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

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 Finnish 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

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
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
Who creates the data in the future?

Lots of new data sources – health data being one example

- Data collected by individuals / unregulated data
- Data collected by professionals / regulated data

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

Regulated data

Unregulated data

More value!
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
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)
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

Service Provider

End User

Data

Value

Value
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
How IHAN® works

Requests for data → Service provider

Data providers

Consent to My Personal Data

Consumer/Patient

Service
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?

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
From IHAN components to fair data economy

**IHAN Governance Model**

- **IHAN compliant Components & repositories**
- **IHAN Fair Label**
- **Legal Ethical Semantic Technical**
- **IHAN Leap**

**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

**Business Pilots & emerging ecosystems**

- MyData
- IHAN Rulebook
- IHAN compliant
- Components & repositories
- IHAN Fair Label

**IHAN Blueprint**

- Concept Building
- Data Ecosystem Workshops
- Business Trials
- Partner engagement
- IHAN Leap

**Technical pilots**

- A
- B
- C
- D

- Open Source Repository
- IHAN Blueprint
RISE TO SHINE!
IHAN® - MEASURING A CHILD’S BLOOD SUGAR
EHTEL, BARCELONA
DEC. 4TH, 2019

Birgit Paajanen
Development Manager
HUS Development Group
WHERE IS YOUR PERSONAL DATA?

Ref.
Antti Poikola, Kai Kuikkaniemi, Harri Honko
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
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

The first Open Source consent based code delivered 9/2019

Measuring a child’s blood sugar
Parents set up a patient engagement service, and connect it with the blood sugar monitoring service. Using the service, a secure connection with HUS is formed and consent is given to retrieve the blood sugar data. 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. The doctor has near real-time access to Child’s blood sugar levels, and also a direct engagement channel with the parents.

**On boarding**

- Parents
- Child (patient)
- Blood sugar levels
- Patient engagement service

**Consenting**

- Testing the Open Source code
- Parent engagement
- Real-time data
- Doctor

**Data Access**

- HUS IT environment
- Blood sugar levels
- Consents

**KEY COMPONENTS OF THE SOLUTION ARCHITECTURE**

- Parents
- Child (patient)
- Blood sugar levels
- Patient engagement service
- Testing the Open Source code
- Data Access
- Real-time data
- Children’s Diabetes Consent & 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.
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.
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.
Giving consent

John receives the consent request and approves it.

Now the doctor has access to Jessica’s data.
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.
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.
Dream catchers
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

A good usercase
Service architecture connects service operation and information flow

Patient’s personal path connected with unique services

Professional’s profile connected with services to support patient’s personal path
## My Care Services

### Proactive Services
- My wellness 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

### Monitoring Services
- Monitoring service for the effectiveness of treatment
- 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
- Aide service
- Play therapy service

### Patient Support Services
- Appointment service
- Advisory service
- Information service
- Nutritional therapy service
- Peer support service
- Work integration service

### Patient Care Services
- Nutrition service
- Clothing service
- Transportation service
- Laundry service

### Advisory Services
- Appointment service
- Information service

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

### Unique Treatment Services
- Planning service for unique treatment
- Pharmaceutical care service
- Palliative care service
- Research care service
- Care measure service
- Radiotherapy service
- Fertilization care service
- Psychiatric therapy care
- Prognostication care service
- Obstetric care service
- Surgery care service
- Supporting care service
- Symptomatic care treatment

### Accommodation Services
- Accommodation services for relatives
- Psychological support service for relatives
- Peer support for relatives

### Services for Patient’s Family
- Accommodation services for relatives
- Psychological support service for relatives
- Peer support for relatives

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Image: HUSMAP® Service Platform Diagram

Image: HUSMAP Palveluarkkitehtuuri
PRE COMPETITIVE COLLABORATION AND HUSMAP PLATFORM PILOT
After the testing and the bidding phases HUS can by the solution created according of the HUS architectural principles.

Before calling for bids an option to develop the solution at the HUSMAP-platform is offered. The platform architecture is owned by HUS.

### 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.

### Environment
- **Sandbox / environment**

### Data
- **Synthetic data**
- **Synthetic data/or a limited, consent based real patient data**

### Production environment (Patient information systems)
- **Consent based real patient data**
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
HUS ECOSYSTEM RESOURCES TO IHAN

- ICT-platforms
- Hardware
- Facilities
- Patient data
- Partnering and innovation projects
- Clinical capability

Measuring child’s blood sugar
SCALABLE SERVICE PATH

Measuring child’s blood sugar
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.
THANK YOU
Henrique Martins
President of the Portuguese Shared Services for the Ministry for Health
Transformação Digital

CASOS DE SUCESSO

SHARED SERVICES FOR MINISTRY OF HEALTH (SPMS)
Electronic Health Record (EHR)

- Electronic Death Certificate
- Assignment of the Special Tax Regime for Medication and Other Benefits
- National Network of Integrated Continued Care
- Medical Tax (Status, Payments and Notification to the Revenue Authority)
- Scheduling Medical Appointments
- Telehealth
- Paperless Exams
- Paperless Prescription
- Online Waiting List and Check In
- Online Sick Leave
- Complaints/Suggestions
- Permanent Disability Benefit
- Emergency Mental Health Warrant
- Telecare and Chronic Disease Management Programmes
- Portuguese NiS Contact Center
- Feedback on Treatment Quality
- Temporary Disability Benefit
- Surgical Waiting List Appointment/Health Data Collection
- Chronic Medication Renewal
- Epidemiological Monitoring/Infectious Disease Statement
- Rare Diseases Card
- Immunization Record
- Travel Health Appointment
- European Health Insurance Card
- Health Data Exchange within Europe/International
- Multipurpose Medical Statement
- Driver’s License Medical Statement
- Citizen’s ID Card
- New Household/Family Physician
- Medical Tax Exemption
- Occupational Health/Medicine in the Workplace

CITIZEN’S LIFE CYCLE

IT Health Events
- Accomplished
- Under Development
- To Be

Birth Record, Citizen’s ID Card and National Patient Registry
- Citizen’s ID Card Codes for Parental Access
- Child and Youth Health eBooklet available online
- Immunization Record available online
- Medical Record, Household Information, Family Physician, Family Nurse and Children and Youth Health Programme Registry

- Immunization Record available online
- Community Health
- National Platform for Screenings
- Health Programmes
- Personal Care Plan
- Monitoring, Screenings and Health Surveys
- Living Will
- Oral Health Booklet
- Exercise Card

- Immunization Record
- Medical Statements of Ability /Other Statements
- Signalling Children/Youth at risk

- Medical Reports
- Immunization Record
Electronic Health Record (EHR)
Electronic Health Record (EHR)
Electronic Health Record (EHR) – Citizen’s Area
# Electronic Health Record (EHR) – Citizen’s Area

## Personal Data
- Identificação
- Contactos de Emergência
- Autorizações
- Histórico de Acessos

## Health Summary
- Contactos de Saúde
- Os meus registos
- Resumo de Saúde
- Doenças Raras
- Testamento Vital
- Certificado de Incapacidade Temporária
- Meus documentos

## Care Plan
- Calendário
- Plano Individual de Cuidados
- Questionário de Saúde
- Calculadora de Risco da Diabetes
- Medicações de Saúde
- Boletim Infantil e Juvenil
- Boletim de Vacinas
- Boletim de Saúde Oral

## Surgery & Prescription
- Consultas
- Marcações
- Estado Pedido Referência
- Receitas
- Guias de Tratamento
- Medicação Crónica
- Exames
- Resultados
- Guias de Prestação
- Cirurgias
- Estado da Inscrição
- Cuidados Respiratórios
- Domiciliários
- Guias de Tratamento

## Services
- Beneficios SNS
- Comprovação de Presença
- Pesquisa Prestadores
- Mobilidade de Doentes
- Sistema de Informação Taxas
- Moderadoras
- Isenção Taxas
- Moderadoras
- Consultar Taxas
- Moderadoras
- Contacto com a Unidade de Saúde

## NHS Benefits
- www.spms.min-saude.pt
Electronic Health Record (EHR) – Citizen’s Area

- Citizen Portal - @RISK (Diabetes risk calculator)
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

Autorizações

Autorizo que os profissionais de saúde credenciados consultem os registos por mim inseridos na Área do Cidadão.

Autorizo que os profissionais de saúde credenciados consultem a minha informação clínica, registada nos diversos sistemas de informação do Serviço Nacional de Saúde, através da Plataforma de Dados de Saúde.

Concordo que parte do meu Resumo Clínico Único do Utente (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.

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 da Plataforma de Dados de Saúde.

Autorização para receção dos emails institucionais da Área do Cidadão e do Ministério da Saúde.

✓ **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
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

AWARENESS
Acknowledge the need

Search Information
Seeks support

Medical Assistance
Addresses Health Unit

Patient Feels sick and searches for support

• Medical Assistance at the Hotel or local Pharmacy
• Search on SNS website, SNS24, Social Security, CrossBorder website, other
• Contact Portuguese Embassy
• Contact Support Centre: atendimento@SNS24.gov.pt

Obtain Medical Care

Travel to

Luxembourg
Croatia
Malta
Czech Republic

Portuguese Citizen

Creates Patient Summary
Consents Patient Summary sharing

RSE
Área de Cidadão

Approves Patient Summary

Doctor

WHERE TO FIND INFORMATION

Hospitals

Embassies

Websites:

SNS 24

Conselhos aos Viajantes do Portal das Comunidades Portuguesas - MNE

Portuguese Citizen

Websites:

Embassies

Travel Services:

Airlines, Airport, Cruises, Hotels

Websites:

Embassies

Travel Services:

Airlines, Airport, Cruises, Hotels

Embassies

Travel Services:

Airlines, Airport, Cruises, Hotels

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Airlines, Airport, Cruises, Hotels

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Travel Services:

Airlines, Airport, Cruises, Hotels

Embassies

Travel Services:
Patient Journey - Patient Summary Country B

CZECH CITIZEN FEELS SICK AND SEARCHES FOR SUPPORT TRAVELS TO PORTUGAL

- Medical Assistance at the Hotel or local Pharmacy
- Call SNS24: 808 24 24 24
- Search the CrossBorder website
- Contact Czech Embassy

FIND A COMPATIBLE HEALTH UNIT

IDENTIFIES PATIENT AND ITS PATIENT SUMMARY

WHERE TO FIND INFORMATION

Websites:

- SNS 24 Centro de Contacto SNS Nacional de Saúde
- SNS Hospital do Oriente
- SPMS
- anf afp
- Pharmacies
- Hospitals
- Embassies
- Cross Borders, Travel Agencies, Airlines, Airport, Cruise, Hotels

Obtain Medical Care
Patient Journey - ePrescription / eDispensation Country A

**AWARENESS**
Acknowledge the need

**SEARCH INFORMATION**
Seeks support

**MEDICAL ASSISTANCE**
Addresses Health Unit

Feels sick and searches for support
- Medical Assistance at the Hotel or local Pharmacy
- Search on SNS website, SNS24, Social Security CrossBorder website, other
- Contact Portuguese Embassy
- Contact Support Centre: atendimento@SNS24.gov.pt

Where to find information

- **SNS 24** (Centro de Contacto SNS24/Global
- Websites: [SNS](#), [SNS24](#), [SPMS](#)
  - Embassies: Cross Borders, Visa, Agreements, Airlines, Airport, Cruise, Hotels
  - Conselhos aos Viajantes do Portal das Comunidades Portuguesas - MNE

- **SNS 24** (Centro de Contacto SNS24/Global
- Websites: [SNS](#), [SNS24](#), [SPMS](#)
  - Embassies: Cross Borders, Visa, Agreements, Airlines, Airport, Cruise, Hotels

- **SNS 24** (Centro de Contacto SNS24/Global
- Websites: [SNS](#), [SNS24](#), [SPMS](#)
  - Embassies: Cross Borders, Visa, Agreements, Airlines, Airport, Cruise, Hotels
  - Conselhos aos Viajantes do Portal das Comunidades Portuguesas - MNE

Obtain Medical Dispensation

- Pharmacy
  - eIDToken, ePrescriptionID, eDispensationID

- Cross Borders, Travel Agencies, Airlines, Airport, Cruises, Hotels
- Embassies

- Medical Assistance at the Hotel or local Pharmacy
- Search on SNS website, SNS24, Social Security CrossBorder website, other
- Contact Portuguese Embassy
- Contact Support Centre: atendimento@SNS24.gov.pt
# Patient Journey - ePrescription / eDispensation Country B

**SERVICE 4**

**FINNISH CITIZEN**

1. **TRAVELS TO PORTUGAL**
2. **FIND A COMPATIBLE PHARMACY**
   - eID Token
   - ePrescription ID
   - eDispensation ID
3. **Obtain Medical Dispensation**

**WHERE TO FIND INFORMATION**

- Websites:
  - SNS 24 Centros de Contacto
  - SNS Serviço Nacional de Saúde
  - SPMS - Serviços Partilhados do Ministério da Saúde
  - anf afp
  - Pharmacies
  - Hospitals
  - Embassies
  - Travel Agencies, Airports, Hotels

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06/12/2019

www.spms.min-saude.pt
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

YES.
Individuals can be identified from data

Linkage to Consent Database

Has the patient consent share data for research?
(data and purpose)

Yes.

Is personal data involved?

NO.
The data does not relate to identifiable individuals

RICA
(Anonymised Clinical Information Repository)

What we have

What we don’t have (yet!)
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

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<th>Period of agreement</th>
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<td><strong>Protegido</strong></td>
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<th>Intended use of the data</th>
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<td><strong>Protegido</strong></td>
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<th>Constraints on use of the data</th>
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<td><strong>Protegido</strong></td>
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<th>Data confidentiality</th>
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<td><strong>Protegido</strong></td>
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<th>Methods of data-sharing</th>
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<td><strong>Protegido</strong></td>
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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

96,953
Total of emitted paperless prescription

217,532
Total of medicine packages
ePrescription - iPrescription

iPrescription

Notification Patient

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

PATIENT

"1 pill once a day during 3 months"

Electronic Dispensation of the medicines

Paperless Prescription
Prescription for Physical Exercise

Publications:

Mobile Applications – MyNHS Family

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

**MyNHS TIMES**
APP that allows the consult of average waiting times in the NHS hospital institutions.

**MyNHS WALLET**
APP that gathers information about the patient data in the NHS.
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 with 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.

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**September 2019**

**Prescription & Treatment Guides**: 3,41 M

**Health Access**: 741,77 K

**Vaccination**: 612,75 K

**ADSE**: 173,80 K

**Allergies**: 158,16 K
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
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)

All-in-one app:
Design the cards (drag & drop), map the services and configure the metadata.
IMPROVING THE HEALTH OF THE PORTUGUESE, CARD BY CARD

Mobile Applications
From the SDK to MyNHS Wallet
SNS 24 – WEBSITE

ANALYTICS

1 288 279 users

1 834 771 accesses

63,9% Mobile
33,6% Desktop
2,6% 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
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
Good climate

- Everybody CEO of their own health
- Living at home longer, self sustainable
- Self-measurements
- New treatments with big data and AI
- Tele-health

Fertile ground

- Basic infrastructure
  - Standards
  - Registers
  - Same language
  - Authentication
  - Monitoring
  - 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**.
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

- General Practitioner
- Hospital care
- Medication
- Lab results
- Self measurements
- Online appointments
- Case assessment
- PDF
- Mental Healthcare
MedMij programme products

Framework

Financing

€

Standards
Financing system

**Care Provider**
- Maternity care (Babyconnect) 15 million
- Care (InZicht) 90 million
- Primary Care (OPEN) 75 million
- GGZ (VIPP GGZ) (mental healthcare) 50 million
- Hospitals (VIPP) 105 million
- Hospitals (VIPP 5) 75 million

**Individual**
- Stimulus financing PHE suppliers
  - 25 suppliers €160.000 each
- Stimulus financing PHE use
  - €7,50 per user
- Structural financing PHE use

**Years**
- 2017 (and further)
- 2018
- 2019
- 2020
- 2021
- 2022
- 2023
Governance of MedMij Foundation

Strategic

End-users
Healthcare professionals

Township

Foundation MedMij
Owner’s Council

Board with staff support
executive organization

financiers
participants
Operational
Future plans
The PHE as a dashboard for healthcare

FUNCTIONAL MODULES
- appointments
- reminders
- caregiver access
- e-consult
- personal health plan
- research data
- data analytics
- telemonitoring

PERSONAL SERVICES
- self measurements
- sport data
- questionnaires

DATA MANAGEMENT
- practitioner
- hospital
- mental healthcare
- care
- medication

DATA EXCHANGE
- pictures and videos
- e-Health data

Health data providers
- PIS
- HIS
- ECF
- MIS
- EPF
- municipalities
- NIHE
- Physio & sport
- And many other providers
Challenges

• Who owns the data?
• User friendly Personal Health Environments
• Change in healthcare
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.
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
Pathway to a fair data ecosystem

1. Roles
- Common vision and objective
- Main roles
- Value matrix
- Data needed

2. Business Models
- Combined role based business models
- Data and cash flows
- Shared capabilities

3. Rulebook
- Data ecosystem business model in a contract format
- Entities’ responsibilities, duties and roles in a contract

4. Technical Solutions
- Interfaces
- Data contents & formats
- Technical section of the rulebook

Self-regulation based on a common rulebook for data sharing ecosystems
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 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
Rulebook interoperability validation process

- Ensures that the resulting rulebooks conform to set quality and content standards
- Also ensures interoperability between data ecosystems
**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
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
PLEASE SIGN TO OUR IHAN NEWSLETTER TO GET INFORMATION ON OUR FAIR DATA ECONOMY PROJECT:


+ tick a box "IHAN® – Human-driven data economy
RISE TO SHINE!