American Society of Hematology
Helping hematologists conquer blood diseases worldwide

July 23, 2026 *Submitted via ONC portal*

Thomas Keane, MD, MBA
National Coordinator for Health Information Technology
Office of the National Coordinator for Health Information Technology
U.S. Department of Health and Human Services

Re: USCDI+Sickle Cell Disease: Request for Public Feedback

Dear Dr. Keane,

On behalf of the American Society of Hematology (ASH), thank you for the opportunity to comment on the draft USCDI+ Sickle Cell Disease (SCD) Diagnosis and Emergency Care use cases. ASH supports the Office of the National Coordinator for Health Information Technology's (ONC) effort to improve the exchange of health information needed to provide timely, high-quality care for people living with SCD and to address the fragmentation that patients experience across health care settings. We appreciate ONC's focus on improving care access, treatment, service coordination, research, and reducing health disparities through a shared SCD data infrastructure.

ASH represents more than 18,000 clinicians and scientists committed to studying and treating blood and blood-related diseases. These disorders encompass malignant hematologic disorders such as leukemia, lymphoma, and multiple myeloma, as well as classical hematology conditions such as SCD. ASH members include basic, translational, and clinical scientists, as well as physicians providing direct patient care. For over a decade, ASH has sustained a multifaceted commitment to improving the lives of individuals living with SCD, which has grown into a globally recognized initiative spanning clinical care, research, workforce development, advocacy, and multidisciplinary stakeholder collaboration. ASH serves as a convener, catalyst, and champion, mobilizing stakeholders, shaping systems, and delivering tools that support measurable progress in advancing access to high-quality care, prioritizing high-impact research, and promoting coordinated action on SCD.

In 2018, ASH established the ASH Research Collaborative (ASH RC) to foster partnerships that accelerate progress in hematology and improve the lives of people affected by blood diseases. The ASH RC Data Hub was created to facilitate the secure aggregation and exchange of high-quality, curated data on hematologic diseases to support scientific inquiry and improve clinical care. Its SCD program reflects ASH's longstanding commitment to developing a data infrastructure that supports better evidence generation, care delivery, and outcomes for people living with SCD.

ASH has elected not to submit comments on individual data elements at this stage, as we believe it is most appropriate for individual clinicians to share their perspectives on specific elements. The Society has encouraged ASH members to provide feedback directly to ONC regarding these data elements. Instead, based on discussions with the Society's clinical and informatics experts, we offer the following recommendations to help ensure that the eventual USCDI+ SCD standard is clinically meaningful, technically feasible, and trusted by the clinicians and patients it is intended to serve.

Accuracy, Specificity, and Provenance

ASH strongly supports the goal of identifying individuals with SCD consistently across care settings and the program should prioritize accurate and clinically validated identification over maximizing the number of records captured. Our own experience in development of the ASH RC Data Hub illustrated that many individuals without SCD may have this diagnosis in their electronic health record (EHR) data. Inaccurate or insufficiently specific diagnoses can lead to inappropriate clinical decisions, flawed research conclusions, and diminished trust in exchanged information. The diagnosis use case appropriately recognizes the importance of communicating SCD subtype, which is essential to anticipating complications and personalizing treatment. ONC should establish a clear approach for communicating diagnosis provenance and verification status. Clinicians receiving information should be able to determine whether a diagnosis is based on laboratory confirmation, a specialist assessment, a problem-list entry, or another source, as well as when it was last confirmed. This is especially important where diagnoses may be carried forward in a record, documented in free text, or derived from incomplete historical information. The draft request appropriately seeks feedback on whether provenance is sufficient to trace a diagnosis and acknowledges the challenge of maintaining accurate, current diagnoses in EHR problem lists.

Clinical Usefulness at the Point of Care

The value of USCDI+ SCD will depend on whether it changes what a clinician can reliably see and use during an actual clinical encounter. In particular, emergency medicine clinicians need timely, structured, and readily interpretable information, not simply an expanded set of information somewhere in the record. ONC's emergency care use case correctly identifies the importance of relevant diagnoses, laboratory results, procedures, treatment history, medications, care plans, and pain management plans when caring for a person with SCD during an acute episode.

ASH recommends that ONC define the intended clinical workflow for each use case and make clear which information must be available in an actionable, structured form at the point of care. For example, our experts noted that clinically consequential information, such as transfusion history, including the date and type of transfusion, and current medications, may exist in another institution's record but is not consistently visible or readily accessible through existing exchange workflows. Making this information available in structured, usable form could materially improve emergency care and longitudinal care coordination.

Implementation Clarity and Testing

ASH's experts raised an important practical question: what will be different for a clinician, patient, or health system if the USCDI+ SCD use cases are adopted? Some of the concepts under consideration may already be represented in USCDI or captured in individual EHRs, but may not currently be exchanged in a way that is useful for SCD care. ONC should clearly distinguish between information already available in existing standards, information that is newly prioritized for SCD exchange, and information that requires new implementation.

ONC should also publish simple, use case specific workflow diagrams that show the current state of data availability and exchange, the future state if USCDI+ SCD is implemented, the source of each data type, and how the information is displayed to a receiving clinician. This would help clinicians, patients, implementers, and other stakeholders understand the operational impact of the standard and provide more focused feedback. ASH experts specifically recommended a comparison of current and future data flows to clarify how the proposed work would improve clinical and research access to information.

Before broad implementation, ASH recommends that ONC consider conducting pilots in diverse care environments, including pediatric and adult SCD programs, emergency departments, community hospitals, and systems that routinely exchange records across organizational boundaries. These pilots should assess whether the information is available when needed, accurate, complete, timely, understandable to receiving clinicians, and interoperable across EHR products. ONC indicated that pilot testing will be necessary to determine what information is returned, whether it can support care, and whether systems can deliver it in a timely manner.

Separation of Clinical Care and Secondary Uses

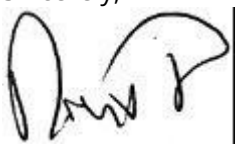
ASH recognizes the potential of better data exchange to support both clinical care and evidence generation, including the ability to understand outcomes across sites for people receiving transformative (e.g., gene-editing) therapies. At the same time, the program should be explicit about the distinction between information exchanged for direct patient care and information used for research, surveillance, quality measurement, or other secondary purposes.

Any secondary use must be supported by appropriate governance, privacy protections, permissions, and transparency for patients and participating institutions.

We appreciate and applaud the ONC for the robust community input that is part of this USCDI+ initiative. We sincerely hope the opportunity remains for ongoing input from stakeholders, including ASH, as the Sickle Cell Disease Diagnosis and Emergency Care use cases are implemented and evolve. Additionally, ASH appreciates ONC's leadership in advancing a more interoperable and patient-centered approach to SCD care. The Society recommends that ONC prioritize validated and well-provenanced information; specify how the proposed use cases will improve clinical decision-making at the point of care; clearly communicate the difference between current and future exchange capabilities; and test implementation across real-world settings before broad adoption. These steps will help ensure that USCDI+ SCD delivers meaningful improvements for people living with SCD, the clinicians who care for them, and the health systems and researchers working to improve outcomes.

Thank you again for this opportunity to provide feedback. Should you have any questions or require further information, please contact ASH's Director, Government Relations and Public Health Stephanie Kaplan at 202-776-0544 or *skaplan@hematology.org*.

Sincerely,



Robert Negrin, MD
President