Past is Prologue: The Essential Role of Advocacy in Shaping the Future of Primary Care Research

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The Case for Primary Care Research Advocacy: Picture a country where primary care research is a national priority, with enough grants to support primary care focused investigators, early career researchers, and infrastructure. Primary care researchers serve in leadership roles in the funding agencies, and study section members understand the value, methods, and context of primary care. Unfortunately, in the US, funding today for primary care research is inadequate, concentrated within a small number of institutions, and poorly coordinated, all of which deprives the system of much-needed innovation.[1–4] Without research in primary care, primary care clinicians lack the evidence needed to deliver the high-quality care for whole people that can improve health and reduce disparities. This inhospitable funding environment serves as a ceiling that restricts the potential of the primary care research enterprise. Historically, this environment has been perceived to be immutable. Research funding is viewed as a product of the research enterprise as opposed to a contextual factor that can be influenced.[5] While the power of individual investigators and institutions may be limited, funding can be influenced through advocacy efforts at the national level. Without such efforts, the loudest voices will attract attention and continue to divert resources away from primary care research.

Federal Advocacy: Advocacy at the federal level is important for several reasons. Policymakers shape national priorities, like the Cancer Moonshot Initiative, which allocated $1.8 billion to cancer research.[6,7] Though necessary, priority setting without funding is inadequate. While the Agency for Healthcare Research and Quality (AHRQ) is supportive of primary care, consistent funding has remained elusive.[8] Policymakers also control funding for infrastructure. Academic Administrative Unit (AAU) grants through the Health Resources and Services Administration (HRSA) establish departments, build analytic capacity, and facilitate scholarly activities.[9] Unfortunately, AAU grants were last awarded in 2015. AHRQ supports practice-based research networks (PBRNs), but funding for these primary care laboratories has similarly dried up.[10] Finally, policymakers determine how primary care is perceived and valued. Within federal

agencies, primary care researchers can take on leadership roles, serving as staff, on study sections, and on advisory boards. Once in these positions, they can more directly advocate for primary care funding. For instance, in 2022, the Patient Centered Outcomes Research Institute earmarked funds to study the role of telehealth in managing multiple chronic conditions in primary care.[11]

A Family Medicine Coalition: The Academic Family Medicine Advocacy Committee (AFMAC; previously the Academic Family Medicine Organizations (AFMO) Subcommittee on Legislation and Federal Advocacy) was founded in 1992. At the time, academic family medicine organizations supported the Clinton Administration's efforts to reform health care but desired visibility, recognition, and collective power. After the creation of the Council of Academic Family Medicine (CAFM; which includes the Society of Teachers of Family Medicine, North American Primary Care Research Group, Association of Departments of Family Medicine, and Association of Family Medicine Residency Directors), the committee was renamed AFMAC (which includes CAFM plus the American Academy of Family Physicians (joined in 2010) and the American Board of Family Medicine (joined in 2014)).

AFMAC coordinates efforts, negotiates disagreements, and unifies diverse voices, by following the decision-making process outlined in its 2015 charter. Member organizations appoint up to three representatives who attend twice yearly meetings. Outside these convenings, CAFM's Director of Government Relations advances the legislative agenda. Although each organization has distinct priorities, this integration strengthens academic family medicine's positions, particularly those related to workforce, education, and research. If AFMAC members cannot reach a consensus, a two-thirds majority is needed for motions to pass. Policy endorsements require approval from each member organization; without consensus, no official AFMAC stance is taken.

Advocacy Success: This coalition has facilitated numerous advocacy successes. First, AFMAC helped to establish and fund the AHRQ Center for Primary Care Research. In 1993, Howard Rabinowitz, a family physician at Thomas Jefferson University, served as a Robert Wood Johnson Health Policy Fellow in the Office of Senator John D. Rockefeller IV. During the fellowship, he worked on the reauthorization of AHRQ and included a new section establishing the Center. Initially introduced in 1994 (S 2513), the bill's authors argued that primary care research received almost no funding and that primary care clinicians needed evidence to make informed decisions.[12] With support from family medicine, internal medicine, pediatrics, nurse practitioners, physician assistants, and the Association of American Medical Colleges, the Center was officially created in 1999, serving as the only federally-mandated unit responsible for supporting primary care research.[13] While the initial, 1994 bill authorized $15 million ($30.5 million in 2023 with adjustments for inflation) to establish the Center, no funding was appropriated, leading to a disconnect between the Center's charge and impact. AHRQ's stability, more broadly, has been tenuous, with its funding threatened multiple times. In 2022, nearly 30 years after the first bill was introduced, an effort led by CAFM successfully advocated for $2 million for the Center, demonstrating the time horizon needed for advocacy efforts.

Second, CAFM advocated for the inclusion of primary care research in a study to assess the adequacy of funding for health services and primary care research. President Trump's 2018 budget dissolved AHRQ and moved to the National Institutes of Health (NIH), some of its functions, though not the Center for Primary Care.[14] Congress did not move AHRQ into the NIH but rather directed AHRQ to study the national strategy for health services and primary care research. Draft language within the Consolidated Appropriations Act of 2018 only included health services research; however, CAFM was able to advocate for primary care research to be included. They argued that primary care research is not merely a subset of health services research but a unique field and that AHRQ's mandate to support primary care research

needed to be considered. In 2020, the RAND report echoed CAFM's stance, recognizing primary care research as a unique field with inadequate funding (1% of all funded projects). The report underscored the necessity of a dedicated entity to coordinate federal primary care research.[3] These findings were used by CAFM to advocate for funding for the Center for Primary Care Research (now the National Center for Excellence in Primary Care Research (NCEPCR)) and were cited in the landmark, 2021 report on primary care, published by the National Academies of Sciences, Engineering, and Medicine.[15]

Because of the paucity of NIH funding, departments of family medicine have relied on other sources,[2,16] including the Primary Care Training and Enhancement Program, overseen by HRSA and authorized by Title VII, Section 747 of the Public Health Service Act. Initially, these grants were not designated for research. However, in 2010, AFMAC successfully advocated for the inclusion of research into AAU's authorizing language.[17] As a result, departments use these funds to develop research infrastructure, facilitate scholarly activities, conduct evaluation and quality improvement work, support practice-based research networks, and ultimately generate new knowledge.[9]

Recommendations for Action: To enhance primary care's ability to deliver evidence-based care, a comprehensive research advocacy plan is imperative.

First, we recommend that federal funding for primary care research be proportional to the primary care spending (currently 5% for Medicare).[18] While the funding of AHRQ's NCEPCR is an important first step, more is needed for a hub to coordinate such research across federal agencies, as recommended by the RAND study. AHRQ's NCEPCR could perform this function with more funding and authority. Alternatively, an Office for Primary Care Research within the NIH could coordinate NIH's spending on primary care research and provide strategic direction for NIH's primary care initiatives.

Second, increased funding is needed to develop a pipeline of primary care researchers. Career development awards specifically designated for primary care are needed to support early career researchers and provide flexibility for clinicians who want to stay engaged in patient care. Systems are needed to engage and mentor community-based clinicians, who have research questions that are highly relevant to patients and communities.

Third, support is needed for infrastructure. Historically, indirect dollars have been used to support infrastructure for bench research and research centers. Universities lack incentives to use these dollars to develop research outside its walls and within communities. As such, ongoing funding is needed to support practice-based research and community engagement.

Finally, more primary care researchers are needed in leadership positions and on study sections. Leaders who understand the complexities of primary care research can direct investments to high-yield and promising domains. With respect to study sections, primary care researchers can teach their colleagues about the realities of conducting research in community settings and demonstrate how proposals advance the broader primary care literature. Consequently, we recommend that all study sections evaluating primary care proposals have primary care researchers as members.

Accomplishing these goals will help advance primary care research to improve outcomes for the patients and advance health equity in communities facing disparities. By engaging in advocacy to pursue these goals, primary care clinicians and researchers can together improve the evidence behind the care provided.

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