2021 ANNUAL REPORT

PEOPLE

PRACTICE

POLICY

Celebrating Ten Years of SIDM
# Society to Improve Diagnosis in Medicine

## Table of Contents

<table>
<thead>
<tr>
<th>Page</th>
<th>Section</th>
</tr>
</thead>
<tbody>
<tr>
<td>2</td>
<td>Letter From Leadership</td>
</tr>
<tr>
<td>3</td>
<td>Reflections From Paul Epner</td>
</tr>
<tr>
<td>4</td>
<td>10 Years of SIDM</td>
</tr>
<tr>
<td>6</td>
<td>People</td>
</tr>
<tr>
<td>8</td>
<td>Fellowship</td>
</tr>
<tr>
<td>10</td>
<td>Practice</td>
</tr>
<tr>
<td>14</td>
<td>Policy</td>
</tr>
<tr>
<td>16</td>
<td>Conference</td>
</tr>
<tr>
<td>18</td>
<td>Financials</td>
</tr>
<tr>
<td>19</td>
<td>Board &amp; Staff</td>
</tr>
<tr>
<td>20</td>
<td>Contributions</td>
</tr>
</tbody>
</table>
OUR VISION
Creating a world where no patients are harmed by diagnostic error.

OUR MISSION
The Society to Improve Diagnosis in Medicine (SIDM) catalyzes and leads change to improve diagnosis and eliminate harm from diagnostic error, in partnership with patients, their families, the healthcare community, and every interested stakeholder.

STRATEGIC PRIORITIES

PEOPLE
Recruit and develop key organizational leaders to the improve diagnosis movement, including those from patient, provider, disease-focused, or other key stakeholder organizations.

PRACTICE
Catalyze growth in clinical interventions designed to improve diagnostic outcomes in major clinical practice settings, including clinic, emergency department, and hospital inpatient.

POLICY
Leverage organizational engagement to increase funding to support diagnostic excellence, with a principal focus on federal funding to create a national network of Centers for Diagnostic Excellence.
A LETTER FROM LEADERSHIP

It’s an understatement to highlight that we live in a moment of challenges and change. With frontline staff working harder than ever, hospitals facing unprecedented numbers of patients needing care, and patients and providers adapting to new technology and means of participating in care, COVID-19 has upended how we all approach health care.

Amidst all of this change, at this most tumultuous time, SIDM—in its 10th year—continues to grow in importance and influence.

From a humble beginning in 2011, SIDM has grown to include a Coalition of more than 60 organizations working together to improve diagnosis. It has distributed funding to more than 30 grantees that are studying potentially scalable interventions and promoted research that advances our understanding of the diagnostic process, including a report on the “Big Three” diseases that are the largest contributors to inaccurate diagnoses.

As we enter the next phase of this organization’s future, we continue to refine and focus SIDM’s strategic priorities. First, we’re forging partnerships with champions of diagnosis, the people making a difference in the world of diagnostic excellence—among them patients, clinicians, and healthcare system leaders. Our Coalition to Improve Diagnosis (page 6) and Fellows (page 8) are examples of leaders making incredible strides.

We know more about the causes and consequences of diagnostic error today than ever, and we have an organization dedicated to bringing us together to explore these issues.

We’re identifying implementable actions to improve the practice of diagnostic safety and quality. SIDM’s DxQI Seed Grant (page 10) program is making tremendous progress in testing interventions that are replicable, scalable, and hold promise in improving clinical outcomes.

We’re pushing policy advances within Congress to further the mission of improving diagnosis. The House Appropriations Committee designated $8 million for diagnostic quality and safety work at the Agency for Healthcare Research and Quality (AHRQ) this year (page 14), an amount greater than the past three years combined.

We couldn’t have gotten here without Paul Epner, SIDM’s co-founder. After a decade at the helm, Paul is now stepping down as chief executive officer (CEO). His leadership unquestionably catapulted the field of diagnostic safety and quality forward. We know more about the causes and consequences of diagnostic error today than ever, and we have an organization dedicated to bringing us together to explore these issues.

We are thrilled to announce that Jennie Ward-Robinson, PhD, will be joining us as the new CEO of SIDM.

The Board strongly believes she is the right person to lead SIDM in pursuit of achieving its mission. Her experience, leadership abilities, and perspective make us very confident she will have a positive impact on the organization and the field.

ROBERT TROWBRIDGE, MD
President, SIDM Board of Directors
A LETTER FROM PAUL L. EPNER, MBA, MEd

It has been ten years since SIDM was founded, and what a journey it has been. From a small community of passionate and committed researchers and educators, spearheaded by the visionary Mark L. Graber, MD, FACP, the reduction of diagnostic error is now a global movement. SIDM held conferences in the United States, Europe, and Asia, chartered a chapter affiliate in Australia, and witnessed a burgeoning group in South America. Diagnostic error has evolved from what the National Academy of Medicine called health care’s “blind spot,” to the focal point of the more than 60-member Coalition to Improve Diagnosis comprised of organizations of clinicians, testing professionals, researchers, policymakers, educators, healthcare delivery organizations, government agencies and, of central importance, patient advocacy groups.

In 2011, little was written about diagnostic error in peer-reviewed literature. Today a search on PubMed for “diagnostic error” shows a quintupling of hits. SIDM now has its own peer-reviewed journal, Diagnosis. Abstracts submitted to SIDM’s annual Diagnostic Error in Medicine Conference have increased five-fold to 150 at last count.

In the early days, patients attending conferences told heart-rending stories that urged medical professionals to do better. Today, patients (the only constant presence throughout an often-fragmented diagnostic journey) are essential members of SIDM’s teams. SIDM’s commitment to involve patients in all diagnostic improvement efforts led us to establish a curriculum to train patients to participate in the design, execution, and dissemination of research.

SIDM has evolved from a volunteer-run organization to a staff-run entity with a several million-dollar budget. We expanded from a society that seeks grants, to one that awards quality improvement seed grants that catalyze innovation and develop a community committed to diagnostic excellence. Additionally, SIDM oversees an annual fellowship program that recruited eight fellows this year.

I am amazed that in 2021, smallpox, an eradicated disease, receives federal research funding that exceeds comparable funds to reduce and eliminate diagnostic error. In recent years, SIDM successfully advocated for Congress to approve new and growing line-item appropriations to AHRQ to address diagnostic error and create an inter-agency taskforce to coordinate efforts of federal agencies. We now routinely engage with CMS, CDC, and AHRQ among other agencies to raise the profile of this most common, catastrophic, and costly of all medical errors. SIDM attracted other major funders to tackle this issue. The Gordon and Betty Moore Foundation announced an $86 million investment over six years. Coverys announced a $3 million granting program. Constellation, in partnership with SIDM, is funding a QI collaborative. A decade ago, such initiatives did not exist.

On a personal note, in January 2021, I informed SIDM’s Board of Directors that I will step down as CEO because I believe that every organization needs periodic change in staff leadership. I am immensely grateful for the opportunity to operationalize SIDM’s mission the last 10 years and am fortunate to have worked with committed Board members and talented staff who are deeply invested in SIDM’s success. Much remains to be done, but it has been an honor to help SIDM ensure that diagnostic error is no longer a “blind spot” in health care.
THIS YEAR MARKS THE 10TH ANNIVERSARY of the founding of the Society to Improve Diagnosis in Medicine (SIDM). While officially incorporated in 2011, SIDM’s history dates to 2008 with the first annual Diagnostic Error in Medicine Conference, held in collaboration with the American Medical Informatics Association (AMIA). The annual conference helped build a small, but very diverse community that recognized the importance of diagnostic quality and safety. Still, leaders in the field realized the conference alone wasn’t enough.

In 2011, SIDM was officially established, allowing continuous discussion, exploration, and improvement around diagnostic quality and safety. However, there was no website, no newsletter, little money, and few friends a decade ago—only the commitment and dedication to create a world where no patients are harmed by diagnostic error.

While much has changed since SIDM was incorporated, our vision remains the same. SIDM’s efforts to raise awareness, improve practice, and inform policy have significantly altered how national, state, and local health leaders and providers work to find solutions that improve diagnostic safety and quality, reduce harm, and ensure better health outcomes for patients.

Thanks to the tireless work of the SIDM community and our partner organizations, the discussion around the diagnostic process has become more widespread in hopes that patients receive the care they need. While SIDM’s work is far from over, we are proud of what we have accomplished in our first 10 years.

In my view, a signature accomplishment has been to reach out, expand our horizons to include nurses and other members of the diagnostic team, and especially our successes in engaging patients at every level of our work, while managing to retain our expert physician core.

Ruth Ryan, RN, Founding Board Member

During a SIDM leadership retreat in the Spring of 2013, the SIDM Board of Directors set in motion the creation of the foundational NAM Improving Diagnosis in Health Care report.
SIDM’s Accomplishments

- **Publication of a Landmark Report Raises Awareness of Diagnostic Error.** The first charge of the newly formed SIDM was to raise awareness around the impact of diagnostic error. To do this, SIDM petitioned the National Academies of Sciences, Engineering, and Medicine (formerly the Institute of Medicine) to conduct a review of the field and helped secure funding for the report. The landmark *Improving Diagnosis in Health Care* report, published in 2015, put diagnostic quality and safety on the radar for healthcare organizations around the country.

- **Forming a Coalition to Generate Real, Lasting Change.** Convened by SIDM in 2015, the Coalition to Improve Diagnosis was created to gain maximum impact for the *Improving Diagnosis in Health Care* report. Originally comprised of 14 healthcare organizations, the Coalition now includes more than 60 of the nation’s leading healthcare organizations, who have pledged to work together to bring attention, awareness, and action to improving diagnostic quality and safety.

- **Securing Partnerships to Drive Organizational Growth.** Having a big picture vision of what it takes to improve diagnostic quality has been key to the success of the organization. But the development of partnerships with grantors and other supporters has provided financial support that has helped develop new programs and has grown the organization to continue our focus.

- **The DxQi Seed Grant Program Catalyzes Solutions.** The establishment of the DxQi Seed Grant Program has allowed SIDM to help clinicians, hospitals, and health systems take specific steps to improve diagnostic quality and safety by building an evidence base of effective interventions. The program supports SIDM’s vision of an inclusive approach to reducing diagnostic errors where patients and frontline health professionals engage in developing and testing approaches to improve diagnostic quality and safety.

Beyond these milestones, our most important reflection is how grateful we are to have worked with committed partners over the last decade. We look forward to strengthening existing partnerships and creating new ones to improve diagnostic quality and safety over the next 10 years and beyond.

THE STORY OF SIDM’S LOGO

The SIDM logo is an artistic rendition of a commemorative medal crafted by the gifted and prolific Portuguese artist Irene Vilar (1931–2008). The original medal was designed for the 4th Congresso Nacional de Medicina in Lisbon, 1980.

The ‘half-veiled man’ conveys the inherent uncertainty of the diagnostic process, and the constant quest to clarify truth in science, medicine, and diagnosis.

INDIVIDUAL FOUNDING MEMBERS

Founding members donated $1,000 or more to SIDM to help promote its mission and vision.

- Robert Ashton, MD
- Muhammad Athar, MD
- Dawer Azizi
- Robert Centor, MD
- Carmel Crock, MD
- Paul Epner, MBA, MEd
- Mark Graber, MD, FACP
- David Newman-Toker, MD, PhD
- Elizabeth Montgomery
- Carolyn Oliver, MD, JD
- Frank Papa, MD
- Art Papier, MD
- Jack Rubenstein, MD
- Ruth Ryan, RN
- Gordon Schiff, MD
- Paul Tibbits, MD
RECRUIT AND DEVELOP key organizational leaders to the improve diagnosis movement, including those from patient, provider, disease-focused, or other key stakeholder organizations.

Coalition to Improve Diagnosis

Six years ago, SIDM brought together representatives of 14 organizations that were leaders in the diagnostic quality and safety space—a relatively new field of research and education in medicine—but one gaining traction with the release of the seminal Improving Diagnosis in Health Care report.

Under the leadership of SIDM co-founders Paul L. Epner, MBA, MEd, Chief Executive Officer, and Mark L. Graber, MD, FACP, President Emeritus, SIDM recognized that to move the field forward, there would need to be coordinated focus and action to build support for diagnostic quality research and education, and ultimately changes in clinical practice to reduce diagnostic error.

SIDM and the other founding Coalition to Improve Diagnosis members understood that diagnosis is inherently a team activity, where all involved in health care—clinicians, nurses, lab professionals, healthcare executives, payers and patients—contribute to diagnostic quality and safety.

With the active support of the Gordon and Betty Moore Foundation and The Mont Fund, the Coalition to Improve Diagnosis has grown fivefold over the last five years. With more than 60 members, the Coalition represents every healthcare sector and is made up of members committed to driving diagnostic quality and safety efforts, not only in their home institutions, but across all of health care.

We believe in the power of collaboration and being part of this Coalition is very important to us. SIDM is leading the conversation around the burden of diagnostic error. By joining together, we are better able to address the problem and find solutions that reduce harm and ultimately ensure better outcomes for patients.

Orlaith Staunton, Co-Founder and Executive Director of END SEPSIS, the legacy of Rory Staunton
## Coalition to Improve Diagnosis Members

**CONVENER**
Society to Improve Diagnosis in Medicine

**CLINICIAN**
- ABIM Foundation
- American Academy of Pediatrics
- American Association of Nurse Practitioners
- American College of Emergency Physicians
- American College of Physicians
- Council of Medical Specialty Societies
- National Association of EMS Physicians
- National Association of Pediatric Nurse Practitioners
- Primary Care Collaborative
- Society of Bedside Medicine
- Society of Hospital Medicine

**HEALTHCARE MANAGEMENT**
- American College of Healthcare Executives
- American Society for Health Care Risk Management

**HOSPITAL ASSOCIATION**
- Colorado Hospital Association
- Michigan Health and Hospital Association
- Northwest Safety & Quality Partnership

**HOSPITAL, HEALTH SYSTEM OR MEDICAL GROUP**
- Advocate Aurora Health
- AMGA (American Medical Group Association)
- Ballad Health
- Baystate Health
- Children’s Hospital of Philadelphia
- Cleveland Clinic
- Geisinger
- Intermountain Healthcare
- Johns Hopkins Medicine
- Medical University of South Carolina
- MedStar Health
- Nationwide Children’s Hospital
- Northwell Health
- Penn State Health, Milton S. Hershey Medical Center
- The Permanente Federation, Kaiser Permanente
- UCSF Health
- University Hospitals

**PATIENT**
- American Cancer Society Cancer Action Network
- American Heart Association
- Colorectal Cancer Alliance
- Consumers Advancing Patient Safety
- END SEPSIS, the Legacy of Rory Staunton
- Sepsis Alliance
- WomenHeart

**MEASUREMENT AND ASSESSMENT**
- American Board of Internal Medicine
- American Board of Medical Specialties
- COLA, Inc.
- National Quality Forum
- The Joint Commission
- The Leapfrog Group

**MEDICAL EDUCATION AND TRAINING**
- Accreditation Council for Graduate Medical Education
- Alliance for Academic Internal Medicine
- Association of American Medical Colleges

**INSURERS AND PAYERS**
- Medical Professional Liability Association

**QUALITY AND SAFETY**
- American Health Quality Association
- Children's Hospital Association
- ECRI Institute
- Health Care Improvement Foundation
- Institute for Healthcare Improvement
- Maryland Patient Safety Center
- Massachusetts Coalition for the Prevention of Medical Errors
- Midwest Alliance for Patient Safety
- National Association for Healthcare Quality
- Pennsylvania Patient Safety Authority
- Washington Patient Safety Coalition

**TESTING**
- American Association for Clinical Chemistry
- American Society for Clinical Laboratory Science
- Association of Clinical Scientists

**FEDERAL LIAISONS**
- Agency for Healthcare Research and Quality
- Centers for Disease Control and Prevention
- Centers for Medicare & Medicaid Services
- Veterans Health Administration

*Views and knowledge shared by federal liaisons to the Society to Improve Diagnosis in Medicine (SIDM) and the Coalition to Improve Diagnosis (CID) are limited to activities consistent with the mission of the respective federal agencies. Federal participants serving in their official capacity must not be interpreted as agency endorsement of either SIDM or CID’s activities, business practices, or efforts to advocate or lobby for federal funds.*
NOW IN ITS SIXTH YEAR, the SIDM Fellowship in Diagnostic Excellence attracts early-career scholars who demonstrate commitment to diagnosis-related work and pairs them with recognized experts who serve as advisors and mentors.

Including this current class, our fellowship program has trained 32 professionals since its inception. In just the last year, our previous Fellows have published more than 70 articles in peer-reviewed publications.

In 2021, SIDM expanded its Fellowship in Diagnostic Excellence to include eight new Fellows. They join a distinguished group of scholars who influence the fields of health professions education and research.

Our Fellowship in Diagnostic Excellence program continues to attract exceptional candidates who are poised to advance the field of diagnostic quality and safety. We look forward to supporting this crop of burgeoning researchers, educators, and leaders who will advance our communal goal to end harm from diagnostic error.

Paul Bergl, MD (pictured right), fellowship director and 2017 Fellow
CARL BERDAHL, MD, MS, Cedars-Sinai Medical Center / UCLA / RAND Corporation
Project: Prospectively study the frequency of, contributors to, and patient experiences with diagnostic errors occurring among adults discharged from the emergency department. The study will target patients triaged as having urgent or emergent needs but who are sent home from the emergency room.

LEAH BURT, PhD, APRN, ANP-BC, University of Illinois-Chicago
Project: A Diagnostic Reasoning Course Toolkit will serve as a free-of-charge blueprint for NP faculty across the country to implement evidence-based diagnostic reasoning education at individual institutions. The Toolkit will target identified areas for diagnostic improvement, as well as provide support for faculty.

DA JIN, MD, Oregon Health & Science University
Project: Develop a predictive model using machine learning algorithms to identify women at high risk for coronary artery disease presenting with atypical symptoms to an ambulatory setting. Ultimately such a predictive model may be embedded into the electronic health record to serve as the basis for clinical decision support at the point of care.

CASEY MCQUADE, MD, UPMC Presbyterian Shadyside / University of Pennsylvania
Project: By examining how novices versus experts craft a written summary statement (also known as a problem representation) of unknown cases’ salient details, they hope to improve the teaching of clinical problem analysis to trainees by developing a set of evidence-based best practices.

EDWIN ROSAS, MD, University of Chicago Medicine
Project: Seeking to develop a structured diagnostic timeout for hospitalized patients at risk for clinical deterioration. This work will involve nurse-physician collaboration and will build upon nurses’ SBAR communication model.

ELIEZER SHINNAR, MD, Indian Health Service (Phoenix AZ)
Project: Seeking to ascertain the frequency of types of diagnostic errors that occur around transfers into and out of the Indian Health Service hospitals.

SARAH SLONE, DNP, APRN, Johns Hopkins University
Project: Defining treatment patterns and diagnostic accuracy of clinical scoring systems and non-invasive imaging as predictors of coronary revascularization in patients presenting with NSTE-ACS to rural hospitals in a southeast regional healthcare system.

KELSEY UFHOLZ, PhD, Case Western Reserve University
Project: Identify rates of recognition of unintentional weight loss in a diverse sample of patients and to determine what proportion of patients with unintentional weight loss, both recognized and unrecognized, are subsequently diagnosed with cancer and other conditions.
CATALYZE GROWTH in clinical quality improvement (QI) interventions designed to improve diagnostic outcomes in major clinical practice settings, including office-based clinic, emergency department, and hospital inpatient.

DxQI Seed Grant Program

SIDM, with funding from the Gordon and Betty Moore Foundation, awarded the second of three grant rounds of up to $50,000 to 16 healthcare organizations as a part of the competitive DxQI Seed Grant Program. The selected projects focus on testing interventions to improve the quality, accuracy, and timeliness of diagnosis.

Over half of the grantees selected will focus on developing interventions to reduce diagnostic errors in three specific disease categories—cancers, vascular events, and infections—which account for most inaccurate or delayed diagnoses that result in serious harm or death. Many grantees are also including a focus on improving diagnostic quality outcomes related to health disparities associated with age, race, gender, or other social determinants of health.

Examples of funded projects include:

- **BETH ISRAEL LAHEY HEALTH PRIMARY CARE** is developing a data-driven model to identify primary care patients at high risk of a missed or delayed cancer screening ordered during virtual visits, increasing the equity and quality of the care provided to these patients.

- **CHILDREN’S HOSPITAL OF PHILADELPHIA** is improving the way its emergency department providers communicate diagnostic uncertainty within the care team, including patients’ family members, to reduce the risk of diagnostic errors if the patients are admitted to the hospital.

- **CINCINNATI CHILDREN’S HOSPITAL MEDICAL CENTER** is closing gaps in communication with parents of hospitalized children with uncertain diagnoses to give them the information they need to ask questions and serve as engaged members of the diagnostic team.

- **COOK COUNTY HEALTH** is using an automated electronic medical record tool for language preference to decrease infection-related diagnostic errors in patients with limited English proficiency.

- **INTERMOUNTAIN HEALTHCARE** is improving screening for intimate partner violence in clinics that offer OB/GYN care with tools that help patients and providers start and normalize conversations on this topic.

The grant allowed us to internally reflect and see things that we didn’t initially see when we first started this project. Some of the data we’ve uncovered has really shown just how big an impact we’ve made.

Christina Bird, UT San Antonio/University Health, 2020 DxQI Seed Grant Awardee

The DxQI grant helped us get this project on its feet. These kinds of opportunities are what helps us make practice changes that can help our patients.

Monica Thim, Maine Medical Center, 2020 DxQI Seed Grant Awardee.
Investing time and resources in reengineering diagnostic workflows, implementing reliable HIT systems and boosting communication processes will not only help reduce diagnostic errors; it will also help create stronger care teams, increase efficiency and productivity, and improve the diagnostic process.

Laurie Drill-Mellum, MD, Chief Medical Officer, Vice President for Patient Safety, Constellation®

Constellation® Diagnosis-related Claims

<table>
<thead>
<tr>
<th>Stage 2: Tests and results processing</th>
</tr>
</thead>
<tbody>
<tr>
<td>6. Tests preformed</td>
</tr>
<tr>
<td>7. Tests interpreted</td>
</tr>
<tr>
<td>8. Test results transmitted/received</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Stage 3: Follow-up and coordination</th>
</tr>
</thead>
<tbody>
<tr>
<td>9. Clinician follows up with patient</td>
</tr>
<tr>
<td>10. Referrals/consults</td>
</tr>
<tr>
<td>11. Pt info communicated among the care team</td>
</tr>
<tr>
<td>12. Patient and providers establish follow-up plan</td>
</tr>
</tbody>
</table>

Taking Action to Close the Loop on Diagnostic Error

Constellation®, a medical professional liability insurance company, and SIDM joined together to create a new quality improvement collaborative focused on closing the loop on test results. Almost half of Constellation® member diagnosis-related malpractice claims involve follow-up system failures.

The virtual collaborative launched in the summer of 2021 and includes a small group of critical access hospitals and academic medical centers focused on closing the loop on test results and follow-up care. The collaborative will participate in a virtual community, take part in monthly group calls and regular webinars, and participate in a quality improvement summit.

Transforming Education on Diagnostic Reasoning

Education on diagnostic reasoning requires collaboration, teamwork, and measurement. SIDM, with funding from Coverys Community Healthcare Foundation, partnered with the Human Diagnosis Project and Kaiser Permanente to develop a guidance document on implementing a diagnostic reasoning quality improvement intervention that is scalable and can be implemented in any healthcare system. The education quality improvement intervention focuses on collaboration, teamwork, and measurement of clinical reasoning.
Diagnosis and Telemedicine

The COVID-19 pandemic transformed telemedicine usage overnight and became a mainstay for healthcare delivery across the nation. To help navigate this new era of telemedicine and diagnosis, SIDM, with funding from the Patient-Centered Outcomes Research Institute, conducted an environmental scan of available literature and hosted a series of virtual listening sessions with patients, clinicians, and others to identify the must-know research questions for safe and effective telediagnosis.

The final project findings were published in an issue brief that stakeholders can use to help shape future research, inform strategic planning and implementation, support education and training efforts, and improve patient engagement.

Research questions about telediagnosis fell into four categories:

1 TECHNOLOGY—what technology obstacles do certain patients face and how can telemedicine be used to create greater access for patients without primary care clinicians and specialists nearby?

2 CLINICAL EXPERIENCE—how can telemedicine replicate the benefits of in-person visits through the screen and how can telehealth simplify and make routine testing and evaluation more efficient?

3 MEASURING EFFECTIVENESS—could patient surveys ask about diagnostic accuracy and could virtual care provide a mechanism for better tracking/reporting missed diagnoses?

4 FORECASTING—how will the effectiveness of telediagnosis be assessed for reimbursement purposes and how will it impact medical malpractice laws?
Exploring Disparities in Diagnosis

Upon first entry in the diagnostic process, the age, race/ethnicity and/or sex of the patient are the first characteristics visible to healthcare providers. There is strong evidence that these visible factors matter in diagnostic decision-making. To date however, little research has focused on how and when these visible factors influence the risk of diagnostic error.

To help address this gap, SIDM partnered with Johns Hopkins University and Patient and Research Advisory Boards, to conduct a two-year project exploring and addressing disparities in diagnosis related to visible patient factors. The project, funded by Coverys Community Healthcare Foundation, included patient interviews, clinician responses, literature review, data analysis, and multiple solutions-generating workshops. A collaborative network has been established from the project, creating broader awareness of diagnostic disparities and shifting thinking around conducting diagnostic disparities research.

Building a Research Agenda to Improve Diagnosis of Heart Disease in Women

Although heart disease has been the number one killer of women for decades, perceptions of heart disease as a “man’s disease” have dominated the narrative and caused misdiagnosis and delay in treatment for women with heart disease. In January 2021, WomenHeart with funding from the Patient-Centered Outcomes Research Institute, partnered with SIDM to host a convening on missed and delayed diagnosis of heart disease in women.

The meeting brought together women with heart disease, clinicians, hospital personnel, advocates, and researchers to develop ideas for patient-centered research focused on solutions. The results were highlighted in a webinar and published in a report that includes a list of diagnostic challenges and possible interventions reframed as research questions. The ideas presented in the report are intended to provide support for future research that will lead to more timely and accurate diagnosis of heart disease in women.
LEVERAGE ORGANIZATIONAL ENGAGEMENT to increase funding to support diagnostic excellence, with a principal focus on federal funding to create a national network of Centers for Diagnostic Excellence.

Increased Funding for Diagnostic Quality and Safety

SIDM maintains regular contact with leaders in Washington to educate them about the scope and scale of diagnostic error and opportunities to reduce patient harm. With the transition to the Biden-Harris Administration, SIDM has the opportunity to highlight this issue for a new audience and profile the importance of diagnostic quality and safety.

This year, the House Appropriations Committee designated $8 million for diagnostic quality and safety work at the Agency for Healthcare Research and Quality (AHRQ), an amount greater than the last three years of funding combined. AHRQ has identified diagnostic quality and safety as a priority in its overall patient safety research program. This increase in funding could accelerate its work in the field and lay the foundation for robust research and a quality improvement program for diagnosis at the agency.

In an effort to advocate for the bill as it moves to the Senate, SIDM launched a grassroots effort and leveraged its community by providing materials and guidance to over 7,000 individuals, encouraging them to contact their state Senators to emphasize the importance of diagnosis as a critical patient safety issue. Additionally, Coalition to Improve Diagnosis members signed a letter to the Appropriations Full and Subcommittee leaders requesting dedicated increase in funding for the AHRQ’s patient safety portfolio, specifically to expand and accelerate the agency’s work to improve diagnostic safety and quality. SIDM is hopeful that these efforts will encourage the Senate to pass the $8 million funding level.

Connecting Partners with Lawmakers

All this work takes resources to accomplish. SIDM members and the Coalition to Improve Diagnosis have been instrumental in bringing diagnostic safety and quality to policymakers’ attention, raising awareness, educating them about the scope and scale of the problem, and calling for increased research funding to identify and implement scalable solutions. Deeply motivated individuals also have championed this issue to their own elected officials.

SIDM continues to work with both individuals and organizations to coordinate messaging, timing, and communication with elected officials, as well as educate about the funding process and the impact communication with representatives could have on diagnostic quality and safety.
Diagnostic Safety Event Reporting – Shared Action to Improve Diagnosis

A critical challenge in improving diagnostic safety and quality is that there are not consistent methods for tracking where, when, and how diagnostic safety events happen in health care. Hospitals and health systems lack a standardized method for data collection around these events, limiting visibility into the scale of the problem and making research, quality improvement, and patient safety efforts more difficult.

Thanks in part to SIDM’s advocacy efforts, Congress continues to provide additional focus and funding to diagnostic quality and safety, allowing federal agencies to expand the scope of activities to improve diagnosis. In early 2020, AHRQ announced they were in the process of developing Common Formats for Event Reporting in Diagnostic Safety. It was clear that SIDM and the Coalition to Improve Diagnosis’ efforts to elevate diagnostic safety as a critical patient safety issue had been an important driver of their action. However, we also recognized there is much more work to be done to inform the conversation about diagnostic safety event reporting. The SIDM Coalition team developed and implemented a plan to leverage the Common Formats activities to:

- **REINFORCE** more broadly the importance of addressing diagnostic quality in health care.
- **ENGAGE** the broad expertise of the Coalition to facilitate the vitally important conversation, with stakeholders across health care, about how to identify and track diagnostic safety events.
- **ENSURE** patients and other important diagnostic team members are engaged to influence the final Common Formats.

On June 1, 2021, AHRQ issued a call for comments on draft Common Formats for Event Reporting in Diagnostic Safety. Immediately, SIDM and experts from the Coalition reviewed the draft and discussed elements that were effective and areas that could be improved. 32 organizations signed on to SIDM’s formal comments to AHRQ. If organizations wanted to submit their own comments, SIDM provided step-by-step guidance on how to submit comments.

Once the Common Formats are formally issued in late 2021, the Coalition will continue to work to support the field in developing common reporting structures for diagnostic safety events, and potentially leveraging connections to develop systems for testing and promulgating AHRQ’s Common Formats.

Despite the complexity, uncertainty, and variability associated with diagnosis, the proposed Common Formats for Event Reporting - Diagnostic Safety (CFER-DS) represents a starting point for a broader discussion around the need for consistent approaches to diagnostic safety event reporting...

*SIDM’s Letter to National Quality Forum Expert Panel on Common Formats*
Patient Summit: Disparities in Diagnosis in the Time of COVID-19: A Multicultural Perspective

The 2020 Patient Summit focused on the political, policy, and patient-level diagnostic concerns around COVID-19 shared by various populations including women, BIPOC, and people with chronic conditions. Featured speakers included The Honorable Peggy Flanagan, Lieutenant Governor of Minnesota; Ron Wyatt, MD, MHA, Vice President and Patient Safety Officer, MCIC Vermont; and Victor Montori, MD, MSc, Professor of Medicine, Knowledge & Evaluation Research Unit, Mayo Rochester.

Her continued work to improve diagnostic error and her commitment to the upcoming generation of diagnostic researchers are a testament to her contribution to reducing diagnostic error now and in the future.

Mark L. Graber Diagnostic Quality Award

CARMEL CROCK, MD, was awarded the Mark L. Graber Diagnostic Quality Award. The Award Review Committee selected Dr. Crock for her research, advocacy and leadership in the field, as well as her efforts to expand the field of diagnostic quality and safety internationally.
The conference sessions were well-connected and the interactions with patient advocates among the sessions [were] engaging and important to have their voices.

SIDM2020 Conference Attendee

Great virtual conference platform, engaging sessions focused on practice strategies.

SIDM2020 Conference Attendee

As a result of this conference, I will be working to increase engagement from patient advocates, as well as seek to find opportunities to address racial and ethnic disparities in improving diagnosis.

SIDM2020 Conference Attendee

Programs for Action and Feedback Loops

- First identify missed/learning opportunities
- But clinicians have concerns & fears
- Develop non-punitive strategies to give feedback to clinicians
- ACT on data

Joint Commission Journal

Hardeep Singh, MD, MPH, presenting at the Advancing the Science and Implementation of Diagnostic Safety Measurement concurrent session.

Marjorie Roberts-Crafton, DBA, (right) share her COVID-19 diagnostic error story in a session with David Meyers, MD, MBE, FACEP, (left) during the Patient Summit.

Kimberly Manning, MD, FACP, FAAP, during her keynote session: When Grief and Crises Intersect: Perspective of a Black Physician in the Time of Two Pandemics.

Conference attendees were able to chat with each other during sessions to connect, share ideas, and ask questions.
# FINANCIALS

## Fiscal Revenue Ends June 30

<table>
<thead>
<tr>
<th></th>
<th>FY 2018</th>
<th>FY 2019</th>
<th>FY 2020</th>
<th>FY 2021*</th>
</tr>
</thead>
<tbody>
<tr>
<td>Revenue</td>
<td>$4,624,726</td>
<td>$2,682,080</td>
<td>$6,112,313</td>
<td>$2,337,234</td>
</tr>
<tr>
<td>Expenses</td>
<td>$2,820,748</td>
<td>$3,557,014</td>
<td>$3,464,896</td>
<td>$3,210,743</td>
</tr>
<tr>
<td>Net</td>
<td>$1,803,978</td>
<td>($874,934)**</td>
<td>$2,647,417</td>
<td>($873,509)**</td>
</tr>
<tr>
<td>Unrestricted Net Assets</td>
<td>$262,397</td>
<td>$86,343</td>
<td>$129,586</td>
<td>$354,705</td>
</tr>
<tr>
<td>Restricted Net Assets</td>
<td>$3,305,274</td>
<td>$2,606,394</td>
<td>$5,210,568</td>
<td>$4,111,941</td>
</tr>
<tr>
<td>Total Net Assets</td>
<td><strong>$3,567,671</strong></td>
<td><strong>$2,692,737</strong></td>
<td><strong>$5,340,154</strong></td>
<td><strong>$4,466,646</strong></td>
</tr>
</tbody>
</table>

*Unaudited Results
**Budgeted grant awards

## Sources of Revenue

<table>
<thead>
<tr>
<th>Source</th>
<th>FY 2018</th>
<th>FY 2019</th>
<th>FY 2020</th>
<th>FY 2021*</th>
</tr>
</thead>
<tbody>
<tr>
<td>Individual Giving</td>
<td>$342,498</td>
<td>$425,282</td>
<td>$488,880</td>
<td>$466,475</td>
</tr>
<tr>
<td>Organizational Giving</td>
<td>$127,600</td>
<td>$137,500</td>
<td>$57,000</td>
<td>$346,960</td>
</tr>
<tr>
<td>Grants</td>
<td>$3,846,337</td>
<td>$1,523,646</td>
<td>$5,045,817</td>
<td>$1,071,000</td>
</tr>
<tr>
<td>Contract Services</td>
<td>$48,379</td>
<td>$25,260</td>
<td>$47,330</td>
<td>$229,422</td>
</tr>
<tr>
<td>Conferences</td>
<td>$235,691</td>
<td>$538,811</td>
<td>$439,309</td>
<td>$222,300</td>
</tr>
</tbody>
</table>

## 2021 Sources of Revenue

- **Grants**: $4,111,941
- **Organizational Giving**: $3,305,274
- **Individual Giving**: $342,498
- **Contract Services**: $48,379
- **Conferences**: $235,691

**SIDM 2021 | Annual Report**
INTRODUCING J ENNIE WARD-ROBINSON, PHD

After an extensive national search, SIDM is excited to announce that J ennie Ward-Robinson, PhD, has been appointed as the organization’s new Chief Executive Officer. Dr. Ward-Robinson is an internationally recognized global health leader with more than 20 years of executive leadership experience within academic, multilateral, nonprofit, and for-profit organizations.
SIDM is the only organization focused exclusively on improving diagnostic quality and safety. SIDM is a 501(c)(3) non-profit organization. When you support SIDM, you help lead the way to better health care for everyone. Thank you for your generosity.

**Funders**
(current and multi-year projects)
- Agency for Healthcare Research and Quality
- Constellation
- Coverys Community Healthcare Foundation
- Gordon and Betty Moore Foundation
- Jewish Community Foundation of Southern Arizona
- The Human Diagnosis Project
- Josiah Macy Jr. Foundation
- Patient-Centered Outcomes Research Institute
- PCPI Foundation
- WomenHeart

**Corporate Members**
- SILVER
  - EmPRO
  - InSimu
  - VisualDx
- BRONZE
  - Constellation
  - Covera Health
  - Coverys Community Healthcare Foundation
  - CRICO
  - Isabel
- MEMBER
  - Integrated Project Management Company
  - MCIC Vermont

**Health Institution and Nonprofit Organization Members**
- PATRON
  - Johns Hopkins Armstrong Institute for Diagnostic Excellence
- BENEFACCTOR
  - Advocate Aurora Health

**Individual Donors**

**$20,000+**
- Paul L. Epner
- The Mont Fund
- David Newman-Toker

**$10,000+**
- Timothy J. Mosher
- Tom Rebbeccchi
- Daniel Sullivan
- Robert Trowbridge
- Beth Ullem

**$600-$1,399**
- Anna Gaffey
- Tom S. Lee
- Michael Jon Lippitz
- Patrick McCabe
- Randal Moseley
- Doug Salvador
- Gordon D. Schiff
- Jack W. Schuler

**$300-$599**
- Naomi Aronson
- Stephen Beerman
- Dan Berg
- Janet Buckstein
- Adriane Budavari
- Mohamud Daya
- Leandro Arthur Diehl
- Alex Dummett
- William Follansbee
- Kim Hill
- Beatrice Krauss
- Carly Magnusson
- Andrew J. Majka
- Nargiz Muganlinskaya
- Rahul S. Nanchal
- Carrie E. Nelson
- Andrew P.J. Olson
- Laura O’Neill
- Frank J. Papa
- Brian Paul
- Alec Bijan Rezigh
- Jack Myron Rubenstein
- Rodney Schaffer
- Barbara Schildkrout
- Richard Schuster
- Lee Shapiro
- Hardeep Singh
- Kelly Smith
- Miguel Villamil
- Jason Waechter
- Roger D. Wilson
- Tim Wolff
- Sharon Wolters

**$<151**
- Aaron Abend
- Brian Acunto
- Jonathan Akre
- Ayad Al-Moslih
- Lorenzo Alonso Carrion
- Hussam Ammar
- Joel Appel
- Reuben Arasaratnam
- Ginelle Bader
- Michael Barron
- Stefano Bassetti
- Margaret Bavis
- Charles Beavers
- Richard A. Beck
- Caroline Bell
- Janice Benson
- Carl Berdahl
- Paul Bergl
- Lon Berkeley
- Kennan Bernard-Kravitz
- Jaap Beutler
- Renee Biedlingmaier
- Jack Bierig
- Denise Bockwoldt
- Boris Boskholov
- Jerry Both
- Kathy Boutis
- Paul Bowe
- Timothy Bowman
- Jeffrey Brensilver
- Nick Brestoff
- Christopher Bronson
- Jeff Brown
“Improving diagnosis is not only possible, but it also represents a moral, professional, and public health imperative.”

National Academies of Sciences, Engineering, and Medicine