

Availability of clinical patient data for research in Tays

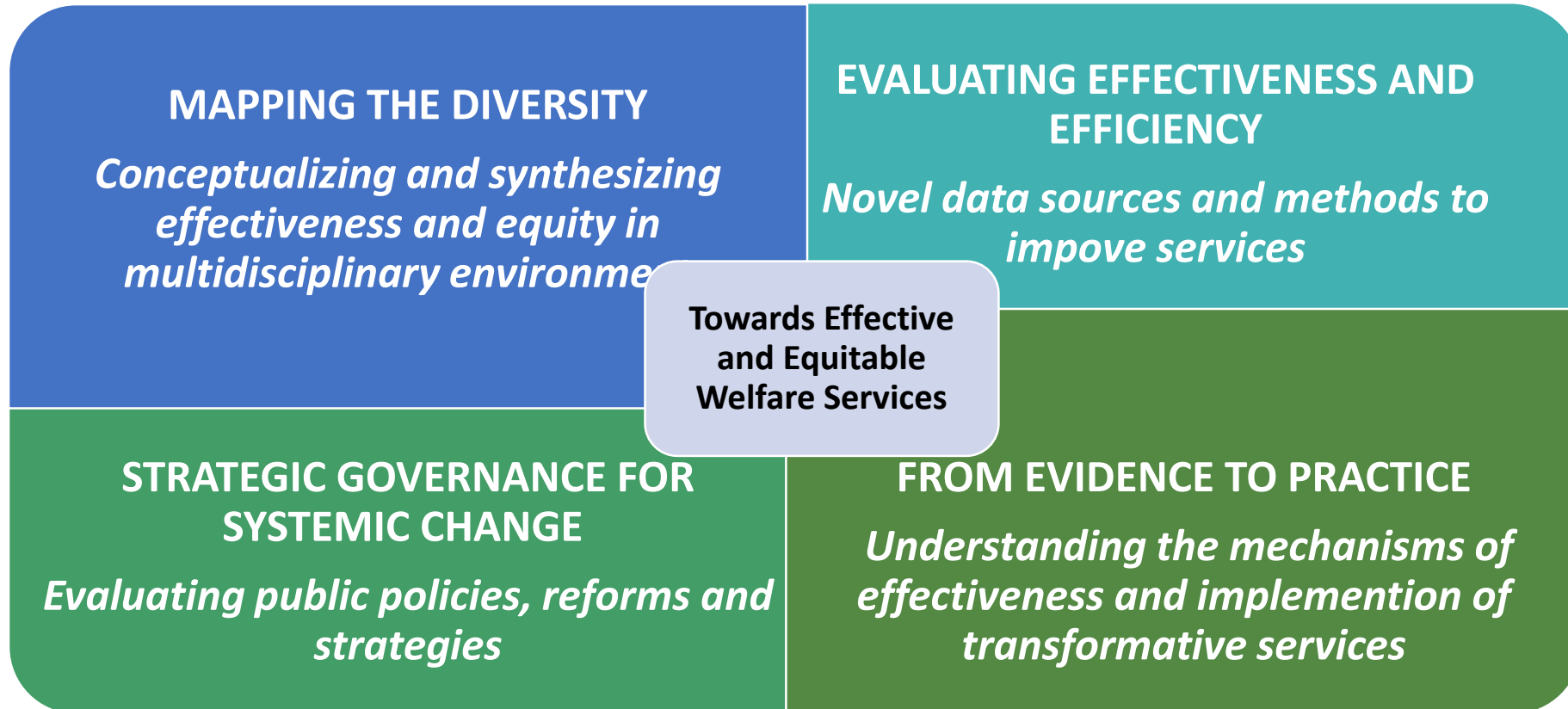
11th Jan 2022

TRANSFORMING WELFARE SYSTEMS -kick off event

Tarja Laitinen, Director of Research

PSHP

Translating Scientific Knowledge into Improved Practices and Outcomes (TRANSFORM)



effectiveness, efficiency and equity

Data driven Tays (strategic decisions based on data analysis and interpretation)

- Health care
 - performance improvement
- Clinical decision making
 - (cost)effectiveness of cure



Future Medicine

We would like to have

- predictive, preventative, personalized, participatory

At the same time we have to avoid

overtesting, overdiagnosis, overtreatment, overcharging

How can we become the best possible partner ?

- Secured access to patient data
 - Clear process, good services
 - Costs reasonable and transparent
- Test environment for new treatment strategies, pathways and guidelines
 - Good possibilities to run practical clinical trials, mini-intervention studies
- Not only as Tampere University Hospital, but including The Pirkanmaa Social welfare and health care region (SOTE-region)
 - Possibility: One patient registry for primary and secondary health care and social services – one local permission process (Tietolupa)
 - Challenge: data quality and heterogeneity



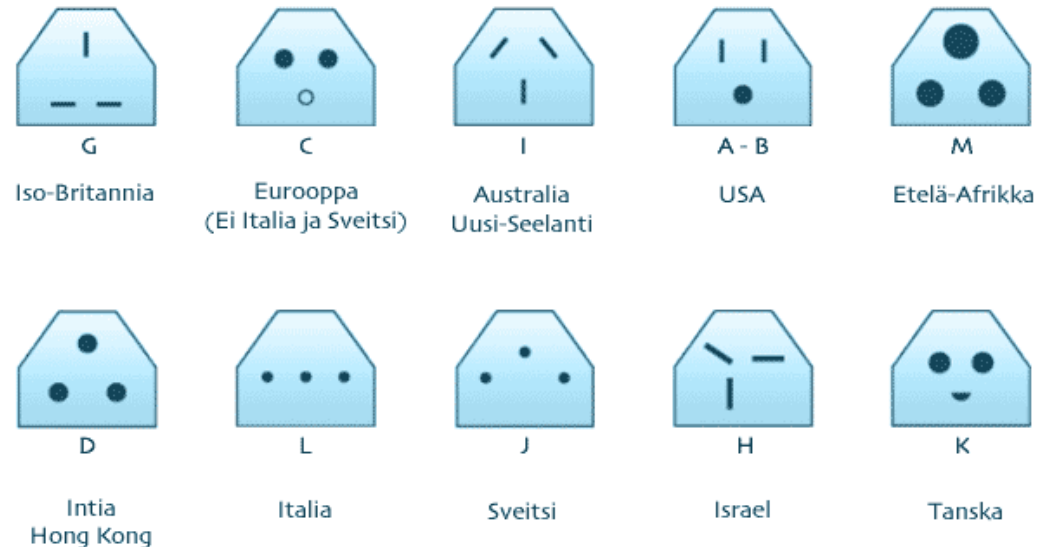
Act on Secondary Use of Patient Data

General Data Protection Regulation GDPR

- FinData, National Authority has a central role
- Several challenges in the present legislation
 - International collaboration and Open science –demands
 - GDPR is interpreted differently among EU countries
- FinData slow and complex processes
 - Act is working best with ‘ready to go’ -data sets
- Patients data security by regulation is extremely important
- Only national health registries should be included into the jurisdiction of FinData

Poor interoperability slows down national and international collaboration

- Real World Data science is coming more and more important
 - Quality of data has improved
 - Access to the data has improved
 - Faster and less expensive compared to RCTs
 - Large cohorts can be built



Observational Health Data Sciences and Informatics (OHDSI)

Fin-OMOP vocabulary and Common Data Model: all university hospitals, THL and FinnGen involved

EU funding 100K€

OHDSI By The Numbers

- 2,367 collaborators
- 74 countries
- 21 time zones
- 6 continents
- 1 community

OHDSI COLLABORATORS

Our community is ALWAYS seeking new collaborators. Do you want to focus on data standards or methodological research? Are you passionate about open-source development or clinical applications? Do you have data that you want to be part of global network studies? Do you want to be part of a global community that truly values the benefits of open science? Add a dot to the map below and JOIN THE JOURNEY!

OHDSI.org #JoinTheJourney

Services for researchers 1

- Helpdesk (Neuvontapalvelu)
 - Registry research team
 - rekisteritutkimustiimi@pshp.fi
 - Istekki Tietopalvelu
 - Tailoring of the requested data
 - 'Ready to go' –materials almost do not exist
 - Target group, time period, and what data should be included
 - CoBu -cohort builder available
- Research permission and agreement
 - Tietolupahakemus, riskienarviointilomake, tietosuojaseloste and research plan
 - Will become more detailed



INKLUUSIOKRITEERIT

Aikarajaus

11.2019 - 31.12.2019

DIAGNOOSIN LUONNE (include | OR)

(All)

DIAGNOOSI (include | OR)

(All)

DIAGNOOSI (include | AND)

(None)

TOIMENPITEEN LUONNE (include | ...)

(All)

TOIMENPIDE (include | OR)

(All)

TOIMENPIDE (include | AND)

(None)

Potilaan ikä

Hoidon alkaessa

22

111

Inklusiokriteeri 1

Sukupuoli

(All)

Inklusiokriteeri 2

Kotikunta

(All)

EKSKLUUSIOKRITEERIT

DIAGNOOSI (exclude)

(None)

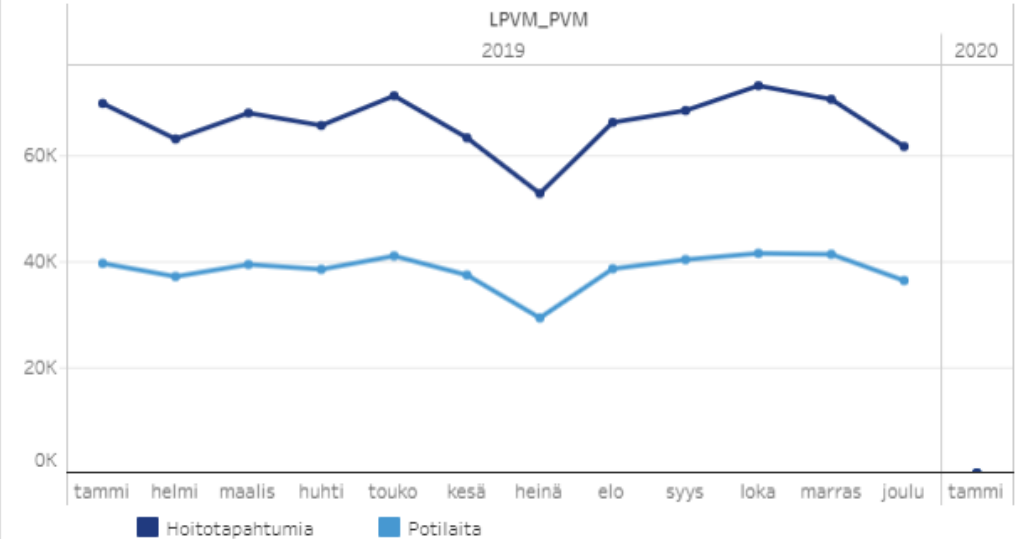
TOIMENPIDE (exclude)

(None)

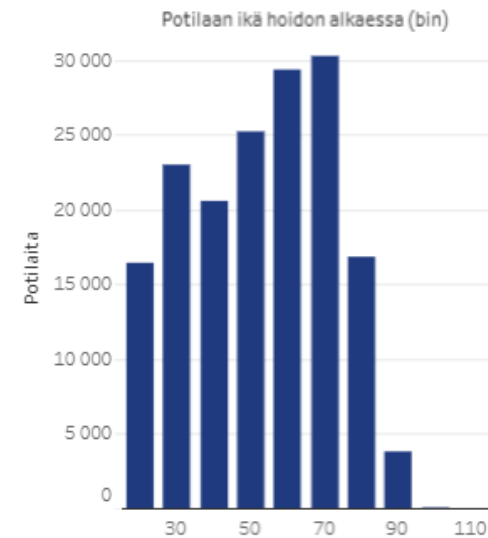
Määrät

Palveluala	Hoitotapahtumia	Potilaita
Ajanvarauskäynti, ensikäynti	87 156	66 371
Ajanvarauskäynti, uusintakäynti	492 438	114 601
Konsultaatiokäynti	24 846	14 151
Päivystyskäynti	106 910	67 803
Päiväkirurgia	10 218	9 447
Sairaalan/terveyskeskuksen vuodeosasto	73 308	44 461
Grand Total	794 876	165 460

Määrät kuukausittain/vuosittain



Ikäjakauma



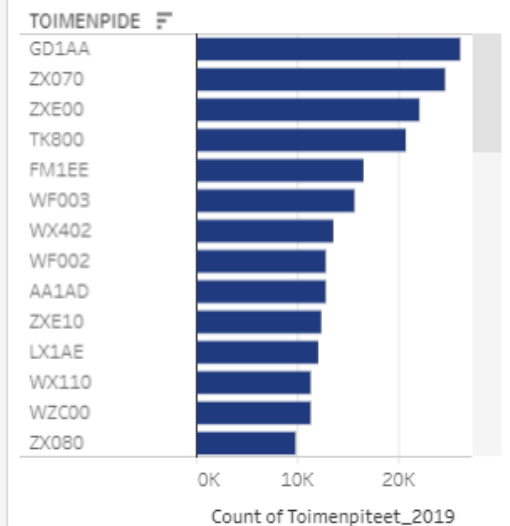
Kiireellisyys



Diagnoosityypit

Pitkä nimi (Diagoosin_luonne)	Potilaita
	1 262
Diagnoosin tapaturmatyyppi	19 702
Diagnoosin ulkoinen syy	22 849
Haittavaikutuksen seuraus	1 970
Haittavaikutuksen syy	1 970
Pitkäaikaisdiagnoosi (oire)	1 015
Pitkäaikaisdiagnoosi (syy)	21 969
Pitkäaikaisdiagnoosin tapaturma..	4
Pitkäaikaisdiagnoosin ulkoinen syy	4
Päädiaagnoosi (oire) tai ensisijaine..	5 077
Päädiaagnoosi (syy) tai ensisijaine..	165 116
Sivuddiagnoosit (oire) tai muut kä..	3 858
Sivuddiagnoosit (syy) tai muut käy..	81 684
Grand Total	165 460

Top 50 toimenpiteet

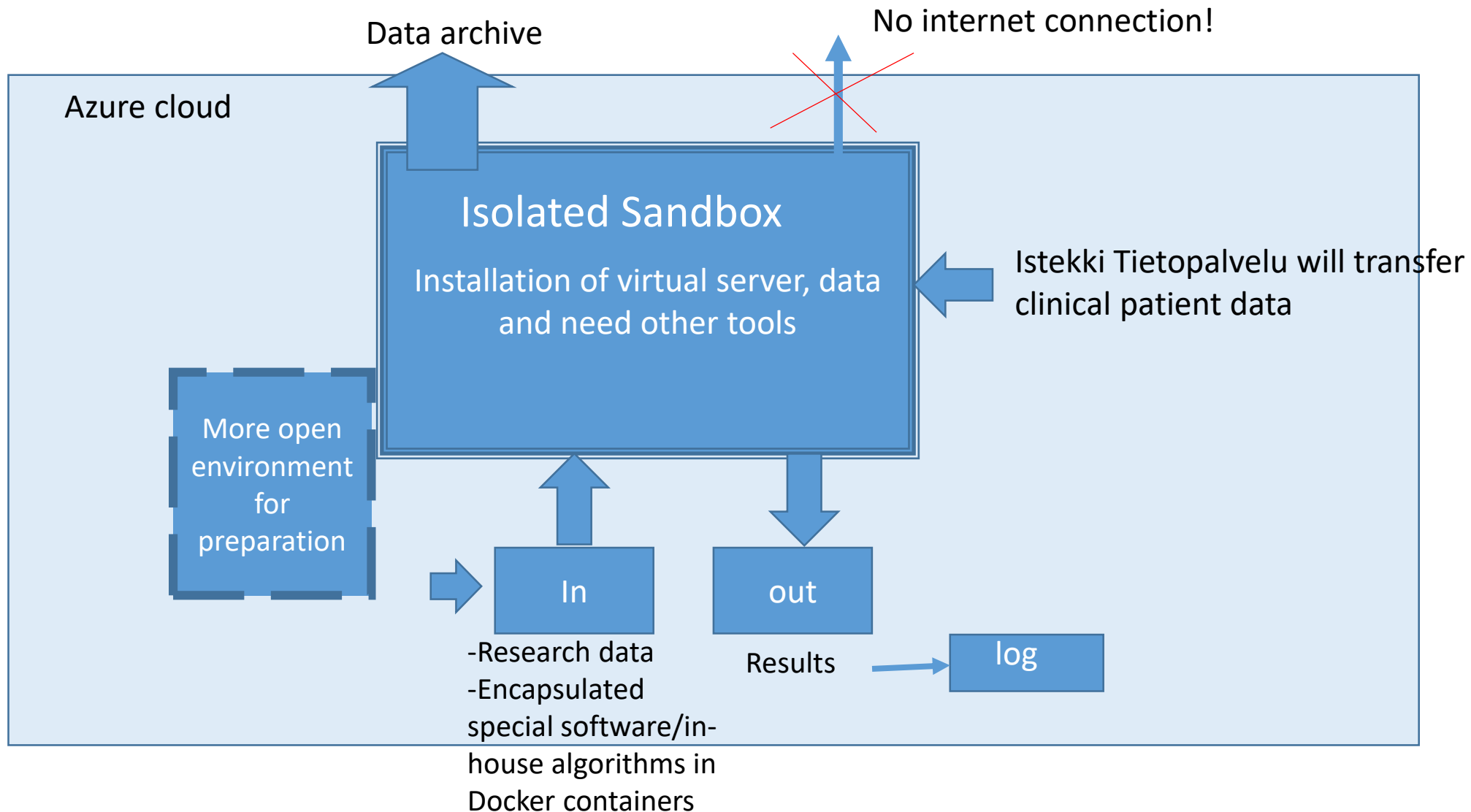


Services for researchers 2

- Virtual server (S-XL) in isolated sandbox
 - Username/password
 - Login through two phase authentication
 - Clinical patient data set available
 - Use based billing system
 - Certain programs are by default available, you can order also tailor made server
- Results are released, but source data not
- Archiving of the source data and results

Tays secured data environment

will be audited in Feb 2022



Clinical Informatics – Tays Research Services



Leena
Data Chief



Tiina
Biostatistician



Mika
Biostatistician



Marianna
Designer
FinnGen data



Petri
Designer



Sampo
Designer



Toni
Designer



Nita
Designer

Conclusions

- We appreciate that Tampere University is putting effort to this new platform
- We would like to be the best possible partner
- We see that secondary use of patient data is very valuable for research and development of the hospital as well as the Pirkanmaa Sote-region
- Still we are not there yet
 - Technology based
 - Regulation based
 - Resource based challenges