OREGON HEALTH AUTHORITY
Health Policy and Analytics Division
Office of Health IT & Analytics Infrastructure

2026

House Bill 2940 Report

Hemoglobinopathy Emergency Department Notification Program

Acknowledgments

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Executive summary

Report purpose

This report updates the Oregon Legislature on the Oregon Health Authority's (OHA) progress implementing 2025 House Bill (HB) 2940. HB 2940 directs OHA to create a program that alerts emergency departments (EDs) when a patient with a hemoglobinopathy – such as sickle cell disease – arrives for care and provides information on how to contact a hematologist. HB 2940 requires OHA to report to the Legislature on program implementation progress and input gathered from hospitals, hematologists, public health partners, community organizations, and others. The notification program must be implemented by May 1, 2026, subject to available funding.[1]

Health equity context

HB 2940 aims to improve emergency care for Oregonians with hemoglobinopathies, a group of inherited blood disorders that can result in severe pain, life-threatening complications, and inequitable treatment in ED settings.[2,3] The most common hemoglobinopathy in the United States is sickle cell disease.[4] Nationally, more than

90% of individuals living with sickle cell disease are Black,[5] and patients often report experiencing bias, undertreatment of pain, stigma, and delayed care in emergency rooms.[2] Oregon's small sickle cell disease population[6] means clinicians may have limited experience treating this condition, potentially contributing to inequities.

The HB 2940 program seeks to address these inequities by ensuring ED clinicians know when a patient has a documented hemoglobinopathy diagnosis, helping them anticipate complications, provide timely pain management, and engage specialist support, as appropriate. In this way, the program aligns with OHA's goal of eliminating health inequities by 2030.[7]

Report highlights

1. Program implementation is on track and will leverage existing statewide technology infrastructure – the Emergency Department Information Exchange (EDIE).[8]
2. ED notifications will identify patients with sickle cell disease and other hemoglobinopathies and prompt staff to follow their organization's treatment protocols.
3. The program will identify patients using diagnosis data from two sources to maximize program reach: the Oregon All Payer All Claims (APAC) reporting program[9] and the EDIE system, which receives diagnosis data related to hospital events.
4. Consulted partners broadly supported OHA's implementation approach and identified important considerations and opportunities for future work, which this report describes.
5. Core program design, contracting, and funding work are underway and on schedule.

Accessing the full report

This report is available online at: https://www.oregon.gov/oha/HPA/OHIT/Documents/HB2940-Report-Hemoglobinopathy-ED-Notification-Program.pdf.

Background and legislative context

Overview of House Bill 2940

Oregon HB 2940 (2025 Regular Session) directs the Oregon Health Authority (OHA) to establish a program that provides real-time notifications to hospital emergency departments (EDs) when patients with hemoglobinopathies (such as sickle cell disease) present for care. The notifications must provide EDs with information on how to contact a hematologist. The bill requires OHA to consult specified partners to inform program implementation – including hospitals, hematologists, emergency clinicians, public health organizations, and community organizations – and to submit a report on information received and the status of program implementation to the Legislature by March 1, 2026. Implementation of the ED notification program must occur by May 1, 2026, subject to available funding.[1]

Clinical and equity context

Hemoglobinopathies are a group of inherited disorders that affect the structure or production of the hemoglobin molecule in red blood cells. They include conditions such as sickle cell disease and thalassemias. Because hemoglobin is essential for oxygen delivery to tissues, disruptions in its normal function can lead to a range of clinical problems including chronic anemia, fatigue, organ damage, pain crises, and in severe cases life-threatening complications.[3] Over 3,000 Oregonians have been diagnosed with a hemoglobinopathy, according to administrative health care data reported to Oregon's All Payer All Claims Reporting Program.

Sickle cell disease is the most common hemoglobinopathy in the U.S., estimated to affect approximately 70,000 to 100,000 people.[4,10] Sickle cell disease disproportionately impacts Black or African American people, who are estimated to make up over 90% of the disease population in the U.S. The disease is also present among populations with South Asian, Middle Eastern, Hispanic, and Mediterranean ancestry. Sickle cell disease occurs in about 1 out of every 365 Black or African American births and about 1 out of every 16,300 Hispanic American births.[5] Patients with sickle cell disease often require urgent treatment for pain crises, infection, or severe anemia.[4]

HB 2940 aims to address several significant issues faced by patients with sickle cell disease and other hemoglobinopathies in ED settings, including:

- Inadequate pain relief: patients may not promptly receive needed pain management from clinical staff due to a lack of objective indicators of hemoglobinopathy-related pain crises beyond their reports of pain.[11]
- Accusations and stigma: patients are sometimes wrongfully accused of exaggerating their pain or exhibiting drug-seeking behavior, leading to undertreatment.[2]
- Lack of understanding: many healthcare providers lack sufficient knowledge about sickle cell disease and related hemoglobinopathies, especially in Oregon, which has a small sickle cell disease population.[6]
- Incomplete medical records: patients' hemoglobinopathy diagnoses may not be included in their medical records at all hospitals they visit, especially when traveling, hindering appropriate and timely care.

By alerting ED staff when a presenting patient has a sickle cell disease or other hemoglobinopathy diagnosis and offering guidance on how to contact a hematologist, this program aims to help staff anticipate potential complications, prioritize rapid pain management, and tailor treatment plans accordingly. The program supports OHA's goal to eliminate health inequities by 2030 by potentially improving emergency care for populations historically affected by systemic inequities in access and treatment.[7]

Existing infrastructure: EDIE/PointClickCare

OHA intends to use the Emergency Department Information Exchange (EDIE) technology platform to support the notification component of the HB 2940 program. Operated and governed by HIT Commons,[8] EDIE is Oregon's statewide infrastructure to share critical hospital information across the health care system. EDIE enables secure, real-time notifications to EDs, intended to share brief, actionable information on how to provide the best care for the patient while in the ED. PointClickCare is the technology vendor that provides EDIE services. Hospitals also send real-time event data to EDIE when patients are admitted to, discharged from, or transferred between ED and inpatient hospital settings. The EDIE/PointClickCare platform in Oregon also provides access to hospital event notifications to organizations outside of hospital

settings, such as coordinated care organizations, payers, dental plans, ambulatory clinics, and state agency programs, to support care coordination activities. OHA contracts with PointClickCare to provide platform access to certain entities coordinating care for Medicaid patients in Oregon and to support specific projects that utilize the EDIE notification mechanism.

Leveraging EDIE for the HB 2940 program offers several advantages:

- Integration: EDIE notifications are already embedded into hospital ED workflows.
- Statewide coverage: every Oregon ED participates in EDIE except Veterans Affairs (VA) hospitals.
- Efficiency and cost savings: using existing infrastructure avoids the expense and time required to design and deploy a new statewide notification platform.

Scope of the report

This report fulfills HB 2940's statutory requirement for OHA to update the Oregon Legislature on the status of program implementation and information gathered from consultations with interested partners. The report summarizes program design and input from partner engagement; outlines limitations and remaining gaps; and identifies next steps toward full implementation.

Program implementation and status

Implementation approach

OHA's approach to implementing the program mandated by HB 2940 was informed by impacted community partners. A summary of partner input is provided in the section below. The program will use the existing EDIE/PointClickCare software platform to facilitate hemoglobinopathy notifications to hospital EDs using the platform in the U.S. and Canada. Details about program data privacy and security are provided in the Privacy and security section below.

The program integrates three key components:

1. **Patient identification**

   Data from multiple sources will be used to identify as many individuals diagnosed with hemoglobinopathies as possible for inclusion in this program's notifications:

   - Oregon All Payer All Claims (APAC) reporting program[9]: OHA will use health care claims data reported to APAC to identify individuals diagnosed with hemoglobinopathies using standardized diagnosis codes (ICD-10).
   - PointClickCare: PointClickCare will use real-time hospital event data fed from its network of participating hospitals to identify individuals diagnosed with hemoglobinopathies using standardized diagnosis codes (ICD-10).

2. **Notification routing**

   When a patient with a hemoglobinopathy registers in the ED of a hospital using EDIE, the platform will automatically issue a real-time alert to ED clinicians. The alert will display a brief notice indicating the patient's hemoglobinopathy status and a statement suggesting that staff follow organizational protocol for contacting a hematologist to support care delivery and coordination, as needed. Separate alerts will be generated for sickle cell disease as opposed to other hemoglobinopathies. See the Notification content section below for more detail on notification language.

   Most Oregon hospitals have configured EDIE alerts to be viewed within the normal electronic workflow of their ED clinicians, i.e., within their electronic health record, or digital charting, software. Some Oregon hospitals receive EDIE alert content via fax or secure ED network printer delivery. These hospitals tend to be rural and/or critical access hospitals that are not using a major electronic health record software platform, such as Epic or Oracle.

3. **Hematologist contact**

   To provide information on how to contact a hematologist in real time, the program's notifications will include a general statement to ED staff suggesting they follow their organizational policies and procedures for contacting a hematologist, as needed. Based on guidance from Oregon hospital ED leaders

and the Hospital Association of Oregon, the program will avoid mandating or altering internal hospital ED clinical protocols around consulting a hematologist when a presenting patient has a known hemoglobinopathy.

Technical design highlights

Notification type

OHA will utilize an EDIE/PointClickCare software functionality called “Flags” to categorize patients with hemoglobinopathies and route notifications to EDs. Flags provide information that applies across a specific patient population in an automated fashion. The platform also allows users to manually enter patient-specific care considerations to be included in ED notifications, known as “Insights”.

While Insights entered by a patient’s care team may support improved patient treatment and experience in acute care settings, OHA and consulted partners agreed that Flags should be used for this program’s notifications given the following circumstances:

- Flags can be implemented without manual work by a patient’s provider(s) allowing for more hemoglobinopathy patients to benefit from the program.
- OHA does not have an active, appropriate, and/or enforceable policy lever to require providers to adopt the EDIE/PointClickCare platform and manually enter information about their hemoglobinopathy patients.
- Flags can only be added, removed, or edited by the authoring organization, ensuring OHA has control of the content of the program’s ED notifications.
- Flags require limited staff resources to operate, allowing for automation of data delivery, patient identification, and notification routing once implemented. Insights require more manual upkeep, only generating ED notifications for 18 months (unless edited or updated).
- ED clinicians report they would see value in receiving flag-driven notifications that identify patients with sickle cell disease or other hemoglobinopathies, potentially being able to respond more swiftly and appropriately to the treatment needs of this population in an emergency setting.

Notification content

Two types of notifications will be established: one capturing patients with known sickle cell disease diagnoses and the other patients with known hemoglobinopathy diagnoses other than sickle cell disease. Partners recommended specifying sickle cell disease distinctly from other hemoglobinopathies due to the known, specific challenges faced by sickle cell disease patients seeking emergency care.

The language displayed to clinicians in these notifications will be as follows:

- Notification category #1: “Sickle cell disease – claims or other clinical records indicate this patient has a sickle cell disease diagnosis. Please refer to your organization’s treatment protocols, including consulting a hematologist, as needed.”
- Notification category #2: “Non SCD hemoglobinopathy - claims or other clinical records indicate this patient has a hemoglobinopathy diagnosis other than sickle cell disease. Please refer to your organization’s treatment protocols, including consulting a hematologist, as needed.”

Data sources

As mentioned above, the program will use hemoglobinopathy diagnosis information from two sources to support patient identification. Additional details about these data sources is provided in this section.

- All Payer All Claims (APAC) reporting program database: APAC collects and houses administrative health care data on Oregonians who receive coverage through commercial insurers, Medicaid, and/or Medicare. APAC receives data on most Oregon residents except those who are uninsured, covered by Federal programs such as Tricare or VA, covered by commercial insurers or third party administrators that cover fewer than 5,000 Oregonians, or covered by self-insured plans not reporting to APAC.[12] Health care claims are typically reported to APAC between two and twelve months from the date of service.
- PointClickCare hospital event feeds: PointClickCare receives hospital admission, discharge, and transfer (ADT) data feeds from participating hospitals, which provide real-time information about patient encounters and

care transitions. Over 2,700 hospitals[13] in the US and Canada, including all Oregon hospitals (except the VA), contribute ADT data to PointClickCare. While ADT data typically include diagnosis codes, the completeness of these data can vary based on how hospitals capture and code information in their ADT data feeds, and diagnosis details are not always included.

Privacy and security

The HB 2940 program is designed with a strong commitment to data privacy and security. All data handling and notification processes will comply with the Health Insurance Portability and Accountability Act (HIPAA)[14] to ensure the protection of patient health information. The program will leverage the EDIE platform operated by PointClickCare, which is HITRUST[15] certified, demonstrating adherence to rigorous information security standards. Data used to identify patients with hemoglobinopathies – such as claims from Oregon's APAC reporting program – will be managed in accordance with OHA data governance policies and privacy safeguards. These measures ensure that patient information is accessed and shared only for authorized purposes and within secure, compliant systems.

Funding approach

No dedicated funding was allocated by the Oregon Legislature for this program. OHA is utilizing existing staff resources to support the design, development, and implementation phases. To support program sustainability, OHA may seek ongoing General Fund support for continued operations, including technology costs. In addition, OHA is pursuing federal Medicaid Enterprise Systems cost sharing to help offset ongoing operational expenses.

Program communications

OHA and HIT Commons will develop materials with information about the program to accompany its launch. The materials will be made available online and aim to educate EDIE users about the new notifications.

Status of implementation (as of January 27, 2026)

Program implementation remains on track, with core design, contracting, and funding activities proceeding as planned. OHA completed partner engagement and received

broad endorsement of the proposed technical and programmatic approach to implementing HB 2940 (see the Partner consultation section for more information).

A contract amendment with PointClickCare is in progress and expected to be executed in early 2026, enabling configuration, testing, and implementation of new hemoglobinopathy notifications in EDIE to begin. OHA is also finalizing a federal cost-sharing request to the Centers for Medicare & Medicaid Services, with submission expected by the end of 2025. A request to utilize APAC data for the program is in progress, and if approved, design of data delivery to PointClickCare is expected to begin in January 2026. While some risks to successful program implementation remain (as detailed in the Limitations and remaining gaps section below), overall, OHA anticipates meeting the statutory implementation and legislative reporting requirements established under HB 2940.

Limitations and remaining gaps

While program implementation is proceeding as planned, several limitations may affect program performance, measurement, and impact.

The program intentionally **does not establish a registry or require direct patient enrollment**, which means it will not capture the entire population of individuals with hemoglobinopathies who may seek emergency care in Oregon. Instead, the program will rely on two primary data sources – the APAC database and hospital diagnosis data from PointClickCare – to identify and flag patients. As a result, notifications will be limited to patients whose data appear in one or both systems, leaving out certain groups. For example, uninsured hemoglobinopathy patients, individuals who do not reside in Oregon, and insured Oregon patients who have not received health care in the claims time period will not have claims records in APAC.

The APAC dataset does not include Social Security Numbers, which means that **patient matching accuracy rates** across systems have the potential to be lower, which may reduce the number of individuals correctly identified in the EDIE environment for notifications. As described above, OHA will supplement APAC data with hospital diagnosis data from PointClickCare to increase the proportion of hemoglobinopathy patients who receive ED notifications.

Funding and resource uncertainty could affect the long-term sustainability of the program. Although the 2025-27 OHA agency budget currently supports planned activities, potential reductions during the 2026 session or other resource constraints within OHA could limit ongoing program funding.

Measurement and evaluation constraints may limit the ability to assess the impact of the program. The EDIE platform can track where and when notifications are sent, but it cannot confirm whether ED clinicians review or act upon the notification content. This limits OHA's ability to measure the direct clinical impact of the notifications. OHA will contract with PointClickCare to receive reporting on where and when notifications are sent to hospitals. OHA may consider gathering feedback on the program from hospitals, patient advocates or others over time, depending on resources.

Partner consultation

Approach and participation

HB 2940 requires that OHA consult with interested partners to inform OHA in implementing the program, including hospitals, hematologists, emergency clinicians, public health organizations, and community organizations. OHA staff identified partners for consultation by leveraging connections through existing contacts and contacting other partners that met the requirements of the bill. OHA presented an overview of the bill, the EDIE/PointClickCare platform and the proposed program implementation approach to identified partners. OHA then met with partners individually to solicit their input on the program approach, their experience with patients with hemoglobinopathies, and any additional insights.

View Appendix A: list of partners consulted for a full list of consulted partners, their titles and organizational affiliations.

Overall support

Consulted partners broadly supported OHA's implementation approach and identified important considerations and opportunities for future work, which are described in the following sections.

Partner input on implementation approach

OHA's proposed implementation approach, to use Flags in the EDIE platform, was supported by nearly all partners interviewed. Partners generally felt that this approach would be a positive step in supporting ED clinicians to better care for hemoglobinopathy patients, with one provider sharing that prompt notification of a known diagnosis will help save time in their workflow. OHA initially proposed a single Flag for any hemoglobinopathy, but several partners mentioned that it would be more valuable to have two Flags: a sickle cell disease specific Flag, and a Flag for all other hemoglobinopathies. OHA adjusted its approach given this advice.

Local public health officials shared they do not have specific programs serving the sickle cell and other hemoglobinopathy population but acknowledged the existence of unfair bias and assumptions influencing the care of patients that visit the ED for hemoglobinopathy-related pain crises.

Staff also consulted with OHA's Public Health Division on their Northwest Regional Newborn Bloodspot Screening Program, which is designed to identify infants affected by specific medical conditions in time to prevent impairment.[16] This program tests all babies born in Oregon for both sickle cell disease and trait. The program identifies fewer than five newborns with sickle cell disease per year and approximately 180 newborns with sickle cell trait (carriers) per year. Due to the small number of infants identified per year, the bloodspot screening program will not be used as a data source for the HB 2940 program.

Some partners cautioned OHA on using EDIE to support condition-specific notifications and expressed concern that adding more notifications for providers to view contributes to notification fatigue (i.e. monitoring an excessive number of alerts) and may not be valuable in improving patient care. One partner shared that this approach has the potential to further single out sickle cell disease over other conditions not flagged in EDIE, possibly leading to additional marginalization and stereotyping of these patients as high burden. Other concerns included that the EDIE notifications will not contain patient-specific care plan information, making the information less actionable at the point of care. Additionally, one partner reported that notifying ED clinicians to contact a hematologist as needed may interrupt hospitals'

preferred clinical workflows, causing clinicians to reach out to hematologists preemptively with little information or without patient consent.

The HIT Commons, the entity that governs EDIE in Oregon and disseminates best practices for adoption and use of the platform, hosts the EDIE Notification Advisory Committee (ENAC). ENAC reviews new content proposed for EDIE notifications and vetted the proposed program implementation approach and notification language. They raised the sentiment that future state legislation should not dictate how patient care is delivered in the emergency department or what content is included in EDIE notifications. ENAC requested being consulted as early as possible if future legislative concepts implicating use of EDIE are developed.

One partner recommended interviewing a patient with sickle cell disease to help inform the program design. Although OHA interviewed the Sickle Cell Anemia Foundation of Oregon, staff ultimately did not identify a patient representative to consult as part of the design and development of the program.

Considerations for future work

Consulted partners raised several matters that could be considered for future work in support of improving the care and experience of hemoglobinopathy patients in EDs.

Some partners suggested providing more patient-specific care plan information in EDIE notifications using the Insights feature (see the Notification type section above), as it is more patient-centric than flagging general condition diagnoses. OHA or HIT Commons could also support greater adoption of the EDIE/PointClickCare platform by hematologists and encourage appropriate use of the Insights feature to push care information to EDs. OHA and HIT Commons worked with one hematologist interested in contributing to Insights. OHA and HIT Commons will continue to explore opportunities to support hematologist adoption of the platform, such as sharing best practices and resources developed by HIT Commons.

One partner raised the importance of measuring success of the program and the potential difficulties in doing so (see the Limitations and remaining gaps section above). Subject to resource availability, OHA plans to monitor the technical implementation of this program's notifications over time and solicit qualitative feedback

from ED clinicians on their experience with the notifications at quarterly HIT Commons ENAC meetings, subject to resource availability.

Although partners generally thought adding EDIE notifications for hemoglobinopathy patients would be valuable, technology is only one component in addressing bias or lack of timely, effective treatment. One partner shared that additional opportunities for training Oregon clinicians on culturally competent best practices for treating patients with sickle cell disease or other hemoglobinopathies may be valuable, given that the relatively small prevalence of these conditions in Oregon limits opportunities for clinical exposure.

No recommendations for policy changes or new legislation emerged from OHA's partner consultations on the design and implementation of this program.

Appendix A: list of partners consulted

Conference of Local Health Officials' Health Officer Caucus

- Carolina Amador, Health Officer, Benton County
- Adam Brady, Health Officer, Linn County
- David Candelaria, Health Officer, Josephine County
- Bob Dannenhoffer, Health Officer, Douglas County
- Emilio DeBess, State Public Health Veterinarian, OHA
- Tom Duncan, Health Officer, Clatsop County
- Teresa Everson, Deputy Health Officer, Multnomah County
- Rich Fawcett, Health Officer, Deschutes County
- Tom Jeanne, Deputy Health Officer, Oregon Health Authority
- Kathleen Wilder, Health Officer, North Central Public Health District
- Sarah Lochner, Executive Director, CLHO Coalition of Local Health Officials
- Patrick Luedtke, Health Officer, Lane County
- Lydia Luther, Section Manager, Immunization, OHA
- John Mahan, Health Officer, Jackson County
- Sarah Present, Health Officer, Clackamas County
- Dean Sidelinger, State Health Officer, OHA
- Melissa Sutton, Medical Director, Respiratory Viral Pathogens, OHA
- Christopher Van Tilburg, Health Officer, Hood River County
- Deborah Woodbury, Health Officer, Umatilla County

HIT Commons EDIE Notification Advisory Committee (ENAC)

- Samara Brusati, RN, IS Application Analyst, Providence
- Hans Notenboom, MD, Medical Director, Tracktown USA

Hospital Association of Oregon

- Katie Harris, Associate Vice President of Policy and Federal Advocacy
- Travis Meuwissen, Director of Government Affairs

Kaiser Permanente

- Nick Mulcahy, DO, Emergency Physician in Charge, Kaiser Permanente Sunnyside Medical Center
- Jennifer Walker, DO, Regional Chief of Emergency Medicine, Kaiser Permanente Sunnyside Medical Center
- Alisa Zook, MSN, RN, CNML, NE-BC, CCRN, ED Care Without Delay Director, Kaiser Permanente Sunnyside Medical Center

Legacy Health

- Cameron Klug, MD, Vice President and Hospital Chief Medical Officer for Legacy Health Willamette Region

OHA Northwest Regional Newborn Bloodspot Screening Program, Public Health Division

- Amber Gamel Miller, Public Health Nurse, Newborn Screening Program
- Patrice Held, Newborn Screening Program Manager
- Megan Sanders, Legislative Analyst
- Charina Walker, Public Health Division Legislative Policy Lead

OHSU Hematology and Medical Oncology

- Mortuma Murry, D.N.P., CPNP-AC/PC, Hematology provider
- Trisha Wong, M.D., M.S., Hematology provider

Oregon Representative Travis Nelson

Sickle Cell Anemia Foundation of Oregon

- Marcia L. Taylor, Executive Director/Founder

Note: OHA staff were unable to identify emergency medical technicians or paramedics interested in being consulted for this program.

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