

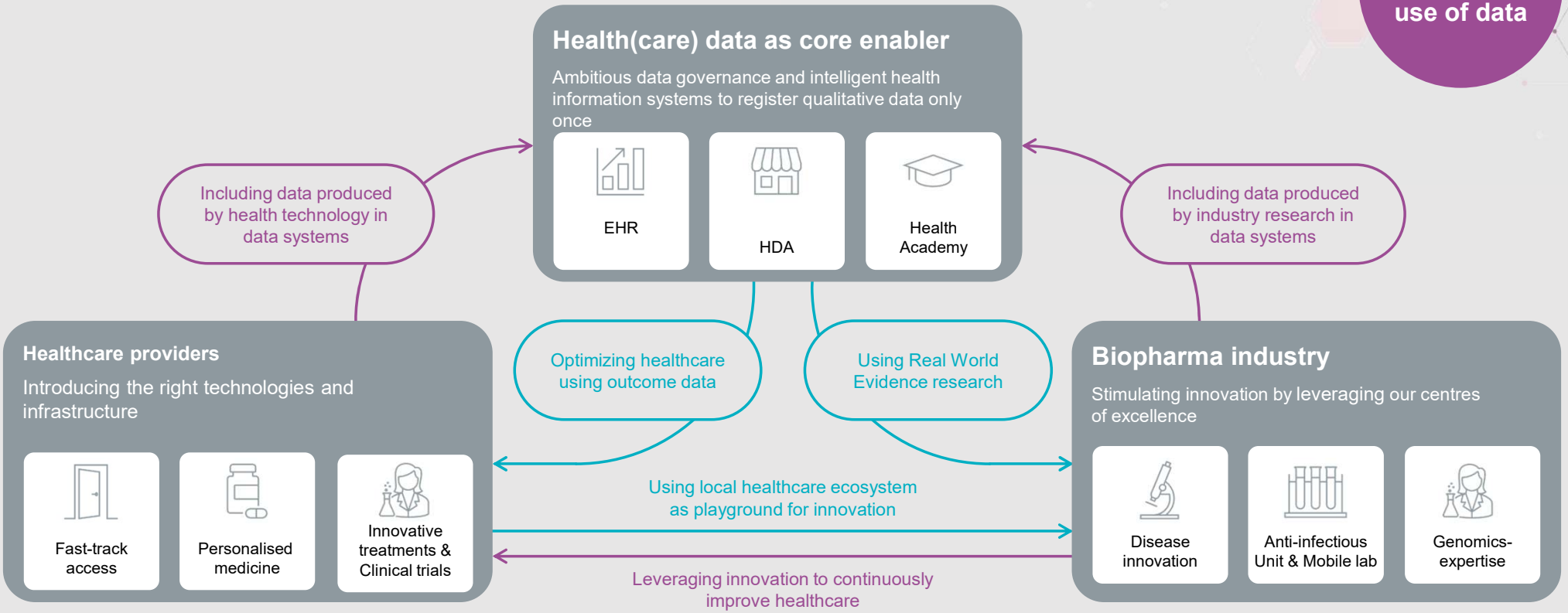
RWD collaborations: The experience from BELFHINDA

Karen Crabbé- 30/09/2026

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ASSOCIATION GÉNÉRALE DE L'INDUSTRIE DU MÉDICAMENT
ALGEMENE VERENIGING VAN DE GENEESMIDDELENINDUSTRIE

A continuous circle of data-driven health improvements & pharmaceutical innovation

due to **secondary use of data**



pharma.be

Belgian Hospital-Industry Alliances:

Car-T:
3 companies & 4 ref centers & BCR

MG register:
4 companies & 7 ref centers & sciensano

BELHINDA

GDPR guideline & Templates RWD agreement: Course: Guideline of GDPR and secondary use of patient data | HD Academy

BelFhinda:
9 companies & 5 hospitals & FHIN

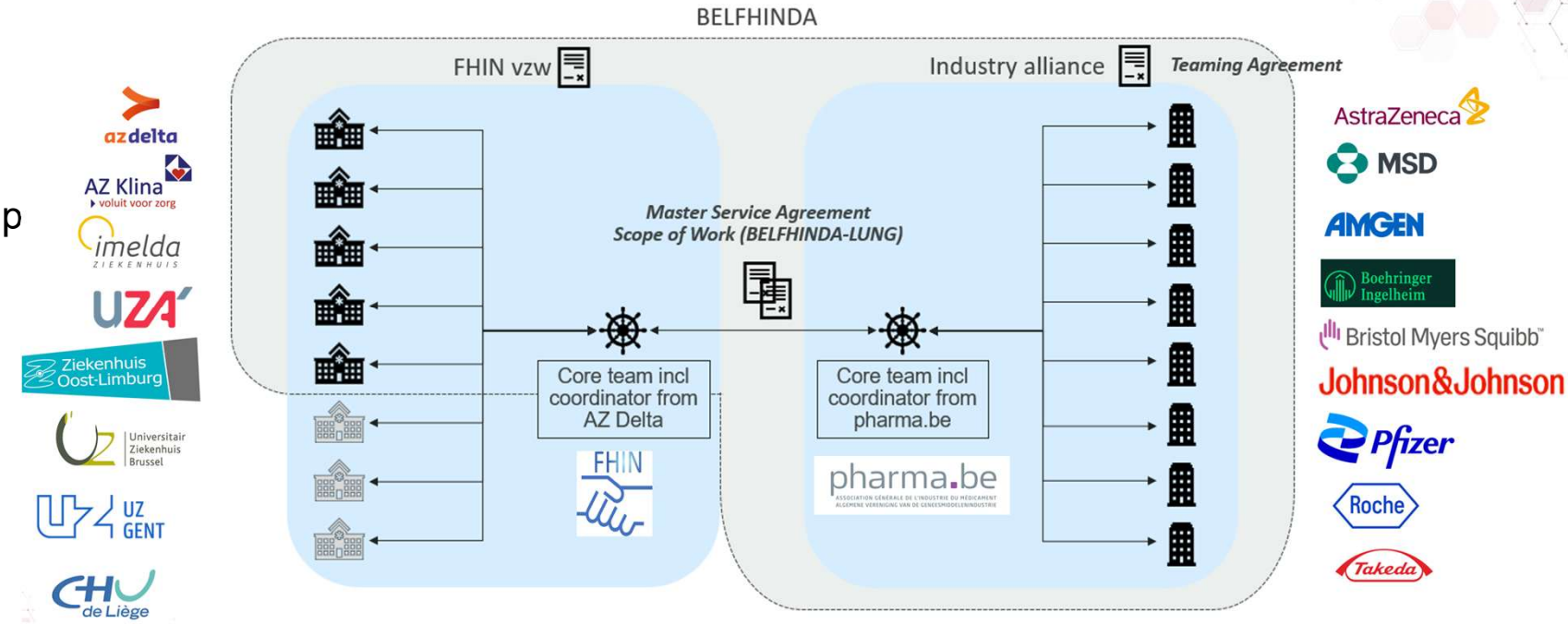
Health data talk series articles: HD Academy: All courses | HD Academy

Pioneers in collaboration, process, data infrastructure or approach, output reporting, funding, ...

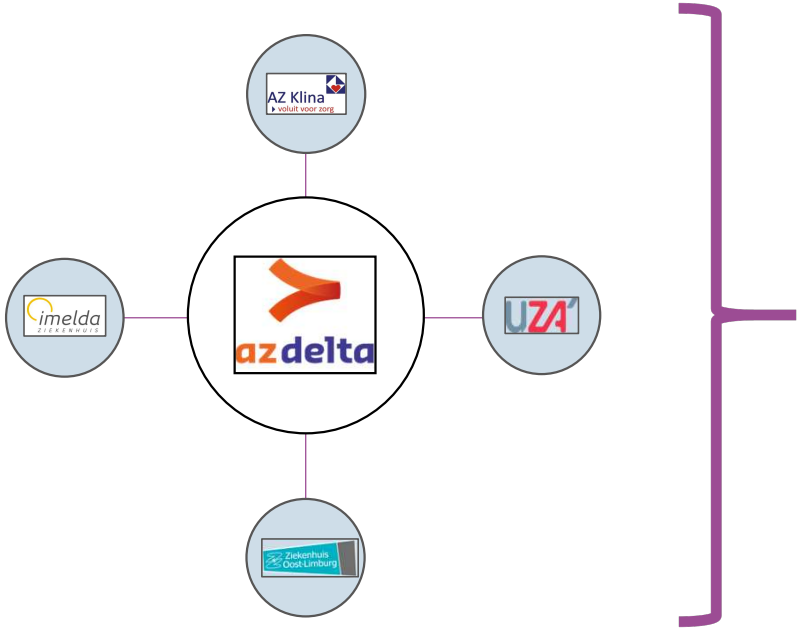
BELFHINDA: Belgian FHIN-Industry data alliance

Principles:

- Multi-partnership
- Contract & governance simplification
- Non-competitive collaboration: RWE feasibility in NSCLC
- Privacy by design set-up



Project implementation



Workshops

Query development

Report Compilation

Lessons learned:

Time investment

Coordinator

Distribution work packages

BELFHINDA-Lung set-up

OMOP database from 5 FHIN Hospitals

Prevalent and incident stage I–IV NSCLC patients diagnosed 1 Jan 2020 – 31 Dec 2024

Data catalogue

Based on 2 workshops, 15 data categories and 92 subcategories representing >2000 data points were defined

Feasibility Assessment

1. Quality assessment (DQD)
2. Data availability evaluation in OMOP vs EHR
3. Feasibility descriptive analyses (e.g., OHDSI treatment regimen finder, patient counts)

BELFHINDA-Lung results

Results

1. Quality assessment (DQD): **high conformance**, **moderate to high plausibility** and **moderate completeness**
2. Data availability evaluation in OMOP: highly variable between data (sub)categories and between hospitals
   - **Consistent availability (≥4/5):** patient demographics, smoking status, **lab results, WHO/ECOG scores,** TNM staging, comorbidities, and medications
   - **Mixed availability (1-3/5)**: Genetic mutations, imaging, surgery, FEV1
   - **Limited availability (≤1/5)**: PD-L1, lines of therapy, PROMS & PREMS, disease progression
3. Very limited capabilities for descriptive analyses (e.g., treatment regimen/line, adjuvant therapy, ...)

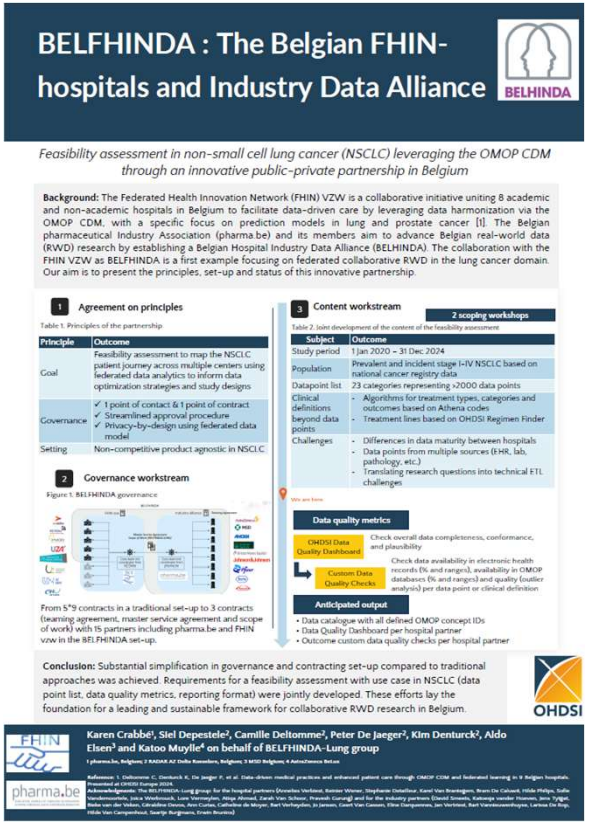
	N 650-700	N 850-900	N 750-800	N 100-150	N 450-500
Lab result	**Hospital A**	**Hospital B**	**Hospital C**	**Hospital D**	**Hospital E**
CRP	84	98	99	97	99
Hemoglobin	84	98	99	97	99
Leukocytes	84	98	99	97	99
LDH	76	95	98	96	95
Platelets		98	99	97	99
CEA		54	87	72	67
CA-125		2	2	2	1
CA 19-9		7	4	8	2
CA 15-3		5	3	4	4
NSE		36	68	1	41
Creatinin	84	98	99	97	99
AST	72	91	98	88	50
ALT	76	97		97	58
GGT		97	99	97	58
eGFR	84	98	99	97	99
WHO/ECOG	**Hospital A**	**Hospital B**	**Hospital C**	**Hospital D**	**Hospital E**
Total		88	100	66	99
Grade 0		16	14	19	26
Grade 1		54	58	34	50
Grade 2		9	18	10	17
Grade 3		5	7	1	4
Grade 4		3	2	2	2
Grade 5		0	0	0	0

BELFHINDA-LUNG: CONCLUSIONS

1. The set-up allows for smooth **multi-stakeholder collaboration** with delivery within short timelines while preserving data sovereignty.
2. **Financial cost** was high
3. The OMOP databases of the 5 FHIN hospitals **show high conformance** and **high overall patient volume**.
4. Consistent **availability, completeness** and **analytics** capabilities should be improved to allow advanced RWE research questions.

BELFHINDA publications:

OHDSI EU 2025



BELFHINDA : The Belgian FHIN-hospitals and Industry Data Alliance

Feasibility assessment in non-small cell lung cancer (NSCLC) leveraging the OMOP CDM through an innovative public-private partnership in Belgium

Background: The Federated Health Innovation Network (FHIN) VZW is a collaborative initiative uniting 8 academic and non-academic hospitals in Belgium to facilitate data-driven care by leveraging data harmonization via the OMOP CDM, with a specific focus on prediction models in lung and prostate cancer [1]. The Belgian pharmaceutical Industry Association (pharma.be) and its members aim to advance Belgian real-world data (RWD) research by establishing a Belgian Hospital Industry Data Alliance (BELHINDA). The collaboration with the FHIN VZW as BELFHINDA is a first example focusing on federated collaborative RWD in the lung cancer domain. Our aim is to present the principles, set-up and status of this innovative partnership.

1 Agreement on principles

Table 1. Principles of the partnership

Principle	Outcome
Goal	Feasibility assessment to map the NSCLC patient journey across multiple centers using federated data analytics to inform data optimization strategies and study designs
Governance	✓ 1 point of contact & 1 point of contract ✓ Streamlined approval procedure ✓ Privacy-by-design using federated data model
Setting	Non-competitive product agnostic in NSCLC

2 Governance workstream

Figure 1. BELFHINDA governance

From 5*9 contracts in a traditional set-up to 3 contracts (teaming agreement, master service agreement and scope of work) with 15 partners including pharma.be and FHIN vzw in the BELFHINDA set-up.

3 Content workstream — 2 scoping workshops

Table 2. Joint development of the content of the feasibility assessment

Subject	Outcome
Study period	1 Jan 2020 – 31 Dec 2024
Population	Prevalent and incident stage I-IV NSCLC based on national cancer registry data
Datapoint list	23 categories representing >2000 data points
Clinical definitions beyond data points	- Algorithms for treatment types, categories and outcomes based on Athena codes - Treatment lines based on OHDSI Regimen Finder
Challenges	- Differences in data maturity between hospitals - Data points from multiple sources (EHR, lab, pathology, etc.) - Translating research questions into technical ETL challenges

Data quality metrics

OHDSI Data Quality Dashboard — Check overall data completeness, conformance, and plausibility

Custom Data Quality Checks — Check data availability in electronic health records (% and ranges), availability in OMOP databases (% and ranges) and quality (outlier analysis) per data point or clinical definition

Anticipated output

- Data catalogue with all defined OMOP concept IDs
- Data Quality Dashboard per hospital partner
- Outcome custom data quality checks per hospital partner

Conclusion: Substantial simplification in governance and contracting set-up compared to traditional approaches was achieved. Requirements for a feasibility assessment with use case in NSCLC (data point list, data quality metrics, reporting format) were jointly developed. These efforts lay the foundation for a leading and sustainable framework for collaborative RWD research in Belgium.

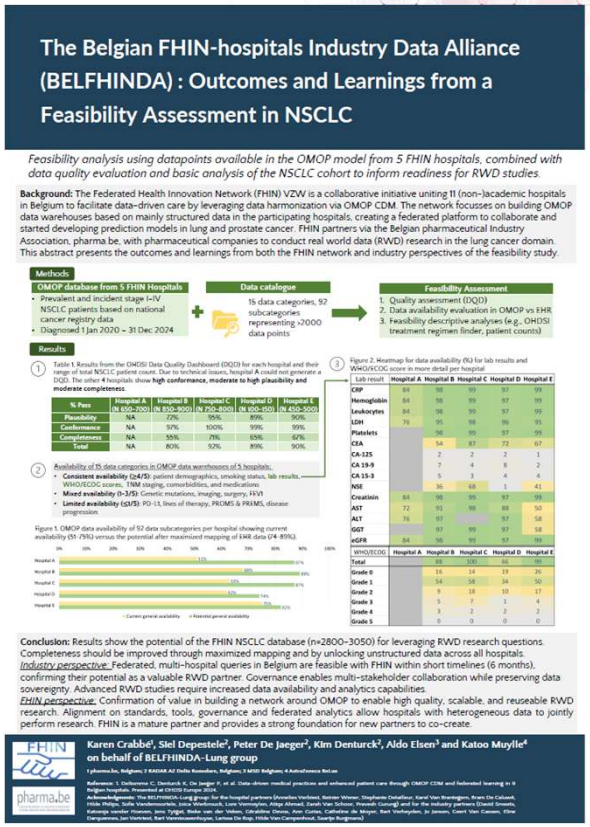
Karen Crabbé[1], Siel Depestele[2], Camille Deltomme[2], Peter De Jaeger[2], Kim Denturck[2], Aldo Elsen[3] and Katoo Muylle[4] on behalf of BELFHINDA-Lung group

1 pharma.be, Belgium; 2 RADAR AZ Delta Roeselare, Belgium; 3 MSD Belgium; 4 AstraZeneca Belux

References: 1. Deltomme C, Denturck K, De Jaeger P, et al. Data-driven medical practices and enhanced patient care through OMOP CDM and federated learning in 9 Belgian hospitals. Presented at OHDSI Europe 2024.

Acknowledgements: The BELFHINDA-Lung group: for the hospital partners (Annelies Verbiest, Reinier Wiener, Stephanie Detailleur, Karel Van Brantegem, Bram De Caluwé, Hilde Philips, Sofie Vandemoortele, Joice Werbrouck, Lore Vermeylen, Aliga Ahmad, Zarah Van Schoor, Praveeh Gurung) and for the industry partners (David Smeets, Katooja vander Hoeven, Jens Tydgat, Reika van der Velden, Cátrédine Devos, Ann Curtas, Catherine de Moyer, Bart Verheyden, Jo Jansen, Caert Van Cassen, Elne Dangumeau, Jan Verhiest, Bart Vanmoesenhuyse, Larissa De Rop, Hilde Van Campenhout, Saartje Burgmans, Erwin Brunkst)

OHDSI EU 2026



The Belgian FHIN-hospitals Industry Data Alliance (BELFHINDA) : Outcomes and Learnings from a Feasibility Assessment in NSCLC

Feasibility analysis using datapoints available in the OMOP model from 5 FHIN hospitals, combined with data quality evaluation and basic analysis of the NSCLC cohort to inform readiness for RWD studies.

Background: The Federated Health Innovation Network (FHIN) VZW is a collaborative initiative uniting 11 (non-)academic hospitals in Belgium to facilitate data-driven care by leveraging data harmonization via OMOP CDM. The network focusses on building OMOP data warehouses based on mainly structured data in the participating hospitals, creating a federated platform to collaborate and started developing prediction models in lung and prostate cancer. FHIN partners via the Belgian pharmaceutical Industry Association, pharma.be, with pharmaceutical companies to conduct real world data (RWD) research in the lung cancer domain. This abstract presents the outcomes and learnings from both the FHIN network and industry perspectives of the feasibility study.

Methods

OMOP database from 5 FHIN Hospitals
- Prevalent and incident stage I–IV NSCLC patients based on national cancer registry data
- Diagnosed 1 Jan 2020 – 31 Dec 2024

Data catalogue
15 data categories, 92 subcategories representing >2000 data points

Feasibility Assessment
1. Quality assessment (DQD)
2. Data availability evaluation in OMOP vs EHR
3. Feasibility descriptive analyses (e.g., OHDSI treatment regimen finder, patient counts)

Results

Table 1. Results from the OHDSI Data Quality Dashboard (DQD) for each hospital and their range of total NSCLC patient count. Due to technical issues, hospital A could not generate a DQD. The other 4 hospitals show **high conformance, moderate to high plausibility and moderate completeness**.

% Pass	Hospital A (N 650-700)	Hospital B (N 850-900)	Hospital C (N 750-800)	Hospital D (N 100-150)	Hospital E (N 450-500)
Plausibility	NA	72%	95%	89%	90%
Conformance	NA	97%	100%	99%	99%
Completeness	NA	55%	71%	65%	67%
Total	NA	80%	92%	89%	90%

Availability of 15 data categories in OMOP data warehouses of 5 hospitals:
- **Consistent availability (≥4/5)**: patient demographics, smoking status, lab results, WHO/ECOG scores, TNM staging, comorbidities, and medications
- **Mixed availability (1–3/5)**: Genetic mutations, imaging, surgery, FEV1
- **Limited availability (≤1/5)**: PD-L1, lines of therapy, PROMS & PREMS, disease progression

Figure 1. OMOP data availability of 92 data subcategories per hospital showing current availability (51-75%) versus the potential after maximized mapping of EHR data (74-89%).

Figure 2. Heatmap for data availability (%) for lab results and WHO/ECOG score in more detail per hospital

Lab result	Hospital A	Hospital B	Hospital C	Hospital D	Hospital E
CRP	84	98	99	97	99
Hemoglobin	84	98	99	97	99
Leukocytes	84	98	99	97	99
LDH	79	95	98	96	95
Platelets		98	99	97	99
CEA		54	87	72	67
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WHO/ECOG	Hospital A	Hospital B	Hospital C	Hospital D	Hospital E
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Grade 2		9	18	10	17
Grade 3		5	7	1	4
Grade 4		3	2	2	2
Grade 5		0	0	0	0

Conclusion: Results show the potential of the FHIN NSCLC database (n=2800–3050) for leveraging RWD research questions. Completeness should be improved through maximized mapping and by unlocking unstructured data across all hospitals. *Industry perspective:* Federated, multi-hospital queries in Belgium are feasible with FHIN within short timelines (6 months), confirming their potential as a valuable RWD partner. Governance enables multi-stakeholder collaboration while preserving data sovereignty. Advanced RWD studies require increased data availability and analytics capabilities. *FHIN perspective:* Confirmation of value in building a network around OMOP to enable high quality, scalable, and reuseable RWD research. Alignment on standards, tools, governance and federated analytics allow hospitals with heterogeneous data to jointly perform research. FHIN is a mature partner and provides a strong foundation for new partners to co-create.

Karen Crabbé[1], Siel Depestele[2], Peter De Jaeger[2], Kim Denturck[2], Aldo Elsen[3] and Katoo Muylle[4] on behalf of BELFHINDA-Lung group

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