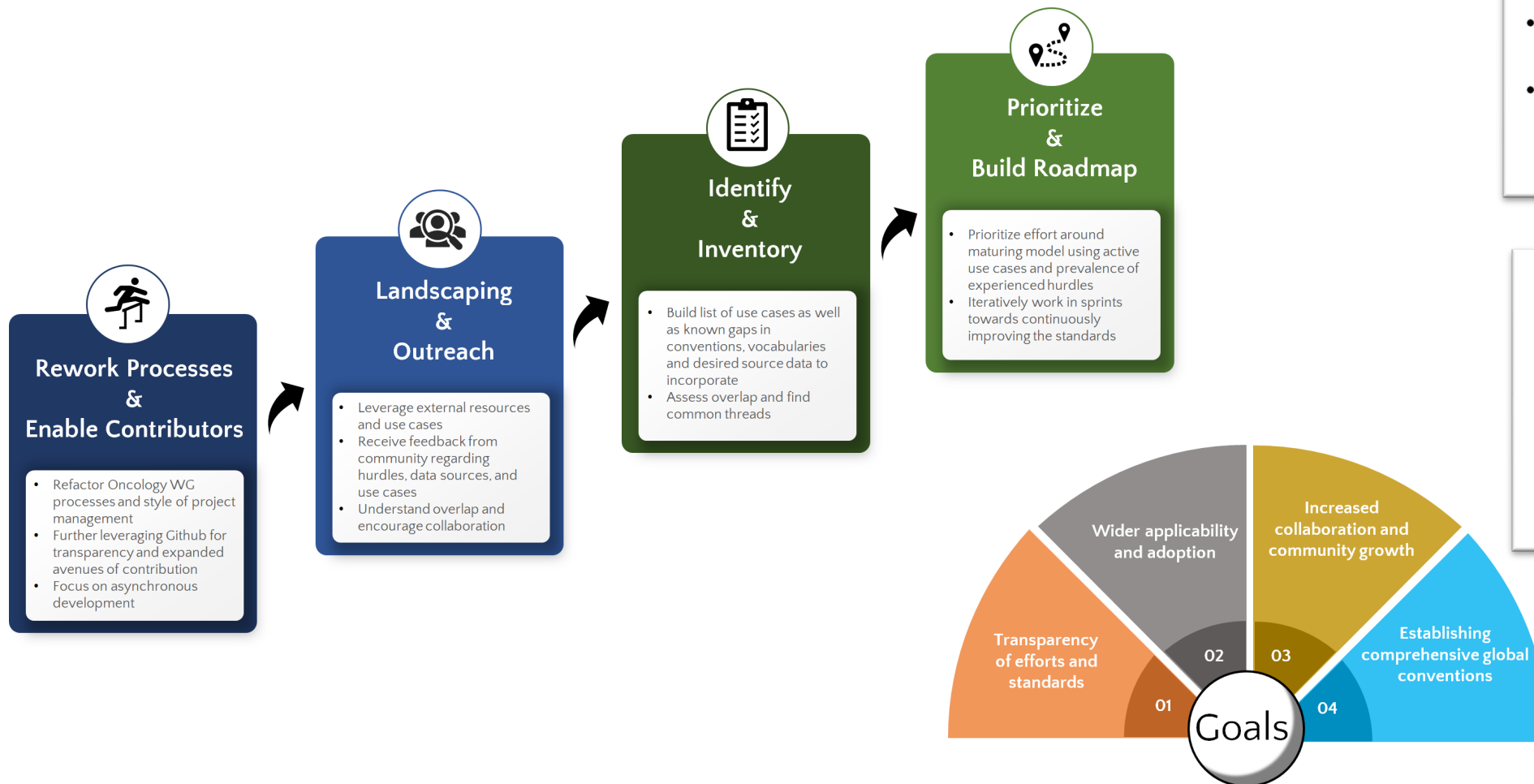
# Upcoming Workgroup Calls



Date	Time (ET)	Meeting
Tuesday	12 pm	Common Data Model Vocabulary Subgroup
Wednesday	7 am	Medical Imaging
Wednesday	9 am	OMOP CDM Oncology – Outreach/Research Subgroup
Wednesday	12 pm	Latin America
Wednesday	4 pm	Vulcan/OHDSI Meeting
Thursday	9:30 am	Network Data Quality
Thursday	7 pm	Dentistry
Friday	9 am	Phenotype Development and Evaluation
Friday	10 am	GIS – Geographic Information System
Friday	11 am	Clinical Trials
Friday	11:30 am	Steering Group
Monday	10 am	Healthcare Systems Interest Group

# Oncology Standards Maturity Effort (1 / 2)

## 2023: Outreach & Preparation



Community sentiment towards effort **overwhelmingly positive**

- Viewed as worthwhile and impactful
- Many community members willing to contribute time and resources

Landscaping & outreach have shown **significant overlap** in:

- Implementation barriers and roadblocks experienced
- Data sources and variables of interest
- Use cases and interest in network research

# Oncology Standards Maturity Effort (2 / 2)

## 2024: Collaborative Development

### *The stage is set!*

A **Github Project** has been created with:

- An inventory of the outstanding work identified by the outreach efforts
- Documentation on project processes, methods and contribution mechanisms
- Tasks broken down into smaller “chunks” to enable many small, and often asynchronous, contributions (rather than singular large bodies of work)
- Plan: complete as much as we can, prioritized by use cases, in preparation for a new stable release

### *Who should get involved?*

To achieve international and source-agnostic interoperability, specifically the harmonization of diverse data representations, a diverse group stakeholders, data sources and contributors is required.

### *Let's get to work!*

An OHDSI forum post contains an overview of the effort and relevant links : [t.ly/XbspZ](https://t.ly/XbspZ)

To supplement the documentation, there is a meeting scheduled tomorrow ( Teams/Onc/Dev Vocab Subgroup ) at this same time to give an overview and answer any questions. This will be recorded and linked in the documentation

Please see the “Getting Involved” section of the docs to **#joinTheJourney**



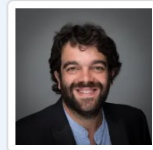
# 2024 Oxford Summer School: June 17-21

## Oxford Summer School 2024: Real World Evidence using the OMOP Common Data Model

### COURSE DIRECTORS

**Daniel Prieto-Alhambra**

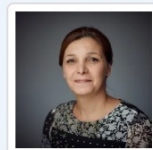
Professor of Pharmaco- and Device Epidemiology



### COURSE ADMINISTRATOR

**Mahkameh Mafi**

Personal Assistant to Professor Prieto-Alhambra



# Oxford Summer School 2024

*Real world evidence using the  
OMOP Common Data Model*

17 - 21 June 2024

Registration is now open





# #OHDSISocialShowcase This Week

## MONDAY

# Mapping of Critical Care EHR Flowsheet data to the OMOP CDM via SSSOM

(Polina Talapova, Andrew Williams, Nicolas Matentzoglou, Anna Ostropolets, Michael Kallfelz)

### Mapping of Critical Care EHR Flowsheet data to the OMOP CDM via SSSOM

PRESENTER:

Polina Talapova

polina.talapova@sciforce.tech



#### INTRO

In Intensive and Critical Care, patient data from Flowsheets are diverse. Current mapping methods within the OHDSI community lack adequate mapping metadata and documentation, which affects precision, especially for complex terms. This study recommends using the Simple Standard for Sharing Ontology Mappings (SSSOM) to improve and ensure reliable semantic mapping.

#### METHODS

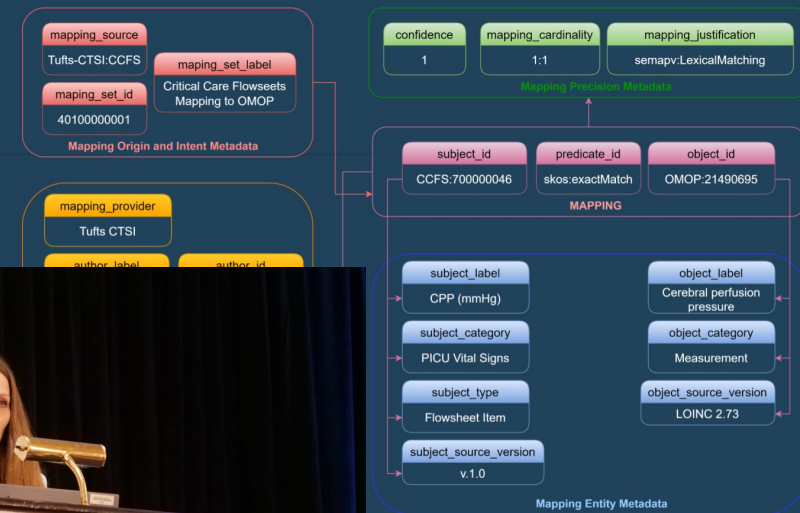
- Data harmonization of EHR Flowsheets using OMOP and SSSOM for:
  - structural mapping
  - semantic mapping
- A Python tool to integrate SSSOM mapping tables into OMOP CDM instance.



## PRECISE MAPPING = RELIABLE EVIDENCE

### SSSOM can bring OHDSI to this equation!

### A Simple Standard for Sharing Ontology Mappings



The MAPPING\_METADATA table:

CDM Field	Datatype	Required
mapping_concept_id	Integer	Yes
confidence	Float	Yes
predicate_id	varchar	Yes
mapping_justification	varchar	Yes
mapping_provider	varchar	Yes
author_id	int	Yes
reviewer_id	int	Yes
reviewer_label	int	Yes
mapping_tool	varchar	No
mapping_tool_version	varchar	No

#### CONCLUSION

- OMOP-on-SSSOM approach utilization pledges easy ETL pipeline integration and computationally-efficient mapping exchange and exports.
- Precision and uncertainty in mappings are explicit with SSSOM.
- Users can filter for top-tier confidence and accuracy in mappings.
- Mapping\_metadata table allows to store mapping metadata in OMOP CDM for transparency.
- SSSOM is effective for anomaly detection in OMOP Vocabularies.

#### FUTURE PLANS

- Evaluate the methodology based on user experience.
- Generate mapping metadata for ICD-10-CM-to-OMOP mappings.
- Request deduplication of standard concepts in OMOP Vocabularies.
- Promote SSSOM integration with mapping-related OHDSI tools, such as Jackalope, Usagi, Atlas, Athena, and Rabbit-in-the-Hat.



THE TEAM:  
Polina Talapova, Andrew Williams, Nicolas Matentzoglou, Anna Ostropolets, Michael Kallfelz



SSSOM  
SIMPLE STANDARD FOR SHARING ONTOLOGY MAPPINGS

Tufts CTSI Tufts Clinical and Translational Science Institute

sciforce







# #OHDSISocialShowcase This Week

## WEDNESDAY

# Generating Synthetic Electronic Health Records in OMOP using GPT

(Chao Pang, Xinzhuo Jiang, Nishanth Parameshwar Pavinkurve, Krishna S. Kalluri, Elise L. Minto, Karthik Natarajan)



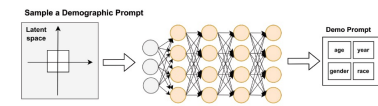
## Generating Synthetic Electronic Health Records in OMOP using GPT

Chao Pang<sup>1</sup>, Xinzhuo Jiang<sup>1</sup>, Nishanth Parameshwar Pavinkurve<sup>1</sup>, Krishna S. Kalluri<sup>1</sup>, Elise L. Minto<sup>1</sup>, Karthik Natarajan<sup>1</sup>  
<sup>1</sup>Columbia University Irving Medical Center, Department of Biomedical Informatics

### Background

This work focuses on synthetic data generation and demonstrate the capability of training a GPT model using a patient representation derived from CEHR-BERT, enabling the generation of patient sequences that can be seamlessly converted to the OMOP data format bi-direction.

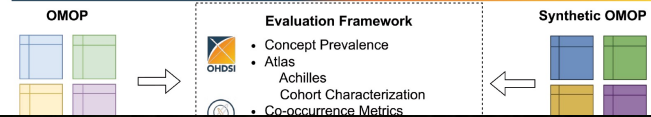
Current approach: Bag of Word + GAN Model



Use cases of synthetic EHR data:

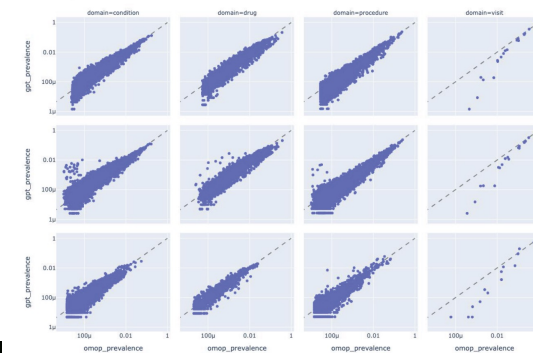
- Phenotype algorithm validation
- Prediction research
- Tool development
- External validation
- Training and education
- Debiasing the source data
- Counterfactual dataset

### Methods – Framework

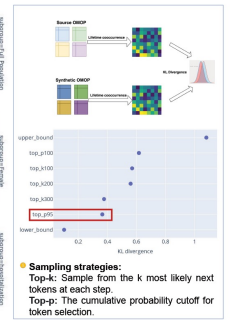


### Results

#### Concept Prevalence



#### Co-occurrence Metrics



#### Machine Learning Performance Metrics

Target Cohorts	Real data	Top P <sup>+</sup> cumulative probability cutoff P (%)		Top K <sup>+</sup> K concepts with the highest probabilities	
		Top P = 95%	Top P = 100%	Top K = 100	Top K = 300
HF Readmission	Pre = 25.7 AUC = 65.7 PR = 39.3	Pre = 27.6 AUC = 69.2 PR = 45.7	Pre = 28.4 AUC = 65.9 PR = 41.8	Pre = 30.7 AUC = 68.1 PR = 47.8	Pre = 26.5 AUC = 64.9 PR = 39.3
Hospitalization	Pre = 5.6 AUC = 75.3 PR = 19.5	Pre = 5.2 AUC = 77.1 PR = 21.4	Pre = 7.3 AUC = 68.3 PR = 16.5	Pre = 2.8 AUC = 87.0 PR = 22.1	Pre = 6.3 AUC = 78.7 PR = 24.6
COPD Readmission	Pre = 34.5 AUC = 74.2 PR = 83.8	Pre = 37.8 AUC = 76.4 PR = 84.4	Pre = 47.2 AUC = 74.1 PR = 67.2	Pre = 26.4 AUC = 75.9 PR = 90.3	Pre = 34.5 AUC = 68.9 PR = 80.2
Atib Ischemic Stroke	Pre = 8.7 AUC = 84.0 PR = 48.5	Pre = 10.2 AUC = 78.9 PR = 41.2	Pre = 10.4 AUC = 70.7 PR = 39.1	Pre = 16.6 AUC = 77.1 PR = 50.5	Pre = 10.8 AUC = 76.8 PR = 38.5
CAD CABG	Pre = 7.1 AUC = 88.4 PR = 55.9	Pre = 4.1 AUC = 81.5 PR = 25.2	Pre = 4.4 AUC = 52.9 PR = 4.3	Pre = 7.2 AUC = 75.6 PR = 38.5	Pre = 4.0 AUC = 79.0 PR = 24.1

### Conclusions

- First framework generated longitudinal synthetic EHR data using OMOP CDM.
- Designed an innovative patient representation by incorporating temporal information which allowed for an accurate reconstruction of patient medical timeline as compared to state of art methods.
- Comprehensive evaluation procedures showed that the synthetic data preserved the fundamental patient characteristics of the real population.

Contact: CEHR-BERT@lists.cumc.columbia.edu







# #OHDSISocialShowcase This Week

## THURSDAY

# Comparing concepts extracted from clinical Dutch text to conditions in the structured data

(Tom M. Seinen, Jan A. Kors, Erik M. van Mulligen, Peter R. Rijnbeek)

Comparing concepts extracted from clinical Dutch text to conditions in the structured data

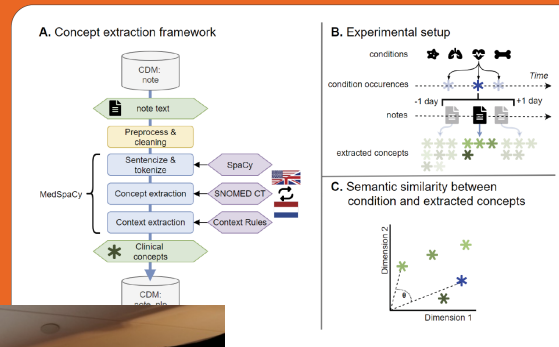
PRESENTER: Tom Seinen

**INTRO:** Unlocking valuable hidden information in clinical narratives is crucial for clinical research and practice. This study focuses on assessing the semantic similarity between coded conditions and extracted concepts using a Dutch concept extraction framework, contributing to bridging the gap for non-English language processing in healthcare.

### METHODS

- Data:** Integrated Primary Care Information (IPCI) Dutch general practitioner EHR database.
- Concept extraction:** MedSpaCy with Dutch resources.
- Setup:** We applied the concept extraction framework to clinical notes related to commonly occurring ICPC-1 coded conditions.
- Semantic similarity:** SNOMED CT concept (text and ontology-based) embeddings were used to calculate the similarity between coded conditions and extracted concepts.

## The information difference between coded conditions and their related clinical notes



### Methods Extra

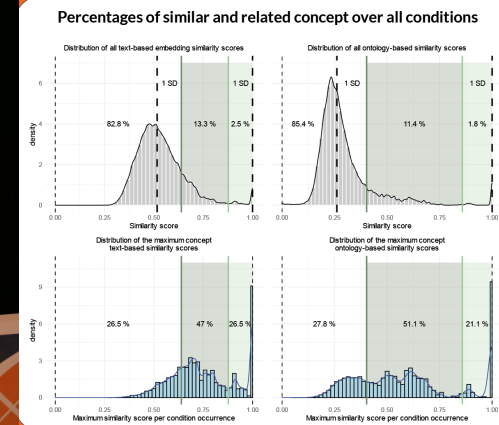
- Concept extraction framework:**
- Proprocessing:
    - Lowercase
    - Remove numbers
  - SpaCy dutch tokenization
  - QuickUMLS concept extraction
    - Dutch Snomed CT +
    - Patient preferred terms
  - Medspacy context extraction
    - Dutch context rules
- Annotation:**
- 2000 code occurrences
  - 200 different codes
- Embeddings:**
- Text-based embeddings (4)
  - Ontology-based embeddings (4)
- Similarity thresholds:**
- Similar concepts
    - From 1 SD from the max (1)
    - To the max (1)
  - Related concepts
    - From 1 SD from the median
    - To 1 SD from the max (1)
- Some numbers:**
- Codes occurring >100k times
  - 317 different ICPC condition codes
  - 29 million condition occurrences
  - 110 million notes
  - 429 million extracted concepts

### Future steps

- Concept extraction framework:**
- Adding more Dutch synonyms from UMLS
  - Comparison to other concept extraction frameworks
  - Try the same for another language



Tom Seinen, Erik van Mulligen, Jan Kors, Peter Rijnbeek  
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# #OHDSISocialShowcase This Week

## FRIDAY

# Finding a constrained number of predictor phenotypes for multiple outcome prediction

(**Jenna M Reps**, Jenna Wong, Egill A. Fridgeirsson, Chungsoo Kim, Luis H. John, Ross D. Williams, Patrick Ryan)

**Title:** Finding a constrained number of predictor phenotypes for multiple outcome prediction

PRESENTER: **Jenna M. Reps**

AIM:

- Can we perform a large-scale characterization study to identify a constrained set of predictors that generally discriminate whether a patient will develop a future outcome?
- If so, we can use these predictors to predict 100s or 1000s of outcomes.

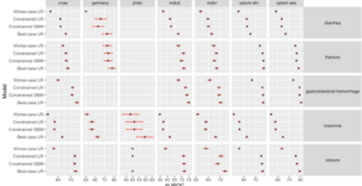
METHODS

1. We used six OMOP CDM databases (MDCR, MDCC, CCAE, JMDC, Germany and Australia).
2. We investigated candidate covariates consisting of conditions/drugs (grouped using the hierarchy) that are recorded in the 1-year prior to target cohort

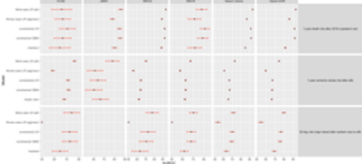
## It is possible to develop high performing models using the same small set of predictors



### RESULTS



The models using the constrained predictor sets (constrained LR/GBM) often performed similarly to the models that had thousands of candidate predictors (best case LR) and did better than models trained using only age/sex predictors (worse-case LR).



### EXPLORE YOUR RISKS

View: [WhatIHappenToMe.org](http://WhatIHappenToMe.org)



Jenna M Reps<sup>1</sup>, Jenna Wong<sup>2</sup>, Egill A. Fridgeirsson<sup>3</sup>, Chungsoo Kim<sup>4</sup>, Luis H. John<sup>5</sup>, Ross D. Williams<sup>6</sup>, Patrick Ryan<sup>7</sup>  
<sup>1</sup> Janssen Research and Development, Raritan, New Jersey, United States, <sup>2</sup> Department of Population Medicine, Harvard Pilgrim Health Care Institute and Harvard Medical School, Boston, MA, USA, <sup>3</sup> Department of Medical Informatics, Erasmus University Medical Center, Rotterdam, The Netherlands; <sup>4</sup> Department of Biomedical Sciences, Ajou University Graduate School of Medicine, Suwon, Republic of Korea



are a picture to  
w the predictors



# Opening: Research Information Specialist at UNC



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of NORTH CAROLINA  
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## Research Informatics Specialist

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- Print Preview
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Please see Special Instructions for more details.  
Working hours are Monday-Friday, 8:00 am – 6:00 pm EST with flexibility available within that window.

### Posting Information

Department	TraCS Institute-429801
Career Area	Information Technology
Posting Open Date	12/13/2023
Application Deadline	01/30/2024
Open Until Filled	No
Position Type	Permanent Staff (EHRA NF)
Working Title	Research Informatics Specialist
Appointment Type	EHRA Non-Faculty
Position Number	20060002
Vacancy ID	NF0007640
Full Time/Part Time	Full-Time Permanent
FTE	1

### Position Summary

Responsibilities include:

- \* Perform SQL-based programming against UNC’s clinical data warehouse to identify patient cohorts and develop patient datasets.
- \* Consult with and collaborate with researchers to ensure programming work aligns with project needs.
- \* Develop ETL (extract, transform, and load) and data integration processes to support common data models (OMOP, PCORnet) using appropriate technologies (SQL, Python, or R).
- \* Carefully following UNC’s regulatory and governance policy to ensure data integrity and security.
- \* In collaboration with IDSci team, identify potential enhancements in current workflows and data architecture.
- \* Implement quality assurance strategies, such as data validation and peer code review.
- \* Write and maintain up-to-date supporting documentation. Ensure code is well-commented and use GitLab/GitHub to manage code changes and track data lineage.
- \* Provide technical leadership and direction for assigned projects and/or data requests.

### Minimum Education and Experience Requirements

Master’s and 1-2 years’ experience; or Bachelors and 2-4 years’ experience; or will accept a combination of related education and experience in substitution.

### Required Qualifications, Competencies, and Experience

This position requires two or more years of relevant work experience and:

- \* Expert-level knowledge of SQL programming, data modeling, and relational database systems such as Oracle, Microsoft SQL Server, MySQL, etc.
- \* Past experience working with health care data in an analytic capacity, particularly electronic health record and/or claims data.
- \* Demonstrable past experience in scoping technical projects in terms of length of time, competencies and cost. Individual will be expected to manage multiple projects at once while delivering high-quality work on time.
- \* Excellent written and oral business communication skills. Public speaking at meetings and conferences may be required. The ability to clearly convey technical concepts to non-technical clients is a must.



# Opening: Data Steward at EBMD

## Description

**Are you looking for a job where you can make a difference and work in a non-profit?  
Would you like to be a part of an ambitious and international organisation on the cutting edge of science?  
Then this position might be right up your alley.**

**The EBMT is a non-profit medical and scientific organisation which hosts a unique patient registry providing a pool of data to perform studies and assess new trends.**

### **OUR MISSION**

**Save and improve the lives of patients with blood-related disorders.**

### **The Registry**

Holding the **data of over half a million patients**, the EBMT registry is the **starting point for all studies** carried out through the EBMT working parties. The department focuses on data collection processes, data quality monitoring, and maintenance of the database.

### **YOUR MISSION**

**Responsible for collecting, collating, and evaluating issues and problems with data and enforcing data usage policies.**

### **RESPONSIBILITIES AND TASKS**

#### **Data Stewardship:**

- Design, implementation and testing of new data collection processes including data collection forms (DCFs) development.
- Take care of the mapping of new items from DCFs to the OMOP CDM
- Providing input on data quality reports
- Check and clean data on request and ad hoc.
- Data retrieval including designing data reports and data report running.
- Carry out computerized system validation activities.
- Supporting consolidation/harmonization of data
- Creating standard data definitions, and maintain a consistent use of data assets across the organization
- Documenting data policies and data standards



# Where Are We Going?

**Any other announcements  
of upcoming work, events,  
deadlines, etc?**





# Three Stages of The Journey

**Where Have We Been?**

**Where Are We Now?**

**Where Are We Going?**





# Jan 23: 2023 UK Study-a-Thon Lessons Learned



**Dani Prieto-Alhambra**

Professor of Pharmaco- and Device Epidemiology, Oxford University



**Jennifer Lane**

NIHR Clinical Lecturer in Trauma and Orthopaedic Surgery, Barts Bone and Joint Health, Queen Mary Univ. of London



**Katherine Donegan**

Head of Epidemiology, MHRA



**Annika Jodicke**

Senior Researcher in Pharmacoepidemiology, University of Oxford



**The weekly OHDSI community call is held every Tuesday at 11 am ET.**

**Everybody is invited!**

**Links are sent out weekly and available at:**  
**[ohdsi.org/community-calls](https://ohdsi.org/community-calls)**