



Indivo X

The Open-Source Personally Controlled Health
Record (PCHR) Program

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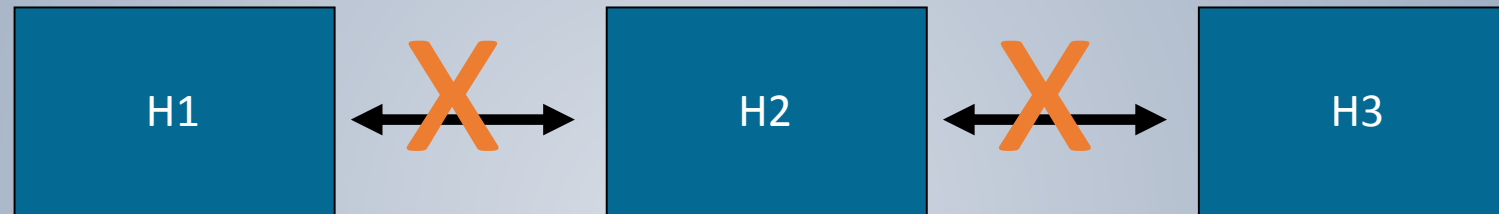


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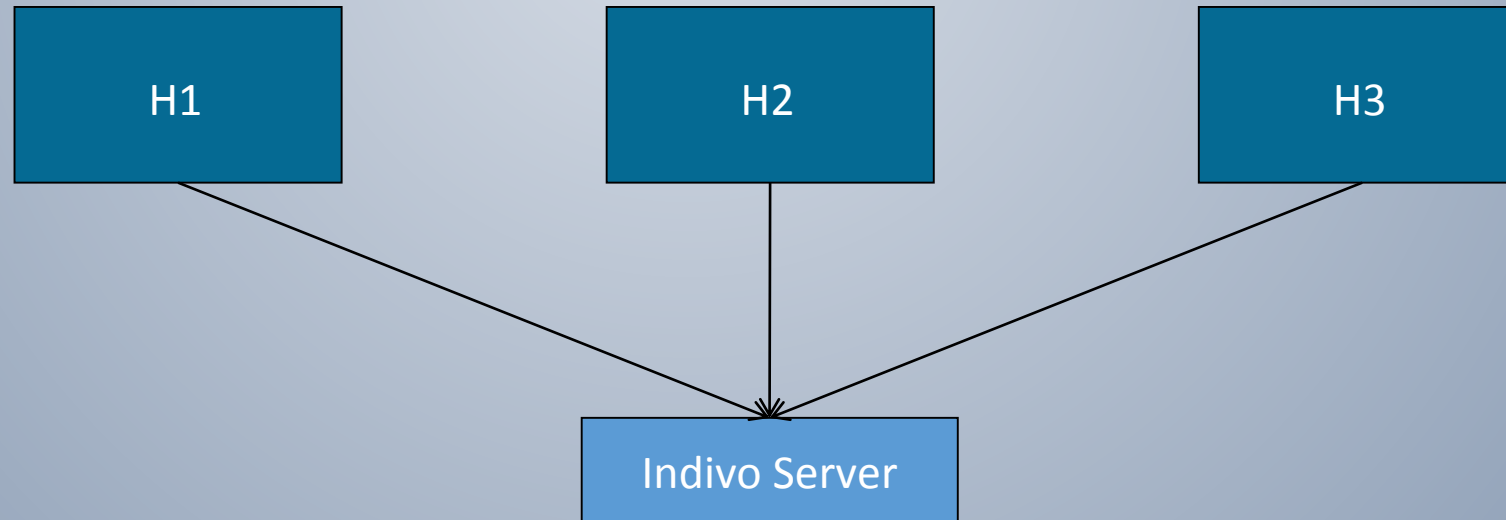
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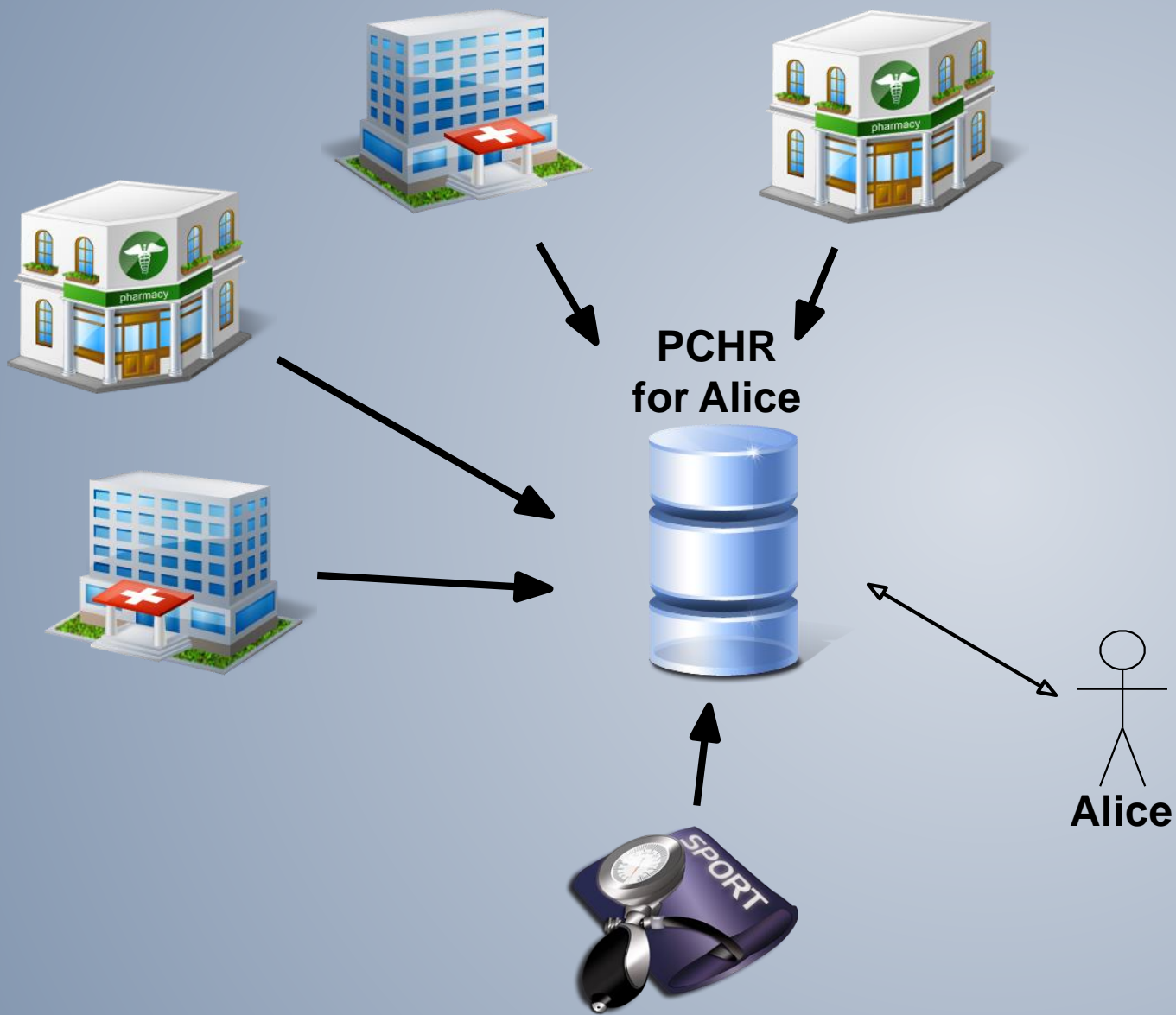
Purpose

- › Health institutions rarely share data, reasons being – proprietary data, perceived competition, privacy, and mainly no dedicated resources

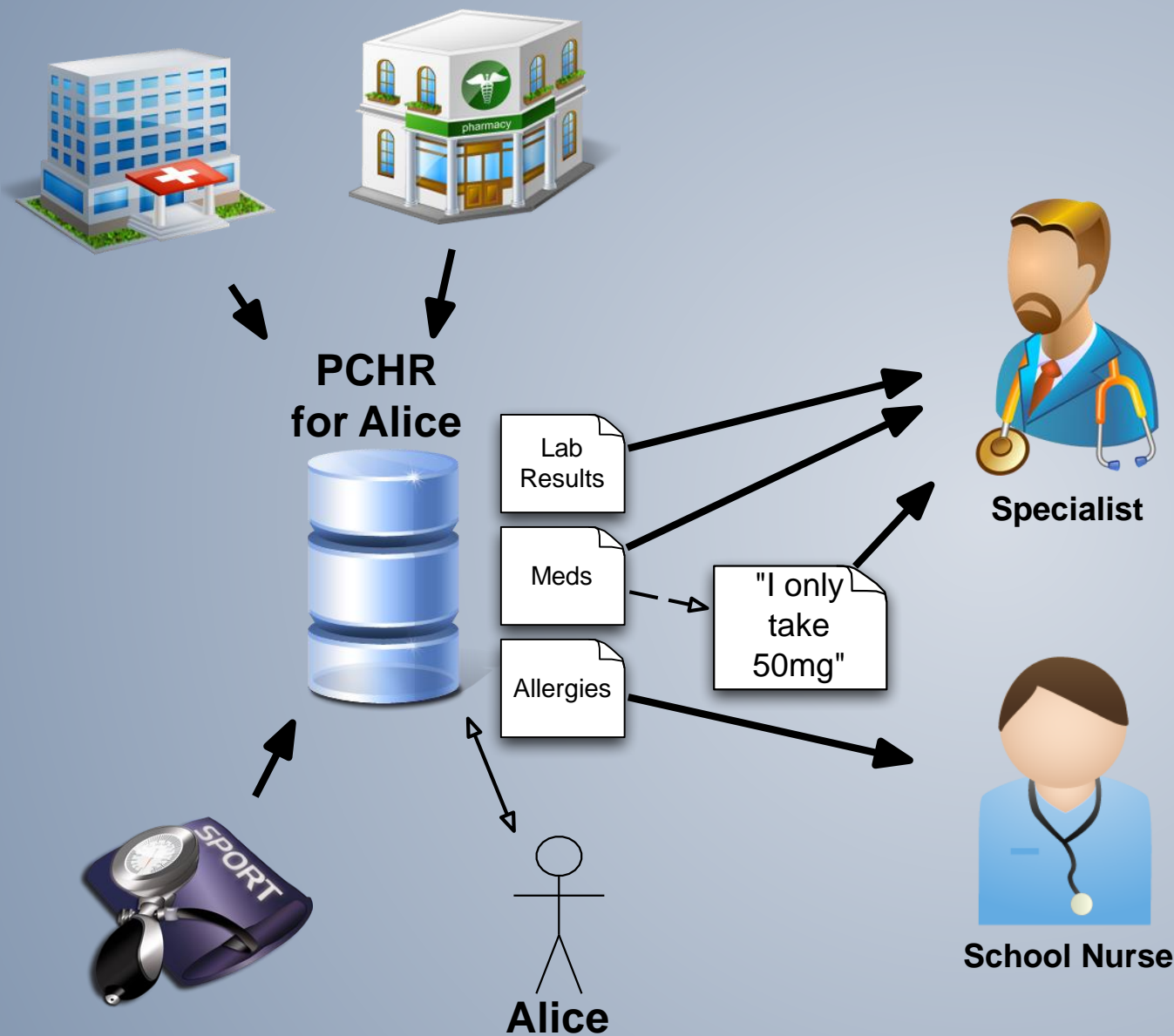


- › But, a patient needs an aggregate view on data.





Aggregation



Sharing
Management



Vision

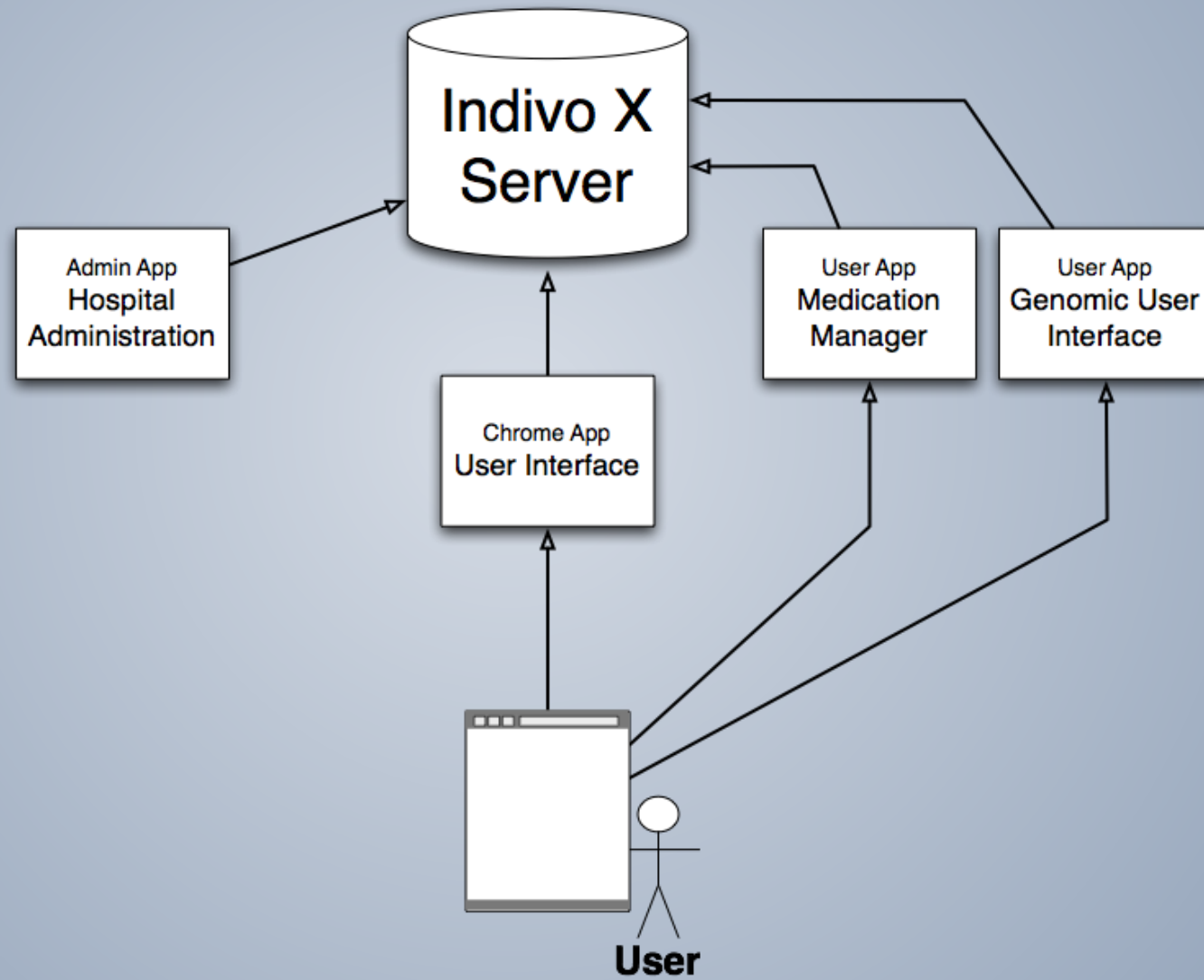
- › A standardized way to download medical information that's stored online (regardless of its source) with standardised security and privacy.



PCHR Model

- › A digital Web-based collection of a patient's comprehensive medical history
 - Copies of medical reports
 - Reports about diagnosed medical conditions
 - Medications
 - Immunizations
 - Laboratory results
 - Personal characteristics.
- › The design integrates medical and social information across sites of care and overtime within a structure that is readily accessible to and controlled by individuals.

Indivo's Architecture

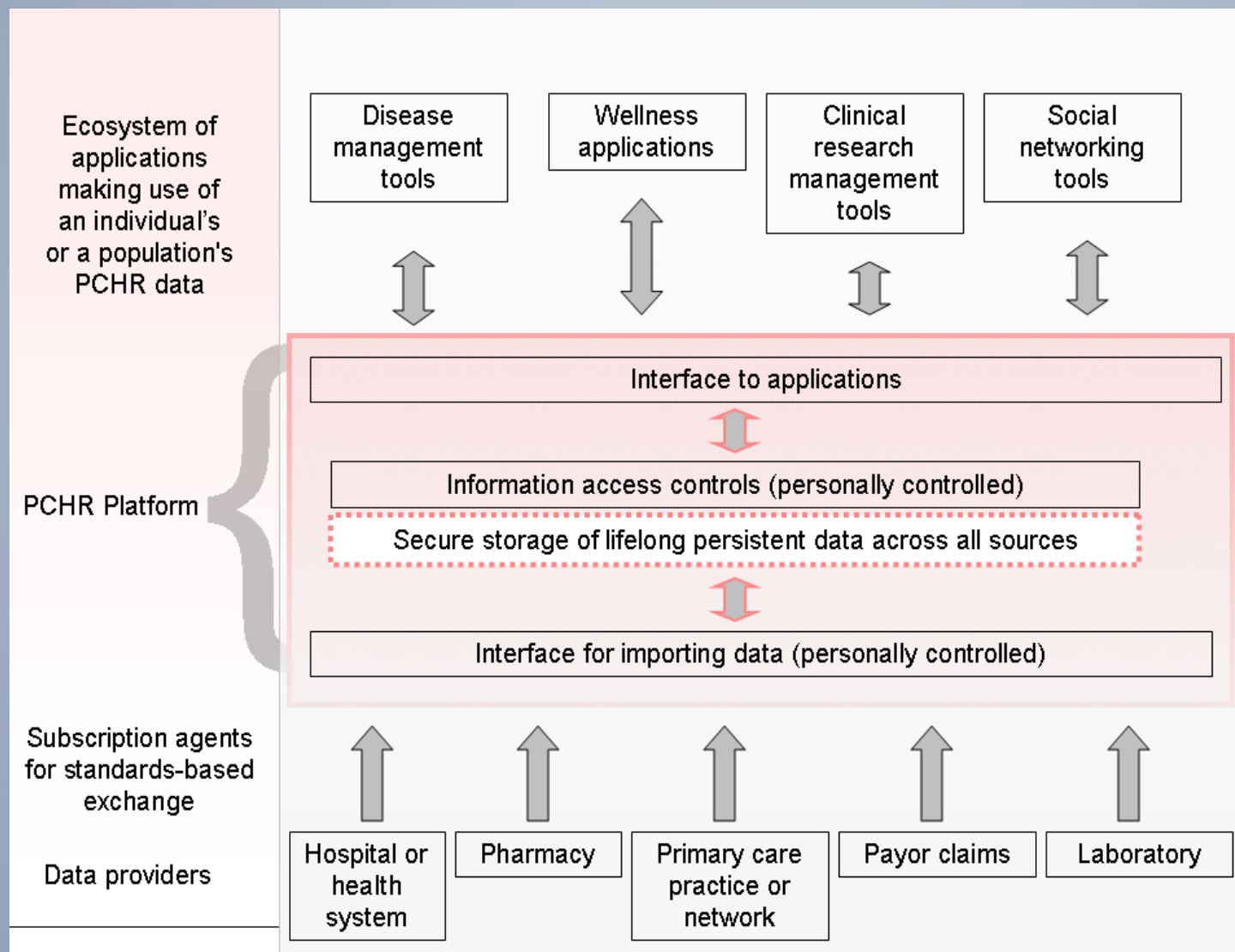




- › **Indivo X Server** - For a given Indivo installation, the Indivo X server:
 - stores all Indivo account information, as well as the medical records and documents,
 - is responsible for authentication and authorization before granting access to Indivo data,
 - exposes an API for access by administrative and user applications, and by the Indivo User Interface.
- › **Indivo User Interface/Indivo Chrome** – It implements the web-based visual interface that an Indivo user will view and use. It connects to Indivo X using the standard Indivo API, including some specific calls accessible only to the Chrome component.
- › **Administrative Application** - An Admin Application can connect to Indivo X and
 - create new Indivo accounts and records
 - reset of passwords
 - manage ownership of records, i.e. assigning an account as the owner of a record.

An admin application cannot access medical data, it can only manage a record's metadata.
- › **User Application/Personal Health Application** - An application that Indivo users manually add to their record to provide more functionality. An example of PHA functionality -> Diabetes management. User applications generally provide a web interface to the Indivo user, while connecting to the user's Indivo record directly with the Indivo X Server. Users are fully in control of what data a user application can access.

Indivo as a Repository



Indivo is a repository with a Data Model. It does two things: acquire data from multiple sources, and lets you interact with that data via apps.

Indivo as the Stack

Ubuntu (RHEL/ OSX/ CentOS)

Postgres (Oracle/ MySQL)

Python

Django

Apache

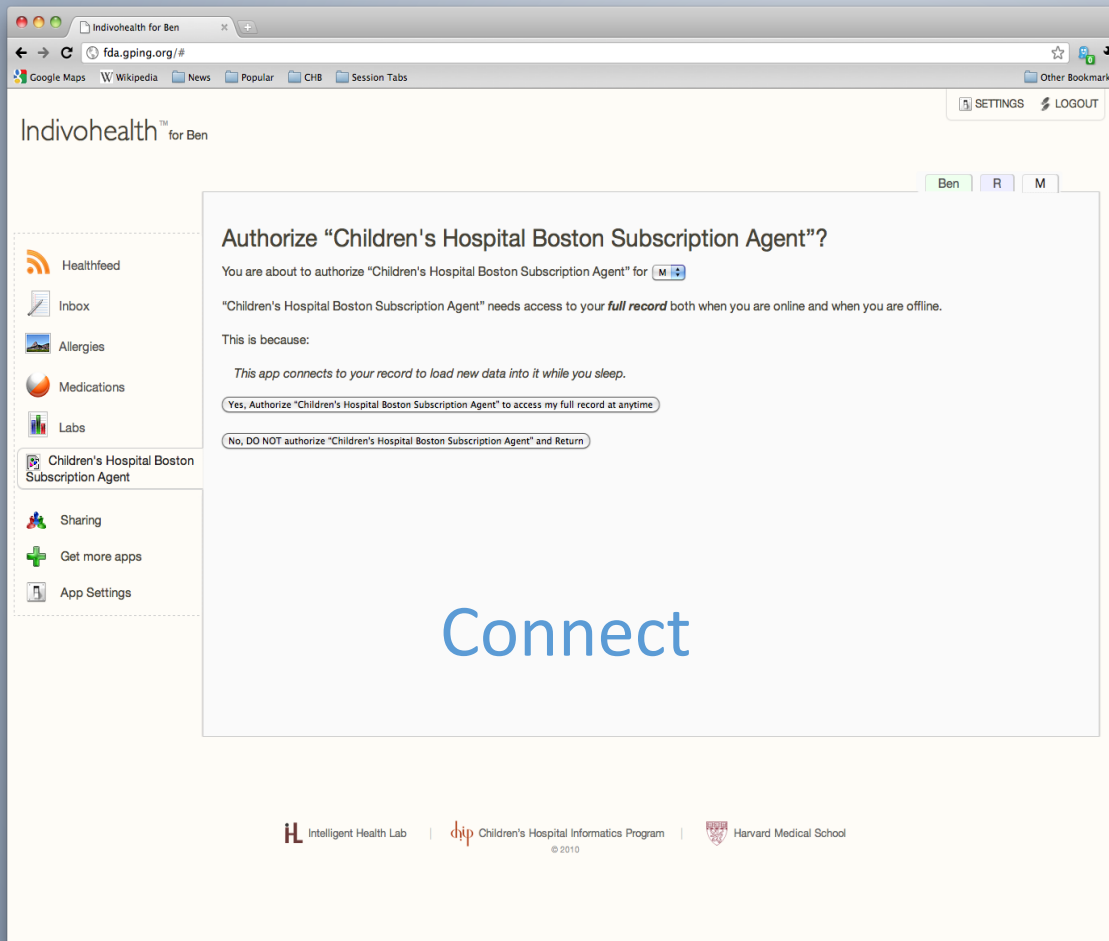


Indivo as the Verbs

Connect

Add
Apps

Share



The screenshot shows a web browser window with the URL `fda.gping.org/#`. The page title is "Indivohealth™ for Ben". On the left, there is a sidebar menu with icons and labels for: Healthfeed, Inbox, Allergies, Medications, Labs, Children's Hospital Boston Subscription Agent, Sharing, Get more apps, and App Settings. The main content area displays an authorization prompt: "Authorize 'Children's Hospital Boston Subscription Agent'?" followed by explanatory text and two buttons: "Yes, Authorize 'Children's Hospital Boston Subscription Agent' to access my full record at anytime" and "No, DO NOT authorize 'Children's Hospital Boston Subscription Agent' and Return". At the bottom of the page, there is a footer with logos for "Intelligent Health Lab", "Children's Hospital Informatics Program", and "Harvard Medical School", along with the copyright year "© 2010".

Connect

Available Apps



Allergies



Labs



Medications

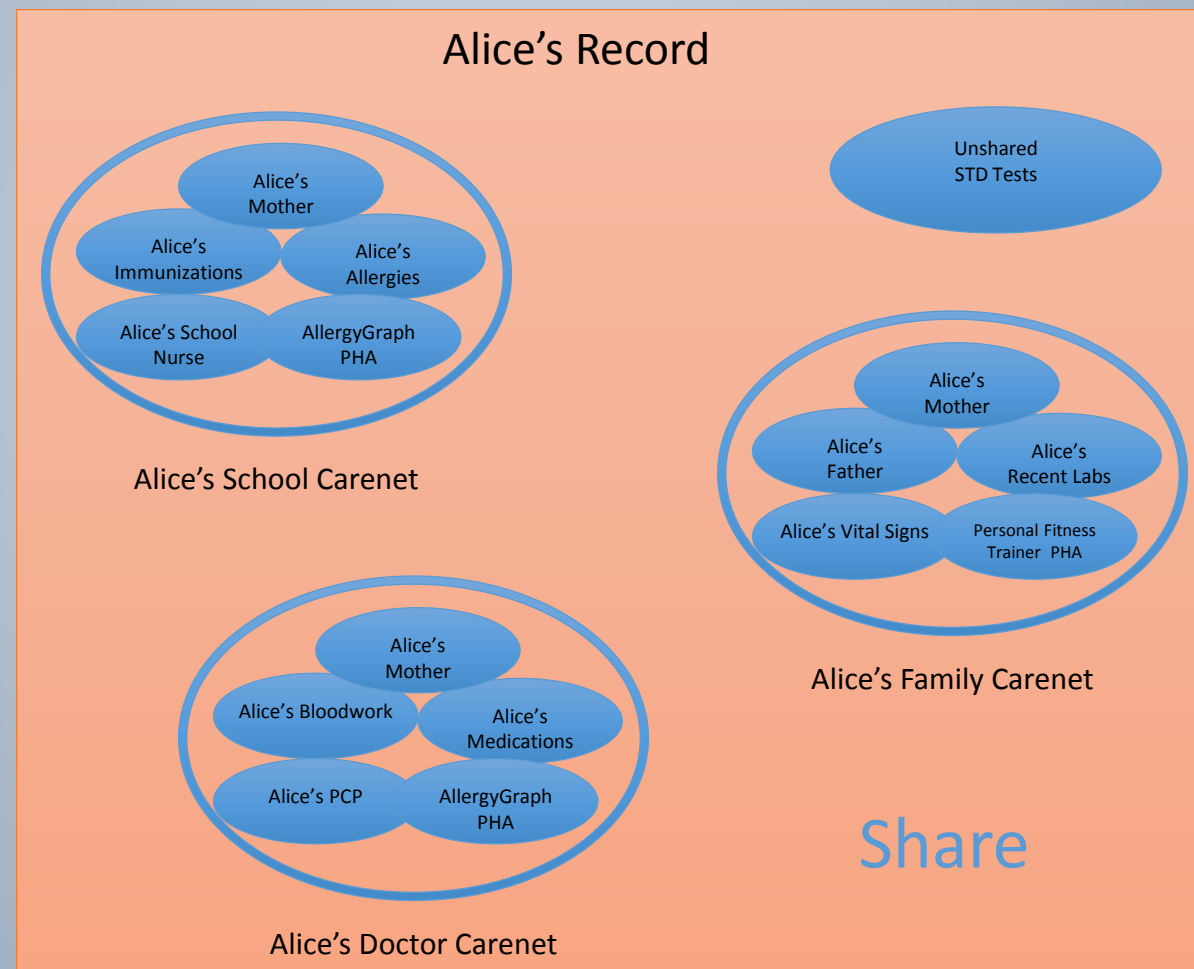
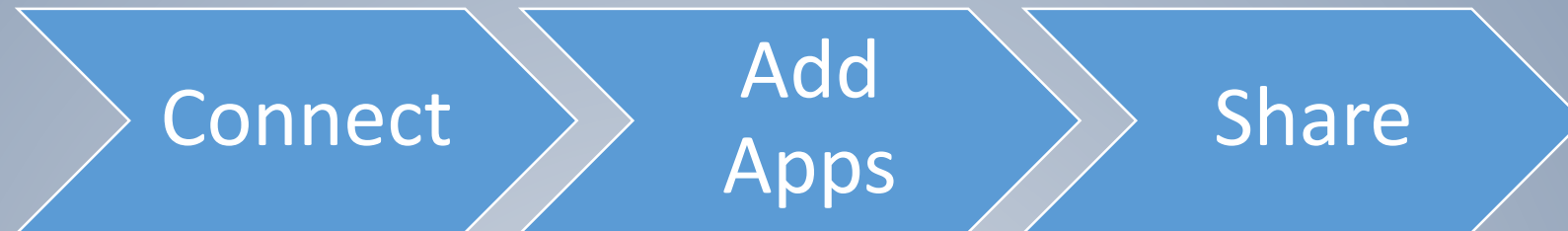


Problems



Surveys

Add Apps



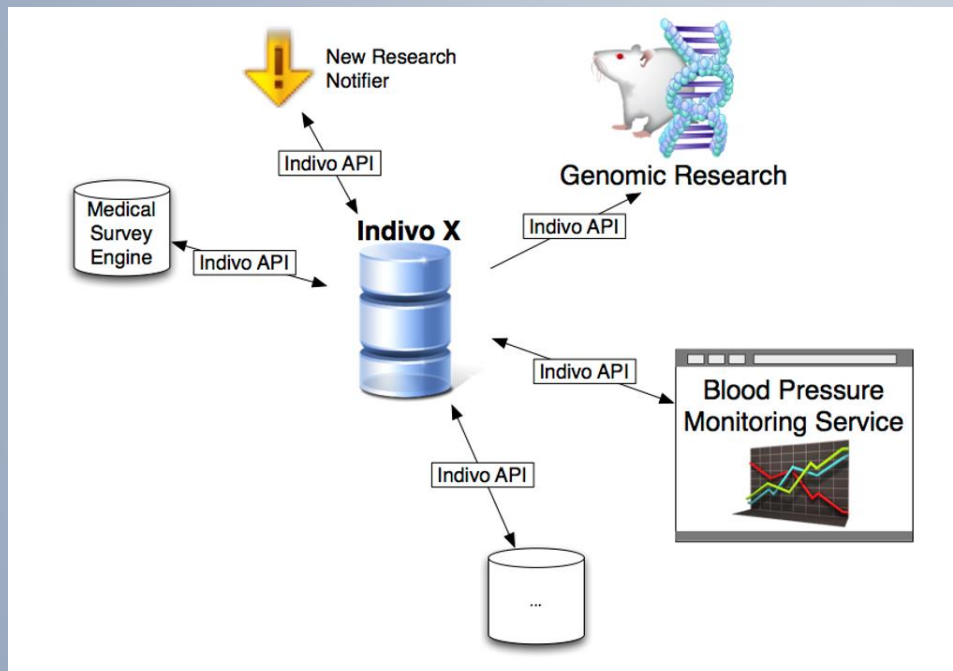


Indivo as the Terminology

- › **Indivo Record:** the complete set of medical information stored by Indivo about a single individual.
- › **Indivo Account:** a username/password to log into Indivo. One account may be able to access any number of Indivo Records, and one Indivo Record may be accessible by multiple Indivo Accounts.
- › **Indivo Document:** a piece of medical information stored in an Indivo Record. A **demographics document** is also included, which details the individual's contact information and name.
- › **Data Models** in Indivo describe the format in which Indivo represents medical information.
- › **Schemas** in Indivo are used to describe valid formats in which data may enter Indivo. Currently, only XSDs are used.

The Indivo API

- › The Indivo API provides an interface for Personal Health Applications to extend the functionality of the Indivo PCHR
- › Functionality
 - Records and Documents
 - Messaging and Notifications
 - Medical Reports
- › Personal Health Applications (PHAs) make HTTP calls to the Indivo API endpoint using the REST convention. OAuth is used to authenticate all calls.





Applications

We consider three types of applications:

- › **User Applications**, which individual Indivo users can add to their record.
- › **Administrative Applications**, which are used to perform account and record manipulations.
- › **UI Applications**, which provide the public user interface to Indivo features.

Per Indivo installation, there is a small handful of UI and administrative applications, and quite a number of user applications.



Coding Systems

- › For Indivo, and in general for a number of health applications, coding systems are used for interoperability.
- › Examples include vaccine disease codes, allergy codes, procedure codes, etc.
- › Beyond the basic attributes (name, publisher, description), a coding system includes - a way to list all codes, a way to look up a single code, a way to search for codes matching a simple text query (e.g. “diab” should match “diabetes.”)
- › A single code entry will have, at least a code, an abbreviation, a full title, (optionally) a description, (optionally) relationships to other codes.
- › Data Representation – JSON
- › Sources:
 - For Immunizations => HL7 V3
 - For Labs => LOINC
 - For Problems => SNOMED CT
 - For Medications => RxTerms

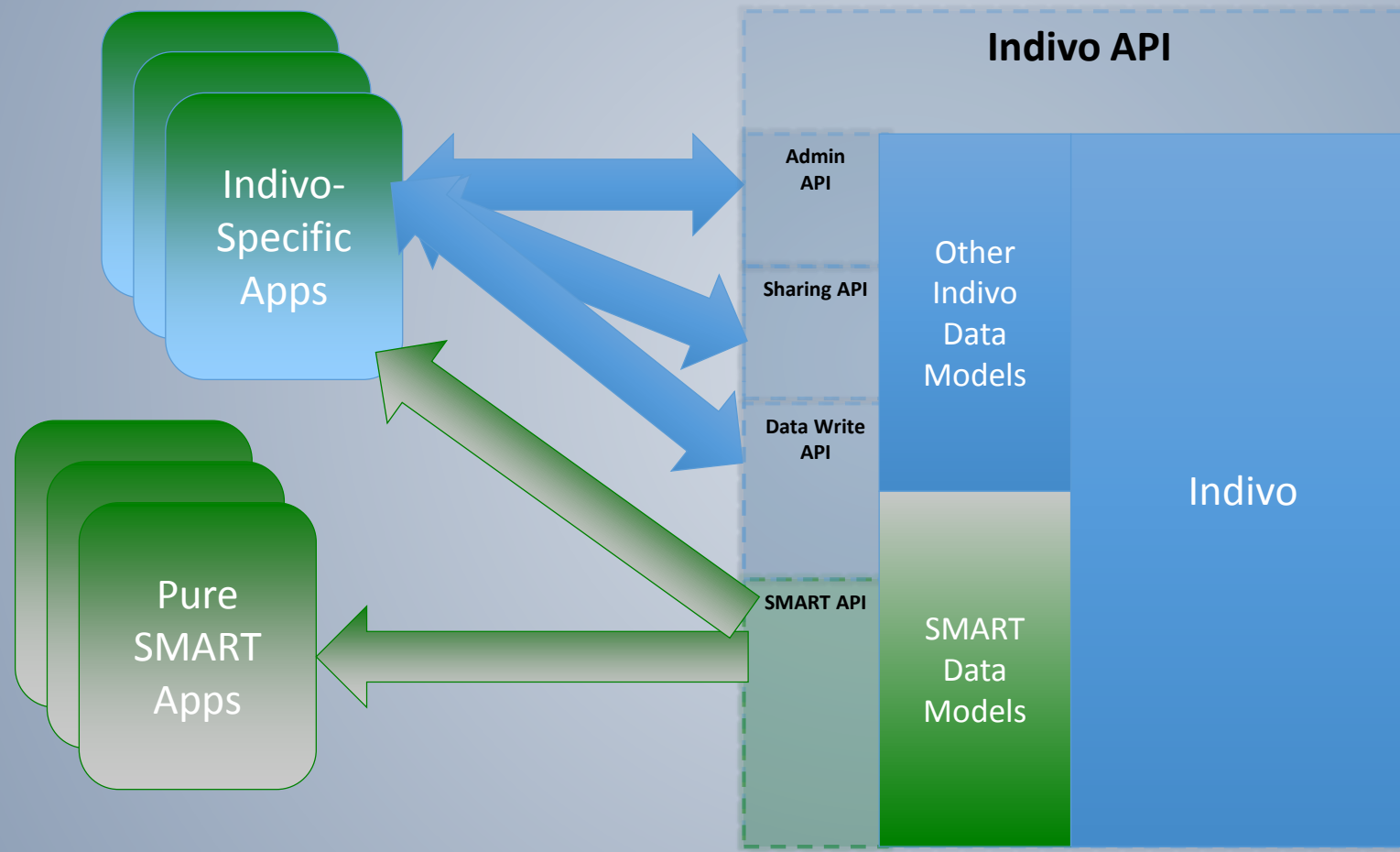
Indivo and Smart

- › SMART provides a unified mechanism for diverse applications to interact with medical-record data.
- › Substitutable apps can run anywhere: not just on Indivo
- › Avoidance of vendor-lock: if you can easily substitute value-generating apps, you don't need to depend entirely on a vendor with possibly different priorities
- › Enable existing (and future) SMART apps to run against Indivo
- › Shift Indivo apps towards adopting SMART standards
- › Enable hybrid SMART/Indivo apps that offer additional functionality when run against Indivo



SMART

Indivo and Smart





Uses

- › Indivo X used as backend for **CollaboRythm** - CollaboRhythm uses Indivo X as a collaborative health record back end in which patients own and control the sharing of all of their data but that also allows clinicians to use it as their primary record for patient care.
- › **TuAnalyze** - The application enables members to submit their Hemoglobin A1C as part of a massive data donation drive. The information submitted by members will be displayed in a map of the United States on the TuDiabetes network, with states lighting up according to the aggregate A1c data. Once a threshold of participants in each state is reached, the state's color reflects whether the average A1c submitted is within the range recommended by physicians.