Research Data Management for Health

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Our customers' problems in data-driven health research

Setting up & managing patient consent: time-consuming & expensive

New studies may need additional consent.

Consent across multiple studies.

Extraction, normalisation and aggregation of data

Integrating biosensor and genomic data will be a challenge.

My database too small for the research I am planning.

Large datasets are needed for Precision Medicine

Weak mechanisms for secure data sharing

HIPAA & Ethics: difficult to use EHR data

De-identified data may not provide insight and value.

Implementing the Precision Medicine Initiative Security Framework (NIST, GDPR and ISO 27001) to keep personal data secure: substantial effort.

My institution is concerned about data breach

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The research data management for health components each address a customer problem

Trust Center and **Consent Management**: The Trust Center maintains patient identities and consent separate from the data center. The consent management process documents patient consent. The Trust Center links data sets from different sources and authorizes data use.

Data Acquisition

Electronic Health Records

Genomics

Images

Biosensors

Electronic Data Capture for clinical trials.

Integration Engine: Integrations connect to multiple provider data sources to normalize and clean health data at scale.

Virtual Biomedical Database is the raw resource for research and analytics. Patient data is linked from different sources (with consent). Search and build virtual cohorts from multiple public and private sources.
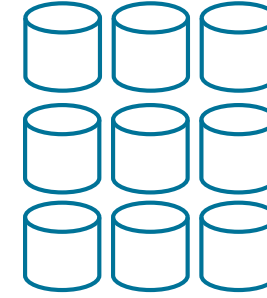
Workspaces enable collaborations and sharing of data, both within an institution and with outside partners. Includes a flexible Docker container environment and data and compute orchestration.

Researchers extract insight from the data by applying the **analytic software** within their workspaces.

Secure Data Center: A secure big data analytics environment for health care data sets. Flexible large-scale virtual machine compute. HIPAA, FISMA, FEDRAMP compliant.

Orchestration Layer, Compute Federated Data : manages analytics-to-data and data-to-compute. Transport big data sets only on demand.

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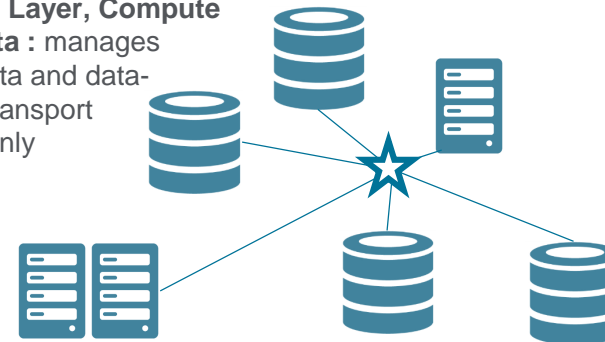
We are inviting top academic med centers to become a member of the world's largest consented healthcare database for research

join the community:

- use larger and more detailed healthcare datasets
- remove the burden of managing patient consent
- recruit more patients for trials (e.g. through embedded cohort trials)
- reduce compliance effort and security risk in a world of data breaches
- extract data automatically via integrations (EHR, genomic, biosensor)
- employ advanced automated data cleansing (ontologies)
- high performance compute on demand

enable your researchers to:

Secure funding

Do more groundbreaking research

Make more effective use of their resources

Engage patients for data-driven health research

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To enable groundbreaking bio-/medical research through secure collaboration

Via Oncology serves 44 US providers treating 500,000 new cancer patients p.a. ~2.5m patient base

Databiology is an early partner of Genomics England, assisting researchers to interpret the data from the 100,000 Genomes Project

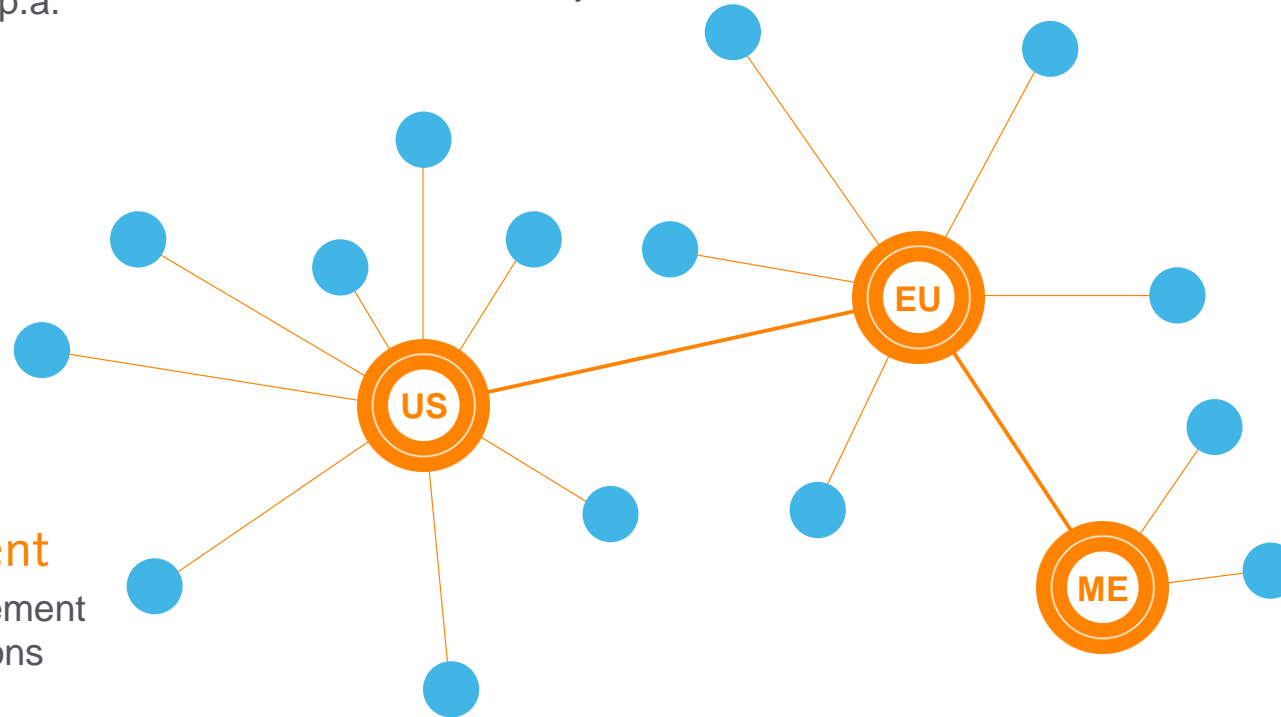Elsevier will host 500,000 patient data sets for the European Blood & Marrow Transplant registry

LexisNexis Risk Solutions has
- 150m patient claims and
- 300m socio-economic data sets in the US

Patient Engagement

Elsevier Patient Engagement has over 2000 integrations with US hospitals[1]

MACRO electronic data capture software for clinical studies and trials serves 51 universities in Europe and is used in ~1000 clinical trials

1: push information but do not yet extract data

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It is your data. You decide.

- Health data is a valuable resource. Patients who generously make their data available can expect the highest level of security, but also that their data is actively and broadly used to further science in accordance with their wishes.

- Elsevier wishes to support the scientific community: we will pre-invest and share the effort across many shoulders in the US, Europe, the Middle East, and later Asia.

- It is your data. You decide for which projects and with whom to securely share. Your institutional review board (IRB) governs the process. Elsevier will implement your decisions and ensure that no data "leaks away". You are the data controller, Elsevier is the data processor.

- Elsevier will pre-install widely used software packages, but researchers themselves decide which analytic software to load and use. Docker containers flexibly support most use cases.

- We expect groundbreaking bio-/medical research and scientific publications to occur, given this resource. We would be delighted to receive your papers for peer-review, but of course you are free to select any publication and publisher.

governance

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