



Congress Centre Lombardia Region 08/11/2022

Connect to win

possible subtitle

DigiCore



Intelligent Ecosystem to improve the governance, the sharing and the re-use of health Data for
Rare Cancers

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Rare cancer
data ecosystem

Advance research

Increase knowledge

Improve quality of care

Ensure access to optimal treatment

Underpin data economy towards the European Health
Data Space



Available at www.sciencedirect.com

SciVerse ScienceDirect

journal homepage: www.ejconline.com



Rare cancers are not so rare: The rare cancer burden in Europe

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Burden and centralised treatment in Europe of rare tumours: results of RARECAREnet—a population-based study

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Summary

Lancet Oncol 2017; 18: 1022–39

Published Online

July 4, 2017

[http://dx.doi.org/10.1016/S1470-2045\(17\)30445-X](http://dx.doi.org/10.1016/S1470-2045(17)30445-X)

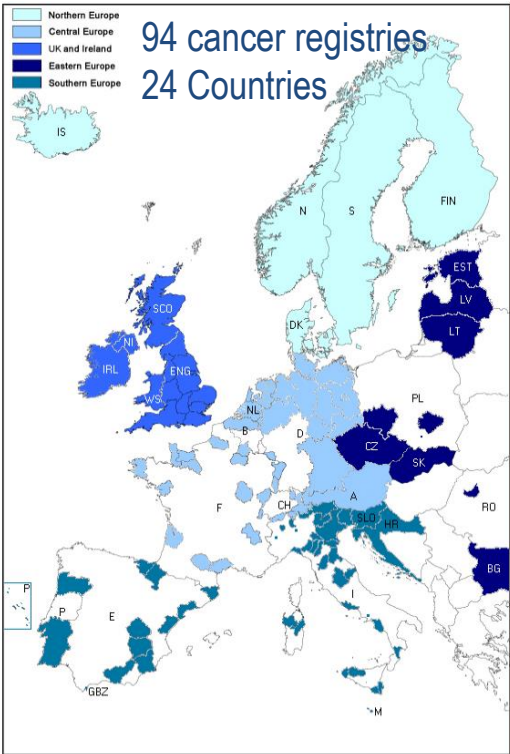
This online publication has been corrected. The corrected version first appeared at theLancet.com/oncology on July 26, 2017

See Comment page 983

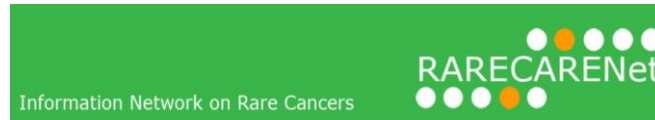
Background Rare cancers pose challenges for diagnosis, treatments, and clinical decision making. Information about rare cancers is scant. The RARECARE project defined rare cancers as those with an annual incidence of less than six per 100 000 people in European Union (EU). We updated the estimates of the burden of rare cancers in Europe, their time trends in incidence and survival, and provide information about centralisation of treatments in seven European countries.

Methods We analysed data from 94 cancer registries for more than 2 million rare cancer diagnoses, to estimate European incidence and survival in 2000–07 and the corresponding time trends during 1995–2007. Incidence was calculated as the number of new cases divided by the corresponding total person-years in the population. 5-year relative survival was calculated by the Ederer-2 method. Seven registries (Belgium, Bulgaria, Finland, Ireland, the Netherlands, Slovenia, and the Navarra region in Spain) provided additional data for hospitals treating about

Rare cancers: incidence < 6/100,000/year in EU



EUROCARE-5 adult database



RARE CANCER AGENDA 2030

Ten Recommendations from the EU Joint Action on Rare Cancers

1. Rare cancers are the rare diseases of oncology
2. Rare cancers should be monitored
3. Health systems should exploit networking
4. Medical education should exploit and serve healthcare networking
5. Research should be fostered by networking and should take into account an expected higher degree of uncertainty
6. Patient-physician shared clinical decision-making should be especially valued
7. Appropriate state-of-the-art instruments should be developed in rare cancer
8. Regulation on rare cancers should tolerate a higher degree of uncertainty
9. Policy strategies on rare cancers and sustainability of interventions should be based on networking
10. Rare cancer patients should be engaged

RARE CANCER AGENDA 2030

Ten Recommendations from the EU Joint Action on Rare Cancers





European Reference Networks



EURACAN

European Reference Network on Rare Adult Cancers (solid tumors)





Open to Not EURACAN health care providers
Contribution from national DB/network available



Head and Neck Cancer International Group

*A data ecosystem is a platform that combines data from different data providers and **creates value** through the usage of the data*

Closed data ecosystems

Organizations share data in a closed environment



Strategic partnerships

Small number of organizations share data for a dedicated purpose



Open data ecosystems

Organizations share data for the public good openly

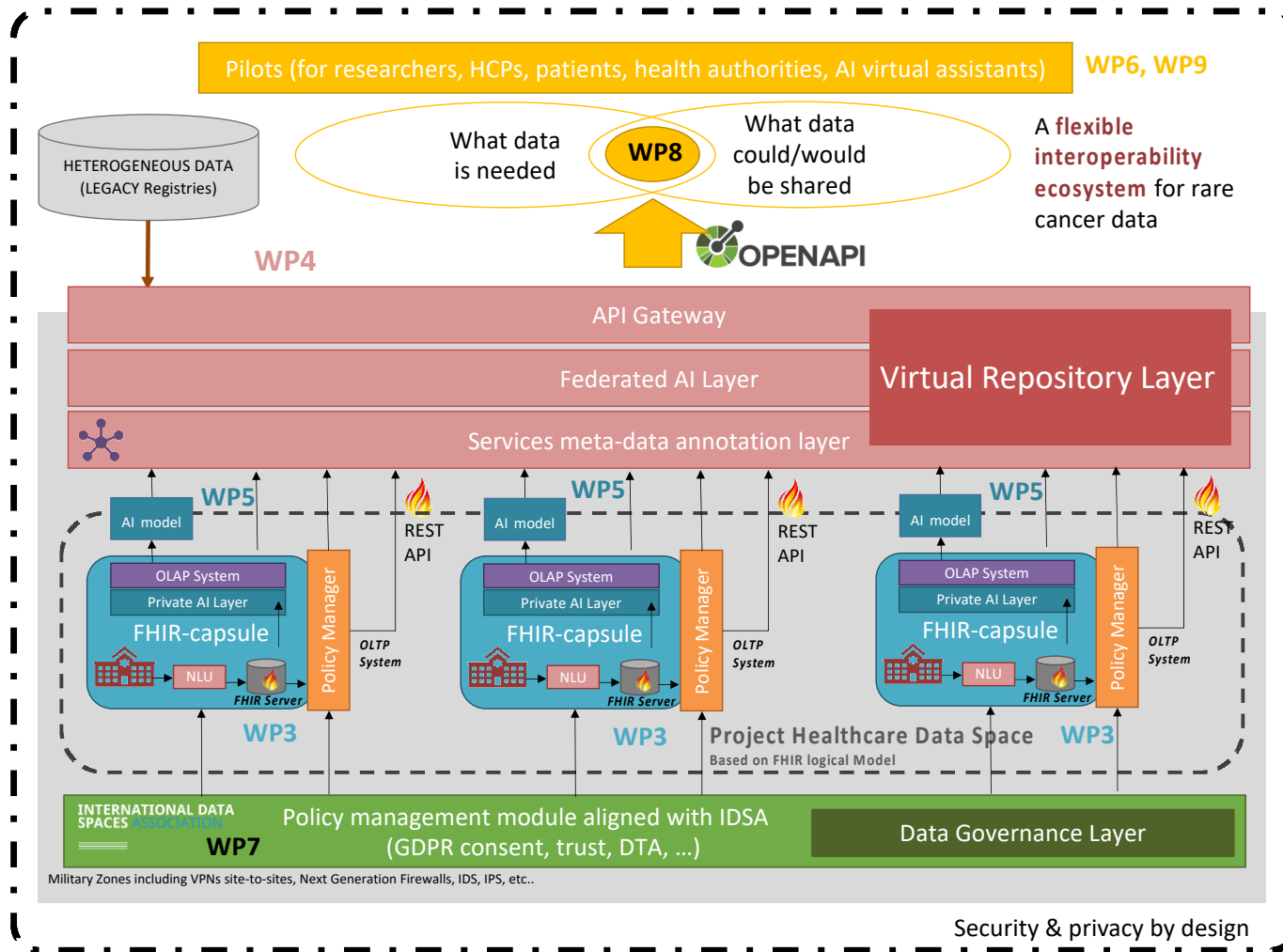




Partner	Resources	Cases available
INT	EHR for inpatients and outpatients; reports of pathology and imaging, radiotherapy DB, drugs DB, laboratory DB; administrative DB	about 8000/year in the EHR (available from 2018 onwards)
	EUROCARE6 and RARECAREnet population base dataset on rare cancers	>1,000,000 rare cancers cases
CLB	EHR for inpatients and outpatients; Images, genomic data,	200,000 all cancers; about 30,000 rare
APHP	EHR for inpatients and outpatients; reports of pathology and imaging, radiotherapy DB, drugs DB, laboratory DB; administrative DB. Clinical data warehouse in OMOP and FHIR	600 new cases/year of head and neck cancers; >3000 since 2017
	The registry of the French Network of head and neck cancers (REFCOR). It is a national clinical registry on head and neck cancers with pathological and imaging reports (pdf repository).	10,000 head and neck cancer cases
FJD	Electronic health records (inpatients and outpatients). Pathology reports, imaging, labs available online.	about 1000 cases of sarcomas
VGR	Spanish registry	about 2500 sarcomas
	EHR for inpatients and outpatients; reports of pathology and imaging, radiotherapy DB, drugs DB, laboratory DB	about 2500 rare cancers/year; 1000 cases of sarcomas already available + about 300 new sarcomas (year);
NIOC	Electronic health records (inpatients and outpatients). Clinical DB, institutional sarcomas DB	>5000 rare cancers; 200 sarcomas in a dedicated database
MUH	EHR for inpatients and outpatients; reports of pathology and imaging, radiotherapy DB, drugs DB, laboratory DB	7000 cancer cases (about 1000 rare cancers) + 2000 new cancer cases/year (about 300 rare cancers).
OUS	EHR for inpatients and outpatients; reports of pathology and imaging, radiotherapy DB, drugs DB, laboratory DB; administrative DB; hospital registry for common and rare cancers (e.g., sarcoma, neuroendocrine tumours); national registry for common and rare cancers (i.e., quality registry for sarcoma)	about 1500 rare cancer/year data available in the last 20 years
MMCI	EHR for inpatients and outpatients; reports of pathology and imaging, radiotherapy DB, laboratory DB; administrative DB; Genomic/biomolecular data	>10,000; >1500 rare cancers
	Czech National Cancer Registry https://www.uzis.cz/index-en.php?pg=about-us	about 10,000 rare cancers/year
FPNS	EHR (inpatients and outpatients); reports of pathology and imaging, radiotherapy DB, drugs DB, laboratory DB; administrative DB	>50,000; >7000 rare cancers
UKE	EHR for inpatients and outpatients; reports of pathology and imaging, radiotherapy DB, laboratory DB; administrative DB; Tumor board data set	> 2000 rare cancers; mainly head and neck cancers and sarcomas

Technical approach

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action
and

leads
to
care



Strasbourg, 3.5.2022
COM(2022) 197 final

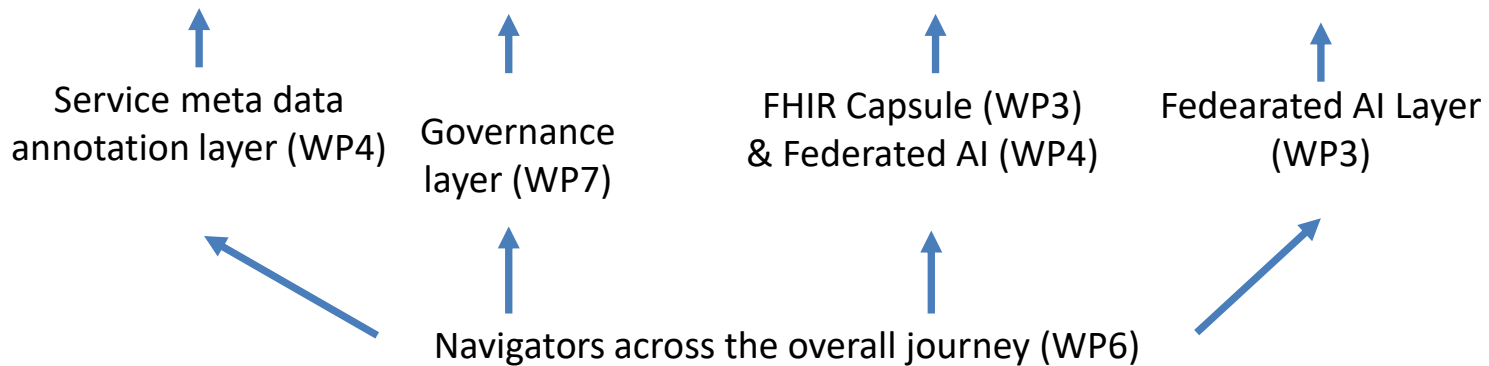
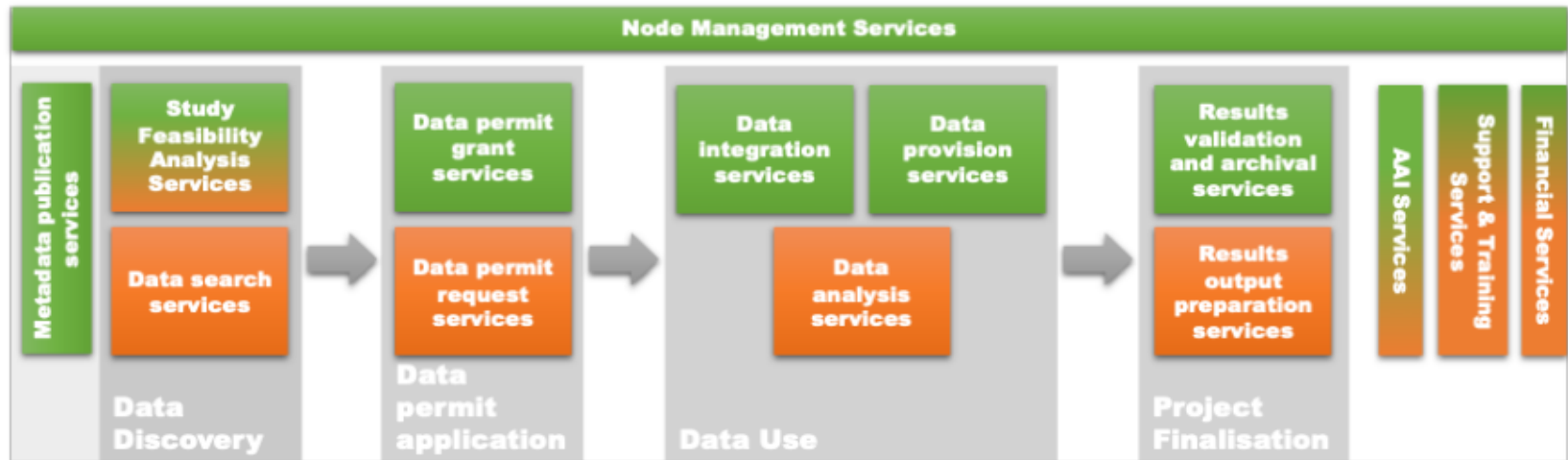
2022/0140 (COD)

Proposal for a
REGULATION OF THE EUROPEAN PARLIAMENT AND OF THE COUNCIL
on the European Health Data Space

(Text with EEA relevance)

{SEC(2022) 196 final} - {SWD(2022) 130 final} - {SWD(2022) 131 final} -
{SWD(2022) 132 final}

IDEA4RC and TEHDAS user journey support



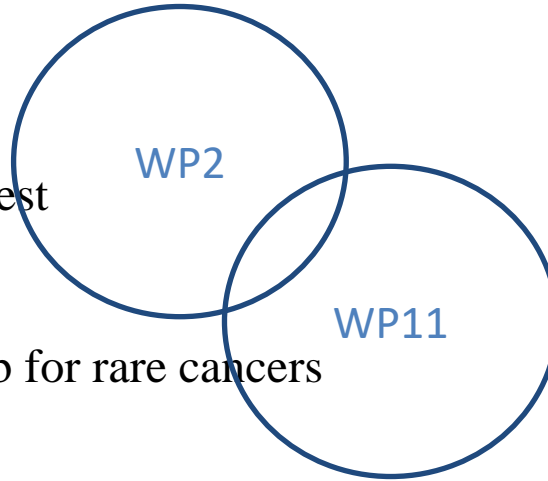
WP10 – Rare Cancer Data Ecosystem enlargement and liaison

T10.2 Community of interest

WP2

T10.4 A data exchange hub for rare cancers

WP11



Privacy Symposium 2023

April 17-21 2023
Venice, Italy



www.privacysymposium.org



Health and Medical Data Compliance and Secondary Use

Monday April 17 2023



Thank you

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