Collaborator Showcase: Rapid Fire Presentations

Katia Verhamme, MD, PhD
Associate Professor of Use and Analysis of Observational Data
Adoption of the OMOP Common Data Model in the UK

Alex Knight
Health Data Research UK, UK
Poster: 42
Adoption of the OMOP Common Data Model in the UK

OHDSI Europe 2024
UK Landscape

- The UK National Health Service holds detailed health data on 67 million people – potentially an invaluable resource for research
- However, data is distributed across many healthcare providers and formats
- NHS England establishing a network of secure data environments (SDEs/TREs) to support research
- Wales and Scotland already have their own SDEs

- The UK’s national institute for health data science
- 103+ leading healthcare and research organisations
- Establishing best practice for the ethical use of UK health data for research at scale

https://datainsights.uk/
Activities in support of OMOP adoption

- Collaboration with EHDEN, funding 5 new data partners to transform to OMOP
- Partnership with OHDSI UK
- Collaboration with NHS England’s network of Secure Data Environments to support their adoption of OMOP
- Survey of OMOP Landscape in the UK
- Community activities including OMOP events
- Developed the Health Data Research Innovation Gateway which acts as a single hub for metadata on UK data sets, (many in OMOP format).
UK Data Custodians with OMOP Data Sets

- 42 organisations with
- 81 OMOP data assets (or mapping under way)
Data Types of UK OMOP Data

Data types cover the full spectrum of routine care and research data types.

Conclusions:
- Significant momentum behind OMOP adoption in the UK
- Significant barriers and limitations remain

Next steps include:
- Improve researcher/analyst skills and capabilities
- Identify use cases and priority research
- Agree a minimum viable OMOP dataset
- Work with national data collections and GP Data
Piloting the Transformation of Multiple Sclerosis Real-World Data to the OMOP CDM: Lessons Learned

Tina Parciak
Uhasselt, Belgium
Poster: 51
Piloting the Transformation of Multiple Sclerosis Real-World Data to the OMOP CDM: Lessons Learned

Tina Parciak¹,²,³, Kirstin Tümler⁴, Alexander Stahmann⁵, Emma Gesquiere⁶, Freija Descamps⁶, Liesbet M. Peeters¹,²,³

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³ UHasselt, Data Science Institute (DSI), Agoralaan, 3590 Diepenbeek, BELGIUM
⁴ German Center for Diabetes Research (DZD), Munich, Germany
⁵ German MS Register by the German MS Society, MS Research and Project Development gGmbH (MSFP), Hanover, GERMANY
⁶ edenceHealth NV, Veldkant 33 A, 2550 Kontich, BELGIUM
Background / Motivation

Multiple Sclerosis (MS)
Background / Motivation

MS real-world data (RWD) coming from registries and cohorts
Real-world evidence (RWE) generation within MS community
Multiple sclerosis?

RWE generation outside MS community

How about the OMOP CDM?
Materials & Method

- MS DataConnect
- German MS Registry
Lessons learned

MS registry or cohort datasets differ from EHR data.

Standardisation to OMOP CDM can still result in heterogeneous outputs.
Lessons learned

Exchange of experiences and alignment for registry-type data transformations is necessary.

Transforming MS RWD demands substantial time investment and interdisciplinary knowledge.
Annotation-preserving machine translation of English corpora to validate Dutch clinical concept extraction tools

Tom Seinen
Erasmus MC, The Netherlands
Poster: 112
Temporary kidney enlargement in the newborn infant

Recognition
+ Linking

Disorder 4104152
Person 4046034

Many extraction tools exist for English
cTakes, MedTagger, MedCAT, QuickUMLS, ...

Only a few tools for Dutch
UMCU: MedCAT, EMC: MedSpaCy

However: How good are these Dutch extraction tools?
**ANNOTATED CLINICAL CORPORA**

**Ground truth**: sample texts with manually annotated concepts

Temporary kidney enlargement in the newborn infant

> C0542518: kidney enlargement [10-28]  
> C0021289: newborn infant [36-50]

**Evaluation**: Does the tool extract the **correct concepts** at the **correct locations**?

**English tools** are evaluated using **English clinical corpora**  
(MedMentions, ShARE/CLEF, i2b2, etc.)

**Few problems:**
- There are no large **Dutch corpora**...
- **Creation is difficult**: very labor intensive, sensitive patient data
TRANSLATION OF EXISTING CORPORA

Translation + Alignment (Language dependent)

Temporary kidney enlargement in the newborn infant

Tijdelijke niervergroting bij de pasgeboren baby

Embedding + Translation + Extraction (Language independent)

Temporary kidney enlargement in the newborn infant

Tijdelijke niervergroting bij de pasgeboren baby

C0542518: kidney enlargement [10-28]
C0021289: newborn infant [36-50]

C0542518: kidney enlargement [??????]
C0021289: newborn infant [????????]

C0542518: niervergroting [11-25]
C0021289: pasgeboren baby [33-48]
ANNOTATION-PRESERVING TRANSLATION

Google Cloud Translate API
• Dedicated translation model
• Out-of-the-box, Fast
• One model, no tweaking
• Makes formatting errors (1%)
• Keeps all annotations (1% missing)

OpenAI GPT-4 API
• SoTA generative model
• Needs prompting, Slower
• Endless optimalization possibilities
• Makes almost no formatting errors (<<1%)
• Ignores some annotations (1-6%)

Temporary [[[kidney enlargement][C0542518]] in the [[[newborn infant][C0021289]]]

...[[niervergroting]_C0542518]... ... bij de pasgeboren baby ...

Large agreement between the translations (BLEU~0.5, chrF~0.8)
CONCEPT EXTRACTION PERFORMANCE

Experiments: 2 extraction tools (MedCAT, MedSpaCy), 3 different English corpora

Good overall performance from both tools

No significant difference between English and the Dutch translations

Conclusion:
- Generated: Dutch annotated corpora, Evaluated: Dutch clinical extraction tools
Beyond Diagnosis Codes: A Weakly Supervised Learning Framework for Accurate Multimorbidity Identification in Electronic Health Records

Bernardo Neves
Luz Saúde, Portugal
Poster: 111
Beyond Diagnosis Codes: A Weakly Supervised Learning Framework for Accurate Multimorbidity Identification in Electronic Health Records

Bernardo Neves¹,²,³, Jorge Cerejo¹, Simão Gonçalves¹, José Maria Moreira¹, Nuno A. da Silva¹, Francisca Leite¹, Mário J. Silva³

¹Hospital da Luz Learning Health
²Departamento de Medicina Interna, Hospital da Luz de Lisboa
³INESC-ID, Instituto Superior Técnico, Universidade de Lisboa
Secondary use of EHRs

- Phenotyping chronic conditions typically relies on direct mentions (diagnosis codes), however there are many indirect surrogate markers (Labs, procedures, etc.)

- Expert validation is hard/unfeasable at scale: weakly-supervised learning is a possible approach\(^1\)

- Goals:
  - To develop a phenotyping dictionary to identify common chronic conditions in EHRS using diverse data sources
  - To explore unsupervised approaches to validate phenotyping rules

\(^1\)Swerdel JN et. Al. J Biomed Inform. 2019 Sep;97:103258
Methods

- Weakly-supervised learning phenotype validation

OMOP database

- Concepts
- Measurements
- Procedure
- Drugs

Specific cohort

2 condition codes

Logistic regression

Heart Failure
- Conditions: 316139, 4111554...
- Drugs: 2160133...

CAD
- Conditions: 4185932...
- Procedures: 9898098, 90999
- Drugs: 19092898

CKD
- Lab: 78087, 85898

Without any code from the dictionary

<table>
<thead>
<tr>
<th>Patient</th>
<th>Model prediction</th>
<th>Dictionary</th>
<th>TP</th>
<th>FP</th>
<th>TN</th>
<th>FN</th>
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<td>-</td>
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<td>1</td>
<td>0.60</td>
<td>0.20</td>
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<td>...</td>
<td>...</td>
<td>...</td>
<td>...</td>
<td>...</td>
</tr>
</tbody>
</table>

Phenotype algorithm performance
Results

Labs, drugs and procedures contributed to 215,696 (+57%) additional diagnoses.

42,976,012 codes
7,452,487 hospital episodes
838,980 adult patients
Results

Absolute F1 Scores for Each Condition

- Condition Codes
- Best Dictionary Rules

Number of Patients Identified for Each Condition

- Condition Codes
- Best Dictionary Rules
**Conclusions**

**Key points**

- **Enhanced Detection Methodology**: Using expert-defined phenotyping rules with lab, procedure, and drug codes to identify patients with multimorbidity outperforms traditional condition codes.

- **Quantifiable Benefits**: Our automated method measures benefits from additional data sources, balancing true and false positives without manual labeling.

- **Future Improvements**: Integrate alternative data sources, like clinical text, to enhance recall and precision in phenotyping where condition coding is incomplete.
OHDSI meets Flowise to Streamline Biomedical Data Discovery and Analysis

João Almeida
University of Aveiro, Portugal
Software Demonstration
A Chatbot to Streamline Biomedical Data Discovery and Analysis

João Reis, João Rafael Almeida, Tiago Almeida, José Luís Oliveira
University of Aveiro, Portugal
Motivation

• Population characterisation multicentre study
  – For instance, about Rheumatoid Arthritis patients

• Multicentre = multiple institutions

• Questions
  – Which datatypes are available?
  – Who are the contacts for the relevant databases?
  – What can we learn from the governance process?
Where do we find data?
EHDEN Network Dashboards

New entry on database catalogue → Database Catalogue → Databases of interest for research question

- Database fingerprinting
- Uploading metadata
- Network Dashboards

Data Custodian

Researcher
Chatbot overview

• Enable **discovery** and basic **feasibility enquiries**
  – Using EHDEN Network Dashboards data

• Compare basic characteristics
  – With other Data Partners in the network

• Provide suggestions of **most suitable databases**
  – Information Retrieval
  – Large Language Models
  – RAG techniques
Future directions

• Chatbot to help defining studies

You are invited to visit our demo and poster!

Researchers interested in conduct a study
ReportGenerator: Automating study reports and visualization apps for DARWIN EU® research

Cesar Barboza Gutierrez
Erasmus MC, The Netherlands
Software Demonstration
How to automate reports for off-the-shelf studies

Cesar Barboza, Ger Inberg and Ross Williams

OHDSI Europe Symposium 2024
Developing tools to scale up to:

Analyzing Data from

40 data partners
and

130 million patients

140 Studies delivered annually
by 2025
The Problem is complexity

It increases if we want to integrate results from multiple analytical packages

• Deliver standard reports to the European Medicines Agency (EMA).

• Reports should have a standardized format and be able to show results from multiple analyses.
The tool aims to:
1. Supports the Principal Investigators with creating tables and figures for the study report
2. Facilitate the automatic generation of a Shiny app for each study
A standard output format for study results which makes it easier to bind results from multiple data partners.
## Data Visualization

Each analytical package provides its own tables and figures to display results according to DARWIN’s Catalog of Standard Analytics.

<table>
<thead>
<tr>
<th>CDM name</th>
<th>Strata name</th>
<th>Strata level</th>
<th>Variable name</th>
<th>Variable level</th>
<th>Estimate name</th>
<th>Drug</th>
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<tbody>
<tr>
<td>CDWBordeaux</td>
<td>Icu status</td>
<td>Icu</td>
<td>Number records</td>
<td>Na</td>
<td>N</td>
<td>Cisatracurium 306</td>
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<tr>
<td></td>
<td></td>
<td></td>
<td>Number subjects</td>
<td>Na</td>
<td>N</td>
<td>Dexamethasone 3,812</td>
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<td>Duration</td>
<td>Na</td>
<td>Median [Q25 - Q75]</td>
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<td></td>
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<td></td>
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<td></td>
<td>1.00 to 72.00</td>
<td></td>
</tr>
<tr>
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<td>Initial daily dose</td>
<td>Na</td>
<td>Median [Q25 - Q75]</td>
<td></td>
</tr>
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<td></td>
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<td></td>
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<td></td>
<td>Na [na - na]</td>
<td></td>
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<td></td>
<td>Na [na - na]</td>
<td></td>
</tr>
<tr>
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<td></td>
<td></td>
<td></td>
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<td>Na [na - na]</td>
<td></td>
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<td></td>
<td>Inf to -inf</td>
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<td>Inf to -inf</td>
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<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td>Inf to -inf</td>
<td></td>
</tr>
</tbody>
</table>
Tables and Figures

- Incidence/Prevalence Plots
- Survival Plots from CohortSurvival
- Characterisation tables for PatientProfiles
- Sunburst plots and Sankey Diagrams for TreatmentPatterns
Functionality

1. Load data
2. Interactive item selection
3. Visualization dashboard and item preview
3. Visualization dashboard and item preview
4. Menu to generate a Shiny app or a Word report
Introduction of the DARWIN EU® ReportGenerator
Next steps:

- Complete integration with summarisedResult format
- Interactive selection of features when generating the Shiny project
- Provide enough functionality to support results for all studies

Thank you!
Analysis of Lung Cancer Patient Treatment with Immune Checkpoint Inhibitors Using Natural Language Processing for Data Extraction from Electronic Health Records

Clara L. Oeste and Annelies Verbiest
Lynxcare, Belgium
Poster: 67
Analysis of Lung Cancer Patient Treatment with Immune Checkpoint Inhibitors using NLP for Data Extraction from EHRs

Dr. Annelies Verbiest, MD, PhD
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Clara L. Oeste, PhD
LynxCare Inc., Leuven, Belgium
clara.oeste@lynx.care
Objectives of the research group:

- Set up a pipeline to develop large-scale OMOP-CDM granular warehouses (GDPR compliant)
- Bring together a consortium of hospitals (EHDEN project)
- Perform project-specific data dictionary and validation
Study Design

A Multidimensional Data Warehouse

Assessing the use of immune checkpoint inhibitors (ICI) across different:

- Cancer types
- ICIs
- Treatment settings
- Hospitals
- Performance status
- …

... and in DIFFERENT COHORTS

Adapted from Open Data Communities, DLUHC UK
Data Dictionary Example

Determining patient treatments (OncoRegimenFinder)

**SYSTEMIC TREATMENT**

- **Calculation logic:**
  - All antineoplastic agents
  - Follows ATHENA hierarchy
- **Data source:** structured
- **OMOP table:** Drug exposure

**DRUG ERA**

- **Calculation logic:**
  - Span of time when Person is exposed to active ingredient.
  - Successive periods of exposure: ERA
  - Max time window between exposures: 30 days
- **Data source:** structured
- **OMOP table:** Drug exposure

**TREATMENT REGIMEN**

- **Calculation logic:**
  - Follows OncoRegimenFinder
  - Occurrence of ≥ 2 drug eras within 30 days: combined into REGIMEN
- **Data source:** structured
- **OMOP table:** Drug era

**TREATMENT LINE**

- **Calculation logic:**
  - First regimen after initial cancer diagnosis
  - Change in line if change in regimen: when new drug introduced
- **Data source:** structured
- **OMOP table:** Episode

Clinical validation at a glance
**Results**

<table>
<thead>
<tr>
<th>Hospitals</th>
<th>3</th>
</tr>
</thead>
<tbody>
<tr>
<td>Data sources</td>
<td>10</td>
</tr>
<tr>
<td>Lung cancer patients</td>
<td>730</td>
</tr>
<tr>
<td>Median age</td>
<td>67</td>
</tr>
<tr>
<td>Sex (male)</td>
<td>67%</td>
</tr>
<tr>
<td>ICI administrations</td>
<td>8145</td>
</tr>
<tr>
<td>Median OS</td>
<td>22 months</td>
</tr>
</tbody>
</table>

### Smoking status (%)
- **Current**: 47.7%
- **Former**: 25.9%
- **Never smoker**: 8.6%
- **Unknown**: 17.8%

### Metastatic status (%)
- **Metastatic**: 60.6%
- **Non-metastatic**: 22.7%
- **Unknown status**: 16.7%

### ICI treatment (%)
- **Durvalumab**: 9.4%
- **Atezolizumab**: 12.4%
- **Nivolumab**: 15.4%
- **Pembrolizumab**: 62.4%

### Treatment characteristics (%)
- **Monotherapy 1L**: 28.7%
- **Monotherapy 2L+**: 24.8%
- **Combination therapy 1L**: 41.9%
- **Combination therapy 2L+**: 4.6%

### Performance status (% of patients)
- **PS 0**: 21.5%
- **PS 1**: 56.3%
- **PS 2**: 10.7%
- **PS 3-4**: 1.6%

### Overall survival probability
- **PS 0**
- **PS 1**
- **PS 2**
- **PS 3-4**

**Hospitals**
3

**Data sources**
10

**Lung cancer patients**
730

**Median age**
67

**Sex (male)**
67%

**ICI administrations**
8145

**Median OS**
22 months

**ICI**
administrations
8145

**Medications**
8145

**Smoking status**
47.7%

**Metastatic status**
60.6%

**ICI treatment**
9.4%

**Treatment characteristics**
28.7%

**Overall survival probability**

**P**
< 0.0001

**Number at risk**
77
193
67
9
55
124
36
0
55
124
36
0

**Time (months)**
0
10
20
30
40
50
60

**Lung cancer patients**
730

**Sex (male)**
67%

**ICI**
administrations
8145

**Medications**
8145

**Smoking status**
47.7%

**Metastatic status**
60.6%

**ICI treatment**
9.4%

**Treatment characteristics**
28.7%

**Overall survival probability**

**P**
< 0.0001

**Number at risk**
77
193
67
9
55
124
36
0
55
124
36
0

**Time (months)**
0
10
20
30
40
50
60
An Exploration of Ovarian Cancer Therapy Sequence Utilization in Treatment-naïve Women from 2008-2020

Whitney Burton
Taipei Medical University, Taiwan
Poster: 24
An Exploration of Ovarian Cancer Therapy Sequence Utilization in Treatment-naive Women from 2008-2020

Whitney Burton, Quynh Nguyen, Mohammad Solihuddin Muhtar, Christianus Heru Setiawan, Septi Melisa, & Jason Hsu
Student, Taipei Medical University
College of Management
College of Pharmacy
Background

• In women, ovarian cancer is the 8th leading cancer and the 8th cancer-related mortality cause¹

• Regionally, women located in Europe and Southeast Asia at at-increased vulnerability for the disease¹,²,³

• Low and medium-income counties experience disproportional mortality rates in juxtaposition with incident rates²

• Global treatment guidelines call for appropriate surgical staging and debulking surgery followed by biomedical interventions (i.e., oral or intravenous)¹

References:
Study Design

- **Aim:** To characterize real-world ovarian cancer therapy sequence utilization patterns
- **Dataset:** Taipei Medical University Clinical Research Database (TMUCRD)
- **Study Population:** 1,190 women treatment-naïve women from 1/1/2008-31/12/2020
- **Tools:**
  - **Outcomes:**
    - 1st three medication pathways
    - 3 pathways: Chemotherapy, Targeted therapy, and Hormone therapy classes
      - 13 sub-class for the analysis: Alkaloids, Alkylating agents, Anthracyclines, Antimetabolites, Taxanes, Anti-estrogens, Aromatase inhibitors, PD-L1 inhibitors, CKD inhibitors, HER2, monoclonal antibodies, mammalian target of rapamycin (mTORs), and multi-target inhibitors
Preliminary Findings

Implications:

• Leveraging of OHDSI tools enabled a standardized analysis of treatment pathways

• Improves our understanding of therapy utilization patterns

• This study can guide resource allocation within healthcare systems by highlighting gaps in treatment, accessibility, and clinical alignment/misalignment with guidelines
Acknowledgments

• Research team at Taipei Medical University’s College of Management
• National Science and Technology Council of Taiwan
• Early insight from international partners
  • Dr. Seng Chan You, Yonsei University
  • Dr. Nicole Pratt, University of South Australia
  • Dr. Celine Sze Ling Chui, The University of Hong Kong
Call to Action

“We’re told to sit with discomfort and that it’s normal until it’s too late. Then, we’re questioned about not being proactive... I won't be siloed or silenced any longer. I am one person. A solo datapoint. But if we come together, we can make a dataset, and that set makes all the difference. It has the power to change fortunes and futures from prediction models to improve the quality of care. Let’s make a representative data tapestry that reflects us and changes the narrative. Let’s change the course of ovarian and gynecological cancers.”

-39 yo Female
Baseline Characterization and Treatment Pathways of Patients With Alport Syndrome Across Geographies: Exploring a Rare Disease in a Multi-Database Retrospective Cohort Study

Katrin Manlik
Bayer AG, Germany
Poster: 79
Baseline Characterization and Treatment Pathways of Patients With Alport Syndrome Across Geographies: Exploring a Rare Disease in a Multi-Database Retrospective Cohort Study

Katrin Manlik, Glen James, Andrea Scalise, Charlie Scott, Daloha Rodriguez Molina, David Vizcaya (Bayer)

Rotterdam, June 03, 2024
Usually manifests in early childhood

Mutations in the COL4A3, COL4A4 and COL4A5 genes lead to defective collagen production

Patients treated with Angiotensin-converting enzyme inhibitors (ACEi), Angiotensin receptor blockers (ARB) and Sodium-glucose cotransporter-2 inhibitors (SGLT2i) to delay onset of kidney failure

Hematuria, proteinuria, ocular abnormalities, hearing loss, progressive loss of kidney function leading to kidney failure

Rare genetic kidney disease

Alport syndrome

Research question: What are the characteristics of patients diagnosed with Alport syndrome and how are these patients treated in a real-world setting across different countries?
Methods

Data sources

- 6 OMOP databases from 3 countries, each analyzed separately
- Study start date 01-JAN-2012
- Inclusion criteria:
  - 1 diagnosis code for AS
  - age between 1 and 40 years at index
  - at least 12 months of continuous enrolment
- Exclusion criteria:
  - prior kidney failure before or on index

A longitudinal retrospective cohort study

- 6 OMOP databases from 3 countries, each analyzed separately
- Study start date 01-JAN-2012
- Inclusion criteria:
  - 1 diagnosis code for AS
  - age between 1 and 40 years at index
  - at least 12 months of continuous enrolment
- Exclusion criteria:
  - prior kidney failure before or on index
Results – Baseline characteristics

Overall 1819 AS patients were identified from 6 databases across 3 countries

<table>
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<tr>
<th>Variable</th>
<th>CPRD Aurum EHR</th>
<th>CPRD GOLD EHR</th>
<th>MarketScan Claims</th>
<th>OPTUM Claims</th>
<th>OPTUM EHR</th>
<th>RWD Co EHR Claims</th>
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<td>Country</td>
<td></td>
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<tr>
<td>Japan</td>
<td></td>
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<tr>
<td>Patient Count</td>
<td>158</td>
<td>58</td>
<td>585</td>
<td>314</td>
<td>688</td>
<td>16</td>
</tr>
<tr>
<td>Female %</td>
<td>52.5</td>
<td>41.4</td>
<td>54.7</td>
<td>51.3</td>
<td>57.6</td>
<td>56.2</td>
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<td>Age at diagnosis (in years)</td>
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</tr>
<tr>
<td>Overall Median (IQR) Age</td>
<td>13 (8–28)</td>
<td>14 (7–25)</td>
<td>19 (10–29)</td>
<td>19 (10–32)</td>
<td>23 (13–32)</td>
<td>24 (17–26)</td>
</tr>
<tr>
<td>Female Median (IQR) Age</td>
<td>16 (9–30)</td>
<td>14 (9–30)</td>
<td>23 (12–32)</td>
<td>24 (11–33)</td>
<td>27 (18–33)</td>
<td>24 (24–25)</td>
</tr>
<tr>
<td>Male Median (IQR) Age</td>
<td>11 (6–24)</td>
<td>14 (5–18)</td>
<td>16 (9–26)</td>
<td>16 (9–25)</td>
<td>17 (9–28)</td>
<td>23 (4–26)</td>
</tr>
</tbody>
</table>

Demographics

- A higher proportion of females with AS in all DBs except UK CPRD GOLD.
- In the US, patients were diagnosed with AS around the age of 20. Male patients were 7-10 years younger than females at index.
- In the UK, patients were diagnosed with AS in their early teens, in Japan around the age of 24.

Comorbidities

- Across all data sources hematuria (12-56%), proteinuria (6-44%) and kidney disease (22-69%) were common.
- Arterial hypertension ranged from 5 to 44%.
- Hearing impairment was more prevalent in males compared to females in all databases.
- Hematuria and kidney disease were more prevalent in females compared to males in the US.
- Vision impairment was prevalent in up to a quarter of patients (3-25%).
Results - Treatment pathways after diagnosis

- **ACEi most frequently used** 1st line therapy in US and UK – around 3/4 of patients.
- **ARBs second most frequently used** 1st line therapy in US and UK – nearly 1/4 of patients, but most frequently used in Japan.
- **SGLT2i were rarely used** in the AS population.
- **Less than half of patients** were treated with cardiorenal protective therapies after diagnosis.
Conclusions & Next steps

1. **Alport syndrome**, a rare genetic kidney disease, shows **notable gender and regional differences** in patient characteristics.

2. This study provides **new insights into demographics, clinical characteristics, and treatment utilization** of patients with AS. These data are useful to gain knowledge about the disease, provide better support to clinicians and healthcare providers and most importantly, improve patient's quality of life.

3. Use of **OMOP data sources and OHDSI tools** provides an excellent opportunity to gain **insights into rare diseases** across multiple geographies and healthcare settings in a standardized approach.

- **Kidney function measures**
- **Cardiovascular and kidney composite outcomes**
- **Healthcare resource utilization**

We are eager to expand the study to further databases, Data Partners are welcome to participate!

Thank you!

katrin.manlik@bayer.com
Collaborator Showcase: Rapid Fire Presentations

THANK YOU!
Lunch, Collaborator Showcase, and Early Investigator meetings

La Fontaine & Odyssee Room

The Collaborator Showcase
13:00

Queen’s Lounge

Early Investigators Mentor Meetings
14:00

We will be back here at 16:00!