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Towards the FAIRRREST Principles in Health Data Sharing

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As digital health technologies proliferate, the potential to harness real-world data (RWD) for improving healthcare outcomes grows dramatically. However, the realization of a truly responsive Learning Health System remains hindered by the complexities surrounding health data sharing. These complexities span technical, legal, regulatory, financial, organizational, and ethical domains and are influenced by factors including consent, purpose of use, data type, and stakeholder incentives.

Bringing order to the complexity of health data sharing has been on the research and organisational agenda for some time, however a mature vocabulary and shared vision for health data sharing governance among stakeholders is yet to emerge. It is worth recognising that the ubiquitous term ‘data sharing’in health refers to 4 distinguishable levels:

1. Patient Care –Primary use of data for direct clinical treatment, reliant on system interoperability.

2. Quality Improvement and Contextual Evidence Generation (SeConts) –Secondary use for audits, surveillance, patient safety, and non-interventional research.

3 (a) Original Research –Data use for generating new knowledge, with increasing overlap with quality improvement initiatives.

3 (b) Completed Research –Sharing datasets from published studies to support reproducibility and broader scientific use.

The ubiquitous use of the term ‘data sharing’amongst these activities, leads to further complexity in efforts to define health data sharing governance frameworks. The most recognisable are likely the FAIR principles (Findable, Accessible, Interoperable, Reusable) which were developed to improve data utility and reproducibility, focussing on re-use and sharing of scientific and scholarly data. While broadly adopted, their application in health contexts often overlooks key socio-ethical considerations. FAIR was never intended to operate in isolation, and it notably does not address moral or ethical questions around openness and data misuse.

To address this gap, several complementary frameworks are emerging. The TRUST principles (Transparency, Responsibility, User focus, Sustainability, Technology) emphasize societal accountability. The CARE principles (Collective Benefit, Authority to Control, Responsibility, Ethics), developed by the Global Indigenous Data Alliance, foreground Indigenous data sovereignty and ethics. Similarly, FAIR-Health and other adaptations suggest additional factors like data quality, privacy-respecting practices, and incentives for data stewardship.

Despite this proliferation of frameworks, key recurring themes emerge across governance documents, especially within North American and European contexts. These include the societal value of data, equitable distribution of risks and benefits, respect for data contributors, and the imperative to build public trust through engagement and reciprocity.

Drawing from these insights, this article proposes the FAIRRREST principles—a unified governance framework that builds upon the foundational FAIR principles while incorporating vital ethical, societal, and sustainability dimensions:

- Findability: Ensuring that data and metadata are easily discoverable by both humans and machines.
- Accessibility: Establishing clear, transparent procedures for data access.
- Interoperability: Facilitating seamless integration and analysis across diverse platforms and systems.
- Reusability: Enabling meaningful reuse through standardized metadata, documentation and practices across different settings.
- Responsibility: Emphasizing accountability and shared obligations among all stakeholders, from data donors to users, when giving, receiving, or using data.
- Reciprocity: Ensuring data sharing meets community expectations, enables community collective benefit

and social justice and also allows beneficial social institutions to grow, collaborate and receive recognition.
- Ethicality: Upholding the objective application of ethical values including respect, merit and integrity, justice, beneficence and balance of risk and benefit in all activities involving data re-use.
- Sustainability: Supporting long-term preservation and access to data and related services.
- Transparency: Promoting decision making with respect to who gets access to data and who does not, and for what purposes and what counts as appropriate involvement in the data-sharing and data-access policy process

The FAIRRREST principles address the need for nuanced and inclusive governance mechanisms that can navigate the complexity of health data sharing. They are particularly suited for guiding data reuse across the full spectrum of health-related activities—from clinical care and service improvement to academic and public health research.

By fostering shared understanding and trust across all data-sharing stakeholders, FAIRRREST offers a platform for aligning the diverse objectives of patients, providers, researchers, data custodians, and communities. It also lays the foundation for further stakeholder-driven consensus building to refine and implement ethical, practical, and sustainable data sharing policies. In doing so, it supports the realization of digital health's full potential to deliver equitable and impactful care.

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