



How to Write a Successful Research Application for De-Identified Data from the NFR-CRS

April 2021





KEY FUNDING PARTNER

FEDERAL ACKNOWLEDGEMENT

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HOUSEKEEPING

Before we get started

- This webinar is being recorded and will be available on the National Center's webpage (URL: www.ncfrp.org).
- Participants are muted. Use the question and answer box to ask questions.
- Due to the large number of participants, the speakers may be unable to answer all questions. Unanswered questions will be answered and posted with the recording.
- Contact the National Center (email: info@ncfrp.org) for any tech problems.





EVALUATION

<https://www.surveymonkey.com/r/32BRMMX>

Diane Pilkey, RN, MPH

Welcome and Introductions

Senior Nurse Consultant

Division of Child, Adolescent and Family Health

Maternal and Child Health Bureau

Health Resources and Service Administration





HRSA'S VISION FOR THE NATIONAL CENTER

IMPROVING SYSTEMS OF CARE AND OUTCOMES FOR MOTHERS, INFANTS, CHILDREN, AND FAMILIES

Assist state and community programs in:

- Understanding how CDR and FIMR reviews can be used to address issues related to adverse maternal, infant, child, and adolescent outcomes
- Improving the quality and effectiveness of CDR/FIMR processes
- Increasing the availability and use of data to inform prevention efforts and for national dissemination



Background information on the NFR-CRS

What you need to know before you start, including most appropriate types of studies.



Completing Section A.

Designing and describing your study in the NFR-CRS research application.



Completing Section B.

Summarizing investigators, their expertise, and roles.



Completing Section C.

Describing data security protocols.



Completing Section D.

Finalizing administrative information from the reviewing institution.



Presentation Goals

Patricia Schnitzer, PhD

Epidemiologist

- Data systems consultant
- Leads the National Center's Data Quality Initiative
- 20+ years of fatality review experience

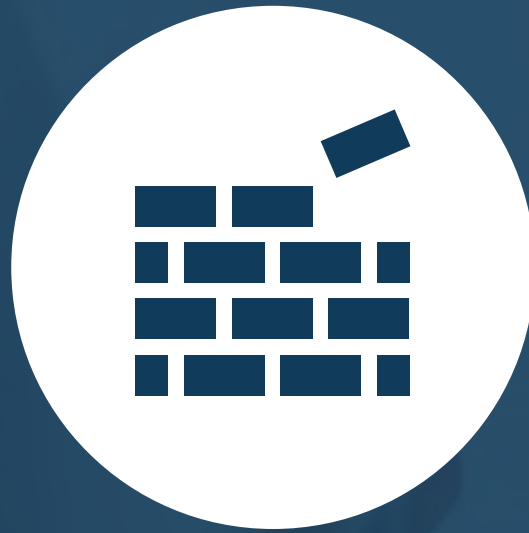




Requesting Data for Research

It's Possible!

- We **want** researchers to request and analyze our data
- We are **here to help** guide you through the process
- We have created information and **tools to help**
 - Tips for writing a successful application
 - Sample application with annotations on what makes it a successful application
 - Sample shell tables for reporting results
 - Bibliography of published research
 - Data dissemination policy and guidelines for requesting a de-identified data for research purposes
- This presentation will focus on Sections A and B of the application



BACKGROUND

National Fatality Review – Case Reporting System (NFR-CRS)

National Fatality Review- Case Reporting System

Started as the Child Death Review Case Reporting System, 2004

The purpose of NFR-CRS is to systematically collect, analyze, and report comprehensive fatality review data that includes:

- Social/demographic information on child, family, and supervisor
- Death investigation information
- Risk factors for specific mechanisms of injury death



The US National Child Death Review Case Reporting System

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ABSTRACT

The National Child Death Review Case Reporting System (NCDR-CRS) was developed in the USA to provide child death review teams with a simple method for capturing, analysing, and reporting on the full set of information shared at a child death or serious injury review. The NCDR-CRS is a web based system currently being used by 35 of the 50 US states. This article describes the purpose, features, limitations, and strengths of the

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originally proposed that the system would be a minimal dataset, capturing only the final outcomes of a case review. The 30 volunteer designers argued instead for a system that would capture the whole story of a child's death or serious injury, such that the version in use today contains over 1700 data elements.³

Thirty-five states are now enrolled in this web based system and have entered more than 84 000 reviewed child deaths. The database primarily reflects a period of review between 2005 and 2009. Table 1 provides a summary of the types of cases entered as of December 2010.

PURPOSE AND OBJECTIVES OF THE NCDR-CRS

The purpose of the system is to provide CDR teams with a simple method for capturing, analysing, and reporting on the full set of information shared at a child death or serious injury review, so that the

Although a bit dated, this paper provides

- Important background
- Strengths
- Limitations

Types of Studies

Paediatric suicide in the USA: analysis of the National Child Death Case Reporting System

Theodore E Trigylidas,¹ Eliza M Reynolds,¹ Getachew Teshome,¹ Heather K Dykstra,² Richard Lichenstein¹

Additional material is published online only. To view please visit the journal online (<http://dx.doi.org/10.1136/ebjopen-2015-041796>).

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Received 12 August 2015
Revised 1 December 2015

Abstract
Importance Suicide is a leading cause of death among youths. The relationship between mental health, psychosocial factors and youth suicidality needs further analysis.

Objective To describe paediatric suicide in the USA and the impact of mental health and substance abuse using the National Child Death Review Case Reporting System (CDR-CRS). To identify psychosocial correlates contributing to suicide and whether these factors are more common among individuals with history of mental illness or substance abuse.

Design Deidentified data (CDR-CRS) from 2004 to 2012 was obtained from 29 participating states. Demographic data and psychosocial correlates, including age, gender, cause of death, history of mental illness and/or substance abuse, school concerns, previous suicide attempts and family history of suicide, were collected.

Results A total of 2850 suicides were identified. Mean age was 15.6±1.9 years; (range 7–21 years) 73.6% male and 65.1% Caucasian. The leading causes of

the leading suicide method among American youths, followed by asphyxia/strangulation and self-poisoning.² However, hanging/asphyxiation recently became the most common method, the reasons for which are unclear.^{2–11} Given these evolving trends, it is important to continue to study the updated demographics, psychological and psychosocial risk correlates contributing to paediatric suicide.

Psychiatric disorders identified as risk factors for adolescent suicide include substance abuse, mood disorders, major depressive disorder and personality disorders.¹² Other risk correlates include complex family-related, environmental and psychosocial problems (eg, family discord, school concerns, child abuse). Many papers have described the significance of the ‘connectedness’ that an adolescent feels to his or her family or school system as an important predictor of suicidal behaviour.^{13–14}

Specifically, a sense of social connection or belonging within the family, school or community can be associated with a decreased risk of suicidal thoughts

Sleep Environment Risks for Younger and Older Infants

WHAT'S KNOWN ON THIS SUBJECT: Sudden infant death syndrome and other sleep-related causes of infant mortality have several known risk factors. Less is known about the association of these risk factors at different times during infancy.

WHAT THIS STUDY ADDS: Risk factors for sleep-related infant deaths may be different for different age groups. The predominant risk factor for younger infants is bed-sharing, whereas rolling to prone, with objects in the sleep area, is the predominant risk factor for older infants.

AUTHORS: Jeffrey D Colvin, MD, JD,^{1,2} Vicki Collier-Merr, PhD, MPH,¹ Christy Schumm, MD/PhD and Rachel Y Moon, MD^{1,4}

¹Department of Pediatrics, Children's Mercy Hospital and Clinics, Kansas City, Missouri; ²Department of Pediatrics, University of Missouri-Kansas City School of Medicine, Kansas City, Missouri; ³Work Group for Community Health and Development, University of Kansas, Lawrence, Kansas; ⁴Kansas Infant Death and SIDS Network, Wichita, Kansas; ⁵Goldberg Center for Community Pediatric Health, Children's National Health System, Washington, District of Columbia; and ⁶Department of Pediatrics, George Washington University School of Medicine and Health Sciences, Washington, District of Columbia

KEY WORDS: SIDS, suffocation, injury

ABBREVIATIONS: CCI—complex chronic condition
CI—confidence interval
NCFPCD—National Center for the Review and Prevention of Child Deaths
OR—odds ratio
SIDS—sudden infant death syndrome

Dr Colvin participated in the study design and analysis and interpretation of the data, was the primary author of the manuscript, and provided critical intellectual content in the revision of the manuscript; Drs Collier-Merr and Moon participated in the study design and analysis and interpretation of the data, were authors in the manuscript, and provided critical intellectual content in the revision of the manuscript; Ms Schumm participated in the interpretation of the data and provided critical intellectual content in the revision of the manuscript, and all authors approved the final version of the manuscript as submitted.

abstract

FREE

OBJECTIVE: Sudden infant death syndrome and other sleep-related causes of infant mortality have several known risk factors. Less is known about the association of those risk factors at different times during infancy. Our objective was to determine any associations between risk factors for sleep-related deaths at different ages.

METHODS: A cross-sectional study of sleep-related infant deaths from 24 states during 2004–2012 contained in the National Center for the Review and Prevention of Child Deaths Case Reporting System, a database of death reports from state child death review teams. The main exposure was age, divided into younger (0–3 months) and older (4 months to 364 days) infants. The primary outcomes were bed-sharing, objects in the sleep environment, location (eg, adult

Sofas and Infant Mortality

AUTHORS: Lauren R Rechtman, MD,¹ Jeffrey D Colvin, MD, JD,^{1,2} Peter S Blair, PhD,³ and Rachel Y Moon, MD^{1,4}

¹Department of Pediatrics, George Washington University School of Medicine and Health Sciences, Washington, District of Columbia; ²Department of Pediatrics, Children's Mercy Hospital and Clinics, Kansas City, Missouri; ³Department of Pediatrics, University of Missouri-Kansas City School of Medicine, Kansas City, Missouri; ⁴University of Bristol, Bristol, United Kingdom; and ⁵Goldberg Center for Community Pediatric Health, Children's National Health System, Washington, District of Columbia

KEY WORDS: SIDS, suffocation, injury, sofa

ABBREVIATIONS: aOR—adjusted odds ratio
ASS—accidental suffocation and strangulation in bed
CDR-CRS—Child Death Review and Case Reporting System
CI—confidence interval
SIDS—sudden infant death syndrome

Dr Rechtman carried out the initial analyses and drafted the initial manuscript; Dr Colvin conducted data analysis and reviewed and revised the manuscript; Drs Blair and Moon

WHAT'S KNOWN ON THIS SUBJECT: Sleeping on a sofa increases the risk of sudden and unexpected infant death.

WHAT THIS STUDY ADDS: Infant deaths on sofas are associated with nonsupine placement, being found in side position, surface sharing, changing sleep location, and experiencing prenatal tobacco exposure. These results may help explain why sofa sleeping is hazardous for infants.

abstract

FREE

OBJECTIVE: Sleeping on sofas increases the risk of sudden infant death syndrome and other sleep-related deaths. We sought to describe factors associated with infant deaths on sofas.

METHODS: We analyzed data for infant deaths on sofas from 24 states in 2004 to 2012 in the National Center for the Review and Prevention of

ARTICLE

J Behav Med (2019) 42:584–590
<https://doi.org/10.1007/s10865-019-00037-0>

Check for updates

Firearm suicide among youth in the United States, 2004–2015

Patricia G. Schnitzer,¹ Heather K. Dykstra,¹ Theodore E. Trigylidas,² Richard Lichenstein¹

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Abstract Suicide is a leading cause of death among children in the United States; firearms cause 37% of these deaths. Research is needed to better understand firearm accessibility among youth at risk for suicide. We reviewed data from the National Fatality Review Case Reporting System (NFR-CRS). Firearm suicide deaths of children ages 10–18 occurring 2004 through 2015 with completed suicide-specific section were included. Children who had talked about, threatened or attempted suicide were identified as ‘Greater Risk’ (GR). Odds ratios (OR) and 95% confidence intervals (95%CI) were calculated. Of the 2106 firearm suicide deaths, 1388 (66%) had a completed NFR-

Suicide remains a critical and preventable cause of death among youth in the United States (US); firearms play an important role in these deaths. The Web-based Injury Statistics Query and Reporting System (WISQARS) maintained by the Centers for Disease Control and Prevention reports 42% of suicide deaths occurring between 2004 and 2016 among children aged 10 to 19 years were caused by firearms (Centers for Disease Control and Prevention, 2018).

Household firearms account for a large proportion of firearm-related injuries. In the US, at least one firearm is present in 34% of households with children; 21% of



Most Appropriate

- Descriptive studies
- Investigating associations between variables



Not Appropriate

- Studying temporal trends
- Calculating rates
- Geo-mapping or data linkage studies



Carefully read NCFRP Data Dissemination Policy & Guidelines

https://www.ncfrp.org/wpcontent/uploads/NCFRP_Data_Dissemination_Policy_Guidelines_v5_Sept2020.pdf).



Read February 2011 Supplement to Injury Prevention

<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

Review the data dictionary

https://www.ncfrp.org/wp-content/uploads/NCRPCD-Docs/DataDictionary_v5_1.pdf.



Contact Us!

We are here to help

info@ncfrp.com



BEFORE YOU START



Section A. Proposed Study

Completing the Application

Background and Rationale

What will you study and why is it important

- Choose a title that reflects the purpose and goals of the study
- Describe the proposed research in the context of what is known and how the results will contribute to prevention
- Clearly state your research aims/objectives
- Briefly summarize relevant literature, document rationale for and significance of your study
- End with a clear statement of the purpose of your research



Study Design and Methods

Identify Variables Necessary for the Study



DEFINE YOUR STUDY POPULATION



State inclusion and exclusion criteria using NFR-CRS data elements



EXPLICITLY DEFINE CONCEPTS AND KEY VARIABLES



Use NFR-CRS data elements



INDEPENDENT AND DEPENDENT VARIABLES



Identify your dependent and all independent variables using NFR-CRS data elements

Include a comprehensive list of requested variables.

- It is helpful if these variables are included in table format
- Include both section and question number, plus text
- Include only variables necessary for your analysis
- Identify independent and dependent variables
- If using terms for categories of variables (e.g., demographic characteristics) clearly identify which category the variable will be included in
- Ensure you are using the most current version of the data form. The variables shown here are from Version 5.1

Table 1. Variables Requested for Study

NFR-CRS Section/Question	Analysis plan
A4. Child age	Demographic characteristic for descriptive and comparative analysis
A5. Child race	Demographic characteristic for descriptive and comparative analysis
A6. Child Ethnicity	Demographic characteristic for descriptive and comparative analysis
A7. Child sex	Demographic characteristic for descriptive and comparative analysis
A13. Child history of disability/chronic disease	Social characteristic for descriptive and comparative analysis
A22. History of child maltreatment	Social characteristic for descriptive and comparative analysis
A23. Open CPS case at time of death	Social characteristic for descriptive and comparative analysis
D1. Supervision at time of incident	Incident characteristic for descriptive and comparative analysis
D3/4. Person responsible for supervision	Incident characteristic for descriptive and comparative analysis
D15. Was supervisor asleep	Incident characteristic for descriptive and comparative analysis
D16. Was supervisor impaired	Incident characteristic for descriptive and comparative analysis
E2. Incident time of day	Incident characteristic for descriptive and comparative analysis
E3. Incident place	Incident characteristic for descriptive and comparative analysis
E12. Child's activity at time of incident	Incident characteristic descriptive analysis, + use for defining fireplay
E13. Number of child deaths	Incident characteristic for descriptive and comparative analysis
F15. CPS action because of death	Incident characteristic for descriptive and comparative analysis
H2a. Fire source	Fire characteristic descriptive analysis, + use for defining fireplay
H2e. Type of building	Fire characteristic for descriptive and comparative analysis
H2f. Building's construction material	Fire characteristic for descriptive and comparative analysis
H2g. Fire started by person	Fire characteristic for descriptive and comparative analysis
H2h. Fire started by fire alarm	Fire characteristic for descriptive and comparative analysis

Data Analysis

How will you complete your study?

- Include a detailed analysis plan that tracks with the study aims
- Include shell tables to show how your results will be presented
- State the analysis software that will be used
- Describe how you will handle small numbers and missing/incomplete data
- Address the limitations of the NFR-CRS data as they related to your proposed research; how will these limitations be mitigated?
- Describe strategies for addressing health equity

Results Table 2. Unintentional Fire Deaths: Fireplay vs Non-Fireplay, Children Ages 1-14, 2004-2016.

	Fireplay Deaths (n=###) # (%)	Non-Fireplay Deaths (n=###) # (%)	OR (95% CI)
<u>Demographic and Social Characteristics</u>			
Child age in years			
1-4			
5-9			
10-14			
Child sex			
Male			
Female			
Child race/ethnicity			
White, non-Hispanic			
Black, non-Hispanic			
Hispanic			
Other			
Child history of disability/chronic illness			
Yes			
No			
Missing			
History child maltreatment			
Yes			
No			
Missing			
Open CPS case at time of death			
Yes			
No			
Missing			
<u>Incident Characteristics</u>			
Incident place			#
Child's or relative's home			
Other			
Missing			
Incident time of day			
8a-1 ⁵⁹ p			
2p-7 ⁵⁹ p			
8p-1 ⁵⁹ a			
2a-7 ⁵⁹ a			
Missing			

Final Components in Section A

Be thoughtful and specific.



TIMELINE

Include a reasonable timeline for completing your research



ANTICIPATED PRESENTATIONS AND PUBLICATIONS

- State which national or international conferences you plan to present your study
- List appropriate peer-reviewed journals where you will submit your findings for publication



Section B. Investigators

Completing the Application



Identify the Principal Investigator and each Co-Investigator



Describe the responsibilities each will have in conducting and completing the research



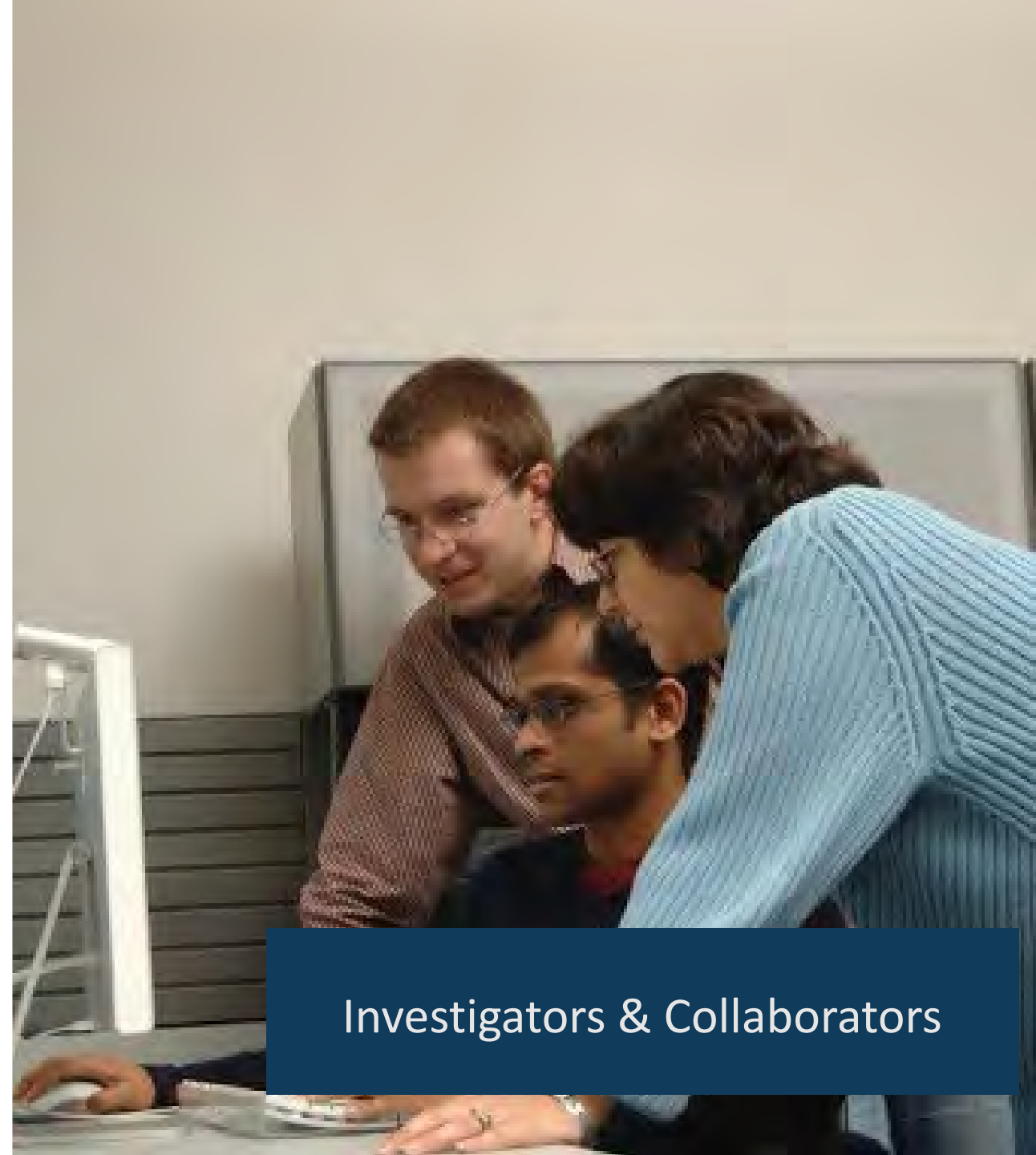
Attach a CV or resume for each investigator



Attach a completed and signed confidentiality agreement for each investigator



If you are a novice researcher, be sure your team includes co-investigators with the skills for which you need support



Investigators & Collaborators



Section C. Data Security

Completing the Application



Section D. Reviewing Institution

Completing the Application

Don't forget the details.

In addition to the research proposal, a complete application includes:

- Signed confidentiality agreements from each person who will have access to the data
- A current resume or CV from each person with access to the data
- Proof of registration of the receiving institution's IRB
- A completed application checklist



Before Submitting

You're almost there.

- Carefully read the sample contract template
- Review the four attachments in the application packet
- Complete the Checklist on the final page of the application packet
- Contact the National Center if you have any questions about the application process





Questions?



EVALUATION

<https://www.surveymonkey.com/r/32BRMMX>



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