Open Trackers for (Open) Science

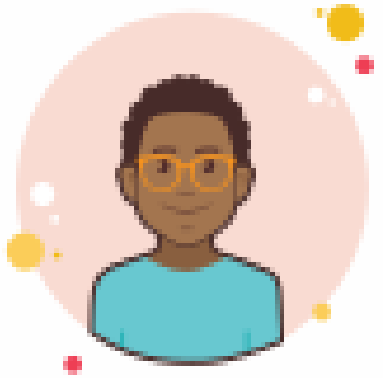
Daniela Gawehns, Froscon 2020.

Universiteit
Leiden
The Netherlands

Outline

Three Personas I

Persona I : Mark



Three Personas II

Persona II : Janine

Three Personas III

Persona III : Karla

Three Personas

Summary Feedback

The Why

What makes those activity trackers so attractive?

- tracking of activity, heart rate, location, interactions, momentary emotional assessment
- passively, (almost) non-intrusive
- longitudinal studies (several weeks)
- real life data

Summary of Use Cases

	Children	Ex-Detainees	Nursinghome
Data Collection			
Accelerometer	X	X	X
EMA	X		
GPS/Location	X	X	X
Call Logs		X	
Participants			
Age	< 13	20-60	> 65
Somatic Health	healthy / hoh	healthy	geriatric patients
Mental Health	some special education schools	some psychiatric patients	dementia

The How - Balancing Acts

The How - Current Hardware Options

Medical Research Devices

- Shimmersensing.com
- Actigraph
- Empatica

The How - Current Hardware Options

Medical Research Devices

- Shimmersensing.com
- Actigraph
- Empatica

Consumer Grade Devices

- Apple WatchOS
- fitbit
- Garmin Watch OS
- Wear OS / Android for wearables
- Tizen for Wearables
- astroid

The How - Apple Watch

- Partner with the Apple Research App
- Researchkit and Carekit frameworks

The How - Apple Watch

- Partner with the Apple Research App
- Researchkit and Carekit frameworks
  - bring your own data storage (?!)
  - locked into what the frameworks allow (e.g., no background data collection)
  - locked into Apple Watches

The How - Apple Watch

- Partner with the Apple Research App
- Researchkit and Carekit frameworks
  - bring your own data storage (?!)
  - locked into what the frameworks allow (e.g., no background data collection)
  - locked into Apple Watches
- Apple Watch App (e.g. Apple Watch SensorLog)
  - locked in by certification/ app store process
  - locked in to Apple Watches

The How - Fitbit

- Use Fitabase
- Use web API
  - Companion Application to Watch Application file transfer
  - locked in certification
- Use bulk download via fitbit account

The How - Garmin

- Use Fitabase - a company providing research support
- Use the Health API
- Use the Health SDK

The How - Using Big Tech

- Availability, Scalability
  - https://corona-datenspende.de

The How - Using Big Tech

- Availability, Scalability
  - https://corona-datenspende.de
- Design Choice - Working with participants or patients

The How - Choices

”To **enhance acceptability** and minimize user burden and stigma, widely available consumer-oriented technologies were therefore considered. The user groups favored the wrist-worn Fitbit Charge HR (Fitbit Inc, San Francisco) due to its **appearance as a lifestyle device** that is acceptable to both younger and older users and the **ability to view metrics** relating to sleep and activity via the Fitbit app.”

Meyer N., et al (2018): Capturing Rest-Activity Profiles in Schizophrenia Using Wearable and Mobile Technologies: Development, Implementation, Feasibility, and Acceptability of a Remote Monitoring Platform

The How - Choices

”Do these devices, therefore, have a role as tools for clinical prediction?
We suggest that they do, **depending on the question being asked** [**58**]. Our goal is not to draw conclusions about sleep parameters (eg, total sleep time, sleep efficiency) per se, for which the use of unvalidated devices would be inappropriate. Rather, our **objective is to ask whether changes in longitudinal rest-activity patterns** at the within-person level, captured using wearable device and smartphone sensors, **predict deterioration** in clinical status.”

Locked - in: corona-datenspende

	Fitbit	Garmin	Polar	Withings	GoogleFit	Apple Health
Soziodemografische Daten						
Größe & Gewicht	✓	✓	✓	✓	✓	
Geschlecht & Alter	✓		✓			✓
Aktivitäten						
Aktivitätsinformationen						
Aktiv	✓	✓	✓	✓	✓	
Aktivitätsdetail (Laufen, Radfahren, Sport etc.)	✓	✓	✓	✓	✓	
Ruhe	✓	✓	✓			
Schritte	✓	✓	✓	✓	✓	✓
Kalorienverbrauch	✓	✓	✓	✓		
Zurückgelegte Strecke	✓	✓	✓	✓	✓	
Gestiegene Treppen	✓	✓		✓		
Schlaf	✓	✓	✓	✓	✓	✓
Vitaldaten						
Puls	✓	✓	✓	✓	✓	✓
Körpertemperatur				✓	✓	
Gewicht	✓	✓	✓	✓	✓	

The How - Summary

Summary: We have solutions for:

- Lab Studies

The How - Summary

Summary: We have solutions for:

- Lab Studies
  bulky, precision technology and access to the raw data

The How - Summary

Summary: We have solutions for:

- Lab Studies
  bulky, precision technology and access to the raw data
- Big Data Studies

The How - Summary

Summary: We have solutions for:

- Lab Studies
  bulky, precision technology and access to the raw data
- Big Data Studies
  wide spread use of consumer grade devices and access to summary statistics

The How - Summary

Summary: We have solutions for:

- Lab Studies
  bulky, precision technology and access to the raw data
- Big Data Studies
  wide spread use of consumer grade devices and access to summary statistics
- Real life Data Collection

The How - Summary

Summary: We have solutions for:

- Lab Studies
  bulky, precision technology and access to the raw data
- Big Data Studies
  wide spread use of consumer grade devices and access to summary statistics
- Real life Data Collection
  if the data supplied by platforms are in accordance with what you want to achieve

The How - Case Studies

	Children	Ex-Detainees	Nursinghome
Data Collection			
Accelerometer	X	X	X
EMA	X		
GPS/Location	X	X	X
Call Logs		X	
Participants			
Age	< 13	20-60	> 65
Somatic Health	healthy / hoh	healthy	geriatric patients
Mental Health	some special education schools	some psychiatric patients	dementia

The How - Case Studies

	Children	Ex-Detainees	Nursinghome
Data Collection			
Accelerometer	X	X	X
EMA	X		
GPS/Location	X	X	X
Call Logs		X	
Participants			
Age	< 13	20-60	> 65
Somatic Health	healthy / hoh	healthy	geriatric patients
Mental Health	some special education schools	some psychiatric patients	dementia

The How - Case Studies

Photo by Eduard Militaru on Unsplash

The How - What has been done

Own Solution - Samsung

The How - What has been done

Own Solution - Samsung

The How - What has been done

Own Solution - Samsung
Possibilities - Positives
Negatives and Downsides/ Limitations

Open Source Operating System

https://asteroidos.org/news/

The Future

- Data Privacy is paramount - Research platforms allow access to some but not all data - API's do not allow access to all data - Interoperability - Robust Findings - independent of tech - Validity of measurements - Research questions independent of tech/ pre-trained black boxes - Modularity to ensure only those sensors that are needed are included (and that they ARE included) - Costs are high - open science might be an answer? - Using big tech at exploratory research level might be fine - but where are you going with this – access only to those who can afford it and dependent on companies to not change the modeling? - Usually we are working towards sth - let's make sure it is in accordance with what we want to create with the tech– also already at exploratory levels

The Future

- Show design process until now - mission and network of stakeholders - Multifaceted problem - Difficult to get people on board, who commit and stay on board - certainly at beginning - How do you build a OS / Open Hardware community? - What are the benefits - especially when trying to get academics involved - incentive structure is not built for such projects

Wake-up Activity

Activity with Audience: collect possible solutions to move forward