

How can AI provide benefits to citizens and contribute to building the data culture for society?



Bariş Erdođan, PhD
Chief Executive Officer



Switzerland
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How can citizens support AI?

AI needs to be trained and validated on data.

Why would a citizen need AI in healthcare?

- For the early detection of diseases.
- Understanding more about disease risks and causes.
- Developing new treatments and preventing from diseases.
- Improving diagnosis and avoiding mis-diagnosis
- Improving individual care and allowing personalized treatments.

Healthcare Data Collaboration is Challenging

FACT: Healthcare AI Algorithms need to be trained and validated **on citizen data**.



Standards

Curating data from different EMR systems at multiple hospitals is a **very costly** option



Privacy & Ethics

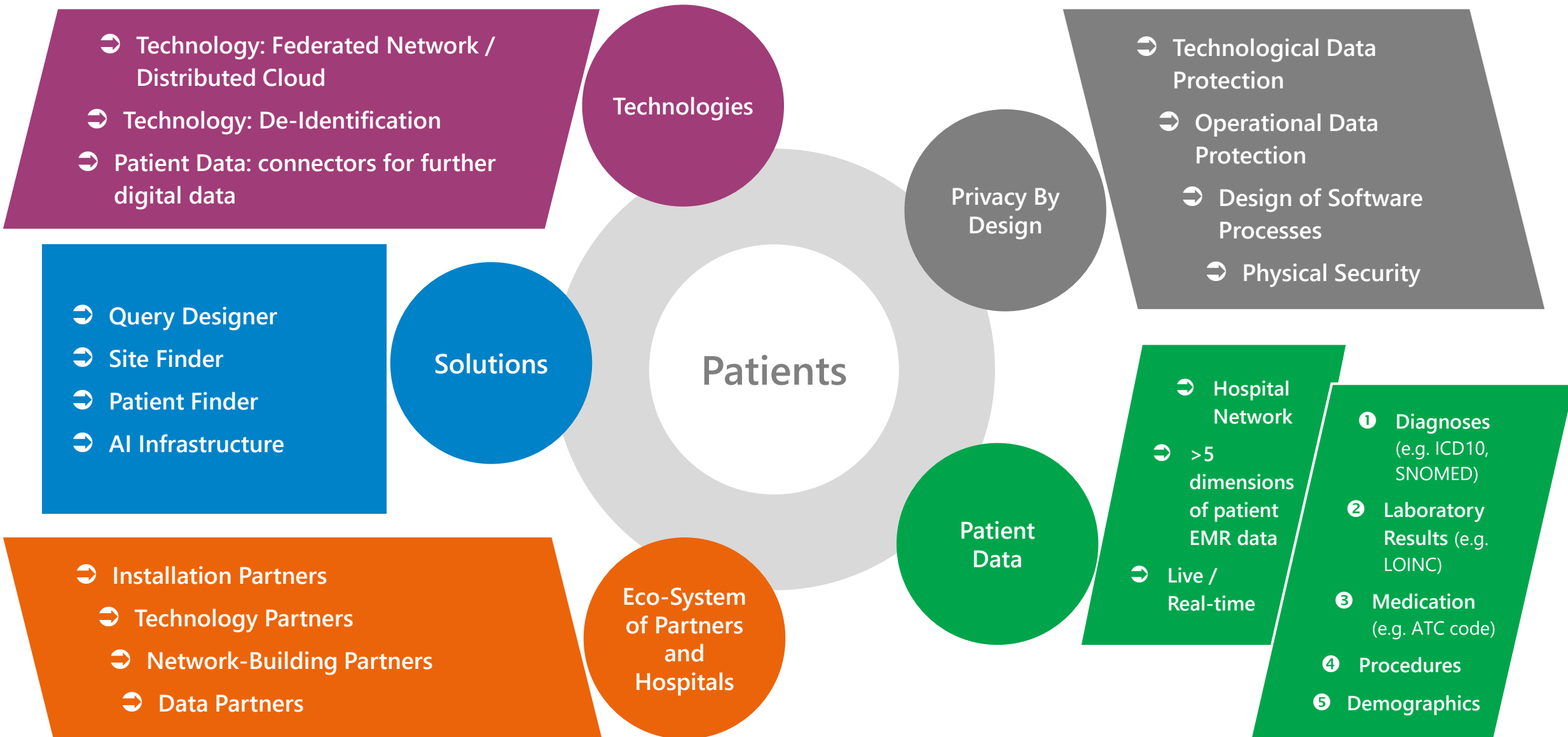
Different countries have different privacy laws and ethical approval standards for working with health-care data



Limited Solutions

Projects focus on ONE large hospital with sufficient data for AI research, limiting applicability to other countries

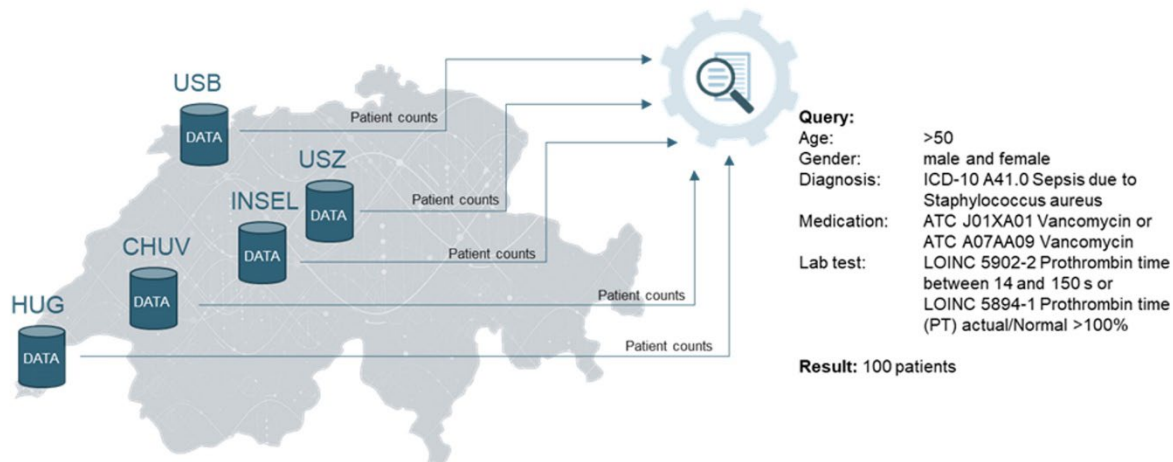
Patient-Centered Technologies Needed



Federated AI & RWD Research Ecosystem

Case study: the Federated Query System (FQS) of the Swiss Personalized Health Network (SPHN)

- Operates across all five of Switzerland's university hospitals
- Enables AI model training and queries for multisite data-driven research projects on clinical data in all hospitals, simultaneously
- >70 million data elements from >450'000 patients: a (consented) subset of patients from the five hospitals
- Fully anonymized, complies with privacy requirements, only aggregated search results are shared with users and small patient numbers are obfuscated to prevent potential re-identification
- Hospitals to retain full control over their data



- Centre hospitalier universitaire Vaudois – CHUV (Lausanne University Hospital)
- Hôpitaux Universitaires de Genève – HUG (Geneva University Hospitals)
- Inselspital, Universitätsspital Bern – INSEL (University Hospital of Bern)
- Universitätsspital Basel – USB (University Hospital of Basel)
- Universitätsspital Zürich – USZ (University Hospital of Zürich)

Data Driven Publications & Articles 2019–2022



Realising International Data Access Through Data Collaborations
European Pharmaceutical Contractor
Publication date: February, 2019



Finding and Treating Rare Disease Patients in a Global Digital Haybale
Journal for Clinical Studies
Publication date: September, 2020



AI/ML to Generate Medical Insights ... While Maintaining Patient Data Security and Privacy
Journal for Clinical Studies
Publication date: February, 2022

Report
Assessment of the distribution of patients with ASCVD and ASCVD risk factors among individuals with T2DM
With Inonu University and AstraZeneca



Case Study
Crohn's Disease
Patient Finder Case Study



How EHR-based Recruitment & Retention supports Patient Centricity
Journal for Clinical Studies
Publication date: May, 2019



An Electronic Data Model for a More Efficient Health System in Latin America
Clinical Research Insider
Publication date: May, 2021



Possibilities to increase number and scope of trials in Poland
Chapter in Industry Clinical Trials In Poland, by the Polish Association of Innovative Pharmaceutical Companies (INFARMA) & Polish Association for Employers of Contract Research Organizations (POLCRO)
Publication date: February, 2022

Report
Identification of Pompe Patients by Modeling Disease-Specific Phenotypes
With Istanbul University Medical Faculty & Sanofi



White Paper
Identifying undiagnosed rare disease patients by modelling disease-specific phenotypes using EHR data



Recruitment Challenges in Oncology
Clinical Research Insider
Publication date: June, 2020



A Vision for Real-World Data Technology
International Clinical Trials
Publication date: December, 2021



Why Do We Need Patient Diversity in Clinical Trials?
Journal for Clinical Studies
Publication date: October, 2022

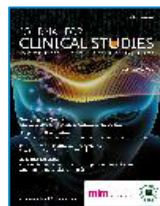
Report
Identification of Fabry Patients by Modeling Disease-Specific Phenotypes Using EHR Data
With Istanbul University Medical Faculty & Sanofi



White Paper
Clinerion Technology Vision for RWD Insights
Enabling a full digital patient profile from EHR to enhance physician access, clinical research, and patient care.



The New Healthcare, Digital by Design
Journal for Clinical Studies
Publication date: July, 2020



Health Outcomes in Clinical Trials
Journal for Clinical Studies
Publication date: December, 2021

Poster
Strategies Toward Identifying Undiagnosed Rare Disease Patients
by Douglas Drake & Christopher Rudolf



Posters
A multicenter RWE study of Whooping cough (pertussis) patients in Türkiye
by Sinan Findik



COVID-19 pushes Digital Trial Revolution...
Clinical Research Insider
Publication date: September, 2020



Clinical Research & Healthcare Digitalization in the Middle East & Turkey
Chapter in Clinical Research at MENA, by Fatih Özdener
Publication date: February, 2022

Posters
Investigation Of The Estimated Regional Distribution of Transthyretin Familial Amyloid Polyneuropathy (TTR-FAP) Disease In Konya
by Sinan Findik



Poster
Seasonal variation of injection numbers in patients with wet type age-related macular degeneration
With Roche



Posters
Identifying Gaucher disease in patients by modelling disease-specific phenotypes using EHR data at Istanbul University
With Istanbul University & Sanofi



Poster
Challenges and Opportunities of Using Electronic Health Records in Multi-Country Studies
With OPEN Health



Use of Electronic Health Record Data in Clinical Investigations

Guidance for Industry

U.S. Department of Health and Human Services
Food and Drug Administration
Center for Drug Evaluation and Research (CDER)
Center for Biologics Evaluation and Research (CBER)
Center for Devices and Radiological Health (CDRH)

July 2018
Procedural



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A vision for use of real-world evidence in EU medicines regulation

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News 24/11/2021

Enabling the use of real-world evidence (RWE) and establishing its value for regulatory decision-making on the development, authorisation and supervision of medicines in Europe by 2025: this is the vision of European regulators as outlined in an [article from Peter Arlett, Head of Data Analytics and Methods at EMA, Jesper Kjær, Director of Data Analytics Centre at the Danish Medicines Agency, Karl Broich, President of the Federal Institute for Drugs and Medical Devices \(BfArM\), and Emer Cooke, EMA's Executive Director](#), published in Clinical Pharmacology & Therapeutics.

Sponsor

- Real-world data and evidence-based research and publications
- Actionable insights for medical affairs division

Hospitals

- Insights on own patient cohorts
- Treatment improvement for involved patients
- Possibility for clinical trials with sponsor

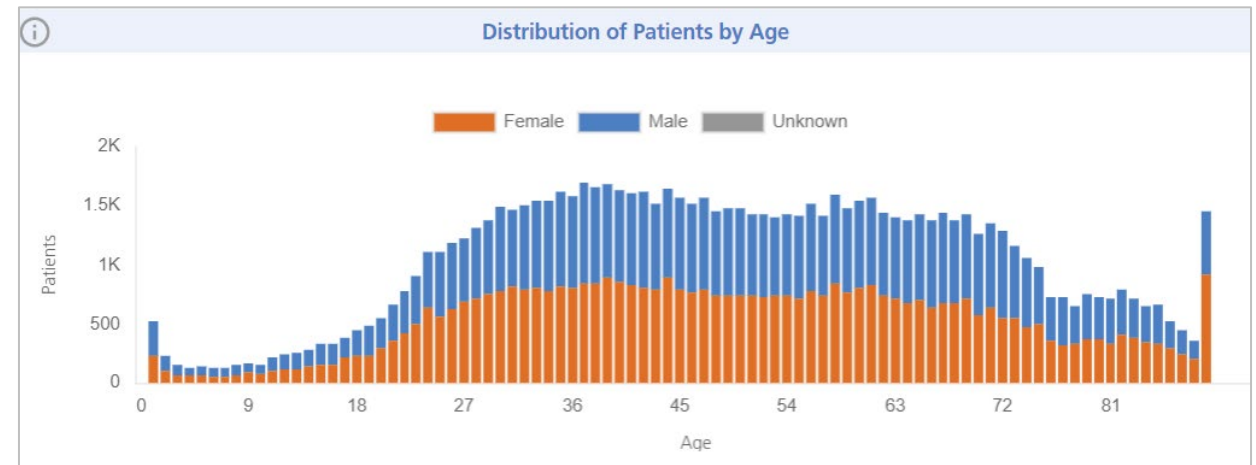
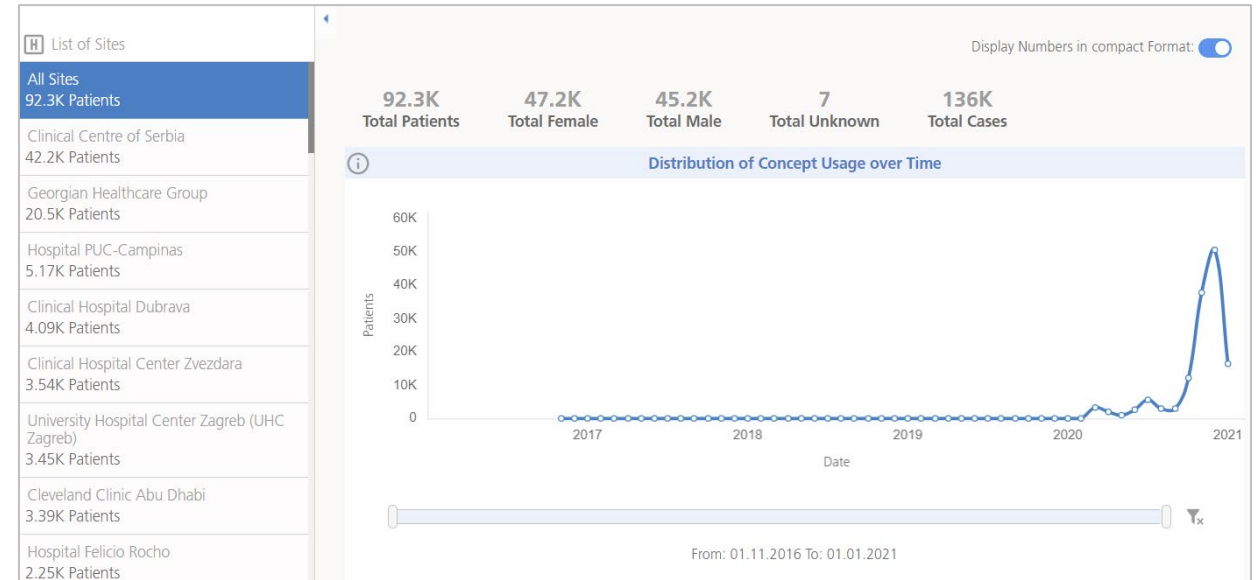
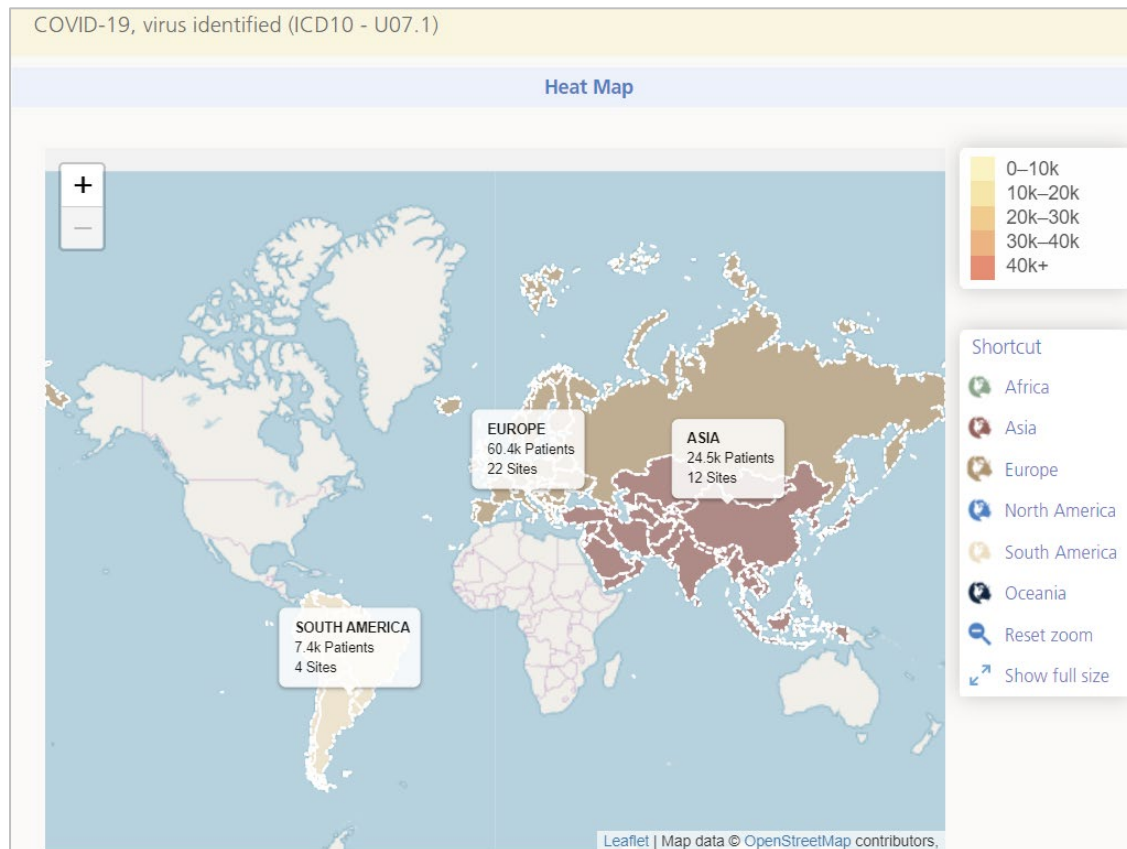
Intermediary*

- Enablement and maintenance of innovative platforms as part of the collaboration

* Bridge between the industry and the healthcare providers.

AI Models to Predict COVID Progression

Real-time patient metrics and mapping



Longevity

Increase survival rates even for lethal diseases with early detection.

Covid Pandemic opened up a new era on data and AI:

- Online symptom checkers and e-triage
- Detecting high-risk patients before critical stage and start preventive treatment
- Diagnosing rare disease patients which are often mis/un-diagnosed
- Identifying eligible patients for Clinical Trials for innovative treatments
- Creating synthetic control arms and speeding up the new therapy development being available

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