Published in final edited form as:
Am J Bioeth. 2018 April ; 18(4): 26–28. doi:10.1080/15265161.2018.1431327.

The Role of the Health Care Provider in Building Trust Between Patients and Precision Medicine Research Programs

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Kraft and colleagues identify the importance precision medicine initiatives should place on building trusting relationships with diverse populations; they argue this is necessary in order to achieve the scientific goal of providing a platform for transformative precision medicine research. For these programs to be successful in improving the health of all Americans, Kraft and colleagues contend it is critical to understand diverse patients' perspectives and reported that these populations' "willingness to participate in precision medicine research was conditional on the trustworthiness of the physicians, researchers, health care system, government and corporate institutions that owned, funded managed or were otherwise involved in the operations of the research initiatives" (Kraft et al. 2018, 9).

We agree and maintain that physician trustworthiness can promote the success of programs in recruiting and engaging underrepresented populations. Trust remains the cornerstone of the patient-provider relationship. The importance of this bond cannot be understated; it often predicts the willingness of a patient to seek care, share confidential information, comply with treatment regimens, and participate in biomedical research (Nguyen et al. 2009; Marrast et al. 2014). Research has shown that the nature of the patient-provider relationship can even impact the effectiveness of a therapy. This quote from a focus group conducted by Kraft and colleagues exemplifies the way in which healthcare providers are uniquely positioned to build bridges between patients and large-scale, population-based, precision medicine programs.

> I might trust my doctor to use my information more than some third, fourth, fifth party removed in some library [biobank, precision medicine research program] somewhere. I know my doctor. I have trust with my doctor, and I know my doctor is going to do right by me. And so, in some ways I'm like, okay doc, look if you want them to use my information to figure out something for me, I'd go at it. (Kraft et al. 2018, 9)

Because physicians are often situated at the interface between the research and medical worlds, these caregivers wield considerable influence in their patients' decisions to participate in research (Wynia and Gamble 2006).

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As of 2018, there is a growing number of large biobank, genomic, environmental and lifestyle precision health research resource initiatives supported by the federal government, state governments, academic institutions, and health care organizations. The success and impact of this research will be largely determined by how well the participants reflect the age, sex, ethnic, geographic, and socioeconomic diversity of their patient population and the country (Bonham et al. 2016). If the research programs are only able to recruit high socioeconomic status, Non-Hispanic White populations, the potential promise of the programs will not be fulfilled (Bonham et al. 2016; Burchard 2014). Kraft and colleagues found important differences between ethnic groups related to the confidence that precision medicine would benefit their community's health (Kraft et al. 2018). Of note, the legacy of exploitation of research participants from racial and ethnic minority backgrounds, and the failure of new discoveries to benefit minority communities, have made individuals cautious of the integrity of researchers and research institutions. Therefore, relying on extant trust in patient-provider relationships may be the key to breaking down this barrier to research participation.

As information about opportunities to participate in precision medicine programs continues to be disseminated, physicians will likely be approached by their patients for input regarding the merits and risks of the longitudinal studies. We identify three specific, important roles for the health care provider within precision medicine research programs and discuss what makes them uniquely positioned to be a bridge between the research programs and patient-participants. First, as a frontline recruiter-agent for many of the precision medicine research programs, physicians will have the opportunity to discuss these research opportunities with their patients during everyday clinical encounters. Second, if the patient is considering participating in a precision medicine research program as a direct volunteer and goes online to learn about the program, the patient's provider is the frontline medical expert with whom the patient is likely to consult. Third, when the patient participates in the program and receives findings from conducted studies, the patient-participant's physician will be the trusted health care provider relied upon to interpret the results and their implications for the patient-participant's health. Consequently, the physician is likely to be a key conduit for these precision medicine research programs because of the established trustworthy relationship with their patients; studies have illustrated that physicians remain a trusted source for individuals' health and research questions (Heese et al. 2005; Ciardiello et al. 2016; Comis et al. 2009; Lee and Hornik 2009).

While physicians carry incredible potential to serve as agents and mediators of trust between patients and research institutions, there are potential impediments that may undermine this process if not considered carefully. Historically, there has been limited improvement made in the inclusion of racial and ethnic minority groups within biomedical research (Burchard 2014; Marrast et al. 2014; Popejoy and Fullerton 2016). Failing to break away from this chronicled pattern will undermine the mission of research resource programs. Due to the documented shortage of physicians practicing in underserved areas where many minority and underrepresented populations in biomedical research reside, implying larger patient-to-physician ratios, time constraints and lack of adequate incentives may effectively prevent overburdened physicians from discussing precision medicine research opportunities with their patients (Marrast et al. 2014). This, along with noted preferences of racial and ethnic minorities to seek care from trusted physicians in their communities, highlights the significant position physicians can potentially fill within the precision medicine research enterprise. However, physicians must take care to avoid forsaking the needs and values of their patients in the name of research and overall societal benefit. Marcia Angell, in her 1993 article “The Doctor as the Double Agent,” delves into the original role of the doctor as the patient’s fiduciary or agent, and how this role has changed with time. She argues that the physician became a “double agent” with the evolution of the business of medicine and warns against shifting from a patient-centered mindset in the wake of other obligations (Angell 1993). If providers are to help in facilitating trust between patients and the precision medicine research enterprise, they should be mindful of the fragility of the trust in their own relationships with patients. They risk breaking the patient-physician trust if they unwittingly become “double agents” of these precision-based, longitudinal programs. In addition, with increasing knowledge of the links between genomics and health outcomes being amassed, patients who participate in precision medicine research may return to their physicians with genomic results that the physician is poorly equipped to interpret (Jagsi et al. 2017). Thus, it is imperative to find ways of filling these gaps in understanding at the point of care, while also engaging in efforts that have a more long-term impact; for example, through the implementation of robust genomic medicine curriculum within medical education. Lastly, failure of the research enterprise to deliver on its promises may adversely impact the trusting relationship physicians have with the patients who participate in precision medicine research resource programs, causing damage to the physician’s own reputability and integrity, which can ultimately undermine clinical care in the long term.

Despite the advent of the information age and increased availability of various communication conduits, such as the radio, magazines, television, and the Internet, physicians are still rated by patients as being the most relied upon source of health-related information (Heese et al. 2005). One study took a comparative look at levels of trust in 23 different sources of health information among both the public and among cancer survivors; of the 23 sources, physicians were found again to be the most trusted among both groups, with nationally recognized institutions, such as the National Cancer Institute, and professional societies also rated highly (Comis 2009). Interestingly, while faith in physicians as leaders of medicine has declined considerably over the past half century, the majority of the public do not question their physicians’ integrity or ethical standards (Blendon, Benson, and Hero 2014). Research has also illustrated that patients would prefer to be asked to participate in a research study by their physician, rather than by a medical researcher. In light of these behavioral patterns and preferences, it is clearly evident that physicians may play a major role in the ultimate decision patients make to trust researchers with their biospecimens and electronic health records. This will be especially true in moments of hesitation and apprehension, when patients may experience the tension between wanting to advance human health and feeling concerned by possibilities of misuse, lack of transparency, and intentional harm.

The field of biomedical research is at a pivotal turning point in time. Large-scale, longitudinal precision medicine research initiatives that examine the intersection of biology, genomics, lifestyle, and environment have the potential to revolutionize the way we understand health and disease, ultimately fostering a more holistic practice of medicine.

Even more, precision medicine research efforts embody second chances for the research enterprise; a second chance to rewrite the narratives of researchers' trustworthiness; a second chance to be inclusive by increasing populations underrepresented within biomedical research; and a second chance to ensure the fruits reaped from research efforts are shared by all. While physicians are well-positioned to help build bridges between patients and precision medicine research programs, the strength of these bridges will depend on active efforts to keep patient-participant and community values at the center, as well as the training and infrastructure-based support for physicians working at the interface of these two worlds. There is much at stake; however, if the path forward is paved with equity, respect, and integrity, then the hopes of precision medicine are likely to be realized.

Acknowledgments

FUNDING

The preparation of this commentary is supported by the Intramural Research Program of the National Human Genome Research Institute.

DISCLAIMER

The opinions expressed in this article are those of the authors. No statement in this article should be construed as an official position of the National Human Genome Research Institute, National Institutes of Health, or Department of Health and Human Services.

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