

› UNDERSTANDING CLIENT'S PRIVACY PREFERENCES AND ATTITUDES

ECP -PI.lab Privacy by design meeting | Marc van Lieshout

TNO innovation
for life

ZORGRING

**inno
valor**

WORKING ON A PRIVACY DASHBOARD IN CARE

Drivers

- › Need to organise consent ('Wet gebruik BSN in de Zorg', chapter 3A: Electronic processing of data)
- › GDPR

2016 Activities (PIME) – Start-up of privacy app for pregnant women (Geboortehart, Hoorn).

Survey among 1500 patients

- › Privacy attitude and Willingness to share

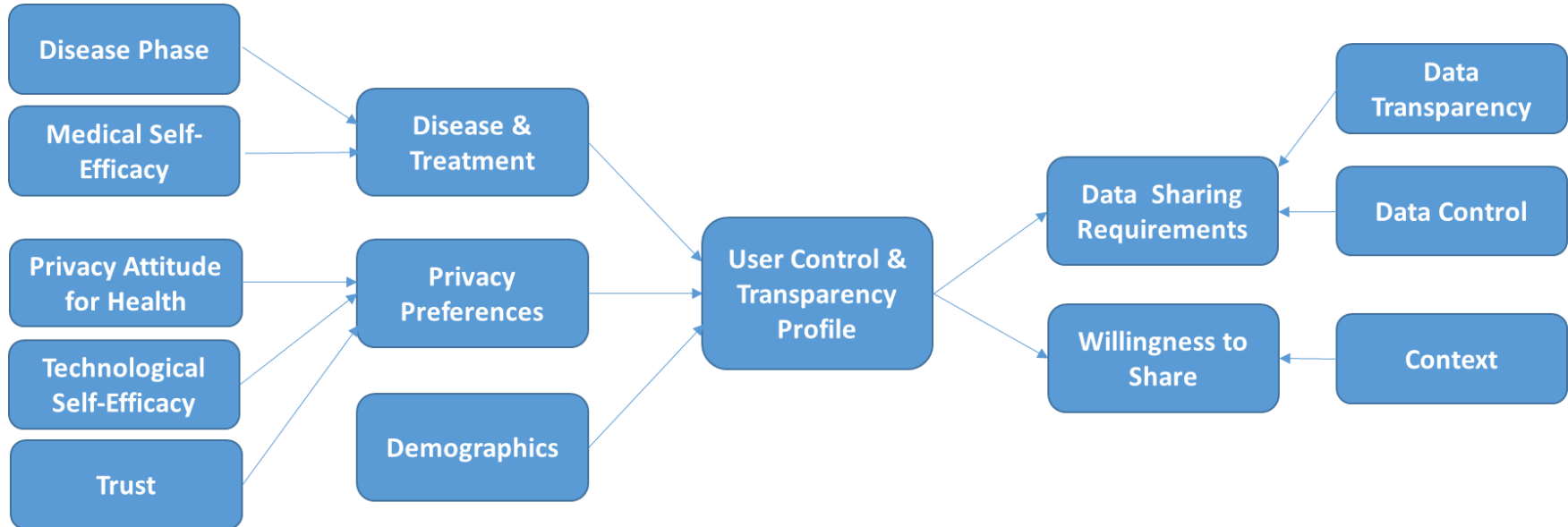
Development of a demo; limited number of patients

- › Sharing data, overview on care processes, ability to indicate data or change data

Role of a privacy dashboard for care providers:

- › Daily work; effectiveness; contact with colleagues

CONCEPTUAL MODEL



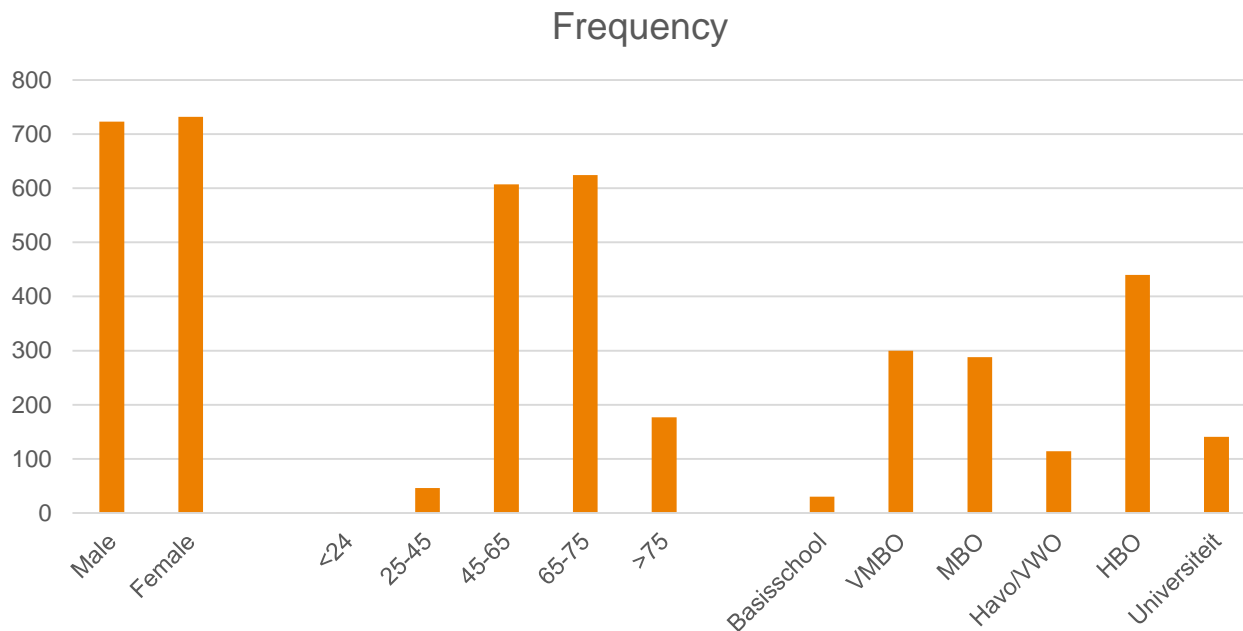
LARGE SCALE SURVEY

- › Constraints
 - › ~1500 respondents, organised through Nederlandse Patientenfederatie
 - › Most respondents have a chronic disease
 - › Average age is skewed to above 50 years
 - › Men and women are equally represented

- › Not a representative sample of Dutch population

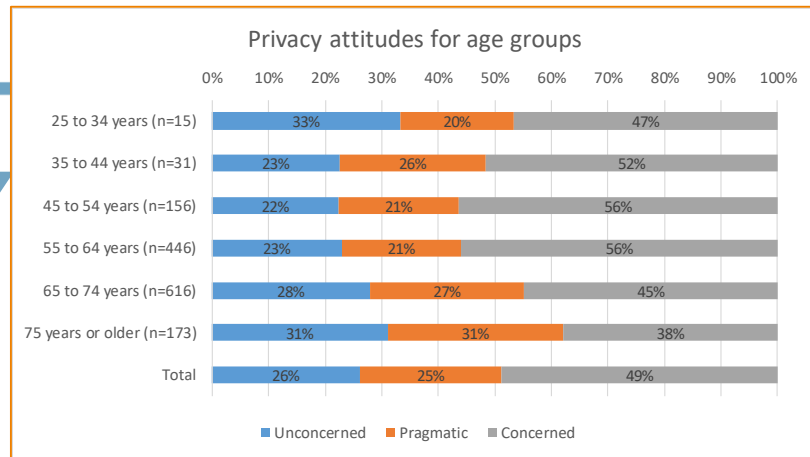
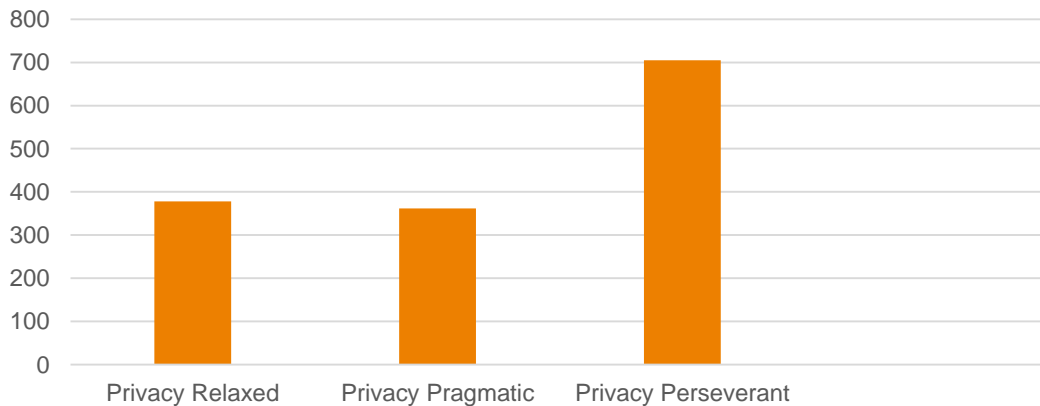
- › 1455 respondents completed the questionnaire

DEMOGRAPHIC FEATURES



ATTITUDE TOWARDS PRIVACY

Respondents



Wat mijn medische gegevens betreft, ben ik bezorgd over mijn privacy.

Ik vind dat zorgverleners te veel informatie willen hebben over mijn persoonlijke en medische situatie.

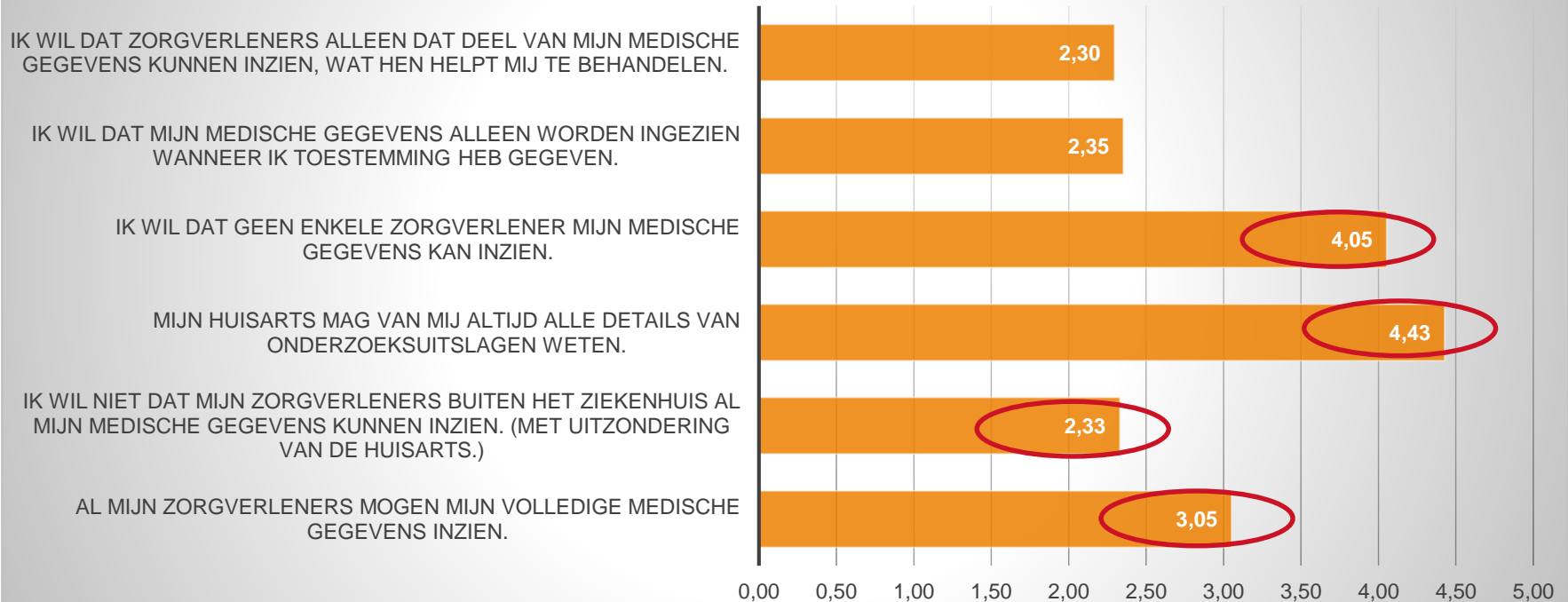
De overheid en zorgverzekeraars willen steeds meer weten over de gezondheid van burgers, ten koste van de privacy.

Mensen hebben steeds minder controle over wat er met hun medische gegevens gebeurt.

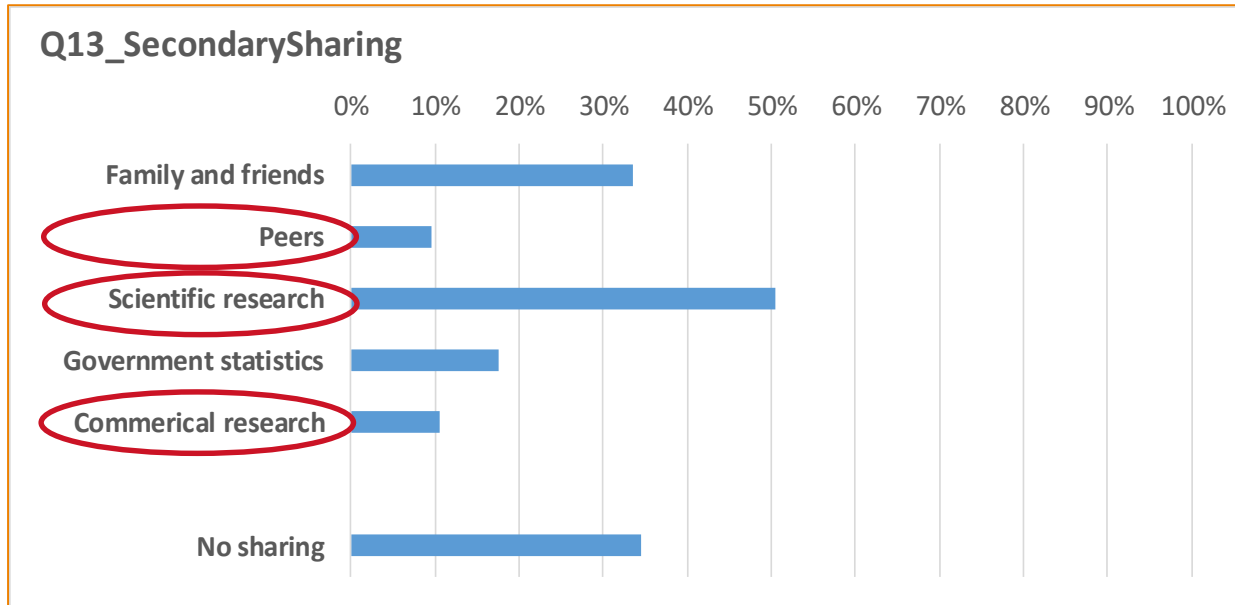
RELEVANCE OF PRIVACY ATTITUDE

	Relaxed	Pragmatic vs Relaxed	Perseverant vs Relaxed	Pragmatic vs Perseverant
	Mean	Mean	Mean	Mean
Q05_Trust	3.81	-0.06	-0.34	-0.28
Q06_TechnologicalSelfEfficacy	3.48	-0.04	-0.12	-0.08
Q08_CurrentInsightIntoData	3.14	-0.24	-0.58	-0.35
Q09_DataTransparency	4.04	+0.10	+0.19	+0.09
Q10_DataSharingRequirements	3.86	+0.27	+0.65	+0.38
Q11_Control	3.25	+0.31	+0.82	+0.51
Q12_WillingnessToShare	3.53	-0.30	-0.75	-0.45
Q13_SecondarySharing	1.40	-0.10	-0.15	-0.05
Q14_EffectOfDataSharing	3.70	-0.09	-0.28	-0.19
Q15_PerceivedEffect	3.56	-0.07	-0.22	-0.16

'Willingness to share'



SECONDARY SHARING

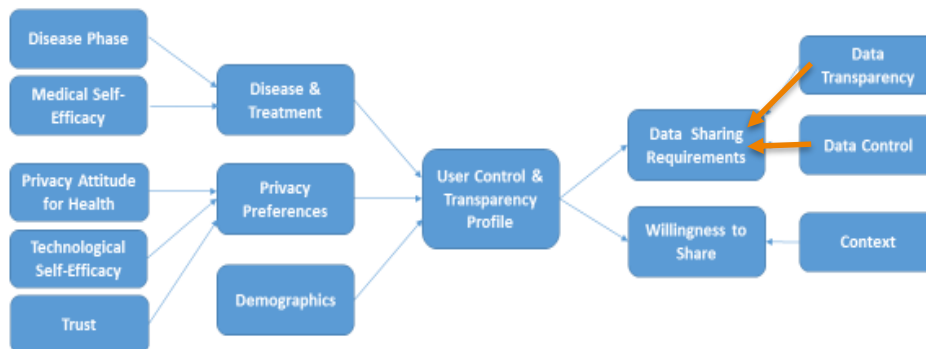


Met wie zou u uw medische gegevens willen delen?

- Familie of vrienden
- Lotgenoten
- Wetenschappelijk onderzoekers
- Overheidsinstanties voor onderzoek en statistiek
- Bedrijven om producten te verbeteren en te ontwikkelen
- Niemand

WILLINGNESS TO SHARE AND DATA SHARING REQUIREMENTS

1. **Data control** and **data transparency** both contribute significantly to data sharing requirements ($R^2 = 0,69$)
2. Having experience with **access to an EHR** contributes to a (slightly) higher Willingness to share (3.16 versus 3.05)
3. People that are less willing to share tend to impose stricter requirements on data sharing.



OVERALL RESULTS

Dependent factor	R ²	Demographics			Disease Characteristics		Privacy Characteristics		
		Age	Gender	Education	Disease Phase	Medical Self Efficacy	Privacy Attitude	Trust	Technological Self Efficacy
		> 65	Female	High	Chronic				
Data Transparency	0.26	x				x	x		x
Data Sharing Requirements	0.41					x	x		x
Control	0.47	x		x		x	x		
WillingnessTo Share	0.53		x	x			x	x	x
Secondary Sharing	0.29		x				x		x

OVERALL RESULTS

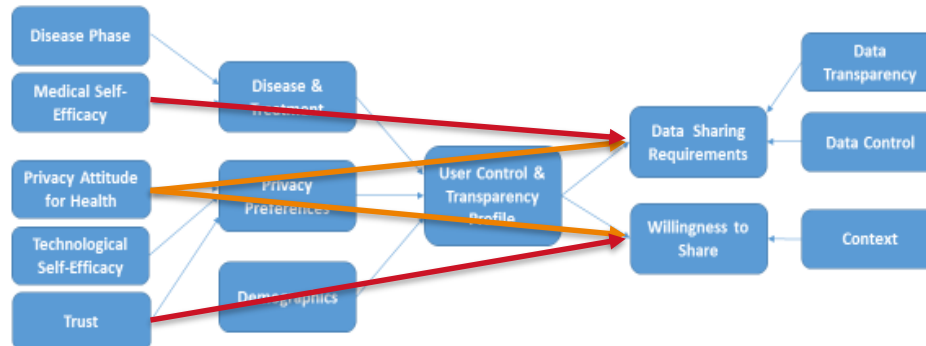
Dependent factor	R ²	Demographics			Disease Characteristics		Privacy Characteristics		
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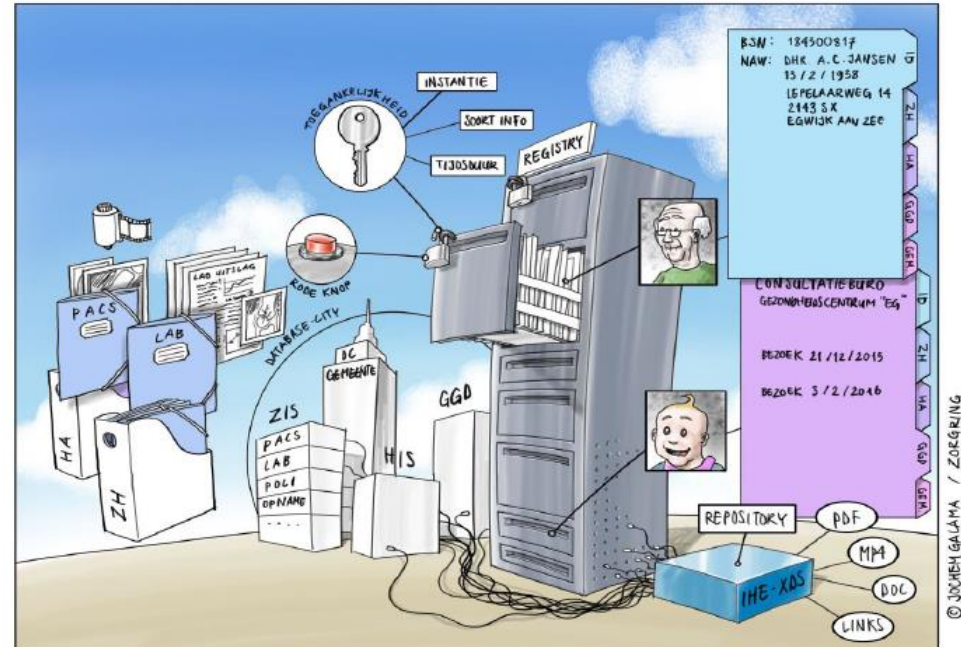
CONCLUSIONS

- › **Privacy attitude** is a relevant determinant for all features of data sharing and willingness to share
- › **Medical self-efficacy** is relevant for data sharing requirements but less for willingness to share
- › **Trust** is only relevant for willingness to share
- › **Technological self-efficacy** is relevant for all features except for control
- › **Gender** is relevant for willingness to share, not for data sharing requirements



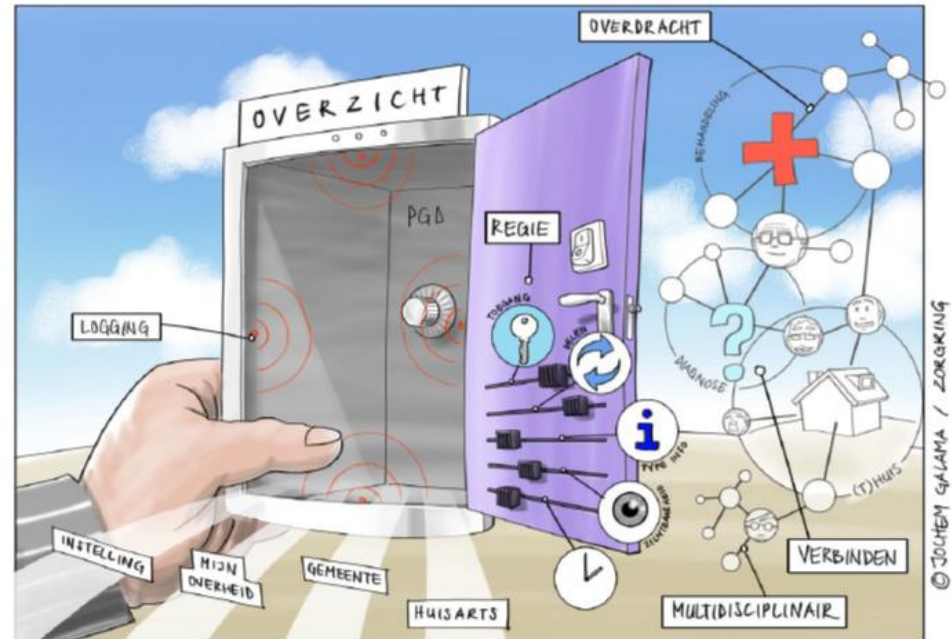
THE REGISTRY (ORGANISED BY FORCARE)

- › Within the registry, per patient a record is kept where data of participating organisations are stored.
- › Every organisation can access files on the basis of patient consents (BPPC)
- › BPPCs can be given per category of data and category of caregivers



TRANSPARENCY FEATURES FOR THE PATIENT

- › The patient can see what data is available.
- › The patient is given control over who can use what data.
- › Access and use are logged (cf Act recently passed by the Senate on specific patient consent).



FOCUSGROUPS – HIGHLIGHTS (1/3)

Be aware: only inspirational!

- › An app providing oversight on medical data is useful only when:
 - › It presents real data (**be aware for only information about data**)
 - › Information and data are explained and made intelligible
- › **Prints and paper are outmoded**
- › Only sharing with care providers that are **directly relevant** for the care process
- › Generic consent for sharing data with a large environment is **not appreciated**
- › **Keep the app focused!**

FOCUSGROUPS – HIGHLIGHTS (2/3)

Be aware: only inspirational!

Data control

- › Being able to have overview about who has had access to your data is appreciated
- › No need for overview on personal level; category of caregiver is sufficient
- › Add purpose for access
- › No need to be informed on administrative details (such as access for billing purposes)

Willingness to share

- › No “Facebook button” to share with friends and relatives
- › (Anonymous) sharing for scientific research is OK; but: which data, which purpose, which organization; no Wild Card
- › No sharing for commercial purposes
- › Option for breaking the glass is appreciated

FOCUSGROUPS – HIGHLIGHTS (3/3)

Be aware: only
inspirational!

About **security**

- › No need for SSO (preference for secure log-in, such as Digid).
- › Automatic log-off when inactive for a specified period of time

Over **Nice to have's**

- › Being able to make notes (for instance for the next visit)
- › Information about pregnancy (FAQ)
- › Introduction of baby book
- › Structuring events on the basis of consult or specialism

INTERVIEWS CARE GIVERS HIGHLIGHTS

INFORM and CONTROL by clients

- › Good idea!
- › Information must be comprehensible: that is the purpose!
- › Support the idea that clients get opportunities to exercise control

Effects at daily activities

- › No major changes in what data will be shared
- › The way of sharing will change (more protocols and oversight)
- › Potential relief of administrative burden
- › Beneficial for quality of care (now that the client can exercise control)

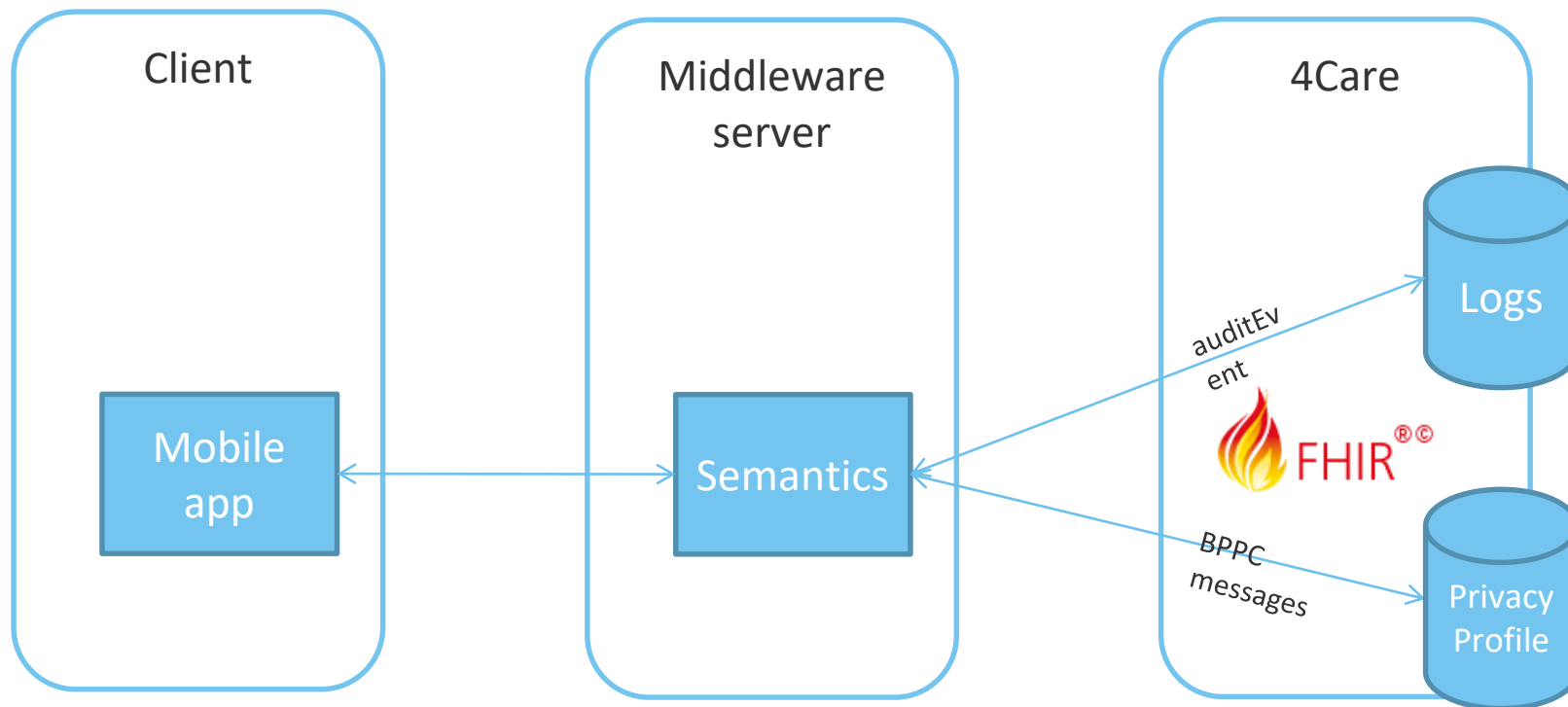
Safeguarding privacy

- › Need for reliable auditing and monitoring system
- › Client must be able NOT to provide specific information

SET UP OF PRIVACY DASHBOARD

- › Layered approach of providing information:
 - › Information on roles and responsibilities (how are processes, roles and responsibilities organised?)
 - › Information on data processes and purposes (what kind of data are collected for what purposes by whom under what circumstances?)
 - › Information on data ('meta-data': who has had access at which moment; 'real data': patient data)
- › Layered approach of offering control
 - › Check who has had access, when and how (specified consent)
 - › Check validity of data
 - › Check for which purposes consent is provided or withdrawn
 - › Check further reaching rights (data portability/right to be forgotten)

HIGHER LEVEL ARCHITECTURE



DEMO MOBILE APPLICATION

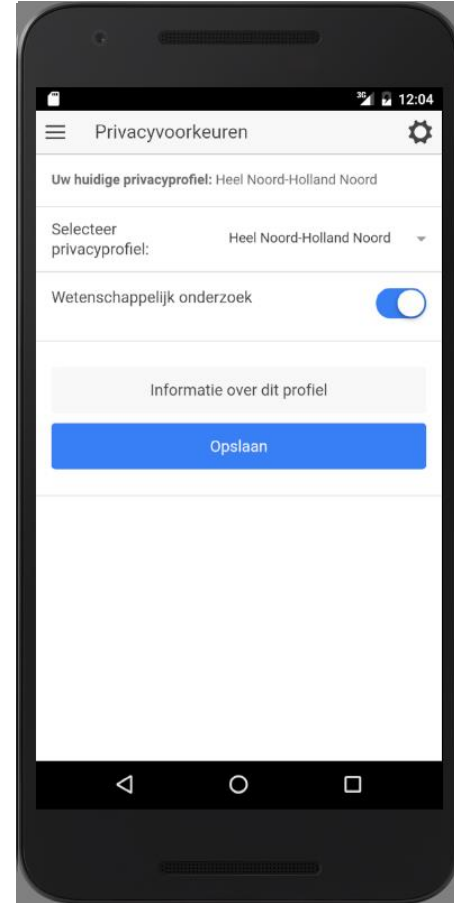
Welcome screen

Login

Dashboard

Log entry

Privacy settings



NEXT STEPS

- › Working on a follow-up project, TKI funding
- › Same population (pregnant women)
- › Same region (Noord Holland)
- › Same partners (Zorgring, Forcare)

- › On-going development of privacy app and implementation in the XDS-based registry of ForCare, using the BPPCs as starting point.

A nighttime city street scene featuring a modern building with a curved facade and a glass railing in the foreground. The image is filled with light trails from moving vehicles, including prominent green and white streaks. The background shows a cityscape with lit-up buildings and streetlights.

**THANK YOU FOR YOUR
ATTENTION**

QUESTIONS?

Take a look:
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