Opinion Paper

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The role of philanthropy in advancing diagnostic excellence and the legacy of the Gordon and Betty Moore Foundation

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Abstract: In America, medical research is largely driven by large investments of federal funding administered by government agencies. However, the problem of diagnostic error falls outside the usual funding categories for government-sponsored biomedical research. While federal resources are vital to support academic institutions and research teams, private funders and philanthropic organizations often contribute a significant source of support for medical research, particularly for critical gaps in funding and for high risk or innovative ideas. In 2017, the Gordon and Betty Moore Foundation launched an initial exploration into work that addressed diagnostic error and subsequently committed $85 million to their Diagnostic Excellence Initiative. Their model of strategic philanthropy proposed a pathway to improved diagnostic outcomes. Their three-pronged strategy and a summary of their portfolio of work for Diagnostic Excellence is described in this article. Lessons from their experience are worth reflection: real-world problems with diagnosis and reliable delivery of diagnostic care are complex and solutions require coordinated efforts across many disciplines; and efforts are more effective when done in partnership with like-minded organizations. We celebrate the contributions of the Moore Foundation and acknowledge their contribution to helping build a community committed to diagnostic excellence, develop infrastructure for quality improvement, and advance ideas for the use of technology to improve care.

Keywords: diagnosis; diagnostic error; diagnostic excellence; philanthropy; Gordon and Betty Moore Foundation

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Introduction

Possibly the greatest impact of the 2015 National Academies of Sciences, Engineering, and Medicine (National Academies) report on “Improving Diagnosis in Health Care” was its role in stimulating financial investment in the nascent issue of diagnostic error [1]. The report was an authoritative summation of evidence that documented the magnitude of the diagnostic error problem and asserted that improvement in diagnosis was “a moral, professional, and public health imperative”. A fortunate coincidence played a key role: The National Academies report was Dr. Harvey Fineberg’s last major project as the President of the Institute of Medicine (since renamed the National Academy of Medicine, NAM) before he assumed the leadership role as president of the Gordon and Betty Moore Foundation. When Mark Graber appealed to the Moore Foundation to consider support for work in diagnostic safety, the suggestion received a warm reception. The foundation already had a Patient Care Program focused on patient safety honoring the interest and passion of Betty Irene Moore. The transition to support diagnostic safety was clearly aligned with the foundation’s focus in health care quality and safety and its commitment to substantive issues. This article serves to preserve the history of the Diagnostic Excellence Initiative and celebrate its many achievements.

The Moore Foundation’s mission is to advance scientific discovery, environmental conservation, and the special character of the San Francisco Bay Area [2]. The foundation operates on a philosophy that prioritizes work in promising areas that are important, difficult, but otherwise neglected by other funders or entrepreneurs, with a willingness to take risk where others won’t. The foundation stimulates work, tests ideas and strategies, but retains a willingness to exit if strategies fail or the broader field begins to take the lead. The challenge to improve diagnosis described in the National Academies report satisfied these basic criteria: It identified an important problem and a gap in science, and other funders were reluctant to wade into an area that had yet to establish a mature understanding or realistic solutions.

However, the problem of diagnostic error was acknowledged at the outset as one that eventually required a committed focus by the government – no other single organization could commit the resources, or operationalize a plan for national health, supported by public policy and payment.

The Diagnostic Excellence Initiative

The Moore Foundation initiated its investment by launching a $6 million "exploration" which supported program fellows (Drs. Jeffrey Jopling and Daniel Yang) to investigate the problem and develop a strategy and budget for a potentially larger initiative. The exploration in 2017–2018 culminated in a successful proposal that was adopted by the Moore Foundation's Board of Trustees, with an initial commitment of $85 million over six years to launch the Diagnostic Excellence Initiative [3]. The authors (KC, DY) directed the new initiative and were later joined by a third team member to lead focused work on technology (TW).

The exploration determined that a focus on diagnostic error did not seem adequate to the aspirations of the initiative. Rather, a vision of diagnostic excellence framed the focus on optimal diagnosis that was safe, effective, patient-centered, timely, efficient, and equitable [4]. Program staff determined that the health care space and the challenge to improve diagnosis were too broad to expect to achieve measurable success in a short timeline needed to assess progress; thus, the initiative strategically focused on three prioritized conditions thought to contribute the most to preventable harm (cardiovascular conditions, infections, and cancer) [5].

The Diagnostic Excellence Initiative was grounded in a theory of change with three strategies, each requiring continuous assessment, monitoring, and adaptation to assure the efforts were yielding lessons and informing potential solutions (Figure 1). The strategies included:

a. Field building (also referred to as People in Figure 1): Support individuals to create a community committed to advancing diagnostic excellence. This strategy was expanded to include partnerships with organizations to increase impact.
b. Infrastructure: Develop validated measures of diagnostic quality and replicable models of success.
c. Technology: Identify and/or develop technology to support diagnostic excellence.

Brief summaries of substantive work are described below by strategy.

Strategy #1. Field building: Develop a workforce of individuals and engage with organizations committed to and passionate about improving diagnosis

People

The people sub-strategy was designed to attract and develop talented individuals and promote interest in solving the multifaceted challenges to diagnostic excellence. The foundation reached out to provide financial support for the burgeoning mentoring fellowship at the Society to Improve Diagnosis in Medicine (SIDM), an unfunded program that was launched by volunteers from the SIDM Education Committee. The fellowship committee members may well recall paying for meeting and dinner costs for the fellows in the first few years to allow the group to assemble together at the annual Diagnosis Error in Medicine (DEM) meeting. With the support of the Moore Foundation, fellows began receiving a modest stipend to cover registration fees and travel expenses to the DEM meeting, with some funds left over to support administrative project costs. Based on the enthusiasm and success of the SIDM fellowship, two new fellowship programs were launched, including one hosted by the National Academy of Medicine (NAM) in partnership with the Council of Medical Specialty Societies (CMSS) [6, 7] and a second with the Society of Bedside Medicine [8]. In addition, positions specific to diagnostic excellence were added for existing fellowship programs, including the American Board of Medical Specialties Visiting Scholars Program [9] and the Institute for Healthcare Improvement (IHI) Fellowship Program [10]. Through the generous grants, the fellowship programs provided financial support for scholarly activities and expanded the types of opportunities provided for engagement such as webinars and networking activities. These five programs have since supported over 100 Diagnostic Excellence Fellows and Scholars – many who have published in high impact journals, sit on national committees and hold leadership positions. In conversation with Yumi Phillips, the National Academy of Medicine (Aug 25 2025), the NAM/CMSS program alone has hosted 54 scholars from 17 states in over 20 specialties, and in a recent survey, 61.5 % reported having developed diagnostic initiatives with their specialty society or other organizations.

Partnerships with organizations

The initiative also established productive partnerships with several organizations, the most notable including SIDM, the NAM, the National Academies, The John A. Hartford

Appendix A

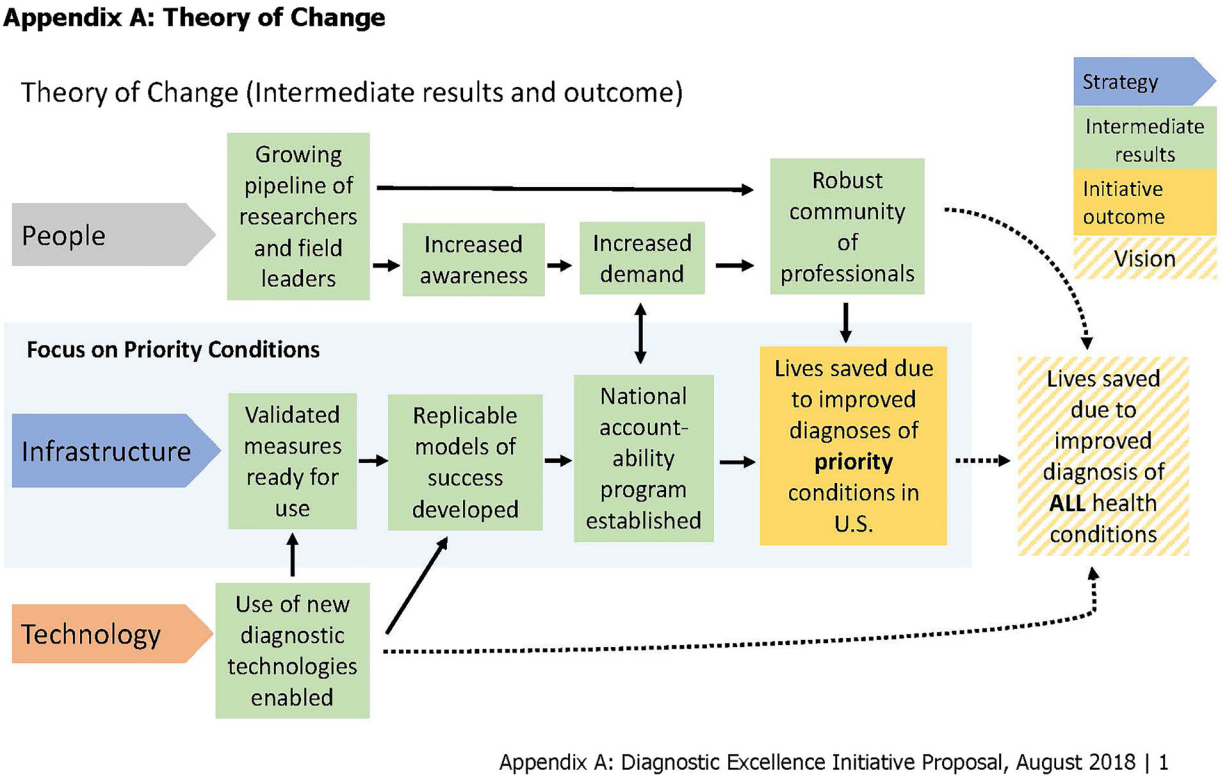

Figure 1: The theory of change for the diagnostic excellence initiative. Reproduced with permission.

Foundation (JAHF), IHI, CMSS, and AcademyHealth. These organizations participated alongside the Diagnostic Excellence Initiative in numerous activities. A selection of some of some of their joint activities with the Moore Foundation are described briefly below.

- SIDM was quickly recognized as an important body that brought together stakeholders, including investigators, healthcare leaders and a growing patient community, all energized to drive improvement strategies. The initiative provided support for SIDM for a variety of projects. As a fledgling nonprofit, it was paramount for SIDM to develop a sustainability model (or at least understand models and options for nonprofits). A sustainability grant helped inform their vision and mission as a catalyst organization. As SIDM worked to engage interest by healthcare leaders and organizations, the Moore team supported an Awareness and Engagement Campaign and a convening of the Coalition of Organizations to Improve Diagnosis that recruited interest from chief medical officers, chief quality officers and other leaders of health care organizations, challenging them to commit efforts to improve diagnosis. The Diagnostic Excellence Initiative also engaged the SIDM community in broader activities, including a quality improvement grants program described in Strategy #2 below.
- The National Academies proved to be an important partner, providing access to their national network of experts and leaders to serve as mentors, and applying their robust process for managing convenings that result in impactful and authoritative reports. In addition to the Scholars program in Diagnostic Excellence managed by NAM [6], the Moore Foundation also supported a series of seven one-day National Academies workshops convening experts around selected topics for diagnostic excellence [11] and they funded a National Academies Forum on Advancing Diagnostic Excellence to foster dialogue and opportunities for improvement [12].
- Other organizations: Several organizations participated, led, or co-sponsored many projects alongside the Moore Foundation: supporting fellows and scholars, co-sponsoring convenings, and administering grant

programs to recruit projects in diagnostic excellence. The contributions of JAHF [13–16], IHI [10, 17], CMSS [7, 18], and AcademyHealth [19–22] generated a great deal of interest and energy to the field and significantly expanded the influence of the Diagnostic Excellence Initiative.
- Many of the goals of the initiative were achieved by investigators in academic research sites, but also done in partnerships with other nonprofit organizations, by journalists and podcasts, professional medical societies, and medical journals (such as the JAMA series dedicated to topics on Diagnostic Excellence) [4, 23].
- In some instances, other organizations were vital in providing informal thought leadership. For example, Moore met regularly with leaders in the Agency for Healthcare Research and Quality (AHRQ), the major government agency leading federal efforts at patient safety and diagnostic safety. This engagement helped assure that public and private investments were synergistic and not duplicative.

Strategy #2. Infrastructure: Develop a national model of diagnostic excellence for a subset of priority conditions, demonstrating measurable improvements in diagnostic performance

Develop novel clinical quality measures for diagnosis

The heart of the infrastructure strategy focused on the development, adoption and use of clinical quality measures designed to assess diagnostic quality as a lever to move institutions toward improved performance. At the start, few if any existing measures related to diagnostic quality had been proposed or in use, and with good reason. For the most part, standards did not exist for accuracy or timeliness of diagnosis, and quality in diagnosis did not impact reimbursement. Institutions did not track diagnostic errors or diagnostic quality [24]. But the most critical problem was that existing healthcare data was not designed to capture the type of granular details or sufficient context to assess diagnostic quality. The Moore Patient Care team developed a cohort of measure developers who participated in a collaborative model to tackle challenges in diagnostic quality measurement. The cohort was led by Battelle, who offered technical assistance as well as managed networking meetings. Near the end of the initiative, highlights of the measure development grantee pool were featured in a listening session with leadership of the Centers for Medicare and Medicaid (CMS) [25, 26]. Ultimately, several of these measures were introduced into a portfolio of measures undergoing testing and to be piloted for public use by AHRQ – work that is currently in progress and the topic of a recent Request for Information on Diagnostic Excellence Measurement [27, 28]. Several other quality measures in the Moore cohort have been endorsed by the consensus-based entity (by National Quality Forum, or the Partnership for Quality Measures, PQM); notably, a quality measure for venous thromboembolism has been endorsed by the PQM and included in the Measures Under Consideration (MUC) list by the Centers for Medicare and Medicaid [29, 30]. Other measures have been included in Merit-based Incentive Payment System (MIPS) programs sponsored by specialty societies, and many are in use in local and regional health care systems. The idea of measuring diagnostic quality, once an almost foreign concept, is now part of routine conversations in quality circles and even the topic of a chapter in a newly released textbook on Quality Measurement [31].

Based on the challenges identified in their measure development, the foundation also provided support for ongoing projects led by the National Quality Forum (NQF) to assess how new analytics and methods using machine learning (ML) and natural language processing might eventually be developed and endorsed for use in formal national measures. The NQF team continues work today on the development of informatics infrastructure to capture symptoms and better collect diagnostic codes to address challenges identified in the Moore cohort [32].

Promote quality improvement activities

A second layer of work for infrastructure evolved to support quality improvement activities for small tests of change that ultimately might be disseminated broadly. That work centered on a series of quality improvement grant programs funded by the Moore Foundation but managed by SIDM, IHI and CMSS [16, 17]. These programs attracted interest in diagnostic quality improvement across a broad spectrum of medical specialties and health care settings. Further, funding provided support for convenings of project leaders to share success and challenges.

The initiative also launched a family of specialty-specific learning collaboratives through the American College of Radiology, focusing on prioritized areas of diagnosis, including improvements in technical performance of mammograms (optimal positioning for quality scans) and prostate MRI, and improved compliance with lung cancer screening [33–37]. The collaborative received an initial $3 Million investment but was designed to be self-sustaining, and it remains active today.

Incentivize diagnostic improvement

While quality measures are important drivers for institutions, incentive programs also contribute. The Initiative sponsored a new incentive program for diagnostic excellence developed by and administered by The Leapfrog Group, a program that continues to evolve with expert recommendations and guidelines for hospitals [38, 39]. The program provides a playbook for institutions with guidance for recommended practices that can help them improve diagnostic safety and quality and is supplemented by resources to help them achieve success, including a Root Cause Analysis specifically designed to assess cases of diagnostic error.

Strategy #3. Technology: Identify technology that will support and accelerate progress in improving diagnosis

As the Diagnostic Excellence Initiative launched in 2019, it was becoming increasingly clear that data would play a key role in how most – if not all – technologies would support improving diagnosis. This included the generation and availability of quality data, the methods to analyze this data, and the models and applications built on this core resource. Several key trends in health and health care data were converging in ways that shaped the Initiative's technology strategy:

- There was growing recognition that much of the existing public data sources available for research and development of new diagnostic tools and applications represented a relatively narrow portion of the U.S.
- There was growing evidence and promise of how "new" data – new types of data, novel methods of collecting data, and exponentially growing volumes of these data – would require new methods for analysis.
- Rapid advancements in artificial intelligence (AI), including computer vision and deep learning, were demonstrating impressive and occasional super-human performance for specific and narrow diagnostic tasks

Resources for the public good

One key sub-strategy was supporting the development of public good resources to advance the development and validation of diagnostic decision support tools and AI algorithms. This included working with funding partners on collective efforts, for example, at the Lacuna Fund, Nightingale Open Science, as well as the American Heart Association and other COVID registries.

Novel data

In parallel with these efforts was more methods-driven grants exploring the use of novel data sources to understand and enhance clinical diagnosis. This included efforts to link new sources of data to more traditional electronic health record data, including partnering with AcademyHealth on the potential use of internet search logs to understand the patient's earliest diagnostic journey as well as funding a multi-site grant to explore the use of electronic medical record audit log data to deliver insights on drivers of diagnostic excellence and error.

Responsible use of AI

The Diagnostic Excellence Initiative largely coincided with an increasingly clear potential impact of AI on diagnosis that continues to the current day with growing excitement around both machine learning (ML) and generative AI applications. In those emerging days of AI use cases, model development, and initial implementation efforts, the Initiative took a lead in promoting the responsible use of AI. Some key contributions include the following:

- Convening key multi-sectoral stakeholders – The initiative was a partner and funder in several key efforts including the NAM AI Code of Conduct [40], Coalition for Health AI (CHAI), and the Health AI Partnership (HAIP). All three efforts continue to date and impact ongoing national and international discussions around Health AI policy, regulation, and implementation.
- Funding internal and third-party approaches to model validation – While many efforts are still in progress, some Initiative-funded work has emerged as potentially scalable approaches. These include Stanford University's approach of "virtual model deployment" with its Fair, Useful, and Reliable Model (FURM) framework [41]; Dandelion Health's piloted free AI validation service; and the American College of Radiology's registry-based approach.
- Seeding emerging efforts in prospective, real-world evaluation – In the early days of the initiative, most health systems and model developers focused exclusively on analytic performance. There was and continues to be a clear dearth of real-world evidence that demonstrates impact of AI tools and applications on patient outcomes. The initiative took inspiration from an early funding experience with Providence Health to support its multi-site evaluation of AI/ML for diagnostic decision making to co-design and launch Kaiser Permanente's (KP) Augmented Intelligence in Medicine and Healthcare Initiative (AIM-HI). KP's Division of Research is approaching its second year in supporting and

coordinating the valuation and implementation of AI/ML algorithms at five distinct U.S. sites, including two in safety net settings.

Conclusion of the Diagnostic Excellence Initiative

The total work product from the Diagnostic Excellence Initiative is astonishing; this article merely scratches the surface of their contributions. However, no amount of private investment can successfully sustain a national program for health for the population at large without the government exerting leadership and assuming responsibility. Other organizations and bodies can advocate, provide solutions, and advance technology, but healthcare organizations ultimately are molded and influenced by accreditation standards and policies set in motion by governing bodies such as local boards of health, the Joint Commission, insurers, and funders of health. Philanthropy can identify questions and solutions, recruit partners and advocate, but they do not control regulation or financing for the national health care ecosystem.

Ultimately, the Board of Trustee decided that the contributions to date were adequate to stimulate others to step in. Federal funding had begun to increase, and AHRQ had launched 10 national centers of diagnostic excellence supported by a coordinating hub. The Moore Foundation executed a thoughtful and deliberate exit strategy. At the conclusion of the Diagnostic Excellence Initiative, the foundation bolstered several of the key existing programs, continuing funding for some projects for several years beyond their exit. To secure their gains and invest in future work, they invested $15 Million to launch a Coordinating Center for Diagnostic Excellence (CODEX) at the University of California, San Francisco which committed to develop a self-sustaining model to extend diagnostic excellence activities past the seven-year timeline of funding [42]. CODEX is designed to serve the community as a national coordinating entity for work to improve diagnosis, and features four core activities: an engagement hub, to build a community of scholars; a learning hub, to make information accessible and usable; an action incubator, to develop and promote collaboration that can drive ideas and advancements forward; and an innovation hub, to facilitate novel programs for emerging areas [43].

Conclusions

While the contributions of the Moore Foundation are important to acknowledge, there are other key lessons important to highlight.

- The role of private citizens and philanthropy can be substantive. Funding through private funders may at times be more flexible than federal funds, and grantees can expect to be more engaged with funders who may consider themselves as partners in the work.
- Partnerships (both public and private) are essential and can significantly broaden the impact of all funders.
- There is value in connecting diverse specialties for cross-disciplinary work for impactful innovation.

The community of stakeholders who have joined forces to improve diagnosis are deeply appreciative of the profound contribution of the Moore family and their foundation. This review would be remiss not to acknowledge the many contributions across the field by other nonprofits and private individuals – including many volunteers and patients – who have contributed to improvements in diagnosis. The field has moved forward in the last 10 years, although slower than many had hoped. But a curtain is rolled back to reveal a future ripe with possibilities, and with it, the need for new investments.

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