

Patient Identity Task Force

Industry sector: [Health Care](#)

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Objectives

1. Advance the development of a patient identity ecosystem governance framework (EGF) and support technical stack development to promote decentralized identity leveraging a national patient identifier.
2. Coordinate and collaborate with supporting TOIP task forces and standards development organizations to integrate prospective Patient ID TIPs into health data standards.
3. Represent TOIP in advancing the concept of decentralized patient identity to health SDOs and health associations as part of advocacy and standards adoption for healthcare.

Background/Context

Recognizing the concept of Decentralized Identity (DID) has significant ramifications for many industries, in healthcare decentralized identity has enormous potential for disruption, and arguably sits in the middle of any envisioned "patient-centric" healthcare construct. Patient identity, even without decentralization, is gaining new attention with the advancement of digital health. Challenges to patient identity management fall into two significant issue areas:

Patient Identification: Establishing reliable, let alone immutable or self-sovereign, patient identities has been largely hindered by the lack of effective patient identification. Patient identification encompasses not only physical identification of the patient, but technologies capable of improving the accuracy of patient identification as well. Today, lack of widespread operational principles as well as limitations in processes and technologies result in inaccurate patient identification, putting patients and providers at risk.

Patient Privacy: While the Health Information Portability and Accountability Act (HIPAA) of 1996 specifically addressed "privacy" as an administrative safeguard, HIPAA reflects a construct that does not account for big data, analytics and individual safeguards such as consent and granular, attribute based access controls (ABAC). Patient identities can be stolen through direct data breaches, reverse analyzing de-identified data, or simple health data marketing practices.

The SARS-Cov2 pandemic has cast a new light on patient identity, especially with the enormous logistical tasks of testing, reporting, and possible vaccine distribution once developed. Coupled with new calls for [digital identity](#) for citizens post-COVID, decentralized patient identity demands immediate consideration for standardization and adoption.

Organizing Committee

1. [Jim St.Clair](#)

Interested Participants

1. [Philippe Page](#)
2. [Ken Adler](#)
3. [Paul Knowles](#)
4. [Scott Whitmire](#)
5. [Chris Raczkowski](#)

Deliverables

Key deliverables will include, but are not limited to:

1. TBD

Intellectual Property Rights (Copyright, Patent, Source Code)

As a Task Force (TF) of the Ecosystem Foundry WG (EFWG), the Patient ID TF inherits the IPR terms from the [EFWG JDF Charter](#). These include:

- Copyright mode: [Creative Commons Attribution 4.0](#). For the Patient ID TF, this is probably the only relevant licensing provision.
- Patent mode: **W3C Mode** (based on the [W3C Patent Policy](#)). The Patient ID TF is not expected to produce any deliverables subject to patent rights.
- Source code: **Apache 2.0**, available at <http://www.apache.org/licenses/LICENSE-2.0.html>. Then Patient ID TF is not expected to produce source code.

Milestones

Key milestones will include, but are not limited to:

1. Publish a draft of the Patient ID Ecosystem Use Case to support the EFWG deliverables.
2. Contribute to creation of draft ToIP Integration Profile (TIP)
3. Support liaison and integration of Pt ID GF and TIP into other SDO development efforts (ISO, ANSI, IEEE, HL7)

The work of the Patient ID TF will be complete when the participants are ready to instantiate an IoE governance authority to implement the IoE EGF.

Meeting Schedule

Meetings occur every other Thursday as of September 17th at 11:00am ET (18:00 UTC)

Communication

Slack Channel ([#trustoverip.slack.com](https://trustoverip.slack.com)) #efwg-patient-id-tf

References and Links

https://www.windley.com/archives/2016/11/sovryn_use_cases_healthcare.shtml

<https://hieofone.com/>

<https://truu.id/>