



Harnessing Health Data: What new processes are needed?

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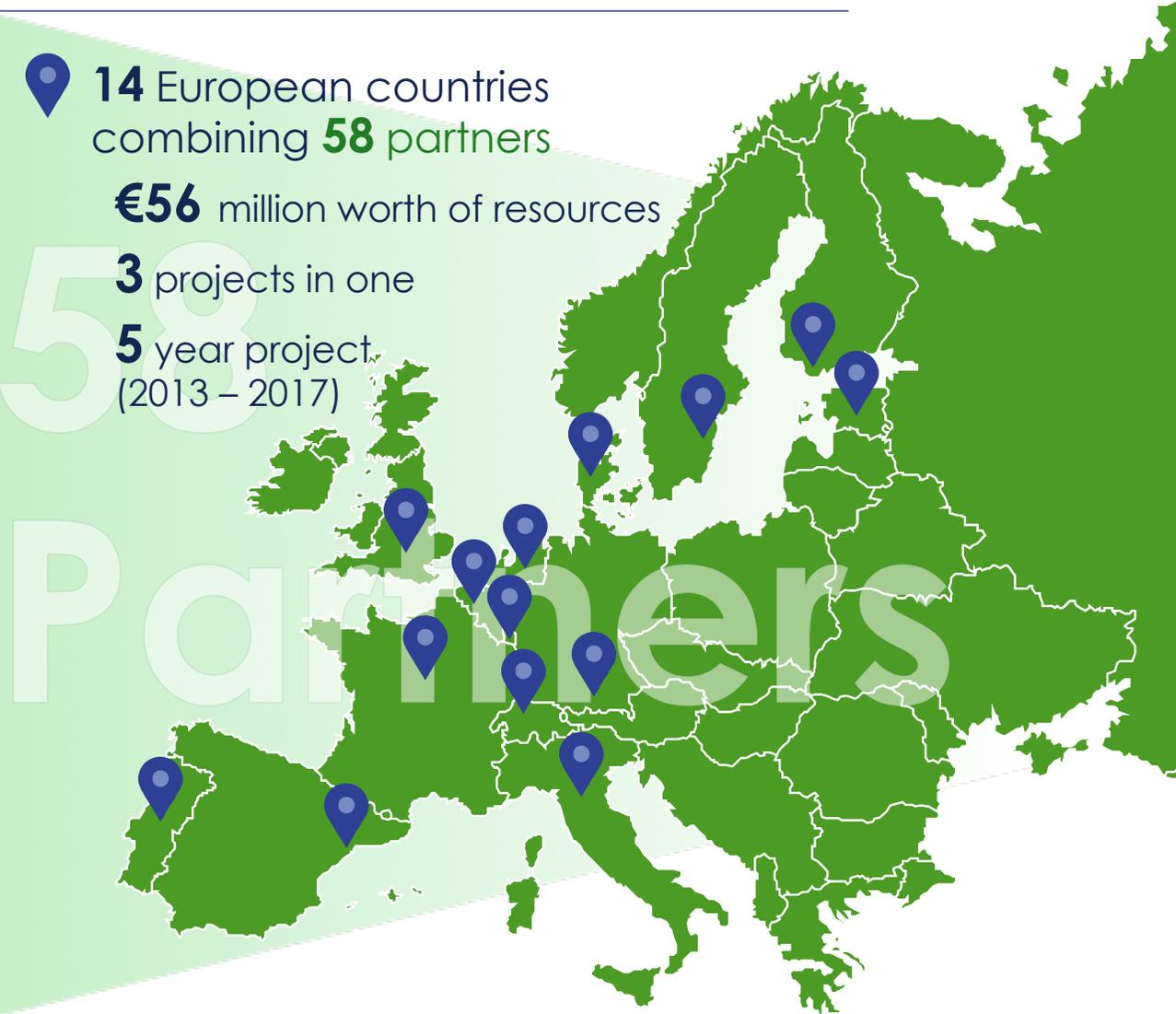
Project overview



ACADEMIC PARTNERS 38



14 European countries combining **58** partners
€56 million worth of resources
3 projects in one
5 year project (2013 – 2017)



SME PARTNERS 9



EFPIA PARTNERS 10



PATIENT ORGANISATION 1

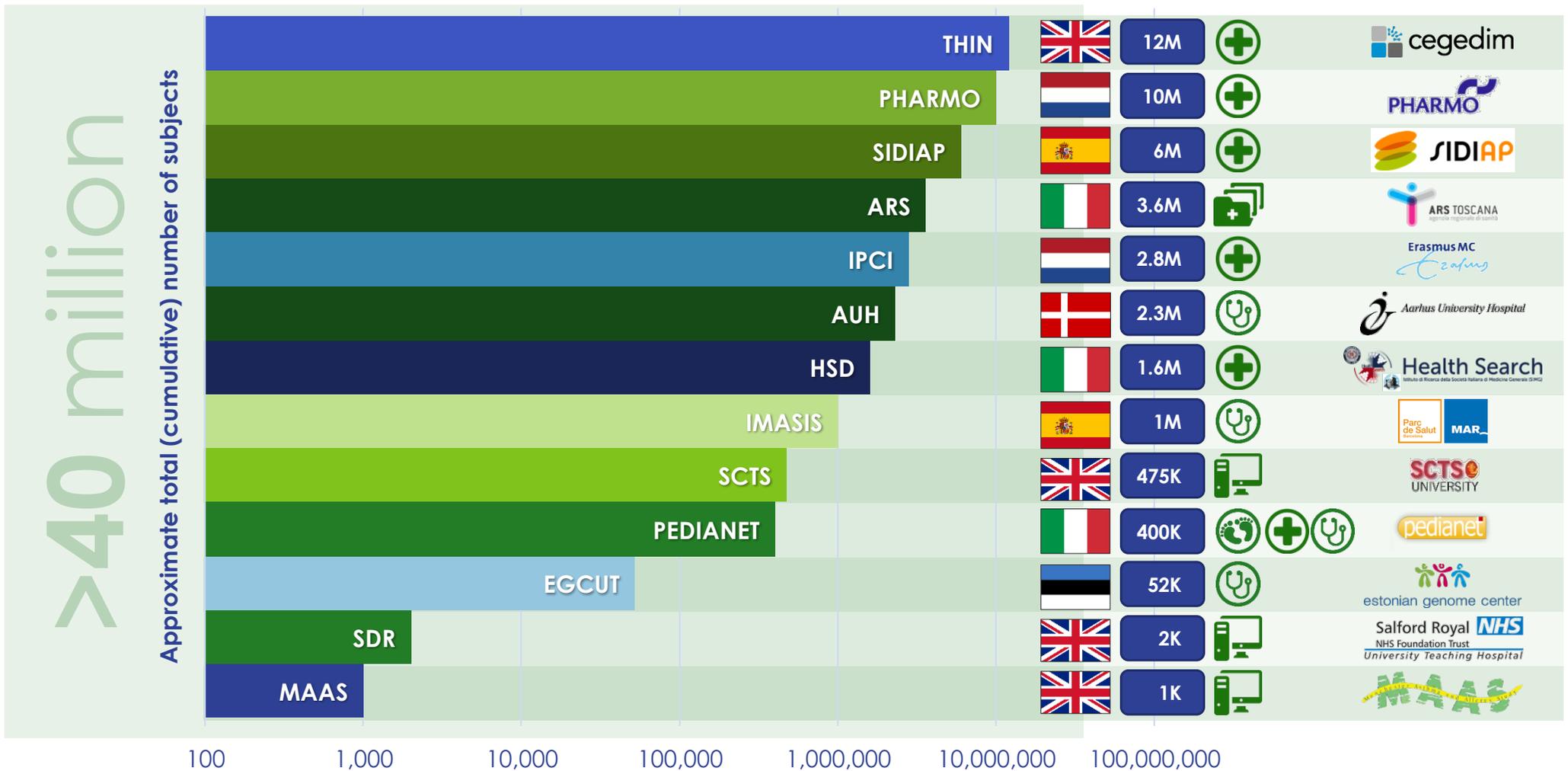


Available data sources



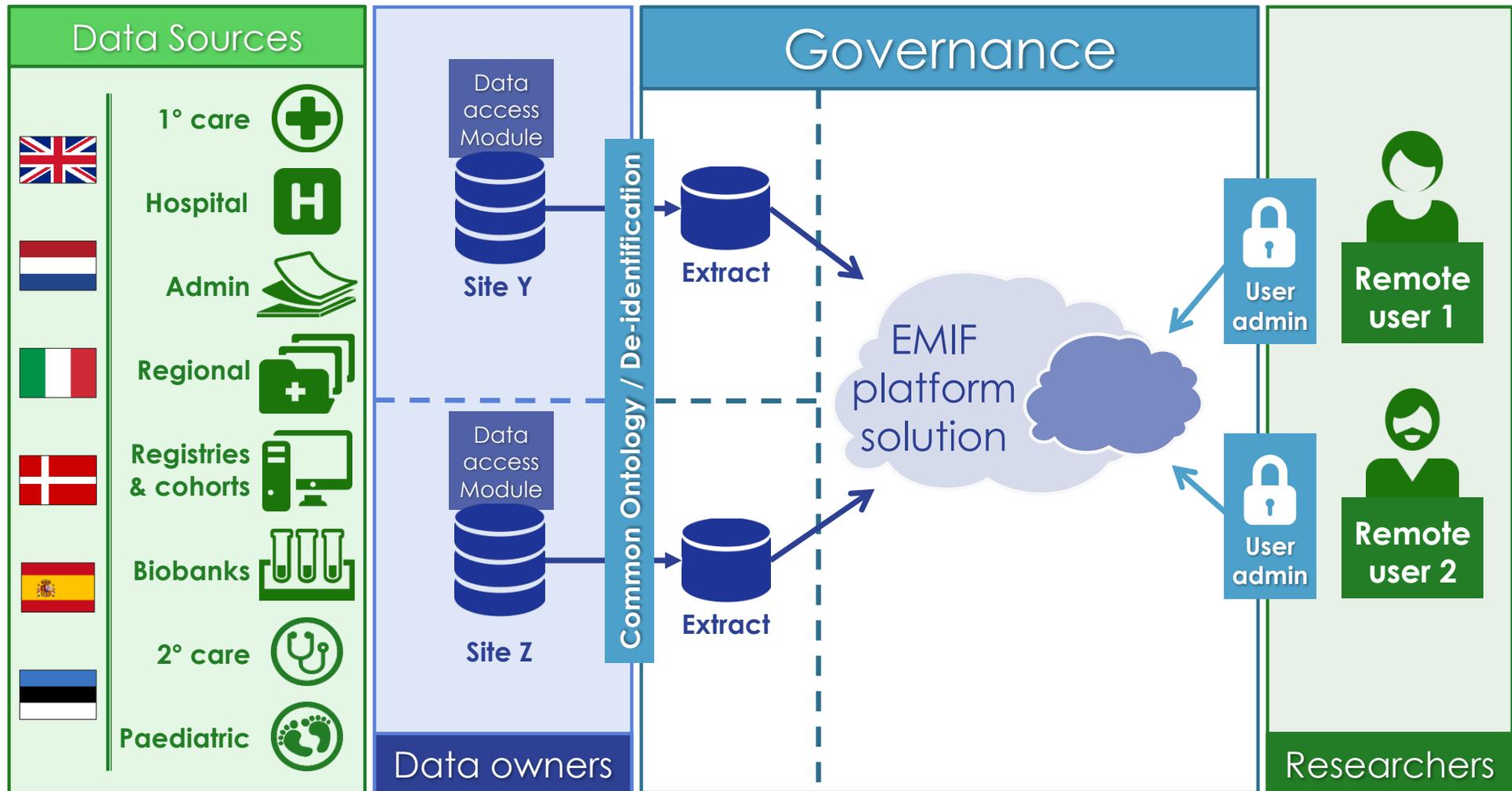
EMIF-Available Data Sources; EXAMPLES

Status Jan 2016



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- Data starvation?
 - Moving from data starvation to data overload
 - Challenge: finding the best data for my question
 - ‘Intentionality’ of data is still an issue

EMIF system overview





At present

- IT is not the rate-limiting factor
- Consensus emerging
 - Distributed approach
 - Federation
- We face a socio-technical construct
- Changing roles and responsibilities

- “Learning healthcare system”

- Learning Healthcare system:

“science, informatics, incentives, and culture are aligned for continuous improvement and innovation, with best practices seamlessly embedded in the delivery process and new knowledge captured as an integral by-product of the delivery experience”

IOM, 2015



Needed new processes

- Patient as owner and controller of data
 - But Rights come with Duties
 - Limits on 'free riders'
- Analysis of data: Better Methodology
 - Transparency
 - Replication
- Acceptance of evidence by
 - Regulators / payers (EMA, HTA bodies, etc.)
 - Physicians
 - Patients