

**More comparable health data and indicators,
through collaboration and privacy-enhanced analytics**

**A shared framework for non-communicable disease
surveillance across Europe**

20

experts

engaged across the project

11

European countries

in the expert network

13

final deliverables

across 5 areas of work

9

meetings held

6 expert · 3 stakeholder

Five areas of work

13 final outputs, from indicator definition to data governance

01

Indicators and FAIR foundations

Metadata, definitions and the Diabetes Indicators Core Set

3 deliverables

02

Privacy-enhanced analytics and methods

Frameworks, studies, source assessment and contextualisation

5 deliverables

03

Patient involvement

Review and roadmap for registries and participatory platforms

1 deliverable

04

Privacy, governance and interoperability

Data protection, ethics, linkage and DIGA assessment

3 deliverables

05

Closing synthesis

CHIEF Final Report

1 deliverable

Coordination and exchange

6

expert meetings held

from the first Annual Meeting (2022) through October 2026

3

stakeholder meetings held

including technical summits and IDF / EUDF events

●

Final meeting held at JRC Ispra

12-13 October 2026

Romagna diabetes field test

Incidence and care indicators reported as aggregated, anonymised tables

Scientific output

5

CHIEF papers published

2

manuscripts submitted · 2026

3

associated papers

Published themes

Privacy-enhanced analytics · FAIR foundations
DIGA · indicator taxonomy · CHIEF framework

Associated themes

Data quality · semantics · regional registry

CHIEF · 2022-2026

A European initiative connecting health data, expertise and analytical methods.

EUROPEAN HEALTH DATA SPACE

A European Commission initiative: Collaborative Health Information European Framework (CHIEF) FINAL PRODUCTS

Table 1. List of reports

#	Activity	Deliverable (authors)	Version	Deadline
1	1	Metadata - definition, semantic description, and FAIR-ification. F Carinci, S Cunningham, S Fava, N Klazinga, A Lavens, J Lepiksone, M Massi Benedetti, T Poljičanin, P Rossing, J Sándor, I Štotl	Final (v. 1.0)	18/2/2025
2		Indicator framework. Diabetes Indicators Core Set. F Carinci, S Cunningham, S Fava, N Klazinga, A Lavens, J Lepiksone, M Massi Benedetti, T Poljičanin, P Rossing, I Štotl	Final (v.5.1.3)	6/4/2025
3		Technical report specifying the description, metadata and contextualisation of indicators from data sources and registries to enable routine federated reporting of NCDs in Europe. F Carinci, S Cunningham, J Dimnjaković, S Fava, T Poljičanin, I Štotl	Final (v.1.0)	25/9/2026
4	2	Use of federated software to measure the impact of risk factors and data quality for cardiovascular risk prediction among people with diabetes, using cohorts extracted from federated diabetes registers in Europe. F Carinci, S Cunningham, I Štotl, Z Baltane, S Fava	Final (v.1.1)	17/9/2024
5		Operational plan to build a coherent EU Information System for NCDs: design of targeted studies for the timely reporting of NCD indicators in the European Health Data Space. F Carinci, I Štotl	Final (v. 1.1)	11/3/2025
6		Updated method to carry out automated reviews of data sources and registers across NCDs in EU countries: an application on needs and gaps for CVD risk stratification in diabetes. F Carinci, S Fava, I Štotl	Final (v. 0.5)	17/4/2025
7		A proposal for a federated data analysis framework with practical examples provided of specific indicators S Fava, F Carinci	Final (v. 0.3)	28/4/2025
8		Integration of federated analytics with metadata contextualisation in a multidisciplinary collaborative framework for the routine reporting of NCD indicators in Europe. F Carinci, P Di Bartolo, I Štotl, S Fava, S Cunningham, L Pennells, Z Baltane, S Reiff, T Poljičanin, J Dimnjakovic	Final (v 1.0)	25/9/2026
9	3	Patient involvement in chronic disease registries. M Massi Benedetti, E Dupont, C Michael, F Carinci, S Cunningham, J Dimnjakovich, T Poljicanin, I Štotl, N Nicholson	Final (v 1.0)	22/6/2026
10	4	Privacy, data governance and ethics in the handling of sensitive data: assessment of current practices in the field of diabetes. CT Di Iorio, E Ronchi, I Pristas, T Buble	Final (v. 4.0)	15/3/2025
11		Data Linkage & Interoperability. C T Di Iorio, E Ronchi, I Pristas, T Buble	Final	20/7/2024
12		Monitoring privacy, data protection, data governance, interoperability and ethics in registries and health information systems to balance compliance with the accurate reporting of NCD indicators CT Di Iorio, E Ronchi, F Carinci, I Štotl, I Pristas, T Buble	Final (v. 5.0)	15/7/2026
13	5	CHIEF Final report	Final (v. 2.3)	7/10/2026

PAPERS

Submitted

1. **Di Iorio CT, Carinci F, Štotl I, Pristas I, Buble T, Nicholson N, Ronchi E.** How ready are data holders for the European Health Data Space? Results of an international survey using a refined version of Data Protection, Interoperability and Data Governance Assessment (DIGA), Submitted, 2026.
2. **Massi-Benedetti M, Michael CM, Carinci F, Cunningham S, Dimnjakovic J, Poljicanin T, Štotl I, Nicholson N and Dupont E,** Patient involvement in chronic disease registries: a narrative review and roadmap for the implementation of participative European data platforms, Submitted, 2026.

Published

1. **Carinci F, Fava S, Štotl I, Nicholson N.** Federated analytics for non-communicable disease surveillance in the European health data space: a scoping review and conceptual framework. *Front Public Health*. 2026 Aug 21;14:1911992. Available at: <https://pmc.ncbi.nlm.nih.gov/articles/PMC13543158/>.
2. **Štotl I, Carinci F, Fava S, Lavens A, Lepiksone J, Massi-Benedetti M, Poljičanin T, Cunningham S, Sándor J, Nicholson N,** FAIR Foundations of a Novel Indicator Vault for Non-communicable Diseases in the European Union: Feasibility Study for Effective Contextualization of Indicators, *Front. Digit. Health*, 16 December 2025. Available at: <https://www.frontiersin.org/journals/digital-health/articles/10.3389/fdgth.2025.1685733/full>.
3. **Carinci F, Nicholson N,** Linking registries to deliver standardised NCD indicators in the European Health Data Space: why do we need a Collaborative Health Information European Framework, *Front. Public Health*, 03 November 2025. Available at: <https://www.frontiersin.org/journals/public-health/articles/10.3389/fpubh.2025.1684947/full>.
4. **Di Iorio CT, Ronchi E, Pristas I, Buble T, Nicholson N, Carinci F,** Data Protection, Interoperability and Governance Assessment (DIGA) Tool: results from a proof-of-concept survey, *Front. Digit. Health*, 27 October 2025, Volume 7, 2025. Available at: <https://www.frontiersin.org/journals/digital-health/articles/10.3389/fdgth.2025.1685774/full>
5. **Carinci F, Poljičanin T, Cunningham S, Fava S, Štotl I, Lepiksone J, Nicholson N, Massi Benedetti M and Klazinga N,** A taxonomy of indicators for Non-Communicable Diseases: agreement, definition, and contextual description using diabetes as a case study, *Front. Public Health*, 13 October 2025, Volume 13, 2025. Available at: <https://www.frontiersin.org/journals/public-health/articles/10.3389/fpubh.2025.1685731/full>.

ASSOCIATED PAPERS

1. **Nicholson N, Carvalho R, Stotl I,** A FAIR perspective on data quality frameworks, *Data*, 10, 9, 2025, p. 136, MDPI AG. Available at: <https://data.europa.eu/doi/10.3390/data10090136>.
2. **Nicholson N, Stotl I,** A Generic Framework for the Semantic Contextualisation of Indicators, *Frontiers in Computer Science*, ISSN 2624-9898, 6, 2024. Available at: <https://www.frontiersin.org/journals/computer-science/articles/10.3389/fcomp.2024.1463989/full>.
3. **Carinci F, Messina R, Mencarelli M, Micheline MM, Bici A, Berardo A, Cas AD, Iezzi E, Aldigeri R, Di Iorio CT, Gualdi S, Fantini MP, Bonadonna R, Nicholson N, Benedetti MM, Di Bartolo P.** Implementing a federated regional diabetes register in a decentralized health system: implications for healthcare organization and the European Health Data Space. *Front Public Health*. 2026 Jul 16;14:1864673. Available at: <https://www.frontiersin.org/journals/public-health/articles/10.3389/fpubh.2026.1864673/full>.

FIELD TEST ANALYTICS

- 1. Collaborative agreement CHIEF-AUSL Romagna, Italy. Service contract “CHIEF DATA COLLECTION FIELD TEST”.** Provision of a set of indicators describing aspects of diabetes incidence and care in the Romagna region, delivered in the form of tables containing aggregated and anonymized data, in compliance with applicable data protection regulations.

Table 2. List of experts involved by country

#	Country	Expert
1	Belgium	Elisabeth Dupont
2		Astrid Lavens
3	Croatia	Tamara Buble
4		Jelena Dimnjakovic
5		Tamara Poljicanin
6		Ivan Pristaš
7	Denmark	Peter Rossing
8	France	Elettra Ronchi
9	Hungary	Janos Sandor
10	Italy	Fabrizio Carinci
11		Tania Di Iorio
12		Massimo Massi Benedetti
13	Latvia	Zane Baltāne
14		Jana Lepiksone
15	Malta	Stephen Fava
16		Sascha Reiff
17	Netherlands	Niek Klazinga
18	Slovenia	Iztok Stotl
19	United Kingdom	Scott Cunningham
20		Lisa Pennells

Table 3. Expert Meetings

#	Year	Meeting	Date
1	2022	1 st Annual Meeting	4/11/2022
2		IDF Lisbon Conference Meeting	8/12/2022
3	2024	2 nd Annual Meeting, JRC Ispra	25/10/2024
4	2025	3 rd Annual Meeting, JRC Ispra	19/12/2025
5	2026	4 th Annual Meeting, JRC Ispra	3/7/2026
6		Final Meeting, JRC Ispra	12-13/10/2026

Table 4. Stakeholder Meetings

#	Year	Meeting	Date
1	2023	IDF Europe Regional Council & TEAM WHO Europe-IDF Europe High-Level Technical Summit on Diabetes	28/11/2023
2	2024	IDF Europe Regional Council Meeting, Rome, Italy	13/10/2024
3		Diabetes Registries: Enabling High-Quality Diabetes Care, EUDF Symposium at EASD Conference	11/9/2024