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American Association of Neurological Surgeons and Congress of Neurological Surgeons Statement for the Record of the House Ways and Means Subcommittee on Health Hearing "Health at Your Fingertips: Harnessing the Power of Digital Health Data" July 9, 2025

Chairman Buchanan, Ranking Member Doggett, and members of the Committee, thank you for the opportunity to provide comments on how access to digital health data can help improve patient health and the challenges associated with adopting such technology. The American Association of Neurological Surgeons (AANS) and the Congress of Neurological Surgeons (CNS), which represent over 4,000 neurosurgeons in the United States, collaborate to advance the specialty of neurological surgery through education, research, and advocacy, while promoting the highest quality of patient care.

The AANS and the CNS appreciate the Committee's interest in this vital topic and see great promise in the ability of digital health data to transform our healthcare system. The application of digital technologies in healthcare, along with the integration of digital data from various sources, has the potential to enhance patient outcomes, increase efficiency, and reduce healthcare-related costs. Importantly, digital tools have the potential to track care longitudinally and support transitions of care, which is crucial for surgeons who may not have a continuous relationship with a patient. Digital health data can also support improved healthcare research and recruitment for research-related purposes. Additionally, if thoughtfully designed, digital health tools have the potential to enhance care delivery, improve patient access (particularly among rural and underserved populations), increase patient engagement, and improve patient and clinician satisfaction.

Interoperability and Information Sharing

The AANS and the CNS appreciate federal actions over the last 10 years to promote interoperability and prevent information blocking, which helps to support more coordinated, safer, and higher-quality patient care. However, patients and clinicians still face challenges accessing and exchanging data, particularly those in small and/or private practices that lack the resources of a large health system.[1, 2, 3 4,5,6,7] More action is needed to ensure a truly seamless and safe data exchange environment that is accessible to all care providers, regardless of size or resources. Only in that environment can we harness and benefit from the power of digital health data.

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[1] 21st Century Cures Act (Pub. L. 114–255), 2016, Title IV, Sections 4001-4008.
[2] *U.S. Department of Health and Human Services, Office of the National Coordinator for Health Information Technology. (2024, December 17). Health Data, Technology, and Interoperability: Protecting Care Access (Final rule, 89 Fed. Reg. 102512). Federal Register. Retrieved July 9, 2025, from https://www.federalregister.gov/documents/2024/12/17/2024-29683/health-data-technology-and-interoperability-protecting-care-access.*
[3] *U.S. Department of Health and Human Services, Office of the National Coordinator for Health Information Technology. (2024, December 17). Health Data, Technology, and Interoperability: Protecting Care Access (Final rule, 89 Fed. Reg. 102512). Federal Register. Retrieved July 9, 2025, from https://www.federalregister.gov/documents/2024/12/17/2024-29683/health-data-technology-and-interoperability-protecting-care-access*
[4] Holmes, J. H., Beinlich, J., Boland, M. R., Bowles, K. H., Chen, Y., Cook, T. S., … & Methods/Information — Medicine Team. (2021, May). Why is the electronic health record so challenging for research and clinical care? *Methods of Information in Medicine*, 60(1–2), 32–48. Retrieved July 9, 2025, from https://www.ncbi.nlm.nih.gov/pmc/articles/PMC9295893/
[5] Office of the National Coordinator for Health Information Technology. (n.d.). *State of interoperability among major U.S. cities* (Data Brief). Retrieved July 9, 2025, from https://www.healthit.gov/data/data-briefs/state-interoperability-among-major-us-cities.
[6] Forbes Technology Council. (2024, October 8). *Interoperability challenges in health tech: The gaps and solutions*. Forbes. Retrieved July 9, 2025, from https://www.forbes.com/councils/forbestechcouncil/2024/10/08/interoperability-challenges-in-health-tech-the-gaps-and-solutions/.
[7] Everson, J., Hendrix, N., Phillips, R. L., Adler-Milstein, J., Bazemore, A., & Patel, V. (2024). *Primary care physicians' satisfaction with interoperable health information technology. JAMA Network Open, 7*(3), e2437931. https://doi.org/10.1001/jamanetworkopen.2024.37931.

Adoption of Imaging Standards

One critical and ongoing challenge is that there are currently no regulations requiring electronic health record (EHR) and imaging archive system vendors to support the secure, efficient, and interoperable electronic exchange of images between healthcare entities, as there are for general clinical data. As a result, imaging-related data exchange is limited to the imaging report (i.e., text). Remarkably, individuals can access their money through any ATM in almost any place in the world, yet patients cannot move their images to a facility down the road without having to complete numerous forms, wait numerous days, and still only be given a CD that may or may not be readable on another provider's computer. The ongoing exclusion of imaging from federal standards that govern electronic data exchange creates a critical gap that burdens patients, delays care, and leads to unnecessary repeat imaging and radiation exposure. The AANS and the CNS support the addition of Digital Imaging and Communications in Medicine (DICOM) images to federal interoperability standards, specifically the United States Core Data for Interoperability (USCDI), to promote standardized and interoperable image sharing across healthcare systems.

Patient Matching

The AANS and the CNS also support a national framework to improve patient matching, which would improve electronic health information exchange, as well result in more effective and efficient care delivery by minimizing duplicative tests and procedures, linking clinical results across providers and settings, ensuring greater patient safety, and supporting more comprehensive and longitudinal research. Patient matching would also help ensure more accurate attribution of patients and episodes of care to providers for the purposes of performance-based payment models and metrics.

Clinical Data Registries

Although the 21st Century Cures Act[8] included a provision for the creation of a real-world evidence (RWE) task force within the Department of Health and Human Services (HHS), little progress has been made over the last several years in this regard. The AANS and the CNS continue to believe that real-world data sources, such as properly designed prospective clinical data registries, are more effective alternatives to costly and time-consuming randomized controlled trials. In addition to utilizing registry data to expedite innovation and device approval, registry expertise is also beneficial for post-market surveillance. Clinical data registries are equally valuable in the context of quality reporting and performance measurement, where they capture more granular and patient-focused data points, including patient-reported outcomes, compared to more limited administrative claims datasets. They also support longitudinal tracking of surgical patients and provide more meaningful and real-time performance feedback compared to what the Centers for Medicare and Medicaid Services (CMS) can provide under its federal quality programs.

Organized neurosurgery has almost 20 years of experience in developing high-quality prospective data registries. This work led to the establishment of the NeuroPoint Alliance (NPA) in 2008, aimed at improving the quality of neurosurgical care.[9] The NPA supports evidence development, performance assessment, comparative effectiveness studies, and adoption of new treatments into routine clinical practice. Currently, the AANS and the CNS, through the NPA, are involved in various clinical data collection projects, including multispecialty projects such as the American Spine Registry (a collaborative project with the American Academy of Orthopaedic Surgeons), an initiative with the Society of NeuroInterventional Surgery to establish a single registry for neurovascular surgical procedures and a prospective registry for stereotactic

[8] 21st Century Cures Act (Pub. L. 114–255), 2016, Title III, Section 3022.
[9] NeuroPoint Alliance. (n.d.). Transforming data into quality patient care. Retrieved July 9, 2025, https://www.neuropoint.org/.

radiosurgery procedures (with the American Society for Radiation Oncology) to assess patient care in neurosurgery and radiation oncology. We have also established a registry to determine neurosurgical care for patients with primary and metastatic brain tumors.

Despite recent federal efforts to enhance electronic information exchange and limit information blocking, registries still face challenges in extracting data seamlessly from EHRs and accessing federal health plan claims data, as discussed below. Many of our registries need to track patients over the long term—some, such as our Tumor registry, throughout a patient's life. Although the data is out there and available to some stakeholders, such as payers, it lives in disparate places and is challenging for registries to access and bring together. To ensure registry populations are representative of patient populations, these system barriers must be addressed.

Other factors that currently contribute to the siloed nature of healthcare data, posing additional challenges to registries, are security and privacy laws such as HIPAA and proprietary ownership needs. We cannot build a nationwide network of data without first addressing these realities. The regulation of health-related data is outdated and does not account for the proliferation of health-focused apps and wearable devices, which are not regulated by HIPAA, or the rapid advancements in artificial intelligence (AI) and machine learning (ML).

Meaningful Access to Federal Health Plans' Claims Data

The Cures 2.0 Act included *Sec. 411. Meaningful Access to Federal Health Plan Claims Data*, which requires the HHS secretary to establish a new program to provide clinician-led clinical data registries with timely, broad, and continuous access to Medicare claims data for purposes of research, quality of care measurement and reporting to health care providers, linking such data with clinical data, and performing risk-adjusted, scientifically valid analyses and research to support quality improvement or patient safety.[10] As acknowledged in Cures 2.0, clinician-led clinical data registries play a critical role in promoting, facilitating, and conducting medical research, as well as improving the quality of healthcare by providing timely and actionable feedback to practitioners on their performance in relation to other practitioners and best clinical practices. However, they are hindered in their ability to promote medical research and quality improvement due to their limited access to meaningful claims data. Although CMS has established programs for providing access to claims data, including the Qualified Entity (QE) program and the Virtual Research Data Center (VRDC) (also known as the ResDAC process), these programs each have unique limitations and continue to fail to provide clinician-led clinical data registries with sufficient and meaningful access to such data for broader quality improvement and patient safety purposes. Claims data acquisition under these existing programs is also costly and time-consuming, and specialty societies have faced delays in trying to access such data.

The AANS and the CNS urge Congress to reintroduce the ***Access to Claims Data Act***,[11] which would promote data transparency and enhance clinical and research utility of Medicare data by requiring the e the Secretary of Health and Human Services to establish a process to expand access to claims data under certain Federal health plans in order to facilitate research and quality improvement. It is critical that Congress put pressure on CMS to establish a new program— separate from any existing data access programs— for providing clinician-led registries with access to federal claims data so that they can better track patient outcomes over time, expand their ability to assess the safety and effectiveness of medical and surgical treatments, and assess the cost-effectiveness of such treatments. Specialty societies would be

[10] DeGette, D., & Upton, F. (2021, November 17). Cures 2.0 Act (H.R. 6000). Introduced in the House. Retrieved July 9, 2025, from https://www.congress.gov/bill/117th-congress/house-bill/6000/text#toc-H00BDA86703774A4E8BF65B4A5C352D22.
[11] Bucshon, L. (2024, September 25). *Access to Claims Data Act* (H.R. 9805). Introduced to the House. Retrieved July 9, 2025, from https://www.congress.gov/bill/118th-congress/house-bill/9805.

willing to assist the federal government with more robust and accurate quality and cost analyses, but cannot do this without reasonable access to timely Medicare claims data.

Ongoing Limitations to Measuring Quality and Value in Medicine under MACRA

The AANS and CNS request that Congress reevaluate the way that CMS measures and holds clinicians accountable for value. The current Merit-based Incentive Payment System (MIPS) — which ties Medicare physician payments to performance on quality, cost, and interoperability metrics — has evolved into an overly complex, disjointed, burdensome, and clinically irrelevant program for many specialists. In an October 2021 report, the U.S. Government Accountability Office (GAO) expressed concern that MIPS performance feedback is neither timely nor meaningful, questioned whether the program helps to improve quality and patient outcomes. It highlighted the program's low return on investment.[12] As we continue to move toward more seamless and automated data exchange and approach an AI-powered future, it is time to reassess our conventional thinking around quality reporting and performance measurement. Performance analyses of the future should require little to no manual abstraction, should span multiple disciplines, and should adopt a more holistic view of the patient. They should not rely exclusively on administrative claims data, given the limitations of this dataset, which was built for billing and not for in-depth quality assessment. Physicians who participate in the design of this new framework, contribute data, and help with real-world validation (e.g., participate in a clinical data registry and track their performance over time) should be rewarded for that participation rather than having to navigate a maze of resource-intensive and constantly shifting requirements under programs like MIPS, that in the end do little to improve patient care.

We also believe that if our healthcare system is going to continue to emphasize value-based care and pay based on the outcomes and cost of patients, Congress needs to ensure the appropriate infrastructure is in place. As noted earlier, how do we capture a patient's entire journey, especially when they move across different providers and payers? And in this context, how do we ensure that clinicians are only being held accountable for factors that are within their direct control?

Telehealth in Medicare

Although much of the care neurosurgeons provide takes place in highly specialized facilities such as tertiary care hospitals, some clinical visits and monitoring are appropriate for telehealth. For example, electronic analysis and programming of implanted deep brain neurostimulators can be performed remotely by a neurosurgeon.[13, 14, 15] This is an issue we have raised with CMS as part of a review of the CMS Medicare Telehealth Services List. For several years, we have safely used these systems via a stable, secure 2-way telehealth connection. These systems route through a secure HIPAA-compliant server and allow the managing physician to remotely control all essential functions of the patient device while providing real-time audio and video for patient assessment and feedback. These systems ensure that the patient controller has a "safe" program (set of stimulation parameters). Suppose there is an interruption in the remote connection.

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[12] U.S. Government Accountability Office. (2021, October 1). Medicare: Provider performance and experiences under the Merit-Based Incentive Payment System (GAO-22-104667). Washington, DC. https://www.gao.gov/assets/gao-22-104667.pdf.

[13] Gharabaghi A, Groppa S, Navas-Garcia M, Schnitzler A, Muñoz-Delgado L, Marshall VL, Karl J, Zhang L, Alvarez R, Feldman MS, Soileau MJ, Luo L, Zauber SE, Walter BL, Wu C, Lei H, Herz DM, Chung MH, Pathak Y, Blomme B, Cheeran B, Luca C, Weiss D. Accelerated symptom improvement in Parkinson's disease via remote internet-based optimization of deep brain stimulation therapy: a randomized controlled multicenter trial. *Commun Med (Lond)*. 2025 Jan 31;5(1):31. doi: 10.1038/s43856-025-00744-7. PMID: 39890864; PMCID: PMC11785990.

[14] Jergas H, Steffen JK, Schedlich-Teufer C, Strelow JN, Kramme J, Fink GR, Visser-Vandewalle V, Barbe MT, Wirths J. Video-Guided Optimization of Stimulation Settings in Patients with Parkinson's Disease and Deep Brain Stimulation. *Brain Sci*. 2024 Sep 11;14(9):914. doi: 10.3390/brainsci14090914. PMID: 39335409; PMCID: PMC11430434.

[15] Esper, Christine D., Aristide Merola, Lyndahl Himes, Neepa Patel, Yarema B. Bezchlibnyk, Drew Falconer, Daniel Weiss, Corneliu Luca, Binith Cheeran, and Zoltan Mari. "Necessity and feasibility of remote tele-programming of deep brain stimulation systems in Parkinson's disease." *Parkinsonism & related disorders* 96 (2022): 38-42.

In that case, the device automatically reverts to this “safe” program so that the patient is not left with a potentially problematic set of programming parameters. Advancements in technology that allow for remote adjustments and consultations reduce the need for frequent travel by these patients and ensure greater access to critical care.

Traditional regulation of medical devices may be inadequate for novel digital technologies. Flexibility and ongoing validation of technologies, particularly where the technology can be adaptive, are necessary. A new framework for this should focus on quality systems and ensuring the ongoing validity of software tools in medicine to ensure safety and patient benefit. A primary challenge is ensuring that products utilizing Artificial Intelligence (AI), including generative AI, continue to perform as intended in the real world, based on the same benchmarks used to evaluate them for market entry. We support the development of additional technological tools to help continually assess generative AI products in the healthcare space while maintaining physician oversight in their use for patients. As the FDA, CMS, and other federal agencies consider appropriate regulation of AI, we must be vigilant about any unintended consequences. AI, in conjunction with the clinical judgment of a physician, looking at each patient as a unique individual, has much to offer. Neurosurgery has sponsored numerous opportunities for our members to learn about AI innovation, and we are eager to provide policymakers with feedback on neurosurgeons' experiences in this area. Members of our AANS/CNS Drugs and Devices Committee have participated in the FDA-facilitated Implantable Brain-Computer Interface Collaborative Community (iBCI-CC), and we look forward to continued interaction with the FDA, as well as the development of BCI devices that interface with the nervous system and utilize software to interpret neural activity.

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The AANS and CNS appreciates your consideration of our concerns and recommendations. If you have any questions, please contact Charlotte Pineda at cpineda@neurosurgery.org.