



Member Roundtable:
***Navigating Exchange, Management, and Use of
Sensitive Reproductive Health Data***

March 21, 2023
12:00 – 1:00 p.m. ET

Housekeeping Reminders

- This is a Zoom meeting.
- Please **mute** yourself when you are not actively speaking.
- Please use the **raise hand** function to chime in with questions or comments and/or use the **chat** to share.
- Please share video if you are able.

Agenda

- **Welcome and Civitas Updates** – Jolie Ritzo, Civitas Networks for Health, Senior Director of Network Engagement
- **Case Study with CRISP and Impact on National Networks/TEFCA** – Nichole Sweeney, General Counsel and Chief Policy Officer; Steven Lane, Chief Medical Officer, Health Gorilla; Matt Becker, VP of Interoperability, Kno2 LLC
- **Consent Management for HIEs** – Carol Robinson, Founder and CEO, Midato Health
- **Enterprise Architecture for Consent Management** – Mike O'Neill, President and CEO, MedicaSoft
- **Data Segmentation for Privacy** – Steven Lane, Chief Medical Officer, Health Gorilla

Civitas Updates

Upcoming Events



- Civitas will be hosting the first Quarterly Public Policy Briefing of 2023 on April 4 from 12:30 - 1:30 p.m. ET. [Register Here!](#)
- Keep an eye out for registration information for our Collaboratives in Action event focusing on our Health Data Utility Framework. This event will take place April 13 from 3:00 – 4:30 p.m. ET.
- Please note we will not be holding Network News in April due to the timing of HIMSS. Our regular cadence will resume on Wednesday, May 17.

Case Study: Maryland SB786

- [Senate Bill \(SB\) 786](#) was introduced in both the Maryland Senate and the House of Representatives this session
- Part of a suite of bills in response to *Dobbs* that the newly elected Governor, Wes Moore, publicly backed
- Senate President and Speaker of the House both publicly committed to securing the votes for the bill
- CRISP was aware that “privacy bills related to *Dobbs*” would be a part of the session and proactively met with relevant Maryland Delegates and lobbyists, stating the need for a technical input

Case Study: Maryland SB786 (cont.)

- First Version of the Bill:
 - A Health Information Exchange may not disclose [a record containing Legally Protected Health Care] to a treating provider, business entity, or health information exchange located outside [Maryland].”
 - Exceptions:
 - For adjudication of Claims;
 - To a specific treating provided with the consent of the patient; and
 - To a parent if the parent is required to consent to the services.
 - “**Legally Protected Health Care**” means all reproductive health services, medications, and supplies related to the direct provision of support of the care related to pregnancy, contraception, assisted reproduction, and abortion that is lawful in [Maryland].

Case Study: Maryland SB786 (cont.)

- Bill written to provide a “Part 2-ish” paradigm for “reproductive services”
- “Reproductive services” not defined
- Technological Challenges with First Version:
 - Without a definition of “reproductive services,” likely that any record containing documentation regarding contraception, pregnancy, abortion, etc. would be entirely blocked unless patient affirmatively consented
- Potential Solutions:
 - Filter records originating from certain facilities/departments (e.g., obstetrics)
 - Filter certain code sets
 - Either solution requires a definition of the sensitive departments/codes

Case Study: Maryland SB786 (cont.)

- Current Version of the Bill:
 - A health information exchange or electronic health network may not disclose . . . sensitive health services as determined by the Secretary
 - “Sensitive Health Services” are certain code sets the Secretary, through a Commission, determines applicable
 - Law would take effect December 2023, but would not be enforced until June 1, 2024

Case Study: Maryland SB786 (cont.)

- Technological Implications:
 - HIEs/EHNs will need to be able to parse and filter data based on the code set provided by the Commission
 - HIEs/EHNs will need to be able to allow affirmative patient consent
 - Some HIEs/EHNs have publicly stated that they do not intend to/do not have the ability to do the above and will block the record entirely
- National Network/TEFCA Implications:
 - If the technology solutions cannot be achieved, likely that any queries to Maryland related to “sensitive code sets” would be blocked in their entirety
 - Practically, this would mean that most individuals with uteruses would not have interoperable data

Technology Solutions: Maryland SB786 (cont.)

- Parsing Data
- Filtering Data
- Allowing Affirmative Patient Consent for Disclosure

Discussion/Work Session: Affirmative Patient Consent

CRISP DC Consent Consent History

Consent to Disclose My Substance Use Disorder Treatment Information Next

From I authorize disclosure by any of my past, present, and future Substance Use Disorder treatment providers that share data with CRISP.

To Whom I authorize disclosure to CRISP Shared Services affiliate HIEs, who may then disclose the information to any of my past, present or future providers involved in my care who participate with the HIE. I can request a list of all providers who have received my information by going to <https://disclosures.crisphealth.org>.

Type and Amount of Data

Purpose The information shared will be used to help my health care team coordinate my care and provide health care treatment.

Consent Options

Disclose All Substance Use Disorder Treatment Data
This could include my treatment plan, medications, lab results and clinical notes about my care.

Disclose Substance Use Disorder Treatment Providers Contact Info Only
The information will include only my Substance Use Disorder treatment provider's name and contact information.



Consent Management for HIEs

Prepared by Midato Health

March 2023

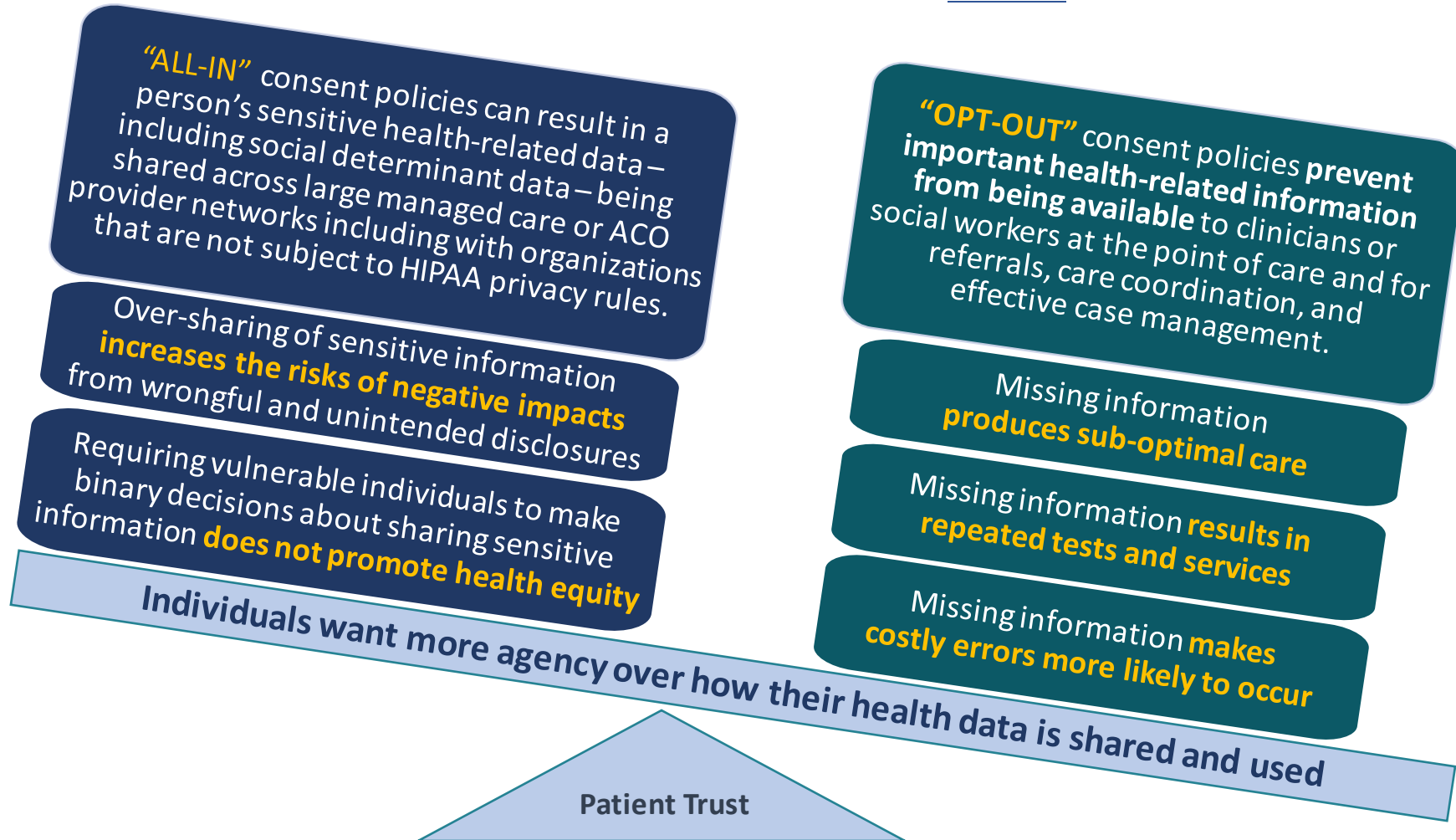
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What's All the Fuss About Consent?

Common Consent Conundrums

- ❖ Many medical records are locked up in EHRs and HIEs to protect patient privacy
 - Especially when a medical record indicates substance use disorder, HIV, depression, mental illness, a sexually-transmitted infection (STI), transgender or nonbinary identification, and reproductive healthcare
 - Also true for adolescents in most states
- ❖ Laws protecting health data privacy differ substantially between states
 - Organizations with operations in multiple states must deal with a patchwork of rapidly changing health privacy laws
- ❖ Consent processes collect a point-in-time patient decision in a static document
 - Once a signature has been collected, significant manual intervention is needed to change or revoke a consent decision

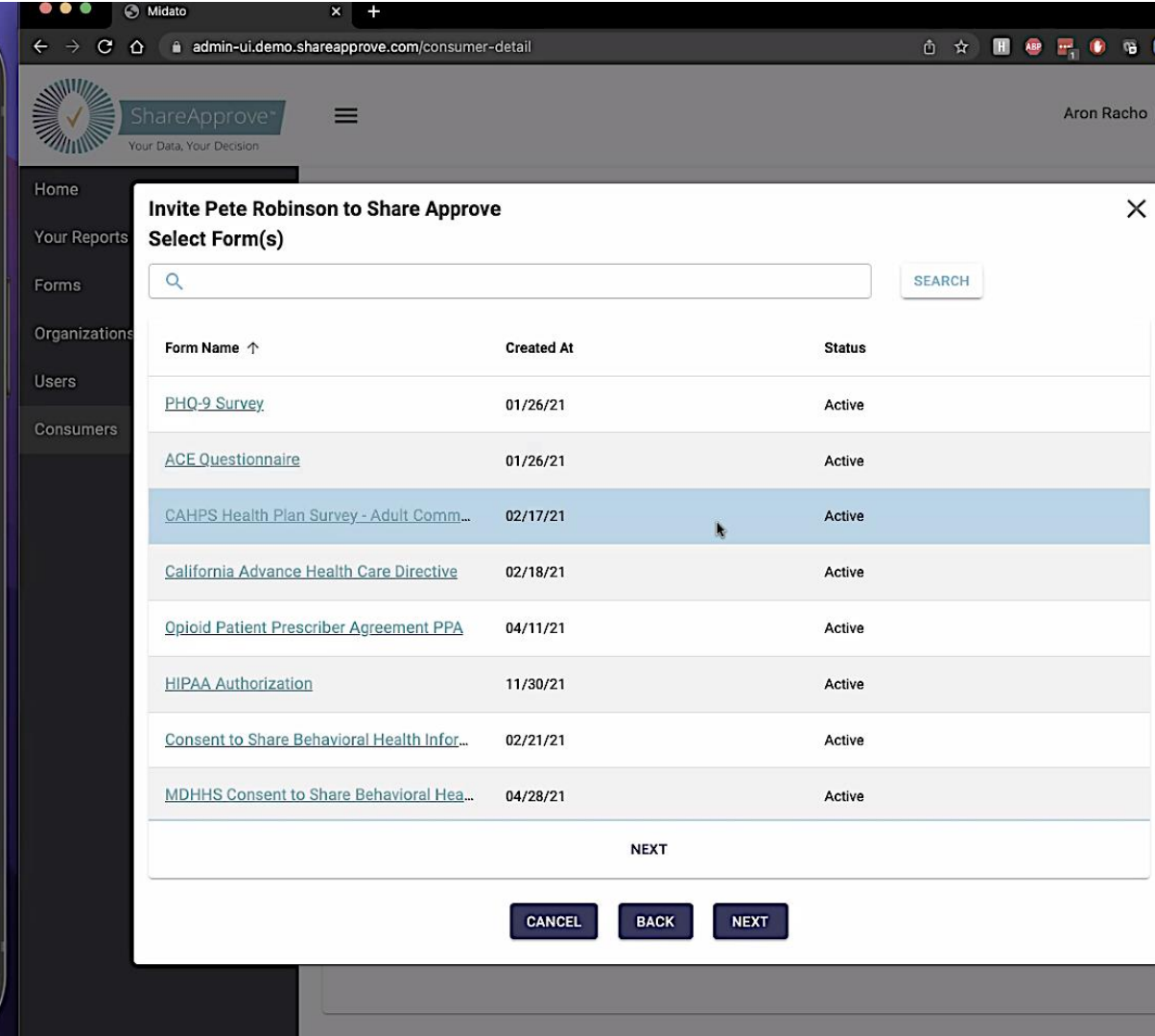
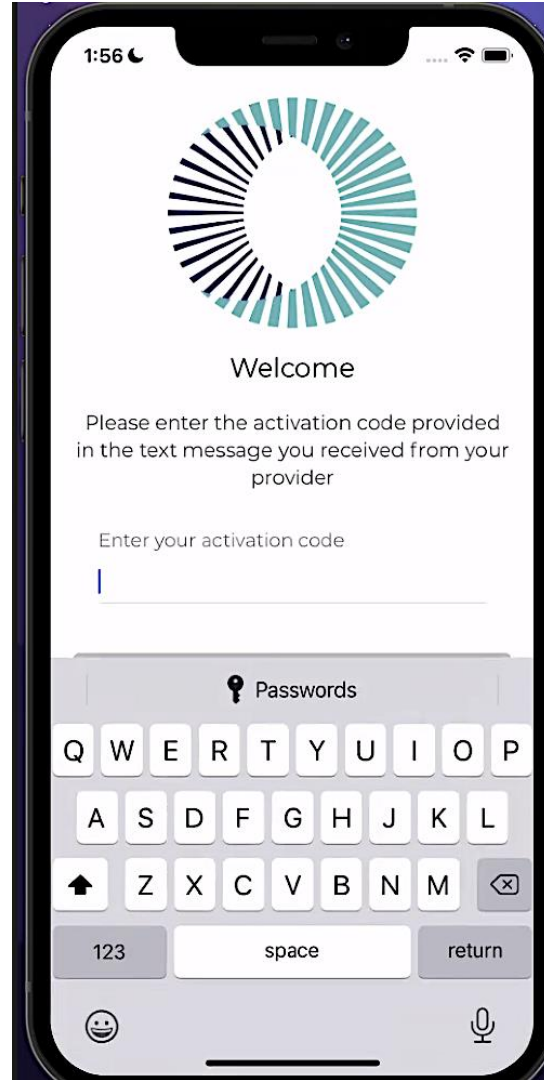
Current Consent Management Practices Put Patients and Providers at Risk





Midato Health's ShareApprove

- **ALLOWS INDIVIDUALS TO CHOOSE WHO VIEWS** their health-related data
- **ALLOWS THE PURPOSE OF USE** to be specified
- **ALLOWS EXPIRATION TIMEFRAMES** to be set for consent authorizations
- **ALLOWS INDIVIDUALS TO REVOKE OR REVISE** a consent that was authorized in the past*



* Revocation of an affirmative consent for data-sharing will not guarantee the destruction of data previously shared with legal consent.



A Connected Consent Decision Service

Simplifying Consent Across Communities of Care

- Sharing Substance Use Disorder Treatment Data*
- Social Needs & Medical Acuity Assessments
- Medical Proxies & Power of Attorney Forms
- Sensitive Data with High Need for Care Coordination
- Advance Directive Registries
- Manage Consent for National Networks
- Increase Engagement & Institutional Trust
- Reduce Liability Risks
- Consent for Treatment, Surgery, Anesthesia, etc.

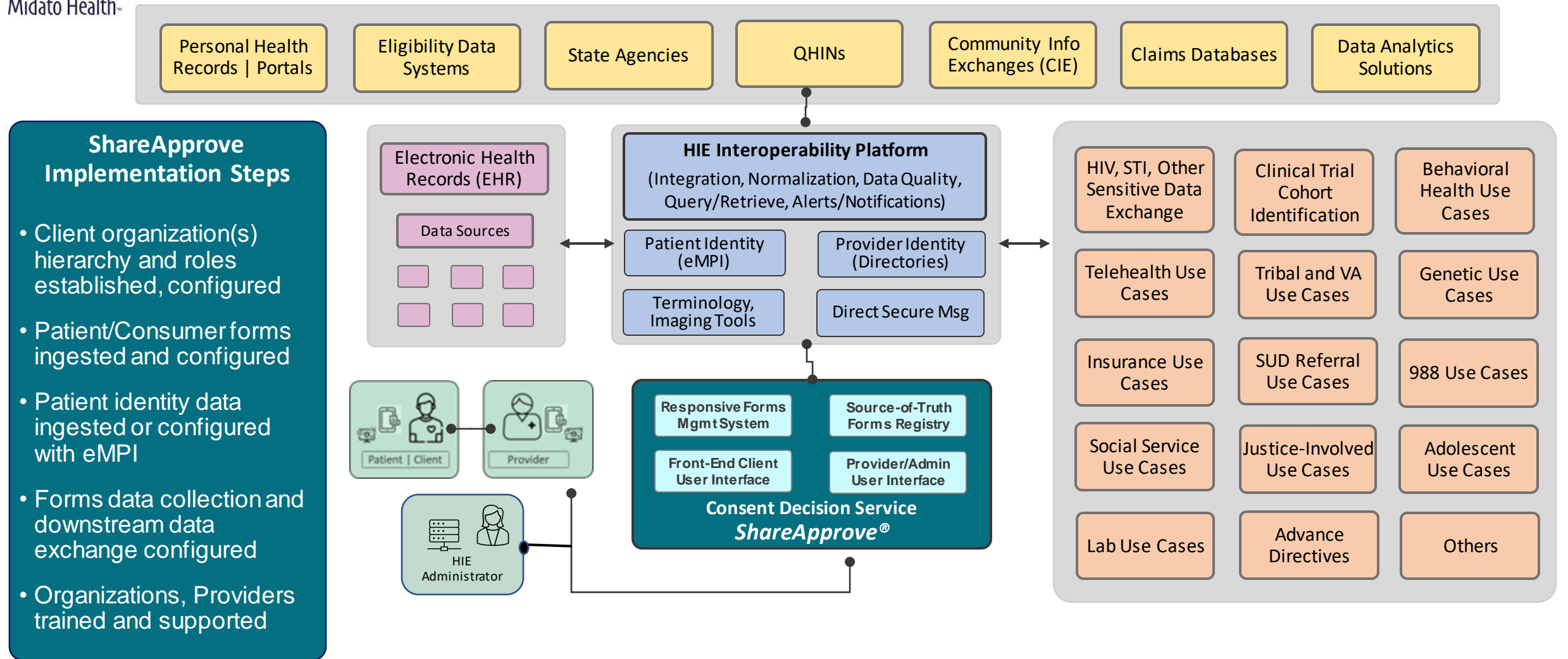


- Coordinate Services for Shared-Risk Contracts
- Patient Surveys for Quality Payments
- Sharing Data for Care Coordination
- Medical Record Reviews
- Eligibility & Benefit Determinations
- Health Histories
- Closed Loop Referrals
- Consent to Access HIE Data for Clinical Trials
- Consent to Be Notified of Clinical Trial Eligibility

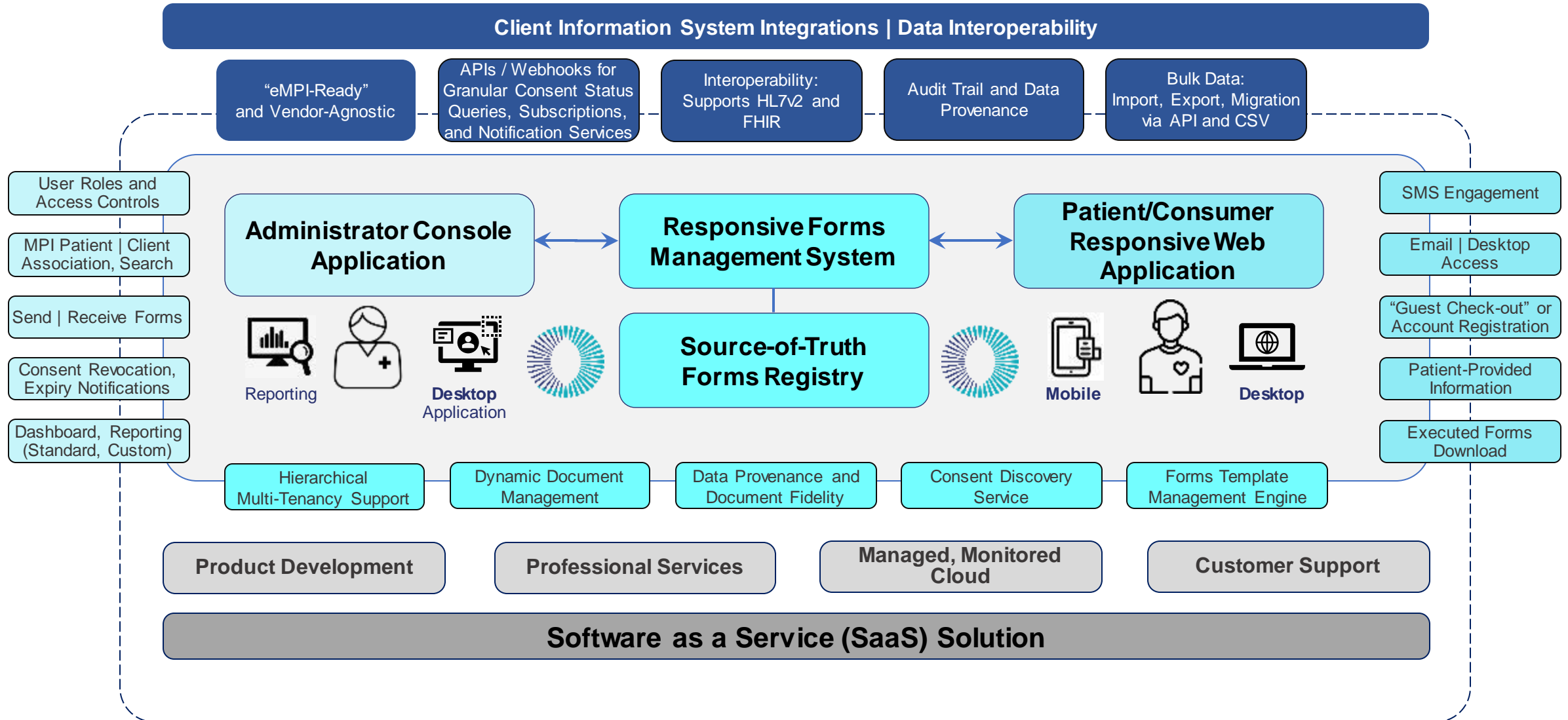
Scalable by Design	Master Tenants
	Sub-Tenants & Single Tenants



HIEs Can Support More Data Exchange With Consent Management



ShareApprove Solution Overview



Enterprise Architecture for Consent Management



Patients

Control Sharing of Data



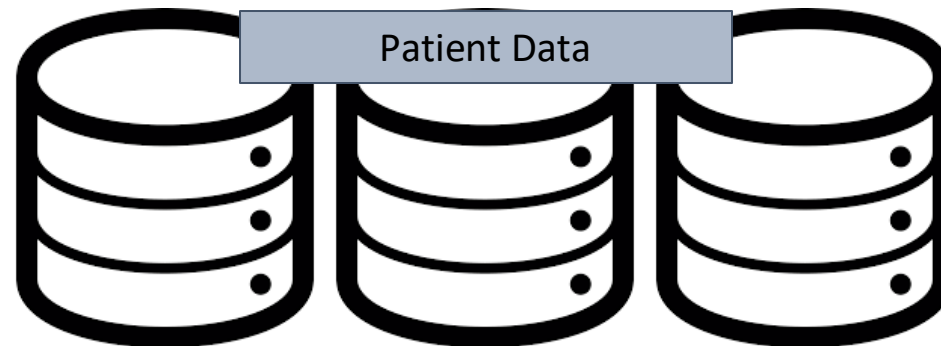
Providers

Assist Patients with Sharing Preferences
Use Patient Data for Treatment



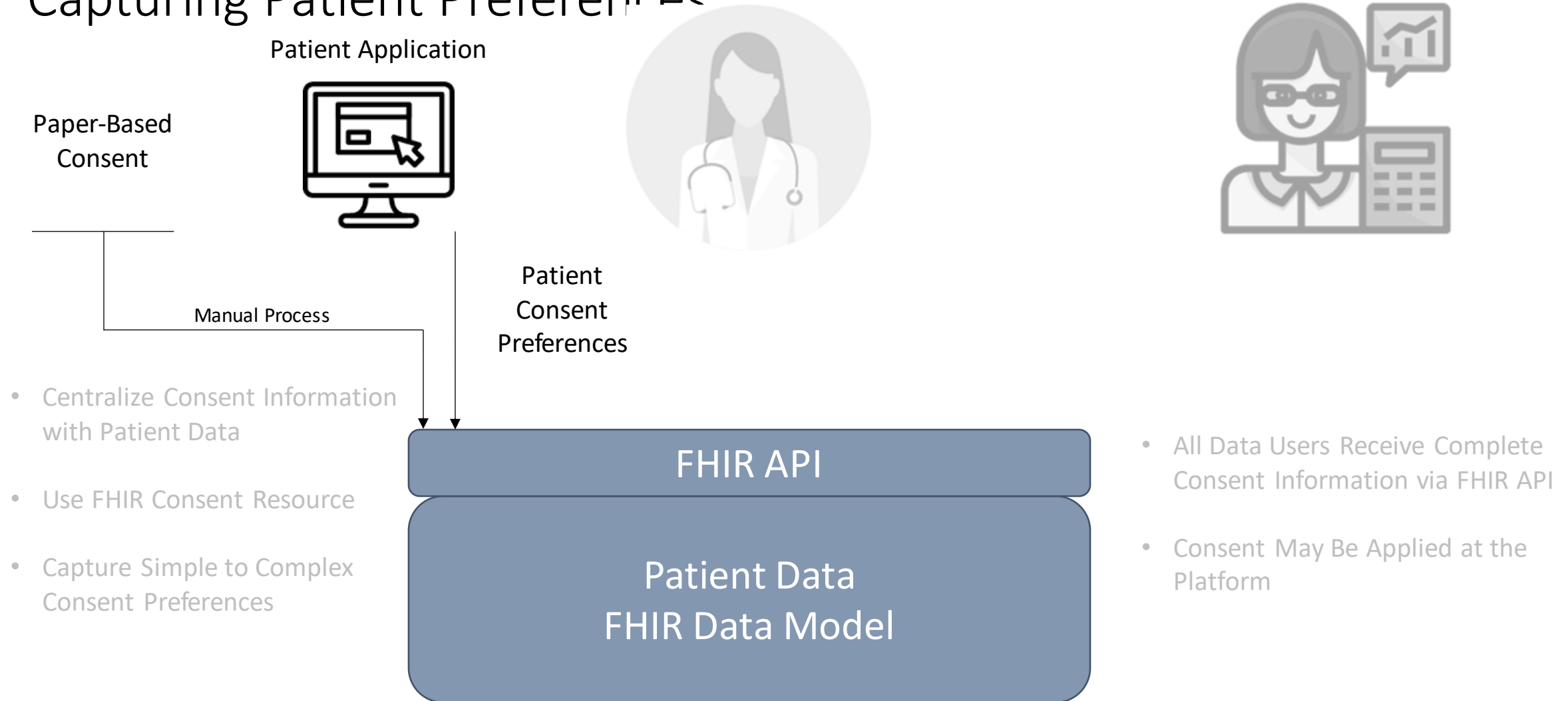
Payers and Providers

Access Data for Analytics & Reporting
Non-Treatment Purpose of Use



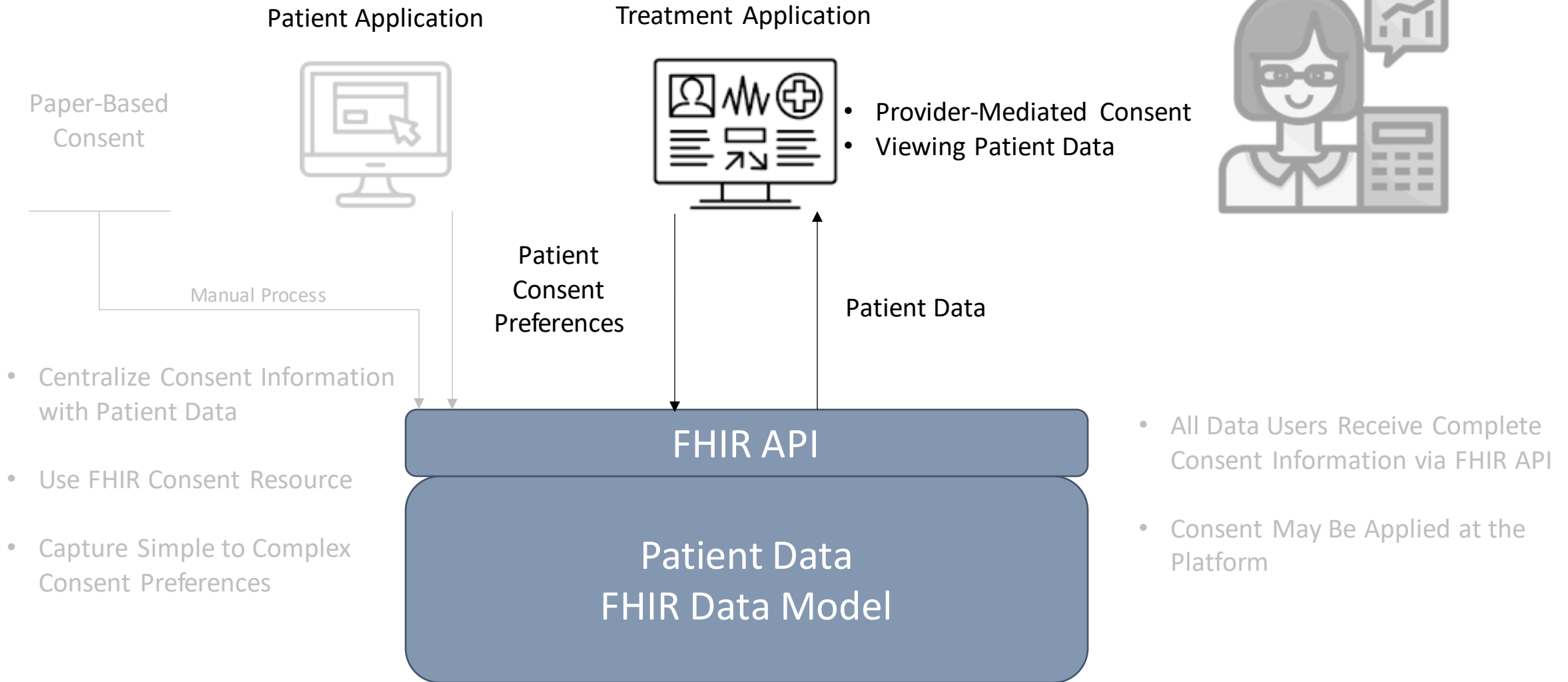
Enterprise Architecture for Consent Management

Capturing Patient Preferences

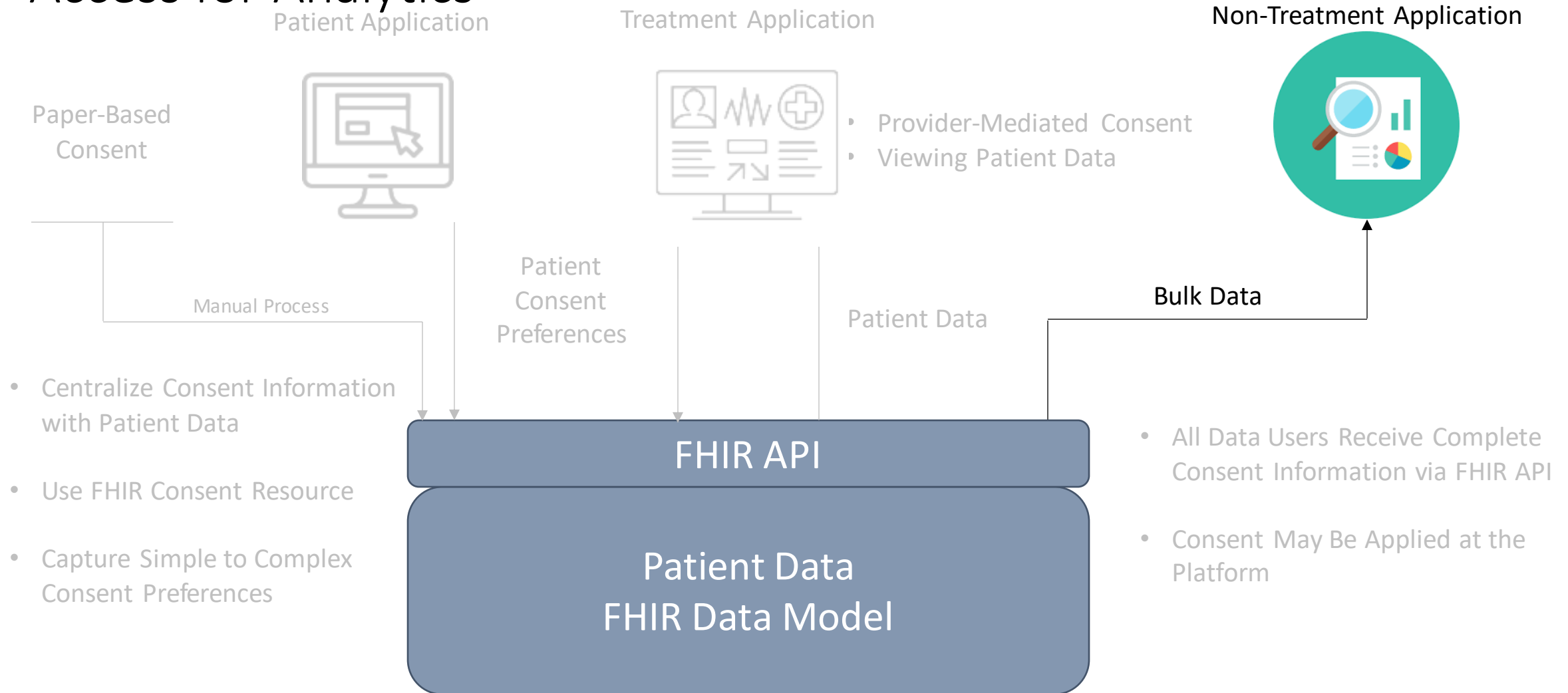


Enterprise Architecture for Consent Management

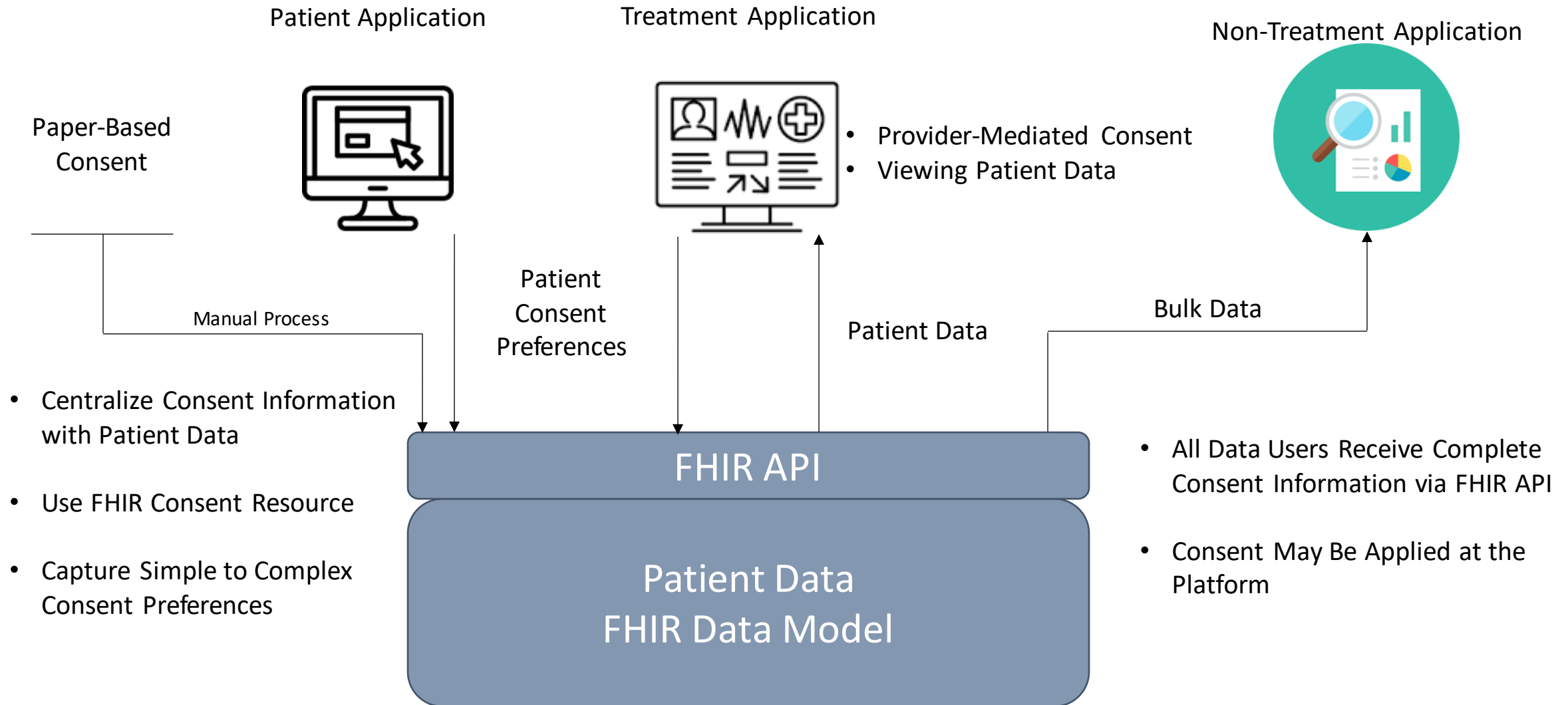
Provider Access for Treatment



Enterprise Architecture for Consent Management Access for Analytics



Enterprise Architecture for Consent Management



Data Segmentation for Privacy (DS4P)

DS4P Resources –

- [ONC 2015 Edition Final Rule: Data Segmentation for Privacy \(DS4P\)](#)
- [ISA: Security Tags for Sensitive Information](#)

C-CDA:

- For C-CDA transmission, document level DS4P is required in the C-CDA General Header. Therefore, adoption levels may be higher for document level tagging (vs. section or data element level).
- [Security Tags for Sensitive Information](#)
- [2015 Edition Final Rule: Data Segmentation for Privacy](#)

FHIR:

- [GitHub: HL7 FHIR DS4P](#)

[USCDI: Security Label Data Element Submission - Currently at Level 1](#)

Participant Poll: Did you learn something valuable or new, make a new connection, and/ or was this a valuable use of your time?

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