

Innovating the use of health data – the Finnish model

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Sitra in a nutshell

1. A think, do and connect tank.
An independent future house.
2. A gift from Parliament to the
50-year-old Finland 51 years
ago. Under the direct control of
the Finnish Parliament.
3. Works towards a fair and
sustainable future.
4. Funded by returns on
endowment capital and capital
investments.
5. The vision is implemented by
three themes and hundreds of
projects.

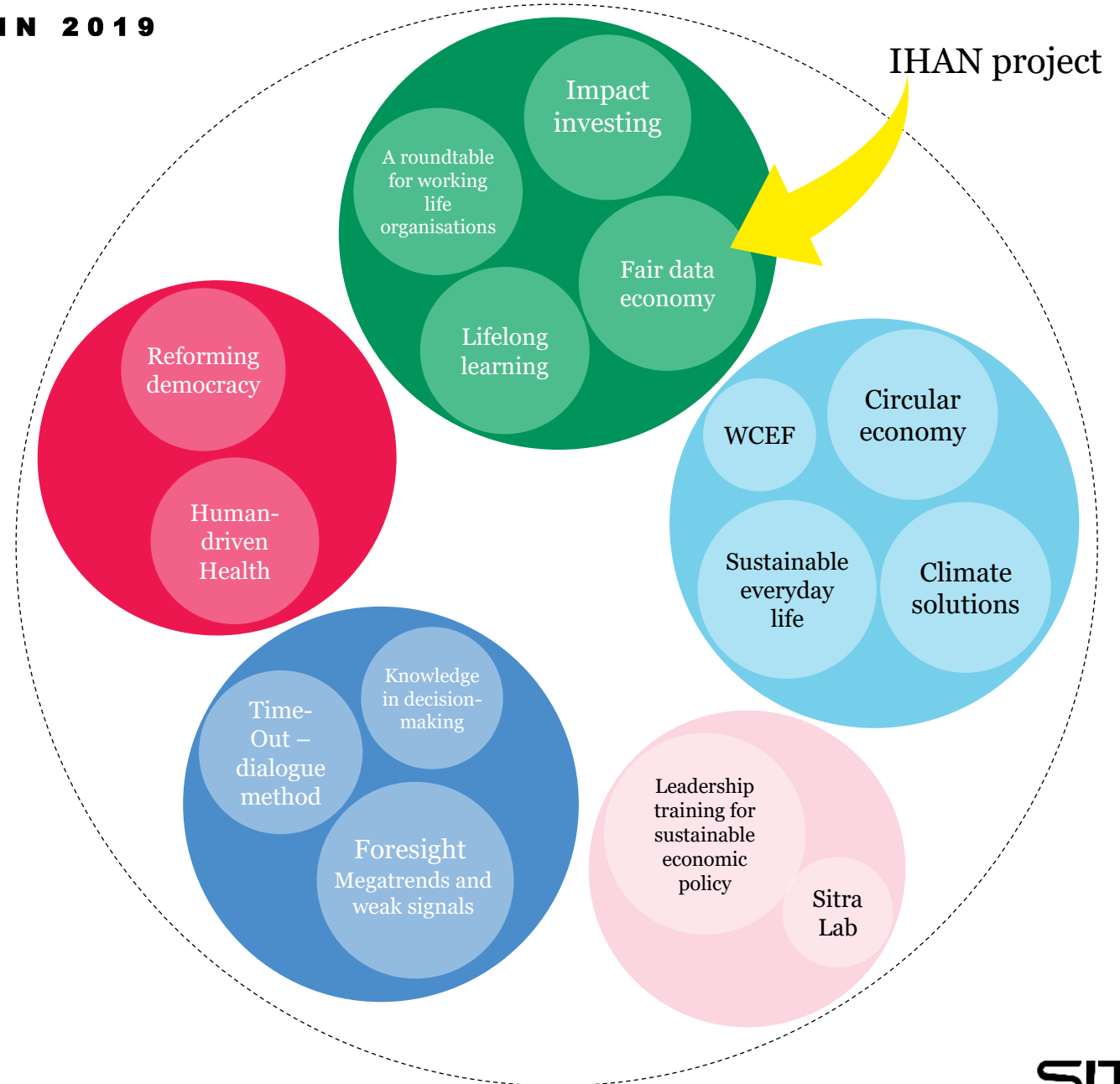
+ the most important of all

Building our future *together*.



SITRA'S FUTURE-ORIENTED WORK IN 2019

-  **FORESIGHT**
-  **SOCIETAL TRAINING**
-  **A CARBON-NEUTRAL CIRCULAR ECONOMY**
-  **CAPACITY FOR RENEWAL**
-  **NEW WORKING LIFE AND A SUSTAINABLE ECONOMY**



THE SECONDARY USE OF HEALTH AND SOCIAL CARE DATA

Project Isaacus 2015-2018

Findata 2020-

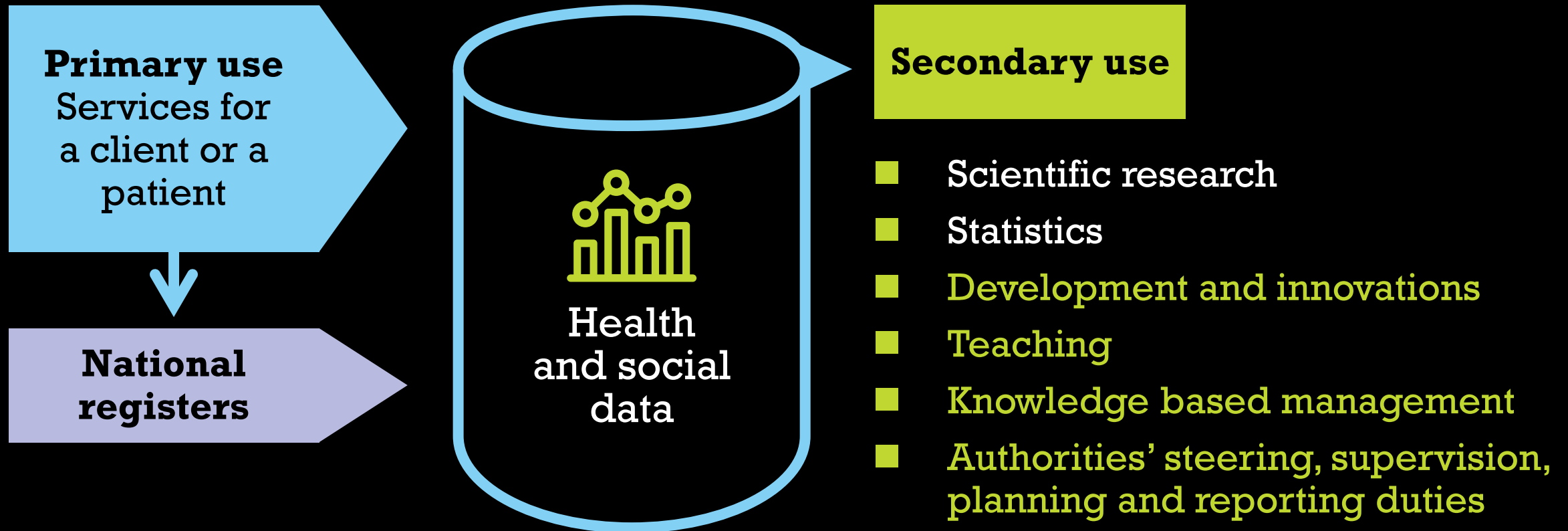
Great news from Finland!

- **New legislation** on Secondary Use of Social and Healthcare Data entered into force on 1 May 2019
- It enabled the founding of a national Social and Health Data Permit Authority **Findata** – a one-stop shop which offers permits, advisory and access to data for research, development and innovations.
- It opens up the national social and healthcare registers, but also data from the operational client and patient systems in primary care, specialist healthcare and social services.



Website in English!

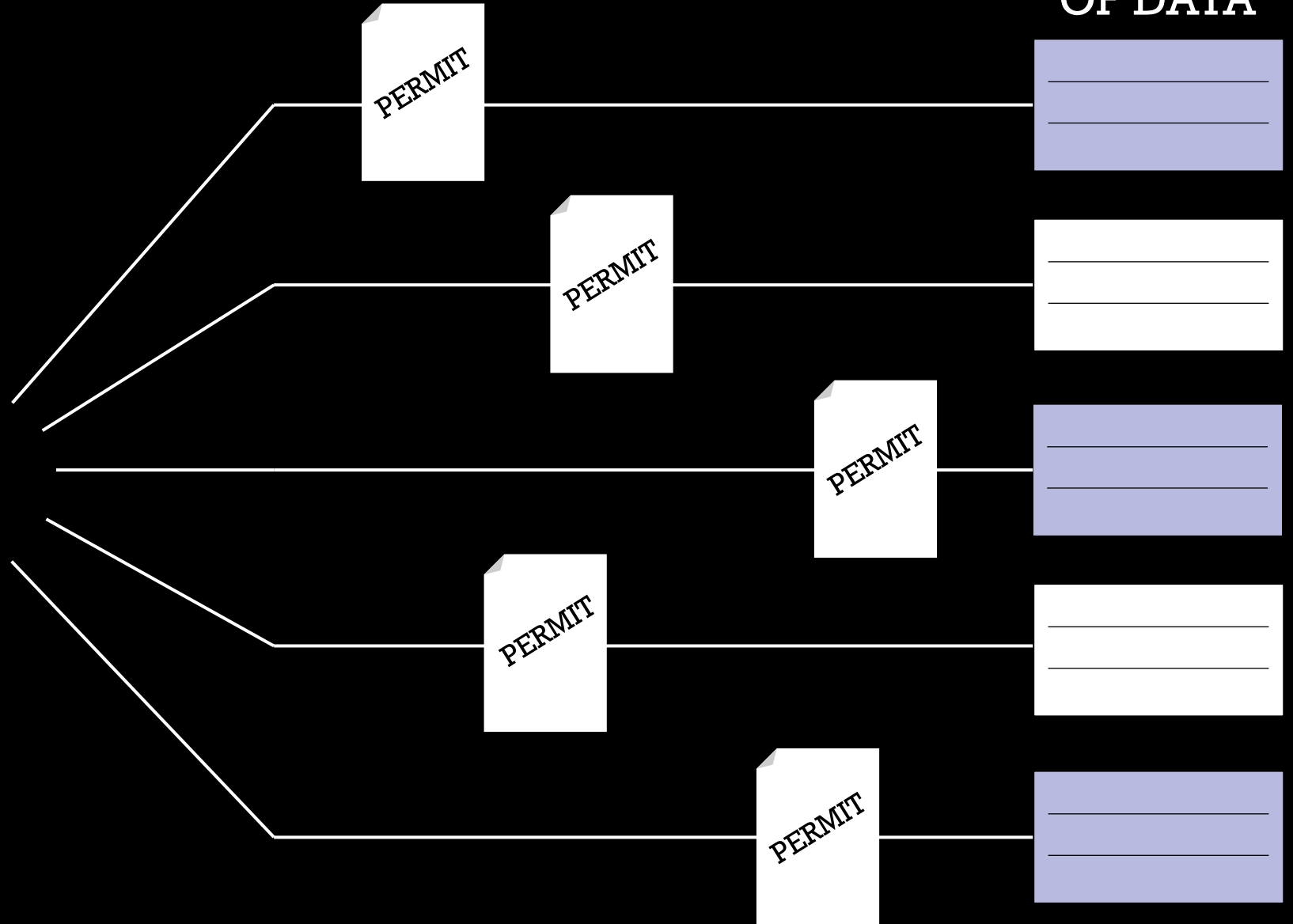
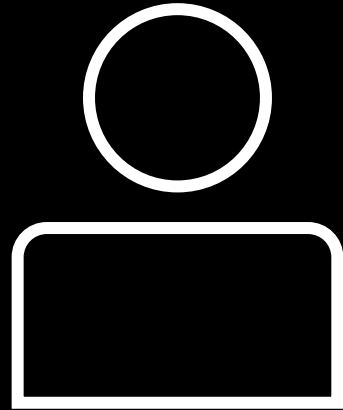
Primary and secondary use of personal data



Based on the Act on the Secondary Use of Health and Social Data (552/2019)

FIND DATA

BEFORE

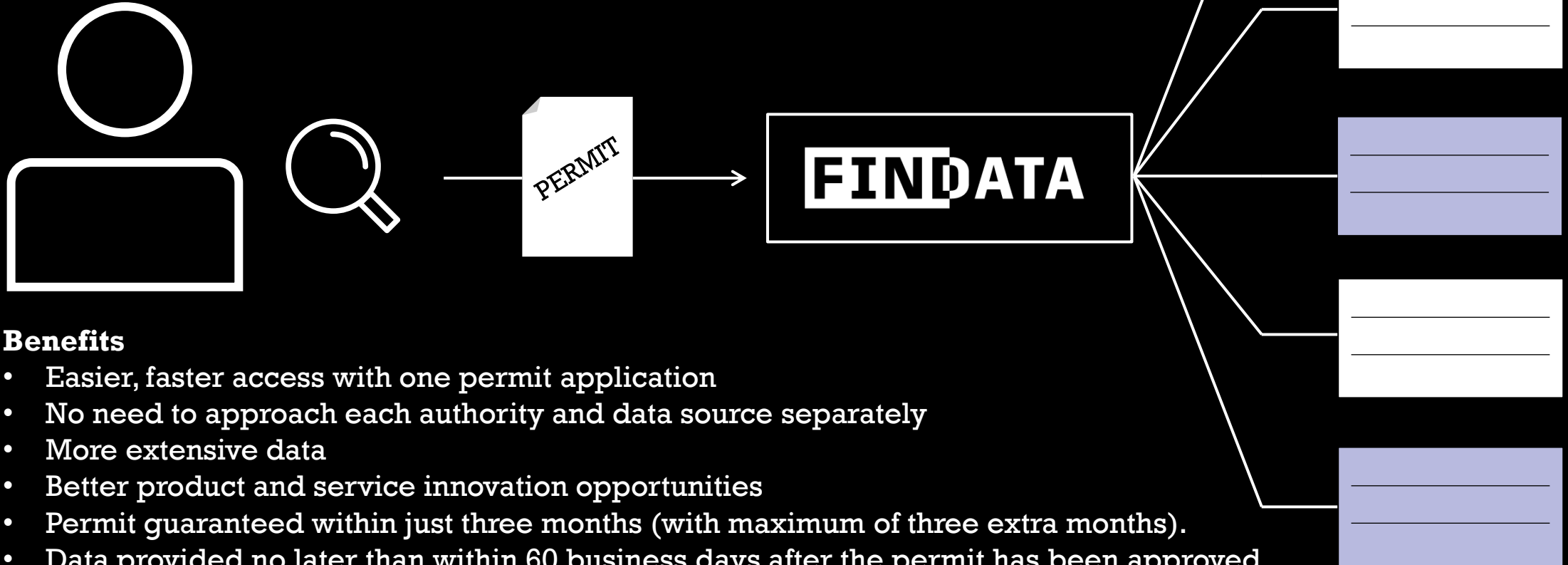


CONTROLLERS
OF DATA

FINDATA

CONTROLLERS OF DATA

AFTER



Benefits

- Easier, faster access with one permit application
- No need to approach each authority and data source separately
- More extensive data
- Better product and service innovation opportunities
- Permit guaranteed within just three months (with maximum of three extra months).
- Data provided no later than within 60 business days after the permit has been approved

Services

One-stop shop for the **secondary use** of health and **social data**

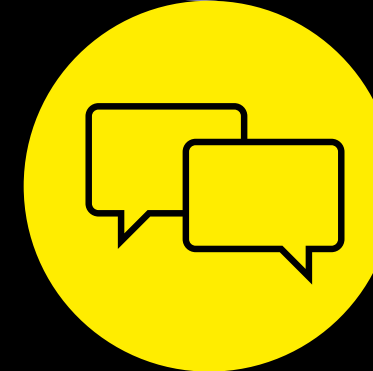
Operates directly under
the Ministry of Social
Affairs and Health

**Grant data
permits** when
data are
requested from
multiple
registers

Help Desk for
data users

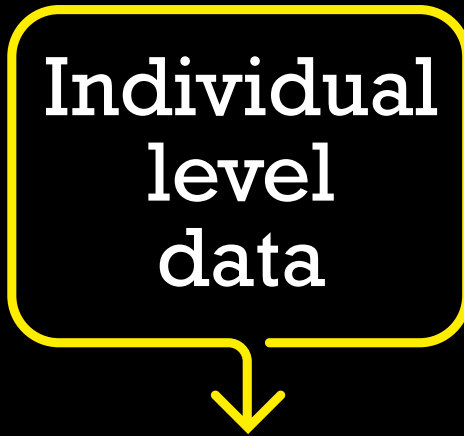


**Collect and
process** the
data



**Provide the
data** in a
secure IT-
environment
for data users

What kind of data is available



Data Permit



Data Request

A data utilisation plan is always required to access data sets

How to access data sets

Individual
level
data



- Findata started receiving data permit applications 1.4.2020
- Available in a secure remote use environment for a set period
- Data sets are only available without individual's direct identifiers
- For the purposes specified in the Act

Statistical
level
data



- Findata started receiving data requests 1.1.2020
- Delivered to the customer
- Free use for the purposes specified in the Act

The following controllers will provide access to data specified in the Act through Findata

National Institute for Health and Welfare (THL)

- Cancer register
- Infectious disease register
- Hospital discharge register
- National vaccination register
- Medical birth register
- Register of induced abortions
- Register of congenital malformations
- etc.

Finnish Institute of Occupational Health

- Occupational illnesses
- Occupational exposures

Digital and Population Data Services Agency

- Population data
- Families
- Residence
- Building information

Social Insurance Institution (Kela)

- Prescriptions
- Social benefits

Statistics Finland

- Register on causes of death

Finnish Centre for Pensions (ETK)

- Benefits and incomes
- Diagnoses

Social and health care operating units (public and private)



Data saved in Kanta services (National electronic health record system for citizens and health care professionals)

- “My Kanta Pages” for citizens (medical records and prescriptions)
- (e-)Prescription service
- Pharmaceutical Database
- Patient Data Repository
- Archiving of old patient data
- Client data archive for social welfare services
- Sharing of medical certificates

National Supervisory Authority for Welfare and Health Valvira

Finnish Medicines Agency Fimea

Regional State Administrative Agencies (AVI)

Sitra's Isaacus project 2015-2018

- Prepared the basic principles and an operating plan for Findata
- Piloted, tested and developed service models and processes, metadata descriptions, data lakes and co-operation models with authorities and stakeholders

How we did it

State's supplementary budget proposes allocating 2.5 million euros for the year 2019 towards launching the operations of the data permit authority and the construction of a data-secure environment.

REGULATION

DATA PERMIT AUTHORITY

Working Committee prepares a new Act on the Secondary Use of Health and Social Data.
Working term: April 2015 to December 2017.



Proposal submitted for the first hearing in August 2016.

Government proposes the new act (October 2017).

Parliamentary work, expert hearings and debates, and the social affairs and health committee suggests amendments in April 2018. Adjusted proposal returned to the committee in October 2018.

The new act is approved by Parliament (March 2019). Act enters into force on 1 May 2019.

Findata – new one-stop shop in operation. Helpdesk open in November 2019. Information requests from January 2020.

2015 -

2016 -

2017 -

2018 -

2019 -

2020 -

PROJECT ISAACUS

Project Isaacus starts in November 2015.

Eight pre-pilots begin with Sitra's funding support (of between 30 and 70%).

Isaacus phase 1 completed in September 2017. Pre-production pilots give an insight into future ICT services.

Sitra extends the project to ensure the impact of the work. Sitra funds Project Management Office to support the temporary Steering Group assigned by the Ministry of Social Affairs and Health.

TEMPORARY STEERING GROUP

Temporary Steering Group prepares the launch of Findata operations.

Further readings

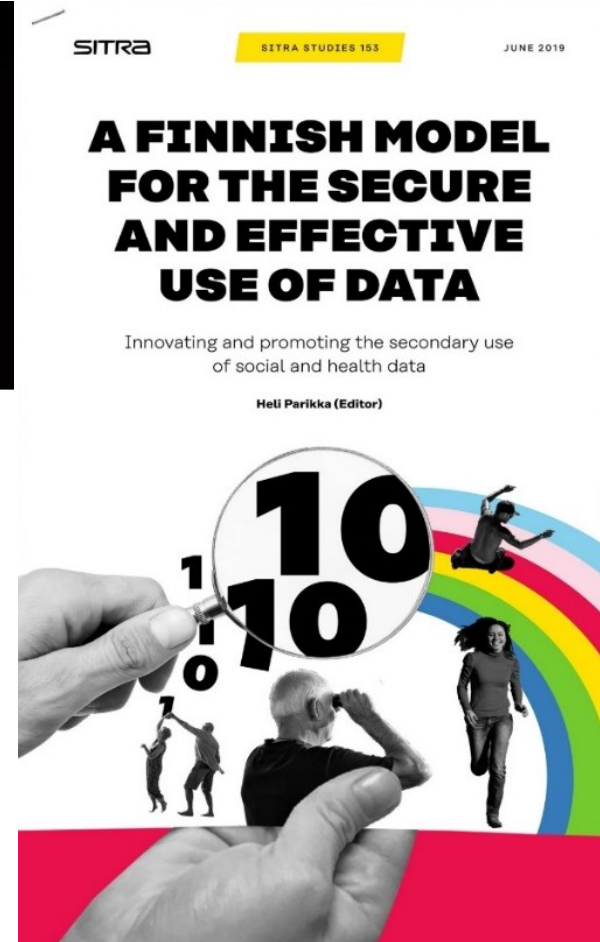
- Findata website
 - <https://www.findata.fi/en/>
- Blog post 5/2019
 - New legislation will speed up the use of Finnish health data <https://www.sitra.fi/en/blogs/new-legislation-will-speed-use-finnish-health-data/> (includes the act in English)
- Sitra study “A Finnish Model For The Secure And Effective Use of Data”
 - Lessons learned from Sitra’s Isaacus project
 - <https://www.sitra.fi/en/publications/a-finnish-model-for-the-secure-and-effective-use-of-data/>



< WELL-BEING DATA
Photo: Miikka Pirinen
Published May 14, 2019

New legislation will speed up the use of Finnish health data

Finland is showing the way by passing new enabling legislation on the secondary use of social and health data.



SITRA

Sitra chosen to co-ordinate Joint Action under the EU Health Programme

Joint Action under the European Commission's third Health Programme will begin next year. The Ministry of Social Affairs and Health has appointed Sitra to act as the competent authority for the initiative in Finland and member states have today chosen Sitra to co-ordinate the Joint Action.

<https://www.sitra.fi/en/news/sitra-chosen-to-co-ordinate-joint-action-under-the-eu-health-programme/>



Finland's role in the joint action is to promote the uptake of EU-wide common practices, particularly in the field of the secondary use of health data.

Coordinator: Sitra

Involved countries: 24

Duration: 2,5 years

Starting date: March 2021

Budget: € 2,5M



Joint Action addressing differences in national General Data Protection Regulation (GDPR) implementation in the health sector, including the European Health Data Space and the health data use

- Helps the Member States and the Commission to develop sharing of health data for better healthcare, policy making, research and innovation
- Three themes
 - **Data governance and rules**
 - Mapping of GDPR implementation
 - Governance structures for secondary use of health data
 - Access of regulators to health data
 - **Data quality and interoperability**
 - Electronic Health Record Exchange Format
 - Making data FAIR
 - **Infrastructure and technology**
 - MyHealth@EU, ERN, 1+ million genomes initiative, existing research infrastructure
 - New projects: upscale MyHealth@EU, use of data for policy making, research and innovation

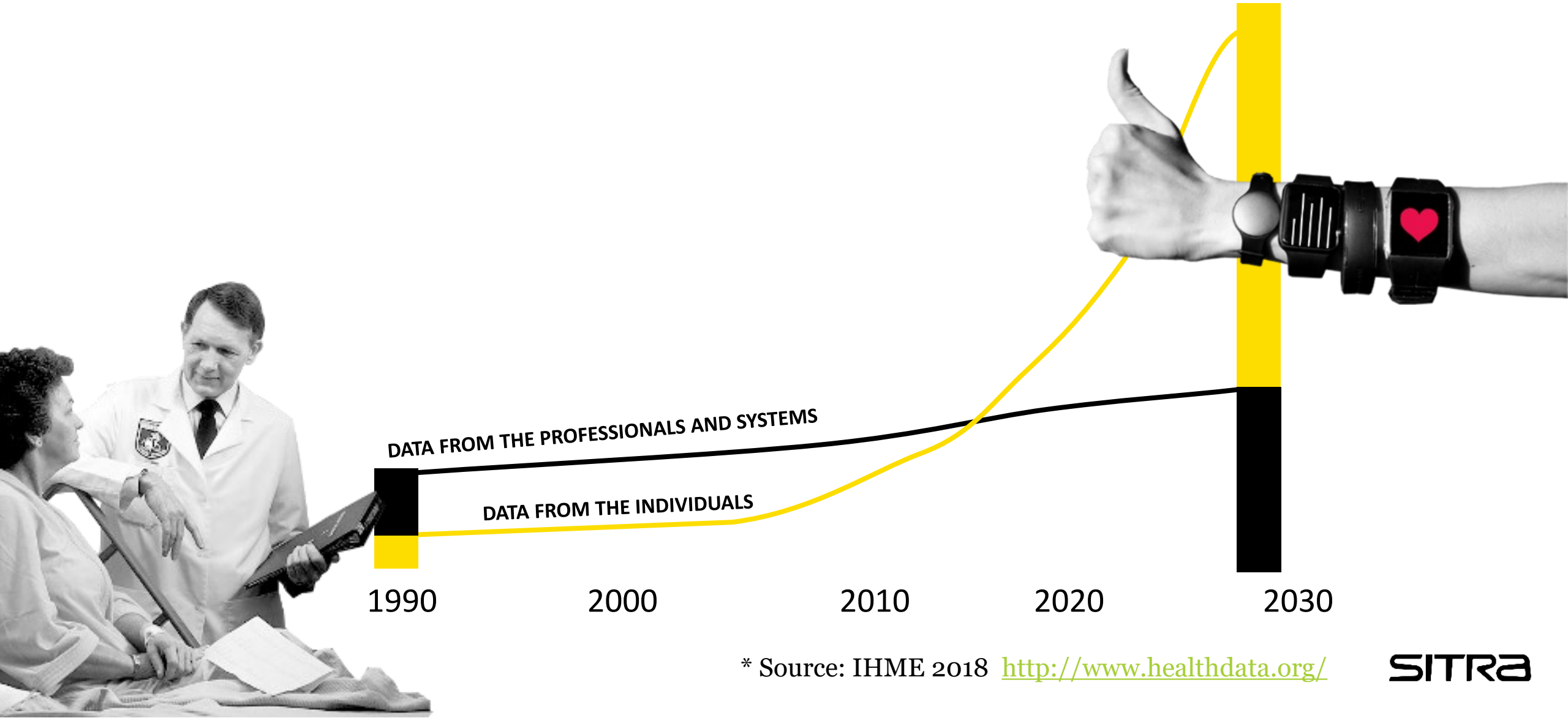
NEXT PHASE FOR VALUE CREATION – COMBINING REGULATED DATA WITH DATA COLLECTED BY INDIVIDUALS

Project IHAN 2018–(2021)

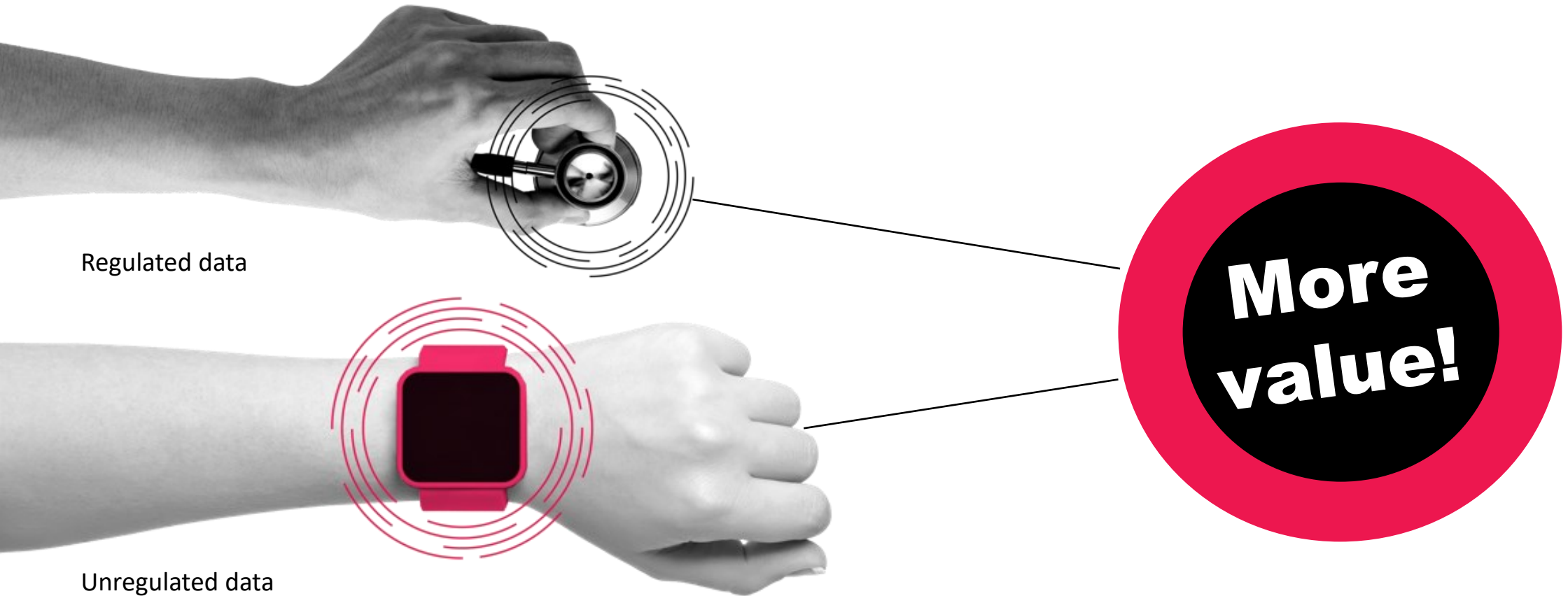
Introduction to Sitra's IHAN®

**FAIR DATA
ECONOMY**

It's Going to Get a Lot More Personal



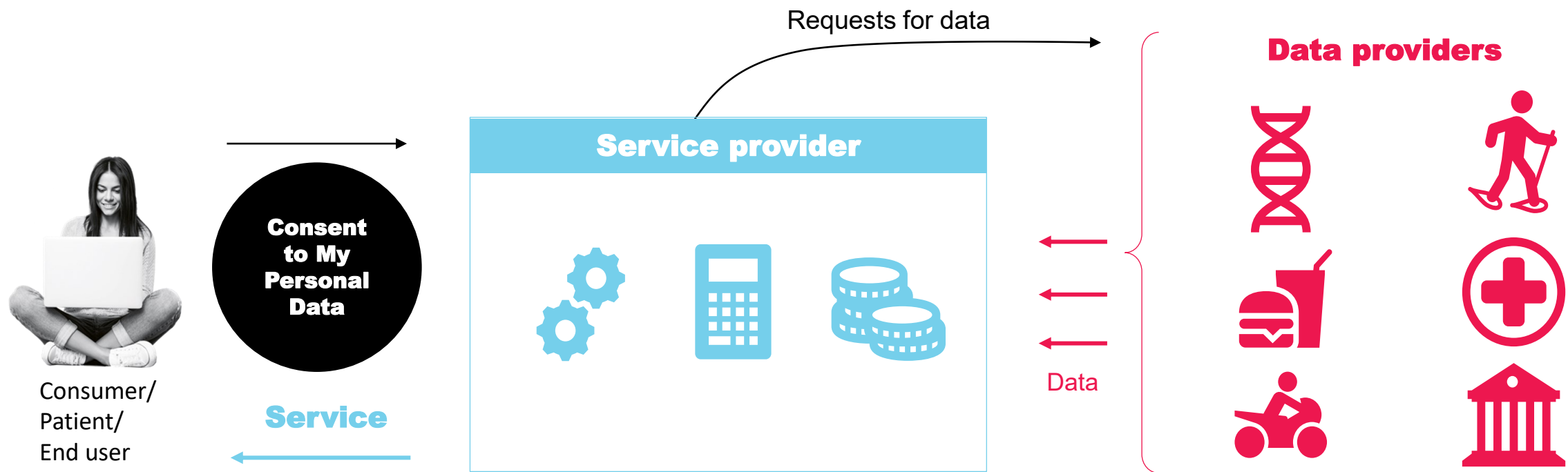
Combining data from professionals and systems with data collected by individuals leads to next phase for value creation



IHAN[®] project

- Building the foundation for a **fair** and functioning **data economy** and creating a common **concept for data sharing**.
- Setting up **European level rules and guidelines** for fair use of data.
- **Piloting** new concepts based on personal data in **collaboration** with pioneering **businesses**.
- Developing an easy way for **individuals** to **identify reliable services** that use their data in a fair way.
- Project started 4/2018 and it runs until (6/2021)

How IHAN[®] works – consent-based data sharing



End user

- New and better services
- Control of personal data – “My consent is needed”
- Trust for fair data use
- Empowerment

Service provider

- No need to beg data from competitors
- Direct authorisation from individuals to use data from other service providers
- Possibility to create new services
- Possibility to collaborate with other service providers

Data provider

- Additional value
- New innovation opportunities
- Public data sources in better use

A European strategy for data

MyData

Corporate
Sustainability

Privacy and Digital Rights

Data Ethics

AWARENESS BUILDING

IHAN® FOR POLICY MAKERS

Facts for Policy
Improvement, Roadmap,
surveys and studies

IHAN® FOR CITIZEN

DigiTrail,
DigiProfile-test,
Campaigns, surveys and
studies

IHAN® FOR BUSINESSES

New Data Economy
Rainmakers –
programme
Corporate responsibility
Focus Group

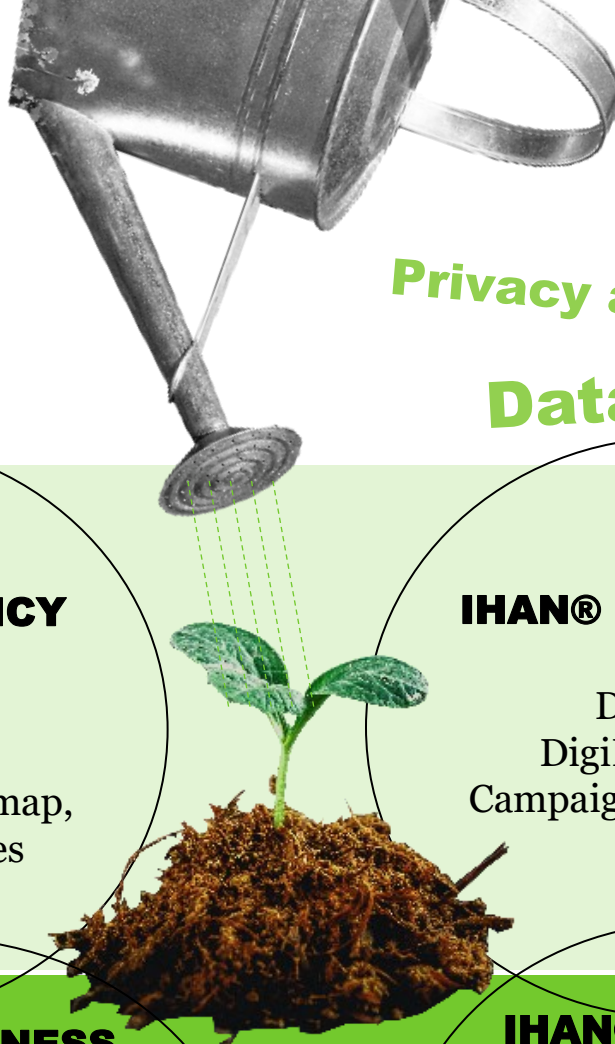
CAPABILITIES BUILDING

IHAN® BUSINESS CAPABILITIES

IHAN® Rulebook for
Fair Data Sharing
IHAN® Business
Programme
Competence development

IHAN® ENABLING ARCHITECTURE

IHAN® Blueprint
IHAN® Testbed
[www.ihan.fi]
Technology Pilots
Governance



Fact-based recommendations



A Roadmap for a Fair Data Economy
35 Proposals to make the European data strategy work
Citizen Survey – the Use of Digital Services
Report on Citizens' values | The Digitrail Survey
The Digiprofile Test

Do you want to
find out more?
Click on the links!

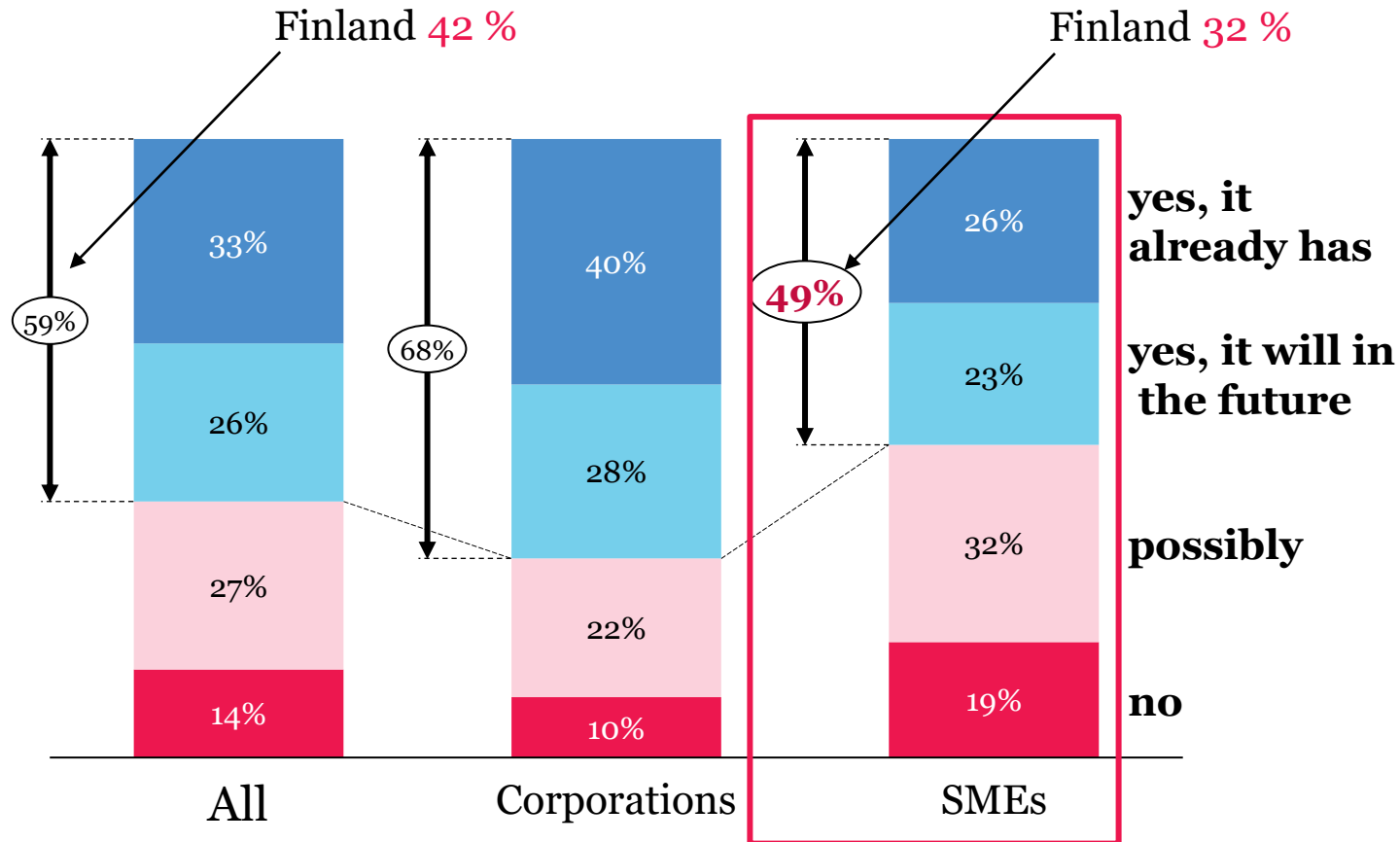
SITRA

Survey details

- **1667 responses** from Finland, Netherlands, Germany and France
- **Respondents** large enterprises and SMEs (excluding entrepreneurs)
- **Survey data was collected** in April and May of 2019.



Less than half of the SMEs saw possibilities in the data economy now or in the future



Source: Sitra Business Survey 05/2019. Question: "Attitude towards data economy: Could data exchange produce competitive edge for your company?" n = 1654

IHAN Business Programme for SMEs

Duration 6 months

**Companies do not
compete with
products, services
nor technologies.**

**Companies compete
with Business
Models**



**State of art
development tools
and processes
tailored for SMEs.**

**Expert support on
demand**

Helping SMEs to create new business
based on shared data

Problem

- SMEs don't necessarily have the needed competencies, resources and time to undertake a full-blown digital transformation initiative
- They do not always possess the energy, will, and know-how to **execute** the change



IHAN Business Programme Objective

1

Support companies to create new data-driven products and services that are based on the principles of fair data economy, delivering value to everyone - the companies, their customers and partners.

2

Lowering the threshold for companies to make decisions and to drive the change in their own organisation.

Programme helps by equipping the companies with new competencies and tools.

3

Scale the program to engage many companies, first 30, then 300 and 3000 to make a lasting and visible impact on national economy as a whole.

Long-term objective is to scale the programme to **other countries** as well.

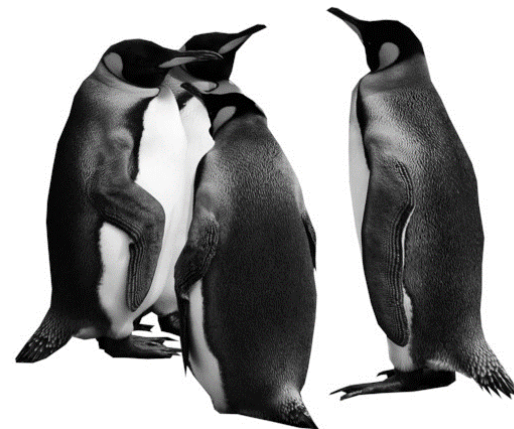
**ONE OF SITRA'S IHAN PROJECT OBJECTIVE IS
TO PROMOTE THE DEVELOPMENT OF DATA
ECOSYSTEMS AND PARTNERSHIPS AND TO
FIND ENTITIES WHO BUILD BUSINESS PILOTS
IN ACCORDANCE WITH IHAN PRINCIPLES.**

DATA ECOSYSTEM IS A GROUP OF ENTITIES THAT WANT TO CREATE **NEW BUSINESS BY** **SHARING DATA WITH EACH OTHER.**

Data is shared with the individual's permission and according to the rules set in the data ecosystem's rulebook. An ecosystem that follows fair rules creates value for all participants. Data can be shared in the ecosystem more freely, transparently and safely.

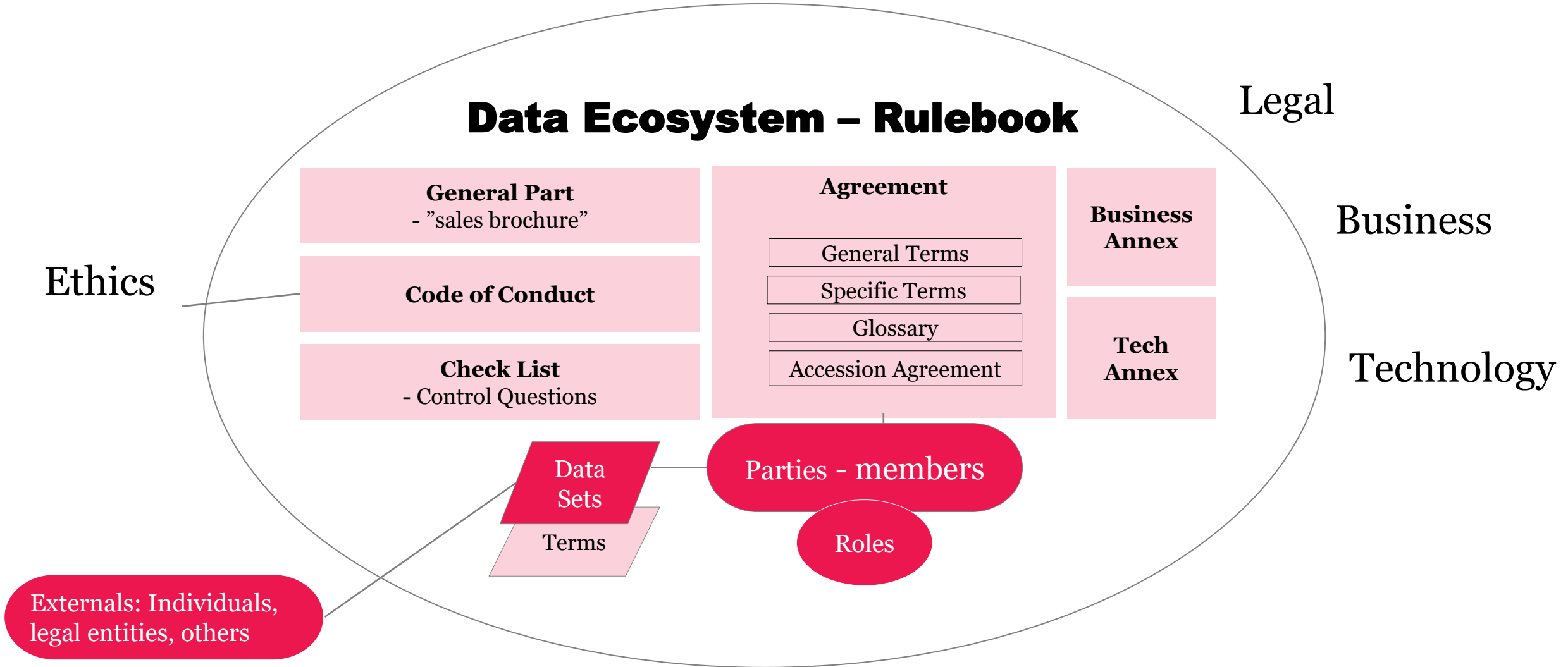
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Value for end-user,
service provider,
data provider and
others...



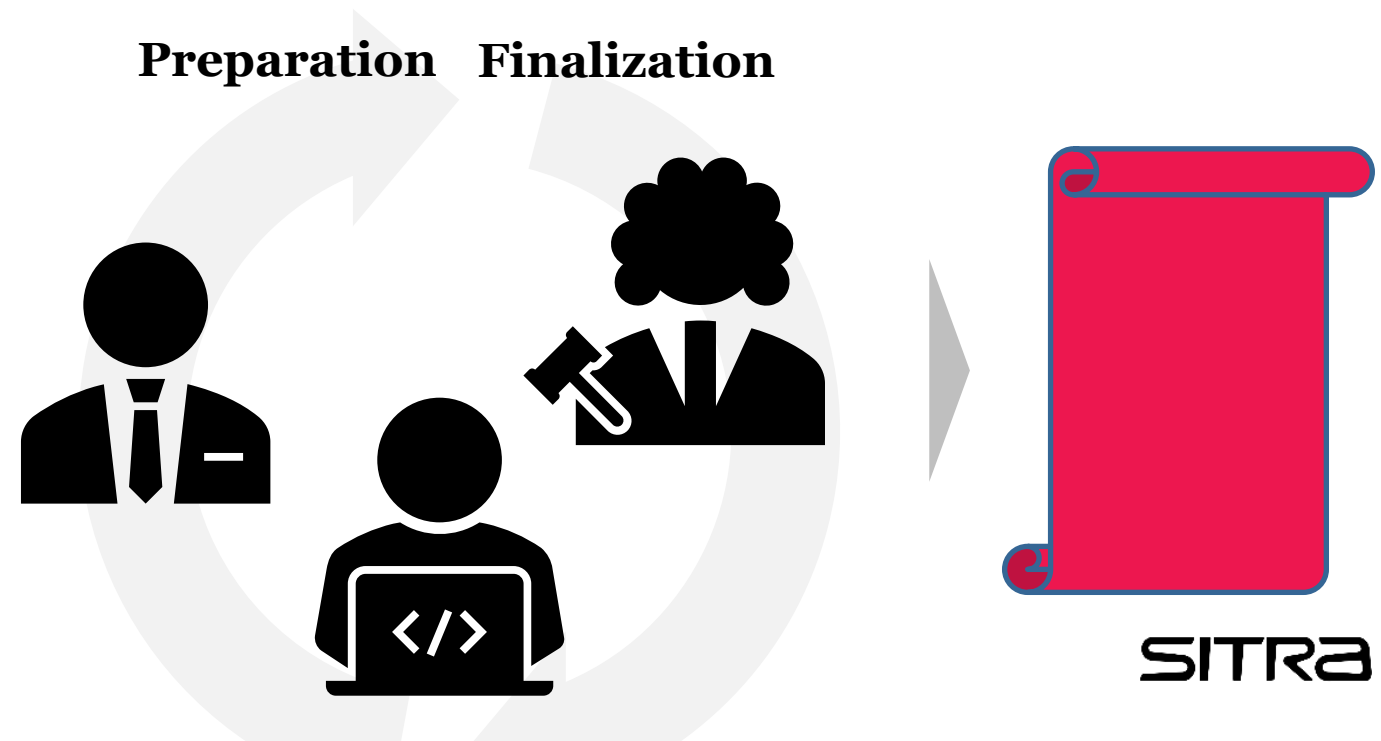
— We are so much
more together!

**RULEBOOK DESCRIBES ORGANISATIONS'
LEGAL, BUSINESS, TECHNICAL, ETHICAL AND
GOVERNANCE FRAMEWORK IN A DATA
ECOSYSTEM. IT IS A FOUNDING DOCUMENT
THAT MEMBERS SIGN TO ADHERE TO.**



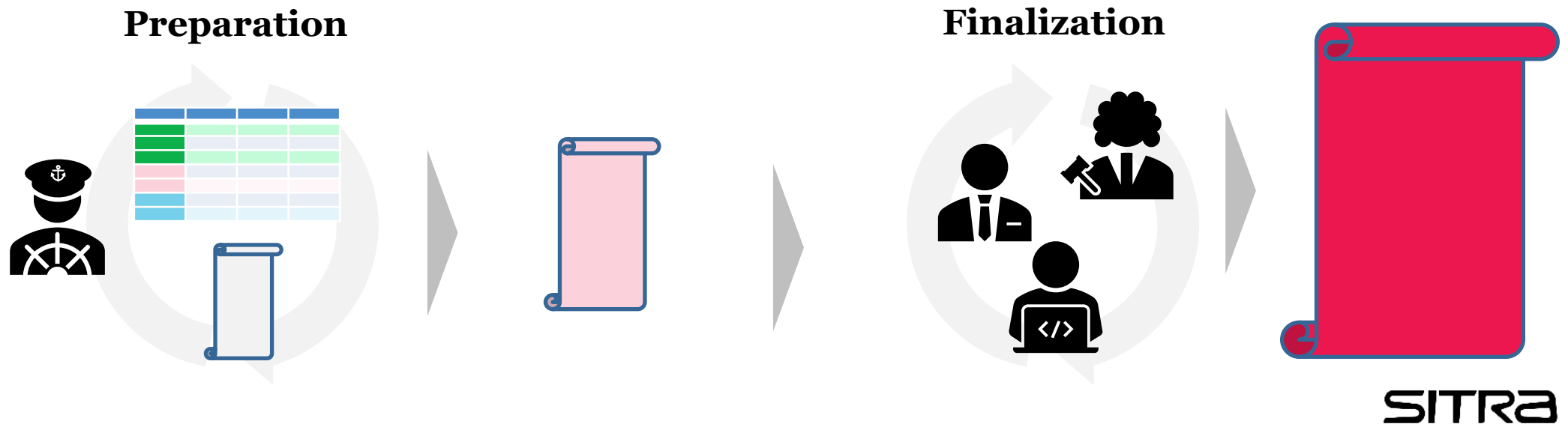
Current state

- Rulebooks are handwritten by expensive experts – lawyers, business developers and IT architects - who start from scratch each time a new rulebook needs to be written
- Very little or no reuse
- Extra iterations are **costly** because these expensive experts are involved in both preparation and finalization phases



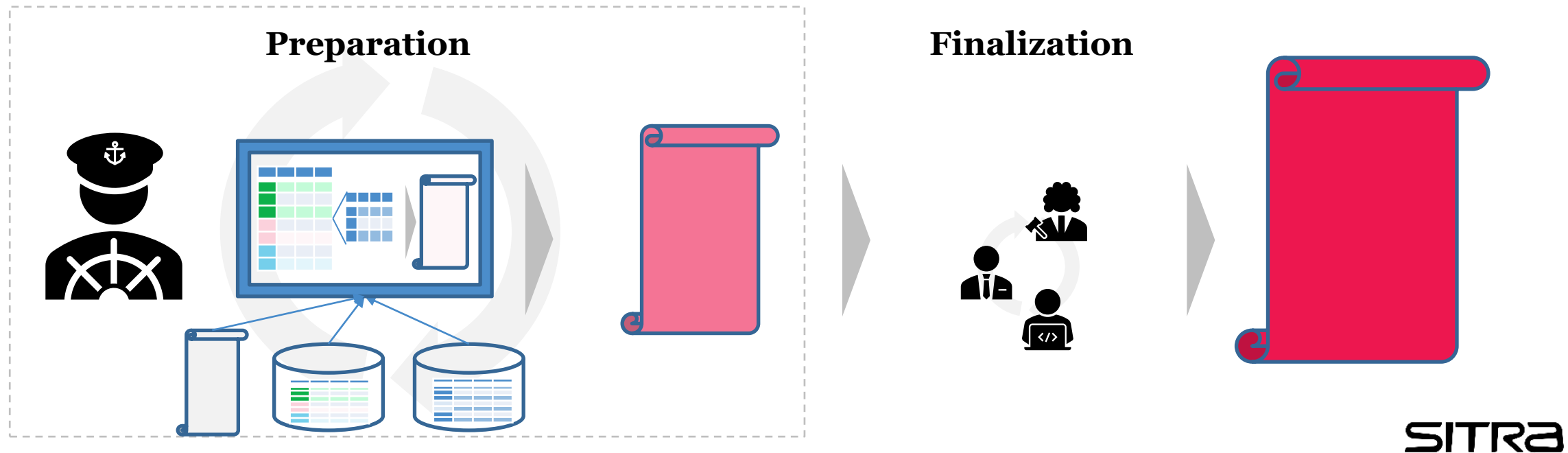
Near future state

- Preparation phase is separated from Finalization phase by creating an initial list of control questions
- By answering to these questions, respective sections in the rulebook template are filled
- This creates the initial rulebook which experts then finalize
- Iterations in the Finalization phase are **reduced**



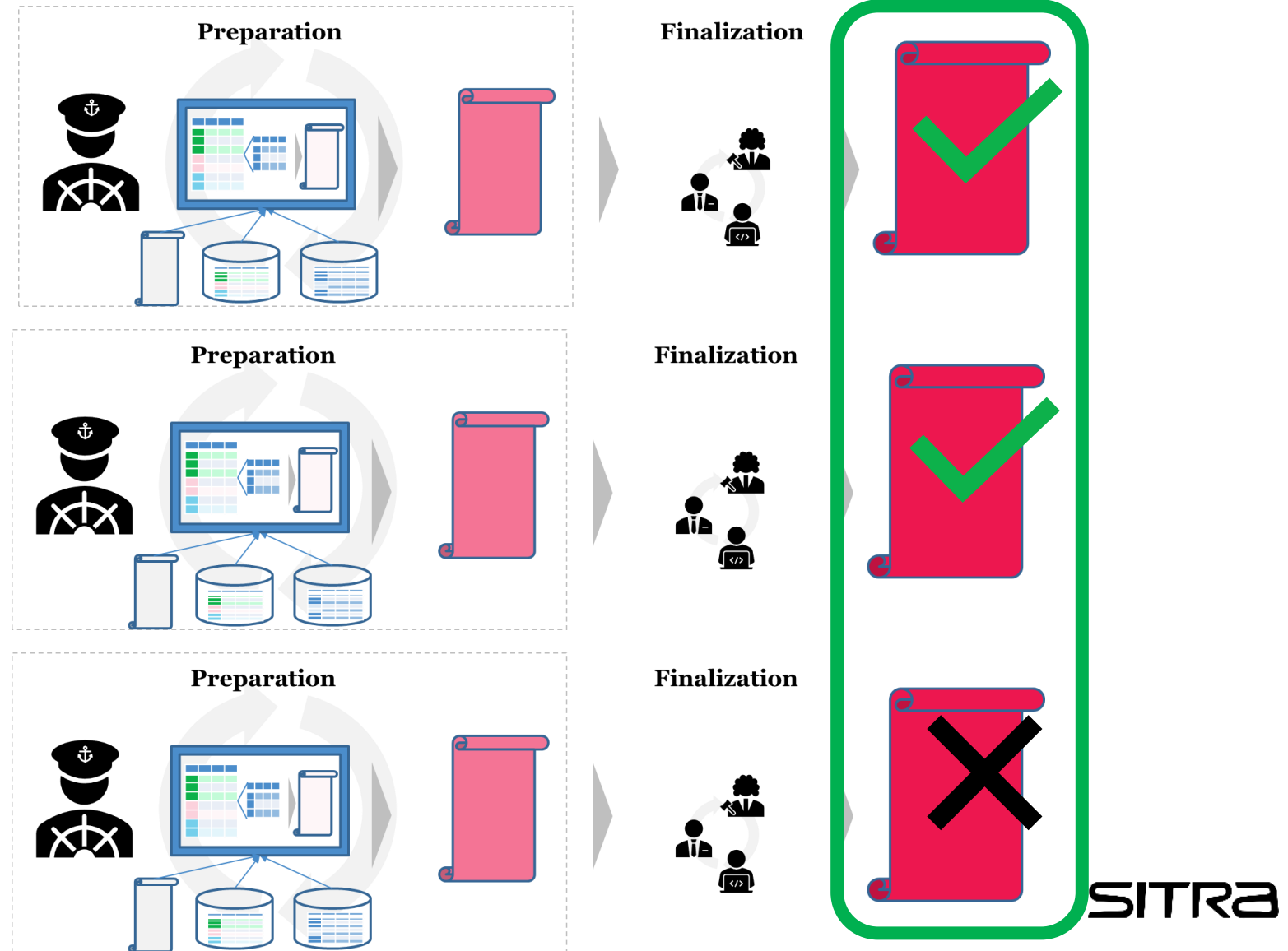
End state

- A tool which automates the creation of the initial rulebook as much as possible and guides the business leaders to go through the control questions
- Iterations in the Finalization phase are **minimized**
- Control questions and rulebook structure are stored in an updateable data repository



Rulebook interoperability validation process

- Ensures that the resulting rulebooks conform to set quality and content standards
- Also ensures interoperability between data ecosystems





Oh yeah!

Benefits

- Easier and cost-efficient creation of the ecosystem rulebook
- Possibility for organisations to join various data ecosystems more easily
- Increasing know-how, trust and common market practises
- Ensuring fair, sustainable and ethically business within the data ecosystems

Next steps

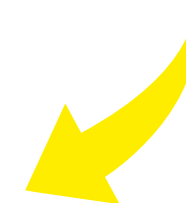
- The first version of the Rulebook is available (since December 2019)
- Rulebook version 2.0 will be available by the end of 2020 including significant improvements from practical experience
- Tool creation will commence after baseline has been stabilized

From European Data Spaces to Global Data Markets

**Data is a product
that must be
exchanged like
any other commodity
in global economy**



**We are building
the future web standards
for global data exchange
with fair rules**



the European data economy testbed

Provided by the Finnish Innovation Fund Sitra, the closed alpha version is out!

access and offer data

On the IHAN testbed you can build apps with harmonised data, offer data as data products with new business models and give authenticated users the control over their data.

do global business

We are building the future business models for global data exchange covering both monetary and ethical values. How does access to data change our economy, trade, consumer behaviour, finance and taxation and how can your company benefit the most?



use future standards

Turn the internet into fair data markets. The IHAN community is defining the technologies and standards for the next era of the internet.

get started!

IHAN testbed is the playground for the future data economy in practice. It shows how the data can change our lives for the better. What is your story?

PLEASE SIGN TO OUR IHAN **NEWSLETTER TO
GET INFORMATION ON OUR FAIR DATA
ECONOMY PROJECT:**

<https://www.sitra.fi/en/topics/fair-data-economy/#newsletter>

+ tick a box "IHAN® – Human-driven data economy"

RISE TO SHINE!



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