SPHN International Advisory Board

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- **Joan Dzenowagis**, World Health Organization
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- **Prof. Oliver Kohlbacher**, University of Tübingen, Germany
- **Prof. Dan Roden**, Vanderbilt University, USA
- **Prof. Amalio Telenti**, The Scripps Research Institute, USA

Pre-requisites for personalized health

- Data (medical records, molecular data, wearable/sensor)
  - Collected
  - Organized/Harmonized
- Analytic capabilities
  - De-identification
  - Query/Semantic search
  - AI/Machine Learning
- Infrastructure
  - Consent
  - Data sharing
  - Governance
  - Security/Privacy/Confidentiality
  - Regulatory
- Compelling clinical applications
  - Identify areas where "one size fits all" does not work

2017 - 2018: Call for Proposals
With Personalized Health and Related Technologies program (PHRT)

- 76 Proposals over two years, 24 selected with balance
- **Infrastructure Development Projects:** Develop and test technologies which address bottlenecks in personalized health research. (13 projects)
- **Driver Projects:** Demonstrate the value of personalized health research and guide the development of infrastructure and national capabilities by "test driving" them. Address scientific questions linked to infrastructure development. (11 projects)

BUILDING BLOCKS:
Infrastructure Projects 2017-2019

- Clinical interpretation of **genetic variants**
- Personalized reference **lab values**
- **Pediatric dose** optimization
- **Encrypted** exchange of sensitive health information
- Standardization of **CT images**
- **Data governance** and quality best practices
- **Standards** for exchange of lab data

- General **electronic consent** capabilities
- Harmonization of **pediatric data** collection
- **Automated coding** of tumor clinical information
- **Citizen-centered consent** processes
- Methods for **de-identifying** clinical text (French, German, Italian)
- Intepretation of **cancer-related genetic variations**

TESTING CAPABILITIES:
Driver Projects 2017-2019

- Cohort of **ageing** citizens (imaging, genetics)
- Use of imaging to predict **brain cancer**
- **Ocular** image analysis with AI for diagnosis
- **Heart Failure** diagnosis and risk assessment
- Integration of diverse clinical data across centers

- Methods for quantifying and assessing **frailty**
- Assessment of patient **immune competence**
- Understanding **autoimmunity**
- Personalized **oncology**
- Molecular **Pathology**
- Personalized diagnosis and treatment of **sepsis**

Achievements 2017-2019

- Hospitals participated in creating governance, staff, processes to support personalized health research and infrastructure

- Core agreements for ethics, legal, social implications (ELSI)

- Role of Data Coordination Center defined

- BioMedIT resources deployed collaboratively

- Ongoing project review and feedback

- Identified opportunities for synergies (sharing best governance practices, consent templates)

Achievements 2017-2019

Challenges

(1)   organizational/legal/governance challenges,

(2)   data sharing challenges,

(3)   public awareness.

Driver projects helped uncover these!

2021-2024 Follow on programs:
National Data Streams Demonstrator Projects

- **National Data Streams:** Consortia form national networks, using pre-existing infrastructure and data sets. Addresses clinical and analytical challenges in personalized health. Data should be FAIR (findable, accessible, interoperable, reusable). Sustainable.

- **Demonstrator Projects:** Demonstrate added value of SPHN resources for research in personalized health, clinical medicine, public health. Test "fit for purpose" of resources. Targeted activities: Infrastructure application or transfer AND/OR Routine healthcare data for research.

PUTTING IT TOGETHER:
SPHN-PHRT National Data Streams 2021-2024

- Personalized assessment of **infection in the ICU**
- Identifying **low value care** in hospitals
- Personalized **oncology**
- **Pediatric** data sharing

USING THE CAPABILITIES:
Demonstrator Projects 2022-2024

- **Pediatric drug response** data warehouse
- Therapy-related **secondary cancers**
- **Pediatric primary care** nationwide aggregation
- Monitoring **infectious diseases**
- Faster detection of **neonatal sepsis**
- Integration of **transplant** cohort

- **Childhood asthma** data monitoring
- Improved querying of **real-world clinical data**
- Tools for **routine de-identification** of patients for research
- Data integration for **cerebral palsy**
- Integration of **wearable** data with clinical data

SUMMARY: Ongoing Implementation Projects

- Collaboration Agreements with the Swiss Universities
- ELSI Projects
- HospFair
- SPHN Connector
- SPHN Federated Query System
- Swiss Cohort Metadata on Maelstrom
- Swiss Federated Genomics Network
- TI4Health/MedCo

Lessons Learned

- Difficulty AND value of engaging hospitals in the personalized health research and implementation enterprise
- Importance of engaging many stakeholders (patients, physicians, politicians, payers, technologists, administrators, public health…)
- Importance of clear governance of consent, data sharing, financial support models
- Critical to define standards for data representation, aggregation and sharing (FAIR)
- Swiss strength in cancer, pediatrics, imaging, acute care among many others
- Value of combining national data for both research/discovery as well as quality of clinical care. Integration with registries.

The road ahead

- SPHN has become a biomedical data, governance, sharing authority. Should document impact and victories!
- Keep existing infrastructure alive and extend
- Large language models and AI/machine learning as a tool for curation, query, prediction
- Industry collaboration opportunities are critical
- International collaborations in research now enabled
- Possibility of a National Health Data office — standardize data collection in primary care, including patient-reported outcomes
- Future focus on lifelong data, multimorbidity, and health trajectories -> predictive care
- Future focus on social determinants of health (economics, social)

Thank you!

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