



1918

TALLINN UNIVERSITY OF
TECHNOLOGY

Digital data driven health care for citizen and physicians

Estonian experience of implementation of nation- wide health information system since 2009

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21.09.2016

Big Data, Small Data, and My Data: What Future Role for Patient Information
STOCKHOLM, SWEDEN



Prelude

How we make health related decisions?

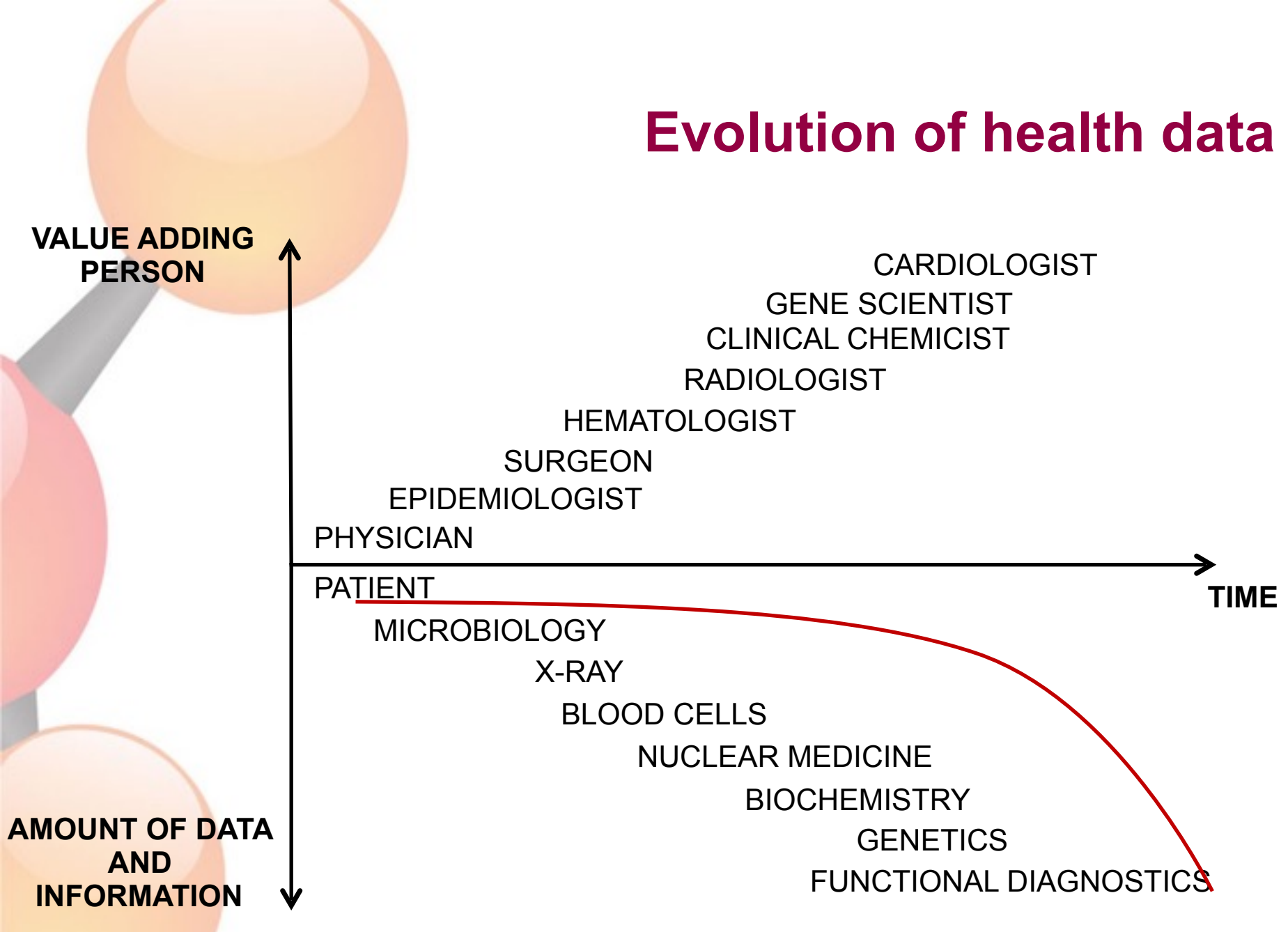
DATA - INFORMATION - KNOWLEDGE - ACTIVITY



Today's keywords?

- **Primary use of data**
 - Impact for performance
 - Personal outcome
- **Secondary use of data**
 - Impact for society/economy/quality
 - Public outcome

Evolution of health data



Evolution of health data

VALUE ADDING
PERSON



PHYSICIAN

PATIENT



AMOUNT OF
DATA AND
INFORMATION

CARDIOLOGIST
GENE SCIENTIST
HEALTHCARE PROFESSIONAL
CLINICAL CHEMIST
RADIOLOGIST
HEMATOLOGIST
SURGEON
EPIDEMIOLOGIST
PATIENT
SOCIETY

TIME

MICROBIOLOGY
X-RAY
BLOOD CELLS
NUCLEAR MEDICINE
BIOCHEMISTRY
GENE MAP
FUNCTIONAL DIAGNOSTICS
Presentation of health data in the proper context and in visually understandable mode



Outline

- Facts about Estonia
- Estonian nation-wide Health Information Information System (EHIS)
 - Services for healthcare professionals, citizens and society
- Utilization of existing services
- Findings of use of digital medical data
- Observations and difficulties
- Future trends

Facts about Estonia

➤ Basic facts

- Population is 1,3 million
- Income tax 20% (flat tax); Currency – Euro
- Every citizen has unique ID-code (like in Scandinavia)

➤ Health care system

- Compulsory health insurance paid by employers; 13% of payroll tax
- Health care costs make up to 6% of GDP (9,5% in OECD)
- Healthcare providers are private, municipal or governmental
- Hospital system – publicly owned private hospitals
- General practitioners are private entrepreneurs

➤ Facts about e-services

- 88% of households have broadband connection (2015)
- 96% of income tax declarations are made via the E-Tax Board (2014)
- 31% of votes were cast over the internet on (2014)
- 99% financial transactions (bank transfers) carried out electronically
- 90% fishing permits given out electronically

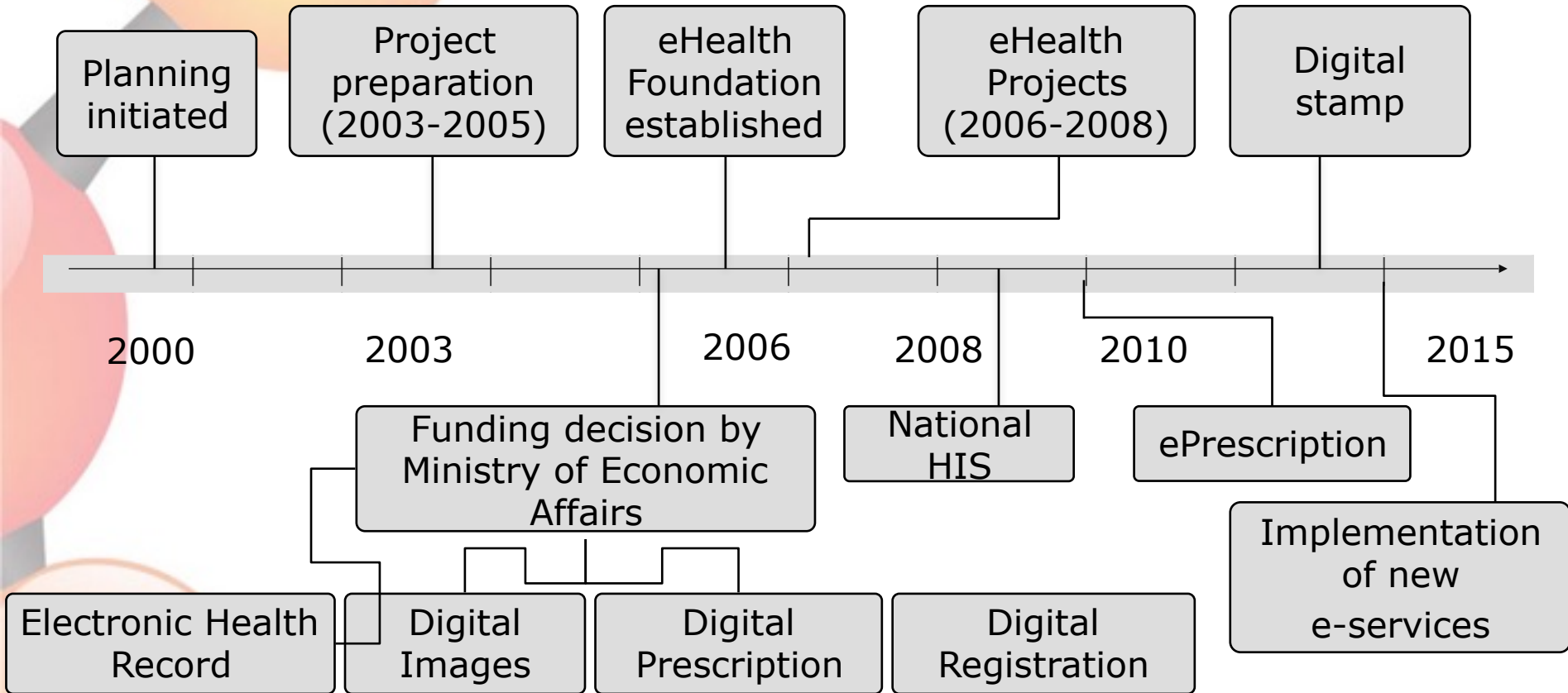




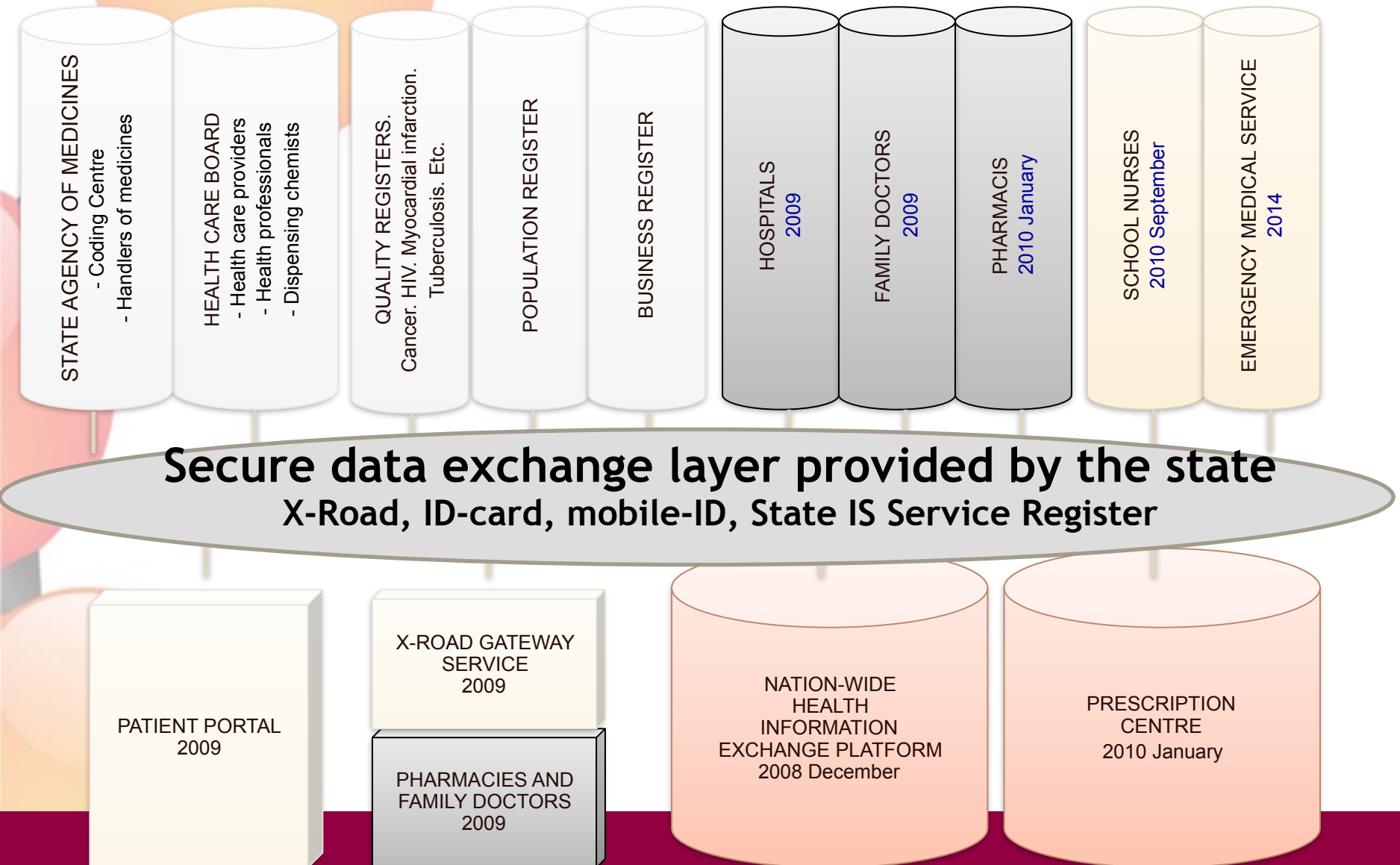
Estonian nation-wide Health Information System (EHIS)

- The Estonian HIS is unique as it
 - Encompasses the whole country
 - Registers virtually all residents' health history from birth to death, and
 - Is based on the comprehensive standard based IT infrastructure

HIS platform history



Estonian eHealth architecture



eHealth services in Estonia

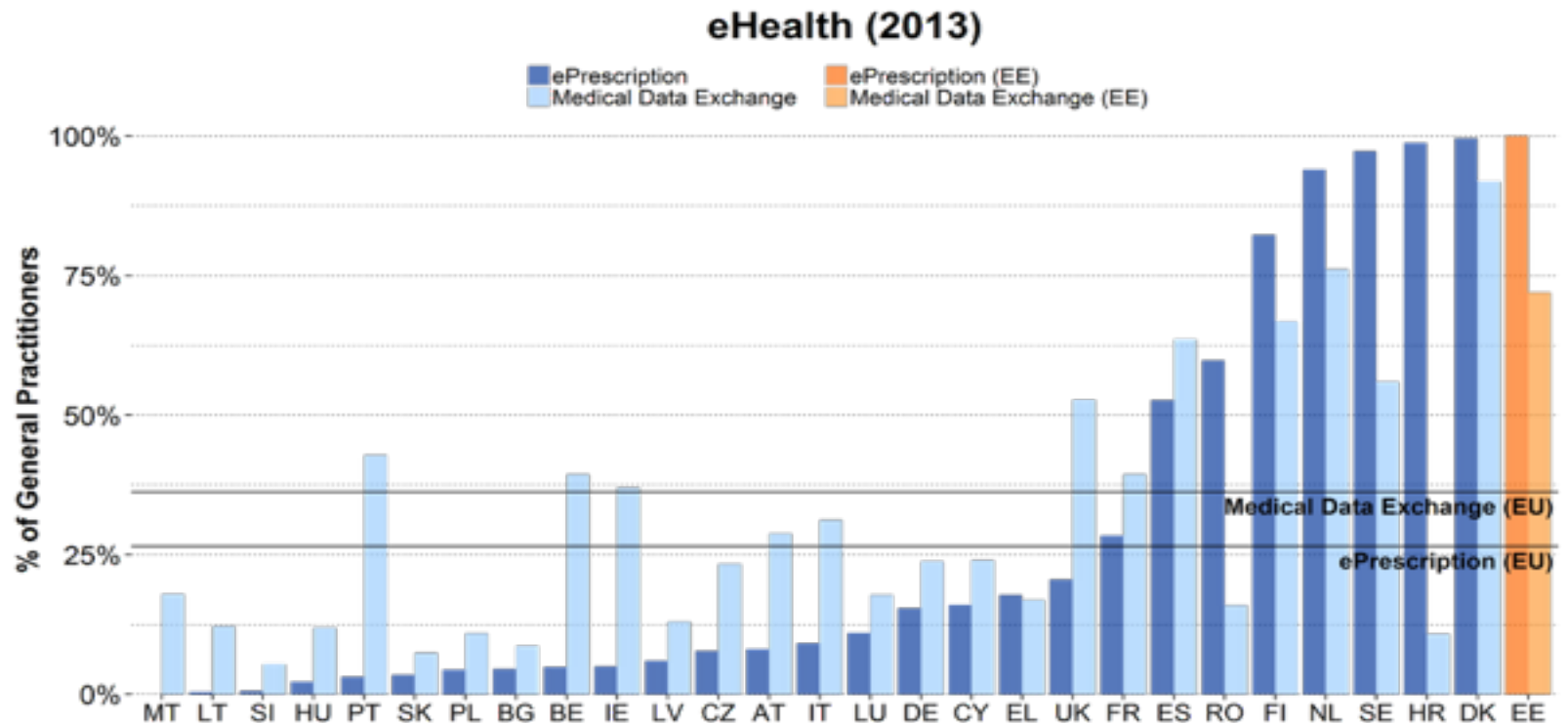
- Nation-wide health information system
 - Available documents
 - Time critical data (allergy, chronic diseases)
 - General practitioners and hospital visits
 - Summary of ambulatory and stationary case
 - Link to medical images
 - Referral letter
- ePrescription
- Digital images
 - Available all over the country
- eReferral
- eAmbulance
- Drug-drug interaction service
- Cross-sectoral services
 - Health declaration for driver licence exchange
 - Working incapacity assertion

Current situation

- **24 397 387** medical documents
 - 14 different documents
- Health information about 1 490 879 inhabitants (Estonia has 1 320 000 million inhabitants)
- Ambulatory case summaries – 13 107 254
- Exam reports – 5 863 450
- Stationary case summaries – 1 525 280

Digital Public Services: eHealth

100% of Estonian General Practitioners send prescriptions electronically to pharmacists
(27% in the EU)
and 72% exchange medical information electronically with other healthcare providers
(36% in the EU).



Patient Portal

- Log in with ID-card or Mobile-ID
- View and update personal data and add contact data of close relative
- View his/her medical data (electronic health records) from health care providers
- View electronic referral letters
- View all electronic prescriptions
- Add representatives for him-/herself for different actions (e.g. buying out e-prescriptions)
- Make declarations of intent (e.g. donation of organs)
- Access health insurance data
- Mask sensitive health data for doctors or representatives
- Fill in a health declaration form for health certificate
- Get the overview from a log file of who has viewed his/her data.

Lõplik kliiniline diagnoos

Haigusjuhtum Lõplik kliiniline diagnoos Anamnees Objektiivne leid Uuringud ja operatsioonid

Kokkuvõtte revist Ravialased soovitused

Sõnaline diagnoos

Statistiline
lik

Z10.0 - Kindla isikuteühma tavaline tervise üldkontroll, töotervishoiualane läbivaatus

Kindla isikuteühma tavaline tervise üldkontroll, töotervishoiualane läbivaatus

-



Print



Up

Anamnees, diagnoosi põhjendus ja haiguse kulg

Anamnees

Töötab: ITK - radioloog ajates 1994a. praegu 0,5 koomusega, 100 arvutiga, B-kat kiirgustöötaja. Töökohanna terviseohutusest teadik. Täiskoomusega on TTU õppejõud. Olulisi tervisekaebusi ei esita. Kõr haigus ei ole.

Objektiivne leid

Uuringud ja protseduurid

Kuupäev

HK Hinnakirja kood

07.01.2016

7903 - Röntgeniülevõtte rindkere piirkonnast (üks ülevõtte)

Röntgeniülevõtte RÖ rindkerest PA, AP (otse) RÖNTGENOGRAMM RINDKEREELUNDITEST P-A SUUNAS: LEID: Diafragma kuuplid kumerad, selgepiiriliselt, tavalisel kõrgusel. Lateraalsiirused vabad. Hiirused rahuldava struktuurusega. Kopsude õhustatus tavaline, kopsujoonis reasusteta. Kopsudes koldelisi sh. infiltratiivseid muutusi esile ei tule. Südame vari on ristimõõdus norm laiusega. Mediastinum foonil laavarje esile ei tule. KOKKUVÕTE: Aktuaalse patoloogiata.

Analüüsid

Nimetus	Referentsväärtus	Tulemused	Ühik
a1178 - Hemogramm viieosalise leukogrammiga*		Kuupäev 07.01.2016 07:57:00	Tulemus
a2034 - WBC	4,5 .. 10,4	Kuupäev 07.01.2016 07:57:00	Tulemus 7.18
a2054 - NEUT%	1,8 .. 7,8	Kuupäev 07.01.2016 07:57:00	Tulemus 3.45
a2055 - LYMPH%	1,0 .. 3,5	Kuupäev 07.01.2016 07:57:00	Tulemus 2.49

Suusisene uurimine

Anamnees Kliiniline vaatlus Staatused Teostatud töö

Suuõõne hügieen kirjeldus

Limaskestad

Limaskestade kirjeldus

47407200011 MARIA CARLSON



Prindi



Üles

Hammaste staatused

Hamba nr	Staatus	Vaata kirjeldust
	-	
	-	
	-	
	K04.5 - krooniline apikaalne periodontit	<input checked="" type="checkbox"/>
	Arsti sõnaline diagnoos	

dmft indeks 15.6

CPI indeks	1	2	3
	4	X	9



FINDINGS

ePrescription, Estonia

98% of prescriptions are issued in electronic form

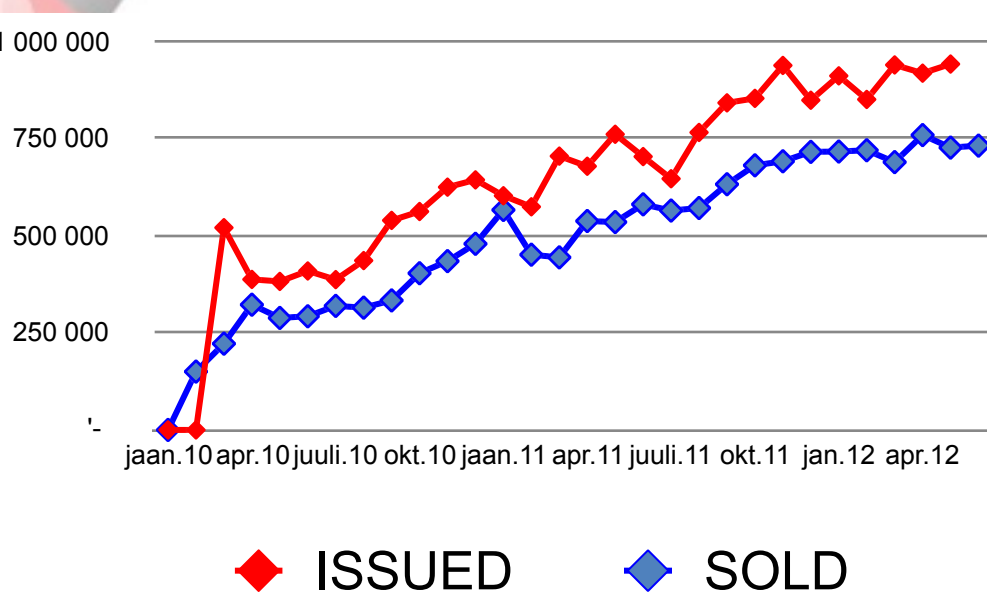


Figure 4. Prescription forms bought by the EHIF in 2009–2013.

Use of eHealth platform by healthcare professionals, Estonia

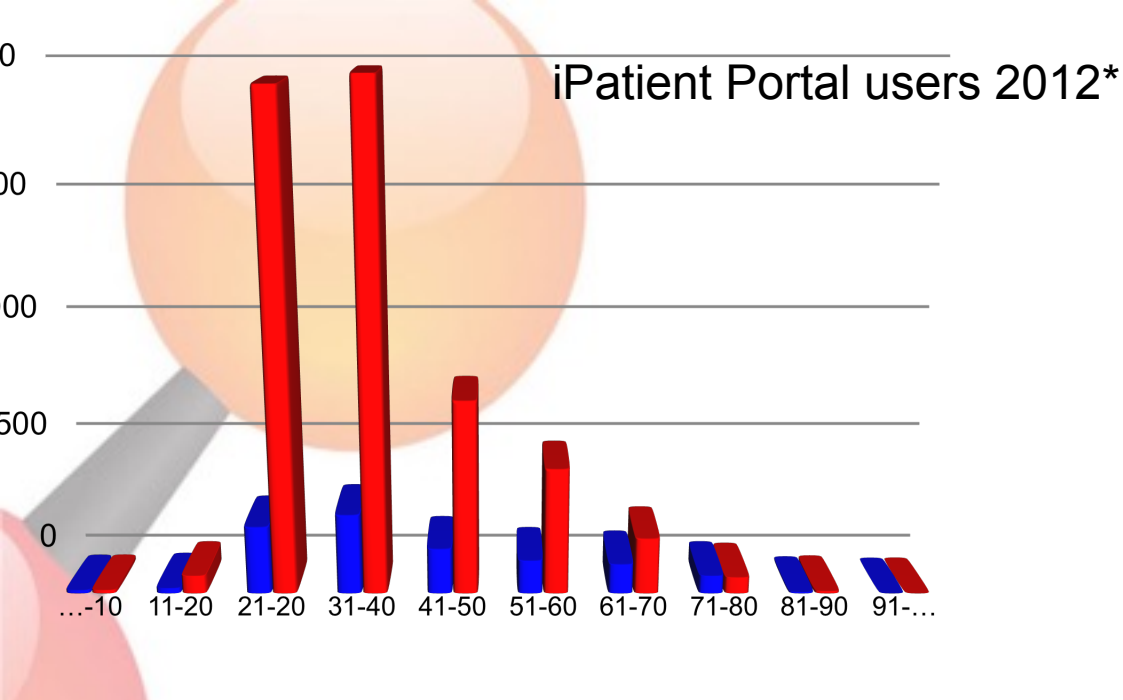
Number of queries



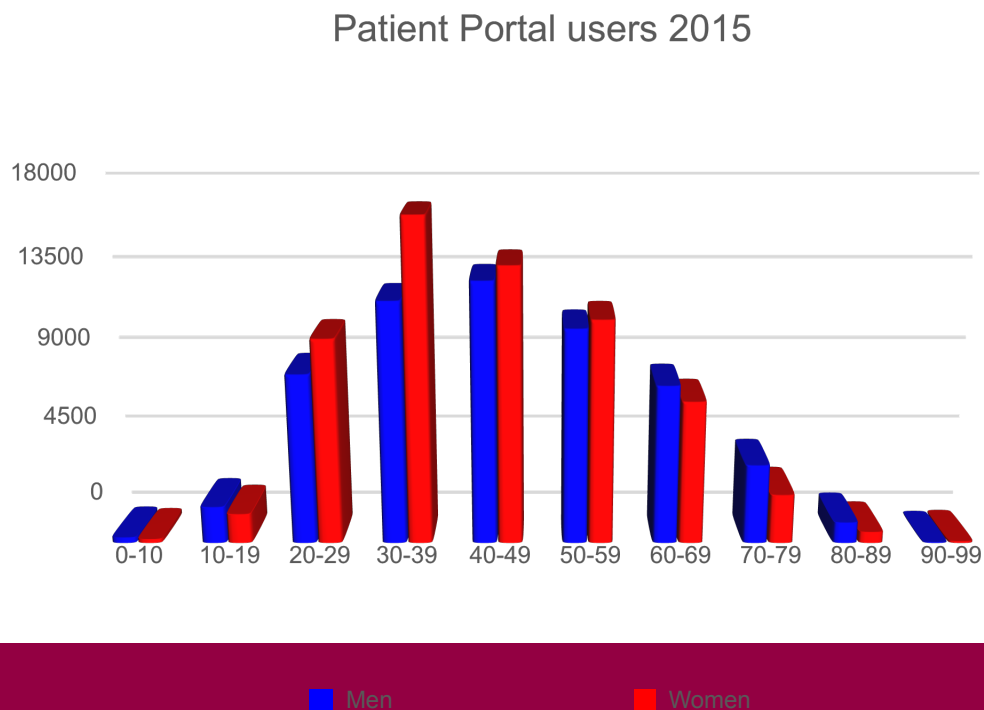


Acceptance

- ePrescription covers 98% of issued prescriptions
- Close to 100% of Hospital discharge letters are digital
- Ambulatory case summaries sending level is high
- Patient portal usage is good and increasing
 - **258 157** unique visitors (17% of residents)
 - **1 490 879** persons have documents
- 100% of insurance claims are digital



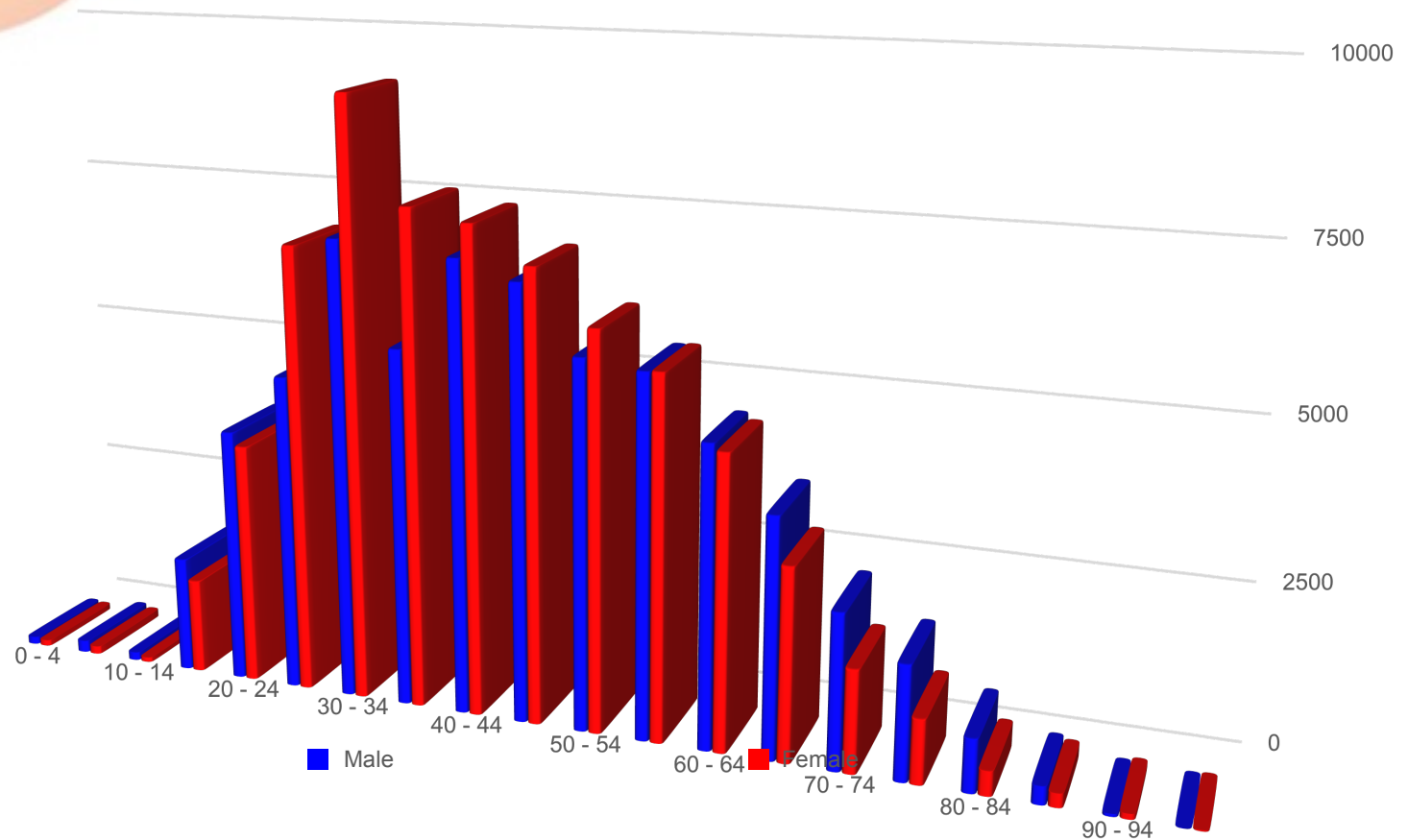
Logins to iPatient Portal in 2012* and Patient Portal users in 2015 by age and gender



*2012 January - August

Unique Patient Portal users by age and gender in 2015

Patient portal users 2015



Viewing of radiology images (2010)

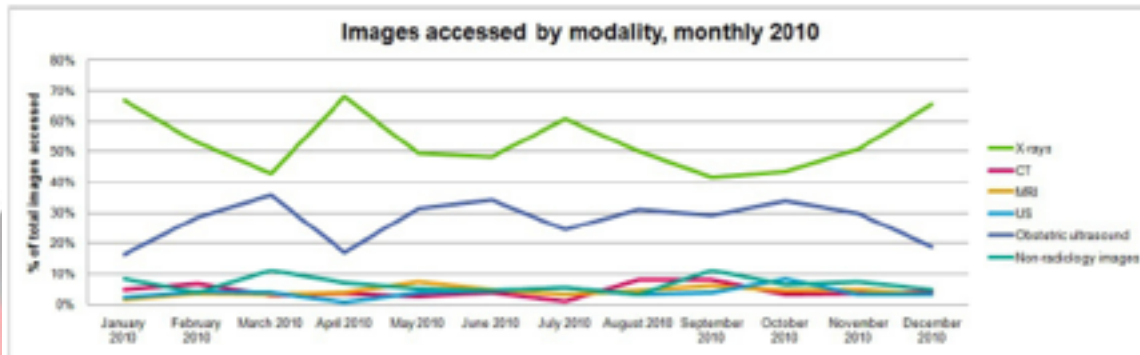
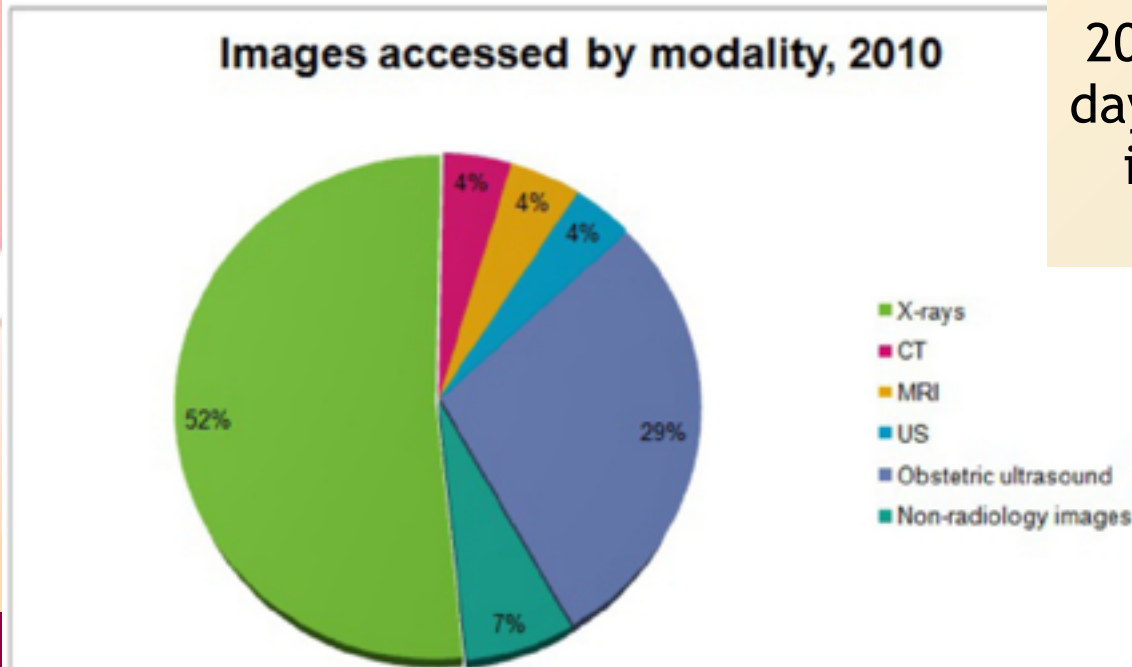


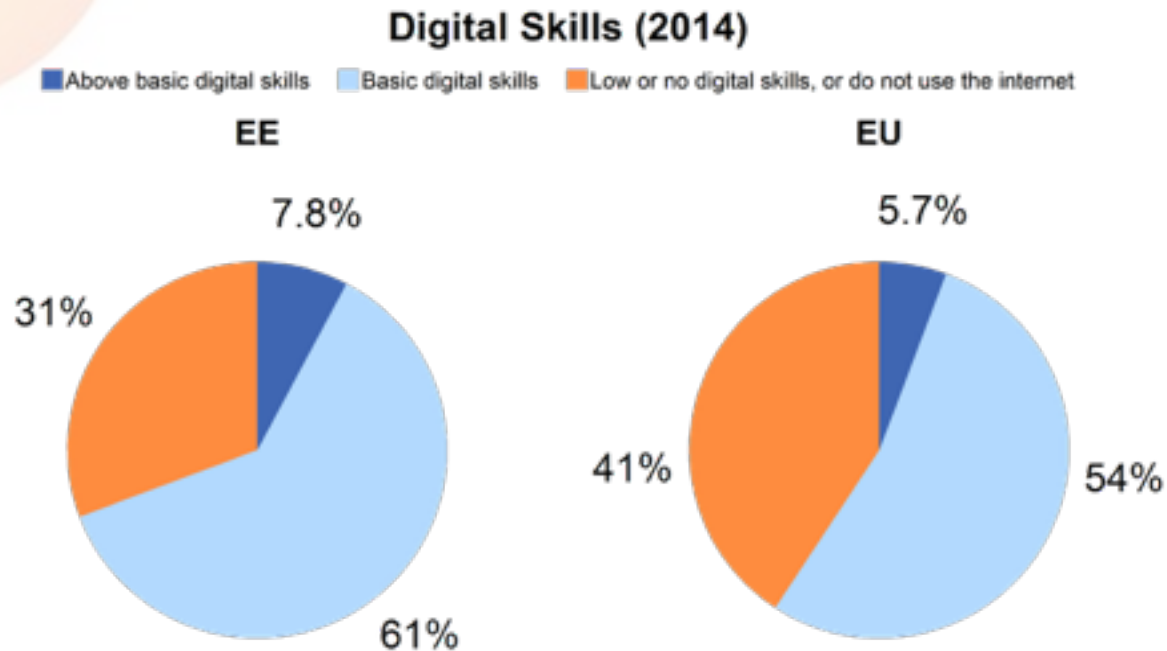
Fig. 1: Images accessed by modality in 2010.



During 12 months (Jan-Dec 2010) there were 3750 (11/day) patients accessing their images from outside the hospital.

Human Capital: Digital Skills

In Estonia 61% of citizens have basic digital skills (54% in the EU) and 7.8% have above basic digital skills (5.7% in the EU)

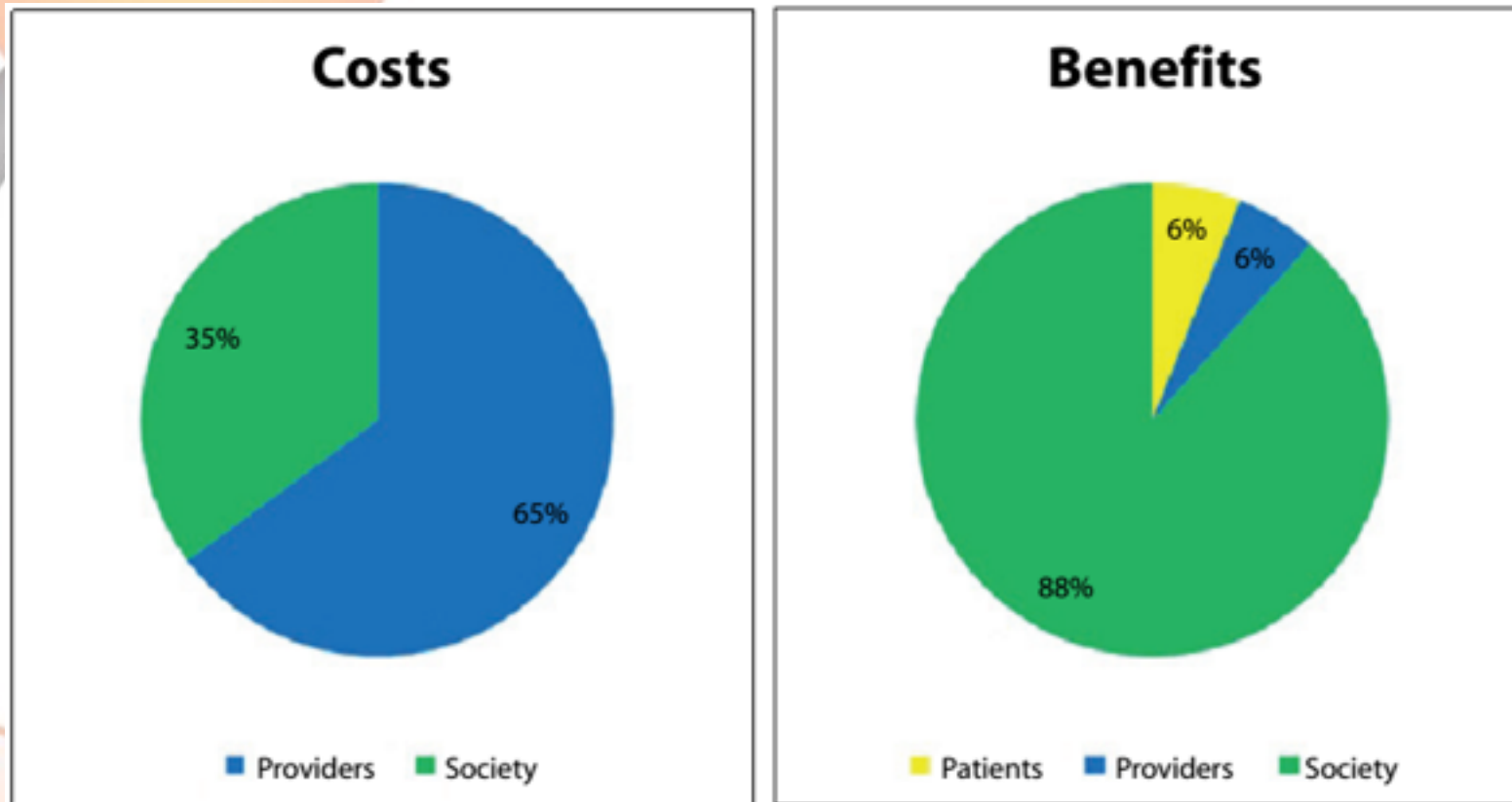


Source: Pilot work carried out by DG CONNECT in relation to action 62 of the Digital Agenda to propose "EU-wide indicators of digital competence". It is proposed for regular implementation starting with the 2015 survey.

Utilization of data – current situation

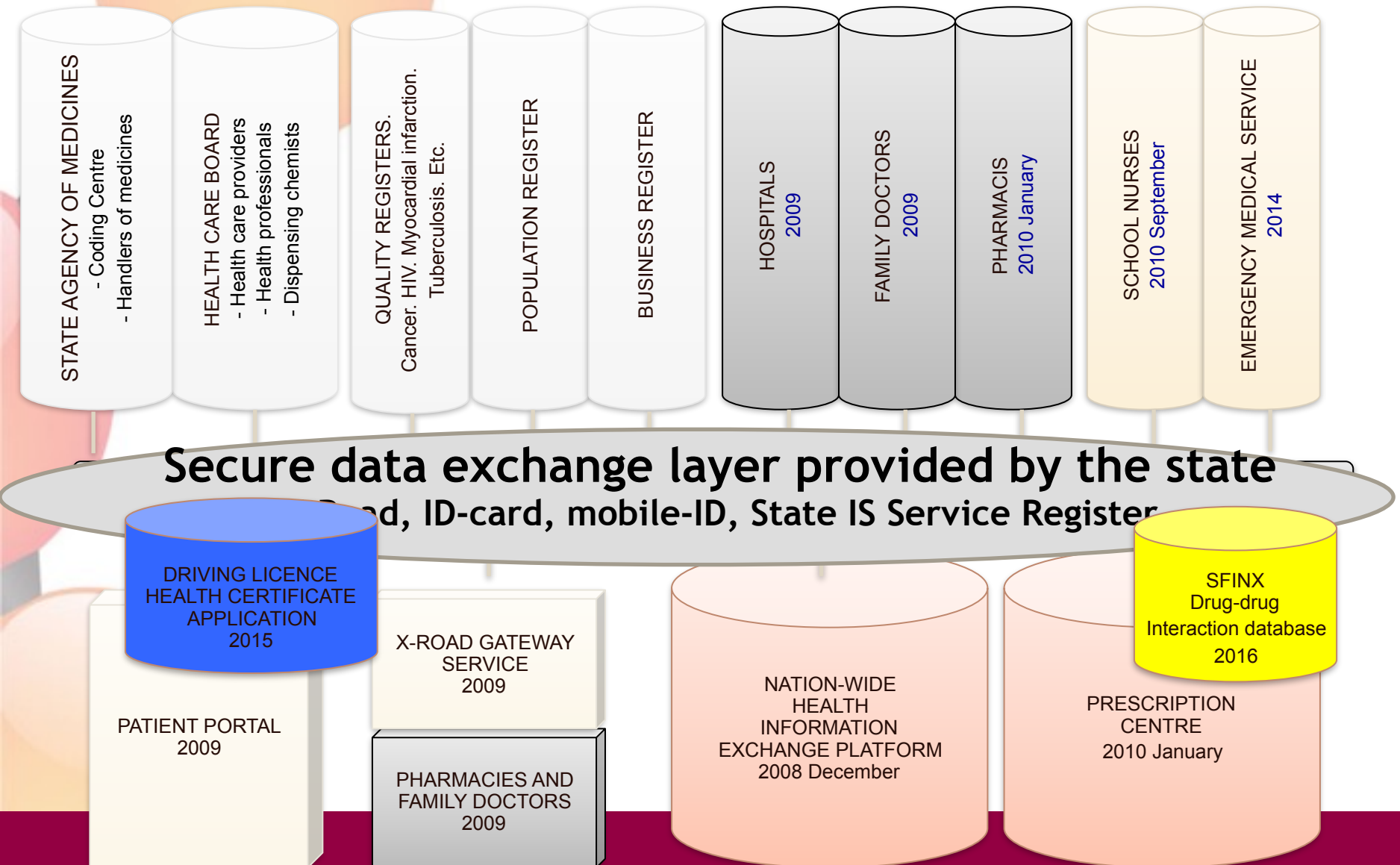
Actors	Primary use of data	Secondary use of data
Citizen/Patient	Low	Moderate
Physician	High	Moderate
Nurse/Midwife	High	Low
Physiotherapist/Other medical specialist	Low	Low
Pharmacist	High	Low
Social worker	Low	Low
Paramedics	Moderate	Low
Researchers	Low	Low
Insurance official	Low	High
Civil servant	Low	Low

Distribution of costs and benefits of large scale health information system




Saluste et al. 2010. Assessing the Economic Impact/Net Benefits of the Estonian Electronic Health Record System DIGIMPACT.

New e-services





Public service. Driving licence application


 MAANTEEAMET


SISENEK


EST | RUS

 AVALEHT

 JUHT

 SÕIDUK

 MAANTEE

 ÜHISTRANSPOORT


Avalaht »

Tere tulemast!

Olete Maanteeameti e-teeninduse avalehel. Toimingu sooritamiseks palume sisse logida.

Maanteeameti e-teeninduses saab:

- vormistada sõiduki ostu-müüki või kasutajate muutmist 20% soodsama riigilõivuga ja tellida sõiduki registreerimistunnistus postiga tasuta koju,
- sõiduki registrist ajutiselt kustutada,
- vahetada juhiluba.


 Viimased uudised »


22.01.2015 Täna saab taotleda erilubasid kuni 52tonnisteks puiduveudeks »


Maanteeamet väljastab alates tänasest, 22. jaanuarist erilubasid kuni 52tonnise töötle mata ümarpuidu veoks riigimaanteedele, kus tee on külmunud vähemalt poole meetri sügavuseni.


22.01.2015 Sõidukite tehnoloogivaatus on ennekõike liiklusohutuseks »


Normal 0 21 false false false ET X-NONE X-NONE /" Style Definitions /" table.MsoNormalTable (mso-style-name:"Table Normal"; mso-tstyle-rowband-size:0; mso-tstyle-colband-size:0; mso-style-noshow:yes; mso-style-priority:99; mso-style-parent:""; mso-padding-alt:0cm 5.4pt 0cm 5.4pt; mso-para-margin-top:0cm; mso-para-margin-right:0cm; mso-para-margin-bottom:10.0pt; mso-para-margin-left:0cm; line-height:115%; mso-pagination:widow-orphan; font-size:11.0pt; font-family:"Calibri","sans-serif"; mso-ascii-font-family:Calibri; mso-ascii-theme-font:minor-latin; mso-hansi-


 Sõiduki taustakontroll →


 Liiklusregistri infotelefon 620 1200 →

 Maanteeinfo telefon 1510 →

 Proovieksami info →

 Teeinfo kaardil →

 Peatus.ee →

 Teekaamerad →

Maanteeamet

Põhnu mnt 463a

10916 Tallinn

Abi

Klienditugi: 620 1200

Maanteeinfo: 1510

Lisaks

Brauseri aeg »

Ennustused ja sõit »

Maanteeamet soovikab

Otsustajatel.ee »

Maanteeamet Facebookis »

Users and impact

Purpose	Primary use of data	Secondary use of data
Data user	Healthcare professional Citizen/Patient	Researcher, Epidemiologist Civil servant
Information system	Local EPR	Data warehouse
Expectations for user interface	Very high demands (but usually very poor)	Has no big expectations
Level of digitalization	High	Low
Influence to workload	Very high	Low
Standards Taxonomy	HL7, FHIR, CDA SNOMED-CT, ICPC	ICD-10 IHE
Level of structuring	Low	Must be very high
Data quality	Low	???
Governance	Local level – GP, hospital, etc.	Region State
Beneficiaries	Healthcare professional	Society Decision makers



Observations and difficulties

- Physician and other professionals have to change the way they fill in the medical files in some extent – the trend is towards more uniform language
- General acceptance of hospital personnel to share medical data in patient portal with patient is problematic
- Much attention has to be paid on the security and electronic authentication of the users
- User interface development is underestimated
- Medical data is not what people are looking for – they are interested of services
- Huge change management issues that digitalization brings to healthcare masks real benefits of secondary use of health data



FUTURE TRENDS



Different scenarios

- Virtual registers
 - Simultaneous queries from different data repositories
- Shared services
 - Social care and healthcare
 - Crowddiagnosis
- Personalized medicine
 - Use of genome and phenome data
 - Personalized care pathways
 - Bright chances for personalized promotion, prediction and prevention

Feasibility Study for the Development of Digital Decision Support Applications for Personalised Medicine

DSS Usage Clinical Scenarios



Scenario A: Prevention

Personalised Prevention Plan for
Genetic Breast Cancer Risk



Scenario B: Chronic Patient

Monitoring and Personalised Treatment
(CVD, Diabetes Type II)



SOTSIAALMINISTEERIUM



Eesti Teadusnõukogu
Estonian Research Council

TerVE



This developmental research project is commissioned by the Ministry of Social Affairs and carried out by the Tallinn University of Technology from March to June 2015. The project is supported by the European Union Structural Funds via the programme TerVE implemented by the Estonian Research Council.

Scenario B: Chronic Patient

Monitoring and Personalised Treatment (CVD, Diabetes Type II)



Ants Kask, 60

Hypertension and diabetes type II risk

Two years ago Ants was diagnosed with hypertension (I10) and obesity (E66.0). Since then Ants has taken frequent blood pressure measurements and logged them to his patient portal. Ants is an Estonian Gene Bank donor, who's genes have been fully sequenced during the personalised medicine pilot. To find out more regarding his potential genetic disease risks, Ants has attended genetic counselling and imported the resulting data to his patient portal. Based on the sequenced data, Ants learnt that he has a high risk of myocardial infarction as well as high risk of diabetes.

1. Notifications.
Invitation for Screening

2. Yearly Checkup. Diagnosing.
Personalised Treatment Plan

3. Keeping Patient Diary

4. Emergency Hospitalisation
+ Diagnosing Diabetes Type II

5. Yearly Check-up Visits



Ants



Clinical Appointment Notification
Receives notification: last GP visit more than 1 year ago. Visits patient portal. Books GP visit.



GP

Patient Portal PHR Notifications

HEALTH PROFILE

MY DATA & DIARY

MEDICAL HISTORY

GENETICS

ACTIVITIES AND NOTIFICATIONS

U

Your last visit to GP was more than 1 year ago. Please contact with the GP.

P

BMI is in the range of Obesity. You may benefit of Diet counseling.

P

Physical activity is low. See suggestions for additional activities.

PROBLEMS

Hypertension

2008 - ...

Obesity

2010 - ...

Pre-diabetes

2011 - ...

Dyslipidemia

2011

ANTS KASK, 55

CURRENT MEDICATIONS

Micardis 60mg Tablet morning
Rosuvastatin 10mg Tablet night

GENERAL DATA

06.03.1960
31,6 BMI (182cm/105kg)
130/80 mmHg BP
B blood type

RISKS

High Type II Diabetes Risk

Risk score 15-20 points. Among this risk group, it is estimated 1 in 3 will develop the disease.

High risk of Myocardial Infarction

1.6 times higher potential risk of myocardial infarction.

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Ants

Professional EHR Patient List and Notifications

PATIENT

BOOKINGS

GROUP MANAGEMENT

SETTINGS

Chronic patients

Chronic Patients List

First Name	Family Name	Age	Diagnosis	Plans	Check-up Status	Select
Ants	Kasik	60	Hypertension, Pre-diabetes	Hype 1 + PreDia	due 1 year	<input checked="" type="checkbox"/>
Agne	Kasik	72	Hypertension	Hype1	due 4 months	<input type="checkbox"/>
Art	Kasik	65	Pre-diabetes	Self care for Prediabetes	due 2 months	<input type="checkbox"/>
Adi	Kasik	58	Hypertension, Diabetes Type II	Hype1 + Dia2	due 2 months	<input type="checkbox"/>
Ala	Kasik	67	Diabetes Type II	Dia2	Checked	<input type="checkbox"/>
Andar	Kasik	62	Diabetes Type II	Dia2	Checked	<input type="checkbox"/>

Send Message

Assign to Plan

Refer to

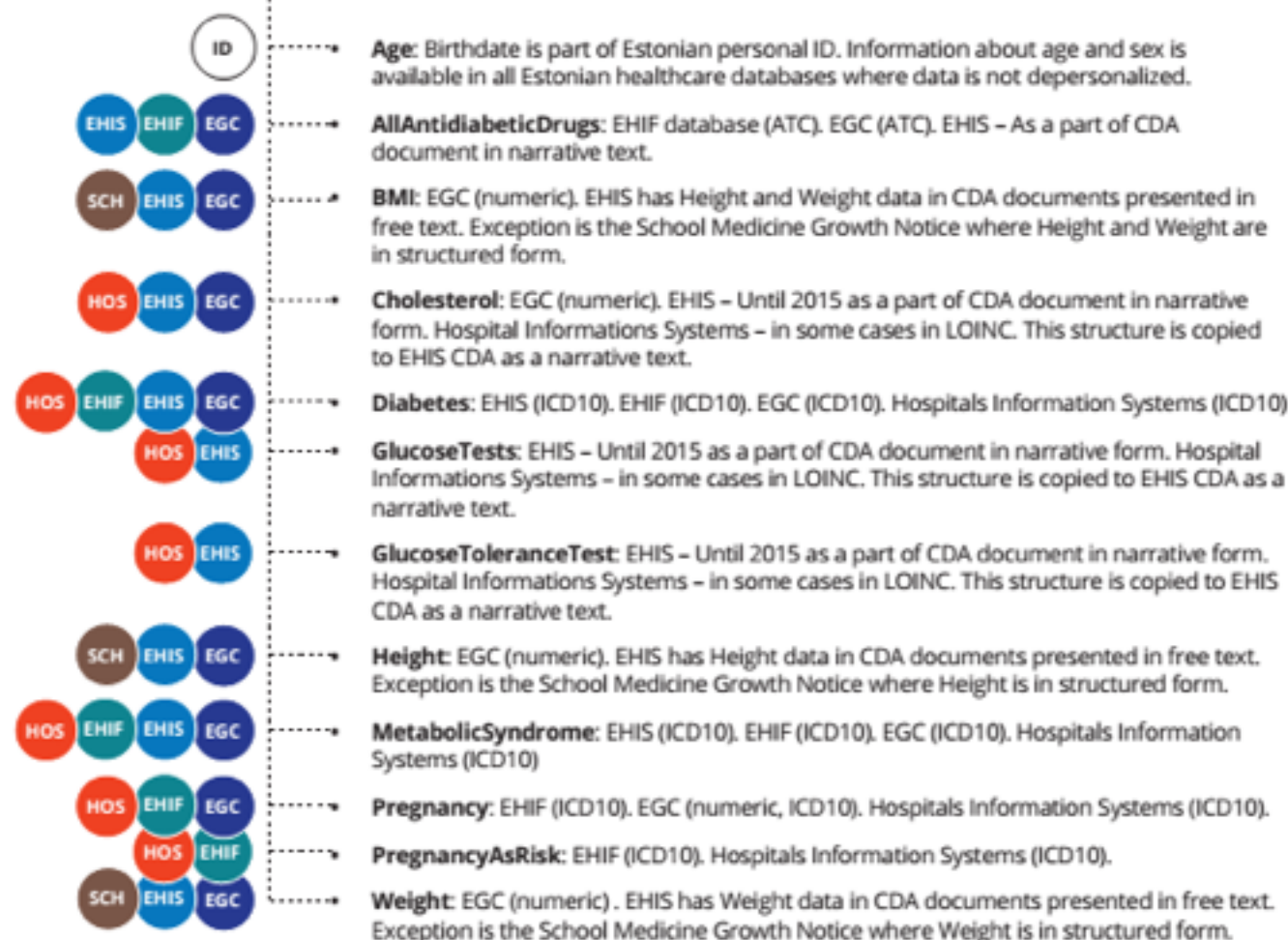


GP

EBMeDS: Glucose and lipid tests for patients with BMI above 32

For patients aged 15-74 years, the script checks if the body mass index is above 32 kg/m² or if body weight is above 100 kg (in cases where body length is not recorded in the patient record). If such a patient does not have a diagnosis of diabetes or metabolic syndrome, or medication implying diabetes, and if tests to detect impairments of the glucose metabolism have not been performed during the last two years, reminder 1 suggests that they are due. If lipid tests have not been performed during the last five years, reminder 2 suggests that they are due. For patients aged 15-74 years, the script checks if the body mass index is above 32 kg/m² or if body weight is above 100 kg (in cases where body length is not recorded in the patient record). If such a patient does not have a diagnosis of diabetes or metabolic syndrome, or medication implying diabetes, and if tests to detect impairments of the glucose metabolism have not been performed during the last two years, reminder 1 suggests that they are due. If lipid tests have not been performed during the last five years, reminder 2 suggests that they are due.

EBMeDS: Glucose and lipid tests for patients with BMI above 32



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Ants



Yearly GP Visit

Yearly GP visit for hypertension check-up.



GP

GP checks Ants' blood pressure diary and receives **DS suggestions for running further tests**. As Ants' genes have been sequenced during the personalised medicine pilot and he has shared the genetic counselling disease risk results on his patient portal, his GP sees that Ants has a **high genetic risk of developing type II diabetes**. GP decides to assign a panel of blood tests, lipid profiling and ECG stress test.

DS:
Suggestions
for clinical
procedures and
diagnose

Notifications:

- Patient has a high genetic risk of diabetes — please perform HbA1c, send to nutritional specialist and give suggestion to be physically more active.
- Patient has a high risk of myocardial infarction — perform ECG and stress test; perform lipid profile.

1. Notifications.
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Ants

Professional EHR Diagnosing and Treatment Suggestions

PATIENT BOOKINGS GROUP MANAGEMENT SETTINGS

ANTS KASK, 60

CURRENT MEDICATIONS
Metformin 500mg Tablet morning

GENERAL DATA
06/03/1960
31.4 BMI (182cm/105kg)
135 / 80 mmHg BP
B Blood type

PROBLEMS
Hypertension 2008 - ...
Obesity 2010 - ...
Pre-diabetes 2011 - ...
Dyslipidemia

DECISION SUPPORT
⚠️ **Diagnostic:** Prediabetes (R73.0) based on: HbA1c 6.2%
Dyslipidemia (E78.2). [See blood test results >>](#)
💡 **Treatment suggestions:** Diet therapy, physical activity plan.
[Assign plans >>](#)
💊 **Medications:** Initial dose of Rosuvastatin 10 mg (1x at night for dyslipidemia)

RISKS
High Type II Diabetes Risk
Risk score 15-20 points. Among this risk group, it is estimated 1 in 3 will develop the disease.
Risk of Myocardial Infarction
Low genetic risk

DS:
Notifications for over threshold measurements

DS:
Gene based medication suggestions

DS:
Patient steering guideline (personalised screening plan)

Diagnosing Pre-diabetes + Dyslipidemia

Receives test results. DS indicates that Ants might have pre-diabetes. Diagnoses pre-diabetes based on HbA1c: 6.2%.

Assigning Treatment Plan

DSS gives a list of personalised suggestions for diabetes prevention. DS suggests changes for meal plan, activity and fitness plan, keeping diary of regular blood sugar level measurements. Assigns Ants activity and meal plan with infrequent blood glucose measurements. Also assigns an initial dose of rosuvastatin recommended by DS.

Established Risk Factors for Diabetes Type II

Finnish Diabetes Association Diabetes Risk Assessment Form

<http://www.diabetes.fi/files/502/eRiskitestilomake.pdf>

		ID•	Age: ID-code
SCH	EHIS	EGC•	Weight: EGC (numeric); EHIS has Weight data in CDA documents presented in free text. Exception is the School Medicine Growth Notice where Weight is in structured form.
SCH	EHIS	EGC•	Height: EGC (numeric); EHIS has Height data in CDA documents presented in free text. Exception is the School Medicine Growth Notice where Height is in structured form.
	EHIF	EGC•	High blood pressure medications (has ever taken or not): EGC (ATC); EHIF (ATC).
	EHIS	EGC•	Waist circumference: EGC (numeric). EHIS has Waist circumference data in CDA documents presented in free text, if any.
	EHIS	EGC•	Physical activity (more than 30 min a day): EGC (coded questionnaire). EHIS has behavioural data in CDA documents presented in free text, if any.
	EHIS	EGC•	Diet (eating vegetables, fruit or berries every every day or not): EGC (coded questionnaire). EHIS has behavioural data in CDA documents presented in free text, if any.
	HOS	EHIS•	High blood glucose (ever found or not): EHIS – Until 2015 as a part of CDA document in narrative form; Hospital Informations Systems – In some cases in LOINC. This structure is copied to EHIS CDA as a narrative text.
	EHIS	EGC•	Diabetes diagnosed in immediate family, other relatives (own parent, brother, sister or child, grandparent, aunt, uncle or first cousin): EGC. EHIS has genealogy data in CDA documents presented in free text, if any.

1. Notifications.
Invitation for Screening

2. Yearly Checkup. Diagnosing.
Personalised Treatment Plan

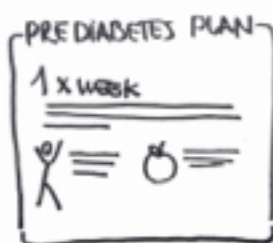
3. Keeping Patient Diary

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+ Diagnosing Diabetes Type II

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Ants



Patient Portal Treatment Plan

Sees personalised treatment plan reviewed by GP in the patient portal. Sees information regarding physical activity and diet suggestions as well as medications and further clinical appointments.



Device Card

Receives a device card, which enables him to buy blood glucose monitor 50% cheaper and get 50 test strips for free every 6 months.



GP

- Physical activity 10000 steps per day
- Diet recommendations (low fat and carbs)
- Lose weight 10% during one year
- Medications: Micardis 80 mg (1x at night) + Rosuvastatin 10 mg (1x at night)
- Monitoring guidelines: Continue blood pressure measurements and start blood glucose measurements.
- Appointment with GP after 1 year

Connecting the Device

Buys a blood glucose monitor based on the suggested models. Connects his device with patient portal automatically over WiFi.

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Ants



Activity Plan

Follows the activity plan to walk over 10000 steps a day. Collects his daily steps using a smartphone app.



DS:
Disease Risk
Index (patient
phenotype data
+ gene data +
family risk)

Disease Risk Index

After a few weeks of tracking sees progress and improvements on the disease risk index.



GP



DS:
Notifications
for data reviews
and patients
requiring
attention

Virtual Review

Every 3 months receives notification from DSS to check Ants' measurements and progress. Checks Ants' health report and sees data regarding blood sugar measurements as well as lifestyle changes. Confirms checking Ants' data and gives instructions for further steps.



CONCLUSIONS



Conclusions (1)

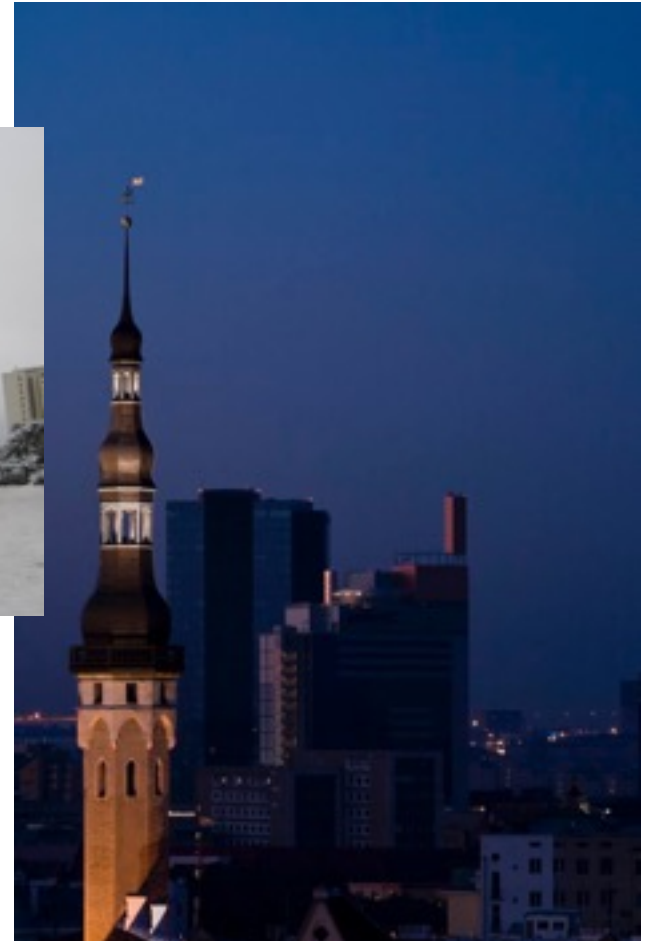
- Paradigm change in healthcare professional's mindset – primary data users
 - Data ownership change
 - Formalization of entered data
 - Structured descriptions and reports
 - Less assumptions/analysis
- Gradual change of data usage
 - Use of shared health, social and medical data
 - Acceptance of more extensive involvement of citizen/patient
- Change of workflows and pathways in healthcare
 - From linear to matrix
 - More pre-analyzed data – big data services



Conclusions (2)

- Improve the communication between different parties
 - To empower patients and motivate doctors to use the collected information and eHealth services
- It is important to motivate physicians to tell patients about the possibilities to view and to be aware of their basic health data
- It is important to inform patients about these possibilities and to support them actively inform their physicians that they know how to use their health data.

Thank you!
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- Citizen
- Healthcare provider
- Society

Challenges of healthcare

Business process development

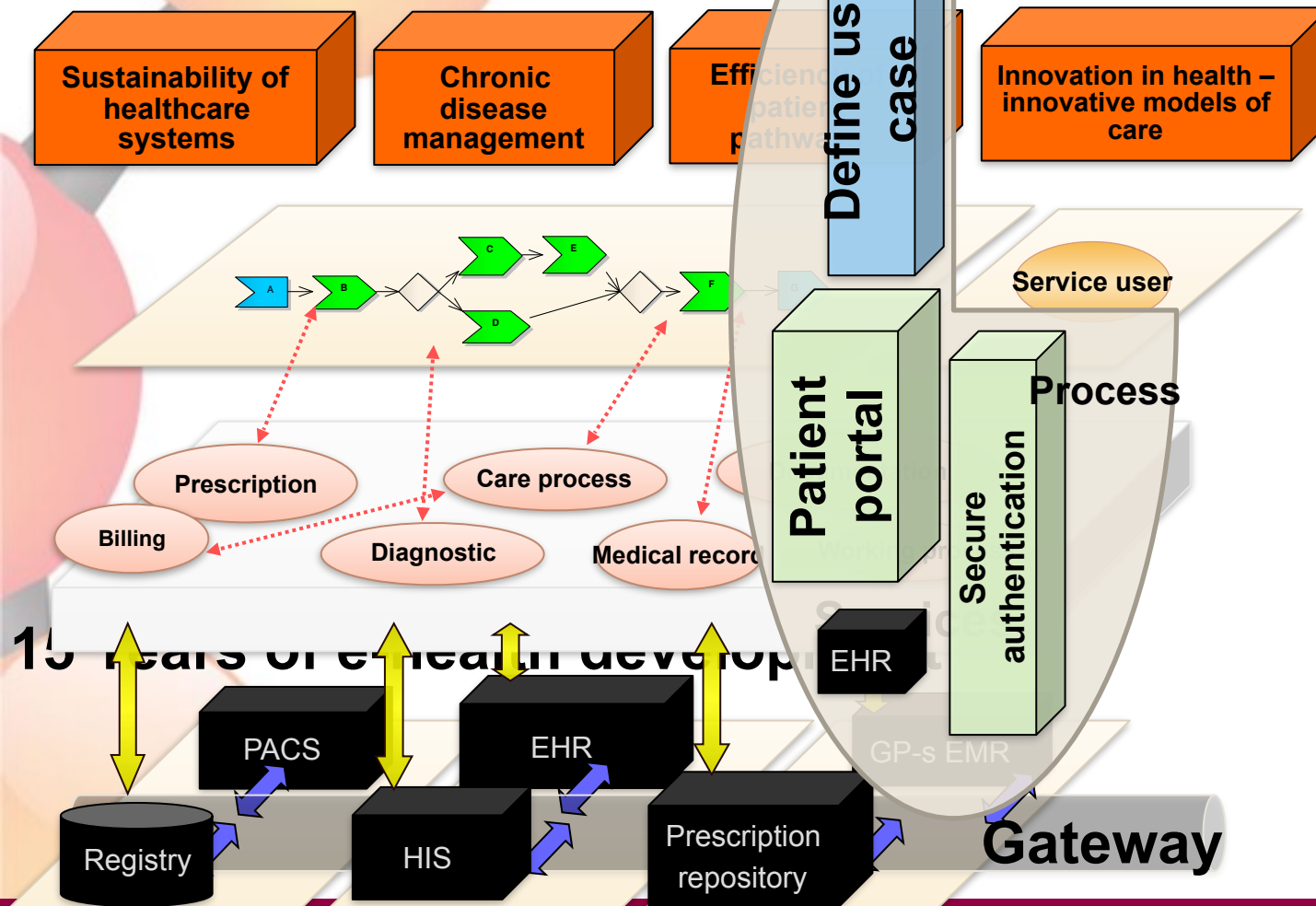
- **Basic process**
- **Supportive processes**
- **Roles, stakeholders**
- **Data, materials**

Shared services

- **Case stories**
- **Standard contents**
- **Service levels**
- **Owners**
- **Service users**
- **Service providers**

Application integration

- **Messages exchanges**
- **Users rights**
- **Sharing data**
- **Coordination of changes**
- **Monitoring**



Digital stamp for general practitioners

