



THE PRINCIPLES OF DATA EXCHANGE FOR EQUITABLE HEALTH AND SOCIAL CARE

VERSION III- AUGUST 2020

Preamble:

The goal of the Gravity Project is to foster health equity across cultural, institutional, and social contexts. Toward this end, the Gravity Project works to enable health, human, and social service providers, patients and clients, researchers, funders and policymakers to communicate with each other with trust and reliability about social contexts and personal needs, associated goals, interventions and outcomes. The Gravity Project thus offers and encourages the use of common vocabularies and standard protocols for sharing and usage of personal information, and information about related health and social care activities, as documented by cross-disciplinary actors across diverse technological and institutional boundaries.

Our work is grounded in the knowledge that health equity is contingent upon many structural forces and social risks that impact people's health and well-being in myriad ways. We know that there are tradeoffs and risks inherent in this work, and that our best intentions cannot ensure that the outcomes of this Project will be benign.

Therefore, the Gravity Project has articulated these Principles of Data Exchange for Equitable Health and Social Care. We intend these principles to establish an ethical framework to guide our work – and any initiative that might apply the products of our work — through the entire lifecycle of scoping, design, implementation and governance of electronic documentation systems that facilitate personal information creation and exchange. Each principle is interdependent of the others; they should be applied in tandem, as a continual system of analysis and evaluation that can promote trust and accountability among care providers, patients, their communities, and the institutions that serve them.

1. Improving personal health outcomes: Exchange of digitalized personal information should improve the effectiveness of care for people and the quality of the outcomes thereof. Enhancing the ability of providers to exchange personal information and coordinate care, is assumed to improve patients' capacities to heal and thrive.

2. Improving population health equity: Exchange, aggregation, and analysis of personal information should help to identify and eliminate inequities in health outcomes among communities. Such records, appropriately de-identified, can form the basis of population health research and community engagement. These processes should be facilitated by the use of common vocabularies that can be used by all involved in care and support of patients. By enhancing capacities for communities and the public at large to access, understand, and make decisions with aggregated information about communities' health and social circumstances, we can facilitate the removal of obstacles to health that disproportionately affect the quality of life among various groups.

3. Ensuring personal control: Exchange and use of personal information should account for the diverse needs of all stakeholders, without erecting barriers or diminishing function or quality for those with differing abilities, languages, or cultural contexts. Patients should have ready and complete electronic access to data about themselves wherever these are created and maintained, as well as to tools and educational resources, in their primary or preferred languages, to make meaningful use of that information. Each individual has the right to consent to, and challenge the collection, content, retention, use or disclosure of information relating to them, including the right to have the particular information corrected or omitted.

4. Designing appropriate solutions: Appropriate solutions are designed with care for the context of their use, recognizing that solutions which might be appropriate in one context might be inappropriate in other contexts. Appropriate solutions are designed at the simplest level that can effectively achieve the intended outcome, without creating new barriers to access or collaboration. Appropriate solutions are transparent to stakeholders, subject to their evaluation, and adaptable as necessary by those who use them and/or are affected by them.

5. Ensuring accountability: Entities that collect, access, or use health data, and the institutions that oversee them, must be accountable for these activities and their impacts — both to concerned individuals and their respective communities. Accountability entails transparency as to what personal information exists, for what purpose or purposes it may be used, who can access and use it, how decisions are made with it, and who retains it. Furthermore, accountability entails capacity to address and redress violations, errors, unexpected consequences and unmet expectations.

6. Preventing, reducing, and remediating harm: Exchange of personal information should be protected against misuses and abuses – from malicious action to human error – as well as unanticipated harms that might otherwise arise from such exchange. This includes not only mitigating risks but identifying and rectifying harms that may occur.