# Challenges in the development of the EU Health Data Space through the lens of COVID-19 experiences

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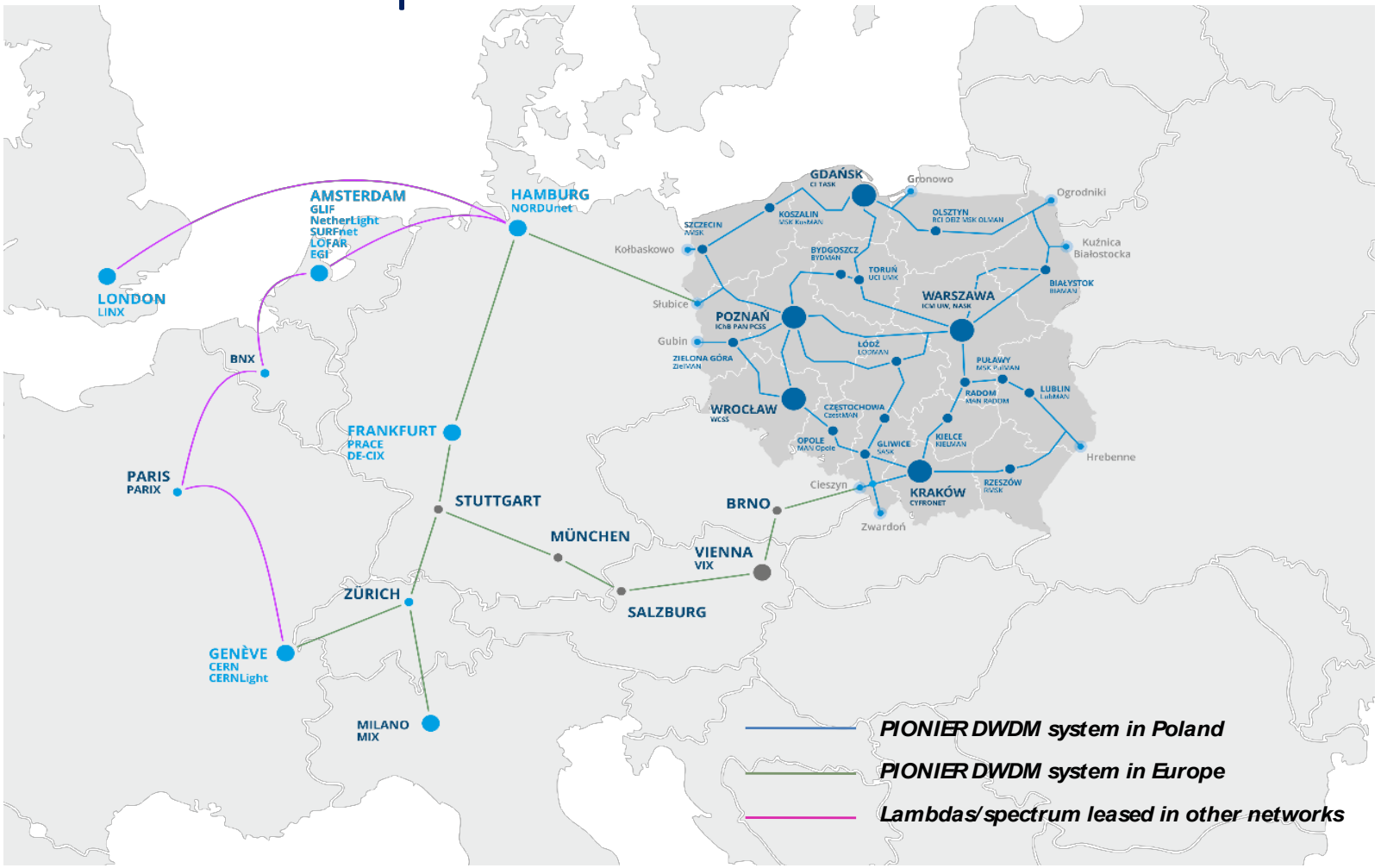
V4 seminar on
European Health Data Space
Brussels, 23rd November 2021

# Institute of Bioorganic Chemistry PAS

- The Institute of Bioorganic Chemistry of the Polish Academy of Sciences (IBCh PAS) is a unique research unit in Europe, which carries out interdisciplinary research in chemistry, biology, bioinformatics and computer science
- Together with its affiliated Poznań Supercomputing and Networking Center (PSNC) it is one of the largest institutes of Polish Academy of Sciences, employing in total over 750 people
- The core mission of PSNC is to foster scientific excellence by providing reliable and cutting-edge e-Infrastructure such as communication networks, data and supercomputing systems, as well as highly-specialized laboratories

# PIONIER – Polish Optical Internet



# Focus on Digital Transformation based on advanced einfrastrucutre

- Continuous R&D activities related to information and communication technologies and their innovative applications

| | | | |
|---|---|---|---|
| Continuous Financing for eInfrastructure in Poland | 21 Metropolitan Area Networks | Polish Optical Network PIONIER | 5 Supercomputing centres |
| Polish Rodmap for Research Infrastructures 2020 | Research infrastructures projects (10/70) | Medical, biological & agricultural sciences (3/17) | Digital infrastructures (6/6) |
| European Research Funding Programmes since 2004 | Technology driven innovation pipeline | 295 international R&D projects | No 1 Polish scientific institute in EU funding |
| Poznan Supercomputing and Networking Center | Data Driven Organization | Focus on platform architecture and service design | Value-added research infrastructure |

**28**
years of activity

**1.34M***
scientific users
* all users served for 21 MANs

**1680***
customers
* since 2016

**432**
employees

**301**
projects

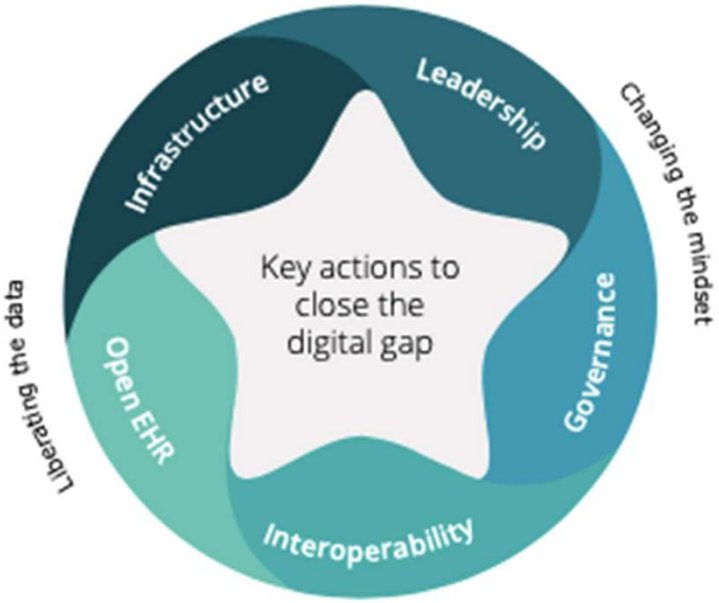
# Digital Transformation: Shaping the future of European healthcare – Deloitte report (2020)

Top challenges facing HC organizations in implementing digital technologies

Europe

1. **Bureaucracy in healthcare (57.4%)**
2. **Cost of technology (50.3%)**
3. **Finding the right technologies (49.0%)**
4. Training staff to adequately use technology (35.8%)
5. Complexity of technology (28.9%)
6. Challenges in sharing patient data (27.7%)
7. Convincing staff of the benefits of technology (20.5%)
8. Scaling up the use cases of technologies (16.1%)
9. Existence of evidence of outcomes (12.5%)

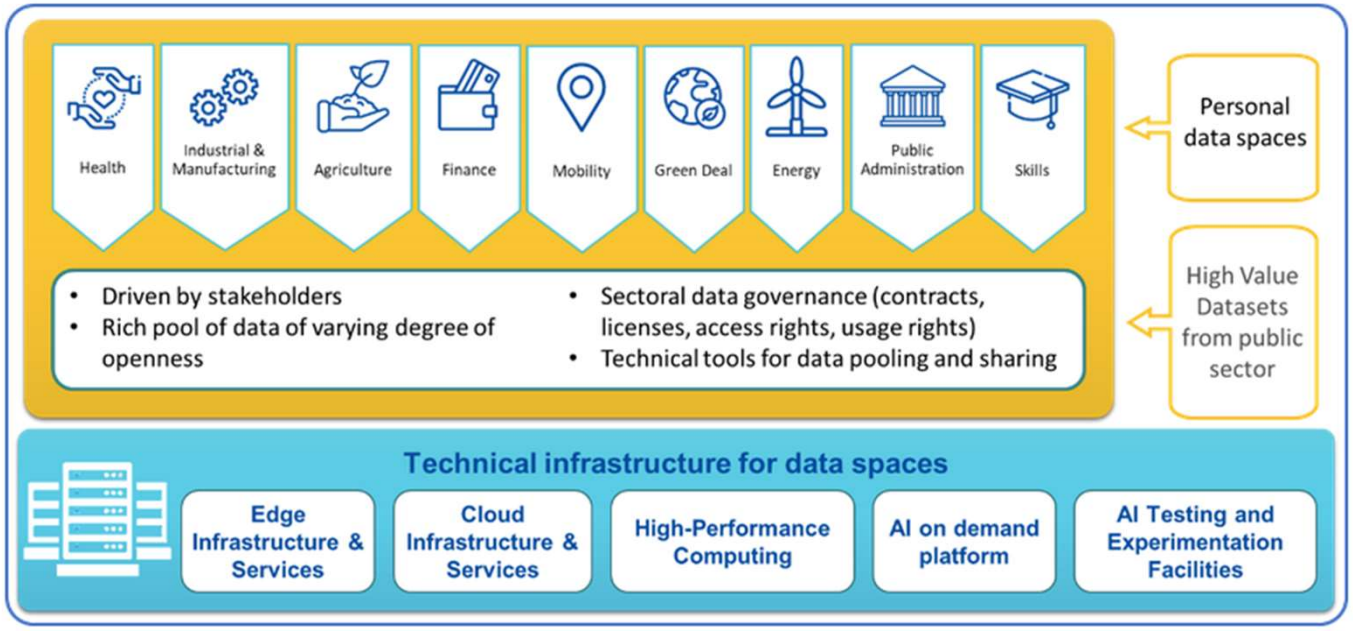
**Figure 12. Key actions to close the digital gap**

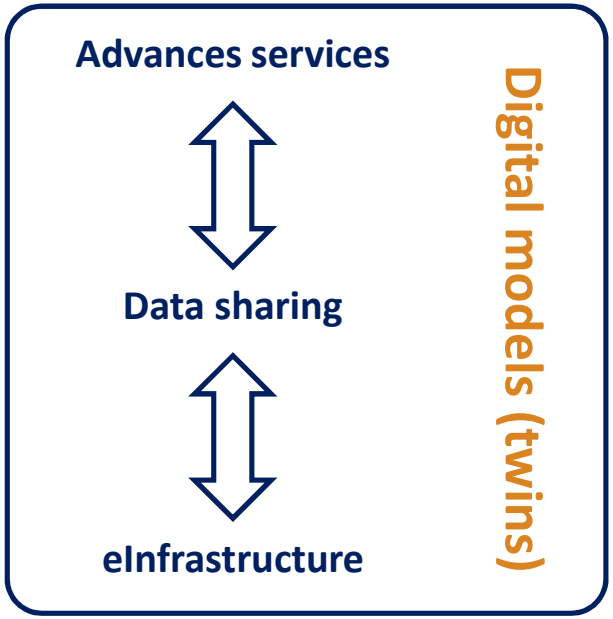



Source: Deloitte research and analysis, 2020

# Common European data spaces

- The medicine of today is increasingly employing IT technologies to better understand the observed processes and support diagnostic and individual therapeutic procedures based on digital models




https://digital-strategy.ec.europa.eu/en/library/building-data-economy-brochure

# Healthcare – our emphasis on data management and integration towards better diagnosis and treatment

- ICT
  - ADMIRE - Adaptive multi-tier intelligent data manager for Exascale (Brain Super-resolution imaging )
  - INSENSION - Personalized intelligent platform enabling interaction with digital services to individual with PMLD (Profound and multiple learning disabilities)
  - GlaucomAI - Multimodal Advanced Glaucoma Diagnosis Model
  - medVC - Real-time audio-video collaboration for doctors
- AAL
  - PELOSHA: Personalizable services for supporting healthy ageing
  - Fit4Work: Self-management of physical and mental fitness of older workers
- eInfrastrucutre
  - NEBI – National Imaging Centre for biological and biomedical sciences
  - MOSAIC – AI Platform to integrate and analyze multiomics and clinical data for new insights and tools for broadly accessible, personalized prevention, diagnosis and medical therapy

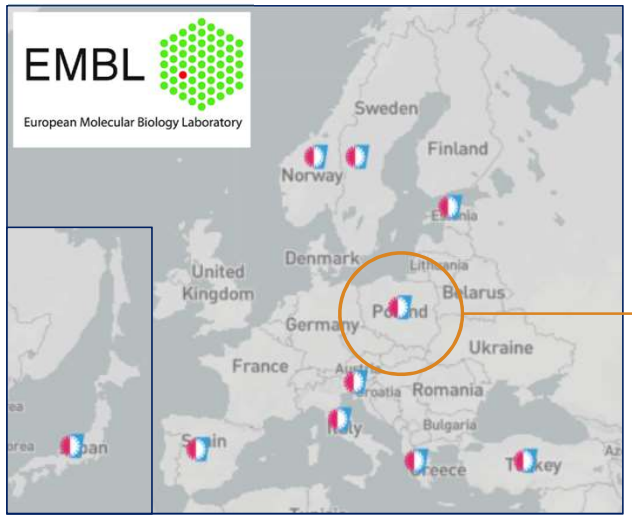
# Data sharing at the times of pandemic
# National SARS-CoV-2 Data Hub and Research Platform in Poland

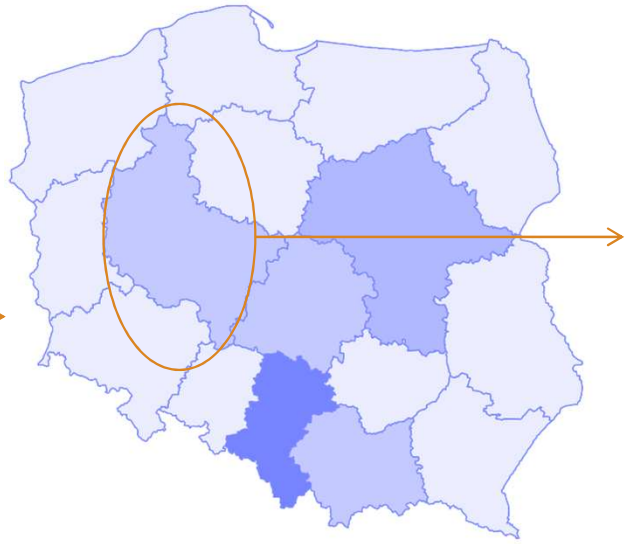
# National SARS-CoV-2 Data Hub and Research Platform in Poland

COVID-19 Data Portal

COVID-19 Data Portal POLAND

REGIONAL COVID-HUB Wielkopolska



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Ministry of Science and Higher Education
Republic of Poland

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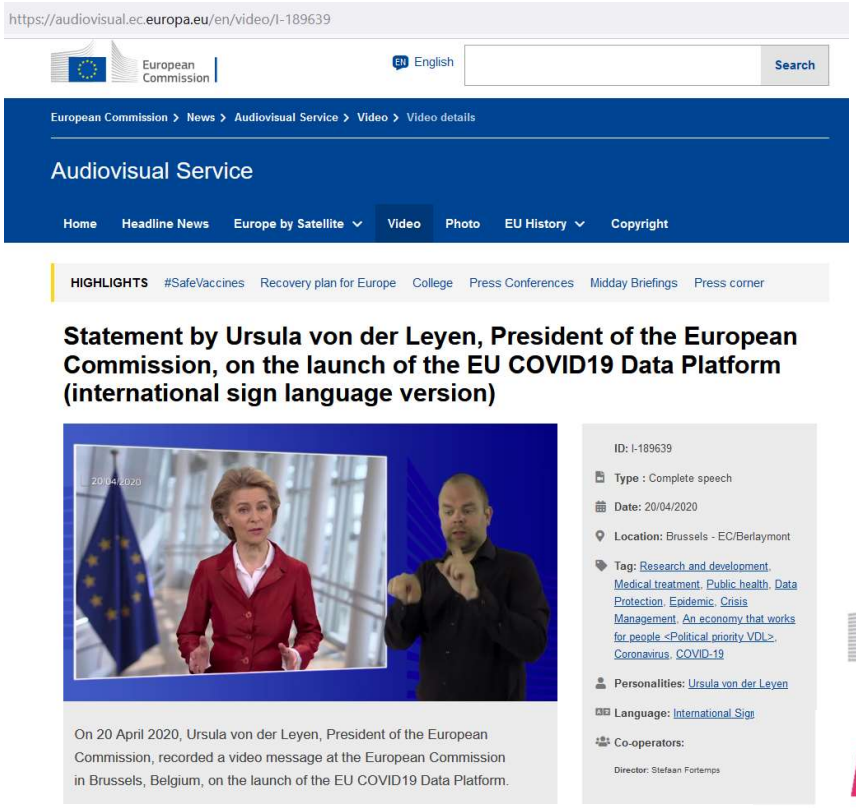
# European COVID-19 Data Platform




- Open and rapid access to data, tools and workflows for the European COVID-19 response and research
- FAIR data for the global research communities
- Long-term sustainable solutions, build on open standards and aligned with the European Open Science Cloud (EOSC)

European Commission

Digital Response to COVID-19

BY-COVID beyond covid

VEO

EOSC-Life

elixir CONVERGE

Re CoD ID

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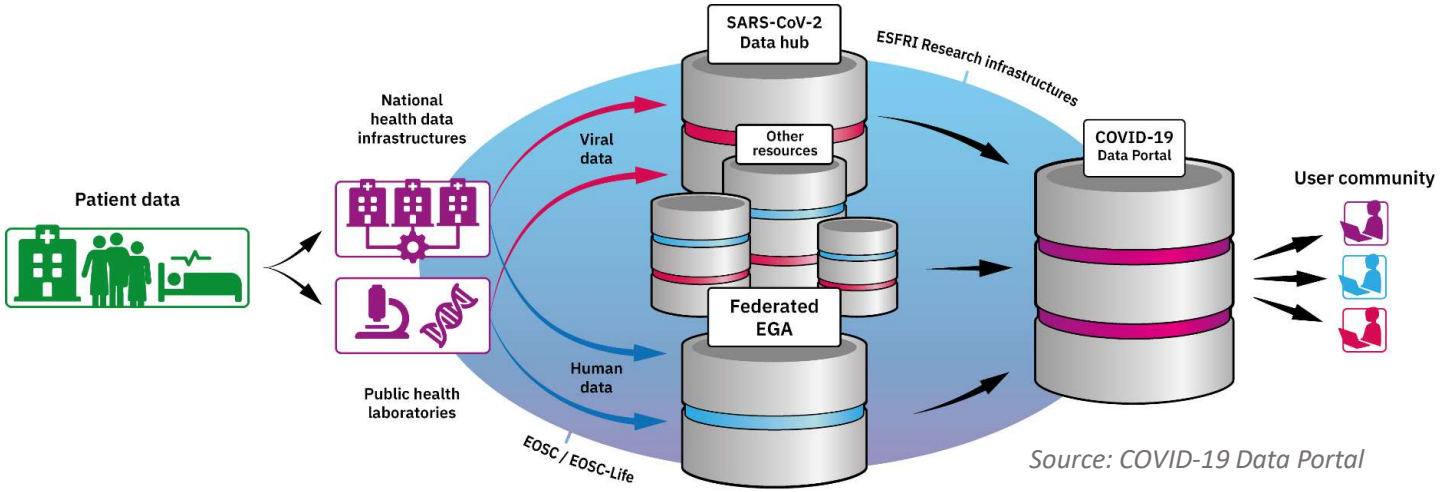
# European COVID-19 Data Platform components

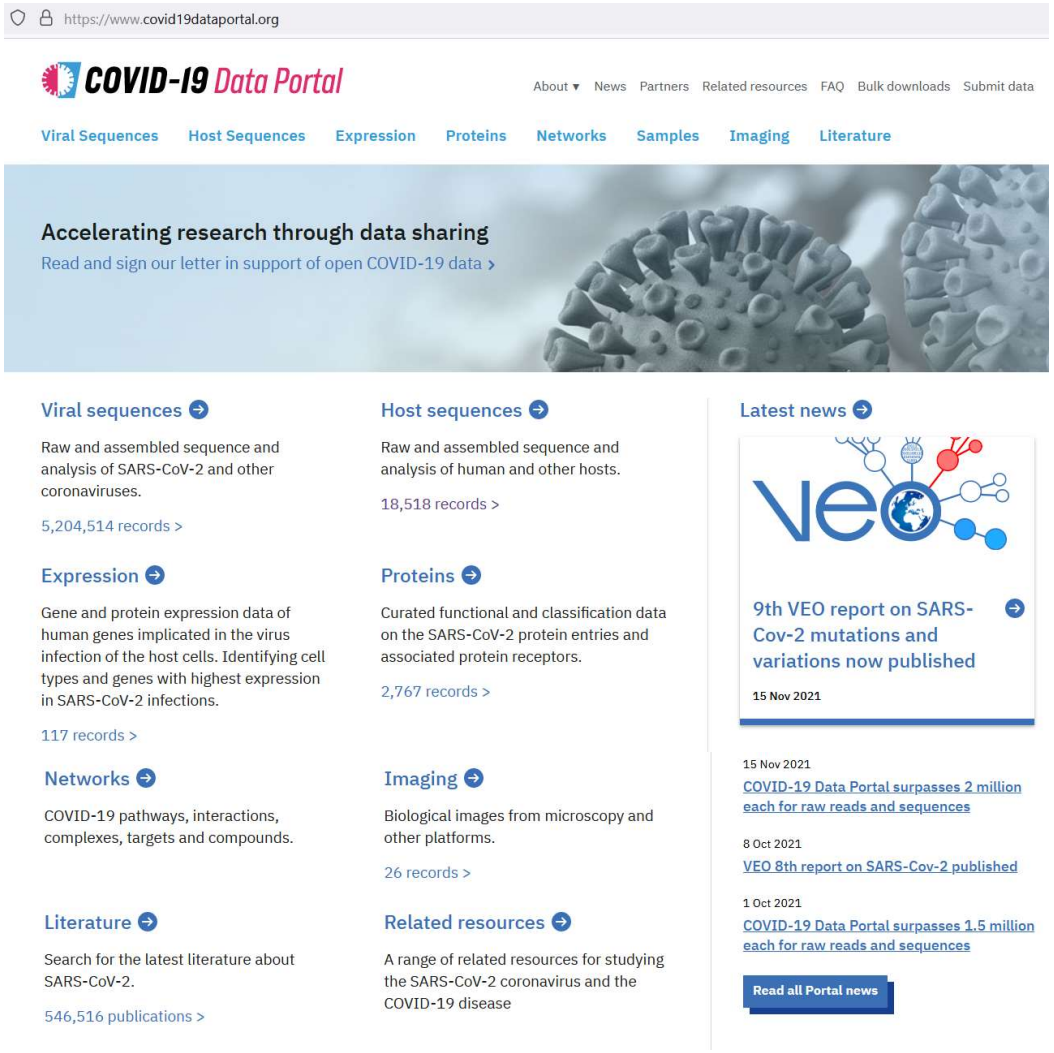
- SARS-CoV-2 Data Hubs – organize the flow of SARS-CoV-2 genomic data, offer deep user support
- Federated European Genome-phenome Archive – provides secure, controlled access sharing of sensitive patient and COVID-19 research data
- COVID-19 Data Portal – brings together relevant COVID-19 datasets and tools, hosts sequence data sharing and facilitates access to other SARS-CoV-2 resources




*Source: COVID-19 Data Portal*

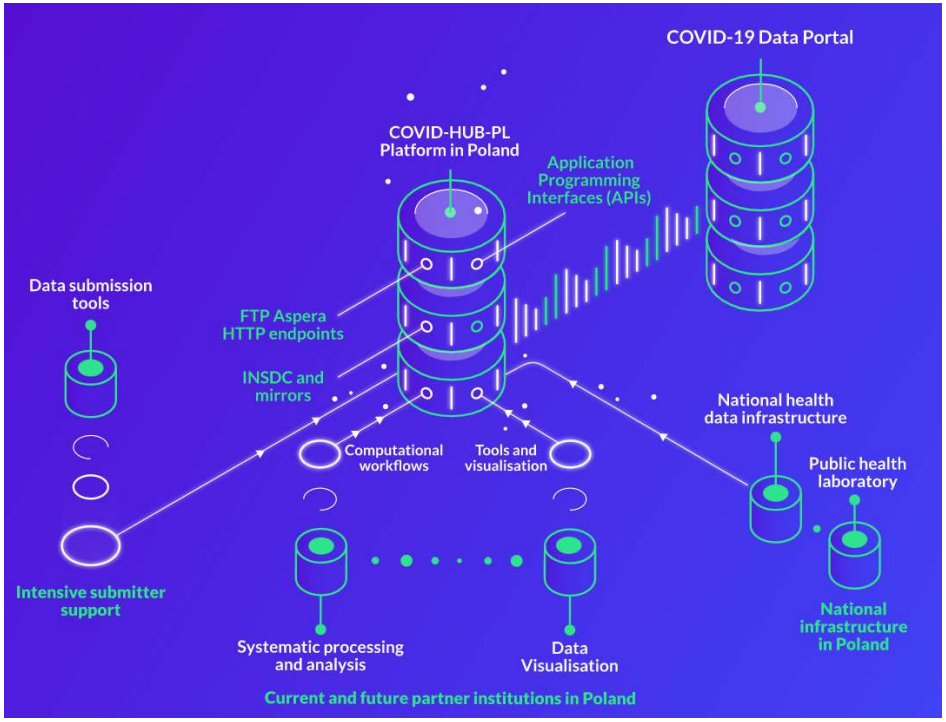
# COVID-19 Data Portal

- Over 5M records across molecular platforms and literature
- Nucleotide and amino-acid sequences, protein structures, expression data, compound screens, bioimaging data and scientific publications
- Includes a federation of 8 national data portals (Italy, Japan, Norway, Poland, Slovenia, Spain, Sweden, Turkey)




https://www.covid19dataportal.org/

# National COVID-19 data hub and research platform COVID-HUB-PL



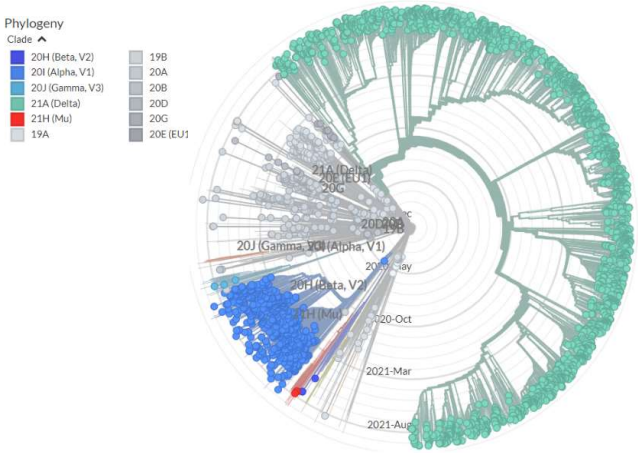

https://covidhub.psnc.pl/eng/

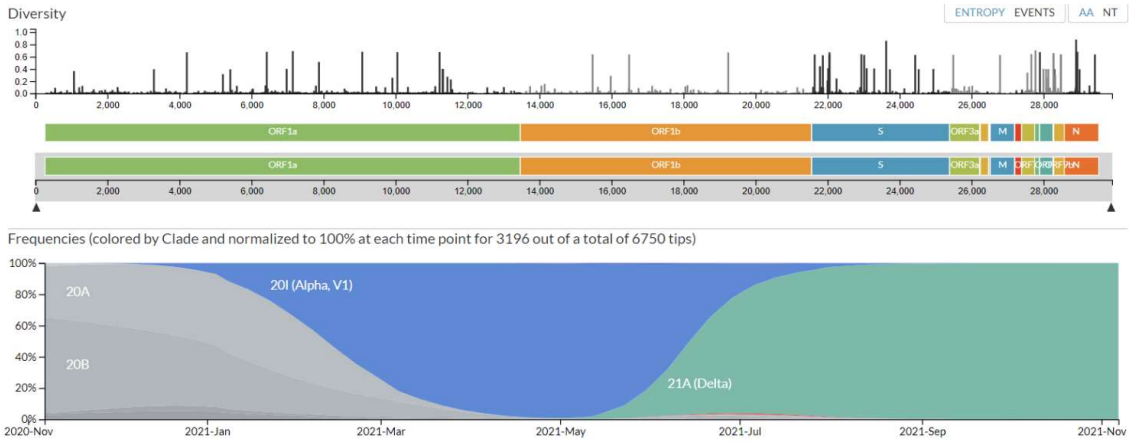
- Provides information, guidelines, tools and services to support researchers in creating and sharing research data on COVID-19,
- Large data repository and dedicated storage space at PSNC created to collect and share:
  - Genomic data
  - Clinical data
- Higher priorities established for accessing HPC resources by computational tasks related to COVID-19
- IaaS/PaaS environments available at PSNC for data and service providers
- Utilizes EOSC ecosystem in Poland (PIONIER NREN)

# COVID-HUB-PL Tools & Services

COVID-19 Data Portal POLAND

- Genomic data analysis
- Genome visualization based on a dedicated Nextstrain instance https://nextstrain.covidhub.psnc.pl/ncov/poland
- Other tools, e.g.: automatic analysis of medical imaging data using AI/MLs, support tools for remote access to SARS-CoV-2 reference databases in Poland, Europe and worldwide

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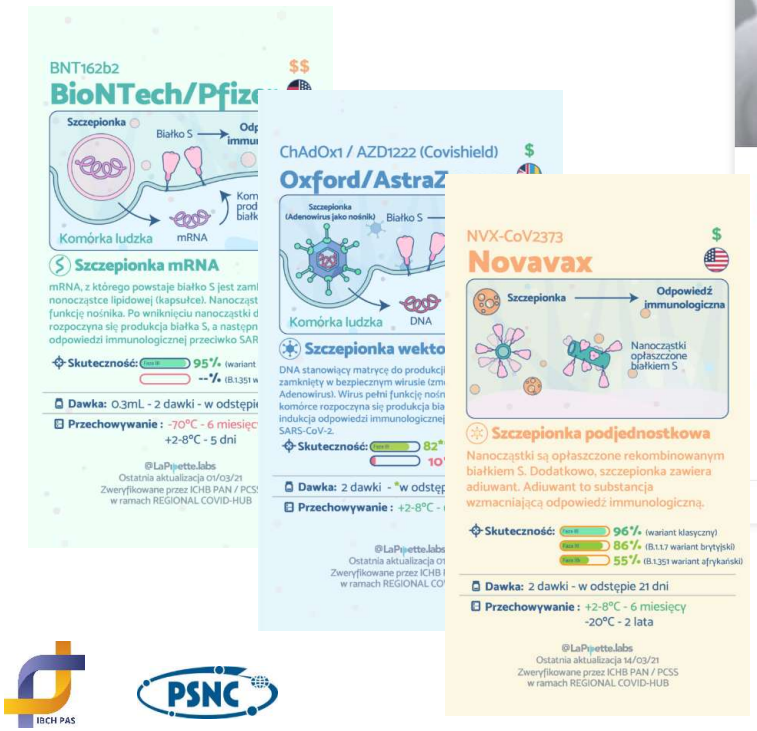
# COVID-HUB-PL for the general public

COVID-19 Data Portal POLAND

- Aggregated and relevant news regarding COVID-19 and R&D activities in Poland
- Raising public awareness of science and disseminating knowledge
- COVID-19 dashboard

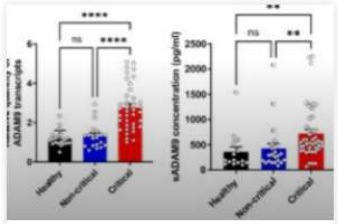



New drugs to treat COVID-19 approved by EMA

The European Medicines Agency (EMA) has approved two monoclonal antibodies, Regkirona (regdanvimab) and Ronapreve (casirivimab / imdevimab), as biological drugs in the fight against COVID-19.

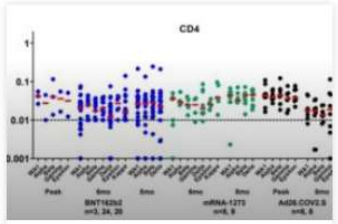
READ MORE

18 November



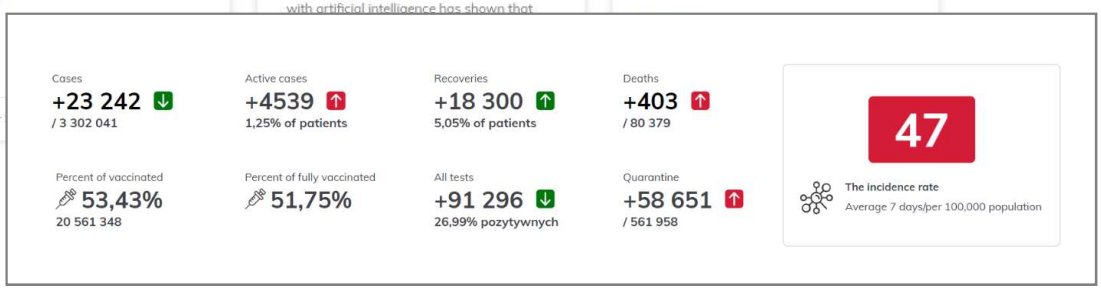
Identification of driver genes for critical forms of COVID-19 in a deeply phenotyped young patient cohort

Research using multi-omics analysis (whole genome sequencing, RNA sequencing, proteomics, cytokine profiling and high-throughput immunophenotyping) combined with artificial intelligence has shown that




Differential Kinetics of Immune Responses Elicited by Covid-19 Vaccines

A study published in NEJM shows how the cellular and humoral response changes within 8 months of receiving either the two-dose BNT162b2 or mRNA-1273 vaccine or the single dose Ad26.COV2.S vaccine

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# REGIONAL SARS-CoV-2 DATA & e-SERVICES PORTAL

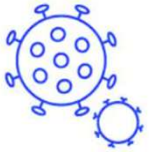
REGIONAL COVID-HUB
Wielkopolska

The aim of the REGIONAL COVID-HUB project is to provide e-services to help research and public institutions (Sanitary-Epidemiological Stations, hospitals, Marshal of the Wielkopolska Region), as well as general public to counteract COVID-19 pandemic in Wielkopolska region.

Research institutions

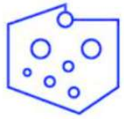
Hospitals

Sanitary-epidemiological Stations



Society

Local authorities



Project duration: 2020.07.01 – 2022.06.30

European Funds
Regional Programme

Republic of Poland

WIELKOPOLSKA REGION

EUROPEAN UNION
European Regional Development Fund

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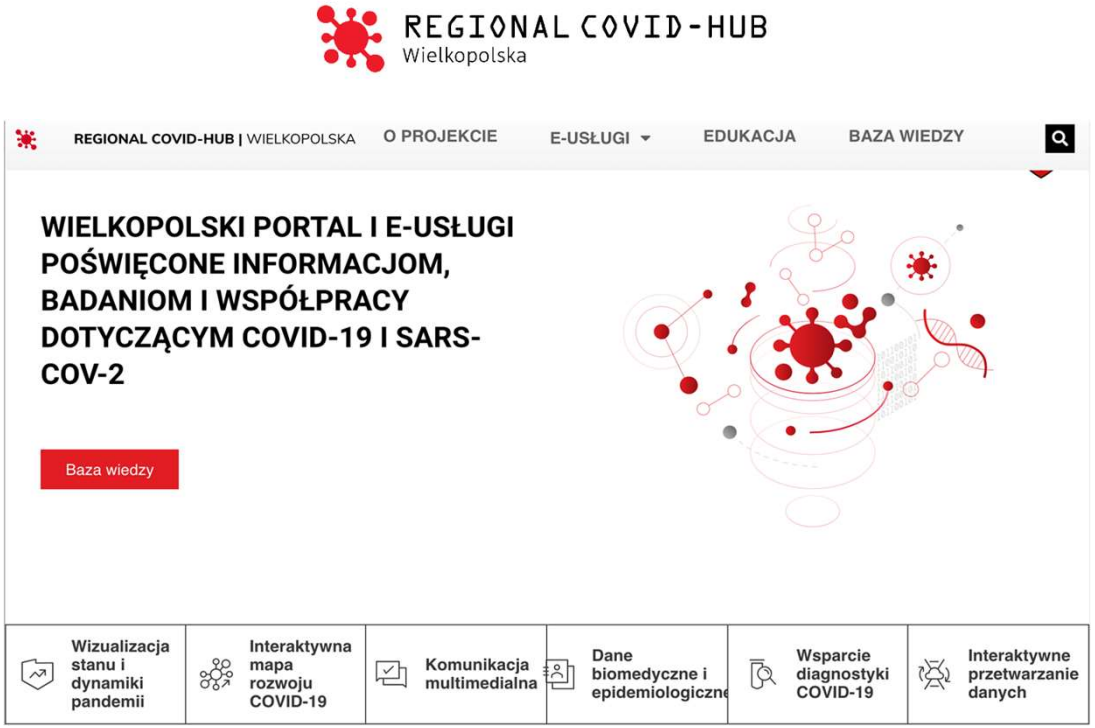
# REGIONAL SARS-CoV-2 DATA & e-SERVICES PORTAL

- COVID-19 dashboard,
- Knowledge base (FAQ, expert-verified information on SARS-CoV-2, useful links),
- Lesson plans and educational materials (immunology, virology, genomics)
- Interactive COVID-19 map (Nextstrain),
- Dedicated storage space for collecting and sharing COVID-19 biomedical and epidemiological data (according to FAIR principles) together with open/public documents for institutions and citizens in Wielkopolska region,
- e-service for remote communication and tele-consultation.



# Conlusions – Challenges for Personal Medicine solutions

- An interdisciplinary approach in medicine no longer means only medical teams working together
- For data-driven solutions, it is crucial to have access to sufficient numer of records to avoid imbalances between numer of parameters and the size of the set to analyze
- Data mining leading to determination of the crucial parameters which characterize the case and disease should be strictly supervised by the physician's expertise
- Feedback loop for improved understanding – modeling based on medical knowledge and physiology cross-referencing while working with data and model
- Advancing beyond diagnosis support towards specific therapeutic interventions suggested for physicians
- Sustainable and transparent science communication and citizen empowerment strategies contributing to openness and trust are fundamental for the public dialogue about the research use of healthcare data and implementation of new technologies in medicine

# Contact

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