HOUSE . . . . No. 4554

The Commonwealth of Massachusetts

HOUSE OF REPRESENTATIVES, September 29, 2025.

The committee on Financial Services, to whom was referred the petition (accompanied by bill, House, No. 1346) of Bud L. Williams and David M. Rogers for legislation to to improve sickle cell disease care, reports recommending that the accompanying bill (House, No. 4554) ought to pass.

For the committee,

JAMES M. MURPHY.

FILED ON: 9/19/2025

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The Commonwealth of Massachusetts

In the One Hundred and Ninety-Fourth General Court
(2025-2026)

An Act to improve sickle cell care.

Be it enacted by the Senate and House of Representatives in General Court assembled, and by the authority of the same, as follows:

SECTION 1. Chapter 118E of the General Laws is hereby amended by inserting after section 10Z the following section:

Section 10AA. (a) For the purposes of this section, the following words shall, unless the context clearly requires otherwise, have the following meanings:-

(1) "Iatrogenic infertility", in impairment of fertility by surgery, radiation, chemotherapy, or other medical treatment affecting reproductive organs or processes, including without limitation treatment for sickle cell disease.

(2) "Physician", an individual licensed to practice under section 2 of chapter 112.

(3) "Qualified enrollee", an individual who:

(A) is enrolled in the MassHealth program pursuant to section 9;

(B) has been diagnosed with a form of cancer or other disease by a physician;

(C) needs treatment for that cancer or other disease that may cause substantial risk of sterility or iatrogenic infertility, including surgery, radiation, or chemotherapy; and

(D) has a primary illness that has impaired the patient’s fertility and ability to reproduce normally.

(4) "Standard Fertility Preservation Services", procedures based upon current evidence-based standards of care established by the American Society for Reproductive Medicine, the American Society of Clinical Oncology, or other national medical associations that follow current evidence-based standards of care, and includes the retrieval and storage of two complete oocyte cycles and the collection and storage of two sperm samples.

(b)(1) Before January 1, 2024, the division of medical assistance shall apply for a Medicaid waiver or a state plan amendment with the Centers for Medicare & Medicaid Services of the United States Department of Health and Human Services to implement the coverage described in subsection (b).

(2) If the waiver or state plan amendment described in subsection (a) is approved, MassHealth shall provide coverage to a qualified enrollee for standard fertility preservation services.

(c) Before November 1, 2025, and before November 1 of each third year after 2025, the division of medical assistance shall calculate the change in state spending attributable to the coverage described in subsection (b)(2), and report this amount to house and senate committees on ways and means

Commercial Insurance Coverage for Fertility Preservation Services

SECTION 2. (a) Notwithstanding any general or special law to the contrary, any policy, contract or certificate of health insurance subject to chapters 32A, 176A, 176B, 176G, 176I, 176J or 176Q of the General Laws, or any blanket or general policy of insurance described in subdivision (A), (C), or (D) of section one hundred and ten which is issued or subsequently renewed by agreement between the insurer and the policyholder, within or without the commonwealth, during the period within which this premium is effective, or any policy of accident or sickness insurance as described in section one hundred and eight which provides hospital expense and surgical expense insurance and which is delivered or issued for delivery or subsequently renewed by agreement between the insurer and the policyholder in the commonwealth, during the period within which this provision is effective, or any employers' health and welfare fund which provides hospital expense and surgical expense benefits and which is issued or renewed to any person or group of persons in the commonwealth, during the period within which this provision is effective, must provide coverage for medically necessary expenses for standard fertility preservation services when a necessary medical treatment may directly or indirectly cause iatrogenic infertility to an enrollee.

(b) In determining coverage pursuant to this section, an insurer shall not discriminate based on an individual's expected length of life, present or predicted disability, degree of medical dependency, quality of life, or other health conditions, nor based on personal characteristics, including age, sex, sexual orientation, or marital status.

(c) For the purposes of this section, the following words shall, unless the context clearly requires otherwise, have the following meanings:-

"Iatrogenic infertility", in impairment of fertility by surgery, radiation, chemotherapy, or other medical treatment affecting reproductive organs or processes, including without limitation treatment for sickle cell disease.

"May directly or indirectly cause", the likely possibility that treatment will cause a side effect of infertility, based upon current evidence-based standards of care established by the American Society for Reproductive Medicine, the American Society of Clinical Oncology, or other national medical associations that follow current evidence-based standards of care.

"Standard fertility preservation services", procedures based upon current evidence-based standards of care established by the American Society for Reproductive Medicine, the American Society of Clinical Oncology, or other national medical associations that follow current evidence-based standards of care, and includes the retrieval and storage of two complete oocyte cycles and the collection and storage of two sperm samples.

STATEWIDE SCD STEERING COMMITTEE

SECTION 3. (a)(1) Notwithstanding any general or special law to the contrary, there is hereby established a Statewide Steering Committee on Sickle Cell Disease within the department of public health.

(2) The Steering Committee under this section shall consist of:

(A) two representatives from the Massachusetts Sickle Cell Disease Association including the Executive Director or their designee;

(B) three medical professionals from major Sickle Cell Disease treatment centers in the commonwealth who shall be appointed by the commissioner;

(C) the Executive Director of the Massachusetts Association of Community Health Workers or their designee;

(D) the President of the Massachusetts Chapter of the National Association of Social Workers or their designee;

(E) two members who shall be appointed by the commissioner, one of whom shall be an expert on the biology of the disease, and one of whom shall be an expert on the psycho-social aspect of the disease;

(F) two representatives of the department of elementary and secondary education who shall be appointed by the commissioner, including one of whom is knowledgeable about the right to comparable education, supportive services and accommodations under section 504 of the Rehabilitation Act of 1973;

(G) one representative of the Black and Latino Caucus who shall be appointed by the commissioner;

(H) one representative of the Asian Caucus who shall be appointed by the commissioner;

(I) two sickle cell disease patients who shall be appointed by the Governor, one of which shall be over 25 years in age and the other shall be between 18 and 25 years in age;

(J) a parent of a minor child with sickle cell disease who shall be appointed by the Governor;

(K) a parent of a secondary or post-secondary school age youth with sickle cell disease who shall be appointed by the commissioner; and

(L) one representative who has a background in racial health disparities who shall be appointed by the Governor.

The representatives of nongovernmental organizations shall serve staggered 3–year terms. Vacancies of unexpired terms shall be filled within 60 days by the appropriate appointing authority.

(3) The Steering Committee under this section shall:

(A) establish institution and community partnerships, including hospitals, and institutions of higher education;

(B) establish a statewide network of stakeholders, including parents, home health care providers, school-based nurses, and the Massachusetts Sickle Cell Disease Association who are committed to care for individuals with sickle cell disease collaboratively in an inclusive setting;

(C) establish a statewide network of racially and culturally competent stakeholders who include general and special education administrators and teachers and paraprofessionals;

(D) oversee the development of educational materials for individuals with sickle cell disease, the public, and health care providers about the assistance available to such individuals in the commonwealth, including local school district responsibilities for care of such individuals;

(E) identify funding sources for implementing or supporting the actions, studies, policies required by federal and state laws and regulations, or recommended by the Steering Committee, including funding from:

(i) state, federal, and local government sources; and

(ii) private sources;

(F) investigate and report on a standard of basic, multidisciplinary care for patients across the commonwealth; and

(G) establish subcommittees as appropriate.

(4) The department may, in consultation with the Statewide Steering Committee, provide services relating to sickle cell disease, including:

(A) educational programs on sickle cell disease for individuals affected by the disease, including:

(i) education on the rights of individuals with sickle cell disease, such as, without limitation, the right not to be discriminated against and the right to receive appropriate educational programming, health related services and accommodations necessary to access such programming and services;

(ii) expectations, options, and responsibilities of families of individuals with sickle cell disease;

(iii) challenges and responsibilities of caregivers of individuals with sickle cell disease;

(iv) obligations of employees at primary and secondary schools; and

(v) challenges and responsibilities of health care providers;

(B) social services support to individuals with sickle cell disease, including support from social workers and community health workers to provide information on services that may be available to the individual;

(C) hemoglobin electrophoresis or genetic testing for the presence of sickle cell disease;

(D) genetic counseling;

(E) assistance with any available reimbursement for medical expenses related to sickle cell disease;

(F) education and counseling services for parents and other family members and caretakers after the receipt of sickle cell trait test results from the Newborn Screening Program as required by section 270.006(A)(2)(e) of chapter 105, Code of Massachusetts Regulations, provided that, with the consent of parents and other family members and caretakers, such services may be provided in whole or in part by the Massachusetts Sickle Cell Disease Association; and

(G) any other programs or services that are necessary to decrease the use of acute care services by individuals who have sickle cell disease.

(5) The department shall, in consultation with any other agency of the commonwealth as the department determines appropriate, provide the services in paragraph (4) through community–based organizations, including specifically, pre-K, elementary and secondary schools as well as institutions for higher education for all affected school-age children, youth, and older students to the extent practicable.

(6) The Steering Committee, in conjunction with the department and other relevant stakeholders, shall study and make recommendations on:

(A) how to enhance access to services for individuals with sickle cell disease with a focus on areas in the commonwealth where there is a statistically high number of individuals with sickle cell disease or in areas where there is a lack of providers with expertise in treating sickle cell disease;

(B) whether to establish a sickle cell disease registry, and if recommended, the process and guidelines for establishing a registry and obtaining information consistent with informed consent and protecting data privacy;

(C) how to enhance the coordination of health care services for individuals with sickle cell disease who are transitioning from pediatric to adult health care, including the identification of available resources for individuals who are transitioning; and

(D) how to engage with community–based health fairs and other community–sponsored events in areas with a statistically high number of individuals with sickle cell disease to provide outreach and education on living with sickle cell disease and how to access health care services.

(b) The department shall, in consultation with the Steering Committee, establish and implement a system the provides information on the sickle cell trait to any individual who has the sickle cell trait and, if the individual is a minor, to the individual’s family.

(c) The department shall include the following in the information provided under subsection (b):

(1) how the sickle cell trait impacts the health of an individual with the trait;

(2) how the sickle cell trait is passed from a parent to a child; and

(3) implications for pregnancy.

(d) The department shall maintain in a conspicuous location on its website a list of resources for health care practitioners to use to improve their understanding and clinical treatment of individuals with sickle cell disease or the sickle cell trait, including information on the health impacts of carrying the sickle cell trait.

(e) For the purposes of this section, the following word shall, unless the context clearly requires otherwise, have the following meaning:-

"Steering Committee", the Statewide Steering Committee on Sickle Cell Disease.

SICKLE CELL DISEASE DETECTION AND EDUCATION PROGRAM (ADULT SCREENING AND EDUCATION- RELATED GRANTS)

SECTION 4. (a) Notwithstanding any general or special law to the contrary, there is hereby established within the department of public health the sickle cell disease detection and education program to: (1) promote screening and detection of sickle cell disease, especially among unserved or underserved populations; (2) educate the public regarding sickle cell disease and the benefits of early detection; and (3) provide counseling and referral services.

(b) The program under this section shall include:

(1) establishment of a statewide public education and outreach campaign to publicize evidence-based sickle cell disease screening, detection and education services. The campaign shall include: general community education, outreach to specific underserved populations, evidence based clinical sickle cell disease screening services, and an informational summary that shall include an explanation of the importance of clinical examinations and what to expect during clinical examinations and sickle cell disease screening services;

(2) provision of grants to approved organizations pursuant to subsection (c) and for community based organizations pursuant to subsection (d);

(3) compilation of data concerning the program and dissemination of such data to the public; and

(4) development of health care professional education programs including the benefits of early detection of sickle cell disease and clinical examinations, the recommended frequency of clinical examinations and sickle cell disease screening services, and professionally recognized best practices guidelines.

(c)(1) Under the program, the commissioner of public health shall make grants in amounts appropriated to approved organizations for the provision of services relating to the evidence-based screening and detection of sickle cell disease as part of this program. The services required to be provided under such grants shall include:

(A) promotion and provision of early detection of sickle cell disease, including clinical examinations and sickle cell disease screening services;

(B) provision of counseling and information on treatment options and referral for appropriate medical treatment;

(C) dissemination of information to unserved and underserved populations as determined by the commissioner, to the general public and to health care professionals concerning sickle cell disease, the benefits of early detection and treatment, and the availability of sickle cell disease screening services at no cost to such populations;

(D) identification of local sickle cell disease screening services within the approved organization's region;

(E) provision of information, counseling and referral services to individuals diagnosed with sickle cell disease; and

(F) provision of information regarding the availability of medical assistance, including medical assistance for an individual who is eligible for such assistance pursuant to section 9 of chapter 118E of the General Laws, to an individual who requires treatment for sickle cell disease.

(2) The commissioner shall give notice and provide opportunity to submit applications for grants under the program. In order to be considered for a grant, an applicant must show evidence of the following, relating to the services the applicant proposes to provide:

(A) ability to provide and to ensure consistent and quality services under the program;

(B) expertise in providing the service;

(C) capacity to coordinate services with physicians, hospitals and other appropriate local institutions or agencies;

(D) ability to provide the service to unserved or underserved populations; and

(E) ability to provide the service in accordance with the standards specified in subdivision three of this section.

Applications shall be made on forms provided by the commissioner.

(3) The commissioner shall develop standards for the implementation of grants under the program by approved organizations, which shall ensure the following:

(A) integration of the approved organization with existing health care providers;

(B) maximizing third party reimbursement; and

(C) provision of services to unserved or underserved populations.

(4) Within the amounts of state or federal funds appropriated for the program, approved organizations may be authorized by the department to provide such services for populations served under this title. Services may include evidence based screening, patient education, counseling, follow-up and referral.

(5) Every organization receiving grants under this subsection shall submit to the commissioner, on or before October first of each year, a report of such organization's activities, including an assessment of the organization's programs and such data as the commissioner deems relevant and necessary to accomplish the purposes of the program

(d)(1) Under the program, the commissioner shall make grants within amounts appropriated for community based organizations to provide post-diagnosis counseling, education and outreach programs for persons diagnosed with sickle cell disease based upon criteria to be developed by the commissioner.

(2) The commissioner shall provide notice and opportunity for community-based organizations to submit applications to provide post-diagnosis sickle cell disease counseling, education and outreach programs. Such applications shall be on forms established by the commissioner.

(e) The commissioner shall submit, on or before December first of each year, an annual report to the governor and the legislature concerning the operation of the program. The reports shall include the experience of the program in providing services under this act. The annual report shall include strategies for implementation of the sickle cell disease awareness program and for promoting the awareness program to the general public, state and local elected officials, and various public and private organizations, associations, businesses, industries, and agencies. Organizations receiving grants under this act shall provide data and assessments as the commissioner may require for the report. The report shall include any recommendations for additional action to respond to the incidence of sickle cell disease in the commonwealth.

(f) For the purposes of this section, the following words shall, unless the context clearly requires otherwise, have the following meanings:-

“Community-based organizations”, free-standing organizations in which sickle cell disease survivors hold significant decision-making responsibility, and which offer a broad range of sickle cell disease education and support services free of charge.

“Program”, sickle cell disease detection and education program.

“Unserved or underserved populations", people having inadequate access and financial resources to obtain sickle cell disease screening and detection services, including people who lack health coverage or whose health coverage is inadequate or who cannot meet the financial requirements of their coverage for accessing detection services.

SCD REGISTRY AND REPORTS- COMPREHENSIVE DATA COLLECTION ON PEOPLE LIVING WITH SCD OR ITS VARIANTS

SECTION 5. (a)(1) Notwithstanding any general or special law to the contrary, the commissioner of public health or designee shall, in accordance with regulations adopted by the department of public health pursuant to subsection (b), and in consultation with the Massachusetts Sickle Cell Disease Association, establish and maintain a system for the reporting of information on sickle cell disease and its variants. Said system shall include a record of the cases of sickle cell disease and its variants which occur in the commonwealth along with such information concerning the cases as may be appropriate to form the basis for: (A) conducting comprehensive epidemiologic surveys of sickle cell disease and its variants in the commonwealth; and (B) evaluating the appropriateness of measures for the treatment of sickle cell disease and its variants.

(2) Hospitals, medical laboratories, and other facilities that provide screening, diagnostic or therapeutic services to patients with respect to sickle cell disease and its variants shall report the information prescribed by the regulation promulgated pursuant to subsection (b).

(3) Any provider of health care who diagnoses or provides treatment for sickle cell disease and its variants, except for cases directly referred to the provider or cases that have been previously admitted to a hospital, medical laboratory or other facility described in paragraph (2), shall report the information prescribed by the regulation adopted pursuant to subsection (b).

(b) The department of public health shall, by regulation:

(1) prescribe the form and manner in which information on cases of sickle cell disease and its variants must be reported in compliance with any applicable federal privacy law;

(2) prescribe the information that must be included in each report, which must include, without limitation: (A) the name, address, age and ethnicity of the patient; (B) the variant of

sickle cell disease with which the person has been diagnosed; (C) the method of treatment; (D) any other diseases from which the patient suffers; (E) information concerning the usage of and access to health care services by the patient; and (F) if a patient diagnosed with sickle cell disease and its variants dies, his or her age at death and cause of death; and

(3) establish a protocol for allowing appropriate access to and preserving the confidentiality of the records of patients needed for research into sickle cell disease and its variants;

(4) establish a protocol for allowing information, in accordance with the preceding subsections, to be communicated with Statewide Steering Committee on Sickle Cell Disease, the sickle cell disease services program, and within the department as determined appropriate by the commissioner.

(c) The chief administrative officer of each health care facility in the commonwealth shall make available to the commissioner or designee the records of the health care facility for each case of sickle cell disease and its variants. The department of public health shall abstract from the records of a health care facility or shall require a health care facility to abstract from its own records such information as is required by regulations promulgated pursuant to subsection (b). The department shall compile the information in a timely manner and not later than 6 months after receipt of the abstracted information from the health care facility. The department shall by regulation adopt a schedule of fees which must be assessed to a health care facility for each case from which information is abstracted by the department. Any person who violates this section is subject to an administrative penalty established by regulation by the department.

(d) The department shall publish reports based upon the information obtained pursuant to subsections (a), (b), and (c) and shall make other appropriate uses of the information to report and assess trends in the usage of and access to health care services by patients with sickle cell disease and its variants in a particular area or population, advance research and education concerning sickle cell disease and its variants and improve treatment of sickle cell disease and its variants and associated disorders. The reports must include, without limitation:

(1) information concerning the locations in which patients diagnosed with sickle cell disease and its variants reside, the demographics of such patients and the utilization of health care services by such patients;

(2) the information described in paragraph (1), specific to patients diagnosed with sickle cell disease and its variants who are over 60 years of age or less than 5 years of age; and

(3) information on the transition of patients diagnosed with sickle cell disease and its variants from pediatric to adult care upon reaching 18 years of age.

(e) The department shall provide any qualified researcher whom the department determines is conducting valid scientific research with data from the reported information upon the researcher's: (1) compliance with appropriate conditions as established under the regulations of the department; and (2) payment of a fee established by the department by regulation to cover the cost of providing the data.

(f) The commissioner or designee shall analyze the information obtained pursuant to subsections (a), (b) and (c) and the reports published pursuant to subsection (d) to determine whether any trends exist in the usage of and access to health care services by patients with sickle cell disease and its variants in a particular area or population.

(g) If the commissioner or designee determines that a trend exists in the usage of and access to health care services by patients with sickle cell disease and its variants in a particular area or population, the commissioner or designee shall work with appropriate governmental, educational and research entities to investigate the trend, advance research in the trend and facilitate the treatment of sickle cell disease and its variants and associated disorders.

(h) The department shall not reveal the identity of any patient, physician, or health care facility which is involved in any reporting required by this section unless the patient, physician or health care facility gives prior written consent to such a disclosure. A person or governmental entity that provides information to the department pursuant to this section shall not be held liable in a civil or criminal action for sharing confidential information unless the person or organization has done so in bad faith or with malicious purpose.

(i) For the purposes of this section, the following words shall, unless the context clearly requires otherwise, have the following meanings:-

“Sickle cell disease and its variants”, an inherited disease caused by a mutation in a gene for hemoglobin in which red blood cells have an abnormal crescent shape that causes them to block small blood cells and die sooner than normal.

SCD REGISTRY AND REPORTS- DATA COLLECTION ON SCD TRAIT

SECTION 6. (a)(1) Notwithstanding any general or special law to the contrary, if a newborn screening for hereditary disorders performed pursuant to section 270.006(A)(2)(e) of chapter 105, Code of Massachusetts Regulations detects the presence of sickle cell trait, the laboratory performing the screening shall notify the physician responsible for the newborn’s care and shall document the patient's information in the central registry established pursuant to paragraph (2) in a manner and on forms prescribed by the department of public health.

(2) The physician responsible for such newborn's care shall provide the patient's parents with information concerning the availability, benefits, and role of genetic counseling performed by a genetic counselor licensed pursuant to section 253 of chapter 112 of the General Laws, including a document available in multiple languages (as determined by the department) that identifies at least 10 genetic counselors and the public health care payers and private health care payers which contract with each such genetic counselor. In the case a physician described in the preceding sentence is not identified, the laboratory described in paragraph (1) shall provide the patient's parents with such information relating to genetic counseling. Genetic counseling concerning a diagnosis of sickle cell trait shall include, but not be limited to, information concerning the fact that one or both of the parents carries sickle cell trait and the risk that other children born to the parents may carry sickle cell trait or may be born with sickle cell disease.

(b)(1) The commissioner of public health shall establish a central registry of patients diagnosed with sickle cell trait. The information in the central registry shall be used for the purposes of compiling statistical information and assisting the provision of follow-up counseling, intervention, and educational services to patients and to the parents of patients who are listed in the registry including, but not limited to, information concerning the availability and benefits of genetic counseling performed by a genetic counselor licensed pursuant to section 253 of chapter 112 of the General Laws.

(2) The commissioner shall establish a system to notify the parents of patients who are listed in the registry that follow-up consultations with a physician are recommended for children

diagnosed with sickle cell trait. Such notifications shall be provided: at least once when the patient is in early adolescence, when the patient may begin to participate in strenuous athletic activities that could result in adverse symptoms for a person with sickle cell trait; at least once during later adolescence, when the patient should be made aware of the reproductive implications of sickle cell trait; and at such other intervals as the commissioner may require.

(3) The commissioner shall establish a system under which the department shall make reasonable efforts to notify patients listed in the registry who reach the age of 18 years of the patient's inclusion in the registry and of the availability of educational services, genetic counseling, and other resources that may be beneficial to the patient.

(4) Information on newborn infants and their families compiled pursuant to this section may be used by the department and agencies designated by the commissioner of public health for the purposes of carrying out this act, but otherwise the information shall not be a public record and shall be confidential and not divulged or made public so as to disclose the identity of any person to whom it relates, except as exempted or consented in accordance with section 10 of chapter 66 or section 70G of chapter 111 of the General Laws, respectively.

DEVELOPMENT OF A COMPREHENSIVE SCD DISEASE QUALITY STRATEGY IN MEDICAID MANAGED CARE

SECTION 7. (a) Notwithstanding any general or special law to the contrary, the division of medical assistance shall ensure the availability of accessible, quality health care for individuals with sickle cell disease who are enrolled in Medicaid managed care organizations or accountable care organizations that have a contract with the division to provide services to individuals enrolled under MassHealth pursuant to section 9 of chapter 118E of the General Laws. Such health care shall include, but not be limited to the following:

(1) comprehensive integrated care management for sickle cell disease, including primary care, specialized care, and mental health services;

(2) sickle cell trait testing and genetic counseling;

(3) social work services as well as education on disease management to patients, caregivers, and providers; and

(4) support navigating health insurance coverage and support with transportation to treatment centers.

(b) Not later than January 1, 2027, the division of medical assistance shall require Medicaid managed care or accountable care organizations to implement a sickle cell disease quality strategy for children and adults with sickle cell disease that includes, but is not limited to, the following components:

(1) measurable goals to improve the identification of members with sickle cell disease within 90 days after enrolling in the contracted health plan;

(2) to the extent practicable, adequate provider network capacity to ensure timely access to sickle cell disease specialty service providers, including, but not limited to, hematologists;

(3) care coordination strategies and supports to help members with sickle cell disease access sickle cell disease specialists and other related care supports;

(4) delivery of a training curriculum approved by the division of medical assistance to educate primary care providers on sickle cell disease, including information on emergency warning signs and complications, evidence-based practices and treatment guidelines, and when to make referrals to specialty sickle cell disease treatment providers; and

(5) in the case of an individual who is diagnosed with sick cell disease, exceptions to otherwise applicable prior authorization or dispensing limits for pain medications that are designed to reduce barriers for such an individual to be able to obtain the appropriate dosage and amount of a pain medication in a timely manner.

(c) The division of medical assistance shall also do the following:

(1) Not later than January 1, 2027, require each Medicaid managed care organization and accountable care organization to report, on a quarterly basis, an unduplicated count of children and adults identified as having sickle cell disease enrolled with the contracted plan during the quarter. The department shall publish these reports, by contracted plan, on the department's website.

(2) Not later than January 1, 2027, and in partnership with Medicaid managed care organizations and accountable care organizations, identify, document, and share best practices regarding sickle cell disease care management and care coordination with Medicaid-enrolled primary care and sickle cell disease specialty providers with a goal of improving services for members with sickle cell disease and their families.

(3) Enter into a contract not later than January 1, 2027, with a publicly funded university to develop a sickle cell disease-focused comprehensive assessment tool or a supplement to an existing comprehensive assessment tool to screen members identified with sickle cell disease for

comorbidities, medical history for the treatment of sickle cell disease including disease-modifying medications and pain management, psychosocial history, barriers to accessing or completing treatments, social supports, other care coordinators working with the member, community resources being used or needed, quality of life, and personal preferences for engagement with a care coordinator.

(4) Not later than January 1, 2027, establish performance measures relative to access to care and available therapies, engagement in treatment, and outcomes for individuals with sickle cell disease, with the metrics to be reported annually by the comprehensive health care program to Medicaid managed care organizations and accountable care organizations and with incentive payments attached to the measures.

(5) Not later than January 1, 2027, develop a plan for improving the transition from pediatric care to adult care for adolescents with sickle cell disease who are aging out of the Medicaid program, and a plan for helping qualified beneficiaries maintain Medicaid coverage under another eligibility category, in order to maintain continuity of care.

(d) The division of medical assistance shall provide an annual sickle cell disease management and accountability report to the senate and house committees on ways and means, including the status of sickle cell disease-focused access to care, quality of services, health outcomes, and disparities in the commonwealth.

(e) The division of medical assistance shall incorporate the sickle cell disease management and accountability standards into its contracts with managed care plans and accountable care organizations, including financial or administrative penalties for lack of performance. Contracted plan rates must be adjusted to reflect enhanced care or other provisions that are shifted to the contracted plans.