Using NFR-CRS Data for Research: Tips for writing a successful application for de-identified data for research

Before starting your application

- Carefully read the "NCFRP Data Dissemination Policy & Guidelines for Requesting De-identified Data from the National Fatality Review Case Reporting System (NFR-CRS) for Research Purposes" document (https://www.ncfrp.org/wp-content/uploads/NCFRP_Data_Dissemination_Policy_Guidelines_v5_Sept2020.pdf).

- Read February 2011 Supplement to Injury Prevention (Covington TM. The US national child death review case reporting system. Injury Prevention 2011; 17 Suppl 1:i34-i37) for information about the origins of the NFR-CRS (formerly known as the Child Death Review Case Reporting System. This article not only describes the strengths of the data, but also addresses some limitations, including cautions against trend analysis, and the unsuitability of the data for calculating rates. Although this article is a bit dated, the description of the data and potential limitations are still relevant. The article can be found here: https://www.ncfrp.org/wp-content/uploads/NCRPCD-Docs/InjuryPreventionSupplement2011.pdf.

- Download and review the pdf NFR-CRS report form (https://www.ncfrp.org/wp-content/uploads/NCRPCD-Docs/CDR_CRS_v5-1.pdf).

- For information about specific data elements, please review the data dictionary (https://www.ncfrp.org/wp-content/uploads/NCRPCD-Docs/DataDictionary_v5_1.pdf).

- Contact the Center if you have any questions about the process or appropriate topics. We are happy to assist at any stage as you refine your research topic, prepare your study proposal, and complete your application. Center staff are also available to advise if any research has already been conducted or planned on proposed research topic using NFR-CRS data. The best way to contact us is info@ncfrp.com.

Completing the application: Section A. Proposed Study

- Choose a title that clearly reflects the purpose and goals of the study.

- In describing your study demonstrate thoughtful consideration of the proposed research in the context of how it will contribute to what is currently known on the topic and how the results might inform prevention.

- Clearly state your research question(s) or study objectives/specific aims. The aims should be directly related to your title.

- Briefly summarize the relevant literature, documenting the rationale for and significance of your proposed research. End this summary with a clear statement of the purpose of the research.

- Define your study population and state inclusion and exclusion criteria using NFR-CRS data elements. For example, if your study population is infants who die suddenly and unexpectedly (sudden unexpected infant deaths, SUID), you would need to state how you will define SUID and how these deaths will be identified as there is no "SUID" variable in the NFR-CRS.

- Explicitly define concepts and key variables using NFR-CRS data elements. For example, if you plan to explore whether deaths were related to child abuse, how will you define abuse? Will you include all deaths where the manner of death is homicide? If so, will you require that the perpetrator was a parent or caregiver of the child? Will you require that CPS action was taken as a result of the death (question F15)? Will you include deaths where question I5a is marked yes and the primary reason is marked abuse, regardless of the manner of death?

- Include a comprehensive list of the variables you are requesting that are needed to carry out the study.
    - It is very helpful if these variables are included in a table format.
    - Include both the Section and question # (i.e., A28 Did child have problems in school)
    - Include only variables necessary for the planned analysis, that is, they should be directly related to the stated aims of the research.
    - Identify whether the variable will be used as an independent or dependent variable. If using terms for categories of variables, (e.g., child demographic characteristics, family characteristic), clearly identify which category each variable will be included in.

- Ensure that you are using the most current version of the data form when preparing your list of variables and note important skip patterns.

- Clearly identify and define your main independent (exposure, risk factor, confounding) and dependent (outcome) variables, using NFR-CRS data elements. For example, if one of your independent variables is "premature birth" state how you will define and identify infants born prematurely in the NFR-CRS data.

- Include a detailed analysis plan. This should track closely with the aims of the study and be appropriate for the stated study design. State the analysis software that will be used, and the statistical tests planned.

- Include shell tables that show how your results will be presented.

- Describe how you will handle small numbers and missing/incomplete data. Some of the data elements in the NFR-CRS have high proportions of missing data making them challenging to include in research. We encourage applicants to contact the Center staff to discuss key variables. Staff can run frequency analyses to evaluate the % of missing data.

- If you choose to include variables with high proportions of missing data in your study, please provide details on how you will assess and reduce the potential for bias that may be introduced.

- Address the limitations of the NFR-CRS data as they relate to your proposed research and state how these limitations will be addressed or mitigated. The limitations of the NFR-CRS data have been outlined in publications that are included in the list of publications in the application packet. We encourage you to review these publications, identify the limitations as they apply to your research, and state how you plan to reduce any bias they might produce.
- Knowing that systemic inequities contribute to some families losing infants, children, and youth, please include a description of strategies for addressing diversity and equity in your research. This might include how data analysis and interpretation will address differences by factors such as socioeconomic status, race, ethnicity, sex, gender identity, sexual orientation, and geography.

You should consider the role of inequitable systems and policies, population health, the complex interactions of risk factors, and identify how interventions can be shaped at the community, local, state, or national levels.

- Include a reasonable timeline for completing your research. Typically, it takes several months for applications to be approved and a dataset to be provided. Please take this into consideration as you plan your timeline.

- Specifically state the national or international conference(s) you plan to present your study results, and the peer-reviewed journals you will consider for manuscript submission. It is important that the research conducted through this application process is published in peer-reviewed journals. The significance of the research question(s), quality of the proposed research, and intent to publish are key considerations in reviewing and approving applications.

Completing the application: Section B. Investigator/researchers

- As instructed in the application, identify the Principal Investigator and each co-investigator/collaborator
- Describe the specific responsibilities each investigator will have in conducting and completing the research.
- Attach a curriculum vitae for each investigator.
- Attach a completed and signed confidentiality agreement for each investigator.
- If you are a novice researcher without documented experience in data management, data analysis, or peer reviewed publications, you will need to include a co-investigator(s) with these skills on your team.

Completing the application: Section C. Data Security

List everyone who will have access to the data file. It is not necessary to include those people who will only be reviewing aggregate data or completed analyses.

Completing the application: Section D. Receiving Institution

The application must be signed by the PI and a representative of your Institution. This representative varies by Institution, it may be a Director or Assistant Director in your department, or a grants/contracts office at your institution. Check with your institution to determine the appropriate person.

Although IRB approval is required before providing data to researchers once an application is approved, applications can be sent to NCFRP for review and consideration while you are awaiting IRB approval.

Before submitting the application

- Carefully read the sample contract template.
- Review the four attachments.
- Complete the checklist on the final page of the application packet.
- Contact the National Center if you have any questions about the application process (info@ncfrp.org).