HEALTH IN THE DIGITAL SOCIETY
DIGITAL SOCIETY FOR HEALTH

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Free flow of health data in Finland, the citizen's perspective

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@eHealthTallinn #eHealthTallinn
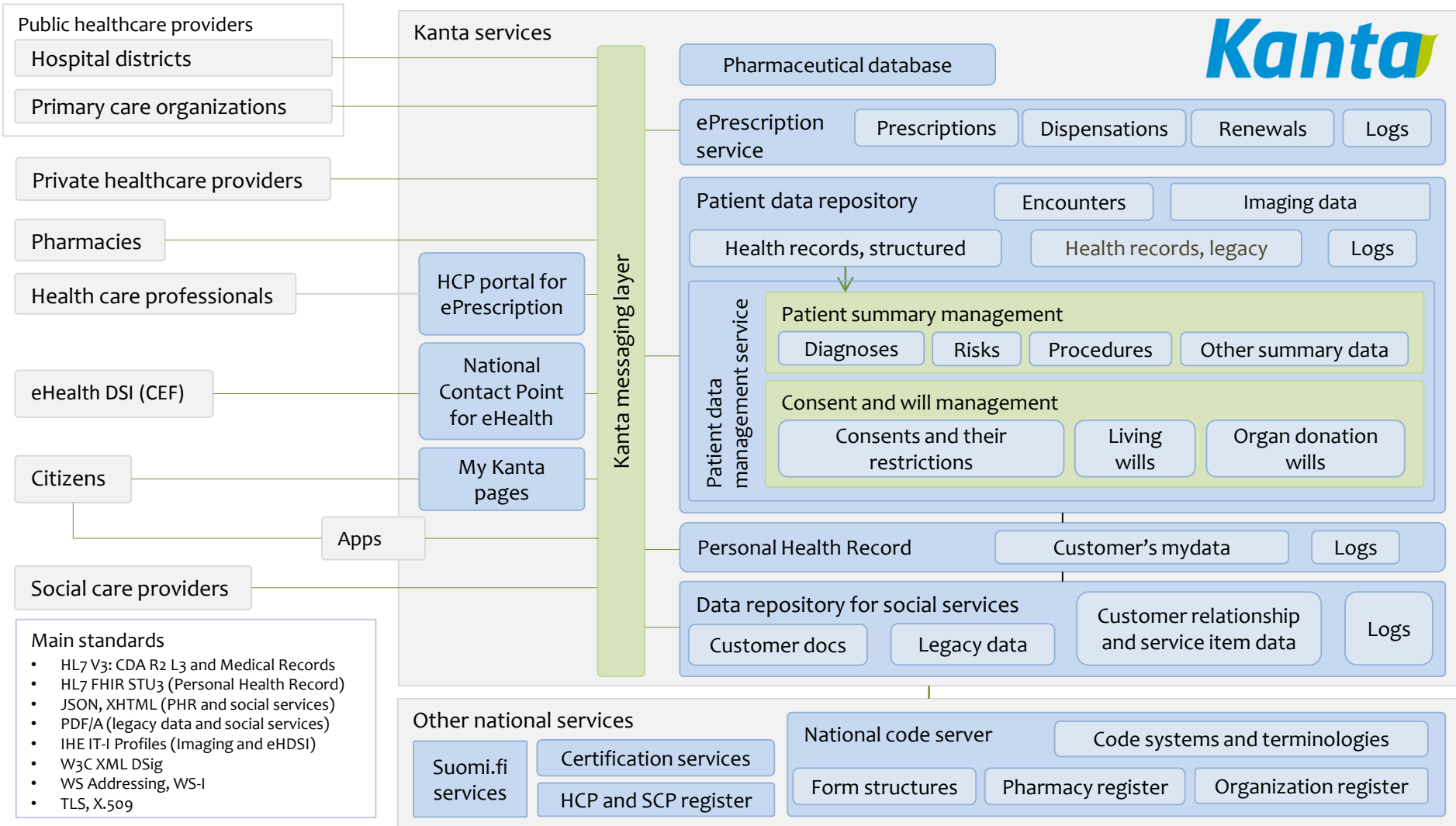www.ehealthtallinn2017.ee

OUTLINE

- Status update
  - Kanta overview
  - eHealth is popular!
- Upcoming legislation changes
  - Government reform
  - GDPR-related changes
- Citizen's perspective
  - Personal Health Record
  - New features to patient portal (My Kanta pages)
- Challenges and summary

KANTA OVERVIEW

- Kanta = Finnish national eHealth infrastructure designed for healthcare, social services, pharmacies and citizens
    - Centralized architecture
    - First parts (ePrescription) in production since 2010
- Goals
    - Offers healthcare and social care professionals up-to-date information about patients' health and wellbeing and its history, and serves as a data mediator between organizations
    - Decreases the need for local archiving
    - Provides a foundation for statistics, reports, research and other secondary use

Public healthcare providers
- Hospital districts
- Primary care organizations

Private healthcare providers

Pharmacies

Health care professionals

eHealth DSI (CEF)

Citizens

Apps

Social care providers

Main standards
- HL7 V3: CDA R2 L3 and Medical Records
- HL7 FHIR STU3 (Personal Health Record)
- JSON, XHTML (PHR and social services)
- PDF/A (legacy data and social services)
- IHE IT-I Profiles (Imaging and eHDSI)
- W3C XML DSig
- WS Addressing, WS-I
- TLS, X.509

Kanta services

Kanta

Kanta messaging layer

HCP portal for ePrescription

National Contact Point for eHealth

My Kanta pages

Pharmaceutical database

ePrescription service
| Prescriptions | Dispensations | Renewals | Logs |

Patient data repository
| Encounters | Imaging data |
| Health records, structured | Health records, legacy | Logs |

Patient data management service

Patient summary management
| Diagnoses | Risks | Procedures | Other summary data |

Consent and will management
| Consents and their restrictions | Living wills | Organ donation wills |

Personal Health Record
| Customer's mydata | Logs |

Data repository for social services
| Customer docs | Legacy data | Customer relationship and service item data | Logs |

Other national services

Suomi.fi services

Certification services

HCP and SCP register

National code server
| Code systems and terminologies |
| Form structures | Pharmacy register | Organization register |

ELECTRONIC PRESCRIPTION UPDATE

- Electronic prescription is mandatory by law since 1.1.2017
  - Doctors may not write paper prescriptions or prescribe over the phone, except in extraordinary situations
  - Any paper or phone prescriptions are entered in the Prescription Centre by the pharmacies.
  - Kela provides a web-based service (HCP portal named Kelain) for handling electronic prescriptions, used mainly by individual doctors.
- Separate project tracking the use of paper prescriptions (very small and decreasing percentage)

PATIENT DATA REPOSITORY UPDATE

- A national centralized repository into which patient records are entered nationwide
  - Contains the patient's structured health record, data about encounters and periods of ward care. Lab results, referrals, procedures, risks, diagnoses, etc.
- All public healthcare organizations store data in the Patient Data Repository (1.12.2015)
- Most private healthcare service providers have joined the Patient Data Repository in 2016.
- Key statistics (10.10.2017):
  - 290 million treatment documents containing data about
  - 240 million service events of
  - 5.7 million persons (living population of Finland is 5.5 million)
  - Over 900 million document versions altogether

- Kanta.fi is 2nd most appreciated web service in Finland (national broadcaster YLE is #1)

NEW STRUCTURE OF FINNISH HEALTH AND SOCIAL SERVICES
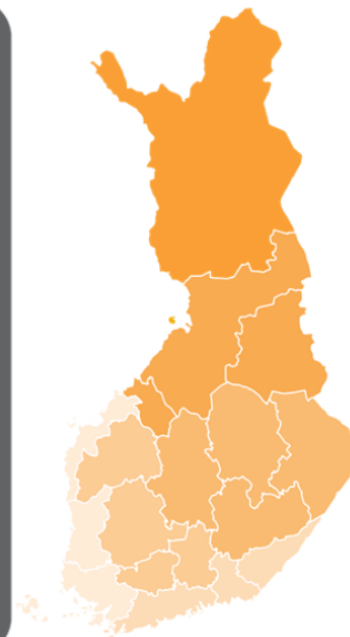
PREPARATION AND IMPLEMENTATION OF THE HEALTH, SOCIAL SERVICES AND REGIONAL GOVERNMENT REFORM

PLANNED TIMETABLE, ENTRY INTO FORCE ON 1.1.2020

PARLIAMENT WILL CONSIDER THE GOVERNMENT PROPOSAL 15/2017 (HEALTH, SOCIAL SERVICES AND REGIONAL GOVERNMENT REFORM) AND THE NEW PROPOSAL FOR THE ACT ON FREEDOM OF CHOICE REPEALING GOVERNMENT PROPOSAL 47/2017 ARE CONSIDERED IN THE SAME CONNECTION:
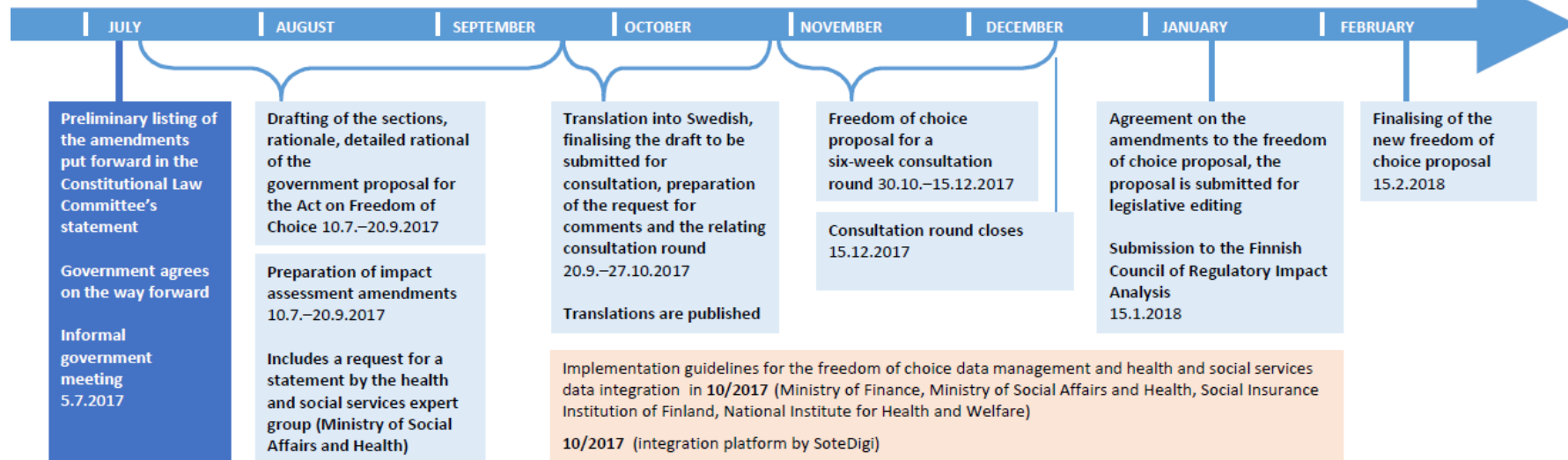
County elections in 10/2018 and the reforms enter into force as of 1.1.2020.
Proposed timetable with due respect to the principles of good law drafting.

PRINCIPLES

- Compliance with the principles of good law drafting
- Careful implementation of the changes put forward in the statement 26/2017 by the Constitutional Law Committee
- Realistic schedule and means of implementation
- The proposal for the health, social services and regional government reform considered as a package

2017

2018

JULY | AUGUST | SEPTEMBER | OCTOBER | NOVEMBER | DECEMBER | JANUARY | FEBRUARY

Preliminary listing of the amendments put forward in the Constitutional Law Committee's statement

Government agrees on the way forward

Informal government meeting
5.7.2017

Drafting of the sections, rationale, detailed rational of the government proposal for the Act on Freedom of Choice 10.7.–20.9.2017

Preparation of impact assessment amendments 10.7.–20.9.2017

Includes a request for a statement by the health and social services expert group (Ministry of Social Affairs and Health)

Translation into Swedish, finalising the draft to be submitted for consultation, preparation of the request for comments and the relating consultation round 20.9.–27.10.2017

Translations are published

Freedom of choice proposal for a six-week consultation round 30.10.–15.12.2017

Consultation round closes 15.12.2017

Agreement on the amendments to the freedom of choice proposal, the proposal is submitted for legislative editing

Submission to the Finnish Council of Regulatory Impact Analysis 15.1.2018

Finalising of the new freedom of choice proposal 15.2.2018

Implementation guidelines for the freedom of choice data management and health and social services data integration in **10/2017** (Ministry of Finance, Ministry of Social Affairs and Health, Social Insurance Institution of Finland, National Institute for Health and Welfare)

10/2017 (integration platform by SoteDigi)

CONSENT MANAGEMENT MODEL CURRENTLTY

- Data may be stored in Kanta without informing a citizen
  - Every organization (registrar) can fetch their own data, no restrictions applied
- Sharing data, i.e. access to data stored by other organizations, requires an informed consent of the citizen (written or electronic)
  - 48 % of people have provided consents
  - Consent may be qualified by prohibiting access to data of certain service events or data stored by certain organizations
  - 2 % of those who provided a consent have restricted it
- Access to ePrescription data is allowed with verbal consent
  - All ePrescription data is in Kela's register

GDPR AND REFORM RELATED CHANGES

- New legislation has not been fixed yet, **only drafts are available**
- Public registers become much bigger
  - Private registers are not affected, but new service provision models in which private providers get direct access to public registers become more common
  - Influence of data access restrictions becomes smaller
- Currently used consents are planned to be replaced by other tools
  - The legal base for access to data is provision of health or social care or treatment, not consent
  - Access may be restricted by the citizen who may deny access to data of certain service events
  - Very roughly speaking, opt-in is replaced by opt-out
- Some new consents are introduced
  - Secondary use of data
  - Access to Personal Health Record data entered by citizen
  - Acting on behalf of the other person
  - Ability to "plug in" PHR applications – considered to be a form of consent

Changing
the operating model for
health and welfare services

PERSONAL HEALTH RECORD

- Personal Health Record will enable citizens to enter their own health-related data in Kanta.
  - Kela builds the PHR data management platform
  - Third parties will develop services which produce, store and analyze the data
- Nationally and regionally coordinated projects are already developing self care solutions.
  - ODA is a nationally sponsored project for transforming primary healthcare through digitalization
  - Virtual Hospital (Virtuaalisairaala) is another publicly sponsored big project.
- Health and social care professionals will be able to access the data with citizen's consent.
- First phase ready by end of 2017.

PRINCIPAL ELEMENTS OF PHR
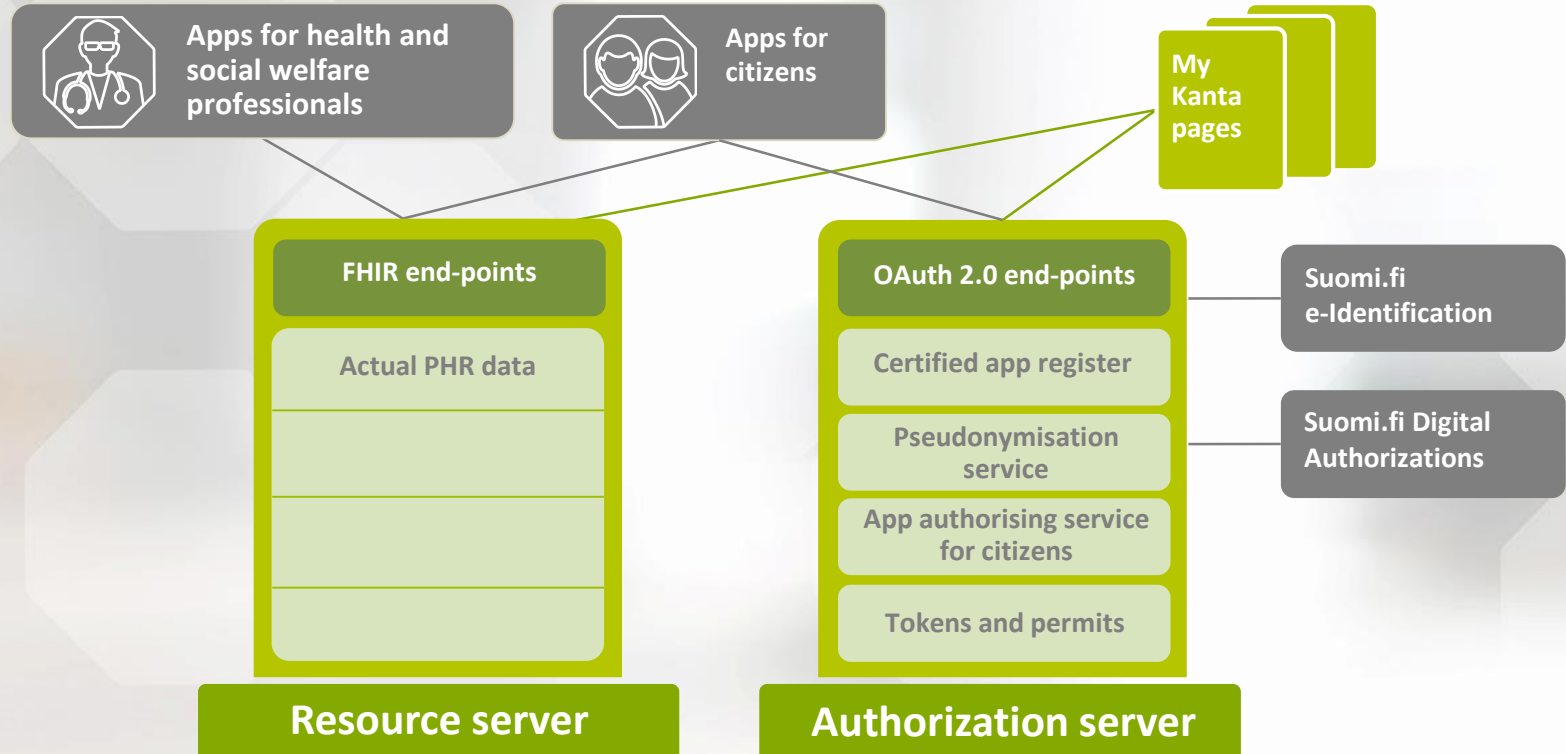
PHR ecosystem

Empowers citizens to be more involved

Supports self-care of chronic diseases

Promotes self-care and responsibility

Promotes preventive self-care

UPCOMING MY KANTA PATIENT PORTAL FEATURES

- PHR-related features (browsing data and apps, disconnecting apps)

- Access to social services data

- New consents and information related to them, restrictions of access to health data

- Acting on behalf of other people (based on the national Suomi.fi service)

- Patient Summary elements

- New types of data: optometrics, dental care, medication list

- Freedom of choice related features: browsing and selecting a service provider, etc

CHALLENGES AND SUMMARY

- Unclear political situation makes technical work more difficult
  - But not impossible
  - Dialogue of the legislator with technical implementors is becoming more agile (clearly moving further away from a waterfall model)

- Current consent model is not compliant with GDPR
  - Not explicit consent, though many interpretations exist
  - The current model is understood relatively well by the citizens, but the new legal basis is more straightforward and may improve free flow of data

- More tools for citizens are needed for better digitalization of healthcare
  - We are on it!