



Building The OHDSI Evidence Network Sprint, Final Session

OHDSI Community Call
Aug. 20, 2024 • 11 am ET



Upcoming Community Calls

Date	Topic
Aug. 20	Building The OHDSI Evidence Network Sprint – Open Discussion
Aug. 27	canceled due to ISPE 2024
Sept. 3	New Standardized Vocabularies Release
Sept. 10	Asia-Pacific Regional Updates
Sept. 17	TBA
Sept. 24	Recent OHDSI Publications



Three Stages of The Journey

Where Have We Been?

Where Are We Now?

Where Are We Going?





OHDSI Shoutouts!



Congratulations to the team of **Najia Ahmadi, Michele Zoch, Oya Guengoeze, Carlo Facchinello, Antonia Mondorf, Katharina Stratmann, Khader Musleh, Hans-Peter Erasmus, Jana Tchertov, Richard Gebler, Jannik Schaaf, Lena S. Frischen, Azadeh Nasirian, Jiabin Dai, Elisa Henke, Douglas Tremblay, Andrew Srisuwananukorn, Martin Bornhäuser, Christoph Röllig, Jan-Niklas Eckardt, Jan Moritz Middeke, Markus Wolfien and Martin Sedlmayr** on the publication of **How to customize common data models for rare diseases: an OMOP-based implementation and lessons learned** in the *Orphanet Journal of Rare Diseases*.

Ahmadi et al.
Orphanet Journal of Rare Diseases (2024) 19:298
<https://doi.org/10.1186/s13023-024-03312-9>

Orphanet Journal of
Rare Diseases

RESEARCH

Open Access



How to customize common data models for rare diseases: an OMOP-based implementation and lessons learned

Najia Ahmadi^{1*}, Michele Zoch¹, Oya Guengoeze², Carlo Facchinello², Antonia Mondorf², Katharina Stratmann², Khader Musleh², Hans-Peter Erasmus², Jana Tchertov¹, Richard Gebler¹, Jannik Schaaf¹, Lena S. Frischen⁴, Azadeh Nasirian⁷, Jiabin Dai¹, Elisa Henke¹, Douglas Tremblay⁵, Andrew Srisuwananukorn⁶, Martin Bornhäuser⁸, Christoph Röllig⁸, Jan-Niklas Eckardt^{8,9}, Jan Moritz Middeke^{8,9}, Markus Wolfien^{1,10} and Martin Sedlmayr¹

Abstract

Background Given the geographical sparsity of Rare Diseases (RDs), assembling a cohort is often a challenging task. Common data models (CDM) can harmonize disparate sources of data that can be the basis of decision support systems and artificial intelligence-based studies, leading to new insights in the field. This work is sought to support the design of large-scale multi-center studies for rare diseases.

Methods In an interdisciplinary group, we derived a list of elements of RDs in three medical domains (endocrinology, gastroenterology, and pneumonology) according to specialist knowledge and clinical guidelines in an iterative process. We then defined a RDs data structure that matched all our data elements and built Extract, Transform, Load (ETL) processes to transfer the structure to a joint CDM. To ensure interoperability of our developed CDM and its subsequent usage for further RDs domains, we ultimately mapped it to Observational Medical Outcomes Partnership (OMOP) CDM. We then included a fourth domain, hematology, as a proof-of-concept and mapped an acute myeloid leukemia (AML) dataset to the developed CDM.

Results We have developed an OMOP-based rare diseases common data model (RD-CDM) using data elements from the three domains (endocrinology, gastroenterology, and pneumonology) and tested the CDM using data from the hematology domain. The total study cohort included 61,697 patients. After aligning our modules with those of Medical Informatics Initiative (MII) Core Dataset (CDS) modules, we leveraged its ETL process. This facilitated the seamless transfer of demographic information, diagnoses, procedures, laboratory results, and medication modules from our RD-CDM to the OMOP. For the phenotypes and genotypes, we developed a second ETL process. We finally derived lessons learned for customizing our RD-CDM for different RDs.

Discussion This work can serve as a blueprint for other domains as its modularized structure could be extended towards novel data types. An interdisciplinary group of stakeholders that are actively supporting the project's progress is necessary to reach a comprehensive CDM.



OHDSI Shoutouts!



Congratulations to the team of **Mathilde Fruchart, Paul Quindroit, Chloé Jacquemont, Jean-Baptiste Beuscart, Matthieu Calafiore, and Antoine Lamer** on the publication of **Transforming Primary Care Data Into the Observational Medical Outcomes Partnership Common Data Model: Development and Usability Study** in *JMIR Medical Informatics*.

JMIR MEDICAL INFORMATICS

Fruchart et al

Original Paper

Transforming Primary Care Data Into the Observational Medical Outcomes Partnership Common Data Model: Development and Usability Study

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Abstract

Background: Patient-monitoring software generates a large amount of data that can be reused for clinical audits and scientific research. The Observational Health Data Sciences and Informatics (OHDSI) consortium developed the Observational Medical Outcomes Partnership (OMOP) Common Data Model (CDM) to standardize electronic health record data and promote large-scale observational and longitudinal research.

Objective: This study aimed to transform primary care data into the OMOP CDM format.

Methods: We extracted primary care data from electronic health records at a multidisciplinary health center in Wattrelos, France. We performed structural mapping between the design of our local primary care database and the OMOP CDM tables and fields. Local French vocabularies concepts were mapped to OHDSI standard vocabularies. To validate the implementation of primary care data into the OMOP CDM format, we applied a set of queries. A practical application was achieved through the development of a dashboard.



OHDSI Shoutouts!



Congratulations to the team of **Nicola Barclay, Edward Burn, Antonella Delmestri, Talita Duarte-Salles, Asieh Golozar, Wai Yi Man, Eng Hooi Tan, Ilona Tietzova, OPTIMA Consortium, Daniel Prieto-Alhambra and Danielle Newby** on the publication of **Trends in incidence, prevalence, and survival of breast cancer in the United Kingdom from 2000 to 2021** in *Scientific Reports*.

scientific reports



OPEN Trends in incidence, prevalence, and survival of breast cancer in the United Kingdom from 2000 to 2021

Nicola L. Barclay¹, Edward Burn¹, Antonella Delmestri¹, Talita Duarte-Salles^{2,3}, Asieh Golozar^{4,5}, Wai Yi Man¹, Eng Hooi Tan¹, Ilona Tietzova⁶, OPTIMA Consortium*, Daniel Prieto-Alhambra^{1,3,6} & Danielle Newby¹

Breast cancer is the most frequently diagnosed cancer in females globally. However, we know relatively little about trends in males. This study describes United Kingdom (UK) secular trends in breast cancer from 2000 to 2021 for both sexes. We describe a population-based cohort study using UK primary care Clinical Practice Research Datalink (CPRD) GOLD and Aurum databases. There were 5,848,436 eligible females and 5,539,681 males aged 18+ years, with ≥ one year of prior data availability in the study period. We estimated crude breast cancer incidence rates (IR), prevalence and survival probability at one-, five- and ten-years after diagnosis using the Kaplan–Meier method. Analyses were further stratified by age. Crude IR of breast cancer from 2000 to 2021 was 194.4 per 100,000 person-years for females and 1.16 for males. Crude prevalence in 2021 was 2.1% for females and 0.009% for males. Both sexes have seen around a 2.5-fold increase in prevalence across time. Incidence increased with age for both sexes, peaking in females aged 60–69 years and males 90+. There was a drop in incidence for females aged 70–79 years. From 2003–2019, incidence increased > twofold in younger females (aged 18–29: IR 2.12 in 2003 vs. 4.58 in 2018); decreased in females aged 50–69 years; and further declined from 2015 onwards in females aged 70–89 years. Survival probability for females after one-, five-, and ten-years after diagnosis was 95.1%, 80.2%, and 68.4%, and for males 92.9%, 69.0%, and 51.3%. Survival probability at one-year increased by 2.08% points, and survival at five years increased by 5.39% from 2000–2004 to 2015–2019 for females, particularly those aged 50–70 years. For males, there were no clear time-trends for short-term and long-term survival probability. Changes in incidence of breast cancer in females largely reflect the success of screening programmes, as rates rise and fall in synchronicity with ages of eligibility for such programmes. Overall survival from breast cancer for females has improved from 2000 to 2021, again reflecting the success of screening programmes, early diagnosis, and improvements in treatments. Male breast cancer patients have worse survival outcomes compared to females, highlighting the need to develop male-specific diagnosis and treatment strategies to improve long-term survival in line with females.



OHDSI Shoutouts!



Congratulations to the team of **Nhung TH Trinh, Jared Houghtaling, Fabian Bernal, Saeed Hayati, Luigi Maglanoc, Angela Lupattelli, Lars Halvorsen, and Hedvig Nordeng** on the publication of **Harmonizing Norwegian registries onto OMOP common data model: Mapping challenges and opportunities for pregnancy and COVID-19 research** in the *International Journal of Medical Informatics*.



Harmonizing Norwegian registries onto OMOP common data model: Mapping challenges and opportunities for pregnancy and COVID-19 research

Nhung TH Trinh^{a,*}, Jared Houghtaling^b, Fabian LM Bernal^c, Saeed Hayati^a, Luigi A Maglanoc^c, Angela Lupattelli^a, Lars Halvorsen^b, Hedvig ME Nordeng^{a,d}

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COVID-19
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OMOP
Common data model

ABSTRACT

Objective: Norwegian health registries covering entire population are used for administration, research, and emergency preparedness. We harmonized these data onto the Observational Medical Outcomes Partnership common data model (OMOP CDM) and enrich real-world data in OMOP format with COVID-19 related data.

Methods: Data from six registries (2018–2021) covering birth registrations, selected primary and secondary care events, vaccinations, and communicable disease notifications were mapped onto the OMOP CDM v5.3. An Extract-Transform-Load (ETL) pipeline was developed on simulated data using data characterization documents and scanning tools. We ran dashboard quality checks, cohort generations, investigated differences between source and mapped data, and refined the ETL accordingly.

Results: We mapped 1.5 billion rows of data of 5,673,845 individuals. Among these, there were 804,277 pregnancies, 483,585 mothers together with 792,477 children, and 472,948 fathers. We identified 382,516 positive tests for COVID-19 in 380,794 patients. These figures are consistent with results from source data. In addition to 11 million source codes mapped automatically, we mapped 237 non-standard codes to standard concepts and introduced 38 custom concepts to accommodate pregnancy-related terminologies that were not supported by OMOP CDM vocabularies. A total of 3,700/3,705 (99.8%) checks passed. The 5 failed checks could be explained by the nature of the data and only represent a small number of records.

Discussion and conclusion: Norwegian registry data were successfully harmonized onto OMOP CDM with high level of concordance and provides valuable source for federated COVID-19 related research. Our mapping experience is highly valuable for data partners with Nordic health registries.



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Upcoming Workgroup Calls



Date	Time (ET)	Meeting
Tuesday	1 pm	Common Data Model
Wednesday	4 pm	Joint Vulcan/OHDSI Meeting
Wednesday	7 pm	Medical Imaging
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	11:30 am	Steering Group
Monday	9 am	Vaccine Vocabulary
Monday	10 am	Healthcare Systems Interest Group
Monday	10 am	CDM Survey Subgroup



2024 Global Symposium

Oct. 22-24 • Hyatt Regency Hotel, New Brunswick, N.J.

Registration is OPEN for the 2024 OHDSI Global Symposium. Collaborator Showcase notifications are taking place this week. Agendas and tutorial/workgroup schedules are posted.

Tuesday: Tutorials

Wednesday: Plenary/Showcase

Thursday: Workgroup Activities

ohdsi.org/OHDSI2024





2024 APAC Symposium

Dec. 4-8 • Marina Bay Sands & National University of Singapore (NUS)

Preliminary Dates To Know

Sept. 15: Collaborator Showcase Submission Deadline

Sept. 16-20: Collaborator Showcase Submission Review

Oct. 31: Notification of Acceptance

Symposium Agenda

Dec. 4: Tutorial at NUS

Dec. 5-6: Main Conference at Marina Bay Sands

Dec. 7-8: Datathon at NUS

Registration Information is coming soon!

ohdsi.org/APAC2024





The Center for Advanced Healthcare Research Informatics (CAHRI) at Tufts Medicine welcomes:



Ismail Gögenur, MD, DMSc

Dr. Gögenur is Chair of Surgery at the University of Copenhagen and Director of the Center for Surgical Science at Zealand University Hospital.

Andreas Weinberger Rosen, MD, MPM

Dr. Weinberger Rosen is a Researcher at the Center for Surgical Science at Zealand University Hospital.



'AI-augmented decision support for surgical oncology – The Danish experience'

August 29, 2024, 11am-12pm EST Virtually via [Zoom](#)

Please contact Marty Alvarez at malvarez2@tuftsmedicalcenter.org for calendar invite or questions.

TuftsMedicine
Tufts Medical Center



#OHDSISocialShowcase

MONDAY

Transforming Clinical Trial Data to the OMOP CDM

(**Cynthia Sung**, Mike Hamidi, Zhen Lin, Tom Walpole, Rebecca Baker, Melissa Cook, Shital Desai, Priya Gopal, Dan Hartley, Vojtech Huser, Priya Meghrajani, Tra Nguyen, Paul Orona, Katy Sadowski, Sebastiaan van Sandijk, Philip Solovyev, Ramona Walls, Kenneth J. Wilkins, Qi Yang, and the Clinical Trial Working Group)



Transformation of clinical trial data to the OMOP CDM will open new opportunities to compare observational real world data (RWD) and data from randomized controlled trials (RCTs)

Transforming Clinical Trial Data to the OMOP CDM

Cynthia Sung¹, Mike Hamidi^{2*}, Zhen Lin^{3*}, Tom Walpole^{4*}, Rebecca Baker⁵, Melissa Cook⁶, Shital Desai⁷, Priya Gopal⁷, Dan Hartley⁸, Vojtech Huser⁹, Priya Meghrajani¹⁰, Tra Nguyen¹¹, Paul Orona¹², Katy Sadowski¹³, Sebastiaan van Sandijk⁸, Philip Solovyev⁸, Ramona Walls⁵, Kenneth J. Wilkins¹⁴, Qi Yang¹⁵, and the Clinical Trial Working Group; *CTWG Co-leads

¹Duke-NUS Medical School, ²Independent Consultant, ³Robot Bacon Corp, ⁴ZS, ⁵CDISC, ⁶Essex Management, ⁷Flatiron Health, ⁸C-PATH, ⁹Odyssey ¹⁰Talosix, ¹¹Boston Medical Center, ¹²Kaiser-Permanente, ¹³TrialSpark, ¹⁴National Institute of Diabetes, Digestive and Kidney Diseases, ¹⁵IQVIA

Background

The OMOP Common Data Model (CDM) was originally designed to conduct analyses on observational data, rather than clinical trial data. Yet, a large volume of patient-level data exists from clinical trials that would be informative to compare to observational data. The Clinical Trial Working Group (CTWG) is developing a general guideline to facilitate Extract-Transform-Load (ETL) of CDISC SDTM data to the OMOP CDM and proposing conventions for handling unique aspects of clinical trial data.

Methods

The Critical Path Institute (C-PATH) provided deidentified data for TB-1015 (NCT02193776) "A Phase 2 Open-Label, Partially Randomized Trial to Evaluate the Efficacy, Safety and Tolerability of Combinations of Bedaquiline, Moxifloxacin, PA-824 and Pyrazinamide in Adult Subjects with Newly Diagnosed, Drug-Sensitive or Multi Drug-Resistant Pulmonary Tuberculosis". The team benefitted from the diverse healthcare and informatics backgrounds of its members to understand the clinical context, CDISC standards and OMOP CDM conventions to guide the ETL process. Team members worked asynchronously to propose strategies for selecting the best standard concept. These proposals were deliberated upon during the biweekly meetings to reach consensus.

Results

Source SDTM Files to Target OMOP CDM Tables

SDTM file & description	OMOP CDM Table
dm demographics	PERSON
sv subject visits	VISIT_OCCURRENCE
ae adverse events	
ce clinical events	CONDITION_OCCURRENCE
mh medical history	
ex drug exposure to experimental drugs	DRUG_EXPOSURE
cm concomitant meds	
lb laboratory test results	
ms microbiology susceptibility findings	MEASUREMENT
mb microbiology specimen	
vs vital signs	
cm concomitant meds	PROCEDURE_OCCURRENCE
pr procedures	
ae adverse events	OBSERVATION
dd death details	

Selected Issues and Proposed Solutions

Issue	Proposed Solution
CR.001 USUBJID is the identifier linking the same patient across all SDTM tables. Values often contain text characters.	Reference USUBJID to autogenerate an integer value for PERSON_ID. Record USUBJID in PERSON_SOURCE_VALUE
Handling Relative Dates	
CR.002 SDTM start of a trial STDY = 1; OMOP CDM requires calendar dates	Use the study start date as the reference start date (RFSTDT) for all patients. This information can be found in the trial publication or the trial registry such as ClinicalTrials.gov
STDY is a positive number	Add (STDY - 1) to RFSTDT
STDY is a negative number (screening visit)	Add (STDY) to RFSTDT
CR.004 Construct a unique number for cdm.<table name>. OCCURRENCE_ID	Concatenate USUBJID and SEQ to autogenerate an integer value for <table name>. OCCURRENCE_ID
CR.008 Construct a unique number for cdm.VISIT_OCCURRENCE_ID	Concatenate USUBJID and SVSTDY to autogenerate integer value for VISIT_OCCURRENCE_ID
Find closest matching Standard Concept id	Concatenate entries in these columns using paste() ... It can use 'lag' to propose best matches to standard concept_id
lb.csv	'LBTEST','LBSTAT','LBSPEC','LBSTRESU'
cm.csv	'CMDECOD','CMDOSE','CMDSU','CMROUTE'

Conclusion

We have reached consensus on several conventions and developed mapping guidelines for doing an ETL of CDISC SDTM data to the OMOP CDM. We welcome new members as we undertake the next stage of work to translate the rules and guidelines into SQL code, perform quality checks, and test the robustness of the methodology when applied to other clinical trials.



Join the Clinical Trial Working Group, which meets biweekly Friday at 11:30 ET.





#OHDSISocialShowcase

TUESDAY

OMOP Harmonization and Integration of Surgical Procedure Database into EHDEN with BC Platforms' Solutions

(**Mai Nguyen**, Stefano Gamage, Serena Ciaburri, Kalle Parn, Viktoria Sassi-Prantner, Hang T.T. Phan)

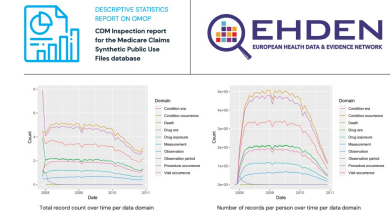
ENHANCING HEALTHCARE INSIGHTS

OMOP Harmonization and Integration of Surgical Procedure Database into EHDEN with BC Platforms' Solutions

BACKGROUND: Real-world data (RWD) offers valuable insights into healthcare patterns and outcomes, serving as a cornerstone for evidence-based decision-making in healthcare. BC Platforms, an EHDEN certified SME and a global leader in building data networks for the life sciences industry, offers OMOP harmonization services. BC Platforms provided the OMOP solutions for the Data partner, who wanted to harmonize the clinical data of +750,000 patients collected between 2014 and 2022.

BC Platforms provides a comprehensive solution for OMOP harmonization:

1. Ensuring the capture of the information to the greatest extent possible from the data partner's database
2. Facilitating the seamless integration of healthcare records into global healthcare research initiatives



METHODS

Figure 1: Schema of ETL flow for OMOP harmonization solution

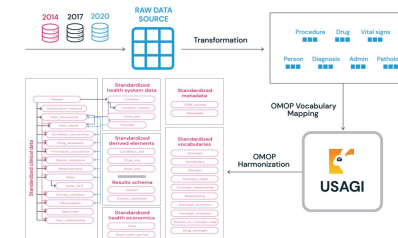
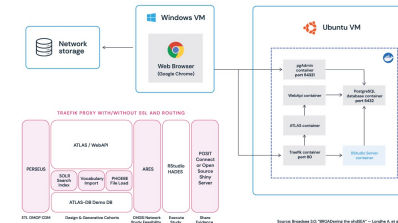


Figure 2: Portable docker solution for OMOP database and EHDEN integration in multi-layer virtual machine (VM) infrastructure



DISCUSSION:

- Understanding the raw data are required careful before implementing the harmonization solution
- Manual curation and translation to English were needed for free-text mapping to OMOP vocabularies
- Relationships between OMOP tables required manual adjustments to address issues related to the raw data

RESULTS

1. Encapsulating the raw data, OMOP solutions with tables across multiple domains, and the development of ETL documents together with source code to facilitate the ETL of data into the final OMOP database
2. Facilitating seamless synchronization with OMOP data, empowering DPs to make informed decisions while ensuring compliance with privacy regulations
3. Enabling the seamless integration of surgical databases into healthcare research initiatives across Europe, fostering collaboration and facilitating evidence-based decision-making in the healthcare domain

References:

1. Dang A. Real-World Evidence: A Primer. *Pharmaceut. Med.* 2023; Jan(7):125–36. doi: 10.1007/s40201-022-00456-8. Epub 2023 Jan 6. PMID: 36904369. PMCID: PMC9818190.
2. Londhe A, et al. *Broadsheet 3.0: "BRGAD"ing the ohdSEA*. 2023. OHDSI work package



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#OHDSISocialShowcase

WEDNESDAY

Creating clinically meaningful cancer groups from SNOMED for care systems and care quality research: a head and neck case study

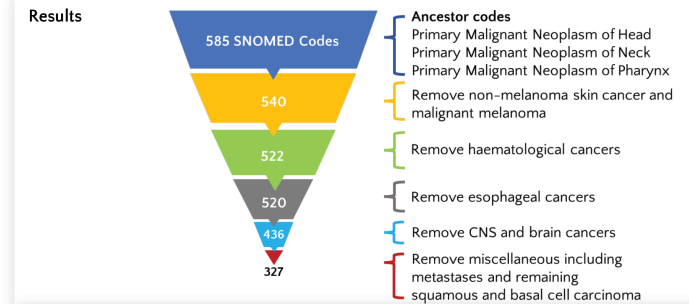
(Hayley Fenton, Elisabeth Ross, Elin Hallan Naderi, Anne-Lore Bynens)

Identification and mapping of SNOMED concepts for head and neck cancer

A DigiONE initiative of DIGICORE
(The Digital Institute for Cancer Outcomes and Research)

Creating clinically meaningful cancer groups from SNOMED for care systems and care quality research: a head and neck case study

Background Standardization of cancer data increases the potential to deliver data-driven care quality research and clinical dashboards for international collaborations in cancer care. However, to achieve a clinically meaningful and appropriate grouping of cancer indications within organ sites is challenging. This grouping can be described using ICD-10 hierarchies in Europe but alignment with the standard SNOMED concepts is complex. We present here a concept mapping case study from an international COVID-19 analysis that traces pandemic influence on cancer diagnoses and outcomes in hospitals in the UK, Norway and the Netherlands.



Conclusion Our approach aimed at adaptation of coding hierarchies based on clinical consensus as an essential step in developing relevant national and international research protocols and data guides.

Hayley Fenton^{1,2}, Elisabeth Ross³, Elin Hallan Naderi³, Anne-Lore Bynens⁴



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#OHDSISocialShowcase

THURSDAY

Integrating NLP-derived results in the OMOP CDM

(Gabriel Maeztu, Mónica Arrúe, Mariona Forcada, María Quijada, Paula Chocrón, Miguel Ángel Mayer)

Integrating NLP-derived results in the OMOP CDM

Enhancing Real-World Clinical Data Analysis

Hospitals generate vast quantities of data daily, with up to 80% of this data being collected in an unstructured format such as free text. Converting this data into a structured format is essential to unlock its value. In this context, integrating the output of NLP algorithms with the OMOP CDM offers a compelling solution for enhancing the analysis of real-world clinical data using standard tools such as ATLAS or HADES.

Methods

A study in the field of dermatology was conducted across four hospitals in Spain. We employed multiple NLP techniques to standardize clinical data from clinical notes into OMOP concept_ids. In this study, 132 relevant concepts were defined and extracted using NLP. The results of the NLP were stored in an expanded NLP schema^[1] specifically tailored to efficiently store the NLP outputs. This schema was developed to address the complexities of NLP outputs and facilitate their transformation into the standard OMOP CDM v5.4 structures. Notably, OMOP CDM v5.4 includes a 'note_nlp' table intended for storing NLP results; however, querying this table can often be complex and inefficient.



We finally compared in ATLAS the result of enriching the OMOP with NLP-derived data against structured data.

OMOP Domain	Structured registries	NLP registries	Increase
Condition	10393	295723	2746.25%
Procedure	84	1410	1578.57%
Drug	6970	104629	1398.99%
Measurement	6602	45182	584.18%
Observation	0	78099	+78099

Registries increment per OMOP domain by including NLP results



Patient increment per OMOP domain & inclusion criteria by including NLP results (number of patients masked per compliance reasons)

Results: Integration of NLP-derived results into the OMOP CDM led to significant enhancements in data richness. Firstly, we identified **224% more patients** across four different hospitals in Spain who met the inclusion criteria thanks to NLP-derived data. Moreover, the dataset incorporating NLP demonstrated a substantial increment in the proportion of records across different OMOP domains compared to the dataset without NLP. The structured inclusion of NLP-derived results facilitated more comprehensive analyses, enabling deeper insights into treatment patterns and patient outcomes.



[1] Extending the OMOP CDM to store the output of NLP pipelines. M.Arrue et al. OHDSI Global Symposium

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#OHDSISocialShowcase

FRIDAY

Standardizing European sarcoma registry data to the OMOP Common Data Model: the retroperitoneal sarcoma use case

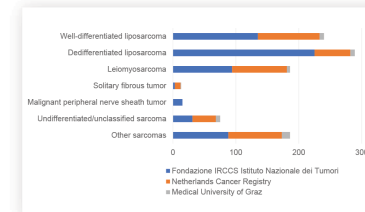
(Peter Prinsen, Paolo Lasalvia, Roberto Lillini, Vittoria Ramella, Anna Alloni, Joanna Szkandera, Espen Enerly, Maaïke van Swieten, Siri Larønningen, Julien Bollard, Audrey Pons, Thomas Gaudin, Claire Chemin-Airiau, Alric Sans, Jean-Yves Blay, Arnaud Malfilatre, Danielle Newby, Gijs Geleijnse, Annalisa Trama)

Power in numbers: overcoming the scarcity of rare cancer data by harmonizing European sarcoma registries

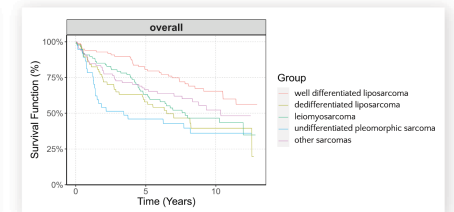
Standardizing European sarcoma registry data to the OMOP Common Data Model: the retroperitoneal sarcoma use case

Background: Research in rare cancers is hampered by low patient numbers, dispersed clinical data and tumor samples, and a limited number of experts per rare cancer diagnosis. The ERN EURACAN (European Reference Network for Rare Adult Solid Cancers) was established to bring together data and knowledge of European Healthcare professionals.

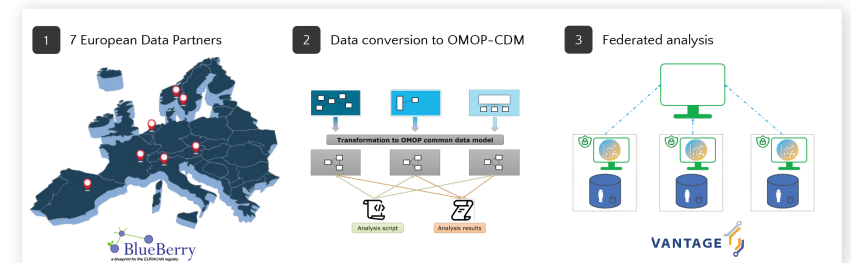
Result 1: # patients of each of the retroperitoneal sarcoma types in each registry



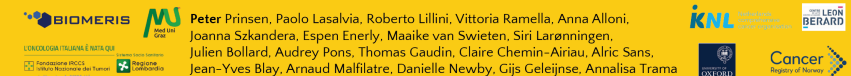
Result 2: Examples of survival curves generated with the CohortSurvival package.



Methods



Limitation: Conversion of each of the data sources to the OMOP-CDM and setting up a node for federated analysis requires a lot of technical expertise. The OHDSI tools have a steep learning curve.





Opening: Sr AD, Real World Evidence & Analytics Boehringer Ingelheim

SR AD, Real World Evidence & Analytics

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JOB ID - 13278

Description

The purpose of this job is to:

- Generate real world evidence (RWE) to support in-line and pipeline products.
- Provide statistical advice on the analysis of real world data (RWD) to various internal and external stakeholders.
- Contribute to the RWD acquisition strategy and tool evaluation.



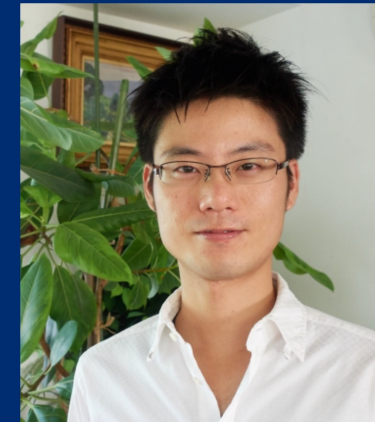
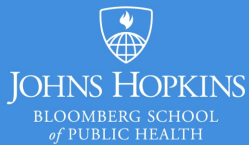
Openings: Postdoctoral Fellow, Johns Hopkins Univ.

PHARMACOEPIDEMIOLOGY POST-DOCTORAL TRAINING PROGRAM

Co-Directors: Caleb Alexander, MD, MS and Jodi Segal, MD, MPH

The **Pharmacoepidemiology Training Program** at the Johns Hopkins Bloomberg School of Public Health (BSPH) is currently **seeking to support postdoctoral fellows**. All supported trainees work with core faculty on existing or newly developed research projects on pharmacoepidemiology, so as to optimize the safe and effective use of medicines to treat heart, lung and blood diseases in the United States. |

Deadline for applications: rolling





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?





Building The OHDSI Evidence Network

1. What are some examples of network studies completed previously?
2. How do I get IRB approval to participate?
3. Is there a deadline to join this initiative? It would be great to get some clarity about the timelines.
4. Is there an expectation to submit updated DbDiagnostic results on a regular basis? Is there a QA process and re-submission required after each run?



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