

The National Network of Depression Centers: Building a Virtual Learning Health System for Mood Disorders

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Disclosures: None

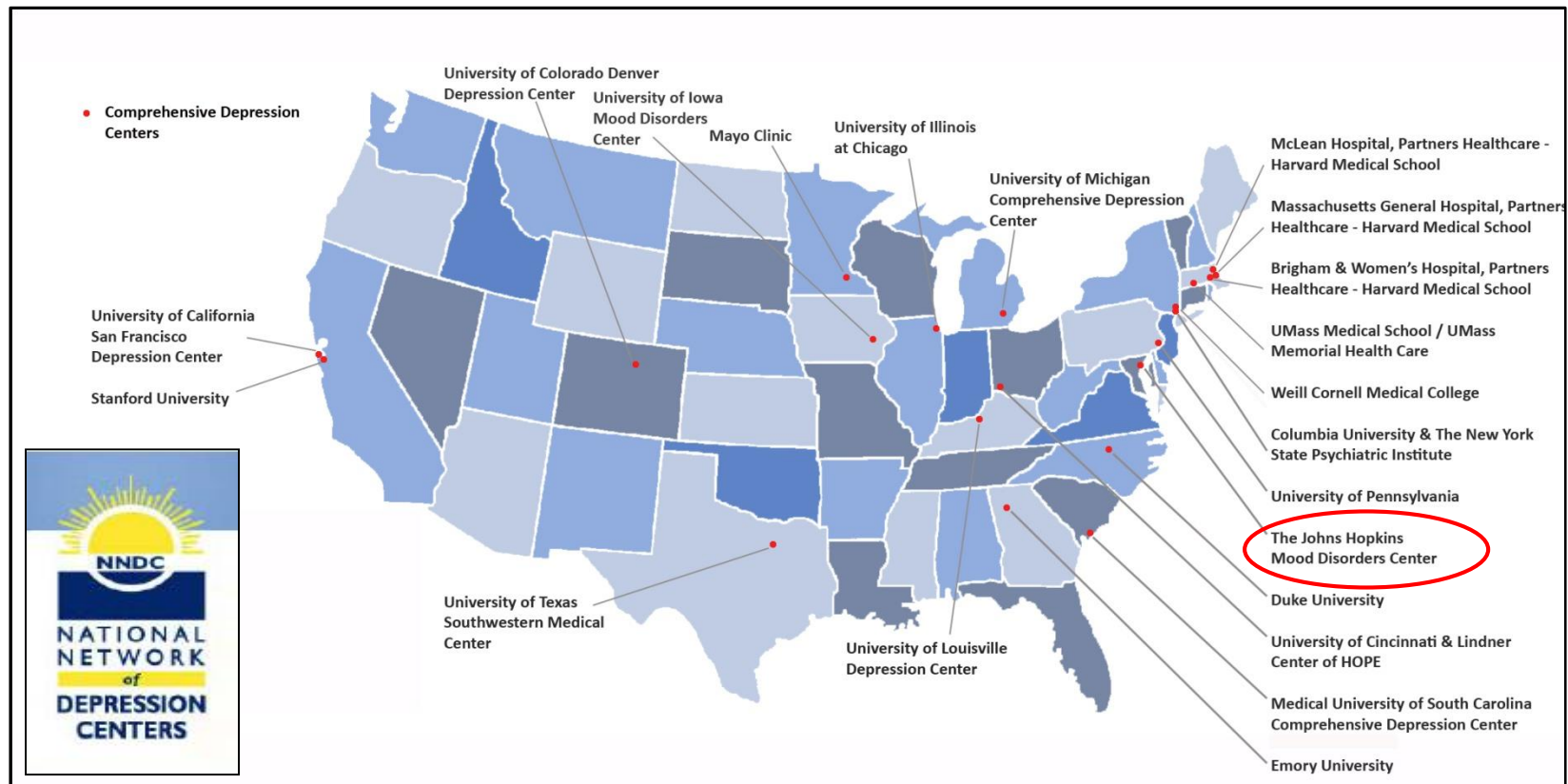
Learning Objectives

- Explain what are learning health systems
- Describe NNDC experience in building a “virtual” learning health system for mood disorders
- Discuss NNDC plans for using “virtual” learning health system for mood disorders

Public Health Burden

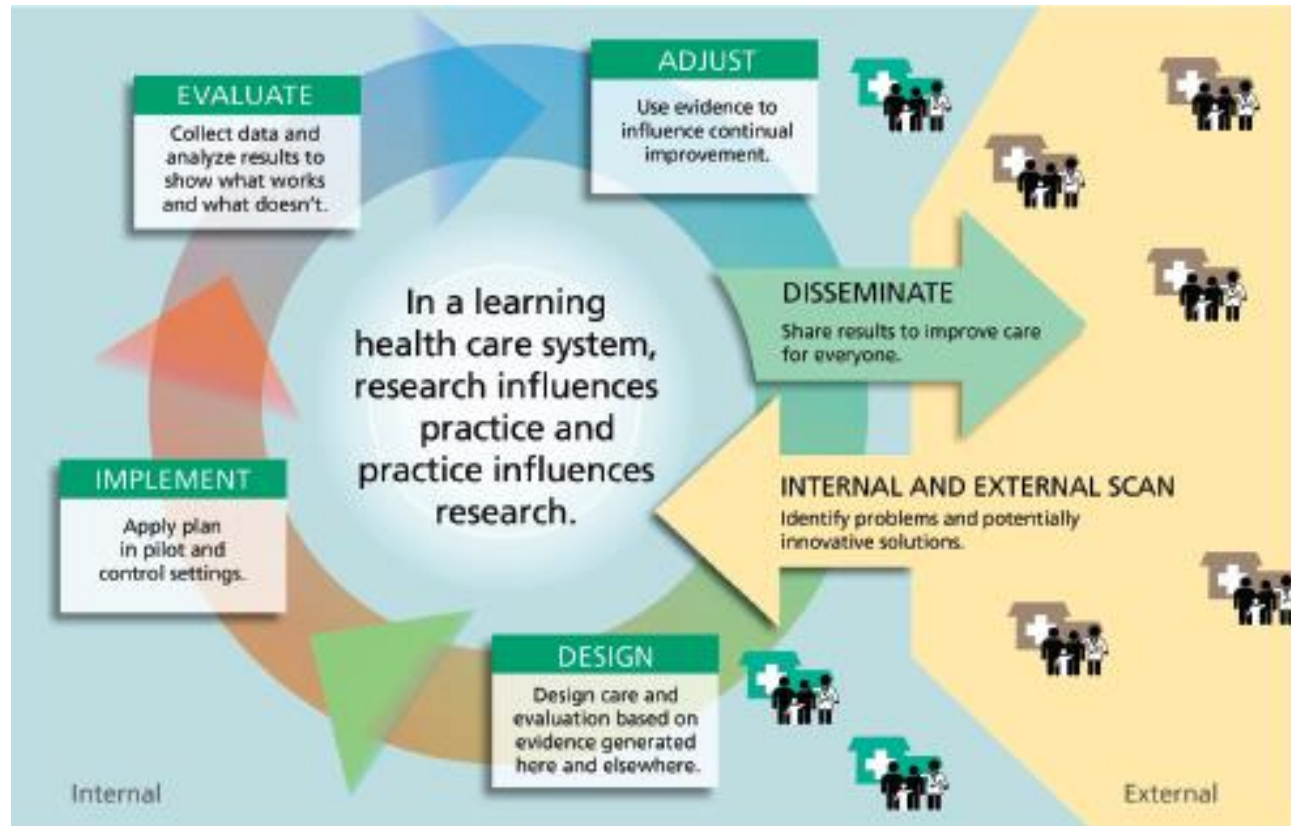
- Mood disorders, including depression and bipolar disorder, affect between 15-20% of adults
- It is the second costliest disorder at \$210.5 billion in increased medical expenses and lost productivity annually
- Up to 15% of patients with mood disorders die by suicide
- There are treatments for these disorders but they are only partially effective and often associated with side-effects that discourage adherence
- Motivation to develop more effective and safer treatments for these disorders and to develop strategies for selecting the right treatment for the individual patient when he/she needs it

The NNDC



NNDC: A network of 26 academic centers caring for patients with mood disorders with a tripartite mission to advance clinical care, research and patient education

Learning Health Systems



“A system in which progress in science, informatics, and care culture align to generate new knowledge as an ongoing, natural by-product of the care experience, and seamlessly refine and deliver best practices for continuous improvement in health care” (Institute of Medicine)

Mood Outcomes Program

A virtual learning health system that integrates clinical care and research in order to “learn” how to better treat mood disorders and use what we learn to improve the care we provide patients

- Foster measurement based care of patients
 - Capture standardized PRO and present results to clinicians in real time
 - Provide clinical decision support and promote evidence-based practice
- Facilitate quality improvement across clinics
 - Population health monitoring to drive continuous care improvements
- Support large scale prospective research
 - Enable research of captured clinical data
 - Establish a platform for embedded research studies

System Requirements

- Collect patient reported measures and return results to clinical team in real time as part of standard of care as the “fuel” for driving uptake of the program
- Leverage new modalities for capturing clinical data, particularly EMR’s, to minimize burden on patients
- Require minimal support for implementation from research and provider staff to minimize friction of uptake
- Adaptable to diverse clinical settings including outpatient mental health specialty clinics and primary care

System Architecture



Capturing patient reported outcomes

Patient Portal



Other sources of patient data



Capturing provider recorded information

EMR Integration

NNDC KnowledgeBase

LHS Engine



Supporting Clinical Care

Measurement Based-Care

Quality Improvement

Supporting Research

Research w/ Captured Data

Embedded Studies

Stage 1: Clinical Care



Capturing patient reported outcomes

Patient Portal

NNDC KnowledgeBase

LHS Engine

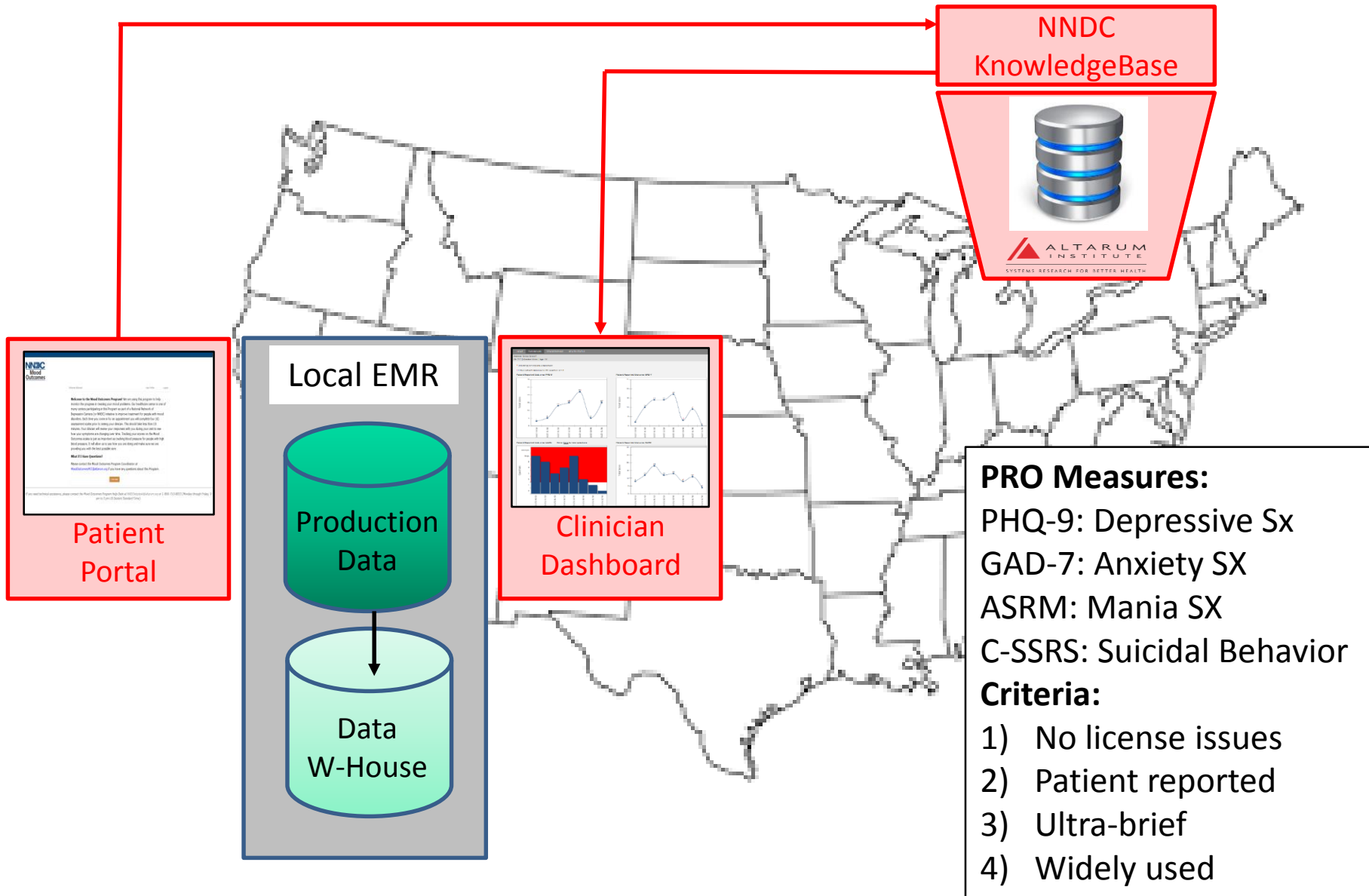


Supporting Clinical Care

Measurement Based-Care

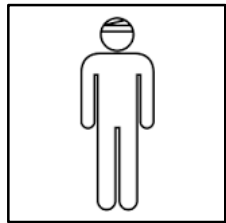
Quality Improvement

Implementation



Workflow

Patient Level



Patient



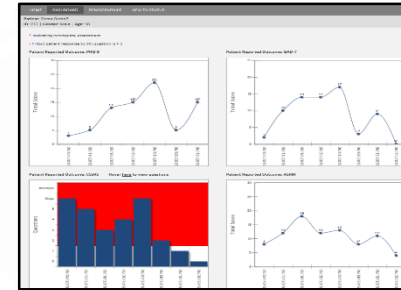
Waiting room



Complete ePRO
(PHQ9, GAD7,
ASRM, C-SSRS)

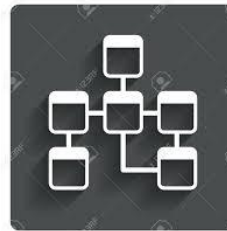


Doctor signs in
NNDC registry

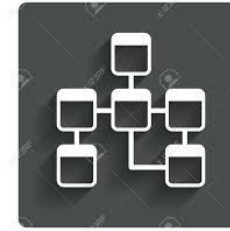


Reviews results with
patient in encounter

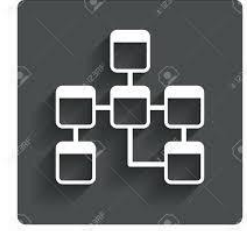
Data Level



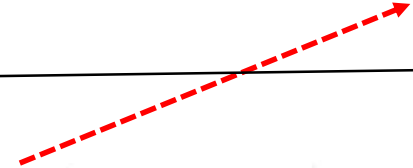
Patient portal
schema (ePRO)



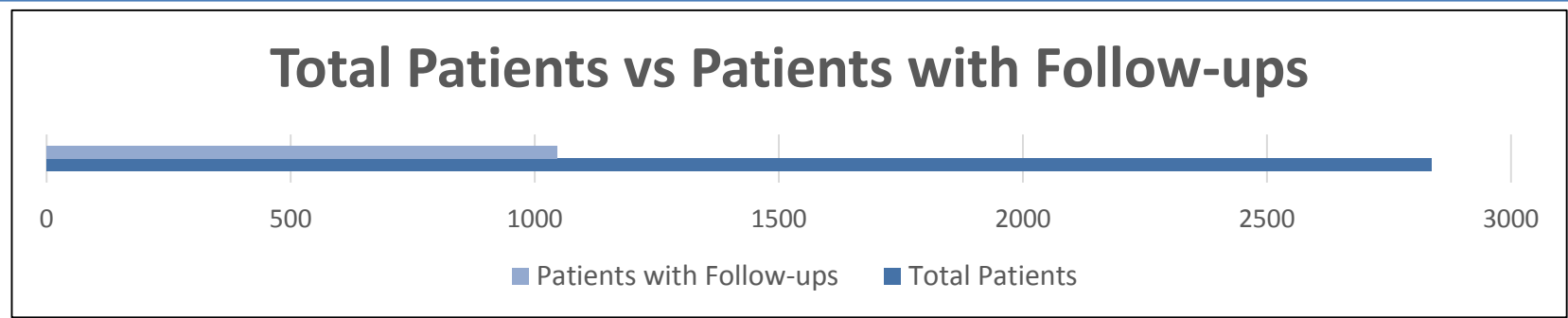
Registry schema
- Multi-tenant
- Houses PHI



De-identified
research schema



Current Status



Site	Patients	Follow-up	<18	>= 18	Dx Code	No Dx
Johns Hopkins	139	106	6	133	122	14
Mayo Clinic	252	15	1	251	247	5
University of Iowa	2,122	792	3	2,038	2,109	13
University of Michigan	130	19	1	129	105	25
University of Louisville	168	202	1	167	153	15
University of Illinois at Chicago	26	12	0	26	0	26
Totals	2,837	1,045	12	2,744	2,736	101

- Over 60% major depression; the rest bipolar disorder and other
- Goal is to enroll +5,000 by end of year 2017 and +10,000 by end of year 2018

Ethical Challenges

- How to manage patient consent?
 - No consent required for clinical care/quality improvement (PRO captured as part of standard of care)
 - No consent required for research use of de-identified data that has been captured for clinical/QI purposes
 - Obtain consent PRN through patient portal for re-contact for research
 - Obtain consent PRN for embedded studies with identifiable information
- How is patient confidentiality protected?
 - PHI captured to manage clinical care/QI (BAA agreement with Altarum)
 - Patient data de-identified per HIPAA guidelines for research (Altarum serve as honest broker)
- How is patient safety protected – e.g., suicide risk?
 - PRO evaluated as part of clinical encounter to address any immediate risks

Technical Challenges

- Multiple data systems in the clinic
 - Clinical teams must work with two systems (Altarum and local EMR), and sometimes even more (e.g. University of Michigan: EPIC, MStrides, and Altarum)
- Dueling QI/registry programs in the clinic
 - Patients/provider may have to work with more than one QI/registry programs in their clinics that may have overlapping purposes or work at cross-purposes
 - An increasing number of stakeholders are interested in such programs (e.g, the American Psychiatric Association (APA) clinical care registry)
- Management of patient registration and login
 - Registration and login designed to be self-service to minimize research/provider staff burden but still may require some hand-holding
 - Patients may not have email and frequently forget login credentials
- Certain patients unable/uncomfortable using technology
 - Paper back-up is not an ideal solution

Stage 2: Research



Capturing patient reported outcomes

Patient Portal



Capturing provider recorded information

EMR Integration

NNDC KnowledgeBase

LHS Engine



Supporting Clinical Care

Measurement Based-Care

Quality Improvement

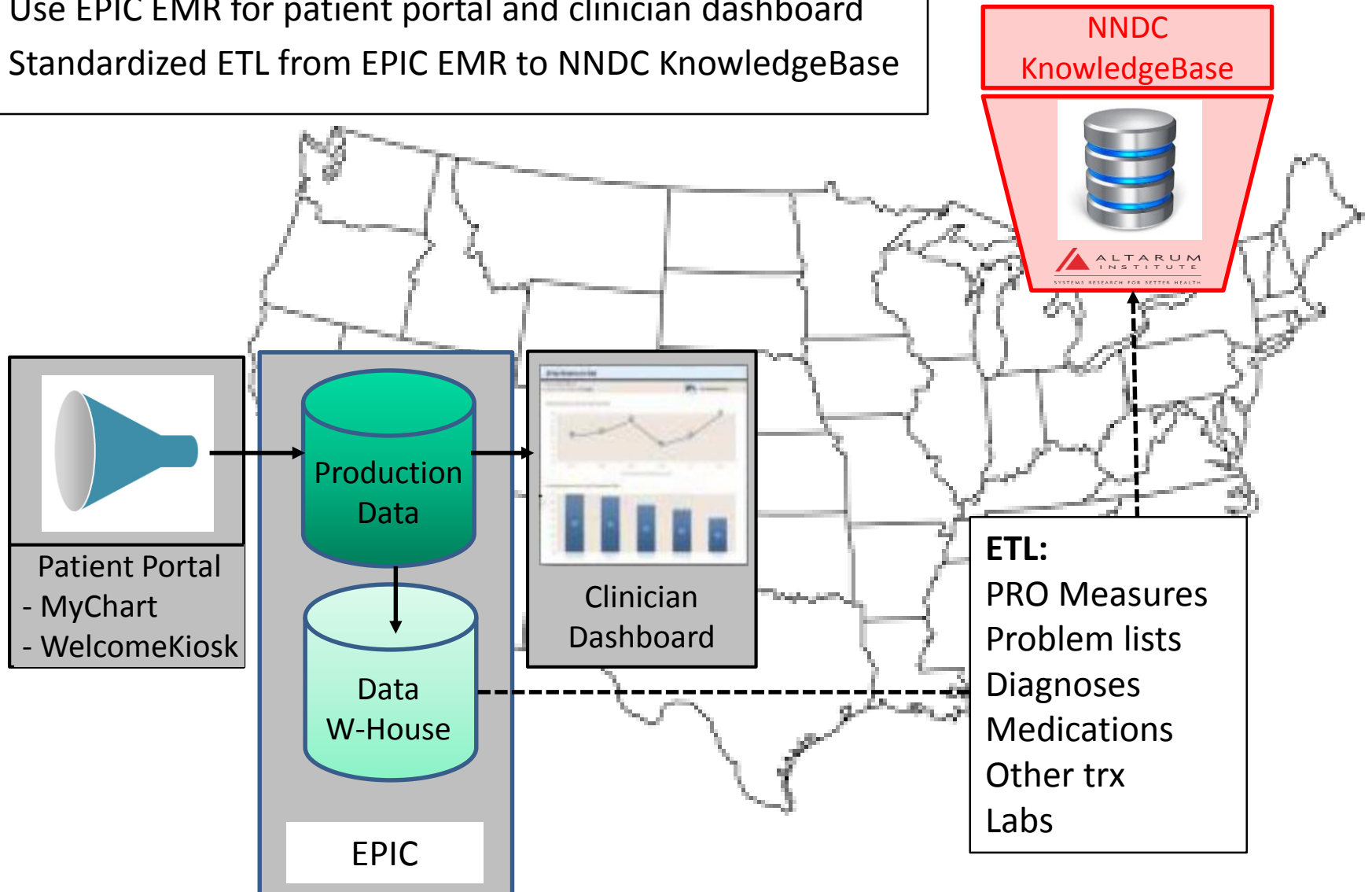
Supporting Research

Research w/ Captured Data

Embedded Studies

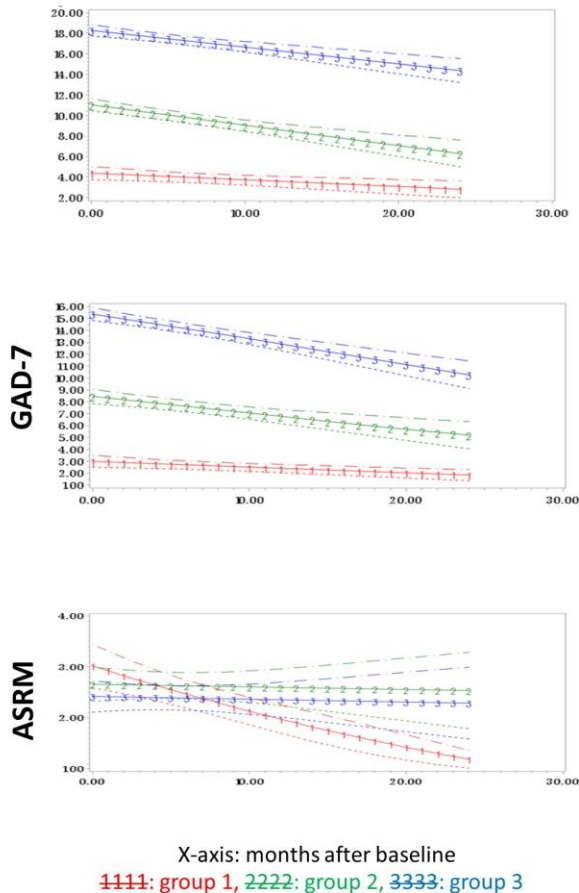
EPIC Collaboration

- Over two-thirds of NNDC sites use EPIC
- Use EPIC EMR for patient portal and clinician dashboard
- Standardized ETL from EPIC EMR to NNDC KnowledgeBase



Research with Captured Data

Figure 2: Estimated trajectories of the ASRM, GAD7, and PHQ9 from Multi-trajectory Latent Models



Class	Covariate	Estimate	OR (95% CI)	p value
2 vs 1	age at consent	-0.03	0.97 (0.96, 0.98)	<0.0001
	female sex	0.26	1.29 (0.91, 1.83)	0.15
	race	0.19	1.20 (0.90, 1.65)	0.20
	education	-0.15	0.86 (0.75, 0.98)	0.02
	suicidal ideation	1.85	6.34 (3.31, 12.13)	<0.0001
	suicidal behavior	0.29	1.34 (0.87, 2.08)	0.19
3 vs 1	age at consent	-0.03	0.97 (0.96, 0.98)	<0.0001
	female sex	0.23	1.26 (0.92, 1.70)	0.15
	race	0.87	1.09 (0.83, 1.43)	0.53
	education	-0.44	0.64 (0.57, 0.72)	<0.0001
	suicidal ideation	3.09	22.07 (11.91, 40.87)	<0.0001
	suicidal behavior	1.01	2.74 (1.85, 4.05)	<0.0001

- Association between latent trajectories on PRO measures and suicidal behavior
- Data on 4,905 observations from 1,428 patients: average age 40.09 (SD 15.87); 33.12% male; 82.91% Caucasian; and 77.59% more than high school degree

Embedded Research

- **ConLiGen: Retrospective Study of Lithium Response**
 - Global consortium of 22 sites recruited patients with bipolar disorder patients and assessed response in past to lithium with Alda Scale
 - GWAS of retrospectively assessed lithium response (n=2,563)
- **PGBD: Prospective Study of lithium response**
 - Multi-site (n=11) “clinical trial” of maintenance treatment w/ lithium monotherapy for patients with bipolar disorder and 2 year prospective follow-up
 - GWAS of prospectively assessed lithium response (n=329)
- **NNDC: Embedded Study of Lithium Response**
 - All NNDC sites (n=26) to identify patients who are new initiators of lithium and consent them for collection of biological material
 - Use PRO and EMR follow-up data of clinical care to define lithium response
 - GWAS of prospective point-of-care defined lithium response (n=10,000)

Stage 3: Enhancements



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Other sources of patient data



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Quality Improvement

Supporting Research

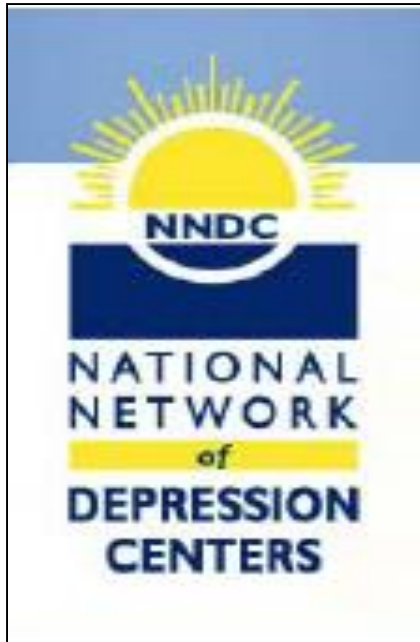
Research w/ Captured Data

Embedded Studies

Stage 3: Future Enhancements

- Expand to different clinics across NNDC sites (Transitional Youth, Women's Mood, ECT & rTMS, Primary Care)
- Establish a biobank and consent all NNDC patients to provide biological material for general research purposes
- Develop mobile platform to extend the reach of virtual learning health system and follow patients (with active and passive sensing) beyond point-of-care

NNDC Team



NNDC **Mood Outcomes**

- **Pat Rinvelt, Executive Director**
 - prinvelt@nndc.org
- **Mood Outcomes Steering Team**
 - David Katzelnick – co-chair
 - Peter Zandi – co-chair
 - Paresh Patel
 - Ray DePaulo
 - John Greden
 - Pat Rinvelt
 - Dane Larsen