OVERVIEW OF RECOMMENDATIONS AND STRATEGIC PLAN

STRATEGY A

Establish a national system to collect and link data to characterize the burden of disease, outcomes, and the needs of those with sickle cell disease across the life span.

Recommendation 3-1: The Centers for Disease Control and Prevention should work with all states to develop state public health surveillance systems to support a national longitudinal registry of all persons with sickle cell disease (Chapter 3).

Timeframe: 1–2 years

Recommendation 3-2: The Health Resources and Services Administration, the National Institutes of Health, and the Agency for Healthcare Research and Quality should develop a clinical data registry for sickle cell disease. The registry would allow for identifying best practices for care delivery and outcomes (Chapter 3).

Timeframe: 1–2 years

Recommendation 3-3: The Office of the Assistant Secretary for Health should establish a working group to identify existing and disparate sources of data that can be immediately linked and mined. These data can be used to provide needed information on sickle cell disease health care services usage and costs in the short term (Chapter 3).

Timeframe: 1-2 years

STRATEGY B

Establish organized systems of care that ensure both clinical and nonclinical supportive services to all persons living with sickle cell disease.

Recommendation 2-1: The Social Security Administration should review disability insurance qualifications to ensure that the qualification criteria reflect the burden of the disease borne by individuals living with sickle cell disease (Chapter 2).

Timeframe: 1–2 years

Recommendation 2-2: States should expand and enhance vocational rehabilitation programs for individuals living with sickle cell disease who need additional training in order to actively participate in the workforce (Chapter 2).

Timeframe: 2–3 years

Recommendation 5-1: The Office of the Assistant Secretary for Health, through the Office of Minority Health, should convene a panel of relevant stakeholders to delineate the elements of a comprehensive system of sickle cell disease (SCD) care, including community supports to improve health outcomes, quality of life, and health inequalities. Relevant stakeholders may include the National Minority Quality Forum, National Medical Association, American Society of Pediatric Hematology/Oncology, American Academy of Pediatrics, American Board of Pediatrics, American College of Physicians, American Society of Hematology, the Sickle Cell Disease Association of America Inc., the Sickle Cell Adult Provider Network, and other key clinical disciplines and stakeholders engaged in SCD care; health systems; and individuals living with SCD and their families (Chapter 5).

Timeframe: 2–3 years

STRATEGY B (CONTINUED)

Recommendation 5-2: The Centers for Medicare & Medicaid Services should work with state Medicaid programs to develop and pilot reimbursement models for the delivery of coordinated sickle cell disease health care and support services (Chapter 5).

Timeframe: 3–4 years

Recommendation 5-3: The U.S. Department of Education should collaborate with state departments of health and education and local school boards to develop educational materials to provide guidance for teachers, school nurses, school administrators, and primary care providers to support the medical and academic needs of students with sickle cell disease (Chapter 5).

Timeframe: 1–2 years

STRATEGY C

Strengthen the evidence base for interventions and disease management and implement widespread efforts to monitor the quality of sickle cell disease care.

Recommendation 4-1: Private and public funders and health professional associations should fund and conduct research to close the gaps in the existing evidence base for sickle cell disease care to inform the development of clinical practice guidelines and indicators of high-quality care (Chapter 4).

Timeframe: 3–5 years

Recommendation 5-4: The National Heart, Lung, and Blood Institute; Health Resources and Services Administration; Centers for Disease Control and Prevention; and U.S. Food and Drug Administration should collaborate with the American Society for Hematology, Pediatric Emergency Care Applied Research Network, Patient-Centered Outcomes Research Institute, and private funders of quality improvement initiatives to foster the development of quality improvement collaboratives (Chapter 5).

Timeframe: 3–5 years

Recommendation 6-1: Federal agencies including the Agency for Healthcare Research and Quality; National Heart, Lung, and Blood Institute, Health Resources and Services Administration; Centers for Disease Control and Prevention; and the U.S. Food and Drug Administration should work together with and fund researchers and professional associations to develop and track a series of indicators to assess the quality of sickle cell disease care including the patient experience, the prevention of disease complications, and health outcomes (Chapter 6).

Timeframe: 1–2 years (to identify and develop list of quality indicators); 3–5 years (to implement monitoring program to track performance of those indicators)

Recommendation 6-2: The Centers for Medicare & Medicaid Services and private payers should require the reporting of expert consensus-driven sickle cell disease (SCD) quality measures and other metrics of high-quality health care for persons with SCD (Chapter 6).

Timeframe: 3–5 years

Recommendation 6-3: The U.S. Department of Health and Human Services should fund efforts to identify and mitigate potentially modifiable disparities in mortality and health outcomes. Specific subgroups to consider include young adults in transition from pediatric to adult care, pregnant women, and older adults (Chapter 6).

Timeframe: 1–2 years

STRATEGY D

Increase the number of qualified health professionals providing sickle cell disease care.

Recommendation 6-4: The National Institutes of Health should disseminate information on loan repayment opportunities to incentivize health care professionals interested in conducting research on sickle cell disease (SCD). The Health Resources and Services Administration should add populations with SCD as a designated population health professional shortage area under the National Health Service Corp program and create a loan repayment program for health care professionals working with SCD populations (Chapter 6).

Timeframe: 1–2 years (disseminate information about existing programs); 3–5 years (develop criteria for loan repayment and similar programs for health professionals working specifically with the SCD population)

Recommendation 6-5: Health professional associations (American Society of Hematology, American College of Obstetricians and Gynecologists, American College of Emergency Physicians, American Association of Family Practitioners, American Academy of Pediatrics, National Medical Association, American College of Physicians) and organizations for other relevant health professionals such as advanced practice providers, nurses, and community health workers should convene an Academy of Sickle Cell Disease Medicine to support sickle cell disease providers through education, credentialing, networking, and advocacy (Chapter 6).

Timeframe: 2–3 years

Recommendation 6-6: Health professional associations and graduate/professional schools should develop early and effective mentoring programs to link early career health professionals with seasoned providers to generate interest in sickle cell disease care (Chapter 6).

Timeframe: 3–5 years

STRATEGY E

Improve sickle cell disease awareness and strengthen advocacy efforts through targeted education and strategic partnerships among the U.S. Department of Health and Human Services, health care providers, advocacy groups and community-based organizations, professional associations, and other key stakeholders (e.g., media and state health departments).

Recommendation 2-3: The U.S. Department of Health and Human Services should engage with media to improve awareness about the disease and address misconceptions about the disease and those affected (Chapter 2).

Timeframe: 1–2 years

Recommendation 8-1: The U.S. Department of Health and Human Services, in collaboration with health professional associations, health care providers, and other key stakeholders, should partner with community-based organizations and patient advocates to translate and disseminate emerging clinical research information to people living with sickle cell disease and their families in order to improve health literacy and empower them to engage in the care and treatment decision-making process (Chapter 8).

Timeframe: 2–3 years

STRATEGY E (CONTINUED)

Recommendation 8-2: The U.S. Department of Health and Human Services, in collaboration with state health departments and health care providers, should partner with community-based organizations and community health workers to engage the sickle cell disease (SCD) population in designing educational and advocacy programs and policies and in disseminating information on health and community services to individuals living with SCD and their caregivers (Chapter 8).

Timeframe: 1–2 years

STRATEGY F

Address barriers to accessing current and pipeline therapies for sickle cell disease.

Recommendation 7-1: The Centers for Medicare & Medicaid Services in collaboration with private payers should identify approaches to financing the upfront costs of curative therapies (Chapter 7).

Timeframe: 2–3 years

Recommendation 7-2: The U.S. Department of Health and Human Services should encourage and reimburse the practice of shared decision making and the development of decision aids for novel, high-risk, potentially highly effective therapies for individuals living with sickle cell disease (Chapter 7).

Timeframe: 1–2 years (to identify and synthesize criteria for the use of new medications); 3–5 years (to develop guidance for shared decision making and tools for implementation)

Recommendation 7-3: The National Institutes of Health, U.S. Food and Drug Administration, pharmaceutical industry, and research community should establish an organized, systematic approach to encourage participation in clinical trials by including affected individuals in the design of trials, working with community-based organizations to disseminate information and recruit participants, and conducting other targeted activities (Chapter 7).

Timeframe: 2–3 years

STRATEGY G

Implement efforts to advance understanding of the full impact of sickle cell trait on individuals and society.

Recommendation 3-4: The Health Resources and Services Administration should work with states to standardize the communication of and use of newborn screening positive results in genetic counseling and should create a mechanism for communicating this information across the life span and ensuring access to needed support and services (Chapter 3).

Timeframe: 2–3 years

Recommendation 4-2: The National Institutes of Health should fund research to elucidate the pathophysiology of sickle cell trait (Chapter 4).

Timeframe: 2–3 years

Recommendation 4-3: The Office of the Assistant Secretary for Health should partner with community-based organizations, the media, and other relevant stakeholders to disseminate information to promote awareness and education about the potential risks associated with sickle cell trait (Chapter 4).

Timeframe: 1–2 years

STRATEGY H

Establish and fund a research agenda to inform effective programs and policies across the life span.

Federal and private funders should collaborate to provide funding to clinician scientists and scholars with expertise in sickle cell disease (SCD), race, and stigma to advance research on pressing topics. The oversight body established by the Office of the Assistant Secretary for Health at the U.S. Department of Health and Human Services should collaborate with health professional associations, researchers, individuals living with SCD, and funders to develop a robust research agenda with priority topics that need to be studied.

Timeframe: Ongoing

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