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Designing human data interactions in Healthcare

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1. Introduction

The advancements in healthcare data enabled technologies, such as data sensing and mining techniques, data analysis, and visualisations have made possible that relevant healthcare data becomes accessible to all stakeholders in the healthcare ecosystem. Health researchers can benefit from this data to generate populational knowledge, to predict illness, to detect early symptoms, and ultimately prevent the development of chronic diseases [1,8]. Health practitioners can benefit by providing personalized care and support extramural and telecare [26,27]. Government can benefit by developing effective policies for prevention as well management of outburst or epidemics. Patients and general public can benefit by increasing their health literacy and owning more responsibility of their own health condition [12,16].

Solutions are being developed with special attention to technology advances in data algorithms such as deep learning and soft computing [13,18,22], innovative sensing techniques [10,20,30], decentralised and standardised data management platforms [2,24,25], among others. This is bringing crucial knowledge and understanding on how technologies can innovate healthcare practices. Data collection becomes more accessible, accurate and valuable by innovation in medical and commercial body sensors and therefore enlarging data collection to wider healthy and not healthy population. Data management becomes decentralized providing innovations to privacy and security. Data algorithms become more efficient and effective in using imperfect data sources and providing trustful description and predictions of health conditions. Cross platform data are emerging to provide standardization for sharing and using data from different healthcare systems and infrastructures.

An important aspect to these technological efforts is understanding that these innovations are ultimately used by humans in the different roles and contexts they are involved within the healthcare system . The success of these solutions are in practice determined by humans needs, preferences and ability to use them when and in the intended way they have been designed and developed for [5,11]. Understanding human's needs, concerns and values they associate to data and the interactions they engage with data should be a central concerned when designing these technologies [29]. In this way, key issues regarding acceptability of technology innovations, long term adoption of technologies in daily health management, appropriation of innovative health practices in which existing roles are redefined will be addressed [17,19].

2. Human data interactions in healthcare

Human data interactions (HDI) is a recent discipline that has emerged in the last 5 years to respond to the increasing available volume of (personal) data, the power of analytical tools and the complex practices to manipulate, exchange and manage such large datasets. These advancements have resulted in humans being constantly producting and revealing data in various ways. Crabtree and Mortier [9] emphasize the distinction between three types of data: data that is consciously created, data that is collected from behavioural monitoring and data that is inferred from related data (created by others). The authors identify three key principles underline HDI as a discipline involving computer science, design, sociology, psychology, behavioural economy and data analysis community:

- Legibility: make collection and processing of data transparent and comprehensible to ordinary people. The questions at stake are: what data is being discloed? What inferences are made? What's the implication of this new data on me?
- Agency: giving people the ability to control and interact with data related to them. The core questions are: how to opt in or out on data been collected? how to correct and update collected data?
- Negotiability: giving people the ability to change their preferences of data management. The questions to be addressed are: how to change preferred settings for specific or future scenarios?

Considering these principiles from a human centered perspectives, aims to balance the power that collectors and aggregators of personal data execute on private individuals. From a design perspective, the interactions or data practices that are needed to enforce the above principles need to be carefully designed to fulfil people abilities, needs and preferences of data management.

HDI finds applications in the design and development of complex healthcare systems that aim to support the complex social arrangements and interactions that occur in the healthcare domain. This complexity is characterized by unstructured and spontaneous processes instead of rule-based workflows, where multiple actors and physical locations are involved [14,23]. A socio-technical perspective in the design of healthcare systems, addresses this complexity by integrating both technical functionality and social interactions between people in their various roles and activities. This integration should be informed by the values and interests of the actors in the medical system in order to support the distribution of competences and functions between humans and technologies [6,15]. For example, the role of technology in automating processes should be investigated with regards to the need for control, overview and decision-making by humans.

Acknowledging the variety of logics and needs from different actors as well as the changing nature of people's interests and values and their roles, there is a need for designing a flexible and dynamic system to provide a resilient care systems[3,14].

3. Future Prospective

Technology advances on data capturing (e.g. sensing networks), data processing (e.g. machine learning) and data interactions (e.g. digital and physical displays) offer a variety of possibilities for integrating health-care and non-healthcare data of patients in the care process. Whether new forms of care could be supported by data with the goal to increase quality of care, there are several considerations to take such as privacy and trust from patients [3], and non-adoption or resistance to use from care professionals [4,21,31].

From the field of Human-Data Interaction [9] the focus is on delivering personalized, context-aware, and meaningful data from large datasets while enabling user control over the use of 'my data'. From the field of Human-Computer Interaction [7] it is suggested to work with an iterative design process that a) enables user adoption and system adaptation and b) identifies the driving forces and responsible roles to introduce and advocate a sociotechnical healthcare system, in which data issues are addressed from a social perspective [28].

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