



# The value of data: ODI-C4IR Roundtable

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December 2023

**Serbia**  
Centre for the  
Fourth Industrial  
Revolution

Open Data Institute

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## About

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# Executive summary

*In Serbia, health data presents a tremendous opportunity for advancing healthcare outcomes, medical research and public health initiatives. Recognising the significance of data sharing is paramount, as it not only contributes to the individualised care of patients but also holds immense potential for broader societal benefits.*

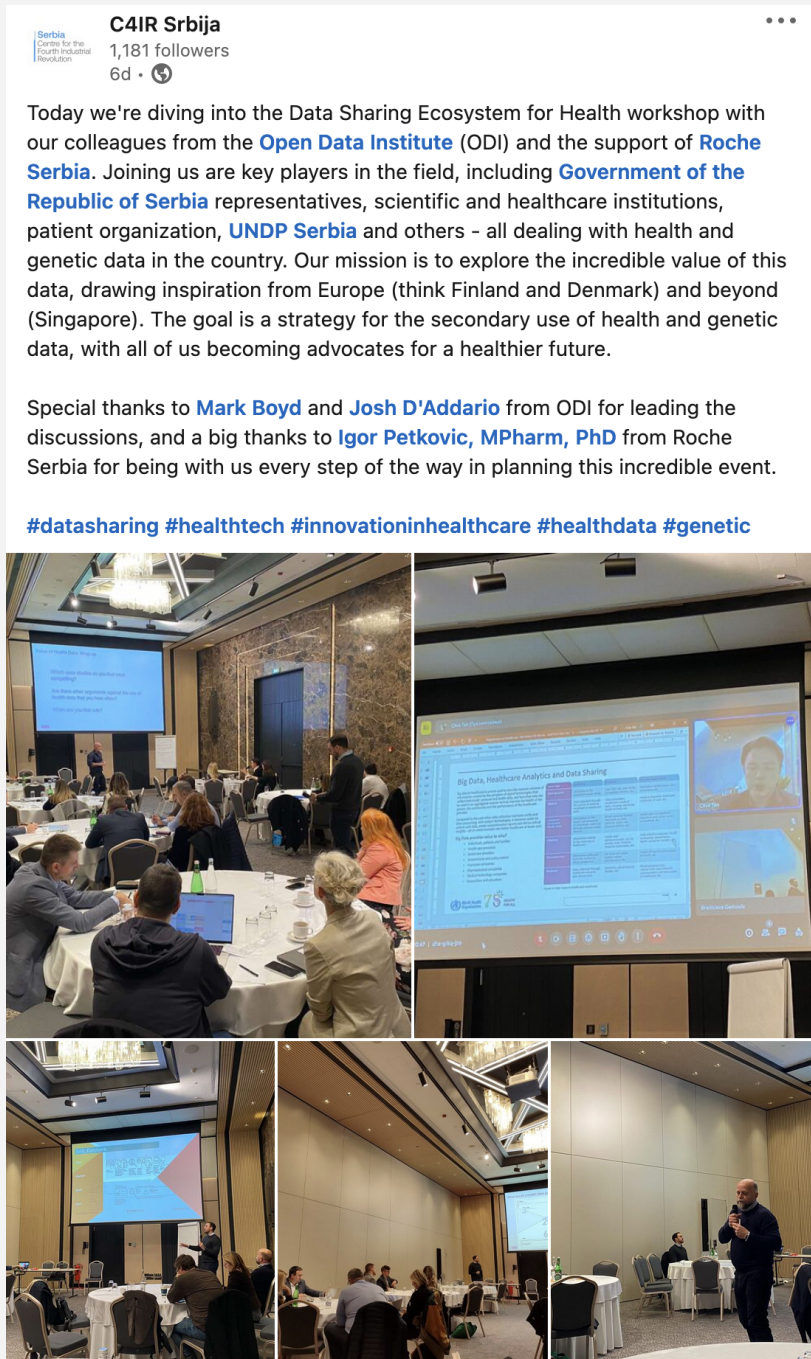
The ODI-C4IR Roundtable in Serbia explored the value of health data, emphasised the importance of overcoming existing barriers through case studies, highlighted the benefits of enhanced data sharing, and elucidated the pivotal role of health data access bodies.

Serbia faces challenges in health data sharing, including concerns about privacy, data security and regulatory compliance. Case studies play a crucial role in illustrating successful implementations of data use practices in similar contexts. Examining instances where health data has been used responsibly and ethically can serve as a practical guide for navigating legal and ethical considerations, building trust among stakeholders and demonstrating the positive impact of health data governance.

Enabling better health data use and appropriate data sharing in Serbia holds multifaceted benefits. It facilitates more comprehensive medical research, accelerates the development of innovative treatments, and enhances epidemiological surveillance capabilities. Improved health data governance contributes to evidence-based policymaking, leading to more effective public health interventions. Additionally, health data supports the optimisation of healthcare services, resource allocation, and the overall efficiency of the healthcare system.

To promote responsible data sharing, the establishment of health data access bodies is crucial. These entities can serve as intermediaries, ensuring compliance with privacy regulations and ethical standards, and fostering collaboration among healthcare stakeholders. Health data access bodies play a pivotal role in building a framework that balances the interests of individual privacy with the broader societal benefits of data sharing. Their role includes establishing protocols, monitoring data access, and promoting transparency to cultivate a culture of responsible data use in Serbia's healthcare ecosystem.

# Summary of roundtable discussions



Summary of workshop shared on LinkedIn

(Source: [https://www.linkedin.com/posts/c4ir-rs\\_datasharing-healthtech-innovationinhealthcare-activity-7130555548525092864-dJNj/](https://www.linkedin.com/posts/c4ir-rs_datasharing-healthtech-innovationinhealthcare-activity-7130555548525092864-dJNj/))

## Objectives of the event

1. To encourage new discussions around the value of health data when it is accessible, shared and used.
2. To agree on processes that can protect the sensitivity of health data while enabling its reuse.
3. To discuss what resources and next steps will help us accelerate action towards participating in the Serbian eHealth Strategy.

## Workshop approach

This full-day event focused on:

1. Overcoming barriers to sharing health data.
2. Defining success for the Serbian health data ecosystem.
3. Understanding key elements of a health data access body.
4. Prioritising next steps when advocating for the use of health data.

## Overcoming barriers to sharing health data

The first facilitated session encouraged participants to make use of case studies that demonstrate the value of data when discussing how to improve local health data ecosystems. This enables participants to advocate for action by using case study examples demonstrating how other initiatives were used to overcome similar barriers and local challenges.

Participants were asked to use real-world [case studies](#) to overcome typical barriers posed by different types of key actors within a health data ecosystem, including patients, medical professionals and policymakers. This process uncovered a number of key benefits. It is possible that, if articulated to data-sharing blockers within the ecosystem, this could help to overcome these barriers, and improve data sharing.

## Key arguments from case studies

- Often the data shared is either **aggregated and/or non-identifiable**, thereby greatly reducing any risks of causing harm to individuals
- The data involved should be used with the **consent of patients**, so data privacy and protection laws are not broken
- Data sharing or use should be **aligned with the purpose** and mission of the organisation or initiative
- The data should be **well-defined and bounded**, so that only the data aligned with a particular purpose is shared, keeping data use in line with principles of data minimisation
- Sharing data can **drive efficiencies** in the healthcare system by breaking down silos, avoiding duplication of effort, and supporting important research and innovation
- Sharing data will **ensure that those who need it** for research, innovation and policy purposes **can access it**
- The **value, benefits and use cases** of the data to be shared are **clearly articulated** to key stakeholders
- Data should be shared to **drive collaboration with researchers and other experts**, which increases the value of the use case and reduces the risks
- There is **sufficient recognition and reward** for researchers and innovators to make their data more available (e.g. high-profile citations, open research awards)
- Increasing access to data will help **better educate the public** on the value of data sharing for secondary use of health data

## Resources that help overcome challenges to making better use of health data

Challenge	Potential actions (resources)
Concerns around theft of data or disclosure of personal/sensitive information	Use aggregated and anonymised data
Access to data can result in discrimination i.e. access to services is prohibited	Consider formal policy, such as the Canadian <a href="#">Genetic Non-Discrimination Act</a> which focused on ensuring actors, for example insurers or employers cannot discriminate against individuals because of genetic information obtained. (In theory, such policies could be expanded further)
Return on investment of standardised data models	For policymakers, describe reduced costs, health system savings For patients, describe more efficient/effective health delivery and higher-quality experience
Not using health data for government planning	Healthier populations lead to more productive citizens and stronger economies (for example, see ' <a href="#">World Development Report 2021: DATA FOR BETTER LIVES</a> ').

## Case study cards

Data identified that maternal mortality rates in rural areas in Brazil were higher after withdrawing the intern doctor programme. Data helped advocate for new policies and funding to reintroduce the visiting doctor programme. Maternal mortality reduced as a result.

### Source

ODI (2021), [‘Pre-read: Health Data as a Global Public Good’](#).

Data on diabetes care helped identify those most at risk of glaucoma and patients were prioritised for diagnosis. Hospital and diagnostic testing resources were allocated to those with greater priority, and subsequent early diagnosis prevented eyesight loss

### Source

PMC/EClinicalMedicine, (2022), [‘Development and validation of predictive risk models for sight threatening diabetic retinopathy in patients with type 2 diabetes to be applied as triage tools in resource limited settings’](#).

American Diabetes Association (2022), [‘Using Data to Improve the Management of Diabetes: The Tayside Experience’](#).

In the US, diagnosis of breast cancer occurs at Stage 3 or 4 amongst African-American women. Healthcare providers increased mammogram access for all African American women, using data on patient zip codes in concentrated areas of Black neighbourhoods to trigger automatic diagnostic referrals, and a review of data on mammogram ordering versus completion rates was used to monitor and address barriers in real-time.

### Source

American Hospital Association (n.d.), [‘Leveraging Data for Health Care Innovation’](#).

Data held by a healthcare provider in Minneapolis showed that patients with atrial fibrillation (AFib) after cardiothoracic surgery had longer lengths of stay by two days than patients without AFib. After new post-op nursing care protocols were introduced, there were no differences between AFib and non-AFib health outcomes or hospital stay rates. More than \$60m was saved over five years through reduction in acute care service delivery.

### Source

American Hospital Association (n.d.), [‘Leveraging Data for Health Care Innovation’](#).

More than 180 countries have shared genomic sequences of Covid-19 variants on the GISAID platform. To date, 2 million genomes have been catalogued. The platform is the most trusted for the sharing of Covid-19 genome data, with African and South American scientific contributions to the platform more than doubling between January and April 2021. Data has been used to assess vaccines and diagnostic medical devices. Interactive real-time platforms and variants can be tracked for policy and therapeutic intervention planning.

The WorldWide Antimalarial Resistance Network (WWARN) has established collaborative platforms and data-sharing models to aid researchers and policymakers. Across the Western Pacific region, there was a 61% decrease of Plasmodium falciparum cases and a 32% decrease of P. vivax cases compared to the same period in 2019.

### Source

ODI (2021), [‘Pre-read: Health Data as a Public Good’](#).



<p><b>Source</b> ODI (2021), <a href="#">‘Health Data Governance Summit Pre-read: The health data landscape’</a>.</p>	
<p>Clinical trials data, created using standardised data models and clear data governance processes such as creation of a data dictionary, reduced the estimated costs of data sharing by 50% (from 3K to 2K in this study).</p> <p><b>Source</b> Trials (2017), <a href="#">‘Resource implications of preparing individual participant data from a clinical trial to share with external researchers’</a>.</p>	<p>Data on genetic markers for rare cancers can be used to better identify which therapies would suit which patients.</p> <p><b>Source</b> Future Oncol (2022), NIH (2021), <a href="#">‘Real-world data on diffuse large B-cell lymphoma in 2010-2019: usability of large data sets of Finnish hospital data lakes’</a>.</p> <p>Tietovry (n.d.), <a href="#">‘HUS facilitates clinical data exploitation through an integrated HUS-DataLake solution’</a>.</p>
<p>Data collected with patient-organisations represented on ethics and organisational boards led to faster diagnostic systems, identification of novel biomarkers of systemic diseases and resulted in greater trust amongst patients for sharing of their health data.</p> <p><b>Source</b> Current Opinion in Ophthalmology, (2022), <a href="#">‘Building trust in real-world data: lessons from INSIGHT, the UK’s health data research hub for eye health and ophthalmics’</a>.</p> <p>ODI (2020), <a href="#">‘Sharing eye health data: Putting patients at the heart of decision-making’</a>.</p>	<p>A study using genomic data to identify patients at greater risk of breast cancer increased the diagnosis of a known mutation in 63% of patients, allowing 11% of them to benefit from more targeted/personalised treatment care plans.</p> <p><b>Source</b> Genomcore (n.d.), <a href="#">‘AGATA, a pilot study to implement personalized therapy for patients with advanced or metastatic breast cancer’</a>.</p> <p>Frontiers in oncology, (2021), <a href="#">‘First Nationwide Molecular Screening Program in Spain for Patients With Advanced Breast Cancer: Results From the AGATA SOLTI-1301 Study’</a>.</p>
<p>Analysing data on waiting lists and quality of care for the most disadvantaged populations with learning disabilities in one UK county found that ethnic minority groups waited between 7.2 and 8.2 weeks longer than white patients. New strategies introduced based on the data reduced waiting times for two ethnic minority groups to an equivalent waiting time as white patients.</p> <p><b>Source</b> NHS England (n.d.) <a href="#">‘How one Yorkshire Trust eliminated the elective care backlog for people with a learning disability’</a>.</p>	<p>Researchers from the Behavioral Diabetes Institute and the Scripps Whittier Diabetes Institute examined caregivers’ experiences with real-time continuous glucose monitoring data sharing and its impact on quality of life and health outcomes for patients with type 1 diabetes. Most agreed that data sharing improved their quality of life by giving them peace of mind (88.4% parents; 87.7% partners), contributing to lowering their anxiety (84.8% parents; 86.3% partners), and helping them feel confident about their ability to help their child/partner (92.1% parents; 94.3% partners).</p>

	<p><b>Source</b> Journal of Diabetes Science and Technology (2022), '<a href="#">Impact of Real-Time CGM Data Sharing on Quality of Life in the Caregivers of Adults and Children With Type 1 Diabetes</a>'.</p>
<p>The Institute of Medicine reported that the sharing and use of health data improves patient safety by reducing medication errors, reducing adverse drug reactions, and improving compliance to practice guidelines.</p> <p><b>Source</b> Saudi Med Journal, (2017), '<a href="#">The impact of health information technology on patient safety</a>'.</p>	<p>Cancer patients in the Netherlands now have to wait less time for new and expensive cancer treatments (often precision oncology or tumour-agnostic therapies), thanks to the Drug Access Protocol (DAP) developed by Dutch oncologists, insurers and healthcare institute Zorginstituut Nederland. The protocol allows patients to access new treatments free of charge, while price agreements are being made between the government and manufacturer. The manufacturer therefore bears the financial risk, because they won't get paid if the treatment does not work, but in exchange, the company is able to collect valuable, real-world data about the effect of the treatment.</p> <p><b>Source</b> NL Times (2021), '<a href="#">New cancer medicine more quickly available to Dutch patients</a>'.</p>
<p>New York State created the Statewide Health Information Network for New York (SHIN-NY) to allow the electronic exchange of clinical information and connect healthcare professionals statewide. The SHIN-NY enables collaboration and coordination of care to improve patient outcomes, reduce unnecessary and avoidable tests and procedures, and lower costs. Use of the SHIN-NY to access patient information is associated with a 50% reduction in the rate of hospital admissions, a 26% reduction in the rate of Emergency Department admissions, and a 35% reduction in the rate of repeat imaging procedures.</p> <p><b>Source</b> NYeC (n.d.), '<a href="#">Statewide Health Information Network for New York(SHIN-NY)</a>'.</p>	<p>Allina Health, a not-for-profit healthcare system in Minnesota that includes 11 hospitals, more than 90 clinics, 52 rehabilitation locations and 15 pharmacies, implemented a system-wide data-driven approach using the Health Catalyst platform. This data integration and analysis platform was able to identify and manage unwarranted clinical variations, and identify, measure, and improve clinical value by quantifying the value of clinical change to improve outcomes. Since the implementation of this data-driven approach, Allina Health identified nearly \$33m in potential cost savings for the first three quarters of 2017.</p> <p><b>Source</b> Alina Health (n.d.), '<a href="#">About Allina Health</a>'.</p> <p>Health Catalyst (n.d.), '<a href="#">Data-Driven Approach Identifies Nearly \$33 Million of Savings Annually</a>'.</p>

## Defining success for the Serbian health data ecosystem

The second session began with a presentation by Dr Clive Tan from Singapore's Public Health Association on health data-sharing best practices and their implementation in Singapore. It was followed by a workshop on which of the successes Serbia is keen to achieve could be developed from the Singapore example.

The participants listed a number of success factors that would bring substantial value to the healthcare system in Serbia.

### Goals to be enabled by data sharing

- **Widespread digitalisation of the healthcare sector** is a high priority goal in Serbia. Implementing this digitalisation is expected to bring improvements around:
  - **Efficiency** – through reduced duplication of effort across organisations and initiatives
  - **Interoperability** – to connect medical professionals, researchers and innovators more easily
  - **Security** – through strong data privacy, protection and cybersecurity
  - **Resilience** – by providing digital backups of valuable and sensitive medical information
  - **Effectiveness** – through pilot innovation projects to deliver new and better services (for example, e-procurement)
- Allowing for **locally-focused systems** to be created across the country, supported by a **centralised coordinating and storage function**.
- Addressing the need to **integrate public and private healthcare systems**, providing the ability for greater medical collaboration, patient coverage and quality of care.
- Addressing the need to **better connect with the public**, through providing education on the potential uses of health data and how to provide informed consent, as well as collecting information at point of care to better understand healthcare equity in Serbia.

## Resources that help overcome challenges observed in other countries

<p>Strong data ecosystems need two things:</p> <ol style="list-style-type: none"> <li>1. Role clarity: for example, data generator, data user, data processor</li> <li>2. Modality of data sharing: for example, including bilateral and licensing.</li> </ol>	<p>For navigating role clarity, the ODI's <a href="#">Data Governance Playbook</a> can help users move beyond functions to roles within data governance as well.</p>
<p>National University of Singapore (2022) 'White Paper, <a href="#">Responsible Data Sharing in Health and Healthcare</a>'.</p> <p>Challenges/barriers to data sharing:</p> <ul style="list-style-type: none"> <li>• Political: identifying stakeholders and beneficiaries who can drive the change</li> <li>• Regulatory: focus on personal data protection laws (not data sharing)</li> <li>• Technological: data warehousing data exchange and data security</li> <li>• Cultural: trust and public perception.</li> </ul>	<p>Regulatory reference is the <a href="#">European Data Governance Act</a> that works to set regulation for data sharing.</p> <p>The ODI's '<a href="#">Data Spectrum</a>' serves as a tool to help consider how open/closed to make respective data types.</p> <p>Trust reference book on insights into health data use: Policy Press (2023), '<a href="#">What is Public Trust in the Health System? Insights into Health Data Use</a>'.</p>
<p>Acknowledged the need for digitalisation within the health system. However, what are the timelines and how to approach this work?</p>	<p>MIT CISR (2021), '<a href="#">Update on the Four Pathways to Future Ready</a>', while focused on companies, has relevant considerations and things to 'watch out for' on digital transformation approaches and journeys.</p> <p>Alberta Health Services (2023), '<a href="#">Connected Care: Implementation Timelines</a>' for four million patient catchment across all levels of care (primary to tertiary etc.)</p>
<p>Cybersecurity – how to address?</p>	<p>The war in Ukraine has forced the Ukrainian government to quickly develop and deliver a diversified cybersecurity strategy. Microsoft supported this work and could serve as a thought partner in this work in Serbia.</p>
<p>National Electronic Health Records goal is in place. However, national data governance is an opportunity for improvement at the national level.</p>	<p>The UN-commissioned '<a href="#">Mapping and Comparing Data Governance Frameworks</a>' offers validation for national (and international) data governance frameworks and recommendations for what these frameworks should consider/include.</p>

## Building a health data access body

The third session began with a presentation by Josh D’Addario from the ODI on research into [health data access bodies](#) and a proposed framework for implementation. This was followed by a facilitated session that identified the recent past, the current situation, and potential futures that could be created from building a health access body, and how to define an ideal path forward.

### Body for secondary use of health data

#### Current situation

- In May 2024, the health data sharing by-laws will go into effect. These by-laws will lay the legal framework for decision making regarding the implementation of system access for the secondary use of health data.

#### Key past events and developments

- Some work on implementation approaches and processes for a health access body was started six months ago, but it was shelved until the by-laws were set up. A meeting this week on developing the new action plan has established a working group to decide on implementation and system access to secondary use of health data.

#### Future visions of the health data access body

- A one-stop shop and source of truth for reporting on the public health of Serbia, which could make aggregated medical data across the country available in a trusted and trustworthy way to the media, for use by different communities, and by citizen scientists.
- An entity at the heart of the healthcare sector that focuses on building and fostering trust among sector experts and the public. This is supported by representative governance panels including medical experts, researchers and patients’ organisations. It is additionally underpinned by transparency – both for activities and for outcomes that demonstrate the benefits of sharing health data in secure ways.
- A vehicle that helps to build a cultural change in the sector by encouraging digitisation, improving data maturity and demonstrating the benefits of more open collaboration and innovation.

## Resources that help overcome challenges to establishing a data access body

<b>Role of ethics board and ethics in ecosystems</b>	<p>Key Opinion Leaders on topics (particularly as it pertains to genomics): for example, Bartha Knoppers (<a href="#">interview</a>)</p> <p>Could also consider resources from <a href="#">GA4GH</a></p> <p>For Roche team, reference <a href="#">Roche Data Ethics Principles</a> (available on roche.com)</p>
<b>Citizen science</b>	<p>Roche Canada's <a href="#">Roche Data Science Coalition</a></p>

## Prioritisation of next steps

Following a presentation by Troels Bierman Mortensen from the OSCAR Project in Denmark, which has established a data sharing technology platform, a final facilitated session saw delegates discuss what ecosystem stakeholders need to manage expectations and advocate for the responsible, ethical and available use of health data, in order to implement Serbia's digital health action plan.

Participants focused firstly on identifying what other key stakeholders need to be involved. This list included:

- [Health Insurance Fund](#)
- [Ministry of Health of the Republic of Serbia](#)
- General practices
- Startups and other businesses
- [Institute of Public Health of Serbia](#)
- [Statistical Office of the Republic of Serbia](#)
- Ethical board
- Patient organisations

Participants then focused on what some of the next steps should be in order to continue demonstrating the value of increased use and sharing of health data in responsible and ethical ways.

## Next steps and longer-term activities

### Next steps

- **Build a bank of evidence** that demonstrates the value of data sharing and other helpful information, such as how to mitigate risks or what pitfalls to avoid. Evidence should include case studies and research from healthcare sectors in other countries, as well as in other sectors with highly-sensitive data sharing.
- **Engage with leading organisations and initiatives in the secondary use of health data**, such as [Findata](#), [OSCAR](#), [UK Biobank](#) and [others](#) to learn from their positive and negative experiences.
- **Explore high-value use cases** for secondary use of health data to begin planning pilot projects around the secure sharing of health data (e.g. digital pathology).
- **Design a potential health data access body** that could deliver these high-value use cases, using the [Facilitating Safe Access Framework \(FSAF\)](#). Include the legal foundation, commercial terms, technical infrastructure and governance or decision-making processes that would safely allow data access for these purposes.
- **Explore potential anonymisation techniques and other privacy enhancing technologies (PETs)** that could be used to improve access to health data while retaining the privacy of data subjects. Where data is currently aggregated and open, or disaggregated and shared, [see where PETs could improve openness or granularity](#).
- **Continue to support the development of data policies and data strategies** within the public sector and health sector specifically that would encourage the secure sharing of health data for secondary use.

### Longer-term activities

- **Conduct research on different [data access models](#)** that could support the long-term goals for the secondary use of health data, such as centralised repositories like [data institutions](#), or more [decentralised data access approaches](#).
- **Discuss the potential to create genetic data-sharing partnerships with other countries in the region**, examining the benefits of an increased pool of genetic data from countries with similar demographics, alongside the potential risks of exclusion of minority populations within those countries.

# Appendix 1:

## Health data access bodies

### Framework: Facilitating Safe Access to Sensitive Data

#### Overview

Data institutions are organisations that steward data on behalf of others, often towards public, educational or charitable aims. The ODI describes ‘stewarding data’ as working to realise the value and limit the harm that data can bring. This includes making important decisions about who has access to data, for what purposes and to whose benefit.

There is value in increasing access to sensitive data, such as data about health, transport or demographics, but it must be done in ways that respect things like privacy, commercial sensitivity and national security.

The Facilitating Safe Access Framework (FSAF) breaks down the different mechanisms available throughout a ‘data-use journey’ that data institutions use to control:

- who can access the data,
- what data can be accessed,
- how that data can be accessed, and
- what that data is used for.

#### These mechanisms include:

- **Registration** of a few important details before being allowed to access data
- **Application** with more detail, including rationale for data access and use
- **Internal review** by experts within the data institution
- **External review** by technical or subject-matter experts outside the organisation or communities affected by data use



- **Audit** of a prospective user's facilities or competencies as part of the review process
- **Training** courses, to be completed as proof of accreditation or certification in relevant areas
- **Contracts**, data sharing agreements and licences, to define who can access the data
- **Pricing** models to control access to data
- **Modified data** to limit sensitivity or the risk of re-identification
- **Unmodified data** that has not undergone a process to remove sensitive information
- **Insights**, trends or signals drawn from the data that are actionable while limiting the risk of re-identification
- **Individual and aggregate datasets**, depending on the need for granularity and associated risks
- **Direct transfer** or download (can be a one-off download or a regular, recurring transfer of data)
- **Data streams** and APIs that expose a formatted version of data, usually in an automated way
- **Interfaces** that allow users to run their own queries against a restricted subset of data fields
- **Secure virtual research environments** where data stewards can closely monitor and control what data users interact with, and how
- **Secure physical research environments** are similar to virtual environments, but are physical locations where researchers can access datasets directly

### Lessons for the Serbia healthcare data ecosystem

With the value of data and data sharing established, access to sensitive health data will need to be designed and controlled in various ways, depending on the needs of data users and use cases. Health data access bodies and processes should use the FSAF to design the governance processes around who has access to what data, and for what purposes. Some examples of health data institutions from the UK can be found below.

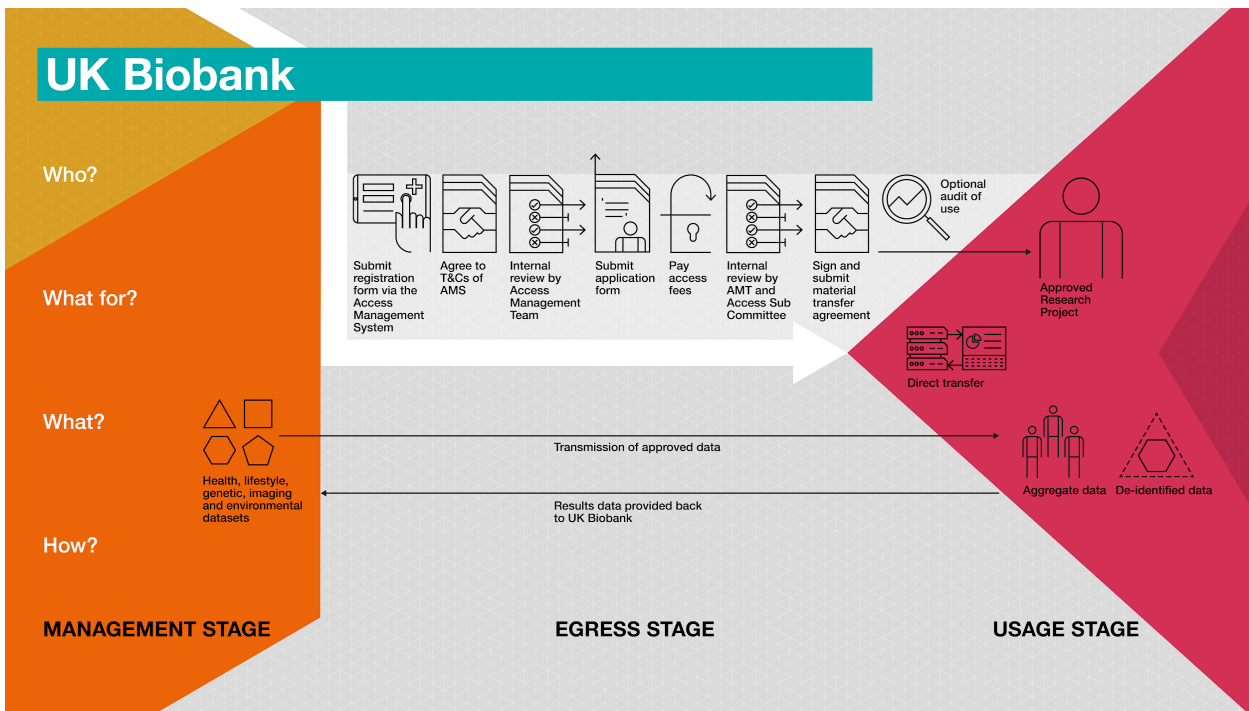


Figure 1: UK Biobank, ODI

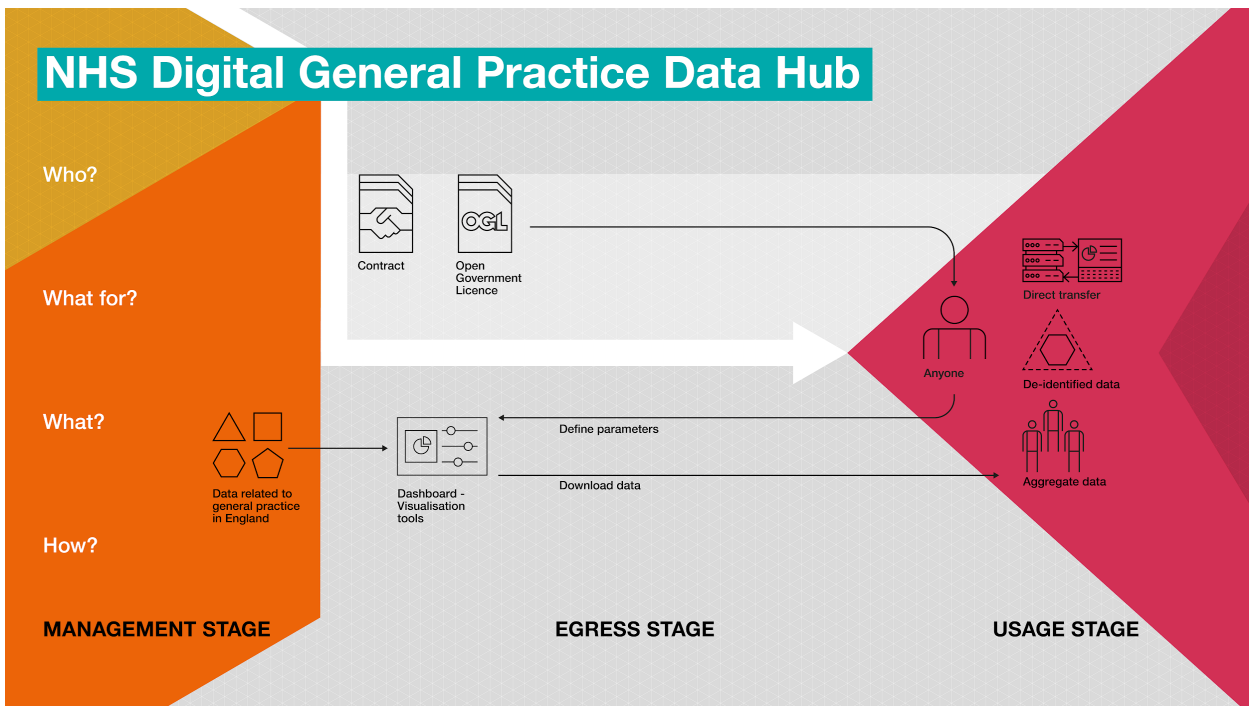


Figure 2: NHS General Practice Data Hub, ODI

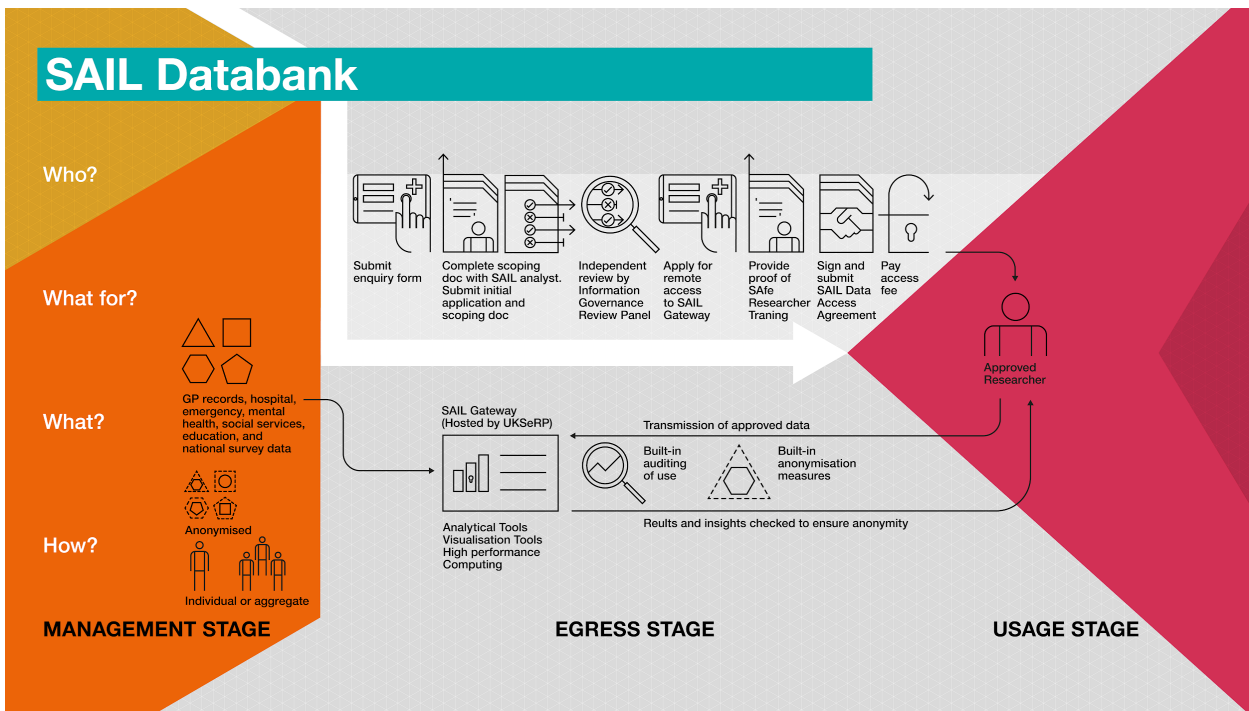


Figure 3: SAIL Databank, ODI

## Case study: Findata

### What it is

Findata is the Health and Social Data Permit Authority, and its activities are based on the Act on the Secondary Use of Health and Social Data (552/2019). Findata improves the data security of data materials containing health and social data and enables more efficient utilisation of these materials. Findata operates in conjunction with the National Institute for Health and Welfare, but is separate from the institute's other activities.

### Findata's services include:

- granting permits for the secondary use of social and healthcare data
- collecting, linking, pseudonymisation and anonymisation of data
- providing a help desk
- providing the Kapseli® service, a secure processing environment for data analysis

### How it works

Findata operates as the 'one-stop shop' for social and healthcare register data in Finland by providing equal and extensive access to all service providers' and national data controllers' repositories. This approach not only ensures equitable access, but also enhances data security and safeguards individuals' data protection rights.

An independent permit authority oversees the process, ensuring compliance with data subject rights and restricting data analysis to secure processing environments. Furthermore, the system offers valuable tools and support both to clients and data controllers, providing guidance, materials and regulations for data descriptions and permit applications. This comprehensive approach serves as a model for ensuring efficient and secure access to vital social and healthcare data.

### Lessons for the Serbia eHealth ecosystem

Findata significantly improved the processing of permits and data consolidation from various registries, promoting the secure use of health and social data. Serbia can draw valuable lessons from Finland's experience in implementing Findata, a data intermediary for health data access.

Firstly, it's crucial to recognise that establishing such systems requires time and substantial resources. Serbia should also ensure a clear legal foundation for nationally monitoring data, considering updates in light of the European Health Data Space (EHDS). Engaging stakeholders early on with transparency is key, and investing in data literacy training for healthcare providers can highlight the importance of high-quality data input for research.

Finally, prioritising a user-friendly electronic health record system is essential, as low customer satisfaction can hinder successful implementation.

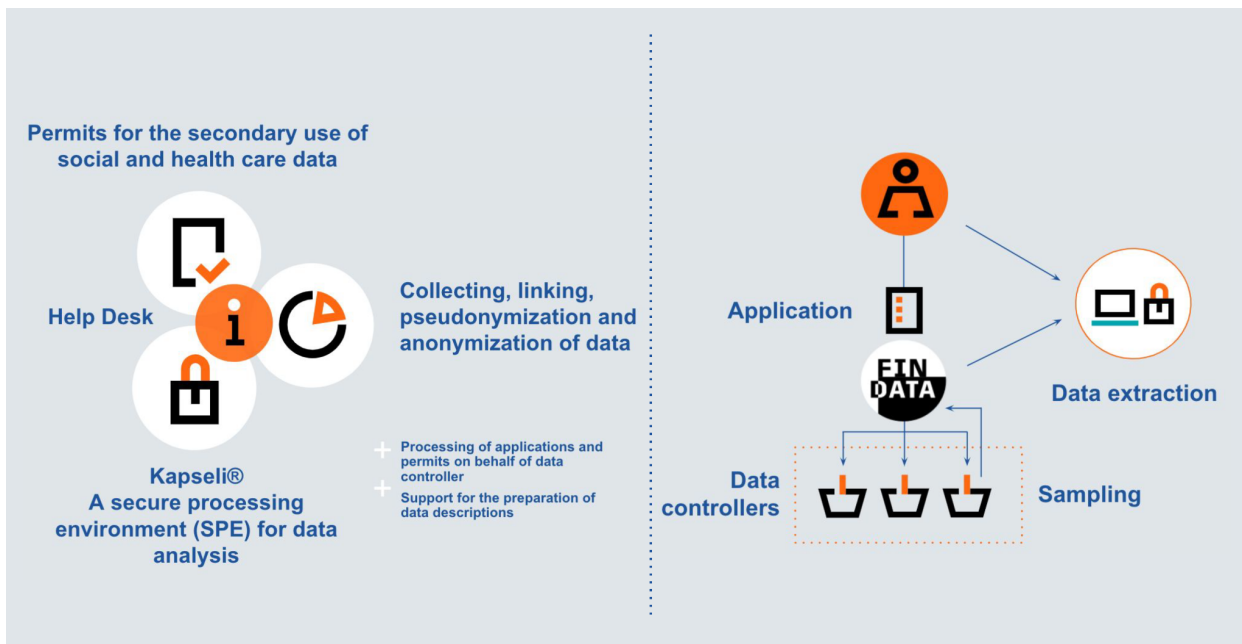


Figure 4: Findata presentation, 2023.11.15

# Appendix 2:

## Full list of attendees

### Participants

Name	Organisation
Branislava Gemovic	C4IR Serbia
Nemanja Bogavac	C4IR Serbia
Dejana Ranković	Prime Minister Office
Đuro Radović	Ministry of Health
Slađana Đukić	Ministry of Health
Ilija Antović	Ministry of Health
Marina Soković	Ministry of Science, Technological Development and Innovations
Jelena Bojović	C4IR Serbia
Siniša Milošević	C4IR Serbia
Goran Šehović	Office for Information Technologies and e-Government
Milan Josimov	Office for Information Technologies and e-Government
Branko Tomić	Institute of Molecular Genetics and Genetic Engineering
Saša Todorović	Institute of Molecular Genetics and Genetic Engineering
Irena Vidaković	Data Protection Body
Nevena Veljković	Heliant/C4IR/Vinča
Slobodan Marković	UNDP
Miljana Tanić	Institute for Oncology and Radiology of Serbia
Isidora Šmigić	NALED
Ana Milovanović	NALED
Amalija Pavić	AmCham Serbia
Jennifer Pougnet	Roche Group
Aleksandra Vidakovic-Lazic	Roche Serbia
Igor Petrovic	Roche Serbia

### Open Data Institute (ODI)

Mark Boyd	Associate
Josh D'Addario	Principal Consultant

### Workshop presenters

Clive Tan	National Healthcare Group, Singapore
Troells Biermen Mortensen	OSCAR/DataFair ApS

# Appendix 3:

## ODI resources and links

- The ODI-Roche playbook '[Health data governance: a guide for non-technical leaders](#)' supports healthcare leaders and professionals in accessing, using and sharing data in responsible, ethical and equitable ways.
- [ODI 'Secondary use of health data' tool and report](#) – commissioned by Roche – compares the policy readiness of countries across Europe for the secondary use of health data, and identifies good practice across the region.
- The report '[Understanding the social and economic value of sharing data](#)' and the [Value of Data Canvas guide](#) explore how organisations can assess the potential social and economic value of sharing the data they hold or have access to.
- ODI research on [data institutions](#), including [how they facilitate safe access to sensitive data](#) and their [socio-economic impact](#).
- '[Mapping data ecosystems](#)', a guide introducing a tool for documenting and mapping data ecosystems.
- '[The Data Ethics Canvas](#)'. The ODI's new approach for organisations to identify and manage data ethics considerations.
- '[Data Skills Framework](#)'. The ODI's simple, three-tier framework that describes the knowledge and skills of anyone interacting with open data, from beginner through to expert level.
- The '[ODI Learning](#)', a site which includes a variety of digital training options, such as:
  - Free courses, for example '[Open data essentials](#)' and '[Finding stories in data](#)'
  - Courses focused on data ethics, such as '[Introduction to Data Ethics & the Data Ethics Canvas](#)' and '[Becoming a Data Ethics Professional](#)'
  - Courses to develop '[Strategic Data Skills](#)', available as tutored or [self-paced](#)
- Additional ODI health data access research, such as '[Transforming mental health research through longitudinal datasets](#)' and '[Applying new models of data stewardship to health and care data](#)'.