

Faculty Development

Family Medicine, the NIH, and the Medical-Research Roadmap: Perspectives From Inside the NIH

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Background and Objectives: *Family medicine has had little engagement with the National Institutes of Health (NIH), and it is unclear what NIH officials think about this. **Methods:** Purposive sampling identified 13 key informants at NIH for open-ended, semi-structured interviews. Evaluation was by content analysis. **Results:** NIH officials expressed the perception that family physicians have strong relationships with patients and communities and focus on interdisciplinary collaboration but that they do limited research and have weak research infrastructure. They also indicated that NIH has repackaged its stated focus, to include areas of research that might be applicable to family medicine, but whether this represents real change is questionable; NIH still emphasizes basic science and exclusionary trials. While NIH officials suggested that family physicians still have no obvious NIH home, they also suggest that family physicians are well-poised to recruit patients and inform questions, if not lead research. Family physicians have opportunity with Clinical and Translational Science Awards (CTSAs) but need areas of expertise and additional formal research training to succeed with greater research participation. **Conclusions:** NIH key informants generally appreciated family medicine clinically but viewed family medicine research as underdeveloped. Some identified opportunities for family medicine to lead, particularly CTSAs. Greater self-advocacy, research training, and developing areas of expertise may improve family medicine's engagement with NIH.*

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Family physicians manage the complex issues arising from patients' biological, psychological, and social conditions. Family physicians are trained to focus not only on individual patients but also to contextualize patients within the families and communities in which they live. Through uniquely varied clinical and community experiences, and by providing the greatest number of health care encounters of any single specialty in the country,¹ family physicians have the potential to lend unique perspectives to the national research landscape, particularly at the point of translating scientific innovation into effective clinical practice.^{2,3}

Unfortunately, since becoming an official medical specialty in 1969,⁴ family medicine has struggled to reach its research potential.⁵⁻¹² Of particular note is minimal interaction with the National Institutes of Health (NIH),^{11,12} the predominant supporter of biomedical research in the United States.¹³ With its largely disease-specific and/or specialty-based institutes and centers (ICs), the NIH has historically funded basic-science investigations not typically well aligned with family medicine research agendas. By focusing instead on specialty scientists, the NIH may be missing opportunities to support the kind of practice- and community-based translational research that could enhance public health in this country.^{2,14,15}

Recent developments may improve alignment between family medicine and the NIH. In October 2006, the NIH director announced the launch of an initiative to transform how clinical research is conducted: Clinical and Translational Science Awards (CTSAs).¹⁶ Emerging from the NIH Roadmap for Medical Research,¹⁷ CTSAs focus on multidisciplinary collaborations to bring "new scientific advances to real-world practice."¹⁷

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The stated goals of CTSA are “reaching underserved populations, local community organizations, and health care providers” to make medicine more “predictive, personalized, preemptive, and participatory.”¹⁶ These goals are entirely consistent with the mission and expertise of family medicine. Indeed, the CTSA program encourages community engagement and collaborations with community-based physicians, potentially creating new opportunities for family medicine on the NIH Roadmap.^{10,17,18} However, with CTSA being housed strictly in academic health centers—where less than 1% of the population receives care annually¹⁹—the program may maintain familiar barriers to community collaboration and family medicine involvement. The potentially major disconnect – between the Roadmap’s intent and its actual implementation – highlights a need to understand what insiders at the NIH think.

There are no prior studies evaluating perspectives of NIH officials about family medicine and NIH-funded research. The objective of our study was to explore awareness, knowledge, attitudes, and perceptions of NIH key informants with regard to family medicine, NIH research initiatives, and the interplay between the two, particularly with regard to the Roadmap and CTSA.

Methods

This study was part of broader investigations about family medicine and the NIH at the Graham Center for Policy Studies. The protocol was approved by the American Academy of Family Physicians Institutional Review Board.

Data Collection

Primary data consisted of investigator jottings and field notes generated from semi-structured interviews with NIH officials. Given anticipated difficulty in persuading government officials to participate and speak candidly, investigators decided not to audiorecord interviews.

The principal investigator (PI) e-mailed invitation letters to high-ranking officials in (1) each of nine ICs having presumed alignment with FM and/or primary care interests and (2) two offices in the Office of the Director (Table 1). The letter requested referral to an alternative official if invitees felt they were not the best-choice informant.

Among recipients of the initial invitation, three chose to participate, one never responded (despite repeat invitation), three declined (“booked solid,” “unavailable,” “I tend to decline such invitations”), and four suggested referrals (some to NIH personnel outside of their own office or IC). We then invited personnel to whom we

Table 1

The Sample of Interviews With NIH Key Informants, Distributed by the NIH Institute, Center, or Office

<i>Institute/Center/Office</i>	<i>Abbreviation</i>	<i># of Interviews With NIH Key Informants</i>	<i># of Initial Invitees Who Declined* or Did Not Respond</i>
1. National Cancer Institute	NCI**	1	0
2. National Center for Research Resources	NCRR	1	0
3. National Human Genome Research Institute	NHGRI	1	0
4. National Heart Lung and Blood Institute	NHLBI	2***	0
5. National Institute on Aging	NIA	1	0
6. National Institute on Alcohol Abuse and Alcoholism	NIAAA	2	0
7. National Institute of Child Health and Human Development	NICHHD	0	1
8. National Institute on Drug Abuse	NIDA	2	0
9. National Institute of Diabetes and Digestive and Kidney Diseases	NIDDK	0	1
10. National Institute of Mental Health	NIMH	1	1
11. Office of Extramural Research (Office of the Director)	OER	0	1
12. Office of Portfolio Analysis and Strategic Initiatives (Office of the Director)	OPASI	1***	0
13. Office of Behavioral and Social Science Research (Office of the Director)	OBSSR**	1***	0
	Total	13	4

NIH—National Institutes of Health

* Reasons for declining participation included non-response, “booked solid,” “unavailable,” and “I tend to decline such invitations.”

** NCI and OBSSR were not among the sites initially invited for interviews.

*** Both interviews in Offices of the Director and one interview at NHLBI were by phone; all other interviews were conducted in person.

were referred, and they accepted, declined, or referred in turn. Ultimately, the PI conducted 13 interviews in June 2007 after each participant gave verbal consent. Three officials elected to be interviewed by telephone, while 10 officials gave in-person interviews (Table 1).

The PI used an interview guide that was informed by (1) notes from a 2007 encounter between an NIH representative and family medicine leaders, (2) a review of existing literature, and (3) insights from quantitative data collected as part of our broader study.¹² First, we developed nine questions, representing three content domains of awareness, knowledge, and attitudes. We then requested input from a past and a current family medicine department chair—both active in efforts to expand family medicine research. With input, and through discussion, we refined our content domains and finalized seven questions (Table 2).

Interviews with officials ranged from 30 to 90 minutes. The PI recorded information during these interviews through jottings, using verbatim quotes when appropriate. The PI also collected basic interviewee information (eg, position title, specialty, number of years at NIH) and created field notes within 3 hours following each interview. Field notes, including direct observations and felt impressions, were transcribed along with jottings into Microsoft Word documents.

Identifying information on datasheets was stored separately from interview data, linkable only via identifiers kept in a password-protected file to which only study investigators had access. All primary handwritten notes were destroyed after transcription.

Data Analysis

We used descriptive content analysis²⁰ to summarize main ideas in the interview data. The PI initially sorted quotations, ideas, and perceptions from interviews into nine content categories. Coinvestigators reviewed this process and corroborated categorizations based on the primary data. Analysis occurred concurrently with data capture and evolved with new data. Through discussion among coinvestigators, overlapping categories were collapsed, diverging categories were expanded, and subcategories with positive and negative aspects were identified. The data and categorical assignments were then reviewed by an outside investigator, unaffiliated with family medicine and uninvolved in the study but expert in qualitative methods. Through discussions among co-investigators, a table (Table 3) and schematic (Figure 2) were created to express final categorizations. Informant data such as title, number of years at NIH, and medical specialty were analyzed descriptively and linked to perceptions when applicable.

Table 2

Interview Guide

- (1) Tell me what you know about family medicine.
- (2) What role do family physicians have in medical research?
- (3) Are there family physicians funded through your institute (or center)?
- (4) Are there family physicians on staff at your institute (or center) or who sit on councils, committees, panels, or study sections?
- (5) How would you define translational research?
- (6) What role might family physicians/practice-based research networks (PBRNs) play in translational research/Roadmap/CTSAs?
- (7) How can family medicine better position itself at the NIH?

NIH—National Institutes of Health
CTSAs—Clinical and Translational Science Awards

Results

Through 13 interviews, the PI spoke with personnel at eight of 27 ICs and two of 15 offices under the Director (Table 1). The level of key informants ranged from office director and IC deputy director to research fellow (Figure 1). More than half of key informants had been at the NIH less than 3 years and, with the exception of one with >10 years experience, all had less than 7 years at NIH.

Familiarity with family medicine ranged from graduating from a family medicine residency to training at a “medical school where family medicine practically didn’t exist.” Clinical specialties informants represented included family medicine, psychiatry, pain medicine, neurology, internal medicine, genetics, geriatrics, and a pediatric subspecialty. Three key informants had PhDs without medical degrees. Two key informants had family medicine training.

We sorted responses into three broad categories. Each supportive category had two unsupportive subcategories, and each of these had supportive/positive and unsupportive/negative ideas (Table 3, Figure 2).

Perceptions of Family Medicine

NIH officials generally appreciated the clinical contributions of family physicians, particularly their strong relationships with patients, ties to communities, and ability to think and collaborate across disciplines. Not all informants distinguished family medicine from other primary care fields though, and some felt family physicians deal only with mild disease and uncomplicated care decisions.

Most informants believed family physicians do little research or only do limited health services research.

There was consensus that family medicine does not have well-developed research infrastructure. The majority of key informants were unfamiliar with practice-based research networks (PBRNs). While some NIH officials valued the real-world, patient-centered focus of family physician research, only a minority could name a family physician grantee or committee member at their IC (and when checked via the Internet, almost half of the names given by informants were actually of internists).

Perceptions of NIH

With regard to the direction of NIH research, most key informants believed there has been significant repackaging of NIH’s stated research focus but little-to-no real change. The emphasis is still on basic science, and important clinical questions still have no home (eg, “medication adherence . . . what institute studies that?”). The least doubtful opinions came from those with the shortest time at NIH, who felt NIH’s Roadmap represents genuine innovation, with new focus

Table 3

Perceptions of NIH Key Informants Organized Into Categories and Sub-categories, With Supportive/Positive (+) and Unsupportive/Negative (–) Ideas

PERCEPTIONS OF FAMILY MEDICINE	
Of the specialty and its clinicians	
(+)	<ul style="list-style-type: none"> • “Front-line,” “holistic,” “comprehensive care” of the “whole person” for a “full range of ages and diseases.” • Treat patients in “complex systems” with “appreciation of the psychosocial, family, and community” contexts. • “Generalists” who think about “how to collaborate across disciplines” and who “take a team approach.” • “Something unique about family medicine,” “incredible relationships” with patients and serve as “incredible bridgers” to communities • “Your offices are where most health care encounters occur.”
(–)	<ul style="list-style-type: none"> • Referred to as “primary care doctors” and “generalists” (without distinction from other primary care specialties). • “When patients become severe, they go somewhere else. Family medicine might still be involved, but it is the specialist who makes the complicated care decisions.” • “You have all this turf stuff: you may be delivering front-line hypertensive care, but you will butt heads with cardiologists who are perceived as the experts.”
Of family medicine’s place in research	
(+)	<ul style="list-style-type: none"> • Family medicine research gives vital “real-world perspective.” • Family medicine research “is key.”
(–)	<ul style="list-style-type: none"> • Family medicine is “more clinical than investigational” with “not a whole lot going on” in research. • Doing “just health services research,” “More for AHRQ or HRSA.” • “Family medicine departments don’t have research infrastructure” or “academic bases.” • “Certainly you won’t find any [family physicians] here. Institutes will have researchers and experts in specialties.” • One key informant mentioned some family medicine proposals were received in response to the IC’s request for application (RFA) and were “unimpressive.”
PERCEPTIONS OF THE NATIONAL INSTITUTES OF HEALTH (NIH)	
Of NIH and its direction	
(+)	<ul style="list-style-type: none"> • “NIH, at least [informant’s specific IC], is full of ‘forward-looking,’ ‘open-minded,’ ‘great people.’” • NIH is “looking for a different perspective;” “doing it differently;” “created a whole new biomedical discipline [translational research] that never existed before” to try to get “researchers and clinicians to speak each others’ language” and now “really focused on community.”
(–)	<ul style="list-style-type: none"> • “Much like the way policy works in Washington, themes at NIH are just fad and fashion;” “Translation is this director’s theme” but it’s more of a “buzzword” from a “political appointee playing a political game.” • “Fundamentally, the mission of the NIH has always been the same: to discover the pathophysiology of disease and search for potential cures.” • “The director has said as recently as six months ago that we must protect our basic science base.” • “Verbiage has very little to do with what is actually taking place;” Roadmap and CTSA are “just a different package;” “Roadmap was to re-engineer clinical research enterprise but there’s no clue how to do it.” • “NIH invests into building research infrastructure, but it is not entirely congruent with the way medicine is organized;” “clinically important questions have no home.”
Of translational research initiatives at NIH	
(+)	<ul style="list-style-type: none"> • NIH is now focusing on “more representative settings in the real world, in real practices, with real patients.” • “Getting interventions into widespread use” and emphasizing “bidirectional” communication between researchers and clinicians.
(–)	<ul style="list-style-type: none"> • “The title is wrong: translation is trying to talk between two different areas” but NIH is just “communicating between different specialty scientists, not translating to the practice communities.” • “NIH’s idea of translational research hasn’t really moved much beyond bench-to-bedside approaches.” • “Too much focus on controlled trials” which are “not real world;” “we exclude the people we really need to see.” • Re: translation—“Not neat and tidy,” “different things to different people,” “I don’t think [my IC] has a definition for that.”

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Table 3
(continued)

OPTIMIZING FAMILY MEDICINE'S POSITION AT NIH	
Prospects	
(+)	<ul style="list-style-type: none"> • Family physicians can “drive the research agenda,” and “change the culture of investigation at the grassroots.” • One key informant quoted a family physician: “To get more research into practice, we need to get more practice into research.” • Family physicians “can take the lead” in “post-efficacy research,” and “improve how trials are done.” • Family physicians are “well-poised” for dissemination and “can move the science forward.” • “I really don't think we need an Institute of Primary Care; bring the family practice perspective to the question, not the question to family practice;” “Family practitioners need to be at the table.” • “Getting a few people who are generalists in higher places might change the world;” it would allow us to “truly re-engineer the clinical research enterprise” and help us “apply the findings from clinical trials to real-world practices” to ultimately get a public health “return on our research investment.”
(-)	<ul style="list-style-type: none"> • “The system doesn't know what to do with family medicine.” • NIH is “two thirds basic science” and “disease based.” There is “no Institute of Primary Care,” and family physicians have “no natural home for seeking funding.” • “You get a seat at the table by doing funded research.” Family physicians will have to develop “interests that overlap with the institutes' agendas.” But, “trying to become content experts is a losing pathway.” • Family physicians might have subordinate roles in “recruiting subjects,” “communicating messages from research to patients,” “informing questions,” or as “clinician generalists who can run clinical trials.” • “Nothing is going to be handed to you.”
Opportunities (+) and Challenges (-)	
(+)	<ul style="list-style-type: none"> • Family physicians “should do more research.” • CTSAAs are a “huge opportunity” for “active leadership” instead of “passive recruitment.” • Develop “a specific area of interest,” like “chronic disease management” or “management of clinical trials.” • “Sit down with the directors of NIH and NCR (CTSA administrator) and let them know, “This is what we can do for you.” • “I would love to have a family doc at the head of [IC_a or IC_b].”
(-)	<ul style="list-style-type: none"> • NIH is “very competitive;” research is for those “who have a question, can frame it, apply for funding, and carry out the work.” • Family physicians need “additional formal training” in research methods, “statistics or epidemiology, or thinking in public health”—eg, “MPH, MS, MBA, or even a PhD” or “a 2-week course in continuing education in research design, methods,” etc. • Focus on the “preparation pipeline;” “A critical thing is mentoring;” “paired mentoring,” “K awards,” “or an R25 collective training grant.” • “Get a pilot project running at a CTSA site to show that partnership with family medicine is beneficial.” • “You have to convince the clinical research infrastructure of specialists that you have something of value to add. I don't think family medicine has done that yet.”

CTSA—Clinical and Translational Science Awards
IC—NIH Institute or Center

on community and real emphasis on communication between scientists and clinicians.

Most NIH informants could define translational research, eg, “T1 brings science to bedside. T2 is the dissemination component.” Most thought, however, that NIH was still too focused on T1 and exclusionary, nonrepresentative clinical trials. Others felt “translation” has more to do with “biomarkers, genetics, and genomics.” In fact, in declining to participate in our study, one official thought we would be better served speaking to genetic counselors and genomics researchers at NIH.

Optimizing Family Medicine's Position at NIH

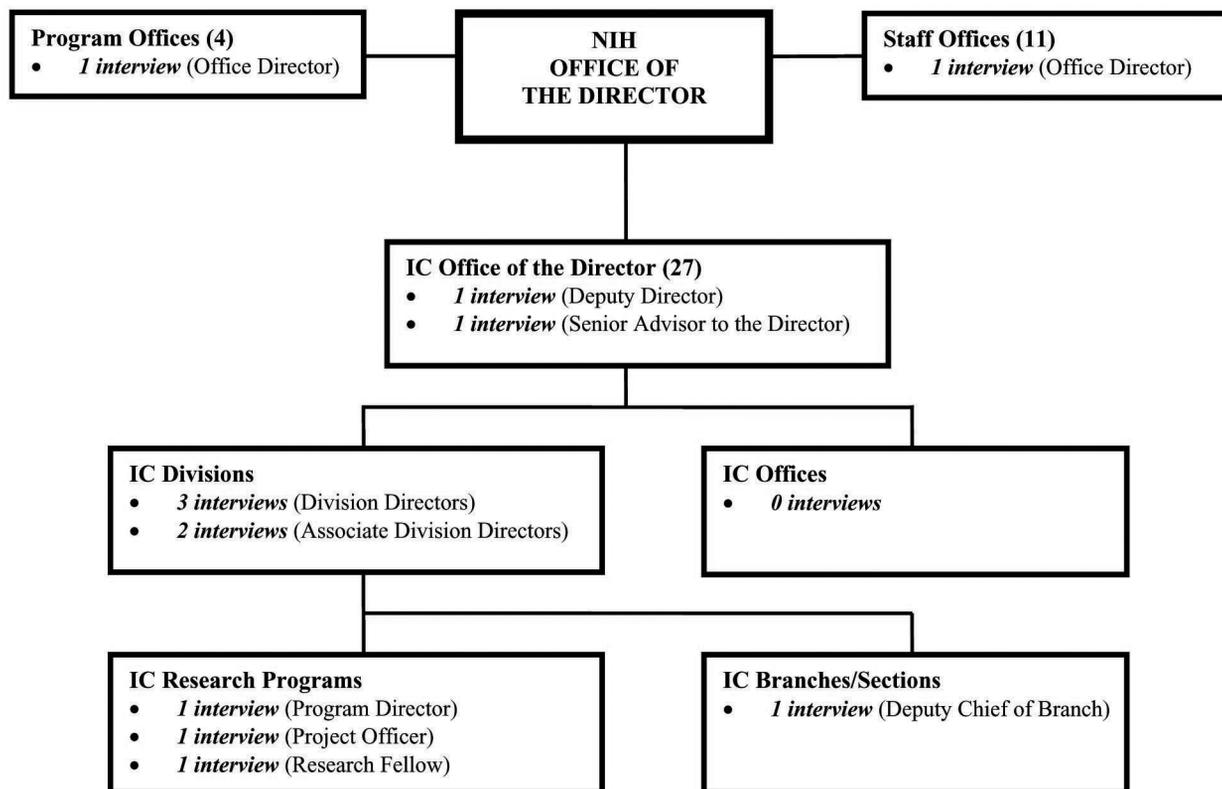
Optimistic informants felt family physicians could “take the lead” in T2 and that getting more generalist perspective at ICs could enhance the way research is done, speed the translation of innovation to community

practice, and improve the overall state of public health in this country. Pessimists (in the minority) felt there is no clear place for family medicine at NIH, not only because of a firmly established disease-based system, but also because family physicians have underdeveloped research capacity and skills; any role for family medicine would need to be subordinate.

Some key informants saw CTSAAs as a real opportunity for family medicine—not for subsidiary participation but for leadership. Others felt a family physician could even head an IC. However, significant barriers were mentioned, eg, an intensely competitive research environment defined by those who are better trained, more experienced, and endowed with greater research infrastructure and support. There was consensus that for greater NIH involvement, family physicians need more formal training in research methods and more practical experience in research conduct.

Figure 1

Distribution of Interviews by Generalized NIH Organizational Structure



IC—NIH Institute or Center

The actual organizational structure varies substantially by Institute or Center (see <http://www1.od.nih.gov/oma/manualchapters/management/1123/>)
Two key informants were family physicians by training.

Discussion

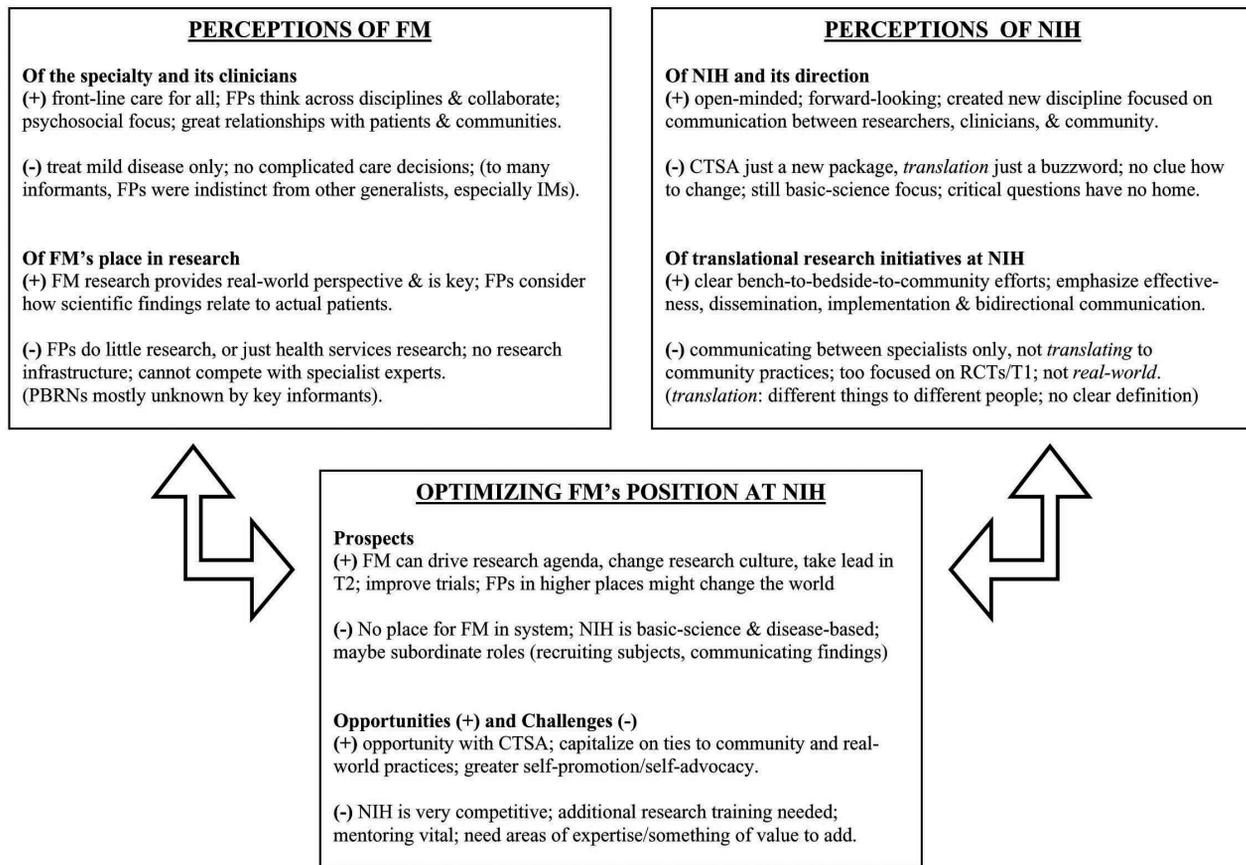
Perspectives within NIH about family medicine, NIH initiatives, and family medicine-NIH engagement ranged from guarded optimism to outright pessimism. Some NIH informants appreciated family medicine's clinical excellence, but many did not distinguish family medicine from other primary care specialties. When distinction was made, family medicine's ties to communities and collaboration across disciplines were noted as particular strengths. However, NIH insiders tended to view family medicine research—capacity, training, expertise, and output—as below average, and many informants proposed subordinate roles for family medicine within NIH initiatives. Even the most optimistic insiders recognized barriers to family medicine advancement inherent in: (1) limited family medicine research infrastructure and experience, (2)

NIH's disease-based organization and deeply rooted emphasis on basic science. With regard to the former, family medicine has struggled to build research infrastructure and increase research involvement, funding, productivity, and credibility since the specialty's inception.⁵⁻¹² With regard to the latter, Roadmap and CTSAs potentially offer new opportunities,^{10,18} but informants suggest real uncertainty about how genuine these initiatives are or how consistently they are understood by decision-makers at NIH.

From our study and prior literature, we can suggest strategies for how family medicine can improve its engagement with the NIH. Continuing work and developing expertise in novel research models is one strategy. Many NIH key informants agreed with past authors that uniting the worlds of scientific research and community practice will come only from multi-method, trans-disciplinary studies in real-world primary care

Figure 2

Summary Schematic of Perception Categories and Sub-categories, With Supportive/Positive (+) and Unsupportive/Negative (-) Ideas, From Interviews With NIH Key Informants



FM—family medicine, FP—family physician, IC—NIH Institute or Center, IMs—internal medicine physicians, NIH—National Institutes of Health, PBRN—Practice-based Research Network, RCTs—randomized controlled trials, T1—first stage translation (basic science discovery to clinical trials; “bench to bedside”⁰, T2—second stage translation (dissemination/implementation; “bedside to clinical practice”).

settings,^{2,21-24} not from the highly exclusive controlled trials of specialists at tertiary-care sites.^{2,7,15} Some family physicians already do the kind of practical, practice-based research the NIH is trying to foster.² Family medicine can take the lead in furthering studies of implementation and dissemination and ensure that important clinical questions have a home. Roadmap and CTSA initiatives may provide opportunities for such studies.

For more family physicians to competently assume leadership roles in research, however, solid preparation will be necessary. Virtually every key informant emphasized the need for extra training—particularly in biostatistics, epidemiology, and research methods. Medical education is not enough. There was also con-

sensus that formal mentored experiences were needed²⁵ and agreement with prior authors about the importance of K awards for career building.^{9,14,26,27} The availability of established mentors and protected time for research activities are particular problems for family medicine though.²⁷ The specialty has had limited past engagement with the NIH^{11,12} (with a consequently small pool of experienced NIH-funded research mentors), and historically, family medicine department chairs have placed little premium on research.⁶ Moreover, recent threats to funding from the Health Resources and Services Administration (HRSA), from both Title VII grants and National Research Service Award (NRSA) funding may undercut the already sparse research training available to family physicians outside of NIH

opportunities. Detailed suggestions on how family medicine might address some of these challenges, to both increase engagement with NIH and build its research capacity, have been described elsewhere.^{12,25-27}

Obstacles to advancement within family medicine are matched by barriers at the NIH. While Roadmap was designed to focus on “clinical,” “translational,” and “interdisciplinary” research,²⁸ definitions of these terms may vary, and many key informants agree that despite the Roadmap, NIH maintains a predominant basic-science emphasis. Doing health services research was discounted by some informants, even though this kind of research may be critical to NIH’s translational vision: elucidating, for example, why findings from randomized controlled trials have been so difficult to apply in everyday practice.^{14,15,22,29} Unfortunately, much of the effectiveness studies and practice-based research efforts occurring in primary care offices and PBRNs across the country often do not fit neatly into IC agendas, and such research remains largely unknown to the participants in our study. It is unclear to what extent Roadmap and CTSA will change this. But family medicine can be instrumental in informing how NIH’s requests for applications (RFAs) are focused and worded, highlighting primary care’s potential to translate bench science to actual practice.¹⁰

Limitations

Our study is the first to describe the perspectives of insiders from various positions and levels within NIH. It is unique as a qualitative exploration and synthesis of knowledge, attitudes, beliefs, and perceptions but has two potential limitations.

The first is that note-taking by the PI alone had the potential to introduce bias: his positions as a family physician and researcher could have influenced what was heard and/or recorded during interviews. Also, our group’s prior quantitative work on family medicine’s position at NIH (showing miniscule grant funding and minimal advisory committee membership)¹² certainly informed the questions we asked. To minimize the risk of bias, verbatim quotations were noted when possible, and interview notes were explored without *a priori* assumptions about domains or directionality. The recorded perspectives ran the gamut between highly supportive and openly negative within each of the categories that developed logically from our interview questions. This result reassures against partiality by our family medicine research team. Also, peer debriefing among co-investigators helped enhance trustworthiness and objectivity by requiring defensible arguments for coding and categorization of results. Finally, an independent analyst—a nonphysician without affiliation to family medicine—reviewed and approved categorizations and sortings.

The second potential limitation is that purposeful but selective sampling risked missing the full range of

potential perspectives at NIH. Also due to refusals by several NIH officials, the PI was not able to interview representatives from potentially relevant offices and ICs. However, despite a relatively small and limited sample, we believe we reached saturation of ideas and perspectives held at NIH: there was substantial redundancy in perceptions expressed in early interviews, with additional interviews adding few new ideas.

Conclusions

The director of NIH has a goal: to transform medicine from the curative paradigm of today to a more “predictive, personalized, and preemptive” model of tomorrow.²⁸ Just as the delivery of medical care in this country is fragmented and broken,^{30,31} so too is the performance of biomedical research fragmented and broken—focusing on parts of patients, rather than patients as a whole, and not bringing applicable innovations to the communities for which they were developed.^{2,14,23,25} Family medicine and NIH might work together for mutual benefit to change this. The Roadmap and CTSA initiatives can help family medicine reach its goals of building research infrastructure, training more investigators, and enhancing the value of research for practicing family physicians, their patients, and the public.²⁵ At the same time, greater family medicine involvement can help CTSA evolve, facilitate cross-cutting between ICs, and help make the director’s vision—to redefine clinical research and bring meaningful innovations and better health to the American people—a reality. Roadmap suggests paths; family medicine and NIH leaders must now tread boldly.

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