

Medical Information Ecosystem Use Case

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Use case concepts: Medical Information (MI): Deliver medical information, including clinical data and imaging, organized around a 3D anatomical model of an individual patient, providing the patient or their representatives control over access and use of that information. This requires the creation of one or more consortia that organize healthcare systems, insurance companies, healthcare providers, government agencies, and patients into an ecosystem in which they fill the various roles in the ToIP architecture.

Personas:

- Amy (convener) - Assigned by the IEEE to lead a standards working group
- Joe (issuer verifier) - Represents a healthcare provider
- Jean (issuer verifier) - Represents a health insurance company
- Sam (user) - Represents an independent research lab
- Ralph (user) - Represents a public health agency
- Andrew (user) - Represents a patient advocacy group

User stories:

- Amy has been asked to lead the creation of an IEEE standard for open, secure, patient controlled medical information, and feels that the resulting community will be a lot like a ToIP ecosystem
- Joe wants to ensure that the healthcare system he represents will not have to convert to yet another new electronic medical records system (EMR) because the last conversion was so painful. His primary focus is on collecting clinical data for immediate patient care
- Jean wants to ensure continued access to patient medical information for the purpose of administering health plans and to a lesser extent, researching ways to reduce the cost of care
- Sam wants to ensure easier access to large pools of de-identified data for research activities., including examination and analysis of medical imaging

- Ralph wants to ensure access to anonymized, aggregated data for use in predicting and managing public health crises, and to help improve the overall health of the population
- Andrew represents patients and want to ensure that each patient is in complete control of their medical data, and that the notion of “ownership” of this data shifts from healthcare providers and insurance companies to patients (this has been a long running effort).

Learn:

- Amy learns about the ToIP architecture and recognizes that the pattern for an ecosystem matches her vision for the resulting standard
- Amy recruits the other team members, who also start to learn about ToIP and other standards and organizations in this space
- The full team makes the decision to convene

Convene:

- The team meets and decides that the standards effort will not be a ToIP Ecosystem Project but will be an externally sponsored effort (by the IEEE) to create the governance framework and ToIP Interoperability Profile for a ToIP Ecosystem.

Define:

- The team creates a draft IEEE standard that consists of a governance framework and TIP for a ToIP Ecosystem and submits it to the IEEE balloting process
- After several rounds of revisions, the balloting group approves the standard which is then adopted by the IEEE-SA Board of Directors

Create:

- Each team member convinces their organization to found a consortium to cooperatively run an instance of the ecosystem.
- They also recruit other organizations
- A competitor for Jean’s company recruits other healthcare systems to for a competing consortium, but since they use the same GF and TIP, they are able to interoperate easily

Implement:

- With the help of several software companies, the consortium creates the technology to fill gaps in the TIP, including the patient's wallet through which they access and share their medical records
- These new tools, and many existing tools, are submitted to the Trusted Utility

Grow:

- Participating healthcare systems and insurance companies find their patients love the new concepts and tools and find that being a member of the consortium becomes a competitive advantage
- The competing consortium also thrives
- Both discover the ease by which patients can switch between members of the two consortia and begin cooperatively advertising this capability