

1. When I saw the announcement, I assumed that this was new multi-year funding from HRSA to continue the program. I'd previously seen the forecast in a link that you'd sent and was a little confused. However, I did see your link and explanation in the RFP documents. Could you confirm that this is not the HRSA continuation grant?

This RFP is part of the current 2017-2021 Health Resources and Services Administration (HRSA) grant. The funding must be spent by May 31, 2021. Any new community based organizations (CBOs) who are selected will join the current 16 organizations on the grant. We're looking forward to the next iteration of HRSA funding but don't have additional information on it yet.

2. Is the funding for this grant part of SCDAAs spend down?

No, this funding is not part of SCDAAs spend down.

3. If a currently funded CBO applies, is there an expectation that there will be a comparable increase in the number of newly identified individuals (inactive)?

The goal of this funding is to reach and serve more clients than we are currently reaching. We believe newly-funded CBOs can do this by reaching clients in new communities. Currently funded CBOs may consider increasing hours for community health workers (CHWs), using social media advertising, or other innovative strategies to reach individuals. Because the goal of the additional funding is to reach more clients, we would expect that an increase in funding is tied to an increase in clients reached.

4. How will considerations of the outreach restrictions imposed by the current pandemic be made regarding individuals reached (again the focus is on inactive and not ongoing care coordination)?

We will consider an organization's work plan and proposed activities in light of the current pandemic restrictions. We are not requiring any travel or in-person interaction as part of the activities. We echo HRSA's statements from this spring; our first priority is the health and safety of staff, contractors, clients, and volunteers. We understand that activities will be impacted by local policies and guidelines. We are ready to assist in brainstorming new ways to conduct outreach virtually or through social distancing.

5. If an organization desiring to hire and utilize CHWs would like to apply but may not meet all of the capacity requirements to qualify, could another organization serve as a fiscal agent?

We would love to work with smaller organizations, but at this time the applicants must meet the eligibility requirements outlined in the RFP. We hope to highlight how more established CBOs can contribute to capacity building for smaller groups so that they could be eligible in the future.

6. Does the fiscal agent have to be a CBO (e.g. could it be a hospital)?

Yes, the sub-grantee funded by SCDA must be a CBO who meets the eligibility criteria outlined in the RFP.

7. Can the funding be used for something like a transition liaison who works with pediatric and adult care centers to more aggressively get transitioning adults into care after leaving pediatric care?

Yes, this person could be an employee or a contractor of the CBO.

8. Can you provide definitions of medical home, counseling, and education?

Medical home: A medical home is not a physical structure but an approach to the provision of coordinated, comprehensive, culturally competent and family-centered care using seven principles: (1) access to a personal physician; (2) physician-directed medical practice; (3) whole-person orientation, (4) coordinated and/or integrated care; (5) quality and safety as hallmark; (6) enhanced access to care; and (7) ensuring patient insurance coverage.

A successful medical home for individuals with sickle cell disease: (1) provides care coordination and health promotion using evidence-based treatment for sickle cell and non-sickle cell related health issues; (2) provides sickle cell disease health education and outreach with input from patient and community-based groups; (3) performs routine screening and testing for sickle cell disease and its complications; (4) assists with transition services; and (5) engages in efforts that help identify the sickle cell population and ensure patients have access to services.

Counseling: The provision of assistance and guidance around a particular topic, especially for young adult transition, sickle cell trait, or psychosocial needs. Counseling should be delivered by a CBO to individuals with sickle cell disease and their families.

Education: The provision of information about sickle cell disease, sickle cell trait, hydroxyurea, genetic counseling, or other related topics. Education should be provided by a CBO to individuals with sickle cell disease and their families.

9. Does this grant cover only newborns or people with sickle cell disease across the lifespan?

The primary population focus is families of individuals identified with sickle cell disease (SCD) through newborn screening; however, all individuals with SCD will be included. CBOs can work with individuals with SCD across the lifespan, including infants, children, teenagers, young adults, and adults.

Sickle Cell Disease Association of America
Sickle Cell Disease Newborn Screening Follow-Up Program
Grant No: SCDAANBS2020
Questions Received and Answered
Last updated October 9, 2020

10. Does SCDA expect HRSA to release a new NBS grant in January of next year; a grant that will continue after the current grant ends on May 31, 2021?

Yes. A new iteration of the Sickle Cell Disease Newborn Screening Follow-Up Program was recently announced by the Health Resources and Services Administration (HRSA). The funding forecast is available here: <https://www.grants.gov/web/grants/view-opportunity.html?oppld=328460>

At this time, SCDA does not have any more information than what is included in the forecast.

11. Is there a quota / target number of new clients to be reached during the project period? What about making contacts to existing clients?

Yes. Because the goal of the additional funding is to reach more clients, we would expect that an increase in funding would be tied to an increase in clients reached. SCDA would work with sub-grantees to determine this goal. A recruitment goal will be determined based on organizational capacity, state SCD population, ability to create partnerships, and the current COVID-19 situation. Sub-grantees can also serve existing clients through virtual workshops, support groups, referrals, and other services.

12. We're looking at each tab [in the work plan template], for example Patient Recruitment and Assessment. Are we to select (1) activity unless otherwise required such as the Partnership Building Tab in an effort to meet the requirements of the 6 areas?

In the work plan, please complete each item (1A, 1B, 3A, 3B). For example, in Patient Recruitment and Assessment, please complete items 1A through 1E. You can write between 1 to 4 activities for each item. For example, for 1A, you may write 2 activities, and for 1B, you may write 1.

The place where this differs is the Partnership section, as you mentioned. There, you can choose 2 of the items to focus on.

13. One area of focus is to host a series of advocacy workshops. Are we allowed to use any funding toward consulting or honorariums for any leaders interested in educating our community on certain "How To's" when working with Legislators? This is a big question we are looking to definitely get an answer on.

Grant funding could not be used for workshops or other events focused on advocacy or working with legislators. The reason is that this could be construed as lobbying, and we're prohibited from funding that with federal funds.

Sickle Cell Disease Association of America
Sickle Cell Disease Newborn Screening Follow-Up Program
Grant No: SCDAANBS2020
Questions Received and Answered
Last updated October 9, 2020

You could use grant funding for workshops on educational topics such as transitioning, disease education, hydroxyurea, mental health care, etc.

14. Should we plan on 5 months or 7 months or 12 months funding?

Please plan on the additional funding going from November 2020 to May 2021, so 7 months of funding.