How to build trust and transparency with regard to citizens' health and care data

Moderated by Michele Calabrò, Director of EUREGHA

In this session

1. Welcome
2. Panel on different POVs
3. Panel on use cases
4. Breakout discussions
5. Session wrap-up: final recap

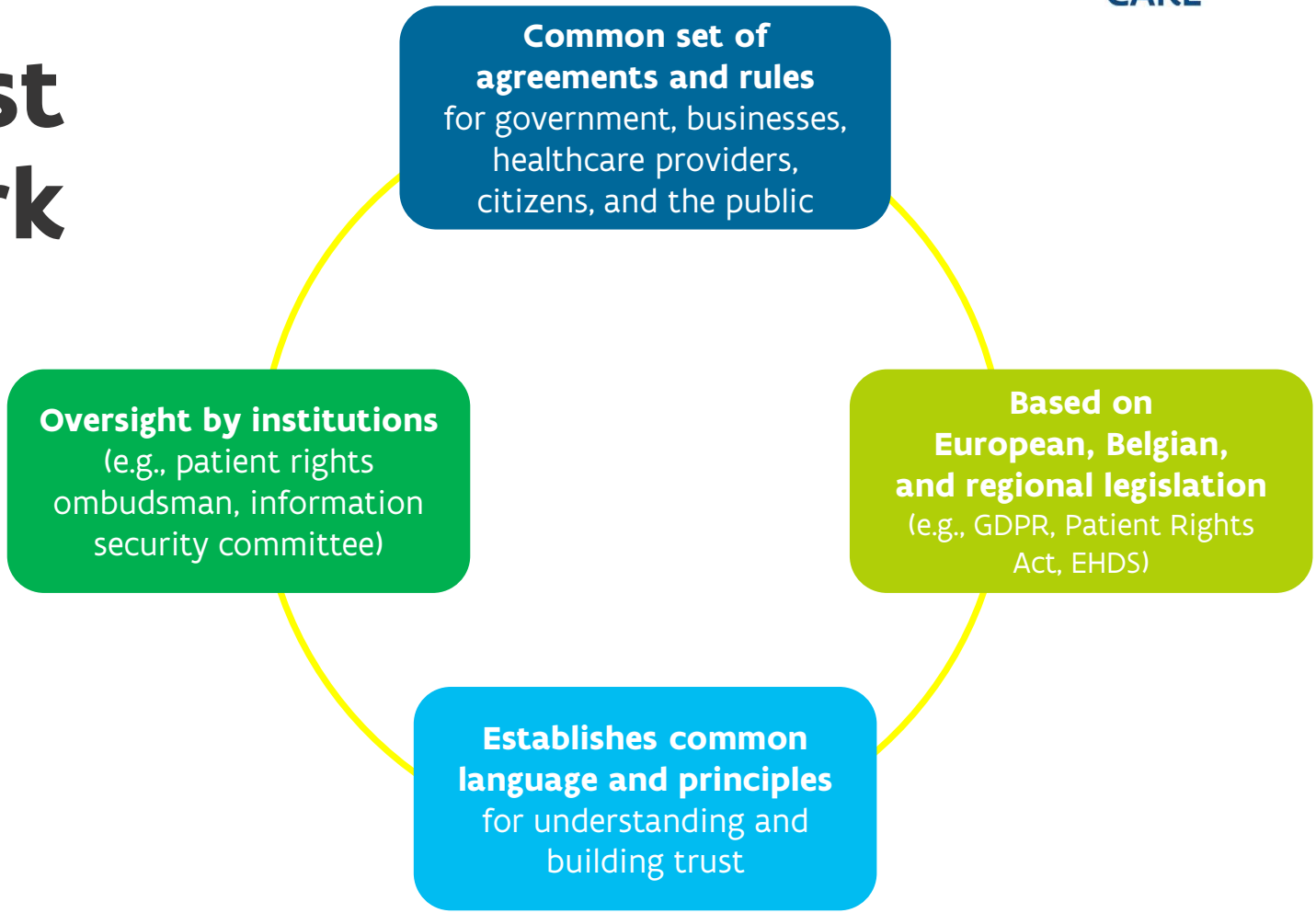
Welcome
by Michele Calabrò

Panel: individual/population based views on trust and transparency

Policy/implementation POV	**Thomas Van Langendonck**, Vitalink Analist, Team eHealth of the Department of Care, Flanders
Research POV	**Wannes Van Hoof**, Scientific Assistant – Sciensano, Public Health and Surveillance, Cancer Centre, Belgium
Citizen-patient POV	**Milana Trucl**, European Patient Forum
Innovation POV	**Tino Martí**, Digital health facilitator, EHTEL - European Health Telematics Association, Belgium

DEPARTMENT OF CARE

Trust Framework



Thomas Van Langendonck – Vitalink Analist, eHealth Team, Department of Care, Flanders

DEPARTMENT OF CARE

Specific Measures for Building Trust

Belgian rules for health data sharing

- **Explicit permission** for health and care data sharing:
  - → Obtainable at GP, hospital, or online
  - → Clear rules and easily revocable
- Access limited to healthcare professionals with **registered care relationships**
  - → Manageable online by citizens
  - → Relationship verification with each transaction
- **Citizens can exclude** specific care providers from accessing their data
- **Access matrix** determines healthcare professionals' access to information
- **Logging of all data access** with timestamp, identity, and role of the person accessing data

Thomas Van Langendonck – Vitalink Analist, eHealth Team, Department of Care, Flanders

DEPARTMENT OF CARE

Additional measures and technological solutions

Technologial measures by Vitalink
(in collaboration with eHealth-platform)

vitalink
gegevens delen, van vitaal belang

- **Access governed by eHealth-platform rules** (electronic authentication and authorization)
- **Double encryption of all data with end-to-end access** only upon eHealth-platform rule compliance
- **Future pseudonymization** of personal identification data for increased privacy
- Implementation of **high-level security and availability measures**

Thomas Van Langendonck – Vitalink Analist, eHealth Team, Department of Care, Flanders

DEPARTMENT OF CARE

Empowering citizens with concrete tools



Access to personal health data online
(via mijngezondheid.be)



Ability to view or request access logs

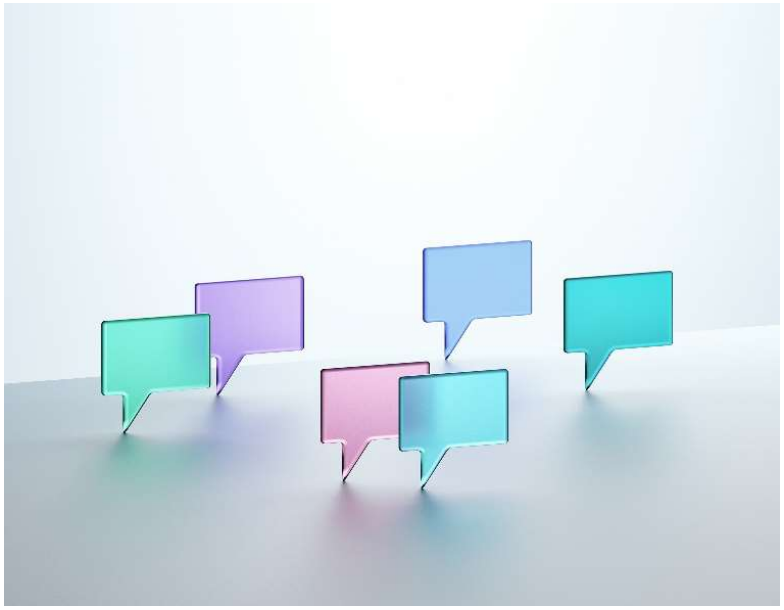


Online management of therapeutic relationships, exclusions, and informed consent

Thomas Van Langendonck – Vitalink Analist, eHealth Team, Department of Care, Flanders

DEPARTMENT OF CARE

Inclusive Governance and Decision-making

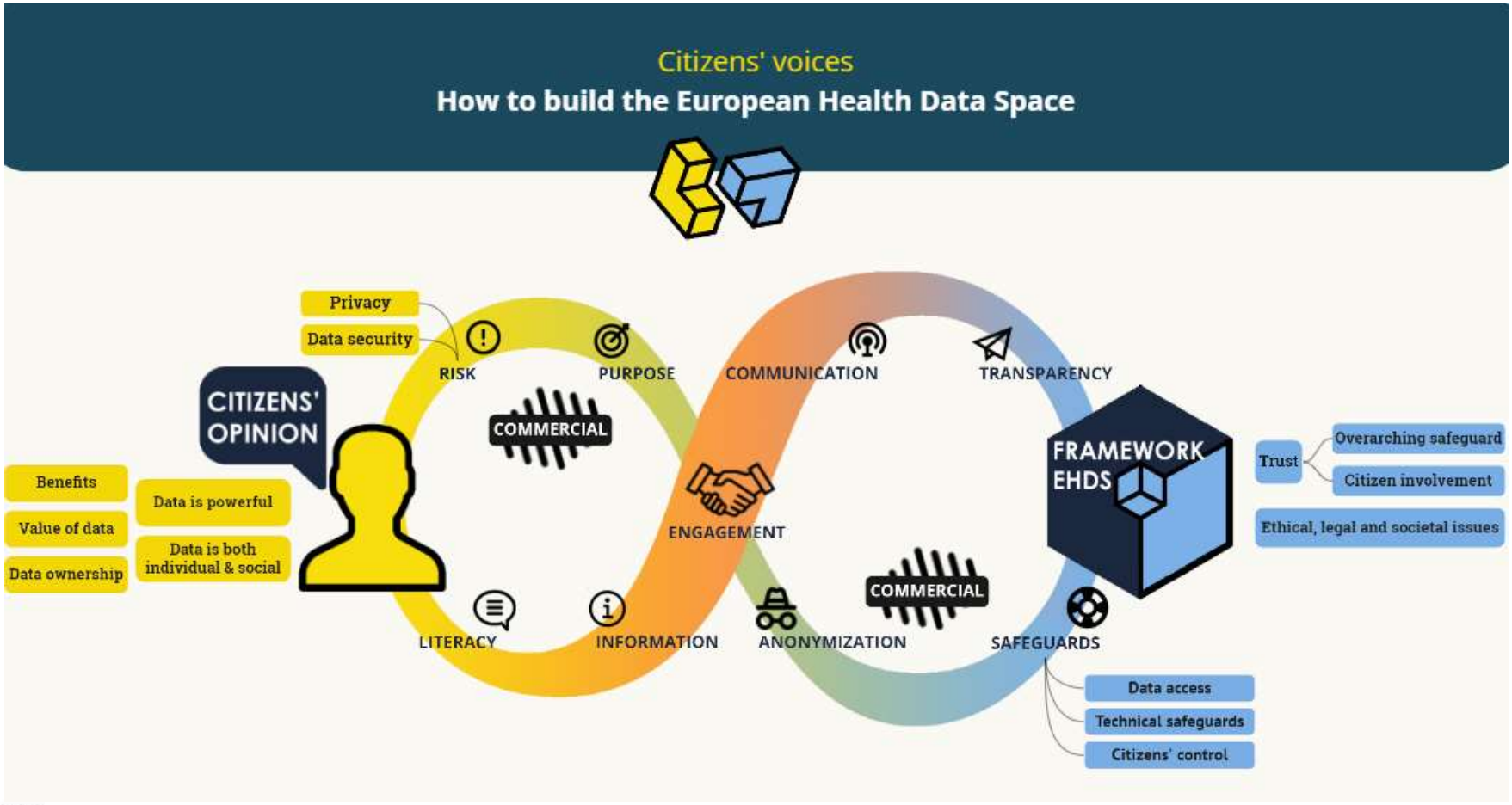


Stakeholder representation

- Key stakeholders involved in management and decision-making
- Representation from patient advocates, healthcare professionals, hospitals, and eHealth-platform

Thomas Van Langendonck – Vitalink Analist, eHealth Team, Department of Care, Flanders

individual/citizen/population-based views on trust and transparency



sciensano

.be

Data Saves Lives

#DataSavesLives



#DataSavesLives

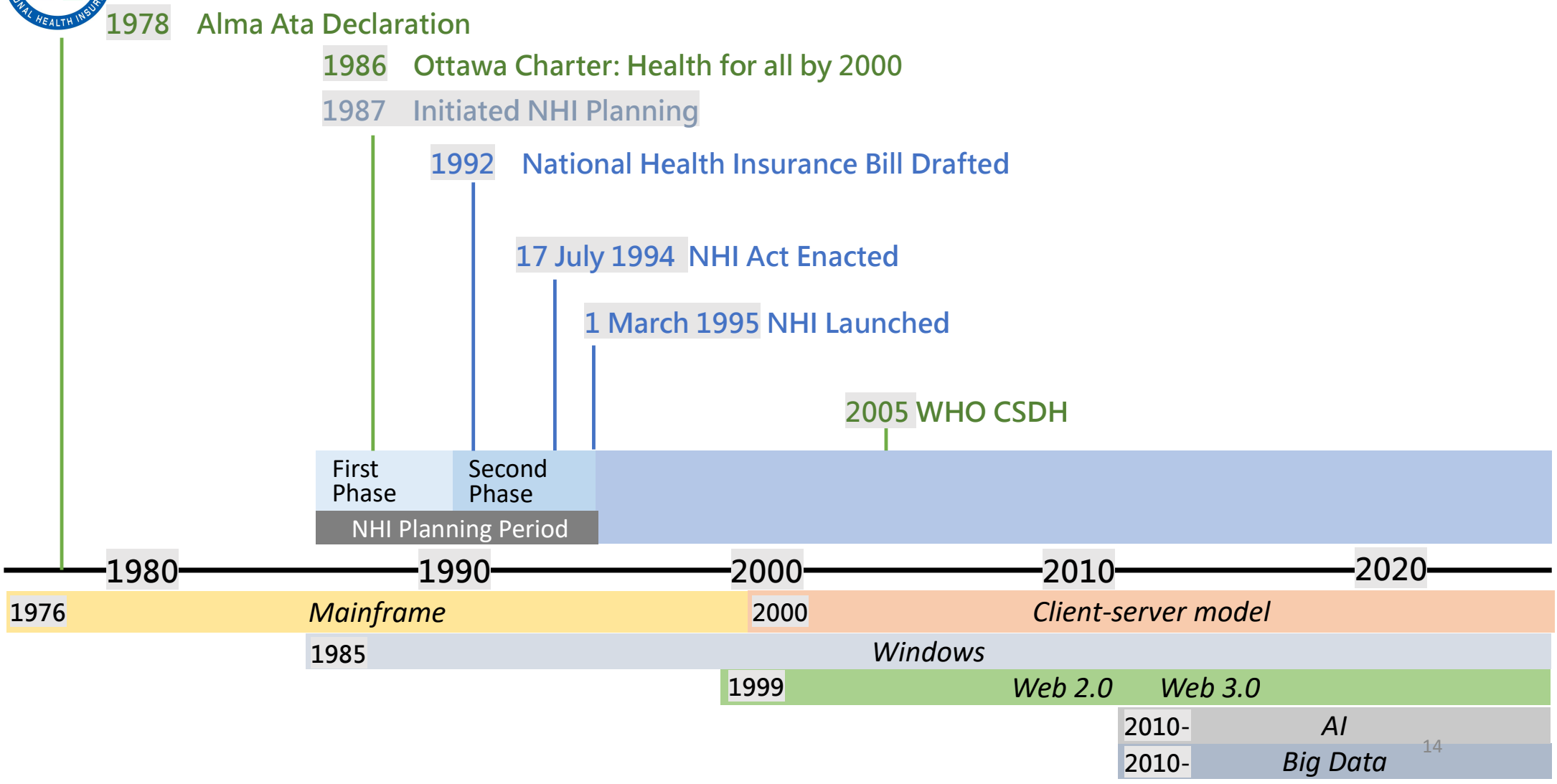
Panel: use cases focusing on trust and transparency

Digital transformation on regional level	**Sarah Smits**, Business Unit Lead Health – athumi, the Flemish Data Utility Company, Flanders
Digital transformation on country level	**I-Ming Parng,** Deputy Director-General of the National Health Insurance Administration (NHIA) of the Ministry of Health and Welfare, Taiwan
Experiences of citizens on health information	**Wannes Van Hoof**, Scientific Assistant – Sciensano, Public Health and Surveillance, Cancer Centre, Belgium
Interaction between research and innovation	**Josep Roca,** Senior Researcher at Hospital Clinic Barcelona IDIBAPS, Professor of Medicine at the University of Barcelona

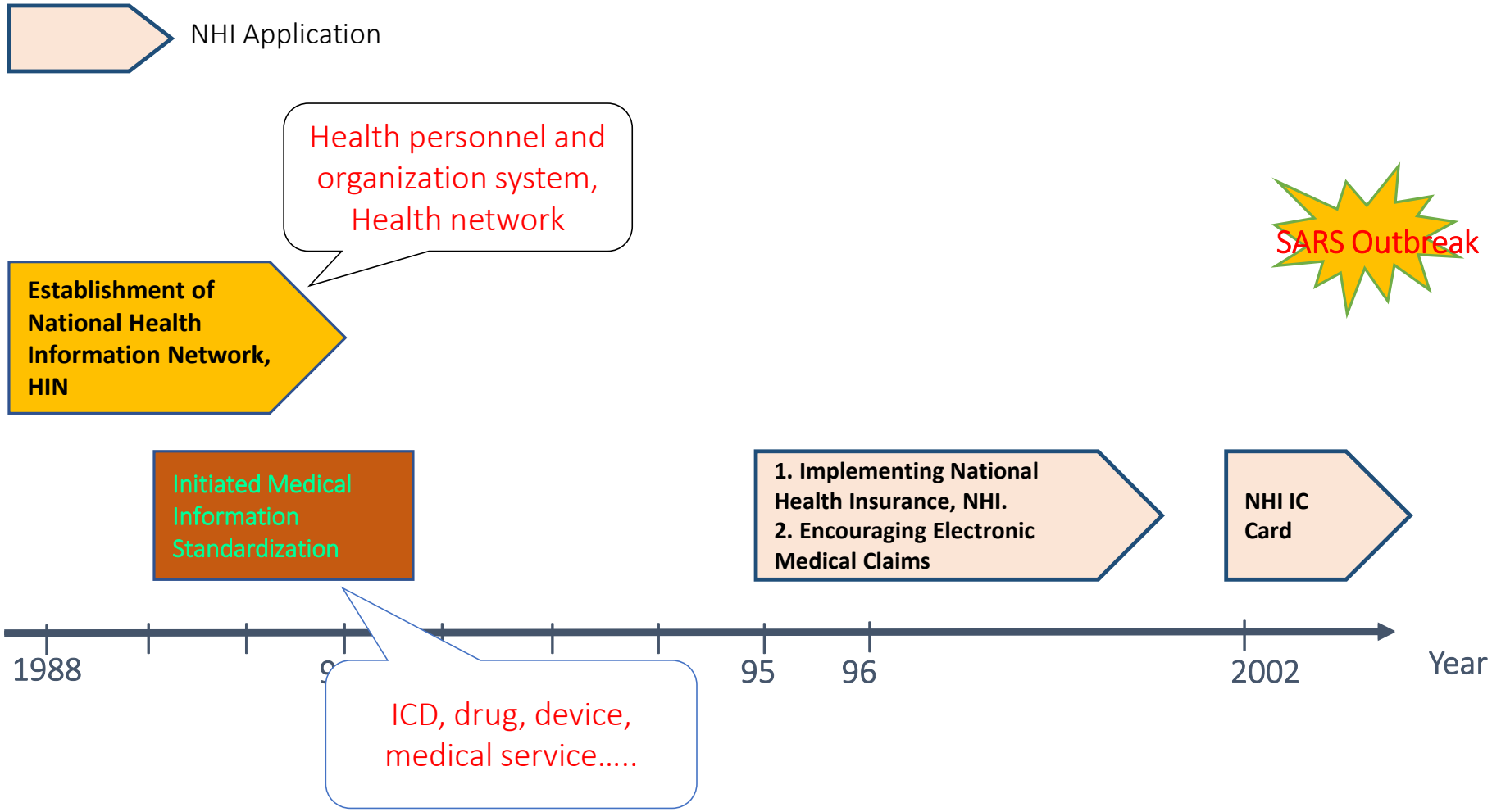
Digital Transformation: How Taiwan Utilizes IT to Support Health Reform

I-Ming Parng, Deputy Director-General,
National Health Insurance Administration,
Ministry of Health and Welfare,
Taiwan

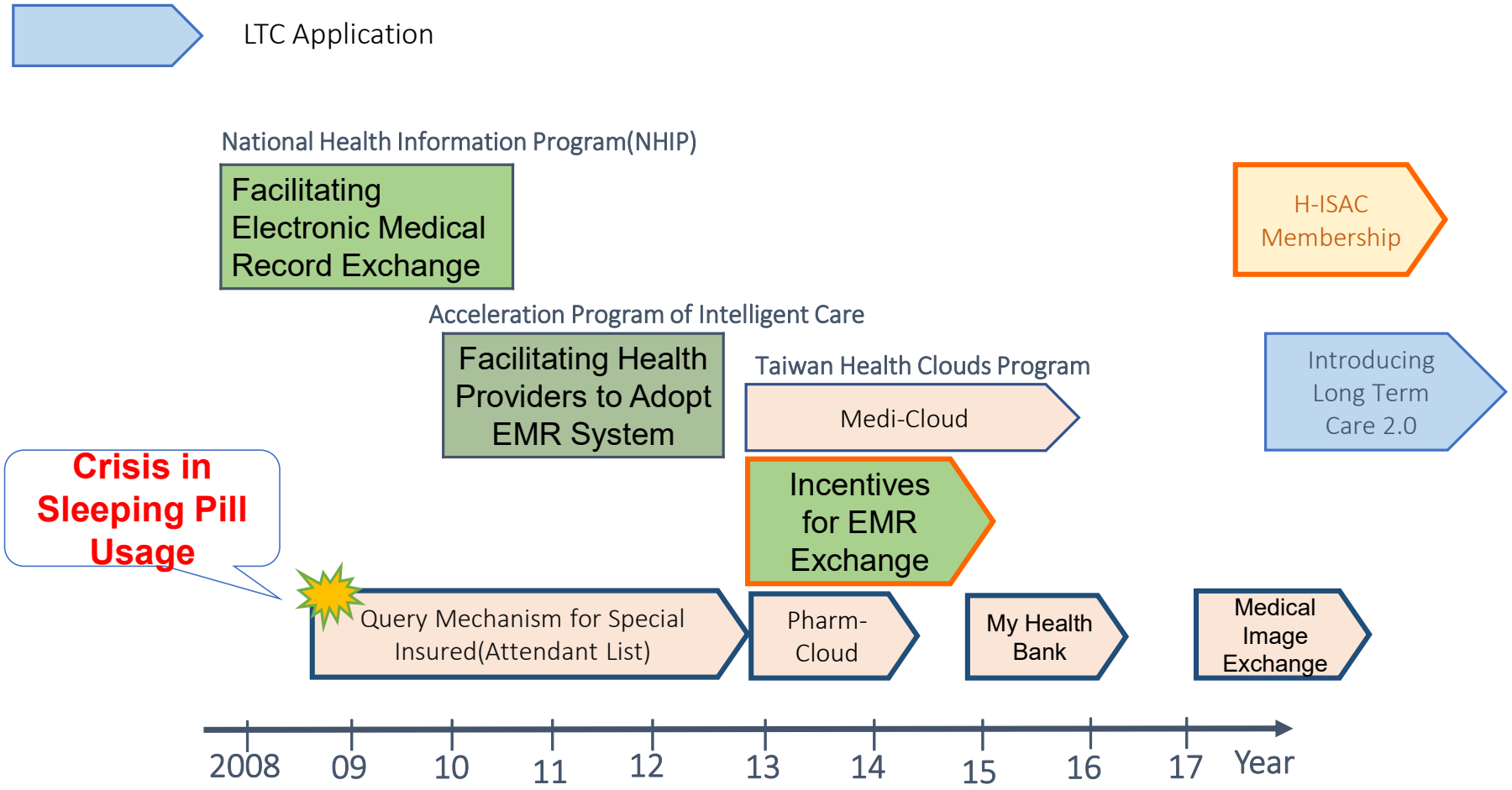
Evolutions of IT and Health Policy Perspectives



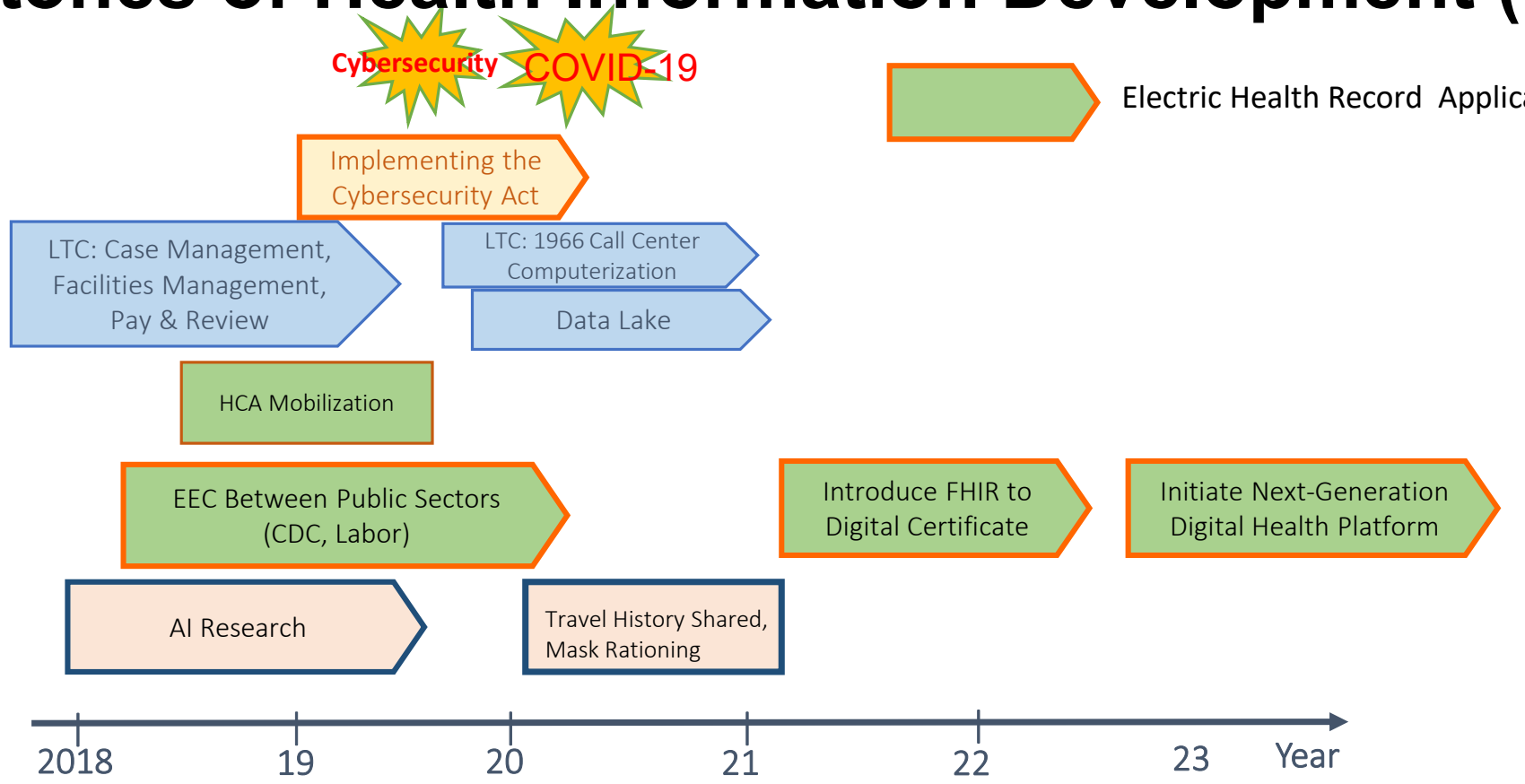
Milestones of Health Information Development (1)



Milestones of Health Information Development (2)



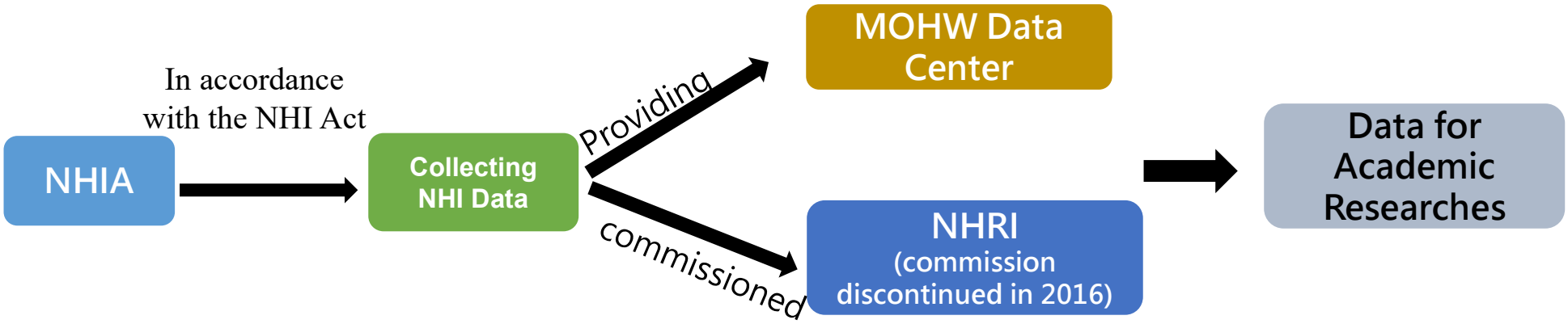
Milestones of Health Information Development (3)

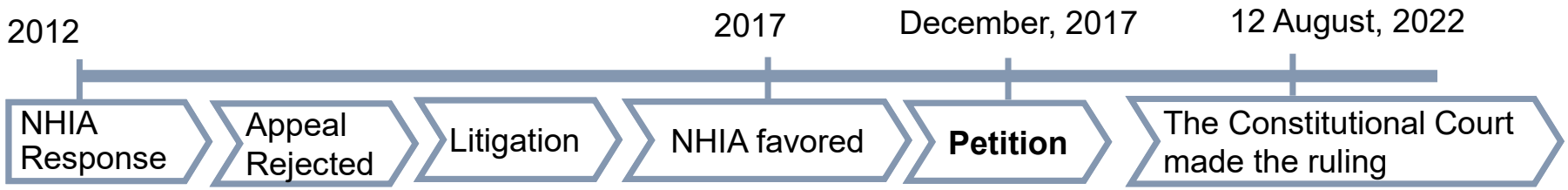


HCA: Health Certification Authority, Digital Certificate for Health Personnel

LTC: Long Term Care EEC: **Electronic** Medical Record Exchange Center

Judicial Review of NHI Data Utilization: Civic Groups' dispute on NHI Data use





- Civic groups filed a statement refusing the NHIA's release of their unidentified NHI information to a third party.
- The civic groups filed a petition with Taiwan's Constitutional Court regarding the National Health Insurance Research Database.

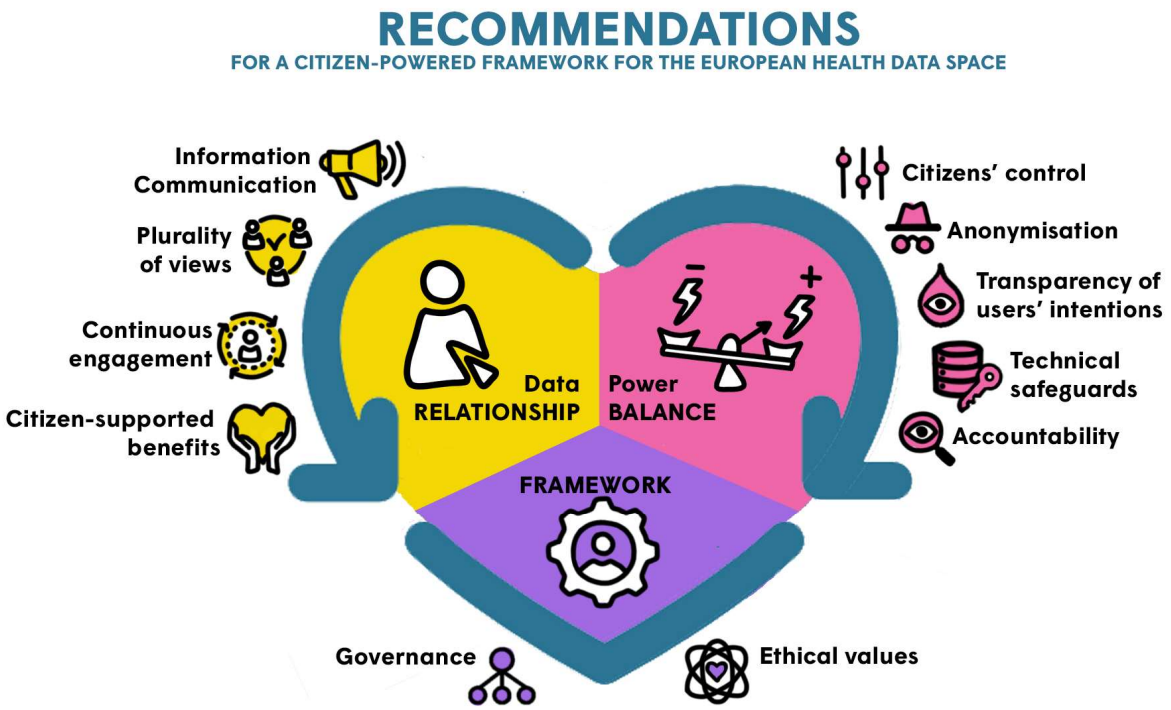
National Health Insurance Administration

Ministry of Health and Welfare

Thank you!



Use case trust transparency: EHDS



Research & Innovation on Digitally Supported Integrated Care Services

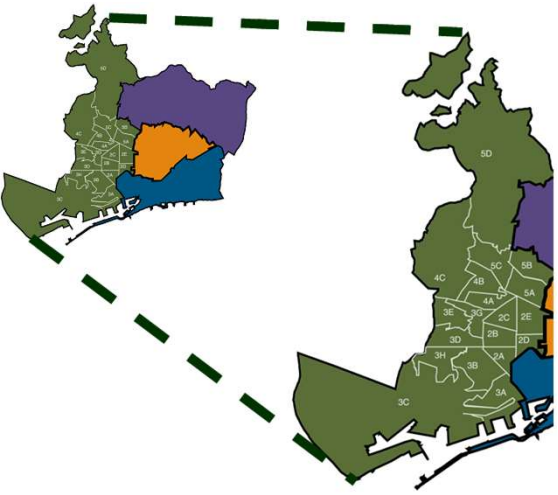
Josep Roca, IDIBAPS-HCB

Jordi Piera, Director Digital Health Strategy for Catalonia, CatSalut

Isaac Cano, IDIBAPS-HCB, CEO Health Circuit SL

Rubèn Gonzalez-Colom, IDIBAPS-HCB

Catalonia (7.8 M citizens): Health District o





Hosp
de E
Cen

World Health Organization Europe

2020 Report

THIRTY-YEAR RETROSPECTIVE of CATALAN HEALTH PLANNING

Driver of Health System Transformation

- *19 Primary Care Units with a wide variety of healthcare providers*
- *Population-health orientation & Collaborative Adaptive Case Management approach integrating:*
  - *Specialized Care*
  - *Intermediate Care*
  - *Primary Care*
  - *Social Support*

2000-2003

CHRONIC

Research

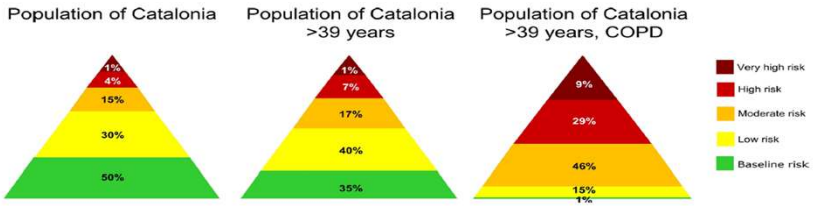
2011-2015 & 2016-2020

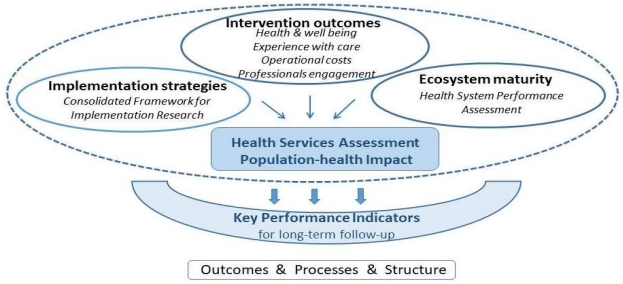
- ✓ Continuity of care
- ✓ Digital health transformation

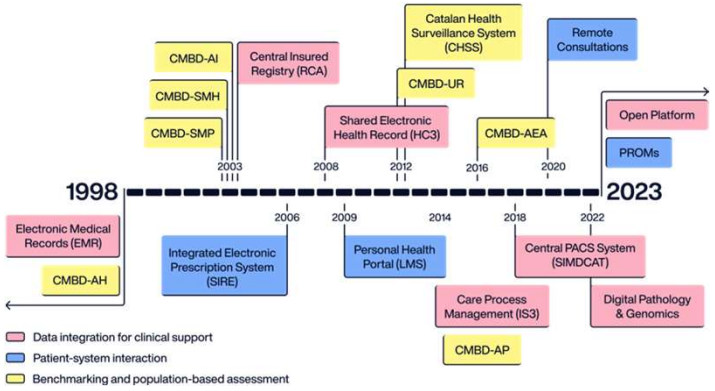
Integrated Care & Precision Medicine

Research & Innovation on Digitally Supported Integrated Care Services

Three Blocks (site customized designs)







B1 ❯ **Health Risk Assessment**

(population health & Enhanced clinical decision making)

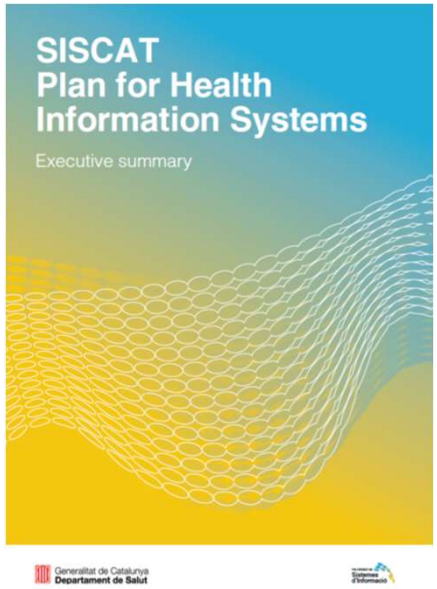
B2 ❯ **Scale-up of Integrated Care Services**

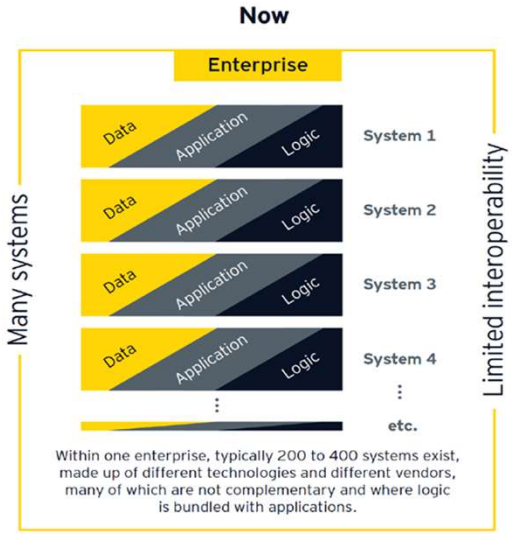
1.(Efficacy proven)
2.(Effectiveness testing)
3.(Value-generation as a goal) – Quintuple Aim
4. (KPIs for quality maintenance after adoption)

B3 ❯ **Digital Health Transformation**

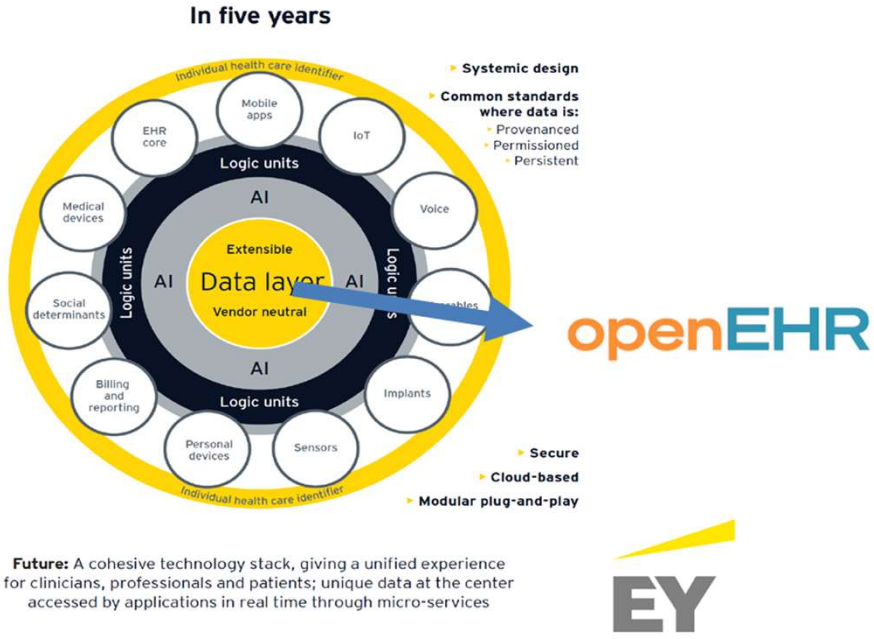
(Transition toward Open EHR & Collaborative Adaptive Case Management)

Catching up the time: Digital Health Strategy for Catalonia





Present: Many systems all with intimately bound data logic and applications



Future: A cohesive technology stack, giving a unified experience for clinicians, professionals and patients; unique data at the center accessed by applications in real time through micro-services

Adaptive Case Management (ACM) allows healthcare professionals themselves to create and modify all aspects of a case at any time (including the case model).

The case manager using ACM is responsible not only for the outcome of a case, but also for how the handling of that kind of case improves over time (www.healthcircuit.es)



Gaining trust in a rapidly evolving scenario

- Demonstration of healthcare value generation of each innovative service in the real-world scenario

  (health outcomes + patients' & professionals' engagement + costs + equity)

- *Secondary use of electronic health data is still a challenge*

  (Proposal for a Regulation of the EHDS – Section 2.Governance and Mechanisms …, 2022)

- Involvement of key opinion leaders & citizens in the cultural change

Key Lessons Learned

- Generate well-structured roadmaps for the deployment of each innovation
- Involvement & engagement of all key actors (co-design processes)
- Combine quantitative & qualitative protocol designs to reduce the efficacy-effectiveness gap
- Improve applicability of the tools for assessment of the deployment processes
- Maturity of digitally enabling technologies is required for large scale implementation
- Ethical & Regulatory compliance does not necessarily mean rigidity

Breakout tables

2 x 20 mins

1. Balancing data-protection with health innovation and policy innovation
   - Sarah Smits (athumi, Flanders) and Erik Laes, (VITO, Flanders)
2. Different data users = different levels of trust?
   - Elke Wijnants and Thomas van Langendonck (Department of Care, Flanders)
3. Data saves lives
   - Milana Trucl (European Patients Forum)
4. Engage in citizens' life-course communication
   - Pr. Dr. Josep Roca (Hospital Clinic Barcelona and University of Barcelona, Catalonia) and Jordi Piera (Coordinator digital strategy, Catalonia)
5. Legislative co-creation
   - Wannes Van Hoof (Sciensano, Belgium)

Breakout tables

2 x 20 mins

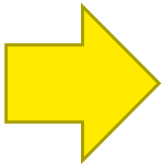
Choose a table.

Engage in conversation. The table moderator will facilitate you.

Write down your ideas.

After 20 mins, we will **switch tables.**

After two rounds, there will be a **short wrap-up**



When the arrow reaches here: time to switch!

Breakout tables

2 x 20 mins

Choose a table.

Engage in conversation. The table moderator will facilitate you.

Write down your ideas.

After 20 mins, we will **switch tables.**

After two rounds, there will be a **short wrap-up**



When the arrow reaches here: time to switch!

Session wrap-up

Final recap