



A real-world solution to secondary health data use in cancer: the IDEA4RC project Moderator: Elena Martinelli

May 21st, 2025 afternoon

1.00-1.15 pm	Intelligent ecosystem to improve the governance, the sharing, and the re-use of health data for rare cancers (IDEA4RC): an introduction
	Andreas Muth (Sahlgrenska University Hospital)

1.15-1.30 pm **The need for data in rare cancer – a patient perspective** Magnus Carlsson (former chairman of the Swedish Sarcoma Association)

1.30-3.00 pm Showcase Data-reuse challenges tackled with IDEA4RC solutions

- Data re-use for research: which challenges? Annalisa Trama (National Cancer Institute of Milan)
- The data holder journey in IDEA4RC Eugenio Gaeta (Universidad Politécnica de Madrid)
- Security, privacy and trust in IDEA4RC Eugenio Gaeta (Universidad Politécnica de Madrid)
- Extract transform and load (ETL) for IDEA4RC. A new paradigm for data gathering
 - Vincenzo Falanga (Engineering Ingegneria Informatica S.p.a.)
- Data modelling, interoperability and NLP for data extraction Unai Zulaika (Universidad de Deusto)
- The user journey with IDEA4RC solutions Itziar Alonso (Universidad Politécnica de Madrid)
- Data findability and understanding: solutions by IDEA4RC Adrián Dantas (Universidad Politécnica de Madrid)
- Federated analysis Frank Martin (Netherlands Comprehensive Cancer Organisation)
- Breaking barriers to collaboration: IDEA4RC access Ioanna Drympeta (Centre for Research & Technology, Hellas)

3.00-3.30 pm Coffee break

Moving ahead: Contemporary legal/privacy challenges in secondary health data use, a European, Nordic and Swedish perspective

Moderator: Vasiliki Tsiompanidou

3.30-3.50 pm	Legal/privacy challenges of today: EU perspective Guillaume Byk (European Commission)
3.50-4.10 pm	Danish perspectives on secondary use – moving towards EHDS Sigrun Gyrtrup (Danish Health Data Authority)
4.10-4.30 pm	Legal/privacy challenges of today in Sweden Tina Chavoshi (Swedish eHealth Agency)
4.30-5.00 pm	Round Table The way ahead from a Nordic countries and European perspective moderated by Sébastien Ziegler (European Center for Certification and Privacy)

