

PROPOSED REGULATIONS OF THE STATE BOARD OF HEALTH

Italics, blue: New proposed language

~~[Red]~~: Removed language

AUTHORITY: [Assemble Bill 254](#) of the 80th Legislative Session (2019);

Section 1. Chapter 439 of NAC is hereby amended by adding thereto the provisions set forth as sections 2 to 12, inclusive, of this regulation.

Sec. 2. *As used in sections 2 to 12, inclusive, of this regulation, unless the context otherwise requires, the words and terms have the meanings ascribed to them in those sections of AB 254.*

Sec. 5. *“System” means the system established pursuant to section 5 of AB 254 for the reporting of information on sickle cell and its variants.*

Sec. 6. 1. *Except as otherwise provided in section 7 of this regulation, any healthcare facility, medical laboratories and other provider of healthcare that diagnoses sickle cell and its variants and/or sees an individual where sickle cell is their primary complaint, per an ICD-10 code that lists ‘sickle cell’ in their description shall report to the Chief Medical Officer using an electronic or paper form prescribed by the Chief Medical Officer:*

(a) The name, address, date of birth, sex at birth, gender identity, race and ethnicity of the patient;

(b) The name, address and telephone number of the facility or provider of health care;

(c) The date on which the patient was diagnosed or treated;

(d) The name, address and telephone number of any hospital, medical laboratory or other facility to which the patient was referred for further diagnosis or treatment specific to sickle cell;

(e) The variant of sickle cell with which the patient has been diagnosed;

(f) The method of treatment, including, without limitation, any opioid prescribed for the patient and whether the patient has adequate access to that opioid;

(g) Any other diseases from which the patient suffers, including, without limitation, pneumonia, asthma or gall bladder disease;

(h) If a patient diagnosed with sickle cell and its variants dies, his or her age at death; and

(i) Any other information requested by the Chief Medical Officer.

3. A company that owns and operates multiple health care facilities may satisfy the requirements set forth in this section for all such health care facilities in one report without segregating by health care facility, or by provider of health care, the records subject to reporting.

4. Providers are exempt from reporting pursuant to subsection 1 for cases directly referred to the provider or cases that have been previously admitted to a hospital, medical laboratory or other facility, unless sickle cell is the primary complaint for the individuals medical visit or if the provider initiates a new course of treatment for sickle cell.

5. Hospitals that report discharge data to the division are exempt from reporting, but may be asked to provide additional medical records or patient details for specific individuals as requested by the Division.

Sec. 7. A report required pursuant to section 6, subsection 1 must be made:

(a) For a diagnosis made, medical visit where sickle cell was the primary complaint, and/or treatment initiated on or after January 1 and on or before June 30 of any calendar year, not later than September 30 of the same calendar year.

(b) For a diagnosis made, medical visit where sickle cell was the primary complaint, and/or treatment initiated on or after July 1 and on or before December 31 of any calendar year, not later than March 31 of the immediately following calendar year.

Sec. 8. 1. Any healthcare facility, medical laboratories and other provider of healthcare that provides screening, diagnostic or therapeutic services to patients with respect to sickle cell and its

variants or provider of health care may request that the Division collect the information described in section 6 or 7, as applicable, of this regulation, from the records of the facility or provider.

2. A request made pursuant to subsection 1 must be made before the date by which the provider is otherwise required to report the information pursuant to section 6 or 7, as applicable, of this regulation.

3. If the Division collects information from a facility or provider upon a request made pursuant to subsection 1, the Division may charge a fee consistent with the amount of time it takes to abstract the data.

4. Any healthcare facility, medical laboratory and/or other provider of healthcare that diagnoses sickle cell and its variants and/or care for individuals where sickle cell is their primary complaint that do not fulfill this requirement will be subject to a \$200 fee annually, per calendar year.

Sec. 9. 2. A qualified researcher in sickle cell and its variants who applies for access to the records shall be granted access, pursuant to Division data usage agreement policies that are in place to protect confidentiality, while promoting access to epidemiological data that could improve health care outcomes for individuals diagnosed with sickle cell and its variants.

Sec. 12. A person or governmental entity that provides information to the Division in accordance with sections 6, 7 and 8 of this regulations must 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.