



American Glaucoma Society Position Paper: Information Sharing Using Established Standards Is Essential to the Future of Glaucoma Care

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In an effort to better serve the needs of our patients, the American Glaucoma Society (AGS) calls on our commercial partners to improve electronic data standardization. Better data interoperability will improve patient safety and care by ensuring all clinical information is associated with the correct patient and can be easily integrated with data from multiple locations to better allow true disease monitoring over time. The Coronavirus Disease 2019 (COVID-19) pandemic has hastened a transition to nontraditional care models such as hybrid visits and home disease monitoring that will depend on adoption of these standards. Likewise, growing research interests in areas such as big data and artificial intelligence rely on accurate and fluid data integration to meet their potential. We make the case for working with our vendors to achieve widespread adoption of both existing and new standards to improve the care we provide.

Information Standards in Eye Care

Electronic health records (EHRs) have long promised the free flow of patient information both within and between clinical settings. Underlying this promise is an assumption that all of our clinical information systems have a common way of capturing and storing each data element that we want to move from place to place. Although this problem may sound easy to address, take a moment to consider the number and diversity of data elements collected during a typical glaucoma patient visit: patient demographics, encounter information (type, date, provider), medications, allergies, diagnoses, clinical exam data, in-office testing results (imaging, perimetry, biometry), laboratory results, diagnostic and therapeutic procedures (type, documentation), and billing/coding details. Only some of these elements have well-defined standards for how they are recorded and transmitted to other systems. Diagnoses are commonly represented using International Classification of Diseases billing codes,¹ procedures with the Current Procedural Terminology codes,² medications with RxNorm, imaging by Digital Imaging and Communication in Medicine (DICOM), and laboratory results with Logical Observation Identifiers Names and Codes. Some EHRs have image management software built in, while other

EHRs pair with Picture Archive and Communication Systems, which are databases that store information output from medical devices. Digital Imaging and Communication in Medicine ensures that the same type of image from different machines or vendors can be viewed and shared.

As a relatively small specialty, ophthalmology has only slowly developed standards that can be used to represent our exam findings and our in-office testing results. Work started approximately 20 years ago focused on adding eyecare-specific terminology to the Systematized Nomenclature Of MEDicine.³ Soon after, the ophthalmology working group of DICOM began developing a series of standards to represent findings from our most common ocular imaging and testing devices.⁴⁻⁷ Unfortunately, there remains no standard way of documenting and sharing even the most routine of our clinical findings obtained on patients with glaucoma, such as visual acuity and intraocular pressure.

If there are some available standards for eye care, what is preventing easy sharing of data with one another? Part of the answer is that the standards alone are not enough to allow data exchange. The vendors who make our information systems (EHRs, image management systems) have to do the work of implementing those standards. Given the significant expense involved and the relative lack of enforcement of any requirement to permit data exchange, those standards, particularly DICOM, have only slowly been deployed in our medical specialty despite calls to do so.⁸⁻¹⁰

Impact on Patient Care and Engagement

The adoption of the available DICOM standards in ophthalmology has been slow. Newer testing devices often provide some level of DICOM-based integration with other clinical systems, but many older devices do not. Specifically, devices can be expected to receive a worklist of that day's patients from the EHR to minimize errors in the entry of patient demographics. This feature significantly improves patient safety because it reduces the number of instances where a patient exists in multiple versions within a system due to mistyped names and birth dates. Such mis-entry makes it difficult to follow patients over time if some of

their data are captured under one name and other data under a different name. Those same devices can also be expected to send back some combination of reports (similar to printed pages) or actual data in a DICOM format to the EHR. These features go a long way toward ensuring that all of the data are available for each patient from anywhere in a given practice.

Glaucoma management relies on clinicians being able to integrate many sources of patient information, including detailed histories, clinical exam findings, and ancillary testing quickly and seamlessly into clinical decision-making. When these data are collected over many years from multiple practices, patients reasonably expect this information to be shared when they authorize a record transfer to permit continuity of care. However, a new physician often does not have access to prior data or may just receive a summary note without the original test results. If office staff or the patient is persistent, records may be faxed, mailed, or scanned and emailed, but they usually arrive after the date of care, and may be illegible or exceedingly lengthy with the important information distributed across many pages and difficult to locate. As such, it can be challenging to access past test results from ocular diagnostic testing equipment. Depending on the EHR system, physicians can access some outside EHRs using available standards for exchange; however, the interface is often not user-friendly and search ability is limited. We have all seen a new patient without records who is unsure which eye had a laser trabeculoplasty or which glaucoma medication caused eye irritation. Imagine the utility of easily downloading a patient's complex history with intraocular pressure levels on various medication regimens or following different interventions, let alone their associated ancillary testing. To build such a future, we need to work together to prioritize interoperability standards for EHR and Picture Archive and Communication Systems.

Greater implementation of DICOM standards for in-office testing would facilitate sharing of ancillary studies performed on the same patient at different practices. Simulations suggest that it takes, on average, more than 4 years of annual visual field testing to identify progression with mean deviation loss of -1 decibels/year with 80% power.¹¹ In actuality, patients may be restarting their clocks every time they switch providers, resulting in delayed detection of glaucoma progression. If all testing modalities were DICOM compliant and there existed better mechanisms of data exchange, eye care providers could easily share raw data for visual fields and OCT imaging so that it is not a new baseline every time the patient switches providers. Unifying testing standards could reduce patient burden and costs from redundant testing and make old test results easier to integrate into algorithms moving forward. Radiology research suggests accessing previous patient data via health information exchanges can reduce the odds of a patient undergoing repeat imaging by 25%.¹² Furthermore, patient data could be analyzed by automated progression algorithms if received in a standardized format from different testing platforms. For example, rather than manually reading and comparing decibel measurements on

printed copies of visual fields from a referring provider, software could integrate a patient's prior visual fields with the tests performed on different machines with automated progression analysis.

Improving DICOM compatibility would not only improve communication and decision-making for eye care providers caring for patients with glaucoma but also greatly facilitate data sharing with the patient. The 21st Century Cures Act Interoperability and Information Blocking Rule mandates that healthcare providers give patients access to their health information. Patient access to their clinical and diagnostic testing data may improve health outcomes by increasing education, promoting adherence to therapeutic interventions and follow-up care, and improving patient autonomy and self-efficacy.¹³ Radiology studies that assessed benefits of imaging exchange programs corroborated what one might expect: Patients involved in image sharing projects reported improvements in both patient satisfaction and the perceived patient-physician relationship.¹⁴ Unless data standards are implemented by diagnostic equipment vendors, patients will likely encounter the same difficulties accessing their test results that providers do. Likewise, they may become frustrated and demand action.

Impact on Future Glaucoma Care

Developing consistent standards around ophthalmic imaging and functional testing will also be critical to the further advancement of telemedicine in ophthalmology. Interest in tele-ophthalmology initially arose from a need for access to specialty care in settings like the Veterans Administration Healthcare System or geographically remote areas, as well as a means to screen for disease in high-risk populations.^{15,16} In these asynchronous models of telemedicine, functional testing and imaging data are obtained and then reviewed remotely by a specialist. The COVID-19 pandemic accelerated the broader adoption of tele-ophthalmology when in-person care became severely restricted and federal regulations were relaxed, allowing payments for telemedicine visits on par with in-person visits.^{17,18} In addition to synchronous visits for urgent eye symptoms for patients unable to come in for in-person care, hybrid visits involving an abbreviated in-person testing visit coupled with a follow-up telehealth visit also provide patients and physicians another model for timely care. There are also a growing number of portable devices that allow patients and their caregivers to perform ophthalmic testing at home, which provide ophthalmologists additional data to help remotely monitor diseases such as glaucoma and macular degeneration.¹⁹⁻²¹ Performing telehealth in all these settings would be greatly facilitated if data collection standards were consistently applied to the ophthalmic data being obtained, stored, shared, and interpreted remotely.^{22,23} Standards like DICOM would facilitate the integration of remote data into clinical decision-making, especially in chronic disease management for which the ability to identify disease progression is paramount. Adhering to best practices and standards would

also help address cyber-security and privacy challenges when healthcare data are obtained, shared, and reviewed remotely. Achieving 100% implementation of standards for ophthalmic testing would ultimately elevate the quality of our telehealth models of care and create additional opportunities for ophthalmic patients to receive subspecialty care.²⁴

Impact on Research

The DICOM imaging standard has long been used to eliminate incompatibilities among medical device vendors and reduce proprietary file formats. Like the fields of radiology, pathology, and dermatology, ophthalmology also generates big data—enough information to make it impractical or unfeasible to be analyzed by humans to permit discovery of new insights. In this new era of computationally driven research using large data sets (i.e., discovery science and implementation science), investigators need all forms of data to be unlocked, shareable, and labeled in an organized and consistent way to harness the potential insights from big data, especially heterogenous data aggregated across the nation. Although several professional societies, including the AGS,⁸ American Academy of Ophthalmology,⁹ and National Eye Institute,¹⁰ have all strongly encouraged industry to adopt DICOM imaging standards, there are still many devices that have not been updated, and some vendors tout their products to be DICOM compatible when in actuality they are not fully compatible with all the standards. Research also relies on building consensus standards, because it is difficult to compare results across studies if each researcher has a different definition for a given disease entity or outcome measure.

Once imaging and EHR standards are implemented across the majority of ophthalmic devices and health systems, it should become easier to train machine learning and artificial intelligence algorithms from the collected data. Modern deep learning methods have the potential to transform healthcare delivery and improve care by

increasing access to care through automated autonomous screening and by acting as a clinical decision support tool with predictive analytics. Without a DICOM standard for easy data access, tracking, and sharing, it will be difficult to build trust in the algorithms and to acquire diverse enough datasets to permit generalizability of results to a diverse group of patients and minimize bias. As we continue to transition to a completely digital world and into the cloud, supported by a government mandate for interoperability, it is an opportune time to advocate for 100% compliance with available data standards.

Action Items

The AGS believes that improved adherence to data standards such as DICOM is critically important to permit our members and all eye care providers to provide high-quality care to our patients, develop new delivery models to improve accessibility and efficiency of patient care, and permit cutting-edge research. The Centers for Medicare and Medicaid continues to push a national agenda for better health information exchange including implementation of health data component and format standards, authentication standards, and mobile app standards, something for which the AGS also strongly advocates. Although it may have been acceptable in the past for vendors to limit access to ocular diagnostic test results, the AGS strongly believes this is now unacceptable. In an attempt to improve transparency and accountability, our organization has been reviewing vendor adoption and compliance with data standards and may soon share this information with our members and the public. The AGS welcomes dialogue with vendors of glaucoma diagnostic testing equipment to work together to find ways to overcome any hurdles or obstacles that limit adherence of their equipment to DICOM standards and to look for ways to facilitate improved interoperability, accessibility of data, and data sharing. On behalf of our patients, the AGS calls on our industry and governmental partners to improve data standardization and interoperability.

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