Imagine 2029: Our data, our health, our care – 20th anniversary of EHTEL

Kindly hosted by TIC Salut Social

09:30 – 10:45 [S7]

Aula 1
First Floor

Health Data in Use: People – to Services – and back to the People

Guided by the IHAN governance model on fair data use, this session – sponsored by the Finnis Innovation Fund Sitra - demonstrates how to "make data work for people's health".

Session Chair: Jaana Sinipuro, Finnish Innovation Fund Sitra, Helsinki, Finland

IHAN – Building Fair Data Economy in Europe
Hannu Hämäläinen, Finnish Innovation Fund Sitra, Helsinki, Finland

Consent Based Data Exchange for the Benefit of a Diabetic Child – IHAN/HUS Pilot
Birgit Paajanen, HUS Helsinki University Hospital, Helsinki, Finland

SITRA

Citizens as Active Health Data Users and Givers
Henrique Martins, SPMS, Shared Services of the Ministry of Health, Lisbon, Portugal

MedMij - How to Cooperate in Data Ecosystems
Renske Trul, Netherlands Patients' Federation, Utrecht, the Netherlands

The Need for a Common Rulebook for Data Sharing
Saara Malkamäki, Finnish Innovation Fund Sitra, Helsinki, Finland

Q&A and Conclusions by the Session Chair

Symposium Gold Sponsor SITRA

Symposium Silver Sponsors DM+ Coach

T-Systems Let's power higher performance

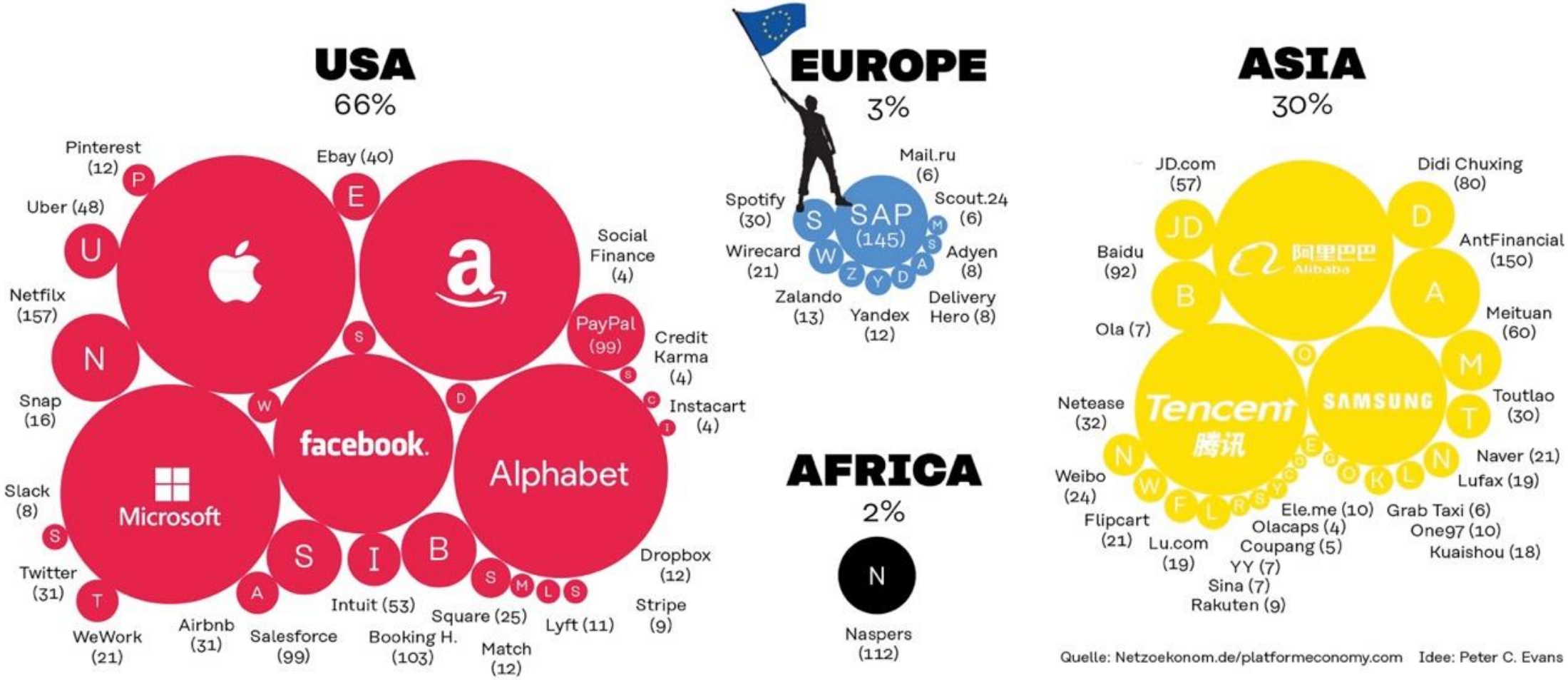
#EHTEL_Symposium #EHTEL_BCN @ehtel_eHealth

IHAN – Building Fair Data Economy in Europe

Hannu Hämäläinen
Senior Advisor
Finnish Innovation Fund - SITRA

Europe’s role in data economy?

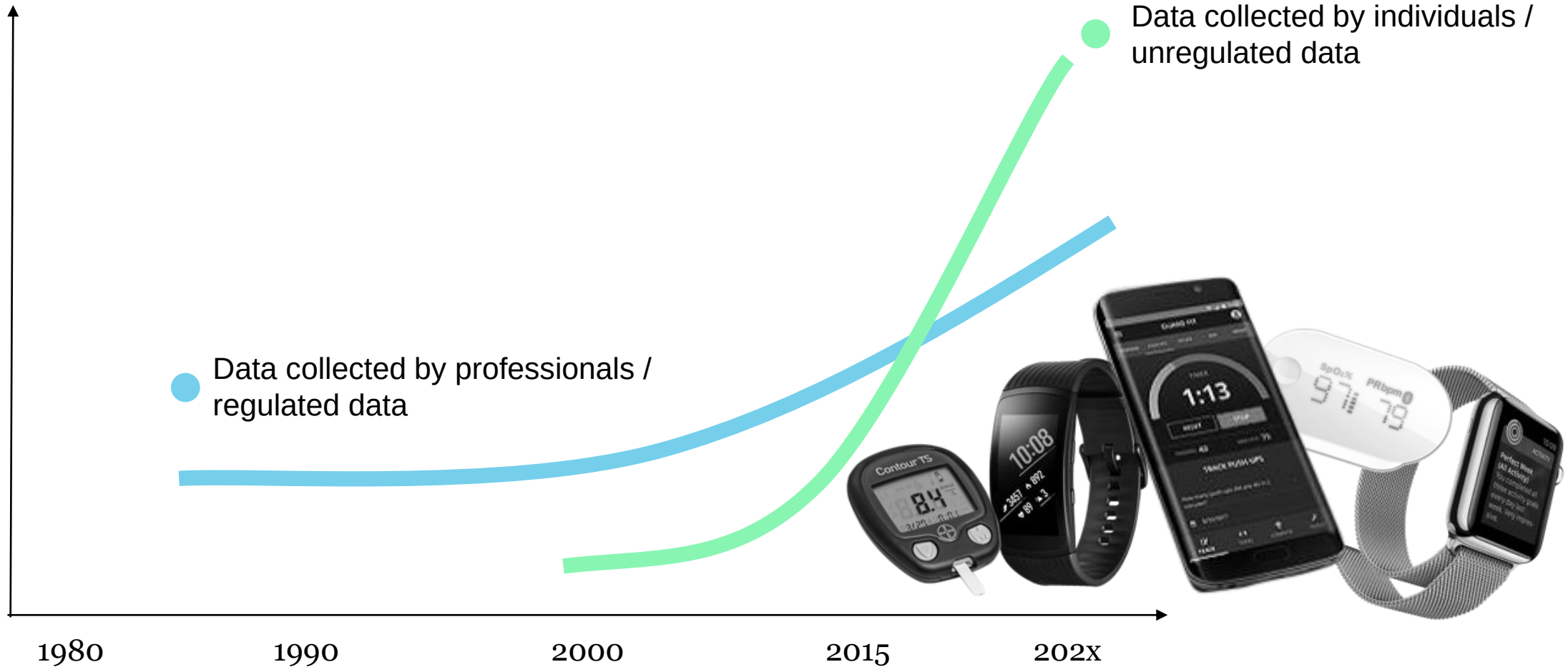
60 platform companies worth
7 trillion USD



Quelle: Netzoekonom.de/platformeconomy.com Idee: Peter C. Evans

Lots of new data sources
– health data being one example

Who creates the data in the future?



Combining regulated data with data collected by individuals leads to next phase for value creation

Regulated data

Unregulated data

SITRA

Great timing!

#GDPR

General Data Protection Regulation and especially Article 20

#PSD2

Payment Services Directive

#eIDAS

EU regulation on electronic identification and trust services for electronic transactions

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Trust – Europe's biggest opportunity?

The European Fair Data Economy Model Based on Transparent Data-Sharing with Individuals' Consent to Lead the New, Sustainable Way.

FAIR DATA ECONOMY

IHAN® project at Sitra 2018–(2021)

SITRA

HIGHLIGHTS

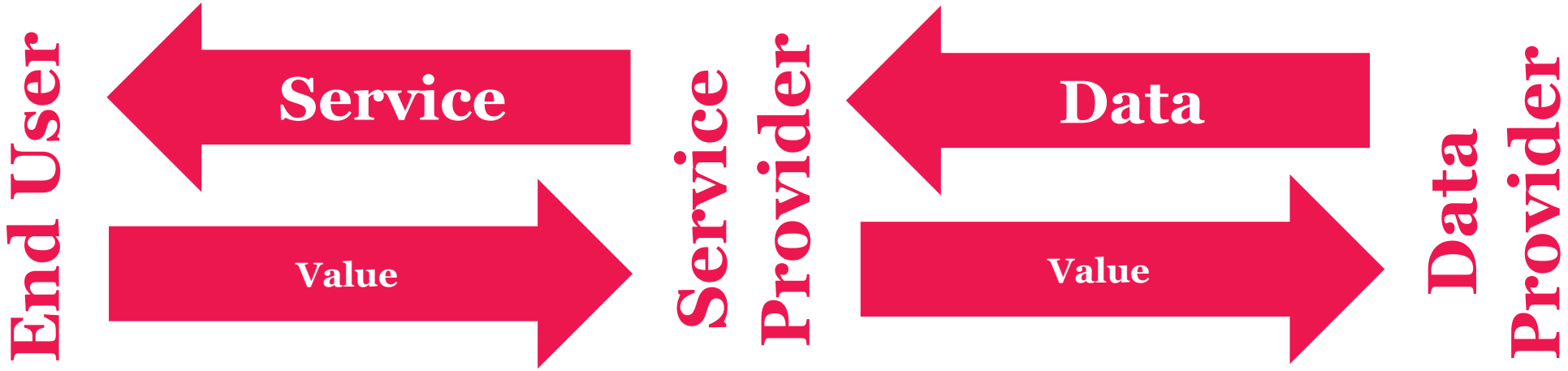
Europeans' attitudes towards the use of personal data survey

- **GDPR rights are quite well-known and the change of actions has already started.**
- **The lack of trust is an obstacle.** It prevents people from using digital services.
- **Data leaks have had a big effect on people's behaviour.** Approx. 1/3 have stopped using some services or changed their privacy settings because of misuse.
- **Two out of three respondents want fair digital services to be identifiable**.
- **Having the power to make decisions is important to people.**

Respondents aged 18-65 in Finland, the Netherlands, Germany and France.
8,004 responses. Finland 2,000, Netherlands 2,000, Germany 2,004, France 2,000.
Survey data was collected in November and December 2018.

Data economy must be FAIR for

End User
Service Provider
Data Provider



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 runs until 6/2021

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How IHAN® works

Consumer/
Patient

Consent to My Personal Data

Service

Service provider

Requests for data

Data

Data providers

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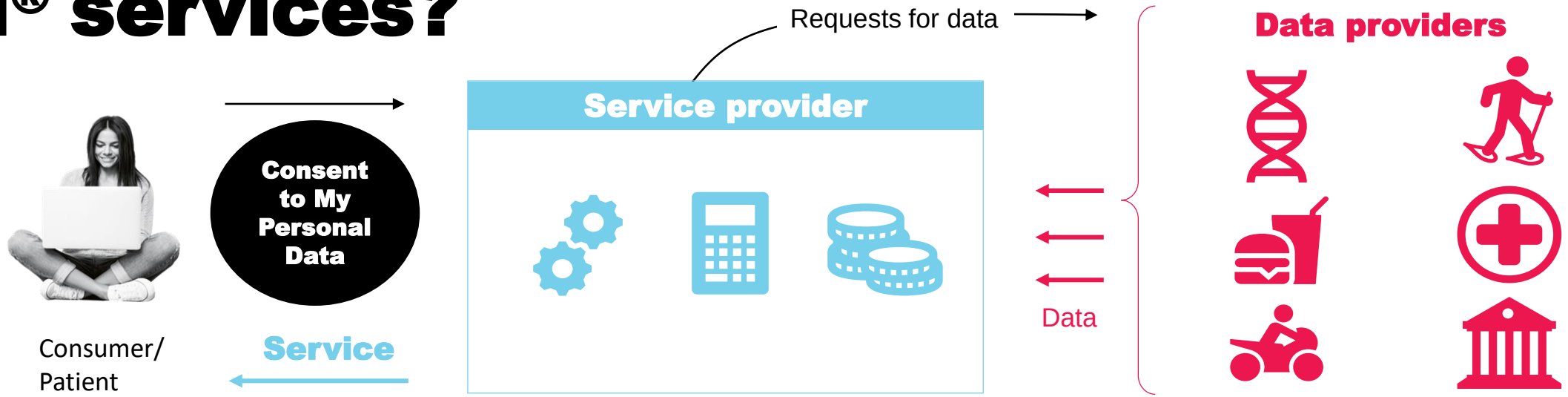
Main findings

1. Most businesses see possibilities in the data economy now or in the future 59 % (Finland 42 %)
2. SMEs have difficulty building competitive edge in data economy.
3. GDPR high achievers understand the value of their data repositories and are ready to create new data-based products and services.
4. One needs to be an ecosystem player to succeed in data economy – Dutch companies have the lead

How does the world look like with IHAN® services?



IHAN

	End User	Service Provider	Data Provider
Identity	Personal Identity Wallet		
Data		Inbound Data Adapter	Outbound Data Adapter
Consent	Personal Consent Directory	Service Provider Consent Directory	Data Access Control
Services	Personal Service Directory	Service Provider Service Directory	
Log	Personal Log	Service Provider Log	Data Provider Log

Outside IHAN boundaries, to be agreed by providers:
Levels of authentication, semantics, data transportation, service delivery, security procedures, industry standards, best practices

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From IHAN components to fair data economy

Technical pilots

A B C D

Open Source Repository

IHAN Blueprint

Concept Building

Data Ecosystem Workshops | Business Trials | Partner engagement | IHAN Leap

MyData

IHAN compliant repositories

Fair Data Economy Policy Brief

Business Pilots & emerging ecosystems

MyData

IHAN Rulebook

Legal
Ethical
Semantic
Technical

IHAN compliant

Components & repositories

IHAN Fair Label

IHAN Governance Model

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RISE TO SHINE!

sitra.fi
@sitrafund

SITRA

IHAN® - MEASURING A CHILD'S BLOOD SUGAR

EHTEL, BARCELONA

DEC. 4TH, 2019

Birgit Paajanen

Development Manager

HUS Development Group

WHERE IS YOUR PERSONAL DATA?

Figure 1.1: Personal data is everywhere. Businesses in all sectors as well as governmental organizations collect increasing amounts of data about us.

Ref.
Antti Poikola, Kai Kuikkaniemi, Harri Honko

MyData
– A Nordic Model for human-centered personal data management and processing

MEASURING CHILDREN'S BLOOD SUGAR WITH THE CONSENT BASED DATA USE

WHY IS THE CHANGE NEEDED?

- Current data flow
- Cost parameters
- Customer/patient support
- Data transparency
- Consent based data usage
- Service – just in time
- Quality decision making

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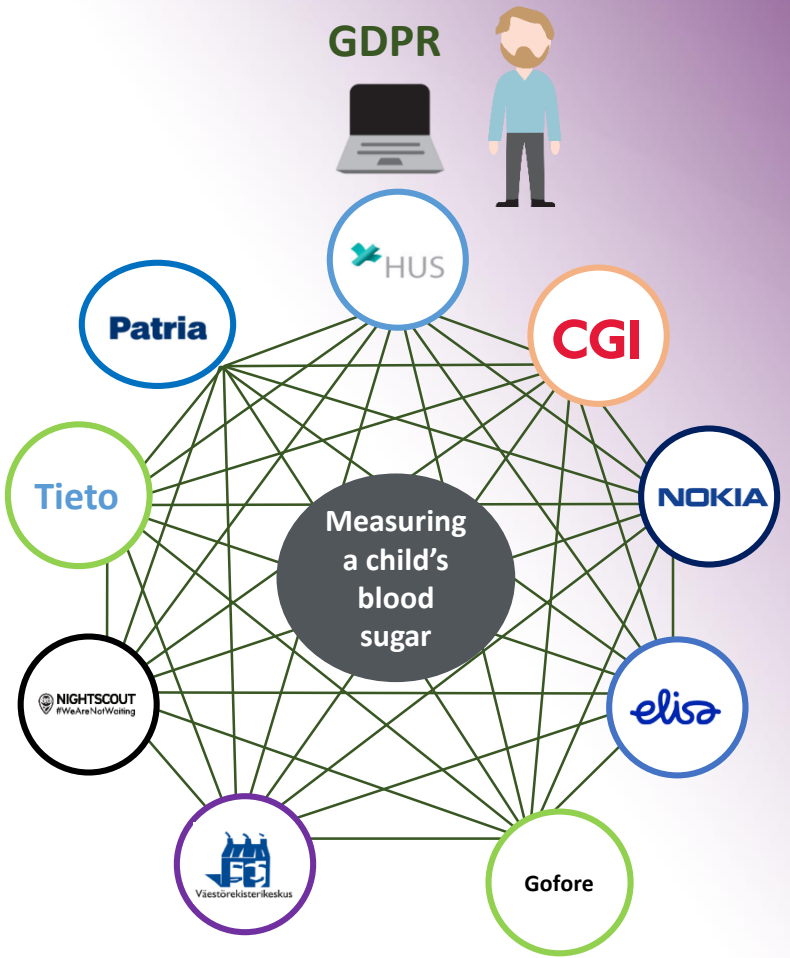
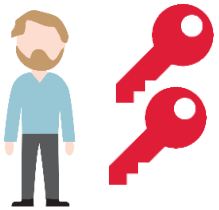
HUS/IHAN®

Distributed ledger technology,
a consensus of replicated,
shared, and synchronized
digital data spread
across multiple sites



KEY COMPONENTS OF THE SOLUTION ARCHITECTURE

Identification



Agreements

Data flow

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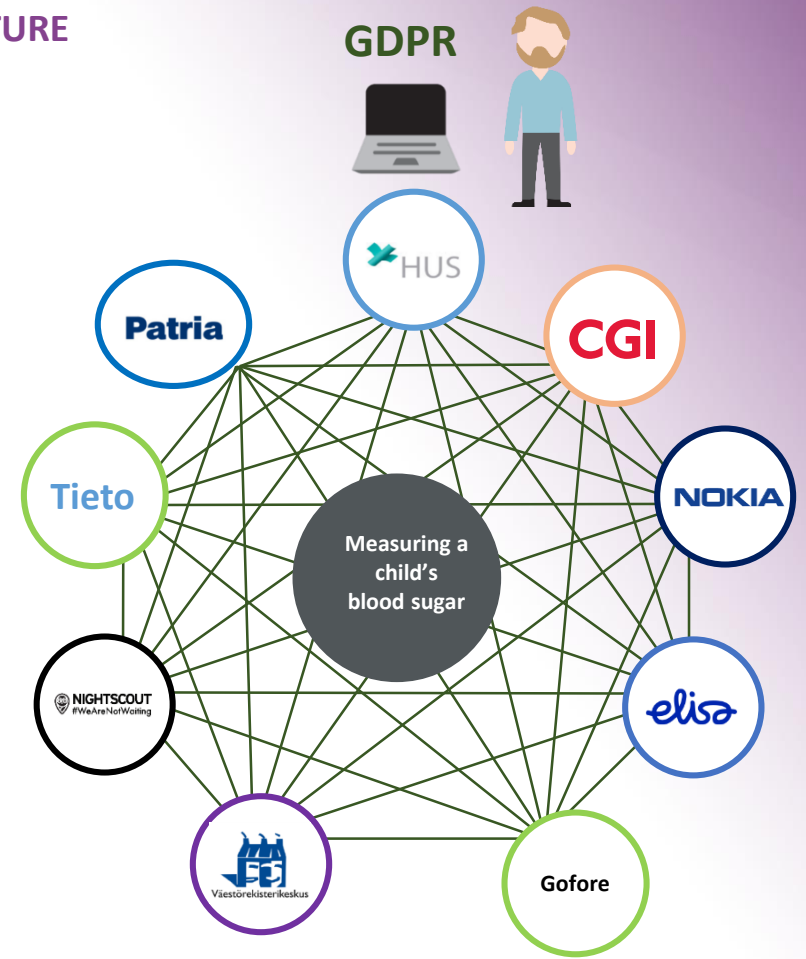
The first Open Source consent based code delivered 9/2019

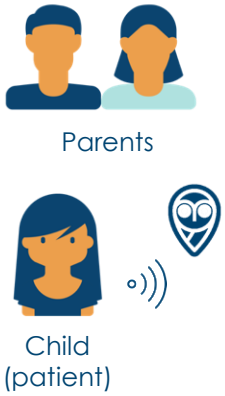


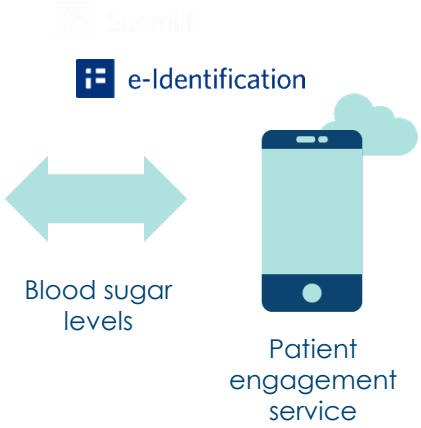
KEY COMPONENTS OF THE SOLUTION ARCHITECTURE

HUS

1. Parents set up a patient engagement service, and connect it with the blood sugar monitoring service.
2. Using the service, a secure connection with HUS is formed and consent is given to retrieve the blood sugar data.
3. Child's data is streamed to HUS IT systems, and the family's diabetes doctor is able to request a consent to directly access the data.
4. The doctor has near real-time access to Child's blood sugar levels, and also a direct engagement channel with the parents.

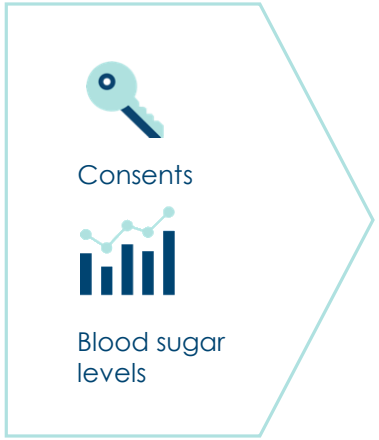
1 On boarding



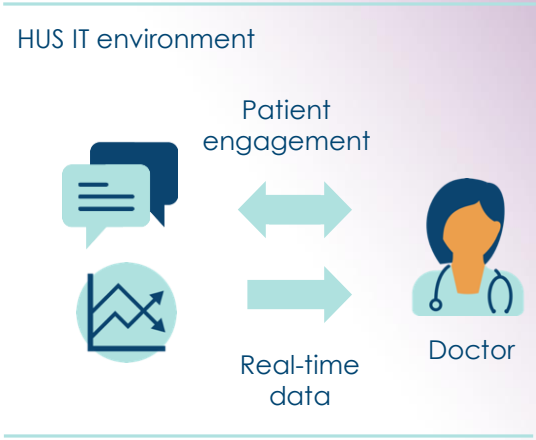


2 Consenting

Testing the Open Source code



3 Data Access

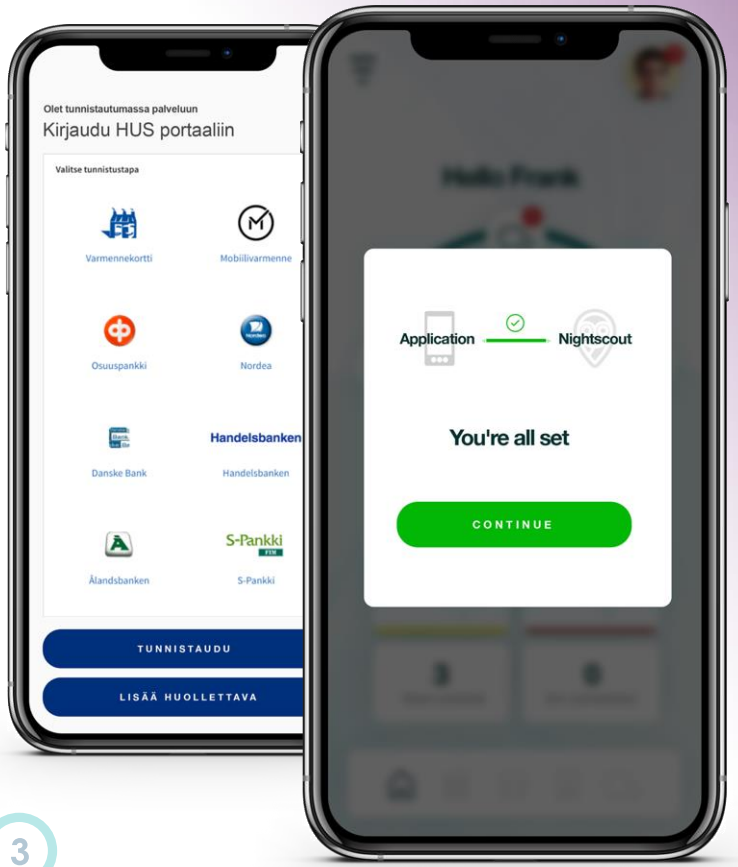


Child's Diabetes Consenting & Data Access

Setting up the patient engagement service

John authenticates to the system, sets up the patient engagement service and links it to blood sugar monitoring system.

Now John is ready to connect with HUS and other data providers.



1 On boarding

2 Consenting

3 Data access

HUS

On boarding

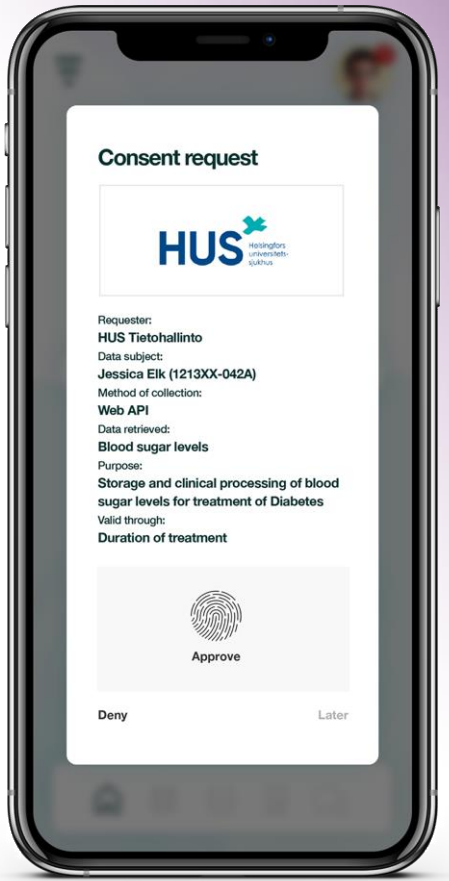
After connecting, John gets a consent request from HUS.

He gives consent to retrieve Jessica's blood sugar levels from her monitoring system.

Consent parties

Data type

Biometric authentication



1 On boarding

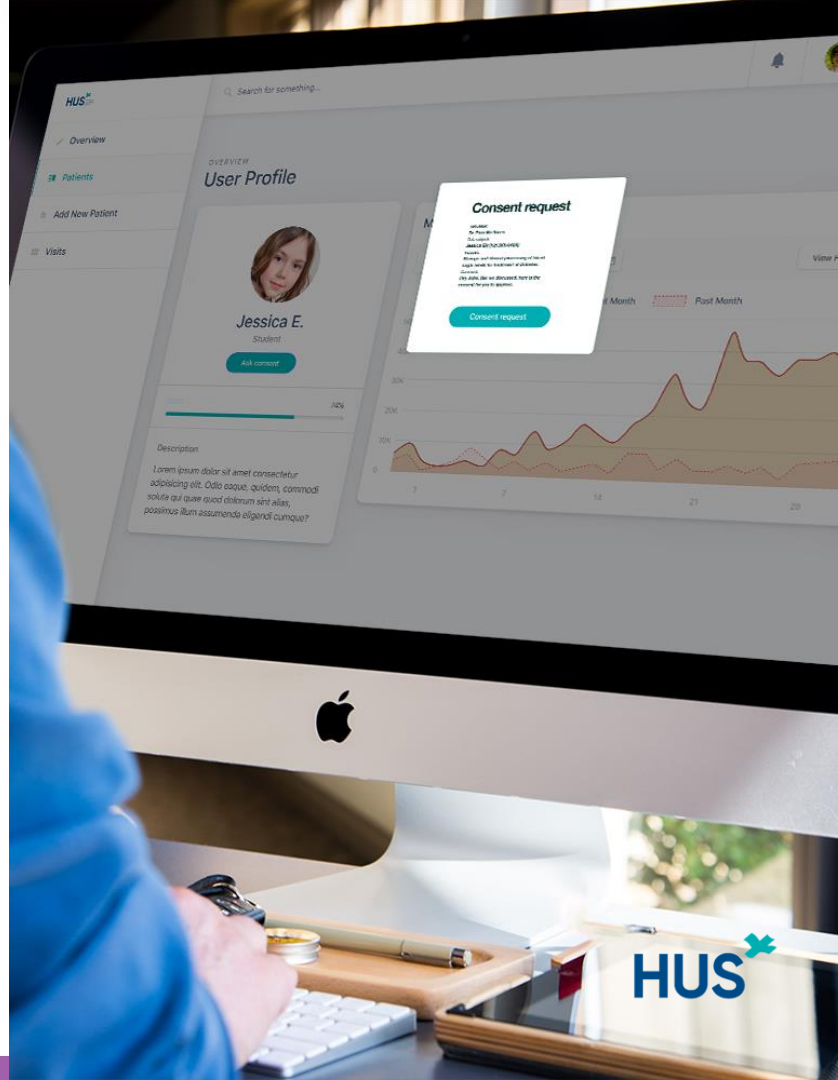
2 Consenting

3 Data access

Requesting consent

Doctor gets a notification that Jessica's blood sugar data is available, but requires separate consent to access the data at HUS IT systems.

Doctor sends a consent request to John for getting access to Jessica's data.



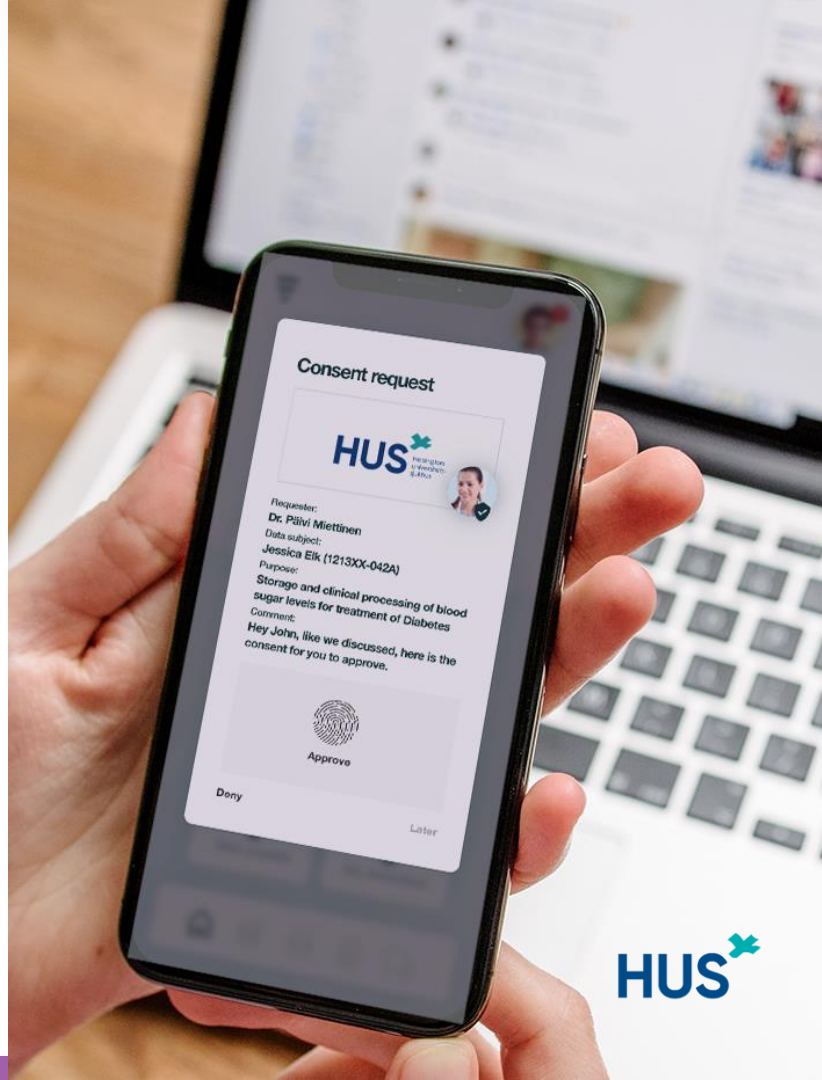
1 On boarding — 2 Consenting — 3 Data access

Giving consent

John receives the consent request and approves it.

Now the doctor has access to Jessica's data.

1 On boarding — 2 Consenting — 3 Data access



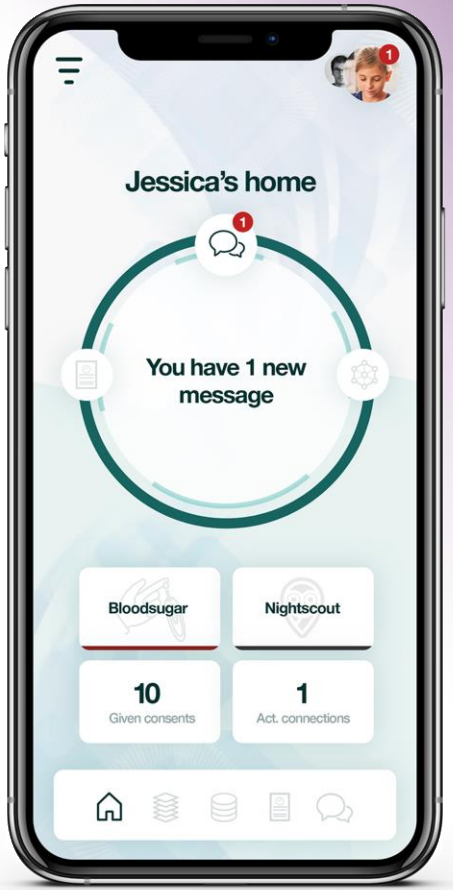
The connection is working

Jessica's blood sugar data is now available to the doctor and she can support John better with Jessica's treatment.

Messages

Health dashboard

Consents



1 On boarding

2 Consenting

3 Data access

HUS

Patient engagement

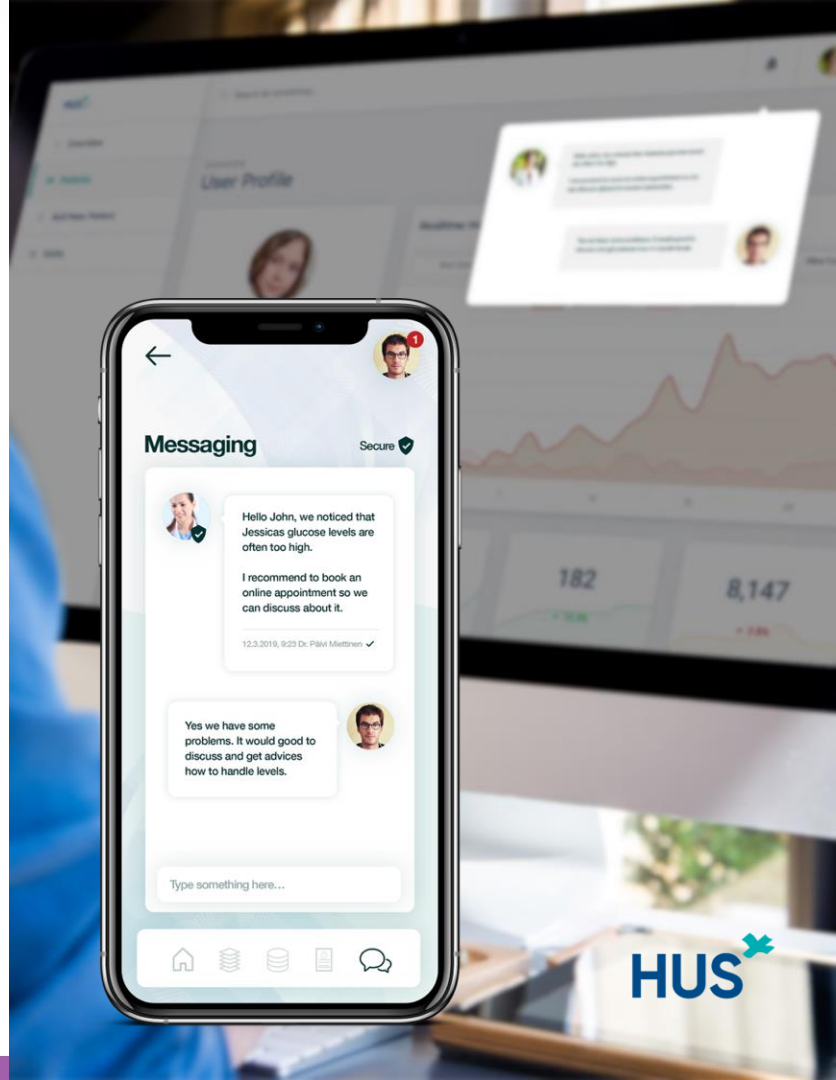
The doctor monitors Jessica's blood sugar levels and notices that her blood sugar keeps crossing the threshold levels.

She wants to check if John needs any additional support.

1 On boarding

2 Consenting

3 Data access



Dream catchers

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Measuring child's blood sugar

WHAT IS NEEDED

in order to change the status quo?

- EA and service architecture
- Service paths
- Data lake
- Consent based data usage
- Platforms
- Scalability
- Partners
  - pre competitive collaboration
- Partnering concept

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SERVICE MAP PROVISION AND INFORMATION FLOW PROCESSES

Patient's personal path connected with unique services

Service selection

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Service selection

Professional's profile connected with services to support patient's personal path

Service architecture connects service operation and information flow

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HUSMAP® SERVICE PLATFORM

PROACTIVE SERVICES *MY CARE*

- My wellnes support
- My health risk follow up services
- My care personalized consultation service

MEDICAL CARE DEFINITION

- Screening
- Care planning services
- Assessment of care needs
- Diagnostics services

SERVICES FOR UNIQUE TREATMENT

- Planning service for unique treatment
- Unique care consultation service
- Psychiatric therapy care
- Surgery care service
- Pharmaceutical care service
- Palliative care service
- Radiotherapy service
- Supporting care service
- Research care service
- Care measure service
- Fertilitation care service
- Obstetric care service
- Symptomatic care treatment

MONITORING SERVICES

- Monitoring service for the effectiviness of traetment
- Referral to care service
- Follow up care planning service
- Discharging service

REHABILITATION, THERAPY AND AID SERVICES

- Physiotherapy service
- Physiatry service
- Occupational therapy service
- Psychosocial support service
- Aid service
- Play therapy service
- Nutritional therapy service
- Speech therapy service
- Peer support service
- Social service
- Work integration service
- Interpretation service

PATIENT SUPPORT SERVICES

PATIENT CARE SERVICES

- Nutrition service
- Clothing service
- Transportation service
- Laundry service

ADVISERY SERVICES

- Advisery service
- Information servie

APPOINTMENT SERVICES

- Appointment service

ACCOMODATION SERVICES

- Patient hotel service

SERVICES FOR EXPERT

- Research service
- Partnership service
- Expert service
- Consultation service
- First aid on-duty physician service
- Preparation and preparedness planning
- Education service

SUPPORT SERVICES FOR PATIENT'S FAMILY

- Accomodation services for relatives
- Psychological support service for relatives
- Peer support for relatives

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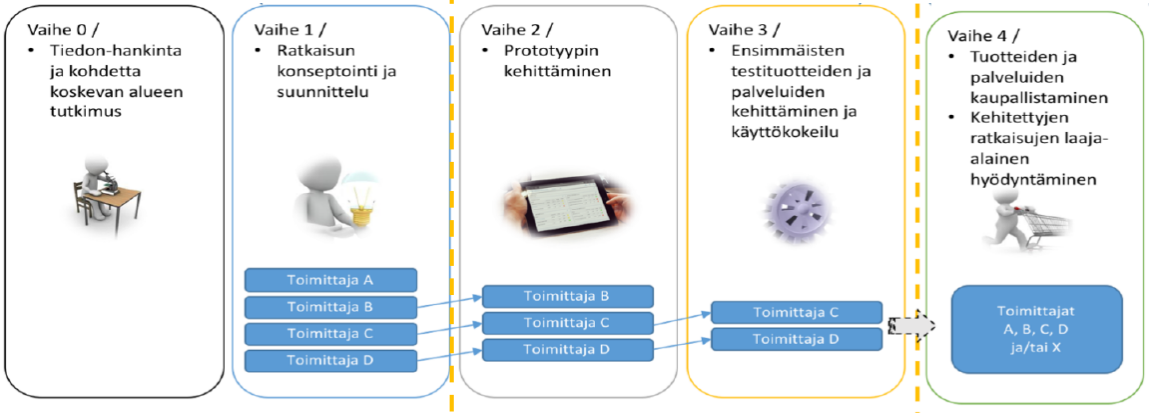
PRE COMPETITIVE COLLABORATION AND HUSMAP PLATFORM PILOT

DEVELOPMENT PLATFORM FOR PRE COMPETITIVE COLLABORATION

Business modelling	Before calling for bids an option to develop the solution at the HUSMAP-platform is offered. The platform architecture is owned by HUS.		After the testing and the bidding phases HUS can by the solution created according of the HUS architectural principles
Environment	Sandbox / environment		Production environment (Patient information systems)
Data	Synthetic data	Synthetic data/or a limited, consent based real patient data	Consent based real patient data



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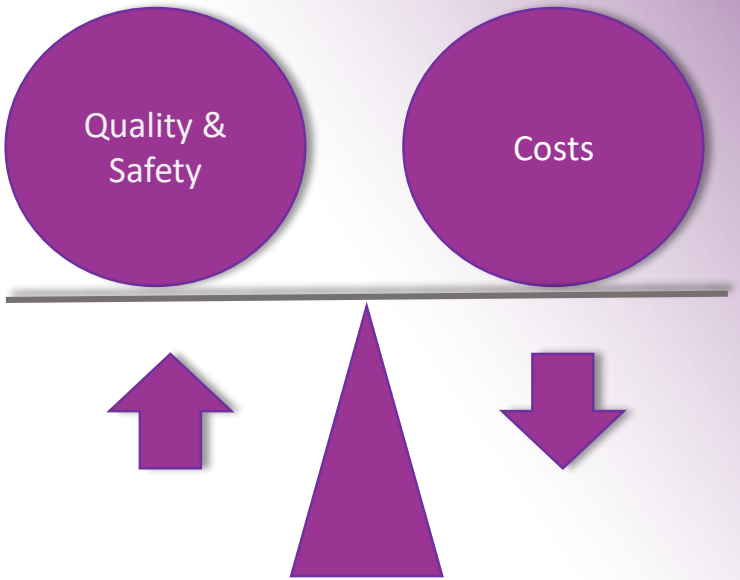
HUS PILOT AND PRE COMPETITIVE COLLABORATION

- HUS collaboration model rules apply
- Funding parties conditions apply e.g. Sitra
- Public sourcing and mandatory regulation apply
- Access to collaborate first restricted due to focus and time to deliverables pressure -> goal to open this in later phases
- Deliverables after finishing open to all
  - Open source code
  - API's and their descriptions
  - IHAN specific architecture and code
  - IPR policy created by HUS



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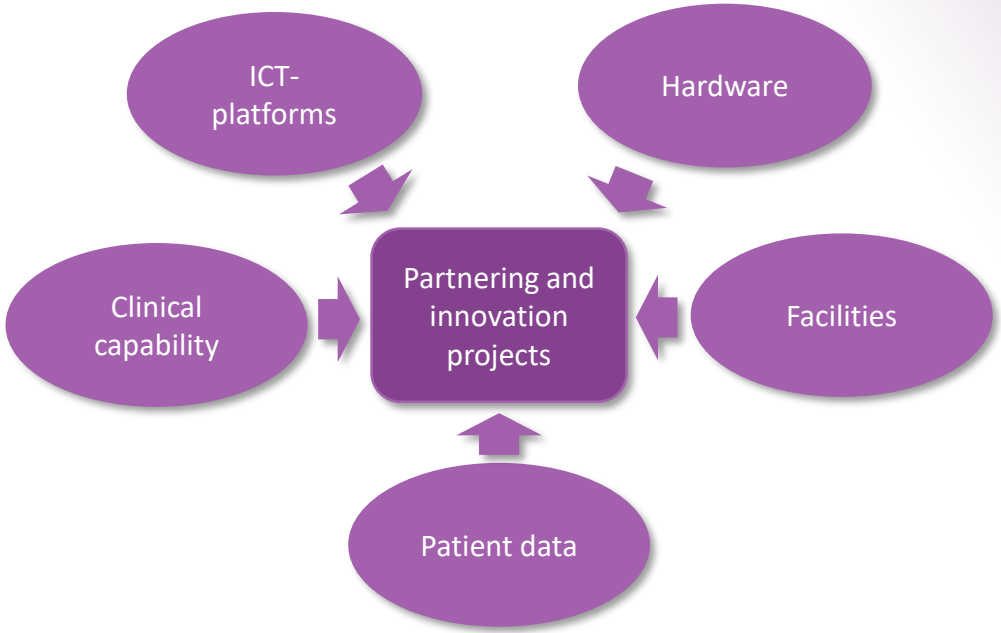
HUS ECOSYSTEM RESOURCES TO IHAN ®

Measuring child's blood sugar



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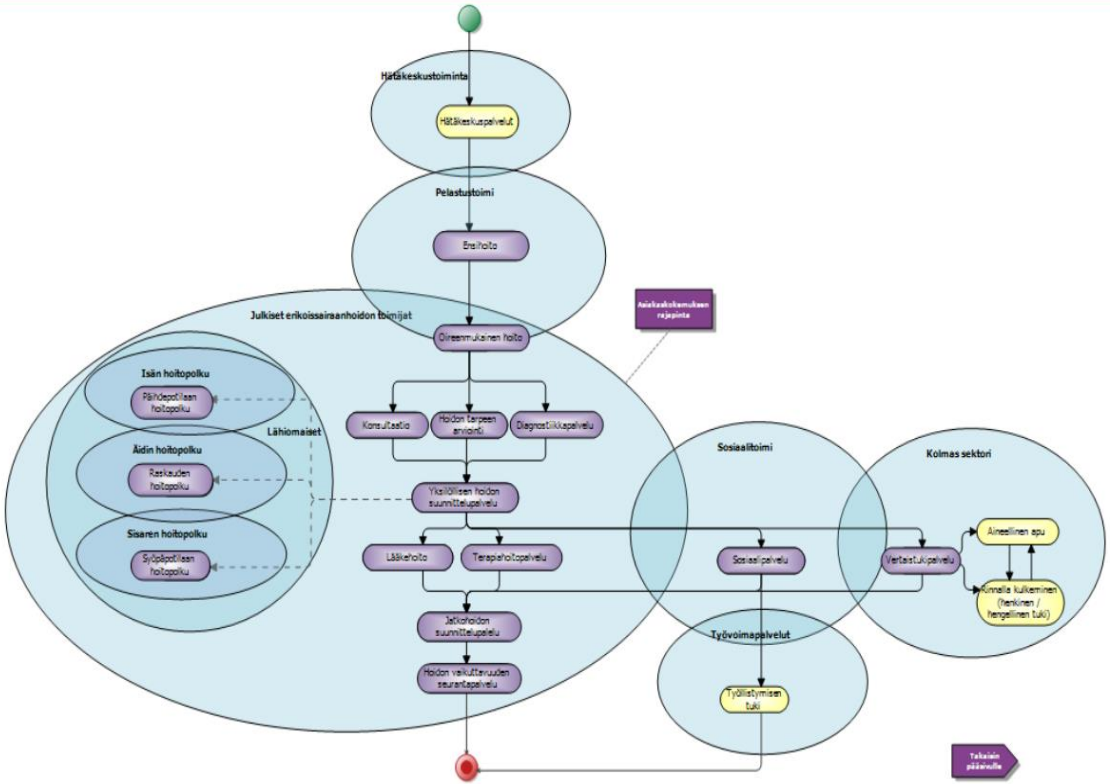
SCALABLE SERVICE PATH



Measuring child's blood sugar

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HUSMAP® AND IHAN® SOLUTION AIM

- *The whole development concept is aiming to build a sustainable development platform to carry the critical and authorized information like blood sugar level between different parties e.g. the patients' families, health professionals and schools and sport clubs to support daily life's safety of diabetic children.*

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THANK YOU

Imagine 2029: Our data, our health, our care – 20th anniversary of EHTEL

EHTEL 2019 Symposium

Henrique Martins
President of the Portuguese Shared Services for the Ministry for Health

REPÚBLICA PORTUGUESA
SAÚDE

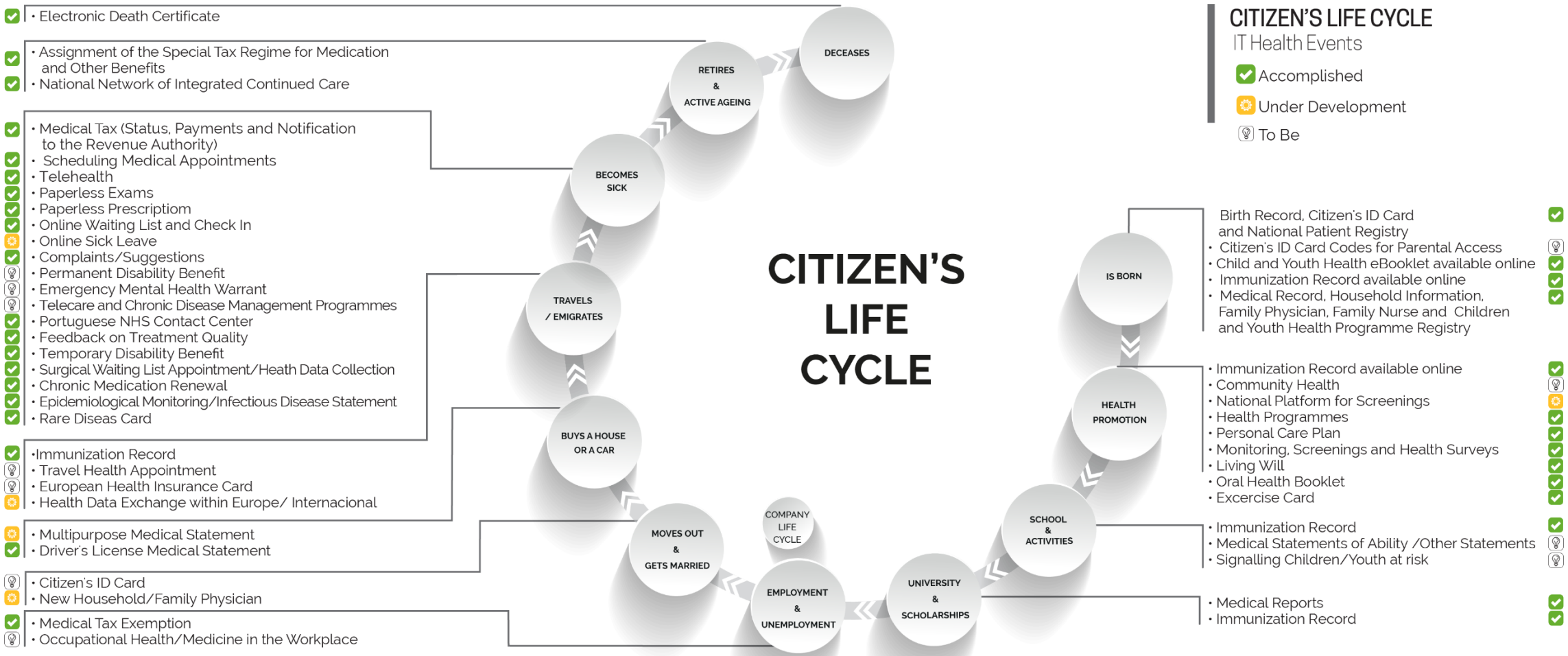
40 ANOS SNS SERVIÇO NACIONAL DE SAÚDE 1979-2019

SPMS EPE
Serviços Partilhados do Ministério da Saúde

EHTEL

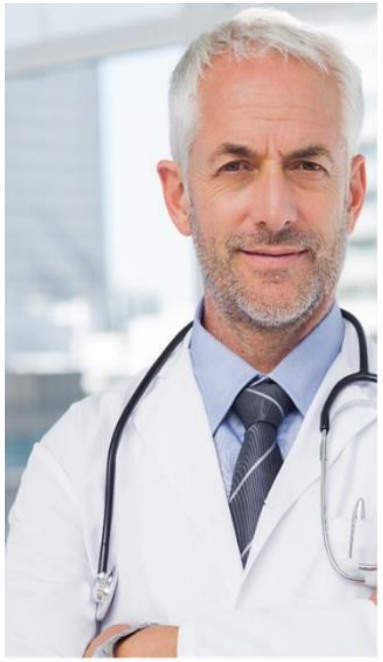
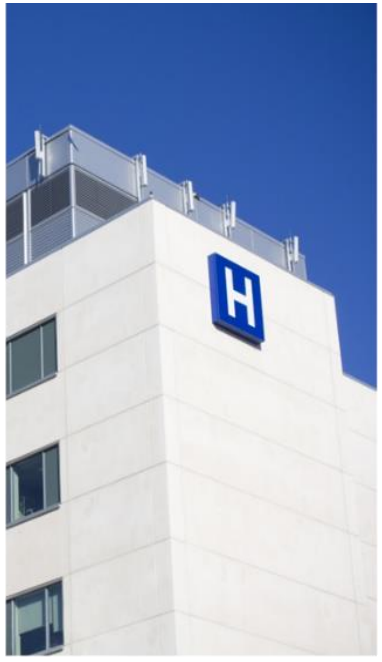
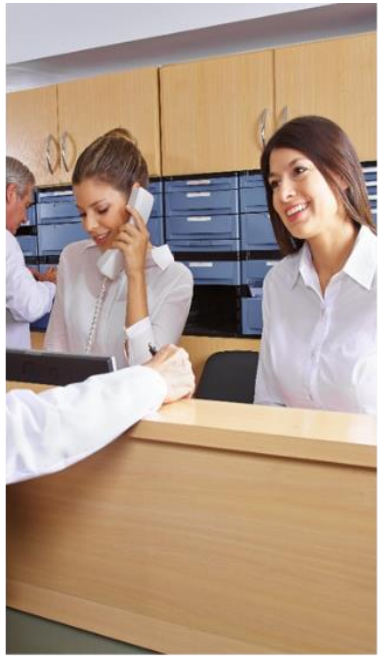
SHARED SERVICES FOR MINISTRY OF HEALTH (SPMS)

Electronic Health Record (EHR)



Electronic Health Record (EHR)

Electronic Health Record (EHR)

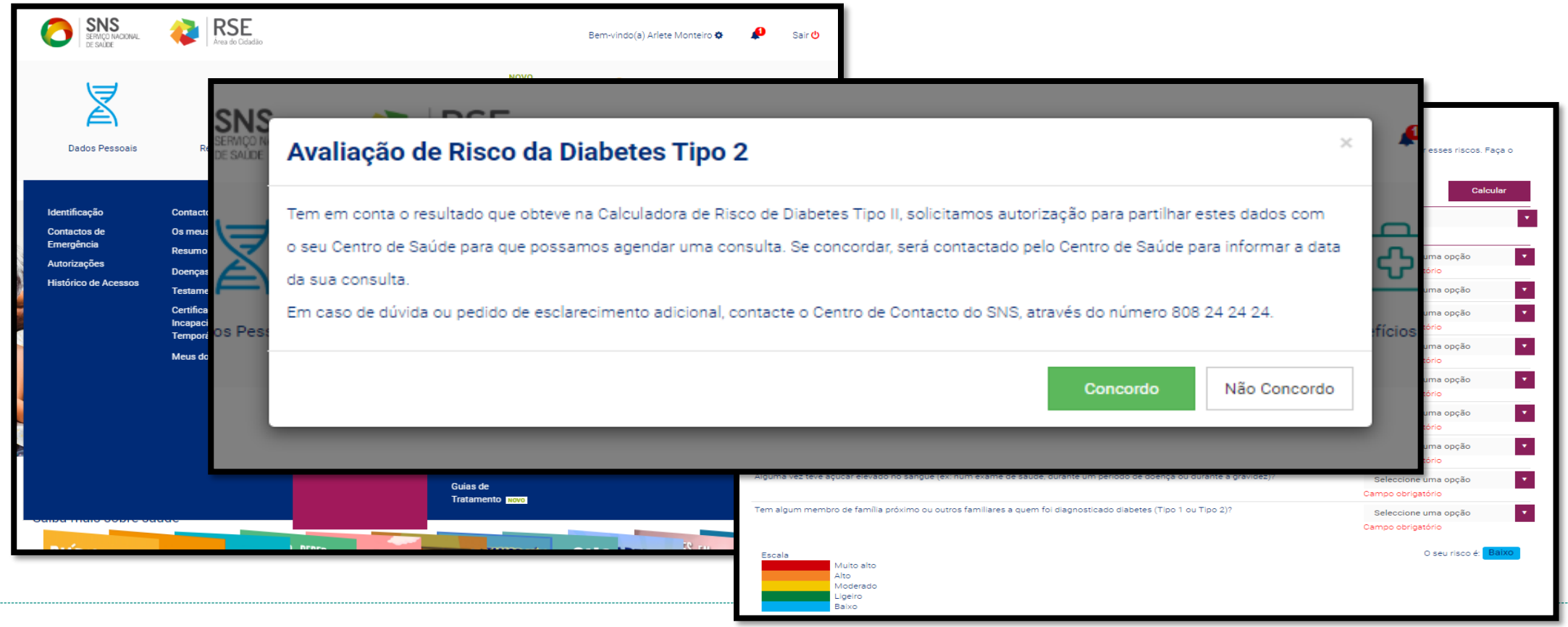
CITIZEN'S AREA	PROFESSIONAL'S AREA	INSTITUTIONAL AREA	ADMINISTRATIVE AREA
			

Electronic Health Record (EHR) – Citizen's Area

Electronic Health Record (EHR) – Citizen's Area

Electronic Health Record (EHR) – Citizen's Area

- Citizen Portal - @RISK (Diabetes risk calculator)



SPMS - Serviços Partilhados do Ministério da Saúde, E.P.E. www.spms.min-saude.pt

Electronic Health Record (EHR) – Citizen's Area

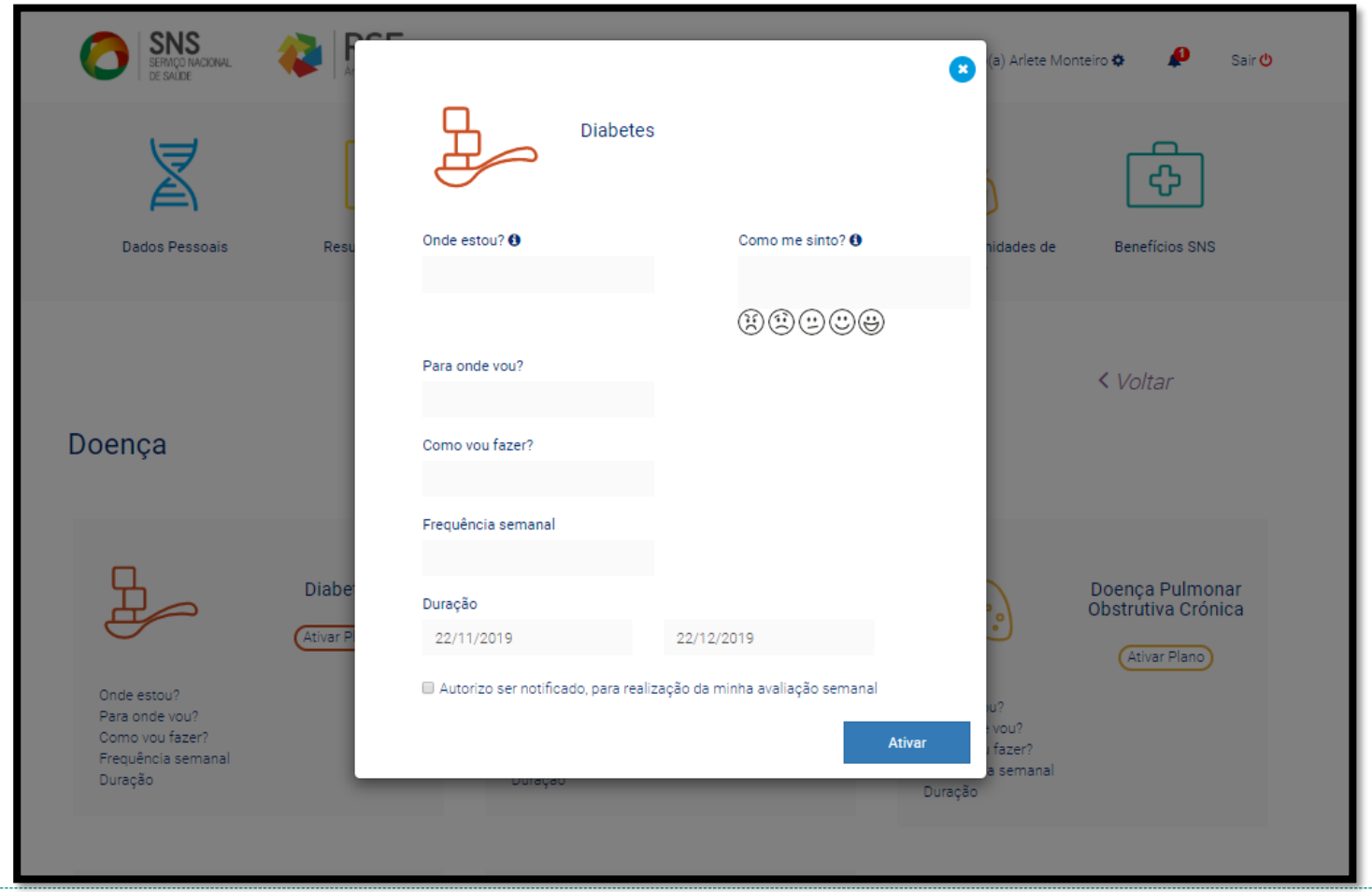
- Citizen Portal - @RISK (Diabetes risk calculator)

From **01/01/2019** to **31/10/2019**:

- **6.160 Citizens** used the @RISK Tool through the SNS Citizen Portal to evaluate their Diabetes type II Risk;
- **3.122 Citizens** got a Severe, High or Very High test result;
- Those 3.122 Citizens were invited to be contacted by their Primary Care Unit to book an appointment for a diabetes screening: only **900 Citizens** accepted.
- Until now, **713** of those 900 Citizens already went to the appointment for diabetes screening at their Primary Care Unit;
- **26 Citizens** were diagnosed with diabetes;
- At this point, **10** of those 26 Citizens are medicated with an oral antidiabetic, with an average cost of 12,00€ per person, per month = (10x12x12euros= 1240 Euros)
  - (the cost of a 3 days hospital stay for inaugural diabetes varies between 1.320,00€ and 4.630,00€ (with or without coma).

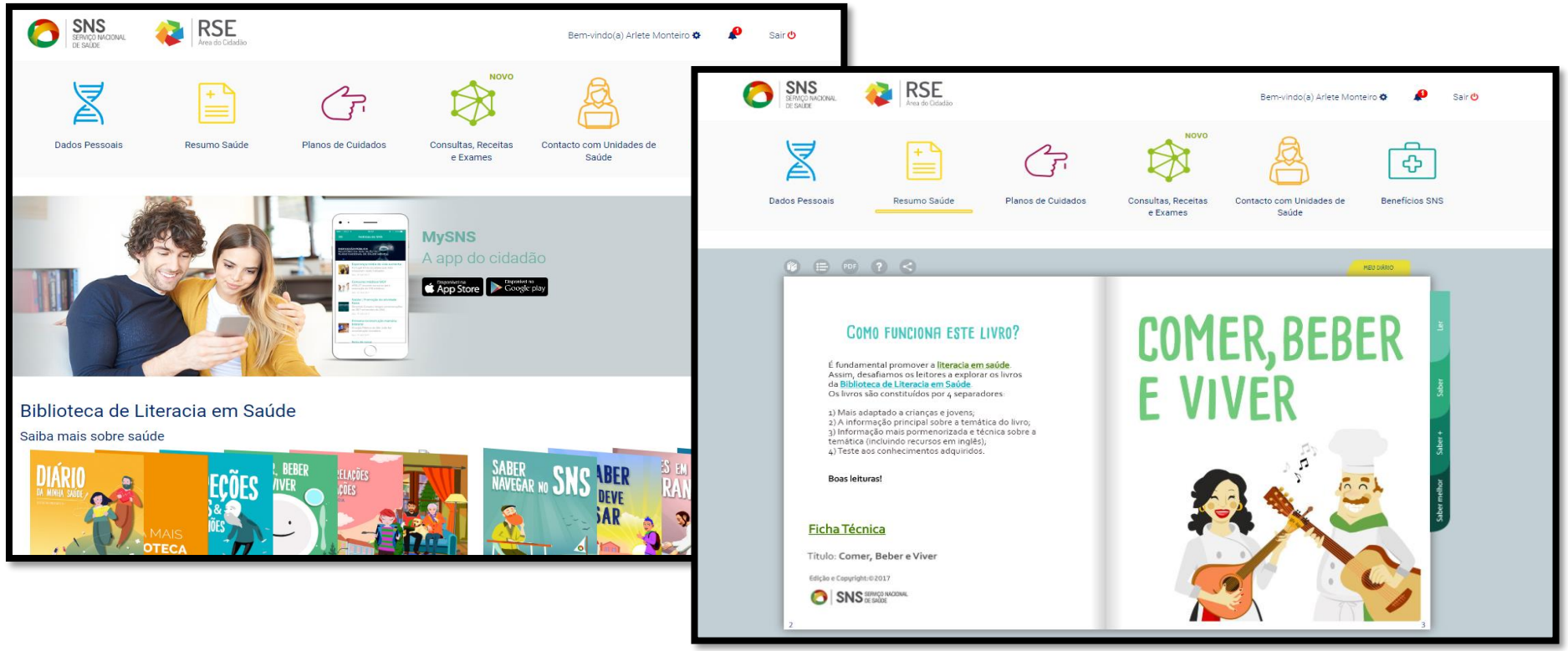
Electronic Health Record (EHR) – Citizen's Area

Citizen's Area – Individual Care Plan



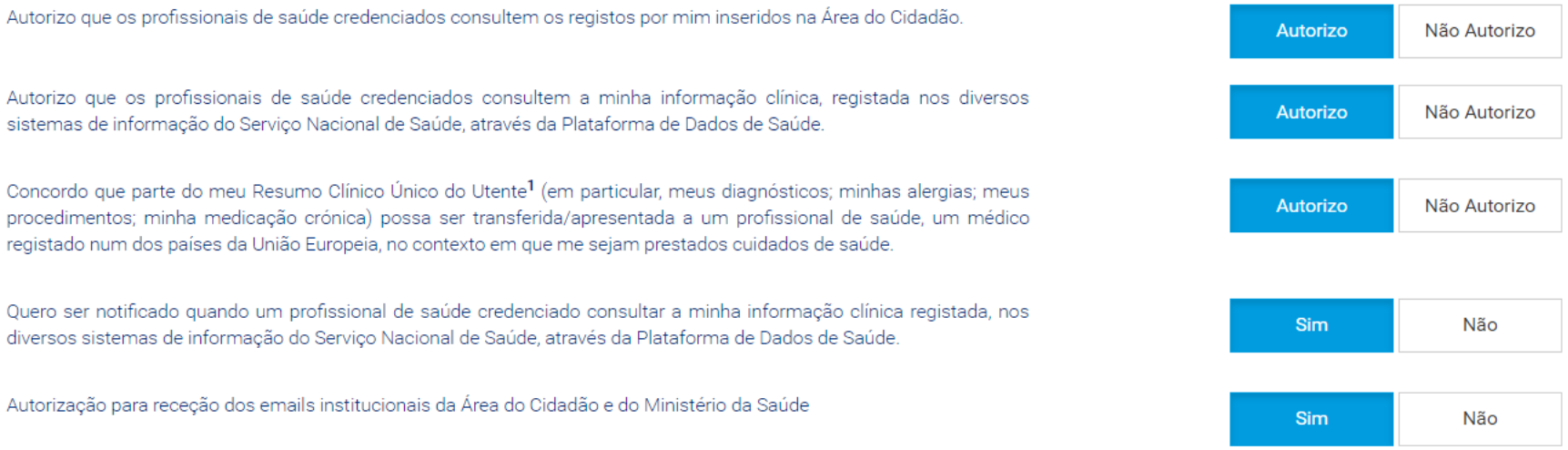
Electronic Health Record (EHR) – Citizen's Area

Citizen Portal – Literacy Resources



Electronic Health Record (EHR) – Citizen's Area

Citizen's Consent



- ✓ Compliant with CNPD (Autorização n.º 940/2013)
- ✓ Citizen Authorization on Data Sharing

Electronic Health Record (EHR) – Citizen's Area

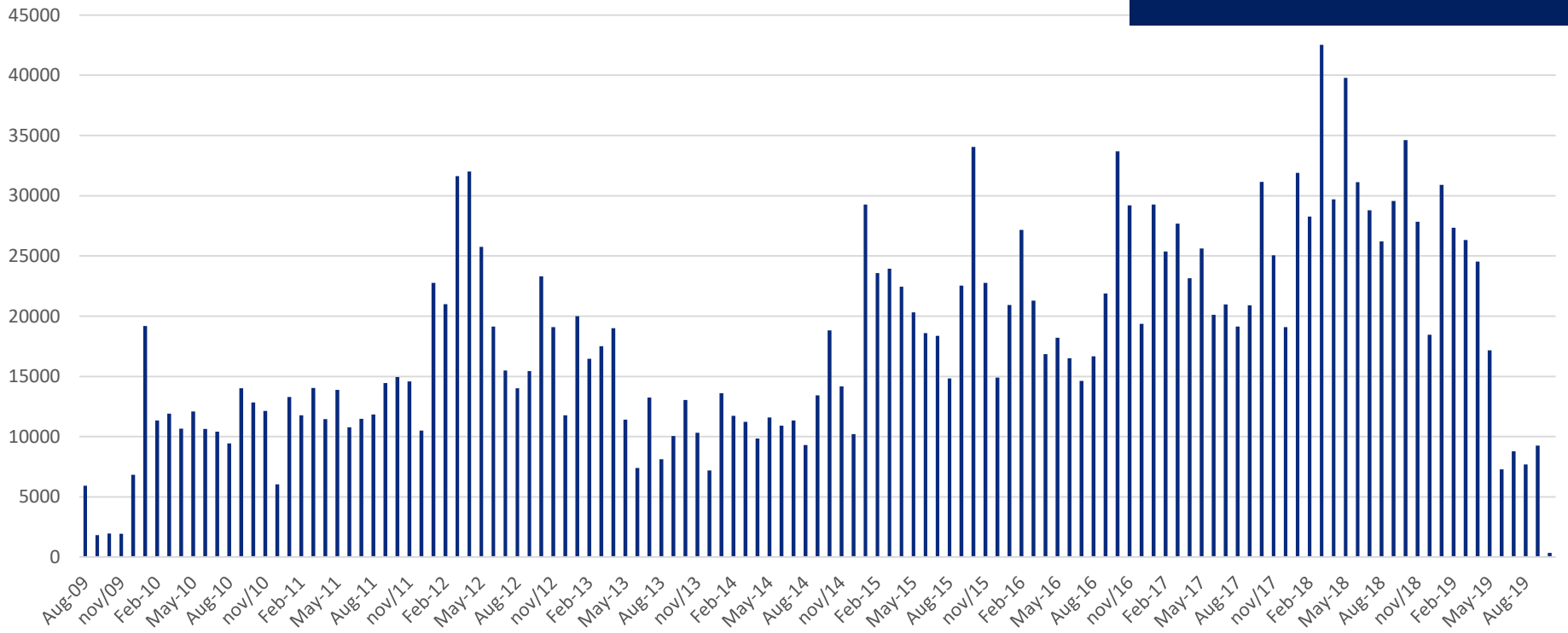
Health Summary

- ✓ HEALTH EPISODES
- ✓ MEDICATION
- ✓ RARE DISEASES
- ✓ VITAL WILL

Electronic Health Record (EHR) – Citizen's Area

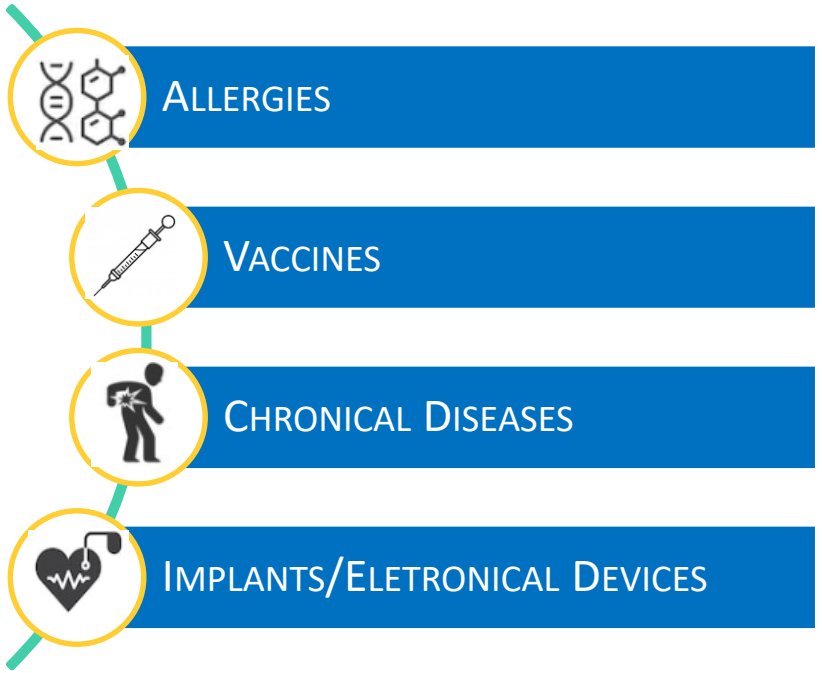
Number of citizen's registrations

2 261 857
ecitizens



Electronic Health Record (EHR) – Citizen's Area

The patient summary allows citizens of the member states can use and benefit from **cross-border health services**, thus ensuring **greater safety in health care**.



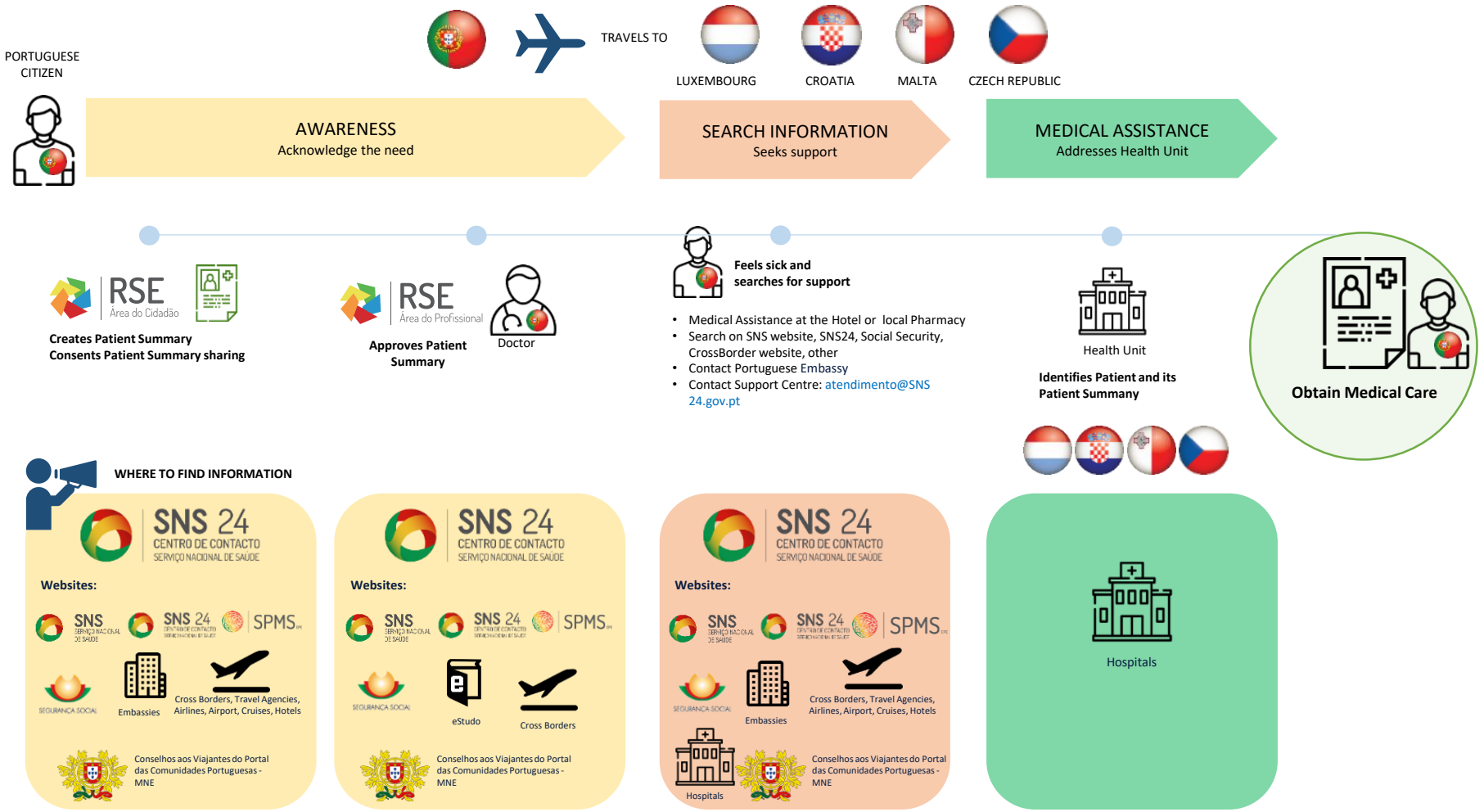
RSE | Citizen Area of the NHS Portal

The **Patient Summary** can be activated by the citizen anytime and anywhere, through the RSE | Citizen Area.

The citizen can authorize or withdraw the authorization for the viewing of their **Patient Summary** by health professionals in the **Citizen Area of the NHS Portal**. They can simply access their Citizen Area of the NHS Portal via **Digital Mobile Key** or Citizen Card, select “Patient Summary” and click on the “Click here to generate your Patient Summary” pop-up. The citizen will be notified that their Patient Summary has been successfully generated.

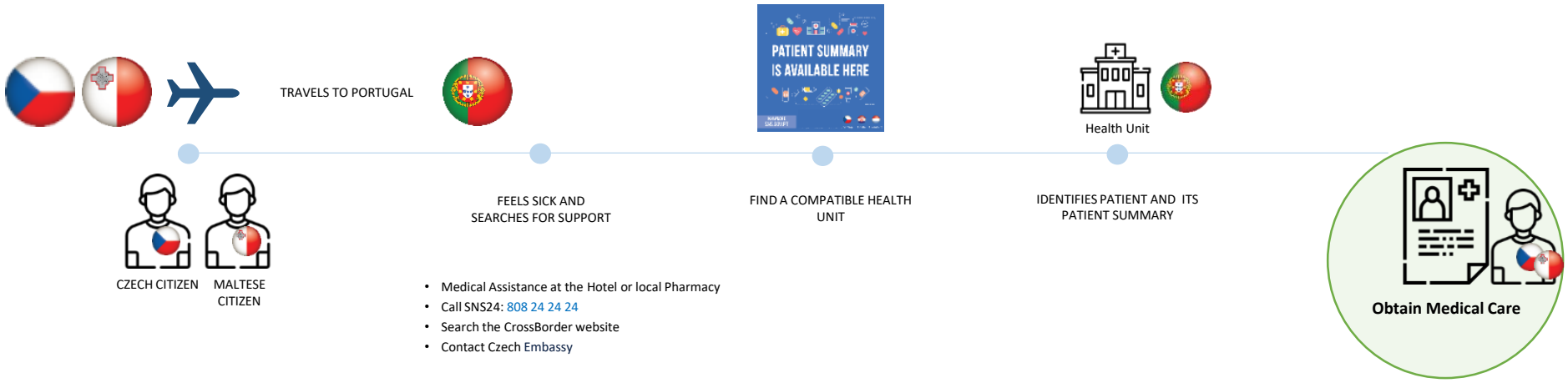
Patient Journey - Patient Summary Country A

SERVICE 1



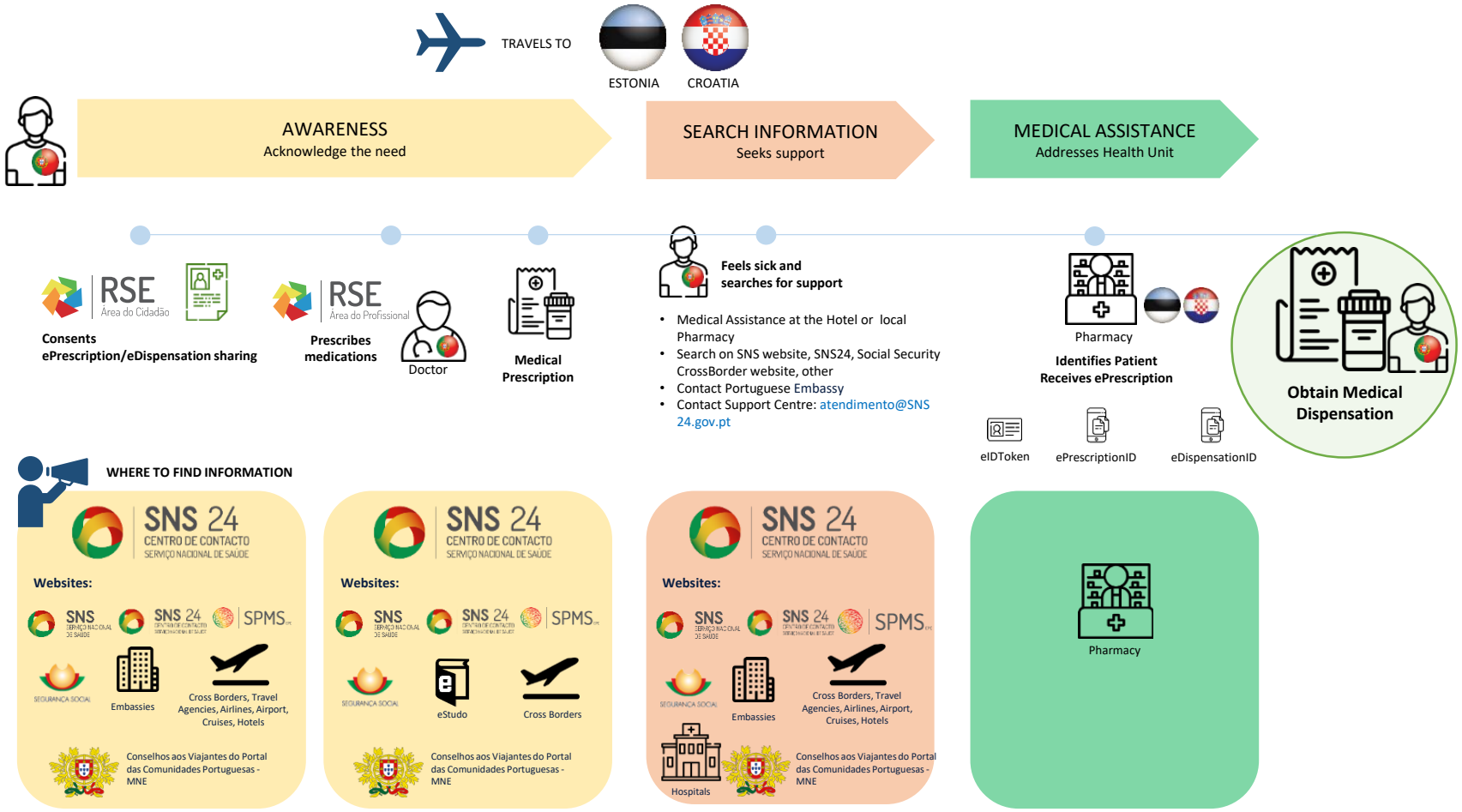
Patient Journey - Patient Summary Country B

SERVICE 2



Patient Journey - ePrescription / eDispensation Country A

SERVICE 3



Patient Journey - ePrescription / eDispensation Country B

SERVICE 4

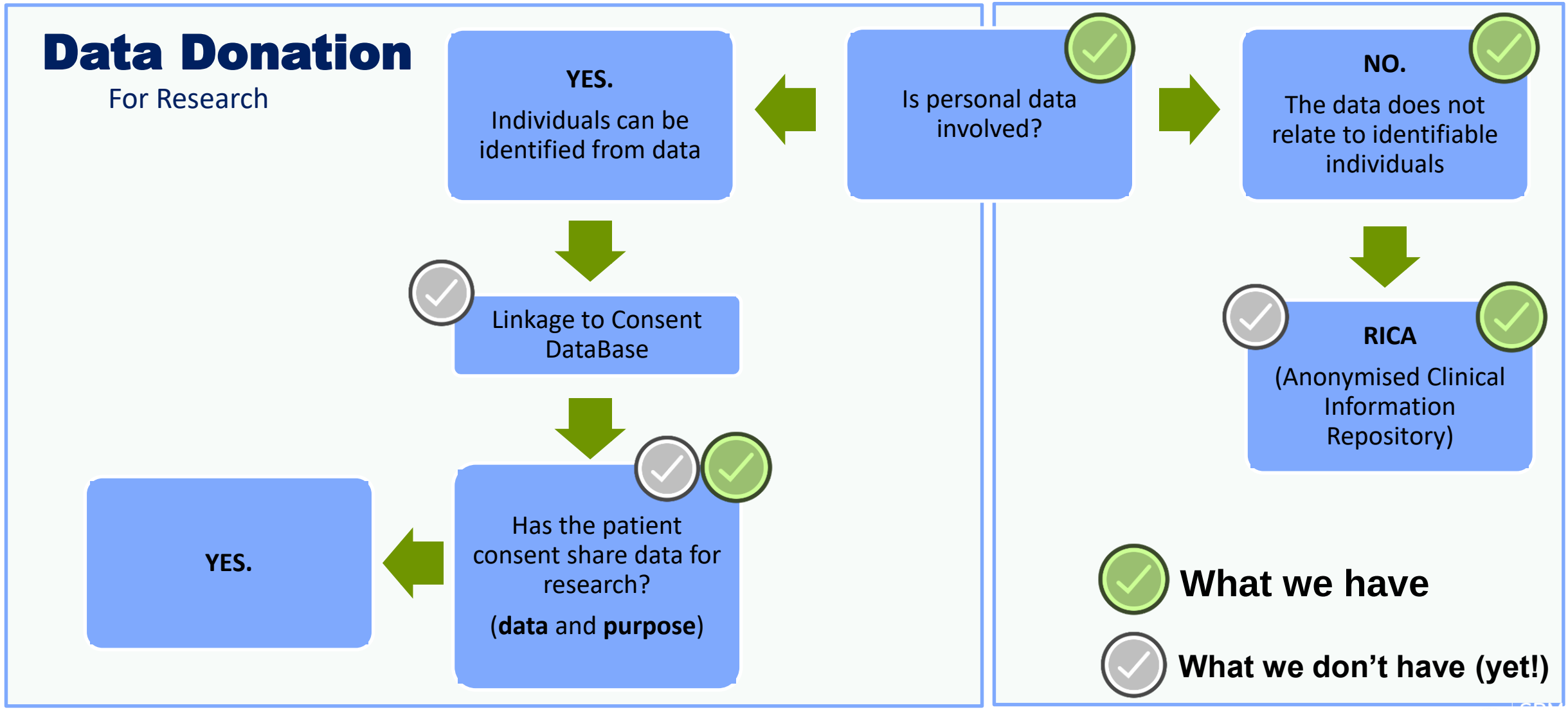
Data Donation

In which circumstances can patient's health data be processed?

- **If the patient gives explicit and unambiguous consent to the use of their data**
- If the patient makes the data public himself or herself
- If it is in the patient's vital interest
- For healthcare purposes
- For public interest in the area of public health
- To carry out the right of the person that controls patients' data in the field of employment, social security and social protection law

Data Donation

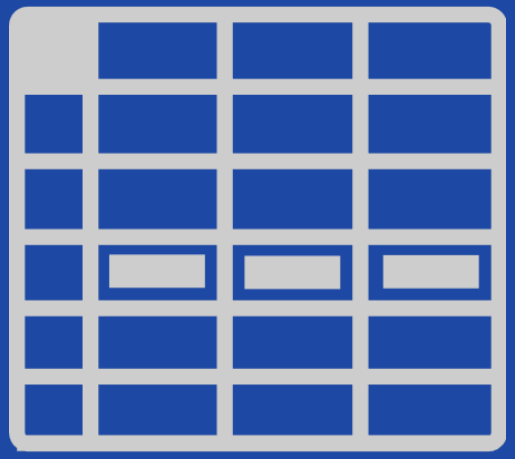
For Research



Data Donation

For Research

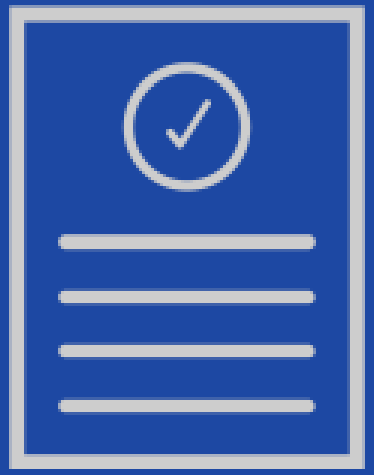
Full Anonymised data



Clinical Repository (RICA)

+

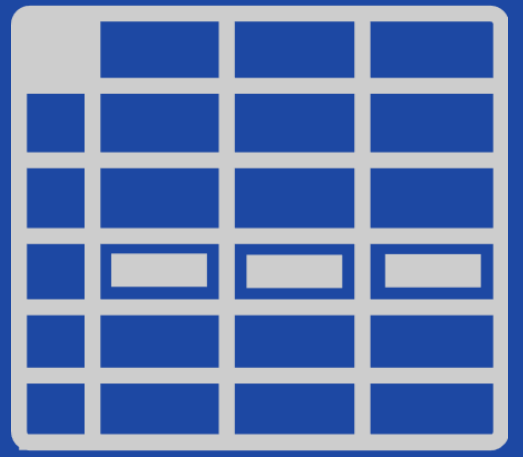
Consent Information



Eletronic consent information (Portal's Citizens Area)

=

Raw Data for research purpose

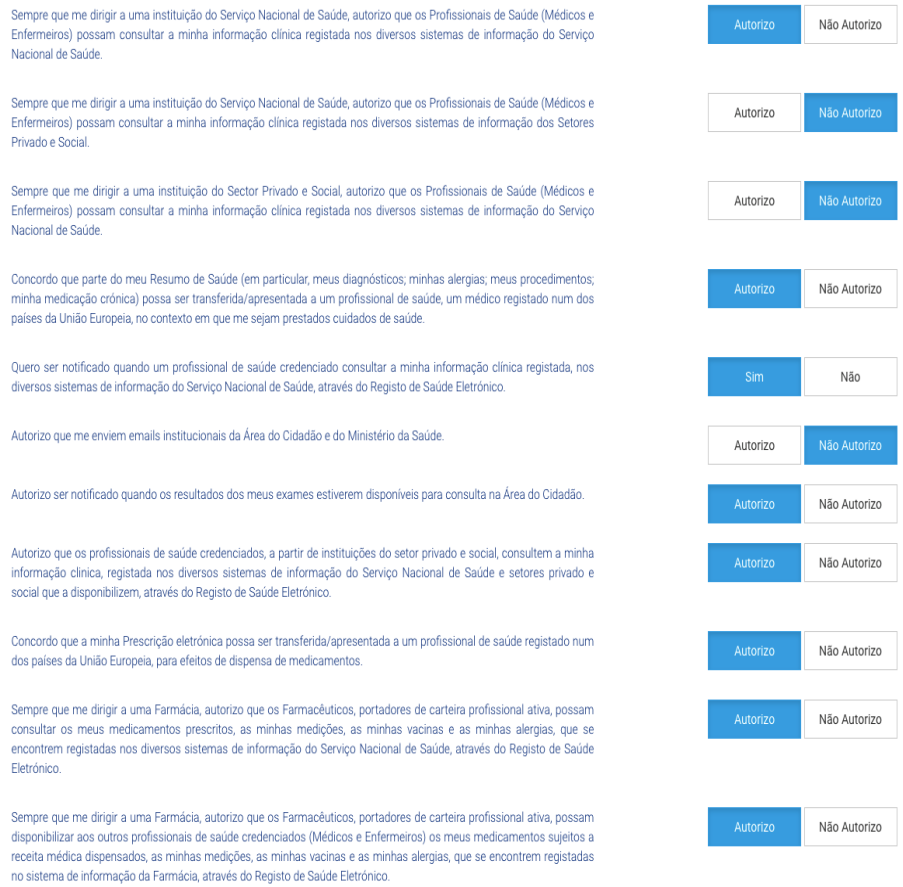


Feedback to patient

Data Donation

Data Sharing Agreement

- Period of agreement
- Intended use of the data
- Constraints on use of the data
- Data confidentiality
- Data security
- Methods of data-sharing



Sempre que me dirigir a uma instituição do Serviço Nacional de Saúde, autorizo que os Profissionais de Saúde (Médicos e Enfermeiros) possam consultar a minha informação clínica registada nos diversos sistemas de informação do Serviço Nacional de Saúde.	Autorizo	Não Autorizo
Sempre que me dirigir a uma instituição do Serviço Nacional de Saúde, autorizo que os Profissionais de Saúde (Médicos e Enfermeiros) possam consultar a minha informação clínica registada nos diversos sistemas de informação dos Setores Privado e Social.	Autorizo	Não Autorizo
Sempre que me dirigir a uma instituição do Sector Privado e Social, autorizo que os Profissionais de Saúde (Médicos e Enfermeiros) possam consultar a minha informação clínica registada nos diversos sistemas de informação do Serviço Nacional de Saúde.	Autorizo	Não Autorizo
Concordo que parte do meu Resumo de Saúde (em particular, meus diagnósticos; minhas alergias; meus procedimentos; minha medicação crónica) possa ser transferida/apresentada a um profissional de saúde, um médico registado num dos países da União Europeia, no contexto em que me sejam prestados cuidados de saúde.	Autorizo	Não Autorizo
Quero ser notificado quando um profissional de saúde credenciado consultar a minha informação clínica registada, nos diversos sistemas de informação do Serviço Nacional de Saúde, através do Registo de Saúde Eletrónico.	Sim	Não
Autorizo que me enviem emails institucionais da Área do Cidadão e do Ministério da Saúde.	Autorizo	Não Autorizo
Autorizo ser notificado quando os resultados dos meus exames estiverem disponíveis para consulta na Área do Cidadão.	Autorizo	Não Autorizo
Autorizo que os profissionais de saúde credenciados, a partir de instituições do setor privado e social, consultem a minha informação clínica, registada nos diversos sistemas de informação do Serviço Nacional de Saúde e setores privado e social que a disponibilizem, através do Registo de Saúde Eletrónico.	Autorizo	Não Autorizo
Concordo que a minha Prescrição eletrónica possa ser transferida/apresentada a um profissional de saúde registado num dos países da União Europeia, para efeitos de dispensa de medicamentos.	Autorizo	Não Autorizo
Sempre que me dirigir a uma Farmácia, autorizo que os Farmacêuticos, portadores de carteira profissional ativa, possam consultar os meus medicamentos prescritos, as minhas medições, as minhas vacinas e as minhas alergias, que se encontrem registadas nos diversos sistemas de informação do Serviço Nacional de Saúde, através do Registo de Saúde Eletrónico.	Autorizo	Não Autorizo
Sempre que me dirigir a uma Farmácia, autorizo que os Farmacêuticos, portadores de carteira profissional ativa, possam disponibilizar aos outros profissionais de saúde credenciados (Médicos e Enfermeiros) os meus medicamentos sujeitos a receita médica dispensados, as minhas medições, as minhas vacinas e as minhas alergias, que se encontrem registadas no sistema de informação da Farmácia, através do Registo de Saúde Eletrónico.	Autorizo	Não Autorizo

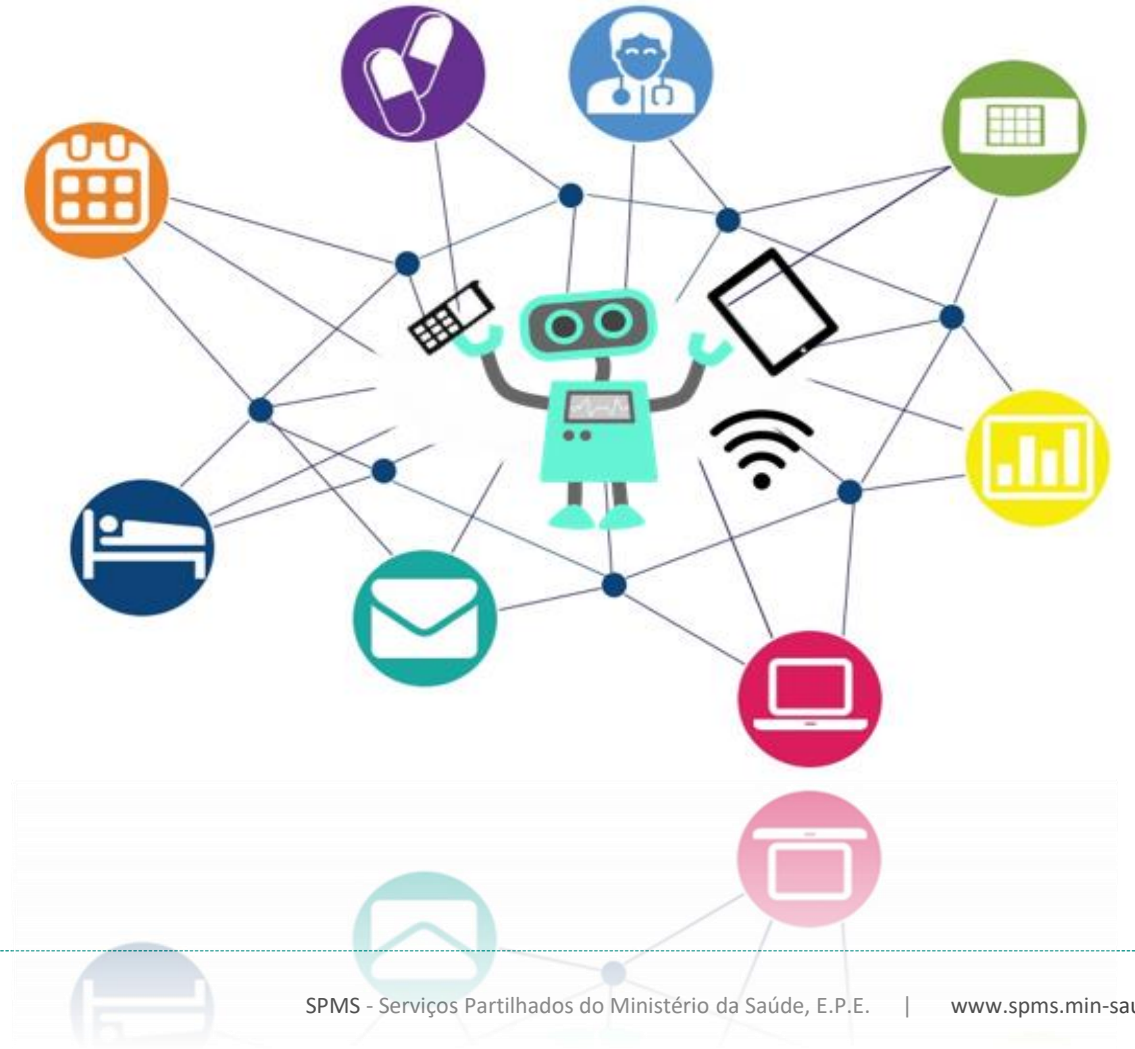
Data Donation

For Research

With patient consent, we feedback him about the purpose of using his data

- Inform the patient by e-mail
- Inform the patient that his data (medication, diagnosis, exams, …) was used
- Inform the patient that his data was used for THIS research purpose
- Inform the patient research's results
- **All about giving FEEDBACK to the patient**

Mobile Applications



THERE IS AN APP FOR THAT !

Mobile Prescription - Overview

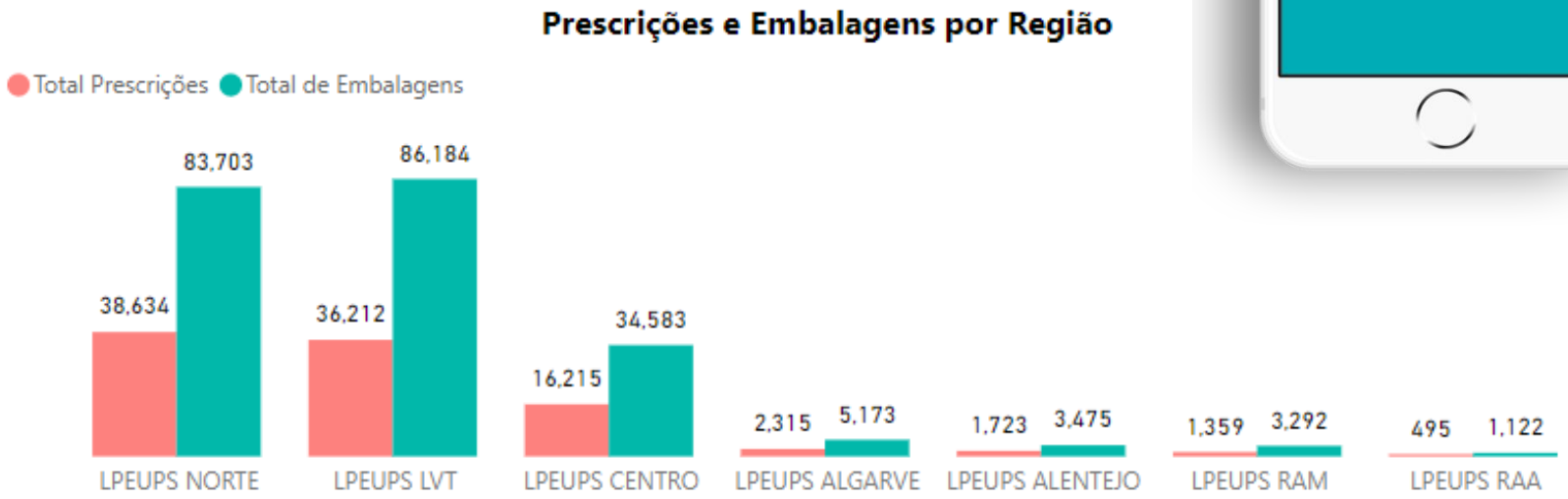
- Available since 20th February;
- Strong Authentication and digital signature thru Digital Mobile Key;
- Mobility for physicians and patients;
- Secure and fast prescription;
- **Interactive PRESCRIPTION AND DISPENSATION**

217 532

Total of medicine packages

96 953

Total of emited paperless prescription



PEM
Prescrição Eletrônica
Médica

ePrescription - iPrescription

ePrescription

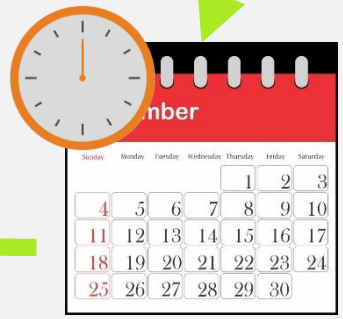
Paperless Prescription

iPrescription

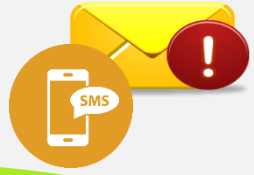
PEM Móvel
Prescrição Eletrónica Médica

YES

Eletronic Dispensation of the medicines



"1 pill once a day during 3 months"



Notification Patient

"Your medicine package is over in 5 days.
Do you want to ask for a new prescription?"

PATIENT

Prescription for Physical Exercise

Publications:

Mendes, Romeu & Silva, Marlene & Silva, Catarina & Marques, Adilson & Tomás, Rita & Alexandre, António & Carvalho, Cristina & Nascimento, Nilton & Leite, Celina & Martins, Henrique & Teixeira, Pedro. (2018). **Primary health care digital tools for physical activity surveillance and brief advice in the Portuguese National Health Service.** Journal of Physical Activity and Health. 15. S246.

Mobile Applications – MyNHS Family

APP that allows to consult general information and news about the NHS.

MyNHS

APP that alows the consult of average waiting times in the NHS hospital institutions.

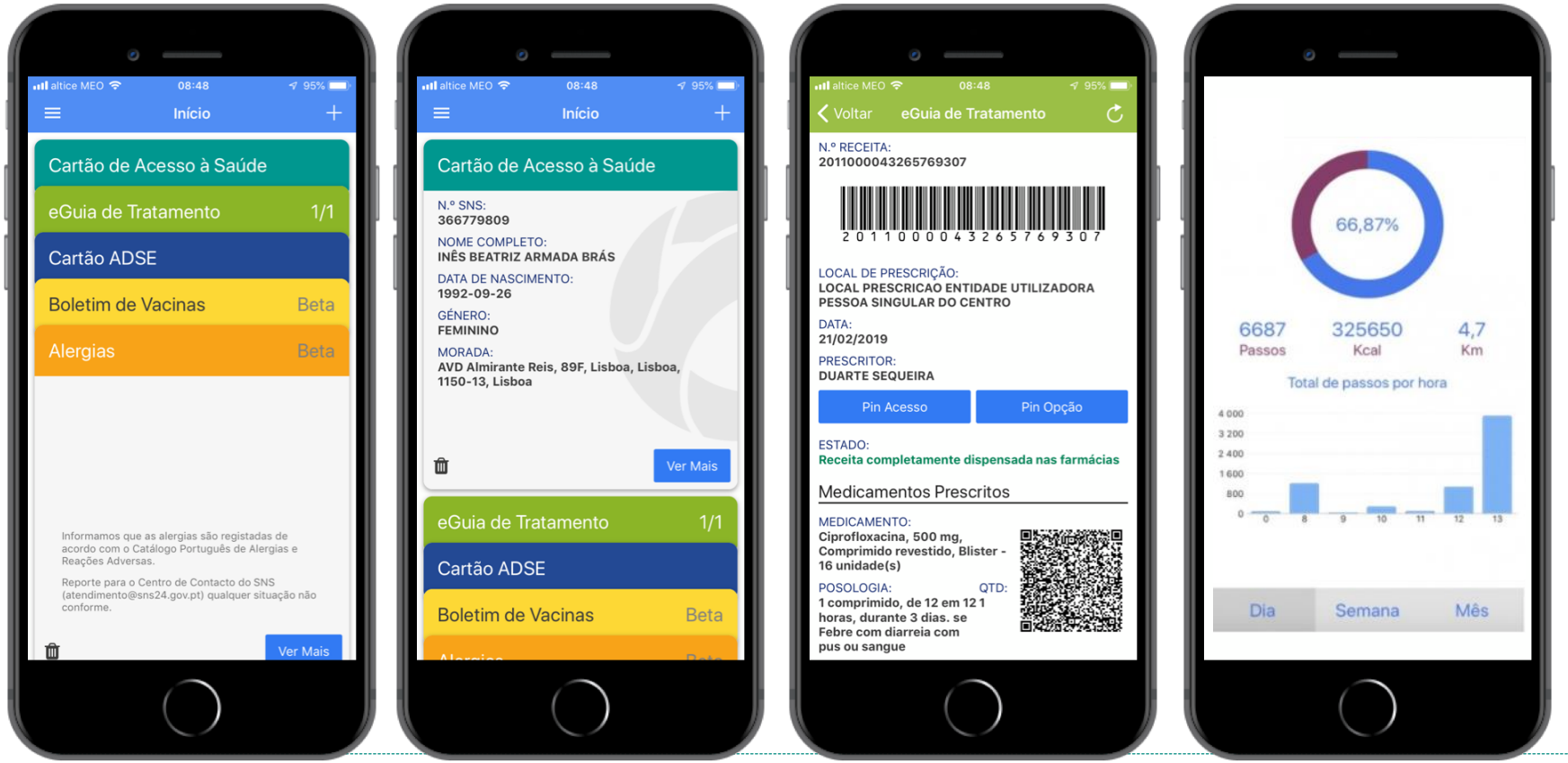
MyNHS Times

APP that gathers information about the patient data in the NHS.

MyNHS Wallet

Mobile Applications – MyNHS Family

MyNHS Wallet



- ✓ Health Access Data
- ✓ Treatment Guide
- ✓ ADSE
- ✓ Living Will
- ✓ Vaccines
- ✓ Allergies
- ✓ Rare Diseases
- ✓ Physical Activity

MyNHS Wallet

Cards Downloads – TOP 5*

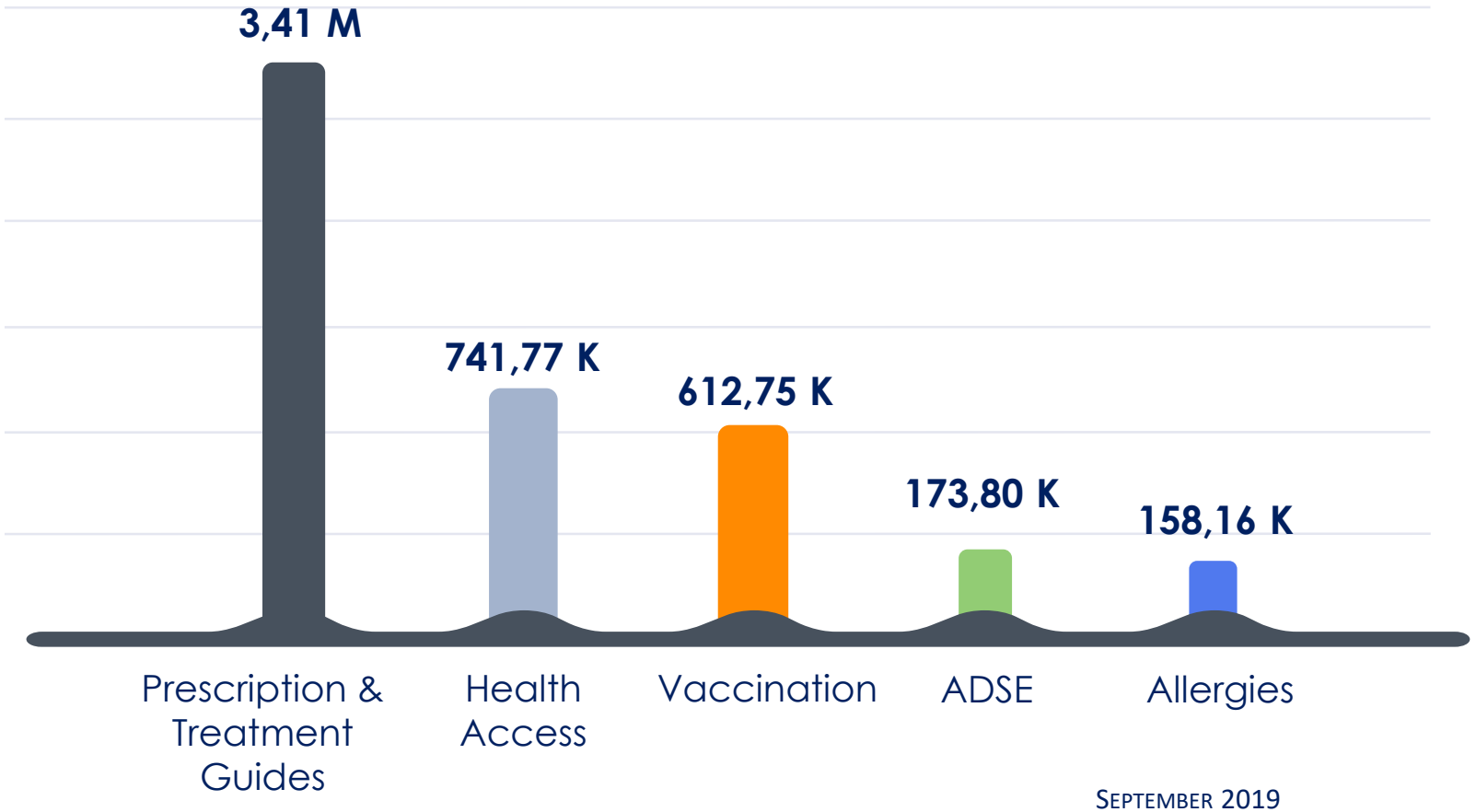
PRESCRIPTION AND TREATMENT GUIDE
Card with prescriptions and treatment guides.

HEALTH ACCESS CARD
Card wih data that identifies the patient in the NHS.

VACCINATION CARD
Card with the patient's vaccination record.

ADSE CARD
Card with information about subsystem data.

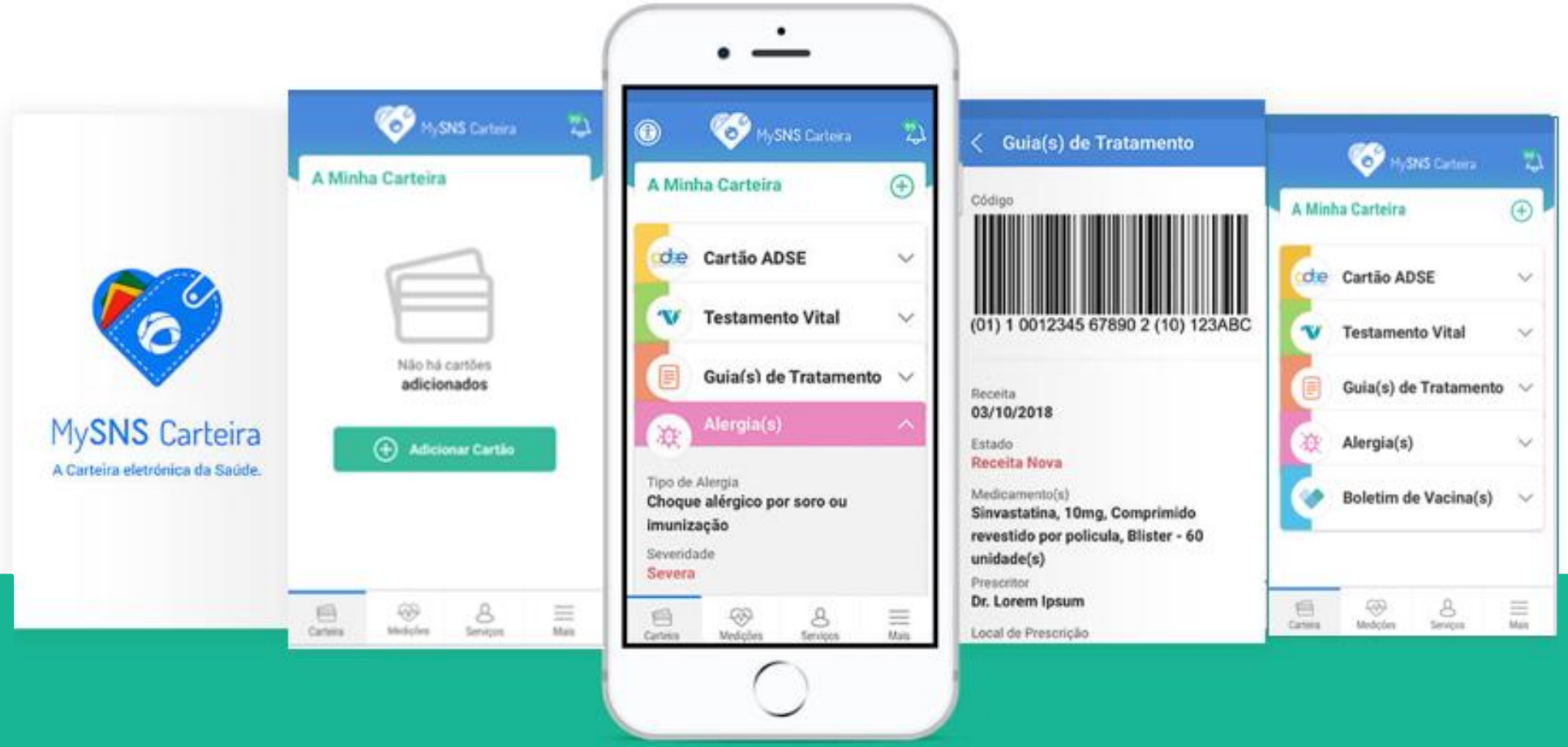
ALLERGIES CARD
Card with information about the patient's registered allergies.



SEPTEMBER 2019

NEW EDITION!!

Awaiting store validation

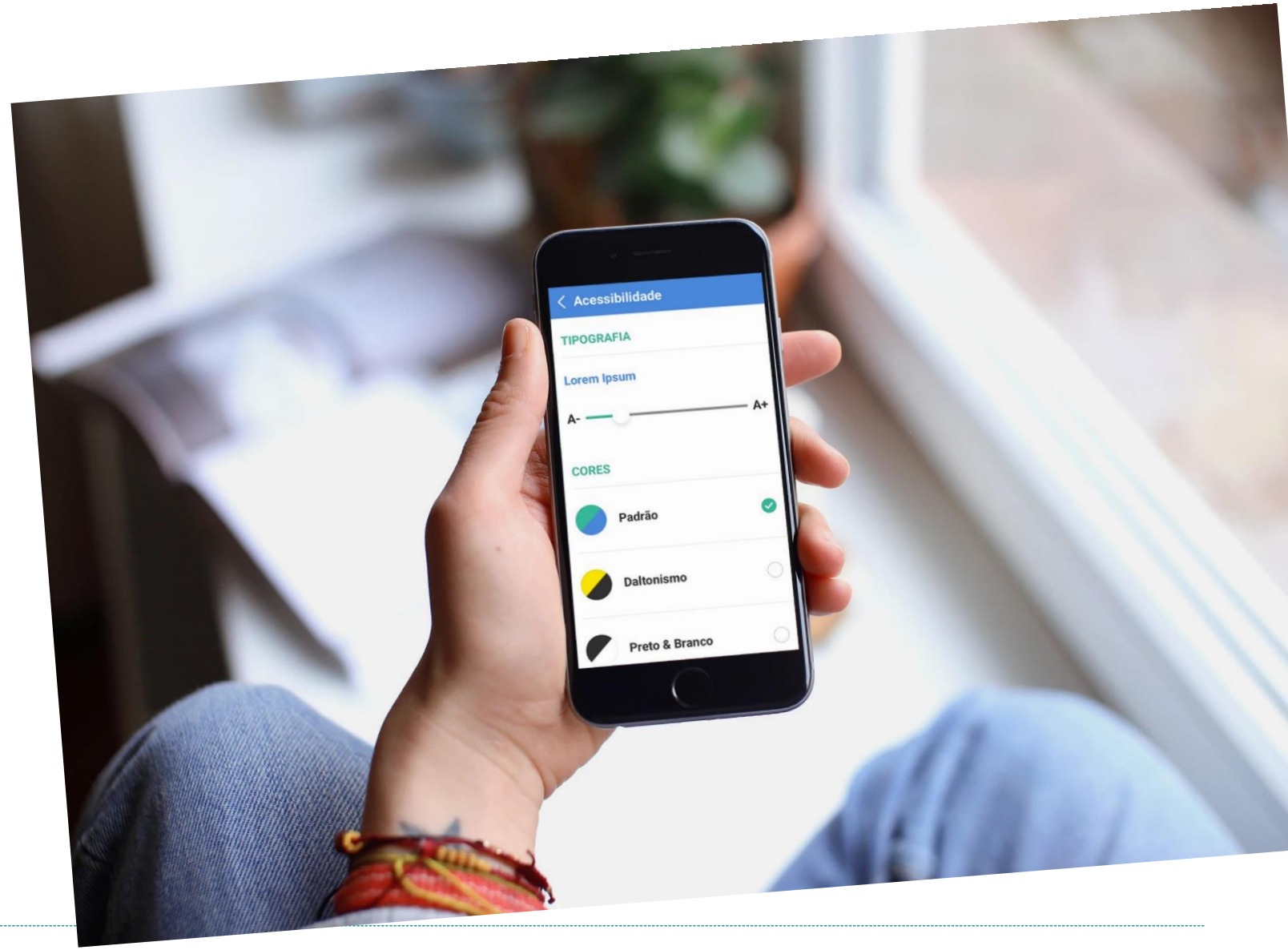


Design | Usability and Experience | Performance |

New Features

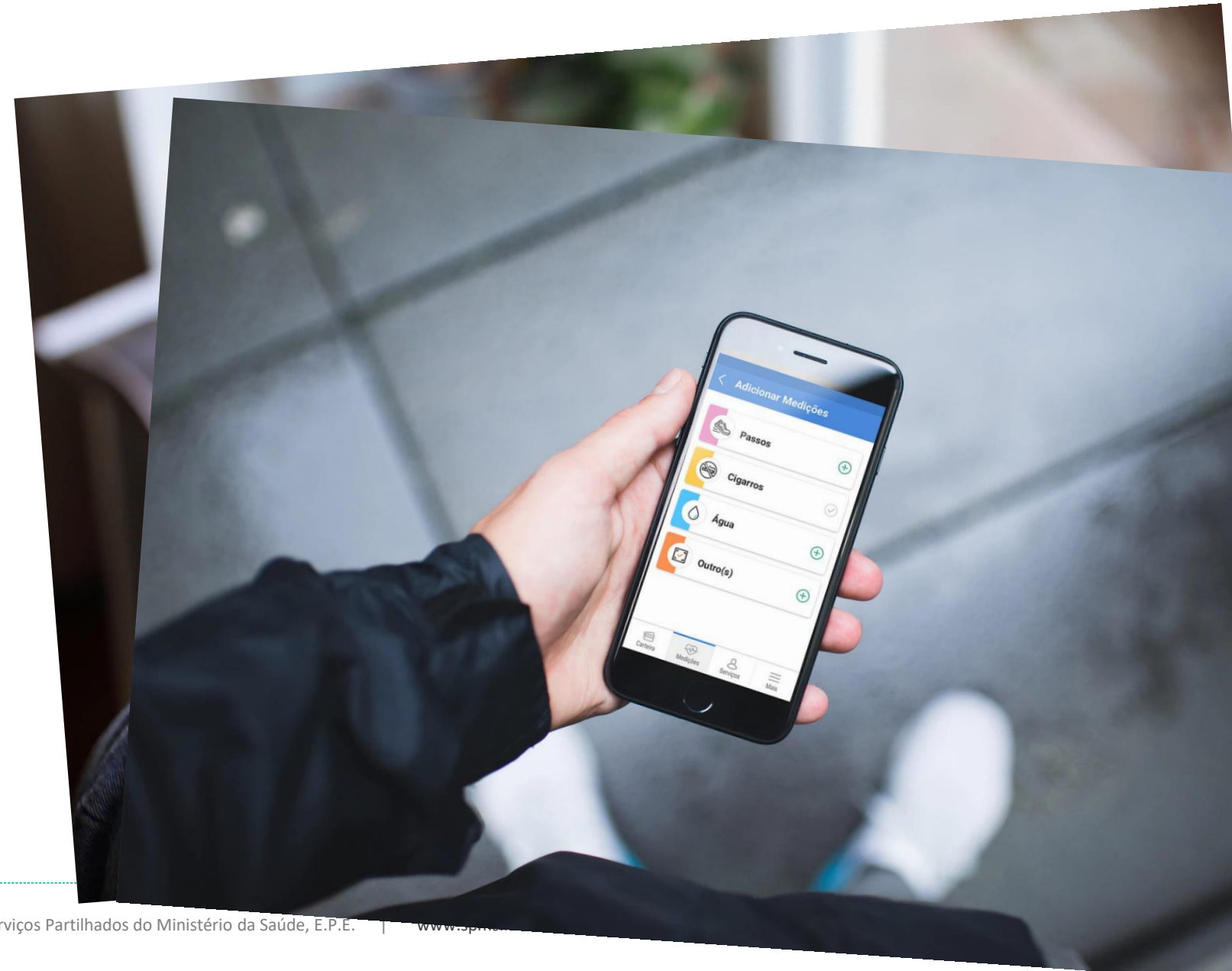
Acessibility

Inclusion of Accessibility options applicable to the entire APP interface.



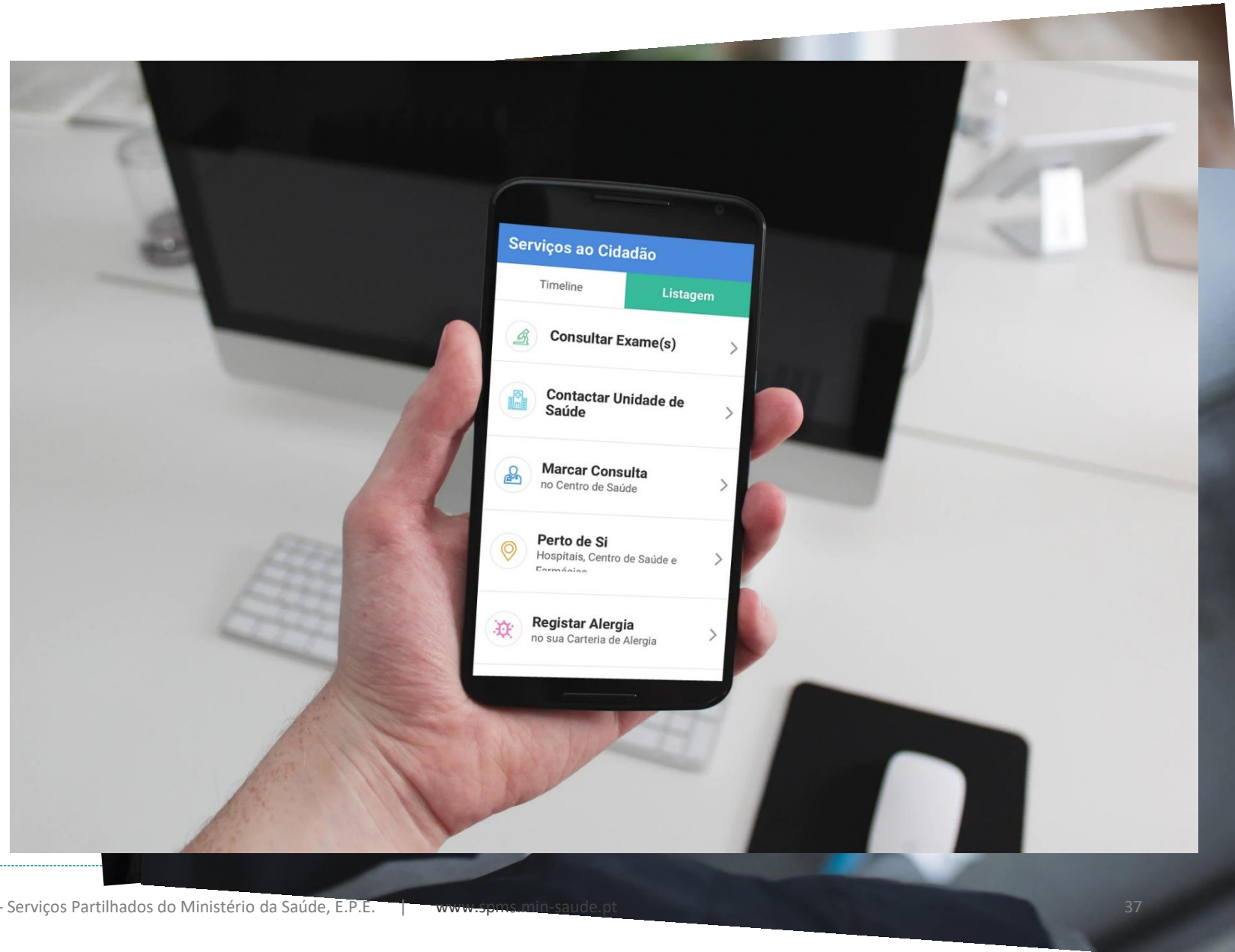
Health Measurements

Menu dedicated to promoting a healthy lifestyle, where citizens can record and track their health measurements.



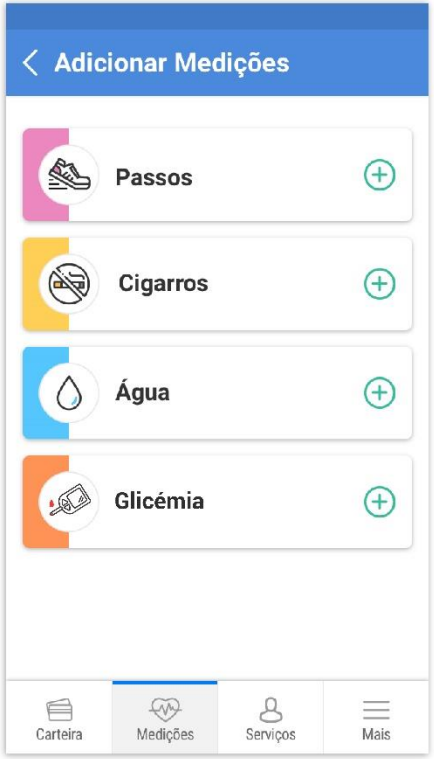
Services

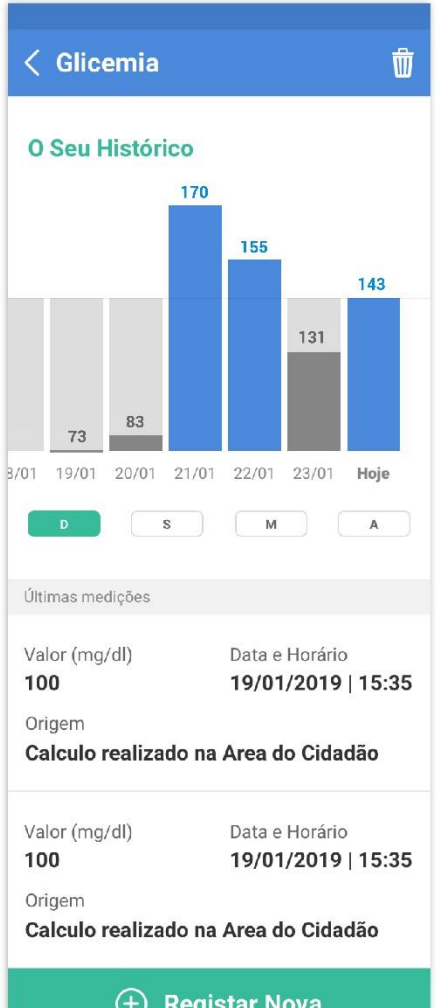
Menu where useful services are available to the citizen, such as Contact with Health Units or Make Appointments

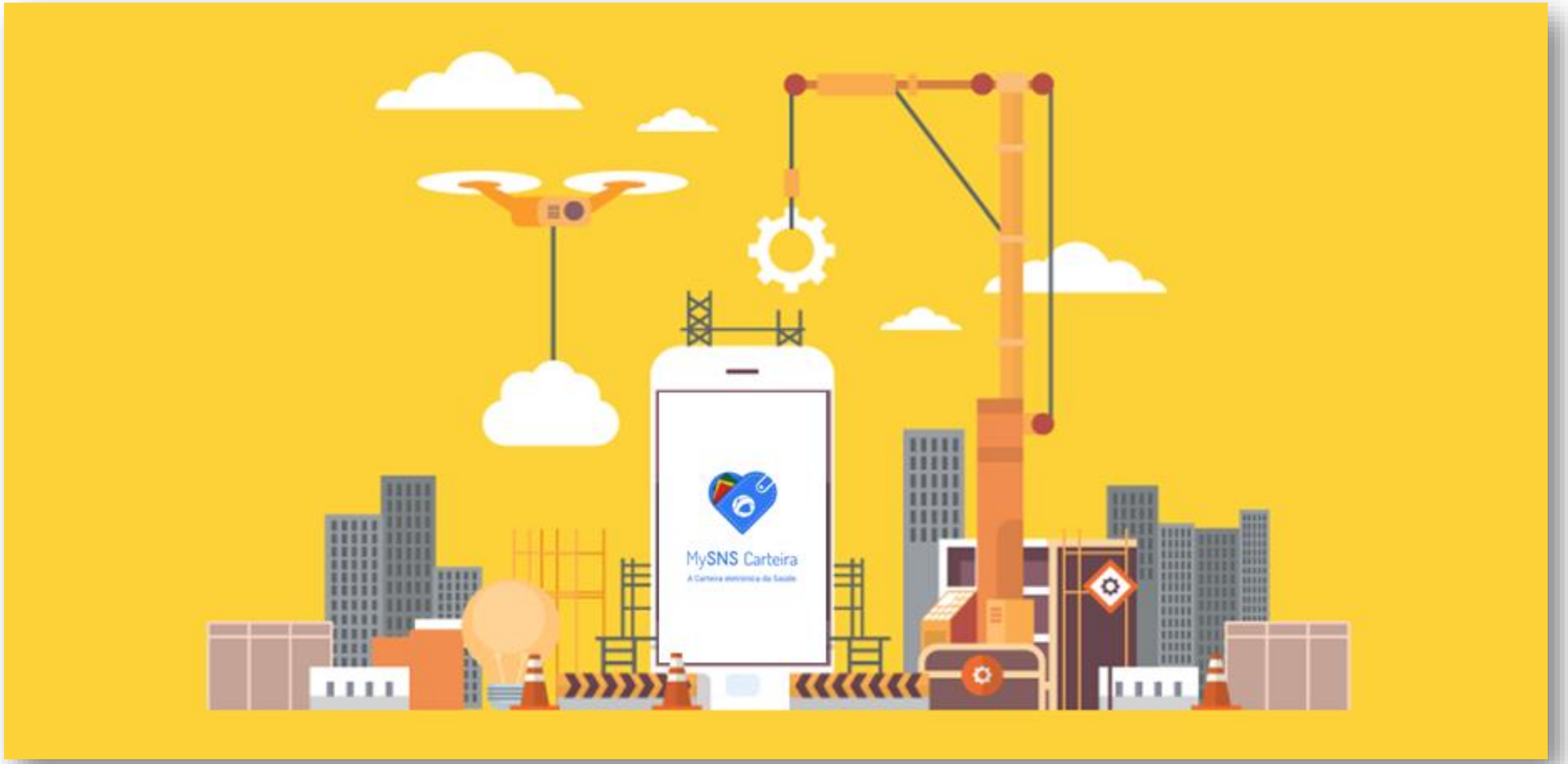


MyNHS Wallet

A new way to manage your health



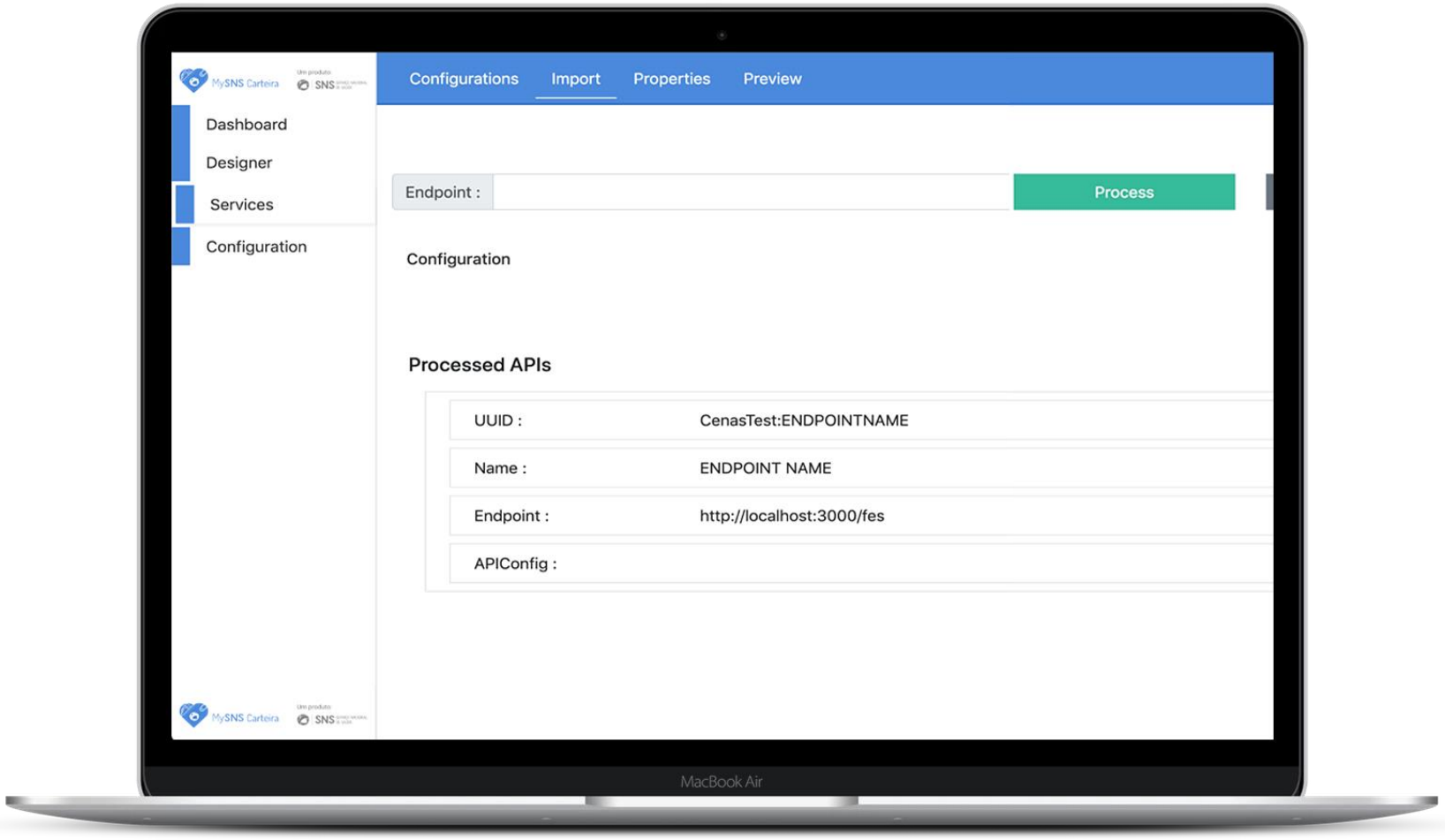



MySNS Carteira

Mobile Applications

MyNHS Wallet - Software Development Kit (SDK)

Software that will allow any Health entity to develop cards for the MyNHS Wallet

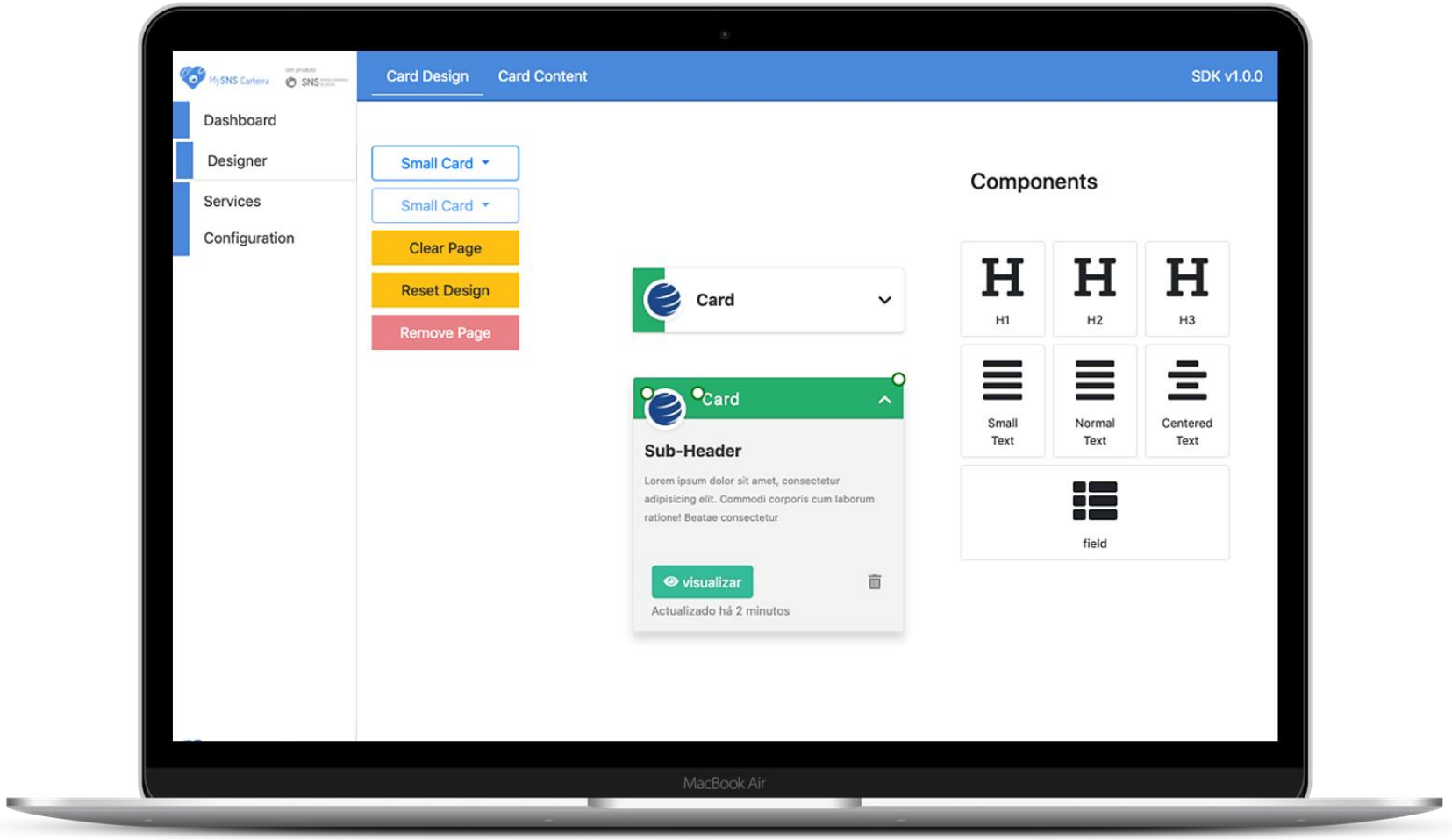


Mobile Applications

MyNHS Wallet - Software Development Kit (SDK)

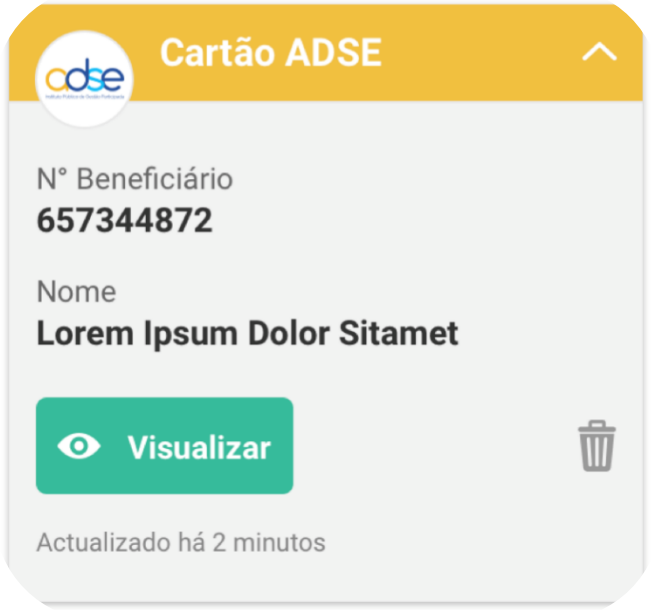
<u>All-in-one app:</u>

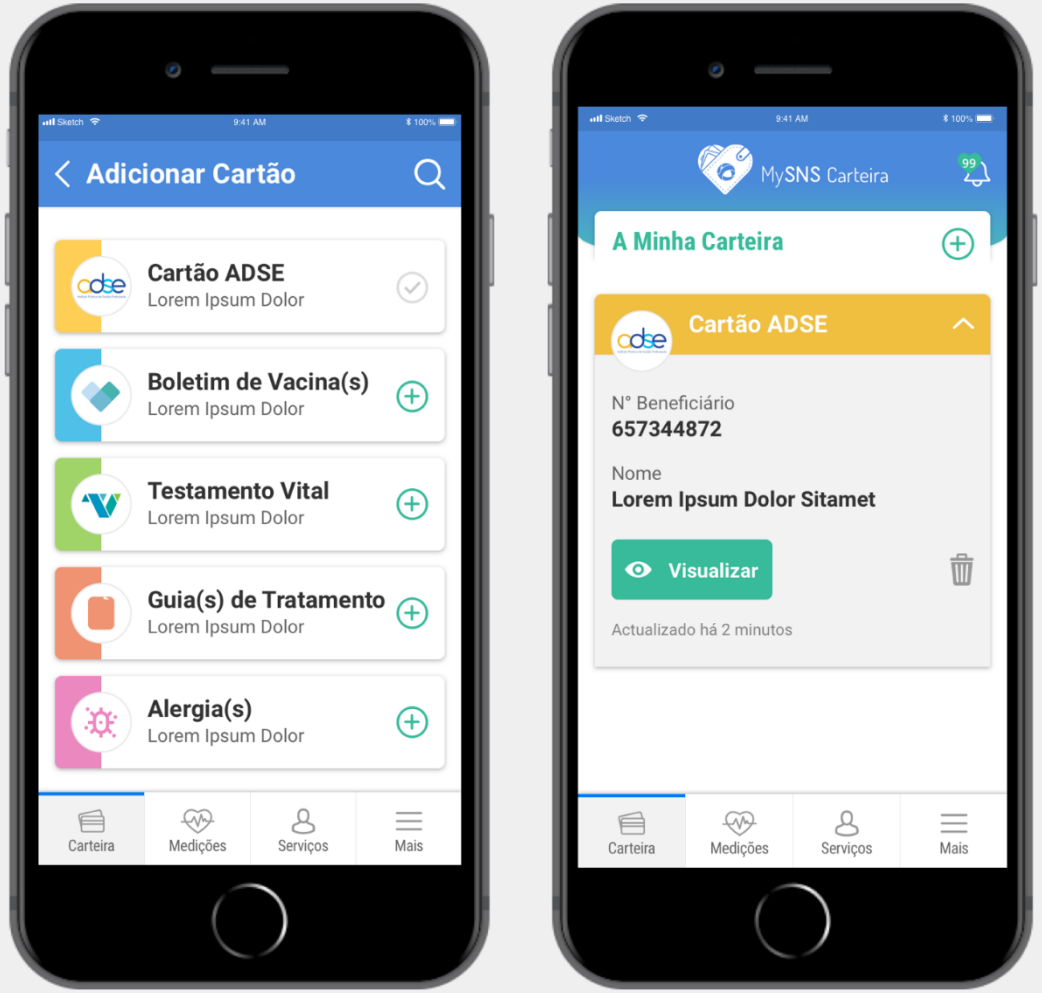
Design the cards (drag & drop), map the services and configure the metadata.



Mobile Applications

From the SDK to MyNHS Wallet





SNS 24 – WEBSITE
ANALYTICS

1 288 279 users

1 834 771 acesses

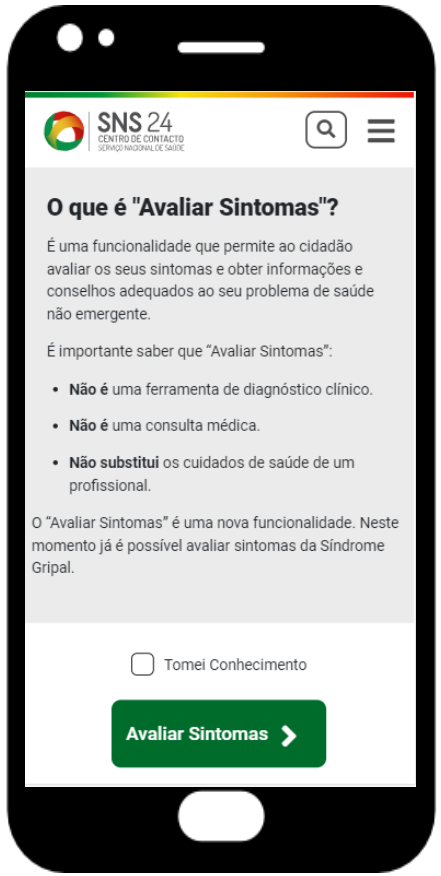
63,9%	33,6%	2,6%
Mobile	Desktop	Tablet

*From 18/01/2019 until 02/12/2019

SNS 24 – WEBSITE

SYMPTOM CHECKER

- Flu
- Nausea and vomiting
- Cough
- Skin allergies
- Respiratory allergies



237 646 users

28 969 concluded algorithms

*From 18/01/2019 until 02/12/2019

THANK YOU

Henrique Martins
Shared Services for Ministry of Health

Portugal
September 2019

REPÚBLICA PORTUGUESA
SAÚDE

40 ANOS
SNS
SERVIÇO NACIONAL DE SAÚDE 1979-2019

SPMS EPE
Serviços Partilhados do Ministério da Saúde

How to Cooperate in Data Ecosystems

Renske Trul, MSc

EHTEL Conference
Barcelona, December 4th 2019

MedMij

Personal health data
in the palm of your hand

The urgency for The Netherlands

- 75 people in hospital per day due to medication errors
- Ageing population: pressure on informal care
- Digital society

Timeline

2011

No EHR

National EHR rejected in Parliament

2013

Vision PHE published

Personal Health Environment

2015

Information Council Healthcare

Make it happen!

2015

Madurodam

Now continue with PHE

2016

Start MedMij

More control over your health

MedMij

Grip op je eigen gezondheidsgegevens

Good climate

Living at home longer, self sustainable

Everybody CEO of their own health

Self-measurements

New treatments with big data and AI

Tele-health

Fertile ground

Sustainable healthinformation complex

Standards

Registers

Same language

Authentication

Monitoring

Basic infrastructure

Patient access

Agreements

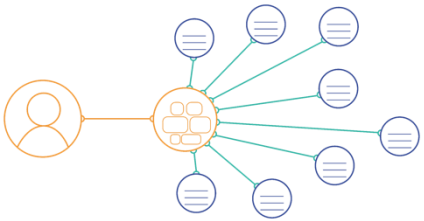
Indicators

Safe communication

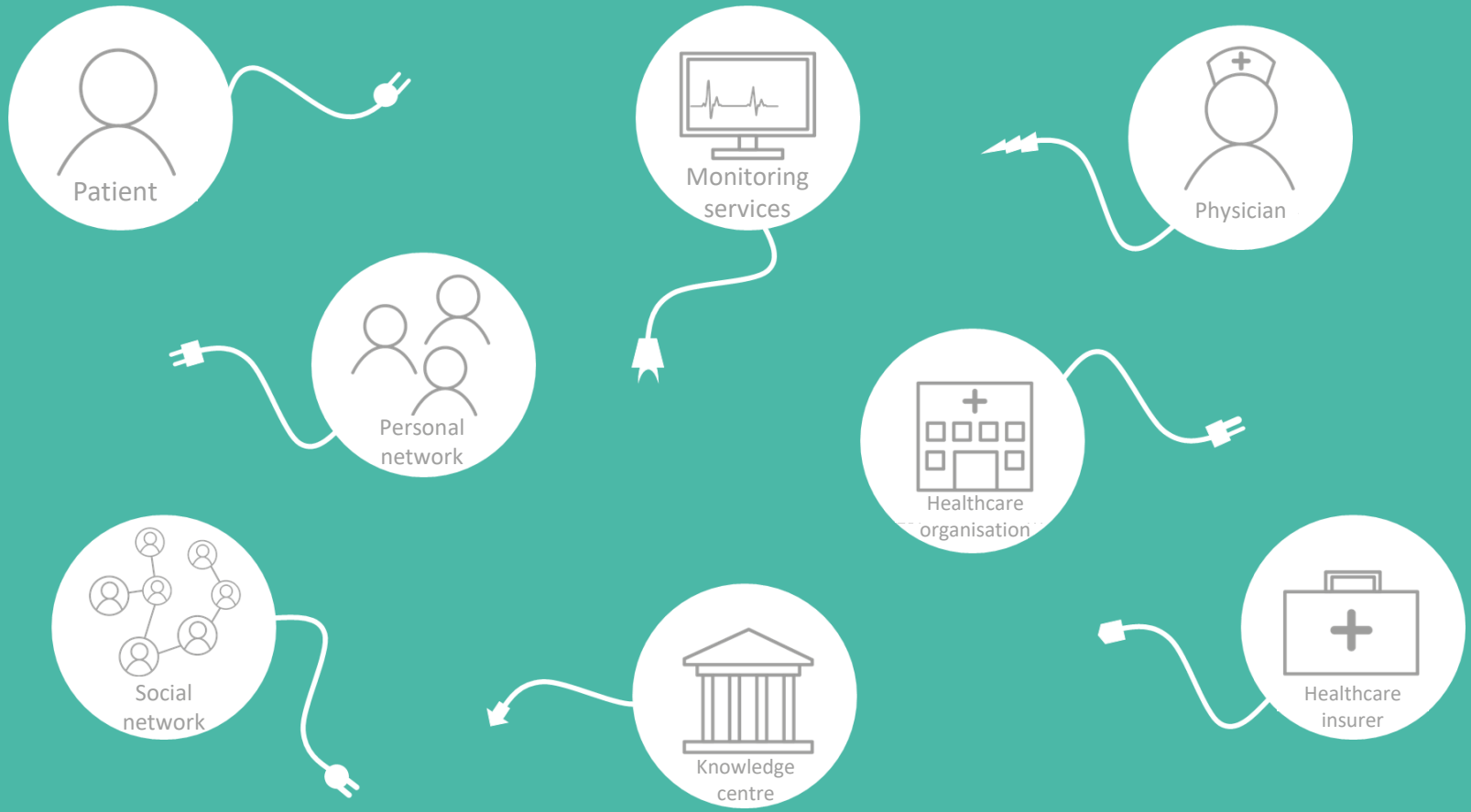
Financing

Payment models

MedMij allows you to collect, share and manage your health data in your own **personal health environment**

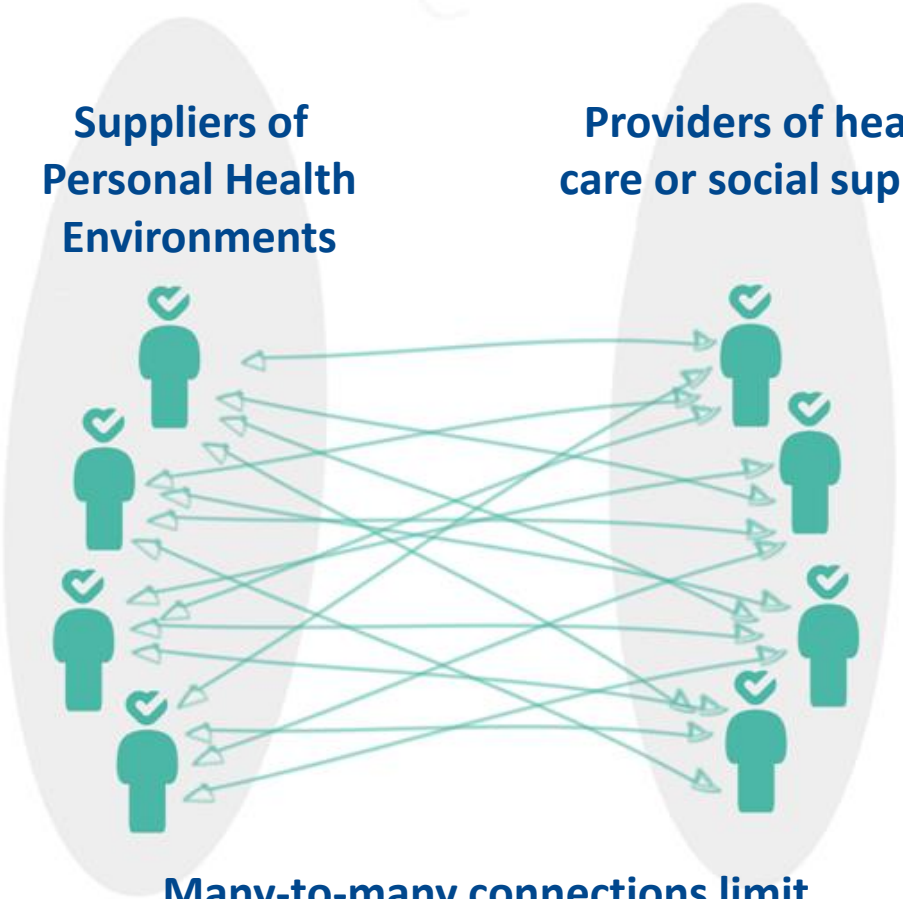


MedMij

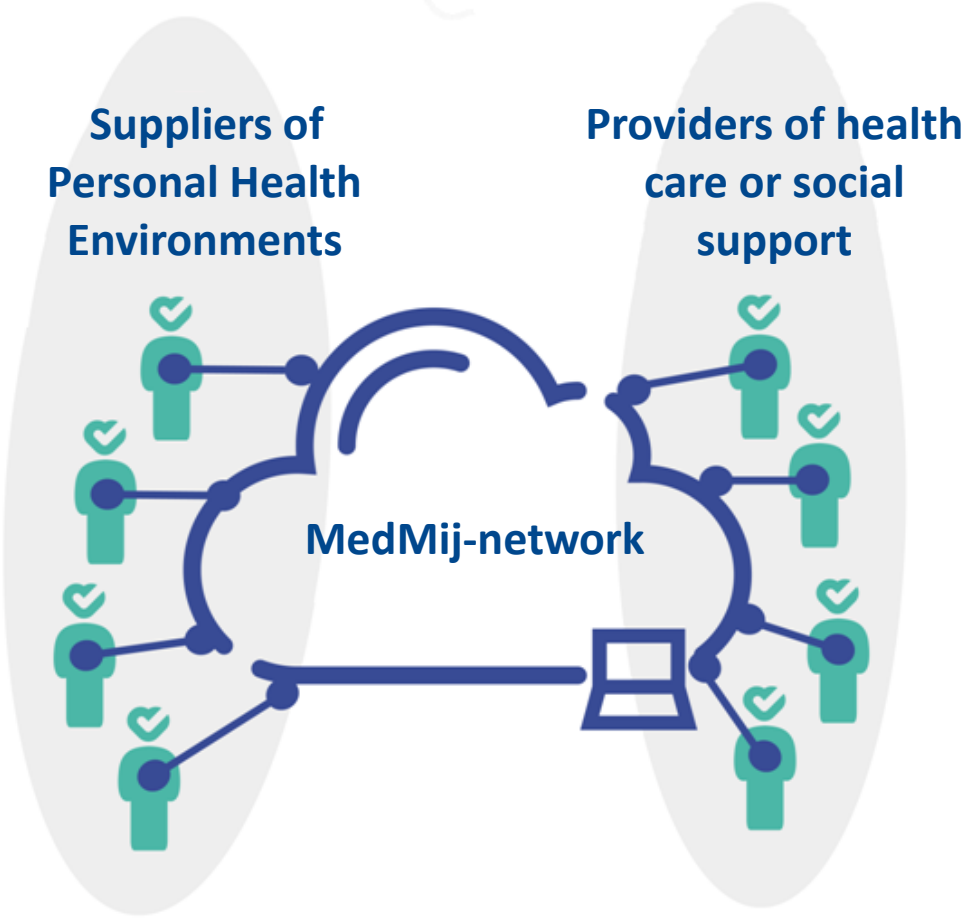

Patient
Monitoring services
Physician
Personal network
Healthcare organisation
Social network
Knowledge centre
Healthcare insurer

Suppliers of Personal Health Environments

Providers of health care or social support

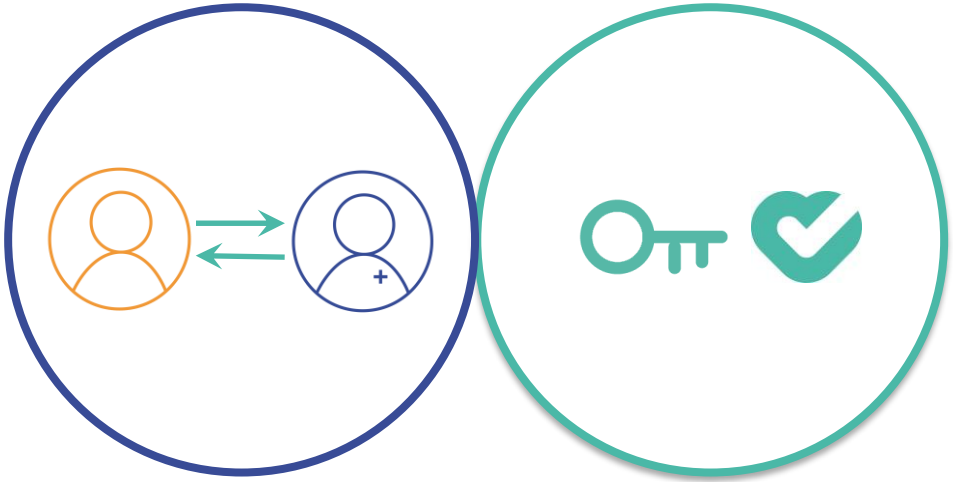


Many-to-many connections limit innovation, give higher costs


Suppliers of Personal Health Environments
Providers of health care or social support
MedMij-network

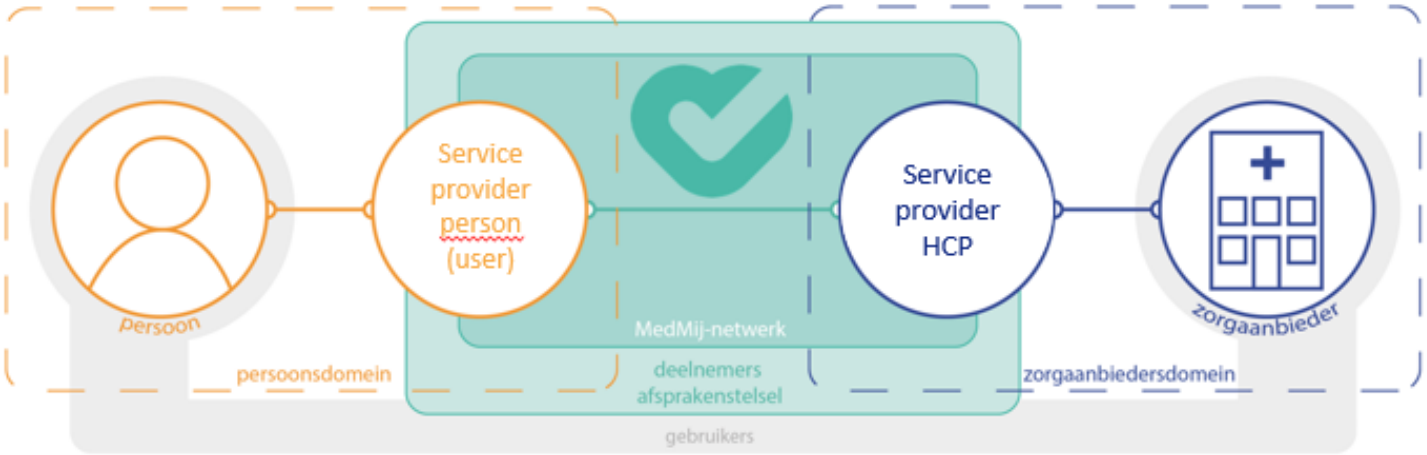
Core tasks of MedMij

Facilitate digital exchange of health data between residents of the Netherlands and their healthcare providers



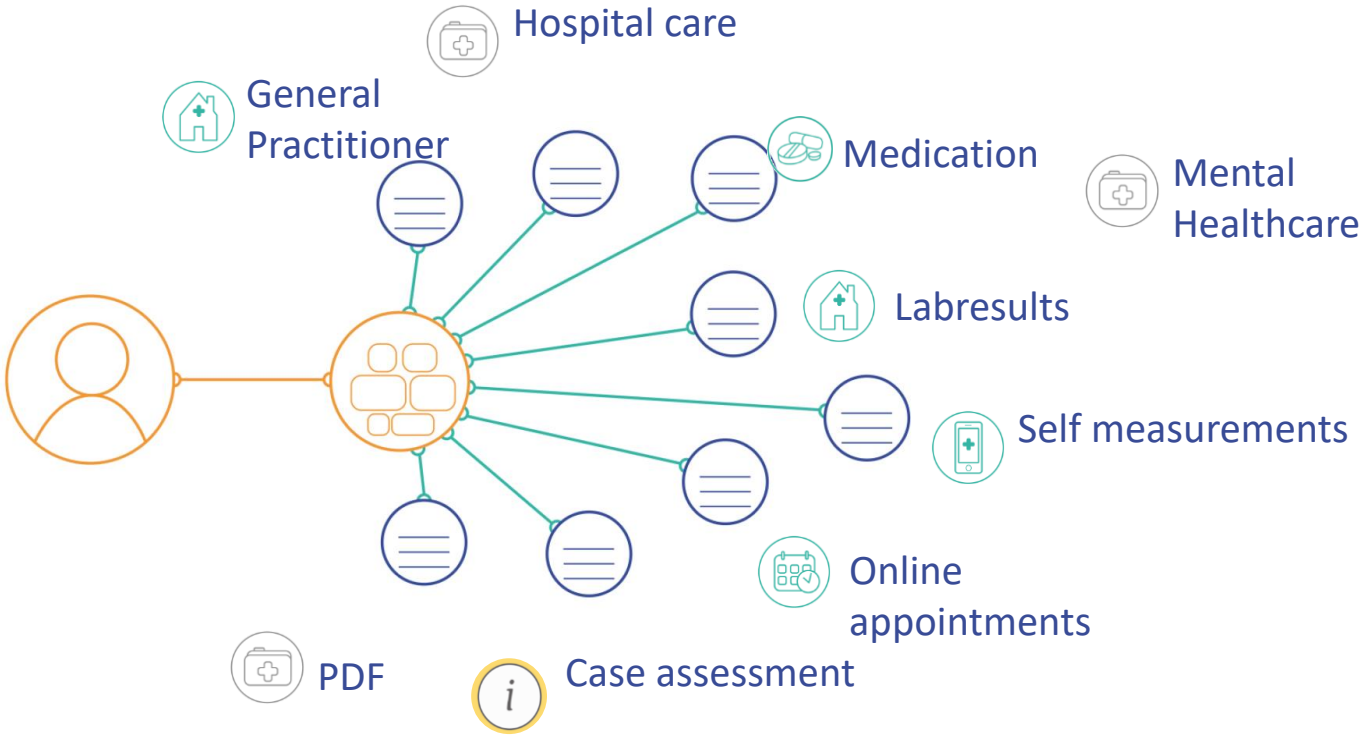
Creating confidence that this is done in a safe, sustainable, affordable and user-friendly way

What does the framework do?



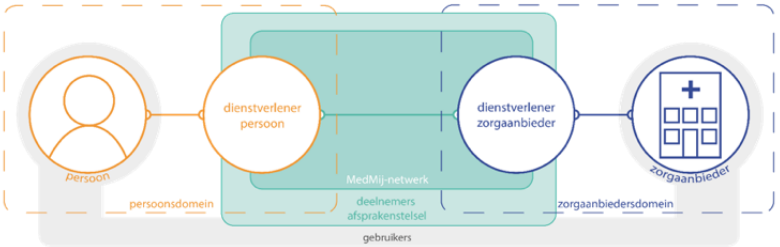
- ✓ It states which parties fulfill the roles of data exchange
- ✓ Agreements between these parties about rights, obligations, incentives, sanctions, testing and objections
- ✓ It has clear governance
- ✓ It's maintained and secured

MedMij Information Standards



MedMij programme products

Framework

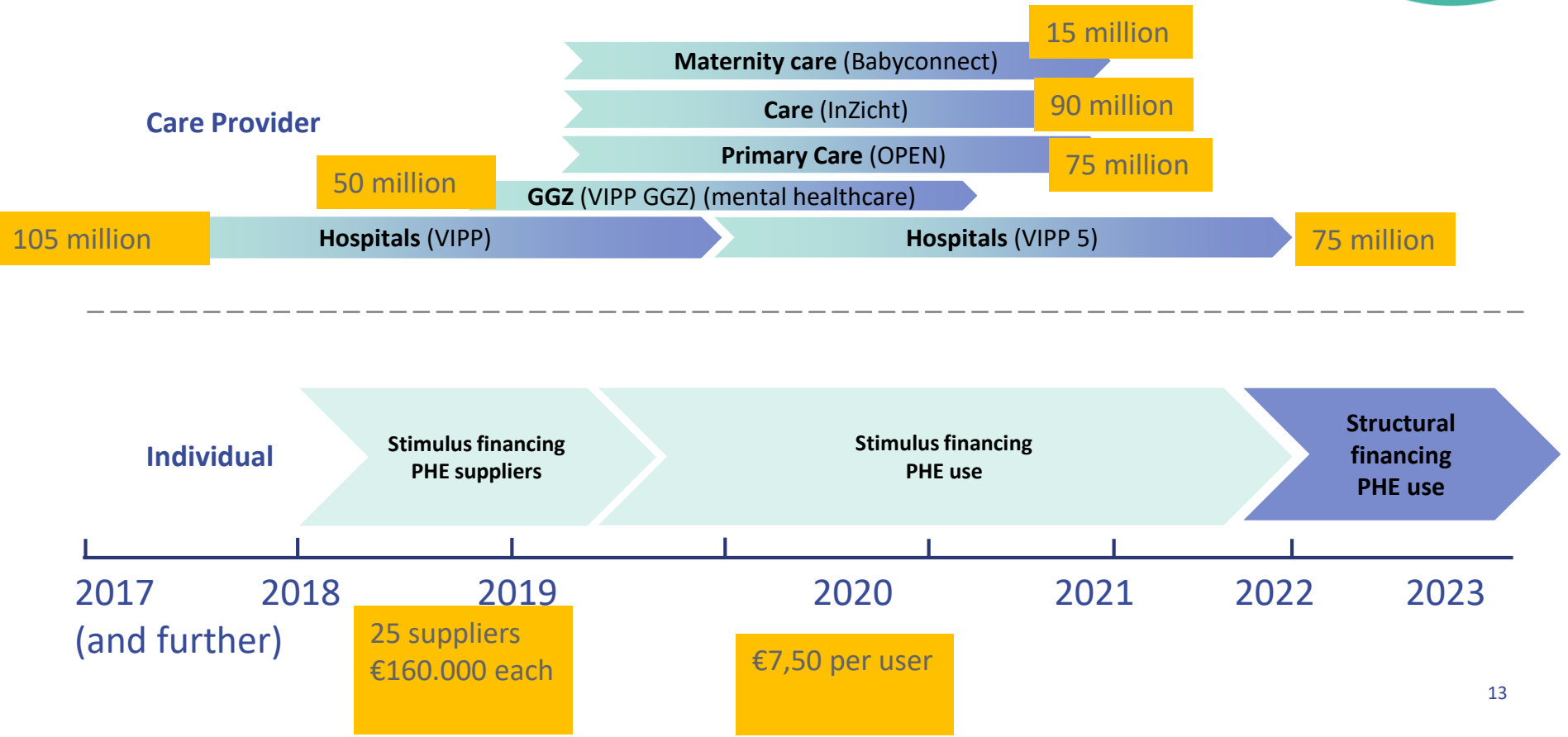


Standards

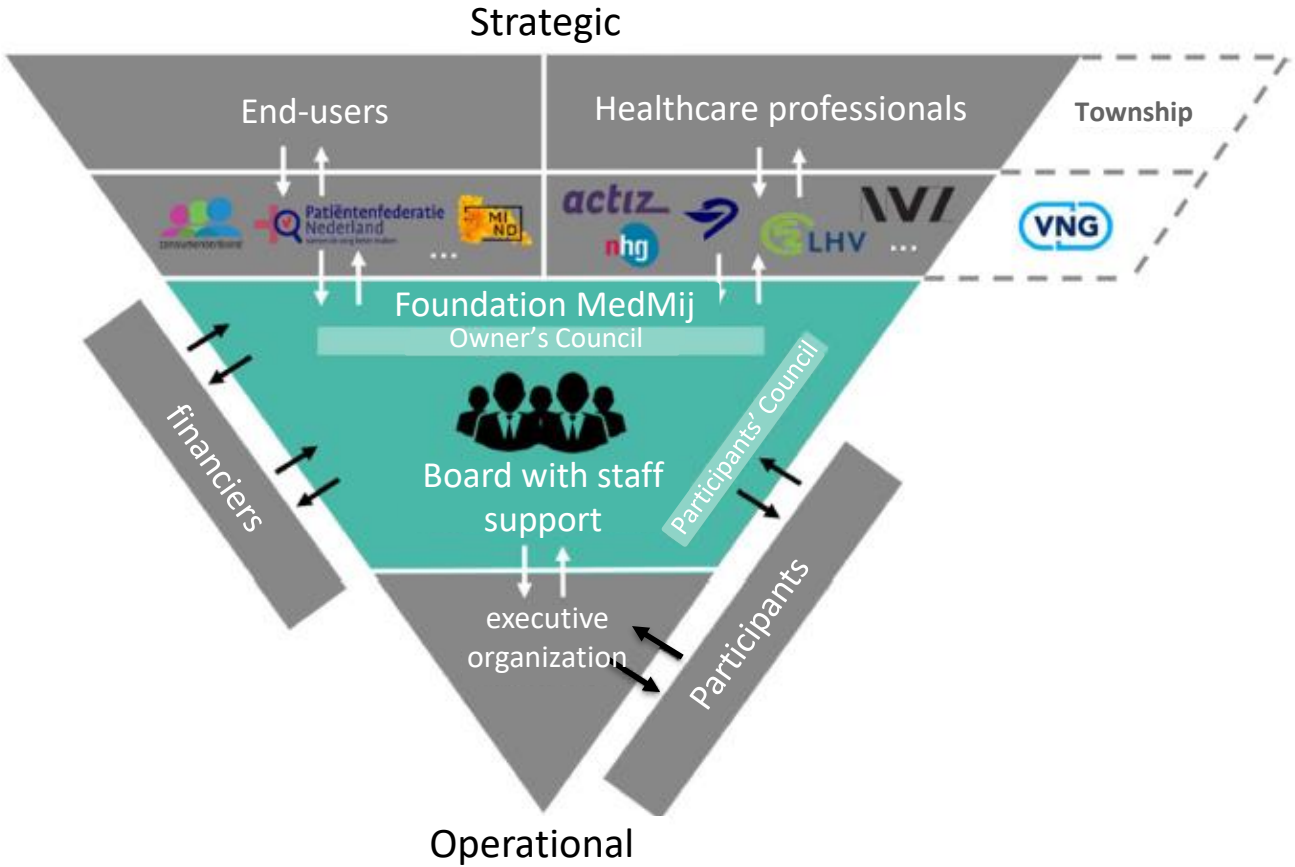
Financing

€

Financing system

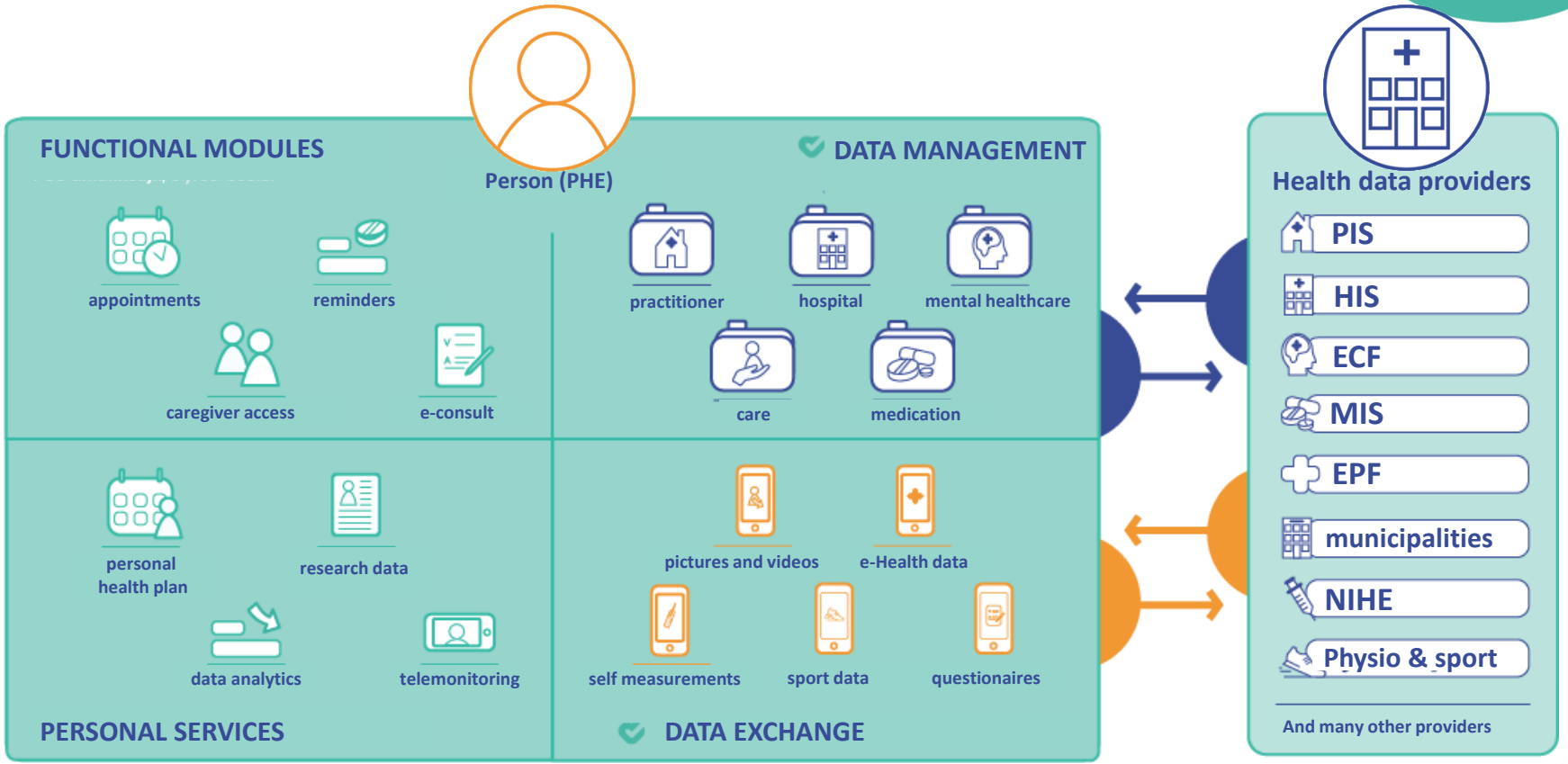


Governance of MedMij Foundation



Future plans

The PHE as a dashboard for healthcare



Challenges

- Who owns the data?
- User friendly Personal Health Environments
- Change in healthcare

MedMij

Grip op je eigen gezondheidsgegevens

Thank you

Questions?

Email to r.trul@medmij.nl

The Need for a Common Rulebook for Data Sharing

Saara Malkamäki

Specialist, IHAN project

Sitra – the Finnish Innovation Fund

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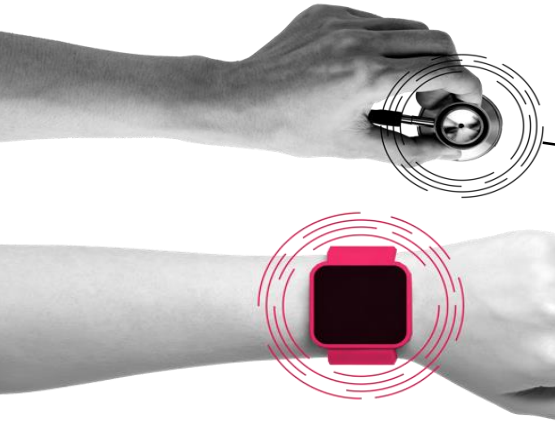
Everyone needs to get value in a fair data ecosystem



Value for all!

+ Leader & external stakeholders

Subcontractor

End User

Service

Value

Service Provider

Data

Value

Data Provider

Infrastructure Provider

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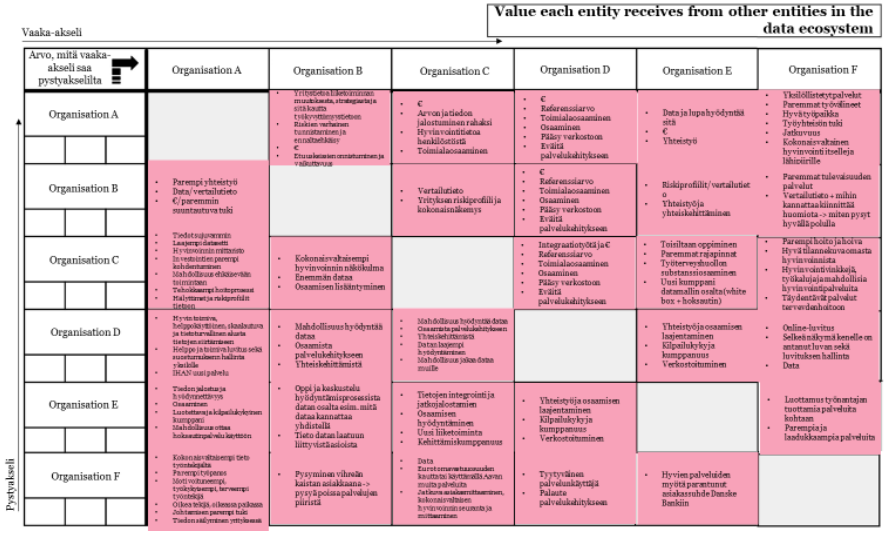
Examples of value creation from a data ecosystem

- New collaboration and co-creation opportunities
- Trustworthy and reliable partners
- Increase in knowhow
- More data
- Faster and better use of data
- Opportunity to share data
- Permit to use data
- Comparative data
- Better analysis and further processing of data
- Euros €
- New business opportunities
- Increase in competitiveness
- Better targeting of the investment path
- Possibilities in preventive work
- More effective treatment process
- Products and services in wider use
- Launch for new products and services
- Feedback to service development
- Enhanced services development
- Comprehensive understanding of end user
- Happy end user
- Increase in trust
- Personalised services
- Right doer in the right place at the right time
- Valuable support
- Better knowledge management
- Wider well-being perspective
- Better impacts and impact measurement
- Reference and brand value
- Increase in industry expertise
- Access to a network
- Better API services



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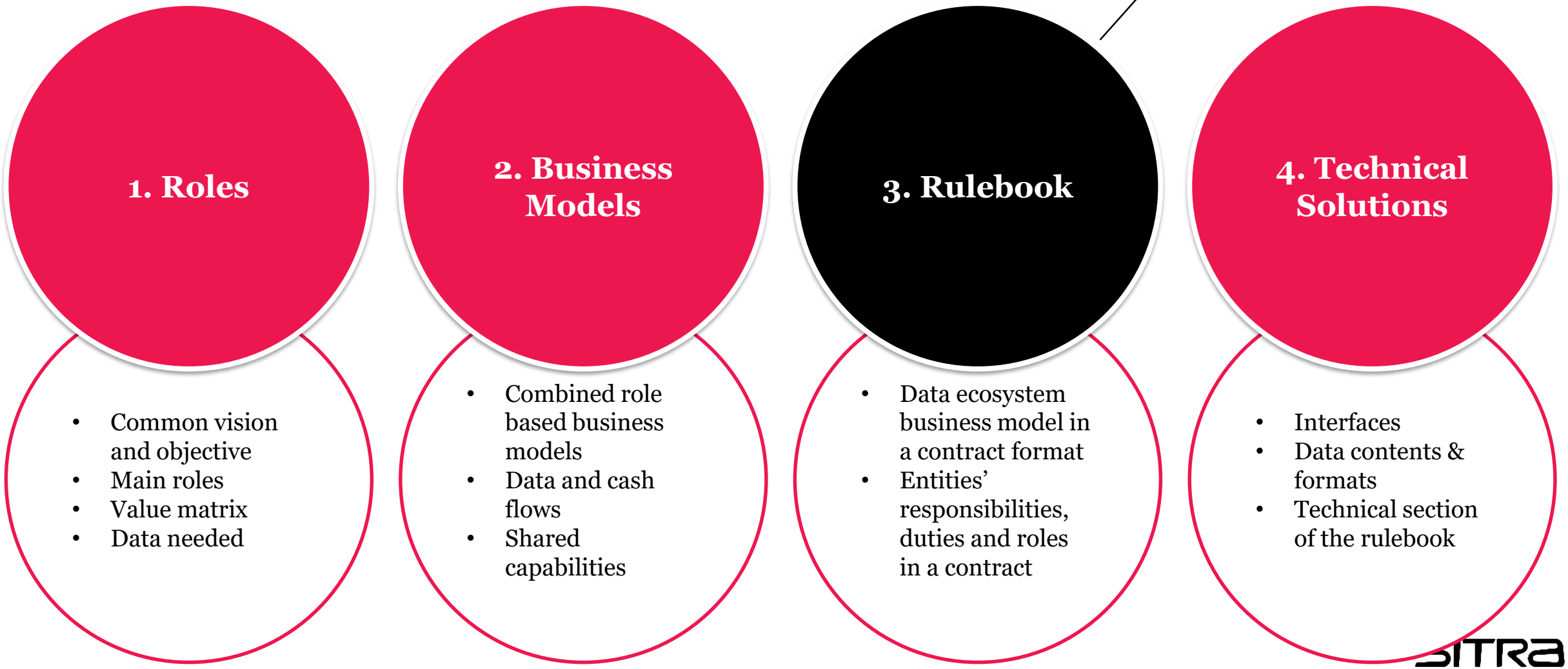
Pathway to a fair data ecosystem

Self-regulation based on a common rulebook for data sharing ecosystems



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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.

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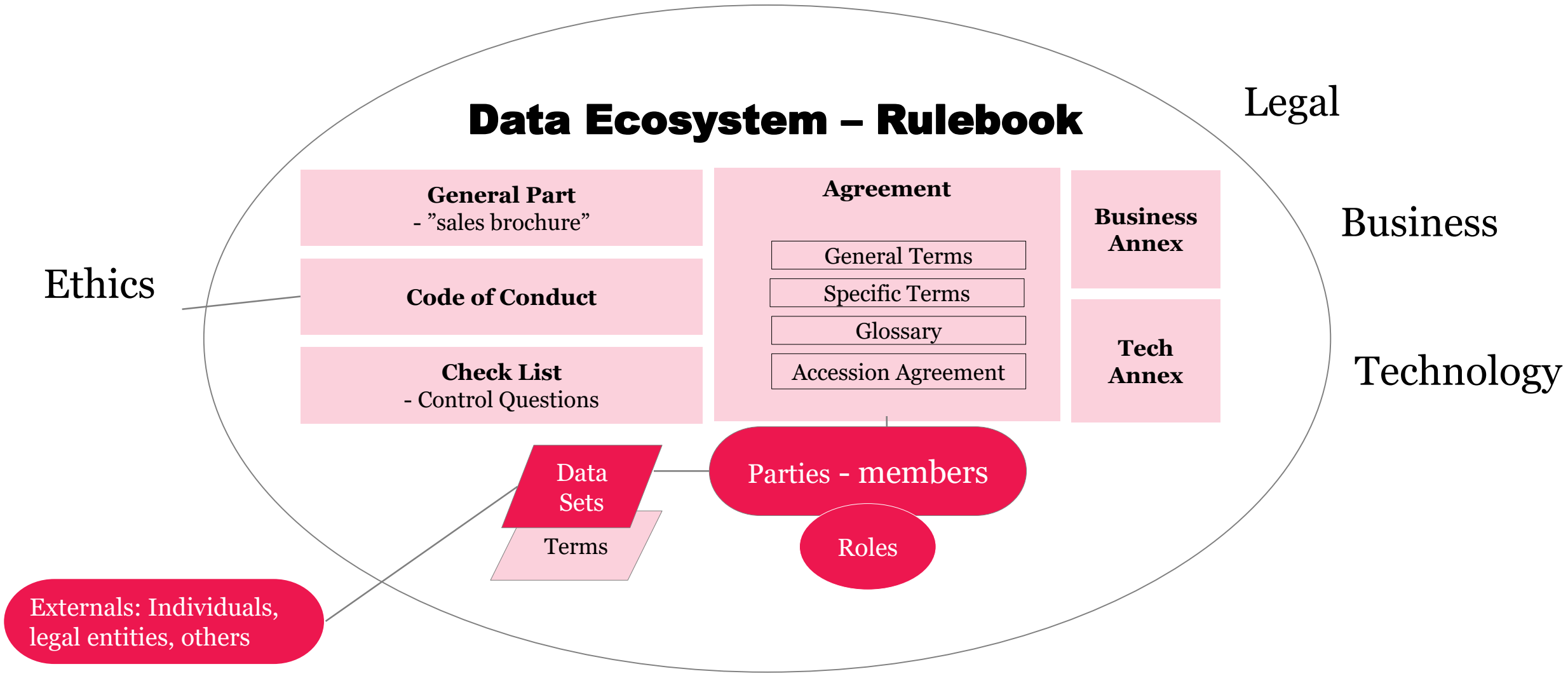
Data Ecosystem – Rulebook
Legal
Business
Technology
Ethics
General Part
- ”sales brochure”
Code of Conduct
Check List
- Control Questions
Agreement
General Terms
Specific Terms
Glossary
Accession Agreement
Business Annex
Tech Annex
Data Sets
Terms
Parties - members
Roles
Externals: Individuals, legal entities, others

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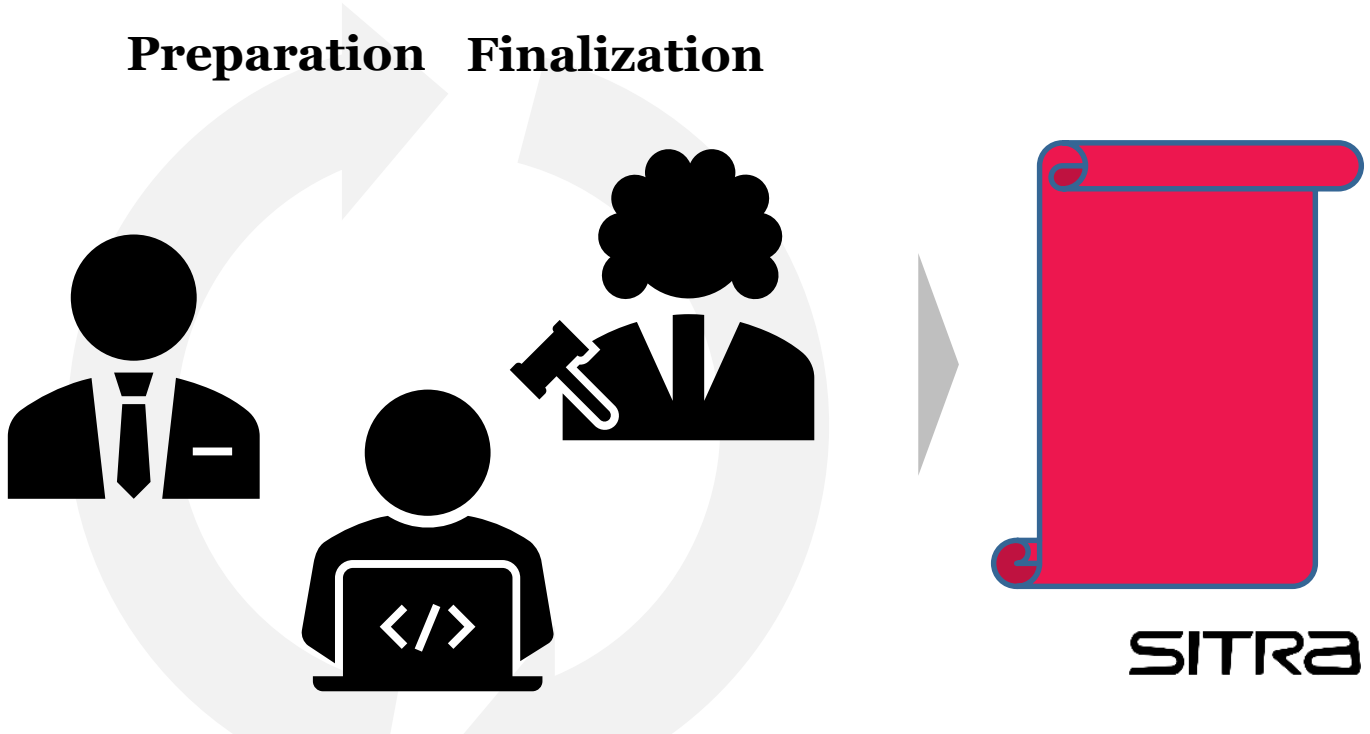
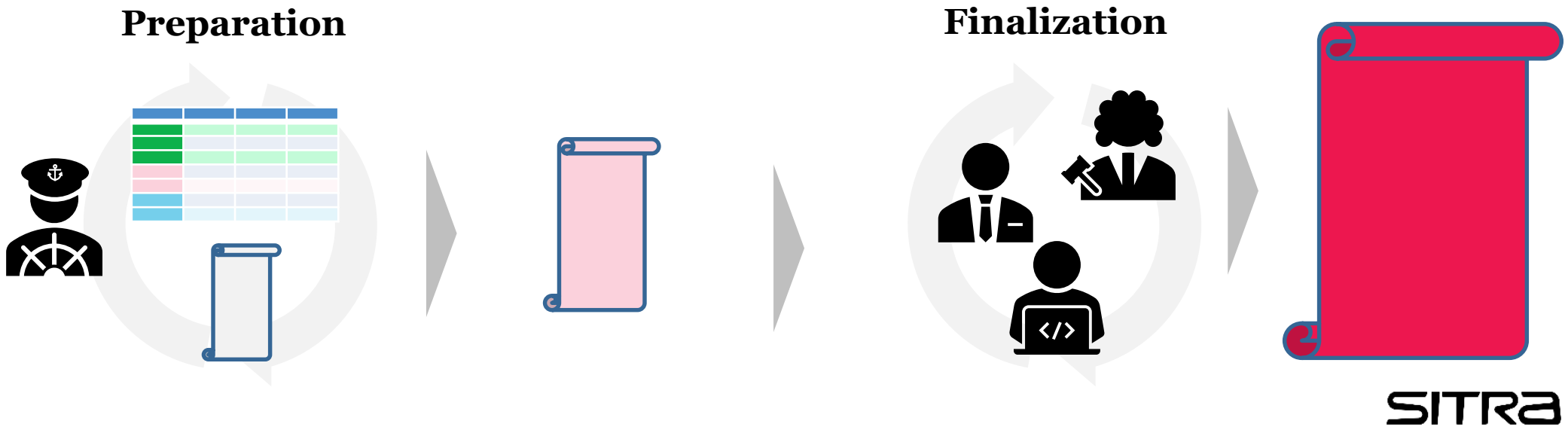
Current state

- Rulebooks are hand written 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



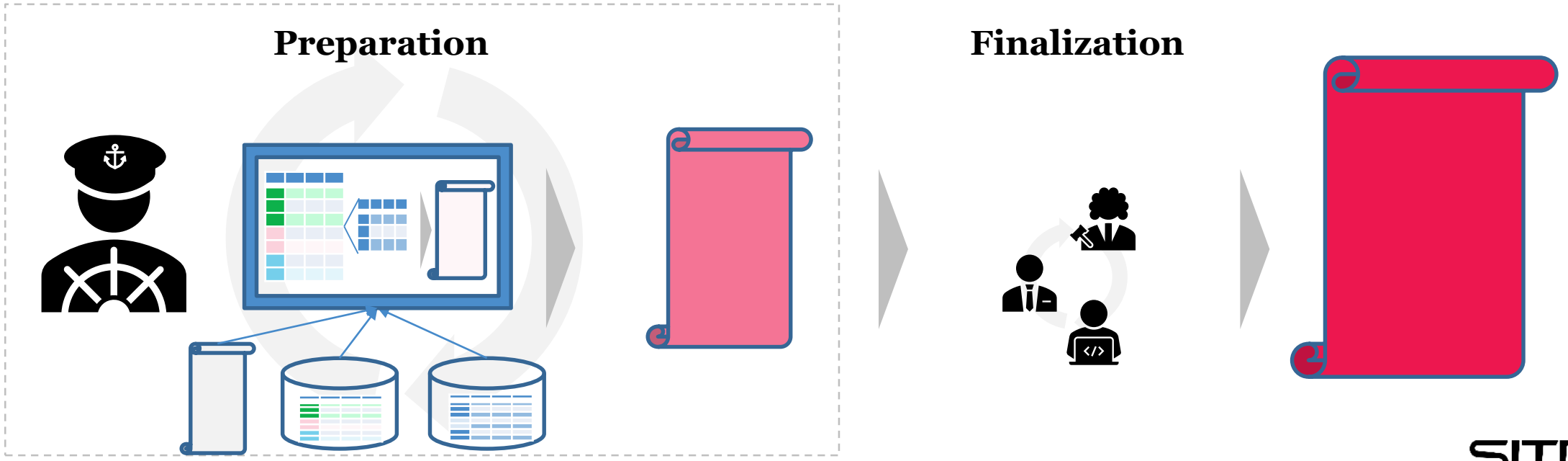
Near future state

- 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



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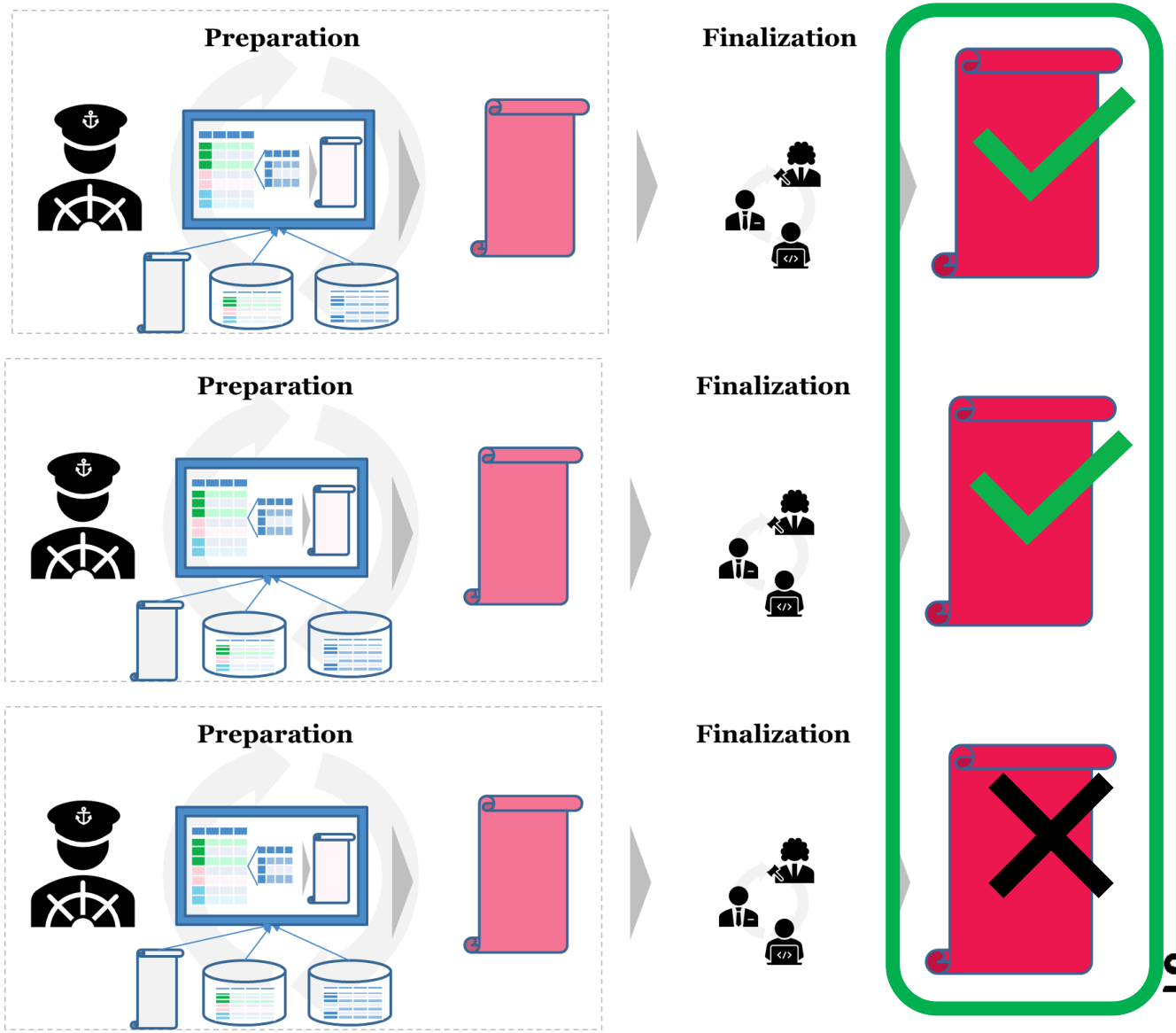
Rulebook interoperability validation process

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



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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

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Rulebook next steps

- The first version of the Rulebook is available on 3 December 2019
- A public seminar on the Rulebook will be held on Tuesday 21 January 2020
- 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

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

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

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