



NIA IMPACT
COLLABORATORY
TRANSFORMING DEMENTIA CARE

AHCA
AMERICAN HEALTH CARE ASSOCIATION



Long-Term Care Data Cooperative

Webinar: December 7, 2022

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David Dore, PharmD, PhD, Exponent, Inc.

Introductions

- Vincent Mor, PhD, MPI of the NIA funded IMPACT Collaboratory and Professor, Department of Health Services, Policy & Practice, Brown University School of Public Health
- David Gifford, MD, MPH, Chief Medical Officer, American Health Care Association and Professor of the Practice, Brown University School of Public Health
- David Dore, PharmD, PhD, Principal Scientist, Exponent and Adjunct Professor, Brown University School of Public Health

Background: What is a Data Cooperative?

- Opportunity for data owners to pool data
- Can be “vertical” (an integrated hospital system)
- Can be “horizontal” (all hospitals in a state)
- OR can be both vertical and horizontal (state all-payer claims database, multi-institutional integrated electronic medical record [EMR] systems)

Background: Different Types of Data Consortia

- **Data Repositories**

- OptumLabs (United Health Insurance Claims and EMR data linked)
- Health Care Cost Institute (multiple companies' insurance claims)
- Centers for Medicare & Medicaid Services (CMS) Medicare Claims linked to nursing home Minimum Data Set (MDS) and home health agency (HHA) Outcome and Assessment Information Set (OASIS) assessments

- **Data Linkage Services**

- Datavant uses tokens to link individuals' records across different data sources and creates de-identified files

- **Federated Data Systems**

- Use a common data model in multiple data systems; data remain distributed; same analysis code used to create common tables

Centralized Data Sharing Consortia

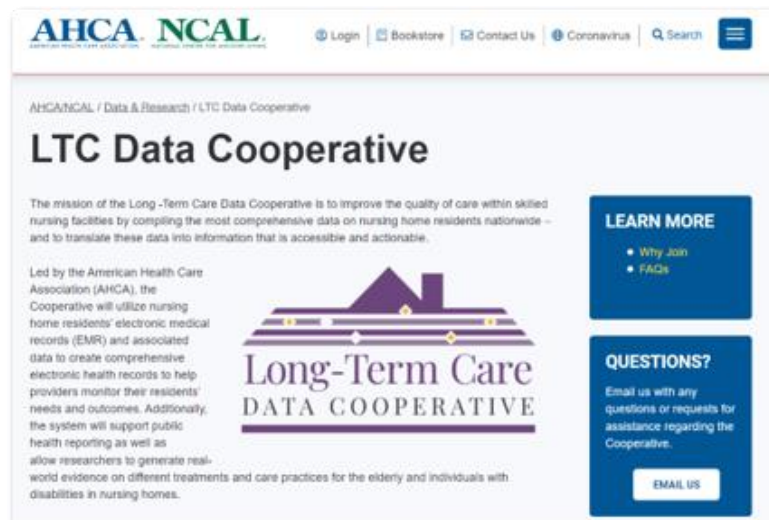
- Rare
- Privacy concerns at both patient AND provider level
- Regulatory complications (HIPAA/HITECH Act, liability, etc.)
- Require trust
 - Data security
 - Control over how the data are used (which questions are asked)
- All parties involved must see value
 - Providers must benefit from data sharing
 - Receive alerts about new information

Long-Term Care Data Cooperative Mission

The mission of the Long-Term Care (LTC) Data Cooperative is to improve the quality of care within skilled nursing facilities by compiling the most comprehensive data on nursing home residents nationwide – and to translate these data into accessible and actionable information designed to help clinicians, managers and policy makers improve care.

LTC Data Cooperative Functions

- Support improved healthcare operations, including care coordination;
- Public health surveillance;
- Support research funded through National Institutes of Health-funded academic partners; and
- Support research, including Phase 3 and Phase 4 clinical trials



The screenshot shows the AHCA/NCAL website page for the LTC Data Cooperative. The page features the AHCA and NCAL logos at the top, along with navigation links for Login, Bookstore, Contact Us, Coronavirus, and Search. The main heading is "LTC Data Cooperative". Below this, a mission statement reads: "The mission of the Long-Term Care Data Cooperative is to improve the quality of care within skilled nursing facilities by compiling the most comprehensive data on nursing home residents nationwide – and to translate these data into information that is accessible and actionable." To the right of the mission statement is a blue button labeled "LEARN MORE" with links for "Why Join" and "FAQs". Below the mission statement is a paragraph describing the cooperative's work: "Led by the American Health Care Association (AHCA), the Cooperative will utilize nursing home residents' electronic medical records (EMR) and associated data to create comprehensive electronic health records to help providers monitor their residents' needs and outcomes. Additionally, the system will support public health reporting as well as allow researchers to generate real-world evidence on different treatments and care practices for the elderly and individuals with disabilities in nursing homes." To the right of this paragraph is a blue button labeled "QUESTIONS?" with the text "Email us with any questions or requests for assistance regarding the Cooperative." and an "EMAIL US" button.

<https://www.ahcanal.org/Data-and-Research/Pages/LTC-Data-Cooperative.aspx>

Partners Serve Distinct Roles

Brown University School of Public Health

- Received National Institute on Aging (NIA) grant; contracts with AHCA, Exponent, and Acumen
- Solicits researchers to work with the data

American Health Care Association

- Oversees operations of the LTC Data Cooperative
- Recruits NHs to enroll
- Contracts with EMR vendors to transfer EMR data to Exponent
- Reviews research applications and gets input from providers

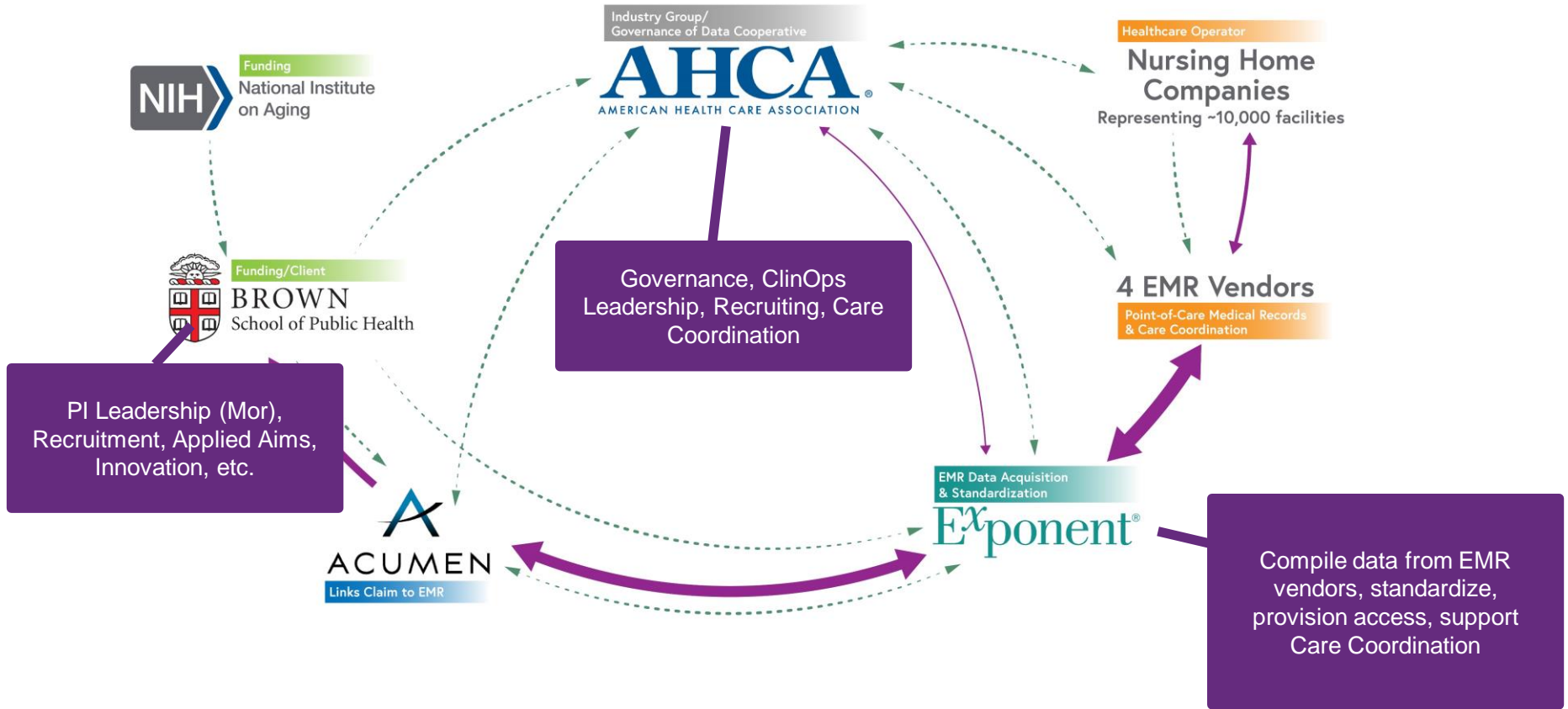
Exponent

- Oversees the data
- Receives the data directly from EMR vendors
- Curates data into core data model across EMR vendors
- Transfers data to Acumen for matching with CMS claims

Acumen

- Matches coded EMR data to Medicare claims and records

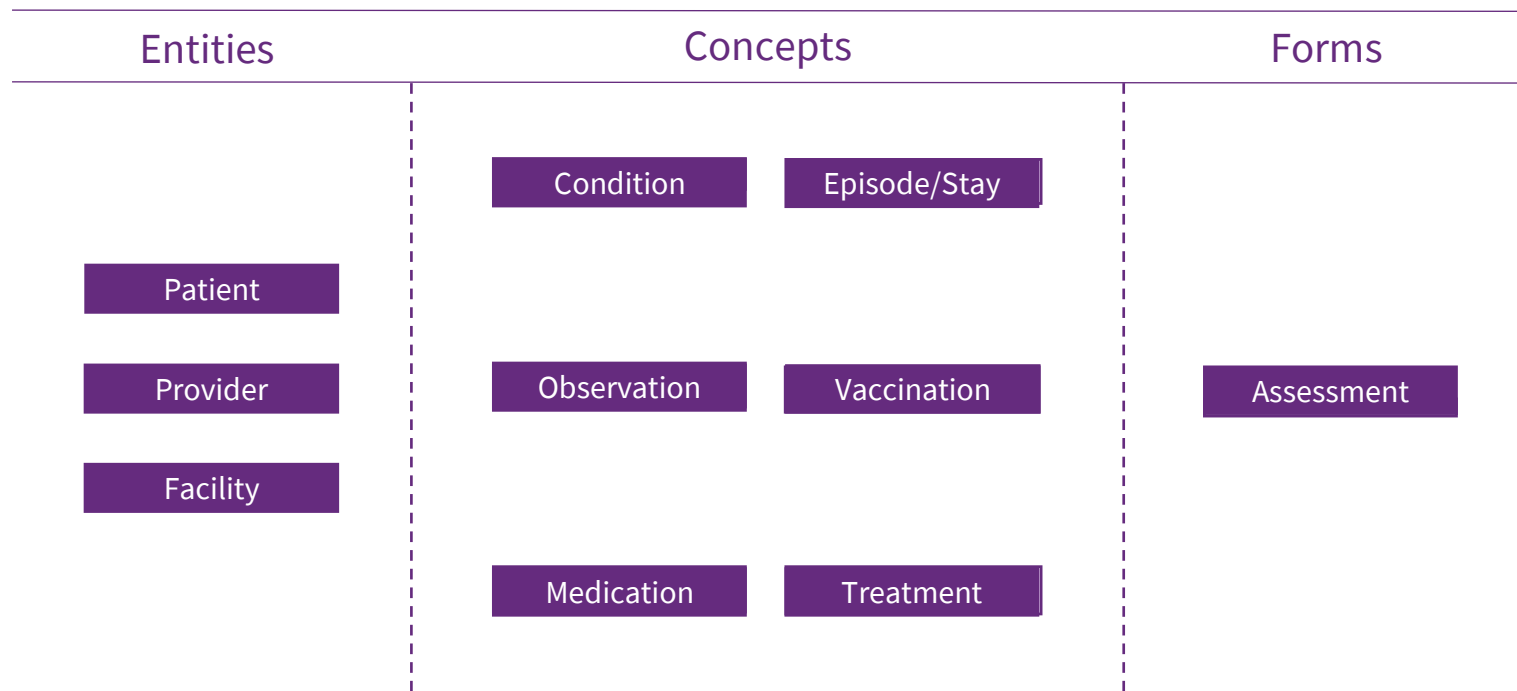
Structure and Data Flow



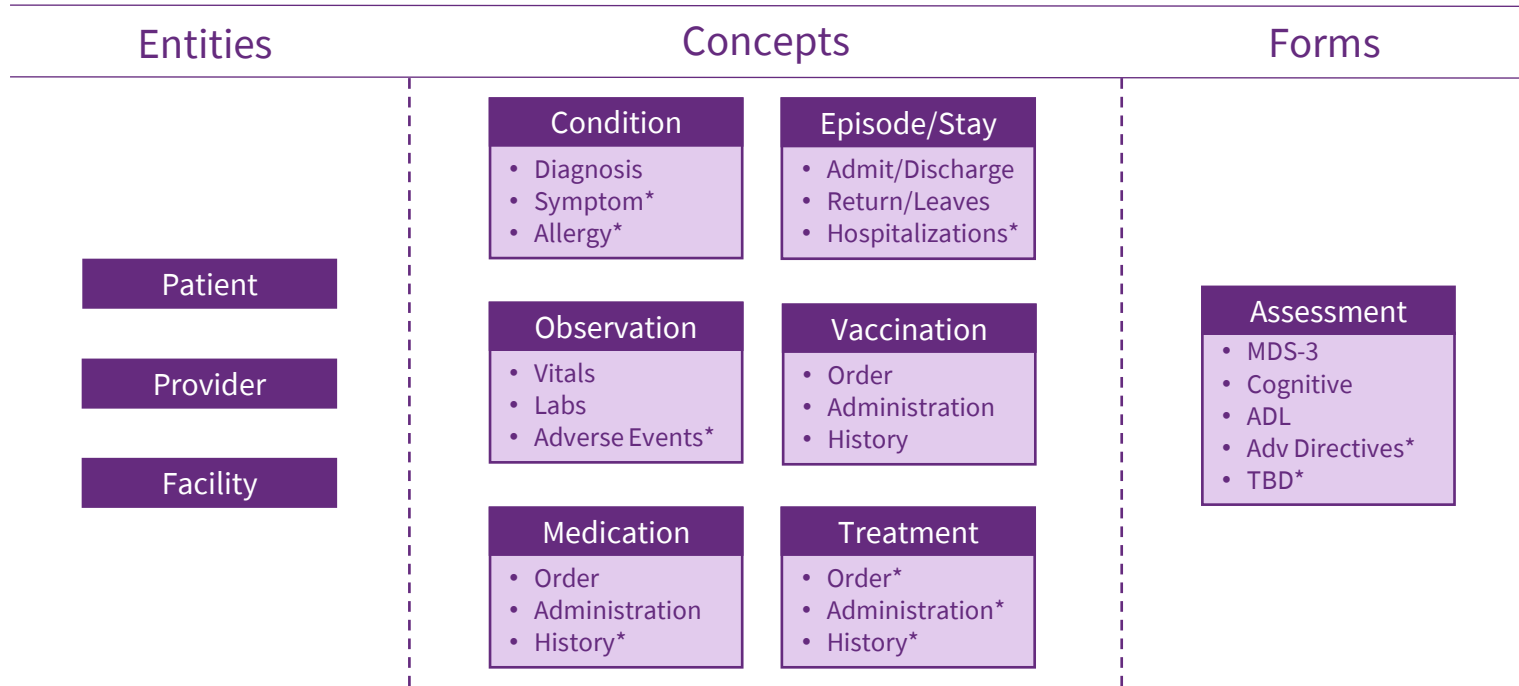
Surveillance and Research Functions

- Public health surveillance
 - Estimating incidence & prevalence and determinants of infections
- Observational treatment effectiveness research
- Comparative effectiveness of drugs, therapies and treatments
- Testing and re-testing patient risk algorithms
 - Using changing vital signs to improve hospitalization risk models
- Recruitment into clinical trials
 - Comparative effectiveness of two FDA-approved treatments in cluster RCT
 - Recruit facilities and then get patient consent for Phase 3 clinical trials

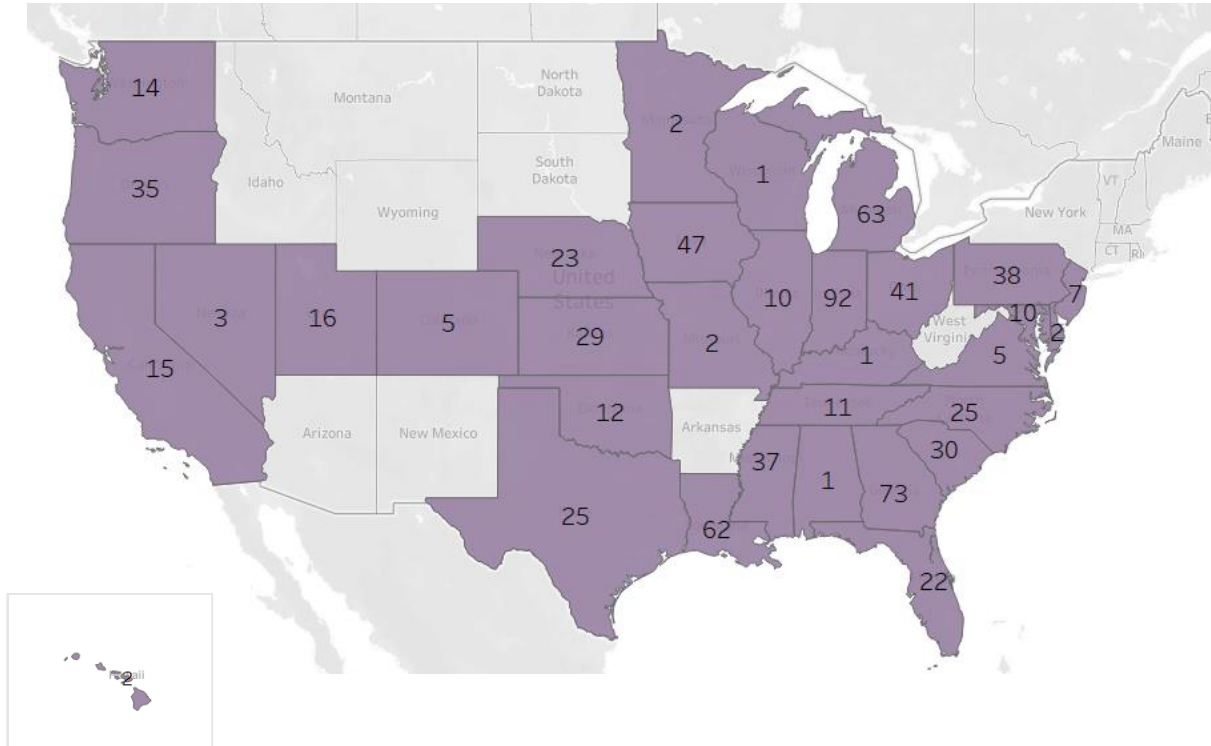
Core Data Model



Core Data Model



Current Geographic Coverage of Facilities



Data Example: Medication Order Details

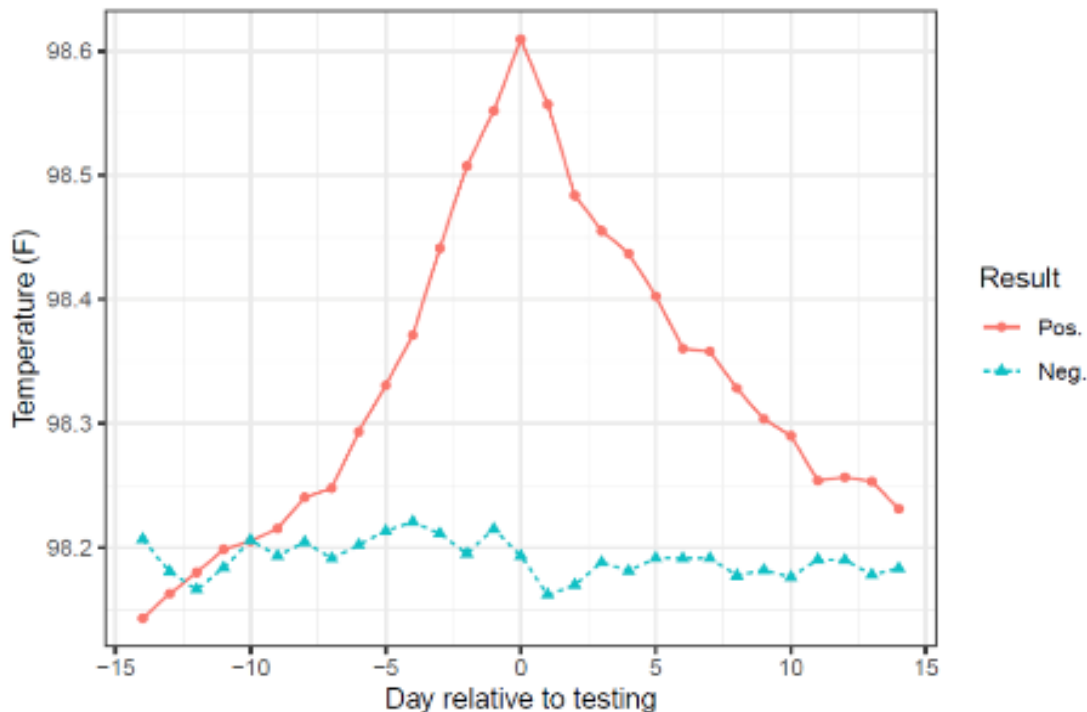
<u>Order Summary</u>	<u>Communication Method</u>	<u>Order Status</u>	<u>Order Date</u>	<u>Start Date</u>	<u>End Date</u>
Aspirin Tablet 325 MG Give 1 tablet by mouth one time a day for antiplatelet	Phone	Active	03/17/2020	03/18/2020	
Cholecalciferol Tablet 1000 UNIT Give 2 tablet by mouth one time a day every Mon, Wed, Fri, Sat for supplement	Phone	Active	03/17/2020	03/18/2020	
Claritin Tablet 10 MG (Loratadine) Give 1 tablet by mouth one time a day for allergies	Phone	Active	03/17/2020	03/18/2020	
Cyanocobalamin Tablet 1000 MCG Give 1 tablet by mouth one time a day for supplement	Phone	Active	03/17/2020	03/18/2020	
Ditropan XL Tablet Extended Release 24 Hour 10 MG (Oxybutynin Chloride ER) Give 1 tablet by mouth one time a day for urinary spasms	Phone	Active	03/17/2020	03/18/2020	



Study Examples (earlier Coop data structure)

- Value of daily (or more frequent) vital signs
- Value of dated incident diagnoses
- Value of clinical symptoms for improving mortality prediction
- Randomized Clinical Trial to increase COVID vaccination

Daily Temperature Relative to COVID-19 Testing



McConeghy KW, White E, Panagiotou OA, Santostefano C, Halladay C, Feifer RA, Blackman C, Rudolph JL, Mor V, Gravenstein S. Temperature Screening for SARS-CoV-2 in Nursing Homes: Evidence from Two National Cohorts. *J Am Geriatr Soc. J Am Geriatr Soc.* 2020 Dec;68(12):2716-2720.

Correlation Between Positive COVID-19 Test Date and COVID-19 Diagnosis Date

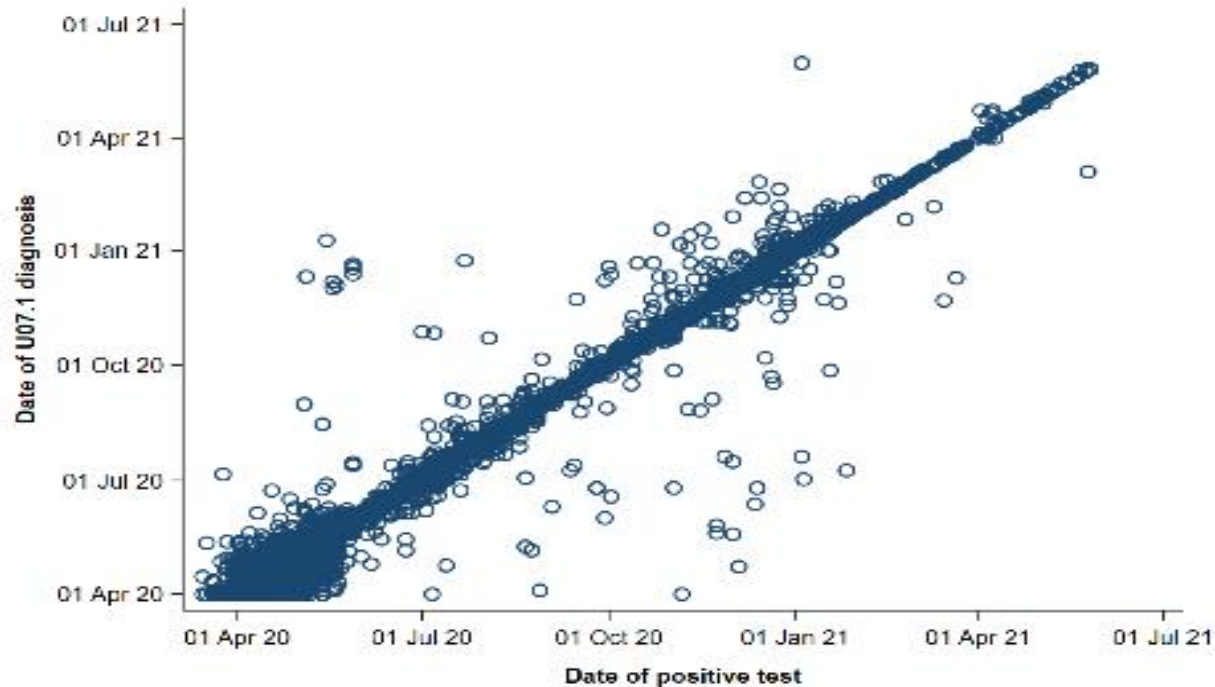
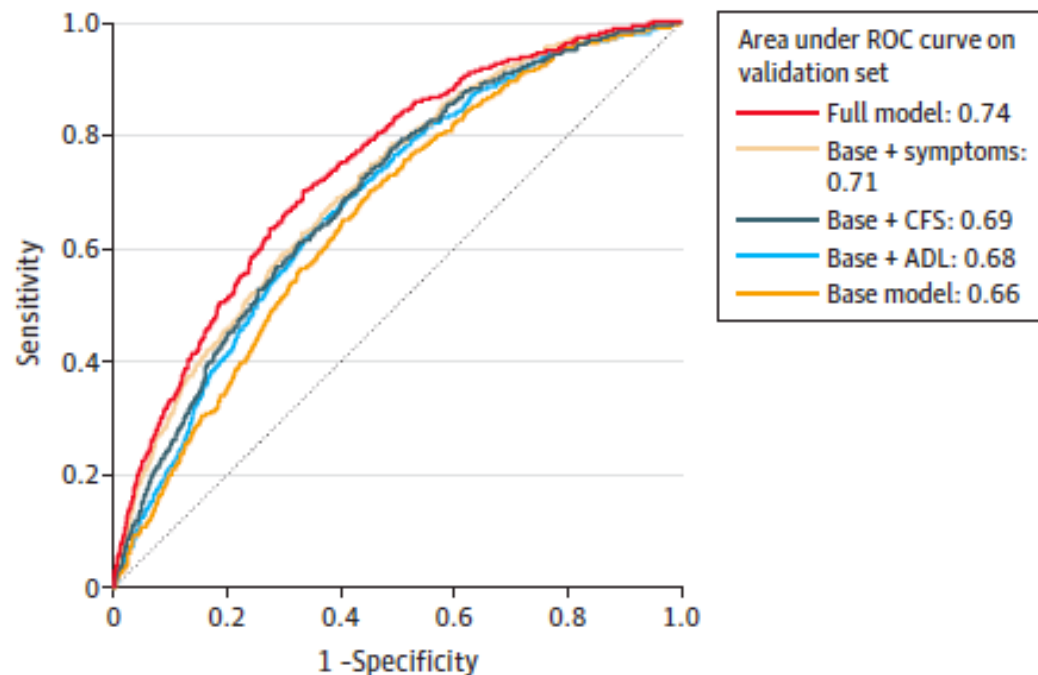


Figure 1. Receiver Operating Characteristic (ROC) Curves for 30-Day All-Cause Mortality Based on 5 Different Models



The base mode consists of established risk factors (ie, age, sex, race/ethnicity, and comorbidities). ADL indicates activities of daily living; and CFS, Cognitive Function Scale.

Figure. CONSORT Diagram Describing Selection of Intervention and Usual Care Facilities, Residents, and Staff in the IMPACT-C Trial

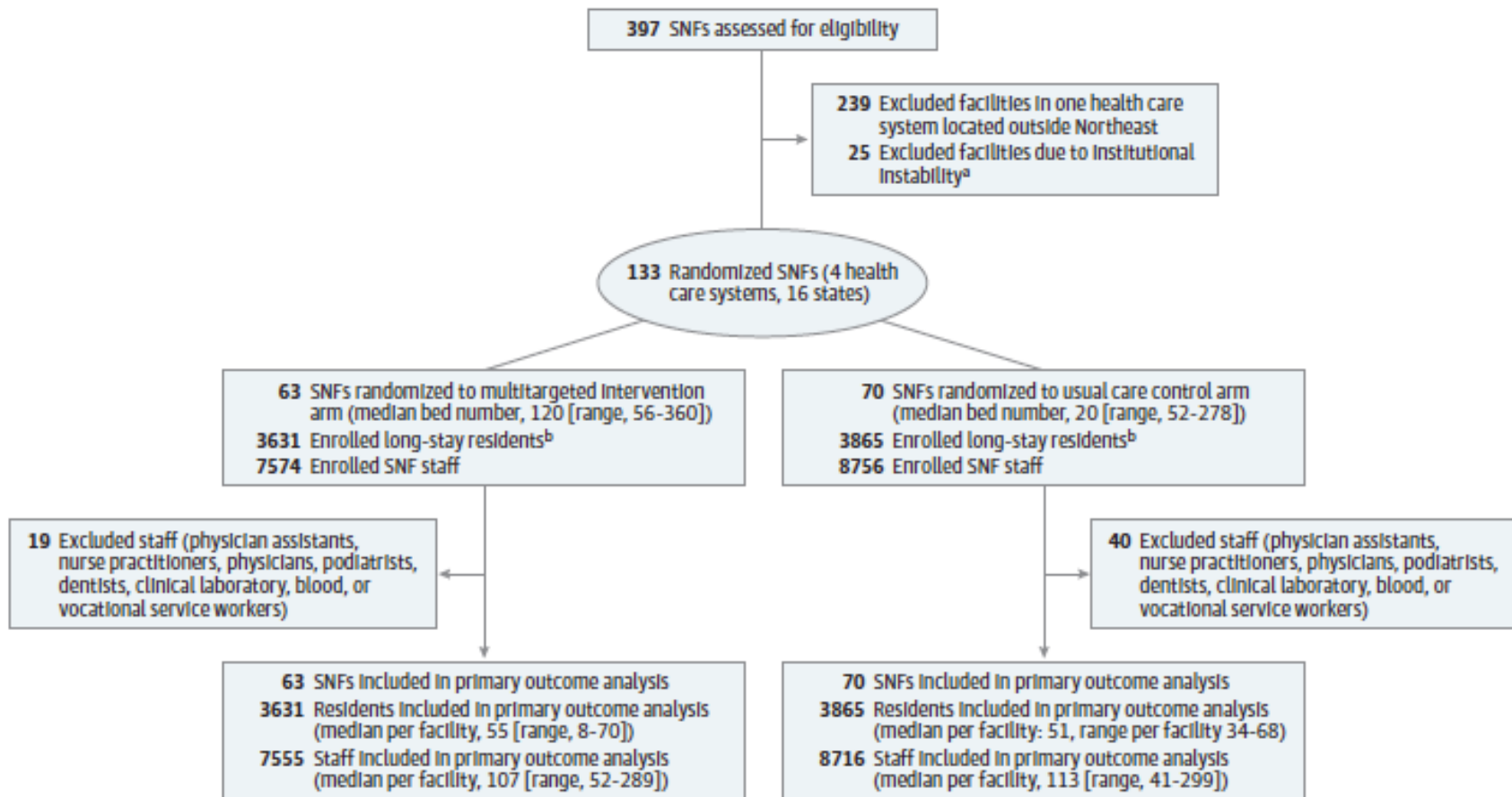


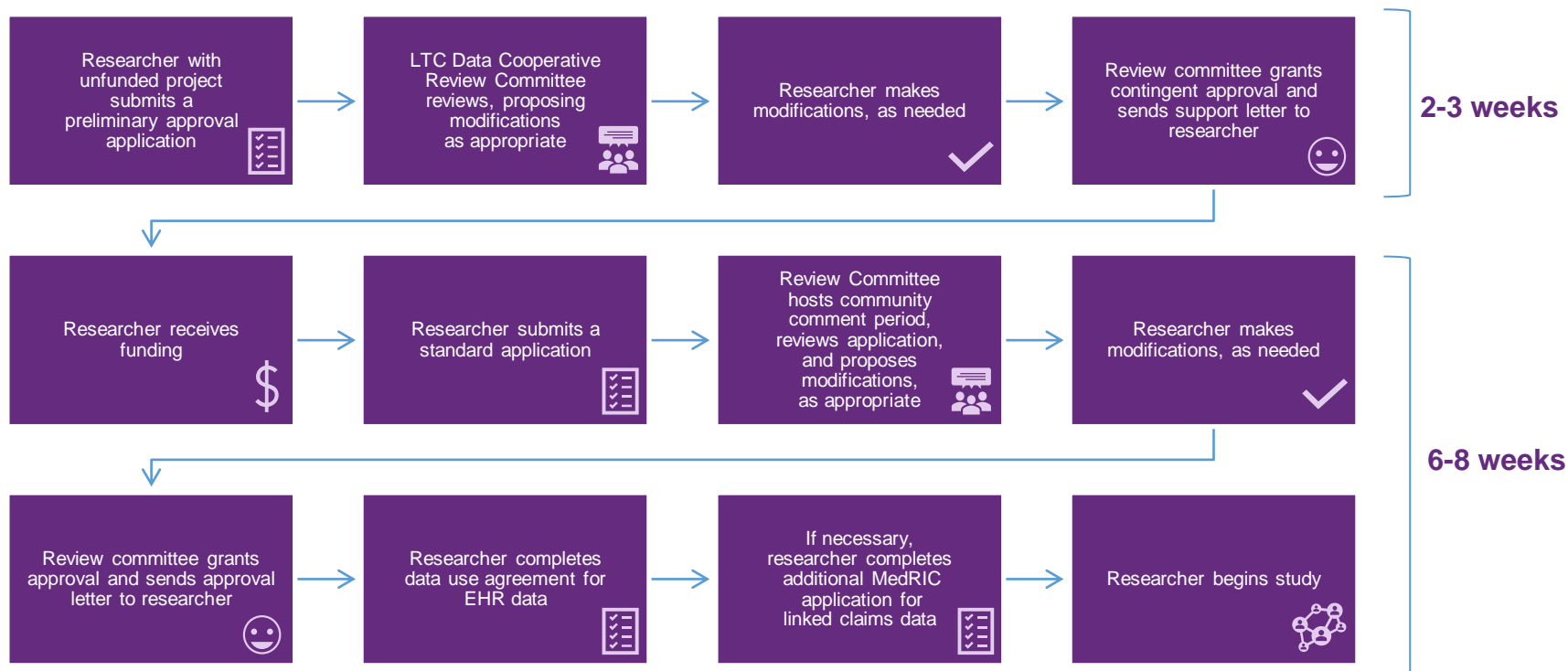
Table 2. Results of a Multicomponent Intervention on COVID-19 Vaccination Coverage in Skilled Nursing Facility Residents and Staff

	No. vaccinated		No. eligible		Marginal probability of vaccination (intervention vs usual care), % (95% CI)	Log odds ratio (95% CI)
	Intervention arm	Usual care arm	Intervention arm	Usual care arm		
Primary outcomes in skilled nursing facility residents and staff						
Residents	2994	3083	3631	3865	0.8 (-1.9 to 3.7)	0.06 (-0.24 to 0.36)
Staff	4098	4643	7555	8716	-1.5 (-3.4 to 0.6)	-0.09 (-0.24 to 0.06)
Sensitivity analyses in skilled nursing facility staff						
Nurses/nurse aides	2260	2416	5159	5792	-0.1 (-2.1 to 2.0)	-0.01 (-0.23 to 0.21)
Longer look-back to identify eligible staff (July-December 2020)	4098	4643	8274	9689	-0.4 (-4.2 to 3.1)	0.05 (-0.16 to 0.26)

Tips to Know Before Applying

- The LTC Data Cooperative is a ***provider-led initiative***
- All funded applications require approval from the LTC Data Cooperative participants through a public comment period
- If a preliminary approval application has been submitted:
 - Principal investigator will receive a letter of support
 - Once funding has been granted, final review and approval will be granted through the LTC Data Cooperative participants and the LTC Data Cooperative Review Committee
 - Once funding has been granted, a full application with updated materials must be submitted

Application Process



Frequently Asked Questions (1/3)

Q: Now that my research proposal has been approved, what happens next?

A: The appropriate person at your organization signs the LTC Data Cooperative Data Use Agreement (DUA) and returns it to the recipient specified in the DUA instructions. Once the signed DUA has been received and reviewed for completeness, an email with instructions on how to access the data environment will be sent to you within 1-2 weeks.

Q: Do I need to download any software to access the data?

A: Data environment access is granted through a web browser; common analysis software is pre-installed in the environment. Additionally, a desktop client for PC or Mac can be downloaded to access the environment.

Frequently Asked Questions (2/3)

Q: I need MedRIC access—what do I do?

A: There is a separate application process for the MedRIC Enclave. Once approval has been received from the LTC Data Cooperative, investigators will receive a letter of approval which will need to be delivered to Acumen to begin the application process.

Q: When can I get started?

A: You may begin analysis after successfully accessing the environment and having the requested data revealed to you. Standard data extracts will generally be available within one week. Custom data cuts may take longer.

Frequently Asked Questions (3/3)

Q: Who do I contact with questions about access to the data environment, data extraction, or data security?

A: Please email ltcdc@exponent.com with your study name, principal investigator name, and institutional affiliation.

Q: Who do I contact with general questions about the LTC Data Cooperative, including application-specific questions?

A: Please email LTCDDataCooperative@ahca.org with your study name, principal investigator name, and institutional affiliation.

Helpful Links

- [Datavant](#)
- [Health Insurance Portability and Accountability Act](#)
- [HITECH Act Enforcement Interim Final Rule](#)
- [LTC Data Cooperative](#)
- [MedRIC Enclave Application](#)



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Questions?

