



IN THE GENERAL ASSEMBLY STATE OF

Sensitive Life-Changing Test Results Protection Act

1 Be it enacted by the People of the State of _____, represented in the General
2 Assembly:

3 **Section 1. Title.** This act shall be known as and may be cited as the “Sensitive Life-Changing
4 Test Results Protection Act.”

5 **Section 2. Purpose.** The Legislature hereby finds and declares that:

6 (a) The 21st Century Cures Act, Pub. L. No. 114-255, made sharing electronic health
7 information the expected norm in health care and established information blocking as
8 practices by health care providers, including physicians, that are likely to prevent,
9 materially discourage, or otherwise inhibit the access, exchange, or use of electronic
10 health information but permits states to establish exceptions to the requirement.

11 (b) Rules implementing the 21st Century Cures Act effectively require the immediate
12 electronic release of all test results to patients before patients have had an opportunity to
13 talk with their physician, leading to patient confusion and potential emotional as well as
14 mental harm to the patient.

15 (c) Patients have a fundamental right to access their own health information. However,
16 inflexible rules do not allow for those rare, brief pauses to allow physicians to contact
17 patients with bad news and respect patient preferences. Rules around outreach to patients
18 should recognize the complexities and consequences of certain test results, medical
19 reports, and clinical notes that benefit from physician review.

1 (d) In the rare instances when a radiologic test, biopsy, or other procedure reveals
2 unexpected and life-changing bad news, the ordering physician must have an opportunity
3 to review the results prior to their release as part of the patient's electronic health record
4 or patient portal in order to share the news more personally with the patient, provide
5 appropriate medical guidance and support, answer questions about prognosis as well as
6 treatment options, and gather appropriate resources for the patient.

7 (e) According to an American Medical Association (AMA)-led [survey](#) of 1,000 patients in
8 2022, 65 percent of patients want to speak with their physician first before getting life-
9 changing test results. Participants were asked if they prefer their health care provider to
10 contact them about results of lab tests or diagnostic studies before the results show up in a
11 patient portal and nearly 43 percent said "No." For those who said "No," participants
12 were then asked if it made a difference if the results showed a debilitating, life-limiting,
13 or terminal illness. More than 50 percent of people said, "Yes," they want a physician to
14 review and contact them with life-changing test results before this information is posted
15 to a patient portal.

16 (f) Patients who wish to receive their test results immediately and express a desire to do so
17 should still be able to request and receive their information without delay.

18 (g) The Legislature should protect patients and not needlessly put them at risk. by creating an
19 exception to this forced immediate disclosure requirement under the 21st Century Cures
20 Act.

21 **Section 3. Definitions.**

22 (a) Electronic health record is defined as an electronic record of health-related information
23 on an individual that is created, gathered, managed, protected, and consulted by
24 authorized health care clinicians and staff.

1 (b) Patient portal is defined as secure online system that provides patients access to
2 electronic personal health information and is directly linked with an electronic health
3 record.

4 (c) Sensitive, life-changing test results are defined as the results of a clinical laboratory test;
5 imaging scan, such as an x-ray, magnetic resonance imaging, ultrasound, or other similar
6 technologies; or other medical test or procedure that tests for serious mental or physical
7 illness that the treating physician in their clinical judgement determines may indicate
8 permanent impairment, loss of function, or death.

9 **Section 4. Prohibition on release of sensitive, life-changing test results.**

10 (a) Except as permitted by subsection (b) of this Section, sensitive, life-changing test results
11 may not be disclosed to the patient or patient representative as part of the patient's
12 electronic health record or patient portal earlier than three business days after the date
13 that the sensitive test results are finalized unless the patient's treating health care provider
14 directs the release of the sensitive test results before the end of the three-business day
15 period or in compliance with Subsection (b).

16 (b) Sensitive, life-changing test results may be disclosed to the patient if the patient requests
17 to receive their results without delay.

18 (c) The person or entity responsible for administration of the patient's electronic health
19 record and patient portal is required to implement the provisions of Subsection (a) of this
20 Section.

21 (d) Compliance with Subsection (a) of this Section shall not be considered information
22 blocking under 42 U.S.C. sec. 300jj-52.

23 **Section 5. Effective.** This Act shall become effective immediately upon being enacted into law.

1 **Section 6. Severability.** If any provision of this Act is held by a court to be invalid, such
2 invalidity shall not affect the remaining provisions of this Act, and to this end the provisions of
3 this Act are hereby declared severable.