Sickle Cell Disease Transition in Care
Quality Improvement Grant Program/Request for Proposals

Introduction:

Pfizer and National Alliance of Sickle Cell Centers are collaborating to offer a new grant opportunity seeking proposals for quality improvement initiatives that will increase the number of sickle cell centers with successful transition programs focusing on adult care.

National Alliance of Sickle Cell Centers

National Alliance of Sickle Cell Centers' (NASCC) mission is to support sickle cell disease centers in providing high-quality comprehensive care by setting standards of care and promoting their adoption, identifying opportunities and resources to strengthen sickle cell disease centers, and advocating for access to comprehensive care to improve patient health outcomes, quality of life, and survival.

Pfizer

Pfizer Global Medical Grants (GMG) supports the global healthcare community's independent initiatives (e.g., research, quality improvement or education) to improve patient outcomes in areas of unmet medical need that are aligned with Pfizer's medical and/or scientific strategies.

Grants will be awarded in support of organizations/institutions working to improve the competence and performance of both the healthcare professionals and healthcare systems in which they work with the goal of optimizing the care and outcomes of individuals living with sickle cell with special focus on transition from pediatric to adult care.

For all quality improvement grants, the grant requester (and ultimately the grantee) is responsible for the design, implementation, and conduct of the independent initiative supported by the grant. Pfizer must not be involved in any aspect of project development, nor the conduct or monitoring of the quality improvement program.

Pfizer and NASCC are jointly issuing this Request for Proposal (RFP). Grant funding will be provided directly from Pfizer. NASCC will select the Expert Review Panel (ERP), create a community of practice for the selected Grantees and share existing knowledge and tools related to transition in care programs.

I. Eligibility

Geographic Scope/Location of Project:

- United States

Applicant Eligibility Criteria

- The following may apply: medical, nursing, allied health, and/or pharmacy professional schools; healthcare institutions (both large and small); professional organizations; government agencies; and other entities with a mission related to healthcare improvement.
- Only organizations are eligible to receive grants, not individuals or medical practice groups (i.e., an independent group of physicians not affiliated with a hospital, academic institution, or professional society).
- The applicant must be the Project Lead/Principal Investigator (PI) or an authorized designee of such individual (e.g., Project Lead/PI's grant/research coordinator).
- The Project Lead/PI must be an employee of the requesting organization.

II. Requirements

Date RFP Issued

- July 24, 2024

Clinical Area

- Sickle cell disease (SCD)

Specific Area of Interest for this RFP:

- A successful transition from pediatric to adult sickle cell disease (SCD) care is crucial to ensure quality care and continued improvements in care for individuals living with sickle cell. Transition from pediatric to adult care is a difficult time for young adults. With this in mind, it is our intent to support projects that focus on:
  - decreasing the quality gap in sickle cell disease transition from pediatric to adult care
  - establishing coordinated care for individuals living with sickle cell beyond acute care service.
  - Identifying tools to improve success of transfer/ transition to and subsequent engagement in adult care using the following definitions of successful transfer/transition **as determined by consensus by NASCC centers**:
    - Recommendation: A successful transfer of care is defined as 2 visits with a comprehensive adult sickle cell program in the first year. Visits can be in person or via telemedicine
    - Recommendation: A successful transition of care or integration to adult care is defined as completion of at least 50% of annual comprehensive visits in the 5-year period after transfer of care and the patient identification of the adult center as their sickle cell medical home

It is not our intent to support clinical research projects. Projects evaluating the efficacy of therapeutic or diagnostic agents will not be considered. Additional examples of out-of-scope projects include clinical research projects, basic science research, prevalence studies, and registry development.

Target Audience

- Healthcare teams providing care to young adults/adults living with sickle cell disease

Disease Burden Overview

- Sickle cell disease (SCD) affects about 100,000 people in the United States; more than 90% are non-Hispanic Black or African American, and an estimated 3%–9% are Hispanic or Latino.[1]
- Among individuals with SCD, a rise in mortality occurs in the early young adulthood years (ages 20 to 24 years)[2]
- During this transition period, there is an increase in disease severity and acute care utilization rises with significantly higher hospital admissions[2, 3]

Recommendations

- The NASCC pediatric and adult recommendations recommend the presence of both a pediatric and adult transition coordinator (www.sicklecellcenters.org) however this is not consistently implemented.

Barriers

Socio-Behavioral Factors

- Low patient engagement[2,3,4]
- Fear of being able to establish trust with a new provider[3]
- Lack of preparedness – disease knowledge, self assurance skills[2,5]
- Patient beliefs – anxiety or fear of new provider and navigating new health care system[2,4,5]

Health System Factors

- Structural, institutional, and interpersonal racism, that interacts and exacerbates stigma associated with the disease condition and the needs of pain treatment[6]
- Lack of specialized adult providers[2]
- Loss of insurance coverage[3,6]
- Poor care coordination[2]
- Many individuals living with sickle cell are transferred to a general internist for their adult care but few internists express comfort in being the primary provider for individuals living with sickle cell[4]

Current National Efforts to Reduce Gaps

- Got Transition®: The National Alliance to Advance Adolescent Health (**https://www.gottransition.org/**)

Expected Approximate Monetary Range of Grant Applications:

- Individual projects requesting up to $75,000 will be considered. We anticipate funding 2-3 projects.
- Award amounts include direct costs, institutional overhead costs (capped at 11%), and indirect costs.
- The amount of the grant Pfizer will be prepared to fund for any project will depend upon the expert review panel's evaluation of the proposal and costs involved and will be stated clearly in the grant agreement.

Length of Projects:

- Proposed QI projects should be conducted within a 12 timeframe to allow for a meaningful data collection period. An additional 3 months for outcomes/evaluation can be included.

Key Dates:

- RFP Release Date: **July 24, 2024**
- Application Due Date: **September 10, 2024**
    - Please note the deadline is 23:59 Eastern Standard Time (e.g., New York, GMT -5).
- Review of Proposals by Expert Review Panel: **September/October 2024**
- Anticipated Notification Date: **October 2024**
- Anticipated Project Start Date: **December 2024**
    - Selected Grantees will work with NASCC regarding potential presentation about their projects at NASCC 5th Annual Member Center and Consensus Recommendations Conference: **July 2026**

How to Submit:

Note: Please read this section carefully since applications submitted not following these instructions will not be accepted and will be cancelled.

- Please go to www.cybergrants.com/pfizer/QI and sign in. First-time users should click “Create your password”. *[Note: there are individual portals for each grant application type. Please be sure to use the URL above.]*
- Click the "Start a New Quality Improvement Application" button.
- In the application:
    - For the question “Competitive Grant?” select Yes
    - Select the following Competitive Grant Program Name: 2024 RD US NASCC SCD Transitions in Care QI
- Requirements for submission:

  Complete all required sections of the online application and upload your project proposal (see Appendix) in the Full Proposal Submission field.
- If you encounter any technical difficulties with the website, please click the “Technical Questions” link at the bottom of the page.

IMPORTANT: Be advised applications submitted after the due date will not be reviewed

Questions:

- If you have questions regarding this RFP, please direct them in writing to the NASCC President, Julie Kanter MD (jkanter@sicklecellcenters.org) and Pfizer Grant Officer, Amanda Stein (amanda.j.stein@pfizer.com) , with the subject line “SCD Transitions in Care QI”.”

Grant Agreements:

- If your grant is approved, your institution will be required to enter into a written grant agreement with Pfizer. Please click here to view the core terms of the agreement.
- The agreement is expected to be signed by both parties within 2024 and without change.
- Under Pfizer's competitive grant program, modifications to grant agreements will not be reviewed unless a genuine conflict exists as between applicable law and the terms of the relevant grant

agreement. Applicant is encouraged to share the core terms with counsel for approval prior to submitting an application.

- Except where prohibited by applicable law and, in any case, subject to review by Pfizer Legal, payment of grant funding may only be paid to the grantee organization.

Review and Approval Process

- A specific grant program RFP uses an expert review panel (ERP) to make final grant decisions.
- The panels are comprised of professionals from the medical community with advanced degrees and expertise in sickle cell disease affiliated with the National Alliance of Sickle Cell Centers as well as one Pfizer Medical Affairs colleague.
- The panel will review submitted proposals in accordance with National Institute of Health (NIH) Simplified Framework for Peer Review

Mechanism by which Applicants will be Notified:

- All applicants will be notified via email by the dates noted above.
- Applicants may be asked for additional clarification during the review period.

References

1. Data and statistics on Sickle Cell Disease. Centers for Disease Control and Prevention. May 15, 2024. Accessed July 9, 2024. https://www.cdc.gov/sickle-cell/data/index.html.
2. Saulsberry AC, Porter JS, Hankins JS. A program of transition to adult care for sickle cell disease. Hematology Am Soc Hematol Educ Program. 2019 Dec 6;2019(1):496-504. doi: 10.1182/hematology.2019000054. PMID: 31808907; PMCID: PMC6913425.
3. Cronin RM, Hankins JS, Byrd J, Pernell BM, Kassim A, Adams-Graves P, Thompson A, Kalinyak K, DeBaun M, Treadwell M. Risk factors for hospitalizations and readmissions among individuals with sickle cell disease: results of a U.S. survey study. Hematology. 2019 Dec;24(1):189-198. doi: 10.1080/16078454.2018.1549801. PMID: 30479187; PMCID: PMC6349225.
4. Lebensburger JD, Bemrich-Stolz CJ, Howard TH. Barriers in transition from pediatrics to adult medicine in sickle cell anemia. J Blood Med. 2012;3:105-12. doi: 10.2147/JBM.S32588. Epub 2012 Sep 19. PMID: 23055784; PMCID: PMC3460672.
5. Bemrich-Stolz CJ, Halanych JH, Howard TH, Hilliard LM, Lebensburger JD. Exploring Adult Care Experiences and Barriers to Transition in Adult Patients with Sickle Cell Disease. Int J Hematol Ther. 2015;1(1):10.15436/2381-1404.15.003. doi: 10.15436/2381-1404.15.003. Epub 2015 Sep 6. PMID: 26900602; PMCID: PMC4756764.
6. Calhoun C, Luo L, Baumann AA, Bauer A, Shen E, McKay V, Hooley C, James A, King AA. Transition for Adolescents and Young Adults With Sickle Cell Disease in a US Midwest Urban Center: A Multilevel Perspective on Barriers, Facilitators, and Future Directions. J Pediatr Hematol Oncol. 2022 Jul 1;44(5):e872-e880. doi: 10.1097/MPH.0000000000002322. Epub 2021 Sep 22. PMID: 35731941; PMCID: PMC9218344.

Appendix

Specific RFP Submission Requirements

Applications will be accepted via the online portal listed in the How to Submit section. Project Proposals/Protocols should be single-spaced using Calibri 12-point font and 1-inch margins. Note there is a 12-page limit exclusive of references. When uploading your Full Proposal please ensure it addresses the following sections:

Goals and Objectives

- Briefly state the overall goal of the project. Also describe how this goal aligns with the focus of the RFP and the goals of the applicant organization(s).
- List the overall objectives you plan to meet with your project both in terms of learning and expected outcomes. Objectives should describe the target population as well as the outcomes you expect to achieve as a result of conducting the project.

Assessment of Need for the Project

- Please include a quantitative baseline data summary, initial metrics (e.g., quality measures), or a project starting point (please cite data on gap analyses or relevant patient-level data that informs the stated objectives) in your target area. Describe the source and method used to collect the data. Describe how the data was analyzed to determine that a gap existed. If a full analysis has not yet been conducted, please include a description of your plan to obtain this information.

Target Audience

- Describe the primary audience(s) targeted for this project. Also indicate whom you believe will directly benefit from the project outcomes. Describe the overall population size as well as the size of your sample population

Project Design and Methods

- Describe the planned project and the way it addresses the established need.
- If your methods include educational activities, please describe succinctly the topic(s) and format of those activities.

Innovation

- Explain what measures you have taken to assure that this project idea is original and does not duplicate other projects or materials already developed.
- Describe how this project builds upon existing work, pilot projects, or ongoing projects developed either by your institution or other institutions related to this project.

Evaluation and Outcomes

- In terms of the metrics used for the needs assessment, describe how you will determine if the practice gap was addressed for the target group. Describe how you expect to collect and analyze the data.
- Quantify the amount of change expected from this project in terms of your target audience.
- Describe how the project outcomes will be broadly disseminated.

Anticipated Project Timeline

- Provide an anticipated timeline for your project including key activities/milestones and start/end dates.

Additional Information

- If there is any additional information you feel Pfizer/NASCC should be aware of concerning the importance of this project, please summarize here.

Organization Detail

- Describe the attributes of the institutions / organizations / associations that will support and facilitate the execution of the project and the leadership of the proposed project. Articulate the specific role of any partner in the proposed project.

Budget Detail

- The budget amount requested must be in U.S. dollars (USD).
- While estimating your budget please keep the following items in mind:
  - General organizational running costs such as legal fees, insurance, heating, and lighting etc. should be included in an Institutional Overhead (if required). These costs are not specific to a grant request and therefore, should not appear as line items in budgets. However, costs that are specific to the study (e.g., some countries require insurance to be taken out on a per-study basis for clinical research) would be acceptable to be included as line items.
    - The inclusion of overhead costs cannot cause the amount requested to exceed the budget limit set forth in the RFP.
  - Pfizer does not provide funding for capital purchases (infrastructure expenses such as equipment, purchases of software or software licenses, technology or bricks and mortar). Equipment hire/leasing is acceptable and may be included in project budget.
  - It should be noted that grants awarded through GMG cannot be used to purchase Pfizer therapeutic agents (prescription or non-prescription).
- The maximum allowable budget overhead under this mechanism is an 11% indirect rate.