When an externally funded research project pays the **5% Data Services Fee** for the **Cardiac Arrest Registry to Enhance Survival (CARES)** dataset, they are essentially paying a cost-recovery fee for the specialized epidemiological and administrative support required to handle de-identified clinical data. The CARES data team will help PIs and their respective research teams with the following activities:

1. Curated Data Extraction & Delivery

Rather than receiving a "raw" database, researchers receive a custom-tailored data slice.

- **De-identification:** CARES staff strip the dataset of protected health information (PHI) to ensure HIPAA compliance.
- **Standardization:** Data is pulled from three distinct sources (911 dispatch, EMS records, and hospital outcomes) and linked into a single, analysis-ready file.
- **Geocoding:** The fee covers the annual geocoding process where CARES links incident locations to census-tract level variables like median income, educational level, and urbanicity found in the American Family Survey.

2. Methodological & Epidemiological Consultation

The data services fee provides access to the expertise of the CARES data team to ensure the research is scientifically sound.

- **Epidemiological Oversight:** Access to a CARES epidemiologist for inquiries regarding data definitions, variable calculations and nuances (e.g., clarifying "presumed etiology" or "witness status" variables).
- **Validation:** Review of the research proposal by the CARES Data Sharing Committee to ensure the methodology aligns with how the data was originally collected in the field.
- **Data Orientation Meeting:** The CARES epidemiologist will schedule a virtual meeting with PI and statistical teams to review the dataset and explain the data sharing and file exchange process. Prior to this orientation meeting they will assist the PI/statistical team with executing an NDA agreement before the de-identified dataset can be released.
- **Data Analysis Support**: The CARES Descriptive data tables should be shared with the CARES epidemiologist for review prior to further analysis. This will allow for feedback regarding inclusion/exclusion criteria, data element interpretation, and coding in advance of more sophisticated analyses.
- **GIS Analyis Support**: The CARES senior GIS analyst is available for proposals that involve a geospatial analysis and/or linkage of data sets that require a geofence and honest broker approach.
- **Statistical Analysis Support**: The CARES data team is available to support PIs and their statistical team members as it relates to the dataset. However, the actual statistical methods, analysis and review need to be performed by the research teams themselves.

3. Administrative & Compliance Management

Managing a national registry involves significant legal and logistical overhead that the fee helps offset.

- **Data Sharing Agreements:** Coordination of the legal agreements required to transfer data between the registry (housed at Emory AWS) and the researcher's institution.
- **Confidentiality Protection:** Oversight to ensure that individual EMS agencies or hospitals are not identifiable in any resulting publications, protecting the anonymity of participating stakeholders.
- **Conflict Resolution:** Ensuring the proposed project does not duplicate current efforts or "data mine" in a way that conflicts with existing approved research.

4. Technical Infrastructure Support

A portion of the fee maintains the "myCares" software and the Submittable platform used for data requests.

- **Platform Access:** Use of the secure online platform for all project communications, file transfers, and feedback loops.
- **Maintenance:** Contribution toward the long-term storage and security of the national dataset, which has over 1.5 millions of records from over 2,500 EMS agencies and 2,000 hospitals (2025).