

Standardizing Social Justice in Digital Health: An HDI-Informed Health Informatics Architecture

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ABSTRACT

The bivalent nature of technology and its potential for adverse impacts are giving impetus to global efforts to ensure that the outcomes of technology are consistent with societal values and desired futures. Instruments such as legislation, standards, and ethical frameworks are being employed towards this end. This research investigates the domain of digital health, specifically health informatics, and asks the questions: What values should inform technical solutions in this domain? How can data justice, the infusing of social justice imperatives in data systems, be standardized in this domain? The paper presents findings from a review of data justice in health informatics supported by findings from a survey that explored key considerations for health data collection, processing, use, sharing, and exchange. The paper then presents the operationalization of the human data interaction framework through a health informatics system architecture to illustrate how the principles of legibility, agency, and negotiability can be standardized, mainstreamed, and embedded in health informatics.

KEYWORDS

Data Justice, Digital Health, Human-Data Interaction, Standardization

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INTRODUCTION

As Postman aptly noted, “Technology giveth and technology taketh away, and not always in equal measure. A new technology sometimes creates more than it destroys. Sometimes, it destroys more than it creates” (Postman, 2013). The benefits of technology in society have been innumerable: enhancement of trade and economy, improvements to governance, transportation, health, education, leisure and entertainment, and livelihoods. The ensuing fourth industrial revolution (4IR) and the associated frontier technologies are also set to transform society in many fundamental ways including through the societal evolution towards the infosphere (Floridi, 2014), human augmentation through biotechnology, and the pervasiveness of robotics, autonomous computing and artificial intelligence (AI).

The potential of technology to contribute to advancing sustainable development imperatives is broadly recognized hence the explicit inclusion of technology as a means of implementation for the UN Sustainable Development Goals. Notwithstanding these benefits, the challenges and risks presented by technological developments are also increasingly being recognized and understood including growing inequalities, new forms of marginalization and exclusion, algorithmic bias and injustice, digital waste, the decimation of norms, and what has broadly been termed the “dark side” of technology.

This bi-valent nature of technology and its potential to have adverse impacts in society is giving impetus to global efforts to ensure that the outcomes of technology are consistent with the societal values and desired futures. At various levels (e.g., organizational, national, global) and across many societal domains, including digital health, which is the focus of this research, there are efforts to standardize, mainstream, and embed societal goals in technology solutions. Some of the instruments that are being used towards this include legislation, standards, and ethical frameworks.

Legislation provides a legal and mandatory regulatory framework towards specific societal outcomes. While the legislative process has often been blamed for being too slow in addressing the challenges introduced by technological developments, it provides an effective mechanism for legal enforcement. Some of the relevant legislation for digital health is around the protection of individuals’ privacy in data systems, for example, the General Data Protection Regulation (GDPR), the Health Insurance Portability and Accountability Act (HIPAA), and the Protection of Personal Information Act (POPIA).

Beyond legislation, standards provide a consensus creation mechanism that provides voluntary “rules, guidelines and characteristics for activities or their results, aimed at achieving the optimum degree of order in a given context” (ISO, 2019). Although they have traditionally been technical documents and operated within the technical domain, standards have implications beyond technology and are being used to address broad societal issues such as responsible innovation, sustainability, justice, and ethics (Busch, 2011; De Vries et al., 2018; Jakobs, 2019; Wickson & Forsberg, 2015). Examples of relevant standards for the digital health domain include the ISO/

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