NATIONAL CFRP
Center for Fatality Review & Prevention

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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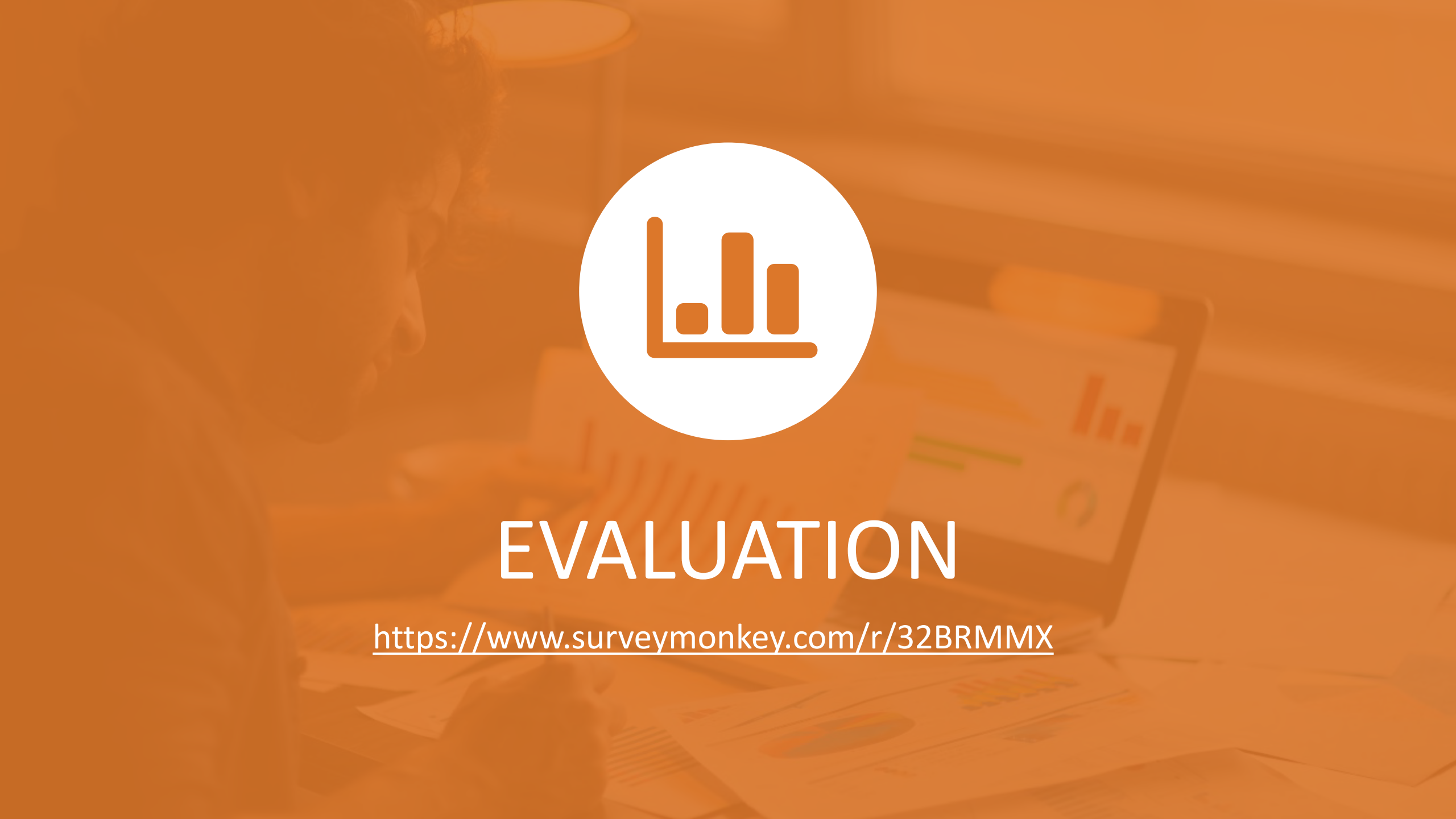
HOUSEKEEPING

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.

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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

Theresa M Covington[1,2]

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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

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.

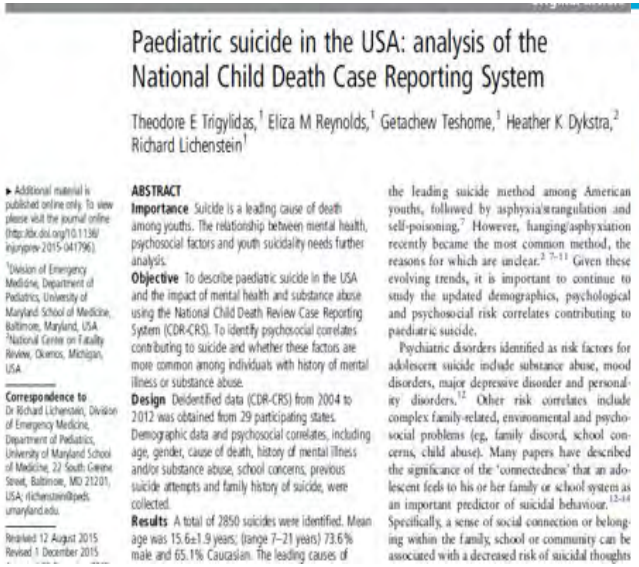
PURPOSE AND OBJECTIVES OF THE NCDR-CRS

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

Although a bit dated, this paper provides

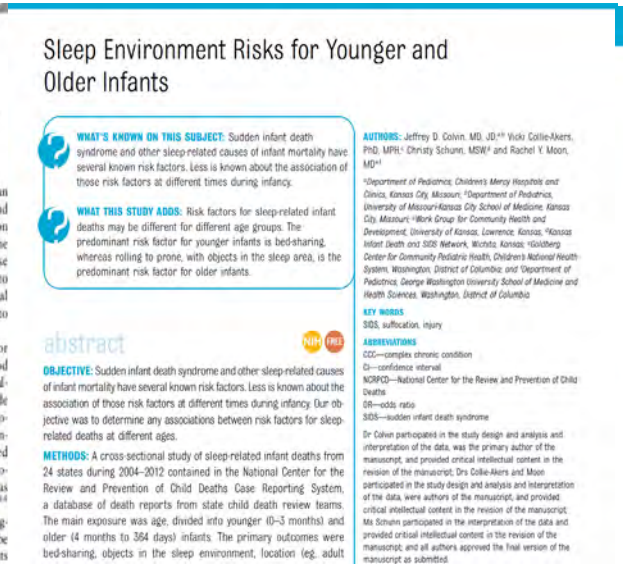
- **Important background**
- **Strengths**
- **Limitations**

Types of Studies



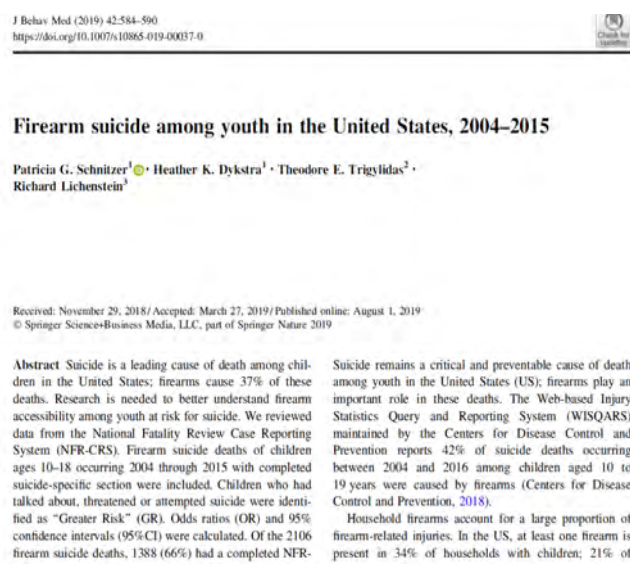
Paediatric suicide in the USA: analysis of the National Child Death Case Reporting System

Theodore E Trigylidas,[1] Eliza M Reynolds,[1] Getachew Teshome,[1] Heather K Dykstra,[2] Richard Lichenstein[1]



Sleep Environment Risks for Younger and Older Infants

Sofas and Infant Mortality



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

Patricia G. Schnitzer[1] · Heather K. Dykstra[1] · Theodore E. Trigylidas[2] · Richard Lichenstein[3]

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

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
Demographic and Social Characteristics			
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			
Incident Characteristics			
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

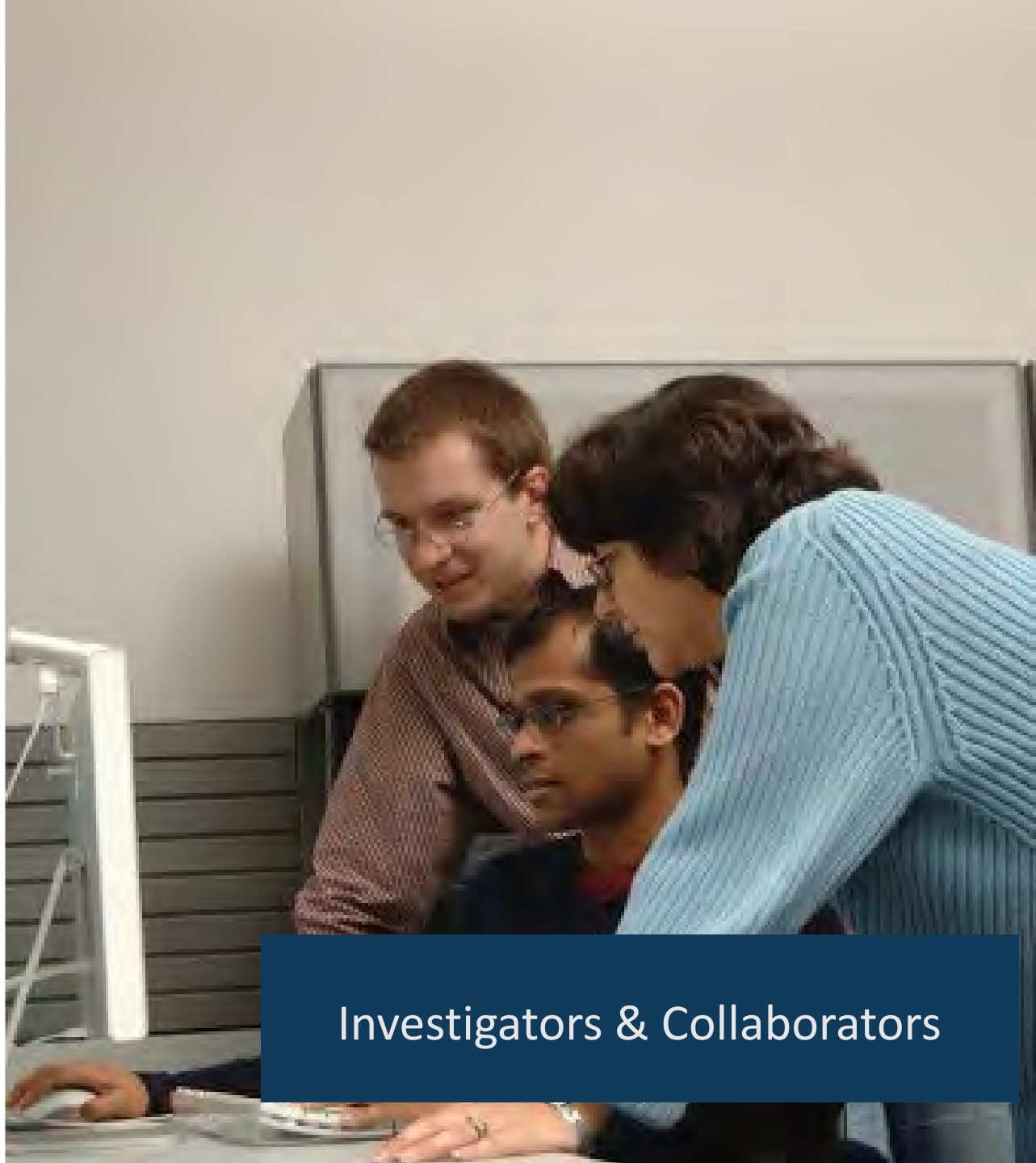
- State which national or international conferences you plan to present your study
- List appropriate peer-reviewed journals where you will submit your findings for publication

Section B. Investigators

Completing the Application

Investigators & Collaborators

- 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



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:

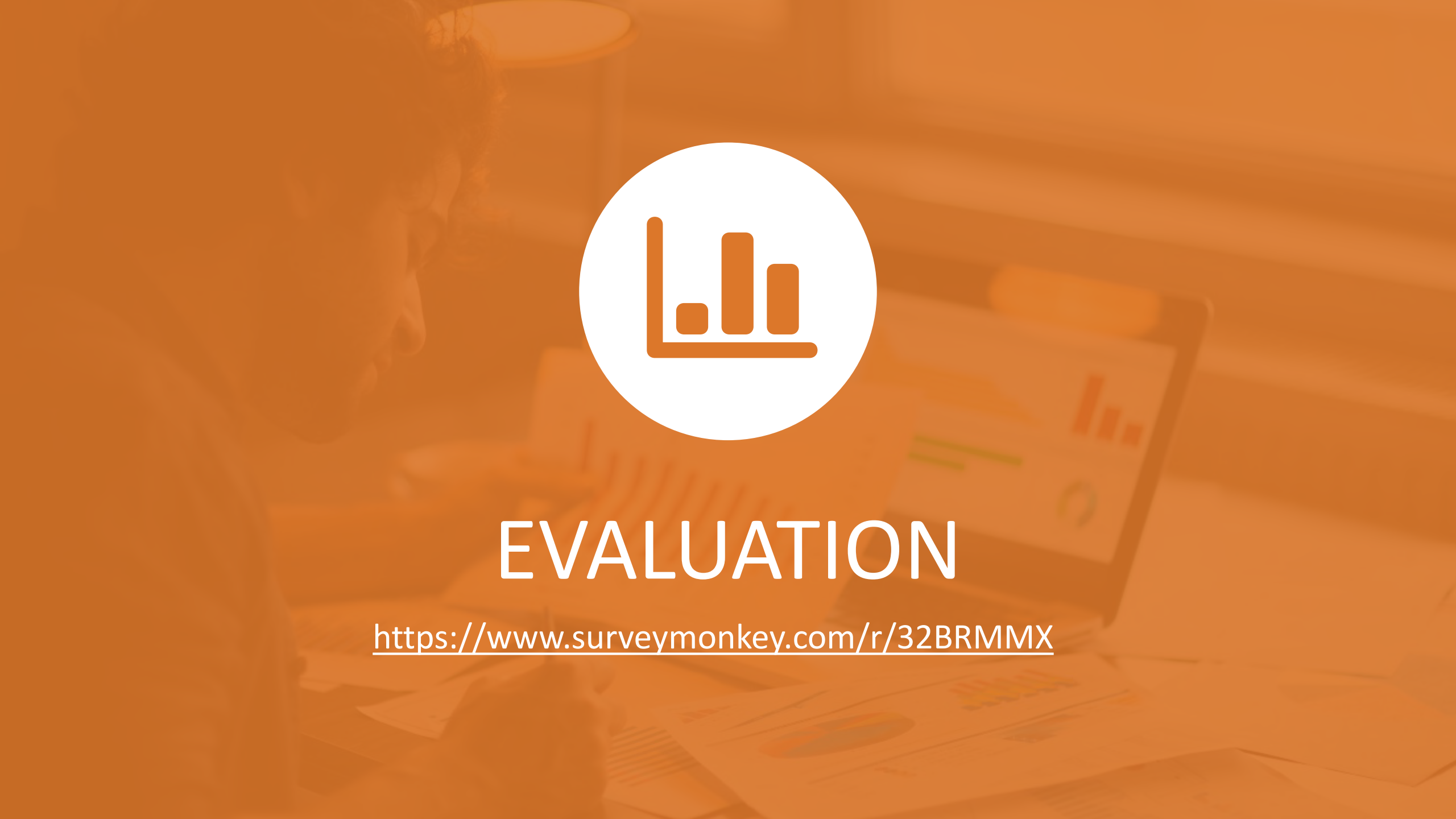
- Signed confidentiality agreements from each person who will have access to the data
- A current resume or CV from each person with access to the data
- Proof of registration of the receiving institution’s IRB
- A completed application checklist

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?



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