CITIZEN DATA FOR HEALTH AND WELLBEING

Citizens in control of their health data and connected to relevant and actionable insights towards health and wellbeing outcomes

INTRODUCTION

In recent years, the increasing abundance of personal data related to health and wellness presents new opportunities for discovery and insights, and has led to the growing use of personal health data by individuals towards informing their wellbeing goals and imperatives.

Beyond individuals, the use of personal health data in areas such as life-logging and self-tracking has potential impacts supporting targets and indicators within the sustainable development goal on "health and wellbeing" (SDG3). Formulating strategies for enhancing individuals' active **participation** within the sustainable development agenda entails understanding the dynamics and the issues around individuals' participation within the data ecosystem. Towards this end, this research is focused on understanding and linking individuals' use of personal health and wellbeing data towards the achievement of the SDG3.

THE BACKGROUND

As data becomes more ubiquitous, we see increasing attempts to understand the potential use of, as well as challenges and impacts of data for informing decision-making and action across levels and sectors. In the context of data for development, each variety of data (e.g. open data, big data, citizen-generated data, real-time data) has their own characteristics and the associated dynamics that influence how the data can be used and what value can be derived from the data.

The growing practice, by stakeholders in the private and public sectors, of solely using big data approaches to inform decision-making and policy-making, has a number of associated risks. Beyond the extractive nature of this approach, further risks include perpetuating marginalization of certain population groups due to the focus on capturing macro-level aggregate phenomena, as well as the risk of ignoring the complex, nuanced, and context-specific human issues in the situation.

Small data approaches, on the other hand, give people agency over decisions on what data is collected, what it is used for, and how it is used. Small data, focuses on the individual as the locus of data collection, analysis, and utilization. The use of small data can provide individuals with more actionable and relevant insights towards their aspirations and goals.

Interrogating the affordances of specific data varieties, the benefits and challenges of different data approaches, as well as the interaction dynamics between different data, helps to frame a suitable mix of data solutions towards specific outcomes.

THE OBJECTIVES

This research aims to contribute better understanding of individuals' attitudes and values on health monitoring, as well as their current practice, including the use of information and communication technology (ICT) tools, towards health monitoring, in the context of SDG3.

1 INVESTIGATE CITIZENS ATTITUDES AND PRACTICE

The research is framed around the Stage-Based Model of Personal Informatics to investigate individuals' data collection and monitoring practice around personal health informatics; individuals' motivations and incentives for data use; data utility, sharing, and social sense-making practice; and individuals' willingness to share personal health data with specific stakeholders within the health data ecosystem, as well as the factors informing their willingness to share.

| PREPARATION | COLLECTION | INTEGRATION | REFLECTION | ACTION |
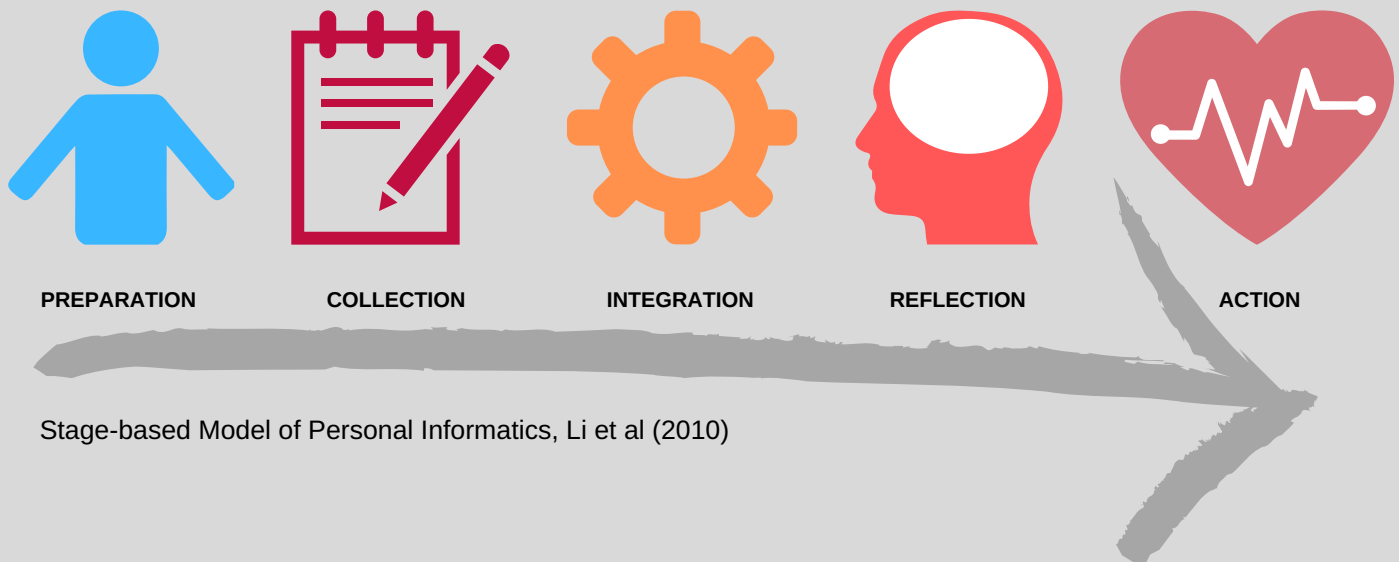
Stage-based Model of Personal Informatics, Li et al (2010)

DEVELOP SMALL DATA HEALTH TOOLS 2

The research further aims to develop small data Information and Communication Technology tools, informed by the findings from the research, to amplify the capability of individuals to engage meaningfully and actively with their health and wellbeing data.

THE METHODS

1   ONLINE SURVEY

An online survey has been conducted in this research for data collection. The survey, comprising close-ended and open-ended questions, was framed to identify the data, metrics, and information that individuals are currently utilizing for their health and wellbeing indicators monitoring; the motivations and reasons for collecting and monitoring health and wellbeing data; attitudes on data sharing; as well as the tools and techniques that they utilize for monitoring.

A mixed method approach, combining descriptive statistics for the quantitative data, and template analysis and open coding procedures for the qualitative data, was utilized for the analysis of the survey responses.

2   DESIGN SCIENCE AND SOFTWARE ENGINEERNING

Design science research combined with software engineering approaches have been employed towards the development of small data health tools. The design of the mobile application developed in this project has been informed by the findings from the survey.

THE FINDINGS

1 **PERSONAL HEALTH INFORMATICS PRACTICE**

Individuals undertake the monitoring of their health and wellbeing at a much more nuanced level. They make use of not only quantitative observational output data, but also qualitative perception data and data that is associated with small incremental and individual level changes. Beyond using the health and wellbeing data for the basic monitoring, integration and reflection associated activities, individuals also use data to inform behavior change and for reaching new goals and improving their health and wellbeing.

2 **HEALTH DATA SHARING**

The research found that individuals are most willing to share their personal health data with their health service providers, followed by sharing data with friends and family members. They were least willing to share data with external stakeholders within the wider health ecosystem. The research has also found that individuals engage in data sharing with others for social sense making purposes.

3 **OVERALL FINDINGS**

Findings from the research have provided important considerations which contribute to the general discussions around data ownership, data sharing, data provenance, and incentives and motivations for sustainable development data – and how these can be infused with more human-centric considerations.
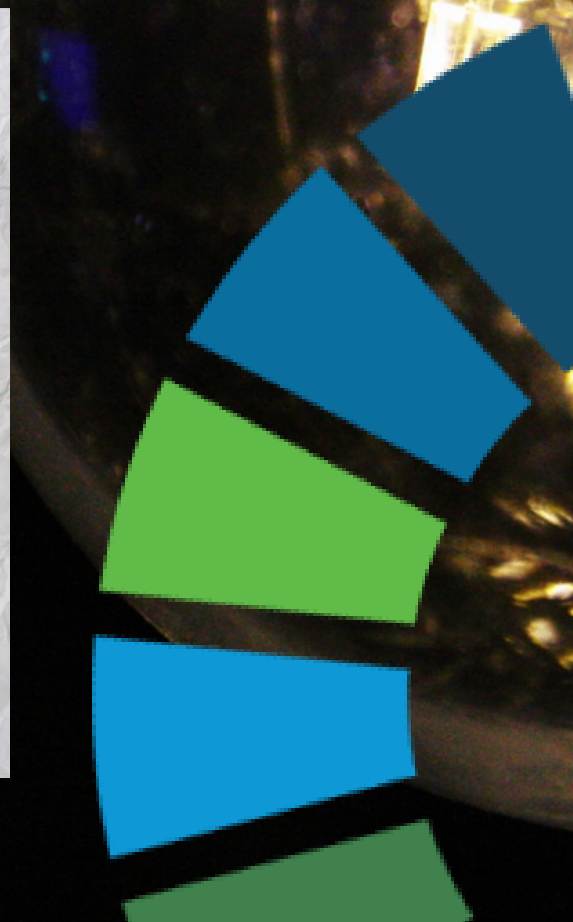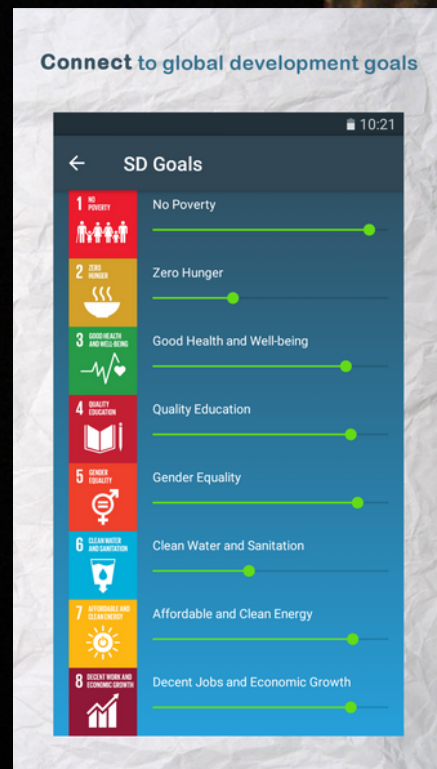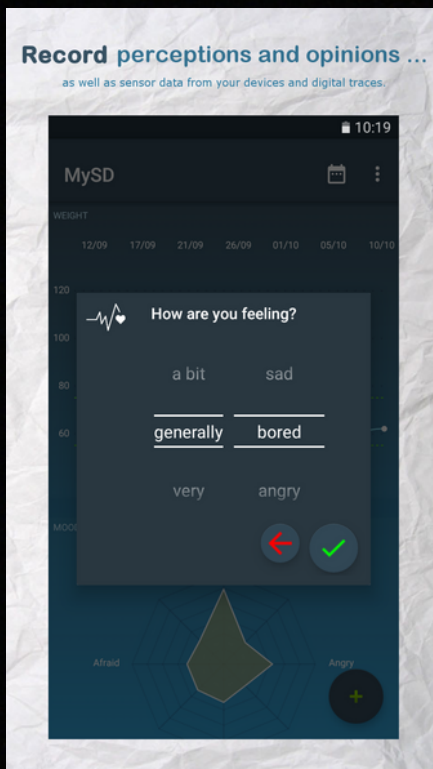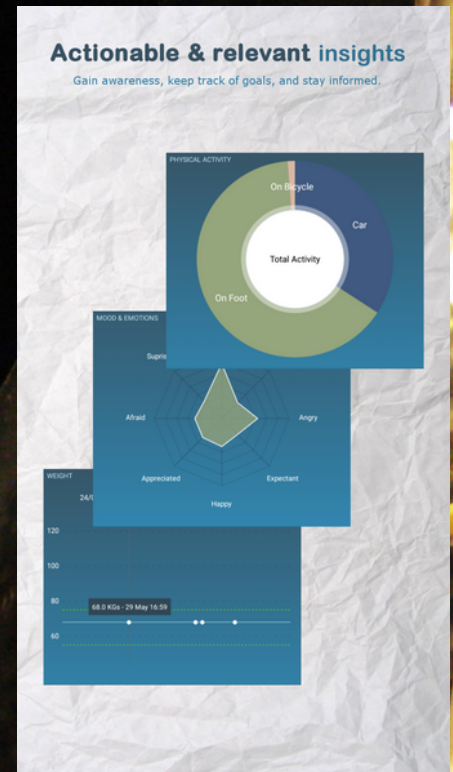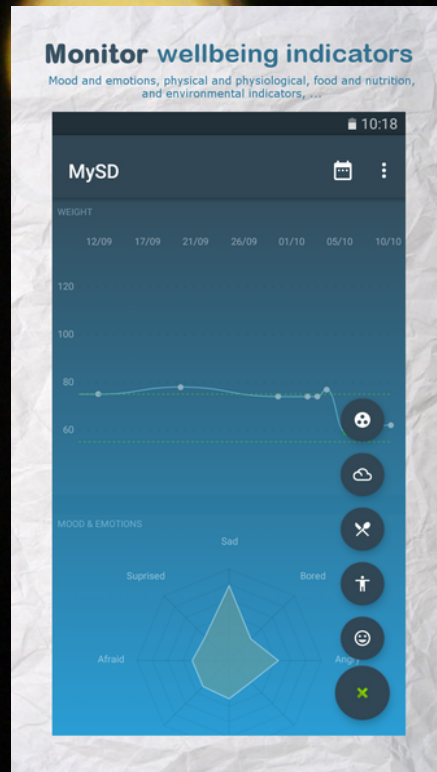
Further and detailed findings are discussed in the project outputs.

THE ICT ARTIFACT

My | Small Data | Sustainable Development

The findings from the survey have also informed the development of **MySD**, a mobile tool for indicators monitoring, consumption, and production to support the active engagement of individuals in the use of data towards the achievement of the SDG3.

Monitor wellbeing indicators
Mood and emotions, physical and physiological, food and nutrition, and environmental indicators, ...

Actionable & relevant insights
Gain awareness, keep track of goals, and stay informed.

Record perceptions and opinions ...
as well as sensor data from your devices and digital traces.

Connect to global development goals

THE FACTSHEET

TOPICS

SMALL DATA, HEALTH INFORMATICS, DATA JUSTICE

RELEVANT OUTPUTS

Thinyane, M. (2017). **Small data and sustainable development — Individuals at the center of data-driven societies**. In 2017 ITU Kaleidoscope: Challenges for a Data-Driven Society (ITU K) (pp. 1–8). IEEE.

Thinyane, M. (2017). **Investigating an Architectural Framework for Small Data Platforms.** In Data for societal challenges-17th European Conference on Digital Government (ECDG 2017) (pp. 220–227).

Thinyane, M. (2018). **Towards Informing Human-centric ICT Standardization for Data-driven Societies**. Journal of ICT Standardization, 6(3), 179-202.

Thinyane, M. (2018). **Engaging Citizens for Sustainable Development: A Data Perspective**. United Nations University Institute on Computing and Society

Christine D. I. & Thinyane M. (2019) **Small Data approaches provide nuance and context of health datasets**, The Conversation

Thinyane, M. (2019). **Operationalizing Data Justice in Health Informatics**. In 2019 ITU Kaleidoscope - ICT for Health: Networks, Standards and Innovation (ITU K). IEEE.

PEOPLE

Mamello Thinyane, Debora Christine

"Enhancing citizens' use of data and technology towards healthy lives"