Notice of Funding Opportunity

**Application due Monday, October 26, 2026**

U.S. DEPARTMENT OF
HEALTH AND HUMAN SERVICES
CENTERS FOR DISEASE
CONTROL AND PREVENTION

Division of Birth Defects and Infant Disorders
National Center on Birth Defects and Development Disabilities

# Long-term health outcomes of people living with spina bifida

Opportunity number: CDC-RFA-DD-26-0222

# Contents

# Before you begin

If you believe you are a good candidate for this funding opportunity, secure your SAM.gov and Grants.gov registrations now. If you are already registered, make sure your registrations are active and up to date.

### SAM.gov registration (this can take several weeks)

You must have an active account with SAM.gov. This includes having a Unique Entity Identifier (UEI).

See Step 2: Get Ready to Apply

### Grants.gov registration (this can take several days)

You must have an active Grants.gov registration. Doing so requires a Login.gov registration as well.

See Step 2: Get Ready to Apply

### Apply by the application due date

Applications are due by 11:59 p.m. Eastern Time on Monday, October 26, 2026.

To help you find what you need, this NOFO uses internal links. In Adobe Reader, you can go back to where you were by pressing Alt + Left Arrow (Windows) or Command + Left Arrow (Mac) on your keyboard.

# Step 1:
# Review the Opportunity

### In this step

# Basic information

**Centers for Disease Control and Prevention (CDC)**

Division of Birth Defects and Infant Disorders

National Center on Birth Defects and Development Disabilities

## Ensuring long-term follow-up to improve health outcomes for people living with spina bifida.

## Summary

This NOFO has two funding components:

- **Component A**: National Spina Bifida Patient Registry (NSBPR).
- **Component B**: Urologic Management to Preserve Initial Renal Function Protocol for Young Children with Spina Bifida (UMPIRE).

The purpose of this NOFO is to:

- **Component A**: Collect high-quality longitudinal data on children and adults with spina bifida (SB) who get care in specialized SB clinics that are part of the National Spina Bifida Patient Registry (NSBPR).
- **Component B**: Carry out and evaluate the Urologic Management to Preserve Initial Renal Function Protocol for Young Children with Spina Bifida (UMPIRE) iterative protocol in infants and young children with myelomeningocele.Building on existing longitudinal data collection, recipients will collect and analyze data on patients with SB to:
  - Better understand health outcomes after interventions and treatments.
  - Share findings to identify opportunities to improve care of patients with SB.

You may apply to either Component A or Component B, or both.

**Have questions?**
Go to Contacts and Support.

### Key facts

**Opportunity name:** Long-term health outcomes of people living with spina bifida

**Opportunity number:** CDC-RFA-DD-26-0222

**Assistance listing:** 93.073

**NOFO version:** Original

### Key dates

**Application submission deadline:** Monday, October 26, 2026

Informational call: September 17, 2026

**Optional letter of intent deadline:** September 26, 2026

**Expected award date:** August 1, 2027

**Expected start date:** September 1, 2027

See Submit Your Application for other time frames that may apply to this NOFO.

# Funding details

**Funding type:** Cooperative agreement

**Expected awards:**

- **Component A:** 8-11
- **Component B:** 6-9

**Period of performance:** Three years in 12-month budget periods.

**Expected total program funding over the performance period:**

- **Component A:** $2,400,000 – $6,600,000
- **Component B:** $900,000 – $2,700,000

**Estimated average award per applicant over the period of performance:**

- **Component A:** $300,000 – $600,000
- **Component B:** $150,000 – $300,000

**Expected funding per applicant per 12-month budget period:**

- **Component A:** $100,000 - $200,000
- **Component B:** $50,000- $100,000

The number of awards is subject to available funds and program priorities.

# Funding strategy

Average one-year award, per recipient:

- **Component A**: $100,000-$200,000.
- **Component B**: $50,000-$100,000.

# Eligibility

## Eligible applicants

**Only these types of organizations may apply.**

- State governments.
- County governments.
- City or township governments.
- Special district governments.
- Independent school districts.
- Public and state-controlled institutions of higher education.
- Native American tribal governments (federally recognized).
- Public housing authorities and Indian housing authorities.
- Native American tribal organizations, other than federally recognized tribal governments.
- Nonprofits having a 501(c)(3) status, other than institutions of higher education.
- Nonprofits without 501(c)(3) status, other than institutions of higher education.
- Private institutions of higher education.
- For-profit organizations other than small businesses.
- Small businesses.
- Bona fide agents applying on behalf of state, territorial, local, and tribal government organizations.

Bona fide agents must submit documentation that demonstrates their arrangement with the eligible applicant. See attachments.

## Responsiveness criteria

We will review your application to make sure it meets these requirements.

These are the basic requirements you must meet to move forward in the competition. We won't consider an application that:

- Is from an organization that doesn't meet all eligibility criteria. See requirements in eligibility.
- Is submitted after the deadline.

You must provide a document labeled “Responsiveness criteria” for each component you apply to.

For **Component A**, the document should include:

- The number of patients currently enrolled in NSBPR, with at least one visit in the registry between January 2020 and August 2024, and one of the following diagnoses:
  - Myelomeningocele.
  - Meningocele.
  - Lipomyelomeningocele.
  - Fatty/thickened filum.
  - Split cord malformation.
  - Terminal myelocystocele.
- The proportion of individuals seen between January 2020 and August 2024 who have more than five visits.
- At least one letter of commitment from a representative of the participating clinic or hospital system where patients receive care that documents:
  - Access to patients with spina bifida.
  - The collection of the data elements in the NSBPR (see Findings from the National Spina Bifida Patient Registry | Spina Bifida | CDC to view some of the data elements collected).

For **Component B**, the document should include:

- The number of patients previously enrolled in UMPIRE with a diagnosis of myelomeningocele, who have at least one visit between January 2020 and August 2024.
- The curriculum vitae of a pediatric urologist who is part of the study team.
- At least one letter of commitment from a representative of the participating clinic or hospital system where patients receive care that documents:
  - Access to patients with spina bifida.
  - The collection of the data elements in the UMPIRE (see Findings from the National Spina Bifida Patient Registry | Spina Bifida | CDC to view some of the data elements collected).

See the application checklists to understand which elements of your application are part of the responsiveness criteria.

# Application limits

You must follow these limits on the number of applications your organization can submit.

You may apply to either Component A or Component B, or both. Each organization (normally identified by having a unique UEI number) may submit one application for each component. So, at the most, you may submit two applications.

# Cost sharing and matching funds

This program has no cost-sharing requirement, meaning you do not need to contribute to the costs of this project.

If you choose to include cost-sharing funds, we won't consider it during review. If you receive an award, we will include your voluntary commitment in the award, and you must report on the funds.

### Post-award requirements

Before you apply, make sure you understand the requirements that come with an award.

See Step 6: Learn What Happens After Award for information on regulations that apply, reporting, and more.

# Agency priorities

## Required alignment with CDC priorities

The recipient of this award must implement any funds awarded under this NOFO to effectuate program goals or agency priorities in accordance with the Centers for Disease Control and Prevention (CDC) Priorities when authorized (for a full description of the CDC Priorities please follow the provided hyperlink).

Funded activities must:

- Align with CDC's core priorities by demonstrating a commitment to gold-standard science, transparency, and evidence-based practices.
- Support CDC's mission to protect Americans from infectious and chronic diseases, strengthen public health systems, and advance innovation in health data and infrastructure.
- Contribute to rapid, science-driven responses to health threats, promote global health leadership, and adhere to principles of integrity, accountability, and compliance with applicable laws and federal priorities.

Consistent with CDC's values, in carrying out any project funded under this NOFO, the recipient must adhere to the following principles where consistent with the authority and scope of the award and its activities:

- **A commitment to gold-standard science and ensuring trust, transparency, and credibility:** To build trust and improve CDC's ability to lead during health crises, CDC will increase transparency, be more accountable, and follow strict, gold-standard scientific practices that are open, unbiased, and based on clear evidence.
- **A commitment to global leadership:** With staff in 63 countries and supporting 20 more, CDC's Global Health Center:
  - Fights HIV, tuberculosis, vaccine-preventable diseases, and emergency and refugee health.
  - Detects health threats early, sends response teams, trains health workers, and provides personal protective equipment, vaccines, and medicines.
  - Tests disease samples from around the world to prepare for flu and other serious outbreaks.

    - Has strengthened systems to better protect people at home and abroad after the COVID-19 outbreak.

- **A commitment to ensuring rapid, evidence-based responses to crises:** During public health emergencies, ensuring rapid, science-driven responses is critical to minimizing harm, maintaining public trust, and restoring stability. To meet this goal, CDC must continue to strengthen its emergency response systems by:
    - Streamlining internal processes.
    - Improving risk communication strategies.
    - Ensuring that laboratory capacity is fully equipped and tested—capable of rapidly developing and deploying scalable diagnostics during crises.
    - Embedding structures for real-time learning, independent after-action reviews, and the application of lessons learned will ensure that each crisis response is smarter, faster, and more effective than the last.
- **A commitment to vaccine safety and efficacy research:** CDC will apply "gold-standard" science to all of its vaccine safety and effectiveness research. It will make vaccine data, research methods, and related datasets publicly available through simple data use agreements to improve transparency, accountability, and trust.
- **A commitment to advancing our understanding of the causes of autism spectrum disorder (ASD), neurodevelopmental disorders (NDDs), and chronic disease:** CDC conducts research and works with partners to better understand the causes of autism spectrum disorder, neurodevelopmental disorders, and chronic diseases. It will use new and existing data to study the rise in these conditions, including the increase in autism diagnoses from 1 in 150 to nearly 1 in 31 over the past 25 years.
- **A commitment to modernizing public health infrastructure and enhancing our approach to health data:** CDC will modernize public health infrastructure to create a faster, more efficient health system that can detect and respond to outbreaks in real time. This effort includes:
    - Replacing data silos with integrated systems.
    - Using advanced technology.
    - Strengthening partnerships with states to ensure shared responsibility and strong local health data systems.

    - Emphasizing collaboration across federal and state partners, resilient and adaptable systems, and accountability for funded programs to ensure they align with these priorities and federal requirements.

- **Conflicts of interest:** CDC will not support funding programs with conflicts of interest and ensure its work is based on transparent, unbiased science.
- **Immigration:** CDC funds will not be used to support or encourage illegal immigration, consistent with federal law.
- **Protecting life and the family:** CDC funds will not be used to support elective abortions, consistent with the Hyde Amendment, and will promote maternal health, the dignity of life, and strong families.
- **Ending disorder on America's streets:** CDC will prioritize evidence-based programs that reduce homelessness, drug use, and public disorder. It will support comprehensive services for people with serious mental illness and substance use disorder. CDC will not fund housing first strategies, harm-reduction or safe consumption sites, or related activities. To the extent allowable by federal law, CDC intends to give priority to grantees in States and municipalities that have laws and policies that support and enforce CDC's priorities.
- **Gender ideology and protecting children:** CDC will not fund medical interventions for minors seeking gender transition and will define sex based on biological criteria.
- **DEI:** CDC will not fund DEI initiatives based on group identity and focus on merit-based, evidence-driven approaches to improve health outcomes.
- **Parental rights:** CDC will support policies that protect parental authority, promote transparency, and give parents greater control over their children's education.

The recipient must demonstrate ongoing compliance with the full description and listing of CDC values and priorities, in all programs that are authorized to advance them, through program design, implementation, reporting, and evaluation.

Failure to meaningfully align funded activities with the applicable requirements may result in corrective action, additional reporting requirements, or other enforcement actions consistent with federal grant regulations found at 2 CFR Part 200 and the terms and conditions of this award. The full CDC Priorities Statement can be found here: Centers for Disease Control and Prevention (CDC) Priorities.

# Program description

## Background

### Overview

An estimated 160,000 people in the United States (U.S.) currently live with spina bifida (SB). It's the most common permanently disabling birth defect.

The care of individuals with SB is complex, involving different organ systems and different clinical specialists. Many of those affected by SB receive specialty care in one of 96 (estimated) SB multidisciplinary clinics in the U.S.

### National Spina Bifida Patient Registry

In 2008, the Centers for Disease Control and Prevention (CDC) established the National Spina Bifida Patient Registry (NSBPR) as a cooperative agreement with nine SB clinics across the U.S.

Since then, CDC has continued cooperative agreements with clinics to collect, analyze, and publish findings from longitudinal data. This includes clinical interventions and health outcomes for individuals with some of the more severe types of SB, such as myelomeningocele.

Currently, 14 funded clinics participate in the NSBPR. Six other clinics not currently funded also contribute data to NSBPR. Data with limited identifiers from the NSBPR registry sites are stored at CDC and are managed by CDC staff.

As of September 2024, over 12,000 individuals with SB have been enrolled in the NSBPR. Approximately 17% have two recorded visits. Over 63% have 3-16 recorded visits at NSBPR clinics.

Principal investigators from each of the participating clinics and CDC staff work together to oversee the details of the project in a coordinating committee (CC). The NSBPR Committee on Science and Publications (CSP) reviews analytic proposals and publications that result from NSBPR data.

### The UMPIRE protocol

In 2014, nine NSBPR clinics were funded to establish and carry out the Urologic Management to Preserve Initial Renal Function Protocol for Young Children with Spina Bifida (UMPIRE) protocol.

The UMPIRE protocol was established to evaluate and manage the urinary systems in infants and young children with myelomeningocele to preserve normal kidney function.

Currently, eight clinics participate in UMPIRE. Data with limited identifiers from the UMPIRE registry sites are stored at CDC and managed by CDC staff. As of October 2024, over 600 infants and young children are enrolled in UMPIRE, with more than 4,000 patient encounters.

## Work needed

Over the years, the NSBPR and the UMPIRE protocol have made progress in identifying best practices for people living with SB, but more work is still needed.

Most of the NSBPR and UMPIRE publications so far have focused on describing the data. Descriptive investigations are important. But analyses of longitudinal data are necessary to identify the health care and clinic practices associated with the best outcomes for individuals with SB.

Additional years of NSBPR and UMPIRE protocol data will provide insights on long-term outcomes. It'll help us better understand how current treatment recommendations can benefit these children and their families.

In addition, evaluation and refinement of the UMPIRE surveillance protocol will help identify the best possible course of care for infants and children with myelomeningocele.

## Related work

CDC has a long history of support for SB work related to long-term health outcomes.

This NOFO will build on the success of the previous NOFOs:

- Spina Bifida Patient Registry Demonstration Project (U01) DP08-001.
- National Spina Bifida Patient Registry - Clinic Demonstration Project (U01), DD-11-001.
- Research Approaches to Improve the Care and Outcomes of People Living with Spina Bifida, DD14-002.
- Research Approaches to Improve the Care and Outcomes of People Living with Spina Bifida, DD19-001.

The National Spina Bifida Patient Registry (NSBPR) and Urologic Management to Preserve Initial Renal Function Protocol for Young Children with Spina

Bifida (UMPIRE) have improved the understanding of SB care received in SB clinics.

As of October 2025, 35 manuscripts have been published using NSBPR or UMPIRE data. The current NOFO will build upon the work by continuing to follow patients with SB longitudinally to evaluate their clinical outcomes.

# Purpose

The purpose of this NOFO is to:

- Collect longitudinal data from SB specialty clinics to describe key outcomes.
- Identify healthcare and clinic practices that are associated with the best outcomes for individuals living with SB.

The goal is to improve the health and quality of life for individuals of all ages living with SB.

# Approach

## Overview

There are two components to this NOFO with separate, but complementary approaches. Each contributes uniquely to the overall purpose of this NOFO:

### Component A

The approach of Component A is to track the health status of children and adults with SB who receive care in specialized SB clinics. The longitudinal aspect of data collection is critical for the analytic value of the NSBPR.

This NOFO focuses on expanding longitudinal data collection and incorporating data quality measures in standard activities.

### Component B

The approach of Component B is to carry out and evaluate the UMPIRE protocol. This iterative protocol aims to clinically manage the urinary system in infants and young children with myelomeningocele to preserve kidney function as much as possible as they age.

As with Component A, the longitudinal aspect of data collection is critical. Many of the important outcomes can only be measured in individuals who have been enrolled in the protocol for more than five years.

## Program logic model

The following logic model includes the strategies and activities required under this NOFO.

The logic model also includes the program's expected outcomes. Outcomes are the results that you intend to achieve. They usually show the intended direction of change, such as increase or decrease.

The **asterisked ( * )** outcomes are those we expect you to achieve during the 3-year period of performance. You are required to report on these outcomes.

Not all outcomes apply to all strategies. The table shows how they apply. You will use these outcomes as a guide for developing performance measures.

**Table: Strategies and outcomes**

| Strategies and activities | Short-term outcomes | Intermediate outcomes | Long-term outcomes |
|---|---|---|---|
| **Component A**<br><br>**Strategy 1: Collect annual longitudinal data from SB specialty clinics**<br>• Collect follow-up visit data on children and adults with SB already enrolled in NSBPR.<br>• Prevent loss to follow-up in participants already enrolled in NSBPR.<br>• Approach all eligible potential enrollees and collect longitudinal data on participants who enroll.<br><br>**Strategy 2: Data management and reporting**<br>• Securely submit standardized and validated data with limited identifiers to CDC for data pooling.<br>• Conduct data quality checks, address data quality errors, and | **Components A and B**<br><br>Improved longitudinal data quality from SB specialty clinics and increased information for clinical decision-making.*<br><br>Improved science base of SB care among key audiences.*<br><br>Increased awareness of findings among key audiences.* | **Components A and B**<br><br>Improved standard of care for children and adults living with SB.<br><br>**Component B**<br><br>Improved management of the urinary and kidney systems in infants and young children living with SB. | **Components A and B**<br><br>Improved health and quality of life for children and adults living with SB. |

| Strategies and activities | Short-term outcomes | Intermediate outcomes | Long-term outcomes |
|---|---|---|---|
| report on findings in collaboration with CDC.<br>• Participate in initial and ongoing data collection training.<br><br>**Strategy 3: Data analysis and sharing**<br>• Collaborate with CDC to develop data analysis proposals, analyze data, and share findings with key audiences.<br>• Attend annual, quarterly, workgroup, and committee meetings in collaboration with CDC.<br><br>**Component B**<br><br>**Strategy 1: Collect longitudinal data from SB specialty clinics**<br>• Collect follow-up visit data on participants already enrolled in UMPIRE.<br>• Prevent loss to follow-up in participants already enrolled in UMPIRE.<br><br>**Strategy 2: Data management and reporting**<br>• Securely submit standardized and validated data with limited identifiers to CDC.<br>• Conduct data quality checks, address data quality errors, and report on findings in collaboration with CDC.<br>• Participate in initial and ongoing data collection training.<br><br>**Strategy 3:** Data analysis and sharing<br>• Collaborate with CDC to develop data analysis proposals, analyze data, and share findings. | | | |

| Strategies and activities | Short-term outcomes | Intermediate outcomes | Long-term outcomes |
|---|---|---|---|
| • Attend annual, quarterly, workgroup, and committee meetings in collaboration with CDC.<br>• Evaluate and refine UMPIRE protocol. | | | |

## Strategies and activities

This section elaborates on the strategies and activities described in the logic model and provides details about how we expect you to implement your program.

### Component A

For Component A, you will perform the following strategies and activities:

**Strategy 1: Collect annual longitudinal data from SB specialty clinics**

- Collect follow-up visit data on children and adults with SB already enrolled in NSBPR.
  - Enhance participant retention by conducting or enhancing activities to follow-up with enrolled NSBPR participants to increase the likelihood that the patients return to the clinic. Collect and report additional data on enrolled participants who are lost to follow-up.
- Approach all eligible individuals for participation. For those who have provided consent, collect data according to the surveillance protocol. NSBPR eligible SB diagnoses include:
  - Myelomeningocele.
  - Meningocele.
  - Lipomyelomeningocele.
  - Fatty/thickened filum.
  - Split cord malformation.
  - Terminal myelocystocele.
- Each year, collect and report to CDC on minimal non-identifiable data (e.g. sex, race/ethnicity, insurance status) on eligible patients who did not enroll in the NSBPR to identify potential differences with enrolled patients.

- Clinics should describe their ability to participate in other optional data collection efforts such as:
  - Skin breakdown bundle materials.
  - Quality of life.
  - Sleep disordered breathing.
  - Cognitive and adaptive testing.
- Conduct a linkage with state death records or the National Death Index to identify deaths among enrolled patients.

**Strategy 2: Data management and reporting**

- Adhere to and use the CDC-developed data collection instruments and data system.
- Submit standardized, validated data with limited identifiers (e.g., date-shifted birth date, clinic visits, surgeries, and procedures, as well as zip code) monthly to CDC for additional data quality review and data pooling.
  - Date shifting is a method of date de-identification using a complex randomized algorithm embedded in the data collection tool, so no true date is shared.
- Conduct data quality checks, address data quality issues, and report on findings per CDC guidance.
- Participate in initial and ongoing data collection and data management training per CDC guidance.

**Strategy 3: Data analysis and sharing**

- Participate in quarterly virtual meetings, one annual in-person or virtual principal investigator meeting, and other committee or workgroup meetings, as appropriate.
- Collaborate with CDC and other recipients to develop data analysis proposals, analyze data, and share findings with key audiences, based on pooled NSBPR data.
  - Participate in the development of data analysis proposals and analytic plans using pooled NSBPR data.
  - Perform analysis of pooled NSBPR data and interpret results.
  - Share findings from data analysis projects, using pooled NSBPR data, in presentations and publications.
  - Annually, deliver at least one presentation on NSBPR data to key audiences.
  - Key audiences include:

- Public health and clinical researchers.
- Providers.
- SB partners.
- Individuals with SB.
- Families or caregivers of individuals with SB.

## Component B

For Component B, you will perform the following strategies and activities:

**Strategy 1: Collect longitudinal data from SB specialty clinics**

- Collect longitudinal data, according to the UMPIRE surveillance protocol for participants currently enrolled.
- Enhance participant retention by conducting or enhancing activities to follow-up with enrolled UMPIRE participants to increase the likelihood that the patients return to the clinic.
  - Collect and report additional data on enrolled participants who are lost to follow-up.
- Collect information regarding any deviation from the UMPIRE surveillance protocol. Include a description of the type of protocol deviation and the reason for deviating from the protocol.

**Strategy 2: Data management and reporting**

- Use the CDC data collection forms and data system (see findings from the National Spina Bifida Patient Registry | Spina Bifida | CDC to view some critical data elements collected).
- Submit standardized, validated data with limited identifiers (e.g., date-shifted birth date, clinic visits, surgeries, and procedures, as well as zip code) monthly to CDC for additional data quality review and data pooling.
  - Date shifting is a method of date de-identification using a complex randomized algorithm embedded in the data collection tool, so no true date is shared.
- Conduct data quality checks, address data quality issues, and report on resolution.
- Participate in initial and ongoing data collection training per CDC guidance.

**Strategy 3: Data analysis and sharing**

- Participate in quarterly virtual meetings, one annual in-person or virtual Principal Investigator meeting, and other committee or workgroup meetings as appropriate.
- Collaborate with CDC and other recipients to develop data analysis proposals, analyze data, and share finding with key audiences, based on pooled UMPIRE data.
    - Participate in the development of data analysis proposals and analytic plans using pooled UMPIRE data.
    - Perform analysis of pooled UMPIRE data and interpret results.
    - Share findings from data analysis projects using pooled UMPIRE data through presentations and publications.
    - Annually, deliver at least one presentation on UMPIRE data to key audiences.
    - Key audiences include:
        - Public health and clinical researchers.
        - Providers.
        - SB partners.
        - Individuals with SB.
        - Families or caregivers of individuals with SB.
- Collaborate with CDC and other recipients to:
    - Develop analytic plans.
    - Analyze and interpret data to inform evaluation and any potential revision of the UMPIRE surveillance protocol for infants and young children.

## Outcomes

This section includes information about the outcomes we expect you to report progress on and achieve within the performance period.

For **Components A and B**, you will work to achieve these outcomes:

- Improved longitudinal data quality from SB specialty clinics and increased information for clinical decision making.
- Improved science base of SB care among key audiences.
- Increased awareness of findings among key audiences.

## Key audiences

Key audiences include:

- Public health and clinical researchers.
- Providers.
- SB partners.
- Individuals with SB.
- Families or caregivers of individuals with SB.

# Work plan

You must provide a work plan for your project. The work plan connects your performance outcomes, strategies and activities, and measures. It provides more detail on how you will measure outcomes and processes.

For both **Component A** and **Component B**, you must submit a detailed work plan for the first year of the project and a high-level work plan for subsequent years.

**Table: Sample format**

| Activities you will implement | Progress or process measures<br>From the data, monitoring, and evaluation section. | Relevant period of performance outcomes<br>From the outcomes section. | Responsible position or party | Completion date |
|---|---|---|---|---|
| **Strategy 1:** | | | | |
| 1. | | | | |
| 2. | | | | |
| 3. | | | | |
| **Strategy 2:** | | | | |
| 1. | | | | |
| 2. | | | | |
| 3. | | | | |

# Data, monitoring, and evaluation

## CDC strategy

CDC collects and reports on indicators to measure progress toward achieving the activities and outcomes. CDC will also use results for program planning, improvement, accountability, and reporting. CDC may share the results within the Federal government, consistent with applicable law and grant regulations.

CDC will work with you throughout the life of an award to ensure that all activities and expected outcomes align with your strategies and goals, and those of the U.S. government.

You should dedicate some of award funds to evaluate and monitor the performance of your project. You and CDC will agree on the final funding amount, but we expect that you will dedicate approximately 5 to 10% of your project's funding to monitoring, reporting, and evaluation activities.

The evaluation and performance measurement strategy will assess project performance. Measures are subject to change. You must track evaluation and performance measures and report progress to CDC using a CDC-defined format and timeline.

With your application, you must include an evaluation plan that:

- Aligns with strategies and activities from the logic model.
- Includes performance measures.
- Describes assigned personnel.
- Includes a timeline.
- Describes expected outcomes.
- Describes the use of results to improve your program.

You and CDC will use evaluation findings to:

- Ensure that improvements are continually being made.
- Show that progress is being made in reaching short-term outcomes and program goals.
- Improve ongoing and future data collection activities.

# Required performance measures

This section describes the draft performance measures you will need to report on after award. We will likely refine the required measures for this program. If so, we will work with you and finalize them before we require you to submit any data.

## Draft process measures

**Strategy 1: Collect annual longitudinal data from SB specialty clinics**

- Report number of follow-up visits among currently enrolled NSBPR or UMPIRE participants.
- Report number of new participants enrolled in NSBPR.
- Report number of individuals who have not been seen in the last three years.
  - Decrease by 5% over three-year period.
- Report methods (new and ongoing) to prevent or recall lost patients.
- Percent of non-deceased enrollees with a visit in the past 12 months.
  - Increase by 5% over the three-year period

**Strategy 2: Data management and reporting**

- Adherence to CDC-developed data dictionary. This includes incorporating any updates or revisions to data collection instruments within two weeks of receiving updates.
- Submission of standardized and validated datasets with limited identifiers to CDC (monthly).
- Return of data quality report findings and correction of any data quality errors (monthly).

**Strategy 3: Data analysis and sharing**

- Report site representation at annual, quarterly, workgroup, and committee meetings per CDC guidance (annually).
- Provide list of approved data analysis proposals or manuscripts involving multi-site pooled data that you've led or participated in (annually).

### Draft outcome measures

**Outcome 1: Improved longitudinal data quality from SB specialty clinics and increased availability of data**

- Quantitative measures showing improvement in the accuracy, completeness, or timeliness of data submission (annually).
  - 80% of data extracts submitted on time.
  - 100% of submissions include data validation check prior to export.

**Outcome 2: Improve the science base of SB care among key audiences**

- Provide list of manuscripts accepted or published in peer-reviewed journals (annually). Include the journal name.
  - At least one manuscript accepted or published each funding year.
  - Consistent with the Public Access to CDC Funded Publication Policy, all peer-reviewed publications funded by CDC must be made available to the public for free and full use with no embargo period (see CDC Public Access to Publications).

**Outcome 3: Increased awareness of findings among key audiences**

- Provide list of presentations given to key audiences (annually). Include the title, presentation venue, type of audience, and number of attendees.
  - Provide at least one presentation to a key audience each funding year.
- Optional: Share examples of improvements to clinical standard of care of patients (annually).

## Evaluation and performance measurement plan

You must provide an evaluation and performance measurement plan. Use the measures required under the CDC strategy.

### Methods

Describe how you will:

- Collect the performance measures.
- Respond to the evaluation questions.
- Incorporate evaluation and performance measurement into planning, implementing, and reporting project activities.
- Use evaluation findings for continuous program quality improvement.

Additionally, explain:

- How key program partners will participate in the evaluation and performance measurement process.
- How feasible it will be to collect appropriate evaluation and performance data.
- How you will share evaluation findings with communities.
- Other relevant information, such as performance measures you propose.

## Data management plan

For all public health data you plan to collect, you must have a data management plan (DMP). For a definition of "public health data" and more information about CDC's policy on the DMP, see Data Management and Access.

Submit your DMP with your application and include:

- The data you will collect or generate, and what its sources will be.
- Who can access data and how you will protect it.
- Data standards that explain what documentation the released data will have. That documentation should describe collection methods, what the data represent, and data limitations.
- Archival and long-term data preservation plans.
- Any reasons you cannot share data collected or generated under this award with CDC. These could include legal, regulatory, policy, or technical concerns.
- How you will update the DMP as new information becomes available over the life of the project. You will provide updates to the DMP in annual reports.

## Evaluation activities

You must take on specific evaluation activities. Describe:

- The type of evaluations you will complete, such as process, outcome, or both.
- Key evaluation questions these evaluations will address.
- Measures and data sources.
- Any other relevant information.

Submit a draft of your evaluation and performance measurement plan, including the DMP, with your application. You must submit a more detailed plan within the first six months of the award. See reporting.

## Paperwork Reduction Act

Any activities involving information collection from 10 or more individuals or organizations may require the Paperwork Reduction Act (PRA) approval. The PRA requires review and approval of the information collection by the White House Office of Management and Budget. To determine if a proposed activity requires PRA approval, contact your program contact.

Collections include items like surveys and questionnaires. If you have collections requiring PRA approval, CDC is responsible for working with OMB to gain the approval.

For more information about CDC's requirements under PRA see CDC Paperwork Reduction Act Compliance.

# Organizational capacity

You must describe your organization's capacity to perform project activities, including:

- Performing longitudinal data collection from SB specialty clinics. This includes previous experience minimizing loss to follow-up.
- Program and performance management and evaluation.
- Data management. This includes experience securely transferring data files, data cleaning, and data quality improvement.
- Data analysis. This includes participating in the development of data analysis proposals and analytic plans and performing analyses using NSBPR or UMPIRE data.
- Sharing findings. This includes participating in the development of presentation materials, manuscripts, and the presentation of findings from NSBPR or UMPIRE.

When describing your capacity to collect longitudinal data from SB specialty clinics, address:

- Your ability to submit standardized datasets with limited identifiers to CDC to include in a pooled dataset.
- Your existing processes to share data with us. If relevant, describe any barriers that you've experienced in data sharing.

## Staff capacity

You must include a staffing plan that clearly defines staff roles to achieve the project outcomes.

Describe:

- The staff responsible for the activities of this NOFO.
- The percentage of time they'll devote to the project (such as full-time equivalent).
- Whether they're existing staff or will be hired.

Include job descriptions, two-page resumes or biosketches, and an organizational chart to help show your organization's capacity to perform project activities.

For **Components A and B**, also describe:

- Committed relationships your staff has with relevant specialists who will provide access to patients with SB and to the collection of data.
- Your staff's ability and previous experience collecting and using or analyzing longitudinal data (including publications, if applicable), for instance from NSBPR or UMPIRE. Include your organization's enrollment history of individuals in NSBPR or UMPIRE.
- A data coordinator should be included on staff, as well as a description of their capacity to support the implementation of data management and timely data submission to CDC.
- Your staff's ability to develop scientific manuscripts for peer-review. Demonstrate your organization's record of research that has advanced the field of SB clinical care.

For **Component A only**, also describe:

- Your staff's ability to analyze data (you should have a data analyst).
- Your capacity to support analyses.

For **Component B only**, also describe:

- Evidence that the pediatric urologist you include in your application works closely with the initial hospital where the affected newborn presents at the hospital/clinic.

## Collaborations

We expect you to maintain existing partnerships and establish new partnerships, as needed, to accomplish the goals of the NOFO. This includes relationships with clinicians and clinician groups who treat patients with SB.

We expect you to collaborate with patient support groups to share information relevant to individuals with SB and their families and caregivers.

If you're awarded funds under this cooperative agreement, you must collaborate with other awardees and CDC. This includes sharing of data as described in this NOFO.

# Funding policies and limitations

## Changes in HHS regulations

As of October 1, 2025, HHS adopted 2 CFR 200, with some exceptions included in 2 CFR 300. These regulations replace those in 45 CFR 75. You can find details in HHS Summary of Regulatory Changes, which is posted in the Grants.gov Related Documents tab for this opportunity.

## General guidance

All activities proposed in your application and budget narrative must align with applicable law, including but not limited to statutes, executive orders, federal regulations and applicable judicial holdings. Accordingly, discretionary awards shall not be used to fund, promote, encourage, subsidize, or facilitate; racial preferences or other forms of racial discrimination by the recipient, including activities where race or intentional proxies for race will be used as a selection criterion for employment or program participation; denial by the recipient of the sex binary in humans, or the belief that sex is a chosen or mutable characteristic; illegal immigration; or any other initiatives that compromise public safety. If an application does not align, the application will not receive funding to the extent permitted by law and applicable court orders.

- You may use funds only for reasonable program purposes consistent with the award, its terms and conditions, and federal laws and regulations that apply to the award. If you have questions about these purposes, ask the grants management specialist.
- Support beyond the first budget year will depend on:
    - Appropriation of funds.

    - Satisfactory progress in meeting your project's objectives.
    - A decision that continued funding is in the government's best interest, program goals, and priorities.
- If needed, and where consistent with the scope of the NOFO:
    - You may use funds to support your jurisdiction's vital records office (VRO) to do any of the following:
        - Build its capacity through partnerships.
        - Provide technical or financial assistance to improve vital records timeliness, quality, or access.
        - Support vital records improvement efforts.

If we receive more funding for this program, we will consider options such as:

- Funding more applicants.
- Extending the period of performance.
- Awarding supplemental funding.

See also program-specific limitations.

## Unallowable costs

You may not use funds for:

- Clinical care, except as allowed by law.
- Pre-award costs, unless we give you prior written approval.
- Other than for normal and recognized executive-legislative relationships:
    - Publicity or propaganda purposes, including preparing, distributing, or using any material designed to support or defeat the enactment of legislation before any legislative body.
    - The salary or expenses of any grant or contract recipient, or agent acting for such recipient, related to any activity designed to influence the enactment of legislation, appropriations, regulation, administrative action, or executive order proposed or pending before any legislative body.
    - See Anti-Lobbying Restrictions for CDC Grantees.
- For guidance on some types of costs that we restrict or do not allow, see 2 CFR Part 200 Subpart E - General Provisions for Selected Items of Cost.

## Indirect costs

Indirect costs are those shared across multiple projects and not easily separated. Learn more at CDC Budget Preparation Guidelines.

To charge indirect costs you can select one of two methods:

**Method 1 — Approved rate**. If you currently have an indirect cost rate approved by your cognizant federal agency, you may use that rate.

Enclose a copy of the current approved rate agreement in your attachments.

**Method 2 — *De minimis* rate.** If you do not have a current negotiated indirect cost rate, you may elect to charge a *de minimis* rate(see 2 CFR 200.414(f)). This rate may be up to 15% of modified total direct costs (MTDC). See the definition of MTDC (2 CFR 200.1). You can use this rate indefinitely.

### Other indirect cost policies

As described in 2 CFR 200.403(d), you must consistently charge items as either indirect or direct costs and may not double charge.

Indirect costs may include the cost of collecting, managing, sharing, and preserving data.

## Salary rate limitation

The salary rate limitation in the current appropriations act applies to this program. As of January 2026, the salary rate limitation is $228,000. We update this limitation when it changes.

## Program income

If you earn any money from your award-supported project activities (known as program income), you must use it for the purposes and under the conditions of the award. Find more about program income at 2 CFR 200.307.

## Expanded authority

For more information on expanded authority and pre-award costs, see the HHS Grants Policy Statement and speak to the grants management contact.

Pre-award costs may be allowable as an expanded authority, but only if we authorize the costs.

# Statutory authority

This program is authorized under Sections 301 and 317C of the Public Health Service Act, (42 USC Sections 241 and 247b-4).

More specifically, as set out in 317C(a)(2), CDC acting through the Secretary is authorized to:

- Collect and analyze data on birth defects and developmental disabilities.
- Operate regional centers for the conduct of applied epidemiological research on the prevention of birth defects and developmental disabilities.
- Provide information and education to the public on the prevention of birth defects and developmental disabilities.

# Step 2:
# Get Ready to Apply

### In this step

# Get registered

## SAM.gov

You must have an active account with SAM.gov to apply. SAM.gov registration can take several weeks. Begin that process today.

To register:

- Go to SAM.gov Entity Registration and select Get Started. From the same page, you can also select the Entity Registration Checklist for the information you will need to register.
- You must agree to the financial assistance general certifications and representations specifically. Those for contracts are different.

When you register, you will also receive your required Unique Entity Identifier (UEI).

Once you register:

- You will have to maintain your registration throughout the life of any award.
- If your organization has multiple UEIs, use the one associated with your physical location.

## Grants.gov

You must also have an active account with Grants.gov. You can see step-by-step instructions at the Grants.gov Quick Start Guide for Applicants.

**Need help?** See Contacts and Support.

# Find the application package

You can find it online. Go to Grants Search at Grants.gov and search for opportunity number CDC-RFA-DD-26-0222. After opening the opportunity, select the “package” tab to see the forms.

We recommend that you select the Subscribe button from the View Grant Opportunity page for this NOFO to get updates.

If you can’t use Grants.gov to download application materials or have other technical difficulties, including issues with application submission, contact Grants.gov for assistance.

# Help applying

For help related to the application process and tips for preparing your application, see How to Apply on our website. For other questions, see Contacts and Support.

# Join the informational call

For more information about this opportunity, join our informational call.

Join Zoom meeting.

- **Date:** Thursday, September 17, 2026
- **Time:** 2 to 3 p.m.ET

If you are not able to join through your computer, you can call in.

- **Phone number:**
  - 1 404-498-3000,,655577698# United States, Atlanta
  - (888) 994-4478,,655577698# United States (Toll-free)
  - Find a local number
  - Phone conference ID: 655 577 698#
- **Meeting ID:**271 787 011 563 234
- **Passcode:** M82f3cu6

We will record the webinar. If you are not able to join live, you can replay it .

The goals of this session are to review the NOFO's key content, walk through major requirements, and highlight important deadlines to ensure applicants have a clear understanding of the opportunity and the application deadline. Joining and participating is voluntary and does not affect eligibility, application scoring, or award selection. You can attend anonymously.

# Step 3:
# Build Your Application

### In this step

# Application checklist

This checklist includes every component you will need to submit a complete application:

## Narratives

| Item | Grants.gov form | Page limit | Responsiveness factor? |
|---|---|---|---|
| ☐ Project summary | Project Abstract Summary form | 1 page | No |
| ☐ Project narrative | Project Narrative Attachment form | 20 pages | Yes |
| ☐ Budget narrative | Budget Narrative Attachment form | None | Yes |

## Attachments

Put all of your attachments into a single Other Attachments form.

| Attachments | Page limit | Responsiveness factor? |
|---|---|---|
| ☐ 1. Table of contents | None | No |
| ☐ 2. Responsiveness criteria | None | Yes |
| ☐ 3. Indirect cost agreement | None | No |
| ☐ 4. Resumes and job descriptions | None | Yes |
| ☐ 5. Organizational chart | None | No |
| ☐ 6. Letter(s) of commitment | None | Yes |
| ☐ 7. Report on overlap | None | No |
| ☐ 8. Data management plan | None | No |

# Other required forms

| Other forms | Grants.gov form | Responsiveness factor? |
|---|---|---|
| ☐ Application for Federal Assistance (SF-424) | Form SF-424 | Yes |
| ☐ Budget Information for Non-Construction Programs (SF-424A) | Form SF-424A | Yes |
| ☐ Disclosure of Lobbying Activities (SF-LLL) (if applicable) | Form SF-LLL | No |

See submission requirements and deadlines to see if there are other requirements beyond the application itself.

See responsiveness criteria to understand how they affect your application.

# Application contents and format

Applications include narratives, attachments, and other required forms. This section includes guidance on each.

You may apply to either Component A or B, or both. Submit a separate application for each component you apply to.

Identify the component you're applying for in the title of the document, as follows:

- Component A NSBPR
- Component B UMPIRE

Each application will be evaluated separately. If you get funding for one component, it doesn't guarantee the other will also be funded.

### Required format

Required format for project summary, project narrative, and budget narrative.

**Font:** Calibri

**File format:** PDF

**Size:** 12-point font
Footnotes and text in graphics may be 10-point.

**Ink color:** Black

**Spacing:** Single-spaced

**Margins:** 1-inch

Include page numbers.

# Project summary (0 points)

**Page limit:** 1

**File name:** Project summary

Provide a self-contained summary of your proposed project, including the purpose and outcomes. Do not include any proprietary or confidential information. We use this information when we receive public information requests about funded projects.

# Project narrative (100 points)

**Page limit:** 20

**File name:** Project narrative

Your project narrative must use the exact headings, subheadings, and order as follows.

| Evaluation criterion | Scoring |
|---|---|
| **Background and approach** | **40 points section total** |
| **Evaluation and performance measurement plan** | **25 points section total** |
| **Organizational capacity** | **35 points section total** |

# Background and approach (40 points)

**Table: Scoring criteria for Component A**

| Reviewers will evaluate the extent to which the applicant provides: | Point value |
|---|---|
| Describes a clear background problem and how their application will address it. | 2 points |
| Provides strategies, activities, and outcomes that are consistent with the program's logic model and appropriate to accomplish the project outcomes. | 3 points |
| Demonstrates ability and experience collecting longitudinal data on patients with spina bifida. | 4 points |
| Reports the number of individuals seen between 2020 and 2024. The proposed site should have at least 300 individuals with clinical SB surveillance data recorded. (≥300=10 pts; 200=6pts; 100=3pts)Note: more than one clinic (e.g. smaller clinics, pediatric or adult clinics) can join and apply to this NOFO as one organization. | 10 points |
| Shows the proportion of individuals with recorded data between 2020 and 2024, with more than five total visits. (≥50%=10; 25%=5; <5%=1) | 10 points |
| Describes the proposed site's population distribution by age and race/ethnicity. | 2 points |
| Describes their intent to adhere to the data system required by CDC and their ability to securely transfer data with limited identifiers to CDC for data quality checks and data pooling. | 4 points |
| Work plan is aligned with the strategies, activities, outcomes, and performance measures in the approach and is consistent with the content and format proposed by CDC. | 5 points |

**Table: Scoring criteria for Component B**

| Reviewers will evaluate the extent to which the applicant provides: | Point value |
|---|---|
| Describes a clear background problem and how their application will address it. | 3 points |
| Provides strategies, activities, and outcomes that are consistent with the program's logic model and appropriate to accomplish the project outcomes. | 3 points |
| Demonstrates ability and experience collecting longitudinal data on patients with spina bifida. | 8 points |
| Demonstrates that between 2020 and 2024, the proposed site had at least 20 individuals with myelomeningocele whose clinical data was recorded. | 12 points |

| Reviewers will evaluate the extent to which the applicant provides: | Point value |
|---|---|
| Describes the proposed site's population distribution by age and race/ethnicity. | 2 points |
| Describes their intent to adhere to the data system required by CDC and their ability to securely transfer data with limited identifiers to CDC for data quality checks and data pooling. | 5 points |
| Work plan aligns with the strategies, activities, outcomes, and performance measures in the approach and is consistent with the content and format proposed by CDC. | 7 points |

## Evaluation and performance measurement plan (25 points)

You must provide an evaluation and performance measurement plan. This plan describes how you will fulfill the requirements in the data, monitoring, and evaluation section of the program description.

**Table: Scoring criteria for Components A and B**

| Reviewers will evaluate the extent to which the applicant provides: | Point value |
|---|---|
| Their ability to collect the data needed for evaluation and performance measurement on the process and outcome measures specified. | 10 points |
| Their ability to report on process and outcome measures and demonstrate the outcome measures specified. | 8 points |
| How they will report and use performance measurement and evaluation findings to demonstrate outcomes and for continuous program quality improvement. | 7 points |

## Organizational capacity (35 points)

Describe how you will address the requirements in the organizational capacity section of the program description.

Describe how you will collaborate with programs and organizations, either internal or external to CDC. Explain how you will address the requirements in the collaborations section of the program description.

You must provide these attachments to support this section:

- Resumes and job descriptions
- Organizational chart

**Table: Scoring criteria for Component A**

| Reviewers will evaluate the extent to which the applicant provides: | Point value |
|---|---|
| Relevant experience and capacity to implement the activities and achieve the project outcomes. Experience includes management, administrative, and technical experience. | 10 points |
| Experience or capacity to implement the evaluation plan.<br><br>The applicant demonstrates their committed relationships with relevant specialists who will provide access to patients with SB and to the collection of data by providing at least one letter of commitment from a representative of the participating clinic or hospital system to participate as described. | 10 points |
| A staffing plan, including roles, that is sufficient to achieve the project outcomes and clearly defines staff roles.<br><br>A data coordinator should be included on staff, as well as a description of their capacity to support the implementation of data management and timely data submission to CDC.<br><br>A data analyst should be included on staff as well as a description of their capacity to support research analyses. | 8 points |
| An organizational chart that supports the structure. | 2 points |
| Collaborations that support the applicant's capacity or add value to the project. | 5 points |

**Table: Scoring criteria for Component B**

| Reviewers will evaluate the extent to which the applicant provides: | Point value |
|---|---|
| Relevant experience and capacity to implement the activities and achieve the project outcomes. Experience includes management, administrative, and technical experience. | 10 points |
| Experience or capacity to implement the evaluation plan.<br><br>The applicant also demonstrates their committed relationships with relevant specialists who will provide access to patients with SB and to the collection of data by providing at least one letter of commitment from a representative of the participating clinic or hospital system to participate as described. | 10 points |
| A staffing plan, including roles, that is sufficient to achieve the project outcomes and clearly defines staff roles.<br><br>A data coordinator should be included on staff, as well as a description of their capacity to support the implementation of data management and timely data | 8 points |

| Reviewers will evaluate the extent to which the applicant provides: | Point value |
|---|---|
| submission to CDC. The applicant should also include a pediatric urologist on staff and provide a copy of their curriculum vitae. | |
| An organizational chart that supports the structure. | 2 points |
| Collaborations that support the applicant's capacity or add value to the project. | 5 points |

# Budget narrative

**Page limit:** None

**File name:** Budget narrative

The budget narrative supports the information you provide in Budget Information for Non-Construction Programs (Standard Form 424-A). See other forms.

As you develop your budget, consider if the costs are reasonable and consistent with your project's purpose and activities. We will review your budget and approve costs prior to award.

The budget narrative must explain and justify the costs in your budget. Provide the basis you used to calculate costs. See CDC Budget Preparation Guidelines.

Your budget narrative must follow this format:

- Salaries and wages.
- Fringe benefits.
- Consultant costs.
- Equipment.
- Supplies.
- Travel.
- Other categories.
- Contractual costs.
- Total direct costs (total of all items).
- Total indirect costs.

See funding policies and limitations for policies you must follow.

# Attachments

You will upload attachments in Grants.gov using a single Other Attachments form. When adding the attachments to the form, you can use PDF, Word, or Excel formats.

## Table of contents

**File name:** Table of contents

Provide a detailed table of contents for your entire submission that includes all the documents in the application and all the headings in the project narrative section. There is no page limit.

## Responsiveness criteria

**File name:** Responsiveness criteria

Attach a one-page document describing how your application meets the basic requirements that must be met to move forward in the competition. See responsiveness criteria section.

## Indirect cost agreement

**File name:** Indirect cost agreement

If you include indirect costs in your budget using an approved indirect cost rate, include a copy of your current agreement approved by your cognizant agency for indirect costs. If you use the *de minimis* rate, do not submit this attachment.

## Resumes and job descriptions

**File name:** Resumes and job descriptions

For key personnel, attach resumes for positions that are filled. If a position isn't filled, attach the job description with qualifications and plans to hire.

## Organizational chart

**File name:** Organizational chart

Provide an organizational chart that describes your structure. Include any relevant information to help us understand how parts of your structure apply to your proposed project.

## Letters of commitment

**File name:** Letter of commitment (if you upload each letter separately, add the name of the supporting organization to each letter)

Attach **at least one** letter from a relevant organization supporting your organization's successful work.

## Report on overlap

**File name:** Report on overlap

You must provide this attachment only if you have submitted a similar request for a grant, cooperative agreement, or contract to another funding source in the same fiscal year and that request may result in any of the following types of overlap.

### Programmatic

They are substantially the same project.

A specific objective and the project design for accomplishing it are the same or closely related.

### Budgetary

You request duplicate or equivalent budget items that already are funded by another source or requested in the other submission.

### Commitment

Given all current and potential funding sources, an individual's time commitment exceeds 100%, which is not allowed.

We will discuss the overlap with you and resolve the issue before award.

## Bona fide agent documentation

If you are applying on behalf of another organization as their bona fide agent, you must include documentation that demonstrates your arrangement.

## Data management plan

**File name:** Data management plan

For all public health data you plan to collect, a data management plan (DMP) is required. See data management plan section for information on what to include in your DMP.

# Other required forms

You will need to complete some other forms. You will use the forms in Grants.gov. You can find them in the NOFO application package or review them and their instructions at Grants.gov Forms.

**Table: Required standard forms**

| Grants.gov form | Submission requirement |
|---|---|
| Application for Federal Assistance (SF-424) | With the application. |
| Budget Information for Non-Construction Programs (SF-424A) | With the application. |
| Disclosure of Lobbying Activities (SF-LLL) | If applicable, with the application or before award. |

## Important: public information

When filling out your SF-424 form, pay attention to Box 15: Descriptive Title of Applicant's Project.

We share what you put there with USAspending. This is where the public goes to learn how the federal government spends their money.

Instead of just a title, insert a short description of your project and what it will do.

See instructions and examples.

# Step 4: Understand Review, Selection, and Award

## In this step

# Application review

## Initial review

We will review your application to make sure that it meets the responsiveness criteria. If your application does not meet these criteria, we will not move it to the merit review phase.

**We will not review any pages over the page limit.**

## Scoring process

A panel reviews all applications that pass the initial review. They use the criteria outlined in Step 3: Build Your Application.

We do not consider **voluntary** cost sharing as part of the merit review process.

## Risk review

Before making an award, we review the risk that you will not manage federal funds prudently. We need to make sure you've handled any past federal awards well and demonstrated sound business practices.

We use the SAM.gov Responsibility / Qualification to check this history for awards. We also check Exclusions. You can comment on your organization's information in SAM.gov. We'll consider your comments before deciding about your level of risk.

We may ask for more information before award based on the results of the risk review.

If we find a significant risk, we may choose not to fund your application or to place specific conditions on the award.

You can see more details about risk review at 2 CFR 200.206.

# Selection process

We will fund applications in order by the rank that the review panel determines.

We may:

- Fund applications in whole or in part.
- Fund applications at a lower amount than requested.
- Decide not to allow a prime recipient to subaward if they may not be able to monitor and manage subrecipients properly.
- Fund no applications under this NOFO.

Our ability to make awards depends on available appropriations.

## Funding priorities for alignment with agency priorities

Before we make final funding decisions, CDC leadership will review all potential awards. They will check for:

- Adherence to applicable laws.
- Alignment to agency priorities (see Centers for Disease Control and Prevention (CDC) Priorities).

To the extent permitted by law and applicable court orders, award applications which are aligned with agency priorities will receive a funding priority. For example, applications that demonstrate the capacity to contribute high-quality longitudinal data and advance evidence-based understanding of long-term outcomes of individuals living with spina bifida will be eligible for a funding priority.

# Award notices

If we decide to award you funding, we will email a Notice of Award (NoA) to your authorized official.

We will notify you if your application is found not responsive or unsuccessful.

The NoA is the only official award document. It tells you the amount of the award, important dates, and the terms and conditions you need to follow. Until you receive the NoA, you don't have permission to start work.

By drawing down funds, you accept all terms and conditions of the award.

Learn more about NoA contents at Understanding Your Notice of Award at CDC's website.

# Step 5:
# Submit Your Application

### In this step

# Submission requirements and deadlines

## Application

**Due on Monday, October 26, 2026 at 11:59 p.m. ET.**

You must submit your application through Grants.gov. See get registered.

For instructions on how to submit in Grants.gov, see the Quick Start Guide for Applicants.

Keep in mind:

- Grants.gov creates a date and time record when it receives the application. If you submit the same application more than once, we will accept the last on-time submission.
- Your organization's authorized official must certify your application.
- Do not encrypt, zip, or password-protect any files.
- Make sure your application passes the Grants.gov validation checks, or we may not get it.

The grants management officer may extend an application due date based on emergency situations such as documented natural disasters or a verifiable widespread disruption of electric or mail service.

See Contacts and Support if you need help.

## Intergovernmental review

Executive Order 12372, Intergovernmental Review of Federal Programs does not apply to this NOFO. You do not need to take any action.

# Step 6: Learn What Happens After Award

### In this step

# Post-award requirements and administration

## Administrative and national policy requirements

There are important rules you need to read and know if you get an award. You must follow:

- All terms and conditions in the Notice of Award (NoA), including CDC General Terms and Conditions. The NoA includes the requirements of this NOFO.
- The rules listed in 2CFR 200, Uniform Administrative Requirements, Cost Principles, and Audit Requirements, effective October 1, 2025. These replace those in 45 CFR 75, with some exceptions in 2 CFR 300.
- The HHS Grants Policy Statement (GPS). This document includes policies relevant to your award. If there are any exceptions to the GPS, they'll be listed in your Notice of Award.
- All federal statutes and regulations relevant to federal financial assistance, including the cited authority in this award, the funding authority used for this award, and those highlighted in the HHS Grants Policy Statement, Appendix D: HHS Administrative and National Policy Requirements.
- All anti-discrimination laws: By applying for or accepting federal funds from HHS, recipients certify compliance with all federal antidiscrimination laws and these requirements and that complying with those laws is a material condition of receiving federal funding streams. Recipients are responsible for ensuring subrecipients, contractors, and partners also comply.

# Reporting

If you are successful, you will have to submit financial and performance reports. These include:

**Table: Financial and performance reports**

| Report | Description | When |
|---|---|---|
| Recipient Evaluation and Performance Measurement Plan | Builds on the plan in the application. Includes measures and targets. Shows how data are collected and used (data management plan). | Six months into award. |
| Annual Performance Report | Serves as yearly continuation application. Includes performance measures, successes, and challenges. Updates work plan. Includes how CDC could help overcome challenges. Includes budget for the next 12-month budget period. | No later than 120 days before the end of each budget period. |
| Annual Federal Financial Report (FFR) | Includes funds authorized and disbursed during the budget period. Indicates exact balance of unobligated funds and other financial information. | 90 days after the end of each budget period. |
| Data on Performance Measures | Includes information similar to the Annual Performance Report. | CDC will only require this report if the award needs more frequent reporting than in the Annual Performance Report. |
| Final Performance Report | Includes information similar to the Annual Performance Report. | 120 days after the end of the period of performance. |
| Final Federal Financial Report (FFR) | Includes information similar to the Federal Financial Report. | 120 days after the end of the period of performance. |
| Foreign Tax Report | Includes the amount of foreign taxes assessed, reimbursed, and unreimbursed by each foreign government. Also applies to subawards. | Annually by November 16. Quarterly by January 15, April 15, July 15, and October 15 each year. |

To learn more about these reporting requirements, see Reporting on the CDC website.

# CDC award monitoring

If you receive an award, CDC will monitor your activities. To learn more about CDC award management, see Resources for CDC Recipients.

# CDC's role

In a cooperative agreement, we are involved in program activities and will perform the following tasks:

- Provide technical help on the collection of longitudinal data from SB specialty clinics.
- Provide technical help on improving data quality.
- Provide a data dictionary and guidance on reporting data to CDC.
- Provide timelines for ongoing data transmission and other key activities.
- Store and manage data with limited identifiers collected by SB specialty clinics.
- Facilitate review of proposals to analyze multi-site data.
- Provide technical help on conducting analyses and sharing findings.
- Provide guidance for evaluation of the project.

# Contacts and Support

## In this step

# Agency contacts

## Program

**Matthew Williams**
vgx3@cdc.gov
770-448-2679

## Grants management

**Robyn Byrant**
ppa4@cdc.gov
770-488-2881

# Help with systems

## Grants.gov

Grants.gov provides 24/7 support. Hold on to your ticket number.

- Phone: 1-800-518-4726
- Email: support@grants.gov

## SAM.gov

If you need help, you can:

- Call 866-606-8220
- Live chat with the Federal Service Desk

# Helpful websites

- U.S. Department of Health and Human Services (HHS)
- CDC Dictionary of Terms
- CDC Grants: How to Apply
- CDC Grants: Already Have a CDC Grant?
- Grants.gov Accessibility Information
- Code of Federal Regulations (CFR)
- United States Code (U.S.C.)