ITU KALEIDOSCOPE
ATLANTA 2019

Operationalizing Data Justice in Health Informatics

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4-6 December
Atlanta, Georgia,
USA

"This report offers insights into the risks and opportunities of using Information and Communication Technologies to achieve the Sustainable Development Goals"

Antonio Guterres

Foreword to **Fast-forward progress: Leveraging tech to achieve the Global Goals**

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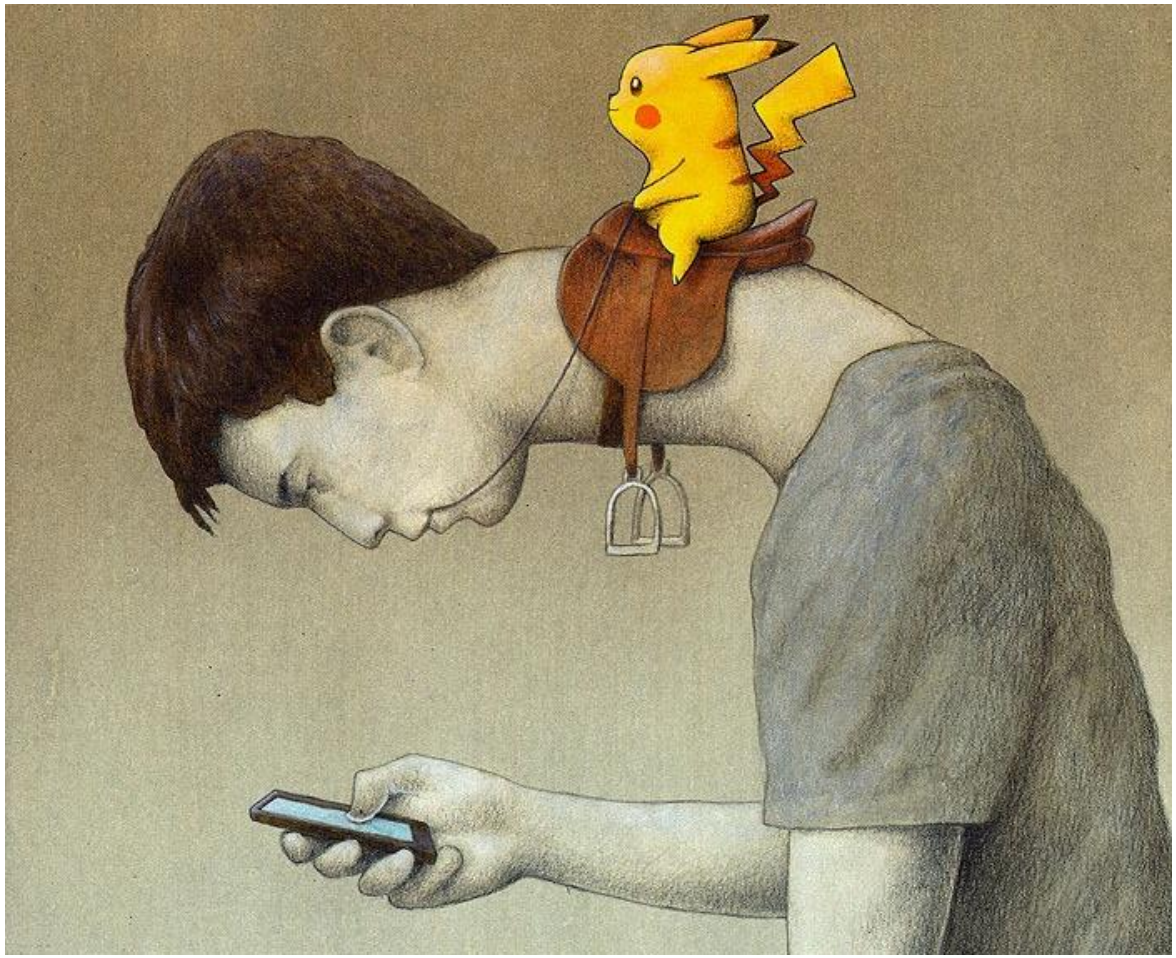

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Human Data Interaction

Agonistic participatory design

Participatory design

Computer ethics

Asilomar AI principles

Value sensitive design

Ethical OS principle

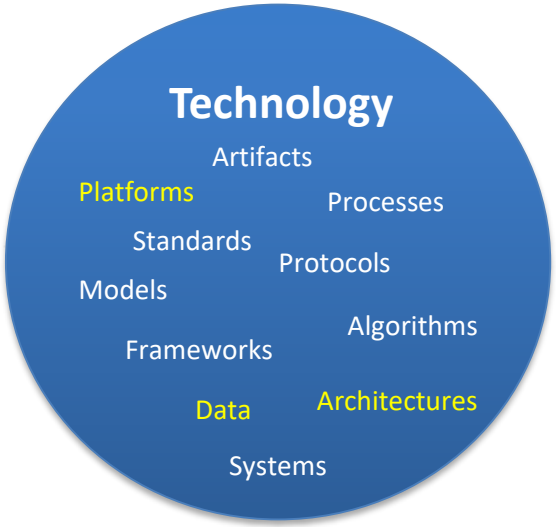
Data Justice

Social influences of technology

Nudging

Captology

Persuasive technologies



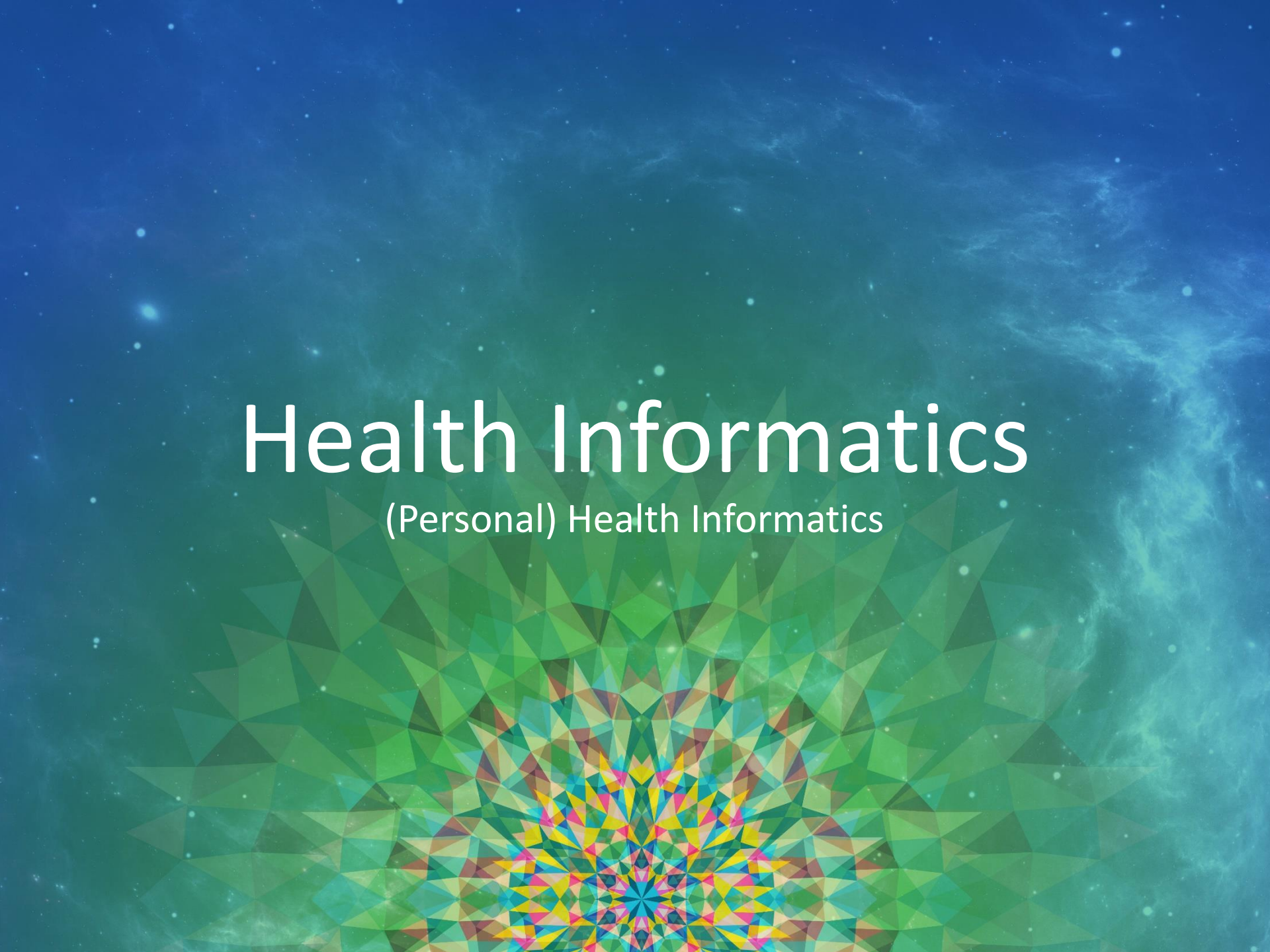
Digital Health

Need to “ensure that digital health solutions complement and enhance the existing health service delivery models, strengthen integrated, people-centered health services and contribute to health, health equity including gender equality and addressing the lack of evidence on the impact of digital health”

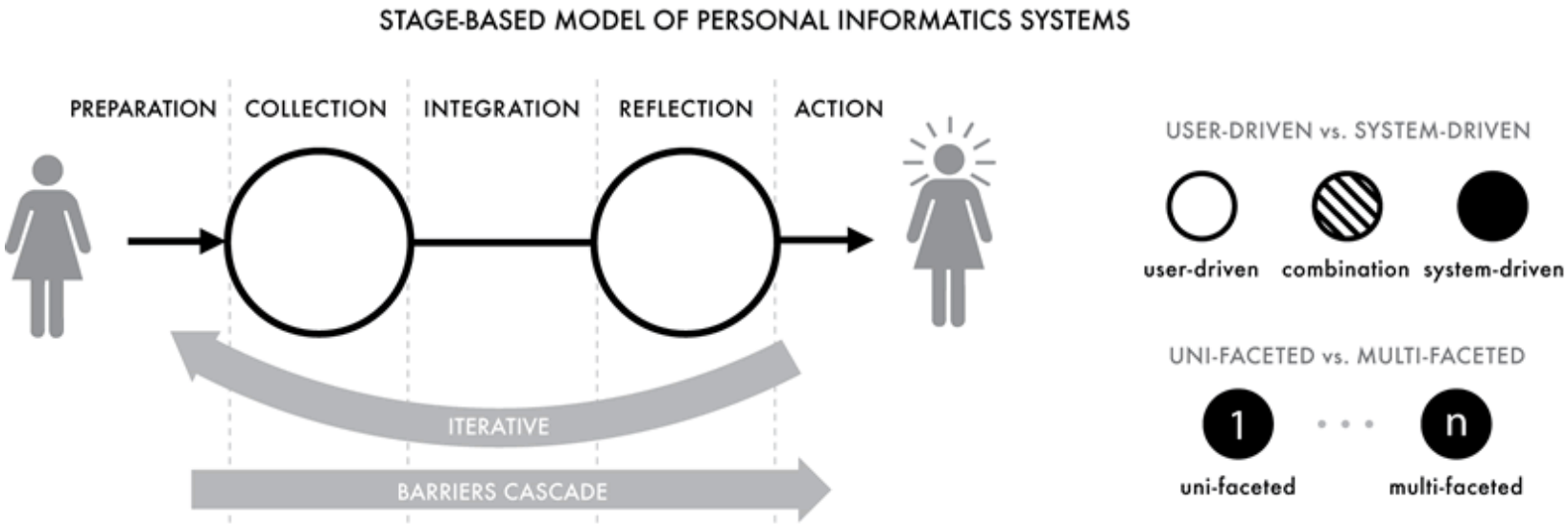
71st World Health Assembly

Health Informatics

(Personal) Health Informatics

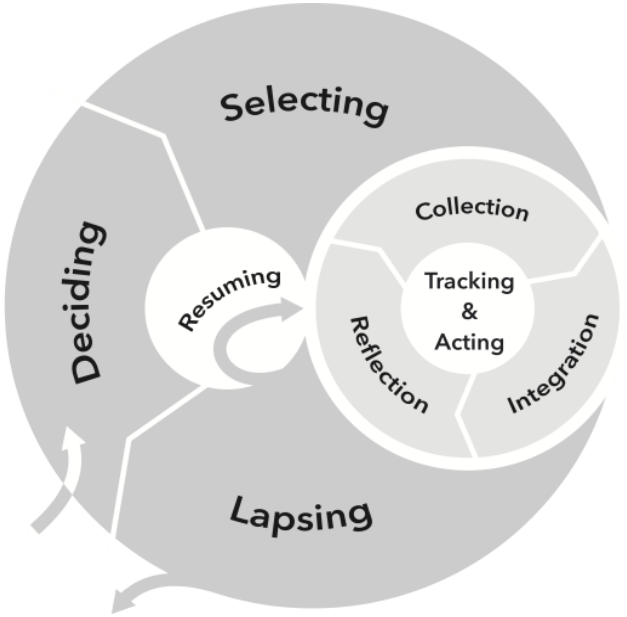


Personal Health Informatics



Li, I., Dey, A., & Forlizzi, J. (2010). A stage-based model of personal informatics systems. In *Proceedings of the 28th international conference on Human factors in computing systems - CHI '10* (p. 557). New York, New York, USA: ACM Press. https://doi.org/10.1145/1753326.1753409

Lived Informatics model of Personal Health Informatics



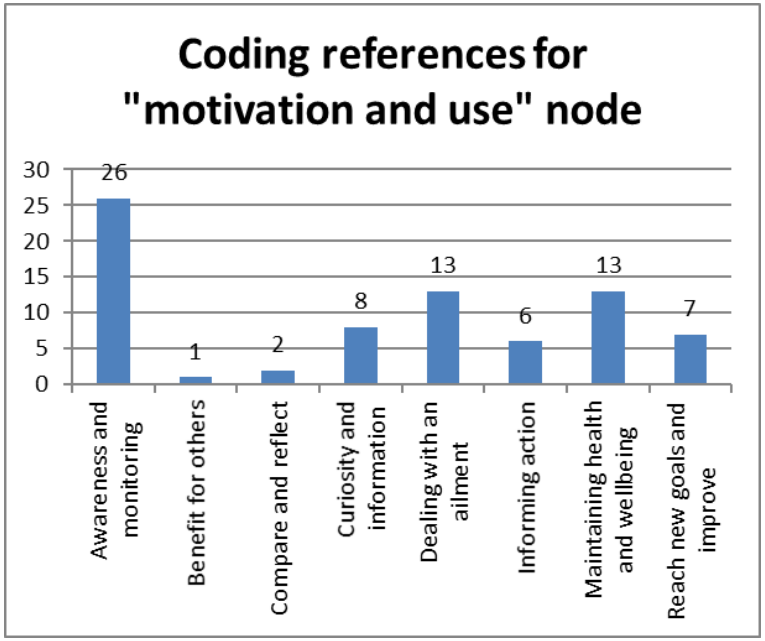
Epstein, D. A., Ping, A., Fogarty, J., & Munson, S. A. (2015). A lived informatics model of personal informatics. In *Proceedings of the 2015 ACM International Joint Conference on Pervasive and Ubiquitous Computing - UbiComp '15* (pp. 731–742). New York, New York, USA: ACM Press. https://doi.org/10.1145/2750858.2804250

Motivations in personal informatics
"Styles" in personal informatics

- **Directive tracking**
  - Towards goal achievement e.g. number of steps a day
- **Documentary tracking**
  - Documenting their lives, journaling
- **Diagnostic tracking**
  - Identifying links between phenomena e.g. diet and ailments
- **Collecting rewards**
  - Specific rewards e.g. reduced insurance premium
- **Fetishized tracking**
  - Exciting technology

Rooksby, J., Rost, M., Morrison, A., Chalmers, M. C., Rooksby, J., Rost, M., … Chalmers, M. C. (2014). Personal tracking as lived informatics. In *Proceedings of the 32nd annual ACM conference on Human factors in computing systems - CHI '14* (pp. 1163–1172). New York, New York, USA: ACM Press. https://doi.org/10.1145/2556288.2557039

Motivations and use in personal informatics



Motivation & use / Tracking style	Directive	Documentary	Diagnostic	Rewards	Fetishized
Awareness and monitoring		■			
Benefit for others					
Compare and reflect			■		
Curiosity and information					
Dealing with an ailment	■		■		
Informing action	■				
Maintaining health and wellbeing		■			
Reach new goals and improve	■				

INFORMED PATIENTS

DIGITALLY ENGAGED PATIENTS

EMPOWERED PATIENTS

Yes, but...

...Data Injustice!

Data Justice

"fairness in the way people are made visible, represented, and treated as a result of the production of digital data"

- (In)visibility
- (Dis)engagement with technology
- Anti-discrimination

Taylor, L. (2017). What is data justice? The case for connecting digital rights and freedoms globally. *Big Data & Society*, *4*(2).

Data Justice

"the primary ethical standard by which data-related resources, processes, and structures are evaluated"

- Instrumental
- Procedural
- Distributive rights-based
- Structural data justice

Heeks, R., & Renken, J. (2018). Data justice for development: What would it mean?. *Information Development*, *34*(1), 90-102.

Human Data Interaction > Data Justice

"the human at the center of the flows of data, and providing mechanisms for citizens to interact with these systems and data explicitly"

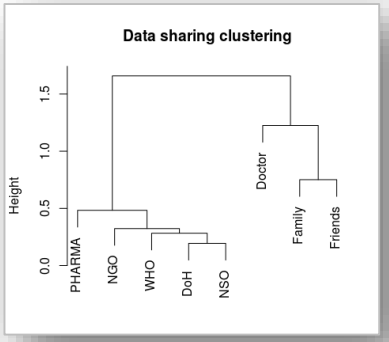
- Legibility
- Agency
- Negotiability

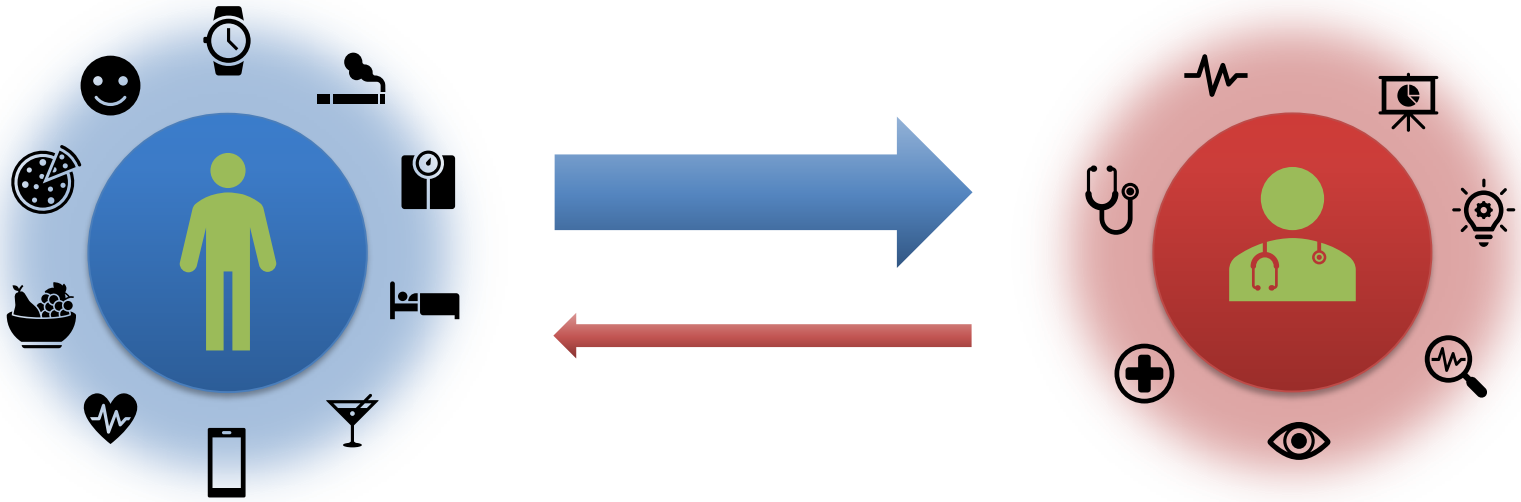
Mortier, R., Haddadi, H., Henderson, T., McAuley, D., & Crowcroft, J. (2014). Human-data interaction: The human face of the data-driven society. *Available at SSRN 2508051*.

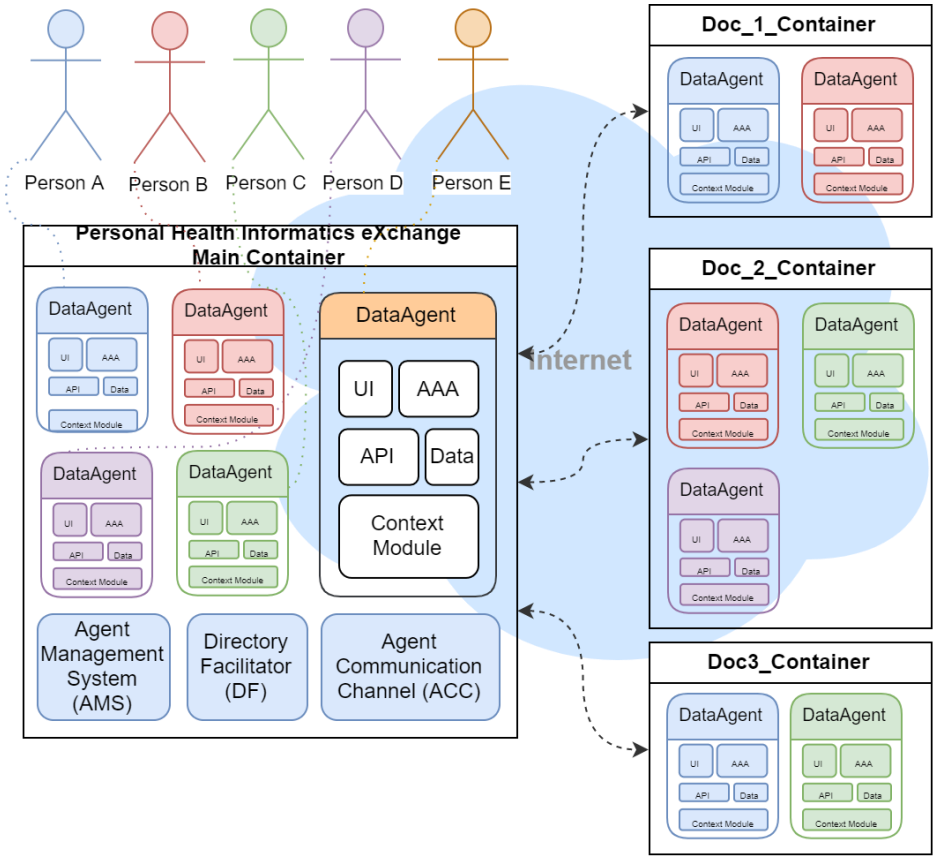
HDI Principles	Relevant features and functionality
Legibility: "being able to be understood by people they concern, as a precursor to exercising their agency"	• Accounting and auditing • Feedback and notification • Relevant insights
Agency: "the capacity for the humans to act in these data systems"	• **Permission and access control** • Consent and withdrawal • **Revocation of data**
Negotiability: "active and engaged interaction with data as contexts change"	• **(Perpetual) Control** • Data provenance • **Contextual integrity** • Anonymization and delinking • Contribution to data commons

Specific Context & Scenario

Sharing of personal health data with health service providers in a manner that is consistent with the Data Justice principles e.g. users in (perpetual) control of their data and the sharing thereof, data provenance, context integrity.







PHIX
Personal Health Informatics eXchange

Informed by JADE MAS platform

- FIPA compliant
- Interoperable complex agent systems
- Platform agents: AMS, RMA, DF, Sniffer, Clone, Migrate

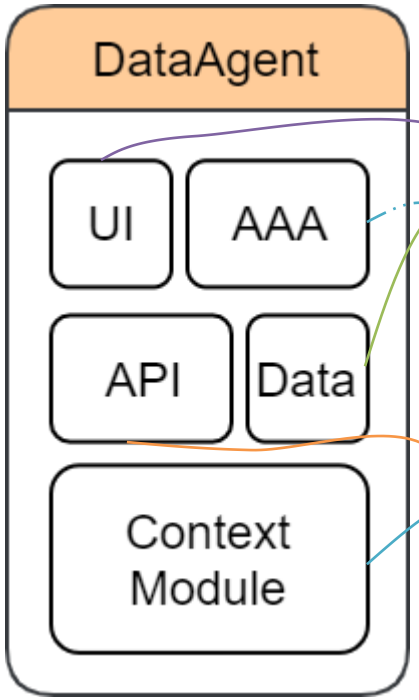
Distributed agent containers

- Hosted at health providers
- Redundant Main Container

Community of DataAgents controlled by users

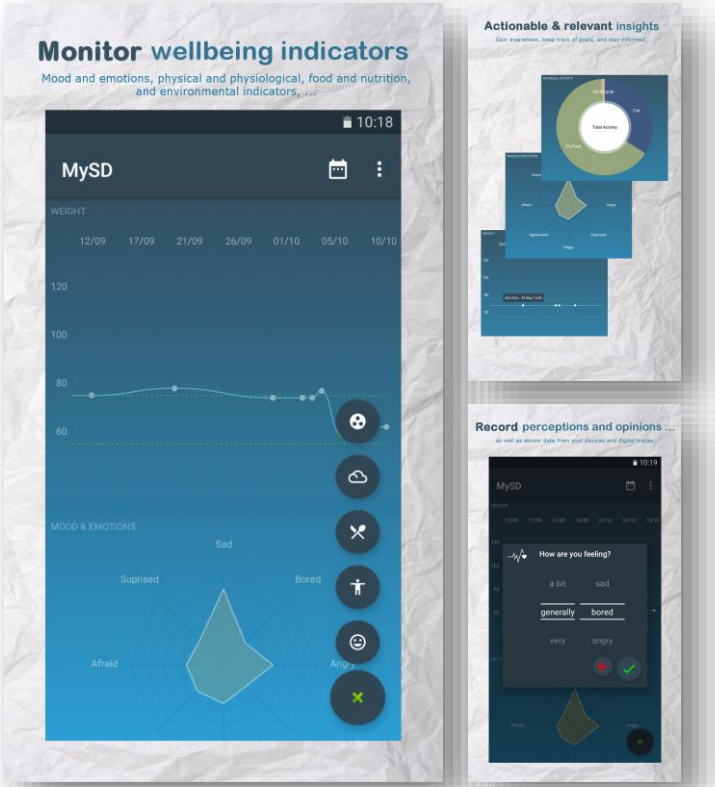
DataAgents

PHIX
Personal Health Informatics eXchange

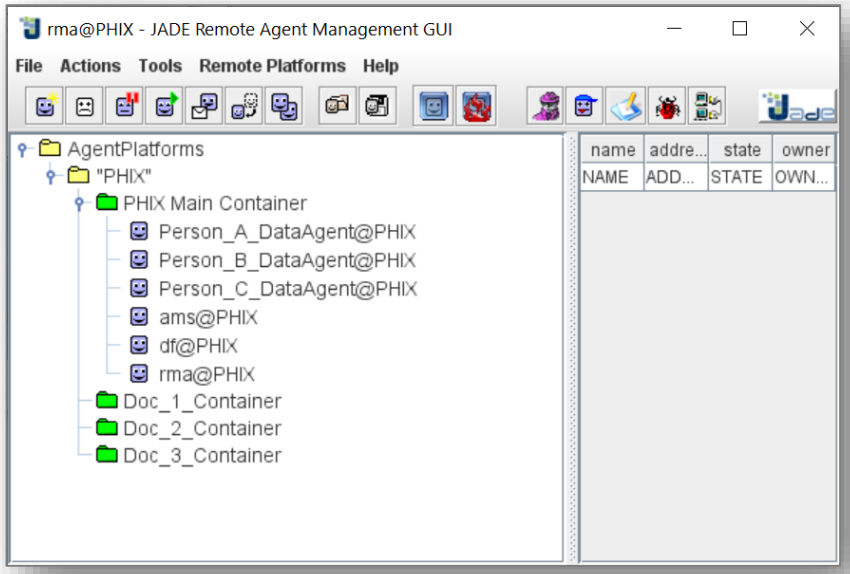


DataAgent	•Secure mobile virtual data double •Data sharing via cloning and migration •Encapsulating data and functionality to operate on data
Knowledge Representation	•Ontologies (RDF/RDFS) •Databases •Remote Repositories
User interaction and data presentation	•Data visualization •Commands to operate on data
Context integrity	•Access control and permissions •Enforcing contextual constraints (e.g., temporal constraints)
External Interactions	•Remote execution •External interfacing (e.g., SDMX, REST)

MySD
small data for sustainable development



PHIX
Personal Health Information eXchange



MeD-lights

(Adams et al, *MeD-lights: a usable metaphor for patient-controlled access to electronic health records*, 2010)

- Traffic light metaphor to label sensitivity of personal health data
- Intuitive specification of privacy and confidentiality requirements

Databox

(Mortier et al, *Human-Data Interaction: The human face of the data-driven society*, 2014)

- Federation of personal health data with APIs to the data
- Moving processing to the data

PHIX DataAgent

- Mobile – data sharing via cloning and migration
- Virtual "data double" DataAgent – data plus functionality
- Puts the individual in control of their data
- Ensures contextual integrity

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Thank you

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