Future health networks

Advanced networks architecture

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Medical data is hard to handle. But in an emergency, it can be the difference between life and death.

Why is it so difficult to access it?

How it started

- I have a health card in my pocket. If I get in an accident in Italy, can it tell my blood type?
- What about my allergies?
- What about in Japan?

Following this thread brought me to

The sad state of healthcare data handling

Some questions:

- Can Japan access my healthcare data?
- Can a private hospital access my healthcare data?
Can I choose what they can see?
- Can I access my healthcare data online?

Every ~~region country network~~ hospital does it their own way

- Complicated to compare
- Some countries do not have a centralized platform to view your medical data/book appointments
- Some countries have nationalized healthcare, others have fractured privatized entities

Roadmap

1. SOTA: What is the state of healthcare data?
2. EPIPHANY: any kind of inter-country network is currently science-fiction (laws/bureaucracy)
3. USECASE: What would I want in my health data network?
4. DESIGN: What elements do we need to design a system to cover our use cases?
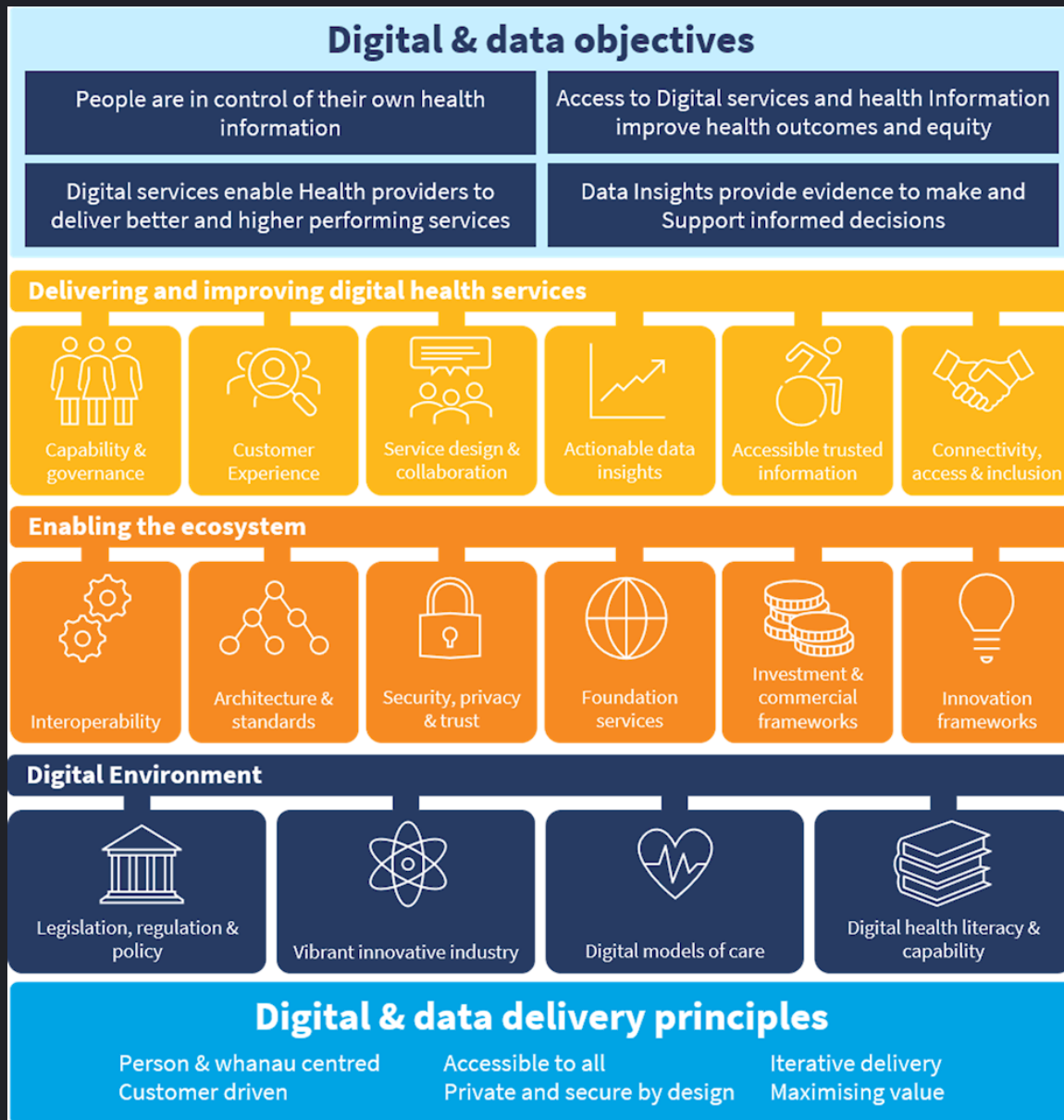
This is what a lot of national "data" or "healthcare data strategies" look like.

National data: WHO's SCORE

SCORE was the best national health data index I found. It addresses availability of timely, reliable, validated and comparable health data to propose:

"Essential interventions, recommended actions, tools and resources that aim to support countries in addressing challenges in meeting health information systems (HIS) needs"

SCORE evaluation

articulated in 5 elements (interventions):

- **SURVEY** population and health risks
- **COUNT** births, deaths and causes of deaths
- **OPTIMIZE** health service data
- **REVIEW** progress and performance
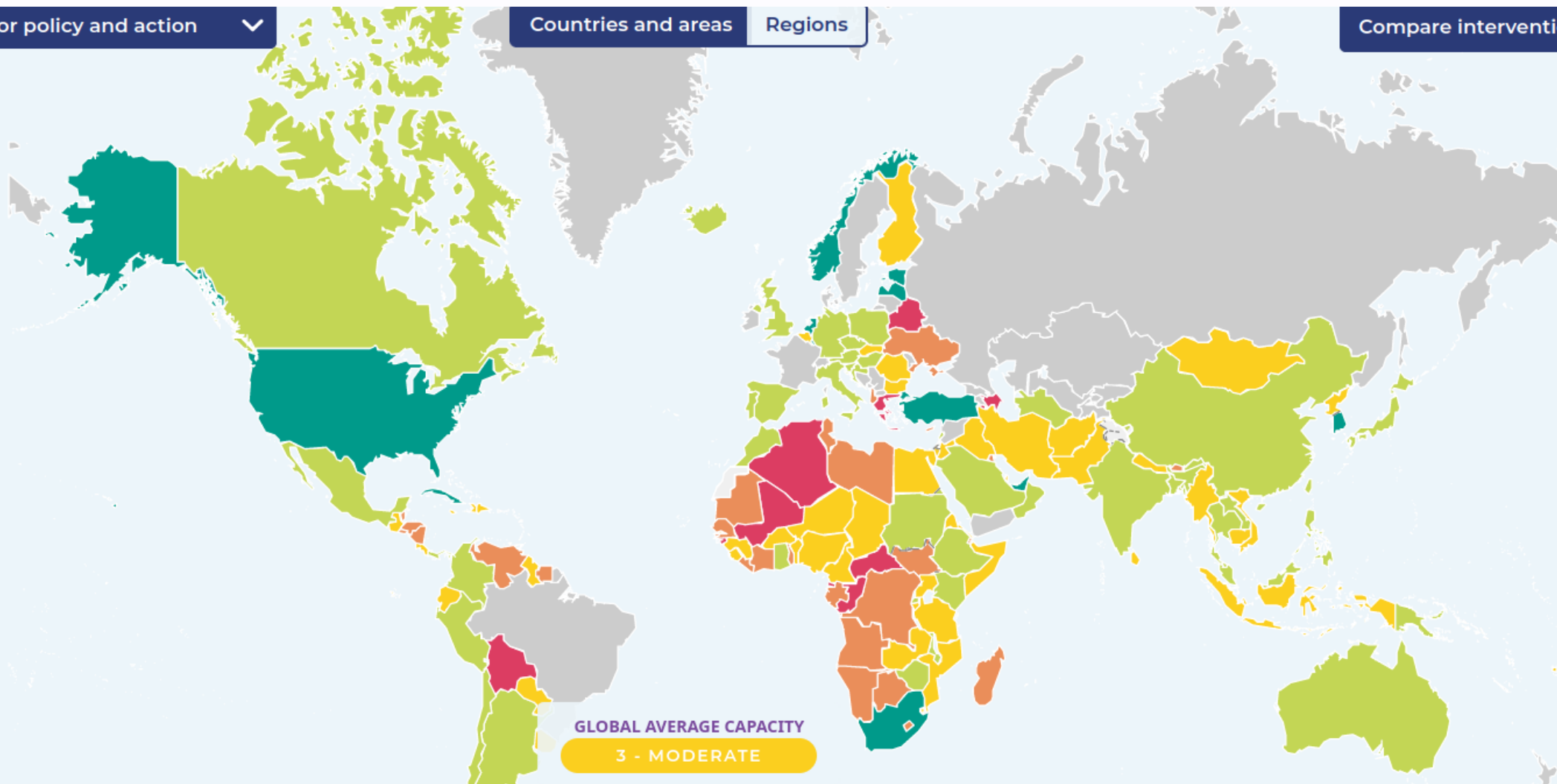- **ENABLE** data use for policy and action

KEY ELEMENTS

C1. FULL BIRTH AND DEATH REGISTRATION

NEARLY
40%
of the world's deaths are not registered.

C2. CERTIFICATION AND REPORTING OF CAUSES OF DEATH

ONLY
8%
of reported deaths in low-income countries show causes of death.

Some countries do not collect, publish or use national healthcare data!

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But what does this mean for me?

- National healthcare data does not need to be communicated
- As long as the data ingestion policy is more or less agreed upon, the government can achieve perfect SCORE without adopting any common standard
- I want my data to be **shareable** (***)

Communication standards

- The Healthcare Information and Management Systems Society (HIMSS), propose conferences to demonstrate healthcare interoperability
- "There are over 40 different SDOs in the health IT arena"

Use Cases

1. Last year, I broke my ankle.
   - Private/public healthcare
   - National/privatized health insurance
   - Private physiotherapy
2. I've had to show I was vaccinated a million times. And when you travel? It's a mess!

Use cases

3. I got in 2 car accidents in Canada
    ○ I was 17. Did I know my grandparents' medical history?
    ○ What if I needed a blood transfusion? Do you know your allergies well enough?
4. I have trust in science research; I want my records to be used, anonymized, for research.

Into Requirements

Use Case	Affected Requirements
1-ankle	Interoperability, Storage
2-vaccine	Interoperability, Availability, API
3-emergency	Interoperability, Availability, Consent
4-research	Anonymization, API

Nonfunctional requirements

What else?

- Privacy and consent
- Security
- Scalability
- Usability (user+clinician+implementer)
- Maintainability

Interoperability - levels

1. **Foundational**: Securely communicate data
2. **Structural**: Securely communicate interpretable data in shared format and syntax

- *Technical interoperability* At this level of interoperability, data is exchanged across systems using a communication protocol. At the plug-and-play, signal, and protocol levels, technical interoperability establishes harmonization.
- *Syntactic interoperability* Is the capacity of two or more systems to share data and services using a common interoperability protocol like the High Level Architecture [24].
- *Pragmatic interoperability* When interoperating systems are aware of one other's processes and procedures; this level of interoperability is attained. This means that the participating systems comprehend the data's use or the context in which it is used.
- *Dynamic interoperability* Two or more systems are considered to have achieved dynamic interoperability when they can understand and take advantage of state changes in the assumptions and limitations they are making over time.
- *Conceptual interoperability* When the assumptions and restrictions of a meaningful abstraction of reality are aligned, conceptual interoperability is achieved.
- *Structural interoperability* Multimedia, hypermedia, object oriented data and other forms of information is recorded.
- *Functional interoperability* Refers to the requirement for functional requirements to be delivered in a consistent, established manner.
- *Semantic interoperability* Semantic interoperability refers to the ability of two or more systems to automatically comprehend meaningful and correct information transferred in order to deliver useful results as defined by the systems' end users. Consequently, even if their instances are heterogeneously represented, that is if they are differently structured and/or use different terminology or natural language, the systems can recognize and process semantically similar information homogeneously. Semantic interoperability is distinguished from the other levels of interoperability because it assures that the receiving system understands the meaning of the sent information, even if the receiving system's algorithms are unknown to the sending system. That is why it is used more than other levels [25, 26].

Interoperability - levels

3. **Semantic**: Common underlying models and codification of the data (standardized definitions, coding vocabularies), providing shared understanding and meaning
4. **Organizational**: Includes governance, policy, social, legal and organizational considerations to facilitate the secure, seamless and timely communication and use of data. (consent, trust and integrated workflows).

Interoperability - HL7 FHIR

- An interoperability standard intended to facilitate the exchange of healthcare information
- Articulated in 2 sections:
  - a content model in the form of 'resources' (XML/JSON, extensible)
  - a specification for the exchange of these resources in the form of real-time RESTful interfaces

Interoperability - FHIR - Adoption

- 2016 Obama 21st Century Cures Act "requires EHR systems to provide a patient-facing API to maintain their federal certification"
- FHIR mandatory for those that receive payments for Medicare or Medicaid services
- Adoption level is... surprisingly hard to gauge

FHIR CURRENT USE
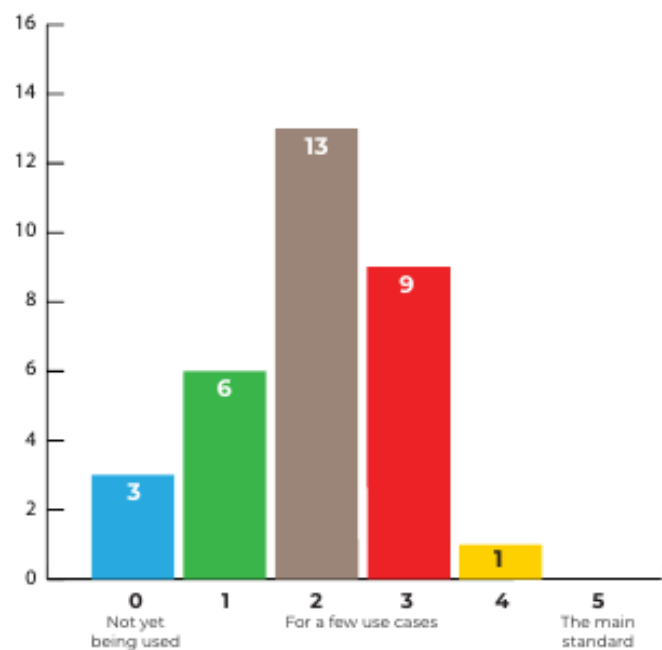
Q. **To what extent is FHIR already being used to exchange healthcare data in [your country]?**

Chile rated itself highest on the extent to which FHIR is being used in the country. The majority of respondents said FHIR is being used for a few use cases. Three (3) countries, Cyprus, Mexico and Slovakia, reported that FHIR is not yet being used.

0 – Cyprus
Mexico
Slovakia

1 – Brazil
Estonia
Germany
Luxembourg
Peru
Taiwan

2 – Argentina
Australia
Brazil
Canada
Colombia
France
Germany (2)
Israel
Netherlands
New Zealand
Peru
United Kingdom

3 – Canada
Denmark
Finland
Germany
New Zealand (2)
Norway
Thailand
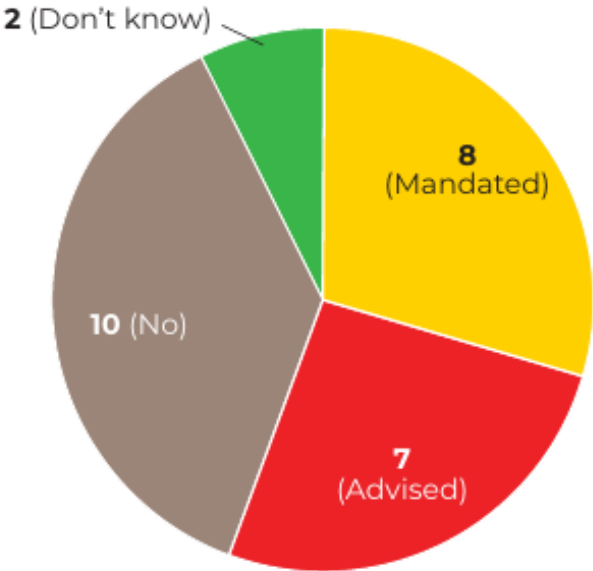United States

4 – Chile

CURRENT REGULATION
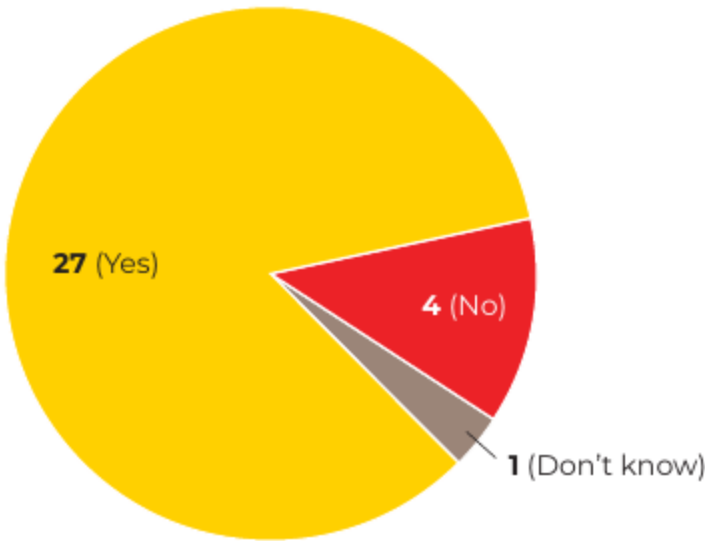
Q. **Is there any regulation in place that prescribes the use of standards in electronic health data exchange?**

Nearly all of the respondents (27 of 32) reported that their respective countries had regulation in place for the use of standards in electronic health data exchange.

YES regulation in place
Argentina
Brazil (2)
Canada (2)
Chile
Colombia
Cyprus
Denmark
Estonia
France
Germany (4)
Luxembourg
Mexico
Netherlands
New Zealand*(2)
Norway
Peru (2)
Slovakia
Taiwan
Thailand

NO regulation in place
Australia
Israel
New Zealand*
United Kingdom

Don't know
Finland

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REGULATION MENTION FHIR

2 (Don't know)

8 (Mandated)

10 (No)

7 (Advised)

Q. **Does the regulation specifically mention FHIR?**

Among those respondents who said there is regulation in place, more than half (15 of 27) said FHIR is either mandated or is being advised in their country's most important regulation that prescribes the use of standards in electronic health data exchange.

YES, FHIR is mandated	Yes, FHIR is being advised	No, FHIR is not mentioned
Brazil*	Argentina	Brazil*
Germany*	Canada	Chile
Netherlands	France	Colombia
New Zealand (2)	Germany*	Cyprus
Peru*	Norway	Estonia
Thailand	Peru*	Germany* (2)
United States	Taiwan	Luxembourg
		Mexico
		Slovakia

REGULATION FINES

6 (Don't know)

4 (Yes)

17 (No)
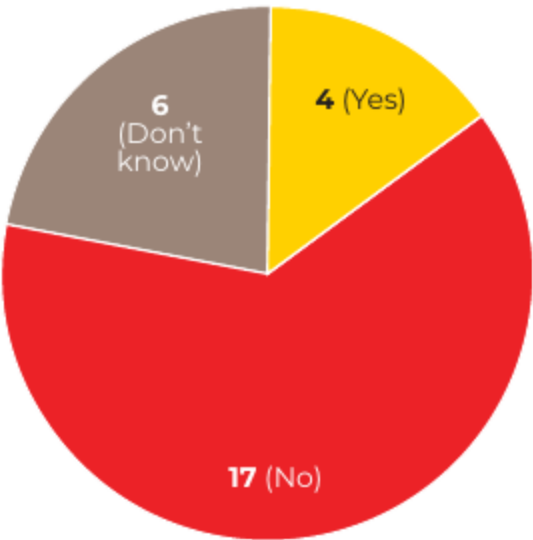
Q. **Are there fines imposed in case the regulation is not met before the deadline?**

Among those respondents who said there is a regulation in place, the majority (17 of 27) said there are no fines if the deadline to comply with the regulation is not met.

Yes	No	Don't know
Chile	Argentina	Canada
Cyprus	Brazil (2)	Denmark
Germany*	Canada	Estonia
Slovakia	Colombia	France
	Germany* (2)	Germany
	Luxembourg	Netherlands
	Mexico	
	New Zealand (2)	
	Norway	
	Peru (2)	
	Taiwan	
	Thailand	
	United States	

Availability

- Overall duration for which the clients can seamlessly access the resources
- 5 nines standard
- Difficulties: connectivity, security... cost
- How to achieve it (redundancy, offline first)
- Reliability...?

Consent/Privacy

- Medical data does not need to be seen in full
- *Digital Twin* vs *Patient Summary*
- Difficulties: implementation and legality
- How to achieve it

Anonymization

- Healthcare data is under growing pressure for use in data science purposes
- Could you query the entire network, or a subset?
- `k-Anonymization` (generalization, dropping)
- Difficulties: only a dataset is anonymized, explicit regulation is still missing, explicit consent must be given

Security

- The more complete the data, the more valuable it becomes
- The larger the network, the harder to secure
- Luckily, FHIR on HTTP -> SSL/TLS (public-private)
- What's the best way to keep data safe?
- Is E2E relevant?

Why is this magic network not here yet?

- FHIR is not the only possible solution! OpenEHR completely different approach
- Limited budgets
- Localized needs
- Legacy systems
- Clinician-focused efforts are lacking

Conclusion

Today, we explored the world of healthcare data and envisioned a bright future which specifically covers all **my** usecases. Then, we evaluated the main pillars that will get us there, and understood why we're not there yet.

Some of the sources that lead us here:

- IBM's page on interoperability
- An overview on Non-Functional Requirements
- Interoperability of heterogeneous health information systems: a systematic literature review
- SCORE home
- HIMSS interoperability page
- HL7 standard home
- openEHR dev
- general info about

Good questions you could ask

- Is FHIR the future?
- What about my XXX usecase?
- Who should be in control of the Standard?
- What about AI?

Appendix

openEHR example

👁 Age

🗂 ✳ **ADL** ⬇ ✖ 🏵 🔗 🖨 🗂 ✉ 🖨 English ▼

| Header | Attribution | Data | Protocol | Events | Reference model |

Concept Name Age

Concept Description Details about the age of an individual at a specific point in time.

Purpose To record details about the age of an individual at a specific point in time.

Use Use to record parameters about the age of an individual at a specific point in time.

Use within a template alongside other contextually relevant archetypes. Including, but not limited to;
- to record the adjusted age of an infant as part of monitoring child growth patterns or;
- to record the actual age at the time of a physical examination or;
- to record a category or range in which the individual first became aware of symptoms.

Misuse Not to be used to display the individuals current age in the user interface of an electronic health record.
Use a formal patient registry or archetypes based on the openEHR demographic information model for this purpose.

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Thanks!