

Transcript: NOFO Informational Webinar

Long-Term Health Outcomes of People Living with Spina Bifida

NOFO CDC-RFA-DD-26-0222

September 17, 2026 | Informational call | Approximately 30 minutes

Reader note: This is a cleaned AI generated transcript intended for readability, not a certified verbatim transcript. Obvious spelling and automated-transcription errors have been corrected, and repetitive presentation cues have been reduced where they did not affect meaning.

OPENING, PURPOSE, AND PROGRAM OVERVIEW

Kyle Lloyd Kilvington (CDC/NCBDDD/DBDID), Contractor | 0:05

Our goal today is to help you understand this funding opportunity, its requirements, review criteria, and deadlines. We will begin with an overview and funding details, then explain the program approach for Components A and B, eligibility and responsiveness, the application package, scoring, submission and review, and finally post-award expectations.

Participation in today's call is voluntary and does not affect eligibility or scoring. This presentation summarizes the NOFO, so please refer to the published document for full details.

Component A focuses on collecting high-quality longitudinal data in the National Spina Bifida Patient Registry (NSBPR) at clinics serving children and adults with spina bifida. Component B focuses on implementing and evaluating the Urologic Management to Preserve Initial Renal Function (UMPIRE) protocol for infants and young children with myelomeningocele, with the goal of preserving renal function.

Applicants may apply for Component A, Component B, or both, but a separate application is required for each component. The overall purpose is to ensure long-term follow-up and improve health outcomes for people living with spina bifida.

KEY DATES AND FUNDING DETAILS

The informational call is September 17, 2026. An optional letter of intent is due September 26, 2026. Applications are due October 26, 2026, by 11:59 p.m. Eastern Time. Awards are expected to be announced around August 1, 2027, with a projected project start date of September 1, 2027.

Applicants who have not already done so should register with SAM.gov and Grants.gov early, because access may take a week or two.

For Component A, CDC expects to make approximately 8 to 11 awards over a three-year period, with total program funding ranging from \$2.4 million to \$6.6 million. Each recipient may receive approximately \$300,000 to \$600,000 over the three-year period, or about \$100,000 to \$200,000 per year.

For Component B, CDC expects to make approximately 6 to 9 awards, with total program funding ranging from \$900,000 to \$2.7 million. Each recipient may receive approximately \$150,000 to \$300,000 over the three-year period, or about \$50,000 to \$100,000 per year.

These are cooperative agreements with no cost-sharing requirement. Awards depend on available funds and program priorities.

PROGRAM APPROACH AND BACKGROUND

Jacqueline Mix (CDC/NCBDDD/DBDID) | 3:37

The National Spina Bifida Patient Registry, or NSBPR, was established in 2008. The registry tracks health status, clinical interventions, and outcomes among children and adults with spina bifida who receive care in specialized spina bifida clinics. The NSBPR currently includes more than 12,000 participants.

The UMPIRE protocol, established in 2014, is a standardized protocol involving monitoring and testing of the urinary system to preserve kidney function. UMPIRE has enrolled more than 600 infants and young children and has recorded more than 4,000 encounters over the years.

NSBPR and UMPIRE have helped identify best practices for people living with spina bifida, but more work is needed. Much of the analysis and publication to date has been descriptive. Additional longitudinal data collection and analysis are needed to identify health care and clinic practices associated with the best outcomes for individuals with spina bifida. Additional years of NSBPR and UMPIRE data will also provide insight into long-term outcomes, and continued evaluation and refinement of UMPIRE will help identify the best possible course of care for infants and children with myelomeningocele.

The program approach centers on three strategies:

- Collect longitudinal data by following enrolled participants, reducing loss to follow-up, and approaching all eligible participants for enrollment in NSBPR.
- Manage and report standardized, validated data with limited identifiers on a monthly basis using CDC tools; conduct data-quality checks and resolve data errors.
- Analyze pooled data and share findings through presentations and publications while collaborating with CDC and other recipients and participating in meetings, committees, and workgroups.

COMPONENT A: NSBPR ACTIVITIES

For Component A, recipients will collect follow-up visit data for children and adults already enrolled in NSBPR. They will perform activities to enhance study retention and collect information on participants lost to follow-up.

Additional data activities include reporting minimal, non-identifiable data on eligible individuals who are not enrolled; describing capacity for optional data-collection efforts; and, where applicable, collecting information on skin breakdown, quality of life, sleep-disordered breathing, and cognitive and adaptive testing. Activities may also include linking with state death records or the National Death Index to identify deaths among enrolled participants.

Recipients will also develop proposals and analytic plans using pooled NSBPR data, analyze and interpret findings, and present findings to key audiences each year.

COMPONENT B: UMPIRE ACTIVITIES

For Component B, recipients will conduct protocol follow-up activities by collecting longitudinal data for enrolled UMPIRE participants. They will also work to improve participant retention by conducting or enhancing follow-up activities intended to increase the likelihood that patients return to the clinic, including reporting additional information on participants lost to follow-up.

Recipients will collect information on and document protocol deviations, including the type of deviation and the reason for it. Data-management activities include using CDC forms and data systems, submitting validated data with limited identifiers, conducting monthly data-quality checks, and participating in CDC trainings.

Another key activity is evaluating and refining UMPIRE. Recipients will collaborate on analytic plans and pooled analyses, use results to refine the UMPIRE protocol, and share findings annually.

PERFORMANCE MEASURES, WORK PLAN, EVALUATION, AND DATA MANAGEMENT

Over the three-year performance period for both Components A and B, expected outcomes include improved data quality, increased information for clinical decision-making, an improved science base for spina bifida care, and greater awareness of findings among key audiences.

Draft performance-measure targets include decreasing the number of participants not seen in the last three years, increasing recent visits, producing timely and validated data extracts, and completing at least one manuscript and presentation each year. These measures are draft and may be refined with recipients before reporting is required.

Applicants must provide a work plan that connects outcomes, strategies, activities, and performance measures. The application should include a detailed work plan for the first year and a high-level plan for subsequent years. The published NOFO includes a sample table that may be used as a template.

CDC will collect and report indicators to measure progress toward activities and outcomes and will use this information for program planning, improvement, accountability, and reporting. Applicants must submit an evaluation and performance-measurement plan aligned with the logic model, including personnel, timelines, expected outcomes, and how findings will be used for improvement. CDC expects approximately 5% to 10% of project funding to be dedicated to monitoring and evaluation.

A data management plan is also required for public health data collected. The plan should address data sources, access, standards, preservation, sharing limitations, and how the plan will be updated as new information becomes available during the life of the project.

ELIGIBILITY AND RESPONSIVENESS

The eligibility information presented on the call is not an exhaustive list; applicants should consult the published NOFO for full eligibility requirements.

Eligible organizations include state, county, city, and special-district governments; independent school districts; public and private institutions of higher education; tribal governments and organizations; housing authorities; nonprofit organizations; for-profit organizations and small businesses; and bona fide agents of eligible government organizations. Each organization may submit one application per component, for up to two applications total.

All applications must meet eligibility requirements, be submitted on time, and include a document labeled “Responsiveness Criteria” for each component.

For Component A, the responsiveness criteria should include the number of participants currently enrolled in NSBPR with at least one registry visit between January 2020 and August 2024; the proportion of individuals seen during that period who had more than five visits; and at least one letter of commitment from a representative of the participating clinic or hospital system documenting access to patients with spina bifida and access to the data elements included in NSBPR.

For Component B, the responsiveness criteria should include the number of patients previously enrolled in UMPIRE with a diagnosis of myelomeningocele who had at least one visit between January 2020 and August 2024; the CV of a pediatric urologist who is part of the study team; and at least one letter of commitment from a representative of the participating clinic or hospital system documenting access to patients with spina bifida and access to the data elements included in UMPIRE.

APPLICATION PACKAGE AND SCORING

Jennifer Knapp (CDC/NCBDDD/DBDID) | 15:11

The application package should include a one-page project summary, a project narrative of no more than 20 pages, and a budget narrative with no stated page limit. Attachments should be submitted in PDF format.

Other materials include a table of contents, the responsiveness criteria document, indirect cost agreements if applicable, resumes and/or job descriptions for participating individuals, an organizational chart, letters of commitment, a report on overlap if applicable, and a data management plan. Standard Forms SF-424 and SF-424A are responsiveness factors; include the SF-LLL if applicable.

The project narrative is scored as follows: 40 points for Background and Approach, 25 points for the Evaluation and Performance Measurement Plan, and 35 points for Organizational Capacity. Applicants should use the exact headings, subheadings, and order specified in the NOFO.

Formatting requirements include Calibri 12-point font; graphics and footnotes may use 10-point font; single spacing; black text; 1-inch margins; and page numbers. Materials should be submitted as PDFs, with separate applications for each component for which the organization applies.

REVIEW EMPHASIS, STAFFING, AND COLLABORATION

For Component A, reviewers will emphasize the number of individuals with clinical spina bifida surveillance data and the proportion with more than five visits. For Component B, reviewers will look for at least 20 individuals with myelomeningocele and recorded clinical data. Longitudinal-

data experience, secure data transfer, and an aligned work plan are also substantial scoring elements.

Evaluation and performance review will consider the ability to collect specified measures, report outcomes, and use findings for continuous improvement. Organizational capacity will be scored on relevant management and administrative capacity, technical experience, evaluation capacity, special relationships, the staffing plan, the organizational chart, and collaborations that add value.

For both components, applicants should clearly define staff roles, level of effort, and whether staff are existing personnel or planned hires. A data coordinator capable of timely data management and data submission should be included. Applicants should demonstrate relationships with specialists, access to patients and/or their data, and capacity to develop peer-reviewed scientific manuscripts.

Component A should include data-analysis and analytic capacity and a named data analyst. Component B should include a pediatric urologist and a close connection with the initial screening hospital or clinic. Recipients should maintain partnerships with clinicians and patient-support groups and collaborate with CDC and other recipients.

BUDGET AND AGENCY PRIORITIES

The budget narrative should explain and justify each cost and calculation using the required NOFO categories. For indirect costs, applicants should use their approved negotiated rate or, if eligible, up to the 15% de minimis rate applied to modified total direct costs.

The salary rate limitation stated for 2026 is \$228,000. Funds may not be used for clinical care except as allowed by law, and pre-award costs require authorization. Federal anti-lobbying requirements and cost principles apply. Support beyond year one depends on appropriations, progress, and priorities.

Funded activities must align with CDC priorities, applicable laws and regulations, and award terms. The NOFO emphasizes gold-standard science, transparency, evidence-based practice, data modernization, integrity, accountability, and compliance. CDC leadership reviews awards for legal compliance and alignment. Applications demonstrating capacity to contribute high-quality longitudinal data and an advanced evidence-based understanding of long-term outcomes may receive funding priority.

SUBMISSION, REVIEW, AND AWARD

Applications must be submitted through Grants.gov by October 26, 2026, before 11:59 p.m. Eastern Time. The authorized official must certify the application. Do not encrypt, zip, or password-protect files. Ensure that the submission passes all Grants.gov validation checks. If an application is resubmitted, CDC accepts the last on-time submission.

Maintain active SAM.gov and Grants.gov registrations, use the correct application package, and subscribe to the Grants.gov opportunity for updates.

CDC first checks responsiveness criteria. Nonresponsive applications do not advance, and pages over the stated limit are not reviewed. Panels then score responsive applications using the

published criteria. CDC conducts a pre-award risk review, including SAM.gov responsibility and qualification information.

Applications are generally funded in rank order, subject to appropriations and priorities. CDC may fund an application in whole or in part, may fund it at a lower amount, or may make no award. The Notice of Award is the only official award document.

POST-AWARD EXPECTATIONS AND CLOSING GUIDANCE

After award, recipients must submit a detailed evaluation and performance-measurement plan within six months, annual performance and financial reports, and a final report after the period of performance.

CDC provides technical assistance for data collection and quality, data dictionaries and reporting guidance, timelines for data transmission, storage and management of limited-identifier data, facilitation of multisite analysis proposals, and support for analysis, dissemination, and evaluation.

In closing, applicants should choose the component or components that match their patient population, expertise, and capacity; treat responsiveness criteria as a gate; assemble required counts, CVs, and commitment letters early; and build the narrative around the published scoring criteria, especially longitudinal-data capacity and the work plan.

Applicants should plan from day one for monthly data submission, data-quality work, pooled analysis, dissemination, and evaluation; register early; follow formatting guidelines; validate the Grants.gov submission; and submit before the deadline.

QUESTIONS AND CONTACT INFORMATION

Participants were invited to submit questions in the Q&A portion of the meeting. The meeting remained open briefly to allow participants to formulate and type questions, and responses were to be compiled afterward.

For additional questions after the meeting, the presenters directed program questions to Matthew Williams at vgx3@cdc.gov and grants-management questions to Robin Bryant at ppa4@cdc.gov. The call also referenced Grants.gov and SAM.gov support resources. Applicants were directed to search Grants.gov for CDC-RFA-DD-26-0222 for application materials and updates. Answers to written questions were to be posted on the CDC website at the link shown in the presentation slides.

Matthew R. Williams (CDC/NCBDDD/DBDID) | 27:44

Thank you, Jennifer, and thank you everyone for joining. This concludes our informational presentation. If you would like to submit a question, please feel free to do so. We will leave the meeting open for the next few minutes to compile those questions. As Jennifer mentioned, we will compile the questions and publish them on the website shown on the screen. Thank you, everyone.