

Data Science in Digital Health in Uganda

Prof. Dr. Mirjam van Reisen

On February 27, 2019, Kampala International University (KIU) was the venue of a conference “Digital Health and Development in Data Science in Uganda”. The conference was opened by the Vice Chancellor, Dr. Mouhamad Mpezamihigo, who welcomed the seminar to reflect on the relevance of data science from a medical perspective on the assessment of challenges and opportunities in digital health in Uganda.

Dr. Mike Barongo, computer scientist from Makerere University, referred to data scientists as the “alchemist of the 21st century”, and stressed on the importance of education in data science at African Universities, so that the processes would remain accessible and demystified for use in applications. He defined digital health as all digital instruments that enhance health services. Having experience in the area of livestock diseases, he identified the potential of data science for the life sciences, but also asked critical questions, such as the disappearance of data to repositories in the United States of America and the concern as to who owns data repositories. Emphasizing the rapid growth of data, Dr. Barongo emphasized the need for data science to always be serving the objective of improved well-being of the communities. He further stressed the job market for young people in data science as an important perspective that should encourage universities to establish courses in this area.

Challenges in digital health

Mrs. Mariam Basajja presented her investigation in the obstacles for increased sustainability of digital health from a data science perspective. She identified mobile health as a particularly well-developed component of the digital health solutions in Africa, given the continent’s dependency on mobile connectivity. Mrs. Basajja pointed to the challenges of ownership of the data and their findability, the need for management of protection and accessibility of data and the need for study of the data interoperability and reusability of data produced in health apps. Identifying the principles of Findability, Accessibility, Interoperability and Reusability, with the acronym FAIR, as a possible solution that would enhance coherence in digital health and help increase the sustainability of its underlying data-analytics. Mrs. Basajja presented the findings of a study on the worldwide implementation of FAIR, noting that no such implementation had taken place in Africa or in Uganda, despite its potential. She presented her research in terms of the objective to test the feasibility of an implementation of a FAIR Data Point for digital health in Uganda with the ultimate aim to study its potential to enhance the sustainability of digital health in the country.

Dr. Primrose Nakazibwe addressed the question of data ownership applying a value chain approach to data-analytics. “Data is the new oil or the new gold of Africa”, stated Dr. Nakazibwe, positing that while data were extracted freely, the profits remained outside the continent. She emphasized the need for reflection on data ownership and to ensure that the production of data and its analytical contribution have a value that the continent should recognize. The key question we need to ask, she said, is: how does this translate into wealth and who benefits from this? We need to be aware of the data we generate in Africa and how these are put to use, she concluded in her final statement.

FAIR Implementation Network for Africa

Prof. Dr. Mirjam van Reisen, speaking for the Leiden Centre of Data Science, introduced the third generation of the internet as a new phenomenon that could help solve some of the questions addressed in the seminar. With the data-ownership identified as closest to the data-subject, the accessibility of data is set on a clear principle that respects that data remain closest to the object of the data and these should not be removed to other places. It also recognized the sensitivity of health

data, in which clear precautions are taken to protect personal data. The Internet of Data and Services establishes a machine-readable internet of data. Based on the FAIR data principles, the data management put in place recognizes the role of the public sector and sovereignty of the government, especially the Ministry of Health, as the responsible public authority for data management of health data to protect patients and the public. The applicability both in science and in services would potentially be revolutionary for digital health. A FAIR Implementation Network for Africa could potentially contribute a strong element to the Internet of Data and Services. Especially the need to address contextuality of data for interpretation and its transformation into information as an area that would need to be addressed.

The Vice Chancellor concluded the meeting in stating that the University accepted the challenges or 'assignments' brought to its attention during the seminar and would proceed in spearheading solutions based on African values integrating the new potentials offered by data analytics for digital health as a new area of research in data science.