

Notes - Group B – Data Privacy

Moderation: Ioannis Tarnanas, ETH Zürich

Notes: Eva-Maria Markutzik, Business Creation Manager, EIT Health Germany

- **Intro by Ioannis Tarnanas, ETH Zurich/Altoida**
 - Using digital biomarkers to measure cognitive outcomes
 - AR exercises to predict probability of Alzheimer's Disease
 - tool could be used for further neurodegenerative diseases
 - Neuro Motor Index: 94% accuracy
 - tools is currently under review for FDA 510k Med Device and MDR (EU) clearance
 - can be used as companion diagnostic and for progression monitoring
 - big data: 250 features are measured at 300Hz
- **Question: Added value for patients?**
 - Lifestyle modification could help preventing/delaying AD
- **Who has access to these data sets?**
 - in the case of Altoida, they have an exclusive access
 - Miracum consortium: federal data storage
 - Achmea: Anonymized data can be shared with universities but also companies
- **Data privacy:**
 - Germany: 16 data privacy regulations (federal concept)
 - hardliner: people would even need to approve that their data will be anonymized → Health literacy: If people would know what kind of benefit their data to bring, would they be rather willing to allow the use of their data
 - New EU data protection rules (will be implemented until May 2018) will set a new framework
 - General question: Do we rather trust research than companies?
 - Overprotection versus social need → finding people who are willing to share their data → creating a community with a culture of sharing data → requirements: trust and education
 - EIT Health could create an example of such a community
 - EMA is very diverse which also hinders clearance for new data-driven products/services → In the US, companies like Apple and Big Pharma work closely with FDA for faster clearance

Relevant link recommendation from Ioannis Tarnanas:

<https://www.beckershospitalreview.com/ehrs/dr-eric-topol-3-steps-to-shift-medical-data-ownership-to-the-patient.html>