

National Center for Data to Health update

CTSA PI Meeting, July 25, 2018



Informatics in healthcare and clinical research are rapidly evolving to keep pace with technology advancements and new policies

Old Way

- ◆ Siloed data
- ◆ Unimodal data
- ◆ Static or slowly evolving methods
- ◆ Bespoke tools



New Way

- ◆ Data sharing
- ◆ Integrated, multimodal data
- ◆ Social coding & collaborative development
- ◆ Distributed & cloud computing

The CTSA Program is primed to take the lead in leveraging informatics to advance precision medicine

CTSA Program hubs have led the charge in developing informatics tools that have played an important role in advancing translational science:



Clinical Data Warehouses

By better coordinating and integrating informatics across CTSA Program, the CD2H aims to accelerate innovation and help fully realize the potential of CTSA Program to improve patient care!

CD2H: Data-to-Health Coordinating Center for the CTSA Program

Accelerating Informatics Innovation to Advance Translational Research



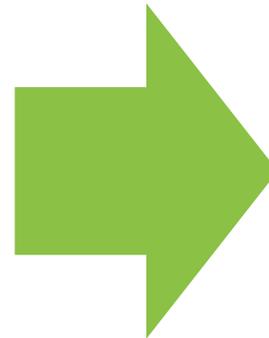
Make Data Easier to Share and Re-use



Make Tools More Accessible and Interoperable



Leverage Expertise and Foster a More Collaborative CTSA Culture



Better translation of research and improved patient care

Who we are and who we serve



The community we serve



9 CD2H Sites

iDTF



larger informatics community

We convene the informatics
community

We pilot collaborative solutions



We implement for impact





CD2H Innovation Process

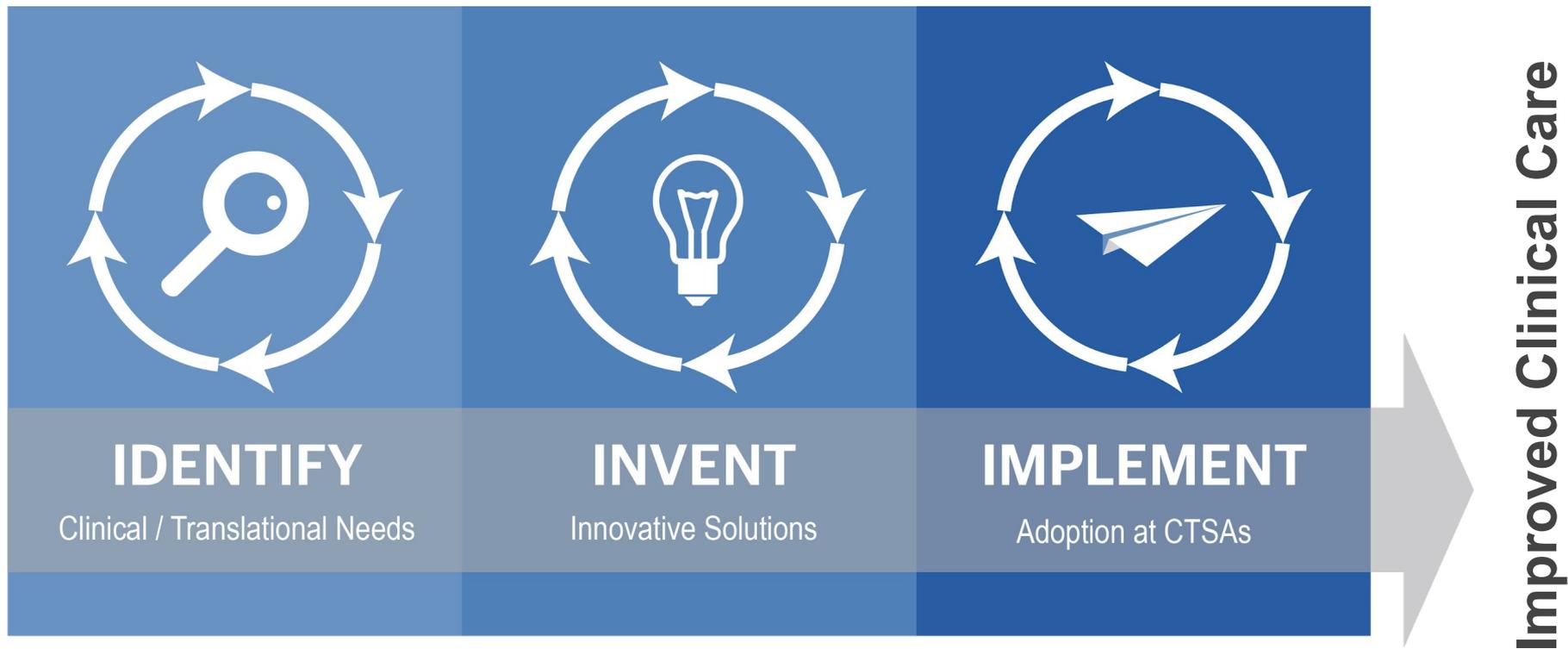
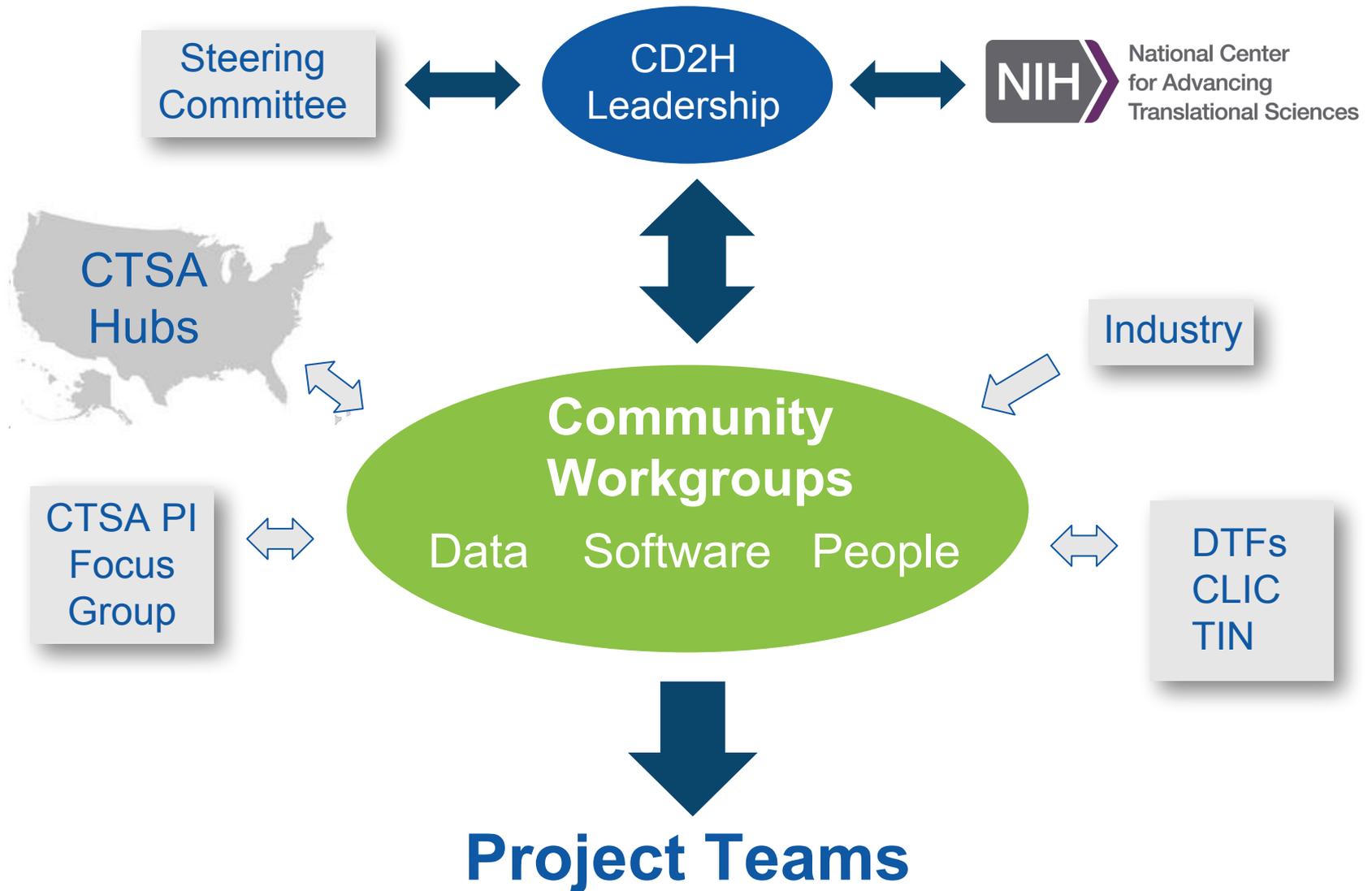


Image loosely adapted from Stanford Biodesign

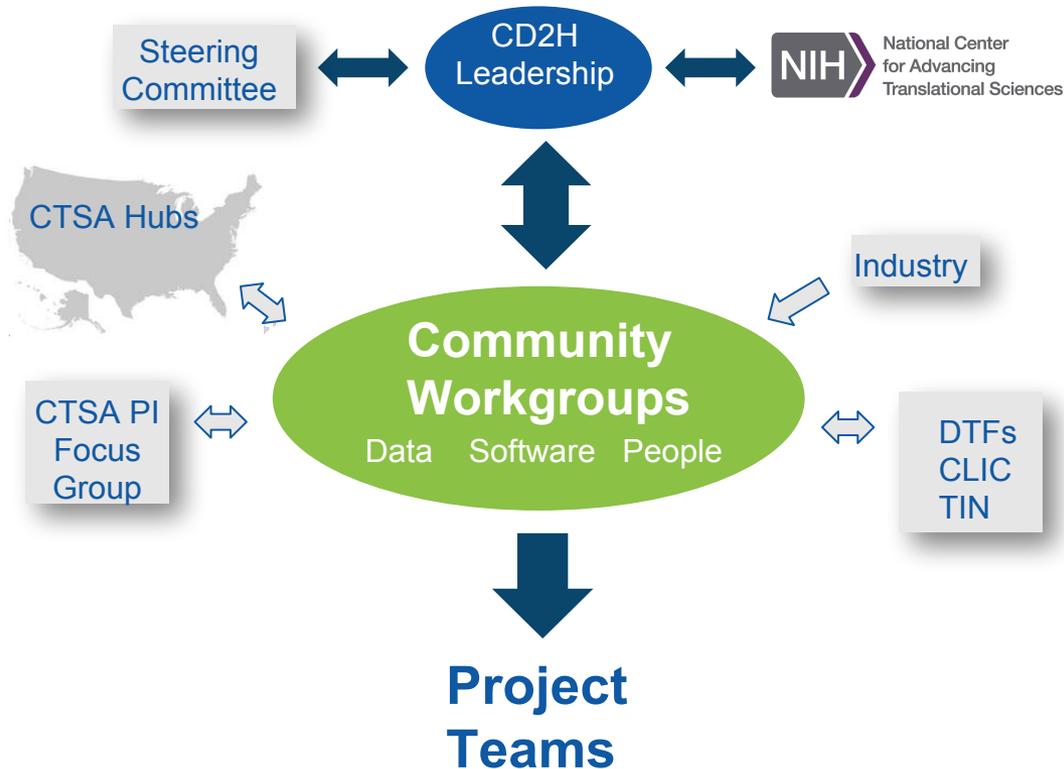


Identify: CD2H Community





Identify: CD2H Community



CTSA Engagement Opportunities

- ◆ Suggest a key clinical and translational need for the CD2H to address
- ◆ Participate in a workgroup to brainstorm solutions
- ◆ Join a project team to work to develop a solution
- ◆ Provide recommendations on projects and approaches through the CTSA PI Focus Group or iDTF
- ◆ Host a site visit



Identify: CTSA Informatics Challenges

Based on initial outreach, we identified some key informatics questions to address.

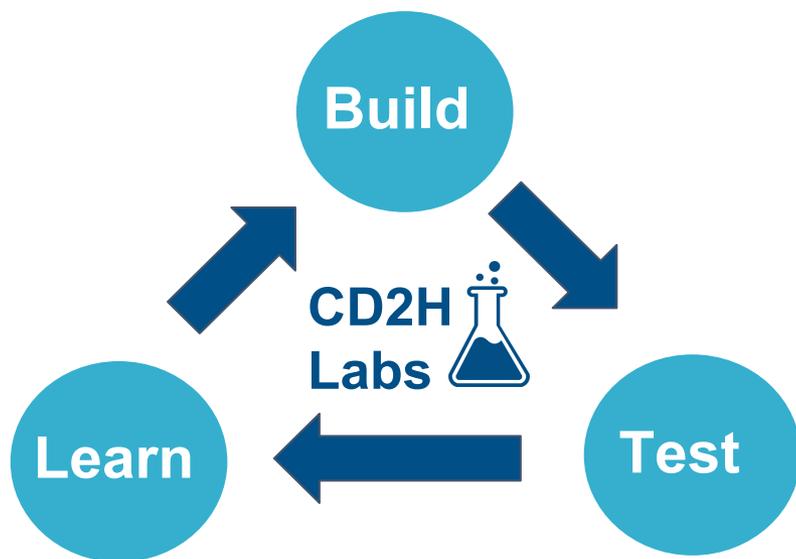
How can CTSA:

- ◆ Take advantage of cloud computing?
- ◆ Efficiently manage interoperability between clinical data models?
- ◆ Easily identify expertise and resources across hubs?
- ◆ Effectively utilize EHR data for research and the clinic?
- ◆ Make clinical data governance and research licensing easier and more impactful?
- ◆ Better integrate basic and clinical research?
- ◆ Leverage informatics to do translational science more effectively?
- ◆ Improve diverse workforce knowledge and use of informatics resources?



Invent: CD2H Collaborative Innovation Platforms

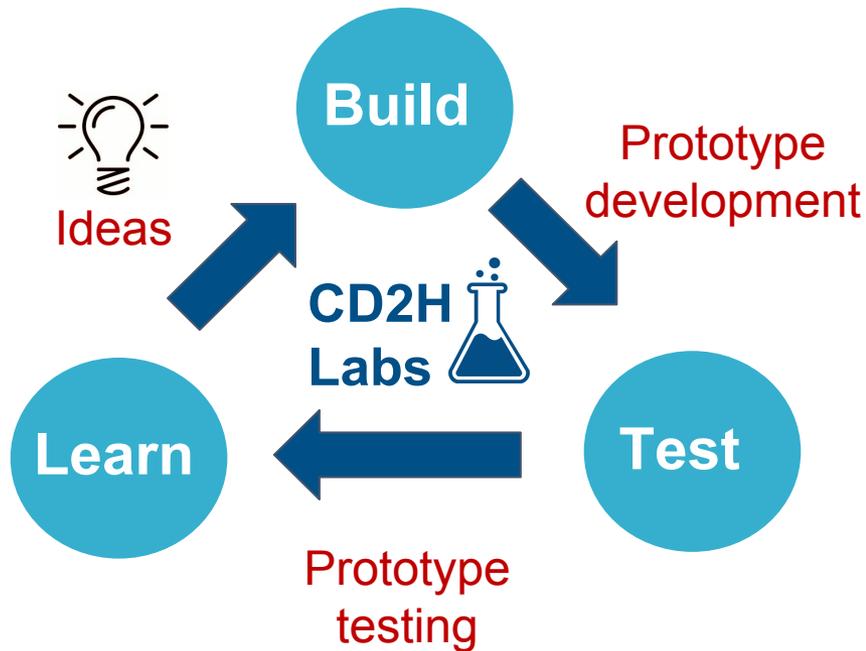
Innovate with us!



DREAM CHALLENGES



Invent: CD2H Labs



CTSA Engagement Opportunities

- ◆ Test prototypes
- ◆ Providing feedback
- ◆ Share YOUR prototypes
- ◆ Participate in bimonthly CD2H Show and Tell Webinars to see updates on prototype development
- ◆ Pilot prototypes at your site



Invent: Current Project Highlights



LOINC2HPO



Discovery Storefront



Informatics Maturity Model



Project Highlight: LOINC2HPO

Laboratory test results across the country are recorded using LOINC codes

This approach is not interoperable with other phenotype data

Improved translational informatics, cohort discovery, and interoperability with LOINC was the #1 suggestion from the iDTF F2F Ontology breakout

Project Highlight - LOINC2HPO

Develop a tool for converting LOINC laboratory codes and values into more phenotypically meaningful language (Human Phenotype Ontology) to allow for translational interoperability and new analytics

Steps

- ◆ Develop a software tool to map LOINC codes to HPO terms
- ◆ Develop software to convert EHR observations into HPO terms for use in clinical research

LOINC	Outcome
2657-5 “Nitrite [Mass/volume] in Urine”	Numeric
20407-3 “Nitrite [Mass/volume] in Urine by Test strip”	Numeric
32710-6 “Nitrite [Presence] in Urine”	Positive/Negative
5802-4 “Nitrite [Presence] in Urine by Test strip”	Positive/Negative
50558-6 “Nitrite [Presence] in Urine by Automated test strip	Positive/Negative

HPO: Nitrituria

Project Highlight - LOINC2HPO



Benefits for CTSA Program



- ◆ New approaches to defining cohorts within and across systems and sites
- ◆ Identify rare disease patients and target diagnostics
- ◆ Support phenotype-driven diagnostics
- ◆ Discovery and mechanistic research (e.g., disease-specific sex differences)

Project Highlight - LOINC2HPO

Next steps and Opportunities for engagement



- ◆ Looking to partner with medical informatics group conducting research on EHRs
- ◆ Data will be used to develop algorithms
- ◆ Seeking input and collaboration on algorithm development and their application to machine learning and discovery research in EHR data
- ◆ Data will be used to develop algorithms

**CD2H
Labs**



- ◆ Provide feedback and input on the LOINC2HPO project

**Test our
prototype
on your
EHR data**

**Provide
feedback via
CD2H Labs!**



Project Highlight:
**Discovery
Storefront**

How can we more effectively enable CTSA hubs to find, develop, collaborate, and use software, tools, algorithms, and datasets of importance to CTSA hubs?

Project Highlight - Discovery Storefront

Inventorizing and developing infrastructure for developing, discovering, disseminating and hosting tools and data in use at CTSA Hubs, as well as enabling discovery of educational resources and expertise.

Data Discovery Engine

- ◆ Identify and extend metadata and API standards
- ◆ Annotate and expose datasets

Tool Inventory API

- ◆ Hosted management and/or discovery of collaboratively developed software and tools
- ◆ Central point for finding software tools for CTSA

People Finder

- ◆ Integrate institutional and public data about CTSA persons
- ◆ Develop search engine and APIs
- ◆ Create a user interface for data visualization and use in CTSA program impact assessment



Schema.org
Rich Snippets/ Structured data



Global Alliance
for Genomics & Health
Collaborate. Innovate. Accelerate.



CTSAsearch



Project Highlight - Discovery Storefront

Benefits for CTSA Program



- ◆ Facilitate resource sharing across CTSA hubs
- ◆ Discovery storefront supports discoverability, reuse, contribution
- ◆ Identify and leverage connections between expertise, software tools, datasets, and analytics for translational science
- ◆ Better understand impact and use of translational informatics within and across CTSA hubs

Project Highlight - Discovery Storefront

Next steps and Opportunities for engagement



- ◆ Disseminate CTSA tools, software and datasets
- ◆ Community awareness of best practices and tool utilization
- ◆ Gap analysis and collaborative development of needed resources

Complete landscape analysis: Inventory and expose CTSA hub datasets and tools



- ◆ Enhance educational ontologies for discovery
- ◆ In partnership with other NIH initiatives
- ◆ Gap analysis and discovery of core learning modules in clinical research

Include educational resources in our discovery storefront



Project Highlight:
Informatics
Maturity
Model

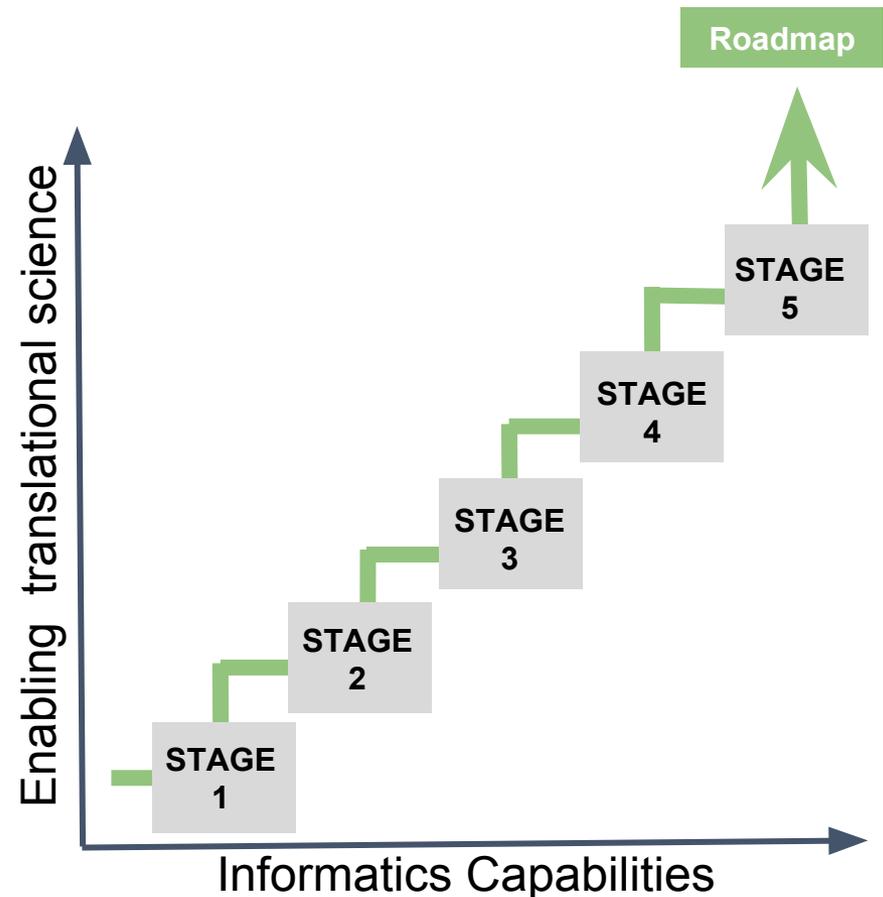
What informatics capabilities are integral to effective translational science?

How can we help CTSA's assess their informatics maturity to inform strategic planning?

Project Highlight - Informatics Maturity Model

We are developing a CTSA self-assessment which can determine informatics maturity in the realms of data, governance, and policy.

- ◆ Determine critical informatics capabilities (data, governance, and policy) associated with maturity and the steps taken to get there
- ◆ Define informatics maturity stages and best practices
- ◆ Create a self assessment and roadmap for informatics growth
- ◆ Promote use of maturity model for assessment and planning



Project Highlight - Maturity Model

Benefits for CTSA Program



- ◆ Organizational learning
- ◆ Identification of best practices
- ◆ Discovery of opportunity area
- ◆ Defined pathways to increase capacity
- ◆ Strategic planning and roadmap for informatics

Project Highlight - Maturity Model

Next steps and Opportunities for engagement



- ◆ Help test and further refine the Maturity Model self assessment
- ◆ Collaborate with existing maturity model efforts in CTSA community

Join our CD2H Data Community Workgroup Meeting on September 14 to help chart next steps



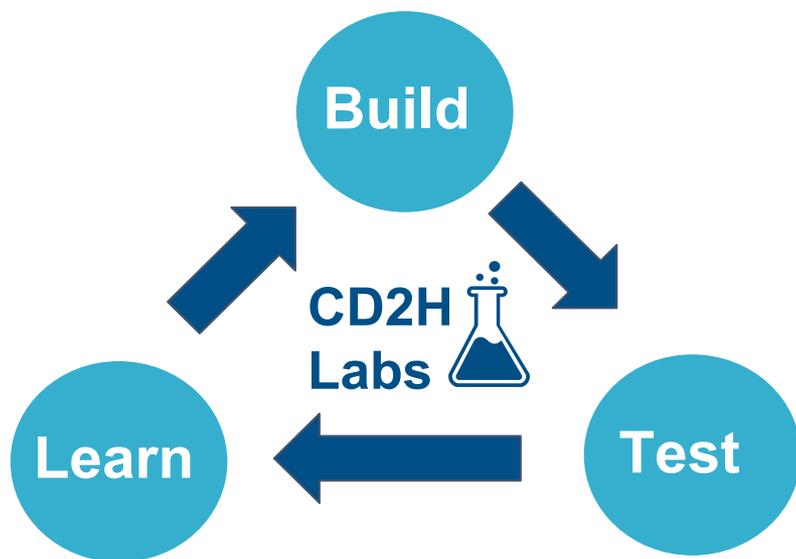
- ◆ A measure of CTSA informatics maturity and capacity
- ◆ An aspirational 'roadmap' to assist in CTSA informatics strategic planning
- ◆ Rollout and implementation in scope for CD2H

Participate in assessment of existing landscape in advancing organizational maturity



Invent: CD2H Collaborative Innovation Platforms

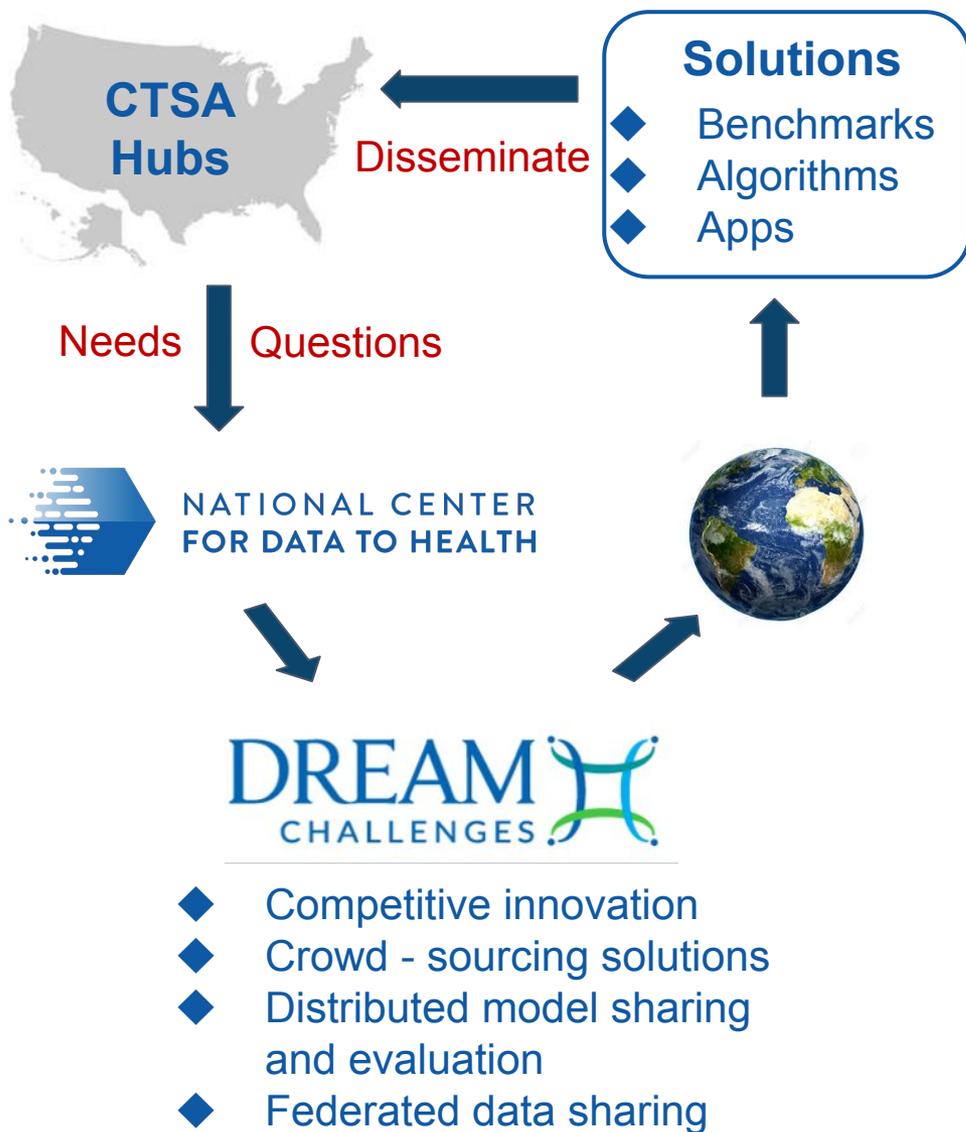
Innovate with us!



DREAM CHALLENGES



Invent: CD2H DREAM Challenges



CTSA Engagement Opportunities

- ◆ Propose a question or need
- ◆ Champion a challenge
- ◆ Contribute data
- ◆ Participate in the competition as part of a team
- ◆ Pilot solutions at your site



Invent: Prior DREAM Challenge

Past DREAM Challenge

The Digital Mammography DREAM Challenge

Out of every 1000 women screened, only 5 will have breast cancer. But 100 will be recalled for further testing. **We can do better.**

Build a model to help reduce the recall rate for breast cancer screening.
Calling all coders to join the Challenge.

Up to a **\$1,000,000** in cash prizes for winning models.
May the best model win.

- ◆ Ran from Sept 2016 - Nov 2017
- ◆ 240 participants organized into 140 teams
- ◆ Primary dataset: Kaiser (86k women; 140k exams; 640k images)
- ◆ Secondary dataset: Karolinska (600k images)

	AI		Radiologist		AI + Radiologist	
	AUC	Spec	Sens	Spec	AUC	Spec
All exams (Kaiser)	0.895	0.761	0.859	0.905	0.942	0.920
Invasive (Kaiser)	0.907	0.839	0.817	0.905	0.935	0.936
DCIS (Kaiser)	0.864	0.354	0.963	0.905	0.961	0.877

Successful demonstration of a "**model to data**" challenge, utilizing hidden imaging data for algorithm benchmarking in the cloud

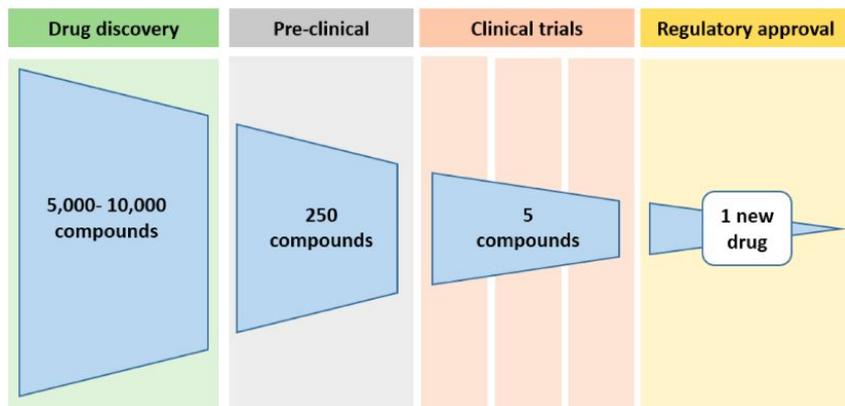
Guinney, et al, "Alternative form of biomedical data sharing", Nat Biotech, 2018



Invent: CD2H DREAM Challenges

DREAM Challenge Pipeline

- ◆ 5 DREAM Challenge proposals are currently under development
- ◆ Please [submit your ideas!](#)
- ◆ Launching first CTSA DREAM Challenge the fall



Current DREAM proposal under development

Predict poor chronic disease outcomes among patients with identified mental health disorders

Predict who will:

- Develop a chronic disease(s)
- Have difficulty managing their chronic disease

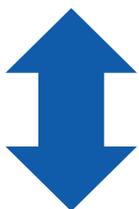
Why?:

- Patients with mental health disorders are at risk for premature death and severe physical illness

DREAM approach and outcomes are extensible to other diseases



Implement: Solution Dissemination



COLLABORATIVE SOLUTIONS



Adoption by stakeholders



CD2H Innovation Process

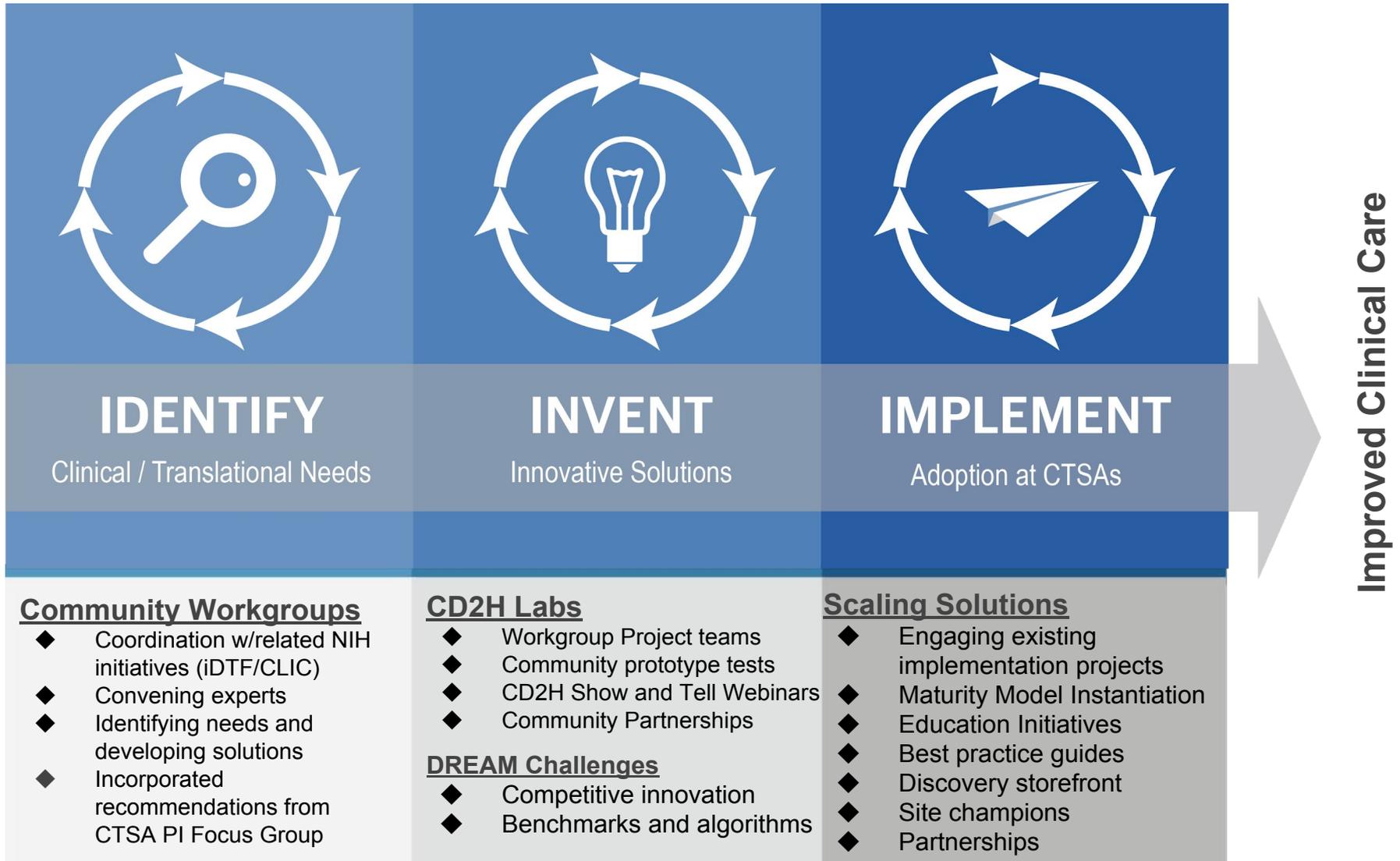


Image loosely adapted from Stanford Biodesign

Join Us!

Please join us!
Show and Tell Webinar
Featuring the CD2H Data Workgroup
July 27, 11 am- noon PT, 2- 3 pm ET

This first Show and Tell will feature current CD2H Data Workgroup project leads sharing progress on their work. This will be a great opportunity for the CTSA community to learn about the exciting work underway and provide valuable input and feedback. We hope you'll join us. Register [here](#).



Adam Wilcox, PhD

Developing a maturity model to guide effective data use for open science to accelerate research and translation across CTSA's



Chunlei Wu, PhD

Data Indexing Initiative: Achieving data integration within, between, and beyond CTSA's



Peter Robinson, PhD

Mapping LOINC codes and FHIR encoded results to HPO terms to facilitate data exchange across CTSA's

Join Us!

Community Workgroups



- ◆ Data, Software, People
- ◆ Join us for our first quarterly meetings in Sept to provide input on next steps
- ◆ [Join here](#)

CD2H Labs

- ◆ Test a prototype
- ◆ Share a prototype
- ◆ [Give feedback](#)

DREAM CHALLENGES

powered by Sage Bionetworks

- ◆ Join a challenge
- ◆ Suggest a challenge

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Thank You!

