

Health data drives innovation



*ConV2X Conference
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*The European Health
Data Space
and other health data spaces*



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Individual level health data

EHR systems, apps, sensors, genomics,
Clinical Decision Support, AI

Used for:

- Health status monitoring
- Continuity of care (including the patient and caregivers)
- Care pathway tracking, clinical workflow management
- Real-time feedback and guidance to patients and clinicians
- Personalised medicine
- Disease interception, prevention and wellness
- Healthcare provider reimbursement

Population level health data

EHR systems, regional & national
eHealth infrastructures

Reused for:

- Healthcare provider performance and planning
- Quality and safety, care pathway optimisation
- Medical device and algorithm refinement
- Pharmacovigilance
- Public health surveillance
- Public health strategy
- Health services and resource planning

Big health data

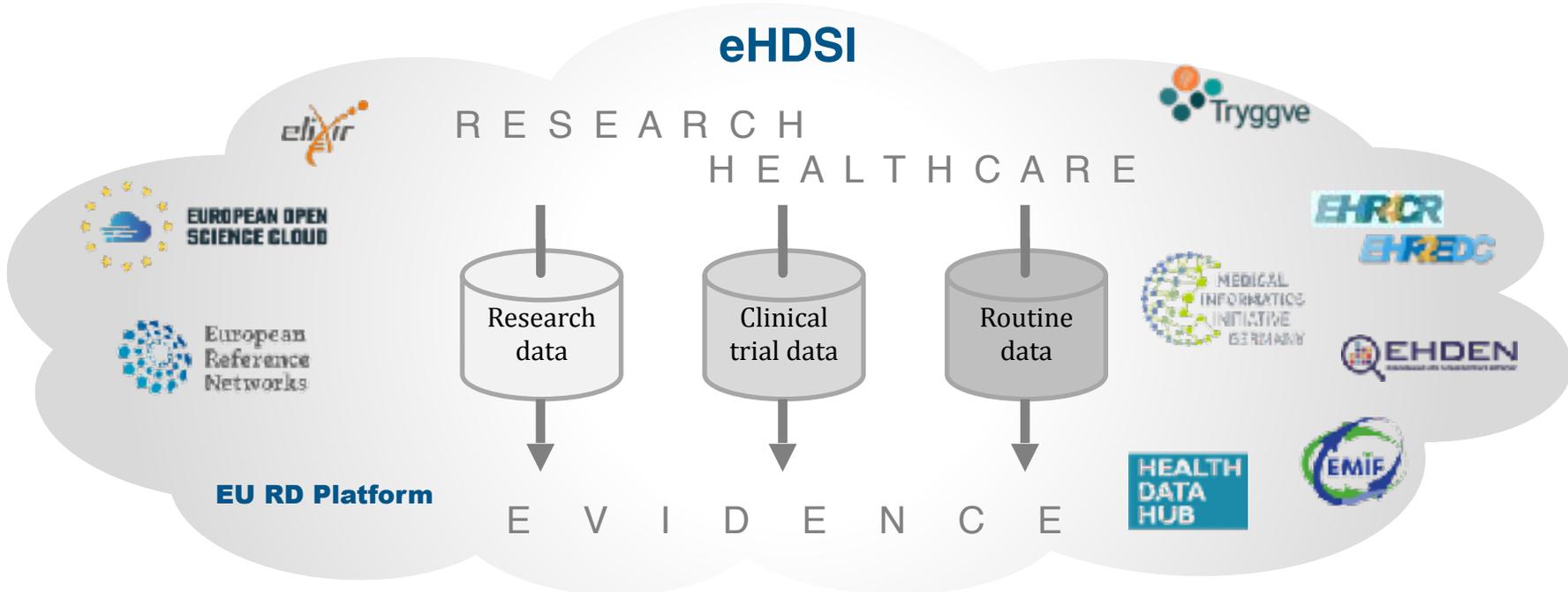
national & international research
infrastructures,
federated query platforms
+ cross-sectoral services

Reused for:

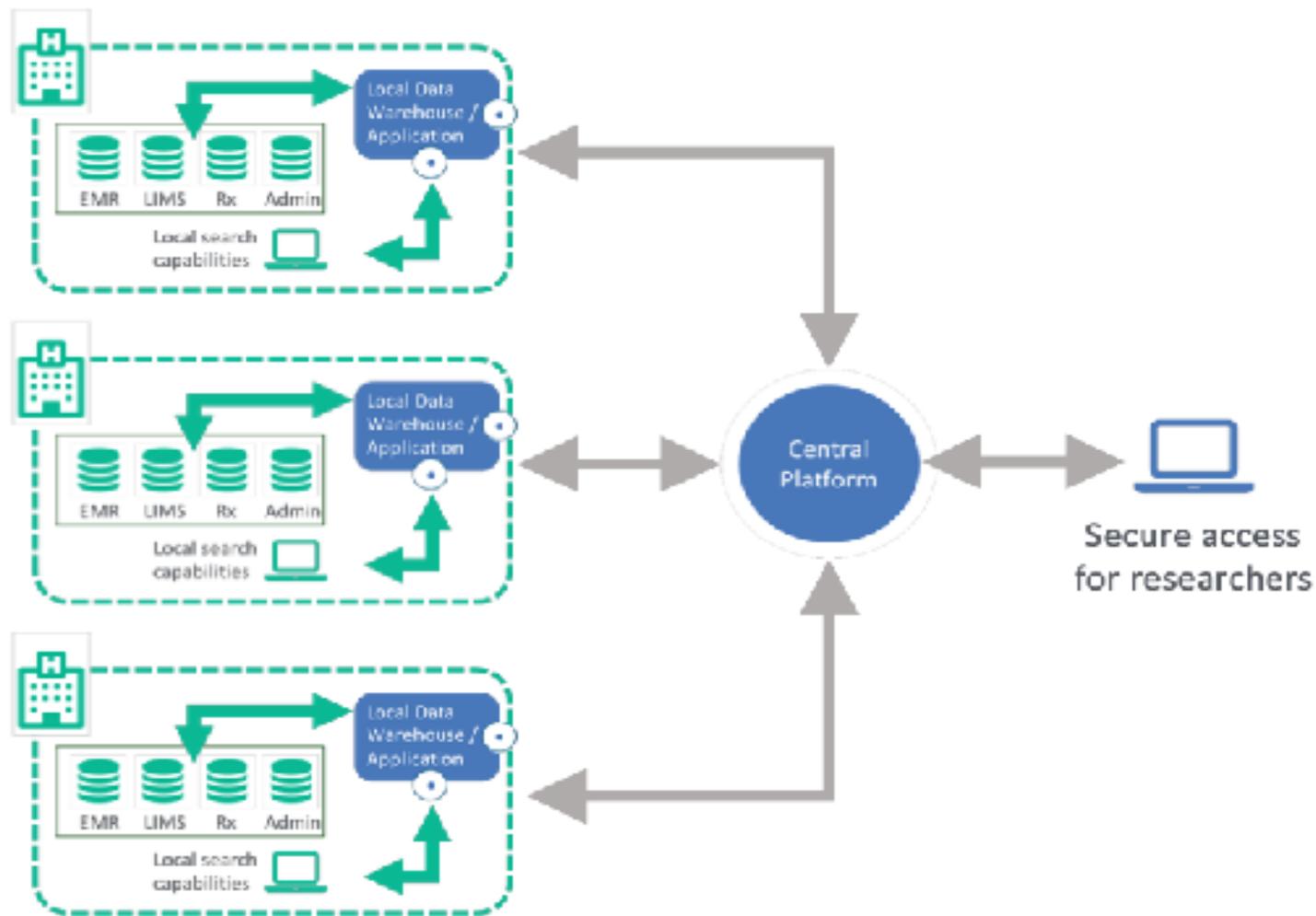
- Epidemiology
- Digital innovation: devices, sensors, apps
- AI development
- Personalised medicine and bio-marker research
- Diagnostics development
- Drug development
- Disease understanding and stratification

Big health data sharing initiatives

- Myriad of initiatives to share health data across jurisdictional, institutional and domain borders:
 - Sharing data for cross-border care or for research
- Emerging paradigm for analysing personally-identifiable health data:
 - federated infrastructure model: network of repositories with an overarching governance and interoperability layer



European Health Data & Evidence Network (EHDEN)



Benefits of federated networks

- Data remains under the control of the data owner
- Locally required legal and ethical approvals apply
- No patient level data leaves the owner's site, only aggregated counts, thereby ensuring patient privacy
- GDPR – *'Privacy by Design'*
- Analysis is "brought to the data" rather than creating central data repository
- Use of common data model allows for efficient search / analysis across multiple data sets
- Requires close collaboration with data owners which builds trust

European Strategy for Data

A common European data space, a single market for data





Multi-stakeholder consensus recommendations to maximise the acceptance and value of the EHDS

1 **Raise the digital, literacy & skills of all stakeholders**

2 **Generate and value trustworthy Real World Evidence**

3 **Accelerate interoperability across Europe and globally**

4 **Demonstrate benefits to society from data access, use and reuse**

5 **Adopt a risk stratification approach**

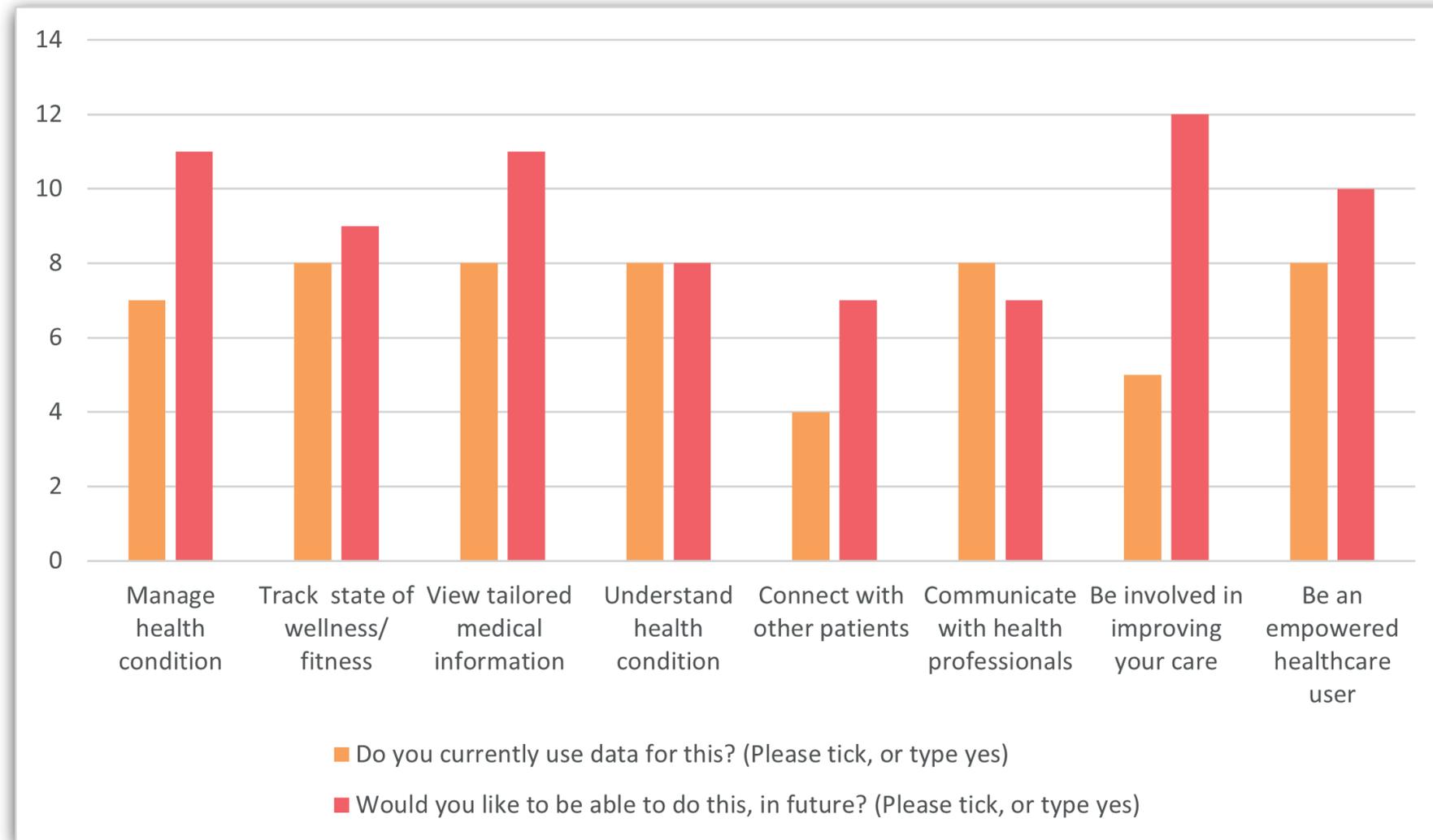
6 **Build a trustworthy framework for data access and use**

7 **Adopt a transformational approach to health data**

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Why do patients want to make more use of their own health data?



The challenge with gaining public acceptance of health data reuse

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Big health data

national & international research infrastructures, federated query research platforms + cross-sectoral infrastructures & services

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Decreasing public understanding of why and how data are used

Increasingly unfamiliar data users

Increasing distance of data results from the patient

Increasing time from data use to demonstrated value

Perceived lessening choice and greater cybersecurity risk = harder to trust

How do we reach societal acceptability?

- Data protection regulations prioritise the **rights of the individual** to privacy
- Clinical research can bring important benefits **to society**
- Many surveys indicate **patients are in favour** of their data being re-used for research
 - But the GDPR hype sometimes breeds fear (public, DPOs, CEOs...)
- The public need **greater transparency** about why and how health data are used, safeguarded, and the benefits of that use

We need to find the right balance between the rights of the individual and the benefits for society