



Medical University of Graz



# Trusted Health Data Environment and Biobanks

Kurt Zatloukal

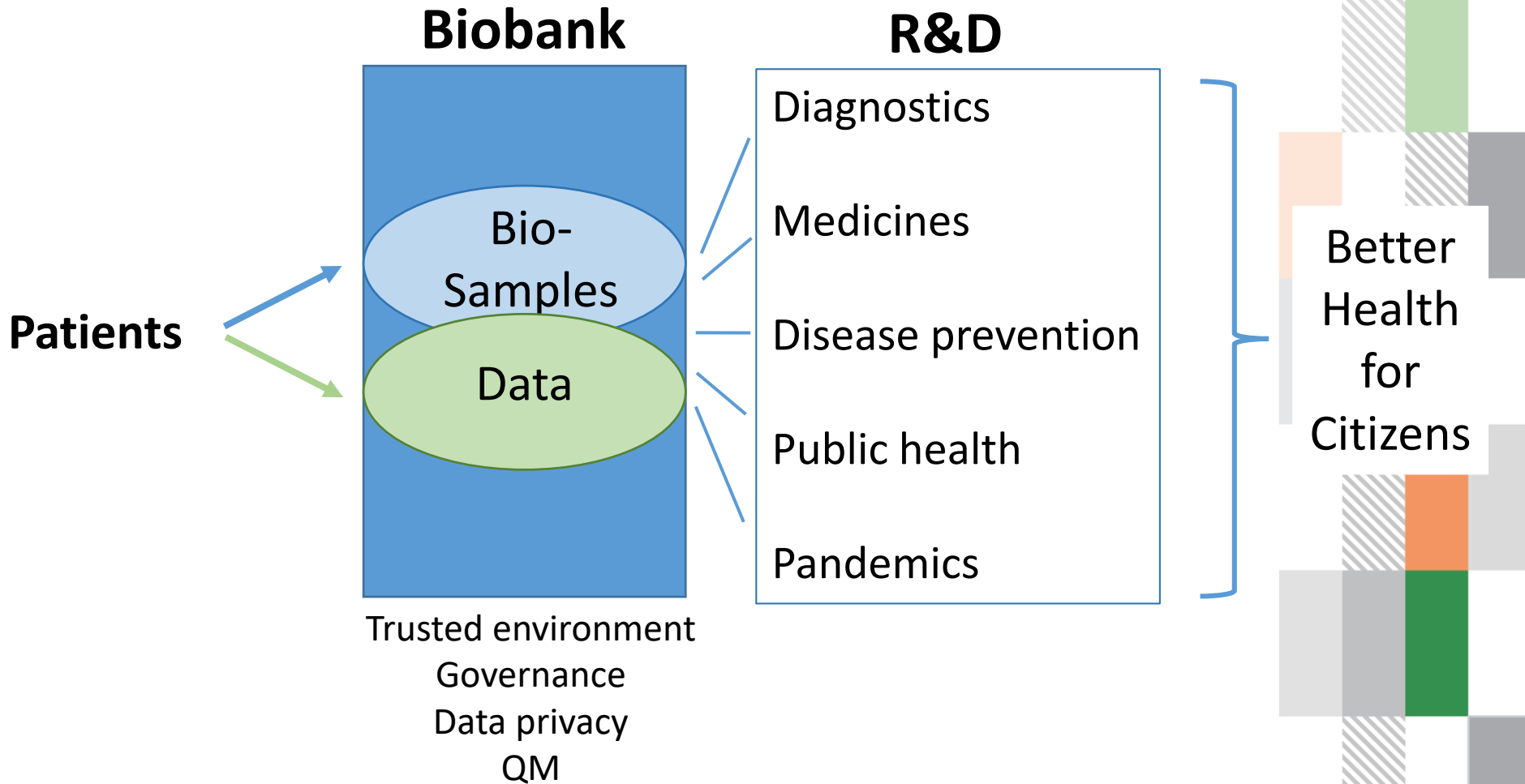
Diagnostic and Research Center for Molecular Biomedicine

Medical University Graz, Austria

**Workshop - Multi-national Opportunities  
for Sample Search Platforms**



# Biobanks and the Health Innovation Chain



# The Issue of Sample Quality

## Reproducibility Depends on Quality

OBBR Office of Biorepositories  
and Biospecimen Research

**GARBAGE IN ⇒ GARBAGE OUT**

## Many SOPs Around the World: Which are the Best?

OBBR Office of Biorepositories  
and Biospecimen Research

- Impossible to call any one "best" (even NCI's)
  - All have strengths and weaknesses
  - No single set of SOPs are applicable to all clinical and research analytical platforms
  - Very few SOPs are based on **scientific evidence**

Where we need to go

from C. Compton

# Data Quality and Inclusiveness

**Report of UN Secretary-general's high-level Panel on Digital Cooperation:**  
*"Gaps in the data on which algorithms are trained can likewise automate existing patterns of discrimination, as machine learning systems are only as good as the data that is fed to them."*



All people should have a chance to be included !

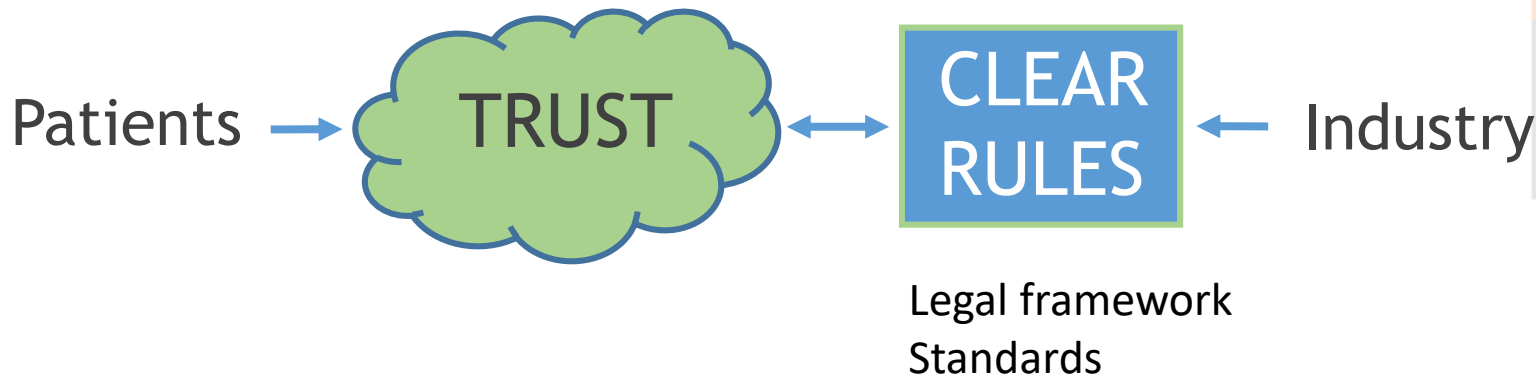
# Why do We Need Data from Patients?

- Understanding the impact of environment and lifestyle on health and disease
- Hospitals have only snapshot data of diseases
- Patients have full data on
  - Lifestyle - environmental exposure
  - Disease course (primary therapy-follow up)
  - Compliance (e.g., lifestyle intervention)
  - Impact on quality of life

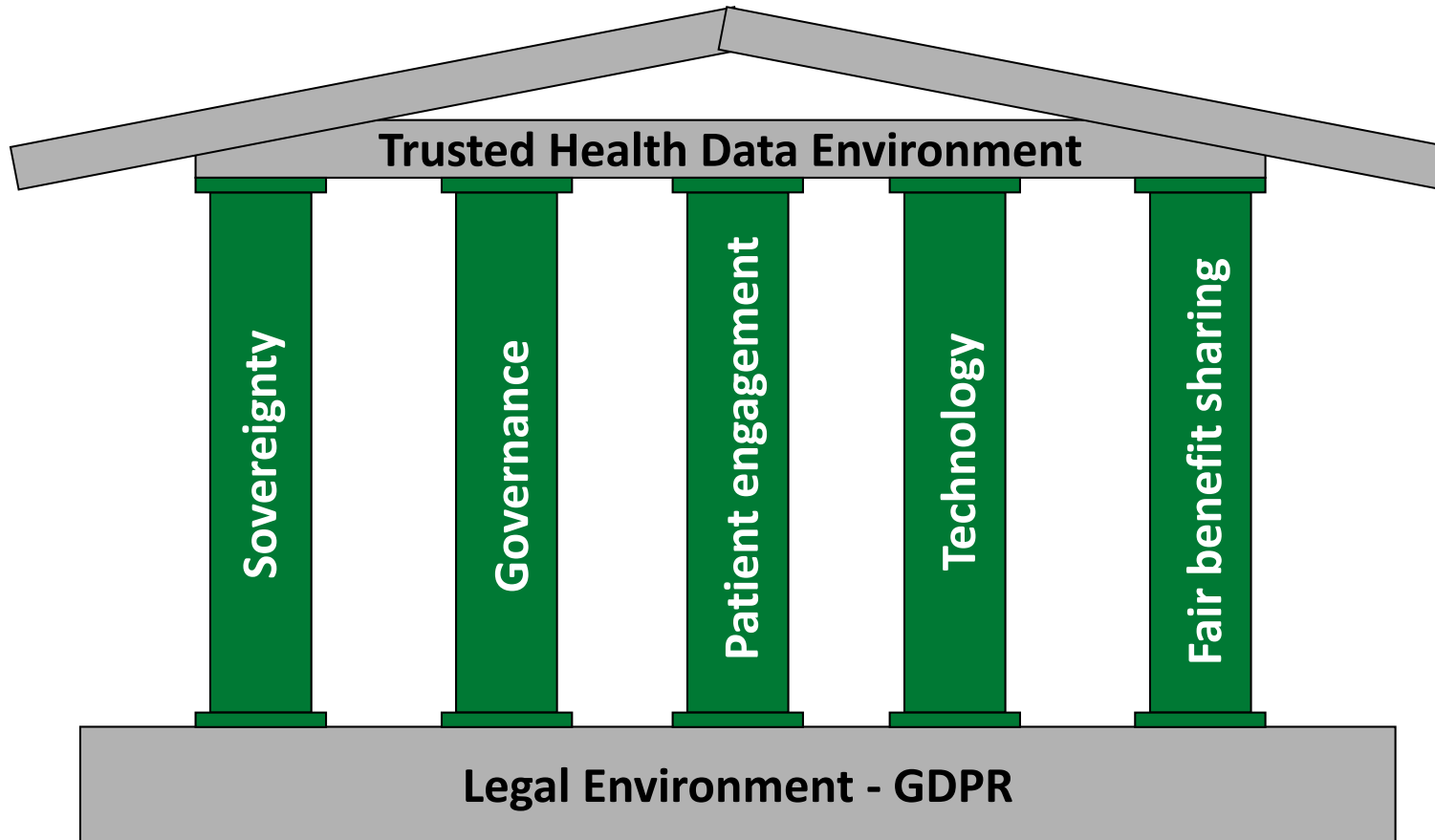


# Digitalization in Health Care

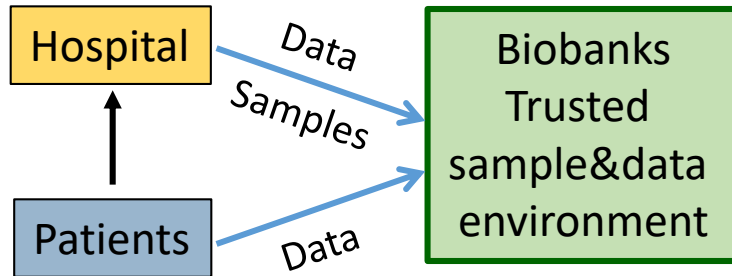
A socio-economic (disruptive) game changer



# How to Build a Trusted Research Environment for Patient Data

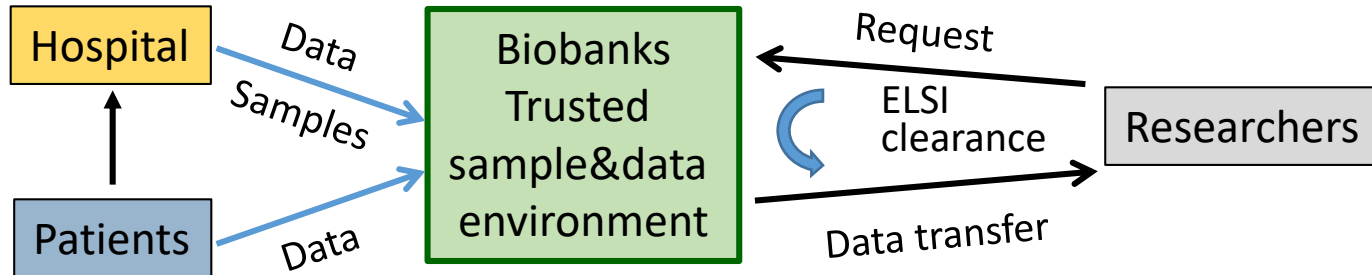


# Example of a Trusted Health Data Environment for Research and Innovation





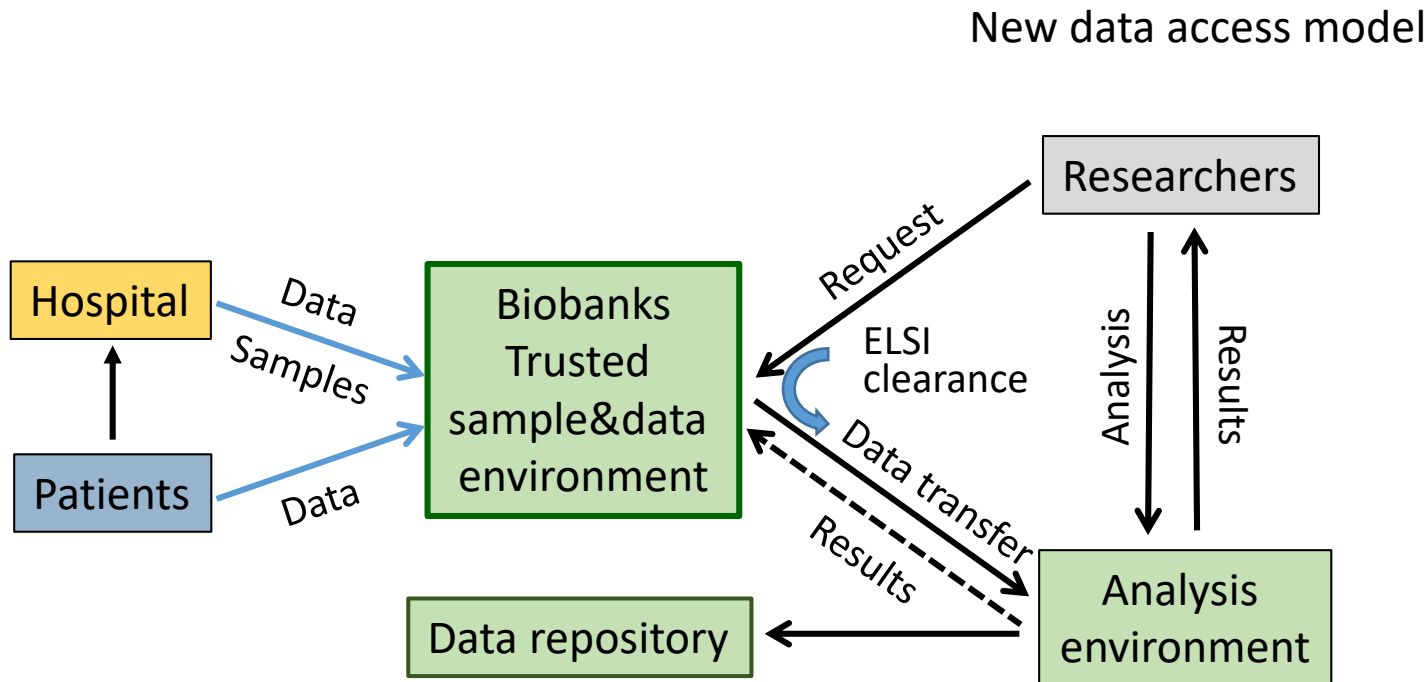
# Example of a Trusted Health Data Environment for Research and Innovation



Classical data access model



# Example of a Trusted Health Data Environment for Research and Innovation



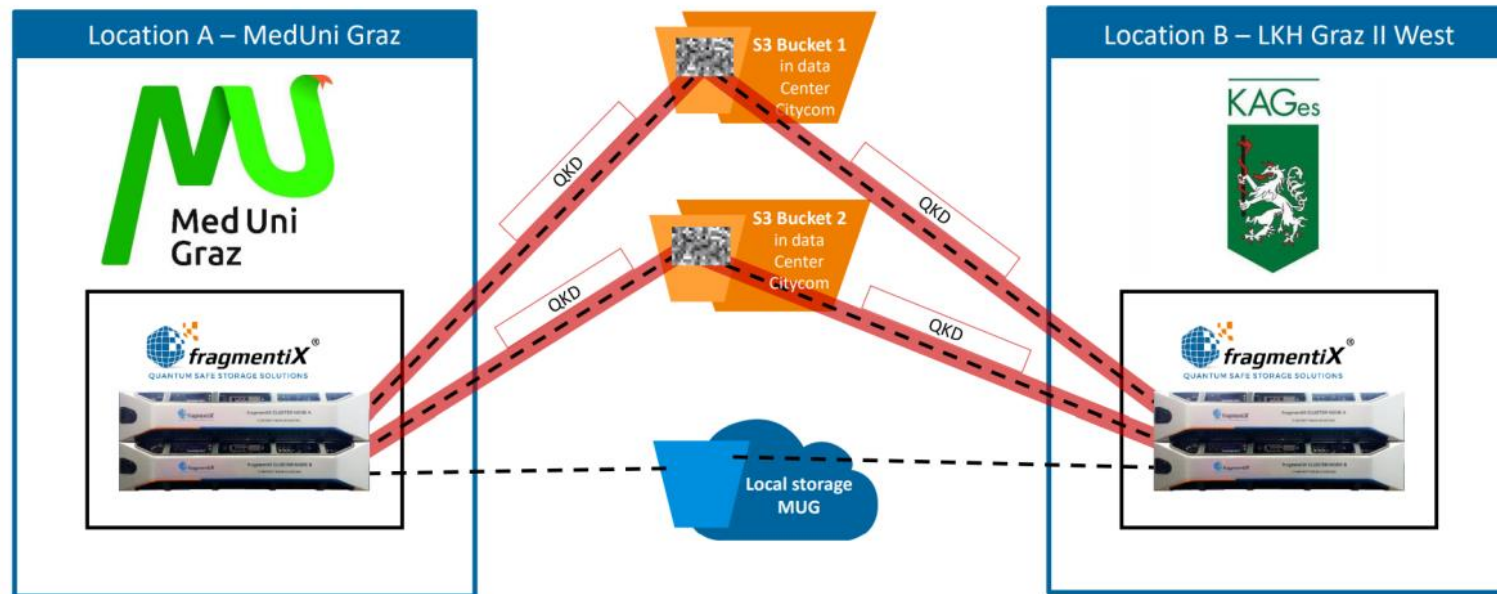
# Advantages of Data Analysis in Their Local Trusted Environment over Sending Data to Researchers

- Patients can better exert their rights (e.g., withdrawal of consent, return of results)
- Reduced risk of reidentification of patients
- Reduced data protection (GDPR) compliance issues in international collaboration
- Model to generate FAIR benefits for data access



# Innovative Data Technologies

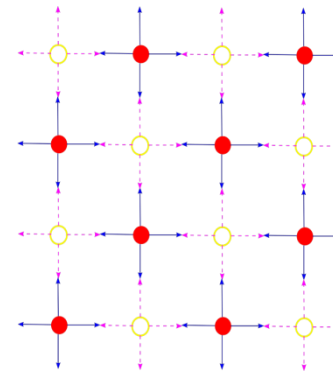
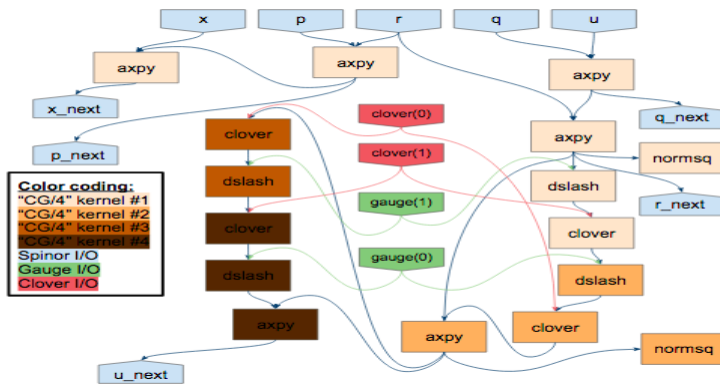
## fragmentiX CLUSTER - technology



Quantum key distribution

# Maxeler Dataflow Advantage

## Berlin Quantum Chromodynamics on Maxeler Dataflow compared to IBM BlueGene



	2 racks of Jülich IBM BlueGene/Q machine	10 MPC-X boxes	Factor
Volume	6.75 m <sup>3</sup>	0.25 m <sup>3</sup>	27.2
Time to Solution	1076.41 s	689 s	1.56
Energy to Solution	115.8 kWh	1.91 kWh	60.6
Volume x TTS	7,265.77 m <sup>3</sup> s	171.27 m <sup>3</sup> s	42.4

# Carbon Neutral Computing

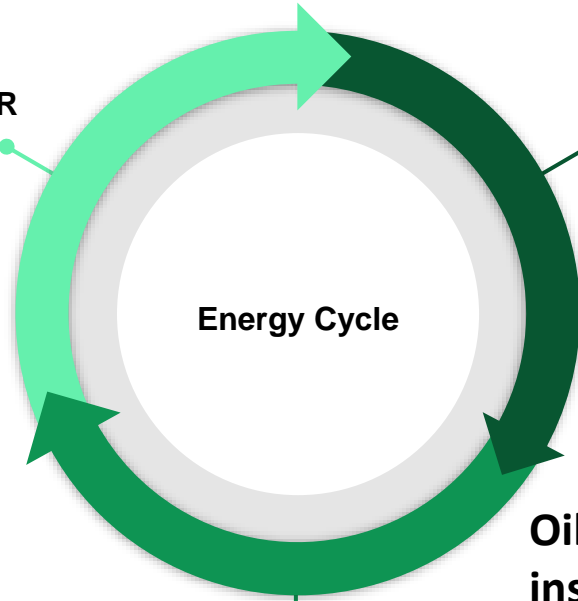


SOLAR



WIND

Energy Storage  
Hydrogen

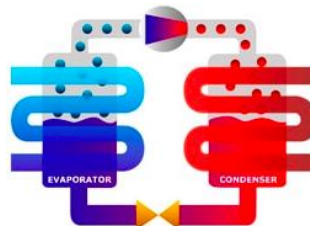


Energy Cycle

Dataflow  
Optimized  
Eco  
Datacenter

Oil Cooling  
instead of  
Fans or  
Water

Heatpumps



# the age of digital interdependence

Report of the UN Secretary-General's  
High-level Panel on Digital Cooperation



## 4. We **recommend** the development of a **Global Commitment on Digital Trust and Security**

1A: We recommend that by 2030, **every adult should have affordable access to** digital networks, as well as **digitally-enabled financial and health services**, as a means to make a substantial contribution to achieving the SDGs.



# Conclusions

- Health data is a key resource for digital transformation of health systems
- Health data is becoming an important biobank component
- Making health data accessible has to build on trust
- Need for internationally harmonized
  - Legal framework
  - Approach for preserving privacy
  - Governance models to ensure
    - data sovereignty
    - transparent business models
    - fair benefit sharing

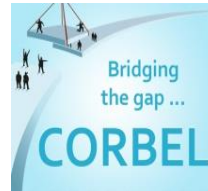




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Biobanking and  
BioMolecular Resources  
Research Infrastructure



Project number: 676550



European Research Infrastructure  
on Highly Pathogenic Agents



Cell-based regenerative medicine:  
new challenges for EU  
legislation and governance



BBMRI GA Nr. 212111  
1.2.2008-30.04.2010

Thank You for Your Attention!

