



Federated Data Network in practice (HONEUR)

27 September 2022

Sander Dalhuisen, MD

Sr. RWE manager BENELUX



Why Janssen?

Create disease insight

Optimization of Multiple Myeloma treatment & input R&D

Predictive Medicine

Best-suited treatment in subgroups based on outcomes measured in practice

Access

Ensure availability of the best treatments for the group of patients who cannot wait

Cohort

Connecting patient cohorts for sufficient analysis power in rare diseases and/or subpopulation

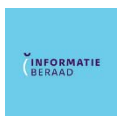
Governance

Regie op Registers



Zorginstituut Nederland

VWS



UMCs, NVZ



Nederlandse Vereniging van Ziekenhuizen



EUROPEAN MEDICINES AGENCY
SCIENCE MEDICINES HEALTH

User Initiatives



Luscii
bringing care to you



veilig online uitwisselen
van gezondheidsgegevens



Regionale
Oncologienetwerken

Technical/Data Infrastructure Initiatives



SDV SKR

Technical players



End-user applications developers



Data-users & associations



NEDERLANDSE FEDERATIE VAN
UNIVERSITAIR MEDISCHE CENTRA



Nederlandse
Vereniging van
Ziekenhuizen



santeon



Stakeholders & associations



Nederlandse Vereniging voor Hematologie



Federatie
Medisch
Specialisten

Patient's associations



(Quality) Registries/ Databases



orphanet



Zorg voor Data

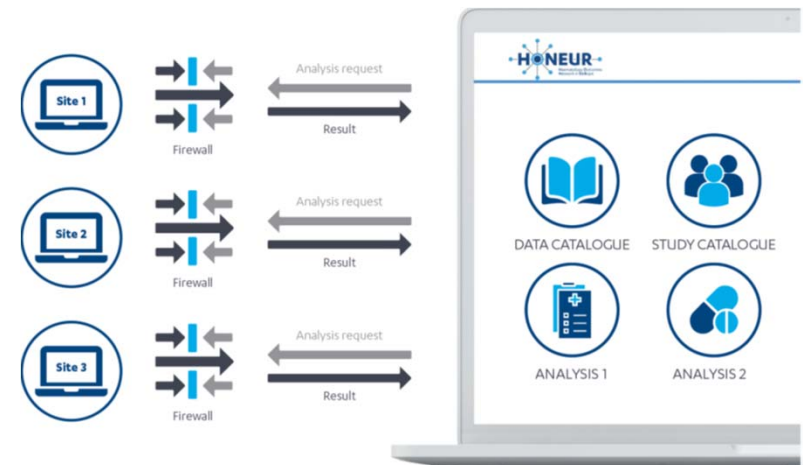


PHARMACEUTICAL COMPANIES OF
Johnson & Johnson

RWD is highly fragmented due to heterogeneous data collection systems

HONEUR overcomes this challenge with a common data model, the data stays at the hospital/registry

Our mission is to create a collaborative platform to liberate the potential of Real-World Evidence in Hematology



Scientific and technical output

Systematic Literature Review

1

The Value of Federated Data Networks in Oncology: What Research Questions Do They Answer? Outcomes From a Systematic Literature Review

Matthias Hunger, PhD, Kristina Bardenheuer, MSc Epi, Alun Passey, PhD, René Schade, PhD, Ruchika Sharma, MPH, Clare Hague, PhD

Published in Value in Health in May 2022

2

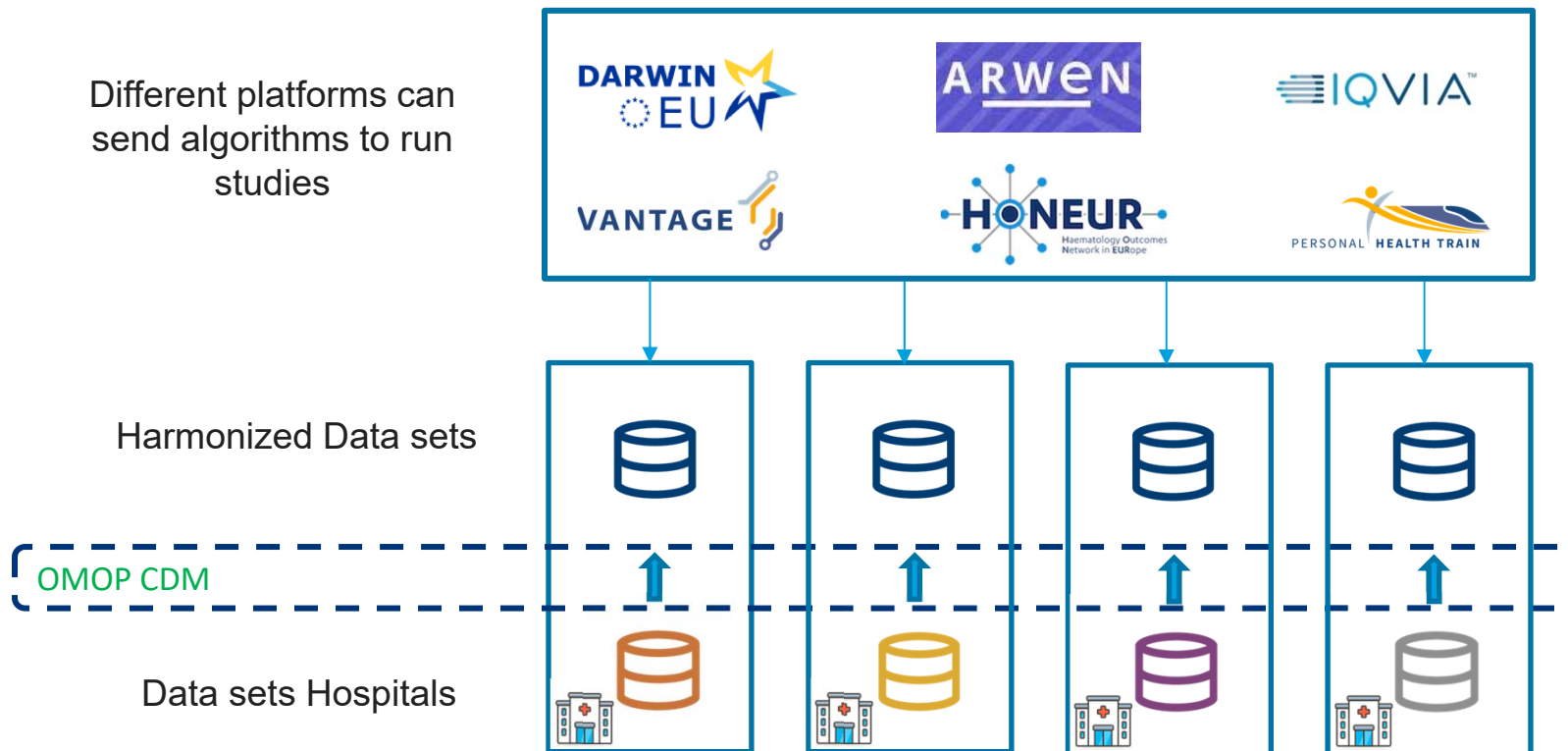
Haematology Outcomes Network in Europe (HONEUR)—A collaborative, interdisciplinary platform to harness the potential of real-world data in hematology

Kristina Bardenheuer | Michel Van Speybroeck | Clare Hague | Enkeleida Nikai | Martin Price

Published in the European Journal of Haematology in June 2022



Hospitals can participate or refuse to participate



Implementation Time vs Effort

	Phase 1 Checking Prerequisites	Phase 2 Contractual Agreement	Phase 3 Onboarding	Phase 4 Using the Network
Time	2 months	3 - 6 months	3 - 4 months	To be defined (depending on research question)
Effort	1 day	1-2 days	15 days 1 day for HCP	

