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PHYSICIAN CLINICAL REGISTRY COALITION

January 16, 2026

VIA ELECTRONIC MAIL

The Honorable John Joyce, M.D.
Co-Chair
GOP Doctors Caucus
U.S. House of Representatives
2102 Rayburn House Office Building
Washington, DC 20515

The Honorable Gregory F. Murphy, M.D.
Co-Chair
GOP Doctors Caucus
U.S. House of Representatives
407 Cannon House Office Building
Washington, DC 20515

The Honorable Kim Schrier, M.D.
Chair
Democratic Doctors Caucus
United States House of Representatives
1110 Longworth House Office Building
Washington, DC 20515

Re: Physician Clinical Registry Coalition's Comments on Medicare Access and CHIP Reauthorization Act of 2015 Modernization

Dear Chairs Joyce, Murphy, and Schrier and Members of the GOP and Democratic Doctors Caucuses:

The undersigned members of the Physician Clinical Registry Coalition ("Coalition") appreciate the opportunity to provide comments on the Request for Information ("RFI") on modernizing the Medicare Access and CHIP Reauthorization Act of 2015 ("MACRA"). The Coalition is a group of medical society-sponsored clinical data registries that collect and analyze clinical outcomes data to identify best practices and improve patient care. We are committed to advocating for policies that encourage and enable the development of clinical data registries and enhance their ability to improve quality of care through the analysis and reporting of clinical outcomes.

As Congress considers the development of a new quality reporting and performance program, we respectfully urge Congress to expressly preserve and strengthen the role of clinician-led clinical data registries as foundational infrastructure for quality measurement, improvement, and value-based payment. Clinical data registries are organized data collection and analysis systems operated by or affiliated with a national medical society, hospital association, or other health care association. These registries collect and analyze data on specified outcomes submitted by physicians, hospitals, and other types of health care providers related to a wide variety of medical procedures, diagnostic tests, and/or clinical conditions. They perform data aggregation

and related benchmarking analyses that support one or more predetermined scientific, clinical, or policy purposes, including, but not limited to, describing the natural history of disease, determining the effectiveness (including the comparative effectiveness) of therapeutic modalities, and measuring quality of care. Because registries are built on detailed clinical data, including patient-reported outcomes, they are among the most important sources of real-world evidence in the healthcare system. The measures developed by registries are clinically meaningful to providers and their patient populations. They capture important information that is not available from claims data alone.[1]

Clinician-led clinical data registries are uniquely suited to serve as the foundation of any innovative quality-based payment program.[2] By benchmarking provider performance against peers, registries can identify variations in care delivery, reveal best practices, and highlight opportunities for improvement. Registries' analytical capabilities can be utilized to assess whether services are clinically effective and cost-effective.

Reflecting this value, the federal government, health care products manufacturers, accreditors, and state and local governments have increasingly come to rely on clinical data registries for a wide variety of purposes. As you are aware, clinical data registries report clinical data to the Centers for Medicare and Medicaid Services ("CMS") on behalf of their participating health care providers for purposes of the Merit-based Incentive Payment System ("MIPS") and for more general patient and disease tracking.

Congress has long recognized the importance of registries in federal health policy. MACRA requires the Secretary of Health and Human Services ("Secretary") to encourage the use of Qualified Clinical Data Registries ("QCDRs") for reporting measures under the quality performance category of the MIPS program.[3] In addition, section 105(b) of MACRA directs the Secretary to provide Medicare claims data to QCDRs "for purposes of linking such data with clinical outcomes data and performing risk-adjusted, scientifically valid analyses and research to support quality improvement or patient safety."[4]

Despite these Congressional directives, registries continue to face barriers in carrying out these statutory mandates and improving care quality. CMS has adopted policies (such as measure

[1] For further information on the value of clinical data registries, please refer to the enclosed white paper, which details the capabilities and expertise of specific PCRC member registries in Appendix A.
[2] EHRs are not designed to support longitudinal quality measurement, benchmarking, or population-level improvement, nor can they offer the same specialty-focused expertise. EHR systems are primarily built to serve billing, documentation, and internal clinical workflow needs. Clinician-led clinical data registries also are designed by clinical experts within a specific medical specialty, ensuring that the data are clinically accurate, relevant, and meaningful to specific patient populations. In contrast, EHRs are administrative tools not developed by clinical specialists and may lack the clinical nuance required for specialty-specific insights. Simply put, registries are far better suited for evaluating care coordination, disease progression, and outcomes over time.
[3] MACRA, Pub. L. No. 114-10, § 101(c), 129 Stat. 87 (2015).
[4] *Id*. § 105(b)(1)(A).

testing,[5] data validation,[6] harmonization,[7] scoring,[8] and topped out policies[9]) that contravene the language and intent of MACRA, including policies that disincentivize development of meaningful specialty measures.

As Congress contemplates a successor to MIPS, we respectfully urge Congress to:

- Direct CMS to leverage clinician-led clinical data registries as core infrastructure for quality measurement and improvement in any new quality or value-based payment model.

- Establish a statutory framework that affirmatively supports registry participation and removes unnecessary administrative and financial barriers.

- Promote the development and use of registry-developed, specialty-driven measures that reflect real-world clinical practices and patient-outcomes.

- Direct CMS to accommodate more innovative, out-of-the-box solutions related to cost measurement, such as the integration of clinical registry data with claims data to most accurately evaluate value and the use of appropriate measures to assess cost.

- Ensure that clinician-led clinical data registries have meaningful, timely, and reliable access to Medicare claims data for quality improvement. We respectfully urge the House of Representatives to swiftly pass bipartisan legislation—H.R. 4331, the Access to Claims Data Act—introduced by Dr. Joyce and Dr. Schrier. This legislation would establish a process to provide clinician-led clinical data registries with timely, comprehensive, and continuous access to federal claims data. The integration of clinical registry data with claims data would most accurately evaluate value and the use of

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[5] All QCDR measures must meet "face validity" for the initial MIPS payment year for which the measure is approved. 42 C.F.R. § 414.1400(b)(4)(iii)(A)(3). "Face validity" is the "extent to which a measure appears to reflect what it is supposed to measure 'at face value.'" *Measures Testing*, CMS Measures Management System (Mar. 2025), https://mmshub.cms.gov/measure-lifecycle/measure-testing/evaluation-criteria/scientific-acceptability/validity. For subsequent years after being initially approved, all QCDR measures must be fully developed and tested, with complete testing results at the clinician level, prior to submitting the QCDR measure at the time of self-nomination. 42 C.F.R. § 414.1400(b)(4)(iii)(A)(3). To be included in an MVP, a QCDR measure must be fully tested. *Id*. § 414.1400(b)(4)(iii)(A)(3).

[6] Beginning with the 2021 performance year, QCDRs and qualified registries must conduct annual data validation audits for the payment year before submitting any data for that payment year to CMS for purposes of the MIPS program. *Id*. § 414.1400(b)(3)(v). If a data validation audit identifies one or more deficiencies or data errors, the QCDR or qualified registry must conduct a targeted audit into the impact and root cause of each deficiency or data error and correct such deficiencies or data errors prior to the submission of data for that MIPS payment year. *Id*. § 414.1400(b)(3)(vi).

[7] Through the measure harmonization process, CMS may provisionally approve the individual QCDR measures for one year with the condition that QCDRs address certain areas of duplication with other approved QCDR measures or MIPS quality measures in order to be considered for the program in subsequent years. *Id*. § 414.1400(b)(4)(iii)(A)(5). If such areas of duplication are not addressed, CMS may reject the QCDR measure. *Id*.

[8] Beginning with the 2023 performance year, MIPS eligible clinicians receive zero points for reporting on a measure that lacks a benchmark. *Id.* § 414.1380(b)(1)(i)(A)(1).

[9] A topped out measure is a measure with a median performance rate of 95 percent or higher. *Id.* § 414.1305. CMS can remove topped out measures from the program. *Id.* § 414.1400(b)(4)(iv)(D).

appropriate measures to assess cost. However, current regulatory barriers prevent such integration. The Virtual Research Data Center ("VRDC") does not provide clinician-led clinical data registries with the type of timely, broad, and continuous access to claims data necessary for registries to effectively link their outcomes data with claims data. The VRDC is limited to narrowly defined research questions and is slow, costly, and cumbersome. Moreover, CMS's decision to treat QCDRs as quasi-qualified entities for purposes of obtaining access to claims data does not provide QCDRs (or other clinician-led clinical data registries) with long-term, continuous, and timely access to claims data. The scope of the data provided under the Qualified Entity Program does not satisfy registry needs. In addition, the Qualified Entity Program requirements on eligibility, operations, and governance are extremely lengthy and burdensome. The Access to Claims Data Act (H.R. 4331) would establish a process to provide clinician-led clinical data registries with timely, comprehensive, and continuous access to federal claims data. It would require the Secretary to establish a process to expand access to claims data under certain Federal health plans in order to facilitate research and quality improvement. These improvements would enable clinician-led clinical data registries to better track patient outcomes over time, expand their ability to assess the safety and effectiveness of medical treatments, and provide them with the information necessary to assess the cost-effectiveness of alternative therapies.

- Prioritize measures developed by clinician-led clinical data registries over vendor-led registries. Vendor-led registries do not have clinical expertise or in-depth understanding about quality measurement. Instead, they are created only for commercial purposes. For-profit companies, such as EHR companies, do not appear to have any population health impact, as measured by published articles in the scientific peer-reviewed literature and practice guidelines for clinicians. Clinician-led clinical data registries are designed by clinical experts within a specific medical specialty, ensuring that the data are clinically accurate, relevant, and meaningful to specific patient populations. Without the leadership and contribution of medical societies, the measures available to eligible clinicians may be poorly defined and inaccurately capture quality performance.

Absent explicit Congressional direction, there is a substantial risk that the same structural and policy barriers that have undermined registries under the MIPS program will persist in any replacement program. Ensuring that registries are fully integrated into the next generation of quality policy will promote more accurate measurement, greater clinician engagement, and better patient outcomes.

We greatly appreciate your leadership on these issues and continued commitment to working with stakeholders to develop a quality measurement framework that is clinically meaningful and focused on advancing patient care. The Coalition appreciates your consideration of our recommendations. If you have any questions, please contact Leela Baggett at Powers Pyles Sutter & Verville, PC (Leela.Baggett@PowersLaw.com).

Respectfully submitted,

American Academy of Dermatology Association
American Academy of Ophthalmology
American Academy of Otolaryngology-Head and Neck Surgery
American Association of Neurological Surgeons
American College of Gastroenterology
American College of Rheumatology
American Urological Association
American Society for Gastrointestinal Endoscopy
Congress of Neurological Surgeons
Outpatient Endovascular and Interventional Society
Society of Interventional Radiology
Society of NeuroInterventional Surgery
The Society of Thoracic Surgeons

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PHYSICIAN CLINICAL REGISTRY COALITION

White Paper on Clinical Data Registries: Background and Value

The Physician Clinical Registry Coalition ("Coalition") is a group of medical society-sponsored clinical data registries that collect and analyze clinical outcomes data to identify best practices and improve patient care. We are committed to advocating for policies that encourage and enable the development of clinical data registries and enhance their ability to improve quality of care through the analysis and reporting of clinical outcomes. Most of the members of the Coalition meet the definition of clinician-led clinical data registry under the 21st Century Cures Act. This white paper provides an overview of the current and potential social value of clinical data registries with respect to quality improvement, performance feedback, research, and payment reform.

Background on Clinical Data Registries

Clinical data registries are organized data collection and analysis systems operated by or affiliated with a national medical society, hospital association, or other health care association. These registries collect and analyze data on specified outcomes submitted by physicians, hospitals, and other types of health care providers related to a wide variety of medical procedures, diagnostic tests, and/or clinical conditions. They perform data aggregation and related benchmarking analyses that support one or more predetermined scientific, clinical, or policy purposes, including, but not limited to, describing the natural history of disease, determining the effectiveness (including the comparative effectiveness) of therapeutic modalities, and measuring quality of care. Clinical data registries are major sources of real-world evidence, including patient-reported outcomes data. The comprehensive and valuable measures developed by clinical data registries are meaningful and relevant to participating providers and their patient populations. These measures provide important information that is not available from claims data.

The appropriate collection and use of protected health information ("PHI") is the foundation of registry work. Most clinical data registries serve as business associates of the hospitals, physicians, and other covered entity sites from which they receive PHI and other data. These clinical data registries perform data aggregation, curation, benchmarking, and analytic services on behalf of these covered entities. They also perform secondary research on de-identified data and "limited data sets" that provide real-world evidence. The Health Insurance Portability and Accountability Act ("HIPAA") rules effectively ensure that PHI that registries collect is properly safeguarded. Clinical data registries take data security very seriously and diligently comply with the HIPAA Privacy and Security Rules.

The federal government, health care products manufacturers, accreditors, and state and local governments have increasingly come to rely on clinical data registries for a wide variety of purposes. For instance, clinical data registries report medical and clinical data to the Centers for Medicare and Medicaid Services ("CMS") on behalf of their participating health care providers

for purposes of the Merit-based Incentive Payment System ("MIPS") and for more general patient and disease tracking.

Value of Clinical Data Registries

Clinical data registries are uniquely positioned to drive the health care system forward and play an important role in the quality-based payment paradigm. Clinical data registries provide a valuable data collection infrastructure to accomplish numerous objectives, including:

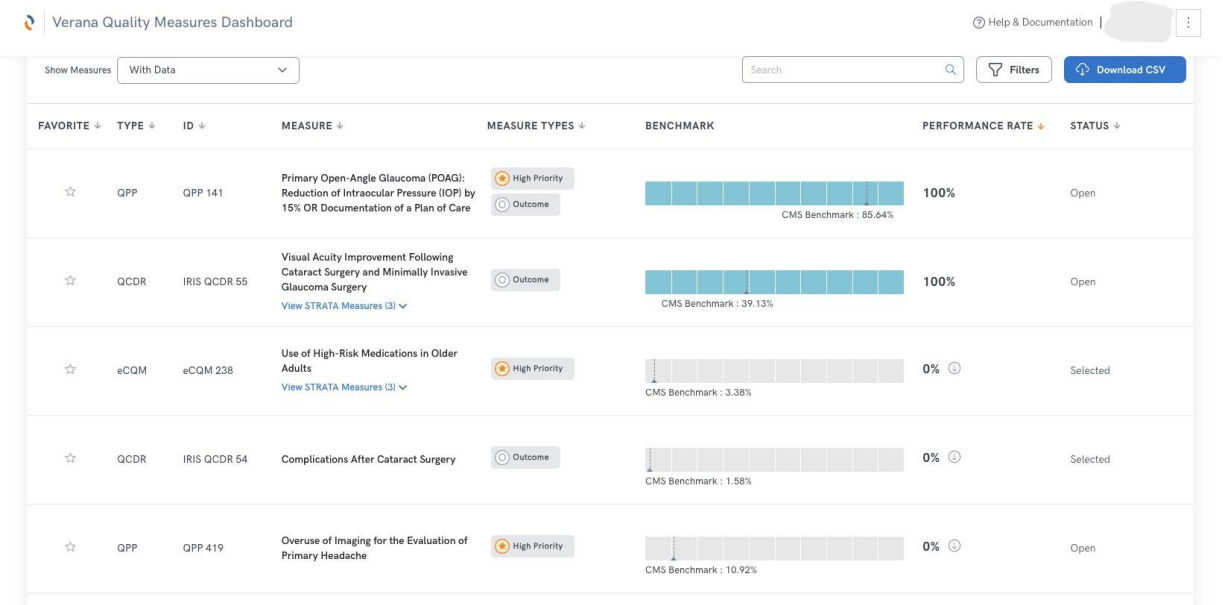
- Improving the quality of care;
- Monitoring the prevalence and trends of specific conditions and diseases;
- Monitoring the effectiveness, cost-effectiveness, and comparative effectiveness of specific devices or treatments; and
- Performing research and identifying opportunities to research patient outcomes.

Accordingly, registry data can and should be the foundation of any innovative quality-based payment program.

Improving Quality of Care

Clinical data registries improve quality of healthcare by providing timely and actionable feedback to practitioners on their performance. This quality improvement effort is typically achieved by developing benchmarks on performance/treatment outcomes from data submitted by all registry participants and sharing those benchmarks with each registry participant. Registry data helps identify best clinical practices, determine the relative value of physician services, and identify deficiencies or disparities in care that require corrective action.

An example of the metrics provided to a registry participant is as follows:



Monitoring the Prevalence and Trends of Specific Conditions/Diseases

The data collected and analyzed by clinical data registries also provide valuable insight into the prevalence and trends of specific medical conditions and diseases. The Centers for Disease Control and Prevention ("CDC") and state and local governments rely on registries to provide this data. For instance, the American Academy of Ophthalmology's Intelligent Research in Sight ("IRIS") Registry provides data to the CDC's Vision and Eye Health Surveillance System, which creates composite estimates of vision loss and major eye disease prevalence at the national, state, and county level.

The American College of Emergency Physicians' ("ACEP") Clinical Emergency Data Registry ("CEDR") exemplifies the role registries play in monitoring conditions and treatments. CEDR has developed 19 emergency medicine-specific quality measures and hosts 22 additional public domain measures, ensuring the specialty is well represented. CEDR's data provide robust and valuable information on clinical conditions, diagnostic accuracy, the utilization of pharmaceuticals, and other quality improvement measures.

Monitoring the Effectiveness/Cost-Effectiveness/Comparative Effectiveness of Specific Devices/Treatments

Clinical data registries play an important role in monitoring the effectiveness and cost-effectiveness of health care services and devices. Real world evidence collected and aggregated by clinical data registries is increasingly being used to develop alternative treatments paths, substantiate whether a service or item is "reasonable and necessary," and support evidence-based guidelines development. For instance, cardiovascular registries help increase our understanding of treatment management for complex cross-disease impacts. Numerous HbA1c management medications have added cardiovascular and renal indications and require ongoing monitoring or real-world outcomes to ensure cost effective and efficient treatments that effectively manage all patient health risks and reduce paying for unnecessary or insufficient treatments.

The American Association of Neurological Surgery and its registry organization, the NeuroPoint Alliance, utilizes its neuro-oncology registries, the Tumor Registry and the Stereotactic Radiosurgery ("SRS") Registry to monitor various intercranial tumor surgical interventions and overall treatment dynamics to inform safe and effective intervention and radiation treatment levels. These registries also generate insights on effective care pathways informing optimal intervention progression. The NeuroPoint Alliance's work in spine registries have long prioritized patient reported outcomes that not only help inform the effectiveness of surgical intervention but further generate insights on macro socio-economic impacts. The NeuroPoint Alliance's Quality Outcomes Database spine registry has not only provided general insights on how a patient feels and functions but also on their ability to return to work.

For instance, the Food and Drug Administration ("FDA") has been encouraging drug and device manufacturers to work with registries to conduct investigational and post-approval surveillance studies to ensure that both unapproved and approved drugs and devices are safe and effective. Although not specific to the US healthcare system, registries provide a resource for monitoring effectiveness of medical devices in the real world leveraged by the UK and EU as a source option for European Union Medical Device Regulation. This contributes to the overall utility of

registries to provide real insights into treatment effectiveness and cost-efficiencies in universal patient context.

In addition, CMS has required participation in registries as a condition of reimbursement for certain medical procedures that involve investigational or off-label (i.e., unapproved) uses of drugs or devices. Participation in The Society of Thoracic Surgeons' and the American College of Cardiology's TVT Registry is a condition of participation for certain Medicare reimbursement purposes, which provides valuable information on the safety and effectiveness of the transcatheter valve therapies.

Identifying and Facilitating Research Opportunities

Clinical data registries can be used to identify research opportunities to enhance general knowledge about the safety and effectiveness of various medical procedures, diagnostic tests, treatments, and health care products. Clinical data registries and their robust data sets can enable quicker and less expensive randomized clinical trials, longitudinal studies, and other observational studies. They support innovation and access to care for patients by streamlining and decreasing the costs of clinical trials for the approval of investigational new drugs or devices by the FDA.

For example, after years of data collection, CEDR's databases are able to fast-track new measure testing and clinical protocol generation for rare disorders (e.g., ruptured abdominal aortic aneurysm, sickle-cell disease, and bacterial meningitis). Furthermore, during and after the 2020 COVID-19 pandemic, ACEP was able to report important statistics on patient volumes, demographics, emergent conditions, vaccinations, and workforce burden. These structured and standardized data sets are now being leveraged to generate timely evidence, primary research, policy supplements, and point-of-care testing, as well as to drive the overall digital transformation of emergency medicine. Specifically, government agencies such as the CDC and the National Institutes of Health are pursuing projects that leverage CEDR's big data to answer complex questions and provide national insights, including through studies on opioid use disorder and the implementation of opioid reversal medications, improvements in geriatric and pediatric care, diagnostic accuracy, and other lifesaving initiatives.

Conclusion

Clinical data registries provide a valuable data collection and analysis infrastructure and stand well-positioned to serve as the lynchpin of any value-based payment program.

Respectfully submitted,

American Academy of Ophthalmology
American Academy of Otolaryngology–Head and Neck Surgery
American Academy of Physical Medicine and Rehabilitation
American Association of Neurological Surgeons
American College of Gastroenterology
American College of Radiology
American College of Rheumatology

American Society for Gastrointestinal Endoscopy
American Urological Association
Association for Clinical Oncology
Center for Professionalism and Value in Health Care
College of American Pathologists
Outpatient Endovascular and Interventional Society
Society of Interventional Radiology
The Society of Thoracic Surgeons

APPENDIX A

SUMMARY OF REGISTRIES

AMERICAN ACADEMY OF DERMATOLOGY

The American Academy of Dermatology's ("AAD's") DataDerm™ is the largest dermatologic clinical data registry in the world. DataDerm is recognized by the Centers for Medicare and Medicaid Services ("CMS") as a qualified clinical data registry ("QCDR"), providing benchmarks to participants on the Merit Based Incentive Payment System ("MIPS") program performance measures and allowing deep data analysis of the practice of dermatology through the addition of aggregated data sets. It connects data on millions of patients from thousands of dermatologists nationwide, and it provides powerful research and quality assurance tools. DataDerm was created by dermatologists for dermatologists. Since its inception in 2016, over 5,000 clinicians have contributed data on nearly 15 million patients and approximately 54 million patient visits. DataDerm allows clinicians to benchmark performance against peers, track trends in patient populations, and drill down to individual patients for key best practices. Participants also can access a full range of data, enabling comparison of the types and severity of diseases seen, across diverse patient demographics. In addition, DataDerm provides unique opportunities for clinical education and informs advocacy initiatives.

AMERICAN ACADEMY OF OPHTHALMOLOGY

The American Academy of Ophthalmology ("AAO") Intelligent Research in Sight ("IRIS®") Registry is the nation's first comprehensive eye disease clinical registry. AAO developed it as part of the profession's shared goal of continual improvement in the delivery of eye care. All U.S. ophthalmologist AAO members in good standing are eligible to participate in the IRIS® Registry as a free member benefit.

Since its start in 2014, over 14,000 practicing U.S. ophthalmologists across 2,967 practices have contributed more than 788 million records from 84.87 million unique patients. Physicians participating in the IRIS® Registry are provided timely feedback that can be used to monitor and report their quality performance with little to no reporting burden. The IRIS® Registry database also represents a remarkable opportunity for knowledge discovery and collaborative studies. It can inform the natural history of diseases, track the prevalence of rare conditions, monitor technology adoption, analyze comparative effectiveness, and more—all in real-world settings. To date, 163 peer-reviewed publications have been published using IRIS Registry data.

AMERICAN ACADEMY OF OTOLARYNGOLOGY-HEAD AND NECK SURGERY

The American Academy of Otolaryngology - Head and Neck Surgery established a clinical data registry, Reg-ent, in 2016, which has grown to become the largest otolaryngology data repository in the world. The Reg-ent registry harnesses the power of data to guide the best otolaryngology care. Reg-ent focuses on quality improvement and patient outcomes and also provides the specialty with the foundation for research, government reporting (i.e., MIPS reporting), and quality measure development. Reg-ent provides extensive MIPS support to its Reg-ent participants by alleviating the reporting burden, assessing and educating on policy changes, and assisting with the development of innovative and robust quality measures. As of December 2023, Reg-ent's de-identified data set included over 10 million unique patients and 48.5 million patient encounters extracted from the real-world electronic health records of

otolaryngology private and academic practices ranging from small, solo practices to large hospital and health system departments. The data is leveraged by our members for clinical research studies, process improvement projects and to support clinical practice guideline development. Reg-ent provides the ability for our members to assess patient reported outcomes using a Reg-ent PROM module and offers an interactive dashboard to evaluate outcomes and assess the impacts of social determinants of health.

AMERICAN ACADEMY OF PHYSICAL MEDICINE AND REHABILITATION

The American Academy of Physical Medicine and Rehabilitation ("AAPM&R") Registry is a single repository of data that will track "real-world" care nationally to define rehabilitation practice, move rehabilitation forward, and improve patient outcomes. The AAPM&R Registry is the first for physical medicine and rehabilitation, capturing data for both low back pain and ischemic stroke. Patient-Reported Outcome ("PRO") measures are increasingly being utilized to evaluate success of clinical care. Many physiatrist stakeholders find benefit in capturing this patient perspective to best provide a full picture of rehabilitation care. Recognizing this, the AAPM&R Registry has made a commitment to facilitating capture of this patient-reported data through its Registry platform. AAPM&R's Registry will provide data that is actionable to physiatrists in their journey to improve the lives of their patients.

AMERICAN ASSOCIATION OF NEUROLOGICAL SURGEONS

The American Association of Neurological Surgeons ("AANS") NeuroPoint Alliance ("NPA") was established in 2008 as the registry organization to cover the surgical specialties of neurosurgery and partnership with related specialties. The NPA's suite of registries includes the American Spine Registry ("ASR"), the Neurovascular Quality Initiative – Quality Outcomes Database ("NVQI-QOD"), Tumor Registry, and Stereotactic Radiosurgery ("SRS") Registry. The NPA has also delivered the Registry for the Advancement of Deep Brain Stimulation in Parkinson's Disease ("RAD-PD") assessing the effectiveness of deep brain stimulation as interventional therapy for Parkinson's patients. NPA registries prioritize long-term follow-up of at least one year and multiple patient-reported outcomes measures.

The American Spine Registry ("ASR") launched in 2020 in collaboration with the American Academy of Orthopaedic Surgeons, leveraging the successes of the NPA's QOD Spine Registry as a platform for all US spine surgeons. As of May 2025, the ASR includes more than 365 participating sites contributing more than 393,000 patients and more than 475,000 degenerative lumbar or cervical procedures. The ASR is already providing reporting to inform medical device monitoring and is the largest spine surgery data registry in the United States.

NVQI-QOD joined the Society of NeuroInterventional Surgery ("SNIS") NVQI registry with the NPA's Neurovascular Quality Outcomes Database in 2020. As of May 2025, the registry includes 41 centers across 24 states with more than 26,000 patients and 27,000 procedures submitted. It is the most comprehensive endovascular registry in the United States delivering modules for acute ischemic stroke, cerebral aneurysm, and arteriovenous malformation. The registry is actively generating medical device performance reporting satisfying European Union Medical Device Reporting ("EU-MDR") requirements and supports US medical device projects as well.

The QOD Tumor Registry launched in 2021 and is growing with 16 sites already participating and more than 6,000 patients submitted from 110 participating surgeons. The NPA's Tumor Registry is beginning to see substantial growth in one year follow-up and has begun accepting research proposals to support further insights on patient outcomes.

The SRS Registry launched in 2015, in conjunction with the American Society for Radiation Oncology to collect data and improve care on radiosurgical treatment of brain metastases, primary malignant and benign brain tumors and arteriovenous malformations. The SRS leverages treatment planning software to support data collection and inform outcomes. The registry includes data contributed from 27 leading US radiosurgical sites with more than 6,300 patients and 12,300 treatment events captured. The data collection includes image contorting and informs artificial intelligence algorithms to enhance software-based tumor identification capabilities.

These and other NPA projects and programs contribute to a substantial clinical research apparatus that has produced or contributed to more than 1,000 manuscripts and abstracts since 2009. These publications address socioeconomics, clinical outcomes, and treatment quality and safety across spine, tumor, trauma, vascular, pediatric, functional, and general neurosurgery, and address scientific gaps and help ensure patient access to appropriate care and care options.

AMERICAN BOARD OF FAMILY MEDICINE

The American Board of Family Medicine's ("ABFM's") PRIME Registry is the largest and most reliable primary care clinical registry in the nation. Its suite of patient and population tools help practices of all sizes provide better care and align with a growing number of programs aiming to improve quality and meet social needs. Established by the ABFM in 2016, PRIME Registry was designed to help provide family physicians and primary care clinicians a faster, easier way to evaluate practice performance, improve primary care practice and patient outcomes, and reduce the burden of reporting for CMS payment programs (like MIPS, Primary Care First Model, and Making Care Primary Model) at no extra cost. Compatible with most electronic health records ("EHRs"), PRIME Registry can support all Center for Medicare & Medicaid Innovation alternative payment models, as well as provide data-sharing and reporting support for both accountable care organizations ("ACOs") and their member practices. The PRIME Registry is open to all primary care clinicians, including family physicians, general internists, general pediatricians, nurse practitioners, physician assistants and many other clinical team members.

In addition to providing an efficient, low-cost solution that makes EHR data more valuable and actionable, PRIME Registry's robust data set serves as primary care's quality measure development test bed. The Measures That Matter to Primary Care initiative, led by the Center for Professionalism and Value in Health Care, is making progress in developing measures that are more meaningful. The Core Quality Measures Collaborative announced that the Person-Centered Primary Care measure and the Continuity of Care measure, both developed as part of the Measures That Matter to Primary Care initiative, have been included in the core measure set for ACOs, Patient Centered Medical Homes, and Primary Care. The rich EHR data set is also informing the Centers for Disease Control and Prevention, Food and Drug Administration, and National Institutes of Health about population health, epidemic detection and response, medication availability to underserved populations, and artificial intelligence testing and clinical decision support development.

AMERICAN COLLEGE OF RADIOLOGY

Established in 2008, the American College of Radiology ("ACR") National Radiology Data Registry ("NRDR") is a procedure-specific, specialty-wide clinical quality improvement registry that provides benchmarking data to support improved patient care in lung, breast, and colorectal cancer screening, radiation dose monitoring, general radiology services, and clinical 3D printing for participating

radiologists practicing across multiple care settings. The NRDR's suite of seven registries receives over 60 million patient exams from more than 4500 unique sites annually and now contains nearly 425 million exams since its inception. Facilities have access to "real-time" interactive facility and physician performance feedback reports--and quarterly PDF reports--on registry specific measures such as cancer detection rate, adherence to screening, the timeliness of patients receiving recommended additional imaging, radiation dose optimization, or radiology report turnaround time. Performance is compared against various peer groups as well as all registry participants.

In addition to performance reporting for quality improvement, NRDR has also been a CMS-approved QCDR for purposes of MIPS reporting since 2014. And upon request, data from the registries is available for quality improvement analysis and has been used for publication in peer-reviewed journals including projects to establish procedure diagnostic reference levels, to inform treatment guidelines and identify inequities in patient care.

For more information about the NRDR, please visit https://nrdrsupport.acr.org and for a list of publications, or to request an analysis project, please visit https://www.acr.org/Practice-Management-Quality-Informatics/Registries/NRDR-Publications.

AMERICAN COLLEGE OF RHEUMATOLOGY

The American College of Rheumatology's Rheumatology Informatics System for Effectiveness ("RISE") registry is the first and largest electronic health record ("EHR")-enabled rheumatology registry in the United States. As a HIPAA-compliant Qualified Clinical Data Registry, RISE attracts widespread participation among rheumatology clinicians and providers. With over 1,100 rheumatology clinicians and 3.7 million patients, RISE is instrumental in advancing the specialty through improving care and expanding research. The RISE registry is a developed to help clinicians and researchers:

- Optimize patient outcomes;
- Navigate the Quality Payment Program Merit-based Incentive Payment System and MIPS Value Pathway reporting requirements;
- Make discoveries that advance rheumatology; and
- Demonstrate the value of rheumatology to key influencers.

AMERICAN COLLEGE OF GASTROENTEROLOGY AND AMERICAN SOCIETY FOR GASTROINTESTINAL ENDOSCOPY

The GIQuIC Quality Improvement Consortium, a joint collaboration of the American College of Gastroenterology and American Society for Gastrointestinal Endoscopy, established the GIQuIC registry, a clinical benchmarking and quality improvement registry addressing a wide range of digestive disease conditions. Since its inception in 2010, over 5,000 practicing U.S. gastroenterologists and colorectal surgeons have contributed more than 27 million procedural cases to the registry. Physicians and their teams have real-time access to actionable reports for ongoing performance monitoring on key quality metrics. Further, GIQuIC has held QCDR status continuously since 2014 to support seamless data submission to public quality reporting programs. Led by a board of practicing gastroenterologists, GIQuIC improves patient outcomes by establishing standards for defining, measuring, and improving the quality of digestive health care.

AMERICAN UROLOGICAL ASSOCIATION

The American Urological Association ("AUA"), a not-for-profit 501(c)(6) corporation, established the AUA Quality ("AQUA") Registry in 2014. The AQUA Registry is a U.S.-based QCDR designed to measure, report and improve healthcare quality and patient outcomes. The AQUA Registry collects real-world data directly from participants' EHR systems to help urologists improve patient diagnosis and treatment outcomes. As of 2023, the AQUA Registry includes over 2,300 urologic providers, from more than 200 practices, spanning various setting types such as academic, hospital, multi and single specialty groups. Additionally, as a QCDR with national coverage of patients with urologic diseases, data collected through the AQUA Registry can fuel health services and policy research. The AQUA Registry data has the potential to support basic science and translational research to help fill current knowledge gaps. All data used in published reports or articles are de-identified at aggregated levels. Visit the AQUA in Action webpage to view examples of publications utilizing the AQUA Registry data.

COLLEGE OF AMERICAN PATHOLOGISTS

The College of American Pathologists ("CAP") Pathologists Quality Registry was established in 2017 as a quality improvement and payment model-focused registry covering a wide range of pathology subspecialties including gastrointestinal pathology, dermatopathology, thoracic pathology, and more. As of 2023, the registry includes more than 1700 pathologists from over 130 practices covering a mix of rural, urban, and suburban settings. Participants include practices with as few as one pathologist or as many as over 80 practicing pathologists. With the expertise of a diverse committee of board-certified pathologists, the registry develops, tests, and maintains a suite of performance metrics based on clinical practice guidelines to identify key areas of improvement for pathologists. Capabilities of the registry include data aggregation and benchmarking to support quality improvement activities such as decreasing turnaround times for specimens. The Pathologists Quality Registry supports various pathways of quality measure data reporting including, but not limited to, data extraction from laboratory information systems.

OUTPATIENT ENDOVASCULAR AND INTERVENTIONAL SOCIETY

The Outpatient Endovascular and Interventional Society ("OEIS") National Registry is the first registry focused on indications and outcomes measures for all office based endovascular and interventional procedures. OEIS National Registry aims to promote quality and to identify benchmarks for best practices within the outpatient intervention sector. The peripheral arterial disease ("PAD") module was launched in 2017, with over 40,000 procedures entered as of 2023. A new cardiac module is currently in development, with plans to expand offerings to a venous module, hemodialysis AV access module, and others in the future.

Office-based labs, also referred to as outpatient interventional suites, access centers, or office-based endovascular suites, offer many distinct advantages and provide an alternative care delivery model to patients, payers, and physicians that is believed to be more efficient and cost effective than many hospital-based interventions. The Outpatient Endovascular and Interventional Society is a multidisciplinary society created to address the unique needs and promote the attributes of these outpatient interventional suites. Provider specialties include interventional cardiology, interventional radiology, vascular surgery, and other interventionalists.

SOCIETY OF INTERVENTIONAL RADIOLOGY

The Society of Interventional Radiology ("SIR") launched the VIRTEX data registry to provide dedicated clinical data for the interventional radiology ("IR") specialty. VIRTEX will be a clinical data analytics platform that will help advance IR by using real-world evidence to show that IR therapies, procedures, and treatments are high quality, evidence-based, first-line solutions that are often less invasive and more efficient than traditional approaches while delivering equivalent or better outcomes. VIRTEX aims to improve the quality and safety of the care and treatment of all patients that undergo an IR procedure. VIRTEX will track outcomes, compare and evaluate the effectiveness of different treatments and approaches, monitor the safety and effectiveness of equipment and devices, and drive quality payment initiatives including appropriate reimbursement, coverage, and access.

Utilizing a near real-time, automated data ingestion process, VIRTEX will enable participating physicians and facilities to compare and improve their quality and performance not only by benchmarking against national and regional aggregates, but also having the ability to drill down to the practice, site, and physician level to evaluate their daily practice patterns and outcomes.

THE SOCIETY OF THORACIC SURGEONS

The STS National Database, launched in 1989, is one of the largest clinical registries with nearly 10 million cardiothoracic procedures performed by 4,300+ surgeons. Through its four component database programs – Adult Cardiac Surgery, General Thoracic Surgery, Congenital Heart Surgery, and Intermacs/Pedimacs, the Database supports quality assessment and improvement for cardiothoracic patients, participating surgeons, and their teams. Research published from the STS Database can be found here: https://www.sts.org/sts-research-and-analytic-center/published-research.

Adult Cardiac Surgery Database: The STS Adult Cardiac Surgery Database ("ACSD") is the world's premier clinical outcomes registry for adult cardiac surgery. With 95% of Adult Cardiac surgery procedures, the Database provides a true national clinical benchmark. The ACSD contains more than 8.5 million cardiac surgery procedure records and has nearly 3,800 participating physicians, including surgeons and anesthesiologists. The database collects data on procedures of the heart and thoracic aorta.

General Thoracic Surgery Database: The STS General Thoracic Surgery Database ("GTSD") is the largest and most robust clinical thoracic surgical database in North America. The GTSD contains more than 700,000 general thoracic surgery procedure records and has more than 1,000 participating surgeons. The Database collects procedures for primary cancer of the lung and esophagus.

Congenital Heart Surgery Database: The STS Congenital Heart Surgery Database ("CHSD") is the largest database in North America dealing with congenital cardiac malformations. The CHSD contains more than 600,000 congenital heart surgery procedure records and has more than 1,000 participating physicians, including surgeons and anesthesiologists. The CHSD collects procedures performed for congenital abnormalities of the heart, lungs, great vessels, airway, and other intrathoracic structures.

Intermacs/Pedimacs Database: Intermacs, along with its Pedimacs component, is a North American registry for the clinical outcomes of patients who receive an FDA-approved mechanical circulatory support device to treat advanced heart failure. The Intermacs/Pedimacs Database includes longitudinal data for the life of a patient with a mechanical circulatory support device. Approximately 36,000 patients are currently enrolled at more than 220 sites.