



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

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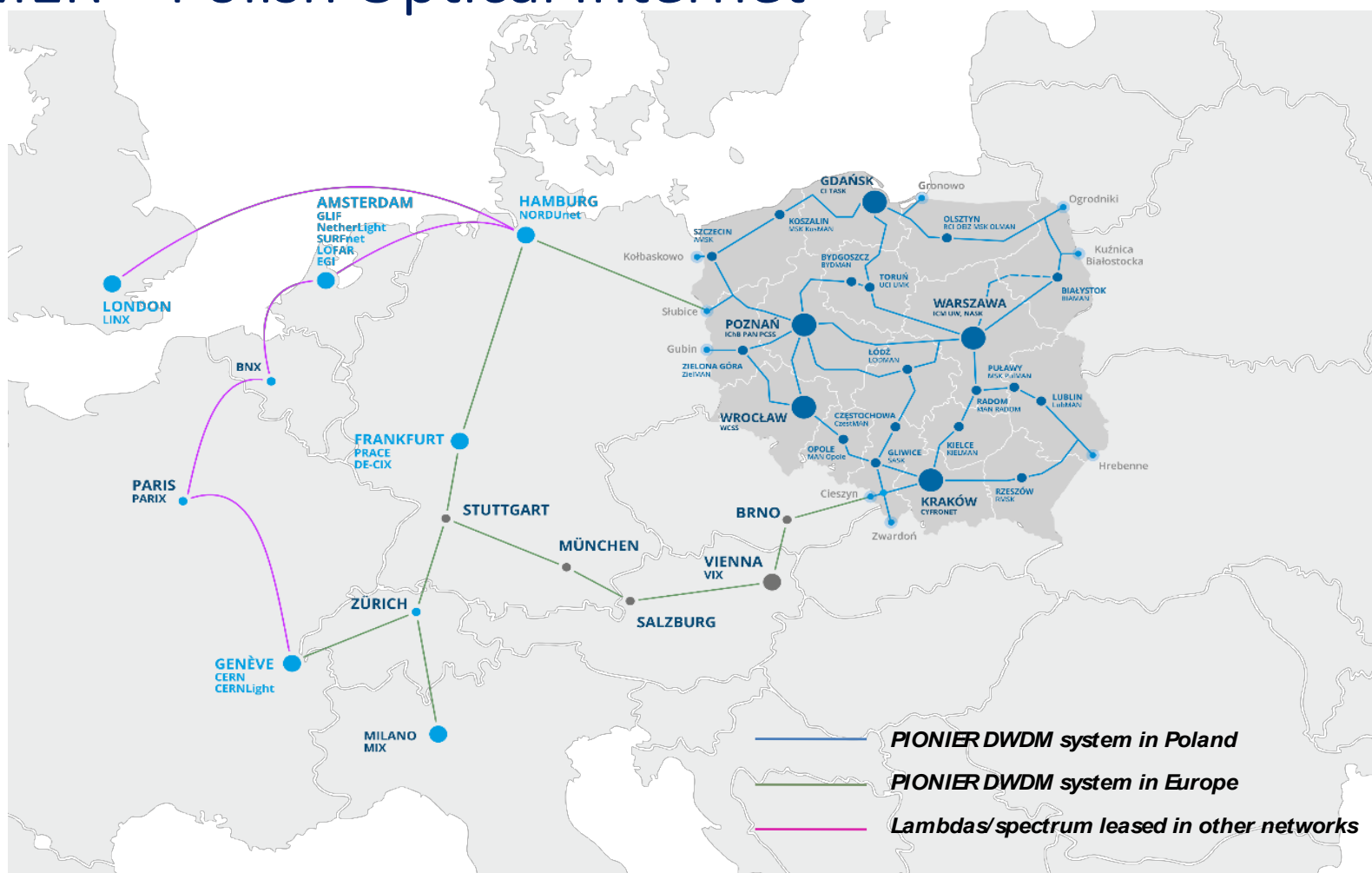
V4 seminar on
European Health Data Space
Brussels, 23rd November 2021

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

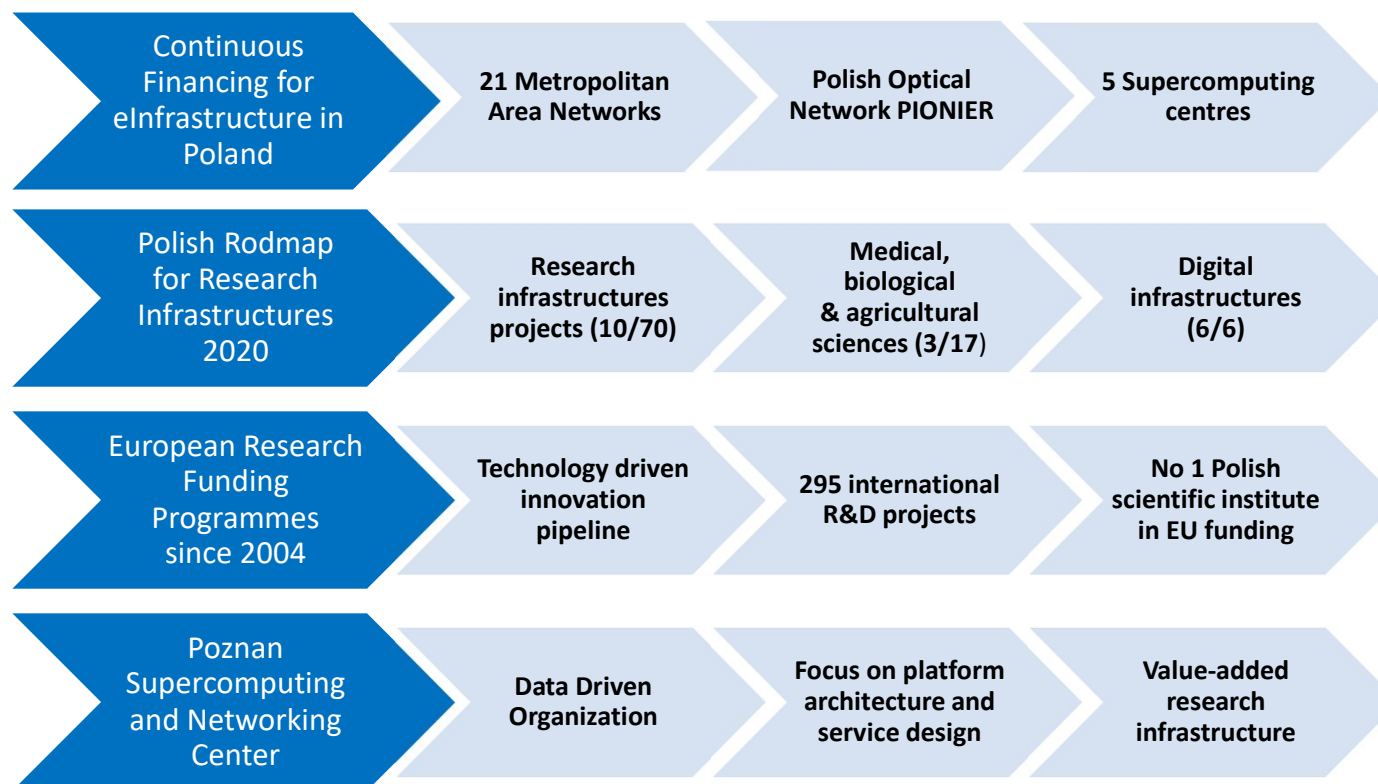


PIONIER – Polish Optical Internet



Focus on Digital Transformation based on advanced einfrastrucutre

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



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










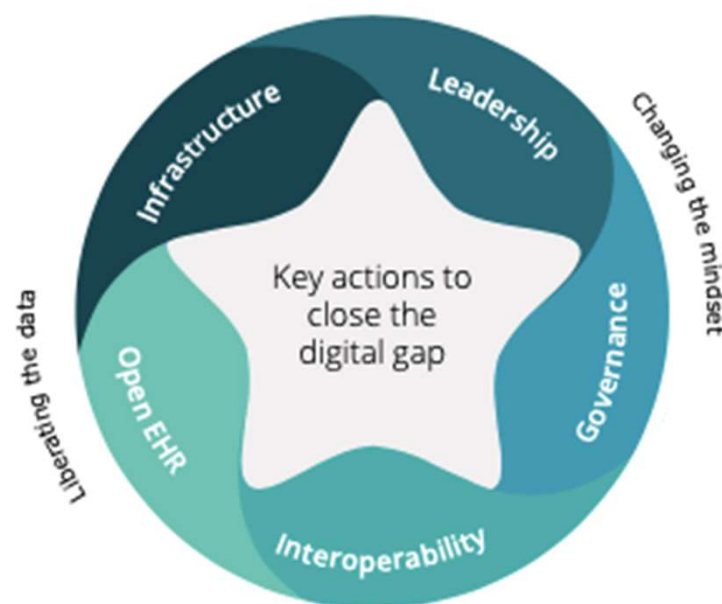
- 1  **Bureaucracy in healthcare (57.4%)**
- 2  **Cost of technology (50.3%)**
- 3  **Finding the right technologies (49.0%)**
- 4  **Training staff to adequately use technology (35.8%)**
- 5  **Complexity of technology (28.9%)**
- 6  **Challenges in sharing patient data (27.7%)**
- 7  **Convincing staff 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

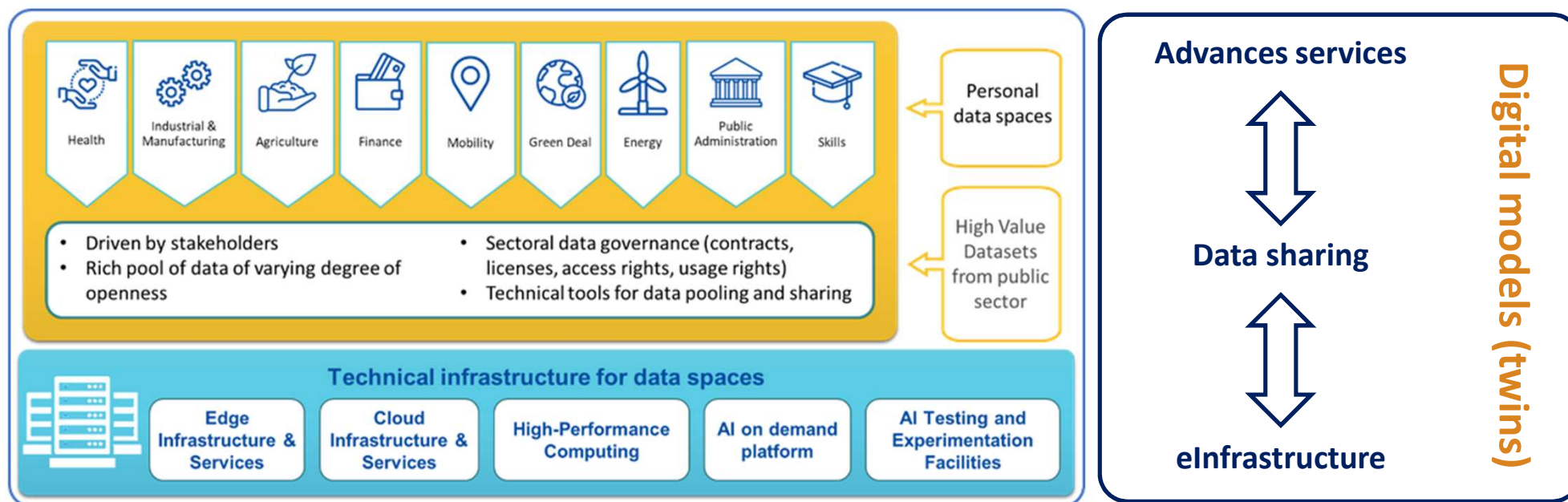


Source: Deloitte research and analysis, 2020

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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

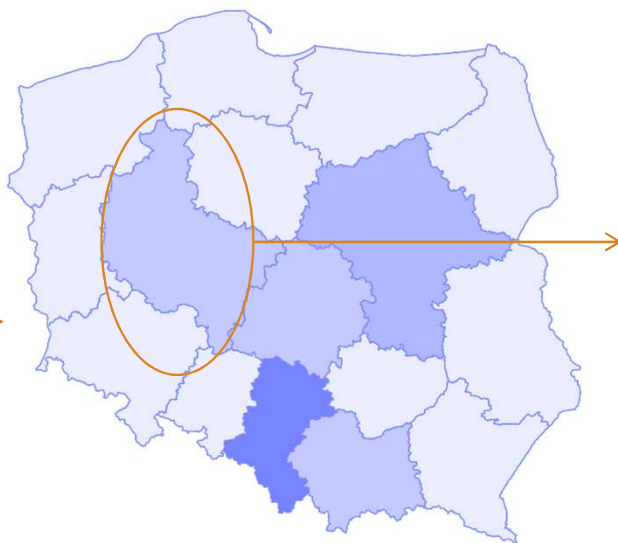
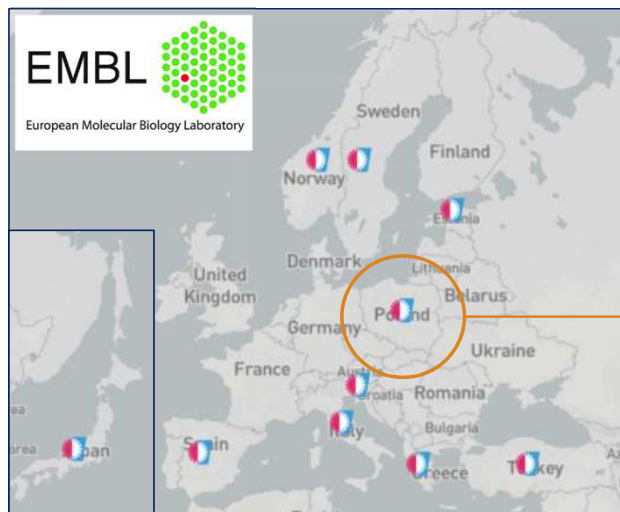


Data sharing at the times of pandemic

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



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



Co-funded by the Horizon 2020 programme of the European Union



Ministry of Science
and Higher Education
Republic of Poland



WIELKOPOLSKA
REGION



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European COVID-19 Data Platform

https://audiovisual.ec.europa.eu/en/video/I-189639

European Commission

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Statement by Ursula von der Leyen, President of the European Commission, on the launch of the EU COVID19 Data Platform (international sign language version)



20/04/2020

ID: I-189639

Type : Complete speech

Date: 20/04/2020

Location: Brussels - EC/Berlaymont

Tag: [Research and development](#), [Medical treatment](#), [Public health](#), [Data Protection](#), [Epidemic](#), [Crisis Management](#), [An economy that works for people](#), [Political priority VDL](#), [Coronavirus](#), [COVID-19](#)

Personalities: [Ursula von der Leyen](#)

Language: [International Sign](#)

Co-operators: Director: Stefan Fortemps

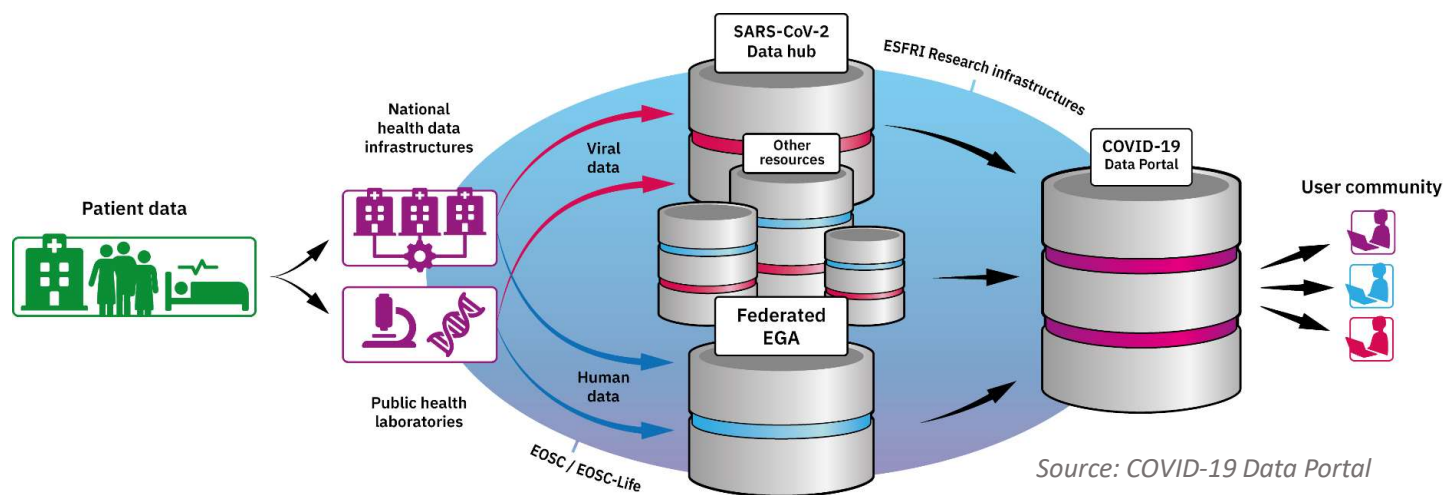
On 20 April 2020, Ursula von der Leyen, President of the European Commission, recorded a video message at the European Commission in Brussels, Belgium, on the launch of the EU COVID19 Data Platform.

- 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)



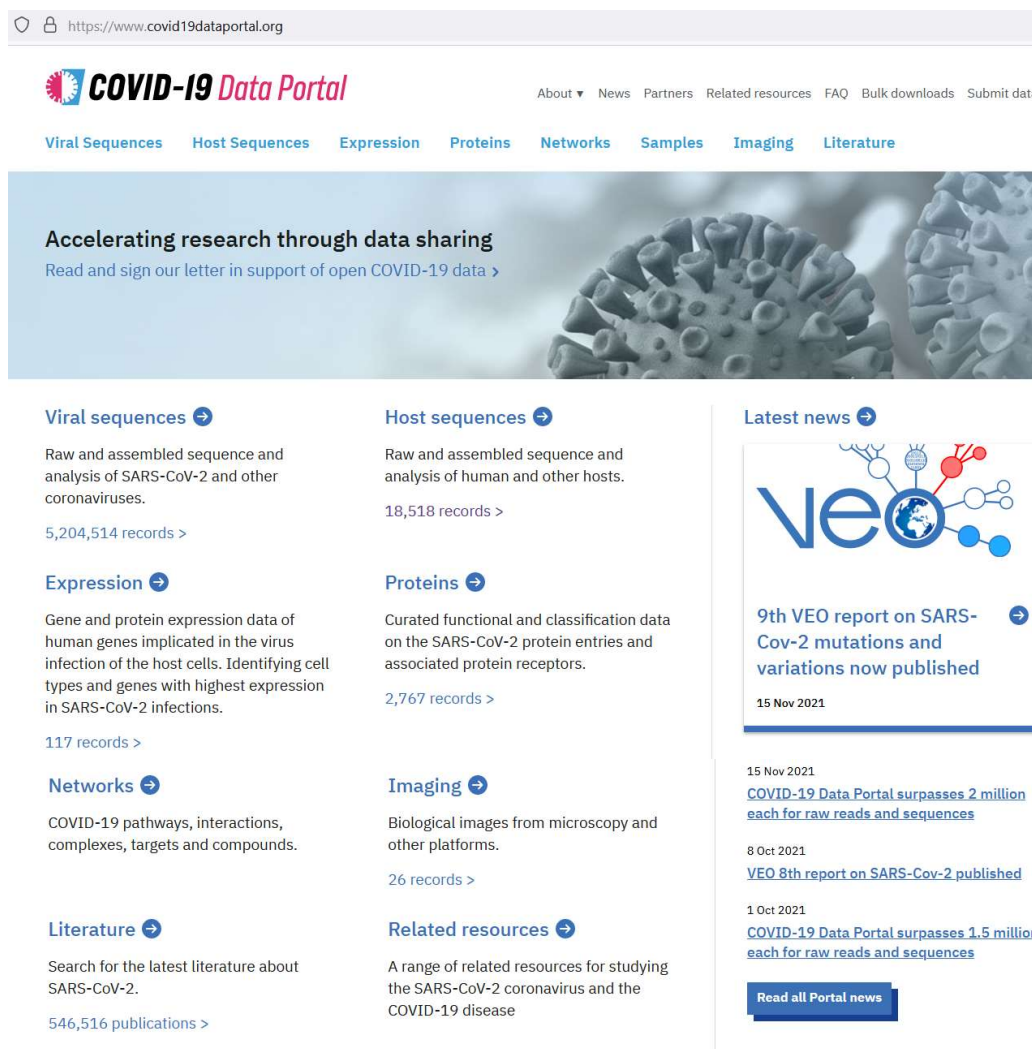
European COVID-19 Data Platform components

- **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



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)



The screenshot shows the COVID-19 Data Portal website. The header includes the URL <https://www.covid19dataportal.org> and the portal's logo. A navigation bar lists categories: Viral Sequences, Host Sequences, Expression, Proteins, Networks, Samples, Imaging, and Literature. A banner below the navigation bar reads "Accelerating research through data sharing" with a link to "Read and sign our letter in support of open COVID-19 data". The main content area is divided into two columns. The left column lists categories with their respective record counts: Viral sequences (5,204,514 records), Expression (117 records), Networks (COVID-19 pathways, interactions, complexes, targets and compounds), and Literature (546,516 publications). The right column lists categories with their respective record counts: Host sequences (18,518 records), Proteins (2,767 records), Imaging (26 records), and Related resources (A range of related resources for studying the SARS-CoV-2 coronavirus and the COVID-19 disease). A "Latest news" section on the right features a "9th VEO report on SARS-CoV-2 mutations and variations now published" dated 15 Nov 2021, and two other news items dated 15 Nov 2021 and 8 Oct 2021, both mentioning "COVID-19 Data Portal surpasses 2 million each for raw reads and sequences". A "Read all Portal news" button is located at the bottom of the news section.

<https://www.covid19dataportal.org>

COVID-19 Data Portal

About ▾ News Partners Related resources FAQ Bulk downloads Submit data

[Viral Sequences](#) [Host Sequences](#) [Expression](#) [Proteins](#) [Networks](#) [Samples](#) [Imaging](#) [Literature](#)

Accelerating research through data sharing
[Read and sign our letter in support of open COVID-19 data >](#)

Viral sequences →
Raw and assembled sequence and analysis of SARS-CoV-2 and other coronaviruses.
[5,204,514 records >](#)

Expression →
Gene and protein expression data of human genes implicated in the virus infection of the host cells. Identifying cell types and genes with highest expression in SARS-CoV-2 infections.
[117 records >](#)

Networks →
COVID-19 pathways, interactions, complexes, targets and compounds.

Literature →
Search for the latest literature about SARS-CoV-2.
[546,516 publications >](#)

Host sequences →
Raw and assembled sequence and analysis of human and other hosts.
[18,518 records >](#)

Proteins →
Curated functional and classification data on the SARS-CoV-2 protein entries and associated protein receptors.
[2,767 records >](#)

Imaging →
Biological images from microscopy and other platforms.
[26 records >](#)

Related resources →
A range of related resources for studying the SARS-CoV-2 coronavirus and the COVID-19 disease

Latest news →

9th VEO report on SARS-CoV-2 mutations and variations now published →
15 Nov 2021

15 Nov 2021
[COVID-19 Data Portal surpasses 2 million each for raw reads and sequences](#)

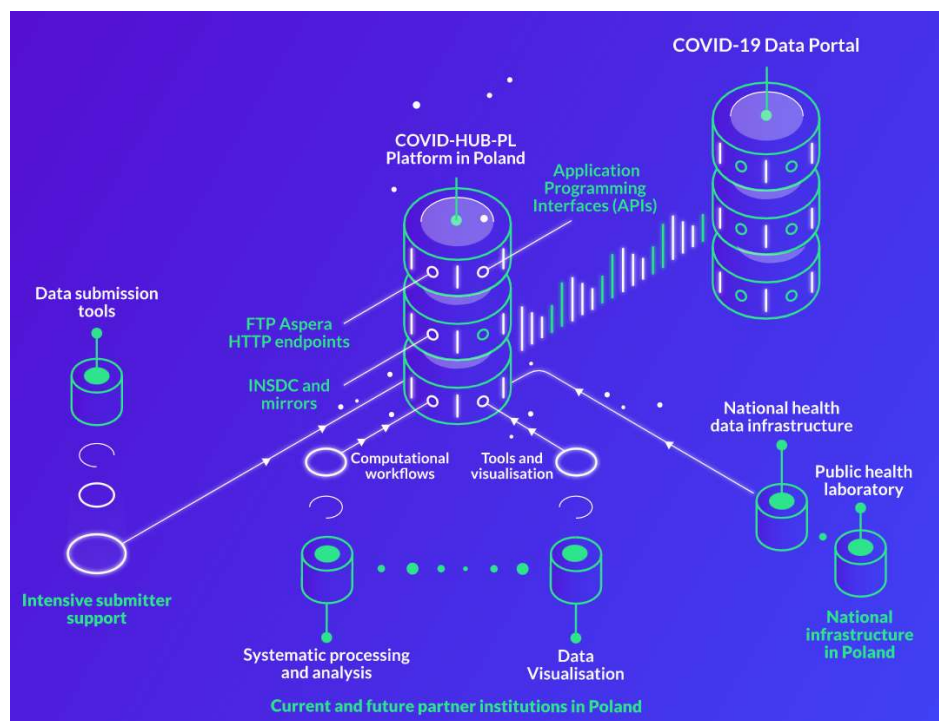
8 Oct 2021
[VEO 8th report on SARS-CoV-2 published](#)

1 Oct 2021
[COVID-19 Data Portal surpasses 1.5 million each for raw reads and sequences](#)

[Read all Portal news](#)

National COVID-19 data hub and research platform

COVID-HUB-PL



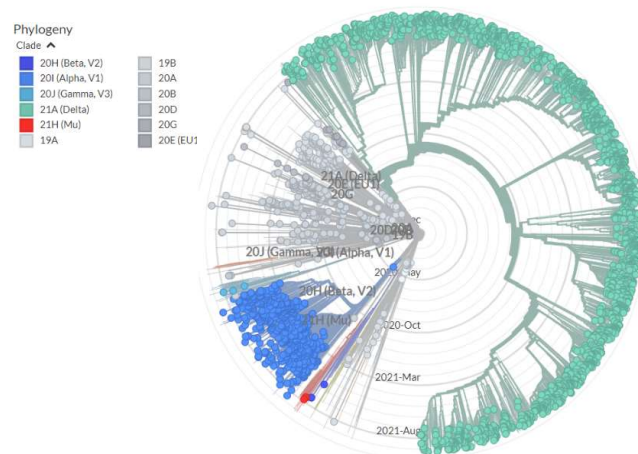
<https://covidhub.psnk.pl/eng/>

- 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



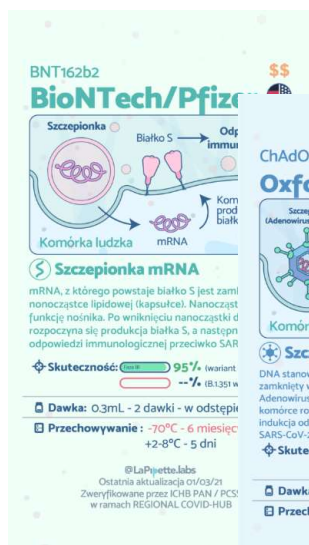
- Genomic data analysis
- Genome visualization based on a dedicated Nextstrain instance
<https://nextstrain.covidhub.psnc.pl/ncov/poland>
- Other tools, e.g.: automatic analysis of medical imaging data using AI/MLs, support tools for remote access to SARS-CoV-2 reference databases in Poland, Europe and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



COVID-HUB-PL for the general public



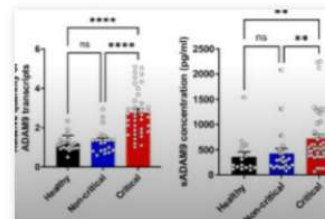
- Aggregated and relevant news regarding COVID-19 and R&D activities in Poland
- Raising public awareness of science and disseminating knowledge
- COVID-19 dashboard



New drugs to treat COVID-19 approved by EMA

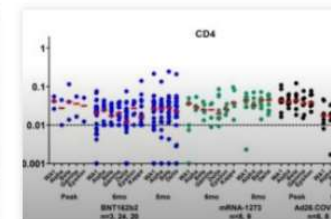
The European Medicines Agency (EMA) has approved two monoclonal antibodies, Regkirona (regdanvimab) and Ronapeve (casirivimab / imdevimab), as biological drugs in the fight against COVID-19.

[READ MORE](#)



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

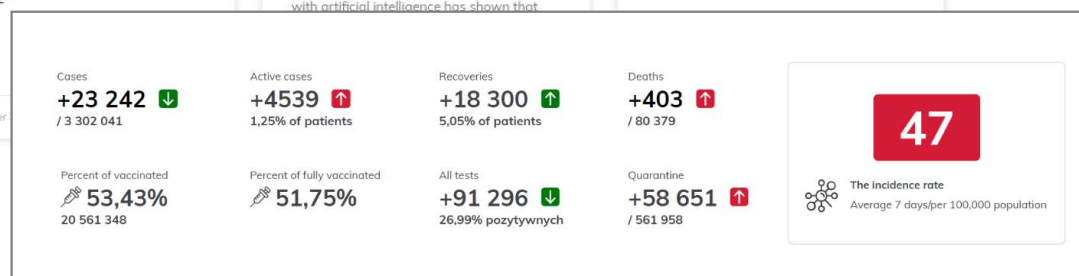
Research using multi-omics analysis (whole genome sequencing, RNA sequencing, proteomics, cytokine profiling and high-throughput immunophenotyping) combined with artificial intelligence has shown that



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

18 November

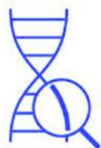


REGIONAL SARS-CoV-2 DATA & e-SERVICES PORTAL



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.

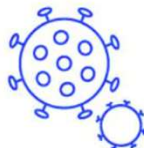
Research
institutions



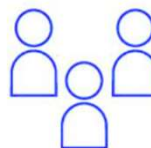
Hospitals



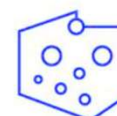
Sanitary-
epidemiological
Stations



Society



Local
authorities



Project duration: 2020.07.01 – 2022.06.30



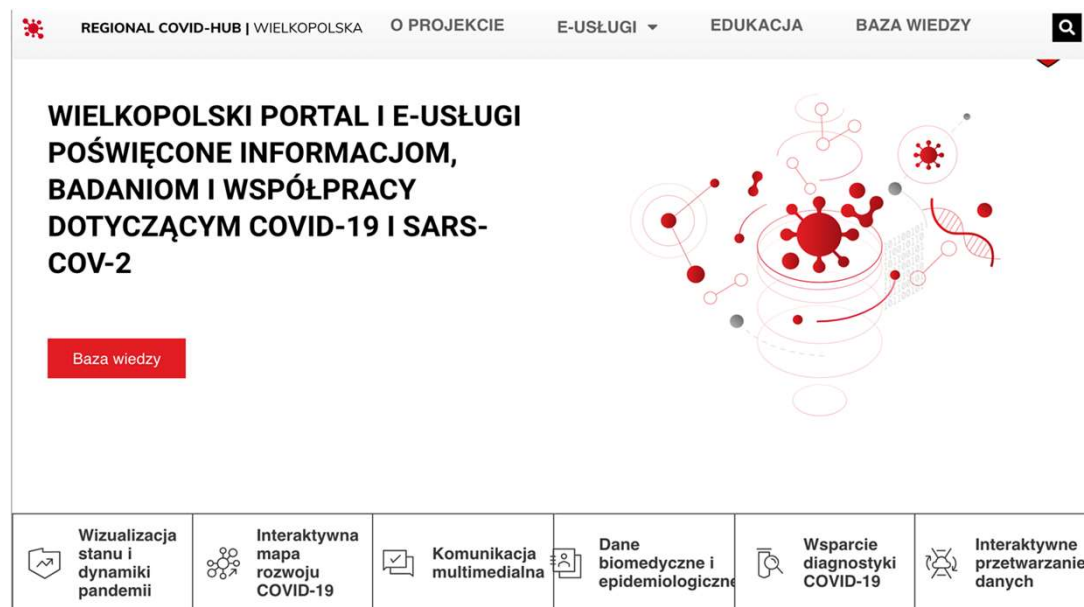
Republic
of Poland



EUROPEAN UNION
European Regional Development Fund

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**.



Conclusions – 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 number of records** to avoid imbalances between number 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

6th European Laryngological Live Surgery Broadcast
24th November 2021 | 9.00 16.00 (GMT+1)

Save the date

els.livesurgery.net





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