

# *Consent to Share: An Iterative Journey*

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*May 18, 2022*



*Empowering  
data-driven decisions*

- *The Need*
- *Technical Considerations*
- *Workflow Implications*
- *Progress to Date in Delaware*
- *Next Steps*



# *Industry Drivers*



# *Health Record Exchange*

- Broad adoption of Electronic Health Records
- More health record exchange options
  - State & regional Health Information Exchanges
  - National networks – eHealth Exchange, CommonWell, Carequality
  - Emerging API capabilities
- Regulations
  - ONC and CMS both require or encourage health data accessibility and interoperability

# *Expanding Beyond Treatment*

- Most health record sharing is in support of medical treatment
  - Providing more complete patient record
  - More efficient referral process
  - Reducing duplicate tests
- The payer community is increasingly accessing health records to support non-treatment use cases
  - Benefits claims processing
  - Care coordination
  - Value-based care

# *Patient Benefits; Patient Control*

- Higher levels of health record sharing benefits patients
  - Better care outcomes
  - Improved efficiency & convenience
  - Lower costs
- Patients must be able to exercise privacy rights
  - Patient consent for treatment and non-treatment use cases
  - Ability to share/not share certain types of records
  - Ideally, fully granular control over sharing of health data

# *Patient Consent Ecosystem*

- Ability for patients to manage consent preferences
  - Create, revoke, and modify consent preferences
- Ability to store current consent preferences
  - Make consent preferences easily available to all applications and data consumers
- Ability to apply consent preferences to each use case
  - Applications, APIs, databases, etc. – all must be able to apply consent to the data they use

# *The HIE as Patient Consent Ecosystem*



# *The Need*



# “Basic” Consent

- HIPAA privacy requirements allow sharing without explicit patient consent for Treatment, Payment, Operations, Public Health purposes
- DHIN has always had an “opt out” consent model – data is sharable for HIPAA-compliant purposes unless the patient explicitly requests otherwise
- We require informed consent (signed statement of understanding) for opting out
  - Your data will still be aggregated and stored by DHIN on behalf of the performing entity
  - Your data will still be shared where required by law or regulation (e.g. Public Health)
  - Your clinical results will still be electronically delivered by DHIN to the ordering provider
  - Your clinical information will NOT be shared with others involved in your care
  - Your clinical information will NOT be discoverable in an emergency situation
- In 15 years of operation, and with over 3M unique individuals in our MPI, we’ve had a total of 57 individuals opt out

# “Sensitive” Consent

- State law in DE (and other states) restricts sharing of certain sensitive data without explicit patient consent
  - Genetic testing and test results
  - Reproductive information pertaining to adolescents (use of birth control, pregnancy testing, STI data...)
- Other information, while legally sharable, is sensitive
  - HIV testing and test results
  - Behavioral health
- Opt-out has been “all or none” – restriction of sharing of sensitive data meant opting out of sharing ALL data

# “Part 2” Consent

- Disclosure of Part 2 data requires affirmative written consent of the patient unless the disclosure meets an exception
- Consent must specify:
  - Name of the patient
  - Who can disclose data
  - How much and what type of data may be disclosed (include specific reference to SUD)
  - To whom data may be disclosed (can be a person, a category of persons, or an entity)
  - Allowed purpose of disclosure (can be stated generally for “payment and health care operations,” and includes care coordination and/or case management)
  - The date, event, or condition upon which consent will expire (cannot be open ended)
- Disclosure must be accompanied by a warning against re-disclosure without patient consent

# Exceptions Allowing for Disclosure of Part 2 Data Without Consent

- Internal communications
- Audit/Evaluation of a covered Part 2 program
- Reporting suspected child abuse/neglect
- Court order
- Crime on premises or against program personnel
- Reporting to a state PDMP
- **With a Qualified Service Organization Agreement**
- **Medical Emergency**
- **De-identified data**
- **Research**

Relevant  
for HIEs

# The Need

- Growing need to integrate medical and behavioral health data
- ACOs have financial risk across all settings of care
- Urgent need for research to support policy formation, allocation of resources in addressing opioid crisis
- ***DATA SILOS KILL PEOPLE!***

# *Technical Considerations*



# Enterprise Architecture for Consent Management



Patients

Control Sharing of Data



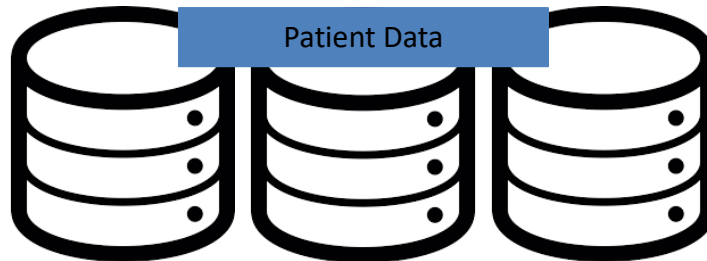
Providers

Assist Patients with Sharing Preferences  
Use Patient Data for Care



Analysts

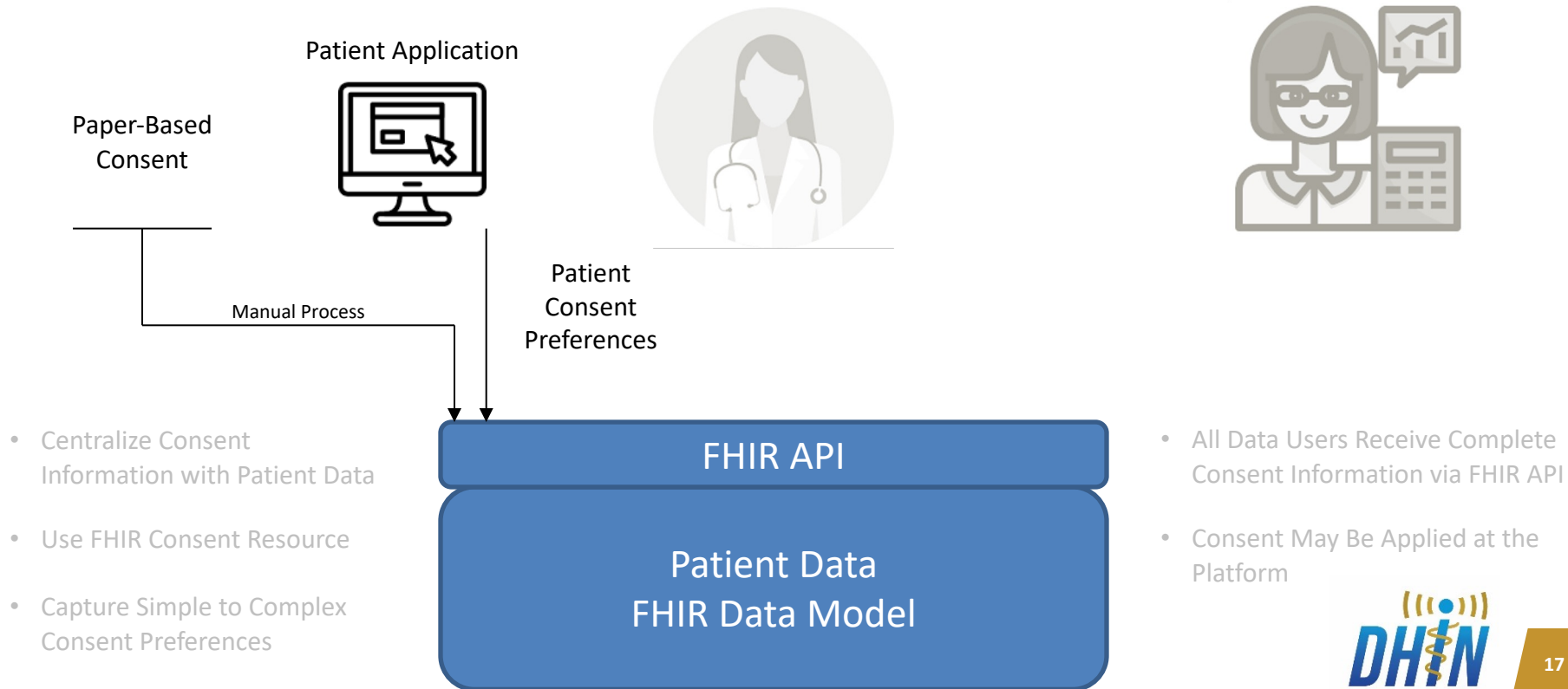
Access Data for Population Health



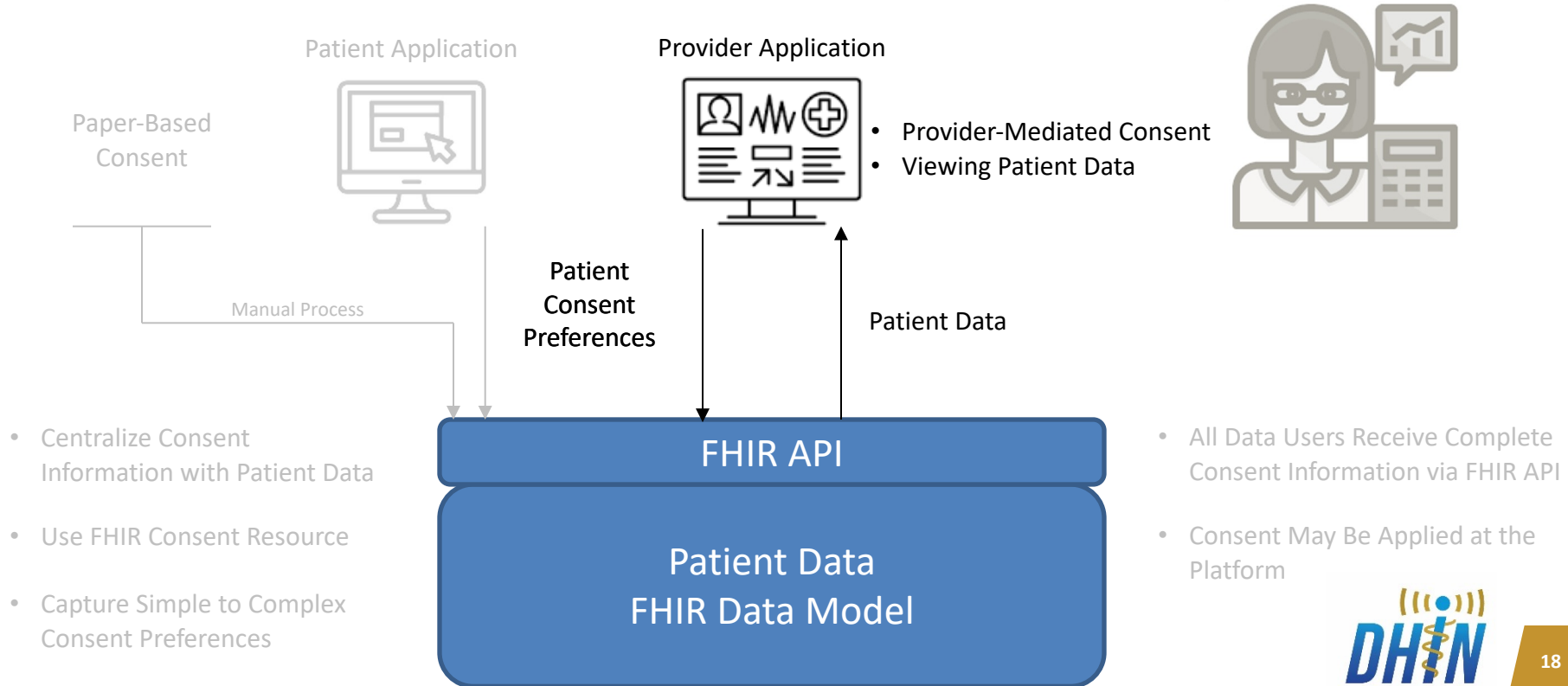


# Enterprise Architecture for Consent Management

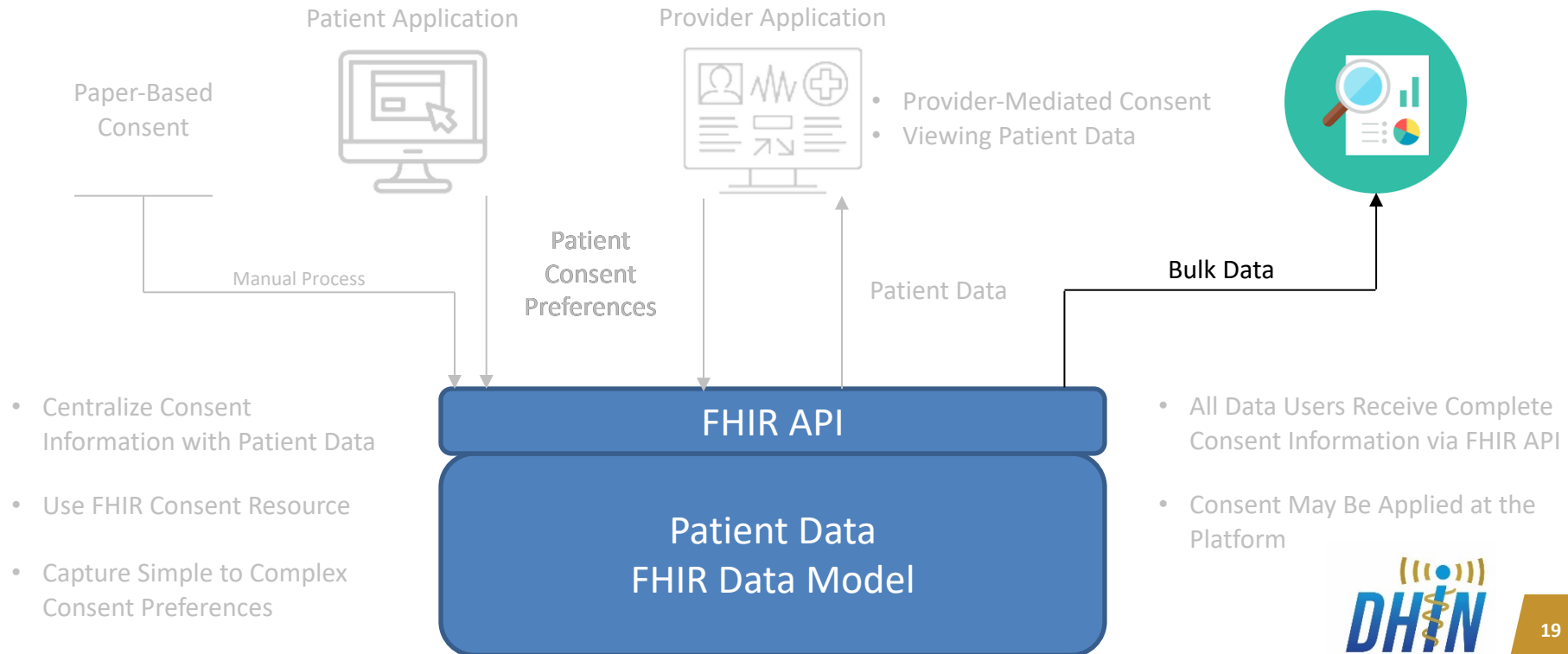
## Capturing Patient Preferences



# Enterprise Architecture for Consent Management Provider Access



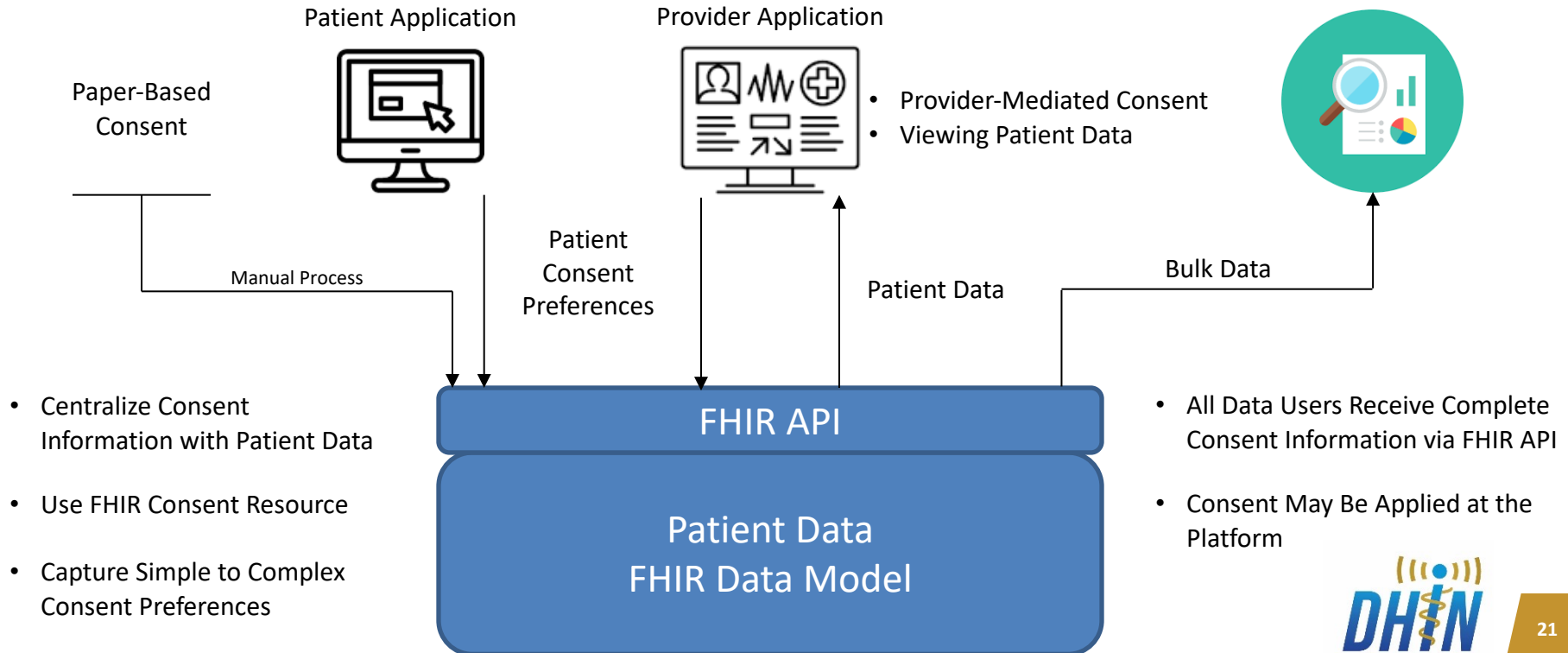
# Enterprise Architecture for Consent Management Access for Analytics



# *Additional Considerations*

- Audit Requirements
  - Track changes to patient consent preferences
  - Track data access
  - Track application of consent in applications
- Tagging Patient Data
  - Identifying sensitive data requires collaboration
  - Tracking data provenance can assist

# Enterprise Architecture for Consent Management



# *Workflow Implications*



# Data Sender Workflow

- DHIN delivers reports and clinical results on behalf of Covered Entities, some of which have both Part 2 and non-Part 2 service lines
- Currently, these data senders must segment Part 2 and non-Part 2 data before sending to DHIN
- Workflow for data senders would be more efficient if DHIN could deliver Part 2 data as well as non-Part 2 data on their behalf
- Requires the data sender to clearly identify Part 2 data vs other
- Need a governing QSO agreement, analogous to BAA

# Provider Workflow

- Improved efficiency if Part 2 results/reports are delivered across the same channels as all other health data (i.e. through DHIN)
- Non-Part 2 providers must be able to sequester and restrict re-disclosure of Part 2 data – not in DHIN's control, but we must inform them of the requirement
- Search for unknown data – improved efficiency if through existing channels
  - Through the PDMP
  - Through the Community Health Record – must be discoverable ONLY if the patient has granted consent – including the simple fact that SUD data exists
- Incorporate into clinical and/or office workflow the facilitation of getting the patient's signed consent



# Patient Workflow

## GOAL: “No wrong door”












- Provider-mediated access to the consent tool – must be integrated into workflow at the practice
- Through the DHIN PHR
  - Under complete control of the patient at all times
  - Allows DHIN to provide automated reminders that the period of consent is about to expire and should be renewed if the patient so desires
  - Integrates into an existing consumer engagement tool
- Paper-based consent – DHIN requires in-person form completion or notarized mail-in


# *Progress to Date in Delaware*




# Consent Tool

- Phase I – two-part blunt instrument – released to production in FY21
  - All-or-none permission to disclose Part 2 data “to all providers involved in my care”
  - All-or-none “General Consent” to share other medical data
- Phase II – More granular consent – released to production in FY22
  - Sharing specified at the provider/practice level for Part 2 data
  - All-or-none “General Consent” to share other medical data
- Chicken and egg situation! We have the tool, now we need the data!
- DSAMH is currently sending us Part 2 data, but they aren’t facilitating obtaining patient consent to disclose
- Soliciting engagement with other Part 2 providers; financial as well as trust barriers must be overcome

-  My Dashboard
-  **Consent Editor**
-  Health Timeline
-  Health Profile
-  My Health Files
-  My Messages
-  My Apps & Devices
-  My Appointments
-  To Do's
-  History
-  Directory

 **PATRICK MURRAY**  
37 years old  
[Edit Social History](#)

**Allergies**



No active Allergies recorded

**Appointments**

No future active appointments recorded.

**Blood Pressure**




No Blood Pressure recorded

**Conditions**




No active Conditions recorded

Tuesday May 3




Current temp:  
**72.8°**  
73°/58° 💧 61%

**Heart Rate**




No Heart Rate recorded

**Health Files** 1



Patient Consent  
Dec 14, 2021

**Exercise**



No Exercise recorded

**Lab Results** 1



Testost SerPI-mCnc  
**100 ng/dL**  
Sep 4, 2020


**Health Tips**

**Hepatitis Outbreak in Children: What to Know**


[WebMD Health](#)

⋮

**Immunizations**



**Medications**



**Procedures**



**Respiratory Rate**





My Dashboard



Consent Editor



Health Timeline



Health Profile



My Health Files



My Messages



My Apps & Devices



My Appointments



To Do's



History

## Consent Editor

Current

History

Add

Part 2

HIE

All

**Period**

**Status**

**Consent Type**

**Date signed**

01/07/2022 11:36 AM

Opted In

HIE

01/07/2022 11:36 AM

Part 2

HIE

## Period

01/07/2022 11:36 AM

## Request for Non-Participation



## DESCRIPTION

## CONSENT

Patient Name	Date of Birth	Address
MURRAY, PATRICK	05/17/1984	250 K Street NE Apt. 1001, Washington, DC 20002

Please check the box to indicate that you have read and understand each of the following statements:

- By checking here, I acknowledge my understanding that if I previously opted out of having my medical records securely shared through DHIN, this form will change that decision. By executing this consent I revoke any opt-out form that I had previously submitted to DHIN.
- I hereby authorize DHIN to block access to my test results and medical health information through DHIN.
- I understand that I may choose to participate in DHIN again at any time by completing a Cancellation Request form.
- I understand that DHIN will continue to deliver my results to DHIN Users associated with the result or my treatment and will continue to provide medical information pursuant to my authorization or my being included on a patient panel submitted to DHIN by or on behalf of a health care provider or payer.

## EFFECTIVE DATE AND SIGNATURE

Signature

05/03/2022 04:57 PM

- By checking here, I acknowledge that I intend for DHIN and the identified providers to be permitted to rely upon my authorization and my electronic signature is intended to be fully binding and the same as a handwritten signature for the purposes of validity, enforceability, and admissibility.

Close

Save

# Part 2 Consent Opt-In



My Dashboard



Consent Editor



Health Timeline



Health Profile



My Health Files



My Messages



My Apps & Devices



My Appointments



To Do's



History



Directory Services

Part 2

HIE

All

### Period

01/07/2022 11:36 AM

## Consent to Release Federally Protected Substance Use Treatment Records

Patient Name  
MURRAY, PATRICK

Date of Birth  
05/17/1984

Address  
250 K Street NE Apt. 1001,  
Washington, DC 20002

By executing this consent, I authorize all of my health care providers, including those providers where I have received mental health treatment and/or treatment for alcohol, drug, or other substance abuse, to release all information about my treatment through the Delaware Health Information Network ("DHIN"), the State of Delaware's sanctioned provider of health information exchange services, to any medical providers enrolled as participants in DHIN and that have a treating provider relationship with me.

By executing this consent, I authorize the following health care providers, to release all information about my treatment through the Delaware Health Information Network ("DHIN").



DHIN may only disclose data to such providers for treatment purposes.

By checking here, I acknowledge my understanding that if I previously opted out of having my medical records securely shared through DHIN, this form will change that decision. By executing this consent I revoke any opt-out form that I had previously submitted to DHIN.

### CONFIDENTIALITY OF RECORDS AND REVOCATION OF CONSENT

### SUMMARY OF DISCLOSURES

### EFFECTIVE DATE AND SIGNATURE

Signature

05/03/2022 04:56 PM

By checking here, I acknowledge that this consent will be effective starting the date that I add my electronic signature and click "save" below, and will cover all Part 2 Information that has already been or will be provided to DHIN in the future by authorized providers, for such time period as I have authorized the consent to remain in effect.

This consent will automatically expire  years following its execution. (05/03/2022 04:56 PM - 05/03/2025 04:56 PM)

By checking here, I acknowledge that I intend for DHIN and the identified providers to be permitted to rely upon my authorization and my electronic signature is intended to be fully binding and the same as a handwritten signature for the purposes of validity, enforceability, and admissibility.

Close

Save

Search

Current

History

Add

### Type Date signed

01/07/2022 11:36 AM

Part 2 Consent  
Opt-In  
Provider Selection  
Screen

### Add Health Care Provider

Practitioner Organization Name Taxonomy

NPI Number City State

Organization Name Search

Name	Taxonomy	NPI Number	City	State
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Close Save

SUMMARY OF DISCLOSURES

EFFECTIVE DATE AND SIGNATURE

Signature 05/03/2022 05:07 PM

By checking here, I acknowledge that this consent will be effective starting the date that I add my electronic signature and click "save" below, and will cover all Part 2 Information that has already been or will be provided to DHIN in the future by authorized providers, for such time period as I have authorized the consent to remain in effect.

This consent will automatically expire 3 years following its execution. (05/03/2022 05:07 PM - 05/03/2025 05:07 PM)

By checking here, I acknowledge that I intend for DHIN and the identified providers to be permitted to rely upon my





Clinician  
Dashboard

Patient Charts

### Patient Selection

**Patient Search**

Show Advanced Search Fields

Last name	First name	Gender	DOB	Age	Pt Records Available	Address	Status
Jones	Bridget	Female	09/24/1967	54	All	123 Main street, Claymont, DE 19709	

SUD Viewer  
Patient Search



Patient Charts

All sources

**Jones, Bridget (F, 54)**  
DOB: 09/24/1967

Address: 123 Main street, Claymont, DE 19709

**SUD Viewer  
Patient Charts**

Green Clinic Labs Attender: NG UYEN, KIM A.

Summary

All Results

Date: All Status: All Final

Test	Type	Date	Provider	Status	Source
History and Physical RPT	Trans	06/25/2021 16:16	Hall, Serena	Final	Green Clinic Labs
CT ABDOMEN PELVIS W CONTRAST	Radiology	06/25/2021 15:53	KHAN, AAMER A.	Final	Green Clinic Labs
789254 9+Oxycodone -Bund	Lab	06/23/2021 08:03		Final	Green Clinic Labs
789112 5+Crtr-Bund	Lab	06/21/2021 07:16	Andrews, Meghan	Final	Green Clinic Labs
789112 5+Crtr-Bund	Other	06/21/2021 07:16	Andrews, Meghan	Final	Green Clinic Labs
789112 5+Crtr-Bund	Other	06/19/2021 07:16	Andrews, Meghan	Final	Green Clinic Labs
788799 5+Crtr-Bund	Other	06/17/2021 08:03		Final	Green Clinic Labs
789254 9+Oxycodone -Bund	Other	06/15/2021 08:03		Final	Green Clinic Labs
XR ANKLE LT 3 VW	Other	06/04/2021 00:00	DELLIGATTI, BRIAN J	Final	Green Clinic Labs

Labs (last 5 panels displayed, trendline displays last 5 results if available)

Panel	Test	Value	Interpretation	Trendline	Elapsed Time
789254 9+Oxycodone-Bund	Amphetamines, Urine	Negative			3m 1w
	Barbiturates	Negative			
	Benzodiazepines	Negative			
	Cannabinoid	Negative			
	Opiates	Negative			
789112 5+Crtr-Bund	Oxycodone/Oxymorphone, Urine	Negative			3m 1w
	Phencyclidine	Negative			
	Methadone Screen, Urine	Negative			
	Propoxyphene, Urine	Negative			
	Amphetamines, Urine	Negative			
789112 5+Crtr-Bund	Cannabinoid	Negative			
	Cocaine (Metab.)	Negative			
	Opiates	Negative			
789112 5+Crtr-Bund	Phencyclidine	Negative			
	Cocaine, Urine	Negative			

Administration

Audit

Clinician Dashboard

Patient Charts

Patient Consent



### Patient Selection

Clinic  
Dash

Patie

Patie  
Conse

Opt Out of Part 2  
Consent

First name	Gender	DOB	Age	Pt Records Available	Address	Status
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#### Recently viewed patients

Patient	Pt Records Available	Address	Status
Jones, Bridget (F, 54) DOB: 09/24/1967	All	123 Main street, Claymont, DE 19709	
REST, MIMI (F, 48) DOB: 09/12/1973	All	1212 DHIN Way, Dover	No Part 2 Consent Available
Bebe, Kids (F, 10) DOB: 09/20/2011	All	123 Main dr, Newark, DE 19713	No Part 2 Consent Available



Clinician  
Dashboard

Patient C

Patient  
Consent

## Opt Out of Part 2 Consent

### Restricted information

THIS PATIENT HAS REQUESTED THAT HIS RECORDS NOT BE ACCESSED.

Cancel



Search

Name	Gender	DOB	Age	Pt Records Available	Address	Status
------	--------	-----	-----	----------------------	---------	--------

#### Recently viewed patients

Patient	Pt Records Available	Address	Status
Jones, Bridget (F, 54) DOB: 09/24/1967	All	123 Main street, Claymont, DE 19709	
REST, MIMI (F, 48) DOB: 09/12/1973	All	1212 DHIN Way, Dover	No Part 2 Consent Available
Bebe, Kids (F, 10) DOB: 09/20/2011	All	123 Main dr, Newark, DE 19713	No Part 2 Consent Available

# *Next Steps*



# Next Steps

- Phase III – granular consent to share other sensitive data types
  - Each must be addressable individually
- Would be useful to be able to integrate the consent tool into the patient portal of our customers
- We are currently prioritizing work for FY23 and will have to see if this can be slotted

# Q & A





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*[www.DHIN.org](http://www.DHIN.org)*

***Thank you.***