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Vision and Eye Health in Children 36 to <72 Months: Proposed Data System

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ABSTRACT

Purpose. This article provides a rationale for developing an integrated data system for recording vision screening and eye care follow-up outcomes in preschool-aged children. The recommendations were developed by the National Expert Panel to the National Center for Children's Vision and Eye Health at Prevent Blindness and funded by the Maternal and Child Health Bureau of the Health Resources and Services Administration, US Department of Health and Human Services. Guidance is provided regarding specific elements to be included, as well as the characteristics and architecture of such a data system. Vision screening for preschool-aged children is endorsed by many organizations concerned with children's health issues. Currently, there is a lack of data on the proportion of children screened and no effective system to ensure that children who fail screenings access appropriate comprehensive eye examinations and follow-up care.

Results. The expansion of currently existing, or developing integrated health information systems, which would include child-level vision screening data, as well as referral records and follow-up diagnosis and treatment, is consistent with the proposed national approach to an integrated health information system (National Health Information Infrastructure). Development of an integrated vision data system will enhance eye health for young children at three different levels: (1) the child level, (2) the health care provider level, and (3) an epidemiological level.

Conclusions. It is critical that the end users, the professionals who screen children and the professionals who provide eye care, be involved in the development and implementation of the proposed integrated data systems. As essential stakeholders invested in ensuring quality eye care for children, this community of professionals should find increasing need and opportunities at local, state, and national levels to contribute to cooperative guidance for data system development. (Optom Vis Sci 2015;92:24–30)

Key Words: children's vision, vision screening, integrated medical database, integrated health care, State Immunization Information System (SIIS)

The Maternal and Child Health Bureau established the National Center for Children's Vision and Eye Health (NCCVEH) to recommend methods that would increase

rates of vision screening and eye examinations in children aged 36 to younger than 72 months. The NCCVEH facilitated an independent expert panel of professionals in eye care, pediatrics, and related fields; this panel established guidelines, recommendations for data collection, and performance measures to track national goals related to children's visual health. The rationale and process used to develop the recommendations are fully described in the Appendix, available online at <http://links.lww.com/OPX/A191>.

The United States Preventive Services Task Force recommends vision screening for all children at least once between the ages of 3 and 5 years to detect the presence of amblyopia or its risk factors.¹ At the present time, the United States lacks reliable data on the proportion of children in the population that receive this recommended preventive service. Existing national estimates suggest a rate of vision screening between 30 and 64%.^{2,3} Other literature states that rates may be as low as 2 to 6%.⁴ The disparity in these rates appears to be related to the manner in which the data are

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collected. The higher estimates (30 to 64%) are seen in data from Medicaid administrative claims, whereas direct observation yields significantly lower rates (2 to 6%). As part of Healthy People 2020, national targets have been set to increase the rate of vision screening of children younger than 5 years to a modest goal of 44%.⁵

Vision screening alone will not lead to the earlier diagnosis and treatment of amblyopia and other vision problems. Screening is important to identify who is at risk for a vision problem; a comprehensive eye examination is imperative to diagnose and make the appropriate treatment recommendations. An integrated data system is recommended to help ensure that pediatricians and others who conduct and/or monitor vision screening can view the results of the screening and make the necessary referral to an optometrist or ophthalmologist for appropriate diagnostic testing and treatment. There are few data on the proportion of children who have failed a vision screening and subsequently accessed comprehensive eye care, and even fewer data on outcomes of vision screening at a population level.⁶

Currently, there is no uniform approach to documentation of vision screening results. Many vision screening data records are paper based, whereas other data reside on individual software programs that have been developed for internal reporting based on the needs of specific local programs or providers. Such software programs typically do not offer standardization of the type of information collected, nor have they been developed to be compatible with school health or electronic medical records. Finally, there is little, if any, monitoring of subjects who fail screenings to verify that follow-up care with an ophthalmologist or optometrist for diagnosis and treatment has been completed.

Providers of vision screening services may be unaware of previous attempts to screen an individual child, the results of those screenings, or whether the child accessed appropriate diagnostic and treatment services, which leads to poor coordination of services for these children. This lack of communication can generate both duplication and omission of vision screening efforts. An integrated data system could provide standardized data collection and reporting formats, as well as a tracking mechanism to ensure that eye care diagnosis and treatment are completed for children who fail a vision screening. Better data systems will work toward improving communication, reducing duplication of health services, and enhancing receipt of appropriate eye care. This article discusses the considerations for the development of such a system.

Inclusion of Vision Screening Data in an Integrated Health Information System

The panel considered possible approaches to the development of data systems for monitoring vision screening and follow-up eye care services and ultimately favored a model that merged vision screening data with an integrated health information system at the state level.⁷ Such a system allows for the combination of health data from various sources that can be used to derive information about health status, health care provision, use of services, and impact on health.⁸ The National Committee for Vital and Health Statistics was chartered to advise the Secretary for Health and Human Services on health data, statistics, privacy, and national health information issues. The National Committee for Vital and Health Statistics has proposed national guidelines, the National

Health Information Infrastructure (NHII), that would lead to uniformity in integrated health information systems. They outlined the important role that a uniform approach to integrated health information will serve—allowing information to be used on three distinct levels: (1) personal level: to support subjects in their own wellness and health care decision making; (2) health care provider level: to ensure access to comprehensive and accurate patient data that will aid in clinical decision making; and (3) epidemiological level: for improved surveillance, monitoring changes, and development of interventions including public health awareness and education.⁹

With a truly integrated system, state-level vision screening data would be entered in a uniform manner, following NHII guidelines, and using established data validity and reliability protocols. This system would incorporate vision screening data from screenings administered at various sites such as in the educational-, community-, or public health–based settings. The data could be uploaded into the integrated system individually per child or via a digital file generated off-line at the time of the screening. Appropriate identifying information would allow data to be assigned at the child level and reduce duplication of record entry via an established data algorithm. The system would allow direct online entry from vision screenings administered in the medical home, as well as limited eye examination data from an optometrist or ophthalmologist. The primary care provider, or community vision screening program, would be able to review the data (according to data security access levels) to determine if the child had already received a vision screening, and the results of that screening. If the child had not been screened, the provider or community screener would conduct the screening as recommended.¹⁰ If the child had been referred for a comprehensive eye examination, the provider would have an opportunity to review the limited outcome data from the eye examination. If the eye examination had not yet taken place, the provider could reinforce the importance of and/or facilitate scheduling an appointment with an ophthalmologist or optometrist. Similarly, the community vision screener would have information that a vision screening had already been performed during the period when the child was 36 to younger than 72 months old. In most instances, community screeners cannot be expected to assume responsibility for monitoring medical care; however, they should take the opportunity to reinforce the need for the parents to follow through with recommendations for additional care.

The introduction of vision examinations for children as an essential health care benefit, as part of the Patient Protection and Affordable Care Act, suggests that information from optometrists and ophthalmologists be integrated into a general electronic health record (EHR) for the child. One expectation of the NHII guidelines is that communication across a variety of EHRs will ultimately be possible and practical. It is anticipated that eye doctors would share information regarding diagnosis and treatment for an individual child that would be accessible to the primary care provider and the school health care provider through a Health Information Exchange. Access to this information would improve communication among patient families, schools, community programs, primary health care providers, and optometrists and ophthalmologists, thereby empowering all individuals involved in a child's vision health. The integrated database proposed here for

vision screening would be the beginning of such a monitoring system. As EHRs become better integrated into the anticipated Health Information Exchange, such a system would provide quality surveillance data that can be used to document the prevalence of eye disorders, determine the accessibility of intervention services from optometrists and ophthalmologists, and ultimately allow monitoring of vision and eye health performance measures to facilitate the reduction of health care disparities.¹¹

Integration of Vision Data with other Child Health Data at the State Level

The panel recommends that efforts to integrate vision care data with other child health data should build on existing state-level approaches to data integration following national guidelines for uniform data collection. A targeted protocol would include expansion of the statewide immunization information systems to incorporate information on vision screenings and eye care. These systems already have the appropriate security measures to safeguard privacy of information. This approach would allow monitoring of vision care services provided by different types of health care professionals, including tracking of receipt of follow-up care and outcome measures. Although ophthalmology and optometry currently do not use these systems, it is recommended that they be allowed to review existing data and to add limited clinical results and treatment recommendations from their comprehensive eye examinations.

At least four states (Michigan, Minnesota, Ohio, and Rhode Island) have developed integrated immunization systems during the last 5 to 10 years. The state of Ohio provides a specific successful example for vision: Ohio's immunization registry, Impact Statewide Immunization Information System (Impact SIIS), is a secure, Web-based immunization information system housed at the Ohio Department of Health that provides an accurate, efficient way to ensure that children and Ohioans of all ages receive the appropriate vaccinations. As of December 2011, Impact SIIS was expanded to include data from vision and hearing screening programs, allowing screening data from multiple types of providers to be entered into the system.¹²

Characteristics of an Effective Child Vision Health Data System

A robust data system must be user-friendly with regard to data entry, monitoring, and retrieval of information. Data entry should be accepted from educational, community, or public health settings, as well as primary care- or eye care-based screenings. This approach to data integration will require systematic data collection, including child-specific identifiers to ensure that the data are accurately linked to the correct child.

Data Flow

Vision screening data would be input by a variety of vision screening programs. Primary care providers, school nurses, and educational settings would continue to have access to this integrated database while respecting applicable privacy laws (the Health Insurance Portability and Accountability Act and the Family Educational Rights and Privacy Act). Optometrists and

ophthalmologists would be able to access information related to vision screening outcomes as well as share results from comprehensive eye examinations and additional follow-up services. This proposed design would ideally enhance the interchange of information concerning specific children among ophthalmologists, optometrists, primary care providers, and community programs, any of whom would be able to inspect the successful completion of vision screening, screening referral, and limited follow-up plan for an individual child. Furthermore, this system should be designed so that the family is able to review medical information contained within the system, albeit without the ability to modify any data.

Demographic Information Required for a Robust System

Demographic information must be included in the vision screening record to ensure that the data entered are linked to the

TABLE 1.
Data items for unique identification of each child¹⁰

Patient ID (previously listed as "Medicaid Number")
Patient ID: assigning authority ID (i.e., owning source)
Patient ID: type (e.g., medical record number, IIS ID)
Patient name: First
Patient name: Middle
Patient name: Last
Patient alias name: First
Patient alias name: Middle
Patient alias name: Last
Patient date of birth
Patient gender
Patient multiple birth indicator
Patient birth order
Responsible person name: First
Responsible person name: Middle
Responsible person name: Last
Responsible person name: Relationship to patient
Mother's name: First
Mother's name: Middle
Mother's name: Last
Mother's name: Maiden Last
Patient address: Street
Patient address: City
Patient address: State
Patient address: Country
Patient address: Zip code
Patient address: County of residence
Race
Ethnicity
Birth facility name
Patient birth state
Patient primary language
Patient telephone number
Patient telephone number type (e.g., home, cell)
Patient e-mail address

Source: United States Department of Health and Human Services, Centers for Disease Control and Prevention. Immunization Information System Recommended Core Data Elements Atlanta; 2007. <http://www.cdc.gov/vaccines/programs/iis/func-stds.html#appB> (Accessed on May 28, 2014).¹⁰

correct child and to prevent unnecessary duplication of individual children in the database. The US Centers for Disease Control and Prevention (CDC) has defined a set of “core data items” for this purpose (Table 1).¹⁰ These data items have been adopted by the American Immunization Registry Association and the CDC in order to standardize the Immunization Information System (IIS) across states. The standards were developed by the Immunization Information Systems Support Branch, CDC/National Center for Immunization and Respiratory Diseases (NCIRD), through a consensus process involving input from a variety of IIS managers and technical experts from across the United States. These data elements are considered critical for electronic data exchange and are intended as Functional Standards for all IISs from 2013 to 2017. It is possible that a smaller set of identifiers could be used in specific circumstances if the other data items can be auto-populated. However, this must be determined for each screening site through consultation with appropriate state offices.

Specific Vision Care Data Elements to be Included

The panel considered the vision-related data elements that should be included in any state data system. Fig. 1 shows the minimum

data components to be included in an integrated vision data system. The “Vision Screening Process” column lists data that will verify that a valid vision screening process has been completed. The “NOT Screened” column details fields that should be reported when a vision screening is *not* completed, and finally the “Screening Outcome” column details data fields that should be captured after a completed screening. These data components align with the recommendations presented in the manuscript from the expert panel on Vision Screening for Children Aged 36 to Younger than 72 Months: Recommended Practices.¹³ Individual states may choose to collect additional data points such as visual acuity for each eye that can allow for increased surveillance of screening program quality.

Additionally, the system needs a standard method of delivering vision screening results and a referral plan to the parents or guardian of the child being screened. The system should have a mechanism to provide feedback to the educational-, community-, or public health–based vision screening programs that the primary care provider or medical home has accessed the information from the vision screening.

Finally, the integrated vision data system should contain a component that would capture the results summarizing outcome and treatment recommendations from a comprehensive eye examination.

Vision Screening Process
➤ Unique Identifiers (See Table 1)
➤ Date of screening
➤ Site of screening (e.g., medical, community, educational, child care/Head Start)
➤ Specific location of screening (e.g. name of school or clinic)
➤ Zip code of screening location
➤ Job title of screener (physician, nurse, volunteer, eye care provider)
➤ Provider's ID Code (if appropriate)
➤ Visual acuity test used (selected from accepted list in Cotter, et al.) ¹³
➤ Testing Distance
➤ Stereopsis
➤ Instrument based photoscreening: Device used

NOT Screened
➤ AUTOMATIC REFERRAL* based on DIAGNOSIS**
➤ known neurodevelopmental disorder
➤ systemic diseases requiring eye surveillance
➤ medication side effect profile
➤ prematurity <32 weeks gestation
➤ OBSERVATION OR HISTORY
➤ recognized eye abnormality
➤ relevant family history
➤ parental request
➤ prior eye examination requiring follow up
➤ no consent from parent(s) available

Screening Outcome
➤ PASS: completed screening; No follow up needed
➤ REFER*: completed screening
➤ UNTESTABLE and
➤ LIKELY to complete screening later: RESCREEN as soon as possible, at least within 6 months
➤ UNLIKELY to complete screening later: REFER*
* Any referral must be validated by date of appointment and name of optometrist or ophthalmologist providing initial eye exam.

FIGURE 1.

Vision screening data elements. **It may not be possible for community screening programs to determine these diagnoses; however, automatic referral from a medical home screening would be expected to include these categories.

The minimal information that should be entered would allow the effectiveness of the screening program to be evaluated at least with regard to the accuracy of children who fail the screening and are referred for a comprehensive eye examination. Specific items are detailed in Table 2 and include the following: provider's ID code, refractive error measured for each eye, if glasses were prescribed and the correction prescribed for each eye, yes/no questions concerning specific diagnoses, timeline for next visit to the eye doctor, and if an additional referral was required.

Operating Characteristics of Integrated Vision Care Data System

The panel provided the following recommendations for the data system operation:

1. User-friendly data entry that can be accomplished through online Web-based entry or uploading of a digital file that was generated off-line at the time of vision screening.
2. Data security mechanisms to safeguard privacy of health and education records, in accordance with guidelines from the Health Insurance Portability and Accountability Act and the Family Educational Rights and Privacy Act. Patient confidentiality procedures should include informed consent for access to health data by authorized individuals. Parents of children being screened should authorize and be made aware of such disclosures.
3. Use of the screening data should be evaluated periodically to ensure that the system is of high quality, is accessible to those

who need the information, and demonstrates appropriate use by stakeholders.

Follow-Up Considerations

It is expected that this data system will include a surveillance component to track both individual vision screening results and receipt of follow-up care provided by an optometrist or ophthalmologist. At a minimum, these data can be used on a population level to measure the proportion of children who are screened, the proportion who are referred from the screening, and the proportion of those who receive eye care. Explicit performance metrics were also developed by this panel (see Marsh-Tootle et al.¹⁴ in this issue).

Considerations for Successful Integration

There are significant concerns that use of electronic data systems for vision screening and eye examination results may increase patient care documentation time.¹⁵ Placing additional demands on the health care provider must be counterbalanced with appropriate compensation. Mechanisms for incentives and funding need to be in place to ensure that data are entered within a specified time frame after screening, that data are entered consistently and completely, and that a quality assurance system is devised to verify data. Developing an integrated child health information database will require federal funding. "Meaningful use"¹¹ standards should be applied to the development of this data system. Community and volunteer programs should be able to obtain reports from the system to demonstrate the effectiveness of their programs.

Unique challenges will be encountered in monitoring homeless, undocumented, or transient children, as well as children who reside in nontraditional family settings, such as foster care. Additionally, appropriate eye care services need to be accessible for children who lack adequate insurance.¹⁶ It should be possible to analyze data by subpopulations (e.g., uninsured, specific minorities), which will provide evidence regarding health disparity issues and facilitate the development of programs to decrease such disparities.

CONCLUSIONS

Vision screening for preschool-aged children is endorsed by a number of organizations concerned with young children's vision and eye health issues. However, there is a fundamental lack of reliable data on the proportion of children in the population that receive preventive vision services, as well as the impact of vision screening programs on eye health for children aged between 36 and younger than 72 months. Current data collection approaches for vision screening are fragmented; the results from vision screenings are isolated from referrals and diagnostic care. The expert panel to the NCCVEH recommends that vision screening referral and outcome data be integrated with other child health data systems, such as existing state immunization information systems and EHRs. Demographic identifiers and results from vision screening for all children should be entered into the system to reduce duplication of services, and data should be accessible to

TABLE 2.

Data from eye care provider

Data from initial eye examination

Date of eye examination

Provider's ID code

Visual acuity OD

Visual acuity OS

Were any of the following diagnoses determined:

Yes/No amblyopia

Yes/No strabismus

Yes/No other diagnosis

If "Other," please define:

Were glasses prescribed? Yes/No

If yes, please indicate:

Refractive error: OD

Refractive error: OS

Correction prescribed OD:

Correction prescribed OS:

Time to next follow-up in months

Was an additional referral to another specialist required? Yes/No

If yes, what kind of specialist?

Data from follow-up eye examination

Date of follow-up eye examination

Provider's ID code

If glasses were prescribed at initial visit, did the child obtain them

Yes/No

If previously diagnosed with amblyopia, is this diagnosis confirmed? Yes/No

appropriate individuals and agencies, while respecting applicable privacy laws.

A standardized data collection, reporting format, and tracking mechanism will enable better monitoring of follow-up eye care for all children who are referred after a vision screening. Furthermore, this will enhance communication between providers and allow for population-level surveillance of children's vision health. Involvement of ophthalmologists and optometrists in the development of integrated data systems is essential to ensure that appropriate data elements are included and that data entry requirements are concise, practical, and useful for vision care tracking and surveillance. Optometrists and ophthalmologists are encouraged not only to participate but also to take on leadership roles in this realm.

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APPENDIX

The Appendix, a description of the rationale and process used to develop the recommendations, is available at <http://links.lww.com/OPX/A191>.

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