

Healthcare Identity Decentralized Lab

Distributed-ledger based unique identifiers
for rare disease patient registries

Project Mission Statement

HIDE Lab's mission is to develop a decentralized rare disease identity system (RDIS) to provide participants of rare disease communities—and beyond—with uniform representations and management of their identities used in clinical communications. This infrastructure will increase the security and interoperability of patient data significantly reducing the financial and social costs of identity mismatching related medical errors. The project will consist of three parts: a standardized patient identity model, the RDIS infrastructure for sharing and managing of data, and an integrated evaluation to assess the solution's efficacy.

The Cost of Healthcare Identity Mismatching

1

Varying formats

Each patient registry has its own formats and standards for collecting patient information

2

Unresponsive to change

Patient information collected is subject to change, yet those changes may not be recorded in every patient registry or their healthcare provider (HCP) with the patient's information

3

Many IDs representing one patient

Patient IDs are created by each disparate effort (eg. rare disease patient support group or HCP) and although they may represent the same patient, the IDs are not reconciled

4

Spelling errors

Manual data entry is prone to typographical errors

195,000 deaths per year are due to medical errors 59% of which are caused by "wrong patient errors"

Financial costs:

- costs of storing duplicate patient records
- denial of reimbursement claims due to "out of date or incorrect information"

Repeated tests or treatment delays

from the difficulty of sharing test results across different HCPs

Incomplete or incorrect medical data

A Three Part Research Project

1



Standardized Digital Identity Model

A decentralized digital identity model for participants in rare disease communities which will uniquely represent patients without directly exposing their sensitive information.

2



Rare Disease Identity System Infrastructure

Enabling stakeholders to manage and verify patient identities created as well as record transactions (i.e., queries and accesses) of patient identity for clinical communications.

3



Integrated Evaluation Using Cloud Services

Simulation of the system using synthetic patient profiles created using cloud services (such as AWS) to evaluate the system's ease of identity collection & verification as well as the system's overall scalability.

Our Solution: Standardized Digital Identity Model

To maximize the security and privacy of patients with rare diseases' data, we propose to develop a decentralized digital identity which separates the patient's identifier from their sensitive personal data.

Key research questions:

1. How does the proposed model warrant both the **privacy** of the identity holder and **access** to linked data? What if identities are lost or stolen?
2. How are the new identity profiles **distributed** and **managed** by patients?



1



Unique Decentralized ID (UDID)

General identity profile including public identifier document adhering to W3C DID v1.0 open standards. This document will be recorded on a UDID registry.



Public identifier document*



Private key phrase



A user must prove linkage of their private key to their UDID to access, query, or update their personal data

2



Mobile client to securely manage UDIDs

Develop an interface which will securely maintain the private key of patients and issue UDIDs adhering to W3C DID v1.0 open standards. Could also be outsourced to a trusted third party.

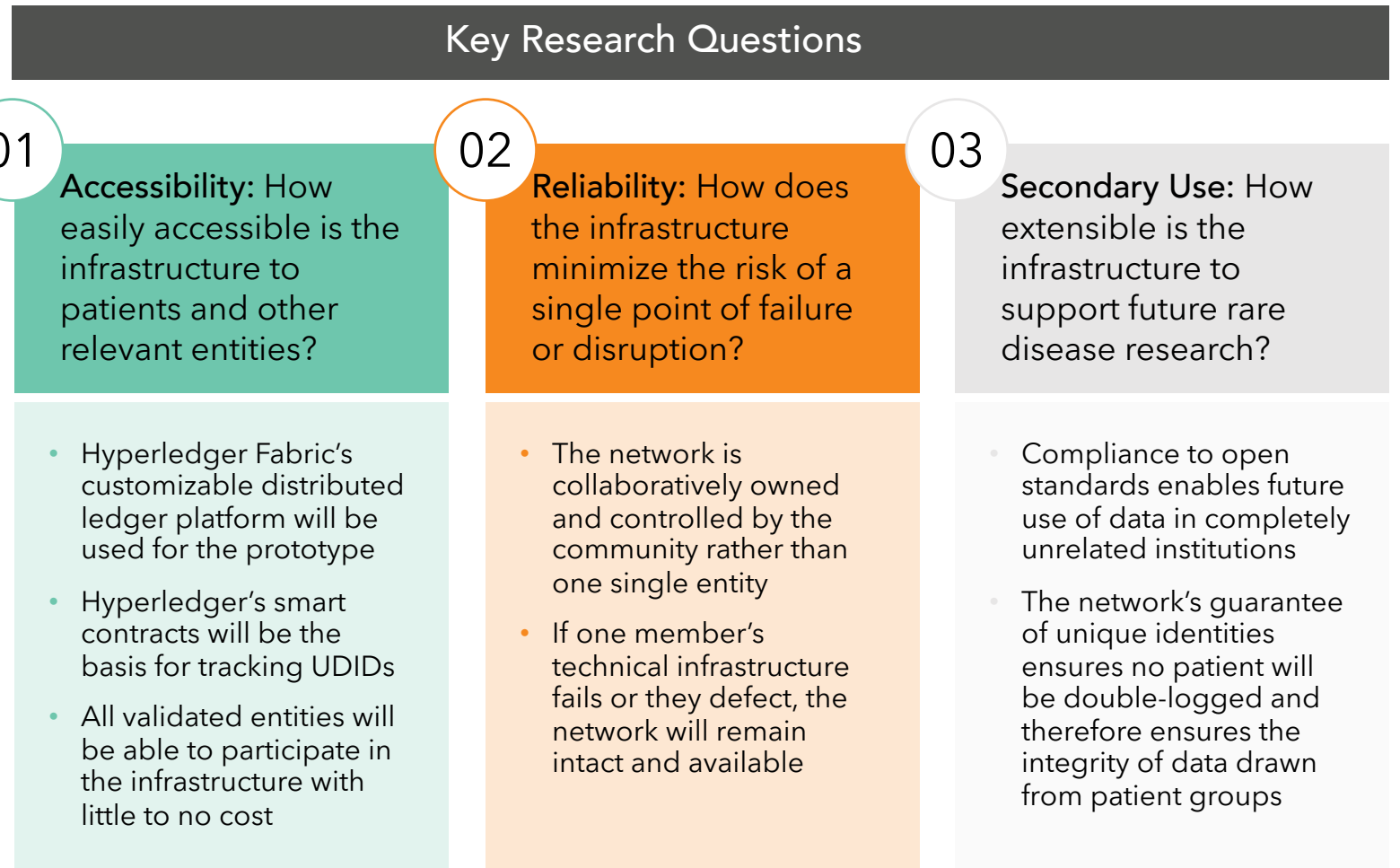
* The public identifier document will not contain any sensitive patient data, only when linked to its private key can a user access the data.

Our Solution: RDIS Overview

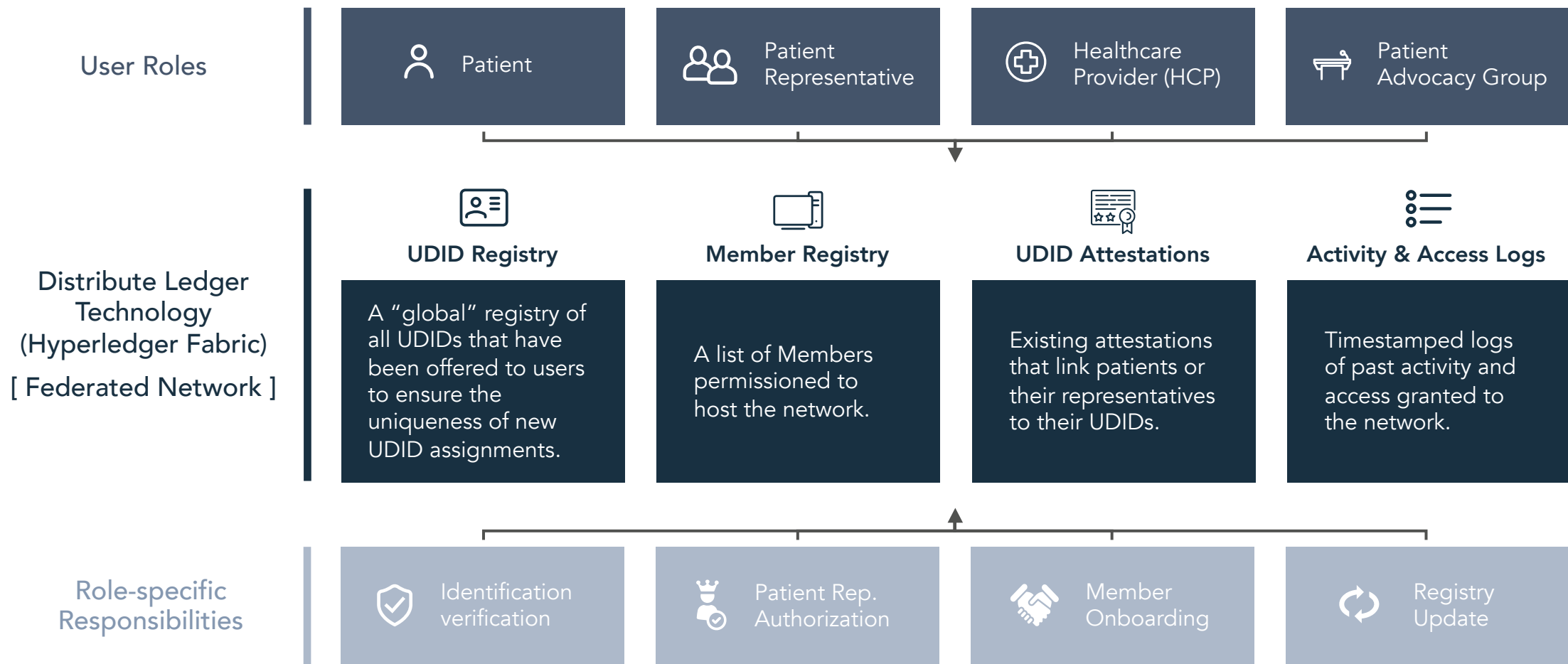
Rare disease communities lack access to—and control of—a low-cost and reliable technical infrastructure for aggregating patient data from multiple different sources.

This problem necessitates the development of an identity infrastructure which maximizes utility and long-term support for rare disease communities.

The infrastructure developed will focus on the following questions.



Our Solution: RDIS Components



RDIS: User Identification and Verification

