

# Information Collection Request New Supporting Statements Part B

## Sudden Death in the Young Registry

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## **List of Attachments**

1. Applicable Laws
2. Federal Register Notice
  - a. 60-day FRN
  - b. Summary of Public Comments
3. NCRPCD Case Reporting System - SDY Module
4. MPHI Security Policy, #06-02
5. NCRPCD Child Death Review – Case Reporting System Security Information
6. SDY grantees and expected number of cases
7. NCRPCD secured login screen
8. SDY Steering Committee members

## **B. Collection of Information Employing Statistical Methods**

1. Respondent Universe and Sampling Methods
2. Procedures for the Collection of Information
3. Methods to Maximize Response Rates and Deal with Non-response
4. Tests of Procedures or Methods to be Undertaken
5. Individuals Consulted on Statistical Aspects and Individuals Collecting and/or Analyzing Data

## Supporting Statement B

### B. Collection of Information Employing Statistical Methods

#### 1. Respondent Universe and Sampling Methods

An evaluation) of sudden unexpected deaths within 10 grantee jurisdictions is being sought; thus no sampling methods will be employed. It is estimated that approximately 900 cases will be reported annually through SDY Registry grantees. The SDY Registry currently funds 10 grantees (Attachment 6).

#### 2. Procedures for the Collection of Information

Through their existing Child Death Review (CDR) programs, grantees will compile data on a defined set of SDY questions and convene an advanced review team with clinical knowledge. This information will be compiled from primary data sources including medical examiner/coroner reports, death investigation reports, medical records, and child protective services records. Data will be entered into the National Center for the Review of Prevention of Child Deaths (NCRPCD) Case Reporting System. Password controlled access is granted and monitored by the NCRPCD per NCRPCD's data security policies and user agreements. The secured login screen is included as Attachment 7. There are roughly 70 new variables in the NCRPCD -Case Reporting System SDY module, but not every new variable will apply to every case. The module will be completed during the advanced review team meetings, which will consist of state health personnel, pediatric cardiologists, epileptologists, neurologists, and forensic pathologists. CDC will not be conducting any general research on the information collected from SDY cases within this pilot evaluation. This pilot project will inform future research through expansion of existing methodologies to other states participating in child death review.

#### *Estimation Procedures*

No estimation procedures will be employed.

#### *Degree of Accuracy*

This issue does not apply to this methodology.

#### *Unusual Problems*

None noted.

#### 3. Methods to Maximize Response Rates and Deal with Non-response

This issue is not relevant with this methodology since a 'respondent' is a grantee and there are ten grantees that agreed to participate and are funded for this pilot program. CDC does however provide guidance to grantees on strategies to minimize missing or unknown responses to SDY-specific variables. These methods include building partnerships with agencies that collect the primary data and providing feedback to these agencies so they might improve the investigation of these SDY cases. As outlined in the funding announcement, the CDC and the Data Coordinating Center will provide grantees with a quarterly Data Quality Summary that will include the frequency of missing and unknown responses that are considered essential to the case definition and classification protocol. This allows CDC and grantees to track the outcome of data improvement strategies and to compare the grantee's progress over time.

#### 4. Tests of Procedures or Methods to be Undertaken

This issue is not relevant with this methodology given that data analysis is not an objective of this program. CDC

and the Data Coordinating Center do run frequencies on missing and unknown data fields for each grantee on a quarterly basis. The goal of this cooperative agreement is to improve a state's own data so that they may use it to develop state and local public health programs and evaluate the impact of those programs.

**5. Individuals Consulted on Statistical Aspects and Individuals Collecting and/or Analyzing Data**

There are no statistical aspects related to the SDY Registry. This issue is not relevant to this request.

The CDC is not solely responsible for project design. The CDC works in partnership with the NHLBI, NINDS, and the Data Coordinating Center through a Steering Committee (Attachment 8) to develop the project design. The CDC representatives on the Steering Committee are Lena Camperlengo, [gtx6@cdc.gov](mailto:gtx6@cdc.gov), 770-488-6322 and Carrie Shapiro Mendoza, [ayn9@cdc.gov](mailto:ayn9@cdc.gov), 770-488-6263

The CDC is not responsible for overseeing data management. This project provides guidance and consultation to users of the NCRPCD's Case Reporting System and the NCRPCD oversees data management per their data security policies. The person responsible for overseeing data management at NCRPCD is Teri Covington, [tcovingt@mphi.org](mailto:tcovingt@mphi.org), 517-324-07332.

CDC is not responsible for interpreting findings. The findings involved in this request represent aggregate data quality measures and process measures used internally to plan and develop technical assistance. Person responsible for interpreting findings at NCRPCD is Teri Covington, [tcovingt@mphi.org](mailto:tcovingt@mphi.org), 517-324-07332