



July 24, 2026

VIA ELECTRONIC MAIL

Virginia Payne
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Charleston, WV 25301
virginia.m.payne@wv.gov

RE: West Virginia Health Information Network, Inc.'s Comments to the Bureau for Public Health's Amendments to the Newborn Screening System Legislative Rule

Dear Ms. Payne:

On June 25, 2026, the West Virginia Bureau for Public Health ("BPH") issued a Notice of Public Comment Period ("Notice") with respect to its amendments to the Newborn Screening System Legislative Rule, W. Va. Code. R. § 64-91-1 *et seq.* ("Rule"). The Notice detailed that the written comment period ends on July 25, 2026 at 5:00 p.m. Accordingly, on behalf of the West Virginia Health Information Network, Inc. (hereafter "we," "us," "our" or the "WVHIN"), please accept our timely comments on, and proposed revisions to, the Rule.

Implementing the WVHIN's proposed revisions detailed herein would assist BPH in advancing the purposes already reflected in the Rule. The Rule is designed to ensure that newborns are screened promptly, that positive results are reported quickly, and that infants identified with a disorder receive continuing care and treatment through a collaborative effort including individuals and entities such as parents, providers, facilities, and public health officials.

As further detailed herein, the WVHIN proposes that the Rule be revised so that authorized WVHIN users can view newborn screening results in the WVHIN's health information exchange, which would speed up recipients access to necessary results.¹ Furthermore, the WVHIN proposes that the Rule expressly detail that uses and disclosures of confidential information pursuant to the Rule can be made as required and/or permitted by applicable federal and/or state law. Furthermore, as detailed herein, the WVHIN proposes that the Rule permit uses and disclosures to be made for a "Permitted Purpose," which would be a term that expressly outlines certain uses and disclosures permitted by existing law. For example, the WVHIN's proposed revision includes as a "Permitted Purpose" a purpose that is permitted

¹ The WVHIN understands current practice is to send the results from BPH to the birthing hospital via facsimile. That necessitates manual entry into the patient's electronic health record.

by HIPAA. This revision would clarify that newborn screening results could be shared for uses and disclosures beyond treatment, including, but not limited to, payment and care coordination.

The WVHIN believes that implementing its proposed revisions would strengthen the Rule's existing collaborative framework by ensuring that the right participants can obtain newborn screening results in a timely, secure, and reliable manner. Such revisions would also greatly improve the BPH's ability to promote continuity of care of newborns after discharge. The screening results could be used by the newborn's providers, care coordinators, and payors, which could electronically incorporate the information into the newborn's applicable health record and may improve the newborn's care by making this information available in a more timely manner and reducing the opportunity for human error by automating the results reporting process. Ultimately, the WVHIN believes that its proposed revisions can improve compliance, reduce uncertainty about permissible disclosures, and support more consistent statewide implementation of the Rule.

Furthermore, the WVHIN's proposed revisions reflect certain provisions of existing West Virginia law. For example, the AIDS-Related Medical Testing and Records Confidentiality Act, W. Va. Code § 16-3C-1 *et seq.*, and its applicable rule at W. Va. Code R. § 64-64-1 *et seq.* both detail how human immunodeficiency virus (HIV) test results may be accessed through the WVHIN's health information exchange and how such results may be used in accordance for purposes permitted by law.² Additionally, the Reportable Diseases, Events and Conditions Rule, W. Va. Code R. § 64-7-1 *et seq.*, details how certain entities can engage in electronic reporting via the WVHIN's health information exchange.³ The WVHIN's proposed revisions significantly track language of this existing law.

The WVHIN's proposed revisions pertaining to each section of the amendments to the Rule are detailed below:

1. § 64-91-3. Definitions.

The WVHIN proposes that a definition be added for the term "Permitted Purpose" at § 64-91-3.11:

3.11 Permitted Purpose -- A disclosure permitted by the Health Insurance Portability and Accountability Act of 1996, as amended, or a disclosure consented to or authorized in accordance with applicable law.

Furthermore, the term "West Virginia Health Information Exchange" or "WVHIN" should be defined at § 64-91-3.15 as the following:

3.15 West Virginia Health Information Exchange ("WVHIN") -- The health information exchange that is operated by the West Virginia Health Information Exchange, Inc., a West Virginia nonprofit corporation, that is recognized by the State of

² See W. Va. Code § 16-3C-1(p) (defining a "Permitted Purpose" to include disclosures permitted by HIPAA); § 16-3C-3(5) (detailing that health care providers and health facility personnel may disclose HIV-test results for a Permitted Purpose or as permitted by law); § 16-3C-3(10) (detailing that disclosures of HIV-related test results may be made to "persons, health care providers, or health facilities" through a health information exchange, like the WVHIN, and that disclosures may be made for a Permitted Purpose); W. Va. Code R. § 64-64-8.5 (providing that HIV test results may be disclosed to facilitate health information exchanges).

³ See, e.g., W. Va. Code R. § 64-7-1.5 (detailing that the rule is applicable to the WVHIN); § 64-7-2.54 (defining the "WVHIN").

West Virginia pursuant to W. Va. Code § 16-29G-1a et seq., and whose purpose includes facilitating the electronic exchange of health information as required and/or permitted by applicable federal and/or state law by and among authorized WVHIN users that have been authorized to access the WVHIN in accordance with applicable participation agreements and policies governing access to and use of the WVHIN.

2. **§ 64-91-8. Screening Reporting and Assistance to Afflicted Children.**

The WVHIN proposes that a new W. Va. Code R. § 64-91-8.4 be inserted as follows:

8.6 The Bureau, the state laboratory, a birthing facility, a primary care provider, or other person or entity responsible for reporting, receiving, maintaining, or transmitting newborn screening results under this rule may disclose newborn screening results to facilitate the WVHIN.

3. **§ 64-91-9. Confidentiality.**

As detailed above, WVHIN requests that W. Va. Code R. § 64-91-9.1 be clarified to expressly permit both uses and disclosures of confidential information that are “permitted by” applicable law as opposed to the current language that only provides for “required” disclosures. Furthermore, a caveat should be added to W. Va. Code R. § 64-91-9.2 because authorized WVHIN users are bound to maintain confidentiality in accordance with applicable federal and state law by virtue of executing participation agreements with the WVHIN. Accordingly, the WVHIN requests that this section be revised to the following:

9.1 Confidential information obtained while performing the required screenings may only be ~~disclosed to~~:

9.1.a Disclosed to ~~Reporting~~ reporting sources;

9.1.b. Disclosed to ~~Persons~~ persons demonstrating a need essential to health-related research or care of the infant; or

9.1.c. Used and disclosed for a Permitted Purpose and/or ~~As~~ as required and/or permitted by applicable federal and/or state law.

9.2. Prior to receipt of confidential information, the requestor must agree to maintain the confidentiality and privacy of the information as required by law; ~~provided, however,~~ the foregoing agreement shall not be required if such requestor will be receiving the confidential information through authorized access to the WVHIN.

The WVHIN greatly appreciates the opportunity to offer comments and proposed revisions to the Rule. Like BPH, the WVHIN takes great pride in aiding public health in the State of West Virginia.

Sincerely,



Sonia D. Chambers
Executive Director
West Virginia Health Information Network, Inc.