PATIENT-CONTROLLED MEDICAL RECORD SHARING

SGWG PANEL

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AGENDA

1 GRANULAR DATA SHARING

2 FINDINGS
- Patient
- Provider
- Law
- Technology

3 FUTURE RESEARCH

CONSENT-BASED GRANULAR DATA SHARING

Patients should have a greater degree of choice to determine, at a granular level, **which personal health information should be shared**, **with whom**, and **for what purpose**

ONC, Health Information Policy Committee, 2010

Office of the National Coordinator for Health Information Technology

Support for Granular Data Sharing

PATIENT-CONTROLLED DATA SHARING

R01 -My Data Choices

Communicable Diseases
Genetic Information
Mental Health
Sexual and Reproductive Health
Substance Use Information

2016-2021

NIH
National Institute of Mental Health

R01- Substance Use Health Record Sharing (SHARES)

Substance Use Information

2023-2028

NIH
National Institute on Drug Abuse

Adela Grando, PhD
Principal Investigator

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GRANULAR DATA SHARING

Driving forces

Patient	Data privacy & stigma
Provider	Effective & safe care
Law	Data sharing requirements
Technology	Data interoperability & standards

GRANULAR DATA SHARING

Patient Perspectives

Laxatives are **mental health information.** I take them to counteract the effects of mental health meds.

I used to drink. Substance use information is **not sensitive to me anymore.**

25 Patients

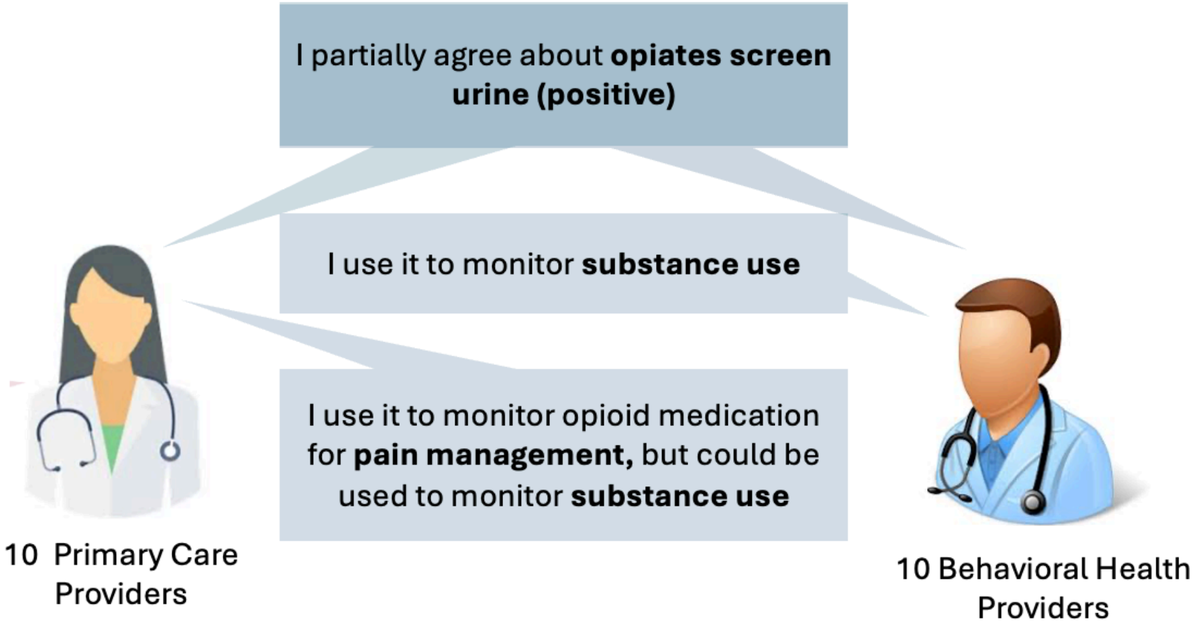
750 Data Items

66.4% agreements & 37.5% disagreements with providers' classifications

Soni et al. (2020) State of the art and mixed-method personalized approach to assess patient perceptions on medical record sharing and sensitivity. JBI

GRANULAR DATA SHARING

Provider Perspectives



1,000 data items

50.0% agreements, 32.5% partial agreements & 17.5% disagreements

Banerjee et al. (2023) Physicians differ in their perceptions of sensitive medical records: survey and interview study. Health Informatics Journal.

GRANULAR DATA SHARING

State & Federal Laws

Communicable Diseases

Genetic Information

Mental Health

Sexual & Reproductive Health

42 CFR Part 2 Federal Law

Substance Use

Prescribed Control Substances

Saks et al. (2018) Granular Patient Control of Personal Health Information: Federal and State Law Considerations. Jurimetrics.

PATIENT PORTAL: FRONT END

Granular data sharing

GREG GATES7 ONDRICKA1975 PATIENT PORTAL | My Record Summary | My Sharing Settings | Documentation | Patient Selection | Leave Feedback

Please share my medical information

- With no exceptions
- Under no circumstances
- Only for certain categories I specify

- Disabilities
- Genetics
- Infectious Diseases
- Mental Health
- Sexual and Reproductive Health
- Social Determinants of Health
- Substance Use
- Violence

Remove Date Restrictions

Start
2024-03-05
Begins at this date in yyyy-mm-dd format.

End
2025-03-04
Ends at this date in yyyy-mm-dd format.

For purposes of

- Treatment providing or supporting my care
- Research intended to benefit others

With the following organizations

AHC HOME HEALTH CARE OF MURRAY, LLC Organization/195247 Remove

Search for more...

Search

Search for organizations to whom your wishes will apply.

Authorization

Your Full Legal Name
Greg Gates

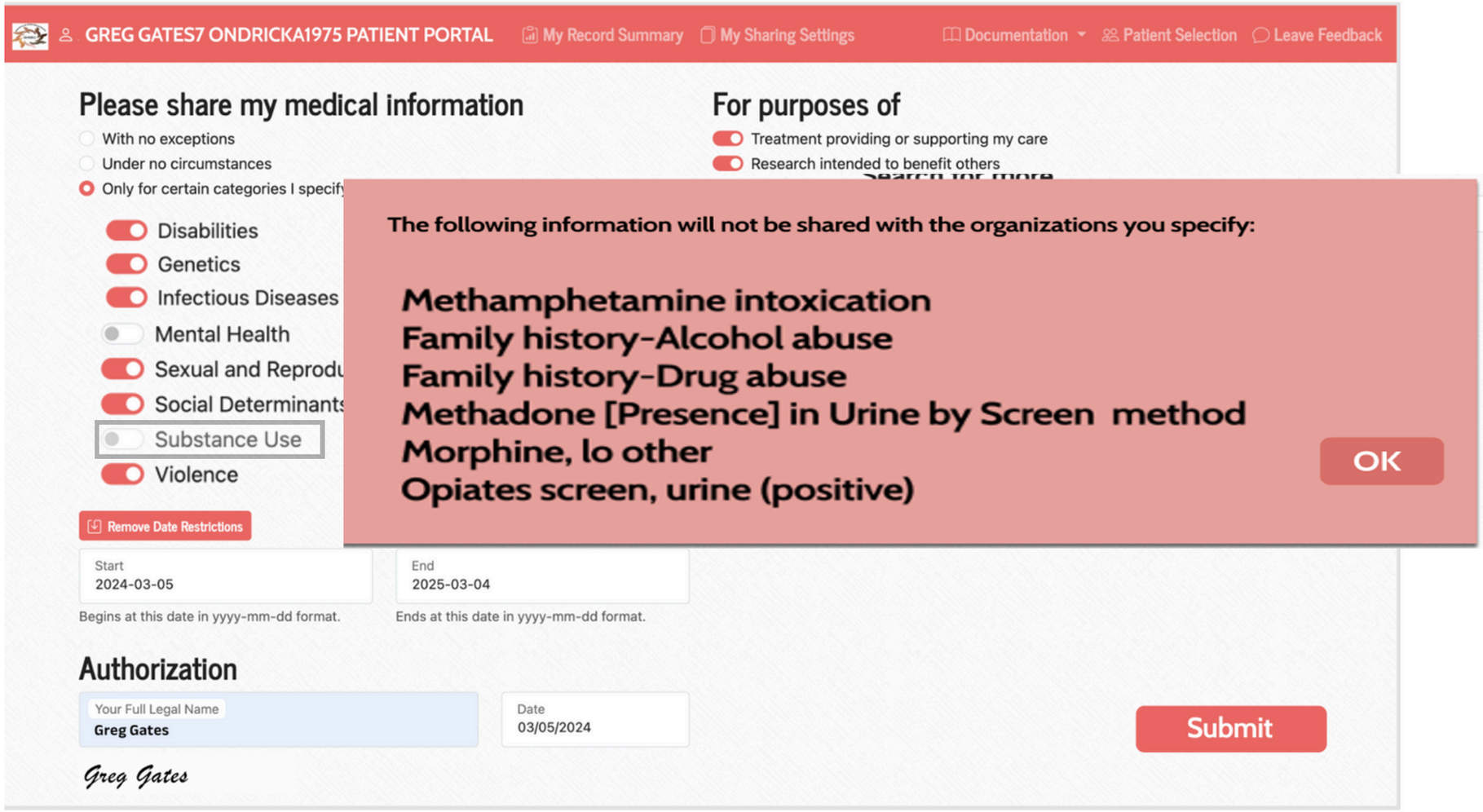
Date
03/05/2024

Greg Gates

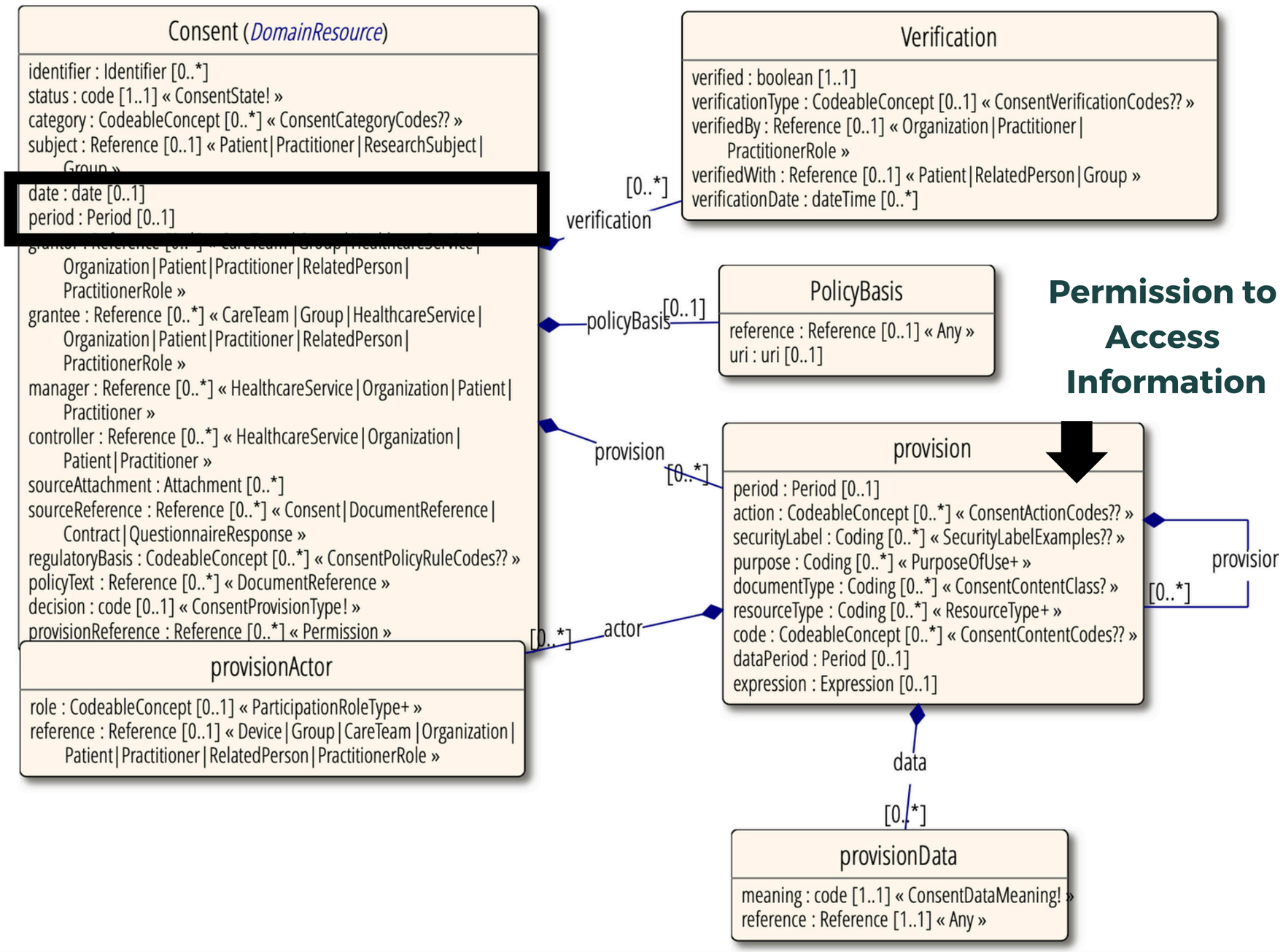
Submit

PATIENT PORTAL: FRONT END

Granular data sharing



PATIENT PORTAL: BACK END

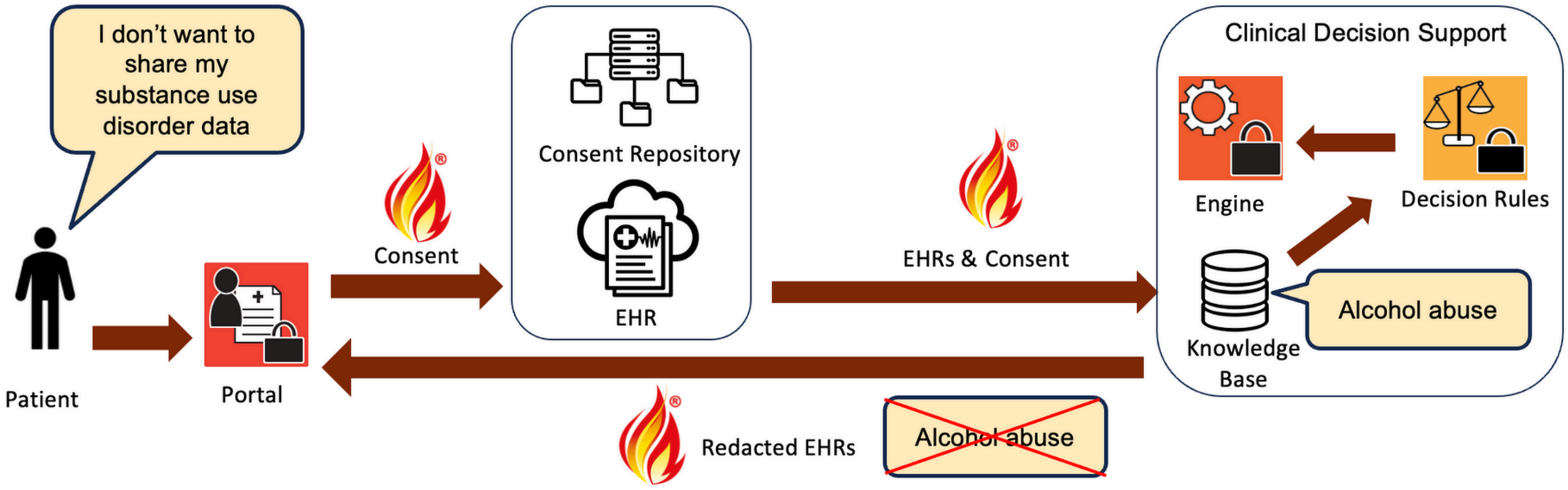


Permission to Access Information

FHIR = Fast Healthcare Interoperability Resources

CLINICAL DECISION SUPPORT SYSTEM

FHIR-based granular data sharing



P. Lee, D. Mendoza, M. Kaiser, E. Lott, G. Singh, M.A. Grando (2024) FHIR Granular Sensitive Data Segmentation. ACI.

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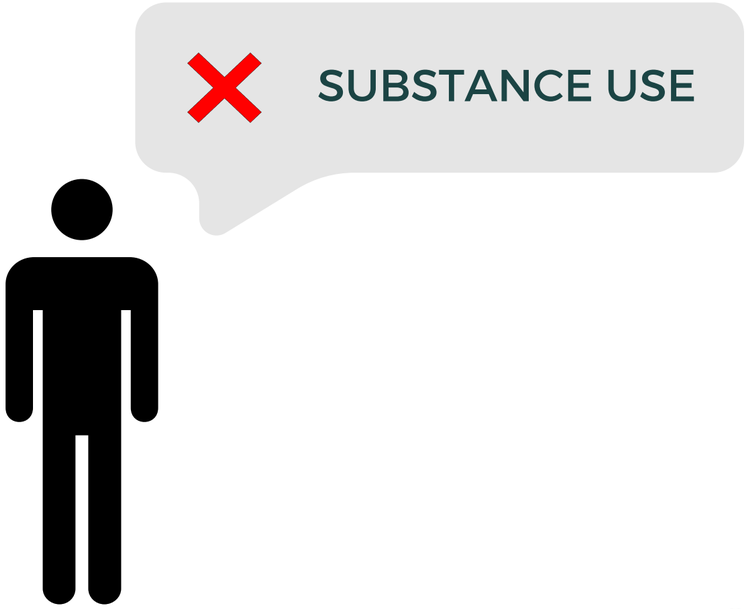
CONTEXTUAL REASONING

Partial agreement

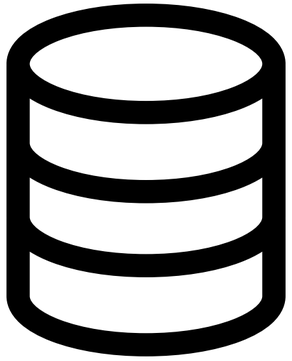


EHR

Opiates Screen Urine (positive)

More context needed ?

SUBSTANCE USE
Knowledge Base



Opiates Screen Urine (positive)

ACKNOWLEDGMENTS

Research Collaborators

Advisory Board

Individuals with Lived Experiences

Students