Registry Challenges in the US
Cardiac Arrest Registry to Enhance Survival

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CARES
Cardiac Arrest Registry to Enhance Survival

Measuring Outcomes.
Improving Care.
Saving Lives.

What is CARES?

- OHCA registry that identifies who, when, where of cardiac arrests in communities

- Use a secure Web database with restricted access for authorized users

- Links dispatch, EMS, and hospital data sources to create a single de-identified record for each OHCA event

- What parts of the system work well vs. need improvement?

- Allows longitudinal, internal benchmarking of key performance indicators

Current Participant Map
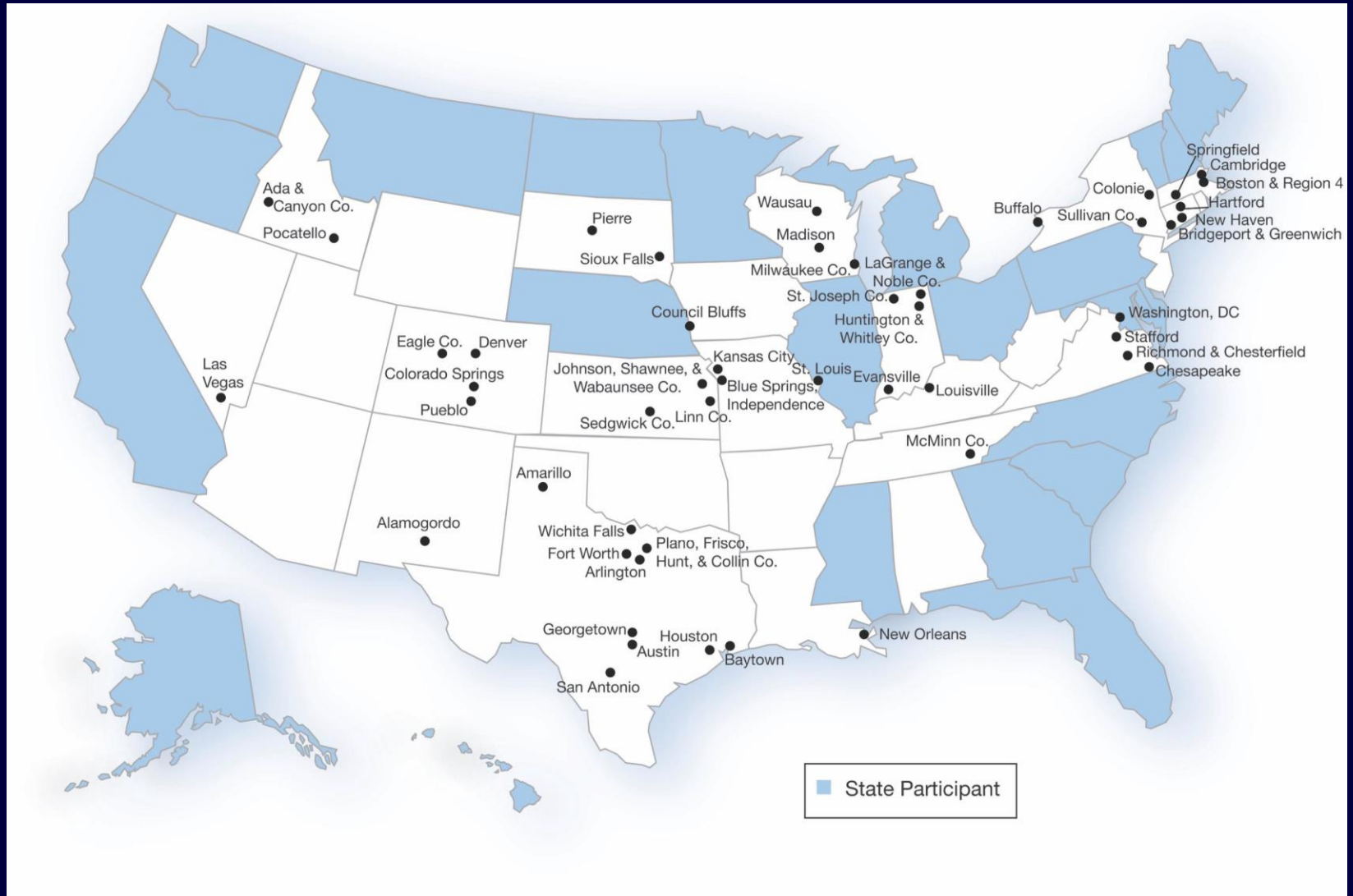
2018 Footprint

- 120 million catchment area

- 38% US pop covered

- More than 1,400 EMS Agencies

- More than 2,000 Hospitals

- 66 communities in 18 states

- 24 statewide participants

CARES Annual Call Volume
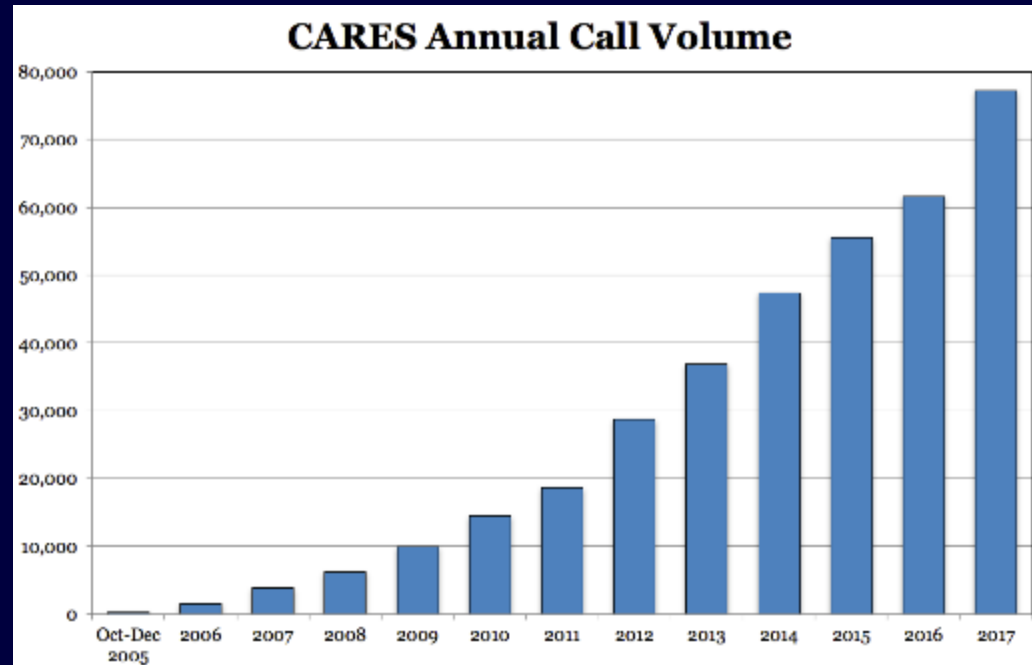
Registry Challenges

- Program Funding

- Participant Compliance

- Data Management & Sharing

- Vendor Relationships & Compliance

- Staff & Contact Turnover

- Data Quality

- Marketing

- Technology & Evolution of Data Collection Mechanisms

- Data Security

Program Funding

- Budget Constraints
- Resource Scalability
  - Staff
    - National level
    - Subject matter experts
  - Website/Software Planning
    - Design
    - Reports
  - Data Storage/Server Capacity
- Long-Term Planning
  - Instability with subscription fees and anticipating agency or state adoption and/or dropout
  - Maintaining sponsors
  - Need for future public-private partnership funding model

Participant Compliance

- Oversight of contacts we don't employ
  - Agencies/Hospitals
    - Contacts meeting entry and audit feedback timelines
  - State Coordinators
    - Guiding and managing them to follow national audit timelines and quality
- Maintenance of existing sites
  - "Problem" Sites - 10% of sites take up 90% of our time
  - General unresponsiveness
- Leadership involvement
  - Are they communicating importance/value of participation?

Data Management & Sharing

- Ensuring that data confidentiality is maintained
  - Places constraints on the type of research that can be conducted
- Management of various projects, at national & state levels, as program grows
  - CARES data is accessible to public, rather than limited to in-house analyses
- Changes to the data form over time
  - Ensuring answer choices map
  - Updates to reports and documentation
  - Balancing "too many" vs. "too few" data elements
- Enrollment is rolling; cohort of participants is constantly changing
- Scaling infrastructure needs as size of dataset increases

Staff & Contact Turnover

- Registry-related "staff"
  - National team
    - Potential loss of institutional knowledge
    - Program expansion is paused or reduced
  - State Coordinators
    - Inefficient program expansion and data collection
    - Sunk cost with multiple trainings
  - Local agency/hospital contacts
    - Ineffective participation
- Determine ways to maintain current staff
  - How to keep them engaged and excited in the role?

Vendor Relationships & Compliance

- Vendor buy-in and competing priorities
  - Timeline management on behalf of CARES and customer
  - Incorporating CARES elements into ePCR product at no cost to the agency
  - Vendor focus is their product vs. CARES' focus is our product and data integrity/quality
- "Middle-man" between customer and vendor
- Communication Management
  - Inconsistent messaging with vendor business model
- Compliance with CARES protocols
  - Upload threshold
  - Setup, testing and go-live processes
    - Derailment of standardization when each vendor process is customized
- NEMSIS (National EMS Information System) Alignment

Data Quality

- Self-reporting of data
  - Training providers
  - Updating documentation
- Case ascertainment
  - Confirming accuracy of monthly call volumes
  - Biannual Assessment
- Interpretation of data definitions
- Standardization of training demos and content
  - Decentralized process with the train-the-trainer model

Marketing

- Promoting CARES as the US national OHCA registry
- Define messaging and target audience
  - Value proposition varies depending on "type" of user
  - Consistent communication about benefits and why important
- Identifying best channels for communication
- Social Media presence
  - Is it important?
  - What kind of engagement is valuable?
  - Maintenance and resource needs

Technology & Evolution of Data Collection Mechanisms

- Developing new approaches to remain relevant and add value to users
  - Ex: Health Information Exchanges, Enterprise Access/Reporting for Health Systems, State Level EMS Data Extraction
- Adapting to changing data platforms in the field
  - Paper → Scannable Form → Manual Entry → ePCR extraction
- Relevancy of data elements according to introduction of new protocols and devices
- Evolving with ePCR vendor advancements
  - Consolidator model, Bi-directional outcome data

Data Security

- Agency concern regarding data sharing and access
- Hospital concern of PHI and facility identifiability
- Adapting to state requirements
- Compliance and legal hurdles
  - External Agreements
- Maintenance of relevant agreements and letters of support
  - CDC, JCAHO, CARES Site Agreement
- Incorporating new legislation (as applicable)

Q&A Discussion