Individual Data, Individual Control, Collective Wellbeing

Individuals’ health data issued as a credential to certify wellness.

Personal blockchain wallet holds all health credentials.

Private key keeps data safe.

Individuals securely consent to sharing health credentials using their private key.

Receive rewards for sharing & wellness.

Researchers use Credentials to personalize healthcare.
Big Data DNA Data Storage - Bioethics, Personalized Medicine and Genomics

- Genetic data need to be shared across institutions and researchers to improve health research and care

- Genetic data are uniquely identifying

- Proliferation of privacy norms: laws, ethical policies, standards resulting in a complex, indigestible, patchwork

- Trends: Internationalisation of research, genetic data in the cloud, direct-to-consumer genetic testing
Big Data DNA Data Storage - Bioethics, Personalized Medicine and Genomics

- The Global Alliance for Genomics and Health (GA4GH)
  - An international, nonprofit alliance formed in 2013 to accelerate the potential of research and medicine to advance human health.
  - 500+ leading organizations working in healthcare, research, patient advocacy, life science, and information technology,
  - Data Privacy and Security Policy (2019 Ver. 2.0)
  - Framework for Responsible Sharing of Genomic and Health-Related Data (2014)
  - Monthly GDPR Briefs
Big Data DNA Data Storage - Bioethics, Personalized Medicine and Genomics

- Genetic Discrimination: insurance, employment, identification/profiling

- Incidence?

- Genetic Non-Discrimination Act (S.C. 2017, c. 3)

Governance
Genetic Discrimination Observatory (GDO)

17 jurisdictions represented

BENEFITS OF PETS
Click here to learn more about the historic launch of the Marathon of Hope Cancer Centres network.

MARATHON OF HOPE
CANCER CENTRES
The Roadmap to Cure Cancer™