

# LTC DATA COOPERATIVE

## Participant Frequently Asked Questions

### GENERAL



#### **Q: What is the Long Term Data Cooperative?**

A: The Long-Term Care (LTC) Data Cooperative is a provider led effort that collects electronic medical record (EMR) data across multiple long term care providers 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. The Cooperative will be the largest assembly of data from geographically and structurally diverse nursing homes and the residents they care for that has ever been assembled.

#### **Q: What EMR companies are participating?**

A. Currently providers that utilize American Health Tech (AHT), MatrixCare or Point Click Care (PCC) can participate but we are always looking for additional EMR data to add to the Cooperative.

#### **Q: Can assisted living participate?**

A: Currently, assisted living is not participating but in future years we hope to add assisted living.

#### **Q: What are the goals of the Long-Term Care Database?**

A: This database will be used for three broader purposes:

- (1) To provide reports back to enrolled providers that can assist them with clinical care and operations. These may take the form of quality measure reports with comparative benchmarks, resident-at-risk profiles, or reports to help with your discussions with managed care organizations. The content of the reports is suggested by enrolled organizations and are designed to complement or fill gaps in existing reports available from other sources.
- (2) Provide public health monitoring such as the prevalence of Multi-Drug-Resistant Organisms (MDRO) or respiratory viral infections, including Influenza or COVID-19 that will be securely shared with the Food and Drug Administration or the Centers for Disease and Control.
- (3) Provide data for academic researchers who are federally funded to conduct effectiveness research, that is research that looks at how well different treatments or care practices can improve resident outcomes. Decisions on research are made by a provider led committee.

#### **Q: Who is overseeing and running the Cooperative?**

A: The Cooperative is a provider led effort that is part of AHCA Solutions Inc, a subsidiary of AHCANCAL that is funded by the National Institute of Aging (NIA). An advisory committee comprised of AHCA Board members, AHCA committee participants and providers at large along with a representative from the EMR vendors, academic research provide advice and input on the Cooperative and major decisions. Researcher access to the data is granted by a

research review committee comprised principally with providers (see research Q&A). A provider user's group provides input on data reports. Input from enrolled organizations is also sought prior to major decisions or changes.

**Q: Who do I contact if I have questions?**

A: Feel free to reach the Cooperative team at [LTCDataCooperative@AHCA.org](mailto:LTCDataCooperative@AHCA.org) for any questions or concerns you may have. A representative will respond within 24-48 hours. For data and security questions, please contact Exponent, Inc. at [ltcdc@exponent.com](mailto:ltcdc@exponent.com).

**BENEFITS**

**Q: What do I get from joining?**

A: Participants will receive customized reports for free that can help with clinical care or operations. These reports will be developed with input from enrolled organizations but can take the form of quality measures (existing and new), at risk resident profiles (such as hospitalization, falls, adverse events from medications), antibiotic stewardship, information to help with your discussions with insurance companies, benchmarks of peers and care practice profiles such as use of antivirals for COVID-19 positive residents. Reports are intended to complement existing reports available from other sources and are developed with input from enrolled organizations.

**Q: How does this help the LTC community?**

A: A major barrier to developing appropriate clinical and operational responses during the COVID-19 pandemic was the lack of evidence on what works such as how well do the antivirals work? This led to CMS and CDC mandating data submission to NHSN that had limited value. We need more real-time data to rapidly answer these types of questions. In addition, many of the clinical decisions, treatments and practices in nursing homes are based on evidence from younger individuals or healthier elderly living in the community. We need to understand what works and does not work. Also, risk profiles can help better target residents who need different care, but most risk assessments used were not developed in nursing home populations. This cooperative will provide a comprehensive data set for academic researchers to help answer these questions.

**Q: How is the database beneficial to providers, medical and health care professionals, patients, and the community?**

A: This database will allow public health experts to examine how the vaccines and other treatments are working across nursing home residents. Those providing treatment to patients will be able to use the data to evaluate treatment plans for patients that have similar health conditions and concerns.

**Q: How does this help with public health surveillance?**

A: The rapid detection and spread of multi-drug resistant organisms (e.g. C auris) is needed to help better inform more timely and tailored public health recommendations. The cooperative will help with surveillance of the spread of infections in a much timelier and more comprehensive manner than currently possible.



## PARTICIPATION REQUIREMENTS

### Q: What do I have to do after enrolling?

A: You need to notify us of all your facilities that use each type of EMR. You also should identify us when you acquire or sell new facilities. There are opportunities to participate in various committees and groups but participation is voluntary and not required.

### Q: Are facilities or staff required to do anything after enrolling?

A: No, there is no requirement that nursing homes enrolled do anything. The parent organization does need to identify a primary contact that Cooperative staff can communicate with and share data reports. There is no requirement that the data reports be used. You do need to keep us informed of any new facilities that you acquire or sell.

### Q: Do we have to participate in research?

A: All research opportunities that involve participation by the facility (e.g. evaluating which of two different treatments work better or how staff educational program improves resident outcomes) are voluntary and participation is never required. Research done by the researcher that only analyses data in the cooperative is approved by the research review committee after seeking voluntary input from all enrolled organizations.

### Q: How much insurance coverage should an organization have?

A: Please email us at [LTCDDataCooperative@ahca.org](mailto:LTCDDataCooperative@ahca.org) if you have specific questions regarding insurance.

## DATA COLLECTED

### Q: What data is collected from my EMR?

A: The goal is to collect all the clinical information in the EMR but initially the actual data transfer is dependent on the technology and structure of data each EMR

### Q: How frequently is my data transferred?

A: this will depend on the type of EMR used; and varies from daily to monthly.

## ENROLLING

### Q: Do I need to sign a business associate agreement (BAA) to participate?

A: Yes, a BAA is required to share data with the Cooperative.

### Q: What forms do I need to enroll?

A: Complete and submit the required legal agreements, which include a participation agreement, business associate agreement and authorization form to your EMR company to share data with the Cooperative. You can review these documents by emailing [LTCDDataCooperative@ahca.org](mailto:LTCDDataCooperative@ahca.org). You will receive a confirmation email within 72 hours of receipt. Once all parties have signed the legal agreements the data release form will be sent to your EMR Vendor and Exponent, Inc. to begin the data transferring process.

### Q: For assistance with applying to the data cooperative whom should I contact?

A: Please contact us at [LTCDDataCooperative@AHCA.org](mailto:LTCDDataCooperative@AHCA.org) for any questions or concerns you

may have. A representative will respond as soon as possible but no later than 24-48 business hours.

**Q: How do I know if my company is eligible to participate in this data cooperative?**

A: All nursing homes are eligible to participate at no cost!

**Q: If my vendor does not participate, can I still join this cooperative?**

A: Yes! You may participate in the data cooperative even if your EMR vendor does not choose to participate since EMR data is your data. Please complete all the steps to register. A team member from AHCA will notify your EMR provider of your participation.

**Q: What are the next steps after completing the registration?**

A: You will receive a confirmation email once all requirements have been successfully submitted. The email will be sent to your appointed primary point of contact. The application will be reviewed by an AHCA team member to ensure all appropriate documents have been received and accurately completed. Your EMR provider will then be notified of your participation.

**Q: Do I need to reach out to my vendor first?**

A: No! An AHCA team member will notify your EMR vendor of your participation. We currently have data transfer arrangements set up with AHT, MatrixCare and PCC.

**Q: Can I disenroll from the Cooperative?**

A: Yes, you can disenroll at any time. You need to notify the Cooperative staff. However, data that has already been transferred to the cooperative will continue to be used since removal would impact ongoing research and data reports.

**Q: How much does it cost to join?**

A: There is no cost to the provider to enroll or stay in the cooperative. The Cooperative is funded by the National Institute of Aging (NIA).

## **DATA ACCESS**

**Q: Who has access to the data?**

A: Data is stored securely by two AHCA's contractors – Exponent and Acumen that can be accessed by the AHCA team to generate reports. Also approved academic researchers who are federally funded and have received all the appropriate IRB and other government approvals to use this type of data will be granted access. The data will not be downloadable or transferred to users but will be accessed through a secure cloud based research environment. Also, aggregate reports may be shared with public health agencies for surveillance and research evaluation purposes.

**Q: What access to our data do the other Participants have?**

A: Consortium Participants will not have access to any of your data. Consortium participants will only have access to aggregate reports and PHI reports specific to their unique facility.

**Q: Will federal regulators or state licensing agencies have access to the data?**

A: No; neither Survey and Certification at CMS nor state licensing agencies of providers will have access to the data.



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**Q: Can other individuals get access to the data such as hospital systems, insurance companies, etc.,?**

A: No; only providers and approved academic researchers will have access to the data. Decisions on the use and sharing of data are made by the Cooperative which is provider led. There is an Advisory Committee comprised of leaders from AHCA (board members, committee chairs/members) and the participating EMR companies.

**Q: Will my data be shared with (Health Information Exchanges) (HIEs) or other provider systems (e.g. such as hospital or physician EMRs)?**

A: No; this data will not be shared with HIEs or other provider settings' EMRs.

**Q: Will my data be sold to others?**

A: No, The Cooperative will not be selling your data. The data will be used for your benefit or for research that is federally funded. NIA funds the Cooperative, so researchers do not need to pay for the data.

**Q: What steps will my organization need to complete to start the data-sharing process?**

A: There are no additional steps. The authorization you've provided in the consortium participation agreements will be sent to your EMR provider.

**Q: Is there a tutorial on how to obtain our data reports once the data is shared?**

A: Not yet, but there will be a secure portal that will allow access to the reports.

## SECURITY

**Q: How secure is the data?**

A: The cooperative takes data security extremely seriously. The data is stored in a secure environment only accessible by Cooperative staff. The data is converted into a usable database for use by academic researchers. For additional data and security questions, please contact Exponent, Inc. at [ltcdc@exponent.com](mailto:ltcdc@exponent.com).

**Q: What data security and protection does Exponent, Inc. provide?**

A: Information security and data protection are cornerstones of the Long-Term Care Data Cooperative. Exponent that administers the data base demonstrates its commitment to these principles by adopting multiple industry-standard frameworks, such as:

- National Institute of Standards and Technology (NIST) Cybersecurity Framework (CSF), which serves as an overarching framework for understanding and communicating information cyber security
- International Organization for Standardization (ISO) 9001:2015 (and others), which confirms Exponent's commitment to a robust, independently assessed quality management system
- Amazon Web Services, which provides an encrypted HIPAA and HITECH-compliant environment in which data are stored and analyzed

Exponent will continue to uphold its commitment to quality, security, and privacy by adopting new and emerging risk management techniques as they are available. Should you require any additional detail, please email [ltcdc@exponent.com](mailto:ltcdc@exponent.com).

## RESEARCH

### **Q: What is the review process for research applications to use the data?**

A: Academic researcher's applications are initially reviewed by Cooperative staff to assure its consist with the mission and purpose – use for effectiveness studies and is funded by federal sources. Then all Cooperative participants will receive a summary to review and provide comments. All comments will be forwarded to a research review committee comprised of up to 13 people – 9 providers, 2 cooperative staff and 1 academic researcher who will make a decision on its acceptability.

### **Q: How will researchers 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.

### **Q: What information would be included in Research Results or Work Product?**

A: This would be a publication or results of a study that used the LTC Data Cooperative as their data source. As part of all researchers DUA's who access the LTC Data Cooperative, any material that is created as a reflection of the results of a study using the LTC Data Cooperative must be thoroughly reviewed, and approved by the research review committee BEFORE public display. The review committee is made up of providers and Long-Term Care experts who will ensure the integrity of the Long-Term Care community is not compromised.

### **Q: Will the Academic Researcher Applicants need to budget for an analytic plan?**

A: Yes, a budget for an analyst or analytic plan will be the responsibility of the Academic Researcher. Exponent, Inc. Will build an analytic file for the Academic Researcher to use, but the researcher will be required to analyze their own data. The Data Analyst hired by the Academic Researcher will be given access to the secure server that Exponent hosts the live data.

### **Q: I'm a researcher and I want to use analytic software to analyze the LTDCDC data, what software is available?**

A: You can use open-source software (R or Python) or Stata. Using SAS(r) Software is possible, but researchers will need to supply their own SAS Server license.





## CONFIDENTIALITY AND CONSENT

### **Q: How will resident confidentiality be protected?**

A: All data is stored in a secure environment – see security. All academic researchers requesting access must complete an application process, demonstrate proof of federal funding for research, as well as obtain Institutional Review Board (IRB) approval for human subject research with medical record information. Please contact [LTCDDataCooperative@AHCA.org](mailto:LTCDDataCooperative@AHCA.org) for more information.

### **Q: Do I need to get consent from my residents?**

A: Consent is not required to enroll in the Cooperative since each enrolled organization will be signing a BAA with the Cooperative. For research uses, the need for consent will be decided by the Institutional Review Board (IRB) and will be the responsibility of the researcher to obtain. For most research that just uses the data to compare effectiveness of what has already happened, an IRB waiver from consent is commonly granted. If research involves a new “intervention” (e.g. unknown treatment or care practice) then consent is frequently required and will be the responsibility of the academic research team. As part of the application process, we review to make sure all the appropriate IRB reviews and waivers are in place

### **Q: Will my organization’s name be publicly shared or mentioned in research?**

A: the name of your organization will only be shared if you grant permission to do so. All public reports, publications or presentations, will report data in aggregate and a form that should not allow identification of the participating organizations.

