

NIA IMPACT
COLLABORATORY
TRANSFORMING DEMENTIA CARE

Building a Public-Private Long Term Care Data Sharing Cooperative

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Never Let a Crisis Go to Waste

- COVID-19 pandemic has disproportionately affected long-term care residents – 7% of cases in US, but 40% of deaths
- Need richer, real time data on US nursing homes (NHs)
- Experience with one company, Genesis, revealed potential
- Partnering with American Healthcare Association, Acumen LLC, and Exponent to build data repository using EMR data
- Potential for monitoring of future pandemics and policy changes AND to selectively recruit facilities to participate in embedded RCTs of interventions

Origins of the Brown-Genesis COVID Partnership

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- **Built on pre-pandemic collaboration**
- Key considerations
 - Existing professional relationships
 - Prior data sharing arrangements
 - Interprofessional team with all the right expertise
 - Pace of traditional research and publication vs. need for speed
 - Risk management
 - Trust – most important
- Brown IRB review
- DUA approved by Brown and Genesis legal teams

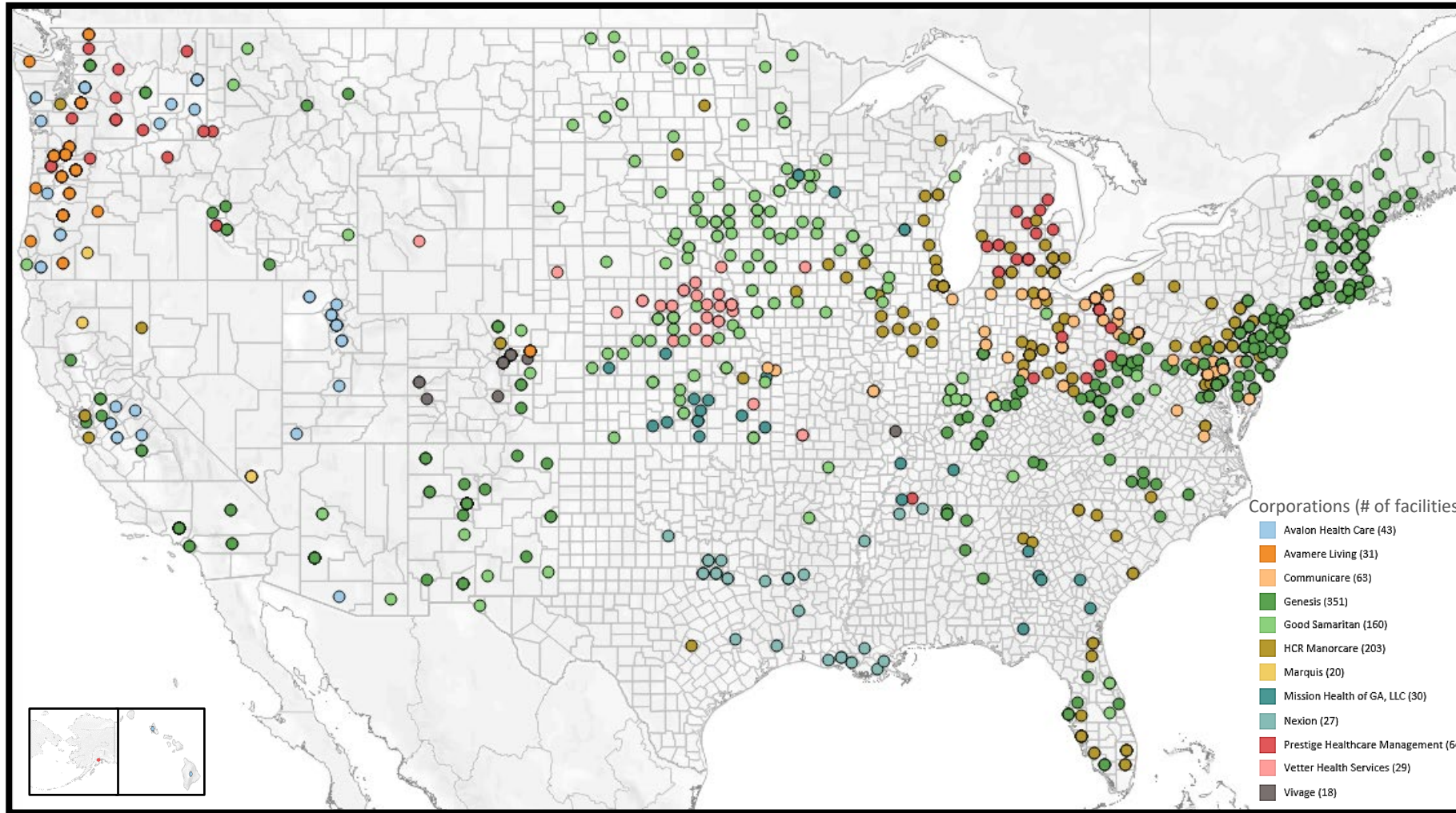
Research Results from Genesis Collaboration

- Examined environmental, Organizational and Clinical Determinants of a COVID-19 Outbreak
- Mortality Risk found to be much higher among Cognitively Impaired, and very old even controlling for many disease measures
- 30 day survival even among long stay NH residents improved even as prevalence increased in adjacent communities (Fall 2020)
- CDC supported real time vaccine adverse event monitoring; no short term adverse events found
- Vaccine effectiveness studies reveal mRNA vaccines >99% effective and breakthrough infections are 75% asymptomatic

IMPACT: Technical & Data Core Resources



Geography of Facilities: NH Data Sharing Cooperative



Genesis

THE EVANGELICAL LUTHERAN
Good Samaritan Society®
In Christ's Love, Everyone Is Someone.

VSL Vetter Senior Living

MARQUIS
COMPANIES

CommuniCare
FAMILY OF COMPANIES

AVALON
HEALTH CARE
GROUP

nexion

PRESTIGE
HEALTHCARE

AVAMERE
A FAMILY of COMPANIES

ManorCare

VIVAGE
SENIOR LIVING

MISSION
HEALTH

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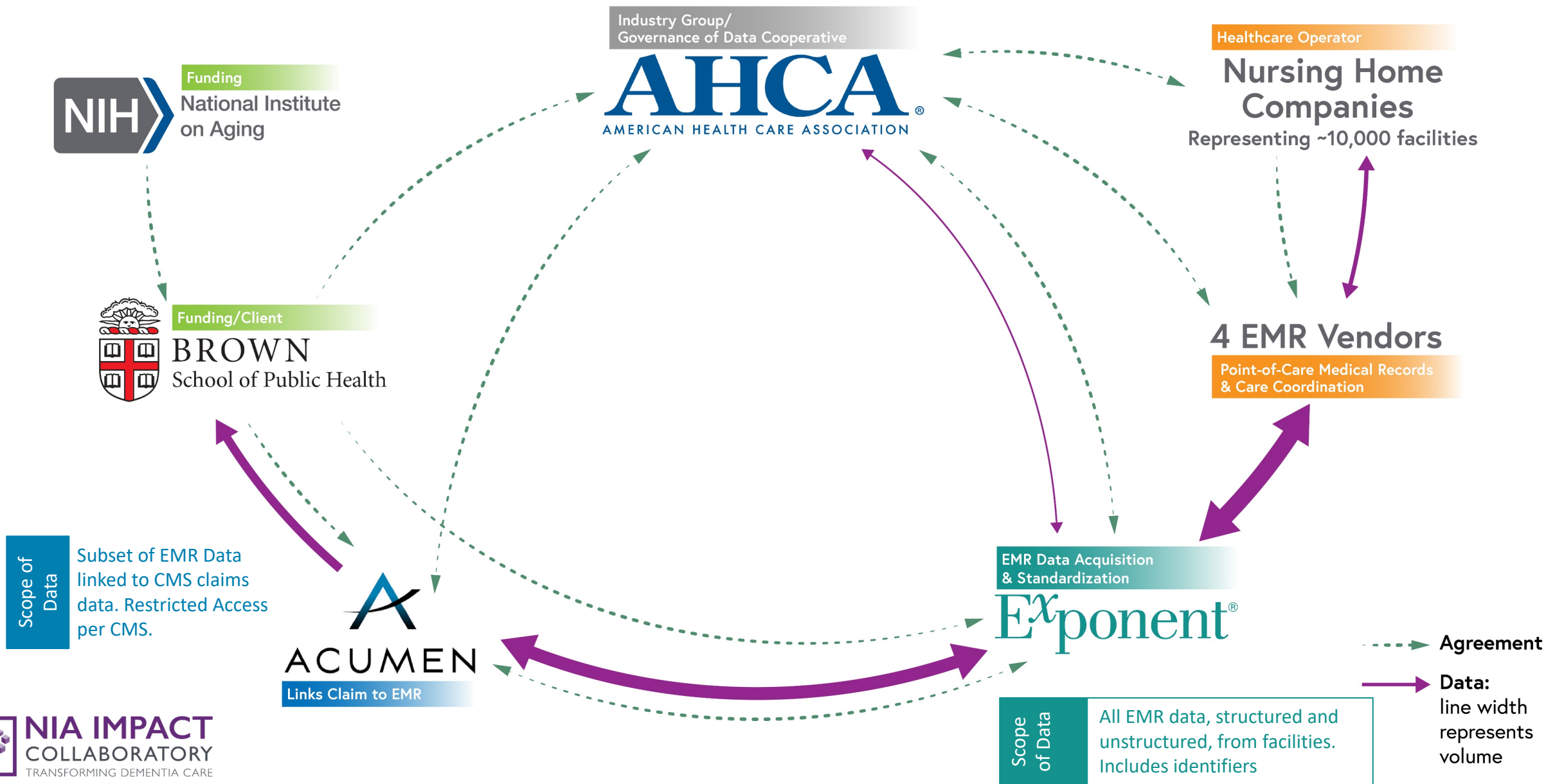
Current COVID Related Studies using Coop Data

- Variation in Staff Testing Rates (RADx-UP)
- Cluster RCT of intervention designed to increase vaccine uptake among residents and staff (RADx-UP)
- Analysis of vaccine effectiveness among post-acute admissions to SNFs, using admission days before vs. after facility clinics
- Tracking breakthrough infections among vaccinated and unvaccinated residents by local COVID prevalence and staff vaccination rates

Expansion to the LTC Data Cooperative

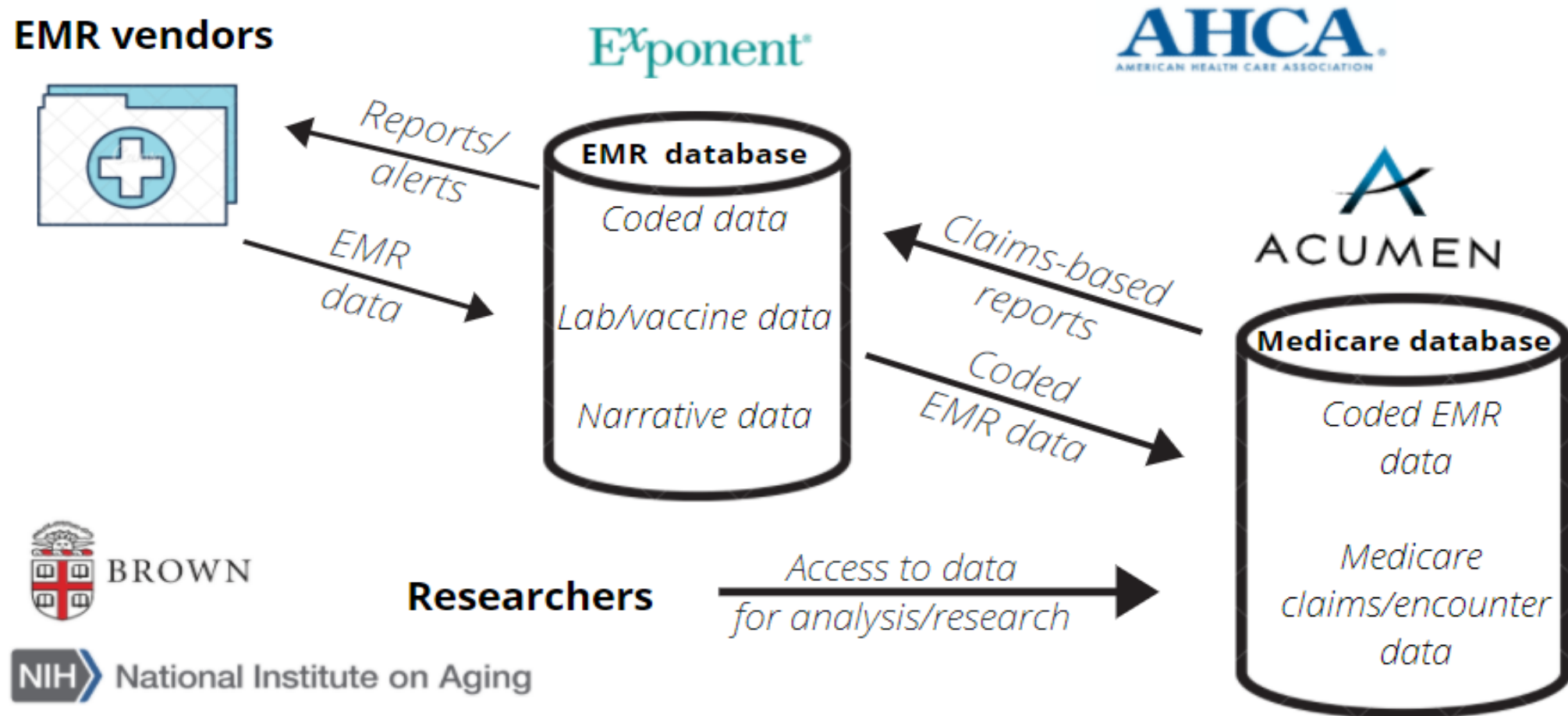
- IMPACT Supplement brings together Brown, American Health Care Association (AHCA) and a technology company, Exponent, to increase the size, scope and breadth of data sharing
- AHCA negotiated relationship with long term care EMR vendors and recruits providers to authorize their EMR vendor to transfer data to Exponent
- Exponent standardizes the coded and uncoded EMR data, generating summary reports to providers and transferring coded data for merger with Medicare claims

Organizational Structure: NH Data Sharing Cooperative



Data Structure: NH Data Sharing Cooperative

AHCA-led Governance Structure



Future of NH Data Sharing Cooperative

- Brown and IMPACT investigators will be first “users” of data:
 - Planning for other NIA investigators to use Acumen linked data
- Anticipated uses of data for future research:
 - EMR only data:
 - Recruiting facilities for cluster randomized trials
 - Recruiting facilities for clinical research, patient monitoring, etc.
 - Recruiting for real-world phase III trials
 - EMR & claims matched data:
 - Public health surveillance
 - Pharmaco-Epidemiological research
 - Impact of new treatments
 - Impact of new policies