



A4L_BRIDGE

Alliance4Life Bridging the Research and Innovation Gap in Life Sciences

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D10.1 - Maps of Data Potential

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1 INTRODUCTION

The deliverable D10.1 – Maps of Data Potential summarizes the first key activity within Work Package 10 (WP10) of the Alliance4Life BRIDGE project, focused on unlocking the data potential across participating institutions. The deliverable is based on two primary sources:

- The strategic outline and expectations formulated during the WP10 Focus Group meeting in Ljubljana, Slovenia (February 2025), and
- An initial online survey conducted in March–May 2025, gathering institutional insights on data practices, challenges, and sharing policies.

This document presents the outcomes of this mapping effort, offering a comprehensive view of data types, usage, sharing mechanisms, barriers, and institutional priorities. It provides a foundation for follow-up activities, including capacity building, data harmonization, and collaborative data projects within the consortium.

The overall aim of WP10 is to improve the accessibility, interoperability, and value generation of health- and research-related data, aligning with the FAIR principles and ensuring long-term sustainability and collaboration across the Alliance4Life network.

2 EXECUTIVE SUMMARY

This report presents the outcomes of the data mapping exercise carried out under WP10 – "Unlocking Data Potential" of the Alliance4Life BRIDGE project. The primary objective of this activity was to collect and analyze information about the types of data used across institutions, identify existing barriers to data-driven research, and outline opportunities for collaboration and capacity building.

The survey was completed by eight member institutions representing various biomedical research and clinical domains. Key findings include:

- **Diversity of data use:** Institutions work with a broad range of data types – from clinical and laboratory data to omics, imaging, and epidemiological datasets.
- **Common barriers:** Legal and ethical limitations (especially GDPR compliance), lack of internal support structures (e.g., data stewards), data quality issues, and infrastructural fragmentation.
- **Data sharing practices:** While most institutions share data with partners, only a minority engage in open data practices. Technical and legal constraints persist.
- **High potential areas:** Genomic data infrastructure, predictive modeling using clinical and omics data, and AI-based health record analysis.

This deliverable forms the baseline for further actions in WP10, particularly the development of training activities, identification of high-potential joint data projects, and advancement of FAIR data practices.

3 METHODOLOGY

The mapping activity was conducted via an online survey hosted on FNUSA-ICRC's REDCap platform. The survey was distributed to institutional representatives in early 2025 and closed in March 2025.

The survey covered the following areas:

- Types and categories of data used.
- Tools and methods for data acquisition and processing.
- Challenges in managing and analyzing large-scale data.
- Internal and external data sharing practices.
- Access to clinical data and its secondary use.
- Current institutional data projects.

A total of **8 institutions** completed the survey. Responses were aggregated and analyzed both quantitatively (e.g., frequency of data sharing) and qualitatively (e.g., thematic analysis of implementation challenges). The survey was not limited to one response per institution. In one case (University of Ljubljana), two responses were received from different departments within the same institution, which provided a more nuanced insight into internal diversity in data use and management.

4 INSTITUTIONAL LANDSCAPE

The participating institutions represent a wide spectrum of biomedical research and clinical care:

- **University of Ljubljana** (Faculty of Medicine, Immunology and Microbiology department): Clinical and microbial genomic data, prediction of viral evolution.
- **University of Zagreb**: Retrospective data analysis.
- **Medical University of Lodz**: Clinical hospital partnerships for data projects.
- **Vilnius University**: Biomarkers and stratification.
- **FNUSA-ICRC**: Development of the “Patient Finder” EHR database.
- **Medical University – Sofia**: Participation in the EU Genomic Data Infrastructure.
- **Latvian Institute of Organic Synthesis**: Non-clinical data (project not relevant for data sharing).
- **University of Ljubljana** (Faculty of Medicine, Pathophysiology department): Additional basic medical data projects.

4.1 TYPES OF DATA USED

Institutions across the Alliance4Life consortium engage with a variety of data types, reflecting the complexity and diversity of their research areas. The most commonly used data types include:

- Clinical data, such as electronic health records (EHRs), physiological measurements, and laboratory results, form the backbone of many translational and clinical research initiatives.
- Genomic and omics data, including DNA, RNA, and proteomic profiles, are increasingly used in precision medicine, diagnostics, and biomarker discovery.
- Epidemiological and field-collected data are essential for public health surveillance and modeling of disease trends.
- Imaging and histopathological data are applied in diagnostic support, outcome prediction, and machine learning-driven analyses.

4.2 DATA SHARING PRACTICES

Data sharing plays a crucial role in collaborative research, but practices and levels of openness vary across institutions. According to the survey results:

- Six out of eight institutions reported that they engage in data sharing with external partners, typically through formal collaborations or joint research projects.
- Only two institutions indicated that they openly share data, for example, via public repositories or shared research infrastructures.
- Data sharing is primarily implemented through direct bilateral partnerships, specific project agreements, or institutional memoranda of understanding.

4.3 ACCESS TO EXTERNAL DATA

While sharing data is relatively common, accessing external data poses a more significant challenge. From the responses:

- Only two institutions confirmed that they have regular access to clinical data from outside sources.
- This limited access is often attributed to a lack of formal agreements, concerns over data privacy, and the absence of interoperable technical frameworks.

5 IDENTIFIED CHALLENGES

5.1 LEGAL AND ETHICAL BARRIERS

One of the most frequently cited challenges involves navigating the complex legal and ethical landscape of data sharing. Specifically:

- The General Data Protection Regulation (GDPR) and related national laws pose hurdles to cross-border data sharing and re-use, especially when personal health data is involved.
- Institutional policies are often unclear or inconsistent, making it difficult for research teams to understand what is permissible.
- The lack of legal support or pre-defined templates for data-sharing agreements further slows down collaborative initiatives.

5.2 TECHNICAL AND INFRASTRUCTURAL LIMITATIONS

From a technical perspective, institutions struggle with the fragmented nature of data systems and resources. Key concerns include:

- A lack of standardized formats and metadata hampers interoperability and efficient data integration.
- There is a widespread absence of dedicated data stewards or technical staff to oversee data management and quality assurance.
- Storage capacity, data security frameworks, and user access protocols vary significantly across institutions, limiting scalability.

5.3 ORGANIZATIONAL ISSUES

Several organizational-level issues also emerged from the analysis. These include:

- Limited administrative and IT support for research teams working with large or sensitive data sets.
- Constraints on available funding and human resources, often preventing the establishment of sustainable data infrastructures.
- Low institutional awareness of the importance of FAIR data principles (Findable, Accessible, Interoperable, Reusable) among both researchers and decision-makers.

6 OPPORTUNITIES AND RECOMMENDATIONS

Despite these challenges, the survey responses and group discussions highlighted clear areas of opportunity and strategic direction for WP10. These include both immediate needs and longer-term goals:

6.1 COMMON NEEDS ACROSS INSTITUTIONS

There is a shared recognition among Alliance4Life partners regarding the foundational elements needed to improve data potential:

- Harmonizing data formats, structures, and documentation is seen as a critical first step toward broader interoperability.
- Many institutions would benefit from legal tools such as standardized GDPR-compliant data sharing agreements or internal policy templates.
- There is a growing demand for training in data stewardship, responsible data use, and ethical principles to build internal capacity and promote good data governance.

This effort aligns with similar initiatives undertaken by other projects and initiatives, including those within the European Health Data Space (EHDS) and the European Open Science Cloud (EOSC), which aim to facilitate secure and standardized health data sharing across borders and disciplines.

6.2 STRATEGIC ACTIONS FOR WP10

In response to the mapping exercise, WP10 can address these needs through coordinated actions and initiatives, such as:

- Organizing targeted training events, including a dedicated “Data Summer School,” led by Semmelweis University, to enhance skills in data management and FAIR principles.
- Publishing a collection of short abstracts that showcase ongoing or planned “data projects” at participating institutions.
- Establishing an online dashboard where institutions can share information about their data assets, technical tools, and research partnerships.
- Supporting the development of institutional policies that explicitly allow for the responsible secondary use of clinical and research data, thereby fostering an enabling environment for data reuse.

7 ANNEXES

7.1 SURVEY INSTRUMENT

Link for survey:

<https://redcap.fnusa.cz/redcap/surveys/?s=CHDYXXY7RRKK9KX3>



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WP10 - Unlocking data potential Initial Survey Questions

Identifying Challenges in Data-Driven Projects, Especially Big Data

Institution

Contact person

Contact e-mail

General Data Agenda Overview

1. What categories of data does your organization most frequently use for research?

- ☐ Primary patient data
- ☐ Other pseudonymized clinical data
- ☐ Anonymized clinical data
- ☐ Imaging data (MRI, CT, RTG etc.)
- ☐ Signaling data (ECG etc.)
- ☐ Omics data
- ☐ Preclinical data
- ☐ Other biometric
- ☐ Other

2. What types of data does your organization most frequently use for research?

- ☐ Structured data (tables, databases)
 - ☐ Unstructured data (texts, images, audio)
 - ☐ Time series data (sensors, logs)
 - ☐ Other
-

3. What methods and tools do you use for data acquisition and processing?

- ☐ Automated tools for data collection
 - ☐ Manual paper data collecting
 - ☐ Manual electronic data collecting
 - ☐ Software for data analysis and visualization (BI tools, AI tools, etc.)
 - ☐ Other
-

4. What are the main obstacles you face when implementing projects based on collecting and analyzing large data sets (Big Data)?

- ☐ Insufficient infrastructure (server performance, storage, etc.)
- ☐ Lack of specialists (data analysts, engineers)
- ☐ Complexity of integrating data from different sources
- ☐ Legal or ethical barriers
- ☐ Other

5. What prevents you from fully utilizing the potential of data?

- ☐ Legal or methodological barriers (for example internal approval procedure)
- ☐ Lack of suitable tools for data analysis
- ☐ Lack of qualified personal
- ☐ Insufficient competencies or training focused on data
- ☐ Data quality issues (errors, incompleteness)
- ☐ Lack of support from management or budget
- ☐ Other

6. Do you share data with other institutions?

- ☐ Yes
- ☐ No

[reset](#)**7. Do you share your data openly?**

- ☐ Yes
- ☐ No

[reset](#)**Accessing and Using Clinical Data****8. Does your organization allow using clinical data for secondary usage?**

- ☐ Yes - *Internal policies exist for data management and Informed consents applied*
- ☐ No - *Encounter legal or ethical obstacles*
- ☐ Not relevant

[reset](#)**9. Do you share clinical data with other institutions?**

- ☐ Yes
- ☐ No
- ☐ Not relevant

[reset](#)**10. Can you access health or clinical data from other institutions?**

- ☐ Yes
- ☐ No
- ☐ Not relevant

[reset](#)

11. Can you describe your current data projects and the challenges you face in implementing them?

Criteria	Description
Project Type (e.g., data analysis, trend prediction, data cleaning)	<div></div> <div>Expand</div>
Project Objective	<div></div> <div>Expand</div>
Main Implementation Challenges	<div></div> <div>Expand</div>
Types of Data Used	<div></div> <div>Expand</div>
Specific Technologies	<div></div> <div>Expand</div>

Submit

7.2 SUMMARY SLIDES

Alliance4Life

WP10 - Unlocking data potential

Identifying Challenges in Data-Driven Projects, Especially Big Data

Evaluation of Initial Online Survey (FNUSA-ICRC REDCap)
April/May 2025



Alliance4Life Basic information

Eight institutions:

- Institute of Microbiology and Immunology, Faculty of Medicine, University of Ljubljana
- University of Zagreb, School of Medicine
- Medical University of Lodz
- Vilnius University
- Institute for pathological physiology, Medical Faculty, University of Ljubljana
- St. Anne's University Hospital Brno, International Clinical Research Center (FNUSA-ICRC)
- Medical University – Sofia
- Latvian Institute of Organic Synthesis

12.5.2025

2



General Data Agenda Overview

12.5.2025

3



1. What categories of data does your organization most frequently use for research?

Categories of data	Ljubljana Uni., M.I.	Zagreb Uni.	Lodz Uni.	Vilnius Uni.	Ljubljana Uni., P.P.	FNUSA-ICRC	Sofia Uni.	Latvian Ins.	Overall; N (%)
Primary patient data	✓	✓	✓	✓		✓	✓		6 (75%)
Other pseudonymized clinical data		✓	✓	✓		✓	✓		5 (62.5%)
Anonymized clinical data	✓	✓	✓	✓					4 (50%)
Imaging data (MRI, CT, RTG etc.)		✓	✓	✓		✓	✓		5 (62.5%)
Signaling data (ECG etc.)			✓	✓		✓			3 (37.5%)
Omics data	✓		✓	✓			✓		4 (50%)
Preclinical data			✓	✓	✓	✓	✓	✓	6 (75%)
Other biometric							✓		1 (12.5%)
Sequencing data	✓								1 (12.5%)

12.5.2025

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Alliance4Life 2. What types of data does your organization most frequently use for research?

Types of data	Ljubljana Uni., M.I.	Zagreb Uni.	Lodz Uni.	Vilnius Uni.	Ljubljana Uni., P.P.	FNUSA-ICRC	Sofia Uni.	Latvian Ins.	Overall; N (%)
Structured data (tables, databases)	✓	✓	✓	✓		✓	✓	✓	7 (87.5%)
Unstructured data (texts, images, audio)			✓	✓	✓	✓	✓		5 (62.5%)
Time series data (sensors, logs)			✓	✓	✓				3 (37.5%)
Other									0 (0%)

12.5.2025

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Alliance4Life 3. What methods and tools do you use for data acquisition and processing?

Methods and tools	Ljubljana Uni., M.I.	Zagreb Uni.	Lodz Uni.	Vilnius Uni.	Ljubljana Uni., P.P.	FNUSA-ICRC	Sofia Uni.	Latvian Ins.	Overall; N (%)
Automated tools for data collection	✓			✓			✓		3 (37.5%)
Manual paper data collecting	✓	✓	✓	✓		✓			5 (62.5%)
Manual electronic data collecting	✓	✓	✓	✓		✓	✓		6 (75%)
Software for data analysis and visualization (BI tools, AI tools, etc.)	✓			✓	✓		✓	✓	5 (62.5%)
Other									0 (0%)

12.5.2025

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Alliance4Life 4. What are the main obstacles you face when implementing projects based on collecting and analyzing large data sets (Big Data)?

Main obstacles	Ljubljana Uni., M.I.	Zagreb Uni.	Lodz Uni.	Vilnius Uni.	Ljubljana Uni., P.P.	FNUSA-ICRC	Sofia Uni.	Latvian Ins.	Overall; N (%)
Insufficient infrastructure (server performance, storage, etc.)		✓	✓	✓					3 (37.5%)
Lack of specialists (data analysts, engineers)	✓	✓	✓	✓	✓		✓	✓	7 (87.5%)
Complexity of integrating data from different sources	✓	✓		✓		✓	✓		5 (62.5%)
Legal or ethical barriers	✓	✓	✓	✓			✓		5 (62.5%)
Other									0 (0%)

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Alliance4Life 5. What prevents you from fully utilizing the potential of data?

Types of barriers	Ljubljana Uni., M.I.	Zagreb Uni.	Lodz Uni.	Vilnius Uni.	Ljubljana Uni., P.P.	FNUSA-ICRC	Sofia Uni.	Latvian Ins.	Overall; N (%)
Legal or methodological barriers (for example internal approval procedure)	✓	✓	✓			✓			4 (50%)
Lack of suitable tools for data analysis		✓	✓						2 (25%)
Lack of qualified personal		✓					✓	✓	3 (37.5%)
Insufficient competencies or training focused on data	✓	✓		✓	✓		✓		5 (62.5%)
Data quality issues (errors, incompleteness)		✓		✓		✓			3 (37.5%)
Lack of support from management or budget		✓	✓				✓	✓	4 (50%)
Other									0 (0%)

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Alliance4Life 6. Do you share data with other institutions?

Data sharing	Ljubljana Uni., M.I.	Zagreb Uni.	Lodz Uni.	Vilnius Uni.	Ljubljana Uni., P.P.	FNUSA-ICRC	Sofia Uni.	Latvian Ins.	Overall; N (%)
Yes	✓	✓	✓	✓		✓		✓	6 (75%)
No					✓		✓		2 (25%)

- For institutions that share data (N = 6), 3 additional questions have been included (with summary on the following slides)
 - What categories of data does your organization most frequently share?
 - How do you share the data with other institutions?
 - Which hospital/s are you working with on data projects?

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Alliance4Life 6. Do you share data with other institutions? → Yes (N = 6)

- What categories of data does your organization most frequently share?

Categories of data	Ljubljana Uni., M.I.	Zagreb Uni.	Lodz Uni.	Vilnius Uni.	FNUSA-ICRC	Latvian Ins.	Overall; N (%)
Primary patient data							0 (0%)
Other pseudonymized clinical data		✓			✓		2 (33.3%)
Anonymized clinical data		✓	✓	✓	✓		4 (66.7%)
Imaging data (MRI, CT, RTG etc.)							0 (0%)
Signaling data (ECG etc.)							0 (0%)
Omics data				✓			1 (16.7%)
Preclinical data					✓	✓	2 (33.3%)
Other biometric							0 (0%)
Other (not specified)	✓	✓					2 (33.3%)

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Alliance4Life 6. Do you share data with other institutions? → Yes (N = 6)

- How do you share the data with other institutions?

Data sharing method	Ljubljana Uni., M.I.	Zagreb Uni.	Lodz Uni.	Vilnius Uni.	FNUSA-ICRC	Latvian Ins.	Overall; N (%)
Online data sharing platforms		✓	✓			✓	3 (50%)
Removable storage media	✓				✓		2 (33.3%)
Peer-to-peer networks							0 (0%)
Cloud Database management platforms		✓	✓	✓	✓	✓	5 (83.3%)
Other							0 (0%)

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Alliance4Life 6. Do you share data with other institutions? → Yes (N = 6)

- Which hospital/s are you working with on data projects?
 - Ljubljana Uni., M.I.:** University Medical Centre Ljubljana
 - Zagreb Uni.:** Hospitals affiliated to the University of Zagreb School of Medicine
 - Lodz Uni.:** Clinical hospital of MUL
 - Vilnius Uni.:** Specialists have a number of personal projects; hospitals/clinical centers also pursue strategic partnerships with other European clinical and research centers
 - FNUSA-ICRC:** Faculty Hospital Brno, Masaryk Memorial Cancer Institute, Motol University Hospital, CEITEC Masaryk University, Faculty of Medicine Masaryk University
 - Latvian Ins.:** "not relevant"

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Alliance4Life 7. Do you share your data openly?

Open data sharing	Ljubljana Uni., M.I.	Zagreb Uni.	Lodz Uni.	Vilnius Uni.	Ljubljana Uni., P.P.	FNUSA-ICRC	Sofia Uni.	Latvian Ins.	Overall; N (%)
Yes			✓					✓	2 (25%)
No	✓	✓		✓	✓	✓	✓		6 (75%)

- For institutions that share data openly (N = 2), 1 additional question have been included (with summary below)

- Where do you share it?

Repository	Lodz Uni.	Latvian Ins.	Overall; N (%)
Disciplinary repositories	✓	✓	2 (100%)
Institutional repositories	✓		1 (50%)
Own database			0 (0%)
Other (Zenodo)	✓		1 (50%)

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Accessing and Using Clinical Data

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Alliance4Life 8. Does your organization allow using clinical data for secondary usage?

Using clinical data for sec. usage	Ljubljana Uni., M.I.	Zagreb Uni.	Lodz Uni.	Vilnius Uni.	Ljubljana Uni., P.P.	FNUSA-ICRC	Sofia Uni.	Latvian Ins.	Overall; N (%)
Yes - Internal policies exist for data management and informed consents applied				✓		✓	✓		3 (37.5%)
No - Encounter legal or ethical obstacles		✓	✓*						2 (25%)
Not relevant	✓				✓			✓	3 (37.5%)

- * Comment: „Depends on project, in general we do not have knowledge about sharing practices of different research teams.“

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Alliance4Life 9. Do you share clinical data with other institutions?

Data share with other institutions	Ljubljana Uni., M.I.	Zagreb Uni.	Lodz Uni.	Vilnius Uni.	Ljubljana Uni., P.P.	FNUSA-ICRC	Sofia Uni.	Latvian Ins.	Overall; N (%)
Yes			✓	✓		✓			3 (37.5%)
No	✓	✓					✓		3 (37.5%)
Not relevant					✓			✓	2 (25%)

- For institutions that share clinical data with other institutions (N = 3), 1 additional question have been included (with summary below)
 - What type of data do you share?

Type of data	Lodz Uni.	Vilnius Uni.	FNUSA-ICRC	Overall; N (%)
Anonymized	✓	✓		2 (66.7%)
Pseudonymized			✓	1 (33.3%)
Raw				0 (0%)

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Alliance4Life 10. Can you access health or clinical data from other institutions?

Access data from other institutions	Ljubljana Uni., M.I.	Zagreb Uni.	Lodz Uni.	Vilnius Uni.	Ljubljana Uni., P.P.	FNUSA-ICRC	Sofia Uni.	Latvian Ins.	Overall; N (%)
Yes				✓		✓			2 (25%)
No	✓	✓					✓		3 (37.5%)
Not relevant			✓		✓			✓	3 (37.5%)

- For institutions that can access data from other institutions (N = 2), 1 additional question have been included (with summary below)
 - What type of data can you access?

Type of data	Vilnius Uni.	FNUSA-ICRC	Overall; N (%)
Anonymized	✓		1 (50%)
Pseudonymized		✓	1 (50%)
Raw			0 (0%)

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Current data projects and the challenges in implementing them

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Alliance4Life Institute of Microbiology and Immunology, Faculty of Medicine,
University of Ljubljana

- **Project Type:** Clinical and microbial genomic data analysis, antimicrobial resistance data analysis, Modeling of vector-borne diseases, Prediction of viral evolution, reinfections
- **Project Objective:** Prediction of outbreaks, Understanding microbial pathogenesis and impact on clinical outcome, Understanding viral evolution, Determining virulence
- **Main Implementation Challenges:** Complexity of integrating data from different sources, Data quality issues (errors, incompleteness), Lack of support from management or budget, Legal barriers
- **Types of Data Used:** Primary patient data, Clinical data, Microbial genomic/omic data, Presence/absence data from field, Epidemiological data

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Alliance4Life University of Zagreb, School of Medicine

- **Project Type:** Text analysis, data cleaning and preparation; Most of the projects are retrospective analyses of data
- **Project Objective:** CAST ELISA to drug allergies negative predictive value
- **Main Implementation Challenges:** Kit cost, data retrieval and analysis
- **Types of Data Used:** Lab data, clinical data and text analysis
- **Specific Technologies:** R programming language data analysis

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Alliance4Life Vilnius University

- **Project Objective:** Predictive biomarkers, patient stratification for specific clinical objectives, early therapeutic potential scoping out
- **Main Implementation Challenges:** Data compatibility, specialist and personnel requirements, streamlining cross-institution partnerships
- **Types of Data Used:** Omics, clinical/physiological readouts
- **Specific Technologies:** Multiple to support omics, clinical data collection (e.g., imaging), histopathology and other evidence collection

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**Alliance4Life FNUSA-ICRC**

- **Project Type: Patient Finder** – Creating the accessible Electronic Health Record (EHR) database for research
- **Project Objective:** Get the ability to read and analyze the current and historic data in Hospital Information System and allow electronic search (almost 1,7 million EHR)
- **Main Implementation Challenges:** Legal and Data protection discussion, Hardware installation, Data mapping, Annotation
- **Types of Data Used:** Electronic Health Record
- **Specific Technologies:** Artificial Intelligence – Natural Language Processing

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Alliance4Life Medical University – Sofia

- **Project Type:** Genomic Data Infrastructure (GDI), Grant agreement no: 101081813, European Union's Digital Europe Programme
- **Specific Technologies:** Secure federated infrastructure and data governance needed to enable sustainable and secure cross border linkage of genomic data sets in compliance with the relevant and agreed legal, ethical, quality and interoperability requirements and standards

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