Concept

Motivation

Much is made in this era of translational research of the need to cross boundaries between biomedical research organizations that individually have insufficient patient-subjects. Concurrently, the noisiness and high dimensionality of genome scale measurements has made it all the more pressing to increase sample size to overcome problems of false discovery, and irreproducibility that stem in part from insufficiently powered studies. Building on the success of SPIN, the Pathology Specimen Locator (PSL) is a core developed to facilitate translational research requiring human specimens. The PSL is a distributed network of databases containing de-identified information on archived specimens from IRB-approved repositories within Dana-Farber/Harvard Cancer Center affiliated institutions.

Approach

Using a peer-to-peer architecture, institutions become PSL members (nodes) by securing institutional review board (IRB) approvals and deploying the PSL software. At any time, an institution can withdraw from the network without leaving their data behind or disabling the network. PSL nodes can serve as *peers* or *supernodes* to query local databases or networks of child nodes, respectively.

PSL allows institutions to expose de-identified pathology reports while keeping corresponding reports containing Protected Health Information (PHI) disconnected from the Internet. A randomly generated unique identifier is assigned to both the PHI and de-identified reports in a locally controlled *codebook*. The machine storing the codebook is disconnected from the Internet and protected according to each participating site's policies. The resulting solution is flexible and compliant with HIPAA regulations.

PSL provides 3 levels of increasing access commensurate with investigator credentials and IRB approvals.

- 1. First, feasibility studies are conducted using a statistical level query that returns only aggregated results.
- 2. Second, individual de-identified cases are selected by investigators certified by one of the participating institutions.
- 3. Third level allows requests for specimens and clinical data that must be approved by the institution storing the requested data.

Request Human Tissue for Cancer Studies

- Search the archives of the Harvard teaching hospitals to ascertain if there are enough specimens available for your study
- Submit a request for specimens (Recommended Path) with Pathologist Consultation