



# **Session F:**

# **New Perspectives on Old Problems**

**Moderator:**

**Nickolas Zaller**  
**JCOIN Steering  
Committee Chair**

# **Presentations by:**

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- 1. Danielle Rudes – CTC & Harold Pollack – University of Chicago Hub/MAARC)***
- 2. Carrie Pettus & Danielle Rudes - CTC***
- 3. Ralph Brooks – Yale-ACTION Hub***
- 4. Michael Dennis – Chestnut Health Systems Hub***
- 5. Dennis Watson – Chestnut Health Systems Hub***



# No Help Finding Help: The Search for MAT/MOUD Treatment in Critical Access Areas

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**Harold Pollack**

Francis Lee

University of Chicago

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JUSTICE COMMUNITY OPIOID INNOVATION NETWORK  
expressed



# Critical Access Areas in the U.S.

- Persons living in the U.S., particularly in low-service and rural areas, may experience high rates of substance/opioid use disorder with limited treatment options available in their locale.

60M Americans  
live in rural areas

Rural adults have  
higher usage rates  
for many  
substances

100+ rural  
hospitals closed  
2013-20 = further  
travel


Rural 1<sup>st</sup>  
responders may  
have more limited  
SUD experience


Telehealth  
challenging w/o  
wide access to  
broadband



Rural populations  
include higher #s  
non-whites &  
veterans

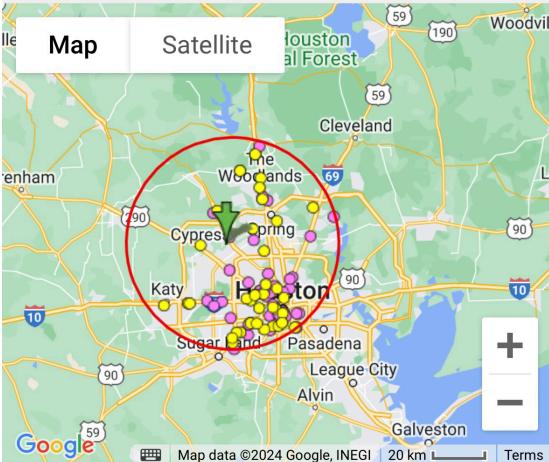


# SAMHSA'S TREATMENT LOCATOR

FindTreatment.gov 


Your Location  
Houston, TX 77070, USA 


 Sort & Filter  View in a Map






**Legend: Facility Types**


- Substance Use
- Mental Health
- Health Care Centers
- Buprenorphine Practitioner
- Opioid Treatment Program


FindTreatment.gov 


Your Location  
Houston, TX 77070, USA 

 Sort & Filter  View in a Map






 **Set Search**

State  County  Distance 25 miles 

Sorted by: Distance: Low to High 

 **Filter by**

**Facility Types** (select all that apply)

- Substance Use 
- Mental Health 
- Health Care Centers 
- Buprenorphine Practitioner 
- Opioid Treatment Programs 

## Prior Literature Noting SAMHSA's Treatment Locator Weaknesses

- Anyanwu, P., Varisco, T. J., Wanat, M. A., Bapat, S., Claborn, K., & Thornton, J. D. (2022). Comparing two databases to identify access to buprenorphine treatment for opioid use disorder. *Journal of Pain & Palliative Care Pharmacotherapy*, 36(2), 103-111.
- Barenie, R. E., Winbigler, B. L., Heidel, R. E., & Wheeler, J. S. (2022). Accuracy of publicly-listed locator information for buprenorphine waived practitioners and opioid treatment programs in the US, 2020. *Substance Abuse*, 43(1), 999-1003.
- Burns, A., Menachemi, N., Yeager, V. A., Vest, J. R., & Mazurenko, O. (2023). Adoption of best practices in behavioral health crisis care by mental health treatment facilities. *Psychiatric services*, *appi-ps*.
- Chen, K., Oldfield, B. J., Joudrey, P. J., Biegacki, E. T., & Fiellin, D. A. (2023). Associations between Patient Experience and Addiction Treatment Facility Services: Results of the Addiction Treatment Locator, Assessment, and Standards Surveys. *Journal of Addiction Medicine*, 10-1097.
- Flavin, L., Malowney, M., Patel, N. A., Alpert, M. D., Cheng, E., Noy, G., ... & Boyd, J. W. (2020). Availability of buprenorphine treatment in the 10 states with the highest drug overdose death rates in the United States. *Journal of Psychiatric Practice*, 26(1), 17-22.

Few initial appointments  
available

Incomplete information

The Substance Abuse and Mental Health Association  
(SAMHSA) created a Treatment Locator in 1992 with  
funding from the U.S. Congress.

**This locator has some weaknesses...**

Lack of treatment adhering  
to SAMHSA's best  
practices

Few treatment services  
include information  
regarding patient  
experience ratings

# Our Study

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Sought to interview individuals working within the top 200 “Critical Access Units” in the United States as identified by Pollack, Lee, Paykin, and Rojas-Aguilera (2023).

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At least 3 emails/phone calls to each one for interview(s)

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Google search of each CAU to compare address, phone number, treatment services, business status with SAMSHA Treatment Locator

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Follow up phone/emails if initial number/emails differed from identified CAUs (from SAMSHA Treatment Locator)



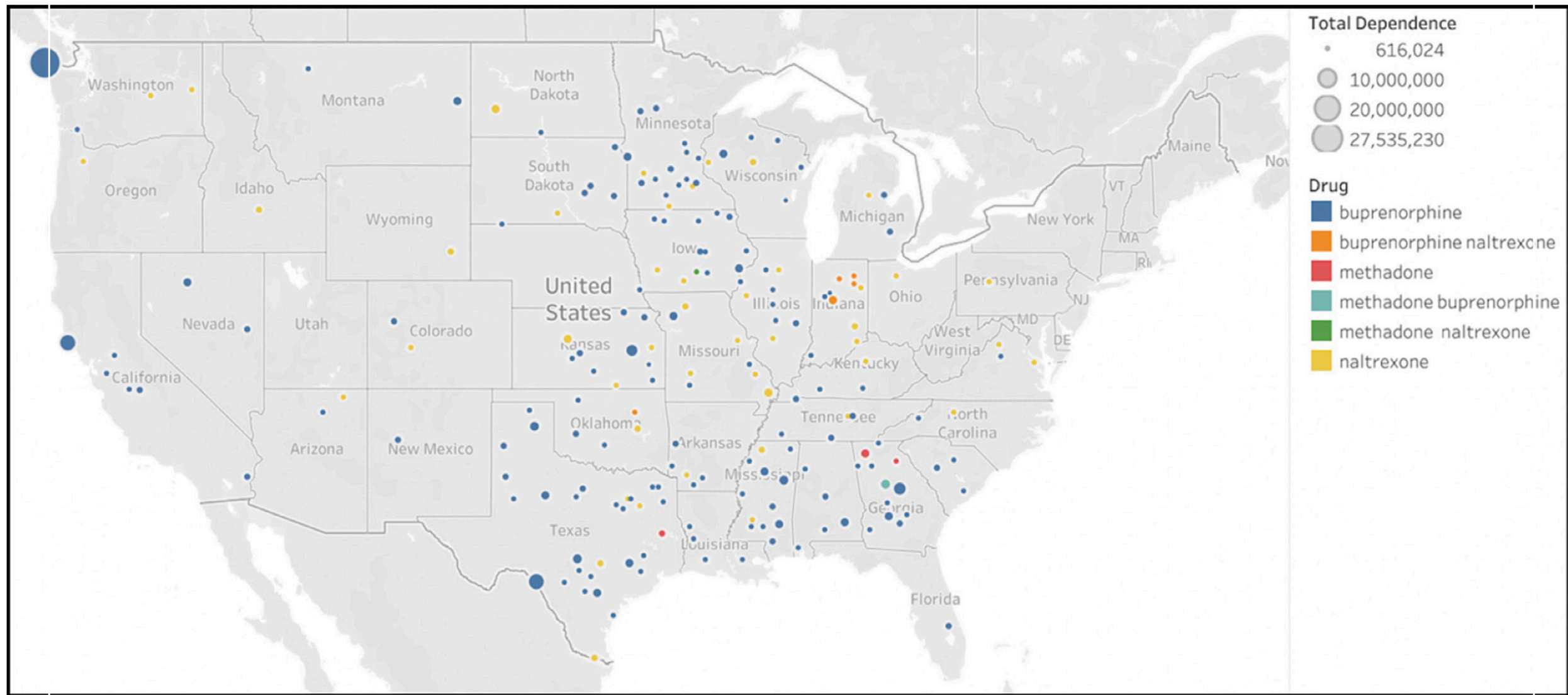


Fig. A1. Top 200 Critical Access MOUD treatment facilities, Continental United States.

Active sites with MAT (or likely MAT)	Active sites with no MAT or were a referral service only	Closed sites or sites w/ services unrelated to MAT	Sites on sample also on current SAMSHA locator
64 (32%)	51 (26%)	81 (41%)	88 (44%)

**Only 32% of the treatment sites were ACTIVE**

**67% of the treatment sites were not providing MOUD, only referred to MOUD, or were out-of-business**

**Less than 1% would talk to us**

# Discussion & Implications

**Without being able to identify, contact, and/or access critical care units, persons who need services face an increased likelihood of poor health outcomes, including increased potential for suicide and overdose.**

**Additionally, researchers cannot conduct necessary data collection to inform clinicians, policy makers, and communities regarding resource strategies to improve MOUD Treatment access and service availability for those most in need of assistance.**





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# Thank You

Please direct questions to  
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[haroldp@uchicago.edu](mailto:haroldp@uchicago.edu)



# Developing and Evaluating a Behavioral Health Literacy Curriculum in State Prisons: A COMMUNITY-ENGAGED APPROACH WITH CARCERAL STAFF AND RESIDENTS

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**Danielle S. Rudes**, Sam Houston State University

**(JCOIN CTC)**





# THE BHL TEAM



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Teisha Sanders



Jennifer Joseph



Sarah Schnautz



Sarah Tamburri



Rachel Fulmer



Danielle S. Rudes



Bryce Kushmerick-McCune



Chelsey Narvey



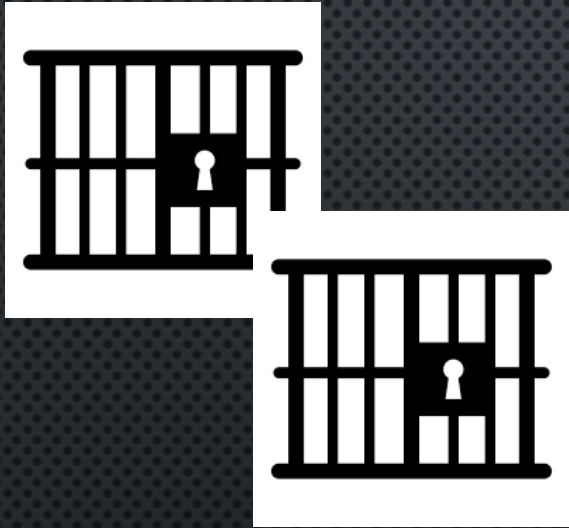


# BEHAVIORAL HEALTH LITERACY

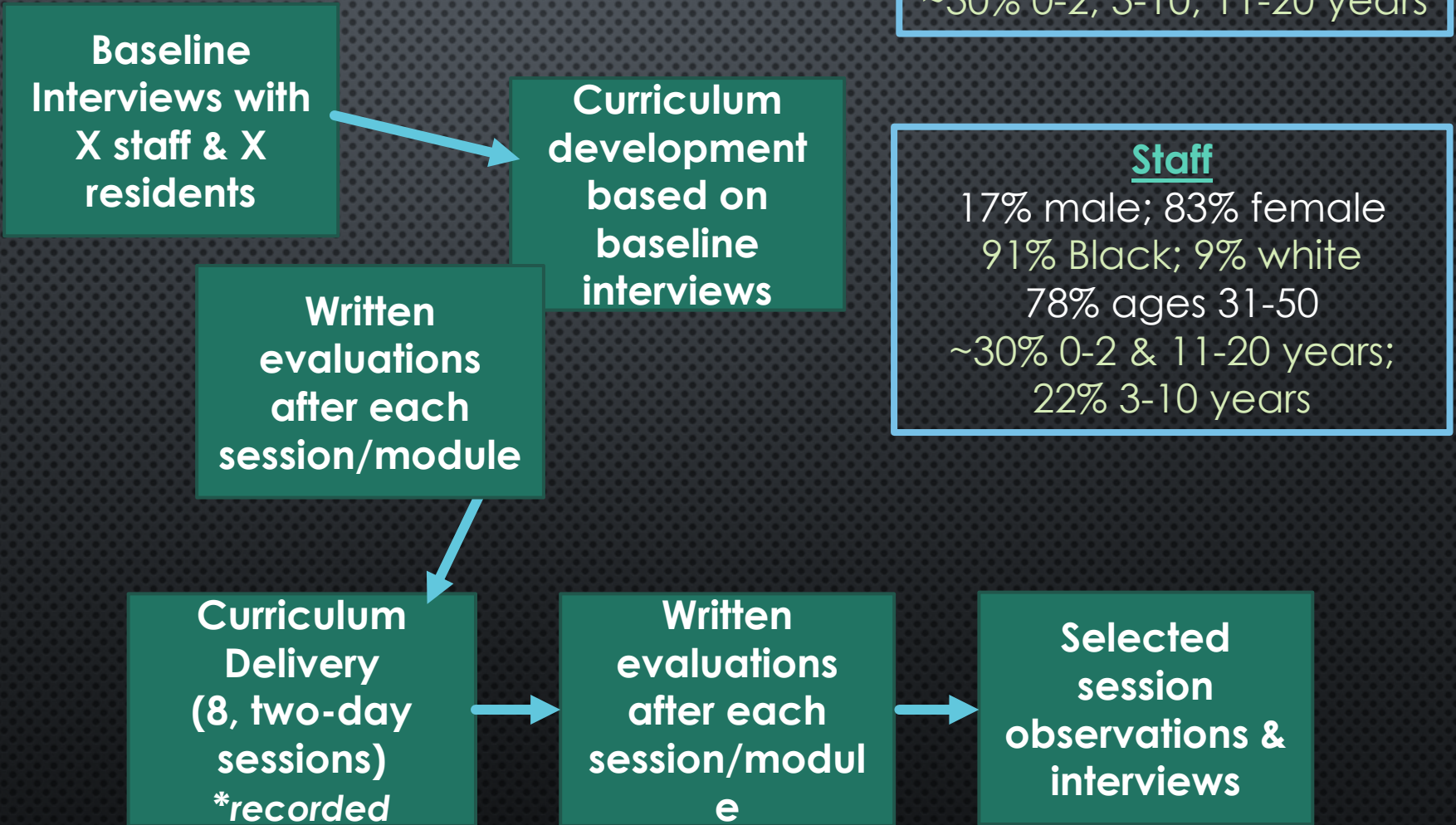
- The understanding of mental health and substance use disorders including their etiology, their impact on daily living, and potential informal and formal supports for coping with life challenges related to mental health and substance misuse.
- Enhancing BHL among both prison staff and residents can facilitate better understanding, support, and management of mental health and substance use disorders, leading to improved outcomes for individuals and the prison environment as a whole.



# BHL PRISON PILOT PROJECT



2 SC prisons  
(1 male/1 female)



**Residents**  
50% male; 50% female  
50% Black; 46% white  
64% ages 31-50  
~30% 0-2; 3-10; 11-20 years

**Staff**  
17% male; 83% female  
91% Black; 9% white  
78% ages 31-50  
~30% 0-2 & 11-20 years;  
22% 3-10 years

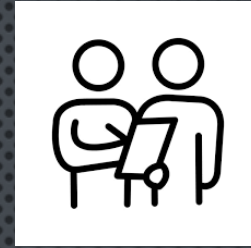


# BASELINE INTERVIEWS



## RESIDENTS DESIRE

1. Regular & sustained access to treatment
2. Trust and rapport with other individuals in treatment and therapy folks/counselors
3. Safety & security
4. A plan with short- and long-term goals and a pathway to achieve something within custody and post-release



## STAFF DESIRE

1. Regular and sustained resident treatment access
2. Treatment availability during lockdowns and other prison-related interruptions to daily living/programming/movement
3. Incentives for residents to go to/complete treatment
4. Program staff want better collaborative relationships with custodial staff
5. Programs to keep residents with mental health challenges busy
6. Deeper, more meaningful training for residents that uses a holistic approach to the "whole" person
7. Gender-informed mental health trainings; particularly trauma



# BHL CURRICULUM

**Understanding  
Behavioral  
Health Disorders**

**The Origin of  
Behavioral  
Health Disorders**

**Triggers**

**Relation to Self &  
Others**

**Maintaining  
Healthy  
Behaviors**

**Seeking Support  
for Behavioral  
Health Disorders**

**Communication  
& Collaboration  
with Safety &  
Security in Mind**

**Moving Forward**



# Next steps



Complete curriculum delivery



Conduct Ethnographic observation of training



Complete Informal interviews with staff and resident training participants



Analyze recordings, fieldnotes, interview notes, and session/course evaluation forms



Conduct Curricular revision (as needed)



Prepare R-01 proposal for NIH to expand BHL training into additional carceral institutions

# THANK YOU

...AND SPECIAL THANK YOU TO THE NATIONAL  
INSTITUTE OF DRUG ABUSE (NIDA) VIA JCOIN

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# Timeline Followback & Event Review Cycles: New Tricks for REDCap

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Alysse Schultheis, Project Coordinator

**NIDA JCOIN ACTION Study (Grant #U01DA053039)**

M-PIs: Sandra Springer, MD

Ank Nijhawan, MD, MPH, MSCS

Kevin Knight, PhD

June 12, 2024

# Disclosures

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- The presenter has no conflict of interest.



# Yale ACTION Project

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- A NIDA-funded, hybrid type 1 randomized controlled trial comparing effectiveness of **patient navigation** to **mobile health unit** service provision for persons involved in the justice system with a history of opioid and/ or stimulant use to evaluate:
  - length of time to taking Pre-exposure prophylaxis (PrEP) or antiretroviral therapy (ART) based on HIV status (primary outcome)
  - the full cascades of care for HIV, HCV, and OUD (secondary outcomes)
- JCOIN's only HIV-focused justice-involved study

*Study Protocol: Springer et al., BMC ID, 2022*



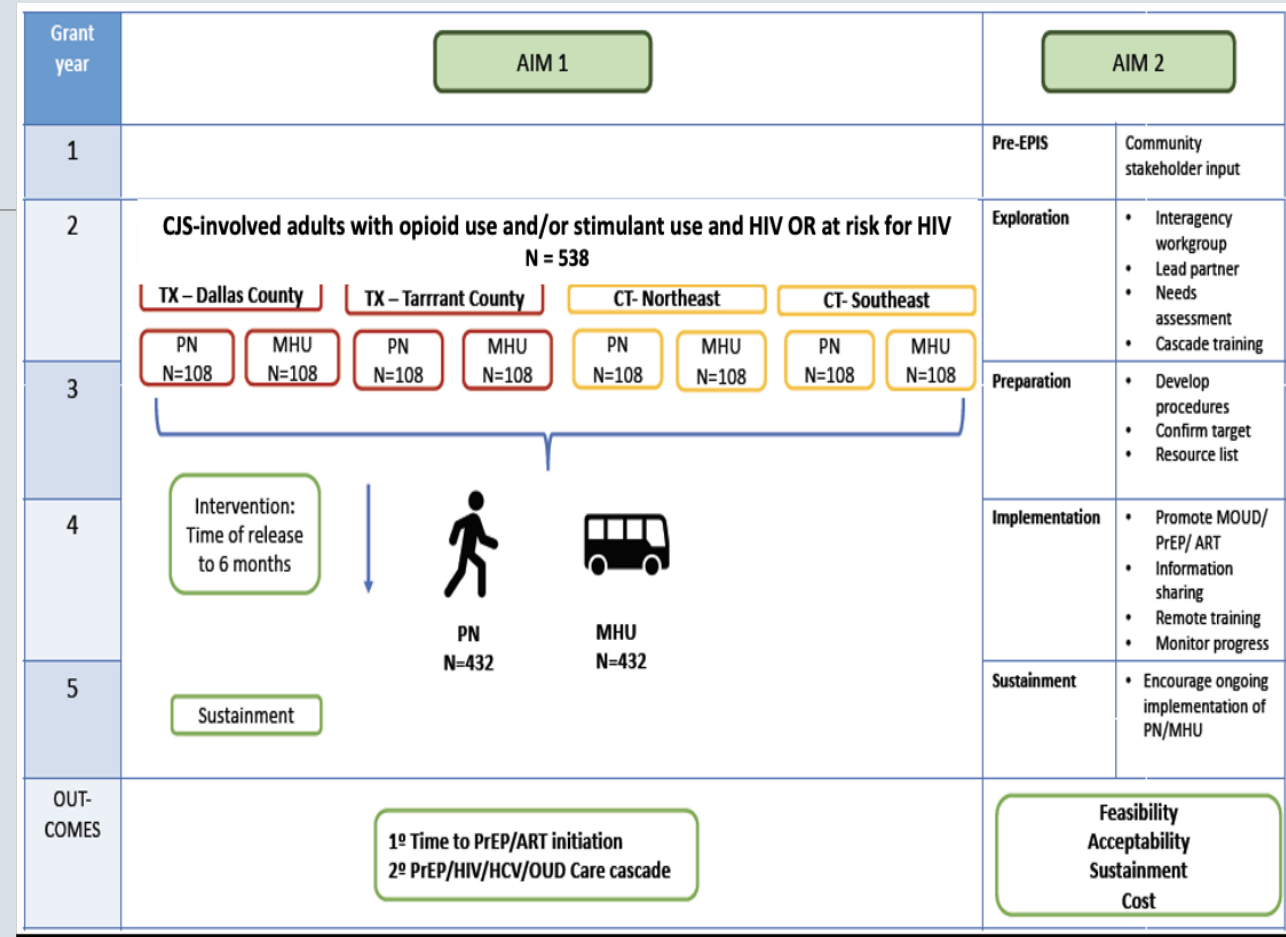
# Yale ACTION Project

- Up to 864 Participants across 4 sites
- over 500 consented so far
- 5 timepoints / 12 months
- Goal: All data capture by REDCap

• Non-standard Data Opportunities

➔ Timeline Followback (TLFB) to understand substance use between visits

➔ PI approval cycles for Data Requests and SAEs



- Interagency workgroup
- Lead partner
- Needs assessment
- Cascade training

- Develop procedures
- Confirm target
- Resource list

- Promote MOUD/PrEP/ART
- Information sharing
- Remote training
- Monitor progress

- Encourage ongoing implementation of PN/MHU

# Timeline Followback (TLFB)

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- The gold standard for substance use self-report calendar-based daily retrospective tool for research / clinical use that utilizes anchoring events to quantitate frequency estimates
- Validated for multiple drugs
- Developed by Linda Sobell, published in 1996

<https://cde.nida.nih.gov/instrument/d89c8e23-16e5-625a-e040-bb89ad43465d>

# Picture of TLFB

	A	B	C	D	E	F	G	H	I	J	K	L				
1	<b>Drug Category: Click on the yellow box below, and then the arrows to the right of it, to choose drug.</b>								Name of Prescription Drug	Lock All Days BEFORE						
2										2/10/24						
3	Client ID:	Gender:	TLFB Start Date:	30 Days Back	This Coming Saturday's Date	Session	Days Entered	Days Left to Enter	Complete?	Lock All Days AFTER						
4	1	Male	3/10/24	2/9/24	3/16/2024		0	30	Not Complete Yet	3/10/24						
6	<b>30 DAY TIMELINE FOLLOWBACK CALENDAR</b>							3/11/2024	Today's Date							
7	SUN	MON	TUE	WED	THURS	FRI	SAT	<b>*BEFORE ADMINISTERING PLEASE READ INSTRUCTIONS*</b>								
8	4-Feb	5-Feb	6-Feb	7-Feb	8-Feb	9-Feb	10-Feb	<p>The purpose of these instructions are to explain how to <b>darken and lock the cells</b> that you do not want the user to enter information into.</p> <ol style="list-style-type: none"> <li>Any date before (not including) the date at the top of the excel document marked "30 Days Back" should be darkened in and locked. Any date after (not including) the date at the top of the excel document marked "TLFB Start Date" should also be darkened in and locked.</li> <li>To <b>darken cells</b>, highlight all of the cells you want to darken, select "Home" from the uppermost tabs (this should be the default tab), select the downward facing triangle next to the paintbucket (directly below tab named formulas), and select the color you want to change the cells.</li> <li>To <b>lock cells</b>, highlight all of the cells you want to lock, right click on the cells you want to lock, choose the "format cells" option (has a little sheet with bullet points next to it), select the tab on the far right of the popped-up screen marked "Protection," and select the checkbox labelled "Locked." Then select "ok." This stops users from entering numbers into the cells you select.</li> <li>Lastly, you can password protect the sheet so that the user cannot unlock the cells by selecting "Review" in the uppermost tabs, select "Protect Sheet" (the icon has a spreadsheet with a lock next to it), and ONLY select the checkbox labelled "select unlocked cells." Be sure to enter a password (and reenter it when prompted) before you click "ok."</li> </ol>								
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10																
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27	<b>STOP HERE-NOTIFY ADMINISTRATOR</b>															

<https://www.nova.edu/gsc/forms/other-drug-use-yes-tlfb-2015.xlsx>



# Implementation Considerations

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TLFB normally Paper or Excel Based

- Paper forms → need transcription
- Excel .xlsx → need aggregation for analysis. (864 clients, 5 times points = 4320 files)

Desired solution: Single Step (no transcription or aggregation)

→ TLFB in REDCap

- Fewer errors and less time for data capture overall
- But REDCap doesn't handle dates as smoothly as Excel.
- No built-in calendar, no 7-day display, does not understand dates as days of the week
- Recent updates have improved the ability to add, subtract, and count dates, but additional functionality is limited.

# Our Build – Aims / Goals

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- Accommodate all participant records (up to 4320 files)
- Monitor an array of drugs ( 10 Opioids, 4 Stimulants, 1 “Other”) with routes of administration
- Accommodate timepoints with varying target and maximum look back periods (all time since previous visit):
- Summary of days of use by drug type and drug class

Timepoint	Target Look Back (days)	Maximum Look Back (days)
Baseline	30	Same
Month 1	30	Same
Month 3	60	90
Month 6	90	180
Month 12	30	Same

# Our Build – Appearance + Function

(Week -5)	Sunday	Monday	Tuesday	Wednesday	Thursday	Friday	Saturday
<b>Date</b>	02-05-2023 <a href="#">View</a> equation	02-06 <a href="#">View</a> equation	02-07 <a href="#">View</a> equation	02-08-2023 <a href="#">View</a> equation	02-09-2023 <a href="#">View</a> equation	02-10-2023 <a href="#">View</a> equation	02-11-2023 <a href="#">View</a> equation
<b>Were drugs used during this day?</b>	<input checked="" type="radio"/> Yes <input type="radio"/> No <small>reset</small>	<input type="radio"/> Yes <input checked="" type="radio"/> No <small>reset</small>	<input type="radio"/> Yes <input checked="" type="radio"/> No <small>reset</small>	<input checked="" type="radio"/> Yes <input type="radio"/> No <small>reset</small>	<input checked="" type="radio"/> Yes <input type="radio"/> No <small>reset</small>	<input checked="" type="radio"/> Yes <input type="radio"/> No <small>reset</small>	<input checked="" type="radio"/> Yes <input type="radio"/> No <small>reset</small>
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<b>Date</b>	02-05-2023 <a href="#">View</a> equation	02-06 <a href="#">View</a> equation	02-07 <a href="#">View</a> equation	02-08-2023 <a href="#">View</a> equation	02-09-2023 <a href="#">View</a> equation	02-10-2023 <a href="#">View</a> equation	02-11-2023 <a href="#">View</a> equation
<b>Were drugs used during this day?</b>	<input checked="" type="radio"/> Yes <input type="radio"/> No <small>reset</small>	<input type="radio"/> Yes <input checked="" type="radio"/> No <small>reset</small>	<input type="radio"/> Yes <input checked="" type="radio"/> No <small>reset</small>	<input checked="" type="radio"/> Yes <input type="radio"/> No <small>reset</small>	<input checked="" type="radio"/> Yes <input type="radio"/> No <small>reset</small>	<input checked="" type="radio"/> Yes <input type="radio"/> No <small>reset</small>	<input checked="" type="radio"/> Yes <input type="radio"/> No <small>reset</small>
<b>Drugs Used (without a prescription)</b>	<input checked="" type="checkbox"/> Heroin (alone) <input type="checkbox"/> Heroin (with other drugs - 'Speedball') <input type="checkbox"/> Morphine <input checked="" type="checkbox"/> Fentanyl <input type="checkbox"/> Oxycodone <input type="checkbox"/> Oxycontin <input type="checkbox"/> Methadone <input type="checkbox"/> Buprenorphine <input type="checkbox"/> Percocet <input type="checkbox"/> Hydrocodone <input type="checkbox"/> Cocaine, powdered <input type="checkbox"/> Cocaine, rock (crack) <input type="checkbox"/> Amphetamines (speed) <input type="checkbox"/> Methamphetamines (crystal meth) <input type="checkbox"/> Other <input type="checkbox"/> None			<input checked="" type="checkbox"/> Heroin (alone) <input type="checkbox"/> Heroin (with other drugs - 'Speedball') <input type="checkbox"/> Morphine <input type="checkbox"/> Fentanyl <input type="checkbox"/> Oxycodone <input type="checkbox"/> Oxycontin <input type="checkbox"/> Methadone <input type="checkbox"/> Buprenorphine <input type="checkbox"/> Percocet <input type="checkbox"/> Hydrocodone <input type="checkbox"/> Cocaine, powdered <input type="checkbox"/> Cocaine, rock (crack) <input type="checkbox"/> Amphetamines (speed) <input checked="" type="checkbox"/> Methamphetamines (crystal meth) <input type="checkbox"/> Other <input type="checkbox"/> None	<input checked="" type="checkbox"/> Heroin (alone) <input type="checkbox"/> Heroin (with other drugs - 'Speedball') <input type="checkbox"/> Morphine <input type="checkbox"/> Fentanyl <input type="checkbox"/> Oxycodone <input type="checkbox"/> Oxycontin <input type="checkbox"/> Methadone <input type="checkbox"/> Buprenorphine <input type="checkbox"/> Percocet <input type="checkbox"/> Hydrocodone <input type="checkbox"/> Cocaine, powdered <input type="checkbox"/> Cocaine, rock (crack) <input type="checkbox"/> Amphetamines (speed) <input type="checkbox"/> Methamphetamines (crystal meth) <input type="checkbox"/> Other <input type="checkbox"/> None	<input checked="" type="checkbox"/> Heroin (alone) <input type="checkbox"/> Heroin (with other drugs - 'Speedball') <input type="checkbox"/> Morphine <input type="checkbox"/> Fentanyl <input type="checkbox"/> Oxycodone <input type="checkbox"/> Oxycontin <input type="checkbox"/> Methadone <input type="checkbox"/> Buprenorphine <input type="checkbox"/> Percocet <input type="checkbox"/> Hydrocodone <input type="checkbox"/> Cocaine, powdered <input type="checkbox"/> Cocaine, rock (crack) <input checked="" type="checkbox"/> Amphetamines (speed) <input type="checkbox"/> Methamphetamines (crystal meth) <input type="checkbox"/> Other <input type="checkbox"/> None	<input type="checkbox"/> Heroin (alone) <input type="checkbox"/> Heroin (with other drugs - 'Speedball') <input type="checkbox"/> Morphine <input type="checkbox"/> Fentanyl <input type="checkbox"/> Oxycodone <input type="checkbox"/> Oxycontin <input type="checkbox"/> Methadone <input type="checkbox"/> Buprenorphine <input type="checkbox"/> Percocet <input type="checkbox"/> Hydrocodone <input type="checkbox"/> Cocaine, powdered <input type="checkbox"/> Cocaine, rock (crack) <input checked="" type="checkbox"/> Cocaine, rock (crack) <input type="checkbox"/> Amphetamines (speed) <input type="checkbox"/> Methamphetamines (crystal meth) <input type="checkbox"/> Other <input type="checkbox"/> None
<b>If 'Other', describe</b>							
<b>ROUTES</b>							
	<input type="checkbox"/> Snorted / Sniffed (intranasal)			<input type="checkbox"/> Snorted / Sniffed (intranasal)	<input type="checkbox"/> Snorted / Sniffed (intranasal)	<input type="checkbox"/> Snorted / Sniffed (intranasal)	

ROUTES							
<b>Heroin (alone)</b>	<input type="checkbox"/> Snorted / Sniffed (intranasal) <input checked="" type="checkbox"/> IV <input type="checkbox"/> Smoked <input type="checkbox"/> Oral <input type="checkbox"/> Other			<input type="checkbox"/> Snorted / Sniffed (intranasal) <input checked="" type="checkbox"/> IV <input type="checkbox"/> Smoked <input type="checkbox"/> Oral <input type="checkbox"/> Other	<input type="checkbox"/> Snorted / Sniffed (intranasal) <input checked="" type="checkbox"/> IV <input type="checkbox"/> Smoked <input type="checkbox"/> Oral <input type="checkbox"/> Other	<input type="checkbox"/> Snorted / Sniffed (intranasal) <input checked="" type="checkbox"/> IV <input type="checkbox"/> Smoked <input type="checkbox"/> Oral <input type="checkbox"/> Other	
<b>Heroin (with other drugs - 'Speedball')</b>							
<b>Morphine</b>							
<b>Fentanyl</b>	<input type="checkbox"/> Snorted / Sniffed (intranasal) <input checked="" type="checkbox"/> IV <input type="checkbox"/> Smoked <input type="checkbox"/> Oral <input type="checkbox"/> Other						
<b>Oxycodone</b>							
<b>Oxycontin</b>							
<b>Methadone</b>							
<b>Buprenorphine</b>							
<b>Percocet</b>							
<b>Hydrocodone</b>							
<b>Cocaine, powdered (coke)</b>							
<b>Cocaine, rock (crack)</b>						<input type="checkbox"/> Snorted / Sniffed (intranasal) <input type="checkbox"/> IV <input checked="" type="checkbox"/> Smoked <input type="checkbox"/> Oral <input type="checkbox"/> Other	
<b>Amphetamines (speed)</b>						<input type="checkbox"/> Snorted / Sniffed (intranasal) <input type="checkbox"/> IV <input type="checkbox"/> Smoked <input checked="" type="checkbox"/> Oral	



# Our Build – Client Summary

Weekly totals  
by drug



Editing existing Study ID test.						
Event: Summary						
Study ID		test				
BASELINE						
TOTAL DAYS: -30						
OPIOID Days of Use - Part 1						
	Heroin (alone)	Morphine	Fentanyl	Oxycodone	Oxycontin	
Week -6	1	0	0	0	0	
Week -5	4	0	1	0	0	
Week -4	0	0	0	0	0	
Week -3	0	0	0	0	0	
Week -2	0	0	0	0	0	
Week -1	0	0	0	0	0	
TOTALS	5	0	1	0	0	
OPIOID Days of Use - Part 2						
	Methadone	Buprenorphine	Percocet	Hydrocodone	Heroin (with other drugs - 'Speedball')	
Week -6	0	1	0	0	0	
Week -5	0	0	0	0	0	
Week -4	0	0	0	0	0	
Week -3	0	0	0	0	0	
Week -2	0	0	0	0	0	
Week -1	0	0	0	0	0	
TOTALS	0	1	0	0	0	

# Our Build – Client Summary

Editing existing Study ID test.

Event: **Summary**

Study ID test

**BASELINE**

TOTAL DAYS: -30

**OPIOID Days of Use - Part 1**

	Heroin (alone)	Morphine	Fentanyl	Oxycodone	Oxycontin
Week -6	1	0	0	0	0
Week -5	4	0	1	0	0
Week -4	0	0	0	0	0
Week -3	0	0	0	0	0
Week -2	0	0	0	0	0
Week -1	0	0	0	0	0
<b>TOTALS</b>	<b>5</b>	<b>0</b>	<b>1</b>	<b>0</b>	<b>0</b>

**OPIOID Days of Use - Part 2**

	Methadone	Buprenorphine	Percocet	Hydrocodone	Heroin (with other drugs - 'Speedball')
Week -6	0	1	0	0	0
Week -5	0	0	0	0	0
Week -4	0	0	0	0	0
Week -3	0	0	0	0	0
Week -2	0	0	0	0	0
Week -1	0	0	0	0	0
<b>TOTALS</b>	<b>0</b>	<b>1</b>	<b>0</b>	<b>0</b>	<b>0</b>

Weekly totals by drug

Time period Total by drug

# Our Build – Client Summary

Editing existing Study ID test.

Event: **Summary**

Study ID test

**BASELINE**

TOTAL DAYS: -30

**OPIOID Days of Use - Part 1**

	Heroin (alone)	Morphine	Fentanyl	Oxycodone	Oxycontin
Week -6	1	0	0	0	0
Week -5	4	0	1	0	0
Week -4	0	0	0	0	0
Week -3	0	0	0	0	0
Week -2	0	0	0	0	0
Week -1	0	0	0	0	0
<b>TOTALS</b>	<b>5</b>	<b>0</b>	<b>1</b>	<b>0</b>	<b>0</b>

**OPIOID Days of Use - Part 2**

	Methadone	Buprenorphine	Percocet	Hydrocodone	Heroin (with other drugs - 'Speedball')
Week -6	0	1	0	0	0
Week -5	0	0	0	0	0
Week -4	0	0	0	0	0
Week -3	0	0	0	0	0
Week -2	0	0	0	0	0
Week -1	0	0	0	0	0
<b>TOTALS</b>	<b>0</b>	<b>1</b>	<b>0</b>	<b>0</b>	<b>0</b>

Weekly totals by drug

Time period Total by drug

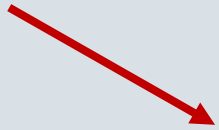
Totals for each of 10 opioids



**STIMULANT Days of Use**

	Cocaine, powdered	Cocaine, rock (crack)	Amphetamines (speed)	Methamphetamines (crystal meth)
Week -6	0	0	0	1
Week -5	0	1	1	1
Week -4	0	0	0	0
Week -3	0	0	0	0
Week -2	0	0	0	0
Week -1	0	0	0	0
<b>TOTALS</b>	<b>0</b>	<b>1</b>	<b>1</b>	<b>2</b>

Totals for each of 4 stimulants



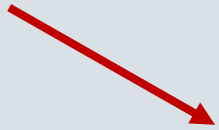
**Calculated Days of Use**

	Opi Occasions	Stim Occasions	Other Occasions	None	Total DAYS (per 7 day week)
Week -6	2	1	0	0	1
Week -5	5	3	0	2	5
Week -4	0	0	0	0	_____
Week -3	0	0	0	0	_____
Week -2	0	0	0	0	_____
Week -1	0	0	0	0	_____
<b>TOTALS</b>	<b>7</b>	<b>4</b>	<b>0</b>	<b>2</b>	<b>6</b>

**STIMULANT Days of Use**

	Cocaine, powdered	Cocaine, rock (crack)	Amphetamines (speed)	Methamphetamines (crystal meth)
Week -6	0	0	0	1
Week -5	0	1	1	1
Week -4	0	0	0	0
Week -3	0	0	0	0
Week -2	0	0	0	0
Week -1	0	0	0	0
<b>TOTALS</b>	<b>0</b>	<b>1</b>	<b>1</b>	<b>2</b>

Totals for each of 4 stimulants



**Calculated Days of Use**

	Opi Occasions	Stim Occasions	Other Occassions	None	Total DAYS (per 7 day week)
Week -6	2	1	0	0	1
Week -5	5	3	0	2	5
Week -4	0	0	0	0	_____
Week -3	0	0	0	0	_____
Week -2	0	0	0	0	_____
Week -1	0	0	0	0	_____
<b>TOTALS</b>	<b>7</b>	<b>4</b>	<b>0</b>	<b>2</b>	<b>6</b>

Totals for all opioids combined; all stimulants Combined and # of days



# Our Build – How accomplished

- 6-weeks per form;
- Dates are anchored to Saturday AFTER “today’s” interview using a Setup form.
- Forms are not ‘repeated’, each visit has its own form set
  - The original 6 week form has been ‘cloned’ to capture additional months
- Events schedule is based on expected visits and maximum day number at time point
  - Baseline, M1, M12
    - use 1 x 6 week form (up to 42 days)
  - M3 uses up to 3 x 6 week forms
  - M6 uses up to 5 x 6 week forms

Data Collection Instrument	Baseline	M1	M3	M6	M12	Other	Summary
Setup	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	
Tifb	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	
Tifb2			<input type="radio"/>	<input type="radio"/>		<input type="radio"/>	
Tifb3			<input type="radio"/>	<input type="radio"/>		<input type="radio"/>	
Tifb4				<input type="radio"/>		<input type="radio"/>	
Tifb5				<input type="radio"/>		<input type="radio"/>	
Summary							<input type="radio"/>



# Progress

---

- Data Access group controls established
  - sites can view their own records only
- Large Database: Total Fields = 4,194
- So large that:
  - Needed to be its own database project
  - Dataset Export specific for each timepoint
- Holds TLFB data for **486** clients so far

<b>Total Records</b>	<b>1387</b>
<b>Baseline</b>	<b>486</b>
<b>M1</b>	<b>336</b>
<b>M3</b>	<b>253</b>
<b>M6</b>	<b>201</b>
<b>M12</b>	<b>112</b>

# TLFB Next Steps

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- Adapt to other studies
- Expand to include other substances: e.g., alcohol and xylazine
- Collapse Mode of Administration from daily (radio) to weekly (checkbox) measure
  - Saves 2720 fields (removes: 6 days x 6 weeks x 5 forms x 14 drugs)

→ Feasible since coding and modular structure allows straightforward conversion:

Drugs substance fields in the calendar are identified by numbers (drug number, week number, and day number) and not name

# Event Review Cycles

---

- Several study workflow processes require notification / review / approval by the PIs:
  - Data Pull Requests → (Non-Repeating form)
    - For dissemination: poster/presentation development and manuscript creation
  - Serious Adverse Events (SAEs) → (Repeating form)
    - For notification to IRB and DSMB
- Both types use REDCap notifications to distribute survey links for approval



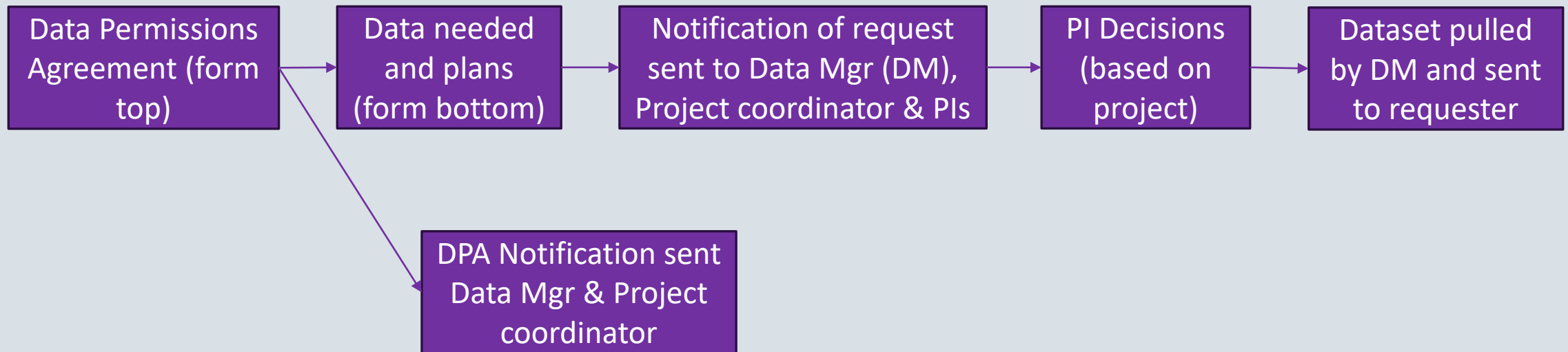
# Data Pull Requests (DRs)

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- DR database covers multiple projects; applicable co-PIs review DRs
- Includes: Data Permissions Agreement (DPA), Data Elements, Dissemination plans, PI approvals
- All co-authors submit DPAs; reviewed by Data Manager (DM).
- For DRs, PI can: Deny, Approve, or Approve with Modifications.
- REDCap structure: Main Request form plus 1 form for each PI.
  - Each enabled as survey. No REDCap login or access required for the submitter or PI
- PIs submit Decision via survey, by link in DR notification email
  - Each PI has own notification email with individual survey link

# Data Request Workflow

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# Sample DR Data

Request	Project #	DUA fields			existing req#	Data to be pulled		Dissemination Plans			APPROVALS				
											PI-1	PI-2	PI-3	PI-4	PI-5
1	1	x	x	x		A	x	x	x	x	x	x			
2	1	x	x	x		B	x	x	x	x	x	x			
3	2	x	x	x		x	x	x	x	x	x	x	x		
4	3	x	x	x		x	x	x	x	x	x			x	
5	2	x	x	x	3										
6	3	x	x	x		x	x	x	x	x	x			x	
7	3	x	x	x	4										

DUA Only

Same project,  
different data

Different PI approvals  
based on project

# Serious Adverse Events (SAEs)

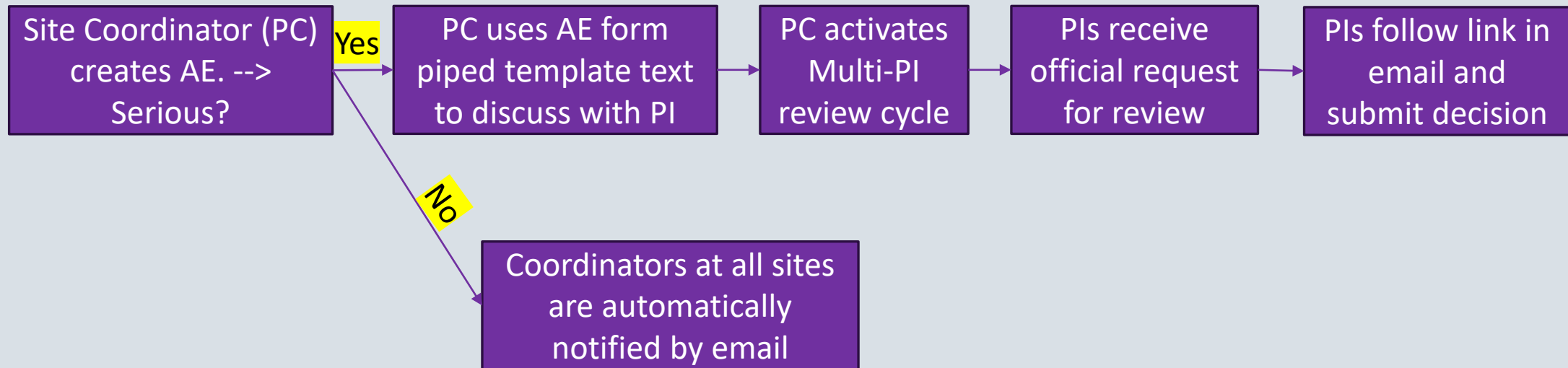
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- All AEs are tracked and managed; only SAEs need PI approval.
- AE form pulls information from REDCap records and combines with AE fields to create boilerplate text for discussion with site PI.
- PIs submit decision (Agree, Disagree) via survey link in notification email
  - Each PI gets own email but with common link
  - Ability to reuse survey links must be selected within the project.
  - SAE Decisions are made within AE form itself (different than DRs)
    - in hidden table at top of form
  - PIs cannot complete simultaneously or else there will be a sharing violation.



# Serious Adverse Events (SAEs)

---



# SAE Piping for Boilerplate Text & PI Table

This is a notification that the [summary\_arm\_1][record-dag-label] Team has become aware of an SAE for patient [studyid] randomized to the [rand\_arm\_1][interarm] arm in [baseline\_arm\_1][siteloc]. [summary\_arm\_1][record-dag-label] team was made aware on [summary\_arm\_1][notification\_date].

Patient [studyid], a [baseline\_arm\_1][age\_calc] year old [baseline\_arm\_1][d3] [baseline\_arm\_1][d5] was randomized to [rand\_arm\_1][interarm] at this date and time: [rand\_arm\_1][rand\_timestamp].

**Dates of Most Recent Completed Study Visits (blank if unattended or still pending)**

Baseline [baseline\_arm\_1][visdate]

M1 [m1\_arm\_1][visdate]

M3 [m3\_arm\_1][visdate]

M6 [m6\_arm\_1][visdate]

M12 [m12\_arm\_1][visdate]

The following note summarizes the event: [summary\_arm\_1][sae\_description].

[summary\_arm\_1][death\_cause]

[summary\_arm\_1][life\_threat\_describe]

[summary\_arm\_1][hospital\_describe]

[summary\_arm\_1][disability\_describe]

[summary\_arm\_1][defect\_describe]





[summary\_arm\_1][tx\_describe]

[summary\_arm\_1][sae\_other\_describe]

Regarding expectedness and relatedness to the study:

After discussion with the site PI, we believe the SAE should be classified as [expected] and [sae\_related] as mentioned below.

**PI REVIEW & APPROVALS**

	PI (or Proxy) name	Decision, comment (if any)	Signature	Timestamp
1	<input type="radio"/> Kevin Knight <input checked="" type="radio"/> Proxy for Dr. Knight <input type="text" value="MArk"/>	<input checked="" type="radio"/> Agree with Classification <input type="radio"/> Agree, but with comment <input type="radio"/> Disagree, but with comment <input type="radio"/> Disagree	 <a href="#">signature_2023-06-12_1438.png(0.01 MB)</a>	06-12-2023 13:5
2	<input type="radio"/> Irene Kuo <input checked="" type="radio"/> Proxy for Dr. Kuo <input type="text" value="BROOKS"/>	<input type="radio"/> Agree with Classification <input checked="" type="radio"/> Agree, but with comment <input type="radio"/> Disagree, but with comment <input type="radio"/> Disagree <input type="text" value="fix wording on the 'crushe"/>	 <a href="#">signature_2023-06-12_1351.png(0.01 MB)</a>	06-12-2023 13:5
3	<input type="radio"/> Ank Nijhawan <input checked="" type="radio"/> Proxy for Dr. Nijhawan <input type="text" value="Mark"/>	<input checked="" type="radio"/> Agree with Classification <input type="radio"/> Agree, but with comment <input type="radio"/> Disagree, but with comment <input type="radio"/> Disagree	 <a href="#">signature_2023-06-12_1438.png(0.01 MB)</a>	06-12-2023 13:5
4	<input type="radio"/> Sandra Springer, MD <input checked="" type="radio"/> Proxy for Dr. Springer <input type="text" value="r brooks"/>	<input type="radio"/> Agree with Classification <input type="radio"/> Agree, but with comment <input checked="" type="radio"/> Disagree, but with comment <input type="radio"/> Disagree <input type="text" value="taquitos are unrelated to t"/>	 <a href="#">signature_2023-06-12_1416.png(0.01 MB)</a>	06-12-2023 14:1

# Acknowledgments

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- NIDA for funding (grant #U01DA053039)
- Sandra Springer (PI, Yale School of Medicine)
- Ank Nijhawan (PI, Univ. TX Southwestern)
- Kevin Knight (PI, Texas Christian Univ.)
- The Whole ACTION TEAM
- Yale's REDCap Administrators

Yale SCHOOL OF MEDICINE

TCU

UTSouthwestern  
Medical Center

CHERISH  
Center for Health Economics of Treatment Interventions for  
Substance Use Disorder, HCV, and HIV

Milken Institute School  
of Public Health  
THE GEORGE WASHINGTON UNIVERSITY

# Development and Validation of a Shorter Version of the PROMIS Quality of Life and Patient Preference Rating (PROPr) with People Coming out of County Jails with Opioid Use Disorders



Michael L. Dennis, Ph.D., M. Kate Hart, M.S., Jason E. Chapman, Ph.D., Sierra Castedo de Martell, Ph.D., & Richard D. Lennox, Ph.D.

Chestnut Health Systems, Lighthouse Institute  
Normal, IL, Chicago, IL, & Eugene, OR  
Wednesday June 12, 2024, 1030-1145am

*Chestnut Research Center, NIDA Grant #: UG1DA050065.*

NIH • Helping to End Addiction Long-term



# Background and Goals

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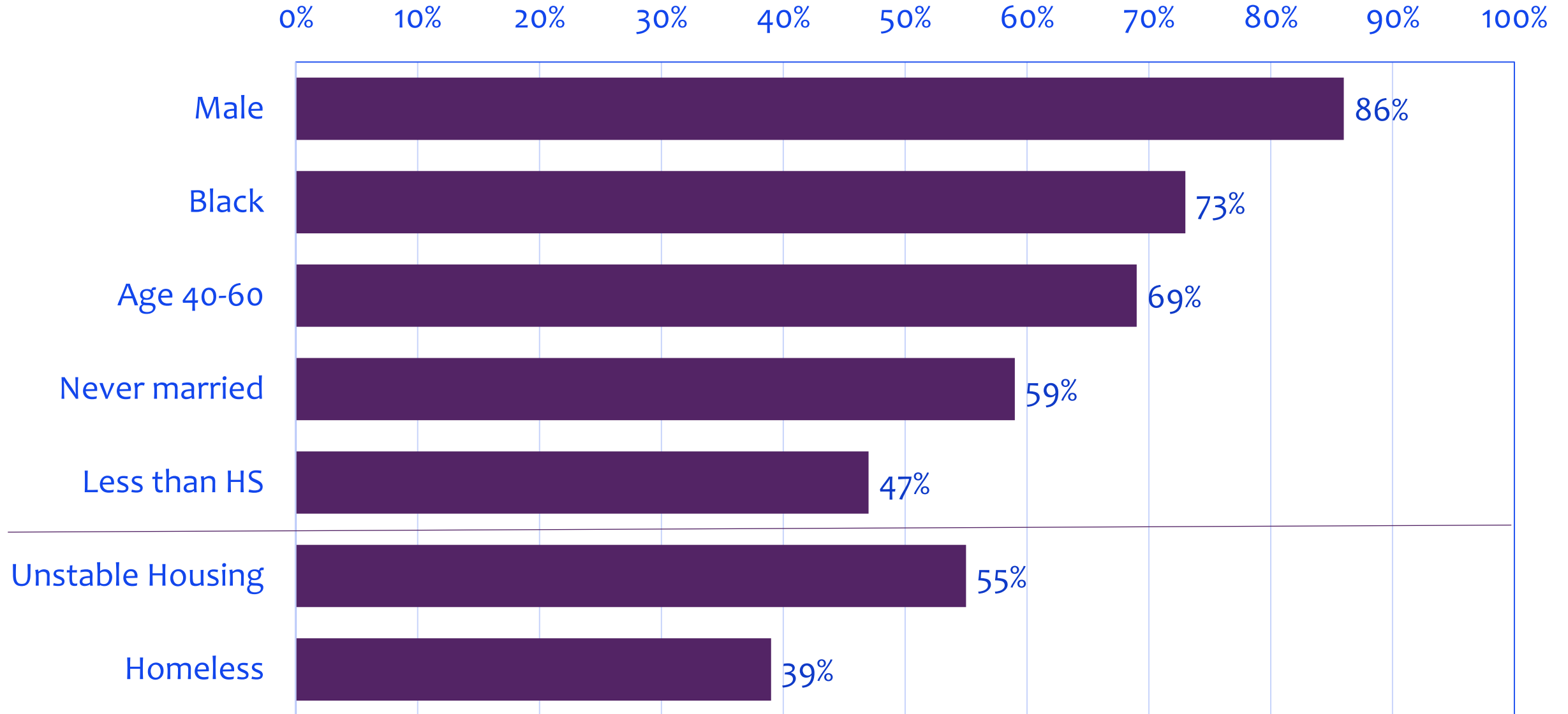
- The core JCOIN measures use the 31-item (aka 29+2) PROMIS clinical profile of functioning in the past week that includes 2-5 item ratings in each of 8 areas (sleep, cognitive functioning, pain, fatigue, anxiety, depression, social roles/functioning, physical functioning); it does NOT have a summary measure.
- PROMIS<sub>7</sub> can be (1) calibrated to a **separate** measure of Patient Preference Rating (PROPr) disease states and (2) used to generate quality of life adjusted years (QALY) for use in economic analysis.
- The goals of this paper are to: 1) create a summary measure, 2) validate it to the Rasch Measurement model, 3) create a shorter version, and 4) validate the long to short versions of measures to each other and external constructs.

# Methods

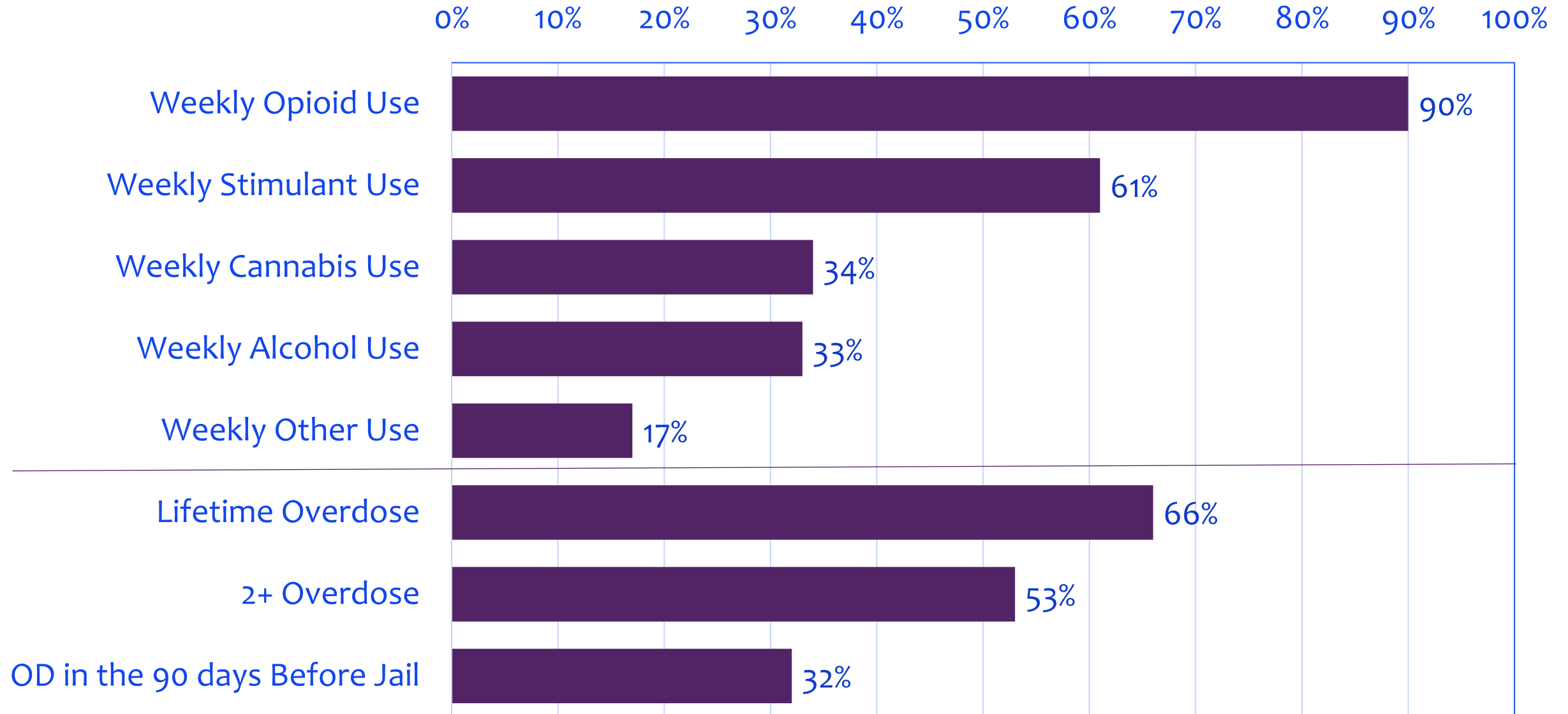
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- **Data** from enrollment and quarterly observation through 24 months later from Chestnut Research Hub between 8/29/21 And 12/31/23: 308 Unique people and 1319 Observations (1-9 per person).
- **Created a raw summary measure** based on the average rating after reversing positive items
- **Validate to Rasch Measurement Model** using Winsteps, version 5.7.2, observations nested within respondents, separated reliability of measures and respondents, using a partial credit model per 5 point rating scale with Joint Maximum Likelihood Estimation (JMLE)
- **Created a 8-item version of PROMIS** in an iterative process with a goal of 1 item per domain and high (.9 or more) correlation between short and long versions; Compared to the 31-item PROMIS Raw, Rasch, and PROPr measure, including relationship with individual domain measures and other JCOIN CORE/GAIN measures for further construct validation.

# Sample Characteristics



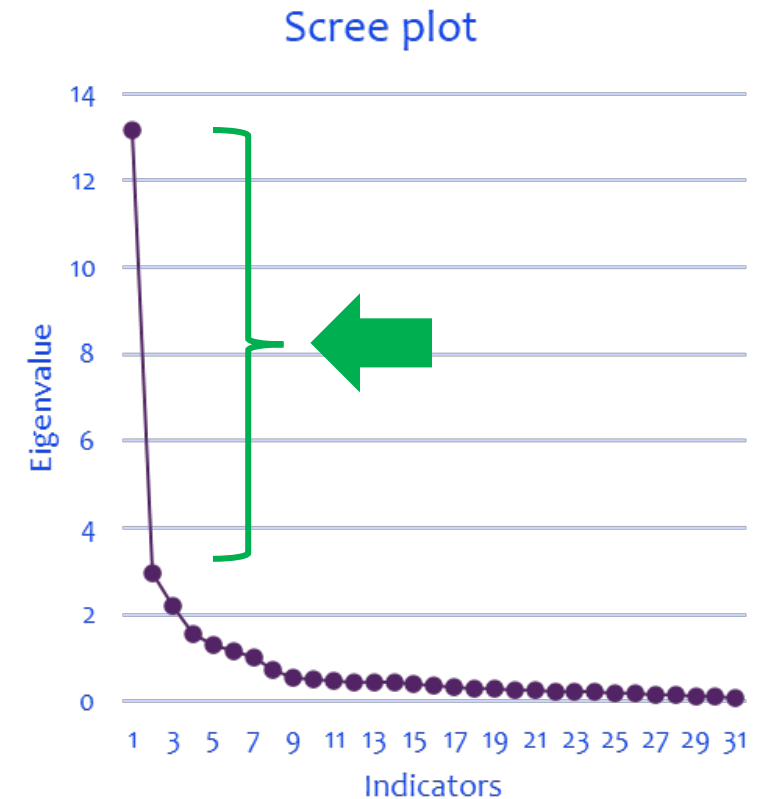
# Clinical Characteristics





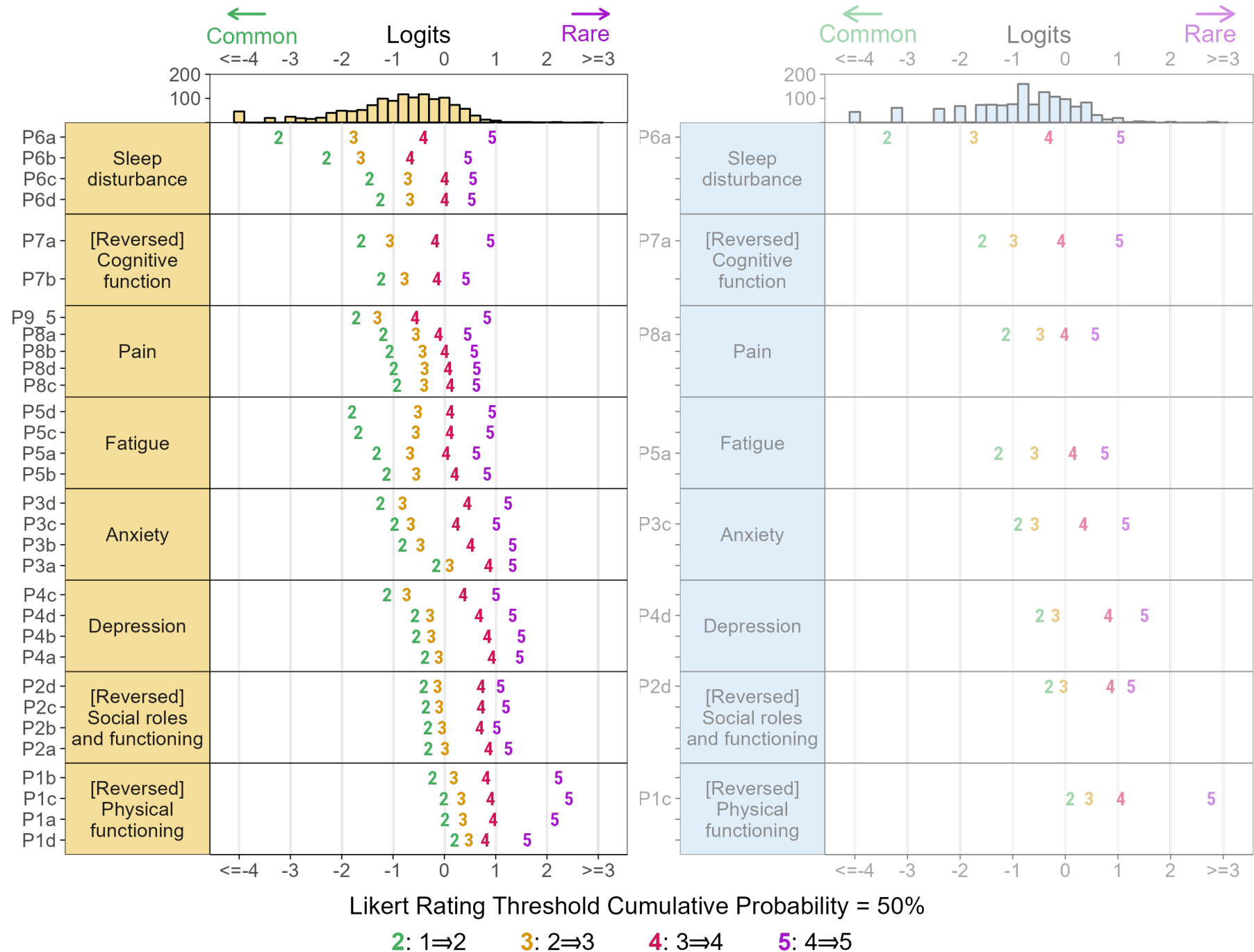
# Results

- **Raw Summary Score:** Calculated as the average of the 31 Likert ratings, with an alpha of .95; suggest that most of the variance is being explained by the first principal component.
- **Exploratory Factor Analysis:** The exploratory factor analysis identified that the first factor had an eigen value 13.2, the next 3 much smaller (3.0, 2.2, 1.6) and the rest rounding to 1.0 or less. This scree suggests that most of the variance is best represented as a total score.
- **Rasch Analysis:** Alpha .95, Raw to Rasch Correlation .89, Person separation 2.89; item separation 16.87
- **Correlations (95% CI) of 31 and 8 PROMIS Summary Measures:**
  - RAW,  $r = 0.97$  (0.96-0.97)
  - RASCH,  $r = 0.94$  (0.94 - 0.95)
  - PROPr,  $r = 0.94$  (0.94 - 0.95)

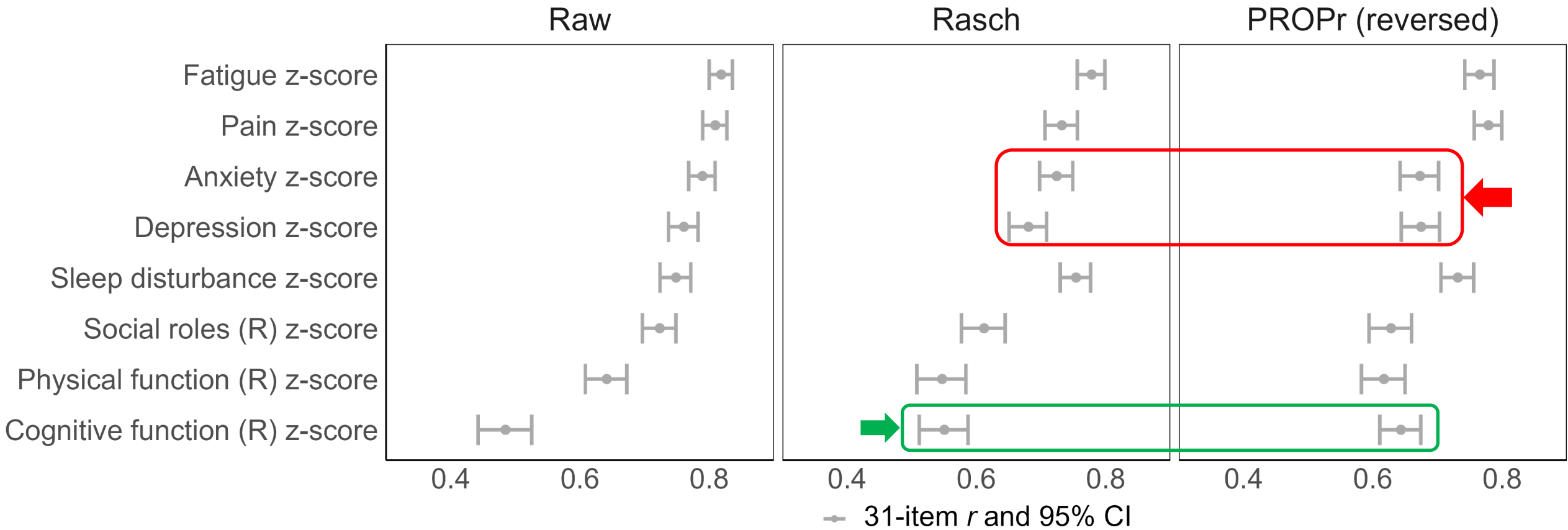


# Rasch Validation

- Positive items reversed so high scores mean more problems.
- Distribution in logits at the top of the graph
- Sorted domains and items (rows) by average rating in rows
- Each number is the point at which 50% to transition to next rating
- Shorter scale (in blue), took 1 item per domain, towards mean for domain, optimize spread (which limits ability to measure / predict change).

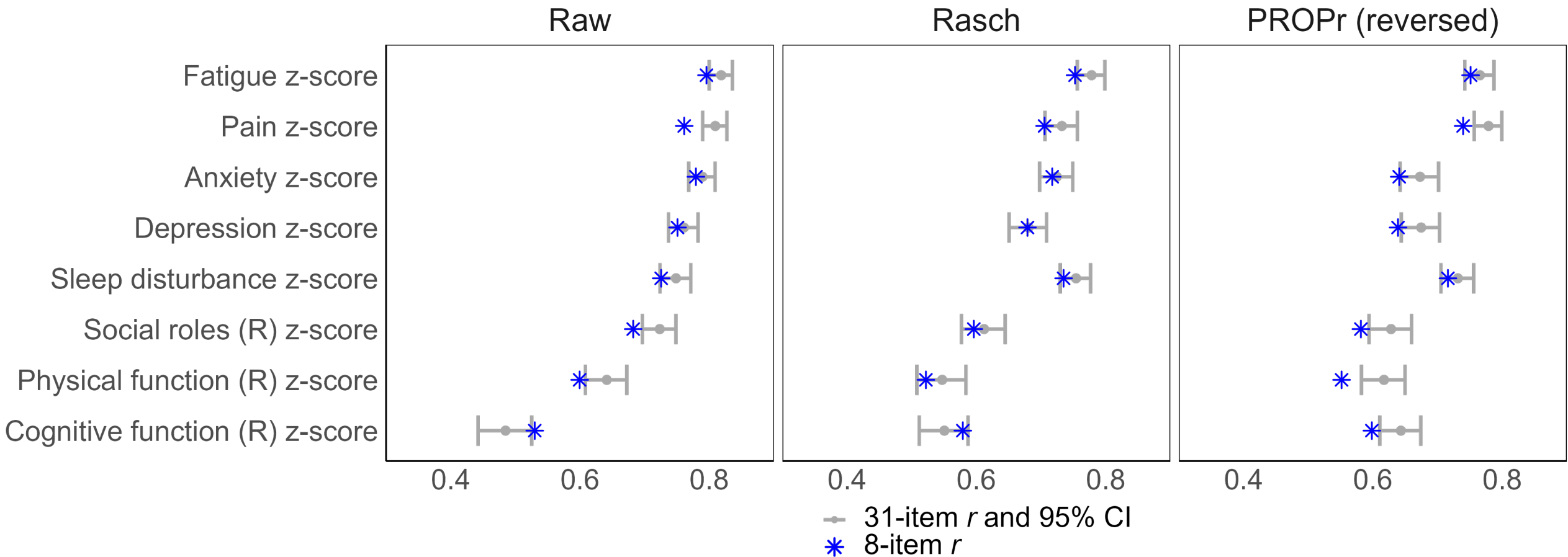


# Structural Validation: Domain to Total Score



- Similar rank order of correlations/ 95% confidence intervals (CI)
- But Rasch and PROPr give less weight to anxiety, depression, and more weight to physical and cognitive functioning

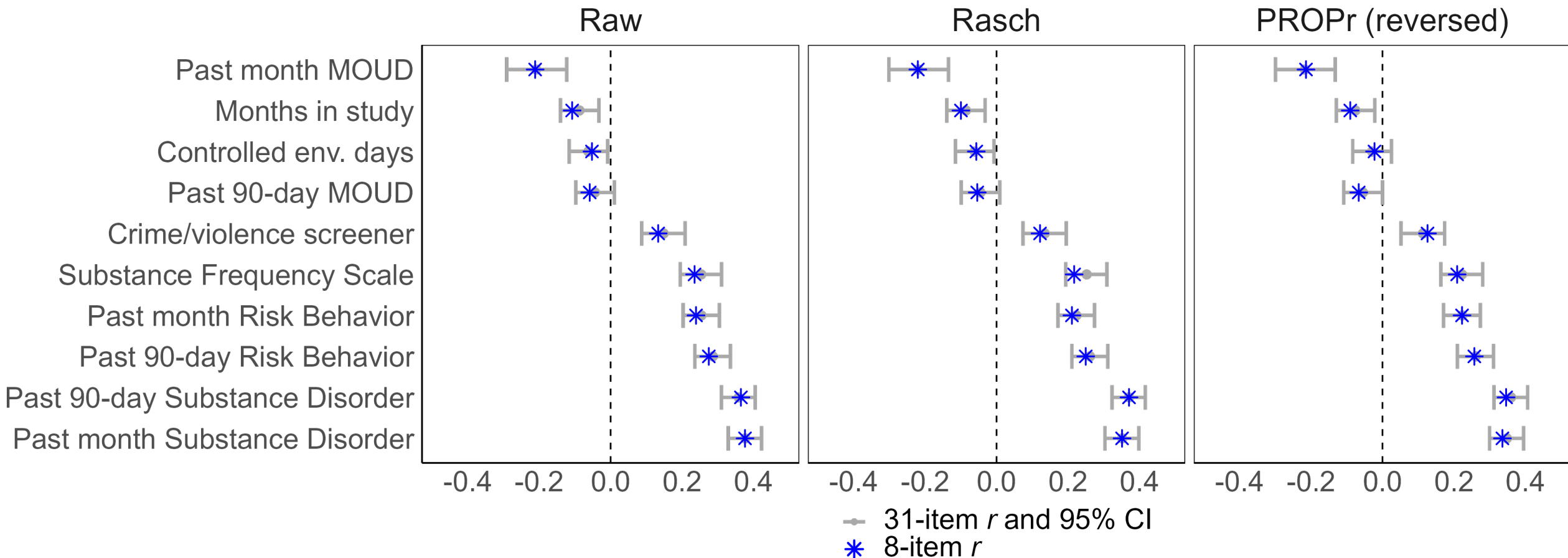
# Structural Validation: Domain to Total Score



- 15/24 8-item correlations (\*) within 95% CI; All with R are within 0.1
- Thus 8 item version has similar relationship to domain for Raw, Rasch & PROPr



# Construct Validation: Other Variables to Total Score

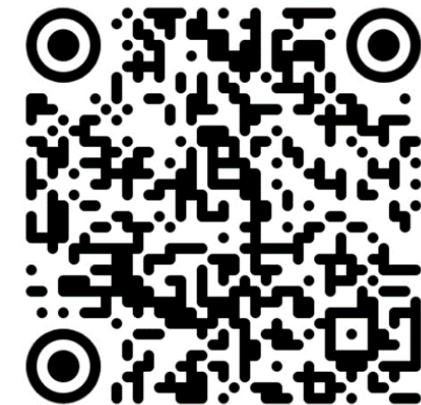


- Relationship of 3 summary measures (panels) to 10 other outcomes (rows) all very similar
- 30/30 correlations 8 item summary measure to 10 other outcomes within 95% CI of 31 item correlation with the respective outcome –most at or near point estimate

# Discussion

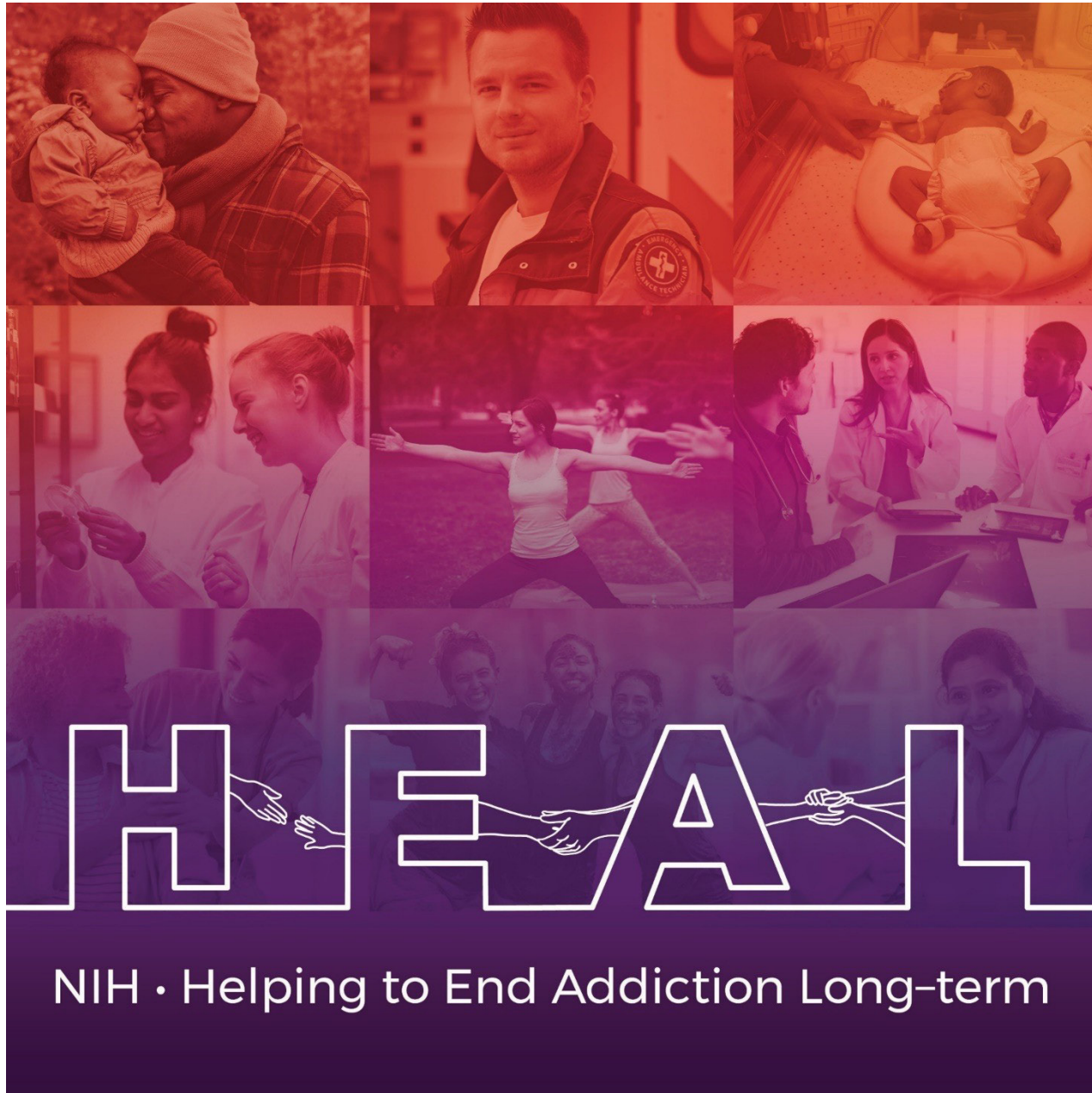
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- The variance in the PROMIS clinical profile varies primarily along dimension that can be summarized with a 31 item or an 8 item Raw, Rasch or PROPr with similar structural and construct validity.
- At the same time, this version maintained one of the best fitting items for each of the 8 domains to convey a similar breadth and structure
- As the field pushes for more nuanced measures of recovery/ quality of life and QALY to support economic analyses, cutting a measure by 73% (8/30) makes it much more feasible to include the PROMIS measure even covering the same domains.
- **Questions?**



# Appendix: Variable Names and descriptives

CHS items	Content area		In PROMIS8	<- Rating ->					Mean	SD	
	Original name	Item - short label		1	2	3	4	5			
<b>Sleep Disturbance</b>										2.8	1.3
QP3_r	sleep109	P6a_r Sleep quality (reversed)	X	9%	19%	34%	26%	11%	3.1	1.12	
QP4a_r	sleep116	P6b_r How refreshing was your sleep (reversed)		16%	13%	27%	26%	18%	3.2	1.32	
QP4b	sleep20	P6c Problems with sleep		33%	21%	22%	12%	13%	2.5	1.38	
QP4c	sleep44	P6d Difficulty falling asleep		37%	18%	21%	11%	13%	2.4	1.41	
<b>[Reversed] Cognitive Function</b>										2.6	1.41
QP4h_r	pc6r	P7a_r were you able to concentrate	X	28%	15%	26%	20%	10%	2.7	1.34	
QP4j_r	pc27r	P7b_r were you able to remember to do things, like take medicine or buy something you needed		37%	14%	21%	13%	15%	2.5	1.47	
<b>Pain</b>										2.4	1.4
QP5_5	global07	P9_5 how would you rate your pain on average ( <i>rescaled from 0-10 to 1-5</i> )		25%	11%	23%	28%	13%	2.9	1.38	
QP4k	painin9	P8a how much did pain interfere with your day to day activities	X	38%	20%	15%	13%	14%	2.4	1.46	
QP4m	painin22	P8b how much did pain interfere with work around your (home, pod, pier, cell or living space)		42%	21%	14%	12%	12%	2.3	1.41	
QP4p	painin34	P8d how much did pain interfere with your regular chores (in your home, pod, pier, cell or living space)		44%	20%	15%	11%	11%	2.2	1.39	
QP4n	painin31	P8c how much did pain interfere with your ability to participate in social activities		46%	18%	16%	10%	11%	2.2	1.39	
<b>Fatigue</b>										2.3	1.3
QP4g	fatexp40	P5d how tired or fatigued were you on average		27%	32%	19%	14%	8%	2.4	1.25	
QP4f	fatexp41	P5c how run-down did you feel on average		29%	29%	19%	13%	9%	2.4	1.28	
QP4d	hi7	P5a Feel tired or fatigued	X	36%	19%	22%	12%	12%	2.4	1.38	
QP4e	an3	P5b have trouble starting things because you were tired		40%	18%	22%	11%	9%	2.3	1.33	
<b>Anxiety</b>										2.1	1.2
QP2h	edanx53	P3d Felt uneasy		38%	13%	33%	11%	6%	2.3	1.24	
QP2g	edanx41	P3c Worries overwhelmed you	X	45%	11%	25%	12%	8%	2.3	1.34	
QP2f	edanx40	P3b Hard to focus on all but anxiety		49%	12%	25%	9%	5%	2.1	1.24	
QP2e	edanx01	P3a Felt fearful		69%	9%	15%	4%	3%	1.6	1.07	
<b>Depression</b>										2.0	1.2
QP2m	eddep29	P4c Felt depressed		41%	12%	30%	10%	7%	2.3	1.29	
QP2n	eddep41	P4d Felt hopeless	X	57%	10%	22%	7%	4%	1.9	1.19	
QP2k	eddep06	P4b Felt helpless		57%	10%	23%	6%	3%	1.9	1.14	
QP2j	eddep04	P4a Felt worthless		62%	10%	21%	4%	3%	1.8	1.10	
<b>Social Roles and Functioning</b>										1.8	1.1
QP2d	srpper46_caps	P2d you had trouble doing all of the activities with friends that you want to do	X	62%	10%	20%	4%	5%	1.8	1.17	
QP2c	srpper23_caps	P2c you had trouble doing all of your usual work (include work at home or jail)		63%	10%	18%	5%	4%	1.8	1.16	
QP2b	srpper18_caps	P2b you had trouble doing all of the family activities that you want to do		64%	10%	17%	4%	5%	1.8	1.17	
QP2a	srpper11_caps	P2a had trouble doing all of your regular leisure activities w/others		64%	11%	18%	3%	4%	1.7	1.10	
<b>Physical Function</b>										1.5	1.0
QP1b	pfa21	P1b Go up and down stairs at normal pace		66%	14%	12%	7%	1%	1.6	1.02	
QP1c	pfa23	P1c walk around for 15 mins	X	72%	12%	9%	6%	1%	1.5	0.95	
QP1a	pfa11	P1a Able to bend down, pick up clothing off floor		73%	12%	9%	5%	1%	1.5	0.94	
QP1d	pfa53	P1d Lift 10lbs above shoulder		78%	10%	6%	5%	2%	1.4	0.94	
PROMIS 31 item problem count (alpha=.95)				25%	42%	26%	6%	1%	2.2	0.80	
PROMIS 8 item problem count (alpha=.82)				X	18%	47%	26%	9%	1%	2.3	0.83
<b>Notes:</b> N = 308, 1319 observations											
' _r' denotes reversed item											
P9_5 rescaled where 1 = 0-1; 2 = 2-3; 3 = 4-6; 4 = 7-8; 5 = 9-10.											



# Using Cognitive Interviews to Explore Discrepancies in Criminal Legal System-Involved Study Participants' Urine Test Results and Perceived Fentanyl Exposure

Chestnut Health Systems Hub

Dennis P. Watson, Katie Clark, Michael L. Dennis, Christine E. Grella, and Kate Hart

JCOIN Research Conference 2024

Funding: UG1DA050065





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During the past 90 days, on how many days did you use fentanyl (alone or mixed with other drugs)?

# Chestnut UT and SR protocol

Collect UT sample



Read UT results



Ask past 90-day SR substance use questions

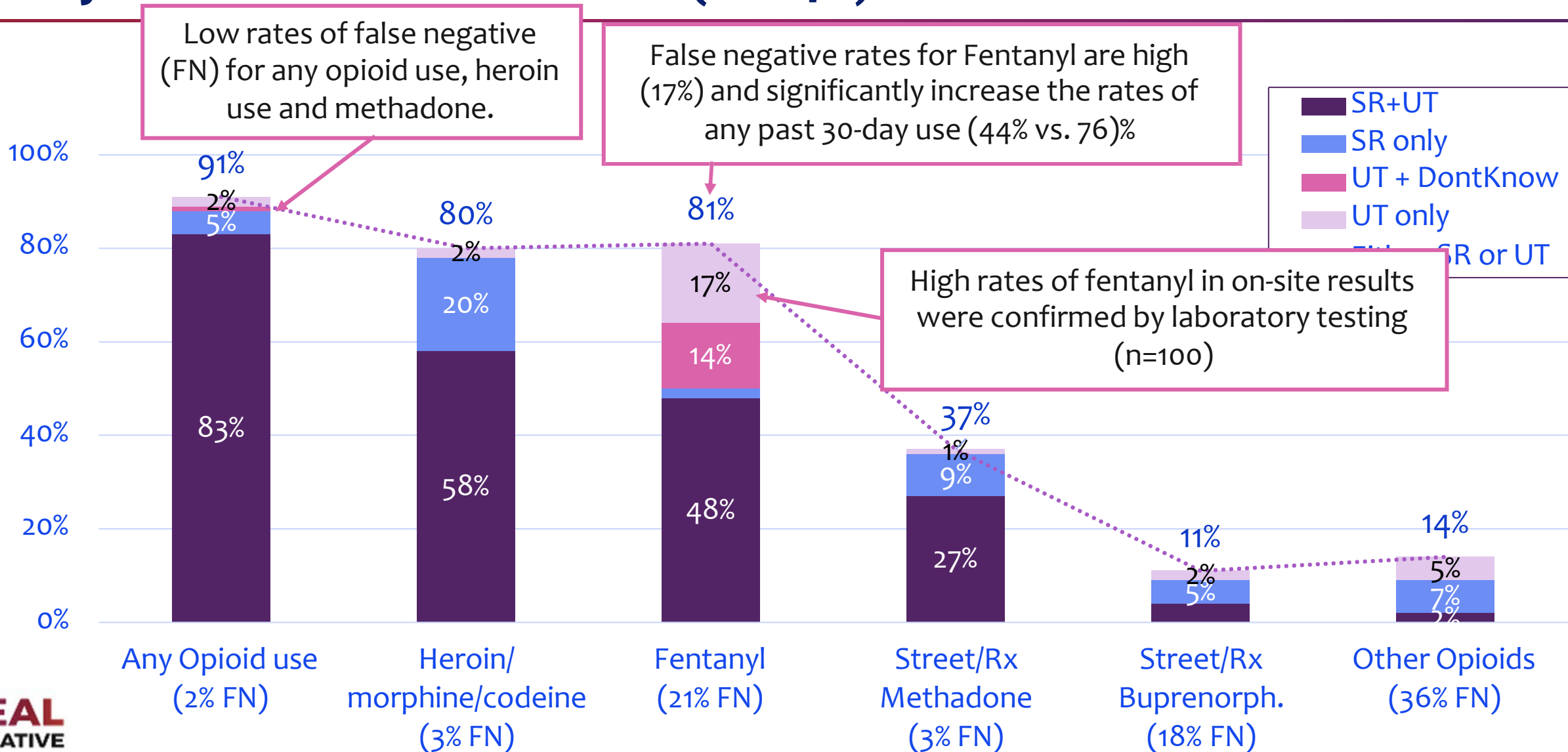


Past 30-day validation pop-up question

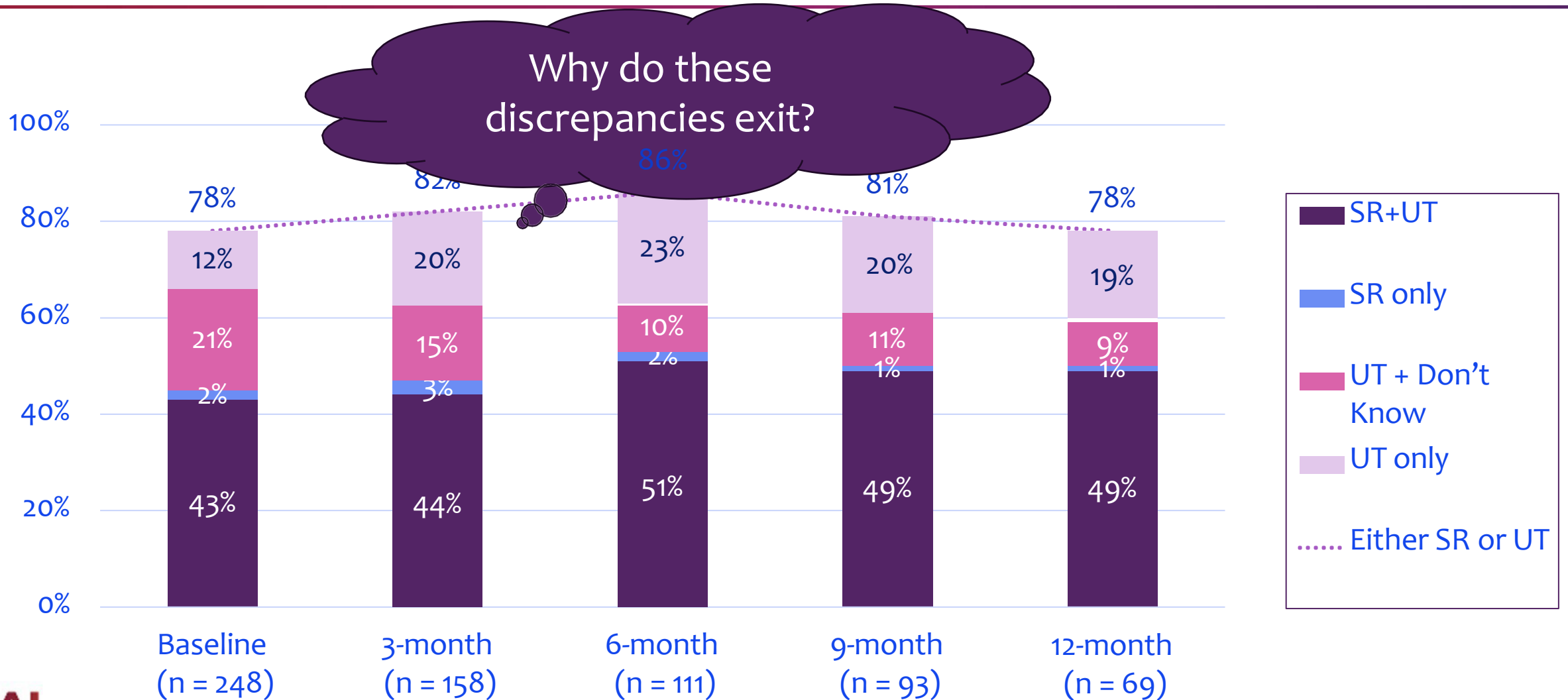


I need your help, I may have made a mistake or misunderstood. The urine test today indicates that there is some kind of fentanyl in your system but I wrote down that you had no fentanyl use. Can you think of any reason why the urine test would be positive? (Might it have been mixed with something else, you were exposed to it or maybe you forgot?)

# Any Self Report (SR) and Urine Test (UT) for Opioid Use in the 30 Days Before Randomization (n=248)



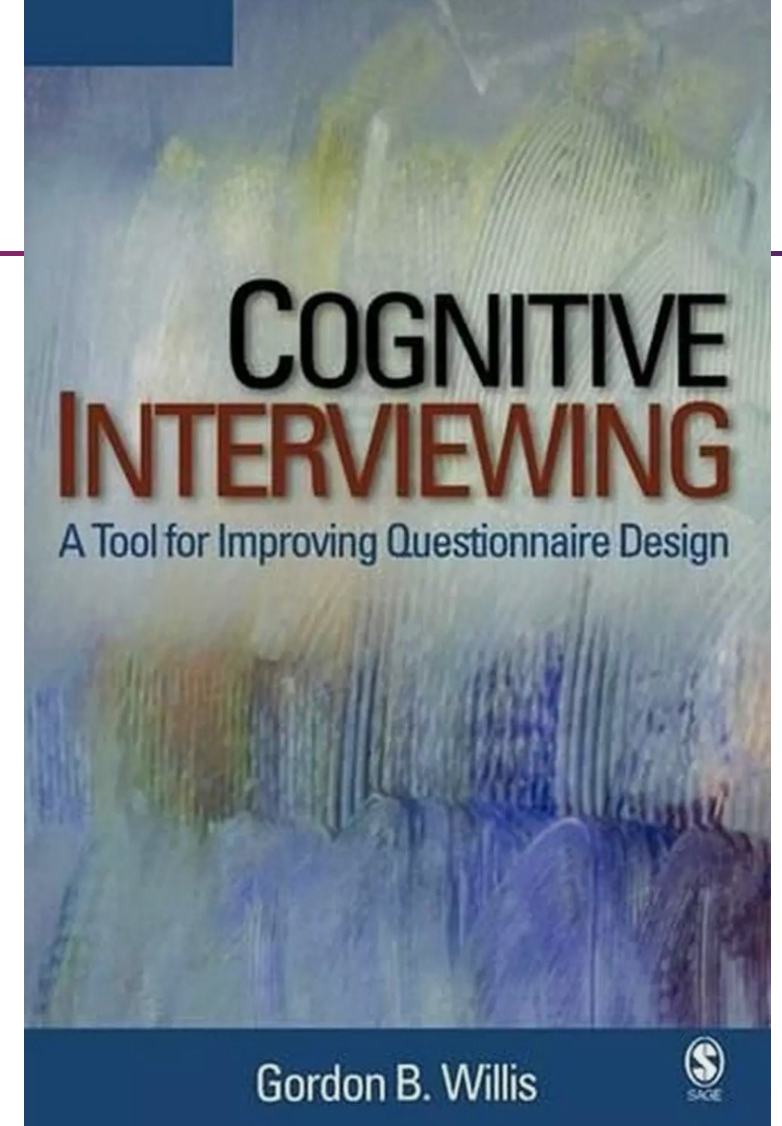
# Self Report (SR) and Urine Test (UT) for Fentanyl Quarterly





# Cognitive interview methodology

- Widely used qualitative method for improving surveys and questionnaires.<sup>1</sup>
- Evaluates the quality of participant responses to determine if the question generates intended information.<sup>2</sup> Can be conducted rapidly with a relatively small sample (Willis, 2004).<sup>1</sup>



<sup>1</sup>Willis, G. B. (2004). *Cognitive interviewing: A tool for improving questionnaire design*. sage publications.; <sup>2</sup>Beatty, P. C., & Willis, G. B. (2007). Research synthesis: The practice of cognitive interviewing. *Public Opinion Quarterly*, 71(2), 287-311.

# Sample

- 10 total participants
- Recruitment between 11/3/2023 and 12/8/2023
- Eligibility
  - Part of JCOIN or RIMO study
  - Positive UT for fentanyl
  - Answered “0 days” or “I don’t know” to both fentanyl self-report questions

## Cognitive interview participant characteristics

Variable	Value	M	SD
Age		41.9	12.4
Years of opioid use		21.19	12.05
		N	%
Gender	Female	3	30%
	Male	7	70%
Race	Black	6	60%
	White	3	30%
	More than one race	1	10%
Ethnicity	Hispanic or Latino	2	20%
	Not Hispanic or Latino	8	80%
Opioid of choice	Heroin	9	90%
	Prescription pills	1	10%
Response to fentanyl use questions			
	0 days	5	50%
	I don't know	5	50%

# Data collection & analysis

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- Interview questions:
  - Repeat fentanyl use question in own words.
  - Describe how someone would know they took fentanyl
  - Why provided “o day” or “IDK” answer
  - Report how difficult the question was to answer
  - How well they remembered past 90-day drug use
  - Understanding of UT results
  - Suggestions for better wording
- Flexible probing approach
- \$35 incentive provided
- Inductive coding

# Findings: Understanding UT results

## Themes

- Nine remembered UT result.
- All believed UT result.
- Only one participant who used recreationally conveyed shock at the result.

## Quotes

I: So, after you had been asked this question, a little bit further into the interview, they had given you a urine test, right? And the urine test came back and had a fentanyl result. Do you remember what that said on it?

R: Positive.

I: Okay. And do you have any issues with trusting the results of that test, or?

R: No, I'm pretty confident.

I: That it was positive?

R: Yeah.

# Findings: Remembering past 90-day use

## Themes

- No difficulty remembering past 90-day substance use
  - Eight used daily.
  - One was abstinent for most days but used and overdosed the day before interview.
  - One described in detail all events of recreational prescription opioid use.

## Quotes

- I remember it down to a T, because I don't really do nothing much of everything every day. So, it's like I can recall, or I can estimate roughly how many I did...So, I could say, yeah, I'm very, and I got a good memory
- I only got high once...I remember before ODing [I] was snorting it and then waking up in the ambulance



# Findings: SR question interpretation

## Themes

- Only one participant could repeat the question back in a manner indicating understanding of researchers' intent.
- All participants adamant answer was truthful
- Most indicated knowing heroin was adulterated with fentanyl, but believed the question was seeking to understand explicit knowledge of fentanyl use.
- Of note, one participant thought the question was asking how many times he used drugs alone/without others present.

## Quotes

Interviewer: I'm going to repeat the question. During the past 90 days, on how many days did you use fentanyl alone or mixed with other drugs?

Participant: Well, I didn't know it was fentanyl, but they mix it with the heroin. So, every day I use [fentanyl]...

Interviewer: So [asking to repeat the question again], during the past 90 days, on how many days did you use fentanyl alone or mixed with other drugs?

Participant: How many days have I used fentanyl along with other drugs? Every day.

Interviewer: Okay. And what does that question mean to you?

Participant: It means what, I don't know they putting fentanyl in the drugs, but when I drop, fentanyl is coming up.

# Findings: SR question interpretation

## Themes

- Two lines of rationale for why they lacked fentanyl use knowledge:
  - Seeking out heroin or other opioids (not fentanyl).
  - Told they were receiving heroin or other opioids.
  - Did not test drugs before use.

## Quotes

- I answered none [no to the question]. Well, my intent [at the time they used] was not looking for, specifically fentanyl. So, I didn't have the intent of that. Possibly it [the heroin they took] was mixed with it [fentanyl]
- I don't know what I was putting my system when I went and bought it. They [drug dealers] don't give you no note and tell you if it's got fentanyl, or oxycontin, or cornbread, or ham hocks in the heroin.

# Findings: Better wording

## Themes

- Asking about perceived fentanyl used might yield better answers

## Quotes

I: So, during the past 90 days, on how many days do you think you may have used fentanyl?

R: I would say eight.

I: Eight. Okay. Why did you come up with eight there?

R: Because I, when I relapsed on the 20th, so, there were several episodes where I overdosed, or became under the influence very quickly, or something like that. And then I had to get Narcaned.

I: Okay. And so, you had, you had used more than eight times, but there were eight times specifically you're thinking of, where you had to have Narcan administered because of something that was going on after you've taken the drugs.

R: Yeah.

# Discussion

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- Participants believe the question is getting at their knowledge or intent at the time of use, and they were not seeking out fentanyl or testing their drugs.
- Showing people the urine test before asking the question is unhelpful because of the way they were interpreting the question.
- Data implications:
  - Responses for most participants reporting no fentanyl use likely represent perception vs. reality.
  - Unknown how the question was perceived by those reporting 1+ days of fentanyl use.
  - Must be aware of protocol differences regarding when the question was asked.

# Possible question modifications

- In transition, before asking about days of drug use, **add a clarification:** “Many drugs today are cut with fentanyl or other drugs so that even people who are trying not to use fentanyl or other drugs may end up accidentally using them.”
- Replace “alone” with “by itself” to avoid confusion with “using alone” vs. with other people.
- If want to know about perceived use: “**Even if you were not seeking fentanyl,** on how many days in the past XX days **do you believe (or think) you may have used** fentanyl by itself or mixed with other drugs?”
- If want to know about intended use: “During the past XX days, on how many days did you **intentionally use** fentanyl by itself or mixed with other drugs?”



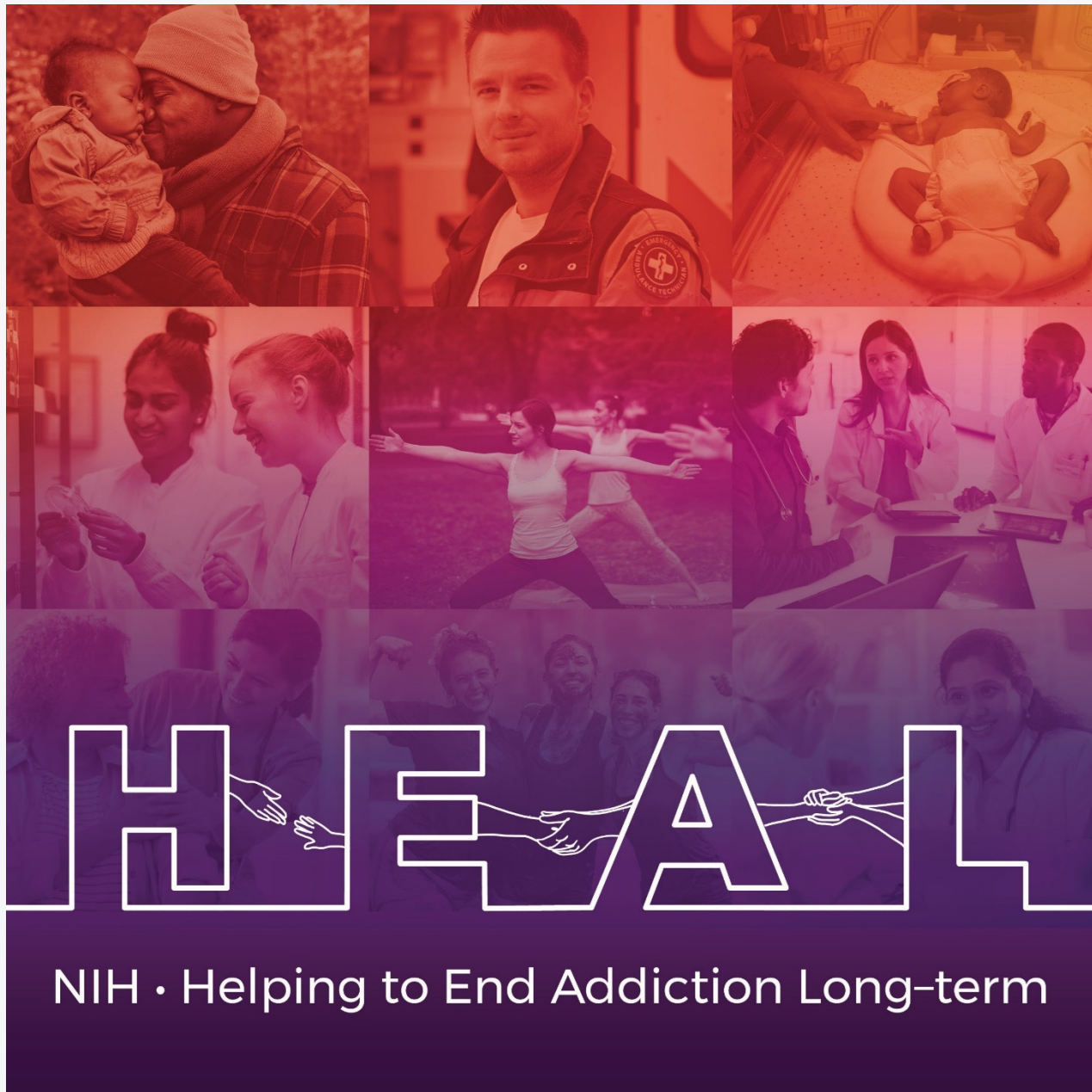


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# Thank you!

## The next session will begin at 12pm.