Medical Information TF

Despite continued technical advances in the health and life sciences industry, current global standards for personal health data, medical imaging and other information are not aligned with IEEE standards for ethical design and value-based design for intelligent systems. Current standards governing patient data and medical image files do not stipulate full patient rights for full control of use, sharing, and access of their personal medical imaging data and associated information. Further, current global standards do not stipulate protection of core values of the medical profession, including protection of the professional fiduciary relationship between physicians and patients, and the ability of the patient and/or caregivers to manage their patient identity and corresponding health information in a decentralized fashion.

The MITF envisions the creation of ecosystems and governance frameworks that allow for precise communication among global experts of different domains that includes patient identity, clinical imaging, artificial intelligence, and ethics for augmented intelligence systems that maintain a central role for the medical professional subject matter experts in managing and using health data and image-based information. 3D digital topological mapping of this information and data to human macroanatomy and microanatomy including coordination with existing disease coding across global datasets will optimize its use for maximal societal benefit. The MITF will work to assure systems integrate human-in-the-loop principles to assure accuracy, reliability, and clinical utility of generated information for safe optimal use in clinical decision-making. The MITF will also draw upon its relationships within ToIP Foundation members, and in partnership with standards organizations such as HL7, IHE, and ISO TC215, to establish a framework for decentralized digital identity and credentialing to support patient-centric health data exchange and consent management.

The MITF sees this as part of a larger effort to fully realize portable medical records and patient identity that is under patient control, a concept that has been just beyond reach for many years.

Mission and Scope

In conjunction with various standards efforts already underway, the MITF will design and enable the creation of the data infrastructure necessary to fulfill the vision described above. The MITF will lead the way in the creation of ToIP ecosystems for medical information, combining clinical data and imaging into a unified package centered on individual patients, organized anatomically, and controlled directly by the patient.

The scope of the MITF is the creation and maintenance of schema bases and overlays necessary to combine clinical data with imaging data for individual patients. The mission includes proof-of-concept activities such as creation of Open Source tools to stand up and operate the data aggregation necessary to make information available that originates with multiple, often competing providers.

Intellectual Property Rights (Copyright, Patent, Source Code)

This TF uses the same IPR licensing selections as the ToIP Decentralized Semantics WG:

- Copyright mode: Creative Commons Attribution 4.0.
- Source code: Apache 2.0.

Conveners

- Scott Whitmire (Mayo Clinic)
- Moira Schieke (Cubismi)

Interested Members (add your name and organization if you may be interested in joining this TF)

- Paul Knowles
- Robert Mitwicki
- Safwan Halabi
- John Walker
- Mukundan Parthasarathy
- Marie Wallace
- Jim St.Clair
- Victoria Lemieux
- Jamie Stirling
- Scott Warner
- Burak Serdar
- Chris Raczkowski
- Ken Adler

Objectives

The objectives of the MITF are to:

- Design and develop schema bases and overlays to enable most common clinical data to be captured, searched, retrieved, stored, and shared
- Building on the work of the Imaging TF, create extension overlays for the commonly used types of medical imaging (e.g. MRI, PET, CT-Scan, CAT-Scan)
- Create or enable the creation of prototype data vaults that support the capture, search, retrieval, and sharing of medical data organized by patient and their anatomy
- Participate in consortia to develop entire ecosystems based on the concept of patient-controlled, shareable clinical and imaging data for use by the wider healthcare community, including research and public health
Support the concept of a trusted, decentralized digital identity that can be associated with patient data and incorporate national patient identifiers and patient matching mechanisms.

Technical components

The MITF architecture will build upon the core components of Decentralized Semantics.

Other candidate technologies include:

- Blockchains and Smart Contracts – with strong auditing properties
- Ontologies and knowledge representation languages which enable conversion of medical terminology and processes into machine-readable formats
- Flexible and expressive data modelling provided by Overlays Capture Architecture (OCA)
- Advances in digital identity and verification – such as Decentralized Identifiers (DIDs) and Verifiable Credentials (VCs)

Example use case

Deliverables

Proposed schedule

Shared documents and links