Universiteit Leiden

Leiden Institute of Advanced Computer Science

FAIR Global Digital Health Network, LIACS

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The LIACS-based FAIR Digital Health Group investigates the potential and compatibility of Findable, Accessible, Interoperable and Reusable (FAIR) Guidelines with Digital Health. The FAIR Guidelines provide an established basis for connected data, establishing the Third Generation Internet of FAIR Data and Services, particularly relevant for the life sciences. The group is coordinated by Prof. Dr. Mirjam van Reisen.

The focus of the research is on innovation adoption decisions related to digital health in the context of the emerging Internet of FAIR Data and Services, with particular attention for:

(i) *Data quality, representativity and diversity*, the problem understood as under-representation of diverse populations on our understanding of human disease and exacerbating health inequalities. (Giorgio Sirugo, Scott M. Williams, and Sarah A. Tishkoff, (2019); Van Reisen et al., 2019a)

(ii) *Compatibility* defined "as the degree to which an innovation is perceived of being consistent with the existing values, past experiences, and needs of the potential adopters" (Rogers, 2003; Kawaljeet Kaur Kapoor, Yogesh K. Dwivedi & Michael D. Williams, 2013; Van Reisen et a, 2019b);

(iii) *Compliance and Governance of Sensitive Health* Data with existing and developing frameworks on personal data, processing and profiling within the sovereign governance structures for health (see for instance, EAC Digital Reach Initiative);

(iv) *Machine Learning and Algorithmic Transparency for Consent of Data Subjects* (Bryce Goodman and Seth Flaxman "whereby a user can ask for an explanation of an algorithmic decision that was made about them" (2016));

(v) *Digital social processes* associated with health care such as Health Care Orientation, Remittances and other processes (Van Reisen, 2018);

(vi) *Applicability of FAIR for digital health in Africa* and learnings of this for FAIR Guidelines international (Van Reisen, et al, 2019);

(vii) *Establishing Implementation Network for FAIR in Africa* (GO FAIR IN Africa. GO Build/GO Change/GO Train).

Contributors to the FAIR Global Digital Health Research Network:

Mariam Mutoni Bassaja – PhD candidate. Machine Learning and Digital Health Sustainability in Uganda (2018 – 2022) – supervisors: Prof Dr Mirjam van Reisen, Prof Dr Venansius Baryamureeba, Dr Katy Wolsencraft.

Wenqi Yin – Health Orientation and Remittances for Health in Digital Africa (2018 – 2019) – Supervisors: Prof Dr Mirjam van Reisen, Dr. Stokmans, Prof Ronald de Jong;

Kudakwashe Chindoza – aspirant PhD candidate: The Implementability of FAIR as a Basis for Enhancing Interoperability of Digital Healthcare Data in Zimbabwe (2019 – 2023). Supervisors: Prof Dr Mirjam van Reisen, Prof Dr Venansius Baryamureeba, Dr Katy Wolsencraft. Support from prof Dr Munyaradzi Mawere.

Master projects:

Annastasia Magoma – Designing a FAIR Data Point for Digital Health Services in Eldoret, Kenya (2018 – 2019). Supervisors: Prof Dr Mirjam van Reisen, Tyron Offerman.

Annisa Hedlina Hendraputri – Masters ICT4B: Compatibility of Data-driven Health Care in Rural Indonesia (2018 – 2019). Supervisors: Prof Dr Mirjam van Reisen, Werner Heijstek

Aliya Aktau – Masters CS: Governance and Predictive Algorithm Use in Interoperable and Reusable Data-driven Health Care in Kazakhstan (2019). Supervisors: Prof Dr Mirjam van Reisen, Dr Katy Wolsencraft

Clemens Gonesh – Inclusion and Exclusion in Health Data (2019). Supervisors: Prof Dr Mirjam van Reisen, Peter van Veen.

Ashley Bonte - Physical Health in Sedentary Employment Conditions (2019). Supervisors: Prof Dr Mirjam van Reisen, Peter van Veen.

Givan Lieu-Hew - Implementation of digital personal health environments in collaboration with patients' federations. Supervisors: Prof Dr Mirjam van Reisen, Dr Katy Wolsencraft

Hargurjit Singh – Designing a FAIR Data Point for LIACS (Bachelor) –(2018 – 2019). Supervisors: Prof Dr Mirjam van Reisen.

Embedding:

The LIACS-network works in close collaboration with Leiden Centre of Data Science (LCDS), Go-FAIR Leiden Office, Institute of Social Studies Rotterdam University in The Hague campus, Global Health Group Erasmus University Rotterdam and the LDE Healthy Society (Leiden University – Delft University – Erasmus University Rotterdam). The group is part of the Research Network Globalisation, Accessibility, Innovation and Care (GAIC).

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Output:

Mirjam van Reisen, Mia Stokmans, Mariam Basajja, Antony Otieno Ong'ayo, Christine Kirkpatrick, Barend Mons (2019) Towards the Tipping Point of FAIR Implementation. In: *Data Intelligence: FAIR best practices 2019* (eds. Mons, B., Jacobsen, A. & Schultes, E.). Forthcoming 2019, article under review.

Mirjam van Reisen, Mia Stokmans, Antony Otieno Ong'ayo, Mariam Basajja, Primrose Nakazibwe, Munyaradzi Mawere, Christine Kirkpatrick, Kudakwashe Chindoza, Venansius Baryamureeba (2019) FAIR practices in Africa. In: *Data Intelligence: FAIR best practices 2019* (eds. Mons, B., Jacobsen, A. & Schultes, E.). Forthcoming 2019, article under review.

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Hargurjit Singh (2018) FAIR Data Point for LIACS. Bachelor Project. Poster Presentation

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https://www.k4health.org/sites/default/files/digital-reach-initiative-roadmap.pdf

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Buskens, I. & Reisen, van, M. (2016). Theorising agency in ICT4D: Epistemic sovereignty and Transformation-in-Connection. In: *Underdevelopment, development and the future of Africa.* (Ed. M. Mawere). Bamenda: Langaa, pp.394-432.

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