



Ocular Health and National Data Standards: A Case for Including Visual Acuity in the United States Core Data for Interoperability (USCDI)

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Health care data standards are critical for information exchange between clinical information systems such as electronic health record systems, imaging devices, and picture and archiving communication systems. Data standards are also important for facilitating care coordination for patients across different care settings. Recent federal regulations such as the 21st Century Cures Act have brought health care data standards to the forefront of national discourse. While the need for greater adoption of imaging data standards in ophthalmology has been recently highlighted,¹ there is, similarly, an ongoing need to expand other data standards for ophthalmology.² Health care data standards applicable to other areas of medicine often do not take into account the unique data elements captured in an eye exam. Here, we provide an overview of the United States Core Data for Interoperability (USCDI), a standardized set of data elements intended to enable nationwide, interoperable health information exchange.³ Furthermore, we discuss some reasons why ocular data elements should be included in the USCDI, with reference to specific use cases published in the ophthalmology literature that demonstrate the potential public health impact of including these elements.

Overview of the USCDI

The 21st Century Cures Act, signed into law in December 2016,⁴ was designed to help accelerate medical product development and bring new innovations for patients who need them faster and more efficiently.⁵ One important aspect that the law addresses is data sharing in the context of health information technology. Specific elements that are required to be exchanged are organized under the USCDI.

The regulations adopted to satisfy the 21st Century Cures Act set the expectation that elements of a patient's health information that are stored electronically should be available in

patient-facing health care applications and able to be exchanged easily among health information systems such as electronic health records and patient portals. Such exchange has been challenging due to different representations of the same data across diverse clinical systems.⁶ The approach taken to overcome this challenge has been to define a minimum set of specific data elements within specific health data classes for information that need to be exchanged between vendors. The goal of USCDI is to delineate a core set of structured and unstructured elements needed to support patient care and patient access across health information technology.

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Additionally, these harmonized data elements would ideally also be relevant across use cases outside of clinical care and patient access, such as research and technology development. The USCDI will expand over time in an incremental process that will include collaboration and public engagement.

The USCDI defines *data elements* as granular data that are organized into *data classes*. For example, the vital signs data class includes body temperature as a data element. To comply with USCDI, clinical systems are required to record body temperature using a standard coding system (Logical Observation Identifiers Names and Codes)⁷ and the unit of measure (e.g., Cel, defF) with Unified Code for Units of Measure. In this way, the USCDI sets a foundation for increased standardization to enable clinical data sharing in order to improve patient care.

Over time, the Office of the National Coordinator for Health Information Technology (ONC), part of the U.S. Department of Health and Human Services, will solicit suggestions for the expansion of the USCDI and will set realistic timelines for incorporation of new data elements and their interoperability requirements. Through continued expansion, future versions of the USCDI will be certified. At the time of writing, the ONC is considering additional data elements for USCDI, Version 3 (v3), prioritizing elements that focus on mitigating health and health care inequities and

disparities; addressing the needs of underserved communities; and addressing public health reporting, investigation, and emergency response.

Advocacy for Including Ocular Data Elements in the USCDI

The National Institutes of Health has encouraged researchers to adopt and use the USCDI standards.⁸ In this vein, the National Eye Institute has submitted public comments to support the addition of ocular data elements (refraction, visual acuity, and intraocular pressure) to the USCDI. These ocular elements were designated as level 1, meaning that the elements require more well-defined use cases and stated value to potential users. The USCDI v3 has a clinical test data class that includes “nonimaging or non-laboratory test performed on a patient” with a proposed required minimum set of data elements based on Logical Observation Identifier Names and Codes (LOINC). This is currently the USCDI data class in which the ONC plans to include ocular data. The authors believe that while some ophthalmic data should be a core data element (i.e., vision) within this minimum set, it would also be beneficial for the ophthalmic community to develop a more robust list of elements that should be included in a comprehensive stand-alone ocular data class, i.e., not bundled within the general clinical test data class. A well-defined, standardized ocular data class, for example, can potentially help improve patient care through predictive analytics, which depends on standardized inputs. Having ocular data readily available across care settings and institutions could also enable longitudinal surveillance of patients’ outcomes. In addition to visual acuity, this ocular data class could include elements such as intraocular pressure, refraction, and imaging metrics (e.g., retinal nerve fiber layer thickness, central macular thickness). The exact components of this ocular data class would require input and further engagement from the ophthalmic community.

Here, we focus on 2 specific use cases illustrating how including visual acuity as a core data element aligns with the focus areas for USCDI and would have widespread, cross-cutting public health impact: (1) diabetic retinopathy screening and (2) children’s vision screening.

Diabetic Retinopathy Screening

Diabetic retinopathy is the most common microvascular complication of diabetes and the leading cause of blindness and visual impairment among working-age adults in the United States. Clinical guidelines from the American Academy of Ophthalmology recommend annual screening for diabetic retinopathy,⁹ but prior studies have demonstrated poor adherence to these guidelines.^{10,11} Racial and ethnic minorities are more likely to be affected by vision-threatening complications from diabetic retinopathy complications and have lower rates of eye care utilization.¹² A recent analysis found that individuals residing in more disadvantaged neighborhoods (based on the

neighborhood deprivation index) were also significantly less likely to undergo diabetic retinopathy evaluation.¹³ Once vision-threatening diabetic retinopathy is detected, rates of becoming lost to follow-up increase for racial minorities and patients residing in areas with lower regional adjusted gross income.¹⁴

Diabetic retinopathy is clearly a condition where health disparities abound. Including visual acuity in the USCDI would assist in conveying the vision status (and potentially screening status) of individuals diagnosed with diabetes across the spectrum of their care, which is often complex and involves multiple specialties. Furthermore, because diabetic retinopathy screening facilitates early detection and treatment that can mitigate the risk of vision loss, it is a key quality metric in overall diabetic care and incorporated into incentive programs such as the Merit-based Incentive Payment System and quality metrics such as Healthcare Effectiveness Data and Information Set measures. Both of these metrics involve multiple specialties beyond ophthalmology, including family medicine, internal medicine, and endocrinology. Although some patients with diabetic retinopathy may not have decreased visual acuity, the lack of any visual acuity measurement would at least help highlight potential gaps in DR screening, particularly in non-ophthalmic settings such as primary care. Incorporating visual acuity into the USCDI would facilitate public health reporting to monitor eye examinations and diabetic retinopathy screening at a population scale and identify gaps, providing key data to inform future, coordinated efforts at narrowing current inequities.

Children’s Vision Screening

Another key example of the broad applicability of visual acuity as a core data element for interoperability is children’s vision screening. The U.S. Preventive Services Task Force recommends vision screening at least once in all children aged 3 to 5 years.¹⁵ The Affordable Care Act goes further and has mandated that pediatric vision care (for children under the age of 19 years) should be included as one of its 10 essential health benefits. Subsequently, children’s visual acuity is frequently measured during pediatric primary care well-child visits and in school-based screening programs. Early detection of decreased visual acuity can facilitate early diagnosis of amblyopia, a treatable condition. Decreased vision in children can also sometimes be a sign of early onset myopia, which is a risk factor for high or pathologic myopia as an adult, causing irreversible vision loss. Correcting refractive error in childhood can optimize academic performance,^{16–18} and documentation of decreased visual acuity can also enable children to receive additional educational and social support services. Therefore, the impact of monitoring visual acuity measurement in children is broad, reaching far beyond ophthalmology and optometry alone. Including visual acuity in the USCDI would facilitate information exchange regarding pediatric vision across health care settings and also help with monitoring compliance with the Affordable Care Act mandate.

Broad Implications of Including Visual Acuity in the USCDI

Besides the 2 specific use cases illustrated above, including visual acuity in the USCDI core data set would be broadly important for incorporating vision care as a key component of overall health and well-being. It is well known that aging places individuals at a higher risk of eye disease, especially for cataract, glaucoma, and macular degeneration.¹⁹ Many of these diseases are asymptomatic in the early stages, where detection and treatment are paramount to prevent future visual impairment. Unfortunately, literature shows that people are less likely to receive regular eye exams as they age, right at the highest-risk time in their lives.¹⁹ Furthermore, as the population continues to age, these ocular diseases will become more prevalent. Regularly measuring visual acuity in the primary care setting and tracking it in a uniform manner in health information technology will emphasize the importance of vision care, helping to identify those who need to be referred to eye care providers for evaluation. In addition, being able to trend visual acuity over time for patients with established eye conditions (e.g., cataracts) may help with monitoring/surveillance across care settings to help identify the point where they reach the threshold for an intervention (e.g., cataract surgery), again assisting with prompt referral to eye care providers when appropriate.

Moreover, it is well known that vision impacts people's quality of life, with visual impairment linked to increased morbidity and mortality. Visual impairment has been linked to increased falls, higher risk of going to nursing homes,²⁰ and greater self-isolation and depression. Having visual acuity as part of the medical record in other nonophthalmic visits will allow for more holistic care of the patient. For example, if a geriatrician knows their patient has decreased vision, regardless of the etiology or likelihood of permanence, precautions can be taken to minimize falls and depression. Furthermore, if vision is part of USCDI, it can help identify patients who might benefit from low vision rehabilitation or social programs. Finally, quality of life assessments have become central to cost-benefit analyses

and economic evaluations of health care interventions. Given prior studies that demonstrate clear associations between visual impairment and quality-adjusted life years,^{21,22} having visual acuity data readily available across care settings will be useful for conducting these evaluations, particularly as value-based approaches to health care governance are increasing.

Including vision with the other systemic USCDI elements will improve outcomes research and "big data" studies. For example, literature suggests that cataract surgery reduces dementia symptoms and risk.²³ Future studies on dementia treatment could clarify this association. Having visual acuity measurements across the country can also facilitate identification of geographic areas where vision health disparities exist, allowing for public health officials to target these areas for future action.

This group suggests that the USCDI standard for visual acuity accommodates standard notations and includes optional fields to record the test method (Snellen, ETDRS, etc.), distance or near, and correction status (with/without).

Conclusion

Measurement and documentation of visual acuity have far-reaching implications beyond ophthalmology or optometry alone. Vision is intricately linked with a wide range of clinical, economic, and educational outcomes. Including visual acuity in the USCDI would enable improved public health reporting, facilitate the ability to measure and reduce disparities, and help advance ongoing efforts in the development and adoption of data standards relevant to vision and eye health. We urge the ONC to strongly consider including visual acuity in the USCDI.

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